

Protecting the neglected from disease: the role of gender, health equity and human rights in the fight against neglected tropical diseases

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List of abbreviations

WHO- World Health Organization
NTD- Neglected tropical disease
DALY- Disability-adjusted life-years
LF- Lymphatic filariasis
WASH- Water, sanitation and hygiene
HAT- Human African Trypanosomiasis

Preface

This work is the result of a collaboration between Polygeia, (University of Cambridge) and WHO TDR, who commissioned the project. The research team executed this project on a voluntary basis over a 9 months-period, with regular guidance provided by WHO mentors.

Polygeia is a non-partisan student-run think tank that aims to create collaborations between students and global health-focussed organisations. The aim of Polygeia is to foster a mutually beneficial partnership between mentor organisation and student teams, providing students with real-world experience in global health policy research while delivering tangible research outcomes for mentors.

The Department of Control of Neglected Tropical Diseases coordinates and supports policies and strategies to enhance global access to interventions for the prevention, control, elimination and eradication of neglected tropical diseases, including some zoonotic diseases. Consistent with World Health Assembly resolutions and in line with the new [WHO NTD Roadmap](#), the NTD department supports Member States to expand access to prevention, diagnosis, treatment and care interventions for all those in need.

TDR, the Special Programme for Research and Training in Tropical Diseases, is a global programme of scientific collaboration established in 1975. Its focus is to improve the health and well-being of people burdened by infectious diseases of poverty through research and innovation. TDR is based at the World Health Organization (WHO) and is sponsored by the United Nations Children's Fund (UNICEF), the United Nations Development Programme (UNDP), the World Bank and WHO.

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Executive Summary

Overview:

Poverty and inequality are both the starting point, and the ultimate outcome, for most neglected tropical diseases (NTDs). As a group of 20 diseases, NTDs are typified by their prevalence among the poor, excluded, and marginalised within society. In the absence of quality healthcare provision, many NTDs lead to long term disability, disfigurement, and stigma, which in turn act to reinforce the exclusion and poverty experienced by the afflicted. The path leading to illness is often determined by a widespread lack of access to formal education, timely healthcare, adequate living conditions, employment and nutrition. The reasons for such deprivation are complicated, but ultimately reduce to a persistence of inequalities in affected regions. These inequalities can manifest differently depending on the demographic being studied: gender, ethnicity, geographic location, level of formal education, can all determine the ease with which NTDs are transmitted, diagnosed or treated. Yet, regardless of contextual differences, NTDs continue to persist because individuals within endemic regions experience a healthcare system that is, either directly or indirectly, inequitable. The healthcare system referred to in this context is not confined to simply formal healthcare settings. Rather, it encompasses local healers, community healthcare professionals or volunteers, drug administration programmes, community mental health provision, the formal education system, and, in extension, even the infrastructure that exists to physically connect individuals to their healthcare provider. Failing to ensure parity across each of these components for every citizen equates to a discriminatory healthcare system which fails to recognise the individual's basic human right to "a standard of living adequate for the health and well-being of themselves and of their family, including food, clothing, housing and medical care and necessary social services" (Article 25- Universal Declaration of Human Rights). To ensure NTDs are managed in a way that is sustainable in the long term, the underlying societal inequalities which allow them to persist must be first understood.

Objectives:

This report aims to present the ways in which human rights, health inequity, and sex and gender inequality intersect with NTDs and, in turn, how the acknowledgement of this intersection can inform future healthcare policy. Accordingly, this report intends to offer recommendations on how WHO's NTD 2030 Roadmap can be used to tackle the inequalities that underlie NTDs.

Key findings and recommendations:

1. Human rights and NTDs

Human rights are not fulfilled when individuals are unable to access adequate working conditions, adequate living conditions, formal health education and clean water. Such conditions can also significantly increase the risk of contracting an NTD within endemic regions. Once afflicted, the stigma and disability that often accompanies NTD infection can in turn prevent the attainment of other basic human rights such as the right to formal education, work, and to live free from discrimination.

Key human rights-focussed recommendations:

1. Raise public awareness of the right to health.
2. Encourage policymakers to follow a rights-based approach to tackle NTDs.
3. Recognise, address and budget for the right to attain the best mental health.
4. Encourage governments to incorporate the right to health into their constitution.
5. Support and monitor claims to the right to health in court.
6. Encourage pharmaceutical companies to adopt human rights guidelines.
7. Identify duty holders currently using human rights as a framework.

2. Health inequity and NTDs

Given that NTDs predominantly affect individuals from a lower socioeconomic background, ensuring universal healthcare access is key to tackling NTD burden. However, this report identifies five main barriers that can prevent access to treatment. These are (i) the under-provisioning of health care systems, (ii) a mistrust of healthcare systems, (iii) a deficiency in community health knowledge, (iv) geographical barriers and (v) financial barriers.

Key health inequity-focussed recommendations:

1. Increase community trust in healthcare professionals.
2. Increase NTD-awareness amongst communities alongside treatment.
3. Ensure NTD interventions do not weaken other aspects of healthcare systems.
4. Tailor MDA delivery systems to the local region and to the disease being treated.
5. Collect and interpret data on NTD treatment programmes and MDA coverage at a local level.

3. Sex and gender inequality and NTDs

Gender-related differences in access to healthcare and MDA programmes, knowledge of sex-specific symptoms, awareness- raising on health and disease, perceived stigma and health-seeking behaviour are evident for neglected tropical diseases. In order to tackle NTDs while promoting gender and sex equity, these differences need to be addressed.

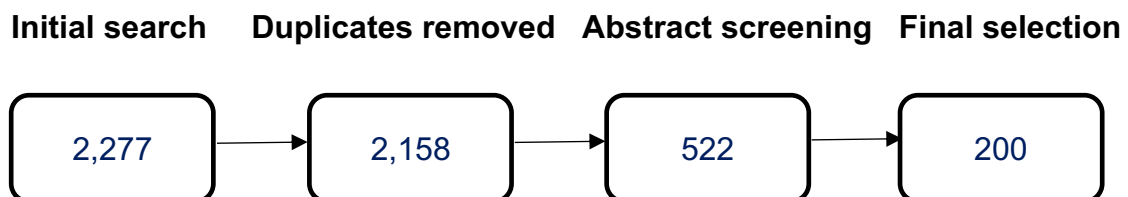
Key gender identity-focussed recommendations:

1. Publish sex-disaggregated data, gender-disaggregated data and intersectional gender analysis on NTDs and MDA programmes on a local level.
2. Research the effect of gender of healthcare workers in general and specifically community healthcare workers.
3. Tailor programmes to gender-specific factors and include women in design of programmes.
4. Pay particular attention to pregnant women when designing NTD programmes.
5. Address gender-related stigma and increase access to health information on NTDs.
6. Address power dynamics in households and empower women to be autonomous.

Methods

A systematic search was carried out to collect literature on neglected tropical disease as a general term, in combination with human rights, gender and sex inequity, and health inequity terms. Database-specific search strategies were applied to MEDLINE and EMBASE, both conducted with Ovid, as well as Global Health via EBSCO and the Cochrane Library. The individual searches can be found in *appendix 1*, which were discussed with Veronica Phillips, a trained librarian at the University of Cambridge. It was decided to not expand on the EMBASE subheadings, as the amount of results were disproportional to other databases and included a substantial amount of papers that were not relevant to our search question. The searches in all databases were conducted in August 2020 and were collected in the bibliographic database Mendeley.

Searches in the 4 databases identified a total of 2,277 citations: 733 for EMBASE, 717 for MEDLINE, 816 for Global Health, and 11 for Cochrane Library (including 4 reviews and 7 clinical trials). After duplicates were removed, a total of 2,158 citations were divided among the authors for title and abstract screening. Authors screened the references based on whether the title and/or abstract mentioned one or more neglected tropical diseases, or the NTD term in general, and at least one mention of a term relating to human rights, healthy inequity or gender/sex. Of the 2,158 unique citations, 522 papers were selected for full-text evaluation and were allocated to individual authors. A total of 200 papers were selected after full-text evaluation, and information including first author, year of publishing, title, NTDs reported on (incl. NTDs in general), country or area if specified, inequalities and inequities discussed, author affiliations subdivided into government, NGO or academic and main points of the paper, was extracted. Based on this information, papers were grouped into three groups: gender-specific papers (60 papers), citations focusing on health inequities (97 papers) and papers discussing human rights related to neglected tropical diseases (43 papers). Additional references, originally not included in the search results, were identified during full-text selection. Individual researchers focused on sections of this manuscript as indicated in the relevant sections and KMLM supported the project as editor and as writer of the remaining sections.



General limitations

The literature search methodology identified relevant papers by searching general terms associated with NTDs, rather than terms specific to each of the 20 NTDs. This decision was made to limit the amount of search results to a level that was manageable within the available timeframe for this project. Consequently, relevant disease-specific studies may have been missed, and future work should expand on the search terms to incorporate NTD-specific papers. This is particularly necessary to understanding whether a bias currently exists in the literature in terms of the relative coverage of each individual NTD. Indeed, within this search certain diseases such as Human African Trypanosomiasis, Lymphatic Filariasis, soil-transmitted helminths, and Chagas disease were more frequently mentioned than others. However, the validity of this bias cannot be relied upon without a more comprehensive search being carried out. Similarly, a more expanded search would reveal the existence, or absence thereof, of a bias of literature coverage between human rights, health inequity and gender/sex inequality. Additionally, only literature written in English was included, meaning some reports that were potentially relevant were excluded.

The identified literature on human rights and health inequity related to NTDs seemed to be less in-depth compared to the studies related to gender inequity in particular, potentially revealing a lack of specialized studies in these broad fields. As a consequence, the recommendations for these sections are broad recommendations that could be made more in-depth if specific studies on human rights and health inequity related to NTDs become more available. Further limitations, specific to human rights, health inequity or gender inequity are described later in the respective sections. Further limitations, specific to human rights, inequalities or gender inequity are described later in the respective sections.

Introduction:

There are currently over 1 billion people, living in 146 countries or territories, suffering from NTDs, with those living in poor communities with little social or political capital disproportionately affected (WHO, 2011). At least 100 countries are endemic for two or more NTDs and 30 countries are endemic for six or more (Sun & Amon, 2018). Such prevalence has been estimated to result in 57 million disability-adjusted life-years (DALYs) being lost every year to NTDs (Sun & Amon, 2018). However, NTDs are often considered a low priority relative to more “deadly” diseases because, although many inflicted with NTDs suffer from long term disabilities, diseases such as HIV/AIDS and malaria have a higher relative death rate. For example, DALYs due to NTDs are constituted for 56% by years lost due to disability (YLD) and for 44% by years of life lost (YLL). This compares to 7% of YLD and 93% of YLL for malaria. However, NTDs inflict a substantial economic and social burden on individuals and society owing to lost productivity and the high costs associated with long term care. This can in turn contribute to an entrenched cycle of poverty and ill-health for neglected populations (Fitzpatrick *et al.*, 2017).

Sufferers of NTDs can be burdened by the direct costs associated with the financing of diagnosis and treatment, both of which can be significant. In Ghana, the cost of care per patient with Buruli ulcer in a household in the poorest earning quartile was reported as 242% of their annual earnings (Xu *et al.*, 2003). Similarly, the average family in Thailand caring for a child with dengue can pay up to US\$74 for treatment, more than an average monthly salary (Clark *et al.*, 2005). For some, costly healthcare provision is simply not an affordable option, leading to individuals deferring treatment, sometimes until it is too late. In Sri Lanka, the poorest patients with lymphatic filariasis were reported to be driven into a ‘medical poverty trap’, in which they delayed engaging with the healthcare system, thereby allowing the symptoms to progress, making eventual treatment difficult or impossible (Whitehead, Dahlgren, & Evans, 2001).

The pressure to pay for medical bills can also be compounded by the indirect cost of experiencing a reduced ability to work, and, therefore reduced wages. In Bangladesh, a study of the productivity of tea pluckers showed a negative correlation between worker productivity and the intensity of infection of three worm infections (*Ascaris lumbricoides*, *Trichuris trichiura*, and hookworms) (Gilgen, Mascie-Taylor, & Rosetta, 2001). Similarly, in Egypt, workers with schistosomiasis benefited from increased productivity if they could access early detection and treatment (Torgerson, 2003). NTD infections can also impact educational productivity of afflicted children. Infections of children with soil-transmitted helminths and schistosomes are associated with reduced formal education levels, along with reduced school performance and attendance (Hotez, Fenwick, Savioli, & Molyneux, 2009; Miguel & Kremer, 2004; Sakti *et al.*, 1999). This in turn can impact a child’s prospects and, therefore, earnings in the long term. Indeed, a study based in the Southern states of the USA found a substantial increase in literacy levels and income when hookworm infection levels were reduced in affected areas (Bleakley, 2007). Accordingly, as NTDs continue to propagate, millions of individuals are at risk of becoming trapped within a cycle of ill health and poverty.

Although NTDs are far from homogenous, many of them share characteristics that make them difficult to eradicate. These include the fact that many NTDs have limited visibility due to being restricted to specific geographical areas, affecting the most marginalised communities of society. Similarly, they very rarely spread to higher-income countries. As a result, NTDs generally remain a low priority for mainstream research and funding bodies: there is generally a minimal market incentive to develop medicines and vaccines for impoverished communities.

Despite this, many NTDs also share attributes that make them relatively easy to treat. NTDs are a disease of poverty, meaning that basic measures that act to alleviate such poverty can in many cases also alleviate the burden of NTDs. This includes measures such as ensuring access to basic public healthcare systems, access to formal education and to clean water and sanitation. Indeed, interventions promoting clean water and adequate sanitation could support the eradication of 17 of the 20 NTDs (NTD 2030 Roadmap, WHO, 2020). Provisions to ensure drinking water is separated from faeces and urine, which can contain worm eggs, can reduce the transmission of schistosomiasis and soil-transmitted helminthiasis. Improved water management can also help reduce proliferation of mosquito populations which act as vectors of lymphatic filariasis, dengue and chikungunya. Furthermore, improving infrastructure by building vector-free housing that supports safe storage of water; building drains that do not support mosquito breeding; and building houses that are easily cooled can potentially help support the management of 13 of the diseases (NTD 2030 Roadmap, WHO, 2020). NTDs treatment interventions are also relatively cost-effective, returning on average US\$25 for every US\$1 invested into preventative chemotherapy (Fitzpatrick *et al.*, 2017). This demonstrates that interventions have the potential to be effective when supported by the right level of targeted and informed investment.

Progress has been made towards alleviating the global burden of NTDs. Currently 500 million fewer people require interventions against NTDs than in 2010, and 40 countries, territories and areas have eliminated at least one disease (WHO roadmap 2030). In 2019, China and Yemen declared that trachoma and elephantiasis were no longer public health problems, respectively. In 2020, Myanmar and Togo made similar statements for trachoma and Human African trypanosomiasis, respectively. Progress over the past decade has predominantly been achieved by countries committing to reaching more people with NTD interventions, the pharmaceutical industry donating billions of treatments for NTDs, and philanthropists providing generous funding to implement NTD interventions (Sodahlon *et al.*, 2020). An emphasis on expanded disease mapping has also led to the number of people identified as being at risk from NTDs being increased from 1.5 billion (2016) to 1.75 (2018) (Engels & Zhou, 2020). Nonetheless, NTDs continue to remain prevalent in some areas, meaning interventions must go further if full eradication is to be achieved.

Poverty and inequality are both symptoms and causes of NTDs. Thus, their prevalence is often an indicator of the extent to which universal health care has or, in most instances, has not been achieved within endemic areas. Consequently, NTDs intersect with axes of inequity, such as ethnicity, socioeconomic status, occupational status, age, gender, sex and disability. Indeed, coverage of NTD interventions has been proposed as an “equity” tracer within the 2030 Sustainable Development Goals (SDGs) (Fitzpatrick & Engels, 2016). Social and economic positioning within society dictates the vulnerability of an individual to being infected with an NTD, while gender

roles, geography, socioeconomic status, among others, can determine the likelihood of an NTD being diagnosed and treated. Such cases continue to persist despite the universally recognised human right to health: “the right to the enjoyment of a variety of facilities, goods and services and conditions necessary for the realisation of the highest attainable standard of health” (CESCR, General Comment No. 14, 2000: para. 9). People afflicted by NTDs are in turn vulnerable to violations of their human rights, including the rights to life, non-discrimination, privacy, work, education, and to enjoy the benefits of scientific progress. Thus, continues the cycle of poverty, powerlessness, and discrimination.

A healthcare system which fails to engage with all individuals equally is discriminatory. Indeed, the Committee on Economic, Social and Cultural Rights (CESCR) states that non-discrimination and equal treatment are among the most critical components of the right to health (CESCR, General Comment No. 14, 2000: paras 18–19). Given the relationship between NTDs and poverty, for NTDs to be eradicated in a meaningful and sustainable way, the ways in which existing inequity and poverty continues to allow NTDs to persist must be understood and rectified. To this end, this report will present an overview of the current literature that addresses the ways in which NTDs intersect with social and economic inequalities and, in extension, human rights abuses. Healthcare inequity, whether as a result of gender, sex, geography, ethnicity, and beyond, is demonstrative of a failure to recognise the individual’s right to non-discriminatory healthcare provision. For this reason, the report will begin by introducing the ways in which the persistence of NTDs is a human rights issue. The report will subsequently explore specific socioeconomic factors that can lead to discriminatory healthcare provision such as financial, geographic and educational factors. Specific attention will be drawn to the ways in which NTDs intersect with gender roles, this being a long-ignored risk factor for some NTDs. By drawing on the literature, this report will also make recommendations as to how future healthcare programmes can effectively acknowledge and tackle the role that socioeconomic inequities play in NTD prevalence. Finally, the ways in which these recommendations can complement the current 2030 NTD Roadmap will be discussed.

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Human rights and neglected tropical diseases

Delphine M. Depierreux

Summary

There is a correlation between NTD prevalence and the violation of human rights (Hotez & Pecoul 2010). Identifying and addressing which human rights are undermined as either a cause or a consequence of NTDs, and who, in turn, is accountable for such failures, is key to designing efficient interventions and policies. Hence, this section presents an overview of the literature reporting on the link between human rights and NTDs, before outlining recommendations to tackle NTDs from a human rights perspective.

Our search revealed how the non-provision of several human rights, such as the right to a formal education, the right to adequate working conditions and a basic standard of living, and the right to access medicines and enjoy scientific progress, can contribute to NTDs prevalence. Our search also highlighted how NTDs can lead to the denial of the right to non-stigmatisation and non-discrimination, which can impact individuals' mental health and also impede the right to a formal education and work. Moreover, our search highlighted how the non-provision of a human right can in turn impact the fulfilment of others, leading to a vicious cycle that aggravates the risk of NTDs.

Whilst the recommendations stemming from published articles mostly relate to the provision of underlying determinants of good health, useful lessons can be drawn from our search and framed into human rights specific recommendations. Accordingly, we recommend promoting awareness of the right to health; encouraging rights-based policy; addressing the right to non-stigmatisation within NTD interventions; advocating for the right to health to be incorporated into national constitutions; encouraging pharmaceutical companies to adopt human-rights guidelines; and supporting claims to the right to health in court.

Since the right to health is closely related to many other human rights, the advancement of one right typically leads to the advancement of others. Hence, a rights-based approach to tackling NTDs has the potential to be a platform that not only improves NTD burden, but that also globally reduces deprivation of other human rights.

Introduction

The right to health was first expressed in the WHO constitution in 1946, as follows: *“Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition”*.

Importantly, the right to health is different than a guarantee to be healthy, which is influenced by factors that are beyond the control of a government. Hence, the right to health rather refers to a guarantee of the enjoyment of services, facilities, goods and conditions that are necessary to attain the highest standard of physical and mental health within a given context.

The right to health is recognised by multiple treaties¹. Such international bodies clarify the requirements for the right to health be fulfilled: the state must promote all aspects of environmental and industrial hygiene; prevent, treat and control epidemics; ensure the provision of medical services in the event of sickness; ensure that health care is accessible (physically, economically, as well as without discrimination), acceptable (religiously, culturally, socially) and of a good quality. Moreover, the right to health is related to, and dependent on, several other human rights such as the right to food, water, adequate standard of living, non-discrimination, education, work, and the enjoyment of scientific progress. Hence, the right to health not only includes the provision of appropriate healthcare, but also of health determinants.

Significantly, every country has signed at least one international human rights agreement that grants the right to health to their nationals (Kinney 2002), and more than 100 countries have recognised the right to health in their national constitution (Hogerzeil *et al.* 2006). In practice, this means that all governments must have an obligation to take all measures possible to guarantee the right to health to their nationals. A state is legally obligated to protect, respect and fulfil the right to health, without discrimination, and to take concrete steps towards its realisation, with emphasis on vulnerable and marginal groups. If a government does not respect or engage with the realisation of the right to health, it can be punished by international courts and obliged to remedy to it. Nonetheless, treaties also recognise that low-income countries have limited capacities and, therefore, outlines incremental steps that should be taken towards the realisation of the right to health.

In the context of NTDs, a link between NTD prevalence and the violation of human rights has been identified (Hotez & Pecoul 2010). There are two main points of intersection between human rights and NTDs. The first is where the non-fulfilment of human rights leads to an individual or groups becoming more vulnerable to NTDs. The second is when those afflicted with NTDs are deprived of some of their human rights. NTD burden is more likely to be high in areas where access to formal education,

¹ such as the European Social Charter, the International Covenant on Economic, Social and Cultural Rights (ICESCR), the Convention of the Elimination of all Forms of Discrimination against Women, the International Convention on Protection of the Rights of all Migrant Workers and Member of their Families, the African Charter on Human and People’s Rights, the International Convention on The Rights of the Child.

inclusion in the work market, gender-role or sex equity, racial non-discrimination is not guaranteed.

Generally, sufferers of NTDs are politically and economically underrepresented in society. This means that fewer opportunities exist for them to advocate for their rights. Therefore, designing and implementing human-rights based policies and interventions to tackle NTDs is valuable for protecting the human rights of NTDs sufferers generally. The right to health can be used as a framework to shape national laws and health policies. Typically, a rights-based approach to NTDs involves designing and implementing interventions and policies that have been guided by human rights principles. Generally, these interventions will be implemented without discrimination, and will encourage community participation, provide accountability and pay greatest attention to the most vulnerable. Importantly, they will emphasise the State's obligations to honour the right to health. However, while the primary duty bearer is the State government, accountability also extends to businesses, donors, international organisations, and non-governmental organisations. Since right-based advocacy provides accountability, it can lead to greater political commitment and results in more sustainable NTD eradication programmes.

Failing to fulfil human rights contributes to the NTD burden

The right to education

As outlined in article 13 of the ICESR², individuals have the right to primary and secondary formal education. A failure for this right to be recognised can lead to an inability of individuals to recognise early symptoms of ill-health or disease. Indeed, misconceptions surrounding NTDs and their symptoms are a factor contributing to their transmission (Shahvisi *et al.* 2018). Without a sufficient understanding of NTDs causes and symptoms, individuals may turn to local healers or rely on alternative medical beliefs to treat their illnesses. This can in turn lead to a delay in proper diagnosis and treatment of NTDs. **In Ghana, a study reported that 53% of individuals did not know the cause of Buruli ulcer and 71% indicated that they would seek treatment first from herbalists. Only as a last resort, would they refer themselves to hospital (Renzaho *et al.* 2007).** In West Africa, low literacy levels correlate with the medical choices of individuals, while also predicting an individual's willingness to conform to formalised medical advice (Ekeigwe 2019). In South Sudan, a lower level of formal education was correlated with a mistaken knowledge of African trypanosomiasis treatability. Moreover, prevalence and belief in myths and hearsay negatively influenced health-seeking behaviour (Bukachi *et al.* 2018).

Beyond this, a lack of health-related education can also lead to discrimination and stigmatisation. Abdulmalik *et al.* (2018) report that in Nigeria there is a common belief that "*lymphatic filariasis is a spiritually inflicted illness resulting from the individual walk on a charm placed on the ground by their enemies*". Thus, other communities members wish to keep their distance from the affected individual to avoid being

² primary and secondary education be available and accessible to all by appropriate means.

affected by the “charm” (Abdulmalik *et al.* 2018). This leads to discrimination towards the afflicted individual, which in turn has an impact on their mental health.

The right to a formal education is not only crucial to ensuring individuals are aware of NTD symptoms and effective treatments, but the lack of a formal education can also lead to fewer job opportunities, in turn leading to an increased chance of experiencing poverty. As poverty is a contributing factor to NTD vulnerability, this can lead to a vicious cycle that aggravates the risk of NTDs.

Together, these examples demonstrate that insufficient or inadequate level of formal education can be a contributing factor to NTD susceptibility and health outcomes. Interventions should therefore aim to improve health-related education in areas where NTDs prevalence is high. Several methods can be used to spread health-related information, and local populations should be involved in the choice to spread such information. Indeed, a study reported that radio was the most effective and preferred way to receive such information in South Sudan (Bukachi *et al.* 2018). Different methods of engagement will be appropriate for different areas and communities, and a tailored, nuanced approach should be taken over a “one size fits all” educational programme.

The right to safe working conditions and a basic living standard

The non-fulfilment of the right to satisfactory working conditions (as Article 7b of ICESCR and Article 15 of the African Charter on Human and Peoples’ Rights), can contribute to NTDs prevalence. For example, **it is documented that a lack of inappropriate footwear can lead to podoconiosis development through long-term exposure to irritant soils (Shahvisi *et al.* 2018)**. Once podoconiosis has developed, standard footwear becomes inappropriate because of the larger foot size and shape, leaving the patients with bespoke shoes as only option. Such footwear is often stigmatised within the community (Ayode *et al.* 2016). Similarly, the failure to grant the right to an adequate basic standard of living (article 11 of the ICESCR³ and Article 25 of the Universal Declaration of Human Rights⁴) is linked to higher NTDs prevalence. Lack of access to potable water, sanitation (particularly excrement management), waste disposal, animal control, or proper housing have been reported to increase transmission of NTDs (Yamey, 2002). For example, **a study conducted in Brazil, reported that the individuals most affected by hookworms were children who walked barefoot playing football in muddy streets and walking along footpaths that had been flooded with sewage water during the rainy season**. These children typically live in large households, with poor housing conditions and low income (Lesshafft *et al.* 2012). Therefore, by improving the basic standard conditions of living and the conditions of the public space, and thereby fulfilling the right to a basic standard of living, the spread of NTDs can be reduced.

³ Right of everyone to an adequate standard of living for himself and his family, including adequate food, clothing and housing.

⁴ Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services”.

Access to medicine and the right to enjoy the benefits of scientific progress

The right to access quality healthcare physically, economically and without discrimination, is described in ICESCR⁵. Problems accessing healthcare are prevalent in many countries where NTDs are endemic.

Case study: Bolivia (Eid *et al.*, 2019)

Eid *et al.* (2019) report that in Bolivia, barriers to accessing healthcare, resulting from the government's failure to take a rights-based approach, are the most significant factor that prevents individuals from receiving adequate diagnosis and treatment for leishmaniasis. Indeed, cultural factors such as the preferential use of traditional medicines were found to be only secondary. For example, the presence of the parasite causing leishmania must be confirmed before treatment is delivered because of the risks associated with the drugs. However, the health facilities that can perform these tests, and the department offices delivering the treatment, are located in peri-urban areas which are far from leishmania-endemic zones. The long-distance, the poor road conditions and the unsafe mean of travelling are barriers to seek diagnosis and treatment. Moreover, the economic cost associated with the transport, lodging, food, and the lost time at work are additional limiting factors. Thus, diagnosis and treatment are often unavailable for the population at risk of leishmania. Moreover, the quality of the healthcare system is not met since some physicians lack the experience to recognise the disease, which in turns leads to loss of trust in Western medicine and the Bolivian healthcare system (Eid *et al.*, 2019). Overall, this case demonstrates how the Bolivian state has failed to ensure the right to health by failing to recognise the right to a physically accessible and high standard healthcare service.

An issue frequently reported in the context of NTDs in low-income countries is a drug-manufacturing problem which limits their access. Ekeigwe *et al.* (2019) report that in West Africa, drug development and manufacturing is almost non-existent, while the distribution of medicine is insufficiently regulated. Inauthentic and low-quality medicines enter the supply chain, making it difficult for the poorest to access drugs that meet the required quality standard. Ekeigwe *et al.* (2019) identifies factors contributing to this problem: i) a government that does not provide incentives to promote local manufacture of medicines and investment in R&D, ii) a government poorly enforcing laws against falsified medicine smuggling, iii) a lack of infrastructure such as transportation, communication, and therefore a reduced capacity to make profits from manufacturing drugs, iv) a brain-drain effect responsible for the skewed distribution of training and qualified healthcare providers towards urban areas where the disease burden is not the highest (Ekeigwe, 2019).

⁵ states are required to ensure that health care is available, accessible (physically, economically, and informationally, as well as without discrimination), of an acceptable ethical standard and with due regard to local cultural needs, and of good quality.

Case study: Sub-Saharan Africa (Chippaux & Habib, 2015)

Chippaux & Habib (2015) report that in Sub-Saharan Africa (SSA), there is poor access to quality snake antivenom. The main reason for this is the absence of local manufacturing of anti-venoms, at the exception of South Africa. Other factors such as faulty communications, lack of transport vehicles or poor road conditions make anti-venom distribution difficult and expensive. Moreover, when there are some antivenoms available in SSA, their quality is often poor, and their efficacy has not been rigorously tested in clinical trials (Chippaux & Habib 2015). Besides the availability of quality anti-venom itself, another issue is that healthcare providers in rural areas lack the resources, and personnel are often not trained to choose the appropriate antivenoms. Generally, governments in SSA do not provide the necessary financial support for antivenoms. Chippaux et al. (2019) describe a plan of action to improve access to antivenoms in SSA. Their recommendations focus on the development of antivenom manufacture in SSA by implementing the transfer of technical knowledge (maintenance of snake farms, venom milking and traceability, plasma treatment, purification and lyophilization of antibodies). They proposed that these actions should be financed by international, regional and local funding and compensated by interest on the sale of antivenoms. The governments should be responsible for finding local support from international donors or private companies but should also invest themselves to ensure the long-term sustainability of the project. For example, governments could offer land without charging, pay salaries, grant subsidies, reduce taxes and guarantee a minimum order of antivenoms (Chippaux *et al.* 2019). Some trials are currently ongoing in Burkina Faso, Cameroon, Côte d'Ivoire and Togo, where local governments are supporting 50-95% of antivenom costs (Chippaux *et al.* 2016) and will be useful resources to guide the future interventions aimed at reducing snakebite burden.

Human rights violated in the context of conflicts and political instability

There is a body of evidence demonstrating an association between the prevalence of NTDs and the deprivation of human rights in areas with conflicts. In 1996, during the civil war in the Democratic Republic of Congo, African trypanosomiasis re-emerged. This was attributed to corruption and violence related to treatment attainment, which subsequently led to a delay in seeking medical care and enhanced disease transmission (Ekwanzala *et al.* 1996). Similarly, in 2003, during civil conflicts in Somalia, visceral leishmaniasis emerged, which was partially linked to the conflict repercussion on food insecurity (Marlet *et al.* 2003). In Angola, DRC and South Sudan, onchocerciasis surveillance is poor which impairs interventions implantation and in Liberia and Côte d'Ivoire programmes against onchocerciasis even stopped as a consequence of the instability caused by conflicts (Burnham & Mebrahtu 2004). Moreover, in Burma, which is ruled by the military and is notorious for ignoring human rights, lymphatic filariasis-burden is high. This in part stems from the government neglect of public health where **only 3% of national expenditures are committed to health while 40% is committed to the military sector (Beyrer *et al.* 2007)**. Moreover, there are no incentives of the government to implement MDAs, there is weak medical infrastructure, frequent mass population displacement and medical staff are unable to deliver medical aid and supplies.

Beyrer *et al.* (2007) report that Colombian conflict zones present high prevalence of Chagas Disease, leishmaniasis and yellow fever. With conflicts, the budget for military expenses increased while public health budget has been reduced, the conflict has led to population displacement and research, access to prevention, diagnosis and treatment have been impaired. The civil war has driven migrants from endemic rural areas into cities. Individuals are not tested, since the only opportunity of getting a test is to donate blood which is uncommon practice in Colombia (<1% of the population). However, due to the adverse effects of Chagas disease treatment, a diagnosis is required for providing the treatment. Moreover, the vector-control programme has been interrupted by violence and the access to diagnosis and treatment is rendered complicated by the way the government is organising distribution.

Together, these examples demonstrate how conflicts can lead to a breakdown of community health infrastructures, thereby limiting the access to healthcare. Typically, conflicts result in a reduced budget for public health interventions, population displacement from NTDs endemic zones but also limited surveillance, prevention treatment and vector control. Nonetheless, military forces interrupting civilians from accessing medical treatment is a violation of Article 23 of the Geneva Convention of 1949⁶. Such cases highlight the importance of NTD surveillance and research within war zones, as it allows international agencies and law groups to make informed decisions to provide aid. They also highlight that human rights instruments have been successfully leveraged to make treatment available and stress that in a warzone or conflict areas, the knowledge that access to healthcare is a right and is legally guaranteed can have a positive impact on the provision of care.

How can NTDs have an impact on the provision of human rights?

Stigmatisation and discrimination

Discrimination and social stigma are both causes and consequences of NTDs. The right to protection from discrimination recognises that stigma has an impact on the social and economic opportunities of individuals. However, unlike discrimination, stigma is not a legal concept. Stigma can be defined as “a social process, characterised by exclusion, rejection, blame or devaluation that result from experience, perception or reasonable anticipation of an adverse social judgment about a person or group” (Weiss *et al.* 2006). There are different types of stigma: enacted stigma corresponds to a situation where the individual is discriminated or socially excluded by the community (e.g: avoidance, disrespect, name-calling, ridiculing, abuse, exclusion), the anticipated stigma corresponds to the anticipation of the enacted stigma and the internalised stigma (e.g: embarrassment, shame and inferiority, and reduced dignity) is the result of negative stereotypes and attitudes, leading to the self-exclusion of social contacts (Weiss 2008).

⁶ Each High Contracting Party shall allow the free passage of all consignments of medical and hospital stores intended only for civilians of another High Contracting Party, even if the latter is its adversary

In the context of NTD, stigma typically consists of differential treatment of affected individuals at social events, isolation from the community, limited marriage prospects, reduced access to education, and limited job opportunities (Shahvisi *et al.* 2018). For example, Sun *et al.* (2018) report that physical deformities resulting from lymphatic filariasis, Buruli ulcer and yaws, can affect an individual's ability to work, to marry, and to care for their family and also lead to social exclusion. Similarly, Renzhaho *et al.* (2007) report how NTD-related stigma can directly impact individual rights. **In Ghana, more than a third of the interviewed individuals declared that they would not accept a leader suffering from Buruli ulcer, 40% stated that they would not let their children play with a Buruli ulcer victim and 7% believed that Buruli infected individuals should be locked up in a room.** This demonstrates that NTDs are associated with enacted stigma and discrimination. In their systematic review Hofstraat & van Brakel (2016) report widespread stigma related to lymphatic filariasis, podoconiosis, Buruli Ulcer, onchocerciasis, Schistosomiasis, leishmaniasis and leprosy. Moreover, less evident but still significant, stigma was reported for Chagas diseases, African trypanosomiasis, trachoma and soil-transmitted helminthiasis, suggesting that most NTDs lead to some forms of stigma and discrimination.

The three types of stigma were often reported and typically stemmed from fear of contagion, appearance due to disfigurement, misconceptions such as concerns regarding the hereditary aspect of the disease, traditional belief such as a curse, but also arise from the inability of the affected individual to reproduce, have sexual relationships and from being an economic burden to their family because of the treatment cost and the missed earnings of their reduced ability to work. Importantly, stigma can enhance the spread of NTDs as patients may reject diagnosis, delay treatment-seeking or hide the disease. This can lead to both worsening personal health and an extended period in which transmission of the diseases can occur, or the source of a disease going unaddressed within a community. Furthermore, healthcare staff can stigmatise the patients by fear of contracting the disease, which can impact the quality of diagnosis and treatment for NTDs (Alonso & Alvar 2010). In their study, Shrinivas *et al.* (2018) develop a scale to measure the attitudes of health care staff towards leprosy patients. Such a tool could be useful for gaining insight into attitudes of health care providers and be used to design appropriate programmes aimed at improving positive attitudes of medical staff towards NTDs patients. When designing interventions, it is also important to consider that NTD-related stigma may be worse for certain groups, such as women who are reported to suffer more than men from disfiguring conditions because of their impact of marriage prospect (Coreil *et al.* 1998). Van't Noordene and colleagues also report that stigma extends to family members of individuals suffering from NTDs and that divorce or difficulties to marry affect both the patient and their family members (van 't Noordende *et al.* 2020), which emphasizes the need to take into account not only the sufferers but also their families when designing interventions aimed at tackling NTDs.

International treaties guarantee that human rights are enjoyed without discrimination of any kind such as defined for example in ICESCR⁷. However, this right is often not

⁷ discrimination of any kind based on race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status such as disability, age,

granted to individuals suffering from NTDs. Hunt *et al.* (2007) report that the poor and marginalised have the highest burden of NTDs. This vulnerability is often heightened by gender-, sex- or race-based discrimination. For example, women often lack ownership of resources, which leads to impaired capacities to seek treatment for NTDs (Hunt *et al.* 2007). Similarly, women are often victims of misconceptions surrounding NTD such as the impact of NTD on their reproductive health and putative transmission to their offspring in a way that men are not (Litt *et al.* 2012). Discrimination also extends to access to diagnosis and treatment for certain marginalised groups. **For example, Coulborn *et al.* (2018) report that mobile workers in Ethiopia are more vulnerable than non-mobile workers because of insufficient familial support or as a result of transitory lifestyle or a lower socioeconomic class.** The decision of mobile workers to seek care is typically associated with a loss of income and their illness is often not diagnosed or treated properly due to the visits with different healthcare providers (Coulborn *et al.* 2018a).

Discrimination towards NTDs sufferers can sometimes arise from national laws. Cruz *et al.* (2018) reports that there are laws in more than 20 countries that give different rights to leprosy sufferers and which relate to topics such as segregation, marriage, employment, housing, voting rights or immigration (Cruz, 2018). For example, in Japan, in 1953, leprosy patients were required by law to isolate in distant mountains or on islands. A court ruled in 2001 that the Japanese state had violated human rights by forcing leprosy patients into isolation (Hunt *et al.* 2007).

Case study: The Dominican Republic (Key *et al.*, 2015)

Keys *et al.* (2018) reported that in the Dominican Republic, lymphatic filariasis occurs mainly in Bateyes, a home for Haitian migrant labourers. In 2003, a law called Sentanica, stripped Haitian-descendant Dominicans of their citizenship by reinterpreting a law that had been in effect since 1929. This violated fundamental human rights of Haitians who are now unable to register a child at birth, get health insurance, enrol for education, and present claims in court. This had led to their legal economic and societal marginalisation and discrimination. Despite these difficulties, the Dominican Republic ran a programme for the elimination of lymphatic filariasis which succeeded in partially counteracting the discrimination and social exclusion resulting from the sentanica by providing non-discriminatory access to testing and treatment to all (Keys *et al.* 2018). The programme has been positively perceived by the population and suggests that NTD programmes can also be a platform for improving human rights.

Historically, few cases related to NTDs discrimination have been brought to court. However, one case involved the Inter-American Court of Human Rights declaring that Paraguay violated an indigenous community's rights to life and non-discrimination when it forced the community to live on uninhabitable land with a high risk of

marital and family status, sexual orientation and gender identity, health status, place of residence, economic and social situation.

contracting Chagas disease. As a result, Paraguay was ordered to improve medical facilities, parasitic disease control programme for this community and the government had to compensate families of the individuals who died from the living conditions that were imposed on them (Cruz, 2018). Similarly, in Argentina, protection orders were issued by the Supreme Court of Justice for an indigenous community whose rights to life and health had been violated by national and provincial governments (Cruz, 2018). Together, this demonstrates that a right-based approach allows for accountability and can be used as a legal platform to enforce the state to take action to tackle NTDs in a non-discriminatory fashion.

Despite existing stigma, some communities in Ghana report a high rate of social acceptance of individuals suffering from NTDs such as Buruli ulcer (Renzaho *et al.* 2007). Similarly, in South Sudan, 71% of individuals interviewed said they would offer social support to patients with African trypanosomiasis (Bukachi *et al.* 2018). A literature review on leprosy indicated that provision of information, counselling and coping skills development programmes are particularly worthwhile (van 't Noordende *et al.* 2020). In their systematic literature review, Hofstradt *et al.* (2016) report that stigma associated with different NTDs all show strong similarities in terms of their origins, forms and consequences, which suggests that a joint approach to reduce their burden is possible. They propose to develop global strategies to tackle NTD-related stigma with interventions such as health education to reduce community-led stigma, disease management and counselling to mitigate the consequences internalized, anticipated and experienced stigma.

The right to attain the best mental health

Another important aspect to consider in right-based approach to NTDs is the high prevalence of mental illness associated with NTDs as a result of discrimination and stigma. Although the right to enjoy the highest possible state of mental health has been ratified by many countries, the mental health burden associated with NTDs is often not acknowledged and forgotten in the design of interventions. Mental illness is defined by WHO as “a state of wellbeing in which an individual realises his or her abilities, can cope with the normal stresses of life, can work productively and can contribute to his or her community” (Litt *et al.* 2012). Mental health conditions are predicted to become the leading burden (Murphy 2013) of DALYs by the year 2030 and 75% of this burden occurs in the developing world where NTDs are prevalent.

It has been reported that the global burden of mental illness associated with lymphatic filariasis was nearly twice as high as the DALYs directly attributed to the disease itself (Ton *et al.* 2015).

A study in Ethiopia on individuals suffering from leprosy, podoconiosis, lymphatic filariasis has shown that the majority of the persons affected (n = 21/39) described a mental health issue (van't Noordende *et al.* 2020). Further, this study revealed that the mental health of those required to care for sufferers of leprosy, lymphatic filariasis and podoconiosis is also affected: caregiving families reported a reduced quality of life, resulting from an inability to participate within their community, marginalisation, discrimination, divorce, difficulties finding a spouse, school dropouts, mental health problems and poverty (van 't Noordende *et al.* 2020). Another study in Liberia, reported that all individuals (n=27) suffering from NTDs described significant negative impacts on their mental wellbeing such as depression, anxiety and suicide (Dean *et al.* 2019).

Similarly, **a study in South India reports that 97% of Lymphatic filariasis patients suffered from depression or a feeling of inferiority (Suma et al. 2003)**. In some case, mental health issues that accompany NTD stigma leads to suicidal thoughts or even suicide attempts: leprosy, filariasis, onchocerciasis studies have all reported some case of suicidal thoughts/ suicide attempts. Litt *et al.* (2012) also reported that even patients with no economic problems report mental issues due to their stigmatized disease. They also found that poor mental health was particularly associated with leprosy, Buruli ulcer, filariasis, onchocerciasis, trypanosomiasis, cysticercosis, trachoma patients. The physical disability and disfigurement related to such NTDs lead to social stigmatisation, subsequent marginalisation, leading to mental health issues.

Strikingly, there is a scarcity of studies focussing on the impact that NTDs can have on sufferer's mental health. This is perhaps, in part, due to the difficulties to quantify levels of anxiety and depression (Amon & Addiss 2018). Nonetheless, failure to acknowledge this aspect of NTDs will only lead to further denial of the right of sufferers to obtain the best attainable mental health. Indeed, Amon and Addis (2018) suggest that "*quantification of the disease burden [of mental health-related issues] provide[s] a basis for accountability and international donor funding toward eradication*". Further, the design of NTD eradication programmes which often relies on curative disease models fails to address the burden of mental health and social stigma associated with NTDs. Abdulmalik *et al.* (2018) report that MDA programmes often fail to address mental health morbidity associated with NTDs because they only represent a small fraction of the budget for NTD eradication.

For example, if lymphatic filariasis was eradicated, people would be still be left with lymphedema and would likely suffer from it from a mental health aspect while funding would then be hard to raise as the disease would be declared eradicated. Moreover, Abbas *et al.* (2018) report that during the 2015-17 migrant crisis and refugee crisis, the basic needs of migrant populations, such as the right to mental health as described in article 23 of the refugee convention⁸ and in article 25 of the Universal Declaration of Human Rights,⁹ was often not fulfilled. The humanitarian response is often under such financial and time constraints that their objective is to help migrants arrive at their destination but is struggling to focus on providing healthcare along the transit route.

Interestingly, a study demonstrates that NTDs related mental health burden can be reduced by a right-based counselling approach participation (Lusli *et al.* 2016). Their study describes patients suffering from leprosy in Indonesia that received medical information about leprosy and awareness of rights (e.g. right to healthcare, right to education) during counselling sessions. A total of 260 people received counselling from lay and peer counsellors that had been affected by leprosy themselves. The results showed that the **counselling intervention was effective in reducing stigma, promoting the rights of people with leprosy and facilitating their social participation (Lusli et al. 2016)**. This study demonstrates that interventions can be

⁸ Which guarantees the right of refugees to public relief, that is, to access physical and mental health services at the same level as other residents.

⁹ states that for universal health coverage to occur, research and public health action must take place all along the migratory route, not just upon arrival in a host country

successfully implemented to reduce the burden of mental health disease associated with NTDs. Together, it highlights that following a right-based approach to design public health interventions can ensure that important aspects, such as mental health disease burden, are not forgotten.

The right to education and work

Besides mental health issues, discrimination and stigma can also impair the right to access education or work. In the context of podoconiosis, **school dropout has been reported in response to stigmatisation related to the illness (Deribe *et al.* 2013)**. Individuals suffering from lymphatic filariasis in Nigeria reported to have difficulties accessing their right to education and work (Abdulmalik *et al.* 2018). The right to work enshrined in ICESCR under article 6,7,8 can be compromised in the context of NTD because of the physical impairment resulting from the illness, or the effect of its discrimination of even stem from lack of skills due to poorer education which can itself be violated because of NTD as explained above. For example, **individuals suffering from Chagas disease report diminished work opportunities as they did not pass hiring assessment or were fired from work (Guariento *et al.* 1999)**. Along the same lines, individuals suffering from lymphatic filariasis in Nigeria reported not being able to farm successfully due to their physical (Abdulmalik *et al.* 2018). Together, these examples suggest that the right to work and access education are undermined by violations of the right to health care, the right to safe working conditions, or the right to non-discrimination, and illustrates how human rights are related and interdependent.

Limitations of this work

There were a limited number of articles specific to human rights identified in our search (see details in the Methodology section). Similarly, primary literature such as those relating to court cases concerning NTDs and human rights were not identified by our search. Future work should include i) the use of alternative databases that collate documents such as court cases, ii) a systematic literature search that focuses primarily on terms related to human rights and secondly on terms related to NTD, iii) a search for grey literature (non-peer-reviewed published articles) to expand the scope of the search and identify more resources discussing specifically of NTDs under the human rights perspective.

Recommendations

As outlined in this section, human rights are tightly linked with NTDs and the failure to fulfil one human right can lead to the deprivation of others. Likewise, the improvement of one human right can facilitate the advancement of others. Hence, a right-based approach to tackle NTD has the potential to be a platform that not only improves NTD diagnosis and treatment but also globally reduces deprivation of several human rights. The relative lack of power of individuals affected by NTDs means that there are few opportunities for them to advocate for their rights. Therefore, the use of legal instruments recognising the human right to health, is necessary for protecting the various human rights of individuals affected by an NTD. A rights-based approach leaves no one behind and provides local communities and affected individuals with a

legal basis to demand support for government and international organisations. While the primary duty bearer is the State government, accountability also extends to pharma companies, international organisations, and non-governmental organisations. Importantly, right-based advocacy provides accountability and can lead to greater political commitment which may result in more sustainable NTD eradication programmes.

General recommendations:

The following recommendations are for the majority well established in the field but are relevant to tackling NTDs from a rights-based perspective for the reasons already outlined within this section. The challenges remaining for such recommendations is to implement them at the country level.

1. **Provide basic necessities:** To fulfil the right to health, the provision of underlying determinants to health such as adequate housing, clothing, clean water, waste management are essential. For example, promoting shoe-wearing is important to prevent podoconiosis (Shahvisi *et al.* 2018) and adequate waste disposal can help prevent hookworms infections (Lesshafft *et al.* 2012).
2. **Improve accessibility, availability, affordability, and acceptability of quality healthcare:**
 - **Access:** Specific populations such as women, children, migrants, ethnic minorities, elderly, disabled, or mobile populations should benefit from greater attention as they encounter greater barrier to access NTD diagnosis and treatment (Coulborn *et al.* 2018b). For example, permanent local clinics or mobile clinics should be established. Similarly, governments could encourage farm owners to offer fair contracts that allow for paid sick leave, salary advances (Coulborn *et al.* 2018b). For example, local manufacturing of anti-venoms is desirable since their efficacy is greater when they derive from local snake species. To this end, government and international organizations should support local drug manufacturing development (Chippaux *et al.* 2019) by providing rent-free land or ensuring a minimum order to ensure financial income to companies.
 - **Availability:** The availability of drugs was found as a determinant factor in interventions against leishmania in Peru (Guthmann *et al.*, 2019). Existing drugs should not become unavailable for administrative reasons. Where possible, the protocol to deliver NTD treatment should be simplified to ensure that drugs can reach the patient. This is particularly true for mobile workers (Coulborn *et al.*, 2018) and populations in areas of conflicts (Beyrer *et al.*, 2017). Similarly, in countries where NTDs are not endemic such as Europe, the access to drugs for NTDS should be simplified and immigrants systematically screened for such diseases (Cenderello *et al.* 2016).
 - **Acceptability:** Inclusion and active participation of persons affected by NTDs themselves in interventions to tackle NTDs contribute for to better access to treatment for leishmania (Keys *et al.* 2019) for monitoring and

improving mental health disease related to NTDs. Further, it is necessary to engage with local healers and chemists to ensure that they redirect patients towards designated health centers that can provide adequate care.

- **Affordability:** Providing drugs and treatments that are affordable or free is key for tackling NTDs. The availability of free drugs was shown to be key in successful NTDs interventions in Peru (Guthmann et al., 2005).
- **Quality:** Health professionals should receive appropriate training including pathogenesis identification and be provided with adequate resources to perform diagnostic tests (Ekeigwe 2019). Smuggling of counterfeit drugs should be punished by governments.

3. **Provide formal health-related education:** Lack of formal health education can lead to stigmatization, discrimination, delay in treatment-seeking and enhance poverty. Similarly, appropriate training of health workers to recognise better NTDs is key (Guthmann *et al.*, 2018; Bukachi *et al.*, 2018; Coulborn *et al.*, 2018). Importantly, the best way to disseminate health-related information needs to be identified and the population involved in the process.
4. **Increase research efforts:** There is a consensus in the literature concerning the importance of research for new drugs or vaccines or the improvement of current treatments, but also disease surveillance and mapping. Moreover, there is a need to quantify NTD-related co-morbidities to provide material for advocacy. Even in conflict areas, research and surveillance should continue as safely as possible to design evidence-based interventions but also monitor progress (Beyrer *et al.* 2007).

Human-rights specific recommendations:

1. **Raise public awareness about the right to health:** Empower individuals and communities suffering from NTDs by increasing the awareness that the lack of access to NTD healthcare is a denial of their rights rather than a failure of their government health policies. The understanding that one is legally entitled to demand aid from the government is likely to trigger activism and mobilisation among communities suffering from NTDs.
2. **Encourage policymakers to follow a rights-based approach:** Rights-based policies can increase political commitment and ensure that interventions comprehensively tackle NTDs and reaches all NTDs sufferers effectively.
3. **Address and budget for co-morbidities:** There is a need to quantify better, and study comprehensively, the burden of NTDs on mental health to design better interventions and provide a basis on which to claim aid. Indeed, in some instances, the consequences of stigma related to NTDs caused more suffering than the NTD itself (Ton *et al.*,2015; Murphy 2013). There is a need to budget for stigma and mental health disease management rather than solely focusing on the eradication of the pathogen to break its transmission chain.

For example, right-based counselling was shown to be effective to tackle the consequences of stigma and discrimination related to NTDs (Lusli *et al.*, 2016). The similarities in stigma types, manifestations, and consequences among several NTDs, suggest that joint approaches to reduce NTD-related stigma is possible (reviewed in Hofstraat *et al.*, 2016). Such global approaches should not only aim at persons affected by NTDs but also include their families (van 't Noordende *et al.* 2020).

- 4. Encourage governments to incorporate the right to health into their constitution:** While all countries have signed an international instrument recognizing the right to health, only 100 countries have incorporated it into their constitution (Kinney., 2002). Incorporating the right to health in the national constitution is likely to increase political commitment as it provides a framework and a stronger legal basis to demand aid. It is also likely to result in increased accountability. Moreover, it can ensure the commitment of a national budget for public health interventions. Domestic laws can, for example, recognise the state responsibility to provide essential healthcare, guarantee fair drug pricing and align intellectual property and trade with national public health objectives.
- 5. Support and monitor claims to the right to health in court:** Although bringing cases of human rights violation in the context of NTDs to court should be the last resort, increasing the knowledge that it has, in some instance, resulted in the access to essential medicines (Hogerzeil *et al.* 2006) or the abolishment of discriminatory laws (Cruz 2018; reviewed in Hunt *et al.*, 2017) is empowering for NTDs sufferers. However, NTDs sufferers often have little opportunities to advocate for their rights and a framework to help them doing so should be implemented.
- 6. Encourage pharmaceutical company to adopt human rights guidelines:** Emphasize pharmaceutical businesses' and companies' responsibility in providing aid for low-income countries and encourage them to acknowledge the right to health and integrate it in their strategies, projects and research activities. Engage in discussion with pharmaceutical companies to identify priorities and promote research on NTDs vaccine/drugs/diagnostic that are non-attractive because they offer small market opportunities and/or low profit. Share the burden of research activities cost and set rules for fair pricing.
- 7. Identity duty holders utilising human rights as a framework:** Since a human rights-based approach encompasses the dimension of accountability, it can be used to identify duty holders. Accountability for the provision of the right to health should be emphasized in interventions and policies. Governments are the main duty holders but high-income countries, business, international organizations also have a responsibility to contribute to case of emergency. Governments where NTDs prevalence is high should be encouraged to provide a detailed plan of action with clear objectives that matches their capacities. Mechanism for monitoring progress should be systematically put in place.

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Health Inequity and neglected tropical diseases

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Summary

This chapter focuses on five main sources of inequity in NTD treatment and considers approaches to tackle these issues. These sources of inequity all relate to barriers, or deterrents, to accessing treatment which differently inhibit different groups of society.

First, we discuss the impact of under provisioned health centres on access to adequate healthcare for NTDs. There is a lack of both human resources (in terms of absolute staff numbers, and numbers of adequately trained staff) and physical resources (such as diagnostic tests and treatments). Resource shortages are especially prevalent for non-endemic diseases, and for all diseases in areas plagued by internal conflict. Next, we discuss mistrust of healthcare systems. Mistrust of healthcare professionals can arise from fear of painful screening or treatment procedures, aggravated by mistrust of the motivations of healthcare workers (for example, if they are incentivised to find cases). We consider the important role that stigma around NTDs plays in such mistrust. Fears around confidentiality deter treatment-seeking for stigmatised NTDs - such stigma is especially felt by marginalised groups, who are deterred from seeking healthcare due to poor treatment by medical professionals. Third, we discuss the impact of community health knowledge on health seeking behaviours, and thus on treatment inequity between groups. We find that NTD-knowledge gaps exist around awareness of treatment options (and the risks and harms of such treatment) and symptom recognition. Fourth, we discuss the inequities stemming from geographical barriers to access. We find geographical access-inequities resulting from poor infrastructure and sparse healthcare services in rural areas. These inequities can be aggravated by insurance plans restricting the healthcare institutions and service types that can be accessed (as observed for Chagas patients in Colombia). Finally, we discuss the financial burdens related to NTD treatment, and how such costs can lead to greater inequities. These burdens may relate to direct costs of treatment, or, more commonly, to indirect costs of lost work time or travel.

We end by recommending approaches to overcome some of these inequities. Specifically, we call for treatment interventions to be delivered in an integrated fashion; for use of interdisciplinary research methods when designing interventions; for increased use of interventions to increase community health knowledge and to increase trust in healthcare workers; for improved infrastructure; for increased care when designing interventions to prevent negative impacts on health system stability; and for mass-drug administration to be tailored to, and analysed according to, the local region. We recognise the importance of community involvement to ensure sustainable, culturally appropriate interventions.

Introduction

Access to healthcare broadly encompasses three aspects: physical, economic and information accessibility (*WHO, 25 Questions and Answers on Human Rights*). Physical access refers to the availability of services within reasonable reach of all groups in a population, accommodating for ethnic minorities, persons with disabilities, rural populations and other vulnerable groups (Bulletin of the World Health Organization 2013; 91:546–546A). In addition to the availability of healthcare service itself, the quality of healthcare must also be considered, which includes factors such as staffing, attitudes of healthcare providers, appointment systems and other aspects of the healthcare delivery. Economic accessibility measures the ability to pay for healthcare services without causing financial hardship, as well as the associated indirect costs, such as transport and time away from work. Lastly, informational accessibility is the right to ‘seek, receive and impart information and ideas concerning health issues’, while maintaining a right to confidentiality regarding personal health information (*WHO, 25 Questions and Answers on Health and Human Rights*). This involves more complex issues regarding the gaps in education (such as risk perception, recognising symptoms and treatment), communication from healthcare providers, and the handling of health information, particularly for stigmatised conditions. At the root, these factors reflect the inequalities in social standing and economic background, such as in the reduced quality of healthcare services and differential treatment by healthcare providers.

Inequity in access to healthcare for NTDs can be attributed to each of these different aspects, according to the local context and the specific disease in question. Hence, it is important to study instances in which each of these factors can act as a deterrent and/or a barrier to healthcare.

Poor healthcare provisioning as barrier to access

A key component of health equity is the attainment of universally accessible resources and knowledge relating to healthcare provision, as equal health outcomes cannot be obtained without everyone having prior knowledge of the appropriate actions to take when faced with NTD diagnosis or an increased risk of NTD infection. Poor, or even ineffective, disease management by healthcare providers can in some cases be attributed to a lack of medical knowledge on the part of healthcare professionals. **In Ethiopia, 98% of healthcare workers had one or more substantial misconceptions about the cause of podoconiosis (Sun and Amon, 2018), including 54% who believed podoconiosis was infectious and so were afraid to treat patients.** Similarly, knowledge gaps were reported with regards to Chagas disease in Colombia (Martinez-Parra *et al.*, 2018) and in the US (Forsyth *et al.*, 2019), onchocerciasis in remote areas in Cameroon (Njim and Aminde, 2017), strongyloidiasis in indigenous populations in Australia (Miller *et al.*, 2014), visceral leishmaniasis in north-west Ethiopia (Coulborn *et al.*, 2018) and rabies in Tanzania (Hampson *et al.*, 2008) - in these cases, clinicians often had not heard of the disease, or were not aware of the symptoms. Inability to recognise symptoms of NTDs can lead to patients failing to be correctly diagnosed: visceral leishmaniasis patients in Bangladesh were found to generally attend seven different clinics before a correct

diagnosis could be made (Alvar *et al.*, 2006). The fact that NTDs are misunderstood by medical professionals in a variety of countries highlights the necessity of comprehensive training and education programs for medical staff within NTD healthcare settings.

However, in some contexts, poor diagnosis and treatment outcomes are associated with healthcare centres being oversubscribed, resulting in a generally poor standard of care, or a system which does not consider NTDs as a priority. In the L. Victoria Islands, Uganda, healthcare providers are often overwhelmed by other prevalent diseases such as HIV and malaria, resulting in schistosomiasis management being considered less of a priority (Kabatereine *et al.*, 2014). A study on leishmaniasis in Satipo Province, Peru found a similar situation of healthcare staff being overworked, such that it led to poor quality of diagnosis, poor supervision of patients during treatment and a lack of patient follow-up (Guthmann *et al.*, 2005).

Poor medical resources can also lead to substandard NTD-related healthcare. This can be manifested at both the diagnostic and the treatment level. Insufficient diagnostic provision has been observed in Colombia, where **a lack of diagnostic tools means that over 95% of infected rural immigrants are never tested for *T. cruzi*** (Breyer *et al.*, 2007). Diagnostic test kits of visceral leishmaniasis are unavailable at the primary healthcare level in north-west Ethiopia, partly due to resources being allocated to local hospitals according to the population size, but without accounting for the large numbers of mobile workers (Coulborn *et al.*, 2018), and in many Somalian hospitals (Sunyoto *et al.*, 2017). In instances where there are diagnostic tests available, the tests can harbour a low-sensitivity, leading to many false negatives. This was found to be the case in Cameroon, where Onchocerciasis is diagnosed with a low-sensitivity skin-snip test, leading to a large number of false negatives (Njim *et al.*, 2017). Examples of lacking treatment provision have also been identified: Hampson *et al.* (2008) report that 10% of those attending a healthcare centre in Tanzania with suspected rabies exposure were unable to access post-exposure prophylaxis, often because there was none available.

Shortages of medical supplies have also been reported in non-endemic areas, where migrant influx has brought a sudden demand for NTD diagnosis and treatment provisions. For example, Forsyth *et al.* (2019) reported on the limited testing capacity for Chagas disease among migrants in the US. Similarly, Cenderello *et al.* (2016) used the example of the shortage of schistosomiasis drugs in Italy to advocate for the importance of European countries having stocks of medicines for diseases endemic in populations from which migrants travel. Similarly, knowledge gaps are especially common in areas where diseases are non-endemic – this is a problem when migrants become infected before returning home to non-endemic areas (Cenderello *et al.*, 2016; Coulborn *et al.*, 2018). As global levels of migration increases, recognising, and preparing for, the spread of NTDs into non-endemic areas could be crucial for containing future outbreaks.

Given the aforementioned evidence, the strength of healthcare systems is a major area of inequity – and interventions to increase access are more likely to be beneficial when health systems are robust (Cavalli *et al.*, 2010). Thus, horizontal interventions (broad policies targeted at bolstering health systems and increasing capacity) have an important role alongside vertical interventions (those targeted at treating specific

diseases in a specific group). One horizontal intervention which demonstrated the benefits of a strengthened health system was performed in Peru by Guthmann *et al.* (2005) (see case study 1). Moreover, there is evidence that some vertical interventions can in fact further weaken healthcare systems through disrupting existing healthcare delivery systems (Mounier-Jack *et al.*, 2017). For example, an NTD control initiative in Mali led to a decrease in provision of routine care services in 14 of 16 health centres providing the mass chemotherapy intervention (Cavalli *et al.*, 2010). However, it should be noted that the same vertical intervention in Mali did lead to improved quality of care at the two clinics with a stable, motivated workforce - this demonstrates that vertical interventions can be effective when used in appropriate contexts. Therefore, a nuanced approach is required when designing treatment interventions – for example, ensuring that intervention-specific training for healthcare workers does not interrupt service provision and thus in turn erode community confidence in the health centre (Cavalli *et al.*, 2010).

Case study: Peru (Guthmann *et al.*, 2005)

A two-year intervention involving the collaboration between the ministry of health, a national research institute and an international non-governmental organisation (Médecins Sans Frontières) aimed to ensure that healthcare staff were appropriately paid and had the necessary training, facilities, infrastructure and medications. This intervention led to improved relations and trust between healthcare providers and patients and improved the quality of both diagnosis and treatment (increasing the proportion of patients who completed treatment) for leishmaniasis. This study neatly demonstrates the power of a strengthened, reliable healthcare system to improve health outcomes. In particular, this program benefitted from continual availability of drugs. Moreover, this intervention also demonstrates the benefits of a collaborative approach involving multiple stakeholders with differing agency, resources and local knowledge.

One approach for achieving stronger and more sustainable healthcare interventions is increasing community involvement. For example, Amazigo *et al.* (2012) used evidence from river blindness control initiatives to argue that community-driven interventions (CDIs) can maximise access to, and the effectiveness of, an intervention. This can be due to the ability of local-led teams to deliver services in hard-to-reach areas, as is the case in regions of Somalia affected by conflict (Sunyoto *et al.*, 2017). Support for local-led programmes comes from Fitzpatrick *et al.* (2018), who state that community-based services are more likely to reach poorer members of society, and thus are important for equitable coverage. Finally, use of community volunteers can be important in areas with insufficient healthcare worker manpower to ensure high intervention coverage. For example, community volunteers can be necessary to distribute drugs for mass drug administrations (Ramaiah *et al.*, 2001), or to carry out health surveillance in areas lacking government health surveillance systems (Sunyoto *et al.*, 2017).

In general, sustainable healthcare interventions should utilise an interdisciplinary and/ or intersectoral approach. This approach recognises that many factors, not just healthcare, can contribute to good health - for example, housing, education and broader social, economic or political factors (Gazzinelli *et al.*, 2012) - and thus recognises the importance of collaboration across sectors. For example, as discussed above, zoonotic diseases necessitate collaboration between medical and veterinary services (Hampson *et al.*, 2008), or between health and agriculture departments for vector control activities (Gazzinelli *et al.*, 2012). Since, as will be discussed below, education is so beneficial to intervention success, coordination with education departments and/or schools is important. More broadly, collaborations with urban planning/ water resources/communication institutions and engagement with other disciplines such as social sciences and engineering should be explored (Gazzinelli *et al.*, 2012). From an equity perspective, a consideration of these other factors is crucial, as there is often vast discrepancy observed here (for example, wealth discrepancies impact sanitation and living conditions, which can be risk factors for NTDs).

Mistrust as a barrier to access

Reluctance to seeking help from healthcare professionals can stem from previous experiences with the public services, where “often, the first contact of participants with Western medicine in the health centres failed to solve the problem, which subsequently generated mistrust.” (Eid *et al.*, 2019). These individuals are deterred from seeking healthcare, and hence less likely to be able to achieve the full potential of their health, leading to inequity. Stories of such ineffectual experiences within healthcare systems, whether they are due to poor diagnostic, treatment or long-term management, can propagate through communities. In some cases, this can lead individuals to feel discouraged from approaching healthcare centres as they perceive modern medicine as being ineffective. This, once again, highlights the importance of training programmes for medical staff in NTD interventions. Indeed, Adhikari *et al.* (2011) found that nearly 60% of patients with visceral leishmaniasis in Nepal reported that the primary criteria for choosing which service to use is the quality of service provided, while only 34% had positive views towards modern hospital facilities. Patients’ attitudes towards public medical services are a key factor in determining their usage along with the limitations of the public sector in some cases. Concerns about treatment being ineffective can, in some cases, lead to patients seeking services from providers that they trust more, such as traditional healing, or turning to self-medication (Brieger *et al.*, 2015; Perera *et al.*, 2007).

In some contexts, communities may feel actively opposed to seeking medical intervention based on fear of being treated poorly or even harmed. Some medical procedures may seem invasive and unnecessary to individuals. **For example, screening for Human African Trypanosomiasis (HAT) requires painful lumbar punctures, and treatment with the drug melarsoprol can cause side effects such as paralysis and tremors, and even lead to death (Mpanya *et al.*, 2012).** When participants are not fully informed of the reasons behind these painful or dangerous interventions, they are unsurprisingly loathe to participate. Indeed, participants of a study on HAT in Congo generally had negative attitudes towards screening and treatment (Mpanya *et al.*, 2012). This was due to the lumbar puncture screening taking place in public, which individuals felt was humiliating. Additionally, some people considered screening to be healthcare workers causing intentional harm. This was likely due to the fact that healthcare teams in the past received premiums for finding

cases, raising suspicion that they falsely declared healthy people to be sick. Moreover, cases of severe melarsoprol side-effects stay within a community's collective memory for a long time, leading to accusations of sorcery and malicious intent (Robays *et al.*, 2007). This can heighten the atmosphere of fear surrounding such medical interventions within a community – and such fear becomes a strong deterrent against seeking out these services.

Therefore, where possible, changes in screening or treatment methods should be made to reduce the myths about their danger and toxicity. For example, melarsoprol for HAT can be switched to eflornithine, a less toxic drug, to reduce the negative associations between HAT treatment and side effects - this could therefore increase participation and compliance (Robays *et al.*, 2007). Additionally, there is need for research into medication for chronic Chagas disease, as the efficacy of current medication decreases as the length of infection increases, which may reduce the patients' belief that there is benefit in seeking healthcare services (Nijm *et al.*, 2017).

Other than concerns regarding the trustworthiness and confidentiality of treatment, stigma associated with NTDs also gives rise to fears of judgement or ridicule from healthcare professionals. This can act as a barrier to an individual's access to healthcare, by reducing their willingness to seek care (Sun and Amon, 2018). In particular, the differential treatment of vulnerable groups reduces their access to healthcare services, meaning they are more likely to experience poorer health outcomes. For example, Odhiambo *et al.* (2014) found that discouraging attitudes of healthcare staff regarding schistosomiasis deterred patients from seeking treatment. Similarly, Hofstraat *et al.* (2015), found that withdrawal from healthcare services and society was particularly observed in individuals with Buruli ulcer, lymphatic filariasis (LF), onchocerciasis and schistosomiasis. In some instances, worries about the treatment by healthcare professionals are not unfounded: Alvar *et al.* (2006) found that patients face disrespectful treatment by healthcare providers for visceral leishmaniasis in particular. Moreover, patients often avoid healthcare services due to a lack of trust in healthcare providers' ability to maintain confidentiality - which could potentially lead to the patient's ailments becoming known within the community. When these ailments are stigmatised, knowledge of an individual's diagnosis could lead to discrimination and exclusion from the community. Such stigmatisation is seen in the case of tungiasis, as societal notions link ectoparasites with childcare neglect - and thus parents are discouraged to seek healthcare for their children (Feldmeie *et al.*, 2008). Another example is LF; individuals with LF can experience stigma due to the visible deformities in limbs and genitals (Perera *et al.*, 2017). Since government clinics in Sri Lanka provide little privacy around procedures or consultations, such that identifiable information about LF may be disclosed to the community, patients may opt for private services instead (Perera *et al.*, 2007). In some cases, due to the nature of treatment, it is not possible for healthcare professionals to maintain confidentiality around a patient's diagnosis. Such is the case for scabies, the treatment for which has a strong distinctive odor which could contribute to stigmatisation (Feldmeie *et al.*, 2008). Therefore, patients may be disinclined to seek treatment.

To increase the trust for public health services, healthcare programmes' public services should endeavour to provide privacy to their patients. This can be achieved by, for example, setting up private locations for screening and treatment. Emphasis within treatment programmes should also be placed on ensuring confidentiality is

maintained and data is stored securely. Healthcare workers should also be encouraged to directly reassure communities and individuals that their medical records will be maintained confidentially and the ways in which this will be ensured should be communicated clearly. Ukwaja *et al.* (2020) suggest that NTD clinics could be set up separate from other parts of public hospitals or clinics, so that individuals can get treatment in a more private setting where they may feel less exposed, and hence more likely to use these services. The effect of stigma on health-seeking behaviour is, however, not entirely conclusive. For example, Weiss *et al.* (2008) argues that there is anecdotal evidence that suggests the stigma associated with certain NTDs may actually encourage individuals to seek help to become free of the conditions - though this requires other factors to be present, such as trust that the healthcare system can help. and more research on this area is needed. Therefore, more research is needed to investigate the impact of stigma on access to healthcare - i.e. the role of stigma in leading to health inequity.

In addition to NTD-specific stigma, prejudices that exist against specific groups or communities of people is a source of inequity, as it can make individuals more reluctant to seek help. This can be exacerbated by the additional cultural barrier when patients belong to certain minority communities, while their healthcare providers do not. For example, Brieger *et al.* (2015) found that a reason for reduced usage of the public sector in Africa is the poor quality of the staff and their poor attitude towards nomadic populations. Similarly, Dell’Arciprete *et al.* (2014) reports that indigenous communities in North Argentina faced discrimination due to their ethnicity when being treated for Chagas disease, including incidents of patients being ‘scolded’ by the healthcare workers, and doctors refusing to see them without appointment despite doing so for non-indigenous people. Furthermore, the language barriers restrict communication and understanding, further worsening their experience and reducing their incentive to use the public healthcare system.

Lack of cultural sensitivity to minorities can also lead to healthcare systems that are inflexible and, therefore, marginalise specific groups such that they experience unequal access to healthcare. Ways of living and occupations that involve higher mobility across different regions generally result in greater difficulties in accessing healthcare. The policies and programmes often are not compatible with these populations so that their conditions can be neglected by the public sector. Nomadic people in Africa are disproportionately affected by NTDs, yet they are not targeted by public outreach programmes (Brieger *et al.*, 2015). A mobile occupation can also lead to increased difficulties in utilising healthcare services fully: mobile workers in rural Peru can travel to clinics to receive diagnosis or treatment for leishmaniasis, but may return to their villages before getting their results or completing a course of treatment, such that they cannot receive the full benefit of healthcare (Guthmann *et al.*, 2005). Mobile workers who have to commute between their villages and distant workplaces, for example mines or crop fields, have been found to be excluded from screening for HAT due to their work schedules coinciding with when the screening teams arrive (Mpanya *et al.*, 2012). The binding contracts of mobile workers which do not provide compensation for sick leave or partial work can also restrict them from seeking care, leaving them at high risk for diseases (Coulborn *et al.*, 2018). Similar experiences were also found in US Latino migrants who tended to have occupations that did not provide paid leave (Forsyth *et al.*, 2019).

Mistrust of healthcare workers is a further reason for the benefit of CDIs, as these do not suffer from issues resulting from a lack of trust in healthcare workers, fear of medical treatment and drugs, and communication barriers. Indeed, through involving trusted members of the community, CDIs are a possible way to enhance trust between healthcare providers and the patients, and so improve healthcare provision more generally. This can prevent patients from turning to ineffective traditional treatments. For example, Martinez-Parra *et al.* (2018) detail how control programmes are sometimes rejected by communities because they lack cultural sensitivity – this could be ameliorated by utilising community volunteers with an understanding of the local norms. Healthcare workers, such as community drug distributors for preventive chemotherapy, can be recruited and trained from the local community, so that people may feel more comfortable receiving drugs from them (Nijm *et al.*, 2017). Similarly, Tamiru *et al.* (2019) advocate for healthcare workers to provide information via locally trusted traditional healers who have access to the target community - these healers can be trained so that they are able to disseminate the correct information regarding NTDs, make more accurate diagnoses, and provide more effective treatment. Akin to the need to utilise community members to ensure local appropriateness, it is important to localise all aspects of interventions to the specific target area. This ensures maximum effectiveness and efficiency of interventions (whether curative or preventative) and ensures that the most affected populations in each area can be targeted in order to reduce health inequalities (Armah *et al.*, 2015).

Lack of healthcare knowledge within communities

Healthcare knowledge regarding NTDs is the awareness of different aspects of the disease that is needed to take appropriate action. This includes knowledge of transmission, prevention, symptoms, possible outcomes and treatment options. Different communities have differing degrees of knowledge and misconceptions regarding the NTDs they are susceptible to. As previously outlined, education is a human right and a failure to recognise this right can have lasting consequences on an individual's health and prospects. This section will focus on the personal understanding of NTDs by individuals, rather than the knowledge of their healthcare providers and whether they are treated appropriately. Personal understanding will affect individuals' perception of their health and the actions they take to maintain it, and the gaps in understanding will reflect the general attitude and level of awareness within the community. The impact of such gaps in knowledge or misconceptions can be relatively harmless, for example enforcing prohibitions after being treated for HAT, such as not walking in the sun or having warm meals. However, such gaps can also have dangerous effects, for example when there is a lack of first-aid knowledge after a snake bite (Mahmood *et al.*, 2019), or when it results in people choosing traditional remedies for rabies. This is the case which for most of the fatal rabies cases recorded at the Ethiopian Health and Nutrition Research Institute (Kabeta *et al.*, 2015). Hence, it is important to investigate the weaknesses in NTD-specific health knowledge in different communities, and the results impacts on health-seeking behaviour.

In some communities, a lack of understanding of NTDs has led to individuals not being aware that the disease that they are suffering from can be treated and so do not attempt to obtain healthcare advice. Marco-Crespo *et al.* (2018) found that young rural individuals in Ecuador had more exposure than their urban counterparts to healthcare

promotion and hence had more knowledge on Chagas disease risk factors, but some also had the misconception that there was no treatment available for it. Similarly, Bukachi *et al.* (2018) found that a minority (6%) of individuals were not sure or did not believe that HAT could be cured. This reflects a clear need to focus on raising awareness about the basics of NTDs within vulnerable communities, so that individuals are aware that medical treatments and interventions exist.

More commonly, individuals may not seek medical services due to the lack of recognition that they are suffering from a disease. NTD symptoms can be mistaken for other illnesses by the community. Misconceptions of symptoms can produce a false sense of security when the expected symptoms do not occur after exposure (eg. after snakebites or dog bites for rabies). For example, individuals who falsely believe that Russell's Viper bites cause neurological symptoms may believe that they were not affected by the toxin when these symptoms do not occur, so they may be less likely to seek medical care, while the danger of acute kidney injury is not recognised (Mahmood *et al.*, 2019). Additionally, Legesse *et al.* (2018) found that **over half of participating community members, including some healthcare providers, could not correctly recognise the symptoms of dengue fever; this could result in dengue fever being misdiagnosed as other febrile illnesses and hence not effectively treated.** Furthermore, even when the symptoms can be accurately recognised, health-seeking behaviour can be hindered when patients may believe they are not at risk of the NTD. This is seen in caretakers of children in rural China, many of whom believe that Soil-Transmitted Helminthiases are diseases of the older generation only, so they do not often suspect infection in their children and are more likely to ignore symptoms and delay medical intervention (Lu *et al.*, 2015). Hampson *et al.* (20018) also found that individuals did not seek treatment for rabies because they believed they were not at risk. Some mistook a tetanus vaccine for rabies treatment, and hence believed they did not require further treatment; this may reflect insufficient or inaccurate explanations given to them about their medical treatments. However, treating the disease at hand is not always sufficient for diseases, such as strongyloidiasis, that can recur, as patients who are not aware of this are less likely to attend follow-up sessions (Miller *et al.*, 2014).

Lastly, a lack of understanding may lead to the underestimation of the necessity or benefits of treatment, so that patients with lower levels of knowledge are less likely to comply with medical treatment (Adhikari *et al.*, 2011). Individuals may feel fear and distrust towards the drugs they are prescribed if they do not understand the aim of the treatment, hence are less likely to comply with it (Nijm *et al.*, 2017). This can be exacerbated by myths of the detrimental effects of drugs, such as poisoning or infertility, or myths that the disease is not harmful, for example the myth in relation to STH that 'worms are present in everyone' (Lu *et al.*, 2015). Myths and suspicion were also observed where the quality of healthcare services was poor, suggesting that a lack of understanding may contribute to the negative impression of healthcare workers.

Filling knowledge gaps and correcting misconceptions is an important next step to take for tackling inequity in NTDs, so that individuals will know when to seek medical treatment and have the trust to comply. For example, health education should be community-based, where all community members can be informed, rather than facility-based where only patients are informed. This would increase preventative awareness

and knowledge of when to seek help (Coulborn *et al.*, 2018). An emphasis can be placed on finding more culturally appropriate means of raising awareness, which the local community may be more likely to understand and trust. Such approaches have been trialled in several places. In rural Indonesia, to support MDA programs treating STHs, educational entertainment using traditional puppetry productions improved knowledge and behaviour (albeit to a smaller extent than knowledge) (Kurscheid *et al.*, 2018). In an aboriginal community in Australia, **a 'Trachoma story kit' was integrated into the school curriculum and various advertisements, resulting in improvements in knowledge in clinical and school settings, and also in particular for community work staff in the community setting (Lange *et al.*, 2017).** More generally, computer-based programs can be used to standardise the key educational messages while having flexibility to adapt to different audiences. The video game 'The Vicious Worm' targeting *Taenia solium* infections has been trialled in both adults and schoolchildren, and succeeded in significantly increasing knowledge of the disease (Hobbs *et al.*, 2019; see case study 2). An educational animation focused on STH was also used in China, with positive effects seen both in knowledge levels and behaviour (for example, handwashing); this resulted in successfully lowering the incidence in the intervention group to 50% lower than in the control (Franziska *et al.*, 2013).

Another strategy to raise NTD awareness levels is to involve the younger generation more heavily in promoting education. This can be particularly beneficial for NTDs which have high incidence rates in children. For example, children are very susceptible to schistosomiasis and soil-transmitted helminth (STH) infections (Amazigo *et al.*, 2012). Such approaches may also lead to dissemination throughout the community, as children are likely to discuss what they have learnt in school with their family or wider community (Amazigo *et al.*, 2012). Indeed, Al Khateeb (1996) found **that children who were prepared to teach their parents about communicable diseases after attending school or summer camp in Upper Egypt were able to increase their parents' knowledge after six months.** Mwanga *et al.* (20018) supported this finding with a study in Tanzania, where the students and parents responded positively to children adopting the role of educators while their parents learned from them. More educational programmes for children can be created with a goal of teaching them material which they can disseminate to their community. Furthermore, the younger generation in Ecuador are keen to participate in health promotion and to share their knowledge, specifically regarding Chagas disease - however, they often can feel unheard (Marco-Crespo *et al.*, 2018). Hence, more structured recruitment of youth to roles supporting the education of their community could both benefit the youth and improve the level of health knowledge. For example, youth could be involved in designing educational programmes. However, cultural contexts should be taken into account; for example, in some regions with strongly ingrained age-hierarchies, elders may be less likely to listen to children, and/or children may feel uncomfortable teaching their seniors. Therefore, finding the most suitable demographic to educate is important. For instance, Mwidunda *et al.* (2015) found that secondary school-aged children are more respected in the community and hence more likely to be able to influence their community. Since this is the group often targeted by school-based mass drug administration (MDA) programmes, an additional educational element for teenagers could be integrated into these programmes - for example, an explanation of the disease and the infectious agent which the distributed drug is targeting, and how it can be prevented/ treated. They can then spread the

information in their community, which can help reach the populations that school-based MDAs do not cover.

Case study: Zambia (Hobbs et al., 2019)

This intervention trialled the health education programme 'The Vicious Worm' with primary school-aged children in Eastern Zambia to raise awareness of *Taenia solium* infections, which cause neurocysticercosis. The programme is a computer-based interactive programme set in a sub-Saharan African context, with options for the different target audiences. Previous trials conducted with local medical and agricultural professionals have shown success in significantly increasing knowledge levels, driving behavioural changes and knowledge dissemination. Knowledge levels of the school children regarding diagnosis and prevention of *Taenia solium* were significantly higher after one year of intervention than at baseline. However, the study identified weaknesses in the programme in increasing understanding of the life cycle of the parasite, and some misconceptions regarding the transmission of the epilepsy associated with neurocysticercosis remained uncorrected. This intervention demonstrates the ability of a culturally appropriate computer programme to effectively raise health awareness for various populations, in particular school-aged children, who may be able to play an important role in disseminating the learned information to their own communities.

A school-based approach to MDAs is attractive since it provides an efficient mechanism to reach large swathes of susceptible individuals using pre-existing infrastructure - this means it can be relatively cheap to achieve relatively high coverage among the school-age demographic. However, school-based education programmes are not entirely inclusive as this system excludes those children who do not attend school (e.g. King *et al.*, 2013). This is concerning since these children are often those from poorer families, and so those more at risk of neglected tropical diseases. In terms of equity, this is especially worrying, as equitable MDAs would cover populations in proportion to their risk - i.e. provision of treatment would be determined by need alone, rather than by other factors such as wealth (Lo *et al.*, 2019). Indeed, Lo *et al.* found evidence for the inequity of MDAs, showing that across all continents, deworming of preschool children increased with household wealth. Moreover, they showed that regions with higher coverage were generally more equitable – indicating the importance of achieving high coverage for deworming programs. Further evidence of the inequity in MDA coverage comes from Seider *et al.* (2016), who similarly found that deworming of children in Nigeria increased linearly with wealth quintile, and also with the level of maternal education. They also found that coverage was higher in urban areas than in rural areas. Moreover, carrying out MDAs through schools also relies on the strength of the education system – and indeed, deworming coverage in Kenya varies by county, according to the quality of education system (Nikolay *et al.*, 2015). Additionally, school-based MDAs exclude children below school age – and, for example, as Kibira *et al.* (2019) note, these children are at high risk of schistosomiasis and have the highest rates of schistosomiasis infection in Uganda.

Therefore, there is an argument for utilising community-based drug administration instead of, or in addition to, school-based programs, as these would reach those members of a community not attending school, while still providing coverage to schoolchildren (Amazigo *et al.*, 2012). Indeed, a community-based deworming program in Tanzania was just as effective as a school-based program at decreasing STH prevalence among schoolchildren, and more effective at decreasing *Schistosoma haematobium* infection rates (Massa *et al.*, 2008). However, even a community-based drug administration program may miss another section of the population often excluded from mass chemotherapy programs; mobile migrants (Gazzinelli *et al.*, 2012). Therefore, research is required on how to ensure equitable coverage by MDAs.

Geography as a barrier to access

An important source of inequity is differences in availability of healthcare services within reach of those who need them. Various studies have cited transportation issues of patients living in rural areas as a barrier to healthcare access. Such issues include the distance to the nearest health centre. For example, many individuals have to travel long distances on foot to access Human African Trypanosomiasis (HAT) treatment in South Sudan. In a study by Bukachi *et al.*, (2018), almost half the respondents reported this as a reason for not seeking treatment. This study also emphasized that, as HAT patients may die in hospitals that are too far for family to visit, this further deters individuals seeking healthcare services. Patients can also struggle due to poor transportation routes, such as the routes between villages in Santiago Province, Peru, and leishmaniasis treatment centres, which are inaccessible by car during the several months of rainy season (Guthmann *et al.*, 2005). Moreover, poor road infrastructure can cause safety issues (Eid *et al.*, 2019). Ambulance services for more urgent conditions such as snakebites are often limited and unreliable (Harrison *et al.*, 2016). These shortcomings reduce patients' willingness to seek medical treatment for conditions that do not appear immediately urgent, resulting in delays and adverse outcomes. Hampson *et al.* (2008) showed that distance was an important predictor of delays in treatment delivery for rabies, as exposed individuals who lived further away from medical facilities were more likely to develop rabies than those who lived closer. Additionally, healthcare workers also face geographical impediments. For example, mobile healthcare workers may struggle to access rural populations, such as isolated populations in a forest, especially as these workers are often already overwhelmed with the demands of treating leishmaniasis (Guthmann *et al.*, 2005).

Accordingly, there have been many calls to improve local infrastructure and/or ambulance services to ensure patients have timely access to care. For example, Harrison *et al.* (2019) calls for this in relation to snakebite treatment. To supplement the limited ambulance service for emergent conditions, Sharma *et al.* (2013) found success in trials of a motorcycle volunteer program for rapidly transporting patients. Case fatality rate decreased with this intervention, likely due to the increased reliability of transport systems meaning a greater proportion of snakebite victims were treated at professional medical facilities and fewer by traditional healers.

Lastly, the difficulties of transport can be heightened by the fragmentation of healthcare services as a result of insurance plans. Some insurance companies in

Colombia have contracted services with different facilities (primary care, laboratory tests etc), forming a monopoly on the institutions that can be accessed by patients (Martinez-Parra *et al.*, 2018). **They provide ‘subsidised’ insurance plans which limits access by providing fewer healthcare facilities those under the plan can use, and the type of service they can access at each location may vary as well. Patients then have to make many trips between different services to fully receive diagnosis and treatment.** Given the range of complications Chagas disease patients may have (cardiac, digestive, neurological), they particularly experience the burden of increased travelling to access the various departments and services they require (Martinez-Parra *et al.*, 2018). The poor quality of facilities as discussed previously could also produce a similar problem, where due to the lack of diagnostic equipment, drugs or healthcare staff, patients have to travel to several facilities in order to find one that can effectively help them manage their disease. Cavalli *et al.* (2010) presented the problem that, though many individuals have comorbidities, they may travel long distances for NTD drug collection only, missing the opportunity for healthcare staff there to identify and treat their other conditions. To manage geographical inaccessibility for certain areas, other than improving transport, medical services can be made more efficient to minimise the number of journeys that patients have to take through integrated approaches. An integrated approach was trialled for targeting both soil-transmitted helminths and canine-mediated human rabies in Tanzania, where treatments for both diseases were carried out together at the same centre. It received generally positive responses from the participants, and was able to reduce travel time and cost to the participant (Lankester *et al.*, 2019). This could save opportunity costs for participants who have to miss work for medical care. This ‘two for one’ approach could apply to various different combinations of NTDs if they are found roughly in the same geographic area.

Finances as a barrier to access

With NTDs most commonly being found in low-income populations in the tropical and subtropical region, financial barriers are an important determinant of access to healthcare. Even where knowledge and risk perception are high, low health-seeking behaviour can still be observed, and can be partially attributed to financial concerns. Kumaran *et al.* (2018) found that the amount of time individuals delayed seeking healthcare was strongly correlated with their socio-economic status. When considering the financial cost of seeking medical care, it is often the indirect and opportunity costs that create significant financial hardship and not the cost of medical treatment alone, although it can also be prohibitively expensive (Universal Health Coverage and Universal Access, Bulletin of the World Health Organization 2013; 91:546-546A). These additional costs include transportation costs, unofficial charges such as tips and bribes, the time away from work due to long travel times and waiting times etc, and act as the main financial where treatment itself is free (Coulborn *et al.*, 2018).

Although some treatments and procedures are provided free of charge in certain locations, the direct cost of healthcare may still be a major deterrent. For example, Williams (2015) emphasised the high cost of antivenom for snakebites, ranging from 56 to 540 USD, which often accounts for a significant portion of annual income for those at risk. In Latin America, where antivenom is provided free of charge, the

mortality to occurrence ratio is much lower than in places where antivenom costs are high, which suggests the cost of antivenom to be an important determinant of outcome (Harrison *et al.*, 2009). For more long-term conditions that require hospitalisation or continued treatment, individuals may refuse diagnosis and/ or treatment to avoid the high costs. Balen *et al.* (2013) found that, because of a lack of financial resources, one-third of interviewed individuals would ask to be discharged early once their schistosomiasis symptoms improved only slightly, resulting in an incomplete recovery.

Financial concerns can exacerbate geographical inequalities. Adhikari *et al.* (2011) found that despite government-funded hospitals providing free treatment for visceral leishmaniasis, **more than 80% of interviewed households (possibly due to the cost of travelling the long distances) reported having to borrow money for the treatment** – and requiring loans was associated with a reduced likelihood of using public healthcare services. The total cost of transportation and lodgings can be a significant financial burden, which can reach 500-600 USD in total for leishmaniasis in Bolivia (Eid *et al.*, 2019). Treatment for echinococcosis in China can exceed the total annual income of a family, resulting in significant debt (Yang *et al.*, 2010).

Another common reason for patients missing screening or treatment opportunities, even where it is free of charge, is the indirect cost of spending time away from work. Boelaert *et al.* (2010) found that this can be the largest financial consideration; indeed, lost income from visceral leishmaniasis treatment may account for up to 60 % of total household income (Meheus *et al.*, 2006). Individuals, particularly those who feel healthy enough to work, may avoid screening for HAT in the Democratic Republic of Congo out of fear of income lost from both attending the screening and from the potentially long hospitalisation period if they tested positive (Robays *et al.*, 2007). If symptoms are experienced, patients still often delay treatment until there is no choice, such as when the symptoms impede working. **Travel costs and lost income deterred individuals with LF from seeking free drugs at government clinics, and delayed diagnosis by 3.5 years on average for low-income groups (compared to 2.2 months for high-income groups) until the disease severely affected their livelihood, risking irreversible damage to their health (Perera *et al.*, 2007).** Similarly, leishmaniasis patients, may not feel the need for medical consultation since their skin lesions are only mildly painful, while the loss of wages associated with the 20-30 days of work lost (for travel and long duration of treatment) is more problematic (Guthmann *et al.*, 2005). Overall, this suggests that lowering the cost of treatment and testing itself is not enough to provide access to residents of rural areas, and more must be done to tackle the associated costs.

Furthermore, there is a concern that free government clinics may not have the necessary drugs in stock. **Patients will be forced to buy from private pharmacies instead, where the prices can be inflated up to three times their official price, such that the cost of treatment adds significant financial burden** (Sharma *et al.*, 2006). The alternatives for refusing treatment are to self-medicate or seek traditional medicine. Cavalli *et al.* (2010) reported another alternative to avoid buying costly drugs is to delay seeking treatment to wait for the next round of mass drug administration, where they can obtain the necessary drugs for free. Overall, financial constraints are a deterrent for health-seeking behaviour, as patients delay treatment until their symptoms are unbearable, and stop treatment when the symptoms minimally improve.

Reducing the cost of treatment alone is insufficient in providing true access without also considering the high associated costs.

Limitations of this work

There was considerable variation in coverage of different NTDs within health inequity-relevant literature. For example, Human African Trypanosomiasis, Lymphatic Filariasis, soil-transmitted helminths, and Chagas disease were frequently mentioned, whereas diseases such as trachoma, yaws, dracunculiasis and taeniasis were referenced relatively less frequently.

Recommendations

General recommendations:

There are many inequities in access to healthcare for NTDs, spanning physical, economic and information barriers. An understanding of the inequalities in access in region can allow creation of policies which attempt to both acknowledge and compensate for such barriers. Moreover, while it can be difficult to tackle the root causes of some inequalities, especially where they relate directly to the healthcare system of the given country (for example, the insurance structure), there are some overarching principles which can be used to improve access to healthcare. These relate to strengthening the healthcare system of a country to ensure sufficient capacity and thus sustainability. Recommendations on best practice for tackling inequity in NTD interventions are thus as follows.

Firstly, literature around equity in NTDs provides further evidence for some recommendations relating to best practice for health interventions. These are as follows:

- 1. Improve infrastructure:** To tackle access problems related to travel, general infrastructure should be improved (Harrison *et al.*, 2019). This is also an example of the need for intersectional approaches focused on more than simply healthcare. This will reduce inequities between rural and urban patients and ensure that all patients can receive timely care. For example, Sharma *et al.* (2013) demonstrated the benefit of increasing motorcycle infrastructure in allowing access to treatment.
- 2. Implement interventions in an integrated fashion:** Many access barriers stem from difficulties travelling to receive healthcare (Bukachi *et al.*, 2018; Harrison *et al.*, 2016; Guthmann *et al.*, 2015; Perera *et al.*, 2019), whether due to transportation issues directly or the financial costs associated. When interventions are delivered in an integrated manner, it not only reduces costs to the provider, but potentially increases uptake by ensuring maximum efficiency for the patient. (For example, an individual is much more likely to be able to take a single day off work to receive treatment for two diseases than to take

multiple days off). The success of such an integrated program was shown in Tanzania with a program which targeted STHs alongside rabies (Lankester *et al.*, 2019).

While this principle holds for diseases in general, it is especially relevant to NTD-intervention planning, as NTDs particularly afflict patients from the lowest socioeconomic groups who can least afford the time and travel costs involved with attending interventions. Moreover, multi-morbidity is very common among NTD patients, since the same socioeconomic conditions are risk factors for many NTDs, and thus patients often require multiple treatments.

- 3. Promote an interdisciplinary approach:** Many factors contribute to the health of an individual, including healthcare itself, but also education, housing and agriculture, among others. Therefore, to be truly effective, any intervention must also consider these factors. This requires an interdisciplinary approach. This is needed both at the research and the treatment level. For example, social science methods are important to understand context-specific access barriers in different communities, and so how to address these. An example at the treatment level is zoonotic diseases, which must be controlled through integrated medical/veterinary/agricultural interventions to prevent vector transmission as well as treat patients (Gazzinelli *et al.*, 2012; Hampson *et al.*, 2008). This is linked to the principle of One Health. Considering, and addressing, inequities in sectors other than healthcare will increase the overall equitable access to good health: Again, this is true for many diseases - however, this principle is especially important when designing NTD-interventions because NTDs are so inherently linked to poverty and other social determinants of health.

Health-inequity specific recommendations:

- 1. Increase community trust in healthcare professionals:** One barrier to treatment uptake noted by many studies was a lack of trust in healthcare professionals (Adhikari *et al.*, 2011; Eid *et al.*, 2019; Robays *et al.*, 2007). This was due to fears of judgement, worries about quality of care (Adhikari *et al.*, 2011), and fear of a lack of confidentiality (Mpanya *et al.*, 2012). As aforementioned, community education may help to tackle some of these fears. In addition, there is a need for increased education of healthcare professionals themselves to ensure quality, stigma-free care is always provided. Care must also be taken to ensure patients' confidentiality. Additionally, community-involvement could improve the perception of interventions, thus increasing uptake (Coulborn *et al.*, 2018). Overall, improved community trust could strengthen health systems - one of the key NTD Roadmap aims.

Increasing trust in healthcare workers is important in many contexts, not just related to NTDs. However, the literature emphasises that this is particularly a problem in the case of NTDs as these are often stigmatised, and so there is greater mistrust and concern around seeking treatment.

- 2. Increase NTD-awareness amongst communities alongside treatment:** One specific factor which should be integrated alongside healthcare treatment is health education. A lack of accurate information is a key determinant of access, with uninformed individuals unaware when or how to seek treatment for NTDs (Mahmood *et al.* 2019; Legesse *et al.*, 2018; Lu *et al.*, 2015; Hapmson *et al.*, 2018; Bukachi *et al.*, 2018; Marco-Crespo *et al.*, 2018). In general, these individuals are those who are less educated, poorer, and live in more rural areas. This disparity between regions and individuals raises equity concerns. Providing comprehensive health education to all members of a society, rather than simply those being treated, will both increase healthy behaviours, thereby decreasing the need for medical care, and increase appropriate treatment-seeking behaviour. This will also ensure that interventions are better accepted by a community, and so increase uptake. Crucially, such interventions must be targeted to the community to ensure it is culturally appropriate and effective. For example, different educational techniques should be used for different age groups, and locally trusted leaders could be used to disseminate information. Younger populations may also act as an important target for education, as they have been shown in some communities to be eager to help (Marco-Crespo *et al.*, 2018), and have the potential of further disseminating information throughout their community (Amazigo *et al.*, 2018). Moreover, education will help to decrease stigma, which itself acts as an access barrier for many people.

Health knowledge around all diseases is important. However, it is especially important to increase understanding around NTDs because of the current lack of knowledge - given that the diseases are “neglected”, there are much lower levels of awareness than for other diseases. Additionally, there is especially low health knowledge among those at risk of NTDs, compared to those at risk of different diseases, since NTDs mainly afflict the poor and less educated. Therefore, NTD-related health education is especially important. This is recognised in the NTD Roadmap; critical action 1 for snakebite is to build community awareness in prevention and seeking treatment, and critical action 3 for foodborne trematodiasis is to raise awareness of MDA, WASH and One Health interventions. These actions must be implemented.

- 3. Ensure NTD interventions do not weaken other aspects of healthcare systems:** Care must be taken when performing vertical interventions to ensure that they do not divert crucial resources from other avenues of care (Mounier-Jack *et al.*, 2017; Cavalli *et al.*, 2010). This requires considering the local healthcare capacity, and adjusting plans accordingly, before carrying out interventions. This is another way in which community involvement could help, as volunteers could help to deflect the extra NTD campaign pressure away from health care workers.

One way to ensure NTD interventions do not overload health systems is to integrate such interventions into the main workload so that they are planned and budgeted for. This is known as mainstreaming and is a key goal of the NTD Roadmap.

- 4. Tailor MDA delivery systems to the local region and the disease treated:** For example, consider whether a school-based MDA will effectively

and equitably ensure high coverage, or whether a community-based approach would be better suited to the region (Amazigo *et al.*, 2012). This could depend on the rates of schooling in the area, the strength of the education system (Nikolay *et al.*, 2015), and the age-group most affected by the specific disease (Kibira *et al.*, 2019). Such effective targeting of MDAs is key to achieving equitable coverage (i.e. coverage of populations according to their need (Lo *et al.*, 2019)).

- 5. Collect and interpret data on NTD treatment programmes and MDA coverage at a local level:** When understanding access barriers in different regions, it is important to have precise data. This relates to the “tyranny of averages”; the fact that the average data of a region might conceal vast differences between population groups - for example, that economically disadvantaged regions might receive far lower coverage of MDAs (Lo *et al.*, 2019). This precise local data is important for ensuring effective interventions. From an equity perspective, such data is crucial, since averaged data may conceal equity concerns.

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The role of sex and gender roles in neglected tropical diseases

Simone R. de Rijk

Summary

This chapter describes different factors that can determine gender differences in general access to healthcare, and more specifically for neglected tropical diseases. Gender-related differences in access to healthcare and MDA programmes, knowledge of sex-specific symptoms, awareness raising on health and disease, perceived stigma and health-seeking behaviour are evident for neglected tropical diseases. Access to healthcare, and specifically in the context of mass drug administration programmes may be influenced by within-family dynamics, whether community drug distributors or men or women, and what the level of access is for pregnant and breastfeeding women. The limited availability of sex-disaggregated data and especially gender-disaggregated data on a local level, leads to gender-based differences in access going unnoticed. Access to information on NTDs is often lower for women than for men, and healthcare workers are not always aware of sex-specific manifestations of NTDs for females. This influences health-seeking behaviour. Stigmatisation is another major factor influencing health-seeking behaviour for NTDs, especially for NTDs that change the physical appearance, which in its turn can have a major influence on someone's position in society. Gender-based division of labour has influence on the healthcare delivery that is preferred. Recommendations are made on what topics should be covered in NTD programmes.

Introduction

Neglected tropical diseases may affect each sex and gender differently (Uniting To Combat NTDs, 2016). Gender is different from biological sex, and can be described as the “the socially constructed roles, behaviours, activities, attributes and opportunities that any society considers appropriate for men and women, boys and girls” and people with non-binary identities’ (WHO, 2020b, 2020a). Biological sex is assigned at birth, and is defined by characteristics such as genitals, gonads, chromosomal and hormonal patterns (UNDP, 2019; WHO, 2020b). The biological factors of sex are known to have an impact on health when it comes to diseases such as urinary tract infections and cardiovascular disease (Rogers *et al.*, 2010; UNDP, 2019; Valiquette, 2001). Although biological differences can play a role in NTDs, such as the increased risk of anaemia for pregnant and lactating females with an hookworm infection, **it is rather the assigned gender roles, and their accompanying societal norms, that define exposure to pathogens, risk of infection and the severity of the course of the disease** (Herrick *et al.*, 2017; P. Hotez & Whitham, 2014; Michelson, 1993; UNDP, 2019). As an example, reinfection rates for schistosomiasis are higher for fishermen in Uganda due to their occupation, while in other areas women and children are more exposed to the parasitic worms causing schistosomiasis due to water-related activities such as washing, bathing and water drawing (Michelson, 1993; UNDP, 2019).

Socially constructed gender roles are often characterized by three variables that are influenced by different gender dimensions: economic and productive activities, social activities and personal factors (Periago *et al.*, 2004; Rathgeber & Vlassoff, 1993). Economic and productive activities include division of labour by gender, available substitute labour when ill, exposure to infection in the workplace, access to healthcare and financial resources. Social activities include factors such as health roles in the household, cultural norms affecting exposure, available support networks, decision-making power, social stigma and utilisation and quality of health services. Lastly, personal factors include knowledge about disease, beliefs and fears about disease and the provider-patient relationship based on gender (Periago *et al.*, 2004; Rathgeber & Vlassoff, 1993). If someone does not fit the gender norms of the society they live in, it often leads to stigma, discriminatory practices or social exclusion, which can negatively impact health (UNDP, 2019).

Gender as a social construct and other social stratifiers such as age and socioeconomic status are important to help understand the patterns relevant to health outcomes for different groups within the same society (Aya Pastrana *et al.*, 2020; Johnson *et al.*, 2009). However, disaggregating data and data interpretation by gender is relatively uncommon in the current literature, while sex-disaggregated data is also not standard (Aya Pastrana *et al.*, 2020; Theobald *et al.*, 2017). At national level in particular, sex-disaggregated data and gender-disaggregated data seems limited in NTD studies, meaning that interventions cannot act on local differences in sex or gender that would improve healthcare for all (Theobald *et al.*, 2017). **Examining how gender identity and the assigned local gender roles influence risk of infection with NTDs and what the subsequent health outcomes are, will help understand gender inequities and how to address them (Ozano *et al.*, 2020).** Additionally, studies on gender and health have shown interactions between gender inequalities in healthcare and social determinants of health, such as socioeconomic status, which

can magnify the existing inequalities (Gazzinelli *et al.*, 2012). Furthermore, **health policies failing to incorporate gender roles may exacerbate gender inequalities in certain countries** (Gazzinelli *et al.*, 2012). It, therefore, seems of utmost importance to understand, and report on, gender roles for NTDs.

The aim of this chapter is to examine the factors that can determine gender differences in general access to healthcare, including mass drug administration programmes, knowledge on NTDs per gender, social stigma and health-seeking behaviour. Recommendations of gender-responsive data collection, policies and interventions are made.

Gender and sex equity in access to healthcare in the context of mass drug administration programmes

Equality in healthcare includes having equal chances and opportunities to access healthcare, as well as protection while accessing healthcare, regardless of gender or social status. **Gender equity refers to more than just gender equality, as it incorporates different needs, preferences and interests of different genders and the consequent adaptation of the form of healthcare provision offered to different genders based on their needs, preferences and interests (WHO, 2011).**

Programmes for mass drug administration (MDA) of preventive chemotherapy (PC), as well as mass vector control programmes, offer a chance to reflect on the issues of gender and sex equity in access to healthcare for NTDs specifically on a large scale (Cohn *et al.*, 2019; Rilkoff *et al.*, 2013). On a national level, sex-disaggregated data of MDA programme coverage most commonly suggests that female and male coverage are similar, or that female coverage is higher than male coverage (Cohn *et al.*, 2019; Rilkoff *et al.*, 2013). In a study by Cohn *et al.* looking at the MDA coverage in 16 different countries on national and district level from 2012 to 2016, overall female MDA coverage was 85.5%, this compared to 79.3% for males. However, 3.3% of the districts researched showed over 10 percentage points higher coverage for males, showcasing how MDA coverage data on national level might not reflect MDA coverage on local level (Cohn *et al.*, 2019). This **emphasizes the need to understand local specific contexts in order to successfully address gender inequalities.**

One of the most important factors identified in the literature, when it comes to understanding gender-specific barriers and facilitators to MDA programmes, is the within-family dynamics. For example, **a study on within-family dynamics and the compliance with MDA programmes for Lymphatic Filariasis in an endemic region in Indonesia, showed how the power dynamics in each family decided whether women accepted the preventive chemotherapy or not (Krentel & Wellings, 2018).** This phenomenon is also seen in other countries such as Benin, Cameroon and Nigeria (Agbo *et al.*, 2019; Burki, 2020). A focus group in Benin, discussing gender-specific barriers to MDA programmes, noted that men sometimes do not see themselves at risk, and therefore have less demand for, for example, deworming, while women reported to seek increased involvement in MDA programmes. They concluded that door-to-door community-wide MDA programmes may improve general coverage, while at the same time “empower women by

facilitating increased decision making” on behalf of their families (Geyer *et al.*, 2020). However, the success of these programmes highly depends on the local gender roles, as in northern Nigeria drug distributors are sometimes unable to hand out PC when the man, as the head of the family, is not present in the house, meaning the entire family misses out on the preventive medication even in a door-to-door community-wide MDA programme (Burki, 2020). This becomes an even larger issue because of the frequent occupational travel of men, meaning less access for men to PC in general as well as for their families, if the family-dynamics do not allow for women to accept the PC (Rilkoff *et al.*, 2013; Theobald *et al.*, 2017). In contexts where women are accepting PC from door-to-door programmes, for example in Eastern Uganda, women were found to be more accepting of the programme as a whole while rumours regarding harmful effects of the treatment offered were prevalent among males. This could be explained by a difference in knowledge about the programmes if the drug distributors are more commonly speaking to women at the house (Rilkoff *et al.*, 2013).

Whether community drug distributors (CDD) are men or women, even with limited data available, also seems to matter to the success of the MDA programmes (Ozano *et al.*, 2020). For example, men distributors in some social contexts might not be able to administer treatment to women in households directly, while in some instances, for example in nomad communities in Sudan, the drug distributors are not even allowed to have contact with women and girls due to cultural and traditional norms (Cohn *et al.*, 2019; Theobald *et al.*, 2017). **Gendered power dynamics are usually well understood by local CDDs and in particular women CDDs are perceived as being well-suited when it comes to handling health matters that might affect reproductive health** (Naimoli *et al.*, 2015; Theobald *et al.*, 2015). CDDs are in a unique position to observe, on a micro-level the social factors that have an influence on participation in MDA programmes. They are often part of the same community as that they serve in, and are therefore more likely to be aware of the social and cultural influences that influence MDA programme participation (Theobald *et al.*, 2015). Vector control programmes in Sudan, Kenya and Indonesia, showed that “women are more likely to create self-sustaining vector control programs and that such programs can contribute towards broader gender equity” (Ernst *et al.*, 2018; Rahman *et al.*, 1996; Wenham *et al.*, 2020).

An important group to mention within MDA access are pregnant and breastfeeding women, as they are sometimes excluded from certain types of MDA for which they are eligible under WHO guidelines (Cohn *et al.*, 2019; Rilkoff *et al.*, 2013). This could be explained by certain MDA programmes being aimed at school children, while in some instances pregnant women are ineligible to participate in MDA programmes under national guidelines. **Even when the WHO encourages participation in MDA programmes for pregnant and breastfeeding women, misconceptions exist regarding pregnancy complications from PC, which might undermine public trust in the MDA programmes as a whole and for women in particular.** In Mozambique, for example, this has led to lower overall female coverage in MDA programmes (Cohn *et al.*, 2019). Pregnant women not being part of MDA programmes is particularly worrisome as pregnant women are more likely to experience serious health effects from NTDs (Rilkoff *et al.*, 2013). For example, hookworm infections often lead to anaemia in pregnant women and schistosomiasis has been associated with increased maternal morbidity and low birth weight (Friedman *et al.*, 2007; P. J. Hotez, 2009; P. J. Hotez *et al.*, 2004).

Knowledge of NTDs and access to NTD information across genders

Access to information on NTDs and sex-specific manifestations of NTDs is important both for patients and for healthcare workers. **Often, both at local and national level, it is thought that the prevalence of certain NTDs is higher for men. However, it is argued that women are simply not showing in the data because they have trouble accessing healthcare** for reasons that are outlined in the next paragraph. For example, women are evidently missing in leprosy data (Sarkar & Pradhan, 2016; Theobald *et al.*, 2017). Apart from misconception of NTD prevalence across genders, **this also leads to certain sex-specific manifestations of NTDs going unnoticed or being misdiagnosed by both patients and healthcare workers.** For example, female genital schistosomiasis, with symptoms such as vaginal discharge and itching, is often misdiagnosed as a sexually transmitted infection (Aagaard-Hansen *et al.*, 2009; Burki, 2020; Talaat *et al.*, 2004; Theobald *et al.*, 2017). Misdiagnosis of female genital schistosomiasis even led to some health workers believing that females of all ages hardly ever get infected with schistosomiasis in general (Kukula *et al.*, 2019).

Access to information on NTDs, including risk factors, prevention, symptoms and treatment, often determine the efficacy of health programmes. **Women often seem to have less access to health-awareness raising than men, partially because health programmes are not always catered to women's schedules, including the time women spend working in, or for, their household** (Okwa, 2007). Limited access to education in general for women, is suggestive of women being exposed to less information about disease (Okwa, 2007). Especially for school-based health programmes, including health education and drug administration, this imposes a problem (Cohn *et al.*, 2019). Additionally, providing information on disease to the illiterate is a challenge, for example by not being able to read the health awareness-raising posters or directions on medications, that is not always accounted for in health programmes (Vlassoff, 1997). Once NTDs reach a household, especially NTDs such as onchocerciasis, which can cause blindness, and other NTDs affecting the skin, girls are often expected to stay at home to take care of the family member in question. They commonly receive less formal education because of the care-taking duty they are fulfilling, maintaining and further aggravating the education gender gap (P. J. Hotez, 2009; UNDP, 2019). Severe manifestations of NTDs within school-age children can also lead to impaired physical and cognitive development, which in its turn can lead to poor school performance, as has been shown for schistosomiasis (Ezeamama *et al.*, 2012; UNDP, 2019).

When women do have access to information on NTDs, a ripple effect can be seen throughout the community. A focus group on NTDs in Ethiopia noted how in this case the information is passed on to other women, further preventing disease among children and adults who are part of their community due to women's typical care-taking roles (Wharton-Smith *et al.*, 2019).

Gender-specific stigma and health-seeking behaviour

Gender, as a social construct, influences health-seeking behaviour. Stigmatisation, an important factor in health-seeking behaviour, is a significant problem in the fight against neglected tropical diseases. The stigma around NTDs is maintained by fear of social rejection, transmission, disfigurement, loss of status and fear of stigma itself (Dijkstra *et al.*, 2017; Try, 2006; Varkevisser *et al.*, 2009). Stigma can be aggravated by lack of knowledge on health and disease or having incorrect knowledge, but also exists in case of sufficient correct knowledge about the disease (Dijkstra *et al.*, 2017). Fear of stigmatisation can lead to a delay in seeking treatment, especially when the stigmatisation is expected to take place while seeking treatment. For example, the earlier mentioned female genital schistosomiasis and misdiagnosis of the disease as a sexually transmitted infection, often had girls face accusations of sexual promiscuity even before becoming sexually active. A qualitative study on urogenital schistosomiasis in an endemic region in Ghana, showed that adolescent girls saw this as a key barrier to seeking healthcare and reverted to at home herbal solutions (Kukula *et al.*, 2019).

Gender-specific stigmatisation is more often researched for women than for men, leading to underreporting of stigmatisation for men (Dijkstra *et al.*, 2017). In general, women appear to be particularly vulnerable to stigmatisation. For example, a systematic review on Leprosy showed that a higher percentage of women perceived stigma, had a lower quality of life score and a higher mental burden compared to men with leprosy. Only one of the 18 articles of the leprosy-focused systematic review by Dijkstra *et al.* showed higher perceived stigma for men (Dijkstra *et al.*, 2017). Women's more inferior position in societies makes them face more rejection from their community, family, partners and prospective partners. This can lead to more social avoidance, treatment delay, self-stigmatisation, withdrawing or being forced to withdraw from school and social activities and mental health issues (Dijkstra *et al.*, 2017; Dunn *et al.*, 2015; Ozano *et al.*, 2020). **The lower status of women can therefore be enforced by the burden of stigmatisation surrounding NTDs, which in its turn enforces the negative effects of stigmatisation** (Dijkstra *et al.*, 2017).

An important form of stigmatisation happens between partners and potential partners. Marriage prospects, often an important part in life in endemic areas, are influenced by NTDs, particularly when an NTDs changes the physical appearance and, or someone's physical capabilities, which is the case for NTDs such as podoconiosis, onchocerciasis and cutaneous leishmaniasis (Chahed *et al.*, 2016; Dunn *et al.*, 2015; Ozano *et al.*, 2020; Tsegay *et al.*, 2018). To give an example, onchodermatitis, caused by onchocerciasis, is known as "the disease that prevents a girl from getting married" in certain parts of Nigeria (Dunn *et al.*, 2015; Guderian *et al.*, 1997). The influence of NTDs on marriage prospects are seen for both men and women (Chahed *et al.*, 2016). However, as marriage is often considered central to the woman's identity in endemic areas, the burden of reduced marriage prospects can lay heavier on women and their role in society (Dunn *et al.*, 2015). **When married, women with NTDs more commonly experience intimate partner violence, defined as physical, sexual or psychological harm by a current or former partner** (Tsegay *et al.*, 2018). In a qualitative study in rural regions of Ethiopia, 80% of women with podoconiosis

experienced intimate partner violence, while 50-71% of women in Ethiopia do at baseline (Tsegay *et al.*, 2018). The same qualitative study also noted that the increase in intimate partner violence often worsens the disease outcome as men often obstruct healthcare access or access to self-care items such as water or bandages. Intimate partner violence also has a negative effect on children within the household, as it is associated with school drop-out and children leaving the house early, reinforcing poverty as an NTD-associated risk factor for the next generation (Tsegay *et al.*, 2018).

Gender-related factors affect health-seeking behaviour for NTDs. In particular when it comes to symptoms related to body parts such as the genitalia for both sexes and breasts for females (Wharton-Smith *et al.*, 2019). Not discussing these types of symptoms with other sexes is a social norm in many NTD-endemic countries, both outside and inside healthcare settings. Women, in a schistosomiasis and lymphatic filariasis-endemic region in Ethiopia, “experiences of discomfort, fear and shame in situations where the patient was seen by a health worker of the opposite gender for diseases affecting the genitalia” (Wharton-Smith *et al.*, 2019). They also experienced shame when having to report on swelling of the limbs (Wharton-Smith *et al.*, 2019). Men reporting on genital symptoms, such as hydrocele as a consequence of lymphatic filariasis, are often reluctant to talk about, or show their symptoms for fear of not being seen as masculine (Burki, 2020). **It is important for all sexes to seek for early consultation on genital-specific symptoms and other symptoms that suffer from taboos** (Wharton-Smith *et al.*, 2019).

Barriers to seeking healthcare are often complex and apart from the already discussed stigmatisation experienced for different genders, can include factors such as geographical access, health beliefs, availability, financial implications and power dynamics (Cohn *et al.*, 2019; Jayakumar *et al.*, 2019; Kumaran *et al.*, 2018; Okwa, 2007; UNDP, 2019; Vlassoff, 1997; Wharton-Smith *et al.*, 2019). **Men in general are more likely to seek medical care than women in endemic areas, as is shown in studies looking at health-seeking behaviour for dengue and visceral leishmaniasis** (Jayakumar *et al.*, 2019; Kumaran *et al.*, 2018). Barriers that men experience may include wanting to protect their idealized masculine image, fears of economic implications of diagnosis and treatment and expectation of having to migrate temporarily for employment, thus not being able to receive treatment (Cohn *et al.*, 2019; UNDP, 2019). In some situations, older men may refuse treatment from young female health workers (UNDP, 2019).

For women, an important barrier to seeking healthcare in general, is the work they do and the expectations related to carrying out domestic duties (Okwa, 2007). Going to a health centre would mean that women couldn't do their domestic duties, which often includes childcare, for which she has no replacement. Men in endemic areas will often not help with domestic duties, and women may experience fear of their husbands taking on a co-wife in their absence to maintain the house. Examples of such activities are mentioned by women in Benin with Buruli Ulcer (Agbo *et al.*, 2019). A woman's health problems, in general, need to be advanced enough for her to go seek medical care, which could mean she can't walk, stand or talk before she goes to seek treatment. In some societies, such as shown in a qualitative study on visceral leishmaniasis in an endemic region in India, weakness is seen as an enduring female health condition. Therefore, women are often not seeing general fatigue as a symptom of a disease (Jayakumar *et al.*, 2019). Women often prefer local

traditional healers for their health problems, which for instance is shown in a study on Leishmaniasis in Columbia, as this has less of an effect on her domestic duties (Darío Vélez *et al.*, 1997; Okwa, 2007). Men are frequently in charge of finances in the household, and women are dependent on the men in her family to provide funds for treatment. Men also often decide whether women are allowed to disclose their symptoms and seek care, in particular when symptoms are stigmatised, as was noted in a study on NTDs in an endemic district in Ethiopia (Wharton-Smith *et al.*, 2019). These factors combined can potentially lead to women thinking their health is of low priority, which is often reinforced by health workers when they are not treated with respect (Burki, 2020; Okwa, 2007). Experiencing low priority of health by women is in particular a problem for women with low income and socioeconomic status (Cohn *et al.*, 2019). **Decentralized treatment is often preferred by women, as they can either remain within their household or close to their household. Women experience less fear of consequences to their domestic duties, financial burden, abandonment or replacement and impact on their image** (Agbo *et al.*, 2019).

Limitations of this work:

For gender in particular, the terminology was not consistent across included papers, using gender as a social construct, gender as an identity and biological sex interchangeably. Especially when it comes to disaggregation of data, the interpretation of studies was not always straightforward because of that.

Recommendations

Recommendations are made on what topics should be covered in NTD programmes, including three more established recommendations (#3, 5 and 6):

- 1. Sex-disaggregated data, gender-disaggregated data and intersectional gender analysis on NTDs and MDA programmes needs to be published on a local level and incorporated in programme design:** Drawing conclusions on NTD and MDA programmes on a national level may mask gender and sex inequity specific to certain communities (Aya Pastrana *et al.*, 2020; Theobald *et al.*, 2017). It is important that this data is collected on a community level rather than per health centre, as health centres can be sparse in some endemic areas and may include a variety of communities (Theobald *et al.*, 2017). Implementation of research that is gender transformative (e.g. including specific adaptations to the different work schedule of men and women in a specific community), and not just based on sex differences, will benefit all when designing NTD programmes (Ozano *et al.*, 2020; WHO, 2020b). Tools such as the WHO Gender Analysis Matrix will help understand gender differences at a local level by separating health-related considerations by gender, for example health-seeking behaviour and experiences in healthcare settings (WHO, 2011). It is important that this data is updated and reimplemented in programme design, as gender roles are not fixed social constructs, they change with time (UNDP, 2019). The collection of gender-disaggregated data on a local level, for example by including it as a requirement

in data quality assessment tools of funding bodies, will increase the scientific understanding of gender and NTDs and will help fill up gaps in research that hinders progress towards achieving the NTD roadmap goals (Ozano *et al.*, 2020).

- 2. Evaluate the effect of gender of healthcare workers in general and specifically community healthcare workers:** Whether community drug distributors (CDDs) are men or women matters when it comes to accessing certain members of certain households but is not always well understood for each community (Ozano *et al.*, 2020; Theobald *et al.*, 2017). It is, for example, often not known whether difficulties in accessing certain household members also has an effect on adherence for other members (Theobald *et al.*, 2017). Community healthcare workers usually understand gender-specific access issues, as they come from the community they serve. Using their knowledge by emphasizing critical thinking and creating forums where they can discuss the gender-related issues they experience within their role, may tackle some of these access issues (Theobald *et al.*, 2017). When it comes to general healthcare, it is recommended to ask patients, where possible, what gender or sex healthcare worker they would prefer (Wharton-Smith *et al.*, 2019). This might remove some of the barriers to seek healthcare when it comes to symptoms of the genitalia or breasts in particular caused by NTDs. Community drug distributors play an important role in the prevention and treatment of NTDs and data collection on influences of their gender on participation, as well as using the knowledge and experiences of local CDDs on gender power dynamics, will help understand and evaluate local differences in participation caused by gender roles.
- 3. Tailor programmes to gender-specific factors and include women in design of programmes:** Understanding daily schedules of all genders will help when designing effective health programmes (Ozano *et al.*, 2020). As previously mentioned, decentralised treatment and prevention programmes, such as door-to-door drug distribution, usually favour women more than a centralized approach does (Agbo *et al.*, 2019; Geyer *et al.*, 2020). This has to do with the household labour and responsibility that women have to their household, they are likely irreplaceable and often face consequences when needing to access healthcare for themselves. Including ways to access men during occupational travel might increase compliance for men. It is important to note, that even on a local level, men and women are not homogenous groups and therefore programmes should be designed in a way that is open to diversity. Awareness of groups being heterogenous might “help prevent programmes that inadvertently reproduce existing inequalities and injustices” (Wenham *et al.*, 2020). Including women in health programmes has often been beneficial to the efficacy of the programmes by being a source for reaching missed groups, and should be encouraged (Geyer *et al.*, 2020; Okwa, 2007). Examples of this are vector control programmes that are often more self-sustaining and effective when created by women, which contributes to gender equity, as well as the involvement of women in sanitation programmes (Rahman *et al.*, 1996; Thys *et al.*, 2015; Wenham *et al.*, 2020).

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- 4. Pay particular attention to pregnant women when designing NTD programmes:** As previously mentioned, oftentimes pregnant women are wrongfully not given medication such as preventive chemotherapy for NTDs, even when World Health Organization guidelines recommend doing so. National guidelines for medication for pregnant women should be taken into account when designing NTD programmes, as well as the stigma that is associated with it, as is noted in the NTD roadmap. In some instances, it has been described that this may lead to a negative opinion on the particular drug, even when not pregnant (Cohn *et al.*, 2019; Theobald *et al.*, 2017).
 - 5. Address gender-related stigma and increase access to health information on NTDs:** Programmes should be aimed at removing stigma from both the community as the health workers when it comes to NTDs (Ozano *et al.*, 2020). One way to do so is by increasing access to information on health and disease for women, for example through local community health workers who are well-placed to understand the gender power dynamics and how to get information to women, who will pass the information on as caretakers of the household (Wharton-Smith *et al.*, 2019). Illiterate members of the community should have access to the same information on disease as literate members. Oftentimes in rural areas, more women are illiterate than men, and they might be excluded from information related to health and disease when distributed in written form (Ejembi *et al.*, 1997).
 - 6. Address power dynamics in households and empower women to be autonomous:** Understanding power dynamics in households for specific communities will help incorporate issues related to access to health, for example for MDA programmes as well as to address barriers to seeking healthcare once ill. As described under recommendation 2, community health workers are often mentioned as well placed to understand these issues (Theobald *et al.*, 2017). Empowering women and making them autonomous when it comes to decisions on their health and access to healthcare, might increase the prioritisation women give their own health which could lead to earlier consultation for NTD-related symptoms (Jayakumar *et al.*, 2019).

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Achieving equity through the NTD 2030 Roadmap

Last year, WHO outlined their second 10-year road map for tackling NTDs between 2021-2030. This roadmap places cross-cutting interventions at its forefront by aiming to support measures that are multi-sectorial and target several diseases simultaneously. Such measures are well positioned to address the role that socioeconomic inequities play in NTD prevalence, as they focus not only on primary healthcare provision, but also on the circumstances that contribute to NTD vulnerability within many communities, such as inadequate WASH provision, inadequate education and inadequate housing. The current roadmap also places an emphasis on increased research and reporting on NTDs in an attempt to fill any knowledge gaps; as highlighted throughout this report, research into the ways in which gender and social structures hinder NTD diagnosis and treatment is severely lacking.

The following section presents the recommendations from within the report and suggests how they can be addressed through the interventions outlined within the 2030 NTD roadmap in terms of both the level at which the intervention operates and the specific type of intervention.

1. Provide basic necessities (housing, water, sanitation, food, clothing).

→ Planning and programme management:

- **Strategy and action planning-** working at the national level to improve availability of clean water, housing, sanitation, food, appropriate footwear and clothing

→ Implementation:

- **Vector control-** prevention and control of human-vector interaction. For example, distribution of mosquito nets and the improvement of housing conditions.
- **Self-care:** provide self-care packages and educate individuals and their families how to use them, e.g. foot hygiene, hand washing
- **Social mobilisation-** promoting awareness within communities of their rights to access basic necessities such as food, clean water, appropriate clothing and those who are responsible for ensuring it
- **Coordination-** sectors such as vector control and WASH make critical contributions to progress on NTDs, and working together more effectively can accelerate and sustain progress towards disease elimination and control.

2. Improve accessibility, availability, affordability, and acceptability of quality healthcare.

→ Planning and programme management:

- **Strategy and action planning-** working at the national level to improve not only healthcare provisions but also the infrastructure which allows patients to access treatment and diagnosis.
- **Quality assurance of health products-** developing harmonized quality guidelines

→ Implementation:

- **Social mobilisation-** promoting awareness within communities of their rights to healthcare access and those who are responsible for ensuring it.
- **Rapid response systems-** development and use of emergency response systems for rapid access to medical treatment for diseases that require immediate attention.
- **Self-care-** as above
- **Provision of assistive device** – to manage disabilities resulting from NTDs, for example adequate footwear for podocoinosis sufferers
- **Healthcare worker training-** improving the levels of healthcare training will improve the quality of care provided.

→ Monitoring and evaluation:

- **Pharmacovigilance-** monitoring adverse effects, effective assessment of the risk benefit of the drugs (for example drugs for Chagas disease)
- **monitoring and evaluation-** monitoring drug effectiveness, antimicrobial resistance, quality control, particularly in countries where falsified drugs are common

3. Provide formal and informal health-related education and better training for medical staff.

→ Implementation:

- **Social mobilisation-** joint awareness building within communities, identifying respected members of a community who can support the dissemination of knowledge.
- **Support networks-** supporting the educational circles within communities and community support networks.
- **Self-care-** supporting individuals in managing their disease personally and/or providing family members with the knowledge and resources to provide supportive care.

4. Increase research efforts.

- **Monitoring and evaluation:** improving data collection and management, analysis, mapping, impact assessments, surveillance and reporting systems
- **Advocacy and funding:** Research and innovation are fundamental enablers of programmatic progress for all diseases
- **Planning and programme management:**
 - **Mapping-** Mapping several NTDs in a specified area or a defined population to enhance understanding of disease incidence and prevalence.
 - **Data management-** Hosting a data management tool (e.g. a cross-disease dashboard within the broader national health management information system) to collect, store and display disaggregated data for several NTDs for decision-making and reporting

5. Encourage policymakers to follow a rights-based approach.

- **Planning and programme management:**
 - **Strategy and action planning-** a rights-based approach should be encouraged when developing a national strategy and annual plan to tackle NTD
- **Implementation:**
 - **Joint awareness and community education-** increasing awareness of the right to health

6. Address and budget for co-morbidities such as stigma and mental health burden in NTD eradication programmes.

- **Implementation:**
 - **Counselling and psychological support-** provision of and support for counselling and support for NTD patients.
 - **Routine assessment of mental health-** for patients with specific NTDs, particularly those with chronic conditions
 - **Social mobilization-** focussing on behavioural change and stigma as well as direct healthcare provision.

7. Encourage governments to incorporate the right to health in their constitution.

- **Planning and programme management:**
 - **Strategy and action planning-** a rights-based approach should be encouraged when developing a national strategy and annual plan to tackle NTD, dialogues should be encouraged with

governments to incorporate the right to health in the constitution which likely will enhance political commitment

8. Support claims to the right to health in court.

→ Planning and programme management:

- **Strategy and action planning-** develop a framework and national guidelines to identify violation of human rights and support a claim in court as a last resort

→ Implementation:

- **Social mobilisation-** increase awareness of the right to health, to trigger social mobilization and engagement of communities to demand aid
- **Rapid response system-** when human rights are violated, particularly in areas of conflicts and war zone, or when a discriminatory law is implemented, a rapid response system should be in place to remedy to the rights deprivation

→ Monitoring and evaluation:

- **Monitoring-** monitoring cases of human rights violation as neglected populations typically do not have the power to advocate for their rights, particularly in areas of conflicts or in dictatorship
- **Reporting-** collecting evidences and cases of human rights violation/deprivation in relation with NTDs to provide material for advocacy and decision-making

9. Encourage pharmaceutical companies to adopt human rights guideline.

→ Planning and programme management:

- **Strategy and action planning-** dialogues should be encouraged with pharmaceutical companies to secure drugs donations, encourage fair pricing, fair use of intellectual property and encourage research and development for diagnosis and treatment for NTDs which represent low-profit opportunities
- **Supply chain management-** engaging in negotiations with pharma companies to ensure provision of treatments and diagnostics

10. Identify duty holders utilising human rights as a framework.

→ Planning and programme management:

- **Strategy and action planning-** a rights-based approach should be encouraged when developing a national strategy and annual plan to tackle NTD, dialogues should be encouraged with all stakeholders – donors, pharmaceutical companies, implementing partners, nongovernmental organizations and academic institutions – to increase their commitments to overcoming NTDs in the coming decade

11. Implement interventions in an integrated fashion.

→ Planning and programme management:

- **Strategy and action planning-** focussing on cross-cutting interventions such as WASH and integrated vector-control programmes that can tackle multiple NTDs.

12. Promote an interdisciplinary approach.

→ Planning and programme management:

- **strategy and action planning-** developing cross-cutting strategies at the national level that focus on the joint delivery of interventions that are common to several diseases.

→ Implementation:

- **Social mobilisation-** focussing on behavioural change and stigma as well as direct healthcare provision.

→ Implementation:

- **One Health approaches-** understanding how social norms influence transmission, diagnosis and treatment patterns.

13. Increase NTD-awareness amongst communities alongside treatment.

→ Implementation:

- **Social mobilisation-** joint awareness building within communities, identifying respected members of a community who can support the dissemination of knowledge.

→ Implementation:

- **Support networks-** supporting the educational circles within communities and community support networks.

→ Implementation:

- **Self-care-** supporting individuals in managing their disease personally and/or providing family members with the knowledge and resources to provide supportive care.

14. Increase community trust in healthcare professionals.

→ Planning and programme management:

- **Quality assurance of health products-** by ensuring treatment options are safe and effective, trust in the healthcare system will increase.

→ Implementation:

- **Social mobilisation-** educating healthcare professionals on NTDs may lessen discriminatory behaviour and prejudice. This will in turn promote better relations between patient and healthcare provider, thereby increasing trust within the community.

→ **Implementation:**

- **Healthcare worker training-** building the capacity of healthcare workers to diagnose, treat and care for patients with NTDs will be improve treatment outcomes for patients.

15.Ensure NTD interventions do not weaken other aspects of healthcare systems.

→ **Implementation:**

- **Active case-finding-** focussing on preventative measures such as searching for contacts with large transmission potential can help reduce the burden of NTDs.

→ **Implementation:**

- **Healthcare worker training-** building the capacity of healthcare workers to diagnose, treat and care for patients will increase the speed and efficiency with which patients can be managed.

→ **Implementation:**

- **Point of care diagnosis-** using a point-of-care multiplex diagnostics platform which can be used to test populations for multiple endemic NTDs will man diagnostic procedures are more time efficient.

→ **Implementation:**

- **Preventative chemotherapy-** supporting community led and managed distribution and administration of drugs on a volunteer basis such that the pressure of the formal healthcare service is lessened.

→ **Implementation:**

- **Self-care-** supporting individuals in managing their disease personally and/or providing family members with the knowledge and resources to provide supportive care.

16.Collect and interpret data on NTD treatment programmes and MDA coverage at a local level.

→ **Planning and programme management:**

- **Mapping-** Mapping several NTDs in a specified area or a defined population to enhance understanding of disease incidence and prevalence.

→ **Planning and programme management:**

- **Data management-** Hosting a data management tool (e.g. a cross-disease dashboard within the broader national health management information system) to collect, store and display disaggregated data for several NTDs for decision-making and reporting.

17. Tailor MDA delivery systems to the local region and the disease treated.

→ Planning and programme management:

- **Strategy and planning-** ensure nationwide strategies are both over-arching but are also tailored to specific needs of specific areas. This will be combined with improved mapping.

→ Planning and programme management:

- **Mapping-** Mapping several NTDs in a specified area or a defined population which allow the best form of drug/care administration programme. This is particularly important when gathering data, as there is a need to understand the whether the disease prevalence varies depending on gender, ethnicity, locations. This will help inform MDA plans that are culturally sensitive.

18. Sex-disaggregated data, gender-disaggregated data and intersectional gender analysis on NTDs and MDA programmes needs to be published on a local level and incorporated in programme design.

→ Planning and programme management:

- **Data management-** gender-disaggregated data, as well as sex-disaggregated data, should be collected on a local community level to not mask inequity by only looking at national levels.

→ Monitoring and evaluation:

- **Surveillance/Reporting-** sex-disaggregated data, gender-disaggregated data and intersectional gender analysis should be updated and reimplemented in programme design, as gender roles are social constructs that change with time.

19. Evaluate the effect of gender of healthcare workers in general and specifically community healthcare workers.

→ Planning and programme management:

- **Data management-** include data collection of whether healthcare workers, and in particular community health workers, are men or women in combination with gender-disaggregated data of patients.

→ Implementation:

- **Social mobilisation/Healthcare worker training-** Emphasize critical thinking and evaluation to community healthcare workers when it comes to gender-specific access issues.

→ Monitoring and evaluation:

- **Reporting-** evaluate the influence of whether healthcare workers, and in particular community health workers, were predominantly men or women and the effect it has had on the outcome of the programme. Include knowledge of community healthcare workers on local gender-related issues in evaluation.

20. Tailor programmes to gender-specific factors and include women in design of programmes.

→ **Planning and programme management:**

- **Mapping-** include daily schedules of all gender roles while mapping out NTD programmes, to allow for gender equity when designing NTD programmes.

21. Pay particular attention to pregnant women when designing NTD programmes.

→ **Planning and programme management:**

- **Strategy and action planning-** include information on national access to preventive chemotherapy for pregnant women when designing NTD programmes.

→ **Monitoring and evaluation:**

- **Reporting-** report on results of availability of preventive chemotherapy to pregnant woman and relate to drug-related stigma.

22. Address gender-related stigma and increase access to health information on NTDs.

→ **Implementation:**

- **Social mobilisation/Healthcare worker training-** once sufficient research has been carried out into the ways in which gender-related stigma prevents individuals from seeking help or being diagnosed, a concerted effort should be made to counteract such stigma through increasing access to health information and knowledge exchange within communities, for example through community healthcare workers.

23. Address power dynamics in households and empower women to be autonomous.

→ **Implementation:**

- **Preventative chemotherapy-** supporting the formation of MDA programmes which are gender transformative, can promote the role that women play in healthcare provision within communities. Supporting involvement of women in MDA programmes can not only make accessing preventive healthcare easier for other women in the community, but also provide women with outwardly facing roles within the community.

Appendix

Search terms per database

EMBASE via Ovid

1. neglected disease/ or tropical disease/ or neglected tropical disease/
2. neglected disease*.tw. or tropical disease*.tw. or neglected tropical disease*.tw
3. gender/ or gender-based violence/ or gender bias/ or gender identity/ or "sexual and gender minority"/ or sexism/ or rights, human/ or human rights abuses/ or human rights violation/ or health equity/ or health care delivery/ or health care disparity/ or health care access/
4. gender.tw. or sexism.tw. or sexist.tw. or discrimination.tw. or women's right.tw. or prejudice.tw. or child advocacy.tw. or citizenship.tw. or civil right*.tw. or consumer advocacy.tw. or freedom.tw. or human dignity.tw. or patient advocacy.tw. or patient right*.tw. or reproductive right*.tw. or right to life.tw. or social justice.tw. or women's right*.tw. or sexual right*.tw. or discrimination.tw. or equality.tw. or right to health.tw. or rights.tw. or privacy.tw. or dignity.tw. or human right*.tw. or universal health care.tw. or universal healthcare.tw. or equal healthcare.tw. or equality.tw. or equal access.tw. or health care reform.tw. or health policy.tw. or healthcare reform.tw. or health policy.tw. or health care disparit*.tw. or healthcare disparit*.tw. or health care delivery.tw. or healthcare delivery.tw. or health equity.tw. or right to health.tw. or health equity.tw. or health care access.tw. or healthcare access.tw. or socioeconomic.tw. or ethnic minorit*.tw. or sexual right*.tw. or universal healthcare.tw.
5. #1 OR #2
6. #3 OR #4
7. #5 AND #6

MEDLINE via Ovid

1. exp neglected diseases/
2. neglected disease*.tw. or tropical disease*.tw. or neglected tropical disease*.tw
3. exp gender identity/ or exp sexism/ or exp prejudice/ or exp women's rights/ or exp human rights/ or exp delivery of health care, integrated/ or exp health equity/
4. gender.tw. or sexism.tw. or sexist.tw. or discrimination.tw. or women's right.tw. or prejudice.tw. or child advocacy.tw. or citizenship.tw. or civil right*.tw. or consumer advocacy.tw. or freedom.tw. or human dignity.tw. or patient advocacy.tw. or patient right*.tw. or reproductive right*.tw. or right to life.tw. or social justice.tw. or women's right*.tw. or sexual right*.tw. or discrimination.tw. or equality.tw. or right to health.tw. or rights.tw. or privacy.tw. or dignity.tw. or human right*.tw. or universal health care.tw. or universal healthcare.tw. or equal healthcare.tw. or equality.tw. or equal access.tw. or health care reform.tw. or health policy.tw. or healthcare reform.tw. or health policy.tw. or health care disparit*.tw. or healthcare disparit*.tw. or health care delivery.tw. or healthcare delivery.tw. or health equity.tw. or right to health.tw. or health equity.tw. or health care access.tw. or healthcare access.tw. or

socioeconomic.tw. or ethnic minorit*.tw. or sexual right*.tw. or universal healthcare.tw.

5. #1 OR #2
6. #3 OR #4
7. #5 AND #6

Global Health via EBSCO

1. DE "neglected tropical disease" OR DE "neglected disease"
2. TX "neglected tropical disease**"
3. DE gender relations OR DE sexual discrimination OR DE sexual roles OR DE women workers OR DE human rights OR DE food security OR DE water security OR DE civil rights OR DE equality OR DE social classes OR DE minorities OR DE attitudes OR DE ethnic groups OR DE equity
4. TX gender OR TX sexism OR TX sexist OR TX discrimination OR TX "women's right*" OR TX prejudice OR TX "child advocacy" OR TX citizenship OR TX "civil right" OR TX "consumer advocacy" OR TX freedom OR TX "human dignity" OR TX "patient advocacy" OR TX "patient right*" OR TX "reproductive right*" OR TX "right to life" OR TX "social justice" OR TX "women's right*" OR TX "sexual right*" OR TX discrimination OR TX equality OR TX "right to health" OR TX rights OR TX privacy OR TX dignity OR TX "human right*" OR TX "universal health care" OR TX "universal healthcare" OR TX "equal healthcare" OR TX equality OR TX "equal access" OR TX "health care reform" OR TX "health policy" OR TX "healthcare reform" OR TX "health policy" OR TX "health care disparit*" OR TX "healthcare disparit*" OR TX "health care delivery" OR TX "healthcare delivery" OR TX "health equity" OR TX "right to health" OR TX "health equity" OR TX "health care access" OR TX "healthcare access" OR TX "socioeconomic" OR TX "ethnic minorit*" OR TX "sexual right*" OR TX "universal healthcare"
5. #1 OR #2
6. #3 OR #4
7. #5 AND #6

Cochrane Library

1. MeSH descriptor: [medline exp terms] explode all trees
2. neglected disease* OR tropical disease* OR neglected tropical disease*
3. MeSH descriptor: [medline exp gender terms] explode all trees
4. gender OR sexism OR sexist OR discrimination OR women's right* OR prejudice OR child advocacy OR citizenship OR civil right OR consumer advocacy OR freedom OR human dignity OR patient advocacy OR patient right* OR reproductive right* OR right to life OR social justice OR women's right* OR sexual right* OR discrimination OR equality OR right to health OR rights OR privacy OR dignity OR human right* OR universal health care OR universal healthcare OR equal healthcare OR equality OR equal access OR health care reform OR health policy OR healthcare reform OR health policy OR OR health care disparit* OR healthcare disparit* OR health care delivery OR healthcare delivery OR health equity OR right to health OR health equity OR health care

access OR healthcare access OR socioeconomic OR ethnic minorit* OR sexual
right* OR universal healthcare

5. #1 OR #2
6. #3 OR #4
7. #5 AND #6