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ACCOUNTABILITY FOR HEALTH EQUITY: GALVANISING A MOVEMENT FOR UNIVERSAL HEALTH COVERAGE

Editors Erica Nelson,
Gerald Bloom and Alex Shankland



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Neglected Tropical Diseases and Equity in the Post-2015 Health Agenda*

Emma Michelle Taylor and James Smith

Abstract The Millennium Development Goals' focus on just three infectious diseases (HIV/AIDS, malaria, and belatedly, tuberculosis) configured the global health funding landscape for 15 years. neglected tropical diseases (NTDs), a group of 17 or so diseases that disproportionately afflict the world's 'bottom billion', are a symbol of global health inequities, in terms of prioritisation, research attention, and treatment. This article traces efforts to include NTDs in the Sustainable Development Goal (SDG) agenda and, having achieved that goal, lobby for an influential position in the post-2015 aid agenda. The SDGs herald a shift to a more expansive approach and there is a risk that NTDs will once again be left behind, lost in a panoply of new goals and targets. There is, however, an opportunity for NTDs to lever their 'neglect' and be recast as a tool of accountability, acting as both a target for and proxy indicator of health equity for the SDGs.

Keywords: NTDs, SDGs, MDGs, global health, evidence, indicators, health policy.

1 Introduction

'To fulfil our vision of promoting sustainable development, we must go beyond the MDGs. They did not focus enough on reaching the very poorest and most excluded people...'

A New Global Partnership: Eradicate Poverty and Transform Economies through Sustainable Development. The Report of the High-Level Panel of Eminent Persons on the Post-2015 Development Agenda, High-Level Panel of Eminent Persons on the Post-2015 Development Agenda 2013, page i

'The NTD agenda... is fundamentally aligned with the SDG commitment to leave no one behind'

Integrating Neglected Tropical Diseases into Global Health and Development: Fourth WHO Report on Neglected Tropical Diseases, World Health Organization, 2017, page 66

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This article is part of *IDS Bulletin* Vol. 49 No. 2 March 2018: 'Accountability for Health Equity: Galvanising a Movement for Universal Health Coverage'; the Introduction is also recommended reading.

Box 1 Neglected tropical diseases

Neglected tropical diseases (NTDs) are a group of parasitic and bacterial infections which are usually endemic in low-income populations in Africa, Asia, and the Americas. They affect over 1 billion people and are a significant disease burden. Populations living in poverty, without adequate sanitation, and in close proximity to vectors and livestock are amongst the most vulnerable. Some NTDs have known preventative measures or medical treatments – there may be a problem of access. These include: schistosomiasis; soil transmitted helminthiasis; lymphatic filariasis; onchocerciasis; trachoma. Some require new tools – drugs, diagnostics, and control measures. These include: leishmaniasis; Chagas' disease; human African trypanosomiasis (HAT).

Source: WHO (2010).

Equity and inclusion are threads running through the Sustainable Development Goals (SDGs). The goals are conceptualised as both a pathway to equity and as targets that cannot be sustainably achieved without being built on an equitable base. The jump from eight Millennium Development Goals (MDGs) to 17 SDGs underpinned by a range of sub-goals, and the devolution of the delivery of goals down to nation states is welcome, and is partly a byproduct of more accountable notions of development. While the SDGs present a fuller and more grounded concept of development and how it might be achieved, they present significant challenges: firstly, for how one counts, and accounts for, 'progress'; and secondly, for who is responsible for progress. This is perhaps especially true for global health, where the institutional landscape is particularly complex: the MDGs cast a long shadow, increasing funding for certain diseases and often-vertical programmes; state and non-state actors have proliferated; and demands for transparency and accountability have driven calls for better evidence, policy, and practice.

Global development goals – whether they be millennium or sustainable – are fundamental to questions of accountability and equity for global health. The transition from the MDGs in 2000 to the SDGs in 2015 was a febrile time for health advocacy as intense lobbying sought to create new goals to reflect new priorities and aspirations (Buse and Hawkes 2015). In this article, we use the case of neglected tropical diseases (NTDs) to reflect on the relationships between equity, accountability, and priority in global health. The NTDs, a group of 17 or so diseases that, it is argued, especially within the NTD community, disproportionately afflict the world's 'bottom billion' (Collier 2007), are a symbol of health inequities, in terms of prioritisation, research attention, and treatment (see Box 1; also Hotez *et al.* 2014). This article tracks the course of ostensibly successful lobbying for these diseases to

receive special attention in the post-2015 agenda (*cf.* Smith and Taylor 2013, 2016). The SDGs herald a shift to a more expansive approach to development, but there is a risk that the NTDs could fail to gain traction in the new agenda, lost in a panoply of goals and targets. There is also, conversely, an opportunity for the NTDs to lever their earlier ‘neglect’ and be recast as tools of accountability – to act as both a primary target for, and a proxy indicator of, health equity in the framework. In this article, we highlight the politics that have struggled to place the NTDs centre stage, partly by recasting them as indicators of equity in the post-2015 agenda, as a means to reflect on what the shift to SDGs may mean for accountability.

2 Why the MDGs?

Prior to the time-bound goals and related targets established by the *Millennium Declaration* in 2000 (United Nations 2000), a striking feature of development diplomacy in the twentieth century was the tendency of governments to rehash the same vague commitments time and again, without recourse. A key example of what William Easterly has labelled the ‘historical amnesia’ (2002: 49) of the development industry was the pledge that governments would provide 0.7 per cent of their gross national product as official development assistance (ODA). Originally set as a target in 1970, it took 45 years for the UK to honour the UN aid commitment. When it did, it became the first G7 country to do so. There are countless other examples of unmet development pledges – the point being that for much of development’s history, there was no consequence for aid donors who chose to promise one thing, then do another.

The MDGs, then, marked a sea change in how development was approached. Galvanised by the seeming simplicity of tackling ‘development’ via eight narrowly focused, time-bound goals (as tracked through 18 targets and 48 technical indicators), the international community showed commitment to delivering on the MDGs in a manner not witnessed before. Data collection methods were devised, and data systems built to provide the evidence needed to track progress against the goals. To support the goals, new resources were leveraged, and dedicated aid-disbursement initiatives such as the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) were established to increase the likelihood that goals would be met on time. In 2005, the Paris Declaration on Aid Effectiveness set out five principles that helped to further align and harmonise aid to focus on results and accountability (OECD 2005). A sea change in the delivery of development was emerging, theoretically at least. It is significant that the adoption of the MDGs came at the end of a decade in which the purpose and usefulness of official development aid had come under increased scrutiny. A changing political climate in the 1990s, coupled with the poor results of decades of work and billions of dollars aimed at improving social and economic conditions in poor countries, led to a questioning of the effectiveness of aid and development practices (Riddell 2007). In response, there was a renewed appetite to make aid work for development.

The MDGs gave a new prominence to the health issues affecting poor populations. However, their focus was narrow and derived from top-down deliberation rather than broader participatory approaches. Consequently, the narrowness of the MDGs left gaps in coverage, and failed to realise potential synergies between the discrete foci of the goals (education, health, poverty, and gender) (Waage *et al.* 2010). MDG 6, in particular – *combat HIV/AIDS, malaria and other diseases* – effectively sidelined many of the communicable and non-communicable diseases that perpetuate the cycle of poverty in developing countries (including the NTDs). Conversely, singling out HIV/AIDS and malaria within MDG 6 raised the profile of these diseases, stimulating a reconfiguration and refocusing of ODA for health. Global health initiatives such as the GFATM and the President's Emergency Plan for AIDS Relief (PEPFAR) ushered in an era of vertical aid on an unprecedented scale, diverting resources away from existing health programmes (Shiffman 2008). In a funding climate of narrowing focus, advocacy groups were left to argue that it was *their* disease being referred to in the ambiguous wording: 'other diseases'.¹

3 Establishing the NTDs – fighting for a voice

The 17 NTDs identified by the World Health Organization (WHO) in 2010 represented some of the MDGs' 'other diseases'. Their neglected tag stems from the disparity between the attention and funding they receive (0.6 per cent of ODA for health), and their large impact in terms of Disability-Adjusted Life Years (DALYs) (Liese and Shubert 2009; Murray *et al.* 2012). The NTDs are repeatedly identified as drivers of poverty (Durrheim *et al.* 2004), undermining efforts to meet a host of development goals and targets through an erosion of people's ability to live, thrive, and work (Hotez *et al.* 2006; Global Network 2013). In the context of the MDGs, the narrow focus of the goals, the health goal in particular, tended to drive a siloed approach to interventions. The consequent lack of emphasis on the interrelationships between the goals limited concerted efforts to focus on the NTDs.

The omission of NTDs from the MDGs led to a group of concerned stakeholders working hard to place NTDs firmly on the international agenda. The emergence of a global alliance of stakeholders – ranging across the gamut of global health actors – mobilised to raise the profile of NTDs (Smith and Taylor 2013). Progress was swift: in 2003, the Drugs for Neglected Diseases *initiative* (DNDi) and the Foundation for Innovative Diagnostics (FIND) were established. In 2010, WHO released its *First Report on the NTDs*, pinning down the disparate 17 diseases we now know by the shorthand 'NTDs' (WHO 2010).² Progress was such that the then WHO Secretary-General, Dr Margaret Chan, somewhat ironically described the story of the NTDs in the twenty-first century as one of 'rags to riches' (Chan 2012), given the great efforts expended to intrinsically link tackling the NTDs to pulling the 'bottom billion' out of poverty (Hotez *et al.* 2009).

4 The NTDs and the SDGs – leaving no one behind

On 1 January 2016, the SDGs came into force. The particulars of the goals were finalised at the UN summit in September 2015, with the NTDs gaining a special mention in SDG 3.3: ‘By 2030, end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases’ (United Nations General Assembly 2015: 16). The decade-long effort of the NTD lobby had been successful, they had ‘won’.

While it was important to be name-checked, and have one’s seat at the global goal table, it was apparent that the SDGs were to be quite different from the MDGs. A recurrent critique of the MDGs was that they were restricted in focus and conceived of by committee. This cannot be levelled at the SDGs, which were the result of an extensive three-year consultation, involving multiple perspectives from government, civil society, expert groups, the private sector, and individuals. Instead of eight goals, there are now 17 accompanied by 169 targets. Has the High-Level Panel which originally drafted the framework document been ignored? ‘The international community will need to ensure that a single, sustainable framework agenda is not overloaded with too many priorities. A product of compromise rather than decisions...’ (HLP 2013: 14).

The post-2015 vision – enacted through the SDGs – is to create a single universal agenda in which the social, economic, and environmental dimensions of sustainability are integrated, underpinned by the tenet ‘leave no one behind’ (HLP 2013: 7). This tenet presents an opportunity for the NTDs.

5 Framing the NTDs as cross-cutting

The success of a name-check in SDG 3.3 was tempered by extensive references to other health concerns, as detailed in the overarching Goal 3: *Ensure healthy lives and promote wellbeing for all at all ages*. Goal 3 is accompanied by nine targets and four means of implementation, and covers everything from maternal health to non-communicable diseases and traffic accidents. There is a risk of the NTDs disappearing amongst a panoply of other targets.

For those concerned with tackling NTDs, there is also a pressing financial need for NTDs to gain greater prominence and policy traction if they are to be effectively addressed. Current funding commitments for the NTDs (from various sources including ODA, philanthropic giving, and national budgets) for the period 2015–20 have been projected at less than US\$200 million a year;³ yet WHO has suggested that the total investment needed to support the NTD Roadmap for the 2015–20 period is US\$18 billion (WHO 2015a: 24). This is a problematic disparity, yet one that could feasibly be lessened by the NTDs’ impact being emphasised across the SDG framework. As editor of *The Lancet*, Richard Horton, has suggested: ‘Unless high-level political recognition is given to NTDs by their inclusion in new development goals, the financing to meet WHO’s targets is unlikely to materialise’ (*ibid.*: 758).

The NTD lobby has, unsurprisingly given its genealogy, been proactive in formulating a case that the NTDs should be anchored across the broader SDG agenda, whether that be rhetorically (the argument that the NTDs are both outcomes and drivers of poverty has already been rehearsed (Durrheim *et al.* 2004)), by partnering directly with other agendas such as water and sanitation for health (WHO 2015b), or by proxy, by suggesting the NTDs should be used as tracer indicators for other SDG targets (Smith and Taylor 2016).

The recently retired director of the WHO Department of Control of Neglected Tropical Diseases, Dirk Engels, has argued that it is necessary to use the NTDs as 'tracers' (or proxy indicators) for a number of other SDG targets, such as Universal Health Coverage (SDG 3.8) and access to safe water (SDG 6.1) to monitor equity in the post-2015 agenda, 'precisely because NTD endemic populations are the least likely to have access to these services at present' (Engels 2016: 224). In this manner, the burden of NTDs is suggested as 'a proxy for inequitable access to the systems – especially health systems – through which people improve their health and wealth' (WHO 2015a: 12), and Universal Health Coverage (UHC) depicted as 'one of the most powerful social equalizers among all policy options' (Margaret Chan, cited in WHO 2015a: x).

In WHO's fourth Report on NTDs – *Integrating Neglected Tropical Diseases into Global Health and Development* – the case is made that 'tackling NTDs significantly improves the prospects of attaining all of the SDGs, from reducing poverty and malnutrition to improving water and sanitation, gender equality and education' (WHO 2017: 66). Specifically, it has been argued by the NTD lobby that NTDs directly impact on six of the 17 SDGs.⁴ Although even outside those goals, 'more subtle' alignments and potential synergies are hinted across the broader framework (WHO 2017: 68; also see Bangert *et al.* 2017 for a fuller discussion on all the ways the NTDs are argued to impact on the SDG framework).

The underpinning importance of the NTDs for the attainment of a wider range of SDGs is repeatedly stressed by adherents. Moreover, a value-for-money argument is supported by creating the logic that investment in the NTDs could maximise returns across a broad range of SDG goals and targets – a point Dirk Engels has been quick to stress:

I do not share the opinion that the main outcome for the inclusion of the NTDs within the Sustainable Development Goals would be more money for the NTDs. Inclusion of NTD indicators and tracers will, on the contrary, help to maximise returns on investments in a broad portfolio of Sustainable Development Goal targets (2016: 224).

WHO's most recent report on the NTDs suggests NTD interventions could act as 'tracers of equity' in relation to six goals and eight targets (WHO 2017). Effectively, NTDs are being framed as both *a target for, and an indicator of* equity in the new SDG framework.

6 Lobbying for primary and proxy indicators

Increasing demands for accountability for health present both a challenge and an opportunity for the NTD lobby (Smith and Taylor 2016). If accountability drives increasing demands for targets and evidence to measure progress against those targets, it is vital for NTDs to secure indicators if they are to access resources and marshal activity. The indicator that most concerns the NTD community seeks to measure the ‘number of people requiring interventions against neglected tropical diseases’ (IAEG-SDG 2015: 9). In theory, these data could be collected from a number of existing sources (for example, accounting for donated medicines for preventative chemotherapy or results from active screening for disease) to inform an overarching indicator. There is, in fact, no precedent for collecting these kinds of data systematically or universally, and WHO admits to several data gaps in the current NTD reporting systems (2017).

Thanks in part to their inclusion in the MDGs, the ‘big three’ diseases already boast indicators with proven data collection methodologies. The NTDs are not so well endowed, with the groups addressing the 17 diseases tending to affect the people who live outside the formal health-care systems now being tasked with tracking interventions. To address the data gaps, WHO has suggested that a comprehensive information management system will need to be developed. This would be a mammoth task but one that helps underline the SDG’s equity focus:

The NTD indicator [for SDG target 3.3] counts, and thus renders visible for the first time the more than one billion people estimated to require treatment and care for NTDs... this indicator will drive efforts and in some cases build from the beginning, systems that will greatly improve the lives of neglected populations (WHO 2017: 108).

The NTD indicator can help focus attention on neglected populations; a need for data can prompt the development of systems to count and assess activity and impact. NTD proxy or tracer indicators can do more than that, helping to build health systems. For this reason, arguments are being made in favour of an NTDs tracer being adopted as an indicator for SDG 3.8 on UHC.⁵

UHC has been defined as ensuring that all people have access to needed promotive, preventative, curative, and rehabilitative health services, of sufficient quality to be effective, while also ensuring that people do not suffer financial hardship when paying for these services (WHO 2015c). UHC needs to be understood within country contexts, the reality and ambition of health-care service coverage being limited by funding, capacity, and often political will. Regardless of income, virtually every country strives to provide greater health-care service coverage, hence ‘the UHC endeavour is generally referred to as a journey rather than a destination, as a dynamic, continuing process rather than a permanent solution or state that can be achieved’ (WHO 2017: 87).

Of all the SDG targets that the WHO department for NTDs has determined could benefit from NTD tracers, UHC is the one it has attached the most importance to. It argues that this is because 'UHC is the only target that binds all of the targets of the health goal, as well as addressing linkages with health-related targets in the other goals' (WHO 2017: 85). In short, UHC, much like the NTDs themselves is viewed as cutting across the SDG agenda, and pivotal to the success of several goals. This effectively allows NTDs to not only directly piggyback on certain goals but also potentially interact with other goals indirectly via UHC, should it indeed become a proxy indicator.

Due to the complex nature of UHC – which presents a shifting target, and one that will not look the same in every context – it is acknowledged that measuring progress towards SDG 3.8 will prove very challenging. There cannot therefore be one indicator, but many – all effectively proxies/ tracers – that will serve to track people's ability to access a basic package of health-related interventions and services. Moreover, the precise composition of this package will differ by country to reflect the context-specific health priorities at play. Despite this, and in order to help assess regional and global progress towards the UHC target, WHO has determined that it would be helpful to identify a set of tracer indicators that could then be combined to form a monitoring index. To date, 16 tracer indicators (things like child immunisation and HIV treatment) have been adopted and grouped under the four categories of: reproductive, maternal, newborn, and child health; infectious diseases; non-communicable diseases; service capacity and access; and health security. So far, no NTD interventions have been included in the UHC coverage index. Nevertheless, WHO has developed an 'NTD coverage index' based on the coverage of preventative chemotherapy for five of the NTDs, and continues to campaign for its adoption. In short, the campaigning around the NTDs' meaningful inclusion in the SDG framework continues, with WHO arguing that 'it is clear that monitoring NTD coverage could still make a significant contribution to tracking the coverage of essential health services' (WHO 2017: 117).

7 Discussion: not forgetting what is left behind

The changing relationship between the NTDs and Global Goals highlights the dynamics of the relationship between accountability and global health, which help us problematise and reframe current notions of accountability. Bruen *et al.* (2014: 12) argue that 'accountability is a frequently invoked though arguably less questioned concept in global health operation'. Accountability is rather more complex than one actor holding another to account; rather, it is a dynamic process that shapes and is shaped by relationships between increasingly diverse sets of actors, and framed by priorities, data, and evidence.

The reference to NTDs within a Global Goal and the realities of the transition from MDGs to SDGs highlights dimensions of accountability that warrant further analysis if we are to develop more transparent, participatory, and equitable methods of delivering a transformational global health agenda.

The MDGs were criticised as being top-down, too narrowly focused, and too disconnected from each other. The emergence of the SDGs are themselves a recognition of this, specifically recognising the interactions between goals (one of the proposed selling points of the NTDs) and greatly broadening our conceptions of health and development, as well as developing a broader sense of who is responsible for delivering on them (Buse and Hawkes 2015). The SDGs are also a reflection of broader shifts in development thinking, towards holistic, integrated, intersectoral, indivisible goals for which the responsibility of delivering is collective. Equity is conceived of as both an overarching aspiration and a prerequisite for delivering the goals. The potential place of the NTDs within an SDG-inflected world presents important implications for accountability with regard to global health.

Firstly, the NTDs highlight practical challenges for accountability: how are priorities set and how is progress measured? There is an emphasis on countries to set their own targets that reflect their national circumstances. The concentration of NTDs in less-developed countries, which typically have less capacity to deliver the sorts of systematic interventions necessary to, for example, deliver active disease screening or mass drug administration, presents a challenge, and suggests that tough decisions around priorities and programmes have to be made. This may be viewed as an opportunity for NTDs, given their connections to other goals and targets and potential to act as proxies of progress, thus cementing investment and focus. At this stage, however, it is unclear whether increased efforts aimed at controlling NTDs may supplement or complement broader efforts to map, measure, and tackle global health concerns, or whether NTDs may become again lost in a panoply of priorities in resource-constrained settings.

Secondly, the cross-cutting nature of the SDGs and NTDs in particular suggests complications around the who of accountability. Cross-cutting approaches to NTD control, often but not always embedded in national contexts, require broader sets of actors, including the private sector in, for example vector control, or local communities with regard to mass drug administration. There are of course many examples of intersectional approaches to dealing with health and development issues, but the broadening of the ambitions of the SDG agenda suggest both a broadening of responsibility to deliver against that agenda and attendant issues around which countries, agencies, and actors will be held to account.

There is a risk that accountable practices, so important to the thinking behind the concept of Global Goals and central to the delivery of the SDGs, will become lost or unimplementable amongst the white noise of multiple goals and targets. Accountability may suffer from the technical perspective of difficulties in measuring progress across complex topographies of goals, targets, and nations; from the conceptual perspective of truly understanding how interventions interact between goals and targets; and from the ethical perspective of whom can legitimately be held to account when so many are involved in delivery.

The NTDs underline some of the problems of accountability in the emerging SDG era. A more complex, nuanced, and ambitious global health and development agenda requires new ways of doing things. There are technical and conceptual challenges, which may be partially addressed by new technologies and data sets that can map progress and shed light on the relationships and trade-offs between economic, social, and environmental development. There are issues of ethics and equity, who is responsible for what, and how priorities are arrived at. This may be more difficult to address, and involves us reflecting on just who is responsible for delivering development. Plural pronouns are powerful, but are they organisationally useful?

The NTDs themselves, until recently hidden in the netherworld of global health, can act as a mirror to accountability. For many years unprioritised, recently recognised, with ambitious elimination plans not yet realised (or accounted for). Their attraction is partly that they are multipurpose, they are a global target and may be adopted as a useful proxy indicator. This attractiveness highlights some of the immense difficulty of realising accountability in the new era of complex, multiple, connected goals and associated indicators. We should not forget that NTDs are diseases of poverty: controlling and treating them will improve lives and livelihoods and help progress towards equity, and as the SDGs assert, this is a concern for all of us.

Notes

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- 1 It is noteworthy that tuberculosis was able to transcend 'other diseases' through its close association with HIV/AIDS, as witnessed in the focus of the GFATM. It showed that lobbying and making associations could shape discourses and influence priorities around global health.
- 2 Note that in 2017, the list of NTDs has been enlarged to include chromoblastomycosis and other deep mycoses, scabies and other ectoparasites, and snakebite envenoming.
- 3 Not including in-kind donations of drugs.
- 4 Goal 1: End poverty in all its forms everywhere; Goal 2: End hunger, achieve food security and improved nutrition and promote sustainable agriculture; Goal 3: Ensure healthy lives and promote wellbeing for all at all ages; Goal 4: Ensure inclusive and equitable quality education and promote lifelong opportunities for all; Goal 6: Ensure availability and sustainable management of water and sanitation for all; Goal 11: Make cities and human settlements inclusive, safe, resilient and sustainable (WHO 2017: 68).
- 5 While indicator 3.8 is the most important, WHO is also making a similar case for NTD 'tracers of equity' to help monitor six SDGs and eight targets (WHO 2017: 119).

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