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# **Who Lives, Who Dies and Who Cares? Valuing Life through the Disability Adjusted Life Year Measurement**

## **Introduction**

‘If access to health is a human right, then who do we consider human enough to have that right?’ (Farmer 2005, 206)

Sobering in its simplicity, the question posed by Farmer confronts one of the central issues within contemporary global health governance. Today, against the backdrop of advancing technologies and pharmaceutical breakthroughs that are manipulating and politicising life in an unprecedented manner, large swathes of people struggle to access even the most basic health care. Increasingly, work has turned to the vital politics being opened up by advancements into this ‘new medical territory’ (Rose 2007, 10), and centred around the biopolitics of life when life itself has become molecularised. However, Kearns and Reid-Henry argue that attention should focus ‘less on the possibilities opened up by new technologies and more on the problems of their uneven distribution because, clearly, less novel and more mundane material inequalities exist alongside (and in some cases are being re-shaped by) the technological developments that pre-occupy much of the recent literature on the politics of life’ (2009, 555). This paper joins with those who have turned attention to these ‘mundane’ material inequalities, inequalities often born out of a biopolitical regime that is

increasingly driven by the logic of profit and the pursuit of capital accumulation (Craddock 2007 2009; Sparke and Anguelov 2012; Sparke 2009).

As Belcher et al. (2008) note, the work of Giorgio Agamben, and in particular his thesis *Homo Sacer: Sovereign Power and Bare Life* (1995, English translation 1998), has become influential within Human Geography, employed by those seeking to understand the topologies of abandonment within contemporary society and grapple with seemingly legitimised human rights abuses. The opening question raised by Farmer is predicated on access to health as being a fundamental human right. With the discourse of 'health' increasingly woven together with that of 'human rights', 'the right to health' has emerged as a somewhat blanket term encompassing a growing political movement, as well as providing a theoretical lens through which health inequalities can be analysed. It is perhaps ironic that as the 'right to health' movement proliferates, it becomes ever more distanced from its legal origins. This paper, however, invokes 'the right to health' neither as political nor intellectual movement, but rather as a legal right enshrined in numerous international treaties and conventions (see Heywood, 2002). Despite these legal frameworks, for many the right to health remains repeatedly violated, with entire populations abandoned from the tripartite state obligation to respect, protect, and fulfil the rights of citizens. Farmer's question attests to the politicisation of life in the context of human rights abuses, by alluding to a shifting scale of 'humanness' upon which individuals can be judged. As Agamben himself writes, '[i]n the 'politicisation' of *bare life* - the metaphysical task *par excellence* - the humanity of living man [sic] is decided' (1998, 8). It is through this task then, that some lives are given

political value while others are reduced to bare life and abandoned. Thus, Farmer's question, as to who is considered human enough to be afforded the right to health, speaks directly to the metaphysical tradition of judging individuals' humanity in order to decree their inclusion to, or exclusion from, the *polis*. Drawing on the work of Agamben, therefore, this paper will discuss the way in which this metaphysical task is undertaken - and the value of populations judged - to decree who is human enough to enjoy the right to health. Important work has been conducted around biological and therapeutic (non)citizenship and the violent abandonment of those suffering from HIV/AIDS (see for example Craddock 2009 Biehl 2001). This paper, however, focuses attention on vector-borne diseases in sub-Saharan Africa utilising this branch of diseases as an entry point to discuss aspects of global health governance more broadly.

The rise of a 'global' perspective on health has been fuelled by growing international connections, where the boundaries between 'here' and 'there' can easily crumble, and 'the acceleration of international travel and commerce expose[s] new populations to disease once thought to be contained in remote locations' (King 2002, 768). A growing body of literature, however, argues that 'the notion of global health is a misnomer' (Heywood 2002, 218) recognising local and unequal articulations of so called 'global' phenomena: from the highly lucrative philanthropic 'Global Health' hub situated in Seattle (Sparke 2011); the new 'scramble' for Africa as US Universities seek to cash in on the popularity of Global Health Programmes and quickly establish (unequal) institutional partners (Crane 2011 2010); the stock-piling of finite medicines by prosperous countries during the 'global' H1N1 virus (Spark and Anguelov 2012); the inequitable

access to anti-retroviral treatment and the search for a vaccine of the 'Clade B' subtype of HIV, most prominent in US and Europe but representing a tiny fraction the 'global' HIV make-up (Craddock 2007); and the finger of blame continually pointed 'over there' as to the source of the 'global' disease (Farmer 2005; Craddock 2009; Sparke and Anguelov 2012). Against this backdrop of emerging 'global' infections, and the task of managing health performed at an international level, age-old vector-borne diseases require careful consideration. Frequently referred to as 'tropical diseases', vector-borne diseases represents the collective term for illnesses where the pathogenic microorganism causing the illness is transmitted between vertebrates (both human and animals) through a hematophagous arthropod vector such as the mosquito (responsible for transmitting pathogens causing malaria, yellow fever, dengue) or tsetse fly (capable of transmitting trypanosomiasis). As this paper will argue, the specific ecological environment required to support the life cycle of these blood-feeding arthropods has assisted in the construction of the imagined geography of sub-Saharan African. With the 'production of knowledge about life... bound up with the construction of geographical knowledge more broadly' (Kearns and Reid-Henry 2009, 556), this imagined geography acts as a springboard for understanding the lives of citizens and the illnesses they experience, underpinning an abstract devaluation of life within the continent. This abstract devaluation of life, I argue, has become written into global health governance via the Disability Adjusted Life Year (DALY) calculation. Devised to encourage policy makers to take seriously the non-fatal disease outcomes, the initial provocation for DALYs was deeply laudable. As this paper argues, however, DALYs are predicated on an individual's economic worth for society; they represent an

increasingly market-led biopolitical regime where the attempt to ascribe a value to life has paradoxically led to the *devaluation* of certain populations. As such, this paper argues DALYs are complicit in decreeing ‘the humanity of living man’ (Agamben 1998, 8).

Developing over three parts, the paper opens with a brief discussion of Agamben’s thesis and the construction of the concept of violence, before utilising Agamben’s thinking to analyse the abstract devaluation of life within sub-Saharan Africa with reference to vector-borne diseases. Finally, the paper will turn attention to the DALY, to analyse the way in which this abstract devaluation of life has spilled over into global health governance.

### ***Homo Sacer* and Systemic Violence**

Agamben knits together the work of Arendt, Foucault and Schmitt, to contend that modern democratic society came into existence when biological life was incorporated within the political sphere. By erasing and blurring the distinct boundaries between ‘the body’ and ‘the political’, sovereign power is allowed to penetrate individual bodies and thus gain power over life itself. Agamben considers this politicisation of life as constituting the ‘decisive moment of modernity and signals the transformation of political-philosophical categories of classic thought’ (1998, 4). While this is said to continue to characterise our political existence today, Giroux (2006) argues biopolitics is undergoing a decisive shift, increasingly governed by neoliberal ideology that blurs the boundaries not only between ‘the body’ and ‘the political’, but ‘the economy’ too. The inclusion of the economy within biopolitics has also altered the role of the

sovereign, de-coupling (biological) citizenship from the nation state, as non-state actors exercise unprecedented power (Sparke and Anguelov 2012; Sparke 2009).

Traditionally, it has been the most obvious and spectacular forms of violence and right abuses that have warranted international attention and condemnation. Mirroring wider society's fixation within the spectacular, Agamben's work has predominantly been drawn upon to conceptualise and analyse spectacular forms of violence, and extraordinary spaces of exception – becoming particularly prominent in the literature analysing the 'War on Terror' and the spaces of exception created by it (Gregory 2006 2004; Minca 2005 2006 2007; Butler 2009; Hannah 2006). This paper, however, seeks to bring Agamben out of the battlefield and away from arresting forms of subjective violence, employing his thinking to disclose the apparatus behind systemic violence. Subjective violence refers to spatially and temporally bounded events that are commonly considered an aberration from a peaceful status quo. Žižek, however, has challenged the myth of this non-violent status quo, arguing that systemic violence is 'the catastrophic consequence of the smooth functioning to our economic and political systems [where violence] is no longer attributed to concrete individuals and their 'evil' intentions, but is purely objective, systemic, anonymous' (2008, 9). Thus, while such violations take place without an identifiable perpetrator, the violent outcomes are no less 'spectacular' to the individuals experiencing them: such violence can be understood as a 'crime without a criminal' (Gupta 2012, 21). A growing number of scholars are drawing on the concept of violence to politicise suffering and deaths from preventable or treatable illnesses for 'not

recognising millions of preventable deaths as a form of genocide... maintains the status quo of global governance and condones through collective silence the primacy of corporate over human capital' (Craddock 2009, 288).

### **Geographies of Abandonment: Sub-Saharan African as 'The Camp'**

Agamben's thesis is fundamentally rooted in space, for the *homo sacer* does not only metaphorically occupy the space of exception; 'he [sic.] inhabits and moves through real spaces' (Minca 2006, 392). The physical manifestation of these bounded spaces, known to Agamben as '*The Camp*', are spaces where the 'state of exemption, which was essentially a temporary suspension of the law on the basis of a factual state of danger, is now given a permanent spatial arrangement' (Agamben 1998, 169). This spatial element of the abandonment process has become painfully pertinent post '9/11', and the reactionary 'War on Terror', which ushered in new and terrifying possibilities, stretching the political imagination as to what could be considered as 'right' or 'justifiable' in the name of 'homeland security'. As principle architect of the 'War on Terror', George W. Bush infamously inscribed the 'Axis of Evil' across the globe, through doing so identifying the coordinates of the 'State of Exemption' upon the geopolitical map of the day (Minca 2005; Gregory 2004). Recognising the geopolitical potency of the term 'Axis of Evil', Comaroff argues sub-Saharan Africa represents 'another otherness, less an 'Axis of Evil' than an 'Axis of Irrelevance'' (2007, 201). This 'Axis of Irrelevance' has long-standing coordinates, which has been continually redrawn throughout history. Pratt unveils the importance of geography in the unfolding story of the *homo sacer*, writing:

'...geographies do more than simply contain or localise bare life. Geographies are part of the process by which certain individuals and groups are reduced to bare life. They are therefore integral to the process that Agamben describes to us' (2005, 1055)

The role played by geography is evident in both the 'Axis of Evil' and the 'Axis of Irrelevance', whereby long harboured racial stereotypes are stirred, goaded and built upon in a continual process that facilitates contemporary articulations of historic representations (Gregory 2004).

While a discourse of disease has long been married with sub-Saharan Africa, the familiar coupling gained significant currency with the advent of the global AIDS pandemic. This contemporary coupling fed of, and into, an established discourse of disease and associations with 'tropical' ailments. Reviewing the tales written by European explorers concerning their early encounters with sub-Saharan Africa, Bankoff (2001) argues that accounts of 'lushness' and 'paradise' were only fleeting, promptly substituted for the discourse of 'disease' and 'danger'. It was through this tropical discourse that the continent was set 'apart as somewhere culturally, politically and even environmentally different from temperate areas' (Bankoff 2001, 21). Indeed, during imperial expansion, deathly fevers and 'bad air' saw the continent attain the reputation as the 'White Man's grave' (Lock and Nguyen 2010, 148 see also Kearns and Reid Henry, 2009). The geographical association between vector-borne, or 'tropical', diseases heightens the notion of otherness, with the connection to the tropical latitudes crafting

them as an inevitable environmental outcome. Environmental inevitability not only naturalises the suffering induced by vector-borne diseases, but conveniently shifts attention away from the unnatural political and socio-economic environments supporting disease transmission. Over 50 years ago, Director of the Calcutta School of Tropical Medicine, Chaudhuri, expressed concerns over the terms 'tropical disease' and 'tropical medicines' as 'they perpetuate a false idea that tropical countries, try as they may, are doomed to suffer from these disease... our knowledge of these diseases, their prevention and their cure [have] outstripped practical application' (1954, 4886). Today, the cleavage between knowledge and application remains, with the vast majority of vector-borne diseases both preventable and/or treatable. The environments that support disease transmission, therefore, are as much political and economic as they are ecological, yet the notion of ecological inevitability assuages aspirations for elimination and fosters complacency in disease interventions. Such aspirations are also tempered given vector-borne diseases are ecologically contained and so pose little threat to 'the West's' way of life<sup>i</sup>. King (2002) argues that throughout history Western countries' involvement in international health matters have been tinged with self-interest. This self-interest remains intact today with the disease/security nexus recurrently being strengthened. This has been particularly evident in rhetoric of HIV/AIDS interventions (Singer 2002; Ostergard 2002; Ingram 2009 2005; Elbe 2006 2005; McInnes and Rushton 2010), but also brought to life with the H1N1 epidemic that demonstrated the ease and speed for which viruses could disregard political boundaries (Brown 2011; Sparke and Anguelov 2012). Governments have been explicit in reaffirming and invoking the rhetoric of national security in discussions of global

health interventions, with the rationale for investment sold as being necessary for ensuring disease is maintained at a safe distance (Ingram 2011; Primarolo et al 2009). This has, in turn, led to certain countries being pathologised, and heightened ancient perceptions of 'dangerous' and 'diseased' countries (see also Spark and Anguelov 2012).

### ***Homo Sacer* and Sovereign Power**

The protagonist of Agamben's thesis, *homo sacer*, is an archaic figure first found in Roman Law understood as 'one whom the people have judged on account of a crime, it is not permitted to sacrifice the man, yet he who kills him will not be condemned for homicide' (cited in Agamben 1998, 71). Not considered 'fully human' or a politically qualified life, the normal rules of law are suspended and the *homo sacer* becomes legally abandoned. 'Abandonment is not equivalent to exclusion' writes Pratt, making reference to the paradox at the heart of the *homo sacer's* existence, 'it is a more complex topographical relation of being neither inside nor outside the juridical order' (2005, 1054). For Agamben, the ancient figure of the *homo sacer* is reincarnated throughout time and across different cultures, approximating the *homo sacer* with that of the Wargus – the wolf man or banned man – found within ancient Germanic Law. More specifically, Cavalca believes that 'to ban someone is to say that anyone may harm him or that he was even considered to be dead. Whoever is banned from the city on pain of death *must be considered as dead*' (cited in Agamben 1998, 104-5 emphasis added).

Within contemporary thinking on vitalism, Kearns and Reid-Henry (2009, 558) argue that the 'discourse of life' and 'geographical discourse' can be considered

'mutually constitutive'. That is to say, the imagined geography of the continent of Africa is in part constructed through the representations of individuals: images of children with distended bellies and flies resting on their sores, of mothers with breasts void of milk, those close to dead and those dead already, all captured on film and consumed in newspapers and on rolling news channels. As Butler attests, 'if certain lives do not qualify as lives or are from the start not conceivable as lives within certain epistemological frames then these lives are never lived nor lost in the full way' (2009, 1). The belief that vector-borne diseases are an inevitable consequence of living in the tropics is supported by the images of individuals close to death. Together they help construct the imagined 'axis of irrelevance' as a space where 'wombs incubate death...misery is endemic, life is cheap and people are disposable' (Comaroff 2007, 207).

Standing at opposing ends of the political-juridical order, the sovereign power and the *homo sacer* are intimately connected, each requiring the other in order to exist. Agamben draws upon the work of Carl Schmitt, and his definition of the sovereign as the individual with the 'power to proclaim the state of exception... the power over life itself' (1998, 15). The sovereign is also said to possess the 'power to disregard the law which they have set, the power to exclude, the power to suspend law, to strip existence of civil and social value' (Comaroff 2007, 209). As such, the sovereign exists in a similar paradoxical state as the *homo sacer* - included in the law by being placed outside it. Richard Nixon captured the paradoxical existence of the sovereign, and the power to disregard the law that they have set, in his infamous response to David Frost when he stated 'I am saying when the president does it that means it is not illegal'. Traditionally, the

nation state grants citizenship on account of an individual's birth or residence within a country, with individuals enjoying the rights afforded to them as a citizen. It has been the nation state - with the power both to decree citizenship and expel individuals from the *polis* - that has assumed the role of sovereign power. Today, however, the image of a sovereign state is misleading as 'political power is exercised... through a profusion of shifting alliances between diverse authorities in projects to govern a multitude of facets of economic activity, social life and individual conduct' (Rose and Miller 1992, 174). As Sparke (2009) argues, while nation states are by no means dead entities, neither are they autonomous bodies with borders sealed to external forces. Rather, the promotion of the *laissez faire* economic system has given rise to 'market fundamentalism' shaping a 'new and dangerous version of biopolitics' (Giroux 2006, 181). This requires looking outside the nation state in order to adequately analyse the biopolitical regimes, and identify sovereigns enacting power over lives.

Nodding to the particularities of biopolitics enmeshed with the neoliberal regime, Agamben suggests this democratic-capitalist project 'transforms the entire population of the Third World [sic] into bare life' (1998, 180). Others have approximated the figure of the *homo sacer* with those living with, and dying of, HIV/AIDS in the Global South, on account that they have become 'scarcely human beings condemned... to a death without sacrificial value; a being left untreated in an era of pharmaceutical salvation' (Comaroff, 2007, 207). Such an assertion should not be restricted to anti-retroviral drugs, however, with populations denied access to numerous essential medicines. Drugs have become

‘the means of life itself, the means to control body and mind’ (Comaroff, 2007, 213), with modern society ever expectant of the pharmaceutical industry’s ability to find the cure to all ailments. In turn, pharmaceutical companies have come to hold phenomenal power over all our lives. Operating within the rules of the free market, pharmaceutical companies direct the development of new drugs and dictate their price once coming to market through a system Craddock has dubbed ‘medical capitalism’ (2007, 1043). Within the neoliberal system the worst crime one can commit is to hinder the process of capital accumulation, as such, unprofitable populations are deemed worthy of exclusion on account of this crime (Giroux 2006). Such exclusion is not exclusively the work of pharmaceutical companies, but facilitated by surrounding apparatus and an array of global assemblages, including the Trade Related Aspects of Intellectual Property Rights (TRIPS) (Craddock 2007 2009 2012). Ostensibly devised to allow pharmaceutical companies to recuperate investment in research and developing drugs, TRIPS are considered by some as the lifeblood of the pharmaceutical company. For others, however, TRIPS mark ‘a major departure for any such consideration of access to drugs as part of basic human rights (Craddock, 2007, 1045). The inherent inequity of ‘medical capitalism’ was crystallised in the case of *eflorithine* - a drug capable of treating the vector-borne disease typanosomiasis. Despite the efficacy of the drug, production was halted when it proved unprofitable, only to be taken over by another company when tests revealed a by-product reduced unwanted female facial hair (MacDonald and Yamey 2001). When the value of drugs is judged in dollars made rather than lives saved, lifestyle drugs are prioritised over life saving drugs<sup>ii</sup>. This jarring juxtaposition has led Haywood to contend ‘the only

conclusion that can be drawn is that some kinds of life are not considered worthy of health... this creates a hollow ring to the assertion... that “all humans being are born equal in dignity and rights” (2002, 221).

The above discussion has demonstrated how a discourse of disease has constructed an imagined geography of sub-Saharan Africa which has devalued lives and naturalised suffering, directing discussions away from entrenched structural inequalities, and the social-economic and political aetiology of avoidable illness. For the remainder of this paper, attention will turn to the Disability Adjusted Life Years measurement, to argue that the imagined geography and abstract devaluation of life discussed this far has spilled into a literal (de)valuation of life, where a biopolitics regime underpinned by neoliberal ideology is also in operation within the international health arena.

### **Disability Adjusted Life Years**

In December 2012 The Lancet published '*Disability-Adjusted Life Years (DALYs) for 291 diseases and injuries in 21 regions, 1990-2010: A systematic analysis for the global burden of disease study 2010*'. Led by the Director of the Institute for Health Metric and Evaluation, Professor Murray (who originally devised DALYs), the paper had over 350 co-authors with affiliations to more than 230 institutions. Importantly, The Bill and Melinda Gates Foundation, arguably the most influential actor in the global health arena today, funded this study. Having previously declared 'the disease burden as measured by disability-adjusted life years is the most important consideration in our [The Gates Foundation] funding decisions' (Yamada 2009, 2195), their financial backing is testament to the

significant value of DALYs and the role they play in allocating resources within contemporary global health governance. As suggested by the title of the paper, the aim of the study was bold: to capture the global disease burden and its shifts over two decades. In representing the disease burden through the DALY measurement, the authors argue they are laying 'the foundations for a debate on priorities for health policy action and research that is clearly informed by the best evidence available' (Murray et al. 2012, 2198). As Stefanini reminds us, 'allocating scarce resources in an attempt to respond to ever increasing demands on health care is a daunting task, even more so under conditions of extreme poverty and greatest social needs' (1999, 709). The current global financial climate has altered these conditions further, negatively impacting on the available budget for health interventions, with donors also putting sharper focus on 'cost-effectiveness' and 'value-for-money' (Sharp et al. 2010). Consequently, resource allocation has become an even more difficult or 'daunting' task, and one increasingly managed by economists who currently hold 'unfettered influence within health policy' (McMaster 2007, 10). DALYs are reflective of the influence exercised by economists, becoming a favoured device in the allocation of funding within the developing world. Moreover, they are entangled with this ever potent goal of 'cost-effectiveness' and 'value-for-money' with DALYs providing a directly comparable measurement for tracking investment (Arnesen and Kapiriri 2004). The then UK Secretary of State for International Development, Andrew Mitchell, for example, reiterated the UK government's commitment to cost-effective interventions and quantifiable results: writing in the forward of the UK Department for International Development (DfID) publication on malaria control *Breaking the Cycle: Saving Lives and Protecting the Future*, 'value-for-money' is

stated as part of their four-fold focus (2010, 1). It is under this rubric that the document introduces DALYs to the debate, drawing on them to determine the cost-effectiveness of various intervention strategies to tackle malaria, within the document's wider discussion on 'value-for-money' (2010, 10). DfID are not alone in drawing upon DALYs. Since being devised in 1993 by the World Bank, DALYs have come to transcend their original institutional boundaries and are presently invoked by numerous actors. They have become common place in the lexicon of contemporary health governance (King and Bertino 2008). For discussions of the disease burden to be centred around the DALY once again is telling of the persuasiveness DALYs maintain 20 years after conception. Indeed, Murray et al. (2012) celebrate the persuasiveness of DALYs in priority setting and resource allocation, citing over 50 publications that have turned to DALYs to quantify the disease burden and make decisions based on the results. Their list is by no means exhaustive, with DALYs routinely peppering policies and papers. Roll Back Malaria's *The Global Malaria Action Plan* (2008), for example, utilises 'DALYs averted' to demonstrate the cost effectiveness of tackling malaria and the rationale for intervention. Likewise the WHO's *Working on the Global Burden of Neglected Tropical Diseases 2010* is punctuated with the DALY measurement, which is introduced to outline the disease burden of a series of 'tropical' diseases (p.13); demonstrate the cost of prevention versus the 'disease burden' of lymphatic filariasis (p.17); the general cost-effectiveness of a series of diseases through a DALY averted measurement (p.18); and demonstrate the success of trypanosomiasis intervention (p.83). This is characteristic of how DALYs are employed within policies - as a figure given with little explanation, but served up as invitation and invocation for action, as well as a mechanism through which the

'success' of interventions can be measured. As such, they are ostensibly employed to legitimise intervention rather than justify abandonment. However, as the following discussion will demonstrate, various aspects of the DALY measurement are highly problematic and deeply rooted within a capitalist thinking that considers health in relation to economic productivity. These assumptions are implicitly reproduced each time the DALYs are utilised, often contradicting the wider message and actions of the actors who employ them.

Against a backdrop of austerity, and with the recent Lancet publication catapulting DALYs into the centre stage once more, it is timely to revisit the DALY measurement for 'the basic question is not so much whether one agrees or not to the effects of the currently used choices but if one knows about them' (Arnesen and Kapiriri 2004, 147). Furthermore, it is pressing to embed this discussion on DALYs within wider conversations on the vital politics of today, for DALYs are telling of a subtle but decisive shift within global health governance under pressure to provide quantifiable results and which is pushing for efficiency over equity.

#### *Calculating DALYs and Calculating Individual Worth*

Originally conceived to measure the burden created by individual diseases, much of the appeal of DALYs lies in their ability to provide a directly comparable measurement, treating diseases on a 'like by like' basis and so providing a common language across multiple ailments with vastly different impacts. Until DALYs were conceived, attention had predominantly been focused upon mortality rates of individual diseases. DALYs, therefore, took the laudable and

necessary step of taking seriously the time spent ill with disease and not only fatalities - the sole focus of mortality rates.

DALYs are most commonly encountered as a single neat figure and, as with the authority afforded to many statistics, presented as if to be 'neutral information' (Arnesen and Kapiriri 2004, 147). The information incorporated within the measurement, however, is far from neutral and in the years that followed their conception DALYs not only reaped considerable currency but also harvested significant critique (see, for example, Anand and Hanson 1997; Williams 1996; Stefanini 1999; Lyttkens 2003; Metts 2002; Arnesen and Nord 1999; King and Bertino 2008; Grosse et al. 2009). As demonstrated by the recent Murray et al. (2012) publication and continual use with many policy documents, despite this level of critique DALYs remain an important measurement in global health governance. The equation employed in calculating the DALY is by no means accessible for the mathematically shy or uninitiated (see Figure 1). The weighty equation is far removed from the lean figure of the DALY value displayed in policy documents, and almost without exception this equation is entirely absent from documents. The aforementioned DfID publication, for example, neither displayed the equation nor provided a substantial explanation of how the DALY is calculated stating only, in a footnote, that '[a] DALY can be thought of as one lost year of healthy life, due to disease or injury' (DfID, 2010, 10).

$$DALY = YLDS[r, K, \beta] + YLLs[r, K, \beta]$$

where:

$$YLLs[r, K, \beta] = \frac{KC e^{ra}}{(r + \beta)^2} \{ e^{-(r+\beta)(L+a)} [-(r + \beta)(L + \alpha) - 1] - e^{-(r+\beta)a} [-(r + \beta) a - 1] \} + \frac{1 - K}{r} (1 - e^{-rL})$$

$$YLDS[r, K, \beta] = D \left\{ \frac{KC e^{ra}}{(r + \beta)^2} \{ e^{-(r+\beta)(L+a)} [-(r + \beta)(L + A) - 1] - e^{-(r+\beta)a} [-(r + \beta) a - 1] \} + \frac{1 - K}{r} (1 - e^{-rL}) \right\}$$

Where  $a$  is the age at death,  $L$  the remaining standard life expectancy at death,  $r$  the discount rate (0.03),  $\beta$  the parameter for the age-weighting factor (0.04),  $K$  the age-weighting factor (1), and  $C$  a constant (0.1658). The formula for  $YLD$  is basically the same except it is multiplied with a numeric disability weight ( $D$ ), and that  $a$  is the age of onset of disability and  $L$  is the duration of disability.

Figure 1: Disability Adjusted Life Year Equation (Arnesen and Kapiriri 2004, 139)

As evident in Figure 1, DALY is a sum of two values: the first (YLL) represents a value for life lost through premature mortality, and the second (YLD) is a value for years lived with consequential disability or illness. Both YLL and YLD are composite of a series of variables, assumptions, and estimates: at the most simplified level, YLL subtracts the age of death from the standard life expectancy before multiplying this value with the so called 'age weight' and 'future discount', while the YLD is calculated by multiplying the duration of illness with the disease prevalence, together with the a score assigned to the severity of disability

induced by the illness, the 'age weight' and 'future discount' (King and Bertino 2008). The outcome of what is referred to as 'weighting', together with the other assumptions employed in the equation, is that females, the relatively young and old, and those living with unrelated disability are all given a lower individual value than their male, twenty-something year old, able bodied counterparts<sup>iii</sup>. With respect to age, DALYs give optimum 'weighting' to a 25 year old, while a life lived at 70 is considered to be 20 per cent the value of life lived at 25 year old (Anand and Hanson 1997, 589). Demonstrating the extent to which certain groups are devalued, Arnesen and Kapiriri have calculated that 'the DALY loss would be the same if 185 new-borns, seventeen 6 month olds, five 2 year olds, one 25 year old, two 67 year olds or three 83 year olds suffered the same disability for one month' (2004, 139). Similarly, should two individuals present with the same illness, and all things being equal bar the fact one has a pre-existing, entirely unrelated disability, treating the able bodied individual would avert an entire DALY compared to treating the individual with pre-existing disability which would avert only half a DALY each year (Anand and Hanson 1997, 589). Women are also disfavoured within the DALY because of the life expectancy used within the calculation (Arsen and Nord 1999, 1423). Engaging with the equation that produces the DALY it is clear that the final value is far from the neutral, self-referential figure as so often presented, not to mention far more complex than the definition provided by DfID as merely 'one lost year of health life, due to disease or injury' (2010, 10). Rather, the calculation is loaded with predetermined subjective judgments about an individual's worth, judgements that are far from evident when the ostensibly objective value of the DALY is encountered. Alongside these characteristics within the calculation,

health status is also recorded on a scale from nought to six, with six denoting full functioning and perfect health, while nought denotes zero functioning - a state more commonly known as death. This floating scale 'reduces death to merely another health status' Anand and Hanson (1997, 689) and is emblematic of a biopolitical paradigm that blurs the distinct categories of 'life' and 'death'. 'Life and death' Agamben argues 'are no longer properly scientific concepts but rather political concepts, which as such acquire meaning precisely through a decision' (1998, 164). Once more, what constitutes life and death and the variations in between are subjective decisions contained within the calculation.

#### *DALYs and the Politicisation of Life*

The 'disease burden' that DALYs measure refers to a reduction of the functioning capacity of individuals, defined as the 'ability to perform activities of daily living such as learning, working, feeding and clothing oneself' (Anand and Hanson 1997, 689). Conceptualising the disease burden in this way is demonstrative of a biopolitical paradigm which 'judges worth in terms of self care' (Brown 2003, cited in Pratt 2005, 1055). The calculation was justified by Murray by drawing upon an ontological conceptualisation of an individual as 'a type of machine with costs, maintenance and expected outputs [whereby] the value of time of each human production machine should be proportionate to productivity' (Murray 1994, 435). It is this conceptualisation of the individual as a machine that underpins the DALY, which, intentionally or not, allows for the logic of capital accumulation to encroach into the arena of international health governance when DALYs are utilised. This is an intrusion of a particularly capitalist mind-set whereby the 'category of "waste" ... includes no longer simply material goods but

also human beings, particularly those rendered redundant in the new global economy, that is, those who are no longer capable of making a living, who are unable to consume goods, and who depend upon others for the most basic needs' (Bauman 2000, 2003, cited in Giroux 2006, 187). Giroux discusses the 'new politics of disposability' whereby 'hyper-neoliberalism is now organised around the best way to remove or make invisible those individuals and groups who are either seen as a drain or stand in the way of market freedoms, free trade, consumerism' (2006, 175). The conceptualisation drawn upon by Murray crafts certain sectors of society as 'drains', overlooking individuals' contributions beyond productivity and waged labour where those considered 'incapable of living up to the new requirements of market competitiveness and profitability are socially included through their dying in abandonment' (Biehl 2001, 139). As a result of the lower value ascribed to certain populations considered 'un-productive' within a capitalist model, their experiences of illness are made less visible within the overall disease burden presented in the DALY. Together with the lower value assigned to certain individuals, the invisibility of certain populations is heightened because of the difficulty in attaining data on disease prevalence amongst the poorest populations. Many of the poorest populations fail to access formal health care, or report to over-stretched health systems that struggle to maintain data on disease prevalence ultimately meaning many experiences of illness, often vector-borne, go unreported. This is not simply 'lost data' left out when DALYs are calculated: these are invisible populations whose experiences of disease are absent within the DALY value and therefore invisible in debates where DALYs are employed. The WHO, for example, have chosen not to provide a DALY value for a series of vector-borne diseases including

cysticercosis, dracunculiasis, and echinococcosis, within the aforementioned report, because such diseases are so underreported. As Kearns and Reid-Henry argue 'it is important to consider how individuals are rendered either visible or invisible to the system as their visibility clearly shapes how they are positioned relative to vital knowledge' (2009, 559). Given the extent to which DALYs now produce this 'vital knowledge', questions must be asked as to what becomes of diseases – such as those mentioned above – where data is missing, excluding them from discussions that revolve around DALYs. More importantly, what becomes of the individuals who suffer from these diseases?

Agamben draws upon Binding's *Die Freigabe der Verichtung Lebensunwerten Leben* (*Authorisation of Annihilation of Life Unworthy of Being Lived*), a text which sanctions the euthanasia of individuals who 'posses neither the will to live, nor the will to die' (1920, 91 cited in Agamben 1998, 138). Thinking through this text, Agamben discloses the mechanism through which individuals are devoid of value and their lives deemed unworthy of being saved. To evaluate the 'worth' of individuals, Binding asks 'Are there human lives that have lost the quality of legal good that their very existence no longer has any value either for the person leading such a life or for society?' (Ibid.). Today, DALYs begin to answer this question, by focusing on an individual's economic contribution in order to assess their societal worth. The question is answered, of course, with little understanding of how ones 'productivity' can ever be properly quantified. Additionally, this approach to societal worth and the ontological conceptualisation of the body as a type of machine overlooks the non-quantifiable assets individuals offer beyond economic outputs. Society, of

course, does not simply value people through an economic lens: it is not only the most economically productive whose lives are mourned and households do not make economically 'rational' decisions on who to let live, and whom to let die.

Agamben believes that health plays a central role in the politicisation of life and is crucial in defining the *homo sacer*. Demonstrating the *ménage a trois* which exists between 'the body', 'the political' and 'the economy', Agamben draws upon the 1942 *État et Santé* (State and Health), which acknowledges the need to create a 'budget' in order to establish the value of living people. Agamben understands this as representing a shift in the meanings and duties of the medical profession, which transcends beyond solely the need of the patients to encompass wider society where the body become nationalised, or, indeed, internationalised (Agamben 1998). Agamben argues that medical practices became 'increasingly integrated into the function and organs of the state', with *État et Santé* continuing:

Just as the economist and the merchant are responsible for the economy of material value, so the physician is responsible for the economy of human value... it is absolutely necessary that the physician contributes to the rationalised human economy, that he [sic.] recognises that the level of the peoples health is the condition for economic gain... Fluctuations in the biological substance and in the material budget are usually parallel (1942, 40 cited in Agamben 1998, 145).

DALYs offer what is considered the 'logical synthesis between biology and the economy' (Ibid.), a synthesis supported through their focus on economic productivity. Individuals' economic contributions, however, are merely perceived and based on Western notions of economically productive years or economically productive persons, overlooking the unwaged labour conducted by woman and young children in the Global South. Under the rubric of DALYs, individuals' health becomes almost exclusively considered a 'condition for economic gain' (Ibid.).

#### *DALYs and 'The Camp'*

The World Bank report that first established DALYs in the field of health governance advocated for different criteria to be employed between low and high income countries. Stefanini discloses the 'North-South double standards' that allow for only the cheapest services to be considered 'essential' in Global South, while in Global North 'expensive and sophisticated interventions can also be deemed essential' (1999, 710). 'Essential', therefore, becomes a malleable term whose elastic boundaries are stretched to the needs of citizens of the North, but quickly snapped back for those citizens living in the Global South. Agamben argues that the body 'waivers between life and death according to progress of medicines' (1998, 186). As technology and medicines advance, decisions on who lives and who dies are increasingly biopolitical rather than biological for life is 'neither delimited by the poles of illness and health' (Rose 2007, 3). Against this backdrop, that Rose (2007) argues is politicising life anew, the denial of existing (and often cheap) medical interventions that causes entirely preventable death and suffering cannot but be conceived as the violent abandonment of

populations (Craddock 2007). The employment of the 'north-south double standard' within global health governance sees individuals' medical entitlement based on the 'Geography of Luck', premised on the basis that 'some lives simply do not count' (Kearns and Reid-Henry 2009, 560). This decision politicises life and produces an 'epidemiology of inequality' (Sparke and Anguelov 2012), implicitly legitimising the denial of medical interventions, and the abandonment of individuals, which would have been considered 'wrong' or a violation of human rights elsewhere. This buoys up the 'axis of irrelevance', the naturalising of suffering experiences at the tropical latitudes suggesting, once more, an inevitability of suffering and the expendability of individuals living in *The Camp*. Once more, we are reminded of the importance of geography within the abandonment process, whereby *The Camp* in part constructs, not only contains, the *homo sacer*.

While the different geographical context was taken into account in terms of defining 'essential' medicines, many of the other decisions were made without any geographical context (King and Bertino 2008). The 'weight' of the disease burden, for example, was derived from a 'personal-trade off process', whereby a series of 'objective' decisions were made on the perceived impact of living with disability. These figures were not derived from patients' lived experiences and realities of illness, but rather initially decreed as part of a round table discussion, where individuals were asked to reach a consensus on what disabilities would be worse to live with (see King and Bertino 2008 for further discussion on the personal trade off methodology). These decisions were reached on the assumption that the lived experiences of a disability or ailment would be

universally identical, deliberately avoiding the social, cultural, economic and political contexts within which individuals' experiences ill health (Reidpath et al 2003; Kearns and Reid-Henry 2009). It is, at best, naïve to assert that individuals' experiences of disease-induced disability can ever be universally identical or that the burden is uninfluenced by the existence of a welfare state and conditions of the health system, and unaffected by the margin of survival within which a person lives (Kearns and Reid-Henry 2009). Thus, while the likes of WHO (2010) have argued that DALYs are an important tool in bringing to the forefront the impact of neglected diseases by equipping activists with a number which they can wield to demonstrate the burden, this geographical vacuum means they simply do not go far enough in documenting the personal cost of surviving with diseases. DALYs rely on a linear model of impact, which is particularly problematic in understanding the complexities of vector-borne disease and the poverty medical cycle. Poverty not only heightens risk, but also amplifies the 'impacts of infections and restricts access to care' (King and Berino 2008, 209). Failure to understand the context within which individuals experience disease cannot *but* undermine the disease burden for vector borne ailments. Arnesen and Kipiriri (2004) also argue that non-communicable disease – the primary set of diseases within high income countries – are overvalued in comparison to communicable diseases. The authors note that decision makers with a focus on cost-effectiveness look to the difference between disability weight with, and without treatment. The difference in the disability value pre and post treatment between communicable diseases, such as vector borne diseases, is far lower than non-communicable disease. Schistosomiasis, for example, shows no change in disability value whether

treated or not, far from the experience of patients experiencing a plethora of symptoms from headaches, fever, muscle aches (Ibid.). The burden of vector-borne diseases is further underestimated because of the difficulty in tracing maladies such as anaemia, diarrhoea and fatigue back to their pathogenic aetiological root. All of these issues could be incorporated in open discussions on resource allocation, but are filtered out in the DALY calculation in order to create a neat figure that can then be introduced to debates without such complex baggage.

'Geography', therefore, becomes an accommodating tool that has been employed where necessary to legitimise the denial of medical interventions, only to be avoided in other situations that would recognise the true extent to the disease burden experienced by certain populations. This tactical employment of geographical context contributes to the 'Geography of Luck' discussed by Kearns and Reid-Henry (2009) while also legitimising the abandonment of certain populations and overlooking a specific category of illness that affect predominantly poor individuals.

#### *DALYs and Management of Life*

In her inaugural address to staff as Director-General of the World Health Organisation, Dr Margaret Chan (2007, np) quoted the old adage 'what gets measured gets done'. This turn of phrase – one that Chan has repeatedly returned to during her time in office – captures the power and persuasiveness of numbers within global health programmes. Inscription and accumulation of data have been central to the biopolitical regime as 'the birth of biopolitical age in 18<sup>th</sup>

Century Europe also coincided historically with the vast explosion in the number of demographers evaluating these population dynamics in quantitative terms... [this] formed the basis for a plethora of biopolitical interventions trying to regulate the observed population dynamics' (Elbe 2005, 403). DALYs are, therefore, part of a long lineage of numerical ordering employed within biopolitical regimes generally, but more specifically, the biopolitical regimes that manages lives in the Global South. As Rose (1991, 676) writes:

'events must be inscribed in standardised forms, the inscriptions transported from far and wide and accumulated in a central locale. Through the development of such complex relays of inscription and accumulation, new conduits of power are brought into being between those who wish to exercise power and those over whom they wish to exercise.'

Spark (2011) recognises that much of the management of 'global' health is concentrated in Seattle. This one city has become the 'central locale' (Rose 1991, 676) where health data are accumulated and vital knowledge of life ordered. Located just a few blocks away from the Gates Foundation in Downtown Seattle, sits the headquarters for the Institute of Health Metric and Evaluation (IHME). IHME has become the leading research centre for gathering health data and devising new and innovative measurement systems. In a recent editorial in *The Lancet*, Horton (2013) applauds the IHME for helping to strengthen global conversations about health, before expressing concerns over the IHME's monopoly in producing health metrics. Criticising the decision of the Gates

Foundation to pull funding from the Child Health Epidemiology Reference Group (CHERG) and concentrate their investment in IHME, Horton (2013, 2) believe the Gates Foundation 'is crafting the kind of monopoly that IHME originally intended to challenge'. Horton's (2013) concerns highlight the 'conduits of power' (Rose 1991, 676) formed by data collection. Moreover, by arguing the need for plurality in the field of data collection, he dispels the myth that data are neutral despite 'conferring legitimacy on political authority' (Rose 1991, 673). Horton (2013, 2) also contends that 'the persistent failure of countries and donors to press the case for, and invest in, civil registration and vital statistics systems show again that the basic framework on which we hang the field of global health and global health metrics is weak and fractured'. Despite the loaded use of the term 'failure', his remarks are a pertinent reminder of the unequal geographical power relations in data gathering that inevitably play out in the DALYs and similar health metrics. When basic health needs are still to be met in low-income countries, the priority should surely be in investing in the health of citizens, rather than in systems to accumulate data on them. With this in mind, however, what cannot be counted must not be neglected.

## **Conclusion**

Murray claims DALYs 'were not intended to present a new paradigm for measuring health' (1994, 430). As others have noted, however, DALYs have indeed 'become normative because many health policy makers and their funding partners use the DALY as their only measure of disease impact in programmatic analysis' (King and Bertino 2008, 2). DALYs have ushered in, or at the very least, propped up, an epoch in global health governance whereby resource allocation is

justified on the premise of 'cost-effectiveness', 'value for money' and 'goods return for investment'. Today, this management of human bodies and human suffering is tied closely with economic management, where scientific rationalism is exercised to 'ensure' capital accumulation and the body is incorporated within the functioning of the economy (Agamben 1998). DALYs are ultimately predicated on the ontologically thin conceptualisation of individuals as exclusively economic beings. However, the figure of the *homo economicus* merges and melts into *homo sacer* when individuals fail to live up to the economically productive 'ideal'. DALYs are complicit in devaluing the lives of certain individuals, by asserting the values of individualism in relation to wider economic gain where 'in effect, under neoliberal dispensation, they almost lost that human-ness as soon as they become not only poor, but unproductive too. This is a regulation of life that, producing subjectivities through economic discipline, legitimises a conflation of "worth exploiting" with "worth letting live"' (Kearns and Reid-Henry 2009, 561). As imperfect as DALYs undeniably are, perhaps the problem is less with DALYs as a measurement in and of itself, but rather with the unflinching faith that has been placed in them by mainstream institutions. While William warns against rejecting DALYs 'simply because they fall short of perfection' (1997, 1830), the alternative is no more attractive – that DALYs are employed and presented as if they are the perfect expression of the disease burden. Thus, the suffering induced by vector-borne diseases is naturalised once more, treated like any other disease as a biological and economic problem, which offers no challenges to the entrenched structural inequalities that cause much of the problem. As Arnesen and Kipiriri note, 'who benefits from health interventions is a value-laden question. The setting of

priorities is essentially not a scientific but a political and social process, which involves debate and requires public accountability. In terms of seemingly exact numbers of the DALY, important questions of ethics and politics may appear to have found a scientific answer. This may hinder rather than enhance important and difficult discussions of setting priorities in the health sector' (2004, 147).

The paper opened with a question posed by Farmer, asking '[i]f health is a human right, who is considered human enough to have that right?' (2005, 206). According to Agamben, the humanity of living man has, throughout history, been judged and it is through this metaphysical tradition that each society has come to decide whose lives have value. Today, these judgements are increasingly based upon economic productivity or the pursuit of capital accumulation where certain (wealthier) lives are considered more valuable than others. DALYs are reflective of this, capturing the 'disease burden' through economic loss, but also answering Farmer's question as to who is valuable, or who is human enough, to be afforded the right to health.

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<sup>i</sup> Malaria may be considered as a vector-borne disease the 'West' has been willing to invest in. However, despite reaching level records of investment of \$2billion in 2011 for malaria, there remains an estimated \$9.7billion shortfall required funds over the next 3 years (WHO 2011). Furthermore, financial support has wilted against the backdrop of economic turmoil with funding witnessing a reversal of fortune from the 2011 peak (Ibid.). Cohen et al. (2012) have outlined the financial frailty of malaria successes in the past, with significant resurgence correlating with drops in funding of previous elimination efforts, findings which are concerning to today's funding environment. Thus, while there has been an increase in malaria this neither reached the level required for successful inroads to be made, nor been sustained and, therefore, do not represent a wholesale shift in traditional apathy towards vector-borne diseases.

<sup>ii</sup> While pharmaceutical companies have entered into charitable partnerships, donating drugs to global health initiatives, such acts are mere window dressing that can neither begin to address forces that ultimately produce the '10/90'

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problem, nor dismantle the apparatus that protects the industry, and are far removed from proposed alternative systems such as the Health Impact Fund (see Pougé 2010). Indeed, such acts run the risk of further disguising the inherent structural violence enacted through the current system by projecting the image of an industry changing, while pharmaceutical companies simultaneously protect TRIPS and pursue legal cases against the manufacturing of generic drugs within developing countries (Craddock 2009).

<sup>iii</sup>While the Global Burden of Disease 2010 publication has omitted discounting and age weighting this has been done to ‘simplify’ DALYs in this particular multi-region multi-disease study (Murray et al. 2012, 2199), rather than a decision based on ethical issues with the weighting system generally. The paper did not call for these to be permanently omitted from individual DALY calculations being made in further policies. Furthermore, older data that has used the traditional DALY measurement has been used, and as such, the old assumptions are present within the new study.