

# The **10/90** Report on **Health Research** **2003 - 2004**

A message to Ministers of Finance

An overview of the Global Forum for Health Research

Correcting the 10/90 gap

Priority setting in health research

Progress in measuring the 10/90 gap

Gender, the MDGs and health research

Research capacity strengthening

Information networks in health research

Some networks in the priority research areas

## 10/90 Report on Health Research 2003-2004

This report was prepared by the Secretariat of the Global Forum for Health Research, under the direction of Louis J. Currat, on the basis of the work of the Global Forum and its partners during 2002 to 2004, as well as drawing on presentations and discussions at Forum 7, held in December 2003 in Geneva, and at Forum 6, held in October 2002 in Arusha, Tanzania. The Secretariat alone is responsible for the views expressed.

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## Abbreviations and Acronyms

<b>AAVP</b> .....	African AIDS Vaccine Programme	<b>FIND</b> .....	Foundation for Innovative New Diagnostics
<b>AFRO</b> .....	WHO Regional Office for Africa	<b>G7, G8</b> .....	Group of Seven Countries, Group of Eight Countries
<b>AGORA</b> .....	Access to Global Online Research in Agriculture	<b>GAIN</b> .....	Global Alliance for Improved Nutrition
<b>AHILA</b> .....	Association for Health Information and Libraries in Africa	<b>GAVI</b> .....	Global Alliance for Vaccines and Immunization
<b>AIDS</b> .....	Acquired Immuno-Deficiency Syndrome	<b>GBD</b> .....	Global burden of disease
<b>AIDSCAP</b> .....	AIDS Control and Prevention project	<b>GDI</b> .....	Gender-related Development Index
<b>AIREN</b> .....	Association internationale pour la recherche et l'enseignement en neurosciences	<b>GDP</b> .....	Gross domestic product
<b>ANRS</b> .....	Agence nationale de recherches sur le sida (France)	<b>GEM</b> .....	Gender empowerment measure
<b>BIREME</b> .....	Latin American and Caribbean Center for Health Information	<b>Global Fund</b> .....	Global Fund to Fight AIDS, Tuberculosis and Malaria
<b>BMJ</b> .....	British Medical Journal	<b>GNP</b> .....	Gross national product
<b>CAM</b> .....	Combined Approach Matrix	<b>GRANT</b> .....	Gap Reduction Achievable National Target
<b>CAP</b> .....	United Nations Inter-Agency Consolidated Appeal	<b>GSK</b> .....	GlaxoSmith Kline
<b>CBO</b> .....	Community-based organization	<b>GTZ</b> .....	German Technical Cooperation Agency
<b>CDC</b> .....	Centers for Disease Control and Prevention (USA)	<b>HAART</b> .....	Highly active antiretroviral therapy
<b>CDSI</b> .....	Committee on the Dissemination of Scientific Information	<b>HDI</b> .....	Human Development Index
<b>CHNRI</b> .....	Child Health and Nutrition Research Initiative	<b>HEALY</b> .....	Healthy Life Year
<b>CHOICE</b> .....	Choosing Interactions that are Cost-Effective	<b>Hib</b> .....	<i>Haemophilus influenzae</i> type b
<b>COHRED</b> .....	Council on Health Research for Development	<b>HIF</b> .....	Health Information Forum
<b>CRA</b> .....	Comparative risk assessment	<b>HINARI</b> .....	Health InterNetwork Access to Research Initiative
<b>CSO</b> .....	Civil society organization	<b>HIPC</b> .....	Heavily Indebted Poor Countries
<b>CTP</b> .....	Collaborative Training Programme	<b>HIV</b> .....	Human Immunodeficiency Virus
<b>CVD</b> .....	Cardiovascular disease	<b>HPI</b> .....	Human Poverty Index
<b>DALY</b> .....	Disability-Adjusted Life Year	<b>HPSR</b> .....	Health Policy and Systems Research
<b>DFID</b> .....	Department for International Development (UK)	<b>HPTN, HPTU</b> .....	HIV Prevention Trials Network, HIV Prevention Trials Unit
<b>DGIS</b> .....	Dutch Ministry for Development Cooperation	<b>HPV</b> .....	Human Papilloma Virus
<b>DHHS</b> .....	Department of Health and Human Services (USA)	<b>HRP</b> .....	UNDP/UNFPA/WHO/World Bank Special Programme of Research, Development and Research Training in Human Reproduction
<b>DOTS</b> .....	Directly Observed Treatment, Short Course strategy (TB)	<b>HRSA</b> .....	Health Research Systems Analysis
<b>EDCTP</b> .....	European and Developing Countries Clinical Trials Partnership	<b>HSV2</b> .....	Herpes Simplex Virus Type 2
<b>EMRC</b> .....	European Medical Research Council	<b>HVTN</b> .....	HIV Vaccine Trials Network
<b>ENHR</b> .....	Essential National Health Research	<b>IAVI</b> .....	International AIDS Vaccine Initiative
<b>EPI</b> .....	Expanded Programme on Immunization	<b>ICC</b> .....	Inter-agency Coordinating Committees
<b>FAO</b> .....	Food and Agriculture Organization	<b>IC Health</b> .....	Initiative for Cardiovascular Health Research in Developing Countries
<b>FCTC</b> .....	Framework Convention on Tobacco Control (WHO)	<b>ICMR</b> .....	Indian Council of Medical Research
		<b>ICPD</b> .....	United Nations International Conference on Population and Development
		<b>ICSU</b> .....	International Council for Science
		<b>ICT</b> .....	Information and communication technology

## Foreword

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This is the fourth report of the Global Forum for Health Research since its creation in 1998, reporting on the progress in the 10/90 gap in health research. Despite the title, which still refers to a 10/90 gap, much progress has been made in the past few years in the understanding of this gap. Also, a number of measures have been taken which should lead to substantial improvements in the coming years, if efforts by all partners continue with the same determination.

A first positive result is the fact that, from an unknown concept in 1990, the 10/90 gap is now widely recognized. This recognition was indeed a pre-condition for attacking the problem. Also, substantial progress has been made in the past decade in the measurement and understanding of the two components of the gap, i.e. the burden of disease and resource flows into health research. From a situation in 1990 where information regarding these two components was practically nonexistent, there is today a vast amount of information, which has changed the way of looking at health research.

Another pre-condition to finding a solution to the 10/90 gap was the development of a sound methodology and a scientific process for the identification of the research priorities which will make the largest contribution to people's health at the country and global levels. This is a very difficult task, given the large number of actors and factors which enter into the equation. Major progress was made in the 1990s in this respect also, with the development of the Essential National Health Research approach proposed by the 1991 Task Force on Health Research for Development and the Combined Approach Matrix proposed by the Global Forum for Health Research. These instruments are complementary and

constitute a very solid basis for countries and global institutions to define their health research priorities.

Finally, the 1990s have witnessed the creation of a large number of initiatives and networks at the global, regional and country levels in response to the need to correct the 10/90 gap. These networks bring together key actors in the public and private sectors, at the global and country levels, for finding solutions to problems which none of the institutions concerned could solve alone.

Daunting challenges nevertheless remain for the coming years if we want to reach the Millennium Development Goals by 2015 and very determined actions by all governments will be needed, particularly in the following areas.

A first area of action is for all governments to measure their investments in health research and bring these into line, as far as possible, with their country's burden of disease, using a systematic methodology for research priority setting. High-income countries should, in addition to the national burden of disease, take also into account the global burden of disease and allocate appropriate research resources to high-burden diseases and high-burden risk factors threatening world health.

Particular attention should be paid here to research outside the bio-medical sector, which has been largely underfunded if one takes into account its potential impact on people's health. By this I mean research into behavioural, management and social sciences in general (including the functioning of health systems and services), research into sectors outside the health sector (e.g. education, environment, safety) which have a large impact on people's

health, and research into macroeconomic policies as they relate to health.

A second area of action is for all countries to ensure that research addresses all key obstacles explaining why the burden of disease is and remains so high for a large portion of humanity. Experience has shown that many discoveries and research results remain upstream in the research continuum and are not transformed into health products for people, or, if they are, only with substantial delays of years or even decades.

A third area of action is that of research capacity strengthening in low-income countries. Despite over three decades of efforts to build up capacity, during which thousands of scientists from developing countries have been trained, results have been very disappointing in many countries. Large numbers of trained scientists are not working in their countries of origin and many countries cannot summon the necessary human and financial resources to tackle the key health problems affecting their people. A determined joint effort for research capacity strengthening is urgently needed, based on the numerous experiments which have been conducted in recent years.

Fourth, following the remarkable progress made in the field of international collaboration to solve major world health problems, with the creation of about 70 public-private partnerships between 1995 and 2003, we must now ensure their

continued viability, efficient delivery of health products, and strong positive synergies with the national health and health research system.

Finally, a necessary and global condition for success in our enterprise is the systematic integration of gender issues in all the actions mentioned above and all aspects of the work on the correction of the 10/90 gap. The actions undertaken in the 1990s in this field need to be accelerated in the years to come.

Without a quantum change in health research and a re-orientation of research towards the key health priorities in the world, we will not win the war on poverty, we will not reach the Millennium Development Goals by 2015 and we will not succeed in the fight against AIDS, tuberculosis and malaria. The responsibility for that change lies primarily with the public sector, which must create the conditions for the private sector to join the efforts.

The ambition of the Global Forum for Health Research is to continue to be one of the key partners to catalyse that change.



Richard G.A. Feachem  
Chair, Foundation Council  
Global Forum for Health Research

# Chapter 1

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## *A message to ministers of finance: health and health research are possibly the best economic investments*

### *Section 1*

*Investments in health and health research rank among the most productive investments for both individuals and the economy as a whole*

### *Section 2*

*Why such low investments in health?*

### *Section 3*

*Health: moving closer to the centre of the development agenda*

### *Section 4*

*Efforts of the international community towards reaching the MDGs*

### *Section 5*

*Role of health research in reaching the MDGs*

### *Section 6*

*Conclusions*

## Section 1

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### Investments in health and health research rank among the most productive investments for both individuals and the economy as a whole

#### 1. The costs of bad health and the benefits of better health for individuals

For the average person in a low- or middle-income country, falling sick for any length of time seriously endangers the economic situation and well-being of both the individual and their family, in the short and long term, for the following reasons:

- bad health will have a severe impact on the individual's level of income (treatment costs, immediate loss of revenue, longer term loss of revenue due to reduced work opportunities, revenue losses due to premature death);<sup>1</sup>
- it will decrease the capacity of the individual or other family members to acquire an education;
- it will also affect the family's productive opportunities as some members of the family will be called upon to help the member who has fallen ill;
- if ill health persists, the family may fall into absolute poverty (due to loss of income and the "catastrophic payments" needed to regain health);
- finally, it will decrease substantially both their own and their family's psychological well-being.

Therefore it is not surprising that in a survey commissioned by the United Nations in preparation the Millennium Summit in September 2000, respondents from around the world overwhelmingly ranked health as

their "number one" desire.<sup>2</sup> Nor is it a coincidence that "good wishes" cards for the New Year from anywhere in the world normally include health as one of the top wishes. There seems to be a wide consensus among people throughout the world that health is their primary asset.

If the United Nations poll had focused exclusively on the poor in these countries, it is likely that the answers would have been even more forceful, since for them and their family, bad health may make the difference between life and death, as a result of the vicious circle of poverty and ill health, in one or more of the following ways:

- disease for one member of the family means an increase in malnutrition as a result of additional spending on treatment;
- malnutrition increases the risk of unemployment or underemployment, further reducing family revenues;
- an already poor housing situation risks further deterioration;
- both the sick and the family members looking after them miss opportunities for education and training in the formal or informal sector;
- in the long run, the already low productivity level of the family may further decrease in the competitive environment;
- access to health care services, safe drinking water and social services in general may become even more precarious as a result of

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<sup>1</sup> Report of the Commission on Macroeconomics and Health, *Macroeconomics and Health: Investing in Health for Economic Development*, December 2001.

<sup>2</sup> Millennium Poll, United Nations, New York, 2000.

- lower revenues and less education;
- poorer families tend to have more children, in the hope that at least one of them will support the parents in old age (a form of long-term insurance);
- there is an elevated risk of unwanted pregnancies and substance abuse;
- the sale of assets for survival may force the family to move to a more degraded environment;
- the overall impact is to reinforce the powerlessness of the family members, putting at risk the survival of the family itself.

In the higher income countries, the effects of bad health on the economic situation of individuals are mitigated, at least in the short run, by public and social insurances and the social system in general. However, even in these countries, in the long run the negative effects are felt by individuals, especially those at the lower end of the socioeconomic ladder.

In summary, bad health will directly and profoundly affect the economic situation and well-being of any individual in any society. This is particularly true in the lower income countries (as their social safety nets are weaker or non-existent) and for the absolute poor, due to the vicious circle of poverty and ill health.

Conversely, better health will boost the individual's level of income (lower treatment costs, increased revenue, longer term increase in revenue due to better work opportunities, increase in revenues due to longer life-expectancy); it will increase the individual's capacity to acquire an education; it will increase the family's productive opportunities by freeing the members who would otherwise have been called upon to care for the sick; and it will increase substantially the psychological well-being of both the individual and the family. The benefits of good health will be

even greater for the absolute poor, as they may transform the vicious circle of poverty into a virtuous circle, with better nutrition, lower risks of unemployment or underemployment, better housing, better use of training opportunities, higher productivity, and, overall, better control over the individual's life situation and that of the family.

## 2. Costs of bad health and benefits of better health for the economy as a whole

The costs of bad health for the economy as a whole are enormous and correspond to: (a) the sum of the individual losses mentioned above in all their dimensions; and (b) the losses resulting from the so-called externalities.

In summary, bad health means irrecoverable losses in production due to the absence of the sick labour force and of the relatives who may be called upon to help the sick. It also means a less well trained labour force as education and training opportunities are missed by the absentees. Furthermore, it absorbs resources for treating illnesses (both human and financial) that could otherwise be invested in alternative activities. The so-called externalities include lower productivity in general, a less competitive economy, lower profitability of enterprises, higher labour force turnover and disruption in the national budget. In the long run, bad health will endanger the survival of the less competitive enterprises as well as the country's ability to attract foreign investments. Employment opportunities in the economy will be lower, increasing the number of unemployed. Other externalities will take the form of a higher rate of disease transmission due to the larger size of the population that is sick.

Conversely, the benefits of better health for the economy are also enormous. They include an increase in production, a better trained and

more productive labour force, increased competitiveness of the economy, financially more solid enterprises, lower unemployment and a lower rate of disease transmission. Needless to say, the whole process is complex and difficult to quantify, but even very conservative estimates suggest that health investments are yielding the highest rates of return compared to other public investments. A few examples are given below.

The dramatically negative impact of bad health and the large benefits from better health, for both individuals and economies as a whole, have been again underlined in a number of recent international conferences and reports.<sup>3</sup>

### 3. A few examples

#### *Southern Europe in the 1940s and 1950s*

The Report of the Commission on Macroeconomics and Health<sup>4</sup> suggests that the take-off in economic growth in the southern European countries such as Greece, Italy, Spain and Portugal in the 1940s and 1950s was linked to the dramatic reduction in the incidence of malaria and other severe diseases in these countries during this period.

#### *Smallpox*

In the 1950s, it is estimated that smallpox killed more than 5 million people a year and that over 1 million people a year were blinded and over 10 million people disfigured by the disease. Following the adoption of vaccination programmes by a large number of

countries, these figures were dramatically reduced in the latter part of the 1960s. By 1968, the annual cost of smallpox vaccination, quarantine programmes and treatment had reached US\$ 300 million worldwide. By contrast, the entire eradication programme, which was launched in 1967, cost a total of US\$ 300 million over 12 years.<sup>5</sup> The economic benefits of the eradication of smallpox probably reach into the tens of billions of dollars per annum, i.e. a return of more than US\$ 10 for every dollar invested. This rate of return is exceptional, even in the health and health research sectors. It is a multiple of even the highest rates of return in any other sector of the economy, where a return of US\$ 1.2-US\$ 1.5 for every dollar invested is more the norm (not taking into account the large deficits experienced in some sectors following huge investments, e.g. in the heavy industry, tourism or transportation sectors). Yet the vote to pursue smallpox eradication was adopted by the World Health Assembly in 1966 by a two-vote margin.<sup>6</sup>

#### *Polio*

Polio is also likely to be eradicated in the near future. Until the discovery of Sabin's oral polio vaccine in 1961, about half a million people were permanently paralyzed by the disease every year. In 1988, the disease was still endemic in more than 125 countries, disabling about 350 000 people a year. Today, following the efforts of the Global Polio Eradication Initiative, polio is endemic in only seven countries. In 2003, there were about

<sup>3</sup> United Nations Millennium Summit, September 2000.

People's Health Assembly. *People's Charter for Health*, December 2000.

World Bank. *World Development Report 2000/2001, Attacking Poverty*, September 2000.

Commission on Macroeconomics and Health. *op.cit.*

WHO. *The World Health Report 2002, Reducing Risks, Promoting Healthy Life*.

UNDP. *Human Development Report 2003, Millennium Development Goals: A compact among nations to end human poverty*, New York, 2003.

Global Forum for Health Research, Forum 7, Geneva, 2-5 December 2003.

<sup>4</sup> Commission on Macroeconomics and Health. *op.cit.* (page 39).

<sup>5</sup> World Bank. *World Development Report 1993, Investing in Health*, Washington D.C., 1993 (p.17).

<sup>6</sup> Commission on Macroeconomics and Health. *op.cit.* (page 43).

700 cases of the disease. It is estimated that the world may be certified polio-free by 2008.

An estimated US\$ 370 million is needed to carry out the remaining vaccination campaigns<sup>7</sup> but the eradication of polio will result in savings and economic benefits amounting to billions of dollars every year, i.e. once again a return of several dollars for every dollar invested.

#### *Onchocerciasis*<sup>8</sup>

Onchocerciasis (river blindness) is a parasitic disease which causes unbearable itching, disfigurement and ultimately blindness. The total cost to date of the Onchocerciasis Control Programme and its successor the African Programme for Onchocerciasis Control (1974 to 2003) is estimated at about US\$ 700 million, covering 11 Sahelian countries and a population of 30 million people (which is being gradually expanded to 60 million people in 19 countries), i.e. less than US\$ 1 per person per year. So far, the overall Programme is estimated to have prevented itching in millions of persons, prevented 600,000 cases of blindness, and opened up 25 million hectares of agricultural land, enough to feed 17 million people a year.

#### *Malaria*

Malaria causes at least 300 million cases of acute illness and more than one million deaths per year, with severe economic consequences for the countries concerned. It is estimated that production losses due to malaria cost the African economies US\$ 12 billion a year.<sup>9</sup> The Commission on Macroeconomics and Health estimated that an economy affected by malaria will experience a

rate of growth about 1% lower than a malaria-free economy, adding up to a difference of about 25%-30% over a generation. While these calculations are subject to considerable uncertainty, the orders of magnitude point to the central role of health in economic development and are supported by individual experiences.

#### *HIV/AIDS*<sup>10</sup>

More than 60 million people worldwide have been infected with HIV/AIDS, and of these, an estimated 20 million have died. About 5 million new infections occur every year, more than half of them among young people under 25. About 30% of those with HIV/AIDS are co-infected with TB. AIDS is now the leading cause of death in sub-Saharan Africa and the fourth leading cause of death worldwide. This situation has dramatic economic consequences for the countries worst affected, adding up to tens of billions of dollars in lost production, and could reverse the economic gains achieved in recent decades.

Massive investments in prevention would amount to a small fraction of the economic costs of the disease. Successful examples have been demonstrated in Thailand, Uganda and Brazil. Treatment costs are currently estimated at US\$ 500-US\$1000 per patient per year and the WHO "3 by 5" Initiative aims to provide access to treatment for 3 million people in low-income countries by 2005.

#### *Success stories in developing countries*<sup>11</sup>

In a joint publication with partner agencies in 2000, WHO highlighted a large number of effective medicines and other interventions for HIV/AIDS, TB, malaria, childhood diseases

<sup>7</sup> Brundtland GH. *Health: The Key to Human Development*, EXPO 2000 (page 77).

<sup>8</sup> World Bank 1993. op.cit. (page 19) and Onchocerciasis website at WHO and World Bank.

<sup>9</sup> Roll Back Malaria published data.

<sup>10</sup> UNAIDS published data.

<sup>11</sup> WHO, UNICEF, UNAIDS, World Bank, UNESCO, UNFPA. *Health: A Key to Prosperity, Success Stories in Developing Countries*, Geneva, 2000.



and maternal and perinatal conditions which have been applied in low- and middle-income countries with high rates of return on investment. Examples of these include:

- Anti-TB medicines are 95% effective in curing TB and cost US\$ 10 for a six-month course of treatment.
- Oral rehydration therapy is highly effective in treating dehydration caused by diarrhoeal diseases and costs US\$ 0.33 per treatment.
- Antibiotics for pneumonia are 90% effective and cost US\$ 0.27 per dose.
- Antimalarials are 95% effective and cost US\$ 0.12 per dose.
- Bednets can reduce child deaths due to

malaria by 25% and cost US\$ 4 for an insecticide-treated bednet.

- Vaccines are 85% effective in preventing measles and cost US\$ 0.26 per dose.
- Latex condoms are highly effective in preventing HIV and cost US\$ 14 per person for a year's supply.

#### *Macroeconomic calculations*

In 2001, the Commission on Macroeconomics and Health, recognizing the high rates of return on investments in health for both the individuals and the countries concerned, recommended a massive increase in these investments in the coming years (Insert 1.1). From an estimated level of US\$ 53.5 billion in

## **Insert 1.1**

### *Commission on Macroeconomics and Health*

#### *Recommended country and donor commitments for health and global public goods, 2001- 2015 (in billions of constant 2002 US\$)*

<b>Financing</b>	<b>2001</b>	<b>2007</b>	<b>2015</b>	<b>Increase 2001-2015</b>
<b>Country financing</b>				
• Least Developed Countries	7.0	11.0	16.0	9.0
• Other low-income countries	43.0	62.0	74.0	31.0
• Middle-income countries	n.a.	n.a.	n.a.	n.a.
<b>Donor assistance to countries<sup>12</sup></b>				
• To Least Developed Countries	1.5	14.0	21.0	19.5
• To other low-income countries	2.0	6.0	8.0	6.0
• To middle-income countries	2.0	2.0	2.0	0.0
<b>Donor assistance for global public goods</b>				
• Global health research fund	0.0	1.5	2.5	2.5
• Other R&D	<0.5	1.5	1.5	1.0
• International agencies	1.0	2.0	3.0	2.0
<b>Total donor assistance (commitments) to countries and global public goods</b>	<b>7.0</b>	<b>27.0</b>	<b>38.0</b>	<b>31.0</b>

*Source:* Commission on Macroeconomics and Health

<sup>12</sup> Including contributions to the Global Fund to Fight AIDS, TB and Malaria for amounts of US\$ 8 billion and US\$ 12 billion in 2007 and 2015 respectively.

2001, the Commission recommends a more than doubling of investments in health in the least-developed and other low-income countries over the 14-year period to 2015, to reach US\$ 119 billion in 2015. This increase of US\$ 65.5 billion would be financed by an increase in country-level commitments of US\$ 40 billion and an increase in donor assistance of US\$ 25.5 billion (from an estimated US\$ 3.5 billion in 2001 to US\$ 29 billion in 2015).

Given the expected high rates of return on such investments, the Commission estimates that the increased investment of about US\$ 65

billion per annum by 2015 would increase the Gross Domestic Product (GDP) of the countries concerned by at least US\$ 186 billion, i.e. a rate of return of US\$ 3 for every dollar invested. The benefits could be much higher and reach US\$ 4 or US\$ 5 for every dollar invested if less conservative assumptions are made regarding (a) the impact of the health programmes and (b) the contribution of healthy life years to the growth of GDP. Such high rates of return are mostly unheard of in other sectors of the economy.

## Section 2

### Why such low investments in health?

Insert 1.2 summarizes the amount spent on health by governments, donors and private individuals.

The Commission on Macroeconomics and Health estimated that the minimum level of health spending needed in low-income countries to cover essential interventions is

US\$ 30-US\$ 40 per person per year (as compared to the estimated current level of US\$ 11 and US\$ 25 in the least developed and the other low-income countries respectively). This means that the level of health in these countries may continue to deteriorate in the coming years unless urgent and large-scale actions are undertaken in the very near future.

### Insert 1.2

#### *Health spending per capita by level of development*

Development category	Tax revenue (% of GDP)	Health spending per capita (in US\$)			
		Public	Donors	Private	Total
Least Developed Countries	14%	6.0	2.3	2.7	11.0
Other low-income countries		13.0	0.9	11.1	25.0
Lower middle-income countries	19%	51.0	0.6	41.4	93.0
Upper middle-income countries	22%	125.0	1.1	114.9	241.0
High-income countries	31%	1,356.0	0.0	551.0	1,907.0

*Source:* Richard Feachem, then Director, Institute for Global Health, University of California. Paper presented at Forum 5, Global Forum for Health Research, October 2001.

*Given this large contribution of health to the development of the national economy and the fact that citizens around the world overwhelmingly rank health as their “number one” desire, why are governments not investing a larger proportion of public resources in health?*

The main reasons include the following:

### **1. Traditional reluctance to apply concepts of rates of return on investments in health**

There has been a traditional reluctance on the part of public officials (and economists) to apply the tools of economic analysis to the delivery of health services, as this gives the impression that people's health is treated as a simple commodity. It is often considered derogatory to try to apply “rates of return calculations” to expenditures in this sector.

To avoid this political trap, officials described the health sector as a “social sector”, with the understanding that social sectors should receive high priority in the allocation of public funds. However, this high priority was never defined and therefore open to free interpretation. As a result, allocations of public funds to this sector never had to *compete* formally with the so-called economic sectors (e.g. transportation, electricity, telecommunications, agriculture, industry, credit, forestry and tourism). However, this apparent advantage turned out to be a disadvantage in many cases and many countries as health as a sector never had the chance to *demonstrate* its considerable contribution to economic growth and development. The direct negative consequences of this situation were the following:

- a) allocations of public funds to this sector remained largely arbitrary, based on the respectively favourable or unfavourable political circumstances in each country;
- b) the extremely high rates of return on

investments in health (as summarized in section 1 above) were largely overlooked;

- c) investments in this sector remained below the level they would have reached if the contribution of health to growth and development could have been better taken into consideration, on the basis of the application of systematic tools.

### **2. Complexity of the calculations**

Another reason for the public sector's under-investment in health relative to its potential contribution to growth and development is the difficulty involved in assessing the impact of such investment on health, production and the overall well-being of society. The complexity of the calculations is linked to the number of variables and uncertainty regarding the links between these variables and the outcomes of these investments. Other sectors are not confronted with the same degree of complexity and uncertainty. Although a possible explanation, the complexity and uncertainty of the calculations are no excuse for the under-investment by the public sector in health. Relatively simple calculations, with very conservative assumptions as to the expected impact of the investments on people's health, show rates of return which are a multiple of the normal rates of return expected from investments in other sectors of the economy.

### **3. Health often considered as a consequence of the development process rather than one of its engines**

Improvements in health are partly due to an increase in the standard of living of a society, i.e. of rising incomes leading to greater purchasing power for improved nutrition, housing, water and medical services. Similarly, improvements in health are due to the impressive increase in the average level of education, which has led to better

understanding by families of the importance of nutrition, hygiene and sanitation.<sup>13</sup> As a result, public officials have tended to rely on the development process to bring health to the people and to consider health as a consequence of the development process rather than one of its engines. In this sense, health has traditionally mostly been valued for its social welfare and redistributive role,<sup>14</sup> and considered by officials and citizens alike more as a consumption item than an investment. This is of course a serious mistake which explains, at least in part, the massive under-investment in health by the public sector, to the benefit of other sectors with lower impact on growth and development.

#### 4. Health pays only if all conditions are fulfilled for high rates of return

In many cases, the potentially very high rate of return for the economy and society from investing in health has been considerably reduced and possibly wiped out by the following factors:<sup>15</sup>

(a) *Poor governance of health services:* including poor leadership, poor management, lack of appropriate incentives, constant turnover, corrupt practices in nominations and procurement, lack of accountability and lack of public service motivation.

(b) *Concentration on the urgent and the visible at the expense of the efficient and effective:* thus, high-cost treatment of acute cases in secondary and tertiary facilities is absorbing a high portion of the public health budget at the expense of preventive actions with much higher benefits for the population as a whole, such as primary health care, immunization and nutrition.

(c) *The problem is compounded by the fact that public health services tend to serve the richer section of the population* which is better informed and has better access to health services, at the expense of the population as a whole, particularly the poor, thus foregoing an important part of the benefits of investing in health. According to Nancy Birdsall, “oral rehydration therapy, which is of far more benefit to rural populations with little access to safe water, is likely to be a less popular item in the budget than increasing the availability of antibiotics in urban health centres.”

(d) *The bias of the public health services in favour of the urban richer populations in tertiary centres squeezes out the funding left for preventive services* that would benefit the overall population. It may even substitute, in some cases, public funding for private funding (in cases of patients with private health insurance), thus wiping out the benefits of an increase in public funding.

The factors described above will considerably reduce the rates of return on an increase in public funding for health services and may cause public officials to decide against such an increase in public funding for health, even though there is a very strong theoretical case for much larger public budget allocations to health.

These factors explain why, for the same level of per capita spending on health services, some countries obtain very high results in terms of public health while, for other countries, the return on public health investments remains very limited.<sup>16</sup>

<sup>13</sup> Birdsall N. *Ignorance Should Not Be Bliss: Policy Research on Health Systems and Health Services in Developing Countries*, Paper presented at Forum 7, Geneva, December 2003. Nancy Birdsall is President, Center for Global Development, Washington, DC.

<sup>14</sup> Rodriguez-Garcia R and Goldmann A. *The Health Development Link*, PAHO/WHO, 1994.

<sup>15</sup> Birdsall. op. cit.

<sup>16</sup> WHO. *World Health Report 2000, Health Systems: Improving Performance*, Geneva, 2000.

## Section 3

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### Health: moving closer to the centre of the development agenda

#### 1. Evolution of the concept of development

*The concept of development has evolved considerably over recent decades.* At the risk of oversimplifying, in the 1960s the donor community largely believed that the way to advance development was through the financing of basic infrastructure projects, for example in the fields of electricity, transportation and telecommunications. The preparation and management of such projects was also somewhat less complex than projects in many other sectors. This was followed and complemented by major efforts in the 1970s to develop agriculture, industry and the financial sector. Macroeconomic stability and appropriate global economic policies were then thought to be crucial conditions for growth and development and were added to the development agenda. In the late 1970s and 1980s, the fight against poverty became a major objective of the development community, together with programmes in the fields of environment, health, education and social safety nets, *representing a shift from a focus on physical capital to an emphasis on human capital.* Furthermore, the concept of good governance and citizen participation became “key elements of the strategies which now focus on countries rather than on projects or sectors”.<sup>17</sup> This evolution in the concept of development has been reflected since 1990 in the Human Development Index (HDI)<sup>18</sup> and

other such indices developed by the United Nations Development Programme (UNDP), providing alternatives to the traditional GDP per capita as a measure of development.

Gradually, a fundamental distinction was made between human development (an objective) and economic growth (a means to reach the objective). According to the UNDP *Human Development Report 2003*,<sup>19</sup> the main components of human development are living a healthy life, being educated, having a decent standard of living (thus eliminating poverty and hunger) and enjoying political and civil freedoms to participate in the life of one’s community. Poverty is the negation of human development in all its dimensions. Economic growth is a tool to reach human development and not an objective in itself. But human development will promote economic growth, which in turn will advance human development.

*In this virtuous circle, it is important to be sure which one is the objective (human development) and which one the tool (economic growth) because economic growth will not automatically translate into human development without a clear political will in the public sector.*

This evolution from physical capital to human capital has led to a parallel evolution in the

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<sup>17</sup> Ingram GK. "The Challenges of Development Evaluation: Some Conclusions", in *World Bank Operations Evaluation Department, The First 30 Years*, Washington DC, 2003.

<sup>18</sup> The HDI is a summary measure of three dimensions of the human development concept: health, education and standard of living. Three supplementary indices have been developed in the 1990s: the Human Poverty Index (HPI), the gender-related development index (GDI), and the gender empowerment measure (GEM).

<sup>19</sup> UNDP 2003 op. cit. (page 28).

sectoral allocation of aid resources, although not in a linear fashion. Thus, public administration (including economic management, law and justice), health, education, natural resource management and the environment have become increasingly important in the development agenda over the past decade. The health sector, for its part, has seen an increase in its share of total Official Development Assistance (ODA) from an estimated 3.8% in 1990 to 6.8% in 2002, in spite of a decrease in the overall ODA during this period.<sup>20</sup>

*This evolution culminated in the adoption of the Millennium Development Goals (MDGs) by the United Nations in September 2000.*<sup>21</sup>

## 2. The Millennium Development Goals

### (a) Historical development

It is no exaggeration to say that the United Nations Millennium Declaration, the Road Map towards the implementation of this Declaration, and the MDGs are the best summary of the efforts undertaken by the international community over the past 40 years to find a path for sustainable development for all members of the global community. They succeed in encapsulating both the great achievements of the past 40 years of development cooperation and the great challenges confronting the world today. The MDGs in particular list the most urgent tasks to be accomplished in the coming years under eight goals and 18 targets. These are presented in Insert 1.3.

### (b) The place of health in the MDGs

The fight against poverty and ill health are at the centre of the MDGs, together with

education, gender and the environment. Of the eight MDGs, four are explicitly directed to health targets, while the other four are closely associated with health. In other words, after forty years of development cooperation and hard thinking about the concept of development, the MDGs have succeeded in placing health and education at the centre of the development process, both as (i) crucial engines for development and against poverty as well as (ii) the ultimate goals of the development process. For the first time, there was a consensus on a comprehensive agenda for development among the 189 Member States (including 147 Heads of State and Government) who adopted the MDGs in September 2000. Earlier formulations of development had included some of these considerations, at least implicitly, but they had never been formulated so clearly and so universally. This is a major step forward, which has profound policy implications.

What progress have countries made so far in achieving the MDGs?

According to the *Human Development Report 2003*, “since 1990, the East Asia and Pacific region, led by China, has nearly halved extreme income poverty – and is making significant progress on the other Goals as well. For the Arab States and Latin America and the Caribbean, achieving the Goals by 2015 will be challenging but possible. But for other developing regions, achieving the Goals remains a huge challenge. Unless things improve, it will take sub-Saharan Africa until 2129 to achieve universal primary education, until 2147 to halve extreme poverty and until 2165 to cut child mortality by two-thirds.”<sup>22</sup>

<sup>20</sup> Michaud C. Development Assistance for Health: Recent Trends and Resource Allocation, Paper prepared for the Second Consultation, Coordination on Macroeconomics and Health, Geneva, 29-30 October 2003.

<sup>21</sup> The *UNDP Human Development Report 2003* argues that the full realization of human development requires more than achieving the MDGs. But achieving the MDGs is a key step towards the full realization of human development.

<sup>22</sup> UNDP 2003. op. cit. (page 33).

The World Bank, in a paper prepared for the Development Committee at the September 2003 Annual Meeting, estimated that the aid levels would have to double in order for the MDGs to be achieved. Section 4 below reviews the efforts recently undertaken by the international community to confront the huge challenge of meeting the MDGs by 2015.

### 3. A common denominator for the MDGs: human security?<sup>23</sup>

Is there a common denominator for the MDGs which could represent the ultimate evolution in the concept of development and therefore the ultimate criterion for judging policies and actions on the road to global human development? A possible candidate is “human security”, which was first mentioned in the UNDP *Human Development Report 1994* and much discussed in international meetings and academia since then.

The Report lists seven components of human security:

- health security in a broad sense (including communicable and noncommunicable diseases (NCDs), violence and injuries, and all health risk factors)

- food security
- environmental security
- economic security (including education and training)
- personal security
- community security
- political security.

This definition corresponds to the so-called broad definition of human security. The first four components are generally referred to as “freedom from want”, whereas the last three constitute the “freedom from fear” components (which are also considered as the narrow definition of human security).

Thus it appears that the concept of human security in its broad definition can incorporate the MDGs and constitute a very useful common denominator for judging progress in the field of overall human development, at the micro- and the macro-level, in the field of policies or concrete investments, and for the actions of governments, the private sector, civil society or individuals. It makes a clear distinction between the tools and the ultimate objective of human activity and lends itself to an overall measurement of progress for countries and the international community through the application of a human security audit.

## Section 4

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### Efforts of the international community towards reaching the MDGs: vertical and horizontal approaches

Confronted with the challenge of meeting the MDGs by 2015, the international community has responded by launching new programmes as well as by accelerating and renewing their commitment to existing programmes. Some of these can be described as “vertical approaches” (e.g. targeting specific diseases

and conditions), while others are characterized by a “horizontal approach” (e.g. focusing on improvements in public health services and attacking the basic causes of poverty). Some examples of both approaches are given below.

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<sup>23</sup> This section has been written on the basis of a master's thesis by Emily Munro, *The Human Security Network: a case study on the application of a policy of human security by States*, Graduate Institute of International Studies, Geneva, October 2003.

## Insert 1.3

### Millennium Development Goals (1990-2015)

GOALS AND TARGETS	INDICATORS
<p><b>Goal 1: Eradicate extreme poverty and hunger</b> Target 1: Reduce by half the proportion of people living on less than a dollar a day.</p> <p>Target 2: Reduce by half the proportion of people who suffer from hunger.</p>	<ol style="list-style-type: none"> <li>1. Proportion of population below US\$1/day.</li> <li>2. Poverty gap ratio (incidence and depth of poverty).</li> <li>3. Share of poorest population quintile in national consumption.</li> <li>4. Prevalence of underweight children (&lt;5)</li> <li>5. Proportion of population below minimum level of dietary energy consumption.</li> </ol>
<p><b>Goal 2: Achieve universal primary education</b> Target 3: Ensure that all boys and girls complete a full course of primary schooling.</p>	<ol style="list-style-type: none"> <li>6. Net enrolment ratio in primary education.</li> <li>7. Proportion of pupils starting grade 1 who reach grade 5.</li> <li>8. Literacy rate of 15-24 year-olds.</li> </ol>
<p><b>Goal 3: Promote gender equality and empower women</b> Target 4: Eliminate gender disparity in primary and secondary education preferably by 2005, and at all levels by 2015.</p>	<ol style="list-style-type: none"> <li>9. Ratio of girls to boys in primary, secondary and tertiary education.</li> <li>10. Ratio of literate females to males (15-24).</li> <li>11. Share of women in wage employment in the non-agricultural sector.</li> <li>12. Proportion of seats held by women in national parliament.</li> </ol>
<p><b>Goal 4: Reduce child mortality</b> Target 5: Reduce by two-thirds the mortality rate among children under five.</p>	<ol style="list-style-type: none"> <li>13. Under-five mortality rate.</li> <li>14. Infant mortality rate.</li> <li>15. Proportion of one-year-olds immunized against measles.</li> </ol>
<p><b>Goal 5: Improve maternal health</b> Target 6: Reduce by three-quarters the maternal mortality ratio.</p>	<ol style="list-style-type: none"> <li>16. Maternal mortality ratio.</li> <li>17. Proportion of births attended by skilled health personnel.</li> </ol>
<p><b>Goal 6: Combat HIV/AIDS, malaria and other diseases</b> Target 7: Halt and begin to reverse the spread of HIV/AIDS.</p> <p>Target 8: Halt and begin to reverse the incidence of malaria and other major diseases.</p>	<ol style="list-style-type: none"> <li>18. HIV prevalence among 15-24 year-old pregnant women.</li> <li>19. Contraceptive prevalence rate.</li> <li>20. Number of children orphaned by HIV/AIDS.</li> <li>21. Prevalence and mortality due to malaria.</li> <li>22. Proportion of population in malaria risk areas using malaria prevention and treatment.</li> <li>23. Prevalence and mortality due to tuberculosis.</li> <li>24. Proportion of TB cases detected and cured.</li> </ol>

Source: UN General Assembly, Report of the Secretary-General, *Road map towards the implementation of the United Nations Millennium Declaration*, September 2001.



## Insert 1.3 (continued)

### Millennium Development Goals (1990-2015)

GOALS AND TARGETS	INDICATORS
<p><b>Goal 7: Ensure environmental sustainability<sup>24</sup></b>            Target 9: Integrate the principles of sustainable development into country policies and programmes. Reverse the loss of environmental resources.</p> <p>Target 10: Reduce by half the proportion of people without sustainable access to safe drinking water.</p> <p>Target 11: Achieve significant improvement in lives of at least 100 million slum dwellers, by 2020.</p>	<p>25. Proportion of land area covered by forest.            26. Land area protected to maintain biodiversity.            27. GDP per unit of energy use.            28. Carbon dioxide emissions (per capita).</p> <p>29. Proportion of population with sustainable access to an improved water source.</p> <p>30. Proportion of people with improved sanitation.            31. Proportion of people with secure tenure.</p>
<p><b>Goal 8: Develop a global partnership for development</b>            Target 12: Develop further an open trading and financial system that is rule-based, predictable and non-discriminatory, includes a commitment to good governance, development and poverty reduction – nationally and internationally.</p> <p>Target 13: Address the least-developed countries' special needs. This includes tariff- and quota-free access for their exports; enhanced debt relief for heavily indebted poor countries; cancellation of official bilateral debt; and more generous official development assistance for countries committed to poverty reduction.</p> <p>Target 14: Address the special needs of landlocked and small island developing countries.</p> <p>Target 15: Deal comprehensively with developing countries' debt problems through national and international measures to make debt sustainable in the long term.</p> <p>Target 16: In cooperation with developing countries, develop decent and productive work for youth.</p> <p>Target 17: In cooperation with pharmaceutical companies, provide access to affordable essential drugs in developing countries.</p> <p>Target 18: In cooperation with the private sector, make available the benefits of new technologies – especially information and communications technologies.</p>	<p><u>Official Development Assistance (ODA)</u>            32. Net ODA as percent of DAC donors' GDP (target of 0.7% and 0.15% for LDCs).            33. Proportion of ODA to basic social services (basic education, primary health care, nutrition, safe water and sanitation).            34. Proportion of ODA that is untied.            35. Proportion of ODA for environment in small island developing States.            36. Proportion of ODA for transport sector in landlocked countries.</p> <p><u>Market access</u>            37. Proportion of exports (excluding arms) admitted free of duties and quotas.            38. Average tariffs and quotas on agricultural products and textiles and clothing.            39. Domestic and export agricultural subsidies in OECD countries.            40. Proportion of ODA provided to help build trade capacity.</p> <p><u>Debt sustainability</u>            41. Proportion of official bilateral HIPC debt cancelled.            42. Debt service as per cent of exports.            43. Proportion of ODA provided as debt relief.            44. Number of countries reaching HIPC decision and completion points.</p> <p>45. Unemployment rate of 15-24 year-olds.</p> <p>46. Proportion of population with access to affordable essential drugs on a sustainable basis.</p> <p>47. Telephone lines per 1000 people.            48. Personal computers per 1000 people.</p>

<sup>24</sup> The selection of indicators for goals 7 and 8 is subject to further refinement.

## 1. Examples of vertical approaches

### (a) *The Global Polio Eradication Initiative*<sup>25</sup>

Established in 1988, the Global Polio Eradication Initiative pre-dates the efforts undertaken since 2000 to reach the MDGs. However, the completion of this Initiative is very much part of achieving the MDGs. After the smallpox eradication campaign, this Initiative is one of the most successful public health efforts in history against one of the world's oldest diseases.

It is generally agreed that the achievements of the Global Polio Eradication Initiative (see Section 1.3 above) are the result of a number of key factors, which provide valuable insights for the massive scaling up that will be needed to reach the MDGs. The major factors which contributed to this success include the following:

- A unique partnership forged between governments, international agencies, humanitarian organizations and the private sector: this partnership started in 1988 with the decision of the World Health Assembly to launch an initiative to eradicate polio. WHO, UNICEF, Rotary International and the US Centers for Disease Control and Prevention (CDC) formed the core of this partnership, which developed into an extensive network of national governments, international agencies, private corporations, foundations, bilateral donors, humanitarian organizations, non-governmental organizations (NGOs) and development banks.
- The effective engagement of political leaders: this played a crucial role in the success of the National Immunization Days (NIDs), requiring the immunization of every child under five years of age over a period of one

to three days, several times a year for several years. The engagement of political leaders also played a key role in the mobilization of financial and human resources outside the health sector. Countries have drawn heavily on ministries of information, transportation and defence, and on the engagement of private sector companies to reach all children during the NIDs.

- Adequate financing: it is estimated that the polio eradication campaign has succeeded in mobilizing a total of more than US\$ 5 billion (about 50% of this as contributions in-kind) over two decades, including a substantial proportion for the strengthening of the routine immunization and surveillance services, thereby contributing to the better delivery of other health services.
- Sufficient human resources: in countries where the formal health system was weakest, it was only possible to achieve the scaling-up of the programme of polio immunization after substantial reinforcement of the health system. Furthermore, given the large number of people required during the NIDs, the success of these campaigns was largely due to the massive number of volunteers who joined the campaign. It is estimated that in 2001 alone about 10 million volunteers and health workers immunized 575 million children.
- Learning from successful examples: in Latin America and the Caribbean, the scaling up benefited greatly from the successful Cuban example and from the strategies and management processes developed by the Pan American Health Organization (PAHO) in its work to achieve the regional elimination of polio.
- Coordinating committees at the international and country level: these

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<sup>25</sup> WHO. *World Health Report 2003* (Chapter 4).

committees played an important role in sharing information on successful practices and in ensuring that national authorities were always at the centre of key decisions.

These lessons will be very useful in the process of scaling up programmes to achieve the MDGs.

*(b) The Global Fund to Fight AIDS, TB and Malaria<sup>26</sup>*

AIDS, TB and malaria are preventable diseases which together account for over 6 million deaths a year and for about 10% of the total global disease burden. The Global Fund was created in 2002 to mobilize energies and substantial funding worldwide for the prevention and treatment of AIDS, TB and malaria. It is an independent organization, governed by an international Board of 18 members, representing donor and recipient governments, NGOs, the private sector (including business and philanthropic organizations) and affected communities.

In its two years in operation, the Global Fund has approved grants for 224 programmes in 121 countries for a total amount of US\$ 2.1 billion, with total disbursements at the end of 2003 amounting to more than US\$ 200 million. The largest share of the funding has been committed to Africa (the continent worst affected) and 60% of overall funding has been allocated for use in efforts to combat HIV/AIDS.

The Global Fund represents a new approach to international health financing. It relies on local ownership and planning to ensure that new resources are directed to programmes on the frontlines of this global effort. Beyond the

Fund's Board and Secretariat, its key structures include the following:

- Country Coordinating Mechanisms composed of the main actors at country level (government agencies, NGOs, community organizations, private-sector institutions, people affected by AIDS, TB and malaria, as well as bilateral and multilateral agencies) responsible for the development and submission of grant proposals to the Global Fund, the monitoring of their implementation and coordination with other donors and domestic programmes.
- An independent Technical Review Panel composed of health and development experts, which provides a rigorous review of the technical merit of applications.
- The Principal Recipient: a local entity nominated by the Country Coordinating Mechanism and the Global Fund to be legally responsible for grant proceeds and implementation of the programme at the country level.
- The Local Fund Agent: an independent local organization hired by the Global Fund Secretariat to assess the Principal Recipient's capacity to administer funds and report on financial and programmatic progress.

*(c) The "3 by 5" Initiative<sup>27</sup>*

In 2003, in a renewed response to the HIV/AIDS emergency, another vertical initiative (the "3 by 5" Initiative) was launched by WHO and other partners (UNAIDS, other UN agencies, the Global Fund, governments of affected countries, NGOs and the private sector). This new Initiative aims to ensure that by 2005, 3 million people living with HIV/AIDS in developing countries have access to antiretroviral treatment. This is a huge challenge in itself, even though it will reach

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<sup>26</sup> Global Fund published data.

<sup>27</sup> WHO and Global Fund published data.

less than 10% of the HIV-infected population. However, it is hoped that it will lay the foundations for scaling up the programme after 2005.

*(d) Roll Back Malaria Partnership<sup>28</sup>*

The Roll Back Malaria Partnership (RBM) was launched in 1998 by WHO, UNICEF, UNDP and the World Bank to provide a coordinated global approach to fighting malaria. The objective of RBM is to halve the burden of malaria by 2010, thus contributing to the achievement of the MDGs by 2015. The RBM Partnership is made up of several constituencies: malaria-endemic countries, bilateral aid agencies, multilateral development partners, the private sector, NGOs and community-based organizations, research institutions and academia, and foundations. The main activities of RBM in 2003-2004 were the following:

- development of partnership management structures
- development of global consensus on strategies
- efforts to ensure that malaria remains high on the global development agenda
- providing technical and programmatic support to countries.

*(e) Global Alliance for Vaccines and Immunization<sup>29</sup>*

According to conservative estimates, every year 33 million children miss out on immunization and at least 1.5 million children under five years old die from vaccine-preventable causes, including 450 000 due to Hib-related pneumonia and meningitis. The Global Alliance for Vaccines and Immunization (GAVI), together with its financial arm, the Vaccine Fund, was created in 1998 as a public-private partnership focused on increasing children's access to vaccines in poor countries. Partners include national governments,

UNICEF, WHO, the World Bank, the Bill & Melinda Gates Foundation, the vaccine industry, public health institutions and NGOs. The Alliance provides a forum for partners to agree upon mutual goals, share strategies and coordinate efforts.

In its five years in operation, GAVI has received about US\$ 1 billion in commitments and vaccinated about 30 million children against hepatitis B, 4.3 million children against *Haemophilus influenzae* type b (Hib), and 1.6 million against yellow fever. In addition, GAVI estimates that countries have been able to provide basic vaccination to 8.3 million children who would not otherwise have been reached with any vaccines. GAVI estimates that about 300 000 deaths have been prevented as a result of the resources provided so far. At present, about 68 countries are receiving support from the Alliance for their health infrastructure, vaccines and supplies, which represents an unprecedented scaling up of the vaccination programmes in these countries.

GAVI is anxious to avoid duplication of efforts and to be country based. This is reflected in its decision-making structure which, beyond its 16-member Board and its Secretariat, includes the following:

- A Working Group composed of managers in the GAVI partner institutions who are responsible for translating the Alliance's priorities into the respective agency work plans.
- GAVI Task Forces (advocacy, financing, implementation, and research and development) which draw upon a wide network of expertise to guide action.
- Regional Working Groups to coordinate and provide technical support to countries.
- National inter-agency coordinating committees (ICCs) to provide a forum for

<sup>28</sup> RBM published data (for more information see chapter 9, section 10).

<sup>29</sup> GAVI published data.

joint strategy development and monitoring at the country level.

*(f) Public-private partnerships for health*

Between 1995 and 2003, at least 70 public-private partnerships for health were created (compared to about 12 during the 1980s) in response to the need to bring together interested partners from the public and private sector, when it was recognized that neither sector acting alone could identify and deliver the solution. For a list of these partnerships, see the partnership database on [www.ippph.org](http://www.ippph.org). In 2000, the Global Forum for Health Research launched the Initiative on Public-Private Partnerships for Health (IPPPH), whose aim is to increase the effectiveness of public-private collaboration, particularly by helping those seeking to develop and improve access to health products to fight neglected diseases in developing countries. A summary of the work of IPPPH and its perspectives for the coming two years appears in chapter 9, section 16.

## 2. Examples of horizontal approaches

Despite the efforts of all vertical approaches, it is unlikely that the MDGs will be met without major efforts in the use of horizontal approaches as well. These approaches are based on the belief that health is mostly determined by broad factors of a political, economic, social and environmental nature,

and that health improvements therefore depend on developing systems and policies with a broad impact on those factors. It is also believed that, in many ways, acting across the spectrum of diseases and conditions may be more efficient and effective than acting on a disease-by-disease basis. A few examples of horizontal approaches are reviewed below.

*(a) Strengthening of health systems: Alma-Ata 1978, People's Health Movement 2000 and WHO 2003*

The origin of the health system movement, particularly the "primary health care movement", is to be found in the Alma-Ata Declaration signed by 134 States in September 1978.<sup>30</sup> In summary, the main principles underlining the Alma-Ata Declaration are as follows:<sup>31</sup>

- universal accessibility to health services on the basis of need;
- comprehensive health care with an emphasis on disease prevention and health promotion;
- community and individual involvement and self-reliance;
- intersectoral action for health;
- appropriate technology and cost-effectiveness in relation to the available resources for health care.

The 1978 Alma-Ata Declaration was strongly endorsed by the People's Health Assembly at

<sup>30</sup> Article I: "A main social target of governments, international organizations and the whole world community in the coming decades should be the attainment by all peoples of the world by the year 2000 of a level of health that will permit them to lead a socially and economically productive life. Primary health care is the key to attaining this target as part of development in the spirit of social justice."

Article VI: "Primary health care is essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination. It forms an integral part both of the country's health system, of which it is the central function and main focus, and of the overall social and economic development of the community. It is the first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process."

Article VIII: "All governments should formulate national policies, strategies and plans of action to launch and sustain primary health care as part of a comprehensive national health system and in coordination with other sectors. To this end, it will be necessary to exercise political will, to mobilize the country's resources and to use available external resources rationally."

<sup>31</sup> Sanders D. *Twenty-five years of Primary Health Care: Lessons Learned and Proposals for Revitalization*, School of Public Health, University of Western Cape, South Africa and People's Health Movement, August 2003.

its meeting in Bangladesh in December 2000 and in the ensuing *People's Charter for Health*, which is based on the following principles:

- The attainment of the highest possible level of health and well-being is a fundamental human right, regardless of a person's colour, ethnic background, religion, gender, age, abilities, sexual orientation or class.
- The principles of universal, comprehensive Primary Health Care, envisioned in the 1978 Alma-Ata Declaration, should be the basis for formulating policies related to health. Now more than ever, an equitable, participatory and intersectoral approach to health and health care is needed.
- Governments have a fundamental responsibility to ensure universal access to quality health care, education and other social services according to people's needs, not according to their ability to pay.
- The participation of people and people's organizations is essential to the formulation, implementation and evaluation of all health and social policies and programmes.
- Health is primarily determined by the political, economic, social and physical environment and should, along with equity and sustainable development, be a top priority in local, national and international policy-making.

In the *World Health Report 2003: Shaping the Future*, WHO underlines the importance of strengthening health systems as a key element for achieving the MDGs, pointing out that in the coming years "resolute commitment to the primary health care values of equity, universal access to care, community involvement and intersectoral action will be more important than ever." According to WHO, the renewed focus on health systems and services involves

all areas of WHO work including: the "3 by 5" Initiative to increase the availability of antiretroviral treatment for HIV/AIDS; a newly refocused drive to reduce maternal mortality; and work on chronic diseases and mental health. All of these initiatives contribute to the development of better health care in countries, and all require strong health systems to succeed.

There is broad consensus that in the coming years the much needed strengthening of health care systems will require substantial and determined actions in the following fields:

- governance: leadership, management, incentives, procurement, accountability, motivation;
- human resources: a massive increase in the number and quality of the workforce at all levels, including training in the organizational aspects of health systems;
- at least a doubling of funding for health systems, from both domestic and international sources;<sup>32</sup>
- substantial improvements in health systems policies, identifying best practices based on the lessons learned in more than two decades since the Alma-Ata Declaration;
- development of health information systems capable of identifying the most pressing health needs, orienting the programmes towards those needs, and measuring the results of interventions;
- finally, and based on the points above, development of comprehensive health programmes, integrating and linking the health promotion activities involving the health sector, other sectors (education, sanitation, environment, agriculture, etc.), the communities themselves and the macroeconomic policies.

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<sup>32</sup> In a recent development in November 2003, WHO called on the world donor community to provide a total of US\$ 341 million to help finance health services in 21 countries suffering from a particularly severe crisis. This is part of a United Nations Inter-Agency Consolidated Appeal (CAP) for a total of US\$ 3 billion to support these 21 countries in various sectors.

A number of promising examples are emerging in different countries such as China, Cuba, Sri Lanka and the Indian State of Kerala. In all cases, it appears that the primary condition for success is the political commitment of the authorities and of crucial civil society organizations (CSOs) to the promotion of human capital at the centre of the development process.

*(b) Poverty Reduction Strategy Papers*

Started in 1999, Poverty Reduction Strategy Papers (PRSPs) are national frameworks for low-income countries wishing to access concessional loans from the World Bank or the International Monetary Fund (IMF), or wishing to benefit from debt relief under the Highly-Indebted Poor Countries (HIPC) initiative.<sup>33</sup> The papers describe macroeconomic, structural and social policies and programmes to promote growth, reduce poverty and make progress in areas such as education and health, indicating domestic and external financing requirements. The Papers are prepared by governments through a participatory process involving civil society and development partners. Most donors have agreed in principle to align their programmes with PRSPs.

As of 2002, 53 countries were at different stages of preparation and implementation of PRSPs, 26 of them having reached the so-called “decision point” under the HIPC initiative, which will translate into debt relief amounting to US\$ 41 billion over time. As a result, it was estimated that health, education and other social expenditures in these countries would increase from 6% of GDP in 1999 to 9% in 2002.

What is the impact of PRSPs on the implementation of the MDGs? According to the UNDP<sup>34</sup>, PRSPs increasingly mention the MDGs but do not yet provide a systematic review of the policies and financial resources (both domestic and external) needed to achieve them. A similar point is made by Dodd and Hinshelwood<sup>35</sup>, but it is agreed that we are still in the early years of both the PRSP process and the MDGs and that the PRSPs are potentially a key instrument to reach the MDGs.

*(c) Follow-up to the Report of the Commission on Macroeconomics and Health*

The Report of the WHO Commission on Macroeconomics and Health in December 2001 was endorsed by the World Health Assembly in May 2002 and the Report's Action Plan was described as “a useful approach to the achievement of the Millennium Development Goals”. The Report recommends that total donor commitments for health should increase from US\$ 7 billion in 2001 to US\$ 27 billion by 2007 and US\$ 38 billion by 2015, while funding from domestic resources in low-income countries should increase from US\$ 50 billion in 2001 to US\$ 73 billion in 2001 and US\$ 90 billion in 2015.<sup>36</sup>

Following the Report, the effort is now pursued at the country level and two consultations were organized by WHO to address the need to significantly increase investments in health. In the Second Consultation, held in Geneva in October 2003, ministers of health, finance and planning from 40 developing countries came together with representatives from donor countries, international organizations and CSOs. The work at the country level is led by

<sup>33</sup> Dodd R and Hinshelwood E. *Poverty Reduction Strategy Papers: Their Significance for Health*, WHO, 2002.

<sup>34</sup> UNDP 2003. *op.cit.*

<sup>35</sup> Dodd and Hinshelwood. *op.cit.*

<sup>36</sup> Commission on Macroeconomics and Health. *op.cit.* (page 20)

a high-level national commission composed of representatives from different sectors focusing on the following objectives:

- achieve better health for the poor
- increase investments (both domestic and external) in health
- progressively eliminate non-financial constraints.

The ‘macroeconomics and health process’ at the country level includes the following three phases:

*Phase 1:* promotion of high-level awareness through national workshops with key stakeholders; 24 countries were in phase 1 at the end of 2003.

*Phase 2:* in-depth assessment of the country health situation and analysis of health infrastructure, including epidemiological surveys, analysis of the capacity of health systems to absorb additional funding, assessment of funding gaps; at the end of phase 2, countries develop multisectoral health investment plans, including high-priority and cost-effective interventions; China, Ethiopia, Ghana, Indonesia, Mexico and Sri Lanka had reached phase 2 at the end of 2003.

*Phase 3:* implementation of the health investment plan and monitoring of its impact.

In the conclusions of the Second Consultation, the ministers of finance, planning and health drew particular attention to the following points, among others:

- the follow-up to the Report of the Commission on Macroeconomics and Health has helped countries to develop their own political, financial, economic and health strategies, and the process should be continued;
- advocacy for the value of health and its importance to economic growth and poverty alleviation is a core part of the process;

- a multisectoral approach beyond the health sector (taking into account water, sanitation, education and gender issues) is necessary and requires appropriate coordinating mechanisms;
- improved capacity for research and analysis must provide the foundations for the national Health Investment Plans;
- lifting of the human resource constraints is critical for improving the performance of the health system;
- additional investments, from both domestic and external sources, will be required to finance health investments, including strengthening infrastructure and human resources, pursuing health system reforms, and scaling up of essential health interventions;
- the focus has to be on results, emphasizing improved access to health services and better outcomes for the poor.

*(d) The “human rights” approach*

As each MDG can be linked to economic, social and cultural rights enumerated in the Universal Declaration of Human Rights and other human rights instruments,<sup>37</sup> the proponents of this approach argue that the fight for human rights is a direct contribution to the realization of the MDGs. However, the full realization of economic, social and cultural rights goes further than the full implementation of the MDGs. For example, the full realization of the human right to education goes further than achieving universal literacy and primary education, as it requires that people also participate in public decisions. Thus it is argued that achieving the MDGs is part of the realization of human rights, which is the most horizontal and broadest approach to achieving the MDGs.

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<sup>37</sup> UNDP 2003. op.cit. (page 28)



References to the “human rights” approach appear increasingly in the literature. For example, in an editorial in the *Bulletin of the World Health Organization*<sup>38</sup> in 2003, Adetokunbo O. Lucas argued that the code on health rights should make it easy for citizens to assess how well their national health systems are performing.

The human rights approach to achieving the MDGs was presented and discussed at the UNESCO Bergen Consultation of June 2003.<sup>39</sup> The Consultation concluded with the following two recommendations to UNESCO:

- To concentrate its work on clarifying the legal and political implications of using the human rights violation framework to achieve poverty abolition, and what this means in terms of legal and political actions.
- To work closely with other bodies and organizations, within and outside the UN system, to minimize duplication of projects.

### 3. Both horizontal and vertical approaches are needed to reach the MDGs

Proponents of “vertical approaches” argue that emergencies require exceptional actions. The most obvious example is HIV/AIDS. In the words of WHO, “unless the global health community responds now to the need for AIDS treatment in the same way it responds to other emergencies, with exceptional action, the fight against this most powerful enemy will not be won. The days of a ‘business as usual’ approach to AIDS are over.”<sup>40</sup>

Proponents of “horizontal approaches” have just as strong a position, arguing that the fight for better health must be fought on a broad

front through better health services, as the same facilities and personnel are required to care for a whole range of diseases and conditions. They go further by saying that vertical approaches may at times divert resources in favour of one disease and one section of the population at the expense of the other diseases and the rest of the population.

In fact, both approaches are needed to achieve the MDGs, much in the same way that both warp and weft are needed to make a fabric. A joint use of vertical and horizontal approaches will lead to better overall results than either approach alone, provided that “vertical approaches” are used to actually strengthen health services and to support a broad horizontal build-up of the capacities of health systems.<sup>41</sup>

A good example is provided by the Haitian model for HIV prevention and care, which can be considered as a vertical approach, but which includes a number of horizontal dimensions as follows:<sup>42</sup>

- a complete range of prevention services and practices to reduce HIV transmission in all settings;
- improvements in women’s health, including access to family planning and safe childbirth;
- improved TB case-finding and treatment;
- diagnosis and treatment of all sexually transmitted diseases.

The complementarity of vertical and horizontal approaches can be illustrated by the matrix presented in Insert 1.4.

<sup>38</sup> *Bulletin of the World Health Organization*, 2003 (81/1).

<sup>39</sup> International Social Science Council, Comparative Research Programme on Poverty (CROP), Consultation on *Abolishing Poverty Through the International Human Rights Framework: Towards an Integrated Strategy for the Social and Human Sciences*, Bergen, 5-6 June 2003 (organized by CROP for UNESCO).

<sup>40</sup> WHO, 2003, op. cit. (page 53)

<sup>41</sup> Ibid. (page 105)

<sup>42</sup> Ibid. (page 51)

## Insert 1.4

### *Complementarity of vertical and horizontal approaches to health care*

	Global Polio Eradication	Global Fund	“3 by 5” Initiative	GAVI	Public-private partnerships	Other vertical approaches
Health systems strengthening						
Poverty Reduction Strategy Papers		Active complementarity between the vertical and horizontal approaches means that each approach consciously feeds its information and experiences into the others, avoids weakening them by taking away their human or financial resources, takes into account their needs and, more generally, makes a conscious effort to situate its activities in the context of the overall needs and functioning of the global health care system.				
Follow-up to Report of the Commission on Macroeconomics and Health						
Human rights approach						

Source: Global Forum for Health Research

For optimal results at the country level, vertical and horizontal programmes must be managed jointly (along the lines illustrated in Insert 1.4) and budget allocations to each programme made on the basis of their

estimated impact on the health of the population, with particular attention to the specific risks inherent in both vertical and horizontal programmes and efforts to maximize their synergies.

## Section 5

### Role of health research in reaching the MDGs

#### 1. Definition

According to the OECD and UNESCO, research comprises creative work undertaken on a systematic basis in order to increase the stock of knowledge and the use of this knowledge to devise new

applications. Thus health research is the systematic generation of new knowledge in the field of medical, natural, social, economic and behavioural sciences and its use to improve the health of individuals or groups.

Based on this definition and in the view of the Global Forum for Health Research, *health research does not end until people's health is improved in a measurable way.*

## 2. Research needed to achieve the MDGs

*(a) Our present stock of knowledge is insufficient to reach the MDGs or reach them efficiently*

As discussed above, in view of our present stock of knowledge in the fields of medical, natural, social, economic and behavioural sciences, foreign aid would have to double and domestic investments in health be increased considerably in order to reach the MDGs by 2015. However, it is possible that – whatever the level of foreign and domestic investments – the MDGs may not be reached at all, or not reached efficiently, due to our insufficient knowledge. In this respect, it is useful to distinguish between two types of gaps in our present knowledge:

- Type 1 gap: the knowledge in the field of medical, natural, social, economic and behavioural sciences exists but is not applied in a systematic, efficient or effective way to reach the MDGs. To fill this type 1 gap, implementation and operational research is needed.
- Type 2 gap: the knowledge in the above-mentioned fields does not exist and new inventions are needed. To fill this type 2 gap, new research is needed.<sup>43</sup>

In the words of Richard Feachem,<sup>44</sup> “we will not win the war on poverty, we will not reach the MDGs by 2015, and we will not succeed at the Global Fund in fighting AIDS, TB and malaria without a quantum change in health research, a reorientation of research towards the key health priorities in the world

and towards the critical challenge of implementation – overcoming absorptive constraints to make use of the new resources available to improve global health.”

*(b) Opinions expressed by keynote speakers at Forum 7*

In her keynote speech at Forum 7 of the Global Forum for Health Research, Nancy Birdsall<sup>45</sup> drew attention to both type 1 and type 2 gaps in research in the following way: “On the one hand, the successes of the past owe much to tremendous advances in research and new technologies and their relatively widespread deployment, including to the poor, in developing countries. Similarly, future challenges can and will be met in part by the deployment of new biomedical and other technologies. Vaccines against AIDS and malaria would make a huge difference, as have past technological breakthroughs in combating polio and smallpox.

On the other hand, what is striking is that the full benefits of existing technologies are far from being fully realized. Despite the availability of medicines that are seemingly easy and cheap to deliver, high levels of child mortality persist, especially among the poor, and easily preventable chronic diseases are on the rise. In the case of HIV/AIDS, financial constraints have been important but are clearly not the only barrier to making universally available antiretrovirals to manage the disease. In fact, the challenges that bear down on us now reflect in large part our inability to *deploy* more fully and effectively existing technologies, especially in developing countries. The bottom line is that these and any new technologies in the end rely for their

<sup>43</sup> In reality, the frontier between the two types of research is often blurred in the continuum between basic, applied, operational and implementation research in the field of medical, natural, social, economic and behavioural sciences.

<sup>44</sup> Message from Richard Feachem (Chair of the Foundation Council of the Global Forum for Health Research and Executive Director of the Global Fund to Fight AIDS, TB and Malaria) to the participants in Forum 7, Geneva, December 2003.

<sup>45</sup> Birdsall. *op. cit.*

full exploitation on health systems, i.e. on policies and politics, on people (as providers and consumers), on infrastructure and on the adequate motivating, financing and technical support for all of these soft inputs”.

In the second keynote address delivered at Forum 7, Carlos Morel<sup>46</sup> emphasized the same points regarding the crucial importance of research (both type 1 and type 2) to reach the MDGs:

“Better use of existing health interventions – e.g. impregnated bednets and drugs for malaria, DOTS for tuberculosis, and condoms and antiretrovirals for HIV/AIDS – are indeed critical for achieving the MDGs. Improving access of afflicted populations to these tools must receive high priority from donors, industry and endemic countries. Equally important, and economically sound, however, is to simultaneously invest in the development of new, improved and equitably affordable interventions. The MDG goals will only be achieved if new tools become available to replace those that will inevitably fail.”

He drew attention to the crucial dilemma of the 1950s over whether to invest in more and better iron lungs to treat the effects of polio or to invest in a polio vaccine to prevent it. The issue was resolved on 12 April 1955, when Salk’s polio vaccine was declared to be safe and effective. A similar dilemma of treatment versus prevention existed in the fight against smallpox prior to the discovery of the smallpox vaccine.

*(c) Research needed to reach the MDGs*

- In relation to MDG 1 concerning poverty

reduction (often seen as the overarching goal), detailed operational research is needed into the risk-taking behaviour of poor populations, preventive actions and the best mechanisms for ensuring access for the poorest sections of the population to health goods and services. In addition, as shown by analytical work carried out by the Global Forum for Health Research,<sup>47</sup> little is known about the impact of macroeconomic policies on the health of the poor. There is also limited knowledge on the most efficient and effective ways to promote health among the poor through educational or environmental measures. Furthermore, few countries have the information needed to identify the policies and actions with the greatest potential impact on people’s health for the available resources. Health investments are made on the basis of limited information and habit rather than effectiveness in combating poverty, thus sharply decreasing the rates of return which could be obtained from investments in health. To ensure the high rates of return on investments in health mentioned in Section 1 above and in many publications,<sup>48,49,50</sup> detailed and disaggregated investigations are needed at country level.

- Nutrition research (focusing on maternal and child nutrition, micronutrient deficiencies and environmental factors) is vital to help inform policies and programmes which target poor and vulnerable groups (cf. MDGs 1, 4, 5 and 7).
- There is overwhelming evidence that links attendance and performance in education with both the health status and the wealth

<sup>46</sup> Morel C. Health and Health Research: Essential Requirements for Achieving the Millennium Development Goals and Economic Development, Paper presented at Forum 7, Geneva, December 2003. Carlos Morel was then Director, UNDP/UNICEF/World Bank/WHO Special Programme for Research and Training in Tropical Diseases (TDR), Geneva.

<sup>47</sup> Global Forum for Health Research. *The 10/90 Report on Health Research 2001-2002*, Geneva, 2002.

<sup>48</sup> Commission on Economics and Health. *op. cit.*

<sup>49</sup> Brundtland. *op. cit.*

<sup>50</sup> World Bank 1993. *op. cit.* and Onchocerciasis websites at WHO and World Bank.

status of learners and their families. At its most extreme, the impact of ill health on schooling is demonstrated by the HIV/AIDS epidemic in Africa, which is threatening the demand, supply and quality of education.<sup>51</sup> Further research is needed into identifying and ameliorating the health and nutrition, sanitation and environmental factors that limit school attendance and performance if all boys and girls of school age are to be able to complete a full course of primary schooling by 2015 (cf. MDGs 1, 2, 3, 6 and 7).

- While the specific indicators under MDG 3 relate to education, employment and gender representation in parliament, it is well understood that discrimination against women pervades every aspect of society. The disadvantages that women face in each field are compounded by the gendered roles they are assigned and by their poorer health status in most developing countries. Women and girls are the ones most affected by gender aspects of health care (not only in reproductive health but also in their susceptibility to diseases as well as in the diagnosis, treatment and outcomes of diseases).<sup>52</sup> Research has been undertaken in recent years into the linkages between gender, poverty and health, but much more needs to be learned about how to alter gender biases and achieve equality and empowerment, especially in the most resource-poor settings (cf. MDGs 1, 3, 6 and 7).
- Health research is needed to identify new tools (e.g. drugs, diagnostics, delivery systems, health services, health promotion and disease prevention campaigns – relevant in particular to MDGs 4, 5 and 6) that are appropriate to the economic and social circumstances in the poorest countries and

communities; and to improve knowledge of how best to deliver them and ensure access and their optimum use in local conditions.

- There are major gaps in knowledge about the health impact of changing patterns in the use of land and environmental resources, and a need for research into more effective ways to implement water, sanitation and housing programmes for the poorest sections of society (cf. Goals 1 and 7).
- An essential component of the global partnership for development must be the evolution of better systems for creating global public goods, including in the health field. Recent examples of public-private partnerships for the development of drugs for neglected diseases demonstrate the potential for breaking the logjam in areas such as malaria and TB. The negative consequences of unfair systems of trade and finance on poverty, health and development need to be further delineated. Research into the health impact of policies relating to the Agreement on Trade-Related Intellectual Property Rights (TRIPS), labour mobility and other aspects of globalization will be needed to inform the evolving global partnership (cf. Goals 1, 6 and 8).

Without determined and focused research efforts in the fields indicated above, the vicious circle of poverty and ill health which is targeted by the MDGs will not be broken. This perspective will inform the deliberations at the World Summit on Health Research and the associated annual meeting of the Global Forum for Health Research (Forum 8) which will be held in Mexico on 16-20 November 2004. It will also contribute directly to the evolving programmes of the Global Forum, its initiatives and partners, helping to shape

<sup>51</sup> Matlin SA (ed.). *Commonwealth Education Partnerships 2003*, London, HMSO, 2002.

<sup>52</sup> Doyal L. *Sex, gender and the 10/90 gap in health research*, Geneva, Global Forum for Health Research, 2002.

priorities for action in the years ahead.

### 3. Today's dilemma: the 10/90 gap in health research

Although global health research is crucial to efforts to reach the MDGs, it suffers from a severe misallocation of resources in that less than 10% of funding for health research worldwide, by both the public and private sectors, is directed to 90% of the world's health problems. This imbalance in health research funding – known as “the 10/90 gap” – is described in chapter 5.

There are numerous reasons for this imbalance in research funding:

- The failure of the public sector in high-income countries to allocate health research funding on the basis of a systematic analysis of priorities, taking into account both national and international health issues.
- The limited capacity for research in the public sector in many low- and middle-income countries due to limited funding for research in general and lack of appropriate policies and organization.
- The lack of adequate commercial incentives for the private sector in all countries to undertake research on neglected diseases and determinants of disease.

The main consequence of the 10/90 gap in health research is that the vast majority of the world's population, particularly the poor, benefit little, if at all, from health research. More specifically, the consequences can be summarized as follows:

- The state of health of the majority of the world's population is far worse than it would be with the benefits of health research, with direct consequences not only for the individuals and their families, but

for the overall growth and development of their country.

- For the absolute poor (at least 20% of the world's population) who are trapped in the vicious circle of ill health and poverty, the 10/90 gap in health research means that the hope of breaking out of that circle is slimmer than it would otherwise be.
- Finally, for the world as a whole, this results in lower growth and development and increased global insecurity.

### 4. Proposals to increase financial resources for health research and correct the 10/90 gap

(a) *Proposal by the Commission on Health Research for Development*<sup>53</sup>

The Commission recommended that governments in developing countries invest 2% of national health expenditures for research and capacity building, and that development agencies earmark at least 5% of their financing in the health sector for the same purposes.

(b) *Proposal by the Commission on Macroeconomics and Health*<sup>54</sup>

To help correct the 10/90 gap, the Commission on Macroeconomics and Health strongly advocated the following measures:

- the creation of a Global Health Research Fund which would channel research funding of about US\$ 1.5 billion per year to research on neglected diseases and the most important risk factors;
- an additional US\$ 1.5 billion per year in health research to be channelled through existing research institutions such as the Special Programmes for Research and Training in Tropical Diseases (TDR) and Reproductive Health (HRP) at WHO, the Global Forum for Health Research and others;

<sup>53</sup> Commission on Health Research for Development. *Health Research: Essential Link to Equity in Development*, New York, 1990.

<sup>54</sup> Commission on Macroeconomics and Health. *op. cit.* (page 19).

- an additional annual investment of US\$ 1 billion by 2007 and US\$ 2 billion by 2015 in favour of international agencies such as the World Bank and WHO to finance other global public goods such as disease surveillance at the international level, data collection and analysis of global health trends (e.g. burden of disease), analysis and dissemination of international best practices in disease control and health systems.
- capacity strengthening of African institutions through sustained funding for human resources, physical infrastructure, information technologies and networks;
- promotion of research in African countries;
- support for effective linkages between research institutions, health systems and civil society.

*(c) Exploration of health research funding options*

In a paper presented at Forum 6 in November 2002, Gerald Keusch<sup>55</sup> explored the pros and cons of various options for international health research funding, including the creation of a common funding pool (such as the Global Health Research Fund proposed by the Commission on Macroeconomics and Health), the creation of a common research network, the creation of a totally new institution, and the creation of a “virtual” international institute of health research.

*(d) Discussions under the G8 umbrella*

At the G8 meeting of June 2002 in Canada, discussions among the Personal Representatives for Africa of the G8 Member Countries drew attention to the fact that the imbalance between research needs and resources is most pronounced in Africa. They examined the possibility of creating an African health research fund amounting to US\$ 500 million per year to meet the health goals of the New Partnership for African Development (NEPAD) and the health-related MDGs, based on the following strategies:

*(e) Criteria for financing mechanisms for health research in developing countries*

In a presentation at Forum 7 in December 2003, Andrew Kitua<sup>56</sup> listed the main criteria which have to be fulfilled in order to reach the “primary objective of any financial support for health research in developing countries, i.e. to enable the target country to develop and achieve adequate capacities for solving its own health problems.” His proposed criteria are the following:

- At the level of engagement: type of commitment made by both the provider and the receiver; capacity building in terms of personnel, infrastructure and equipment; type of partnership; and amount and process of funding.
- At the level of action: involvement of public and private stakeholders; monitoring mechanism; ownership of the implementation process; extent of capacity building; amount of funds actually used in the recipient country.
- At the level of deliverables: evidence of an internal and external evaluation process; evidence of capacity building; new knowledge generated and applied; new partnerships being developed; and transfer of technology.

<sup>55</sup> Keusch G. Director, Fogarty International Center. Health Research and Development: What issues after the 2001 Commission on Macroeconomics and Health. Paper presented at Forum 6, Arusha, November 2002.

<sup>56</sup> Kitua A. Director General, National Institute for Medical Research, Tanzania. Challenging Approaches for Financing Health Research in Developing Countries. Paper presented at Forum 7, Geneva, December 2003.

## Section 6

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### Conclusions

The message to ministers of finance can be summarized as follows:

- According to a survey commissioned by the United Nations in preparation of the Millennium Summit in September 2000, citizens from countries around the world overwhelmingly ranked health as their “number one” desire.
- For economies as a whole, the rates of return on investments in health and health research are often a *multiple* of the rates of return on public investments in other sectors of the economy (see for example the rates of return on investments in the fight against smallpox, polio, onchocerciasis, malaria, TB, oral rehydration therapy, pneumonia, measles and HIV prevention). This is not surprising, as the benefits of better health for an economy are enormous and appear in the form of increased production, a more productive labour force, greater competitiveness in the economy, financially more solid enterprises, lower unemployment, increased ability to attract foreign investments, higher tax revenues and a sounder public finance situation, giving the government more resources to finance activities that are in the public interest.
- There is therefore both a strong political and economic interest for governments to invest more in health and health research, as recommended by the Commission on Macroeconomics and Health.
- Fortunately, the concept of development has evolved considerably over recent decades, from a focus on physical capital in the 1960s and 1970s, to a greater focus on human capital in the 1980s and 1990s, and finally to a current focus on efforts to meet the MDGs, which focus entirely on poverty, health, education, the environment and development partnerships. In the first years of the new millennium, a distinction is finally being made between tools (economic growth) and ultimate objectives (human development and human security).
- To reach the MDGs, a large number of so-called “vertical initiatives” (such as the Global Polio Eradication Initiative, the Global Fund, the “3 by 5” Initiative, the RBM Partnership and GAVI) and “horizontal initiatives” (such as the revival of the primary health care movement, PRSPs, the follow-up actions to the Report of the Commission on Macroeconomics and Health, and the human rights movement) have been launched or accelerated. In spite of their multiplicity, which is sometimes confusing to some actors, these developments are extremely positive and illustrate well the shift from physical to human capital in the pursuit of the MDGs. To avoid the risk of duplication and optimize the results of these vertical and horizontal initiatives, it is important that: (a) they be managed jointly at country level with a view to maximizing their synergies and (b) budget allocations to each programme be made on the basis of their estimated impact on people’s health.
- Finally, our present stock of knowledge, both at the global and national levels, is insufficient to reach the MDGs or to reach



them efficiently by 2015. Thus it is crucial for governments to increase their health research budgets to at least 2% of national health expenditures (as recommended by the 1990 Commission on Health Research

for Development) and for donor agencies to increase their contribution to the correction of the 10/90 gap in health research.

## Chapter 2

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*An overview of the  
Global Forum for Health Research*

For a summary of this chapter, see the Executive Summary, page xv.

# Overview

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## 1. The problem

Health research is essential to improve the design of health interventions, policies and service delivery. Every year more than US\$70 billion is spent worldwide on health research and development by the public and private sectors. But only about 10% of this is used for research into 90% of the world's health problems. This is what is called “the 10/90 gap”.

## 2. Central objective

The Global Forum's central objective is to help correct the 10/90 gap by focusing research efforts on diseases representing the heaviest burden on the world's health and facilitating collaboration between partners in both the public and private sectors. A reallocation of one per cent of research spending would provide US\$700 million for priority research.

## 3. Our partners

The Global Forum believes that solutions to current health challenges will depend on the strength of the partnerships created between members of the following constituencies, which are all represented in the Global Forum:

- governments (policy-makers)
- multilateral organizations
- bilateral aid donors
- international foundations
- national and international civil society organizations (CSOs) and community organizations
- women's organizations
- research-oriented institutions and universities
- private-sector companies
- the media.

## 4. The nature of the Global Forum

In summary, the Global Forum for Health Research (and other networks with similar characteristics) can play an important role in the overall governance of health research, contributing to the integration of the whole. Its specific nature includes the following characteristics:

- a network of networks, linking the efforts of very diverse institutions which have an impact in reducing the 10/90 gap
- catalyst (no substitute for the efforts of other institutions)
- promoter of participation in joint efforts
- informal contact point between partners
- non-bureaucratic decision-making mechanism: response to opportunities; seed money.

## 5. Our strategies

### (a) The annual meeting (Forum)

Throughout the year and especially at its annual meeting, the Global Forum acts as a marketplace where problems can be examined by a variety of policy-makers and researchers. Presentations at the Forum address the latest thinking on the 10/90 gap and act as a catalyst for action during the coming year.

- Forum 4 was held in Bangkok in October 2000, as part of the International Conference on Health Research for Development.
- Forum 5 took place in Geneva in October 2001.
- Forum 6 is scheduled to take place in Arusha, Tanzania, on 12-15 November 2002.

### **(b) Priority-setting methodologies**

Selecting research priorities is as important as conducting research itself. The Global Forum aims to stimulate the discussion of methodologies to help set priorities in health research. The ultimate aim of the discussions is to better relate the resources invested into various areas of health research to the magnitude of the disease burden and its determinants, resulting in a measurement of the 10/90 gap.

In particular, the Global Forum stimulates discussion and networking in the following areas:

- priority-setting methodologies (including a “combined approach matrix”)
- resource flows in health research
- burden of disease and health determinants
- cost-effectiveness of health interventions.

### **(c) Support to networks**

The Global Forum supports networks in health research bringing together a wide range of partners in a concerted effort to find solutions to priority health problems, thus attracting new financing to these areas. Current examples include:

- Alliance for Health Policy and Systems Research: the identified priorities for the Alliance are the mapping of health systems research, identification of gaps, development of tools and methodologies, and capacity building.
- Initiative on Cardiovascular Health Research in Developing Countries: the research priorities of this initiative are assessment of existing capacity, access to knowledge, surveillance system, etiological research, health promotion, hypertension, tobacco and capacity development.
- Child Health and Nutrition Research Initiative: the objectives of this initiative include the definition of disease burden,

the identification of priority research areas and the dissemination of information.

- Medicines for Malaria Venture (one of the five strategies of the Roll Back Malaria Programme led by WHO) is aimed at R&D for the discovery, development and marketing of new antimalarials.
- Initiative on Public-Private Partnerships for Health (IPPPH): the priorities of this initiative are the analysis of existing public-private partnerships and the promotion of effective new partnerships.
- Research initiatives in the area of tuberculosis research, such as the Global Alliance for TB Drug Development.
- Sexual Violence against Women: the objective of this initiative is to develop a framework for measuring the magnitude of the problem and developing a better understanding of its determinants and interventions.

A detailed review of the objectives, strategies, activities over the past two years and expected results over the coming two years for each of the initiatives listed above is presented in Chapter 7.

At its annual meeting, the Global Forum welcomes presentations and discussions of efforts undertaken by all networks active in the correction of the 10/90 gap. It is ready to study various other forms of support based on proposals from its partners. Discussions are under way, for example, in the field of road traffic accidents, mental health and neurological disorders, and child abuse.

## **6. Operations and financing**

- The Global Forum for Health Research is an independent international foundation established in 1998. It is managed by a 20-member Foundation Council, assisted by a Strategic and Technical Advisory Committee.
- The small Secretariat is based in Geneva.

- The Global Forum is supported financially by donations from the Rockefeller Foundation, World Bank, World Health Organization and the governments of Canada, the Netherlands, Norway, Sweden and Switzerland. In addition, individual networks supported by the Global Forum receive funding from the Bill and Melinda Gates Foundation, the Institute of Medicine of the US Academy of Sciences, the Department for International Development of the United Kingdom, and others.
- Assessing progress in the correction of the 10/90 gap is an integral part of the Global Forum's work.

### 7. Perspectives on the 10/90 gap

- Correcting the 10/90 gap constitutes a major contribution to growth, development and equity.
- Correcting the 10/90 gap is possible: it

requires the individual and concerted efforts of thousands of institutions.

- The Global Forum works as a catalyst to spur such efforts.
- Between 1997 and 2001, the Global Forum :
  - held five annual Forum meetings to review past achievements and define future joint actions in helping to correct the 10/90 gap;
  - supported various research initiatives in priority areas;
  - stimulated discussion and networking in the field of priority-setting methodologies.
- Future progress on the road to correcting the 10/90 gap depends on both individual efforts and real and effective partnerships.
- In each research area, the Global Forum emphasizes research capacity strengthening and gender issues.

## Insert 2.1

### Selected documents and publications

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#### Global Forum for Health Research

*Monitoring financial flows for health research\** (October 2001)

*Interventions against antimicrobial resistance: a review of the literature and exploration of modelling cost-effectiveness* by Richard D. Smith *et al.* (October 2001)

2000 Operations Report and Audited Financial Statements (April 2001)

Workplan and Budget, 2001-2002 (December 2000)

*The 10/90 Report on Health Research 2000\** (April 2000)

*Economic analysis of malaria control in sub-Saharan Africa* by Catherine Goodman, Paul Coleman & Anne Mills (March 2000)

*The 10/90 Report on Health Research 1999\** (March 1999)

#### Supported networks

*Child Health Research: a foundation for improving child health.* Publication of WHO/CAH and the Global Forum for Health Research/Child Health and Nutrition Research Initiative (March 2002)

*Annual Report 2000: Medicines for Malaria Venture* (May 2001)

see also [www.mmv.org](http://www.mmv.org)

*Alliance for Health Policy and Systems Research: Report 2000 & Workplan 2001-2003* (February 2001)

see also [www.alliance-hpsr.org](http://www.alliance-hpsr.org)

*Cardiovascular Health in Developing Countries: Workplan and Budget 2000-2003* (December 2000)

see also [www.ichealth.org](http://www.ichealth.org)

*Eliminating sexual violence against women: towards a global initiative.* Report on the Consultation on Sexual Violence Against Women, The University of Melbourne, 18-20 May 2000 (September 2000)

*Sexual violence against women: a working bibliography.* Consultation on Sexual Violence Against Women, The University of Melbourne, 18-20 May 2000. CD Rom (September 2000)

*Creating global markets for neglected drugs and vaccines: a challenge for public-private partnerships.* Consensus statement. Carmel Valley, California, February 2000.

see also [www.ippph.org](http://www.ippph.org)

For the work of the Global Alliance for TB Drug Development, see also [www.tb Alliance.org](http://www.tb Alliance.org)

#### Work specifically supported by the Global Forum

*Small Arms and Global Health*, WHO Contribution to the UN Conference on Illicit Trade in Small Arms and Light Weapons 9-20 July 2001, WHO, Geneva, 2001

*Neurological, Psychiatric and Development Disorders: Meeting the Challenge in the Developing World*, Institute of Medicine, National Academy Press, USA, 2001

*Gendered Health Research for Development: A Vital Contribution to Health Equity*, Latin American and Caribbean Women's Health Network (LACWHN), 2000

*Report of the Consultation on Child Abuse Prevention 29-31 March 1999*, WHO, Geneva, 1999

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\*available on the website [www.globalforumhealth.org](http://www.globalforumhealth.org)

# Chapter 3

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## *Correcting the 10/90 gap: from the 1990 Commission to the 2004 Mexico Summit*

### *Section 1*

*The nineties: the beginning of a revolution in health research*

### *Section 2*

*Implementation of the recommendations of the 1990 Commission on Health Research for Development*

### *Section 3*

*Implementation of the recommendations of the 1996 Ad Hoc Committee on Health Research*

### *Section 4*

*Implementation of the recommendations of the 2000 Bangkok Action Plan*

### *Section 5*

*Summary of the recommendations made since 1990, main results and challenges for the Mexico Summit, Forum 8 and beyond*



## Section 1

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### The nineties: the beginning of a revolution in health research

The 10/90 gap in health research was first identified by the Commission on Health Research for Development in its 1990 Report, which made far-reaching recommendations for its correction.

These first efforts were followed by the 1996 Report of the Ad Hoc Committee on Health Research which made 17 recommendations in the fields of infectious diseases, new and re-emerging microbes, NCDs, health policies and systems, and institutional arrangements.

In October 2000, the first International Conference on Health Research for Development was convened in Bangkok. The Conference adopted the Bangkok Action Plan which made important recommendations for the correction of the 10/90 gap at the global, regional and national levels.

In addition to the three events singled out above as the main events of the 1990s which led to a reorientation of health research, many other organizations, events, conferences and reports have contributed much to an increase in global awareness of the misallocation of resources in the field of health research.

As a result, the nineties can be considered as the beginning of a revolution in health

research. In this chapter, an attempt is made to identify examples of actions taken by the international community to follow up on the recommendations made by the 1990 Commission, the 1996 Ad Hoc Committee and the 2000 Bangkok Action Plan.

However, the examples are presented here with the following caveats:

- These are only examples, which are chosen to illustrate the emergence during the 1990s of a major international movement for the correction of the 10/90 gap. Lack of space prevents the inclusion of many others, particularly at the national and local levels, which are less widely known but are also contributing in a major way to the movement for correction of the 10/90 gap.
- Some of the examples described were a response to the Report of the 1990 Commission, the 1996 Ad Hoc Committee or the Bangkok Action Plan, while others were only influenced or boosted by them, or would have occurred in any case. As a result, the examples illustrate the results of this movement as a whole rather than focusing exclusively on the outcome of the three main events.

## Section 2

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### Implementation of the recommendations of the 1990 Commission on Health Research for Development for correcting the 10/90 gap

The recommendations made by the 1990 Commission on Health Research for Development<sup>1</sup> are summarized in Insert 3.1 together with some of the main actions which have been taken since 1990 to implement them.

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<sup>1</sup> Commission on Health Research for Development. *Health Research: Essential Link to Equity in Development*, 1990; and Task Force on Health Research for Development. *Essential National Health Research: A Strategy for Action in Health and Human Development*, 1991.

## Insert 3.1

### Implementation of the recommendations of the 1990 Commission on Health Research for Development

Fields of action	Recommendations	Implementation (as of December 2003)
<p>1. Essential National Health Research</p>	<p><b>R1: Essential National Health Research (ENHR)</b> To help correct the 10/90 gap, each developing country should build its research capacity and conduct Essential National Health Research.</p> <p><b>R2: Two principal objectives of ENHR: (a) country-specific research; (b) international research on global health problems which are of high priority for the country in question.</b> At present, the most urgent need in virtually every country is for a rapid enlargement of capacity for country-specific research.</p> <p><b>R3: To build research capacity for ENHR, a country will need:</b></p> <ul style="list-style-type: none"> <li>To invest in individuals and institutions, particularly in epidemiology, social sciences, and management research.</li> <li>To set national priorities for research.</li> <li>To build career paths to attract able researchers.</li> <li>To develop reliable links between researchers and users.</li> <li>To invest at least 2% of national health expenditures in ENHR.</li> </ul>	<p><b>R1, 2, 3: Examples of actions</b></p> <ul style="list-style-type: none"> <li>Since 1990, the concept of ENHR has been disseminated and promoted by COHRED and about 35 countries have developed an ENHR programme (such as Guinea, Indonesia, Nicaragua, Philippines, South Africa, Tanzania and Uganda).</li> <li>Regional Health Research Forums have been launched in Asia and Africa, while Latin America and the Caribbean have witnessed important networking efforts in health research.</li> <li>In a limited number of countries, a National Health Research Forum has been created (e.g. Tanzania).</li> </ul> <p><b>Weaknesses</b></p> <ul style="list-style-type: none"> <li>The research capacity in many developing countries remains very limited and the research budget remains only a small fraction of the recommended 2% of national health expenditures.</li> <li>Priority setting in research taking all dimensions of health at country and global levels is still very limited.</li> <li>Links between international research and ENHR are far from systematic.</li> </ul>
<p>2. International Partnerships</p>	<p><b>R4: International research networks</b> Promote the steady growth of collaborative international research networks as the principal means for mobilizing scientific talent to attack common problems.</p> <p><b>R5: Support international networks in the following fields:</b></p> <ul style="list-style-type: none"> <li>Tropical diseases (TDR) and reproductive health (HRP).</li> <li>Diarrhoeal diseases (Centre for Health and Population Studies).</li> <li>Acute respiratory diseases.</li> <li>Tuberculosis.</li> <li>Micronutrient deficiencies: in particular vitamin A, iron, iodine.</li> <li>Diabetes, coronary heart disease and hypertension.</li> <li>Injuries, STIs, substance abuse.</li> <li>Mental health.</li> <li>Environmental and occupational health.</li> </ul> <p><b>R6: Support to develop health research capacity in countries</b></p> <ul style="list-style-type: none"> <li>Coordination of international programmes at country level.</li> <li>Creation of a facilitation unit (financed internationally and by developing countries) to develop health research capacity.</li> <li>Annual meetings of scientists interested in country-specific health research.</li> <li>International awards for country-specific health research.</li> </ul>	<p><b>R4, 5, 6: Examples of actions</b></p> <ul style="list-style-type: none"> <li>A number of collaborative international research networks and programmes were created (or substantially developed) in the early 1990s in key areas of health and health research such as the Children's Vaccine Initiative in 1990, the Micronutrient Initiative in 1992, the Infectious Disease Research Institute in 1993, the UNFPA Contraceptives Access Project in 1994 and the Consortium for Industrial Collaboration in Contraceptive Research (CICCR).</li> <li>The movement accelerated in the latter part of the 1990s under the further push of the World Bank <i>World Development Report 1993</i>, the Ad Hoc Committee on Health Research (1996) and the WHO Advisory Committee on Health Research (1997) According to an analysis carried out by the Initiative on Public-Private Partnerships for Health (<a href="http://www.ippph.org">www.ippph.org</a>), more than 70 partnerships and networks were created between 1995 and 2003 (as compared to about a dozen in the 1980s), particularly in the fields of HIV/AIDS, TB, malaria, leishmaniasis, schistosomiasis, pneumococcal diseases, STIs, dengue, meningitis, human trypanosomiasis, nutrition, road traffic injuries, health policies and systems, CVDs, cancer and mental health.</li> </ul>

## Insert 3.1 (continued)

### Implementation of the recommendations of the 1990 Commission on Health Research for Development

Fields of action	Recommendations	Implementation (as of December 2003)
2. International Partnerships (continued)	<p><b>R7: Recommendation to industrialized countries</b></p> <ul style="list-style-type: none"> <li>• Provide career opportunities for young scientists from the South.</li> <li>• Promote the strengthening of schools of public health, medical schools and research institutions in the South.</li> <li>• Provide more aid resources for health research in the South.</li> </ul>	<p><b>R7: Examples of actions and limitations</b></p> <ul style="list-style-type: none"> <li>• Many projects co-financed by donor agencies include training opportunities for scientists from the South or collaboration between schools of public health and research institutions in the North and South. However, it does not appear that these efforts have been systematic, nor that an overall view exists of such efforts in capacity building. Such a platform would be needed to make a systematic move in the field of research capacity strengthening.</li> </ul>
3. Mobilizing Research Funding	<p><b>R8: Substantial increases in funding for health research</b></p> <ul style="list-style-type: none"> <li>• Developing countries: should invest at least 2% of national health expenditures in research and research capacity building.</li> <li>• Aid agencies: should invest at least 5% of their health budget in research and research capacity building.</li> </ul> <p><b>R9: Increase the quality and quantity of research and research capacity strengthening efforts</b></p> <ul style="list-style-type: none"> <li>• Much longer time horizon for research capacity building.</li> <li>• Innovative financing strategies (debt for health research, funding pools, funding intermediaries, etc.).</li> <li>• Foundations and special research agencies (e.g. International Development Research Centre, Swedish Agency for Research Cooperation with Developing Countries) should continue their pioneering role and mobilize broader support.</li> </ul>	<p><b>R8, 9: Examples of actions and limitations</b></p> <ul style="list-style-type: none"> <li>• Based on a study undertaken by the Global Forum for Health Research and its partners,<sup>2</sup> only Brazil and Cuba approached the 2% mark. Most other countries invest only a fraction of the 2% recommended. See also chapter 5 on “Progress in measuring the 10/90 gap”.</li> <li>• Only limited information exists on investments in health research financed by aid agencies as a proportion of their health budget. See also chapter 5 on “Progress in measuring the 10/90 gap”.</li> <li>• Substantial efforts were undertaken in the 1990s in the field of research capacity building, but no overall view or synthesis of these efforts exists at this stage. See also chapter 7 on “Research capacity strengthening”.</li> <li>• At country level, some innovative financing strategies have been developed, for example in Brazil. At the global level, in 2001 the Commission on Macroeconomics and Health proposed the creation of a Global Health Research Fund. Other proposals and options are under study, such as the creation of a “virtual fund”.</li> </ul>
4. Forum for Review and Advocacy	<p><b>R10: Establish an international independent mechanism to monitor progress in health research. In particular:</b></p> <ul style="list-style-type: none"> <li>• Promote when needed financial and technical support for research on health problems of developing countries.</li> <li>• Be sufficiently independent to be objective in recommendations.</li> <li>• Mandate should not be to operate research programmes but to promote action by others.</li> </ul>	<p><b>R10: Examples of actions</b></p> <ul style="list-style-type: none"> <li>• INCLen was created in 1980 (and became INCLen Trust in 2000) to disseminate knowledge and tools for the most efficient and effective prevention and treatment strategies. Today: 64 institutions in 26 countries.</li> <li>• COHRED was created in 1993 to advocate for the ENHR strategy and provide technical assistance on the strategic elements of ENHR: advocacy, ENHR mechanism, priority setting, capacity strengthening, networking, financing and evaluation. See also chapter 9, section 15 on COHRED.</li> <li>• The Global Forum for Health Research was created in 1998 with the specific mandate to “help correct the 10/90 gap”. See also Chapter 2.</li> </ul>

Source: Global Forum for Health Research

<sup>2</sup> Global Forum for Health Research. *Monitoring Financial Flows for Health Research*; October 2001.

## Section 3

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### Implementation of the recommendations of the 1996 Ad Hoc Committee on Health Research for correcting the 10/90 gap

The recommendations made by the 1996 Ad Hoc Committee on Health Research<sup>3</sup> for correcting the 10/90 gap are summarized in

Insert 3.2 together with some of the main actions which have been taken since 1996 to implement them.

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<sup>3</sup> Ad Hoc Committee on Health Research Relating to Future Intervention Options. *Investing in Health Research and Development*, WHO, Geneva, 1996.

## Insert 3.2

### Implementation of the recommendations of the 1996 Ad Hoc Committee on Health Research

Problems (1990-2020)	Recommendations (R)	Implementation (as of December 2003)
<p><b>1. The unfinished agenda: avoidable deaths, sickness and disability</b></p> <p>Health advances and public education over the last century have produced numerous vaccines, cures and treatments for many common infectious diseases. Despite this progress, infectious diseases, malnutrition and poor maternal and child health account for one-third of the global disease burden and for as much as half of the disease burden in the poorest countries.</p>	<p><b>R1: Package development and evaluation</b></p> <ul style="list-style-type: none"> <li>Evaluate the package for the Integrated Management of Childhood Illnesses (IMCI).</li> <li>Understand the relative importance, in different environments, of increased nutrient intake and control of infectious diseases as a means to reduce malnutrition.</li> <li>Develop and evaluate the mother-baby package for pregnancy, delivery and neonatal care.</li> <li>Evaluate the implementation of a range of family planning packages (wide choice of methods).</li> </ul> <p><b>R2: New tools</b></p> <ul style="list-style-type: none"> <li>Evaluate rotavirus vaccine in low-income countries.</li> <li>Evaluate conjugate pneumococcal vaccine and existing vaccine against Haemophilus influenzae type b in low-income countries.</li> <li>Improve the Expanded Programme on Immunization (EPI) by simplifying delivery and maximizing the use of opportunities for immunization.</li> <li>Evaluate insecticide-impregnated bednets (possibly for inclusion in future Healthy Household package).</li> <li>Develop new contraceptive methods.</li> </ul>	<p><b>R1: Examples of actions</b></p> <ul style="list-style-type: none"> <li>IMCI: WHO programmes have taken the lead in designing the IMCI package which has been implemented in over 100 countries. WHO has established a multicountry evaluation of costs and impact using scientific methods.</li> <li>Nutrient intake and infectious diseases: research on nutritional interventions for pregnant women and children is currently underway by governments, medical research councils (MRCs), foundations, research institutions and civil society. These studies include micronutrients supplementation (e.g. vitamins and minerals), high calory intake supplementation and improved ways to handle food to keep its nutritional value intact.</li> <li>Mother-baby package: the package was pilot-tested and is now operational in several low- and middle-income countries. WHO is spearheading this effort.</li> <li>Evaluation of family planning packages: contraceptive mix has been researched for over four decades. The Human Reproduction Programme of WHO (HRP) has taken a major role in this regard since its inception. The challenge since the 1994 International Conference on Population and Development in Cairo has been to integrate reproductive health services with family planning programmes. Operations research on implementing the package is currently well under way in a number of countries.</li> </ul> <p><b>R2: Examples of actions</b></p> <ul style="list-style-type: none"> <li>Evaluation of the rotavirus vaccine: phase III trials are under consideration.</li> <li>Evaluation of the conjugate pneumococcal vaccine and Hib vaccine: Phase III trials are ongoing. Some positive results have been reported in the introduction of these vaccines. The joint efforts between the private and public sectors have been a key component of this progress.</li> <li>Improving the EPI: EPI programmes face the following two main challenges: reaching and maintaining high coverage and linking programmes with other interventions (e.g. EPI plus, with micronutrient supplementation). These programmes are being tested at the operational level in a number of countries and have been implemented in others. Current challenges include the marked decrease in coverage in some African countries.</li> <li>Evaluate the insecticide-impregnated bednets: the impact of bednets in preventing malaria has been conclusive in areas with endemic malaria. Operations research is ongoing on the production, purchase and re-impregnation of bednets. Recent work has been successfully conducted on bednets which will not need to be re-impregnated. Governments, MRCs and universities have played an important role in this research.</li> <li>Develop new contraceptive methods: much progress has been achieved in this area. Work on long-term injectable contraceptives and male contraceptives is ongoing. HRP has played an important role, together with governments, universities and research institutions.</li> </ul>

Source: Global Forum for Health Research

## Insert 3.2 (continued)

### Implementation of the recommendations of the 1996 Ad Hoc Committee on Health Research

Problems (1990-2020)	Recommendations (R)	Implementation (as of December 2003)
<p><b>2. New and re-emerging microbes</b></p> <p>A growing number of drug-resistant microbes threaten to create new health emergencies and are leading to the resurgence of diseases, such as tuberculosis, malaria, and pneumococcal disease, long thought to be under control.</p>	<p><b>R3, 5, 6: Intervention development</b></p> <ul style="list-style-type: none"> <li>• Develop strategies to extend the coverage of Directly Observed Treatment Short Course (DOTS) for TB.</li> <li>• Develop an effective prophylactic for TB.</li> <li>• Conduct trials of conjugate pneumococcal vaccines.</li> <li>• Develop an HIV vaccine.</li> <li>• Improve methods for the diagnosis, prevention, and treatment of STDs, including vaginal microbicides.</li> <li>• Develop new antimalarials and a vaccine.</li> <li>• Develop collaboration between the public and private sectors.</li> </ul> <p><b>R4: Strategic research</b></p> <ul style="list-style-type: none"> <li>• Sequence the genomes of the major pathogens.</li> <li>• Investigate influences on the spread of antimicrobial resistance.</li> </ul>	<p><b>R3, 5, 6: Examples of actions</b></p> <ul style="list-style-type: none"> <li>• Extending the coverage of DOTS: the challenge is to scale up interventions. Operations research is ongoing in a number of countries. TB initiatives have played a major role.</li> <li>• Developing an effective TB prophylactic: work is ongoing in universities and research institutions.</li> <li>• Trials of conjugate pneumococcal vaccines: successful efficacy trials have been reported. Collaboration between public and private institutions played an important role in these trials. Operations research continues in this field.</li> <li>• Developing an HIV vaccine: the International Aids Vaccine Initiative (IAVI) was launched in 1996, with the objective of reducing the obstacles to vaccine development and filling the gaps in current efforts, involving both the public and private sector. Very serious technical challenges and insufficient funding have slowed progress (0.6% of total health research funding as compared to more than 5% of total disease burden).</li> <li>• Treatment of STIs. The following areas of research are receiving particular attention: improvement of diagnostic methods, case management, operations research in low- and middle-income countries.</li> <li>• Malaria drugs and vaccines: the Medicines for Malaria Venture (MMV) was created in November 1999 to discover, develop and deliver new antimalarial drugs through effective public-private partnerships. Insufficient funding is a major problem (malaria: 0.2% of total health research funding as compared to 2.8% of total disease burden).</li> <li>• The Malaria Vaccine Initiative (MVI) was launched in 1999 with the mission to accelerate the development of promising malaria vaccines and ensure their availability and accessibility in developing countries.</li> <li>• The Initiative on Public-Private Partnerships for Health (IPPPH) was created in 2000 under the Global Forum for Health Research to increase the effectiveness of public-private collaboration, particularly with respect to the development of, and access to, health products in developing countries.</li> </ul> <p><b>R4: Examples of actions</b></p> <ul style="list-style-type: none"> <li>• The genomes of a number of pathogens, including the <i>A. gambiae</i>, an important malaria vector, have now been sequenced.</li> <li>• In 2001, WHO published a <i>Global Strategy for Containment of Antimicrobial Resistance</i>.</li> </ul>

## Insert 3.2 (continued)

### Implementation of the recommendations of the 1996 Ad Hoc Committee on Health Research

Problems (1990-2020)	Recommendations (R)	Implementation (as of December 2003)
<p><b>3. Increase in NCDs, injuries and violence</b></p> <p>Epidemics of NCDs such as CVDs, neuro-psychiatric conditions and chronic respiratory infections, as well as the burden of violence and injuries, are increasing in low-income countries.</p>	<p><b>R7, 8: Establish a special programme for research and training in NCDs</b></p> <ul style="list-style-type: none"> <li>• Develop low-cost methods for collecting reliable data (disease surveillance points).</li> <li>• Study the burden and determinants of NCDs in developing countries.</li> <li>• Concentrate on epidemiological and behavioural research (biomedical research is comparatively well supported in industrialized countries).</li> <li>• Develop strategies for the cost-effective prevention, diagnosis, treatment and rehabilitation of NCDs (for example tobacco, psychiatric disorders).</li> </ul> <p><b>R9, 10: Establish a special programme for research on injuries</b></p> <ul style="list-style-type: none"> <li>• Develop low-cost methods for collecting reliable data on the epidemic.</li> <li>• Study the burden of injuries and determinants.</li> <li>• Develop strategies for the cost-effective prevention and treatment of injuries.</li> </ul>	<p><b>R7, 8: Examples of actions</b></p> <ul style="list-style-type: none"> <li>• In the 1990s, the bias against NCDs was in part corrected as epidemiological studies showed that developing and developed countries suffered equally from these diseases (burden of disease per 100 000 people). Efforts were undertaken to study the burden of NCDs in developing countries. For example: creation of the Global Forum on NCD Prevention and Control in 2001 (with annual meetings).</li> <li>• Epidemiological and behavioural research in developing countries was strengthened with the creation of the INDEPTH network in 1998 (<a href="http://www.indepth-network.net">www.indepth-network.net</a>) and by other efforts.</li> <li>• Substantial efforts were also undertaken for prevention, diagnosis and rehabilitation of NCDs, including research in these fields. Examples: adoption of WHO Framework Convention on Tobacco by the World Health Assembly in May 2003; launch of the Initiative on Cardiovascular Diseases in Developing Countries in Delhi in 1999 (under the umbrella of the Global Forum for Health Research); the WHO Mental Health Gap Initiative and other initiatives in the field of mental health and neurological disorders; the creation of the Global Alliance for Cancer Control.</li> </ul> <p><b>R9, 10: Examples of actions</b></p> <ul style="list-style-type: none"> <li>• Networking efforts were undertaken, particularly in the field of road traffic injuries, in several countries and at the global level. A <i>World Report on Road Traffic Injury Prevention</i> will be published by WHO, the World Bank and other partners in April 2004.</li> </ul>
<p><b>4. Inequity and inefficiency in the delivery of health services</b></p> <p>Countries vary enormously in how efficiently and equitably they provide health services. Current efforts in health care reform require international research and information exchange on: effective health policies, disease burden, resource flows, and cost-effectiveness interventions.</p>	<p><b>R11, 12, 13: Establish a special programme for research and training on health policy and systems</b></p> <p>The work of this programme could focus on:</p> <ul style="list-style-type: none"> <li>• Research and data collection in health systems policy, including evaluating health intervention packages.</li> <li>• Development of international indicators for the measurement of health systems performance.</li> <li>• Capacity building in health policies and systems.</li> <li>• Turn research results into action through tools for health workers: essential medicines lists, model legislation, priority intervention packages, pricing policies, practical manuals for health workers, summaries of research results for health workers and decision-makers.</li> </ul>	<p><b>R11, 12, 13: Examples of actions</b></p> <p>The Alliance for Health Policy and Systems Research was launched in March 2000 by the Global Forum for Health Research, WHO and other partners. The objectives of the Alliance in the fields of health policies and systems research are the following:</p> <ul style="list-style-type: none"> <li>• generation and synthesis of knowledge</li> <li>• capacity building on national and global issues</li> <li>• dissemination and use of knowledge in health policies and systems.</li> </ul> <p>See: <a href="http://www.alliance-hpsr.org">www.alliance-hpsr.org</a> and chapter 9 (section 14) for a summary of the recent activities of the Alliance for Health Policy and Systems Research and its perspectives.</p>

Source: Global Forum for Health Research



## Insert 3.2 (continued)

### Implementation of the recommendations of the 1996 Ad Hoc Committee on Health Research

Problems (1990-2020)	Recommendations (R)	Implementation (as of December 2003)
<p>5. Institutional problems</p> <ul style="list-style-type: none"> <li>At the level of the national research agendas</li> </ul>	<p><b>R14: Develop national agendas for health research, with the active involvement of all relevant actors (policy-makers, research institutions, community leaders, health care providers, etc.) dealing with major national health issues, including:</b></p> <ul style="list-style-type: none"> <li>capacity building</li> <li>translation of research results into policies and interventions</li> <li>development of competitive procedures for staffing and allocation of funds among institutions.</li> </ul>	<p><b>R14: Examples of actions</b></p> <ul style="list-style-type: none"> <li>In the 1990s, a number of priority-setting methods were developed for the establishment of national agendas for health research. The main efforts have been the following:</li> <li>ENHR proposed by the 1990 Commission on Health Research for Development and promoted since 1994 by COHRED in about 35 countries (e.g. Cameroon, Chile, Ghana, Guinea, Indonesia, Malawi, Mali, Nicaragua, Pakistan, Philippines, South Africa, Tanzania, Uganda).</li> <li>The Five-Step Process proposed in the 1996 Report of the Ad Hoc Committee on Health Research.</li> <li>The Visual Health Information Profile (VHIP) proposed in 1997 by the Advisory Committee on Health.</li> <li>The Combined Approach Matrix proposed by the Global Forum for Health Research which incorporates the criteria and principles for priority setting of the three methods mentioned above, and expands them into a matrix to take into account the actors/factors determining the health status of a population. A comparison of the four methods appears in Chapter 4, insert 4.1.</li> </ul> <p><b>Limitations</b></p> <p>These efforts are a very good start, but suffer from the following three limitations:</p> <p>(a) the research capacity in many developing countries remains limited and the research budget only a small fraction of the recommended 2% of national health expenditures.</p> <p>(b) Few priority-setting exercises for health and health research systematically take into account actors and factors beyond the biomedical field, i.e. the individual, behavioural and community dimensions; the sectors other than health having a profound effect on the health status of a population (such as education, environment); and macroeconomic policies.</p> <p>(c) Links between international and national research agendas are far from systematic.</p> <p>Attention to these three problems should be part of the priority agenda for the coming years.</p>
<ul style="list-style-type: none"> <li>Regarding the role of the public and private sectors</li> </ul>	<p><b>R15: Explore the development of new instruments (beyond the current patents system) for engaging the skills and energy of the private sector in the development of vaccines, medicines, diagnostic tests, and equipment for use among low-income populations through, for example:</b></p> <ul style="list-style-type: none"> <li>subsidies</li> <li>guaranteed markets</li> <li>streamlined regulatory requirements.</li> </ul>	<p><b>R15: Examples of action</b></p> <ul style="list-style-type: none"> <li>More than 70 health-related public-private partnerships were created between 1995 and 2003.</li> <li>The creation of the Global Fund is an important “pull” factor for the markets.</li> <li>Tax credits were also allocated to engage the private sector in research for neglected diseases.</li> </ul>
<ul style="list-style-type: none"> <li>At the international level</li> </ul>	<p><b>R16: Create a forum for investors in international health research to provide a mechanism for the review of needs and opportunities, making use of data on:</b></p> <ul style="list-style-type: none"> <li>disease burden</li> <li>level of ongoing efforts (resource flows)</li> <li>R&amp;D opportunities.</li> </ul>	<p><b>R16: Example of action</b></p> <p>Creation of the Global Forum for Health Research in 1998.</p>
<ul style="list-style-type: none"> <li>Regarding the overall allocation of resources: reallocate health sector resources to R&amp;D</li> </ul>	<p><b>R17: Reallocate health sector resources to research and development as a means to bring substantial gains, particularly for the health of poor populations</b></p> <ul style="list-style-type: none"> <li>Since much R&amp;D provides an international public good, there is a particularly strong case for public sector investors in the market economies to reallocate their health portfolios to increase R&amp;D funding.</li> </ul>	<p><b>R17: Example of action</b></p> <p>The 10/90 gap discussions and the new interest in health and health research as crucial factors for the development agenda are attracting more funding for health research for neglected diseases. However, measurement is very weak and a considerable and systematic effort is needed in the coming years.</p>

## Section 4

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### Implementation of the recommendations of the 2000 Bangkok Action Plan

Ten years after the 1990 Report of the Commission and four years after the 1996 Report of the Ad Hoc Committee, the major partners in the correction of the 10/90 gap organized the first International Conference on Health Research for Development with about 800 participants from 102 countries.

The Conference concluded with the adoption of the Bangkok Action Plan.

Insert 3.3 summarizes the main recommendations made in the 2000 Bangkok Action Plan together with some of the main actions which have been taken since 2000 to implement them.

## Insert 3.3

### Implementation of the recommendations of the 2000 Bangkok Action Plan

Problems	Recommendations	Implementation (as of December 2003) <sup>4</sup>
<p>1. Knowledge production</p>	<p><b>Global level</b></p> <ul style="list-style-type: none"> <li>• Strengthen role of universities.</li> <li>• Foster public-private partnerships.</li> <li>• Support initiative on sexual violence.</li> <li>• Advocate for research on child health.</li> </ul> <p><b>Regional level</b></p> <ul style="list-style-type: none"> <li>• Identify gaps in knowledge.</li> <li>• Establish regional clearinghouses/ database on human and institutional resources, projects, funds and best practices.</li> <li>• Develop regional mechanisms to promote health research.</li> <li>• Promote N/S + S/S collaboration in priority areas.</li> <li>• Promote regional health research journals.</li> </ul> <p><b>National level</b></p> <ul style="list-style-type: none"> <li>• Systematic assessment of research quality.</li> <li>• Dissemination of knowledge based on the latest communications technology.</li> <li>• Involvement of all stakeholders in the knowledge cycle.</li> <li>• Build capacity for information and communication technologies (ITCs).</li> <li>• Conduct research synthesis.</li> <li>• Support national burden of disease studies.</li> <li>• Develop national research policies and priorities.</li> <li>• Promote multi- and inter-disciplinary research.</li> </ul>	<p><b>Examples of action at the global level</b></p> <ul style="list-style-type: none"> <li>• An analysis undertaken by the Initiative on Public-Private Partnerships for Health (<a href="http://www.ippph.org">www.ippph.org</a>) showed that more than 70 health-related public-private partnerships and networks were created between 1995 and 2003 (as compared to about a dozen in the 1980s), particularly in the fields of HIV/AIDS, tuberculosis, malaria, leishmaniasis, schistosomiasis, pneumococcal diseases, STDs, dengue, meningitis, human trypanosomiasis, nutrition and child health, sexual violence, road traffic injuries, health policies and systems, cardiovascular diseases, cancer and mental health.</li> <li>• INCLEN (1980) became INCLEN Trust in 2000 (64 institutions, 26 countries) (<a href="http://www.inclen.org">www.inclen.org</a>).</li> <li>• World Summit on Children in May 2002.</li> </ul> <p><b>Examples of action at the regional level</b></p> <ul style="list-style-type: none"> <li>• INCLEN Trust activities at the regional level (<a href="http://www.inclen.org">www.inclen.org</a>).</li> <li>• Creation of INDEPTH network in 1998 (<a href="http://www.indepth-network.net">www.indepth-network.net</a>) with regional activities.</li> <li>• Creation of the Asia-Pacific Health Research Forum in 2000.</li> <li>• Creation of the South Asian Forum for Health Research in 2003, as chapter of the Asia-Pacific Forum.</li> <li>• Creation of the African Health Research Forum at the Global Forum for Health Research meeting in Arusha (Forum 6, 2002).</li> <li>• Regional collaboration meetings in Central and Latin America, Central Asia, francophone Africa.</li> </ul> <p><b>Examples of action at the national level</b></p> <ul style="list-style-type: none"> <li>• COHRED Working Group on communication: objective is to strengthen communication at country level (action in Brazil, Cuba, Ghana, Indonesia, Philippines, South Africa, Tanzania, Thailand).</li> <li>• Brazil CAPES (Ministry of Education) links Brazilian researchers with some 3000 international journals.</li> <li>• India: Health Internet Project on malaria and tobacco at disposal of health personnel.</li> <li>• Philippines: Zonal Health Research Centers in almost all regions of the country.</li> <li>• Thailand: e-libraries and networks of researchers from universities on interdisciplinary health issues.</li> <li>• Uzbekistan: launching in 2002 of a national ENHR network with some 80 national organizations.</li> <li>• Creation of a number of important information networks, with impact at the national, regional and global levels. See chapter 8 "Information networks in health research".</li> </ul>

Source: Global Forum for Health Research

<sup>4</sup> A number of examples are drawn from the study undertaken by M. Jegathesan for the Secretariat of the Interim Working Party, following the 2000 Bangkok Conference, entitled *A Biennium since Bangkok: Progress Visited*, Geneva, October 2002.

## Insert 3.3 (continued)

### Implementation of the recommendations of the 2000 Bangkok Action Plan

Problems	Recommendations	Implementation (as of December 2003)
<p>2. Capacity development</p>	<p><b>Global level</b></p> <ul style="list-style-type: none"> <li>• Funding agencies to integrate capacity development in each project.</li> <li>• Develop guidelines and tools.</li> <li>• Develop access to literature/database.</li> <li>• Develop strategic partnerships.</li> </ul> <p><b>Regional level</b></p> <ul style="list-style-type: none"> <li>• Develop models for research capacity building specific to the region.</li> <li>• Promote political commitment for regional collaboration.</li> <li>• Map centres of excellence for regional capacity building.</li> </ul> <p><b>National level</b></p> <ul style="list-style-type: none"> <li>• Management and leadership training programmes.</li> <li>• Viable research careers.</li> <li>• Efforts should primarily focus on institutional development, involving communities and health care providers.</li> </ul>	<p><b>Examples of action at the global level</b></p> <ul style="list-style-type: none"> <li>• In 2004, WHO will publish <i>Knowledge for Better Health</i> focusing on an analysis of health research systems and their central contribution to improving health at country level.</li> <li>• Capacity development is a policy of many organizations. However, there is no systematic review of the results achieved. This should be on the priority agenda for the coming years, together with the development of strategic partnerships. See also chapter 6.</li> <li>• The WHO-led Health Internetwork Access to Research Initiative (HINARI, started in 2001) currently provides access to 2000 electronic journals for low-income countries, on a free basis or at very favourable rates.</li> </ul> <p><b>Examples of action at the regional level</b></p> <ul style="list-style-type: none"> <li>• The objectives of the Regional Forums for Health Research include the Bangkok recommendations regarding the promotion of regional political commitment and collaboration in research capacity development.</li> </ul> <p><b>Examples of action at the national level</b></p> <ul style="list-style-type: none"> <li>• A Collaborative Training Project (CTP) was launched in 2002 by the Alliance for Health Policy and Systems Research, COHRED, the Global Forum for Health Research and INCLIN with three modules: priority-setting methodology, knowledge management, advocacy and leadership. This is work in progress which is being pilot tested.</li> </ul>
<p>3. Governance</p>	<p><b>Global level</b></p> <ul style="list-style-type: none"> <li>• Establish an international Working Party to review options and prepare a proposal for a governance structure.</li> <li>• Regular convening of an international conference on health research for development.</li> </ul> <p><b>Regional level</b></p> <ul style="list-style-type: none"> <li>• Mapping of health research and capacity building networks.</li> <li>• Develop appropriate governance.</li> <li>• Establish Regional Health Research Forums.</li> <li>• Regional structures should be based on country needs.</li> </ul> <p><b>National level</b></p> <ul style="list-style-type: none"> <li>• Take stock of status of national health research system.</li> <li>• Strengthen national governance structures.</li> <li>• Involve all stakeholders in a National Health Research Forum.</li> </ul>	<p><b>Examples of action at the global level</b></p> <ul style="list-style-type: none"> <li>• An Interim Working Party was formed following the Bangkok Conference and replaced the idea of a formal governance structure with a more decentralized approach based on the support for national and regional health research forums and the convening of a world health research conference on a four-year basis (Bangkok 2000, Mexico Summit in November 2004), in parallel with the regular annual meeting of the Global Forum for Health Research.</li> </ul> <p><b>Examples of action at the regional level</b></p> <ul style="list-style-type: none"> <li>• The objectives of the Regional Forums for Health Research include the mapping of health research centres and capacity building networks. Countries are generally well represented and their voices heard at the Regional Forums.</li> </ul> <p><b>Examples of action at the national level</b></p> <ul style="list-style-type: none"> <li>• COHRED Working Group on national health research systems works with country teams from Brazil, Cambodia, Cuba, Ghana, Indonesia, Laos, Philippines, South Africa, Tanzania, Thailand.</li> <li>• Only a few countries in the world have created a National Health Research Forum (for example Ecuador, Tanzania). The development of national governance structures in most countries is only in the beginning stages.</li> </ul>

## Insert 3.3 (continued)

### Implementation of the recommendations of the 2000 Bangkok Action Plan

Problems	Recommendations	Implementation (as of December 2003)
<p>4. Lack of financing</p>	<p><b>Global level</b></p> <ul style="list-style-type: none"> <li>• 2% of national health budgets + 5% of health-related foreign aid.</li> <li>• Explore the possibility to generate funds for health research through debt relief for health research or a travel tax.</li> <li>• Urge international agencies to reserve a percentage of funding for health research.</li> <li>• Stimulate public-private partnerships.</li> <li>• Develop tools for the monitoring of resource flows for research.</li> </ul> <p><b>Regional level</b></p> <ul style="list-style-type: none"> <li>• 2% of national health budgets + 5% of health-related foreign aid.</li> <li>• Urge regional organizations to reserve a percentage of their budgets to create a fund for health research.</li> <li>• Regional priorities should be based on country priorities and determined by burden of disease, social and economic determinants, gender and social equity.</li> <li>• Establish database to identify resource needs, track results and leverage resources.</li> </ul> <p><b>National level</b></p> <ul style="list-style-type: none"> <li>• 2% of national health budgets + 5% of health-related foreign aid.</li> <li>• Establish a Central Planning Unit (involving the government, donors and NGOs) to ensure that health research funding is aligned with national priorities.</li> <li>• Negotiate with donors long-term funding of research.</li> </ul>	<p><b>Examples of action at the global level</b></p> <ul style="list-style-type: none"> <li>• The recent efforts to better prioritize health research are key to increasing financing for priority research.</li> <li>• Starting in 1999, the Global Forum for Health Research together with partners sponsored the Resource Flows Project. Results were published in October 2001. See also Chapter 5 below on "Progress in measuring the 10/90 gap".</li> <li>• Since the proposal by the Commission on Macroeconomics and Health in December 2001 to create a Global Health Research Fund, various options were discussed at Forum 6 in November 2002 and continue to be studied, including the creation of a virtual fund.</li> <li>• Only limited information exists on investments in health research financed by aid agencies as a proportion of their health budget. See also chapter 5 below on "Progress in measuring the 10/90 gap".</li> <li>• More than 18 health-related public-private partnerships were created during the period 2001-2003.</li> </ul> <p><b>Examples of action at the regional level</b></p> <ul style="list-style-type: none"> <li>• Very limited action in the mobilization of financing at the regional level. However, preliminary discussions on global financing needs include partners at the global, regional and country levels.</li> <li>• Efforts to systematically define health research priorities at the country, regional and global levels are at an early stage. Much more work is needed in order to develop a method for mapping priorities with a systematic link between country, regional and global priorities. It is urgent to accelerate this process, particularly at the country level, applying the principle of subsidiarity for defining the research to be undertaken at the regional and global levels.</li> </ul> <p><b>Examples of action at the national level</b></p> <ul style="list-style-type: none"> <li>• Based on a study undertaken by the Global Forum for Health Research and its partners,<sup>5</sup> only Brazil and Cuba approached the 2% mark. Most other countries invest only a fraction of the 2% recommended. See chapter 5.</li> <li>• Only limited information exists on investments in health research financed by aid agencies as a proportion of their health budget. See also chapter 5.</li> </ul>

<sup>5</sup> Global Forum for Health Research, *Monitoring Financial Flows for Health Research*, October 2001

## Section 5

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### Summary of the recommendations made since 1990, main results and challenges for the Mexico Summit, Forum 8 and beyond

There is a remarkable consensus between the 1990 Commission, the 1996 Ad Hoc Committee and the 2000 Bangkok Action Plan on the actions needed to correct the 10/90 gap. Basically, all three reports focus on the following five recommendations:

#### 1. The imperative need to correct the 10/90 gap in health research and set priorities taking into account the global burden of diseases and their determinants

The three reports drew attention to the need to correct the 10/90 gap and to set priorities taking into account the global burden of diseases and their determinants. Furthermore, the reports drew attention to the need for health research to focus not only on (a) biomedical research, but also (b) on sectors other than health which have a profound influence on people's health, (c) on social and behavioural sciences, (d) management, (e) health policies and (f) allocation decisions.

The major health challenges facing the world today will not be solved without this massive reallocation from low- to high-priority projects, both at the country and the global levels. In the words of the 1996 Ad Hoc Committee Report, "Health research will be as vital for the future as it has been in the past 100 years. There are many health problems that remain unsolved because too little is understood about them, or because there are too few or no tools yet available to prevent or treat them, or because the existing tools are not being put to the most efficient use for technical or policy reasons."

#### *Results to date:*

- From a totally unknown concept in 1990, the existence of the 10/90 gap is now widely recognized. For lack of reliable data, it is not known whether it has changed much since 1990, but it is undeniable that many actions have been undertaken in the past 14 years (see Inserts 3.1, 3.2 and 3.3) which have had a substantial impact on the promotion of research on neglected diseases and health determinants.
- Considerable progress has been made in the field of priority setting. From a concept largely unknown in 1990, the need for priority setting is now largely recognized and a number of countries have defined their research priorities based on the ENHR approach with support from COHRED. Furthermore, the Global Forum for Health Research developed the Combined Approach Matrix for priority setting (combining the different methods developed in the 1990s), which has been used as a guide by TDR for defining its future research agenda and is starting to be applied by a number of global health research networks and a number of countries.

#### *Challenges for 2004 and beyond*

- With the combined efforts of all partners, the objective should be to move from a 10/90 gap today to a 20/80 gap in 10 years' time.
- Priority-setting exercises are still limited to a few countries and institutions and a major effort is needed in the coming years to ensure that all countries and institutions

base their resource allocations on the burden of diseases, the main determinants of health and equity considerations in a systematic exercise for priority setting.

- Few priority-setting exercises for health and health research systematically take into account actors and factors beyond the biomedical field (i.e. the individual, behavioural and community dimensions; the sectors other than health having a profound effect on the health status of a population, such as education and environment; and macroeconomic and health policies). These dimensions need to be systematically included in the priority-setting exercises in the future, to ensure the most effective and efficient use of the limited resources available for health research.
- Finally, a major effort will be needed in the future to more systematically link the international and national health research agendas.

## 2. Build the capacity of health research systems in developing countries

Research capacity building in developing countries is the second strong recommendation of the three reports and is considered as a central element of the correction of the 10/90 gap. Capacity building is viewed as necessary for a country to define and address its specific priority problems and to be able to join the efforts of the international community on problems which are considered of high priority at the national level.

*Results to date:*

- Capacity building is a policy of most organizations and important efforts were undertaken in the 1990s in this field. A number of countries have succeeded in building a substantial research capability and are active partners in international health research.

- However, most low-income countries have very limited research capability to identify and confront their priority health problems and to benefit from international health research collaboration.
- The WHO publication *Knowledge for Better Health* (2004) focuses on an analysis of health research systems and their central contribution to improving health at the country level.

*Challenges for 2004 and beyond*

- A systematic review of the results achieved over the past 10 years and the development of a “facilitation unit” (as proposed by the 1990 Commission) for capacity building in the Least Developed Countries should be part of the priority agenda for the coming years.
- A comparison of research capacities with the priority list of health problems at the national level will enable countries to identify the necessary measures to ensure the best match between the two.

## 3. Create international research networks and public-private partnerships

In the words of the 1990 Commission, it is essential to “promote the steady growth of collaborative international research networks as the principal means for mobilizing scientific talent to attack common problems.” Within this context, the Committee strongly recommended the involvement of the private sector and the development of public-private partnerships when neither the public sector nor the private sector alone could solve the problems at hand.

*Results to date:*

- The number of collaborative international research networks and programmes increased rapidly between 1995 and 2003, when more than 70 health-related public-private partnerships and networks were

created (as compared to about a dozen in the 1980s), particularly in the fields of HIV/AIDS, TB, malaria, leishmaniasis, schistosomiasis, pneumococcal disease, STIs, dengue, meningitis, human trypanosomiasis, nutrition, road traffic injuries, health policies and systems, CVDs, cancer and mental health.

#### *Challenges for 2004 and beyond*

- These partnerships are very important instruments linking the public sector, the private sector and international organizations, where none of them could succeed individually. The challenge for the future will be to ensure their continued viability, efficient delivery of products and strong linkage with the national health systems.

#### **4. Increase funding for health research by developing countries**

All three reports recommended that developing countries substantially increase their health research budgets to ultimately reach the target of 2% of national health expenditures. They also recommended that foreign aid agencies invest 5% of their health budget in health research and capacity building. The 1996 Ad Hoc Committee went further by recommending that resources be reallocated from the health budget to the health research budget, based on the high returns expected from investments in health research. The 2000 Bangkok Action Plan proposed that tools be developed to systematically monitor resource flows to health research.

#### *Results to date:*

- Based on a study undertaken by the Global Forum for Health Research and its partners<sup>6</sup>, only Brazil and Cuba approached the

2% mark. Most other countries invest only a fraction of the 2% recommended (see also chapter 5). Regarding foreign aid agencies, very limited information is available on investments in health research financed by them as a proportion of their health budget.

#### *Challenges for 2004 and beyond*

- A systematic effort is needed in the coming years at the international and national level to measure the allocation of health research funds by disease and by determinant for all countries and institutions, based on the first preliminary efforts undertaken in the past few years.
- The work of the Commission on Macroeconomics and Health should be systematically pursued at country level to document the high benefits for each country and for the world as a whole of prioritizing health research at the global, regional and national levels and of redirecting health research from low- to high-priority projects.
- This information should be made widely available at cabinet level in each country and in general to all stakeholders in health and health research.
- The links between the horizontal and vertical approaches to improving health and developing health research should be systematically studied and reinforced.

#### **5. Governance and monitoring progress in health research**

The 1990 Commission and the 1996 Ad Hoc Committee recommended the creation of an independent forum for investors in international health research to monitor the progress made in the correction of the 10/90 gap and to promote financial and technical support for research on health problems in developing countries. This mechanism should

<sup>6</sup> Global Forum for Health Research, *Monitoring Financial Flows for Health Research*, October 2001



not operate research programmes, but rather promote action by others. In this field of action, the 2000 Bangkok Action Plan went further and recommended that this central forum for health research be complemented by regional health research forums as well as national health research forums. National forums should include all stakeholders in health and health research, i.e. representatives of the various ministries concerned with health and development (health, finance, education, environment, etc.), research institutions, media, community organizations, private-sector companies and advocacy groups.

*Results to date:*

- COHRED was created in 1993 to advocate for the ENHR strategy. The Global Forum for Health Research was created in 1998 with a mandate to help correct the 10/90 gap. INCLEN, created in 1980, became INCLEN Trust in 2000 to disseminate knowledge and tools for the most efficient and effective prevention and treatment strategies.
- At the regional level, the Asia-Pacific Health Research Forum was created in 2000 (followed by the South Asian Forum for

Health Research in 2003, as a special chapter of the Asia-Pacific Health Research Forum). The African Health Research Forum was created in 2002. Numerous collaboration meetings have been held in the Central and Latin American region, as well as in francophone Africa and Central Asian countries.

- At the national level, a few countries (e.g. Ecuador and Tanzania) have launched a National Health Research Forum.

*Challenges for 2004 and beyond*

- The regional and national health research forums represent the backbone of the “pluralistic, worldwide health research system that will nurture productive national scientific groups linked together in transnational networks to address both national and global health problems” referred to by the 1990 Commission on Health Research for Development. They are still in the very early years of their development and require considerable support from the international community, both financially and technically. These are great challenges for the coming years but very promising investments.

# Chapter 4

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## *Priority setting in health research*

*Section 1  
About priority setting*

*Section 2  
Comparison of experiences in priority setting: processes and methods*

*Section 3  
The Combined Approach Matrix*

*Section 4  
Application of the Combined Approach Matrix*

*Section 5  
Technical issues concerning the economic dimensions of priority setting*

*Section 6  
Comparison of outputs of priority-setting exercises*

*Section 7  
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## Section 1

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### About priority setting

#### 1. Priority setting is a long-term process

Priority setting is as critical as conducting the research itself. Since the funding available for health research is low in comparison to its very high potential benefits, it is essential that it be based on a rational priority-setting process. The use of a sound methodology and a scientific process are critical to ensure the identification of the research priorities which will make the greatest contribution to people's health.

Priority setting is a long term, iterative process. Priorities are not static and need to be regularly reviewed. Priority setting must be based on evidence of potential impact and use of comparative advantages of the various actors, rather than on short-term political considerations. However, this long-term perspective often hinders political approval for research, as the benefits are not always immediately available, causing research to be misunderstood as a 'luxury' item.

#### 2. Deficiencies in priority setting and consequences

The failure in practically all countries to establish a process for priority setting based on the burden of diseases and their causes has led to a situation in which only about 10% of health research funds from public and private sources are devoted to 90% of the world's health problems (measured in Disability-Adjusted Life Years or DALYs).<sup>1,2,3</sup> This

extreme imbalance in research funding has a very high economic and social cost for individuals, countries and the world as a whole. To make matters worse, even the 10% of funds allocated to the 90% of the world's health problems are not used as effectively as they should be.

Reasons for this imbalance in health research funding include the following:

##### (a) In the public sector

- Over 90% of research funds are in the hands of a small number of countries (see chapter 5) which, understandably, have given priority to their own immediate national health research needs, even though this may be a short-sighted position.
- Decision-makers are often unaware of the magnitude of the problems outside their own national borders. In particular, they are unaware of the impact on their own country of the health situation in the rest of the world both directly (e.g. rapid growth in travel, re-emerging diseases, development of antimicrobial resistance) and indirectly (e.g. lower economic growth, migration).
- The decision-making process is influenced by a range of factors including the personal preferences of influential scientists or decision-makers, competition between institutions, donor preferences, career ambitions and tradition.

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<sup>1</sup> Global Forum for Health Research. *The 10/90 Report on Health Research 2000*.

<sup>2</sup> Global Forum for Health Research. *The 10/90 Report on Health Research 2001-2002*.

<sup>3</sup> Ad Hoc Committee on Health Research Relating to Future Intervention Options. *Investing in Health Research and Development*, WHO, September 1996.

- There is insufficient understanding of the role the public sector could play in supporting the private sector in the discovery and development of drugs for ‘orphan’ diseases.

#### (b) In the private sector

- Decision-makers in the private sector are responsible for the survival and success of their enterprise and for the satisfaction of their shareholders. Their decisions are based largely on profit perspectives which inevitably limit investment in diseases prevalent in low- and middle-income countries, as market potential is often underestimated.
- In low- and middle-income countries, pharmaceutical companies have the potential to develop and produce products for diseases prevalent in those countries. However, their funding capacity is comparatively small in global terms and therefore this potential remains largely untapped.

### 3. Priority setting in health research: tools versus process

In everyday life, setting priorities is a difficult process. This is much more so in the field of health research, where a larger number of factors and actors enter into the equation.

It is important to differentiate between the *process* of priority selection and the *tools* used for that purpose.<sup>4</sup> The process is the mechanism by which constituencies and stakeholders are involved and decide upon research priorities. It is evident that ensuring the participation of communities and users is a necessary part of the process.

The tools are the instruments which facilitate (i) the organization of the huge mass of information (regarding burden of disease, available resources, determinants, present

knowledge) which is necessary to establish priorities on a scientific basis and (ii) its presentation in a way which permits analysis and comparison of the various possible fields of research, eventually permitting the identification of the areas with the most promising impact on people’s health.

### 4. From local research priorities to national and global priorities

The exercise of priority setting should take place at the local, national and global levels, as resources are invested in health research, in one form or another, at all three levels. The challenge is to relate, in an efficient and effective way, the results of exercises undertaken at the local and country levels with those at the regional and global levels for specific diseases and conditions, based on the respective comparative advantages. A practical way to relate the three levels is presented in section 4 below, “Application of the Combined Approach Matrix”.

### 5. Whose priorities?

Lists of priorities are only as good as their inputs and the process leading to the identification of these priorities. As far as the process is concerned, the dominating constituency will invariably tend to impose its own view of the problem. The Commission on Health Research for Development<sup>5</sup> drew attention to the fact that the “perception of health problems may differ according to the people consulted.” It made its point by reporting on a study in which the priority ranking of health problems by citizens in Bangkok contrasted markedly with that analysed by health professionals. In that study, citizens’ views only vaguely matched the views expressed by epidemiologists.

<sup>4</sup> De Francisco A. Paper presented in Forum 7, Geneva, December 2003.

<sup>5</sup> Commission on Health Research for Development. *Health Research, Essential Link to Equity in Development*, 1990.

Lomas<sup>6</sup> defines ‘technical’ and ‘interpretative’ models of priority setting, the former being based on available data and the latter on more subjective judgements made by participants taking part in the exercise. The objective of the priority-setting process is to ensure that the views of a range of health professionals, citizens and other stakeholders are well represented and balanced, if not entirely reconciled.

In summary, the priority-setting process is a *subjective* process, i.e. the priorities identified at the end of the process are those of the actors having participated in the process. In order to make the results as *objective* as possible, i.e. as representative as possible of the priorities of the *whole* local community, the *whole* nation, or the world as a *whole*, it is essential (i) to adopt a priority-setting *process* which is as transparent and as participatory as possible, and (ii) to apply a methodology which is as scientific as possible, even though both are costly in terms of the financial and human resources needed.

## 6. From research to action

A fundamental requirement for research to be effective is to ensure that the results of

research are transformed into actual and measurable improvements in people’s health. Unfortunately, too many priority-setting exercises end when the priorities are identified. The link between research and people’s health is largely embedded in the health and health research systems in all their dimensions and complexities. An important contribution of research is to throw light on the reasons why, in particular instances, the findings of health research do not result in improvements in people’s health.

The preliminary results of a three-year study on health research systems in a number of countries were presented in Forum 7,<sup>7</sup> underlining the difficulties of translating research results into policies. In his analysis, Hanney<sup>8</sup> indicated that priority should be given to the following themes: (i) priority setting; (ii) the interface between the health system, the health research system and policy-making; and (iii) the role of the beneficiaries of health research. In this context, it is not only important to know whether research was used in policy formulation, but also to know how it was used.<sup>9</sup>

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<sup>6</sup> Lomas J et al. “On being a good listener: setting priorities for applied health services research” in *The Milbank Quarterly*. Volume 81, Number 3, 2003.

<sup>7</sup> Sadana R. Towards analyses of national health research systems - update on a pilot study involving some 20 countries. Paper presented in Forum 7, Geneva, December 2003.

<sup>8</sup> Hanney SR et al. “The utilisation of health research in policy-making: concepts, examples and methods of assessment” in *Health Research Policy and Systems* 2003, 1:2

<sup>9</sup> Lavis J et al. “Measuring the impact of health research” in *Journal of Health Services Research and Policy*, Vol 8 No 3, July 2003.

## Section 2

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### Comparison of experiences in priority setting: processes and methods

Since the Commission on Health Research for Development in 1990,<sup>10</sup> priority-setting exercises have used various methods and processes. The objective of this section is to compare these various efforts on prioritization in health research in order to highlight their similarities and complementarity. An overview of this analysis is presented in Insert 4.1 which summarizes and compares the characteristics of the major priority-setting approaches for health research which have emerged since the Commission's Report. Recent developments in each of the approaches are briefly summarized below.

#### 1. Priority setting using the Essential National Health Research strategy (1991)<sup>11</sup>

Based on the Commission's recommendation to "encourage all countries to undertake Essential National Health Research (ENHR)," the Council on Health Research for Development (COHRED) was established in 1993 to assist developing countries with the implementation of this strategy to organize and manage research (See chapter 9, section 15 below).

COHRED has worked in about 65 countries (see Insert 9.15.2) and has made a significant contribution to health research in low- and middle-income countries by advocating for

the ENHR strategy and by supporting countries to prioritize and manage health research resources more efficiently.<sup>12,13</sup> In its promotion of the ENHR concept, COHRED emphasized the following principles: countries as the key actors in health research for development;<sup>14,15</sup> the need for solid evidence to underpin an inclusive health research agenda; the need to involve all stakeholders in the prioritization process; and the need to link research results to policy and to action.

#### (a) Process

The three essential stages to increase the potential success of the priority-setting process are the following:

##### *Planning the priority-setting process*

- Identifying leadership for the process, namely the central government or a body officially assigned by the government to coordinate health research in the country.
- Identifying and involving stakeholders, i.e. decision-makers (at various levels), researchers, health service providers and communities.
- Gathering and analysing information for setting priorities (situation analysis) in three broad categories:
  - health status (main health problems,

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<sup>10</sup> Commission on Health Research for Development. op. cit.

<sup>11</sup> Paper contributed by Sylvia de Haan, Carel Ijsselmuiden and Lisa Myers, COHRED, January 2004.

<sup>12</sup> See COHRED website for information on specific countries (<http://www.cohred.ch>).

<sup>13</sup> COHRED (2002). *Health Research Priority Setting: Lessons Learned*. Learning Brief 2002.6

<sup>14</sup> Neufeld V and Johnson N (eds). *Forging Links for Health Research. Perspectives from the Council on Health Research for Development*, IDRC, 2001.

<sup>15</sup> COHRED. *Health Research. Powerful Advocate for Health and Development, based on Equity*. Document 2000.2

common diseases, determinants or risk factors)

- health care system (current status, deficiencies and problems)
- health research system (availability of human, fiscal and institutional resources for research).

#### *Setting the priorities*

- Preparation of the information into a manageable list of priority health problems and related research areas/issues.
- Step-by-step process of stakeholders who determine the criteria for selecting priorities and a method for weighting the priorities.
- Determination of the scope of the expected

outcome (from broad lists of priority health problems to a detailed list of priority research questions).

#### *Implementing the priorities*

- From research priority areas to research portfolio: transformation of the broad list of research priority areas into a research portfolio.
- From meeting report to policy decision: integration of priorities into an appropriate governmental plan, agenda or policy to ensure political backing.
- Research priorities and a changing environment: periodic review, update of priorities.
- Investing in research priorities.

## Insert 4.1

### Comparison of various priority-setting approaches<sup>16</sup>

Characteristics	Essential National Health Research Approach	Ad Hoc Committee on Health Research Approach	Advisory Committee on Health Research Approach	Global Forum Combined Approach Matrix
<b>1. Objective of priority setting</b>	Promote health and development on the basis of equity.  Help decision-makers make rational choices in investment decisions.	Help decision-makers make rational choices in investment decisions so as to have the greatest reduction in the burden of disease for a given investment (as measured by number of DALYs averted).	Address problems of critical significance for global health: population dynamics, urbanization, environment, shortages of food and water, new and re-emerging infectious diseases.	Help decision-makers make rational choices in investment decisions so as to have the greatest reduction in the burden of disease for a given investment (as measured by number of DALYs averted), on the basis of the practical framework for priority setting in health research (matrix presented in Insert 4.2).
<b>2. Focus at the global or national level?</b>	Focus on situation analysis at country level; residual problems to be studied at global level.	Focus on situation analysis at the global level; method also applicable at the country level.	Priority to "significant" and "global" problems, requiring "imperative" attention.	Method applicable at both global and national level.
<b>3. Strategies/principles</b>	Priorities set by all stakeholders.  Process for priority setting should be iterative and transparent.  Approach should be multidisciplinary.	Five- step process.  Process should be transparent.	Priorities should be set by all stakeholders.  Process should be transparent and comparative.  Multidisciplinary approach.	Priorities should be set by all stakeholders.  Transparent and iterative process.  Approach should be multidisciplinary (biomedical sciences, public health, economics, environmental sciences, education sciences, social and behavioural sciences).
<b>4. Criteria for priority setting</b>				
Burden of disease	Based on an estimate of severity and prevalence of disease.	Measured by DALYs (number of years of healthy life lost to each disease).	Allocate resources to the problems deemed of "greatest global burden".	Measured by DALYs (number of years of healthy life lost to each disease) or other appropriate indicators.
Analysis of determinants of disease burden	Analysis of multidisciplinary determinants (biomedical, economic, social, behavioural, etc.).	Analysis of mostly biomedical determinants.  Other determinants implicit.	Analysis of multidisciplinary determinants (biomedical, economic, social, behavioural, etc.).	Analysis of determinants at following intervention levels: – individual/family/ community – health ministry and research institutions – sectors other than health – government macro-economic policies.
Cost-effectiveness of interventions (resulting from planned research)	Some attempts at measurement in terms of impact on severity and/or prevalence.	Cost-effectiveness measured in terms of DALYs saved for a given cost.	Implicit reference to cost-effectiveness analysis.	Cost-effectiveness measured in terms of DALYs saved for a given cost.

Source: Global Forum for Health Research

<sup>16</sup> Global Forum for Health Research: *The 10/90 Report on Health Research 2001-2002* (Insert 4.1, pages 50-51).



## Insert 4.1 (continued)

### Comparison of various priority-setting approaches

Characteristics	Essential National Health Research Approach	Ad Hoc Committee on Health Research Approach	Advisory Committee on Health Research Approach	Global Forum Combined Approach Matrix
<b>4. Criteria for priority setting (continued)</b>				
Effect on equity and social justice	Central criterion in ENHR approach (not directly measured).	Inbuilt equity orientation, based on same weights given to year of healthy life saved for poor and rich population (effect on equity not directly measured as yet).	A number of indicators in the VHIP draw attention to the situation of the poorer segments of the population.	Inbuilt equity orientation, based on same weights given to year of healthy life saved for poor and rich population (effect on equity not directly measured as yet).
Ethical, political, social, cultural acceptability	This criterion is present, although in varying degrees, in various approaches, either explicitly (particularly in the ENHR approach) or implicitly.			
Probability of finding a solution	Specifically mentioned in the ENHR approach.	Part of the cost-effectiveness analysis (step 4).	Implicit.	Part of the cost-effectiveness analysis.
Scientific quality of research proposed	Pre-condition in all approaches.			
Feasibility (availability of human resources, funding, facilities)	Specifically mentioned in the ENHR approach.	Implicit.	Implicit.	Feasibility is part of the list of criteria.
Contribution to capacity strengthening	Explicitly mentioned in the ENHR approach.	Not mentioned. Could be integrated in the cost-effectiveness analysis.	Not mentioned. Could be integrated.	Can be integrated in the cost-effectiveness analysis.
<b>5. Critical problems and priority research areas</b>	Will depend on each country's situation.	<p>Infectious diseases, malnutrition and poor maternal/child health.</p> <p>New and re-emerging infectious diseases due to antimicrobial resistance (TB, STD, HIV/AIDS, malaria).</p> <p>Increase in NCD and injuries.</p> <p>Inequities and inefficiencies in delivery of health services.</p>	<p>Infectious diseases: TB, vaccine-preventable childhood diseases, STD, HIV/AIDS, tropical diseases, maternal and child health.</p> <p>Noncommunicable diseases: cardiovascular diseases, diabetes, cancer, injuries, mental disorders, substance abuse.</p> <p>Health policies and health systems.</p> <p>Environment, nutrition, behaviour.</p>	<p>Health system research (efficiency and equity of health systems).</p> <p>Child health and nutrition (diarrhoea, pneumonia, HIV, malaria, vaccine-preventable diseases, nutritional deficiencies, TB).</p> <p>Maternal and reproductive health (mortality, STDs and HIV, nutrition, family planning).</p> <p>Noncommunicable diseases (cardiovascular, mental and neurological conditions).</p> <p>Injuries.</p>
<b>6. Implementation tools</b>	Essential national health research plans.	<p>Forum for investors in international health research.</p> <p>National agendas.</p> <p>Public/private collaboration.</p>	Under preparation.	<p>Analytical work for priority setting.</p> <p>Research networks (initiatives) for priority diseases.</p> <p>Annual meeting of partners to help correct the 10/90 gap.</p>

## **(b) Tools**

Over the past decade, there has been significant progress in health research priority setting, both in the process and the development of methodologies, tools and approaches.<sup>17,18</sup> The outstanding challenges and opportunities are discussed in chapter 9 (see section 15 on COHRED).

## **2. Ad Hoc Committee on Health Research (1996)**

The characteristics of the priority-setting approach proposed by the Ad Hoc Committee are presented in Insert 4.1. It involves a so-called “five-step process” that focuses on the “economic dimensions” of priority setting.

## **3. Advisory Committee on Health Research (1997)**

In its 1997 publication,<sup>19</sup> the Advisory Committee on Health Research set out the Visual Health Information Profile, a computer-based visual display showing the “totality of the health status of a country” in a way that enables comparisons of health status (i) for a given country over time and (ii) between countries at a given point in time. It draws attention to the large diversity of actors and factors affecting the health status of a population and defines indicators of a country’s health status permitting these comparisons over time and across countries.

## **4. National Institutes of Health (NIH), USA**

A paper presented in Forum 5<sup>20</sup> explored the process of setting priorities at the National Institutes of Health (NIH) in the United States. The aim of the paper was to identify

the extent to which disease burden was a criterion in the allocation of research funds. The NIH is one of the 12 operative agencies of the US Department of Health and Human Services (DHHS). It is the only agency within DHHS with a singular mission of biomedical research and training to improve the health of the American population and people worldwide. In addition to the Office of the Director, it is composed of 27 centres, independently funded from yearly Congressional appropriations. Even though the centres focus mainly on the domestic health research priorities of the United States, the majority of them also have a substantial international programme. The Fogarty International Center is specifically charged with the promotion and support of international research and research training.

NIH funding increased over the past decade from approximately US\$ 10 billion in 1992 to approximately US\$ 23 billion in 2002. This has further increased to US\$ 27 billion in 2004. Over recent years, funding for collaborative research between US and foreign investigators, direct funding of foreign researchers, and training of non-US scientists increased at a faster rate than the rest of the NIH programme. About US\$ 300 million dollars were provided in 2002 for international research collaboration or direct funding (including about one third for training).

### **(a) Selection of research projects**

Each year NIH receives a large number of research grant proposals for peer review. The number has risen from about 22 000 in 1992

<sup>17</sup> *A Manual for Research Priority Setting using the ENHR Strategy*. Prepared by David Okello, Pisonthi Chongtrakul and the COHRED Working Group on Priority Setting, COHRED, Document 2000.3. Also available in French and Spanish.

<sup>18</sup> *Health Research for Policy, Action and Practice, Training Modules. Module 1: Priority Setting*. Collaborative Training Programme, 2002. The Collaborative Training Programme is supported and coordinated by the Alliance for Health Policy and Systems Research, COHRED, the Global Forum for Health Research and the INCLIN Trust.

<sup>19</sup> Advisory Committee on Health Research. *A Research Policy Agenda for Science and Technology to Support Global Health Development, A Synopsis*, WHO, December 1997.

<sup>20</sup> Paper presented by Gerald T Keusch (then Director, Fogarty International Center, USA) in Forum 5.

to almost 35 000 in 2003. Approximately 70% are investigator-initiated, on any topic of interest to the investigator, and address research questions developed by the investigator. The remaining 30% are submitted in response to programme areas defined by the NIH itself.

#### **(b) Method used to identify priorities**

NIH uses the following five major criteria in setting its research priorities:

- *Public health needs*, based on the prevalence and severity of the problem, as reflected in national and international data.
- *Scientific quality of the proposed research*, based on a stringent two-stage peer review mechanism. This factor, essential to the NIH mission, is designed to separate politics and science and is firmly embedded in the culture of the NIH. Strict procedures are also in place to help eliminate conflict of interest in the decision-making process itself.
- *Potential for scientific progress*, based not only on the soundness of the research design, but also on the potential for scientific advances that open new lines of inquiry or the development of new instruments or methods that make it feasible to explore long-standing questions with greater sophistication or open up new questions to investigation.
- *Portfolio diversification*, to ensure that a broad base of science is being explored. This includes multiple studies on similar topics but using a multiplicity of approaches, as well as a large number of different topics being supported. The research portfolio ranges from basic, through clinical and translational research to applied research, including studies of rare or orphan diseases as well as those common in the population. Portfolio diversification also means that funding encom-

passes both national and international health research priorities.

- *Human resources and infrastructure support*. The support for human capital is of paramount importance to NIH and includes considerable attention to gender and minority issues.

### **5. WHO's Department of Reproductive Health and Research (RHR)<sup>21</sup>**

#### **(a) Process of priority setting**

In 2002, a process was carried out by RHR to define priorities for work in 2004-2009 in research, normative work and technical support to countries. It involved the following steps:

*Step 1: Surveying current issues and needs in sexual and reproductive health.* A document prepared in-house, together with other WHO departments, reviewed the current issues in the field of reproductive health, to elicit feedback from advisory bodies. Criteria used to select priorities included the following: public health significance, utility and sustainability of products, impact on reproductive rights and gender issues, feasibility, and time and cost implications. These priorities were not for WHO but for the field at large.

*Step 2: Seeking feedback from expert resource.* A questionnaire was used to take the 'pulse' of the international community. In all, experts were asked to score 25 issues in sexual and reproductive health on the basis of their assessment of the needs at national and global level, practical guidelines at national and global level, and country support at national level, for each issue. This served to consolidate the review prepared under step 1.

*Step 3: Selecting potential operating areas for WHO.* This was implemented using the logical

<sup>21</sup> Catherine d'Arcangues, RHR/WHO. Presentation in WHO, 2003.

framework approach and taking into consideration the WHO/RHR comparative advantages. The selection among the priorities defined under step 1 was based on the following factors: credibility as a technical organization of high scientific standards, neutrality, objectivity and independence, convening power, wide resource base, position as an inter-governmental agency focusing on the needs of developing countries, capacity building, leadership role, avoiding duplication with other WHO departments and other agencies/institutions.

*Step 4: Redefining priority setting.* A ranking exercise was undertaken on the basis of the outputs of step 3 above. The ranking was undertaken in a workshop in which experts used a combination of ‘scoring’ and ‘ranking’ of identified priorities. Consideration was given to the feasibility and likely impact of projects and to the ability of the programme to deliver.

*Step 5: Presentation to governing bodies of RHR.* The Strategic and Technical Advisory Group discussed the process and results in February 2003. They commended the methods and outcomes, and advised on further prioritization of the selected themes based on the strengths of the programme and on financial resource allocation.

#### **(b) Methods used to identify priorities**

As a result, priority areas were identified in each of the eight areas of sexual and reproductive health listed below, thus operating a shift in focus for RHR:

- technical cooperation with countries
- family planning, including infertility
- maternal and neonatal health
- sexually-transmitted infections (STIs) and reproductive tract infections (RTI) including HIV/AIDS and cervical cancer
- prevention of unsafe abortion
- sexual health, including female genital mutilation
- gender issues and reproductive rights
- adolescent sexual and reproductive health .

#### **6. The Combined Approach Matrix**

Based on previous methodologies for priority setting, in particular those proposed by the ENHR, the Ad Hoc Committee on Health Research and the Advisory Committee on Health Research, the Global Forum for Health Research proposed the Combined Approach Matrix (CAM) in 2000.<sup>22</sup> The developments in the method over the past three years are presented in Section 3 below, while Section 4 deals with the concrete application of the matrix for identifying priorities. Section 5 discusses the technical issues surrounding the economic dimensions of priority setting.

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<sup>22</sup> Global Forum for Health Research. *The 10/90 Report on Health Research 2000*, Geneva, May 2000 (pages 37-41).

## Section 3

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### The Combined Approach Matrix

#### 1. Principles

The CAM is a tool (i) to help classify, organize and present the large body of information which enters into the priority-setting process; (ii) to identify gaps in health research; and, on this basis, (iii) to identify health research priorities, based on a process which should include the main stakeholders in health and health research.

Priority setting in health research must take into account an “economic dimension” as underlined in the Five-Step Process of the 1996 Ad Hoc Committee as well as an “institutional dimension”, which is emphasized by the 1991 ENHR approach and the 1997 Visual Health Information Profile proposed by the Advisory Committee on Health Research. The institutional approach argues that the health status of a population depends on actors and factors outside the health sector just as much as on the national health system itself.

*The objective of the CAM is to incorporate both the economic and institutional dimensions into a single tool for priority setting. The resulting matrix for priority setting is presented in Insert 4.2.*

For practical purposes, information on disease burden and resource flows will only be considered at the global level and not disaggregated by broad category of actors and factors. The advantage of the proposed matrix is that it will help organize, summarize and present all available information on one disease and facilitate comparisons between the likely cost-effectiveness of different types of interventions at different levels. The information will inevitably be partial, and probably even sketchy in some cases, but it will progressively improve and even limited information is sometimes sufficient to indicate promising avenues for research.

## Insert 4.2

### The Global Forum Combined Approach Matrix for priority setting

	Global level	A. Individual family and community	B. Ministries of health, research institutions, health systems	C. Sectors other than health.	D. Central government and macro-economic policies
1. Disease burden					
2. Determinants for persistence					
3. Present level of knowledge					
4. Cost and effectiveness					
5. Resource flows					

Source: Global Forum for Health Research

## 2. The main elements of the CAM

### (a) The economic dimensions of priority setting

The components of the Five-Step Process identified in the 1996 Report of the Ad Hoc Committee are the following:

#### Step 1: Magnitude of the disease burden

Measure the disease burden as years of healthy life lost due to premature mortality, morbidity or disability. Summary measures, such as the DALY, can be used to measure the magnitude. Other methods serving the same purpose can also be used.

#### Step 2: Determinants (risk factors)

Analyse the factors responsible for the persistence of the burden, such as lack of knowledge about the condition, lack of tools, failure to make use of existing tools, limitations of existing tools or factors outside the health domain.

#### Step 3: Current level of knowledge

Assess the current knowledge base available to help solve the health problem and evaluate the applicability of solutions, including the cost and the effectiveness of existing interventions.

#### Step 4: Cost-effectiveness

Assess, against other potential interventions, the promise of the R&D effort and examine if future research developments would reduce costs, thus allowing interventions to be compared and applied to wider population segments.

#### Step 5: Resources

Calculate the present level of investment in research on the specific disease and/or determinant.

### (b) The institutional dimensions of priority setting

The institutional dimensions include the following groups of actors and factors:

- Individual, family, community: in the CAM, this column will review elements which are relevant to the reduction of disease burden and can be modified at the individual, family or community level. This includes relevant interventions on, primary care, prevention and education. In the case of malaria, for example, prevention using barrier methods such as insecticide-impregnated bednets is a key intervention at the individual level.
- Health ministry, health systems and services, health research community: this column in the matrix will review the contribution of the ministry of health and health research systems to the control of the specific disease or condition being explored. The column focuses on (i) biomedical interventions and their application throughout the health system as a whole; (ii) policies and structures which can help the health system reduce the burden of a specific condition; and (iii) the potential for the health research community to provide tools, processes and methods for the same purpose.
- Sectors other than health with a major impact on people's health: examples include the role of the transport sector in the prevention of road traffic injuries, or the role of the education system (both formal and informal) in changing people's health behaviour (washing hands, smoking, substance abuse, avoiding risky behaviour in general).
- Central government and macroeconomic policies: this column in the matrix focuses on elements at the central government level or those outside the country which can have a role in the control of diseases or conditions. An example of this is the impact of World Trade Organization agreements concerning intellectual property rights on the provision of antiretrovirals for the treatment of people living with HIV/AIDS.

### 3. Functions of the CAM

The CAM combines the respective advantages of the methods developed in the 1990s (ENHR, the Five-Step Process of the Ad Hoc Committee on Health Research and the Visual Health Information Profile of the Advisory Committee on Health Research), while remaining relatively simple.

Thus information gathered in past priority-setting exercises conducted at country, regional and global levels can be introduced into the CAM as a common framework to organize and present the collected information (as a basis to identify gaps in health research and health research priorities).

In summary, the CAM:

1. Brings together in a systematic framework all information (current knowledge) related to a particular disease or risk factor.
2. Identifies gaps in knowledge and future challenges.
3. Relates the Five-Step Process in priority setting (economic axis) with actors and factors (institutional axis) determining the health status of a population.
4. Permits the identification of "common factors" by looking across the diseases or risk factors.
5. Is applicable to priority setting in the field of:
  - national, regional or global problems
  - diseases as well as risk factors.
6. Permits the linkage of priorities in the field of health and health research.
7. Enables the rapid identification of the effect of a change in one of the 'boxes' of the matrix on the other 'boxes'.
8. Permits taking into account the large number of factors outside the health sector which have an important impact on people's health.

## Section 4

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### Application of the Combined Approach Matrix

#### 1. How to use the CAM at the national level

The first step is to estimate the burden for each of the main diseases and risk factors in the country and to engage with all institutions and stakeholders in the country with particular knowledge of that disease. Each institution will feed into the matrix the information at its disposal. As a result, the matrix will gradually incorporate the best available information regarding a specific disease or risk factor. In many cases, instead of solid information, the matrix will reveal how little information is available to make rational, cost-efficient and effective decisions in the fight against specific diseases. These gaps in the information matrix are all candidates for research.

The second step is to identify which information would have the largest impact on the disease. This will be a time-consuming process as it is likely that various stakeholders will have different opinions as to the most important factor(s) to be studied to reduce the burden of that particular disease. It should be an iterative process in which each institution presents its point of view and listens to the point of view of other institutions, until gradually a consensus and a list of research priorities for each disease emerges from the discussion and the comparison of the arguments.

The next step is to compare the research priorities across diseases and come up with a final list of top priorities in the various research fields, comprising those research topics likely to have the greatest impact in reducing the burden of disease for the country (i.e. those research topics likely to lead to the largest number of 'healthy life years' for a given research budget).

This overall list of research priorities for the country is then divided up among the various research institutions in the country based on their respective comparative advantages.

Similar types of processes can be followed at the local and global levels to determine the health research priorities at these levels. Such processes can be applied by individual institutions as well as by local and national governments and development agencies, to identify their priority areas for engagement in, or support to, health research.

This is a long-term effort. The information will inevitably be partial in the first exercises, probably even sketchy in some cases, but the tool should demonstrate its usefulness at an early stage by highlighting the most important gaps in the information needed to make evidence-based decisions and by enabling some decisions to be made despite the limited information available.



## Insert 4.3

### *Generic steps to use the CAM to identify key research projects at national level*

1. Estimate the burden for each of the main diseases and risk factors.
2. For each disease and risk factor, bring together all institutions and stakeholders in the country with particular knowledge of that disease or risk factor.
3. For each of the selected diseases and risk factors, feed into the matrix the information at the disposal of each institution, thus gradually incorporating into the table the best available information regarding that disease or risk factor.
4. Complete the matrix with information from other sources which may be relevant for your country.
5. Identify which missing information would, if made available, be likely to contribute the most to decreasing the burden of that disease or risk factor.
6. Identify research projects which can fill these gaps in information. This would be the list of research priorities for that disease or risk factor.
7. Compare research priorities thus identified across diseases and risk factors and come up with a final list of top priorities in the various research fields, which will be composed of those research topics likely to save the largest number of 'healthy life years' for a given budget.
8. Allocate the priority research projects among the research institutions in the country based on their comparative advantages.

Source: Global Forum for Health Research

## **2. Linking research priorities at the local, national and global levels**

Theoretically, health research priorities should be established by local communities, based on the local burden of disease and determined through a participatory process involving the use of scientific tools. A comparison of the priorities identified at community level will enable the identification of those priorities which are common to several or possibly all communities, thus indicating that these may become national priorities.

National authorities should then identify the national health research priorities, based on information about the national burden of disease and the results of the priority-setting exercises of the local communities, again through a participatory process and the use of scientific tools. The definition of the national and local priorities and actual research activities should be the result of an iterative process between the two levels, the ultimate result being based on comparative advantages.

International organizations and institutions with a global remit should then identify global health research priorities, based on the global burden of disease and the national priorities defined by as many countries as possible, using a participatory process and scientific tools. Here also, the definition of the global and national health research priorities should be the result of an *iterative process* between the two levels, the ultimate result being based on comparative advantages.

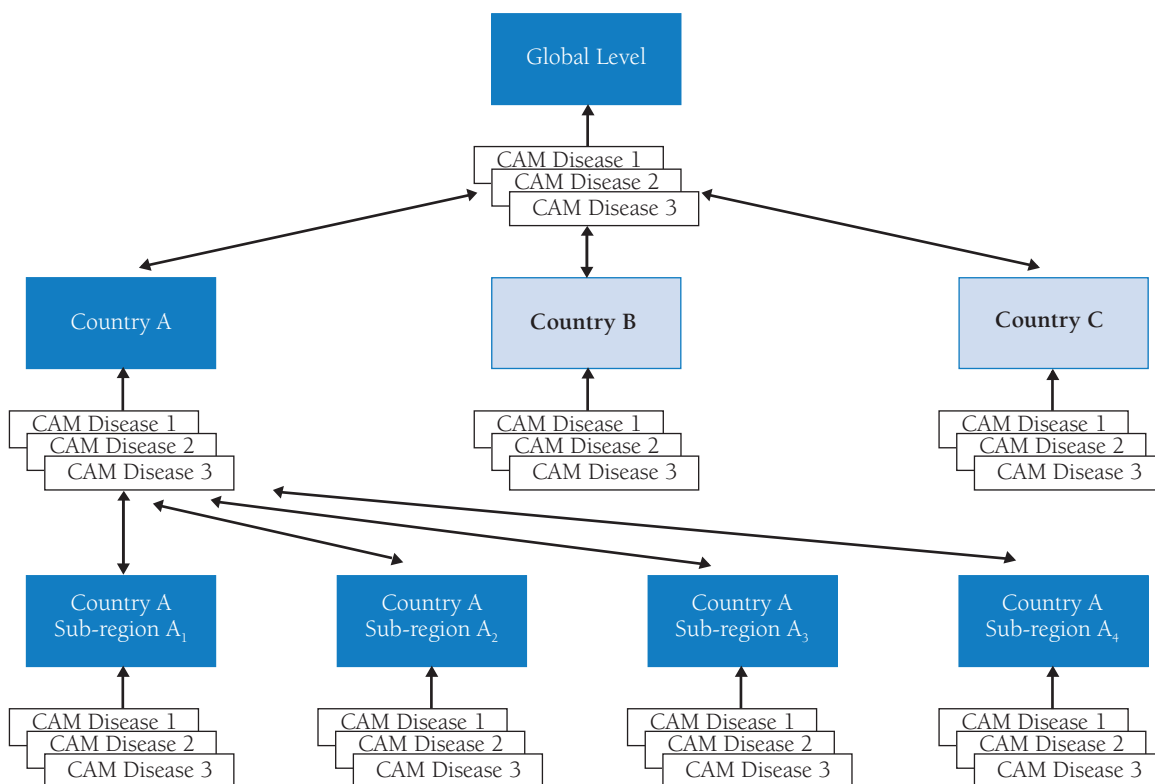
*In practice*, the process can start anywhere in the chain of responsibilities between the local community level, the national level and the global level, the important points being the following:

- since few if any countries and institutions have instituted a scientific process for identifying health research priorities, it is important that the process should now get under way and that the 'mosaic' should be gradually filled; an attempt is made in Insert 4.4 to represent the system and the linkages between the various levels;

- for a given disease or risk factor, priorities are unlikely to be determined once and for all, but rather to evolve over time, based on new discoveries and the evolution of the disease burden anywhere in the system; thus, it is important that the process of defining research priorities be continuous and iterative between the local, national and global levels;
- it is also unlikely that a priority problem will be researched at only one of the three levels; in reality, a research programme is more likely to have local, national and global components, with the solution depending on the optimum combination of the solutions found at each of the three levels.

### Insert 4.4

*Iterative process for the definition of disease research priorities at the local, national and global levels*



Source: Global Forum for Health Research

### 3. Experiences using the CAM at the global level

#### (a) Early experiences

A first application of the CAM at the global level focused on epilepsy and was presented in a table entitled “Epilepsy: risks, obstacles and opportunities for interventions” in *The 10/90 Report on Health Research 2000* (Insert 5.2, pages 90-91).

Further applications in 2000 and 2001 focused on malaria, onchocerciasis and indoor air pollution and were presented in *The 10/90 Report on Health Research 2001-2002* (Inserts 4.11, 4.12 and 4.15 respectively).

#### (b) The example of TDR

Based on these first experiences, a priority-setting exercise was undertaken in 2002-2003 to re-align TDR’s strategic focus in research to address the disease control priorities of the next five years. A summary of this exercise is presented below:<sup>23</sup>

The first step in the prioritization process of TDR was to bring together the TDR Disease Research Coordinators, TDR staff, disease control experts from within WHO, country programme managers and disease experts (Disease Reference Group and Scientific Working Groups) to analyse rationally and transparently the current situation of each disease. This included taking into account the current status of research and the comparative advantages of TDR. The result was the

definition of a set of “strategic TDR emphases” (or priorities) in the scientific and technical areas of work for the following five years.

The exercise was based on the following documents:

- the analyses carried out by TDR, WHO and the World Bank between 1993 and 1996 which culminated in the 1996 Ad Hoc Committee Report;<sup>24</sup>
- the Global Forum’s proposed CAM for setting priorities in health research.<sup>25</sup>

A modification of the Combined Approach Matrix led to the definition of the following seven steps used in the TDR prioritization process:

- (i) What is the size and nature of the disease burden and epidemiological trends?
- (ii) What is the current disease control strategy?
- (iii) What are the major problems/challenges for disease control?
- (iv) What research is needed to address these problems/challenges?
- (v) What is currently being done in R&D, and what research opportunities exist?
- (vi) What are TDR’s comparative advantages?
- (vii) Strategic emphases for R&D.

A comparison of the CAM of the Global Forum for Health Research and the TDR seven-step approach (Insert 4.5) shows the close parallels between the two methods.

<sup>23</sup> Lazdins J, TDR. Presentation in Forum 7, Geneva, December 2003.

<sup>24</sup> Report of the Ad Hoc Committee. op. cit.

<sup>25</sup> See Insert 4.2.

## Insert 4.5

### Comparison of the CAM<sup>26</sup> and the 2003 TDR ‘Seven-Step Process’<sup>27</sup>

Combined Approach Matrix	TDR Seven-Step Process
1. Disease burden: measure the disease burden as years of healthy life lost due to premature mortality, morbidity or disability.	(i) What is the size and nature of the disease burden and epidemiological trends?
2. Determinants for persistence: assess factors responsible for the persistence of the burden (lack of knowledge, lack of tools, failure to make use of existing tools, limitations of existing tools or factors outside the health domain).	(ii) What is the current disease control strategy?
3. Present level of knowledge: assess the current knowledge base to solve the health problem and evaluate the applicability of solutions, including the cost and the effectiveness of existing interventions.	(iii) What are the major problems/challenges for disease control?
4. Cost and effectiveness: assess, against other potential interventions, the promise of the R&D effort and examine if future research developments would reduce costs, thus allowing interventions to be compared and applied to wider population segments.	(iv) What research is needed to address these problems/challenges?
5. Resource flows: calculate the present level of investment on research for specific diseases and/or determinants.	(v) What is currently being done in R&D and what research opportunities exist?
Other: specific to TDR only	(vi) What are TDR’s comparative advantages?
	(vii) Strategic emphases for R&D.

Source: Global Forum for Health Research

The TDR prioritization strategy led to the following results: a transparent and objective prioritization process, the active participation of partners from both health research and disease control, a direct link between strategic emphases and the research needs of disease control, an efficient mechanism to communicate its strategic choices to its partners, and a continuous monitoring system for incorporating new priority needs.

Diseases in which TDR is working were categorized into the following three groups:

*Group 1: Emerging and uncontrolled diseases.* Diseases in this group include African trypanosomiasis, dengue and leishmaniasis. The epidemiological pattern of these diseases indicates that these are increasing in prevalence and the tools are not well developed or applicable to large segments of

<sup>26</sup> Ibid.

<sup>27</sup> Full results of the TDR priority-setting exercise are presented in “Strategic emphases for tropical diseases research: a TDR perspective” in *Trends in Parasitology*, December 2002.

the population. Research is required to improve the tools and the strategies to implement mass programmes.

*Group 2: Control strategy available but disease burden persists.* Diseases in this group include malaria, schistosomiasis and TB. Effective interventions are available which can be applied on a wide scale with the potential to reduce the disease burden but this has not yet taken place.

*Group 3: Control strategy effective and elimination is planned.* Diseases in this group include Chagas disease, leprosy, lymphatic

filariasis and onchocerciasis. There are tools and strategies available to control these diseases and probably to eliminate them in the medium-term. Operations research to achieve these objectives is required as the prevalence is declining and elimination targets are evident.

### **(c) Ongoing experiences**

Priority-setting exercises using the CAM are under way focusing on various diseases and risk factors. Work on TB and schizophrenia is presented in Insert 4.6 and Insert 4.7 respectively.

## Insert 4.6 Tuberculosis: application of the CAM

Levels of potential intervention →	A. Level of the individual, family & community	B. Level of the health ministry, health research institutions, and health systems & services	C. Level of sectors other than health	D. Level of central government and macroeconomic policies
<b>1. Disease burden</b>				
<b>2. Why does the burden still persist? What are the determinants?</b>	<ul style="list-style-type: none"> <li>• Exposure to infections (by sputum smear-positive PTB)               <ul style="list-style-type: none"> <li>– poor housing</li> <li>– overcrowded conditions</li> <li>– undernourishment</li> </ul> </li> <li>• HIV impact (relative risk for TB is 30 times higher for people infected by both HIV and Mycobacterium tuberculosis)</li> <li>• Inadequate care seeking</li> <li>• Non-compliance with treatment regime</li> <li>• Inadequate access to health services</li> </ul>	<ul style="list-style-type: none"> <li>• Neglect of the problem               <ul style="list-style-type: none"> <li>– inadequate case detection, diagnosis and cure</li> <li>– inadequate organization of services</li> <li>– unavailability of TB drugs</li> <li>– lack of quality control</li> <li>– inaccessibility of services for many patients</li> </ul> </li> <li>• Inadequate case management               <ul style="list-style-type: none"> <li>– failure to cure cases that were diagnosed</li> </ul> </li> <li>• Inadequate treatment regimes               <ul style="list-style-type: none"> <li>– failure to ensure directly observed treatment</li> <li>– lack of an information management system for rigorous evaluation of treatment outcomes</li> </ul> </li> <li>• Over-reliance on BCG (i. e. vaccination for children)</li> <li>• Spread of multidrug-resistant (MDR) strains of M. tuberculosis</li> <li>• Inappropriate research agenda</li> <li>• Changed role of the MoH under “health sector reform”, away from service provider to regulator/purchaser</li> </ul>	<ul style="list-style-type: none"> <li>• Poor infrastructure due to poverty               <ul style="list-style-type: none"> <li>– communication</li> <li>– transportation</li> </ul> </li> <li>• Poor drug distribution</li> <li>• The HIV pandemic (high risk of TB in HIV patients)</li> <li>• Stigma against patients suffering from TB, e.g. at workplace</li> <li>• Insufficient diagnosis &amp; treatment of TB in prison populations</li> </ul>	<ul style="list-style-type: none"> <li>• Poverty</li> <li>• Weak governance               <ul style="list-style-type: none"> <li>– inadequate political commitment</li> <li>– no transparent resource allocation</li> <li>– inadequate drug supply</li> <li>– poor control of private &amp; public sectors</li> </ul> </li> <li>• Inadequate financing within and between countries</li> <li>• Lack of knowledge of economic burden caused by TB and cost-effectiveness of control</li> <li>• Changing role of State away from service provision</li> </ul>

### 3. What is the present level of knowledge?

<p>a. Interventions currently available</p>	<ul style="list-style-type: none"> <li>• WHO's DOTS strategy</li> <li>• Preventive therapy</li> <li>• BCG vaccination</li> </ul>	<ul style="list-style-type: none"> <li>• WHO's DOTS strategy</li> <li>• Preventive therapy</li> <li>• BCG vaccination</li> <li>• Environmental controls</li> </ul>	<ul style="list-style-type: none"> <li>• Programmes to raise awareness of politicians, health professionals and the general public about the efficacy of existing interventions</li> <li>• Programmes against TB</li> <li>• Education programmes about the nature and treatment of TB, particularly in schools, the workplace, related to prison populations</li> <li>• Programmes against poverty             <ul style="list-style-type: none"> <li>– poor housing</li> <li>– overcrowded conditions</li> <li>– undernourishment</li> </ul> </li> <li>• Support to DOTS strategy by some parts of civil society, e.g. faith-based organizations</li> </ul>
<p>b. How cost-effective are current interventions?</p>	<ul style="list-style-type: none"> <li>• DOTS highly cost-effective in most settings. Exceptions are:             <ul style="list-style-type: none"> <li>– isolated areas</li> <li>– when stigma is attached to TB (particularly in HIV areas)</li> <li>– in very poor areas when indirect costs cannot be met</li> </ul> </li> <li>• Preventive therapy is cost-effective in some high HIV settings only (and even this is disputed)</li> <li>• BCG suffers random variations in effectiveness; it is, however, affordable and acceptable</li> </ul>	<ul style="list-style-type: none"> <li>• DOTS highly cost-effective in most settings. Exceptions are:             <ul style="list-style-type: none"> <li>– Dense urban &amp; remote rural areas</li> <li>– In some countries where it is considered too labour intensive &amp; expensive</li> </ul> </li> <li>• Preventive therapy unfeasible due to low capacity in health sector</li> <li>• BCG feasible and cost-effective and widely applied</li> <li>• Environmental controls generally ineffective and costly</li> </ul>	<ul style="list-style-type: none"> <li>• Awareness and education programmes: not very feasible in many settings, due to poverty &amp; lack of political will</li> <li>• DOTS in private sector cost-effective</li> <li>• Involvement of civic society cost-effective</li> </ul>

### Insert 4.6 (continued) Tuberculosis: application of the CAM

Levels of potential intervention →	A. Level of the individual, family & community	B. Level of the health ministry, health research institutions, and health systems & services	C. Level of sectors other than health	D. Level of central government and macroeconomic policies
4. What is to be expected in the future?	a. Interventions	<ul style="list-style-type: none"> <li>• Social mobilization</li> <li>• Health education (regarding TB)</li> <li>• Improving health seeking behaviour of patients</li> </ul>	<ul style="list-style-type: none"> <li>• Strategies to extend coverage DOTS and increasing its applicability and acceptability</li> <li>• Improved treatment (better drugs &amp; drug supply)</li> <li>• Improved diagnostics and clinical algorithms for the detection of smear-negative patients</li> <li>• New prophylactic interventions – a new vaccine (broader application than BCG for children)</li> <li>• mass chemoprophylaxis</li> <li>• MDRTB case management</li> </ul>	<ul style="list-style-type: none"> <li>• Involvement of civil society in TB control</li> <li>• Involvement of industry in TB control</li> <li>• Involvement of prisons in TB control</li> </ul>
	b. Cost-effectiveness	<ul style="list-style-type: none"> <li>• Unknown</li> </ul>	<ul style="list-style-type: none"> <li>• Operational interventions: some evidence of cost-effectiveness</li> <li>• New tools: unknown cost-effectiveness</li> </ul>	<ul style="list-style-type: none"> <li>• Unknown</li> </ul>
5. Resource flows				

Source: Global Forum for Health Research



## Insert 4.7 Schizophrenia: application of the CAM

Levels of potential intervention →	A. Level of the individual, family & community	B. Level of the health ministry, health research institutions, and health systems & services	C. Level of sectors other than health	D. Level of central government and macroeconomic policies
1. Disease burden				
2. Why does the burden still persist? What are the determinants?	<ul style="list-style-type: none"> <li>There is no proven method of primary prevention of schizophrenia</li> <li>Biological risk factors include               <ul style="list-style-type: none"> <li>– Genetic vulnerability (polygenic); heritability 69% - 80%</li> <li>– Early developmental insults (low birth weight; perinatal brain damage; early neuroinfection)</li> </ul> </li> <li>Environmental/psychosocial risks               <ul style="list-style-type: none"> <li>– Urban birth</li> <li>– Stigma</li> <li>– Social isolation</li> </ul> </li> <li>High co-morbidity (e.g. substance misuse)</li> </ul>	<ul style="list-style-type: none"> <li>There is no cure for schizophrenia</li> <li>Insufficient recognition in treatment programmes that level of burden is shaped by interaction between intrinsic vulnerabilities caused by the disease and the psychosocial environment</li> <li>Hospitalization with the aim of removing people with schizophrenia from public places or facilities, or otherwise restricting their freedom</li> <li>Severe adverse effects of antipsychotic drugs (neurological extrapyramidal effects), interfering with psychosocial and vocational adjustment, lead to non-compliance with medication, and contribute to stigma.</li> <li>Treatment gap in developing countries: 67% or 17 million patients are not receiving treatment</li> <li>Lack of specialists and general health workers with the knowledge and skills to manage schizophrenia across all levels of care</li> <li>Lack of resources</li> </ul>	<ul style="list-style-type: none"> <li>Stigmatizing environment (including workplace)</li> <li>Mental health legislation inadequate or absent</li> <li>Neglect of the large number of patients who have lost their supportive network and are homeless, vagrant or in prison</li> <li>Poor coordination between services including non-health sector</li> </ul>	<ul style="list-style-type: none"> <li>Insufficient awareness of the size of the problem and the existence of cost-effective interventions capable of reducing the burden of the disease</li> <li>Lack of a coherent mental health policy</li> </ul>

## Insert 4.7 (continued) Schizophrenia: application of the CAM

Levels of potential intervention →	A. Level of the individual, family & community	B. Level of the health ministry, health research institutions, and health systems & services	C. Level of sectors other than health	D. Level of central government and macroeconomic policies
<p>a. Interventions currently available</p>	<ul style="list-style-type: none"> <li>• Reduction of stigma</li> <li>• Protection of patient's human rights</li> <li>• Prevention of premature mortality (e.g. suicide)</li> <li>• Prevention of criminal and offending behaviour</li> <li>• Skills training and illness self-management</li> </ul>	<ul style="list-style-type: none"> <li>• Antipsychotic medication (conventional antipsychotics, (e.g. phenothiazines) and atypical antipsychotics (e.g. clozapine)</li> <li>• Cognitive-behavioural therapy for psychotic symptoms</li> <li>• The Primary Health Care model</li> <li>• Family interventions</li> <li>• Group interventions focused on the patient</li> <li>• Therapeutic communities</li> <li>• Short-term hospitalization for acute care in accordance with ethical guidelines by international bodies, such as WHO</li> </ul>	<p>• In contrast to prevention, there is sufficient knowledge of interventions that can substantially ameliorate the course of schizophrenia and reduce the resulting impairments and disabilities:</p> <ul style="list-style-type: none"> <li>• Supported employment approach to vocational rehabilitation</li> <li>• Nonstigmatization programmes</li> <li>• Mental health legislation</li> <li>• Consumer empowerment</li> </ul>	<ul style="list-style-type: none"> <li>• Formulation of mental health policy (e.g. as part of health sector reforms)</li> <li>• Mental health awareness programmes (e.g. declaration of a mental health day)</li> </ul>
<p>b. How cost-effective are current intervention?</p>	<ul style="list-style-type: none"> <li>• Community-based management programmes involving at least three operational components: <ul style="list-style-type: none"> <li>– Pharmacological treatment aimed at symptom control in acute episodes, maintenance of stabilization and prevention of relapse, and means of ensuring adherence to treatment protocol</li> <li>– Mobilization of family and community support, including provision of education about the nature of schizophrenia and its treatment, involving the family in simple problem-solving skills training, and involving the local community in providing a supportive and nonstigmatizing environment</li> <li>– Local rehabilitation, such as maintaining the patient in appropriate work and social roles within the community, and creating opportunities for occupational and social skills training</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Antipsychotic medication: conventional drugs are effective and inexpensive (chlorpromazine) but cause severe adverse effects. Atypical drugs cause fewer</li> </ul>		

3. What is the present level of knowledge?	<p>adverse effects, but are more expensive. Cost-effectiveness studies of conventional vs. atypical antipsychotics originate in developed world. To achieve universal availability at low cost conventional antipsychotics are clearly to be preferred (pending that current atypicals come off-patent).</p>		
	<ul style="list-style-type: none"> <li>• Many of the psychological approaches have not been evaluated by economists, nor have the newest atypical antipsychotics.</li> <li>• There are few if any evaluations of specific combinations of pharmacological and psychological therapies.</li> <li>• There is little evidence of the economic consequences of side effects or non-compliance, yet one would suspect these to be important drivers of long-term costs.</li> <li>• Research findings point to areas where cost savings may be achieved in principle, but they may not lead to cost savings in practice: with the growth of community-based care involving multiple agencies with their own budgets and their own ways of working, there is little evidence about the incentives and constraints that might help or hinder integrated responses to schizophrenia</li> </ul>		
4. What is to be expected in the future?	<p>a. Interventions</p> <ul style="list-style-type: none"> <li>• Research into the aetiology of schizophrenia, particularly genetic epidemiology, neurobiology</li> <li>• Research into prognosis and outcome of schizophrenia in developing countries</li> </ul>	<ul style="list-style-type: none"> <li>• Research into interactive interventions involving the patient, the family, and the community, cognizant of the fact that biological vulnerability and environmental influences interact and potentiate each other at every stage of schizophrenia (treatment, stabilization, and residual)</li> <li>• Research into preventive intervention, e.g. through early detection and avoidance of treatment delay</li> </ul>	
	<p>b. Cost-effectiveness</p>	<ul style="list-style-type: none"> <li>• Research capacity building through on-site education, exchange programmes and distance learning</li> <li>• Development of local networks that link centres with the requisite expertise to their surrounding community, and creation of regional networks linking such centres through joint training programmes, staff exchanges and collaborative research</li> <li>• Partnerships between lead institutions in high-income countries and such collaborative networks in low-income countries</li> </ul>	
5. Resource flows			

Source: Global Forum for Health Research

#### 4. Experiences using the CAM at the country level

The CAM is currently being used as a tool to help identify research priorities in the following exercises:

##### (a) Perinatal and neonatal health in Pakistan

In Pakistan, the CAM was used to assess potential research priorities in perinatal and neonatal care, widely acknowledged to be a greatly under-researched and under-resourced area.<sup>28</sup> The following main areas were highlighted for targeted research in future programmes:

- better regional and national estimates of perinatal and neonatal mortality/morbidity;
- evaluation of the socio-behavioural determinants of perinatal and neonatal mortality/morbidity in diverse but representative settings;
- evaluation of the current barriers for care-seeking and potential acceptability of future intervention strategies.

It was highlighted that there were several large and community-based data sets on reproductive health and related behaviour already available from several government agencies and autonomous bodies.

As a specific proposal, it was suggested that these disparate data sets and additional information could be pooled under a collaborative research exercise to yield composite national estimates of disease burden. This composite analysis would give a comprehensive picture of existing reproductive health behaviour and practices that impact on perinatal and neonatal care in

Pakistan. Any gaps remaining could be the subject of further research.

Recommendations were made for studies to be conducted on cost-effective interventions in perinatal and neonatal care, especially those that combine elements of maternal and postnatal care. A specific attempt was made to address one such area, low birth-weight, using the CAM. Further assessment of other priority areas in perinatal and neonatal care – for example, birth asphyxia, infections and prematurity – is under way.

##### (b) The Indian Council of Medical Research

A paper presented in Forum 7<sup>29</sup> described the priority-setting exercise undertaken in 2003 by the Indian Council of Medical Research (ICMR) using the Combined Approach Matrix, which included the following steps:

- (i) The concept of priority setting was first discussed with the ICMR staff.
- (ii) A workshop was carried out amongst workers in ICMR and other agencies in India (including civil society) on health research and health research priorities.
- (iii) Directors of all ICMR Institutes met to discuss priorities in their area of work.
- (iv) An expert group of scientists from various disciplines in each Institute summarized the current knowledge in their respective fields and fed this information into the CAM.
- (v) A Strengths, Weaknesses, Opportunities and Threats (SWOT) analysis was undertaken using the completed CAM tables. Major achievements and contributions in the field were listed.
- (vi) Consultations with government officials,

<sup>28</sup> Ali N. Deputy Director, Save the Children, USA. A preliminary assessment of priorities in perinatal and neonatal care in Pakistan using the combined approach matrix. Paper presented in Forum 7, Geneva, December 2003.

<sup>29</sup> Kant L. Application of CAM to Identify Research Priorities of Indian Council of Medical Research. Paper presented in Forum 7, Geneva. December 2003.

NGOs and the community were undertaken on the basis of the results of the exercise. This helped to compare lists of priorities and gaps identified with those already set out by other groups in India, and by bilateral and international agencies.

- (vii) Gaps in health research relevant to India were then identified, among which ICMR selected malaria and visceral leishmaniasis for a more detailed analysis and identification of priority health research projects. The tables on malaria will be compared with those prepared by TDR. The two exercises will highlight the respective advantages and complementarity of the two institutions in malaria research (TDR at the global level and ICMR at the national level in India).
- (viii) The next step is for ICMR and its partner institutions to determine which institution in the Indian context will take responsibility for which priority research

project in the fields of malaria and visceral leishmaniasis (in which ICMR has a comparative advantage). Other research institutions will take responsibility for the other priority research projects, based on their own comparative advantages.

In summary:

- The priority-setting exercise compels institutions to think rationally and focus institutionally.
- The exercise requires training and practice to fill in the CAM.
- In the first phase, the exercise often identifies more gaps than priorities as a large amount of information essential for rational decisions on research priorities is unavailable, particularly in the fields of cost-effectiveness data, factors affecting health behaviour and the impact on people's health of sectors other than health and of macroeconomic policies.

## Section 5

### Technical issues concerning the economic dimensions of priority setting

#### 1. Comparison of mortality with DALYs

In the past, mortality figures were the leading concern of policy-makers. Deaths attributable to specific diseases had the power to advocate for specific interventions focusing on the causes of mortality. However, this mortality-focused approach has gradually shifted following the development in the early 1990s

of the summary measures integrating mortality, morbidity and disability in a single burden of disease index.

As shown in Insert 4.8, mortality measures and summary measures (such as DALYs) lead to a very different ranking of diseases by burden.

## Insert 4.8

### Comparison of mortality measures and DALY measures for all countries

Mortality measure	% of total	Ranking	DALY measure	% of total	Ranking
Ischaemic heart disease	12.6	1	Ischaemic heart disease	3.9	6
Cerebrovascular disease (stroke)	9.6	2	Cerebrovascular disease (stroke)	3.3	7
Lower respiratory infections	6.6	3	Lower respiratory infections	5.8	2
HIV/AIDS	4.9	4	HIV/AIDS	5.8	3
Chronic obstructive pulmonary disease	4.8	5	Chronic obstructive pulmonary disease	1.9	>10
Perinatal conditions	4.3	6	Perinatal conditions	6.5	1
Diarrhoeal diseases	3.1	7	Diarrhoeal diseases	4.1	5
Tuberculosis	2.8	8	Tuberculosis	2.4	10
Trachea, bronchus, lung cancers	2.2	9	Trachea, bronchus, lung cancers	0.8	>10
Malaria	2.1	10	Malaria	3.0	8
			Unipolar depressive disorders	4.5	4
			Road traffic accidents	2.6	9

Source: Global Forum for Health Research

Note: Ischaemic heart disease and cerebrovascular disease (stroke) are the two leading causes of death globally, followed by lower respiratory infections and HIV/AIDS. However, among the diseases accounting for the highest disease burden (i.e. including mortality, morbidity and disability) perinatal conditions, lower respiratory infections, HIV/AIDS and unipolar depressive disorders are ranked highest. In terms of age-related DALYs, 36% of the world's burden of disease and injury, in 2002, was accounted for by children aged less than 15 years, and almost 50% by adults aged 15–59 years.

## 2. Developments regarding DALYs

The measure of DALYs has been used in the Global Burden of Disease Study (GBD)<sup>30</sup> and in a number of National Burden of Disease Studies. One DALY can be thought of as one year of 'healthy' life lost and the burden of disease as a measurement of the gap between current health status and an ideal situation where everyone lives into old age free from disease and disability.

WHO is currently undertaking version 3 of the GBD Project for the year 2000,<sup>31</sup> using DALYs as a summary measure. The

primary objective of the GBD study is the development of comparable, valid and reliable epidemiological information on a wide range of diseases, injuries and risk factors. In summary, the objectives of the GBD 2000 study are the following:

- develop internally consistent estimates of mortality from 135 major causes of death, disaggregated by age and sex, for the world and major geographic regions;
- develop internally consistent estimates of the incidence, prevalence, duration and case-fatality for over 500 sequelae resulting from the above causes;

<sup>30</sup> Murray CJ and Lopez A. *Global Burden of Diseases and Injuries*. Volume 1, WHO, 1996.

<sup>31</sup> Global Programme on Evidence for Health Policy, Discussion Paper No. 54, WHO, 2003.

- quantify the burden of premature mortality and disability by age, sex and region for 135 major causes or groups of causes;
- analyse the contribution to this burden of major physiological, behavioural and social risk factors by age, sex and region.

The *World Health Report 2003* presents burden of disease estimates for 2002 based on Version 3 of the GBD study. The data sources and methods used for Version 3, together with methods used to prepare country-specific estimates of burden of disease and healthy life expectancy, are also documented.

### 3. Further research on disease burden measurement

#### (a) Deficiencies in contextual measurement

Current assessments of population health that attempt to account for the burden of morbidity tend to ignore the contexts in which the health conditions occur, i.e. the social, cultural or environmental context. This failure to take account of contextual considerations has important implications, as a study funded by the Global Forum has highlighted.<sup>32</sup> The authors argue that the disability weights associated with each condition are currently fixed across all social, cultural and environmental contexts. Thus, blindness in the UK is given the same disability weight as blindness in Niger in spite of structural interventions in the UK that make the disability less severe than in Niger. The authors conclude that the lack of consideration of contexts results in a measure that will underestimate the burden associated with morbidity in disadvantaged populations and overestimate the burden in advantaged populations.

Using qualitative and quantitative techniques,

the study examined the impact of two health conditions (epilepsy and paraplegia) on people living in different contexts. The contexts were varied by country (Australia and Cameroon) and by environment (urban and rural); the effects of gender and socioeconomic status were also examined.<sup>33</sup> In each context, the participants completed a variety of tests and interviews.

Not surprisingly, both qualitative and quantitative tools revealed that people with paraplegia in Australia were substantially better off than those in Cameroon. The lack of infrastructure in Cameroon in general and in the rural areas in particular made coping with paraplegia extremely difficult. Indeed, in Cameroon paraplegia is generally regarded as a terminal condition, while facilities available in Australia make it possible to cope with this condition. In addition, it was evident that participants who were financially better off could buy the equipment and services they required to improve their quality of life.

The study underlined the importance of distinguishing summary measurement of health (using measures such as DALYs which attempt to quantify average levels of health in the population) from measurement of broader quality of life or well-being. Ignoring the context in which health conditions occur may reinforce existing inequalities in health. In the past two years, WHO has embarked on large-scale efforts to improve the methodological and empirical basis for the valuation of health states.

#### (b) Co-morbidity

It is also important to quantify the effect of co-morbidity (i.e. more than one disease or condition affecting the same individual). The GBD 1990 study used an additive model in

<sup>32</sup> Reidpath D et al. "Measuring health in a vacuum: examining the disability weight of the DALY" *Health Policy and Planning* 18(4):351-356.

<sup>33</sup> Ibid.

which, for the same individual, the average time spent in two different health states were combined. The GBD 2000 work being undertaken at WHO is examining co-morbidity in more detail, particularly for mental disorders.

#### **(c) Measuring the impact of a health problem on third parties**

A condition affecting one individual can also have a major impact on others (e.g. a relative of an alcoholic or drug addict). While the measurement of disease burden would estimate the impact of alcohol or drugs on morbidity, disability and mortality, it would not estimate the time invested by third parties in caring for these patients.

Taking these effects on third parties into account could substantially increase the assessment of burden of certain diseases and change the ultimate ranking of diseases, in a way that would reflect the different context in each country or community. This has important implications for health research policies.

#### **(d) Future steps**

Over the past decade, information on the global burden of disease has had a powerful influence on policy-makers and led to a radical shift in policy. The challenge now is to continue promoting and refining these methods as a quantitative tool, and to use the information to guide research priorities and the allocation of funding. Continued work is needed to improve the usefulness of these summary measures, in particular with respect to contextual measurement, co-morbidity, and measuring the impact of ill health on third parties. Ignoring these factors may reinforce already existing inequalities in health.

#### **4. Challenges in research into risk factors**

The expansion of focus from disease burden to risk factors is an important step for future improvements in policies. Modification of risk factors, such as reducing malnutrition in a given population, is likely to have a large impact on a variety of diseases. In some cases, determinants may not only be relevant in efforts to prevent disease but also in treatment, as in the case of reducing salt intake for high blood pressure, for example.

Version 2 estimates of the GBD 2000 study measured the prevalence of selected major causes of disease burden by sub-region.<sup>34</sup> It formed the basis for the comparative risk assessments for 20 major risk factors and the analyses of the cost-effectiveness of interventions for these risks which were the main topic of the *World Health Report 2002*.

Over 30 countries are at various stages in undertaking these assessments and WHO support to these efforts through the provision of best “prior” estimates of national burden of disease not only ensures better data for planning but also enables further development and testing of tools to facilitate burden of disease assessments. This iterative process contributes towards the ongoing updating of the global and regional burden of disease estimates.

Work is under way to develop national ‘comparative risk assessment’ software tools for the assessment of the attributable burden of 20 major risk factors.

Insert 4.9 details the selected risk factors to be studied in the GBD 2000 study.

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<sup>34</sup> World Health Organization, *World Health Report 2002*.



## Insert 4.9

### *Risk factors included in the CRA component of the Global Disease Burden 2000 Study*

1. Alcohol	11. Selected occupational risks
2. Blood pressure	12. Ambient air pollution
3. Cholesterol	13. Physical inactivity
4. Climate change	14. Tobacco
5. Illicit drugs	15. Unsafe injection practices in medical settings
6. Indoor smoke from biofuels	16. Unsafe sex and unplanned pregnancies
7. Lead	17. Unsafe water, sanitation and hygiene
8. Childhood and maternal under-nutrition	18. Non-breastfeeding
9. Obesity and overweight	19. Childhood sexual abuse
10. Lack of fruit and vegetable intake	20. Distribution of risk factors by poverty

Source: GBD 2000

The GBD 2000 study selected risk factors on the basis of the following criteria:

- (i) leading causes of disease burden
- (ii) neither too specific nor too broad
- (iii) high likelihood of causality
- (iv) reasonably complete data
- (v) potentially modifiable.

These characteristics are more likely to fit proximal determinants in the causal web rather than distal determinants. Poverty is an example of a distal determinant (see chapter 1, section 1 on the vicious circle between poverty and ill health). The distribution of risk factors by level of poverty has been attempted and may lead to new approaches to tackle these problems. The challenge now is to expand this analysis and to obtain better estimates of the contribution of risk exposure to disease.

### **5. Challenges in the cost-effectiveness analysis of health interventions**

Cost-effectiveness analysis requires the following information: (i) the extent to which current and potential interventions improve

population health (i.e. effectiveness); and (ii) the resources required to implement the interventions (i.e. costs).

Cost-effectiveness analysis is a useful tool to help policy-makers and programme managers decide between different ways of spending scarce resources in efforts to improve population health. It provides information on which interventions are likely to provide the greatest improvements in health for the available resources, a key input for decision-makers. Cost-effectiveness analysis can identify whether a new tool or product is likely to lead to larger number of healthy life years gained for a given cost.

Some of the main difficulties encountered in cost-effectiveness analysis are summarized below:

#### **(a) Little information available from low- and middle-income countries**

There is a dearth of information on the cost-effectiveness of interventions in low- and middle-income countries. Transfer of findings

from high-income to low- and middle-income countries is not reliable given the extensive differences in causal relationships, infrastructure, costs and capacity.

Economic evaluation has acquired significant prominence among decision-makers, and many ministries of health in low- and middle-income countries have expressed an interest in designing a national package of essential health services using this method. Given the high cost of many economic evaluations in low- and middle-income countries, interest has also been generated in pooling data and the results of previously published studies.

A review of published literature demonstrated that very few economic evaluations of communicable disease interventions in low- and middle-income countries were published during 1984-1997.<sup>35</sup> Although the situation has improved since then, much remains to be done, including with regard to the development of tools for comparing cost-effectiveness measures across health interventions.

### **(b) Need for comparative data**

Why is it necessary to compare a wide variety of health interventions? Policy-makers are concerned with two questions requiring evidence on costs and effects:

- *Do the resources currently devoted to health achieve as much as they could?* To answer this question, the costs and effects of all interventions currently employed must be compared with the costs and effects of alternative interventions. Reallocating resources from inefficient to efficient interventions can substantially increase population health with no change in costs.
- *When additional resources become available,*

*how can these be best used?* This type of analysis is critical for ensuring that, as societies become wealthier, additional resources are well used. But it is pointless asking this type of question if the current mix of interventions is inefficient; both questions need to be asked together.

### **(c) Developing tools for generalized cost-effectiveness analysis**

In order to tackle the difficulties stated above, WHO has initiated the WHO-CHOICE project (*CHOosing Interventions that are Cost-Effective*). WHO-CHOICE is an 'aid to policy' which provides information on intervention costs and effects. The aim is to improve health systems performance. Health systems with very similar levels of health expenditure per capita show wide variations in population health outcomes. This is partly explained by variation in non-health system factors, such as the level of education of the population. But it is also due to the fact that some systems devote resources to expensive interventions with little impact on population health, while low-cost interventions with potentially greater benefits are not fully implemented.

WHO seeks to provide the evidence decision-makers need to set priorities and improve the performance of their health systems. WHO's Global Programme on Evidence for Health Policy has contributed to this question in the following way:

- developing tools and methods for generalized cost-effectiveness analysis;
- assembling regional databases on the costs, impact on population health, and cost-effectiveness of key health interventions.

The Project is currently assembling regional databases on the cost and effectiveness of

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<sup>35</sup> Walker D and Fox-Rushby J. "Economic evaluation of communicable disease interventions in developing countries: a critical review of the published literature" in *Health Economics* 2000; 9(8): 681-698.

approximately 500 preventive, promotive, curative and rehabilitative health interventions using a standardized methodology. Regional databases containing raw data on costs and effects are being developed for analysts from different

countries to use and, if required, to modify the basic assumptions to make them consistent with their own settings. Completed examples of the use of CHOICE are available for over 250 interventions.<sup>36</sup>

## Section 6

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### Comparison of outputs of priority-setting exercises

This section reviews the recommendations made over the last 14 years by different international bodies regarding the priority areas for research into diseases/conditions and risk factors, which show a large consensus on the priority diseases and determinants to be studied at the global level. These are typically the high-burden diseases receiving very little research funding, which are easily identifiable.

In order to correct the 10/90 gap, more investments are needed for research into these diseases. There are two ways to accomplish this. One is to focus research investments on disease-specific interventions (such as medicines, vaccines and diagnostic tools) and disease-specific policies. A second approach is to focus on cross-cutting factors which influence the burden represented by these diseases, such as poverty, malnutrition,

population pressure, inequity and inefficiency of health services, behavioural factors, corruption or lack of health research capacity. Both approaches (diseases and risk factors) are essential and their interaction is vital if health research is to be effective and efficient.

Insert 4.10 offers an overview of the global recommendations made by different international committees over the past 14 years on priority diseases for health research, while Insert 4.11 summarizes the priority risk factors which need to be addressed.

Beyond this, it is also essential to establish what the research priorities are within each of these priority areas. This issue is dealt with in chapter 9, which reviews the actions undertaken in the past two years by specific disease networks and partnerships in addressing specific risk factors.

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<sup>36</sup> Available at [www.who.int/evidence/cea](http://www.who.int/evidence/cea)

## Section 7

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### Conclusions

In summary:

- The failure in practically all countries to establish a process for priority setting based on the burden of diseases and their causes has led to a situation in which only about 10% of health research funds from public and private sources are devoted to the diseases that account for 90% of the world's health burden.
- This extreme imbalance in research funding has a tremendous economic and social cost for individuals, countries and the world as a whole.
- To make matters worse, even the 10% of research funds allocated to 90% of the world's health problems are not used as effectively as they should be and need to be better prioritized.
- The prioritization of health research should take place at the local, national and global levels, as resources are invested in health research, in one form or another, at all three levels. The three levels should be linked in an iterative process and involve all stakeholders.
- The priority-setting process is a subjective process. In order to make the results as objective as possible, it is essential (i) to adopt a priority-setting process which is as transparent and as participatory as possible and (ii) to apply a methodology which is as scientific as possible.
- A number of processes and methodologies for the prioritization of health research were developed in the 1990s (in particular ENHR, the Five-Step Process and the Visual Health Information Profile).
- The CAM is an attempt to combine the main advantages of these methods. It incorporates both the economic and institutional dimensions of priority setting in health research.
- The prioritization process in health research should encompass all factors affecting people's health, i.e. not only basic, biomedical, clinical and laboratory research, but also health systems, demography, social and behavioural sciences, economics, management, macroeconomic policies, and sectors other than health having a large impact on health in the country.
- Priority setting is a long-term effort. The information will inevitably be partial in the first exercises, probably even sketchy in some cases, but the tool should demonstrate its usefulness at an early stage by highlighting the most important gaps in the information needed to make the best possible use of the limited resources available for health research, so as to have the largest impact possible on people's health (i.e. the largest number of healthy life-years saved) for a given research budget.

## Insert 4.10

### Key recommendations for health research regarding diseases/conditions over the past 14 years

Health research priorities	Commission Report (1990)	Ad Hoc Committee (1996) <sup>1</sup>	ACHR (1997)	ENHR Projects (1999) <sup>2</sup>	International Conference (2000) <sup>3</sup>	Fogarty International Center (2001)	Global Forum (2002)
Tropical diseases (malaria, schistosomiasis, leprosy)	•	•	•	•	The International Conference 2000 focused on the need to improve health research systems to deal with nationally prevailing diseases	•	•
TB-HIV	•	•	•	•		•	•
Childhood diseases (diarrhoeal diseases and respiratory diseases)	•	•	•	•		•	•
Sexually transmitted infections	•	•	•	•		•	•
Dengue				•		•	•
Maternal mortality	•	•	•	•		•	•
Cancer/diabetes			•	•		•	•
Cardiovascular diseases	•	•	•	•		•	•
Mental/neurological diseases	•	•	•	•		•	•
Violence and injuries	•	•	•	•		•	•
Chronic degenerative diseases	•	•	•				

<sup>1</sup> Recommended establishment of a programme to review health systems, NCDs and capacity development.

<sup>2</sup> See ENHR projects (Indonesia, Tanzania and South Africa) reported in *The 10/90 Report on Health Research 2000*, Global Forum for Health Research, 2000 (pages 22-26).

<sup>3</sup> See chapter 3 for recommendations at the national, regional and global levels.

## Insert 4.11

### Key recommendations for health research regarding risk factors over the past 14 years

Health research priorities	Commission Report (1990)	Ad Hoc Committee (1996) <sup>1</sup>	ACHR (1997)	ENHR Projects (1999) <sup>2</sup>	International Conference (2000) <sup>3</sup>	Fogarty International Center (2001)	Global Forum (2002)
Health policies and systems	•	•	•	•	•	•	•
Health information systems	•	•	•			•	•
Gender and socioeconomic inequalities	•	•	•	•	•	•	•
Health equity				•	•		•
Health cost and financing	•	•	•			•	•
Capacity building for health policies	•	•			•	•	•
Health behaviour research				•	•	•	•
Health impact of development of other sectors	•		•	•	•		•
Sustainable health research linked to development	•		•	•	•		
Environmental degradation			•			•	•
Child nutrition research	•	•	•				•
Food security			•	•			
Formal education			•	•	•		•
Education by health sector	•		•	•	•		•
Food and water management			•	•			•
Research on social justice				•	•		
Occupational health				•			•
Reproduction and contraception	•	•			•	•	•
Population dynamics	•		•			•	•

<sup>1</sup> Recommended establishment of a programme to review health systems, NCDs and capacity development.

<sup>2</sup> Recommendations depend on each country situation. See ENHR projects (Indonesia, Tanzania and South Africa) reported in *The 10/90 Report on Health Research 2000*, Global Forum for Health Research, 2000 (pages 22–26).

<sup>3</sup> See chapter 3 for recommendations at the national, regional and global levels.

# Chapter 5

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## *Progress in measuring the 10/90 gap*

### *Section 1*

*Measuring financial flows: review of ongoing efforts*

### *Section 2*

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## Section 1

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### Measuring financial flows: review of ongoing efforts

#### 1. Background

The Commission on Health Research for Development drew attention to the importance of health research as the “essential link to equity in development.”<sup>1</sup> It proposed that low- and middle-income countries should review and strengthen the management of health research so as to meet their national needs as well as contribute to the global fund of knowledge. The Commission also recommended that governments in low- and middle-income countries should allocate at least 2% of national health expenditures for research and that 5% of the foreign aid budget in the health sector be assigned to health research and capacity strengthening. The Commission hoped that these financial arrangements would provide a secure foundation for funding the priority research needs in low- and middle-income countries, based on the new concept of Essential National Health Research (ENHR).<sup>2</sup>

However, with few exceptions, neither the low- and middle-income countries nor the donor community enthusiastically followed up the Commission’s recommendations. Furthermore, since most low- and middle-income countries were not actively tracking the pattern of spending on health research, it was difficult to know how close they were to the target and what trends were occurring

over time. One major obstacle was the lack of tested methodologies for monitoring spending on health research at the country level.

In an attempt to fill this gap, the Global Forum and its partners have tackled the problem through their support of a network of investigators. This chapter summarizes the main points of the most recently published report measuring financial flows for health research<sup>3</sup> and ongoing efforts in this area. The tentative results from a few countries should stimulate others to follow the example and provide data from many more countries. Ideally, other studies will adopt the core definitions in order to facilitate comparisons among countries and also to examine trends over time.

#### *Why measure resource flows?*

Knowledge of resource flows for health research is an important input into priority setting. Although funding agencies and companies in the public and private sectors may have internal mechanisms to track health R&D expenditures, the available data is very fragmented. The Organization for Economic Cooperation and Development (OECD) is the only institution with a mandate to regularly collect and disseminate standardized national statistics on aggregated health-

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<sup>1</sup> Commission on Health Research for Development. *Health Research: Essential Link to Equity in Development*, New York, Oxford University Press, 1990.

<sup>2</sup> Task Force on Health Research for Development. *Essential National Health Research. A Strategy for Action in Health and Human Development*, Geneva, UNDP, 1991.

<sup>3</sup> Global Forum for Health Research. *Monitoring Financial Flows for Health Research*, October 2001.



related R&D for its Member States. R&D funds are reported as part of science and technology (S&T) information. While no equivalent institutional mechanism exists in low- and middle-income countries, information on resource flows has recently begun to emerge, as described below.

The challenge now is to institutionalize health R&D indicators which can be collected in low- and middle-income countries, countries in transition and high-income countries. Wherever possible, such indicators should draw on existing international statistical standards. Consistency will facilitate comparisons between countries while also meeting national and regional needs.

A detailed mapping of resource flows will help decision-makers in both high-income and low- and middle-income countries to target, and therefore better allocate, funds supporting health R&D. Mapping will also help monitor shifts in R&D funding allocations towards the most important health conditions and determinants, identify the areas which do not attract enough funding, and avoid unnecessary duplication of research efforts. These measures, in turn, are expected to have a significant impact on reduction of the burden of disease and injury in low- and middle-income countries, particularly among the poor.

Following on from the 1990 Report of the Commission on Health Research and Development, the 1996 Report of the WHO Ad Hoc Committee on Health Research reiterated the importance of establishing an institutional mechanism for the systematic tracking of investments in health R&D.<sup>4</sup> Although the Ad Hoc Committee Report

provided summary data on public and private investments in health research and estimated global health research investments at US\$ 56 billion, the authors acknowledged the complexity of developing a reliable system to monitor resource flows. The report also confirmed the earlier finding that less than 10% of health research funding worldwide was allocated to the diseases and conditions that account for 90% of global disease burden.

A number of initiatives are under way to measure financial flows. The major challenges are to standardize the methodologies used for data collection, gather high quality information, and present this in a way which is relevant and useful for policy-makers.

The following are examples of ongoing efforts to measure financial flows.

## 2. Global Forum for Health Research

The Global Forum and other institutions embarked on a project to collect information with the goal of improving priority setting through developing a database of internationally comparable statistics on global resource flows for health research. The results from the first phase of this project were reported in *Monitoring Financial Flows for Health Research*<sup>5</sup> which tracked resources for the year 1998. The report estimated that in 1998 global funding for health research had risen to US\$ 73.5 billion and that 21 developing countries (15 from Latin America, four from South East Asia, plus Turkey and India) financed 3% of this total. The report noted that where data was available, health research expenditure from middle-income countries was considerably higher than that estimated for the 1996 Ad Hoc

<sup>4</sup> Ad Hoc Committee on Health Research. *Investing in Health Research and Development*, Geneva, WHO, September 1996.

<sup>5</sup> Global Forum for Health Research. *op. cit.*

Committee Report. The extent to which this funding addressed the priority health needs of developing countries was not assessed. However, the need for disaggregated data on health research expenditure to be collected and disseminated was re-emphasized, as was the need for this data to include both the public and private sectors.

In addition to producing global results, the project was based on the following four strategies:

*Strategy 1:* Measure resource flows in additional developing and transition countries using the methodology developed in this study.

*Strategy 2:* Encourage the entities already compiling health statistics (e.g. OECD, UNESCO) to pay greater and more detailed attention to the monitoring of health research investments.

*Strategy 3:* Periodically obtain disaggregated data from large investors in advanced countries including ODA agencies, foundations and pharmaceutical companies.

*Strategy 4:* Influence partners with established interests and expertise in specific disease areas to do periodic studies of resource flows for the conditions representing the highest burden of disease in the world (e.g. International Union Against TB and Lung Disease, Wellcome Trust, WHO/TDR, WHO).

The Global Forum and other institutions are currently updating the information of the 2001 report on financial flows for health research and the results are expected to be

available at the World Summit on Health Research and Forum 8 in November 2004 in Mexico.

### 3. World Health Organization

As part of the Health Research Systems Analysis initiative, WHO plans to conduct national surveys to collect resource flows data.<sup>6</sup> A framework for conducting these studies was outlined in a background paper presented at Forum 7<sup>7</sup> including data on sources of funds, burden of disease and type of research activities conducted. The paper highlighted the importance of gaining data in a disaggregated format on sources of funds, diseases addressed and type of research conducted.

### 4. Council on Health Research for Development

COHRED's approach to measuring resource flows lies in the principle of strengthening in-country capacity to measure investments in health research. It produced original information for three Asian countries<sup>8</sup> and has currently completed the measurement of six other countries (see section 2, part 3 below).

### 5. National R&D surveys (OECD, UNESCO)

In many countries, the process of data collection has been institutionalized within the framework of S&T indicators, on the basis of relatively standardized methods. The OECD book *Measuring Expenditure on Health-Related R&D*, edited by Alison Young,<sup>9</sup> gives an excellent description of the complexities of these datasets and their strengths and weaknesses. In addition to the OECD, routine R&D data are collected on an international basis by the Ibero American

<sup>6</sup> Pang T *et al.* "Knowledge for better health - A conceptual framework and foundation for health research systems" in *Bulletin of the World Health Organization*, 2003.

<sup>7</sup> Kennedy A *et al.* Paper presented in Forum 7, December 2003.

<sup>8</sup> Alano B and Almeida S. *Tracking country resources for health research*, Manila, Centre for Economic Policy Research, 2000.

<sup>9</sup> OECD. *Measuring Expenditure on Health-Related R&D*. Paris, 2001.

Network of Science and Technology Indicators (RICYT)<sup>10</sup> (see below) and UNESCO. These routine data collection methods, whilst well established and producing stable reliable estimates of overall national funding for R&D, have some limitations when used to measure health-related R&D. UNESCO is currently revising the recommended system of S&T indicators for developing countries.

- *OECD R&D information*

The OECD R&D database includes data for 39 countries (of which 24 are advanced countries, seven transition countries and eight middle-income with two more, India and South Africa, on the verge of inclusion). This coverage goes beyond OECD membership to include countries which are formal or informal members of the OECD Committee for Scientific and Technological Policy or because they are included in the outreach exercise of the Directorate concerned.

The main data series are published twice yearly in *Main Science and Technology Indicators*. The more detailed series needed to estimate national expenditure on health-related R&D are mostly included in *Basic R&D Statistics* which is published annually on CD-ROM and every two years in printed format.

Between 1999 and 2001, groups led by individual countries reviewed various areas of national and R&D survey methodology and practice with a view to making proposals for changes in the underlying methodology for R&D surveys known as the *Frascati Manual*. Statistics Canada led a group to review the problems of measuring health-related R&D.<sup>11</sup>

- *OECD R&D in national health accounts*

The principal goal for developing national health accounts (NHA) is to support health systems governance and decision-making by providing a fully coherent set of tables which give a complete account of all expenditure for health regardless of its origin, destination or the objective of the actors involved and which can be used for ongoing analysis (as opposed to one-time study).

The OECD published *A System of Health Accounts* in 2000. It has recently been followed by the *Guide to Producing National Health Accounts with special applications for low- and middle-income countries* promoted by the World Bank, WHO and USAID (WHO, 2003).<sup>12</sup>

## 6. The Ibero American Network of Science and Technology Indicators (RICYT)

The Ibero American Network of Science and Technology Indicators (Red Iberoamericana de Indicadores de Ciencia y Tecnología – RICYT) was created in 1995. Its general aim is to promote the development of instruments for the measurement and analysis of science and technology in Latin America, within a framework of international cooperation, with a view to increasing their use as a political instrument for decision-making.

RICYT organizes workshops on the methodological problems of science and technology indicators in Latin America (one result has been the publication of a Latin American manual of indicators on technological innovation, the *Bogotá Manual*), collects and publishes indicators for the region, creates mechanisms of mutual

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<sup>10</sup> RICYT (Red Iberoamericana de Ciencia y Tecnología). *El estado de la ciencia: principales indicadores de ciencia y tecnología Iberoamericanos/Interamericanos*, Quilmes, RICYT, 2000.

<sup>11</sup> OECD, op. cit.

<sup>12</sup> WHO, World Bank, WHO and USAID. *Guide to Producing National Health Accounts with special applications for low-income and middle-income countries*, Geneva, 2003.

assistance in Latin America and diffuses information about its activities via *Indicios*, a news and opinion bulletin and web page ([www.ricyt.org](http://www.ricyt.org)).

RICYT manages a database for 28 countries, covering financial and human resources for R&D and S&T (also including education and other scientific activities), bibliometrics, patenting and innovation activities. The data, sources and methods for each country can be consulted online and are published annually in *Main Ibero and Inter-American Science and Technology Indicators (Principales Indicadores de Ciencia y Tecnología)*. RICYT's

work on health research has been predominantly in the area of bibliometrics.<sup>13</sup>

## 7. Approaches regarding disease-specific investments

To measure the 10/90 gap, it is essential to obtain information on disease-specific investments (see below). The Wellcome Trust and Médecins Sans Frontières Access to Essential Medicines Campaign<sup>14,15</sup> have undertaken studies to estimate investments in specific tropical diseases research. In addition, research is currently under way to track disease-specific investments, in particular using bibliometric approaches.<sup>16</sup>

## Section 2

### Measuring financial flows: results to date

The main results of the work undertaken by the Global Forum and its partners in the past three years can be summarized as follows:<sup>17</sup>

#### 1. Global estimates

Based on partial estimates, public and private sources worldwide invested a minimum of US\$ 73.5 billion in health R&D in 1998 (i.e. about 2.7% of total health expenditures

worldwide). Governments in high-income countries, countries in transition and low- and middle-income countries invested at least US\$ 37 billion (50% of the total) and the pharmaceutical industry US\$ 30.5 billion (42%). Private, non-profit and university funds provided the remaining US\$ 6 billion (8%) (see Insert 5.1).

<sup>13</sup> Munoz TF et al. *Análisis de la Producción Científica en Ciencias de la Salud de los países de América Latina y el Caribe (Periodo 1999-2000)*, Madrid, RICYT, 2003.

<sup>14</sup> PRISM Report No. 7. *Malaria Research, an audit of international activity*, London, Wellcome Trust, September 1996; and Paper presented by Catherine Davies in Forum 7, Geneva, December 2003.

<sup>15</sup> Médecins Sans Frontières Access to Essential Medicines Campaign. *Fatal Imbalance: The Crisis in Research and Development for Drugs for Neglected Diseases*, Geneva, 2001; and Paper presented by MSF in Forum 5, Geneva, October 2001.

<sup>16</sup> Lewison G, Lipworth S and de Francisco A. "Input indicators from output measures: a bibliometric approach to the estimation of malaria research funding" in *Research Evaluation*, 2002. Vol 11, (3):155-163; and paper presented in Forum 6, Arusha, November 2002.

<sup>17</sup> Global Forum for Health Research. op. cit.

## Insert 5.1

### Estimated global health R&D funding 1998 (in billion of current US\$)

Sources of financing	Total (billion US\$)	Per cent of total
Public funding: high-income and transition countries	34.5	47
Public funding: low- and middle-income countries	2.5	3
Private funding: pharmaceutical industry	30.5	42
Private non-profit funding (foundations and universities)	6.0	8
Total	73.5	100

Source: Global Forum for Health Research, *Monitoring Financial Flows for Health Research*, 2001.

Overall investments in health R&D from public, industrial and non-profit sources increased in real terms in high-income countries during the 1990s, in contrast to a general decrease in the countries in transition. The figure of US\$ 73.5 billion contrasts with that of US\$ 56 billion in 1992. It is estimated that up to one third of the increase between 1992 and 1998 is in real terms. Data from low- and middle-income countries, when available, indicate considerably larger R&D investments in health from national sources than earlier studies had estimated.<sup>18</sup> While this increase reflects real growth in overall investments in health R&D, it probably also reflects better reporting for these countries.

## 2. Funding of health R&D in high-income and transition countries

### (a) Public funding of health R&D in high-income countries

Governments in high-income countries

invested US\$ 34.2 billion in health R&D in 1998. The United States provided over half of this amount, investing US\$ 19.5 billion. Japan contributed US\$ 2.9 billion, Germany US\$ 2.4 billion, France US\$ 2.2 billion, the United Kingdom US\$ 1.8 billion and Canada US\$ 0.75 billion. Together, the G7 countries (including a rough estimate for Italy) accounted for about 90% of total publicly funded health R&D in the high-income countries. All other high-income country governments together contributed an estimated US\$ 3.5 billion. These data were drawn from OECD and Eurostat R&D databases and reports of national R&D surveys and budgets.

For the United States, public funds spent for health R&D are estimated at about 0.22% of GDP, the highest figure among high-income countries. This is followed by Austria, Finland, France, the Netherlands and Sweden. The National Institutes of Health (NIH/USA) are by far the largest institutions

<sup>18</sup> Michaud C and Murray CJL. *Resources for health research and development, 1992: a global overview*. Annex 5 of *Investing in Health Research and Development*. Report of the Ad Hoc Committee on Health Research relating to future intervention options, Geneva, WHO, 1996.

funding health research worldwide. The NIH has doubled its budget over the last five years, to US\$ 27.3 billion in 2004 (see chapter 4).<sup>19</sup>

*Funding of global health issues by members of the European Medical Research Council*

At its Plenary Meeting in April 2002, the European Medical Research Council (EMRC)<sup>20</sup> identified the need to standardize and collect information on financial flows and the 10/90 gap. The group initiated a survey to test a methodology with a view to its implementation by all Member Organizations. The questionnaire was tested for the year 2001 in the following countries: Denmark, Finland, France, the Netherlands, Norway, Portugal and Sweden. The results of this pilot test indicated that the percentage of their total research budget allocated to global health issues was below 6% in all cases and was highest for the Netherlands Organization for Health Research and Development closely followed by Denmark. The remaining Member Organizations allocated less than 4% of their resources to global health research initiatives. The group suggested extending the survey to all countries represented in the EMRC Standing Committee, reiterated its commitment to research work addressing the 10/90 gap and established a working group for this purpose.

*(b) Public funding of health R&D in transition countries*

In 1998, the Czech Republic, Hungary, Poland, Romania, the Russian Federation, the Slovak Republic and Slovenia spent the equivalent of approximately US\$ 360 million on health R&D, of which government financing accounted for just over US\$ 200

million. However, the magnitude of R&D efforts is not adequately reflected in these dollar figures as a result of these countries' weak currencies. Comparisons of purchasing power parities reflecting the average cost of goods and services in each country, raises total health R&D funding to US\$ 800 million, of which an estimated US\$ 450 million was financed by public sources.

*(c) Funding of health R&D by foundations*

Private foundations and other not-for-profit organizations spent an estimated US\$ 3.4 billion on health research in 1998 of which US\$ 1.9 billion came from the United States, US\$ 700 million from the United Kingdom, US\$ 240 million from Japan, US\$ 200 million from Canada and US\$ 120 million from France. An estimated US\$ 200 million came from all other high-income countries combined.

The Bill and Melinda Gates Foundation contributed an amount of US\$ 189 million to health research in 2001. Other large private sponsors of research in 1998 were the Wellcome Trust in the United Kingdom and the Howard Hughes Medical Institute in the United States.<sup>21</sup> The Wellcome Trust aims to both extend the international knowledge base in tropical medicine and foster a productive research environment in developing countries so that these countries are better equipped to combat their own health problems.

The Howard Hughes Medical Institute is a biomedical research organization that supports biomedical research and education through geographically and topically defined competitive research grants. It currently has

<sup>19</sup> *The Lancet*, Vol 363 (9406) 31 January 2004.

<sup>20</sup> Paper presented by Ragna Valen, Research Council of Norway, in Forum 7, Geneva, December 2003.

<sup>21</sup> Global Forum for Health Research. op. cit.

programme grantees in 29 countries and is increasingly focusing on governments and scholars in low- and middle- income countries. It is involved in developing modular programmes that can improve science education and provides students with research opportunities in the laboratory.<sup>22</sup> The Institute invested around US\$ 389 million in 1998.<sup>23</sup>

The Nuffield Trust for Research and Policy Studies in Health Services was established in 1940 to help coordinate hospital and associated medical services throughout the United Kingdom.<sup>24</sup> Over the years, through its research grants, seminars, fellowships, publications, and national and international partnerships, in addition to funding health services research, the Trust has contributed significantly to the development of policy thinking on health services research.

*(d) Funding of health R&D by universities*

In addition to these sources, at least US\$ 2.5 billion was contributed to health research through the private funds of universities and colleges in Canada, Japan and the United States.

*(e) Funding of health R&D by the private pharmaceutical sector*

The pharmaceutical industry, including biotechnology companies, spent an estimated US\$ 30.5 billion in 1998, corresponding to 42% of all health R&D funding (Insert 5.2). Reported investment in R&D as a share of sales in the pharmaceutical industry ranged from 12% to 21% of turnover in the 15 companies with the largest R&D investment. The share was higher still in the 10 biotechnology companies making the largest R&D investments, corresponding to allocations of 26%-67% of revenues to R&D (Insert 5.2).<sup>25</sup>

It is estimated that in 1998, US-based pharmaceutical companies invested US\$ 20.3 billion in R&D in pharmaceuticals for human use, of which US\$ 16.9 billion was spent in the United States and US\$ 3.4 billion abroad.<sup>26</sup> Information on the cost of research and clinical trials for the discovery and development of medicines was not considered in this study.

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<sup>22</sup> Paper presented in Forum 7 by Jill Conley, Howard Hughes Medical Institute, USA.

<sup>23</sup> Global Forum for Health Research. *op. cit.*

<sup>24</sup> Paper presented in Forum 7 by John Wyn Owen, Secretary, Nuffield Trust, United Kingdom.

<sup>25</sup> Global Forum for Health Research. *op. cit.*

<sup>26</sup> Pharmaceutical Research and Manufacturers of America. *PMA Annual Survey 2000.*

## Insert 5.2

*R&D expenditures by major pharmaceutical and biotechnology companies, 1998  
(in millions of US dollars)*

15 leading pharmaceutical companies with largest R&D	R&D expenditures	As % of total pharmaceutical sales
AstraZeneca	2,183	17
Glaxo Wellcome	1,927	15
Roche	1,893	19
Merck & Co	1,821	12
Novartis	1,801	16
Bristol-Myers Squibb	1,559	12
Hoechst Marion Roussel	1,426	18
Johnson and Johnson	1,400	16
SmithKline Beecham	1,394	18
American Home Products	1,389	16
Rhone-Poulenc Rorer	1,010	17
Boehringer Ingelheim	866	19
Bayer	852	18
Novo Nordisk	420	21
Yamanouchi	415	17
<b>10 biotechnology companies with largest R&amp;D</b>		
Amgen	663	26
Chiron	108	NA
Genentech	396	55
Biogen	177	45
Alza	156	67
Immunex	92	NA
Genzyme	63	NA
British Biotech	20	NA
Chiroscience	51	NA
Genset	10	NA

Source: SCRIPS 1999, Pharmaceutical Company League Tables; Ernst and Young: European Life Sciences 99, Sixth Annual Report.



### 3. Funding of health R&D in low- and middle-income countries

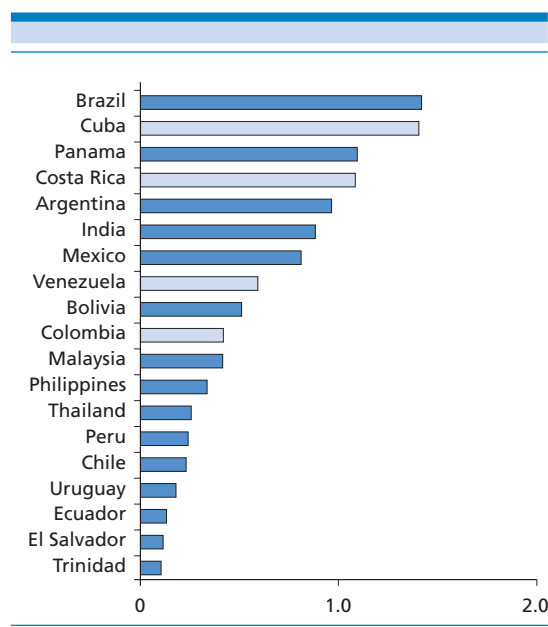
The study supported by the Global Forum and partners did not attempt to be a comprehensive review of all low- and middle-income countries investing in health research. It focused both on countries for which published information was available and on a few selected countries in which teams conducted special surveys on health R&D. A summary of the available information is provided below.

It is estimated that Argentina, Brazil, India, Malaysia, Mexico, Panama, Peru, the Philippines, Thailand and Turkey spent a minimum of US\$ 2.3 billion in 1998 on health R&D. Data for other low- and middle-income countries, among them countries which spend considerable amounts on health research such as the People's Republic of China, are not available at this stage and will be explored in the future.

The Commission on Health Research for Development recommended that at least 2% of national health expenditures in low- and middle-income countries should be allocated to health research and capacity building. Of the countries included in this study, Brazil and Cuba approached the 2% mark (Insert 5.3). Turkey was not included in Insert 5.3 as higher education subsidies in that country, particularly in state universities for medical education, influenced the high percentage reported.

### Insert 5.3

*Estimated health R&D in selected low- and middle-income countries as percentage of total health expenditures\**



Sources: Health R&D data supplied by specific country surveys; GDP: World Bank (2000) and RICYT (2000); Health expenditure: WHO (2000) and OECD (2000).

\* Pale countries are particularly rough estimates.

A three-country study supported by COHRED in Malaysia, the Philippines and Thailand traced investments in health R&D from the funding sources to the performers of the research projects concerned.<sup>27</sup> The survey concluded that these three countries spent over US\$ 33 million in 1997 and US\$ 30 million in 1998 (total expenditures by public and private sectors), with Thailand spending about 50% of the total.

Following the three Asian studies described above, a comparative report and manual were

<sup>27</sup> Alano and Almeida. op. cit.

designed and used to undertake studies in the following countries: Burkina Faso, Cameroon, Cuba, Kazakhstan and Hungary. In addition, studies are currently under way in Uzbekistan and Brazil.

The results of recent studies supported by COHRED were presented in Forum 7.<sup>28</sup> In summary, the main results and conclusions of the country studies reflected the following:<sup>29</sup>

- Hungary has by far the largest expenditure of the group of countries. The Hungarian government has committed to increase the ratio of gross expenditures on R&D to 1.9% of GNP after its accession to the European Union.
- In Burkina Faso and Cameroon foreign funds make up the majority of health R&D funds, whereas in Kazakhstan, Malaysia, Philippines and Thailand, the government sector is the largest contributor. The

dependency on foreign funds for health research projects has a large influence on the possibility of re-allocating funds towards the country's health and health research priorities.

- In Cuba all but 4% of funds were allocated to priority topics. But in Kazakhstan, less than 20% of total health R&D funds were allocated to health research priorities, despite the fact that government funds make up 90% of the national total and the Ministry of Health controls 95% of these funds. This difference may be attributed to the strength of the links between the national priority setting and fund allocation mechanisms.
- In both Kazakhstan and Indonesia<sup>30</sup> attempts are being made to institutionalize the tracking of resource flows. This will facilitate the improved linkage between health research priorities and resources.

## Section 3

### Measuring financial flows: difficulties encountered

Obtaining information on financial flows is time consuming, expensive and difficult due to the following factors:

- definitions are normally not standardized
- organizations surveyed do not systematically track or monitor health research in comparable ways
- staff are normally too busy to provide

information beyond the scope of their records and sometimes do not see the value in conducting these exercises

- questionnaires sent to funders in high-income countries are frequently not returned
- decentralization of management in ODA and multilateral organizations contributes

<sup>28</sup> Paper presented by Bing Alano in Forum 7, Geneva, December 2003.

<sup>29</sup> Details of the studies and further results can be accessed at [www.cohred.ch](http://www.cohred.ch).

<sup>30</sup> Indonesia has conducted resource flows studies on a regular basis since 1998.

- to problems in obtaining data on financial resources
- the importance and the relevance of the data on resource flows for investor organizations is often unclear when compared to other priorities
- fluctuations in exchange rates complicate the interpretation of data, especially long-term funding trends
- double counting is a problem which needs special attention
- obtaining data from funders in advanced countries on research funds actually spent in low- and middle-income countries is difficult
- lack of information, in particular on:
  - the global allocation of funds to R&D for specific diseases
  - public funding by advanced countries for northern institutions conducting R&D on problems important to low- and middle-income countries
  - pharmaceutical industry funding in low- and middle-income countries
  - disaggregated information from the pharmaceutical industry
  - cost of R&D to develop drugs and vaccines, including the costs of clinical trials
  - regular budget allocations by UN agencies such as WHO to health research (as differentiated from earmarked contributions)
  - link between health priorities identified by low- and middle-income countries and projects funded by national and international sources
  - share of public funds invested in fundamental research which eventually led to a marketed drug
  - funding for social science and health economics research.

## Section 4

### Measuring financial flows: an attempt to standardize the methodology by the Global Forum and its partners

There is a need to standardize the methodology for measuring health R&D financial flows. Improving the data available requires national ‘champions’ who will build an informed constituency bringing together producers and users of such data. In their efforts to improve the information on R&D investments in health research and tackle some of the problems mentioned above, the Global Forum and its partners have attempted to standardize the methodology in the following ways:

#### 1. Definition of health research and development

The OECD and UNESCO definitions were adopted for this study:<sup>31</sup>

*“Research and experimental development comprises creative work undertaken on a systematic basis in order to increase the stock of knowledge, including knowledge of man, culture and society, and the use of this knowledge to devise new applications.”*

<sup>31</sup> OECD *The Measurement of Scientific and Technological Activities, Proposed Standard Practice for Surveys of Research and Experimental Development, Frascati Manual 1993*, Paris, 1994.

## Insert 5.4

### Representation of health research funding

- A = R&D by high-income countries  
B = R&D by low- and middle-income countries  
A/B = R&D efforts converge or overlap  
(see text for details)



Source: Global Forum for Health Research, *Monitoring Financial Flows for Health Research*, 2001.

Under this definition, health research is a process for generating systematic knowledge and testing hypotheses, within the domain of medical and natural sciences as well as social sciences including economics and behavioural science. The information resulting from this process can be used to improve the health of individuals or groups.

### 2. Representation of health research funding

One objective of tracking financial flows in the project supported by the Global Forum was to measure total funding for health R&D worldwide, with a particular emphasis on R&D for or by low- and middle-income countries. Insert 5.4 illustrates the main components:

- “Area A” corresponds to the health R&D efforts of high-income countries.
- “Area B” represents the health R&D efforts of low- and middle-income countries.
- The overlapping “Area A/B” depicts where these efforts converge or overlap.

These three areas could be further defined in several ways. For the purpose of financial flows in the present study, “Area A” describes all health R&D *funded by* high-income

countries; and “Area B” describes all health R&D *financed by and carried out in* low- and middle-income countries. The “Area A/B” corresponds to R&D funded by high-income countries and carried out in and for the primary benefit of low- and middle-income countries. The area also incorporates R&D carried out in high-income countries which is for, or relevant to, the needs of low- and middle-income countries; and R&D carried out in low- and middle-income countries which is for, or relevant to, the needs of high-income countries. The three areas constitute the framework for project data collection.

Data on health R&D expenditures can be collected from the unit providing the funds (“the funder”) or from the unit actually carrying out the research (“the performer”). The data compiled within areas “A” and “A/B” were generally collected from funders, whereas the data for area “B” were collected from both performers and funders. Because the three categories of data were compiled using different approaches and from different sources, it was challenging to aggregate them into the global total, and especially to avoid double counting of area A/B.

The countries undergoing transition from centralized to market economies do not fit easily into the model. They are examined in a separate section but are also treated in the discussion of area A/B, as they are eligible for some of the types of support for health R&D traditionally oriented towards low- and middle-income countries.

### 3. Research classification framework

The main research categories used in the project supported by the Global Forum and its partners are presented in Insert 5.5. The aim was to produce a set of categories that would be useful for decision-makers, especially in low- and middle-income countries. It would, in addition, serve as a

framework for special surveys and for documenting data compiled from other sources.

### 4. An institutional classification

There are other dimensions by which R&D resource flows are commonly classified. These may include activity, discipline, topic, location, beneficiary and development outcome. Insert 5.6 represents an institutional classification of the main types of health R&D funders and performers.<sup>32</sup>

The user/performer classification was developed during the experimental health R&D surveys in selected low- and middle-income countries (Area B in Insert 5.4 above).

## Insert 5.5

### Classification of resource flows for health research

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Levels of aggregation of R&D funds

1. Basic research: non-oriented, fundamental research
2. Health conditions, diseases or injuries
  - Group I (communicable, maternal, perinatal, nutritional conditions)\*
  - Group II (noncommunicable diseases)\*
  - Group III (injuries)\*
3. Exposures, risk factors that impact on health (determinants)
  - Risk factors within the health system
  - Risk factors outside the health system
4. Health systems research
  - Policy and planning research
  - Health services delivery research
  - Surveillance
5. Research capacity building
  - Recurrent expenses
  - Capital expenditures

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Source: Global Forum for Health Research, *Monitoring Financial Flows for Health Research*, 2001.

\* Follows the Global Burden of Disease classification (Murray CJL et al, 1996).

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<sup>32</sup> Alano and Almeida. op. cit.

## Insert 5.6

### Classification of funders and performers

Sectors	Funders	Performers in low- and middle-income countries
<b>Public sector</b>	Government departments (national aid agencies)	Government departments Research institutes and universities Hospitals Others
<b>Private sector</b>	Pharmaceutical firms Private non-profit organizations	Pharmaceutical firms Academic/research institutes Hospitals/laboratories NGOs Others
<b>International</b>	Multilateral Bilateral	Foreign institutions Government departments Others

Source: Alano B and Almeida S, *Tracking country resources for health research*, Centre for Economic Policy Research, Manila, 2000.

#### 5. Diversification of data sources

Previous global resource flow studies have mainly focused on data from existing databases and estimated the data from low- and middle-income countries. The Global Forum-supported project extends that work by developing special surveys based on the new classification by making more extensive use of recently published datasets and by undertaking institution-specific case studies

involving personal contacts with funding agencies and low- and middle-income country institutions,<sup>33</sup> including:

- Funder questionnaires
- Special surveys for low- and middle-income countries
- Funder surveys/databases
- Government S&T surveys
- Evaluations, annual reports, websites
- Interviews/personal contacts.

<sup>33</sup> Global Forum for Health Research. op. cit.

## Section 5

### Measuring the 10/90 gap: comparing disease burden with investment in health research

The ultimate objective of measuring resource flows in health research is to make a judgement as to whether the limited research resources are allocated in the most efficient and effective way, as compared to the major health problems affecting a country. As shown in chapter 4, resource flows broken down by disease and risk factors are a crucial input in the CAM for priority setting in health research (Insert 4.2) which enables the measurement of overall progress in the 10/90 gap.

#### 1. Relating disease burden to investments in health research

Many diseases and risk factors accounting for a high level of burden in terms of morbidity

and mortality<sup>34</sup> suffer from very low levels of funding for research. These include, in particular, acute respiratory infections, diarrhoeal diseases, TB, tropical diseases, perinatal conditions and HIV/AIDS.

Although there has been no comprehensive review of financing flows relating to disease burden for all diseases, available evidence indicates that there are marked differences in the magnitude of research expenditures in comparison to the magnitude of the current or projected burden of disease.

### Insert 5.7

#### *Investment in health research for selected conditions*

Condition	Global disease burden (% total 1990 DALYs)	Investment in US\$ per DALY	Percentage of total investment in health research
Malaria	2.80%	1.89	0.10%
Acute lower respiratory infections	8.20%	0.51	0.10%
Diarrhoea	7.20%	0.32	0.06%
Road traffic injuries	2.50%	0.83	0.05%
TB	2.80%	0.68	0.05%

Source: Based on Murray CJ and Lopez A, *Global Burden of Diseases and Injuries*, WHO, 1996 and Report of the Ad Hoc Committee on Health Research and Development, 1996

<sup>34</sup> Murray CJ and Lopez A. *Global Burden of Diseases and Injuries. Volume 1*, WHO, 1996.

A study in 2000 indicated that in that year total expenditures for research on selected tropical diseases (leishmaniasis, malaria, trypanosomiasis and TB) which together accounted for about 5% of the total global disease burden (or 75 million DALYs), amounted to US\$ 383 million.<sup>35</sup> Of this, approximately US\$ 85 million was for drug R&D (0.11% of total global investment in health research) and a mere US\$ 1.13 per DALY. Investment in research into malaria,<sup>36</sup> for example, a disease which accounted for 3% of the global disease burden in 2002, mainly in

poor countries, is estimated to be US\$ 100 million a year or US\$ 2.2 per DALY – less than one twentieth of the average investments in health research per DALY as calculated by the Global Forum (US\$ 52 per DALY).

The table below illustrates the global research effort on specific diseases and the persistence of the 10/90 gap in health research financing. Funding for research on conditions occurring overwhelmingly or exclusively in low- and middle-income countries is extremely low.

## Insert 5.8

### Global research effort for three classes of diseases

Disease type and category	Global research effort	Epidemiology	Examples	Notes
(I) Not neglected diseases	High	<ul style="list-style-type: none"> <li>• Occurring in both rich and poor countries</li> <li>• Large vulnerable populations worldwide</li> </ul>	<ul style="list-style-type: none"> <li>• Hepatitis B</li> <li>• <i>Haemophilus influenzae</i> type b (Hib)</li> <li>• Diabetes</li> <li>• CVD</li> </ul>	<ul style="list-style-type: none"> <li>• High incentives for R&amp;D</li> <li>• Not widely applicable, nor accessible or sustainable for low- and middle-income countries</li> </ul>
(II) Neglected diseases	Low	<ul style="list-style-type: none"> <li>• Occurring in both rich and poor countries</li> <li>• Substantial proportion of burden in poor countries</li> </ul>	<ul style="list-style-type: none"> <li>• HIV/AIDS</li> <li>• Tuberculosis</li> </ul>	<ul style="list-style-type: none"> <li>• Substantial research ongoing in rich countries</li> <li>• Level of R&amp;D spending not commensurate with disease burden on a global basis</li> <li>• Low accessibility for poor countries</li> </ul>
(III) Very neglected diseases	Very low	<ul style="list-style-type: none"> <li>• Overwhelming or exclusive incidence in poor countries</li> </ul>	<ul style="list-style-type: none"> <li>• Malaria*</li> <li>• Chagas disease</li> <li>• Schistosomiasis</li> <li>• Leishmaniasis</li> <li>• Trypanosomiasis</li> <li>• Onchocerciasis</li> <li>• Lymphatic filariasis</li> </ul>	<ul style="list-style-type: none"> <li>• Extremely little R&amp;D funding</li> <li>• No commercially-based R&amp;D in rich countries</li> </ul>

Source: Global Forum for Health Research, *The 10/90 Report on Health Research 2001-2002*.

\* belongs also to category II, according to the Commission on Macroeconomics and Health.

<sup>35</sup> Médecins Sans Frontières Access to Essential Medicines Campaign. *Fatal Imbalance: The Crisis in Research and Development for Drugs for Neglected Diseases*, Geneva, 2001; and paper presented by MSF in Forum 5, Geneva, October 2001.

<sup>36</sup> Wellcome Trust. op. cit.



## 2. Bibliometric approaches

A review of papers published in the Science Citation Index between 1996 and 2001 presented in Forum 6<sup>37</sup> reflected the intensity of publications on research by disease. The study explored over 1.6 million papers published during this six-year period.

Of these published papers, research on diseases occurring predominantly or exclusively in low- and middle-income countries was low. For example, the total number of papers on pneumonia, diarrhoeal diseases, malaria and dengue accounted for less than 2% of the total, whereas the burden of these four diseases was over 13% worldwide in 2002 (as measured by DALYs). In the field of noncommunicable diseases (e.g. cardiovascular, mental and neurological diseases), which affect developing and developed countries almost equally, a very limited number of papers was devoted to the detection and management of these diseases at the primary health care level in low- and middle-income countries.

## 3. Challenges

### (a) Basic research and the 10/90 gap

A large proportion of public health research funds is invested in 'basic research', i.e. research which cannot be identified with a particular disease or risk factor and which opens new avenues for finding solutions to a large variety of known and unknown problems affecting all countries. Therefore, when ascertaining the 10/90 gap, the question arises whether these investments should be considered (i) as part of the research undertaken to attack diseases prevalent in low- and middle-income countries; (ii) as part of the research undertaken to attack diseases

prevalent in high-income countries; or (iii) taken out of the calculation of the health research gap altogether.

Based on the fact that, between 1975 and 1997, only 13 out of the 1233 drugs that reached the global market were for tropical infectious diseases that primarily affect the poor, investments in basic science have been categorized as part of the 90% of health research allocated to less than 10% of the global disease burden.

This draws attention to the fact that a determined effort by the public sector should be undertaken in the coming years to better link the results of basic research to the development of remedies for high-burden diseases. The private sector itself may also be attracted by the transformation of basic research results into products for high-burden diseases, given the growing market potential for these diseases.

### (b) Transferability of benefits of research from high- to low-income countries in general, and from rich to poor societies in particular

As a result of the demographic and epidemiological transitions experienced in low- and middle-income countries, these countries are likely to increasingly benefit from the research findings undertaken in high-income countries. However, the direct transferability of findings from high-income countries to low- and middle-income countries in general, and from rich to poor societies in particular, is limited by the following factors:

- communicable diseases not prevalent and not researched in high-income countries or richer societies continue to account for

<sup>37</sup> Lewison, Lipworth and de Francisco op. cit. and Lewison G Personal communication, 2002.

a large share of disease burden in low- and middle-income countries and poor societies

- vaccines developed for industrialized country markets may not be effective against the different types of viruses and bacteria prevalent in low- and middle-income countries
- determinants of ill health vary greatly between and within countries
- the level of development and performance of health systems and services vary greatly between and within countries
- access to treatment, medicines and other research results are very different between and within countries
- interventions for NCDs available in more advanced countries and richer societies

may not be directly adaptable, appropriate or cost effective in low- and middle-income countries and poorer societies due to costs and infrastructure requirements.

The communicable disease burden (as measured by the number of DALYs per 100 000 persons) is 13 times higher in low- and middle-income countries than in high-income countries.<sup>38</sup> For injuries, the burden in DALYs per 100 000 people is three times higher in low- and middle-income countries than in high-income countries, whereas NCDs have the same prevalence in both groups of countries. These differences are important in view of the fact that 85% of the world's population live in low- and middle-income countries.

## Section 6

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### Conclusions and future steps

- Although a crucial input for setting priorities in health research, there is very limited information about resource flows for health research and little awareness about their usefulness.
- Major obstacles are the lack of financial and human resources as well as the lack of tested methodologies for monitoring spending on health research at the country level.
- In an attempt to fill this gap, the Global Forum and its partners have tackled the problem through their support of a network of investigators and the development of methodologies which should facilitate comparisons among countries and permit identification of trends over time.
- The most recent (1998) figure available for

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<sup>38</sup> Global Forum for Health Research. *The 10/90 Report on Health Research 2001-2002*. 2002.

total global resource flows for health R&D is US\$ 73.5 billion, of which 50% is invested by governments, 42% by the private commercial sector and 8% by private non-profit institutions. These figures are currently being updated.

- None of the low- and middle-income countries funded health research to the level of 2% of national health expenditures as recommended by the Commission on Health Research for Development in 1990, with the large majority of them below 1%.
- Although substantial progress has been made in the understanding of the 10/90 gap and a number of strategies have been developed to tackle it since 1990 (see also chapter 3), the 10/90 gap in health research largely remains. Very determined efforts by all governments will be needed in the coming years to correct it in the following ways: (a) systematically link investments in health research to the burden of disease, both at the national and global levels; (b) establish strong links between basic research and the development of remedies for high-burden diseases and risk factors; and (c) invest research funds in improving the functioning of health systems and services.
- The establishment of an International Health Statistics Institute would be well placed to:
  - provide standardized methodologies and working definitions across the various institutions and countries
  - collect and collate received information on a routine basis
  - produce reports and disseminate information, allowing both global and local monitoring of trends and of the impact of policies and initiatives
  - act as a partner for capacity building at national and international levels.

# Chapter 6

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## *Gender, the MDGs and health research*

*Section 1  
Sex, gender and the 10/90 gap*

*Section 2  
Gender and the MDGs*

*Section 3  
Conclusions*

## Section 1

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### Sex, gender and the 10/90 gap<sup>1</sup>

#### 1. Introduction

The Global Forum believes that a systematic approach to gender issues must be a central part of its strategy for helping correct the 10/90 gap. It is estimated that around 70% of the world's poor are women. The health of these women is often adversely affected not only by their poverty but also by the gender inequalities that continue to divide many of the world's poorest countries. In response, the Global Forum is committed to achieving greater gender sensitivity in all its work.

Ensuring greater gender sensitivity in health-related research does not mean that this is concerned only with women. Men's health too may be affected in fundamental ways by both their sex and their gender and this is reflected in the analysis which follows. It is also important to emphasize that differences in the health problems of women and men are not only related to their reproductive biology or its social implications. Though these are important, it is also clear that more general health problems may be experienced very differently by women and men and may have different implications for their lives. The main emphasis in this chapter will therefore not be on the reproductive health problems specific to women (or men) but on the sex and gender differences in those health problems that affect both sexes.

#### 2. Sex, gender, health research and development

In recent years, gender issues have been highlighted by most organizations concerned with the promotion of development and the enhancement of human well-being. They have integrated these issues into their ongoing work, justifying this with two main arguments.

First, efficiency and effectiveness require that both women and men be at the heart of development. So long as artificial constraints prevent the full participation of both sexes, societies will be unable to reach their potential for meeting the needs of their citizens.

Second, equity requires that both women and men should have the same opportunity to be active citizens, participating in the development process and having equal access to its benefits. Unless this is achieved, individuals will not be able to realize their potential for health and well-being. These arguments are increasingly accepted in the international health arena and policies and practices are gradually being reshaped in recognition of the need for gender sensitivity. However there is considerable confusion about how this should best be done. Though they have many health problems and health care needs in common, women and men are divided by both their biological sex and their social gender.

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<sup>1</sup> Adapted from Doyal L. *Sex, gender and the 10/90 gap*, Geneva, Global Forum for Health Research, October 2002 (full text available at: [www.globalforumhealth.org](http://www.globalforumhealth.org)).

Unless these differences are taken seriously, the delivery of medical and public health services will be severely constrained in their efficacy and their equity. Under these circumstances it is likely to be women in the poorest communities who will be worst affected.

The level of avoidable sickness and death among poor women remains enormous. Over one third of the years of healthy life lost by women in developing countries are caused by reproductive health problems, especially those related to pregnancy and sexually transmitted diseases. The most immediate indicators of this burden are maternal mortality and morbidity rates. Around 600 000 women die each year as a result of pregnancy and childbearing and many times this number are permanently disabled. The immediate cause of these huge losses is lack of access to effective sexual and reproductive health services, especially in rural areas. However they also reflect more basic social and economic inequalities between women and men.

Women are more likely than men to have less income than they need to sustain the health of themselves and their families. This poverty can have many causes including lone parenting responsibilities, low wages, less access to state benefits and reliance on work in the informal sector. As well as material poverty, women's health may also be damaged by their low status and lack of physical and psychological security. Recent research shows that depression and related disorders are associated with female gender, poverty and low education. Poor women have been shown to be particularly vulnerable to high levels of stress because of their multiple responsibilities, the frequency of domestic violence in many communities and the inequalities in their relationships with men. These examples reflect the fact that women and men have very different experiences of

health and illness. However the reasons for this are complex and are not always well understood by medical researchers. Male and female patterns of morbidity and mortality will be shaped by biological or sex differences but at the same time they also reflect gender differences in the social expectations of women and men. The reality of their daily lives will expose women and men to different hazards and will also give them unequal access to the resources necessary to sustain health. Both biological sex and social gender therefore play an important part in shaping the health of all human beings and the next sections will explore each of these in turn. However it is also essential to recognize that these two determinants of health are interconnected in complex and profound ways that need to be carefully explored if health care is to meet the needs of both women and men.

### 3. Understanding sex and health

The biological differences between women and men are reflected in the health problems they experience. Some of these stem from male and female reproductive functioning, with women facing major hazards as a result of their capacity for pregnancy and childbearing. This gives them 'special needs' for care, which have to be met if they are to realize their potential for health. Other conditions are not directly connected with sexual or reproductive functioning but are nonetheless sex specific because they affect particular organs: cancers of the prostate and cervix, for example.

There are also marked sex differences in the incidence, symptoms and prognosis of a wide range of diseases and conditions that affect both males and females. These are evident in NCDs such as coronary heart disease and lung cancer, and also in a wide variety of communicable diseases including TB and malaria. Recent studies suggest that these

differences are due in large part to previously unrecognized genetic, hormonal and metabolic differences between women and men. More research is needed to map these differences in greater detail. However the following facts give some indication of why biological differences between the sexes need to be taken seriously in all areas of health research:

- Men typically develop heart disease 10 years earlier than women.
- Women are around 2.7 times more likely than men to develop an autoimmune disease.
- Male-to-female infection with HIV is more than twice as efficient as female-to-male infection.

#### 4. Understanding gender and health

Biological differences are not the only ones shaping variations in male and female patterns of health and illness. Women and men often lead very different lives and this too will have a major effect on their well-being. Differences in their living and working conditions and in the nature of their duties and their entitlement to resources will put women and men at differential risk of developing some health problems while protecting them from others.

There is now an extensive literature documenting the relationship between economic, cultural and social factors and women's mental and physical well-being. The gender divisions in domestic work have been highlighted as a potential risk, especially when they are combined with waged work outside the home. The *UNDP Human Development Report 1998* pointed out that there are no societies in which women are treated as equals with men. However it is clear that many of the most extreme gender inequalities are to be found in the world's poorest countries. If the determinants of women's health are to be properly understood

and appropriate interventions developed, the impact of these gender inequalities will need to be central in the research agenda.

As the problems faced by women are increasingly recognized, the links between masculinity and well-being are also beginning to emerge. At first glance, maleness might seem to be straightforwardly beneficial to men's health because it offers them privileged access to a range of potentially health-promoting resources. But being a man may also require the taking of risks, which can be damaging to health. In many societies the traditional role of breadwinner continues to put men at greater risk than women of dying prematurely from occupational injuries. In order to demonstrate their masculinity they are also more likely to engage in dangerous and/or violent activities including smoking, drinking to excess, driving too fast and indulging in unsafe sex.

Again, these examples of gendered health risks may be most pronounced in the poorest societies, and researchers need to take them into account if they are to provide policy-makers and practitioners with appropriate evidence. Indicators of the importance of gender as a determinant of the health of both women and men are given below:

- In most countries, more men commit suicide than women, but women are more likely to attempt it.
- Both community-based studies and research on treatment-seekers indicate that women are two to three times more likely than men to be affected by common mental disorders such as depression or anxiety.
- Men are more likely than women to die of injuries, but women are more likely to die of injuries sustained at home.
- The large differences between male and female smoking rates are beginning to narrow as young women are taking up the habit more frequently than young men.

## 5. Sex, gender and health care

As well as being a major determinant of health, gender also influences the access of individuals to health care. This operates through a number of different routes. In many households there is evidence of gender bias in the allocation of resources. Females of all ages may be assigned a lower status and will have less entitlement to food and health care. This bias will be especially damaging in poor communities where there is little state provision and care has to be bought with cash. Alongside the cultural and material obstacles to care, individuals themselves may feel unable to seek the help they need. In the case of women, this may reflect their socialization into a culture of sacrifice, which means that they see themselves as being of little value. In the case of men, access to health care may be limited by the desire to appear 'strong'. In order to appear masculine, they cannot admit weakness and this may prevent them from seeking necessary help.

There is also evidence that once they have accessed a service, women and men may receive treatment of differing quality. Many women have spoken of the lack of respect they experience from workers in reproductive health care and this seems to be especially severe among poor women. Research in the developed countries has also indicated that women may be offered care that is less effective than that received by men with the same condition. More research is therefore needed to explore both the gendered obstacles to care and the quality of the services received by women and men in different settings.

Recent studies relating to the HIV/AIDS epidemic have highlighted the continuing importance of these issues. Evidence about poor women in high-income countries such as the United States as well as those in sub-Saharan Africa suggests that they have a

shorter life expectancy than their male compatriots. This reflects a range of barriers they face in accessing care as well as inequalities in the treatment itself. Studies in a number of countries have shown that women are much less likely than men to be given anti-retroviral drugs for instance, even when their need is at least as great.

## 6. How can researchers be sex- and gender-sensitive?

Sex and gender are major determinants of health in both women and men. They are closely linked with other variables such as age, race and socioeconomic status in shaping biological vulnerability, exposure to health risks, experiences of disease and disability, and access to medical care and public health services. Researchers who ignore these differences run the risk of doing bad science. Failures to incorporate sex and gender in research designs can result in failures of both effectiveness and efficiency. Practice based on incomplete or misleading evidence is likely to lead to avoidable mortality, morbidity and disability as well as wasted expenditure of scarce resources. It will also perpetuate or exacerbate existing gender inequalities. Lost opportunities of this kind are obviously unacceptable especially in the context of the existing 10/90 problem.

It is therefore essential that all those involved in the commissioning and funding of research take issues of sex and gender seriously. Whether they are private companies, government bodies, research councils or charities, appropriate recognition of gender issues should be one of the criteria used for evaluating both the relevance and the scientific quality of proposals. Researchers themselves need to be aware of gender concerns at all stages of their work from the initial design to the dissemination process. And policy-makers need to look very carefully at the sex and gender implications of all



research findings before deploying them in the development of services.

Strategies for ensuring that research is gender-sensitive will vary depending on the type of study being undertaken. However the overall objective must be to ensure that both sex and gender are incorporated as key variables in all research designs unless there are clear reasons for assuming that they are not relevant to the problem under investigation.

Thus the population of subjects needs to include sufficient numbers of women and men so that any sex or gender differences can be identified in the analysis. Any differences that do emerge then need to be clearly presented in the findings and their implications discussed. In the context of clinical trials this will need to include an assessment of the significance of any differences for the future use of the treatment being evaluated with male and female patients.

Sex- and gender-sensitive studies of this kind will not be easy to achieve without a coherent set of policies to build capacity among researchers. Such policies are now beginning to emerge in a few of the developed countries but if the 10/90 problem is to be tackled in the most effective and equitable way, they will need to be spread more widely. More conceptual work is needed to disentangle the links between biological sex and social gender and their relationship with wider determinants of health. Guidelines and educational tools also need to be developed to encourage greater awareness of these issues among health researchers.

More research will be needed across the biological/social divide. In order to

understand the full range of influences on human health, more collaborative studies will be needed with social scientists, psychologists and biomedical researchers working together. In many areas of health care the best knowledge base is one which is produced through a combination of quantitative and qualitative methods. The value of integrated approaches of this kind has been clearly demonstrated in recent years in the fields of sexual and reproductive health and mental health, where new techniques have been developed to explore those intimate concerns of both women and men which are vital to the development of sensitive and appropriate policy.

Finally it is essential that strategies be devised for ensuring the more active participation of women in health research as scientists and as advocates. In most countries there is a marked absence of women researchers and this is especially true in those countries where research capacity is least developed. Policies designed to enhance these capacities should therefore include strategies for removing the obstacles that currently limit the numbers of women able to enter medical research and to proceed through a career structure on equal terms with men.

At the same time it is essential that a broader range of women are enabled to become actively involved in the determination of research priorities and in the design and conduct of individual studies. One way of achieving this is through formal dialogues between researchers and representatives from local communities and women's organizations. Good practice in the conduct of such processes is already being developed in the arena of reproductive health research in particular.

## Section 2

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### Gender and the Millennium Development Goals

*“There is no time to lose if we are to reach the Millennium Development Goals by the target date of 2015. Only by investing in the world’s women can we expect to get there.”*

Kofi Annan, Secretary General of the United Nations

In September 2000, 189 nations adopted the United Nations Millennium Declaration, an ambitious document affirming the right of every human being to development and laying out a path towards freedom from want for every woman, man and child. To ensure that progress towards this end could be measured, representatives of UN agencies and other international organizations defined a set of eight goals, 18 targets, and 48 indicators (see chapter 1, section 3) to be achieved between 1990 and 2015 for combating poverty, hunger, disease, illiteracy, environmental degradation and discrimination against women.

The MDGs explicitly acknowledge that gender<sup>2</sup> – i.e. what a given society believes about the appropriate roles and activities of men and women, and the behaviours that result from these beliefs – can have a major impact on development, helping to promote it in some cases while seriously retarding it in others. MDG number 3 is, in fact, specifically about gender, calling for an end to disparities between boys and girls at all levels of education.

There is general agreement that education is vital to development, and ensuring that girls as well as boys have full opportunities for schooling will help improve lives in countless ways. However, it would be wrong to conclude that the relevance of gender to development is confined to the educational sphere. Both women and men participate in nearly every aspect of life in communities throughout the world. As a result, the rules that regulate the behaviours and values of women and men in a given society (i.e. its gender system) have the potential to impact nearly every aspect of life.

Therefore, while only one of the MDGs is specifically about gender, addressing gender is of critical importance to every MDG.

#### **MDG 1: Eradicate extreme poverty and hunger**

**Target 1: Reduce by half the proportion of people living on less than US\$ 1 a day**

**Target 2: Reduce by half the proportion of people who suffer from hunger<sup>3</sup>**

In some parts of the world, a marked preference for male offspring may result in lower investment of resources in girl children, which could lead to girls being nutritionally disadvantaged in at least two ways: girls may receive the second choice of available food, after brothers and/or parents, leading to

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<sup>2</sup> Adapted from WHO Department of Gender and Women’s Health. *Engendering the Millennium Development Goals*, Geneva, WHO, 2003.

<sup>3</sup> Ibid.

inadequate nutritional intake when resources are scarce; and girls may receive less medical and other care than their brothers, leading to greater ill health with potential nutritional effects. How often this sort of discrimination occurs is not clear, and it may be limited to certain parts of the world.

However, it is something that researchers working on the problem should be considering, most basically by ensuring that all data they collect are disaggregated by sex. Researchers should also watch for and guard against the possibility that, in areas where girls are routinely undervalued, standards of *normal* growth for them (based on average values in the population) may be set at unhealthily low levels.

The definition of poverty has traditionally been based on per capita income. Focusing solely on this indicator, global poverty at present encompasses more than 1 billion people who live on less than US\$ 1 a day or, more broadly, over 2.5 billion who live on less than US\$ 2 a day. But the definition of poverty has been broadened to encompass other dimensions such as lack of empowerment, opportunity, capacity and security. Meeting the poverty goal will therefore require a multidimensional approach. Because many aspects of gender inequality influence the different dimensions of poverty, interventions that promote gender equality are critical in the design of strategies and actions to meet the poverty goal.

In many poor households, women have relatively little influence over how the available resources are used, and more research is needed into how this “within-the-family” poverty exacerbates the disadvantages that women face in their access to health care, medicines, information, etc.

By raising the productivity of labour and improving the efficiency of labour allocation, gender equality has a direct impact on economic growth and the reduction of income poverty; it also increases economic opportunities and empowers women. The importance of gender equality for economic growth makes it critical in accelerating progress towards achieving the income poverty target. The Poverty Reduction Strategy Papers provide a good forum for adapting the MDGs to country circumstances and for integrating gender throughout a country’s poverty reduction strategy.

Not only does gender inequality exacerbate poverty but poverty also exacerbates inequality between males and females. Inequalities between girls and boys in access to schooling or health care are more acute among the poor than among those with higher incomes. Whether measured in terms of command over productive resources, or in terms of power to influence the political process, poor men tend to have less influence in the community than non-poor men, and poor women generally have the least influence. These disparities disadvantage women and girls and limit their capacity to participate in and benefit from development.

## **MDG 2: Achieve universal primary education**

### **Target 3: Ensure that all boys and girls complete a full course of primary schooling**

In its report on the *State of the World’s Children 2004*, UNICEF points out that: “Efforts at international development may have left hundreds of millions of girls and women uneducated and unable to contribute to positive change for themselves, their children, or their communities.”<sup>4</sup>

<sup>4</sup> UNICEF. *State of the World’s Children 2004*, December 2003.

The main points highlighted by the Report are the following:

- Illiteracy rates are still far higher among women than men.
- There is compelling evidence that enabling girls to get a basic education of good quality would improve other indicators of human well-being.
- The majority of countries with the lowest secondary school enrolment rates for girls also have among the highest rates of child mortality – with more than 15% of children dying before the age of five years.
- Girls denied an education are more vulnerable to poverty, hunger, violence, abuse, exploitation and trafficking; they are more likely to die in childbirth and are at greater risk of disease, including HIV/AIDS.
- As mothers, educated women are more likely to have healthy children, and more likely to ensure that their children, both girls and boys, complete school.
- The standard approach to achieving universal education has fallen short because it assumed that generic efforts to enroll more children would benefit all children equally, an assumption that has not examined or addressed the specific barriers faced by girls.
- Nine million more girls than boys are still left out of the classroom completely, and girls who are enrolled drop out faster, on average, than boys.
- Accelerated action is needed to get more girls into school over the next two years.
- Bringing down the barriers that keep girls out of school would benefit both girls and boys as well as their countries.

The report presents an agenda for action with the following recommendations:

- (i) Creation of a *national* ethos recognizing the value of educating girls as well as boys

- (ii) Education to be included as an essential component in *development plans*
- (iii) The *elimination of school fees* of every kind
- (iv) Integration of education into national plans for *poverty reduction*
- (v) Increased *international funding* for education.

The first of the MDGs to come due is the goal of gender parity in education by 2005. UNICEF argues that major progress towards achieving that goal is still possible with the strategic acceleration of national efforts and international support.

### **MDG 3: Promote gender equality and empower women**

#### **Target 4: Eliminate gender disparity in primary and secondary education by 2005 and at all levels by 2015**

According to the World Bank report on *Gender equality and the MDGs*,<sup>5</sup> in no region of the developing world are women equal to men in legal, social and economic rights. Gender gaps in access to and control of resources, in economic opportunities and in power and political voice are widespread.

In most countries, women continue to have less access to social services and productive resources than men:

- Women remain vastly under-represented in national and local assemblies, accounting on average for less than 10% of the seats in national parliaments.
- In most low-income countries, girls are less likely to attend school than boys. Even when girls start school at the same rate as boys, they are more likely to drop out (in many cases after getting pregnant, often due to lack of access to reproductive health services).
- In industrial countries, women in the

<sup>5</sup> World Bank Gender and Development Group. *Gender equality and the Millennium Development Goals*, April 2003.

waged sector earn an average of 77% of what men earn. In developing countries, they earn 73% of the male average. Only about one fifth of the wage gap can be explained by gender differences in education, work experience or job characteristics.

One of the main findings of the *Arab Human Development Report 2002* is that the low empowerment of women is one of three deficits which have seriously hampered human development in the region over the last three decades.<sup>6</sup> Thus, an approach to development that strives to increase gender equality has high pay-offs for human well-being.

The global data for Goal 3 as presented by the United Nations Development Fund for Women (UNIFEM)<sup>7</sup> provides an international cross-country assessment of the situation of women at the beginning of the new millennium. The report compiles and analyses data on all four indicators linked to the gender equality goal (ratio of girls to boys in primary, secondary and tertiary education; ratio of literate females to males; share of women in waged employment in the non-agricultural sector; and proportion of seats held by women in national parliament). Its main findings are the following:

**First**, only seven high-income countries (Sweden, Denmark, Finland, Norway, Iceland, Netherlands and Germany) have achieved high levels of gender equality on all four of these indicators. Among developing countries, best practices were noted in Argentina, Costa Rica and South Africa. On the other hand, the report finds that

countries with the lowest rates of equality for women in education, literacy and non-agricultural wage employment also tend to be among the poorest.

**Second**, the average presence of women in parliament accounts for only about 14% in 2002. There seems to be no systematic difference between rich and poor countries, and considerable variations exist within each region. In 2002, only 11 countries (Sweden, Denmark, Germany, Finland, Norway, Iceland, the Netherlands, South Africa, Mozambique, Costa Rica and Argentina) had achieved the benchmark of 30% female representation in parliaments set in the Beijing Platform for Action.

**Third**, there are an estimated 140 million illiterate young people in the world, of whom more than half – 86 million – are young women. In 38 % of countries, mainly in sub-Saharan Africa and South Asia, literacy rates are lower for girls than boys. And in countries where less than 50% of young women are literate, progress has been too slow. At the current rate, none of these countries will achieve literacy for all young women by 2015.

**Fourth**, women's share of non-agricultural waged employment approaches parity with that of men in less than half of the countries (39 out of 87) for which data are available.

Some evidence suggests that gender gaps persist in pay and conditions even when women's share of jobs approaches parity with men's share. Although women's share is increasing in most countries and barriers to their employment are crumbling, the benefits to women are less clear. The report also points

<sup>6</sup> UNDP Arab Fund for Economic and Social Development. *Arab Human Development Report 2002. Creating Opportunities for Future Generations*, 2002.

<sup>7</sup> UNIFEM. *Progress of the World's Women*, 2002.

to the fact that many of the poorest women are employed in agriculture or informal manufacturing and services sectors, and employment statistics often fail to capture these workers.

**Fifth**, a majority of countries for which data are available have achieved gender equality in secondary school education or have more girls enrolled at the secondary level (the report does not cover primary school education as it is being tracked in relation to Goal 2). Forty-eight percent have a higher secondary school enrolment rate for girls than boys, often because boys leave school for employment earlier than girls. Thirty-four percent, mainly in sub-Saharan Africa and South Asia, have a lower enrolment rate for girls than boys. The report cautions that although nearly half the countries surveyed had a higher enrolment rate for girls than boys, this does not mean that girls in those countries are more empowered than boys. Nor do the gender gaps in education match the gender gaps in adult life. The Report touches on some of the persisting inequality women face in today's world. The report concludes that the target and indicators selected for Goal 3 provide information only on a small part of women's daily lives.

Despite persistent gender inequalities worldwide, there has been progress since 1975, when the first World Conference on Women was held in Mexico City. In many parts of the world, gender inequalities in schooling and health have decreased, though significant gaps persist in some countries. Progress has also been made in recognizing the cross-cutting nature of gender issues and their relevance to development effectiveness and poverty reduction. There is now a shared understanding within the development

community that development policies and actions that fail to take gender inequality into account and fail to address disparities between males and females will have limited effectiveness and serious cost implications.

#### **MDG 4: Reduce child mortality**

##### **Target 5: Reduce by two thirds the under-five mortality rate<sup>8</sup>**

Worldwide, the under-five mortality rate is approximately equal for boys and girls. In Asia, more young girls die than young boys; in every other region, rates are approximately equal, or young boys die at a higher rate. Health professionals working on this target should keep these differentials in mind and, where they result from preventable causes (son preference in Asia, for example), should seek to eliminate them. Certain diseases (including the MDG target diseases malaria and TB), when they occur during pregnancy, can lead to underweight and premature babies whose chances of survival are diminished. It follows, then, that treating these diseases in pregnant women will also help reduce under-five mortality.

Reducing the amount of heavy physical labour that many poor women continue to perform far into their pregnancies may also contribute to improving under-five survival rates, as may provision of greater financial resources and support to women in their roles as mothers.

Small-scale studies in South Asia find sex differences in the proportion of children who are fully immunized. Generalizing from these studies is difficult but it is possible that, in areas where son preference is common, the lower level of resources devoted to female children might mean that they are less likely

<sup>8</sup> Adapted from WHO Department of Gender and Women's Health. *op. cit.*

to be vaccinated. Mechanisms need to be established to detect sex differences in immunization coverage, interventions developed to redress these imbalances, and routine monitoring systems established to ensure that immunization systems reach all children.

In the 1990s, all regions except sub-Saharan Africa reduced under-five mortality rates.<sup>9</sup> However, no region is currently on track to meet the 2015 goal. Annual reductions in child mortality of between 5.3% and 7.6% will be required to meet this goal.<sup>10</sup> Fortunately, much is known about the causes of infant and child mortality, including: the importance of clean water and the benefits of oral rehydration therapy for diarrhoea; the role of immunization, especially against measles; the value of insecticide-treated nets and prophylactics for malaria prevention and treatment; the importance of pre-natal and post-natal interventions in reducing mother-to-child transmission of HIV; and the education of mothers in basic infant and young child care.

Progress in under-five mortality has been slowest among the poorest countries, where the problem is most acute. Between 1990 and 2000, 31 low- and middle-income countries reduced their under-five mortality rates fast enough to achieve the goal of a two-thirds reduction by 2015. Of these, nine were upper middle-income, 16 lower middle-income and only six low-income countries. Of the 15 that suffered increasing mortality rates, 10 were low-income countries. However, the regional and income-group averages disguise much variation. Two of the countries making the fastest progress over the decade were

Tajikistan and Azerbaijan, both low-income countries, while Botswana, an upper middle-income country that has been badly affected by the spread of HIV/AIDS, saw under-five mortality rates rise from 62 to 100 per 1000 live births in just 10 years.<sup>11</sup>

## **MDG 5: Improve maternal health**

### **Target 6: Reduce by three quarters the maternal mortality ratio<sup>12</sup>**

Although the direct, first-level targets and beneficiaries of maternal mortality interventions by definition are always women, maternal mortality and the conditions that heighten or diminish the problem do have a gender dimension:

- Poor nutrition of girls and women due to gender discrimination can increase the chances of life-threatening complications at the time of pregnancy.
- Societal norms that limit women's mobility, or that require that women obtain the consent of a male family member before seeking health care, can dangerously delay, or even prevent, women's access to life-saving care in the event of an obstetrical emergency.
- Women's education is strongly correlated with positive maternal health outcomes. High rates of illiteracy/low rates of school attendance among women and girls, which are common in some parts of the world, are likely to contribute to maternal mortality.

Furthermore, certain diseases (such as malaria, anaemia, hepatitis and possibly TB), when experienced during pregnancy, can be especially severe and contribute to maternal mortality. Targeted efforts to reduce the incidence of these diseases in women should

<sup>9</sup> World Bank. *World Development Report 2000/2001: Attacking Poverty*, New York, Oxford University Press, 2000.

<sup>10</sup> United Nations. *Road Map Towards the Implementation of the United Nations Millennium Declaration*, New York. 2001 (A/56/326).

<sup>11</sup> UNICEF. *op.cit.*

<sup>12</sup> Adapted from WHO Department of Gender and Women's Health. *op.cit.*

have the additional benefit of reducing maternal mortality ratios.

True rates of maternal mortality are difficult to measure accurately. Deaths as a result of pregnancy or childbirth may not be captured in general purpose surveys or those with small sample sizes. Furthermore, maternal deaths may be underreported in countries that lack good administrative statistics or where many births take place outside of the formal health system. Maternal mortality is such a compelling problem because it strikes exclusively young women undergoing what should be a normal process, and because the difference in outcomes is so extreme between those who live in rich countries, where the average maternal mortality ratio is around 21 deaths per 100 000 live births, and those who live in poor countries, where the ratio may be as high as 1000 deaths per 100 000 live births.<sup>13</sup>

Because of the lack of comparable time-series data, it is difficult to assess progress toward this goal. The last global estimates of maternal mortality for 1995 concluded that about 500 000 women died during pregnancy and childbirth, most of them in developing countries.<sup>14</sup>

Data on the proportion of births attended by skilled health personnel are indicative. In Latin America, where the proportion of births attended by skilled health care workers is high, maternal mortality is relatively low, while very high maternal mortality occurs in Africa, where skilled attendants are not readily available.

Significant progress in reducing maternal mortality will, however, require more than

increasing the number of skilled birth attendants: deaths in childbirth often involve complications such as haemorrhage that require fully equipped medical facilities. The maternal mortality ratio is thus an indication of the overall capacity of the health care system to meet the needs of the entire population.

#### **MDG 6: Combat HIV/AIDS, malaria and other diseases**

**Target 7: Halt and begin to reverse the spread of HIV/AIDS**

**Target 8: Halt and begin to reverse the incidence of malaria and other major diseases<sup>15</sup>**

HIV/AIDS affects men and women in different ways. 2002 was the first year when the number of adult women worldwide suffering from the disease approximately equalled the number of adult men, suggesting that the disease is now spreading fastest among women. Indeed, in sub-Saharan Africa, the region worst affected by HIV, prevalence rates among women are already distinctly higher than those among men. These figures reflect underlying realities of sex and gender that programme planners will have to grapple with if they are to meet Target 7 of the MDGs:

- In areas where heterosexual sex is the primary means of transmission, HIV infection rates are usually distinctly higher among young women than among young men. This may be partly due to a combination of biological factors relating to the reproductive tract and to social norms. Those norms facilitate older men having sexual relations with much younger women and men in general having more sexual partners than women.
- The only two widely available means of

<sup>13</sup> Abou-Zahr C. Promotion of Maternal Health and Reduction of Maternal Mortality, Paper presented at: Medicine Meets Millennium, World Congress on Medicine and Health, August 2000.

<sup>14</sup> Shantayanan D, Miller MJ and Swanson EV, *Goals for Development: History, Prospects and Costs*, World Bank, April 2002.

<sup>15</sup> Adapted from WHO Department of Gender and Women's Health. op. cit.



preventing HIV transmission – male condoms and abstinence – are generally available to men independent of their partners' wishes, while they can usually only be practised by women with male co-operation.

- The stigma of HIV may be felt most strongly by women, who are often physically, socially and economically more vulnerable than men.
- Effective prevention of mother-to-child transmission may require involving both mothers and fathers, even though planners of such programmes may be tempted to address only women. Although it is women who must take drugs or avoid breastfeeding to prevent mother-to-child transmission, they may not have enough autonomy or financial resources to do so on their own, without their partners' consent and participation.
- Women and girls bear the brunt of the care giving required in this epidemic, which affects large numbers of adults in the prime of life.

Pregnant women and very young children have unusually high incidence and mortality rates for malaria and warrant specific attention in malaria-control programmes. It is also possible that gender norms may affect malaria prevention and treatment via their influence on sleeping and work patterns, on the use of bednets, and on which family members receive medicines and medical care. The direction of such effects probably varies from place to place, but their existence highlights the importance of recording and analysing all malaria-related data by sex, in order to notice and respond to any patterns that do exist.

Regarding TB, the proportion of cases detected and cured under DOTS worldwide, TB prevalence, as well as latent TB infection rates among adult women, are generally lower

than those among adult men. Nevertheless, TB remains a leading cause of death among women of reproductive age. Concerns exist that gender differentials in TB case detection and treatment outcomes may be due to a variety of factors such as differences in reporting of respiratory morbidity, gender-distinctive barriers to access, and stigma. In high-HIV-incidence settings like Africa, more young women between ages 15 and 24 are notified with TB than young men of the same age group.

It appears that women of reproductive age who are infected with TB are more likely than similarly aged men to progress to disease. Furthermore, TB during pregnancy leads to significantly higher rates of poor pregnancy outcome, for both child and mother. Those designing programmes to combat it should keep both of these gender-related aspects of the disease in mind.

Finally, studies suggest that genital TB, a relatively uncommon disease in men, may afflict up to one eighth of women who have pulmonary TB. Genital TB can lead to infertility, which carries shame and stigma in much of the world, and needs to be addressed.

Much research is needed to better understand the factors underlying the situations described above with regard to HIV/AIDS, malaria and TB. Although the paragraphs above deal mainly with specific problems affecting women, just as much research is needed into the factors which are more specific to men, in particular where men are the main group affected or the main source of new infections. Such a gender approach is indispensable to design the most effective and efficient interventions.

Unfortunately, the data on these illnesses, including AIDS, is often incomplete or

collected on an irregular basis. In many countries only one reliable estimate has been made for the HIV/AIDS infection rate, so it is impossible to accurately determine rates of change.

In its *2002 Report on the Global HIV/AIDS*, UNAIDS published the following HIV statistics for the year 2001:

- The number of people infected with HIV was estimated at 40 million, of which 18.6 million men, 18.5 million women, 3 million children below 15.
- People newly infected with HIV were estimated at 5 million, of which 2.2 million men, 2 million women, 800 000 children below 15.
- AIDS deaths reached an estimated 3 million, of which 1.3 million men, 1.1 million women, and 580 000 children below 15.
- The total number of children orphaned by AIDS (having lost one or both parents to AIDS) and living at the end of 2001 reached 14 million.

Overall, it is estimated that 55% of adult infections in sub-Saharan Africa are women, 30% in South-East Asia, and 20% in Europe and USA.<sup>16</sup>

## **MDG 7: Ensure environmental sustainability**

**Target 9: Integrate the principles of sustainable development into country policies and programmes and reverse the loss of environmental resources**

**Indicator 28: Per capita carbon dioxide emissions<sup>17</sup>**

Men's and women's different roles and responsibilities are strongly linked to

environmental sustainability. Women's insecure land tenure rights provide one example. Without title to land, women are often denied access to effective technologies and resources such as credit, extension, seed supply and labour-saving devices that would strengthen their capacity to promote environmentally sustainable practices. A recent study of the impact of pest management training for rice farmers in Viet Nam showed that only 23% of female farmers consulted extension service workers while 55% of male farmers did so.

Ensuring that agriculture is practised in sustainable ways requires that female as well as male farmers receive the information and resources they require. Gender-based differences and roles also affect conservation practices and must be understood if policies are to be effective. Because of the gender-based division of labour, women and men often have different knowledge of plants and growing conditions. Men are often experts in primary cash crops while women are experts in 'neglected' species. This has important implications for the conservation of genetic resources because the decision to conserve a plant variety depends to a large extent on its perceived usefulness to the farm household.

The gender-based division of labour is also closely linked to environmental health. More than half of the world's households cook with wood, crop residues or untreated coal, exposing primarily women and children to indoor air pollution because of the female specialization in cooking and other work inside the home. This results in a number of health problems, such as acute and chronic respiratory infections and blindness. In developing countries, nearly 2 million women

<sup>16</sup> WHO, Fact sheet No. 242, June 2000.

<sup>17</sup> Adapted from WHO Department of Gender and Women's Health. op. cit.

and children die annually from exposure to indoor air pollution. In central Kenya, for example, children and women are disproportionately affected by acute respiratory infections, caused by prolonged exposure to indoor air pollution from the combustion of biomass.

Beyond this, in many parts of the world deforestation has meant that wood – the most widely used solid fuel – is increasingly distant from the places where people live. Collecting wood usually falls to female members of the household, who spend more and more time on this activity at the expense of other crucial activities for themselves or their family.

Making available alternative fuel sources (and the means to use them safely) can thus have a particularly positive effect on the health of women, both by reducing their exposure to damaging fumes, and by reducing the burden on them of a particularly taxing and time-consuming form of labour. Time saving may open up opportunities for education and income generation. This may help break a vicious cycle where solid fuel use restricts economic development, while poverty reduces the ability to switch to cleaner fuels. All these issues require much further research.

Research is also much needed into environmental hazards affecting more particularly the male populations, such as crop spraying, mining activities and heavy industry.

**Target 10: Halve the proportion of people without sustainable access to safe drinking water<sup>18</sup>**

More than 1 billion people presently lack access to clean drinking water, and another

1 billion people lack access to proper sanitation. More than two million children die every year – 6000 a day – due to diarrhoeal diseases including cholera and dysentery. Although there is no reason to believe that there are gender differences in access to improved water or sanitation (since these are generally provided to districts and families, not to individuals), there is still an important gender dimension to water supply.

In places where the source of water (whether improved or not) is distant from the places where people live, the task of collecting water, which falls to female members of a household, is very time consuming. Thus, bringing an improved water supply to somewhere near residential concentrations can both improve the health of a population and reduce the burden of a particularly taxing and time-consuming form of labour, performed largely by girls and women. Improved water supplies located a long distance from homes, on the other hand, might help with the first of these objectives, but not with the second.

In developing countries, coverage of improved drinking water sources rose from 71% in 1990 to 78% in 2000 – leaving an estimated 1.1 billion people without access to safe water. Progress fell far short of the goal set in 1990 to reach universal access to safe water by 2000. Not only was the goalpost moved to 2015, the new MDG target was lowered from universal coverage to halving the proportion of people without access to safe water. Thus, the new target is nearly five times less ambitious than the initial one. At the current rate of progress, the world is on track to reach the new target for safe water by 2015. The fastest progress was made in South Asia; little or no progress was made in the world's poorest nations (the so-called Least

<sup>18</sup> Adapted from Vandemoortele J. *Are the MDGs feasible?* New York, UNDP, July 2002.

Developed Countries). Rural areas lag far behind; the rural-urban gap in terms of access to safe water is greatest in sub-Saharan Africa, where only 45% of the rural population have access – against 83% for their urban counterparts.

During the UN World Summit on Sustainable Development (Johannesburg 2002), countries not only endorsed MDG Target 10 for safe drinking water, but also agreed to commit themselves to a target of reducing the numbers of people who lack access to proper sanitation by 2015. The new commitments agreed to in Johannesburg also call on countries to provide the resources and technical assistance needed to embark on action programmes to meet the goals.

**Target 11: Achieve significant improvement in lives of at least 100 million slum dwellers by 2020<sup>19</sup>**

Almost 2 billion people currently live in urban regions of the developing world. This figure is projected to double over the next 30 years. It is estimated that up to one third of the world's urban population lives in slums. Slum dwellers face higher developmental challenges such as higher morbidity and infant mortality rates than either non-slum dwellers or the rural population.

There are five key components of a successful programme in slum improvement:<sup>20</sup>

- improved water supply: sufficient amount of water for family use, at an affordable price, available to household members without being subject to extreme effort, especially to women and children;

- adequate access to sanitation: excreta disposal system, in the form of a private toilet or a public toilet shared with a reasonable number of people;
- protection against forced eviction (secure tenure): documentation that can be used as proof of secure tenure status; de facto or perceived protection from forced eviction;
- durable housing: house built on a non-hazardous location, offering protection from extremes of climactic conditions such as heat, cold, rain and humidity;
- sufficient living area: not more than two people share the same room.

Just as under any other target of the MDGs, gender aspects are particularly important to consider under this target, as securing tenure for the household does not necessarily secure tenure for women and children, as women's land and housing property rights:<sup>21,22</sup>

- are still not recognized by all countries;
- are often blocked by customary laws, traditions and cultural factors;
- are violated more frequently: women are affected disproportionately by forced evictions and resettlement schemes, slum clearance, civil conflict, development projects and globalization policies;
- are violated by additional actors: women, particularly in Africa and parts of Asia, also face evictions by their spouses and in-laws, a situation made worse by the HIV/AIDS pandemic;
- land, housing and property rights are usually registered in the name of the husband;
- awareness of women's rights among men and women is still alarmingly low.

<sup>19</sup> Adapted from UN-HABITAT. *Improving the Lives of 100 Million Slum Dwellers: Guide to Monitoring Target 11*, 2003.

<sup>20</sup> Ibid.

<sup>21</sup> Global Campaign for Secure Tenure. *Implementing the Habitat Agenda: Adequate Shelter for All*, 2003.

<sup>22</sup> UN-HABITAT. *Land and tenure section brochure*, 2003.

This has profound implications for reaching the gender targets under the other MDGs.

### **MDG 8: Develop a global partnership for development**

To develop a global partnership for development is the most inclusive and complex of the MDGs. It consists of seven specific targets where global partnerships can make a difference in quality of life in poor countries and up to 17 indicators that can measure their success on the ground. From

partnerships that promote trade and debt reduction to those facilitating decent work for youth and access to affordable drugs in developing countries, Goal 8 requires a commitment of all players to work as partners in a development partnership unparalleled in human history.

Partnerships that are gender-sensitive, and have a built-in component for gender as a cross-cutting issue, will stand a better chance of achieving both their own goals and the MDGs, in an effective and efficient manner.

## **Section 3**

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### **Conclusions**

In summary:

- Sex and gender are major determinants of health in both women and men. They are closely linked with other variables such as age, race and socioeconomic status in shaping biological vulnerability, exposure to health risks, experiences of disease and disability and access to medical care and public health services. Researchers who ignore these differences run the risk of doing bad science. Failures to incorporate sex and gender in research designs can result in failures of both effectiveness and efficiency.
- Gender sensitivity means more than just a focus on improving the situation for women. It requires an analysis of the gender-based attitudes and practices of both women and men. It leads also to a

recognition of the need to involve men in achieving gender equality and of the disadvantages that men themselves sometimes suffer as a result of gendered attitudes.

- Overall, the MDGs cannot be reached without an explicit, coordinated and systematic focus on the gender dimension of all MDGs. Gender equality is not just one goal, but also a means to achieving each goal. Without a fully integrated gender perspective in the reporting, campaigning, analysis and implementation of policies and strategies developed towards achieving the 2015 target, the MDGs will not be realized and governmental commitments made through the United Nations will remain unfulfilled.
- The specific MDG on gender equality (Goal

3) has been integrated in a single target calling for the elimination of gender inequality in education. Many have pointed out that access to education is an important signpost for gender equality. But as the Beijing Platform for Action recognized, there are many other dimensions of gender equality (or “critical areas of concern”) that are equally crucial and need to be addressed.

- The United Nations and civil society should ensure that the wide-ranging commitments made in the Beijing Platform for Action and the 1979 Convention on the

Elimination of All Forms of Discrimination against Women remain on the political agenda.

- One of the main challenges facing the inclusion of gender in all processes leading to the achievement of the MDGs is to ensure that the system of national MDG reports takes national commitments to women into account.
- Poverty cannot and will not be eradicated without adopting a gender-sensitive approach. Universal access to education and reproductive health care are crucial steps that can help to eradicate poverty.

# Chapter 7

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## *Research capacity strengthening (RCS): progress and perspectives*

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## Section 1

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### Definition and dimensions

#### 1. Importance of research capacity strengthening to correct the 10/90 gap

Research capacity strengthening (RCS) plays a central role in the process of identification of needs, selection of priorities and development of research strategies that are appropriate and relevant to improving health in individual countries, particularly developing countries.

Health research capacity in many developing countries is weak. As a result, many developing countries are unable to participate fully in national and international health policy development. To ensure that the focus and relevance of the research is maintained, the work is best done within the countries and by the country nationals themselves. Therefore, an integral part of development support is the building-up of national and regional capacity and self-reliance through RCS. This approach should contribute to building a science culture at country level and enable developing countries to build up a critical mass of able and qualified scientists who can undertake research on the priority health problems of the country and participate in the broad international research agenda. This will constitute a crucial step in correcting the 10/90 gap in global research funding since many of the developing countries will get increased funding for their own health problems.

#### 2. Research should not end until people's health improves in a measurable way

A widely accepted definition of health research is “the generation of new knowledge using scientific methods to identify and deal with health problems”.<sup>1</sup> However, a growing number of public health professionals consider that research does not stop at “generation of knowledge” but should complete the logical cycle of benefiting the users, i.e. the full utilization of knowledge to improve health. According to this broader definition, health research should not end until people's health improves in a measurable way.

To ensure and sustain the creation and utilization of research, there is an urgent need to strengthen the health research systems. The Commission on Macroeconomics and Health has argued that mobilizing resources for larger investments in research capacity strengthening is a central issue and is one of the most powerful, cost-effective and sustainable means of advancing health and development.<sup>2</sup>

#### 3. Definition of research capacity strengthening

The UNDP definition of RCS is: “Research capacity strengthening is the process by which individuals, organizations and societies develop abilities (individually and

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<sup>1</sup> Pang T et al. “Knowledge for better health - a conceptual framework and foundation for health research” in *Bulletin of the World Health Organization*, 2003, 81 (11).

<sup>2</sup> Commission on Macroeconomics and Health. *Macroeconomics and Health: Investing in Health for Economic Development*, WHO, Geneva, December 2001.



collectively) to perform functions effectively, efficiently and in a sustainable manner to define problems, set objectives and priorities, build sustainable institutions and bring solutions to key national problems”.<sup>3</sup>

This definition brings out all the key elements that are necessary for effective RCS:

- strengthening the abilities of individuals, institutions and countries to perform functions that they would not otherwise have been able to perform;
- not only the abilities of individuals, but of institutions and countries, which draws attention to the central role of institutional

development and to the need to integrate RCS into the development of the national health research systems (including governance, organizational systems, policies, infrastructure, equipment);

- efficiency, effectiveness and sustainability;
- strengthened abilities directed at the definition of national problems and priorities;
- strengthened abilities directed at solving national problems;
- strengthened abilities to utilize the results of research in policy-making and programme delivery.

## Section 2

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### The problem

The Report of the Commission on Health Research for Development (1990), the World Bank’s World Development Report (1993) and the Report of the Ad Hoc Committee on Health Research published by WHO in 1996 were unanimous in concluding that developed countries have benefited greatly from the increase in knowledge and the advancement of technology derived from scientific research. However, developing countries, and poor populations in particular, have benefited little from this and are now striving to build indigenous research capacity to study and solve their own health problems.

Inadequacy in capacities for research remains a major impediment for the developing world. Despite over three decades of efforts to build up capacity, during which thousands of scientists from developing countries have been trained, most of the expected breakthroughs have not happened. Large numbers of trained scientists are not working in their countries of origin. Building and retaining indigenous capacity for health research must move to centre stage, as this is vital for sustainable development.<sup>4</sup>

There are many agencies and donors who provide financial support for capacity

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<sup>3</sup> UNDP. *Technical Advisory Paper No. 2*, 1999.

<sup>4</sup> Gezairy HA. Regional Director, WHO, EMRO. Message to the seventh meeting of Heads of Research in EMRO (December 2003).

strengthening in developing countries. Their activities have developed over the last half century, using diverse methods. Despite these capacity-building efforts at national, regional and global levels, evaluations have shown limited results and wide gaps in national research capacity in low- and middle-income countries. There now appears to be a strong convergence of views in favour of more systemic and concerted efforts to accelerate research capacity strengthening in developing countries.

Some of the **major gaps and deficiencies** in research capacity strengthening in many countries can be summarized as follows:

1. **Low priority for research.** The recommendation of the 1990 Commission on Health Research for Development on the proportion of national health budgets and foreign aid that should be devoted to research (respectively 2% and 5% of health budgets) is far from being implemented, with only one or two exceptions. In other words, research is generally low on the national priority list.
2. **Inadequate efforts directed towards prioritization of research problems.** Limited information is available on: (a) the major problems affecting the health of populations at country level (burden of disease); (b) their determinants (at the level of the family/community, health systems, sectors other than health and central government policies); and (c) the cross-cutting issues affecting the health level of that population (poverty, gender, health policies). As a result, there is a high risk that the research efforts of a country (and the research capacity strengthening

efforts) are not directed at the priority health problems of the country. This information is necessary (a) to develop a national health plan and (b) to orient the national health research programme as well as (c) the research capacity strengthening efforts.

3. **Contribution of RCS to health systems performance.** Another challenge has been the transformation of research results into health policies and improvements in the functioning of health systems and health research systems. Results from available evidence show that RCS has had a limited impact on the improvement of policies and the functioning of health systems.
4. **Limited use of existing knowledge.** Serious obstacles are encountered in many countries in the application of the best existing knowledge to the country's health situation.
5. **Less than optimum use of the limited human resources.** In many cases, not only are the human resources in the health and health research sector limited, but less than optimum use is made of them. This problem is further compounded when trained health staff, especially researchers, migrate either overseas or from the public sector to the private sector. The movement of skilled and educated members of a nation to other nations is both a response to the lack of opportunity in the home country and to the availability of opportunity in another country.<sup>5</sup> A paper presented by Saravia in Forum 6 indicated that higher education in itself was one of the principal conduits of permanent emigration.

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<sup>5</sup> Saravia N, International Centre for Medical Research and Training, Cali, Colombia. Paper presented at Forum 6, Arusha, October 2003.

6. **Limited monitoring and evaluation of results.** Finally, the results of health research (and RCS) are not often evaluated in terms of their inputs, process, outcome and impact on the health of the populations. Some indicators have been developed over the past years. A particularly useful matrix for the evaluation of RCS efforts was developed in the November 1999 TDR seminar on this topic. It is presented in Insert 7.1. Evaluations to date have identified a number of key factors explaining the success or failure of RCS efforts. These are summarized in Insert 7.2.<sup>6</sup>

In summary, there is a consensus among donors and national governments that capacity strengthening efforts so far deployed have neither made a significant impact on the policy and management decisions in most developing countries, nor had an important impact on the health of populations, even though the efforts have substantially increased capacities in a number of them. In addition, it appears that RCS efforts so far have mostly benefited individuals in low-income countries rather than the institutions and the health research systems as a whole in those countries.

## Section 3

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### RCS for what?

Research capacity (and therefore RCS) is a tool to help a country deal with its national health problems, in as effective and efficient a manner as possible. It is therefore part of the national health system and should be integrated in a comprehensive national health plan for the promotion of health and the delivery of health services to the country.

Ideally, a health research system (and the efforts undertaken for its capacity strengthening) should aim at the following specific objectives:

1. **Advocate higher priority for research.** The health research system should be able to demonstrate the contribution made by research to the solution of national problems and the improvement in the country's health situation, thus having the arguments to convince finance ministers and parliaments of the necessity to increase health research budgets to at least 2% of the national health budget and 5% of the foreign aid budget for health.

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<sup>6</sup> Adapted from Nchinda TC. in *Social Science and Medicine* 54 (2002) 1699-1711.

## Insert 7.1

### Evaluation criteria and potential indicators of impact for research capability strengthening\*

	Individual	Institutional	National	Global
Impact RCS	Incorporation of research results in policy documents and country programmes. Incorporation of individual into policy-making bodies at national, regional, global level.	Cumulative (individual) involvement in national, regional, global level policy-making bodies. Incorporation of institutional representatives into national policy-making bodies (consultations).	Implementation of policy at national level. Budget allocation for research and continuity over time (%GNP).	Implementation of evidence-based policy at regional, global level.
Outcome RCS	Publications: national, international. Citation index. Grants: number, magnitude, diversity of source. Trainees, undergraduate, postgraduate, % women. Collaboration with established international groups. Awards. Tools/patents. Collaborative projects.	Total number of publications and citation frequency over time. Number of national, international trainees. International grants: number, diversity, magnitude and over time. Participation in inter-institutional networks. Proportion of projects that are inter- or trans-disciplinary. Proportion of projects that are collaborative.	Product. Policies. Tools. Introduction of health-improving instruments. Evidence (research results) for policy development. Institutionalization of guidelines.	Product. Policies. Tools. Introduction of health-improving instruments. Evidence (research results) for policy development. Institutionalization of guidelines.
Process	Success in training. Reintegration to home country over time. Promotion record.	Number of funded activities and level of funding: - local - national - regional - international Number of functional research groups. Number of principal investigators within supported centre.	National commitment to research. Existence of national research council. Research included as line item in national budget.	Regional networks in priority research areas.

Source: TDR, Seminar, November 1999.

\* Conclusions of the *Prospective Thematic Review of TDR Research Capability Strengthening*

## Insert 7.2

### *Reasons for success and failure of RCS*

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Success was found to be associated with the following factors:

- Capable and committed scientific leadership
- Continuity of funding for research
- Ability to attract a core of dedicated young scientists and provide them with independent research funding
- Adequate and appropriate infrastructure for research (building and premises)
- Adequate equipment and supplies including modern communication facilities and scientific literature
- Scientific linkage to another (stronger) institution in the South or in the North
- Stable conditions of service with adequate remuneration.

Failure was associated with the following factors:

- Weak scientific leadership, including diverting scientists to other non-scientific tasks
  - Strong external (usually political) influences on the running of the institution
  - Strong adverse socio-political climate creating frustration among the scientists
  - Poor remuneration, compelling the scientists either to seek other sources of remuneration to augment their income or leave the country
  - Inappropriate service conditions, prompting the departure of scientists.
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Source: Nchinda TC in *Social Science and Medicine*, 54 (2002) 1699-1711.

2. **Identify national health research priorities.** Based on a systematic study of the major problems affecting the country's health, their determinants (at the various levels) and the cross-cutting issues affecting the health level of that population (e.g. poverty, gender, health policies).
3. **Translate health research into action.** Systematic attempt to link research to policy and to the delivery of health interventions.
4. **Systematically apply existing knowledge.** Systematic monitoring of the application of existing knowledge to the country's health problems.
5. **Develop an efficient and effective research environment.** Monitoring of the research system in all its components to ensure effective and efficient delivery of health-promoting research products.
6. **Systematic monitoring and evaluation of the results of the system and of its strengthening.** In terms of inputs, process, outcome and impact on people's health.

## Section 4

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### Partners in RCS

#### 1. National level

National medical research councils and academic institutes all over the world are the vanguard and the biggest contributors to health research and RCS. They remain at the forefront of efforts to strengthen health research capacity. In the last two years, Brazil, Cuba, Indonesia, the Philippines, Tanzania, Thailand and South Africa have analysed their research systems successfully and developed capacity-building plans. The Pakistan Medical Research Council and its partners requested the Global Forum to provide support for identifying national health research priorities. Many other efforts are under way by various national medical research councils and their national and international partners to move forward the RCS agenda.

Similarly, civil society organizations are showing an interest in strengthening their own research capacity. A recent success story is from India, where in 2003 more than 200 community-based organizations were helped through a Rockefeller research award to develop their capacities in research methodologies, analyses and report writing.<sup>7</sup> This research grant has successfully demonstrated that there is enormous potential for capacity building through civil society organizations. A summary of the project is described in Insert 7.3.

#### 2. International level

It can be agreed that most research grants in

one way or another contribute to strengthening the research capacity of an individual scientist or, in some cases, of an institution. On this basis, most donor agencies and large foundations can be included among RCS partners. Very varied strategies have been used in these RCS efforts. An attempt is made to list them below (in no particular order):

- Support for the establishment of a research agenda (including a plan for RCS).
- Support for national health research networks.
- Improved use of the new information and communication technologies.
- Training of individual researchers through university scholarships.
- Programme support for specific diseases or risk factors.
- Funding consortia for specific research problems.
- Equipment of research facilities.
- Integration of a research component in health programmes, including health sector reform programmes.
- Training in research management and process (grant writing, research methodology, policies).
- Internships.
- Pairing of research institutions in the North and the South.
- Involving CSOs and local communities in the research efforts.
- Support for national and regional health research networks and forums.
- Monitoring and evaluation of results.

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<sup>7</sup> Yesudian CAK. *Strengthening health research in NGOs in India. Results of a Rockefeller Foundation Award*, India, Tata Institute of Social Sciences, 2003.

## Insert 7.3

### *Developing research capacity in community-based organizations for health in India*

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In India, community-based organizations (CBOs) are grassroots organizations working among the poorest populations in tribal, rural and slum communities. These CBOs can contribute much to finding the best solutions to local problems through research.

This insert briefly explains the process and the outcome of an experiment in developing research skills among CBOs, which was funded through a Rockefeller Award and carried out with some of the CBOs involved in delivering community health services in remote parts of the country.

Instead of selecting the potential CBOs, a strategy of self-selection was adopted. A database of 2667 CBOs was established and a one-page questionnaire was sent to each CBO inviting them to join a health CBO network. A total of 517 CBOs responded and were sent a detailed questionnaire to find out about their research capacity. Of these, 208 CBOs responded and they formed the new health research CBO network.

Seven research method modules were prepared to cover the whole research process and were delivered in four training workshops. After each training workshop, the CBOs went back to implement the module.

A survey research manual was prepared entitled “User Friendly Survey Research and Statistics for Health Workers: A Primer”. This explained the various steps in research and provided examples. In the first training programme, 157 CBOs out of the 208 in the health CBO network participated in eight workshops to prepare the research proposal. This was followed by training in data processing and analysis. The last phase involved a training workshop on report writing.

The research areas included child health, adolescent health, women’s health and communicable and noncommunicable diseases. At the end of the project, an evaluation of the research capacity development exercise was carried out, which revealed that the health CBOs were confident in independently formulating a research problem and designing a research project. They also gained skills in data collection. However, a majority were not confident in using the data processing skills they were taught. Similarly, they needed more assistance in writing research reports. Although many CBOs dropped out at different stages of the project, they gained important research skills for their work in the field.

The three-year action research project brought to light some revealing facts about RCS.

- First, complex health research can be demystified and simplified.
- Second, grassroots workers assimilated research skills, as these were taught in instalments of theory and practice. The principle of “doing is learning” worked well with the CBOs.
- Third, since the research problems were those that were of concern to the CBOs, their involvement in learning was intense. Finally, the learning and application of research skills increased their capacity to plan, organize, implement and monitor community health care programmes, systematically leading to better results.

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*Source: Adapted from Yesudian CAK. Strengthening health research in NGOs in India. Results of a Rockefeller Foundation Award, India, Tata Institute of Social Sciences, 2003.*

## Section 5

### Selected examples of RCS efforts

#### 1. Global Forum for Health Research

In its first years of activity, the Global Forum's role in the RCS field has been focused on the following:

- Development of a priority-setting method: before undertaking a major RCS effort, a country should determine its health research priorities based on analysis of the burden of diseases and risk factors, a cost-effectiveness analysis, and an analysis of its comparative advantages. The Combined Approach Matrix developed by the Global Forum permits national authorities to identify research priorities and the areas in which RCS investments would be most productive for improving the health situation of the country.
- The Global Forum's annual meeting provides a platform for exchange of ideas regarding the development of a systemic approach to RCS efforts.
- Project work and financing: the Global Forum contributed to RCS in a number of projects co-financed in 1998-2003; it also contributed to the Collaborative Training Program (CTP) with INCLEN, COHRED and the Alliance for Health Policy and Systems Research.<sup>8</sup>
- Advocacy: the Global Forum is a strong advocate for RCS efforts and for developing a systemic approach to RCS development.

A brief summary of the RCS topics discussed at Forum 6 (November 2002) and Forum 7

(December 2003) is presented below:

#### Forum 6, November 2002

The main thrust of the session on RCS at Forum 6 was to measure the results of RCS and the sustainability of the efforts. The following issues were highlighted:

- The huge costs of the brain drain and the need for strategies to reduce and possibly control this problem.
- The good results of partnership grants in which the principal investigator was a researcher in the developing country institution.
- The complementarity between individual training and institutional capacity development.
- The importance of PhD research within the country in order to address the national health problems.
- The critical role of the enabling environment at the country level for good research (policies, infrastructure, salaries, equipment, supplies).
- The need to encourage external donors to systematically include capacity-building components in their bilaterally-funded projects.
- The need to define the expected outcomes and impacts of RCS programmes from the outset.
- The importance of monitoring the outcomes, impacts and sustainability of research through measurable indicators.

<sup>8</sup> CTP Modules are resource materials for priority setting in health research, knowledge management and advocacy and leadership. Available on the Alliance website: [www.alliance-hpsr.org](http://www.alliance-hpsr.org).



## Forum 7, December 2003

Beyond the conclusions drawn in Forum 6, the RCS sessions in Forum 7 drew attention to the following:

- The issues of sustainability and the brain drain are becoming even greater challenges in the light of the adverse and deteriorating political and socioeconomic conditions prevailing in many developing countries, especially those in Africa.
- The sustainability of health research may be improved by establishing regional networks of health research scientists with a regional umbrella for RCS governance.
- The promises to invest in RCS made by the international organizations and national governments have not been kept. The role of the Global Forum as a global advocacy voice should be further strengthened.
- Efforts should be made to launch research endowment funds with equal participation from national governments.
- A mechanism for improved coordination of RCS efforts should be developed, both at the country and global levels, with strong involvement of the Global Forum.
- There is a need to document success stories in RCS and follow the example of TDR in this respect.<sup>9</sup>
- RCS impact assessment methodologies are weak and should be systematically developed in discussions at the national, regional and global levels.

## 2. Tropical Disease Research Programme (TDR)

Since its establishment 25 years ago, TDR has continued to invest substantially and strategically in creating or boosting research capacity in developing countries, as an explicit objective of the programme.

Measured in terms of numbers assisted, TDR support for capacity building has encompassed over 1200 individuals from over 400 institutes in 80 countries.

Within TDR's 2002-2005 Strategy, RCS activities will, to a far greater extent than before, be driven by the TDR research and development (R&D) agenda.<sup>10</sup> The new strategy aims to increase the involvement of scientists from developing disease-endemic countries in all stages of the R&D process, optimizing the development of more relevant and affordable intervention tools, strategies and policies for disease control.

The new RCS strategy is part of the overall restructuring of TDR to fine tune and develop measures to evaluate the impact of its capacity-building activities. Three major lines of business will be pursued:

- individual training and career development
- institutional programmes
- targeted R&D initiatives (60% of TDR's RCS budget).

Capabilities to be promoted will cover a broad range of activities, including supporting an enabling institutional framework within national health research systems, development of managerial capacity, R&D skills in biomedical and socioeconomic areas, and capacity to advocate for the integration of research results into policy and practice. Success indicators will be based on critical outcomes such as leadership, relevant scientific productivity and self-reliance.

## 3. Department of Research Policy and Cooperation (WHO/RPC)

More than ever before, RCS is now a priority

<sup>9</sup> TDR, *Investing in Health and Development: Research* (TDR/RCS/GEN/03.1).

<sup>10</sup> TDR, *Research Capacity Strengthening Strategy 2002-2005*.

*capacity building in developing countries*. WHO/TDR, 2003

agenda for WHO/RPC. The Health Research System Analysis (HRSA) work that RPC has initiated and is coordinating across a large number of WHO Member States since 2002 is to describe, analyse and strengthen the research capacity of national health systems. Case studies using qualitative and quantitative approaches, as well as the development of an approach to benchmark national health research systems (phase 1) are currently in progress. This collective work will provide new insights to improve the alignment of health research policies with the critical challenges facing health systems, and help strengthen capacities to produce research, synthesize research and other forms of knowledge, and apply knowledge to improve health systems and health outcomes (phase 2).

The creation of an enabling environment in which researchers can flourish is often a key factor in facilitating capacity development. However, with the existence of disparate health needs and contexts among nations, an operational view of what makes up an enabling environment has proved to be somewhat elusive. In an effort to define the characteristics of an enabling environment,

the HRSA Pilot Study Group has identified 10 “domains” as primary targets for description, analysis and strengthening. These domains are described in Insert 7.4.

Generalizations regarding effective models for RCS with respect to the 10 domains in low- and middle-income countries will be useful for application in cross-national programmes aimed at enhancing research capacity. Specific strategies for capacity strengthening are likely to vary and reflect the specific country situations.

In collaboration with many partners, the HRSA Group is currently conducting a pilot study involving 13 low- and middle-income countries (Brazil, Cameroon, Costa Rica, Indonesia, Iran, Kazakhstan, Laos, Malaysia, Pakistan, the Russian Federation, Senegal, Tanzania and Thailand) to determine the validity of these breakdowns, understand national priorities for strengthening different domains and document potential best practices from the perspective of the various actors involved (researchers, policy-makers and other “users” or beneficiaries of health research).

## Insert 7.4

### *Characteristics of an enabling environment for researchers (Health Research System Analysis Initiative, WHO/ RPC)*

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- **Range and breadth of health researchers:** establish teams of researchers including a variety of health research disciplines ranging from basic science and health systems to social science and epidemiology.
- **Transparency of the funding process:** adopt a merit-based, accountable funding process with clear criteria and timely processing.
- **Quality of the work space and facilities:** provide functional work spaces with access to relevant technologies and materials.
- **Encouragement of collaboration with others:** promote collaboration both home and abroad among researchers as well as between researchers (“producers”) and those who draw on the fruits of research (“users”), including policy-makers, the media and the public.
- **Opportunities to present, discuss and publish results:** provide opportunities and incentives to discuss and present work in progress or completed as well as published results.
- **Relevance of health research activities to health problems and health systems:** address priority areas of research, current or projected health problems, and health problems of disadvantaged or poor populations, both on national and global levels.
- **Remuneration of health researchers:** provide adequate salary and benefits to attract and retain trained health researchers.
- **Nurturing of careers:** recognize work contribution, provide opportunities for mentoring and leadership for young and mid-level researchers.
- **Training and continuing education:** provide up-to-date training on national and international approaches to health research and establish a ‘continuous education’ programme.
- **Access and sharing of information:** ensure access to national, regional and international publications, electronic information sources and reference databases on a range of health research disciplines.

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Source: Health Research System Analysis Initiative, WHO/ RPC

## Section 6

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### Agenda for the coming years

The importance of RCS in health research has been underestimated. A review by the Commission on Macroeconomics and Health suggests that, compared to other sectors (e.g. energy, transport, agriculture) which have long been considered strategic for national development and economic competitiveness, little effort has been invested worldwide in collecting data, deciding what to measure or compare, shaping indicators and documenting lessons about how to build, strengthen and sustain scientific capacity for health research – either within or among countries.<sup>11</sup>

The Global Forum attaches much importance to RCS to help correct the 10/90 gap and seeks to explore ways in which it could contribute to the greater efficiency and effectiveness of RCS efforts along the following lines:

#### 1. Design a framework for defining RCS needs and impact

RCS partners should explore the wishes of interested partners to further articulate the definitions, discuss the challenges and future strategies, and intensify efforts to develop an evaluation framework for RCS. In 1999, TDR developed a framework and indicators of impact for RCS in disease-endemic developing countries (see Insert 7.1).<sup>12</sup> The Global Forum will continue to work with its

partners to refine these indicators and design an evaluation framework.

#### 2. Establishment of a network of RCS partners as a platform for debate, synthesis, measurement of results and advocacy

Given the lack of a systemic and collaborative approach to RCS efforts, it is important to develop platforms (networks) for debate, synthesis, measurement of results and advocacy for RCS. Encouraging researchers to join national, regional and global networks is a way to overcome isolation and increase motivation. Locally managed research is likely to be more relevant to local policy-makers and to be more closely linked to politically feasible reforms and policies and more acceptable to policy-makers and civil society.

At the national and regional levels, there is a particularly important role to be played by the Regional and National Health Research Forums in support of the RCS agenda. The Global Forum will seek opportunities to discuss with its partners the development of a RCS agenda at the national, regional and global levels.

#### 3. Funding RCS efforts

To be successful, such efforts require a strong political commitment from national governments and international donors.

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<sup>11</sup> Freeman P and Miller M. Commission on Macroeconomics and Health. *CMH Working Paper Series*. Paper No. WG2:3, 2001.

<sup>12</sup> Global Forum for Health Research. *The 10/90 Report on Health Research 2000*, Geneva, 2000.

National and international financing of RCS efforts should be included in the ongoing discussions on an international health research fund.<sup>13</sup>

#### 4. Enabling health research systems

RCS partners should help developing countries create favourable policies and conditions for the development of sustainable health research systems.

A daunting challenge for most developing countries remains the loss of health professionals moving from the public to the private sector and from low- to high-income countries.<sup>14</sup> As highlighted above, this has considerably limited the capacity of developing countries to study their own problems, to participate in international health research on problems of priority interest to them, and to participate in the political debates and decisions on global health governance.<sup>15</sup>

RCS partners need to devise strategies to ensure that qualified professionals stay in the

national health research system. An example of such good practice is TDR's re-entry grants to enable returning scientists to initiate independent research in their home institutions.<sup>16</sup>

Another good example is Brazil, where it was demonstrated that the factors that promote migration (poor and unstable compensation, inadequate working conditions, weak leadership and adverse socio-political climate) are also associated with the failure of attempts to build research capacity in developing countries. In response, by mitigating these factors through investment in education and R&D, Brazil promoted in-country opportunities which discouraged emigration. As a result, Brazil now has the capacity to generate over 6000 doctoral graduates each year. Today over 90% of doctoral graduates receive their degree from Brazilian universities, as compared to 60% in 1985.

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<sup>13</sup> Commission on Macroeconomics and Health. op.cit.

<sup>14</sup> "The nonprofit groups, foreign governments and international organizations that have come to help Botswana cope with its AIDS crisis have hired away many skilled health professionals in the country's public health system with offers of better pay and benefits." (Festus G. Mogae, President of Botswana, November 2003).

<sup>15</sup> Sitthi-amorn C et al. "Strengthening health research capacity in developing countries: a critical element for achieving health equity," in *British Medical Journal*, 30 September 2000.

<sup>16</sup> WHO/TDR. *Tropical Disease Research, A Global Partnership at Work: New Approaches to Research Capability Strengthening*, Geneva, 1988.

# Chapter 8

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## *Information networks in health research: an overview*

*Section 1  
Information and communication are key to fighting the 10/90 gap*

*Section 2  
Health InterNetwork Access to Research Initiative (HINARI)*

*Section 3  
INASP-Health*

*Section 4  
Scientists for Health and Research for Development (SHARED)*

*Section 5  
Conclusions and next steps*

## Section 1

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### Information and communication are key to fighting the 10/90 gap

In December 2003, an editorial in the *Bulletin of the World Health Organization* highlighted the progress made during the last 25 years in both health and information technology, pointing out that the world as a whole has made “tremendous strides in life expectancy and disease control, together with an explosion of information technology and techniques.”<sup>1</sup> However, the editorial also notes that these benefits have not been shared evenly:

*By no means everyone has benefited from the overall increased trend of increased life expectancy, however, or from that of increased knowledge and its communicability. This gap goes beyond the notion of the ‘digital divide’. It is a ‘knowledge divide’, in which large sections of humanity are cut off not just from the information that could help but from any learning system or community that fosters problem-solving.*

This chapter will look at both sides of the communication gap: the digital and the knowledge divide.

#### 1. The digital divide

December 2003 was a key moment for tackling the digital divide: the first phase of the World Summit on the Information Society (WSIS) was held in Geneva at that time (phase

2 will take place in Tunis in November 2005). The Summit’s aim was “to bring together Heads of State and Government, Executive Heads of the United Nations agencies, nongovernmental organizations, civil society entities, industry leaders and media representatives to foster a clear statement of political will and concrete plan of action to shape the future of the global information society and to promote the urgently needed access of all countries to information, knowledge and communication technologies for development.”<sup>2</sup> In the event, there were over 11 000 participants from 1500 institutions, including 11 heads of state, prime ministers, presidents, vice-presidents and 83 ministers and vice-ministers from 176 countries who endorsed a Declaration of Principles and a Plan of Action.

The Summit sought commitment to bring together the public and private sectors with civil society in the spirit of partnership for development (see MDG8) and to establish information and communication technologies (ICTs) as a priority. Extensive progress in ICTs is a prerequisite for reaching the MDGs. The WSIS Plan of Action sets goals that include connecting all villages, schools, hospitals and governments with ICT by 2015 and ensuring that half the world’s people are within reach of ICT. Roles and responsibilities of all

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<sup>1</sup> Bailey C. “Using knowledge management to make health systems work” in *Bulletin of the World Health Organization* 2003, 81 (11) 777.

<sup>2</sup> The Declaration of Principles and Plan of Action, as well as extensive documentation concerning the WSIS Geneva phase, are available at [www.itu.int/wsis](http://www.itu.int/wsis). The representatives of civil society agreed on their own Plan of Action during the Summit, also available on the WSIS site or at [www.geneva2003.org/wsis](http://www.geneva2003.org/wsis).

stakeholders including government and the private sector are laid out in the plan (see Insert 8.1 for an overview).

Access to information is a need – and arguably a right – of all peoples. According to the UNESCO *Draft Recommendations Concerning the Promotion and Use of Multilingualism and Universal Access to Cyberspace*, “Universal access is equitable and affordable access by all citizens to information infrastructure and to information and knowledge essential to collective and individual human development.”

For those in the North, it is difficult to remember a working world without access to the Internet and communication via e-mail. For those in the South, access to and sharing of knowledge through ICTs is a necessary step towards 2015. There is recognition that, alongside efforts by multilateral agencies, developing countries themselves “to achieve the benefits of access to health information ... must invest strategically in information production, gathering, storage, dissemination and public health literacy promotion.”<sup>3</sup>

In developing countries, there is a need to strengthen the information-production and knowledge-sharing capabilities of health researchers and of publishers of journals and books. This is to enable southern institutions to share knowledge of relevance and applicability in developing countries. The problem is not only that developing countries have limited access to northern journals, but that the industrialized countries have little access to the journal literature of the South. In this era of rapid air transport and the rise and

proliferation of new diseases, the knowledge and experience of southern institutions is of increasing relevance and importance to the global research community.<sup>4</sup>

In a recent interview with the *New Scientist*, James Tumwine, founder editor of African Health Sciences, described problems of access to the Internet from a prestigious medical school in Uganda:

*Just accessing your email through the medical school connection can take up to three hours. So recently I installed a satellite dish outside my office. I'm paying 500,000 Ugandan shillings (£160) a month, which is more than my salary. Then there are technical problems like computers breaking down. For some the Internet is just another part of life but for us it is part of a bigger struggle.*<sup>5</sup>

This is one side of reality – the reality where communications *technology* is slow and hampers access, i.e. the digital divide. But there is another side, that of accessing and sharing the *content* of the message being communicated, i.e. the knowledge divide which is explored below.

## 2. The knowledge divide

Scientists have been concerned for some time with the question of global information flow. For example, in September 2000 the editors of the *Lancet*, *British Medical Journal* and the editorial director (medicine) of *BioMed Central*, jointly posed the following question: “Might information flow be one of the most important factors for improving health and development in resource-poor settings?”<sup>6</sup>

<sup>3</sup> Oduola AB. “Developing countries must invest in access to information for health improvements” in *Journal of Medical Internet Research* 2003;5(1):e5. Accessed from [www.jmir.org](http://www.jmir.org) on 14 January 2004.

<sup>4</sup> Chris Zielinski underlined the importance of this point and made valuable suggestions on the chapter as a whole.

<sup>5</sup> Tumwine J, in an interview in the *New Scientist*. Accessed from [www.newscientist.com/opinion](http://www.newscientist.com/opinion) on 10 February 2004.

<sup>6</sup> Godlee F, Horton R and Smith R. “Global information flow” in *British Medical Journal* 2000 321:776-7. The text was published simultaneously in the three authors' journals.



Godlee, Smith and Horton made many telling points which are still relevant today:

- The Millennium Declaration stated the right of access to information and communication.
- The information gap between rich and poor is currently widening, both between and within countries. The digital divide is more dramatic than any other inequity in health or income.
- The developed world has too much information, the developing world little or none (e.g. outdated textbooks).
- One solution is to narrow the gap through access to electronic information (providing simultaneous access and searchable data, making possible participation in the academic debate).
- Publishers in the rich world must play their part (free access for developing countries' scientists).
- *BioMed Central* also offers free technical support and hosting to people wanting to start new e-journals.
- The health problems of the world are concentrated in the developing world, and those who live with those problems have more to offer each other than those who view them from London or Geneva.
- The understanding reached in the developing world is applicable in the developed world.
- Many regions are establishing free networks for the exchange of health information: e.g. the Scientific Electronic Library Online ([www.scielo.org](http://www.scielo.org)), Bioline International (<http://bioline.bdt.org.br>) and African

Journals Online (see [www.inasp.info](http://www.inasp.info)).

Their conclusion was that “there seems every chance that information exchange among those interested in health should improve dramatically, leading ultimately to an improvement in health itself.”

Responding to the article by Godlee *et al*, ethicist Singer drew attention to the “global inequities of health information [that] are part of the problem of global inequities in health, arguably the most important ethical problem in the world.”<sup>7</sup>

Four years on, has information exchange among those interested in health dramatically improved? There are certainly substantial efforts under way:

- One concerns access to scientific journals (see Insert 8.2).
- The difficulty expressed by developing country scientists in having articles/contributions published in the major international health/medical journals is also being taken seriously.<sup>8</sup>
- A meeting of the Health Information Forum (January 2004) drew attention to the paucity of systematic reviews of research evidence on topics of relevance to the developing world.<sup>9</sup>
- A review of progress over the past ten years in the provision of information for effective health care in developing countries is planned to take place in 2004.<sup>10</sup> The Global Forum will be involved in this initiative and plans

<sup>7</sup> Singer PA, Letter to the *British Medical Journal* 2001; 322: 673 (17 March 2001). Singer also suggested that the next step towards a solution would be to develop a concept of a ‘global alliance for health information.’

<sup>8</sup> The *British Medical Journal* and *Lancet*, for example, actively encourage submissions from developing country scientists. They have been working to enlarge their pool of reviewers so as to be able to better assess contributions.

<sup>9</sup> Richards T. “Poor countries lack relevant health information, says Cochrane editor” in *British Medical Journal* 2004;328:310 (7 February)

<sup>10</sup> A global initiative is being planned to mobilize and engage key stakeholder groups in the health information field, with a view to reviewing and synthesizing lessons learned and developing a shared agenda for future actions.

## Insert 8.1

### *Targets and Action Lines from the WSIS Action Plan*

*(the numbering follows the original document, available from [www.itu.int/wsis](http://www.itu.int/wsis))*

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#### **Targets**

6. Based on internationally agreed development goals, including those in the Millennium Declaration, which are premised on international cooperation, indicative targets may serve as global references for improving connectivity and access in the use of ICTs in promoting the objectives of the Plan of Action, to be achieved by 2015. These targets may be taken into account in the establishment of the national targets, considering the different national circumstances:
  - a) to connect villages with ICTs and establish community access points;
  - b) to connect universities, colleges, secondary schools and primary schools with ICTs;
  - c) to connect scientific and research centres with ICTs;
  - d) to connect public libraries, cultural centres, museums, post offices and archives with ICTs;
  - e) to connect health centres and hospitals with ICTs;
  - f) to connect all local and central government departments and establish websites and email addresses;
  - g) to adapt all primary and secondary school curricula to meet the challenges of the Information Society, taking into account national circumstances;
  - h) to ensure that all of the world's population have access to television and radio services;
  - i) to encourage the development of content and to put in place technical conditions in order to facilitate the presence and use of all world languages on the Internet;
  - j) to ensure that more than half the world's inhabitants have access to ICTs within their reach.

#### **Action Lines**

8. The effective participation of governments and all stakeholders is vital in developing the Information Society requiring cooperation and partnerships among all of them.
  9. Infrastructure is central in achieving the goal of digital inclusion, enabling universal, sustainable, ubiquitous and affordable access to ICTs by all, taking into account relevant solutions already in place in developing countries and countries with economies in transition, to provide sustainable connectivity and access to remote and marginalized areas at national and regional levels.
  10. ICTs allow people, anywhere in the world, to access information and knowledge almost instantaneously. Individuals, organizations and communities should benefit from access to knowledge and information.
  11. Everyone should have the necessary skills to benefit fully from the Information Society. Therefore capacity building and ICT literacy are essential. ICTs can contribute to achieving universal education worldwide, through delivery of education and training of teachers, and offering improved conditions for lifelong learning, encompassing people that are outside the formal education process, and improving professional skills.
  12. Confidence and security are among the main pillars of the Information Society.
  13. To maximize the social, economic and environmental benefits of the Information Society, governments need to create a trustworthy, transparent and non-discriminatory legal, regulatory and policy environment.
  14. ICT applications can support sustainable development, in the fields of public administration, business, education and training, health, employment, environment, agriculture and science within the framework of national e-strategies. This would include actions within the following sectors:  
*[omitted: e-government, e-business, e-learning, e-employment, e-environment, e-science]*
  18. E-health
    - a) Promote collaborative efforts of governments, planners, health professionals, and other agencies along with the participation of international organizations for creating a reliable, timely, high quality and affordable health care
-

## Insert 8.1 (continued)

### Targets and Action Lines from the WSIS Action Plan

(the numbering follows the original document, available from [www.itu.int/wsis](http://www.itu.int/wsis))

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- and health information systems and for promoting continuous medical training, education, and research through the use of ICTs, while respecting and protecting citizens' right to privacy.
- b) Facilitate access to the world's medical knowledge and locally-relevant content resources for strengthening public health research and prevention programmes and promoting women's and men's health, such as content on sexual and reproductive health and sexually transmitted infections, and for diseases that attract full attention of the world including HIV/AIDS, malaria and tuberculosis.
  - c) Alert, monitor and control the spread of communicable diseases, through the improvement of common information systems.
  - d) Promote the development of international standards for the exchange of health data, taking due account of privacy concerns.
  - e) Encourage the adoption of ICTs to improve and extend health care and health information systems to remote and underserved areas and vulnerable populations, recognizing women's roles as health providers in their families and communities.
  - f) Strengthen and expand ICT-based initiatives for providing medical and humanitarian assistance in disasters and emergencies.
23. Cultural and linguistic diversity, while stimulating respect for cultural identity, traditions and religions, is essential to the development of an Information Society based on the dialogue among cultures and regional and international cooperation. It is an important factor for sustainable development.
24. The media—in their various forms and with a diversity of ownership—as an actor, have an essential role in the development of the Information Society and are recognized as an important contributor to freedom of expression and plurality of information.
25. The Information Society should be subject to universally held values and promote the common good and to prevent abusive uses of ICTs.
26. International cooperation among all stakeholders is vital in implementation of this plan of action and needs to be strengthened with a view to promoting universal access and bridging the digital divide, *inter alia*, by provision of means of implementation.
27. The Digital Solidarity Agenda aims at putting in place the conditions for mobilizing human, financial and technological resources for inclusion of all men and women in the emerging Information Society. Close national, regional and international cooperation among all stakeholders in the implementation of this Agenda is vital. To overcome the digital divide, we need to use more efficiently existing approaches and mechanisms and fully explore new ones, in order to provide financing for the development of infrastructure, equipment, capacity building and content, which are essential for participation in the Information Society.
28. A realistic international performance evaluation and benchmarking (both qualitative and quantitative), through comparable statistical indicators and research results, should be developed to follow up the implementation of the objectives, goals and targets in the Plan of Action, taking into account different national circumstances.
-

to include an information and communication component in annual Forums – thereby providing a platform for continued networking and dialogue.

- A taskforce is currently working on knowledge sharing as a major theme for WHO's forthcoming World Report on Knowledge for Better Health (to be published in October 2004).<sup>11</sup>

The following two tables provide lists of information networks of various types. These lists are not meant to be exhaustive but to provide the reader with additional resources.

Insert 8.2 looks at (a) initiatives offering developing-country users online access to the full text of priced journals for free or at low cost and (b) sites offering free online access to aggregations of full-text journals or parts of these journals.

In the past few years, there has been much activity in the development of new networks for information sharing. Frequently used electronic tools for the dissemination of information on health research include:

- websites (interactive or not): for example, that of the World Health Organization [www.who.org](http://www.who.org)
- list serve mechanisms including electronic newsletters (usually sending a selection of news from an institution to individuals who have requested to be included in the distribution): for example, SciDevNet's weekly news round up or the one from Stop TB
- e-mail discussion groups (of which the best ones are moderated): for example, HIF-net at WHO.
- online versions of print journals (with rapid response mechanisms): for example, *BMJ* or *Lancet*
- e-journals: for example, *Health Research Policy and Systems* ([www.health-policy-systems.com/home](http://www.health-policy-systems.com/home).)

Insert 8.3 gives examples of selected global electronic networks created to share information on health and health research. Most of these were established by organizations working in science and technology and/or development.

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<sup>11</sup> Presentation by Tikki Pang in Forum 7, December 2003 ([www.globalforumhealth.org](http://www.globalforumhealth.org)) and article in the *WHO Bulletin* 81 (2003) 810-815.

## Insert 8.2

### Access to priced journals

(a) Initiatives offering developing country users online access to full-text of priced journals for free or at low cost			
Initiative	Characteristics	Content offered	Who can access and at what cost
<p><b>Access to Global Online Research in Agriculture (AGORA)</b>  <a href="http://www.aginternetwork.org">http://www.aginternetwork.org</a></p>	<p>Online portal providing free access to agricultural journals. Launched in October 2003 by the Food and Agriculture Organization (FAO) in partnership with consortium of publishers and WHO's Health InterNetwork Access to Research Initiative (HINARI).</p>	<p>Over 500 major journals in agricultural and related sciences with tailored subset of CAB Abstracts, all accessed directly from publishers' sites.</p>	<p>Free access to qualifying institutions in eligible developing countries.</p>
<p><b>British Medical Journal (BMJ) Publishing Group</b>  <a href="http://www.bmjjournal.com">http://www.bmjjournal.com</a></p>	<p>Individual publisher offering priced journals for free to developing countries. Participates in HINARI and AGORA.</p>	<p>25 specialist journals, <i>Clinical Evidence</i>, the <i>BMJ</i> and the <i>studentBMJ</i>.</p>	<p>Free to all users in all countries with GNI per capita &lt;US\$ 3000 (as designated by World Bank).</p>
<p><b>Electronic Information for Libraries (eIFL.net)</b>  <a href="http://www.eifl.net">http://www.eifl.net</a></p>	<p>Independent foundation aiming to promote wide availability of electronic resources by library users in transition and developing countries. Main focus on negotiating affordable subscriptions on a multi-country consorsial basis, while supporting the enhancement of emerging national library consortia in member countries.</p>	<p>Over 5000 journals and other content via EBSCO (eIFL Direct); direct from publishers or via Proquest (eIFL Science &amp; Technology).</p>	<p>At a discounted price to national consortia, varying from country to country.            Free to all users of consortia libraries. Aims to be global, currently 40 countries.</p>
<p><b>Health InterNetwork Access to Research Initiative (HINARI)</b>  <a href="http://www.healthinternetwork.org">http://www.healthinternetwork.org</a></p>	<p>Online portal providing free or very low cost access to journals and other full-text resources. Consortium of publishers (currently 50) and other partners, coordinated by World Health Organization.</p>	<p>Over 2300 journals and other full-text resources in biomedical and related social sciences.</p>	<p>Access to qualifying institutions in eligible developing countries.            Free access in 69 countries.            US\$ 1000/institution/year in 44 countries.</p>
<p><b>HighWire Free Access to Developing Economies</b>  <a href="http://highwire.stanford.edu/lists/devecon.dtl">http://highwire.stanford.edu/lists/devecon.dtl</a></p>	<p>List of journals published online with the assistance of HighWire Press, accessible free for users from developing economies, based on either programmes such as HINARI or through HighWire's own programme.</p>	<p>HighWire-based software automatically detects the country of the user and grants access accordingly. Some journals do not offer most recent content.</p>	<p>Free to all users from countries appearing in the World Bank's list of low income economies (currently 62) plus Djibouti.</p>

## Insert 8.2 (continued) Access to priced journals

(a) Initiatives offering developing country users online access to full-text of priced journals for free or at low cost			
Initiative	Characteristics	Content offered	Who can access and at what cost
<b>Oxford University Press (OUP)</b> <a href="http://www3.oup.co.uk/jnls/devel">http://www3.oup.co.uk/jnls/devel</a>	Individual publisher offering priced journals for free or at reduced price to low-income countries through OUP Developing Countries Online Collection offer. Participates in AGORA, HINARI and Programme for the Enhancement of Research Information (PERI).	Circa 150 specialist journals, all disciplines.	Free to qualifying organizations from countries in the World Bank's list of low-income economies (currently 62); greatly reduced subscription rates to qualifying organizations from countries in the World Bank's low-middle income countries (currently 72).
<b>Programme for the Enhancement of Research Information (PERI)</b> <a href="http://www.inasp.info/peri">http://www.inasp.info/peri</a>	International project aiming to provide researchers with online access to international scholarly journals, databases and articles across the widest range of disciplines. Provides training in and support for information use in developing countries. Assists developing country publishers.	Over 7000 journals and other content, via EBSCO and direct from publishers.	Free or differentially-priced country-wide access licenses in
(b) Sites offering free online access to aggregations of full-text journals, or parts of these journals			
Initiative	Characteristics	Content offered	Who can access and at what cost
<b>Bioline International</b> <a href="http://bioline.bdt.org.br/">http://bioline.bdt.org.br/</a>	Not-for-profit electronic publishing service committed to providing access to quality research journals published in developing countries. Focus on helping journals publish online.	42 journals, plus books, documents, databases.	Some content free to all.
<b>BioMed Central (BMC)</b> <a href="http://www.biomedcentral.com">http://www.biomedcentral.com</a>	New journals created on the basis of payments from academic authors or their institutions.	Over 100 online journals published in UK.	Most titles free to all.

<p>e-BioSci  <a href="http://www.e-biosci.org/about.html">http://www.e-biosci.org/about.html</a></p>	<p>Resource, in development by European Molecular Biology Organization (EMBO) providing integrated search of published literature, molecular datasets and image repositories.</p>	<p>Prototype interface offers content in the field of molecular biology and genetics, focus on human genetics.</p>	<p>Free to all.</p>
<p>Directory of Open Access Journals (DOAJ)</p>	<p>Portal aiming to increase the visibility and ease of use of open access scientific and scholarly journals.</p>	<p>Currently 798 journals, all subject areas and languages.</p>	<p>Free to all.</p>
<p>Electronic Journals Library  <a href="http://rzblx1.uni-regensburg.de/ezeit">http://rzblx1.uni-regensburg.de/ezeit</a></p>	<p>Portal listing journals available online, with links, categorized by price and subject.</p>	<p>Currently 18 552 titles, mostly journals, of which 6829 accessible free of charge, all subjects.</p>	<p>All titles marked "freely available" are free to all.</p>
<p>FreeMedicalJournals.com  <a href="http://www.freemedicaljournals.com">http://www.freemedicaljournals.com</a>  <a href="http://www.freebooks4doctors">http://www.freebooks4doctors</a></p>	<p>Portal focusing on links to free medical journals and books.</p>	<p>Over 1340 journals and 600 books, categorized by medical specialty, language. Some journals do not offer access to their most recent issues.</p>	<p>Free to all users.</p>
<p>HighWire Free Online full-text articles  <a href="http://highwire.stanford.edu/lists/freeart.dtl">http://highwire.stanford.edu/lists/freeart.dtl</a></p>	<p>List of journals and other scholarly content published online with the assistance of HighWire Press, offering all or some of their content free.</p>	<p>Circa 190 journals mainly medical and life sciences; some journals do not offer access to their most recent issues.</p>	<p>Currently 702 389 full-text articles free to all.</p>
<p>PubMed Central (PMC)  <a href="http://www.pubmedcentral.nih.gov/">http://www.pubmedcentral.nih.gov/</a></p>	<p>Peer-reviewed archive of biomedical articles.</p>	<p>Over 100 journals in the life sciences; some journals do not offer access to their most recent issues.</p>	<p>Free to all.</p>
<p>Scholarly Publishing and Academic Resources Coalition (SPARC)  <a href="http://www.arl.org/sparc">http://www.arl.org/sparc</a>  <a href="http://www.sparceurope.org">http://www.sparceurope.org</a></p>	<p>Promotes creation of alternative, less-expensive journals to challenge existing expensive journals. Some SPARC journals participate in AGORA and HINARI initiatives.</p>	<p>Numerous journals and projects  Most content only available by subscription, although at lower price than comparable journals.</p>	<p>Some free access.</p>
<p>Scientific Electronic Library Online (SciELO)  <a href="http://www.scielo.org">http://www.scielo.org</a></p>	<p>Cooperative electronic publishing of scientific journals; comprises integrated procedures for the measurement of usage and impact of scientific journals.</p>	<p>200 journals (all Latin America, Caribbean and Spain).</p>	<p>Free to all.</p>

Source: Working document prepared by the World Health Organization (2004).

## Insert 8.3

### *Useful additional resources in health research for development: selected global electronic information networks<sup>12</sup>*

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#### **Alliance for Health Policy and Systems Research** [www2.alliance-hpsr.org](http://www2.alliance-hpsr.org)

Services include: website providing contextual searching to facilitate the location and extraction of information related to health policy and systems research from some 1.5 million documents, including full-text access to many of them. The databases searched include MEDLINE, FreeMedicalJournals.com and *ExtraMED*. Also included are resources created by the Alliance: books, newsletter, case studies, training materials and tools, and training modules in Priority Setting in Health Research, Advocacy and Leadership, and Knowledge Management. The Alliance is supported through the Global Forum for Health Research and has over 340 partners.

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#### **The Communication Initiative** [www.comminit.com](http://www.comminit.com)

Services include: website (over 17 000 pages related to communication for development) which includes: base-line data from development and communication sectors; the Drum Beat, weekly electronic magazine; programme descriptions; evaluation data and methodologies; planning methodologies; change theories; interviews; listing of publications and reports, links; active discussion forums; events calendar; monthly newsletters on classified vacancies and classified training, books, consultants, events.

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#### **ELDIS (English Library Development Information Services)** [www.eldis.org](http://www.eldis.org)

Services include: a directory of over 4500 websites, databases, online research project information, library catalogues and other reference materials; summaries and links to over 10 000 full-text online documents; facilities for organizations and individuals to submit their details and documents for inclusion; subject-specific e-mail updates on new items added; newsfeeds for other websites.

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#### **Exchange** [www.healthcomms.org](http://www.healthcomms.org)

A networking and learning programme that promotes effective health communication. It is hosted by [Healthlink Worldwide](#) and supported by the [UK Department for International Development](#) (DFID). Exchange aims to capture, document and promote lessons learned about effective health communication; involve southern-based organizations more fully; increase the capacity of health communicators to influence policy and practice; support strategic approaches to health communication. Exchange strengthens and links existing networks, supporting new work that needs to be undertaken. As a facilitating body, the programme does not normally play a direct role in funding. As a learning programme and iterative process, Exchange monitors and evaluates its own achievements to be able to respond to changing needs and demands of its constituencies.

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#### **Global Development Network (GDN)** [www.gdnet.org](http://www.gdnet.org)

GDN is a global network of research and policy institutes working together to address the problems of national and regional development. Launched in 1999 and incorporated as a non-profit organization independent of the World Bank in 2001, GDN fosters research and knowledge sharing through annual global development conferences, awards and regional research competitions, global research projects and GDNNet, a web-based programme offering tools and services for researchers working in developing and transition countries. These include interlinked directories of researchers, research papers and policy research institutes.

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<sup>12</sup> Networks with a specific disease or regional focus are not included, even though they can offer useful lessons – for example, the new Population and Health InfoShare library, which focuses on reproductive and child health, HIV/AIDS and population ([www.phishare.org](http://www.phishare.org)) or the University of Toronto's Ptolemy project (see Beveridge M et al. "The Ptolemy project: a scalable model for delivering health information in Africa" in *British Medical Journal* 327 (2003) 4 October 790-793 and [www.utoronto.ca/ois/myweb9/index.htm](http://www.utoronto.ca/ois/myweb9/index.htm)). Likewise out of scope are the resources of the Virtual Health Library at BIREME, the Latin American and Caribbean Center for Health Sciences Information ([www.bireme.org/bvs](http://www.bireme.org/bvs)); but see SHARED, section 4 below.



## Insert 8.3 (continued)

### *Useful additional resources in health research for development: selected global electronic information networks*

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#### **Global Knowledge for Development (GKD)** [www.edc.org/GLG/gkd/](http://www.edc.org/GLG/gkd/)

GKD is a list discussion supported by the Education Development Center, a US-based non-profit organization. It was established to facilitate broad discussion of the role and impacts of knowledge, including information/communications technologies for sustainable development.

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#### **Health on the Net Foundation (HON)** [www.hon.ch](http://www.hon.ch)

HON's mission is to guide the growing community of health care consumers and providers on the Internet to sound, reliable medical information and expertise. Initiatives and services include MedHunt© (an intelligent and specialized Internet search engine), HONselect© (an assisted-search facility that integrated heterogeneous databases to offer users a full assortment of web-based health care information and resources) and the HON Code of Conduct (HONcode© a widely endorsed set of ethical guidelines for the provision of authoritative, trustworthy web-based medical information).

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#### **The Institute of Development Studies (IDS), University of Sussex, UK** [www.ids.ac.uk](http://www.ids.ac.uk)

IDS hosts a number of innovative information and knowledge management services providing access to the latest development and research materials from around the globe. Information services include BRIDGE (information and analysis on development and gender), The Global Development Network's online community linking local development research and poverty ([www.gdnet.org](http://www.gdnet.org)), ELDIS (see above) and id21 (see below).

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#### **id21 health** [www.id21.org](http://www.id21.org)

id21 health is one of four programmes of id21, a fast-track research reporting service funded by DFID. It aims to bring UK-based development research findings and policy recommendations to policy-makers and development practitioners worldwide. Online, in print and through the southern media, id21 showcases recent research findings and policy lessons on major development issues. Currently there are four programmes (society and economy, health, education, and urban poverty)

id21 health (and the other programmes) provide a website with free access to a searchable database of recent research on international development issues; jargon-free, non-partisan, one-page research 'highlights' (by email as well as on website); links to and information about source materials; 'Insights' magazine (on website and in print). Source materials include conference papers, research newsletters, and other 'grey' or pre-publication materials.

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#### **INASP-Health** [www.inasp.info/health](http://www.inasp.info/health) (see Section 3 below)

Services include: INASP Health Links (Internet gateway), INASP-Health Directory (printed, CD-ROM, online), Advisory and Liaison Services, Health Information Forum (thematic workshops), HIF-net at WHO (moderated e-mail discussion list).

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#### **SATELLIFE** (The Global Health Information Network) [www.satellife.org](http://www.satellife.org) and [www.healthnet.org](http://www.healthnet.org)

SATELLIFE is an international, non-profit organization whose mission is to serve the urgent health needs of the world's poorest nations by stimulating the flow of information and creating local knowledge networks in support of healthy communities through the innovative use of ICTs. Strategies include Information Resources, HealthNet Knowledge Networks and ICT in Health. Information resources include: electronic discussion groups; electronic publications providing current, reliable public health and clinical content; and GetWeb, a tool that enables users to obtain text from web pages via e-mail. HealthNet Knowledge Networks have been created to date in six countries (Eritrea, Ethiopia, Kenya, Uganda, Zimbabwe and Nepal). ICT in Health comprises projects in partnership: e.g. a recent trial of handheld computers (PDAs) in East Africa as a tool both to provide and collect information.

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#### **SciDevNet Science and Development Network** [www.scidev.net](http://www.scidev.net)

SciDevNet's mission is to enhance the provision of reliable and authoritative information on science- and technology-related issues that impact on the economic and social development of developing countries. The goal is to ensure that individuals and organizations in the developing world are better placed to make informed decisions. A free-access

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## Insert 8.3 (continued)

### *Useful additional resources in health research for development: selected global electronic information networks*

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website, devoted to reporting on aspects of modern science and technology that are relevant to sustainable development, is at the core of its services. It resembles an electronic news magazine, and includes news, features, editorials, book reviews and links to related organizations as well as 'regional gateway' pages for Latin America, Middle East, South and East Asia and sub-Saharan Africa, and a 'What's New' section in English, French, Spanish and Chinese. A special section exists on open access and scientific publishing and current dossiers include the brain drain, climate change, ethics of research, GM crops, indigenous knowledge and intellectual property. A weekly e-mail list serve provides news headlines, with links to full-page articles.

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**SHARED Scientists for Health and Research for Development** [www.sharingpoint.net](http://www.sharingpoint.net) (see Section 4 below)

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**SPIN Science Policy Information News** <http://www.wellcome.ac.uk/en/1/bioprdsn.html>

SPIN is a weekly newsletter produced by the Wellcome Trust's Policy Unit and Information Service. It provides rapid access to concise digests of articles relating to biomedical science policy. SPIN Online is updated every Friday and the SPIN database, containing all SPIN abstracts since March 1992 can be searched online. Users can subscribe to an electronic or paper copy. Health Policy is one of the regular sections.

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**TDR Special Programme for Research and Training in Tropical Diseases** [www.who.int/tdr](http://www.who.int/tdr)

In addition to current information about its portfolio of diseases, results, products, grants and publications, TDR's website has searchable databases: the Research Publications Database containing more than 11 000 scientific papers and publications arising from TDR-funded research (as reported by TDR researchers in their interim and final reports) and the Image Library, containing more than 11 000 images covering all aspects of TDR's target diseases (copies of images can be obtained on request). Its 'Resources Forum' section includes 'Useful links' and 'Discussion groups and lists'. The 'TDR-Scientists' list is a global electronic mailing list open to any scientist interested in tropical diseases research. It is used as an open forum to broadcast brief messages considered useful to the tropical diseases research community and is especially sensitive to the needs of scientists from developing countries.

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**UK Partnership for Global Health** [www.ukglobalhealth.org](http://www.ukglobalhealth.org)

The UK Partnership for Global Health was established in April 2000 following a year-long policy review and national conference organized by the Nuffield Trust and the Royal College of Physicians. It aims to be a forum for people concerned by the impact of globalization on global health, bringing together people from patient-based organizations, charities concerned with health and development, professional associations of doctors, nurses and others, private-sector companies involved in health and the NHS and Government departments. It is funded from charitable sources and its meetings, finances and papers are entirely open to any member. Current sections on the website include: Commonwealth Forum, Global Change and Health, Global Health, Health and Foreign Policy, Health and Trade, Health Governance, ICT for Health, Responsible Globality and Women's Development. This is an interactive site to which users can post comments and responses on content; it receives 40 000 hits/month from all over the world (December 2003).

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Source: Global Forum for Health Research

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Just before the start of the WSIS, the Global Forum invited three information networks to present their work at Forum 7, the 2003 annual meeting. These are global networks of particular relevance to the Global Forum's own work on the 10/90 gap and to the objectives and targets of the MDGs: the Health InterNetwork Access to Research Initiative (HINARI), the International Network for the Availability of Scientific Information's INASP-Health programme and Scientists for Health and Research for Development (SHARED).

ICTs create the dream of a global knowledge base from which information can be extracted and used at the local level. One issue here is access to scientific journals. This is being tackled by HINARI among others for the health sector (see Section 2).

Improved communications allow the results of local research to be distributed broadly, even globally, facilitating knowledge sharing. Access to knowledge sharing and participation in debate is being tackled by INASP-Health, among others (see Section 3).

Sharing of information concerns unpublished as well as published material. Information is

not only about knowledge and research results: networks share contacts, expertise, details about who is doing what and where. Access to unpublished as well as published research and access to scientists is being tackled by SHARED, among others (see Section 4).

Of these three networks, one in particular – INASP-Health – provides a broad range of activities and tools for knowledge sharing, working across electronic and non-electronic communication channels. HINARI's very nature requires a concentration on electronic communication, although the necessity to provide training for those working in developing country member institutions is recognized and taken up by partners.<sup>13</sup> SHARED also recognizes the need to provide off-line consultative and input possibilities for corresponding researchers and to provide training and advice. Its establishment of regional 'sharing points' and production of CD-ROMs for off-line consultation are an answer to these concerns.

Since the widespread development of information networks on a global scale is only in its infancy, it is still difficult to evaluate the impact of these mechanisms.<sup>14</sup>

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<sup>13</sup> TDR has provided targeted grants for infrastructure (equipment and connectivity) and for 'train the trainer' workshops (bringing together researchers and librarians from the same institution with the aim of building a new information culture) as well as a fellowship for African librarians to get high-level training in electronic services provision.

<sup>14</sup> DFID, an agency that has supported many of the communication initiatives listed here, is evaluating its impact in view of its new research strategy. The draft review of September 2003 (*New DFID research strategy: communications theme*) is accessible from [www.dfid.gov.uk](http://www.dfid.gov.uk). Other mechanisms, such as the Communication Initiative, set great store on on-the-spot user evaluation (requesting feedback, for example, on each webpage consulted).

## Section 2

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### Health InterNetwork Access to Research Initiative (HINARI)<sup>15</sup>

The Health InterNetwork Access to Research Initiative (HINARI) is a programme administered by WHO to strengthen health systems in developing countries through online access to high quality, timely and relevant scientific information at affordable prices. In July 2001, the WHO Director-General described HINARI as “perhaps the biggest step ever taken towards reducing the health information gap between rich and poor countries.”

#### 1. Origin

HINARI was developed in response to WHO consultations with developing country researchers and academics in 1999-2000, which identified their most pressing information problem as access to the ‘priced literature’, particularly journals.

#### 2. Objective

HINARI is an online library of full-text resources in biomedicine and related social sciences. It is designed to support developing country health/medical researchers, academics, policy-makers and senior practitioners and, through them, to support improvements in health services in their countries.

#### 3. Strategies

HINARI provides staff and students of national institutions in developing countries (universities, professional schools, research institutes, government offices, teaching

hospitals and national medical libraries) with free or very-low-cost access to over 2300 international journals and other full-text resources. Institutions in 69 countries (GNP per capita of less than US\$ 1000; HINARI phase 1) receive free access; institutions in a further 44 countries (GNP per capita of between US\$ 1000 and 3000; phase 2) pay US\$ 1000/year.

#### 4. Partners

Partners include publishers (see Insert 8.4), WHO (administrator), Yale University (site architecture), TDR (training workshops, infrastructure grants, HINARI fellowship), National Library of Medicine (tailored PubMed links) and the UN Food and Agriculture Organization (FAO), which administers the sister programme AGORA – Access to Global Online Research in Agriculture.

#### 5. Functioning/decision-making

All decisions concerning the HINARI offer of online access to full-text publications are made by the partners at regular meetings. WHO convenes the meetings, presents the needs of the developing countries and administers the programme.

#### 6. Activities

HINARI is an online service. All communications (e.g. registration for the service, help-desk) are via e-mail, in English, French or Spanish as appropriate to the end-

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<sup>15</sup> Presentation by Barbara Aronson in Forum 7, December 2003 (aronsonb@who.int or hinari@who.int).

user. The HINARI menu is a one-stop gateway to all the resources offered, with a choice of language interfaces. On-site training workshops are organized internationally (by TDR) and locally/nationally by participating institutions.

### **7. Budget/resources/financing**

The publishers provide access to their journals and other publications online. Payments for HINARI access from phase 2 countries have been donated by the publishers to a fund administered by WHO, to be used for in-country training. WHO administers HINARI, underwriting staff salaries and other running costs. Yale University Library donate the time of their librarians, who have built and maintain the databases which are the core of the HINARI menu. Yale librarians have also written the HINARI training modules, and participate in training workshops. TDR has funded workshops, infrastructure grants to participating institutions, and a HINARI fellowship. The National Library of Medicine (USA) has developed customized features on their PubMed site for HINARI users (e.g. direct links to full-text articles from the Medline database, HINARI search filter). All framework development, administrative procedures and policies, site construction, training materials, user support, etc. are coordinated with FAO/AGORA and their partner Cornell University. HINARI and AGORA are collaborating with all partners in an evaluation study.

### **8. Results and impact/output**

Since the launch of the HINARI service in January 2002, 1088 institutions have registered from 101 countries (of 113 eligible). Usage of the service is growing

rapidly. For example, in the first six months of 2003, HINARI users downloaded 34 680 articles from the 214 journals offered by Blackwell Publishing, and during the next six months, the number jumped by 113 percent to 74 734 articles downloaded. The high cost of Internet access and computer equipment and peripherals appears to be a significant limiting factor to accessing journals. Nonetheless, usage levels do not always correlate with the relative economic strength of the country, with some of the biggest users (institutions) coming from the poorest countries. The HINARI model is replicable: AGORA was launched in October 2003. The joint HINARI/AGORA evaluation study will measure the impact of the two programmes. What is already evident, from user feedback, is that this service is both needed and appreciated.

### **9. Perspectives**

HINARI is continuing to add content – focusing on particular subject areas requested by the users and on locally produced journals – and is working to find alternative arrangements for countries not yet included in the offer. From mid-2004, user support and training for Africa will be coordinated for HINARI and AGORA from the AGORA office in Harare, Zimbabwe.

### **10. Who can join the network? how?<sup>16</sup>**

Complete information about the HINARI and AGORA programmes and online registration forms can be found at:

- [www.healthinternet.org](http://www.healthinternet.org)
- [www.aginternet.org](http://www.aginternet.org)

Inquiries should be addressed to:

[hinari@who.int](mailto:hinari@who.int) and [agora@fao.org](mailto:agora@fao.org).

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<sup>16</sup> For a fuller description of HINARI, see Long M. "Bridging the knowledge gap: the HINARI programme" in *The Biochemist* December 2003, pages 27-29 and Aronson B. "Improving Online Access to Medical Information for Low-Income Countries" in *New England Journal of Medicine* 350:10, March 2004, pages 966-968.

## Insert 8.4

### *HINARI Publisher Partners (as of February 2004)*

AAAS (Science)	Journal of Bone and Joint Surgery (Am. Vol.)
American Academy of Pediatrics (AAP)	Journal of Bone and Joint Surgery (Br. Vol.)
American Association for Cancer Research (AACR)	Kluwer Academic Publishers
American Cleft Palate-Craniofacial Assn.	Landes Bioscience
American College of Chest Physicians	Lippincott, Williams & Wilkins
American Society for Biochemistry and Molecular Biology (ASBMB)	Medical Journal of Australia
American Society of Clinical Oncology (ASCO)	Morion
American Society of Hematology (Blood)	National Academy of Sciences
Annals of Internal Medicine	Nature Publishing Group
Annual Reviews	New England Journal of Medicine
Arnold (Hodder Arnold)	Oxford University Press
BioMedCentral	Portland Press Ltd. (Biochemical Society)
BioOne	Royal College of Surgeons of England
Blackwell Publishing	Royal Pharmaceutical Society of Great Britain
BMJ Publishing Group	Royal Society of Medicine Press
Botanical Society of America	Sage
CABI International	Society for the Study of Reproduction
Canadian Medical Association Journal	Springer Verlag
Cochrane Collaboration (Wiley)	Swets & Zeitlinger
Cold Spring Harbor Laboratory	Taylor & Francis
Company of Biologists	Thieme Verlag
Duodecim EMB Guidelines	University of Chicago Press
Elsevier Science	John Wiley & Sons
JAMA & Archives Journals	

Source: HINARI

## Section 3

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### INASP-Health<sup>17</sup>

#### 1. Origin

The International Network for the Availability of Scientific Publications (INASP) is an international NGO founded in 1992 by the International Council for Science (ICSU) and headquartered in Paris: see [www.icsu.org](http://www.icsu.org). It is a programme of the Committee on the Dissemination of Scientific Information (CDSI), one of ICSU's eight special policy and advisory committees. It is charged with providing advice to the ICSU family about scientific publications, new developments in information technology, access to data and information, and pertinent legal issues. INASP-Health is a specific programme of INASP.

#### 2. Objective

INASP-Health was launched in 1996 to promote increased access to information for healthcare providers and researchers in developing countries and countries in transition.

#### 3. Strategies and tools

INASP-Health promotes interdisciplinary cooperation, analysis and advocacy across the 'health information development community', in both the North and South: health care providers, librarians, information specialists, publishers, researchers, educators, economists, policy-makers, social scientists, technologists and others. The programme brings together the full range of stakeholders involved in the exchange of health information, from senior executives of international agencies to frontline health workers.

In order to do this, INASP-Health has developed an integrated package of tools for the international health information community (see Insert 8.5): three communication tools (inner circle) and two complementary reference tools (outer circle).

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<sup>17</sup> Presentation by Neil Pakenham-Walsh in Forum 7, December 2003 ([health@inasp.info](mailto:health@inasp.info)).

## Insert 8.5

### Overview of INASP-Health



#### INASP-Health Communication Tools

- **Advisory and liaison service:** provides a focal point, expertise and brokerage for health information development activities.
- **HIF-net at WHO:** launched with WHO in 2000, this is an e-mail discussion list dedicated to issues of health information access in resource-poor settings. The list has more than 1300 subscribers in 129 countries, representing the full range of stakeholders in health information development.
- **Health Information Forum:** a series of thematic workshops, providing a neutral platform for discussion, debate and sharing of ideas and experience among providers and users of health information. Health Information Forum was conceived as a means of bringing together stakeholders in the UK development community. Similar 'health information fora' are now emerging

in other countries, including the United States, Kenya and Senegal.

#### INASP-Health Reference Tools

- **The INASP-Health Directory:** describes 250 international programmes that support provision of health information in developing countries
- **INASP-Health Links:** an Internet gateway to selected websites for health professionals in developing countries.

INASP-Health is playing an increasingly active and specific role in capacity development, particularly with regard to support for inclusive multi-stakeholder networking at regional and country level.

#### 4. Partners

INASP-Health aims to make its services available to all with an interest in increasing



access to information. It works in cooperation with a wide range of national, regional and international organizations involved in health information development, including AHILA (Association for Health Information and Libraries in Africa), BIREME (Latin American and Caribbean Center for Health Information) and WHO.

### **5. Functioning/decision-making**

INASP is based in Oxford and is advised by an International Advisory Council. The Council meets every one to two years to review and plan strategy.

### **6. Budget/resources/financing**

INASP-Health has one full-time member of staff and its total income/expenditure in 2003 was 80,000 pounds sterling. During 2003, financial support was received from the BMJ Publishing Group, Exchange (a DFID-funded networking and learning programme for health communication), the International Institute for Communication and Development, and Wellcome Trust. During 2003, support in kind was provided by the International Health and Medical Education Centre, Royal College of Nursing, Royal College of Physicians, University of Florida, University of Zambia Medical School and WHO. Individual support in kind is given by some 20 professionals worldwide who provide substantial help with the development of INASP Health Links, Health Information Forum and HIF-net at WHO.

### **7. Results and impact/output**

An external evaluation of INASP-Health is due for publication in April 2004. At the present time, INASP is in a state of transition into becoming an independent organization in affiliation with ICSU.

The programme receives a high level of spontaneous positive feedback from users. HIF-net at WHO, in particular, appears to thrive as part of an integrated communication package. It is effective in harnessing experience; enabling contacts and collaboration; stimulating a sense of belonging to a global community; bringing together different perspectives from different professions worldwide; keeping each other informed about new publications and services.

### **8. Perspectives**

The following challenges have been identified by INASP: How to enhance multi-stakeholder networking among researchers, health care providers and others at country level? How to be more effective in facilitating political and financial commitment and effective action? How to integrate multilingual networking?

### **9. Who can join the network?**

Open to all interested organizations and individuals. Free of charge. Contact Neil Pakenham-Walsh at [health@inasp.info](mailto:health@inasp.info) or visit the website [www.inasp.info/health](http://www.inasp.info/health)

## Section 4

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### Scientists for Health and Research for Development (SHARED)<sup>18</sup>

SHARED is a digital network based on validated information about ongoing medical and health-related research, researchers and institutions.

#### 1. Origins

SHARED started in 1996 with two EC-supported projects in which partners in Europe and Africa designed and developed an IT model for the exchange of information on health research, in order to facilitate contact among scientists and funding organizations. The initial project was followed up by the Netherlands Foundation for Scientific Research (Nederlandse Organisatie voor Wetenschappelijk Onderzoek, NWO) and the German Technical Cooperation Agency (Deutsche Gesellschaft für Technische Zusammenarbeit, GTZ), which continue to support the development of applications useful in resource- and information-poor settings.

#### 2. Objective

SHARED's main objectives include making health-related information available on the web in order to promote cooperation and exchange of information and technology among health-related organizations, to support South-South cooperation and to avoid duplication of efforts in solving common health problems.

SHARED is a virtual network of organizations that serves to promote information sharing on health research projects and results. Its target

groups are scientists, research organizations, funding organizations and policy- and decision-makers. The SHARED system is based on three different layers: *organized data* which allows indexing the information for dissemination; *indexes* which allow filtering for specific purposes; and *interfaces* which are specially designed for different audiences. The system permits cross-language networking. Access/input is available via 'sharing points' (which are regional mirror servers).

#### 3. Strategies

SHARED supports countries to organize and publish their own health-related information sources on the Internet in order to make them available for local knowledge management. At the same time, it allows sharing within the Network and search and matching of content with project descriptions, peer review literature, policy papers, health news and mailing lists from different information sources in different countries in a multilingual environment. SHARED hosts a central database for organizations that cannot host their own information ([www.shared-global.org](http://www.shared-global.org)) and a SHARingpoint site ([www.sharingpoint.net](http://www.sharingpoint.net)) where the 'FingerPrints' – that is, the indexes of the different databases, including the SHARED-Global database, NIH, TDR, Medline, Free Medical Journals, news and mailing lists – are available for search and matching.

#### 4. Partners

NWO, GTZ and regional networks in Latin

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<sup>18</sup> Presentation by Agnes Soares da Silva, Scientific Secretary, SHARED, at Forum 7, December 2003 (soares@nwo.nl).

America and Caribbean (BIREME – [www.bireme.br](http://www.bireme.br)), Asia-Pacific (hosted by CEPR – [www.shared-asiapacific.org](http://www.shared-asiapacific.org)) and Africa (Witwatersrand University of South Africa, Medical Research Council of South Africa, HSRC South Africa, Blair Research Institute of Zimbabwe, Medical Research Council of Zimbabwe, among others; see the homepage at [www.shared-africa.org](http://www.shared-africa.org)).

### 5. Functioning/decision-making

The SHARED network is decentralized, with regional coordination teams in Latin America and the Caribbean, Asia and Pacific, and Africa. SHARED has an International Committee that is now composed mainly of former members of the Advisory Committee of the EC project. The three regional coordinators are members of the International Committee. Each region has its own approach to building the SHARED network, taking into consideration the different levels of networking activities.

All SHARED technology software, including those using the Collexis FingerPrinting technology, is available free of licence fees for the public sector. However, the latter requires signing a Service Level Agreement, which includes costs. Although it is not necessary to install the Collexis technology locally to join SHARED, any public-sector organization located in or working for developing countries, interested in having a local installation of the technology should contact the non-profit organization IntellectualAll (I2A: [www.intellectuall.org](http://www.intellectuall.org)). I2A holds the right to license Collexis technology and offers service support for the public sector using lower pricing criteria than those used for the private sector.

### 6. Activities

Organizational activities consist of sensitization and meetings at central, regional and country levels. Technical activities

include training and capacity building; technology transfer; technical support for actual and new partners; maintenance of the central database and of the SHARingpoint website and applications; development of new tools when needed for the network activities. Networking activities involve acquisition of new partnerships; interaction with other networks of interest on research for development; active search for content of interest (news servers, mail lists, publications, policy papers, projects database, etc.).

### 7. Budget/resources/financing

SHARED received seed money from donors such as NWO and the Dutch Ministry for Development Cooperation (DGIS), which is mainly being used in the regions for expansion, set-up and training. GTZ is also working on the expansion of the network in Africa. Organizations willing to participate in the SHARED network commit themselves through local expenditures related to the organization of their own information. There are many other local initiatives within the network that are seeking or have already received funding for specific projects. NWO also supports SHARED by hosting the Secretariat of the Network.

### 8. Results and impact/output

Over 113 000 projects are accessible through the SHARED network and can be matched with journal articles/abstracts and with new and mailing list postings. A pool of more than 100 000 experts has been derived from these sources. In addition to Medline – the largest server for abstracts from medical journals provided by the NIH – the SHARingpoint has approximately 540 000 full-text indexed articles from more than 600 different journals (such as the *British Medical Journal*, the *Lancet* and *Gene*) and links to about 170 000 full-text articles. Sources and queries are currently accepted in English, Spanish, French, Dutch and German. New languages including

Russian, Portuguese, Bahasa and Chinese will be added soon. A new feature called 'My SHARingpoint' allows the user to define a search profile and to receive e-mails when a new source with the same profile is added to the sharingpoint.net, within a chosen period.

### 9. Perspectives

SHARED has opened new possibilities for sharing information interactively on the Internet without having to build up a central database. The information remains at the origin source and is indexed using the FingerPrinting technology. The resulting 'Collexion of FingerPrints' are available through the SHARingpoint server. This revolutionary technology allows different systems to communicate with each other using a common Internet language, instead of establishing rigid protocols to share information.

Because the main objective of SHARED is to make better use of existing sources of health research information, and especially to improve the link with the policy-making

process, the organization and publication of local information sources is a priority. Having developed a tool that assists organizations to do this, SHARED is in the position to offer an extremely rapid solution for information-sharing – in principle, in any country and using any language.

### 10. How to join the network

The SHARED sites are online and do not require any special procedures or fees. To look for information, go to [www.sharingpoint.net](http://www.sharingpoint.net). New information can be entered directly into the central database [www.shared-global.org](http://www.shared-global.org).

Contact can also be made with the regional coordinators via the following websites:

- SHARED Africa [www.shared-africa.org](http://www.shared-africa.org)
- SHARED Asia [www.shared-asia-pacific.org](http://www.shared-asia-pacific.org)
- SHARED Latin America and Caribbean [www.bireme.org](http://www.bireme.org)

or directly with the SHARED Secretary: [info@sharingpoint.net](mailto:info@sharingpoint.net) or [shared@nwo.nl](mailto:shared@nwo.nl).

## Section 5

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### Conclusions and next steps

#### In summary:

- The new knowledge generated by health research (information) must be disseminated and taken up (communication) so that it may lead to improvements in people's health.
- The full potential of Information and Communication Technologies (ICTs) must be developed so as to remedy both the digital divide and the knowledge divide.
- The first phase of the World Summit on the Information Society, held in Geneva in December 2003, brought together the public and private sectors with civil society in a spirit of partnership for development and to establish ICTs as a priority. The second phase will take place in Tunis in November 2005.
- A large number of information networks have been created in the past decade and play a key role in ensuring access to scientific information and knowledge; they also represent reinforced international cooperation and allow expression of local needs and priorities.
- Three successful networks were examined in some detail in this chapter:
  - HINARI, which is a free or low-cost online library of full-text resources in biomedicine and related social sciences, designed to support health services in developing countries;
  - INASP-Health, which provides a network promoting increased access to information through knowledge sharing and participation in debate for health care providers and researchers in developing and emerging economies; and
  - SHARED, which makes possible sharing of information on projects, people and organizations as well as seamless searching for and matching specific terms between linked databases.
- Planning is in progress for a global initiative to mobilize and engage stakeholders in the health information field, with a view to reviewing and synthesizing lessons learned and developing a shared agenda for future actions.
- One strand of work currently under way is the preparation by WHO of the 2004 World Report on Knowledge for Better Health focusing on what is being called the “know-do gap”, i.e. the disjunction between research and its application. This Report (due to be published in October 2004) and discussions at the World Summit on Health Research and Forum 8 in Mexico City in November 2004 will provide valuable guidance on further steps towards reducing the inequity of the 10/90 gap.

# Chapter 9

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## *Some networks in the priority research areas*

- Section 1  
Global Alliance for Cancer Control*
- Section 2  
Global Alliance for TB Drug Development*
- Section 3  
HIV/AIDS*
- Section 4  
Initiative for Cardiovascular Health Research in Developing Countries*
- Section 5  
Medicines for Malaria Venture*
- Section 6  
Mental and Neurological Health*
- Section 7  
Multilateral Initiative on Malaria*
- Section 8  
Reproductive Health*
- Section 9  
Road Traffic Injuries Research Network*
- Section 10  
Roll Back Malaria*
- Section 11  
TDR*
- Section 12  
Child Health and Nutrition Research Initiative*
- Section 13  
Sexual Violence Research Initiative*
- Section 14  
Alliance for Health Policy and Systems Research*
- Section 15  
Council on Health Research for Development*
- Section 16  
Initiative on Public-Private Partnerships for Health*

## Summary

The chapter reviews some of the priority areas recommended in chapter 4, describing the size of the problem and the results of efforts to build networks which focus on these priority areas (including their objectives, partners, governance, strategies and activities).

Since it would be impossible to review all research efforts currently under way, the chapter describes the efforts undertaken by international networks in only some of the priority research areas. Some of these efforts were supported by the Global Forum for Health Research, others not. They are categorized in the following four groups:

### **A. Networks focusing on diseases and conditions**

- Section 1. Global Alliance for Cancer Control
- Section 2. Global Alliance for TB Drug Development
- Section 3. HIV/AIDS
- Section 4. Initiative for Cardiovascular Health Research in Developing Countries
- Section 5. Medicines for Malaria Venture
- Section 6. Mental and Neurological Health
- Section 7. Multilateral Initiative on Malaria
- Section 8. Reproductive Health
- Section 9. Road Traffic Injuries Research Network
- Section 10. Roll Back Malaria
- Section 11. TDR

### **B. Networks focusing on determinants (risk factors)**

- Section 12. Child Health and Nutrition Research Initiative
- Section 13. Sexual Violence Research Initiative

### **C. Networks focusing on priority-setting methodologies**

### **D. Networks focusing on policies and cross-cutting issues**

- Section 14. Alliance for Health Policy and Systems Research
- Section 15. Council on Health Research for Development
- Section 16. Initiative on Public-Private Partnerships for Health

# A. Networks focusing on diseases and conditions

## Section 1

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### Global Alliance for Cancer Control<sup>1</sup>

#### 1. Burden of disease

Cancer is acknowledged to be a major and increasing public health problem throughout the world. It is estimated that over the next 20 years, the number of cancer deaths worldwide will increase from about 6 million to 10 million a year – significantly increasing both the human and economic burden of cancer.

While some countries address the cancer burden effectively, there is great variability among nations in their capacity, resources and commitment to addressing cancer as a public health priority. In an effort to meet this public health need, WHO and the International Union Against Cancer (UICC) have brought together diverse organizations with the aim of working in partnership to address cancer at the global level.

#### 2. Creation of the network

The need for an Alliance for Global Cancer Control was first addressed at the 18th UICC International Cancer Congress in Oslo in 2002. Representatives of major national and

international organizations and private sector organizations interested in cancer control agreed that such an Alliance should be comprehensive in its approach, but that specific action was needed at the global level in the following four priority areas:

- advocacy for comprehensive national cancer control plans
- global advocacy for cancer prevention and healthy lifestyles
- addressing the needs of cancer patients
- promoting applied research opportunities.

At the 2003 meeting of the American Society for Clinical Oncology, the following major functions were identified for the Alliance:

- identify and increase the opportunities for global cancer control collaboration;
- provide an authoritative voice for global cancer control awareness and actions;
- promote global tobacco control efforts;
- advocate for national efforts in cancer control;
- serve as a communications resource for Alliance members and others;
- increase synergy and cooperation among

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<sup>1</sup> Adapted from a text contributed by the Secretariat of the Global Alliance for Cancer Control.



organizations with an interest in cancer control and already working in countries around the world (e.g. International Atomic Energy Agency radiotherapy programmes in developing countries and those conducting multi-country clinical trials);

- propel cancer-related issues on to the public health agenda. Essential public health functions jointly tested by the WHO Pan American Health Organization (Washington, DC) and the Centers for Disease Control (Atlanta, USA) could serve as a model. The functions include: surveillance, health promotion, workforce development, assessment of the quality of care and access to care, and research and development.

To help narrow the list of proposed actions, those selected were expected to meet the following criteria:

- be meaningful, practical, achievable and fundable
- lead to an early success for the Alliance
- be appropriate for the Alliance
- be proportionate in terms of the effort expended in relation to the expected impact.

### 3. Strategies for the first year

Based on the above criteria, the following actions were identified as priorities for the coming year:

#### **(a) Increase the importance of cancer control on the global health and economic agendas**

Cancer is not currently considered a major global issue in the same way as AIDS, for example. It is critical to establish a climate in which cancer is seen, discussed and acted upon as a major global issue by international organizations. For example, the agendas for the G8 meetings have never addressed cancer as an issue of global importance. Advocacy with such leadership groups is important for gaining international and national attention and taking action to address the cancer

burden. Equally important is the need to build awareness of cancer-related issues within the general population in order to stimulate public pressure on these leadership groups to act.

Thus it was decided to develop a two-pronged strategy for increasing the importance of cancer on the global health agenda:

*(i) Develop a strong case statement including the following:*

- Compelling facts on the extent of the cancer burden in human, social and economic terms.
- A strong sense of urgency that action is required now in order to save millions of lives in future years; cancer as a problem cannot be put off for action by future generations.
- The time to act is now and 'you' must be the ones to act.
- Clear and compelling arguments for why international and national leaders should care about the cancer problem and why they should consider doing things differently than at present.
- A concise definition for cancer control that both explains its comprehensive scope and, where possible, links it to other national and international priorities (e.g. the cost of health care).
- A proposed agenda for action that the Alliance would like to see adopted and which might include such things as: publicly endorsing global and national cancer control efforts; provision of resources for global and national cancer control efforts; taking a major, ongoing leadership role in tracking global cancer control efforts; and holding constituents and peers accountable for their action (or inaction) in cancer control efforts.
- A strong clear statement of what will happen if we fail to take action to reduce the global cancer burden, i.e. what are the consequences of failing to act.

(ii) Put cancer as an item on the global leadership agenda. For example:

- The G8
- World Economic Forum's Global Health Initiative
- International development agencies
- Regional organizations such as the Organization of American States and the WHO Pan American Health Organization
- United Nations bodies
- International media.

**(b) Continue the development of the Alliance**

- The concept of the Alliance has merit and should continue to be developed.
- It was agreed that, for the time being, the Alliance will remain an informal confederation of cancer-concerned organizations and that the structure should be as open as possible.
- UICC has agreed to serve as the Secretariat.

- A small group of WHO/UICC staff will continue to coordinate the process of building up the Alliance. This will include: a communication structure to keep Alliance members informed of progress; engaging Alliance members in its advocacy work; and recruiting additional Alliance participants.

**(c) Tobacco statement**

At the World Conference on Tobacco or Health in Helsinki in August 2003, the members of the Alliance for Cancer Control issued its first public statement in which it supports and accepts shared responsibility for world wide implementation of the WHO Framework Convention on Tobacco Control (FCTC). The FCTC adopted by the World Health Assembly in 2003 sets norms and standards for national legislative action and multilateral cooperation for tobacco control.

## Section 2

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### Global Alliance for TB Drug Development<sup>2</sup>

#### 1. Central problem

One of the most contagious infectious diseases, TB is today at its highest level ever, with one third of the world's population infected. The disease is also responsible for more AIDS-related deaths than any other opportunistic infection. Every year, more than 8 million of those infected with the TB bacillus develop new cases of active TB and 2 million people die from the disease.

Successful treatment of the disease involves a cumbersome, six-month, combination-drug regimen delivered through the DOTS (directly observed treatment, short-course) strategy. However, this treatment is currently reaching only 30% of TB patients worldwide. Moreover, the rise of drug resistance and the convergence of the TB and HIV epidemics have intensified the need for better, faster-acting therapeutics for tuberculosis.

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<sup>2</sup> Adapted from a text contributed by the Secretariat of the Global Alliance for TB Drug Development.

The long and complex regimen imposed by the current class of TB drugs – the most recent of which was introduced in the 1960s – is one of the greatest obstacles to controlling the disease. Because of the length of treatment and side-effects, patient compliance is often poor, resulting in drug resistance. It also involves a considerable health system cost in terms of direct patient observation: at least US\$ 4 billion a year worldwide. This, in turn, further handicaps TB control programmes, fuels drug resistance, and prevents the systematic treatment of latent TB infection, the reservoir for the epidemic.

Recognizing these alarming trends, the Amsterdam Ministerial Conference on Tuberculosis and Sustainable Development, held in March 2000, established new DOTS targets and called upon the international development community to dramatically increase support for TB control efforts. In addition, the Conference called for accelerated research for the development and delivery of new tools in a manner consistent with affordability and accessibility.

New and faster-acting drugs will radically transform the fight against TB in three important ways and the new regimen will become the cornerstone of effective TB control. The target drugs will:

- **Accelerate DOTS:** By shortening to two months or less – or otherwise simplifying the course of treatment – the new regimen will lower the incidence of toxic side effects, improve patient compliance, and increase cure rates. A shorter treatment period will also reduce the costs of TB treatment both for patients and health systems.
- **Treat multi-drug resistant TB (MDR-TB):** By effectively treating resistant strains, a new drug would have a profound impact on the treatment and control of MDR-TB.
- **Improve the treatment of latent infection:** By shortening and improving treatment of

latent infection, a new drug will lower TB transmission rates. Effective treatment of latent TB is particularly important for patients co-infected with HIV.

By reducing the time of therapy, combating drug-resistant strains and improving the treatment of latent TB infection, affordable, faster-acting TB drugs will treat thousands more patients effectively – thereby helping reach the TB control targets of the Millennium Development Goals.

## 2. History of the partnership

### (a) Creation

In February 2000, 120 representatives from academia, industry, major agencies, NGOs and donors from around the world adopted the “Declaration of Cape Town” which provided a road map for action towards TB drug development and the impetus for the creation of the Global Alliance for TB Drug Development (“TB Alliance”) in October 2000.

### (b) Central objective

Using a public-private partnership approach, the TB Alliance’s primary goal is to develop within a decade new anti-TB drugs that shorten and/or simplify treatment, are effective against multi-drug resistant TB, and address both active and latent forms of the disease. At the centre of this mission is the commitment requirement that the resulting medicines be accessible and affordable to all in need.

In working toward this goal, the TB Alliance has established itself as the primary catalyst for TB drug development efforts worldwide. As part of this catalytic role, the TB Alliance invests in platform technologies designed to enhance the probability of success for compounds that enter the drug development pipeline worldwide.

### (c) Main strategies

To deliver a new anti-TB drug within a decade,

the TB Alliance is building, developing and managing a portfolio of promising compounds. The TB Alliance also stimulates TB drug development by providing a framework to support and coordinate various initiatives at every stage of the drug development process. On both fronts, the TB Alliance engages in partnerships with a range of organizations worldwide, including academic institutions, government research laboratories and public health institutions, NGOs, the pharmaceutical industry and contract research organizations.

The TB Alliance was designed to maximize the commitment of both public and private partners to ensure that new drugs for TB are affordable and accessible in poor countries. The public-private partnership model under which it operates is an ideal mechanism to overcome the lack of market incentives that brought TB R&D to a virtual standstill after the 1960s.

The mechanism is designed to ensure that promising anti-TB drug candidates move quickly through all stages of development, receive regulatory approval, are priced affordably and are transferred into effective and accessible clinical use.

Procurement and distribution of resulting medicines will be designed in close collaboration with the Stop TB Partnership's Global Drug Facility and the Global Fund to Fight AIDS, TB and Malaria to ensure equitable access and affordability in endemic countries.<sup>3</sup>

#### **(d) Partners**

**Win-win agreements with industry and public sector.** The TB Alliance forms partnerships where both risks and incentives are shared. In designing partnerships and agreements, the

TB Alliance places a high priority on drug affordability, adoption and accessibility in endemic countries (the "AAA" strategy). An emphasis on win-win agreements allows the TB Alliance to balance affordability and health equity with incentives for collaboration. The organization pursues intellectual property rights in order to ensure the availability of novel technologies for public benefit.

In addition to a landmark licensing agreement for the promising anti-TB compound PA-824 with Chiron Corporation in 2002, the TB Alliance has implemented ways to partner with pharmaceutical and biotechnology companies with drug development know-how and capacity. In 2003 Novartis's newly launched TB research facility in Singapore, the Novartis Institute for Tropical Diseases, pledged to team with the TB Alliance to manage the later-stage development of novel compounds it identifies. Novartis has also committed to make these technologies available without royalties in endemic countries.

**Endemic countries.** As the TB Alliance surveyed R&D capacity globally, it identified promising compounds in countries such as India and Korea, and qualified preclinical development facilities in countries such as South Africa and Brazil. On the drug development front, these countries could have compounds to expand the portfolio, and could offer their laboratories' preclinical capacity to develop the portfolio. At the clinical development stage, patient enrolment is critical. The TB Alliance works in partnership with government agencies in leading endemic countries, as well as with individual companies and laboratories for specific drug candidates and trials.

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<sup>3</sup> The Stop TB Partnership is a public-private collaboration hosted by WHO which aims to expand, adapt and improve strategies to control and eliminate TB.

### **(e) Organization**

The TB Alliance has a Board of currently 11 members, representing international and national government agencies, pharmaceutical and biotechnology companies, private foundations and NGOs.

A 15-member Scientific Advisory Committee assists in evaluating proposals and projects under consideration for investment as part of its TB drugs portfolio. The Committee provides technical expertise on drug research, development, manufacturing and distribution, as well as other medical and scientific issues.

The TB Alliance includes in its governance framework a group of institutions that join in a “Stakeholders Association” and have certain roles and responsibilities in advising, guiding and supporting the organization. Stakeholders represent the breadth of institutions worldwide who share a clear interest and a significant stake in ensuring the development of new TB drugs through the TB Alliance. They include representatives from developing nations, governments, NGOs working in TB, foundations and industry.

Stakeholders participate in the TB Alliance's outreach and advocacy efforts and advise and support the Board of Directors on issues including activities related to access to anti-TB medicines. These responsibilities are exercised through ongoing contacts with the leadership of the organization and through the nomination of candidates for the Board of Directors and the election of a Stakeholders Association President to sit on the Board of Directors.

### **(f) Annual budget and sources of financing**

With a rapid expansion of the portfolio in 2002 and 2003, the TB Alliance budget reached US\$ 5.6 million in 2003 and is expected to increase to US\$ 14.4 million in

2004, with the lion's share of expenses devoted to an outsourced R&D project. These R&D investments are supporting the continued portfolio expansion and projects that lay the groundwork for clinical trials.

The TB Alliance was launched with seed funding from the Bill and Melinda Gates Foundation and Rockefeller Foundation. Further funding also came from the Dutch Ministry of Development Cooperation through the World Health Organization. In addition, the National Institute of Allergy and Infectious Diseases (NIAID) provides in-kind support, offering access to in-house capacity and a network of contractors and grantees. Other contributions include investments in projects by members of the TB Alliance Stakeholders Association, such as the Bayer-CDC moxifloxacin trials supported by the CDC, the clinical trial infrastructure capacity building currently under way by CDC and those planned by the European and Developing Countries Clinical Trials Partnership (EDCTP) through joint calls for proposals with the TB Alliance.

### **3. Main achievements in 2002-2003**

The TB Alliance has assembled a portfolio of 10 compounds in lead identification, lead optimization and preclinical development phases and catalysed the phase II clinical trial in first line treatment of a second-line drug (Insert 9.2.1). Compounds were identified through proactive searches, through calls for proposals and through an active, worldwide business development programme.

The lead novel compound in the TB Alliance portfolio, PA-824, acquired from Chiron Corporation, is widely recognized as one of the most promising new anti-TB compounds and could be in clinical trials by 2005. Another compound (KRQ-10018) is at the lead optimization stage at the Korea Research

## Insert 9.2.1

### Investment portfolio

	LEAD IDENTIFICATION	LEAD OPTIMIZATION	PRECLINICAL	CLINICAL
Compounds	Pyridones and Quinolizines	KRQ-10018 (Quinolone)	PA-824 (Nitroimidazopyran)	Moxifloxacin
	Asciddermin Compounds	MJH-9B-I-B1 and Analogs (Isoniazid analogs)	LL-3868 (Pyroles)	
	Third-Generation Macrolides	PA-647 (Nitroimidazopyran)		
		PA-822 (Nitroimidazopyran)		
		Rifalazil Analogs		
Platform Investments	Database of TB Compounds and Related Technologies			Clinical Trials Capacity Development
		Murine Models		Regulatory Harmonization

Project in Portfolio
  Project in contractual discussions
  Support to Third Parties

Institute of Chemical Technology (KRICT) in Taejon, South Korea. This has demonstrated activity and specificity for TB and is now to be further evaluated for preclinical efficacy. In addition, compounds in the quinolizine, quinolone and pyridone families are being synthesized and tested by KRICT and its partner, the Yonsei University in Seoul. Another drug, moxifloxacin (a quinolone with worldwide regulatory approval developed by Bayer AG for use in the U.S. for the treatment of skin and upper respiratory tract infections and pneumonia) has shown high levels of activity against TB and recent in vivo experiments confirmed its promise to significantly shorten therapy. It is now being tested in phase II clinical trials, facilitated by the TB Alliance and carried out by the TB Trials Consortium of the CDC.

In addition, the TB Alliance has invested in selected platform technologies that support

TB drug development worldwide. These investments help pave the way for clinical trials, drug registration and lead generation. For example, the TB Alliance is supporting the standardization of a network of 15 clinical sites in Africa, Asia and South America. The project, which involves staff training and the upgrading of laboratories, is intended to provide the TB community with a set of potential clinical trial sites and establish guidelines for clinical trials to be used with new anti-TB drugs.

#### 4. Expected outputs for 2004-2005

**(a) Continued portfolio expansion and development.** Over the next two years, the TB Alliance will continue to expand its portfolio and develop promising compounds with public and private partners worldwide. The TB Alliance will also continue to invest in core technologies that enhance R&D capabilities in the field of anti-TB drugs. Specific targets for 2004-2005 include:

- enter PA-824 into clinical trials; accelerate clinical trials with other promising advanced stage compounds, such as moxifloxacin;
- develop a back-up development programme for PA-824 using its analogs;
- acquire 5-6 additional compounds in the portfolio;
- expand organizations and institutions within its outsourcing network;
- expand the R&D team with in-house expertise in research, clinical development, regulatory affairs and project management.

**(b) Initiation of clinical trials and regulatory approval.** With the rapid progress of later-stage portfolio investments, the TB Alliance is anticipating the need for greater worldwide clinical capacity for the development of compounds such as PA-824 and moxifloxacin. Additional lead compounds are under review that will, if selected and successful, require clinical trials to be initiated in 2004-2005. Specific targets include:

- assess, select and strengthen priority sites for clinical trials in endemic countries (i.e. in several African and South American countries, as well as India and South Korea);
- establish collaborative agreements with endemic countries and other partners conducting clinical trials, such as the TB Trials Consortium (TBTC), the European and Developing Countries Clinical Trials Partnership (EDCTP) and the South African Medical Research Council;
- plan the conduct of clinical trials;
- initiate projects to facilitate regulatory approval.

**(c) Enhanced platform investments.** Over the next two years, the TB Alliance plans to continue its support of platform investments, as well as add new projects. These could include efforts such as:

- continued support for animal models;
- projects to enhance development of world-wide clinical trial capacity development;

- development of regulatory guidelines for TB drug development;
- development of a database for the study of surrogate markers to shorten clinical development time;
- establishment of a TB drug database and/or mapping exercise to comprehensively “map” all activities of the Stop TB Working Group members that directly support the development of new TB drugs.

**(d) Expanded outreach to mobilize patient support worldwide.** Over the next two years, the TB Alliance plans to expand a series of outreach initiatives, which complement the primary tasks related to developing and testing new drug candidates. It is critical that the TB Alliance continue to mobilize technical resources and expertise for drug development, as well as secure the conditions necessary for the full adoption of and access to new TB drugs. These activities include:

- develop momentum through public awareness and education, and enrol patient groups;
- foster the development and participation of patient networks and enrol support from healthcare workers;
- mobilize endemic countries and develop high-level collaborative agreements;
- lay further the groundwork to ensure access, including close collaborations with global procurement mechanisms such as the Global Fund and the Stop TB Partnership’s Global Drug Facility;
- ensure early adoption through the mobilization of WHO and endemic countries’ national TB control programmes.

## 5. Conclusions and longer term perspectives

Since the publication of the previous *10/90 Report*, the TB Alliance has transformed itself from a fledgling start-up into an expanding drug development operation. The organization is well grounded, with a rapidly expanding portfolio.

The TB Alliance is also fully integrated in the global health community. It fills a critical piece of the essential medicines puzzle, providing the required “push” mechanism that complements the “pull” effect of initiatives such as the Global Fund and the Global Drug Facility.

As the TB Alliance enters this next crucial phase of drug development, the support of additional partners and donors will be critical to the sustainability and final success of the enterprise. In particular, the initiation of clinical trials, including the establishment of both infrastructure and a network of facilities, will require a rapid scaling up of financial support and expanded endorsements.

Over the last two years, the TB Alliance has made rapid progress in the search for a novel cure. For the first time in 40 years, a robust pipeline of promising new TB drugs is being developed and moving through milestones, with the help of new platform investments. The TB drug development environment worldwide has a new catalyst and new purpose. With the support of its partners and donors, the TB Alliance holds the promise to expand the armamentarium against one of the oldest deadly infectious diseases, and deliver a faster cure, available and affordable to all patients in need, especially in the developing world.

## Section 3

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### HIV/AIDS<sup>4</sup>

#### 1. Problem overview

The global HIV/AIDS epidemic killed more than 3 million people in 2003 and an estimated 5 million became newly infected with HIV – bringing to 40 million the number of people living with the virus worldwide, most of them in low- and middle-income countries. Almost 2000 children under 15 were infected every day, bringing to 2.5 million the number of children living with HIV. Of the 12 000 people aged 15 to 49 infected daily, almost half are women and

about 50% are young people aged 15 to 24. With only an estimated 400 000 people receiving antiretroviral drugs (7% of the estimated 5.9 million people who will die within the next two years without access to antiretroviral drugs), AIDS kills more people annually than tuberculosis or malaria.

Globally, the AIDS response is moving into a new phase. Political commitment has grown stronger, grass-roots mobilization is becoming more dynamic, funding is increasing, treatment

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<sup>4</sup> This text was contributed by Catherine Hankins, UNAIDS, Geneva.



programmes are shifting into gear, and prevention efforts are being expanded. But, measured against the scale of the global epidemic, the current pace and scope of the world's response to HIV/AIDS fall far short of what is required.

## 2. The role of research

Research plays a critical role in guiding an expanded response to HIV/AIDS, whether it focuses on examining the key determinants and effects of political will to address the epidemic, the epidemiology of HIV, behavioural and structural determinants of HIV transmission, or the characteristics of effective evidence-based interventions to reduce transmission, improve health care and support services, and address stigma and discrimination. It is critical that not only the results of research but the process itself should have clear benefits for those areas of the world hardest hit by the epidemic.

From a scientific point of view there are advantages to conducting research in countries where transmission rates are high and substantial numbers of people are living with HIV.

## 3. Research issues

HIV research is having valuable spin-offs for our understanding of other infectious, malignant, neurological, autoimmune and metabolic diseases. It has led to new paradigms in drug design, development and clinical trials, and has helped speed up the approval process. It has also greatly increased our understanding of sexual and drug-taking behaviour as well as of the constructive responses that individuals and communities have taken to reduce transmission. Examples of the latter include study of the impact of multicultural, inclusive, participatory approaches in national level responses; the

effects of increased schooling for girls; the impact of harm reduction strategies; and the effectiveness of methods for adapting cultural practices to reduce HIV transmission risk while retaining their social meaning. Some research priorities in the fields of epidemiology, economics, prevention and care are listed below.

### (a) Epidemiology and economics

The priorities for research in epidemiology and economics include:

- Improved methodologies to monitor, model and estimate current and future epidemic dynamics.
- Research to evaluate the economic determinants and consequences of the HIV epidemic at micro- (household), meso- (community/district) and macro-levels in different settings.
- Development of improved methodologies for documenting actual expenditures, estimating the costs of comprehensive prevention and care programming in resource-constrained settings and tracking resource flows.

### (b) Vaccines

Vaccine development is a complex research challenge from the biomedical, ethical and societal point of view but is critical to eventual control of the pandemic and could also have therapeutic benefits for people living with HIV. Lag times in the development and testing of candidate vaccines must be reduced and numerous parallel and comparative approaches tried rather than the current linear, incremental process. A Global HIV Vaccine Enterprise is being launched to achieve a more integrated and efficient HIV vaccine research initiative with the goal of developing a safe and effective HIV vaccine in the shortest time possible.<sup>5</sup> It is clear that

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<sup>5</sup> Klausner R, Fauci A, Corey L et al. "The need for a global HIV vaccine enterprise" in *Science* 2003; 300: 2036-39.

populations at risk must be integrally involved in the development of vaccine trials for a number of reasons, including ensuring that trial conduct will be culturally sensitive, avoiding increased risk through misperceptions of benefits of trial participation and encouraging planning for the roll-out of an effective vaccine.

### **(c) Behavioural and social science**

Developing, evaluating and scaling up effective behavioural, social and structural prevention strategies to reduce HIV transmission are key to slowing the epidemic. Among the most pressing research priorities are:

- Study of the implications for HIV transmission of the development, testing and implementation of effective prevention strategies addressing complex issues of gender and sexuality, changing patterns of drug use and socioeconomic determinants of risk.
- Better understanding of the correlates of initiation, maintenance and renewal of HIV risk reduction at individual, group and community levels and operations research to assess strategies to strengthen these.
- Evaluation of the net effect on transmission of reduced viral load due to antiretroviral treatment and possible off-setting increased behavioural risk, i.e. the effects of changing perceptions of HIV infection in the face of treatment roll-out.
- Microbicides: assessing combination approaches such as combining physical and chemical barriers, combining microbicides with different specificities and mechanisms of action, rapidly increasing the number of potential microbicides in the research pipeline.
- Improving research methodologies in behavioural and social science, developing innovative approaches for investigating the psychosocial effects of HIV on communities and ways of mitigating these and strengthening community capacity to respond.

- Research into the determinants and consequences of stigma and discrimination and effective ways of reducing these.

### **(d) Clinical, therapeutic**

This field includes both basic science and operations research. Priorities relevant to people living with HIV around the world include discovering new viral and cellular targets and developing therapeutic agents that target drug-resistant virus, have activity in viral reservoirs and cellular compartments, have low toxicity, improved efficacy and are easy to take (high treatment adherence potential). Some specific examples are:

- Continued development of safe, effective, feasible, conveniently administered agents to reduce mother-to-child transmission (MTCT), with special emphasis on breast feeding which is generally the safest infant feeding option but carries significant risk of HIV transmission. Operations research to study linkages between MTCT programmes and treatment for women and their families (MTCT-plus).
- Development and testing of appropriate technology for monitoring HIV treatment in patients in resource-constrained settings.
- Study of the effectiveness of community-based adherence support on clinical progression and therapeutic success as access to antiretroviral treatment is scaled up.
- Investigating optimal therapeutic strategies and their clinical, operational and economic implications in resource constrained settings: early versus late initiation of treatment, change of drugs, sequencing of therapies, effects of treatment interruptions.
- Study of host virus interactions in women and men and their significance for disease progression and treatment.
- Bi-directional effects of co-infection with and treatment of TB, malaria and hepatitis B on HIV disease progression and drug interactions.

#### 4. Selected research networks in HIV/AIDS

While it is not possible to enumerate all the research networks addressing HIV/AIDS, some prominent networks are described below.

##### (a) International Partnership for Microbicides ([www.ipm-microbicides.org](http://www.ipm-microbicides.org))

The International Partnership for Microbicides (IPM) was established in 2002 to accelerate the discovery, development and accessibility of safe, effective, affordable and easy-to-use microbicides to prevent transmission of HIV. Microbicides are products such as gels or creams that women can use to prevent or significantly reduce the transmission of HIV and possibly other disease-causing organisms during sexual intercourse. Ideally, they could be used without the male partner even knowing it. Microbicides could be delivered in other forms, including films, suppositories, and slow-releasing sponges or vaginal rings. Microbicides are essential to the protection of women because they are several times more at risk than men of contracting HIV during sexual intercourse. Research suggests that even a partially effective product that reaches a limited number of women worldwide has the potential to avert nearly three million infections in just three years.<sup>6</sup> Several promising candidates are already in the pipeline.

In seeking to facilitate the development of both contraceptive and non-contraceptive microbicides that ideally would be effective for both vaginal and rectal use, IPM's core areas of work are in R&D and ensuring access to effective products when these are developed. In particular, IPM aims to increase the efficiency of the development and delivery of a microbicide by expanding the breadth

and level of public and private sector funding; identifying critical gaps in R&D, access and advocacy; leveraging partnerships with both new and existing public and private players; and helping to raise awareness of microbicides worldwide. Already IPM has established a standardized screening procedure for new compounds, acquired formulation capabilities and begun work on trial capacity and regulatory strategies.

##### *Achievements*

IPM was launched with support from the Rockefeller Foundation. Since that time, it has already attracted significant donor support from five European governments – Denmark, Ireland, the Netherlands, Norway and the UK – as well as the Bill and Melinda Gates Foundation, the World Bank and UNFPA. With these funds, IPM has built a team of staff and consultants with expertise in molecular biology, antiviral activity, formulations technology, regulatory affairs, clinical trial site development and access issues.

IPM's model is to seek out the most promising new microbicide technologies and form public-private partnerships to accelerate and increase the efficiency of product development at every stage, including formulation and drug delivery research, clinical trials and manufacturing. IPM also convenes industry experts and makes targeted investments to develop resources and technologies that will be shared with others to advance the entire field. These capacity-building activities include animal model testing, clinical trial site development, and research into drug formulation and delivery. The microbicide field is different from others addressing neglected public health technologies because a number of product developers already exist.

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<sup>6</sup> Watts C et al. *Microbicides*, Antwerp, 2002.

However, the vast majority of the entities currently involved are small biotechnology companies, non-profit organizations and academic institutions with limited funding and capacity. IPM will form partnerships with them to address critical gaps and obstacles and promote rapid product development. IPM is also working to enlist large companies with antiviral and formulations technology into the field.

Of the estimated US\$ 775 million in product development costs required over the next five years to develop the entire portfolio, only US\$ 230 million has been committed so far. At the end of 2003, 14 microbicides were in clinical trials and planning was under way for five products to enter phase III effectiveness trials in 2004.

#### **(b) Monitoring the AIDS Pandemic ([www.mapnetwork.org](http://www.mapnetwork.org))**

Monitoring the AIDS Pandemic (MAP) is a collegial network of internationally recognized technical experts seeking to assess the status and trends of the global HIV/AIDS pandemic. MAP was created in 1996, through the collaboration of the AIDS Control and Prevention (AIDSCAP) Project of Family Health International, the François-Xavier Bagnoud Centre for Health and Human Rights of the Harvard School of Public Health, and UNAIDS.

MAP's more than 100 members in 40 countries represent a wide range of disciplines, including epidemiology, mathematical modelling, economics, social and behavioural science, public health and international development. Members are recruited through

a nomination process which is currently guided by the Chair and Board of Directors.

#### *Achievements*

MAP strives to make its greatest impact by providing objective, timely and high-quality analyses of the most current information about the pandemic for the improvement of prevention, care and social interventions worldwide. MAP workshops and membership meetings are held in conjunction with regional and international HIV/AIDS conferences. This enables MAP to function on a small budget and to distribute results from its analyses promptly to conference participants. Specific workshops are convened as needed, with expertise drawn from MAP members and other invited experts. Regional experts are encouraged and supported by MAP in the collection, analysis, synthesis and dissemination of regional information, which is then incorporated into MAP's global reports. Reports published by MAP in conjunction with international HIV/AIDS events are compiled and printed in local official languages and distributed on site.<sup>7</sup> They are also translated into other languages to ensure a wide readership.

MAP works toward building consensus in an atmosphere of collegiality, cultural sensitivity, and mutual respect for conflicting points of view. It functions on the basis of volunteerism and personal and institutional contributions, with limited financial support from international organizations, including UNAIDS, and thus provides an independent perspective on issues raised by the HIV/AIDS pandemic. MAP involves networking through exchanging knowledge and data from around the world;

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<sup>7</sup> Available from [www.mapnetwork.org](http://www.mapnetwork.org): *HIV Infection and AIDS in the Americas*, Havana Cuba 2003; *The Status and Trends of the HIV/AIDS Epidemics in the World*, Barcelona, Spain 2002; *The Status and Trends of HIV/AIDS/STI Epidemics in Asia and the Pacific*, Melbourne Australia 2001; *HIV/AIDS in the Americas: An Epidemic with Many Faces* November 2000; Durban MAP Provisional Report, July 2000; Kuala Lumpur MAP Provisional Report, October 1999.

collection, analysis and dissemination of information on the trends and status of HIV/AIDS; and capacity building to expand national capacities to respond to the pandemic through training and expert advice.

**(c) International AIDS Vaccine Initiative (www.iavi.org)**

Founded in 1996, the International AIDS Vaccine Initiative (IAVI) is a global organization working to speed the development and distribution of preventive AIDS vaccines. IAVI's work focuses on mobilizing support through advocacy and education, accelerating scientific progress, encouraging industrial participation in AIDS vaccine development and assuring global access. IAVI was born out of the recognition that the best long-term solution to the growing AIDS epidemic is the development of an effective AIDS vaccine that can be quickly distributed to all who need it. IAVI is committed to changing business as usual by working across borders and sectors to rapidly move suitable vaccine candidates into clinical testing, identify and develop promising candidates and address key scientific challenges. IAVI focuses on viral strains prevalent in developing countries and works to ensure that vaccines will be accessible and readily available in developing countries at reasonable prices. IAVI enlists developing country scientists, policy-makers, NGOs, international organizations, civil society and industry to support and catalyse activities within countries towards the development of an AIDS vaccine.

*Achievements*

IAVI is probably best known for its efforts to accelerate the development of preventive AIDS vaccines by creating awareness of the need for a vaccine, accelerating applied vaccine development and advocating for incentives to encourage industrial involvement. IAVI's *Scientific Blueprint for*

*AIDS Vaccine Development*, issued in 1998, outlined the steps needed to assure the earliest possible emergence of an effective vaccine against AIDS. Since then, IAVI has created and funded several international AIDS vaccine development partnerships and supported additional product development efforts for four different vaccine strategies. IAVI is also working with a consortium of leading AIDS laboratories to design a fifth vaccine strategy.

The *Blueprint* outlined a five-step global action plan to ensure timely use of a preventive vaccine in all at-risk populations worldwide, minimize delays in vaccine supply and delivery, while respecting intellectual property, and ensure that adequate incentives are in place for the private sector.

In addition to the *Scientific Blueprint*, IAVI brought new leadership to the AIDS vaccine field by investing in a series of innovative international vaccine development partnerships that brought together researchers and scientists in industrialized and developing countries to move promising vaccine candidates toward clinical testing. In the past five years, IAVI has helped advance five vaccines into human tests in 13 clinical trials in seven countries.

IAVI negotiated ground-breaking intellectual property agreements to help ensure that the fruits of vaccine research will be readily available in developing countries. *The IAVI Report*, the first periodical devoted to chronicling HIV vaccine research, has more than 10 000 readers in 140 countries. IAVI put AIDS vaccines onto the global policy agenda, winning significant increases in government funding for AIDS vaccine research and development and laying the foundation for AIDS vaccine clinical trials in East Africa (Kenya and Uganda), South Africa, India, Rwanda and China. With the World Bank it helped establish a task force to study

new financial mechanisms to spur the development, and eventual purchase, of AIDS vaccines for developing countries.

**(d) The African AIDS Vaccine Programme ([www.who.int/vaccine\\_research/diseases/hiv/aavp/en/](http://www.who.int/vaccine_research/diseases/hiv/aavp/en/))**

The first HIV vaccine trial in Africa was conducted in Uganda in 1999, 12 years after the first trial in the United States (1987). Although more than 30 different HIV candidate vaccines have been tested in approximately 70 phase I (safety) or phase II (immunity testing) trials, only four of these have been conducted in Africa (Kenya, Botswana and Uganda). In June 2002, convened by WHO, UNAIDS and the Southern African Development Community (SADEC), a group of 40 African scientists, community representatives and decision-makers met in Nairobi and produced a powerful advocacy document entitled *African Strategy for an HIV Vaccine*. The strategy includes a situation and response analysis, vision and goals, guiding principles, strategic milestones and an activity framework to accelerate HIV vaccine development in Africa. To implement this strategy, the African AIDS Vaccine Programme (AAVP) was established in November 2002 with support from WHO and UNAIDS. The organizational structure includes a steering committee, thematic working groups, forums, affiliated African institutions, sponsors, a secretariat (the WHO-UNAIDS HIV Vaccine Initiative) and a proposed coordinating board composed of representatives from the scientific community, countries, host communities and donors.

The AAVP involves all countries in the region, coordinates a transparent and collaborative process with equitable participation of multiple partners, promotes research respecting human rights, aspires to the highest ethical and scientific standards, encourages and supports simultaneous development and evaluation of

vaccine candidates appropriate for the region while contributing to the development of HIV vaccines in general as an international public good, and is planned as a long-term and sustainable effort. In addition to strategic milestones indicating the number and phase of clinical trials to be developed by specified dates, the AAVP is implementing a number of research/training/capacity building exercises in five areas: biomedical (laboratory and clinical studies); population-based studies (epidemiology and social-behavioural research); ethics, law and human rights; national strategic planning and community preparedness.

*Achievements*

In 2002-2003, the AAVP completed an inventory of existing facilities through questionnaires and site visits in nine countries and developed a database of laboratory resources and needs. More than 80 African scientists were trained in virology and immunology; existing ongoing cohort studies in Africa were assessed as potential sites for vaccines trials, a 15-country review of ethical capacity was completed; training workshops for community groups were conducted and strategies to engage communities were developed. AAVP also developed a policy statement on the implications of genetic variability for HIV vaccine development, supported the development of national AIDS vaccine plans in seven countries and initiated an African network on research ethics focused on HIV vaccines. A number of advocacy materials were developed and a workshop on strategies for the development of vaccine trial sites was conducted in Addis Ababa. AAVP broadened its funding base to include the government of Canada, IAVI and the Swedish government.

AAVP has a seven-year work plan and will focus in 2004-2005 on strengthening sites and infrastructures for the conduct of HIV vaccine clinical trials. This will involve

strengthening virology and immunology expertise in selected laboratories and clinical trial capacity in selected centres, developing standards of laboratory assays for vaccine immunogenicity evaluation, developing generic protocols and supporting research on key socio-behavioural issues and strengthening collaboration with African countries in the development and implementation of national AIDS vaccine plans. AAVP will also develop a normative framework for the conduct of human trials in Africa. This will involve creating consensus on the norms and regulations under which trials are conducted to ensure that the rights of volunteers are fully protected; strengthening ethical review capacity in selected countries; providing guidance for regulatory decisions and supporting national regulatory authorities in the development of criteria and procedures for approving/monitoring clinical trials and for the licensing and use of future HIV vaccines; and supporting the development of policies for the introduction and use of HIV vaccines, including access.

#### **(e) HIV Vaccines Trials Network and HIV Prevention Trials Network**

These two networks, the HIV Vaccine Trials Network (HVTN) and the HIV Prevention Trials Network (HPTN), were created by the NIH in the United States. Both networks receive primary support from the National Institute of Allergy & Infectious Diseases (NIAID) Division of AIDS (DAIDS). The HPTN receives additional support from other NIH components, including the National Institute on Drug Abuse, the National Institute of Child Health and Human Development and the National Institute of Mental Health. International research training activities of both networks are coordinated with the NIH Fogarty International Center.

- **The HIV Vaccine Trials Network (HVTN, [www.hvtn.org](http://www.hvtn.org))**

Established in 1999, the HVTN conducts all phases of clinical trials, from evaluating candidate vaccines for safety and the ability to stimulate immune responses, to testing vaccine efficacy. An international collaboration of scientists, its mission is to develop and test preventive HIV vaccines that will be effective against all isolates and in people throughout the world to reduce the frequency of seroconversion, progression of HIV and transmission of HIV. This is done through multi-centre phase I, II and III clinical trials of candidate HIV vaccines in a global network of more than 12 domestic and 12 international sites. The HVTN has established strong collaboration with vaccine developers and a wide variety of scientists working in the areas of HIV virology, immunology and pathogenesis. The scientific collaborations and scope of exploratory work within the HVTN are by design expansive and more extensive in scientific depth and breadth than in previous vaccine trials networks. The HVTN also has strong relationships with community NGOs and with a wide variety of international organizations involved in the design and conduct of HIV vaccine development.

#### *Achievements*

Among the priorities of the HVTN has been a focus on identifying whether T-cell responses after vaccination differ by vaccine strain or clade (subtype) in studies which have involved administering similar vaccines, doses and schedules for both northern and southern hemisphere sites, while simultaneously evaluating a variety of HIV strains and clades (subtypes). These data are important in defining whether vaccines with predominant T-cell responses can be used in efficacy trials across wide regions of the globe. Given the continuing genetic evolution and

recombination of isolates of HIV, this is a critical issue.

Much of the work of the HVTN to date has focused on site readiness for vaccine trials with the HVTN planning to conduct as many simultaneous trials as it can. International collaboration provides an ideal platform to encourage cooperation between companies and inventors in defining an optimal vaccine regimen. In its efforts to define novel ways to evaluate vaccine effectiveness, members of the HVTN worked with Aventis Corporation in evaluating a series of HIV vaccine candidates.

The HVTN is currently conducting eight clinical trials of HIV vaccine candidates and a number of trials are planned to start in 2004. The HVTN is also studying participants from HVTN Phase I and II trials who become infected with HIV during the course of a trial. This study examines the virological, immunological and clinical natural history of these infected participants, comparing individuals who received vaccines with those who received a placebo. This will help determine whether vaccinated individuals who become infected might be protected in some way from rapid HIV progression.

- **HIV Prevention Trials Network (HPTN, [www.hptn.org](http://www.hptn.org))**

The HPTN is a worldwide collaborative clinical trials network that develops and tests the safety and efficacy of primarily non-vaccine interventions designed to prevent the transmission of HIV. Established in 1999, the HPTN carries out its mission through a strong network of expert scientists and investigators from more than two dozen international sites partnered with a leadership group based at three US academic research institutions. Community involvement is an integral feature of HPTN activities.

The strengths of the HPTN include: leadership by experts in the prevention sciences; a

coordinated domestic-international research agenda; multi-disciplinary study teams of behavioural, clinical, epidemiological, laboratory, operations and statistical researchers; capability to conduct cross-cultural comparisons among different host and viral populations; emphasis on ethical guidelines in research; and priority placed on community involvement in all aspects of the research process, from trial development through implementation. A global network of HIV Prevention Trials Units (HPTUs), each comprised of a principal awardee institution and its affiliated performance sites, conducts trials in the six HPTN research areas (prevention of MTCT, treatment of other STIs to reduce the risk of sexual acquisition or transmission of HIV, antiretroviral chemoprophylaxis to reduce the risk of sexual HIV transmission, behavioural interventions to reduce sexual transmission risk, interventions aimed at injection drug users, and topical microbicides). Scientific and community representatives from these sites participate fully in scientific decision-making and the governance of the HPTN through membership in all working groups and committees.

#### *Achievements*

Research infrastructure development: the development of HPTN international research sites has made the largest single contribution to international clinical research capacity and readiness among NIH-funded research networks. Together with HVTN efforts to develop international sites capable of performing clinical research, HPTN progress in site capacity development has established proven international sites that are now available for participation in research projects conducted by these and other NIH networks. This accomplishment represents an important long-term benefit and will advance the NIH goal of implementing an integrated international programme of research in HIV vaccines, therapeutics, and prevention.



Prevention research studies: HPTN Scientific Working Groups have designed and implemented several new prevention studies. Four site preparedness studies are intended to measure HIV seroprevalence and incidence in specific target populations, and to evaluate and strengthen the capability of new international sites to conduct clinical research. Five phase I/II trials have been conducted to evaluate the safety of candidate topical microbicides and of a chemoprophylaxis intervention for maternal-infant HIV transmission. A large phase II/IIb trial of two topical microbicide candidates is scheduled for implementation in early 2004. Two new phase III trials have been developed and implemented to test the efficacy of a behavioural intervention in injection drug users and to determine the efficacy of STI treatment in reducing the risk of HIV infection. An additional two efficacy trials are scheduled for implementation in 2004. In addition, HPTN has completed five prevention clinical trials initiated under its predecessor, the HIV Network for Prevention Trials.

#### **(f) Other networks and agencies supporting international HIV research**

A number of national research organizations play important roles in HIV/AIDS research internationally. These include the Medical Research Council (MRC) of the United Kingdom ([www.mrc.ac.uk](http://www.mrc.ac.uk)) which has conducted a number of trials of community-based interventions examining the impact of treatment for sexually transmitted disease on HIV incidence and is preparing sites for microbicide trials. The International Development and Research Centre of Canada co-financed the Nairobi cohort studies

which have revealed the genetic basis for partial protection against the virus, while emphasizing the importance of condom provision to sex workers, complementing education strategies. France's Agence nationale de recherches sur le sida (ANRS) has financed a number of research studies in the developing world focused on topics such as strategies to interrupt MTCT of HIV and economic determinants and consequences of the HIV epidemic.

Other networks such as the International AIDS Economics Network ([www.iaen.org](http://www.iaen.org)) bring together researchers interested in studying economics, costing methodologies, resource tracking and the economic impact of the HIV epidemic in resource constrained settings. Several United Nations agencies which are co-sponsors of UNAIDS, play supporting roles in HIV research by convening consensus meetings on topics such as scientific priorities, interpretation of findings and ethical concerns. Examples include the June 2003 meeting convened by WHO on principles and practices for the implementation of ethical guidelines for research on HIV,<sup>8</sup> a meeting the same month on strategic information for the scale-up of antiretrovirals<sup>9</sup> and a WHO/UNAIDS consultation in July 2003 on the standard of care for participants of HIV prevention trials (vaccine, microbicide and behavioural interventions) who become infected during the course of the trials.<sup>10</sup> WHO/UNAIDS guidelines on the ethical conduct of vaccine research have been published<sup>11</sup> along with a number of meeting reports which highlight the discussions that have led to consensus decisions such as the recent WHO-UNAIDS-

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<sup>8</sup> [www.who.int/hiv/strategic/mt020603](http://www.who.int/hiv/strategic/mt020603)

<sup>9</sup> WHO. *Strategic information for antiretroviral scale-up*, Geneva, 2003 ([www.who.int/hiv](http://www.who.int/hiv)).

<sup>10</sup> WHO/UNAIDS. *Draft report of the WHO-UNAIDS consultation on modalities for access and standard of treatment for participants with intercurrent HIV infections during vaccine, microbicide and other prevention research trials*, 2003 ([www.who.int](http://www.who.int)).

<sup>11</sup> UNAIDS. *Guidance document: ethical conduct of vaccine trials in developing countries*, Geneva, 2000 ([www.unaids.org](http://www.unaids.org)).

CDC meeting held to discuss implications for ongoing and future trials before the results from the first phase III trial of an HIV vaccine – the Vaxgen trial – were announced.<sup>12</sup> The World Bank meeting in May 2003 on HIV resistance and its implications for the scaling up of antiretroviral treatment reported a number of priority topics for operational as well as basic research<sup>13</sup> and the Lusaka/Zambia WHO/UNAIDS consultation on the ‘3 by 5’ Initiative produced an agenda of monitoring and evaluation priorities for treatment scale-up.<sup>14</sup>

## 5. Conclusion

HIV/AIDS research is a global public good which can be translated into the effective delivery of research outcomes for the benefit of all people, particularly the poor. International collaboration and coordination in the field of HIV/AIDS research is critical to the speed of progress toward achieving both the targets of the UN General Assembly Declaration of Commitment on HIV/AIDS and the MDG of halting and reversing the HIV/AIDS epidemic by 2015.

Joint actions, which span the globe through research networks and partnerships between

the public sector, academic institutions, the private commercial sector and civil society organizations, bring benefits including quicker generation of research findings, consensus on international standards for the conduct of research and research capacity strengthening. Parallel concurrent efforts with rapid accrual of study participants help to obtain more timely answers to critical questions and can link together diverse approaches and different stages of the research process. International collaboration can lead to consensus on international standards for the conduct of research which respect the human rights of study participants, support the research priorities of host countries, promote community involvement in the design and conduct of research, and ensure that prevention and care interventions that are demonstrated to be safe and effective are made available to all study participants and to other members of the high-risk populations from which they were drawn. Networks contribute to RCS by fostering a critical mass of qualified men and women to undertake research addressing national priorities, participate in policy-making bodies and contribute actively to international research efforts.

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<sup>12</sup> WHO/UNAIDS/CDC. *Public health considerations for the use of a first generation HIV vaccine: report from a WHO-UNAIDS-CDC consultation*, Geneva, 20-21 November 2002. AIDS 2003; 17: W1-W10.

<sup>13</sup> [http://www1.worldbank.org/hiv\\_aids/WHOIATCMeeting.asp](http://www1.worldbank.org/hiv_aids/WHOIATCMeeting.asp).

<sup>14</sup> <http://www.who.int/3by5/publications/documents/zambia/en/>.

## Section 4

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### Initiative for Cardiovascular Health Research in Developing Countries (IC Health)<sup>15</sup>

#### 1. History of the network

##### (a) Central problem

Over recent decades, many low- and middle-income countries have experienced profound changes in population structure and disease patterns that have fundamentally changed their burden of ill health. As a result, in all but the very poorest countries today, NCDs are leading causes of mortality and morbidity. CVDs such as coronary heart disease and stroke are major contributors to these NCD burdens. Moreover, projections over the next few decades suggest that the number of people dying from CVD or living with diabetes in these regions will double. Unchecked, these “epidemics” will result in the deaths of several million middle-aged men and women annually, since about half of all cardiovascular deaths in developing countries occur between the ages of 30 and 69.

Those who survive strokes or heart attacks will frequently be disabled, often in the prime of their working lives. The hidden costs of disability are generally borne by families, resulting in diminished opportunity for family members to engage in paid employment outside the home. The economic hardships brought about by the death or disability of family wage earners in mid-life has far-reaching consequences for young and elderly dependents. Moreover, the expanding need for expensive clinical care for patients with heart disease or stroke diverts scarce health

care resources from other critical areas such as vaccination and HIV/AIDS programmes, with adverse consequences for the health of children and young adults in developing countries. There is increasing evidence that the poor are becoming the most vulnerable victims of the advancing epidemics of CVD in many developing countries, in terms of both increased susceptibility to disease and inability to access appropriate care.

##### (b) Creation

The Initiative for Cardiovascular Health Research in Developing Countries (IC Health) was established in 1999 as a joint programme of the Global Forum and the WHO Noncommunicable Diseases Cluster to provide a research response to the high and increasing burden of CVD in developing countries. As the accelerating epidemics of CVD threaten the poor in increasing numbers, affecting both women and men, research is essential to identify cost-effective mechanisms for applying existing knowledge and to help bridge critical information gaps by generating new knowledge.

##### (c) Objectives

The purpose of the Initiative is to stimulate, support and sustain research which will inform policy and empower programmes for prevention and control of CVD in developing countries. The focus of IC Health is the following:

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<sup>15</sup> Adapted from a text contributed by the Secretariat of IC Health.

*Promoting health research which will enable the early integration of cost-effective interventions for cardiovascular risk reduction in populations and individuals at high risk of CVD into primary health care settings in low- and middle-income countries.*

Such research will include studies of risk factor distributions, burden of disease estimates, health care delivery systems, access to health care, operational methods for delivery of vascular risk reduction programmes, sustainable systems for chronic care, the development of dependable referral systems and health policy research. Health system interventions for vascular risk reduction will also be developed and evaluated for cost-effectiveness.

Apart from such operational research, IC Health also undertakes policy research on the macroeconomic effects of CVD and tobacco policy interventions, analytical studies on research road maps and resource flows into CVD research, and capacity building for research in low- and middle-income countries.

#### **(d) Partners**

Since its creation in 1999, the IC Health partnership has expanded to include the following institutions: Institute of Medicine (USA), World Heart Federation, National Public Health Institute (Finland), World Hypertension League, International Obesity Task Force, International Institute for Health and Development (Australia), Institut de Médecine Sociale et Préventive (Switzerland), Health Canada, Centers for Disease Control (USA), National Institutes of Health (USA), the International Clinical Epidemiology Network (INCLIN), Medical Research Council of South Africa and National Public Health Institute of Mexico. The partnership thus represents a range of international research agencies, public health institutes and health

NGOs. The network of partners is being expanded to include more agencies and institutions in developing countries.

#### **(e) Governance**

The Initiative is governed by a Partnership Council, an Executive Committee (drawn from the Partnership Council) and an International Scientific Advisory Committee. Coordination is ensured by the Scientific Secretariat located in New Delhi.

## **2. Main accomplishments in 2003**

In 2003, IC Health activities included the following:

- Establishment and continued expansion of global and regional research networks.
- Establishment of a multi-institutional global partnership council representing diverse but complementary strengths.
- Prioritization of research and creation of a portfolio of research projects which focus on operational and policy research.
- Research workshop on cardiovascular risk reduction in primary health care settings
- Workshop on priorities for research relevant to tobacco control in developing countries (Insert 9.4.1).
- Completion of studies on capacity assessment for control of CVD and diabetes in India, Cameroon, Thailand (Insert 9.4.2).
- Completion of a survey of practice patterns of management of acute coronary syndromes in different health care settings, through developing country research networks.
- Completion of global overview on macroeconomic effects of CVD and initiation of in-depth country case studies.
- Commencing the systematic definition of priorities in CVD research using the CAM.
- Leveraging support for independently financed research projects (cardiovascular risk factor surveillance in industrial populations in India; INTERHEART global

study on cardiovascular risk factors in acute myocardial infarction; eastern collaborative cohort study on cardiovascular risk factors and events; capacity assessment in Mexico, Guatemala and Nigeria.

- Capacity building for research, through support to World Heart Federation's international ten-day teaching seminars on cardiovascular epidemiology and prevention.
- Assistance to the World Bank in the development of CVD fact sheets; organization of a workshop in Washington D.C. on chronic disease (for World Bank staff); organization of a workshop on NCDs in Chennai, India (for the World Bank-assisted health systems project in the southern Indian state of Tamil Nadu).
- Working with partners (WHO, Global Forum, WHF, CDC) on research, policy advocacy and training-related activities organized by them.
- Technical assistance to research/training workshops organized by regional networks in the Middle East and sub-Saharan Africa.

### 3. Expected outputs for 2004

#### (a) Catalytic role for operational research

The recommendations of the research prioritization workshops form the basis for inviting and judging applications from investigators for Proposal Development Grants. These will fund six months of activity for developing full research proposals. After review by external peer reviewers and the Scientific Advisory Committee of IC Health, the successful projects will be further funded through the award of Startup Grants for completing pilot phase I studies within one year. The products of this research will enable researchers to apply for larger project grants from major funding agencies (national/international). During this period, the researchers will be guided by the Project Advisory Committee constituted of experts

in each specific area of research such as tobacco and nutrition.

In 2003, IC Health conducted several research prioritization workshops on cardiovascular risk reduction in primary health care and interventions for tobacco control. IC Health plans to conduct the following research prioritization workshops in 2004:

- Research for improving the detection and management of acute coronary syndromes in primary health care settings in low- and middle-income countries (April 2004).
- Research on nutritional interventions for reducing cardiovascular risk (October 2004).

Based on the research priorities identified by these workshops, IC Health will initiate research through small grants for proposal development.

Finally, based on the recommendations of the tobacco research prioritization workshop, IC Health will invite applications for five "proposal development grants" to be awarded in June 2004, aiming to integrate tobacco related research into vascular risk reduction programmes in primary health care settings of LMICs.

#### (b) Policy-oriented research for CVD control

IC Health will be supporting two projects related to mapping policy on CVD control in the coming year.

First, it will initiate the second phase of the study on the macroeconomic consequences of CVDs and diabetes. Based on the report submitted by health economists from the Earth Institute at Columbia University, new data collection for in-depth country studies in four low- and middle-income countries will be undertaken aiming to provide refined economic analysis of the impact of CVD. IC Health also plans the publication of the global overview provided by the report and its wide dissemination, to stimulate a debate on the

implications of CVD for low- and middle-income countries and to influence the content of policies and resource allocation.

Second, a census of ongoing cardiovascular and diabetes research activity in low- and middle income countries will be undertaken, with the following components:

- Inventory of ongoing research relevant to CVD prevention and control in developing countries (World Heart Federation with assistance from the IC Health Secretariat).
- Application of the CAM for research mapping in the area of major CVDs, such as coronary heart disease, stroke, rheumatic heart disease and related risk behaviours related to tobacco, nutrition and physical activity. This will include a priority-setting exercise for tobacco and CVD-related research using the CAM.
- Initiation of four in-depth country studies of research priorities, resource flows and research products for prevention and control of CVD in low- and middle-income countries. These studies will be undertaken through national investigators, with coordination by the IC Health Secretariat.

#### **(c) Capacity development for CVD-related research**

IC Health will contribute to the enhancement of research capacity development in low- and middle-income countries by its continued co-sponsorship of the World Heart Federation's

annual International Ten Day Teaching Seminar on Cardiovascular Epidemiology and Prevention. It will also offer short-term fellowships for specific project-related training in research methodology/biostatistics/health economics at INCLEN training centres.

#### **(d) Publications for guiding operational research**

The product of research prioritization workshops and research projects of IC Health have been incorporated in monographs published by the IC Health Secretariat, including the following:

- Research for prevention and control of high blood pressure and associated cardiovascular risk in developing countries. Summary report of an IC Health workshop, October 2001, Geneva.
- Cardiovascular diseases, prevention and control in developing countries: assessment of capacity in Cameroon, India, Thailand. Summary report of methodology and key results, November 2003.
- Cardiovascular risk reduction in developing countries: research to evaluate health system interventions at primary health care level. Summary report of an IC Health workshop, June 2003, Lausanne.

These reports are available on the IC Health website ([www.ichealth.org](http://www.ichealth.org)) and hard copies are available from the IC Health Secretariat in New Delhi.

## Insert 9.4.1

### *IC Health and Tobacco Research Projects*

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IC Health is engaged in developing a tobacco-related research component, as part of its overall cardiovascular research agenda. To initiate this effort, IC Health organized a workshop on 'Priorities for Research Relevant to Tobacco Control in Developing Countries' as a pre-Forum activity on 1 December 2003 in Geneva. The tobacco research prioritization workshop focused on research relevant to critical areas such as policy intervention to reduce tobacco consumption, individual or behavioural intervention to promote cessation and community interventions to reduce tobacco initiation. The workshop agenda involved reviewing the current research situation in developing countries in the area of tobacco control, prioritizing questions for further research, identifying appropriate research designs and also initiating the application of the CAM to identify priority research for tobacco control in developing countries.

The emerging issues and recommendations of the tobacco research prioritization workshop were profiled at the symposium on CVD and tobacco research during Forum 7. The rising rates of tobacco consumption in low- and middle-income countries and its increasing concentration among lower socioeconomic groups require intervention strategies specifically designed to address the determinants of disease and barriers to behaviour change amongst these groups. Attention was drawn to the importance of evaluating the performance of tobacco control activities at different levels of health care and the activities of the various components of the health system, so as to enable the identification of specific health system interventions to scale-up tobacco control activities, both quantitatively and qualitatively.

The workshop identified critical areas of tobacco research for promoting interventions to reduce tobacco consumption and recommended the following:

- a review of the sociocultural norms and practices related to tobacco use
- the identification of the tobacco industry's activities to encourage initiation
- the development of critical community strategies to counter these influences
- a review of the accumulated experience on tobacco control
- the development of a primary health care model for cessation (including health services, social networks, individual factors)
- the initiation and evaluation of youth cessation programmes
- an assessment or situational analysis of available services
- measures to explore cessation strategies specifically designed for smokeless tobacco products
- an evaluation of effective gender-specific cessation strategies
- interventions required to counter industry actions hindering cessation
- interventions directed at health care professionals which improve their knowledge, motivation and skills for promoting cessation
- an economic evaluation of interventions intended to promote cessation
- continuing consultations amongst networks regarding priority research issues, the need for research road-mapping through the CAM and research facilitation through small grants supported by IC Health.

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Source: Secretariat of IC Health

## Insert 9.4.2

### *From capacity assessment to capacity building*

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A detailed study of the capacity for prevention and control of CVD and diabetes was conducted by IC Health in 2002-2003, in Cameroon, India and Thailand. This study utilized both qualitative and quantitative methods to evaluate the current capacity, in terms of health policies, programmes and infrastructure from the perspectives of the communities, patients, different categories of health care providers and policy-makers. While recognition of CVD as a major public health problem was widely shared, knowledge of risk factors and their relation to CVD was inadequate among many community groups. Diabetes, smoking and physical inactivity were not among the well recognized causes of CVD, especially in the lower socioeconomic groups. Primary care physicians felt very ill-equipped (in knowledge, skills and infrastructure) to deal with CVD, including acute emergencies. Inexpensive but life-saving drugs like aspirin were underutilized in the management of acute coronary events. Rural communities had very limited access to facilities for CVD prevention and care and referral linkages were poor, while urban communities felt that widely variable quality of care and high costs were barriers to treatment. Multi-purpose health workers and nurses saw high potential for their role in CVD prevention but said that they were limited by lack of appropriate training. Provincial policy-makers, who were closer to the communities, were convinced that CVD was a growing problem which required urgent measures for prevention and control while national policy-makers were not yet ready to commit resources for this effort.

Capacity building is urgently needed to fill these multiple gaps so that the epidemic of CVD does not overwhelm countries which are unprepared. The summary report of methodology and key results are accessible on the IC Health website ([www.ichealth.org](http://www.ichealth.org)).

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Source: Secretariat of IC Health

## Section 5

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### Medicines for Malaria Venture<sup>16</sup>

#### 1. Central problem

Malaria kills over 1 million people a year, mainly children under five and pregnant women. It is estimated that there are between 300 and 500 million cases of malaria every year in sub-Saharan Africa, Asia and South America. It is likely that more people are infected with malaria today in sub-Saharan

Africa than at any other time in history. This ancient scourge has been making a quiet comeback since the late 1970s mainly due to the effects of drug resistance.

The countries worst affected by malaria do not have the resources to combat the disease effectively. While vector control interventions

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<sup>16</sup> Adapted from a text contributed by the Secretariat of the Medicines for Malaria Venture foundation.



are critical to the fight against malaria, they are insufficient to reverse the resurgence of this disease which affects more than one third of the world's population. New antimalarial drugs are urgently needed to improve case management – to save lives and reduce morbidity – and meet the challenges of increasing drug resistance. However, most of those afflicted are too poor and the global profit perspectives too small to stimulate commercially driven R&D. Prospects for commercial profitability are further diminished when the complicated and costly activities required to make drugs accessible to consumers in developing countries are factored in.

The public sector, while recognizing the pressing medical need for drug R&D, normally only funds basic research. As a result, it cannot respond to this need directly from its own resources. Modern drug R&D requires considerable technological, managerial and regulatory inputs that are most commonly found in the private sector.

The Medicines for Malaria Venture (MMV) was established in response to this situation and to the failure of the market system to provide the required incentives for malaria drug R&D.

## **2. Creation of the network, objectives, partners and governance**

MMV arose from discussions between the Global Forum, private sector representatives (International Federation of Pharmaceutical Manufacturers Associations and Association of British Pharmaceutical Industries), the Rockefeller Foundation, the Swiss Agency for Development and Cooperation, the Wellcome Trust, the World Bank and WHO. The combined expertise and perspectives of these parties was required for the full development of the MMV concept.

MMV was established as a Swiss foundation in November 1999 and is dedicated to discovering, developing and delivering safe, effective and affordable treatments for malaria through public-private partnerships. The keyword illuminating its mode of operation is “partnership” – albeit partnership within a well established contractual win-win framework. MMV's partners include its donors (both public and philanthropic), its researchers (academic and pharmaceutical) and the many public health policy experts who support it. CSOs are also likely to become increasingly involved where they have specific competences – for example in the downstream provision and distribution of drugs. The ultimate result of these partnerships will be new antimalarials specifically designed for the endemic countries. These products will be registered in malaria-endemic countries and become available as public goods that are appropriate for use by poor populations

MMV's portfolio of research and development projects is based on the ‘virtual’ R&D concept. It is managed by a small but experienced and highly motivated team. Its costs for the development of drugs are significantly reduced because of different types of contributions in kind donated by its pharmaceutical and biotech partners. MMV also benefits from much pro bono work; for example that of its Expert Scientific Advisory Committee and its Board members who freely give of their time and talents. The reason for this is that all recognize that they are engaged in something that is of key public interest.

### **(a) Governing Board**

MMV is governed by a Board of Directors of up to 12 members, chosen for their scientific, medical and public health expertise in malaria and related fields, their research and management competence, as well as their

## Insert 9.5.1

### MMV funding and support

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#### MMV receives funding and support from:

Bill & Melinda Gates Foundation  
ExxonMobil Corporation  
Global Forum for Health Research  
International Federation of Pharmaceutical Manufacturers Associations  
Netherlands Ministry for Development Cooperation  
Rockefeller Foundation  
Swiss Agency for Development and Cooperation  
United Kingdom Department for International Development  
Wellcome Trust  
World Bank  
World Health Organization: TDR and Roll Back Malaria

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Source: MMV

experience in business, finance and fund-raising.

#### (b) The Expert Scientific Advisory Committee

The function of this body is to advise on the selection and review of projects for funding by MMV and to provide more general advice and information on appropriate technical strategies for the foundation to achieve its goals. The members come from both industry and academia and cover the full range of expertise required to assess projects in the extremely complex process of drug research and development.

### 3. Strategies

MMV's virtual R&D approach is now well developed and benefits from the fact that drug R&D has become increasingly modular and outsourceable. A key strategy is to link compatible academic and industry groups to optimize access both to the technologies associated with drug R&D, and to the mindset and thinking that is required to generate real world products. In some cases these links may

already be established and in others it may be necessary to broker partnerships. The MMV team, together with the Expert Scientific Advisory Committee, then closely monitor the projects against defined milestones. Continued funding will be dependent on success and progress toward the goal of discovering and developing an appropriate drug.

The virtual drug R&D managed by MMV implies that all laboratory processes are outsourced. This is a model pioneered in the bio-pharmaceutical industry to reduce capital expenditure. However, the paradigm envisaged by MMV is not only to utilize cost-effective cutting-edge science where it already exists, but also to integrate this with cutting-edge managerial approaches facilitated by the ICT revolution. By developing a portfolio approach, assessed by competitive scientific and sustainability criteria, MMV provides a considerably greater chance of achieving success than by the narrowly targeted investment in a single project or single institution. MMV has developed a strategy

that utilizes existing and emerging scientific opportunity to meet both short- and long-term drug R&D needs.

*In the short term*, most hope is attached to the development of existing drug classes such as the artemisinin derivatives, drugs derived from a Chinese herb *Artemisia annua*. However, these drugs currently have to be administered over five to seven days when given alone. In poor countries, where cost of treatment is a major concern and health care infrastructure is poor, the full course is often not completed and recrudescence of the disease can occur. To counter this problem, and in an attempt to reduce the likelihood of drug resistance, it is now accepted by many scientists that these drugs be combined with other drugs for the treatment of malaria. In fact, a WHO advisory group has specifically recommended Artemisinin-based Combination Therapy (ACT) as first-line treatment for endemic countries with problems of resistance to older drugs. Examples of such combinations can be found in the current MMV portfolio.

*In the medium to longer term*, MMV seeks to bring forward entirely new classes of drugs, both singly and in combination, to meet the future challenges of drug resistance and to improve compliance. The availability of the malaria genome sequence has generated a substantial amount of new information that will be a valuable asset to this long-term goal. However, drug discovery is a long and complex process. It takes many years of dedicated biology allied to cutting-edge medicinal chemistry to convert ideas and ‘leads’ into drugs. The chemical compounds have to be designed not only to inhibit the molecular target against which they are directed, but also to be stable, non-toxic and able to be absorbed into the bloodstream and to cross from the blood plasma into the parasitized red blood cell.

#### 4. Project selection and review

MMV’s Expert Scientific Advisory Committee and experienced staff ensure the selection of highly promising research projects. A strong competitive process is generated initially through an open and widely communicated call for proposals. This is coupled with more proactive research and networking on a global scale. The projects must meet MMV’s drug specifications which are aligned with particular public health-driven indications. The requirement that affordable public goods should be one of the fruits of the sponsored collaboration with industry is at the heart of the public-private partnership concept operated by MMV.

MMV’s portfolio management provides value by lowering risks and creating knowledge and cost synergies across projects. The project teams are aware at the outset that continued MMV support is dependent on both progress against milestones and on the project remaining competitive with other projects in the MMV portfolio. All of the projects are reviewed annually by the Expert Scientific Advisory Committee.

Portfolio priorities focus on delivering product indications, which respond to established medical usage, acceptability and affordability requirements. To accomplish this goal, typical drug profile requirements include:

- effectiveness against drug resistant strains of *P. falciparum*
- treatment within three days for compliance
- low propensity to drug resistance emerging rapidly
- safety in small children (< six months in age)
- intermittent treatments in early infancy
- safety in pregnancy
- potential for intermittent treatments in pregnancy
- appropriate formulations and packaging
- affordability for low-income populations in endemic countries

- treatments suitable for emergency situations (e.g. single dose treatment for refugee camps)
- treatments against *P. vivax* (including radical cure)
- treatments against severe malaria
- transmission blocking.

### 5. Results over the past two years and perspectives over the next two years

MMV currently manages 21 projects (11 discovery projects and 10 development projects), the largest portfolio in the history of malaria drug R&D, with eight completely new therapeutic targets in the pipeline. The clinical development projects are gaining momentum and several pre-clinical projects are set to move to the clinical stage in 2004. While innovation is paramount, it does not simply mean new drugs. MMV is also working on a product extension project – a paediatric formulation of artemether and lumefantrine. This could be used as a first-line treatment for infants suffering from acute, uncomplicated falciparum malaria. MMV hopes to launch this new formulation by 2007.

Since 2001, MMV has issued two calls for proposals which generated almost 200 letters of interest and proposals both from developed and developing countries. In June 2003, MMV signed an agreement with GlaxoSmith-Kline (GSK), creating the **GSK/MMV joint portfolio**, which currently groups three exploratory projects, one full discovery project and one development project. MMV is planning to issue a new call for proposals in early 2004. All of these projects were initiated under agreements that give MMV the rights to any compounds that are selected for entry into development. All of MMV's legal agreements are case-by-case and attempt to produce win-win scenarios for all the partners. MMV is committed to and now has the capability to take on management-intensive drug development projects.

MMV has been designated by WHO as “the premier public-private partnership for developing new malaria drugs.” The challenges over the next two years will be to maintain the portfolio by adding promising new projects and eliminating projects that have not reached their milestones, while simultaneously carefully steering the development projects through the crucial stages of clinical development. A portfolio of 20 to 25 projects is modelled to be sufficient to meet the challenge of delivering one new antimalarial every five years. MMV's goal is to register at least one new drug before the original target of 2010. To achieve this, funding will need to increase to about US\$ 30 million a year by 2005, together with equivalent support in kind from industry. MMV's biggest challenge may be to secure adequate sustainable funding in order to support the projects through the more expensive development process. The current portfolio is financed thanks to a reasonably well diversified funding base of governmental and philanthropic donors.

### 6. Indicators of success

Ultimately, MMV's value (its health impact) will be measured in terms of the number of patients successfully cured with improved antimalarial drugs as a result of its work and that of its many partners. Shorter term indicators of success are the size and quality of MMV's pipeline and the rate of pipeline progression compared to industry norms. Such ‘surrogate’ indicators are required for drug R&D because it takes so long to deliver actual products. Unless the drugs discovered and developed by MMV are widely available to patients in disease-endemic regions, the whole venture will be of little practical use. Therefore, MMV is working at several levels in an effort to ensure optimal uptake of its products:

- MMV has set as a goal the discovery of

agents that have low intrinsic costs. Thus, projects will be identified in which manufacturing costs can be kept as low as possible.

- By taking on a large portion of R&D costs and by also taking on the responsibility for managing the projects and assessing their viability as sources of new drugs, MMV is substantially lowering both the cost and the risk for companies wishing to commercialize MMV products downstream.

- Because of this engagement by MMV and the fact that it will actively seek intellectual property rights protection, MMV is in a position to negotiate appropriate arrangements for the out-licensing of its products for commercialization.

By engaging in antimalarial drug R&D within a not-for-profit, yet business-like public-private framework, MMV has made significant progress in 2003 towards delivering much-needed new antimalarial drugs.

## Section 6

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### Mental and Neurological Health<sup>17</sup>

#### 1. Background and size of the problem

For all individuals, mental, physical and social health are closely interwoven strands of life. It is becoming increasingly clear that mental functioning is fundamentally interconnected with physical and social functioning and health outcomes. Mental illnesses and neurological disorders affect the intrinsic human abilities to think, feel, communicate and move, and they erode human productivity in the workplace and in the wider society. Even when they do not meet the threshold for a diagnosis of mental disorder,

mental problems can lead to antisocial and self-harming behaviours, substance misuse and risk-taking behaviours which expose individuals to potential harm from outcomes such as accidents and sexually transmitted diseases.

As our understanding of this interdependent relationship grows, it becomes ever more apparent that mental health is crucial to the overall well-being of individuals, societies and countries. Conversely, optimal mental and neurological health is not only essential for individual well-being, but contributes

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<sup>17</sup> Contributed by Andrés de Francisco, Global Forum for Health Research

to enhancing human capital (individual productivity) and social capital (social cohesiveness), both of which are critical for economic growth and poverty reduction.

Mental and neurological health issues have long been marginalized and stigmatized at the international, national and local levels. In many countries, services have been centralized, institutionalized, professionalized and depersonalized. In addition, myths have spread, e.g. mental disorders are culture-bound syndromes of the West and North; that their incidence and prevalence in developing countries is low; that most are not amenable to effective treatment; and that existing treatment regimens are too expensive for developing countries.

According to WHO's *World Health Report 2003*, neuropsychiatric disorders account for 12.9% of disability adjusted life years (DALYs) and intentional injuries for 2.9%. Mental and substance use disorders represent four of the ten leading causes of years lived with disability (YLDs). In particular, unipolar depressive disorders are the first cause of years lived with disability, accounting for 11.8% of total YLDs. Alcohol use disorders account for 3.3% of total YLDs, schizophrenia for 2.8% and bipolar affective disorder for 2.5%.

The 2002 estimates on leading causes of burden<sup>18</sup> show that unipolar depressive disorders account for 7.3% of total DALYs in developed countries, being the second leading cause of burden; but they are ranked as the first leading cause of burden in developing countries with low mortality, accounting for 6.0% of total DALYs.

There are 450 million people affected by a mental disorder at any given time, which represents one in four families. Mental health problems affect society as a whole, and they are a major challenge to global development. No group is immune to mental disorders, but the risk is higher among the poor, homeless, the unemployed, persons with low education and the most vulnerable groups. Given the prevalence of mental health and substance-dependence problems in adults and children, it is not surprising that there is an enormous emotional as well as financial burden on individuals, their families and society as a whole. The economic impacts of mental illness affect personal income, the ability of ill persons – and often their caregivers – to work, productivity in the workplace and contributions to the national economy, as well as the utilization of treatment and support services. Mental disorders generate costs in terms of long-term treatment and lost productivity and contribute significantly to poverty.

There is now a considerable knowledge base for effective interventions for many mental and neurological conditions. However, most of the work in developing and implementing cost-effective interventions has been carried out in the high-income countries, and this knowledge may not be relevant in many low-income countries, which suffer from a lack of mental health policy, special services, skills in primary care, and essential medicines and treatments, as well as from the stigma surrounding these conditions.

There is a need for high quality cross-disciplinary research and public advocacy of research results to overcome the barriers to

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<sup>18</sup> Mathers CD, et al. Global Burden of Disease in 2002: data source, methods and results. Discussion Paper No. 54. 2003. World Health Organization, Geneva

care for people with mental and neurological disorders and to efficiently change unhealthy behaviour among high-risk groups in low-income countries.

## 2. WHO's strategy<sup>19</sup>

WHO declared 2001 the Year of Mental Health and that year's World Health Day was a resounding success ([http://www.who.int/mental\\_health/en/](http://www.who.int/mental_health/en/)). Over 150 countries organized important activities, including major speeches by political leaders and the adoption of new mental health legislation and programmes. At the 2002 World Health Assembly, over 130 ministers responded positively with a clear and unequivocal message: mental health, neglected for too long, is crucial to the overall well-being of individuals, societies and countries, and must be universally regarded in a new light.

### (a) Mental Health Global Action Programme (mhGAP)

As a result of the activities in 2001, the mhGAP has been created. GAP is WHO's major effort to implement the recommendations of the *World Health Report 2001*. The programme aims to enhance the mental health of populations, based on the following four strategies:

- Strategy 1: Increasing and improving information for decision-making and technology transfer to increase country capacity. WHO is collecting information about the magnitude and the burden of mental disorders around the world, and about the resources (human, financial, sociocultural) that are available in countries to respond to the burden generated by mental disorders. This is pursued by the ATLAS project (<http://www.cvdinfobase.ca/mh-atlas/>). ATLAS's aim is to provide information on

mental health from all countries. The information relates not only to epidemiology but, more significantly, to resources and infrastructure for mental health care within each country.

- Strategy 2: Raising awareness about mental disorders through education and advocacy for more respect of human rights and less stigma. WHO is maintaining constant communication and information networks with professional NGOs, parliamentarians, family members and service users' groups in order to sustain the groundbreaking work of the last two years.
- Strategy 3: Assisting countries in designing policies and developing comprehensive and effective mental health services. The scarcity of resources forces their rational use. *The World Health Report 2001* and the *ATLAS: Mental Health Resources in the World*, have revealed an unsatisfactory situation with regard to mental health care in many countries, particularly in developing countries. WHO is engaged in providing technical assistance to ministries of health in developing mental health policy and services.
- Strategy 4: Building local capacity for public mental health research in poor countries. Besides advocacy, policy assistance and knowledge transfer, mhGAP formulates in some detail the active role that information and research ought to play in the multidimensional efforts required to change the current mental health gap at country level.

### (b) Progress made during the last four years

- The Mental Health Policy Project is helping governments to formulate and implement coherent and comprehensive mental health policies according to their unique needs for

<sup>19</sup> Adapted from a contribution by Anna Gatti and Shekhar Saxena, Department of Mental Health and Substance Abuse, WHO, Geneva.

promotion, prevention and care. WHO prepared and disseminated a comprehensive policy and service guidance package with the purpose of assisting policy-makers and planners to: (i) develop policies and strategies for improving the mental health of population; (ii) use existing resources to achieve the greatest possible benefits; (iii) provide effective services to those in need; and (iv) assist the reintegration of persons with mental disorders into all aspects of community life, thus improving their overall quality of life. The package consists of a series of interrelated user-friendly modules that are designed to address the wide variety of needs and priorities in policy development and service planning.

- The WHO Project on Mental Health and Human Rights is another cornerstone in strengthening countries' capacity to protect and promote the human rights of people with mental disorders and reduce discrimination and stigma. The project focuses specifically on the development and implementation of mental health legislation, as this represents an important means of rights protection.
- A contribution to building local capacity for public mental health research in poor countries has been made by WHO's meeting on Mental Health Research in Developing Countries: Role of Scientific Journals. The meeting was held in Geneva in November 2003 and was attended by 25 editors representing mental health and public health journals. Their contribution to advocacy in low- and middle-income countries was discussed. A catalogue of ideas was also drawn up to guide follow-up actions by individual journals and editorial and international organizations to: (i) bring about policy changes to facilitate the publication of research; (ii) enhance research and publishing capacity of researchers and journals; and (iii) enhance dissemination of research to low and middle-income countries.

- Global campaign against epilepsy: out of the shadows. Today, about 50 million people suffer from epilepsy. The strategy of the campaign raises general awareness and understanding of epilepsy, supports demonstration programmes, assists governments in identifying needs and promoting education, training, treatment, services, research and national prevention.
- Suicide prevention. In the last 44 years suicide rates have increased by 60% worldwide. The project is breaking the taboo surrounding suicide and bringing together national authorities and the public by strengthening countries' capability to develop and evaluate policies and plans for suicide prevention.
- Management of substance dependence projects. Alcohol and other substance-use disorders are also serious mental health concerns worldwide, with an estimated 90 million people affected by alcohol or drug use disorders ([http://www.who.int/substance\\_abuse/en/](http://www.who.int/substance_abuse/en/)). Activity in this area raises awareness in countries of new developments and treatments, and provides assistance in formulating appropriate policies and programmes. WHO prepared a report on neuroscience of psychoactive substance use and dependence with the aim of overcoming misconceptions and stigma associated with substance dependence, thereby improving access to treatment for those in need. WHO promotes strategies for the early identification and management of substance-use disorders in primary health care, which have proved to be cost-effective with regard to alcohol problems.

### (c) Future directions

Even though mental, brain and substance-use disorders can be managed effectively with medication and/or psychosocial interventions, only a small minority of patients with mental disorders receive even the most basic treatment. Initial treatment is frequently delayed for many years.



In order to reduce the increasing burden of mental disorders and avoid years lived with disability or death, priority should be given to prevention and promotion in the field of mental health. Preventive and promotional strategies can be used by clinicians to target individual patients, and by public health programme planners to target large population groups. Integrating prevention and promotion programmes for mental health within overall public health strategies will help to reduce the burden and the stigma attached to the mentally ill and improve the social and economic environment.

To turn plans into action, WHO is adapting the type of implementation to the level of resources of individual countries. In the particular case of developing countries, where the gap between mental health needs and the resources to meet them is greater, WHO will offer differentiated packages of “achievable targets” for implementation (Gap Reduction Achievable National Targets/GRANTs) to countries grouped by level of resources (low, middle and relatively high). These packages provide the minimum required set of feasible actions to be undertaken to comply with the 10 recommendations listed in the *World Health Report 2001*. Achievement of the identified targets will influence both health and social outcomes, namely mortality due to suicide or to alcohol/illicit drugs, morbidity and disability due to the key mental disorders, quality of life, and finally, human rights. GRANTs requires a regular monitoring of the mental health situation in countries. For this purpose, a dedicated monitoring system project has been undertaken by WHO

including a system of indicators which has been defined and tested.

### 3. Global Network for Research in Mental Health and Neurological Disorders<sup>20 21</sup>

The Global Network for Research in Mental Health and Neurological Disorders (<http://www.mental-neurological-health.net>) was created in October 2001 and registered in the USA as a non-profit NGO. It succeeded the International Consortium for Mental Health Policy and Services.

#### (a) Goals, objectives and strategies

The overall goal of the Global Network is to make strategic contributions to the promotion, improvement and protection of global mental and neurological health and to the reduction of the global burden of mental and neurological disorder by (i) promoting research; (ii) collaborating with countries in research capacity building and leadership training; (iii) forging international links between government policy and research; (iv) improving good practice; (v) strengthening research institutions in developing countries; and (vi) collaborating with international and national agencies with a similar goal.

#### (b) Organization

There are currently 35 institutions and agencies which are members of the Global Network, including research institutions both in developing and developed countries, governmental and intergovernmental organizations and research foundations. Other stakeholders are invited to join, particularly to strengthen the representation of (psychiatric) nurses and social workers, as well as patient groups.

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<sup>20</sup> The Global Forum is supporting a study to map institutions active in the field of mental and neurological health with a view to improve capacity in low- and middle-income countries. One of the institutions supported by the Global Forum is the Global Network for Research in Mental Health and Neurological Disorders whose activities are briefly presented here.

<sup>21</sup> Adapted from a contribution by Walter Gulbinat, Executive Secretary, Global Network for Research in Mental Health and Neurological Disorders.

Countries participating in the activities of the network include the following: (i) Europe (Azerbaijan, Bulgaria, France, Georgia, Lithuania, Netherlands, UK, Ukraine); (ii) Americas (Chile, Ecuador, Trinidad & Tobago, USA); (iii) Africa (Kenya, Tanzania, Uganda, Zambia) (iv) Eastern Mediterranean region (Egypt, Iran, Pakistan); (v) Western Pacific (Australia, Malaysia, Philippines); and (vi) South East Asia (India, Nepal, Thailand).

The Global Network for Research in Mental and Neurological Health, Inc. is the legal and administrative arm of the Network, represented by its Board of Directors and the Executive Secretary. A Consultative Committee, which includes 63 experts from 41 countries, provides technical and scientific input on specific issues.

The budget amounts to about US\$ 0.2 million per annum (not including contributions in kind) and is supported by the Global Forum for Health Research, the Association Internationale pour la Recherche et l'Enseignement en Neurosciences (AIREN), a number of governments and individual contributions.

#### **(c) Progress in 2002-2003**

The Global Network started its operations in 2002. Recent achievements include the following:

- Inter-regional research: identification of global research priorities.
- A mental health country profile providing the following information: (i) a description of the underlying concept; (ii) a common format for recording the mental health situation of a country; (iii) a manual guideline for its use; and (iv) the individual country profiles of 16 countries (accessible on the Network website).
- A mental health policy template which displays, in tabular format, the policy elements to be considered in revising or

updating a country's mental health policy or programme.

- Focus groups: a wide variety of constituencies were invited to take part in discussions on mental and neurological disorders at the country level, including NGOs, national government representatives, professional groups and country representatives of UN agencies and programmes.
- An international network of resource centres for policy and systems research was created.

#### **(d) Future activities**

In 2004, activities will focus on the definition of regional research priorities, on the expansion of the Network and the development of its capacity in health economics and finance.

## **4. Conclusions**

Throughout the 20th century, mental health was the 'poor relation' of health and medicine. Despite the rapid rise of mental health disorders, mental and neurological health remained a low priority in the political and research agenda of most countries, and mental health budget were largely underfunded.

The concept of burden of disease contributed much to the growing attention paid to mental and neurological disorders in the recent decade. In 1999, the World Bank created positions for mental health at its Washington DC headquarters and included mental health interventions within its lending programme. In 2001, the WHO devoted its World Health Day to mental health and the *World Health Report 2001* focused exclusively on mental health. It drew attention to the huge burden of mental and neurological disorders in the world, to the many cost-effective and sustainable interventions which exist to fight these diseases, and to the urgent need to strengthen research capacity in low and middle-income countries in this sector.

## Section 7

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### Multilateral Initiative on Malaria: Research Capacity Strengthening<sup>22</sup> (MIM/TDR)

#### 1. History of the network

##### (a) Central problem

There is an urgent need to strengthen all areas of malaria research in order to develop new and more effective tools to reduce the burden of the disease, especially in sub-Saharan Africa. However, efforts are impeded by the lack of a critical mass of investigators, managers and the infrastructure necessary to generate new knowledge on malaria and to develop and effectively deploy tools for management of the disease. The Multilateral Initiative on Malaria in Africa (MIM) was launched to address this need. An international alliance of organizations and individuals concerned with malaria, MIM seeks to maximize the impact of scientific research on malaria in Africa, through promoting capacity building and facilitating global collaboration ([www.mim.su.se/english/index.asp](http://www.mim.su.se/english/index.asp)).

##### (b) Creation of the network

MIM was launched in 1997 following the first Pan African Malaria Conference, held in Dakar, Senegal, where malaria scientists from all over the world identified important research priorities for future malaria research. Following the conference, MIM called on TDR to help bring together stakeholders with an interest in supporting capacity-building research. In the USA, MIMCom (MIM Communications) and MR4 (Malaria Research and Reference Reagent Resource Centre) evolved as components of the initiative to

address other specific needs. MIMCom, created by the National Library of Medicine at the NIH in partnership with institutions in Africa, USA and Europe, is an electronic malaria research network. The network facilitates the establishment and maintenance of fast reliable Internet connections in research facilities across Africa. MR4 was established by the National Institute for Allergy and Infectious Diseases (NIAID) at the NIH and provides malaria research reagents and training workshops to enhance multi-site studies and facilitate technology transfer. The MIM Secretariat (currently housed at the Wenner-Gren Institute, Stockholm University, Sweden) maintains cohesion and ensures good communication between all components of the initiative. The Secretariat also organizes the biannual Pan African Malaria Congress as well as periodic courses, symposia, stakeholders' meetings or workshops.

In 1998, TDR established a Task Force of international experts (50% African scientists) which supports a multidisciplinary network of African scientists, in partnership with MIM, NIH, the World Bank (through the Global Forum) and national governments.

The research grants awarded through MIM/TDR have been a major component of MIM since its inception – providing African scientists with opportunities to “learn by doing”. MIM/TDR has also been a channel

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<sup>22</sup> Adapted from a text contributed by MIM/TDR.

for promoting partnerships, collaboration, technology transfer and training opportunities. Joint research programmes have proved a highly effective method for mutual training. The research teams and institutions supported through MIM/TDR have been the focal points that draw the other components of MIM together. MIMCom provides electronic communication, MR4 provides research materials and the MIM Pan African Malaria Conferences organized by the MIM Secretariat provide a unique opportunity to share research results and foster synergies with disease control and governmental agencies to promote the translation of research into policies and programmes.

### **(c) Objectives**

The MIM/TDR programme on Malaria Research Capability Strengthening in Africa promotes science development as a vehicle for building sustainable research capacity and global partnerships to meet the following specific objectives:

- Develop core groups and regional networks of African investigators and research institutions engaged in high quality malaria research with international research partnerships.
- Optimize the incorporation of research results to enhance malaria control activities.

### **(d) Strategy**

The strategy is to synergize facilities and competence available in Africa with those in the North and advanced developing countries to build capacity and create opportunities for developing leadership and research management skills for mid-career African scientists. The programme supports North-South and South-South collaborative research projects in the following fields:

- research projects on malaria control in Africa
- capacity building of research facilities and establishment of research teams
- partnerships between African and developed countries' research institutions.

The Task Force selects project proposals for funding once a year on a competitive basis, with the participation of the MIM partnership (Secretariat, MR4, MIMCom and WHO).

To date, MIM/TDR has supported 39 research projects, two research networks and training workshops to standardize protocols. The annual budget for MIM activities amounts to US\$ 3.1 million, currently financed by contributions from the NIH, World Bank (through the Global Forum), the Japanese Government and WHO.

This unique mechanism for multilateral funding of research and capacity building in Africa has helped to:

- promote the development of a new generation of African scientists;
- provide human resources and research infrastructure in African institutions;
- facilitate the acquisition, transfer and adaptation of technology in African institutions;
- facilitate the formation of research networks among African investigators;
- facilitate broad-based partnerships between African and international institutions and scientists.

## **2. Main achievements in 2002-2003**

The central strategy of the MIM effort in TDR is the development of groups and regional networks of African investigators and public health institutions who not only engage in high quality research but are also positioned to facilitate and optimize malaria control by utilizing research results. The portfolio of 32 MIM/TDR research projects in 2002-2003 cut across the areas of malaria epidemiology, immunity, pathogenesis, natural products, entomology, insecticide resistance and anti-malarial and drug resistance.

A total of 42 young Africans have completed postgraduate training (25 at Master's level and 17 at Doctoral level) so far under the grant

programme. The results have been shared with the international community through 66 articles published in peer reviewed scientific journals. The studies were based at 36 institutions in 24 African countries (Insert 9.7.1).

The main achievements of the MIM/TDR network of scientists can be summarized as follows:

- Postgraduate training in immunology, biochemistry, epidemiology, clinical pharmacology, entomology, phytochemistry and parasitology.
- Development, standardization and adoption of protocols for collecting data on epidemiology of malaria and antimalarial drug resistance.
- New information on the genetic factors influencing individual variations in severity of disease.
- New information on the development of immune responses to malaria in children living in endemic areas.
- Identification of factors and mechanisms contributing to severe malaria anaemia in African children.
- New knowledge on the clinical pharmacology of drugs used to treat convulsions associated with severe malaria.
- Mapping of anopheles resistance to pyrethroid insecticides in East, West and Southern Africa.
- Identification of potential antimalarial and insect repellent compounds from plants in East and West Africa.
- Enhanced collaboration between research scientists and public health institutions in the area of antimalarial drug resistance.
- An empirical malaria distribution map for Africa and information tool for malaria in Africa (ARMA/MARA).
- Examples of specific achievements of MIM/ TDR projects are presented in Insert 9.7.2.

### 3. Expected outputs for 2004-2005

The strategic orientations of the MIM/TDR Plan in 2004-5 are defined on the basis of the lessons and achievements over the past five years, the recommendations of an independent review of the MIM (October 2002) and the recommendations of the TDR Scientific Working Group on Malaria (March 2003).

The Plan recognizes the increased visibility of malaria in the last three years that has resulted in increased funding opportunities for malaria research and control. These positive shifts create both challenges and opportunities for new alliances and partners for research capacity building for MIM/TDR. The Plan will focus on the generation of new knowledge, the development of new tools, the development of partnerships between public health and research institutions, and the definition of policies for malaria control, in collaboration with Roll Back Malaria (RBM) and the WHO Regional Office for Africa (AFRO).

MIM/TDR will evaluate the impact of the programme over the period 1998-2004. Critical areas for research currently under review are:

- social sciences and health systems research to improve malaria control
- research and development of new malaria control tools from natural products
- vector biology and insecticide resistance
- pathogenesis and immunology of malaria
- antimalarial drug resistance
- burden of malaria in Africa.

### 4. Conclusions and long-term perspectives

MIM/TDR will seek to continue to play a central role in the overall MIM effort to apply multiple approaches to enhance collaboration among all stakeholders in reducing the malaria burden in Africa. The programme will proactively create alliances to build sustainable capacity to conduct high quality

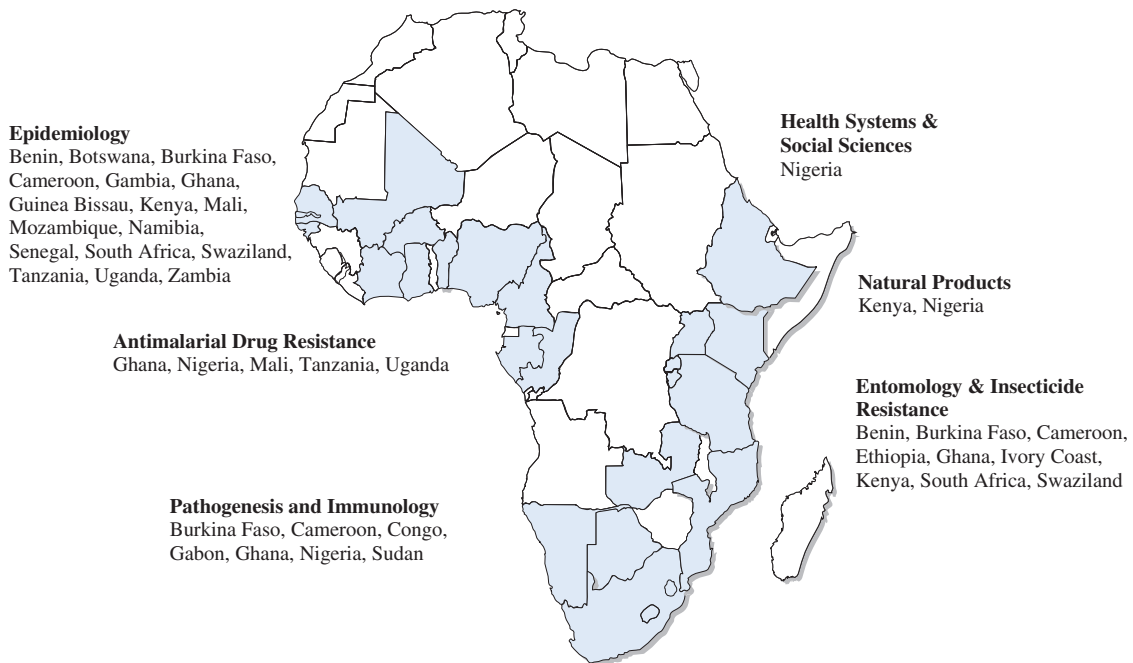
health-science research and translate research results into policies and programmes for malaria control.

In the long term, the outcome of this effort should result in an increase in the number of African institutions and scientists engaged in relevant collaborative research with short- and long-term impact on malaria control and public health in general. The critical measures of success relate to progress in the following areas:

- Increase in the critical mass of African investigators engaged in high quality malaria research.
- Incorporation of research results into policies and programmes effectively enhancing malaria control.
- Number of new tools, strategies and methods which are made available to the public health sector as a result of the research led by African scientists.

## Insert 9.7.1

### *MIM/TDR networks and projects in Africa*



Source: MIM/TDR.

## Insert 9.7.2

### *Examples of specific achievements of MIM/TDR projects*

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#### **Epidemiology (South Africa and Mozambique)**

Two international networks (MARA [www.mara.org.za](http://www.mara.org.za) and MTIMBA – a network of 18 field sites for continuous demographic and health evaluation) provided information for the analysis of the severity, risk and impact of malaria at regional and national levels in collaboration with WHO's Roll Back Malaria Partnership.

#### **Pathogenesis and immunology of malaria (Burkina Faso, Gabon, Ghana, Nigeria and Sudan)**

Six projects were supported, focusing on the relationship between malaria transmission intensity and clinical malaria and immunopathology; risk factors and the immunopathology of severe anaemia in children suffering from falciparum malaria; antibodies that (indirectly) prevent malaria parasites from infecting red cells. New information with potential application in case management and vaccine development was generated.

#### **Antimalarial drug policy and chemotherapy (Burkina Faso, Ghana, Kenya, Mali, Nigeria, Tanzania and Uganda)**

Eight projects are providing information on malaria chemotherapy, antimalarial drug policy, and the clinical pharmacology of some drugs used in the management of severe malaria. The novel application of molecular biology in prediction of drug resistance and the integration of research findings into malaria control policy was implemented by a network of five institutions in East and West Africa. The projects used common protocols to evaluate the different factors that may contribute to antimalarial drug resistance and are providing data to inform antimalarial drug use and policy (<http://www.nlm.nih.gov/adrn/adrn.html>).

#### **Natural products and antimalarial drug development (Kenya and Nigeria)**

Identification of antimalarial and insecticide repellent components used by indigenous populations is the focus of three projects supported in this area. The scientists worked together with the indigenous communities and traditional health practitioners to gather information and select and identify the most promising plants. As a result of this research, mosquito repellent products are now available in the community.

#### **Entomology and vector studies (Benin, Kenya and South Africa)**

Three multi-country partnership projects focused on entomology and insecticide resistance. A total of 13 countries participated in the projects resulting in the establishment of a regional insecticide resistance monitoring network in collaboration with the WHO Regional Office for Africa (AFRO).

#### **Health systems research (Nigeria)**

A project was designed to improve the home management of malaria through better community knowledge of the disease, improved practices, development of new products and improved collaboration between public and private health care providers. The investigators identified contact points that constitute important target groups for better home management of childhood malaria in rural communities. These include: parents and other primary care givers in the home; health workers in and outside health facilities; traditional healers, surrogates and professional associations; patent medicine vendors and their business associations; policy-makers at the local government level.

Individual information about institutions involved is available at [www.mim.su.se/english/index.asp](http://www.mim.su.se/english/index.asp).

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Source: MIM/TDR.

## Section 8

### The UNDP/UNFPA/WHO/World Bank Special Programme of Research, Development and Research Training in Human Reproduction (HRP)<sup>23</sup>

#### 1. The burden of sexual and reproductive ill health

In 2001, it is estimated that sexual and reproductive ill health, including HIV/AIDS, accounted for nearly 20% of global disease burden (in DALYs) among women and nearly 14% among men, with most of the burden in developing countries and countries in transition.

The definition of sexual and reproductive health adopted at the International Conference on Population and Development (ICPD) in 1994 (Insert 9.8.1) captures some of the elements – such as its holistic nature; its extension well beyond the years of

reproduction; the link between generations;<sup>24</sup> and its sociocultural, gender and human rights dimensions – which make this field of health unique.

Worldwide, almost 40% of pregnancies are unplanned and 40-50 million of them are terminated each year through induced abortion; about 19 million of these abortions are unsafe with high risks of severe morbidity or death for the woman.

Every year, over 20 million women experience ill health as a result of pregnancy; for some the suffering will be permanent. Estimates suggest

#### Insert 9.8.1

##### *Definition of reproductive health*

Reproductive health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes.

Reproductive health therefore implies that people are able to have a satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when and how often to do so. Implicit in this last condition are the rights of men and women to be informed and to have access to safe, effective, affordable and acceptable methods of family planning of their choice, as well as other methods of their choice for regulation of fertility which are not against the law, and the right of access to appropriate health-care services that will enable women to go safely through pregnancy and childbirth and provide couples with the best chance of having a healthy infant.

In line with the above definition of reproductive health, reproductive health care is defined as the constellation of methods, techniques and services that contribute to reproductive health and well-being by preventing and solving reproductive health problems.

It also includes sexual health, the purpose of which is the enhancement of life and personal relations, and not merely counselling and care related to reproduction and sexually transmitted diseases.

*Source:* ICPD Programme of Action, paragraph 7.2

<sup>23</sup> Adapted from a text contributed by Catherine d'Arcangues, Special Programme of Research, Development and Research Training in Human Reproduction (WHO/HRP).

<sup>24</sup> Reproductive health is central to the link between generations, not only through genetic inheritance, but also because it is increasingly recognized that conditions preceding or occurring at birth can impact health and reproductive potential later in life.



that the lives of 8 million women are threatened and that over half a million women die every year due to conditions related to pregnancy and childbirth. In addition, about 3 million babies die within the first week of life and some 3.8 million infants are born dead. The majority of this suffering is preventable: cost-effective interventions are known and affordable but often not available due to lack of resources for health care.

Unwanted childbearing is associated with failure to seek advice before pregnancy and unwanted children are at greater risk of neglect, abuse and violence. Certain pregnancies, in particular those among very young women or among older, high-parity women, present greater risk for the health of the woman.

In 1999 there were an estimated 340 million new cases of curable STIs and millions of cases of viral (incurable) STIs, mainly HIV/AIDS. In some areas of South Africa, HIV prevalence rates among pregnant women are now 40%–50%. In addition, an estimated 800 000 paediatric AIDS cases occur annually, the majority due to transmission of HIV from an infected mother during pregnancy, delivery or through breastfeeding.

Other viral infections contribute to reproductive ill health. In many developing countries, it is estimated that over 50% of adults are infected with herpes simplex virus and that 15%–25% of women are infected with human papilloma virus, the major cause of cervical cancer, which accounts for more than 230 000 deaths a year (80% of them in developing countries).

Female genital mutilation is practised primarily in 28 countries in Africa, but also in other parts of the world among immigrant populations. It is estimated that 100–140 million women and girls have undergone female genital mutilation and that every year 2 million girls are at risk of being subjected to the practice.

In addition, an estimated 170–190 million people in the developing world (excluding China) experience infertility. Of these, about 2%–3% of couples have primary involuntary infertility, with 25% or more of couples in some countries affected by secondary infertility.

## **2. The Special Programme of Research, Development and Research Training in Human Reproduction**

The Special Programme of Research Development and Research Training in Human Reproduction (HRP) was established by WHO in 1972 to coordinate, promote, conduct and evaluate international research in human reproduction. While fertility regulation has remained a core area of HRP's research, in recent years its research agenda has been broadened to address other challenges in reproductive health. HRP also carries out activities to strengthen the capabilities of developing countries to meet their own research needs and to enable them to participate in global reproductive health research.

As the focal point for research activities within the WHO Department of Reproductive Health and Research, HRP promotes the use of research results in policy-making and planning at national and international levels and contributes to the setting of norms, standards and guidelines – including ethical guidelines – in the field of reproductive health research. HRP also works to ensure that gender issues, especially the perspectives of women, are reflected in both its research and research capability strengthening activities. The international mandate that drives the work of HRP is based on the agreements adopted at the International Conference on Population and Development, in Cairo (1994) and at the Fourth World Conference on Women in Beijing (1995) and their respective five-year follow-ups, as well as the MDGs.

### 3. Main achievements in 2002-2003

#### (a) Promoting family planning

- A large multicountry study was conducted in Kenya, South Africa, Tanzania, Uganda, Zambia and Zimbabwe on the perspectives of sexually active individuals about the dual risks of sexually transmitted infections, including HIV/AIDS, and unintended pregnancy. Findings suggest that in countries with high HIV prevalence a small but potentially influential group of educated young couples is using condoms with some consistency and that there is untapped potential for increasing condom use within marriage.
- A Phase II study of the use of male hormonal contraception was completed in Indonesia.
- The first ever Phase III trial of an injectable hormonal contraceptive for men is being conducted in China.
- A study was conducted in China on close to 5 000 women, confirming the efficacy of a low-dose oral contraceptive (10 mg mifepristone) for emergency contraceptive use.
- A multi-country study was launched on the comparative clinical performance of two second-generation implantable contraceptive methods.
- A consultation was convened in March 2002 on the implications of a recent research finding that women who have used hormonal contraceptives for longer than five years are at higher risk of developing cervical cancer than non-users.
- Studies on barriers to family planning access examined provider perspectives on the provision of family planning services in several countries. A study in Senegal showed that by using a six-question checklist to rule out the presence of pregnancy, family planning providers were able to reduce the percentage of non-menstruating women being denied contraceptives from 11% to 6%.
- Development of a system for ensuring that family planning guidance is created, and

updated regularly, on the basis of the best available evidence.

#### (b) Making pregnancy safer

- The so-called “MAGPIE” trial showed that the use of the compound magnesium sulphate could more than halve the risk of eclampsia. This finding is expected to lead to a major change in practices related to prevention of eclampsia.
- A study to evaluate the benefit of calcium supplementation in the prevention of pre-eclampsia, including two ancillary studies, ended in 2003, with 8338 women recruited; results will be ready by early 2004.
- Seven new projects were initiated: four randomized clinical trials to evaluate therapeutic and preventative interventions during pregnancy, plus two ancillary studies, and a study to develop a diagnostic tool for birth asphyxia for use at the community level.
- Two new global initiatives were launched: a global collaborative project on basic and clinical research for the prevention and treatment of pre-eclampsia; and the WHO Global Survey for Monitoring Maternal and Perinatal Health (which upon completion will have collected data from over 400 000 deliveries in over 1000 facilities from 56 countries).

#### (c) Control of sexually transmitted and reproductive tract infections

- A technical consultation was held to assess the increasing threat of the herpes simplex virus becoming a major driving force for HIV transmission.
- A protocol was finalized to study the impact of highly active antiretroviral therapies (HAART) on mother-to-child transmission (MTCT) of HIV and maternal health.
- In partnership with CONRAD, the Programme successfully concluded a three-centre randomized double-blind Phase I

study of the safety and acceptability of 6% cellulose sulfate gel compared with placebo (K-Y Jelly) among healthy women volunteers in India, Nigeria and Uganda. Further evaluation of cellulose sulfate for the prevention of HIV infection is now warranted.

#### (d) Preventing unsafe abortion

- A new publication entitled *Safe abortion: technical and policy guidance for health systems* was released in 2003 and distributed to Ministries of Health through WHO Regional Offices. This document is in high demand and is currently being translated into French, Spanish, Russian, Portuguese and Polish.
- New global and regional estimates of unsafe abortion were produced in 2002: nearly 40% of all unsafe abortions occur among women aged 15-24 years. Overall, 7.3 million unsafe abortions are estimated to take place each year in this age group. These estimates are being used in the WHO project on the Global Burden of Disease.
- New estimates of mortality related to unsafe abortion show that some 68 000 women die each year from unsafe abortion, and one in four unsafe abortions in Africa involves a woman of between 15 and 19 years.
- A major study on abortion and contraceptive use found that both may increase concurrently in contexts where fertility is falling rapidly and contraceptive services are unable to meet the growing demand for fertility regulation. However, contraceptive use reduces abortions when fertility is constant.
- A systematic review of medical methods for first trimester abortion was completed. This review found that combined regimens are more effective than single agents, and in the combined regimen the dose of mifepristone could be lowered to 200 mg (from 600 mg) without significantly affecting method effectiveness.
- Results from a study on the use of misoprostol alone suggested great potential for

the sublingual route to be developed into a method of medical abortion.

- A multinational randomized controlled trial was completed of three different misoprostol regimens, following mifepristone administration, for early medical termination of pregnancy.
- As part of technical cooperation with countries, the Programme continued to assist Romania and Vietnam with improving the quality of abortion services, including counselling. The Programme also assisted the Ministry of Health in Mongolia to conduct a strategic assessment of issues related to abortion. In all these countries Ministries of Health are implementing recommendations that emerged from strategic assessments.

#### (e) Promoting sexual and reproductive health of adolescents

- An analysis of demographic and health survey data for young never-married women in Colombia and Peru showed that during the 1990s an increasing percentage of these women were sexually active and that, despite an increase in contraceptive use (especially condoms), a higher percentage of them experienced unintended pregnancy and abortion.
- Thirteen focused in-depth studies from an ongoing research initiative illustrated the persistence of double standards for males and females, lack of communication between young men and women about sex, unequal power between the sexes to negotiate on sexual matters, including safe sex, and social norms that place constraints on young people's access to sexual and reproductive health services.
- Results from the baseline qualitative data collected in an operations research project in five French-speaking African countries (Benin, Cameroon, Côte d'Ivoire, Guinea and Senegal) showed that reproductive health services, especially those in the public sector, are beyond the reach of most

young people owing to cost, lack of privacy and confidentiality, negative attitudes of providers, and the prevailing societal values against sex outside of marriage.

#### **(f) Gender and reproductive rights in reproductive health**

- Publication of a CD-ROM version of *Transforming health systems: gender and rights in reproductive health*, which includes a three-week training curriculum in gender and rights in reproductive health aimed at health managers. An adaptation of the course was conducted in Myanmar for health programme managers and researchers, and a training of trainers course was conducted in Central Asia in preparation for a course to be run in Kazakhstan in 2004.
- A new “policy action tool” was under development, which will help countries to identify – and deal with – barriers and gaps in the legal, policy and normative environment related to maternal and neonatal health and health services. A study to validate the tool was completed in 2003.
- Reports were sent to four United Nations Treaty Bodies on the sexual and reproductive health situation in ten reporting countries.
- A Technical Consultation on Sexual Health in 2002 involving 60 participants from all regions of the world agreed on new definitions of sex, sexuality, sexual health and sexual rights. A medium-term programme of work for this area was developed.

#### **(g) Technical cooperation with countries**

- Twenty Long-term Institutional Development (LID) grants and eight Resource Maintenance Grants (RMGs) were awarded to HRP’s network of collaborating research institutions. In 2003, Research Training Grants (RTGs) were awarded to 24 scientists from these institutions.
- In 2003, with support from HRP and from national and international sources, up to

761 research projects were ongoing in the above institutions, and a total of 736 research articles were published and/or disseminated.

- The participatory approach (known as the Strategic Approach) to improving the quality of care of reproductive health services continued to be used in 22 countries. In addition, two regional workshops to promote the Approach were attended by participants from 11 countries.

#### **(h) Implementing best practices**

- There were more than 13,000 formal subscribers to *The WHO Reproductive Health Library* (RHL) by the end of 2003 and 32 000 copies were distributed during 2003 in English and Spanish.

#### **(i) Monitoring and evaluation**

- Global, regional and subregional estimates for the number of births attended by a skilled attendant were developed and trends, levels and differentials were analysed over the period 1990–2001 (available on [www.who.int/reproductive-health](http://www.who.int/reproductive-health)).
- WHO/UNICEF/UNFPA maternal mortality estimates for 2000 were developed and the global database for anaemia during pregnancy was updated ([www.who.int/reproductive-health](http://www.who.int/reproductive-health)).

Overall, a 2003 external evaluation of the Programme for the period 1990–2002 reported the following: “In the period 1990–2002, HRP clearly met expectations in terms of its core mission to coordinate, promote, conduct and evaluate international research in reproductive health. HRP fulfils a uniquely important role that cannot be taken up by any other existing agency or organization in the world. HRP’s reproductive health research agenda has grown while its budget has contracted. Despite these constraints, the Programme has successfully maintained its leadership role. However, in order to continue to meet the high

expectations of HRP performance by both donors and beneficiaries, additional human and financial support is needed. It is thus very important that HRP, with the help of members of its advisory bodies, gain increased support and commitment from its stakeholders.”

#### 4. Selected expected outputs for 2004–2005

##### (a) Promoting family planning

HRP research will contribute to improving the quality of family planning service delivery through efforts to:

- support the provision of high-quality family planning services, including the production of evidence-based guidance, delivered by a health system committed to continuous quality improvement;
- assure a broad range of safe, effective and acceptable family planning methods;
- foster an enabling environment at family, community, national and international levels for addressing unmet needs and for promoting access to high-quality services for those who desire them.

##### (b) Making pregnancy safer

Ongoing trials are expected to answer important research questions that have potentially far-reaching clinical and public health implications related to the prevention and management of two major complications of pregnancy: pre-eclampsia and urinary tract infection.

HRP research will focus on the leading causes of conditions responsible for adverse pregnancy outcomes, namely pre-eclampsia and intrauterine fetal growth restriction.

HRP-sponsored systematic reviews (disseminated through *The WHO Reproductive Health Library*) will provide updated and solid scientific evidence on the causes, epidemiology and management of the most important pathological conditions that affect maternal and perinatal health.

Work on the WHO global data system for maternal and perinatal morbidity and mortality will create a worldwide system of medical institutions that will periodically collect up-to-date and accurate information on maternal and perinatal health outcomes.

##### (c) Control of sexually transmitted and reproductive tract infections

The main research activities concern the development of new, cost-effective strategies for the control of sexually transmitted infections (STIs) and reproductive tract infections (RTIs) in special populations, as well as new knowledge for the prevention and management of STIs and RTIs. The research will yield new data on the cost-effectiveness and utility of vaccines to prevent human papilloma virus (HPV) and herpes simplex virus type 2 (HSV2) and of improved STI diagnostic methods.

In addition, HRP research is expected to provide new information on the effectiveness of the female condom (compared with the male condom) in preventing both pregnancy and STIs; and the safety and effectiveness of a highly potent combination antiretroviral regimen to reduce the risk of MTCT of HIV.

##### (d) Preventing unsafe abortion

HRP research in this area will:

- contribute to the provision of safe abortion services and post-abortion care in accordance with WHO best practices and national laws;
- improve the safety, efficacy, and acceptability of methods of abortion and post-abortion care;
- strengthen national health system capacities to reduce unsafe abortions and to ensure the availability of high-quality and sustainable safe abortion and post-abortion care in accordance with national laws, ethical principles and relevant international conventions and agreements;

- foster community, individual, and family support for the elimination of unsafe abortion and for post-abortion care;
- assist with the development of national health policies which are based on an up-to-date and in-depth understanding of the determinants and consequences of unsafe abortion.

**(e) Technical cooperation with countries**

*National research capacity strengthening.* HRP will continue to contribute to the strengthening of research institutions in developing countries (both new and those currently receiving support from HRP).

*Policy and programmatic issues.* As a result of support provided by HRP through its participatory approach, countries will be able to strengthen their strategic planning for the provision of reproductive health services.

**(f) Monitoring and evaluation**

HRP will continue to compile global data on maternal mortality and other indicators of reproductive health such as coverage of antenatal and delivery care, perinatal mortality and unsafe abortion. These global databases serve as benchmarks for assessing maternal mortality and morbidity.

*Adolescent sexual and reproductive health.* By evaluating current interventions to improve

reproductive health services for adolescents and by generating new knowledge where there are gaps, HRP will enable countries to meet adolescents' needs more successfully.

*Gender issues and reproductive right.* HRP work will lead to the development of a health and human rights framework for country assessment of laws and policies related to reproductive health. New knowledge will be generated on whether reproductive health service could serve as an entry-point for addressing the problem of violence against women.

*Sexual health.* An evidence base will be built for improving understanding of the context, meaning and motivations behind sexual practices and behaviours, and the role they play in relation to people's vulnerability and risk of sexual ill health. In particular, studies will look at the reproductive health consequences of female genital mutilation and at the effects of using vaginal drying agents on sexual health. New strategies will be developed to provide guidance on how to address sexuality and sexual health appropriately in a variety of settings and for various populations, such as for migrants and sex workers in high STI prevalence areas. To further build the evidence base, HRP will also expand its review on the Global Burden of Disease to issues related to sexual health.

## Section 9

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### Road Traffic Injuries Research Network<sup>25</sup>

#### 1. History of the network

##### (a) Central problem

Each year road traffic collisions take the lives of 1.2 million men, women and children around the world and seriously injure millions more. While the rate of fatalities resulting from road traffic injuries (RTI) varies across regions, the death toll has proved to be highest in low- and middle-income countries, where pedestrians, motorcyclists, bicyclists and passengers are especially vulnerable.

In addition to human suffering, the estimated costs of RTI are between 1% and 2% of GNP per annum in low- and middle-income countries: a loss of approximately US\$ 65 billion every year – more than the total development assistance received worldwide by developing countries. However, these are as yet conservative estimates. Detailed crash cost estimates<sup>26</sup> (including property damage, administrative costs, lost outputs, medical costs and human costs) may swell these estimates.

Projections indicate that RTI will be the third leading cause of death and disability in 2020 unless there is appropriate and prompt intervention. Addressing key issues – such as speeding and driving under the influence of alcohol; promoting the use of helmets, seat belts and other restraints; ensuring that people walking and cycling are more easily

visible; improving the design of roads and vehicles; enforcing road safety regulations; and improving emergency response services – has demonstrated that needless deaths and disabilities caused by road traffic collisions can be prevented.

Few interventions to address RTI have been tested in low- and middle-income countries and even fewer are currently in place. Although high-income countries have had successes in implementing and evaluating such RTI interventions, the experience of these countries cannot be directly transferred to low- and middle-income country settings. As a result, there is a critical need to define global research priorities, conduct strategic research and facilitate implementation of interventions that can prevent the unnecessary loss of life from RTI.

##### (b) Creation of the network

The Road Traffic Injuries Research Network (RTIRN) is a partnership of scientists interested in collaborating on RTI research in low- and middle-income countries.

In 2002, with support from the World Bank, the Global Forum and WHO, the Road Traffic Injuries Research Network formalized its governance by establishing a Secretariat and Board. The network is an evolving partnership involving a broad group of committed

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<sup>25</sup> Adapted from a text contributed by Adnan Hyder, Secretary, Road Traffic Injuries Research Network.

<sup>26</sup> Global Road Safety Partnership, *Estimating Crash Costs*, Geneva, 2003.

individuals and institutions – government, academic and non-governmental – in order to foster research on the impact and determinants of road traffic injuries in low- and middle-income countries, and to identify appropriate, feasible and cost-effective responses to the problem.

### **(c) Central objective**

The central objective of the RTIRN is to establish networking mechanisms and facilitate the establishment of partnerships between RTI researchers and institutions internationally, that will support the development and strengthening of research agendas and research capacity in low- and middle-income countries.

### **(d) Specific objectives and strategies**

The network aims to achieve its objectives by involving multiple partners with diverse competences, who work together synergistically to help find solutions to key health problems. This will be done by supporting relevant research studies, finding common strategies for evaluation, and eventually disseminating results of the studies widely. The specific objectives and strategies of the RTIRN in low- and middle-income countries are the following:

*Objective 1: To advocate for research to reduce the burden of RTI, using the following strategies*

- Development of targeted advocacy plan for donors (public and private), policy-makers, researchers, NGOs, and the community.
- Production and dissemination of advocacy materials, including: brochure, website, powerpoint presentation.

*Objective 2: To set priorities for RTI research, using the following strategies*

- Identification and documentation of priority-setting processes.
- Priority-setting processes discussed in workshops by network members.

- Advocacy of results of priority-setting processes and support for introduction and implementation of these processes in regions/countries where they have not been undertaken.

*Objective 3: To help develop capacity for RTI research, using the following strategies*

- Support researchers in low- and middle-income countries in the preparation and submission of successful research proposals to sponsors.
- Support researchers in low- and middle-income countries in the conduct of research
- Facilitate the dissemination of research findings.
- Facilitate the collaboration and cooperation among public health researchers and transport researchers for reduction of RTIs.

*Objective 4: To promote investments for RTI research, using the following strategies*

- Promote research funding for the conduct of RTI research in low- and middle-income countries.
- Engage a fund-raiser to secure funds for the network and for RTI research projects.
- Link with Global Forum for monitoring resource flows and measuring the 10/90 gap in RTI research.

*Objective 5: To facilitate communication between partners involved in RTI research, using the following strategies*

- Establish regular formal and informal communication between network partners through a listserv, newsletter, conferences, workshops and network meetings.
- Increase the size of the network (through distribution of promotional materials).

*Objective 6: To conduct strategic research on RTI, using the following strategies*

- Identify strategic research for the reduction of RTI burden in low- and middle-income countries.



- Obtain funds to carry out this research and call for proposals for its execution.
- Develop strategic research proposals involving network partners and seek funding for these proposals.

*Objective 7: To disseminate and promote the application of research for policy towards reducing the burden of RTI, using the following strategies*

- Opportunities for dissemination are identified and network partners are supported in this dissemination through conferences/workshops, peer-reviewed and general media publications.
- Opportunities for influencing key policy-makers are identified and pursued.
- Workshops are conducted that provide network partners with the skills and tools to influence key policy-makers.

#### **(e) Partners**

The RTIRN involves more than 100 partners collaborating on RTI research in low- and middle-income countries. These represent researchers, research institutions, users of research in both public and private agencies. The partners are continuously interacting through the electronic listserv and are linked each month through the network newsletter.

#### **(f) Organization**

A network Board was established in 2002 comprising individuals who have made concrete efforts over the past three years in the formation of the network and are motivated to establish procedures for its sustainability. As the goal of the network is to promote research in low- and middle-income countries, it is intended that by 2005 the secretariat will be located in a low- or middle-income country.

#### **(g) Annual budget and sources of financing**

Funds for the activities of the network have been provided by the Global Forum for

Health Research, WHO, the World Bank and the Institute of International Health in Australia. To date the funding has been used to facilitate meetings of the network and to finance pilot research projects. In addition, critical material support has been provided by other key partners. The network hopes to double its operating budget over the next three years.

### **2. Main accomplishments in 2003**

The main outputs of the RTIRN by the end of 2003 include the following:

- development of RTIRN brochure;
- initiation of discussions on priorities for research in low- and middle-income countries;
- abstract submission and planned workshop at the 7th World Conference on Injury Prevention and Safety Promotion (June 2004);
- lectures on RTI at meetings organized by partners, to provide information and raise the profile of RTI research issues;
- technical assistance to and oversight of three research studies in Kenya, Pakistan and Uganda;
- preparation of a business plan for fund-raising;
- distribution of monthly RTIRN newsletters electronically to over 100 partners around the world;
- engagement of over 100 partners in ongoing communication through a listserv;
- presentations to international organizations including the World Bank and the NIH Fogarty International Center.

### **3. Expected outputs for 2004**

Over the next 12-18 months, it is expected that the RTIRN will undertake the following tasks:

- identify and locate the secretariat in a low- or middle-income country;
- consolidate the governance of the network by defining the roles of each structure (Board and secretariat);

- build on existing efforts to promote strategic research in low- and middle-income countries; and identify new research priorities through formal priority-setting process;
- establish a peer review network process for grant applications, abstract preparation and papers;
- document resources available for current RTI research in low- and middle-income countries;
- document current RTI researchers and groups in low- and middle-income countries; and implement fund-raising activities to support RTI research in low- and middle-income countries;
- continue good networking and communication mechanisms (through the electronic monthly newsletter and listserv);
- enhance the number and types of partners in the network (including the transport sector); and initiate specific activities targeted to catalyse the global community of RTI researchers. The first planned activity will take place at the World Conference on

Injury Prevention and Safety Promotion in Vienna in June 2004;

- continue participation in international meetings including Forum 8 in Mexico and the World Conference on Injury Prevention and Safety Promotion in Austria.

#### 4. Conclusions

The dedication of the World Health Day (7 April 2004) to road safety is an opportunity for the network and its partners to promote the critical need for RTI research, especially in low- and middle-income countries. In addition, the publication of the *World Report on Road Traffic Injury Prevention* also provides a means to focus global attention on this preventable cause of death and disability.

By supporting research and research capacity development in low- and middle-income countries, the RTIRN hopes to play a catalytic role in the coming years in global health development.

## Section 10

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### Roll Back Malaria<sup>27</sup>

#### 1. History of the network

##### (a) Central problem

Although many tools exist to fight malaria, it remains a major challenge to ensure access by vulnerable populations to key interventions – such as insecticide-treated mosquito nets, prompt and effective treatment, and intermittent preventive treatment for pregnant women. Investments in malaria control, particularly malaria commodities and delivery systems, are among the best investments a country can make – for both individuals and the economy as a whole. Research has a key role to play in improving existing tools, identifying and developing new ones (such as a vaccine) and scaling up interventions (see Insert 9.10.1).

##### (b) Creation of the Partnership

The Roll Back Malaria Partnership (RBM) was

launched by WHO, UNICEF, UNDP and the World Bank in 1998 to provide a coordinated international approach to fighting malaria. RBM's strength lies in its ability to form effective partnerships both globally and nationally. Partners are working together towards internationally agreed malaria-control objectives and coordinate their activities to avoid duplication and fragmentation and to ensure optimal use of resources.

Another key role of the RBM Partnership is to lead continuing advocacy campaigns to raise awareness of malaria at the global, regional, national and community levels, thus keeping malaria high on the development agenda, mobilizing resources for malaria control, and ensuring that vulnerable individuals are key participants in rolling back malaria.

### Insert 9.10.1

#### *Fighting malaria: the role of research*

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Although funding for malaria research has increased since the launch of the RBM Partnership in 1998, it is still insufficient to meet the continuous need for new or improved weapons against the disease.

A key role of the RBM Partnership is to advocate for increased funding for malaria research. The Partnership also works to identify knowledge gaps, tools and products for rolling back malaria, works with research partners to address needs, and facilitates the transfer of research findings into policies and practice.

The RBM Partnership's priority areas for research are those that can be put into practice to help countries scale up their malaria control interventions in the near term, such as new drug development, further development of long-lasting insecticide-treated nets, intermittent preventive treatment (for pregnant women, infants and children), diagnostic tools and operations research. In the medium term, the development of a malaria vaccine, vector control research, the pursuit of innovative approaches and research capacity-building will be key areas.

RBM partners active in research include the Multilateral Initiative on Malaria (which represents the research and academia constituency on the RBM Partnership Board), Medicines for Malaria Venture, Malaria Vaccine Initiative and Special Programme for Research and Training in Tropical Diseases (TDR).

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Source: RBM Partnership

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<sup>27</sup> Adapted from a text contributed by the Roll Back Malaria Partnership, WHO. Website: <http://www.rbm.who.int>.

### (c) Central objective of the Partnership

The objective of the Roll Back Malaria Partnership is to halve the burden of malaria by 2010, thus contributing to the achievement of the MDGs<sup>28</sup> by 2015.

RBM also has some interim goals, set at the African Summit on Roll Back Malaria<sup>29</sup> held in 2000 in Abuja, Nigeria, where 44 African Heads of State and Government resolved to initiate appropriate and sustainable action to strengthen their countries' health systems to ensure that, by 2005, the following objectives can be reached:

- At least 60% of those suffering from malaria have prompt access to, and are able to correctly use, affordable and appropriate treatment within 24 hours of the onset of symptoms.
- At least 60% of those at risk of malaria, particularly children under five years of age and pregnant women, benefit from the most suitable combination of personal and community protective measures such as insecticide-treated mosquito nets and other interventions which are accessible and affordable to prevent infection and suffering.
- At least 60% of all pregnant women who are at risk of malaria, especially those in their first pregnancies, have access to chemoprophylaxis or presumptive intermittent treatment.
- To achieve these targets, RBM is focusing on the rapid scaling up of interventions within countries, particularly to reach the most vulnerable populations.

### (d) Partners

The RBM Partnership has grown rapidly since its launch in 1998 and is now made up of

more than 90 partners from seven major constituencies: malaria-endemic countries, their bilateral and multilateral development partners, the private sector, NGOs and community-based organizations, research institutions and academia, and foundations.

### (e) Organization

During the concept development phase of RBM (1998–2001), the Partnership functioned as a loose network of partners meeting at global events for the purpose of maintaining shared visions and objectives. An external evaluation<sup>30</sup> of the functioning of the Partnership was carried out in 2001–2002 and called for a more formal governance structure to be adopted for the next phase of RBM, i.e. support to countries for scaling up malaria-control interventions. RBM's new structure, adopted in 2002, is as follows:

#### (i) The RBM Partnership Board

The RBM Partnership Board, created in October 2002, oversees the activities of the RBM Partnership Secretariat and makes decisions on behalf of the Partnership.

Each Board member serves as a representative of one of RBM's voting constituencies, namely: malaria-endemic countries (7 seats), founding partners – WHO, UNICEF, World Bank (3 seats), NGOs (1 seat), the private sector (1 seat), research and academia (1 seat), foundations (1 seat) and OECD donor countries (3 seats). The Executive Secretaries of the RBM Partnership and the Global Fund to Fight AIDS, Tuberculosis and Malaria serve as non-voting ex officio members, while UNDP currently participates as an observer.

<sup>28</sup> <http://www.un.org/millenniumgoals/>

<sup>29</sup> Roll Back Malaria/World Health Organization. *The Abuja Declaration and Plan of Action*. WHO document WHO/CDS/RBM/2003.46. [http://mosquito.who.int/docs/abuja\\_declaration.pdf](http://mosquito.who.int/docs/abuja_declaration.pdf)

<sup>30</sup> Roll Back Malaria External Evaluation Team. *Achieving Impact: Roll Back Malaria in the Next Phase*. Liverpool: Malaria Consortium, 2002. [http://www.rbm.who.int/cmc\\_upload/0/000/015/905/ee\\_toc.htm](http://www.rbm.who.int/cmc_upload/0/000/015/905/ee_toc.htm)

Members may appoint one alternate member to serve in their stead, under policies and procedures determined by the Board. Constituencies determine rotational or renewable status. The Board members sit on the Board for two years or such other term that the Board may determine.

(ii) *The RBM Partnership Secretariat*

The RBM Partnership Secretariat ensures that contributions from individual RBM partners are coordinated and focused on the expressed needs of countries and are in line with good-practice recommendations and WHO technical norms and standards.

The Secretariat is hosted by WHO and managed by the Executive Secretary of the RBM Partnership. It operates at all levels of partner engagement, i.e. at the global, regional, sub-regional and country levels. The four main areas of the Secretariat's work at the global level are:

- partnership development and networking
- country support development
- communications and advocacy
- resource mobilization and financing.

At the regional level, the RBM Partnership Secretariat facilitates liaison between regional partners and assists RBM Partnership Board members with constituency consultations. At the sub-regional level, the Secretariat promotes coordination of the timely provision of country support by RBM partners. At country level, the Secretariat supports partner coordination to ensure optimal implementation of nation-wide malaria-control efforts by governments and their partners.

(iii) *Working groups*

The RBM Partnership has created six thematic Working Groups, which are open to all

constituencies and expected to coordinate with other global initiatives, working groups or other global committees to ensure and maintain consensus on good practices for implementation of malaria control activities. The Working Groups are active in the following areas:

- case management
- communication
- finance and resource mobilization
- insecticide-treated nets
- malaria in pregnancy
- monitoring and evaluation.

(iv) *Sub-regional networks*

RBM's sub-regional networks are responsible for coordinating support to countries. Partners within the networks support countries in delivering critical actions, e.g. addressing any bottlenecks encountered in implementing national-scale malaria control efforts with newly available financial resources from the Global Fund. To date, sub-regional networks have been established in East Africa, West Africa, Amazonia, Hispaniola and the Mekong.

(v) *Country partnership coordinating mechanisms*

In each active RBM implementing country, the in-country RBM partnership has established a coordinating structure – often based on existing structures – generally consisting of an RBM coordinating committee or task force supported by a number of thematic subcommittees. In countries receiving Global Fund grants, a member of the RBM coordinating task force is part of the country coordinating mechanism.<sup>31</sup>

In most countries, the national malaria control programme of the ministry of health has expanded its role to include the provision of a secretariat function to the country

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<sup>31</sup> <http://www.theglobalfund.org/en/apply/mechanisms/>

partnership. The RBM Partnership Secretariat is in the process of deploying Country Partnership Advisers to these programmes to strengthen their capacity to sustain their country-level partnerships.

#### **(f) Annual budget and sources of financing**

An annual workplan with a budget of US\$ 12 million for the RBM Partnership – including its management structures and implementation mechanisms – was approved by the RBM Partnership Board for the March 2003-March 2004 period. Approximately 60% of this amount was earmarked for regional, sub-regional and country activities and staff.

RBM and its Secretariat have been funded by diverse bilateral and multilateral sources. Over the past five years, these have included the governments of Australia, Belgium, Canada, France, Germany, Italy, Japan, Luxembourg, Sweden, the United Kingdom and the United States, as well as the Rockefeller Foundation, UNICEF, the World Bank and the World Health Organization.

## **2. Main accomplishments 2003–2004**

The emphasis of the RBM Partnership Secretariat's workplan, as mandated by the RBM Partnership Board, was on implementing the recommendations of the external evaluation as well as the Partnership's operational framework. The primary challenges were:

#### **(a) To develop Partnership management structures**

The Partnership strengthened governance and management mechanisms throughout the year by:

- holding twice-yearly RBM Partnership Board meetings;

- holding monthly Board teleconferences;
- making the RBM Partnership Secretariat fully functional at the global and regional levels (Geneva-based global secretariat and Harare-based regional focal point).

#### **(b) To develop global consensus**

In order to ensure optimal use of Global Fund resources and to support the development of new proposals, the Partnership supported the establishment of a consensus on good practices for the scaling up of malaria interventions by:

- establishing six thematic Working Groups, which are fully operational and developing strategic frameworks to guide countries and partners;
- holding an Expert Consultation on the procurement and financing of antimalarial drugs.

#### **(c) To maintain malaria high on the global development agenda**

To ensure that malaria remains an important issue to all partners – from communities and individuals to OECD donors – and to the general public, RBM coordinates partners' advocacy efforts for maximum impact. Achievements in 2003 included:

- negotiating with country health officials to ensure that malaria receives sufficient attention in health sector reviews, planning meetings and related reports;
- launching the WHO/UNICEF *Africa Malaria Report 2003*;<sup>32</sup>
- supporting Africa Malaria Day 2003 activities at country level;
- promoting Africa Malaria Day 2003 at the global level;
- attending key international, regional and country meetings to highlight malaria issues.

<sup>32</sup> WHO/UNICEF. *Africa Malaria Report 2003*. WHO document WHO/CDS/MAL/2003.1093. <http://mosquito.who.int/amr2003/amr2003/pdf/amr2003.pdf>

#### **(d) To provide technical and programmatic support to countries**

Focusing on 14 African countries with a high degree of readiness to implement national-scale malaria-control programmes, the Partnership began the process of (i) identifying bottlenecks hampering this implementation, and (ii) coordinating partners' support for country level scaling-up of malaria control activities. Key achievements include:

- identifying the 14 African countries with a high degree of readiness (including availability of Global Fund financing) to implement national-scale malaria-control programmes and therefore having high potential for reaching the 2005 Abuja targets;
- supporting five sub-regional networks (East Africa, West Africa, Amazonia, Hispaniola and Mekong) to coordinate consensus-building and activities;
- deploying two sub-regional RBM focal points (one each for East Africa and West Africa);
- completing country consultative missions in 14 countries;
- identifying the package of support required for the 14 countries visited;
- holding meetings to promote the sharing of experiences between countries.

### **3. RBM Partnership Secretariat: expected outputs 2004–2005**

#### **(a) Partnership development and networking**

The key outputs in this area target the strengthening of Partnership governance and mechanisms to create a structure ensuring optimal support to countries in their scaling up of malaria control interventions, without duplication or fragmentation of efforts. These outputs include:

- strategic frameworks, developed by the Working Groups, to guide partners and countries on approaches for scaling up interventions;
- an operational Partnership Performance

Tracking System and RBM Partnership global workplan, providing RBM partners with a clear understanding of their roles and responsibilities, resource commitments and performance criteria;

- targeted partnerships for the development of new tools and mechanisms for malaria control;
- a strategy for engaging the private sector and NGOs more effectively;
- a finalized RBM Partnership operational framework;
- operational governance mechanisms (e.g. full biannual Board meetings, monthly Board teleconferences, Working Group meetings).

#### **(b) Country support development**

The main objectives in this area are to achieve consensus on the critical steps that need to be taken by individual countries to make maximum progress towards the Abuja targets by 2005, and to support these countries and their partners in implementing their national malaria control programmes. Key outputs include:

- fully operational sub-regional networks in Africa (4), Asia (1) and the Americas (2);
- fully functional focal points deployed or designated at four sites in Africa and three sites outside Africa;
- fully functional country partnerships in 35 African countries;
- management system support for 24 African countries;
- mechanisms and processes to ensure effective translation of working group products into country guidance for policy, strategy and guideline formulation;
- operational arrangements for coordinating and catalysing partnership programmes for supporting policy, strategy and guideline development.

#### **(c) Communications and advocacy**

These key outputs are intended to maintain global awareness of malaria, co-ordinate

partners' advocacy efforts to boost resource mobilization, support country-level malaria communication efforts and keep partners informed of Partnership issues. These outputs include:

- global promotion of Africa Malaria Day 2004;
- a global advocacy strategy and workplan for 2004-2005;
- a mechanism allowing RBM to receive donations from the general public;
- a revised set of RBM communications and advocacy materials;
- communications strategies for 14 African focus countries, along with support to implement them;
- a good practices framework document to assist countries;
- funds disbursed for country-level radio projects in five countries.

#### **(d) Resource mobilization and financing**

In order to support countries and other RBM partners in procuring antimalarial commodities, forecasting resource needs, mobilizing resources and optimizing resource use, the key outputs in this area will include:

- a coordinated system for facilitating access to antimalarial medicines and supplies;
- a reference document on sources and prices of antimalarial medicines and supplies;
- documentation of country resource requirements for rolling back malaria between 2005 and 2010;
- guidance notes on malaria control financing issues;

- reports on efficiency in the use of existing resources for malaria control;
- research findings on the economic costs of malaria;
- a comprehensive status report on estimated costs of developing new tools and transferring knowledge;
- a malaria control financing database (to be updated quarterly).

#### **(e) Human and financial resources to undertake 2004 tasks**

In 2004-2005, the RBM Partnership Secretariat expects to increase its presence at the sub-regional and country levels, requiring an increase in budget over 2003-2004. Staffing requirements will be met, where possible, through secondment of staff from RBM partner institutions.

#### **4. Conclusions**

The Roll Back Malaria Partnership is working to help the coordination among stakeholders and to translate national commitments and global support for malaria control into action on the ground – where the strength of the RBM Partnership can make the difference.

Many tools exist to control malaria, but technology is not enough: the fight against malaria requires commitment, coordination and cash – US\$ 2 billion per year in Africa and US\$ 1 billion per year for other malaria-endemic areas. However, fighting malaria also requires much further research to make the existing tools more efficient and effective and to discover new tools.



## Section 11

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### TDR: Evolving with the changing disease situation<sup>33</sup>

#### 1. Creation and objectives

The Special Programme for Research and Training in Tropical Diseases (TDR) is an independent global programme of scientific collaboration. Established in 1975 and co-sponsored by UNICEF, UNDP, World Bank and WHO, it aims to help coordinate, support and influence global efforts to combat a portfolio of major diseases of the poor and disadvantaged.

Its objectives are to improve existing approaches and develop new ones for preventing, diagnosing, treating and controlling neglected infectious diseases which are applicable, acceptable and affordable by developing endemic countries, which can be readily integrated into the health services of these countries, and which focus on the health problems of the poor. It also aims at strengthening the capacity of developing endemic countries to undertake the research required for developing and implementing these new and improved disease control approaches.

TDR's mandate includes the following diseases: African trypanosomiasis (sleeping sickness), Chagas disease, dengue, leishmaniasis, leprosy, lymphatic filariasis, malaria, onchocerciasis, schistosomiasis and tuberculosis.

#### 2. Progress and evolution since 1975

Since 1975, TDR has produced a steady stream of practical tools for making progress

against the 10 diseases in its mandate. Many of the drugs and operational procedures that have made it possible to launch elimination campaigns owe their origins to TDR research, often in partnership with academia from developed and developing countries, national institutions and public and private sector partners. Some examples from a long list include ivermectin for onchocerciasis, multidrug therapy for leprosy, and eflornithine and the card agglutination test for African sleeping sickness. Recently the registration in India of miltefosine, the first oral drug for the treatment of visceral leishmaniasis, has resulted in extensive phase IV studies to assess whether it is appropriate for use on a wide scale in public health.

TDR-sponsored research also led to the development and availability of praziquantel for use in mass treatment for schistosomiasis, the use of fumigant canisters to control the vector that causes Chagas disease, and the introduction of insecticide-treated nets for malaria following extensive field testing by TDR. TDR-sponsored projects also led to the establishment of Artemisinin Combination Therapy as the preferred treatment for malaria. In addition, many practical procedures, including rapid epidemiological mapping and community-directed treatment, have also contributed to the effectiveness of control programmes and are now a standard component of several tropical disease control programmes.

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<sup>33</sup> Adapted from a text contributed by Jens Kastberg, TDR Secretariat.

TDR has evolved over the years in line with the changing infectious disease situation and the new challenges that have emerged, some of which are formidable. Diseases such as malaria, TB, dengue and African sleeping sickness continue to impose a heavy burden among the poorest populations. Resistance to first-line drugs has developed and spread at an alarming rate. HIV/AIDS – unknown when TDR was created – is undermining global health and exacerbating the clinical course of TB and leishmaniasis. Positive developments have likewise created new demands at the operational level. For example, the control strategies being used by several of the new public-private partnerships have intensified the need for TDR support.

TDR itself has also catalysed and fostered the establishment of many new partnership organizations including, notably, the Global Forum and the Medicines for Malaria Venture.

TDR recently undertook a major review of its activities utilizing the Global Forum's Combined Approach Matrix (see chapter 4, section 3). The exercise was based on the following documents:

- the analyses carried out by TDR, WHO and the World Bank between 1993 and 1996 which culminated in the 1996 Ad Hoc Committee Report;<sup>34</sup>
- the Global Forum's proposed CAM for setting priorities in health research.<sup>35</sup>

This led to the definition of a set of “strategic TDR emphases” (or priorities) for the following five years, based on a transparent and objective prioritization process with the active participation of partners from both health research and disease control. The new

TDR strategy calls for a much closer interaction with health systems and disease control programmes, supported by the continued exploitation of scientific and technological advances – from basic to applied research, from biomedical to human sciences, and from laboratory-based to field research.

Whenever successful interventions and progress have been made to control a particular disease, or collection of diseases within a given region, the value of research has invariably manifested itself through:

- (i) the availability of improved tools and methodologies;
- (ii) continued inclusion of research into how best to implement these interventions as the tools and methodologies are taken into use and scaled up.

If research issues are recognized at the earliest stages of disease control efforts, then a culture of research and analysis can be created that will continue to inform programmes of potential issues and allow strategies to be developed to address them. Building of research capacity and of capacity to undertake disease control programmes through national health systems go hand in hand and should be seen as complementary endeavours. Similarly, both disease control needs and the context in which health care is provided should be recognized and understood by researchers as soon as they embark on applying science to practical outcomes, if their output is to have any value. There is a need for close liaison between those involved in disease control and those engaged in research. Operational interactions between research and control need to focus on research outputs, new concepts and new tools, implementation and scale-up research.

<sup>34</sup> Report of the Ad Hoc Committee on Health Research, Investing in Health Research and Development, WHO, 1996.

<sup>35</sup> Global Forum for Health Research. *The 10/90 Report on Health Research 2001-2002*.

Researchers and those involved in disease control often come from different cultures and backgrounds, which has led to a differing set of priorities and gaps in understanding and appreciation of each other's viewpoint. An added complication is that international thinking about research issues and global disease control assessments requires a categorization of issues into manageable 'topics' and organizational units (e.g. by disease and underlying public health issue). At national and sub-national levels, these categorizations

often become increasingly less meaningful as they have to be made relevant to health systems having to deal with multiple diseases in a specific public health context (e.g. facing social and behavioural issues at the local level and health policy and financing issues at the macro-level).

### 3. Research capacity strengthening and transferring technology

Miltefosine (Insert 9.11.1) is an example of an oral drug for treatment of visceral

## Insert 9.11.1

### *TDR and miltefosine: an example of an oral drug for treatment of visceral leishmaniasis (kala-azar) developed through a public-private partnership*

#### **A unique partnership brought together by TDR**

In 1988, TDR-funded research discovered that miltefosine, a drug then under development for cancer treatment, had anti-leishmaniasis activity. In 1995, Zentaris (then ASTA Medica) signed an agreement with TDR that led in 2002 to the registration of miltefosine for the treatment of visceral leishmaniasis. TDR established a Product Development Team (PDT) involving clinical investigators from India and from Zentaris, Germany. Managed by the PDT, the whole process to registration was completed in less than seven years and phase IV studies are now near completion.

The partnership now includes researchers from Nepal and Bangladesh who are currently assessing the applicability and public health relevance of making this new drug accessible to the larger population affected by the disease. The drug will be made available to the public sector at a reduced price to reflect public sector investment in visceral leishmaniasis. The total cost of developing miltefosine was about US\$ 16 million, of which about US\$ 1 million was contributed by TDR. This is considerably below the hundreds of millions often quoted as the cost of new drug development. Some of the main reasons that made this lower cost possible in this case are the following:

- **R&D process:** TDR funding of general screening activities allowed the identification of leishmaniasis activity in a drug already being developed for other purposes, i.e. cancer treatment. This avoided the huge costs of running discovery laboratories as well as the costs of failures.
- **Public-private partnership:** organizing the field trials through the PDT and involving Zentaris, Indian government research institutions, public health care facilities, as well as the Indian regulatory authorities throughout the process helped keep down the cost of the field work and of the registration in India.
- **TDR's operational capabilities:** making it possible to establish and run a virtual product development organization, focusing only on the development of miltefosine, drawing on world leading experts, and with negligible fixed and overhead costs.

Miltefosine is expected to revolutionize the treatment and control of visceral leishmaniasis and alleviate the suffering of millions of adults and children. By reducing the disease burden in populations affected by the disease, miltefosine could help boost economic and social development in some of the world's poorest communities.

The drugs currently used to treat visceral leishmaniasis are toxic (often involving severe adverse reactions), highly expensive and of limited therapeutic efficacy. By contrast, miltefosine is affordable and has a proven cure rate of about 98%. An additional asset is that it does not require refrigeration for storage.

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Source: TDR Secretariat.

leishmaniasis (kala-azar) developed through a public-private partnership with far-reaching benefits in terms of capacity strengthening. All the clinical trials for miltefosine were conducted in India, where Indian laboratories, doctors and administrators were involved in the process, with guidance and monitoring provided by TDR. Laboratories were set up with state-of-the-art equipment and individuals were trained to carry out clinical research under Good Clinical Practice (GCP). As a result, the data gathered from these clinics are not only reliable but also the safety of patients is ensured under good ethical procedures. This resulted in the galvanization of local institutions and increased the Indian research capacity beyond the miltefosine studies. From an initial focus on phase II and III clinical development studies, the emphasis has now shifted to training for phase IV clinical studies and to the development of a multinational disease control programme (India, Bangladesh and Nepal).

While each case is unique, some of the determinants for success in the development of miltefosine may be intrinsic to the way TDR is set up and operates. These include the following:

- A level of credibility that facilitates the involvement of leading scientists and R&D partners.
  - Country networks which help facilitate the organization of complex studies, including clinical trials.
  - A flexible funding procedure that allows TDR to pursue quality opportunities when they occur.
  - A management mechanism (the product development team) which allows quality professional management of each individual product development in which it engages.
  - The product development team can draw on a full complement of ancillary expertise in TDR (e.g. in pre-clinical and clinical coordination, data management, capacity building).
- A managerial infrastructure which allows it to establish and run ad hoc virtual project organizations, tailored to the needs of each development project.

#### 4. Looking ahead

Ideally, interventions developed in partnership with TDR should be cost effective, robust under the harsh conditions and resource-poor settings of developing countries, and be operationally as simple to implement as possible. They should also be acceptable to communities and sustainable. In line with this pragmatic approach, TDR also conducts implementation research to assist the introduction of new tools into disease control programmes in endemic countries. Practical factors that influence the access of populations to treatment are thus an important research focus, underscoring TDR's concern to see that new tools, once available, work well in practice.

There has been an increased level of interest in malaria and TB research in recent years which TDR has promoted and is seeking with others to capitalize on. However many of the other TDR diseases remain under-resourced for research and control activities and require continued promotion and new ideas. At the same time, the increasing impact of the HIV/AIDS pandemic, and its influence on the communities affected by TDR diseases, require TDR to work at the interfaces of HIV/AIDS and other diseases, from basic research through to implementation research. The growing interaction of social, economic and behavioural research with biomedical research is an area that will require attention in the coming years. Of crucial importance in this respect is the need to partner with others to further develop research capacity in developing countries.

## B. Networks focusing on determinants (risk factors)

### Section 12

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#### Child Health and Nutrition Research Initiative<sup>36</sup>

The size of the problems affecting child health and the rationale for the creation of the Child Health and Nutrition Initiative in 2000 were presented in *The 10/90 Report on Health Research 2001-2002* (Chapter 8, Section 9, pages 181-187). It described the objectives, strategies and governance of this Initiative and identified the key priorities in the field of malnutrition and perinatal health as follows:

##### *Recommendations for research on malnutrition*

- Interventions to reduce low birth weight
- Prompt implementation of interventions for the management of diseases and conditions in low-birth-weight children
- Calculate the burden and describe the functional consequences of micronutrient deficiencies
- Improvement of nutritional status of the family and the population through development efforts
- Breaking the vicious cycle of infection and malnutrition
- Rehabilitation and early stimulation of low-birth-weight infants

- Investigation of the prevalence of micronutrient deficiency and anaemia in young children
- Intervention involving food fortification or dietary changes
- Operations research to improve implementation of existing interventions
- Cost-effectiveness comparison of interventions
- Establishment of the role of childhood diets in the development of noncommunicable diseases.

##### *Priorities in the field of perinatal research:*

##### *Epidemiological research*

- Country-specific data on causes and determinants of newborn deaths in the community
- Validated verbal autopsy tool to determine biological causes, and sociocultural and logistical determinants of perinatal and neonatal deaths in the community.

##### *Formative research*

- Household maternal and newborn care practices, especially regarding delivery and early newborn care

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<sup>36</sup> Adapted from a text contributed by the Child Health and Nutrition Research Initiative.

- Barriers to seeking and receiving care
- User perceptions and expectations of the formal health system
- Models of community participation.

#### *Operations research*

- Effectiveness of packages of maternal and newborn interventions delivered at the community level
- Workers and infrastructure needed to support delivery of lifesaving interventions at the community level, especially during the postpartum period.

#### *State-of-the-art research*

- Detection and management of maternal reproductive and urinary tract infections
- Models of breastfeeding promotion
- Strategies for maternal and/or newborn nutritional supplementation
- Prevention of mother-to-child HIV transmission
- Prevention, recognition and management of newborn infections, birth asphyxia and hypothermia
- Optimal umbilical cord care in the community.

In 2001, a first request for proposals (RfP1) was issued on the regional assessment of research priorities and research institutions (results in 2004). In 2002, RfP2 was issued for research on scaling up programmes on breast-feeding in low- and middle-income countries. In 2003, RfP3 was issued on low birth weight and its determinants. Research is presently being carried out on these various projects and reports will be periodically issued on progress.

Following a thorough selection process, the Centre for Health and Population Research (ICDDR,B) in Bangladesh was selected to host the CHNRI Secretariat for an initial two-year period. The transition from the interim secretariat to the Dhaka centre is expected to take place in mid-2004.

CHNRI fills an important gap as an initiative focusing on child health and nutrition research in the most vulnerable populations of the world. It hopes to serve as a platform for a wide array of partners to discuss critical issues, share experiences, decide on key priorities for research and implement strategies to fulfil a critical need in the global health research agenda.

## Section 13

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### Sexual Violence Research Initiative<sup>37</sup>

#### 1. History of the network

##### (a) The central problem

Sexual violence is defined as “any sexual act, attempt to obtain a sexual act, unwanted sexual comments or advances, or acts to traffic against a person’s sexuality using coercion, by any person regardless of their relationship to the victim, in any setting, including but not limited to home and work”.<sup>38</sup>

Sexual violence is both a public health problem and a violation of human rights. It occurs across continents and cultures and has a profound impact on physical and mental health both immediately and many years after the assault. In addition to injuries, it is associated with an increased risk of a range of sexual and reproductive health problems such as unwanted pregnancy, unsafe abortion, STIs and HIV/AIDS, urinary tract infections, chronic pelvic pain, vaginal bleeding or infection. Sexual violence also contributes to the development of high-risk sexual practices such as non-use of condoms, multiple partners, and participation in sex work. Mental health consequences are just as serious as physical injuries and may often confer increased risk of poor emotional health during the lifetime of the affected individual. Mental health disorders related to sexual violence often include depression, post-traumatic stress disorders and sleep difficulties.

Sexual violence also has profound consequences for the victim’s social well-being. It may result

in dropping out of school, homelessness at an early age, as well as stigmatization and rejection by families and communities. If women have children, all of these factors may also seriously affect their children’s health and development. Mortality associated with sexual violence may occur through suicide, HIV infection, and murder – either during the attack in the case of rape or subsequently in murders committed in the name of ‘honour’.

Despite its significance, sexual violence has received little attention from researchers, policy-makers and programme designers. In many parts of the world, there is virtually no research on the issue. However, available data indicate that as many as one in five women report sexual violence by an intimate partner and up to one third of girls report forced sexual initiation. In many countries, interventions to prevent or respond to sexual violence are limited and most have not been evaluated. Moreover, since these interventions have been predominantly developed in industrialized countries their relevance to low resource settings is mostly untested.

To respond effectively to the problem of sexual violence, there is a need for reliable data from all regions of the world, but particularly from developing countries and central and eastern Europe. Data are needed on the magnitude and nature of the problem, its health impact and risk factors, so as to better estimate the burden of the disease and

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<sup>37</sup> Adapted from a text contributed by the Secretariat of the Sexual Violence Research Initiative. Website: [www.who.int/gender/violence/sexual\\_research/en](http://www.who.int/gender/violence/sexual_research/en)

<sup>38</sup> WHO, *World Report on Violence and Health*, 2002.

improve knowledge of why it persists. Equally, there is a need for more knowledge of existing interventions and their cost-effectiveness, starting initially with those in the health sector.

### **(b) Creation of the network**

The Sexual Violence Research Initiative (SVRI) aims to build an experienced and committed network of researchers, policy-makers, activists and donors to help ensure that the many dimensions of sexual violence are addressed from the perspective of different disciplines and with a multicultural outlook. It was established in April 2003 with initial funding by the World Bank (through its contribution to the Global Forum) and will be hosted initially by WHO.

### **(c) Central objective of the SVRI**

The SVRI focuses on the sexual abuse and coercion of adult and adolescent women, child sexual abuse, sexual torture and sexual violence in war situations, female genital mutilation and trafficking in women and girls for sex.

The global objective of the SVRI is to promote and disseminate research to reduce and respond to sexual violence in low- and middle-income countries through identifying gaps, building capacity, supporting research, raising awareness and building partnerships.

### **(d) Partners**

Over the past two and a half years, many individuals and organizations have been involved in shaping the goals and agenda of the SVRI. These include individuals from international organizations, national and international NGOs, universities and other research institutions and government departments. These partners interact with one another through the SVRI list serve from which research teams and technical experts can be identified ([\[violence/sexviolresearch/en/\]\(http://www.who.int/gender/violence/sexviolresearch/en/\)\). Details of how to become a member of the SVRI and join the list serve are available on the website.](http://www.who.int/gender/</a></p></div><div data-bbox=)

The SVRI also links up with other initiatives that work on violence against women such as the WHO Multi-Country Study on Women's Health and Domestic Violence Against Women, the International Research Network on Violence Against Women and the Global Coalition on Women and HIV/AIDS.

### **(e) Organization of the SVRI**

#### *Coordinating Group*

A Coordinating Group with nine members provides overall guidance to the work of the SVRI. This group meets annually and holds a teleconference at least once a year to review the work of the SVRI.

#### *Technical Support Team*

A Technical Support Team provides technical and administrative support to the Initiative and is based in WHO for its first two years of activity, after which another host institution will be selected through an open process to host the Initiative.

## **2. Main achievements in 2003**

The annual meeting of the Coordinating Group in August 2003 agreed on a detailed plan of action for the first year of operations. The recruitment of a full-time Programme Officer for the SVRI was initiated at the end of 2003.

The following research priorities have been identified:

- nature and magnitude of sexual violence, including qualitative research on masculinity and other risk factors;
- health consequences of sexual violence;
- women's responses to sexual violence;
- medico-legal responses to sexual violence;
- alternative forms of justice in cases of sexual violence.



### 3. Expected outputs for 2004-2005

The planned activities for 2004-2005 are grouped under five key strategies, designed to meet the SVRI objectives:

*Strategy 1: Strengthen and expand a network of stakeholders including researchers, NGOs and policy-makers*

- A directory of organizations/programmes working in the field of sexual violence will be developed.
- E-mail and web-based discussion to promote dialogue among researchers, policy-makers and other interested individuals/organizations will take place via the SVRI interactive website.

*Strategy 2: Establish a resource database to provide technical assistance to researchers and information on sexual violence*

The SVRI website will also include:

- information on sexual violence research instruments and methodologies;
- information on ethical considerations in sexual violence research;
- links to the latest sexual violence research reports and publications.

*Strategy 3: Identify research gaps, set research priorities and undertake pilot research*

Desk reviews will be commissioned on:

- sexual violence research instruments
- alternative forms of justice
- health sector responses to sexual violence
- women's responses and recovery pathways after sexual violence.

*Strategy 4: Help raise funds and pool human resources to carry out needed research in a coordinated and consistent way for the following research priorities*

- health sector responses to sexual violence
- women's responses and recovery pathways after sexual violence
- alternative forms of justice
- development of a database of technical

experts on sexual violence

- development of a database of donors funding work on violence.

*Strategy 5: Engage in dialogue across sectors by participating in key forums and conferences of health professionals*

- Participation in international events and panels to highlight the work of the SVRI.
- Organization of a technical workshop to build capacity in sexual violence.
- Organization of a conference on sexual violence research, to present the preliminary results of any research undertaken under the SVRI, as well as other research and key developments in the field.

The process for identifying a new host institution for the SVRI technical support team will also be developed during 2004 through an open call for proposals and subsequent review. It is envisaged that a successor will be identified through this participatory process by the end of 2005.

### 4. Conclusions

The SVRI slogan is 'Living Free from Sexual Violence' – reflecting the Initiative's goal to engage in research that will result in concrete action to address this global problem.

Through the SVRI, approaches and interventions that address sexual violence can be documented, evaluated and shared with a wide and diverse audience. Research and evaluation methodologies can be developed and implemented. The Initiative will also seek to influence donor agencies to include sexual violence in their agendas.

The SVRI is an initiative that reflects both geographical and professional diversity. It aims at reducing the incidence of sexual violence by simultaneously addressing the lack of research on the different aspects of sexual violence, as well as drawing the

attention of a wide range of people, including policy-makers and the media, to this important public health and human rights issue. Through the SVRI, emphasis will be placed on local research, particularly in developing countries, where there is very little data. This critical research has the potential

to lay the foundation for interventions that are both effective and sustainable. By engaging with researchers, activists and policy-makers in different areas of the world, a cohesive movement against sexual violence can be developed and supported.

## C. Networks focusing on priority-setting methodologies

Please refer to Chapter 4, which summarizes the efforts undertaken by various institutions in the 1990s in the field of priority-setting methodologies. In particular, the chapter reviews the following methodologies:

- the *Essential National Health Research strategy* proposed by the 1991 Task Force on Health Research for Development
- the *five-step approach* proposed by the 1996 Report of the Ad Hoc Committee on Health Research
- the *visual health information profile* proposed in the 1997 Report of the WHO Advisory Committee on Health Research
- the *Combined Approach Matrix* proposed by the Global Forum for Health Research in 1999
- the methodologies applied by the National Institutes of Health (USA), WHO's Department of Reproductive Health and Research, and the TDR Programme.

# D. Networks focusing on policies and cross-cutting issues

## Section 14

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### Alliance for Health Policy and Systems Research<sup>39</sup>

#### 1. History of the network

##### (a) Creation

The Alliance was established in November 1999 and formally launched in March 2000 under the legal umbrella of the Global Forum and with its Secretariat based in WHO. The Alliance has its origins in the recommendations of the 1996 Report of the Ad Hoc Committee on Health Research, which identified lack of health policy and systems research (HPSR) as a key problem impeding the improvement of health outcomes in low- and middle-income countries. The Alliance was created to raise the international profile of HPSR, and to encourage knowledge generation and use ([www.alliance-hpsr.org](http://www.alliance-hpsr.org)).

##### (b) Central problem

The central problem that motivates the Alliance for Health Policy and Systems Research is that there is, first, a gross lack of information on the performance of health systems and on how policies affect performance. This knowledge gap is particularly apparent given current efforts to expand funding for the health sector, engage in new forms of

development partnership and scale up health services for specific diseases. Second, even when knowledge is available, it is not necessarily known to or used by policy-makers. Finally, the availability of knowledge and its appropriate use are both associated with low capacity to produce and disseminate research. These are examined in turn below.

#### *Problem 1: Lack of knowledge about health policies and health systems*

The research areas of health policy and health systems have until recently been neglected, especially in low- and middle-income countries. The Ad Hoc Committee on Health Research concluded that: “Health care systems vary greatly in their performance – in how efficiently they improve health conditions, extend access and contain expenditure growth; yet there remains a surprising lack of information on the performance of systems and on how policies have affected performance.”<sup>40</sup>

Since 1996, there have been two notable initiatives. First, important efforts have started to measure and compare the performance of

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<sup>39</sup> Based on a text contributed by the Secretariat of the Alliance for Health Policy and Systems Research.

<sup>40</sup> Ad Hoc Committee on Health Research. *Investing in Health Research and Development*, Geneva, WHO, 1996.

health systems worldwide.<sup>41</sup> Indicators are now being used at country level to monitor on a continuous basis stewardship functions, health expenditure, resource allocation, equity in financing and the responsiveness of health systems to people's expectations. Second, the report of the Commission on Macroeconomics and Health has investigated the impact of health on development and recommended a plan of action to promote growth and reduce poverty through better health.<sup>42</sup> The proposal of the Commission is for a five-fold increase in donor assistance to low-income countries for essential health interventions, including HPSR.

Despite the progress made since the 1996 Report of the Ad Hoc Committee, there is still an urgent need to improve our understanding of how societies organize themselves to achieve health goals, including how they plan, manage and finance activities to improve health, as well as the roles played by different actors in these efforts, their perspectives and interests. In particular, there is an urgent need to provide scientifically sound, socially relevant and ethically acceptable guidance for more effective, efficient and sustainable health policies and systems. Research is required both on the process of health policy-making and on the desirable content of health policies.

### *Problem 2: Low utilization of research results*

The importance of using the findings of health research in policy-making, and therefore the need to understand the mechanisms involved, is increasingly recognized.<sup>43</sup> Efforts to substantially increase resources to improve

health in developing countries, and global pressures for sustainability and accountability, highlight the importance of research-informed policy-making. But little effort has been directed at improving research utilization in the field of health policy and systems development.

More attention needs to be given to developing the interfaces between producers and users of research.<sup>44</sup> Actions by individuals can be useful in generating interaction, but it is important to consider the role of the wider health research system in encouraging or facilitating interactions, networks and mechanisms at a system-wide level. There is increased recognition of the significance of policy-makers demanding and actively assimilating research. More attention needs to be given to promoting incentives, both for researchers to produce research results which are geared to the problems confronting policy-makers, and for policy-makers to formulate their research needs and make use of research results. Improving the interaction across the research and policy interfaces involves developing an institutional framework or enabling environment that takes into consideration the needs of researchers, policy-makers and programme managers.

Explicit and well institutionalized mechanisms for the utilization of research need to be in place before research funding can be scaled up to the amounts that have been proposed. If governments and donors are to increase funding, they need to be convinced that effective research-to-policy processes have been tested, and that results have been

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<sup>41</sup> WHO. *World Health Report 2000: Improving the performance of health system*. Geneva, 2000.

<sup>42</sup> WHO Commission on Macroeconomics and Health. *Investing in Health for Economic Development*, Geneva, 2001.

<sup>43</sup> Hanney SR et al. "The Utilisation of Health Research in Policy-Making: Concepts, Examples and Methods of Assessment." in *Health Research Policy and Systems*, 1:2 2003.

<sup>44</sup> Alliance for Health Policy and Systems Research. *User-driven health policy and systems research. Experiences from the North and South. Workshop report and case studies*, Talloires, France, September 2002.

applied to the benefit of people's health. There is therefore a need to develop and evaluate sustainable institutional mechanisms to relate the producers and users of research at all levels of the national health system as well as at regional and global levels.

### *Problem 3: Low capacity to produce and fund research*

The problems of limited knowledge and limited use are associated with low capacity, though this is by no means the only explanation.

Data collected by the Alliance provide a snapshot of the current situation with regard to institutional capacity.<sup>45</sup> Producers of HPSR are mostly small public and increasingly private institutions/units. On average, they have per annum three projects, eight researchers and a total project portfolio of less than US\$ 200 000. It is estimated that only 7% of projects receive financing of US\$ 100 000 or more, accounting for 54% of total project funding, with most projects funded at much lower levels. Direct funding from international sources accounts for 69% of total project funding, while national governments account for 26%. Experience, attainment of critical mass and stakeholder engagement are low, with only 19% of researchers trained at PhD level.

These data can be tentatively extrapolated to an estimated 650 HPSR producer institutions in low- and middle-income countries with which the Alliance has had contacts. There are an estimated 5500 researchers working in the field

of HPSR – of whom about 1000 have PhDs – and there are about 2000 HPSR projects under way. Annual project funding is estimated at US\$ 58 million, with international donors accounting for US\$ 39 million, governments for US\$ 16 million and private and other (national) sources for US\$ 3 million.

The US\$ 16 million which governments spend annually is much lower than the amounts that development institutions earmark for HPSR as part of their health lending to governments. The reason may be that this multilateral support for HPSR is either spent outside the country through contracting agencies in the North or is not spent in spite of being earmarked within development projects. Anecdotal evidence suggests that a large part may go unspent due to the low priority assigned to research by decision-makers, lack of capacity in country to undertake the competitive tendering required, lack of competitive bidders and/or inappropriate loan disbursing requirements on the part of development institutions.<sup>46,47,48</sup>

The estimated share of HPSR project funding relative to total health expenditure is estimated to be 0.007% for developing countries in general. The 1990 Commission on Health Research for Development recommended that total health research expenditure in the South should be 2% of national health expenditure. If HPSR accounted for a modest 5% of this total, HPSR should be 0.1% of total health expenditure. On this basis, current HPSR expenditure at 0.007% is 14 times below this norm.

<sup>45</sup> Gonzalez-Block MA and Mills A. "Assessing Capacity for Health Policy and Systems Research in Low- and Middle-Income Countries" in *Health Research Policy and Systems*, 1:1 2003.

<sup>46</sup> Yepes FJ et al. *Funding Research for Policy in Colombia's Reformed Health Sector*, Alliance HPSR, Working Paper No. 11, Geneva, 2002.

<sup>47</sup> Salem MA. *Policy Research in Egypt's Health Sector Reform*, Alliance HPSR, Working Paper No. 13, Geneva, 2002.

<sup>48</sup> World Bank. *Sector Strategy: Health, nutrition and population*, Washington DC, 1997.

A variety of grant mechanisms/instruments have been developed for implementing research strengthening activities including: institutional grants, partnership grants, research training grants, re-entry grants, workshops and small grants. In all cases, to be successful, capacity building should be research-based and respond to national needs and priorities.<sup>49</sup> So far, it has not been possible to identify from a cost-effectiveness point of view one approach or mechanism with maximum benefit/impact. Indeed, it is likely that multiple approaches are required, their impact being greater than the sum total of individual grants/mechanisms.

It is clear from Alliance analysis to date that HPSR producers need to increase their capacity and critical mass to engage effectively in policy debates and interaction with stakeholders, and to absorb a larger volume of resources. In addition, support needs to be provided for institutions to network, both nationally and internationally. Finally, capacity development must encompass research users from the start of the research process, in order to maximize chances that the research needs of policy-makers are met.

### **(c) Objectives and strategies**

The Alliance aims to promote the generation, dissemination and use of knowledge for enhancing health systems performance. More specifically, the objectives of the Alliance are:

- To stimulate the generation and synthesis of knowledge, encompassing evidence, tools and methods.
- To facilitate the development of capacity for the generation, dissemination and use of knowledge among researchers, policy-makers and other stakeholders.
- To promote the dissemination and use of

knowledge to improve the performance of health systems.

To reach these objectives, the strategies of the Alliance are the following:

- monitoring and publicizing the global progress of HPSR
- synthesizing, disseminating and funding research on priority areas
- encouraging the attainment of a critical mass of researchers in the field of HPSR
- promoting policy-relevant research and evidence-based decision-making
- ensuring widespread access to HPSR knowledge through effective communications strategies
- monitoring and evaluating progress in the Alliance partnership.

### **(d) Partners**

Key actors for the Alliance are policy-makers and service managers willing to integrate research into their daily work, researchers striving to apply their knowledge for health system and policy development, professionals in technical support roles to policy-makers, and investors funding health systems development and research. These actors are usually organized in autonomous institutions that require interfacing through mechanisms and institutions to ensure their most effective interaction.

To date the Alliance collaborates with 341 partner institutions in 88 countries. Insert 9.14.1 shows their distribution by region. About 28% of them are private institutions and 68% are research producers, while the rest are policy analysis and consulting units. Over half of them (55%) have less than 10 years' experience.

<sup>49</sup> Alliance HPSR. *Report on the consultation held in Bangkok (14 October 2000) and Implications for Capacity Strengthening*, Alliance HPSR, Working Paper, Geneva, 2000.

## Insert 9.14.1

### *Distribution of Alliance partners by WHO Region*

REGION	Percent
Africa	22
Americas	25
Middle East and Northern Africa	4
Europe	11
South East Asia	21
Western Pacific	15
International Agency	2
<b>Total</b>	<b>100</b>

#### **(e) Organization**

The Alliance Board (composed of up to 20 members) is assisted by an Executive Committee (five members selected among the members of the Alliance Board). The Secretariat is responsible for reaching the objectives defined by the Board within the given policies and budgets and reporting as appropriate to the Board and the EC.

#### **(f) Annual Budget and sources of financing**

Between 1999 and 2003, financial support to the Alliance has been provided by the Governments of Canada (IDRC), Norway (NORAD), Sweden (Sida/SAREC), UK (DFID), USA (US Agency for Healthcare Research and Quality), the World Bank and WHO. The total budget amounts currently to close to US\$ 2 million per year.

## **2. Main accomplishments in 2003**

### *Under Strategy 1: Monitoring and publicizing the global progress of HPSR*

A Biennial HPSR Review to advocate for HPSR as a tool for policy development at all levels of the health system is under preparation. In collaboration with WHO, a methodology to

assess the impact of research on policy was piloted and a study launched in six countries. The historical assessment of HPSR in the first Biennial Review will highlight that, in spite of significant growth, large gaps in understanding health systems, policies and interventions persist. Examples of how HPSR has influenced policy and practice will be highlighted to help advocate for greater demand, funding and utilization. The mechanisms and processes whereby HPSR is or can be brought to bear on policy will be reviewed with examples from diverse countries and situations. Special attention will be given to the role of bilateral and multilateral institutions in the demand for and utilization of research.

Using bibliometric techniques, HPSR literature trends in the last 10 years will be analysed and research gaps and imbalances identified. A review of research will be carried out, focusing on specific areas such as: the expansion of private services, decentralization, social insurance, user fees, community health insurance, management reforms and accountability. With the support of a survey, the review will also identify research priorities as defined by HPSR institutions in developing countries, their actual project portfolio and their research capacity.

### *Under Strategy 2: Synthesizing, disseminating and funding priority research*

During 2003, the Alliance followed up on the progress of 30 funded projects to support the generation of knowledge in high priority areas. A third call for research-to-policy studies was launched with the selection of 17 projects. Two multi-centric, strategic research projects were supported in Africa on the retention of human resources in rural areas. Six projects were seed-funded and technically supported in collaboration with IDRC to focus on governance, equity and health in Eastern and Southern Africa.

### *Under Strategy 3: Encouraging the attainment of a critical mass of HPSR researchers*

In collaboration with the Global Forum, COHRED and INCLIN, the Alliance supported the preparation of resource modules in the field of priority setting, advocacy, leadership and knowledge management. These were tested through four regional workshops as training and research development tools.

A call for applications was launched to strengthen the capacity of teaching programmes to address HPSR. The call aimed to increase the interest of students in research into health policy and systems, supporting dissertations in this area and to further the policy relevance of postgraduate HPSR teaching and dissertations. A total of 37 applications were received (Asia 15, Latin America and the Caribbean 14, Africa 4, and Europe and Central Asia 4).

### *Under Strategy 4: Promoting policy-relevant research and evidence-based decision-making*

An evidence and expertise search engine focusing on increasing the utilization of HPSR were launched as part of the Alliance Impact on Policy Web pages.<sup>50</sup> Besides the search engine, resources include relevant links, case studies and training resources. Consultations were undertaken to identify methods to facilitate the policy impact of HPSR through synthesis of knowledge.

### *Under Strategy 5: Ensuring widespread access to HPSR knowledge through effective communications strategies*

A book entitled *The new public/private mix in health: exploring the changing landscape*<sup>51</sup> was

published, seeking to give some examples of the ways in which developing countries are grappling with managing aspects of their mixed health care economies. The book contains a set of case studies organized around four themes: regulation of the private sector; public health roles of private providers; public/private mix in health insurance; the quality/affordability trade-off in public and private settings. In addition, the *Alliance Newsletter* is published three times per year and distributed to all Alliance partners.

### **3. Expected outputs for 2004**

Activities planned by the Alliance for 2004 include:

- promotion of strategic research on high priority issues
- in collaboration with IDRC, funding of two projects on governance, equity and health in Southern and Eastern Africa
- launch of the first issue of the Biennial HPSR Review
- assessment of the collaboration with regional HPSR networks and planning of a new phase of support for the next three years
- further analytical work on the interface between research and policy
- synthesis of HPSR results appropriate for the realities of the South as a means to promote evidence-based health policy development
- publication of the *Second Version of the Resource Modules* on priority setting, advocacy and knowledge management
- presentation of the results of the work of the Alliance at Forum 8 and the Ministerial Summit on Health Research, to be held in November in Mexico City.

<sup>50</sup> [http://www3.alliance-hpsr.org/asp\\_files/production/rtophomems.asp](http://www3.alliance-hpsr.org/asp_files/production/rtophomems.asp)

<sup>51</sup> Söderlund N, Mendoza-Arana P and Goudge J (eds.). *The new public/private mix in health – exploring the changing landscape*. Geneva, Alliance for Health Policy and Systems Research/Global Forum for Health Research, 2003.



## Section 15

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### Council on Health Research for Development (COHRED):<sup>52</sup> building research systems for health and development

#### 1. History of COHRED

In 1990, the Commission on Health Research for Development noted that decision-makers and communities often fail to recognize the value of health research. Health research is often considered to be irrelevant to local concerns and realities. As a result, research findings are either not made available – on time or in the appropriate format – or are rarely used in policy-making and health action. The Commission on Health Research for Development also highlighted the “gross mismatch between the burden of illness overwhelmingly in the Third World – and investment in health research, which overwhelmingly focused on the health problems of industrialized countries.”<sup>53</sup>

Based on the Commission’s recommendation to “encourage all countries to undertake Essential National Health Research (ENHR)”, a Task Force on Health Research for Development was established in 1990 to assist developing countries in implementing the ENHR strategy and to propose strategies for implementation of all other recommendations of the Commission. In 1993, the Task Force – led by majority membership of countries in the South and supported by key donors and institutions from the North – recommended the establishment of the Council on Health Research for Development (COHRED). This

recommendation was endorsed during the first International Conference on Health Research for Development (Geneva, 1993).

Over the past decade, COHRED has made a significant contribution to health and health research in the South by advocating for ENHR and by strengthening the capacity of countries to better prioritize and manage health research resources. Basing its approach on the participation of all stakeholders (not only researchers and research institutions) and on increasing the evidence base for health decision-making at all levels of the health sector, COHRED emphasized countries as the key actors in health research for development.<sup>54,55</sup> Many of the concepts pioneered by COHRED (ENHR; “countries first”; inclusive health research agenda setting and prioritization; increasing the accountability of health research; emphasizing the need for solid evidence to underpin health sector reform) have now become mainstream concepts.

In 1999, COHRED organized and facilitated extensive regional consultations aimed at reviewing global developments in health research 10 years after the publication of the report of the Commission on Health Research for Development. Through this process, the voice of countries – especially those in the

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<sup>52</sup> Adapted from a text contributed by Sylvia de Haan, Carel Ijsselmuiden and Lisa Myers, COHRED.

<sup>53</sup> Commission on Health Research for Development. *Health Research: Essential Link to Equity in Development*, New York, Oxford University Press, 1990.

<sup>54</sup> Neufeld V and Johnson N (eds.). *Forging Links for Health Research. Perspectives from the Council on Health Research for Development*, IDRC, 2001.

<sup>55</sup> COHRED. *Health Research. Powerful Advocate for Health and Development, based on Equity*, 2000 (Document 2000.2).

South – became the driving force behind the global discussion on the achievements of the decade, the challenges ahead and on ways to address these. The International Conference on Health Research for Development held in Bangkok in 2000 – a joint effort by COHRED, WHO, the Global Forum and the World Bank – was the culmination of these extensive regional and national efforts. The resulting action plan provided a framework for harmonizing and enhancing health research development efforts throughout the world, at both national and global levels, by focusing on the potential of health research systems to optimize the relevance and products of health research. Building on the principles of ENHR, COHRED has subsequently broadened its work to include the development and strengthening of effective national health research systems.

## 2. Reaching the Millennium Development Goals: the essential role of health research systems

Health care systems need robust health information if they are to understand and effectively address the health needs of populations, especially the poor and marginalized; to measure the costs and effects of interventions; and to assess and improve the performance and responsiveness of the system. Yet the use of health information for the management of health services at the local and district levels remains limited throughout the world. Very few countries in the South have developed effective, efficient and sustainable health information systems that take into account the needs of different levels of users at local, national and global levels. Much of the information collection and analysis done in the South is driven by vertical

health programmes, often in the context of international initiatives, and integration with national information systems is seriously lacking.<sup>56</sup>

After several years of emphasizing global and condition-specific health programmes and health research, there is growing recognition that strengthening national health systems (including health research systems) is a key component to achieving the health-related MDGs. Although the MDGs do not specifically deal with health systems strengthening (a fact that has drawn extensive criticism) it is becoming increasingly clear that in many low- and middle-income countries, the health-related MDG targets will not be attained or sustained without significant efforts to strengthen their overall health systems. A major focus on tackling health system constraints will be central to achieving the MDGs and many other health goals.<sup>57</sup> According to the UNDP, the inefficiency of some vertical programmes, which are often not well integrated in the general health systems of countries, is one of the reasons why the health goals of the MDGs currently remain out of reach for millions of people.<sup>58</sup>

The building and strengthening of effective national health research systems in the South is a crucial contribution to achieving health and effective and efficient health care. Effective national health research management in the South can ensure the compilation and analysis of existing health information and the production of relevant new knowledge; improve the management, dissemination and utilization of existing knowledge to and by all potential users; help

<sup>56</sup> WHO. *The World Health Report 2003: Shaping the Future*, Geneva, 2003.

<sup>57</sup> Ibid.

<sup>58</sup> UNDP. *Human Development Report 2003, Millennium Development Goals: A compact among nations to end human poverty*. New York, Oxford University Press, 2003.

prioritize areas for investment of scarce health sector funding; improve equity in the allocation of health sector resources; make the health sector more accountable; and become a nucleus around which communities, researchers, health, and academic institutions can grow in a sustainable manner. Insert 9.15.1 highlights some of the reasons for using a systems approach to health research.

Because national health research systems form part of national health systems (they are not limited to health systems but can also be parts of other systems such as the education or science and technology systems), it is appropriate to define the functions of health research systems in analogy with the functions of health systems as follows:<sup>59</sup>

*Financing* including revenue collection, fund pooling and purchasing. In terms of health research systems, the function of financing implies at least two aspects:

- Mobilization of funds for health research using all the mechanisms that are open to countries, including allocations from regular national budgets, grants and donations from NGOs, transfers from donor agencies, loans, competitive and international research budgets, private-sector research resources and line-item contributions as part of vertical health and development programmes.
- Allocation of revenues to institutional or individual providers of research, as much as possible in line with health priorities for the country or population concerned, and the conduct of associated accounting, monitoring and evaluation.

## Insert 9.15.1

### *Why use a systems approach to health research?*

- In many countries, health research is not well coordinated and often fragmented, resulting in inefficiencies, gaps and duplications. A more systematic and managed approach to health research can help to address these problems.
- Certain research questions or needs of the health system require collaboration and linkages between different research organizations and different disciplines. A research system can enhance synergies, ensuring that the total effect of national health research is more than the sum of individual efforts alone.
- In many countries – both in the South and North - health research is inadequately linked to the priorities and goals of the health system. There is a need for a more systematic approach to aligning health research to health priorities and to health system goals to optimize the impact of the scarce health and development funding available
- Many outputs of health research are not adequately translated into health system change nor into desired health and equity outcomes. A national research system can develop a more systematic application of research to policy, planning and care delivery, and encourage a more systematic link between researchers and the users of research.
- To develop national research capacity that can tackle national needs and become sustainable, there needs to be a far more systematic approach to research capacity development and to mobilization of resources to support this – again an essential result of approaching health research for development as a system rather than in the form of individual programmes.
- A key outcome of health research for development has to be equity in health and health care access. Without a system to focus on equity, this cornerstone of development will remain largely ignored.

<sup>59</sup> Murray CJL and Frenk J. “A Framework for Assessing the Performance of Health Systems” in *Bulletin of the World Health Organization*, 78 (6), 2000.

*Provision of services.* In terms of the health research system, this function refers in the first place to the generation of information and knowledge, both new and existing. In addition, for such knowledge to become useful, it should be shared with other researchers and communicated to the many different stakeholders in a manner that is conducive to the use of research findings: it needs to be translated into policy and practice or absorbed into the existing knowledge/technology base. This requires structural arrangements for the relationships between researchers (individuals and institutions) and also between researchers, research users and research funders, political authorities and communities.

*Resource generation* including personnel, facilities and knowledge. The health research system must take on the production, maintenance, improvement and retention of individuals, institutions and infrastructure required for the production, utilization and management of health research. Although other functions of the health research system imply capacity development, this function in particular requires an explicit and direct focus on capacity development. The health research system has to ensure the generation of the resources or capacities of individuals, institutions and infrastructure to provide relevant, understandable and timely research of high quality to the relevant partners.

*Stewardship* (going beyond the conventional notion of regulation). For a health research system, 'stewardship' encompasses a range of activities intended to ensure that health research systems demonstrate leadership, are productive, have strategic direction and operate in a coherent manner. Stewardship (or governance) in the context of health research can be divided into a number of distinct sub-functions. These include: strategic vision, overall system design and policy formulation;

priority setting; performance and impact assessment; promotion and advocacy; setting of norms, standards and ethical frameworks (sound practice) for the conduct of research; and networking.

### 3. COHRED's work

COHRED believes that a horizontal and systems approach to health research is essential for health systems development and is a key contributor to the development of better health for the poor and marginalized, both in the South and in the North. Therefore COHRED engages in any activity needed to enhance the performance of health research systems, especially of countries in the South. As an international NGO focusing specifically on health research systems building, it is led mainly by partners from the South with support from key partners from the North.

#### COHRED's vision

Attain a system of effective health research to improve health and development in all countries, based on the values of equity and social justice.

#### COHRED's mission

Work towards improving health and development by enhancing effective national health research systems, especially in developing countries (based on the ENHR strategy). This contributes to the development and strengthening of countries' capacity to manage research on priority health problems and utilize the results to improve the health of their populations.

#### (a) Main objectives

COHRED's objectives do not only reflect its concern with equity in health and health care access, and with the development of effective national health research systems, they also emphasize COHRED's role at the regional and global levels. Thus, COHRED advocates for a horizontal approach in international health

and health research initiatives, for an approach to international health research that strengthens national research systems, and for the consideration of national health research needs and priorities in global health and health research initiatives. The major objectives guiding COHRED's work are the following:

(i) *Supporting the development and strengthening of effective and sustainable National Health Research Systems.* COHRED partners countries in their continued efforts to characterize their national health research priorities and capacity, and in the development of strategies to increase the capacity of systems to be more effective and sustainable, and to reach more of their potential for improving health and equity. COHRED promotes exchanges of experience within and between countries while emphasizing South-South links and alliances. Special attention is paid to documenting and sharing experiences related to this objective through a communication process focusing on countries.

(ii) *Working for equity in health and health research.* COHRED strives to attain equity in health and in health research in the conviction that targeting equity is a crucial component of achieving optimal health and development. COHRED focuses on equity in health research systems and on promoting research on equity in health. The latter illustrates the organizational belief that any health research system, besides coordinating and facilitating health research, has a specific role to play in drawing attention to persisting inequities in health through stimulating research on these issues.

(iii) *Amplifying the voice and participation of countries in the South in global health research.* The Commission on Health Research for Development reported that 95% of global health research spending addresses conditions

that affect only 5% of the world's population. One of COHRED's tasks is to assist in reducing this health research inequity by providing a platform for health research in the South to help define solutions and advocate for these at global level.

(iv) *Strengthening cooperation at global and regional levels for health research systems development.* Establishing appropriate channels, operating principles and mechanisms for global and regional cooperation is critical to the development of health research in developing countries. COHRED builds on existing partnerships at regional and global level to support the strengthening of health research systems in countries in greatest need. Africa, Asia and Latin America all have nascent supra-national research forums to enhance inter-country cooperation and southern alliances. COHRED has been instrumental in their conception and remains a partner in their development.

**(b) Key strategies to achieve the objectives**

(i) *Networking and partnership building.* At the national level, COHRED promotes the conduct of "country consultations" as an instrument to assess health research systems in and by countries; to raise awareness and create commitment among relevant actors, including researchers, policy-makers, health care providers, representatives of communities and the media; and to jointly develop plans of action for strengthening health research at national and sub-national levels. Experience shows that such consultative processes greatly facilitate further collaboration between the interested parties in countries and ensure broad-based ownership of the processes and activities involved.

In addition to networking at national level, COHRED supports networking at sub-regional and regional levels. The principle of subsidiarity is applied – ensuring that

(sub)regional groups only undertake those activities that cannot be carried out effectively at country or institutional level. The Asian and African ENHR networks were good examples of this. Over recent years, these networks have evolved into the Asian and Pacific Forum for Health Research and the African Forum for Health Research respectively. Certain geographical and other realities may justify supporting sub-regional networks such as networks in francophone West Africa and in the Central Asian Republics. Barriers to accessing the anglophone research world and the absence of a joint health research history make a specific emphasis on networking among these groups of countries a worthwhile investment.

At international level, the Geneva-based COHRED Secretariat has developed partnerships with many other relevant health and health research organizations including WHO (both through its headquarters and regional offices), the INCLIN Trust, the Global Forum and its Alliance for Health Policy and Systems Research. The COHRED Board, the organization's policy-making body which is mostly constituted of members from the South, is instrumental in developing and maintaining these partnerships, especially with regional partners.

*(ii) Analysis, communication and advocacy.* To support and inform its work at country level, COHRED uses two main strategies. Firstly, the establishment of working groups on key issues of relevance to health research development. Working groups have been dealing with issues such as priority setting in health research; community participation in health research; linking research to action and policy-making; advocacy for priority health research; coordination of health research; monitoring of financial flows for health research; national health research system development; and monitoring and

performance assessment of national health research systems.

Secondly, the outcomes of the working groups have resulted in the publication of a large number of tools and documents (see COHRED's website: [www.cohred.ch](http://www.cohred.ch)). These publications are widely disseminated in print or electronically. COHRED's communication, information and advocacy activities are key to its work. It is through these activities that partners in the South will be enabled to assess and build their own health research systems, to advocate for increasing the evidence-base for decision-making in the health sector, and for modifying international and global health research to better suit the needs and priorities of the South.

### **(c) Key activities and achievements**

Through the ENHR strategy and the mobilization and support of country and regional networks, COHRED has contributed substantially to the building of health research systems in the South. Ten years after COHRED's inception, ENHR remains an important strategy to assist countries in optimizing the benefits from investments in health research. From just a handful of countries in 1993, ENHR has spread around the globe. Over the years, over 50 countries (Insert 9.15.2) have embraced the strategy and used it towards strengthening their own health systems and in defining health research priorities. In some countries, ENHR has been formalized through legislation, while in other country programmes and networks the underlying principles of ENHR have been applied without explicit reference to the strategy.

Furthermore, by providing a platform for countries and regions to voice their needs, concerns and ideas in international fora, COHRED has helped to promote equity in health research.

These last two strategies have in recent years led to the establishment of an increasing number of national health research fora (e.g. in Ecuador, Tanzania and the Philippines).

In addition, communication support is provided in the form of assistance in preparing publications, technical reports and learning materials. Advocacy for the ENHR approach has resulted in growing interest and commitment, ranging from explicit inclusion of ENHR in national health plans to the establishment of regional networks for inter-country cooperation.

To illustrate in more detail some of COHRED's recent work and the remaining challenges it faces, two major activities are highlighted below:

#### (i) National Health Research System development

The past decade of operations has involved working with a wide range of countries in describing and analysing their health research systems and in developing strategies to strengthen these. This has involved a wide range of different interventions. For instance, through a working group on national health research systems development, teams from Brazil, Cuba, Indonesia, Philippines, South Africa, Tanzania and Thailand have analysed their research systems and developed plans for their future development. COHRED provided both technical and financial support to these country teams. As the following examples show, this has led to some interesting developments.

- Decentralizing priority-setting in Cuba  
Despite its centralized system, Cuba focused

on involving all levels (municipal, provincial and national) in a discussion on the needs and priorities for further developing its health system through research. As a result, new priorities were identified, leading to the reformulation of ministerial (i.e. national and provincial) research programmes. A call for proposals was published, promoting inter-institutional cooperation and emphasizing the utilization aspects of research.<sup>60</sup>

- Adjusting the research agenda to health priorities in Brazil

Brazil has an impressive health research sector which is characterized by substantial human resources, reasonable infrastructure and high level of public funding, making it independent from external funding. However, it is facing the health problems of both developing and developed countries. In addition, it needs to find a balance between contributing to the advancement of global knowledge and adjusting the research agenda to the health priorities of the country. This led the Brazilian Ministry of Health to focus on developing a health research policy which includes the establishment of a priority research agenda aimed at better targeting the available resources but also contributing towards the growth of these resources.<sup>61</sup>

- Coordinating the health research effort in the Philippines

The analysis of the Philippine health research system illustrated the difficulties in coordinating all interested parties in the Philippines. In this case, the Ministry of Health and the Philippine Council for Health Research and Development both supported health research initiatives. However, there was no clear coordination between them and, as a result, duplications occurred. This analysis

<sup>60</sup> Martinez Torres E and Alvarez Blanco AS. *Technical report of the research project: Cuban national co-ordinated actions for improving efficiency in the NHRS* (Unpublished document (2003) available from COHRED, 11 Rue de Cornavin, 1201 Geneva, Switzerland).

<sup>61</sup> Guimarães R. "Directing Brazil's Health Research Resources towards Health Priorities" in *Research into Action*, COHRED Newsletter, Issue 33, 2003.

led to a commitment by key stakeholders to rectify this problem and establish a Philippine Health Research Forum which would provide a platform for exchange and coordination.<sup>62</sup>

One of the main benefits for all country teams participating in these projects was the opportunity for exchanging experiences. Despite obvious variations in national health research systems, certain common difficulties (e.g. dependency on external resources to conduct national health research) and opportunities (e.g. mechanisms for the coordination of the wide range of actors in health research, better utilization of existing and new knowledge for policy change) are shared by many countries.

#### (ii) Defining national health research agendas: opportunities and challenges

In addition to overall assessments of health research systems, COHRED also works with country teams on specific aspects of their health research system. These have generally been identified as high priority areas by national partners. Over the past few years the main focus has been on priority setting and monitoring financial flows for health research within countries. COHRED specifically focused on the strengthening of capacities to carry out this type of work.

Defining health research priorities is crucial for any health research system as it will help:

- focus scarce resources on research that will optimize health benefits and increase health equity;
- identify the human and financial resources for health research in the face of competing and overwhelming demands;

- strengthen the link between research, action and policy, so that health policy and related actions are firmly based on the best available scientific evidence.<sup>63</sup>

An increasing number of countries are defining their health research priorities to structure and coordinate their research efforts.<sup>64</sup> However, for these national priorities to be implemented, the global health research community needs to build on these priorities and use them to inform regional and global health research agendas.<sup>65</sup> By developing a well defined health research agenda, countries can be empowered when negotiating with international development agencies and research institutions. A challenge for the international community is to be responsive to these national needs. Other lessons learned from COHRED's work in priority setting and outstanding challenges include:

- *Priority setting as a country-specific activity:* Although there are certain general lessons to be learned from country experiences and issues to be addressed in any priority setting initiative, each country has to define its own way of setting health research priorities, and to adapt the tools for priority setting in a way that is acceptable and appropriate to its own culture, health system and health problems.
- *Priority setting as an evidence-based activity:* Lack of data and the poor quality of available information, particularly regarding the health system and the health research system, represent serious obstacles to evidence-based priority setting, leading to problems of reliability, credibility, and accountability.
- *Priority setting as a multi-stakeholder activity:*

<sup>62</sup> For more information on the Philippines Health Research Forum see: <http://www.pchrd.dost.gov.ph/healthforum2003/>

<sup>63</sup> COHRED. *Health Research Priority Setting: Lessons Learned*. Learning Brief 2002.6, 2002.

<sup>64</sup> See COHRED website for information on specific countries (<http://www.cohred.ch>).

<sup>65</sup> COHRED Working Group on Priority Setting. "Priority Setting for Health Research: Lessons from Developing Countries" in *Health Policy and Planning* 15 (2): 130-136, 2000.



Despite a growing consensus that science and research in general and health research in particular are owned by societies as a whole, and therefore a growing consensus about the necessity of involving many different stakeholders in the priority-setting process, 'community involvement' remains an often unresolved issue. Future priority-setting initiatives should make more explicit efforts to experiment with and document this aspect of the process.

- *Priority setting as a value-driven activity:* The ultimate goal of any health research priority-setting activity is to define an investment portfolio of health research and development with the greatest possible impact on the health of the majority of the population, in particular its poorer sections. While equity is included in most lists of possible criteria for priority setting, it is certainly not used effectively. Operationalizing equity as a criterion for priority setting deserves urgent attention and action.

To increase the usefulness of a priority-setting process, adequate knowledge on available human, logistical and financial resources is essential. By describing and monitoring national financing systems for health research, their adequacy in addressing country needs and priorities can be assessed. If conducted on a regular basis and if directly linked to priority-setting processes, resource flow data can be a powerful tool for advocacy at national and international levels. COHRED has therefore supported the development of a methodology for monitoring resource flows at national level<sup>66</sup> and has trained and supported researchers to conduct this work in their own countries (see chapter 5).

#### 4. The way forward

COHRED's future work will build on the key approaches, successes and lessons learnt in its first decade of work and will include:

- supporting countries in prioritizing and managing their own national health research for optimal impact on health, specifically of poor individuals, groups, and countries as a whole;
- providing countries with tools to implement ENHR, measure resource flows, communicate results and involve communities;
- defining health research not simply as a technical, compartmentalized activity, but as an essential aspect of social development that involves all stakeholders: not only researchers (i.e. from health, social and development sciences) and research funders, but also consumers, patients, community groups, politicians, academics and many others;
- defining the results of health research not as the end-points of studies but as the measured impact on health status, on health care access, on quality of health care, on equity in national and international health and, ultimately, on development.

In the future, increasing priority will be given to a number of new challenges faced by the national and global health research communities, such as:

- Key under-researched conditions and situations that are of great relevance to countries and to the South in general but that are of no political or financial interest to the major research funders in the North;
- Interaction of environment, health and development, as it is progressively becoming clearer that the people in the South will bear the brunt of global

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<sup>66</sup> Alano BP and Almario ES. *Tracking Country Resource Flows for Health Research and Development (R&D). A comparative report on Malaysia, the Philippines and Thailand with a manual on tracking country resource flows for health research and development*, Philippines Center for Economic Policy Research, 2000.

environmental damage while having the least research and other means available to modify its impact.

- Ethics of health research, not only in terms of the ethics of research studies and programmes, but also of the social justice, prioritization, ownership and benefit distribution aspects of local and international health and medical research.
- Promoting all aspects of research capacity assessments and development and selecting key partners to effect these. This will also include attempts to engage in public-private partnerships.
- Helping define and make the concept of national health research systems useful in practice in order to optimize investments in health.
- Strengthening the capacity of the South to have a more substantial influence on the global and international research agenda and on its implementation, including taking progressively more responsibility for funding and controlling research priorities in the South and its coordination and sustainability.
- Identifying new key partners in both the South and North to implement COHRED's goals.
- Lastly, research in a number of low-income countries largely depends on external funding. Two key challenges for the coming

years are: (i) conceptualising health research in the South as a key contributor to economic growth and development and to retention of highly skilled personnel, thus motivating more internal funding for health research; and (ii) increasing the overall funding available for health research in the South by accessing vertical and condition-specific intervention programme funding and international private and competitive research funding.

With the World Summit on Health Research in Mexico in November 2004, another key opportunity has been created for the global health research community to obtain high level political commitment for a common cause: the need for more and more relevant health research that can be used as a powerful advocate for health and development, if based on the principle of equity.

Building on its experience and its network, COHRED will continue working towards this cause. The current discussions around the role of health systems to reach the health-related MDGs form an important opportunity to raise the awareness of the need for relevant evidence to inform health systems in their decision-making. Transforming awareness into real action will remain a challenge.

## Section 16

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### Initiative on Public-Private Partnerships for Health<sup>67</sup>

#### 1. History of the initiative

##### (a) Central problem

The poor in developing countries are disproportionately affected by global diseases such as HIV/AIDS, TB and pneumonia, as well as tropical diseases such as malaria, sleeping sickness or river blindness.

While interventions exist to prevent or treat some of these diseases which account for the rich-poor differences in health status – either in the form of inexpensive off-patent medicines or new products – these products are not reaching those who need them. Strategies and infrastructure for appropriate delivery of existing products and health services has often been neglected in poor countries. WHO estimates that over half of the population in many poorer countries still have no access to the most basic essential medicines.

In other cases, there is a need to develop new products: ones to replace those whose effectiveness is threatened by resistance to drugs or insecticides, or ones better suited to developing country settings. Unfortunately, developing products for poor populations is commercially unattractive.

Reducing health disparities will require the capacities of both the public and private sectors, working collaboratively to:

- develop new drugs, vaccines or other health products to control these neglected diseases or conditions;

- devise and implement strategies that ensure the accessibility of poor populations to existing and new products and services;
- create environments conducive to product quality, appropriate use, sustainability and commercial viability, both nationally and globally;
- establish health as a central strategy for poverty alleviation and mobilize more resources for improving health.

While neither the public nor the private sector alone can eliminate health inequities, focused partnerships involving both sectors have the potential to contribute to their reduction. The potential of targeted, new approaches to solve hitherto intractable problems led to a marked increase in partnerships in general, in response to urgent needs. This in turn led to concerns about a number of key issues including:

- the relationship between targeted interventions and broader capacity strengthening efforts;
- the lack of communication (i) between the many new initiatives themselves and (ii) with the traditional players in international health;
- “partnership fatigue” arising from the need to engage with, and possibly fund, a much larger number of partnerships.

Against this background, the Initiative on Public-Private Partnerships for Health (IPPPH) was launched in 2000 to look at ways to optimize the benefits and minimize the

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<sup>67</sup> Adapted from a text contributed by the Secretariat of the Initiative on Public-Private Partnerships for Health.

potential negative consequences of public-private collaboration for health.

### **(b) Creation of the initiative**

IPPPH grew out of early efforts by the Global Forum to support and foster public-private collaboration to address the 10/90 gap by focusing on some high-burden diseases (e.g. partnerships such as MMV and IAVI) and also out of recognition by the Global Forum and the Rockefeller Foundation of the need for a more systematic response to catalysing effective public-private collaboration. Based in Geneva, the IPPPH Secretariat currently operates under the aegis of the Global Forum.

### **(c) Central objective**

The mission of IPPPH is to increase the effectiveness of public-private collaboration, particularly by helping those seeking to develop health products or to improve access to such products needed to fight neglected diseases and other health problems in developing countries.

### **(d) Main strategies**

To achieve its mission, IPPPH supports public-private partnerships through the following strategies selected in consultation with them:

- *Information services*: making available relevant and up-to-date information on individual partnerships (currently highly fragmented and dispersed) and their operational experiences to date.
- *Research and analysis*: providing health alliances with pragmatic answers to specific

challenges they face, to identify practices which maximize health returns on funds invested, and to minimize the potential risks associated with such alliances.

- *Communication and networking*: organizing the exchange of acquired knowledge and experience among partnerships and their supporters; promoting understanding between the public, private for-profit and private not-for-profit sectors; and encouraging the participation in collaborations of all potential contributors, including industry, public agencies and civil society.
- *Advisory services*: providing expertise and guidance on the formation of new public-private partnerships or improving the effectiveness of existing partnerships in areas including: organizational structure, governance mechanisms, sectoral characteristics and motivations, partner selection (involving referrals or linkages, where requested), phased development, operational features and financing options.

### **(e) Partners**

Created in 2000, IPPPH is sponsored by the Bill & Melinda Gates Foundation, the Global Forum for Health Research, the Rockefeller Foundation, DFID (UK) and the World Bank. It works actively with a large number of public-private partnerships. For a full list of public-private partnerships in the field of health and health research, searchable by purpose, disease, partner, funding, etc., see the partnership database on website [www.ippph.org](http://www.ippph.org).

## **(f) Organization**

The initiative's Advisory Board is composed of up to 20 members selected in their individual capacities from a range of constituencies: public health policy, multilateral institutions, research institutions, health sector industry, NGOs and foundations. The purpose of the Advisory Board is to guide the IPPPH Secretariat in establishing its strategic direction and implementing its activities. The Advisory Board functions under the legal umbrella of the Foundation Council of the Global Forum.

## **(g) Annual budget and sources of financing**

In 2003, IPPPH expenditure was slightly over US\$ 1 million. In 2004, it may reach US\$ 1.5 million (including designated support) in order to achieve the desired level of services to the public-private partnerships which are the clients of IPPPH.

## **2. Main achievements in 2002-2003**

Major activities conducted in 2002-2003 include the following:

### **(a) Information services**

- Expansion of the IPPPH Partnerships Database, which provides a single source of searchable information on about 90 health collaborations so far.
- Publication of a study by Sibongile Pefile: *Public-Private Partnerships for Access to Drugs for HIV/AIDS: Documenting the Early History of the Diflucan® Partnership Program and the Viramune® Donations Program*.

### **(b) Research and analysis**

(i) *Operational issues for public-private partnerships, including strategies for meeting challenges shared by partnerships engaged in product development or improving access to products*

- Publication of a DFID-funded study: *Impact of Public-Private Partnerships Addressing Access to Pharmaceuticals in Low-Income*

*Countries – Uganda Pilot Study*. This study in Uganda involved an assessment of the health and health systems impact of public-private partnerships for improving access to pharmaceuticals in relation to leprosy, lymphatic filariasis, onchocerciasis, sleeping sickness and HIV/AIDS. The aim was to examine issues of ownership, integration, coordination, implementation and impact, with a particular focus on the unique strengths and problems of these access PPPs compared with other programmes in which drugs are competitively procured.

- Another publication, *Valuing Industry Contributions to Public-Private Partnerships for Health Product Development* by Hannah Kettler, issued in May 2003, provides information on the contributions that private industry makes in pursuit of products to combat diseases of poverty prevalent in the developing world including HIV/AIDS, TB, malaria and Chagas disease.

(ii) *Guidance on best practices in the development and management of effective partnerships for health*

- A joint workshop was held with INSEAD Business School in Paris in June 2003 on *Partnerships for Developing World Health: Decision and Management Issues for Pharmaceutical Companies*. The report is available on request.

### **(c) Communications and networking**

(i) *Communication*

- Development of a new website including an expanded Partnerships Database, an online library of publications related to public-private collaboration and global health, relevant news updated daily and the Counterparts Network, a password-protected area where members can share information, questions and lessons with regard to their work.

- Development of *News Digest*, an electronic newsletter on neglected diseases and particularly items related to public-private collaboration to increase their impact.
- Publication of a report from a meeting in Arusha, Tanzania, in November 2002 on *Public-Private Partnerships Addressing Access to Pharmaceuticals: Lessons from Field Implementation in Selected Countries*. The report is available on request.

(ii) *Networking*

- Networking meeting: *Liability and Other Legal Issues for Organizations Engaged in Product Development through Public-Private Collaboration*, organized by IPPPH and hosted by the Rockefeller Foundation in New York (April 2003). The report is available on request.
- Preparation for Counterpart Networks to be hosted via IPPPH website.

(iii) *Advisory services*

- The number of requests for consultation continues to rise from various groups, including PPPs, donors, industry and management consulting companies.

### 3. Expected outputs for 2004

The planned activities for 2004 can be summarized as follows:

**(a) Information services**

- In 2004, IPPPH will continue its systematic effort to compile and compare approaches and experiences in public-private partnerships, and provide the information in the Partnerships Database. It will also document specific new partnerships to capture their early history and lessons, e.g. Coartem, Technology transfer for Multidrug-Resistant TB (MDRTB) Drugs, Foundation for Innovative New Diagnostics (FIND) and the Global Alliance for Improved Nutrition (GAIN).
- IPPPH will continue to expand its collection of materials on PPPs and related topics including 'grey literature', internal

and external evaluations, books and articles. Key materials will also be made available on the website.

- It will also provide customized responses to major client groups such as partnerships, funders and participants in partnerships.

**(b) Research and analysis**

(i) *Developments and trends in the field of public-private collaboration*

- Publication of a first major overview of public-private collaborations addressing developing country health problems: *Public-Private Partnerships Addressing Global Health Inequities: Towards Better Understanding and Defining their Contributions*.
- Background papers for a networking meeting on the financing of product development partnerships: *Combating Health Problems Associated with Poverty: Financing Strategies for Product Development and the Potential Role of Public-Private Partnerships*.

(ii) *Organizational issues for public-private partnerships, particularly in the areas of legal status, governance and mechanisms for balanced representation of stakeholders*

- Background papers for a networking meeting on optimizing governing boards: *Optimizing of the Role of Governing Boards in Operations of Partnerships for Health*.
- Analysis of the composition of governing boards in relation to the goals, role, responsibilities and accountability of public-private partnerships.

(iii) *Operational issues for public-private partnerships, including strategies for meeting challenges shared by partnerships engaged in product development or improving access to products*

- Paper commissioned on intellectual property management to ensure access to new products for poor populations, in preparation of a networking meeting.
- Completion of papers on 'Planning Production' and 'Product Pricing'.

- Development of studies on health and health systems impact of PPPs addressing access in three additional countries (Sri Lanka, Zambia and Botswana), similar to the DFID-funded study in Uganda. A report will be published in 2004.

(iv) *Guidance on best practices in the development and management of effective partnerships for health*

- Revision and expansion of the current IPPPH *Guidelines on Establishment and Operations of Public-Private Partnerships for Health* to include experience accumulated in recent workshops and studies. Guidelines would include specific recommendations for product development, product access, global coordination and other categories of partnership.
- Development of guidelines on best practices for major pharmaceutical companies: discussions with major pharmaceutical companies on terms of reference, feasibility, necessary participants and funding requirements for consensus development on what types of pharmaceutical company action on developing country health problems represent the best 'value' from a public health development perspective.

**(c) Communications and networking**

(i) *Communications*

- Continue and expand Internet-based communications activities:
  - Breaking News service on the website.
  - *News Digest*, electronically delivered to around 1300 recipients.
- Publication and/or dissemination of a number of IPPPH documents will be completed during 2004 including various reports and background papers from meetings as well as research projects (see above).

(ii) *Networking*

- Extend the Counterparts Network facility under the IPPPH website to include new groups, including PPP Chief Scientific Officers and Finance/Accounting Managers.
- A major meeting will take place in London in April 2004 entitled 'Combating Health Problems Associated with Poverty: Financing Strategies for Product Development and the Potential Role of Public-Private Partnerships'. The meeting is planned with the Rockefeller Foundation, Bill and Melinda Gates Foundation, Wellcome Trust, World Bank, WHO and DFID. A Follow-up Monitoring Group will be established from among key participants to continue discussions and develop conclusions and recommendations to be delivered after one year of follow-up activities.
- A working retreat is planned for May 2004 on 'Optimizing the Role of Governing Boards in PPP Operations'. The event will bring together chief executive officers and chairs of governing boards from the major, legally independent product-development partnerships. A Follow-up Monitoring Group will be established from among key participants to continue discussions and develop conclusions and recommendations to be delivered after one year of follow-up activities.
- Subject to availability of resources, a further networking workshop may be convened on the topic 'Intellectual Property Management for Ensuring Access to New Products for Poor Populations'.

**(d) Advisory services**

Continue to provide consultation and support to various groups on request, including new and established partnerships, funders in particular bilateral agencies and foundations, and potential participants in collaborations, including industry.

The technical support given by COHRED to countries in the process of health research system capacity building includes a variety of country-level strategies such as:

- setting priorities for national health research (processes supported in over 30 countries; the COHRED website provides country reports of this work);
- engaging communities in setting national research agendas;
- building capacity for health research management – through workshops and the provision of tools and manuals, but also through providing support for developing capacity development strategies;
- monitoring resource flows for health

research (supported studies in 10 countries);

- monitoring and evaluation of national health research systems through: (i) support of studies to define national health research profiles (in over 10 countries); (ii) national consultations (i.e. the consultations prior to the International Conference on Health Research for Development in 2000 in which over 60 country teams participated); and (iii) the development and dissemination of tools;
- supporting networking and coalition building;
- strengthening coordination of health research.

## Insert 9.15.2

### *COHRED's work with countries*

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Since 1993, COHRED has worked with the following countries in strengthening national capacities to attain effective health research systems:

#### **Africa**

Benin, Burkina Faso, Burundi, Cameroon, Egypt, Ethiopia, Ghana, Guinea, Ivory Coast, Kenya, Malawi, Mali, Mauritius, Mozambique, Nigeria, Senegal, South Africa, Sudan, Swaziland, Tanzania, Uganda, Zambia, Zimbabwe

#### **Asia and Pacific**

Bangladesh, Cambodia, China, India, Indonesia, Iran, Lao PDR, Malaysia, Myanmar, Nepal, Pacific Islands (i.e. Fiji, Vanuatu), Pakistan, Philippines, Thailand, Vietnam

#### **Caribbean and Latin America**

Barbados, Brazil, Chile, Colombia, Cuba, Ecuador, Jamaica, Mexico, Netherlands Antilles, Nicaragua, Trinidad and Tobago

#### **Eastern Europe and Central Asia**

Azerbaijan, Hungary, Kazakhstan, Kyrgyzstan, Tajikistan, Uzbekistan

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## Executive Summary

### Chapter 1 A message to ministers of finance: health and health research are possibly the best economic investments

Ill health has a major impact on the economic situation and well-being of *an individual in any society*. This is particularly true in the lower income countries (where social safety nets are weak or non-existent) and for the absolute poor, due to the vicious circle of poverty and ill health.

Conversely, improvements in health will boost the individual's level of income (due to lower treatment costs, higher revenue, a longer term increase in revenue due to better work opportunities, and overall growth in revenues due to longer life-expectancy); increase the individual's capacity to acquire an education; increase the family's productive opportunities; and greatly improve the psychological well-being of both the individual and the family. The benefits of good health will be even greater for the absolute poor, as they may transform the vicious circle of poverty into a virtuous circle, with better nutrition, lower risks of unemployment or underemployment, better housing, better use of training opportunities, higher productivity and, overall, better control over their life situation and that of their family.

*For an economy as a whole*, ill health means irrecoverable losses in production; a less well trained labour force as education and training opportunities are missed by those who are sick; larger health budgets; lower productivity in general; a less competitive economy; lower profitability of enterprises; higher labour force turnover and disruption in the national

budget. In the long run, ill health will threaten the survival of the less competitive enterprises as well as the country's ability to attract foreign investment. Employment opportunities in the economy will be lower, increasing the number of unemployed.

Conversely, improvements in health will bring substantial benefits for the economy. These include an increase in production, a better trained and more productive labour force, a more competitive economy, financially more solid enterprises, lower unemployment and a lower rate of disease transmission.

Although the overall process is complex and difficult to quantify, even conservative estimates suggest that health investments often yield the highest rates of return compared to other public investments, as shown by examples such as investments in combating smallpox, polio, onchocerciasis and malaria, where rates of return may reach more than US\$ 10 for every dollar invested. This is a multiple of even the highest rates of return in other sectors of the economy, where a return of US\$ 1.2-US\$ 1.5 for every dollar invested is more the norm (without taking into account the large deficits experienced in some sectors following huge investments, e.g. in the heavy industry, tourism or transportation sectors).

There is therefore both a strong political and economic rationale for governments to invest more in health and health research, as recommended by the Commission on Macroeconomics and Health in its December 2001 Report. This Commission, *recognizing the high rates of return on investments in health for both the individuals and the countries concerned of at least US\$ 3 for every dollar invested*, recommended an 80% increase in

the health budget of low-income countries between 2001 and 2015 and a seven-fold increase in donor assistance to these countries for health over the same period.

In view of the major contribution that health can make to the development of the national economy, why are governments not investing a larger proportion of public resources in health? The main reasons are:

- a traditional reluctance to apply concepts of rates of return on investments in health, which meant that the health sector never had the chance to *demonstrate* its considerable contribution to economic growth and development;
- the complexity of the calculations (due to the large number of variables involved);
- the fact that until recently both governments and individuals have considered health to be a consequence of the development process, rather than one of its main engines;
- the fact that health ‘pays’ as an investment only if a number of key conditions are fulfilled in relation to management, efficiency, effectiveness and equity.

The concept of development has evolved considerably over recent decades, from a focus on physical capital in the 1960s and 1970s, to a greater focus on human capital in the 1980s and 1990s, and finally to the present Millennium Development Goals adopted by the United Nations in September 2000, which focus entirely on poverty, health, education, the environment and development partnerships. In these first years of the new millennium, a distinction is finally being made between tools (economic growth) and ultimate objectives (human development and human security).

The shift in focus, in particular since 1990, is so fundamental that it amounts to a revolution in the concept of development,

with health, education and environment now at the forefront of development efforts. As a result, a large number of so-called “vertical initiatives” (such as the Global Polio Eradication Initiative, the Global Fund to Fight Tuberculosis, AIDS and Malaria, the WHO “3 by 5” Initiative, the Roll Back Malaria Partnership and the Global Alliance for Vaccines and Immunization) and “horizontal initiatives” (such as the revival of the primary health care movement, the Poverty Reduction Strategy Papers (PRSP) process, the follow-up actions to the Report of the Commission on Macroeconomics and Health, and the human rights movement) have been launched or accelerated in the 1990s. Although the multiplicity of these initiatives can sometimes cause confusion, *these developments are extremely positive and a good illustration of the shift from physical to human capital in the pursuit of the MDGs.*

However, this revolution in development thinking will remain a “paper revolution” and the MDGs will not be reached by 2015, unless the following conditions are fulfilled:

- the vertical and horizontal initiatives referred to above should be well coordinated at country level in order to avoid the risk of duplication, optimize the results and maximize their synergies;
- a reallocation of resources within national budgets and international development assistance should be made at country level to ensure increased funding for health (as recommended by the Commission on Macroeconomics and Health), education and environment, in proportion to the key contributions of these sectors to development;
- since our present stock of knowledge, both at the global and national levels, is insufficient to reach the MDGs or to reach them efficiently by 2015, it is crucial that governments increase their health research budgets to at least 2% of national health

expenditures (as recommended by the 1990 Commission on Health Research and Development).

## Chapter 2

### An overview of the Global Forum for Health Research

One of the critical roles of health research is to ensure that measures proposed to help break the vicious circle of ill health and poverty are based, as far as possible, on evidence, so that the resources available to finance them are used in the most efficient and effective way possible.

Despite this critical role, health research has suffered from an overall lack of funding and from a huge discrepancy between the allocation of research funding and the diseases or conditions that account for the highest global disease burden. For the past decade, following the ground-breaking work of the Commission on Health Research for Development in 1990, this discrepancy in health research funding has been captured in the expression “the 10/90 gap” – drawing attention to the fact that of the US\$ 73 billion invested annually in global health research by the public and private sectors, less than 10% is devoted to research into the health problems that account for 90% of the global disease burden (measured in Disability-Adjusted Life Years or DALYs).

The overall objective of the Global Forum is to help correct the 10/90 gap in health research and focus research efforts on the diseases and risk factors which account for the highest disease burden worldwide yet receive relatively little funding for research.

Efforts to correct the 10/90 gap require the commitment of thousands of institutions and individuals in the North and South. They include government decision-makers,

research institutions and universities, multilateral and bilateral agencies, private foundations, private-sector companies, NGOs and the media. Since all of them have an impact on the 10/90 gap they are each considered to be partners in the Global Forum and most of these constituencies are represented on the Foundation Council. No attempt is made to establish formal “membership” of the Global Forum as such, not only because of the practical difficulties involved but also because many of the institutions, for different reasons, would not become members, yet continue to have a large impact on the 10/90 gap. The aim is rather to create a movement for the correction of the 10/90 gap in which partners concerned about the very serious consequences of such misallocation of resources contribute in very different ways to the overall objective.

*One of the strategies of the Global Forum in helping to correct the 10/90 gap is the organization of an Annual Forum meeting. The main results of the Annual Forum meetings over the past seven years include:*

- a systematic review of progress in correcting the 10/90 gap
- a regular exchange of views on work undertaken to establish a methodology for setting priorities in health research
- an annual report on the work of major networks engaged in efforts to correct the 10/90 gap
- regular discussions on cross-cutting issues in the field of poverty, gender and research capacity strengthening as they relate to the 10/90 gap in health research
- annual presentations of new perspectives on the 10/90 gap in health research
- discussion and definition of priority actions needed for the continued correction of the 10/90 gap
- linkages with larger periodic conferences, such as the Bangkok Conference on Health

Research (2000) and the forthcoming Mexico Summit (2004).

*A second strategy is the development of a methodology for setting priorities in health research.* Results to date include the development of one such methodology, called the Combined Approach Matrix, and its application to a number of diseases and risk factors, both at the global and country levels. Chapter 4 outlines the development and application of the Combined Approach Matrix (CAM) while Chapter 5 focuses on the measurement of resource flows and the 10/90 gap.

*A third strategy of the Global Forum is communication and information about the progress made in correcting the 10/90 gap in health research,* through publications, a website, media contacts and participation in key international conferences.

*A fourth strategy involves measuring results* through the monitoring of progress indicators and periodic external evaluations. The most recent external evaluation was carried out in 2001 and the next is scheduled to take place in 2006.

The Global Forum Secretariat is supported by contributions from the World Bank, the Rockefeller Foundation, WHO (in kind) and the governments of Canada, Denmark, the Netherlands, Norway, Sweden and Switzerland. In addition, individual networks supported by the Global Forum receive funding from donors including the Bill and Melinda Gates Foundation, the Institute of Medicine of the US Academy of Sciences (IOM) and the UK Department for International Development (DFID).

Correction of the 10/90 gap can be achieved. But it will depend on the individual and combined efforts of thousands of institutions.

This achievement will provide a major contribution to growth, development, the fight against poverty and global security. The Global Forum works as a catalyst to spur such efforts and to monitor results on a regular basis. With the efforts of all partners, it is not unrealistic to anticipate a substantial correction of the 10/90 gap in the next ten years.

### Chapter 3 Correcting the 10/90 gap: from the 1990 Commission to the 2004 Mexico Summit

Since 1990, a number of reports and international conferences have focused on the 10/90 gap and made a number of key recommendations on ways of establishing priorities for health research funding:

- In 1990, the Commission on Health Research for Development first identified the 10/90 gap and made far-reaching recommendations for its correction;
- In 1996, the Ad Hoc Committee on Health Research made 17 recommendations on infectious diseases, new and re-emerging microbes, noncommunicable diseases (NCDs), health policies and systems, and institutional arrangements;
- In 2000, the first International Conference on Health Research for Development in Bangkok adopted the Bangkok Action Plan with important recommendations for the correction of the 10/90 gap at the global, regional and national levels.

There is a remarkable consensus between the 1990 Commission, the 1996 Ad Hoc Committee, and the 2000 Bangkok Action Plan on the actions needed to correct the 10/90 gap. All three reports focused on the following five main recommendations, (which led to a number of key developments in the 1990s and early 2000s):

### *The need to correct the 10/90 gap and set priorities*

From a totally unknown concept in 1990, the existence of the 10/90 gap is now widely recognized. Progress has been made in the field of priority setting with the application of the Essential National Health Research (ENHR) approach (with support from the Council on Health Research for Development) and the CAM developed by the Global Forum for Health Research.

The challenges for the coming years are the following:

- The objective should be to move from a 10/90 gap today to a substantially improved situation in 10 years' time.
- Priority-setting exercises are still limited to a few countries and institutions and a major effort is needed to ensure that all countries and institutions base their resource allocations on the burden of diseases, the main determinants of health, and social justice.
- Few priority-setting exercises for health and health research systematically take into account key actors and factors beyond the biomedical field (i.e. the individual, behavioural and community dimensions; sectors other than health which have a profound effect on the health status of a population; and macroeconomic policies); these dimensions need to be systematically included in the priority-setting exercises in the future, to ensure the most effective and efficient use of the limited resources available for health research.
- A major effort will be needed to more systematically link the international and national health research agendas.

### *The need to build up the capacity of health research systems in developing countries*

A number of countries have succeeded in building a substantial research capability and are active partners in international health

research. However, a systematic review of the results achieved over the past 10 years and the creation of a "facilitation unit" (as proposed by the 1990 Commission) for developing health research capacity in the least developed countries should be part of the priority agenda for the coming years. Moreover, a systematic comparison should be made between research capacities and priority health problems at the national level, so as to enable countries to ensure the best match between the two.

### *The need to create international research networks and public-private partnerships*

Remarkable progress has been made in recent years in the development of international collaboration to solve major global health problems: between 1995 and 2003, more than 70 public-private partnerships and networks were created (as compared to about a dozen in the 1980s) particularly in the fields of HIV/AIDS, TB, malaria, leishmaniasis, schistosomiasis, pneumococcal disease, sexually transmitted infections (STIs), dengue, meningitis, human trypanosomiasis (sleeping sickness), nutrition, road traffic injuries, health policies and systems, cardiovascular diseases (CVDs), cancer and mental health.

The challenge for the future will be to ensure their continued viability, efficient delivery of products and strong linkage with the national health systems, and to systematically reinforce the positive links and mutual support between the horizontal and vertical partnerships and networks.

### *The need to increase funding for health research by developing countries*

All three reports recommended that developing countries substantially increase their health research budgets to ultimately reach the target of 2% of national health expenditures. They also recommended that

international development agencies invest 5% of their health budget in health research and capacity building. However, a study undertaken by the Global Forum for Health Research and other institutions found that only Brazil and Cuba approached the 2% mark. Most other countries invest only a fraction of the 2% recommended (see also Chapter 5). Very limited information is available on investments in health research financed by international development agencies as a proportion of their health budget.

A systematic effort is needed in the coming years to measure the allocation of health research funds by disease and by health determinant for all countries and institutions, based on the first preliminary efforts undertaken over the past few years. Furthermore, the work of the Commission on Macroeconomics and Health should be systematically pursued at country level to document the high benefits for each country and for the world as a whole of prioritizing health research at the global, regional and national levels and of redirecting health research from low- to high-priority projects.

#### *The need to create health research forums to monitor progress in health research*

The 1990 Commission and the 1996 Ad Hoc Committee recommended the creation of an independent forum for investors in international health research to monitor the progress made in the correction of the 10/90 gap. The 2000 Bangkok Action Plan went further and recommended that this central forum for health research be complemented by regional as well as national health research forums. Following the creation in 1993 of the Council on Health Research for Development (COHRED) to advocate for the ENHR strategy and the Global Forum for Health Research in 1998 with a mandate to “help correct the 10/90 gap”, the following actions were taken:

the Asia-Pacific Health Research Forum was created in 2000 (followed by the South Asian Forum for Health Research in 2003, as a special chapter of the Asia-Pacific Health Research Forum). The African Health Research Forum was created in 2002. Numerous collaboration meetings have been held in the Central and Latin American region, as well as in francophone Africa and Central Asian countries. At the national level, a few countries (e.g. Ecuador and Tanzania) have launched a National Health Research Forum.

However, the regional and national health research forums are still at a very early stage and will require support from the international community, both financially and technically. These are great challenges for the coming years but very promising investments.

## Chapter 4: Priority setting in health research

### *The need to set priorities*

The process of setting priorities in health research is as critical as conducting the research itself. Since the funding available for health research is low in comparison to its very high potential benefits, it is essential that it is based on a rational priority-setting process.

The failure in almost every country to establish a process for priority setting based on the burden and determinants of diseases has led to a situation in which only about 10% of global funding for health research from all sources is devoted to 90% of the world's health problems (measured in DALYs). To make matters worse, the 10% of research funds available are not even used as effectively as they could be and need to be better prioritized.

In everyday life, setting priorities is a difficult process. This is even more so in the field of health research, where a very large number of different factors and actors enter into the equation. The use of a sound methodology and a scientific process are critical to ensure the identification of the research priorities which will make the greatest contribution to people's health. Thus, in order to make the results as objective as possible, i.e. as representative as possible of the priorities of a local community, a nation or the global population, it is essential (i) to adopt a priority-setting process which is as transparent and participatory as possible, and (ii) to apply a methodology which is as scientific as possible – even though both are costly in terms of the financial and human resources needed.

#### *The various methodologies for setting priorities developed in the 1990s*

Since the Commission on Health Research for Development in 1990, priority-setting exercises have used various methods and processes. This chapter reviews priority-setting methodologies (process and methods) used by the Essential National Health Research Task Force (1991), the Ad Hoc Committee on Health Research (1996), the Advisory Committee on Health Research (1997), the National Institutes of Health (US), the Human Reproduction Programme of WHO and the Global Forum for Health Research.

#### *The methodology of the Combined Approach Matrix (CAM)*

In proposing the CAM in 2000, the Global Forum attempted to combine the main advantages of the various methodologies for priority setting proposed in the 1990s, in particular those proposed by the ENHR approach, the Ad Hoc Committee on Health Research and the Advisory Committee on Health Research. The developments in the

methodology over the past three years are presented in Section 3, while Section 4 deals with the concrete application of the matrix for identifying priorities. Section 5 discusses the technical issues surrounding the economic dimensions of priority setting.

In summary, the Combined Approach Matrix is a tool (i) to help classify, organize and present the large body of information which enters into the priority-setting process; (ii) to identify gaps in health research; and, on this basis, (iii) to identify health research priorities, using a process which should include the main stakeholders in health and health research. The prioritization process in health research should encompass all factors affecting people's health, i.e. not only basic, biomedical, clinical and laboratory research, but also health systems, demography, social and behavioural sciences, economics, management, macroeconomic policies and sectors other than health which have a major impact on health in the country.

*The process of the Combined Approach Matrix*  
Health research priorities should be established by local communities, based on the local burden of disease and determined through a participatory process involving the use of scientific tools. National authorities should then identify the national health research priorities, based on information about the national burden of disease and the results of the priority-setting exercises of the local communities, again through a participatory process and the use of scientific tools. The definition of the national and local priorities and actual research activities should be the result of an iterative process between the two levels, the ultimate result being based on comparative advantages. International organizations and institutions with a global remit should then identify global health research priorities, based on the global burden of disease and the national priorities defined

by as many countries as possible, using a participatory process and scientific tools. Here also, the definition of the global and national health research priorities should be the result of an iterative process between the two levels, the ultimate result being based on comparative advantages.

Examples of the application of the CAM methodology are reviewed in the chapter. It has been applied both at the global level and country level (India, Pakistan) and for both diseases and risk factors.

Priority setting is a long-term effort. The information will inevitably be partial in the first exercises, probably even sketchy in some cases, but the tool should demonstrate its usefulness at an early stage by highlighting the most important gaps in the information needed to make the best possible use of the limited resources available for health research in order to have the largest possible impact on people's health (i.e. the largest number of healthy life-years saved) for a given research budget.

## Chapter 5 Progress in measuring the 10/90 gap

### *Measuring resource flows*

Although a crucial input for setting priorities in health research, there is very limited information about resource flows for health research and little awareness of the usefulness of such information. Major obstacles are the lack of financial and human resources as well as the lack of tested methodologies for monitoring spending on health research at the country level.

In 1999, the Global Forum and partners embarked on a project to collect information with the goal of improving priority setting through developing a database of

internationally comparable statistics on global resource flows for health research. The results of the first phase of this project were reported in the Global Forum publication *Monitoring financial flows for health research* which tracked resources for the year 1998.

The report estimated that global funding for health research (private and public sources) amounted to at least US\$ 73.5 billion in 1998 (i.e. about 2.7% of total health expenditures worldwide). National governments invested at least US\$ 37 billion (50% of the total) and the pharmaceutical industry US\$ 30.5 billion (42%). Private, non-profit and university funds provided the remaining US\$ 6 billion (8%). At the country level, only Brazil and Cuba approached the level of 2% of national health expenditures recommended by the Commission on Health Research for Development, with most low- and middle-income countries investing well under 1%.

In relation to the second phase of the study, the 2001 Report of the Global Forum recommended research in the following four areas:

- measure resource flows in additional developing countries and countries in transition;
- encourage the entities already compiling health statistics to pay detailed attention to the monitoring of health research investments;
- periodically obtain disaggregated data from large investors in developed countries including ODA agencies, foundations and pharmaceutical companies;
- ask partners with established interests and expertise in specific diseases to do periodic studies of resource flows for the high-burden diseases.

The Global Forum and partners are currently updating the information on financial flows for health research. The results are expected to be available at Forum 8 and the World



Summit on Health Research in November 2004 in Mexico.

In their efforts to improve the information on R&D investments in health research, the Global Forum and its partners have attempted to standardize the methodology. This effort will require national “champions” who are able to build an informed constituency bringing together producers and users of such data.

#### *Measuring the 10/90 gap*

The ultimate objective of measuring resource flows in health research is to make a judgement as to whether the limited research resources are allocated in the most efficient and effective way, *given the major health problems affecting a country or the world as a whole*. Although there has been no comprehensive review of financing flows relating to disease burden for all diseases, the evidence available indicates huge discrepancies between the burden of diseases and the allocation of research funds.

While research intensity is quite high for diseases that occur in both rich and poor countries, it is very limited for diseases that occur exclusively or predominantly in low- and middle-income countries. For example, of the 1233 drugs that reached the global market between 1975 and 1997, only 13 (1%) were for use in combating tropical infectious diseases, which primarily affect the poor. These differences are important in view of the fact that 85% of the world’s population live in low- and middle-income countries.

As a result of the demographic and epidemiological transitions experienced in low- and middle-income countries, these countries stand to benefit increasingly from the research undertaken in high-income countries. However, the direct transferability of findings from high-income countries to

low- and middle-income countries is limited.

Although substantial progress has been made in the understanding of the 10/90 gap and a number of strategies have been developed since 1990 to combat the problem (see also Chapter 3), the 10/90 gap in health research persists. Very determined efforts by all governments will be needed in the coming years to correct it through efforts to: (a) systematically link investments in health research to the burden of disease, both at the national and global levels; (b) establish strong links between basic research and the development of remedies for high-burden diseases and risk factors; and (c) invest research funds in improving the functioning of health systems and services.

The establishment of an International Health Statistics Institute would provide a means to develop standardized methodologies and working definitions across the various institutions and countries; collect and collate information received on a routine basis; produce reports and disseminate information; and act as a partner for capacity building at national and international levels.

## Chapter 6 Gender, the MDGs and health research

### *Gender and development*

The Global Forum believes that a systematic approach to gender issues must be a central part of its strategy to help correct the 10/90 gap. It is estimated that around 70% of the world’s poor are women. The health of these women is often adversely affected not only by their poverty but also by the gender inequalities that continue to divide many of the world’s poorest countries. In response, the Global Forum is committed to achieving greater gender sensitivity in all its work.

However, efforts to ensure greater gender sensitivity in health research do not relate exclusively to women. Men's health too is affected in fundamental ways by both their sex and their gender. Unless these differences are taken seriously, the delivery of public health services will be severely constrained – both in their efficacy and their equity.

### *Sex and health*

The biological differences between women and men are reflected in the health problems they experience. Some of these stem from male and female reproductive functioning, with women facing major hazards as a result of their capacity for pregnancy and childbearing. This gives them 'special needs' for care, which have to be met if they are to realize their potential for health. Other conditions not directly connected with sexual or reproductive functioning are nonetheless sex-specific because they affect particular organs (cancers of the prostate and cervix, for example).

Over one third of the years of healthy life lost by women in developing countries are caused by reproductive health problems, especially those related to pregnancy and sexually transmitted diseases. The most immediate indicators of this burden are maternal mortality and morbidity rates. Around 600 000 women die each year as a result of pregnancy and childbearing and many times this number are permanently disabled. The immediate cause of these huge losses is lack of access to effective sexual and reproductive health services, especially in rural areas. However they also reflect more basic social and economic inequalities between women and men.

### *Gender and health*

Beyond biological differences, differences in the living and working conditions of men and women, in the nature of their duties, and their entitlement to resources will put women and

men at differential risk of developing some health problems while protecting them from others. As well as being a major determinant of health, gender also influences the access of individuals to health care and the quality of the treatment received.

Sex and gender are major determinants of health in both women and men. They are closely linked with other variables such as age, race and socioeconomic status in shaping biological vulnerability, exposure to health risks, experiences of disease and disability, and access to medical care and public health services. Researchers who ignore these differences run the risk of doing bad science. Failure to incorporate sex and gender in research designs can result in failures of both effectiveness and efficiency.

### *Gender and the Millennium Development Goals (MDGs)*

In September 2000, 189 nations adopted the United Nations Millennium Declaration, an ambitious document affirming the right of every human being to development and laying out a path towards freedom from want for every woman, man and child.

The MDGs explicitly acknowledge that gender can have a major impact on development, helping to promote it in some cases while seriously retarding it in others.

Overall, it is clear that the MDGs cannot be reached without an explicit, coordinated and systematic focus on the gender dimension of all MDGs. Gender equality is not just one goal, but also a means to achieving each goal. Without a fully integrated gender perspective in the reporting, campaigning, analysis and implementation of policies and strategies developed towards achieving the 2015 target, the MDGs will not be realized and governmental commitments made through the United Nations will remain unfulfilled.

The specific MDG on gender equality (Goal 3: promote gender equality and empower women) has been integrated in a single target calling for the elimination of gender inequality in all levels of education by 2015. Many have pointed out that access to education is an important signpost for gender equality. But as the Beijing Platform for Action recognized, there are many other dimensions of gender equality (or “critical areas of concern”) that are equally crucial and need to be addressed. The United Nations and civil society should ensure that the wide-ranging commitments made in the Beijing Platform for Action and the 1979 Convention on the Elimination of All Forms of Discrimination against Women remain on the political agenda.

One of the main challenges facing the inclusion of gender in all processes leading to the achievement of the MDGs is to ensure that the system of national MDG reports takes national commitments to women into account.

## Chapter 7 Research capacity strengthening: progress and perspectives

Research capacity strengthening (RCS) is one of the most important activities in the correction of the 10/90 gap. RCS plays a central role in the process of identification of needs, the selection of priorities and the development of research strategies that are most appropriate and relevant to improving health in individual countries, particularly in low- and middle-income countries.

The Report of the Commission for Health Research and Development (1990), the World Bank’s World Development Report (1993) and the Report of the WHO Ad Hoc Committee on Health Research published in 1996 were unanimous in concluding that high-income countries have benefited greatly from the

increase in knowledge and the advancement of technology derived from scientific research. However, due to limited research capabilities, many developing countries have been unable to benefit to the same extent and develop their own solutions to the problems confronting them. To ensure that the focus and relevance of the research is maintained, the work is best done within the countries and by the country nationals themselves. Efforts to build up national and regional capacity should contribute much to establishing a science culture at country level, and enabling developing countries to build a critical mass of able and qualified scientists who can undertake research on the priority health problems of the country and participate in the broad international research agenda. This will constitute a crucial step in correcting the 10/90 gap in global research funding.

Despite over three decades of efforts to build up capacity, during which thousands of scientists from developing countries have been trained, most of the expected breakthroughs have not happened. Large numbers of trained scientists are not working in their countries of origin. Building and retaining indigenous capacity for health research must move centre stage, as this is vital for sustainable development.

Some of the major gaps and deficiencies in research capacity strengthening in many countries include the following: low priority for research; inadequate efforts towards prioritization of research problems; limited impact of RCS on the improvement of policies and the functioning of health systems; limited use of existing knowledge; less than optimum use of the limited human resources; and limited monitoring and evaluation of results.

Ideally, a health research system (and the efforts undertaken for its capacity strengthening) should aim at the following

specific objectives: advocate higher priority for research; identify national health research priorities; translate health research into action; systematically apply existing knowledge; develop an efficient and effective research environment; and systematically monitor and evaluate the results of the system and of its strengthening.

The Global Forum attaches much importance to RCS as a means to help correct the 10/90 gap, and in the coming years will explore ways in which it could contribute to the greater efficiency and effectiveness of RCS efforts along the following lines:

- *Design a framework for defining RCS needs and impact:* interested RCS partners should join forces to further articulate the definitions, discuss the challenges and future strategies, and develop an evaluation framework for RCS.
- *Establish a network of RCS partners as a platform for debate, synthesis, measurement of results, and advocacy:* given the lack of a systemic and collaborative approach to RCS efforts, it is important to develop platforms (networks) for debate, synthesis, measurement of results and advocacy for RCS. At the regional and national levels, there is a particularly important role to be played by the Regional and National Health Research Forums in support of the RCS agenda. The Global Forum will seek opportunities to discuss with its partners the development of a RCS agenda at the national, regional and global levels.
- *Funding RCS efforts:* to be successful, such efforts require a strong political commitment from national governments and international donors. National and international financing of RCS efforts should be included in the ongoing discussions on an international health research fund.
- *Supporting efforts to develop an enabling environment for RCS:* RCS partners

should help developing countries create favourable policies and conditions for the development of sustainable health research systems.

## Chapter 8 Information networks in health research: an overview

An editorial in the *Bulletin of the World Health Organization* (December 2003) highlighted the progress made during the last 25 years in both health and information technology, pointing out that the world as a whole had made “tremendous strides in life expectancy and disease control, together with an explosion of information technology and techniques.” However, the editorial drew attention to the fact that large sections of humanity have been cut off from this progress, not only as a result of the ‘digital divide’ but also by a ‘knowledge divide’. This chapter looks at both sides of this communication gap.

### *The digital divide*

The digital divide describes the inequality of access to information and communications technologies (ICTs) such as the Internet, e-mail and satellite telephone systems. In December 2003, the World Summit on the Information Society (WSIS) drew world attention to the digital divide in seeking to “foster a clear statement of political will and concrete plan of action to shape the future of the global information society and to promote the urgently needed access of all countries to information, knowledge and communication technologies for development.”

The WSIS event attracted 11 000 participants (including 11 heads of state) from 176 countries who endorsed a Declaration of Principles and a Plan of Action. The Summit sought commitment to bring together the

public and private sectors with civil society to establish ICTs as a priority. The WSIS Plan of Action sets important goals for bridging the digital divide, including connecting all villages, schools, hospitals and governments with ICT by 2015 and ensuring that at least half the world's people are within reach of ICT. The roles and responsibilities of all stakeholders, including government and the private sector, are laid out in the plan.

#### *The knowledge divide*

While ICTs have great potential for bridging the digital divide, additional action is needed to bridge the knowledge divide, e.g. information networks and mechanisms to ensure that the information is actually shared and used by the population which currently has no access to that knowledge. Information must be accessible in both directions: just as researchers in the South need to be able to access and contribute to journals published in the North, equally researchers in the North need access to knowledge sources in the South. Bridging this divide is so important that this sharing of knowledge is recognized as a prerequisite for achieving the Millennium Development Goals by 2015.

The WSIS Action Plan lists a number of important actions to be taken in the coming years to bridge the knowledge gap, including the promotion of collaborative efforts by governments, health professionals and international organizations for creating reliable, timely, high quality and affordable health care and health information systems and for promoting continuous medical training, education and research through the use of ICTs (article 18).

Very substantial efforts have been made in recent years in this respect by two different groups: (a) publishers who have offered developing country users online access to the full text of priced journals for free or at low

cost and free online access to aggregations of full-text journals or parts of these journals; (b) networks of scientists who have offered information on their specialized websites (see Inserts 8.2 and 8.3 for selected listings).

The activities of the following three global networks of particular relevance to the Global Forum's own work on the 10/90 gap and to the objectives and targets of the MDGs are presented in the chapter:

- Health InterNetwork Access to Research Initiative (**HINARI**) facilitates free or low-cost electronic access to published information (in journals) in biomedicine and related social sciences.
- International Network for the Availability of Scientific Information (**INASP-Health**) provides a network promoting increased access to information for health care providers and researchers in developing countries and countries in transition.
- Scientists for Health and Research for Development (**SHARED**) makes possible sharing of information on projects, people and organizations as well as searching for and matching specific terms between linked databases.

In 2004, a global initiative – entitled 'Information for effective healthcare in developing countries: a global review of progress and ways forward' – will mobilize stakeholders in the health information field with the aim of reviewing and synthesizing lessons learned and developing an agenda for future actions.

## Chapter 9 Some networks in the priority research areas

The chapter reviews some of the priority areas recommended in chapter 4, describing the size of the problem and the results of efforts to

build networks which focus on these priority areas (including their objectives, partners, governance, strategies and activities).

Since it would be impossible to review all research efforts currently under way, this chapter describes the efforts undertaken by international networks in only some of the priority research areas. Some of these efforts were supported by the Global Forum for Health Research, others not. They are categorized into four groups:

**A** Networks focusing on diseases and conditions

1. Global Alliance for Cancer Control
2. Global Alliance for TB Drug Development
3. HIV/AIDS
4. Initiative for Cardiovascular Health Research in Developing Countries
5. Medicines for Malaria Venture
6. Mental and Neurological Health

7. Multilateral Initiative on Malaria
8. Reproductive Health
9. Road Traffic Injuries Research Network
10. Roll Back Malaria Partnership
11. TDR

**B** Networks focusing on determinants (risk factors)

12. Child Health and Nutrition Research Initiative
13. Sexual Violence Research Initiative

**C** Networks focusing on priority-setting methodologies

**D** Networks focusing on policies and cross-cutting issues

14. Alliance for Health Policy and Systems Research
15. Council on Health Research for Development
16. Initiative on Public-Private Partnerships for Health