### E7 | Essential health research

Research has played a central part in improving health and health care over the centuries. In the past few decades, the growth in new technologies and the generation of new knowledge in the physical sciences has been unsurpassed. At the same time, however, and in stark contrast, millions of people lack access to the most basic medical technologies. The discipline of 'health research', and the accompanying institutions of research, have to be harnessed to address the fundamental challenges of poor health and widening health care inequities.

A report by the Commission on Health Research for Development (COHRED 1990), which had been created by a group of 16 donors from Europe, North America, Asia and Latin America, identified health research as essentially linked to equity in development. To evaluate progress in equity-promoting health research, this chapter looks at what has been achieved since 1990, including plans and declarations from the International Conference on Health Research for Development held in Bangkok in 2000 (jointly initiated and organised by COHRED, the Global Forum for Health Research, WHO and the World Bank); the Ministerial Summit on Health Research held in Mexico in 2004 (organised by WHO); and the eight annual meetings of the Global Forum for Health Research held since 1997 (when the Forum was established as an independent international foundation).

Do governments recognize the links between health research and development? Are they taking steps to foster relevant research in their countries? Do governments and donors allocate sufficient resources to health research? Are 'national health research systems' strengthened or forgotten by global initiatives that have budgets many times greater than those of the countries in which they operate? Does the tremendous increase in international initiatives and private investments in health research help the poor? Is research being used to combat the underlying political and economic causes of widening health disparities within and between countries?

In 1990, the Commission on Health Research for Development noted that only 5% of global investment in health research was devoted to problems faced primarily by developing countries, even though these countries carry over 90% of the global burden of disease – a disparity that has become known as the 10/90 gap. It made four major recommendations that can serve to assess developments in health research since 1990:

# Box E7.1 Essential national health research and national health research systems

The core of an essential national health research (ENHR) strategy is to promote research on country-specific problems that could underpin national and community decisions on health policy and management. It involves researchers, decision-makers and community representatives, who jointly choose the priorities to be addressed. It is aimed at improving the effective use of existing knowledge and technologies. Country-specific research may have limited transferability to other countries or situations, but it guides the wise use of internal resources and strengthens national sovereignty. It places a country in a much stronger position to judge and, if necessary, seek adjustments to external development assistance. Furthermore, it gives each developing country an informed voice in establishing priorities for research on the global scientific agenda (Commission on Health Research for Development 1990).

For health research to be more effectively aligned to meeting national health priorities, a health research system is needed to plan, coordinate, monitor and manage health research resources and activities.

Health research systems exist to plan, coordinate, monitor and manage health research resources and activities in a way that promotes effective and equitable national health development. It is a concept that 'integrates and coordinates the objectives, structures, stakeholders, processes, cultures and outcomes of health research towards the development of equity in health and in the national health system' (WHO 2002). The concept has been delineated in terms of several components of a system including stewardship; financing; values and ethics; roles and functions; capacity and resources; and strategies for strengthening health research systems.

- all countries should undertake essential national health research (ENHR)
   (Box E7.1);
- international partnerships to address priority health research questions should be strengthened;
- funding for research focused on the health problems of the South should be increased and sustained;
- · an international mechanism to monitor progress should be established.

#### Developing national health research capacity

Although some progress has been made with implementing the ENHR strategy (Neufeld and Johnson 2001), consultations with various international and national stakeholders leading up to the 2000 Bangkok Conference (International Organizing Committee 2001) revealed several limitations:

- health research was still not sufficiently valued by national leaderships as an investment in development.
- research systems in general, and health research systems in particular, were often poorly organized and managed.
- many countries lacked a critical mass of researchers, a lack that was often part of a wider problem of inadequate human capacity.
- skills development was mainly focused on the 'supply side' (researchers and research institutions) rather than enhancing the capacity of 'users' of research (e.g. policy-makers and community groups).
- research has not often been translated into policy or action.

In evaluating efforts made to implement the recommendations of the Commission on Health Research for Development, the Bangkok Conference also concluded that:

- a much stronger Southern voice was needed to counter the dominance of Northern institutions over global health research.
- research needed to shift from knowledge generation to knowledge management.
- countries, as units of policy, financing and governance, are key to having an impact on health and development through health research – this led to the concept of a 'national health research system', developed further by WHO and other partners (Box E7.1)
- a more unified and inclusive approach was needed to increase synergy and reduce fragmentation.

Four years later, the 2004 Mexico Ministerial Summit on Health Research addressed some of the shortfalls identified at Bangkok and ensured that a high-level ministerial discussion on health research took place for the first time. A major theme of the discussion was the need to bridge the gap between what is known about how to improve health and what is actually done to change policy and practice – the 'know-do' gap.

The Mexico Summit also emphasized better communication, information-sharing and knowledge dissemination as a means of improving national health research capacity, especially in developing countries. One important

development was a proposal to establish a global register of all clinical trials, aimed at reducing the selective (and biased) publication of trial results, particularly by the for-profit pharmaceutical sector (Dickerson and Rennie 2003, Dwyer 2004). The idea is gaining support from editors of respected medical journals who will not now publish the results of trials that have not been registered (DeAngelis et al. 2004).

One drawback of these initiatives to expand access to scientific knowledge, however, is that they could make 'Northern knowledge' more accessible to developing countries – knowledge that may not only be of limited use or applicability in developing countries (Rochon et al. 2004, Obuaya 2002) but also may reinforce the general Northern bias of the health sector. Southern knowledge, including traditional and tacit or informal knowledge generated through experience, remains mostly inaccessible and undervalued, partly because there are substantial obstacles to publishing the work of Southern researchers (Saxena et al. 2003, Keiser et al. 2004, Horton 2003). Mechanisms being developed to redress the balance, including SHARED and the Forum

## Box E7.2 The value of national health research capacity in low and middle-income countries

- Brazil discovered Chagas disease: Carlos Chagas discovered American trypanosomiasis in 1909.
- India developed oral rehydration therapy: H N Chatterjee published the first human study of ORT in 1953.
- Chile led contraceptive development: Jaime Zipper Abragan and Howard Tatum developed the first copper intrauterine contraceptive device in 1969.
- China developed the treatment of malaria: Chinese researchers isolated the plant extract, artemisinin, from a traditional fever remedy in 1972.
- Sudan changed its malaria treatment protocol: the country used national research on resistance to chloroquine.
- Cuba developed the first meningitis B vaccine: Gustavo Sierra and Concepción Campa published the first randomized controlled trial of their meningitis B vaccine in 1991.
- Thailand built up evidence for health systems development: health research and good research management played a pivotal role in reforming the Thai health system over the past decade, and are considered central to efforts to implement, monitor and evaluate further reforms.

for African Medical Editors (Certain 2004), deserve greater support and should go hand-in-hand with the recognition that the South has produced important research (Box E7.2).

Important efforts are also being made to strengthen national capacity in research ethics and in the review of research proposals. But capacity-building for ethics reviews tends to be driven by a goal of speeding up research and minimizing 'ethical problems' when engaging in international health research. As a result, 'just enough' is done to get international trials reviewed but few resources are made available to generate efficient, sustainable national systems or independent regional mechanisms for continued local capacity development.

The statement issued by the 2004 Mexico Summit reaffirmed the need to strengthen national health research systems, to establish and implement national health research policies, and to support evidence-based public health and health care systems (WHO 2004). Disappointingly, however, it defined national health research systems as 'the people, institutions, and activities whose primary purpose is to generate relevant knowledge adhering to high ethical standards, which can be used to improve the health status of populations in an equitable way'. This definition emphasizes 'generators of knowledge' – researchers – while implicitly diminishing the importance of those demanding and potentially using research such as policy-makers, health managers and civil society. This may reflect the tendency for conferences on health research to be dominated by researchers and their needs. Researchers themselves have to ensure that their research is designed and managed in ways that will bridge the 'know-do' gap (see Box E7.3).

#### **International partnerships**

The second recommendation of the Commission on Health Research for Development in 1990 focused on establishing research partnerships and networks, in the belief that the right mix of expertise, commitment, local knowledge and excellence could result in progress. Partnerships between researchers in South and North should not only be mobilized around priority health problems, but should also strengthen the health research capacity of developing countries.

A number of so-called global alliances has been set up in recent years, including the Multilateral Initiative against Malaria, the European and Developing Country Clinical Trials Partnership, the Global Alliance for Vaccines and Immunization, and the International AIDS Vaccine Initiative, as well as WHO programmes for research and training in tropical diseases and human

#### Box E7.3 Bridging the 'know-do' gap

Much of the discussion at the 2000 Bangkok International Conference on Health Research for Development and the 2004 Mexico Ministerial Summit on Health Research focused on the constraints on researchers. However, several issues about the nature and practice of research itself need to be examined as well (McCoy et al. 2004):

- research cultures and incentive systems have changed so that they now
  encourage researchers to be more concerned with publishing their results in academic journals than with ensuring that their research leads
  to better policy and practice. Reversing this trend may require changing
  how research is evaluated and rewarded, as well as allocating more funding to academic and non-government research institutions in poorer
  countries that work closely with policy-makers, health managers, service
  providers and communities.
- there should be more funding for action research that involves service
  users and providers and that ensures that research is embedded in
  ordinary people's day-to-day contexts and practices (including the fact
  that health care systems are in a state of collapse in some countries). The
  use of participatory research methods can also help poor communities
  shape health systems to meet their needs.
- implementation of health research needs to be aided by a vigorous community of civil society organizations keeping a watch on health policy development and implementation; on the use of research funds to foster civil society's capacity to change the commissioning and priority-setting of research; and on the inclusion of civil society interests in research production and partnerships with academic researchers.
- the capacity of policy-makers, health managers and practitioners needs to be developed to appraise and make use of new information.

reproduction. Collectively these alliances are driven by the research excellence of the North and a focus on a selected number of diseases that cause high levels of morbidity and mortality. While potentially helping to reduce the 10/90 gap, they need to be monitored to ensure that they are not biased towards the development of medical technologies produced by Northern institutions at the expense of, say, health systems research that would directly strengthen the capacity of health services in developing countries.

Neither the consultations leading up to the 2004 Mexico Summit or the Summit itself yielded much progress towards effective research partnerships for health equity and development. Moreover, the dynamics of partnerships that would strengthen the research capacity of developing and transition countries are inadequately understood (KFPE 2001). The statement issued by the Summit does not explicitly address the building of South-South and South-North partnerships to help overcome the barriers to implementing ENHR and to strengthen national and regional health research systems. Global alliances focused on major diseases will be effective only if accompanied by a broad country-based approach to research and research development. An emphasis on piecemeal, disease-based research, rather than on the development of coherent and comprehensive research-systems, mirrors the emphasis on vertical disease programmes at the expense of health systems development, discussed in chapter B1.

At the heart of effective partnerships lies a shared perspective on excellence, relevance and good governance, and a commitment by the Northern partner to emphasize equality in the partnership (Maselli et al. 2004, IJsselmuiden et al. 2004, Chandiwana and Ornberg 2003). But there is as yet no evidence of widespread application of these principles. Most partnerships are implicitly Northern-driven, with few South-South partnerships that have demonstrated any impact.

#### Increased and sustained funding

The 1990 Commission's third recommendation is probably quoted most often: at least 2% of national health expenditure and 5% of health sector project and programme aid from donor agencies should be earmarked for health research and strengthening research capacity. Despite widespread awareness of this recommendation, funding to support essential health research remains scarce, especially at national levels.

Global spending on health research and development more than tripled between 1990 and 2001, but most of it was spent by high-income countries in high-income countries, with the aim of generating products and technologies tailored to high-income health care markets (Global Forum 2004). The lack of interest in funding regional health research developments, including regional networking and partnerships, is a further problem. In Africa, it has proved very difficult to generate effective and equitable research networks, thereby perpetuating the continent's dependence on North-South links for technology transfer.

Country-specific data indicate that some, but not all, developing countries

already invest substantially in health research. However, most of the money is used to maintain the (inadequate) research infrastructure and to pay researchers' salaries (Murray et al. 1990, Kitua et al. 2002, COHRED 2004). Resources to conduct research are therefore reliant on external funds, giving foreign donors an undue influence on the health research agenda of developing countries.

The growth of the huge global initiatives and alliances also erodes countries' control of their most scarce and valuable research resource: expert staff. Many countries are hard pressed to integrate even one vertical programme into their national health research system. This could lead to further fragmentation of Southern research systems as the number of these initiatives grows.

Evidence suggests that current (published) research carried out in developing countries responds not to national needs but rather to global funding availability, and that research in developing countries is not responsive to future health needs (Nakahara et al. 2003, Farley 2005). To correct this, health research funding will have to strengthen the national research management capacity in the South, and to ensure more appropriate health research.

Building health research capacity is a long-term effort requiring sustained financial support over at least 25 years, if not more (KFPE 2001). The challenge is to ensure sustained research funding in the light of the rapidly-changing short-term interests of political, governmental and private donors.

#### International monitoring

The Commission's last recommendation was the establishment of an international mechanism to monitor progress and to promote financial and technical support for research on the health problems of developing countries. This has not been achieved. Instead, new but uncoordinated research initiatives and programmes conceived and funded largely in the North mushroomed during the 1990s.

From a Southern perspective, this fragmentation has made access to funding and expertise in health research for development more difficult and more confusing: there are now many small organizations, each focusing on a narrow, specific aspect of health research for development.

The creation of an alliance of national research councils to form an international institute of health, proposed by the US National Institutes of Health (NIH) in 2002, is one approach to the development of an international architecture for health research. A few national health research councils and other interested parties are discussing it but so far without much progress. While this may help provide greater coordination and collaboration internationally, there are concerns that, again, it could strengthen the influence of Northern-

#### Box E7.4 Asking the social-political research questions

Health research should address the widening inequalities in health and their causes. This requires applying a political lens to research on the more fundamental determinants of health by asking questions such as the following:

- how can health equity be protected from the effects of the current pattern of unfair and unequal economic globalization and the largely unregulated operation of transnational commercial interests?
- why has odious debt not been cancelled? (Odious debts are those contracted by a country without its people's consent and not spent in their interests, of which the creditor is aware.)
- why do many rich countries' development assistance allocations fall short of the UN's 0.7% GDP target?
- why are bilateral and multilateral trade agreements unfavourable, and even punitive, towards the sickest and poorest people?
- who and what are the drivers and effects of the liberalization, segmentation and commercialization of health care systems?

based institutions such as the NIH on research and research systems in developing countries.

The 2000 Bangkok Conference attempted to reduce fragmentation and build consensus among key players. The Conference itself was a collaborative effort of four major players (Commission on Health Research for Development, the Global Forum for Health Research, WHO and the World Bank) and a steering committee of 37 interested organizations. Four years later, however, the Mexico Summit, organized by WHO alone, was less inclusive, marking a step backwards.

#### **Recommendations**

Health research and development has progressed to a certain extent since 1990. One important development has been the recognition that health is central in development. A second, reflected at the 2004 Mexico Summit, is the political interest in health research for development.

Other developments, however, may detract from this progress. The current general focus on the Millennium Development Goals (MDGs) is too narrow and pays insufficient attention to key social, economic and political determinants of ill health and inequity (Box E7.4). The Goals are unlikely to be met in the

poorest parts of the world, and reflect a Northern look at Southern problems, proposing global solutions without sufficiently acknowledging the diversity of nations or local factors. To counter this, a stronger emphasis is needed on capacity development for 'horizontal' health research, so as to increase the capacity of a country to deal with its own priority health problems and to negotiate the balance between local and global priorities. Implicit in this is the need for greater efforts to improve South-South and South-North partnerships and a commitment to fund and strengthen the voice and capacity of the South.

Other issues that may counter any progress are the enormous growth in private sector health research in the South, mostly from pharmaceutical companies, and the effects of intellectual property rights and trade laws on health and health research (see the more detailed discussion in chapter B2). Neither the Bangkok Conference nor the Mexico Summit adequately addressed these issues, even though the pharmaceutical industry is now the single largest contributor to health research funds in the South – by 2000, its investments were worth over US\$ 3 billion. To the best of our knowledge, there has been no concise assessment of the impact on this shift in research funding on research infrastructure, training, ethics, equity and development: it is urgently required.

On a more positive note, it has been increasingly recognized over the past two decades that a strong civil society is a cornerstone of democracy, progress and health (Edelman 2005), not least because of its watchdog function. The role of civil society in health research was recognized at the 2004 Mexico Summit, but was not acknowledged in the final Ministerial statement. Regular review of progress with international declarations, statements, financing, practice and other efforts will be key to the advocacy needed to make health research beneficial for everyone.

This chapter has aimed to outline positive and negative trends in health research in recent years. It concludes with some suggested indicators to measure progress in future:

- national health research systems progress towards impact and self-sufficiency.
- partnerships for health research progress toward equitable partnerships, and their impact on national health priorities.
- health research funding progress towards strengthening local research capacity and addressing national health research priorities.
- effects of health research funded by the private sector understanding its benefits and harms, globally and nationally.

- global architecture for health research governance progress towards better but equitable coordination.
- knowledge management and sharing progress towards increased access to and utilization of knowledge from North to South and South to North.
- health systems research progress towards developing methodologies, building capacity, and implementing research on health system performance.
- effects of health research related to MDGs understanding of potentials and limitations, globally and nationally.
- impact on health documenting and measuring the impact of health research (from any source) on health, health equity and development in the poorest countries.

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