

Institution: London School of Economics and Political Science
Unit of Assessment: 24B: Anthropology and Development Studies: International Development
Title of case study: Rethinking Mass Drug Administration strategies for the control of Neglected Tropical Diseases
<p>1. Summary of the impact (indicative maximum 100 words)</p> <p>A research collaboration between LSE and Brunel University has demonstrated that large-scale programmes to control Neglected Tropical Diseases (NTDs) through Mass Drug Administration (MDA) can be ineffective, primarily because of flawed assumptions about local realities in developing countries. The research findings have helped shift the terms of debate and consolidate pressure for existing strategies to be revised. They have been discussed in the UK Parliament, the biomedical literature, and the news media. In addition, detailed fieldwork has facilitated treatment for specific groups of people in Tanzania and Uganda who would otherwise have been overlooked.</p>
<p>2. Underpinning research (indicative maximum 500 words)</p> <p><i>Research insights and outputs:</i> The UN Millennium Development Goals have focused attention on NTDs, including parasitic infectious diseases such as lymphatic filariasis (elephantiasis), soil-transmitted helminths (such as hookworm) and schistosomiasis (bilharzia). NTDs cause significant morbidity (i.e. poor health, disease or disability) among politically and economically marginal populations. The World Health Organization (WHO) estimates that 120 million people are currently affected by lymphatic filariasis, with about 40 million displaying clinical signs of infection such as hydrocele (swollen scrotum) and lymphoedema/elephantiasis (swollen limbs). Estimates for schistosomiasis are even higher: more than 200 million people are affected and a further 600 million people are at risk of infection. International assistance over the past ten years, including massive donations of medicines, has enabled several countries to design and implement large-scale programmes, referred to as Mass Drug Administration (MDA), in which free treatment is given to adults and children living in areas where these diseases are endemic.</p> <p>From 2005, Professor Tim Allen was part of an international, multi-disciplinary programme (based at Imperial College) to assess the impact of current strategies to control NTDs. Allen and Dr Melissa Parker of Brunel University shared equal responsibility for the social research component of the programme. They each undertook 16 months of fieldwork in Tanzania and Uganda and supervised a dozen postgraduate students from UK and African institutions. Around 100 sites in Uganda and Tanzania were studied intensively between 2005 and 2011. Allen and Parker's findings have highlighted the following:</p> <p><u>Social context:</u> This influences the take-up of drugs with direct consequences for disease transmission. In Uganda, for example, where fisherfolk are highly likely to be infected with schistosomiasis, many are not receiving treatment because they live on islands in the rivers and lakes, whereas drug distribution is focussed in villages on the mainland. This is particularly problematic because the fisherfolk use rivers and lakes as a latrine, potentially causing the reinfection of anyone who has been treated and goes into the water. [1,2,4,5]</p> <p><u>Ineffective communication:</u> Explanations for MDA have not been made a priority. For example, in 2008 violent riots were observed in Tanzania when parents became convinced that tablets were being given out in schools to sterilise their children. [3,5]</p> <p><u>Side-effects:</u> MDA can have side-effects. These not only affect people's willingness to take the drugs, but also raise doubts about the merits of treating those who may be under-nourished, malnourished, immuno-compromised and/or infected with multiple parasitic infections. Allen and Parker were the first to describe significant side effects from mass treatment with praziquantel (for schistosomiasis control) and their research has been recognised in the biomedical literature. [1]</p> <p><u>NTDs differ:</u> It is unhelpful to treat NTDs as a homogenous group. The subjective experiences of their signs and symptoms vary within and between populations and this influences drug uptake. [3]</p> <p><u>Ethical challenges:</u> These are numerous. A particular concern raised by the research was that children were observed being given the incorrect medication by school teachers who had not been appropriately trained. Treatment in schools was also observed to have occurred without adequate parental consent [6]</p>

Monitoring and evaluation: Existing mechanisms for assessing programmes are insufficient. There has been a failure to recognise the low levels of drug take-up in some locations or to adequately assess the biological and social effects of the programme. Assessments of MDA tend to mix advocacy with research in misleading ways. Also, advocates of MDA are prone to making exaggerated assertions. For example, eradication of lymphatic filariasis in coastal Tanzania by 2020 is an impossibility without changing current strategies. [2,5,6]

Key researchers: Tim Allen has been at LSE since 1999. His key collaborator on this research was Dr. Melissa Parker, Senior Lecturer at Brunel University.

3. References to the research (indicative maximum of six references)

1. Parker M, Allen T and Hastings J 2008. 'Resisting control of neglected tropical diseases: dilemmas in the mass treatment of schistosomiasis and soil-transmitted helminths in northwest Uganda.' *Journal of Biosocial Science* 40 (2): 161-181. DOI: <http://dx.doi.org/10.1017/S0021932007002301>
2. Parker M and Allen T 2011. Does mass drug administration for the integrated treatment of neglected tropical diseases really work? Assessing evidence for the control of schistosomiasis and soil-transmitted helminths in Uganda. *Health Research Policy and Systems* 2011, 9:3. DOI: <http://dx.doi.org/10.1186/1478-4505-9-3>
3. Allen T and Parker M 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: <http://dx.doi.org/10.1080/01436597.2011.543816>
4. Parker M, Allen T, Pearson G, Peach N, Flynn R and Rees N, 2012. Border Parasites: Schistosomiasis Control among Uganda's Fisherfolk. *Journal of Eastern African Studies*, 6(1): 97-122. DOI: <http://dx.doi.org/10.1080/17531055.2012.664706>
5. Parker M and Allen T 2013. Will mass drug administration eliminate lymphatic filariasis? Evidence from northern coastal Tanzania. *Journal of Biosocial Science* 45: 517-545. DOI: <http://dx.doi.org/10.1017/S0021932012000466>
6. Parker M and Allen T 2013. De-politicizing parasites: Reflections on Attempts to Control the Control of Neglected Tropical Diseases. *Medical Anthropology*. DOI: <http://dx.doi.org/10.1080/01459740.2013.831414>

Evidence of quality: All papers were peer reviewed. The umbrella programme, of which this project was a key component, was awarded the Queen's Award for Academic Excellence in 2009.

Funding came from the following grants to the Schistosomiasis Control Initiative, Imperial College:

- 'The control of schistosomiasis in sub-Saharan Africa', Bill and Melinda Gates Foundation, 2002-2006, \$31.95 million; 'The evaluation of integrated control of Neglected Tropical Diseases in Africa', Bill and Melinda Gates Foundation, 2006-2009, \$9.975 million

4. Details of the impact (indicative maximum 750 words) (numbers refer to sources)

Clinical impact in Uganda and Tanzania

In Uganda, the underpinning research was used to demonstrate to local leaders and health officers why the existing approaches to treatment were failing. This led to the acceptance of the suggested alternative strategies in several locations. His Royal Highness Charles Okumu Ombidi III confirmed that "At first there was a reluctance by many people here to take the drugs, but after your work and your help with sensitising the people, there was widespread recognition that it is important to get regular treatment for this disease...following your recommendations in 2008 and 2009, the procedure for distributing drugs changed in Panyimur sub-county...the local council representatives took responsibility for distributing the drugs in their localities. This helped a lot. Many people came forward for treatment and coverage was much higher." [A] Similarly, the Mayor of Nebbi District confirmed that "the discussions we had on various updates on your findings, offered us a great insight on the health situations in the district especially along Lake Albert and River Nile...as a result it initiated behavioral and attitude change in the local population who were initially resistant to use of drugs whereas they were in dear need of treatment. This I believe was achieved through your participatory approach of research, community mobilization and sensitization." [B]

In Tanzania, the research showed that the majority of the study population in coastal areas were resisting treatment for lymphatic filariasis. Allen and Parker suggested to Tanzanian officials that

MDA should be supplemented with the provision of free surgery for those with hydroceles (swollen scrotums), because the men who were successfully treated would then become positive examples and advocates for the MDA programme. In 2008 this advice was acted upon and 200 men were offered hydrocelectomies [C]. Research in 2011 confirmed that this had an impact on the uptake of drugs in those locations in which appropriate follow-up occurred. In one study village (with an estimated population of 2000), uptake increased from 40% in 2007 to more than 90% in 2010.

Influencing practice

In 2008 the initial findings [1] were published indicating that MDA in combination with other approaches could be effective but that MDA delivered in a context-free manner commonly faltered or failed. These findings garnered attention from key figures and institutions involved in the battle against infectious disease. The head of the Vector Control Division in the Ugandan Ministry of Health, Dr. Narcis Kabatereine, cited this research in discussing the realities on the ground and the ways in which the current NTD control programme could be "jeopardised". [D] The research was likewise cited by Professor Adel Mahmoud, a highly respected expert on schistosomiasis and global health policy at Princeton University and former head of Merck Vaccines, and Professor Elias Zerhouni at Johns Hopkins Medicine and former head of the US National Institutes of Health. Writing in *Health Affairs*, a journal read by policy-makers, practitioners and scholars worldwide, Mahmoud and Zerhouni [E] echoed Allen and Parker's argument for educational and communications strategies at the local level and agreed that "Winning the battle against infectious diseases will require more than purely technological solutions".

The research was also discussed in numerous formal and less formal meetings, including closed sessions of the Bill and Melinda Gates Foundation in June 2009, at which representatives of WHO were present, and at DfID the following December. The WHO's Tropical Disease Research (TDR) division then commissioned Allen and Parker to write an article on the roll-out of MDA in Uganda as one of a series of papers considering how NTD research and practice "still largely neglect the social, ecological, and other contextual factors that allow diseases to persist in specific populations". The paper [2] was made publicly available on TDR's website in January 2011 [F], and was cited in the lead paper of the series authored by TDR Steering Committee member Pascale Allotey and her colleagues [F] to draw attention to implementation problems at the community level and to call for social science research to assess the effectiveness of NTD control programmes. The paper was also circulated for discussion to delegates at the 2011 International Society for Infectious Diseases conference, and has been noted as one of the most important publications about schistosomiasis in Expert Reviews, which described it as an "important evaluation highlighting that community compliance with praziquantel treatment needs careful attention" [G].

In February 2011 the underpinning research was again featured in an article written by Allen and Parker [3] for a special issue of *Third World Quarterly* called "The Millennium Development Goals: challenges, prospects and opportunities". Allen and Parker's call for a biosocial approach was echoed by UN Secretary General Ban-Ki Moon in his Preface to the issue when he pointed to "knowledge gained over the past decade about the effectiveness of taking a holistic approach".

Challenging MDA strategies

The high profile of the *Third World Quarterly* article, and the call it made to rethink a context-free MDA approach, became the impetus for debate within the infectious disease community. A vehement defence of the mainstream MDA approach in a leading medical journal prompted Allen and Parker to submit a letter to *The Lancet* in January 2012 entitled 'Will increased funding for NTDs really make poverty history?' [H]. The letter again outlined some of the difficulties with current strategies, observed the lack of critical analysis and debate about "what is actually occurring on the ground", and called for an evidence-based and integrated biosocial approach. Published on the front page, the letter was timed to appear on the eve of an international meeting in London at which DfID, USAID, the UAE governments, the World Bank, the Gates Foundation, 13 pharmaceutical companies and other global health organisations were announcing a coordinated partnership to eliminate 10 NTDs by 2020, involving commitments of over \$785 million and significant in-kind support. The timing and content of the letter provoked a storm of controversy, and responses from leading proponents and critics of context-free MDA were

published in *The Lancet*. The debate was noted in the Guardian [I] and by DFID, which had committed £195 million to the NTD global partnership.

Soon, however, the debate began to turn and the significance of the underpinning research to be publicly acknowledged. In June 2012 Allen and Parker made a keynote address at the International Society for Neglected Tropical Diseases conference at the London School of Hygiene and Tropical Medicine. At that meeting, the head of the Schistosomiasis Control Initiative at Imperial College, a leading figure in the MDA community, stated to a surprised audience that the kind of work Allen and Parker had been doing needed to be done at all sites at which mass drug administration was being implemented. In December 2012, Allen and Parker were invited to a meeting in the UK Parliament on the possibilities of mass drug administration, where they discussed their findings with DfID's Chief Scientific Advisor and head of research, Professor Chris Whitty. A month later, Allen and Parker's research was mentioned during a debate on NTDs in the House of Lords, with the Earl of Sandwich, the Lord Bishop of Derby and Lord Rae citing their findings and most of the speakers emphasising communication, training and a biosocial approach [J]. Following this, Allen and Parker were asked to address MPs specifically about the problems with MDA for lymphatic filariasis at the All-Party Parliamentary Group on Malaria and NTDs. In this session, it was openly acknowledged by one of the leading proponents of MDA that their research was having a profound effect on shifting approaches to drug distribution and monitoring.

In July 2013 an international conference was convened in London by Allen and Parker with Dr Katja Polman of the Institute of Tropical Medicine, Antwerp to bring together people from across the debate. The 20-plus attendees included many of the leading supporters of MDA as well as senior figures from African countries. The impact of the research was again explicitly acknowledged and there was detailed discussion of how policies were now being reformulated to take the findings into account. A range of views were filmed and made available online [K].

Wider Implications: Over one billion people are at risk or already afflicted by NTDs, 40 countries have multi-year NTD plans and close to £1 billion in funding and in-kind assistance is committed to the control or elimination of NTDs in the next five years. Only the locally sensitive and effective deployment of this assistance will assure the permanent defeat of these diseases and the alleviation of their deleterious impact on lives, societies and economies around the world.

5. Sources to corroborate the impact (indicative maximum of 10 references)

All sources listed below can also be seen at: https://apps.lse.ac.uk/impact/case_study/view/87

- A. Email from the traditional chief/king in Panyimur sub-county of Uganda. This source is confidential.
- B. Email from the elected Chairman (mayor) of Uganda's Nebbi District. This source is confidential.
- C. Email from head of the Tanzanian lymphatic filariasis control programme. This source is confidential.
- D. The unsung hero of neglected tropical diseases: interview with Narcis Kabatereine. <http://www.plosntds.org/article/info%3Adoi%2F10.1371%2Fjournal.pntd.0000546>
- E. Neglected Tropical Diseases: moving beyond mass drug treatment to understanding the science. Health Affairs. Source file: <https://apps.lse.ac.uk/impact/download/file/991>
- F. WHO website: <http://www.who.int/tdr/news/2011/social-science-ntd/en/index.html>
- G. Advocacy, policies and practicalities of preventative chemotherapy campaigns for African children with schistosomiasis. Source file: <https://apps.lse.ac.uk/impact/download/file/993>
- H. Will increased funding for neglected tropical diseases really make poverty history? *The Lancet*. Source file: <https://apps.lse.ac.uk/impact/download/file/992>
- I. The Guardian article. Source file: <https://apps.lse.ac.uk/impact/download/file/994>
- J. Neglected Tropical Diseases, Question for Short Debate, House of Lords, 30 January 2013. Source file: <https://apps.lse.ac.uk/impact/download/file/995>
- K. Website on biosocial conference on NTDs: <http://www.lse.ac.uk/researchAndExpertise/researchHighlights/WorldRegionsAndDevelopment/Africashealthcrisis.aspx>