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GHP Study Paper 4:

GLOBAL HEALTH PARTNERSHIPS AND NEGLECTED DISEASES

This paper forms part of the 2004 DFID Study: *Global Health Partnerships: Assessing the Impact.*

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PARTNERSHIP ACRONYM LIST

AAI	Accelerating Access Initiative to HIV Care
ACHAP	African Comprehensive HIV/AIDS Partnerships
AHPSR	Alliance for Health Policy and Systems Research
AMD	Alliance for Microbicide Development
AMP	African Malaria Partnership (GSK)
APOC	African Program for Onchocerciasis Control
CF	Concept Foundation
BPD	Building Partnerships for Development
CICCR	Consortium for Industrial Collaboration in Contraceptive Research
CVP	Children's Vaccine Program at PATH
DPP	Diflucan Partnership Program
DNDi	Drugs for Neglected Diseases Initiative
DVP	Dengue Vaccine Project
EL-MDRTBP	Eli Lilly Multi-Drug Resistance Tuberculosis Partnership
EMVI	European Malaria Vaccine Initiative
FIND	Foundation for Innovative New Diagnostics
GAEL	Global Alliance to Eliminate Leprosy
GAELF	Global Alliance for the Elimination of Lymphatic Filariasis
GAIN	Global Alliance for Improved Nutrition
GATBDD	Global Alliance for TB Drug Development
GAVI	Global Alliance for Vaccines and Immunization
GBC	Global Business Coalition on HIV/AIDS
GCM	Global Campaign for Microbicides
GCWA	Global Coalition on Women and AIDS
GDF	Global TB Drug Facility
GET 2020	WHO Alliance for the Global Elimination of Trachoma
GFATM	Global Fund to Fight AIDS, TB and Malaria
GFUNC	Gates Foundation/U. of North Carolina Partnership for the Development of New Drugs
GMAI	Global Media AIDS Initiative
GMP	Global Microbicide Project
GOARN	Global Outbreak Alert and Response Network
GPEI	Global Polio Eradication Initiative
GPHW	Global Public-Private Partnership for Hand Washing with Soap
GRI	Global Reporting Initiative
GSK	GlaxoSmithKline
GWEP	Guinea Worm Eradication Program
HACI	Hope for African Children Initiative
HATC	HIV/AIDS Treatment Consortium (Clinton Foundation AIDS Initiative)
HHVI	Human Hookworm Vaccine Initiative
HIN	Health InterNetwork
HTVN	HIV Vaccine Trials Network
IAMI	International AIDS Vaccine Initiative
IDRI	Infectious Disease Research Institute
ILEP	International Federation of Anti-Leprosy Associations
IOWH	Infectious Disease Research Institute
IPAAA	International Partnership Against AIDS in Africa
IPM	International Partnership for Microbicides
IPPPH	Initiative on Public-Private Partnerships for Health

ITI	International Trachoma Initiative
IUATLD	International Union Against Tuberculosis and Lung Disease (UNION)
JPMW	Japanese Pharmaceutical, Ministry of Health, WHO Malaria Drug Partnership
LAPDAP	Name of anti-malarial treatment development by private-public partnership
LEPRA	British Leprosy Relief Association
LFI	Lassa Fever Initiative
MAP	World Bank Multi-sectoral AIDS Programme
MDP 1	Mectizan Donation Program
MDP 2	Microbicides Development Programme
MDP 3	Malarone Donation Program
MEC	Mectizan Expert Committee
MI	Micronutrient Initiative
MIM	Multilateral Initiative on Malaria
MMV	Medicines for Malaria Venture
MNT	Campaign to Eliminate Maternal and Neo-natal Tetanus
MTCT-Plus	Maternal to Child Transmission
MVI	Malaria Vaccine Initiative
MVP	Meningitis Vaccine Programme
NetMark Plus	<i>(insecticide treated net social marketing programme)</i>
OEPA	Onchocerciasis Elimination Program of the Americas
PARTNERS	Partnership Against Resistant Tuberculosis: A Network for Equity and Resource Strengthening
PEPFAR	US President's Emergency Plan for HIV/AIDS Relief
PDVI	Paediatric Dengue Vaccine Initiative
PneumoADIP	Pneumococcal Accelerated Development and Introduction Plan
RBM	Roll Back Malaria
SCI	Schistosomiasis Control Initiative
SF	Secure the Future Initiative
SIGN	Safe Injection Global Network
Step Forward	<i>(international pharmaceutical company initiative to support AIDS orphans)</i>
TEC	Trachoma Expert Committee
TDR	UNICEF-UNDP-WorldBank-WHO Special Programme for Training and Research in Tropical Diseases
TROPIVAL	<i>(French based R&D partnership for neglected diseases)</i>
VDP	Viramune Donation Program
VF	Vaccine Fund
Vision 2020	<i>(global initiative to eliminate unnecessary blindness)</i>
VITA	Vitamin A Global Initiative
VVM	Vaccine Vial Monitors
WHA	World Health Assembly
WHO	World Health Organisation
WPSS	WHO Programme to Eliminate Sleeping Sickness

ABBREVIATIONS

DALYs	Disability Adjusted Life Years
GHP	Global Health Partnership
GOI	Government of India
GSK	GlaxoSmithKline
IPPPH	Initiative on Public-Private Partnerships for Health
MDA	Mass Drug Administration
MDG	Millennium Development Goals
MDT	Multidrug therapy (for leprosy)
MOU	Memorandum of Understanding
NGO	Non-governmental organisation
SSA	Sub Saharan Africa
TB	Tuberculosis
TDR	UNICEF-UNDP-World Bank-WHO Special Programme for Training and Research in Tropical Diseases
WHA	World Health Assembly
WHO	World Health Organization

EXECUTIVE SUMMARY

Key Findings

- *Most neglected diseases are being addressed by at least one GHP.*
- *Most GHPs for neglected diseases are providing technical support, drugs, and in a few cases funding. All three are likely to be required to sustain programmes. More operational funding is required.*
- *Evidence of impact is still limited. Existing evaluations find these GHPs have a positive impact, especially in accelerating progress, even when shortcomings are identified. Sustainability is the key concern.*
- *More integrated approaches to tackling neglected diseases should be explored.*
- *GHP-led R&D for new tools is intensifying and focused on those diseases with greatest need. Operational research may also require investment.*

Study purpose

This report assesses whether Global Health Partnerships (GHPs) have addressed diseases neglected by other forms of development assistance. It concludes that they have. The study is one of a series commissioned by DFID to contribute evidence-based material for a substantial and wide-ranging assessment of the impact of GHPs.

Identification of neglected diseases

There is no standard global definition of neglected diseases. The key elements are diseases affecting principally poor people in poor countries, for which health interventions - and research and development - are seen as inadequate to the need.

They have characteristically been infectious - usually tropical - diseases, and that bias is reflected in the GHPs. These latter do not yet reflect WHO's more recent attempt to focus wider attention on "three neglected epidemics" of non-communicable disease: cardiovascular disease, tobacco-related disease and road traffic casualties.

This study focuses on 15 internationally accepted 'most neglected' diseases: Buruli Ulcer, Chagas disease, congenital syphilis, cysticercosis, dengue, guinea worm, leishmaniasis, leprosy, lymphatic filariasis, maternal and neonatal tetanus, onchocerciasis, rabies, schistosomiasis, sleeping sickness and trachoma.

GHP coverage of neglected diseases

Most (80%) neglected diseases are being addressed by at least one GHP. No GHPs have been identified for only three: congenital syphilis, cysticercosis and rabies.

While there are a few longer-standing GHPs of this kind, most have been established in recent years and focus on a single disease. The extent and nature of GHP support for the individual diseases varies. Some diseases – Chagas disease, dengue and dengue haemorrhagic fever and leishmaniasis – appear to have GHP support only for the development of new tools, though WHO provides wider support.

For most of these neglected diseases, the relevant GHP provides broad support for raising the profile of the disease and improving the delivery of interventions, usually backed by a drug donation agreement with one or more partner pharmaceutical

companies. In some cases the drug donation provided the rationale for establishing the GHP.

Experience suggests that, to support a successful disease control programme, low resource countries are likely to need three elements: partnership or donor contribution of drugs, funding for some operational costs, and technical assistance. Few GHPs provide direct access to operational funding; GHP failure to do so, or to help mobilise such resources, can seriously curtail programmes. Any DFID consideration of support for this group of GHPs should seek assurances about mobilisation of resources for the full range of needs. Donors collectively should be prepared to contribute to the operational costs of national control programmes.

Several of the diseases are the subjects of time-targeted World Health Assembly eradication or elimination resolutions (see table below). The clarity of the goal – and in some cases, the consciousness of insufficient progress being made towards it – may act as a stimulus to partnership formation. The financial dividend from winding up these GHPs will not be huge but success will relieve affected countries not only of the burden of disease, but also of the burden of dealing with multiple partnerships.

Impact

On the basis of a limited number of evaluations, GHPs are seen as having had a positive – usually a very positive – impact, especially in mobilising commitment and funding, and accelerating progress. This is true even of GHPs where the evaluation finds organisational or relationship shortcomings. Where cost-effectiveness has been assessed, it is high. Sustainability is identified as a concern.

In the poorer countries studied for this work, there are indications that GHPs are beginning to make a real difference in kick-starting or revitalising programmes for these neglected diseases which have typically had a low political profile even at country level. By contrast, in India these GHPs are perceived as making only a limited contribution. The key test will be whether GHPs can deliver on time the targets for eradication and elimination, several of which have proved elusive in the past. There is no indication from Sierra Leone or Sri Lanka that GHPs have operated more effectively than other health agencies during periods of conflict.

Development of a clear strategy, building a consensus around it, and coordinating partner efforts are key areas of added value for GHPs. It is worrying that in some cases there appear to be continuing tensions about technical strategies and operational priorities, in one case (GAEL) leading to partnership breakdown. At the same time, it is unreasonable to expect partnerships of this nature to operate without some strains, given the scale of the programme challenges, the complexity of the dynamics, and the differences in culture between constituent partners.

Alignment and integration

GHPs for neglected diseases tend to be addressing national priorities, working through national systems and are generally welcomed by health services at national and district levels as bringing new resources and drugs.

The wider concern is that the proliferation of the full range of GHPs may begin to overwhelm weaker health systems. Current consideration by WHO of a more integrated approach to tackling at least some of the neglected diseases should be encouraged. The emerging view is that some degree of integration across diseases would be both technically feasible and operationally beneficial. Developments of this kind will require much closer collaboration between individual GHPs for neglected diseases at global as well as country levels.

Research and development for neglected diseases

There are effective and affordable tools for prevention and treatment of many neglected diseases. But for some diseases, there has been a serious unmet need for research and development. One critical problem has been the lack of sufficient market incentive, which is particularly extreme for neglected diseases. The indications are that R&D is now intensifying through the activities of newly-created GHPs. DNDi is targeting the three diseases generally accepted as being in greatest need of new drugs: Chagas disease, leishmaniasis and sleeping sickness. Other GHPs are working on a vaccine against dengue. These new GHPs will need continued support. It is too soon to assess their impact.

More research is needed into prevention and treatment of Buruli Ulcer. Operational research may also require investment to identify best implementation practices and demonstrate opportunities for fruitful collaboration across disease programmes.

Executive summary table : GHPs for neglected diseases

Disease	GHP (function)	Date GHP set up	WHA/Programme target	Drug donations
Leprosy	GAEL (TS)	1999	Elimination by 2005.	1999 WHO/Novartis Agreement to donate Multi Drug Therapy (MDT) until 2005 to help eliminate leprosy; the Agreement is now to be extended to 2010.
Tetanus	MNTE (TS)	WHA resolution 1989	Elimination by 2005.	-
Guinea worm	GWEP (TS)	1986	Eradication by 2005.	Johnson & Johnson donation of Tylenol, forceps and gauze. Also larvicide and filter donations.
Onchocerciasis	APOC (TS)	1996	Elimination in Africa. Phase out APOC by 2010.	1987 Merck/ Mectizan® Donation Program (MDP) commitment to donate all the Mectizan® (ivermectin) required for as long as required to bring onchocerciasis under control as a public health problem.
Schistosomiasis	SCI (TS)	2003	Regular chemotherapy for 75% of schoolchildren at risk in selected countries by 2010.	Funding for country procurement of praziquantel.
Trachoma	ITI (TS)	1998	Elimination by 2020.	1998 Pfizer Inc donation of as much Zithromax (azithromycin) as is needed.
LF	GAELF (TS)	2000	Elimination by 2020.	<ul style="list-style-type: none"> ▪ 1998 WHO/GSK agreement to donate all the albendazole required for elimination of LF. 1998 Merck commitment to donate all the Mectizan® required for as long as required to eliminate LF in African countries where onchocerciasis and LF co-exist.
Sleeping sickness	WPRESS (TS) DNDi (R&D)	2001 2003	No specific time target for elimination.	WHO/Aventis MOU: 2001-6 donations of pentamidine, melarsoprol, eflornithine. Bristol Myers Squibb: raw materials for 1 year's supply of eflornithine. WHO/Bayer MOU: 2002-7 donations of suramin, nifurtimox.
Buruli Ulcer	GBUI (TS)		-	-

Chagas Disease	DNDi (R&D)	2003	-	-
Dengue	DVP (R&D) PDVI (R&D)	2003	-	-
Leishmaniasis	DNDi (R&D)	2003	-	-

Note: TS function - technical/services (including donation, service delivery, technical support)

1 INTRODUCTION

1.1 Study question and TORs

This report assesses whether Global Health Partnerships (GHPs) have addressed diseases which have been neglected by other forms of development assistance.

The study is one of a series commissioned by DFID to contribute evidence-based material for a substantial and wide-ranging assessment of the impact of GHPs.

1.2 Definition of Global Health Partnerships

Previous work¹ in this series defines the concept of Global Health Partnership in a broad manner:

Partnership: the key criterion is a collaborative relationship among multiple organisations in which risks and benefits are shared in pursuit of a shared goal. The focus is on more formal collaborative ventures and not exclusively on public-private partnerships, although these constitute the majority. Some important global health initiatives that are not partnerships per se, such as the World Bank's MAP, are not included.

Health: The goal of the partnerships has to concern the redress of health problems of significance for the poor in low- and middle-income countries.

'Global' is interpreted to capture initiatives that extend across or transcend national boundaries. In this paper for example, APOC – the African Programme for Onchocerciasis Control – is included as a GHP addressing a neglected disease, though technically it operates only within Africa rather than globally. It forms the main operating component of the Global Partnership to Eliminate Riverblindness.

The World Bank's definition of global programs are those partnerships and related initiatives whose benefits cut across more than one region of the world, and in which the partners reach explicit agreements on objectives; agree to establish a new (formal or informal) organization; generate new products or services; and contribute dedicated resources to the program². This is a tighter definition but can generally be applied to the GHPs for neglected diseases discussed below, other than the geographical limitation.

1.3 Selection of Global Health Partnerships

The earlier work described above³ identified some 75 Global Health Partnerships. For the purpose of the broader assessment of the impact of GHPs, DFID selected 19 core partnerships of primary interest but this report refers to all those GHPs identified which have focused on commonly accepted neglected diseases.

1.4 Typology of GHPs

For the purposes of analysis, DFID has defined a typology of GHPs classified under four dimensions: research and development; technical/services (including donation, service delivery, technical support); advocacy (national or international) and financing.

Some GHPs fulfil more than one of these functions, and the mapping work undertaken for this study therefore indicates both primary and secondary roles.

¹ Buse K., 2004. Global Health Partnerships: Mapping a shifting terrain. London: DFID Health Resource Centre.

² Operations Evaluation Department, World Bank. The World Bank's Approach to Global Programs: An Independent Evaluation. The World Bank, August 1, 2002.

³ Buse K., 2004. Global Health Partnerships: Mapping a shifting terrain. London: DFID Health Resource Centre

2 NEGLECTED DISEASES

2.1 Definition of neglected diseases

There is no standard global definition of neglected diseases.

The UN has taken as its definition⁴ a WHO publication description of them as those diseases that “affect almost exclusively poor and powerless people living in rural parts of low-income countries”. This does not seem wholly sufficient, in that it leaves the issue of neglect implicit. But this lack is common to several such definitions, eg “infectious diseases that continue to be the leading causes of death in poor countries but which do not affect industrialised countries”.

The key elements are that these are diseases affecting principally poor people in poor countries, for which health interventions – and research and development - are regarded as inadequate to the need.

They have characteristically been infectious - usually tropical - diseases, and that bias is reflected in the GHPs. These latter do not yet reflect WHO’s more recent attempt to focus wider attention on “three neglected epidemics” of non-communicable disease: cardiovascular disease, tobacco-related disease and road traffic casualties⁵. GHPs are perhaps particularly well-placed to address conditions, such as communicable diseases, which cross national borders. However, given the large and increasing disease burden caused through non-communicable diseases, it would be of concern if support for communicable disease GHPs were at their expense.

While the traditional neglected diseases are by no means homogenous, it has been noted⁶ that many share common characteristics:

- They typically affect the poorest in the community, usually the most marginalized and those least able to demand services. This includes women, children and ethnic minorities, as well as those living in remote areas with restricted access to services. They are a symptom of poverty and disadvantage.
- 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. Improved housing and nutrition would also help in some cases.
- Where curative interventions exist, they have generally failed to reach populations early enough to prevent impairment.
- In particular, fear and stigma attach to some diseases, and lead to delay in seeking treatment. In the case of leprosy, stigma and discrimination are so acute in addition to the physical suffering that the UN Special Rapporteur on Health and Human Rights has suggested it would be instructive to devise a human rights, right to health approach to the elimination of leprosy.
- Although the eradication and elimination of certain diseases can be achieved at low cost per patient, the total cost at the national level can be significant in view of the number of people affected by the diseases. Unless external support is

⁴ Note by the Secretary-General *The right of everyone to enjoy the highest attainable standard of physical and mental health*, 10 October 2003. A/58/427; and Paul Hunt, UN Special Rapporteur on the Right to Health, UN Health and Human Rights Working paper Series No.4, *Neglected Diseases, Social Justice and Human Rights: Some Preliminary Observations*. Berlin, December 2003.

⁵ World Health Report 2003, Chapter 6 www.who.int/whr/2003

⁶ Consequences of Neglected Diseases and Tools to Fight Them, Working Paper 1, International Workshop on Intensified Control of Neglected Diseases, Berlin, 10-12 December 2003

provided, this could have significant opportunity costs and implications for other budgets – or for continued neglect of these diseases.

- The development of new tools – new diagnostics, drugs and vaccines - has been underfunded or neglected, largely because there has been little or no market incentive. This is the ‘10/90 disequilibrium’, under which only 10% of health R&D spending has been directed at the health problems of 90% of the world’s population.

2.2 Specification of neglected diseases in this study

One view⁷ is that, in terms of drug development at least, there are now:

- ‘neglected diseases’ such as HIV/AIDS, tuberculosis (TB) and malaria, that are starting to be tackled by recent public–private partnerships; and
- the ‘most-neglected diseases’, such as sleeping sickness and Chagas disease, that have been virtually ignored in terms of drug development and continue to plague the developing world.

However, with the advent of the GFATM, 3x5, specific targets in the Millennium Development Goals, and a raft of GHPs and other initiatives such as PEPFAR and MAP, it seems inappropriate to continue to designate HIV/AIDS, TB and malaria as ‘neglected diseases’, even if the challenges remain very great. Furthermore, analysis suggests that the number and nature of the GHPs for HIV/AIDS, TB and malaria distinguish these diseases from those in the category of most neglected diseases. The GHPs supporting them tend to be different in terms of scale, cost, operational structure and impact on local systems. This paper therefore does not cover GHPs for HIV/AIDS, TB or malaria.

Polio has also not been classed as a neglected disease, because of the major financial and infrastructure investment in the Global Polio Eradication Initiative over the last twenty years.

The neglected diseases covered in this paper have been identified primarily from the fourteen listed in *Consequences of Neglected Diseases and Tools to Fight Them*, Working Paper 1, International Workshop on Intensified Control of Neglected Diseases, Berlin 10-12 December 2003. The analysis also includes onchocerciasis, given evidence from the country studies undertaken as part of this exercise. The resulting specification includes all ten diseases⁸ covered by TDR, the UNICEF-UNDP-World Bank-WHO Special Programme for Training and Research in Tropical Diseases.

All such classifications are relatively arbitrary and other diseases could have been included, such as Japanese encephalitis and Lassa Fever (for which a Lassa Fever Initiative exists).

The following 15 ‘neglected’ diseases have been selected as the basis for analysis:

- Buruli Ulcer
- Chagas’ Disease (American Trypanosomiasis)
- Congenital Syphilis
- Cysticercosis
- Dengue and Dengue Haemorrhagic fever

⁷ Morel C., *Neglected diseases: under-funded research and inadequate health interventions. Can we change this reality?* European Molecular Biology Organization EMBO reports VOL 4 , special issue, 2003.

⁸ Diseases covered by TDR: Chagas, Dengue, HATS, Leishmaniasis, Lymphatic Filariasis, Malaria, Onchocerciasis, Schistosomiasis, Tetanus, TB.

- Guinea worm
- Human African Trypanosomiasis (Sleeping sickness)
- Leishmaniasis (kala azar)
- Leprosy
- Lymphatic Filariasis
- Maternal and Neonatal Tetanus
- Onchocerciasis
- Rabies
- Schistosomiasis and Soil-transmitted helminthiasis
- Trachoma.

2.3 Epidemiology, prevention and treatment of neglected diseases

These diseases vary in the extent of the burden they impose, and in the availability of appropriate treatments.

Figures in Table 2.1 on disease burden and deaths need to be treated with some care. Current statistics about the extent and burden of these diseases may not be wholly reliable.

Table 2.1: Selected neglected diseases: disease burden and deaths

Disease	Disease burden DALYs* (thousands)				Deaths (thousands)			
	Total	% total	Male	Female	Total	% total	Male	Female
African trypanosomiasis	1525	0.1	966	559	48	0.1	31	17
Chagas disease	667	0.1	343	324	14	0.0	8	7
Schistosomiasis	1702	0.1	1020	681	15	0.0	10	5
Leishmaniasis	2090	0.1	1249	840	51	0.1	30	21
Lymphatic filariasis	5777	0.4	4413	1364	0	0.0	0	0
Onchocerciasis	484	0.0	280	204	0	0.0	0	0
Leprosy	199	0.0	117	82	6	0.0	4	2
Dengue	616	0.1	279	337	19	0.0	8	10
Trachoma	2329	0.2	597	1732	0	0.0	0	0

* DALYs - Disability Adjusted Life Years (the number of healthy years of life lost due to premature death and disability)

Source: World Health Report, 2004

In general, neglected diseases fall into two categories:

- the endemic chronic and disabling diseases for which effective treatment or preventive strategies exist (such as lymphatic filariasis and onchocerciasis); and

- the growing epidemic of deadly diseases for which modern effective treatment does not currently exist (such as Buruli Ulcer and African trypanosomiasis/sleeping sickness)⁹.

Low cost and easy to use tools exist for control and prevention of most neglected diseases, ie those which fall into the first category. For example, multi-drug therapy in blister packs provides a modern, effective, easy to use approach to treatment of leprosy. Trachoma is the world's leading cause of preventable blindness, estimated to cause 15% of all blindness in the world. Yet it can be tackled by a strategy of simple surgery, antibiotics, face washing and environmental improvement (SAFE).

A single annual dose of ivermectin (Mectizan®) is effective against onchocerciasis, and a single annual dose of praziquantel is effective against schistosomiasis. Lymphatic filariasis is ranked by the World Health Organization as the second leading cause of permanent and long-term disability but transmission of the infection can be halted by treating infected individuals once a year, for four to six years, with a single-dose combination of oral medicines.

The tendency for the diseases to be localised assists targeted programme delivery, and population-wide interventions – such as mass drug administration and vector control – are largely free of discrimination and do not further marginalize excluded groups. Several interventions bring rapid physical relief which helps stimulate acceptance and further demand.

The problem in relation to this category of diseases has primarily been one of 'neglect'. Leprosy exceptionally does seem to have attracted longer-standing attention from NGOs. But in general, exploiting the potential of existing tools against diseases like schistosomiasis has not been a priority at either national or international levels.

By contrast, the second category of diseases poses greater challenges. Buruli ulcer is "poorly understood and difficult to treat"¹⁰. Sleeping sickness drugs are mostly old, toxic and difficult to use, requiring hospitalisation, well-equipped clinics and trained staff. Similar problems are found with existing drugs for Chagas disease and leishmaniasis: they are parenteral in use, need multiple administrations, have serious side effects and are increasingly becoming ineffective due to rising resistance. Simpler, more effective drugs and diagnostics are needed, designed for use in resource-poor settings.

Summary details of the epidemiology and current recommended approaches to prevention/ control and treatment for each of these 'neglected diseases' are provided in Annex 1.

⁹ Note for DFID of International Workshop on Intensified Control of Neglected Diseases, Berlin 10-12 December 2003.

¹⁰ Paul Hunt, UN Special Rapporteur on the Right to Health. UN Health and Human Rights Working paper Series No.4, Neglected Diseases, Social Justice and Human Rights: Some preliminary Observations. Berlin, December 2003.

3 NEGLECTED DISEASES COVERED BY GHPS

3.1 GHP coverage of neglected diseases

Of the selected neglected diseases, 12 out of 15 are addressed by at least one GHP:

- Buruli Ulcer: by the Global Buruli Ulcer Initiative
- Chagas Disease: by the Drugs for Neglected Diseases initiative (DNDi)
- Dengue and Dengue Haemorrhagic fever: by the Dengue Vaccine Project and the Paediatric Dengue Vaccine Initiative.
- Guinea worm: by the Guinea Worm Eradication Program
- Human African Trypanosomiasis (Sleeping sickness): by the WHO Programme to Eliminate Sleeping Sickness (WPSS) and DNDi for drug research
- Leishmaniasis (kala azar) : by DNDi for drug research
- Leprosy: by the Global Alliance to Eliminate Leprosy (GAEL)
- Lymphatic Filariasis: by the Global Alliance for the Elimination of Lymphatic Filariasis (GAELF)
- Maternal and Neonatal Tetanus: by the Campaign to Eliminate Maternal and Neonatal Tetanus
- Onchocerciasis: by the Global Partnership to Eliminate River Blindness (encompassing the African Program for Onchocerciasis Control – APOC – and previously the Onchocerciasis Control Programme in West Africa) and Vision 2020, a global alliance to eliminate avoidable blindness.
- Schistosomiasis: by the Schistosomiasis Control Initiative (SCI)
- Trachoma: by the International Trachoma Initiative (ITI), GET 2020 (a WHO-led global alliance for the elimination of trachoma) and Vision 2020, a global alliance to eliminate avoidable blindness. ITI is a partner in GET 2020.

No GHPs have been identified for congenital syphilis, cysticercosis and rabies. However, this does not imply that these diseases have no international support at all. In line with its role, WHO provides a focus for technical advice, oversight and some level of international advocacy. For example, cysticercosis has been considered by the task force on disease eradication and been the subject of WHO reports to the World Health Assembly in both 2002 and 2003. Similarly, WHO has a programme of human rabies surveillance and control activities; a major international meeting took place in Geneva during the period of this study.

3.2 Typology of GHPs for neglected diseases

The extent and nature of GHP support for the individual diseases varies.

In the case of most diseases – for example, guinea worm, sleeping sickness, leprosy, lymphatic filariasis, onchocerciasis, schistosomiasis and trachoma -, the GHP provides broad support for raising the profile of the disease and improving the delivery of interventions, usually aimed at delivering specific targets. Only a few of these GHPs (eg APOC) provide direct access to critically needed operational funding in addition to facilitating drug supply.

Some diseases – Chagas disease, dengue and dengue haemorrhagic fever and leishmaniasis – appear to have GHP support only for the development of new tools, including from the recently-formed DNDi. Again, it should be noted that WHO provides the focus for broader support. For example, there is a WHO Programme for the Surveillance and Control of Leishmaniasis. In 1998 the World Health Assembly passed a resolution to eliminate the transmission of Chagas disease by 2010. In 2000, the World Health Assembly passed a resolution urging Member States to

strengthen surveillance, protection and control of dengue and, in the same year, 41 countries issued a declaration (the Chiang Mai Declaration) on dengue.

Table 3.1: GHPs for neglected diseases by type

GHP	Research and development	International and national advocacy	Financing	Technical support, service delivery, donations and discounted products
APOC		S	S	P
DNDi	P	S		
DVP	P			
GAEL		S		P
GAELF		S	S	P
GET 2020		S		P
GWEP		S	P	S
ITI		S		P
MNTE		S		P
PDVI	P			
SCI		S	S	P
WPESS		S		P
VISION 2020		P		S

P=Primary Role, S=Secondary Role

In the case of the most neglected diseases, with their smaller and more localized burden of disease, there is no real analogue for the all-embracing GHP architecture developed by some of the larger GHPs. The Global Partnership to Stop TB, for example, has capacity to provide international and national advocacy, coordination, financing, drug supply, technical assistance and support for research and development into new tools. Individual public-private partnerships exploring new diagnostics (FIND), new drugs (the Global Alliance for TB Drug Development) and new vaccines (Aeras) have been bound into the partnership and provide the foundation for dedicated Partnership Working Groups whose activities are set out within the Partnership's Global Plan to Stop TB and its progress report. This provides the potential for the implementation and new tools Working Groups to work synergistically.

By contrast, to the extent that there are R&D GHPs for neglected diseases, they tend to be freestanding.

3.3 Research and development for neglected diseases

One long-standing initiative has addressed research into neglected diseases: the UNICEF-UNDP-World Bank-WHO Special Programme for Training and Research in Tropical Diseases (TDR). Because of the then absence of research into neglected diseases, TDR was established in 1975 to help coordinate, support and influence global efforts to combat a portfolio of neglected infectious diseases that disproportionately affect poor and marginalized populations: Chagas' disease, dengue, sleeping sickness, leishmaniasis, lymphatic filariasis, malaria, onchocerciasis, schistosomiasis, tetanus and TB.

Evaluations suggest that TDR has achieved valuable outcomes in terms of contributing to the development of improved tools for controlling several neglected diseases and strengthening research capacity in developing countries through collaborative research. Of the 1233 new drugs identified as reaching the market between 1975 and 1997, only 13 were approved for tropical diseases¹¹. Of these 13, six were developed with TDR support.

Nonetheless, in recent years, there has been increasingly vocal concern about the need for more research and development for drugs and other tools for neglected diseases, particularly as many drugs currently in use were originally developed for veterinary purposes. The key requirement of new products is to combine safety and efficacy with being sufficiently simple and practical for use under difficult conditions. Operational research to identify best implementation practices is also needed for some diseases.

In 2001, a joint working group from WHO and the research-based pharmaceutical industry identified African trypanosomiasis, leishmaniasis, and Chagas disease as being truly "neglected" in terms of priority infectious diseases affecting developing countries and requiring additional R&D¹². TDR reached similar conclusions the following year¹³.

These three diseases will initially be targeted by the new GHP, DNDi. DNDi was established in 2003 to provide a forum for a variety of players to collaborate in raising awareness of the need to research and develop essential drugs for those neglected diseases that fall outside the scope of market-driven research and development. DNDi aims to initiate and coordinate drug R&D projects in collaboration with the international research community, the public sector, the pharmaceutical industry, and other relevant partners and address unmet needs by taking on projects that others are unable or unwilling to pursue. Its primary focus will be the development of new drugs, or new formulations of existing drugs, for sleeping sickness, leishmaniasis (kala azar), and Chagas disease, though it will also consider engaging R&D projects on other neglected diseases. As means permit, it will consider the development of diagnostics and/or vaccines.

The Institute for OneWorld Health, a nonprofit pharmaceutical company, is also developing drugs for visceral leishmaniasis and Chagas disease.

The 2004 World Health Assembly called for intensified research to develop tools to diagnose, treat and prevent Buruli Ulcer. At present, the BCG vaccine, which appears to offer short-term protection, is the only biomedical intervention that may help control Buruli Ulcer in affected areas.

However, overall, R&D is intensifying, and stronger links are developing between public and private research bodies. A 2003 International Workshop on Intensified Control of Neglected Diseases welcomed a trend for grants from private foundations to support research for neglected diseases (for example, the Bill and Melinda Gates Foundation has committed \$55 million to dengue research). Its conclusion noted that this trend may be a signal that neglected diseases are beginning to attract due attention.

¹¹ Pecoul, B. et al. (1999) Access to essential drugs in poor countries: A lost battle? *Journal of the American Medical Association*, 281(4): 361-367

¹² WHO-IFPMA Round Table, Working paper on priority infectious diseases requiring additional R&D, July 2001.

¹³ Remme J.H.F. et al, Strategic emphasis for tropical diseases research: a TDR perspective. *Trends in Parasitology*, Vol. 18, No. 19, October 2002.

3.4 Drug donations in GHPs for neglected diseases

Drug donations are a striking feature of the access GHPs for neglected diseases, and in some cases provided the rationale for establishing the GHP (eg Pfizer partnered with the Edna McConnell Clark Foundation in 1998 to establish the International Trachoma Initiative).

Table 3.2: Drug donation PPPs within GHPs for neglected diseases¹⁴

DISEASE	Global Health Partnership	Drug donation PPPs
Leprosy	<ul style="list-style-type: none"> Global Alliance to Eliminate Leprosy (GAEL) 	1999 WHO/Novartis Agreement to donate Multi Drug Therapy (MDT) until 2005 to help eliminate leprosy; the Agreement is now to be extended to 2010.
Lymphatic Filariasis	<ul style="list-style-type: none"> Global Alliance for the Elimination of Lymphatic Filariasis (GAELF) 	<ul style="list-style-type: none"> 1998 WHO/GSK agreement to donate all the albendazole required for elimination of LF. 1998 Merck commitment to donate all the Mectizan® required for as long as required to eliminate LF in African countries where onchocerciasis and LF co-exist.
Onchocerciasis	<ul style="list-style-type: none"> African Programme for Onchocerciasis Control (APOC) Onchocerciasis Elimination Program of the Americas (OEPA) 	1987 Merck/ Mectizan® Donation Program (MDP) commitment to donate all the Mectizan® (ivermectin) required for as long as required to bring onchocerciasis under control as a public health problem.
Sleeping Sickness <i>(Human African Trypanosomiasis)</i>	<ul style="list-style-type: none"> WHO Programme to Eliminate Sleeping Sickness (WPSS) 	<ul style="list-style-type: none"> WHO/Aventis MOU: 2001-6 donations of pentamidine, melarsoprol, eflornithine. Bristol Myers Squibb: raw materials for 1 year's supply of eflornithine. WHO/Bayer MOU: 2002-7 donations of suramin, nifurtimox.
Trachoma	<ul style="list-style-type: none"> International Trachoma Initiative 	1998 Pfizer Inc donation of as much Zithromax (azithromycin) as is needed.

Guinea worm is likely to be the first disease to be eradicated without a vaccine or specific drug treatment. Even so, the Guinea Worm Eradication Program has benefited from donations of nylon filter cloth and pipe filters, the larvicide ABATE®, and medical supplies from Johnson & Johnson (such as Tylenol®, forceps and gauze).

In some cases, drug donations have been supplemented by financial support from pharmaceutical companies. For example, Aventis has donated US\$25 million over 5 years, and Bristol Myers Squibb US\$400,000 over two years, to support the WPSS.

An earlier study found that the close involvement of pharmaceutical companies in the GHPs had led to a perceived increase in their sensitivity to packaging and formulation. For example, Novartis undertook a major repackaging of MDT for leprosy to introduce a calendar blister pack with easy to swallow capsules. This was found at country level to have enhanced compliance, and the new packaging of 6 packs in one box facilitated the integration of the programme into primary health care

¹⁴ Source: adapted from Caines K. and Lush L., Impact of Public-Private Partnerships Addressing Access to Pharmaceuticals in Low and Middle Income Countries: A Synthesis Report from Studies in Botswana, Sri Lanka, Uganda and Zambia, Initiative on Public-Private Partnerships for Health, Switzerland, 2004. ISBN 2-940286-21-3

through the use of the Accompanied MDT approach. Similarly, Mectizan® was changed from 6mg to 3mg tablets to avoid breaking the tablets in half for lower doses. The tablets were repackaged in 500 tablet containers to assist mass distribution, though this posed difficulties for communities with smaller needs.

3.5 Neglected disease GHPs and eradication or elimination targets

Several of the diseases are the subjects of World Health Assembly time-targeted eradication¹⁵ or, more often, elimination¹⁶ resolutions.

Guinea worm, like polio, is an eradication programme. Leprosy, lymphatic filariasis, maternal and neonatal tetanus, blinding trachoma and sleeping sickness are examples of elimination programmes. The clarity of the goal – and in some cases, the consciousness of insufficient progress being made towards it – may act as a stimulus to partnership formation. It is certainly widely accepted that the key rationale for the establishment of the Global Partnership to Stop TB was the realisation in 1998 by the global TB community that WHA targets for TB control would not be met on time in 2000. Among the most neglected diseases, a similar motivation seems to have underpinned the formation of GAEL.

The International Task Force for Disease Eradication concluded that schistosomiasis was not currently eradicable, but that better control was possible, especially by mass chemotherapy and hygiene education for schoolchildren. The Schistosomiasis Control Initiative (SCI) has adopted the WHA 2001 minimum target of providing 75% of schoolchildren at risk with regular chemotherapy - praziquantel and albendazole. In Uganda, SCI was providing not the drugs themselves but funding for national procurement of drugs, as well as for training and operational support. The GHP is so new that its geographical coverage is still limited but a roll-out programme is planned.

Two other GHPs - GAELF and WPRESS - are also still relatively new in organisational terms and in terms of delivering outcomes.

Table 3.3: GHP links with WHA targets

Disease/GHP	GHP established	WHA/Programme target
Leprosy/GAEL	1999	Elimination by 2005
Tetanus/MNTE	<i>WHA resolution 1989</i>	Elimination by 2005
Guinea worm/GWEP	1986	Eradication by 2005
Onchocerciasis/APOC	1996	Eliminate in Africa. Phase out APOC by 2010.
Schisto/SCI	2003	In selected countries, regular chemotherapy for 75% of schoolchildren at risk by 2010
Trachoma/GET 2020	1997	Elimination by 2020
Trachoma/ITI	1998	Elimination by 2020
LF/GAELF	2000	Elimination by 2020
Sleeping sickness/ WPRESS	2001	<i>No specific time target for elimination</i>

¹⁵ The International Task Force for Disease Eradication has defined eradication as “reduction of the worldwide incidence of a disease to zero as a result of deliberate efforts, obviating the necessity for further control measures.”

¹⁶ The International Task Force for Disease Eradication noted that the term “elimination” can be defined as control of the manifestations of a disease so that the disease is no longer considered “a public health problem,” as an arbitrarily defined qualitative or quantitative level of disease control (e.g., WHO’s goal of eliminating leprosy is defined as reducing its incidence to a level below one case per 10,000 population).

There is a pattern of eradication or elimination targets being missed, sometimes repeatedly.

For example, the WHA target deadline for eradication of guinea worm has successively been 1995, then 2000, and then 2005. On the latest 2004 figures, cases of the disease are still being found in 10 countries, with 96% of cases in Sudan, Ghana, and Nigeria. Although the civil war in Sudan has been a major barrier to completing the eradication of Guinea worm disease, Sudan has made significant strides toward elimination in recent years. Eradication effectively began under a six-month "Guinea worm cease-fire" negotiated by President Carter in 1995. Implementation of interventions has improved steadily since then, including the assembly and distribution of more than seven million pipe filters in 2001. In the 3,613 villages where the program intervened in 2002 and retained access in 2003, the number of indigenous cases reported was reduced by over 50%.

The WHA time target for elimination of neonatal tetanus was originally 1995 and is now 2005. Similarly, the WHA elimination date for leprosy was 2000, which was later extended to 2005. The Global Alliance to Eliminate Leprosy (GAEL) was formed in 1999 to support the "final push" to achieve elimination by 2005, with financial support from the Nippon Foundation/Sasakawa Memorial Foundation and the donation of leprosy multi drug therapy (MDT) by Novartis. By the end of 2003, there were still 10 countries where leprosy remained a public health problem (ie, with prevalence rates above 1 per 10,000 population). The overwhelming majority of the half million plus new cases in 2003 were in India.

If the current targets are met, then three of these GHPs – GAEL, MNTE and GWEP - should now be planning a sensible programme of phasing out, with APOC following by 2010. GAEL has in effect already been disbanded, following disagreement among the partners over technical strategies. The financial dividend from winding up these GHPs will not be huge - certainly nothing like the scale of ending the Global Polio Eradication Initiative. Nonetheless, success will relieve affected countries not only of the burden of disease, but also of the burden of dealing with multiple partnerships. And unlike the case of polio, most of the benefits of eradication or elimination will go to the countries themselves and not the developed world.

3.6 More integrated approaches to neglected diseases

There seems growing consensus that a more integrated approach to tackling at least some of the neglected diseases would be both feasible and beneficial.

Where opportunities arise, integration of technical strategies could include the combined delivery of interventions or joint activities at the levels of mapping, training, procurement of drugs and equipment, and surveillance and monitoring¹⁷. A study in Uganda in mid-2003¹⁸ noted that discussions were underway between the National Onchocerciasis Control Programme, the Programme to Eliminate LF and the Schistosomiasis Control Initiative on how best to integrate activities such as training, supervision, advocacy, registration and drug distribution. Integrated community-directed treatment for onchocerciasis, schistosomiasis and intestinal helminths was planned in 6 districts, with potential for considerable benefit and increased efficiency.

¹⁷ Draft note of issues and recommendations for intensified control, from the International Workshop on Intensified Control of Neglected Diseases, Berlin 10-12 December 2003.

¹⁸ Caines K., et al., Impact of Public-Private Partnerships Addressing Access to Pharmaceuticals in Low Income Countries: Uganda Pilot Study, Initiative on Public-Private Partnerships for Health, Switzerland, 2003. ISBN: 2-94 0286-10-8.

The benefits of integrated activities can be particularly great for control programmes that rely on logistically demanding strategies, such as mass drug administration.

WHO has proposed consolidation of the various components of control for several neglected diseases into a single matrix. This would enable 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.

Developments of this kind will require much closer collaboration between individual GHPs for neglected diseases at global as well as country levels. This collaboration should cover advocacy for a group of diseases rather than an individual disease, as well as support for delivery of technical strategies.

4 EVALUATED IMPACT OF GHPS FOR NEGLECTED DISEASES

4.1 Tentative conclusions from scant material

The literature evaluating the impact of GHPs is small but growing. A 2002 McKinsey study of 30 (unnamed) global health alliances¹⁹ concluded that “more than 80% of public health alliances appear to be working...in sharp contrast to the private sector’s ...success rate of 50%”. ‘Success’ was defined as an ‘acceleration, improvement, or reduction of the cost of initiatives aimed at reducing disease burden in comparison with what could be accomplished on a solitary basis’. Moreover, in most cases the study found that a solitary approach was not feasible, given the objectives. Yet it also concluded that many global health alliances were not reaching their full potential (e.g., through limited resources, difficulties in decision-making, or a slow start).

More recently, some GHPs have themselves sought to define more precisely the areas of added value of partnerships. These areas include:

- harnessing high-quality talent from disparate sources;
- enhanced capability of partners through coordination and consensus-building;
- information on resource flows, identifying funding gaps and priorities, resource mobilisation and funding additional support to countries for supplies and operational costs;
- innovation in processes and actions, and creating synergy between new developments and implementation; and
- consistent high-profile advocacy and broadspread communications.

There are serious limitations on the ability to assess GHPS for neglected diseases against impact in these areas or against their own objectives, on the basis of the literature. Independent evaluations of the GHPs for neglected diseases are relatively scant. The remainder of this section gives key findings from independent evaluations/reviews of APOC and OCP, GAEL and GAELF, as examples.

Great care must be exercised in drawing general conclusions from so small a base. But there are perhaps a few themes which can be discerned in these findings, taken in the context of other GHP evaluations (for example, of the Global Partnership to Stop TB and of RBM):

- GHPs are seen as having had a positive – usually a very positive - impact. This is true even of GHPs where the evaluators find some serious shortcomings, as in the case of GAEL (below). Where cost-effectiveness has been assessed, it is high. Partnerships have accelerated the pace of progress.
- In most cases, GHPs are seen as having achieved success in key areas - particularly in mobilising commitment and funding, and catalysing action - and some have led innovation, eg APOC’s pioneering use of community directed treatment which holds promise of advantageous application in other disease control programmes. However, the sheer existence of a GHP does not of itself guarantee mobilisation of greater resources (see commentary on GAELF below).
- Sustainability is a key concern (see APOC, GAELF).
- Partnership is a complex notion, and partnerships characteristically are subject to considerable stress, particularly in the early stages of partnership working. Governance and administrative issues loom large in the early years. In several

¹⁹ McKinsey & Company (2002) *Developing successful Global Health Alliances*, for the Bill and Melinda Gates Foundation.

GHPs (eg GAELF), the solution to initial organisational and relationship problems tendency has been seen to lie in a transition from early loose structures and processes to more formalised approaches. In the case of GAEL, it appears that relationships became so damaged that dissolution appeared the better option. It should be stressed that GAEL is as yet an outlier.

- Lack of clarity about goals, as well as lack of shared acceptance of them, can undermine partnership cohesion and accountability (witness GAEL). In some cases, there remain differences of view between partners over technical strategies, and some tensions over a pressure to focus on achieving public health elimination targets versus a broader emphasis on morbidity care and rehabilitation.
- There are still risks and challenges (particularly at country level) in attaining GHPs' goals.

The commentaries below on APOC and OCP, GAEL and GAELF should be taken as illustrative rather than representative.

4.2 APOC and OCP: Onchocerciasis

The current APOC initiative was preceded by the Onchocerciasis Control Programme (OCP), which covered 11 countries in West Africa. According to the World Bank in 1995, the OCP was widely recognized as one of the most successful disease control programs in the history of development assistance.

A 2002 evaluation of the OCP²⁰ reviewed the programme as it was about to wind up after 30 years. Main achievements were seen as 40 million people protected, 600,000 cases of blindness prevented, 25 million hectares of arable land capable of helping feed 17 million people freed of onchocerciasis. The report concluded that the programme had largely met its objectives, and that onchocerciasis had virtually been eliminated as a public health problem and as an impediment to socio-economic development in the participating countries. Devolution to those countries had been effectively undertaken, and national programmes seemed able and willing to maintain OCP achievements in coming years. The evaluation estimated that OCP had achieved a 20% economic rate of return on the US\$ 556 million committed by donors to the programme. Success factors were identified as:

- flexibility in strategy and operations;
- a science-based, results-driven programme, effectively utilising operations research;
- a strong country focus, with an emphasis on capacity-building;
- pooled finances;
- a regional approach which generated a strong feeling of collective responsibility;
- collaboration and partnership (based on clearly defined roles) among countries and stakeholders (NGDOs, donors, Merck & Co, sponsoring agencies).

In principle, similar benefits should be obtainable through APOC. A mid-term evaluation²¹ in 2000 found that APOC had made significant and satisfactory progress towards meeting its objectives in its first four years. Working partnerships had been established at many levels, from international to community, and were contributing

²⁰ Kale O, et al. (2002): Onchocerciasis Control Programme External Evaluation 2002, Joint Programme Committee JPC23.9.

²¹ Ransome-Kuti O et al. (2000) African Programme for Onchocerciasis Control (APOC) Report: External Mid-term Evaluation, September 2000.

significantly to the success of APOC's efforts. Generally sound and effective management systems and administrative processes were in place. The capacity of the health services in participating countries had been significantly enhanced, so that they – and village communities – were actively involved in implementing onchocerciasis control. The model of community directed treatment that had been developed and tested was seen to hold great promise for other existing and future disease control programmes. World Bank analysis, updated by Emory University in September 1999, estimated that APOC had a lower-bound economic rate of return of 25% - "highly respectable in net of economic returns for any type of development project".

The evaluation concluded that sustainability was the key issue for the second phase of APOC, and the major challenge for the future of onchocerciasis control. It recommended that the Programme should continue expanding at the then present rate, so that overall Programme objectives could be achieved by 2007. This would require more streamlined governance and administrative procedures, and innovative approaches in countries with significant security problems. APOC also needed to intensify its efforts to integrate onchocerciasis control fully into the health services of participating countries, in order to ensure APOC's achievements were fully sustained when its inputs came to an end. To this end it needed to embark on systematic devolution of responsibility and capacity to country level; to place major emphasis on capacity building; and to identify means of continuing support to essential activities after APOC comes to an end. APOC plans to phase itself out by 2008-2010.

By 2003, APOC had established 107 projects, which treated an estimated 39.8 million people in 16 countries in that year. The ultimate intention is to scale up to 122 projects to treat 90 million people annually in 19 countries, protecting an at-risk population of 109 million.

4.3 GAEL: Leprosy

Overall, the independent evaluation of the Global Alliance for the Elimination of Leprosy²² in June 2003 has been the most critical of any GHP evaluation, concluding that partners lacked understanding about Alliance aims, agreement about governance, and good relations at global level.

Nonetheless, regardless of this, the evaluation found that the Alliance had added important value to the goal of eliminating leprosy as a public health problem. It had mobilized political commitment, financial resources, and free drugs. It had helped to improve the management and reach of multi-drug therapy. It had energized a number of country leprosy control programs. During the course of the Alliance, 16 of 22 endemic countries had been deemed to have met the goal of elimination of leprosy as a public health problem. While much of the good work GAEL carried out might well have happened in any case, the evaluation team believed that the activities had been carried out faster than would have happened without GAEL – an important finding, given the commitment to eliminate leprosy by 2005.

In addition, at the country level, the Alliance appeared to be functioning well. Most countries were actively leading and coordinating their leprosy programs. Collaboration was good, with the World Health Organization (WHO) playing an advisory role and NGOs involved in a range of leprosy efforts in conjunction with WHO and government.

²² Skolnik R, Agueh F, Justice J, Lechat M (2003) Independent Evaluation of the Global Alliance For the Elimination of Leprosy. June 13, 2003.

However, despite these important successes, the evaluation team concluded that GAEL was not adding the value that it could add and that this posed threats to country leprosy programmes and to the reputations of collaborators on leprosy work. GAEL had important problems at global level, where the evaluation report bluntly described relations among some collaborators as very bad. Concerned NGOs, physicians, and scientists had raised with WHO important questions about technical, operational and strategic matters but they had not been resolved. These included questions about validity of the data on prevalence, the apparent suggestion that the duration of treatment be universally shortened, and the perceived encouragement by WHO of accompanied multi-drug therapy in circumstances which many felt to be inappropriate. Many collaborators also believed that GAEL had too exclusive a focus on targets for elimination.

In addition, some collaborators did not have a clear understanding of the aims of the Alliance, or a clear agreement on how the Alliance should be governed. There were strong views among some collaborators that the Alliance was too embedded in WHO and that WHO had not been sufficiently consultative in its management of the Alliance. These issues are dealt with more generally in a parallel paper on the governance of GHPs by Kent Buse, developed as part of the wider study on improving the impact of GHPs²³.

A key concern of the evaluation team was to ensure an effective and inclusive approach to future leprosy control and rehabilitation efforts after the goal of elimination was achieved. It recommended that much of the global work of the Alliance should be convened and led by the NGO and foundation movement. These activities would focus on ensuring effective advocacy, as needed, and promoting learning and inputs into country programs on technical, operational, and strategic issues. They would build on earlier work by the International Association of Anti-Leprosy Associations (ILEP), the International Leprosy Association (ILA), and the Sasakawa Memorial Health Foundation. They would include all groups working with leprosy, including the private sector and groups of people affected by the disease.

The report recommended that, if not already doing so, countries should organize their leadership around a country-level leprosy task force. WHO should play the advisory role to country programs, with effective use of inputs from other collaborators. WHO should also convene a group of technical advisors, selected with the advice of others involved in leprosy, to carry out independent monitoring and evaluation of leprosy activities. The Technical Advisory Group (TAG) of WHO would have its membership strengthened, again with the advice of others.

The evaluation team hoped that the Novartis Corporation, working with the Novartis Foundation for Sustainable Development, would continue to provide drugs and that the Sasakawa Memorial Health Foundation and the Nippon Foundation would continue to support technical cooperation and research, including through its important financial assistance.

It is understood that GAEL as a formal alliance has now been disbanded, or is in the process of disbanding.

4.4 GAELF: Lymphatic Filariasis

There has been no formal evaluation of GAELF, but a current (2004) review²⁴ for DFID of the effectiveness of the support provided by the Liverpool Lymphatic Filariasis Support Centre (LFSC) to GAELF had the secondary objective of providing

²³ GHP Study Paper 5: Increasing GHP impact by Improved Governance by Kent Buse

²⁴ Lorenz N. and Mshinda H., *External Review of DFID's Support to the Lymphatic Filariasis Support Centre*, Liverpool School of Tropical Medicine, August 2004. DRAFT report

an overview of the status of the Global Alliance to Eliminate Lymphatic Filariasis and the Global Programme to Eliminate Lymphatic Filariasis.

The review's preliminary findings are that, though still regarded as a young alliance with some problems of infancy, GAELF is perceived as doing very well compared with other global alliances. 'The widespread perception is that the alliance is "doing more with less" than other global alliances.'

At the start, too many diverging, partly conflicting interests within GAELF combined with the loose structure of the alliance to create deadlocks and hamper the evolution of the alliance. However, this initial very light and loose governance structure was replaced in early 2004 by a more structured organisation and partners are optimistic about the future of the alliance. The review encourages GAELF to continue to strengthen its leadership in order to move forward the possibility of eliminating LF. The strengthened role of the executive group and its secretarial support from the Liverpool School of Tropical Medicine are both moves in the right direction.

There is some criticism of GAELF as being too product driven, with a focus on the mass drug administration and not the morbidity control aspects, which would have a substantial financial impact. At least at the Executive Group level, aspects of LF elimination such as morbidity control are not as strongly represented as the product coalition of GSK and the Mectizan® Donation Program. The absence of representatives of partners from endemic countries is striking in this context. The review recommends the inclusion of suitable representatives from endemic countries in the Executive Group in order to acknowledge that this is a global partnership, in which endemic country partners should have some responsibility.

There are still open questions around eliminating LF. Burden of disease data are still scarce. Potentially troubling is a recent Cochrane review update, which asked for more research on the effectiveness of albendazole and its combinations against LF, because existing evidence failed to prove or refute it. There is still a widely perceived need to get a better evidence basis on the feasibility and achievability of the elimination of LF with the strategy. Appropriate operational research (for example related to the health economics and delivery strategies in urban areas) is needed. The review team advises that, although efforts have been and are being made, more should be undertaken to fill these gaps. In any case, a better evidence basis for LF-elimination would help convince potential donors to buy in.

The review concludes that GAELF is certainly relevant, comparatively effective, not so efficient, but that it has achieved a remarkable impact so far.

The main problem of GAELF at the country level is that of sustainability. So far, GAELF has had little success in mobilising significant additional resources for the elimination of LF. At present, no major resources are available to implement the programme, leading to problems in most endemic countries even to maintain, let alone to expand, the Mass Drug Administration programme. Countries which have succeeded in mobilising resources, for example India, have done so without major assistance from GAELF.

In all countries, considerable efforts are undertaken to integrate LF work at the district level and a majority of country partners interviewed confirmed that there was a national policy on the elimination of Lymphatic Filariasis in their country. Some governments in endemic countries have started to provide financial support to the programme, for example in Tanzania through the Medium Term Expenditure Framework. However, the allocated amounts are comparatively modest.

The review advises that, in many countries, there are future opportunities which need to be explored further, in particular on how to link activities to eliminate LF with health

sector reform process reviews. It notes that efforts are ongoing to ensure that LF activities are seen as part of an integrated activities' package within the health sector and less as a separate LF programme supported by separate donors. Integration at this level is crucial and important.

5 FINDINGS AT COUNTRY LEVEL

5.1 Country level evidence

The literature on whether GHPs have genuinely addressed diseases which have been neglected by other forms of development assistance is still relatively scant. This is in part at least a reflection of how recent several of the GHPs are.

As part of the broader work to assess the impact of GHPs, three country studies have been undertaken in India, Sierra Leone and Uganda²⁵. These provide examples of the focus on neglected diseases but caution should be exercised in drawing general conclusions from this limited evidence.

The overall country study finding was the assessment of informants that the GHPs specific to guinea worm, lymphatic filariasis and onchocerciasis had helped to raise the profile of these diseases in country, and provided much needed support to national eradication programmes as well as access to preventive measures and drug treatment. APOC's role in rebuilding onchocerciasis control efforts in Sierra Leone is seen as highly pertinent, as the oncho-affected geographic zone has expanded because of the conflict. In the case of leprosy, it is unclear what additional benefit having a leprosy GHP has made to leprosy control efforts.

5.2 India

Participation in GAEL and GAELF

India participates in two GHPs for the most neglected diseases: GAEL for leprosy and GAELF for LF.

Leprosy and GAEL

India accounts for about 65% of the global leprosy burden, and the final push to national elimination is being supported by very active NGO involvement, Novartis' donation of MDT and additional financing from the World Bank and bilateral agencies. What is less clear is the role of the Global Alliance to Eliminate Leprosy (GAEL) at country level. GAEL is not mentioned in the 2003 MOHFW report highlighting India's contribution to international efforts to eliminate the disease, whereas ILEP is recognised as an active partner, with members supporting the National Leprosy Eradication Programme in 13 States. Similarly, the extent to which advocacy by GAEL – rather than ILEP – mobilised additional support is unclear. At the international level, as reported in GAEL's 2003 evaluation, disagreement continues between WHO and ILEP about appropriate technical strategies and the balance between care of disabilities and treatment of new cases. ILEP left GAEL in 2003, and has not rejoined. Nonetheless, the India country study found that interviewees in government and ILEP members such as LEPRO were confident that this was not affecting impact on the ground.

As in other countries, there are concerns that the achievement of elimination targets will curtail all leprosy activities prematurely – a certain level of activity will be required to maintain elimination rates, given the long incubation period, and meet the need for rehabilitation services.

Lymphatic filariasis (LF) and GAELF

²⁵ India country study undertaken in September 2004 by Nel Druce and Rajeev Sadanandan; Sierra Leone study undertaken in July 2004 by Cindy Carlson and Jennifer Sancho; and Uganda study undertaken in July/August 2004 by Rose-marie de Looor and Jennifer Sancho.

Over half the population at risk of LF lives in India, so adoption and scale up of the most effective strategies, in the Indian context, are crucial.

The elimination of LF by 2015 is a national priority, and the LF programme is one of the oldest national programmes, established in 1996 before the Global Alliance was established. National programme staff are aware of GAELF, of GAELF's recommended strategies and the global agreement with GSK for the albendazole donation. The Alliance is felt to have contributed to developing stronger international commitment to eliminate the disease. The second GAELF partners' meeting was held in India. Apart from this, the Alliance does not appear to have a substantial profile or influence at country level, and does not feature in the programme's co-ordinating committee discussions. However, WHO (as lead GAELF technical partner) plays a significant role.

Since 2000, GAELF has advocated two technical strategies – mass drug administration (MDA) and combination therapy of albendazole and DEC. The India country study noted a strong emphasis at country level on the importance of India-owned policy development with respect to introducing new LF strategies. While MDA is broadly accepted in India as an effective strategy, there is less agreement on how to deliver it (eg, by mass treatment days) and the best form of community based education. Trials to develop an Indian evidence base for the effectiveness of combination therapy for LF are currently taking place, with a decision due from an expert committee in 2005.

The LF programme in India is largely financed by the GOI. GAELF has facilitated the donation of albendazole, and US\$100,000, to support MDA and community-based education strategies in pilot districts. Otherwise, no additional national funding is attributed to Alliance activities at national or international level. The limited influence of the Alliance means that its impact on the wider health system has been neutral and minimal.

Next year's expert committee may decide in favour of scaling up MDA and combination therapy, if the data are sufficiently convincing. The wider benefits of deworming from albendazole are also acknowledged. Further GAELF inputs at that time may be welcomed, though an issue arises about what kind of support would fit with national policy and strategies. For example, the Alliance is perceived to emphasise public health measures over individual care and rehabilitation. The national LF programme in India would prefer a package to support both prevention and care, and would be keen to reduce the opportunity and transaction costs of accepting external assistance.

Other neglected diseases

A converged programme is developing a new five-year strategy and budget to cover the five major vector borne diseases of poverty (malaria, LF, Japanese encephalitis, dengue, kala-azar). This will be the basis for a new World Bank proposal for a consolidated approach to all five diseases, as opposed to former projects for individual diseases.

Although trachoma is prevalent in India, it is limited to very localised areas. India has an integrated blindness prevention and control programme, based on Vision 2020 principles, and is not a candidate for the ITI.

Assessment

To a large extent, the study found a good fit between the GHPs generally and India's large burden of communicable disease. However, non-communicable diseases now

contribute over half of all DALYs, and investment in prevention and care is regarded as very low relative to need.

India continues to make reasonable progress towards achieving its national elimination targets for leprosy (by 2005) and LF (by 2015), which were set in the National Health Policy 2002 and reflected in the Tenth five year Plan, 2002-2007. However, the study found that the technical and financial contribution of GAEL and GAELF is very limited. In both cases, there have been differences of view over technical strategies.

5.3 Sierra Leone

Participation in APOC and GAEL

Sierra Leone is a low-income country which has recently emerged from over a decade of civil conflict, characterised by destruction of basic infrastructure and brutalisation of the civilian population. As a result of this instability, it ranks last in the human development index ratings (Human Development Report 2004). Only a limited number of Global Health Partnerships operate in Sierra Leone at present.

The main 'neglected diseases' in the country are onchocerciasis and leprosy. Sierra Leone receives GHP support via the WHO for both onchocerciasis (APOC), and for leprosy (GAEL and Novartis' donation of multi-drug therapy).

The onchocerciasis prevention and control programme, much needed given the growing incidence of the disease, is just being restarted due to the availability of APOC funds. APOC has designated Sierra Leone a Special Intervention Zone: onchocerciasis and other eye conditions ranked fourth in the causes of over-five morbidity in 2002. All funding transits through WHO, which is supporting the revitalization of programme activities.

By contrast, the researchers found unclear the extent of the added value GAEL is bringing to what was already a very successful leprosy control programme in Sierra Leone, supported by the German Leprosy Relief Association (GLRA).

Other neglected diseases

While schistosomiasis ranks tenth in the causes of under 5 morbidity in Sierra Leone, the country is not yet a recipient of support from the Schistosomiasis Control Initiative (SCI), and would benefit from SCI activities as they expand to other countries.

The study team argue that malaria could be considered a neglected disease in Sierra Leone. To date, malaria programming has received little donor support in the country, despite the fact that malaria is the leading cause of morbidity in adults and children, and the leading cause of mortality in children. Malaria-related GHPs appear to have been slower to contribute to the national malaria programme, despite the heavy burden of disease that malaria represents.

Assessment

Overall, the picture is patchy – perhaps understandably, given the turbulence of recent years in Sierra Leone. There is no evidence that GHPs were more effective than other forms of assistance in providing support during the period of conflict. For the greater part, GHP activity as a whole is only just getting underway, and the impact of GFATM awards has yet to be felt. Where GHPs are operating, they are addressing diseases neglected by other forms of development assistance - with the possible exception of leprosy which already had an effective programme in place supported by an international NGO. Some neglected diseases, notably schistosomiasis, remain neglected.

5.4 Uganda

Participation in APOC, GAEL, GAELF, GWEP, SCI and WPSS

Uganda is a highly indebted, poor country, heavily dependent on external donors in the health sector. It has adopted a sector-wide approach in health and introduced a Uganda National Minimum Health Care Package for all, addressing the priority components of the national disease burden. All GHPs operating in Uganda address diseases that are included in the Minimum Package, or are designated district specific priorities under the Health Sector Strategic Plan because of their localized endemicity (eg sleeping sickness and LF).

In total, Uganda participates in 17 GHPs aimed at providing technical support and assisting service delivery, (as well as two further GHPs undertaking R&D). Of these, six GHPs relate to 'neglected diseases': guinea worm (GWEP), leprosy (GAEL), lymphatic filariasis (GAELF), onchocerciasis (APOC), schistosomiasis (SCI) and sleeping sickness or human African trypanosomiasis (WPSS).

All the neglected disease GHPs except the Schistosomiasis Control Initiative:

- seek to achieve specific disease eradication or elimination targets, to which the Government of Uganda is committed as a signatory to the relevant World Health Assembly resolutions.
- provide donated drugs to support the programmes.

The SCI provides funding for Uganda to procure drugs.

Although each partnership at the national level may have a different make-up of partners, it operates within the framework of the HSSP. All GHPs are therefore governed by the Health Advisory and Policy Committee as well as the various working groups and Inter Agency Co-ordinating Committees. MoH officials noted that national strategies for disease control were vital as "Uganda did not wish to be led by outsiders".

All the GHPs in this category are working in partnership with MoH, mostly through WHO. The donated drugs enter the national health system through the MOH and are then distributed through the vertically organized control disease programmes to the districts and from there to the lower levels of the health systems. The major, widely appreciated benefit is the assurance of a sustained and consistent supply of free, high quality drugs without unreasonable conditionalities.

In general, the GHPs are operating through district health systems rather than on a project basis. The vital need for this is demonstrated by the example of an MSF project on sleeping sickness. An earlier study²⁶ noted that the Ugandan national plan to revitalise sleeping sickness control, using donated drugs, achieved such success in the West Nile District that, in October 2002, MSF France — who had run the programme there as a project with its own staff — was able to withdraw support in that area. However, 750 new cases were reported in the district in 2003. This suggests that, whatever the transitional arrangements, the districts concerned were not in a position to maintain the required level of activity in both surveillance and mopping up of early cases, and highlights the desirability of integrating project effort with the district health system from the outset.

²⁶ Caines K. and Lush L., Impact of Public-Private Partnerships Addressing Access to Pharmaceuticals in Low and Middle Income Countries: A Synthesis Report from Studies in Botswana, Sri Lanka, Uganda and Zambia, Initiative on Public-Private Partnerships for Health, Switzerland, 2004. ISBN 2-940286-21-3

Uganda's National Minimum Health Care Package has been costed at US\$28 per capita, (not including ARVs, ACTs or the pentavalent vaccine), and the funding available for the package is about US\$8-10 per capita. In view of this large shortfall, all interviewees stated that they highly appreciated the additional resources brought in by these GHPs.

No estimates are available of the dollar value of the donations or of the technical and operational support that these GHPs provide. Since the drug donations are provided in kind, their value has to date not yet come under the scrutiny of national budgetary processes, but the Ministry of Finance, Planning and Economic Development has indicated that in the medium term, the value of drug donations will also be included in the budgetary and MTEF processes. The issue of whether the MTEF ceiling will be raised to reflect GHP inputs is a wider one and now the key issue to be negotiated. If the ceiling is not adjusted, the effect of taking into account the value of the drug donations and other GHP funding will be to squeeze existing budgets.

Although the onchocerciasis and leprosy programmes are making encouraging moves towards sustainability, the ability of Uganda to take on the burden of these programmes has to be seen in the shortfall in funding for delivering the NMHCP.

Other neglected diseases

Trachoma is now mentioned in the draft Health Sector Strategic Plan II, so Uganda might benefit from ITI activities as they expand to other countries.

Assessment

The general view at country level is that these GHPs, and in particular the drug donations, are helping meet a real need (for example, in tackling a dramatic resurgence in sleeping sickness in the country). Interviewees indicated that the GHPs are aligned to the national programmes and have helped implementation of the programmes through the provision of necessary inputs whether those be drugs, training, technical support or advocacy. The current study confirmed the finding of a 2003 study that there was no evidence of any skewing of national or district priorities, not of unhelpful diversion of human and financial resources at central, district or community levels²⁷. Considerable health impact has been achieved by the mature programmes.

²⁷ Caines K. et al. Impact of PPPs Addressing Accesss to Pharmaceuticals in Low IncomeCountries: Uganda Pilot Study. Initiative on Public-Private Partnerships for Health, Switzerland, 2003

6 CONCLUSIONS

- *Most neglected diseases are being addressed by at least one GHP.*
- *Most GHPs for neglected diseases are providing technical support, drugs, and in a few cases funding. All three are likely to be required to sustain programmes. More operational funding is required.*
- *Evidence of impact is still limited. Existing evaluations find these GHPs have a positive impact, especially in accelerating progress, even when shortcomings are identified. Sustainability is the key concern.*
- *More integrated approaches to tackling neglected diseases should be explored.*
- *GHP-led R&D for new tools is intensifying and focused on those diseases with greatest need. Operational research may also require investment.*

6.1 Most neglected diseases are being addressed by at least one GHP

To the simple question of whether GHPs are addressing what have been termed 'neglected diseases', the answer is yes.

Very few GHPs focus on non-communicable diseases²⁸. A substantial number focus on the big three communicable diseases. Earlier work mapping GHPs found that out of 74 GHPs, the majority (60%) relate to HIV/AIDS, TB and malaria, with HIV/AIDS having the lion's share (25 GHPs as compared with 15 for malaria and 5 for TB).

Nonetheless, as shown above, almost all the 'most neglected' diseases are now supported by at least one GHP.

While there are a few longer-standing GHPs of this kind, most have been established in recent years and focus on a single disease. Their mission in almost every case is to secure elimination or eradication of the neglected disease within the next 16 years, so there is some presumption that these GHPs are time-limited – as compared, for example, with the Global Partnership to Stop TB which already has a target for 2050 of reducing the global incidence of TB disease to less than 1 per million population.

6.2 Most GHPs for neglected diseases are providing technical support, drugs, and in a few cases funding. All three are likely to be required to sustain eradication and elimination programmes. More operational funding is required.

The majority of these GHPs are providing much needed support for raising the profile of the disease and improving the delivery of interventions, usually backed by a drug donation agreement with one or more partner pharmaceutical companies.

Advocacy at national and international level is generally an important function to overcome 'neglect' – the lack of priority that has been afforded to these diseases and the poor and marginalized people who suffer from them.

Development of a clear strategy, building a consensus around it, and coordinating partner efforts are key areas of added value for GHPs. It is worrying therefore that in some cases there appear to be continuing tensions about technical strategies and operational priorities. In one case, GAEL, this seems to have led to partnership breakdown. At the same time, it is unreasonable to expect partnerships of this nature to operate without some strains, given the scale of the programme challenges, the

²⁸ Buse K., 2004. Global Health Partnerships: Mapping a shifting terrain. London: DFID Health Resource Centre.

complexity of the dynamics, and the differences in culture between constituent partners.

Only a few of these GHPs (eg APOC) provide direct access to operational funding in addition to facilitating drug supply. Failure by the GHP to provide or mobilise funding of this kind can seriously curtail programmes, as in the case of GAELF – or even jeopardise the value of past investments. Experience suggests that low resource countries are likely to need partnership or donor contribution of three elements to support a successful disease control programme:

- some contribution to providing the necessary drugs (through funding, donation or discounted price)
- funding for some operational costs, and
- technical assistance.

For example, an earlier study of drug access PPPs in Uganda²⁹ found free drug donation to be *necessary* but *not sufficient* to initiate and sustain a full national elimination programme for this kind of disease in its active phase. Given Uganda's limited resources, some source of extra-governmental funding for operational costs was required³⁰.

Any DFID consideration of support for this group of GHPs should seek assurances about mobilisation of resources for the full range of needs. Donors collectively should be prepared to contribute to the operational costs of national control programmes.

6.3 Evidence of impact is still limited. Existing evaluations find these GHPs have a positive impact, especially in accelerating progress, even when shortcomings are identified. Sustainability is the key concern.

The independent evidence base on the impact of this range GHPs is still limited. There have been relatively few evaluations as yet. Globally some GHPs, and within countries some GHP-supported national programmes, have yet to build to full-scale. SCI, for example, was established only in 2003 and has programmes in seven countries, while ITI operates only in 11 countries.

Those evaluations that have been undertaken conclude that GHPs have had a positive impact – especially in mobilising commitment and funding, and accelerating progress -, even when organisational or relationship shortcomings are also identified. This is in line with evaluations of GHPs for malaria (RBM) and TB (the Stop TB Partnership). Sustainability is identified as a concern. The key test will be whether they can deliver on time the targets for eradication and elimination, several of which have proved elusive in the past.

The three country studies undertaken for this study are too few to be the basis of generalised findings. They reached varying conclusions about the impact of GHPs. In India, GHPs for neglected diseases are perceived as making only a limited contribution. In the poorer countries – Uganda and Sierra Leone - and in Sri Lanka³¹

²⁹ Caines K., et al., *Impact of Public-Private Partnerships Addressing Access to Pharmaceuticals in Low Income Countries: Uganda Pilot Study*, Initiative on Public-Private Partnerships for Health, Switzerland, 2003. ISBN: 2-94 0286-10-8.

³⁰ For example, despite the availability of free Mectizan® from 1987 and the development of two national plans, a government-led, integrated Ugandan National Onchocerciasis Control Programme was not implemented until the establishment of APOC in 1996 provided a source of both technical and financial support.

³¹ Caines K. and Abeykoon P., *Impact of Public-Private Partnerships Addressing Access to Pharmaceuticals in Low and Middle Income Countries: Sri Lanka*, Initiative on Public-Private Partnerships for Health, Switzerland, 2004. ISBN : 2-940286-24-X.

in a separate study, there are indications that GHPs are beginning to make a real difference in kick-starting or revitalising programmes for these neglected diseases - diseases which have typically had a low political profile even at country level but which nonetheless seriously affect poor people.

The striking exception to this pattern is leprosy. In the three country studies, successful leprosy control programmes with vigorous NGO support predated GAEL - even in strife-torn Sierra Leone. This finding is supported by studies in Sri Lanka and Zambia³². In each case, earlier support had taken the form of funding, drugs and technical assistance as needed.

There is no indication from Sierra Leone or Sri Lanka that GHPs have operated more effectively than other health agencies during periods of conflict. This contrasts with findings in, say, Sudan where a six-month "guinea worm" ceasefire was negotiated for GWEP by President Carter in 1995.

6.4 More integrated approaches to tackling neglected diseases should be explored.

The GHPs for neglected diseases tend to be addressing national priorities, generally working through national systems and are generally welcomed by health services at national and district levels as bringing new resources and drugs.

The wider concern is that the proliferation of the full range of GHPs may begin to overwhelm weaker health systems. Current consideration by WHO of a more integrated approach to tackling at least some of the neglected diseases should be encouraged. The emerging view is that some degree of integration across diseases would be both technically feasible and operationally beneficial. Developments of this kind will require much closer collaboration between individual GHPs for neglected diseases at global as well as country levels. This could put further strain on the more fragile partnerships.

6.5 GHP-led R&D for new tools is intensifying and focused on those diseases with greatest need. Operational research may also require investment.

There are effective and affordable tools for prevention and treatment of many neglected diseases. But for some diseases, there has been a serious unmet need for research and development. One critical problem has been the lack of sufficient market incentive. The indications are that R&D is now intensifying through the activities of newly-created GHPs, and assisted by closer links between public and private research bodies. DNDi was formed only in 2003, and is filling a gap by targeting the three diseases generally accepted as being in greatest need of new drugs: Chagas disease, leishmaniasis and sleeping sickness. The Institute for OneWorld Health also aims to develop drugs for the first two of these diseases. Other GHPs are working on a vaccine against dengue.

These new GHPs will need continued support. The 2004 World Health Assembly called for intensified research to develop tools to diagnose, treat and prevent Buruli Ulcer. Operational research may also require investment to identify best implementation practices and demonstrate opportunities for fruitful collaboration across disease programmes.

³² Dlamini Q.Q., et al., *Impact of Public-Private Partnerships Addressing Access to Pharmaceuticals in Low and Middle Income Countries: Zambia*, Initiative on Public-Private Partnerships for Health, Switzerland, 2004 ISBN : 2-940286-22-1

ANNEX 1: NEGLECTED DISEASES
<p>Buruli Ulcer <i>Prevalence:</i> little information. Endemic in 32 countries in Africa, the Americas, Asia and the Western Pacific. 3,296 reported cases in 2002; highest numbers in Ghana, Cote d'Ivoire, Benin and Sudan. <i>Prevention:</i> Some short-term protection from BCG vaccination. <i>Treatment:</i> surgery, with lengthy/costly hospitalisation (3-6 months) for extensive disease.</p>
<p>Chagas' Disease (American Trypanosomiasis) <i>Prevalence:</i> Estimated 16-18 million cases. 120 million (25%) of Latin American population, at risk. <i>Control:</i> vector control with insecticides, and screening of blood donors. <i>Treatment:</i> Nifurtimox and benznidazole capable of curing at least 50% of recent infections, but drugs not available to most patients in many endemic countries because not registered or high cost.</p>
<p>Congenital Syphilis <i>Prevalence:</i> 33% of all neonatal deaths due to infection including congenital syphilis, and 8% of still births. 20% of perinatal deaths are due to congenital syphilis. <i>Prevention:</i> Prenatal screening and treatment of pregnant women. <i>Treatment:</i> Penicillin.</p>
<p>Cysticercosis <i>Prevalence:</i> Fragmentary information only; suggests a growing problem in poor areas of Africa, Asia and Latin America where people eat pork (disease caused by larval form of pork tapeworm). <i>Control:</i> case management, reporting and surveillance; identification and treatment of carriers; veterinary sanitary measures (eg meat inspection); clean water and sanitation; health education. <i>Treatment:</i> Praziquantel.</p>
<p>Dengue and Dengue Haemorrhagic fever <i>Prevalence:</i> Number and spread of infections increasing; now endemic in 100+ countries. WHO estimates 50 million infections globally each year, with 2,500 million people now at risk. <i>Prevention:</i> Control of the mosquito vector, and public health and environmental measures. <i>Treatment:</i> No specific treatment. Mortality: from <1% with experienced clinical care, to >20% without.</p>
<p>Guinea worm <i>Prevalence:</i> At start of eradication initiative in 1987, 3.32 million people infected; in 2002, only <55,000 cases, 75% from Southern Sudan. Disease now confined to 13 SSA countries. Eradication in sight. <i>Control:</i> provision of potable water. Community-based surveillance, and case-containment. <i>Treatment:</i> No specific treatment.</p>
<p>Human African Trypanosomiasis (Sleeping sickness) <i>Prevalence:</i> No complete information. HAT endemic in 36/52 African countries, occurring in limited foci. Epidemics re-emerging. Estimated 100,000 deaths each year. <i>Prevention:</i> No effective prevention. Treating those infected; tsetse fly vector control; cattle treatment. <i>Treatment:</i> Drugs available free of charge through WHO, and tend to be old, toxic and/or difficult to administer. Pentamidine, suramin, melarsoprol, eflornithine.</p>
<p>Leishmaniasis (kala azar) <i>Prevalence:</i> Estimated at 1.5 million globally, with 350 million people at risk. 100% death rate from visceral form of leishmaniasis, if untreated (90% of cases in Bangladesh, Brazil, India, Nepal, Sudan). <i>Prevention:</i> Control of sand flies; health education; bednets; health impact assessment of irrigation. <i>Treatment:</i> Long, toxic drug treatment.</p>
<p>Leprosy <i>Prevalence:</i> Currently affects 1 million people in Africa, Asia, S America and the Pacific. Of 122 endemic countries in 1985, only 12 in 2003 had not achieved national elimination, though some major countries, notably Brazil and India, still at risk of missing 2005 elimination target. Intense social stigma. <i>Prevention:</i> No effective primary prevention. Some protection from BCG in some populations. <i>Treatment:</i> Donated multi-drug therapy (rifampicin, dapsone, clofazimine).</p>

<p>Lymphatic Filariasis</p> <p><i>Prevalence:</i> An estimated 120 million people in >80 countries have suffered lymphatic damage, and 1.2 billion (20% of the world's population) are at risk. LF is 2nd leading cause of permanent disability.</p> <p><i>Prevention:</i> Interrupt transmission through mass drug administration (MDA); prevent disabilities through hygiene measures and antibiotics to prevent secondary infections.</p> <p><i>Treatment:</i> Mass drug administration (MDA) of donated albendazole with diethylcarbamazine (DEC), or donated ivermectin where onchocerciasis is co-endemic. Surgical repair of hydrocele.</p>
<p>Neonatal Tetanus</p> <p><i>Prevalence:</i> 2002 estimate of 218,000 cases of neonatal tetanus each year. Elimination targeted for 2005. In mid-2000, 57 countries had yet to eliminate maternal and neo-natal tetanus in all districts.</p> <p><i>Prevention:</i> Immunisation starting in new-borns, with reinforcing doses at older ages. (2 doses of tetanus toxoid vaccine for unimmunised pregnant women).</p> <p><i>Treatment:</i> Antitetanic serum and sedation, though 25-90% infants still die. Without therapy, 95% die.</p>
<p>Onchocerciasis*</p> <p><i>Prevalence:</i> 17.7 million people infected with onchocerciasis; approximately 500,000 with visual impairments, of whom 270,000 are blind. 99% of cases are in Africa.</p> <p><i>Prevention:</i> Vector control, large-scale community directed treatment with donated ivermectin.</p> <p><i>Treatment:</i> Donated ivermectin.</p>
<p>Rabies</p> <p><i>Prevalence:</i> Estimated 55,000 deaths in 1999, mostly in Africa and Asia.</p> <p><i>Prevention:</i> Preventive vaccination of at-risk humans; mass dog vaccination and dog control.</p> <p><i>Treatment:</i> Wound cleansing and post-exposure prophylaxis (vaccines and immunoglobulin).</p>
<p>Schistosomiasis and Soil-transmitted helminthiasis</p> <p><i>Prevalence:</i> Estimated 2001 schistosomiasis prevalence of 200 million. Endemic in 76 countries, mostly in Africa. Reported mortality of 200,000 deaths per year in sub-Saharan Africa alone.</p> <p><i>Prevention:</i> Annual single dose mass drug administration with praziquantel. Target of regular treatment of at least 75% of school children at risk of morbidity by 2010.</p> <p><i>Treatment:</i> Praziquantel/good quality anthelmintic drugs.</p>
<p>Trachoma</p> <p><i>Prevalence:</i> 7.6 million people largely blinded by trachoma, and an estimated 84 million cases of active disease in need of treatment, almost halved from 146 million cases in 1994.</p> <p><i>Prevention:</i> SAFE – surgery, antibiotics, facial cleanliness and environmental improvement.</p> <p><i>Treatment:</i> Topical and oral antibiotics, and surgical intervention.</p>

**Source:* Working Paper 1, International Workshop on Intensified Control of Neglected Diseases, Berlin, 10-12 December 2003, except for onchocerciasis (asterisked) where information taken from relevant WHO website.