

Elements of Ethical Practices for Scientific Research Conducted in Resource-Limited Countries

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Until the 1980s, scientific research conducted in resource-limited countries (RLCs) was mainly applied research, sometimes called “research for development.” Its primary goal was to solve local problems to help improve people’s living conditions in these countries, particularly by promoting or strengthening the capacity to meet their basic needs (such as health, education, food, and infrastructure), although this research was usually defined by foreign teams.

Since then, the landscape of scientific research in RLCs has changed considerably. In Southeast Asia, despite wide disparities between countries, some common trends embody the general direction of science policies, international collaboration, and researchers’ mobility. Research is now characterized by: (i) the relationships and dependence of all countries, to varying degrees, on the science systems of the global Triad, composed of the United States/Europe/Japan; (ii) the increased mobility of scientific personnel (researchers, engineers, and technicians) and competition to attract them, as countries seek to train, attract, and retain increasingly more scientific professionals; (iii) expanding international collaborations in science and technology, global competition that has pushed countries to create networks and promote transnational research projects; and (iv) the incorporation of science policy into national development policy in nearly all countries.¹

This shift in RLC-based scientific research towards the Global Scientific System has had consequences, however. Biological resources (plants, animals, humans) and research itself (clinical trials, GMOs) have become commodities. When research data are circulated around the globe, questions may be raised about who exactly owns the various biological collections and databases. Research has become privatized, and thus subject to competitive strategies (both individual and collective), forcing foreign institutions to

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1. Turpin, T., Woolley, R., Intarakumnerd, P., & Amaradasa, W. (2010). Southeast Asia and Oceania. In S. Schneegans (Ed.), *UNESCO science report 2010: the current status of science around the world* (pp. 437-463). Paris: UNESCO.

choose between selecting the highest bidder or promoting local establishments. Funding and evaluations are based on global scientific criteria (publications, patents, and economic profitability). Lastly, research teams are transnational, composed of a scientific diaspora.

“Development” is obviously a priority in the Millennium Development Goals (MDGs) and the Sustainable Development Goals (SDGs) for RLCs. Scientific research is viewed as a lever for economic and social development for these countries. Yet, the priority objectives for scientific research obviously also respond to many other economic (or political) issues that may influence how research objectives with high economic potential for their sponsors are defined without directly targeting development in the country where this research is taking place.

Inequalities in decision-making power between countries, institutions, and researchers involved in transnational research in RLCs mean ethics must be at the forefront when conducting scientific research in these countries. Several generations of researchers at the Institut de Recherche pour le Développement (IRD), from a broad range of disciplines, have reflected on the ethics of scientific research practices for decades.^{2,3,4} Their reflection led to the development of a Guide on Good Research Practices that specifies the main ethical principles for scientific research in RLCs.⁵

From a general perspective, research should respect the following principles as a minimum: (i) social justice and equity; (ii) compatibility with local needs; (iii) an acceptable cost/benefit ratio for individuals and communities; and (iv) scientific relevance and quality.

Application of these principles should result in: (i) a fair and equitable partnership; (ii) relevant research objectives (of high scientific quality); (iii) participation of the populations concerned; and (iv) equitable distribution of benefits (including ownership of acquired collections and data). Let us briefly review these four points.

1. A fair scientific partnership

For transnational teams, the economic and human resource gap between teams, the differences in researchers' status in their respective countries, and varying levels of participation in global research networks produce asymmetric power relationships that hamper the decision-making

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2. Waast, R. (Ed.). (1996). *20th century sciences: beyond the metropolis: The keynote speeches*. Marseille: ORSTOM.
 3. Bonnet, D. (Ed.). (2003). *L'éthique médicale dans les pays en développement. Autrepart*, (28). Paris: Éditions de L'Aube/IRD.
 4. Vidal, L. (Ed.). (2014). *Expériences du partenariat au Sud : Le regard des sciences sociales*. Marseille: IRD Éditions. doi:10.4000/books.irdeditions.9213
 5. CCDE. (2012). *Guide des bonnes pratiques de la recherche pour le développement*. Marseille: IRD.

power of RLC teams. These teams then might appear to be merely involved in implementing programs that were decided upon elsewhere.

A fair scientific partnership assumes (i) collaboration of researchers and national and foreign institutions when deciding on goals, priorities, and choices for scientific programming; (ii) pooling of human, material, and financial resources to conduct research through joint efforts; and (iii) strengthening of local scientific communities through training, especially to promote local researchers' inclusion in international research networks.⁶

2. Relevant research objectives

Research objectives must be relevant to the country where the research is carried out. In other words, research must respond to issues directly related to the needs of the country where it is conducted, leading to crucial questions. Specifically, who defines the research topics and which arguments underlie their selection? Is this based on the interests of the research sponsor? On foreign or national investigators' interests? On national development priorities?

These questions arise, for example, when clinical trials involve diseases that would not be considered a public health issue in that county, suggesting that these trials amount to off-shored experimentation—or in blunt terms, patient exploitation.⁷

Research objectives should be relevant for a given country. Topics should be defined with the input of representatives from the RLC(s) involved and approval from government authorities, which may create difficulties when these officials lack interest in a disease that has a genuine impact on people's well-being (which is sometimes the case for HIV/AIDS, leprosy, or diseases that are rare but serious or that affect marginalized groups). The research must clearly support the needs of the country where it is conducted (again, this obviously means knowing who defines the objectives and if the influence of various lobbies outweighs public input. Research should also take into account the state of global scientific knowledge; and, lastly, the quality of this research must meet international criteria (Good Clinical Practice).

3. Local community participation in the research process

For a long time, individuals and populations have been viewed as mere "study objects" for research. Consequently, they have been poorly or un-informed about the research objectives, goals, and methods. This lack of

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6. CCDE. (2012). *Éthique du partenariat dans la recherche scientifique à l'IRD*. Marseille: IRD.
 7. Shah, S. (2006). *The body hunters. Testing new drugs on the world's poorest patients*. New York: New Press.

participation fostered misunderstandings between research teams and communities, which in turn led to distrust and even rejection of research teams. Participation of the population being studied is extremely important, and requires serious thought and specific approaches.

Local communities' participation in the research process assumes: (i) fostering the communication and flow of information between research teams and the study population; (ii) clarifying the goals and methods of the research; and (iii) promoting the population's participation in the research process, which proves challenging when this population must focus on other pressing concerns. Theoretically, it boils down to: working *with* and *for* the people.

In the early 1990s, in Western countries, people living with HIV united to set up patient associations. These associations campaigned to address the needs of AIDS patients, accelerate the search for new treatments, improve the conditions of care for medical research participants, and increase access to new drugs. People gained knowledge and expertise inside these associations that approached or equaled that of health professionals and scientists. These "expert patients" have become contacts for scientists and public officials,^{8,9} while associations played and still play an intermediary role between the research teams and the study population or specific social groups within the population. The patient-association model advocating for patient rights and consideration of their needs has gradually become widespread in most of the world's countries, especially in Asia, while also evolving for other diseases. These associations play an indispensable role in the implementation of health research. Similarly, associations representing neighborhoods, villages, regions, users of a specific service, and others are key contacts in all aspects of the research process in any field. Of course, the involvement of these experts from the general public, their role, their activities, and how accurately they represent public opinion varies greatly and must be detailed country by country.¹⁰

Recognition of endogenous knowledge is a form of participation by the population that can test research teams' capacity for listening and adapting to the local context.

4. Equitable distribution of research benefits

Who ultimately benefits from the research? Or more specifically, who receives a benefit and what is it? There is no easy answer because the

8. Lestrade, D. (2000). *Act-up, une histoire*. Paris: Denoël.

9. Dodier, N. (2003). *Leçons politiques de l'épidémie de sida*. Paris: Éditions de l'École des Hautes Études en Sciences Sociales.

10. Bureau-Point, E. (2016). *Les patients experts dans la lutte contre le sida au Cambodge, Anthropologie d'une norme globalisée*. Aix-en-Provence: Presses universitaires de Provence.

impact may be long term, leading many scientists to claim they have the right to develop fundamental research with no immediate utility for RLCs.

This may include research in theoretical mathematics or in the humanities or social sciences, linguistics, or archeology, to name a few.

– Do participants, or the population they represent, draw a direct or immediate benefit from participating in the research? Or will they draw a medium- or long-term benefit? If a drug trial proves beneficial, will the population have access to the drug once the trial is over?

– How does/will the research benefit the team of local researchers (compensation, recognition, career advancement)?

– How does/will the research benefit local research institutions (technology transfer, strengthening local researchers' skills, development of research infrastructure)?

Equitable distribution of research benefits assumes certain outcomes, such as: (i) access by participants and populations to knowledge from innovations introduced through research; (ii) co-publication/co-authorship of findings by all involved researchers; (iii) respect of ownership of biocollections and databases from the country where research is conducted, in easy-to-control conditions; and (iv) applications for patents or licenses for the benefit of all partners.

Conclusion

This brief overview does not of course fully encompass the full range of issues to consider about the ethics of research in RLCs. Ethics guide practice, pointing us toward actions that are "good." It is clear that research practices are determined by strong structural aspects that sometimes—or often—disregard ethics; yet this should not prevent us from defining ethical research practices. Ethical principles are essentially voluntary standards without the weight of any legal regulations, but in recognizing them we imbue them with the meaning of law and thus help monitor and regulate practices.

Integrating scientific research conducted in RLCs into the global science system has raised new ethical issues, resulting in deeper reflection about research ethics. Reflecting on ethics allows us to develop a thoughtful and critical perspective on our practices and is an integral part of scientific research. Just as our understanding is constantly evolving, so should our thinking on the meaning of our research practices and our individual and collective responsibilities.

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Health, Environment, Societies

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