



PAN AMERICAN HEALTH ORGANIZATION
WORLD HEALTH ORGANIZATION

**SUBCOMMITTEE ON PLANNING AND PROGRAMMING
OF THE EXECUTIVE COMMITTEE**

30th Session, 30-31 March 1998

Provisional Agenda Item 7

SPP307 (Eng.)
13 February 1998
ORIGINAL: SPANISH

BIOETHICS

CONTENTS

<i>EXECUTIVE SUMMARY</i>	3
<i>1. Introduction</i>	4
CD37.R9 The Directing Council	5
<i>2. Regional Program on Bioethics</i>	6
2.1 Mission	6
2.2 Functions	6
2.3 Thematic Orientations	7
<i>3. Summary of Activities from 1994 to 1997</i>	8
3.1 1994	8
3.2 1995	8
3.3 1996	9
3.4 1997	10
<i>4. Program Resources</i>	11
<i>5. Conclusions</i>	11

EXECUTIVE SUMMARY

The Pan American Health Organization (PAHO) has taken up bioethics as a new sphere of action through a regional program in order to meet the demands of the Member States for open discussion of many areas that are a continuing source of debate—for example, justice and equity in the allocation of health resources, patients' rights, dying with dignity, the incorporation of palliative care in the health services, the ethics of the beginning and end of life, the ethics of public health and of the relationship between institutions and people, research, the use of drugs, and the exploitation of the environment. In its three and a half years of operation, the Regional Program on Bioethics has developed a significant regional presence and, with relatively limited resources, has become an area of growing importance and demand for technical cooperation within PAHO.

This document reports on the implementation of the Program from its birth in May 1994 through December 1997 and provides a brief historical synopsis of the circumstances surrounding its creation. It also summarizes the objectives of the Program and describes the main activities carried out during that period, within the context of its foundations and the strategic and programmatic orientations of PAHO.

1. Introduction

Bioethics is an emerging discipline in health that is taking on new dimensions as the twentieth century draws to a close. With moral implications extending to other highly diverse areas, its principles and values seek to humanize and mediate the headlong advance of not only science and technology but also the global development in which we are immersed. In the modern era, bioethics has become an aspect of critical importance in the biomedical and social sciences, health care, and public health. Bioethics is the ethics of life in action and an important dimension of biomedical humanities. It submits biological sciences, medical technology, health care, public health, and the doctor-patient relationship to questioning and scrutiny. This new manner of reflection, which restores traditional principles of ethics and incorporates new precepts in order to keep abreast of the times, has gathered such impetus in the past 25 years that there is virtually no entity related to the well-being of humanity that does not acknowledge its place, both now and in the future.

PAHO has taken up this new sphere of action through a regional program that has made it possible to meet the demands of the Member States for open discussion of many areas that are a continuing source of debate—for example, justice and equity in the allocation of health resources, patients' rights, dying with dignity, the incorporation of palliative care throughout the health services, the ethics of the beginning and end of life, the ethics of public health and of the relationship between institutions and people, research, the use of drugs, and the exploitation of the environment.

PAHO's exploration, observation, and recording of bioethical concerns and demands among the countries of the Region began back in 1985. Its first formal response to this concern was the publication of a special issue of the *Boletín de la Oficina Sanitaria Panamericana* (Vol. 108, Nos. 5 and 6, May and June 1990, in Spanish; Vol. 24, No. 4, of 1990, in English) devoted entirely to bioethics. Prepared by distinguished professionals from around the world, its pressrun of some 11,000 copies was sold out, marking an important milestone in the Region. This publication is used as a text in many universities and has become essential reading for people working in this field.

Subsequently, during the 109th Session of the Executive Committee in June 1992, PAHO reported on conversations with the President of the University of Chile about the advances in science and technology and the growing importance of bioethics—talks that aroused a mutual interest in establishing an entity in the Region to focus on this emerging issue.

The Executive Committee shared that concern and agreed that PAHO should take up this issue so closely related to its mission of pursuing equitable access to health and well-being for the peoples of its Member States. The Committee therefore requested that a joint proposal be drafted with the University of Chile and the Government of Chile for submission to the Subcommittee on Planning and Programming.

discussed the possibility of establishing a Pan American institute of bioethics. The 20th session make it possible to achieve the original objectives while consuming fewer administrative resources and strengthening technical cooperation activities. The HBE programming line, Bioethics, was added to the program list of the Organization.

initiative and concluded with the present formulation of the Regional Program on Bioethics (Resolution CD37.R9):

CD37.R9 The Directing Council

Having considered the report of the Executive Committee regarding the establishment of a Regional Program on Bioethics (BioEticaBioEthics) and Document CD3712 presented by the Director; and

Taking into account the commitment of the President of Chile, the University of Chile, and the Ministry of Health of Chile to host and contribute to the establishment and operation of the Regional Program on Bioethics as a decentralized PAHOWHO Program in Chile,

Resolves:

1. To approve the Regional Program on Bioethics as a PAHOWHO technical program, attached to the Office of the DirectorDeputy Director, with headquarters in Santiago, Chile, in association with the University of Chile and the Ministry of Health of Chile.
2. To urge Member States to participate, through voluntary contributions, in the activities of the Regional Program on Bioethics and in the creation and strengthening of national capacities in the field of bioethics in the private and public sectors.
3. To request the Director:
 - (a) To thank, on behalf of the Organization, His Excellency the President of the Republic of Chile, the Minister of Health of Chile, and the President of the University of Chile, for their interest in and support for the establishment of the Regional Program in Chile;
 - (b) To promote the mobilization of extrabudgetary resources to support and expand the Regional Program;
 - (c) To carry out an evaluation of the work accomplished by the Regional Program after five years of operation, including its impact on the development of bioethics in the Region and the significance of its contribution to the health of the peoples of the Americas, and to report the findings to the Executive Committee in the year 2000.

2. Regional Program on

2.1 Mission

objectives. The mission of the Regional Program on Bioethics is to cooperate with the Member applied development of bioethics as it relates to health.

2.2 Functions

The functions of the Program are understood as technical cooperation and, as such, fit into the

2.2.1 Mobilization of Resources

- To promote and coordinate the formation of interest groups or
- To organize a network of centers and institutions devoted to among them and with the Program.

2.2.2

- To cooperate in the education and training of professionals in bioethics.
- To organize and support courses, workshops, and seminars on bioethics.

2.2.3 Dissemination of Information

- To promote, support, guide, advise, and disseminate information to public and private institutions on the development of bioethics and knowledge in the field.
- To report on developments in bioethics with respect to new knowledge and bibliography.
- To keep a current database on activities in bioethics in Latin America and the Caribbean.
- To strengthen the documentation center, making it possible to submit information to the network on books and articles of bioethical interest, as well as conventions, seminars, and other types of activities in the field.

- To publish a periodical that provides information on Program activities and the network of bioethics centers in the Region.

2.2.4 Development of Policies, Plans, and Standards

- To associate bioethics with public health in order to improve, update, and deepen the policy-making process, with special reference to the concepts of equity and solidarity.
- To promote permanent bodies for the discussion of bioethics.

2.2.5 Research

- To promote and support the studies and research on priority issues proposed by the ministries, universities, or bioethics centers.
- To prioritize and target the study of the main program issues, in keeping with the interests of the countries and the policies and objectives of PAHO.

2.2.6 Direct Technical Cooperation

- To motivate and promote the establishment of national mechanisms that develop knowledge and promote the development of bioethics (national health councils, national bioethics commissions or councils).
- To establish the Program as an agency that furnishes advisory services and efficient support for country activities in the field of bioethics.

2.3 Thematic Orientations

The thematic orientations of the Program are the outcome of consultations with PAHO authorities and are grounded in the agreements reached at the First Seminar-Workshop held by the Program (November 1994), “Bioethics in Latin America and the Caribbean.”

These orientations, which constitute the main planning areas of the Program and are consistent with the strategic and programming orientations of the Organization, particularly Health and Human Development, are:

- bioethics in public health;
- clinical or medical ethics;
- research ethics;

training and education in bioethics;

current or emerging problems resulting from scientific and technological advances and the emergence of new diseases

3. Summary of Activities from 1994 to 1997

Bioethics should refer to the goal assigned to it by the SPO for the bioethics in the Region through the identification, analysis, and promotion of policies and programs linked with this new

The previously-mentioned foundations that were defined to structure the Program should also be

3.1 1994

Bioethics for Latin America and the Caribbean commenced its formal activities on 1 May 1994.

the institutional capacity of the program headquarters in Santiago, Chile and begin to establish links with public and private institutions and individuals from the Member States, since in order bioethics in the Region, it was necessary to

Boletín

informativo Programa Regional de Bioética

Bioethics) was published with these objectives in mind, in order to disseminate information on publications in

Region. In addition, the First Seminar-Workshop on Bioethics for Latin America and the Caribbean was held in Santiago, Chile (November 1994), with the participation of representatives from 17 countries and over 40 professionals. The conclusions from that meeting were important, because they described the situation of the discipline in the Region and promoted the design of a strategy to disseminate it while helping to define the thematic orientations to guide activities in this area.

3.2 1995

A few months into its second year, as a pressing need for any future development, the Program set the goal of identifying, promoting, and disseminating information on activities related to bioethics in Latin America and the Caribbean, offering access to regional and worldwide information on bioethics to the Member States and their public or private institutions. The proposed objectives therefore included carrying out a situational diagnosis in the Member States, improving knowledge about bioethics through technical cooperation, and facilitating the creation of a regional network on bioethics. Furthermore, the Program's documentation and information center commenced operations, an information and communications system on bioethics was organized, and data on bioethics experts and centers were compiled. Thus, 1995 was

characterized by an explosive demand for knowledge about bioethics and the Program was obliged to implement an aggressive policy that would enable it to meet and even exceed the goals that had been set.

Visits were made to 15 countries in the Region, which made it possible to carry out a variety of technical cooperation activities in bioethics research in each and to disseminate the programming proposals of PAHO in this area. The main activities were joint efforts with bioethics centers or distinguished individuals in the countries visited, who had been contacted beforehand by the PAHOWHO Representative Offices or by the Program directly. The Second Workshop-Seminar on Bioethics in Latin America and the Caribbean (October 1995) was held in São Paulo, Brazil, while the Third was held the following November in Havana, Cuba. Brief courses to train professionals from hospital ethics committees and bioethics boards were begun. The Program participated in the meeting on Bioethics and Research on the Human Genome, organized by the University of Chile Law School, and the Meeting of Ministers of Health of the Andean Area (REMSAA) in Caracas (November 1995). Through consultants, the Program supported the drafting of the final proposal of the REMSAA, an activity worthy of mention because of the proposal's implications for the Program's future relations and activities with the governments and legislatures of the Member States. In 1995, research on bioethics and the environment began, focusing on the right to environmental information, and the first issues of the *Cuadernos del Programa Regional de Bioética* were published.

3.3 1996

After considerable progress in 1995 in raising awareness about the Program and establishing working relationships with the countries in the Region, activities in 1996 focused on improving knowledge about bioethics, promoting and disseminating information on bioethics activities in Latin America and the Caribbean through specific programs, improving the knowledge and training of professionals, and giving Member States, professionals, and interested institutions access to regional and global information on bioethics in health through a bibliographic database in Spanish and Portuguese.

- Contacts were established with universities and research centers to encourage the incorporation of bioethics courses at both the undergraduate and graduate levels. Notable among these institutions are the Fiocruz School of Public Health (Rio de Janeiro) and the University of Brasília, in Brazil; the Universities of Bahía Blanca and Santa Fe, in Argentina; and the Inter-American Center for Social Security Studies, at its headquarters in Mexico. Particularly important was the Program's support for and participation in the International Seminar on the Teaching of Bioethics in Latin America, held in Villa de Leyva, Colombia.

- One of the main activities of the Regional Program on Bioethics during the period in question were the courses specializing in foundations of clinical bioethics for a Master's Degree in Bioethics, a program certified by the University of Chile and headed by Professor Diego Gracia of the Universidad Complutense of Madrid. These courses were offered in 1996 and 1997, with total resources of approximately 10 million pesetas (approximately US\$ 70,000) from the Ministry of Health and Consumer Affairs of Spain, in addition to the aforementioned

collaboration of the University of Chile and PAHO. The participation of 42 professionals from different countries in the Region, eight of whom have already received their Master's degrees after successfully defending their theses, is a very significant achievement; these individuals will multiply the teaching of bioethics and will also serve as effective collaborators with the governments and institutions of their respective countries to foster the consideration of bioethical principles in health policies and the day-to-day work in health.

- The Program participated in events related to the conflicts that have arisen over the study of the human genome in some indigenous populations without their informed consent. These events included attendance at the First Latin American Meeting on Bioethics and the Human Genome, held in Manzanillo, Mexico, and a joint seminar with the Indigenous Corporation of Chile on Protecting the Human Genome. The Program supported the participation of representatives from ministries of health of the Region in a seminar entitled "The Ethical and Legal Implications of Organ Transplants," held in Spain. It also collaborated with Central American countries in seminars and with WHO in the preparation of regional contributions for special documents and studies.

3.4 1997

In 1997, activities were guided by the expected results for PAHO's 1996-1997 biennium, which indicate that, concerning the development and application of scientific and technical knowledge in health in general and in specific cases, ethical decisions have an impact on life. Special attention should therefore be paid to expanding activities in bioethics.

The institutional framework of the Program was consolidated, and new demands surfaced to address emerging issues whose accompanying ethical dilemmas and controversies will require analysis from a bioethical perspective. The Program participated in meetings and events in Central America and the Caribbean, strengthening the work and contacts in that area. Among these, the following should be mentioned: the Medical Convention of the English-speaking Caribbean in Saint Martin; the Workshop-Seminar on Bioethics in Latin America and the Caribbean for Central America in San José, Costa Rica; and the Caribbean Bioethics Seminar in Puerto Rico, which paved the way for the creation of the Caribbean Bioethics Federation, initially comprised of Cuba, the Dominican Republic, and Puerto Rico. This organization validated its agreements and confirmed its interest in expanding bioethics to other countries in the subregion, with the full backing and participation of the Program in the Caribbean Bioethics Seminar, held at the end of year in the Dominican Republic. Two other activities should also be mentioned. The first is the Program's participation in discussions on the right to environmental information in the seminar "Primary Environmental Care in the Region of the America," organized by PAHO's Division of Health and Environment, in conjunction with its the PAHOWHO Representative Office and the Ministry of Health of Chile, for participants from throughout Latin America. The other is its support for the Argentine Convention on Medical Anthropology, entitled "Health of Indigenous Peoples," held in Tucumán, where it presented the topic "The Ethics of Scientific and Traditional Indigenous Medicine." Finally, in response to the expectation of and demand for information about cloning, background was furnished to the countries, and a large number of publications on the debate under way in legislatures and the

media were compiled and sent to the WHO Committee on Bioethics, in compliance with its request. The Program, it should be noted, is the focal point for the Committee in the Region.

4. Program Resources

From the establishment of the Regional Program on Bioethics in 1994 until December 1997, PAHO provided a total of \$1,028,839 for program operations and activities.

The University of Chile and the Government of Chile have fulfilled the terms of the respective agreement by allocating \$330,565 and providing logistical support and human resources for program operations and activities. The Program has mobilized additional resources; for example, the aforementioned support from the Government of Spain for the Master's Program in Bioethics in 1996 and 1997.

For the 1998-1999 biennium, the sum of \$356,300 from regular PAHO funds was programmed for that same purpose.

Biennium	PAHO Funds	Gov. and Univ. of Chile Funds	Total
1992-1993	20,000	-	20,000
1994-1995	423,539	130,565	554,104
1996-1997	585,300	200,000	785,300
Total	1,028,839	330,565	1,359,404

The Program has three full-time professionals (including the Director), two part-time professionals, and four general services staff, all located at the headquarters provided by the University of Chile in Santiago.

5. Conclusions

In view of all this, as a result of its activities carried out during the period analyzed, the Regional Program on Bioethics has made a number of significant advances in addition to those described above, namely:

- It has become a recognized agency, especially in Latin American and European bioethics, that has effectively collaborated with most of the countries of the Region by organizing and supporting courses, workshops, seminars, and working meetings, in addition to providing technical advisory services and information when needed.

- A line of coordination has been opened with other program areas of the Organization, and all the PAHOWHO Representative Offices in the countries have designated their focal points in bioethics.

- A total of 453 centers conducting activities related to bioethics and 696 professionals working directly or indirectly in this field have been identified in the Region. All of them are registered in the Program's database. This will make it possible to keep them informed about activities in this area, and about other topics of interest. It will also make it possible to obtain information from them and elicit their collaboration, when necessary. Use of the Internet for electronic mail and, very soon, the creation of a link within PAHO's Web page, will make it possible to construct a regional network on bioethics, linking all these centers and professionals with each other and the Organization.

- A documentation system on bioethics has been created and consolidated. It currently has a bibliographic database of 2,600 titles and direct access to 12 worldwide databases for consultation. A joint effort with the Latin American and Caribbean Health Sciences Information Center (BIREME) has led to the creation of 300 LILACS registries and 23 descriptors, thus making bibliographic registries in Spanish and Portuguese available. The electronic mail and Internet connection will also allow for quick and easy access to all this information, although the Program's current capabilities, in terms of hardware and systems operations, are still a constraint.

- Two periodicals have been created: the bulletin *Bioética Informa* (Bioethics Reports) and the *Cuadernos del Programa Regional de Bioética* (Notebooks of the Regional Program on Bioethics). For specific topics there is the *Serie de Documentos del Programa Regional de Bioética* (Document Series from the Regional Program on Bioethics), which is distributed to the different centers and is available to any party interested in delving further into these matters. There are also research and opinion papers, prepared by Program consultants, as well as translations, some of which are significant contributions to the Region.

- Advisory services have been furnished to governments and legislatures through direct participation or supporting documents on bioethics topics that are currently being debated in public forums and are often the subject of legislation. Assisted fertilization, organ transplants, cloning, the human genome project, euthanasia, and assisted suicide are but a few examples.

- Intense work has been carried out in academia, with the main objective of interesting universities in incorporating bioethics in medical, humanities, and social sciences curricula. In this regard, the Program has furnished cooperation and advisory services for working meetings and seminars to discuss methodologies, attempting to link these activities with training centers in the United States and Europe, particularly Spain. The most significant achievement in this regard has been the Master's program on basic and clinical bioethics, the result of a joint effort by health authorities in Chile and Spain, the University of Chile, and the Universidad Complutense of Madrid. It is hoped that this activity will generate a critical mass of experts in the field throughout the Region who can help to establish autonomous, high-quality training and research programs that can influence policy.

In its three and a half years of operation, the Regional Program on Bioethics has developed a significant regional presence and, with relatively limited resources, has become an area of growing importance. This has resulted in a growing demand for PAHO technical cooperation. At a time marked by the changing role of governments and private actors, increasingly complex health systems, and multiple interactions between the factors internal and external to the health sector that determine the health conditions of the population, it is essential to adopt new topics, disciplines, approaches, and methods for generating knowledge and technology development in health, in the theory and practice of public health and biomedical research, and in the development of new ways of organizing the health services and medical practice. Bioethics is one of the new disciplines being called upon to improve knowledge and practice in public health, an area of concern and research, given the new ethical dilemmas stemming from the rapid scientific and technological advances in health, the ethical dimension of patients' rights, and the quest for equity and justice in resource allocation in the health sector.

PAHO has set out to establish fruitful cooperation and collaboration among the Member States, through the creation and implementation of the Regional Program on Bioethics. It is hoped that the evaluation of the Program, scheduled to begin this year, will help to increase the effectiveness, relevance, and impact of the considerable efforts made to date.