

The repackaging of 'neglected tropical diseases': A global policy movement

In the early 2000s a new disease category arose called 'neglected tropical diseases' or NTDs for short, a repackaging of tropical diseases. Why were these diseases given this label and what were the reasons to call them 'neglected'? While the addition of the word 'neglected' and the use of the term 'NTDs' may not appear at first to be a substantial change, I argue that this is an important re-characterisation of disease on social and political grounds. NTDs have been through a repackaging exercise to inspire action and the mobilisation of resources, led by a group of 'activist scientists'. This activity has been driven by the contention that the diseases could benefit from increased funding and R&D, driven by a intensified level of research collaboration, to produce new or improved treatments, preventions, diagnostics, monitoring, surveillance and implementation. However funding and R&D alone is not enough. A raised level of knowledge exchange and collaboration also requires social re-organisation for the restructuring of disease research.

This paper highlights two mechanisms that are important in explaining the policy treatment of diseases and disease groups. Firstly it is a repackaging to use that which already exists in a new form; commodified as part of a global health brand competing for resource and attention, not merely a reframing of the contextual discourse. Secondly it is activist scientists through a global policy movement who have played a leading role in an attempt to 'globalise' NTDs as scientists largely located in the global north. They have worked to create interest in NTDs outside of their domains culminating in commitments from the global public health community.

1. Introduction

'Neglected tropical diseases' (NTDs for short) are a collection of 17 parasitic, viral and bacterial diseases affecting the poorest people in tropical and sub-tropical regions. While defined differently across organisations the most authoritative list of 17 NTDs is provided by the World Health Organisation (WHO): buruli ulcer, Chagas disease, dengue and chikungunya, dracunculiasis (guinea-worm disease), echinococcosis, endemic treponematoses (yaws), foodborne trematodiasis, human African trypanosomiasis (sleeping sickness), leishmaniasis, leprosy (Hansen disease), lymphatic filariasis, onchocerciasis (river blindness), rabies, schistosomiasis, soil-transmitted helminthiasis, taeniasis/cysticercosis, Trachoma (WHO Webpage, 2013).

One persuasive reason for calling these diseases neglected is neglect from the private sector – drug companies specifically – in providing medical interventions for these diseases. It is true that drug companies have typically not invested in NTDs, as they lack a profitable revenue stream. Figures show that only "...1% of

the new chemical compounds registered between 2000 and 2011 were approved for diseases of poverty, even though these diseases make up 11% of the disease burden" (WHO/TDR, 2016, p. iii).

Therefore, R&D¹ for NTDs is often presented by commentaries as an area that could benefit from improved or new forms of collaboration and knowledge exchange (See Allarakhia & Ajuwon, 2012; De Pinho Campos et al., 2011; Dent et al., 2013; Furtado et al., 2014; Grépin & Reich, 2008; Hunter & Stephens, 2010; Morel et al., 2005). This may include activities such as patent pooling, R&D funds, priority vouchers, capacity building, product development partnerships and open innovation projects.

The policy problem of NTDs then is located in a lack of R&D but this only represents one side of the story. The minimal attention that these diseases have received indeed stems from the voiceless and powerless being unable to affect the priorities of 'big pharma' but is also due to the policy logic of global public health. These diseases cause greater morbidity than mortality and have a contained geography in being more chronic than infectious in nature. On the criteria of importance for health issues, this has led to a situation where NTDs have been under-acknowledged and de-prioritised in the agendas of government, NGOs, international organisations, the media and public interest.

Innovation through improved or new medical interventions is needed for NTDs along with other types of intervention concerning implementation, infrastructure and education. Therefore knowledge exchange and collaboration must be encouraged but this behaviour change is as much about policy redesign and political engagement as it is about the innovation processes of co-creation and shared research. These aspects of social organisation and re-organisation, situating research in policy, should not be ignored in understanding biomedical progress to address NTDs.

In other words this paper observes how practices of research collaboration are forged on the policy stage, how they change, why they change, who is responsible and what the outcomes are. What social re-organisation was required for a renewed agenda of collaboration? The result is to show the need for novel social organisation on a macro policy scale that goes beyond micro interventionist activities.

To outline the structure of this paper in making the case for the policy repackaging of NTDs, in section 2 I begin with a presentation of my chosen methodology. In section 3 I outline the relevant literature in health branding, along with a brief historical account of the NTD brand and how this instigated a next generation of NTD scientists. In section 4 I explain the new role of activist scientists in the US and UK and how this constituted a global policy movement in a social reorganisation of research.

¹ Research and development

I also want to outline some important caveats to this paper before going further. My concern has been to show that innovation through collaboration requires social re-organisation through policy engagement and negotiation. This does not include a mapping of innovations for NTDs for which there are already a number of studies (Hotez et al., 2013; Uniting to Combat NTDs, 2015; WHO, 2007) nor is it not an in-depth historical account of NTDs and tropical disease, although I do include historical excerpts and examples to illustrate my arguments.

2. Methods of analysis and data

My intention initially was not to follow scientists. Scientists are seen to be responsible for innovations but do not necessarily instigate policy change. However during the course of this research I found a limited amount of people active in generating policy for NTDs. This may appear to be an obvious point 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 has not been happening (see Epstein, 1996; Klawiter, 2008; Macq, Torfoss, & Getahun, 2007; Rabeharisoa, 2003). Instead there are a dozen core scientists who have been actively involved in promoting the NTD cause.

Pharma companies have varying levels of dedicated involvement from research groups to drug donation programs - this includes Merck & Co., GlaxoSmithKline, Johnson & Johnson, Pfizer, Novartis and Sanofi-Pasteur. As have governments, with the example of USAID's Neglected Tropical Disease Program launched in 2006 and now streamlined under President Obama's Global Health Initiative (GHI) in 2009. Still, the driving actors are the scientists, who have defined the terms, influenced the policy agenda and created networks of interested parties, establishing their own NGOs and lobbying governments for NTDs. Therefore, I have used two methodological approaches as a framework for analysis of the social re-organisation and policy impact lead by scientists: (1) a historical analysis of NTD policy change and (2) semi-structured qualitative interviews with policy actors about strategies for tackling NTDs.

First, I am interested in a socio-historical analysis of policy to understand the context for treatment of NTDs. Here policy historiography is a useful technique, with documentary evidence used to observe changes in policy, including posing critical policy historiography questions about complexity in the account of the policy and who is advantaged or disadvantaged by the arrangements (Gale, 2001, p. 385). I use a wide definition of policy to not only include stated intentions by government but interventions and activities which are directed toward a policy problem. I have concentrated on document analysis of scientific journals, organisation material, media reports (e.g. press releases, articles), policy reports (by government, NGOs, governance institutions) and popular science books. I employed a further level of analysis through 'policy archaeology' and 'policy genealogy' to understand the conditions and uncover reasons for policy change (Gale, 2001, p. 387-9). Policy archaeology is sociologically inspired requiring interviews in order to address the 'who, what and why' and what Gale describes

as policy genealogy is to uncover a number of legitimising strategies for policy agendas (ibid.).

Second, I have interviewed a mixture of policy actors tackling NTDs and the policy process. These include the typical institutional actors such as private businesses (pharma companies), universities and public research institutes, as well as other policy influencers such NGOs. The majority of these could be classed as elite interviews, with high profile scientists and politicians. In total I conducted 51 semi-structured qualitative interviews to better understand views and collect anecdotal evidence.

3. Relevant literature and theoretical basis

The literature I draw upon concerns two mechanisms of the NTD repackaging through a global policy movement: (1) health branding needed for diseases competing for resource and attention, and; (2) the historical origins of the NTD brand through an account of 'The Great Neglected Diseases of Mankind' (or GNDs for short), a Rockefeller health program that ran from 1977 - 2000. I also explore literature on the changing role of tropical disease scientists and show activist scientists playing a leading role in driving the global policy movement.

3.1 Health branding

Considering the branding of diseases, Richard Smith, editor of the British Medical Journal (BMJ) until 2004 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 seen health branding as necessary and even helpful, because, "(a) good brand will inspire and prompt action" by providing meaning and purpose through an exciting visual or verbal form, with a compelling, appealing narrative (ibid.). Smith was convinced that awareness was not enough and only appeals to emotion would evoke action.

This explained his involvement in an explicit version of a branding exercise, seen through an event in 2014 at UCL (University College London) called the 'NCD makeover show'. I had the opportunity for a first-hand experience of the aspiration and acceptability of disease branding when attending this public event to brand non-communicable diseases (NCDs)². Speakers included representatives from a branding company and from broadcasting (the BBC), speaking about charity advertising.

² As an acronym confusingly close to NTDs comparisons between NCDs and NTDs are sometimes made. At one point NTDs were referred to as 'communicable diseases of the developing world'.

NCDs have been known as lifestyle diseases, except this has a negative connotation with being unimportant or easily preventable. Also 'chronic diseases' is being abandoned as a way of characterising this group, with their non-communicability deemed to be the most defining feature. However, the main issue that was identified with NCDs is that they are defined by what they are not, so this does not inspire or prompt action. This is why action needed to be channelled through an accessible outlet people could be part of, to join 'NCDFree', a global social movement (See NCDFree Webpage).

3.2 The creation of the NTD brand

The first part of a global policy movement for NTDs has been the creation of a new brand for tropical diseases. NTDs have already been through a rebranding exercise to inspire action and the mobilisation of resources towards innovation collaboration, led by a group of activist scientists. The arena of global civil society in which health causes take part, 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).

Scientists working in the field saw one reason for the lack of attention from the global policy community as being the tropical disease 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). Similarly, the WHO recognised the importance of 'advocacy' to change this situation³.

It was first highlighted by the Wellcome Trust, that a small group of scientists in the UK, US and Switzerland originally 'coined' the phrase 'Neglected Tropical Diseases' with the use of the term in a paper in 2005 (Regnier, 2012). The main instigators cited were those scientists, who in 2005 went on to establish the 'Global Network for NTDs' (an NGO to raise awareness, political will and funds) including: "Professor Peter Hotez, President of the Sabin Vaccine Institute, Professor David Molyneux, a lymphatic filariasis researcher at the Liverpool School of Tropical Medicine, 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). Hotez describes now: "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

³ In a 2007 report, their 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).

malaria. Goal 6 called for action on those three 'and other diseases... It led to a lot going on in HIV, tuberculosis and malaria, 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).

Those scientists had become aware that the policy focus on Millennium Development Goals (MDGs) in 2000 drew attention to malaria, TB and HIV/AIDs but other endemic diseases were left out of the spotlight. They decided that their diseases needed to become a marketable commodity within a competitive market for public health resource. This ultimately led to the construction of NTDs as a worthy cause appealing to policy, so much so that by the time the WHO published their 'Roadmap' policy document for NTDs in 2010, the writers remarked on how: "The NTD brand has proved to be a useful form of shorthand for communication" (WHO, 2012).

This countered some early scepticism and hesitancy to adopt the new term, as a Reuters report expressed: "We may be sceptical about the rising frequency of 'neglected tropical diseases' in paper titles and keywords... but this branding is a positive signal of policy and political change" (Adams, Gurney, & Pendlebury, 2012, p. 9). It is a health brand that has stuck and continued to be of use. According to branding expert Dorie Clark (Nordrum, 2014) NTDs act as a "brilliant umbrella term" because, "It allows funders to feel like they are addressing something important that has been hidden for a long time". It is a brand that straightforwardly conveys a message of moral urgency, justifying funding. The role of the WHO in the creation of NTDs has not been well publicised. It is also through their own publications that they highlight their involvement and comes across somewhat defensive (See: Savioli et al., 2011, p. 281). It was central that the WHO was on board for such a change. After all one of the key roles of the organisation was to provide leadership on global public health issues.

3.3 GNDs the proto brand and the next generation of scientists

The second part of the global policy movement has been the encouragement of the next generation of scientists towards NTDs and this can be understood from the longer history of the NTD brand. The phrase 'great neglected opportunities' was first used in 1981 by Jonas Salk, the US virologist who developed the polio vaccine, at a meeting of donor agencies and scientists in the Rockefeller Foundation in New York (Warren & Bowers, 1982). Also the 'neglected' wording to some extent was borrowed from the past. Before NTDs there were 'The Great Neglected Diseases of Mankind' (GNDs), a health program that ran from 1977 - 2000. The GNDs were an invention of the Rockefeller Foundation; the foremost philanthropic organisation of that time, with a mission to promote the wellbeing of humanity, using the endowment of \$3.4bn gifted by Rockefeller, then the world's richest man. The GNDs included many NTDs, especially the parasitic

diseases as well as other diseases of poverty⁴: "The emphasis was on parasitic infections that plagued people living in poverty" (Hotez, 2014, p. S32).

In fact the GNDs followed a similar definition to that commonly used for NTDs. Kenneth Warren the director of health services at the foundation and the instrumental figure behind GND program described them as such: "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). He also pondered on how neglect was multi-causal, saying: "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 - to financial and scientific neglect identified by Warren - we could add socially and politically.

Pharmaceutical companies and donors might be the obvious sources of financial neglect and the interest of the scientific community in other research areas a cause of scientific neglect. However, the media, public and governments are also sources of neglect socially and politically. These are the areas that the rebranding has tried to address in order to have an impact more directly on the financial and scientific neglect. For Warren the financing was available to an extent with the Rockefeller endowment, so it was mainly the case of garnering the attention of scientists.

Where the program differed significantly from activity today is in the core aspiration to bring in scientific talent, creating a network of high quality investigators. 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, within in the community the view was that the most able and talented scientists were not directed towards diseases of the developing world. The call of the Rockefeller Institute in 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 had a lasting impact and may be why there no longer exists such an imperative.

4. Findings: The promise of biotechnology

The most significant part of a global policy movement has been the promise of biotechnology to address NTDs. When Warren was bringing in the top scientists this also involved applying the advances that had been made in biotechnology.

⁴ Malaria had already been downgraded within the GND group during the lifespan of the program to a "great 'relatively' neglected disease" (Warren, 1978, p.176). In this vein, the WHO and Doctors Without Borders (DWB) went on to classify the diseases into Global, Neglected and More Neglected. This is one the dimension that remains a concern today: the level of neglect (neglected or more neglected) and the scale (global or other) a disease being addressed.

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). For scientists during the colonial period tropical medicine was often associated with a prestigious and exciting career. Also in comparison to what has been a slowly growing public interest for NTDs, during the heyday of tropical medicine, public interest was at a high (Lemaine et al., 1976, p. 85). This was 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.

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). Warren in associating 'modern science' with tropical diseases challenged a "romantic, post-colonial attitude" to the new technologies (ibid. S28). This was not something that had been on the table before. Molecular parasitology units were established among partners, forming a new geography of training in the next generation of tropical medicine scientists and creating opportunities for collaboration.

The story then of the branding of diseases and the attraction of the next generation of scientists through the GNDs has been about the direction of research collaboration and the arrangements that allow research to happen in different ways. It is still questionable whether the promise of biotechnology for NTDs will deliver. The impact is clear in the re-organisation of tropical medicine as a discipline and policy concern. Warren had created a scientific program and network with the main gap being talented scientists applying advances in scientific understanding and technique. He had to create interest and encourage biotechnology to be used to co-opt the next generation of scientists to join his crusade.

4.1 Big pharma to the rescue

This next generation of scientists would be indebted to Warren, even if now he is a somewhat forgotten figure. One of those would be Peter Hotez, then a young doctoral student, now one of leading activist scientists behind the repackaging of NTDs: "...working on hookworm for my dissertation was a great fit with the Rockefeller Foundation's new Great Neglected Diseases of Mankind (GND) program, launched in 1977" (Hotez, 2014, p. S32). Hotez was inspired by the work of the Rockefeller Foundation on GNDs just as Warren had intended for the eminent young scientists of his day.

It is with little doubt without the policy engagement of Hotez and the other activist scientists NTDs would not have reached the level of attention they now receive. This culminated on the 'London Declaration on Neglected Tropical Diseases' on 30th of January 2012. For this occasion a collection of international politicians, pharmaceutical CEOs and heads of global health organisations (including Bill Gates and the Director of the WHO Margaret Chan) descended on

London. What was striking about this collection of leaders was the presence of big pharma, corralled by Bill Gates, a domineering force in public health through the Bill and Melinda Gates Foundation, which has completely changed the landscape of public health through his \$42bn endowment and the priorities set by the foundation (covering health, development and education).

This was a meeting for setting goals and forming a collective vision to tackle NTDs, echoing the MDGS 12 years before, through a public announcement of commitments. These were eight targets to be reached by 2015, addressing the needs of the world's poorest people and agreed by all countries at UN. The intention was to coordinate action by 2020 on NTDs. 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).

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 explains the pharma company involvement. It was really for the continuation of existing drug donation and research programs. The commitments are summarised as follows:

- To 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.

For these 10 diseases included in The London Declaration, addressing neglect is by providing funding and support for existing Mass Drug Administration (MDA) programs where pharma companies donate drugs. MDA is "...the administration of drugs to entire populations, in order to control, prevent or eliminate common or widespread disease" (ENVISION Webpage). Currently five of the 17 NTDs are being controlled and treated through MDA: lymphatic filariasis, onchocerciasis, schistosomiasis, three soil-transmitted helminths (roundworm, hookworm, whipworm) and blinding trachoma.

The other five of the diseases targeted by The London Declaration are being controlled and treated through intensified disease management. Two are close to eradication and elimination – dracunculiasis (guinea worm) and leprosy respectively. Sleeping sickness (human African trypanosomiasis) has limited options for prevention and treatment but elimination through surveillance is thought possible. Similarly Chagas disease and visceral leishmaniasis are viewed as controllable.

For these diseases there are also prevention strategies related to diagnosis, education, improved water and sanitation or other strategies (table salt/ cooking salt fortified with DEC for lymphatic filariasis). 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). Vaccines and preventative drugs do not exist but would be difficult to justify developing if effective treatments exist for free or cheaply.

The diseases remaining include dengue, which has been somewhat an oddity in the NTD group, in that it is not a chronic disease or restricted to very poor communities. The six other diseases not included: buruli ulcer, cysticercosis/taeniasis, echinococcosis, foodborne trematodiasis, rabies, endemic treponematoses (yaws) are either treatable by antibiotics or animal/food management requiring public health measures in behavioural change and regulations.

Therefore the involvement of biotechnology through big pharma has continued since Warren's GND program. However, this cannot erase historic biases in drug development and even though pharma involvement is welcome it cannot be the wholesale solution for NTDs. Pharma companies are already involved in large drug donation programs for NTDs that are unprecedented in that sector. Further initiatives to encourage research collaboration are also promising in strengthening the pipeline of new and improved treatments, diagnostics and vaccines. However, likewise the task of strengthening health systems and capacity cannot be ignored as the need for prevention strategies, diseases management, surveillance and public health measures in behavioural change and regulations. For these activities to be rationalised, the policy-work and social organisation of the GND and later activist scientists, in forming a global policy movement for NTDs provided an essential grounding.

5. Conclusions

The global policy movement of NTDs has involved activist scientists in an attempt to 'globalise' their diseases by putting NTDs on the global agenda. It is global in the acceptance of the NTD term, formally instituted through organisations such as the WHO and activities as seen with the London Declaration⁵ and NGOs such as 'Unite against NTDs'. Still, it is also an elite movement⁶, in the absence of a concerted social movement or grassroots political interest group. This is particularly unusual in the health realm, as

⁵ A collaborative disease eradication programme for NTDs launched on 30 January 2012 in London.

⁶ According to 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" (Jasanoff, 2005, p. 29).

Epstein discusses, where the public are often a driving force, as is the norm for 'health social movements' (see Epstein, 1996). In summary the idea of a global policy movement opens up the discussion to encompass activism in a different sense, not limited to change directed through the public sphere, social groups or civil society.

This paper shows that the drive for more collaborative research cannot happen in isolation from policy and politics. The changing political economy of research and innovation is often viewed as a global phenomenon, and a globalising policy relies on an idea of north to south knowledge flows. From the perspective of the global north the problem lies most acutely in a market failure of pharma companies and the way that the pharmaceutical system operates in pursuit of the profit-motive. However, while the 'neglected' aspect of NTDs is very apparent from the perspective of the donor to address this problem it is not as straightforward as a problem identification leading us to a solution. Neglect involves all participants including donor governments, NGOs and scientists as well as the frameworks defining the innovation system.

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