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UK Coalition against NTDs: Annual Report 2014-15

Report for the All-Party Parliamentary Group on Malaria and Neglected Tropical Diseases

House of Commons
The All-Party Parliamentary Group on Malaria and Neglected Tropical Diseases (APPMG)

UK Coalition against NTDs: Annual Report 2014-15

Report for the All-Party Parliamentary Group on Malaria and Neglected Tropical Diseases

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Chairman's foreword

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If ever we needed a wake-up call to the vital importance of tackling infectious disease around the world, Ebola has provided it.

This devastating disease which, at the time of writing, seems mercifully to be affecting fewer people each week, has shown us just how important it is to help countries develop strong health systems with universal coverage.

It has also highlighted the bravery and sacrifice of the health workers, who are at the front line of the war on disease. I would like to dedicate this – our final report of the 2010-2015 Parliament – to the memory of all those who have given their lives in Sierra Leone, Liberia, Guinea and elsewhere in service of their fellow human beings.

Strong health systems and dedicated health professionals are key to fighting Neglected Tropical Diseases, as I have learned in the almost five years I have had the honour of chairing this All-Party Parliamentary Group.

APPG members Pauline Latham OBE MP, Fiona Bruce MP, Fiona O'Donnell MP and I are members of the House of Commons International Development Select Committee, which in 2014 reported on the UK Government's investment and progress in Health System Strengthening. During our inquiry, we were informed by a written evidence submission from the UK Coalition against Neglected Tropical Diseases that a coordinated health systems approach is vital for implementing the WHO SAFE (Surgery, Antibiotics, Facial cleanliness, Environmental hygiene) strategy to eliminate blinding trachoma by 2020:

"Surgical interventions, antibiotic distribution and health promotion activities need to be delivered through a health system in order to reach trachoma endemic communities. However, many trachoma-endemic countries have a weak health system with even weaker primary healthcare, as well as little capacity to work across ministries and sectors to deliver components such as water, sanitation and hygiene. The current momentum in reinvigorating primary healthcare with integration of eye care and health system strengthening provides a real opportunity in the drive towards trachoma elimination. Currently only 13 per cent of people receive the treatment they require for this disease." (Report: Para 68).

And what is true for trachoma is true for tackling all NTDs.

Our inquiry also learned of the adverse impact that shortages of health workers, particularly specialists, can have on the fight against NTDs:

"… on our recent visit to Sierra Leone, … we heard that a shortage of doctors, nurses and midwives was a major obstacle to health system improvement. We heard that a scarcity of specialist expertise was a major obstacle to tackling conditions such as neglected tropical diseases. The Global Health Workforce Alliance (GWHA) estimates that more than seven million additional health workers are required to deliver basic services to all, a deficit that could rise to 13 million by 2035 because of projected population growth." (Report: Para 56).

But these continuing challenges should not detract from the great progress which has been made in the past five years in tackling NTDs.

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There is outstanding cooperation between government health services, the private sector – who supply billions of treatments free of charge, research institutes, several based in the UK, NGOs and international donors.

The donors themselves have shown a greater commitment to NTDs since 2010. DFID increased its expenditure from £50 million to £245 million over the four years from 2011-2015. The US Government has also made NTDs a priority allocating over USD $452.5 million over the same timeframe. Both governments appreciate just how much can be done with relatively small sums to help the lives of the 1.4 billion people – more than a sixth of the world's population – affected by these diseases. To put things in perspective, the funding allocated for four years globally by DFID would be enough to run one medium-sized acute hospital in the UK for just one year.

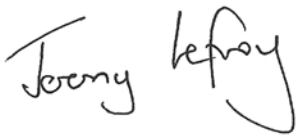
The next Parliament is crucial. Will we maintain this momentum, or will we see attention drawn elsewhere? I trust that there will be MPs and Peers in the next Parliament who will reconstitute the APPG on Malaria and Neglected Tropical Diseases and will continue to make the case to support the efforts to fight NTDs and eventually eliminate them.

I would like to thank my parliamentary colleagues, Pauline Latham OBE MP, Fiona O'Donnell MP, Mark Durkan MP, Fiona Bruce MP, Baroness Hayman, Lord Rea, Lord Trees and Lord Stone for their constant support over the past year.

This is the final report which Susan Dykes as Coordinator of the APPG, has masterminded over the years. We will miss her work greatly – but she will always be part of this group. Rt Hon Stephen O'Brien MP, the founder of the group, has as always shown great support and encouragement. The work we have done together would not have been possible without the generous support of our donors who are listed in this report and on our website. Finally, I am most grateful to Helen Hamilton, Chair of the UK Coalition against Neglected Tropical Diseases who has coordinated the production of this report.

"… There is no silver bullet remedy to helping a country break the cycle of poverty, but investing in the health of its population offers one of the best options for unlocking economic potential. With full support both from national governments and from the global community, we can … put an end to NTDs on the African continent [and beyond]."

His Excellency John Kufuor, President of the Republic of Ghana (2001-2009).



Jeremy Lefroy MP

Chairman of the All-Party Parliamentary Group on Malaria and Neglected Tropical Diseases

Abbreviations

APPG ..... All-Party Parliamentary Group on Malaria and NTDs
CALL ..... Challenging-Anti Leprosy Legislation
DALY ..... Disability-Adjusted Life Years
DFID ..... Department For International Development
GTMP ..... Global Trachoma Mapping Project
MDA ..... Mass Drug Administration
MDG ..... Millennium Development Goal(s)
NNN ..... NGDO NTD Network
NTD ..... Neglected Tropical Disease(s)
SAFE ..... Surgery, Antibiotics, Face-washing and Environmental Hygiene
SDG ..... Sustainable Development Goal(s)
STH ..... Soil-transmitted helminths
UKCNTD ..... UK Coalition against Neglected Tropical Diseases
WASH ..... Water, Sanitation and Hygiene
WHA ..... World Health Assembly
WHO ..... World Health Organization

Acknowledgements

The All-Party Parliamentary Group On Malaria & Neglected Tropical Diseases would like to express its thanks to the UK Coalition against Neglected Tropical Diseases (UKCNTD) for the preparation of this report. We appreciate their focus and dedication to the work of combatting NTDs.

In particular, we would like to thank the Chair, Helen Hamilton (Policy Adviser, Sightsavers) and members of the UKCNTD for their work on the report.

We would like to thank **GlaxoSmithKline** for again generously funding the printing of this report.

The All-Party Parliamentary Group on Malaria and Neglected Tropical Diseases is also most grateful for financial support from:

UK Coalition against Neglected Tropical Diseases

Sabin Vaccine Institute

Global Network for Neglected Tropical Diseases

Medicines for Malaria Venture

Malaria Consortium

Malaria No More UK

Introduction

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The All-Party Parliamentary Group on Malaria and Neglected Tropical Diseases

The future of NTDs post-2015 – Equity, access and inclusion

This year the UKCNTD welcomed the outcomes of two International Development Committee inquiries, one on disability and development, and one on health system strengthening. Both recognised the impact NTDs can have on people's lives, in terms of their health, their social inclusion and their economic contribution within their communities.

For the UKCNTD, the final All-Party Parliamentary Group on Malaria and Neglected Tropical Diseases report of this Parliament is a moment to take stock and recognise the huge strides forward that have been made in combatting NTDs. This is thanks in large part to the continued commitment of the UK Government. Throughout this Parliament the UK has remained a world leader at the forefront of the fight to end these devastating diseases.

This year we've seen the harrowing effects of the Ebola epidemic in Guinea, Liberia, and Sierra Leone, greatly magnified by their weak health systems. Ebola has shone a spotlight on the importance of building health systems to address challenges such as insufficient numbers of qualified health workers, and inadequate surveillance and information systems equipped to respond rapidly to new and existing health challenges.

On the global stage the UK has led the call to 'leave no one behind' in the next set of development goals that will be agreed this year. This call is about ensuring that equity is at the heart of the wider efforts to eradicate extreme poverty by 2030.

Why is this important to the NTD community? In short, because NTDs are diseases of poverty and exclusion. The 1.4 billion people whose families and communities live with the devastating impact of NTDs every day do so because they are left behind in efforts to combat poverty.

This year, with a new set of global development goals being agreed upon, there is a once in a generation chance to address this issue, and get it right. Winning the fight against NTDs would not only benefit individual health outcomes, but benefit programmes designed to improve education, nutrition, water and sanitation, maternal and child health and economic growth.

The UKCNTD would like to thank the current UK Government during this parliamentary session for it's recognition and commitment to addressing these debilitating diseases of poverty and in particular, former Ministers Rt Hon Andrew Mitchell MP and Rt. Hon Stephen O'Brien MP for their championing of NTDs. We thank Jeremy Lefroy MP for his commitment to NTDs as Chairman of the APPG and through his work as a member of the International Development Select Committee.

Helen Hamilton

Chair of UK Coalition against NTDs

Credit: Kate Ixer / LEPRA

Recommendations

2015 is a pivotal year for NTDs. As we approach the UK general election, it is crucial that all UK parties make NTDs a development priority for the next UK Government to ensure there is strong cross-party support. The investment made in combatting these diseases to date is paying off and we are starting to make strong progress. It's now crucial that we protect these successes and continue to build on them in an equitable way.

Specifically, the new UK Government should:

- Maintain its financial commitment to NTD programmes to support the achievement of the WHO NTD Roadmap goals, through the continued implementation of the 2012 London Declaration.
- Ensure that the DFID disability framework and the forthcoming DFID health system framework support a pro-poor NTD response, which delivers prevention, diagnosis, treatment and care for marginalised communities, including women and children, people with disabilities and older people in developing countries.
- Support the full range of research and development for NTDs, including improved strategies and partnerships to develop the next generation of treatments, diagnostics, and vaccines, which will contribute to longer-term elimination goals.
- Ensure that the new DFID health system strengthening framework supports country governments to equip their health systems to deliver essential NTD interventions.
- Promote a cross-sectoral NTD response that supports water, sanitation and hygiene (WASH), nutrition, health, education, maternal and child health and disability partners to collaborate on NTDs.
- Promote the partnership model exemplified by the NTD response, which draws on various public, private and civil society competencies including drug donations, technical assistance, donor funding, political commitment and community engagement.
- Continue to champion investments for NTDs internationally, by supporting the inclusion of NTDs within the health goal in the Sustainable Development Goals (SDGs) and within related SDGs such as those tied to WASH and nutrition.
- Highlight the successes achieved with UK Government investment in NTDs, and urge other governments and multi-lateral institutions to contribute more to the fight against NTDs.

A post-2015 vision for NTDs

The international community is moving into the final stages of negotiations on the post-2015 development agenda to replace the Millennium Development Goals. In this period there is a unique opportunity to ensure a future framework that includes NTDs in a way that maximises health outcomes and sustains achievements in NTD control, elimination and eradication. This cannot be done without strong national systems and an equitable approach that delivers coverage across all population groups.

Poverty remains the single most important determinant for NTDs[1]. Ultimately exposure to poverty-associated risk factors and conditions synonymous with marginalised populations, such as inadequate access to health services, WASH practices, housing and education, allow these diseases to flourish and enable a vicious cycle of disease and poverty.

Inclusion of NTDs in the post-2015 development framework would represent a global commitment to NTD control, elimination and eradication. It would also embed national commitments, ensure equity in access to health services and cement NTDs firmly within the poverty alleviation agenda, alongside universal health coverage.

High quality and equitable interventions for NTDs form an important element of universal health coverage. Actions to secure universal health coverage must be underpinned by access to WASH. This is vital to safeguard and sustain progress made against NTDs, in terms of both NTD prevention and the care for chronic NTD-related conditions.

Progress towards elimination of NTDs also represents an interim indicator for both poverty alleviation efforts and for universal health coverage; to achieve elimination of NTDs, national health services must meet the health needs of the poorest and most marginalised sections of their populations. Moreover, delivering on NTD elimination mandates that other interventions, such as ensuring access to WASH or improving housing standards, are reaching the right groups and being achieved in an effective and equitable way.

For example, highlighting NTD control measures within WASH programmes or efforts to address malnutrition and morbidity management would ensure that where possible, shared solutions are promoted.

A woman leaves the clinic, walking on her own after her eye surgery in Nasir in Upper Nile, South Sudan
Credit: Adriane Ohanesian / Sightsavers.

[1] *Aagaard-Hansen J, Lise Chaignat C (2010) Neglected tropical diseases: equity and social determinants In Blas E, and Sivasankara Kurup A, (eds) Equity, social determinants and public health, World Health Organization p137-157*

NTD spotlight: Blinding Trachoma

Mapping trachoma – getting the full picture

In late 2012 the Global Trachoma Mapping Project (GTMP) was launched. Funded by the UK Department for International Development (DFID), it is the largest infectious disease mapping project ever launched. The project uses innovative mobile technology to map the global prevalence of trachoma and some of its determinants, and represents a vital resource in the fight to eliminate blinding trachoma – the world's leading infectious cause of blindness. It addresses one of the common barriers to effective disease control – lack of good quality data.

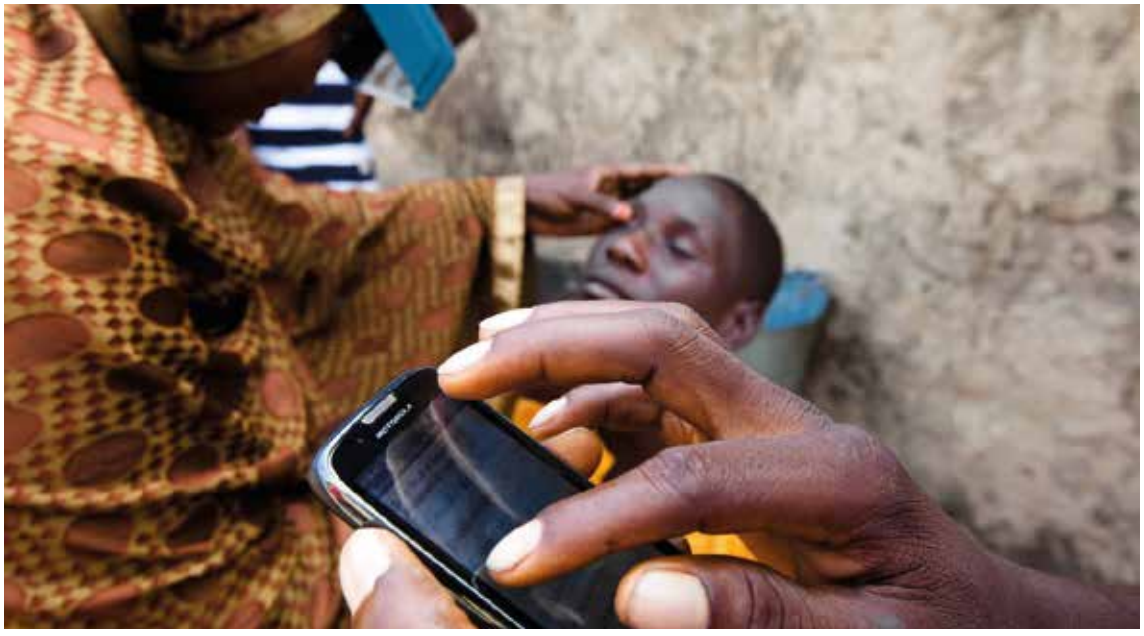
The WHO Alliance for the Global Elimination of Trachoma has set ambitious targets to eliminate blinding trachoma by 2020. However, until 2012, one of the major challenges was the lack of data and information to guide efforts to tackle the disease. To achieve trachoma elimination goals, mapping needs to be completed by the end of 2015, so that the GTMP can deliver data at district level, to inform planning of public health interventions and mobilise resources.

The mapping has already examined the eyelids of over 2 million people in 21 countries across Africa, Asia, Eastern Mediterranean, South America and the Pacific region and has provided programme-ready information for SAFE (surgery, antibiotics, facial cleanliness, environmental hygiene) implementation for over 165 million people in 1,317 districts. It will also provide the first truly global picture of trachoma prevalence and is guiding efforts to eliminate the disease.

Mapping the disease and its determinants

The WASH and trachoma sectors have a common target population—the world's most marginalised communities, as trachoma is endemic where poverty and poor sanitary conditions persist. This population often lacks access to safe reliable services for health and WASH, and as a result they suffer disproportionately from debilitating disease.

The WHO-endorsed SAFE strategy for the elimination of trachoma is based on measures to both treat and prevent the disease by addressing major risk factors. Risk factors for trachoma include water shortages, poor environmental and personal hygiene behaviours and conditions, crowded households and flies. Each of these risk factors is strongly linked to inadequate access to water and sanitation. Due to this link, the GTMP collects data simultaneously on both the prevalence of trachoma and improved and unimproved WASH conditions.



Halima Suleiman is a Grader in Nigeria for the Global Trachoma Mapping Project, she is responsible for carrying out eye examinations to check for signs of trachoma. Credit: Tom Saater / Sightsavers

Bigiltuu Kefeni, 5, from Keta town, Ethiopia, was one of the first people to be examined as part of the Global Trachoma Mapping Project. Credit: Dominic Nah / Magnum / Sightsavers.

An innovative approach

Data for the GTMP are collected by ministry of health field teams on smartphones using the open access LINKS application. They are geo-referenced using global positioning system coordinates. Before the data is uploaded to the Global Trachoma Atlas[2] it is sent to a secure server for cleaning, automated analysis and approval by the relevant ministry of health.

The WASH and NTD sectors collect and use data differently, which traditionally has posed a challenge in mapping efforts. The GTMP methodology addressed this by using internationally agreed definitions of access to improved/unimproved water and sanitation, drawn from the Joint Monitoring Programme - the official WHO/UNICEF mechanism tasked with monitoring water and sanitation progress. This approach ensures that the data collected provides national programme managers with all the information necessary, both on trachoma prevalence and also water and sanitation, to plan and deliver effective and sustainable elimination interventions. Moreover, this standardised approach to training and data collection ensures consistency of quality, and enables collaboration across national borders, between trachoma-affected countries, as well as within them.

All four elements of the SAFE strategy must be implemented for trachoma programmes to be successful and for global elimination targets to be met. If not, trachoma will persist or resurge because the risk factors remain. The GTMP has laid the foundations for quality health services to combat trachoma, which can only be delivered through planning that is informed by good quality data. Trachoma stakeholders are united around a common vision – to eliminate blinding trachoma by 2020 – and the quality and success of this project has leveraged collaboration and support from other funders, such as USAID.

Delivering accurate, detailed and timely data, the Global Trachoma Mapping Project is providing the intelligence to support trachoma and WASH stakeholders to work together in partnership towards the elimination of blinding trachoma by 2020.

[2] *http://www.trachomaatlas.org*

NTD spotlight: Leprosy

Equity, access and inclusion: CALLing for change

Traditionally organisations working on NTDs have focused on immediate medical interventions to combat these diseases particularly, Mass Drug Administration (MDA). This has been where the majority of investment has been focused, as many NTDs can lead to disability. Increased effort is still needed in terms of prevention, early diagnosis and treatment. However, there are millions of people who have not received early treatment and are living with the physical, psychological and social implications of late diagnosis. These people, living with the consequences of NTDs on a daily basis, need to be included in both NTD-specific and mainstream development programmes, yet they are often denied equity, access and inclusion. Research conducted with over 5,000 people affected by leprosy across nine countries revealed that although they had seen changes around them, they did not feel that they had benefited personally from the development efforts undertaken to achieve the Millennium Development Goals[3].

Social Implications

The diagnosis of a disease such as leprosy has huge social implications. Stigma is still high in many countries and it is not uncommon for people to be asked to leave their families, jobs and communities. In India, leprosy change sentence to read: leprosy is legally a ground for divorce and people have been prevented from travelling on public transport due to fear of contagion, even though they have been treated and are non-infectious. Such discrimination means that those affected often withdraw from their community, suffer feelings of worthlessness and lack self-confidence. If the general community fails to integrate people affected by leprosy, the fear of the disease is perpetuated and stigma is further increased.

With support from DFID, over 4,000 people affected by leprosy in Uttar Pradesh and Chhattisgarh States in India have participated in the Challenging-Anti Leprosy Legislation (CALL) project. CALL has worked predominately with communities living in leprosy colonies to make them aware of their rights and entitlements, and to build their self-confidence and self-esteem so that

Noorjhahan lives in the Kusht Ashsam Kharabad leprosy colony in the Sitapur district of Uttar Pradesh, India. Her hands are clearly disabled by leprosy. Recently a bus driver refused to allow her to board because of this and as a result of the CALL project making her more aware of her rights, she successfully challenged him and is now able to travel by bus.

[3] *Arulanantham, S (2014) Addressing inequality and exclusion, Leprosy Review, 85, 133-140*

they can work together to lobby the government to invest in development in their communities. This has included improved infrastructure, ensuring older people and people with disabilities are able to access social safety nets, and enabling the younger generation to access education and skills training, moving from begging to employment. CALL has also worked with the surrounding community using radio, TV, drama, billboards and magic shows to raise awareness about leprosy and reduce stigma.

Over 30,000 people have been involved in the leprosy awareness programme, and as a result people affected by leprosy are reporting greater social inclusion and improved access to health care. They are now invited to community meetings and participate in the Gram Sabha (local governance). They have presented memorandums to the government for village development which have resulted in new roads, electricity connections, clean water, improved sanitation, and the construction of new homes. By building their self-esteem and walking them through the advocacy process, they are now agents of change in their own communities and able to influence others. Working together, they are trying to change legislation that discriminates against them. Their successes have drawn the interest of other marginalised groups who now want to learn from them.

Leaving No One Behind

It is encouraging that DFID's new Disability Framework and the UN Synthesis Report on the SDGs recognises that no-one should be left behind when it comes to development. However, in order for people affected by NTDs to be included in the development process, and to have equity, access and inclusion, approaches to development need to change. We know that NTDs are disease of poverty - found among poor and marginalised communities. NTDs are not just a health issue, they represent an issue of social justice.

As the International Development Select Committee recognised, mainstream development programmes need to actively include people with disabilities, including those with NTD-related disability. Empowerment is a long-term investment, but it is also essential to combatting NTDs and to support countries and their citizens to reach their full economic potential.

World Leprosy Day action by the CALL project in India. People raise awareness about leprosy and stigma. Credit: The Leprosy Mission England & Wales.

Data and surveillance

Monitoring and evaluating the impact of efforts to combat NTDs is a complex challenge. There are more than 1.4 billion people affected by 17 different diseases, with a diverse range of treatment regimens. On the implementation side there are more than 75 countries whose national governments have developed, national, integrated bringing together programmes; a wide variety of development partners, including UN organisations; multi-lateral; bilaterals; inter-governmental organisations; international civil society; and community organisations; academic institutions and the private sector. Working together, these stakeholders are now poised to implement comprehensive NTD programmes and achieve success in elimination/control.

Challenges for effective surveillance include:

- **Sensitivity** - surveillance systems need to have sufficiently high sensitivity to detect individuals with low levels of infection.
- **Attribution** - demonstrating that observed changes in outcomes are due to the intervention and not other factors.
- **Community buy-in** - NTD interventions need to be acceptable to communities and have tangible benefits. The final audience is the communities themselves that are receiving the interventions, yet this group is often neglected in monitoring and evaluating.
- **Measurability** - The use of disability-adjusted life years (DALY) provides a common metric to measure changes in NTDs over time, but estimates are by necessity based on approximations. It is essential that high-quality data is made freely available and is regularly updated.

The data collection requirements for NTD control programmes can be separated into three stages:

1. Monitoring impact of interventions as they are being implemented.
2. Investigating whether programme goals have been reached (e.g. interruption of transmission) and thus interventions can be halted or modified.
3. Undertaking surveillance to detect the re-emergence of transmission.

In terms of costs, good surveillance provides excellent value in the long run, because it helps target resources efficiently. Sufficient support should be allocated to surveillance efforts, considering the main costs:

- Cost for risk-based surveys
- Cost of visiting the population unit
- Cost per sample
- Cost per laboratory diagnosis
- Cost for risk assessment
- Cost for random surveys

Surveillance can have several purposes, including documenting spatial and temporal trends of diseases, monitoring the impact of interventions, the identification of (re)emerging diseases, and confirming the absence of a disease. In elimination programmes specifically, surveillance should not only detect and report foci of transmission but also take responsive action.

Maps are an important part of surveillance efforts, as they visualise data in a more accessible and straightforward way and can easily highlight where resources and interventions are most needed. Maps can also show progress over time, by comparing images from before and after interventions, for example.

Surveillance should be recognised as key to disease control and elimination because it provides information to guide decisions about the nature and scope of interventions. This recognition should be supported by adequate resourcing and prioritisation in NTD programmes, and delivered as part of ongoing efforts to strengthen health systems.

Beself Abera is part of a team surveying people in Ethiopia for the neglected tropical disease trachoma. Credit: Dominic Nahr / Magnum / Sightsavers

Why is R&D for NTDs needed?

As NTDs are diseases of poverty efforts to control and eliminate them are hindered by the additional challenges of limited access to good housing, clean water and sanitation; income available to afford medical services; and treatment. Seven of the highest burden diseases, including schistosomiasis, lymphatic filariasis, soil-transmitted helminths (STH) and trachoma, are "tool ready", with control/elimination programmes equipped with diagnostic, treatment, and follow-up surveillance strategies to implement MDA campaigns. To achieve elimination of NTDs such as schistosomiasis and STH, investment in new tools and vaccines is required. Indeed, a recent survey of almost 400 NTD experts identified the importance of new technologies in reaching London Declaration targets for these diseases[4].

For many other NTDs, such as leprosy, dengue, African sleeping sickness, Chagas disease, and visceral leishmaniasis, vaccines, medicines and diagnostic tests (collectively referred to as products) are either ineffective or completely lacking. In these cases, disease control or elimination will only be achievable with further commitments to research and development (R&D). New tools are urgently needed to improve patient care, respond to the challenge of drug resistance, and enhance prospects for achieving disease elimination.

In the case of sleeping sickness, which continues to kill in remote or unstable pockets of sub-Saharan Africa, diagnostic tools are inadequate (painful lumbar puncture is the only tool), and while nifurtimox-eflornithine combination therapy is an improved optional therapy, it still requires intravenous infusions[5]. For visceral leishmaniasis, which is prevalent in East Africa, India, and Brazil, invasive diagnostics, long treatment duration (30 days), and drug resistance (up to 65% in India)[6] pose obstacles to control. For Chagas disease,

Diagnosing NTDs in the laboratory in Sierra Leone. R&D efforts benefit not only NTD affected communities but also aims to build scientific capacity of technical staff in country to undertake clinical trials and improve implementation of new tools.
Credit: Sabin Vaccine Institute

[4] *Keenan JD et al. Elimination and Eradication of Neglected Tropical Diseases with Mass Drug Administrations: A survey of Experts. PLOS Neglected Tropical Diseases, December 2013. http://journals.plos.org/plosntds/article?id=10.1371/journal.pntd.0002562http://journals.plos.org/plosntds/article?id=10.1371/journal.pntd.0002562http://journals.plos.org/plosntds/article?id=10.1371/journal.pntd.0002562.*

[5] *Priotto G et al. Nifurtimox-eflornithine combination therapy for second-stage African Trypanosoma brucei gambiense trypanosomiasis: a multicentre, randomised, phase III, non-inferiority trial. The Lancet 2009; Vol 374: 56 – 64. DOI: http://dx.doi.org/10.1016/S0140-6736(09)61117-X DOI: http://dx.doi.org/10.1016/S0140-6736(09)61117-X.*

[6] *Croft SL, Sundar S, Fairlamb AH. Drug Resistance in Leishmaniasis. Clinical Microbiology Reviews 2006;19(1):111-126. doi:10.1128/CMR.19.1.111-126.2006.*

no diagnostic test or cure exists, and safe, effective drugs or therapeutic vaccines have yet to be specifically developed for chronic-stage disease[7].

For the filarial parasitic-worm diseases of onchocerciasis (river blindness) and lymphatic filariasis (elephantiasis), which together infect over 150 million people, the standard treatment of ivermectin (alone or in combination with albendazole) can lead to serious and permanent side effects such as brain damage or death in people co-infected with loiasis (Loa loa; African eye worm)[8]. Moreover, current drugs kill only the juvenile worms, and not the adults worms, which continue to infect and will require repeated treatments.

Therefore, while continuing to provide existing medicines for NTD control and prevention, parallel and greatly enhanced R&D initiatives for new drugs and diagnostics are also necessary.

Gaps in NTD R&D

As there is no market for new tools that affect the world's poor, there is a great need for increased funding for NTD R&D in order to help sustain momentum for new health tools, advance products currently in development and to deliver them to people in need. The current system for stimulating R&D has failed to deliver new health technologies for diseases that affect the world's poor; there is no more evidence for this than in the recent outbreak of Ebola which dominated the news in 2014.

The establishment of product development partnerships (PDPs), with their ability to bring together companies, academia, governments and philanthropy to create new medicines for the developing world, has helped to fill this gap. However, funding for NTD R&D at all stages remains well below the levels required, and funding for late-stage product development and a full range of needed global health technologies is urgently needed. Overall, it has been estimated that at least $1 billion per year over the next 10 years will be required to put experimental treatments, diagnostics and vaccines in the pipeline through large human trials, and to obtain permission from regulators to introduce them widely. Ultimately, governments capable of providing developmental assistance have a significant role to play to achieve this level of support.

The staggering rates of NTDs, which occur largely in countries with high rates of instability suggest a role for medical intervention against these diseases as an important diplomatic tool. Incorporating NTD product development into a larger programme of science and technology diplomacy not only serves important humanitarian purposes, but also creates jobs, spurs business, encourages collaboration and addresses health needs among the poor in high-income countries and middle-income countries, like the USA, (given it's recent outbreaks of dengue and Chagas disease in the southern states). Sustained investments in NTD R&D are critical to ensure that the progress made to date is not squandered and the momentum to ensure these new products reach those in need is maintained. These new technologies for NTDs play a vital role in the elimination and post-elimination control measures for NTDs.

Despite difficult global economic conditions and the implementation of austerity measures in recent years, the UK Government has maintained its global leadership for NTD R&D (the third largest public funder in this field, after the US and the EC), making good on its promise "not to balance the books on the backs of the poor". We urge the UK Government to continue to lead the world in this area, and use its position to encourage other donors to invest in innovative tools to treat neglected tropical diseases.

Making headway

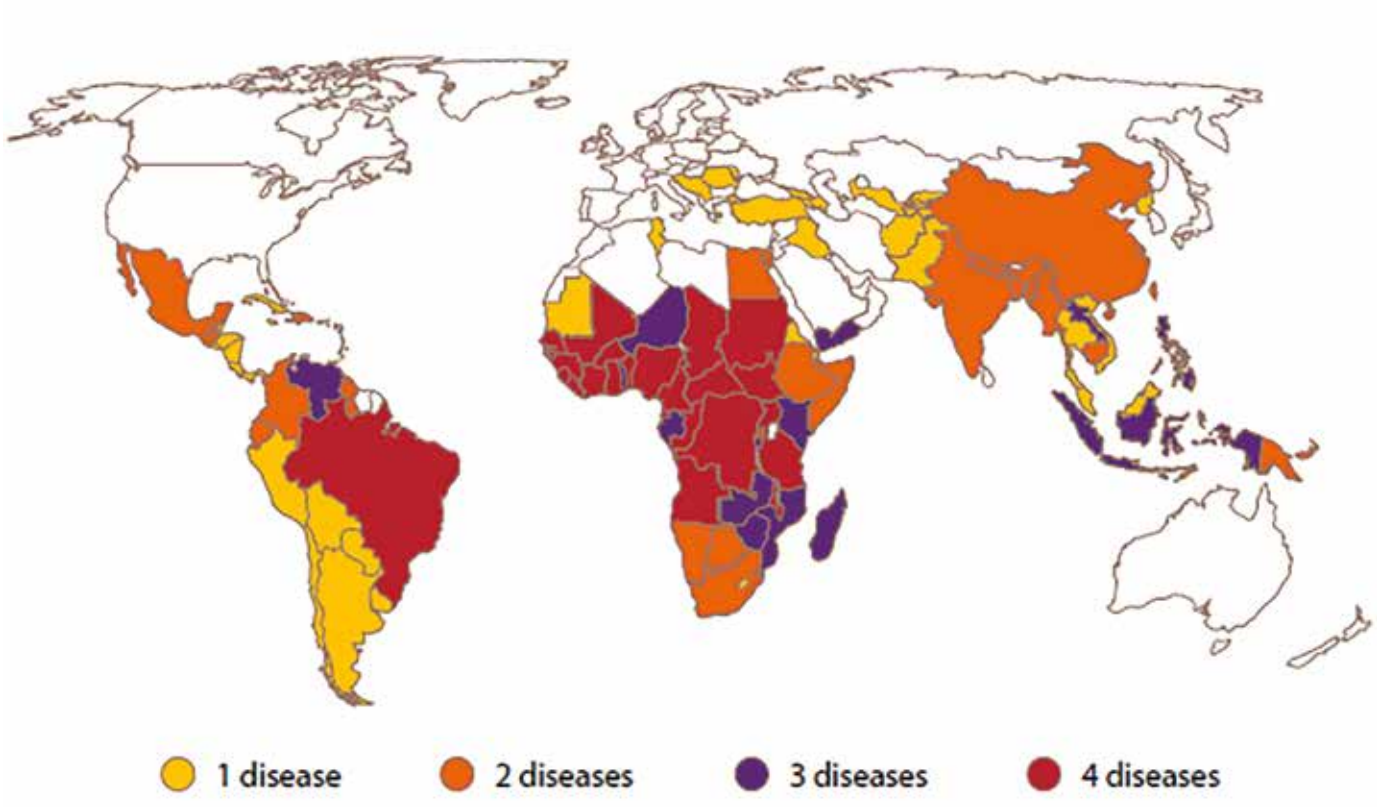
Through PDPs, new vaccines are under development and in clinical trials for several NTDs, including vaccines to combat cholera, hookworm infection, leishmaniasis and schistosomiasis. Additionally, through support from DFID, we have seen new and more effective therapies available for leishmaniasis (2011), sleeping sickness (2013, donated by Sanofi and Bayer) and Chagas disease (2013; a paediatric formulation is now included in the WHO's Essential Medicines List for children), which will significantly reduce the prevalence of morbidity and mortality from these diseases.

[7] *WHO Factsheet: Chagas Disease. Updated March 2014. http://www.who.int/mediacentre/factsheets/fs340/enhttp://www.who.int/mediacentre/factsheets/fs340/enhttp://www.who.int/mediacentre/factsheets/fs340/en.*

[8] *Takougang Innocent and Muteba Daniel (2012). Encephalopathy Related to Ivermectin Treatment of Onchocerciasis in Loa loa Endemic Areas: Operational Considerations, Miscellanea on Encephalopathies, Dr. Radu Tanasescu (Ed.), ISBN: 978-953-51-0499-5.*

Control and elimination

Map to illustrate areas identified for control and elimination of NTDs



NTD	Symptoms / disability	Number of people at risk globally[1]	Global DALY burden	Current Method of treatment and prevention	Target for control elimination and target year to be eliminated	Percentage of at risk population receiving treatment[2]	WASH: Disease prevention	WASH: Care and disability
Chagas disease	The disease is caused by a protozoan transmitted through contact with the faeces of an insect, the triatomine bug, known as the "kissing bug". It can also be transmitted through blood transfusion and organ transplant. Without treatment, is potentially fatal following cardiac and intestinal complications.	100 million people are at risk worldwide Chagas disease is endemic in 21 countries across Latin America and patient numbers are growing in non-endemic countries such as the United States, Australia, and Europe as a result of migration.	0.55 Disability Adjusted Life Years[2].	Existing treatments have an unsatisfactory cure rate and can have toxic side effects There is a great need to develop new treatments for this disease.	The WHO Roadmap for Implementation sets a target of regional elimination of transmission though blood transfusions by 2015 and intradomiciliary transmission in the region of the Americas by 2020.	Only a small proportion of infected people receive appropriate treatment.	The vector, the triatomine ('kissing') bug, is associated with poorly-constructed housing. Although vector control is the key preventive method, good hygiene practices in food preparation, transportation, storage and consumption are also recommended to reduce risk of parasite infection.	
Cysticercosis/ Taeniasis	Taeniosis/Cysticercosis is a parasitic disease that is caused by eating of infected under-cooked pork. The parasite develops into a tapeworm (taeniosis) in the gut of humans causing intestinal disorders but also the parasite can invade other organs (cysticercosis) including the nervous systems and cause neurological problems including epilepsy and can be fatal.	50 million people worldwide are affected cysticercosis causes an estimated 50 000 deaths.	0.50 Disability Adjusted Life years.	Treatment is with anti-epileptic treatments for neurological conditions and praziquantel and niclosamide for the tapeworm. Also confinement of pigs and increased food hygiene combined with improved sanitation prevent the spread of taeniosis/cysticercosis.	No elimination target has been set for taeniosis/ cysticercosis.	Only a small proportion of infected people receive appropriate treatment.	Prevention requires strict meat inspection regimens, health education, thorough cooking of pork, sound hygiene, and adequate water and sanitation by preventing pig access to human waste.	

Dengue	Classic Dengue: symptoms range from mild fever, to incapacitating high fever with severe headache, pain behind the eyes, muscle and joint pain, and rash. Severe Dengue: symptoms include severe abdominal pain, persistent vomiting, bleeding gums, vomiting blood, rapid breathing and fatigue.	Over 2.5 billion people – over 40% of the world's population – are now at risk from dengue. This WHO estimate is superseded by the Oxford University Spatial Ecology & Epidemiology group which puts approximately 3.9 billion at risk.	264 disability-adjusted life years per million population per year are lost.	There is no vaccine or specific medication for dengue fever. Patients should seek medical advice, rest and drink plenty of fluids. Paracetamol can be taken to bring down fever and reduce joint pains. At present, the only method to control or prevent the transmission of dengue virus is to combat vector mosquitoes. Treatment for severe dengue consists of medical care by physicians and nurses experienced with the effects and progression of the disease can save lives. Maintenance of the patient's body fluid volume is critical to severe dengue care.	The Global strategy for dengue prevention and control, 2012–2020 aims to address a 30-fold increase in global dengue incidence over the past 50 years. The specific objectives are to reduce mortality and morbidity from dengue by 2020 by at least 50% and 25% respectively (using 2010 as the baseline).	Only a small proportion of infected people receive appropriate treatment.	As the dengue virus-transmitting Aedes aegypti mosquitoes breed in man-made containers, vector control measures include covering, emptying, and frequent cleaning of domestic water storage containers, and applying appropriate insecticides to outdoor water storage containers.	Care for sick patients requires clean water at home and in healthcare facilities.
Human African trypanosomiasis (sleeping sickness)	HAT is caused by a parasite transmitted by the tsetse fly which invades the nervous system and causes mental deterioration and other neurologic problems and is fatal without treatment.	60 million people are at risk of being infected in 36 African countries.	0.56 Disability Adjusted Life Years[2].	Up until 2009, existing treatments for stage 2 of the disease were toxic or difficult to administer. In 2009, DNDi and its partners launched the first new treatment for HAT in 25 years.	The WHO Roadmap for Implementation sets a target of country elimination in 80% of affected foci by 2015.	Only a small proportion of infected people receive appropriate treatment.	WASH does not play a significant role in control of the disease. However, common risk areas for tsetse fly bites that transmit the parasite include water collection points in forests, and vegetation close to bathing and water collection sites along river banks.	Advanced disease makes water accessibility extremely difficult as affected individuals rely on assistance from others (often children who are prevented from going to school by taking care of their disabled relatives).

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Leishmaniases	The parasite that leads to infection is called Leishmania and is transmitted by sandflies. Leishmaniasis has several different forms; visceral leishmaniasis, (which is fatal without treatment) and cutaneous leishmaniasis are the most common causing disfigurement and stigma.	350 million people living at risk worldwide Leishmaniasis occurs in 98 countries worldwide Over 1 million new cases of cutaneous diseases annually; significant problems in Syria and Afghanistan due to civil unrest.	3.32 Disability Adjusted Life Years[2].	Diagnosis is difficult in visceral disease, existing treatments are difficult to administer, toxic, and costly Drug resistance is also an increasing problem. There is a great need to develop new treatments for this disease.	The WHO Roadmap for Implementation sets a target of Regional elimination for visceral Leishmaniasis on the Indian subcontinent by 2020.	Only a small proportion of infected people receive appropriate treatment.	Poor housing and sanitation conditions such as poor waste management and open sewerage may increase breeding and resting sites of sand flies, the vector that transmits the disease-causing protozoan parasite. Environmental management plays a part in vector control.	Limited access to water and sanitation can lead to poor cleanliness and care, which can contribute to the isolation and exclusion of affected persons. Clean water and hygiene at health facilities and homes for wound management.
Leprosy (Hansen disease)	The disease is caused by Mycobacterium leprae. The disease affects the skin and nerves and can lead to irreparable nerve damage, impairments and disabilities affecting hands, feet and eyes.	ILEP, the umbrella non-governmental federation for anti-leprosy organisations, estimates that leprosy is grossly under reported with several million cases worldwide currently remaining undetected. The number of new cases of leprosy reported during 2013 was 215,656 (WHO figures) from 105 countries. Sixteen countries account for 95 per cent of these cases. India accounts for 59 per cent and Brazil for 14 per cent. It should be noted that in 2010 a total of 141 countries reported a global total of 244 796 new cases of leprosy to the WHO, 36 fewer countries report in 2013. This reduction in countries reporting is one of the reasons why reported cases have reduced. Data on leprosy is incomplete.	There is ongoing discussion on how the figure for Disability Adjusted Life Years for leprosy should be calculated. Previous estimates are now recognised to severely under-estimate the impact of leprosy. It is estimated that over 3 million have permanent WHO Grade 2 (visible) disability as a result of late treatment. Comprehensive disability statistics are not available but ILEP recognise the need to ensure that residual morbidity is identified and addressed. Adjusted Life Years2 220,000 new cases in 2011. India, Brazil and Indonesia account for 83% of new cases in 2011 An estimated 2-3 million remain with WHO Grade 2 (visible) disability but comprehensive disability statistics are unreliable.	6 or 12 months Multidrug therapy (MDT) depending on classification of disease. Early diagnosis and treatment is the best prevention of disability. Prevention – Bacillus Calmette-Guérin (BCG) vaccine provides some protection and trials are also underway to roll out chemoprophylaxis using single dose rifampicin for close contacts. A leprosy vaccine has been developed and first phase clinical trials are due to commence in 2015.	WHO Global target of elimination as a public health problem (prevalence of less than one case per ten thousand population) was achieved by 2000. However, there are still countries with endemic pockets. The current WHO Global Strategy 2011-2015 and recommendation of the WHO Expert Committee (2010) set the key target as reduction of grade two disability rate per 100,000 population by 35 percent by 2015. 2013 data published by WHO revealed that the prevalence rate in 2013 remained the same as 2010 data indicating a lack of progress in reducing disability. The Bangkok Declaration calls for achieving a global target of reducing the occurrence of new cases with Grade II (visible) disability to less than one case per million population by 2020.	Around 15.5 million treated since the introduction of MDT in early 1980s although coverage with MDT for all new cases is still difficult in hard-to-reach populations in areas of conflict, nomadic populations and urban slums. Even once treated, many remain at risk of further disability, stigma and discrimination.	Although the cause of leprosy, a slow-growing bacillus (Mycobacterium leprae) is known, the mode of transmission has not been established; therefore there is no established WASH-related primary prevention strategy. As WASH contributes to more hygienic conditions and better health, and therefore a better immune status, improved WASH conditions may make communities and individuals less susceptible to leprosy.	Leprosy can lead to permanent damage to skin, nerves, limbs and eyes. Resulting disabilities make tasks such as carrying water over distance difficult. Wound management through self-care using clean water is needed to speed up wound healing and reduce disability. People with leprosy are subject to stigma and exclusion by the community, and can be excluded from water and sanitation facilities. Limited access to water and sanitation can lead to poor cleanliness and care, contributing to isolation and exclusion.

Lymphatic filariasis	Severe intermittent fever. Clinical manifestations include hydrocele (severe swelling of the scrotum) and lymphodema (swelling of the limbs, particularly legs).	1.4 billion people living at risk worldwide.	2.77 Disability Adjusted Life Years[2].	Annual preventive chemotherapy with either albendazole and diethylcarbamazine citrate (DEC) or albendazole and ivermectin in countries co-endemic for onchocerciasis for a minimum of 5 years. Morbidity management through hygiene of affected limbs and hydrocele surgery. Integrated vector control particularly in areas where Anopheles is the vector and malaria is co- endemic (bednet usage).	The WHO Roadmap for Implementation sets a target of elimination of lymphatic filariasis as a public health problem by 2020.	41.8% of people at risk currently receive treatment. 73 countries endemic. 5.6 billion people treated in 2013. MDA implemented in 60 countries of which 15 have stopped MDA and started surveillance; 22 have achieved 100% geographical coverage and 23 are conducting MDA but have not reached all endemic areas. MDA has not started in 13 countries considered as requiring preventive chemotherapy to eliminate LF.	Poorly constructed latrines facilitating breeding of the Culex mosquito vector, which transmits the microscopic disease-causing worms from person to person.	Severe forms of the disease include swelling of the limbs and, in men, of the scrotum, as well as thickening of the skin leading to disfigurement (Elephantiasis). All can lead to permanent disability. People with chronic LF disabilities need to maintain rigorous personal hygiene using large quantities of water and soap to prevent secondary infection. People with LF are often subject to stigma, leading to poverty and exclusion, and further challenges to accessing WASH.
Onchocerciasis (river blindness)	Caused by a parasitic worm that is spread by the bite of a black fly. It can cause blindness as well as debilitating skin conditions including intense itching and skin depigmentation.	More than 120 million people living at risk worldwide and an estimated 25 million infected.	0.49 Disability Adjusted Life Years[2].	Treatment of communities at risk of transmission (formerly hyper and meso endemic) by annual community directed treatment with ivermectin. For elimination there is a need to roll out treatment to areas of low endemicity formerly untreated.	The WHO Roadmap for Implementation sets a target of elimination of transmission using ivermectin by 2020 in selected African countries and in the endemic foci in Latin America by 2015. Elimination achieved in Equador and Colombia. Elimination of all transmission in Africa by 2025.	65.7% of people at risk of currently receive treatment.	The blackfly vector, which transmits filarial worms, breeds in fast-flowing rivers and streams. The main control measure is insecticide treatment of larval breeding sites. Water-flow manipulation has been practised in some countries for vector control purposes.	Chronic skin disease may lead to sores and wounds; clean water and hygiene are essential for good wound management, at health facility level and at home. Visually-impaired individuals rely on assistance from sighted people (often children who are prevented from going to school by taking care of disabled relatives).

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Podoconiosis	Long term exposure to irritant mineral particles in genetically susceptible people triggers an abnormal inflammatory reaction, impairing lower limb lymphatic function.	Estimates are still incomplete, but recent mapping suggests 80 million people living in areas conducive for podoconiosis worldwide.	N/A	Prevention of exposure to soil through use of footwear. Morbidity management through hygiene of affected limbs (requires access to water), bandaging and footwear.	No elimination target has been set by WHO yet. The International Podocniosis Initiative vision is 'a world free of podoconiosis in our lifetime'.	Only a small proportion of infected people receive appropriate treatment.	Both prevention and treatment require access to clean water for foot hygiene.	
Schistosomiasis	Disease is caused by repeated infection with schistosome parasites. Symptoms are due to the body's reaction to the parasite eggs. Infection in children can cause abdominal pain, haematuria, anaemia, stunted growth and reduced ability to learn, leading to severe damage of the liver and urogenital tract in advanced cases.	249 million people require treatment worldwide, at least 90% reside in Africa. 700 million people living in at risk areas.	3.31 Disability Adjusted Life Years[2].	Reducing disease through periodic, large-scale treatment of at-risk population groups, including school-aged children to entire communities living in highly endemic areas, with praziquantel (40 mg/kg). Controlling transmission through access to safe water, improved sanitation, hygiene education and snail control.	The current WHO Global Strategy for schistosomiasis is to control morbidity due to schistosomiasis by 2020; to eliminate schistosomiasis as a public health problem by 2025; to interrupt transmission in selected regions, and in selected countries in the African region by 2025.	16.9% of people at risk received treatment in 2012 (42.1 million).	Exposure occurs in infested freshwater during agricultural, domestic, occupational and recreational activities. Control measures include snail control in freshwater bodies; improved sanitation; increased access to safe water; hygiene education to promote behavioural change to reduce contamination of, and contact with, unsafe water.	
Soil-transmitted helminthiases	Infestations with 4 species of nematodes are collectively referred to as soil-transmitted helminthiases: Morbidity is related to the number of worms harboured. People with light infections usually have no symptoms. Heavier infections can cause a range of symptoms including intestinal manifestations (diarrhoea, abdominal pain), general malaise and weakness, and impaired cognitive and physical development. Hookworms cause chronic intestinal blood loss that can result in anaemia.	890 million people living at risk worldwide.	5.18 Disability Adjusted Life Years.	Preventative Chemotherapy with albendazole or mebendazole and improved water sanitation and hygiene.	The current WHO Global Strategy for soil-transmitted helminthiases from 2011-2020 is to control morbidity through the periodic treatment of at-risk people living in endemic areas. The global target is to regularly treat at least 75% of all school-age children at risk of illness from soil-transmitted helminths by 2020. Progress made by each country is measured against this target.	31% of pre-school and school-aged children at risk of currently receive treatment.	Improved sanitation, especially in schools, to eliminate contaminated faeces and urine from reaching surface water can reduce or eliminate transmission, by preventing worm eggs in faeces and urine from entering water. Some species can be transmitted through animal (cow, buffalo) urine or faeces, necessitating protection of freshwater from animals/animal waste contact.	

Trachoma	A bacterial infection that causes repeated conjunctivitis. Repeated infections can turn the eyelid inwards making the eyelashes scratch the surface of the eyeball (trichiasis). Prolonged scratching of the cornea by the eyelashes can lead to irreversible blindness. Trachoma is the world's leading infectious cause of blindness.	Approximately 232 million people live in trachoma-endemic districts (WER 2014).	0.33 Disability Adjusted Life Years[2]. (Global Burden of Disease Study 2010).	The WHO recommended SAFE strategy-Surgery of eyelids, Antibiotics to treat the community pool of infection, Facial cleanliness to reduce transmission and Environmental improvements to reduce the number of flies people come into contact with. The WHO recommends 2 antibiotics for trachoma control: oral azithromycin and tetracycline eye ointment.	The 2011 WHO Roadmap for Implementation sets a target of elimination trachoma as a public health problem by 2020.	24% of people at risk of currently receive treatment (WER 2014).	Facial cleanliness and environmental improvement are the preventive components of the SAFE strategy for trachoma elimination. Face washing removes the bacterial discharge from eyes and interrupts transmission by eye-seeking mosca sorbens flies, fingers and fomites. This requires access to water. Environmental improvement includes proper sanitation for disposal of excreta to reduce fly population.	Trachomatous Trichiasis (the severe form of the disease, in which surgery is needed) surgery for blinding trachoma requires clean water and hygienic conditions; visually-impaired individuals rely on assistance from sighted people (often children who are prevented from going to school by taking care of disabled relatives).

This report was authored with the support of the UK Coalition against Neglected Tropical Diseases. The Coalition is a collaborative effort by UK organisations that are actively engaged in NTD research and implementation and in advocating for effective and sustainable NTD control programmes.

UK COALITION AGAINST NEGLECTED TROPICAL DISEASES

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