

# **NEGLECT IN POLICY PROBLEMS**

The Case of 'Neglected Tropical Diseases'

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## **Declaration**

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

Signed:

Date:

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## Abstract

This thesis is concerned with how previously neglected issues, in this instance tropical diseases, gain prominence on policy agendas, and shows how advocacy and measurement are used to bring issues to the attention of policymakers. The term 'neglected tropical diseases' (NTDs) was coined in the early 2000s to describe lesser-known diseases that existed in the shadow of the high-profile and well-funded “big three” – HIV/AIDS, tuberculosis (TB), and malaria. The case of NTDs demonstrates how a policy problem can be understood amidst connections being drawn or not drawn between issues, and the forms of intervention taken to address neglect in policy. Thus, the central question of this thesis is: How did a re-labeled disease category within a decade result in billions of funding being directed towards a previously 'neglected' issue, with global commitments for control, elimination, and eradication?

The analysis is presented in two parts and shows how NTDs have gained acknowledgement and care through the concept of neglect. The first part involves the conceptualization of common characteristics and methods of standardizing a disease grouping, which is far from a straightforward process as various lists of NTDs attest. The second part, through a socio-historical analysis of the origins and policy development of NTDs, demonstrates how policy appeal is created through the use of both advocacy and measurement, more usually treated as distinct areas within global health policy.

It draws on interviews with 55 actors from scientists, to policy officials, NGO workers, and academics, and also undertakes a documentary analysis, which includes historical sources. Using theoretical perspectives from Science and Technology Studies, Public Policy, and Political Economy, this thesis demonstrates what the concept of neglect brings to understanding policy problems. It concludes that both the perception and responses to neglect in policy can be understood in four distinct and overlapping ways, through: information, action, feeling and thought.

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## Abbreviations and acronyms

- APOC:** African Programme for Onchocerciasis Control
- APPMG:** The All-Party Parliamentary Group on Malaria and Neglected Tropical Diseases
- BMGF:** Bill and Melinda Gates Foundation
- CDC:** Centers for Disease Control and Prevention
- CDTS:** Center for Technological Development in Health
- CL:** Cutaneous leishmaniasis
- CTC:** WHO Division of Control of Tropical Diseases
- DALYs:** Disability-adjusted life-years
- DEC:** Diethylcarbamazine
- DFID:** UK Department For International Development
- DNDi:** Drugs for Neglected Diseases Initiative
- DW:** Disability weights
- EA:** Effective altruism
- EBA:** Evidence-based advocacy
- EBPM:** Evidence-based policymaking
- EBM:** Evidence-based medicine
- ECDC:** European Centre for Disease Prevention and Control
- FDA:** Food and Drug Administration
- GAVI:** Global Alliance for Vaccines and Immunization
- GBD:** Global Burden of Disease
- GFATM:** The Global Fund to Fight AIDS, Tuberculosis and Malaria
- G-FINDER:** Global Funding of Innovation for Neglected Diseases Survey
- GHI:** Global Health Initiative
- GND:** Great Neglected Diseases of Mankind
- HAT:** Human African trypanosomiasis
- IR:** International Relations
- LSE:** London School of Economics and Political Science
- LSHTM:** London School of Hygiene and Tropical Medicine
- LSTM:** Liverpool School of Tropical Medicine
- MDA:** Mass Drug Administration
- MDGs:** Millennium Development Goals
- MDT:** Multi Drug Therapy
- ML:** Mucocutaneous leishmaniasis
- ML:** Multibacillary
- MSF:** Médecins Sans Frontières
- NCDs:** Non communicable diseases

**NGO:** Non-governmental organization  
**NGDO:** Non-governmental development organization  
**NOKC:** Norwegian Knowledge Centre for the Health Services  
**NTDs:** Neglected tropical diseases  
**PEPFAR:** President's Emergency Plan For AIDS Relief  
**PL:** Paucibacillary leprosy  
**QALYs:** Quality-adjusted life-years  
**R&D:** Research and development  
**RCT:** Randomized controlled trial  
**TB:** Tuberculosis  
**TDR:** The Special Programme for Research and Training in Tropical Diseases  
**'The big 3':** AIDS/HIV, TB, and malaria  
**SAFE:** surgery, antibiotics, facial cleanliness and environmental improvement  
**SCI:** The Schistosomiasis Control Initiative  
**SDGs:** Sustainable Development Goals  
**Swiss TPH:** Swiss Tropical and Public Health Institute  
**UAFEM:** Universities Allied For Essential Medicines  
**UCL:** University College London  
**UN:** United Nations  
**USAID:** US Agency for International Development  
**VL:** Visceral leishmaniasis or kala-azar  
**WASH:** Water, Sanitation and Hygiene  
**WB:** World Bank  
**WHO:** World Health Organization

# Chapter 1. Introduction

## 1.1 Caring about neglected narratives

Postcolonial and feminist literature has had a long-held concern with 'the other'. Jean Rhys's 'Wide Sargasso Sea' (1966) is an example of adopting the neglected character's perspective. Rhys takes on a 19th century classic novel 'Jane Eyre' by Charlotte Brontë, through a questioning of where our moral sensibilities and support should lie. As a prequel, 'Wide Sargasso Sea' tells the story of the 'madwoman in the attic' giving voice to Antoinette (later known as Bertha) who is the first wife of one of the main characters Mr. Rochester. In 'Jane Eyre' Bertha is simply mad: "...it grovelled, seemingly, on all fours; it snatched and growled like some strange wild animal" (Brontë, 1847, p. 370). She is a marginalized character, originally devoid of empathy or concern, who is elevated through Rhys's direct attention. A host of other novelists have followed a similar path of enquiry. As Hephzibah Anderson explains, these subversive points of view have produced:

*"...intriguing new insights into classic works of fiction ... By giving voice to the marginalised and the maligned ... parallel tales appeal to our egalitarian worldview. It's a kind of cultural revisionism, yet even as these works challenge the canon, they're simultaneously reinforcing it"* (2016).

Through this thesis it is not my intention to 'give voice' to the marginalized and maligned.<sup>1</sup> This is the job of others, particularly anthropologists. However, as with literary theory, neglected aspects of texts are being revisited and critics are appraising what this means for literary study. In this thesis I am studying the nature of neglect in policy through the case of neglected tropical diseases (NTDs).

I believe that observing how the phenomenon of neglect is perceived and enacted within policy has a similar value, to reveal aspects of policymaking within the context of competition and congruity. It is only more recently that we have begun to care about what policy problems are not currently being addressed but should be, due to being unaware, ignorant, having poor information or other uncertainties (Frickel, 2014; Harman, 2012; Rappert & Balmer, 2016). Exploring why some issues and topics are not on policy agendas,<sup>2</sup> provides insight into how we

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<sup>1</sup> To a lesser degree I have given voice to the marginalized and maligned through scientists in endemic countries, neglected in media and academic accounts. However the truly marginalized and maligned are the patients whose voices are rarely heard, apart from in sound-bites of advocacy campaigns or more comprehensively through anthropological study.

<sup>2</sup> I use a standard, succinct definition of policy agendas supplied by Cobb and Elder for the, "...range of legitimate concerns meriting the attention of the polity" (Cobb & Elder, 1971, p. 905), although I expand the conception from polity and to policy, as outlined in the next chapter.

identify and select problems for policy, with competition between issues but also congruity in the overlapping threads that connect issues to one another.

This remit and the challenges that researching neglect poses, confronted me midway into this PhD. I was presenting my research aims and objectives at a workshop about the 'Changing Political Economy of Research and Innovation' (CPERI), in San Diego. As I was going over how I was interested in the concept of 'neglect' in policy, one of the other participants made the statement: "It's fine looking at the meaning of words, but there are children dying". I have been acutely aware of this point throughout the research project and have been keen for it not to be an esoteric, impractical exploration of a group of diseases that cause immense suffering and death to huge swathes of humanity.

I have been fortunate to observe the admirable efforts of scientists, NGO workers and policy makers in trying to make a difference to this state of affairs. Although it is not the full story about NTDs, I believe their story is worth telling and from a critical perspective that goes beyond the biomedical or journalistic accounts that have been written thus far. More than this I think it important to understand why we characterize policy problems through the lens of neglect, and how, as a result, these policy problems rise in prominence. Names matter and calling diseases 'neglected' has a meaning and an effect, as Rosenberg eloquently describes: "In some ways disease does not exist until we have agreed that it does, by perceiving, naming and responding to it..." (in Rosenberg & Golden, 1992, pp. xiii–xxi).

Specifically the "...choice of the word 'neglect' is pointed and loaded, forcing us to reflect on our social obligations" (Allotey, Reidpath, & Pokhrel, 2010, p. 5). Calling something 'neglected' is a way of determining and asserting importance and priority. In a competitive global health environment, where donors want to differentiate themselves, the 'neglected' terminology carries a weight of urgency, and of making a difference. It is a paradox that an assertion of importance has the effect of spreading recognition of diseases that had not been considered important enough before. The 'packaging' diseases as an object of neglect, through language and associated ideas is what I am interested in exploring further. Therefore, this thesis does not present a practical framework or model to better fund or incentivize research into NTDs, but aims for a deeper understanding about the policy world in which they originate.

## 1.2 Summary

'Neglected tropical diseases' (NTDs for short) are a collection of diseases, coined in the early 2000s that have received growing policy attention within global health. As Koplan, Bond, Merson, Reddy, Rodriguez, Sewankambo and Wasserheit describe, "(G)lobal health is derived from public health and international health, which, in turn, evolved from hygiene and tropical medicine" (2009, p. 1993). NTDs have gone full circle, originally being largely diseases of hygiene and tropical medicine, to be sidelined on many levels (scientifically, financially, socially and politically), and now they are of central interest within global health. These 17 diseases are listed by the World Health Organization (WHO) as the following in alphabetical order.<sup>3</sup>

- Buruli ulcer
- Chagas disease
- Dengue and chikungunya
- Dracunculiasis (guinea-worm disease)
- Echinococcosis
- Foodborne trematodiasis
- Human African trypanosomiasis (sleeping sickness)
- Leishmaniasis
- Leprosy (Hansen's disease)
- Lymphatic filariasis (elephantiasis)
- Onchocerciasis (river blindness)
- Rabies
- Schistosomiasis
- Soil-transmitted helminthiasis
- Taeniasis/Cysticercosis
- Trachoma
- Yaws (Endemic treponematoses)

**Table 1 WHO list of NTDs**

The WHO groups NTDs on the basis of agreed common characteristics – just as was done for tropical diseases in former times, but the methods behind the standardizing this grouping are far from straightforward. The various lists of NTDs attest to this difficulty and I will go into more detail about lists and the politics of categorization in Chapter 5. For now it is worth remarking that the 17 NTDs listed by the WHO tend to be the most well acknowledged and other organizations draw a shorter selection from this list. This is the case for organizations running

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<sup>3</sup> WHO, 2016a, [http://www.who.int/neglected\\_diseases/diseases/en/](http://www.who.int/neglected_diseases/diseases/en/), Accessed 2/4/16

programs that require direct interventions.<sup>4</sup> Only the *PLOS* journal on NTDs has a longer list. Being an academic endeavor there is more reason to encompass a larger number of diseases to have a wide research scope.

Returning to the 17 WHO list, the diseases listed form a mixed bag of not very pronounceable diseases, some of which may be familiar to 'western' audiences. Leprosy and rabies are ancient diseases of the poor (Little, 2007). While travelers can vaccinate against rabies, they may have come across dengue and chikungunya, for which there is no vaccine. Still others may pick up one of the other non-descript 'tropical diseases' from a hot country. Indeed the NTD group derives from a larger grouping of tropical diseases, although some tropical diseases never were especially tropical and have not been (or never were) common. I will discuss this point of why some tropical diseases cannot be only seen as tropical in Chapter 5.

Rather than being rare and exotic, NTDs are in fact a common affliction, not only a threat to travellers. They are often debilitating and sometimes deadly for the majority of the world's poorest people. The scale of NTDs for the global poor is large, with one or more NTD affecting over a billion people in 149 countries (WHO, 2015a). Therefore, despite the label of neglect, and perhaps unfamiliarity in the western world, these diseases are widespread and pervasive.

Progress is being made to tackle NTDs, with 'big pharma' mostly behind the over \$5 billion in anti-parasitic drugs donated (ibid.) and global health commitments made through 'The London Declaration' in 2012 and Sustainable Development Goals (SDGs) in 2015, with national NTD master plans coordinated by the WHO. As of 2015, 27 countries have 75% coverage of Mass Drug Administration (MDA), where drugs are provided for at-risk populations<sup>5</sup> and there have been some strong achievements in elimination (WHO, 2015a). For example, Colombia eliminated onchocerciasis in 2011, followed by elimination by Ecuador in 2014 (ibid.). These are significant successes in the space of approximately 10 to 15 years, seeing as the term NTDs was only coined in the early 2000s. While much more is still to be done, it is remarkable progress. Considering these diseases have been labeled 'neglected', especially in terms of global public health awareness and commitments, what were the events and milestones that lead to such an outcome?

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<sup>4</sup> Organizations with direct NTD interventions are: US Agency for International Development (USAID), Centers for Disease Control and Prevention (CDC), the Department for International Development (DFID), The Global Network for Neglected Tropical Diseases, Uniting to Combat NTDs and Drugs for Neglected Diseases Initiative (DNDi).

<sup>5</sup> Drug provided for at-risk populations are primarily for Soil-transmitted helminthiases (STHs).

### 1.3 Research questions

To explain how progress has been made with NTDs on policy agendas, means first pursuing a more fundamental question, as to where the new disease grouping arose. NTDs as a group reflect how the relative neglect or non-neglect of one issue over another is negotiated through the use of advocacy and measurement. NTDs stand apart from other diseases deemed not neglected – the so-called 'big three' HIV/AIDS, tuberculosis (TB), and malaria (Elliott, 2013), given the name by their advocates as "...three of the deadliest infectious diseases the world has ever known".<sup>6</sup>

In 2000 the big three were causing more than 4 million deaths per year and the UN's Millennium Development Goals set HIV/AIDS and malaria as a priority (ibid.). In 2002 the Global Fund was set up to tackle these diseases along with TB, channeling US\$4 billion a year in funding (ibid.). Since then the big three have received the lions' share of attention in policy, media and academic spheres for being high mortality diseases on a global scale. However, malaria was once a tropical disease, as Kelly and Beisel (2011) note the term 'all except malaria' is shorthand for NTDs. How did unfold that malaria became a tropical disease that is *not* neglected?

The argument of Kelly and Beisel is that political concerns and technical capacities have, "...transformed malaria into a *global enemy*" (2011, p. 71, emphasis added), despite it being a disease 'exclusive to the tropics' (Hamoudi & Sachs, 1999, p. 1). Therefore, malaria in being a killer disease that has eluded eradication campaigns, is made a global enemy through a particular 'vision' of a disease as a common concern, requiring global mapping and capital.<sup>7</sup> HIV/AIDS joins malaria, as a newly emergent disease but another global killer, with high death tolls in both the developed and developing world, and similarly TB has historically been a largely global disease affecting all regions (Daniel, 2006).<sup>8</sup>

Competition between diseases is a feature of global health, from the 'big three' competing for attention, followed by NTDs. However, sign of connections across issues is evident at the WHO: the NTD group has grown, expanding from an original grouping of 13 to 17; TB joined the HIV/AIDS and malaria group to form the big three; and now TB, HIV/AIDS, malaria, NTDs and hepatitis form a larger cluster. The WHO created this new cluster (that individual disease departments sit under for reporting) in 2015, with the acronym 'HTM' for HIV, tuberculosis, malaria, hepatitis and NTDs' (WHO, 2016a). Since NTDs have risen up policy agendas, they

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<sup>6</sup> Global Fund, <http://www.theglobalfund.org/en/overview/>, Accessed 2/4/16.

<sup>7</sup> The main weapon against malaria from the 1950s onwards was aerial DDT spraying, and as a result, "...epidemiological models came to replace detailed entomological reports, malaria shifted further from a situated illness to a global pandemic" (ibid., p. 76).

<sup>8</sup> Due to advancements of treatment and control TB is now mainly a disease of the global poor, in developing countries, with some signs of resurgence in poor communities residing in richer countries (Elliott & Arora, 2011).

are increasingly referred to along with HIV/AIDs, TB and malaria as 'The gang of four' in the global health community (Elliott, 2013).

The question remains as to how NTDs reached a similar status as the big three. Through the course of this thesis, by charting the policy development for NTDs I intend to show that the use of the term 'neglect' matters in how NTDs gained attention. Pinpointing how neglect has been used, involves exploring the conceptual history of NTDs in how neglect has been deployed as a policy rationale, through forms of advocacy and measurement.

Assumptions about the conceptual origin of NTDs as a disease grouping initially point to the World Health Organization (WHO). The WHO positions itself as the strategic authority on global health policy, to standardize disease groupings through their authority and expertise (Ng & Ruger, 2011). However, the socio-historical analysis of this thesis reveals an alternative institutional heritage and organizational agency. This analysis opens the way for an understanding of the positioning and evolution of global health institutions and the struggle for prominence amongst health issues. The aim of this thesis is thus to explore how the coining of the term 'NTDs' has resulted in a group of diseases gaining prominence in policy agendas, at a time then when competition but also connection is a feature of policy. To pursue this aim leads me to the following key questions:

- 1) In charting the policy development of NTDs, what does the concept of neglect bring to understanding policy problems?

In posing this question I mean: how has neglect been used by policy actors to advocate and measure why NTDs should be addressed? But also as an analyst I am interested in: how can neglect help us better understand policy problems, particularly in how they compete and are prioritized? During the course of this research I identified two defining characteristics that respond to neglect and utilize the concept in policy. One is the advocacy for NTDs to move up policy agendas, specifically through activism by scientists. The other is the use of measurement in providing evidence to determine neglectedness<sup>9</sup> and make persuasive arguments for action, leading to the next question of:

- 2) How is advocacy and measurement used in pushing an issue up policy agendas?

The use of advocacy in bringing attention to NTDs has already been noted (Maio, 2014; Manderson et al., 2009). However, through 55 interviews with key actors – including scientists, policy officials, NGO workers, and academics, it became evident to me that measurement also played a central role in bringing policy attention to NTDs. This role was not only in putting measurement to use through advocacy but measurement forming a type of advocacy in the metrics of global health.

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<sup>9</sup> Neglectedness refers to measuring the degree of neglect, discussed in Chapter 7.



Advocacy and measurement tend to be treated as distinct areas of research within global health and public policy more widely. Indeed, a number of studies attest to this separation (see Majone, 1989; Obermeyer, 2003). Research on social movements, action, and activism lean towards questions of emotion, politics and advocacy.

On one hand advocacy is the support or recommendation for a particular cause, the mode of which is argumentative, to make a case in order to spur action. I use the concept in a more narrow sense, referring more to activity to influence decisions. The activity I concentrate on is activism, a stronger version of advocacy involving, "vigorous campaigning to bring about political or social change" (Oxford Dictionaries). On the other hand measurement research often covers the role of metrics and provision of evidence. In this thesis the type of measurement relied on for NTD advocacy by activist scientists and NGOs is shown through metrics and what metrics are able to do beyond direct measurement. The type of measurement I am interested in is that which is described as objective, scientific, and quantitative, dominating the metrics used in global health.

It is not often that advocacy and measurement go hand-in-hand as a research topic, rather features of tension or instrumentality are highlighted. For example Kapilashrami et al. (2015) examine the tensions between public health evidence collected through various measures and advocacy. They question whether practitioners and researchers who belong to the traditional 'evidence-based public health paradigm' can, "...improve and protect the public's health" by being more involved in politics and advocacy" (Kapilashrami et al., 2015, p. 1). To produce evidence through measurement has a legitimizing authority, leading to an overemphasis in public health in the, "...reassuring sense of objectivity and corporeality" (Smith, 2013, p. 71). Furthermore, evidence is thought of as sit outside of political maneuvering through advocacy or other means, and viewed in a neutral fashion. Neutrality is at the heart of the distinction – that advocacy cannot be neutral as it is arguing for one side over another.

The case is also made for the instrumental use of advocacy and evidence. Tillman et al. (2014) argue for the advocacy of "...evidence-based measures to improve the health of society", observing that there should be a "bolder analysis of public health issues" by public health institutions. The pursuit of evidence can also be led by advocacy as seen with the work of AIDS activists. Epstein has demonstrated that AIDS advocacy groups required a mastering of the science to form 'an alternative basis of expertise' in which to acquire and use evidence for advocacy (Epstein, 1996). The use of evidence *for* advocacy has been coined as 'evidence-based advocacy' (EBA), a term that rapidly emerged in the early 2000s onward. As Storeng and Béhague put it: "This term was used to highlight the importance of persuading the broader global health community to invest in maternal health not by making explicit moral claims, but by using quantitative objective evidence" (2014, p. 261).

EBA has been used by maternal health advocates to 'bolster authority' in public health, but can also lead to a technocratic narrowing of policy agendas in borrowing from an 'audit-and business-orientated ethos' (ibid.). In the global maternal health campaigning, EBA signaled a shift from advocacy relying on principled arguments – for example through a human rights approach that emphasized social justice. Evidence is applied to instrumentally, through 'creative epidemiology', in modifying the presentation of statistical data<sup>10</sup> depending on the stakeholder audience (Storeng & Béhague, 2014, p. 268). The use of evidence is explained, but not discussed is where the evidence is from and why some types of evidence is produced and others not.

Science and Technology Studies (STS) has shown how both concepts are contested. Evidence as described by Helga Nowotny intends to bring, "...to the fore what is there to be seen. But not everything that can be made to be seen is admitted as evidence" (2007, p. 481). This description of evidence speaks to the availability and presentation of information and knowledge, with a hierarchy of evidence from the more scientific, measurable and objective at the top, moving to anecdotal, opinion-based and subjective at the bottom (Moore & Stilgoe, 2009). Lambert calls the legitimacy instilled by statistical evidence the 'new regime of truth' (2009, p. 17). Evidence acts as proof and justification for why we should care, while advocacy is thought to rely more on moral and ideological argument.

How does advocacy and measurement in the production of argument and evidence relate to neglect? Arguments pertain for the lack of advocacy and measurement as being a cause of neglect. If measurement is of poor quality and scope can lead to what is referred as an 'evidence trap' in a self-reinforcing circle of neglect through low resource allocation (Storeng & Béhague, 2014). Advocacy can be a moral obligation, with some scholars arguing that the lack of advocacy is a type of neglect in itself (Kapilashrami et al., 2015, p. 1). Others have argued that advocacy for NTDs is legitimized by a moral characterization of neglect:

*"A pragmatic consequence of this moral sense of 'neglect' is that it legitimises the prominent use of advocacy as a key strategy to address NTDs, thus legitimising non-governmental organisations' (NGOs) and other actors' (from civil society to philanthropic entities) participation in the political field"* (Jackson & Stephenson, 2014, p. 998).

I intend to go beyond the view that advocacy is a source of tension in using measurement and that measurement in the production of evidence is used 'for' advocacy, as described by Storeng and Béhague (2014), or in other words the view that advocacy is needed to 'present evidence'. I will argue that measurement can be a form of advocacy in itself. The act of measuring and

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<sup>10</sup> An example of modifying the presentation of statistical data is presenting to a public audience the number of deaths in pregnancy and childbirth in a developing country, compared to developed countries (ibid.). Global level policy actors may view these deaths as too low compared with other issues, so (as with NTDs) the focus needs to be turned from mortality to morbidity and the combined burden of mothers, children and newborns.

provision of metrics can act as advocacy for a cause. I will draw upon the literature on social movements, social policy, evidence-based policy and health metrics to support this argument.

## 1.4 Research relevance

This brings me to four points I want to make on the relevance of this research concerning: (1) the lack of social science research on NTDs; (2) the research approach that has dominated in researching NTDs (and why this has been the case); (3) what approaches could be beneficial to the study of NTDs, and; (4) situating the study of these diseases in a policy context by addressing the meaning of 'policy' used in this thesis. I also briefly discuss the adoption of the NTD term in the medical and health care literature.

Firstly, social science (and in particular policy) research on NTDs has been lacking. There have been a number of review articles (Allotey et al., 2010b; Manderson et al., 2009), an introductory thematic series (of four papers) on NTDs (Allotey et al., 2010) and a series applying a biosocial approach to NTDs focusing on individual NTDs (Parker, Polman, & Allen, 2016a). Even though the number and range of NTD research is rising, there has yet to be an in-depth enquiry on NTDs from a social science and policy perspective (Barry, 2014; De Maio, Llovet, & Dinardi, 2014; Mantilla, 2011). Mantilla even charges that "...it appears that social science has colluded in the low priority and invisibility of NTDs" (2011, p. 118).

I would argue that this charge is only partly true. There has been an enormous amount of research on tropical diseases and only fledging research on NTDs, but these two literatures need to be combined. For example, two historical books of interest are by Farley, on 'Bilharzia: A history of imperial tropical medicine' (Farley, 2003) and 'To cast out disease: A history of the International Health Division of the Rockefeller Foundation (1913-1951)' (Farley, 2004). His exploration of the connection between health, the economy and philanthropy, bringing in socio-political accounts, has wider implications for the study of NTDs.

NTDs form a research topic identified to potentially benefit from 'social science' and 'interdisciplinary research' in reaction to a predominately biomedical lens. As described by Reidpath, Allotey, and Subhash:

*"These diseases represent a rich and dynamic interplay between vector, host, and pathogen which occurs within social, physical and biological contexts. The overwhelming sense, however, is that neglected tropical diseases research is a biomedical endeavour largely excluding the social sciences"* (2011, p. 1).

Particularly the 'intense' advocacy that has brought attention to NTDs is noted as a point to explore further, "...a systematic analysis of this process would make an important contribution to our understanding of advocacy and the dynamic research-policy-practice nexus in public health" (Manderson et al., 2009). Therefore, advocacy has been presented as a key aspect for why

NTDs have gained policy attention but through the course of this research I also found that measurement played a similarly important role. Advocacy and measurement could both fall under a policy understanding of NTDs.

Secondly, the type of theoretical gaps caused by a lack of social science, especially investigator-driven<sup>11</sup> and interdisciplinary research on NTDs have been highlighted by Reidpath et al. (2011), using bibliometric analysis. They argue that the social science research that has tended to accompany NTD research is either a misclassification of pure clinical research or 'handmaiden' research to support the implementation of biomedical solutions (2011, p. 1). What this dominance has resulted in is a lack of interdisciplinary focus on the, "...complex social, cultural, biological, and environmental dynamic involved in human pathogenesis" (ibid.).<sup>9</sup> Reidpath et al. locate a systemic basis to this situation in funding that requires:

*"...more sophisticated funders and priority setters who are not beguiled by uncritical biomedical promises...designed to support (and never challenge) the curative activities of biomedical research. If one of the core ideas underpinning scientific research is that it should challenge and confront existing dogma, then this kind of adjuvant research, though utilitarian, does not contribute to the advancement of science because it is intended to support the activities of a dominant paradigm" (Reidpath et al., pp. 1-8).*

De Maio, Llovet, and Dinardi are not very optimistic of any change, because of a funding bias that, "...may continue to prohibit the social sciences from playing anything but a marginal role in interdisciplinary teams" (2014, p. 373).

Thirdly, De Maio (2014) in reiterating that more needs to be done from the perspective of social science, points toward the scarcity of sociological or anthropological accounts of NTDs beyond two classic works concentrating on one NTD – Chagas disease: Roberto Briceño-León (1990) 'La Casa Enferma: Sociologica de la Enfermedad de Chagas [The Sick House: Sociology of Chagas Disease]' and Joseph Bastien (1998) 'The Kiss of Death: Chagas Disease in the Americas' .

He particularly encourages engagement by sociologists, contending that they have not been involved with the scholarly discussion surrounding NTDs, such that: "...the framing of NTDs has been overly narrow, and a situation that is perhaps best understood as a manifestation of structural violence has instead been seen through a technical rather than socio-political lens" (ibid.).

These accounts encouraged me to pursue NTDs from a predominantly STS and public policy perspective. The social science critiques of the current NTD literature that I have touched upon

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<sup>11</sup> Investigator-driven research is a science policy term where the investigator is the one who designs and implements the study as opposed to being given instructions by someone else (Horizon 2020, <https://ec.europa.eu/programmes/horizon2020/en/h2020-section/excellent-science>, Accessed 2/4/14).

have tended to focus on a dichotomy between the socio-political structural aspect of NTDs, and technical medical interventions. This dichotomy has been overemphasized in my view. I adopt a broadly constructivist theoretical approach to view this global health problem, but recognize that it arises from an ideational *and* material basis (Ruggie, 1998), an approach could be described more specifically as coproductionist, in which natural and social orders produce one another (Jasanoff, 2004).

The notable exception in considering ideational and material factors is De Maio, who sees the progress for NTDs, of advocacy and success in resources being redirected, as falling across three areas: "...epidemiological indicators, research activity and policy attention" (2014, p. 97). I have followed similar themes in this thesis, but have taken more encompassing outlook through a concentration on advocacy (through activism), measurement (through metrics), and the concept of neglect in policy. I intend to ascertain what advocacy and measurement mean, as modes of positioning NTDs as a new disease grouping characterized by neglect. I also believe both aspects of the technical and socio-political are important in understanding neglect. Therefore through this thesis I aim to produce an interdisciplinary enquiry that involves making the connection with colonial tropical diseases and the policy development of NTDs.

Lastly, it is worth noting early on the use of 'policy' in this thesis is described as a directed activity of a diverse group of actors toward a perceived problem. Policy is directed by a group of actors extending further than government but it still means a rationale is driving the activity, revealed through dominant discourses and narratives. Such a discussion is part of a theoretical and practical shift from government to governance, where a wider range of actors participate in what was once a more exclusive process of government (Hill & Hupe, 2014, p. 1). I will go into more detail about this in Chapter 3.

This is a broader conception of policy used by Colebatch in policy being an activity that is "...deliberate and purposeful rather than erratic or random" (1998, pp. 6-72). Policy is more than a set of objectives or guiding principles but standardizes and articulates practice, in how action is framed rather than simply described. It is in this sense that I use policy throughout this thesis, to mean the *activity directed to the problem of NTDs* and the activity I am most concerned with is acknowledgement, attention, and most importantly care as opposites of neglect in policy.<sup>12</sup>

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<sup>12</sup> Characteristics of 'attention, and care' are the opposite to neglect if defined as the failure to give attention or care (Cambridge Dictionary) and I argue that acknowledgment of the need to care is also required.

## 1.4 Thesis structure

The next chapter explains how I approach NTDs as a policy problem through a discussion of the methods and methodology. The research for this thesis was qualitative, based on 55 interviews and I cover the procedures employed to carry out this data collection. I also provide an overview of the documentary sources and key terms I used throughout the thesis, as well as introducing new terms.

*Chapter 3* explores theoretical underpinnings to thinking about policy problems from the perspective of a number of disciplines. I review a diverse literature to provide a theoretical grounding on which to ask questions about how a policy problem is formed, raised in profile, and the types of solutions that are offered. NTDs present a policy problem that involves a tropical disease history, followed by a reconceptualization and branding, which I call a 'repackaging' of the neglected aspect of NTDs. I discuss how problematization has been understood for policy and how 'critical global health' has attempted to problematize global health policy. I then draw attention to the ways innovation has been directed toward policy solutions and the disciplinary lens taken through economics, history, and interdisciplinary approaches to policy problems. By the end of the chapter I begin to consider policy problems related to global health, with how the concept of neglect is positioned within this landscape.

*Chapter 4* covers the most important milestones for the construction of NTDs, with the central contribution being how the present system of global health governance is disaggregated, from the WHO once dominating policy to a situation of numerous important stakeholders (Patrick, 2014). Throughout the chapter I further explore what it means to have a global health landscape of multiple stakeholders. I concentrate on how two early initiatives for NTDs by the Rockefeller Foundation and WHO were both illustrative of the general trends in global health governance and the later conceptualization of NTDs.

In *Chapter 5* I consider the common characteristics for what constitutes an NTD and how the criteria or methods of standardizing the grouping are not clear-cut, as seen in the different lists of NTDs that exist. While there is instability in the category boundaries, the reasons and consequences for why we categorize some diseases as being part of one group and others a part of another is important. It matters for attention of the global community, the policy approaches employed, and funding and resources applied. A utilitarian approach to classification, in which systematic classification serves practical needs, has played a large and ongoing role in how we classify the natural world (Stepan, 2001, p. 17). However, classification is a, "...social and uncertain process" (Freeman & Frisina, 2010). In medicine, diseases are also classified in terms of the people they afflict, rather than only seeking distinctions based on the intrinsic nature of the disease (Bowker & Star, 1999). It is this element of subjective interpretation that I want to expand on in the characterization of one group of people given by another.

*Chapter 6* charts the branding of NTDs by UK and US scientists, who became activists and how this formed part of an elite policy movement of advocacy. I also wanted to ensure endemic countries were included, with 'endemic' referring to the, "...constant presence and/or usual prevalence of a disease or infectious agent in a population within a geographic area".<sup>13</sup> Therefore it was important that this thesis reflected the countries where NTDs are prevalent.

As stated already NTDs affect some 149 countries, so I needed to narrow down my focus to a manageable number to draw insight from individual countries. I began with the idea of the so-called 'BRIC' countries, Brazil, Russia, India, and China.<sup>14</sup> They present a novel angle as countries with the potential to contribute scientifically and strategically to the NTD problem, and represent a move away from western dominance (*ibid.*). I narrowed this choice to Brazil and China to concentrate on (and will elaborate on the reasons why in the next chapter).

For *Chapter 7*, I take stock of how NTD policy development is reflected in public discourse. I chose two leading measurement discourses related to NTDs, to demonstrate the role that measurement has had in conceptualizing the NTD problem. I argue that measurement is a way of caring in global health, and evidence (presented through measurement), has acted as a form of advocacy for raising the profile of NTDs.

The final chapter, *Chapter 8* revisits the initial questions posed by the introduction and discusses the ways that advocacy and measurement showcase neglect. I argue that neglect is present in policy across typologies of action, emotion, thought, and information. Such an understanding of neglect in policy has implications for whom have responsibility and how the concept is used as a resource in global health. I finish this thesis by presenting what might be fruitful next avenues for research on NTDs as a fledgling area of social science research.

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<sup>13</sup> CDC <http://www.cdc.gov/globalhealth/ntd/>, Accessed 2/4/16.

<sup>14</sup> The group acronym 'BRIC' was coined by the former chairman of Goldman Sachs, Jim O'Neill, to represent these countries as being at a similar stage of 'newly advanced' economic development as 'emerging markets' (Tett, 2010).

## Chapter 2. Methods and methodology

### 2.1 Introduction and overview

The methodological approach of this thesis has been guided by an intention to draw out the relationship between NTDs and policy. There could have been a number of ways in which to explore the topic but this study has been shaped by three central methodological research aims, to (1) connect the understanding of NTDs with tropical diseases and their colonial origins; (2) explore the policy development of NTDs in how these diseases have been moved up policy agendas through advocacy and measurement; (3) provide examples – with endemic countries – in which to view the enactment of global policies. This approach is grounded in gaining an account of the policies for NTDs over time, across countries, and through relevant discourses.

At the outset of this research project I began with wanting to know more specifically about the role of innovation in NTD policy, but this quickly moved to becoming a broad concern with the policy process and development of policies for NTDs. Following a series of initial pilot interviews, I widened the research inquiry toward understanding the nature of NTDs and how they are treated in policy. Thus I embarked on a speculative approach rather than following a rigid research design, which helped me become acquainted with a large topic area without becoming fixed upon preconceived themes. I was inspired mostly by a grounded theory approach, in developing working hypotheses as the research progressed and applying theories of others. As Locke, Silverman and Spirduso put it:

*"...grounded theory studies do not start with a theory – they end with one... Also, because theories pronounced tend to be very specific to the content studied, they often have strong implications for the design of effective practice. What they lack in terms of grand generalization they gain in terms of applicability" (2010, p. 192).*

I will elaborate on how this worked in practice later, in the manner in which I treated my object of enquiry. Through the course of the research certain themes did emerge and were likely influenced by my disciplinary leaning and I chose to emphasize to tighten the scope and argument. These were the role of measurement in making policy arguments shown through discourses, and advocacy through activist scientists constituting a policy movement. I qualify this subject matter later in the chapter but these themes demonstrate coverage of the individual, collective, and discursive in policy.

This chapter will describe how the thesis methodology has evolved and my rationale for decisions taken. I have drawn upon a wide range of disciplines including: public policy, history, medical anthropology, sociology, and political economy. Science and Technology Studies



(STS) remains my main disciplinary basis, with encompassment of the other disciplines mentioned. I found that my subject of focus being on scientists and the interaction between science, medicine and policy lent itself to an STS treatment. If STS scholars are concerned with the nature and practices of science and technology, it follows that scientists will be a central subject of study as actors involved with decision-making, priority-setting, and future planning with ramifications for politics, policy and ethics.

## 2.2 Research aims

### 2.2.1 Connecting NTDs with tropical diseases

I have undertaken a socio-historical analysis of NTD policy change to understand the treatment of NTDs. Here critical policy historiography was a useful technique toward documentary evidence to observe changes, including posing questions about complexity in the account of the policy and who is advantaged or disadvantaged by the arrangements (Gale, 2001, p. 385). As noted in the introduction, I use a wide definition of policy to not only include stated intentions by government but also interventions and activities, as well as governance of NTDs directed by various actors. Policy is sometimes narrowly understood as being constrained to politics as the prospective policy of a future government or decisions taken by political leaders to bring state power to bear on particular problems (Colebatch, 1998, p. 2). A wide definition encompasses a number of interpretations of policy problems, which might be more expressed than others through values, systematic activities, routine practice, and goals, all of which manifest as organized action or inaction (ibid.).

Within the document analysis, the majority of my sources were journals and books. See Appendix 1 for an overview of my most cited source types, by number of different individual documents I referred to. The journals contained a mix of health and social science topics, with the *PLOS Neglected Tropical Diseases* journal being my most cited source (with the acknowledgement that PLOS is an open-access platform, attracting different types of papers to a traditional peer-reviewed journal). I also referred to the high-profile science journals the *Lancet*, *Nature*, and *Science*. The books included those of an overview nature for scientists or medical professionals produced by scientists, with a mix of scientist and general reader in mind, including tropical medicine histories. More recently there have been books by activist scientists about NTDs ('Forgotten People, Forgotten Diseases' by Peter Hotez, 2013). In a latter section of this chapter I go into more detail about a series of popular science books by Robert S. Desowitz aimed at a public lay audience interested in the human stories of tropical disease. One other medium has been documentary film, which I provide an overview of later in this chapter.

Other sources included media reports (e.g. magazine articles, commentaries) or reports by government, NGOs and governance institutions (most referenced being the WHO followed by the CDC). I outline the main reports I drew upon further on in this chapter. I paid special attention to grey literature generated by NGOs and research institutes, including through webpages, blog posts, news sites and press releases (e.g. The Nobel Assembly, Fiocruz).

### **2.2.2 Policy development of NTDs – through advocacy and measurement**

I employed a further level of analysis through 'policy archaeology' and 'policy genealogy' to understand the conditions for why policy problems<sup>15</sup> can be viewed as constructions and to uncover the reasons for change (Gale, 2001, p. 387-9). Originally outlined by Scheurich drawing on the post-structuralist work of Foucault, policy archaeology is interested in the social construction of problems to question what constitutes a legitimate problem and solution (Scheurich, 1994). Gale adapted this approach to concentrate on 'policy formation': how constitutive rules are established and the conditions of their realization (Olssen, Codd, & O'Neill, 2004, p. 57). As a method, policy archaeology is sociologically inspired, requiring interviews in order to address the 'who, what, and why'.

Policy genealogy is used to uncover a number of legitimizing strategies for policy agendas, to understand policy production (Gale, 2001, pp. 387-9). Gale has a broader conception of 'critical' policy genealogy than Scheurich, to mean what policy makers license for the items on policy agendas, the actors involved and conditions that regulate the patterns of interaction (Olssen, Codd, & O'Neill, 2004, p. 57). Both of these approaches have proven insightful to understand NTD policy development, in the construction of NTDs as an idea and the resulting policy agenda change.

### **2.2.3 Examples of neglect**

'Endemic' is a term used in epidemiology to describe those countries or populations where a disease is prevalent in a steady state, compared with an epidemic where disease instance is rising rapidly (See Beaglehole, Bonita, & Kjellstrom, 1993, p. 121). I undertook fieldwork interviews in endemic countries Brazil and China for three weeks each, at research institutes and universities, totaling 21 interviews (which included two group interviews). I visited China in 2013 for seven interviews in Shanghai at the National Institute of Parasitic Diseases and The Drug Discovery Centre for Tuberculosis, as well as an interview in Beijing at Tsinghua University where I presented my work at the Institute for Science, Technology and Society. I went to Brazil in 2014, conducting six interviews in São Paulo at the Virology Lab of the Institute of Tropical Medicine and Instituto de Medicina Tropical de São Paulo and Departamento de Parasitologia and two at the Universidade de Sao Paulo. I then went to Rio de Janeiro to conduct two further interviews, one at the Center for Technological Development in Health (CDTS) and another at Fundação Oswaldo Cruz (translated as Oswaldo Cruz Foundation, known as Fiocruz, attached to the Brazilian Ministry of Health). My intention was to explore

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<sup>15</sup> Further detail on connections to the social problem literature is discussed in Chapter 3.

Brazil and China as 'innovative developing countries' (IDCs)<sup>16</sup> adopting strategies that differ from traditional donor-recipient relationships in funding and resource arrangements for global health.

Brazil and China are part of a larger cross-national group, the 'BRICS' also including Russia, India and more recently South Africa. They have received attention in their potential to address NTDs – with the exception of Russia, as it is not endemic for NTDs and to a lesser extent South Africa where HIV/AIDS and TB dominate as the big killers. The WHO has described the BRICS as being, "...uniquely positioned – as a group and as individual countries – to ensure that neglected tropical diseases receive the international attention they deserve" (Cashwell et al., 2014, p. 461). This potential arises from their positioning as emerging economies with growing innovation capacity (See Hotez, 2014b). However, in looking at two BRIC countries, it is important to keep in mind that these countries lack a common vision but share, "...confidence born of economic dynamism and resentment over a global economy they perceived as stacked to favor the West" (Patrick, 2014). Therefore, the BRICS are not a coherent grouping but have in common a positioning to differentiate themselves from other developing countries.

A more useful categorization for this inquiry could very well be 'innovative developing countries' (IDCs) characterized by an advancing R&D capacity, to establish a 'new geography' for NTD research (Adams et al., 2012, p. 3). The number of papers published on NTDs in 2011 from Brazil and China, matched that of Japan, Spain, Switzerland, and Australia, respectively (ibid, pp. 4–5). NTD research forms a significant part of the research base for developing and emergent economies because it has direct economic and social relevance: "Brazil is evidently a global research leader, with a substantial volume of NTD papers in its portfolio" (ibid, p. 5). What drew me to Brazil and China is their heavy investment in science and a historical connection with NTD scientific discovery.

The intention to include Brazil and China was not to produce endemic country case studies but contribute to a more global story, by conducting fieldwork across multiple sites. What this thesis does not include is an explicit and systematic compare-and-contrast between countries. My guiding imperative was to follow the action through the term 'NTDs'. Still it is not enough only to reflect NTD policy through how endemic countries have been involved. This is the reason why I explore 'public discourses of measurement' in Chapter 7 to understand how discourses have implicated NTDs. As these diseases have not been in the public arena I want to pinpoint where they have entered more mainstream public discussions and have found this through wider debates and controversy about measurement.

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<sup>16</sup> The IDC group often also encompasses a wider list of Taiwan, Ukraine, Malaysia, Belarus, Argentina, Mexico, Turkey, Chile and Indonesia.

## 2.3 Qualitative Interviews

In total I conducted 55 semi-structured interviews (including the 21 fieldwork interviews) to better understand views and collect anecdotal evidence (Appendix 2 outlines the interviews in more detail). I started with an initial set of informants that I chose to study 'innovation approaches to NTDs'. However, during the course of the interviews it became apparent that a different story was emerging. These first interviews constituted an early fact-finding and overview of the NTD community. In keeping with a 'grounded theory' approach to theoretical sampling I conducted an NVivo analysis and a new set of conceptual cores emerged around 'measurement' and 'advocacy'. These cores guided my selection of further informants, whose current institutional affiliations spanned across academic, policy and charitable fields.

The next set of interviewees were sampled using an element of 'snowballing' and 'chain-referring' to choose interviewees once I had made contact with a key actor in the field or completed an interview. The strengths of such an approach were to find interviewees within networks that were not so obvious through an outside search. The limitation was being constrained to those original networks and so not including more oppositional viewpoints. As Ruane points out, relying completely on snowballing may risk omitting individuals who are not well 'networked' (2005, p. 118). Therefore, snowballing was in complement to a purposeful sample of interviewees, generally following the criteria of policy awareness or engagement.

The NTD community itself is small and could be regarded as an elite, with high-profile scientists and politicians as policy influencers and participants in policy change. To clarify elite interviewing, I adopted Hochschild's definition of "...discussions with people who are chosen because of who they are or what position they occupy... the term indicates a person who is chosen by name or position for a particular reason, rather than randomly or anonymously" (2009, p. 124). By the end I had interviewed a mixture of policy actors through semi-structured qualitative interviews. As Clifford et al. describe this type of verbal interchange allows the interviewer to elicit information through prepared questions but it is done so in a conversational manner, with the chance for participants to "...explore issues they feel are important" (2016, p. 143). Therefore, it is a more of a two-way process as opposed to survey or structured interview. These interviews were predominantly with research institutes and universities in Europe, the US and Australia, as well as my fieldwork countries Brazil and China (totaling 35). I also identified five 'activist scientists' in the US, UK, and Australia as instrumental in developing policy for NTDs. Finally for a rounded policy picture, the remaining 15 actors I interviewed were from governance institutions (the WHO being especially important), NGOs, and Pharma companies.

In addition, five of the interviews formed part of a podcast series with colleague Erman Sozudogru at UCL. This was an online podcast and workshop series on NTDs called 'Challenging Neglect'. We interviewed five high-profile academics about their work on NTDs in different disciplines ranging from history, philosophy, and the biomedical sciences and held workshops to discuss disciplinary perspectives.<sup>17</sup>

For the fieldwork interviews, where I wanted to meet actors in their work settings, I did not employ a formal translator. I found that as most of my interviewees were engaged in global policy-making and forums for NTDs, English was the *modus operandi*. When I did need assistance with translation this was provided on several occasions at Tsinghua University and the National Institute for Parasitic Diseases by the colleagues of the interviewee. Translation by colleagues aided the conversation, which can sometime be stifled and formalized by the presence of an outside translator. Still, there was a restriction in using English searches of the literature and for interviewees, which means I may not have included some non-English sources of information and insight.

The typical interview time varied from forty-five minutes at the minimum to up to two hours in some cases. Most interviews were held in the participant's office but in cases where this was not possible a Skype or telephone interview was conducted instead. As well as taking detailed notes, I recorded all interviews and transcribed them. The exceptions to recording, included once when the interviewee did not agree and another when the setting was particularly noisy.

The interview questions were centred on six main lines of questioning:

1. Reason for involvement in NTDs: Can you tell me about your background, what led you to the topic?
2. Problem and solution understanding and framings: What are the causes of NTDs and what are the proposed ways of solving them?
3. Approach being taken to address NTDs: Which particular strategies are being pursued and why?
4. Reflections on the change of term: What is your opinion of the use of the term 'NTDs'?
5. What is the relationship between actors: Who are the main partners you work with?
6. Positioning of Brazil and China within global policies for NTDs: What is being done differently in these countries, what are the challenges, what are the strategies being deployed? (The last question I tweaked the most depending on the interviewee).

(See Appendix 3 for a more detailed list of interview questions).

As the interviews progressed I did aim at greater specificity or directness, although it struck me that interviewees still will want to say what they want, rather than what you want, and this is as it should be. I avoided steering the conversation too heavily, only moving to next questions when

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<sup>17</sup> See [www.challengingneglect.com](http://www.challengingneglect.com).

ground was repeated or asking qualifying questions when answers were unclear, rather than due to my being 'unsatisfied' with answers. It may have been because of the type of interviewees, most of whom were senior scientists engaged in policy and public roles, that opinions and accounts of events had already been formed in their minds and some experienced difficulty in looking at these from a new light. When I did ask questions prompting reflexivity, I often had the response of "you tell me" or "I hadn't thought about that before" or a deflecting answer in order to avoid going into too much detail.

These hurdles may be generally reflective of the realities of interviewing as a research method, disciplinary differences, and the type of interviewee. However what I did find surprising was the level of openness interviewees had about airing disputes and being very frank about dislike for individuals, organizations, and activities, even though many did not want to have anonymity. I have not included all of these references as they were not always relevant to the research but they certainly assisted me in navigating and gaining an understanding of the NTD community.

I gave a varied level of anonymity to all the participants ranging from full disclosure to full anonymity, depending on their preference. After the interviews I transcribed the text and coded the field notes to be classified according to themes, topics, and other relevant categories with the aid of the software package NVivo (See Appendix 4 for node listing). Therefore, my data analysis was supported through creating distinctive categories, which allowed linkages to be made between concepts, and comparisons between cases and events. I then analyzed the coded text and other data inspired by a 'grounded theory approach' in order to concentrate on developing theory related to concepts, relationships and explaining actions to identify the perspectives of groups of actors, reflecting on my interpretative role as researcher. Thus following the general steps typical for grounded theorizing, I did not strictly apply grounded theory, concentrating instead on a close and exploratory-oriented reading of the data. I began with the early stage of data collection and continued up until the writing-up stage with the focus of enquiry clarified over the course of the research.

I developed analytical categories to make sense of the data by coding at the level of theoretical codes. The codes were derived from the data rather than being pre-determined and these involved not only substantive codes but the gathering data from various interviews or documentary sources under the same relevant category (Sapsford & Jupp, 2006, p. 251). It is the segmenting and comparison of data from different parts of the data record that "...distinguishes grounded theorizing from other forms of qualitative data analysis" (ibid.).

I also undertook a small amount of participant observation – described as the observation and participation of the social action being documented (Hume & Mulcock, 2004) – at a number of technical (and semi-technical) conferences and events listed in Appendix 5.

### 2.3.1 Ethical considerations

The departmental ethics board approved my research plan and I gained informed consent for all my interviews according to the criteria listed by UCL Research Ethics Committee ([ethics.grad.ucl.ac.uk](http://ethics.grad.ucl.ac.uk)) on qualitative research. Interviewees were given an information sheet with a consent form and a copy for them to keep. The sheet covered the following aspects of the research:

- Research background
- Project aims and objectives
- Information about who is interviewing
- What the interview will be used for and how
- How information is stored and protected

**Table 2 Overview of ethics sheet**

As mentioned earlier, interviewees were asked if they wanted to be anonymous, what level of anonymity and if not whether they wanted to be informed of which quotes were used, with the possibility to change anonymity after circulation.

### 2.3.2 Qualitative secondary analysis

For a subset of interviews in this thesis I undertook a qualitative secondary analysis. I reused qualitative research data in the form of interviews with individuals who, for various reasons, I was not able to interview. Some key figures who were instrumental at the beginning of NTDs developing as a concept were deceased, from both the 'Great Neglected Diseases of Mankind' Program' (GND) and the WHO Special Programme for Research and Training in Tropical Diseases (TDR).

Kenneth Warren (1929 – 1996) was the director of health services the GND. I interviewed historian Conrad Keating who will publish a biography on Warren in 2017 and interviewed Warren's contemporaries.<sup>18</sup> At the WHO, Lee Jong-wook (1945 – 2006) was director general in 2003, when he initiated changes in the organization for the control and elimination of NTDs (which have been called a 'paradigm shift'). In addition I used secondary research through interviews with Lee published in policy documentation. There were a number of other interviews that I refer to of directors of the TDR WHO, published on policy websites (the WHO and Genève Internationale) of: John Reeder: (2012 – present); Robert Ridley: (2004 – 2012); and Adetokunbo Lucas: (1976 – 1986).

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<sup>18</sup> Nick White is Professor of Tropical Medicine Mahidol Oxford Research Unit and David Weatherall is the founding Director of the Weatherall Institute of Molecular Medicine.



Other high profile individuals whom I did not interview but relied on newspaper interviews included Bill and Melinda Gates the founders of the Gates Foundation, and Nobel Prize winner Tu Youyou. A second reason why I relied on secondary qualitative research was because I was interested in the public-facing representation of NTDs. I acknowledge there are limitations in using this type of data source. Sarah Irwin defines qualitative secondary analysis as: "...the use of already produced data to develop new social scientific and/or methodological understandings" (Irwin, 2013). Irwin with Mandy Winterton state that the distance from primary data production and the related knowledge of "...proximate contexts of data production" can present methodological, ethical, and practical concerns (2011, p. 2).

The focus of my analysis was on the representation of arguments and ideas, therefore the context where the sources were generated is less important. Contextual and situatedness of the sources are points that I address when quoting the interviews, addressing the 'problem of data fit' by providing detail on the nature of the source (Heaton, 2010, p. 4). Irwin and Winterton support this view that: "So long as data analysis is fit for purpose then secondary analysis is no poor relation to primary analysis" (2011, p. 2).

## **2.4 Documentary analysis**

The documentary analysis involved collating and comparing how NTDs were listed and portrayed in various policy documents, meaning that I often produced tables to order information. Overall the analysis was pursued with an interest in the broad ideas portrayed rather than a detailed description of the institutional and political workings (of organizations such as the WHO), which I felt would bring me out of scope.

Policy documents have been an important source from which to view changing understandings of policy. There are clear limits to documentary analysis in that the conversations, viewpoints and other material are not included in a formal and official text. Shaw et al. (2004) list a number of practical reasons for using documentary analysis, including a limited availability of other sources at an early stage of policy innovation but see negatives in partiality, superficiality, and being aspirational. I have followed this advice in using these sources, by noting intentions and planned strategies along with their justifications. I have been wary not to take the meanings of texts at face value, and with a degree of skepticism, looking for alternative explanations and meanings held with underlying assumptions and ideologies. The limitation of policy documents is also why I have conducted qualitative interviews in order to gain an understanding of policy that goes beyond the official lines.

The key documents that I analyzed from the WHO begin with the first important report following an international workshop in Berlin, 18–20 April 2005 (the second of two held in Berlin, with the first in 2003). The workshop was co-hosted by WHO with the German government who provided funding (the German Ministry for Economic Cooperation and Development, the

German Ministry of Health, and the Agency for Technical Cooperation and the Development Bank respectively).<sup>19</sup> Present were, "experts from public health, economics, human rights, research, and other fields" (WHO, 2005, p. ii) who deliberated on steps to translate the NTD agenda into action.

I refer to this pivotal 2005 meeting as the 'Berlin Meeting' and the corresponding first report was called 'Neglected Tropical Diseases: Hidden Successes, Emerging Opportunities' (2006b). This report was followed by three more WHO reports (until 2015) on NTDs, which defined the strategy taken by the organization. See Table 3 below.

2010	First WHO report on neglected tropical diseases: Working to overcome the global impact of neglected tropical diseases
2012	Accelerating work to overcome the global impact of neglected tropical diseases: a roadmap for implementation
2015	'Investing to overcome the global impact of neglected tropical diseases: Third WHO report on neglected tropical diseases'

**Table 3 WHO NTD reports**

The first report set out the state of play, the second was a roadmap of goals and the third concentrated on the investment and financing needed. Other key WHO reports are listed in Appendix 6. Important non-WHO reports included the *Global Research Report on Neglected Tropical Diseases* (Adams et al., 2012) published by Thomson Reuters, looking at the research environment for NTDs; *Delivering on Promises and Driving Progress: The Second Report on Uniting to Combat NTDs* (Uniting to Combat NTDs, 2014) covered in the next chapter about the 'London Declaration' and *Neglected Tropical Diseases: Background, Responses, and Issues for Congress* (Salaam-blyther, 2011) informing US policy.

There were also a number of other institutional reports by international organizations that I reviewed.<sup>20</sup> Country-specific reports included the 'OECD Reviews of Innovation Policy: China Synthesis Report' (OECD, 2007). G-Finder is an annual report by the NGO Policy Cures as a comprehensive source of data looking at global investments in tropical disease R&D (G-FINDER, <http://policycures.org/gfinder.html>, Accessed 2/4/16). Some of these reports were historical documents (e.g. 'The Rockefeller Foundation Annual Report', 1978). Using the reference manager 'Mendeley' helped me order and keep track of sources.

Secondary sources consisted of news articles and video clips. I made use of the BBC online archives on the documentary series Horizon, which explores health and other public interest

<sup>19</sup> Gesellschaft für Technische Zusammenarbeit (GTZ), Kreditanstalt für Wiederaufbau (KfW).

<sup>20</sup> The World Bank World Development Report 'Investing in Health' (1993).

topics.<sup>21</sup> The benefit of such documentaries is in how the cultural currency of the BBC allowed for interviews with top scientists and officials at crucial moments in time. Although there are also caveats in using documentaries, as with any source. They are produced for specific purposes, for example they may need to follow a script or narrative (requiring a narrator who is a voice of authority), and so can be less exploratory in nature, relying on sound-bites rather than description. The NIH US National Library of Medicine has produced a 'Guide to Tropical Disease Motion Pictures and Audiovisuals', comprehensively listing documentaries on tropical diseases (NIH U.S National Library of Medicine, 2014).<sup>22</sup> Arguably the neglected, lesser-known, but impactful nature of these diseases make them attractive to documentary film. The promise of eradication also is a powerful narrative for storytelling – with a conclusion in sight through heroic efforts and breakthroughs. A number of films are produced by the WHO, and appear to be part of their health education and advocacy work.

### **2.4.1 The tropical tales of Robert S. Desowitz**

An unexpectedly rich source has been one popular science writer, Robert S. Desowitz. As Donohoe (2012) notes: "Literature, medicine, and public health share a fundamental concern with the human condition. Through literature, readers can vicariously experience new situations, explore diverse philosophies, and develop empathy with and respect for others whose place in society may be very different from their own". This reader placement is true of the writing by Desowitz (1926-2008) who through his books brings to life tales of tropical diseases. He has been described as: "A veritable Sherlock Holmes of parasites and pathogen" reflecting the intrigue, a fast pace and curiosity of his works (Desowitz, 1991). Tropical medicine is viewed through a portrayal of the scientists involved and policy ideas employed. While his writings did not win a major award nor were they sell-out successes, he was praised for his writing style<sup>23</sup> and the topics he brought to life in the science writing community, (including a highly commended prize from The Medical Writers Group<sup>24</sup> and supportive reviews from the New York Times).

Of course there are limitations of using a single-authored resource and it is used in conjunction with a wide variety of other sources, outlined earlier. I also must acknowledge the particular

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<sup>21</sup> Horizon films relevant to NTDs (The TVDB, <http://thetvdb.com>, Accessed 2/4/14) are: The New Face of Leprosy (1986); Mosquito! (1998); Malaria: Defeating the Curse (2005); and Guide to a Pandemic (2009)

<sup>22</sup> Influential films on NTDs have included: Chagas: A Silent Killer, 2005, Ricardo Preve for Al Jazeera (said to be influential to Argentinian footballer Lionel Messi who then did another documentary); Malaria: Fever Wars (2005) by PBS; The virus hunters (2007) by Steven Jones, WHO; Yoro, the empty granary, (1995) by WHO; and the Compassionate exile (1999) by Bob Madey and Larry Thomas.

<sup>23</sup> A quote by two of Desowitz's mentees sums up his writing style: "Bob's rich anecdotes that tropical medicine was a noble discipline of vast importance to human health and also an adventure involving outsized or odd personalities, hilarious incidents, and great failures and successes" (Miller & Duffy, 2008). Another reviewer said of his books: "the life complexities of the microbial agents of disease are more than matched by that of human behaviour" (Wilkinson, 2004).

<sup>24</sup> The Medical Writers Group or the book prize was given for 'Federal Bodysnatchers and the New Guinea Virus' (2004) (Wilkinson, 2004).

lens that he looks through. While culturally sensitive and having spent years in the field, Desowitz is from the US and identifies with an American outlook. For example, at one point he asks why the Mexicans were not grateful for being relieved of yellow fever and speaks from and to an American perspective when reluctantly conceded: "We see only ingratitude where we should, instead, have empathy for the hurt national pride of the beneficiary countries, which may also have antipathy for the donor countries that they too often perceive as economic and political aggressors" (Desowitz, 1991, p. 174).<sup>25</sup> He is not a trained anthropologist, historian or social scientist, he is a doctor and epidemiologist first and foremost.

However, it is also worth highlighting the benefits in exploring one perspective of how tropical disease is communicated to a public and lay audience, which he does exceptionally clearly as a medical specialist. Like other doctors who have written medical histories he is interested in the doctors or scientists and their stories of scientific discovery but does also engage to an extent in the policy and politics of disease. His books spanned the 1980s to early 2000s and he was able to capture the changing story of tropical disease. Desowitz was not active in writing when these diseases made their final iteration as NTDs (and indeed it would have been interesting to see his perspective on them). He had already charted a vividly descriptive evolution of tropical medicine, encapsulated in six books.<sup>26</sup> The book series was compiled from field stories, interviews and many years of experience in tropical medicine as an epidemiologist, official at the WHO and academic, with a career spanning over 60 years, the last 20 of which he spent producing popular science works. These books are shown below in table 4.

Date	Title
1987	New Guinea Tape Worms & Jewish Grandmothers
1988	The Thorn in the Starfish
1991	Tropical Diseases: From 50,000 BC to 2500 AD4
1993	The Malaria Capers
1997	'Who Brought Pinta to the Santa Maria
2004	Federal Body Snatchers & the New Guinea Virus: Tales of Parasites, People & Politics

**Table 4 Books by Robert Desowitz shown by date**

It is the title of his last book that sums up most tidily his contribution in: 'Parasites, People and Politics'. His focus of interest lay in parasites, the people they inhabit, the pursuit of cures and the political treatment that pursuit involves. 'Malaria Capers' was most probably his most famous book, shown through the media coverage at the time. It is his most journalistic and also

<sup>25</sup> The critique of the Rockefeller Foundation as a cultural imperialist is also overlooked, in underlying: "...cultural imposition of American culture and values abroad; favouring elitism rather than equity; ideologically trying to vindicate capitalism; and investing in health to make the tropics safe for commerce" (Chen, 2014, p. 718).

<sup>26</sup> Desowitz began writing for the public in 1976 writing for the public with an article for the Natural History Magazine (Miller & Duffy, 2008). The article was entitled 'How the wise men brought malaria to Africa' and sparked a life-long interest in popular science writing.

his most critical with the second half of the book dedicated to exposing corruption in malaria research, most specifically the illegal mishandling and misuse of USAID funding by scientists (and an administrator). In his other writings this policy gaze was also evident when he took on patents in 'Federal Body Snatchers and in the New Guinea Virus: Tales of Parasites, People and Politics'. Insights taken from Desowitz's body of work will be referred to throughout this thesis.

Desowitz also undertook a self-reflection of his own involvement with tropical diseases. When he began his career in the 1950s he was told: "Malaria is about to be totally eradicated, and you will never make a career, let alone a living, from it" (Desowitz, 1987, p. 12). The supposed near eradication of malaria was why he switched to trypanosomiasis research but "(B)y the 1970s, malaria was more of a threat than ever, at the expense of interest in the trypanosomiasis" (Wilkinson, 2004). Such a snippet is emblematic of a group of diseases that are closely connected to the promise of eradication, to varying degrees, where at least the possibility often appears in near sight. It is a constant movement for which diseases require attention. The quote extends to Desowitz's very premise about the category of tropical disease in challenging preconceived ideas: "Well, these diseases that we call "typically tropical" have been as American as the heart attack" (Killheffer, 1997). He held a deeply informed and open outlook on these diseases in time and space. As well as touching upon the related politics of science and medical practice, he was aware of the effect the term had on how the diseases were viewed.

Terminology forms a topic that I am concerned with throughout this thesis. My disciplinary background in development economics has led me to have a preference for the terms 'developing' and 'developed'. I also see the disciplinary preference in STS to use 'global north' and 'global south', which I do use occasionally but my contention is that these terms send across a false geographic message, even if implicitly, in an imagined or constructed south and north. 'The West' as ideological positioning and political hegemony is a term I use occasionally.

Tariq Khokhar a data editor at the World Bank and colleague economist-statistician Umar Serajuddin reflected on the use of the terms at their institution:

*"Humans, by their nature, categorize. Economists are no different. For many years, the World Bank has produced and used income classifications to group countries. The low, lower-middle, upper-middle and high income groups are each associated with an annually updated threshold level of Gross National Income (GNI) per-capita, and the low and middle income groups taken together are referred to in the World Bank (and elsewhere) as the "developing world." This term is used in our publications (such as the World Development Indicators and the Global Monitoring Report) and we also publish aggregate estimates for important indicators like poverty rates for both developing countries as a group and for the whole world. But the terms*

*“developing world” and “developing country” are tricky: even we use them cautiously, trying to make it clear that we're not judging the development status of any country” (2015).*

This is an interesting consideration of terms, especially as some scholars, such as William Easterly charge that the World Bank means something 'lesser' in referring to 'the Third World' or 'less-developed countries' as places devoid of "liberty, freedom, equality, rights, or democracy" (2014, p. 5). Easterly believed this characterization of countries is shown by the limited role these concepts play in their reports, a linguistic omission to avoid the consideration of government in development. He had the following extraordinary response when querying:

*"Questioned about the remarkably consistent omission of the word democracy from World Bank official reports and speeches, for example, the World Bank Press Office explained to this author that the World Bank is legally not allowed by its own charter to use the word democracy" (ibid.).*

Economist Branko Milanović similarly talks of how the World Bank has preferred not to use the word inequality but the 'watered down' version 'inequity' (see his 2011 book 'The haves and the have-nots') instead, looking for more technical rather than political reasons for poverty: "Every study on inequality, of course, challenges the structures not only of the economy but also of the world we live in, and these questions are not always welcome... it was very, very difficult to get any type of grants for research on inequality..." (Milanović, 2016).

There are evidently problems in using the terms 'developing' and 'developed', not least the question of when does development happen, when does development stop and where is all of this development leading to? It immediately gives the impression that certain countries are done, they have achieved an ahistorical state, while others lag behind, they are lesser, always catching up and always sub-par. At the time of my training 'developing' and 'developed' were deemed better than using 'First world' and 'Third world', which were seen as particularly derogatory. Also commonly used were high-income, middle-income, and low-income. These are more neutral in some ways, although have the drawback of being three groups, that can begin to get messy, especially as more subcategories are used such as 'higher middle income' and 'lower middle income'. I also think that the perceived neutrality of these terms is a misnomer because there remains of politics of categorization, in why some countries belong to one group and some to the other – it is an organization that cannot be done in an objective way.

I have even less preference for the terms 'highly industrialized' and 'unindustrialized' as it is very difficult to say where the cut off is and it sounds especially old fashioned to claim that countries need to have an industrial revolution to develop. To me 'developed' and 'developing' accepts that we have perceptions of some countries being in one group and others in another, dependent on country types, their histories, when they have 'developed', their relationship with other countries, and their aspirations for the future. It is not perfect but they are the terms I find

most agreeable and as long as limitations are acknowledged, especially in providing detail, contradictions, and tracking changing circumstances, they serve an adequate function in this thesis.

The dividing lines and distinctions run deep in understandings between the 'developed', 'global north', 'the West', 'industrialized', 'high-income' and 'the rest', 'subaltern' (in reference to colonial relations) or the 'other'. The status is of inside or outside, with other terms such as the 'centre' and the 'periphery' demarcating that there is somewhere that countries want to be and somewhere else, where they want to move away from. Anthropologists have often considered this positioning between one and another. The ethnographic 'other' according to Rapport and Overing has been the anthropological object, "...reified, homogenized and exoticized" but as objects they are silenced (2000, p. 98). The 'other' has "negative properties in Western thought, for they cannot speak, think, or know" and these descriptions apply to people or peoples, but could very well be applied to countries as well (ibid. p. 99).

One of the central dividing lines, apart from wealth and industry, is science<sup>27</sup> and the epistemological privilege it provides: "...the idea of the superiority of Western culture, particularly its spectacular scientific success, became the potent and decidedly unliberal yardstick through which anthropologists assessed the accomplishments of other cultures" (ibid.). The very analytical categories that we use such as scientific and unscientific, cause unhelpful binaries and ignorance to cultural relativism, as "...the other's local was to be understood within the context of our local, which in the end became a universal standard, not only of judgment, but for description as well" (ibid., pp. 99 - 100). These are important methodological considerations in the use of terminologies and distinction made with the 'other', to take forward throughout the rest of this thesis.

## 2.5 Introducing new terms

I want to introduce some new terms I use that have arisen as out of this research. This was not for want of inventing new jargon but because I did not have the language to adequately describe the NTD story. These are:

1. Activist scientists
2. Policy repackaging
3. Elite policy movement

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<sup>27</sup> in addition to the dividing lines between 'western' and 'other' are associated values of democracy, economic growth or competitiveness, power, military might, culture and education, secularism and so on.

## 2.5.1 Activist scientists

My intention initially was not to follow scientists. However during the course of this research I found it was scientists who were precisely the ones most active in generating policy for NTDs and a more limited activity of other groups. This point may appear to be an obvious if these diseases are 'neglected'. Still it is a common focus of researchers studying other diseases or disease groups to look at how patients have brought attention to diseases, but with NTDs this type of patient activism is not happening (Epstein, 1996; Klawiter, 2008; Macq, Torfoss, & Getahun, 2007; Rabeharisoa, 2003). I found instead that a dozen core scientists have been actively involved in promoting the NTD cause along with a handful of other personalities that span from the economist Jeffery Sachs (see Sachs, 2007) to politicians such as Baroness Hayman in the UK, whose involvement can often be tied back to the core scientists (Interview with author, Hayman, 2013). I will explore activist scientists in Chapter 5.

In addition, student medics have typically been a group concerned with NTDs such as the non-profit organization Universities Allied For Essential Medicines (UAFEM). Pharma companies have varying levels of dedicated involvement from research groups to drug donation programs – including Merck & Co., GlaxoSmithKline, Johnson & Johnson, Pfizer, Novartis and Sanofi-Pasteur. As do governments, with the biggest example being USAID's Neglected Tropical Disease Program launched in 2006 (streamlined under President Obama's Global Health Initiative in 2009). However, the driving actors are the activist scientists, who have defined the terms, influenced policy agendas and created networks of interested parties, establishing their own lobbying governments and NGOs. I show how scientists became politically engaged to transform tropical diseases into NTDs through a policy repackaging.

## 2.5.2 Policy packaging

A term that encompasses both advocacy and measurement is a policy packaging. NTDs are a conceptual packaging – more accurately a repackaging – of what is essentially the same (narrowed-down) collection of tropical diseases. I call this a policy repackaging because it is through policy that tropical diseases have been reconceptualized and is more than a simple renaming.<sup>28</sup> Nor is it turning an issue into a problem by a categorization in different ways as Zahariadis (2016) describes, drawing on Schattschneider's idea of 'redefinition' of issues, although categorization does play a role.

In fact a number of authors use the term repackaging in book and article titles but do not always offer an explanation for what they mean by the term or make explicit relation to policy; it appears

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<sup>28</sup> Chapter 5 outlines the change of type of diseases listed as tropical diseases to the NTDs and what rebranding in health policy means.



to be taken for granted that the meaning is obvious.<sup>29</sup> Joan Fujimura used a notion of packaging in her paper 'Constructing 'Do-able' Problems in Cancer Research: Articulating Alignment' (Fujimura, 1987). Here she referred to 'standardised packages of tasks' in the need to package the work of scientists through modularization and standardization as a strategy to make dissemination easier. Through Fujimura's use of the term, packaging articulates the way science is done through a technique, procedure, or task. Likewise the 'packaging' approach can also be applied in the realm of policy, with the aim of simplifying, regularizing, and providing distinctive boundaries. When I refer to the term policy repackaging this is in relation to the policy treatment of a new way of viewing a policy problem. Other scholars have explored conceptual packaging in policy along similar lines, to refer to how a policy is conceptualized as a representative and coherent whole, but tend not to relate to the means of repackaging as being through policy (see Ferrero-Waldner, 2006; Rusi, 2007).

I use packaging in a similar vein to framing, where to construct meaning through 'frames', is to apply a definition or interpretation to the social world, as I will discuss more in the next chapter. Communications theorist Van Gorp considers 'frame packages' as a way of grouping frames of reasoning about an issue of an event into a coherent collection of for, "...definition, an explanation, a problematization and an evaluation" (Van Gorp, 2007, p. 65). The reason I use the term packaging is the stronger connotations with commodification and marketing. A policy problem is packaged in such a way to compete with other policy ideas and is especially the case in the 'global health marketplace', where diseases vie for their place on policy agendas, to move along priorities and hierarchies of importance and urgency. Chatterjee describes how packaging for a commodity is intended to be visually differentiate in order to attract a particular group (2007, p. 293). As I will discuss in Chapters 5 and 6, repackaging is what the NTD term does in differentiating tropical disease from what it had previously been understood to be.<sup>30</sup> Although as Mata and Louca argue, drawing on the work of George Stigler in the 1960s, the worlds of business and of intellect are not so disconnected in that, "...both fields pay a fair amount of attention to packaging and advertising, and both fields place an absurdly high value on originality" (2009, p. 13).

### 2.5.3 Elite policy movement

Endemic countries may have a different perception of policy repackaging. Indeed when I presented my research to an audience of international researchers, one Brazilian researcher

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<sup>29</sup> Titles referring to 'repackaging' relating to policy include: *Repackaging exemptions under National Health Insurance in Ghana: How can access to care for the poor be improved?* (Derbile & van der Geest, 2013). Or a repackaging of a policy problem through renaming, as Measham and Brain (2005) give the example of 'lager louts' to 'binge' drinkers in "*Binge" drinking, British alcohol policy and the new culture of intoxication.*

<sup>30</sup> Malaria would be later excluded from the NTD grouping as well as the multitude of less serious or well-treated tropical diseases that would not be included under the 'neglected' banner.

remarked: "We do not call these neglected tropical diseases, to us these are diseases" (STS Fellows meeting, Harvard University, 2014). He described NTDs as diseases he had grown up knowing, so in a way it was bemusing that an outside community would give them this label. Indeed NTDs are 'common afflictions' to the world's poorest people.<sup>31</sup> NTDs are heterogeneous diseases, and commonality is not found in pathology or etiology but through labeling based in socio-political grounds. Presented to a donor audience, the diseases cannot be ordinary and it takes a directed form of policy action to construct the idea of why NTDs need to be cared about. The construction of caring has happened through a policy movement.

The idea of a policy movement opens up the discussion to encompass activism on a much broader level, to locate action on a scale and not only radical change within the public sphere, social groups or civil society. However it is elite in being directed by a small group of scientists based in the UK and US to create the NTD repackaging and may not reflect local understandings. I go into more detail about what I mean by this in Chapter 6. It is a privileged group by their permanent contact with key global health organizations, wealthy philanthropists and prestigious academic institutions.

There are inherent problems of globalized policy making, which is universalist in scope, contrasting with statist limitations and contradictions in localized strategies or approaches. Scale considerations go beyond local and global, the division lines of size, reach and expanse of policy making are not clear-cut. Measuring the scale of neglect is an interrelated issue and as a discourse became a prominent theme in this thesis as a form of evidence, to complement how advocacy has been applied through activist scientists.

I have discussed the new terms that I have introduced but at the heart of those conceptions is the methodological question: how can an analyst observe neglect? Neglect is what activist scientists are trying to overcome through their agency and through the means of a policy repackaging, policy movement, and reflected in public discourses of measurement. But how is best to study something that is said not to be known or cared about?

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<sup>31</sup> Global Network, <http://www.globalnetwork.org/>, Accessed 2/4/16.

## 2.6 Exploring neglect

To explore neglect in how it can be analyzed and theorized, I drew insight from a body of work within sociology about the study of absence. Balmer and Rappert in their book 'Absence in Science, Security and Policy: From Research Agendas to Global Strategy' (2016) raise a number of points related to causality between absence and presence, and the production of absence. The presence of certain activities and events such as the Millennium Development Goals (MDGs) can be seen as cause of neglect for tropical diseases. Neglect also does not occur naturally, but is caused by actors, or structures, or both. Pharma companies and global public health policy are pinpointed to identify how neglect has been produced. Crucially, what needs attention is not straightforwardly what is missing recognition, but understanding the type of absence becomes a central point. Neglect is a special type of absence in being defined by what it is not, as with NTDs.

While methodology for the study of absences proves of use for researching neglect, Sudeepa Abeysinghe (2015) also sees neglect through NTDs as a counter case for the ignorance literature where the negative impacts of the social construction of non-knowledge is emphasized. The connection with the ignorance literature and NTDs through Abeysinghe's working paper is welcome, however ignorance may have been a too hastily applied label, possibly because there is not an advanced sociology of neglect literature. She considers a key methodological point about how to investigate issues of ignorance, in that it is not merely the absence of knowledge but used as a rhetorical and constitutive device.

In relation to this thesis, ignorance may be one aspect of neglect but I argue that lack of knowledge or information is one of many other possibilities, which is why the absence literature forms a more inclusive theoretical basis to draw upon. Looking for a methodological framework for exploring absence, I found that Frickel in 'Absences: Methodological Note about Nothing, In Particular' (2014) takes a step toward a conceptual understanding of holes or gaps. In doing so he also notes that STS is characterized by a relative absence of absence-related research, in that:

*"The vast majority of published STS research is about knowledge production, not the non-production of knowledge; our accounts typically privilege action over inaction; we study processes of becoming or emergence, far more than processes of winnowing or submergence; we are more interested in beginnings and successes than endings and failures"* (2014, p. 87).

It is this 'undone science' that Frickel (2014) describes as he studies 'social movement and other civil society actors' to find areas ignored by scientific and regulatory communities, for which he explores: "What explains the selection of certain areas of scientific research and

technological design choices and the neglect of others?" (Frickel et al., 2010, p. 88). Frickel offers ten methodological considerations to study absences, which I use to varying degrees in this thesis (2014, pp. 89-90). These considerations amount to treating neglect not only as an absence of something but a social object and process in its own right, through the making of neglect, that requires: (1) explaining structural conditions; (2) questioning otherness; (3) considering the of meaning of neglect and to whom; (4) a scope with concise and conceptually bounded definitions; (5) considering history, culture and organizational contexts; (6) measuring the shape of neglect in temporal and spatial terms; (7) measurement of relations; (8) and densities of neglect; (9) comparison of neglect through case studies; and finally (10) reflexivity of my treatment of neglect. See Appendix 7 for more detail. This methodological underpinning is not where I end with neglect. I undertake a deeper exploration of the concept in Chapter 3 and will return to thinking on neglect throughout the entire thesis.

## 2.7 Concluding thoughts

This chapter has covered the foundations that I have laid out to research new conceptual ground in relation to NTDs, from the point of view of the advocacy and measurement to address neglect. In the first part I outlined my methods for qualitative research and set out my three main research aims. First was to connect NTDs conceptually with tropical diseases through a brief history of policy; second to explore the policy development of NTDs through advocacy (concentrating on activist scientists) and measurement (to provide evidence and persuade); and third to provide examples of neglect through endemic country stories, mainly encompassing Brazil and China.

In the second part I discussed my main documentary sources and introduced the terms I use throughout. These are: 'activist scientists', 'policy repackaging' and, 'elite policy movement'. I explained what I mean by these, the reasons for limiting my scope, and why I have chosen these terms. It is my contention that NTD research could benefit from new theoretical vocabulary. My overarching objective is to conceptualize what neglect means in policy.

## Chapter 3. Approaches to policy problems

### 3.1 Introduction

The introductory chapter explained how NTDs have been presented as a policy problem and why I am interested in how these diseases arrived at this position. The theory I draw upon for my research is grounded in the way that policy problems can be approached, to make sense of the 'who, what, why and where' that leads to a topic being considered as a problem for policy. This chapter therefore aims to provide a theoretical basis on which to build and interpret my empirical research on NTDs by considering: Whom is it a problem for and what causes it? Where did it originate? Why does it persist? What constitutes a problem for policy? These questions will be revisited throughout the thesis, with the intention of contributing to the debate about the nature of policy problems. In particular I bring together a number of strands of literature about policy problems: (1) the constitution of policy problems; (2) innovation for solutions; (3) the landscape of global health; and (4) neglect as a concept in policy.

Firstly, I ask what a policy problem is. The idea of problematization is a starting point to explore how a policy problem is constituted. I use policy in a broad sense as I have described in the previous chapters, where other actors – including those in the public, private and philanthropic sectors – can contribute. I cover problem types, how measurement and advocacy is used to problematize, and how policy can be expressed as narrative.

Secondly, this chapter will cover the role of innovation in solutions, influenced by the language and ideas of economics. I introduce innovation into thinking about NTD policy because it is pervasively present in strategy, rhetoric, and activities. Consequently for a global health problem, innovation will be a part of the problem and solution rationale. The role of innovation in policy problems will be revisited in various forms in different chapters. In Chapter 5 innovation is observed through the drug-based strategies as solutions for neglect that characterize how neglect is understood. Then in Chapter 6 innovation is understood as the difference between the old 'field-hand' science of tropical medicine, transitioning to a modern science of biotechnology and genomics, as well as challenges to the innovation system.

Thirdly, the various disciplinary approaches taken to policy problems, including how my own approach has been informed, builds upon methodological questions put forward in Chapter 2. However, this is a topic that cannot be covered in one step and remains a thread that I return to throughout the thesis.

Fourthly, I will discuss the meaning of context or setting for global health, through the particular actors involved and an evolving landscape. Health actors are described here as groups of

individuals, organizations, and institutions that play a major part in global health policy processes, providing the landscape of which NTDs are part of. Chapter 4 expands on this premise in charting the background to NTDs as a policy problem through timelines of major events and milestones, the evolving disease lists and the various health actors involved, set amongst changing health institutions, initiatives, and advocacy.

I then move to the particularity of the NTD policy problem characterization: neglect. Neglect is one description of many that can be used to characterize a policy problem and the concept is my central concern in this thesis. Neglect features in each chapter as I address the particular assumptions made about the nature of problems and solutions through the neglected label. Later in this chapter I compare 'neglect' with closely related characterizations of absence and care. To summarize, I draw upon four areas of literature:

- 1. Problematization in policy.** Problematization is an idea that has a well-established intellectual basis through the work of Michel Foucault. I also bring in scholarship by public policy theorists who address policy problems, and present the value of understanding policy as narrative. I consider problem types on the grounds of solvability by through the 'wicked problems' and 'anticipatory problems' literature, and make the case for attention to 'neglected problems'. An ongoing theme in this thesis is the use of measurement and advocacy in constituting policy problems. I primarily discuss 'evidence-based policymaking' and 'social movements' as how measurement and advocacy are commonly described in policy.
- 2. Innovation conceptualization for solutions.** I consider the interaction between policy and ideas of innovation as solutions to policy problems. Economics and political science have formed much of the mainstream thinking, supplemented and challenged through contributions by management science, organizational studies, sociology, innovation studies, and science and technology studies (STS).
- 3. Disciplinary lens: economicization, historicism, and interdisciplinarity.** Economists, historians and a variety of disciplinary actors from epidemiologists to health economists and anthropologists are influential within global public health policy, often as part of interdisciplinary teams. The disciplinary lens taken by analysts towards policy problems has been most evident through economics but other disciplines are also proving influential.
- 4. Global health actors and landscape.** A body of literature has developed charting a new era of 'global health'. Katherine Kenny calls global health the "...preferred label for attempts to govern the health of the global population" and so it is an idea closely tied to interaction and decision-making in the pursuit of health (Kenny, 2015, p. 9). Sophie Harman describes how new institutions and older institutions, including non-governmental organizations (NGOs), and private philanthropy have led to a blurred landscape of global health governance lacking the "...leadership as to how such institutions could work together" (2014). From here I will consider the understanding of neglect, from constructing

a policy problem to the approaches to tackle NTDs, as a feature of policy by drawing on the absence and care literature in sociology and STS.



## 3.2 Problematization in policy

### 3.2.1 Problem types

The nature of problem types<sup>32</sup> in policy is an under-explored question, despite early research by political theorists David Rochefort and Roger Cobb (1993) on the broader topic of 'problem definition'. It should also be noted that despite being used interchangeably, issues and problems are different in that, "(L)exically, an issue is a dispute between parties in which they join in the hope of arriving at a decision or solution" (Strydom, 1999, p. 71). A divergence of opinion is already assumed in how to reach a solution, which is not an uncommon situation for policy problems, as it is unlikely that all parties will be in agreement about the best course of action to reach a resolution. The difference then is that an issue is the emphasis of competing parties and their claims to reach a decision or solution, while a problem emphasizes that a situation is not wanted and needs dealing with, even if it is difficult to achieve. Therefore issues are more about relationships and problems about identification.

A problem is: "A matter or situation regarded as unwelcome or harmful and needing to be dealt with and overcome" (Oxford Dictionaries). It is recognizing that an undesirable situation exists that must be resolved, while a second definition of problem is: "A thing that is difficult to achieve" (ibid.). Therefore, a degree of difficulty is already implicit. To identify problems, make lists, prioritize, is determined by how undesirable the situation is and the difficulty or ease it is to solve. Therefore importance, urgency, and solvability are key tenets of what it means to address a problem. However, directing efforts towards identifying and strategizing problems concerning the public, society, or humankind, has not always happened on a coordinated or high-level manner.

The most famous early instance listing problems was by David Hilbert over a century ago, when he defined a set of 23 unsolved mathematical problems. These problems were listed as a set of 'Grand Challenges' and would be repeated by other disciplines. A global outlook on policy problems has produced more concerted efforts towards generating lists and directing organizational efforts towards solutions. The Bill and Melinda Gates Foundation 'revitalized' the concept in 2003 by identifying 14 Grand Challenges in global health, extending funding to \$100m in 2008 through their 'Grand Challenges Explorations' five-year initiative (Grand Challenges Canada/Grand Défis Canada, 2011). The initiative concentrates on basic research, as Bill Gates describes: "By harnessing the world's capacity for scientific innovation, I believe we can transform health in the developing world and save millions of lives" (quoted by Kelly & Beisel, 2011, p. 79). Other governments, universities and NGOs have since adopted the term, including the Canadian Government (Grand Challenges Canada/Grand Défis Canada, 2011),

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<sup>32</sup> In 'problem types' I mean ideal types in the Weberian sense as an abstract, hypothetical concept (Hekman, 1983), to produce a broad characterization of the nature of a problem.

which focuses on global health and UCL (University College London) with six challenges across different topic areas including global health.<sup>33</sup>

The listing of problems in a goal-orientated way, has been viewed by some to represent a techno-scientific optimism. As Kelly and Beisel caution it is a, "... problematic analogy between global health and algebraic puzzles" (2011, p. 79). I question whether global problem lists are thus a continuation of the modernist epoch described by Isabelle Stengers?:

*"...fifty years ago, when the grand perspectives on techno-scientific innovation were synonymous with progress, it would have been quasi-inconceivable not to turn with confidence to the scientists and technologists, not to expect from them the solution to problems that concern the development they have been so proud to be the motor of. But here too – even if it is less evident – confidence has also been profoundly shaken. It is not in the least bit ensured that the sciences, such as we know them at least, are equipped to respond to the threats of the future" (2015, p. 29).*

Stengers sees the 'grand perspectives' of listing problems as part of an optimistic view of scientists and technologists. However, their ability to address future threats remains uncertain. Indeed, it is the anticipatory problems looking to the future that appear the least solvable by science and technology. Other considerations about types of policy problem tend to centre upon broad topics with an extrinsic as opposed to intrinsic view of problems. They are based on the spheres that problems inhabit (health, development, environment, welfare – as we see with how 'Grand Challenges' are ordered). These are based around public perceptions and government resources. Fewer sources focus on characteristics describing the nature of problems, in terms of their solvability.

The characterizations that I am interested in are problems and their relation to solvability, which plays on dichotomies. Problems can be wicked (opposed to tame) by level of difficulty; anticipatory (opposed to established) by degree of determinability; or neglected (opposed to acknowledged) by amount of attention and care. These problem types may be described as meta-characterizations, as there are many ways that problems can be characterized but I am looking for larger groupings that have been popular in discussions of policy problems. I propose Table 2, as a description of the major types of policy problem based on common characterizations of solvability and opposite (or alternative) scenarios.

Type of problem	Opposite scenario	Values	Reference
<b>Wicked</b> weaker and stronger levels of difficulty with super wicked to	Tame, simple/ straightforward	Past and future, technical, local and global,	(Rittel & Webber, 1973) (Cairney, 2012;

<sup>33</sup> UCL Grand Challenges, <https://www.ucl.ac.uk/grand-challenges>, Accessed 2/4/16.

insoluble or complex and complicated		everyone	Ramalingam, 2014)
<b>Anticipatory</b> grades of determinacy from predictive, forecasted to speculative	Established, current, immediate	Future, technical, global	(Anderson, 2010)
<b>Neglected</b> with wider/public portrayal low-profile and unrecognized	Prevalent, acknowledged, well- known, high-profile	Political, local, minority groups	(Rappert & Balmer, 2016) (Harman, 2014)

**Table 5 Major types of policy problem and opposite scenarios**

Looking at this collection of characterizations I can make some observations about different types of problem. Here we can see where a 'neglected' characterization might fit in relation to other characterizations and what those different policy treatments might mean. It is certainly the case that characterizations follow hype and trends, as certain characterizations are more popularly used at various times than others. The values encompassed relate predominately to how the problem manifests in time and space (local/global or past-looking/future-looking), who is affected (a particular group or everyone) and who is responsible for solutions (depending on a whether it is a technical or political problem). Characterizations may also say something about what types of problems are of concern. I identify three problem types on the grounds of solvability, which are outcome-orientated ways of looking at problems. What connects the problem types is that they confront knowability and knowledge, where uncertainty defines both problems and solutions. Existing knowledge may limit the ability to solve problems, as does knowability in the capacity to know, which might be limited by uncertainty.

### ***Wicked problems***

Wicked problems are those that, "...are difficult or impossible to solve because of incomplete, contradictory, and changing requirements" (Ramalingam, 2014). What is the remedy for difficult or even impossible solvability? Complexity theory has been one proposal, for example the 'Complex Systems Tools project' is a UK Department For International Development (DFID) project looking at what research tools can be developed to study complex systems (ibid.). With an emphasis on systems, it aims to be a reaction and response to the non-linearity of problems (Goldstein, 1999). As a broad field, which purports to span the natural and social sciences, some have called it more of a 'research approach' or even a 'new scientific paradigm'. Complexity theory has taken off in the last forty years in an effort to address large-scale, indeterminate and multi-level problems. Cairney offers the following definition:

*"Complexity theory is generally sold as a new approach to science in which we identify (and then explain) systems or processes that lack the order and stability required to produce universal rules about behaviour and outcomes. When applied to the sciences as a whole, it is described as a revolutionary break from the 'reductionist' approach to science and the 'paradigm of order'..." (Cairney, 2012, p. 347).*

The focus is on interconnectedness, adaptation and unpredictability rather than a mechanistic and reductionist means of science. The method for addressing problems relies on quantitative experimentation through models and simulations, creating computer assisted or generated versions of real-world scenarios, outcomes and interventions.

### ***Anticipatory problems***

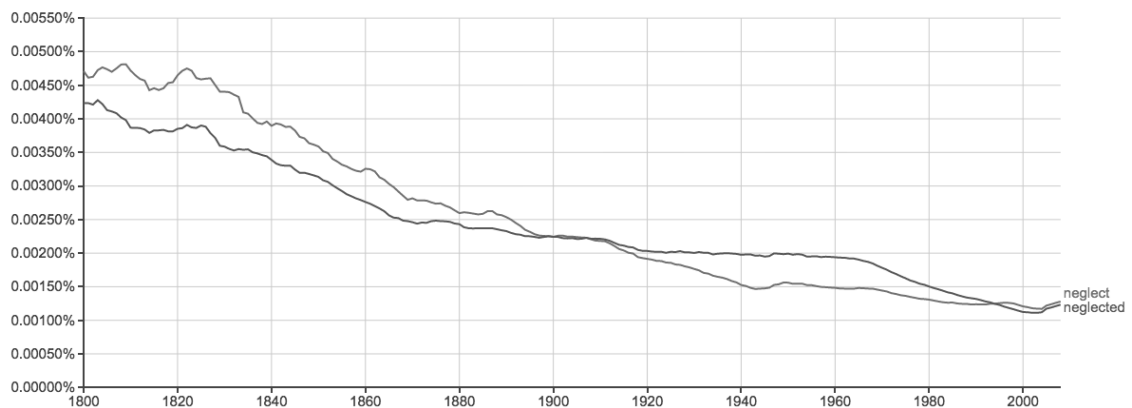
Human geographer Ben Anderson has described how: "Across different domains of life the future is now problematized as a disruption, a surprise. This problematization of the future as indeterminate or uncertain has been met with an extraordinary proliferation of anticipatory action" (2010, p. 777). He argues that we need to think about the future to avoid assumptions about linear temporality but not as a "blank separate from the present or that the future is a telos towards which the present is heading" (ibid., p. 778). Thus we begin to see more concern with anticipatory problems. As Adams et al. describe: "One defining quality of our current moment is its characteristic state of anticipation, of thinking and living toward the future. Anticipation has epistemic value, a virtue emerging through actuarial saturation as sciences of *the actual* are displaced by *speculative forecast*. It is a politics of temporality and affect" (2009, p. 246, emphasis original). Anticipation has been commonplace in governing emerging technologies through geo-engineering, nanotechnology, and synthetic biology as soon-to-be problems (Guston, 2010). Current unforeseeable problems caused by unknown social and ethical consequences – for example of 'de-extinction' (using DNA techniques to bring back extinct species (Zimmer, 2013), the existential threat of asteroids (Matheny, 2007) or uncontrollability of artificial intelligence (Bostrom, 2002).

### ***Neglected problems***

I will discuss the term 'neglected' as a characterization throughout this chapter. Perhaps as a distinct policy problem category it has not been developed fully in the literature, especially compared with wicked problems (Gusfield, 1976) and anticipatory problems (Anderson, 2010). To some extent the idea of neglect has been considered in the public policy literature but without a name given to it. Bachrach and Baratz in the 1960s already conceptualized the study of governmental decision-making where: "Policies reflect not only the preferences and power of those groups whose problems have been addressed" and the ability of groups to limit institutional attention to issues reinforcing or augment the status quo (in Zahariadis, 2016, p. 2). Subsequent research interest has been in the 'pre-political', 'pre-decision-making' and non-decision-making in the 1970s, followed by explorations of the 'policy agenda' (Cobb & Elder, 1971). Today the absence and ignorance literature opens the door to how attention, through knowledge and non-knowledge is applied to policy.

Solutions proposed for neglect is a recognition that attention is needed, as well as associated funding and resources. As a specific policy topic, neglect often encompasses vulnerable groups who are unable to care adequately for themselves, from children to the elderly who are

subjected to a 'passive form of abuse' (Pillemer & Finkelhor, 1988). Still, neglect as a descriptor may have fallen in use over time as indicated by looking at a Google Books Ngram Viewer.



**Figure 1** References to neglect in books 1800 – 2016

(Google Books Ngram Viewer)

Through these characterizations there are some general observations to be made. Two states of opposite problem scenarios are commonly described (as shown in the Table 2, p. 51). A problem is presumed to be a negative state that is fixed, at least in one moment in time, with uncertainty about the state of a problem downplayed. This downplaying is ironic as these problem types are characterized (and have in common their uncertainty) in regard to knowledge and knowability. Problems are portrayed as existing in stable, knowable and certain states that move in a direct line to solution. For Turnbull this direct line is a reliance on the scientific method, to move on an "...artificial, instrumental path from problem to solution" (2008, p. 85)

If we have a negative scenario there must be an imagined possibility of a positive, improved scenario. A name for such a negative-positive scenario is a 'balance routine', used in ignorance studies for the assumption that there are two sides to every problem (Proctor & Schiebinger, 2008). Alternatively, Stengers proposes ways to conceive of a positive ontology for a problematic through an effort to "...slow down' reasoning and create an opportunity to arouse a slightly different awareness of the problems and solutions mobilizing us" (in Latour & Weibel, 2005, p. 994). Differentiation and dichotomy remains a constant source of enquiry for STS scholars and others in the social sciences.<sup>34</sup>

Latour has famously objected to the naturalized dichotomy between nature and society, in subject-object and fact-value distinctions (McGonigle, 2012). Along with other scholars, he has shown that in actuality types are rarely fixed with connections not easily separated. Problem

<sup>34</sup> The most famous study of 'others' is perhaps Said's classic *Orientalism* thesis (2003 [1973]). This was not only a postcolonial study of difference explained by unequal power relations but a way of viewing the distinction made between the east and west structurally, as a discourse. Similarly in reference to regimes, Bauer (1997, p. 55) identifies a structural difference in the opposite universes of, "...universalist, scientific and technological world with particularistic national or religious regimes, having both 'positive consequences' but also 'massive de-socialization'.

types exist on a scale that may regress, may be part solved, are medium-term (or hold short-term and long-term components) have multiple characterizations or two-and-fro between states. The optimism and plausibility of solutions are apparent with a leaning to techno-scientific progress, more commonly described as innovation.

What do problem types and the dichotomy produced between negative and positive scenarios tell us about how problems are constituted? If neglect is a particular problem type, with a positive scenario of acknowledgement and a high profile, how does a problem come to be identified in the first place and secondly with what type of characterization (e.g. neglected, anticipatory or wicked)? To answer these questions I turn to the rich literature on problematization and policy problems.

Michel Foucault describes problematization as being about understanding how and why something becomes a problem and the forging of knowledge and relationships to make a certain thing an object of thought (1999). The process of problematization is not solely a theoretical one, because problematization while being a constructed social action is in fact "an 'answer' to a concrete solution which is real" (ibid, p. 75). In relation to science or innovation policy, problematization thus has been employed to challenge assumptions of a problem in the first place. As Joly notes problematization in policy is framed in terms of: "You have a problem and I have the solution" and "involves the definition of the problem that has to be fixed" (Joly, 2010, p. 6). He gives the example of genetically modified organisms (GMOs) in the 1980s being positioned as a solution for the problem of world hunger and disease, while today the focus has moved onto global warming and sustainable agriculture (ibid).

Such a description of policy problematization is the basis to a large section of the literature on 'framing'. Framing is a persistent idea throughout the policy literature (See Daviter, 2007; Lau & Schlesinger, 2005; Steensland, 2008). 'Frame analysis', is a research method to analyze how people define and interpret situations or activities, by rendering meaning through the ability to, "...locate, perceive, identify, and label" (Goffman, 1974, p. 21). More specifically the process of 'framing' is the process of constructing a frame, through an, "...active, processual phenomenon that implies agency and contention at the level" (Benford & Snow, 2000, p. 614).

Frames construct both problems and possible solutions. As Nick Turnbull describes, policy solutions to be understood in policy science as "...hypothetical conclusions which are supposed to resolve social problems in practice" (2008, p. 83). Problem-solving to define policy problems was also pursued by political scientist Harold Lasswell through a 'scientific' approach to apply scientific knowledge and the use of scientific rationality, methods, and principles (Turnbull, 2008). However, Lasswell was heavily criticized for his simplistic view of problems and lack recognition of framing (or problem/political agendas) in setting a problem definition on a particular path.

A number of scholars have further researched how 'policy problems' are challenged by asking what a problem is represented to be within policy (See Gusfield, 1976; Majone, 1989). Carol Bacchi (1999), inspired by Foucault has further researched problematization in a policy context. Bacchi aims to delve into the way problems are conceptualized in policy making and analysis by interrogating the assumption that 'problems' are readily identifiable and objective (2010, p. 1). She also reminds us that we are mainly talking about social problems when we discuss problems for policy as unique to modern societies, in the public responsibility to act through moral reasoning (Bacchi, 1991, p. 6).

Social problems tend to be defined as a harmful condition or situation. The social problem literature is closely related to policy problem research but with less emphasis on the policy process and more on how society or the public view and construct problems. For example, Hilgartner and Bosk (1988) make an argument about the role of public attention in determining the 'rise and fall' of social problems. Their analysis concentrates on how linkages are made across public arenas, where social problems grow in attention but competition and a need for drama requires new problem definitions to be repeatedly introduced. This emphasis is on the public and public arenas, without a full consideration of the role of policy involving other actors and arenas.

Chaufen et al. note how the social problem characterization has fallen out of fashion (2012). This may be because of the connotation of social problems with moralizing, correct and incorrect moral behaviours. As a result, in the health arena social problems are often reframed as medical problems. These problems are argued to be part a 'medicalization' of life, an idea developed by Ivan Illich to describe medical interference (disguised as care) overstepping due reason (1975). Illich argues how the wide definition of ill health expands the scope of medical care, the outcome of which is a denial of humanity in the process of, "...transforming pain, illness, and death from a personal problem into a technical [one]" (Illich, 2003 in Chaufan et al., 2012).<sup>35</sup>

The push toward treating social or personal problems as technical ones is reflected in government approaches to policy problems. Governments receive a large share of attention in how policy is conceived, even though policy problems involve more than government and affected public, with a variety of institutions, actors and processes engaged in problem solving. The common discussions by policy analysts<sup>36</sup> about what counts as a problem for policy and

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<sup>35</sup> Illich used the "Pyrrhic victories over some tropical diseases" as an example of the belief in an almost limitless progress of medicine, which would then face new challenges in the perpetuation of disease through economic and technological factors. (1975, p. 73).

<sup>36</sup> Policy analysis was a late addition as a research field in the 1960s. At first being a 'tool' of government policy analysis has attempted to become more reflexive and self-appraising (Gale, 2001, p. 380) with concern for being informed, rigorous and based upon research rather than commentary and critique.

the best way to act have therefore been directed at the policy makers. Many have been preoccupied with the use of evidence, in contributing to policy being arbitrary and uninformed. The claim is that: "Policy choices are based on fads, revered exemplars, or abstract theories, rather than solid evidence" (Simmons et al., 2007, p. 451).

### **3.2.2 Evidence and narrative constructing policy problems**

The use of evidence in policy has been heavily influenced by the 'Evidence-based policymaking' (EBPM) approach. EBPM aims to counter the grounds for policymaking deemed to be arbitrary and uninformed, either following political motivations, or borne out of laziness and poor practice. According to Ian Sanderson, EBPM is derived from 'evidence-based medicine' (EBM) in seeking to use information and knowledge more effectively to justify intervention, particularly in the UK and US (2002, p. 1). A general critique of the evidence emphasis by policy analysts has been provided by Majone (1989) who argues that an image projected is one of "technical, nonpartisan problem solvers", while in fact they are more akin to lawyers than engineer or scientist, making policy arguments. Further, the pursuit of being objective and atheoretical can mean policy analysis becomes too abstract, which Gale has argued EBPM leads to a "to-ing and fro-ing between theory and data" (Gale, 2001, p. 380). Finally EBPM has also been scrutinized by those who object to "...the continuing influence of the 'modernist' faith in progress informed by reason" (Sanderson, 2002, p. 1). As Cairney describes, the roots of EBPM lies in:

*"...the early post-war idea that the policymaking process will be improved when we make it more scientific and, therefore, better able to incorporate scientific evidence...This idea has given way to a more recent sense that policymaking will always be messy, and that an appeal to the primacy of science or 'the evidence' can go too far" (Cairney, 2015, p. ix).*

Evidence can be used in different ways for political means with no guarantee of neutrality and objectivity. This acknowledgement of the uses of evidence is why some prefer the term 'evidence-influenced' or 'evidence aware' policy with the understanding of a hierarchy of knowledge being imposed (Nutley et al., in Marston & Watts, 2003). Alternatively, Gale urges us not to think of policy development over time, in terms of progress but rather as 'temporary policy settlements' acknowledging power flows and intentions (2001, p. 389).

Constructivists would go further than materialist acknowledgement of power flows and interests, questioning the existence of an objective scientific knowledge at all and limitations of cultural and historical contingencies in drawing policy implications (Sanderson 2002, p.6). Indeed constructivist theory has much to add in a focus on ideas, in exploring policy norms from institutions and epistemic communities, as well as the social construction of problems. Simmons, Dobbin, and Garrett (2007, p. 451) describe the social construction of policy as constructing both legitimate ends and appropriate means that varies, "...from one period to the next".



There is also a spectrum of constructivism to note, from 'hard' to 'soft', making different claims and holding varying degrees of skepticism about scientific knowledge and the relation with social practices (Robbins, 2012). Hard constructivists will see social constructs as defining our world and science is one social method among many, meaning it cannot adjudicate for all claims about what is real in the world. Soft constructivists tend to believe there is a real and independent objective world but our concepts of reality are also real, reflecting, "...incomplete, incorrect, biased, and false understandings of an empirical reality" (ibid., p. 128).

It must also be kept in mind that "...interests, like everything else, can be constructed" (Latour, 2005, p. 145). Certainly interests can inform our understanding of actions and behaviour in a policy context but there is also a critique of the 'interests approach'. STS scholars including Woolgar, Gilbert, Mulkey and Knorr Cetina see utility in uncovering the social processes for the production of knowledge but remind us that to be aware of our own constructions in putting forward another representation of the world (Webster, 1991, p. 21-2). Therefore, when considering underlying rationales for apparent interests, our own representation of interests must also be considered.

One challenge is that interests of actors and their core identity are assumed to go hand in hand. Ikeda recognizes the fusion of actors and core identities in the, "...public interest view of public policy, which in effect treats persons who have moved from the private sector to government employment as having been thereby transformed from self-interested profit-seeking actors into public-spirited and selfless public servants" (2002, p. 6). Even differing interests may be constrained by the possible options: "policy analysts can appear very similar to policy makers who seek to construct policy problems in ways that match the answers they already have available" (Gale, 2001, p. 384). Presumed (stereotypical) interests ascribed to actors will be important to keep in mind, especially later in this chapter when discussing public health actors. Evidence is one aspect of policy that prompts debate. Another is the need for policy to appear in the form of a narrative, which I will be sensitive to throughout the thesis. I will discuss problem narratives in the next section through the example of 'market failure' in relation to innovation policy problems, which I also argue is a central narrative story for NTDs.

I have discussed in the previous section how evidence has been an important part of producing policy problems and solutions, giving a technical appearance rather than relying on argumentation. Evidence is a route to achieve an appearance of technicality but also important is what form of evidence is presented and what story is told. Policy problems require an outwardly objective and justificational identification. In this sense identifying a problem for intervention is often characterized in terms of market failure, where market forces or private actors do not provide immediate solutions.

Market failure arises from a status quo (or equilibrium) where the market generally provides for societal needs and wants, but when this is not met (e.g. when it is difficult to derive profits or no one is responsible for delivery) government or other non-market actors must amend market conditions or offer provision. NTDs can be understood a result of a market failure for drug and other medical innovations. A typical argument might be: "...the pharmaceutical industry has little incentive to invest in research and development (R&D) for infectious diseases that predominantly plague poor nations, as medicines cannot be sold there at a price that would allow pharmaceutical firms to cover their high R&D costs" (Mueller-Langer, 2013, p. 185). WHO director Margaret Chan called for a public-private partnership (PPP) approach to tackling NTDs, in response to market failure of affordable medicines.<sup>37</sup>

I question why a market failure explanation is required and what might be missing in this characterization of the policy problem. Grounded in welfare economics, market failure is given as a starting point to summarize a policy and determine future action, providing economic legitimization. In critiquing this economic theory, public choice theorists (interested in economics applied to politics), challenge the assumption of a perfect government rather than focusing on market failure itself (Tullock et al 2002; Ikeda, 2002).

In essence my argument is that market failure provides a policy narrative: a starting point and signposting for policy problems but it also directs the potential solution, in providing a narrative for the problematization of a policy problem. Narrative is essential in this analysis and how it is delivered through an economicized language. The imagery is of a well-functioning machine that operates well but cannot cater for all social needs in their entirety, with an underlying assumption that the market provides more than it can and should. Regulation and government intervention must then step in to remedy a sometimes-malfunctioning market. Another way of challenging a malfunctioning market, or to that point a malfunctioning government is bottom up through publics and civil society. One vehicle is through social movements, discussed next.

### **3.2.3 Advocacy through social movements and scientist activism**

NTDs involve an element of social movement, as defined by Hess (in Hackett et al., 2008) in a goal of "fundamental social change". For example, this sentiment can be seen in the scientists at the WHO proclaiming: "it seems to us ethically unacceptable that infected human populations are not administered medication that is freely available while livestock and companion animals are regularly dewormed every year" (Montresor et al., 2013, p. 1). Scientists have been challenging established organizations from pharma companies, donor countries to the WHO in their dealing with NTDs, making moral arguments for increased societal concern.

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<sup>37</sup> WHO, [http://www.who.int/neglected\\_diseases/WHA\\_66\\_seventh\\_day\\_resolution\\_adopted/en/](http://www.who.int/neglected_diseases/WHA_66_seventh_day_resolution_adopted/en/) 2013, Accessed 2/4/16.

What have scholars said about advocacy for societal concern for policy problems? The discussion has tended to centre on social movements. I discuss these next, also pointing out the difference between advocacy and activism. The interest in social change through social movements is something that STS has increasingly focused upon. Moore argues (in Hackett et al., 2008, p. 475) that focus has been not only directed at state actors, such as “science, medicine, and industries” but at patients and other non-state groups. These groups include ‘health social movements’ where ‘the public’ is the driving force (ibid.). Klawiter gives the example of the change in scale and scope of health activism: “the rapid growth in the number, size and funding of women’s cancer and breast cancer organisations; the development of new discourses, cognitive frameworks and other forms of cultural production; the proliferation of new projects, campaigns and coalitions” (2004, p. 847). A reason given for such a change in focus is argued to be neoliberal policies undercutting the “social understanding by which citizens support the state in return for services and protections such as security and health” (ibid.). Hess similarly describes ‘alternative industrial movements’ which operate through institutionalized channels rather than disruptive tactics, including “advocates, entrepreneurs, scientists, and countervailing industries” in calling for a shift in corporate product standards or support for new technologies and products. (Hess, 2015, p. 73).

David Hess also sees scientists as key figures in supporting social movements: “When scientists step out of their role as researchers to defend the need for policy reform that is contrary to the official articulations of public interest by elites, they form a scientific counterpublic, often in alliance with social movements and other civil society organizations”.<sup>38</sup> Scientists can be advocates for policy reform, acting beyond their academic work, in establishing projects and organizations, working for NGOs and public institutes. Frickel, Torcasso, and Anderson have incorporated the role of (scientific and technical) expertise in social movements, as they say, “...social movements now regularly deploy as well as challenge expert knowledge claims” (2015, p. 5).

When it comes to NTDs it is worth pointing out early on that scientists *do not* act predominantly in alliance with social movements and other civil society organizations as Hess often observes. Related developments have been the ‘political opportunity structure’ literature developed by sociologists to look at the conditions where social movements influence policy structures, as well as the ‘advocacy coalition framework’ in public policy to look at the influence of competing interest groups on policy outcomes (Sell & Prakash, 2004, p. 146). Similarly, Frickel and Gross argue scientific and intellectual movements or ‘SIMs’ as “collective efforts to pursue research programs or projects for thought in the face of resistance from others in the scientific or intellectual community” (Frickel & Gross, 2005, p. 206).

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<sup>38</sup> Hess, <http://www.davidjhess.org/movements-and-publics.html>, Accessed 1/12/15.

Patient action is a gaping hole in any reference to NTD policy discussions. NTD patients have been characterized as having a minimal political voice, as in this WHO description: “Neglected tropical diseases such as leprosy, lymphatic filariasis and leishmaniasis are feared and the source of strong social stigma and prejudice. As a result, these diseases are often hidden – out of sight, poorly documented and silent” (WHO, 2006, p. 3). Still, there may very well be other reasons for a lack of voice for patients such as priority for financial concerns or upholding traditional ways of life.

Critical global health researchers have focused on health actors who have gained a more prominent role on the global stage, such as patients themselves. In fact much of the global health literature I draw upon in this thesis is 'critical global health'. It is a research area engaging with the emergence of health actors and their governance activities, largely using post-structural thinking (Biehl & Petryna, 2013; McInnes et al., 2012). Study of global health from a critical perspective encompasses a number of methodological approaches, such as the post-colonial analysis employed by Warwick Anderson (2014) or sociological view of philanthropy for health by Lindsey McGoey (McGoey, n.d.). A growing number of scholars, including Adams (2016a), Biehl (2016), and Reubi (2016) advocate an ethnographical approach and I draw upon these scholars, particularly Adams through her work on metrics in Chapter 7 in the thesis.

Critical global health theorist João Biehl notes the, “...collision between local values and international public health agendas” revealed by ‘peopling’ global health by bringing out people’s stories of how they experience current practices (Biehl & Petryna, 2014, p. 381). People may hold insights and knowledge about these diseases and the policies employed to tackle them, with a potential for use on a policy level, for which anthropologists and others have tried to un-tap. On a wider health level, Petryna and Biehl identify how:

“In key developing democracies — such as Brazil, India, and South Africa — we see activists and patients engaged in struggles over access to high-quality care and, at a more fundamental level, debating the meaning, object and implications of health conceived as a right rather than a privilege or commodity” (Biehl & Petryna, 2014, p. 398).

Other actors that may have been under-researched are scientists taking on an activist role. This role compares with publics becoming expert-activists or experts collaborating with certain publics. For example, Epstein (1995) in his seminal work on HIV/AIDS activism, coined the terms ‘treatment activism’ and ‘lay experts’ to convey the concern of activists in pursuing medical advancement in the treatment of their disease and ability to be credible interlocutors with experts. Also Novas (2009) highlighted the partnership between Sharon Dobkin a patient, and, Dr Melvin Van Woert an academic scientist who together lobbied Congress sponsor to

develop a therapy for the rare condition myoclonus. Novas emphasized the symbiosis of patient groups and academic scientists for rare disease advocacy:

*“The claims of academic scientists played an important role in supporting the struggles of patients’ organizations. They helped to define the contours of the problem, illustrate the difficulties they encountered in attempting to develop promising treatments for rare conditions, and often gave moving accounts of the suffering they witnessed in their clinical practices.”*  
(Novas, 2009, p. 16).

it has been contemporary expectations that policy 'concerns' must be elaborated by patient groups. Activist scientists, working without patient groups I argue, have been central for NTD policy change. By describing scientists as activists, I am emphasizing an active campaigning for policy change, just as activists driving a social movement would be doing. It is a stronger form of advocacy, denoting action in support of a cause. There is some historical precedence for activist scientists, as Donohoe notes (2012) in 'many noteworthy examples' of physicians. In fact activist scientists are not wholly novel but closely reflect an earlier paternalistic era of expert-led activism for policy change. Another critical global health scholar Vincanne Adams has identified an eminent physician in the 19th century, pathologist Rudolph Virchow, as one figure who made valuable contributions to social medicine, arguing that "...many diseases result from the unequal distribution of civilization's advantages" (Adams, 2012, p. 339). He believed physicians to be "...natural advocates of the poor, 'if medicine is really to accomplish its great task it must intervene in political and social life'..." (Virchow quoted in Adams, 2012, p. 339).

Virchow was an advocate through his socially minded philosophical views and voicing his opinion as a legislator against child labour, and for public medical care, universal education, and democracy (ibid.). Where he goes beyond advocate to become an activist is in taking action and having impact, by founding the journal 'Medical Reform' and improving a number of areas related to public health from water and sewage systems, food inspection, to the education and training of health professions (ibid.). This move is what made him an archetype of the politically engaged medical scientist. For Adams it is ironic that this leading scientist was deemed a radical in his commitment to the idea that (medical) science was also political, and view that only under certain political circumstances could scientific truth be made apparent (1998, p. 160).

Donohoe (2012) writes that to be a politically active physician may be more difficult today. While it is unclear what golden era he is referring to when physicians could be politically active, he is specifically talking about the American context. He has argued that in the US there are

lower adjusted voting rates than the general population and limited issues when lobbying Congress<sup>39</sup> with a low number of physician-legislators (ibid.).

In the history of tropical medicine, it has also been a precarious position to be a policy-engaged scientist. Worboys notes that Sir Patrick Manson, often called the 'father of tropical medicine' through his public reputation was appointed physician and medical advisor to the Colonial Office in 1897 (in Lemaine et al., 1976, p. 85). He acted in the capacity of a 'firm's doctor' in an 'influential policy-advisory role' with direct access to the Secretary of State (ibid.). However, this position was officially mandated and compared starkly with his contemporary Ronald Ross. As a working scientist, Ross tried to suggest to the Colonial Office a new scheme of sanitary commissioners, to which he was firmly rebuked. Lemaine et al. saw the message as being: "...scientists should confine themselves to research and not become involved in practical policy" (ibid., p. 92). It appeared that scientists could be instrumental in policy but there was a small scope in how to do so, only if formally designated, with limited room at the top. Jasanoff describes how the separation is part of a 'Jeffersonian ideal of democracy' to keep political authority away from experts, in reflection of the "...popular conviction that decisions cannot be wholly legitimate if they are comprehensible only to the initiated" (Jasanoff, 1990, p. 11).

In more extreme circumstances it is evident that science and politics cannot be easily separated. The politicization of medicine has often arisen when politics is closely embroiled in both problem and solution explanations for ill health. The book 'Doctors for Democracy' about the 1990 Nepali revolution instigated by a group of medical professionals illustrates this point well: "Observing that social inequality and poverty were the root causes of ill health among the masses, some doctors reasoned that the most direct medical interventions they could promote were those of political and social reform" (Adams, 1998, pp. 4–5).

Rationalization of the role of politics in science reflects a conundrum about objective truth, if scientific fact is to be independent of social and political constitution. A view is that politics may compromise objectivity, which should be apolitical but as the case of the Nepalese doctors showed: "Politics, in their view, could be used to reveal and attend to objective truths and therefore could enhance medical practice without compromising scientific objectivity. This objectivity was born from the perceived efficacy of technical interventions provided by a scientific approach to social problems" (Adams, 1998, pp. 4–5). Adams argues that medicine is different as a socially engaged humanistic science opposed to pure science. For her, the politicization of medicine through politically active medical professionals merges two insights: "(1) that medicine must become political to eradicate the cause of ill health and (2) that medically scientific truths are usually formulated in contested political contexts" (ibid., p. 172).

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<sup>39</sup> The issues US doctors pursued when lobbying government were reimbursement and funding for research rather than social justice issues such as, "...access to care for the uninsured, tobacco control, women's rights, violence prevention..." (ibid.).

Chapter 6 will detail how scientists have become activists in a policy movement for NTDs and their rationalizations in the face of concerns for scientific objectivity.

This chapter has explored problematization in policy, beginning with problem types and where neglected problems fit. I then looked at the use of evidence in policy through the rationales for EBPM and how these are often described through narratives, such as market failure to justify policy action. Finally I addressed the role of advocacy in policy through social movements behind problem generation and activist scientists challenging the politics-science distinction. The literature and themes I have considered have been centred on how policy problems are constituted. Next I turn to innovation as presented as a solution to policy problems to explore the underlining theoretical frameworks employed to understand how NTDs are addressed.

### 3.3 Innovation conceptualization for solutions

#### 3.3.1 Explaining innovation solutions through models and tools

Science has long been presented as a solution to societal problems. The twentieth century saw 'big science' have a transformative effect on society through a 'leap in scale and organization', with physics and chemistry becoming directly useful and science becoming a goal-directed economic endeavour (Riecken, 1969). Some, such as Riecken, have argued that science has more implications for 'action' than social sciences, which can be a "...curious kind of 'understanding'..." (ibid.). Turnbull (2008, pp. 82-4) has argued this basis comes from an enlightenment view of social science identifying problems rather than solving them and where science is the most 'sophisticated expression' of problem-solving rationality. Others, for example Fujimura (1987), talk about how science can produce 'doable problems' in the alignment of 'experiment, laboratory, and social world'.

Innovation poses a new relationship with policy problems. In a conventional and widespread definition of "...bringing a new product into the market or into practical use" (Schroeder, 2007, p. 37) there is an emphasis on economic significance and promotion of economic growth. Therefore, innovation connects science and technology to the wellbeing of the economy, to create a concept that is viewed as intrinsically positive and desirable. Today the link between science, technology and the economy is argued to be the 'raison d'être' for science policy and later innovation policy (Webster, 1991, p. 35).

However, innovation as a buzzword is still a contested term in that it is often used ambiguously, with different parties bringing their own meanings to the table. What I would like to draw attention to are the economic meanings as opposed to socio-political meanings. Economists tend to refer to 'technological' innovation in the commercialization of ideas, as described above, particularly technological advancement rather than innovation in ideas, things, and behaviours (Godin, 2010). This is the concept of new products, processes, and services entering the market mechanism.

Innovation applied as a solution to policy problems carries an air of neutrality most often referring to technological innovation but the social and political cannot be demarcated explicitly, so it must be asked who innovation is for in society and why? This question is relevant for global health now more than ever. Innovation is presented as a solution to many of the challenges we face on big global topics such as health, the environment, poverty, and wellbeing. Joly et al. (2010, p. 5) describe how innovation is presented as a solution in itself, a way to "solve human problems" in areas spanning health to sustainability. When looking at policy problems it is common for innovation to be involved (such as OECD, (2011) 'Fostering



Innovation to Address Social Challenges”). In contrast, a lack of innovation is characterized as a problem, which presents innovation as one-dimensional in character – more innovation being good and less innovation being bad. Accordingly a lack of innovation is presented as part of that problem and it is easy conceptual slippage for the amount of innovation itself to be characterized as a problem.

The main measure of whether there is more or less innovation is through the level of R&D, as a discrete element of innovation whose relationship to economic growth is complex, involving continuous feedback (Webster, 1991, p. 100). Governments set targets and offer incentives for R&D as an activity encouraged for innovation, with the view that the market typically under-invests. However measuring the impact of policies related to science, technology and innovation has faced difficulties. The statistical relationship between economic growth and R&D investment has not proved very forthcoming (ibid.).

R&D investment forms part of a linear model of innovation. As Mata and Louçã (2009) explore, there has been a need to formalize innovation studies through theory development, where a model-building approach was championed. Godin points out: “One of the first (theoretical) frameworks developed for historically understanding the relation of science and technology to the economy has been the ‘linear model of innovation’...” (2006, p. 639). The model generally describes the process of technological change sequentially from an idea (drawing from the science base through basic research then applied research), that moves to development, production and finally diffusion within markets and wider society.<sup>40</sup> As a model it outlines a linear progression of discrete stages, shown in the Figure 2 below.



**Figure 2 'The linear model of innovation'**

(Bhirud, Rodrigues, & Desai, 2005)

The model is linear because it is based on an input-output framework that progresses from one stage to another through a series of steps. For NTDs the assumption is that an input change will result in outputs that mean these diseases are better dealt with. Godin argues that the linear model never existed in the form and usage depicted by later theorists arguing for an abandonment of the model in favour of a new version. Others including David Edgerton

<sup>40</sup> Godin notes two further generations of the linear model – a statistical correlation between research and economic growth, productivity, industrial competitiveness, and 'National Innovation Systems' (NIS). Adoption of the linear model fed into a larger policy project justifying government support of science and innovation, as well as the role of “industrialists, consultants and business schools, seconded by economists” in a theoretical construction of innovation (Godin, 2006, p. 640-1).

(Edgerton, 2004) had made this claim before but Godin and Lane (2013) make a more nuanced argument, pointing out that Edgerton concentrates on the originators of the demand-pull model.

The demand-pull model was an early alternative to the linear model, providing a supply-side view of innovation.<sup>41</sup> The supply-side view posits that investment in R&D and scientific discovery leads to innovation, while the demand side comes from the opposite direction in that consumers drive innovation through market demand. With the linear model of innovation, R&D is a means to an end for innovation and economic growth is the dominant and established view. The linear model of innovation is widely adopted, in making this relationship between R&D, innovation and economic growth (despite critique of the model as not reflecting complexity and collaborative or open ways of doing innovation). We will see what the effect of an emphasis on R&D has for NTDs in later chapters.

### 3.3.2 Health for development

A similar reversal in the demand-pull to supply-push example of linearity can be found in the relationship between health, innovation, and development. The idea of 'development for health' has been long established. A first point is that poverty and low socio-economic status causes ill health, shown by the political economy of health (Doyal & Pennell, 1979) and social determinants of health (SDH) literatures (Marmot, 2007). A second point, applied to a country level is that the economy needs to develop first for health outcomes to improve. This argument comes from a technocratic interpretation of 'stages of development' where economic development is sought first with societal improvement expected to follow. Countries want to move up the escalator of progress through 'Rostow's stages theory' of economic growth "...from a pre-industrial state to full economic maturity" (see Rostow, 1971). This 'stages theory' was prevalent in the early postwar period, where to miss a stage could be a disaster:

*"Essentially, the theory says that development proceeds through a linear succession of stages copied from the historical experience of existing industrial countries. This was a historicism in drawing theory from past experiences or examples but also wanted to do away with connections to the past that do not match a pursuit of modernity... the goal was predetermined – it was to be just like contemporary America" (Biel, 2000, p. 74).*

The idea would later be reversed, such that health could precede and contribute to development. As Morel describes: "Health, science and technology are increasingly being recognized as prerequisites for economic and social development, and not merely as their consequences" (2003, p. S35). Linearity is reversed from 'development to health' to 'health for development' (see Figure 3 below). I argue that this change had important implications for global health policy. Instead of identifying poor health being caused by underdevelopment,

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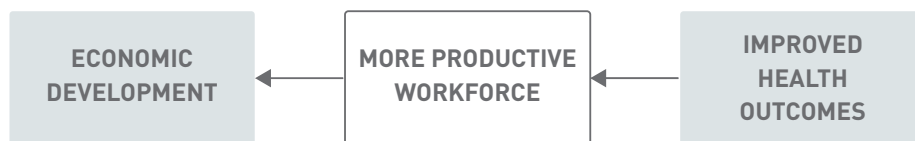
<sup>41</sup> Keynesian economics, widely accepted post-war up until the 1970s and encouraged the consideration of demand-side factors.

improved health could be a reason leading to economic development. Here I am using the term economic development as a marker of a country's progress, as is understood through common metrics to measure improvements in a country (e.g. GDP, literacy, life expectancy, poverty rates). Policies addressing health could move away from a systemic emphasis to economic development (on policies and investment in health systems and infrastructure) to vertical programs addressing individual health issues.

**Development for Health:**



**Health for Development:**



**Figure 3 Reverse linearity of development for health**

The switch in emphasis to 'health for development' can be seen the policy arguments for NTDs as diseases said to be both a cause and a result of poverty and underdevelopment, in a self-reinforcing cycle, with health accepted as a precursor. As a result, demonstrating impact upon economic development reinforces the rationale for intervention in NTDs, as an expected consequence of health improvement.

China was 'proof' as seen through the so-called 'barefoot doctors' that it was economically advantageous to invest in health (Zhang et al., 2008). China's community health workers or 'barefoot doctors' had elementary training in diagnostics, immunization, education, simple treatment, and liaison with the qualified medical sector. They were a cheap resource to improve health and more generally a health intervention being used to promote economic development. However, they are also an example of a politically driven health intervention.

Adams (1998), explores the linking of politics and medicine. She gives the example of the barefoot-doctor program to reflect "...the call for political solutions to basic health problems" (pp. 166–7). The program was seen by many as a successful intervention, driven by supportive political ideals of the Cultural Revolution, which began in 1966. The Cultural Revolution had meant that, "...high-technology orientations became an object of scorn, and so the basic essentials of scientific medical intervention were recast in a framework that made national medical traditions appropriate for health care in the Chinese countryside" (ibid., p. 167). 'Expert' knowledge was seen to be opposed to 'Red' knowledge and downgraded, with also the discrediting to an extent of stages of development from which 'development for health' was grounded in. A move towards the 'health for development' model allows for NTDs to be more appealing as a concern and has shaped the means of dealing with these diseases. Similarly to

the example of 'barefoot doctors' the shift to 'health for development' is grounded in a view of what expertise can provide legitimate evidence. Therefore, the type of expert knowledge being relied upon becomes central to determining how policy problems and solutions are viewed. I take this consideration of expertise further in the next section, which deals with the various disciplinary lens that have been applied to NTDs.

## **3.4 Disciplinary lens: Economicization, historicism, and interdisciplinarity**

### **3.4.1 Economicization (or reverse politicization)**

This thesis has at its core policy problems and their solutions. In the first section I have discussed the literature relating to problematization of policy problems through the use of narrative, paying attention to how problems are addressed through the use of measurement and advocacy (with reference to EBPM and social movements). In the previous section I engaged with solutions proposed to policy problems through innovation conceptualization as a dominant theme and also the role of models.

In this section I develop further the idea of how disciplines guide policy problem-solving. I explore the expertise of economics, history and an interdisciplinary lens, which will include anthropology and epidemiology. What one discipline offers to policy over others depends on a number of factors. I have already made the point that economic thinking is prevalent throughout approaches to policy problems and in policymaking, but why is economics especially useful to policymakers? As discussed previously, economic impact is desirable and a marker of progress, with economics being the discipline that is able to foresee and influence such outcomes. According to McCloskey in subscribing to a modernist methodology the chief goal of economics is prediction and control: "The common claim that prediction is the defining feature of a real science, and that economics possesses the feature..." (1998, p. 487). Other disciplinary approaches may be downplayed and economics is sometimes accused of ignoring other political and social considerations.

Majone (1989) also posits that the very methodology of policymaking – 'decisionism' – favours economics as a generalized logic of choice, where political actors make rational choices from available alternatives, which are the best means to achieve objectives. Here, microeconomics and decision theory as sub-disciplines of economics have been influential, with policy analysts seeking to extend the principles of rational choice from private economic transactions to public policymaking. This policy approach based on rational decision-makers may now be outmoded but its legacy can be found in 'Nudge theory' (Thaler & Sunstein, 2008). Nudge theory is a product of the introduction of psychology to economics<sup>42</sup> and brings behavioural economics into policymaking, assuming irrational rather than rational actors.<sup>43</sup> Economic ideas and the language of economics have also gained further ground through a defining role in innovation

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<sup>42</sup> Psychologists Amos Tversky and Daniel Kahneman are largely responsible for introducing psychology into economics.

<sup>43</sup> While embracing irrationality, Nudge attempts to intervene pushing toward more group rationally beneficial decisions resolving for example public goods problems.

policy. As already discussed, the 'linear model of innovation' and 'market failure' are prevalent ideas within innovation policy narratives.

Economic rationale and justification in policy and intervention can be questioned. Economic approaches and ideas prevailing within policy may be best described as 'economicization' (or economization). Muniesa and Linhardt define economicization as, "...an aspect of practices, procedures and activities in which the calculability of things is put forward and in which, accordingly, action is subjected to optimality and hence made prone to economic assessment" (2009, p. 12). The objection to economicization is in the depoliticization of action, which contradicts the nature of what the state does and is, in being essentially political (Muniesa, 2014, p. 114).

Muniesa and Linhardt explain the two movements of 'politicization' and 'economization', with politicization of the state being "...an emphasis on political will in the conduct of government and in the orientation of civil services and public administrations, but also to procedures or practices aiming at democratizing decisions or at taking into account states of dissent..." (2009, p. 12). Callon, similarly notes the difference of an economic rather than political outlook to state behaviours (2010). Economicization is an approach I will be aware of throughout this thesis as a treatment of NTDs as a policy problem, later explored as a 'policy packaging' where depoliticization is highlighted.

### **3.4.2 Historicism and historiography**

Another disciplinary approach that I address is history, drawing on the history of tropical medicine and also providing a recent policy history of NTDs in this thesis. I next consider the use of historicism and historiography to understand and present policy problems. A definitionally vague and broad term, Karl Popper defined historicism as predicting the future course of history and thought it to be a poor method. He refuted historicism not only in the ability to bear fruits ('The poverty of historicism', 1957) but eventually to be logically impossible ('The logic of scientific discovery', 1959). Popper relied on an innovation or scientific progress thesis, which he described as the growth of knowledge, including scientific ideas. The growth of knowledge produces uncertainty in the future such that it is impossible to be predictive based on the past. Historicism has still been a popular current in policy theories and prescriptions, present for example in the stages of economic growth theory.

However, as Reynolds discusses (2008) the alternative meaning of historicism is more than being a predicting tool of Popper. A common usage of the term is a 'mundane historicism', which has its root in opposition to the enlightenment ideal of an ahistorical and universal rationality (ibid.). Therefore: (1) 'mundane historicism' is to understand things in their historical context; (2) 'methodological historicism' the method for understanding history distinct from those

of the natural sciences that is closer to historiography; (3) 'Popperian historicism' – which I have discussed – is having predictive power in finding laws, rhythms and patterns in history (ibid.).

The use of history, both the mundane and methodological sense, in order to inform policy-making and to better understand public policy has had some resurgence in recent years (see Berridge, 2008; Guldi & Armitage, 2014; Rennie, 1998). This may be a lighter version of historicism in using historical fact to 'confirm' theory, interpretation and even prediction. Haddon et al., who ran a focus group with policy makers about the value of history, found that: "History was talked about as a source of invaluable knowledge about a policy area; in providing instructive parallels; or as a means to challenge existing paradigms and identify major paradigm shifts" (2015, p. 2). What surprised me was the unacknowledged historical basis to innovation theory and adapted for innovation policy, particularly from management science. Historicism in the non-Popperian, mundane sense provides the content to these theories of knowledge. Thus, for NTDs, historicism has been a defining feature through the theories of science, innovation, and economic development applied to disease.

Historiography is perhaps more straightforward to define. It is the methodology that historians employ for their discipline, which can be taken as a study of the history of historical writing, in how individual historians have interpreted events and also by extension the historical work on a specific topic (such as tropical diseases). The historiography of tropical diseases and tropical medicine has been an ongoing project, ordered through national perspectives and also transnational networks of colony or empire, by national institutions and scientists.

One aspect of this historiography then has been the focus on the "...conventional portrayal of tropical medicine" as being "...imbedded in the imperial enterprise of their respective countries", while the colonized context adds "neocolonial, developmentalist, nationalist, and patriotic features to tropical medicine" (Coutinho in Armus, 2003, p. 90). Coutinho argues that an endemic disease was only a problem to the colonizer when the colony was theirs. Once independence is gained, the disease will become part of the newly independent country's search for national identity.

Elements of more established tropical disease and the beginning of an NTD historiography can be found across chapters. Chapter 4 will concentrate on the historical events that led to the creation of NTDs. Chapter 5 goes further back in time to how the tropical disease category was formed. In Chapter 6 I explore historical initiatives, particularly 'The Great Neglected Diseases of Mankind' program (1977–2000) and how their legacy would be instrumental in the creation of NTDs. Therefore, a consideration of historicism informing policy runs throughout this thesis, although it is the historiography of tropical medicine and tropical diseases that forms a basis for charting the policy development of NTDs.

### 3.4.3 Interdisciplinarity in policy problems

Historians and economists, to whom I will add epidemiologists and anthropologists, all have growing positions within global health policy. Researchers from these disciplines, particularly epidemiology and anthropology, often enter public health research projects as part of interdisciplinary teams. They have provided at times critical voices to the rationales and methods of NTDs activity. As this thesis is looking at asking the question of how policy problems are constituted in relation to NTDs, involving different disciplinary approaches, it is also important to unpack the concept of interdisciplinarity. This background to disciplinary approaches will be particularly pertinent for Chapter 7 when I discuss NTD discourses. The different technical choices sometimes constitute a cultural divide but also offer varied insights.

Interdisciplinary work between social and natural science is happening through the integration of societal issues and concerns into scientific practice. Doubleday and Viseu (2010) have questioned how, to date, there had not been a significant discussion on the inclusion of social science by bringing in societal considerations (and how this has worked in practice). They are wary that, "...policy documents suggest this integration is a relatively straightforward process" (ibid., p. 55). One solution offered has been to standardize and manage interdisciplinary work through the practice of 'embedded research'. This practice typically refers to a close working relationship with research subjects, including a sometimes contributory or collaborative role to their research (or an attempt to somehow change, inform or add to existing practices that are related). Embedded research is not a neutral position, with the implications discussed in the remainder of this section.

Parker, Polman, and Allen (2016, p. S6) discuss how in the context of NTDs scholars of different disciplines have worked collaboratively. Most commonly if they were more senior they would work on 'parallel tramlines' separately on their own research or as 'handmaidens of biomedicine' if more junior in schools of public health:

*"In the world of NTDs, and global health more generally, it would be fair to say that it is rare indeed for an epidemiologist, parasitologist or public health specialist to work on an equal footing with an anthropologist, historian or political scientist"* (Parker, Polman, & Allen, 2016, p. S6).

They describe the 'qualitative' social research that is undertaken as elaborating on a, "...factorial model of disease' with complex social and cultural processes being conceptualized as discrete, measurable 'factors', acting as 'barriers' to the effective implementation of global health interventions" (ibid.).

This is a relatively critical perspective taken by Melissa Parker and Tim Allen who are anthropologists (Polman is an epidemiologist). Anthropologists have been sought after in public



health and biomedical research to unlock cultural secrets in being able to understand and gather insight from local communities (Krumeich, et al., 2001). In turn they have also found in health a rich topic of research, hence the emergence of the 'medical anthropologist' in the 1960s (Basehart, 1964). Writer Robert Desowitz noticed this changing positioning of anthropologists:

*"The generic anthropologist began to disappear in the 1950s and 1960s. The biomedical researchers—geneticists, epidemiologists, and microbiologists—discovered the anthropologist's utility in gaining entry into tribal groups as well as their providing a ready-made source of important demographic data. In turn, the anthropologists discovered biology and their calling evolved into specialities" (2004, p. 178).*

For anthropological research on NTDs the focus is on aetiology, signs or symptoms and treatments of individual diseases.<sup>44</sup> Anthropologists Parker and Allen are among the few who have looked at NTDs as a group. Although they do so narrowly by country and are interested in the control method for five of the NTDs called 'mass drug administration' (MDA), which Allen describes as, "...the largest global health programme that the world has ever seen" (Allen, 2016).

They are interested in advocacy for NTDs and have been critical of some aspects, including what they see as an over-promise in the global drive for NTDs, through 'grand claims' and aspirations to achieve the 'Millennium Development Goals' (MDGs) and 'making poverty history'. In their view NTD aspirations have generated 'unprecedented attention' to NTDs (Parker & Allen, 2011, p. 2). Through a community study in Uganda they ask the question: 'Does mass drug administration for the integrated treatment of neglected tropical diseases really work?' (2011). Again the question of politicization returns as a concern:

*"Large amounts of funding are being allocated to the control of neglected tropical diseases. Strategies primarily rely on the mass distribution of drugs to adults and children living in endemic areas. The approach is presented as morally appropriate, technically effective, and context-free." (2013, p. 224).*

As Adams describes, postmodern critical theory politicizes social problems, "...by situating them in historical and cultural contexts, to implicate themselves in the process of collecting and analyzing data, and to relativize their findings" (Lindlof & Taylor, 2011, p. 52). The charge of Parker and Allen is that, "...normative ideas about global health programs are used to set aside social and biological evidence" (ibid.). As anthropologists it is the 'local details' that are set aside but also the country context:

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<sup>44</sup> Anthropologists have uncovered reasons for low take up of drugs because of the experience of schistosomiasis differing for children and adults (Hewlett & Cline, 1997). Many may be asymptomatic but blood in the urine making 'red urine' only tends to be a sign of infection in children so there is a perception that adults do not suffer from the same infection. Adults then are more reluctant to take drugs.

*"... resistance to the take-up of free drugs was linked by many of those with whom we lived to a sense of marginalization, and sometimes outright oppression by the Ugandan government... while some people benefitted from the treatment program, it was unrealistic to assume that it would lift such impoverished and politically excluded populations out of poverty. It is mostly neglected people who are infected with neglected diseases—and this fact could not just be wished away" (ibid., p. 224).*

In '(D)e-politicizing parasites: reflections on attempts to control the control of neglected tropical diseases', Parker and Allen use as a starting point Ferguson's 'anti-politics' thesis (1994), which draws on Foucault in considering hegemonic discourses (ibid.). The original critique by Ferguson related to the aid and development industry, arguing that social realities were depoliticized as a way of control. He argued that technical solutions are implemented context-free using international expertise. Parker and Allen view his account as ignoring the complexities of the development industry and find it more interesting how rhetoric was believed, such that discourse was used as an instrumental tool for vested interests.

Parker and Allen similarly employ a depoliticization argument for their own research. In this case it is directed at the scientists, policymakers and development workers implementing NTD policies. They challenge how the optimism for MDA in controlling NTDs, driven by these actors, ignored a more politicized view of how populations would accept this intervention and whether it was dealing with the root problem. What does not come across so clearly was that Parker and Allen were invited by one of the actors they are indirectly critical of – Alan Fenwick – who runs the Schistosomiasis Control Initiative (SCI), who enabled them to be embedded in the project to implement MDA in Uganda (Reisz, 2013). As described in a *Times* newspaper article in 2013: "Their work had been 'carried out in close collaboration with [those responsible for the control of the worms, insects or snails that transmit diseases], and with relevant district authorities" (ibid.).

My contention is that opposition between disciplines was played upon in this instance, through the contradiction between an anthropological outlook, as opposed to the advocacy work of scientists and other global health actors, to strengthen the claims of Parker and Allen. They have demonstrated how another disciplinary approach provides a new angle to the NTD policy problem and solution. Less contentious interdisciplinary working can be said to be the emergence of interdisciplinary fields, where the convergence of academic fields is a process of compromise. A 1963 article by economist Kenneth Arrow is often cited as the beginning of health economics as a sub-discipline, by considering a market for health care (Cardoso, 2008).

The Arrow article was followed by an influential publication in 1972 of Michael Grossman's model of health production where he considered how to account for demand in health (ibid.). Since then economists have gained a greater role in public health through the emergence of the

'health economist'<sup>45</sup> which has led to the wide adoption of concepts and tools, one example being the 'Global Burden of Disease' work and development of the 'disability-adjusted life year' (DALY) measure pioneered by the physician and health economist Chris Murray along with epidemiologist Alan Lopez. This work by economists is described as a "...systematic effort to quantify the comparative magnitude of health loss due to diseases, injuries, and risk factors by age, sex, and geography over time" (IHME, <http://healthdata.org>, Accessed 2/4/14). I will discuss this work in detail in Chapter 7 as well as what could be termed a disciplinary clash with the so-called 'worm wars', centred on methodological terms between economists and epidemiologists. Indeed, while health economists and epidemiologists often research the same topics, using different disciplinary approaches, this instance may be viewed as social scientists (economists) entering the natural science world (epidemiologists). However, the convergence to the interdisciplinary means also natural scientists entering social science, albeit limited through involvement in policy.

For epidemiologists the encouragement today is to have policy impact through 'translational epidemiology' (Feldscher, 2013; Khoury, Gwinn, & Ioannidis, 2010). Translational epidemiology harks back to the beginnings of public health interventions, which also coincided with the emergence of epidemiology as a "...respected subject in medicine rather than simply a fringe discipline" (Holland, Olsen, & Florey, 2007, p. 3).<sup>46</sup> I aim to draw upon mixture of disciplinary approaches throughout this thesis, with a view to what disciplinary approaches applied to NTDs as a policy problem and potential solutions. Next I focus on the particular policy landscape for NTDs of global health.

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<sup>45</sup> For a sociological review of the health economist see (Ashmore, Mulkay, & Pinch, 1989).

<sup>46</sup> An early translational epidemiology example was English doctor John Snow locating the source of cholera during an epidemic to a water pump. Following this were "...a number of other public health policies influenced by epidemiologic findings, including cigarette advertising bans, food labelling requirements, and air pollution standards" (Feldscher, 2013).

### 3.5 Global health actors and landscape

In order to understand NTDs as a policy problem invokes a discussion of how 'global health' contributes to the constitution of policy problems. As a starting point it is important to recognize that global health is a new phenomenon. The idea of global health policies did not come into being until the 1950s after institutions with a global remit such as the WHO were established (Brown, et al., 2006; Ng & Ruger, 2011; Ruger, 2005).

Tropical diseases and now 'neglected' tropical diseases straddle these two eras of public health. This period spans from the health exploits of empire and colonialization. The first directions of efforts were for the benefit of the colonizers, with the colonized as second priority (Trouiller et al., 2002) and the problems of disease were sometimes worsened by colonizers (Farley, 2003, p. 2).<sup>47</sup> Post-empire priorities were similarly skewed. In the dying days of empire, the 'triumph' of tropical medicine was the "...last justification for imperialism" (ibid.). Then after the colonies gained independence the 'health of the natives' was used as justification for ongoing colonial presence, with the continuation of the US military in the Philippines and Puerto Rico (Biss, 2014).

The change to 'global health' means that theoretically the health of the poorest populations is prioritized, with health initiatives targeted at the poorest and most vulnerable. The idea of 'public health' whether on a national level or globally, is meant to be for everyone but what is really meant is that it is for the poor (Biss, 2014). The rich can already guarantee health to a large extent, so to make health 'public' is to enable access and quality of care for those who cannot easily pay. On a country level, making health public extends to structural inadequacy, from health systems and basic infrastructure to trained medical practitioners and researchers. In addition to – who is the 'public'? – is the question of where global health knowledge is coming from. It is not as simple as to assume research is done globally (i.e. in all countries), or is it only developed country research that flows to developing countries (which may have been more characteristic of the idea of international health).

How did global health emerge and what is the difference to international health? Brown et al (2006) describe the transition from 'international' to 'global' public health. While international health has generally referred to epidemics spanning across geographical borders, global health is concerned with the public health needs of all people regardless of national boundaries (ibid., p. 62). If this is the ideal that is strived for, international health becomes outmoded. As Harman (2014) notes during the Ebola epidemic from 2013 to 2015, the response was: "...indicative of international rather than global health governance" in the failure of co-operation and collaboration, which did not happen across institutions and states.

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<sup>47</sup> Example of the problems of diseases caused by colonialists, were the 'scorched earth' policies of clearing land and insecticide use to control rinderpest, exacerbated sleeping sickness (Scoones, 2014).

There is still some debate about whether global health and public health<sup>48</sup> are usefully distinguishable today. Both encompass a population-based study to view health as a problem of populations and not only on an individual or group basis. This population perspective has grown in popularity alongside epidemiology and health economics to look at causes and understandings of health beyond a strict bio-medical determination. I have opted to follow Fried et al. who argued that:

*“Global health and public health are indistinguishable. Both view health in terms of physical, mental, and social wellbeing, rather than merely the absence of disease. Both emphasise population-level policies, as well as individual approaches to health promotion. And both address the root causes of ill-health through a broad array of scientific, social, cultural, and economic strategies”* (Fried et al., 2010, p. 535).

Global health has tended to be the all-encompassing term; therefore I use global health to also encompass public health as a combined idea in this thesis. The global and public aspects of health are important in order to view NTDs, so I am interested in the academic and policy discussions that consider both. What much of the joint discussion has centred upon is the postwar institutionalization and internationalization of public health, which resulted in a demarcation of tropical diseases from development. Kelly and Beisel (2011) summarize the changes:

*“On one hand, the creation of the WHO as distinct from agencies such as the International Monetary Fund narrowed the scope of public health initiatives. On the other, the internationalization of public health and the subsequent dismantling of colonial governments centralized medical expertise; health decisions were no longer the province of local governments but of committees in Geneva and New York”* (Kelly & Beisel, 2011, p. 76).

The institutional set-up changed from a local to global system of economic governance following World War II, including medical research towards 'large-scale science' that is, "...driven by public-private partnerships, international research collaborations and large-scale development donors" (Schumaker, 2000, in Cooter & Pickstone, 2003, p. 78). By looking at trends of data on global funding towards public health we can have an indication of where economic governance is being driven. In 1990 global health funding was dominated by the WHO alongside USA and other donor countries including France, Sweden and Japan – but by 2011 the NGO share had increased dramatically, particularly from new funds (IHME, 2010). These included 'The Global Fund to Fight AIDS, Tuberculosis and Malaria' (GFATM), and the Global Alliance for Vaccines and Immunization (GAVI) and the Bill & Melinda Gates Foundation (ibid). Funding for NTDs has

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<sup>48</sup> Public health may have the furthest historical roots in the “sanitary movement and contagion eras” (Awofeso, 2004, p. 705).

followed a similar pattern except industry funding plays a bigger role, which is most likely to be due to the drug solution focus.

The 'Global Funding of Innovation for Neglected Diseases (G-FINDER) Survey' has been tracking funding patterns for investment in NTDs (Moran et al., 2012, p. 11). While the tracking only covers R&D, it is capturing some wider trends. Public investment is still the biggest funding source, but this is followed by the private sector and philanthropic organizations, with industry investment increasing 'dramatically' (ibid). The increase reflects how over the past decade the multinational pharmaceutical companies, so-called 'big pharma', made concerted efforts to engage with certain global health issues, and have been drawn to NTDs in recent years.

Therefore, global health has emerged from an institutionalization and globalizing of health, which has seen the entrance of new, predominately private sector and philanthropic health actors. Still the WHO, with some variability, has remained a central player with strategic influence, including for NTDs. The WHO has been involved with framing the policy problem throughout, not straying far from the first 2006 report on NTDs description:

*“With little political voice, neglected tropical diseases have a low profile and status in public health priorities. Lack of reliable statistics and unpronounceable names of diseases have all hampered efforts to bring them out of the shadows”* (WHO, 2006, p. II).

The role of the WHO and its institutional development in providing strategic influence is further discussed in the next chapter. In this section I have discussed how the concept of 'global health' emerged and the establishment new health actors, drawing on research in critical global health. I ended on a note about the continued significance of the WHO, whose institutional changes has reflected a changing global health landscape. Next I will turn to understandings of neglect that go beyond those of the established institutions such as WHO.

### **3.6 Neglect as a policy characterization**

Returning to types of problem characterizations, I want to revisit the first section of this chapter. I argue that neglect has a special link with health, being the opposite of care by describing neglect in the negative as the absence of concern or care – a point that I will revisit in the preceding chapters. Care is central to public health, from a micro level of caring for the sick to the macro of caring for populations and caring about what makes them sick.<sup>49</sup> Conversely Sophie Harman (2012) in looking at care in global health governance finds that different practices of policy can promote care and in some cases the opposite – harm, which is why she

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<sup>49</sup> Chaufan et al (2012), see a tension between 'cure' and 'care', reflected in the historic preference of the US government to invest in NIH biomedical research budgets over basic access or universal healthcare. This may be taken to be illustrative also of the innovation approaches discussed as a response against neglect that relies on feeling and thought rather than action and information.

describes 'neglected health' as a result of the dominance of one issue over another. Neglect of health, happens in issues "...sidelined or ignored because of global prioritising such as health systems and maternal health" (ibid., p. 122). It means that the success advocacy of some, for example pandemic and emerging disease fears (HIV/AIDS, pandemic flu, Ebola), has a negative effect on others. Therefore, care applied disproportionately, or too much care directed to certain issues can produce neglect. Still, this argument does not address how care is decided or normatively why we care about some issues over others.

Caring for NTDs happens in a different way for other health issues. Situating NTDs as the 'other' has an effect in how we imagine them as diseases, especially in relation to other global health issues. Looking at imaginaries helps to explain what is claimed about neglect, by whom and why. Imaginaries are an approach popular in STS to describe a future-looking scenario, where 'sociotechnical imaginaries' of how science and technologies produce "social and collective visions of good and attainable futures".<sup>50</sup> However, in applying the idea of imaginaries I am mainly referring to Taylor's use of the term in making sense of social life and normatively enabling it: "The social imaginary is not a set of ideas; rather it is what enables, through making sense of, the practices of a society" (Taylor, 2004, p. 91).

How neglect is imagined, is a topic that is beginning to be explored in the absence literature, albeit not always explicitly. As Balmer and Rappert (2015) put it, topics generate concern or 'non-concern' and take the limelight, setting priorities and policy agendas. Rappert (in Chapter 1. Sensing Absence: How to See What Isn't There in the Study of Science and Security) highlights how it is the 'social problems' and 'social movements' literatures where there is an implicit commentary that those matters do not generate interest and debate. An imaginary of neglect is thus present in thinking about why topics are in the limelight, and also how priority and agenda setting decisions are made. Absence theorists are interested in why there is lack of concern, interest and debate for topics and why we think some topics matter and others not – it is not spelt out, but this is neglect.

Similarly the call to action by the ignorance studies literature resonates with understanding the nature of neglect. As Proctor and Schiebinger describe, in their seminal book in the field 'Agnotology: The Making and Unmaking of Ignorance',<sup>51</sup> neglect is a mechanism behind ignorance:

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<sup>50</sup> Sociotechnical imaginaries are not as "explicit, less issue-specific, less goal-directed, and less politically accountable" as problem frames and policy agendas, and are "more futuristic and less grounded in historical memory" than master narratives" as well as not being confined by discourse as media packages but "often associated with active exercises of state power and the management of political dissent" (Harvard STS Program, <http://sts.hks.harvard.edu/research/platforms/imaginaries/#references>, Accessed 2/4/14).

<sup>51</sup> Agnotology refers to "...the study of culturally induced uncertainty" (Stilgoe, 2016).

*"Our goal here is to explore how ignorance is produced or maintained in diverse settings, through mechanisms such as deliberate or inadvertent neglect, secrecy and suppression, document destruction, unquestioned tradition, and myriad forms of inherent (or avoidable) culturopolitical selectivity..." (2008, p. vii - viii).*

Therefore deliberate or inadvertent neglect produces or maintains ignorance. The distinction between deliberate or not, implies it can be conscious or not, done purposefully out of lack of concern or care, or done inadvertently, supposedly through a lack of systemic concern or care. It may be inadvertent neglect through misunderstanding or because inquiry is selective and to an extent has to be out of necessity. Taking one step further, deliberate ignorance may be caused by neglect as an active construct, actively engineered and used as a strategic ploy to control social processes. This tactical component means that ignorance can be politicized and directs focus towards who is creating ignorance and why. Proctor and Schiebinger go on to state the connection with forms of knowledge as a reason for neglect:

*Our primary purpose here is to promote the study of ignorance, by developing tools for understanding how and why various forms of knowledge have 'not come to be' or disappeared, or have been delayed or long neglected, for better or for worse, at various points in history (ibid.).*

The postcolonial and feminist critiques of ignorance, in offering alternative views of knowledge, are a persuasive current in this work as it helps to explain the structural and directed causes of ignorance. Neglect can also produce and reproduce ignorance. As these, "...claims to ignorance can sometimes serve to promote policy production" (Abeyasinghe, 2015). Proctor and Schiebinger (2008) argue ignorance can have more neutral or even positive societal benefit, such as a coping mechanism for information and knowledge overload.

The next step is looking at how issues are identified or not and how they are formulated as problems for redress, with institutions, systemic issues, mitigation procedures, and temporality being themes. Shiffman has most prominently brought forward the question of: 'A social explanation for the rise and fall of global health issues' (Shiffman, 2009) on the grounds of attention and neglect. He argues that material factors (e.g. mortality, morbidity, and cost effectiveness) do not offer sufficient explanation for the attention of leaders in global health and social explanation is needed (ibid., p. 608). He acknowledges the importance of rhetorical 'problem claims' on the grounds of severity and neglect, as well as frames in a social constructivist understanding of why issues decline or ascend in global health (ibid. p. 609). I will explore frames later in this thesis and make the argument for why 'repackaging' is the way that I want to portray an issue of problem for policy. While Shiffman (ibid., p. 611) looks for reasons to explain a lack of political attention (grouped around policy communities, ideas, and



institutions), I concentrate on the nature of neglect and types of forms that neglect manifests. This focus lends itself more to a literature on the nature of knowledge and non-knowledge.

Thus returning to Proctor and Schiebinger (2008) again, their argument is that things (or knowledge) is not simply present and absent – they are made so, in what is concealed and revealed or whether it is an issue of concern or non-concern (ibid., p. 6). For neglect taken as separate object of analysis, I argue much can be drawn from the idea that neglect and non-neglect (or even concern or attention) are interwoven. Interestingly, neglect appears to be an important characterization of ignorance as a research problem: "...this strategy can also lead to an acknowledgement of non-knowledge that so far has been neglected, but is suddenly taken seriously and may even be seen as fundamental" (Gross, 2007, p. 748).

Neglect of non-knowledge then is a feature of why ignorance has not been researched extensively in the past, although this point has not been fully appreciated in the literature that, "...closed ignorance means that 'we either neglect problems themselves, or do not take notice of intuitive insights, experience, information, models and methods of solution which are available inside of society'...." (ibid.). The presentation of ignorance is as a field of study that has not been given due attention, it has been neglected and deserves a concerted effort to rectify.

However, my main contention is that neglect itself is a different characterization to absence or ignorance in the implicit assignment of blame and responsibility, and an unequal relationship between the neglecter and the neglected. Crucially, what needs attention is not simply this or that missing recognition. The type of absence becomes a central point to understand, and neglect is a special type of absence. The object of neglect in this thesis – NTDs – is defined by what it is not and the many reasons and ways something is neglected through lacking and absence. I will conclude this chapter in the next section by reflecting on the policy environment to create neglect as one of competition, which both promotes division and connections to be made.

### 3.7 Conclusion: Competition and connection

I have aimed to highlight through this chapter how the literature on policy problems and solutions is closely tied to questions about the use of measurement and advocacy in policy, as well as various disciplinary lens in which to view problem-solving. These strands of policy dialogue will be connected again in the proceeding chapters. I will explore a policy history of NTDs in Chapter 4, how the policy problem of NTDs has been represented in global health in Chapter 5, the form of advocacy taken to promote NTDs in Chapter 6, and dominant public discourses on NTDs, including how measurement evidence has been used in Chapter 7.

I have treated in this chapter: policy problems, solutions, and the global health context somewhat separately. I want to emphasize the on-going tension of how policy problems can be in or out of fashion, prioritized or not, imagined to be neglected, and subject to lobbying and profiling. While global health policy has blossomed into an active field with numerous new actors and disciplinary contributors both competition and congruity remains an intrinsic part. As Naomi Klein describes, for those actors who seek to promote particular issues and movements, connecting disparate threads is a means of achieving justice against the status quo:

*"We face so many overlapping and intersecting crises ...Overcoming these disconnections – strengthening the threads tying together our various issues and movements – is, I would argue, the most pressing task of anyone concerned with social and economic justice. It is the only way to build a counterpower sufficiently robust to win against the forces protecting the highly profitable but increasingly untenable status quo" (2016, p. 15).*

Or as Stengers has described along similar lines, to understand a policy problem (in her example climate change and growing social inequalities) cannot be done in isolation, and this will be a guiding point for chapters that will follow:

*"...There has been an epochal shift: the possibility of a global climate crisis is now upon us. Pollution, the poison of pesticides, the exhaustion of natural resources, falling water tables, growing social inequalities – these are all problems that can no longer be treated separately..." (Stengers, 2015, back cover).*

Where to connect and where to divide becomes an ongoing question for NTDs and determines how an individual policy problem is constructed. The theme of what connection and division is taking place in an evolving global health landscape and in understanding neglect will be further examined. The next steps for the empirical research are to uncover the various events and milestones that have made up the recent policy history of NTDs. In the next chapter I will delve into the case of NTDs as a policy problem, analyzing the conceptual origins and what the dominant strategies for tackling these diseases have been and why.

## Chapter 4. Scene-setting: Timelines, disease lists, and health actors

### 4.1 A history of NTDs as a policy issue

The previous chapter set out the theoretical basis for considering policy problems and their solutions. The current chapter aims to set the scene and tell the story of NTDs as a specific policy problem, through a policy history. Historical accounts of policy are argued by Haddon et al. (2015) to be used by social researchers for three main purposes: one, for comparative case studies; two, to provide a broader temporal context for understanding framing, narratives and discourses; and three, to track how policy paradigms change over time. NTDs have a short policy history, since the term was created in the early 2000s, but preceding this creation was the longer history of tropical diseases (discussed further in Chapter 5). I will cover NTDs as a term, then discuss how policy developed, including the categorization of the NTD disease list and end with an analysis of what arose as dominant strategies for policy influence and effect. Since this overview of the policy development of NTDs will become pertinent over the next three chapters, an exploration of the institutional setting for early NTD related initiatives is required.

Beginning in the 1970s, this chapter will explore the history of NTDs as a policy issue, with sensitivity given to how historical accounts can be misinformed, used instrumentally, mythicized, or contested. I primarily use a comparison of two initiatives that were precursors for the concept of NTDs and provide the context for why key milestones or events happened and a commentary on how the policy thinking has changed over time. Firstly, the chapter will confront the 'short policy history' of NTDs, in the coining of the term and the individuals and institutions that were involved. I begin with two early initiatives from the WHO and Rockefeller Foundation that spurred advocacy for NTDs in the 1970s. The reason for the focus on these initiatives, with an interest in absences that have created neglect, is that I want to know why the current conceptualization of NTDs did not arise directly from an early WHO initiative.

Secondly, I will elaborate on the policy development of NTDs and provide a background of the key events, actors, and initiatives. Changing at the same time as the policies directed toward NTDS were the classificatory lists of diseases that constituted NTDs – in viewing this change I am concerned with which diseases have counted as NTDs and why. There is an ambivalence of categorizations of NTDs that has to do with finding coherent criteria for inclusions or exclusion that also has policy appeal. I discuss how different lists occurred, through the London Declaration list of 10, WHO list of 17 and *PLOS (Public Library of Science) Neglected Tropical Diseases Journal* list of 38. I also show how country or regional NTD characteristics challenge an all-encompassing view.

Thirdly I will conclude by discussing the strategies of policy influence and effect that came to dominate. I argue how the targeting of intervention on five NTDs resulting from historical contingency and scientific challenge has led to some of the diseases being 'tool-ready', which will be explained later. I found that the dominant strategies to treat NTDs came from global campaigns including the Sustainable Development Goals (SDGs), the significance of political connections, and the emergence of new institutions, including the work of the Gates Foundation, focusing on drug donation and R&D to tackle NTDs.

Before tackling these issues, it is crucial to look at the term of NTDs. I draw on the theoretical basis set out in Chapter 2 (Methods and Methodology) and 3 (Approaches to Policy Problems) for how "neglect" can be understood drawing on sociological studies of absence and ignorance. In Science and Technology Studies (STS), there has been some emphasis on risks and uncertainty but as scholars have more recently pointed out, we are more comfortable with considering calculable risks "(B)ut there are areas of uncertainty or ignorance in which we cannot calculate probabilities and we cannot predict consequences" (Stilgoe, 2016). Neglect weighs in as needing calculability, which is why defining NTDs is important and a rationale for why they are neglected.

The question this chapter and following chapters will be preoccupied with is by whom and why neglect is originated and perpetuated, along with the attempts to redress neglect. The broad categories of neglect have concentrated on 'who are the neglectors?' and have been an early point addressed in the academic literature (see Holt, Gillam, & Ngondi, 2012; Liese & Schubert, 2009; Morel et al., 2005). As I already touched upon in the previous chapter, these categories have been centred on science (universities, research institutes), the market (pharmaceutical companies) and public health (donors, international organizations, philanthropy). In this chapter I explore those categories further in order to determine what meaning-making and rationales are at play in order to present different sites of neglect.

The group that has been consistently active in their commitment to and also in encouraging a renewed interest in NTDs is the donor community. Big pharma on the other hand has faced pressure to address issues of global health and this influenced their increased involvement, through donation programs. The result has been that more pharma companies donated drugs as part of their corporate social responsibility obligations. However, the pharmaceutical industry did not form a concerted campaign for advocacy or an expansion of attention towards NTDs. I argue that the legacy in the conceptualization of NTDs can be found in two early initiatives that spurred advocacy for NTDs.

## 4.2 Two early initiatives: 'Bringing science into tropical disease research'

The donor community in the 1970s marked out the territory for NTD policy, through two early initiatives that were run by the major global health actors – the Rockefeller Foundation and the WHO. I will discuss the role of these initiatives in originating NTDs in this section. The Rockefeller Foundation was established as the Rockefeller Sanitary Commission in 1909 as a philanthropic organization funded with an endowment of \$3.4bn from the JD Rockefeller Sr.'s incredibly profitable Standard Oil Company, founded in the 1870s (Farley, 2004). Rockefeller had as his principal aid in philanthropy a former businessman and Baptist minister called Frederick Gates, who decided upon a medical focus. Gates had felt medicine to be a neglected area that deserved more attention: "...I had begun to realize how woefully neglected had been the scientific study of medicine in the United States.' What was needed, he concluded was a research institute given to 'uninterrupted study and investigation, on ample salary, entirely independent of practice'..." (ibid., p. 3). It was an example of scientization<sup>52</sup> of medicine with a desire to scale up funding, bring it into an independent and exploratory laboratory setting, away from patients, hospitals and the 'practice' of health. Also indicated was a need to concentrate on a neglected topic.

Scientific research as being a philanthropic 'cause' may sound unusual but many of the most well-established and well-funded philanthropic organizations have this as their mission.<sup>53</sup> In an era before big science projects of national importance during and after World War II, and when major government funding organizations were in their infancy, philanthropy played a crucial role for research.<sup>54</sup> Global health efforts were more of a rarity before the post-war era, and as a result would come to the health realm relatively late. The WHO was established as a specialized agency of UN concerned with international public health in 1948.<sup>55</sup> Arguably, the WHO's largest and most successful role has been in the global campaign for the eradication of smallpox, yet the initial priorities were wide-ranging: "malaria, tuberculosis, venereal diseases, maternal and child health, sanitary engineering, and nutrition" (McCarthy, 2002, p. 1111).

It would be much later in the histories of the Rockefeller Foundation and the WHO – in the 1970s to 1990s – that the preparatory groundwork was set for the creation of NTDs. The first initiative, established by the WHO, was the Special Programme for Research and Training in

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<sup>52</sup> Scientization is defined as: "to treat with a scientific approach" (Merriam-Webster Dictionary).

<sup>53</sup> Philanthropic organizations with a research mission include the Wellcome Trust and Cancer Research UK.

<sup>54</sup> The National Institutes of Health (NIH) established in 1887 in the US and government funding of the Royal Society initiated in 1850 and 1913 when the Medical Research Committee (later the Medical Research Council) was established (Kaiserfeld, 2013; Rosen, 1993).

<sup>55</sup> The WHO was preceded by the Health Agency of the League of Nations established in 1920 but during WWII "international health work came almost to a standstill" (WHO, 2011c).

Tropical Diseases (TDR) (1974 – present). The Rockefeller Foundation established the second major NTD initiative, the 'Great Neglected Diseases of Mankind' - GND (1978 – 1988). It may not have been appreciated within the public health literature, conducting separate analyses (Farley, 2004; Keating, 2014; Remme et al., 2002; Zhou, Wayling, & Bergquist, 2010) but the purposes of the two initiatives were similar.

Both were premised on bringing science into research for tropical diseases through 'capacity building'. Capacity building in this context meant building the scientific expertise and research capabilities of those working on NTDs, particularly focusing on developing countries, by providing the support and network of developed countries. To begin with, the driving goal of the TDR was to develop new drugs (and other innovations) for neglected infectious diseases in developing countries and have developing country scientists advance their research skills.<sup>56</sup> In line with a capacity building approach, the endemic country took centre stage – although this did still assume a transfer of knowledge and resources from developed to developing countries. For the GND it was, also to develop drugs for neglected diseases but with a greater emphasis on basic research and to introduce new scientific techniques.

The diseases that the initiatives included both held similarities with the current NTD grouping. The TDR included seven diseases that would be later included in the WHO 13, (with the exception of malaria). At the time, the first director of the TDR, Adetokunbo Lucas noted: "These diseases were selected by the criteria of their public health importance, the lack of effective tools for their control, and the likelihood that research can yield the new tools which could bring significant advances in their control" (in Fudenberg, 1983, p. 160). As of 2016, TDR also includes malaria, Ebola and TB. The TDR as the 'Special Programme for Research and Training in Tropical Diseases' does not make the distinction of malaria and TB as being relatively less neglected as part of the 'big three' and nor is Ebola out of scope as an emerging disease. As the focus is on capacity building and scientific progress there is still much to be achieved for these diseases. Rockefeller's 'Great Neglected Diseases of Mankind' - GND - also included diseases not typically described as NTDs, such as diarrheal diseases and other typical diseases of poverty not tropical by nature (see Table 3 below for a comparison of the diseases covered by the TDR, in both 1978 and 2016, and the GND in 1978).

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<sup>56</sup> The Division of Control of Tropical Diseases (CTD) established in 1990, jointly steered the TDR's applied field research in providing technical advice and assistance for endemic countries. In 2007 CTD was incorporated into the HIV/AIDS, TB and Malaria cluster (Lee & Fang, 2013).

	TDR 1978	TDR 2016	GND 1978
<b>Chagas disease</b>	x	x	
<b>dengue</b>		x	
<b>diarrheal diseases</b>			x
<b>Ebola</b>		x	
<b>filariasis (inc. lymphatic filariasis and onchocerciasis)</b>	x	x	
<b>HAT</b>	x	x	
<b>helminthiasis (inc. hookworm)</b>		x	x
<b>leishmaniasis</b>	x	x	
<b>leprosy</b>	x	x	
<b>malaria</b>	x	x	x
<b>schistosomiasis</b>	x	x	x
<b>TB</b>		x	

**Table 6 Comparing TDR diseases to GND diseases**

(Compiled from: U.S. Congress Office of Technology Assessment, 1985; Lucas, 2013)

It would be much later that the WHO also latched onto 'neglected' as a descriptor for tropical diseases. The WHO made references to 'neglect' and also the GND, but this tended to be as a rhetorical device, as described by the WHO in 1990: "Human commitment and resources are required of the world, if tropical diseases are not to become the great *neglected* diseases of mankind" (WHO TDR-CTD; emphasis added). While the TDR may initially appear to be the natural home for the creation of NTDs this proved not to be the case. According to one of the activist scientists:

*"TDR I think dropped the ball... They lost the disease focus... the point is that TDR never invented or had anything to do with the concept of NTDs... they were involved in some excellent work on oncho [onchocerciasis]... they did fundamental early work... TDR are basically an organization that take donor money and redistribute it, the work is done by scientists who apply for grants"* (Interview with author, activist scientist, 2016).

In losing the 'disease focus' what is being implied is that the TDR became more concerned with the distribution of donor money and encouraging capacity building of scientists. This account is one explicit statement about the lack of WHO involvement in originating the concept of NTDs but is reflected from my other informants. The point was made that the WHO is not well placed for advocacy and conceptual input into disease issues. As Nick Kourgialis from Helen Keller International (an organization concerned with causes and consequences of blindness and malnutrition) explained in our interview: "So they're a critical partner but I'm not sure that they've been as directly involved with or important in the advocacy that occurs on the country level, in the US, in the UK and others" (Interview with author, Kourgialis, 2016). Their role was more centred on setting global standards and criteria (e.g. elimination) for reporting and guidance on clinical protocols to highlight the importance of issues and providing a forum for

discussions and assessing progress. Therefore, it is clear while providing early leadership on policy and scientific research, the TDR were not involved in the conceptual construct of NTDs. Some institutional groundwork was laid as tropical diseases were embedded early on in the WHO machinery.

As Keusch writes (in Parker & Sommer, 2010), the TDR was a somewhat unique entity within the WHO, as a partnership with the United Nations Development Programme (UNDP) and the World Bank. The TDR had more independence than usual in being supported by external funds, so that it could determine how to put resources to use without interference from WHO leadership and was determined to keep a degree of independence (ibid.).<sup>57</sup> This reliance on external funds and partners, and encouragement of drug donation, also may have opened the door for private sector and philanthropic actors to become involved later.

Other scholars have explored the institutional settings of the WHO and the Rockefeller Foundation (Haynes, 1999), yet their research has not gone beyond tropical diseases and extended to NTDs. I make the point that institutionally, the Rockefeller Foundation did not need to reach the type of consensus that the WHO needed as a multi-constituency representative body.

Scientific research as the main type of capacity-building was a main pursuit of both programs. The GND at the time of its operation was heavily interested in attracting the 'crème de la crème' of scientific talent, whether that was in developed or developing countries. The TDR was scaling research effort across organizations. In a profile on the WHO website, Lucas (2013 [1978], p. 220) stated how he was hopeful at inception that the TDR "...will produce results which would otherwise not have been attained through the traditional isolated and disjointed approach to such problems" (Fleck, 2015, pp. 292-3). The TDR wanted to bring produce scientific results via developing countries by building their talent base (see Fleck, 2015; Lucas, 2013). Also expectations for new biotechnology advances to solve old problems was high, as Lucas described:

*"...the vigorous application of recent advances in modern biology would yield a better understanding of parasites and parasitism... an interdisciplinary approach using the modern tools of research in immunology, histochemistry, biochemistry, molecular biology, genetics... by focusing attention of scientists on the needs and opportunities for research in this area, more rapid progress can be made" (2013 [1978], p. 220).*

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<sup>57</sup> When some governments disapproved of grant recipients (e.g. Burma), the TDR made their case that they had, "...the right to work with all Member States. Still, we had problems with some individuals. Some countries insisted that the government should nominate grant recipients. We refused, saying that it had to be about science not political favours" (Fleck, 2015, p. 293).



The scientific focus, especially the application of new scientific specialties would become less pronounced and was certainly a perceived need in the 1970s in both GND and TDR.

At the WHO, the TDR focus in later years has moved onto how research can support and improve health outcomes as opposed to an exploratory introduction of biotechnology. The current director (as of 2017) John Reeder explained in an interview with the UN-associated news website *Genève Internationale*<sup>58</sup> that, "...really, it's about putting research into the service of improving people's health" (Genève Internationale, 2014, Accessed 23/4/15). This outlook is a concern for implementation, and operational research, to consider country capacity, delivery, and uptake, as Reeder argues: "What is needed today is different than when we started. Today there are many new medicines and diagnostic tools, but they aren't always getting to the people who need them... Our strategic shift has been downstream towards the diseases in country" (ibid.).

When I interviewed Bernadette Ramirez a scientist working in Reeder's unit, she described how as part of financial prioritization at the WHO, TDR underwent a "refocus of strategy in light of limited resources and reprioritization exercise" (Interview with author, 2013). The focus would remain on capacity building, "...looking at current gaps to add value for the needs of the community" (ibid.). In terms of involvement in cutting-edge research, she explained the view that there already was enough "...capacity on the ground as far as [drug] discovery" (ibid.). TDR could facilitate 'R&D mapping' and research networks had been set up and were embedded in disease endemic countries but, "...TDR is no longer pursuing drug discovery as a major activity" (ibid.)

My overall argument is that this approach, in attracting the best scientific talent would have the biggest legacy to bring about NTDs (a point that I will discuss at length in Chapter 6). The TDR and GND, and their institutional setting show how the ground was set for the concept of NTDs to emerge. I make the argument that the WHO was unable to be the originators of NTDs and this was because their advocacy ability was limited. I point towards the GND as being the conceptual origin for NTDs and further explain why this is the case in Chapter 6, drawing on historical sources and interviews.

In the remaining section, I consider the ongoing role of the WHO and the Rockefeller Foundation, and what the GND and TDR say about the transition from tropical disease to NTDs. This is a key point because there is very little in the literature making this point, apart from largely historical accounts (Hotez et al., 2012; Lammie et al., 2007) that look toward the new configuration of tropical diseases as NTDs.

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<sup>58</sup> *Genève Internationale* is run by the state of Geneva.

The WHO has been criticized for not paying enough attention to diseases of the poor. While the TDR could also be seen as a return to the original goal of 'health for all' (Gillam, 2008) in not forgetting the poorest communities for some this ambition did not go far enough.<sup>59</sup> This was certainly the view of Kenneth Warren, the director of the GND, that the WHO had not concentrated on "...those few diseases that caused the highest mortality among the world's poor" (Keating, 2014, S.25). Their limited advocacy role is still acknowledged. Similarly Kari Stoever at the 'Global Network for Neglected Tropical Diseases', one of the main advocacy NGOs established in 2006, spoke of the difficult position the WHO held:

*"Because of the way they're set up, they're set up to be a bureaucracy and to gain consensus and when you're an advocate you've got to drive to a goal and it's usually very short term... you're trying to push the needle faster than the WHO would be able to convene or develop consensus among their members"* (Interview with author, Stoever, 2016).

It has been the case that from inception in 1948 until the late 1990s the WHO fared variably, described as moving:

*"...from a commanding position as the unquestioned leader of international health to a much-diminished role in the crowded and contested world of global health... WHO was marked from its early days by political and diplomatic entanglements and budgetary constraints that, over five decades, compromised the organization and restricted its operating capacity. Indeed, those entanglements and constraints eventually pushed WHO in the 1990s to try to reinvent itself as a coordinator of global health in a world with many new and powerful players"* (Brown & Cueto in Parker & Sommer, 2010, p. 18).

For the Rockefeller Foundation I make the point that the change of topics of focus is why it has not continued influence with NTDs. Chen remarks in how, "(F)oundations are strange creatures since they are not driven by the accountability of the ballot box, scrutiny of the media, or even restrictive regulations" (2014, p. 719). Therefore the topics of focus are often directed by the individual preferences of the foundation rather than an international organization such as the WHO, which needs to reach consensus between its members.

Before the launch of the GND, the Rockefeller Foundation had been concerned with population growth and agricultural science (or rather the prospect of the green revolution to solve world hunger).<sup>60</sup> The programs in health sciences, which had been the flagship programs at the

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<sup>59</sup> The place of NTDs as a priority by the WHO in the goals of universal health coverage and essential health interventions can be seen in this statement by director Margaret Chan: "We are moving ahead towards achieving universal health coverage with essential health interventions for neglected tropical diseases, the ultimate expression of fairness" (WHO, 2013, p. vi).

<sup>60</sup> NTDs have often been a footnote in history affected by a focus on other scientific areas such as population growth and the green revolution, where also the later backlash against overuse of pesticides

foundation's creation by the 1970s had been waning. In 2016, population growth is not viewed as such a threatening concern. China has relaxed its one child policy, which since 2015 is being formally phased out (BBC News, 2015), also global fertility rates are dropping and even reverse population growth is seen in some countries such as Japan (Walsh, 2012).<sup>61</sup> For example, a major debate was about whether to pursue the control and elimination of malaria because of a knock-on effect would be improved child mortality, worsening the problem of population growth. There was discussion among academics, policy makers and in the media about the desirability of halting the malarial 'cull' which was a 30-40 per cent infant mortality rate to prevent population explosion in Asia and Africa (Fuller, 2015; Smith, 2015).

However, in the 1960s and 1970s population growth was a major concern and a threat to the developed countries, as shown by such dystopian sci-fi films as "Soylent Green" released in 1973, imagining some of the horrors of too many people scrambling for limited resources (Haberman, 2015). This anxiety about the population growing faster than available resources, also predated the green revolution of high-yielding, disease-resistant crops, and the rapid economic growth of developing countries such as Brazil and India now seeing declines in birth rate growth (ibid.).

The Division of Health Sciences at the Rockefeller Foundation reflected these popular sentiments, prevalent in academic circles and the public imagination, however it would experience changes that would bring health concerns back into the picture. Four key members of the division had retired, opening the door for a change of direction (Kreier, 2014). As Warren remarked, because of, "...the relative lack of constraints upon voluntary organizations, this could have been in many different directions" but the leadership of the Director John H. Knowles had set this focus on health (ibid., p. 336). The topic of focus was to be: "... the major diseases of the forgotten three-quarters of the world's people in developing countries" and in a sense a return to the foundation's roots, as it had begun with a major global hookworm campaign (ibid.).

Both the TDR and GND, had returned, through these initiatives to the founding ideals of their institutions, and this I argue was in order to leave behind 'colonial baggage'. The outlook of the initiatives marked a discontinuity with colonial health and was the beginning of a new 'global health'. As the next chapter will discuss further, a previous colonial shaping of tropical diseases meant that in the post-colonial era a new approach would be sought. The emphasis on 'capacity-building' and 'cutting-edge scientific advances' of the TDR and GND signaled a new approach to tropical diseases. These two initiatives formed a view on how best to go about addressing tropical diseases, in ways that differed from the colonial campaigns that existed until most countries achieved decolonization by the 1970s.

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and insecticide (sometimes also called a green revolution in the concern for the environment) had a detrimental effect on their use for vector control (Kinkela, 2011).

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On a final note, the colonial history is a lingering point even in the names of the initiatives. The TDR kept tropical diseases in its name and mission statement (although the acronym 'TDR' is used mostly). The director of the TDR in 2007, Robert Ridley, defended the decision years later in a profile on the WHO website:

*"Q: The concept of "tropical diseases" originates from the medicine practiced by 19th century colonial powers to protect themselves in the tropics. Have you considered changing your name?"*

*A: There has been some discussion about the name. Our new strategy refers more to "infectious diseases of poverty", but if you look at the terms "tropical disease and tropical medicine" they still cover a field that is generally recognized today. You still have associations and institutes with the name and – at WHO – a department of neglected tropical diseases. The name has other connotations which we should be aware of, but given the recognition of the name and loyalty to TDR, particularly in developing countries, we decided to keep it" (Bulletin of the World Health Organization, 2007).*

The GND on the other hand chose to rename what was largely a group of tropical diseases, to emphasize the common humanity implicated in 'diseases of mankind'<sup>62</sup> and the scale and problem of 'the great neglected'.<sup>63</sup> Maybe it had been the historian in Warren (who had studied history and literature before switching to medicine), as director of the GND, who proposed the grandiose title. However, the word 'great' had been used in tropical medicine to elevate the importance, scientifically and to society of tackling these diseases, just as neglected would similarly be used in an instrumental way, this time to highlight moral obligation and need. The wording 'mankind' was a part of what the foundation was about, "to promote the well-being of mankind throughout the world" (Birn et al., 2013, p. 1618). In any case, the GND was the beginning of the NTD brand and would have a conceptual legacy for NTDs that I will go on to discuss the significance through Chapter 6.

In the next section I look towards the reasons why new activities and organizational structures have been required to further the NTD cause, a symptom also of the change in global health. The WHO has been both an influential entity but also an overly bureaucratic institution, that my informants did not view as an advocacy organization. After the launch of the TDR the WHO endured a 'declining role', confounded by the relative ascendance of the World Bank, which was

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<sup>62</sup> "Mankind" was the common word used at that time before being replaced by the gender-neutral 'humankind'. The GND had parallels then to the 'mankind' reference in the Rockefeller charter: "to promote the well-being of mankind throughout the world", described variously as 'noble' (Keating, 2014) and less sympathetically as 'lofty' (Schanke, 2007).

<sup>63</sup> Other uses of 'great' as a characterization of tropical diseases included Ronald Ross in his autobiography, 'Memoirs of 1923', providing the subtitle "with a full Account of the Great Malaria Problem and its Solution" (Bynum & Porter, 2013, p. 562).

able to intervene more actively in world health affairs through 'structural adjustment policies' that tying health to the economy and financial support (Kenny, 2015). The organization has had to contend with new entrants into global health, particularly from the early 2000s onward.

Similarly the Rockefeller Foundation after some initial success with the GND program would find it difficult to maintain relevance following the proliferation of global governance institutions. From the WHO and other UN agencies to the World Bank, widening the health focus in their activities both institutions would face increased competition. Moreover, after the turn of this century the Rockefeller Foundation would be overtaken by the Gates Foundation as the foremost philanthropic donor in public health. Therefore, while both institutions would have a contribution towards the NTD policy cause, it would take a very different set of actors to take tropical diseases forward in a new global health landscape.

### 4.3 Timeline of key events

The stage was then set for a number of milestones in the creation of NTDs as a policy and disease category from the first NTD paper in 2004, to the Berlin meeting in 2005 quickly followed by the creation of the WHO department for NTDs and the first WHO report on NTDs. This collection of milestones then reached a pinnacle with a landmark event in 2012 'The London Declaration' and the formal instillation of NTDs on policy agendas through the 2015 Sustainable Development Goals (SDGs). Below I show a timeline of these key events.



Figure 4 Timeline of main events in creation of NTDs from 1970 – 2015

## 4.4 From the Berlin meeting to The London Declaration

### 4.4.1 The Berlin meeting

The "historical meeting in Berlin" took place between the 18–20th April, 2005 (Savioli, Montresor, & Gabrielli, 2011, p. 486). It is described by WHO representatives Savioli et al from the Department of Control of Neglected Tropical Diseases as when the WHO "formally rebranded this area of work, previously vaguely defined as 'other communicable diseases' or 'other tropical diseases,' meaning other than malaria, tuberculosis, and HIV/AIDS, as neglected tropical diseases" (ibid.). This view was supported by activist scientist Alan Fenwick, who argued that it was at the meeting that much of the groundwork and discussions for coining NTDs happened:

*"...it was a mixture of people who were interested in the various diseases and a selection of African Ministers of Health and whatnot, and we sat down and we talked, and we said what are we going to do? ...And so the big question came up, can we integrate what we're doing and who the hell can pronounce all these names? I'm the only one who can pronounce all these names and spell them. And so we needed a collective phrase and we discussed a number of different phrases and neglected tropical diseases was the one that was selected, NTDs" (Interview with author conducted with Erman Sozudogru, Fenwick, 2015).*

This international workshop was intended to be a 'Strategic and technical meeting on intensified control of neglected tropical diseases' (WHO, 2005). It was co-hosted by WHO, the German Ministry for Economic Cooperation and Development, the German Ministry of Health, Deutsche Gesellschaft für Technische Zusammenarbeit (GTZ), Kredinstalt für Wiederaufbau (KfW), and the TDR. Present were a variety of, "(E)xperts from public health, economics, human rights, research" which explains the focus on these areas in the proceeding report (ibid.).

There had been an earlier meeting in Berlin in 2003 convened by the WHO and GTZ on the 'Intensified control of neglected tropical diseases', which was an important initial meeting in defining a collective response against these diseases (WHO, 2004a). Although the 'Berlin Meeting'<sup>64</sup> that most commentators refer to as the defining one was in 2005, which led to the creation of WHO Department for NTDs. Molyneux describes how: "...Dr Anarfi Asamoah-Baahaba now the Deputy Director General [at the WHO] was at that meeting and decided he would create the department... He said I'm going to do it tomorrow... so that's when it happened that the Department at the WHO was created" (Interview with author, activist scientist, 2016).

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<sup>64</sup> Other meetings followed the Berlin Meeting, on April 17-18, 2007, the WHO convened the first 'Global Partners' Meeting' on NTDs with 200 participants from public, private and philanthropic sectors, including Blaise Compaoré, President of Burkina Faso, and Samuel Eto'o, a Cameroonian footballer (Savioli et al., 2011, p. 487).

Why was this meeting important? It coordinated efforts towards a new strategic approach. Savioli et al. called this a paradigm change within the WHO:

*"In 2003, under the leadership of Dr. J. W. Lee, just appointed Director General, the World Health Organization (WHO) started a process of paradigm shift in the control and elimination of neglected tropical diseases (NTDs). The shift consisted of the adoption of a new vision that abandoned a purely academic approach to adopt one more responsive to the needs of affected individuals and communities. As a consequence, it entailed a strategic rethinking and a move away from a "theoretical," structural classification based on disease biology toward a "practical" one based on the available tools employed to control such diseases" (in Relman & Choffnes, 2011, p. 481).*

The shift was based on the new drug strategy of preventative chemotherapy through Mass Drug Administration (or MDA, discussed in the next chapter). As described by Savioli attention was directed towards policy design and outcomes rather than a technical approach considering the diseases separately. The door was also opened to consider a societal understanding and apply a social science lens with economics and human rights, and also public health – as both a "science and art of preventing disease, prolonging life and promoting health" (Acheson, 1988).<sup>65</sup>

#### **4.4.2 The first paper**

The Berlin meeting was an occasion for the term NTDs to come into being as the best descriptor of a group of tropical diseases that multiple partners were working on, with agreement among many of the central stakeholders. However, the term still needed to be further conceptualized and promoted. I have identified the paper most explicitly referring to NTDs and would prove influential in considering the policy intervention of NTDs as "Rapid-impact interventions": how a policy of integrated control for Africa's neglected tropical diseases could benefit the poor" (Molyneux, Hotez, & Fenwick, 2005b).<sup>66</sup> The three main activist scientists who wrote this paper were David Molyneux, Peter Hotez, and Alan Fenwick, for *PLOS Medicine* in 2005. In the paper they questioned the lack of attention for the successes of NTD interventions from policy makers, donors and public health officials. The vertical programs were working well but could be combined for 'integrated control' and rapid impact'. Synergies could

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<sup>65</sup> Public health as a science and art was a popular definition from the late 1980s, coming from an influential public health inquiry by Acheson – the first since 1871 for the UK Government on 'Future Development to the Public Health Function', which used WHO categories as a basis for categorization (Robotham & Frost, 2005).

<sup>66</sup> The first paper on NTDs was followed by an expanded 2006 paper, 'Incorporating a Rapid-Impact Package for Neglected Tropical Diseases with Programs for HIV/AIDS, Tuberculosis, and Malaria' (Hotez et al., 2006).



be produced by combining delivery of four drugs in a 'rapid impact package' aimed at five NTDs (schistosomiasis, trachoma, lymphatic filariasis, onchocerciasis and soil-transmitted helminths).

These diseases could be treated through the same drugs or delivered through a similar treatment (MDA), especially as at-risk populations often suffered from more than one parasite (called polyparasitism or infestation with two or more parasite species in the same host (Zhou et al., 2010, p. 22), with cost-effectiveness results. The NGO 'Global Network for Neglected Tropical Diseases' calls this 'The Solution' on their webpage: "We have the tools available to defeat the most common neglected tropical diseases (NTDs), and we can do it in our lifetime. Unlike many other global health problems we face today, the solution is relatively simple. For just 50 cents, we can provide a person with treatment against the most common NTDs for an entire year".<sup>67</sup>

When I interviewed Molyneux, he stated the most important paper where he put down his thoughts about neglect but also the successes achieved was already published in 2004 in the Lancet. This first NTD paper was titled: 'Neglected' diseases but unrecognized successes – challenges and opportunities for infectious disease control' including six NTDs (Chagas' disease, guinea worm, lymphatic filariasis, onchocerciasis, schistosomiasis and geohelminths) and also polio as his 'neglected' diseases. His primary motivational argument was that there already existed successful interventions that were not being sufficiently implemented. Therefore, it was the interventions and the success of interventions that were being neglected not the diseases per se. The contrast that Molyneux wanted to make was the 'inherent difficulty' in controlling the 'big three' as opposed to the relative ease of controlling 'chronic biologically stable disabling infections' (Molyneux, 2004, p. 382). For him, NTDs did not arise from the MDGs. Instead the MDGs served as a rhetorical device to demonstrate NTDs had been sidelined in funding streams and priority setting. Therefore, according to Molyneux, the MDG argument was applied post hoc and was not itself a spur for activity. He was surprised by the reaction to his 2004 paper and the paper with Hotez and Fenwick the next year in how the term NTD caught on:

*"None of this was done deliberately... when I wrote that paper in 2004 and then it just then took off, it resonated because we were struggling... we couldn't persuade a donor, be a bilateral donor... to actually buy-in to the concept of a single disease, we had to find another thing and I was frustrated... from 2004 to significant contributions from a whole range of parties... effective partnerships across the patch, I certainly would have dreamt of almost 12 years afterwards from first paper, completely unthinkable" (Second interview with author, Molyneux, 2016).*

The single diseases stood up poorly to the big three and so the MDGs would later form a useful marker in which to provide evidence that NTDs were neglected. Perhaps more concerning to

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<sup>67</sup> Global Network, <http://www.globalnetwork.org/>, Accessed 9/12/12.

Molyneux was the excessive interest in emerging and re-emerging infectious diseases perceived as a threat (Ebola, West Nile virus, nipah virus, and SARS) but a low significance in global public health terms (burden of disease) demonstrated by DALYs attributed (ibid., p. 180).

These academic contributions were policy engaged and orientated. Many papers were later published about NTDs, with authors describing what they viewed as the state of affairs and what should be done about them. Further thought and action came in numerous forms from the establishment of *PLOS Neglected Tropical Diseases journal* in 2007, the G8 Meeting in Japan in 2008 which set NTDs as a priority, to the Presidential Initiative on NTDs and DFID Commitment also in 2008, and the first WHO report on NTDs in 2010.

#### 4.4.3 The London Declaration and disease lists

A culmination of events occurred on the 30th of January 2012 at 'The London Declaration'. On this day, a collection of international politicians, pharmaceutical CEOs and heads of global health organizations, including Bill Gates and the Director of the World Health Organization Margaret Chan, descended on London. What was striking about this gathering of leaders was the presence of big pharma, led by Bill Gates as a domineering force in public health through the philanthropic Bill & Melinda Gates Foundation. Gates was already completely changing the landscape of public health through his \$39.6 billion endowment to the foundation as of 31 December 2015 from 2006 with priorities set in the areas of health, development and education.<sup>68</sup> By the account of Molyneux, Gates was central, but there were others who were instrumental in making the London Declaration happen: "It was DIFID [UK Government Department for International Development] and Gates... supported by pharma partners particularly by Andrew Whitty from GSK [GlaxoSmithKline]<sup>69</sup> with Lorenzo Savioli driving the agenda from the WHO side" (First interview with author, Molyneux, 2016).

This was a meeting for setting goals and forming a collective vision to tackle NTDs, echoing the Millennium Development Goals (MDGs) 12 years before. The MDGs were eight targets set to be reached by 2015, addressing the needs of the world's poorest people and agreed by all countries at UN. The collective prioritization of NTDs and goal-setting at the London Declaration was reminiscent of the MDGs but this time directed specifically at NTDs. Many involved in NTDs highlighted the omission by the MDGs and how donor attention and funding was directed towards the 'big three'. As Molyneux describes, policy-makers and politicians, "...overfocus on unachievable objectives and targets around the 'big three' diseases, which if the planet was viewed by aliens would be seen as the only diseases that existed on the planet" (2008, p. 509).

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<sup>68</sup> Gates Foundation, <http://www.gatesfoundation.org/What-We-Do/Global-Health/Neglected-Tropical-Diseases>, Accessed 2/4/14.

<sup>69</sup> A British pharma company.

At the London Declaration, only 10 of the 17 WHO diseases were addressed, as the signatories decided that these were the ones that could be controlled or eliminated by the end of the decade: the diseases ripe for 'immediate targeted assistance'. This scope was in line with the early papers about integrating successful vertical programmes and explains the pharma company involvement. What the London Declaration was really about was the continuation of existing drug donation and research programs with some encouragement of further R&D. The commitments summarized, were as follows:

- Sustain, expand and extend programs, drug supply and access
- Advance R&D, collaboration/coordination
- Funding for implementation and technical support to evaluate and monitor the interventions

**Table 7 Summary of London Declaration commitments**

Through a public announcement of commitments to NTDs the intention was to address this shortfall and to coordinate action by 2020. NTDs were described as such:

*"These diseases, many of which have afflicted humanity for millennia, affect more than 1.4 billion people. They sicken, disable, and disfigure, keeping people in cycles of poverty and costing developing economies billions of dollars every year. Until recently, NTDs saw little attention from all but a small handful of dedicated supporters. But as their impact grew clearer, more were urged into action" (Uniting to Combat NTDs, 2014, p. 4).*

This is a typical description of NTDs. These are diseases of and causing poverty that have been around a long time (some for millennia), disabling and disfiguring more than killing, still affecting many with an impact on their economies. The final point is the one that must be emphasized the most. It is an acknowledgement that NTDs have been a neglected problem but the situation is improving. There are a number of diseases that can be included in this group, although it is striking there is no global consensus of what these diseases are or any standardized definition, with different organizations defining these diseases differently.

Other organizations' disease lists also tend to have lower more manageable numbers than the 17 making up the WHO list, with one exception. The open-access journal *PLOS Neglected Tropical Diseases* promotes a list of 38, and the journal is open to suggestions for other diseases to be included with appropriate rationale. The *PLOS* journal was established in 2007 through a \$1.1 million grant from the Gates Foundation and with Peter Hotez as the founding Editor-and-Chief (The Official PLOS Blog, <http://blogs.plos.org/plos/2006/09/announcing-plos-neglected-tropical-diseases/>, Accessed 1/5/16). It has science, policy and advocacy mission according to Hotez to: "...be both catalytic and transformative in promoting science, policy, and

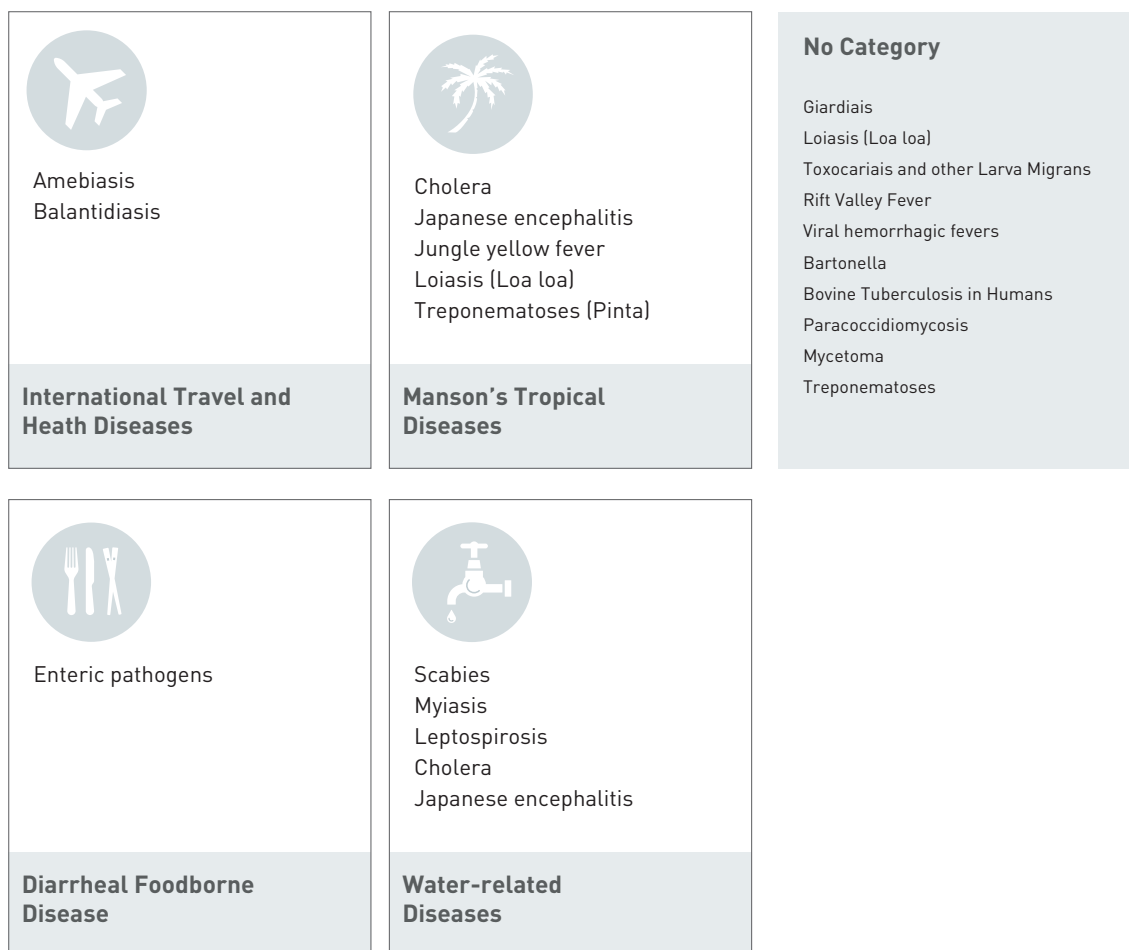
advocacy for these diseases of the poor" (ibid.). The main focus is on poverty and the chronic aspect of these diseases described as: "poverty-promoting chronic infectious diseases" with an impact on "child health and development, pregnancy, and worker productivity, as well as their stigmatizing features" (PLOS Neglected Tropical Diseases, <http://journals.plos.org/plosntds/s/journal-information>, Accessed 4/16/5). The diseases in addition to the WHO 17 are many viral and bacterial diseases, and five (loiasis, Japanese encephalitis, Jungle yellow fever, cholera and pinta) are those originally listed by Patrick Manson. A British physician he was founding director of the London School of Hygiene and Tropical Medicine (LSHTM) and largely behind creating the specialism of tropical medicine. His book 'Manson's Tropical Diseases: A Manual of the Diseases of Warm Climates' (1898),<sup>70</sup> was definitive in the construction of the tropical disease grouping and lists a catalogue of 65 infections or diseases from the minor 'prickly heat' to the more serious malaria and yellow fever.<sup>71</sup> This list will be discussed in greater detail in the next chapter.

The reason for those diseases not to be included in the WHO list appears to be because of the lower incidence rate, or lower level of severity, or both. Japanese encephalitis and jungle yellow fever cause periodic outbreaks, which is why the WHO groups them under information for emergencies. Other diseases listed are what the WHO call 'Water-based diseases' and diseases that come under 'International travel and health'. I have ordered these different groups into the figure below.

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<sup>70</sup> Manson developed the 'mosquito theory' of infectious disease transmission, founded the LSHTM in 1899, and was the first president of the Royal Society. In fact these diseases reflect partly the older tradition of 'diseases of warm climates' included in the title. He places more of an emphasis on the European coping with a tropical environment than what came to be the colonial project of tropical medicine, a more all-encompassing programme of health and sanitation. However, while reflecting on the older tradition, Manson wanted to break with the medico-geographical distinction and bring in modern scientific grounds for differences in disease in temperate and tropical climates (see Edmond, 2006)

<sup>71</sup> The sub-categories Manson outlined are: fevers, general diseases of undetermined nature, abdominal diseases, infective granulomatous diseases, animal parasites and associated diseases, intestinal parasites, skin diseases, and local diseases of uncertain nature. One undetermined disease was the yet to be discovered cause of sleeping sickness (human African trypanosomiasis) transmitted by the tsetse fly.



**Figure 5 PLOS NTDs in addition to the WHO 17**

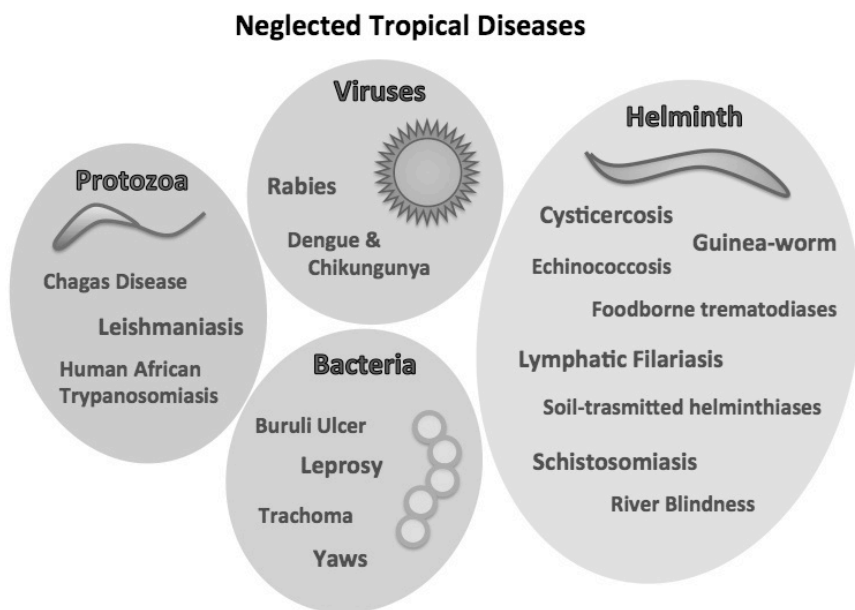
(Figure by author. Source material from PLOS Neglected Tropical Diseases, <http://journals.plos.org/plosntds/s/journal-information>, Accessed 5/4/14, WHO, 2013b)

*PLOS* has more reason to have a wide scope as an academic endeavour, where there will be public health and biological similarities across a wide range of diseases. The main restriction is the 'big three' being excluded, as there exists many other outlets for them.

To conclude this section, the variation in the number of diseases is representative of how NTDs are diversely described. Therefore the NTD label is not a purely biomedical description, as it is related to several social characteristics, such as poverty, stigma and voicelessness. I will go into more detail on categorization in the next section. Teasing out ideas about why certain categories or characterizations are used will provide insight about the 'claims-making' of policy problems (Conrad and Barker, 2010, p. S68). NTDs can thus be understood through other groupings than individual diseases. The different ways to divide up these diseases put forward rationale for disease inclusion. What these sub-groupings of NTDs say about the criteria determining which diseases are included and why will be discussed next.

#### 4.4.4 Different ways to cut a pie

The descriptor the WHO commonly uses for NTDs is by pathogen – ranging from viral (dengue fever and rabies) and bacterial (leprosy and blinding trachoma) to the less well-known protozoa diseases, including Chagas (closely linked with Latin America) and African sleeping sickness (only affecting sub-Saharan Africa). Then there is a large group of helminths (worms, such as guinea worm, lymphatic filariasis and schistosomiasis) see Fig. 6 below.



**Figure 6 NTDs by pathogen**

(Cotton, 2015)

Another pathogen distinction the WHO uses has been macro and micro pathogens. They call this an 'arbitrary classification', but also point out that the division, "...enabled Anderson and May in 1991 to elucidate principles governing the population dynamics, epidemiology and courses of infection of pathogens that severely impair human health" (WHO, 2010, p. 39). Therefore, they were informed by the basic distinction in order to derive epidemiological principles. Microparasites have simple life cycles and can replicate within the host causing a range of infections from acute, recurrent, inapparent to subclinical.<sup>72</sup> On the other hand, macroparasites have complex life-cycles involving intermediate and reservoir hosts, so infections tend to be chronic rather than acute, resulting in lower mortality rates (ibid.). The pathogen distinctions are helpful to understand that the worm macroparasite group is the largest and mostly disability inducing, compared with the microparasites of which particularly the viruses and protozoa result in higher mortality.

<sup>72</sup> The WHO defines infection as: "acute (death or recovery), recurrent (repeated growth and decay of organisms in the host) or unapparent (dormant and difficult to detect) to subclinical (symptomless but detectable)" (WHO, 2010).

**Causes of neglected tropical diseases:**

**Microparasitic pathogens**

- Buruli ulcer
- Chagas disease
- Dengue
- Human African trypanosomiasis
- Leshmaniasis
- Leprosy
- Rabies
- Trachoma
- Treponematoses

**Macroparasitic pathogens**

- Cysticercosis
- Dracunculiasis
- Echinococcosis
- Foodborn trematodiasis
- Lymphatic filariasis
- Onchocerciasis
- Schistosomiasis
- Soil-transmitted helminthiasis

**Box 1 NTDs as micro and macro parasitic pathogens**

(WHO, 2013a)

Another distinction is coverage by geographic region, for which diseases are most prevalent and where. The table 8 divides NTDs by regions.<sup>73</sup>

<sup>73</sup> For a breakdown of country classification by region See United Nations Statistics Division: <http://unstats.un.org/unsd/methods/m49/m49regin.htm#developed>, Accessed 2/4/14.

Specificities and priorities by WHO region	
<b>Africa</b>	Blinding trachoma Buruli ulcer Cysticercosis Dracunculiasis Echinococcosis Human African trypanosomiasis Leishmaniases Leprosy Lymphatic filariasis Onchocerciasis Rabies Schistosomiasis Soil-transmitted helminthiasis Yaws
<b>The Americas</b>	<b>First tier</b> Blinding trachoma Chagas disease Leprosy Lymphatic filariasis Onchocerciasis Schistosomiasis Soil-transmitted helminthiasis  <b>Second tier</b> Fungal and ectoparasitic skin diseases Leishmaniasis Parasitic zoonoses
<b>The Eastern Mediterranean</b>	Leishmaniases Schistosomiasis Soil-transmitted helminthiasis Rabies Other zoonotic diseases
<b>European</b>	Anthrax Brucellosis Rabies Soil-transmitted helminthiasis Tularaemia
<b>South-East Asia</b>	<b>Diseases targeted for elimination</b> Anthroponotic leishmaniasis (Kala azar) Leprosy Lymphatic filariasis Yaws
<b>The Western Pacific</b>	Dengue Lymphatic filariasis Schistosomiasis Soil-transmitted

**Table 8 NTDs by region**

(WHO, 2007, p. 3)

Africa has the highest number of 14 NTDs, followed by the Americas at 10 and where Chagas is unique. In the Americas there are also two tiers of specificities and priorities. For the Western Pacific region, which includes China, there are four diseases including dengue, although incidence is now rising in Brazil. Both the Americas and Western Pacific regions share lymphatic filariasis, schistosomiasis and soil-transmitted helminths as problems. South East Asia, which has many developed countries in the region, has NTDs that are targeted for elimination. The European and Eastern Mediterranean regions as to be expected have lower



levels of NTDs and the severity is lower, including 'other zoonic diseases' in the table as well as anthrax and brucellosis, which are not typically classed as NTDs.

These country and regional NTD characteristics challenge an all-encompassing view of the diseases. NTDs as a category applied to the African region is appropriate as this region has 14 of the 17 NTDs. However, for other regions such as the Americas and the Western Pacific, the number of NTDs is more limited and so diseases have a specific regional character. Therefore, it is the individual diseases themselves that make the NTD grouping the most unclear, contentious and debatable, a point that I will turn to in the next section.

## 4.5 Listing diseases and the politics of categorization

As Rosenberg describes, "...disease classifications serve to rationalize, mediate, and legitimate relationships between individuals and institutions in a bureaucratic society" (in Rosenberg & Golden, 1992, pp. xxi). What is at stake in listing diseases and what are the consequences of the creation of categories to include or exclude? The table below compares the WHO list of 17 diseases to the London Declaration list of 10 diseases, also pointing out the five diseases targeted by United States Agency for International Development (USAID with the project ENVISION) through MDA. These five are controlled and treated through what is generally regarded as cheap and effective drugs. However, some drug improvements are needed, such as medicines effective at killing or sterilizing adult worms for lymphatic filariasis and making praziquantel more child-friendly (effective at lower doses and less bitter taste). For these five diseases therefore, addressing neglect is to provide funding and support for existing MDA programs and ensure implementation.<sup>74</sup> This is an important point as for a core group of diseases the main strategy is to continue MDA and ensure implementation, rather than more R&D or funding.

WHO 17 NTDs	MDA (also constitutes USAID targeted list)	Targeted for elimination or eradication	London Declaration
1. Buruli ulcer			
2. Chagas disease		x	x
3. Dengue and Chikungunya			
4. Dracunculiasis (guinea-worm disease)		x	x
5. Echinococcosis			
6. Endemic treponematoses (Yaws)		x	
7. Foodborne trematodiasis			
8. Human African trypanosomiasis (sleeping sickness)		x	x
9. Leishmaniasis		x	x
10. Leprosy (Hansen disease)		x	x
11. Lymphatic filariasis	x	x	x
12. Onchocerciasis (river blindness)	x	x	x
13. Rabies		x	
14. Schistosomiasis	x		x
15. Soil-transmitted helminthiasis (hookworm, roundworm, whipworm)	x		x
16. Taeniasis/Cysticercosis			
17. Trachoma	x	x	x

**Table 9 WHO lists of diseases compared with the London Declaration list**

(Compiled from: Uniting to Combat NTDs, 2015; WHO, [http://www.who.int/topics/emerging\\_diseases/en/](http://www.who.int/topics/emerging_diseases/en/), 2015, Accessed 7/4/14)

<sup>74</sup> Prevention strategies exist related to diagnosis, education, improved water and sanitation or other strategies (table salt/ cooking salt fortified with DEC for lymphatic filariasis).

These inclusions and exclusions point to what the nature of NTDs might be. The other five diseases targeted by The London Declaration are being controlled and treated through intensified disease management, and so targeted by the WHO for elimination or eradication.<sup>75</sup> Excluded from the London Declaration is dengue, which has been somewhat an oddity in the NTD group (affecting richer communities and not being a chronic disease). I discuss dengue and its contradictory status as not being a disease of poverty or characteristically chronic in more depth in the next chapter.

Also excluded are six other diseases: buruli ulcer, cysticercosis/taeniasis, echinococcosis, foodborne trematodiasis, rabies, endemic treponematoses (yaws). These other diseases sit in a sub-category in that they are either treatable by antibiotics or animal/food management requiring public health measures in behaviour modifications and regulations. The point is that a variety of common tools exist to treat them but they still remain persistent because what is required is more of a systematic change. Therefore, the London Declaration focuses on a more targeted 'tool-ready' list (and USAID even more so) where there is one easily deployable and effective measure of MDA.

The earliest NTD report by the WHO, the 'Report of an International Workshop Berlin' (2004) 'tools for control' were a focus. The discussion focused on the, "...development of new tools and refinement of existing ones" (ibid., p. 41). Effective control tools are available for many NTDs but research is still needed according to the WHO in understanding the pathogens (through genomics or molecular biology) and to identify problems in implementation and determine their economic viability. In particular geographical coverage can be limited by diagnostic and treatment protocols (ibid., p. 42). Of the tools available, MDA is emphasized as "...safe, rapidly effective, and easy to administer in resource-poor settings, delivered by non-specialists, only once-yearly contact... major open-ended drug donations are making these tools available to all in need, as long as needed" (ibid., p. 56). For other diseases the development is required of tools, "...simple and practical for use under difficult conditions, as well as safe and effective" (ibid., p. 55).

In deciding whether an effective control tool exists or not, NTDs are evaluated on whether they are 'tool-ready' for public health interventions. Tool readiness depends on several questions: What options are available for decision-making and implementation? What is the public health strategy and plan for action? Molyneux and Ward (2015) call the successful development avermectin and artemisinin as 'public health tools' as recognized by a Nobel Prize. Hotez and Pecoul (2010, p. 1) had previously outlined how 'tool deficient' NTDs are as a group, in the options and effectiveness tools available.

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<sup>75</sup> Dracunculiasis and leprosy are respectively close to eradication and elimination. Human African trypanosomiasis stands out in prevention and treatment, although elimination is viewed as possible. Similarly Chagas disease and visceral leishmaniasis are viewed as controllable.

They questioned if NTDs had the correct tools available to them, referring to the whole plethora of interventions for NTDs including: drugs, operational research on implementation, field-based diagnostics, health education for prevention, case detection and treatment, vector-control strategies as well as improvements in water and sanitation. Although they make the point that all NTDs are tool deficient in that tools exist to control, or even eliminate NTDs, but the tools and implementation strategies are "suboptimal, incomplete, or inadequate to sustain elimination efforts... Consequently, substantial investments in R&D are urgently needed to develop new-generation control tools and strategies for their improved use and implementation" (ibid, p. 2–3). What comes across is a 'mixed bag' of policy tools available for NTDs.

The term 'policy tool' has lineage within the public policy literature – from the 1980s and 1990s policy design literature to a more current work on instrumentation through policy strategy and implementation (Howlett, 1991). A 'tools approach' by government is a popular means of intervention used to overcome impediments to policy-relevant actions (Schneider & Ingram, 1990, p. 510), and moving the focus away from policy impact to policy choice (Salamon & Lund, 1989). Gales and Lascombes (2007) describe a policy tool as a 'micro device', which can be paralleled in health policy with individual interventions for a disease. I have found that for NTDs the language of 'tools' becomes an essential part of talking about solutions and tools are linked to innovation. As pointed out already, varied 'tool-kit' is imagined for dealing with NTDs. Some diseases are described as 'tool-ready', meaning that they have the appropriate innovations at hand, or 'tool-deficient' when innovation is lacking. These descriptions add to a technical characterization to the NTD policy problem where more innovation is equivalent to more tools to have at one's disposal.

The Table 6 below from the 2007 WHO report 'Global Plan To Combat Neglected Tropical Diseases 2008–2015' shows which NTDs are determined as tool-deficient or 'tool-ready'. Here, tool-ready refers to interventions that can be used effectively to control or eliminate NTDs. The report refers to both NTDs and zoonoses, which may be why anthrax, brucellosis and Japanese encephalitis are included in this list. The table displays a relatively even split between NTDs that are tool-ready or deficient.

<b>Tool-ready diseases targeted for elimination or eradication by resolutions of the World Health Assembly and regional committees</b>	Dracunculiasis Leprosy Lymphatic filariasis
<b>Other tool-ready diseases</b>	Anthroponotic leishmaniasis Blinding trachoma Cysticercosis Echinococcosis Rabies Schistosomiasis Soil-transmitted helminthiasis Yaws

<b>Tool-deficient diseases</b>	Anthrax Brucellosis Buruli ulcer Chagas disease Dengue Human African trypanosomiasis Japanese encephalitis Leishmaniasis
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**Table 10 'Selected neglected tropical diseases and zoonoses to be addressed within the Global Plan'**

(Adapted from WHO, 2007, p. 2)

In other words, what is included and what is not, is important to determine the character of the NTD distinction. For example excluded from the NTD group are diarrheal diseases.<sup>76</sup> One reason for the exclusion could be that these diseases have existed as one of the "major tropical scourges but did not fit the 'insect-vector model' of the turn of the 20th century" (Worboys in Bynum & Porter, 2013, p. 522). Diarrheal diseases are 'WASH-related diseases', with WASH standing for inadequate water, sanitation, and hygiene, with some NTDs included in this list.<sup>77</sup> Infections that cause diarrheal disease for example are cholera, dysentery and typhoid. The lines drawn are fuzzy and stretched, have been based on historical contingencies. Diarrheal diseases form part of an even broader list of 'infectious diseases of poverty', listed in Box 2:

<p><b>Infectious diseases of poverty (NTDs in bold)</b></p> <ul style="list-style-type: none"> <li>• the big 3, also called the three primary poverty-related diseases (PRDs): HIV, TB and malaria diarrheal diseases</li> <li>• salmonella infections</li> <li>• <b>helminth</b></li> <li>• bacterial pneumonia &amp; meningitis</li> <li>• <b>kinetoplastids</b> (human African trypanosomiasis, Chagas disease, and leishmaniasis)</li> <li>• <b>dengue</b></li> </ul>
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**Box 2 List of infectious diseases of poverty**

(Adapted from WHO, 2012)

Malnutrition (or more specifically under-nutrition or nutrient deficiency) does not make an entry into this list of infectious diseases of poverty. First it is a serious public health problem in poor communities but as a 'condition' rather than a 'disease' so it stands alone from the diseases of poverty but is intricately linked with disease as both a risk factor and outcome. Second it is also a MDG so more often included under the banner of infant mortality and maternal mortality, with treatable childhood diseases (measles, pertussis and polio).

<sup>76</sup> Diarrheal diseases are infections of the intestinal tract, with the two most common etiological agents are Rotavirus and the bacteria E. coli.

<sup>77</sup> The WASH NTDs are soil-transmitted helminthiases, guinea worm and schistosomiasis, all caused by parasitic worms except trachoma, which is caused by bacteria.

As should be clear by now, what makes the NTD list and what does not (and indeed many other lists in public health categorization) appears arbitrary in some ways. Therefore, Bhopal et al. question the usefulness of the NTD grouping, specifically with different organizations referring to various sub-categories (and even some additions) to the larger WHO grouping:

*"Different stakeholders using the same term at any given time to encompass different diseases makes it difficult to set specific targets for control or to lobby for funding for NTDs as a group. Consequently, attention and funding are more aligned with the success of advocacy groups for individual diseases, with heavy reliance on pharmaceutical company donations, than to any objective criteria such as disease burden, attributed deaths or the need for new drugs, diagnostics and vaccines" (2013, p. 1).*

Their conclusion is that the NTDs that get the most attention are those part of advocacy groups for individual diseases and it appears in referring to pharma donations that they means the five NTDs controlled through MDA. It is true that individual diseases are still being lobbied for by deploying shorter lists from the WHO 17, through USAID or the London Declaration (with five other diseases).<sup>78</sup> Nick Kourgialis from the NGO Helen Keller International notes that it is an 'interesting discussion' whether to expand the range of diseases from these core five (Interview with author, Kourgialis, 2016). He cites pressure from organizations that represent the other diseases. However, he also recognizes the difficulty in trying to cover a large range of diseases rather than focusing on the smaller group where public health tools are already available to address them, especially where eradication or elimination appears close:

*"...I mean, you know, there's been a lot of debate about that because there the question is whether we, detract from the current efforts to really finish the job to eliminate the diseases that we're focusing on now and there's a lot of investments that still need to be made and we don't want to lose that momentum or progress that's been achieved, because if we stop that, we kind of revert back to situation you had several years ago" (Interview with author, Kourgialis, 2016).*

What Bhopal et al. (2013) ignore is the historical contingency and scientific challenge that has lead to this position of some diseases being 'tool-ready' and others not, which is why five NTD diseases are targeted. Furthermore, the solution they propose is a committee within the WHO Department of Control of Neglected Tropical Diseases, to regularly review, "...which new diseases should fall under the NTD umbrella" and how the, "...successful branding technique of the NTDs can be magnified to deal with current and future neglected diseases" (ibid.). The claim of a lack of coordination and long-term vision is not well grounded, as it has been a defining aim of the NTD advocacy campaign.

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<sup>78</sup> These are: onchocerciasis, schistosomiasis, trachoma, lymphatic filariasis, soil-transmitted helminthiasis (whipworm, hookworm, roundworm).

The clearest example was the London Declaration where coordination was evident across stakeholder groups in projecting a long-term vision. This vision has been further re-enforced by the Sustainable Development Goals and WHO country NTD plans. To be coordinated, new multi-partner NGOs have been established ('The Global Network for Neglected Tropical Diseases' and 'Uniting against NTDs) and existing NGOs have adapted their remits (e.g. Helen Keller International). The contention of Bhopal et al. is to look towards the WHO to provide better leadership on NTDs. However, this argument does not take into account the leadership that has been provided by other groups such as NGOs, and activist scientists (which I will profile in Chapter 6).

To highlight the role of NGOs but also their connection to activist scientists and the Bill and Melinda Gates Foundation (BMGF) as funders, see the table below. The major 12 NGOs addressing NTDs span in their focus from treatment, funding, information, network/advocacy and as I have mentioned already sight charities and worm charities. Two activist scientists that I will later profile in Chapter 6 have had a central involvement in almost half of the NGOs, and all of the NGOs apart from one (Deworm the World, shaded in table) are directly funded by the Gates Foundation. Peter Hotez is the president of one NGO (The Sabin Vaccine Institute), which spun out a key initiative (The Global Network). Alan Fenwick established an NGO (SCI) and helped to found another (The End Fund) and is a partner of one more (Deworm the Worm). Incidentally one of the founders of 'Deworm the World' was development economist Michael Kremer who had written an influential paper on deworming three years before, and I will expand on the discourse surrounding this paper in Chapter 7. Advocacy for NTDs is an elite movement with many of founders of the NGOs being scientists, doctors and academics or from existing organizations.

TYPE	NGO AND THEIR CAMPAIGNS	FOUNDED	MAIN FUNDERS	ACTIVIST SCIENTIST INVOLVEMENT
<b>TREATMENTS</b> 	<b>Drugs for Neglected Diseases Initiative</b> <a href="http://www.dndi.org">http://www.dndi.org</a> - Drug development - The Zero Project	<b>2003</b> Médecins Sans Frontières, and others	<b>BMGF, DFID, Médecins Sans Frontières</b>	-
	<b>Sabin Vaccine Institute</b> <a href="http://www.sabin.org/">http://www.sabin.org/</a> - The Global Network Against Neglected Tropical Diseases	<b>1993</b> Doctors in memory of Albert Sabin	<b>BMGF, CDC</b>	<b>Peter Hotez, President</b> 










<b>FUNDING</b> 	<b>The END Fund</b> <a href="http://www.end.org/">www.end.org/</a> - Funds NGOs	<b>2012</b> Legatum Foundation and others	<b>BMGF, Legatum Foundation, Campbell Family Foundation</b>	<b>Alan Fenwick helped found</b> 
<b>INFORMATION</b> 	<b>Policy Cures</b> <a href="http://www.policycures.org/">http://www.policycures.org/</a> - G-FINDER reports	<b>2004</b> Mary Moran, George Institute	<b>BMGF, Wellcome Trust, AusAID, DNDi, Deutsche Stiftung Weltbevölkerung</b>	-
<b>NETWORK/ ADVOCACY</b> 	<b>Global Network for Neglected Tropical Diseases</b> <a href="http://www.globalnetwork.org/">www.globalnetwork.org/</a> - End 7 Campaign  <b>Project Zero Campaign</b> <a href="http://www.huffingtonpost.com/topic/project-zero">http://www.huffingtonpost.com/topic/project-zero</a> - Raising funds for DNDi	<b>2006</b> Sabin Vaccine Institute  <b>2016</b> Huffington Post	<b>BMGF</b>  <b>BMGF</b>	<b>Peter Hotez, established</b>   -
	<b>Uniting to Combat NTDs</b> <a href="http://unitingtocombatntds.org">http://unitingtocombatntds.org</a> - Annual target report	<b>2012</b> London Declaration	<b>BMGF</b>	-
<b>SIGHT CHARITIES (WITH WIDENED REMIT)</b> 	<b>Helen Keller International</b> <a href="http://www.hki.org/">www.hki.org/</a>	<b>1915</b> Helen Keller and George Kessler, wine merchant	<b>BMGF, The END Fund, Merck, Pfizer</b>	-
	<b>Sightsavers International</b> <a href="http://www.sightsavers.org">http://www.sightsavers.org</a>	<b>1950</b> John Wilson a blind activist	<b>BMGF, The END Fund, USAID, Conrad Hilton Foundation, DFID, EU</b>	-
<b>WORM CHARITIES/ INITIATIVES</b> 	<b>Schistosomiasis Control Initiative (SCI)</b> <a href="https://www.imperial.ac.uk/schistosomiasis-control-initiative">https://www.imperial.ac.uk/schistosomiasis-control-initiative</a>	<b>2002</b> Imperial University, London	<b>BMGF, USAID</b>	<b>Alan Fenwick founded</b> 
	<b>Deworm the World Initiative</b> <a href="https://www.evidenceaction.org">https://www.evidenceaction.org</a>	<b>2007</b> Evidence for Action	<b>The END Fund, Good Ventures, GiveWell, Children's Investment Fund Foundation</b>	<b>Alan Fenwick a partner through SCI</b> 
	<b>Guinea Worm Eradication Campaign</b> <a href="https://www.cartercenter.org">https://www.cartercenter.org</a>	<b>1986</b> Run by the Carter Center	<b>BMGF, CDC, DFID</b>	

Table 11 Major NTD NGOs by type



The diseases that these NGOs cover all vary. Only 'Project Zero' by the Huffington Post working with DNDi covers the full WHO 17. A yearlong media and fundraising campaign funded by the Gates Foundation, it was launched in 2016 to raise awareness around NTDs and efforts to eliminate them. The question of which diseases fall under the umbrella of NTDs is an ongoing debate but one that reflects the competitive and dynamic nature of global public health itself, for which reviews take place continually, including by the WHO. Now that NTDs have some policy currency, there is an obvious temptation to expand the grouping (as the WHO has done, moving from 13 to 17 diseases).

However, there is a concern about diluting the branding that is recognized by the WHO and a need for coherence (an aspect of the WHO's strategic remit) in why diseases are included or not. This criteria on inclusion was formalized on January 2016, at the 138th session of the WHO Executive Board, with the request for the Strategic and Technical Advisory Group (STAG) for Neglected Tropical Diseases to develop a "systematic, technically driven process for the adoption of additional diseases as NTDs" (WHO, 2016b). This includes proposed criteria for classifying a condition as an NTD and process for review of the list of NTDs. The first point has been that WHO Regional Offices (ROs) have their own lists, "...which reflect diversity in geographical distribution of these diseases, and in some regions, they are considered the responsibility of other Departments" (ibid., p 1-2). The second point is on the ground of what advocacy connected to being labeled an NTD could do:

*"There are other conditions that could be classified as NTDs for the purpose of advocacy to motivate action or research for the development of new solutions in low resource settings. These are diseases or conditions that constitute important health issues in populations affected by poverty, but they do not fit the programmatic context as currently defined in WHO's HQ NTD Department's portfolio. Such diseases or conditions may however be included in the NTD list if, based on STAG recommendation, they can benefit from increased international attention in terms of advocacy, mobilization of resources for R&D and development of highly needed novel products and tools, or approaches for control or elimination" (ibid., p. 2).*

Criteria for inclusion is given as:

Disease conditions that:

1. disproportionately affect populations living in poverty; and cause important morbidity and mortality – including stigma and discrimination – in such populations, justifying a global response.
2. primarily affect populations living in tropical and sub-tropical areas
3. are immediately amenable to broad control, elimination or eradication by applying one or more of the five public health strategies adopted by the Department for Control of NTDs and/or
4. are relatively neglected by research – i.e., resource allocation is not commensurate with the magnitude of the problem – when it comes to developing new diagnostics, medicines and other control tools

**Box 3 NTD disease conditions criteria for inclusion** (Adapted from WHO, 2016)

This demonstrates flexibility on the part of the WHO. The regional office for the Americas has two diseases not included in the WHO 17: fascioliasis and hydatidosis. However an overzealous reviewing process presents a danger, as I have noted already, in diluting the NTD brand if the diseases listed are widened or changed too frequently. For example the case has been made for surgical conditions (Ozgediz & Riviello, 2008) and the WHO also lists 'other neglected conditions', which are described "in addition to the listed 17 NTDs".<sup>79</sup> While sense needs to be made out of the label, caution should be applied in the use of the brand, especially if the end is in sight for some NTDs but not others and even though that illusive end point is still yet to be reached.

## 4.6 Categories of inclusion or exclusion

What is included or not can tell us what importance we place on one thing over another. An often cited definition of categories in STS, used as a starting point by Bowker and Star in their monograph on classification (1999), is by Goodwin:

*"In so far as the coding scheme establishes an orientation toward the world, it constitutes a structure of intentionality whose proper locus is not the isolated, Cartesian mind, but a much larger organizational system, one that is characteristically mediated through mundane bureaucratic documents such as forms" (Goodwin 1996, p. 65).*

This description already points towards categorization being more than a means of ordering but as reflecting a way of looking at the world that is part of larger hierarchies and power structures. In 'Sorting things out: Classification and Its Consequences', Bowker and Star cover an extensive array of case studies showing categories as historically situated artifacts with membership of certain groupings (Bowker & Star, 1999, p. 285). The contribution of Bowker and Star is in not theorizing categories originating from the abstract sphere but also as a product of communities of practice or the social world, where we conduct certain activities together. They identify two sets of relationship that exist along the same trajectory: between people being given membership and objects being naturalized.

Bowker had noted earlier that standardized representations are needed so that uncertainties or conflicts over meaning are overlooked, seen particularly through how "...medical classifications split up the world into useful categories" (1998, p. 187). Medicine may require more of an ordering than other areas of human endeavor and the effect of such can be deep and widespread. Chauhan et al. note in relatedly that: "medical categories have the ability to create a social and moral order with a life of its own" (2012, p. 793).

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<sup>79</sup> the other neglected conditions are chronic suppurative otitis media (CSOM), mycetoma, nodding syndrome (NS), podoconiosis, scabies, snakebite and strongyloidiasis (van de Sande et al., 2014).

## 4.7 Global campaigns and the 'Sustainable development goals'

Other diseases of poverty do have their own existing successful groupings. Cholera, dysentery and typhoid all have vaccinations available to prevent illness and are closely associated with the WASH campaign, including a number of initiatives such as the World Water Day, World Toilet Day, International Decade for Action 'Water for Life' 2005-2015.<sup>80</sup> These campaigns are public facing. For NTDS there have also been global campaigns against individual diseases.

One of the first internationally coordinated initiatives addressing a NTD was the Onchocerciasis Control Programme (OCP), launched in 1974, with UN co-sponsorship (Liese, Rosenberg, & Schratz, 2010). OCP marked a highpoint for the WHO in the considerable success achieved. Accounts estimate a total of 27,000 individuals saved from going blind and 3 million children were kept safe from onchocerciasis (Brown and Cueto in Parker & Sommer, 2010, p. 24). The programme was further boosted by the efforts of the Carter Center since 1996 with the goal of eradication, followed by regional programs in Africa and the Americas. Guinea worm (also pursued by the Carter Center since 1986), leprosy and lymphatic filariasis were other notable global programs,<sup>81</sup> all of which were essentially elimination and eradication programs. The OCP had come after the failure of the 'Global Malaria Eradication Programme', which began in 1958 with the monumental task to eradicate malaria, but was formally abandoned in 1969 (Feachem et al., 2010). The failure<sup>82</sup> may have had ongoing effects for the chosen methods of intervention for NTDs being drug rather than environmental based, as the main method used in the Programme was chemical insecticide spraying of DDT to kill mosquitos.

The London Declaration was the most high-profile public-facing event for NTDs and it was preceded by the creation of the 'Global Network for Neglected Tropical Diseases' in 2006. The Global Network is an advocacy group established by the Sabin Vaccine Institute, with Peter Hotez as the president, and has funding from the Bill & Melinda Gates Foundation.<sup>83</sup> The Global Network runs the 'END7 campaign', launched in 2012, with the focus is on the seven most common NTDs that represent 90% of the total NTD disease burden.

The Global Network is different from the other campaigns discussed in that it is specifically an advocacy program to raise the profile of NTDs with the public, philanthropists, policy makers and politicians. Kari Stoeber who was the managing director noted how single disease programs had been operating independently but the idea behind NTDs and the work of the

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<sup>80</sup> UN, Water <http://www.unwater.org/campaigns/world-water-day/en/>, Accessed 1/4/14.

<sup>81</sup> Notable global programs include the: Guinea Worm Eradication Program launched in 1980 at CDC; The Global Alliance for the Elimination of Leprosy launched in 1999; and The WHO Global Programme to Eliminate Lymphatic Filariasis (GPELF) launched in 2000.

<sup>82</sup> Malaria was eliminated in "Taiwan, much of the Caribbean, the Balkans, parts of northern Africa, the northern region of Australia, and a large swath of the South Pacific" (Gladwell, 2001).

<sup>83</sup> Global Network, <http://www.globalnetwork.org/>, Accessed 6/4/14

network was to group the diseases together (Interview with author, Stoever, 2016). Similarly one of the founding partners of the network was Helen Keller International, an NGO concerned specifically with blindness and malnutrition rather than NTDs generally. They found that organizationally they would need to change their strategy to adapt to the new NTD banner, with the approval of funding agencies such as USAID:

*"...there was not a lot of collaboration across program areas, until, these were, particularly by USAID were put under the umbrella of NTDs and, and there were five targeted diseases. So in order to pursue this integrated approach that was being you know, advocated by the USAID we had to add capacity to address these other diseases too, schistosomiasis and LF... the integrated approach was really what was required and, and everybody was interested in the logic of that and the fact that these particular drugs that were focused on were tool-ready and there was really a strong case to be made for why the focus should be on these drugs, the commitment of the drug companies and other factors. And, you know, many of the people at the time had developed a very compelling case to Congress... with the drug companies, convincing people that the real progress could be made in addressing these problems. So for us in order to, to really be part of this effort we had to expand the scope of our activities "* (Interview with author, Kourgialis, 2016).

An 'integrated approach' would allow Helen Keller to benefit from cost efficiencies in order to scale up efforts and also market the diseases better. The adoption of the approach was spurred by, in 2006, the launched an integrated NTD Control Program by USAID. The program was the first 'global effort' to, "...support country programs to integrate and scale up delivery of preventive chemotherapy for five targeted NTDs".<sup>84</sup> It was based on donations of treatments, to fund the scale up of treatment, working with disease-specific national control programs to integrate MDA. Stoever describes the intentions of the network and how momentum was built:

*"These programmes were operating quite robustly as single disease programs around the world but no one had put them all together in any single country and scaled it. So the Global Network was really there to help facilitate that, bring resources, technical experts together to talk about how you would then take vertical programs and create a horizontal approach and cost efficiency for that. We were awarded a grant from the Bill & Melinda Gates Foundation and that enabled us to set up a governance mechanism that would facilitate global scale up. We were quite successful on the advocacy front, mostly in the US to begin with, which enabled countries to access new money to begin the harmonization process while the Global Network and partners advocated for more funding. This became a tipping point issue because we started to get access to private donors as well as other governments and foundations. We were featured at the Clinton Global Initiative three years in a row, and then went to Davos in 2009, so we were getting lot of exposure around the idea"* (Interview with author, Stoever, 2016).

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<sup>84</sup> USAID's Neglected Tropical Disease Program, <http://www.neglecteddiseases.gov>, Accessed 5/4/14.

The success of the Global Network was premised on the political connections forged, on platforms such as the Clinton Global Initiative Annual Meeting and annual World Economic forum in Davos. In the US the connection with Congress – going right up to the president – was also crucial.

## 4.8 Political influence

Previously Jimmy Carter (president 1977–1981) had promoted onchocerciasis eradication after his presidency, through the work of his private foundation the Carter Center. However, NTDs were soon to attract attention of a current president. Molyneux puts the connection with the Bush Whitehouse as being down to Stoeber, who was the Managing Director of the Global Network (First Interview with author, Molyneux, 2016). This involved liaising with the chief of staff on the idea of NTDs when President George W. Bush (2001–2009) went to Africa in 2008 and he felt he had to announce something. Bush later announced \$350m in funding for NTD treatment over a 5-year period. He incorporated integrated NTD control through MDA and the scale up of national programs into the US government's broader global health agenda, especially in sub-Saharan Africa (Hotez & Goraleski, 2011). Barack Obama then expanded programs through his Global Health Initiative.

One NGO worker also spoke of the work of Hotez advocating in Washington, tailoring his message to the audience, including the staff members of Senators in Congress:

*"you have to understand your audience and so you really have to tailor the message to particular individuals and try to find whatever levers you have, that you have to switch to get them on board. And you need certain champions within different settings... I remember, Peter Hotez visited the Hill and talked to some people from book parties where you know, very religious and talk about the Biblical plagues and try to make an association of these diseases with those, the old biblical plagues and try to you know, create a connection in mind with the impact that these diseases were having. And, and so you use whatever you can to convey the importance of this and to link it to people's own concerns and attitudes. So yes, it doesn't take just one approach but you really have to lay out the information and, and provide an economic argument, certainly, but also talk about people's personal stories whenever you can"* (Interview with author, NGO worker, 2016).

In the UK advocacy activity in political circles was matched, taking place there directly through activist scientists. Stephen O'Brien was an MP of Eddisbury in the Liverpool area as well as the International Development Minister<sup>85</sup> and was connected with Molyneux at the Liverpool School of Tropical Medicine (LSTM). Born in Tanzania, O'Brien founded and chaired an All Party

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<sup>85</sup> In 2015 O'Brien would become the Undersecretary Humanitarian Affairs at the UN.

Parliamentary Group on Malaria and Neglected Tropical Diseases in 2004 and pushed the agenda in the British Parliament. Molyneux viewed his "...sympathy for the cause having been born in Tanzania" (First interview with author, Molyneux, 2016). O'Brien argued on the value for money point that, "(T)hose initiatives potentially have the most phenomenal value for money for the British people, as UK taxpayers, to be part of supporting" (House of Commons International Development Committee, 2012).

Another high-profile politician, Baroness Helene Hayman became interested in NTDs through her son who was working with the Sabin Vaccine Institute. In 2011 when she completed her appointment as Lord Speaker, she took over as Vice-Chair of the all-parliamentary group. The group was set up to deal with malaria, and had added NTDs to its remit in 2009. Through her political career Baroness Hayman has seen the competition between diseases, in terms of, "what is at the top of current political priorities, or public awareness" and is why she, "...favours an evidence-led approach taking into account value for money where NTDs score strongly" (Interview with author, Hayman, 2013). NTDs have become a bi-partisan, cross party issue and this wide political support has often relied on individual links to political decision-makers.

The political backdrop has also been important in determining the type of advocacy campaign pursued. As Chaufan et al. (2012) point out the importance of political opportunity structure of the US system for disease specific research approach to funding. I argue also the UK system is receptive to a 'disease specific approach to funding' along with the emphasizing of disease categories that has created a particular opportunity structure. In reference to Alzheimer's disease (AD) emerging as a major health and social concern they contend:

*"The emergence of AD as a social problem that would require significant resources occurred within political and historical contexts that provided a reasonable probability that such a disease specific research approach to funding would succeed. These contexts were given by existing opportunity structures in America that support what one observer has called the 'health politics of anguish'... Disease-specific or 'categorical' approaches were the strategy used by the NIH to 'open wide the public's purse was to call attention to one disease at a time' and allow 'medical researchers [to go] directly to Congress to take advantage of the distinctive good will medicine enjoyed'..." (Chaufan et al., 2012, p. 790)*

## 4.9 The Gates Foundation and technological solutionism

For philanthropic support the major route for funding would be through the Bill & Melinda Gates Foundation. Gates set up his foundation following the model set out by Rockefeller and also Carnegie, in large scale philanthropy and applying business approaches (Solomon, 2011). Following this rationale, the foundation has achieved a tremendous amount since inception in 1994 as a new global health actor. Spending around US\$3 billion annually it has "inaugurated an important new era of scientific commitment to global health predicaments" (Lancet, 2009). In deciding what areas of interest to concentrate on to have the greatest impact the Gateses have said:

*"(W)e concentrate on a few areas of giving so we can learn about the best approaches and have the greatest possible impact... We choose these issues by asking: which problems affect the most people, and which have been neglected in the past" (ibid, p. 21).*

Here the concept of neglect played a central part in their strategy of choosing issues "to solve problems where no one else had stepped in", also informed by the scale of the problem and impact that was possible (ibid, p. 22). However, this line of thinking was not initially obvious. Kari Stoever recounts how the Bill & Melinda Gates Foundation was not interested in NTDs. Bill Gates was at first skeptical but a few years later he said to her that investing in NTDs was one of his proudest moments (Interview with author, Stoever, 2016).

Gates has been described as "relentlessly rational" (Smith, 2015, p. 148). He had been a believer in Thomas Malthus, the 18/19th century economist who warned about the growth of populations faster than the means of subsistence. The Gateses had begun with a Malthus inspired approach when they began looking at public health in 1997 to focus on birth control, "The logic was crisp and Bill Gates-friendly. Health = resources ÷ people. And since resources, as Gates noted, are relatively fixed, the answer lay in population control. Thus, vaccines made no sense to him: Why save kids only to consign them to life in overcrowded countries where they risked starving to death or being killed in civil war?" (ibid.).

However, his thinking would change as he gathered more information about global health, seeing for example that if infant mortality rates dropped, people in developing countries had fewer children, as they would expect more children to survive into adulthood. Gates had been given an 82 book reading list in order to learn about international public health by William Foege, the former director of the CDC (Smith, 2015). He had stepped down from overseeing daily operations at Microsoft in 2008 to focus on the Foundation full time and begun to be acquainted with NTDs. His favourite read from all the books in the reading list was the 1993 World Bank Report and he described what caught his attention exactly:

*"...It was just a graph that had, you know, these twelve diseases that kill,' said Gates. These included leishmaniasis, schistosomiasis, trachoma—the list of leading scourges, preventable at low cost, whose names he'd also never seen before. 'I thought, 'This is 'bizarre',' Gates said. 'Why isn't this being covered?'..." (Gates quoted by Smith, 2015, p. 145).*

There was an appeal in the neglected aspect, as it gave the feeling of making a difference for the largest number, and measurement information about which diseases were a problem contributed to revealing this neglect:

*"We couldn't believe it. You think in philanthropy that your dollars will just be marginal, because the really juicy obvious things will all have been taken. So you look at this stuff and we are like, wow! When somebody is saying to you we can save many lives for hundreds of dollars each, the answer has to be no, no, no. That would have already been done" (ibid.).*

Large amounts of funding has been made available to NTDs as stated in 2016: "To date, our team has committed more than US\$1.02 billion in grants to organizations developing new tools and methods of delivery that make these tools widely available. We also advocate for increased international funding to support these efforts".<sup>86</sup> It is 'new tools and methods' that are sought, as the Gates approach to global health problems also reflects a belief in the funding of science and technology to both see inequities and help address them (Solomon, 2011, p. 23).

How solutions are thought of is reflective of a technological 'solutionism' espoused by the writer Evgeny Morozov as the a dominant ideology of everything needing to be fixed but that we should rather be asking questions about the problem at hand. Solutionism according to Morozov is, "(R)ecasting all complex social situations either as neatly defined problems with definite, computable solutions or as transparent and self-evident processes" for which he questions "both the means and the ends of Silicon Valley's latest quest to 'solve problems'." (Morozov, 2014, pp. 15-27). The technological aspect to solutionism puts forward a quick fix rather than concentrating on more intellectually demanding reform (ibid., p. 34).

Little external scrutiny is directed towards this large-scale problem-solving. As Devi Sridhar and Rajaie Batniji (Lancet, 2009) have argued, there is not enough transparency or accountability of the Foundation's operation. Most grants go to organizations in high-income countries and multinational company collaborators and other important health programmes are distorted by the large grants (McCoy, 2009). Perhaps the most extensive recent critique has been Linsey McGoey (2015) in 'No Such Thing as a Free Gift' where she catalogues some of the failings in the Gates approach to global health problems from the tech solutionism focus on vaccines and

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<sup>86</sup> Gates Foundation, <http://www.gatesfoundation.org/What-We-Do/Global-Health/Neglected-Tropical-Diseases>, Accessed 3/4/16.



disease eradication that discount simpler, short-run solutions. As shown by the 'London Declaration' that Gates helped to orchestrate, NTDs are supported mainly through drug donation for those NTDs closest to elimination or eradication.

#### **4.9.1 From drug donation to R&D**

Aside from the sizeable donations by Gates primarily toward information collection (G-FINDER) as well as advocacy (The Global Network and The London Declaration) the biggest donations have been drugs and this has been generally well received and leveraged. Compared to other areas of public health, donations may be viewed more skeptically. For example in 2016 the NGO 'Doctors without Borders' refused a one-million-dose donation by Pfizer of the vaccine Pevnar 13 (PCV13) against Pneumonia. In justifying the decision this was a quote from MSF to *The Atlantic*:

*"...I'm not absolutely against donations,' MSF's vaccine pharmacist Alain Alshani told me by phone from Paris. In cases of neglected disease where there is little or no market for a product, he explained, "donation becomes a more interesting option for some countries to get access. But in the case of PCV, that's not a solution at all, in any way'..." (Hamblin, 2016)*

The rationale in this case was that the donation did not justify the costs of delivering the vaccine and it was not sustainable nor for a large enough number that included all who would need it. However, drug donations have formed the basis of advocacy for NTDs and have been built upon as an intervention strategy. Drug donations have constituted large-scale interventions for NTDs, notably beginning with the first NTD donation by Merck for onchocerciasis in 1987. This initial donation would lead to pharma companies becoming involved in NTDs through drug donation programs. Merck was the first company to do a large-scale donation of the drug ivermectin (marketed as mectizan) through the 'Merck Mectizan Donation Program' (MDP) operating in sub-Saharan Africa, Latin America, and Yemen in the Middle East, constituting 33 of the 35 endemic countries (Sturchio, 2001).

Ivermectin had followed a successful and very profitable drug for deworming animals, which scientists in Merck realized could have applications to humans. The subsequent donation had not been a foregone conclusion, as Merck sought avenues for donors to pay for the drug. After exhausting all options the decision was made by the CEO to donate the drug, in an unprecedented move for the size and reach of such a donation by a pharma company. Many other drug donation programs followed (see table below), although it was not until the 2000s these rose sharply in number, to be also extended and expanded with the London Declaration in 2012.

Year	Disease and drug	Company
1987	<b>Onchocerciasis:</b> ivermectin	<b>Merck &amp; Co. Inc</b>
1998	<b>Blinding trachoma:</b> azithromycin	<b>Pfizer</b>
1998 (expansion 2010)	<b>Lymphatic filariasis, STH:</b> albendazole	<b>GSK</b>
2000	<b>Leprosy:</b> multi-drug therapy (rifampicin, clofazimine and dapsone in blister packs and loose clofazimine)	<b>Novartis</b>
2001	<b>HAT:</b> eflornithine, melarsoprol and pentamidine	<b>Sanofi</b> <sup>87</sup>
2002	<b>HAT:</b> suramin	<b>Bayer</b>
2007	<b>Schistosomiasis:</b> praziquantel	<b>Merck KGaA</b>
2009	<b>HAT:</b> nifurtimox-eflornithine treatment combination (NEC)	<b>Bayer</b> (PPP with Sanofi to donate)
2009	<b>Fascioliasis</b> (a foodborne trematodiase): Triclabendazole	<b>Novartis</b>
2011	<b>Visceral leishmaniasis:</b> AmBisome	<b>Gilead</b> (Provided at discount since 1992)
2012	<b>Lymphatic filariasis:</b> diethylcarbamazine: DEC	<b>Eisai</b>

**Table 12 Drug donation for NTDs by date**

(Compiled from WHO, 2012a)

However, for every success story of drug donation there is another of failure, highlighting the precarious nature of depending on free drugs (often at the whim of a pharma companies). One example is the drug eflornithine used to treat HAT with fewer (of the quite terrible) side effects compared with previous drugs. Eflornithine had been registered in 1990 by the German pharma company Aventis for treating cancer and subsequently adapted as a female facial hair reduction cream but uptake and sales were low so the company stopped production. This episode led, in the late 1990s, "to an outcry among public health specialists, who persuaded the company to reinstate production and, from 2001, to supply the drug for free in Africa" a commitment that has continued after Aventis was acquired by Sanofi in 2004 (Jack, 2016).

Despite commitments being made, the supply of drugs is not guaranteed – this is surprisingly so even if responsibility is transferred to government. For example 2012 saw a global shortage of the Chagas drug benznidazole. Nine years previously, the technology and production of

<sup>87</sup> French company Aventis which later became part of Sanofi discontinued production of eflornithine as it was not profitable but Médecins Sans Frontières and the WHO persuaded the continued manufacture forces with which led to a comprehensive donation agreement (Potet, 2014).

benznidazole had been transferred from the pharma company Roche, to Lafepe which is a Brazilian government pharmaceutical company (Manne et al., 2012, pp. 173-4). For a government-run operation it could be expected that the drug would be produced without the limitations of profit seeking but production proved to be insufficient and inconsistent, a problem that mounted over the subsequent years.

This issue on the whole is an isolated one. Still an over-reliance on drug donation programs, when quantities being produced need to be sustained may be especially problematic when production plants are not invested in or fail, or the companies go out of business or are acquired by other companies. Whether the production plants are run by pharma or governments may become a bigger problem in the future, as drug donations have been the basis for which the NTD advocacy case and policies have been built. As Stoever describes:

*"...you've got to first start with the basics, the basics are find the people who are infected and get them treated once a year, then strengthen health systems and work with other groups to improve the morbidities, for those who had morbidities, then it was develop new tools, new diagnostics, and not necessarily new drugs at that time although there was some new drugs under development... and then it was improve the R&D agenda for neglected tropical diseases and then when we went to that, working with Lorenzo Savioli and Dirk Engleson at the WHO, that agenda got quite broad, then we're including diseases like loa loa and guinea worm and... I think they even put snakebite at some point, in the NTD category at WHO... people started piling on, once we had political will the agenda broadened quite a bit"* (Interview with author, Stoever, 2016).

All donations typically form a type of public private partnership (PPP) for organization and delivery. Drug donation PPPs would later move onto an R&D agenda where pharma consciously sought to develop drugs for NTDs, as companies still have to keep drugs affordable and innovate for new drugs sometimes through product development partnerships (PDPs) where collaboration centres on producing a new product. R&D projects are expanding to bring in new and improved drugs diagnostics and treatments. It was a criticism of both the TDR and GND that they did not directly produce new drugs, diagnostics or vaccines. The TDR director John Reeder has argued that organizing doing this spun out from TDR in supporting clinical trials: "TDR identified the need for a new type of structure – a product development partnership (PDP). The Medicines for Malaria Venture, the Foundation for Innovative New Diagnostics and the Drugs for Neglected Diseases initiative were incubated within TDR and then spun out as independent entities" (International Innovation, 2014, p. 8). Although others have placed more emphasis on alternative actors originating these organizations.

By 2004 there were over 60 R&D projects<sup>88</sup> according to the G-FINDER survey (Moran, Guzman, Burke, & Francisco, 2006). Of these, four new PPPs conducted nearly 75% of neglected disease drug development projects (ibid.). There are: The Institute for OneWorld Health 'iOWH' founded in 2000, to develop drugs, vaccines and technologies for a range of diseases from malaria to diarrhea. The Drugs for Neglected Diseases initiative 'DNDi', founded in 2003, had a focus on the kinetoplastid diseases and that same year the Foundation for Innovative Diagnostics (FIND) was also established. Other PPPs concentrate on specific diseases. Pharma company Novartis has an active dengue R&D programme at their 'Institute for Tropical Diseases' in Singapore (along with TB and Malaria), a leprosy donation program and fund for R&D in Neglected Diseases (FRIND). Also the small independent pharma company Immtech has an R&D programme for Human African trypanosomiasis (HAT).

Stoever has expressed how PPPs have become standard models: "... to take a methodology and apply it for issue x... what we learnt in the international space on global health is now being applied more and more to domestic issues at least in the US" (Interview with author, Stoever, 2016). She also notes the change in role of pharma from principally providing drug donations: "today I think there's more leadership from the private sector, I like that pharma is embracing this more and is very proud of it" (ibid.). There is a lot of activity within the pharma sector directed towards NTDs today.

Despite the drug dominance through NGOs and public discourse, the WHO has advocated an 'integrated approach' through national plans and a 'three-pronged' strategy of, "...ensuring broader coverage with rapid impact interventions; strengthening vector control to reduce the transmission of several diseases; and improving surveillance and quality of care for diseases with limited control tools" (WHO, 2007, pp. 5-6) This 'three-pronged' strategy later became a 'five-pronged' strategy of:

1. mass drug administration
2. innovative and intensified disease management
3. vector control and pesticide management
4. safe-drinking water, basic sanitation and hygiene services, and education; and
5. veterinary public-health services

(Salaam-Blyther, 2014, p. 3).

Still drug interventions come first and tend to underpin much of the other activity, with R&D also supporting every stage.

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<sup>88</sup> Two Malaria and TB projects are counted in the 60 R&D projects: Medicines for Malaria Venture 'MMV' and the Global Alliance for TB Drug Development 'TB Alliance' (Moran, Guzman, Burke, & Francisco, 2006). They also include TDR, which they say "has operated as a de-facto PPP since the mid-1970s" (ibid).

## 4.9.2 Other sites of neglect

Big pharma is positioned as a main protagonist in why NTDs are neglected. However, often other sites of neglect such as the media are ignored. Conall Watson an epidemiologist at the London School of Hygiene and Tropical Medicine (LSHTM) spoke of the difference media attention makes to a health issue such as typhoid:

*"Unless you can paint stuff as scientific breakthrough I don't know how much of this stuff gets picked up in the mainstream press... there are many ways to block typhoid transmission... [other than the breakthroughs that are reported on]"* (Interview with author, Watson, 2013).

In policy setting typhoid can be a difficult topic to broach, especially in terms of communication, and then the messages do not transfer well into the media:

*"People don't really like to talk about poo on hands and using soap and that sort of stuff it's much nicer to talk about clean water and new vaccinations, which I completely understand. And I suppose the other aspect that we don't often talk about is treatment and use of appropriate antibiotics"* (Interview with author, Watson, 2013).

The incremental work of the international research community and day-to-day typhoid treatment and control is not followed in the mainstream media, as it does not really fit with news agendas. News reporting is selective to scientific breakthrough and more attention-grabbing interventions, such as the use of innovation and technology in sanitation or vaccination. Therefore, media attention is difficult to sustain outside of more obvious news-grabbing headlines.

Balasegaram et al. (2008) surveyed NTDs in the news from 1 January 2003 to 1 June 2007. This light-touch study only looked at English language media and was constrained in a number of other aspects but it was the first study using a content analysis of NTD media coverage. Qualitative interviews of the study revealed that American journalists struggled to cover global health issues as foreign news budgets had been slashed. They had further difficulty in reporting on relatively unknown diseases with limited information – finding it hard to get hold of spokespeople from the Gates Foundation or the WHO or stories from the field. The main findings of the study, which focused on leishmaniasis and trypanosomiasis, found the frames that were important depicted the reality of the diseases but beyond descriptive frames the popular focuses were:

- |  |
|--|
| <ul style="list-style-type: none"><li>• 'Big pharma' where the industry was on the defensive or under pressure</li><li>• scientific developments from genetic research</li><li>• blood safety amidst the threat from Chagas (almost all US media articles)</li></ul> |
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**Table 13 Popular media frames for NTDs** (Balasegaram et al., 2008, p. 4).

As might be expected, placing responsibility and blame for the problem of NTDs, with a focus on big pharma, is a major topic within the media. Science is positioned as a main solution for NTDs and also making the news are threats to developed countries as seen with the blood safety controversy. Seemingly absent are the global public health actors, a situation that may have changed more recently as we observe greater scrutiny of actors such as Gates (Lancet, 2009; McGoey, 2015b; Sridhar & Batniji, 2008). The question of who is viewed as responsible for NTDs and why responsibility is allocated will be an ongoing theme explored through the subsequent chapters.

Despite media reporting only covering limited topics, the advocacy for NTDs has proved successful, a marker of which is in how NTDs have since been included in the Sustainable Development Goals (SDGs) for 2030. Dominic Haslam (2016) the director of policy and programme strategy at NGO Sightsavers called the SDGs a, "...once-in-a-generation chance to reframe NTDs within a more mainstream approach to health and development". Similarly, Molyneux, one of the activist scientists also reflected on what the SDGs meant as a sign of achievement and ongoing accountability of the global health community to NTDs:

*"To have got NTDs included in the sustainable development goals for me was the most important achievement. Had they not been there I would have thought that our efforts and advocacy would have failed. So I really believe that was a big plus because they're embedded there semi-legally and so we can always point to them as being the targets"* (Second interview with author, Molyneux, 2016).

Exclusion from the MDGs in 2000 had set the ball rolling for NTDs in the first place, now the SDG, set out in 2015 specifically states: "By 2030 end the epidemics of AIDS, tuberculosis, malaria, and neglected tropical diseases and combat hepatitis, water-borne diseases, and other communicable diseases" (Target 3.3, Sustainable Development Knowledge Platform, <https://sustainabledevelopment.un.org/?menu=1300>, Accessed 9/4/14). As there are 17 SDGs compared with the 8 MDGs, the expanded agenda has been questioned. Haslam views the SDGs to be potentially unwieldy and undeliverable but he remains optimistic: "...the SDGs are a bold attempt to 'leave no one behind', a call I believe will see NTDs and other so-called 'lost causes' – and the millions of people they represent – finally brought out of the fringes of the development agenda" (2015). Next I will conclude this chapter by putting into perspective this 'end point' of the SDGs with what has passed before, through a summary of the events and milestones that led to the point, and why they mattered.

## 4.10 Conclusion: Beyond the SDGs

I began this chapter with a discussion of two formative initiatives on tropical diseases starting in the 1970s. On one hand the WHO's TDR initiative showed an early commitment to diseases of the poor but ultimately was not the conceptual origin for NTDs. As I have outlined the reasons why were based in the institutional limitations of the WHO and the changing landscape of global health. On the other hand the Rockefeller Foundation's GND initiative, while clearly having an influence in the naming of NTDs, would have more relevance for NTDs in encouraging scientists to be interested in tropical diseases. Therefore the GND was crucial in creating activist scientists and future branding of NTDs, something I explore in depth in Chapter 6. Next in this chapter I moved on to the key events in the policy development of NTDs, highlighting the two seemingly straightforward bookends with the MDGs in 2000 and the SDGs in 2015. The SDGs in comparison to the earlier MDGs include NTDs as a global policy priority and commitment. NTDs have now been confirmed as a mainstream concern through the same institutional setting that had previously left these diseases unacknowledged. The event milestones tracked this move from outlier to status quo through the MDGs to SDGs.

During the policy development of NTDs, organizations have used different lists of NTDs. The WHO has also provided distinctions based on pathogen and geography. The geographical distinction is something I will return to in Chapter 8 as a way of understanding NTDs that challenges the donor and recipient country distinction on nationalist grounds. As I have shown, how the grouping of NTDs has changed over the policy development speaks to the state of public health globally. The WHO expanded their own grouping from 13 to 17, *PLOS* expanded this group and the London Declaration and others shrank this group further. The expansion is a reflection of the competitive nature of public health and the need to align disease to groups appropriately for policy reasons.

Still, the global health policy climate is changing. There exists an optimism in the changing face of global public health with a greater awareness of and interest in issues, and more people want to take a part: "I think with the emergence of Ebola... there are just more kids that want to study in this space, they don't necessarily all want to be scientists but they want to work in global health" (Interview with author, Stoeber, 2016). The next chapter will further explore what the changing face of public health means through the politics of disease categories, going back to the time of tropical diseases to review just how much has changed.

## Chapter 5. The politics of disease categories

### 5.1 Introduction: The transition of tropical diseases

Why did the addition of the word 'neglected' and a new grouping of diseases have such a tremendous effect in global health? Why was the word 'tropical' retained as a descriptor for 17 diseases largely impacting on poor communities? While the last chapter provided a recent policy history of NTDs this chapter aims to address these questions about the politics of the NTD disease category. I will explore the origins of 'tropical' and 'neglected' as categories and ask how this has shaped the definition of the policy problem and solution for NTDs. The problem of NTDs has been presented as a problem through a number of straightforward narratives that I unravel in this chapter, where proposed solutions for NTDs are surrounded by optimism.

The place to begin in considering the transition from 'tropical diseases' to 'neglected tropical diseases' is to interrogate what is meant by tropical and neglected as categories. While NTDs could be taken as a single unit and a categorization in itself, my argument is that 'tropical' and 'neglected' form distinct categories on their own, separate from a prescribed categorization set out by the creators and advocates of NTDs. There is value in looking at all three categories: the 'tropical', the 'neglected' and 'NTDs' as discrete units. Defining disease, the 'tropical' not related to disease, and a detailed history of tropical diseases are out of the scope of this analysis.<sup>89</sup>

I ask what is tropical both in terms of historical and geographic location. This line of enquiry on a historical and geographic basis has precedence in exploring the social embeddedness of disease and has been central to questioning colonial accounts of disease (Anderson, 1996; Bewell, 2003; Blaut, 2012). In exploring the tropical there is a vast literature on the role of tropical medicine in support of the colonial project (Amaral, 2008; Arnold, 1996; Chakrabarti, 2013; McNeil Jr., 2012; Neill, 2012) and a relatively more recent literature on the policy developments for NTDs (Hotez et al., 2014; Molyneux et al., 2005b; Parker, Allen, & Hastings, 2008). These two literatures rarely meet in the middle. Therefore, tropical diseases become diseases of the past, a matter of historical record and only to be understood through the context of colonialism and empire. NTDs are not mature as a disease grouping to have historical account and as discussed in Chapter 1 have not received much of a social science gaze, with sociological and anthropological research being limited. NTDs are a fledging field for social

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<sup>89</sup> Defining disease may be, as philosopher Alex Broadbent puts it in the context of NTDs "...a philosophically more onerous task" (2011, p. 51) but for this chapter, the 'tropical' and the 'neglected' understanding are more relevant. I am less interested in making philosophical observations about disease as others have already dedicated efforts to extensively (as noted, see Broadbent, 2011). Also for a comprehensive study of the of the 'tropical' both in popular imagination and through representations that go beyond disease, see Nancy Leys Stepan's book 'Picturing Tropical Nature' (2001) where she finds 'tropical' to both encompass nature (animals, plants) and people (in culture and aesthetics). A history of tropical disease has been covered more thoroughly through other accounts (see Packard, 2007).



science research but to understand these diseases in any depth requires a connection with the past. Therefore, in this chapter the tropical category is explored through: (1) a brief colonial as well as post-colonial history and (2) current geography, where the chronic characterization of disease and a concept of 'blue marble health' in viewing distribution of disease becomes relevant.

The neglected category is more difficult to pin down. To understand, on one hand, what is neglect from the definitions of the problem, I have surveyed the policy literature and grouped these definitions under themes. On the other hand, understanding what is neglect through solutions proposed by international bodies, I have taken a micro-view of WHO strategies in particular for individual NTD diseases. Here the divisions between environment-based and drug-based strategies offer insight into where neglect lies. To explore the neglected category I have made greater use of primary sources. I draw primarily from media reports, practitioner accounts, and from policy documents of government bodies and international organizations including the World Health Organization (WHO), Uniting to Combat NTDs, Centres for Disease Control (CDC), National Institutes of Health (NIH), The Drugs for Neglected Diseases Initiative (DNDi), and The Food and Drug Administration (FDA).

It becomes apparent that measurement is an important component in bringing forth a workable definition and solution for neglect. The adoption of measurement is both as a metric to determine status, track progress (to collect evidence), but also as a device in the argumentation and rationale for why NTDs are important and require attention (to present evidence). I argue that the metrics that have mattered for NTDs spans from:

1. **'10/90 gap'** illustrating how low R&D is for NTDs compared to other diseases
2. **'DALYs'** showing burden of disease through a chronic or high-morbidity character of NTDs
3. **'50 cents per person'** pointing to cost-effective interventions for a core of NTDs

Metrics prove to be crucial in creating a story that translates into an easily digestible problem and solution definition. First however, I begin with an illustration of how the tropical disease category has transitioned to NTDs.

### **5.1.1 A Nobel Prize view of disease**

The specialism of tropical medicine has been of research interest across what is now an extensive historical, sociological, geographical, political science and anthropological literature (LSHTM, 2014). Joined together are the two literatures of tropical medicine in the context of empire (Amaral, 2008; Arnold, 1996; Chakrabarti, 2013; McNeil Jr., 2012; Neill, 2012) and the new policy developments of NTDs (Hotez et al., 2014; Molyneux et al., 2005b; Parker et al., 2008). While drawing from these disciplines, this thesis follows the STS tradition, a concern

with scientists as key actors and the policy ideas that intersect science, technology and society. Therefore, I want to provide a backdrop to the politics of the NTD category by comparing how scientists within the tropical medicine tradition and the recent NTD tradition have been received in their wider academic community and also publically. This comparison looks to how scientific research on tropical diseases and NTDs have been scientifically acknowledged.

One avenue acknowledging importance of NTDs includes the height of scientific recognition through Nobel Prizes. I want to make a point about the history of scientific prestige and recognition and how this has transitioned from tropical medicine through to NTDs. This is one way of showing how diseases were viewed as worthy of scientific enquiry with the associated moral motivations and resources directed. See Table 9 for a timeline of Nobel prizes awarded for tropical diseases and NTDs.

<b>The Nobel Prize in Physiology or Medicine for tropical diseases and NTDs*</b>			
<b>Year</b>	<b>Award</b>	<b>Disease</b>	<b>Intervention</b>
1902	Ronald Ross "for his work on malaria, by which he has shown how it enters the organism and thereby has laid the foundation for successful research on this disease and methods of combating it"	Malaria	Informed interventions for malaria
		Discovered mosquitos transmitted malaria	
1907	Charles Louis Alphonse Laveran "in recognition of his work on the role played by protozoa in causing diseases"	Protozoa	Informed interventions for malaria and HAT
		Discovered protozoan parasites responsible for malaria and HAT	
1948	Paul Hermann Müller "for his discovery of the high efficiency of DDT as a contact poison against several arthropods"	Arthropods	Vector control
		Discovered DDT poison spray to kill malaria carrying mosquitos (also used to control typhus)	
1951	Max Theiler "for his discoveries concerning yellow fever and how to combat it"	Yellow fever	Vaccine
		Discovered (through experimentation) an attenuated 17D mutant strain of the virus	
2015	William C. Campbell and Satoshi Ōmura "for their discoveries concerning a novel therapy against infections caused by roundworm parasites" and Youyou Tu "for her discoveries concerning a novel therapy against Malaria"	Roundworm parasites and malaria	Drugs
		Discoveries of ivermectin for onchocerciasis and lymphatic filariasis, and artemisinin for malaria (later developed into ACTs)	
*Not included in this list but interesting to note was the 1927 Nobel Prize awarded to Julius Wagner-Jauregg "for his discovery of the therapeutic value of malaria inoculation in the treatment of dementia paralytica", which was malaria treatment by inducing a high fever to treat tertiary syphilis			

**Table 14 Timeline of Nobel Prizes for tropical diseases and NTDs** (Adapted from Nobel Prize, [http://www.nobelprize.org/alfred\\_nobel/will/](http://www.nobelprize.org/alfred_nobel/will/), Accessed 9/7/16)

Ross was one of the 'greats' of tropical medicine who won the 1902 Nobel Prize in Physiology or Medicine for his work on the transmission of the malaria parasite through mosquitos. Malaria is often seen as the most dangerous tropical disease, being both deadly and scientifically complex, having up to 40 species of mosquito that can transmit the parasite, all with different breeding preferences (Dobson, 2015). Following Ross, who received the Nobel Prize a year after it was established, Laveran was also recognized for his work on malaria and HAT protozoa parasites soon after in 1907.

By 1948 Müller had discovered DDT, which would become the main weapon against malaria, beginning with the regional malaria elimination campaigns in the late 1940s and culminating with the Global Malaria Eradication Program, which began in 1955 (WHO, 2011b). The addition, also in the 1950s of the yellow fever discoveries by Theiler, would push both malaria and yellow fever into the 'not neglected' tropical disease camp.<sup>90</sup>

This timeline demonstrates how tropical medicine has had a long connection with scientific prestige and recognition. Colonial medicine, which effectively was tropical medicine, encouraged these advancements. Nearly all of the scientists awarded the prizes were European: Ross (British), Laveran (French), and Müller (Swiss), with the exception being Theiler (South African-American). Ross and Laveran directly served colonial interests, with Ross a surgeon in the Indian Medical Services and Laveran an army doctor in Algeria (Kelly & Beisel, 2011, p. 74).

After World War II the interest in tropical medicine waned. It would not be until 2015 that work on NTDs would be recognized by the Nobel Committee, and would include two scientists not from Europe but from an endemic country for NTDs (China) and previously endemic Japan. The Japanese academic Satoshi Ōmura was awarded the Nobel Prize for their discoveries surrounding roundworm parasites with American scientist William C. Campbell who led a lab at Merck (The Nobel Assembly at Karolinska Institute, 2015). Ōmura cultured a strain of bacteria, which was then purified by Campbell as avermectin and chemically modified to produce the drug ivermectin, effective against two NTDs onchocerciasis and lymphatic filariasis.

Also sharing the 2015 prize was Chinese scientist Tu Youyou from the China Academy of Traditional Chinese Medicine, for 'her discoveries concerning a novel therapy against Malaria'. It was about forty years after she and her team had discovered the method to isolate Artemisinin from the herb *Artemisia annua* (qinghao, 青蒿素).<sup>91</sup> The reception was one of overwhelming enthusiasm towards China's long-awaited Nobel. The last was in 2012 in Literature and before that Peace in 2010 and Physics in 1957. What is largely absent from much of the press

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<sup>90</sup> Yellow fever was one of the most feared diseases because outbreaks were little understood, quarantine did not seem to work and it frequently also caused economic disaster (Bryant, Holmes, & Barrett, 2007).

<sup>91</sup> Chinese herbalists had used Artemisinin for thousands of years to treat many illnesses, including malaria.

coverage for these discoveries was the difficulty of moving the treatments from scientific discovery to drugs to help the world's poor. A strikingly downplayed was the involvement of Merck, where Campbell was working during the discovery and development of the drug ivermectin (the bioactive agent was called avermectin) as well as the involvement of the WHO in the research project.

The Nobel Prize is premised on individual scientific discovery, thus Merck is only mentioned very briefly in the press materials, in the biography of Campbell (The Nobel Assembly at Karolinska Institute, 2015). Similarly the long and complicated struggle of Tu's discovery to reach the market does not find a place in the Nobel Prize announcement and only sparked moderate interest in the news stories that followed. Missing is an account of the agency involved in pushing for a discovery to be adopted as a public health intervention. Even though these discoveries happened in the 1960s and 70s there was a significantly longer lag than for the tropical disease discoveries, which may have reflected the sidelining of these diseases, that would need social and political recognition before scientific recognition was granted.

In Alfred Nobel's will, he wrote that 'prizes [shall be annually distributed] to those who, during the preceding year, shall have conferred the greatest benefit to mankind'.<sup>92</sup> It is a prerequisite then not only to reward discoveries for their intrinsic scientific worth but for their impact in the social world. The 2015 Nobel Committee awarded Campbell, Ōmura and Tu because their discoveries helped "to combat these debilitating diseases that affect hundreds of millions of people annually" (ibid.). The consequences of 'global health' in improving human wellbeing was emphasized in another Nobel Prize, the Peace Prize, awarded to Médecins Sans Frontières (MSF) in 1999. This event was described by Jackson and Stephenson as having 'powerful symbolic meaning':

*"Peace, so far mostly celebrated by the Nobel Committee in its political dimension and embodied by individual heroes, was now linked to health (reworking the connection between health and security... With this award, actions imbued with humanitarian values and principles of social justice were recognised in the same capacity that economics and politics had previously been, as vital tools to forge a better world. The Nobel Peace Prize followed MSF's linking of the moral imperative to consider neglected populations and diseases with the failure of market solutions to support institutional efforts to address the needs of the poorest... It also raised the profile and gave a new political status to non-governmental actors (such as NGOs) as key actors in global politics, a point of recognition following long years of NGOs' playing important political roles."* (Jackson & Stephenson, 2014, p. 999).

NTDs came into prominence not only in a new period of science but a new period of global health involving actors and priorities that had not previously existed. Global health was shown

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<sup>92</sup> Nobel Prize [http://www.nobelprize.org/alfred\\_nobel/will/](http://www.nobelprize.org/alfred_nobel/will/), Accessed 2/4/16. 'Mankind' was the common word used at that time before being replaced by the gender-neutral 'humankind'.

to cross boundaries of social concern to be awarded the prize for peace. Moreover, also recognized was the value of moral consideration through neglect. These sorts of statements would form part of a general tide towards concern about neglect, in the populations and diseases of neglect. The concept of neglect is saying that there is an absence and lacking that we should be paying attention to or caring about. Therefore, beneath neglect is a moral and normative underpinning.

My aim has been to show how tropical disease has been positioned in relation to scientific interest, research commitment and recognition, and what changed for the new categorization of NTDs. In the next section I want to delve further into what changed within the categories of the individual diseases that were included or not. I will start with which diseases originally counted as tropical and why.

### 5.1.2 Transitioning categories

Tropical medicine has been varyingly attributed to diseases thought to be common or more specific to the tropics and sub-tropical regions. Today definitions of NTDs do still differ depending on the source, as mentioned in Chapter 1, with the most definitive list of 17 NTDs is given by the WHO (with the sub-categories of virus, bacteria, protozoa, helminth). Patrick Manson at the turn of the 20th century listed 10 of the 13 (later to become 17) NTDs listed by the WHO (see below Table 10) drawn from his much larger list of 65 (see Appendix 8).<sup>93</sup>

'17 WHO'	'WHO 13'	'Manson 10'
1.Buruli ulcer	x	
2.Chagas disease	x	
3.Dengue and chikungunya		x
4.Dracunculiasis (guinea-worm disease)	x	x
5.Echinococcosis		
6.Endemic treponematoses (Yaws)		x
7.Foodborne trematodiasis		
8.Human African trypanosomiasis (sleeping sickness)	x	x
9.Leishmaniasis	x	x
10.Leprosy (Hansen disease)	x	x
11.Lymphatic filariasis	x	x

<sup>93</sup> In the latest edition of Manson's book in 2013 (Farrar et al., 2013) subcategories largely remain: viral infections (HIV added), bacterial infections (tropical rickettsial infections responsible for many undiagnosed febrile illnesses included), fungal infections, mycobacterial infections (TB would not have been especially tropical in Manson's time), protozoan infections (malaria), helminthic infections (schistosomiasis) and ectoparasites (scabies). These include tropical diseases not judged to be neglected: the 'big three' (HIV/AIDS/ TB and malaria) and those in the Millennium Development Goals: nutrition and maternal/child health. Other health concerns in the tropics that now arguably compete with NTDs are non-communicable diseases (NCDs) and environmental disorders.

12. Onchocerciasis (river blindness)	x	x
13. Rabies		
14. Schistosomiasis	x	x
15. Soil-transmitted helminthiases	x (hookworm, roundworm, whipworm)	x
16. Taeniasis/Cysticercosis		
17. Trachoma	x	

**Table 15 Comparing WHO list of NTDs to Manson's list of tropical diseases**

(Compiled from Manson, 1898; WHO, 2015, Accessed 2/4/16)

Two of the missing diseases appear to have predated discovery (Chagas disease and buruli ulcer)<sup>94</sup> and many diseases are not often seen (plague) or ever seen today (goundou). Others have fallen in importance where vaccines have been developed (yellow fever, Japanese encephalitis, typhoid), are mild conditions easily treatable with medicine like antibiotics (heat-stroke, prickly heat, boils) and what are now called genetic diseases (Mediterranean fever, ainhum, pemphigus contagiosus). Another large section of diseases includes archaic medical terms, being more symptoms than diseases (craw-craw) or hold commonalities with NTDs but are not the specific type now viewed as a problem. For example, dog tapeworm (*distomum heterophytes*), not echinococcosis or tapeworms *taenia nana* and *madagascariensis*, or pig tapeworm (*taenia solium*) the leading cause of preventable epilepsy.

Finally there are still the time-persistent diseases associated with poverty of once pandemic diseases that now cluster in the tropics: malaria, cholera and dysentery. Malaria has since joined the 'big three' grouping and cholera and dysentery are typically called 'diseases of poverty' and 'diarrheal related' but tend to be of most concern during humanitarian emergencies when they can become epidemic. Conversely, rabies would now join this group of clustering in the tropics but at the time was persistent in central Europe for much of the 19th century and is likely to be why Manson did not list it as tropical.

The relationship between disease and scientific discovery and economic development certainly has not been static, despite the persistence of some diseases. Exploring how tropical diseases have become 'neglected' exposes an evolving conception of disease in relation to science and development. This extends to the very premise about the category of tropical disease challenging preconceived notions. Robert Desowitz, a tropical disease specialist and popular science writer, noted on the notion of 'typically tropical': "Well, these diseases that we call 'typically tropical' have been as American as the heart attack" (quoted by Killheffer, 1997). For the scientists connected with these diseases it has been an ever-moving conception of which diseases require attention and the suitable role for science. When Desowitz began his career in the 1950s he was told: "(M)alaria is about to be totally eradicated, and you will never make a

<sup>94</sup> Chagas was not described until 1909 and buruli ulcer was only described a year before the publication.

career, let alone a living, from it" (Desowitz, 1987, p. 12). This was why he switched to trypanosomiasis research but "(B)y the 1970s, malaria was more of a threat than ever, at the expense of interest in the trypanosomiasis" (Wilkinson, 2004).

Such an anecdote is emblematic of a group of diseases that have existed for a long time and are closely connected to the promise of eradication, to varying degrees, where at least the possibility appears in sight. If some diseases are close to eradication or elimination we may ask why are they neglected? Even though some treatments are highly effective, Musgrove and Hotez find that control, basic research, drug (including vaccine and diagnostic) development is still inadequate in relation to the burden (Musgrove & Hotez, 2009).

However, the eradication goal as a policy strategy is stretched further through current calls, based on a neglected criterion. Eradication is closely tied with the 'neglected' advocacy of today as Reidpath et al point out: "The NTDs advocacy has relied on (a) appeals to alleviate the suffering of societies' most neglected, and (b) the scientific promise of the ultimate cure... Most recently we have even had the idea of a 'vaccine against poverty' peddled in the international literature" (2011, p. 8). The very idea of eradication however, goes further back and is closely tied historically to an imperial view of tropical medicine. Stepan finds the Rockefeller campaigns with imperial overtones against the tropical diseases of hookworm, yellow fever and malaria as pioneering the eradication concept (Stepan, 2013, p. 7). Even though, as Cueto and Palmer point out, diseases such as hookworm had already been discovered by Central American physicians, predating the American discoveries of the disease in 1900 and national campaigns were already underway before the Rockefeller 'crusade' of eradication (2014, p. 314). Eradication now carries weight with the technology solutionism of big pharma drug development, global public health machinery and the technocratic Bill and Melinda Gates Foundation.

Two NTDs are currently set out as targets for eradication by the WHO: guinea worm and yaws, with eight for regional and global elimination: trachoma, Chagas disease, African sleeping sickness, leishmaniases, lymphatic filariasis, river blindness, rabies and schistosomiasis (see: WHO, 2015). Eradication by definition is a global endeavour and requires cooperation across countries. This compares to elimination, where disease transmission is interrupted only within a defined geographic area (Hopkins, 2011, p. 19). Some of the diseases once also prevalent in developed countries have now been eliminated.

## 5.2 What is 'tropical'?

To start with tropical, there are two parts to the tropical categorization, the place of tropical in history and the place in geography. Of course these overlap but can be thought of in terms of colonial history and current geography.

### 5.2.1 Colonial history

To provide a general definition of colonialism, the term tends to be described as a practice, while imperialism is the idea driving the practice. As described by Ake, imperialism constitutes the, "... subordination of one country to another or at any rate the attempt to subordinate one country to another in order to maintain a relationship of unequal exchange. The subordination may be military, economic, political, cultural, or some combination of these" (1982, p. 136). Loomba describes colonialism as the practice of "the conquest and control of other people's land and goods" (2005, p. 20).<sup>95</sup>

By the time of the Treaty of Paris in 1783,<sup>96</sup> Spain's dominance as a European power had been broken, giving way to a new era of English colonialism. A few years following, 1787 is identified by Nancy Stepan as when the phrase 'tropical disease' was first used in English medical work for illnesses associated with hot climates (2001, p. 17). Stepan goes on to say: "Almost by definition, tropical medicine was a colonial medicine" (ibid., p. 28). It existed, as Natalie Ring describes, to play "...a pivotal role in negotiating the relationship between the colonized and the colonizers since it constituted a powerful discourse of authority and modernity" (Ring, 2003, p. 5). Post-empire the field is remains in what has been called "...a residual category, synonymous with the additional requirements of imperial medical practice" (Worboys in Bynum & Porter, 2013, p. 512).

Tropical medicine has been a problem-based specialism – based on the problem of undertaking medical practice in the tropical colonies, rather than a biomedical basis to the disease grouping (e.g. based on pathogen or geography) (Lemaine et al., 1976). This is point is striking, to think of today when organizations from universities, governments and NGOs pose global problems as 'grand challenges',<sup>97</sup> and perceive it novel to use science and knowledge to address society problems.

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<sup>95</sup> Earlier definitions of colonialism only referred to the colonizers establishing 'new' land but in every instance of colonization there were already original inhabitants.

<sup>96</sup> The Treaty of Paris was signed at the end of the '7 years war' with Great Britain victorious over France and Spain, marking a new dominance of Britain, expanding to have a global empire (see Blackburn, 1988)

<sup>97</sup> Grand Challenges are run by the Canadian government (Canada/Grand Défis Canada, 2011); and University College London (UCL Grand Challenges, <https://www.ucl.ac.uk/grand-challenges>; Bill and Melinda Gates Foundation <http://gcgh.grandchallenges.org/>, Accessed 13/8/16).



Even at the time of creation the category posed difficulties. Manson, "...acknowledged that the term tropical diseases was 'more convenient than accurate'..." (ibid.). However, this grouping of convenience has had consequences in inheriting the 'geographical assumptions' of colonial medicine (Bewell, 2003, p. 36). The associated meanings of tropical have included 'climatic handicaps', 'inertia', 'degeneration', 'primordial' and 'treacherous', demarking a "...sharp moral and topographical distinctions between tropical and temperate climates" (Ring, 2003, pp. 1-2). These derogatory meanings have led to scientists and policy-makers – especially from the tropics – disputing and challenging the tropical disease characterization.

Afrânio Peixoto, the Chair of Hygiene at Rio de Janeiro's Faculty of Medicine was a vocal objector to the designation because of the denotation of biogeographic curse or fate of climate being responsible for disease. He argued that tropical medicine: "...reinforced the prejudices associated with climatic determinism and old stereotypes created by Europeans who 'defamed' the 'torrid' countries as insalubrious lands unsuited to civilization. Peixoto declared that there were no tropical diseases since there were no climatic diseases" (Kropf, 2011). Some objections were more confrontational. This is an account from Desowitz working on tropical medicine in the 1960s:

*"In 1962, when Indonesia's dictator, Sukarno, was in flower, I attended a meeting of the Southeast Asian Ministers of Education (Secretariat Tropical Medicine Project). The representative from Indonesia opened the session by hotly proclaiming that there was no such thing as 'tropical' medicine; it was a colonial term of denigration (the implication being that the whites were hygienic and the natives unsanitary)..." (Desowitz, 1997, p. 11).*

This reaction was not without reason as a sanitary survey was often 'an integral part' of British colonial medicine and if the question of a nation's authority and modernity are at stake, it is not surprising that there is a need to create distance from what had been seen as diseases of domination and backwardness or an uncivilized past (Ring, 2003, p. 3). As Hotta wrote in 1989, "bacteriology, parasitology, dietetics, sanitary hygiene, etc. derived from, or evolved in parallel with tropical medicine" (Hen, 1989, p. 2). Still, an intellectual movement of the postcolonial world has been criticizing science and medicine in general, as an instrument of Western hegemony through a cultural specificity of scientific truths (see Adams, 1998, p. 9).

One reaction has been to oppose universalist objectivity but in the case of tropical disease we have seen almost the reverse happening. Sandra Harding (1993) describes a 'strategy of universalization' in rejecting the concept of tropical diseases. Here in reaction to the relativist version of disease through tropical places and people was the attachment of disease to a universal idea. This was reflected at a later date through an example taken from the late 1990s, in the suggestion that a new term be used:

*"...when the organisation of European Schools of Tropical Medicine (TropMed Europe) met in Addis Ababa in 1997, they were persuaded by African Colleagues that the term 'tropical medicine' still had patronizing colonial overtones and should be replaced by 'international medicine' although that decision was never implemented"* (Eddleston et al, 2008).

The history of tropical medicine has therefore involved the interplay between universality and particularity. The tropical regions were viewed as particular with their climate of heat and moisture being deemed inhospitable to white people. The formulation of 'germ theory' hailed an era of 'new tropical medicine' (Lemaine et al., 1976, pp. 84-5). A generalized 'European approach' could be applied because the causes of disease were germs, so that scientific knowledge could defeat disease and allow for tropical colonialization (ibid.). Post World War II, tropical medicine would be influenced by other scientific disciplines: "fundamental biology, chemistry, physics, etc." leading to experimental and clinical medicine (Hen, 1989, p. 2).

This colonial past left open a number of possible re-directions to take tropical medicine. What approach would be taken universalist or particularist? Would it be understood as region-based or pathogen-based? Would expertise rely on on-the-ground public health experience or the introduction of new scientific disciplines? Post-empire it looked as if that the name tropical medicine might be dropped altogether.

## **5.2.2 Tropical re-relevance**

Evidently the change to 'international medicine' did not happen (at least not on a wholesale basis)<sup>98</sup> and so a persisting concern amongst tropical disease advocates was whether the term 'tropical disease' lacked relevance. The association with colonialism would be a driver for a renaming, to escape the framing that arises from the aims and visions of a colonial past. The new term 'NTDs' has appeared to displace some of these previous colonial connotations. However, it seems this might go full circle. Bill Gates for example has spoken of his hopes for the neglected to be gone with, still referencing the tropical: "Maybe as the decade goes on, people will wonder if these should be called neglected diseases. Maybe as the milestones go on, we will call them just tropical diseases" (Gates quoted by Boseley, 2012). Hotez and Musgrove have similarly said: "Lymphatic filariasis, onchocerciasis, schistosomiasis, soil-transmitted helminth infections, and trachoma are starting to lose the 'N' from NTD" (2009, p. 1700). The message being sent out is that tropical has been a point of tension and after the renaming it turns into something ostensibly more neutral. However, the intention behind the renaming is that it will serve a purpose and be no longer used at some point.

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<sup>98</sup> Reference to international medicine tends to be made under the banner of international health, referring to health for developing countries. The LSHTM have an MSc programme entitled 'Tropical Medicine & International Health', there is a journal called Tropical Medicine & International Health, and also a European Congress on Tropical Medicine and International Health. NTDs could be now said to sit within global public health, as the current conceptualization of international health.

What we are left with is an interesting conflict that arises when calling something neglected. To label something as neglected by measurement is a labeling act, an evocation for it to be no longer. The diseases are called neglected so that at a point in the future it will no longer be neglected. Thus it is only a temporary term if the hopes of the advocates are realized. However, neglect will exist on a scale and the diseases within will be relatively more or less neglected. This is an impreciseness and definitional quality that is not based on biology and something that some in the scientific community were initially opposed to in the early days of the term. For example, Simon Croft a Professor of Parasitology at the London School of Hygiene and Tropical Medicine (LSHTM), highlighted that 'neglect' was a labeling concept but could cause difficulty in the division made across biological categories:

*"If you start labeling things as neglected, I understand it from an advocacy point of view but... some people don't start looking across the board at the discipline, strategy. Whatever you're doing on infectious diseases it's the same principles... you don't want to fragment things too much... it's great for advocacy to raise the profile and get lots of publicity"* (Interview with author, Simon Croft, 2014).

### **5.2.3 Current geography**

The second positioning of tropical is in geography. The geographical assignment, as pointed out by Manson in establishing the tropical medicine speciality (Manson, 1898), is more convenient than accurate, to assign diseases a locality within tropical or semi-tropical regions. The boundaries were stretched and blurred as to which countries counted as tropical. As Stepan points out Algeria was considered medically tropical in the late 19th century, even though it was not in a literal geographic sense. 'Tropical' was more than a geographic concept and, "...signified a place of racial otherness to the temperate world" (Stepan, 2001). Also the diseases that counted as tropical did not easily fit classification and it is inaccurate to think of these diseases as a foreign 'other', located in the tropics. Manson noted at the turn of the 20th century that "...a volume on diseases peculiar to the tropics would occupy six pages or so" (Worboys in Bynum & Porter, 2013, p. 512). Tropical diseases are certainly more fluid than would be expected and their geography is constantly shifting. What we have called tropical diseases in the past, malaria for example has existed in the US southern states and went as far north as Boston and even Montreal (Conn, 2011).

This is not ancient history either. Up until the beginning of the 20th century the mosquito-borne diseases malaria and yellow fever were a serious problem in the farming regions of the US (Desowitz, 1991). At the turn of the 20th century, one out of every eight citizens of Memphis, Tennessee was dying of yellow fever before it was eradicated in 1949 (Conn, 2011). A 'pin up' calendar for US troops was made by The Center for Disease Control (CDC), which was founded

during World War II as the Office of Malaria Control (see Figure 7). The agency was charged with eradicating malaria in the South of the US, especially around military bases, running mosquito abatement programs and publicity campaigns until the malaria was finally eradicated in the US in 1951.



Figure 7 'Pin-up' calendar poster by Office of Malaria Control

(NPR.com 'How The U.S. Stopped Malaria, One Cartoon At A Time', 2012)

In Italy malaria<sup>99</sup> was also called the 'Italian National Disease'. By 1904 the country had begun a 'crusade against malaria', involving the state, local government and medical profession through mass quinine purchase,<sup>100</sup> a 'quinine tax' of employers and landowners, support of the Italian Red Cross and rural health stations to administer the treatment (Snowden, 2006). The idea of nationhood was prevalent throughout, as Prime Minister Sonnino stated in 1910: "...the fight against the terrible scourge of malaria constitutes an important economic, social, and public health interest for our nation... No effort must be neglected. Only the contribution of everyone, no one excepted, and the unremitting employment of every available means... will make it possible to achieve significant and lasting results" (ibid., p. 61). Thus, now forgotten, tropical diseases have been significant in the histories and defining the character of now developed countries, reflecting their culture and society.<sup>101</sup> Forgetting has been a part of neglect, it is an inadvertent neglect of a past once known but can also be deliberate by ignoring the past.

<sup>99</sup> I have to note the US did not have the more deadly malaria parasite (plasmodium falciparum) that was found in Italy and is what health officials tend to be more concerned about. Although there is an argument that plasmodium vivax should not be regarded as relatively benign because of how debilitating and sometimes life-threatening it can be.

<sup>100</sup> Quinine was the main malaria treatment at the time.

<sup>101</sup> The Italian malaria campaign proponents described it as being based on "rational scientific methods" but the religiosity of the campaign was marked (ibid., p. 56). The health clinic doctors were told to be "...apostles of health and hygiene" and open air clinics held at the end of public mass were set up so that people could be "...treated, medicated and evangelized (ibid., pp. 58-59).

## 5.2.4 Challenging geographic classification: chronically tropical

Today yellow fever and malaria no longer tend to be classed as NTDs. This brings me next to diseases that could be thought of as tropical diseases but are not. HIV/AIDS and tuberculosis (TB), although having high incidence rates in the tropics, are now not viewed as especially tropical. Kamat (2013) explains the shift in perceptions for malaria between 2001 – 2013: "...malaria is no longer indexed as a 'tropical disease'; it is placed on par with HIV/AIDS and tuberculosis as a global killer, at least discursively, demanding renewed attention and enormous resources." (p. 221). This change was partly a result of the Millennium Development Goals (MDGs), agreed by all member countries at the UN and leading development institutions.

It propelled malaria, HIV/AIDS and TB as targets for *global* attention in 2000, rather than being consigned to the tropics. These are global killers, because of the scale of deaths, and so the sixth goal out of the eight poverty reduction goals was, "...to combat AIDS, malaria, and other diseases" (see: United Nations Statistics Division, <http://unstats.un.org/unsd/methods/m49/m49regin.htm#developed>, Accessed 2/4/14). TB was later to be included in this grouping, through the 'Global Fund to Fight AIDS, TB and Malaria'. This example shows how other disease constructs form an identity (the big three) giving rise to disease identities in relation, so that the 'other diseases' in the MDGs became NTDs. We can indeed learn from the outliers to NTDs, in yellow fever – argued by some that it should be included but it is not and dengue fever – argued by some that it should not to be included but is.

### ***Yellow fever***

Yellow fever is not viewed as a particularly neglected disease, although it is certainly tropical with the virus endemic across a huge tropical area of Africa and Latin America covering 44 countries, with an estimated 29,000 – 60,000 deaths in 2013.<sup>102</sup> An effective vaccine exists and control programs have been successful in the past. Therefore, the existence of a vaccine and effective control programs appear to work against yellow fever being included. However, rabies is included when an effective vaccine exists and it is certainly not a chronic disease. Why is it included? It may be because rabies is a zoonic disease, which better fits the NTD profile and vaccination programs are expensive, especially when better animal management can also work, and it affects the rural poor living in remote areas (Bourhy et al., 2010). Therefore half of the characteristics of rabies are a very good fit while the other half are not, which may have tipped the balance, where half of the yellow fever characteristics are a moderately good fit and the other half not.

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<sup>102</sup> WHO, [www.who.int/neglected\\_diseases/NTD\\_STAG\\_report\\_2015.pdf](http://www.who.int/neglected_diseases/NTD_STAG_report_2015.pdf), 2016b, Accessed 2/4/14.

Stepan also suggests yellow fever has been more prominent in the imagination as being more deadly than other diseases, despite killing fewer people other diseases common in the nineteenth century: "...yellow fever, like cholera, was notorious because of the swiftness with which it invaded a community, its high mortality rate (usually twenty percent), and above all because it did not easily fit any known patterns of transmission" (1978, p. 397). With the capacity to bring cities and major industrial projects to a standstill, partly due to the confusion of the etiology of disease, yellow fever once struck fear in many. However, some do identify it as neglected today on the basis of lack of research:

*"...Yellow fever is truly a neglected tropical disease... Even though it continues to cause fatality, it remains understudied. While it is true there is a highly effective vaccine, it remains extremely challenging to get comprehensive vaccine coverage in sub-Saharan Africa and Latin America. Moreover, the vaccine works well if you are between one and 55 years old. It is not safe for babies or the elderly, who could develop yellow fever from the vaccine'..."* (Pittalwala, 2014).

It is also likely not to have been included in the NTD grouping because it is an arbovirus (arthropod-borne virus found in mosquitoes, ticks, flies transmitting pathogens to humans), while NTDs are more dominated by parasitic, protozoal and bacterial diseases. This exclusion on the grounds of pathogen, has led to some scholars, such as LaBeaud making the case for the inclusion of arboviruses as a group of diseases dominated by "...helminths, protozoa, and many tropical bacterial species" ('Why Arboviruses Can Be Neglected Tropical Diseases', 2008, p. 1). The list goes on for diseases that scientists argue should be included:

*"...snakebite is a disease that kills 100,000 a year so should be on list, I think there's a momentum there, now Sanofi has stopped making the anti-venom Africa and Africa are in serious trouble... so I'm really a great advocate for snakebite"* (First interview with author, Molyneux, 2016).

Conversely, arguments attest for other diseases to be taken off the list, as I shall explore next with dengue.

### **Dengue**

Dengue is an example of the changing perception of NTDs as it is an arbovirus and the last disease to be included in the NTD list in 2010 (Hotez, 2011). As yellow fever incidence rates are rising where regular vaccine programs have not been implemented, we may see future inclusion. What appeared to justify inclusion of dengue is the lack of an effective treatment (no drug or vaccine) and its presence in the tropics but the presence is rising "...both in space and time, becoming less and less seasonal, and occurring in more parts of the world" (Conn, 2011). Therefore previous lack of research and intervention tools are crucial, as well as a rising burden

that has not been acknowledged, as Cameron Simmons argues, "(D)engue is neglected in the sense that the true scale of the disease burden is poorly understood and certainly underestimated" (in Regnier, 2012).

However it does raise questions apart from being an arbovirus and not chronic, by not being a disease strongly related with poverty and being a semi-commercial disease for drug companies. Participants at a workshop held by the Institute of Medicine, based in Washington, questioned the inclusion of dengue as an NTD, on the grounds of it not being a chronic disease. The following is the account from the workshop in 2011, where "(T)here was considerable controversy as to whether or not Dengue is an NTD" with some arguing dengue is an emerging (acute febrile) illness, rather than a chronic debilitating one and "therefore does not fit the NTD model" (Relman & Choffnes, 2011). The 'chronic disease nature' is a feature of neglect (which I will cover more on in the next section about the neglected category) as compared with other infectious diseases. Chronic infectious diseases more rarely cause 'explosive outbreaks' making them less visible and they are not well exported to developed countries even though they are communicable, so not seen as a threat (Relman and Choffnes, 2011, p. 17). Therefore, the idea of diseases being 'tropical' is in part due to containment in developing countries. An example of an explosive outbreak that might be thought of as a tropical disease in 2014 was Ebola. However, Ebola, another arbovirus, is classed as an emerging disease<sup>103</sup> even though it is to be found in tropical regions and some do argue it has been neglected.

Dengue has been described as semi-commercial<sup>104</sup> in that some aspects of treatment development in the past have not been commercially viable, but other avenues such as the creation of a vaccine have potentially high rewards if targeted toward richer consumers and countries. Sanofi has invested €1.3bn in their dengue vaccine and expect to recoup their costs: "...analysts at Deutsche Bank say it could become the world's best-selling vaccine with revenues of €1bn a year" (Ward, 2014). If pharma can successfully target consumers and governments in high-income countries such as Singapore and middle-income countries (Brazil and China), they will see profits – especially as dengue does not affect the poor disproportionately. For example, the middle class was the proportionally predominant group affected during the epidemic in Dhaka Bangladesh and upper social classes had higher sero prevalence rates<sup>105</sup> in Fortaleza and San Luis epidemics in Brazil (Guha-Sapir & Schimmer, 2005, p. 5).

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<sup>103</sup> Emerging infectious diseases are identified by the WHO to have arisen in the last 20 years and were previously unknown (as well as being incurable). They include HIV/AIDS, hepatitis C, Lyme disease, hantavirus (pulmonary syndrome) and SARS (severe acute respiratory syndrome) (WHO 'Emerging diseases' [http://www.who.int/topics/emerging\\_diseases/en/](http://www.who.int/topics/emerging_diseases/en/), Accessed 2/4/14).

<sup>104</sup> Certainly dengue is a more commercial disease relative to other NTDs, which is why NGOs such as Policy Cures use the semi-commercial label (Moran et al., 2012).

<sup>105</sup> Prevalence rates mean "the frequency of individuals in a population that have a particular element (as antibodies to HIV) in their blood serum" (Merriam Webster Dictionary)

Mulligan et al (2015) through a systematic review of the research literature found that the relationship between dengue and poverty is not well established. In an earlier paper they questioned what the consequences were in "public health policies that construe dengue as a disease of poverty" and whether there are more appropriate policies for dengue in middle or upper-middle class communities than the current construction as an NTD (Mulligan et al, 2012, p. 409). While it is evident that global strategies for dengue in poor communities become adapted to local conditions, Mulligan et al also make the political observation that:

*"For the WHO, reconsidering dengue-poverty connections may also mean revisiting the question of why dengue is a neglected tropical disease, shifting responsibility for dengue from the characteristics of poor populations and communities themselves to the political decisions that have resulted in under-investment in this rapidly spreading infectious disease"* (ibid. 415-6).

They point toward the decisions of rapidly developing countries where better urban planning is needed, alongside a consideration of public health policies related to new living situations (ibid.). As Gavin Sreaton describes, "(D)engue is predominantly a disease of urbanisation... It poses major challenges to healthcare systems in developing countries because of its epidemic potential causing explosive outbreaks in some major cities" (Regnier, 2012b).

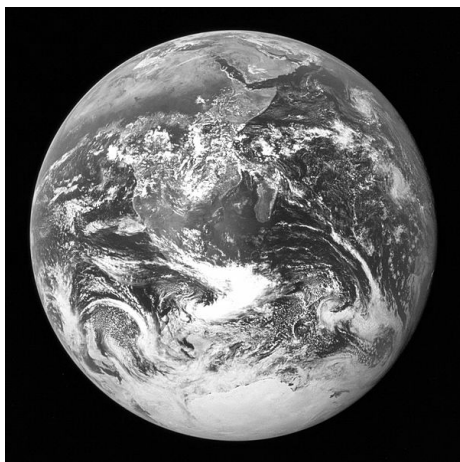
The inconsistencies for dengue with other NTDs form part of a larger debate about disease categorization. The inclusion in the NTD list appears to have been driven by concern about incidence rates and epidemics after the disease was made an international public health priority by the WHO in 2002. There is no other obvious group for dengue to have gone under (apart from perhaps 're-emerging diseases') and so NTDs provide a helpful banner. However, the arguments made by both Mulligan et al and the participants at the Institute of Medicine Workshop expose the consequences of categorization. On a national level the dengue strategy that is characterized by poverty may avoid political questions of urbanization and development, as well as not being well suited to local needs. On a global level there may be raised concerns for dengue, not as a chronic disease but rather for the potential of crossing borders and posing an epidemic threat.

### **5.2.5 Blue marble health**

What then are the consequences of over-focusing on the tropical – in the nature of NTDs being chronic infections and in the poorest countries – and not addressing other considerations? The contradiction between the geographically tropical imagination of these diseases and what some argue as more accurate characterization by poverty (whether that be in a tropical country or otherwise) is the concept espoused by Peter Hotez called 'blue marble health'. The idea of blue marble health is that there is a blurring of health between developed and developing countries so that within G20 countries we also see NTDs. Hotez makes the argument that NTDs still exist



in developed countries within poor communities. Diseases do not affect countries homogenously; instead there are severe local inequalities and disparities. There exist many layers of inequality in global health and this point is made in reference to the photograph of Earth taken by the Apollo 17 astronauts to portray how the extreme poor living among the wealthy disproportionately suffering from the world's NTDs. Hotez described the 'Blue Marble Health' idea when I interviewed him:



*"...we're finding paradoxically that more than half the neglected diseases are occurring among the G20 countries but they are occurring in areas of poverty in those countries. Places like Southern Mexico or Northern Argentina or Northeastern Brazil or in Indonesia... countries have the ability to afford treatments for neglected tropical diseases so it calls on the G20 countries to take responsibility for their own diseases, and, I'll just say that we are often now finding this hidden burden of neglected tropical diseases" (Interview with author, Hotez, 2014)*

**Figure 8 'Blue Marble Earth'**

(NASA <http://www.nasa.gov/>, Accessed 10/12/16)

To summarize, it is already evident that the tropical category causes some tension, as there may be some diseases that are tropical but not neglected and vice versa. The disputes about where inclusion lines are drawn signifies how tropical disease is related to a particular idea of disease that goes beyond even the geographical location and historical categories. From here we next question the neglected categorization and this too is far from straightforward.

### 5.3 What is 'neglected'?

The neglected category is arguably even more contentious. It is significant that we attribute a social-political categorization to a group of diseases. Similar terms that refer to the place of diseases in society and politics, are 'diseases of poverty' such as diarrhea and pneumonia or on the other end of the scale 'lifestyle diseases' caused by obesity and smoking. The influence of epidemiology can be seen to have had a profound effect through concern for the distribution and determinants of disease and also social determinants of health (SDH) (Raphael, 2006). However, these disease categories can be problematic in terms of the values and choices made whether for individuals and/or societies.

What is the difference between a disease of poverty and a lifestyle disease? Ironically today, a disease such as scurvy could be placed in the category of lifestyle diseases (Dobson, 2015), caused by a particular way of living. In the past the disease was seen to be due to a lack of scientific knowledge but now the knowledge is available and it is preventable, responsibility and blame is passed to the patient. Today, both groups of diseases whether poverty or lifestyle, may focus blame on the individual or society. Although lifestyle diseases connote more of an element of choice compared with poverty where people might be blamed for their initial predicament but are constrained in their choices. Thus the argument might follow that the state should not fund treatment for such a disease. Similarly, a disease of poverty connotes stigma, so again there might be social consequences for being within this category.<sup>106</sup> At the Institute for Tropical Medicine in São Paulo the doctors praised recent media campaigns addressing the taboo of TB (Interview with author, Scientist at Institute for Tropical Medicine, 2014). Over time a reaction to NTDs has been stigma and social marginalization, documented by sociological research on the cultural meaning of stigmatized illness:

*"Drawing on the work of Goffman, Gussow and Tracy (1968) were the first to distinguish 'stigmatized illness' as a category using the case of leprosy. Subsequent researchers examined the construction and impact of a number of stigmatized illnesses, including mental illness, epilepsy, cancer, HIV/AIDS, and sexually transmitted diseases (STDs). These researchers have identified how some illnesses become stigmatized, the impacts of stigma, the ways individuals and collectivities manage stigma, and how illness stigma can change over time"* (Conrad and Barker, 2010, p. S69).

Leprosy is a NTD but many of the other NTDs also have similar features in terms of disfigurement and disability (e.g. visceral leishmaniasis and trachoma). The stigma perpetuates the hidden nature of these diseases. It is a, "...lack of political voice among those afflicted by

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<sup>106</sup> The Argentinian soccer player Lionel Messi spoke out about Chagas disease after watching an Al Jazeera documentary on the issue (DNDi, 2013, Accessed 2/4/14).

neglected tropical diseases... neglect diseases of neglected people" (Relman & Choffnes, 2011, p. 17). Therefore, the neglected description can be argued to be an acknowledgement of the already socio-political nature of disease, as we see through stigma and how this has left patients hidden and voiceless.

### 5.3.1 Definitions of neglect

The NTD group as outlined by the WHO relies on a 'new conceptual framework' based in the number of commonalities decided by the organization and set out in the first report on NTDs in 2010. As the WHO points out in the report these are a medically diverse set of diseases (2010) and thus need justification for grouping. These commonalities do offer insight into the policy rationale for grouping NTDs and form a backdrop to the exploration of categories in this chapter:

- A proxy for poverty and disadvantage
- Affect populations with low visibility and little political voice
- Do not travel widely
- Cause stigma and discrimination, especially of girls and women
- Have an important impact on morbidity and mortality
- Are relatively neglected by research
- Can be controlled, prevented and possibly eliminated using effective and feasible solutions

**Table 16 WHO listed commonalities of NTDs**

(Source: WHO, 2010)

Others have followed suit in considering the WHO list of commonalities and providing further detail. Relman and Choffnes have drawn on the NTD experts (Pecoul and Hotez) to give some explanation behind the WHO commonalities (See Box 4 below). The authors place further emphasis on how 'underdevelopment' is exacerbated; contrast between those affected and decision-makers in capital cities; the effect of stigma and discrimination for women's marriage prospects and vulnerability to abuse or abandonment; and NTDs not travelling easily and so a threat to inhabitants of high-income countries. This list appears to draw out the unequal aspects of NTDs between a number of dualities between: the developed and underdeveloped; decision-makers and voiceless; women and men; and high-income inhabitants and low-income inhabitants.

### **NTDs and Their Common Features**

The list of NTDs is vast and virtually open ended. For the time being, WHO's work is confined to a list of 17 selected helminth, protozoal, and bacterial diseases. There are 149 countries and territories where TDs are transmitted, and at least 100 of them are endemic for 2 or more diseases and 30 are endemic for 6 or more (WHO, 2010d).

The NTDs are quite a diverse and heterogeneous group of diseases. However, they share a number of common features:

1. *The Hallmark of Poverty and Underdevelopment*

The most striking common feature of the NTDs is that they affect almost exclusively poor and marginalized populations (Hotez et al., 2009)

2. *Diseases of Non-Decision Makers*

Affected populations often live in remote rural area, in conflict zones, or in urban slums and have little political voice. They cannot readily influence administrative and governmental decisions that affect their health and often seem to have no constituency that speaks on their behalf. Diseases associated with rural poverty may have little impact on decision makers in capital cities (Pecoul, 2005)

3. *Association with Stigma and Discrimination, Especially of Women*

Many NTDs produce disfigurement and disability, leading to stigma and social discrimination. Their impact disproportionately affects women, whose marriage prospects may diminish or who may be left vulnerable to abuse and abandonment

4. *Not Travelling*

Unlike influenza, HIV/AIDS, malaria, and, to a lesser extent, tuberculosis, NTDs generally do not travel and seem to present little threat to inhabitants of high-income countries. Rather, the distribution of NTDs is restricted by climate and its effect on the distribution of vectors and reservoir hosts there appears to be little risk of transmission beyond the tropics (Pecoul, 2005).

### **Box 4 NTDs and their common features**

(Adapted from Relman & Choffnes, 2011)

These commonality lists have since evolved into a more affirmative 'criteria for inclusion' displayed in the last chapter, with the 'STAG' group for Neglected Tropical Diseases developing the process for the adoption of additional diseases as NTDs on January 2016 (WHO, 2016b). The criteria largely repeats the commonalities set out in the first WHO report (2010), adding further detail as Relman and Choffnes have done in identifying common features of NTDs. However, the wording emphasizes the poverty element in how NTDs "disproportionately affect populations living in poverty" and that this is "justifying a global response" (ibid., p. 2). A return is also made to the tropical and sub-tropical character, in describing NTDs to "primarily affect populations" living in the areas. Neglect by research is still there and the point is made stronger in saying that the research allocation is unfair, particularly in "new diagnostics, medicines and other control tools" (ibid.). Therefore, it is the lack of options for intervention and advancements in existing technologies (e.g. diagnostics) that is the problem, rather than there not having been ground-breaking research and viable control tools for many NTDs.

Some commonalities have notably been dropped, including the political voice of those affected, including the emphasis on stigma for girls and women, and the lack of travel of NTDs. This may signal the downplaying of a human rights element, while the major introduction has been the third criteria that the diseases: "are immediately amenable to broad control, elimination or eradication by applying one or more of the five public health strategies adopted by the Department for Control of NTDs" (ibid.). However, this is under the proviso 'and/or' that are

relatively neglected by research. The mixed strategy for surveillance, control, elimination, and eradication of NTDs is acknowledged. What we are left with is neither solely a problem of research for new innovative solutions nor a problem of the attention, resource, funding, and implementation of existing tools.

If neglect is both an outward signal and symptom of neglect in research and implementation, what are the underlying causes? Looking at the common definitions of neglect we can see that these can be grouped under themes, which are often presented in terms of the contradiction (e.g. between the poor and wealthy):

<p><b>a. Poverty and inequality: NTDs affect large numbers the poorest/marginalized, especially women and children but are not a problem for wealthy so do not receive the same attention as other diseases.</b></p>	<p>"NTDs are called "neglected" because they generally are not considered public health problems in <b>wealthier</b> nations and historically have not received as much <b>attention</b> as other diseases" (NIH, <a href="http://www.niaid.nih.gov/topics/tropicaldiseases/">http://www.niaid.nih.gov/topics/tropicaldiseases/</a>, Accessed 2/4/14).</p> <p>"<b>1 billion people</b> are affected by one or more neglected tropical diseases (NTDs). They are named neglected because these diseases persist exclusively in the <b>poorest and the most marginalized communities</b>, and have been largely eliminated elsewhere and thus are often forgotten" (WHO, 2016a).</p> <p>"(NTDs) are a group of parasitic and bacterial diseases that cause substantial illness for more than <b>one billion</b> people globally. Affecting the world's <b>poorest</b> people, NTDs impair physical and cognitive development, contribute to <b>mother and child illness and death</b>, make it difficult to farm or <b>earn a living, and limit productivity</b> in the workplace. As a result, NTDs trap the poor in a cycle of poverty and disease" (CDC, <a href="http://www.cdc.gov/globalhealth/ntd/">http://www.cdc.gov/globalhealth/ntd/</a>, Accessed 2/4/14).</p> <p>"The people who are most affected by these diseases are often the <b>poorest populations</b>, living in remote, rural areas, urban slums or conflict zones. Neglected tropical diseases persist under <b>conditions of poverty</b> and are concentrated almost exclusively in impoverished populations in the developing world. <b>Lacking a strong political voice</b>, people affected by these tropical diseases have a <b>low profile and status in public health priorities</b>" (WHO Features, <a href="http://www.who.int/features/qa/58/en/">http://www.who.int/features/qa/58/en/</a> 012, Accessed 2/4/14)</p>
<p><b>b. Under-development: NTDs have existed for a long time and reinforce poverty/underdevelopment through their impact/cost.</b></p>	<p>"These diseases, many of which have afflicted humanity for <b>millennia</b>, affect more than <b>1.4 billion people</b>. They <b>sicken, disable, and disfigure</b>, keeping people in cycles of <b>poverty</b> and costing developing economies <b>billions of dollars</b> every year. Until recently, NTDs saw little <b>attention</b> from all but a small handful of dedicated supporters" (Uniting to Combat NTDs, 2014).</p> <p>"(NTDs) are a diverse group of diseases with distinct characteristics that thrive mainly among the <b>poorest</b> populations. The 17 NTDs prioritized by WHO are endemic in <b>149 countries</b> and affect more than 1.4 billion people, <b>costing</b> developing economies billions of dollars" (WHO, 2013, Accessed 2/4/14).</p>

<p><b>c. Prioritize to solve: High-mortality diseases are given more attention, while NTDs disable/debilitate rather than kill. Treatment cost is low through existing drugs but new ones are also needed.</b></p>	<p>CDC also present a 'Fast Facts' section on their website (CDC <a href="http://www.cdc.gov/globalhealth/ntd/">http://www.cdc.gov/globalhealth/ntd/</a>, Accessed 2/4/14):</p> <ul style="list-style-type: none"> <li>• 1bn people across 149 countries/territories are affected (by at least one NTD)</li> <li>• 100% of low-income countries are affected by at least <b>five simultaneously</b></li> <li>• 534,000 people are killed worldwide every year</li> <li>• major disease burden, approx. 57 million <b>years life lost</b> to disability or death</li> <li>• <b>treatment cost</b> for most NTD MDA est. at less fifty cents per person, per yr</li> </ul> <p>"Many neglected tropical diseases can be <b>prevented, eliminated or even eradicated</b> with improved access to existing safe and cost-effective tools. Control relies on simple interventions that can be carried out by non-specialists" (WHO Features, <a href="http://www.who.int/healthinfo/global_burden_disease/metrics_daly/en/">http://www.who.int/healthinfo/global_burden_disease/metrics_daly/en/</a>, 2012, Accessed 2/4/14)</p> <p>"NTDs are infectious diseases that generally are rare or absent in developed countries, but are often widespread in the developing world... The availability of <b>new safe and effective drugs</b> for NTDs could provide public health benefit for overall global health, but because these diseases are found primarily in developing countries, existing <b>incentives</b> have been insufficient to encourage development of new drug therapies" (FDA, 2014).</p>
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**Table 17 Definitions of neglect in the policy literature**

(Multiple sources, emphasis added)

### 5.3.2 Measuring for attention: from the 10/90 gap to DALYs

Many of the definitions of NTDs are on the related problems of poverty or under-development and their lack of attention from governments, NGOs and pharma companies. The solution is often also presented alongside the need for prioritization, using existing safe and cost-effective 'tools' or developing new treatments. The lack of attention has been presented in terms of R&D for NTDs through the so-called '10/90 gap', which refers to resource allocation of global R&D compared with the disease burden.

The 10/90 gap is the finding of a report by 'The Global Forum for Health Research' i(2004) that says only 10% expenditure on global R&D is dedicated to problems that primarily affect the poorest 90% of the world's population.<sup>107</sup> The 10/90 gap only reflects R&D, with the argument

<sup>107</sup> Critiques of the 10/90 gap have argued that there has been a change in the epidemiology of developing countries, change in global health actors and also dispute of the size of the burden (Stevens, 2004).

that the market share of pharmaceutical businesses is too small for the 90% of the world who are poor, as pharma lacks profit incentive (Liese et al., 2010). Smith calls the 10/90 gap "(A) staggering example of neglect... International aid couldn't just be the distribution of existing cures. It needed broad innovation" (Smith, 2015). Here it is a mismatch between needs and investment that mark NTDs out. So the 10/90 gap became a part of the argumentation that the problem of NTDs lies in R&D, which would require a change in the innovation system from NGOs and the WHO to academics (Bosman & Mwinga, 2000; Hotez & Pecoul, 2010; Kilama, 2009).<sup>108</sup> Even if the 10/90 gap is not explicitly mentioned the unequal research spending by pharma is frequently referred to in media articles on NTDs (see Balasegaram et al., 2008).

R&D disparity is an important inclusion because it is in this context that neglect becomes striking. The WHO in 2007 stated: "Lack of reliable statistics on the burden of NTDs has hampered raising awareness of decision-makers on NTDs and zoonoses."<sup>109</sup> Accurate assessment of the disease burden is crucial to prioritize use of limited resources, provide timely treatments and prevent diseases" (WHO, 2007, p. 14). However, it is more than simply representing reality. The neglect of NTDs is highlighted through the numbers of people affected. NTDs compare with the small numbers of people affected by rare diseases (sometimes referred to as orphan diseases), which can lack attention and investment as their rarity means they only affect a small proportion of people. Additionally, orphan diseases sometimes include common diseases without a drug company 'adopting them'. The US Orphan Drug Act for example includes non-rare diseases and the European Organisation for Rare Diseases includes neglected diseases.

The 10/90 gap as a measure, marked the beginning of metrics being used in relation to NTDs, to make a policy case for attention. Christopher Murray, the health economist, has been an influential figure behind the drive for better tools for measurement in health. The Gates Foundation invested in the Seattle-based 'Institute for Health Metrics and Evaluation' where Murray is Director. In some part NTDs have also been influential for Murray. In fact Murray met Kenneth Warren the director of the GND in the mid-1980s. These were his thoughts on the program:

*"I think the GND program had a great effect. He coined the term and it has stuck, and now people compete to call their disease 'neglected'; there is a bit of a war about what the borders are, what is in and what is not. Is leprosy neglected? Is rabies? There are a lot of different definitions of what is neglected, and I think that the concept can reasonably be traced back to Ken"* (Keating, 2014, p. S28).

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<sup>108</sup> Unite for sight, <http://www.uniteforsight.org/global-impact-lab/global-health-research>, Accessed 5/6/13.

<sup>109</sup> "A zoonosis is any disease or infection that is naturally transmissible from vertebrate animals to humans" (WHO, 2015).



Furthermore, the NTD schistosomiasis was somewhat of a catalyst for Murray in his journey to create the 'DALY' metric, which stands for disability-adjusted life year'. The DALY is described as a "...measurement of the gap between current health status and an ideal health situation where the entire population lives to an advanced age, free of disease and disability".<sup>110</sup> In the part biographical account *Epic Measures* (Smith, 2015), which charts Murray's career in global health, a defining moment was when Murray travelled with his family to South Africa where they ran a hospital. One day Murray found a sick man and had been horrified after he had brought the man in and his stomach had exploded, a severe complication of schistosomiasis. It stuck with him that the disease was one he had not even heard about before and that it could be so devastating.

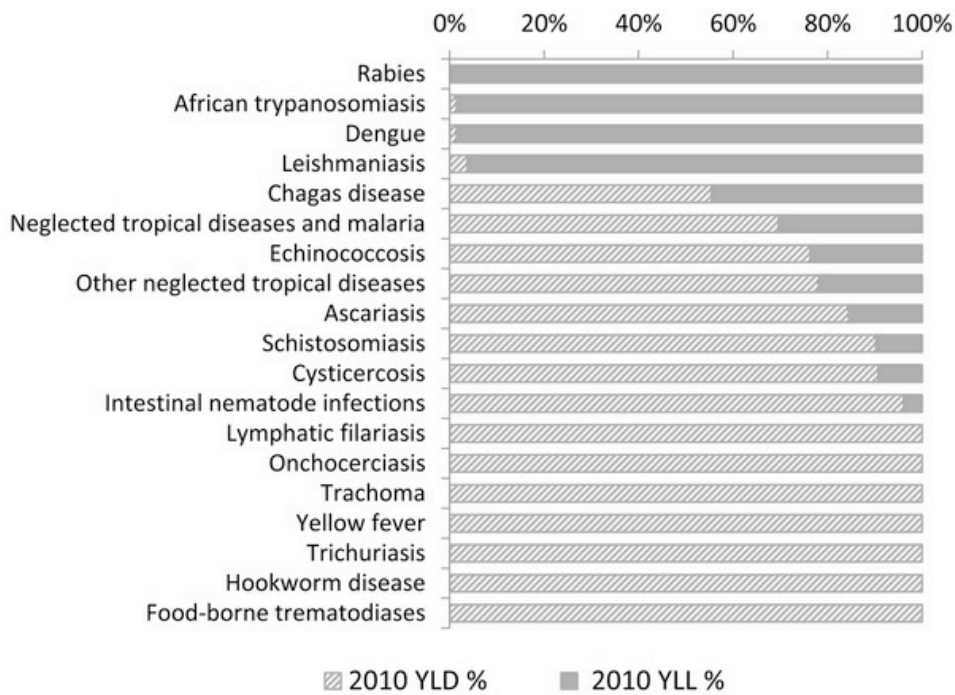
DALYs were developed by the World Bank and WHO in 1993, through the *Global Disease Burden Study* led by Murray with Alan Lopez (Smith, 2014). Murray describes that: "The original idea was you want a metric that can also be used in economic studies: If you spend X amount of money, this is how much health you'll get" (ibid.). The intention has been also said to be in assisting health priority setting otherwise influenced by politics and other pressures. It is also through the DALY measure that NTDs can be exposed, by estimating the burden of disease. These estimates renewed interest in the underlying epidemiological parameters. For example as NTDs mainly cause morbidity rather than mortality, the assessment of the average disability incurred by a diseased individual is crucial for correctly compiling data to global burden estimates. The disability weights (DW) are based on a non-expert or patient opinion but were developed through "highly educated" focus groups (Zhou et al. 2010, Part B, p. 59).

DALYs form a way to support a particular description of the world and how to act upon it. Through the description supplied by the DALY, morbidity is put on par or to a raised position as mortality, working in favour of NTDs to emphasize the size of this problem (ibid., p. 3). Now we have DALYs NTDs can be described as: "...the fourth most devastating group of communicable diseases behind lower respiratory infections, HIV, and diarrheal diseases – ranking higher than either malaria or tuberculosis" (The Henry J. Kaiser Family Foundation, 2015). How NTDs are more debilitating and disabling than life-threatening can be captured, and further constructed as a grouping. This measure provides standardized estimates for years of life lost due to disease, injury and risk factors over time. One DALY is equal to the loss of one healthy life year, as the sum of: Years of Life Lost (YLL) due to premature mortality in the population and Years Lost due to Disability (YLD) for people living with the health condition or its consequences.<sup>111</sup> As shown in Figure 9 below, NTDs tend to cause more of the 'Years Lost due to Disability' than 'Years of Life Lost'.

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<sup>110</sup> WHO Programmes, [http://www.who.int/healthinfo/global\\_burden\\_disease/metrics\\_daly/en/](http://www.who.int/healthinfo/global_burden_disease/metrics_daly/en/), 2015b, Accessed 2/4/14.

<sup>111</sup> WHO Programmes, [http://www.who.int/healthinfo/global\\_burden\\_disease/metrics\\_daly/en/](http://www.who.int/healthinfo/global_burden_disease/metrics_daly/en/), 2015b, Accessed 2/4/15.



**Figure 9 YLDs and YLL of NTDs in 'The Global Burden of Disease Study 2010'**

(Hotez et al., 2014)

Of course as the NTD grouping is not completely coherent there are four outliers in rabies, dengue, leishmaniasis and African trypanosomiasis. These are more fatal than disabling but it can be argued that these diseases should not be fatal if control measures are followed:

- (1) Rabies is preventable, with the existence of a vaccination also available post-exposure;
- (2) Dengue has less than a 1% fatality rate if detected early with access to proper medical care. While there is currently no known cure or treatment, several vaccine candidates are in clinical or pre-clinical development with the most advanced candidate in Phase III clinical trials (WHO Programmes, 2015a);
- (3) There are three types of leishmaniasis. Only one of these, visceral leishmaniasis (also known as kala-azar) is fatal if untreated but all are treatable and curable;
- (4) Lastly African trypanosomiasis (also know as HAT or sleeping sickness) is both difficult to diagnose and treat but has been controlled on the African continent in the past through surveillance methods. It should be noted that there are two forms of HAT depending on the parasite involved, one (*Trypanosoma brucei gambiense*) accounts for over 98% of reported cases causing a chronic infection for months or even years without major signs or symptoms and when more evident symptoms emerge the patient can be in an advanced disease stage (WHO Factsheet N°259, 2015). The other (*Trypanosoma brucei rhodesiense*) only represents 2% of cases but causes an acute infection that develops rapidly and invades the central nervous system (ibid.). The YLL may be due to the low survival rates if surveillance to prevent the disease transmission fails.

Therefore, these four diseases are not strictly disabling, unless we count the repeated illness and recovery times of several months. Rabies is the one that clearly does not fit this profile because it will almost always lead to death, if a person is not vaccinated before infection or vaccinated immediately post-infection before symptoms appear (this has only been challenged more recently by survival by inducing coma, called the 'Milwaukee Protocol' Aramburo et al., 2011). However, the point is that all are preventable and do not need to be fatal.

DALYs were an evolution of the earlier QALY (quality-adjusted life years) measure proposed by Zeckhauser and Shepard in 1976 and widely used in cost-effectiveness analyses for health interventions. The two health economists invented the QALY in 1956 to "...determine the value for money of a medical intervention by quantifying the quality of life gained in relation to the cost of that intervention" (Adams, 2016, p. 26). Where DALYs are a measure of the, "health loss in populations against a normative standard" QALYs tend to be used to, "quantify health gains for interventions" (Mathers, Ezzati, & Lopez, 2007, p. 2).

Some regard QALYs as a better measure of "subtle morbidities and long-term chronicity" (Zhou et al., 2010, Part A, p. 16) but Adams makes the interesting observation that it was "...a crisis of *funding* produced the QALY in the Global North, but I would argue that it was the crisis of *data* that produced its counterpart, the DALY, in the Global South" (Adams, 2016, p. 27). In determining which diseases to bring attention to, the DALY has been crucial, while the QALY has told us more about which interventions to take.

I have outlined that the DALY has the capacity to measure the disabling and debilitating nature of NTDs as a developing country concern. However, does the DALY have an impact in highlighting NTDs within the Global Burden of Disease (GBD)? In the early years NTDs did not show up very highly on overall disease burden (despite some surprise appearances) and "...the NTD community was dismayed by the previous WHO estimates between 1999 and 2004, which assigned DALYs that were equivalent to conditions of comparatively minor global health importance for major diseases such as schistosomiasis" (Hotez et al., 2014, p. 2). The year 2002 was deemed particularly bad as no NTD appeared in the 20 leading DALYs and led to a full revision of burden estimates for 2005. Hotez and Musgrove in 2009 made the argument that because NTDs contribute or are underlying rather than identified as the direct cause of deaths they were overlooked. For example schistosomiasis may lead to death by bladder cancer or deaths attributable to anemia from an NTD. They also argued that uncertainty about prevalence and incidence led to under-reporting of YLDs.

Later estimates calculated that the DALYs attributable to NTDs was US\$56 million, however estimates dropped again in the 2012 GBD study it to be only US\$26.05 million (See Molyneux, 2014, p. 176). This is quite a fall and constitutes only 1% of the total global disease burden. There are several reasons for such a discrepancy. The first is in the geographic spread and

how this is measured as NTD rates vary (by nearly 1000-fold) across regions because of a concentration in the poorest countries. A second point is that burden for diseases associated with long-term morbidity, is determined by DWs and "(T)here is considerable dispute of the DWs attributed to NTDs, and some case studies have seriously challenged both the DWs for different diseases, but also the numbers of people afflicted" (ibid., p. 5). Also direct pathologies associated with NTDs that are not included in the NTD burden such as for cancer and neurological conditions and factors have been ignored in calculating the burden of NTDs, such as mental illness.

At the other extreme, "...the higher DALY estimates for NTDs elevate the status of these diseases to a level at which they could be thought of as the fourth leg to a table built on HIV/AIDS, tuberculosis, and malaria" (Hotez et al., 2014, p. 2). Collectively constructed, NTDs can be counted together adding up the number of DALYs that are attributable. As Hotez et al. document the 2010 measure attempted to resolve earlier difference in estimate and also include more diseases, to provide a resulting figure of 48 million DALYs for NTDs, compared with tuberculosis (49 million), malaria (83 million) and HIV/AIDS (82 million), the later two accounting for two of the world's major diseases (ibid.).

It is important to remember the DALY measurement is a 'calculus of credibility',<sup>112</sup> in that as I described previously, evidence is placed by policy actors on a hierarchy, with RCTs tending to be at the top. DALYs are similarly statistically quantifiable metric and furthermore, they do not sit in isolation and go toward creating the 'Global Burden of Disease index', which ranks diseases according to their DALY score. Therein comes the importance of measuring and creating metrics at all, to be able to list hierarchal and relationally problems for policy that allows on a managerial level comparison and prioritization of funding and resources, on a possibly more ideological level to determine need apart from so-called political pressures. This is where much contention lies, as political process of democracy demands advocacy and different groups to petition elected representatives on the interests, values and causes they support. To 'follow the numbers' may suppress these activities or these activities will adopt the measurement language through the DALY metric.

The Gates Foundation now uses the concept of DALYs on a wide basis to help determine priorities and evaluate potential projects. By quantifying years lost to poor health, disability,, an economic valuing of human life is made by measuring morbidity in addition to mortality. The measure tends not to be used in economic analysis of cost-benefit but rather for cost-effectiveness (Smith, 2015, p. 145). Gates recounted the influence of the 1993 World Development Report with preliminary Global Burden of Disease findings: "...It was just a graph that had, you know, these twelve diseases that kill,' said Gates. These included leishmaniasis,

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<sup>112</sup> 'Calculus of credibility' is a phrase used by Epstein to refer to how different news sources chose what they determine to be credible claims to make for their audiences.

schistosomiasis, trachoma—the leashing scourges, preventable at low cost, whose names he'd also never seen before" (ibid.).

Following the Gales and Lascoumes definition (2007), DALYs are a tool for statistical categorization within the wider instrument of estimating the global burden of health. However, there is a difference between the type of tool described within the NTD community referring to interventions and a metric such as a DALY. This also resonates with public policy instrumentation in the problems posed and chosen path to make policy 'material and operational', orientating relations between political society and civil society. Devices mix technical components (measuring, calculating, the rule of law, procedure) and social components (representation, symbol) (ibid). Instrumentation is expressed in a standardized form, combining obligations, financial relations, and methods of learning about populations through statistical observations (ibid.).

Even if NTDs do not reach the top of the Global Burden of Disease (GBD), DALYs have increased awareness. Activist scientists and NGOs have faired well in playing the measurement game. Measurement advocacy started with the '10/90 gap', a narrative argument of neglect of R&D, especially from big pharma. However this narrative was largely about the injustice of funding for health research and not matching needs. More persuasively, DALYs have taken into account the particular needs associated with NTDs through their disabling nature, which had previously been overlooked on priority lists. The quantification of disability is novel in public health, and so the interweaving of DALYs and NTDs has been more successful. The argument says why we should care about these diseases and why they are important.

Already the second WHO (2013) report on NTDs referenced the 10/90 gap and the DALY measurement. DALYs transformed NTDs into commensurable diseases to be measured alongside the big killers: HIV/AIDS, TB and malaria, where "(T)he calculated economic rates of return suggest that investment in control/elimination of neglected diseases produces an economic rate of return of 15–30%, and is capable of delivery on a large scale" (WHO, 2005, p. 19). However, as Moran et al. have identified, the "DALY approach has clear limitations and should be used with caution as a tool to allocate R&D spending" and they see deviation<sup>113</sup> caused by the mechanism (2006, p. 23).

### 5.3.3 Neglect in measurement

The selection and operation of metrics are not "...a matter of simple technical choices", but a mode of reasoning (Lascoumes & Le Gales, 2007, p. 8). It is not only the interests behind metric or measurement instrument choice that matters but the relationship between metric,

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<sup>113</sup> A limitation of DALYS that has been identified is malaria being favoured because it often kills the young and so the earlier the age of death, more DALYs are lost

publics, and politics. Lascoumes and Le Gales argue that it is a particular representation and problematization of the issue that is at stake in metric choices, which tend to produce inertia to challenge the status quo (ibid., p. 10). Their observations point toward what is not being represented or problematized through the metric, which I consider with the two NTD metrics.

On one hand the representation of attention for NTDs the DALY measure was negative at first. As Canning, in the Berlin report contended, the measurement of NTD impact was in fact a reason for their neglect, because they "...do not score high from a disease burden perspective, and this lies at the crux for their neglect" (WHO, 2005). He argued that NTDs have been subject to the moral imperative of the 'rule of rescue', that we should prioritize diseases that pose an imminent threat to life, where chronic and non life-threatening conditions are overlooked. At the time of writing, NTDs were faring poorly in DALYs (for the period 1999–2005) attributed on the Global Burden of Disease Index (Hotez et al., 2014).

However, as the metric has grown in complexity, more NTDs have been included and as well as more detailed reporting on their disabling effects (ibid.). Similarly the growing pervasiveness of the metric (Adams, 2016) that has both mortality and morbidity as a combined common measure has popularized the idea that morbidity is a major concern and it is measurable so action can be taken.

On the other hand, the representation of the 10/90 gap concentrates on big pharma R&D investment but does not explain the lack of attention for NTDs from other sources. Why have donor governments and NGOs not invested in R&D for NTDs? As Canning has already alluded to, governments and NGOs have been more concerned with high-mortality diseases, while NTDs are less attractive in policy terms because of the number of deaths worldwide only being in the thousands. Therefore neglect of NTDs by those actors has been due to other diseases being of higher priority on policy agendas, with attention directed at the 'big three' high-mortality diseases. To be an attractive proposition for policy, the advocacy for NTDs needed to shift attention from mortality towards morbidity, which had a, "high return on investment" in a low cost intervention that had productivity and economic development impacts to, "attract the ear of finance ministers" (WHO, 2005, p. 11). DALYs have since been utilized by activist scientists and NGOs in a switch in opinion for NTDs, below are the types of headlines employed.

The End Fund an NGO: *"When measured in disability-adjusted life years, the NTD burden is greater than that of malaria or tuberculosis, and ranks among the top four most devastating groups of communicable diseases, along with lower respiratory infections, HIV/AIDS, and diarrheal diseases".*<sup>114</sup>

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<sup>114</sup> The END Fund, <http://www.end.org/whatwedo/ntdoverview>, Accessed 4/6/16.

Activists scientists Hotez, Fenwick, Molyneux and others: *"By some estimates, the neglected tropical diseases are second only to HIV/AIDS as a cause of disease burden, resulting in approximately 57 million DALYs annually"* (Hotez et al., 2006).

Instead of being problematized by DALYs as low in importance by being comparatively low mortality diseases they are characterized as high in importance by being high morbidity diseases. In the section that follows I turn to understanding neglect in solutions that are posed in order to tackle NTDs.

#### **5.3.4 Finding neglect in solutions: '50 cents per person'**

If neglect is understood in how the policy problem of NTDs is defined, this is assisted through measurement of R&D investment (10/90 gap), and of disease burden (DALYs). Moving onto an understanding of neglect in the solutions, in terms of what interventions will make the most difference, it has been a historical legacy of neglect that vaccines and drugs have not been developed for some of the NTDs. Some of the existing drugs are old, in need of improvement, or need continuing research in case there is drug resistance.<sup>115</sup>

For example, successful drugs such as praziquantel, used to effectively treat the schistosomiasis parasite may now be developing resistance. Certainly penicillin, used to treat yaws, is at risk of resistance, with concerns also in the difficulty of refrigeration as well as training to administer in developing country settings (Broadbent, 2011, p. 55). Other strategies for addressing these diseases are available, either suggested as an alternative or alongside a drug-based strategy. Table 12 shows what strategies are recommended by the WHO for each disease. Also see Appendix 9 for an earlier and briefer list of NTDs control strategies by the All-Party Parliamentary Group on Malaria and Neglected Tropical Diseases (APPMG, 2009) and see the Appendix 10 for a comprehensive table of current strategies per disease.

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<sup>115</sup> It was not until 2009 that NECT (Nifurtimox and Eflornithine Combination Therapy) was introduced to treat the early stages of human African trypanosomiasis, as first new improved treatment option in 25yrs for stage 2 of disease. The drugs that had been commonly used are pentamidine, which was discovered in 1940 and suramin to treat the rarer form of the disease, which was discovered in 1920 and can cause urinary tract and allergic reactions (WHO Factsheet N°259, 2015).

<b>Drug-based strategies</b>	trachoma, lymphatic filariasis, onchocerciasis, schistosomiasis, soil-transmitted helminths (5)	MDA of anthelmintics and antiparasitics, along with antibiotics
	buruli ulcer, leprosy, yaws, leishmaniasis (4)	antibiotics or antifungals
<b>Environment al-based strategies</b>	dracunculiasis (1)	safe drinking water, surveillance, awareness among affected and at-risk populations
	Chagas, dengue/chikungunya (2)	vector control
	cysticercosis/taeniasis, rabies, echinococcosis, foodborne trematodiasis (4)	food hygiene and veterinary public health measures or animal management
	human African trypanosomiasis (1)	surveillance through mobile screening teams of at-risk populations

**Table 18 Strategies by disease**

(Compiled from information on CDC <http://CDC.gov.org>; DNDi <http://www.dndi.org>; WHO, 2015)

There are five NTDs (trachoma, lymphatic filariasis, onchocerciasis, schistosomiasis, and soil-transmitted helminths) that are being addressed primarily through Mass Drug Administration (MDA) of anthelmintics and antiparasitics, along with antibiotics. According to the NGO ENVISION: "(MDA) is the administration of drugs to entire populations, in order to control, prevent or eliminate common or widespread disease".<sup>116</sup> MDA used to control NTDs has been hailed as an effective policy intervention, which the WHO describes as a 'preventive chemotherapy' to regularly and systematically administer medicines to populations who may either have an NTD or be at risk (WHO, 2012c).

It is a cheap form of treatment at 50 cents per person, according to the CDC, as "...one of the best buys in public health – with a low cost of about \$0.10 to \$0.50 per person/year and the benefit of helping prevent or treat several different diseases" (CDC, 2010, p.2). As Warren Lancaster, a senior vice president at NGO 'The End Fund' has put it: "for the donor community that's a very attractive proposition" (Interview with author, Lancaster, 2014). Similarly, Professor Alan Fenwick describes MDA at 50 cents per person as "...the best buy for public health" (APPMG, 2009. p. 14), acting as a marketing tool to 'sell' an attractive solution. It proved to be a successful pitch for Fenwick, when the '50 cents per person' caught the eye of Alan McCormick, a Partner at global investment firm Legatum, following an interview Fenwick gave to the Financial Times in 2006:

<sup>116</sup> ENVISION <http://www.ntdenvision.org/>, Accessed 2/4/14.



*"...a phrase from an interesting article on philanthropy implanted itself in his mind: that such treatable ailments 'do not need innovation but simply modest funding and a little imagination in order to distribute drugs to those in need'... He was inspired by the idea that it might be possible to change the lives of millions, to free them from the burden of devastating illness, for as little as 50 cents per person".<sup>117</sup>*

The result was the Legatum Foundation establishing 'The END Fund' as an NGO to finance control initiatives, and supplementing and creating new programs in a bid to control or eliminate the five most common NTDs. However despite the impact, the '50 cents per person' proposition is not problem-free. There is some worry about drug resistance from continued usage at this scale (Barry, Simon, Mistry, & Hotez, 2013) and acceptance by local communities dependent on perceptions and experiences.<sup>118</sup>

Another four NTDs are treatable either through antibiotics or antifungals (buruli ulcer, leprosy, yaws, and leishmaniasis). Still, environmental strategies are crucial for these diseases and are part of well-functioning health systems, including: information/education, clean water, sanitation, early detection/diagnosis/case management, surveillance, control of reservoir hosts, social mobilization and the strengthening of partnerships. For lymphatic filariasis (also known as elephantiasis) in addition to MDA, the WHO recommends an alternative and equally effective environmental strategy. This is the use of common table salt or cooking salt fortified with DEC (diethylcarbamazine) for one year in endemic regions, with vector control as a supplemental strategy. Some diseases are in fact better addressed with environmental-based strategies, replacing drug-based strategies or supplementing them. For example, safe drinking water through surveillance and awareness among affected and at-risk populations is the preferred strategy for dracunculiasis.

Still, the preferred strategy is changeable, dependent on resources, disease spread, and research developments. In the case of onchocerciasis, vector control had been successful in the past but was no longer considered feasible or cost-effective in the remaining APOC (African Programme for Onchocerciasis Control)<sup>119</sup> countries, which is why MDA is now favoured. Also for the mosquito-spread diseases Chagas, dengue, and chikungunya, vector control is the main strategy. This is partly because no vaccine is available, so the strategy may change if one is developed, but also (in the case of Chagas and to some extent lymphatic filariasis) because clinical symptoms are often not present until the disease has advanced in adulthood, such that drugs are less effective and have side effects. Food hygiene and veterinary public health measures or animal management (e.g. deworming of dogs, vaccination of pigs) are the best

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<sup>117</sup> The Legatum Group, <http://www.legatum.com/philanthropy/investing-in-development/united-voices/>, Accessed 4/30/16.

<sup>118</sup> Malaria Consortium, <http://www.malariaconsortium.org>, Accessed 2/4/14.

<sup>119</sup> The APOC programme has closed as of December 2015 and the establishment of a new regional entity is expected to support country programmes.

strategies for cysticercosis/taeniasis, rabies, echinococcosis, and foodborne trematodiasis. Although large-scale preventive chemotherapy in humans through MDA may also be required in endemic areas with high infection rates.

Through comparing environment-based and drug-based strategies a number of points are striking in highlighting the diversity of these diseases (See Appendix 11 for a full list of diseases and the strategies recommended):

1. The diseases that require a mainly drug-based strategy are limited to 10.
2. There is difficulty in developing vaccines/drugs for diseases with a mosquito vector. Vector control strategies work best today but this may change and the development of vaccines needs to be considered against the amount of resources needed.
3. Food and animal related illnesses are overlooked when considering NTDs in policy, as they require social/cultural change.
4. A number of diseases are near elimination or eradication, requiring a large amount of resources (rather than disease control).
5. Some outlier diseases appear to allow for limited strategies of control.

I have shown that problem and solution definitions that are drug-based have 'policy appeal'. Metrics identify the policy problem of NTDs through the 10/90 gap, which says R&D for new drugs is not being directed at the diseases of the poor, and DALYs, which says we should pay attention to chronic diseases of the poor, following cost-effectiveness drugs distribution with MDA. The metric of the '50 cents per person', presented by the NGOs such as 'The Global Network Against Neglected Tropical Diseases' and global commitments including the landmark 'London Declaration' meeting in 2012, emphasize MDA of drugs as a central strategy and encourage involvement of big pharma. These metrics present the degree of neglectedness to be on lack of R&D investment (10/90 gap), the disease burden not being recognized because of morbidity character of the disease (DALYs), and the success of low-cost-high-return interventions not known ('50 cents per person').

However, by returning to the 17 diseases and analyzing what are the preferred individual strategies to control and eliminate or eradicated the disease, the drug-dominant strategy unravels. As I have highlighted, drug-dominant strategies only apply to just over half of the diseases and some outlier diseases have very limited strategies for control. Furthermore, the technical challenge of developing vaccines or drugs for diseases with a mosquito vector is high, while vector control strategies may be effective. A number of diseases have had mixed strategies (both drug and environmental), which have been yielding results. Included here are diseases that are near eradication as a result of vector control, community-level programs and health education alongside drugs (guinea worm and yaws). These diseases now require

continued funding and resources, rather than new drugs or simply the implementation of existing drugs.

### 5.3.5 Drug dominance

Examining the preferred strategies to tackle individual NTDs shows that the existence of drugs does not guarantee successful implementation and neither does the development of new drugs. Clearly, a drug-based solution, emphasized by the measurement and quantification of neglect, forms a large part of the rhetoric of the problem – as a lack of R&D for new drugs or the distributions of existing drugs – but it has limits. This preference is evident when we return to the very definition of what is a neglected disease. When we return to first principles, to the definition of neglect for NTDs, it becomes more evident that the research funding argument assumes already that neglect is primarily pharmaceutical neglect. Neglect from pharma companies is in not providing drugs, treatments and prevention or diagnostic tools. Still, as Broadbent suggests pharmaceutical neglect may not be the best identification of the problem or solution:

*"...the thing that's striking for me about the neglected disease stuff is that... is that people have said, look, not enough research money is being spent on these diseases and that's what neglect is, and, you know, we should fix it by spending more research money on these diseases... it assumes that the way you're going to get rid of these diseases is by developing more drugs... saying okay, we've got to spend more research money on diseases; that's not a way of working out how to cure or treat neglected diseases; it's a way of working out how to do so and make a profit from doing so" (Interview with author, Broadbent, 2014).*

In defining neglect, the concentration is on funding and resources and the potential for solutions to come about through R&D and innovation. Broadbent identified a commercial angle to this, in how research money and a profitable product are needed, rather than say, social and political change, or more intangible changes. He argues on similar grounds that other approaches can be taken, including a consideration of public health systems and initiatives. This is especially true if there are strategies and public health tools available so it is not about starting from scratch or thinking that only solutions produced through research are viable:

*"... there are many other things you can do about diseases. There are public health initiatives. You can just arrange your society in a way that, you know, people receive better medical care... it just struck me that many of the neglected diseases actually are preventable as they stand... none of the actual neglected diseases that are normally listed as neglected diseases, count as being neglected in that sense which is quite strange... they're all things that we could do*

*something about if we just, you know, built some better roads or, you know, delivered refrigerated penicillin in the right places"* (Interview with author, Broadbent, 2014).

What Broadbent appears to mean by saying that none of the neglected diseases count as being neglected – is from a pharmaceutical R&D perspective – because effective interventions are available for many NTDs. If pharmaceutical companies through the policy literature have been placed in the driving seat for a solution for NTDs, this further pushes for drug-based solutions:

*"I mean I think if you look at the sort of interest of pharmaceuticals in this topic, I mean, you know, it's easy to sort of bash pharmaceuticals but, you know, ultimately they are not going to look for ways to help with neglected disease as simpliciter.<sup>120</sup> They're going to look for ways that will also make them money... in some cases that's going to help, but for many things it's just not clear to me that that's... automatically the case"* (Interview with author, Broadbent 2014).

Donations of existing drugs are a common way that a pharma company can help with NTDs but committing to R&D may be a more onerous step and also may also not be the best use of resources, as has been argued for vaccine development. Yaqub and Nightingale consider this issue in depth: "...vaccines are difficult to develop and can cost \$600m–\$1bn to bring to market" (2012, p. 1). The point they make persuasively is that investment does not guarantee success; some poorly funded programmes succeed and some well funded programmes fail, therefore vaccine development cannot only be thought of in terms of supply and demand where incentives are required (ibid.). More research funding towards NTDs may not yield the results that are wanted and there is an opportunity cost in not directing resources towards other strategies that have proven to be effective. The pursuit of such public health 'absolutes' as vaccines or eradication have to be viewed in the same context we apply to public health problems more generally: cost effectiveness, short term and long term goals, priority lists and wider health agendas. As Molyneux describes: "This is where I differ from Peter Hotez, we haven't got the timelines on vaccines to actually make an impact" (First interview with author, 2016).

This point is acknowledged by the WHO and other public health actors, despite the policy push for certain types of solutions. As Margaret Chan, director of the WHO, said when opening the London Declaration in 2012, that previously we may have relied too much on drug donation: "It is one solution... but it is not the only solution" (in Michael Regnier, 2012b). Other participants repeatedly brought up the urgent need for clean water and sanitation in the communities at risk from NTDs but for big pharma they now see their responsibility as met, as Haruo Naito, the president and CEO of Eisai, said: "Supply of drugs will not be the bottleneck" (ibid.).

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<sup>120</sup> 'Simpliciter' means simply or plainly but in philosophical terms tends to mean 'plainly, without qualification' (Philosophy Index).

It is in the characterizations of NTDs that the problematizations and potential solutions are made. To summarize, 'tropical' and 'neglected' as categories to some extent constrain what the solution to NTDs looks like. They invite a technology-based solution, which may overemphasize drug-orientated approaches after surveying the preferred strategies to deal with NTDs. Drug donation and MDA on the scale of interventions are relatively simple and targeted, and more easily produce cost-effectiveness evidence. Thus use of measurement tools further confirms a drug dominance, meaning that the understanding of neglect does not fully acknowledge structural and political causes.

## 5.4 Conclusion: Otherness as an imaginary of neglect

How then do we make sense of neglect through these accounts? The quandary of exploring the tropical category is of why NTDs persist when they have been more or less defeated in some parts of the world. There known ways of controlling, eliminating and or even eradicating these diseases. As countries have developed, they have been incredibly successful at tackling NTDs particularly through environmental interventions (sanitation, safe water, health systems and infrastructure). There has also been an expansion of scientific knowledge directed at certain diseases, as seen with the development of a vaccine for yellow fever. Certainly a lack of drugs does not provide a full reason for why NTDs are a problem.

Uneven technological progress, is a concern held by Nelson (2011) who mainly looking at developed countries, asks why social problems persist despite high levels of technological advancement in other areas. This proposition could be taken to a global scale: why do NTDs persist in some places and not in others? This is not to say that countries were on an even basis in terms of burdens from tropical diseases but some countries have been able to control or eliminate these diseases – developed countries in both non-tropical and tropical regions. A key insight from Nelson is to not only rely on political reasons for disparity but also science-based explanations for why scientific solutionism applied to social problems is not always the correct remedy.

The first point I want to make is the resource requirements and technical complexity of some of NTDs. Dealing with NTDs may be possible through an enormous amount of resources for example with sanitation, water and hygiene systems, viewed to be part of a development solution. Some countries such as Saudi Arabia are able to invest heavily in expensive seawater desalination to prevent the NTD schistosomiasis (Hotez, Savioli, et al., 2012) but these sort of interventions are not feasible in poorer countries.

The technical solutions, which tend to be drug-based, have seen some successes but some of the diseases have still eluded scientists in part because of scientific complexity. Mosquito vectors (causing malaria and dengue) and tsetse fly (causing Chagas disease and HAT) proved to be difficult challenges. As Scoones points out, drawing on early work by ecologist John Ford, the difficulty may lie in how, "...disease, ecology, human practices and wider processes of development are deeply intertwined, and that narrowly focused efforts to eliminate the vector or parasite are doomed to failure" (Scoones, 2014, p. 2). NTDs are both seen as a problem of poverty that is for development to solve and a problem of knowledge for science to solve. Still neither science nor development can be end solutions in themselves. Demographic change and urbanization has brought back dengue as a problem in some more developed countries and

a vaccine for rabies, often viewed as an ultimate technological fix (Sarewitz & Nelson, 2008), has not stopped deaths increasing in recent years (Bourhy et al., 2010).

There are many different shades to neglect of NTDs but also other characterizations are apt, where we have the considerations of:

• Difficulty	In technical solution
• Complexity	In the types of diseases, their different pathogens, vectors, changing environments
• Importance/urgency	How high is mortality and morbidity, how many are affected, a time element, what could be an outbreak?
• Ranking/priority	One intervention over another, one disease over another, other problem topics, which can be most political

**Table 19 Consideration of policy problem characterizations**

Neglect is pertinent to attention, acknowledgement and care, and cannot be wholly characteristic of the disease group. The sense then in which neglect is attributed to the diseases is crucial in showing how the problems and solutions have been imagined in various ways. 'Neglect' has been chosen by activist scientists and others involved in the advocacy for these diseases, as the most compelling way to characterize these diseases. From an exploration of the categories of disease, my argument is that the neglect depiction fits well in repackaging tropical diseases because of the categories 'tropical' and 'neglect' come from the position of *otherness*. The political aspect of otherness is contained in who gets to define neglect. These diseases are located where the viewer is not, in the other tropical world of neglect. If we consider who 'neglects' whom, there is the impression of a stronger force over a weaker one, therefore who does the caring and why becomes crucial. The 'other' needs to be cared for as neglected people are, "those less able to demand services" (Detels & Gulliford, 2015, p. 282).

The emphasis is on the lack of agency or power of the neglected. They are helpless and voiceless, as neglect in a holistic sense for a group of diseases does not lend itself to patient involvement. One party lacks care, where the pharma company fits this mold, as do the developed governments and NGOs that are more interested in other problems. The perceived lack of care sometimes extends to the media and specific actors or structures whether it be government officials or public health programmes.

For NTDs, I have found through this research that there exists a diverse set of understandings of neglect and these perceptions and ideas shape decisions. Fotaki (2010) similarly explores how imaginaries in the context of health policy making as more located in fantasy than reality, as inspired by psychoanalytic thinking imaginaries are the, "...societal fantasies originating in

the imaginary strivings of the subject" (ibid. p. 704). This produces a common understanding or visions about social reality and possibility so is both factual and normative. The understanding of neglect is through relation to a community and the meaning given through current assumptions and expectations of the future. Joao Nunes describes in the context of health that, "...one can understand the reality of health as shaped by an imaginary – an ensemble of deep-seated meanings, expectations and assumptions that delimit actors' self-understandings and their range of desirable and possible action" (Nunes, 2013, p. 88).

For Glasgow and Schrecker (2015) imaginaries of global health are deeply political and by this they mean shaped by neoliberal ideology, which purposefully diverts attention from both the social and political economic determinants. While the globalized imaginaries understandings of neglect become evident through the global prescriptions of problem and solution for NTDs, with the WHO at the lead. Too much of NTD policy ignores endemic countries themselves. This is the next step in uncovering where neglect really lies. This questioning about the role and understandings of disease remind us that NTDs will affect poor communities to varying degrees and they will be experienced as a problem alongside a host of other problems, some more of a concern and priority than others. There are numerous dimensions. Certain values are engrained in the construction of NTDs in an assignment of blame and responsibility, invisibility and visibility, voiceless and empowerment, attention and inattention, and stigma and acceptance. Disease frames the debate about policy and society (Rosenberg & Golden, 1992, p. xxii) and so NTDs say more about inequality – the poorest communities and their participation and benefit from the advances of science, technology, and development.

Therefore, the concept of neglect is problematic to use in universalist terms, as it is a subjective state, affected by localized or national understandings. Should it then be left to individual countries to define neglect? As Detels & Gulliford suggest: "...donors and the international community have a duty to help developing countries enhance their capacity so they can determine their own national and local health research and development priorities, such as neglected diseases" (2015, p. 283). The next chapter treats the agency taken to address neglect through activist scientists and also scientists within endemic countries.



# Chapter 6. Advocacy for neglect: The repackaging of NTDs

## 6.1 Introduction

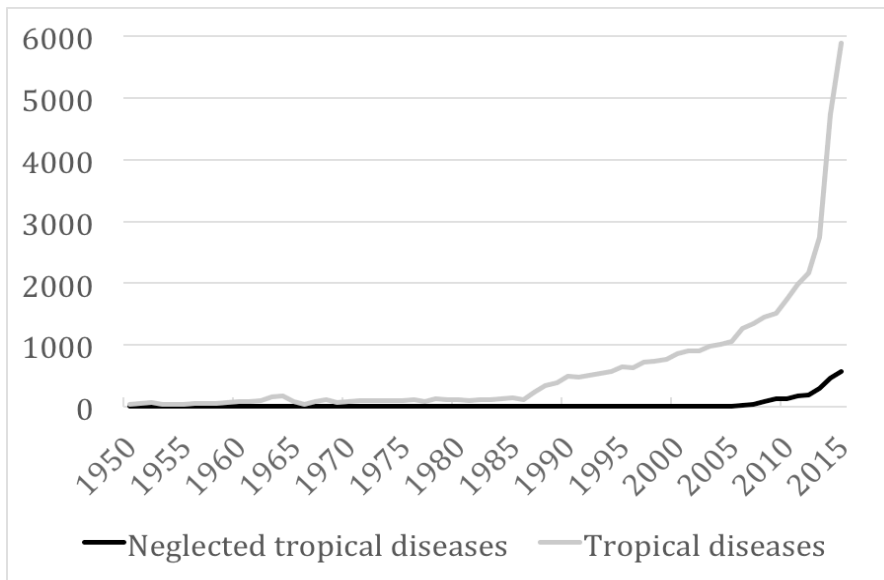
This chapter explores how advocacy was used in the transformation of tropical diseases to NTDs, through a repackaging to foster action and mobilize resources. The advocacy for NTDs has been a branding exercise to repackage tropical diseases into 'neglected tropical diseases' and part of an 'elite policy movement', explained in detail later. I explore the roots of this movement and come to the conclusion that it is 'activist scientists' based in the UK and US who played a leading role. However, this does not discount the contributions on the part of scientists in emerging countries, Brazil and China, their interactions with a policy movement, and furthermore what this says about their relation to NTD policy.

I argue that it is a repackaging to use what already exists in a new form – not merely a reframing of the contextual discourse. This arena for global civil society is described by Clifford Bob as, "...not an open forum marked by altruism, but a harsh, Darwinian marketplace where legions of desperate groups vie for scarce attention, sympathy, and money. In a context where marketing trumps justice..." (2009). The outcome of competition has been to produce a new category of disease, as discussed in the previous chapter. Some diseases are kept in and some are left out, with new criteria (albeit broad and changing) established to provide rationale for commonality between diseases.

As separate categories, tropical diseases and NTDs have received different treatment in policy in terms of acknowledgement, attention, and care. I began in the last chapter to describe how for tropical diseases the policy was part of a colonial endeavour, while NTDs have needed a new basis and rationale for interest. I looked specifically at Nobel Prizes as a way of gaging scientific recognition. In this chapter I am interested in NTDs as a new brand, which stems from a new name and ideas associated with it. As a starting point, I want to point out usage of the term NTDs through references on the Medline PubMed database, listing scientific publications that are medically relevant, shows how the term has risen in popularity (see Figure 10). There has been a sharp increase from 2006 onwards from eight references in 2005, to 28 in 2006 and then increasing every year until 2015 (the last year data was available) at 577 references.<sup>121</sup> Such a keyword search as a blunt measure is only an indication of how the term has entered the scientific literature and how 'tropical disease' may remain the more scientific term but not the issue more broadly.

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<sup>121</sup> Surprisingly also it is only in the post-colonial era that the large increase in references to tropical diseases began.



**Figure 10 PubMed references to 'neglected tropical diseases' and 'tropical diseases' 1950 – 2013**

(Medline PubMed trend, <http://dan.corlan.net/medline-trend.html>, Accessed 2/4/16)

Citations in the medical and health care literature are one indication of the biomedical community's acknowledgement of the importance of NTDs. NTDs today have a fit-for-purpose venue for publication through the *PLOS (Public Library of Science) Neglected Tropical Diseases* journal, launched in 2007 as a dedicated open-access peer-viewed journal. However, there has also been coverage in high-profile scientific journals including, the *Lancet* and the *BMJ* (formerly the *British Medical Journal*). The degree to which something is neglected is a difficult phenomenon to observe, one route to get an indication of neglect as I have begun to show, is through representation in the media and public forums. I will show in the next section how branding is used to create a new disease category and raise its profile.

### 6.1.1 A new disease brand

The use of methods from commercial branding and marketing has become increasingly popular in public health (Crawshaw, 2013). Diseases and health causes will naturally be connected with brands as seen with branding places and personalities, while individual patients or publics will tend to be treated as consumers. Considering the branding of diseases, Richard Smith, editor of the *BMJ* until 2004<sup>122</sup> reflected on the changing thinking about the importance of a brand in the medical context. He said: "Like most doctors, until recently I thought of branding as poppycock, an extravagant and narcissistic way of wasting money. But it's slowly dawned on me that I was wrong" (Smith, 2014b). He had changed his opinion to health branding being necessary and even helpful, because, "(A) good brand will inspire and prompt action" (ibid.) by providing meaning and purpose through an exciting visual or verbal form, with a compelling narrative. Smith had been convinced that awareness was not enough and only appeals to

<sup>122</sup> Smith has made headlines for his frank remarks, such as in one article after retirement where he was criticized saying that cancer was a good way to die (Smith, 2014a)

emotion would evoke action.<sup>123</sup> The idea of simplifying disease, including presenting a solution in an easily digestible form can be seen with NTDs. A phrase on the website of the advocacy NGO the 'Global Network for Neglected Tropical Diseases' says: "While the problem is huge, the solution to NTDs is simple".<sup>124</sup> This solution relates to the NTDs where there are cheap effective drugs available to treat a population through mass drug administration (MDA).

A brand begins with a name. Take diseases named geographically such as Zika, after a forest in Uganda it was first identified and similarly for Ebola named after a river in Zaire in 1976 (Hotez, 2016a). These places will continue to be known through diseases. People can also be implicated in connection to diseases, for example, on the patient side. A clear example of this type of connection was seen with the early names for AIDS creating serious socio-political implications: gay-related immune deficiency or 4-H disease, referring to 'Haitians, homosexuals, hemophiliacs and heroin' (Donovan, 1995). Or it can be on the doctor side. The rare neurological defect was initially named Hallervorden-Spatz disease after the Nazi doctors Julius Hallervorden and Hugo Spatz, who first described it after researching on the brains of exterminated children (NDTV, 2013). This led to families affected by the disease to urge a change in name to Neurodegeneration with Brain Iron Accumulation (NBIA) (ibid.). According to Ab Osterhaus, a virologist, acronyms are another solution because they keep names short (Kupferschmidt, 2015). However, people often forget what the letters stand for but even then they can cause problems as WHO official found in 2003 when they coined SARS, Hong Kong is officially known as Hong Kong SAR (for special administrative region).

These might appear to be unintended consequences of naming but the WHO takes disease branding seriously. In 2015 they urged naming to prevent inaccuracies and stigmas through 'best practices' for naming new human infectious diseases. Keiji Fukuda, the WHO's assistant director general for health security argued these recommendations were necessary because of the emergence of diseases that can create "unintended negative impacts by stigmatizing certain communities or economic sectors" (Gladstone, 2015). Following the guidelines could minimize negative impact of disease names on, "...trade, travel, tourism or animal welfare, and avoid causing offence to any cultural, social, national, regional, professional or ethnic groups" (Kupferschmidt, 2015). However, others such as Christian Drosten, a virologist at the University of Bonn, Germany points to geographic names sometimes being justified. It was clear that MERS, for example, was associated with the Middle East: "Would it have been better if we had named it novel betacoronavirus clade C, type 1?" adding, "You should not take political correctness so far that in the end no one is able to distinguish these diseases" (ibid.). Diseases have social meaning too, which can be shaped or directed through their names.

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<sup>123</sup> Smith was involved in an explicit version of a branding exercise, seen through a public event in 2014 at my university - UCL (University College London) called the 'NCD makeover show'. I had first-hand experience of the aspiration and acceptability of disease branding to brand non-communicable diseases NCDs – an acronym confusingly close to NTDs. Speakers included a representative from a branding company and also from broadcasting (the BBC), speaking about charity advertising (see: UCL, 2014).

<sup>124</sup> Global Network, <http://www.globalnetwork.org/>, Accessed 2/4/14.

Crucially, scientists working on tropical diseases saw one reason for the lack of attention from the global policy community as being the brand itself. The weakness of the brand had been considered a number of times, specifically by a small circle of scientists influential in the field of tropical medicine and the WHO. Their contention was that these diseases have "complex, hard-to-pronounce names" and there was also the unresolved question of which diseases constituted the grouping, with the most common or treatable ones making it into most lists (Relman & Choffnes, 2010, p.17). The scientists decided that these diseases needed to become a marketable commodity within a competitive market for public health resource. Simon Croft reflects on this change from diseases with little in common to having a label on which to build advocacy and action:

*"Other than the label, the NTDs have little in common....The NTD label has had major success in raising the profile of this group of diseases over the past 15 years through a combination of advocacy and scientific and public health programs. This has ensured that NTDs are on the agenda of major international organizations, including the WHO, the UK's Department for International Development (DfID), and the Bill and Melinda Gates Foundation, all of which have dedicated NTD programs. In addition, organizations dedicated to NTDs, for example the Drugs for Neglected Diseases Initiative (DNDi, Geneva), have been established"* (Croft, 2016, p. 1).

Similarly, the WHO recognized the importance of "advocacy to change this situation" (WHO, 2007, p. 24).<sup>125</sup> By the time the WHO published their 'Roadmap' policy document for NTDs in 2010, the writers remarked how: "(T)he NTD brand has proved to be a useful form of shorthand for communication" (WHO, 2012a). According to branding expert Dorie Clark (Nordrum, 2014) NTDs act as a "brilliant umbrella term" because, "(I)t allows funders to feel like they are addressing something important that has been hidden for a long time". Therefore it straightforwardly conveys a message of moral urgency, justifying funding.

A number of (similar) interpretations exist about how the NTD brand came about. One account comes from an interview by the Wellcome Trust with Peter Hotez, President of the Sabin Vaccine Institute. As Hotez describes:

*"The phrase was part of a drive to think about these diseases in a fresh light... After the launch of the Millennium Development Goals in 2000, a lot of attention fell on HIV, tuberculosis and malaria. Goal 6 called for action on those three 'and other diseases... but those of us working on the 'other diseases' felt we were on the outside looking in. We were driven to think afresh, to 'rebrand' these conditions"* (Regnier, 2012a).

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<sup>125</sup> In a 2007 WHO report on NTDs, indicators for performance measurement included the fourth strategic area of 'Evidence for advocacy', which included, 'Increased media coverage of NTD issues' and 'Societal awareness about NTDs' (WHO, 2007, p. 24).

The main instigators have been named as those scientists who established the ‘Global Network for Neglected Tropical Diseases’ in 2005 including “Professor Peter Hotez, President of the Sabin Vaccine Institute, Professor David Molyneux, a lymphatic filariasis researcher at the Liverpool School of Tropical Medicine” (ibid).<sup>126</sup> These creation stories documenting the emergence of the new category and NTD brand point towards a small, concerted group of high-profile scientists who had been working on NTDs, usually specializing in one or two specific diseases throughout their careers, at top-ranking universities as well as at the WHO.

The story of the origins of something new serves a purpose, either to reaffirm the perspective of those involved in the creation or to make a point about the object of creation. The activist scientists felt heavily involved in the creation of NTDs and because they had begun an agenda of high-profile advocacy and policy engagement. Part of their role would be to be vocal about how instrumental they were in creating NTDs. Further, it appears that in wanting to promote the cause of NTDs, there is the human-interest element of the scientist involvement that can be used to draw attention to the diseases. An initial profile in *USA Today* first put a spotlight on Hotez in 2009 – as arguably the most famous of the activist scientists. This news coverage was followed by a Wellcome Trust blog article in 2012 (also including Molyneux and Fenwick) and then a number of similar interpretations about how the NTD brand came about, many of them in the popular press through news stories and articles in science magazines:

Date	Title
2009	This scientist's passion: Ending the scourge of parasitic diseases', <i>US Today</i> (Sternberg) 'Neglected tropical diseases: The campaign trail', <i>The Wellcome Trust Blog</i> (Regnier)
2012	'How Three Scientists 'Marketed' Neglected Tropical Diseases And Raised More Than \$1 Billion', <i>International Business Times</i> , (Nordrum)
2014	

**Table 20 Articles about the creation of NTDs**

The 2014 news story also emphasizes the three scientists as main protagonists (Hotez, Molyneux and Fenwick). This is a business story in the 'International Business Times' rather than in more specialist science publications. The focus is on the marketing and the amount of money raised (referring to the cost of treatments donated by pharma companies).

Creation stories acknowledge the involvement of some actors and not of others, depending on where the emphasis is intended. The role of the WHO in the creation of NTDs has not been emphasized. It is through their own publications that they highlight their involvement (see WHO, 2010). The key scientist from the WHO was Lorenzo Savioli, who was the director of the

<sup>126</sup> Other instigators for the Global Network listed were "Dr Lorenzo Savioli of the World Health Organization, Dr Jeff Sachs at the Earth Institute, Dr Kathy Spahn of Helen Keller International and Dr Jacob Kumaresan, then at the International Trachoma Initiative" (ibid.)

Department of Control of Neglected Tropical Diseases. Savioli, along with Antonio Montresor, and Albis Gabrielli wrote an article on 'Neglected tropical diseases: The development of a brand with no copyright. A shift from a disease-centered to a tool-centered strategic approach' (Savioli, Montresor, & Gabrielli, 2011, p. 281). The authors from the WHO point to Dr Lee, the newly appointed Director General of the WHO in 2003, as responsible for starting a process of paradigm shift in the control and elimination of NTDs. 'Paradigm shift' is the specific choice of words chosen to connote strategic involvement to change thinking rather than adopting the rhetoric of branding or marketing and the direct words of creation or construction. Savioli et al. therefore describe this as a strategic move away from a scientific classification of disease biology to a practical approach based on needs (ibid.. p. 281).

Therefore, while it was central that the WHO was on board for such a change in the branding for NTDs, the activist scientists acted as a driving force. One of the key roles of the organization was to provide leadership on diseases with part of this being categorizing diseases into groups on which to base action. As Savioli et al. describe, it was a change in philosophical position about how diseases and their treatment were viewed.

### **6.1.2 Borrowing from the past: 'Great Neglected Diseases' the proto brand**

As I began to uncover in Chapter 4, the NTD brand has a longer history. However, it has now entered the mainstream, as Regnier points out the first research paper to 'use and define'<sup>127</sup> the term 'neglected tropical diseases' (NTDs) was published in 2005, and since "...the phrase has become a standard part of global health vocabulary" (2012b). Molyneux, Hotez, and Fenwick published the 2005 paper called 'Rapid-Impact Interventions: How a Policy of Integrated Control for Africa's Neglected Tropical Diseases Could Benefit the Poor'. Before this paper Hotez and others referred to a number of different terms including 'tropical infectious diseases' or 'parasitic diseases' (Hotez, 2002; Hotez et al., 2004). Why then was the concept of 'neglected' used for this repackaging?

The wording, to some extent, was borrowed from the past. Before NTDs, as described in Chapter 4, were 'The Great Neglected Diseases of Mankind' (GNDs), running from 1977 – 2000. Coming from the Rockefeller Foundation; the foremost philanthropic organization of that time, the GND name is compatible with the foundation's ambitious mission to promote the wellbeing of humanity. This sort of description at the time appeared to be popular. For example, the phrase 'great neglected opportunities' was used by Jonas Salk, the US virologist who developed the polio vaccine, at a 1981 meeting of donor agencies and scientists in the

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<sup>127</sup> The WHO did make a reference to NTDs earlier (Remme et al., 2002) but did not consistently use the term or define it.

Rockefeller Foundation in New York (Warren & Bowers, 1982). However, the GNDs were making reference to the type of diseases that could be NTDs, including many NTDs, especially the parasitic diseases, as Hotez noted: "(T)he emphasis was on parasitic infections that plagued people living in poverty" (Keating, 2014, p. S32). Similarly the GND was reflecting the changes in 'neglected' and 'non-neglected' tropical diseases. Malaria had already been downgraded during the lifespan of the program to a "great 'relatively' neglected disease" (Warren, 1978, p.176). Therefore, there had already begun to be a distinction between the 'big three' and neglected other diseases.<sup>128</sup>

In fact the GNDs followed a similar definition to those commonly used for NTDs, as Kenneth Warren, the director the GND, described: "These diseases are great in terms of the enormous numbers of people suffering from them and are neglected both financially and scientifically" (Warren, 1978, p 572). The emphasis is on the large numbers of people affected and of course that these diseases are neglected is central to the current day NTD definition. He also pondered on the type of neglect that was occurring – financial and scientific, how neglect was multi-causal, and that is not only rare diseases that are neglected: "There are many reasons, other than rarity, why diseases might be neglected, which go far beyond the profit motive" (Kenneth Warren in Scheinberg, 1989, p. 169). This still holds today, as financial and scientific neglect identified by Warren but we could add social and political, which additional areas of neglect that I argue the rebranding has tried to address. Pharmaceutical companies and donors might be the obvious sources of financial neglect, and the interest of the scientific community the cause of scientific neglect. However, the media, public and governments are also sources of neglect socially and politically. For Warren the financing was available to an extent with the Rockefeller endowment, so his emphasis was in garnering the attention of scientists and addressing the scientific neglect.

### **6.1.2 Attracting scientific talent and the promise of biotechnology**

Where the program differed significantly from NTD activity today is in the core aspiration to bring in scientific talent, creating a network of high-quality investigators. For Desowitz this sort of networking is something that science does well: "(G)lobalization was the business of science centuries before it became the business of business. Networking has been science's tradition and strength" (2004, p. 23). The intention of the GND was to constitute a critical mass of talented scientists, attracting the brightest students, and conducting research of a quality that was rarely seen for tropical diseases in the 1970s (The Rockefeller Foundation, 1978, p. 25). At the time, the view within in the community was that the most able and talented scientists were *not* directed towards diseases of the developing world. The call of the Rockefeller Institute in

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<sup>128</sup> A dimension that remains a concern today: what is the level of neglect (neglected or more neglected) and at what scale (global or other) is a disease being addressed?

1978 would aim to change this situation in asking for "...outstanding basic and clinical scientists to shift their attention to these great neglected diseases" (ibid.). Such an encouragement of scientific interest on an individual level has appeared to have a lasting impact and may be why there is no longer the same need to actively attract scientific talent.

Another aspect of bringing in the top scientists included applying the advances that had been made in biotechnology. Parasitology had once been at the forefront of medical knowledge but "...by the 1970s, the discipline had fallen behind the revolutionary changes... taking place in molecular and cell biology, genetics and immunology" (Keating, 2014, S25). So the work of Warren began as "...an early attempt to apply modern biomedical technology in the understanding of the mechanisms of disease prevalent in developing countries" (ibid. S24). According to Conrad Keating, a medical historian and biographer, Warren stands out in the 20th century in associating 'modern science' with tropical diseases. It challenged a "romantic, post-colonial attitude" to the new technologies (ibid. S28) and was not something that had been on the table before. Therefore, molecular parasitology units were required to be established among partners. Later on Hotez would describe how the network went beyond setting up new units, to training new tropical medicine scientists and creating opportunities for collaboration. Keating argued that tropical medicine collaboration happening on a 'global scale' had been unprecedented (Interview with author, Keating, 2014). The GND formed a new geography of training in the next generation of tropical medicine scientists and in creating opportunities for collaboration:

*"... the activities of these molecular parasitology units would be integrated into a GND network that would meet regularly in Woods Hole or elsewhere. In addition to an extraordinary track record of scientific productivity and international scientific collaboration, the GND program and network trained an entire generation of scientists committed to tropical infections, many of whom remain close colleagues"* (Hotez in Keating, 2014, p. S32).

Warren was making a parasitology network attractive through the meetings. A place like Woods Hole carried prestige but also acted as a retreat, being a harbour town in Cape Cod, Massachusetts on the east coast of the US.<sup>129</sup> Hotez described the appeal of this network and the annual meeting:

*"They had these fantastic annual meetings where everyone funded by the Foundation would come to Woods Hole. We would go to these meetings every year and I would get the chance to meet all of these extraordinary people. This meant a lot because today I am still in touch with a lot of these same people who have gone on to have distinguished careers in tropical medicine..."* (quoted in Esch, 2007, p. 46).

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<sup>129</sup> Woods Hole is a convening place for scientific meetings (Marton, Fensham, & Chaiklin, 1994).



See photo below of the GND members meeting in Woods Hole (in the early 1980s).



**Figure 11 "A meeting of the Rockefeller Foundation GND program in Woods Hole during the early 1980s"**

(Hotez, 2014, p. S32)

Today scientists know they will be applying cutting edge science and also have the appeal of contributing to a social good. Furthermore, it is not only biomedical scientists attracted to this field but statisticians, demographers, epidemiologists and health economists who embody the application of 'new science'. They have become an important group, as the focus for NTD research has moved from scientific application to also questioning research and delivery structures. The involvement of epidemiologists and health economists with NTDs will be discussed further in the next chapter.

I interviewed Conrad Keating (with colleague Erman Sozudogru) a historian of science who spent time with Warren's 'supporters and detractors', including his wife who was present at most of his meetings and many of the GND members. The descriptions of these diseases are dramatic to evoke emotion in 'great' and 'neglected'. Even 'mankind' situates these diseases on a global and historical level of importance. As Warren describes it would not only be the use of new techniques and application of cutting-edge science that would attract the new generation of scientists but a "new spirit of humanitarianism" (Kreier, 2014, p. 337). Keating believes that the origin of the word neglected in the context of tropical diseases comes from the GND, which he admits is "...a rather grandiose title, but he invented really the lingua franca, so now, in your own case, this word 'neglected', this is where it comes from" (Interview with author, Keating, 2014). This view is supported by others including Simon Croft, who described how the concept of NTDs was first proposed by Warren in bringing attention to "...a large proportion of the human population who were poor, who suffered from chronic, disabling but rarely fatal diseases, and who were often stigmatized and unemployed" (Croft, 2016, p. 1).

There was more contention about the term 'great' than over 'neglected', which was viewed by some as grandiose but "it was great because the diseases were killing many people, children

particularly, in the developing world” (ibid.). Similarly Warren found that the GND term was not always well received as a renaming of a group of diseases in a marketing sense. When Warren met with David Weatherall who was the founding Director of the Weatherall Institute of Molecular Medicine<sup>130</sup> (WIMM) in Oxford in 1977: “...he didn’t think it would ever really take off, and people, I think they were already thinking about neglected diseases... from Weatherall’s point of view it seemed an odd title” (Interview with author, Keating, 2014).

Keating also spoke of how ground-breaking the work of the GND was but the way it was as an exclusive club of carefully selected scientists. The chances to open the network or scale up the activity were limited and may have affected the sustainability long-term of the program. However, the legacy of a small elite group of scientists has been impactful:

*“... one of the things that I think annoyed people about the GND was that it was a club. If you’re inside the club it was this great feeling. If you’re outside the club, you notice them. And I think there were accusations of these Johnny-come-latelys. People thought Warren was a kind of a Johnny-come-lately... he was trying to magnify the contribution of the GND and some people would say, you know, that was politically motivated but he certainly rubbed people up the wrong way. I think there was an element, and it’s interesting, the quality of the cohort he chose have gone on to be people who have been enormously important in their separate fields... I think that it was very influential that Warren himself has been neglected... today, as we know ourselves, diseases are fighting to be put into this neglected square so he invented an interesting sort of language and he, himself, has been forgotten...”* (Interview with author, Keating, 2014).

Warren had discovered early on the 'neglected square' as Keating puts it. He saw power in calling something neglected to spur action. Warren's use of neglect is novel in that it brings to focus the advocacy of diseases to a much earlier stage. Instead of only saying something needs to be cared about, it is actively characterized as requiring that care. The GND diseases having the label 'neglected' was the equivalent of a red flag to mark them out. It was not enough to present a problem and solution but to characterize the state of the issue in the first place, in order to be concerned about problem and solution.

Indeed both descriptions of the GND diseases are dramatic to evoke emotion in 'great' and 'neglected'. Even 'mankind' situates these diseases on a global and historical level of importance. For Keating the mankind encompassment that the GND made had a resounding effect on the discipline and it involved an inclusiveness of developing countries to attempt to leave behind a colonial past:

*“... the whole idea of tropical medicine, to medicine and to tropics, has changed because of that [the GND], and I think if you look at the amount of papers that are GND produced, if you look at*

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<sup>130</sup> David Weatherall was director from 1989 – 2000 with the centre named after him upon his retirement.

*the amount of people who were funded in the developing world, it was about, of all the scientists in it, I think it was something like 56% were in the developed world and the rest in the developing world so it wasn't, this wasn't sort of colonialism, so in that way it was a much, much fairer system" (Interview with author, Keating, 2014).*

Even if Warren is now a forgotten figure, his influence is still being felt with the generation of scientists he sought to influence. One of them was a young doctoral student called Peter Hotez, now one of the leading activist scientists behind the repackaging of NTDs. Hotez was inspired by a 1962 Rockefeller publication at the age of 14 describing Hookworm: "...'The Great Infection of Mankind,' affecting 600 million people, he says. 'I thought, 'How can it be that this is one of the great scourges of humankind and nobody's working on it?'" (Sternberg, 2009). This view was further confirmed during Hotez's college years, with hookworm research being a 'great fit' with the GND program (Hotez, 2014, p. S32). He was inspired by the work of the Rockefeller Foundation on GNDs just as Warren had set out to do with eminent young scientists of his day.

The story of the branding of diseases has been about directing research collaboration and the arrangements that allow research to happen. Such research direction was not deemed possible by chemist and philosopher Michael Polanyi (1962). He saw attempts to guide the progress of scientific enquiry towards public welfare but did not believe science could be controlled in that way to meet social means. However, Warren has shown a direction of science through the re-organization of tropical medicine as a discipline and policy concern. Through his leadership and coming from the Rockefeller Foundation, he had the remit and means to care about the GND diseases, he identified the problem and turned it into a scientific program and network. The main gap he saw was the need to attract talented scientists who would apply advances in scientific understanding and technique. Warren created interest and encouraged biotechnology to be used; by coopting the next generation of scientists, which would form the roots of the next era of tropical disease – except it would be the scientists themselves directing the action. It is perhaps not surprising that this is a specialism that has given birth to 'activist scientist' as the high-profile scientist has been nurtured and revered.<sup>131</sup>

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<sup>131</sup> Cook (2007) calls the focus on individual tropical medicine scientists a domination of 'prima donnas'.

## 6.2 Activist scientists: Careers in an unmodern or modern science

In comparison to what is now a slowly growing public interest in NTDs, during the heyday of tropical medicine public interest was at a high, including in the tropical medicine scientists themselves. As Worboys writes, the "...mosquito-malaria work of Manson's disciple Ronald Ross had found the columns of the daily as well as the medical press" (Lemaine et al., 1976, p. 85). For the scientists during the colonial period, tropical medicine was often associated with a prestigious and exciting career. For the tropical medicine 'father' Manson, after first working as a doctor in a lunatic asylum, his way of seeking advancement was "...in the fashion of the age, through a career overseas" (Lemaine et al., 1976).

This public attention and career prestige would be followed by a wavering of interest post-empire to reach a low point in the 1970s, when the diseases were associated with 'unmodern science'. Tropical diseases only began to see a professional renaissance by the 1980s, a sea change engineered by several protagonists, one of whom was Warren at the GND, researched by his biographer Conrad Keating. Keating reflected on the change in perceptions of a career in tropical medicine and the influence of Warren, when interviewing Nick White the Professor of Tropical Medicine Mahidol Oxford Research Unit:

*"...when he went into tropical medicine in the 1970s as a doctor, it had a very, very low status, and today, certainly in Oxford and I think in London, the brightest and the best want to go into tropical medicine. Now, that is because of the application of science, the cutting edge of science ...at the first meeting of the GND, so he [Kenneth Warren] got these people, young biologists, who'd never hear, didn't know anything about a snail or a vector, you know, they were just people who were in at this new science for some reason, and the two people he got to speak to them in New York were George Nelson, and another great giant of British parasitology, and they were able to infuse these people with incredible stories about, you know, being out in the field in South America, and getting these people sort of interested in tropical diseases"*  
(Interview with author, Keating, 2014).

In 1993, Desowitz, similarly spoke of the promises of a new molecular science with a mixture of loss and trepidation: "(E)xpertise has been lost; the last generation of truly experienced 'field hands' are leaving the scene, lost to age and disuse" (Desowitz, 1993, p. 16). The 'field hands' that he talks about spent their time in endemic countries and appeared to have a more direct link with the communities affected by the diseases. For example, the connection with hygiene and sanitation was more pronounced. As Worboys describes, in the early 20th century the European doctors had very different concerns: "(T)heir knowledge and practice was structured around clinical and hygiene concerns, not with advanced science and technology" (in Bynum & Porter, 2013, p. 522). Desowitz was wary of the new phase of scientific enquiry into tropical

diseases, taking place both in the endemic and donor countries, speaking of a replacement: "...in the West and in the research centers of the tropics by the 'molecular types', more concerned with the exquisite intellectual changes of modish science than with seeking practical solutions" (Desowitz, 1993, p. 16). It is noteworthy how Desowitz related the new science with impracticality. The change that new science brought was the loss of something tacit borne through experience, compounded by the discontinuation of teaching of tropical medicine key competencies. Desowitz goes on to question what biotechnology is promising and whether these promises are overly enthusiastic of the expected benefits.

His view strikes a chord with the sociology of expectations literature, where researchers observe that socio-technical promises arise when a new scientific and technological field is emerging and there is a promise of "social desirability and warnings about its potential negation effects" (Lucivero, 2016, p. 37). Desowitz envisions social desirability in the expectation of a 'quick fix', where:

*"(T)he razzledazzle and promise of biotechnology have led Third World health officials to expect the quick fix—the malaria vaccine 'just around the corner,' the genetically altered mosquito that yesterday's press release proclaims will be the last word in controlling vector-borne diseases; and confusing diagnosis with cure, the DNA probe techniques to detect parasites even at clinically insignificant levels" (Desowitz, 1991, p. 16).*

To Desowitz this promise was illusionary and produced negative effects in the distraction from more useful work: "(T)here is an imbalance, a discontinuity between research and reality. This is an imbalance that has inhibited improvement in the health of tropical peoples; but in addition, I believe it has actually contributed to the deterioration of health" (1991, p. 16-17). These words were written in the 1990s when the transition from the practical 'field hand' to the 'modish' molecular biologist was being made within tropical medicine. The continued promise of biotechnology, in anticipation of a momentous payoff is still in operation today (see Nightingale & Martin, 2004). Approximately 25 years later a malaria vaccine is inching closer still and genetically altered mosquitos have become a reality.

Still, the momentous payoff is viewed with a skeptical eye as more time passes. There is less of a harking back to the old practice of 'field hands' in the bush but a growing emphasis on 'basic science' and the established techniques of testing on natural products. Molyneux and Ward make this point when reflecting on the three 2015 Nobel Prize winners in Physiology or Medicine:

*"No rational drug design was employed and no magic bullets were sought. No synthetic chemistry or targeted design was involved in the initial discovery of the active products. The current mantra from the community is focused on the need for new products emerging from our*

*understanding of the science based on our 'omic' interrogation of these complex parasites and the identification of unique biochemical weak points for intervention. The fact that this approach has largely failed to date is not lost to most in the drug discovery area who can point to the success of ivermectin and artemisinin, drugs delivered through bio-prospection and ancient knowledge of herbal remedies" (Molyneux & Ward, 2015, p. 605)*

Today the recognition of tropical medicine once more through the Nobel Prize winners has been a boost to amplify the position of scientists. Next I profile two activist scientists who have been instrumental in re-ordering the place of tropical diseases, the US scientist Peter Hotez and UK scientist Alan Fenwick. I have already introduced these two actors earlier in the thesis. As discussed in Chapter 4 they originally 'coined' the phrase 'Neglected Tropical Diseases' with the first use of the term in a paper in 2005 (Molyneux, Hotez, & Fenwick, 2005a). They sought to make others aware of the policy focus on Millennium Development Goals (MDGs) in 2000 to malaria, TB and HIV/AIDS and how other endemic diseases were left out of the spotlight. This contrast led to the construction of NTDs as a worthy cause by scientists appealing to policy and what has become a policy movement in the momentum created to promote these diseases.

Therefore, I add activist scientists in addition to the more typical global health actors described already with: Pharma Companies, Research Institutes, NGOs, Universities and Governance Institutions.

<b>Pharma Companies</b>	<b>Research Institutes</b>	<b>NGOs</b>	<b>Universities</b>	<b>Governance Institutions</b>	<b>Activist Scientists</b>
<b>4</b>	<b>21</b>	<b>7</b>	<b>14</b>	<b>4</b>	<b>5</b>
Denmark, Switzerland, Australia (e.g. Novo Nordisk, Novartis, Medicines Australia)	Brazil, China, UK, Norway, Switzerland (e.g. Fiocruz, Shanghai Institute for Parasitic Diseases, NOKC)	Switzerland, Australia (e.g. DNDi, FIND Diagnostics, The End Fund, Policy Cures, Link2China)	UK, China, Brazil (e.g. Tsinghua University, LSHTM, University of São Paulo)	Switzerland, and Sweden (WHO and European Centre for Disease Prevention and Control, UK All-Party Parliamentary Group)	Australia, US, UK (The Synaptic Leap, Cambia, Sabin Vaccine Centre, SCI)

**Table 21 Interviews by organization type**

This activist role for scientists is what I will discuss next with specific examples through Peter Hotez from the US and Alan Fenwick from the UK. Even though they are characterised through their geographic location I also want to emphasize their academic backgrounds, which are similar. In the table below I show how all five of the activist scientists I followed were grounded in parasitology, as such their disease focus is limited to the five MDA treatable helminths,

although difference in their specialisms within parasitology has led to differing courses of action to address NTDs.

	<b>Specialism</b>	<b>NTD</b>	<b>Interventions</b>
<b>Peter Hotez</b>	<ul style="list-style-type: none"> <li>- Molecular biology and Vaccinology</li> <li>- No field experience</li> </ul>	<ul style="list-style-type: none"> <li>- Hookworm (also SARs, schistosomiasis, Chagas, leishmaniasis)</li> </ul>	<ul style="list-style-type: none"> <li>- The Global Network for NTDs</li> <li>- PLOS Neglected Tropical Diseases</li> <li>- US Science envoy</li> </ul>
<b>Alan Fenwick</b>	<ul style="list-style-type: none"> <li>- Parasitology</li> <li>- 35 years in the field (Tanzania, Sudan and Egypt)</li> </ul>	<ul style="list-style-type: none"> <li>- Schistosomiasis</li> </ul>	<ul style="list-style-type: none"> <li>- Schistosomiasis Control Initiative (SCI) at Imperial College London</li> </ul>
<b>David Molyneux</b>	<ul style="list-style-type: none"> <li>- Parasitology and medical entomology<sup>132</sup></li> <li>- Field experience in Africa, Latin America and Middle East)</li> </ul>	<ul style="list-style-type: none"> <li>- Lymphatic filariasis (previously HAT, leishmaniasis)</li> </ul>	<ul style="list-style-type: none"> <li>- Lymphatic Filariasis Support Centre, Liverpool School of Tropical Medicine (LSTM)</li> </ul>

**Table 22 Academic specialisms and interventions of three main activist scientists**

### 6.2.1 United States: Media-friendliness and scientific diplomacy

Hotez is part of the new breed of activist scientist, although I acknowledge that there have been historical precedents and it is a continuation of a trend that has existed before. It is true that there have been cases of individual scientists in the past, who figure-headed campaigns and went on to have deep policy impact. They have desired for their discoveries to be meaningfully recognized and this has required an engagement with policy and politicians, from Albert Sabin for the oral polio vaccine to Richard Doll for the connection between smoking and lung cancer. In fact Hotez quotes Sabin at the beginning of his book on NTDs and is clearly inspired by his message: “(A) scientist who is also a human being cannot rest while knowledge which might reduce suffering rests on the shelf” (Hotez, 2013).

Scientists have been deeply committed to causes such as climate change or anti-war advocacy in the 1960s and 1970s (see: Hart & Victor, 1993; Meyer, 1995). However, in these cases they stand alongside many other interested voices. Arguably in the case of NTDs, activist scientists

<sup>132</sup> Medical entomology is a branch of science that deals with the study of insects (Merriam-Webster online dictionary, n.d.).

do not have this type of multi-stakeholder backing and there has not been the same ownership over the policy debate. The previous cases mentioned of Sabin and Doll, their policy intervention is very defined and specified. They do not consider a whole group of diseases but an intervention concerning one disease. Similarly the figures of tropical disease in the past have also been limited in the individual policy points they tended to make for narrow influence.

Activist scientists like Hotez are deeply engaged in policy, coining and popularizing concepts about NTDs in order to put into policy or journalistic terms the issues they care deeply about. Hotez is a prolific writer and commentator in the media.<sup>133</sup> To give an idea of scale, in 2015 he published 33 articles about NTDs. A large number are in *PLOS Neglected Tropical Diseases* (where he is Editor-in-Chief), many in specialist health journals and three high-profile articles in journals *Science* and the *Lancet*. The breadth of his media publications is wide including mass media venues from the *Lancet* (Hotez et al., 2009); *Huffington Post* (2014a); to *New York Times* (2012b). Examples of more unusual connections between NTDs and other topics includes with the: South China Sea (2016b); 2014 World Cup (2014)' Global Christianity (2014a); and 'The four horsemen of the apocalypse: plague, death, famine and war' (2012).

The varying definitions for NTDs mean Hotez can write about these diseases in terms of defense, foreign policy, diplomacy, security, equality, religion, conflict, economics and the list goes on. Often they have similar messages but presented differently. For example 'vaccine diplomacy', about scientific collaboration for and as a result of diplomatic relations, is a topic he did not invent but has written extensively about.<sup>134</sup> As a US citizen he is particularly interested in the American context, playing on the intersection between global health and foreign policy, which has proved to be fruitful. He has been US Science Envoy since 2014 where he focuses on vaccine science diplomacy and joint vaccine development with countries in the Middle East and North Africa (Pathak, 2014).

Hotez has been a leading force in the US, particularly in galvanizing support in political circles and other realms of influence (including in academia through economist Jeffrey Sachs and celebrity endorsement such as Bollywood star Abhishek Bachchan). He has played a role in building institutions such as the advocacy NGO the 'Global Network for NTDs', establishing the first tropical medicine school in the USA 'The National School of Tropical Medicine' and is director of the Sabin Vaccine Institute, developing vaccines and expanding access to vaccines (and other medicines).

The interest in tropical medicine began at a young age and transitioned into the new science era of molecular biology. It was later in his career that his role has become that of an activist scientist. Hotez does not describe himself in exactly those terms but often refers to being an

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<sup>133</sup> The majority of articles are co-authored (4144 as of 2015).

<sup>134</sup> See Hotez (2008) for an article on Cold War diplomacy leading to the first successful polio vaccine.



advocate (see Regnier, 2012b). I prefer the term activist as I think this conveys agency of wanting to bring about change rather than quietly supporting a cause. When I interviewed him he spoke of this journey to activist in terms of signposts that have already been touched upon in this chapter, with the portrayal of tropical diseases in popular science (the bestselling book 'Microbe Hunters' by Kruif, 1926) and the connection to Rockefeller:

*"Well, I've had a lifelong interest in Neglected Tropical Diseases although they were not originally called that. I've had interest in tropical diseases ever since I was in my adolescence, that's when I knew I wanted to study tropical diseases. I had read Microbe Hunters as a child and that had a big influence and by the time I was 13/14 years old I had a copy of "Tropical Diseases" on my night table. So it's kind of an odd beginning... and then went to the Rockefeller University and Cornell Medical College for their MBPhD program where I began to work on Hookworm infection" (Interview with author, Hotez, 2014).*

There has been a shaping of the tropical medicine discipline through these outlets, the book 'Microbe Hunters' and Rockefeller University. The history of science book *Microbe Hunters* is also referenced by other scientists, including several Nobel Prize winners, as an influence in their decision to study medicine (de Kruif, 2002). The book described as "...one of the most successful pop science books of all time" (Henig, 2002) had a wide reach and appears to be accessible for younger readers. *Microbe Hunters* venerated scientists as heroic adventurers and celebrated the momentous discoveries in tropical disease: sleeping sickness, malaria, and yellow fever. The author Paul de Kruif had been at the Rockefeller Institute. Similarly Hotez had gone onto Rockefeller University<sup>135</sup> and he committed himself to being a laboratory investigator in order to develop vaccines for NTDs and it was only later that he became, as he calls himself a 'global health advocate'. He described to me this change in the following statement:

*"I've had a lifelong interest also in trying to develop vaccines for helminth infections [a subgroup of NTDs] and that actually began when I was MBPhD student. So I very much started in Tropical Medicine as a Laboratory Investigator with no real intention of becoming a global health advocate; that actually happened much later in life" (Interview with author, Hotez, 2014).*

Hotez found that he wanted to build momentum after embarking in a career in infectious disease and tropical medicine. For him the major part of advocating for tropical diseases was the renaming as NTDs: "The phrase was part of a drive to think about these diseases in a fresh light... I think as scientists we are taught not to be advocates... That's something I'm trying to correct" (Regnier, 2012). He similarly described how this policy interest materialized to a *USA Today* journalist: "One evening in 2004, in Geneva, Hotez found himself lamenting the lack of

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<sup>135</sup> The Rockefeller Institute became a university in 1965 (The Rockefeller University, <http://www.rockefeller.edu/about/history>, Accessed 2/4/14).

interest in parasites with Alan Fenwick of the Imperial College in London and David Molyneux of the Liverpool School of Tropical Medicine. Over dinner, they founded the Global Network for Neglected Tropical Diseases to yank these afflictions out of the shadows" (Sternberg, 2009). They all had their areas of specialism within tropical disease but united under a common cause. Molyneux, Hotez, and Fenwick all focus on helminths, also known as parasitic worms and they form the biggest group of NTDs. They may have received more airtime as a result compared with the viruses (e.g., dengue), bacteria (e.g. leprosy), or protozoa (e.g. Chagas).

Again there is some precedence in the type of policy involvement that these scientists have engaged with and other tropical disease scientists did lay the groundwork. One of the big names was Donald Hopkins, former director of all health programs at NGO the Carter Center. When I interviewed a Sandy Cairncross at the London School of Hygiene and Tropical Medicine (LSHTM) he gave this animated account of Hopkins:

*"...he got the idea and campaigned, and as an ex deputy director of the CDC he had enough contacts and influence to be successful. He and his colleagues would attend all relevant meetings of the World Health Assembly and lobbied all the country delegates to vote for eradicating guinea worm... So they did a huge amount of advocacy and published a large number of papers with titles such as 'guinea worm; an eradicable scourge'..."* (Interview with author, Cairncross, 2014).

Therefore, through the guinea worm (dracunculiasis) eradication campaign, the method of publishing in the popular press attention-grabbing headlines had already some precedence in the world of tropical disease. Advocacy went right up to former President Jimmy Carter who had become a strong supporter to eradicate guinea worm. He founded the Carter Center with wife Rosalynn to direct funds to 'advance human rights and alleviate human suffering', with guinea worm as their spearhead campaign (Hills, 2015).<sup>136</sup> However, Philip Coyne a former World Bank medical expert, who partnered with the Guinea Worm programme, notes the difference in how such an NTD is treated today, even with the support brought by Carter:

*"...you know back in the late 90s it was fairly obscure. I mean you know the CDC and the Carter Center laboured in almost total obscurity for years on this disease. And there were a lot of people that thought that it was a waste of time. It was a waste of resources to try and actually eradicate this disease... Jimmy Carter brought in... put the influence and fundraising ability of the Carter Center and now we're this close [to eradication]"* (Interview with author, Philip Coyne, 2016).

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<sup>136</sup> Carter lobbied for guinea worm eradication after encountering an infected patient in Ghana while still president.

This campaign eventually reflected a culture of advocacy that requires high-level political influence. It may be that the lobbying environment of American politics is why Hotez is a man on a crusade, who has made many high-profile connections from presidents to celebrities. By 2008 Hotez would have his own Presidential Initiative for Neglected Tropical Diseases established by Bush and continued by Obama (Hanson, 2008).

In the UK, from the next example is of an activist scientist, Alan Fenwick who created 'The Schistosomiasis Control Initiative' (SCI) as a means to intervene on the ground in endemic countries. The initiative comes out of an academic institution so is an example of a university taking practical means, grounded in academic expertise to address a societal challenge. This engagement is part of the wider social remit of universities, while in the US with the predominance of private universities and trustees there is arguably a less receptive grounding for this type of project.

## 6.2.2 United Kingdom: Change on the ground

Alan Fenwick established the Schistosomiasis Control Initiative (SCI) at Imperial College, London. SCI is unusual as a public health intervention program active in developing countries, because it was established by an academic and based at a university. Another NGO providing NTD funding information that I have noted already – 'Policy Cures' – was established by Mary Moran at the London School of Economics & Political Science, and she later transferred it to the George Institute for International Health in Sydney.

For Fenwick establishing SCI was putting his parasitology expertise into organizational practice. After working in Egypt for 15 years, reducing the prevalence of schistosomiasis until it was no longer a public health issue, he wanted to apply this knowledge in other countries (Regnier, 2012a). However, he faced a roadblock in that schistosomiasis did not require further research but implementation (ibid.). Therefore, to best deal with this disease did not require new innovation arrangements but a convincing of funders that knowledge application was important in implementation and not only at the R&D stage.

As he put it: "Many organisations are interested in supporting research... but this left schistosomiasis and others in limbo: most of the research had been done. We had the tools which, if implemented properly, could help some 200 million people in sub-Saharan Africa" (Regnier, 2012a). The emphasis on R&D was having a harmful effect in this instance. To relate this situation to another NTD, guinea worm, it has been noted previously that this disease is close to being eradicated without the need for drugs, vaccines, or other biomedical interventions (Michele Barry, 2007). This is quite a remarkable feat: through health education<sup>137</sup> and

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<sup>137</sup> Health education was principally to learn to filter drinking water contaminated with water fleas infected with larvae of the guinea worm.

surveillance a disease can be defeated and goes against the biomedical model of disease treatment. This solution clearly is not possible for many other diseases, including other NTDs but is starkly demonstrative that the biomedical solution is not the only one.

Returning to schistosomiasis, new organizational arrangements were required through SCI. In 2002 Fenwick received funding from the Bill & Melinda Gates Foundation to buy and distribute praziquantel<sup>138</sup> (an effective schistosomiasis drug treatment) to endemic African countries (Regnier, 2012a). By introducing national control programmes Fenwick wanted to test a proof of principle: "Will these countries implement control if given access to drugs and funding?" (Regnier, 2012b). SCI has proved to be a success, to treat both schistosomiasis and soil-transmitted helminths. At least from the point of view of charity evaluator 'GiveWell', which ranks it as one of the top charities to donate to, mainly because of the 'cost-effectiveness' of the interventions and need for funding.<sup>139</sup> Chapter 7 will address discourses about the effectiveness of de-worming and measuring policy problems through organizations such as GiveWell.

Regnier from the Wellcome Trust asked Fenwick in 2012, how he felt that it has been, "...left largely to scientists to get programmes such as the SCI off the ground?", his answer: "I've never even thought about it... It's invigorating. I passionately believe in treating schistosomiasis... it will be impossible to achieve any of the Millennium Development Goals without tackling NTDs" (2012b). This feeling was similar for Hotez, with his focus has been on soil-transmitted helminths and vaccines. Both Hotez and Fenwick have had a prominent role to play in raising the profile of NTDs and have framed the approach to tackle NTDs.

When scientists enter the political arena there may be resistance to the adoption of a role viewed to be outside of their remit, going against an image of neutrality and objectivity. There is also a perception that scientists do not want to take responsibility for social problems and embark on a political role but this is clearly not the case with NTDs. Some have viewed this type of activism as quasi-religious in character, with one interviewee describing Hotez and Fenwick as 'evangelicals' with a 'missionary spirit' (Interview with author, scientist at LSHTM, 2014). This description not only conveys their commitment but an unfaltering single-mindedness of following a mission.

My argument is that that undertones of religiosity are why it can be claimed by some, including Parker and Allen, that NTD advocacy and interventions are undertaken with over-promise and optimism, without fully considering negative aspects of campaigns or non-technical causes of neglect. There is a moral basis for why NTDs may be pursued single-mindedly, and this is

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<sup>138</sup> The investment of the Gates Foundation into SCI goes against some accusations of the foundation that it is uninterested in implementation, although the framing as a 'proof of concept' project is likely to have helped (Lancet, 2009).

<sup>139</sup> GiveWell, [www.givewell.org/about](http://www.givewell.org/about), Accessed 2/4/14.

more than the charge of a lack of social science critique for NTDs. Keating also talked about “that religious thing” in considering the motivations of tropical disease scientists, based on a moral reasoning: “These people are altruistic-minded. I mean, the idea of medicine is healing, you know, of healing people but there is, there are these things you see in the tropical group, that maybe are not apparent as in another. You need that personal connection to care about somewhere far away from you that you don’t get reminded every day” (Interview with author, Keating, 2014).

Religion and moral duty certainly has played an intermittent role in the motivations and vision for tropical diseases. In the early days of Rockefeller, scientists motivated by 'religious-moral impulses' were pivotal in the establishment of the Rockefeller Foundation and driving the quest for a malaria cure (Desowitz, 1997, p.171). Similarly feelings of a religious nature in making momentous discoveries for mankind have been noted by tropical medicine scientists, such as Ross speaking with Manson about his malaria experiments: "I have a sort of feeling it will succeed – I feel a kind of religious excitement over it!" (Kruif, 2002, p. 280).<sup>140</sup> In my interviews with NTD scientists a religious rhetoric was not particularly present but belief, commitment and moral impulse were repeated themes:

*"...after my medical studies, I did not follow a regular MD career. After ten years as Professor at the University of Brasilia, I went to Rio de Janeiro invited as a researcher of the Oswaldo Cruz Foundation (Fiocruz) a 116-year-old institution affiliated to the Ministry of Health of Brazil. Fiocruz was created to fight endemic diseases that in the beginning of the 20th century were harming the economic development of the country. I wanted to do good science while at the same time addressing the needs of the poor"* (Interview with author, Carlos Morel, 2014).

*"I was brought up into the 1960s when there was a tremendous amount of idealism to do something useful I suppose"* (Interview with author, Simon Croft, 2014).

*"I just do what I think is right, I'm not on the bench doing basic science... I see myself as an ideas person... I think people publish things and nothing happens even though it's self-evident so I feel quite strongly about this. I just do what I think is right and if people want to buy into it that's fine"* (First interview with author, David Molyneux, 2016).

Even for those scientists not on the high-profile NTD circuit, many are called to advocacy. Advocates rather than activists may be less visible in the pursuit of change but will take an issue and work towards addressing it. David Warrell, Professor of Tropical Medicine and Infectious

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<sup>140</sup> Religious connotations can also be found in stories of scientific discovery concerning tropical diseases involving a lot of fumbling around in the dark without any obvious leads. It needed an almost religious dedication, belief and faith that a breakthrough would come and a commitment to the worthiness of the cause.

Diseases at the University of Oxford, has been a leading figure in tropical medicine, while not so much in the media spotlight and in policy circles. Still in answering the question of "what is your ambition in life?" after a well established career his response was to ultimately have an impact on disease burden: "To improve the treatment and prevention of forgotten and unfashionable diseases like snake bite and rabies. They have too few champions and sponsors" (in Shakur, 2005).

The chapter so far has considered how activist scientists introduced a new disease brand, with an early basis for this brand being in the GND program. I then argue how the GND program paved the way for the type of activist scientist, shown through a profile of Hotez and Fenwick, that I see as being eventually behind the creation and promotion of NTDs. The GND therefore had a lasting impact in attracting young scientists to tropical medicine and to apply cutting edge science. In the next section I will explore how pharma company scientists, in site not typically associated with advocacy, have been engaged in activism for NTDs.

### **6.2.3 Pharma company scientists: Pushing for drug donation**

To a degree, one precursor to the activist role for NTDs can be seen in the pharma company scientists (including the CEO) who pushed for ivermectin to be developed for use in humans and then to be donated free and indefinitely in 1987. As I have touched upon in Chapters 4 and 5, ivermectin is a drug to treat river blindness (or onchocerciasis) and was the first NTD drug donation program, opening the door for many others. Collins stresses the part that they played: "...pharmaceutical company employees were often vilified as the industry came under fire for its astronomical profit margins and the rising costs of pharmaceuticals, these employees, like many of us, saw themselves as moral agents working within an ethical framework" (Collins, 2004, pp. 104-5). The 'ethical' work of pharma companies is also a part of the 2015 Nobel Prize in Physiology or Medicine awarded to William C. Campbell and Satoshi Ōmura, that has not been well publicized – the involvement of Merck (and the WHO).

Campbell was employed by the American pharmaceutical company Merck, from 1957 at their Institute for Therapeutic Research, and later from 1984-1990 as Senior Scientist and Director for Assay Research and Development. It was Ōmura's isolated and cultured strains of soil sample streptomycetes (that he had obtained near a Japanese golf course) that Campbell found a component effective against parasites in domestic and farm animals and purified that bioactive agent. The collaboration between Campbell and Ōmura was part of, "a novel international Public Sector–Private Sector partnership" in the 1970s between Antibiotics Research Group at Tokyo's Kitasato Institute, and Merck, Sharp and Dohme (MSD) based in the US (Crump & Ōmura, 2011).

Ivermectin<sup>141</sup> was developed by Merck in 1987 (marketed as Mectizan) (Gill, 2012) and had become a 'blockbuster drug'<sup>142</sup> to treat animals for helminth infections, within two years generating annual sales of over \$1 billion, "...a status maintained for two decades" (Crump, 2014). Once potential was found for humans and the company embarked on a joint research programme with the WHO (Collins, 2004). Merck went on to engage in a number of partnerships for distribution, including enlisting the help of former president Jimmy Carter to act as marketer to high level officials in endemic countries (Saporta, 2012). Such activities targeting an NTD had been isolated until then.

When Merck decided the drug would be produced for free and made available for patients as long as it was required, this was an almost unprecedented undertaking. They had first pursued pricing the drug commercially before seeing this would not work for poor patients and had, "...turned to national and international organizations — such as the WHO, the U.S. Agency for International Development, the U.S. Department of State, European and African governments, and private foundations — but to no avail" (Collins, 2004). The senior management at Merck, particularly CEO Roy Vagelos, had been supportive throughout and the scientists involved were the ones who suggested the possibility of drug donation (ibid.). Some make light of the fact that Vagelos was originally a university researcher, although it is not uncommon for pharma researchers to have previously worked in academia and may rather be attributed to the values held by Merck as an organization:

*"Abandoning the drug was unattractive both in terms of health benefits denied to suffering people in Africa, and in terms of characteristics of Merck and its situation: its corporate culture, its already-existing donation programs, and also its image now that many knew of the existence of this breakthrough..."* (Coyne and Berk, 2001, p. 10-11).

Therefore, the pushing of the scientists and how Merck envisioned itself through its corporate culture led to the "largest on-going medical donation program in history" treating more than 60 million people annually (Merck Website). Also lymphatic filariasis, another NTD, is now being treated by ivermectin. Now the Merck donation success story is used as a case study in business schools of an 'ethical dilemma' for companies, in developing or distributing a drug for the poor, at cost to the company, while wanting to demonstrate social responsibility. The donation did not begin as a dedicated research project but since then other pharma companies have followed suit with their own drug donation programs for NTDs. Many of these programs similarly began as offshoots from commercial drugs for another disease or after no commercially viable market had been found (Coyne and Berk, 2001).

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<sup>141</sup> The bioactive agent of ivermectin was called avermectin and the subsequent chemically modified to produce the more effective compound.

<sup>142</sup> Blockbuster drugs are "...medicines that bring in more than \$1 billion in sales every year" (Lorenzetti, 2016)

## 6.2.4 Scientists adopting alternative approaches

In comparison to the scientists who have been trying to raise the profile of NTDs, either through policy engagement or through their organizations, there are others who have been attempting to adopt alternative innovation frameworks. For these scientists the problem of NTDs lies in the scientific and innovation system itself.

Why these NTDs are neglected has commonly been pointed to the fault of the market and the private sector, while the public sector and third sector (charities, NGO, international organizations) are not placed to address such problems. Two prominent examples that I identified of scientists to be pursuing new innovation arrangements to challenge a pharmaceutical model of dealing with NTDs can be found in Australia. I interviewed Richard Jefferson who set up the NGO 'Cambia' and Matt Todd at the University of Sydney who is behind the initiative 'The Synaptic Leap'. Their interest instead is in how innovation might be arranged differently through open approaches to innovation. I found that their work inhabits a more experimental space, which has seen a less wide-reaching impact on NTDs.

## 6.2.5 Australia: Alternative innovation frameworks

Todd is a scientist working in the Chemistry department at the University of Sydney and is concerned with how open source innovation can assist in drug development. As Christine Årdal and John-Arne Røttingen document (2012), there has been a great deal of theoretical discussion and a number of initial projects based on this idea. Open source for drug discovery is a concept that “borrows two principal aspects from open source computing (i.e., collaboration and open access) and applies them to pharmaceutical innovation” (Årdal & Røttingen, 2012).

Todd originally became interested in the NTD schistosomiasis as a post-doctoral researcher, drawn to molecules that are difficult to make and which hold practical applications. The appeal of the open source philosophy came later: “it mimics the software development term... the aim is clear that the way to gain benefit is to share everything” (Interview with author, Todd, 2013). For Todd it is a way to share research in a complete state so that others can then take it and make changes that they see fit. Based on this rationale, he began a project known as 'The Synaptic Leap' in 2006.

The Synaptic Leap originally consisted of a group of online research communities for malaria, schistosomiasis, toxoplasma and TB. A lab notebook was made visible in the public domain mimicking open source in software development. The project on schistosomiasis was completed in 2011, resulting in improvements to the production of the most common drug used to treat the disease Praziquantel, and this work was published in peer-reviewed journals. While



this project did yield some results, it is still unusual for entrepreneurial practices, particularly those adopting 'open source' approaches in academia.

Other scientists have also taken on a larger entrepreneurial role to establish their own NGOs. Richard Jefferson founded Cambia in 1992. It is now ranked as one of the world's top NGOs (The Global Journal, 2013) and has been receptive to adopting open approaches to innovation. Cambia was the brainchild of Jefferson. A molecular biologist by training, he was critical of multinationals such as Monsanto for controlling critical technologies through patents and access to capital. For him the blockbuster mentality and rent-seeking model in biotechnology has not been working and inhibits innovation: "In that model, you invent a new process, find a drug target, or discover a new gene, then wrap it up in intellectual property protection and try to sell it to the highest bidder. That bidder then has to try to assemble the puzzle into something actually useful. It's a slow, expensive, and cumbersome process" (Interview with author, Jefferson, 2013). As an alternative to this model he has sought to create accessible tools and technologies that enable equitable innovation.

Openness for Jefferson is to create the infrastructure to make innovation equitable and transparent by allowing people to see and align self-interests between disparate groups. In tackling NTDs his NGO Cambia provides 'The Lens' as a tool to search for patents. He explained that there is not a direct initiative for NTDs because the focus is on "making it possible for people to be active in problems and their own solution-set" (Interview with author, Jefferson, 2013). Therefore, he wants to keep the possibilities of using the tool open. Cambia has given a stage to science matters where ownership is of crucial importance, such as plant gene and genome intellectual properties (Jefferson, Köllhofer, Ehrich, & Jefferson, 2015). However, it appears harder to see relevance in open innovation approaches applied to NTDs.

On balance, my argument is that the need for openness to tackle NTDs, while being one strategy to direct research and funding efforts, is not a good match for how the policy problem is understood. This thesis has intended to look beyond the obvious and intuitive idea that neglect of NTDs is mainly on a pharmaceutical basis, due to lack of R&D, and move towards a more encompassing view of neglect. In addition, the emphasis on pharmaceutical responsibility does tend to get confused with treating NTDs as 'for-profit' diseases (e.g. HIV/AIDS which has patients in both the developed and developing world) where there is an issue with access from developing world because of intellectual property rights protecting for-profit research efforts. NTDs are generally not-for-profit diseases and so while open approaches have been novel, and may encourage collaborative working (mainly because it is in their remit), there are not any particular openness barriers that need dismantling. Thus open approaches to innovation do not appear to be addressing a multi-faceted understanding of neglect in the case of NTDs.

Mary Moran outlines this line of argumentation in her critique of WHO pilot projects, which began in 2014 to fund research for NTDs. Her claims are laid out in the provocatively titled *Nature* article: 'WHO plans for neglected diseases are wrong' (Moran, 2014). When I interviewed her she summed up her paper: "Well, basically I'd say, look, I understand that there's problems with accessing commercial and intellectual property, but we don't have that problem in neglected diseases and the solutions you're proposing for neglected diseases don't fit here" (Interview with author, Moran, 2014). Indeed pharma companies when launching open innovation projects give more of the impression of PR exercises, as opposed to the tried-and-tested drug donation model that has been working for some time with NTDs.

### 6.3 Activists by another name? Scientists in China and Brazil

In contrast to the activist scientists in the UK and US I want to gain insight from the scientists in emerging economies and how they are engaged in policy, through the institutions they are based at and through a public reception to scientific discovery. The status of a scientific discovery serves to acknowledge the research prestige of a country, as does the reputation of national institutions. Both Brazil and China had important discoveries in tropical diseases in the 20th Century and have undergone institution building to an extent rivaling the traditional colonial tropical medicine schools. It is in this context that I want to ask what the relationship of scientists in endemic countries has been with the NTD policy movement. As discussed already there are similar descriptions of social movements or groupings and their interactions with policy and research (e.g. 'political opportunity structures', 'advocacy coalition framework' and 'scientific and intellectual movements or 'SIMs'). Haas provides the epistemic community definition, which comes close to the idea of a policy movement but does not completely capture the mode activism and goal of social change: "An epistemic community is a network of professionals with recognized expertise and competence in a particular domain and a policy-relevant knowledge within that domain or issue-area" (Haas, 1992, p. 3). This description is certainly pertinent to the activist scientists, WHO, NGOs and pharma companies that have coalesced under the NTD domain. However, a policy movement conveys what actors do with their expertise and competence.

I argue that scientists in Brazil and China are working on NTDs create their own distinct epistemic community, facing a different environment with their own challenges and concerns. I will explore the differing vision employed to tackle NTDs in Brazil and China, focusing on the differing histories and socio-cultural values at play. For a policy movement to bring attention to NTDs activist scientists have been central but the rationale for intervention and means of justification in country context looks markedly different. Initially it may appear that there lacks a prominent role of activist scientists in emerging economies, however this is not a full picture, especially when taking into account research histories of disease. Activist scientists are part of the attempt to 'globalize' NTDs, alongside the WHO, Gates Foundation and other key stakeholders.

Putting NTDs on the global agenda, the idea has been to 'scale up' efforts to a similar level of policy addressing the 'big three'. At a national level there is another set of competing diseases, political interests, as well as research and innovation priorities. Scientists within the nationalist discourse and their role within a nationalist project form a type of techno-nationalism (described by Edgerton, 2007), where a country's science and technology comes to represent a part of its national identity. As with postcolonial critiques I will draw out some of the 'other' voices that

have been absent and marginalized, dominated by the stories of tropical medicine 'greats' and address the role of scientists in emerging countries in the next section.

### **6.3.1 Endemic countries in a globalized NTD policy**

To fully address questions of technology, science, and national identity in Brazil and China would be a vast undertaking, so my aims are narrower, drawing upon fieldwork interviews in Brazil and China. I reflect upon how NTD policy is positioned from the outside, the characterization of emerging economies with a growing innovation capacity, and the endemic country responses. Adams, Gurney, and Pendlebury have highlighted the growth and impact of research from Brazil and other emerging economies: "This establishes a new geography for NTD research with much benefit to affected populations" (Adams et al., 2012, p. 3). Today NTDs form a significant research topic and base of knowledge for developing and emergent economies "because of obvious economic and social relevance... with a substantial volume of NTD papers in its portfolio" (ibid, p. 5).

We see both in Brazil and China that diseases neglected on global level relate to some countries and not to others. This universalist treatment is a danger in having one umbrella category for disease and of course the next question to ask is whose 'universal' is it? For example, Chagas has been a major concern in Brazil and schistosomiasis in China. As Yang et al note: "Although schistosomiasis is neglected at the global level, this problem is not the situation in China. Political will, coupled with financial, human, and technical resources, has successfully controlled schistosomiasis in most parts of the country" (2014, p. 884). On the other hand, Chagas is only endemic in Latin America. There is also the re-emergence of dengue in both countries. It was repeatedly mentioned in my interviews in Brazil that São Paulo used to be free of dengue. In recent years there have been many cases even in the richest areas, therefore the disease profile in the country is changing.

Other diseases that affect the middle and upper classes, as well as growing populations, mean that NTDs face competition with non-communicable diseases (NCDs). Yang et al argue, "(N)on-communicable diseases dominate the public health arena in China" (2014, p. 881). Here neglect is sometimes characterized as a competition between the new diseases of the wealthy and the old diseases of the poor (Singh & Singh, 2008). Others try to find connections between co-morbidities or in how greater numbers of poorer groups are affected by NCDs (Mehta et al., 2016; Sridhar et al., 2013). NTDs become less frequent in urban areas, meaning some medical schools no longer teach tropical disease pathology. One scientist in Shanghai described how the doctors are concentrating on non-communicable diseases: "They concentrate on heart disease and diabetes" (Interview with author, Senior Researcher at Institute for Parasitic Disease, 2013). Emerging economies such as Brazil and China face their own unique challenges in dealing with NTDs, not only from the perspective of the specific diseases that are

most prevalent but social and demographic changes. Next I look closer at the individual countries.

### 6.3.2 Collectivist science in China

High-profile scientists have not dominated the field of tropical medicine in China. Even for those who have been credited by the international community, the reception has been downplayed to some extent within China. The aspiration for science to be a means to national salvation has been well documented (Cao, 2004; Wang, 2002) but the view of the scientist has been more conflictual, tied for instance to political allegiances. This view is related to how the scientist is positioned within the national consciousness and a radically changing political climate for science. The emphasis of science is on collective effort, and the perception of scientists is still connected with (a not particularly positive view of) elites. Consequently, scientists have not played as active a role in policy and politics as seen in the UK, US and Australia.

Collectively, the National Science Institute in China that conducts basic and applied research 'Chinese Academy of Sciences' (CAS) is the main source of institutional prestige and clout. There are few occurrences of scientist involvement in policy and one of the strongest examples now dates back to 1986. A letter from four leading scientists to former Chinese leader Deng Xiaoping set out a proposal to fund high-tech R&D (Gang & Tan, 2009). The letter resulted in the establishment of the National High Technology Development Program.<sup>143</sup> Afterwards a committee of 200 scientists set the initial strategy for basic science and applied technology.

Surveys of public perception of scientist involvement in politics give some indication of why scientist may not take policy-orientated roles. A *Scientific American* survey in 2010 showed that "almost one-third of scientifically literate Chinese people say that scientists should not get involved in politics, compared with around 10% of respondents in most of the rest of the world" (Cyranoski, 2010). We cannot read too much into such a finding and the accompanying *Nature* article also noted that the small sample size in China compared to the US and Europe (ibid.).<sup>144</sup> It does point towards a more uneasy relationship between scientists and politics but one that is still very much open to interpretation. Wu Yishan, a chief engineer at the Institute of Scientific and Technical Information of China in Beijing "...suggests that the negative connotation of 'politics' in China, deriving from a 'politics first' movement during the communist Cultural Revolution that was used as an excuse for various abuses, might be to blame: it is not that scientists have nothing to contribute, but that politics itself is tainted" (ibid, p. 389).

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<sup>143</sup> '863 Program' related to the date of the letter, March 1986.

<sup>144</sup> "Far from being rigorous, the survey sampled countries unevenly, with thousands of respondents in the United States and several European countries, 1,195 in Japan and just 269 in China" (ibid.).

An example of the tumultuous past for the treatment of scientists during the Cultural Revolution can be seen through scientist T'ang Fei-fan. In 1957 the isolation of elusive agent for the NTDs trachoma was discovered but as with artemisinin had not been known outside of China. UK scientists had been simultaneously working to pinpoint this agent until an article by T'ang Fei-fan et al (from Tong Ren Hospital in Beijing) in a Chinese Medical journal explaining the discovery, was stumbled upon by scientists (at the Lister Institute) (Cox, 1996; Taylor, 2008). What followed was an expansion in research on trachoma, however around the time of China's Cultural Revolution (1966 – 1976) scientists were unpopular. In the lead up there had been infamous communist purges of 'disloyal' subjects in the 'Hundred Flowers' campaign of 1956 when citizens were invited to express their views of the communist regime (Lu, 1969). This period was followed by the 'Anti-rightist' campaign in 1957, a crackdown of those critical of the regime and ideology. There are differing accounts of Tang's death in 1956, after 30 years of work in parasitology and only a year after isolating the trachoma virus, either it was by suicide after being labeled a 'rightist' or murder.<sup>145</sup>

In celebrating Tang in an article, Cheng et al. (2011) recount how the renowned British scientist and Sinologist Joseph Needham said of Tang in a 1979 letter to the then director of the National Vaccine & Serum Institute of China: "Dr. Feifan Tang (F. F. Tang) was indeed 'a friend to man' as our old English eighteenth-century phrase has it; he loved the Chinese people and was a doughty fighter in the fundamental field of preventive medicine. With all friends here, I salute his memory and I am sure he will never be forgotten in China." The authors also note how he may have been overlooked until more recently:

*"His research might have been continued for greater achievements if he had not been appointed to study vaccines of measles and poliomyelitis. Even so, he was still being questioned and judged. In 1958, he gave up his life to protect his integrity and dignity. Until 23 years later when Dr. F. F. Tang was awarded the gold medal by the International Organization against Trachoma, his great contribution became [sic] to be treasured. In 1992, the Chinese government issued a postage stamp in his honor. A bronze statue of Dr. F. F. Tang stands in front of the National Vaccine & Serum Institute, Beijing. It is a great pity that the trachoma study was discontinued in China for a while. Today, when we are in the new era of innovation, the lessons from our predecessors should never be forgotten."* (Cheng et al 2011, p. 350).

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<sup>145</sup> More information about Tang can be found in the archives of the Carnegie Council, where a writer in 1983 describes the contents of 'China Daily', which was the People's Republic of China (at the time) two-year-old English-language newspaper: "Page five is the Culture page, which, in the rhetoric of the New China, includes Technology, Science, and Medicine. One issue tells a chilling story about Tang Feifan (the Western version of his name, 'F. F. Tang', is given in a picture caption), who attained international renown as the isolator of the virus that causes trachoma. The article ends: 'In 1958 Tang was unjustly accused of being 'reactionary.' On September 30, he committed suicide. His only son, Tang Shengwen, now works in the institute where his father devoted his life to research" (Hazard, 2009).

The science-politics tensions were obvious during this period but also the 1950s through to the 1960s had been a peak time for NTD research in China. Successes included public health control measures against hookworm through the Hookworm Commission, leprosy with a nationwide leprosy programme and then schistosomiasis, in an unusual campaign that saw peasants using sticks to remove parasite carrying worms from riverbanks (F. E. G. (ed.). Cox, 1996).

It remained difficult to separate science and politics and a prominent example of the blurring of science and politics goes back to the 1960s. Artemisinin, which has become a key antimalarial, had been discovered and isolated in leaves of herb *Artemisia annua*. Despite this momentous discovery, artemisinin was kept a secret from outside. The drug was part of a large-scale secret government 'Project 523': "involving over 500 scientists in ~60 different laboratories and institutes" (Miller & Su, 2011, p. 855). The project combined western and indigenous knowledge enquiry to, "...research and develop new drugs the Western way, screen traditional medicine and folk remedies to search for a Chinese therapy, and find ways to prevent malaria infection in the first place" (Hao, 2011). The program had been to treat soldiers in the Vietnam War at the request of the North Vietnamese leaders, so due to the military intentions it was shrouded in secrecy and also because "during the tumult of the Cultural Revolution, publication in scientific journals was forbidden" (Miller & Su, 2011, p. 855). By 1977 the work of the group was published, albeit anonymously. Secrecy continued until the Chinese economic reforms in the early 1980s, with the WHO only giving endorsement in 2000 and artemisinin was still not widely available until as late as 2006 (ibid.).

These accounts paint communist China in not the most favourable light as a time of secrecy and isolation. However, a 2005 *BBC* documentary 'Malaria Defeating the Curse' (Horizon) provides a more even handed portrayal where the political climate involving China, the US, and the WHO all contribute to why artemisinin was held back. The point is made that it was not an ordinary scientific project. The research was driven by politics – to directly assist the Vietnam war effort but also ideologically in the encouragement by Chairman Mao to explore traditional Chinese medicine, rather than relying exclusively on western science. The protagonist in the story is Prof Ying Li from the Chinese Academy of Sciences (Shanghai Institute of Materia Medica) who commented:

*"The foreigners seemed to be snooping. They were so arrogant and contemptuous. They were astonished that we Chinese had managed to achieve this amazing breakthrough when they had spent so much time and effort on it and failed"* ('Malaria Defeating the Curse' documentary, Horizon).

There may have been just reason for suspicion as the US military were on the WHO steering committee for anti-malarial drug development, as the military has had a long history in anti-malarial drug development (ibid). On the part of the western scientists the element of disbelief may have partly been grounded in the uncertainty of accurate information coming out of China, including previously exaggerated claims about eradicating schistosomiasis and curing malaria with acupuncture (ibid.). Even though, NTDs were certainly a priority and 'The National Institute of Parasitic Diseases' was established in this heyday. Established in 1951, it is one of the few institutes in China dedicated to NTDs as part of the China's Center for Disease Control and Prevention (CDC) network, the leading public health agency.

Another aspect of secrecy has been that individual scientists were not well recognized. In later years more attention has been given to individual actors on the international stage. Attribution has recently gone to scientist Tu Youyou for the discovery of artemisinin.<sup>146</sup> Tu was head of the research group at the Institute of Chinese Materia Medica for Project 523<sup>147</sup> and part of a national project against malaria. She received international recognition after being awarded the 'Lasker prize' in 2011 a prestigious medical award and was the first Chinese person to win the Nobel Prize in Physiology or Medicine in 2015. She had not been well known within China, with the Chinese newspaper Wen Wei Po remarking how she had been nearly completely forgotten until 2011. Even Youyou herself has remarked modestly and with nationalist sentiment on receiving the Lasker prize: "(I)t is scientists' responsibility to continue fighting for the healthcare of all humans... What I have done is what I should have done in return for the education provided by my country" (McKenna, 2011).

However, despite the publicity of recent years, it does appear that government interest in NTDs has waned. The scientists see underfunding as a major inhibitor to their work, as described when I visited the institute: "we have good drugs but not money to introduce into the market... we should be supported by government or international governance" (Interview with author, Research director at Institute for Parasitic Diseases, 2013). At the institute, despite having invested in more than 20 drug products in last 20 years, few are used in the field and the scientists are frustrated they are 'just sitting there' (Interview with author, Senior Researcher at Institute for Parasitic Diseases, 2013).

This is not to say China has not had more recent successes against NTDs. As Prof. Xiao-Nong Zhou, a senior scientist at the Institute notes in China "NTDs are one of the most prevalent infectious diseases, with more than 100 pathogens recorded to infect humans" but this situation is changing: "(D)ue to great efforts by government leadership, professional guidance and

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<sup>146</sup> Forgotten also were contemporary artemisinin researchers - Yu Yagang and Zhong Yurong. Researchers at Beijing university call for the "roles of others need to be further studied and established" (Hao, 2011).

<sup>147</sup> Some numbers are believed to be auspicious in Chinese tradition (0,2,3,5,6,7,8,9) – the same reason why the National High Technology Development Program contained these numbers.



community involvement, NTDs have declined significantly with the increase in economic development in China” (2013). For example, in 2007 lymphatic filariasis was eliminated in China. However, now these diseases compete with the diseases of the middle and upper class, who are more heavily located in urban areas down the eastern coastal side of the country spanning from Beijing to Shanghai (see Hotez & Ehrenberg, 2010). The rapid changes in the country pose new health risks and obligations.

To summarize, the confrontation of NTDs in China has followed a specific path affected by a changing political environment, as well economic transformation in the country. From secrecy during the time of Chairman Mao, to scientific recognition, and new health challenges, China has faced the NTD problem within a context of multiple concerns and influences. The renaming and higher profile of NTDs has provided an opportunity to reflect on successes but as the China example has shown, individual country priorities will persist over global health prioritization. In Brazil we can a similarly distinct interweaving of approaches to NTDs reflecting the country's historical circumstance, political events, and socio-cultural understandings of disease – particularly defined here through nation-building as a former Portuguese colony.

### **6.3.3 Nationalist sentiments in Brazil**

Tropical medicine in Brazil has been deeply seated in nationalism, personified through the pioneering Brazilian doctors Oswaldo Cruz and Carlos Chagas. They were two giants of public health in Brazil and in pursuit of NTD control and elimination. Cruz had previously been director general of public health in Brazil, which saw him introduce three successful sanitation campaigns against yellow fever, followed by a smallpox vaccination campaign in 1904. He was recognized by the international scientific community in 1907, at the 14th International Congress on Hygiene and Demography in Berlin, with the gold medal in recognition of the sanitation of Rio de Janeiro. As Carlos Morel, Director of the Center for Technological Development in Health at Fiocruz, points out:

*"...by propagating the role that science should play in the development of Brazil, Oswaldo Cruz managed to conquer and receive support from the highest political level [President Rodrigues Alves]; being nominated Director of the Federal Department of Public Health, he could efficiently fight the diseases that were devastating Brazil's economy, particularly yellow fever and plague"* (Morel, 1999, p. 4).

Cruz went on to be the founder and director of the Oswaldo Cruz Foundation or Fiocruz, a public health institution, established in 1900 (Fiocruz, <http://portal.fiocruz.br/en>, Accessed 2/4/14). He was able to attract collaboration from scientists of developed countries, particularly from Germany, who came to work in the institute (Morel, 1999, p. 4). Moreover this collaboration has been a lasting connection, in the visiting fellow program and 'high level

scientist' program there are many from the USA followed by Germany and then a large selection of countries (Interview with author, Morel, 2014).

Chagas took over the directorship of Fiocruz following Cruz's early death at 45. It was Chagas, with guidance from Cruz, who discovered the parasite that caused American trypanosomiasis, later named Chagas disease. Morel highlights the deep significance of the discovery for Brazil on the world stage: "How could one of the major medical discoveries happen in a poor country in the tropics, be published on the first volume of a local institutional journal and yet receive world-wide recognition and be one of the seeds of a whole school of thought and research which still today has such a profound influence in Latin American science?" (Morel, 1999, p. 3).

The discovery is highlighted by Kro and Sà as a: "...symbolically significant event that represented the scientific project that Oswaldo Cruz sought to establish at Instituto de Manguinhos<sup>148</sup>... it was acclaimed as a symbol of Brazilian scientific capability" (2009, p. 14). Chagas disease was also a symbol of the poor and vulnerable in the country being left behind. Chagas spoke of the scourge of disease that would bear his name, in relation to large sections of the population being, "unable to participate in the progressive evolution of the country" and the news reporting picked up on this theme with headlines such as: "Brazil witnesses a step forward for mankind and a step backward in the brutal reality, which the authorities need to address without delay" (ibid.).<sup>149</sup>

Chagas has enjoyed hero-status since, a 'mythification' connected to the, "...status and significance that the discovery and study of new disease played in the institutionalization of Brazilian medicine and science" (ibid, p. 24). Although his status was not without contention, with doubts about the authorship of the discovery that some thought should have been attributed to Cruz, as the one who conducted the experiment (the findings of the Brazilian Academy later disproved this) (ibid., p. 26). His critics further argued against him on ideological grounds, saying that his idea of a 'diseased country' was exaggerated and pessimistic and would discredit Brazil abroad (ibid). Some scholars have argued that critique of Chagas prevented him from receiving a Nobel Prize (Kropf & Sá, 2009).

The interplay between science and nationalist ideas has meant that political events have deeply impacted scientists at Fiocruz. During the military dictatorial regime (1964 – 1985) the country was thrown into upheaval and in 1970 was the so-called "Massacre of Manguinhos", when "renowned researchers from the Institute lost their political rights and were forced into

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<sup>148</sup> The site of Fiocruz is on an old farm of 'Manguinhos'.

<sup>149</sup> The announcement of Chagas' discovery was held at the Academia Nacional de Medicina, electric lighting was used for the first time, "...a symbol of the Belle Époque prevailing in the recently refurbished capital" and disturbing footage of mostly children with neurological disorders, and the 'barbeiro' bug culprits to present an, "...antithesis of 'civilization' – in the center of medicine and capital of the country", with microscopes to see the new parasite (ibid, p. 25).

retirement" (ibid). The instability intensified in the 1980s, as the Director of Brazil's Center for Global Health at Fiocruz, Paulo Buss described how the 'intertwining' between medicine and politics became 'more pronounced' finding a role 'in the fight for democracy': "Our slogan was that Health is Democracy and Democracy is Health... We organised a lot of meetings, putting together postgraduate courses in public health, civil society organisations, and so on. We felt it was very important to agree a construct of health as a right" (Pincock, 2011, p. 1738).

Many within Fiocruz see the inclusion of health as a right to be important. Today Buss has continued an outlook that health must be closely connected to policy and politics: "I think medicine and society, as well as doctors and politicians, do not have very precise boundaries. There is no precise boundary between my work as a doctor of public health and my work in the field of social policy. This is the field where we can transform the world" (ibid). Along these lines Fiocruz has been at the forefront of efforts for dengue with the 'Eliminar a Dengue: Desafio Brasil', part of the international not-for-profit research effort 'Eliminate Dengue: Our Challenge'<sup>150</sup> led from Monash University, Melbourne, Australia (Fiocruz Press Release, 2012) (Fiocruz Press Release). The scientists I interviewed in Brazil often said reiterations of the phrase: "It's not just science, it's social" and the context for dealing with these diseases, which included a culture of inequality (Brazil was the last country to abolish slavery).

Fiocruz remains the pre-eminent scientific and public health institution for research in Brazil and arguably Latin America (Fiocruz, <http://portal.fiocruz.br/en>, Accessed 2/4/14). The Cruz-Chagas period represents what is viewed as a golden age in Brazilian research and public health, followed by attempts to emulate it since. Cruz and Chagas wanted to rival developed countries in Brazilian scientific achievement but also to apply science to the deep social problems of poverty and inequality. Later scientists at Fiocruz, became politically engaged as doctors who were pushing for democracy. Better health was a demand that the government should provide for citizens, and as medical scientists and doctors they saw themselves as well placed to advocate for change. As I showed with the China example, scientists in Brazil have been active in their involvement with tropical diseases, despite a sometimes turbulent political backdrop. A political role in pursuit of other priorities overtook that of advocating for NTDs. What both countries therefore represent is an autonomous course in dealing with NTDs that is quite separate from the brand created to repackage the diseases.

This chapter has traced the emergence of an NTD brand, the pivotal role of activist scientists in the UK and US, and ended with how scientists are perceived in the endemic countries Brazil and China. I began with the question of why activist scientists have not emerged in these countries or last least have not appeared to do so. Through the course of this chapter I have argued that there have been some major contributions by scientists in Brazil and China. In

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<sup>150</sup> The Fiocruz project uses *Wolbachia*, a natural bacterium, introduced into the dengue carrying *Aedes aegypti* mosquito to stop the virus from growing (ibid).

China ground-breaking research by scientists was under-acknowledged because of a sensitive political environment and it has only been more recently that recognition has been bestowed. In Brazil, the relationship between scientific recognition and praise is even more contradictory, being intertwined with nation-building and the need to project a modern disease-free state. The possibility of scientists taking on a more advocacy or even activist role was constrained by these circumstances but also hampered by the way that a policy movement initiated in developed countries became 'global'. This is a point that I will expand on in the concluding section.

## 6.4 Conclusion: An elite policy movement

When the advocacy of a social movement is absent for a policy problem, as in the case of NTDs, an elite policy movement becomes viable. A policy movement is not a grassroots but elite action, through the activist scientists that have created a new disease brand. I have shown that alternatives for dominant public discourses and policy narratives can be offered by elites, and competition exists in elite groups for prominence of problems. According to Sheila Jasanoff: "Not all societal adjustments rise to the level of protest movements nor arise from below, as in the formation of group resistance; to the contrary, many salient adjustments in actors' identities, with profound consequences for the day-to-day conduct of society, occur within elites" (2005, p.29). Adams also wrestles with the idea that "...medical professionals have, by politicizing their medicine, managed to advocate service to the people while preserving their own positions of elites in a still highly stratified and unequal society... with their status as bearers of modernity" (p. 224).

However, the stories of Tu, T'ang, Cruz, and Chagas show scientists who were caught in political conflicts about the ways that NTD research was approached within their countries. Their stories also provide context as to the relationship with research and policy making taking place in developed countries. Political upheavals and social-cultural changes have presented difficulties for NTD research and policy in Brazil and China. However, these developments are not well captured in the policy movement for NTDs. A globalizing policy towards NTDs relies on an idea of developed to developing country knowledge flows and donor-recipient relationship. For scientists in the developed countries, as has been explored, neglect is apparent in policy by donor governments, NGOs, international organizations, and through the pharmaceutical system. It is clear however, that the capabilities of Brazil and China are both different to those of low-income countries and to each other. While the 'neglected' aspect of NTDs is more apparent from the perspective of the donor through a policy movement, it is not so much of a clear-cut case from the other side.

In the next chapter I cast an eye to the effect the policy movement for NTDs has had on two related discourses. These discourses concern the measurement of economic impact through the 'worm wars' and a new conception of philanthropy 'effective altruism' drawing on a measurement ideology. Here there is an overlap between the discursive activities to promote NTDs as a policy problem and the pervasive rationales for policy on measurement terms.

## Chapter 7. Evidence for neglect: Discourses of measurement

*"The metric of success is lives saved, kids who aren't crippled... Which is slightly different than units sold, profits achieved. But it's all very measurable, and you can set ambitious goals and see how you do"* (Bill Gates in Herper, 2011).

*"...only what can be measured, can be managed"* (Nowotny, 2007, p. 479)

### 7.1 Introduction: Measurement in global public health

This thesis has been concerned with how evidence and advocacy have been used to transform tropical diseases into NTDs. Chapter 5 began the discussion with how evidence through measurement is used and what is taken as evidence to characterize NTDs as a policy problem. I have highlighted two metrics that have been the most influential in measuring neglect. The '10/90 gap' positioned NTDs as neglected in terms of pharma R&D, while the introduction of 'DALYs' gave prominence to the disabling effects of NTDs as being neglected by governance institutions. To present an attractive solution, the '50 cents per person' measure of the cost-effectiveness of mass drug administration (MDA) for five NTDs was used. Chapter 6 then explored the form of advocacy that has taken shape to direct NTDs into their current policy formation, to which I attribute significant agency to activist scientists. This chapter takes a step back, to try to ascertain what these modes of policy constitution – evidence and advocacy – mean in a public arena. I move from evidentiary practices to cases where evidence has been contested. What have been the discursive effects and impact on ideas about NTDs, in where these diseases sit in public health policy, and how the policy problem is understood?

Discourses present particular policy narratives, and in doing so conduct conceptual and 'social world' work, that stretches beyond the remit of the metrics in themselves. I have provided an introductory commentary on discourse in the theory Chapter 3 but it is worth bringing in Annemarie Mol's description of a discourse in how: "...words, materialities and practices hang together in a specific, historically and culturally situated way" (2008, p. 9). Discourse therefore, is a means through which various actors can affect a policy situation, providing persuasive evidence for why NTDs should be prioritized by policy agendas.

I present two empirical cases of measurement discourses. First is the so-called 'worm wars' and second 'effective altruism' (EA). For this part of the research project I mainly relied on online material (websites, blogs, etc.) and drew on a small selection of my qualitative interviews, to shed light on aspects of the discourses. I also attended public events that discussed the

discourse topics, including an 'International Society for NTDs' (ISNTD) Conference with a session on school-based deworming (April 2016, Institute for Child Health)<sup>151</sup> and the second a talk by Peter Singer and others introducing about EA (April 2015, Harvard University, see: Min, 2015)). In addition, I had two informal meeting with EA community members.

The worm wars and EA are public discourses of measurement where NTDs are implicated. The measurement discourses encompass a range of ways of counting that I already began to discuss through the 10/90 gap and DALYs but now look to explore their underlying meanings and interactions in the world. Measurement that provides economic development arguments for intervention constitute a dominant discourse but I aim to challenge this with an alternative discourse of human rights, as the moral pursuit of social justice as a global concern. These are discourses that have occurred across various public arenas and form a dialogue about the role of measurement in policy.

As we will see, the worm wars and EA are examples of NTDs entering the public arena through a discussion about measurement. The public discourses that I explore encompass a host of theoretical and practical activities within a certain moment in time and geographical location. The 'worm wars' is a discourse conducted by predominantly academics (anthropologists and epidemiologists) and measurement commentators (the Cochrane report and media figures). Debate and discussion centres on an empirical relationship being made between a public health intervention on parasitic worms and the economic development impact. What followed was a debate about what measurement evidence counts as proof.

EA is a discourse driven by philosophers and philanthropists, and the EA 'community of members and supporters, about the effectiveness of philanthropic giving to causes such as NTDs and how to rank problems as well as their effective interventions. Both the discourses have been quasi-academic, in that they have had academic roots that then spilt over into the public arena, with timing from the early 2000s onwards and being largely located in the US and UK, where the main protagonists are based.

Global health since the turn of the 20th century has been reflecting long-term changes in what counts as robust and justifiable knowledge as well as the convergence of numerous spheres in policy. Vincanne Adams as editor of 'Metrics: What Counts in Global Health' (2016) has explored the impact of metrics, as the vehicles of measurement, in shaping and governing global health. She describes the situation:

*"The links among economy, sovereignty, and the politics of knowledge that have shaped the use of metrics over the past decades in this field suggest that global health strives toward forms*

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<sup>151</sup> ISNTD, <http://www.isntd.org/#/isntd-conferences/4565830915>, Accessed 4/10/16

*of knowledge that are distinguished from those found in an era of postwar, postcolonial international health” (ibid., p. 2)*

Measurement and the production of metrics is intended to be an apolitical, politically neutral or value-neutral form of evidence, as opposed to practices of self-interested colonial health. Adams argues, "...the metrics we rely on to avoid politics often do not avoid politics at all; they become a form of politics in their own right, augmenting the political stakes and political underpinnings of health projects" (ibid., p. 9).

The political nature of numbers is therefore important to explore, more so because of the appearance of neutrality, leading to bias as being hidden. We should ask, what do metrics do? as, "(M)etrics not only enable us to set aside questions of politics; they also turn moral questions.... into problems of numbers" (ibid., p. 25). Speaking to Adams' identification of (1) economy, (2) sovereignty and (3) the politics of knowledge in shaping metrics, it is also on similar grounds through which measurement has been elevated in importance in public discourses.

Firstly, counting health has been closely tied to an economic view of the world. For Reubi et al, it is an underlying health economics perspective that puts greater reliance on evidence-based justification and intervention strategies (2015). This perspective comes out in the metrics used in the two examples of RCTs for the worm wars and effectiveness for EA.

Secondly, measurement increasingly is important on a global scale and not only directed toward sovereign states. Measurement is connected with another word that has regained importance: 'grand'. As I explored briefly in Chapter 4, 'grand challenges' have gained popularity as a global outlook on problems. Grand or the similar word great, convey something momentous, which affects and is important to us all, the whole of humanity. Interviewing Gates about his work in public health Herper refers to a 'grand human problem' (2011).

Thirdly, the metrics used for measurement reflect our ideals and values about knowledge and the way we think about problems. Informed by what we know and what we would like to know, metrics are fulfilling this need, they are "...imagined to offer uniform and standardized conversations about how best to intervene, how best to conceptualize health and disease, and how best to count and be accountable, and how best to pay for it all" (Adams, 2016, p. 6). Metrics are part of a wider politics of knowledge, through the means of acquiring and applying knowledge, which in turn shapes problem understandings. When looking at the two public discourses of measurement I will be concerned with the underlying ideals and values about knowledge.



## 7.1 Counting worms and their treatment

The next section highlights the first public discourse of measurement: the worm wars. I want to begin with some background for the interest in worms and measurement as part of a longer history of statistical counting of parasitic worms dating back to post-war America. This history was marked by a 1947 paper in the *Journal of Parasitology* by Norman Stoll (see Stoll, 1947), a renowned parasitologist and epidemiologist based at the Rockefeller Institute. Stoll played a key role in bringing attention to the problem of parasitic worms in humans. Measurement was needed for advocacy of an undetermined problem in scale and importance. Not being outwardly visible in signs or symptoms, measurement conceptualizes and provides some certainty about the problem. Even if it is rhetorical in that purpose, the work of Stoll in highlighting the problem of worms showed that measurement matters.

The presentation of his paper was through an address to the American Society of Parasitologists reacting to the parasitic worm-infected servicemen returning from the Pacific battlefields of World War II (Klass, 2015). Stoll called it “the great infection of mankind” and highlighted the need to conquer worms for the common good and raise human capabilities: “(F)or only in a society made up of parasite-free individuals will we know of what the human being is capable” (quoted by Klass, 2015). To reach such a state, he posed the crucial question at that meeting: “Just how much human helminthiasis is there in the world?” (quoted by Keiser and Utzinger in Zhou et al., 2010, p. 198). The question of measuring the occurrence of worms proved difficult, as there existed no central source to access the information needed. However, Stoll was able to provide an estimate of the global numbers of infection with major helminthiases, through an extensive review of the literature and consultation with other parasitologists (Utzinger, Bergquist, Olveda, & Zhou, 2010). The review included the NTDs: soil-transmitted helminths (roundworm, hookworm, whipworm, and threadworm) along with lymphatic filariasis, schistosomiasis, and food-borne trematodiasis (ibid.). His estimates showed a roundworm global prevalence in 1940 of 29.8% (with 644.4 million people infected), while that number has now dropped to a 12.4–18.8% global prevalence for 2003–5 but with more people infected (807–1221 million) because of population growth (ibid., p. 199).

Over half a century later Stoll's influence is still being felt. In 2010, taking the title of his highly quoted 1947 article ‘This wormy world’; an online project led by the London School of Hygiene and Tropical Medicine (LSHTM) and ‘www.thiswormyworld.org’ was launched, providing accurate and up-to-date maps of helminth distribution using data from thousands of field surveys.<sup>152</sup> The concern with worm infections has since expanded from the occurrence of worms to the economic and development impact they are having. The pursuit of this question

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<sup>152</sup> ‘This wormy world’ produced the ‘Global Atlas of Helminth Infections’ (This Wormy World, <http://www.thiswormyworld.org/>, Accessed 2/4/14).

about impact has led to the so called 'worm wars', named because of the epistemological and cross-disciplinary debate it has inspired between academics, played out in scientific and popular news outlets. The conflicting views have mainly been with a group of epidemiologists, who found they could not replicate the findings of the work of two development economists, in a scrutiny of methodology used, including basic statistical practices. However it went on to become a wider discussion about the nature of evidence. This discussion concerns what counts as robust evidence and how it is derived through the validity of the metric used, in this case 'cluster controlled' Randomized Control Trials (RCTs), which I will explain shortly. I also argue how the ambition of measurement connection and explanation attempted is of contention. The World Bank has produced an anthology of the controversy, which consists of around 50 links (Evans, 2015).

It is one area where NTDs have entered a public discourse. While beginning as an academic debate it was then picked up upon through various media outlets. According to the World Bank the two high-profile articles that prompted a host of responses were: 'Scientists Are Hoarding Data And It's Ruining Medical Research', *BuzzFeed* (Goldacre, 2015) and 'New research debunks merits of global deworming programmes', *The Guardian* (Boseley, 2015).

Both UK-based, Ben Goldacre is a popular science author and Sarah Boseley the Health Editor for the newspaper *The Guardian*. The ensuing debate happened on blogs (across a whole range of individuals and organisations) and on twitter (with the hashtag #wormwars). However, instead of being referred to as NTDs, it is 'worms' that have reached some prominence in the public arena. The reason is because the worm wars only refer to part of one NTD sub-group - helminths,<sup>153</sup> and so a linkage has not been strongly made with NTDs.

### **7.1.1 School deworming for development**

References to the beneficial effects of school deworming were argued early on in the NTD campaign. The WHO Berlin report (2005) already presented the claim about school deworming that sparked the worm wars, stating: "The package of neglected tropical diseases is a clear example of a rapid-impact intervention with a high pay-off at a very low cost. School deworming, for example, is highly cost-effective" (ibid., p. 8). Here a connection is made with de-worming as an NTD intervention that can be measured in terms of impact, cost-effectiveness, and quick results. The impact is upon better school attendance translating to economic results, as the WHO describes:

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<sup>153</sup> The types of NTD worms that are being referred to in the worm wars (outlined by Miguel and Kramer) are much the same as those that concerned Normon Stoll: soil-transmitted helminths (roundworm, hookworm whipworm) and schistosomiasis.

*"From a microeconomic perspective, tackling neglected tropical diseases provides both health and economic benefits at low cost. There is ample evidence of significant gains in worker productivity as well as impressive effects on school attendance test scores. Externalities also apply to children attending schools without deworming activities, given the lower rate of infection in the community" (ibid. p. 9).*

Therefore, the WHO report relates the lowering of worm infection rates with economic development. The adverse effect of worms begins early in life and carries through to working adults. It is through 'ample evidence' that the argument is made for children suffering nutritionally, educationally, and productively.

The year before, in 2004, an economics paper had been published entitled 'Worms: Identifying Impacts On Education And Health In The Presence Of Treatment Externalities' (Miguel & Kremer, 2004). The paper pushed the evidence for school deworming into the limelight by presenting a correlation between mass deworming with increased school attendance and health. There had been previous papers covering the topic but this paper emphasized the positive benefits of deworming through the externalities observed. Externalities is an economic concept capturing the effect of a production or consumption decision that imposes costs or benefits on others (see OECD, 1993). Although it is not completely clear through the paper what sort of externalities were at work: was it epidemiological where lower numbers of worms interrupted transmission cycles or was it behavioural in that more peers being able to attend school influenced others to attend? Or was it both? The prestige of the journal *Econometrica*<sup>154</sup> and the reputation of the development economists Michael Kremer and Edward Miguel at Harvard and Berkeley respectively, no doubt played a part in raising the profile of the paper. They also presented novel measurement techniques.

Kremer and Miguel conducted a 'cluster controlled trial' to measure the benefit of deworming treatment for school absenteeism, with a group of Kenyan schools that had received the treatment but also included neighbouring schools that had not. A cluster-controlled trial is a randomized control trial (RCT), which is a scientific experiment to compare an intervention with a treated group and a non-treated control group, in school groups using a cluster sample, rather than sampling individuals. The sampling took place through a randomized phasing of 75 Kenyan primary schools for deworming treatment, to show an impact of possible externalities from the deworming treatment on neighbouring schools. The results presented had been sought after in development economics because it appeared to further reaffirm that deworming had a positive effect on school attendance and also had positive externalities. The authors

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<sup>154</sup> *Econometrica* is a well-regarded journal publishing articles in all branches of economics with an impact factor of 3.823 but with a leaning perhaps toward quantitative economics, as it is listed the number two journal in 'Mathematics, Interdisciplinary Applications' (out of 92) and in 'Social Sciences, Mathematical Methods' (out of 44) according to the ISI Journal Citation Reports® Ranking 2012 (The Econometric Society, <http://www.theconometricsociety.org>, Accessed 2/4/14).

contended that previous studies had underestimated the impact of deworming because externalities had not been considered.

Controversy began when a group of epidemiologists from the London School of Hygiene and Tropical Medicine (LSHTM) tried to replicate the findings. Aiken, Davey, Hargreaves, and Hayes replicated the findings using the original dataset but found a lower and no longer statistically significant number of attendances by treated children (2015). Specifically they found that the lines in the program to calculate which schools fell into the 'deworming nearby' category had erroneously excluded the majority of schools, meaning that once that key error was corrected, the benefit for neighbouring schools 'effectively disappeared' (Goldacre, 2015). Even after re-applying analytical approaches originally used, and correcting for various errors, the epidemiologists found little evidence for the previously reported indirect effects of a deworming intervention. Although the evidence varied by method, as shown with another article by some of the same LSHTM authors putting forward a more positive analysis:

*"The evidence supporting an improvement in school attendance differed by analysis method... We find that the study provides some evidence, but with high risk of bias, that a school-based drug-treatment and health-education intervention improved school attendance and no evidence of effect on examination performance" (Davey et al., 2015).*

What followed was a back and forth between commentators about whether the study claims were valid. The worm wars were about evidence – what counts as evidence, how evidence can link a health issue to economic development, what sort of evidence is legitimate (such as conducting an RCT), and how that is defined. In an 'author's response' to the controversy Hargreaves et al., stated that as HIV epidemiologists they wanted to learn about the evaluation methodology guiding economist-led randomized trials of the early 2000s on HIV-risk behaviours, as they found, "...appraising these studies challenging because of different approaches to study design, reporting and analysis" (2015, p. 1). Miguel and Kremer in response viewed the reanalysis as still supporting their initial findings but with the correction of some errors of externality and school participation effects (Kremer & Miguel, 2015).

The message here is not just that measurement is contestable but two key points in how measurement is used to provide evidence for understanding policy problems and their interventions: (1) a connection is sought between an intervention for a policy problem and economic development outcomes; (2) a hierarchy in methods exists for solutions to policy problems privileging the quantifiable, statistical measurement that appears objective, scientific, and comparable.

Whether a connection between deworming and education (attendance and performance) is found is important in order to understand the justification for NTD intervention. The claim that

an intervention – in this case health improvement – leads directly to economic outcomes is a tendency that is widely subscribed to, such as with R&D leading to economic growth (despite a clear link being unproven and yet we carry on investing). There appears to be a concerted need to connect health with economic benefits and to have straightforwardness in the solution. Goldacre acknowledges: "The seductiveness of simple pills, as a solution to complex problems in the developing world, is perhaps overwhelming" (2015). Paul Garner from the Liverpool School of Tropical Medicine (LSTM) goes one step further. As the coordinating editor for the Cochrane Infectious Diseases Group, he classes the current promotion of deworming 'a panacea' in seeking a "...single solution to multiple problems in low- and middle-income countries, and that the belief that deworming will impact substantially on economic development seems delusional when you look at the results of reliable controlled trials" (Boseley, 2015).

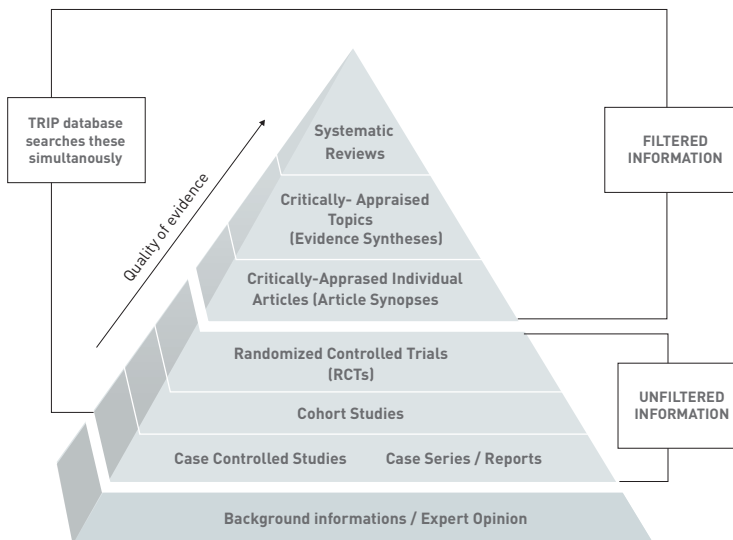
Perhaps the deeper consequences are in the type of evidence that is supported to make the connection between a simple pill and economic benefits. Goldacre describes this situation as, "...an entire movement of people doing proper randomized trials — the most 'fair test' of whether an intervention works — throughout the entire community of development work" (2015). The gold standard of RCTs from medicine had been passed onto some social science research but the RCT standard is a high bar to pass. The original Cochrane review in 2000 that inspired Kremer and Miguel to react had stated:

*"...the evidence of benefit for mass treatment of children related to positive effects on growth and cognitive performance is not convincing. In the light of these data, we would be unwilling to recommend that countries or regions invest in programmes that routinely treat children with anthelmintic drugs to improve their growth or cognitive performance"* (Dickson et al., 2000, p. 1700).

It appears the Cochrane report excluded papers if they were not 'pure' RCTs and historical papers that did not incorporate RCTs (Kremer & Miguel, 2015, p. 2). The measurement is placed on a hierarchy of evidence as judged by an 'Evidence-based Medicine' (EBM) approach to judge the current 'best evidence' in making decisions in healthcare (Sackett, 1997, p. 3).<sup>155</sup> RCTs are rated to be the highest quality of evidence for unfiltered information, ahead of cohort studies and case-controlled studies (for the filtered information, systematic reviews, which Cochrane studies carry out are top). See Figure 12.

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<sup>155</sup> See Chapter 3 for a wider discussion on 'Evidence-based policymaking' (EBPM).



**Figure 12 EBM pyramid**

(Health Sciences Library University of Pittsburgh, 1996)

Not meeting the rigorous requirements of RCTs in the past meant a recommendation against investment in routine schoolchildren deworming because of the lack of evidence for benefit. Such a reaction demonstrates how reliable and robust evidence is important for justifying policy decisions and actions. However, the deworming debate and its contentions has not transferred so straightforwardly to the NTD community. Economic development or socio-economic arguments for NTD interventions are common, particularly for the worm NTDs. For example, a chapter in the Berlin Report (WHO, 2005) was entitled 'Tropical diseases: impact on people, societies, and economies'.<sup>156</sup>

A more recent trend has been to connect worm prevalence directly with human and economic development. Hotez and Jennifer Herricks at the Baylor College of Medicine have produced a 'Worm Index' comparing disease burden data from the WHO (indices range from 0-1, with 1 being the highest) with United Nations Development Programme (UNDP) Human Development Index (HDI).<sup>157</sup> The index appears to show a connection between low HDI and high worm levels.

<sup>156</sup> The author David Canning from the Harvard School of Public Health wrote a paper the year after the Berlin report. He made the argument that interventions against NTDs should be thought of as "investments in human capital and form an integral part of global poverty reduction" (Canning, 2006, p. 503).

<sup>157</sup> The HDI measures a country's achievement in education, standard of living and years of life lived in good health (Sabin Institute <http://www.sabin.org/updates/blog/%25E2%2580%259Cworm-index%25E2%2580%259D-reveals-association-between-ntds-and-human-development>, 2015, Accessed 2/4/14). McGollovray emphasises it is intended to be a comparative measure, as an assessment of "...intercountry development levels on the basis of three so-called deprivation indicators: life expectancy, adult literacy and the logarithm of purchasing power adjusted per capita GDP" (1991).

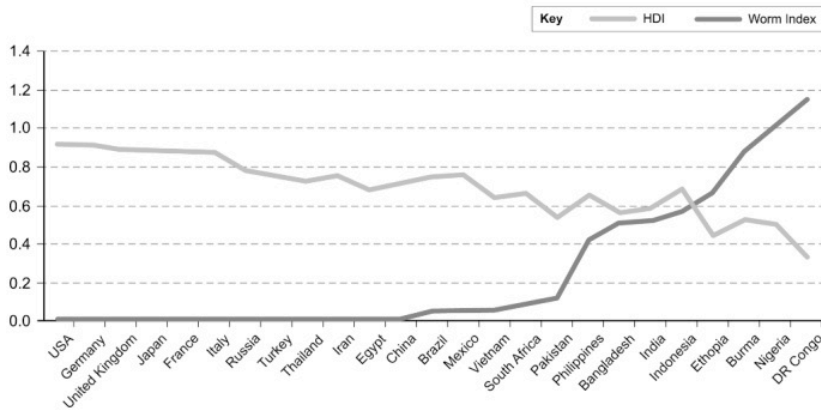


Figure 13 Worm index showing worm prevalence against HDI by country<sup>158</sup>



Figure 14 Worm Index showing worm prevalence on map<sup>159</sup>

The well-used adage may state 'correlation does not imply causation'. However, it is more important to consider what the debate about measuring worms means for NTDs as a policy problem. The worm wars did not seem to enter NTD discussions and may be viewed by some as an unwelcome and detracting controversy on some fronts. Again it has been anthropologists Allen and Parker (2016) who have formed an interest, as school deworming is a main vehicle for mass drug administration (MDA). Their weighing into the worm wars has been to further emphasize how the evidence for MDA of NTDs is lacking, as I have touched upon in previous chapters.<sup>160</sup>

<sup>158</sup> Sabin Institute <http://www.sabin.org/updates/blog/%25E2%2580%259Cworm-index%25E2%2580%259D-reveals-association-between-ntds-and-human-development>, 2015, Accessed 2/4/15

<sup>159</sup> Sabin Institute <http://www.sabin.org/updates/blog/%25E2%2580%259Cworm-index%25E2%2580%259D-reveals-association-between-ntds-and-human-development>, 2015, Accessed 2/4/15

<sup>160</sup> Allen and Parker make an additional point that the use of the term 'deworming' is applied inconsistently to refer to different infections and treatment regimes.

Some debate has also taken place on RCTs specifically and what other options there might be to school deworming interventions that have suited RCT measurement. At the WHO Antonio Montresor has researched RCTs for MDA for parasitic worm NTDs.<sup>161</sup> He believes that there is some delusion of the benefit of MDA and also RCTs in measuring the effects of the intervention. In an interview with Montresor, he recounted how post-war Italy had eradicated NTDs without the distribution of drugs but from quality of life improvements as a result of economic development and Japan showed a similar if not faster results:

*“I think sanitation is a right of a person but is not the case for 99% of people, to replicate some technology that proved to be efficient in Europe – it’s not possible and development like after the war is not possible”* (Interview with author, Montresor, 2013).

For Montresor the prevalence of worms in poor areas means improving sanitation, not through the same technologies of developed countries, but through new, adapted solutions to a different environment. Similarly Simon Croft at the LSHTM has worried about how the good news story of MDA does not encompass some of the drawbacks:

*“...Mass Drug Administration can lead to drug resistance... doesn’t separate out the fact that some worms the ascaris roundworms, 90% sensitive to most of these drugs but trichuris and other worms are only about 30% sensitive.”*<sup>162</sup> *You classify them altogether...*” (Interview with author, Croft, 2014).

The negative consequences are ill-considered and the policy treatment of grouping together as 'worms' or 'NTDs' prevents a tailored approach to interventions.

### **7.1.2 Summarizing the worm wars**

I argue that the worm wars have shown the importance placed on measurement by various actors including academics (economists and epidemiologists in this instance) but also following pressure from policymakers, NGOs and international organizations (for example in World Bank reporting) to present a policy problem through measurement. However, differing disciplinary approaches have been a cause for debate and to me this debate raises more fundamental questions about the difficulty of measuring policy outcomes by making connections between intervention and effect. How does the ability to measure affect which interventions are taken and what arguments are used to make the case for intervention? Likewise what effects are sought and how does the intended effect influence the type of intervention and measurement sought?

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<sup>161</sup> The worms that Montresor refers to are soil-transmitted helminths, schistosomiasis and lymphatic filariasis.

<sup>162</sup> Ascaris and trichuris are types of soil-transmitted helminths,



The worm wars have occurred in relative isolation to NTDs as a broad policy grouping. Reference has only come in the original presumption of a connection between deworming and improved school attendance in the argumentation as to why NTDs have an impact upon economic growth and development. Other interactions with the measurement of worms have been in the seemingly straightforward counting of worm infections and seeking more direct correlations between worms and the HDI index. Some pushback can be found in the use of RCTs to measure the success of deworming interventions and this became apparent when I interviewed the WHO scientist Montresor. Interventions such as improved sanitation may be less easily measured through RCTs, and this may influence whether these types of interventions are pursued or not if the RCT is prized so highly as a metric.

## 7.2 Effective altruism

Another discourse of measurement, concerning NTDs can be seen in the case of 'effective altruism' (EA) a philosophical approach and social movement about how best to give to charity. The EA argument is captured through two defining books by philosophers Peter Singer and William MacAskill: *The Most Good You Can Do* (Singer, 2015) – but with roots in his earlier publications including *The Life You Can Save: Acting Now to End World Poverty* (2009) and essay "Famine, Affluence and Morality" (1972) and *Doing good Better* (MacAskill, 2015).

Singer and MacAskill argue for the need to apply measurement to philanthropic activity, and it is through measuring how we should donate that NTDs have become a cause worth caring about. EA provides an interesting intersection of a group of diseases labeled as neglected on one hand and a group of people who are saying we should care about them on the other.

Singer is a moral philosopher and public intellectual.<sup>163</sup> He first outlined EA through his book 'The Most Good You Can Do: How Effective Altruism is Changing Ideas About Living Ethically' (2015). He describes how best to live an ethical life by donating to the most effective causes. According to Singer, while the public has sought to find out how *efficient* a charity is, by looking at the amount of money that ends up with recipients, the *effectiveness* of interventions has not been given the same attention. EA might sound like a strange juxtaposition between a moral position of 'altruism' and the measurement value of 'effectiveness'. A question that arises is to whom this new way of giving appeals to? There is a cachet, as Singer has professed, with Silicon Valley: "people who are quantitative types, good with data, they understand the point of making a difference, and they have the opportunity to do it" (Cook, 2015).

Applying a similar treatment as the disruptive innovation of technology entrepreneurship,<sup>164</sup> Singer has deemed traditional charitable giving to be ineffective and overly bureaucratic, with even the very method of appealing to 'an imperative of the heart' being outdated. Certainly a need for a new type of charitable giving signals a loss of trust and confidence in the old mechanisms, including public sector institutions. To make altruism 'effective' is to individually make optimal choices guided by rationality and evidence that then have an impact on the inequalities and injustices in our world.

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<sup>163</sup> A controversial figure since the late 70s, Singer has made the case for animal rights by arguing against a moral distinction between animals and humans, and angered disability advocates by saying that severely disabled newborns should be euthanized.

<sup>164</sup> Disruptive Innovation Theory was popularized by Clay Christensen as a "means of broadening and developing new markets and providing new functionality, which, in turn, may disrupt existing market linkages" (Yu & Hang, 2010)

The ideas of his book and also MacAskill's book are put into action through EA-affiliated organizations that I have observed, included below.

- **GiveWell** Charity evaluator  
*Created 2007 by two former investment analysts Holden Karnofsky and Elie Hassenfeld*
- **The Life You Can Save** Information and promotes activities to reduce poverty/inequality  
*Created 2009 by Peter Singer, Professor of Bioethics, Princeton University*
- **Centre for Effective Altruism** Grows and maintains the EA movement
- **80,000 hours** Provides help with ethical and high-impact career decisions  
*Both created 2011 by William MacAskill, Associate Professor of Philosophy, University of Oxford*
- **Giving what we can** Charity evaluator, 10% income pledge for most effective charities  
*Created in 2009 by Toby Ord, Postdoctoral Fellow in Philosophy, University of Oxford*

**Box 5 EA-affiliated organizations** <sup>165</sup>

EA-affiliated organizations implicate NTDs through measurement by to be an 'effective' philanthropic intervention. This section will discuss how EA is measuring NTDs in terms of effectiveness and furthermore what such a form of measuring means for prioritizing policy problems through lists.

The Centre for Effective Altruism describes EA as a "growing social movement founded on the desire to make the world as good a place as it can be, the use of evidence and reason to find out how to do so, and the audacity to actually try".<sup>166</sup> EA-affiliated organizations rank NTDs as an issue to be tackled, high up the scale of importance, in a concern for neglected causes. One of the key figures in the movement, the philosopher William MacAskill, describes the factors to consider when evaluating a charity or a cause as being:

<b>Scale</b>	"how big is the issue in terms of suffering or loss of happiness"
<b>Neglect</b>	"how many resources have already been devoted to it"
<b>Tractability</b>	"how easy is the problem to solve"

**Table 23 Factors to evaluate a charity or cause** (derived from Appleton, 2015)

The issue of global public health and especially NTDs tick all these boxes. Next, the way of taking action is prescribed by Singer and MacAskill to be through an existing charity that can best direct financial resources toward a quantifiable impact. They propose firstly a new way of giving, by donating a large percentage (one third) of salaries. Donating a large amount is permissible and encouraged within EA whether it be from individuals in seemingly non-altruistic careers in developed countries that are highly paid, such as banking, or from those with a very modestly paid job, as earnings will still be higher than that of most of the world population.

<sup>165</sup> [www.givewell.org/about](http://www.givewell.org/about); [www.centreforeffectivealtruism.org](http://www.centreforeffectivealtruism.org); <https://80000hours.org>; [www.givingwhatwecan.org](http://www.givingwhatwecan.org), Accessed 2/4/16.

<sup>166</sup> [www.centreforeffectivealtruism.org](http://www.centreforeffectivealtruism.org), Accessed 2/4/16.

Secondly, the choice must be made to best direct funds toward a quantifiable impact through resources such as GiveWell.<sup>167</sup> They rank charities according to set criteria – chiefly whether they are "proven, cost-effective programs serving the global poor" (ibid.). The top charities are all against tropical disease:

1. Against Malaria Foundation
2. Schistosomiasis Control Initiative (SCI)
3. Deworm the World Initiative

(ibid.).

The next question that arises is what types of people are providing the guidance to make these difficult choices? What kind of rationale and ideology is behind the EA thinking, that gives it authority? Singer relies upon a utilitarian conception of altruism, where the best possible outcome is pursued and so it follows that to make optimal decisions requires assistance from sources of knowledge and expertise.

The message of EA is about the obligations of the affluent to people in extreme poverty, to make the world better rather than simply not doing harm, and that this can be done easily with minimum or no cost. EA draws on utilitarian ideas of creating the greatest good for the greatest number – a maximizing of good (valuable and worthwhile) by reducing suffering and death. Singer is also consequentialist in that it does not matter about what the means are as long as overall welfare is maximized. Similarities can be found with philosopher Thomas Pogge (2001) in the moral obligation to the poor, which claims that our everyday life violates human rights through the rights of the poor. Also aligned is a commentary on the effectiveness of aid where individual giving counters what is seen to be wrong with aid provided by governments and international governance organizations (see Easterly, 2014). Singer's point is that individual donors and not just government should be making judgment about what does not work, what does and what has an impact.<sup>168</sup>

What impact is EA having on NTDs? My contention is that EA uses what Jasanoff (2013) calls 'technologies of rationality,' such as "behavioral economics, social psychology, risk analysis, and public policy," to make rational appeals on a codified basis in order to explain as well as justify actions and behaviours. The guiding principle of technologies of rationality is that humans are characterized as irrational but respond to reason found in technical discourses of expert scientists or politicians. The critical stance for this idea builds upon scholarship in STS, which has shown that the prestige and power of measurement (a topic explored in depth by Theodore Porter in his seminal 1995 book 'Trust in Numbers') and by others since, masks value

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<sup>167</sup> [www.givewell.org/about](http://www.givewell.org/about), Accessed 2/4/14.

<sup>168</sup> Singer builds on arguments by the development economist William Easterly (2014) and others critiquing aid but where he differs is in assigning individual responsibility.

judgments, belief systems, and subjectivity. Similarly Lupton argues that there is a 'politics of measurement' in the perception of neutrality of numbers but the quantification, interpretation of phenomena and purpose for measurement is: "...implicated in social relationships, power dynamics and ways of seeing" (Lupton, 2013, p. 399). Therefore, the growing EA movement capitalizes on the appeal of effectiveness as a technology of rationality: rationalizing the fuzzy idea of charitable giving within a knowable and trustworthy rubric.

Inside the philanthropic sector, the measurement trend was present early on. As Saunders-Hastings identifies, 'scientific philanthropy' was a movement at the end of the nineteenth and start of the twentieth century (Boston Review Forum, 2015). This idea was to replace the pursuit of what the philanthropist Andrew Carnegie disparagingly described as a 'gratifying feeling', with a supervisory approach to monitor unfortunate recipients of charity and assess the progress of the intervention (ibid.). Here blame was squarely placed on the moral deviancy of the poor rather than the rich being to blame or held responsible. A concern for the effectiveness of aid was borne out of the presumption that the poor would not make good use of help if it were not monitored. Saunders-Hastings worries that EA, while not directing moral criticism to the poor, still adopts a paternalistic role in not conferring agency to the poor, instead preferring the route to procure goods, rather than offering beneficiary choice. She gives the example of 'goods' being "...insecticide-treated bed nets to prevent malaria and treatments for neglected tropical diseases" (e.g. through drugs) over cash payouts, where it is left to beneficiaries to decide what is the best course of action (ibid.).

The scientific philanthropy approach today is mostly defunct, although provides intellectual underpinnings to EA in a paternalist preference for creating a community via the donating public rather than through beneficiaries. More influential perhaps is the present era of 'Philanthrocapitalism', also with roots in the philanthropy of businessmen such as Carnegie but now heralded for bringing business ideas to giving (e.g. the Gates Foundation and similar organizations). McGoey describes how it "...is the idea that to do good socially, one must do well financially" (2012, p. 185). Therefore, it is the measure of success that has changed from the moral outcomes of those helped to now a financial or financially measured outcome. In the past it was morally determined in the perceived changes to the poor through a person's character and lifestyle. Today it is reflected in both the ability to measure and the extent of measurable success, drawn from the business world. EA thus seeks to extend scientific knowledge and techniques to philanthropy, with conservative underlying values in a focus on the individual using evidence-based hubris.<sup>169</sup>

The emphasis on individual action rather than systemic change is one of the most common critiques leveled at EA. It is problematic because it negates the need for democratic decision-making from both the philanthropists and the recipients of EA. As Economics Nobel Laureate

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<sup>169</sup> Singer in his book uses many case examples of individuals who have adopted the EA way of life.

Angus Deaton critiques of EA, the subjects are the actual people helped but they remain passive (Boston Review Forum, 2015). Their opinions and agency are missing from the EA narrative, and he also views the problem concerning the effectiveness of altruism itself has been misdiagnosed. The problem of poverty and suffering is neither financial nor technical but political. Furthermore what can be measured or not is a major determining factor of assessing effectiveness, arguably the financial and technical is more measurable than the political.

If appeals to philanthropy are made on an individual basis it may also have an individualizing effect, further eroding trust in public institutions and political engagement, assigning roles of social institutions to individual and groups. Effectiveness is a measurement value to be revered but I question the trust being placed. This preoccupation can be seen as part of a wider trend in the values of modern life, to be determined by the measurability of interventions on a wide range of topics in quantifiable and commensurate terms. Arguably EA is overly reliant on effectiveness expertise on subjective concepts such as neglect, where aspects of emotion and thought are ignored. It is thus an uneven relationship between the public of the neglecter and the public of the neglected.

If we cast an eye to other effectiveness projects, similar to what we have seen with the worm wars, the problems of measurement being a dominant discourse becomes apparent in the shaping of priorities and moral judgment. The measurement tools of effectiveness popular in the health policy world are RCTs and DALYs, discussed in this chapter. What they do, points out sociologist Rachel Kahn Best (2012) is decontextualize illness and place diseases and treatments on a hierarchical scale. These measures have the appearance of rationality but they conceal the complexity and underlying decisions made by the experts who determine the parameters of what to measure and what not to. As Adams also describes health metrics, these are "statistical forms of reason" and the on-the-ground reality of metric quantification in global health 'metrics work' (ibid., pp. 1-9).

For instance, policy officials have placed an increasing importance on disease categories and individual disease severity to ensure effective health spending in the United States Best (2012). This ranking is accompanied by moral judgment of blame for the patients, so that particular diseases (diabetes, lung cancer, and drug addiction) are stigmatized. In the same vein, policies that do not fit into neat disease categories are easily neglected (e.g. environmental health risks, basic research, and equitable access).

Diseases have long-held a moral dimension. Moralizing can happen when there is a threat to social order that transcends body boundaries: "If the body is under threat from a dangerous 'other', then so is society" (Nettleton, 2006, pp. 63–4). Nettleton gives the example of HIV/AIDS: "Certainly during the 1980s the source of HIV always seemed to be elsewhere: either in different countries or in 'different', and often presumed to be 'deviant', social groups" (ibid.). She re-

quotes Susan Sontag that a dominant origin story of AIDS is that it came from the 'dark continent' and is "understood as a tropical disease: another manifestation from the so-called Third World" (ibid., 65). There are parallels here for NTDs, as these diseases are not only 'the other' but the outlook is that they will remain so being mostly confined to poor countries and only offering threat through epidemics, international travel and climate change.

## 7.2.1 Listing problems for humanity

The relevance for NTDs, in measuring effectiveness of philanthropic interventions, is the identification of the problems where interventions have most effect. I return to issue competition, as I began to explore with competition between diseases as in Chapter 4, but now discuss the listing and prioritization of policy problems more broadly. I also look at connectivity between policy problems through development goals and consensus. Here, I am interested in how and why EA identifies problems, which is different from priorities of the aid and development industry. The identification and prioritization of which problems to care about is what drew me to EA in the first place, with NTDs being featured and a high proportion of interest through the charities that are suggested.<sup>170</sup>

Giving What We Can list their criteria as: "Importance, Tractability and Neglectedness".<sup>171</sup> As I began to discuss in Chapter 3, a problem denotes importance, urgency and solvability. The Giving What We Can criteria is similar: Importance is the benefit of a successful intervention; tractability is weighting problems in terms of the progress that can be made to having results (thus related to solvability and how results can be measured) and neglectedness is the number of people already working on the problem. This definition of neglect relies on a measurement of the degree of neglect by assessing resources already being directed through attention, people and funding. EA is interested in systematically underexplored topics, which will have a high-benefit-to cost ratio when attention is re-directed.

Similarly 80,000 Hours, another EA-affiliated organization, have a list of the world's biggest problems, decided on again similar grounds of "Scale, Neglectedness, and Solvability" – see Figure 15. Scale and solvability refers to how big a problem is, related again to importance and how easy it is to solve and neglectedness is again the attention it currently receives. The figure shows their number one world problem as risks from artificial intelligence (AI), rated the highest because solvability is low and the neglectedness and scale is high. Next is promoting EA, followed by global priorities research, all work that is closely aligned with the 80,000 Hours organization. Health issues are included with both non-communicable diseases and NTDs represented. Factory farming is there too, animals have been a main topic of concern for a sub-

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<sup>170</sup> The EA-affiliated organization 'Giving What We Can' has almost the same list of charities as GiveWell.

<sup>171</sup> Giving What We Can, [www.givingwhatwecan.org](http://www.givingwhatwecan.org), Accessed 2/4/14.

section of EA supporters. Others are maybe markedly global in character – security (bio and nuclear), climate change, and land use reform.

Problem	Recommendation	Scale	Neglectedness	Solvability	Total Score
Risks from artificial intelligence	Recommended	14	11	2	27
Promoting effective altruism	Recommended	13	10	3	26
Global priorities research	Recommended	11	11	3	25
Factory farming	Sometimes recommended	11	8	4	23
Biosecurity	Sometimes recommended	12	6	4	22
Nuclear security	Sometimes recommended	14	5	3	22
Climate change (extreme risks)	Sometimes recommended	13	5	3	21
Land use reform	Sometimes recommended	10	9	2	21
Smoking in the developing world	Sometimes recommended	11	7	3	21
Developing world health	Sometimes recommended	13	2	5	20

Figure 15 80,000 Hours list of the world's biggest problems

(Adapted from <https://80000hours.org>, Accessed 2/4/14)

I compare this list next to another collection of global problems, in the form of goals – the Millennium Development Goals (MDGs) set in 2000 by all countries at the UN (Fig. 16 below). These are 'development' goals, they were not global goals or problems but we can still analyze where priorities differ in what is determined to be important and why.



Figure 16 UN Millennium Development Goals

(The Millennium Development Goals Report, 2015)

The 'goal' description already puts each issue area on a more equal footing than a 'list' and even how the goals are presented – not in list-form but in rows – suggest there is less of a hierarchy, or at least a degree of connection between issues. There is no display of 'scores' in the MDGs and therefore less appeal to numbers as an authority. The urgency of need and priority of the very worse off comes across, in comparison with the previous list. The technology skew of the 80,000 hours list is also evident. The risk from AI is still hypothetical, although the consequences could be tremendous. Much of the fears come from the AI community itself and



the wider tech community figures like Elon Musk and Bill Gates.<sup>172</sup> Some sections of EA have also been accused of too much emphasis on animal rights, reflecting chasms in EA priority-setting with those who either favour a focus on technology orientation, poverty reduction, or animal rights.<sup>173</sup> These splits are indicative of the publics that are being served; both from the side of the EAs and also in the publics intended to be helped. Is the EA public of those who give or public intended to be helped by EA concentrated in developing countries or developed?

The new set of MDGs, the Sustainable Development Goals (SDGs), announced in 2015 (Fig. 28 below). The economy, environment, social justice, and security now feature. These are more global, not only focus on developing countries, and possibly more of a tech emphasis (in the innovation reference).



**Figure 17 UN Sustainable Development Goals**

(Sustainable Development Knowledge Platform, <https://sustainabledevelopment.un.org/?menu=1300>, Accessed 2/4/16)

As I have stated earlier on in the thesis, NTDs crucially were not included in the MDGs, a point of contention that led to advocacy for them by activist scientists and NGOs that has led to subsequent inclusion in the SDGs. It is not only through international governance institutions that neglect has begun to feature, the idea of neglected problems has made an entry into other organizations and initiatives concerned with setting development goals.

An institute called the Copenhagen Consensus was, "...conceived to address a fundamental, but overlooked topic in international development: In a world with limited budgets and attention spans, we need to find effective ways to do the most good for the most people".<sup>174</sup> The institute began as an independent body of the Danish government providing economic and

<sup>172</sup> Fear of AI is a phenomenon that psychologist Stephen Pinker believes is down to how: "...alpha male thinking pattern is at the root of our AI fears, and that it is misguided" (2016).

<sup>173</sup> The Effective Altruism Forum also lists 'meta-effective altruism' and 'the far future' as other main focus areas (Effective Altruism Forum, [http://effective-altruism.com/ea/4k/four\\_focus\\_areas\\_of\\_effective\\_altruism/](http://effective-altruism.com/ea/4k/four_focus_areas_of_effective_altruism/), Accessed 20/10/16).

<sup>174</sup> Copenhagen Consensus, <http://www.copenhagenconsensus.com>, Accessed 2/4/14.

environmental cost-benefit analyses and evolved to provide a 'scorecard' to prioritize solutions to ten of the world's most pressing issues. The methodology used is statistical analysis and historical economics.<sup>175</sup> The scorecard relies on an expert panel of economists to appraise the collated data (including Nobel prize winners) who evaluate and rank proposals on being most deserving of aid. Cost is important for the panel to assess the size and pervasiveness of a problem. The biggest global problems listed are:

- Armed conflicts
- Trade barriers
- Malnutrition
- Human health
- Water and sanitation
- Gender inequality
- Education
- Air pollution
- Biodiversity
- Climate change

(Copenhagen Consensus, <http://www.copenhagenconsensus.com>, Accessed 2/4/14)

All problems have since fallen in severity as illustrated in the picture below (It is diagrams such as these that Castañeda may refer to when saying "The aesthetics of data contributes significantly to its power" (2016). 'A Scorecard from 1900 to 2050' quantifies the damage caused by attaching a cost to global problems and is compared on a regional and global level to total human wealth (at the given time) so the problem is measured as a percentage of world GDP. When it comes to human health the prognosis is: "Economic terms give the clearest summary. The cost of poor health at the outset of the 20th century was a phenomenal 32% of global GDP. Today, it is down to about 11%, and by 2050 will have halved again" (ibid.). Here there is a clear reliance on economic expertise to judge and pointedly measure global problems.



<sup>175</sup> See Copenhagen Consensus, , <http://www.copenhagenconsensus.com>, Accessed 2/4/14.

### Figure 18 Copenhagen Consensus biggest global problems

(Copenhagen Consensus, <http://www.copenhagenconsensus.com>, Accessed 4/5/16)

Economist Jeffrey Sachs is one critic of this methodology and argues that:

*"It failed to mobilize an expert group that could credibly identify and communicate a true consensus of expert knowledge on the range of issues under consideration. The panel included distinguished economists but no natural scientists or public-health specialists... A panel of economists brings an important set of tools to the table, but it cannot accurately assess the social costs and benefits of alternative interventions regarding climate, agriculture, disease, water and nutrition without the input of natural scientists, engineers and public-health practitioners" (2004).*

Even if the results were deemed by some to be skewed for many reasons it is still pertinent that through an economic form of measurement NTDs rank highly as a problem worth investing in – shown by deworming being ranked fourth in 2012 by the Copenhagen Consensus panel, rising from 6th place in 2008 (when it was also combined with nutritional programmes). See box below:

1. Bundled micronutrient interventions to fight hunger and improve education
2. Expanding the Subsidy for Malaria Combination Treatment
3. Expanded Childhood Immunization Coverage
4. Deworming of Schoolchildren, to improve educational and health outcomes
5. Expanding Tuberculosis Treatment
6. R&D to Increase Yield Enhancements, to decrease hunger, fight biodiversity destruction, and lessen the effects of climate change
7. Investing in Effective Early Warning Systems to protect populations against natural disaster
8. Strengthening Surgical Capacity
9. Hepatitis B Immunization
10. Using Low-Cost Drugs in the case of Acute Heart Attacks in poorer nations (these are already available in developed countries)
11. Salt Reduction Campaign to reduce chronic disease
12. Geo-Engineering R&D into the feasibility of solar radiation management
13. Conditional Cash Transfers for School Attendance
14. Accelerated HIV Vaccine R&D
15. Extended Field Trial of Information Campaigns on the Benefits From Schooling
16. Borehole and Public Hand Pump Intervention

### Box 6 Copenhagen Consensus investments to solve global problems

(Copenhagen Consensus, <http://www.copenhagenconsensus.com>, Accessed 2/4/14)

Neglect could be seen, then, as an additional concern that gets increasingly included in making sense of what is a problem. Neglect in the way it is used by EA considers the people and resources dedicated to the problem. Scholars who have been theorizing the nature of policy problems have not typically identified neglect as a characteristic as I have pointed out in Chapter 3. For example Rochefort and Cobb have listed: severity, incidence, novelty, proximity, and crisis, which echo other concerns listed before but whether a problem is neglected does not factor (1993, p. 62).

The concern with neglect fits within a general measurement discourse – a strategic prioritization and cost-efficiency rubric. However, it is a certain conception of neglect that fits a measurement sensibility. EA has concentrated on neglect in action through people and resources, as well as how well allocated these are. The claim of EA supporters is that a well-discussed problem is most likely to attract attention (Todd, 2013; MacAskill, 2015). Therefore, it does not make sense for an individual to also be involved in a problem that already receives attention because of diminishing utility<sup>176</sup> of the best opportunities being taken first (ibid.).

For other types of neglect, something might be known as a problem but lacks the emotional response of care and the thought capacity needed is not applied. An example might be the emotional response to AIDS in its early manifestation as a policy problem. According to some accounts, neglect was centred on emotion, through apathy that it was a self-inflicted disease, reflective of morally bad lifestyles and not deserving of problem-solving attention, with the onus on ill individuals being deemed 'responsible'. As Deborah Gould (2009) reflected, it was government neglect and inaction based in part on a lack of compassion, causing activists to then undertake 'emotions work' in the mobilizing of some feelings and suppression of others, to bring about a change in the government response to the AIDS crisis.

Gould writes of the 'emotional turn' of the late 1990s in the study of social movements as "...a response to the excesses of the rationalist paradigms" as emotion had been previously ignored, relegated to the arena of protest, with protestors understood as emotional and political actors being rational, or all actors being rational (ibid. p. 16). Rather than drawing dualistic oppositions Gould argues that neuroscientific research has influenced an understanding of emotion:

*"In short, rather than being a force that interferes with reason that should therefore be sequestered from the public, political realm, emotion here is viewed as crucial means by which human beings come to know and understand themselves and their contexts, their interests and commitments, their needs and their options in securing those needs" (ibid. p. 17).*

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<sup>176</sup> Diminishing utility is the economic concept 'law of diminishing marginal returns or utility' where every additional input yields lower return than the one before (Funke, 2000).

Ignoring the importance of emotion is to reduce advocacy and activism to depoliticized 'acting out' (ibid.).<sup>177</sup> Claims of reductionism and depoliticization have similarly been made against EA (Boston Review Forum, 2015). While some have argued the political is ignored through EA, proponents of EA are keen for it to have the character of a social movement, despite being intellectually driven by philosophers. Their conception of social movement may be different to what is commonly defined in the literature as touched upon before as a pursuit of social change and more akin to activity that is grass-roots, self-reinforcing, and growing in the population.

Regardless of whether EA is a social movement or not, the aspiration to be so is relevant in what it says about publics implicated. In a neglect relationship between two parties (unless we are looking only at diseases where the responsibility is more placed with individuals, such as with obesity), there are two camps, the neglected and the neglectors. The neglected lack agency to make a difference in their own lives, while the neglectors are given agency and character by EA. They are individualized but they also need to be elevated by EA. The neglectors in the case of EA, are those who have the will and the ability to do something about neglect, are constructed as high earners who can contribute in a straightforwardly quantifiable way.

The ability of the neglectors to reason and make rational decisions is a quality preferred over emotion by EA. Emotion is an appeal to 'an imperative of the heart', which Singer views to be outdated for philanthropy, where action based on information is needed instead. It appeals to the cachet that Singer has talked about as coming from Silicon Valley and young, motivated, tech-minded people at elite universities. Banking is another desirable industry because of the consequentialist focus on how much that can be donated rather than the way philanthropy happens.<sup>178</sup> Therefore, EA legitimizes banking and tech entrepreneurship in relation with philanthropy their place in society. Profitable and even morally dubious careers are permissible as long as a sum of money is donated to impactful causes within the EA framework.

## 7.2.2 Reacting to measurement in global health

The intention of the EA discussion in this chapter has not been to make a comprehensive critique of EA, as others have and continue to do (for an example see this selection of articles by the Boston Review Forum, 'The Logic of Effective Altruism', 2015, where academic and professionals discuss EA). I have considered why proponents of EA view NTDs as relevant by exploring its underlying philosophy, including under what criteria EA policy problems are determined and who the intended audiences are. I have discussed why neglect is an important

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<sup>177</sup> Depoliticization is invoked in the suggestion that treating an object of analysis politically means to render it complex, as a part of larger structural reasons and power relations rather than only individually limited behaviour.

<sup>178</sup> The moral argument supporting industries such as banking goes against against criticisms typically levelled (e.g. responsibility for the global financial crisis, corruption, greed, sexism and inequality).

concern because it has measurement appeal, used to identify policy problems and judge whether a problem needs addressing.

Measurement here is a value that is prized, and so the criteria to identify and prioritize problems is part persuasive device to convince those donating in philanthropy that their activity is worthwhile. What measurement does for EA is to rationalize emotive decisions and address uncertainty about whether philanthropic giving is worthwhile. By scientizing (Sarewitz, 2006) decision-making is to treat philanthropy with a scientific approach, a trend that has already existed but now found a new form through measuring effectiveness of charitable choices. This cause selection and prioritization is a driving force behind many new and already dominant organizations not only in the arena of public health but anywhere that is engaged with problems and challenges facing the world. For listing global problems, to rank problems relative to others they are transformed to be important and tractable by measurement, certifying importance and providing information upon which to advocate and take action.

What the act of measurement does is bring an issue into being, labeling something we want to know about and track. As Alain Desrosières (2002) outlined in 'The Politics of Large Numbers', statistical techniques transform social facts into things, shifting the representation of an object of study in the process. The measurement metrics of the 10/90 gap, DALYs and 50 cents per person all shaped how NTDs are represented and assisted in characterizing neglect. Measurement also has a performative function to the objects of measurement in constituting a problem and issue as 'neglected'. The label attached is type of linguistic performativity is Austinian in the use of language and speech to pronounce something into being, as a minister does in proclaiming a couple husband and wife, and in a ship being named with a bottle broken on the hull (Morris, 2016).

In summary, I have argued that neglect is appearing as an issue of concern in the listing of global problems when measurement of the proved effectiveness of an intervention determines whether a problem worth caring about. Neglect provides criteria on which to measure and provide evidence that an issue should be prioritized against others, when there is competition for care, and NTDs are implicated under the neglect label. NTDs featured in public measurement discourses such as the worm wars and EA because of policy packaging of NTDs by activist scientists and NGOs that purport them to be both a symptom of underdevelopment and a precursor to economic development.

This packaging lends itself to measuring progress in development, either through a connection with health intervention as with the worm wars or in determining what is an effective philanthropic intervention with EA in addressing poverty. The policy packaging of NTDs therefore relies on an argument of economic development. Instead of a concern for proving

impact or effectiveness, there are other concerns that could be prioritized but not as easily measured, such as social justice.

### 7.3 Other policy packagings: A human rights approach

In the public health field, Powers and Fadden argue that concerns about justice are, "...commonly understood as external to the moral purpose of public health" (2006, pp. 9-10). Views that justice is an external concern and that health is 'a form of justice' is part of separate-spheres view of justice (ibid.). The consequences of separating justice from health ignores, "...other public policies and social environments are structured or to how people are faring with regard to the rest of their lives" (ibid., p. 9-10). Therefore the economic development packaging may be a too narrow focus for the complex policy problem that is NTDs.

A human rights approach was a policy packaging used early on in the NTD campaign. In the WHO Berlin report a chapter was dedicated to 'Neglected diseases and the right to health' (WHO, 2005, p. 11). From the first WHO meeting on NTDs in 2003 the case was made for three perspectives to tackle NTDs: "economic, public goods, and human rights" (ibid., p. iii). NTDs were presented by the various stakeholders around the table (from the WHO, donor governments to NGOs and scientists) as not gaining international attention because of the preoccupation of individual rather than collective health security. The argument was made that focus was limited to HIV/AIDS, malaria, and tuberculosis, and more generally the global health security of infectious diseases that easily cross borders (ibid.).

A human rights angle has since appeared to drop off the agenda, proving not to be the most effective packaging for NTDs, although some remnants have carried through. Lorenzo Savioli, Director of WHO Department of Control of Neglected Tropical Diseases until 2014, stated in 'A Letter from the Director': "Our actions are aimed to promote the common good of every individual and are based on a human rights approach, which requires that interventions and processes are guided by human rights principles of participation, non-discrimination and accountability".<sup>179</sup> This view of human rights is somewhat narrow, as the principles appear to pertain more to the WHO as an institution upholding human rights in the face of competing interest claims among UN members. As Leslie London sets out, a human rights approach consists of three components, two of these are described by Savioli as accountability, participation (agency) and the third is related to non-discrimination but is more specifically, "...the indivisibility of civil and political rights, and socio-economic rights" (London, 2008, p. 65). The final point is more akin to 'health as a right' where rights are transferred directly to health.

Citizens are beginning to expect their government to ensure the 'right to health'. In Brazil this right is enshrined in the constitution and integrated health systems. As described by the WHO constitution: "...the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being" (WHO, 2007, p. 7). Specifically the 'Office Of The

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<sup>179</sup> WHO, [http://www.who.int/neglected\\_diseases/director/en/](http://www.who.int/neglected_diseases/director/en/), 2011a, Accessed 2/4/14.



High Commissioner For Human Rights' (OHCHR) calls NTDs, "a right-to-health issue with many faces" with clear links to human rights in the discrimination of poor and marginalized populations, where essential drugs are unavailable or inadequate, and health interventions and R&D are underfunded (2008, p. 8).

Does it matter that human rights do not form a main packaging anymore? What could the idea of human rights bring to the understanding and dealing with NTDs as a policy problem? By packaging NTDs as a human rights issue, certain aspects of these diseases and the avenues explored for intervention would be emphasized. The right to health brings up the question of what type of health intervention constitutes social justice, whether access to health is sufficient, or a more directed and purposeful provision is required. As Davies puts it: "At the heart of the debate about health and human rights is a tension between access and provision that mirrors the philosophical distinction between negative and positive rights" (2010, p. 64). Provision tends also to be important in the right to health, ahead of simply only granting access.

I contend that two arguments persist in how the right to health can be taken forward as an approach. First, taking a global rights approach, as Oprea et al. (2009) have noted, international cooperation on NTDs is delayed because of the promotion of national interests, "...rather than social justice at a global level" (ibid., p. 310). Emergency and the threat of epidemic has long been the concentration of efforts within international relations (IR), based on an individual rather than collective view of human security. Recent epidemics have had similarities with NTDs as a public health issue, in that they have originated in poverty-struck regions or involved a shared vector (an agent carrying an infectious pathogen, such as mosquitos) – seen with Ebola and Zika. However, these diseases have epidemic potential while NTDs tend not to. A consequence is an increase in attention to diseases of poverty or towards the shared vector but with the risk of also potentially drawing resources away.<sup>180</sup> Value could be had then in promoting NTDs as an issue in IR, security and cooperation settings or linking the two in policy, media and NGO communication. Activist scientist Peter Hotez has done some promotion and linking as his role as US Science Envoy<sup>181</sup> and in his varied media publications.

Second, taking an individual rights approach, interest groups can be effective forms of patient activism. As I demonstrated in Chapter 6, national visions and priorities can mean that a globalized NTD policy faces challenge. However, patient activism at the national level has not been a forthcoming for NTDs as I have noted previously, because of the nature of the afflicted group being 'voiceless' and 'powerless'. Two limited examples of patient interest group action

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<sup>180</sup> A rights approach may be a way of directing attention to NTDs on the grounds of equality and justice to endemic country governments, countering the arguments of emergency and security threat of individual government interests in the international system.

<sup>181</sup> US Science Envoys are eminent scientists who "...develop partnerships, improve collaboration, and forge mutually beneficial relationships between other nations and the United States to stimulate increased scientific cooperation and foster economic prosperity" (US Department of State, <http://www.state.gov/r/pa/prs/ps/2014/12/234682.htm>, Accessed 4/5/15).

are given by Detels and Gulliford (2015, p. 282). In 1980s Peru patients associations formed to successfully contest the government's lack of provision of drugs and financial compensation for leishmaniasis (also see Guthmann et al., 1997). In Uganda, 'Village Health Teams' have provided delivery mechanisms for NTD community interventions, with also community mobilization to deliver health education measures for the NTD onchocerciasis (Amazigo, et al., 2012). These sorts of activities cannot be directed from above but the promotion of values of participation and inclusiveness are pertinent.

The two avenues presented are ways in which a human rights approach could be taken forward through global rights in IR and patient activism. It is uncertain how receptive the global health community would be, as Adams has described, the human rights approach is seen as a "...bold (and some would say naïve) mission " (2016, p. 5). A perspective of human rights highlights interests and ideals that might be sidelined otherwise, and it demonstrates a different means of measuring success that could be pursued. This is a means that is more concerned with how health actors take ownership of NTDs as a shared problem and the ways that those affected by NTDs make their voices heard by addressing discrimination and inequity. The outcomes would be focused on political and structural change to types of healthcare delivery at the community level.

## 7.4 Conclusion: Measuring is caring?

As this chapter has demonstrated, measurement constructs a particular type of problem to be solved. Certain methods and means are taken, and underlying values and ideas privileged, by displacing humanitarian goals for economic development measurement. A self-reinforcing cycle moves from measurement supporting NTDs, to NTDs supporting measurement as a rhetorical tool. This chapter has explored two public discourses through the 'worm wars' and EA 'effective altruism', and presented an alternative policy packaging of human rights. Both discourses have shown how important measurement has become in defining and advocating for global health problems. The pervasive use of quantitative metrics in global health is having an effect, especially in how metrics are deployed by developed countries to represent developing countries through setting agendas and priorities.

Canning (2006, p. 499) believes that deciding priorities in global health is not merely the question of how best to spend limited resources but with "how to generate increased support for health in the poorest countries of the world from more developed". Thus rather than assuming a transfer of funding, resource and knowledge from developed to developing countries, a consideration is also needed for what the moral imperative is to do so. I have shown that moral imperative is guided by measurement, whether that is measuring impact of health interventions for economic development (with the worm wars) or the effectiveness of philanthropy to do good (EA). In essence, the discussion is not only what should we care about, but *why* should we care. The morality argument to care is the proposition of why should some people in one place and position care about other people in another place and position? This is assuming from the outset that one set are privileged that need to care about others that are not.

Caring about disparities of situation or inequality has had a particular relationship within the health realm. Deaton describes how: "(M)any people who are prepared to accept inequality in the allocation of goods as a (possibly) necessary evil are not prepared to accept similar inequalities in health outcomes" (1999, p. 6). Caring about global problems is a different proposition when it comes to health but the worm wars show that health alone is not a justifiable policy end, it will need to be translated into economic outcomes.

A somewhat paradoxical relationship then exists between health, problem setting, and problem solving. Health can be viewed as an end in itself, however multiple competing problems in the global health realm means that making arguments about economic impact strengthens the intervention case. Health inequalities make uncomfortable decision-making that is compounded by a hierarchical scale needed to decide between health issues. Powers and Fadden thus ask the question: "Which inequalities matter most"? (2006, p. 9). This question is still concerning

why should we care but caring about one inequality over another, where proof of an economic reasoning magnifies the importance of inequality.

There is often a utilitarian basis to this sort of question in public health about prioritization based on having "utilitarian commitments to bring about as much health as possible" (2006, p. 9). EA responds in formalizing how developed countries should help developing countries, what is the moral argument for doing so, and how inequalities should be addressed in terms of priority. With both the worms wars and EA, I have shown how a reliance on metrics helps to make difficult decisions, which have a moral, subjective and value-led core.

Here is where the circle reconnects – in Chapter 5 I argued that measurement is used to characterize NTDs as a policy problem. Two metrics measure the source of neglect: the '10/90 gap' and 'DALYs', and the '50 cents per person' to measure the cost-effective solution. Why were these metrics needed and why does measurement extend to how we locate the problem of NTDs amongst other problems? Measurement metrics are needed because when there is care for a problem, we are driven by a moral imperative but also want to measure it to assess how much we should care and track progress. Caring happens on the basis of the relationship between developed countries towards developing countries – it is caring about the disparity between health opportunities and outcomes (but still requires judgment of other possible cares and assessing of progress).

Adams, who has written extensively about the role of metrics in global health, begins to suggest metrics as being a form of caring. If metrics are telling stories, they encapsulate certain cares and "what those who rely on them care about most... These cares are coded into the naming of some variables as important and the exclusion of others" (Adams, 2016, p. 9). I want to take the idea of measurement as caring further. Cares, to care, and caring should be distinguished, as they do not mean the same thing. The capacity of measurement to reflect cares may be somewhat obvious. To care is a more emotive state; it encompasses the feeling and moral imperative, while 'cares' can merely be inherent in measurement decision, and may be subconscious or an automatic activity. I contend that caring therefore, is to bring together emotion and action to have an effect. It is also an activity that is closely related to health and wellbeing.

Measurement being a form of caring and as this chapter has demonstrated, becomes crucial in solving neglected problems. Annemarie Mol observed that care is, "...something that contrasts with neglect" (2008, p. xi). She noted that a simplified western view of good care, "...helps to hide neglect – a word that risks disappearing from our vocabulary" but that good care can also exist alongside neglect and errors (ibid., p. 6). I have found with NTDs the care and cure distinction may matter more in a developing country context.

Mol finds interesting the distinction between care and choice as two ways of dealing with disease, albeit it is squarely a consideration of what she calls 'clichés of the West' and so may be less relevant for developing countries. However, the point she makes about responsibility is pertinent. In developed countries there is more capacity for choice, which in turn transforms treatment into a private concern (the downside is that the mobilizing of the logic of choice can lead to poor care). If an action is deemed a choice, the responsibility and ownership has to be transferred, from public to private or doctor to patient.

For care to be assumed by developed countries for the health of those in developing countries, responsibility is also implicated. As shown by the measurement discourses I have analyzed, the choice of the 'recipients' or the 'neglected' has not factored. Responsibility and ownership sits with the 'donors' or the 'neglectors'. Cares, to care, and caring becomes paternalistic, as well as the measurement in the service of care. Looking at human rights as another policy packaging, places more agency and priority on the individual and potentially a scope for an autonomous path by endemic countries. The consequences of a change in policy packaging will be discussed in the final chapter.

## **Chapter 8. Conclusion: Using evidence and advocacy to showcase neglect**

### **8.1 Summary of NTDs as a policy problem**

The preceding chapters have focused on how NTDs have developed as a policy problem and the use of evidence and advocacy in the understanding of and response to neglect. I argue that the characterization of advocacy and evidence, shown by this case of NTDs, is markedly different in conditions of neglect. The type of advocacy that responds to neglect is forged out of circumstances that differ from more typical social or health movements. If an issue is neglected it is unlikely to have a constituency ready to advocate for it. Furthermore, advocacy here has different objectives with a need to change how that issue is perceived and constructed into a policy problem. Tropical diseases are repackaged using what already existed in a new form and commodified as part of a global health brand competing for resource and attention. These circumstances for advocacy are why a policy movement arose in response to NTDs and why it was activist scientists that led it.

The type of measurement evidence that provides policy rationale for and in response to neglect also differs. Evidence forms a type of advocacy in itself, as neglect has become a value of concern in global health, and this is separate from an instrumental use in advocacy arguments. The dominant discourses that help to produce certain types of evidence play a role of providing metrics that can direct measurement resources to the disposal of those advocating for NTDs.

DALYs were not developed as an advocacy tool for NTDs but it became evident that an idea of neglect drove the reasoning for why that metric was developed. Similarly, NTDs were only a small part of the diseases that made up the preventable conditions outlined by the 10/90 gap that were not receiving a proportional share of R&D investment. However, a connection between NTDs and the concept of neglect proved a suitable match. Lastly, the '50 cents per person' measurement of MDA for NTDs was not specifically developed to produce policy appeal for MDA, but the wording and phrasing later created policy appeal. The measure was part of an emphasis on measuring cost effectiveness. Neglect is shown to be even more unacceptable if easy, cheap and known solutions are available – it is harder to plead ignorance if measurement both spotlights neglect and shows us how to address it.

Understanding the meaning behind the use of evidence and advocacy in policy therefore, has also required specific attention to the assumptions, practices and implications of 'neglect' in NTD policy. The last chapter was pre-occupied with contemporary public discourses where I have viewed NTDs as a neglected subject matter entering public debate and arenas. The

previous chapters closely analyzed how the NTD concept arose. In Chapter 1, I began setting the background for how NTDs have become a label for a group of diseases, previously called tropical diseases. This included how 'the big three' HIV/AIDS, TB, and malaria have dominated in global health. I identified the two defining trends in raising the prominence of NTDs as advocacy and evidence, explored throughout this thesis.

Chapter 2 presented the methods and methodology as to how to draw out the relationship between NTDs and policy, with three central research aims, (1) to connect the understanding of NTDs with tropical diseases and colonial origins; (2) to explore the policy development of NTDs in the constitution of problem-solution in how these diseases have been moved up policy agendas through advocacy and evidence; (3) provide examples in which to view the enactment of global policies addressing neglect. I noted how a study about neglect builds on recent sociological research into ignorance and absences, but how neglect is differently characterized through the addition of implicit blame and responsibility, between a neglecter and the neglected. I also introduced new terms into the discussion: activist scientists, policy movement, and policy packaging.

Chapter 3 presented the theory I drew upon for my research on how policy problems can be approached, to make sense of the 'who, what, why, and where' that leads to a topic being considered as a problem for policy. I explored how policy can be understood as discourse, the importance of narrative in describing policy problems, and the use of innovation in conceptualizing solutions. I also argued that the disciplinary lens matters in describing policy problems and how understanding of neglect also differs. I was concerned with a dominant economic disciplinary discourse shown through measurement.

For Chapter 4 I provided a view of the conceptualization for NTDs with an exploration of two early initiatives: the 'Special Programme for Research and Training in Tropical Diseases' (TDR) and the 'Great Neglected Diseases of Mankind' (GND). I identified the key events from the 'Berlin meeting' to the 'London Declaration' to put forward a timeline for the policy development of NTDs. I have argued that central to these developments were the listing of diseases, politics of characterization, global campaigns, and political connections forged, which have led to commitments from the Gates Foundation and donations from big pharma.

In Chapter 5 I returned to categorization and took a brief historical look into how NTDs transitioned from tropical diseases, through the colonial history legacy and current geography in determining 'What is tropical?'. In determining 'What is neglected?', the answer is shown to be largely described through ideas of poverty and underdevelopment. I interrogated these categories of tropical and neglected, arguing why a dominant drug-based strategy for intervention has been reached and what this means for understandings of 'neglect'. Neglect imagined through a globalized policy for NTDs, based on an ultimate goal of eradication, differs

on a national and local level. The globalized imaginary arises from a position of 'otherness' and does not consider endemic country needs as it should, and neglect understood in mainly universal terms becomes problematic.

Chapter 6 presented the repackaging of NTDs as a disease brand and the role of activist scientists in creating this re-characterization of what was once tropical diseases. I explored the conceptual beginnings for NTDs: by revisiting the GND, profiling activist scientists in the US and UK, and questioning whether Brazilian and Chinese scientists are activists 'by another name'. I have built on the policy frame literature by introducing the idea of policy packaging, to provide the policy appeal, rather than a reframing of the contextual discourse. I showed how a neglected characterization was created through the advocacy of activist scientists and the use of evidence metrics. These were: DALYs (measuring disease burdens), the '10/90 gap' (measuring R&D investment in relation to disease burden), and the '50 cents per person' (cost effectiveness of MDA measure).

Chapter 7 was dedicated to public discourses of measurement. I analyzed two discourses, the 'worm wars' and 'effective altruism', to then present an alternative policy packaging taking a human rights approach. Finally, I questioned whether measurement can be seen as a form of caring, which I will explore further in this chapter.

In this final chapter, I am compelled to return again to tropical diseases. The need for 'otherness' to play a role has been persistent in the tropical medicine project from an early stage. Edmond describes how, "(A)s Europe slowly freed itself from an epidemiological past of cholera, malaria, leprosy and plague, these and other diseases were banished to the tropics where they became a primary signifier of native otherness" (Edmond, 2006, p. 117–8). While Iris Marion Young (2011) warns against a binary distinction between dominating and dominated groups, but she views domination is a structural phenomenon. Otherness results from fluid and complex relations, that may be unconscious and even arbitrary but is a situation of privilege produced from an unequal relationship. The unstable footing of domination to be 'fluid' and 'even arbitrary' must be acknowledged. In other social spheres that neglect is seen in, who is doing the dominating may be more or less obvious, in the neglect of one responsible party over the other. Examples may be neglect of children by their parents or guardians', elder neglect of the elderly by their carers or family, animal neglect of pets, farming or working animals by their owners, and environmental neglect of buildings or nature.

To understand how domination and otherness both causes and results in neglect, it is worth recalling the object of enquiry this thesis set out upon. The WHO outlines 17 'neglected' tropical diseases (NTDs) as being in need of attention and deeply affecting health in poor communities. Progress is being made: two diseases are targets for eradication (guinea worm and yaws) and eight more are marked for regional and global elimination (trachoma, Chagas disease, African



sleeping sickness, leishmaniasis, lymphatic filariasis, river blindness, rabies, schistosomiasis) (see WHO, 2015). As I noted previously, elimination relates to a defined geographic area where disease transmission is interrupted, while eradication requires global cooperation to rid humankind of a disease completely (Hopkins, 2011, p. 19). Elimination and eradication thus become closely tied conceptually with neglect, and the very idea is ideological. The solution for neglect of diseases, from this perspective, is to eradicate them as a medical problem and not to focus on social, political, and economic circumstances that may be underlying causes.

Stepan argues that eradication has been closely tied historically to an imperial view of tropical medicine (2013, p. 7). Now it carries weight with the technology solutionism of Big Pharma and the technocratic Bill and Melinda Gates Foundation. While NTDs are at various stages on the path to eradication, the end point appears close but not yet met. If this pursuit is ideological, from a position of domination, we must ask what might be lost in the process. An example is whether control and surveillance, as well as short-term measures more generally, are de-prioritized in favour of a long-term goal of eradication? As I demonstrated in Chapters 4 and 5, reviewing the dominant strategies to deal with NTDs suggests that it is not the case long-term goals are prioritized. The availability of cheap drugs to control NTDs – on a short-term basis – are central.

However, there are other non-medical factors that also contribute to the persistence of NTDs. The social, political, and economic factors that create and perpetuate disease, sometimes summarized as the 'social determinants of health' (SDH). The WHO describes SDH as:

*"...Conditions in which people are born, grow, live, work and age, which are key determinants of health equity. These conditions of daily life are, in turn, influenced by structural drivers: economic arrangements, distribution of power, gender equity, policy frameworks and the values of society" (WHO, 2014, p. xvii).*

SDH has reached mainstream public health policy as a way to address inequities in health, as evidenced by WHO reporting, task groups and commitments, and other regional activities such as the 'European policy framework for health and well-being, Health 2020' (ibid.). However, neglect in a policy sense should be understood differently to 'determinants of health'. This thesis has shown the importance of a policy packaging advanced through advocacy and evidence.

There is also a difference for global health policy problems. In solving these problems there is a potential to rid the world of some health issues. While some global problems may appear 'wicked', unprecedented successes in health have included: smallpox eradication, vaccination, sanitation and clean water, antibiotics, better maternal and child health outcomes, and less hunger and malnutrition. Still, disease can fight back, in part because of the social and political

dimension of disease, for example: vaccination hesitancy and refusal, unsustainability of sanitation and water systems across world, war and conflict, antibiotic overuse and resistance. In addition policy choices also play a part; even for model case of smallpox, the virus still exists as stocks in two laboratories, one in the US and the other in Russia. The security and political risk, whether as accidental or purposeful as a deliberate act of biological warfare, is persistent.

Smallpox has also been emblematic as a disease defeated by scientific progress but HIV/AIDS, Ebola, and Zika, have since emerged as new diseases to challenge scientists. There has similarly been a return of dengue and the persistence of malaria. Tropical diseases at one point seemed a victorious battle won, defeated by some developed countries but they have returned as NTDs. Therefore the tropical medicine history of NTDs has shaped their current emergence, de-emergence, and re-emergence in how they are treated in policy, grouped together, defined as a policy problem, and the ways in which solutions are sought.

### 8.1.1 Neglected endemic countries

As noted in the introduction I have been concerned with the distinction between advocacy and evidence in the development of policy problems across sites of high politics of global health and in endemic countries. Still, there are some aspects that I would have done differently with hindsight. My fieldwork from Brazil and China in this research was not used to the level of detail that I had originally intended, in providing endemic country perspectives. Although I believe that these country perspectives are reflected to an extent in the resulting research, I think a more fruitful approach would have been to select a very specific case study site in one of these countries. Endemic country involvement in policy formation does appear to be an understudied area, especially in the responses to a policy context dominated by developed countries (at least from a surface level). Therefore this is one aspect of research that I will further study in the future and believe that should attract attention from more research.

Considering they are the main focus of neglect, the individuals and the endemic countries that are affected by NTDs must be central to any policy for addressing the diseases. However, we also need to understand evidence and advocacy from the side of the 'neglectors', which have a tremendous impact upon diseases of the poorest and most vulnerable. This is where my inquiry was directed towards and why I also chose not to undertake an ethnographic study of individuals affected by NTDs. Parker and Allen have covered a large amount of ground in ethnographic fieldwork focusing on worms and MDA in Tanzania and Uganda. Certainly more ethnographic studies of individual NTDs in specific locations are needed and these are taking place: Chagas in Brazil (Armus, 2003; Dell'Arciprete et al., 2014; Stepan, 2011) and dengue in Malaysia and other new sites predominantly in Asia (Mulligan et al., 2015; Mulligan, Elliott, & Schuster-Wallace, 2012; Stoler et al., 2014). What is uncommon is the extrapolation of results to speak about NTDs more generally. This is what I have been interested in and my attention has been on the actors and circumstances that are directing policy, having drawn upon ethnographic work (especially by Parker and Allen) as secondary sources.

The literature I compiled encompassed a variety of sources that would not normally have been collated together into one analysis. This was principally in combining the established and expansive social science research on tropical diseases and fledgling research on NTDs. Advocacy has been central within social movement literature, but I have found that without a societal backing for NTDs, this has come from elite groups, shown by the activist scientists. I have argued that evidence in addition to advocacy is needed to make a case for care. Evidence is needed through measurement metrics to assess the scale of a problem and provide proof for economic development outcomes for health. I have identified with scholars researching metrics and measurement (such as Vincanne Adams), concerned with a symmetrical evaluation with the "accomplishments, limits, and consequences of using quantitative metrics in global health"

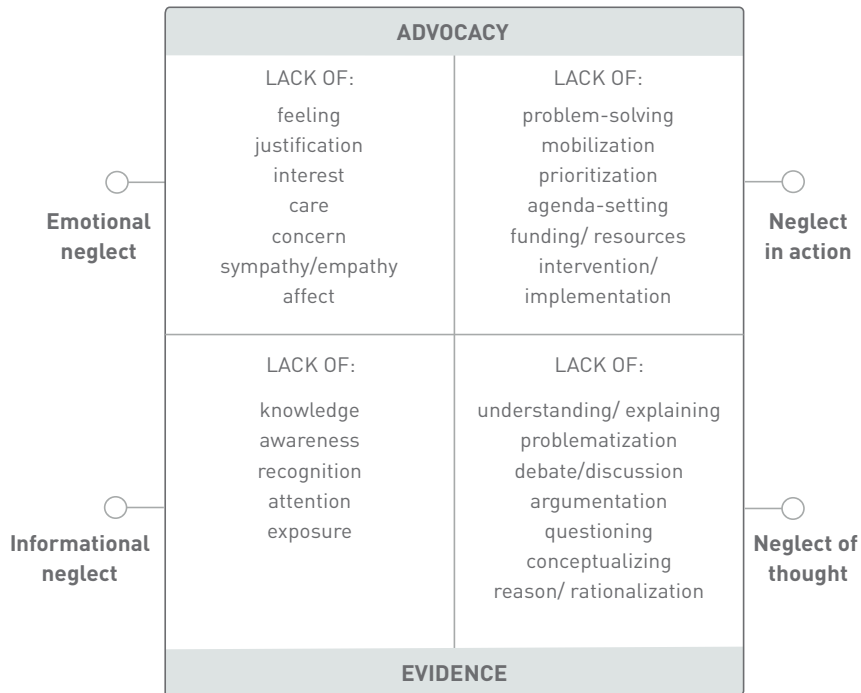
(Adams, 2016). I similarly aimed to highlight what is displaced, sidelined or de-prioritized and worth revisiting in the process of measurement. This eventually led me to address the question of what makes human rights and a humanitarian approach a difficult route to take in approaching policy problems and why an economic development lens of policy packaging is preferable.

### **8.1.2 The concept of neglect in policy**

What has this study of advocacy and measurement contributed to an understanding of neglect in policy? Where are we left with NTDs? NTDs are defined first by what they are not, as the opposite of attention and care. A multitude of descriptors point towards the reasons why something is neglected. This is through an absence, a lack of, or not enough attention and care. Having carried out my research, I have assembled these descriptors, which I see as responses to a type of neglect into a typology. In suggesting a typology I did not want to fall into the trap of what McGoey describes of in ignorance studies of trying to address "immeasurable ways of saying nothing" (2012b, p. 7). Applying scales of neglect would be a difficult undertaking to qualify but types of neglect is something that I did observe.

It became apparent to me that there are different types of neglect in the problem understanding and solutions proposed for policy problems. There are numerous opposites to neglect that exist on a scale from acknowledgement, to attention, and to care. Determining what type of neglect is faced will have implications for response to policy problems. Thus 'neglect' as a policy characterization in the case I have looked at has spanned emotional neglect, informational neglect, neglect of thought, and neglect to act, as contributions to the understanding of policy problems.

This typology has some similarities with four components that Nimmo outlined in his 1974 book 'Popular images of politics: a taxonomy', in how an image of a policy problem is projected and perceived. He identifies how an image is represented as being: perceptual (through direct observation or a processing of information), affective (with feeling or emotion), cognitive (in interpretation or thought), and conative (for action potential) (ibid., p. 9). Nimmo's typology has had limited influence outside research on political campaigning and communication but I see parallels with how political images are represented and perceived, and how policy problems are perceived and responded to. Figure 19 shows how I view neglect as being grouped across four aspects: neglect in information, emotion, thought, and action. I see emotional neglect and neglect in action as being more connected with an advocacy response and informational neglect and neglect of thought as closely related to an evidence response. I go on to consider the four aspects of neglect I have identified one by one.



**Figure 19 A typology of neglect in policy**

**(a) Information**

Information and informational arguments are used to persuade or rank. Information can often be considered as being the first step to provoke emotion, action and thought (although activity might also be spurred through the action of social movements or thought applied to an issue). If information is lacking or what is used to inform policy is not supportive, a policy problem may have difficulty in getting traction. I have explored how information is used through the metrics to measure neglect and present evidence on NTDs, as well as interaction of metrics with audiences through public discourses of measurement (in Chapter 7). Informational neglect may be uneven, depending upon who is finding and presenting the information. We take it as given that everyone does not possess equal information. Economists will call this inequality of information 'information asymmetry', where some hold more information than others and it is a further question as to whether is it the right information (Wankhade & Dabade, 2010).

**(b) Emotion**

I discussed emotion and the relationship with information through the philosophy and social movement 'effective altruism' (EA) in Chapter 7. EA tries to remove the emotion from philanthropy or at least not let it play centre stage. As Warren, the director of the GND, described for epidemiology it is, "...compassion with the tears wiped away" (Keating, 2014, p. S29), therefore emotion has been viewed in the past to somehow degrade serious thought and work. However, as a topic of study, emotion has seen an entry into STS discussions, as response to social issues and as a driving force. Sympathy or empathy is an emotional connection to an issue, which causes attention, interest, awareness, and recognition or more

strongly concern and care. I noted in the previous chapter that emotion has been devalued as a persuasion tool and seen to interfere with the measurement of impact and effectiveness, both through the earlier trend of 'Scientific Philanthropy' to 'Philanthrocapitalism' and more recently EA. Despite a contentious status it remains closely tied to philanthropy.

Public health is another area where emotion is an important aspect. Also in the previous chapter I showed how emotional neglect played a part in response to the HIV/AIDS crisis through the 'emotions work' that was needed. Care, as an emotion of concern or interest is also a defining feature of public health. This spans from micro level caring for the sick to the macro of caring for populations and caring about what makes them sick. I have also shown that measurement is a form of caring, further confirming that emotion should not be discounted as a response to neglect.

### **(c) Action**

Lack of action may appear to be a straightforward form of neglect. Social movements exemplify action but there are also other forms, as with policy movements that I discussed in depth in Chapter 6. Action through policy movements has happened through the repackaging of NTDs, where the term 'tropical diseases' became NTDs. Other ways of describing policy action in the literature have been through 'modes of coordination' or 'regimes of action' (Jessop, 1999). The ways in which caring in global health is connected to action through the ability or capacity to care is described by Reubi et al.:

*"The ability and will to care, in turn, is shaped by the complex, multi-scalar politics and resource flows that condition so much of the global health enterprise. Care implies a need for empathy, responsibility and duty just as much as it does the fair distribution of medical services and resources and the capacity to access and make use of these"* (Reubi et al., 2015, p. 4).

Care is not possible without being able to to distribute medical services and resources, and also to allow access. As described in Chapter 6, much of the activity of a policy movement to create the NTD brand took place in the UK and US, as places of 'high politics' of global health (Storeng & Béhague, 2014, p. 266). A spotlight on this activity through media attention and the skew towards the UK and US in the main events and milestones of the policy movement<sup>182</sup> have meant that the actions of endemic countries have not been well acknowledged, across media, academic and policy circles. While various societal actors can take action (government, big pharma, philanthropy, and international organizations) some actions are more prominent than others.

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<sup>182</sup> The main events and milestones of the policy movement include: The first NTD paper, Global Network, London Declaration, Presidential Initiative on NTDs and the DIFID commitment.

#### ***(d) Thought***

Responding to a global health problem is not only grounded in action, information, and emotion but in thought, too. This is the thoughtful reflection of what problems mean, what is involved, and what is at stake. The theory Chapter 3 began with exploring the literature on policy problems and carried this throughout the thesis. I have understood 'thought' as analytically putting information to work, whether it is to present arguments, structure discussions and debates, make arguments, or problematize issues. For NTDs, thought has been the conceptual work on the NTD brand and the accompanying policy rationale, discussed in Chapter 6. Thought is presumed to put to use reason, rationality, and morality but can also be an argumentative activity, involving justification and rationale. Rationale and incentive can be both emotional and thought-based (as explored in the previous chapter).

Some of the responses to neglect clearly cut across type and there may be overlap. I am aware of the danger in perpetuating dualities or dichotomies (for example between emotion and information already discussed), and potentially drawing lines where they do not truly exist. I argue that this typology is a heuristic to question what is meant by neglect and also an acknowledgement that in sorting meaning we actively place ideas into camps. More widely, this typology seeks an expansion of enquiry for the sociological study of absence and ignorance of problems, which pertain in the main to a lack of or suppression of information (and associated knowledge).

### **8.1.3 Who is responsible?**

Responsibility lies behind information, action, emotion, and thought for NTDs. But where does it lie and with whom? For issues where neglect has become a synonymous characterization, responsibility may appear clearer. For example medical neglect takes place on an individual basis with a doctor or hospital's failure of a duty of care to a patient. Sometimes responsibility can also fall on individuals for not caring for their health adequately (e.g. illness related to obesity or smoking) (Herrick, 2009) or wider institutional, governmental and societal reasons that make medical neglect systematic. Responsibility can shift, as with drug and alcohol abuse, blame can be a moral judgment of behaviour or blamed on being an illness (Martin, 1999).

The agency assigned to the neglected party becomes central. Child and elder neglect are more obvious examples, as the neglected are viewed as weaker and more vulnerable, with a duty of care from the parents, guardians or carers. Child abuse and neglect had to be accepted as a concept (Hacking, 1991), before legal protection and recompense was possible. The first legal case of physical child abuse occurred in 1874 but as the concept had not yet found a legal form it had to be brought forward by the American Society for the Prevention of Cruelty to Animals

(Markel, 2009).<sup>183</sup> It is an example of how neglect can also be systemic even on an individual basis in legal, policy, political, cultural, or social systems. Similarly, the label of neglect was required for the policy problem of NTDs to be identified and dealt with.

NTDs are a complicated proposition to assign blame because of the many societal actors involved. More generally societal neglect is a failure to care when one should and it may include all societal actors, with varying responsibilities. Responsibility for health can be thought of being grouped in the following major areas: personal, governmental, social and environmental (Collins, 2004). The social and environmental perspective has gained ground through the rise of epidemiology looking at health of populations and the governmentality of the populace with responsibility for health placed with the state. The balance between personal and societal responsibility moves back and forth, such as how now epidemiology is interested in individual risk factors of disease and government taxes 'unhealthy' individuals (e.g. sugar, alcohol, cigarettes).

If responsibility is spread amongst various actors as with NTDs, this returns to the question of how it is divided, whether equally or to varying degrees. Big pharma is thought to supply the drugs and innovation or R&D. Whether they need incentives or not to do this has been debated, as has who pays – the donation of drugs was not straightforwardly arrived at. Similarly governments of donor countries and international organizations such as the UN have provided most of the funding for NTDs. Funding has more lately switched to philanthropic foundations including the Gates Foundation and endemic countries themselves, especially innovative developing countries such as Brazil and China.

The expectations of various actors will also change, as big pharma is expected to have a larger corporate social responsibility role, and governments are expected to provide more than access and encompass: "...sanitation, pollution control, food and drug safety, health education, disease surveillance, urban planning and occupational health" (Resnik, 2007, p. 444). Although I have presented how neglect can be thought of as lacking across four areas (information, emotion, action and thought), simply identifying types of neglect, does not assign agency, causality or answer why neglect occurs. The next section will look at questions about the role of neglect in policy that are broader than the case of NTDs.

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<sup>183</sup> Child neglect cases are reported as the most frequent form of child abuse (NSPCC, <https://www.nspcc.org.uk/preventing-abuse/child-abuse-and-neglect/neglect/>, Accessed 2/4/14)



## 8.2 New questions raised, recommendations, and implications

What then are the perceived conceptual weaknesses and future research directions for 'neglect' arising from this thesis, in order to go beyond the case of NTDs? A first consideration to make is that NTDs do not have the monopoly on neglect in global health, despite their name. Neglect can also be part of being a high-profile disease. The relationship between NTDs and the big three has been a constant theme throughout this thesis. Malaria, the non-neglected tropical disease, is exemplary of the continuum of neglect that diseases exist on, until the event of control, elimination, or (unlikely) eradication. As Kelly and Beisel describe:

*"Despite that attention, neglect remains central to malaria's high profile. After the first malaria eradication campaign was abandoned in the late 1960s, funding for malaria-specific health interventions decreased dramatically, causing case numbers to soar... That narrative of abandonment and resurgence, we suggest, is linked to a military industrial concern: an-all-or-nothing commitment that links health advances to technological innovation and pathogen-obliteration, constituting malaria anew along untapped markets and neglected fronts" (2011, p. 72)*

What did it mean for malaria to be neglected, un-neglected, and then neglected again, with the characterization as such? Viewing malaria alongside NTDs, I have found that neglect is a part of the attention that diseases received in the past, how attention has accelerated, and then regressed again. The way of dealing with neglect in the case of malaria is all-out warfare, either everything is thrown in or nothing. A cycle of neglect and attention is also accompanied by memory and amnesia. These are forgotten events, places, people, a collective amnesia, purposeful or accidental, "...cycles of public health amnesia, memory and neglect" (ibid., p. 71). As such, neglect is an enigmatic and increasingly used concept in policy to identify global problems, which warrants further study.

## 8.3 NTDs today: Taking out the 'neglect'

A second consideration provoked by this thesis, is what we are left with when an issue once labeled as neglected is no longer (neglected)? No longer neglected is something that does need to be qualified. Taking the example in Chapter 1, Sudeepa Abeysinghe (2015) saw ignorance claims about NTDs as a call to action. It is not only claims on the grounds of information that invokes action. As I have shown through the typology of neglect, ignorance (through lack of knowledge or information) is only one part corrected by addressing neglect. It is possible then for claims to be made on aspects of neglect on the grounds of emotion, thought and action, but all may not be addressed equally.

However, what if all aspects of neglect are addressed? I have shown the characterization of neglect to be an ongoing process, but what happens when it reaches some sort of desired end? This is part paradox of language, as to call something neglected can be reasonable from the outset but then become contradictory as it reaches a conclusion, with the term being used more and the issue addressed. The strategic power of the neglect label as a discursive construct can be diminished or even become detrimental and if this happened the question would remain what would replace it? My contention is the need for a straightforward and cohesive policy transformation of disease is inherently problematic. NTDs could be no longer be neglected but that does not mean the problem is solved. Action taken could be ineffective, counterproductive or even cause unintended adverse consequences. Therefore the characterization of neglect will not necessarily mean that NTDs are dealt with in the best way possible.

Furthermore, truly neglected issues and topics may be those that are not identified as such in the first place (as found in the sociological 'absence' and 'ignorance' literature). Or some policy problems are not addressed because they are judged not to be neglected enough but require ongoing or new types of support. This quandary of neglect can be demonstrated further through emerging diseases (HIV/AIDS, Ebola), re-emerging diseases (as a threat it was not previously seen with dengue and Zika) and persistent diseases (malaria and polio, with polio continuing to be elusively close to eradication). Neglect rarely reaches an end point in global health – we can only come close to saying this with smallpox, eradicated from the world. Even then, there is a continued threat (as noted previously) and it can also have uses, for example in research.

'Emergence' and 're-emergence' are related topics to 'neglected' and 'un-neglected' in policy problems, pertinent to global health. Emergence relates to the increase in incidence of a disease but also whether it is recognized, while neglect more specifically relates to the policy reaction and implies that it is not enough or insufficient in some way. In how I have criticized the way that the term 'politicized' is used in policy, to call something neglected, de-neglected, or re-neglected should also not be self-evident and it is important to qualify such claims. The compulsion to create categories to place diseases into does not seem to be diminishing. According to the WHO an emerging disease is "...one that has appeared in a population for the first time, or that may have existed previously but is rapidly increasing in incidence or geographic range".<sup>184</sup> The fear of emerging diseases and interest in this category does not look to decrease soon and this clearly has an intimate relationship with neglect. Emerging diseases (whether newly emerging or re-emerging) exist in a world of already established health priorities, disease hierarchies, and competing policy agendas.

A number of outbreaks and epidemics have arisen from diseases originating in poor communities in tropical and semi-tropical regions but with global implications. However, interest in these diseases is also connected to how they affect more affluent countries. Indeed the

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<sup>184</sup> WHO [http://www.who.int/topics/emerging\\_diseases/en/](http://www.who.int/topics/emerging_diseases/en/), Accessed 2/4/14.

Ebola outbreak has opened a door for dialogue on wider lessons for global health security (Heymann et al., 2015).<sup>185</sup> Jackson and Stephenson (2014) similarly view a connection between NTDs and emerging infectious diseases (EIDs) as both socio-political constructs, arguing that the foregrounding of NTDs relates to the prioritization of 'free market, Global North interests' through EIDs. They view the neglect of NTDs is on humanitarian terms, an argument that is seldom made for these diseases apart from at the beginning of their construction in the early WHO reports discussed in the last chapter stating: "We suggest that 'neglect' reflects the rise of a secular humanitarian global health moral not only in the Global North but more pervasively" (ibid., p. 997).

Therefore neglect materializes when we think of health as being a global moral duty deserving of humanitarian intervention. Instead of repeating the 'right to health' humanitarian approach Jackson and Stephenson (2014) invoke action to address neglect as part of the 'right to development'. This approach is a symbiosis of the dominant economic development approach and the mostly disregarded humanitarian approach to NTDs on the global stage. Rather than a view of health in times of emergency, the everyday reality of health is employed for the priorities of international security, design of global infrastructures, and the practices of global governance.

Critical security studies (CSS) theorists such as Joao Nunes (2013) have been considering how health problems can be constructed in certain ways.<sup>186</sup> As Nunes argues for Zika: "While the world is only now beginning to see Zika as an emergency, the conditions that have enabled the spread of the virus and hindered response are "everyday emergencies" for millions of Brazilians" (2013). Nunes with other CSS and International Relations (IR) theorists interested in global health have been influenced by STS. The impact of technical instruments, and scientific practices that permeate international affairs, means that the interdisciplinary field of STS and IR is challenging existing conceptual approaches, and proving insightful to the global challenge of public health (Mayer, et al., 2014). The combination of STS and IR policy ideas could shed new light on neglect in policy across sites of poverty, conflict, and emergency, especially if there were to be overlap with 'critical public health'.

It is at the intersection of disciplines that future research on global health policy looks most promising and mirrors the fundamental changes afoot. The global relations, governance, and politics of health are one example of the challenge of NTDs that manifests as security and IR

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<sup>185</sup> Heymann has highlighted that attention to collective health security is not enough, we also need to acknowledge individual health security: "This is security that comes from access to safe and effective health services, products, and technologies" (ibid., p. 1884). The idea of collective health security has dominated in IR, with the focus being on contagion of infectious diseases across countries, where the political impact of disease across countries is one of emergency. Note some tropical diseases do involve vectors that travel (e.g. dengue) and people who move with disease (e.g. Chagas) (Hotez, 2014).

<sup>186</sup> Critical security studies consider the intentions of international actors, their relations with one another, as well as overarching international policy trends. The characterization of disease and rationales for intervention become spheres of contestation and collaboration between countries, and for the negotiation of policy.

problems.<sup>187</sup> These types of problems involve how countries and international bodies interact on global health issues, overlapping between the critical security studies literature and sociological approaches to security.

Looking forward, neglect in policy requires policy packaging that can encompass more disciplinary lenses than the economic development packaging allows. This thesis has made a first step towards analyzing neglect as an important concept for understanding policy problems, both in terms of how actors use neglect to make certain claims about a problem but also for unraveling the dynamics that allow policy issues to rise in prominence or not. I have argued that neglect in policy is not to know (information), not to care (emotion), not to think about (thought), and not to act on (action). All social actors in global health are implicated, and responsible to varying degrees, but it is under these constraints that advocacy through an activist scientist policy movement, and evidence in the production and use of measurement metrics has come about.

As an in-depth study of NTDs, drawing mostly on STS and public policy theory, this research does stand somewhat in isolation. However, if the sociology of absences and ignorance literature and also critical security studies can be further incorporated, it would make for a more encompassing view of neglect in policy. This would be part of a future agenda in the critical consideration of how policy problems compete, rise in prominence, and coincide.

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<sup>187</sup> NTD specialists Hotez and Pecoul have explored how NTDs destabilize poor societies and contribute to civil or international conflict, affecting agricultural productivity and food security (Hotez & Pecoul, 2010, p. 5).

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## 10 Appendix

<b>News</b>	BBC (5), Financial Times (3), The Guardian (10), The New York Times (6)
<b>Blogs</b>	BMJ (3), Wellcome Trust (4)
<b>High-profile science journals</b>	Lancet (18), Nature (12), Science (3)
<b>Reports</b>	WHO (11), Uniting to Combat NTDs (2)
<b>Websites</b>	WHO (12), CDC Website (7)
<b>PLoS Journals</b>	PLOS Medicine (4), PLOS Neglected tropical diseases (20)
<b>Health and social science journals</b>	Health & place (2), Health research policy and systems / BioMed Central (4), História, Ciências, Saúde-Manguinhos (2), International journal of epidemiology (3), Research Policy (4), Social Epistemology (3), Social Studies of Science (7), Minerva (2)
<b>Books</b>	Robert Desowitz (6)

### Appendix 1 Source type cited more than once in thesis

	Type	Organisation	Location
1.	Universities	University of Sussex	Phone
2.	Universities	LSHTM	London
3.	Universities	LSHTM	London
4.	Universities	LSHTM	London
5.	Universities	LSHTM	Skype
6.	Universities	LSHTM	London
7.	Universities	LSHTM	London
8.	Universities	LSHTM	London
9.	Universities	LSHTM	London
10.	Universities	LSTM	Phone
11.	Universities	University of Johannesburg	Phone
12.	Universities	University of Oxford	London
13.	Universities	Universidade de São Paulo	São Paulo
14.	Universities	Universidade de São Paulo	São Paulo
15.	Pharma companies	Novo Nordisk	Phone
16.	Pharma companies	Novartis	Phone
17.	Pharma companies	Medicines Australia	Phone
18.	Pharma companies	Novartis Foundation	Phone
19.	NGO	FIND Diagnostics	Phone
20.	NGO	DNDi	Phone
21.	NGO	The End Fund	Skype
22.	NGO	Link2China	Phone
23.	NGO	Policy Cures	Phone
24.	NGO	Global Network for Neglected Tropical Diseases	Phone
25.	NGO	Helen Keller International	Phone
26.	Governance Institutions	WHO TDR	Phone
27.	Governance Institutions	WHO	Geneva
28.	Governance Institutions	WHO Regional Office	Phone
29.	Governance Institutions	APPMG	London
30.	Governance Institutions	ECDC	Stockholm
31.	Governance Institutions	World Bank	London
32.	Activist Scientists	Cambia	Skype
33.	Activist Scientists	The Synaptic Leap	Sydney
34.	Activist Scientists	SCI	London
35.	Activist Scientists	Sabin Vaccine Institute	Phone
36.	Activist Scientists	LSTM	1x Phone

			1x London
37.	Research Institutes	Swiss TPH	Basel
38.	Research Institutes	Institute of Tropical Medicine	São Paulo
39.	Research Institutes	Fiocruz	São Paulo
40.	Research Institutes	National Institute of Parasitic Diseases	Shanghai
41.	Research Institutes	Drug Discovery Centre for Tuberculosis	Shanghai
42.	Research Institutes	Drug Discovery Centre for Tuberculosis	Shanghai
43.	Research Institutes	Tsinghua University	Beijing
44.	Research Institutes	NOKC	London
45.	Research Institutes	CDTS	Rio de Janeiro
46.	Research Institutes (Group Interview)	National Institute of Parasitic Diseases	Shanghai

**Appendix 2 Interviews by organizational type and location**

**Information Sheet for Interviewees in Research Fieldwork**

'The policy development of neglected tropical diseases'

Samantha Vanderslott, University College London, 22 Gordon Sq. London s.vanderslott.12@ucl.ac.uk

You will be given a copy of this information sheet. This study has been approved by the UCL Research Ethics Committee

We would like to invite ..... to participate in this research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Ask us if there is anything that is not clear or if you would like more information.

**Details of Study:**

This research aims to explore how have policy understandings and strategies towards NTDs changed over time. This involves asking: What has happened in the change of term and corresponding characterization of the disease group of tropical diseases to be renamed NTDs? As a policy idea, disease grouping, how are NTDs are characterized in terms of problem and solution?

To build case studies interviews have been arranged with individuals that have been involved in addressing NTDs, e.g. from research institutes, NGOs, pharma companies, universities, international organizations and government. Participants will be interviewed following a semi-structured interview guide and recorded if necessary.

Participants can also remain anonymous if they prefer and confidentiality of participant contact details will be maintained.

This research will be published in my thesis and any corresponding research papers or presentations. Participants are able to have access to the final research if requested.

It is up to you to decide whether to take part or not. If you decide to take part you are still free to withdraw at any time and without giving a reason.

**Informed Consent Form for ..... in Research Studies**

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

'The policy development of neglected tropical diseases'

This study has been approved by the UCL Research Ethics Committee

Thank you for your interest in taking part in this research. Before you agree to take part the person organising the research must explain the project to you.

If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you to decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

**Participant's Statement**

I .....

- have read the notes written above and the Information Sheet, and understand what the study involves.
- understand that if I decide at any time that I no longer wish to take part in this project, I can notify the researchers involved and withdraw immediately.
- consent to the processing of my personal information for the purposes of this research study.
- understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.
- agree that the research project named above has been explained to me to my satisfaction and I agree to take part in this study.
- I understand that my participation will be taped/video recorded and I am aware of and consent to, any use you intend to make of the recordings after the end of the project.
- I agree to be contacted in the future by UCL researchers who would like to invite me to participate in follow-up studies.

Signed:	Date:
<p><b>Interview Guide</b></p> <p>Research question: How have policy understandings and strategies towards NTDs changed over time?          What has happened in the change of term and corresponding characterisation of the disease group tropical diseases to be renamed NTDs? As a policy idea and disease grouping how are NTDs characterised in terms of problem/solution?</p> <p>1.To begin with can you tell me a little about your background? What drew you to NTDs or your disease more specifically?</p> <p>2.What is your account of how tropical diseases were given the label neglected? Who were the key actors? What was the timeline of events?</p> <p><u>Brand</u></p> <p>1.Do you think there is an NTD brand? What is it? What are the positives and negatives? What do you think of health branding generally? Are there any changes/clarifications you would like to make to the brand (e.g do you use some terms interchangeably like Neglected Parasitic Diseases)? What will happen after NTDs receive more attention (and the neglected becomes contested or redundant)?</p> <p>2.Have a group of scientists or public health advocates been instrumental in creating the NTD brand?</p> <p>3.What were your intentions, aims, strategies and methods? Was the basic intention to drive NTDs up policy agendas? How did you go about doing this and did you change your aims, strategies or methods along the way?</p> <p><u>Characteristics, criteria, individual diseases</u></p> <p>4.What are the defining features of an NTD? Does this follow the original 6 criteria of the WHO in the first report?</p> <p>5.Are there any diseases you think should be included that aren't or should be taken away? Why do you think zoonotic diseases have been more neglected and what can be done about this? Do you think other diseases of poverty should be included - diarrheal/waterborne diseases? Should the foodborne diseases be included?</p> <p>6.Why did the WHO list change from 13, to 17? Any reflections on other lists/ There appears to be outliers (dengue and rabies high mortality if ill, dengue affect middle class, dengue, Chagas, sleeping sickness limited strategy for intervention?)</p> <p>7.What has been the interaction of individual campaigns for diseases?: guinea worm, worms, leprosy, dengue, Chagas, trachoma, sleeping sickness historical intervention? Your disease?</p> <p><u>Key policy events</u></p> <p>8.How important do you think the London Declaration was? Who was responsible to the lead up for Gates and big pharma involvement? Why were other actors not so prominent (governments)? How does emphasis on drug donation and development relate to the need for say vector control?</p>	

**Appendix 3 Information sheet with informed consent and interview guide**

Free Nodes	Tree Nodes
(1) MDA (2) Big three (3) Malaria (4) Government (5) NGO (6) Gates Foundation (7) Epidemiology (8) Funding (9) Sanitation/water/hygiene (10) Awareness/acknowledgement (11) Neglect (concept) (12) Problem (13) WHO (14) MDGs (15) SDGs (16) Policy (17) Care/caring	(1) Evidence (1.1) Evidence-based medicine (1.2) Measurement (1.3) Metrics (1.4) 50 cents per person (1.5) DALY (1.6) 10/90 gap (1.7) RCTs (2) Innovation in solutions (2.1) R&D (2.2) IP (2.3) Pharma (3) NTD term (3.1) Branding (3.2) History (3.3) Classification (3.4) Categorization (4) Endemic countries (4.1) Global (4.2) Local (4.3) Brazil (4.4) China (5) Advocacy (5.1) Scientist advocates/ Activists (5.2) Media (5.3) Public

**Appendix 4 NVivo coding scheme node listing**

- 'Drugs for Neglected Diseases (DNDi) 10-year anniversary event', 4 & 5 December 2013 at Institut Pasteur, Paris, France
- 'Schistosomiasis Control Initiative Open Day' 2014, at Imperial College London, 26th June 2014 in London, UK
- 'Newton Fund ECR Workshop on Neglected Diseases' hosted by the University of Sussex, and the British council, 17 - 20th November 2015 Belo Horizonte, Brazil
- 'Advances in scientific research for NTD control' hosted by London Centre for Neglected Tropical Disease Research, 27 January 2016, London, UK
- 'ISNTD Coinfections & Comorbidities', Institute of Child Health, 29th April 2016, London, UK

#### Appendix 5 List of technical conferences for participant observation

<b>Disease specific reports and factsheets</b>	<ul style="list-style-type: none"> <li>• Report of the Eighth Meeting of the WHO Alliance for the Global Elimination of Blinding Trachoma (2004)</li> <li>• Making Progress Toward the Global Elimination of Blinding Trachoma (2006); and Trypanosomiasis, human African (sleeping sickness) (Factsheet N°259, 2015).</li> </ul>
<b>Special topic reports</b>	<ul style="list-style-type: none"> <li>• Global public-private partnerships: Part I--A new development in health? (Buse &amp; Walt, 2000)</li> <li>• Neglected diseases: A human rights analysis (Hunt, 2007)</li> <li>• Guidelines For Assuring Safety of Preventive Chemotherapy (First Edition) (2012b)</li> <li>• Health Product Research and Development Fund: A Proposal for Financing and Operation (WHO/TDR, 2016)</li> </ul>
<b>Material on specific diseases, the resolutions on NTDs as a grouping and recommended strategies, updated on WHO NTD webpages</b>	<ul style="list-style-type: none"> <li>• Immunization, Vaccines and Biologicals: Dengue (WHO Programmes <a href="http://www.who.int/immunization/diseases/dengue/en/">http://www.who.int/immunization/diseases/dengue/en/</a>, 2015, Accessed 2/4/14)</li> <li>• World Health Assembly adopts resolution on all 17 neglected tropical diseases (WHO, <a href="http://www.who.int/neglected_diseases/WHA_66_seventh_day_resolution_adopted/en/">http://www.who.int/neglected_diseases/WHA_66_seventh_day_resolution_adopted/en/</a>, 2013, Accessed 2/4/14)</li> <li>• Why are some tropical diseases called "neglected"? (WHO Features <a href="http://www.who.int/healthinfo/global_burden_disease/metrics_daly/en/">http://www.who.int/healthinfo/global_burden_disease/metrics_daly/en/</a>, 2012, Accessed 2/4/14)</li> <li>• The 17 neglected tropical diseases (WHO, <a href="http://apps.who.int/iris/bitstream/10665/152781/1/9789241564861_eng.pdf">http://apps.who.int/iris/bitstream/10665/152781/1/9789241564861_eng.pdf</a>, 2015, Accessed 2/4/14)</li> <li>• Metrics: Disability-Adjusted Life Year (DALY) (WHO Programmes <a href="http://www.who.int/healthinfo/global_burden_disease/metrics_daly/en/">http://www.who.int/healthinfo/global_burden_disease/metrics_daly/en/</a>, 2015b, Accessed 2/4/14).</li> </ul>

#### Appendix 6 Key WHO reports

<b>Methodological consideration to study absences</b>	<b>Use in thesis</b>
1) Develop causal analyses	Explanations over description and look for structural conditions
2) Extend and challenge explanatory symmetry	'Otherness' of tropical disease and NTDs
3) Specify the type or form of absence under investigation	What does neglect mean and to whom? What sort of thing, condition, process and outcome? Who are the actors, sets of knowledge, discourses, infrastructures and techniques?
4) Define the subject	Set scope using concise and conceptually bounded definitions
5) Identify case parameters	Consider history, culture and organizational contexts
6) Measure the shapes of absence	Characterize the environment, place and institution to measure temporal or spatial terms; their status, flow over time in an area, organisational domain and cultural terrain
7) Measure the relations of absences	I primarily do this spatially, geographically and historically
8) Measure densities of absences	Draw upon existing statistics and network analyses (e.g. GFINDER for NTDs)
9) Pursue strategic comparison	Comparative studies to understand processes and outcomes
10) Nurture a modest reflexive awareness	Reflect my terms, understanding and why I use them

#### Appendix 7 Frickel study of absences and relevance for neglect (Adapted from Frickel, 2014, p. 89-90)

Disease	Description	Is it an NTD?
<b>Fevers</b>		
1.Malaria	One of the 'big three' not a neglected tropical disease.	not neglected
2.Yellow Fever	Has a vaccine so now not a neglected tropical disease.	not neglected
3.Plague	Disease caused by bacterium yersinia pestis, usually transmitted from bite of rodent flea carrying bacterium or handling infected animal. Treated by antibiotics. Cases occur in Africa and Asia.	not neglected
4.Dengue	Dengue (grouped with chikungunya by the WHO).	yes
5.Mediterranean Fever	Familial Mediterranean fever a genetic disorder causing recurrent febrile polyserositis prevalent in individuals of Mediterranean descent. Also known as Armenian disease (Zadeh, Getzug, & Grody, 2011). Disease associated with 'tropical people' but would be likely called a genetic disease today.	not tropical
6.Japanese River Fever	Japanese Encephalitis.	not neglected
7.Kala-azar	Kala-azar or visceral leishmaniasis one of three forms of leishmaniasis, caused by protozoan organism, transmitted by sand fly bites (also called Assam fever, black fever, dum dum fever).	yes
8.Tropical typhoid	Infectious bacterial fever treated by antibiotics and a vaccination exists.	not neglected
9.Heat-stroke	Fever when exposed to excessively high temperatures.	not neglected
10.Unclassed Fever	(today there is an argument that malaria is over-diagnosed leading to the category of unknown febrile illness).	not neglected
<b>General diseases of undetermined nature</b>		
11.Beriberi	Nutritional deficit of thiamine (vitamin B1).	not tropical
12.Endemic Dropsy	Results from cooking with mustard oil, especially N. India (Purnell, 2012).	not neglected
13.Negro Lethargy or Sleeping Sickness	African trypanosomiasis or sleeping sickness.	yes
<b>Abdominal diseases</b>		
14.Cholera	Varyingly understood as an imported disease to L. America.	not tropical
15.Dysentery	Type of gastroenteritis caused by a number of types of infection (bacteria, viruses, helminths or protozoa).	not tropical
16.Endemic Gangrenous Rectitis	Disease affecting children in S. America). Also called epidemic gangrenous proctitis, Caribi, Indian Sickness, El Becho.	not neglected
17.Hill Diarrhea	Hill diarrhea or tropical diarrhea are symptoms of tropical sprue.	not neglected
18.Sprue	Tropical Sprue syndrome characterized by acute/chronic diarrhea, weight loss, and malabsorption of nutrients. Exact causative factor unknown, but thought to be intestinal microbial infection (Clarke, Katz, Adediji, & Ozick, 2014).	not neglected
19.Tropical Liver	Hepatitis A, B, C, E (See Beeching & Dassanayake, 2011).	not tropical
20.Abscess of the Liver	Amebic liver abscess is a collection of pus in liver in response to intestinal parasite. Infection occurs worldwide, but is most common in tropical areas where crowded living conditions and poor sanitation exist (U.S. National Library of Medicine, 2013).	not tropical
21.Infantile Biliary Cirrhosis	Linked to copper exposure in Indian families possible through water supply, cooking materials or storage containers (Nayak & Chitale, 2013). Also known as Indian childhood cirrhosis (ICC).	not neglected
22.Ponos	Same as kala-azar or visceral leishmaniasis, however could more specifically refer to disease occurring in young children in Greek islands, possibly infantile form of visceral leishmaniasis (Kontos & Spais, 1989; Macpherson, Meslin, Wandeler, Eds., 2000).	not neglected
<b>Infective granulomatous diseases</b>		
23.Leprosy	Leprosy or Hansen disease.	x
24.Yaws	Yaws or Endemic treponematoses.	x
25.Verruga Peruana	Vector-borne disease found in Andean Valleys of Peru, where severe form is 'Oroya fever', followed by chronic stage verruga peruana and treated with antibiotics (Rothe, 2014, p. 211).	not neglected
26.Ulcerating Granuloma of the Pudenda	Also know as granuloma inguinale or donovanosis a bacterial disease treated by antibiotics.	not neglected
27.Oriental sore	Cutaneous leishmaniasis, a second form of leishmaniasis.	x
<b>Animal parasites and associated diseases</b>		
28.Filaria Nocturna	Elephantiasis or lymphatic filariasis.	x
29.Filaria Diurna	Type of filaria parasite (Clemow, 2011; Hindle, 2011).	unknown
30.Filaria Demarquaii		
31.Filaria Ozzardi		
32.Filaria Perstans		
33.Filaria Magalhaesi		
34.Bilharzia Haematobia & Endemic Haematuria	Schistosomiasis or snail fever.	yes
35.Filaria Medinensis	Guinea worm or dracunculus.	yes



36.Filaria Loa	Loiasis caused by Loa Loa eye worm, occurs in rainforest and swamp areas of W. and C. Africa, transmitted by bites of mango or deer fly and can cause localized swellings (DNDi, 2015).	not neglected
37.Filaria Volvulus	Onchocerciasis or River Blindness.	yes
38.Craw-craw	Skin disease occurring in West Africa, some cases caused by Onchocerca.	unknown
39.Distomum Ringeri & Endemic Haemoptysis	Foodborne parasites.	not tropical
40.Distomum Conjunctum		
41.Distomum Sinense		
42.Pentastomum Constrictum	Intestinal infection of larvae through contact with animals.	unknown
43.Trichocephalus Dispar	Whipworm or trichuris trichiura is a soil-transmitted helminth.	yes
44.Ascaris Lumbricoides	Roundworm or ascaris lumbricoides is a soil-transmitted helminth.	yes
45.Ankylostomum Duodenale and Ankylostomiasis	Hookworm or Ancylostoma duodenale and necator americanus, are types of soil-transmitted helminths.	yes
46.Strongylus Subtilis	Disease caused by roundworm and found in the small intestine in native Egyptians and in intestine of the camel (F. E. G. Cox, 2002).	unknown
47.Amphistomum Hominis	Gastrodiscoides hominis is a large fluke - type of flatworm found in pigs and humans, constituting important parasite of humans in Assam, Indian, the Philippines and Southeast Asia (Dada-Adegbola, Falade, Oluwatoba, & Abiodun, 2004).	
48.Distomum Heterophytes	Type of tapeworm, found in dogs.	
49.Taenia Nana	Now called dwarf tapeworm/ hymenolepis nana. Most common in temperate zones. One of most common intestinal worm/helminth infecting humans, especially children (CDC <a href="http://www.cdc.gov/parasites/hymenolepis/">http://www.cdc.gov/parasites/hymenolepis/</a> , 2012, Accessed 14/4/16).	not tropical
50.Taenis Madagascariensis	Type of tapeworm.	unknown
51.Bothriocephalus Mansoni	Former name for Spirometra mansoni a tapeworm of wild and feral cats, larval form of which (sparganum) may survive in human tissues with few human cases mostly southeast Asian countries (CDC <a href="http://www.cdc.gov/dpdx/sparganosis/">http://www.cdc.gov/dpdx/sparganosis/</a> , Accessed 14/4/16).	
52.Larvae of Diptera	Filamentous fungi associated with mosquito larvae (Pereira, Sarquis, Ferreira-Keppler, Hamada, & Alencar, 2009).	
<b>Animal parasites and associated diseases</b>		
53.Prickly Heat	Also known as miliaria rubra is a rash of small red bumps caused by blockage of sweat glands.	not neglected
54.Sloughing Phagedaena	Also called tropical ulcer, it is a lesion rapidly spreading and associated with clouging or gangreen.	not neglected
55.Boils	A bacterial or fungal infection that affects groups of hair follicles and nearby skin tissue (U.S. National Library of Medicine, 2014a).	not tropical
56.Pemphigus Contagiosus	Rare, autoimmune disease affecting skin and mucous membranes in small percentage of population (NIH, 2015).	not tropical
<b>Skin diseases</b>		
57.Mycetomia or Madura Foot	Also known as eumycetoma, a fungal or bacterial skin infection common in tropical and sub-tropical regions.	not neglected
58.Dhobie Itch	Also known as tinea cruris, a fungal infection on the skin of the groin region treated by antifungal medication.	
59.Tinea Imbricata	Superficial fungal infection of skin, endemic in some islands of S. Pacific (Polynesia), SE Asia, Central and S America, and Mexico (Bonifaz, Archer-Dubon, & Saúl, 2004).	
60.Pinta	Skin disease in Mexico, Central America, and South America.	
61.Piedra	Hair disease caused by fungus.	
62.Chigger	Chiggers are a mite whose bite causes severe itching (U.S. National Library of Medicine, 2014b).	
63.Myiasis	Infection with a fly larva, usually in tropical/subtropical areas (CDC <a href="http://www.cdc.gov/parasites/myiasis/faqs.html">http://www.cdc.gov/parasites/myiasis/faqs.html</a> , Accessed 14/5/16)	
<b>Local diseases of uncertain nature</b>		
64.Goundou or Anakhre	A historical form of yaws that has now disappeared (Mafart, 2002).	not neglected
65.Ainhum	Also called dactylolysis spontanea, condition involving a constriction of base of fifth toe, affects black patients in tropical regions and etiology may be genetic (Selden & Elston, 2015).	

**Appendix 8 Manson list of 65 tropical diseases with detail**

(Adapted from Manson, 1898).

NTD	Status	Type of control Strategy
<b>Diseases controllable by preventative chemotherapy</b>		<b>MDA control</b>
Soil transmitted helminths (STH)	Over 1 billion infected globally	Annual treatment with albendazole or mebendazole
Schistosomiasis (Bilharzia)	200 million infected – mostly in Africa from water contact	Treatment with praziquantel, improved water supplies,
Lymphatic filariasis (elephantiasis)	120 million infected in Africa and the Indian sub continent, but elimination is possible	Administrations with albendazole + Mectizan (in Africa) or albendazole + DEC (elsewhere)
Trachoma (preventable blindness)	80 million infected, 8 million visually impaired – eliminated from Morocco	Annual treatment with Zithromax, as part of a “SAFE” strategy
Onchocerciasis (River blindness)	50 million infections in Africa	Control of symptoms by annual treatment with Mectizan
		<b>Provision of filtered water</b>
Dracunculiasis (Guinea worm)	Close to eradication Individual case finding and case containment	
<b>Diseases requiring individual treatment</b>		<b>Case control</b>
Leprosy	Close to elimination	Case finding followed by multi drug therapy (Novartis)
Buruli Ulcer	Endemic in 30 countries in the Americas, Africa and SE Asia	Early diagnosis, treatment with antibiotics or surgery
Chagas disease	Limited distribution in South America – a disease of poor housing	Control of the bed bugs which carry the disease
Human African Trypanosomiasis	Narrow distribution in Africa dictated by Tsetse fly distribution	Case finding and treatment; vector control where appropriate
Cutaneous Leishmaniasis	1.5 million new cases for CL are considered to occur annually, with an estimated 12 million people occur annually, with an estimated 12 million people presently infected worldwide. 90% of cutaneous leishmaniasis cases occur in Afghanistan, Brazil, Iran, Peru, Saudi Arabia and Syria.	Early diagnosis and prompt treatment; control of sandfly populations through residual insecticide spraying of houses and through the use of insecticide-impregnated bednets;
Visceral Leishmaniasis	500,000 cases per year. 90% of all visceral leishmaniasis cases occur in Bangladesh, Brazil, India, Nepal and Sudan; fatal if untreated.	Case finding and treatment with meglumine antimoniate (Glucantime) or sodium stibogluconate (Pentostam).
Dengue	250 million at risk and 50 million cases per year in over 100 countries	Effective clinical management. Fluids and possibly transfusions Vector control
		<b>Animal zoonosis</b>
Neuro-Cysticercosis	Up to 20% infections in rural Africa and South America	Tape worm control and strict pig meat inspection
Echinococcus	Unknown numbers with cysts in liver	Tape worm control in dogs and careful surgery plus albendazole to remove unbroken cysts
		<b>Animal reservoir</b>
Brucellosis		Pasteurisation of milk
Rabies	Transmitted by dog bites	Vaccination

**Appendix 9 List of NTDs and control strategies for the All-Party Parliamentary Group on Malaria and Neglected Tropical Diseases**

(Adapted from APPMG, 2009)

(Shading shows preferred strategy)	Environmental-based strategy	Drug-based strategy
1.(blinding) trachoma	SAFE strategy of control. Facial cleanliness and environmental improvement by improving access to water and sanitation <b>(WASH)</b> .	Antibiotics to treat infection and surgery to treat the blinding stage of disease. <b>*MDA *targeted for global elimination by 2020.</b>
2.buruli ulcer	Early detection.	Antibiotics used (rifampicin/streptomycin) but larger lesions require surgery. Trials for oral drugs.
3.Chagas disease	Vector control most effective method of preventing transmission through improved housing and spraying insecticide inside housing to eliminate triatomine bugs. Also blood screening to prevent infection through transfusion and organ transplantation. <b>*targeted for control &amp; elimination (regional in the Americas, transmission interrupted by 2020)</b>	No vaccine is available. Antiparasitic treatment nifurtimox and benznidazole is used but pediatric drugs needed to cure patients early and a new drug for chronic disease. For both drugs, side effects are fairly common, and tend to be more frequent and more severe with increasing age.
4.cysticercosis/ taeniasis	Strict meat inspection, health education, thorough cooking of pork, sound hygiene, adequate water/sanitation, improved pig husbandry practices and easy treatment access	Anthelmintics oxfendazole and praziquantel administer through large-scale preventive chemotherapy in humans, and treatment and vaccination of pigs.
5.dengue and chikungunya	Dengue and chikungunya prevention and control solely depends on effective vector control measures, including management of household water storage that can create breeding places for mosquitoes <b>(WASH)</b> .	For dengue early detection/access to proper medical care lowers fatality rates below 1% but several vaccine candidates are in clinical/pre-clinical development. For both diseases there is no cure. Treatment is focused on relieving symptoms.
6.dracunculiasis (guinea-worm disease)	Endemic countries (Chad, Ethiopia, Mali and South Sudan) where surveillance systems working but need awareness among affected/at-risk populations <b>(WASH) *targeted &amp; close to eradication (the first of the parasitic diseases).</b>	No drug and no vaccine to prevent infection but can be prevented through safe drinking water.
7.echinococcosis	Prevention through deworming dogs, improved food inspection, slaughterhouse hygiene, public education campaigns, (vaccination of lambs being evaluated).	Often expensive and complicated to treat, and may require extensive surgery and/or prolonged drug therapy.
8.foodborne trematodiasis	Veterinary public health measures and food safety practices are recommended to reduce the risk of infection through faecal contamination: transmission is linked to human behaviour patterns related to sanitation, hygiene, cooking habits, methods of producing, processing and preparing foods <b>(WASH)</b> .	Safe and effective anthelmintic medicines prevent and treat foodborne trematodiasis: triclabendazole for fascioliasis and paragonimiasis, praziquantel for clonorchiasis, pisthorchiasis, paragonimiasis (can be administered through preventative chemotherapy where large numbers of individuals are infected).
9.human african trypanosomiasis (sleeping sickness)	No universal control methodology. Control/surveillance inc. active/passive case finding, diagnosis, treatment, patient follow-up, vector control, control animal reservoir. New rapid diagnostic test/ vector control needed <b>* targeted for country elimination in 80% of foci and global by 2020.</b>	Eflornithine (hard to administer), melarsoprol (for late stage, hard to administer, toxic and kills) and pentamidine (only for early stage). In 2009, NECT (Nifurtimox and Eflornithine Combination Therapy) introduced as first new, improved treatment option in 25yrs for stage 2 of disease.
10.leishmaniases (cutaneous leishmaniasis, visceral leishmaniasis or kala-azar, and mucocutaneous)	A combination of intervention strategies because transmission occurs in a complex biological system (diagnosis/case management, vector control, disease surveillance, control of reservoir hosts, social mobilization and strengthening partnerships)	Highly effective and safe anti-leishmanial medicines (particularly for VL - AmBisome). Need easy to apply treatments for CL and better treatment for ML. Access to medicines a problem but has significantly improved. <b>*VL targeted for elimination in Indian subcontinent by 2020</b>

11. leprosy (hansen disease - paucibacillary & multibacillary)	Information campaigns about leprosy in high-risk areas crucial so that patients and families historically ostracized from their communities, are encouraged to come forward and receive treatment.	Multi Drug Therapy (MDT) of antibiotics rifampicin and dapsone for PB leprosy patients as well as clofazimine an antimycobacterial for MB leprosy is bringing the disease to elimination. <b>*targeted for global elimination by 2020 and close.</b>
12. lymphatic filariasis (elephantiasis)	Alternative/equally effective community-wide regimen use of table salt/ cooking salt fortified with DEC for 1 year and improved wastewater management as vectors prefer breeding in organically polluted water and faecal matter found in poorly-constructed pit latrines ( <b>WASH</b> ).	Antiparasitic drug ivermectin used but need new medicines to kill/sterilize adult worms (also drugs to reverse or halt lymphedema). <b>*MDA *targeted for global elimination by 2020.</b>
13. onchocerciasis (river blindness)	Vector control is not considered feasible or cost-effective in the remaining APOC countries.	Antiparasitic drug ivermectin but no vaccine or medication to prevent infection with <i>O. volvulus</i> . <b>*MDA, targeted for regional elimination in L. America &amp; selected countries in Africa by 2020.</b>
14. rabies	Elimination of dog-mediated feasible given political will, adequate resources and diligent programme management - mass vaccination most efficacious to reduce incidence. <b>Targeted for regional elimination in Latin America, SE Asia, W Pacific regions.</b>	Vaccine and post-infection vaccine.
15. schistosomiasis (snail fever)	Preventive measures are avoiding wading, swimming, or other contact with freshwater in disease-endemic countries ( <b>WASH</b> ).	No vaccine or drugs for preventing infection but anthelmintic drug praziquantel effective. Need lower dose/ less bitter taste to make child-friendly. <b>*MDA, targeted for elimination selected African countries, regional elimination in E. Mediterranean, Caribbean, Indonesia, Mekong River Basin and by 2020 Americas/ W. Pacific.</b>
16. soil-transmitted helminthiasis (roundworm, hookworm, whipworm)	Education on health/hygiene to reduce transmission and reinfection by encouraging healthy behaviours; p (not always possible in resource-constrained settings) ( <b>WASH</b> ).	Mass deworming using anthelmintic medicines, including albendazole. <b>*MDA.</b>
17. Endemic treponematoses (yaws)	Can be controlled and possibly eradicated as disease occurs only in humans. Information, education and communication (IEC), advocacy and social mobilization needed.	Antibiotic azithromycin (API) available but need development of non-treponemal luminex assay. <b>*targeted for eradication in 2020</b>

#### Appendix 10 Environment-based and drug-based NTD strategies

(Compiled from information on CDC <http://www.cdc.gov/globalhealth/ntd/>; DNDi, <http://www.dndi.org>; WHO [http://www.who.int/topics/emerging\\_diseases/en/](http://www.who.int/topics/emerging_diseases/en/); 2015)

1. Diseases that require a mainly drug-based strategy	Trachoma, lymphatic filariasis, onchocerciasis, schistosomiasis, soil-transmitted helminthiasis, trachoma, buruli ulcer, leprosy, yaws, and leishmaniasis.
2. Difficulty developing vaccines/ drugs for mosquito vector	Dengue, chikungunya, and lymphatic filariasis.
3. Food and animal related disease	Cysticercosis/taeniasis, rabies, echinococcosis, and foodborne trematodiasis.
4. Diseases near elimination or eradication	Especially dracunculiasis and leprosy.
5. Diseases with limited strategies of control	Human African trypanosomiasis has no universal control methodology but is targeted for elimination, with recent improvements in diagnosis and treatment. Dengue has had no cure or treatment but now a vaccine is being developed. Finally Chagas does not have effective drugs for chronic disease, although vector management is typically recommended for control.

#### Appendix 11 List of diseases and their group characteristics