

Latin American Perspectives on Scientific Research

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By

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FOREWORD

This collection of readings in ethics of research from the Interdisciplinary Center for Studies on Bioethics at the University of Chile aims at presenting some information and perspectives derived from its work. The topics cover issues of research integrity, ethics of research education and ethical issues in specific research fields, especially genomics and mental health. The main emphasis is on the Latin American context, although global issues are also considered. The book aims to contribute to training in research ethics considering the need to include ethics of research in curricular fields in universities and implementing mechanisms to safeguard research integrity.

SECTION I:
ETHICS OF RESEARCH TRAINING AND
RESEARCH INTEGRITY

CHAPTER 1

ETHICS OF RESEARCH TRAINING: A LATIN AMERICAN EXPERIENCE

Abstract

This chapter reviews the experience in training Latin American professionals in the ethics of biomedical and psychosocial research at the Interdisciplinary Center for Studies on Bioethics (CIEB Spanish acronym) of the University of Chile, aided by a grant from Fogarty International Center (FIC) – National Institutes of Health from 2002 to 2011 (1, 2). The network formed by faculty and former trainees has published extensively on issues relevant in the continent and has been instrumental in promoting new master-level courses at different universities, drafting regulations and norms, and promoting the use of bioethical discourse in healthcare and research.

Introduction

The Interdisciplinary Center for Studies on Bioethics of the University of Chile was established in 1993 at the oldest and largest university in Chile (founded 1842). It was appointed WHO Collaborating Center in Bioethics in 2007. Partnership with the Pan American Health Organization (PAHO), Regional Office of the World Health Organization (WHO), led to the development of master programs in bioethics at different Latin American institutions (University of San Marcos, Lima, Peru, Instituto Tecnológico de Santo Domingo, Dominican Republic, University of Cuyo and University of Cordova, Argentina, among others) and to substantial contributions to other institutions (Fundacion Santa Fe de Bogota, Colombia, Academia Nacional Mexicana de Bioetica, as examples). Its activities, which are supported by foundations and public institutions, have brought together experts from diverse professional backgrounds and its publications have been used in many different settings. CIEB has participated in training experiences all over the continent. Among its most successful projects are those supported by the Fogarty International Center-

NIH. Throughout the years, scholars and researchers have been able to participate in training experiences. The Center has developed several lines of research at the interfaces between socio-cultural studies, religious beliefs, and health-related behavior, and has been instrumental in promoting bioethics. The main periodical publication, the well-established journal *Acta Bioethica* publishes papers in Spanish, Portuguese, and English (indexed in Scielo, Latindex, Science Citation Index, Social Science Citation Index, Lilacs). Other publications include a series of books, textbooks prepared by former NIH Fogarty Trainees, and monographs, as well as DVDs and web-based materials freely available at <http://www.uchile.cl/bioetica>.

The master-level international program of the ethics of biomedical and psychosocial research of the Interdisciplinary Center for Studies on Bioethics of the University of Chile has selected professionals and academics from Latin America and the Caribbean. Topics covered have been diverse and recruitment of trainees has encouraged multidisciplinary professions and differences in outlooks. Throughout the years, with different emphases, the main goal has been to help increase the number of persons familiar with the ethics of research in the biomedical and psychosocial disciplines and to foster the development of training programs at different institutions of the continent. The program has trained Latin American professionals to assume leadership positions, to produce research with ethical sustainability, collaborate with the formulation of ethics of research regulations in their home countries and participate in ethical review committees at their home institutions.

Program aims

- 1) To train Latin American professionals in the ethics of biomedical and psychosocial research in an interdisciplinary way.
- 2) To provide participants with appropriate knowledge of Bioethics Reasoning, Responsible Conduct of Research, Research Ethics in Anthropological and Social Foundations of Cultural Diversity in Research Practices, Publication Methods and Research Tools.
- 3) To acquaint trainees with dialogical methods, mediation and negotiation in solving bioethical dilemmas and decision-making in scientific ethical review committees.

- 4) To maintain and expand a cadre of professionals able and willing to assume leadership positions in bioethics education and research policies in their institutions and countries.
- 5) To develop skills for formulating public policies and regulations on research ethics.
- 6) To prepare trainees to address ethical and social issues related to scientific research in the context of international activities and cross-cultural environments.
- 7) To enhance critical thinking and responsible identification with the conditions in the countries and institutions that enable meaningful participation in the international scenario of globalized science.
- 8) To form a network of persons and institutions that can enter into responsible discussion and implementation of public policies in health and research in Low and Middle Income Countries (LMIC) of Latin America helping to reduce the “know-do gap” by demonstrating the relevance of research and evidence-based decisions for policy formulation and ethical sustainability.

Curricular development in research ethics – a culture-sensitive approach

Despite improvements in research output in the biological, social, and medical sciences, several problems remain with ethical underpinnings that justify training in research bioethics in the Region of South and Central America. Some aspects relevant to a training program in research ethics were identified and provided the rationale for this training program. The following were highlighted:

1. The 10/90 gap

Enhancements in global health status have mostly benefited developed countries. The lack of equity occurs not only in health coverage but also in research investment. Financial resources for research are insufficient in Latin American countries. In 1999, the Global Forum for Health Research analyzed data about expenditures in health research and found that less than 10% of the budget is expended on research on health problems that account for 90% of the global disease burden, the so-called 10/90 gap. Latin American countries have low scientific research production. Brazil is the

only country in the region that invests more than 1% of its gross domestic product on scientific research. The Global Forum for Health Research recommends that developing countries should carry out more research since scientific productivity increases economic development and more budget could be used in healthcare (3). An increase in research output must be accompanied by enhancement of ethical oversight.

2. Globalization and resource-poor countries

The current trend is toward the globalization of clinical trials and other health research sponsored by industry in multi-centric studies, with a shift in sites towards emerging regions, including Latin America (4). One of the advantages is that the cost of conducting research is less in developing countries than in advanced countries. Furthermore, resource-poor countries often have large patient pools for diseases without treatment, which ensures rapid recruitment and reduction of the time needed to complete time trials. As a social responsibility, public awareness about the need for ethical control of research has increased. The following problems must be taken into account (4, 5):

1. In order to assure valid and accurate results in multi-centric studies, proceedings must be identical in all sites.
2. Genuine informed consent (informed and voluntary) must be obtained, but the task is difficult since often the populations of developing countries are not prepared to understand the complex medical and research language.
3. Difficulties with confidentiality and privacy measures, since data are often maintained in an overseas coordinating center.
4. The use of placebos as a comparison when there is no comparative drug available and where the standard of care for a particular disease in many developing countries is no treatment. Some commentators argue that subjects should receive the best method available worldwide.
5. Reporting adverse events equally in all sites. In phase IV of clinical trials often the mechanisms of pharmaco-surveillance fail in developing countries.
6. Difficulties in monitoring and safety procedures.
7. Guaranteeing benefits for the communities where the research is performed.
8. Variation in the interpretation of regulations by the different scientific ethical review committees of participating sites, often requesting changes that have to be reconsidered by all sites.

9. Often research sponsorship is driven by economic interest and may not reflect the needs of host developing countries.

3. The know-do gap

Another aspect that merits consideration is the translation of knowledge into practice, the so-called “know-do gap”. While information derived from research-based evidence is available on many health-related issues, its translation into policy and practical measures is delayed in developing countries or only appropriated by a minority of the population which has the means to do so and that looks for the highest possible standard derived from scientific progress (6). Equitable distribution of the benefits derived from scientific research needs ethical reflection by the scientific community, policymakers, and the public at large. The bridge between research and public health requires not only the publication of results but also the employment of social strategies to reach the disadvantaged.

4. Research: cultural implications and responsible conduct

Research is structured within a cultural process so that the way it is carried out is influenced by context. In developing countries, some activities may be classified as research, but they would not qualify as such in developed countries. In our experience with trainees, research was confused with other activities, such as surveillance in industry-guided clinical trials; social science research projects were not considered in need of ethical evaluation due to their presumed low risk. Social *demand* for research (as different from *need* or *desire*) continues to be low in Latin America, as reflected in resource allocation, social recognition, and employment opportunities.

The different valorization of research in different societies is due to tradition, belief, social rewards, administrative and institutional arrangements for its accomplishment, and, finally, the definition of research itself. Besides the different meanings that the word research has in different languages, there is also the different approach of the expert communities in the human and the natural disciplines, and the social implications of results (7).

In view of the importance of ethical considerations when conducting research, particularly when it involves human participants, it is noteworthy that the differences in social environments that make research possible or the availability of financial and institutional support have not been given proper attention. Most of the projects in Low and Middle-Income Countries seem to take for granted that this social practice is similarly conceived all

over the world. Under this assumption, it is difficult to conceive that ethically relevant problems are similarly conceived in different settings. The uncritical imposition of norms and procedures that find acceptance in highly scientifically minded societies make it difficult to respect differences that influence the very definition of what constitutes ethical scientific practice. Given the assumption that values such as dignity, autonomy, and justice – as examples – may be similarly constructed, the universality of their concrete representation faces some constraints that remain unchallenged. The homogeneity of the research enterprise across societies and the aspiration to have a universally applicable model may be questioned, although a universal method might be used (8).

Responsible conduct of research is also culturally bounded. For example, risks assessment varies with context, the same can be said of safeguarding confidentiality, avoidance of stigmatization or protection from harm. In this context, experiences of training face-to-face in the cultural community where research is going to take place are important. CIEB's training program confronted trainees with real-life examples of research in specific contexts and/or in response to felt needs of populations and institutions. The special emphasis given to public health topics and anthropological analysis was dictated by the priorities of healthcare systems on the continent and the multicultural, pluralistic environments in which researchers must act.

5. Social roles: clinician and/or researcher

The scarcity of healthcare personnel, professional traditions, and restricted funding provoke confusion between the roles of *caregiver* and *researcher* in many Latin American settings. The “therapeutic misunderstandings” (9, 10) or confusion between the roles of a therapist or treating physician and the role of researcher, is common in countries with weak research capabilities. Subjects often expect that the researcher is giving them adequate personalized treatment for their condition. The different contextual interpretation of guidelines in other cultures and discrepancies between researchers from different countries/traditions/professions causes cultural differences.

Table 1.1 Role of Physician as a caregiver and as a researcher (compiled by the authors)

	Research	Clinical practice
Goals	Systematic research involving human beings to generate generalized knowledge	Diagnosis and treatment for healthcare needs
Activities	Probe a hypothesis to reach a conclusion	Improve the health of patients with the probability of success
Subjects	The individual subject may benefit or not since the goal is the common good	The individual patient expects a direct benefit

6. International collaboration issues

The international collaboration between developed countries and Latin America requires improving local capacity in research together with sound ethical oversight systems, good quality training, and awareness of the needs and expectations of the populations. Even if they are not at the forefront of research, the expanded vision of our trainees about the situation in Latin America and the awareness of the goals of research in its proper context have helped improve the translation of evidence-based facts into value-based actions.

An ethically competent researcher is also a *socially competent* professional, sensitive to the needs of the communities where the research results obtained and outcomes are expected to benefit. These notions are embedded in the idea of the *ethical sustainability* of research outcomes, which implies responsible conduct of the research, the integrity of sound data gathering and data-organizing processes and affordability of evidence-based interventions (11, 12). Several documents (13) reveal that healthcare professionals and biological and biomedical researchers continually confront tension between the advancement of scientific knowledge and the protection of research participants. Improper research conducts at Latin

American institutions demand the need to train professionals and promote research integrity in them (14, 15).

7. Human diversity: challenge and opportunity

Research ethics curricula face the challenge of diversity in multiethnic and multicultural contexts in Latin America. Culturally and ethnically different groups increasingly demand participation in public policies and involvement in research and decision-making. The indigenous population is numerous, usually fragmented in small groups, the average is 8% in Latin America, but varies widely. Some countries such as Bolivia (80%), Guatemala (60%) and Peru (40%) have large populations (16). Language diversity is a factor that hinders research, especially in social studies and public health. There are more than one thousand different indigenous languages. The globalization trend is changing the way of life of these populations very rapidly. Social progress has helped to reduce poverty and has improved access to basic services including health, but the benefits to the indigenous populations are lower, being more represented among the extremely poor (17).

In Latin America, there are still people without access to healthcare services mainly due to social inequalities. The region has experienced fast and complex epidemiological changes in recent decades, combining increasing rates of non-communicable diseases and injuries, and keeping many existing endemic and emerging diseases uncontrolled. The poor and indigenous populations also experience stigmatization or adverse social judgment. There have been reactions against genomic research of indigenous populations, for example, opposing the collection of blood samples used for DNA characterization (18). There is a need for a “culture fair” approach to data gathering and interpretation when doing research in order to respect dignity or request consent. In order to achieve an ideal of justice and right relationships with proper use of power relations, the context where research is taking place must be evaluated, looking for “ethical sustainability”. This notion suggests that any change in attitudes, goals, and practices must be based on sound argument and endure over time.

The training program developed by CIEB has worked on an “ethically sustainable” research agenda in a globalized context by training groups of professionals able to participate as researchers, policymakers, advisors to legislators, and mentors for new generations of academics. Professionals thus trained look to assume positions of leadership in addressing the ethical and social issues of global health research. It is recognized that ethical

oversight of research is best performed locally, thus avoiding mistrust and dependence.

8. Research accountability

As international experience shows, major problems in the ethics of the research enterprise arise from an undue concentration on *products* (publications, money, prestige), disregarding *processes* (interactions between research participants, sponsors, researchers). It is at this level that serious flaws in accountability have been observed in researchers of scientifically alphabetized countries. This is all the more worrisome in researchers from less-developed-countries, who enter into contacts and interactions with their peers in advanced nations and feel immune to criticism as members of an intellectual elite. The issue of accountability (holding research actors responsible for their actions) is increasingly important in international health research as cooperation among parties involves a large number of stakeholders with varying degrees of power and influence (19).

Researchers in Latin America represent a privileged minority and many of them feel that ethical oversight may hamper or limit their contribution to science and technology. Most Latin American countries rely largely on external funding and donors to initiate and sustain long-term research efforts. Despite limited resources, the critical mass of Latin American researchers has produced significant scientific contributions in specific fields (20). Research in poor-resource settings, both in Low and Middle-Income Countries and in industrialized countries, demands the establishment of training programs for professionals conversant with ethical standards and respect for human dignity. All along, the emphasis on accountability of researchers and research has been a permanent feature of our training effort. The idea is to integrate ethical reflection in the complex academic world taking into consideration that there are numerous administrative and structural obstacles to be solved in the Latin American context.

9. Role of bioethics in training

The interdisciplinary group learning strategy of the program followed the deliberative method of bioethics. Concepts presented were subjected to the exchange of points of view according to personal experiences. Different arguments were respected while also trying to reach consensus by identifying common grounds which depart from cultural and educational

background conditioning. In the deliberative method, the different interests rather than being subjected to a process of exchange are universalized, participants are enriched in their relationships and different values are respected (21). The different ethical theories were also learned according to schools of thought including how to argue with a philosophical base. The idea was to interact between the bioethics dialogical method and social and cultural values and philosophical reflection (22). Building up interfaces between institutions, professional groups, community-based organizations, and biopsychosocial health professionals is the very essence of the bioethical approach, with its emphasis on dialog and procedure above belief and philosophical persuasion (23).

Approaches and experiences

The training period at CIEB was mainly devoted to work in small groups (around five multidisciplinary trainees per year) under the leadership of a faculty member, avoiding any resemblance to an asymmetrical relation of the type mentor-trainee or tutor-trainee. This structure of the program allows personalized learning in order to acquire the required skills, with time to reflect outside the usual workload. *The covert dimension of the curriculum was to illustrate practically the dialogical nature of the bioethical enterprise and the development of bioethical discourse through open manifestation of ideas.* Care was taken so that each year promotion had sufficient professional variety (16 different professions in the 10 years) and different countries of origin to enhance interdisciplinary reflection. CIEB trainees came from the following countries: Mexico, Colombia, Argentina, Chile, Peru, Nicaragua, Bolivia, Ecuador, Honduras, El Salvador, Brazil, Paraguay, Uruguay, Dominican Republic, Guatemala, and Venezuela.

Table 1.2: CIEB Fogarty Trainees 2003-2011 (compiled by the authors)

Countries	Professions	Contributions
Mexico – 8 Chile – 8 Colombia – 7 Argentina – 6 Peru – 5 Nicaragua – 3 Ecuador – 3 Bolivia – 2 Honduras – 2 El Salvador – 1 Brazil – 1 Uruguay – 1 Dominican Republic – 1 Guatemala – 1 Venezuela – 1 Total: 50 Men: 16 Women: 34	Medicine – 18 Dentist – 8 Lawyer – 4 Pharmacy – 3 Chemistry – 3 Nurse – 2 Sociology – 2 Philosophy – 2 Microbiology – 2 Obstetrician – 1 Biology – 2 Psychology – 2 Veterinary – 1 International Relations – 1 Epidemiology – 1	Program Research Projects: 50 Additional Research Projects: 14 Publications - Articles: 54 - Books, chapters: 52 - Web: 22 - Online Virtual Modules: 6 - Web Bulletins: 3 - Web Sites: 3 Health Research Policies and Regulations: 26 Country ethics of research workshop interventions: 19 Development of Training programs in the ethics of research: 20 Creation of new Scientific Ethical Review Committees: 8 Participation in Scientific Ethical Review Committees: 27 Participation in National Bioethics Commissions: 6 Honors: 7 Presentations at Conferences: 103

Faculty members of the program were also from different disciplines and a horizontal dialog was promoted between trainees and faculty. The development of trainees' leadership skills, ethical attitudes, communication and problem-solving skills, and ability to design and evaluate research ethically was emphasized. The role of faculty was not just to provide knowledge, but also to advise trainees by tutoring and promoting collaborative deliberation (24). Trainees were exposed to a wide range of content and training experiences. Courses were offered on the philosophical foundations of ethics, the history of bioethical thinking, the applications of bioethical discourse to research questions, statistical reasoning as it pertains to ethical formulation of methods, bioethical problems arising in medical and psychosocial research, qualitative and quantitative research methods, health economics, institutionalization of bioethics, structure and functions of ethics committees, anthropology and bioethics, and other topics selected on the basis of personal interests and available teaching resources. Trainees

participated in sessions of research ethics committees and had the opportunity to interact with international scholars visiting the CIEB and were requested to select a topic to be dealt with in-depth as a final exercise. These essays were presented in evaluation sessions and graded, and constituted publications in accredited journals or presentations at seminars, workshops, or congresses, attendance at which was sometimes covered by special allowances from the program. Trainees participated also in writing grant proposals, debating ethics of research cases by applying the deliberative argumentation of bioethics and they gave lectures at conferences.

When the training period was completed, participants were requested to write formal and publishable papers and to prepare an activity in their home country or at their institution of origin, to which a faculty member was invited. Thus, continuity of effort was assured and support from the home institution assessed.

Conceptual approaches

- 1) The *Comparative Approach* focuses on two or more objects of analysis in order to uncover relationships and evaluate similarities and differences, emphasizing the temporal and territorial aspects of societies with different levels of development and cultural history. By comparing ethical systems in different countries, ways of overcoming obstacles and improving ethical oversight of research are discovered and tried. Cases discussed throughout the training period and those collected afterward are considered in this perspective.
- 2) The *Pluralistic Approach* focuses on the object of analysis from different perspectives and different theoretical frameworks, emphasizing key aspects of argumentation and deliberation. The idea is to provide information on the different schools of thought which have addressed the interrelationships involved in bioethics. A key dimension of the “hidden agenda” of the training program is to emphasize openness and tolerance for different outlooks.
- 3) The *Transdisciplinary Approach* is oriented to identify and differentiate the interactions and intersections of bioethical and social variables. The objective is to map the semantic spaces of the objects of study which require an interdisciplinary analysis, maintaining a pre-eminent interest on inter-disciplines in order to emerge with knowledge transcending the traditional fields of disciplines.

- 4) The *Applied Approach* is oriented towards the formulation, management, execution and evaluation of research from a bioethical perspective, and its personal and social implications in the different contexts in which trainees will act.

The simultaneous use of these approaches allows interaction and exchange among trainees from different cultural backgrounds. As experience demonstrates, issues arising in the training program are inherently interdisciplinary and multidisciplinary. The program strives to take account of different points of view, cultural background, and professional skills.

Key aspects:

Information, knowledge, competencies, and attitudes are four key aspects of the program activities.

Information refers to basic facts and figures needed for an opinion on a given subject matter.

Knowledge is *organized information* in relation to specific applications, outcomes, or goals. [The text of the Helsinki Declaration is information. Its comprehension and application to a given problem constitute knowledge]. The distinction is important for using ethical guidelines and declarations which, divorced from concrete frameworks, may well be meaningless.

Competencies are social skills deemed important for ethical deliberation and decision-making. Patient listening, tolerance for diversity, recognition of personal biases and dogmas, consideration of group dynamics, argumentation techniques, the opportunity for interventions, and others, are considered for each educational objective.

Attitudes are potential ways of behaving and reacting. Unlike competencies, they may not be directly observable in current behavior. Subtle evaluation is needed. Frequently, they can be assessed only after the effects of training are incorporated into routine thinking and acting. Attitudes are best evaluated by their consequences upon long-term behavior patterns. Trainees acquire specific leadership attitudes related to work in collaboration and are able to participate in discussion groups with an improved ability to critical thinking.

Among the guiding principles implemented, the following can be mentioned (1):

- *Methodical pluralism.* “Solutions” given by different disciplines to ethical dilemmas depend on methods, that is, ways of formulating, interpreting, and solving problems. The power of a profession derives from its being able to identify “real” problems and provide appropriate solutions. The teaching of statistical methods, participant observation, qualitative and quantitative approaches to data acquisition and presentation were aimed at reinforcing the idea that no good science (in the ethical sense of good) can be obtained without careful attention to method. In addition, the multi-leveled and complex nature of scientific/ethical problems was underscored by stressing different approaches to problems.
- *Perspectivism.* Not to be confused with moral relativism, the presentation of different perspectives is essential in creating an adequate environment for democratic and fact-producing dialog. This included openness to all facts related to a problem or to decision-making, illustrating a “culture of dialog” that is the essence of bioethical practice in committees and commissions. Deliberation was pursued in an attempt to generate conclusions that are well grounded on argument.
- *Open-mindedness.* This ideal of interaction was sought after by encouraging manifestation of personal preferences and emotion-laden material related to case analyses. Success was measured by requesting a personal evaluation from trainees after the completion of the face-to-face period.
- *Cultural sensitivity.* The interdisciplinary nature of our effort was accompanied by the effort to underscore what is meant by a truly transcultural approach. Contact with anthropologists who illustrated their methods and data with examples drawn from the cultural and the health fields. Their methods and approaches were considered valuable by trainees and helped to create awareness of the multiethnic and multicultural character of Latin American societies. The relevance of this knowledge for culturally fair bioethics was stressed at every point.
- *Attitudinal change.* Although an ambitious goal not always easy to attain, it was expected that after the training period, attitudes toward problems, ethical dilemmas, and current or possible solutions could undergo changes. Again, this was reflected in self-evaluations made by trainees and faculty and was the subject matter of testimonies collected after the experience was finished.

- *Improvement of communication skills.* Trainees were exposed to a variety of approaches aimed at improving written and oral communication, and special training sessions were devoted to the design and development of websites, listserv lists, slide presentations, oral reports, and written materials. This was essential given the different training experiences of participants and the need to represent ideas and attitudes to wider audiences. This portion of the training experience also served to highlight moral problems associated with scientific communication and thus introduce participants to a crucial aspect of research integrity.
- *Tolerance and the ability to listen.* Although implicit, the notion that a crucial competence necessary for the successful implementation of bioethical discourse is tolerance and the capacity to listen to discrepant or adversary views was reinforced throughout the training period and was continued in the aftermath of the face-to-face experience when networking activities at the home institution were supported and followed.

Evaluation of program and outcomes

A complete impact assessment may require an extended time to complete and should probably consider aspects well beyond immediate effects on research ethics. The multiplying effects of the experience through the work and effort of participants need years to show manifest outcomes in research practice, policymaking, and committee work.

Faculty members served as tutors and provided advice and support to trainees throughout the training period and afterward. The evaluation consisted of written reports and feedback to participants on their degree of commitment, collaboration with the long-term goals of the program, and written productions.

Individuals participating in the program provided feedback on their perceptions and accomplishments at the end of each term and their opinions proved valuable for reformulating aims and methods. Their publications attest to a wide range of interests and issues. The program itself was modified in accordance with suggestions and ideas provided by participants.

At the institutional level, the effects can be summarized in the development and implementation of training programs, ethics committees, and structure modifications. The following list summarizes the contributions of trainees (total 50):

- Research projects: 64
- Publications: 54 articles, 52 book chapters, 22 Web publications
- Websites development: 3
- Health research norms: 26
- Ethics of research programs at home institutions: 20
- Creation of new scientific ethical review committees: 8
- Participation as members in scientific ethical review committees at home institutions: 27
- Participation in National Bioethics Commissions: 6

At the national level, the effects are more difficult to estimate. They depend in part on the personal influence each trainee may have in his/her local environment and the recognition of the importance of research ethics by officials and the public.

Lessons learned – the future of ethics training within the research enterprise in Latin America

As important as written materials, in and by itself a good demonstration of success and impact is the fact that both faculty and former trainees established an enduring collaboration which resulted in network programs and continued support. The impact and relevance of the program is framed in a context of realistic expectations, critical evaluation of different cultural inputs, and hands-on experience. Sharing knowledge, attitudes, and responsibilities ensures the two main values of the overall Fogarty program: appropriateness to the context and long-term sustainability.

One important lesson learned from the experience was that the ethics of the research program did make a difference in the careers and outlook of participants. Many of them were able to install and develop ethical review committees and improve ethical oversight in their environments, but they also reported difficulties associated with their contribution. This fact shows that the incorporation of competent human capital into the institutions depends on appropriate conditions in the countries of origin. Individual factors and institutional variables account for different outcomes. It has been important to maintain contact and develop networking activities that reinforce the sense of leadership derived from the successful completion of the training experience.

The experience was also valuable for faculty members. Interactions were not always easy, but everybody benefited from the effort, in ways that were

sometimes unexpected. The interfaces with juridical systems, knowledge of funding procedures for research, the disclosure of sometimes hidden or unknown prejudices were results from the experience of interacting with professionals. There is still some mistrust of ethical oversight which may be due to faulty implementation, lack of adequate development of scientific ethical review committees or vested interests. The effort is worthwhile, the project has been rewarding to carry on, and the need is still growing.

A network for the advancement of biocentric ethics (1)

The experience gathered throughout the years has demonstrated that an ethical approach to science and technology, in the current state of the development of disciplines, by necessity must incorporate specialized knowledge, be based on deliberation and dialog, and depend on an organic and cohesive community. This community includes researchers, policymakers, politicians, administrators, students, and lay people. Since research is a cultural process shaped by expectations, hopes, and practices, it cannot be examined in isolation from other aspects of social life. In point of fact, ethical oversight of research cannot be treated independently of the “ethical level” of the community at large. Political and administrative corruption, if present in a country and accepted as normal, cannot be irrelevant for the establishment of sound scientific practices.

A sustainable effort depends critically on the establishment and maintenance of communities: Epistemic communities (or cultures), Practice communities and Moral communities. These communities do not necessarily overlap, although it might be expected that the moral one embraces the others and includes knowledge and its applications. Biocentric ethics is not simply another form of applied ethics. It represents a change in the paradigmatic construction of the moral universe. Not only does it go beyond classical anthropocentrism in the formulation of moral imperatives, it is knowledge of how to produce, expand, and apply knowledge. It is also an indication that the very foundation of welfare and progress includes a joint consideration of goals and means. Goals are formulated as culture and civilization. Means are legitimated by discursive practices respecting persons, living beings, and environment, accepting diversity and agreeing on basic principles of commonality. In order to achieve this long-term goal, adapted to the historical peculiarities of a world region, our contribution depends on dialog and common discourses. Research ethics is just a part of culture, and culture is life in common. The establishment of a network of users of bioethical discourse has been an important mission of CIEB and

will continue to be in the future. Thanks are to be expressed to the institutions that make it possible (especially the University of Chile) and to the funders (NIH Fogarty, the Alexander von Humboldt Foundation, among others).

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