

Goodness and ethics
in biomedical research *of relevance to*
developing countries:

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The normative system of biomedical research:

From a science ethics point of view medical research may be defined as systematic and socially organised:

- (a) search for,
- (b) acquisition of, and
- (c) use or application of medical knowledge and insight brought forth by acts and activities involved in (a) and (b).

First observation:

The great advantage of an *action-theoretic model* of science is that it makes visible the complex matrix of norms and values that are involved in doing research. These norms and values fall into three different groups:

- internal norms,
- external norms and
- linkage-norms.

Second observation:

Another advantage of an *action-theoretic model* of science is that it makes clear that scientific and technological research is a result of *co-production* and *co-evolution* between different stakeholders

- within the scientific and technological communities, as well as
- between stakeholders in the scientific communities and stakeholders in society at large.

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Possible forms of abusive *planning*
and
search for health-related data and
knowledge:

First observation:

As to the question whether there exist forms of search or planning of research that deserve the label of ‘abusive search’, the norm of *freedom of inquiry* favours a negative answer, in the sense that any prohibition in this early stage of planning and design of a research project seems unjustifiable. A tendency therefore, is to relegate the issue of *forbidden knowledge* to the second phase of research, i.e. to the acquisition phase of scientific inquiry.

Second observation:

The monstrous inequity in the world with respect to who's diseases are favoured in ongoing or planned research programmes hints, however, at the need for a different answer:

«In 1996, ... it was estimated that approximately 56 billion US Dollars was being spent annually on medical research and that at least 90% of this sum was devoted to the health needs of the richest 10% of the world's population. Therefore, the needs of 90% of the world's population have to be met from 10% of research funding. Infectious diseases, such as malaria, are responsible for more than half of the premature deaths among the poorest 20% of the world's population but only 7% of deaths among the richest 20%, who are more likely to suffer from conditions such as cerebrovascular disease and ischaemic heart disease» (British Medical Association, 'Research and Experimentation on Humans', *The Medical Profession & Human Rights. Handbook for a changing agenda*, 2001, p. 228).

Third observation:

In WHO's report on *Macroeconomics and Health: Investing in Health for Economic Development*, this problem is dealt with in considerable detail, and a *research* strategy intended to reduce the gross inequity with respect to health and economic development is also proposed:

The underlying argument permeating the report is that investment in health and essential health services in poor countries and in countries with low levels of income will not only reduce the disease burden in these countries, it will also generate economic growth and human flourishing. In turn, economic development will enable these countries to cope better themselves with their health problems. Such a «global strategy for health» will, however, not be possible without a global medical science policy and research strategy that takes into account the particular research needs of these

countries (World Health Organisation, Report of the Commission on Macroeconomics and Health, Geneva 2001).

Fourth observation:

Four such research needs are identified in the report:

- «operational research at the local level» to learn «what actually works, and why or why not»;
- «a significant scaling up of financing for global R&D on the heavy disease burdens of the poor», such as HIV/AIDS, malaria, tuberculosis, childhood infectious diseases and micronutrient deficiencies;
- «reproductive health», including research to block perinatal transmission of HIV; and
- epidemiological research.

Fifth observation:

If these arguments prove to be valid, then it seems reasonable to draw the conclusion that countries not willing to contribute to this global research strategy for health and economic development should be held accountable for lending support to gross human rights violations in the name of biomedical and health-related research.

On sharing of benefits:

”Benefits resulting from any scientific research and its applications should be shared with society as a whole and within the international community, *in particular with developing countries*” (Article 15, para 1, 'Sharing of benefits', Universal Declaration of Bioethics and Human Rights, 2005, emphasis mine).

First implication:

Even when biomedical research is conducted in developed countries the Member States of UNESCO have committed themselves to share the benefit of this research, *in particular with developing countries.*

Second implication:

For a global strategy for health to become true it is not sufficient to develop a global medical science policy and research strategy that takes into account the particular research needs of these countries.

What is needed in addition is the development of national research policies in the richer part of the world that include sustainable plans for how the benefits resulting from national research programs may be shared with developing countries.



How could developed countries assist
in the co-evolution of a fair and global
policy on scientific literacy and
benefit-sharing?

First tentative answer:

By focusing the attention on ways of involving stakeholders from *developing countries* in the design, conduct and evaluation of national research programs:

- academic stakeholders
- members of National Bioethics Committees
- policymakers

Second tentative answer:

By giving priority to national research programs that aim at forms of benefit also transferable to developing countries.

Third tentative answer:

By giving priority to national research programs that aim at investigating the role and risks of respect for cultural diversity and pluralism in the design, conduct and evaluation of national research programs.

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Concluding observations and remarks:

First remark:

An underlying argument throughout this presentation has been that there is a need for some sort of international instrument or forum to bring evidence to the global community about the gross inequity in the world with respect to who's diseases are favoured in ongoing or planned research programmes and with the responsibility to develop a medical science policy and research strategies aimed at meeting the particular research needs of poor and low-income countries.

Second remark:

Such a forum could also serve as an instrument to monitor on-going research to safeguard communities and populations in those countries from being exploited in the name of biomedical research and medical treatment.

Third remark:

Personally, I believe a forum aimed at uncovering the political and structural deficiencies generating inequities in the world with respect to health related research and treatment would be more needed than an international tribunal aimed at targeting human rights violations committed by individual researchers.

Fourth remark:

For such a forum to be able to function in a pro-active way close collaboration with national health-authorities as well as with international bodies such as the UN, UNESCO, WHO and the World Bank would be important.

Fifth remark:

In the WHO report on *Macroeconomics and Health* two proposals are put forward that seem to prefigure the idea of creating such a forum. For a first, the establishment of *National Commissions on Macroeconomics and Health* in developing countries, with the tasks of:

The tasks:

- assessing «national health priorities»;
- proposing strategies for the «coverage of essential health services»; as well as
- preparing «an epidemiological baseline, quantified operational targets, and a medium-term financing plan».

For a second, the creation of a Global Health Research Fund (GHRF) to «...support basic and applied biomedical and health sciences research on the health problems affecting the world's poor and on the health systems and policies needed to address them».

Last remark:

An endorsement of those proposals by the international political community and commitment on the part of those countries capable of contributing resources to such a research fund would be powerful signals to the world of biomedical and health-related research that human rights matter. The creation of a *Global forum of inequities in health related research* could make this message come true.