

## 2.2.2. Neglected diseases

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*“There is no excuse for failure to give the neglected tropical diseases higher priority, and to integrate strategies for disease control within health and community-based systems”*  
(*Remembering the neglected tropical diseases*, «Lancet» 2007, 370, p. 1880)

### *Neglected diseases, poverty and development*

*Neglected Tropical Diseases* - NTD are a group of 13 infectious diseases\* that affect poor countries in particular. They are called “neglected” because, thanks to improved living standards, they are no longer a problem in industrialised countries, the countries with political and economic power and influence today, thus are also no longer the centre of the world’s attention as a public health problem. Thus one could speak of neglected populations afflicted by diseases that, consequently, are equally neglected, or forgotten. These diseases have the following features in common<sup>1</sup>:

1. are highly endemic in rural or poor urban areas in low income countries (they are the most common infections among the 2.7 billion people who survive on less than \$2 per day);
2. cause chronic diseases which can lead to disability, often underestimated or misunderstood;
3. impede children’s normal growth, cognitive development and education;
4. undermine adult work productivity (it has been calculated that NTDs cause the loss of billion of dollars each year<sup>2</sup>);
5. increase risks during pregnancy.

Many of these diseases lead to physical deformities which stigmatise those affected and increase their social emargination.

These features make NTDs a health problem that exacerbates the poverty in which they flourish and impedes economic change and development in poorer countries trapping them into a vicious circle of poverty and disease. Every year 534,000 people die from NTDs, an enormous burden also for socio-economic im-

\* The 13 most important neglected diseases include (Table 1):

- 3 protozoan infections transmitted by vectors (leishmaniasis, human African trypanosomiasis (sleeping sickness), Chagas disease)
- 3 bacterial infections (trachoma conjunctivitis, leprosy, Buruli ulcer)
- 7 helminthic infections (ascariasis, trichuriasis, hookworm disease, lymphatic filariasis, onchocerciasis, Guinea Worm or dracunculiasis, schistosomiasis)

plications as it amounts to a loss of 57 million DALYs\*\* (**Table 1**). Taken together, NTDs are fourth in importance among communicable diseases, behind respiratory infections (3<sup>rd</sup>); HIV/AIDS (2<sup>nd</sup>); and diarrhoea (1<sup>st</sup>)<sup>3</sup>.

*Table 1.* The main Neglected Tropical Diseases (NTDs): prevalence, population at risk, mortality and burden of disease (Hotez 2006, 2007).

<i>Disease</i>	<i>Global prevalence (millions)</i>	<i>Population at risk (millions)</i>	<i>Deaths</i>	<i>DALYs (millions)</i>
Ascariasis	807	4,200	60,000	10.5
Trichuriasis	604	3,200	10,000	6.4
Hookworm disease	576	3,200	65,000	22.1
Schistosomiasis	207	779	280,000	4.5
Lymphatic Filariasis	120	1,300	-	5.8
Trachoma	84	590	-	2.3
Onchocerciasis	37	90	-	0.5
Leishmaniasis	12	350	51,000	2.1
Chagas Disease	8-9	25	14,000	0.7
Leprosy	0.4	ND	6,000	0.2
African Trypanosomiasis	0.3	60	48,000	1.5
Dracunculiasis	0.01	ND	-	<0.1
Buruli ulcer	ND	ND	-	ND
<i>Total</i>	-	-	534,000	56.6

More and more attention is focusing on the link between health and poverty, especially in relation to the Millennium Development Goals (MDG). Evaluation of progress made so far towards achieving these Goals has revealed that Sub-Saharan Africa is running worryingly late when compared to other areas of the planet. Many of the Millennium Goals concern questions of health, but only “the big three”, the three best known epidemics HIV/AIDS, malaria and tuberculosis (TB) were specifically named. Other infections, which includes NTDs, and which affect at least as many people, were relegated to a generic category of a struggle against “other diseases”<sup>4</sup>.

In 2006, the World Health Organisation (WHO) announced a change in its strategy for dealing with NTDs. Instead of recommending focused campaigns aimed at specific diseases, it would now concentrate on maximising benefits for the greatest number of people at risk who could be treated with a single package of drugs<sup>5</sup>. Furthermore, instead of recommending that there should be separate distribution channels for each control programme, the WHO now proposed exploiting a series of already existing channels, such as the school system and local community structures<sup>6</sup>. It has been calculated that this “fast impact strategy”

\*\* Disability Adjusted Life Years: years of life lost, either because of a disability or from premature death due to a disease.

could cut DALYs by tens of millions each year and help towards achieving the eight MDGs amongst which are: reduce poverty; increase access to primary education; reduce infant mortality; improve maternal health care; continue the struggle against HIV/AIDS, malaria and TB and against all other widespread diseases on the planet<sup>7</sup>.

### *Neglected diseases and human rights*

The neglected diseases are both the cause and the result of violations of human rights. Disregarding human rights, such as the right to clean water, adequate housing, sufficient food, to a healthy environment, to a job, to education and information and to participation, makes both individuals and communities more vulnerable to neglected diseases. People affected by any of the neglected diseases are, in their turn, more vulnerable to violations of their human rights, which include the right to health, to life, to non discrimination, to work, to education and to access to the benefits deriving from scientific advance.

Human rights have important implications for the struggle against NTDs and should be an integral element in health policies and any related strategies. In their turn, NTD control programmes are good examples of how public health interventions can contribute to better observance of human rights<sup>8</sup>. The virtuous circle between public health interventions and human rights observance is clear in the following contexts:

1. promoting health policies that make treatment for NTDs more readily available and accessible for those most at risk and for the most disadvantaged groups within the population: guarantee equality of access to health care;
2. actively involving communities in mass campaigns to control NTDs for example, *Community Directed Treatment Intervention* for the treatment of onchocerciasis (river blindness) with ivermectin, to ensure greater community participation;
3. re-defining priorities through political advocacy that aims to focus more attention on populations in neglected areas arguing for a fairer and more equal distribution of available resources, both at the level of the Governments of countries where the diseases are endemic and by the International Agencies;
4. encouraging the scientific community to become more aware of the NTD problem and to invest more in research and development of diagnostic tools, drugs and vaccines specifically for NTDs;
5. promoting anti-discrimination policies for the struggle against stigmatisation of people with disfiguring diseases, such as leprosy or lymphatic filariasis;
6. improving access to essential drugs for NTD treatment, especially the low cost generic products;
7. reinforcing the primary health care system through an integrated approach, and the replacement of vertically managed interventions.

*Drugs and neglected diseases*

Neglected drugs for neglected diseases which afflict neglected populations. Even researchers are not interested in many of the diseases that afflict the poorer populations of the world and very little is being done to improve either diagnoses or treatments for these illnesses. Treatment is being neglected in two ways: efficacious and effective drugs do exist, but either they are not being administered correctly, or the molecules available are too old, or they have often serious side-effects and research has gone missing.

In the case of parasitic diseases, such as schistosomiasis, intestinal helminthiasis and filariasis, there are drugs available: what is required are prevention and treatment programmes, integrated into local health systems, that can reach out to targeted at-risk populations before the infections have permanent damages. Preventive chemotherapy for helminthic diseases for example, reduces both mortality and morbidity even in pre-school age children, it has a positive effect on child nutrition and, consequently, on progress at school, it also has a positive effect on the health of both pregnant women and of their infants<sup>9</sup>.

For years now, however, research has invested neither funds nor resources in other NTDs and there is a vacuum, called the so-called '10/90 gap' which, first noted in 1990, is still relevant today: 90 per cent of the world's health problems receive 10 per cent of the resources destined for health care<sup>10</sup>. Between 1975 and 2004, a 30 year period, 1,556 new chemical substances became available, but only 10 of these were designed for the neglected diseases. This figure rises to 18 if malaria is included among the neglected group and to 21 if TB is considered too<sup>11</sup>: i.e., just over 1% of all new products. If malaria and TB are left out of the count, this means that researchers have come up with one new drug for neglected diseases every three years. The lack of adequate drugs is diseases, damaging in some diseases, especially for leishmaniasis, Chagas disease and African trypanosomiasis.

*Neglected Research and Development (R&D): sleeping sickness*

Human African trypanosomiasis, or sleeping sickness, clearly illustrates what happens when there is no interest in doing research into diagnosis and treatment. There are an estimated 50,000 to 70,000 cases of infection per year, and if the patient is not treated he/she will die. The disease is transmitted by the tse tse fly and is particularly common in isolated areas of sub-Saharan Africa where either there is no health care service network or it is inefficient. Diagnosis is difficult in the early stages of the disease, because of non-specific manifestations and the lack of sensitive diagnostic tools and methods. In the advanced stage, the neurological phase, when the parasite has already crossed the haematoencephalic barrier, the only drugs available at present are either difficult to administer or have severe side-effects (for example, the arsenic derivatives cause death from encephalopathy in 3% to 10% of cases). The drugs available for treatments in the early phases are more efficacious, easier to administer and have less damaging side-effects, thus early di-

agnosis is vitally important in order to save lives. This situation will not change until researchers manage to introduce on the market more efficacious molecules designed for the later stages of the disease, drugs which will be easily to administer even in poorer countries and will have no deadly side-effects unlike those available today.

In 2003, the *Drug for Neglected Diseases Initiative* was launched as a non-profit collaboration between Research Institutes, Non-Government Organisations (NGOs), various Foundations and many Governments of developing countries<sup>12</sup> in the attempt to meet the outstanding need for greater research efforts to find new, more efficacious and safer drugs to treat trypanosomiasis and other NTDs: new drugs whose costs must be sustainable for countries with limited resources.

### *The cost benefits of control: deworming and development*

Countries with limited resources available must optimise their use when defining priorities and choosing strategies for interventions. The scientific community is, today, beginning to be aware of the need for optimisation and is promoting integrated control of some neglected diseases which, either because they are transmitted in a similar way or because the treatment is similar, can be controlled simultaneously. This increases the overall benefits of the treatment and significantly reduces its costs. The strategies suggested highlight the crucial role of preventive treatment and the Manual produced by WHO in 2006 offers clear indications on how and when to use the drugs, which are given free of charge or at a low-cost<sup>13,14</sup>. Diseases such as onchocerciasis, lymphatic filariasis, schistosomiasis, intestinal helminthiasis and conjunctivitis (trachoma) can be controlled with the administration of a few drug products. All are diseases that are associated with poverty, with poor health and hygiene conditions that facilitate transmission; poverty that the diseases themselves exacerbate because they impede productive economic growth. Preventive chemotherapy can break this vicious circle, thanks to the availability of efficacious and accessible drugs which cost about \$0.40 per year, per person treated, which is very little when compared with the drug costs of malaria (\$100), TB (\$800) and HIV/AIDS (\$1,000)<sup>15</sup>. When these drugs are distributed through horizontal collaborative partnerships reinforcing local health services system, they can even be distributed with a saving of from 26% to 47% on the costs that would be incurred by vertical, non integrated programmes.

NTD control could be integrated with distribution of vitamin A and insecticide-treated mosquito nets, or with vaccination campaigns, and would be a highly effective intervention for improving public health; a priority investment in human capital which would work towards reducing global poverty. It has been estimated that it would cost from 2 to 9 dollars to avoid one DALY (Disability Adjusted Life Year) by deworming campaigns<sup>16</sup>. It has been estimated that investment in the control and elimination of NTDs could yield a 15%-30% return for the investor<sup>17</sup>.

*Towards eradication: guinea worm*

The data on guinea worm or dracunculiasis are encouraging as a further 12 countries were declared free of the disease at the end of March 2007. The first disease to be declared eradicated was smallpox, but in less than two years time, dracunculiasis could become the second success story (and the first of the parasitic diseases to go). Beyond the target of 2009, the efforts made so far to eradicate dracunculiasis have brought the estimate of the number of people infected tumbling from 3 million in more than 20 countries in the 1980s to 25,000 cases in only nine countries in 2007<sup>18</sup>.

Eliminating the guinea worm will improve the socio-economic condition of all affected populations. The disease is spread through drinking contaminated water: people seek relief from the burning skin lesions by immersing them in water. Thus prevention must start from health and hygiene education and from ensuring access to a safe water supply with wells and adequate filtering methods. Once again, this disease thrives on poverty and poor health, hygiene and living conditions and itself helps perpetuate that poverty. The disease usually flares up around harvest time, thus stops people from working (earning-producing) in the busiest (best) period of the year: this makes it harder for parents to care for their children, and increases the risk of malnutrition. In addition, when children have the disease they miss a lot of schooling, so dracunculiasis affects their education and, in the long term, their future lives.

*Conclusions*

Notwithstanding the fact that more attention has been paid to NTDs in recent years than was before, there is a real risk that these diseases will remain neglected, forgotten, when international health policies establish priorities for health interventions. Better known diseases, such as HIV/AIDS, malaria and TB, attract far more global interest and, consequently, receive more funding for disease control. The question that should be addressed is what criteria should be adopted in order to establish intervention priorities<sup>19</sup>. This approach raises three important considerations:

- the first concerns the conviction that priorities should not be established on the basis of the disease (an approach which encourages vertical intervention programmes aimed at single diseases) but should focus on wide spectrum programmes that target the patient, who often suffers from several diseases, and on community-based intervention strategies that seek to guarantee accessible health care for all;
- the second concerns evaluating priorities, that should not be chosen on the grounds of the desired or expected results – the outcomes, but rather should consider how these ends are to be achieved – the process. This calls attention on the role and the importance of community participation in decision-making processes;

- the third concerns better use of scarce resources. Here come the interests of the donors, which have a lot of influence when deciding how resources should be allocated, sometime contrast with the need of the recipients. Donors will usually favour high profile, high visibility interventions which will help them improve their image at home, or interventions against diseases that could threaten industrialised countries too.

If these considerations were to enter the debate on international health policies and development strategies, then the more vulnerable populations of the world would no longer be neglected and the diseases afflicting their life and hampering their health could be cured.

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