Intensified Control of Neglected Diseases
Report of an International Workshop
Berlin, 10 –12 December 2003
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Intensive efforts are currently underway to control and prevent the major killer diseases, HIV/AIDS, tuberculosis and malaria. Nevertheless, many millions of people in the world today are unable to lead healthy, productive lives because they are incapacitated by diseases such as lymphatic filariasis (elephantiasis), schistosomiasis, intestinal parasites, leprosy, sleeping sickness (African trypanosomiasis) and leishmaniasis and are unable to achieve their full potential. Those suffering the most live in resource-poor communities, without political influence, and often in remote areas, conflict zones or urban slums where there is little or no access to health or other services.

These neglected diseases have afflicted humanity since time immemorial, incapacitating millions of people. Paradoxically these diseases have a low profile and status in public health priorities. The lack of reliable statistics on the disease burden, and often even their unpronounceable names, has hampered efforts to bring these diseases out of the shadows and they continue to take a heavy toll.

The high morbidity of neglected diseases affects school attendance, cognitive development, growth and overall productivity. These diseases also often lead to severe disabilities thereby impairing people’s ability to earn a livelihood. The burden of chronic care perpetuates misery and suffering.

As neglected diseases primarily affect marginalized communities, they tend to be hidden below the “radar screens” of health services and politicians. Moreover, as they do not pose a threat to developed countries and do not travel easily, mobilizing international attention, and above all resources, is a major challenge.

There is an urgent need for new tools to tackle some of these diseases as current treatments tend to be very complex and highly toxic. However, new models to finance research and development need to be found as traditional market mechanisms fail in the absence of a commercial market.

The strategy for addressing these diseases needs to be set in the context of wider public health measures and pro-poor policies that also address issues such as lack of educational opportunities and access to clean water and sanitation.
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Successes we can build on

There are, however, good grounds for optimism. New drugs, control tools and implementation strategies have made it possible – for the first time in history – to set time-limited goals for bringing some of these diseases under control. Broadly based partnerships have been formed to achieve these goals, and with this new commitment, momentum is building.

There are striking examples of what has been achieved: more than 13 million people have been cured of leprosy and the prevalence rate has dropped by over 90% since 1985; the number of people suffering from guinea-worm has dropped from 600 000 in 1990 to 32 000 in 2003; the lymphatic filariasis programme now reaches 130 million people in 38 countries; 40 million people have been protected from river blindness.

More needs to be done, however, and done soon. In some cases the challenge lies in scaling up access to existing tools; in others it involves going back to the drawing board, simplifying the strategy or even developing new tools.

The outlines of a framework

The framework for action against neglected diseases needs to address the harsh realities of limited financial resources, a shortage of trained personnel, and the weakness or absence of health infrastructures for reaching affected populations. Strategies also need to respond to the particular mix of health needs under different epidemiological conditions.

However, there is considerable scope for synergies as a result of the geographical overlap of many neglected diseases because of their close association with poverty. This favours the adoption of an integrated approach to tackling neglected diseases. Core activities such as service delivery, advocacy, logistics, monitoring and surveillance can be pooled for use across various diseases with resultant savings and efficiencies.

Experiences in some control programmes have led to ingenious solutions that can be readily adapted to others. Systems carved out for the delivery of one intervention are being used to deliver others.
Research has an indispensable role to play. The most immediately relevant research need is to find ways to improve the use of existing tools as well as to simplify complex treatment guidelines. Safer and more effective drugs are also urgently needed to replace outdated and toxic treatments.

Innovative approaches are needed to make drugs more affordable and accessible to patients. Research capacity within affected countries needs to be strengthened to empower them to develop and test pragmatic approaches to improve communities’ access to treatment.

Financing the interventions poses many challenges, not only in terms of fundraising but also in defining the resources needed and how best to channel them while ensuring accountability. Mobilizing resources and the political commitment to tackle hitherto neglected diseases requires a clear presentation of compelling evidence that captures their broader impact on poverty and development.

**We need a paradigm shift**

We need to move away from a purely disease-centred approach to one that is more sensitive to the needs of communities. We should be looking at neglected communities, and not just at neglected diseases, and providing these communities with an integrated solution to their health problems. This will not only ensure more efficient use of limited resources but also help them pull themselves out of the vicious cycle of poverty and illness.

Ownership clearly has to reside with local communities despite the temptation to adopt a commando approach to obtain quick results. Although from a national perspective, neglected diseases may have a low priority, they have a high priority for those communities affected. They should be closely involved in identifying ways to improve patients’ access to treatment such as community based distribution or accompanied treatment. Every effort should be made to empower patients and communities to manage the long-term effects of the diseases.
The so-called "neglected" diseases are largely ancient infectious diseases that have burdened humanity for centuries. In their long histories, several have acquired notoriety as deforming and disabling diseases, often associated with intense stigma. However, they have not always been neglected. In the past, the magnitude of their impact on health and productivity led to considerable research into their biology-and epidemiology, and effective control tools were developed for most. In addition, as living conditions improved in many parts of the world, opportunities for transmission were reduced. As a result, these diseases are now rarely seen in populations that enjoy good access to health services and a reasonable standard of living.

Neglect – a key feature of neglected diseases

Today, neglected diseases can be usefully considered as a group because they are concentrated almost exclusively in impoverished populations living in marginalized areas – the populations left behind by socioeconomic development.

Number of poor by country earning less than US$ 1 a day

Although medically diverse, neglected diseases share features that allow them to persist in conditions of poverty, where they cluster and frequently overlap.

The Berlin workshop on intensified control for neglected diseases was co-hosted by WHO, German Technical Cooperation (GTZ), German Ministry for Development and Technical Cooperation, Kreditanstalt für Wiederaufbau (KFW), German Ministry for Health and Social Security, and the Special Programme for Research and Training in Tropical Diseases (TDR). It brought together experts from many sectors – public health, economics, human rights, research, NGOs, industry - who deliberated on key challenges to intensify and scale up efforts to tackle neglected diseases. This publication summarizes these rewarding and often intense discussions and outlines a framework for future action. The framework will be further developed in line with country-specific needs, and translated into concrete implementation plans to tackle neglected diseases and address the health needs of neglected populations.

The need to fight neglected diseases is incontestable – from a moral perspective, a human rights perspective and an economic perspective, as well as a global public goods perspective. All interested parties need to work together to simplify the approach and tools to address these problems and develop appropriate strategies. The task is not an easy one, but it can and must be done.

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Neglected diseases, their consequences and the cost of inaction

The so-called “neglected” diseases are largely ancient infectious diseases that have burdened humanity for centuries. In their long histories, several have acquired notoriety as deforming and disabling diseases, often associated with intense stigma. However, they have not always been neglected. In the past, the magnitude of their impact on health and productivity led to considerable research into their biology- and epidemiology, and effective control tools were developed for most. In addition, as living conditions improved in many parts of the world, opportunities for transmission were reduced. As a result, these diseases are now rarely seen in populations that enjoy good access to health services and a reasonable standard of living.

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Although medically diverse, neglected diseases share features that allow them to persist in conditions of poverty, where they cluster and frequently overlap.
Negligible incentives for R&D
Neglected diseases have traditionally suffered from a lack of incentives to develop drugs and vaccines for markets that cannot pay. Research for new products is not commercially viable. When inexpensive and effective drugs already exist, demand for their delivery fails because of the inability to pay. Even when drugs are available at no cost, they may fail to reach populations because delivery systems are rudimentary or non-existent. Inadequate operational and implementation research, as well as inadequate research to develop better and more affordable products, has contributed to this failure.

The high price of neglect
The mortality rates associated with neglected diseases are typically low, but morbidity rates are high. Although the full impact of the neglected diseases has thus far been inadequately documented, there is a growing recognition that it is significant. The toll it takes on human development is reflected in lost potential and reduced productivity due to impaired physical growth and cognitive development, missed days from school and/or work, the care of chronic disabilities, inefficient use of land, etc. It exacerbates the abject poverty existing in the affected areas.

Accurate assessments of socioeconomic impact that go beyond a narrow focus on health care costs could do much to raise the visibility of neglected diseases, place the low cost of interventions in perspective, and demonstrate the remarkable returns on investment. Basic messages about the simplicity and effectiveness of control measures will carry more weight when their ability to avert significant economic costs is part of the argument. This can change only with adequate data that permit a reassessment of the situation. Until such information is available, data for other, better-publicized communicable diseases could serve as a proxy in assessing the impact of neglected diseases.

The burden of communicable diseases divides the world
Gwatkin and Guillot looked at the morbidity and mortality from 25 specific diseases found in the poorest 20% of countries and the richest 20% of countries. This allowed the relative importance of diseases within a specific population group to be assessed in terms of a poverty alleviation strategy, as well as a comparison between the rich and the poor that could lead to an inequality reduction strategy. They found an inverse relationship between economic status and communicable diseases.

Although medically diverse, neglected diseases share features that allow them to persist in conditions of poverty, where they cluster and frequently overlap. Unsafe water and poor sanitation sustain transmission cycles and favour the proliferation of vectors. Lack of access to health services, low levels of literacy, inadequate nutrition and poor personal hygiene all help to increase vulnerability to infection and work against prevention. Where curative interventions exist, they generally fail to reach populations early enough to prevent permanent impairments. Conditions of poverty also work to exclude affected populations from the social systems set up to safeguard health as a fundamental human right.

Neglect occurs at three main levels. At the community level, fear and stigma can sometimes lead sufferers and their families to conceal their condition. At the national level, these diseases are often hidden – out of sight, poorly documented, and silent, as those most affected have little political voice. As a result, neglected diseases are rarely given high priority by ministries of health or finance in endemic countries.

Neglected diseases lack visibility at the international level as well. Tied as they are to specific geographical and environmental conditions, they are not perceived as direct threats to industrialized countries. They impair or permanently disable millions of people, but cause comparatively few deaths. This low mortality diminishes their stature when seeking to gain international attention and funds, and they are frequently given low priority in the agendas of development cooperation agencies.
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Based upon the situation in 1990, they estimated that communicable diseases cause 59% of deaths and 64% of disability-adjusted life years (DALYs) among the populations living in countries with the lowest per capita incomes. Communicable diseases are responsible for 77% of the mortality gap and 79% of the DALY gap between the world’s poorest 20% and the richest 20%.

Although the burden is considerable, it is still considered to be an underestimate of the extent of the problem. A 92% reduction in the burden of communicable diseases in poorest countries would be required to close the mortality gap with the richest countries.

The leading causes of death in the poorest countries are respiratory infections, diarrhoeal diseases and perinatal conditions – all of which are preventable and easily curable. These illnesses are also responsible for the majority of morbidity as expressed in DALYs. Noncommunicable diseases also cause higher rates of disability and death among the poor but these diseases accounted for less than one-fifth of the death/DALY gap between the richest and the poorest countries. The poor–rich differences in the rate of death from communicable diseases appear to be 4–12 times greater than they are for noncommunicable diseases.

**Women and children are more vulnerable**

A significant gender gap was also found in communicable diseases as women face additional barriers to seeking, and often receiving, treatment. Communicable disease morbidity and mortality were higher among poor women than poor men, especially because of maternal health.

Children bear a heavy burden. Nearly 70% of all deaths and 75% of all DALYs in the world from communicable disease occur in children under 14. In the 5–14 age group the death rate from noncommunicable diseases was 5 times higher among the global poor while the death rate from communicable diseases was 56.2 times higher for the poor than for the global rich. For poor countries whose populations are on average much younger than the global rich, this has major implications both for the ability to participate in education and for future economic productivity.
Communicable disease will remain a burden for the poor

Based on the situation in 1990, it was estimated that deaths attributable to communicable disease would fall from 59% to 44% of all deaths among the global poor by 2020. Deaths from noncommunicable disease among the poor would rise from 32% to 42%. DALY loss from communicable disease would fall from 64% to 43% whilst DALY loss from noncommunicable diseases would increase from 23% to 40%.

However, as communicable diseases would also be declining in richer populations, they would continue to be much more important for the poor. Indeed the estimates for 2020 of 44% of deaths and 43% of DALY loss caused by communicable diseases among the global poor can be compared to the 15% of deaths and 20% of DALY loss in the world as a whole and 7% of deaths and 8% of DALY loss among the global rich.

The authors concluded that, if the aim of the global community is to improve the health of the poor to the maximum possible extent and reduce the poor–rich gap, an accelerated overall decline in communicable diseases would benefit the poor much more than the rich and would produce a life expectancy gain of 4.1 years for the former. This would lead to a reduction in the poor–rich life expectancy gap of 3.7 years. By contrast, the same accelerated decline in noncommunicable diseases would actually widen the gap by 3.9 years.

Even when treatment is subsidized, families can be unwilling or unable to pay because of the burden on their limited resources. This needs to be considered when looking at cost-recovery schemes. Moreover such schemes could lead to the exclusion of the poorest members of a community, who are often the target population.

Evidence-based cost-effective strategies are the cornerstone of any successful disease intervention strategy. Unfortunately such strategies have not yet been developed for some diseases and must be developed urgently.

While there is a reasonable body of literature available on the socioeconomic implications for some diseases such as lymphatic filariasis, for many others there has been little or no attempt to quantify the economic implications despite the considerable burden of death, ill health and disability they cause. These studies should look at the wider implications of the disease, and recommended intervention, for the patients and their families as well as for economic productivity, instead of maintaining a narrow focus on health care costs.

There is an urgent need in many cases for improved and integrated disease surveillance and monitoring.

A number of successful programmes aimed at reducing the disease burdens have been provided through schools. However, specific strategies need to be developed to reach the poorest in each society as many children in this category may not attend school. An additional challenge will be addressing the gender issues, in particular reaching girls in societies where it is not common for girls to attend school.

### The cost of inaction should be weighed against the cost for action (in billion US$)

<table>
<thead>
<tr>
<th>Annual cost of...</th>
<th>Financial stability</th>
<th>Multilateral trade</th>
<th>Excessive disease</th>
<th>Climate stability</th>
<th>Peace and security</th>
</tr>
</thead>
<tbody>
<tr>
<td>...inaction</td>
<td>50</td>
<td>260</td>
<td>1138</td>
<td>780</td>
<td>358</td>
</tr>
<tr>
<td>...corrective action</td>
<td>0.4</td>
<td>20</td>
<td>93</td>
<td>125</td>
<td>71</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Costs of inaction</th>
<th>Polio eradication</th>
<th>Dracunculasis eradication</th>
<th>Smallpox eradication</th>
<th>Malaria</th>
<th>TB</th>
</tr>
</thead>
<tbody>
<tr>
<td>Costs of corrective action</td>
<td>1.5 p.a.</td>
<td>0.02 p.a.</td>
<td>17% of annual African GDP</td>
<td>4-7% annual GDP</td>
<td></td>
</tr>
<tr>
<td>Costs of corrective action</td>
<td>2 (full eradication)</td>
<td>0.2 (full eradication)</td>
<td>0.3 (168 in benefits)</td>
<td>2.5 p.a. (2007)</td>
<td>0.5 (2007)</td>
</tr>
</tbody>
</table>

### Challenges posed by neglected diseases

Despite many differences, neglected diseases share a number of common features. Future initiatives should build on these features and the challenges outlined below in order to have a synergistic effect:

- These diseases affect the poorest in the community and efforts to address them should form an integral part of pro-poor policies. A reduction in the communicable disease burden will enable communities to become more economically active, thereby narrowing the gap between poor and rich.

- The introduction of basic public health measures, such as access to education, clean water and sanitation, would significantly reduce the burden of a number of diseases in communities where these elements play an important role.

- There is considerable overlap in the prevention and management of these diseases, permitting useful synergies, and emphasizing the need for combined programmes that are integrated into existing education and health infrastructures, particularly primary health care.

- Although the eradication of certain diseases can be achieved at minimal cost per individual patient, the total cost at the national level can be significant in view of the large numbers affected by the diseases. Unless external support is provided, this could have significant opportunity costs and implications for other budgets. It is thus crucial to look at the cost-effectiveness and cost-benefit impact of different health interventions.
Even when treatment is subsidized, families can be unwilling or unable to pay because of the burden on their limited resources. This needs to be considered when looking at cost-recovery schemes. Moreover such schemes could lead to the exclusion of the poorest members of a community, who are often the target population.

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### Simulation of a schistosomiasis control programme costs for Mozambique

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Unit cost</th>
<th>Quantity</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Screening</td>
<td>0.02</td>
<td>4 800 000</td>
<td>96 000</td>
</tr>
<tr>
<td>Treatment of those infected</td>
<td>0.25</td>
<td>2 800 000</td>
<td>700 000</td>
</tr>
<tr>
<td>Treatment of side effects</td>
<td>0.01</td>
<td>280 000</td>
<td>2 800</td>
</tr>
<tr>
<td>Administration</td>
<td></td>
<td></td>
<td>200 000</td>
</tr>
<tr>
<td>Programme crude cost</td>
<td></td>
<td></td>
<td>998 800</td>
</tr>
<tr>
<td>Savings from averted complications</td>
<td>800</td>
<td>350</td>
<td>280 000</td>
</tr>
<tr>
<td><strong>Programme costs</strong></td>
<td></td>
<td></td>
<td><strong>718 800</strong></td>
</tr>
</tbody>
</table>

Source: Ministry of Health, Mozambique
The control of communicable disease is often a global public good when it benefits all people, in poorer and richer countries, present as well as future generations. However, the reality is that communicable diseases continue to spread relentlessly within and across borders and serve as global public “bads” in economic terms. The persistence of the current disease burden in poor countries in sub-Saharan Africa and elsewhere has potentially serious repercussions for international peace and security, and the prosperity and well-being of industrialized countries. Despite growing recognition of this fact, global public goods policies tend to wait for the emergence of a global public bad and then respond on an emergency basis. The nature and speed of global response depends largely on the extent to which the health of wealthy nations is at risk. Can the global public good argument be successfully used to mobilize a global response against neglected diseases?

Neglected diseases – a global public goods perspective

Very little information is available on the long-term impact of such diseases on children and the extent to which their inability to attend school or residual disability impairs their ability to find well-paid employment.

The impact of disease on women as well as gender-specific barriers to treatment has been under-researched.

There is a need for more qualitative research to seek the views of communities themselves about their perceptions and beliefs about diseases and their attitudes to treatment. Community participation and education are crucial for the sustainability and success of programmes.

For some diseases there has been little research in recent years into new safer and cheaper drugs or the development of vaccines. Public–private partnerships, particularly those involving the pharmaceutical industry, have an enormous contribution to make in such matters.

But there is cause for optimism

Recent developments are making it possible to circumvent many of these long-standing problems. While important constraints remain, the prospects for controlling some of the most burdensome neglected diseases, on a large scale and in sustainable ways, have never looked better. Major achievements have been possible under extremely challenging conditions. As these diseases share common determinants and must overcome similar obstacles to control, hard-won successes against any single disease pave the way for progress against others.
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Neglected diseases still neglected in Millennium Development Goals

Health is a key concern of the global agenda and features prominently in the Millennium Development Goals (MDGs). Fighting the big killer diseases, HIV/AIDS, tuberculosis and malaria, is highlighted as an important goal, whereas neglected diseases remain “neglected“. There is, however, the following reference to neglected diseases in the road map for the MDGs:

“Many of the world’s health needs can only be met at the international level through the provision of global public goods. Among the most critical global public goods for health are the generation and dissemination of knowledge of research, effective health system reforms and the transfer of new technologies. Research and development of new drugs, vaccines and other technologies are desperately needed to prevent and control diseases that primarily affect poor countries.“

Public goods and bads

In economic terms, well-being is determined by the consumption of both private and public goods. Private goods are things such as food, clothing and shelter, whose consumption can be withheld from other individuals (i.e. they are “excludable“, according to economists). Private goods usually have clear property rights attached to them and individuals are prepared to pay the market price for them.
Public goods, by contrast, are non-excludable and are available for all to enjoy (e.g. law and order). Many public goods are also public in provision, since they depend on the contributions of many individuals. For example, enjoying law and order often depends less on one’s own attitudes and behaviour than on the general level of respect that others have for social norms and institutions. Public goods almost always depend on policy choices and are not an inherent characteristic of the good.

Global public goods are public goods that do not “respect” national borders...
The benefits or costs of global public goods extend across countries, people and generations. Many public goods cannot be achieved through domestic policy action alone and depend on international cooperation.

...as are global public bads

The global spread of communicable diseases and the emergence of drug-resistant microbial strains are examples of global public bads. Their prevention, rather than their production, is desirable. However, policy-making is largely organized on a country-by-country basis and as a result, global public goods are increasingly underprovided and global public bads are increasingly overprovided. The response to health challenges is rapidly forthcoming when the health of wealthy nations is directly affected. This is exemplified by the rapid response to the recent outbreak of SARS.

<table>
<thead>
<tr>
<th></th>
<th>Criteria for adequate provision</th>
<th>Global reach</th>
<th>Global awareness</th>
<th>International response implemented</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>SARS</strong></td>
<td>Control</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Polio</strong></td>
<td>Eradication</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes, partially</td>
</tr>
<tr>
<td><strong>AIDS</strong></td>
<td>Control</td>
<td>Yes</td>
<td>Yes</td>
<td>Limited</td>
</tr>
<tr>
<td><strong>Infections with antimicrobial resistant</strong></td>
<td>Containment</td>
<td>Yes</td>
<td>Yes</td>
<td>Minimally</td>
</tr>
<tr>
<td><strong>Sickle–cell disease</strong></td>
<td>Control</td>
<td>Yes</td>
<td>No</td>
<td>Minimally</td>
</tr>
</tbody>
</table>
Available policy response options

There is an urgent need for enhanced policy coherence, notably between global public goods 1 and 8 of the Millennium Declaration, namely universal access to health care and a global system for knowledge management.

Knowledge has significant private properties, because it is typically produced by research teams and can be withheld and made excludable. Moreover, they need to be adequately rewarded for their efforts to ensure continued investment in R&D usually through a system of intellectual property rights and compliance with it worldwide. Knowledge also has important public qualities, such as being non-competitive in consumption, i.e. the marginal cost of sharing knowledge is zero or relatively modest.

It would be more efficient to foster policies that find a balance between rewarding innovation and promoting greater sharing. The varying degrees of utility that any policy has for different population groups will inevitably lead to differences in their preferences and priority as well as room for negotiation. Some measures now being discussed to correct the health care imbalance include the selective use of compulsory licensing and parallel imports, yet durable solutions for stimulating R&D for neglected diseases, such as purchase guarantees, are still lacking.
Improving financing of global health initiatives

Committed funding for health initiatives typically comes from official development assistance (ODA), complemented by donations from private foundations and private-sector contributions. Current ODA funds are about 0.2% of the gross national product of the industrialized countries, well below the internationally agreed target of 0.7%. Considering the enormous, still-unresolved poverty agenda, and the continuing debt burden of many poor countries, it is questionable whether the need for further financial resources for health can be met within the current ODA envelope.

There is also a question of principle: to what extent is it even justified to charge the full cost of communicable disease control to the ODA account? Since disease control is a global public good and in the interest of all, it could be argued that costs should be partly borne by the national health sector budgets of industrialized countries, rather than by their aid budgets alone. This would not be unprecedented: most countries pay their contributions to the WHO regular budget out of the national health sector budget.

The political push for tackling communicable diseases has developed largely on a disease-by-disease basis, as exemplified by the programmes for the eradication of smallpox, polio and onchocerciasis, and current special initiatives are no different. From a global public goods perspective this is desirable and the trend should be reinforced, since it ensures that the good, “disease control”, is produced.

In large measure, public–private partnerships and international coalition-building have been responsible for attracting the attention of policy-makers and placing new health issues on the global agenda.

The key challenge is to strike the right balance between government (public) support for health-related knowledge generation and dissemination and marketbased (private) provision. Examples of knowledge generation include Medicines for Malaria Venture; Global Alliance for Vaccines and Immunization (GAVI) to the extent that it creates the perception that there is demand for innovation; Drugs for Neglected Diseases initiative; differential patenting; and subsidy schemes for pharmaceutical companies in rich countries to engage in relevant R&D.

Incentives for knowledge dissemination include the Global Fund to fight AIDS, Tuberculosis and Malaria; the new United States AIDS policy; GAVI to the extent that bulk vaccines purchases provide incentives to increase immunization rates; and differential pricing. A global regime of knowledge management should generate positive net benefits for all, as well as enhanced policy coherence.

International cooperation for health should be viewed not just as an aid issue, but as a global public goods concern that is in the interests of all, poor and rich.
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The prospect for neglected diseases

An analysis of neglected diseases from a global public goods perspective reinforces the essential importance of international involvement and cooperation. Four policy reforms to this end would establish current health initiatives on a more durable basis. First, international cooperation for health should be viewed not just as an aid issue, but as a global public goods concern that is in the interests of all, poor and rich. Second, government budgets should be tapped to ensure full and reliable funding for global health concerns. Industrialized countries should begin this process. Third, a global research council should be established to foster more efficient management of health-related knowledge. Fourth, disease-specific issue managers should be appointed to facilitate cross-sector partnerships. Changes in these directions are under way and provide an important basis for building further policy reform.

This analysis suggests that notions of private and public goods must be reconsidered. In a globalizing world, the national (private) interest of countries is sometimes best served through international cooperation with others. Even though some goods are privately produced, it is likely to be more efficient when producers keep the public interest in mind. The public interest would include not only the effective demands of the rich, but also the urgent needs of the poor.

There is grave danger that further neglect of neglected diseases will lead to excessive disease burdens that, in turn, exacerbate poverty, civil strife and political instability – global public “bads” that may also affect wealthy actors. The porosity of borders has globalized health conditions and international cooperation in health has become a matter of self-interest and mutual concern. It is crucial that public awareness in rich countries is heightened in regard to the global implications of excessive disease burden, and that this feeds through into the creation of a political environment in which rich countries are willing to pay for the control for the neglected diseases of others – in their own self-interest.
Neglected diseases – the health economics perspective

David Canning

There is an urgent need to move from a rights-based argument to efficiency arguments to justify investment in the fight against neglected diseases. From an economic perspective, health is a sound investment – it fuels economic growth, builds human capital and has long-term impact on economies. However, some diseases should be neglected as they are too expensive to treat. Others need to be prioritized. These arguments and subsequent decisions need to be informed and guided by an empirical evidence base.

Health – the fuel of economic growth

Health is a key component of an individual’s welfare and standard of living. Sickness and ill-health, and the risk of death, are central issues in shaping human capabilities and behaviour. There is therefore a strong argument for health spending on the grounds that it has a direct effect on human well-being and happiness.

There is also a strong economic case to spend on health as it plays a central role in economic development. Health is not just a by-product of economic development: rather, it fuels economic growth. It improves worker productivity and increases human capital.

In developing countries the most effective methods of improving health require public sector involvement. In developing countries the main causes of ill-health and premature mortality are infectious diseases. These can be tackled effectively through the provision of clean water and sanitation systems and wide-scale vaccination programmes. Such preventive public health measures can have a very large impact on the transmission of infectious disease, in many cases leading to the eradication of the disease.

However, developing countries have limited budgets and there are many sectors in which there is a need for government spending. In particular, there is a strong case for poorer countries concentrating their government spending on investment that leads to economic growth; spending on current consumption may lead to welfare gains today but does nothing to cure the long-term problems of poverty.
Sound economic reasons to invest in health

Health is not only a consumption good that adds to well-being, but also an investment good that increases the future productivity of individuals and the economy. Together with the moral argument, worker productivity is often the main mechanism to justify increased transfers to developing countries for health spending. However, there are also more indirect mechanisms that while less obvious, may be more important in practice.

One indirect mechanism is that health can be a complementary input to other forms of human capital. There is a great deal of empirical evidence that productivity and wages rise with education levels and worker job experience. These returns are typically higher for healthy workers, so that the gains from education and work experience accrue mainly to those who are working. In addition, these higher returns usually induce greater investment in education and on-the-job training when workers are healthy. Ill-health and premature death essentially lead to wasted investment in human capital and a reduced incentive to invest in people.

Another indirect benefit of improvements in health is that the prospective lifespan of healthier workers is longer. Longer lives increase the need for retirement income. In countries with low life expectancy, the prospect of retiring is remote. Once longer lifespans become common, retirement becomes a real possibility and workers have to consider saving for their retirement. In developed countries, saving for retirement is the main source of investment funds. Increasing longevity is likely to set off a savings and investment boom.

Finally, reductions in mortality rates change the age structure of the population. Initially, health improvements tend to reduce the mortality rates of infants and children who are particularly susceptible to disease. This causes a “baby boom” cohort. The reduction in child mortality often leads to a reduction in the birth rate as families adjust their fertility behaviour to the new, low-mortality regime. This fall in birth rates means that the large baby boom cohort is unique, with much smaller cohorts before and afterwards. This large cohort can have profound effects on the economy as it enters education, works as young adults, works and saves as older adults and finally enters retirement.
Taken together, we argue that these mechanisms mean that investments in health can have a large impact on economic performance. This makes investment in health in developing countries, where the costs of tackling the problem of infectious disease can be low, very appealing. However, the investment argument for increased health spending in developed countries is much less obvious. In developed countries the gains from improved health mainly accrue to the elderly and tend to prolong retirement with little effect on the productivity of workers. In addition, the cost of treating noncommunicable diseases, such as heart disease and cancer that require intensive interventions by health workers, is relatively high.

The argument that health is an investment good means that the economic prospects of countries with high rates of HIV/AIDS are poor. HIV/AIDS kills and also affects the lives of survivors. Young people in high HIV/AIDS countries have a high risk of illness and death. This will have large negative effects on the economy by reducing their investment in education and savings for old age. HIV/AIDS can also be considered as not just a medical disaster but also an economic disaster.

Health, like education, is a form of human capital and is a fundamental requirement for economic development. The new paradigm shows the possibility of health-led development and spending on health not just for its direct welfare effects but also to boost economic growth.
Open issues for research

Health and income tend to be symbiotic and improve together. A major issue is the direction of causality. While health improvements tend to occur before rises in income, more needs to be done to establish causality; we need a better understanding of population health changes to establish whether they really occur before income increases.

A second problem is that the health assessment measures we use tend to be proxies; it would, for example, be better to use more direct measures of health than to use height as a proxy. There is also an important distinction between the effect of healthier people (morbidity measures) and the effects of increased longevity (mortality measures). Cross-country measures of health usually use life expectancy, a mortality measure, while it is morbidity and disability that matter for worker productivity. This makes it difficult to compare the macro results, based on mortality rates, with the conclusions from height surveys found in micro studies.

Our evidence will be substantially improved when we are able to follow people over a sustained period of time to look at short- and long-run effects of ill-health on work and wages. Randomized (individual or local) allocation of healthcare measures as a controlled experiment will allow us to ensure direction of causality. This requires longitudinal household studies that combine health and income measures with controlled experiments in health provision. Such data are only now becoming available for developing countries.

Difficult choices

By spending money on research and development of drugs tailored to hitherto neglected diseases, even greater health improvements could be achieved. At present, however, this research is not commercially viable because these diseases strike mainly poor people in developing countries.

Despite clear potential health benefits, and the relatively low costs of such programmes, this argument for directing aid funding towards health has so far not proved to be decisive. While there is a strong moral case for the large transfer of cash from rich countries to poorer countries, in practice such transfers are currently small and likely to remain fairly small.

The key issue is not whether spending on health would be good – it is whether spending on health is better than other uses of the limited funds available in developing countries. In practice, every dollar spent on health is a dollar that could be, but is not, spent on food, education or roads.
In assessing the relative benefits of different types of spending, a sharp distinction must be made between goods that provide immediate welfare and those that are investment goods that produce sustainable economic development. Traditionally, development aid has focused on education and infrastructure, such as roads, not because aid agencies do not care about ill-health, but because these investments are a way of generating sustainable economic growth.

Economic growth holds out the prospect of lifting countries out of poverty, allowing them to develop and eventually removing the need for aid. Aid that focuses on current welfare brings immediate gains, but can also lead to an aid dependency that actually undermines development.

Another argument for investing, rather than consuming, is that most aid is not “free“ but is made available in the forms of loans. Even though interest may be at concessionary rates, the loans still have to be repaid. The debt burden in many developing countries is enormous and results in a major diversion of funds from productive and welfare goals to debt repayment. If developing countries are to borrow more we should ensure that this will lead to widening the resource base of their assets and that it will not impose a heavier debt burden on future generations with ever-decreasing possibilities for repayment.

The real argument for spending on health in developing countries is that health is one of the best investment goods around. Healthier people can work harder and have higher productivity. This is particularly true in developing countries, where physical labour is the norm. Health is therefore a direct input into labour productivity.

In addition, health is closely linked to the returns from education. The deaths of young educated workers remove one of the most valuable assets in an economy. These deaths not only waste the huge investments that have been made, in terms of both upbringings and formal education, but also deprive the population of the skilled teachers and caring parents of the next generation.

It is only through a clearer appreciation of the impact of these economic factors that we can create a climate conducive to greater investment in the fight against neglected diseases.
Neglected diseases – a human rights perspective

Paul Hunt

Human rights provide a compelling framework for the formulation of national and international policies for social justice. They are underpinned by universally recognized moral values and reinforced by legal obligations. The norms, values and obligations enshrined in human rights have particular potential to empower marginalized communities and neglected populations. Social justice becomes more than a moral obligation, it becomes a legal obligation.

The most significant value-added of human rights is the framework of accountability it creates for policy-makers and other actors whose actions impact on human rights. Through ratifying international human rights treaties, states accept obligations – which are binding under international law – to give effect to the recognized rights. Based on these human rights, what are the entitlements that are relevant to neglected diseases?

A human rights analysis of neglected diseases

Neglected diseases affect almost exclusively poor and powerless people living in rural parts of low-income countries and result from several problems:

- Existing medicines and delivery mechanisms for neglected diseases do not always reach people living in poverty in developing countries because they are too expensive, or are not available in adequate numbers, or are inaccessible geographically.

- The market mechanism, which increasingly determines research and development (R&D), fails these so-called “neglected diseases” since they do not promise a good return on investment. At the same time, there is a crucial failure in public policy to adequately address this problem.
There are, of course, differences between the various neglected diseases and this has important implications for human rights. For example, leprosy is now treatable, while Buruli ulcer is still poorly understood and difficult to treat. HIV/AIDS represents a global emergency – while there are now drugs that help treat the disease and prevent mother to child transmission, these drugs are still not accessible to millions of people living with HIV/AIDS in developing countries. In the case of sleeping sickness, there is resistance to existing drugs, which are also highly toxic, and R&D is urgently needed to find new treatment solutions and a vaccine.

The right to health

Under international human rights law it is recognized that everyone has the right to the highest attainable standard of physical and mental health. Many aspects of this fundamental human right are subject to progressive realization: they cannot be realized overnight. There are many norms – both freedoms and entitlements – arising from the right to health.

The right to health includes an entitlement to available and accessible quality health care facilities, goods and services, including essential medicines. This entitlement is of central relevance to some neglected diseases. Availability means that essential drugs, including those for neglected diseases, be made available in adequate numbers within countries where there is a need for them. Accessibility means that they should be made accessible geographically, economically and on the basis of non-discrimination to the people who need them.

In recent years, the United Nations Commission on Human Rights has emphasized the particular importance of access to medication. It has adopted resolutions stating that “access to medication in the context of pandemics such as HIV/AIDS, malaria and tuberculosis is one fundamental element for achieving progressively” the right to health. Without targeted interventions by governments, international organizations and pharmaceutical companies, however, drugs for neglected diseases are not always economically or geographically accessible for communities who need them.
Obligations on states

Around the world, 147 states have ratified the International Covenant on Economic, Social and Cultural Rights which, in relation to health, imposes an obligation on them to take steps necessary for: “the prevention, treatment and control of epidemic, endemic, occupational and other diseases” (Article 12). To give effect to the right to enjoy the benefits of scientific progress, states have an obligation to: “take steps necessary for the development and diffusion of science.” (Article 15).

Actions to respect, protect and fulfil the right to health

States are considered to have three types of responsibilities towards human rights under international human rights law: obligations to respect, protect, and fulfil. The obligation to respect means that states must, among other things, refrain from actions that deny people their right to health. There are several examples of obligations to respect that apply to neglected diseases.

The obligation to protect means that states should, for example, ensure that privatization of the health sector does not constitute a threat to the availability, accessibility and quality of health care goods, services and facilities. This obligation has a relevance to neglected diseases since increasing reliance by states on the private sector to conduct R&D has meant that the market, to a large degree, determines R&D.

The obligation to fulfil includes an obligation to promote medical research. It also includes an obligation to take positive measures that enable individuals and communities to enjoy their right to health. Clearly, in the case of neglected diseases, positive measures are required.

Essentially, people are denied the enjoyment of their right to health:

- where there has been inadequate R&D into developing appropriate and effective drugs.

- where there are appropriate and effective drugs, but they are often not economically accessible for poor people living in developing countries; intellectual property regimes have meant that many people have not had access to cheaper generic versions, and even where cheaper generic versions are available, these may still be too expensive.

- where there are affordable and appropriate drugs, they often fail to reach neglected communities who need them because of inadequate health infrastructures to deliver them.

The right to enjoy the benefit of scientific progress and its applications

The right to health is closely linked to the realization of the right to enjoy the benefit of scientific progress and its applications. In practice, scientific progress in the medical field has been biased towards conditions that are prevalent in developed countries, and not towards neglected diseases that primarily affect people living in poverty in developing countries. This is effectively denying neglected populations their right to enjoy the benefits of scientific progress.
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Neglected diseases are becoming a major human rights issue. The human rights community is becoming increasingly aware of neglected diseases and addressing problems associated with access to drugs. The issue has been raised in the United Nations Commission on Human Rights, and, in many countries, civil society organizations are starting to use human rights to strengthen campaigns relating to access to medicines.

Neglected diseases are at the core of human rights as they deal with issues related to poverty, discrimination, stigma and the right to health. Human rights will help focus attention on neglected communities – those living in poverty, women, racial and ethnic minorities, indigenous peoples, people living with HIV/AIDS, and other vulnerable groups. Poverty and discrimination are, of course, extremely important in relation to neglected diseases. The human rights framework adds significant value in making a case for tackling neglected diseases.

Obligation to take concrete action
The right to health includes a range of entitlements. It is clear that many of these entitlements are difficult to provide immediately; it will take time to develop and implement strategies to meet entitlements. Finding new ways of preventing or treating neglected diseases, lowering the costs of drugs, and of building up health systems to deliver these drugs where they are needed— all these interventions will take time. However, states must show that they are taking steps towards providing essential medicines or promoting R&D into new drugs in a deliberate, concrete and targeted way.

Obligation on both domestic and international fronts
International human rights law imposes obligations on states to give effect to human rights within their jurisdictions as well as international responsibilities towards the right to health. These arise from human rights provisions of international assistance and cooperation. Thus, states should take actions that promote and protect the right to health in other countries, and they should refrain from taking actions that jeopardize the right to health in other countries. This may involve a responsibility on rich countries to promote R&D into neglected diseases even though these diseases do not have a high incidence, or indeed occur at all, within rich countries. It also involves an obligation to promote international policies that are conducive to addressing the problem of neglected diseases.

...the private sector and NGOs also have clear roles
While the ultimate responsibility lies with states, a resolution recently adopted by the United Nations Sub-Commission on the Promotion and Protection of Human Rights declares that transnational corporations and other business enterprises shall respect and contribute towards the realization of the right to health and refrain from actions that obstruct or impede the realization of this right.
Neglected diseases are becoming a major human rights issue

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The way ahead

Tackling neglected diseases requires a multiple disease approach within an integrated framework because of the substantial geographical overlap. A close link also needs to be established between surveillance and control activities. Greater decentralization in terms of management, planning and implementation is needed together with centralization of activities such as setting standards and purchasing drugs, vaccines and insecticides. The overall aim is to integrate neglected diseases into primary health care, with close monitoring of uneven service provision.

GTZ in Indonesia: Strengthening health systems through neglected diseases

Allison Krentel

Neglected diseases can be successfully integrated into larger health sector reform projects with lasting positive results for both agendas. This has been proved with the elimination of lymphatic filariasis (LF) in the GTZ project in Alor district, Indonesia. The programme created a positive knock-on effect on health service delivery at the district, provincial and central levels.

Building trust and confidence

The situation at the outset was typical for many remote areas and was characterized by extremely high morbidity and mortality indicators, low utilization of health services, and a breakdown of social systems due to financial and political crises. LF was an important public health problem with prevalence rates ranging from 1% to 27%. The strategy was to manage LF as an integral part of a decentralized district health scheme, thereby contributing to improving trust and utilization of local health services.

Empowerment of local health services

The pilot project was developed and implemented together with the district health team, and provided the opportunity for hands-on technical assistance to improve the quality of the LF programme. Key elements included motivation of the health services staff, drug distribution including simplified protocols (an age-based dosing table), monitoring tools and combined health service- and community-driven approach for distribution.

Simplify, simplify, simplify.
Guidelines and forms can be too complicated for the health workers in the field.

Successes to build on

Brazil: Addressing inequities and inequalities in the health of neglected populations

Dr Jarbas Barbosa da Silva Júnior

Brazil, like many countries, has two distinct sets of health problems – the diseases of affluence and those of poverty, each with radically different demands in terms of policy, resources, and also completely different in their visibility and ability to attract resources. The health services in Brazil have been decentralized since the 1990s and are largely managed by the 5700 municipalities within the 27 states of the country. The Ministry of Health coordinates the whole system and funds 75% of the total budget. Neglected diseases are concentrated in the impoverished states of the north and north-east. All the economic, health and social indicators are significantly poorer in this region. Within these areas there is also considerable geographical overlap in the occurrence of neglected diseases, a situation clearly favouring the adoption of an integrated approach to tackling them.

Efforts need to be intensified

Leprosy remains a public health problem in Brazil with national prevalence rates of around 4 per 10 000 inhabitants, rising to 10 per 10 000 in the north and north-east. This is significantly higher than the WHO elimination target. Important policy decisions have been taken to integrate leprosy services within primary health care services and thereby overcome the key obstacle of poor access to diagnosis and treatment.

Although the total number of reported cases of visceral leishmaniasis has been declining in recent years, areas of high transmission of the disease remain. Eco-epidemiological studies have been initiated to study the localized re-emergence of the disease. Special funds are provided to municipalities to deal with the outbreaks.

In areas with high dengue incidence rates, efforts are being made to improve surveillance and decentralize both vector control and laboratory diagnosis. Controlling dengue involves a multi-sector agenda, including garbage collection and access to clean water.

Despite the steady decline in mortality rates from schistosomiasis in the north-east region, highly endemic areas remain. Considerable progress has been made towards interruption of transmission of Chagas disease.
The way ahead

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Impressive results

There was a dramatic increase in awareness of LF from 20% before the intervention to 89% afterwards. The project achieved a 75% coverage rate for six villages and good community acceptance. This was scaled up to two districts, with the same simplified guidelines and greater community involvement, achieving 80% coverage. Alor has become the reference point for similar projects in the country and national LF policy has been changed on the basis of the evidence generated there. A similar approach is being adopted for malaria control.

Lessons learnt

**Use existing resources and systems** for disease control programmes (discuss and determine what has worked in the past)

**Integrate** wherever possible into existing programmes, both health- and non-health-related

**Simplify, simplify, simplify.** Guidelines and forms can be too complicated for health workers in the field. Test and modify.

**Workshops are not enough.** Hands-on coaching and supervision are more effective.

**Utilize communities and their structures** – encourage a “working together” atmosphere between health staff and community leaders.

**Communication** between different sectors and between donors is key to avoid overlapping and overburdening the health system.

**Advocacy to local government** is essential to give the disease high priority and to secure funding for the five year programme.

Future success in neglected disease control within decentralized health systems relies on empowering local decision-makers and professionals to address health problems at a local level, improving local management capacity, technical thoroughness, good communication among all partners and consistent funding.
Neglected diseases typically affect children, peasants and poor people often causing varying degrees of disability. This reduces their ability to work and has severe economic and development consequences. Although effective and cheap tools are available to control some of these diseases, the results are unsatisfactory. There is a need for simplified guidelines. In recent years neglected diseases have been overshadowed by the three big killer diseases. However fighting the “big three” and controlling neglected diseases are not mutually exclusive.

Let us not “stigmatize” non-fatal infectious and parasitic diseases

Neglected diseases often lose out among health priorities because they do not kill. However, the lack of action has a high price tag, ranging from diminished school performance to retarded growth, absenteeism from school and work, and a loss of productivity. The burden of schistosomiasis, for example, is significant and increasing: the disease affects more than 80% of children assessed in school surveys carried out in various parts of the country.

<table>
<thead>
<tr>
<th>Year</th>
<th>Site</th>
<th>Study population</th>
<th>Prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td>1998</td>
<td>Cabo Delgado</td>
<td>889 schoolchildren</td>
<td>84%</td>
</tr>
<tr>
<td>1999</td>
<td>Manhiça</td>
<td>840 schoolchildren</td>
<td>83%</td>
</tr>
<tr>
<td>1999</td>
<td>Maputo City</td>
<td>879 schoolchildren</td>
<td>37.4%</td>
</tr>
</tbody>
</table>

Source: Ministry of Health, Mozambique

Progress is being made on other fronts. With increasing coverage of leprosy services, there has been a steady increase in new cases. This is completely in line with the strategy to detect all the patients, including those previously hidden, and cure them with multidrug therapy. Leprosy elimination is now an integral part of national health plans as well as the poverty reduction strategies.
The control of dengue, in contrast, is problematic because of the lack of an effective treatment as well as resources. Vector control is currently the only strategy achieving limited success.

The key challenges facing the health ministry as it deals with neglected diseases are the emergence of new diseases and re-emergence of old ones and, above all, limited resources. In this situation, there is a natural tendency to gravitate towards high-mortality diseases. Reaching neglected populations in Sri Lanka is challenging as they are primarily in war-affected areas, the tea growing estates and slums.

One of the major obstacles to planning the fight against neglected diseases is the lack of epidemiological data on their extent and impact. This makes it difficult to establish priority for them, particularly in view of competing high-profile, high-mortality diseases. Together with fuller data on the neglected diseases, a comprehensive policy framework and master plan outlining the overall strategy, tools and resources, with clear focal points, are vital.

Advocacy is needed to mobilize the necessary commitment at the political level and among policy-makers. Peripheral health services need strengthening with human resources development, simplified guidelines, drugs and social marketing. The entire process should be informed and guided by operational research.

The way ahead

There is an urgent need for surveys to provide a better understanding of the extent, scope and cost of neglected diseases. The information should be used to inform policy decisions as well as to raise awareness among primary health care workers. Clinical protocols need to be revised and simple algorithms need to be designed that will enable primary health care staff to diagnose and treat patients. It is crucial that neglected diseases are managed by the public health workers rather than specialized staff. Training and retraining of health care providers is also crucial. Synergies with HIV/AIDS initiatives and other initiatives need to be exploited to ensure better use of available health infrastructure and equipment.

Neglected diseases need to be positioned within community health services, with shared surveillance and monitoring systems. Funds should be channeled through existing mechanisms. An intervention to tackle neglected disease is an investment in health and in health-driven development.

Sri Lanka: Local delivery

Dr H.A.P. Kabandaliyanage

Sri Lanka has an excellent network of health care facilities and provides services free of charge to all inhabitants. The public sector covers 60% of the population and the per capita expenditure on health amounts to US$ 13. Intestinal infectious diseases and malaria rank among the top five causes of morbidity recorded by hospitals.

A possible model

Tremendous progress has been made towards the control and elimination of specific neglected diseases. Leprosy lost its “neglected status” with the launch of a social marketing campaign in 1990 which generated and met demand for leprosy services. The disease has been eliminated at a national level since 1996. Since 2002, leprosy services have been integrated into the general health services thereby improving patients’ access to treatment as well as removing the special status of the disease.

Progress has also been made towards the elimination of filariasis. This has been facilitated by the decentralization of health services, increased surveillance, health educational efforts and mass drug distribution.

Neglected diseases need to be positioned within community health services, with the shared surveillance and monitoring systems.
The control of dengue, in contrast, is problematic because of the lack of an effective treatment as well as resources. Vector control is currently the only strategy achieving limited success.

The key challenges facing the health ministry as it deals with neglected diseases are the emergence of new diseases and re-emergence of old ones and, above all, limited resources. In this situation, there is a natural tendency to gravitate towards high-mortality diseases. Reaching neglected populations in Sri Lanka is challenging as they are primarily in war-affected areas, the tea growing estates and slums.

What needs to be done

One of the major obstacles to planning the fight against neglected diseases is the lack of epidemiological data on their extent and impact. This makes it difficult to establish priority for them, particularly in view of competing high-profile, high-mortality diseases. Together with fuller data on the neglected diseases, a comprehensive policy framework and master plan outlining the overall strategy, tools and resources, with clear focal points, are vital.

Advocacy is needed to mobilize the necessary commitment at the political level and among policy-makers. Peripheral health services need strengthening with human resources development, simplified guidelines, drugs and social marketing. The entire process should be informed and guided by operational research.
Both the acute form of sleeping sickness and the chronic forms of the disease exist in Uganda, the former mainly in south-eastern Uganda and the chronic form in the West Nile region. There has been a new outbreak of the disease in Eastern Uganda. Control activities continue in the West Nile region which remains generally active, as the situation there is occasionally exacerbated by influxes of cases from southern Sudan.

Public–private partnerships have helped to re-energize the control of otherwise neglected diseases. The way forward is to strengthen and expand their implementation.

Viet Nam: Surveillance and response

Dr Nguyen Thi Hong Hanh

Communicable diseases remain a problem in Viet Nam although noncommunicable diseases are gaining in prominence. Dengue presents a particular challenge and requires a multisectoral approach. Rabies continues to cause relatively high mortality and major preventive efforts are being made. Sustaining the steady decline in mortality rates has demanded a broadly based strategy, including surveillance, education and improvements to vaccine production. The vaccination drive in the 5 years to 2000 reached nearly 2.7 million people, mainly concentrated in the Red River and Mekong Delta regions.

Emerging infectious diseases have posed major challenges in Viet Nam. This has led to new mechanisms being set up to monitor developments and strengthen epidemiological surveillance, in order to permit an early response. An emergency response to contain the risk of the infection spreading involves quarantine, monitoring the health of people exposed to the patient, outlining diagnostic and treatment regimens as well as organizing preventive services.

Uganda: Public–private partnerships

Dr Sam Zaramba

As in most developing countries, the health status of the people of Uganda is poor. This is mainly a result of infectious and parasitic diseases, most of which are preventable and/or treatable, illiteracy and perpetual poverty. Most of these diseases fall into the category of neglected diseases and those affected are exclusively poor and marginalized populations with limited geographical access to health care.

Public–private partnerships have helped focus attention on neglected diseases

The neglected diseases in Uganda include lymphatic filariasis, leprosy, schistosomiasis and soil-transmitted helminth infections as well as sleeping sickness. Despite the availability of effective tools and proven strategies for their control, until recently very little was being done for most of these diseases. The health landscape has changed dramatically with the creation of public–private partnerships that address specific diseases with considerable success.

This initiative is fully embraced by the Government of Uganda, which has put into place a national policy and guidelines for partnerships. Partnerships permit the efficient use of resources, increase the likelihood of sustainability, bring in valuable knowledge and skills, prevent duplication of work, reduce costs, increase the scale and scope of activities and deliver results.

Lymphatic filariasis has been mapped in all districts except four, which suffer from insecurity. The disease is endemic in 22 of the 56 districts in the country. The first mass drug administration was carried out at the end of 2002 in two districts, achieving coverage rates of about 75%. The cost per person treated was 10 US cents. The planned scaling up to eight adjacent districts has been hampered by a lack of operational funds and insecurity in the areas.

Leprosy was highly endemic in Uganda, with a prevalence rate of 17.7 per 10,000 inhabitants in 1983 and was eliminated as a public health problem in the late 1990s. Efforts now focus on eliminating the disease at sub-national levels.

Schistosomiasis is endemic in 38 of the 56 districts in the country. The intestinal form is more widespread than urinary schistosomiasis which exists mainly in five districts. Capacity to control the disease has been created in 21 districts, 18 of which have started implementing school-based mass drug administration.
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**Viet Nam: Surveillance and response**

*Dr Nguyen Thi Hong Hanh*

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Emerging infectious diseases have posed major challenges in Viet Nam. This has led to new mechanisms being set up to monitor developments and strengthen epidemiological surveillance, in order to permit an early response. An emergency response to contain the risk of the infection spreading involves quarantine, monitoring the health of people exposed to the patient, outlining diagnostic and treatment regimens as well as organizing preventive services.
Market failure: The vast majority of R&D of new drugs is conducted in the industrialized world, mainly by the pharmaceutical industry whose research agendas are largely defined by the potential return on investment and reflect market prospects rather than health needs. The populations of poorer nations have limited purchasing power and thus their diseases are ignored.

Public policy failure: In spite of visibly waning private-sector interest, governments have been slow to take action against this global problem. In industrialized countries, public policy has long provided incentives such as patents, tax credits, and health-care insurance systems to encourage private-sector investments in drug R&D, but these rarely target neglected diseases. Moreover, in spite of these incentives, there is a bias towards “me-too” and lifestyle drugs for conditions such as impotence and baldness.

Governments in less developed countries, on the other hand, are confronted with a combination of lack of financial resources, absence of willingness to invest in long-term health development, and failure to establish public policy incentives that foster a viable domestic drug development capacity.

The UNDP/World Bank/WHO Special Programme for Training and Research in Tropical Diseases (TDR) was established in 1975 in response to appeals from countries where neglected diseases were endemic. Over the past 25 years, TDR has successfully partnered the development of several new treatments for tropical diseases, but significant unmet curative and preventive medical needs remain, particularly for the most neglected diseases.

Drugs for neglected disease initiative (DNDi)

Dr Bernard Pecoul

The challenge

During the past 25 years, the gulf between the development of drugs for tropical and non-tropical diseases has grown. Tropical diseases such as chloroquine-resistant malaria, human African trypanosomiasis, visceral leishmaniasis (kala-azar), lymphatic filariasis, Chagas disease and schistosomiasis continue to cause significant morbidity and mortality. These disabling and/or life-threatening diseases can be collectively called “neglected diseases”. These diseases are neglected by the very mechanisms that ensure research and development (R&D) of new drugs, as the patients suffering from them do not represent a significant market.

Only 1% of the 1393 new drugs registered during 1975–1999 were for tropical diseases and tuberculosis, yet these diseases constitute more than 10% of the global disease burden. A mere 10% of the world’s health research expenditure is spent on diseases that account for 90% of the global burden of disease. Neglected diseases get an even smaller share of the pie – of the US$ 60–70 billion spent on health research last year, less than 0.001% went towards developing new and urgently needed treatments for this category of diseases.

Despite intense scientific scrutiny, the most neglected of these diseases have been all but ignored by the pharmaceutical industry, which is almost the only generator of new medicines today. Most of the drugs to combat these diseases are too expensive, difficult to administer, toxic at recommended doses, or increasingly ineffective because of drug resistance. People affected by these diseases cannot afford to buy the drugs and are thus off the “radar screen” of drug companies.

The crisis in R&D of drugs for neglected diseases is not due to a lack of scientific knowledge, as a great deal is known, and information continuously generated, about the biology, immunology and genetics of the parasites that cause, for example, human African trypanosomiasis, leishmaniasis, and Chagas disease. In fact the crisis is more the result of the failure of both the market and public policy to promote drugs for neglected diseases.
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DNDi – an innovative approach to research

The not-for-profit Drugs for Neglected Diseases initiative (DNDi) is the brainchild of Médecins Sans Frontières (MSF) and the Drugs for Neglected Diseases Working Group, an independent body of international health experts. DNDi seeks to address the need for research and development of new field-adapted, effective, and affordable drugs for patients suffering from neglected diseases. The idea is simple – to harness accumulated knowledge and cutting-edge science and technology to develop critically needed drugs for neglected diseases, making sure that they are suitable for and accessible to the poorer patients of the world. The modus operandi will be to collaborate predominantly with developing country organizations and governments.

The vision

The DNDi vision is to improve the quality of life and the health of people suffering from neglected diseases by using an alternative, not-for-profit model to develop drugs for these diseases and ensuring equitable access to new and field-relevant health tools. It will address unmet needs by taking on projects that others are unable or unwilling to pursue.

Although DNDi’s primary focus will be the development of drugs for the most neglected diseases, such as sleeping sickness, kala-azar, and Chagas disease, it will also consider undertaking R&D projects on other neglected diseases. As means permit, it will consider the development of diagnostics and/or vaccines.

DNDi will not conduct research and scientific work to develop compounds by itself; rather, it will capitalize on existing, fragmented R&D capacity, especially in the developing world, and complement it with additional expertise as needed. As a virtual drug development organization it will thus significantly lower overhead costs.

It will collaborate with partners from both the developing and developed worlds (public and academic institutions, pharmaceutical and biotech companies etc.), and stringently manage legal issues (including intellectual property). The overall goal will always be to ensure the greatest accessibility to and affordability of the results of DNDi’s work.
The major challenges facing neglected diseases relate to both upstream basic scientific research and downstream implementation-related research. For some of the neglected diseases, new tools are needed. For others, existing strategies and treatment protocols need to be simplified. Innovative, evidence-based solutions need to be found which are fully responsive to the field reality.

TDR: Critical challenges for neglected diseases research

For many neglected diseases there is an urgent need to go back to the drawing board using the state-of-the-art tools of genomics or molecular biology to understand the pathogenesis of the disease. This could help to identify new avenues for research and development.

Research elucidating the pathogenic process of Chagas disease as an auto-immune process, for example, would make the further development of chemotherapy focusing on the parasite obsolete. Elucidating the genomics of the *T. brucei* genome for African trypanosomiasis or improved understanding of cell-parasite interaction in leishmaniasis have key implications for drug development. At the other end of the spectrum, basic social research can clarify issues such as identifying obstacles to access to treatment, health seeking behaviour and adherence to treatment.

Generation of basic knowledge

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New tools

New tools, such as drugs, vaccines, diagnostics and vector control tools, are usually developed in close collaboration with industry. There have been some notable successes through public–private partnership activities (multidrug therapy for leprosy; ivermectin for onchocerciasis; eflornithine for human African trypanosomiasis; miltefosine for leishmaniasis).

Vaccine research faces formidable scientific and technical obstacles and is in its early days for parasitic diseases. There is growing interest in the development of new diagnostics and vector control tools, such as improved pesticides. A key challenge involves translating basic academic research into new drugs, vaccines, diagnostics and insecticides.

New and improved methods

Effective tools exist for some neglected diseases but their geographical coverage is often limited by complex diagnostic and treatment protocols. There is an urgent need to simplify the control of neglected diseases so that it can be managed by local health services with minimal support from specialized staff. This will require refining existing methods and developing new ones. Examples include research on a uniform multidrug therapy regimen for all types of leprosy patients, which would facilitate the further integration of leprosy control into routine health services; studies on the efficacy of increased praziquantel dosage for treatment of schistosomiasis and short-course pentamidine for treatment of African trypanosomiasis. Establishing fixed-dose combinations of existing drugs is another important research avenue as it simplifies treatment delivery, reduces the risk of parasite resistance and simplifies logistics.

Research on new methods can help to improve the effectiveness of disease control. For example, research is ongoing to develop new entomological sampling methods for more cost-effective vector control for dengue. Research on rapid assessment methods to determine the geographical distribution of prevalence and intensity of infection has produced new methods that are of great practical importance for the control of onchocerciasis and lymphatic filariasis.

Often the mere proof of efficacy of new tools and methods is not enough. Their effectiveness must be demonstrated in field conditions. This may require large-scale field trials, which tend to be expensive but are essential to convince health decision-makers to make a new tool or method available through routine health services.
New and improved strategies

Research is also crucial to develop efficient and cost-effective strategies to ensure optimal impact. This is particularly important to reduce the risk of transmission of communicable diseases within a community. Evidence-based control strategies require field research to determine the impact of interventions on transmission and epidemiological modelling to use these results to predict their long-term impact. Such research is ongoing for lymphatic filariasis. However, key questions need to be answered, such as the duration of treatment and minimum coverage rates to interrupt transmission.

There is a need for objective scientific evidence on what works, what does not and why, as a basis for developing and testing strategies better suited for the prevalent socioeconomic conditions. The development of community-directed treatment for onchocerciasis and home management for uncomplicated malaria serve as good examples. Among the new initiatives are research on implementation strategies for mass drug administration for neglected diseases in urban areas and for miltefosine treatment of visceral leishmaniasis. However, funds for implementation research remain very limited.

Research is a continuum from basic research through to implementation research

Good research is vital to make a sustainable impact on neglected disease control. Research must remain an inherent part of the control culture, even as diseases move towards elimination and eradication, to address continuously evolving circumstances and new scientific and operational questions. A dialogue needs to be developed and sustained to ensure that projects are relevant to the needs and concerns of affected populations.
Public–private partnerships

Public–private partnerships (PPPs) for drug discovery and development as well as to improve patients’ access to existing treatments have radically altered the health landscape. The R&D partnerships are built around specific diseases to enable the pooling of resources as well as expertise through the creation of a virtual research team. They foster R&D by matching existing capacity, expertise, and resources from both the public and the private sector. PPPs also help to ensure adequate resources for the various stages of drug development.

These partnerships have taken various forms: some are public programmes with private sector participation such as the Global Alliance for Vaccines and Immunization (GAVI); others are legally independent entities such as the International AIDS Vaccine Initiative (IAVI); Medicines for Malaria Venture (MMV), and the Global Alliance for TB Drug Development. Some come under the auspices of NGOs, such as the Malaria Vaccine Initiative.

PPPs promote product-specific collaborations between public and private sectors, while offering subsidies, grants, and patent extensions to make R&D in the field of neglected diseases more attractive for industry. However, the incentives are focused on developing drugs for diseases that have markets in the north, such as malaria and TB. No PPPs have been set up to develop drugs for the most neglected diseases, as these do not represent a significant market.

The access partnerships are built around the fact that no single organization or sector has the skills and resources to solve the global health inequities alone. Many of the partnerships concentrate on improving access to treatments for neglected diseases and have re-energized efforts to fight diseases such as leprosy, lymphatic filariasis, sleeping sickness and river blindness. However public–private partnerships are not a panacea nor do they relieve the public sector of its responsibilities for public health.
The private sector commitment

Mainstream research and development efforts of the pharmaceutical industry are focused on diseases primarily affecting the industrialized world. This is because of the substantial investments of time, resources and capital needed to bring a drug to market, as well as the high risk of failure.

A few companies, however, have established dedicated research facilities for infectious and tropical diseases. Novartis, for example, established the Novartis Institute for Tropical Diseases (NITD), to leverage the compounds, experience, technology, and databases within the Novartis group in the search for novel drugs for tuberculosis and dengue. Treatments developed by NITD will be made available without profit in developing countries where the diseases are prevalent.

NITD is a collaborative research investment together with the Singapore Economic Development Board (EDB) of about US$ 150 million. It has been operational since 2003 and will have a total scientific and technical team of 70 people plus 30 students. NITD will offer exceptional teaching and training opportunities for post-doctoral fellows and graduate students. It collaborates closely with other partnerships and organizations addressing the same diseases.

GlaxoSmithKline (GSK) has a dedicated drug discovery unit in Tres Cantos, Spain, with 50 scientists working on malaria and tuberculosis. GSK takes an opportunistic approach to developing compounds for other neglected diseases, such as leishmaniasis and helminthiasis, typically in collaboration with external partners. GSK also works in partnership with the National Institutes of Health, Medicine Malaria Venture, Global Alliance on TB and many others.

Novartis is also committed to helping improve patients’ access to its treatments for diseases of poverty. It has signed three Memorandums of Understanding with WHO – to provide free treatment for all leprosy patients in the world, to provide Coartem®, its oral fixed combination antimalarial product, at cost and to provide free TB treatment for half a million patients over five years.

GSK supports the LF elimination programme by donating its antiparasitic drug albendazole and through help with coalition-building, planning, training and communications initiatives. It has developed a new business model for providing HIV/AIDS treatments to the developing world and is committed to passing on cost savings in the manufacture of antiretrovirals to eligible countries and organizations.
Building a framework for action on neglected diseases
Summary of discussions and conclusions

**Growing recognition of the need to act**

The international development community has recognized the intricate ways in which health status and poverty interact to impede socioeconomic progress. In the developing world, the neglected infectious diseases cause the most severe health-related impairment of social and economic activities, and they do so in the poorest populations.

The control of neglected diseases is a pro-poor initiative in line with the Millennium Development Goals, which emphasize the importance of measurable outcomes within the overall framework of poverty reduction. A focus on diseases that significantly impair the health and productivity of impoverished populations holds great promise as a rational approach to poverty reduction. It is also a feasible and highly cost-effective option that can bring rapid results.

Almost all neglected diseases can be controlled using low-cost technologies that are safe, rapidly effective, and easy to administer in resource-poor settings. In several cases, control tools and strategies are sufficiently powerful to interrupt transmission when applied on a large scale for a limited time. Some of the newer drugs bring ancillary benefits, such as improved nutritional status and micronutrient uptake, that support the very foundations of better health status in impoverished populations. Moreover, population-wide interventions, such as vector control and mass drug administration, do not discriminate among the poor or further marginalize excluded groups, and this has ethical appeal as a poverty reduction strategy.

**Evidence needed for a well-rounded case...**

The potential impact of existing control tools is yet to be realized, largely because neglected diseases are not commonly recognized as a priority concern in national and international development agendas. Arguments for doing so are already
Data that fully capture the major costs of these diseases in terms of their multiple consequences for individuals, families, and communities is lacking. Compelling on medical and ethical grounds, but need to be strengthened by data that fully capture the major costs of these diseases in terms of their multiple consequences for individuals, families, and communities. Like the diseases themselves, such consequences are hidden yet significant, and range in nature from lost worker productivity and the burden of home care for chronic disabilities to missed school days, impaired growth and cognitive development, wasted investment in education, inefficient land use, and food insecurity. Accurate assessments of socioeconomic impact that go beyond a narrow focus on health care costs could do much to raise the visibility of neglected diseases, place the low cost of interventions in perspective, and demonstrate the remarkable returns on investment. Basic messages about the simplicity and effectiveness of control measures will carry more weight when their ability to avert significant economic costs is part of the argument.

...involving and empowering affected communities

Prospects for increased political attention can also be strengthened by social marketing and mobilization campaigns, such as those introduced to support mass drug administration. Such campaigns help convince affected populations that disabling and debilitating diseases are not something to be endured as part of their hard lot in life, and that diagnosis and treatment can be demanded as a basic right. Demand can be created, and marginalized populations can be given a voice, despite low rates of literacy. Many interventions bring rapid physical relief, which stimulates acceptance and further demand, even when the disease itself is poorly understood. It is this bottom-line demand that ultimately puts pressure on the political and health systems to deliver in sustainable ways, in line with population needs.
Integrated technical guidance

Potential for a synergistic approach...

The neglected diseases are concentrated where the poor reside and frequently overlap. They share many features that make integrated technical guidance both feasible and advantageous in terms of more efficient use of resources, staff, delivery systems, and opportunities for contact with populations.

An integrated approach at the technical level aims to identify and then capitalize on opportunities for shared activities, whether involving the combined delivery of interventions or joint activities at the levels of mapping, training, procurement of drugs and equipment, and surveillance and monitoring. The benefits of integrated activities can be particularly great for control programmes that rely on logistically demanding strategies, such as mass drug administration.

...also creates the necessary critical mass

Advocacy for a group of diseases, and the collective burden they impose, carries more weight when attempting to raise the profile of neglected diseases at national and international levels. When opportunities for gaining efficiency in a systematic multi-disease approach can be demonstrated, arguments for intensified control are greatly strengthened. An integrated approach also makes good financial sense. As one example, investments in simple surgical facilities and equipment are more easily justified when they serve to mitigate the consequences of several concurrent diseases.

Simplicity and synergistic activities are of paramount importance in settings where every resource must be used to maximum advantage. When neglected diseases are approached as a group, many similar activities needed to control overlapping diseases can be coordinated. Synergies can be built into the delivery system as another way of streamlining and simplifying the work of controlling several diseases.

Multiple treatment protocols can be consolidated into a single schedule indicating drugs, target population, and timing, and thus structure as well as simplify drug administration for patients and staff.

Integration needs to occur at the administrative as well as the operational level in a cross-sectoral and coordinated way. A streamlined schedule of preventive and curative interventions for multiple diseases facilitates synchronized management by the district health team.
WHO is consolidating the various components of control for several neglected diseases into a single matrix. This allows health administrations and district health managers to identify opportunities for shared activities, eliminate redundancies, and thus deliver services with greater efficiency and broader impact on the total burden of disease. A second matrix, organized according to levels of service delivery, matches required activities and categories of personnel with each recommended intervention. This facilitates planning for a continuum of care that extends from the home, to the first-referral level, to the hospital. It also sets the stage for making the contribution of nongovernmental agencies and local networks of volunteers count most effectively by matching the unique strengths of these groups with gaps in service delivery.

While an integrated approach has several advantages, it also brings demands, particularly in terms of staff training and management and planning by the district team. Staff at the first-referral level need to have diagnostic skills for the range of endemic diseases, and facilities need to have the appropriate drugs and other supplies. Coordinated activities require management and planning that may involve numerous actors, also from the non-health sector.
Research underpins the feasibility of an integrated approach. The safety of combined interventions for a single disease or combined interventions for multiple diseases must be assured as a fundamental ethical obligation. Research also helps demonstrate the operational feasibility of combined interventions and uncover the practical needs of implementation, including social acceptability and economic viability. Mapping of needs and existing infrastructures can identify the best distribution system (households, communities, schools) and thus assist in the design of combined delivery programmes.

**Financing**

Neither affected populations nor the governments of endemic countries can be expected to meet all costs of intensified control on their own. Financial assistance from the international community will be needed for some components of control. The amount will vary according to the prevalence of specific diseases, control structures already in place, and the costs of drugs and other interventions, when these are not available as donations. For some neglected diseases, precise calculations of costs, including delivery, are available, and this can assist in the preparation of realistic budgets.

**Basket funding helps...**

In a promising trend, international financing mechanisms have adapted to the need for country ownership through basket funding schemes that are not tied to specific projects or diseases and are thus well-suited to support integrated activities in a decentralized administrative structure. However, a balance needs to be found between autonomy in national financial management and the need to ensure that funds are channelled to target populations and used accountably in ways that contribute to the achievement of expected results.

Financial arguments for control should not focus exclusively on the low unit costs of treatment, but should also cover implementation costs in the interest of realistic assessments for sustainable budgeting, especially when large-scale coverage is needed to reach time-limited objectives. Research can contribute to better estimates of implementation costs.
...as do national budgets

National budgets can be expected to cover some components of control, particularly improvements in the environment and public health infrastructures that address the root causes of disease and extend the benefits of prevention to the population at large. National governments are also responsible for determining the most appropriate schemes for cost-recovery, including the eligibility of certain population groups for payment exemptions.

...and drug donation programmes.

For several diseases, the monetary value of donated drugs is considerable. Estimates of the costs averted through donations, combined with estimates of the expected economic gains, may help encourage ministries of health and finance to increase their investments in control.

Human resources and service delivery

When faced with limited resources for tackling huge health problems of the poor, every opportunity must be found to increase efficiencies in the use of human resources and the organization of services. Integrated technical guidance contributes to this goal by offering simplified, consolidated solutions that can maximize the contribution of different categories of personnel and facilitate coordinated service delivery.

Need to focus on populations – not diseases

For these marginalized diseases, the district health management team is the focus of action. The plan of work needs to be population-based, and not disease-based, and should be guided by an assessment of local needs and capacities. The work-plan should engage communities and households, and consider all existing infrastructures – whether for health, education, or commercial purposes – as potential delivery channels.

Shortages of trained health personnel undermine the efficiency of service delivery in most endemic countries. However, the control of many neglected diseases relies on safe and simple interventions that can be administered by non-specialists, and some require only once-yearly contact with services.
Solutions that have brought success for one disease are being used for others. At the level of human resources, the concept of community-directed distribution, pioneered for ivermectin, is being used in other programmes; studies have shown that the approach is feasible, sustainable, and cost-effective. At the level of service delivery, examples of innovative solutions being used for several diseases include HealthMapper, originally developed to locate foci of guinea-worm disease, blister packs, introduced to improve patient compliance with multidrug therapy for leprosy, and the simple “dose pole”, designed to guide drug administration in onchocerciasis control. Experiences in the drive to eliminate lymphatic filariasis have demonstrated the feasibility of rapidly increasing population coverage, particularly when supported by social marketing and mobilization campaigns. These experiences have also uncovered specific problems that need to be addressed. Competency-based training, aligned with standardized treatment guidelines for these diseases, is needed to ensure that training instils the required skills. In some cases, a reorientation of formal academic training may be needed; this is most likely to happen when health ministries in endemic countries recognize neglected diseases as a priority concern. The issue of incentives for community volunteers also needs to be addressed in the interest of sustainability. Given the disabling nature of neglected diseases and the absence of formal rehabilitation services, innovative informal networks for promoting self-care are another important component of service delivery.

**Tools for control** should be safe, rapidly effective, and easy to administer in resource-poor settings.

**Building on success...**

When assessing the feasibility of intensified control despite resource and service constraints, much can be learned from the success of partnerships, including those involving major drug donations, that have formed to eradicate or eliminate target diseases. For these diseases, conditions that have seemed immutable for centuries are being conquered with great speed. These successes also show how simple tools, when supported by adequate commitment, can bring major and lasting relief to the burden of neglected diseases. For example, the eradication of guinea-worm disease, which is now in sight despite the absence of a vaccine or curative drug, shows the feasibility of behavioural change in poor rural areas and the power of health education to achieve this change.

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These experiences have also uncovered specific problems that need to be addressed. Competency-based training, aligned with standardized treatment guidelines for these diseases, is needed to ensure that training instils the required skills. In some cases, a reorientation of formal academic training may be needed; this is most likely to happen when health ministries in endemic countries recognize neglected diseases as a priority concern. The issue of incentives for community volunteers also needs to be addressed in the interest of sustainability. Given the disabling nature of neglected diseases and the absence of formal rehabilitation services, innovative informal networks for promoting self-care are another important component of service delivery.
The most immediately relevant research often seeks ways to improve the use of existing tools in resource-poor settings. Such research is particularly important when considering how best to integrate control approaches and combine interventions.

Strengthening research capacity in endemic countries is a sensible way to improve local ownership, especially when research and control are closely linked. It also helps ensure that technical guidelines and policies are relevant to local situations.

In all research institutes, ways need to be found to attract the best scientists to work on neglected diseases, and to orient fundamental research towards practical applications. Some endemic countries produce excellent scientists, but lose them to other countries offering superior research facilities.

While robust and effective control tools exist for most of the neglected diseases, research is needed to identify problems in their implementation and determine their economic viability. For some of these diseases, research is urgently needed to develop new drugs and other tools that are sufficiently simple and practical for use under difficult conditions, as well as safe and effective.

Grants from private foundations that support the development of new drugs for neglected diseases are a welcome trend. Moreover, this trend may be another signal that neglected diseases are beginning to attract due attention, particularly as many drugs currently in use were originally developed for veterinary purposes.

The intensified control of neglected diseases may be the most expedient route to a better life for several million people.

The contribution of drug donation programmes to service delivery should not be underestimated. In some areas, drugs donated as part of elimination programmes are the only commodities available in district health services. The capacity of services to deliver even a limited number of effective, quality-assured drugs, especially when these are for diseases given high priority by the community, can be an important incentive for the use of services as well as an important source of motivation for health care staff.

Local ownership

Power to the people...

Though long neglected at many levels, these disabling and debilitating diseases, often associated with great stigma, are given high priority by affected communities. This high priority is a motivating factor once communities understand their right to demand diagnosis and treatment. It also creates an opportunity for a head-start by relying on principles of local ownership, community-based action, health education, and integrated delivery of simple technologies worked out during decades of efforts to strengthen primary health care.

Strategies that aim to reach all at-risk populations with preventive interventions can preclude a large number of permanent disabilities, effectively freeing health systems – and families – from the burden of chronic care.

...enhances credibility of local health services

Innovative solutions, such as the use of community-based distribution schemes, work best when the sense of local ownership is strong. Plans of action that start with an assessment of local needs and capacities are important, as is leadership, at national and local levels, that makes these hidden diseases more visible and gives them due priority. Mechanisms for assessing community needs should ensure that certain groups are not excluded because of the local power structure.

Actions at the community level need to be guided by government policies that establish uniform standards of care, direct the equitable distribution of resources, and ensure that data from local surveillance and monitoring systems are made available for national and international comparisons. Such actions also strengthen the sense that neglected diseases are a priority concern as part of national policy.

...helps ensure sustainable solutions

Neglected diseases are given high priority by affected communities, and this opens the way for community-based approaches with strong local ownership.
Research
Answering crucial questions...

The most immediately relevant research often seeks ways to improve the use of existing tools in resource-poor settings. Such research is particularly important when considering how best to integrate control approaches and combine interventions.

Strengthening research capacity in endemic countries is a sensible way to improve local ownership, especially when research and control are closely linked. It also helps ensure that technical guidelines and policies are relevant to local situations.

In all research institutes, ways need to be found to attract the best scientists to work on neglected diseases, and to orient fundamental research towards practical applications. Some endemic countries produce excellent scientists, but lose them to other countries offering superior research facilities.

...to develop new tools and strategies

While robust and effective control tools exist for most of the neglected diseases, research is needed to identify problems in their implementation and determine their economic viability. For some of these diseases, research is urgently needed to develop new drugs and other tools that are sufficiently simple and practical for use under difficult conditions, as well as safe and effective.

Grants from private foundations that support the development of new drugs for neglected diseases are a welcome trend. Moreover, this trend may be another signal that neglected diseases are beginning to attract due attention, particularly as many drugs currently in use were originally developed for veterinary purposes.
The opportunity

International focus on poverty reduction

Efforts to intensify the control of neglected diseases can draw on several positive trends, including the international priority given to poverty reduction, as well as practical lessons from several successful eradication and elimination programmes. Such efforts need not wait for dramatic improvements in health systems and services, environmental conditions, and levels of community education, or large armies of staff.

Effective tools available...

Tools for control are safe, rapidly effective, and easy to administer in resource-poor settings. Most can be delivered by non-specialists, and many require only once-yearly contact with health services. For some diseases, major open-ended drug donations are making these tools available to all in need, as long as needed.

Control strategies relying on the annual administration of powerful new drugs to all at-risk populations can reduce transmission and the human pool of infection for several diseases, even in the absence of safe water and sanitation. They can also prevent permanent disabilities in large populations, and have ancillary benefits that improve the very foundations of health status in impoverished populations.

Neglected diseases are given high priority by affected communities, and this opens the way for community-based approaches with strong local ownership.

Social mobilization campaigns that accompany some control programmes are helping to change long-standing cultural attitudes towards these diseases while also creating a demand for diagnosis and treatment. Because many drugs bring rapid physical relief, populations can easily link an intervention with a desired outcome, even in the absence of a full understanding of the disease.

...freeing people from disabling diseases

Populations left behind by socioeconomic development are in dire need of safe water and adequate sanitation, better access to health services, more opportunities for education, and improved nutrition. However, they also need to be freed from the burden of disabling and debilitating infectious diseases. Given the power of available interventions to bring rapid and lasting results, intensified control of these diseases may be the most expedient route to a better life for several million people.
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Neglected diseases are given high priority by affected communities, and this opens the way for community-based approaches with strong local ownership. Social mobilization campaigns that accompany some control programmes are helping to change long-standing cultural attitudes towards these diseases while also creating a demand for diagnosis and treatment. Because many drugs bring rapid physical relief, populations can easily link an intervention with a desired outcome, even in the absence of a full understanding of the disease.

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