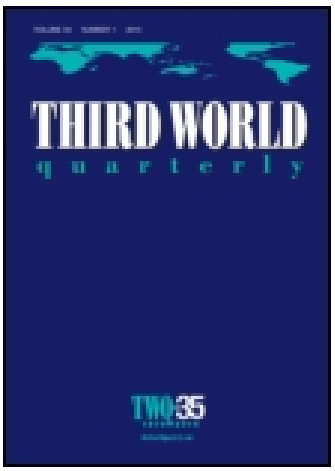

Third World Quarterly
Publication details, including instructions for authors and subscription information:
http://www.tandfonline.com/loi/ctwq20

The 'Other Diseases' of the Millennium Development Goals: rhetoric and reality of free drug distribution to cure the poor's parasites

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Published online: 23 Feb 2011.

To cite this article: Tim Allen & Melissa Parker (2011) The 'Other Diseases' of the Millennium Development Goals: rhetoric and reality of free drug distribution to cure the poor's parasites, Third World Quarterly, 32:1, 91-117, DOI: 10.1080/01436597.2011.543816

To link to this article: http://dx.doi.org/10.1080/01436597.2011.543816

Third World Quarterly, Vol. 32, No. 1, 2011, pp 91–117

Routledge
Taylor & Francis Group

The 'Other Diseases' of the Millennium Development Goals: rhetoric and reality of free drug distribution to cure the poor's parasites

TIM ALLEN & MELISSA PARKER

ABSTRACT *The sixth MDG aims 'to combat HIV/AIDS, TB, malaria and other diseases'. The residual category of 'other diseases' has become the focus of intense interest, partly because it has provided an opportunity to increase resources for the control of the mostly parasitic 'neglected tropical diseases' (NTDs). Intense lobbying has secured large amounts of funding from donors, as well as generous donations of medicines from the major drug companies. A massive programme is now underway to treat the parasites of the poor in Africa via integrated vertical interventions of mass drug administration in endemic areas. The approach has been hailed as remarkably effective, with claims that there is now a real prospect of complete control and, for some NTDs, even elimination. However, a closer look at evaluation and research data reveals that much less is known about what is being achieved than is suggested. Competition between implementing organisations is leading to potentially counterproductive exaggerations about treatment coverage. Detailed local-level research in Uganda and Tanzania shows that actual rates of drug take-up among target populations are often lower than is necessary to effectively control the diseases, and that methods of drug distribution may even lead to active resistance to treatment. If current trends are not corrected, declining rates of NTD infection will not be sustained. Much more rigorous and effective monitoring is essential.*

The sixth Millennium Development Goal (MDG) refers to a vague, residual category. It aims 'to combat HIV/AIDS, TB, malaria and other diseases'. 'Other diseases' is a label that quickly became the focus of intense lobbying,

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ISSN 0143-6597 print/ISSN 1360-2241 online/11/010091–27

DOI: 10.1080/01436597.2011.543816

because capturing it would almost certainly guarantee a huge surge of funding. By the mid 2000s a group of determined and passionate activists had clearly won the day. They had shrewdly pooled their resources and networks to claim that 'one of the most convincing ways to make poverty history' was to control a group of infections referred to as the neglected tropical diseases or 'NTDs'.[1] In 2005 the UN Millennium Project published a set of 'Quick Win' interventions that were devised to deliver rapid results in attaining the MDGs; an aspect of NTD control was highlighted as one of the most important low-hanging fruits.

Campaigners have tended to use the NTD acronym as though it encapsulates a clearly defined and homogenous problem. It actually refers to a diverse range of afflictions, mostly parasitic, which have historically been endemic in large parts of the world. So successful has the NTD-control movement been that we now have remarkable claims being taken seriously. Sachs and Sachs, for example, tell us that 'Controlling the NTDs is nothing less than healing the world',[2] while Hotez and Thompson have published a paper called 'Waging peace through neglected tropical diseases: a US foreign policy for the bottom billion' in a respected medical journal.[3]

More soberly Hotez has explained that the NTDs are among the most common infections of the poor. He estimates that one in four of the world's poorest people are infected with soil-transmitted helminths; one in 10 with schistosomiasis; one in 20 with lymphatic filariasis and trachoma; and one in 50 with onchocerciasis. In total, he suggests, 1.1 billion of the world's 2.7 billion people living on less that US$2 per day are infected with one or more NTDs, and when the global disease burden of the most prevalent NTDs is combined, the disability they cause rivals that of any of the big three.[4] He and his research colleagues have elaborated this latter point in studies comparing the total number of disability-adjusted life years (DALYs), that have been lost from either premature death or disability from NTDs as opposed to HIV/AIDS, malaria and TB. By their calculations, NTDs collectively account for more lost DALYs than either malaria or TB.[5]

The argument that developing integrated NTD control programmes is a cost-effective way forward was found to be particularly compelling. A key paper, published in 2005, was co-authored by three of the most prominent long-term advocates of mass drug administration: David Molyneux of the Liverpool School of Tropical Medicine, Peter Hotez of the Sabin Vaccine Institute in Washington (who has already been mentioned above) and Alan Fenwick of London's Imperial College.[6] The paper argued that it is possible for public–private partnerships to develop integrated control programmes for seven major NTDs in Africa with only four drugs (albendazole, ivermectin, praziquantel and azithromycin) at an estimated cost of $0.40 per person per year. It went on to suggest that if $200 million could be spent each year for five years, it would be possible to treat 500 million individuals. This, in turn, would contribute to current strategies to alleviate poverty among the poorest and most marginal people in the world. By way of contrast, it was also pointed out that it costs $200 each year to treat one person with HIV/AIDS in Africa; a further $200 to treat an individual with TB; and $7–$10 to treat each

bout of malaria. The case to support these 'rapid impact interventions' was stronger still, it was argued, considering the fact that there are millions of people in Africa who are infected with a variety of parasitic infections, but who do not suffer from HIV, TB or malaria.

In sum, those promoting NTD control argued that it represents one of the most efficient and cost-effective means of achieving the MDGs in the areas of child and maternal health, infectious diseases and poverty reduction. It could also be a means of building global partnerships, and 'a step forward in achieving international human rights'.[7] The first WHO global report on NTDs, published in 2010, reiterates these points. In the foreword the Director General claims that NTDs 'weaken impoverished populations, frustrate the achievement of the health-related Millennium Development Goals and impede global development outcomes ... The logic has changed: instead of waiting for these diseases to gradually disappear as countries develop and living conditions improve, a deliberate effort to make them disappear is now viewed as a route to poverty alleviation that can itself spur socioeconomic development'.[8]

In many ways this has been a remarkable and positive change in thinking about global public health. Thirty years ago there was very little funding or support for the control of tropical parasitic infections other than malaria. Indeed, there was not even much interest in the medical profession outside a small coterie of specialists. It must come as something of a surprise to such people that the World Health Organisation (WHO) now claims that treatment of these diseases has always been one of its main priorities.

NTDs mostly affect politically marginal populations in parts of the world that are of little strategic or commercial interest to rich countries. Although there have been important exceptions, in general, when attempted at all, disease control has concentrated on more economically significant places, such as the Gezira/Managil irrigation region of Sudan. Some veterans of combating NTDs, like Alan Fenwick, were involved in those programmes and, whatever their status in the countries concerned, they may well have felt like voices in the wilderness when they attempted to highlight the importance of what they were doing on the global stage.[9] Not now.

A 2009 report to an All-Party Parliamentary Group in the UK posed the question: 'The Neglected Tropical Diseases: a challenge we could rise to—will we?'. The consensus, it seems, was by then already a resounding 'yes'. Since 2004 the Gates Foundation has allocated more than $46 million to NTD control, but this has been dwarfed by the amounts allocated from the US aid programme. US Agency for International Development (USAID) funding will reach $350 million by 2013. The UK's aid programme has also been caught up in the enthusiasm, allocating £50 million by 2010. Compared with what has been available in the past, these are extraordinary amounts of money, and substantial further resources are on their way. At a meeting on NTDs in Geneva on 14 October 2010 huge commitments were pledged by donors, including massive quantities of drugs. GlaxoSmithKline, for example, is now committed to donating a billion albendozole tablets per year to treat school-aged children in Africa. Other drug companies, including Merck, Eisai, Sanofi-Aventis and Johnson&Johnson, have been almost as generous.

So what exactly are these formerly ignored infections that have become the not-so-neglected tropical diseases? Can they really be so readily controlled, and what has been achieved so far? Our answer to the latter two questions is that, perhaps not surprisingly, things are very much more complicated than is claimed.

Controlling the NTDs

The five most common neglected tropical diseases and disease groups are: lymphatic filariasis (otherwise known as elephantiasis), onchocerciasis (river blindness), soil-transmitted helminths (intestinal parasitic worms such as hookworm, ascaris and trichuris), schistosomiasis (bilharzia) and trachoma. Other infectious diseases that are increasingly referred to as NTDs, no doubt in part to jump on the bandwagon and secure resources for treatment, include: African trypanosomiasis; chagas disease; dengue fever; leishmaniasis, leprosy; cysticercosis; dracunculiasis (guinea-worm disease); echinococcosis and foodborne trematode infections. These are all debilitating afflictions and, in some instances, can prove fatal. Those who are also infected with HIV/AIDS and/or TB and malaria are more likely to suffer the severe consequences of one or more of these infections more quickly.

It is important to note, however, that the figures cited above about the specific number of people affected by different NTDs and the data used in calculating DALYs can be little more than 'guesstimates'. Robust demographic and epidemiological data are only now beginning to be collected systematically and still remain surprisingly sparse—a point we discuss below. Nevertheless, it is irrefutable that a large proportion of the world's most deprived and marginalised people are infected with one or more NTD.

According to the first WHO global report on NTDs, which collates evidence from multiple sources, NTDs are endemic in 149 countries and territories, with 30 of these being endemic for six or more NTDs. As the report emphasises, these afflictions are associated with 'substandard housing, lack of access to safe water and sanitation, filthy environments, and abundant insects and other vectors'.[10] Even though it is not only the poor who catch them, it is the poor who are more likely to be exposed to them. The poor have also had little prospect of securing curative therapy, and in places where symptoms are unchecked, the sight of numerous individuals suffering the consequences is not something easily forgotten. There are very good reasons why long-term protagonists like Molyneux, Hotez and Fenwick have remained so committed to NTD control, and why people like Narcis Kabaterine, the head of vector control at the Ministry of Health in Uganda—recently hailed as the 'Unsung Hero of Neglected Tropical Diseases'[11]—have dedicated their professional lives to the cause with such enthusiasm.

In the context of growing interest and concern about these diseases, linked to the possibilities of substantial funding under the auspices of the MDGs, a new approach has been initiated, dwarfing previous efforts to control parasitic infections among impoverished populations. In its 2010 report on NTDs, the WHO claims to have pioneered this paradigm shift in 2003. It

asserts that the process was led by the former Director General and 'involved an important strategic change, from a traditional approach centred on diseases to one responding to the health needs of marginalized communities'.[12] This is a very odd way of accounting for what happened—one that seems to ignore the history of global primary health care policy dating back to the 1970s, in which WHO itself has played an important role.

Also, far from being any sort of grassroots initiative, what was actually being promoted was a reorientation of vertical biomedical interventions towards parasitic and other diseases for which there were potentially cheap, safe and effective cures. There was plenty of talk about comprehensive solutions to improve the overall well-being of target populations but the priority was clear. It was to undertake mass drug administration on a vast scale. One aspect of the enthusiastic response to the approach was that, while medical professionals were struggling to find a viable clinical response to the HIV/AIDS pandemic, here was a rapidly evolving and increasingly well resourced strategic plan to combat dreadful sicknesses by supporting or adapting existing medical systems and using readily available treatments.

In 2008 Molyneux, Hotez and Fenwick joined forces to throw the cat among the pigeons with a paper in an open access medical journal. They called for a new Global Fund to fight NTDs, and argued that 'there are 740 million Africans who are not infected with HIV/AIDS; they deserve a slice of the available interventions'.[13] One of their co-authors was Lorenzo Savioli, of the WHO, and the paper proposed that the new fund could be overseen by a board utilising the WHO's technical resources. However, the proposal was also a potential threat to entrenched interests, and was by no means popular with all staff within the WHO. The institution had been largely sidelined by the setting up of the Global Fund for HIV/AIDS, Malaria and TB, and there were concerns about yet another big competitor. It may be for this reason that the WHO has now attempted to assert—or reassert—the initiative with its 2010 NTD report. A sense of the stakes involved can be gleaned from the wording of a five-year WHO strategic plan for NTD control, dated August 2010, but circulated for some time internally. A highlighted component of the plan is 'strengthening partnerships for NTD control at all levels and repositioning WHO as the preferred partner.'[14] In short, there is much more going on at the moment than the straightforward presentation of evidence about NTD control.

Leaving aside overblown assertions about the ways in which NTD control can resolve the world's problems, as well as rhetoric about mass drug administration going hand in hand with a broad range of poverty alleviation measures, the strategy that is really being promoted by the WHO, its partners and competitors is the massive roll out of drugs to people living in areas where NTDs are endemic. The strategy is based on three key ideas. First, significant reductions in overall child and adult mortality and morbidity can be achieved in poor countries, if relatively small proportions of public health finance directed towards the control of HIV/AIDS, TB and malaria are redirected towards the integrated control of certain parasitic infections. Second, there are a number of drugs with a proven track record of success which can be cheaply manufactured and easily administered to populations

affected by these NTDs. Third, it is more economical to administer the drugs as one integrated, top-down, biomedical intervention, rather than through multiple vertical structures running side-by-side. The main focus is sub-Saharan Africa, where the targeted NTDs are known to be widespread and the population most impoverished.

Against this background, several countries—including those in which we have been researching, namely Uganda and Tanzania—are developing national programmes for NTD control that scale up and aim to integrate vertical treatment procedures. Drugs for selected diseases or groups of diseases—notably schistosomiasis, onchocerciasis, lymphatic filariasis, soil-transmitted helminths and trachoma—have been provided to ministries of health. These programmes attempt to treat school-age children and adults living in endemic areas, free of charge, on a regular basis. In accordance with the World Health Assembly's Global Targets, an endeavour is made to treat high percentages of the population en masse, without first testing individuals to see if they are infected. For example, 75 per cent of at-risk populations are supposed to be treated for schistosomiasis, soil-transmitted helminths and for lymphatic filariasis. This is considered ethical, because the drugs are deemed safe, apart from possible short-term side-effects, and it is much less expensive to provide drugs to everyone in endemic locations than to set up and sustain diagnostic facilities.

The donated drugs are distributed from the headquarters of ministries of health to staff employed at a district level. These staff then take responsibility for mobilising and training school teachers and drug distributors at village level who, in turn, are given responsibility for handing out drugs to all children and adults living in areas where the diseases are endemic. In many locations it is expected that populations will be infected with a combination of NTDs. In these places multiple treatments are given at the same time, or staggered through the year if the treatment protocols require it (such as when there may be possible health risks in taking particular drug combinations).

To give an idea of the scale of these operations, in Uganda enough albendazole and praziquantel tablets have been provided to treat some 0.4 million, 1.2 million, three million, 1.5 million and 1.8 million people for schistosomiasis and soil-transmitted helminthiases in 2003, 2004, 2005, 2006 and 2007, respectively.[15] Since 2007 there has been further expansion, as US funding has come on stream. According to USAID's implementing agency, RTI International, in the third year of their support for programme implementation 27 656 133 treatments were supposedly administered to 13 687 841 people potentially infected with targeted NTDs in 72 districts.[16]

Given the large quantity of resources being provided for these programmes and the needs of those involved in running them to sustain support by producing results, it is perhaps predictable that assessments of what might be achieved and what has been achieved tend to be very positive.[17] The 2010 WHO report on NTDs adopts a similar tone. Towards the start the report notes there are 'challenges that will have to be faced if the current achievements in NTD prevention and control are to be sustained and extended',[18] but there is scant mention of those challenges in the pages that

follow. It is claimed that 670 million people had been reached with preventive chemotherapy by the end of 2008, and that for some diseases there is a prospect of elimination by 2020. As the current Director-General of WHO states in her foreword, 'the overall message is overwhelmingly positive'.

However, there is a growing body of research which suggests that the current approach to distributing drugs for NTDs is facing serious problems. This is not a homogeneous critique, and many of those who have raised concerns are among those who have been most committed to control of Africa's parasitic diseases over the long term. For example, the hazards of relying upon unpaid volunteers to distribute tablets at the village level has been raised by several authors,[19] while others draw attention to the point that current endeavours to 'integrate' vertical control programmes may lead to the development of a parallel health-delivery system, with potentially serious consequences for ministries of health.[20] A related concern is raised by Utzinger *et al*, who question the sustainability of control programmes that rely so heavily upon preventive chemotherapy.[21] Parker *et al* draw attention to a different set of issues by suggesting that it is mistaken for policy makers and public health practitioners to assume that populations receiving drugs, free of charge, will necessarily understand or agree with the rationale for mass treatment. Instead, free treatment may be actively resisted.[22] Finally, a number of authors have highlighted limits in knowledge surrounding the safety and efficacy of combining drugs for some NTDs, and the consequences of repeated treatments over many years.[23]

There is no space here to discuss all these points in detail but, in the light of claims made in the first WHO global report on NTDs, we draw on our research in Uganda and Tanzania to comment on some of them. On page 10 of the report, Brock Chisholm, the WHO's first Director-General, is quoted from something he wrote in 1951:

> Too often countries requesting assistance have been the object of well-meaning but disastrous attempts to superimpose on the local culture foreign patterns which, lacking the necessary foundations, are bound to result in friction, misunderstanding and ultimate failure. In health work, as in all other fields of technical assistance, there can be no question of simply transplanting techniques from one place to another.

Yet transplanting techniques is, of course, what the new agenda for mass drug administration to control NTDs is about. Indeed, the 2010 WHO report is all about doing it. Our research findings, while by no means all negative, indicate that Chisholm's warnings remain highly relevant.

Misleading and partial monitoring and evaluation

In February 2010 an editorial appeared in a well known medical journal:

> The results of this evaluation do not match with the extravagant claims... made about the programme... Evaluation must now become the top priority in global health... complacency is damaging the global health movement.

> Without proper monitoring and accountability, countries and donors—and taxpayers—have no idea whether or how their investments are working. A lack of knowledge about whether aid works undermines everyone's confidence in global health initiatives, and threatens the great progress so far made in mobilizing resources and political will for health programmes in low-income and middle-income countries . . . Evaluation matters . . . It's time that the global health community embraced rather than evaded this message.[24]

These excoriating points in the *Lancet* were directed at UNICEF, in relation to the agency's accelerated Child Survival and Development programme. But identical observations might soon have to be made about the current target-obsessed approach to drug distribution for NTD control. Monitoring and evaluation are systematically inadequate. In large part this is a product of the perceived need to sustain funding by over-stating achievements. It is compounded by the competing claims of institutions, including academic ones, seeking to secure a leading role in what is happening. A consequence is that the rhetoric of mass drug administration for the control of NTDs is in danger of moving ever further from the reality, and there will be a backlash.

It is, of course, not the first time this has happened. There are striking similarities with UNICEF's selective primary health care campaigns in the 1980s, which were shown to have inflated coverage data on a large scale. This perhaps helps explains the irritation in the *Lancet*'s reaction to UNICEF's more recent exaggerations. In recent years somewhat similar concerns have been raised in detailed studies of immunisation coverage in West Africa,[25] and of the control of tuberculosis in Nepal.[26] However, it is fair to say that the problems with respect to rapidly expanding NTD treatment are on a particularly large scale.

In both Tanzania and Uganda we were surprised by the paucity of epidemiological data available. For example, information documenting the prevalence of selected NTDs had been collected at some sites, but not systematically, or rarely in a manner whereby the results could be drawn upon to help evaluate the overall effects of treatment with any confidence. In several instances it was unclear how the sample group had been selected or why a site or sample population was selected in one year but then ignored in subsequent years. In other instances data were collected from the same place over time, but proved difficult to analyse, because there was so much fluctuation in rates of infection and conjecture as to whether or not mass treatment had occurred between the collection of samples. We found that it simply was not a priority to ascertain overall rates of infection or to observe how these change over time.

To give one example, when we showed results from a report we had located in Kampala, Uganda to district medical staff in Moyo District, they said they had never seen them before and were unable to make sense of the data presented. One senior district official explained that we should not draw any conclusions from the various bits of prevalence data we had uncovered, because no one knew how they had been collected or how big the sample had been. He also said that data were being manipulated by politicians, because

they were making arguments about the number of people resident in the district for funding purposes. Exactly how this might affect disease prevalence data was unclear, but it gives a good idea of attitudes. It should be added that we subsequently carried out a small amount of testing for schistosomiasis and soil-transmitted helminths in endemic parts of the district together with some of our medically trained students and the district vector control office. It was not particularly difficult to organise, and the vector control officer himself was very enthusiastic about doing it with us. It seems reasonable to ask why it had not been done before on a regular basis.

Equally difficult to interpret are reports documenting the uptake of drugs. Again, it is often unclear how the summary data have been produced at a district level, let alone nationally. One striking example were data documenting the uptake of drugs for the treatment of lymphatic filariasis and soil-transmitted helminths in Muhesa district, Tanga region, Tanzania. A report prepared at district headquarters showed that take up was 100 per cent. We asked how this was possible, given the guidelines at the time, which specified that pregnant women should not be given the drugs. No one was able to give an explanation of where the 100 per cent rate had come from.

In Tanzania, in particular, we found a persistent practice of increasing treatment numbers as reporting was passed up though the system. In the above mentioned example, the records at a more local level had sometimes been well kept, and corroborated results from our own take-up surveys. Far from being 100 per cent, actual take up was much lower. At all sites it was below the 75 per cent target and, at many sites, far below it. At some locations it was less than 30 per cent (see below for details). Interestingly, even where the take-up of drugs was found to be good, there was still a tendency to inflate numbers. In Ukerewe Island, for example, the uptake of drugs among school children for the treatment of *S.mansoni* and soil-transmitted helminths ranged from 60 per cent to 78 per cent at the 16 schools studied. Nine of the schools reported these data accurately. The other seven inflated them. Thus, 61 per cent in one case became 96 per cent, and 70 per cent in another became 100 per cent. Even a school that achieved one of the highest rates of take-up felt the need to increase the reported take-up of drugs from 79 per cent to 92 per cent.

In Uganda there was less pressure within the national health system to over-report in this way, although we came across examples of this happening in Nebbi and Buliisa districts, northwestern Uganda. More of a problem in Uganda is the fact that good local-level record keeping is much more unusual, and this has been compounded by the proliferation of drug registers and changes in the combinations of drugs administered simultaneously. In the past couple of years the situation has deteriorated, because the USAID-funded organisation, RTI International, has introduced a new kind of register for all targeted NTDs. It is meant to replace the previous register documenting the uptake of drugs for schistosomiasis and soil-transmitted helminiths, as well as the register documenting the uptake of drugs for onchocerciasis and/or lymphatic filariasis. In Moyo district in 2009, for example, numerous distributors were found to have multiple registers in their possession for

different combinations of NTDs, as well as the new USAID/RTI registers. They had, unsurprisingly, become confused as to when to use which register. A few of the most conscientious were found to have abandoned the effort to use any of them properly, and to be keeping records informally in their own notebooks. Others were trying to fill in three sets of registers simultaneously and many others had given up altogether. It had become too complicated and time-consuming to be worth the trouble. In short, the effect of the USAID/RTI scale-up has been to undermine the already weak local reporting mechanisms.

As a consequence, aggregate data on drug uptake in Uganda were found to be more obviously 'estimated' or based on information about the total number of drugs received and distributed at a district level rather than grounded in a detailed reporting of actual take-up or observed consumption. All of this is well known to Ministry of Health staff working on the ground, but such weaknesses in the data rarely find their way into reports or published articles. Indeed, published epidemiological and parasitological research on Uganda overwhelmingly suggests that mass treatment can be shown to have successfully reduced the prevalence and intensity of infection, as well as clinical indicators of morbidity. Uganda is particularly revealing about overall trends in assessment of control of NTDs in that it was the first sub-Saharan African country to adopt integrated drug distribution procedures (launched in 2003 for schistosomiasis and soil-transmitted helminths, and integrated with other NTDs in 2007).

Much of the published research on the country focuses on children, reflecting the programme's emphasis on treatment in the schools of targeted areas. However, even with respect to data on children, there are limitations with the kinds of studies that have been carried out. This may be illustrated with reference to research monitoring the impact of annual mass drug administration on child morbidity.

Cohort studies have re-tested selected school children six months after each annual round of treatment. If they were found to be positive, they were re-treated. The results showed declining rates of infection and intensity of infection (ie worm burden) among those studied.[27] However, it cannot be assumed that these children are representative of all children at the schools they were attending—not least because they were being given the opportunity to be treated twice a year instead of once a year. A further limitation with cohort studies is that they are inevitably biased towards children of long-term and stable residency. Unfortunately, large numbers of children in northwestern Uganda do not experience such stability. This fact explains the high drop-out rates and the eventual abandoning of the research project.

Problems with the generalisabilty of findings apply equally to other methods that have been adopted, such as cross-sectional mapping using the LOT Quality Assurance sampling method. Twenty-four schools were sampled in each study district and 15 children were tested in each school. The results were then mapped using GPS readings for each school.[28] Although the results are visually impressive, the lead researcher himself would not claim that such

small and restricted sample groups can be reliably used for an overall assessment of changing patterns of infection following mass treatment. The research was intended to be indicative, and the claim on one NTD website that the results show that there is a 'realistic chance of bringing bilharzia infection in Uganda to below an intensity level at which it is a major public health problem' cannot be sustained.[29] Indeed, doubts about such a claim were underlined by subsequent parasitological testing carried out by Ministry of Health staff at a small sample of schools in Nebbi district. This was one of the districts surveyed in the study. Results revealed that many school children were still infected. At one school, 84 per cent of those tested were reported to be positive for *S.mansoni* in 2008.

In addition to epidemiological and geographical surveillance data exploring the impact of mass drug administration on schoolchildren in Uganda, endeavours have been made to monitor social responses to mass drug administration in addition to our own. These have largely focussed on adults, whose attitudes are key to the long-term viability of the approach. For example, a 'process evaluation' of schistosomiasis control in Uganda, written by the team implementing the drug distribution, concluded that mass treatment had been delivered effectively, that it was perceived as beneficial and that 'end-users' are appreciative.[30] These findings build on an assessment undertaken by Lubanga.[31] They are based on qualitative data collected in two districts in Uganda: one on the border with Congo and the other on the border with Kenya. A series of quotes from study participants in these two districts are analysed with reference to data documenting the number of drugs distributed from the Ministry of Health's headquarters in Kampala. No attention is paid to the differing political, economic or social contexts in which participants lived and how this may have influenced their perceptions of mass drug administration. It would also have been helpful if the paper had discussed how the drugs were distributed within and between districts; whether people actually swallowed them once they arrived in their villages; and how reported findings related to data documenting the uptake of drugs in Ministry of Health registers.

However, limitations in the work cited above are relatively minor compared to USAID-funded assessments by RTI International. Information from this source suggests impressive levels of NTD treatment coverage across the whole county. A map shown on the RTI website illustrates the hugely successful programme, with links being provided to reports describing how 'community volunteers make a difference' and how 'the NTD control program treats war-torn northern Uganda'. Precisely how the data were collected is not made clear, but from our own observations and discussions with staff in the field, they appear to be based on short questionnaires carried out on a small number of people in each district. There is no indication to suggest that any effort was made to look beneath the surface and to see how stated practice relates to actual behaviour.

Overall, assessments of mass drug administration for NTDs in Uganda raise more questions than they answer. Unanswered questions include the following: what proportion of children living in endemic areas attend

school? What proportion of children who do not attend school or do not attend on a regular basis receive drugs from community drug distributors? What proportion of adults receive drugs from mass drug administration on an annual basis? How are these free drugs perceived by adults and by children? Are they being swallowed? Do local understandings of the aetiology and treatment of 'NTDs' influence the consumption of drugs? Are there any indications to suggest that adults are becoming aware of the benefits of treatment? Are they beginning to demand that they and their children are treated on a regular basis? What are the consequences of institutionalising integrated vertical delivery systems for NTD drug distribution that are effectively discrete from other work carried out by ministries of health? Is there any possibility of treatment for NTDs being incorporated into sustainable national health care systems without continuous, long-term, international donor-driven support?

Selected findings from Tanzania and Uganda

Between 2005 and 2009 we carried out field research on NTD control at a wide range of study sites spread across Uganda and Tanzania. We were interested in the practical ways in which mass drug administration occurred and paid particular attention to finding out what actually happened on the ground. The villages selected for study were located in Nebbi, Buliisa, Moyo and Adjumani districts, northwestern Uganda, and Busia and Bugiri districts in southeastern Uganda. The selected districts in Tanzania were Pangani and Muhesa districts in Tanga region, various locations in Morogoro region, and Ukerewe Island in Mwanza region.

Research sites were selected on the basis that the prevalence of NTDs was high among school children and adults for two or more of these diseases or disease groups. In Uganda the primary focus at all research sites was *S.mansoni* and soil-transmitted helminths. This was also the case in Ukerewe Island, Tanzania. In Muhesa and Pangani districts, Tanga Region, Tanzania, research initially focused on *S.haematobium* and soil-transmitted helminths, but later involved assessing treatment programmes for lymphatic filariasis as the drug, albendazole, was used for this disease as well as the treatment of soil-transmitted helminths. Of all the neglected tropical diseases endemic in the region, it was also the disease that concerned residents the most.

All sites involved the analysis of Ministry of Health registers documenting the uptake of drugs for the treatment of *S.mansoni*, soil-transmitted helminths and lymphatic filariasis among school children and adults. In addition, open-ended, unstructured interviews were undertaken with political figureheads, religious leaders, local healers, farmers and fisherman; and participant observation was carried out (including the observation of what actually happened when free drugs were distributed at schools and villages). The generalisability of ideas emerging from this open and exploratory approach was gauged by undertaking semi-structured interviews with a minimum of 10 per cent of households at selected villages. To date more than 2000 semi-structured interviews have been undertaken.

Below we summarise findings from our research sites, focusing on local attitudes to being on the receiving end of the campaign and whether or not people have actually taken treatment. We do not attempt to answer all the various questions raised at the end of the last subsection, and we do not provide a detailed overview of our own results—those are presented elsewhere.[32] Our aim is to give an indication of how and why responses to NTD treatment vary within and between research sites; to highlight the ramifications of paying insufficient attention to communication with target populations, and to illustrate the realities of mass drug administration with information on actual take-up rates of the distributed tablets.

NTDs are experienced in diverse ways

Diseases falling within the term 'NTD' are very different from each other—biomedically and in terms of their perception among target populations. This profoundly affects local responses, as the following findings illustrate. They relate to the three NTDs most common at our research sites: schistosomiasis, soil-transmitted helminths and lymphatic filariasis. These are discussed in turn.

Schistosomiasis. Schistosomiasis, otherwise known as bilharzia, is the broad descriptive term given to a group of parasitic infections caused by trematode flatworms of the genus Schistosoma. The majority of human infections in sub-Saharan Africa are caused by two species of schistosome: *S.mansoni* and *S.haematobium*. These schistosomes have similar lifecycles involving an aquatic snail intermediate host, the human definitive host and their mutual presence in a common environment where transmission occurs: typically irrigated fields, irrigation and drainage channels, rivers, ponds and ditches.

The signs and symptoms of *S.haematobium* and *S.mansoni* vary. Blood in the urine (macroscopic haematuria) is the most commonly reported symptom of *S.haematobium*, especially among children. In more advanced cases it may cause damage to the kidneys, urinary tract fibrosis and bladder cancer. Women may also present with genital lesions, vaginal bleeding and nodules in the vulva; and men can suffer damage to the seminal vesicles and prostate. It is not unusual, however, for children and adults to be infected with *S.haematobium* for many years, and to remain asymptomatic. Similarly, infection with *S.mansoni* does not necessarily generate obvious signs and symptoms. Over time it can lead to gross swelling of the spleen and liver, blood in the stool, diarrhoea and, in extreme cases, the vomiting of blood. However, this can take years, even decades, to develop and it does not happen in all cases. Indeed, there is some conjecture as to how debilitating infection with *S.mansoni* or *S.haematobium* actually is for the majority of people infected.[33]

S.mansoni was endemic at all study sites in Uganda as well as on Ukerewe Island, Tanzania, whereas *S.haematobium* was endemic in Pangani and Muhesa districts, Tanzania. With very few exceptions, those interviewed were unaware of clinical distinctions between these two species. From a public

health perspective this mattered much more at some sites (notably Nebbi district, Uganda and Ukerewe Island, Tanzania) than at others (notably Pangani and Muhesa districts, Tanzania).

To start with Pangani and Muhesa districts: the Swahili term for schistosomiasis, *kichocho,* is widely known and local understandings of *kichocho* overlap, rather than mirror, biomedical understandings of *S.haematobium*. The main sign of *kichocho* is 'red urine' or 'blood in the urine'. It is widely understood as an affliction of childhood. This is because infected children typically present with 'red urine' or 'blood in the urine' (ie macroscopic haematuria) whereas adults, who may have acquired their infection in childhood, typically lose this sign of infection and present with other signs instead.

The presentation of symptoms influences perceived aetiology and responses to treatment. Among children infection is thought to be acquired while swimming and occurs through their sexual organs or anus. Adults do not swim and rarely present with 'red urine' or 'blood in the urine'. Not surprisingly, then, they are not thought to suffer from *kichocho* in large numbers. The concentration of control programmes in schools confirms these local perceptions.

There is widespread support for the mass distribution of drugs in schools for the treatment of *kichocho* in this part of Tanzania. This, in part, can be attributed to the fact that local understandings of *kichocho* overlap with biomedical understandings of *S.haematobium*, at least for children. Parents and teachers alike observed that children suffering from *kichocho* lose the visible signs of infection, 'red urine', when swallowing the tablets. It works. However, adults in both districts stated that, if mass treatment occurred in 'the community', rather than schools, they would be reluctant to swallow the drugs. As far as they are concerned, *kichocho* is not a significant health issue for adults.

The situation is much more complicated in places where the mass distribution of drugs is for the treatment of *S.mansoni*. In Uganda, for example, the term 'bilharzia' is widely used to describe both *S.mansoni* and *S.haematobium*, although there are very few places where *S.haematobium* is found. In common with northern coastal Tanzania, local understandings of bilharzia differ in important ways from biomedical understandings of either *S.mansoni* or *S.haematobium* and the differences profoundly affect responses to the mass distribution of drugs in schools and communities.

By way of illustration, bilharzia is understood as a type of *okudi* in Panyimur, northwestern Uganda. *Okudi* is a general word for worms. Other types of *okudi* include *okudi ascaris*, *okudi hookworm* and *okudi amoeba*. *Okudi bilharzia* is frequently said to be the type of worm most likely to cause illness and one informant referred to it as 'the chairman of worms'. Local understandings of the signs of *okudi bilharzia* include an extended stomach, diarrhoea, bloody diarrhoea and vomiting blood. Biomedical signs of infection with *S.mansoni* are similar in a number of important respects, but this counts for little at a local level, as understandings of aetiology and effective treatment are so different. With respect to aetiology, a diverse array

of ideas circulates about the aetiology of *okudi bilharzia*. These include drinking dirty water, treading on faeces, not washing hands before eating and swimming in contaminated water. Local informants, including those associated with the delivery of biomedical health care, were rarely able to describe the lifecycle of *S.mansoni* with any accuracy, a fact that can be attributed to poorly designed health education materials. A Ugandan primary school textbook, for example, describes the signs and symptoms of *S.haematobium*, but does not mention *S.mansoni*; and thus conveys the impression that a key sign of infection with bilharzia is red urine. It does not mention that it is possible to be infected for many years and to remain asymptomatic. In addition, several booklets and posters depict the lifecycle of the worm in such a way as to suggest that it possible to see the worms which penetrate the soft part of the skin in water with the naked eye. This, in turn, generates comments like 'we don't have worms like that!'.

It is equally important to note that the signs of infection associated with *okudi bilharzia* can also be interpreted as signs of witchcraft or a local ailment known as *awola*. Inflicted on an individual by a witch as a result of envy, *awola* can only be treated by a kind of witchdoctor known as an *ajoga*. A symptom of this ailment is vomiting blood. The same symptom, along with ascites, is a biomedical indicator of liver damage, a serious and often fatal complication associated with *S.mansoni*. However, treatment with biomedical drugs is deemed dangerous as they are perceived to exacerbate the condition and, in some circumstances, cause death.

Praziquantel is the drug being distributed for the treatment of *S.mansoni*. It is large, strong smelling and has an unpleasant taste. Individuals heavily infected with *S.mansoni* often experience side-effects such as diarrhoea and vomiting after treatment. In many cases this was reported to last for several days and even weeks. Empirical observations of the impact of treatment, in combination with divergent understandings of aetiology and treatment, have led to widespread questioning of the rationale for mass drug administration. Frequently articulated concerns included the following: 'why should I take these drugs? They will make me sick'; others expressed a fear that treatment with praziquantel (usually referred to as 'Bayer') would not only lead to sickness, but also to infertility, miscarriage and even death. In 2005 these concerns contributed in significant ways to the reluctance to swallow drugs in Panyimur. They were still relevant in subsequent years, but some fears diminished as empirical observations were being made that people were taking the tablets without suffering long-term, damaging consequences to their health.

Lymphatic filariasis. Somewhat similar issues arise with lymphatic filariasis, which is more popularly known as elephantiasis. It is caused by three species of mosquito-borne filarial worms: *Wuchereria bancrofti*, *Brugia malayi* and *Brugia timori*. In common with schistosomiasis, it is possible to be infected but free from visible signs and symptoms of infection for many years and to feel well. Over time and repeated bouts of infection, signs and symptoms emerge. These typically include the gross swelling of limbs and genital disease such as hydrocele.

In Pangani and Muhesa districts, Tanzania local understandings of the aetiology of lymphatic filariasis, as well as appropriate responses to the signs and symptoms of infection, differed considerably from biomedical approaches. First and foremost, there is no Swahili word for lymphatic filariasis. While two of the major biomedical signs of infection, enlarged testicles and swollen limbs, are locally recognised 'diseases', they are perceived to have separate aetiologies. The disease '*mabusha*', refers to enlarged testicles and the disease '*matende*' refers to swollen limbs. In the words of a *mganga* (healer) from Pangani: ''Some people have both *mabusha* and *matende* ... but they don't come simultaneously. The fact that *mabusha* can be operated on and *matende* cannot be operated on proves that they are different diseases.''

The majority of people (including health care workers at government dispensaries and health centres) draw upon a pluralistic approach to diagnosis and treatment. As a result, they do not attribute a single cause to either *mabusha* or *matende*. Instead, several causes are likely to be mentioned, with each cause being accorded equal weight. *Mabusha*, for example, was typically attributed to at least one of the following: sex, witchcraft, hernia, diet and sickness sent by God; the vast majority of people were unaware that it was caused by infection from the bite of mosquitoes. By contrast, *matende* was usually attributed to inherited characteristics and/or witchcraft, a kind of fever known as *mgonzo* and, sometimes, the bite of a mosquito.

Perceived aetiology for these two 'diseases' not only influenced the type of treatment subsequently sought, but also responses to mass treatment. With respect to *mabusha* and *matende*, it was also widely noted that there was no observable connection between swallowing the drugs (albendazole and ivermectin) and the alleviation of symptoms. The symptoms did not diminish in size and the drugs did not, therefore, appear to have an impact. This is because treatment had not occurred in time to prevent irreversible damage. It was additionally noted that many people who were being asked to take the drugs had no symptoms and felt quite well. For these adults, the programme remained, at best, a mystery. Others were angry and suspicious. The treatment programme fed into wider concerns about the unspoken agenda of the government and international aid agencies: Why did the government not assist with the bigger problems of HIV/AIDS and malaria? Was this just another endeavour to reduce the birth rate? Were the rural poor being experimented on with drugs that had not been properly tested?

Soil-transmitted helminths. Soil-transmitted helminths are sometimes referred to as intestinal worms. From a public health perspective there are three species that are particularly important: *Ascaris lumbricoides* (roundworm), *Ancylostoma duodenale* (hookworm) and *Trichuris trichua* (whipworm). All three species thrive in areas where there is no sanitation system, as the soil and water can easily become contaminated with faeces containing worm eggs. Humans are infected by ingesting these eggs (typically from uncooked or partially cooked food, water or placing unwashed hands into the mouth). In the case of hookworm, it is also possible for the larvae to penetrate the skin.

That is, eggs hatch into larvae and rest in the soil. If a person walks barefoot on the contaminated soil, the larvae can penetrate the skin. There is no direct person-to-person transmission from fresh faeces as eggs passed in the faeces need three weeks in the soil before they become infectious. Many people infected with soil-transmitted helminths experience one or more of the following symptoms: nausea, abdominal pain and loss of appetite. All three species are also associated with anaemia and vitamin A deficiency.

Local perceptions of soil-transmitted helminths in Tanzania and Uganda were different from biomedical understandings in a number of important respects. In Pangani and Muhesa districts, Tanzania, for example, soil-transmitted helminths are referred to as *minyoo*. They are not associated with particular signs or symptoms of infection and they are not thought to present a major health problem. With the exception of hookworm, which is often referred to as *safura*, very few people (less than one per cent) had any idea that there were different types of worms with different aetiologies. There was, however, widespread local awareness of *minyoo* and recognition that taking a tablet can be curative—not least because those infected could sometimes see the worms in their faeces.

The drug albendazole is used at all sites in Uganda and Tanzania to treat soil-transmitted helminths. When offered in isolation, it did not present any particular problems or concerns to children or adults and was not perceived to cause serious side-effects. However, there has been a decline in the uptake of albendazole among both adults and children at most of the sites in which we have worked, often dropping far below target rates of take-up. This has been a consequence of the NTD control integration procedures, which have often meant providing albendazole together with less widely accepted medicines. A vivid illustration of this point is the fact that, among the Alur in Nebbi district, the drug for bilharzia is known by the name of Bayer (rather than praziquantel) and the drug albendazole is known as 'anti' or the 'escort'. In other words, it is perceived as an antidote to what were locally thought to be serious side-effects associated with the drug praziquantel. In parts of Tanzania dramatic declines in albendozole take-up were also noted, especially in locations where it was provided together with ivermectin for the treatment of lymphatic filariasis.

Declines in albendozole take-up were found to be less steep in schools, because children were more likely to take combinations of NTD drugs if instructed to do so by their teacher. However, health education materials used at the time of treatment tended to be confusing. Children were often informed about soil-transmitted helminths, but not about other diseases, making it hard for them—or their parents—to understand why there were given other drugs too. At sites in coastal Tanzania, for example, Swahili language pamphlets were given out explaining soil-transmitted helminths at the time that school treatment for schistosomiasis was occurring in 2007. On that occasion albendozole was not being distributed, because the children were supposed to have received it as part of an earlier distribution of treatment for lymphatic filariasis. Most teachers were found to be unaware that this was the case and could not explain what the drugs they

were giving out were meant to treat. At a village level no one interviewed knew that albendazole had the multi-purpose of treating *minyoo*, *mabusha* and *matende*.

Inadequate communication and outreach

The distribution of NTD drugs in Uganda and Tanzania was organised in similar ways. Drugs were sent from Kampala and Dar es Salaam to local headquarters (directly to districts in Uganda; to regions and then districts in Tanzania). District vector control officers distributed drugs to primary schools and health centres and, after attending a training session, teachers, volunteer drug distributors and sometimes health workers took on the task of distributing drugs within villages and schools. It sounds relatively straightforward and, at least with respect to treatment programmes in schools, it has often been possible to ensure that the majority of children registered at school and attending on the days of distribution receive free drugs, partly because, as has been noted, they will do what their teachers tell them to do. In these school contexts the actual swallowing of drugs is usually observed by the distributors. However, drug distribution in schools is by no means always so straightforward, and away from school environments serious difficulties are quite common.

In large part this can be attributed to insufficient and inappropriate 'sensitisation' and 'mobilisation'. The type of information conveyed alongside the distribution of drugs is little more than information about how and when to take them. It does not challenge or engage with pluralistic outlooks and ways of thinking, and makes little attempt to explain the aetiology of the diseases being treated, how it is possible to be asymptomatic, how the medicines provided work, and why mass treatment is provided without diagnostic procedures. Various posters are sometimes displayed and occasionally pamphlets are distributed, but these are generally of a poor quality, often confusing or even wrong. One example has already been mentioned: misleading pictures illustrating the lifecycle of schistosomiasis. Another example is the use of photographs in the new NTD integrated treatment registers being distributed in Uganda. These purportedly show symptoms of onchocerciasis. In fact, they depict symptoms of lymphatic filariasis. In short, lip service is paid to the importance of health education but the reality is that communication with target populations is not prioritised, is mostly superficial, and can be experienced as patronising. Indeed, the use of overly-simplistic messages comes close to being a deliberate policy, justified on the grounds that to explain things properly would be too complex for health educators and the target audience.[34]

Not surprisingly, then, responses to these vertical, biomedical programmes remain bound within existing systems that attribute locally understood afflictions such as *awola, mabusha* and *matende* to very different aetiologies, treatments and preventive actions. We have also found that, whenever we have held public meetings to discuss the drug distributions, there is usually a barrage of intelligent questions posed by those being offered them. Among

the most frequently posed are versions of the following: 'why should we take the tablets if we are going to go back in the water, because we will be reinfected?' and 'we have been told not to take medicines unless we are properly diagnosed, so why are you telling us to take treatment when we may not have anything wrong with us?'

On occasion the lack of adequate communication about the rationale for mass treatment for biomedically defined tropical diseases that are not necessarily recognised at a local level has fuelled conspiracy theories and collective resistance. This can range from being absent on distribution days to violent protests. The latter have occurred where school distributions have been particularly poorly handled and where there is local suspicion of the motives of central government or district of authorities. In many respects it is surprising that it has not occurred more often than it has.

Imagine a situation in the UK whereby a healthy child goes to school in the morning, but comes home in the afternoon with stomach pains, vomiting and/or diarrhoea. The child then tells her mother and father that her teachers made her swallow several large tablets and this had been something to do with treatment for invisible worms. The parents not only discover that their child is not making this up, but they also find out that several of the child's friends have become ill with similar symptoms. Almost certainly there would be protests and the school staff would be held to account. This imaginary scenario gives an idea of how mass drug administration to school–aged children in Africa can be experienced the first time it is attempted.

Where there have been several drug distributions, the chances of significant side-effects seem to lessen. This has not been studied systematically but it is probably because the intensity of infection and infection rates have declined with previous treatments. Where this is reported, repeated treatment in schools shows signs of becoming routine. In some research sites, such as in Adjumani District in Uganda, we found that school children had gained a reasonable level of understanding about the control of the diseases being treated. In fact, they often had more precise knowledge about some diseases than community drug distributors or their parents. At other locations in Uganda and Tanzania, however, people became so angry about what was happening that distribution had to be stopped. In both countries there were conspiracy theories that kept circulating about what the drugs were really for, especially in locations in which people feel politically marginal—such as parts of northern Uganda, northern coastal Tanzania and parts of Morogoro.

In Tanzania matters came to a head in places around Morogoro in 2008. Distribution in schools of tablets for schistosomiasis and soil-transmitted helminths provoked riots, which had to be contained by armed police. It became a significant national incident, and one of the consequences has been the delay in Tanzania adopting a fully integrated NTD programme, and the scaling back some existing drug distributions. The riots were by far the most extreme example of resistance to NTD drug distributions, but the sentiments expressed by the protesting mob were far from unique. Drawing on research at all our research sites, a summary of some of our key findings on the take-up of drugs is presented below.

Realities of drug take up

In northwestern Uganda we found that the take up of drugs for *S.mansoni* and soil-transmitted helminths was very variable in locations in Nebbi Distrct. To be more specific: in 2004 the average self-reported uptake of drugs among adults ranged from 62 per cent to 78 per cent in the three parishes that constitute Panyimur sub-county. In 2005 uptake ranged from 32 per cent to 43 per cent in these three parishes; and in 2007 it ranged from 33 per cent to 59 per cent.[35]

Across Lake Albert in Buliisa District rates were also variable, with the average uptake of drugs among adults for schistosomiasis and soil-transmitted helminths ranging from eight per cent to 27 per cent in 2005, four per cent to 15 per cent in 2006; 36 per cent to 58 per cent in 2007 and 46 per cent to 91 per cent in 2008. In villages where the uptake of drugs was low, this could be attributed to a combination of supply problems and local antipathies between resident ethnic groups.

Further north, along the Nile close to the Sudan border, the uptake of drugs among adults in Adjumani and Moyo districts was variable again. This was partly the result of a policy of selective treatment in some years, whereby adults were only encouraged to take the drugs if they thought they might be infected. On the other hand, very high take-up rates occurred at some locations when there was distribution of food relief at the same time as tablet distribution. In Moyo district self-reported survey data from seven villages suggested an average uptake of 39 per cent, 41 per cent and 55 per cent in 2006, 2007 and 2008, respectively. In neighbouring Adjumani district self-reported uptake of drugs for *S.mansoni* and soil-transmitted helminths among adults at seven selected sites averaged 29 per cent, 60 per cent, 51 per cent and 74 per cent in 2005, 2006, 2007 and 2008, respectively. Rates of take-up recorded at primary schools tended to mirror adult take-up, especially in Adjumani district. They reached very high levels on occasions that food was provided to the children at school on distribution days, but were found to drop precipitously when food relief was withdrawn.

At the other end of the country in Busia District, located in the southeast near the Kenyan border, average rates of take-up among adults at selected sites were 67 per cent in 2008 and 64 per cent in 2009. In neighbouring Bugiri district, however, average uptake was 43 per cent in 2007 and 34 per cent in 2008. Mass drug administration did not occur in 2009 as the vector control officer was seriously ill. In the light of information available, it seems likely that the relatively successful figures in Busia district can be attributed to a political agenda of making Busia into a flagship district, partly because a large fish processing plant had been built there. A policy had been introduced to drastically reduce the number of people involved in fishing related activities, and to closely regulate access to the shore of Lake Victoria. Many people were displaced into neighbouring Bugiri district (which includes islands in the lake), leaving the relatively wealthy and well-connected to receive NTD treatment. Not surprisingly there are indications that rates of

schistosomiasis infection in Busia have declined, but the limited evidence available suggests that there are high rates in Bugiri.

Moving to Tanzania, we found that the uptake of drugs among adults for *S.mansoni* and soil-transmitted helminths in Ukerewe Island ranged from 18 per cent to 74 per cent at 14 selected villages in 2007, with an overall average of 44 per cent. As noted previously, the uptake of drugs was much higher among school children and sometimes exceeded the target of 75 per cent coverage.

In areas of Tanga region we found wide fluctuations in the uptake of drugs for schistosomiasis, as well as for soil-transmitted helminthiases and lymphatic filariasis. *S.haematobium* is endemic in this part of Tanzania. Parents were found to be positive about their children being treated at school, with recorded uptake often exceeding the target coverage of 75 per cent. However, the uptake of drugs for the treatment of lymphatic filariasis and soil-transmitted helminthiases was low. In Mwembeni village, Pangani district, for example, self-reported uptake of drugs among adults fell from 70 per cent in 2004 to 49 per cent in 2006 and 36 per cent in 2007. In neighbouring Jaira village uptake fell from 57 per cent in 2004 to 49 per cent in 2006 and 40 per cent in 2007. Similar trends were observed in coastal parts of Muhesa district. In Kigombe East and Kigombe West, for example, uptake fell from 63 per cent and 44 per cent, respectively in 2004 to 27 per cent and 34 per cent in 2006 and 27 per cent and 26 per cent in 2007. Interestingly, closer to Muhesa town, uptake rose from 47 per cent and 40 per cent in 2004 in Bwembwera and Magila, respectively to 68 per cent and 43 per cent in 2006 and 65 per cent and 70 per cent in 2007.

In Doma village, Morogoro, Ministry of Health registers documenting the uptake of drugs for the treatment of onchocerciasis suggested that uptake fell from 31 per cent in 2004 to 29 per cent in 2006 and 17 per cent in 2007.[36] This was a location of considerable antipathy to the NTD distributions, and was the site of some of the worst riots in 2008 when attempts were made to treat schistosomiasis in schools.

Overall our research reveals that claims about the effective delivery of drugs and positive responses to mass treatment by end users in Uganda and Tanzania are not borne out by the evidence. However, there is an eagerness to take the drugs in some locations, and in northern Uganda we found that the majority of people of long-term residence in areas endemic for *S.mansoni* had taken praziquantel at least once. This appeared to be confirmed by testing we carried out ourselves with district health staff and some of our students in Moyo and Nebbi districts, as we found generally low rates of infection among stable residents, even among resident fisherfolk living on the Nile. This contrasted dramatically with very high rates among recent migrants, which doubtless helps explain the very high recorded rates of infection—or re-infection—among school children in Nebbi mentioned above (more than 80 per cent at one school tested). Children swim in Lake Albert, where short-term migrants have to defecate because of a lack of pit latrines.

Finally, while we made every effort to triangulate our findings (by looking at data documenting the uptake of drugs in ministry of health registers, discussing a wide range of issues with community drug distributors, teachers,

other adults and children, and observing drug distribution days), we cannot be sure that all those we recorded as having taken the drugs actually consumed them, or that they consumed them in the correct doses. In many instances, revisiting households and follow-up interviews revealed that tablets had been 'taken' but not swallowed. On numerous occasions we were shown tablets that were being kept in case someone in the family became ill. Observations of distributions made it clear, in some locations, just how hard it was for a drug distributor to insist on watching a recipient consume the medicines. Some teachers tried to force their pupils to do it, not always successfully. With adults this was not an option, although, on a few occasions, informants spontaneously suggested that a degree of force might be appropriate. As one put it 'if it was really important to take these tablets there would be laws to make us'. It was a good point. At only one of our sites was public health legislation used systematically, and that was in Busia, where it was evoked to remove people from the vicinity of Lake Victoria.

Conclusion

There is no question that a focus on the parasites of the poor is appropriate. Anyone who has seen the effects of long-term infection on those suffering from these NTDs would find it hard to deny that treatment should be provided; and the offer of very cheap or free medicines from the major drug companies is very welcome. There is a remarkable opportunity to make a real difference to large numbers of deprived people. However, it is also hard not to be exasperated by the grandstanding rhetoric and exaggerated claims of some protagonists. The targets associated with the MDGs have not helped in this respect, and there is a real possibility that purported achievements will become more and more illusory.

The priorities of institutions competing to secure and sustain funding already seem to be more important than sober assessments of what is happening on the ground. As mass drug administration scales up, it becomes ever harder to learn from what has worked and what is failing. This can only be counterproductive. Thus, while the 2010 WHO report on NTDs is a positive initiative, it is a bit disappointing, not least because it uncritically accepts summative data reporting high rates of drug uptake. Parts of the report read like an elaborate application for funding—particularly those sections asserting the WHO's pivotal co-ordination role with reference to some creative historicising. Would it not be better to set out an agenda for more rigorous research and monitoring?

Everyone we have spoken to inside the drug distribution programmes is well aware that not all of what is claimed is in fact true. But they feel compelled to sweep ongoing problems under the carpet for fear that resources will be withdrawn.[37] People living in places like the Gezira/Managil irrigation scheme in Sudan, where mass drug administration has occurred in the past, are in danger of returning to former levels of infection following the termination of control projects. So it is understandable that those committed

to the approach are sensitive to anything that might jeopardise resourcing and supply. However, a range of problems has arisen with mass drug administration, and if these problems are ignored, they are likely to undermine NTD control programmes anyway.

A good example of the setting aside of critical voices is the response to the concerns raised by Bruno Gryseels. Aware that the reviewing process in conventional medical journals was likely to be very time consuming and would probably require him to tone down his views to secure publication, he decided to write an extended letter to the *Financial Times*.[38] Several of the points we have discussed here are addressed in the letter, as well as a warning that large scale, long-term distribution of drugs may trigger drug resistance in recipient populations. This is a particularly sensitive issue, for obvious reasons. As far as we know, there are no data indicating that it has happened with medicines used in NTD control. But it is hardly an unreasonable point to raise, not least because current methods of monitoring might not pick it up. The response was a formulaic attack, purportedly penned by leading African supporters of current roll-out schemes. Rather than addressing the substantive issues raised (other than to note that drug resistance has not yet been observed), Gryseels was castigated for raising criticisms on the grounds that 'his position from an African perspective is unethical and a violation of the fundamental right to heath and contrary to the health policy of African countries'.[39] Gryseels, it should be noted, is not an anthropologist like us, whose work might be set aside as interesting but 'anecdotal'. He is head of the Institute of Tropical Medicine in Antwerp. Perhaps that was the reason for the co-ordinated rebuttal.

Is closing off debate and discussion in this way ever useful? Are donors and drug companies really so unwilling to accept that there might be complications and problems with the philanthropic efforts they support? Surely there is space to address difficulties and disagreements without resorting to blanket denials and defensive assertions. To repeat the key point in the *Lancet* editorial cited above: 'Without proper monitoring and accountability, countries and donors—and taxpayers—have no idea whether or how their investments are working.'[40] To prevent that happening, an influential institution has to be in a position to lay down guidelines and benchmarks, objectively assess treatment process, and demonstrate that things are not going according to plan, if that is indeed the case. Basically it must be in a position to create adequate space for debate and to learn from what does not work.

It seems that schools of public health are so caught up in a desperate scramble for grants that they will not be able to do that. Our own research has been supported by Alan Fenwick's group based at Imperial College, partly because Fenwick himself recognises the value of an alternative perspective to the consensus-driven analysis that surrounds him—and to which he has himself been such a leading contributor. But his attitude is relatively rare. More generally assessments of programmes by university-based medical research centres are vulnerable to being compromised by soft funding. The situation with subcontracted commercial organisations like RTI International is worse. They are, after all, openly competing with each other to provide services. They are structurally connected with temporal

constraints, pre-defined outcomes, and face continuous pressure to position themselves to bid for the next aid grant. This does not preclude them from operating efficiently, but they could not survive if they chose to rock the boat. It is also unlikely that things will change if a new Global Fund for NTDs is established. Such a fund will channel resources into setting up and sustaining yet another UN-linked bureaucracy, and will do all it can to redirect resources from other institutions by arguing that it can reach targets more quickly. Temptations to exaggerate results will intensify. Do current efforts by the WHO to gain the initiative in co-ordinating global NTD control, underlined by its first ever major report on the issue, mean that it will succumb to similar pressures?

Mass drug administration for several debilitating diseases has the potential to work. We have seen the benefits for impoverished people at some of our research sites. However, it will not succeed overall and what has been achieved will not be sustained unless there is a serious effort to assess what is actually happening on the ground. Practices will need to be adjusted to deal with the kinds of issues we have highlighted in our research. Setting public health benchmarks based on robust information is the kind of role that the WHO was set up to play. It has sometimes found it hard to assert such a position in the past, such as when it was effectively sidelined by UNICEF in the 1980s or by the World Bank in the 1990s. But someone has to be in able to say that the emperor has no clothes when that is the case, and hopefully to do so in time to dress him, before the consequences become too serious.

Notes

Ethical clearance and acknowledgements

The research summarised in this paper is based upon field-work funded by the Schistosomiasis Control Initiative (SCI), Imperial College, under the auspices of the Bill and Melinda Gates Foundation. Ethical clearance was passed by the ethics committee of Imperial College for surveillance and monitoring activities for the evaluation of national control programmes for control of NTDs. Separate ethical clearance applications were also passed through the relevant bodies in Uganda and Tanzania. In both countries we worked closely with ministry of health staff, and obtained appropriate research clearance at regional and district levels.

We are grateful to Professor Alan Fenwick, director of SCI, for his unfailing support, and his encouragement of our work, even when our findings made uncomfortable reading. We are also grateful to other staff from SCI, some of whom have disagreed with our analysis, but who have continued to provide assistance, including Lynsey Blair, Fiona Fleming and Artemis Koukounari. In Uganda we are especially indebted to Narcis Kabatereine from the Vector Control Division, Ministry of Health. We have learned a great deal from the extensive discussions and occasionally heated debates we have had with him since 2005, and we would like to take this opportunity to express our admiration for his passionate commitment to disease control. Many other staff from the Ministry of Health in Uganda are owed additional thanks, including Dr Ambrose Onapa and the vector control officers in all the study districts who, without exception, were enormously helpful. Our research in Uganda would not have been possible without the dedication and commitment of the following postgraduate students and research assistants: Emily Aldis, Rosie Bright, Bono O Edward, Rachel Flynn, Philip Goli, Julie Hastings, Ronald Iya, Stanley Bright Jhopacu, Becky Mitchell, Nstori Onen, Sam Polla, Jill Smith, Ruth Tushememereirwe, Nicola Peach, Georgie Pearson, Nick Rees, Kyla Reid, Laura Storm and Albert Wutham. In Tanzania we have benefitted from challenging discussions with a wide range of personnel working in the health sector, from staff at the National Institute of Medical Research in Mwanza, Muhesa and Tanga to regional and district health staff at all of our research sites. John Changalucha, Roly Gosling, Nicholas Lwambo, Caroline Maxwell and Ursuline Nyandindi, have been especially helpful. Fantastic assistance was provided in the

field by Kombo Iddi, Juma Mohamedi, Mishy Singano, Angela Shija and Polly Wingate-Saul. Lastly we have received valuable insights and comments from Pascale Allotey, Bruno Gryseels and Tom Parker. The views expressed in this paper do not necessarily reflect the views of any of the institutions or the people mentioned above.

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36 This information comes from data collected by Julie Hastings, one of our PhD students, who was working in the area in 2008.

37 A fascinating, and very carefully worded effort to outline some of the ongoing problems and suggest ways of dealing with them is Kabatereine *et al*, *PLoS Neglected Tropical Diseases*. This paper has been written by key players in the Ugandan and Tanzanian NTD control programmes, together with colleagues from Southern Sudan and Mozambique.

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