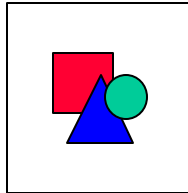


**PAN AMERICAN HEALTH ORGANIZATION**  
*Pan American Sanitary Bureau, Regional Office of the*  
**WORLD HEALTH ORGANIZATION**

**ACHR 35/2000.5**  
**Original: Spanish**



**XXXV MEETING OF THE ADVISORY COMMITTEE ON HEALTH  
RESEARCH**

Havana, Cuba  
17 - 19 July 2000

**DEMOCRATIZING INFORMATION AND KNOWLEDGE  
FOR THE RIGHT TO HEALTH - *DECIDES***

Health Research Coordination  
***Division of Health and Human Development***  
Washington, DC, April 2000



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# **DEMOCRATIZING INFORMATION AND KNOWLEDGE FOR THE RIGHT TO HEALTH - *DECIDES***

## **I. INTRODUCTION**

The Advisory Committee on Health Research (ACHR) of the Pan American Health Organization (PAHO) repeatedly has recommended that the Organization's technical cooperation regarding research should follow four principal strategic orientations: 1) preparation and implementation of a widely participatory research regional agenda; 2) promotion of training and exchange of researchers among the countries of the Region; 3) reduction of the inequalities among these countries with respect to their capacity to generate and access health information and knowledge; and 4) promotion of a greater utilization of scientific information in the decision-making process in health. The cooperation strategy known as *DECIDES* comes into being based on these recommendations and taking advantage of the implementation of the Virtual Health Library.

*DECIDES* is a technical cooperation strategy promoted by PAHO's Research Coordination. Taking advantage of the opportunities offered by the new communication and information technologies, it has the fundamental purpose of expanding the various social actors' participation in the production, dissemination, and utilization of the required information, so that they may take-on a proactive attitude in attaining individual and collective health. *DECIDES* seeks to contribute to reducing the inequities in health in three dimensions: risks, care, and the distribution of power and knowledge by promoting activities in three areas: Science, Services, and the Community.

*DECIDES* settles itself on two basic assumptions:

- An ample access to scientific and technical information is a necessary condition for attaining the right to health;
- The new technologies of information and communication make it possible to promote interactions between various actors (researchers, health professionals, managers and the general public) for the development and exchange of knowledge and information, thus facilitating a broader participation in the decisions about health and research policies and programs.

## **II. STATEMENT OF THE PROBLEM**

Based on these assumptions *DECIDES* intends to contribute to overcoming the following principal problems:

- Restricted participation in the definition of research agendas

The need for agendas to direct the research efforts and the allocation of resources has been increasingly acknowledged, but their preparation, usually, is not done with transparency in the criteria, demands or interests they try to respond. The definition of research priorities should not be,

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as traditionally has been, the exclusive responsibility of experts or government staff members, instead it should be understood as a social task involving various actors with their interests and perceptions expressed in a space that facilitates consensus.

- Low utilization of research findings in health policies and programs

The decision-making process in the formulation of health policies is not, as sometimes perceived, a linear process with several sequential stages that involve a series of decisions taken by a privileged actor, the "decision-maker," who acts rationally, utilizing the best available information. Actually, the process is quite more complex and involves several actors with varied and sometimes contradictory interests. Rather than trying to neutralize the apparent chaos generated by the interaction of these diverse actors, what should be done is increase the utilization of research to formulate and implement health policies, getting to know better the social actors involved, identifying, for each one, their information sources, the type of information needed, how they evaluate the information available, what motivates specific decision-making and with whom they interact, compete or ally to reach decisions. The strategies, channels, and opportunities for the dissemination of research findings should respect these particularities. (Bronfman M, Trotsle J, 1999)<sup>1</sup>

- Shortcomings in cooperation and researchers exchange between LAC countries

Despite some efforts by researchers, which include creating exchange networks such as RELAB and the Southern Cone Research Network in Health Systems, and the existence of bilateral or regional cooperation agreements among countries like MERCOCYT, the truth is that researchers exchange, and full utilization of the potential of these initiatives is far from satisfactory in relation to the need to complement efforts to investigate common problems.

- Inequity of access to health information

Important inequalities in the access to information and knowledge in health exist in the Region. However, if used adequately, the opportunities offered by the new information and communication technologies can help overcome these inequities. High subscription costs hinders access to the international scientific literature by researchers and health professionals. In the case of scientific journals produced in countries of the Region, administrative, publishing, and marketing deficiencies limit their quality, distribution, and access. Non-conventional literature, such as, technical documents, thesis, laws, epidemiological bulletins, etc., which contain information of special interest for decision-makers and the general public, shows an extremely limited circulation due to flaws in the means for its capture, organization and dissemination.

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1 Bronfman, M. y Trotsle, J. (1999) "El papel de la investigación en políticas de salud: una revisión estratégica de la literatura" in "Salud, Cambio Social y Políticas: Perspectivas desde América Latina", EDAMEX, México, ISBN-970-661-066-9.

### III. TRENDS AND OPPORTUNITIES

Aiming to contribute to the elimination of these problems *DECIDES* seeks to take advantage from some trends and opportunities existing in the Region such as:

- Decentralization and democratization of decisions on public policies

Decentralization of public policy-making, as part of the State reform process, has given increased importance to local level decision-making, thus expanding the possibility for more extensive citizens participation. In the health sector case new entities, such as municipal councils or local health forums, have been created for defining policies and programs where representatives of various social sectors participate. An adequate information flow will provide members of these entities with a much better foundation in carrying out their representation.

- Strengthening regional integration mechanisms

The existence of MERCOSUR, NAFTA, CSICA, and other regional integration initiatives, opens major possibilities for establishing mechanisms to strengthen the cooperation among countries aimed to solving common problems that are difficult to handle in isolation.

- Availability of new information and communication technology

One of *DECIDES* basic assumptions is that the new information and communication technology offers enormous possibilities to expand access to the information required to attain the right to health. However, technology in itself is not a guarantee for that to happen. In order to make the most of its enormous potential and prevent it from enlarging the gaps between countries and population groups, implementation of these technologies should be made aiming to improve the living conditions of lower income groups and to strengthen their ability to influence decisions. The Virtual Health Library (VHL) has this orientation, becoming a new paradigm of information treatment and organization that coherently responds to these new challenges.

### IV. GENERAL OBJECTIVE

*DECIDES* aims to play a role in improving quality of life, and the status and provision of health services by expanding the production, access, and utilization of health information and knowledge; generating research agendas; supporting decision-making processes with scientific findings; favoring the participation of various actors in constructing individual and collective health; and maximizing information resources from different institutions.

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## V. STRATEGY AND METHODOLOGY

Major technological advances historically go accompanied by important organizational changes. Just like the factory became the central organizational element of the industrial age, in the case of the information age the critical organizational form is the network (Castells, 1998).

*DECIDES* basic strategy is the constitution of virtual networks to deepen and multiply interactions and collaboration between researchers, health professionals, citizens, journalists, politicians, and other actors by facilitating the creation of debate and discussion groups, virtual research groups, support to exchange and training programs, etc.

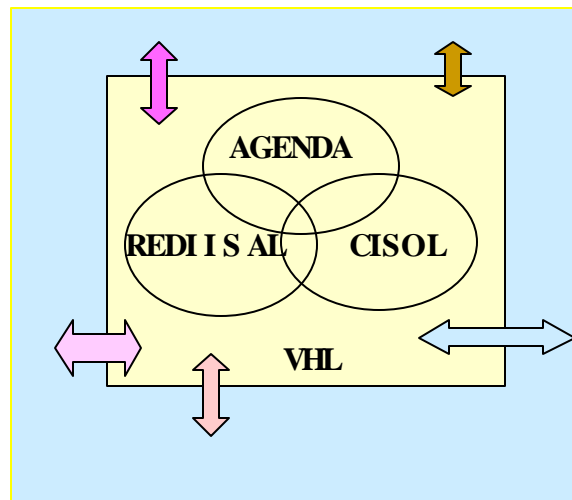
The virtual networks promoted by *DECIDES* are organized in three basic components, which have a relative autonomy, but join one another in the common space of the VHL that gives them support and promotes their cross-pollination:

- *The Interactive Agenda of Health Research (AGENDA)*: promotes interaction between researchers, decision-makers, staff members of research planning and financing organizations, and other actors for the formulation and implementation of a research agenda that responds to priority health problems of the population;
- *Researchers Exchange Network (REDIISAL)*: promotes training and exchange of health researchers through promotion and strengthening of collaboration mechanisms among the countries of the Region;
- *Solidary Cities (CISOL)*: facilitates access to information to the citizens and decision-makers for their self-care, demand of civil rights, and for the formulation of health policies and programs;

The Virtual Health Library (VHL) comprises the technological platform and the common virtual space where *DECIDES* various components are developed.

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2 Castells, M. "Information technology, globalization and social development". Paper presented at the information technology and social development conference held at the Palais des Nations, Geneva, 22-24 June 1998. <http://www.unrisd.org/infotech/conferen/castelp1.htm>.



More details on each component of *DECIDES* follow.

## VI. INTERACTIVE HEALTH RESEARCH AGENDA (AGENDA)

AGENDA is an interactive methodology aimed to the formulation of a research agenda based on the participation of several agents. AGENDA implies a set of decisions that cannot be “implemented” as if they were something pre-existent and finished, but instead they are being constructed based on the constant evolution of interactions among the participants.

The AGENDA construction process requires delimitation of an interaction space in which various actors identify, offer, and demand responses/solutions/support, also encouraging incorporation of the “application context”, that is, the process of integrating users/beneficiaries/clients networks.

AGENDA contents can have different origins and motives. They can stem from a government decision on a subject considered strategic or they can be originated at the initiative of a group of researchers, consultants, entrepreneurs, organized communities, NGOs, public agents, etc., or any combination of these. From these multiple possible origins a given relevant problematic field is defined and the network makes it possible to join resources and capacities that result in research projects, the opportunities for their financing and the means for utilizing their results.

The AGENDA *Web site* will include:

- Forum of discussion on research problems and priorities;
- Project profiles in search of financing;
- Local and international opportunities for projects funding;

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- Publication and discussion of research in progress;
  - National and international agencies research agendas;
  - Call for research proposals;
  - Bibliographic material on research methodology;
  - Directory of institutions or agencies that execute, coordinate, and support research projects;
  - Publication and discussion of preliminary results.

Based on interactions between researchers, funding organizations, decision-makers, S&T policy formulation agencies, and general public, AISS permits the identification of problems, the formulation of research proposals, the exploration of funding opportunities for said proposals, and the dissemination/utilization of research findings. In that way, AGENDA responds to the various parties' interests, pointing out:

- *International funding agencies and other donors:* which can place their funding offers and examine project profiles in which they could be interested;
- *Community of health researchers:* who can discuss a research agenda with the decision-makers, other groups of researchers, and the general community. Furthermore, AGENDA will make it possible for them to place project profiles in the Web site, to explore funding opportunities, to know the research agenda of donor institutions and to disseminate findings of their research;
- *Institutions of coordination and execution of S&T in health activities:* AGENDA will make it possible that these institutions strengthen their relations with various sectors of the society in order to direct their research policies and efforts in relation to social demands;
- *The decision-makers in health:* those who can increase their influence in the definition of research priorities and have access to information and more solid scientific results for the decision-making process.

## **VII. HEALTH RESEARCHERS EXCHANGE NETWORK (REDIISAL)**

Several countries in the Region have an ample researcher training infrastructure, usually oriented to satisfy the local demand. Furthermore, the complexity of health/care problems in the Region poses great challenges in terms of research that could be better dealt with by promoting the complement of efforts and resources of various countries.

Despite the existence of some cooperation agreements among countries to promote researchers exchange, many of these agreements do not succeed in reaching those objectives.

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Among the reasons for the unsatisfactory results of these agreements are the scant dissemination of information about them and the limited participation of the interested parties in their preparation.

REDIISAL, as a *DECIDES* component, will build a virtual communication and interaction platform between research institutions and researchers training programs with the purpose of facilitating and promoting researchers exchange and collaboration among the training programs.

REDIISAL will promote the establishment of cooperative networks among scientific institutions of countries in the Region that will allow the exchange of researchers, educators, and students in order to carry out activities such as training and collaborative research projects. REDIISAL will also promote distance-learning and/or semi-presence courses prepared cooperatively and utilizing electronic multimedia means.

The REDIISAL *site* in the *DECIDES* realm will include:

- Directory, descriptions, and evaluation results of courses and graduate-level programs;
- Information on cooperation agreements, training opportunities, fellowships and grants offers;
- Discussion forums for exchanges among diverse institutions to promote identification of common needs and collaboration agreements;
- Virtual network of doctorate and post-doctoral programs in health to facilitate exchange of students and educators;
- News about courses and events;
- Cooperative production of electronic courses and seminars.

## **VIII. SOLIDARY CITIES (CISOL)**

This component of *DECIDES* has the purpose of increasing availability and access of scientific information for health systems administrators and the general public. CISOL tries to facilitate interconnection among cities participating in communication networks to help them share experiences and information; establish and promote agreements and services to train human resources and analyse management experiences in urban development; promote development of joint projects; and encourage citizen participation in health matters. CISOL also stimulates recording and dissemination of knowledge generated by the daily experience of decision-makers, community leaders, and the general public by encouraging posing topics and questions for the interactive health research agenda (AGENDA).

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The construction of a democratic society is only possible through the citizens' full participation in the decisions that affect them. For this participation to be genuine and furthermore effective, it should be supported by the scientific information available. Thus, the dissemination of knowledge to decision-makers and the general public contributes simultaneously to democratic governance and social capital increase.

An important factor for human development promotion is the degree of vitality of the basic components of social organization such as mutual confidence, communication networks, civic participation, and the reciprocity relationships among people and organizations, which are the fundamental components of social capital. The communication and exchange networks promoted by CISOL are simultaneously the elements of support and the result of the social capital strengthening process.

PAHO has launched various initiatives oriented to development of health at the local level and with full citizen participation, such as, the Local Health Systems and the Health Cities. CISOL becomes a valuable complement to the objectives of these initiatives, being distinguished from them by its emphasis on electronic communications in order to favor an equitable access to the information that permits health self-care, the demand of civil rights, and decision-making.

CISOL's main strategies are:

- *Utilization of scientific information:* CISOL will promote utilization of solidly sustained information so that the attitudes and practices of groups and individuals as well as political decisions lead effectively to a better health situation. To reach this goal, it will contact research centers, many of which are expected to be integrated in cooperation networks promoted by other *DECIDES* components;
- *Users' participation in the information contents design:* CISOL's central strategy is citizens' participation, not only in establishing its demands and information needs, but in the very design of the communication contents;
- *Use of modern communication technology:* CISOL is sustained by the use of electronic communication and the Internet available to decision-makers and general public in locations close to where they work and live. The scientific information will be organized in an adequate format to reach different types of users. Training of staff and community members is also foreseen for the production and dissemination of this information, the utilization of documentary and numerical electronic databases, and the command of modern communication and information technologies.  
Understanding that not all citizens have access to electronic communications media, CISOL foresees the preparation of materials and training of mediators (journalists, teachers, family doctors, lawmakers, and NGOs) between these electronic media and the public. In addition, CISOL will promote establishing access and training

opportunities for the public through the use of the Internet at schools, work sites, and common living areas.

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The principal beneficiaries of CISOL will be:

- *Citizens living in the selected cities:* who will have direct access, or through intermediaries, to information that will allow them to take better care of their health and to participate in health decisions concerning the community;
- *Health authorities and other decision-makers:* who will count with scientific information, shared experiences of neighboring cities, and feedback from the public in support of the decision-making process;
- *Health scientists interested in disseminating knowledge:* who will have communication channels for their research findings to be utilized timely and effectively.

## **IX. VIRTUAL HEALTH LIBRARY (VHL)**

The Virtual Health Library (VHL) is the Internet space on which **DECIDES** basic components are developed. The VHL was formulated and is being constructed by way of cooperative work among those institutions that produce, mediate and utilize health information in Latin America and the Caribbean. These institutions form the Latin American and Caribbean Center on Health Sciences Information, coordinated by the Pan American Health Organization (PAHO), through the Latin American and Caribbean Center on Health Sciences Information (BIREME).

PAHO/BIREME and the Regional System formulated a new technical cooperation strategy based on the construction and operation of the VHL in the context of the new products and information services operation paradigm determined by the Internet,

The VHL can be defined as the shared basis of registered scientific and technical knowledge in health, organized and stored in electronic format in countries of Latin America and the Caribbean, compatible with international bases universally accessible in the Internet. This strategy tries to progressively provide the countries of the Region equitable access to up-to-date relevant information in health. Accordingly, the VHL makes intensive use of information technologies, especially the operation of products and information services in the Internet, in order to overcome the time and space constraints that have characterized the systems for organizing and disseminating information.

The VHL is formed and developed following a compatible methodology, obeying selection and quality control criteria that sets it apart from the group of information sources on the Internet. Thus, the VHL forms a reliable space where, producers and intermediaries can make their products and information services available. In addition, the users interact or navigate through appropriate information sources that respond to their information needs. There is, therefore, a movement resulting

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from the progressive confluence of information producers, intermediaries, and users. The VHL is planned as the meeting space and manager of this confluence.

The principal sources of information that form the VHL are classified as follows:

- *Bibliographic databases* based on the LILACS and MEDLINE system realigned to operate in the VHL/Internet ensuring universal access to what is most relevant of world health sciences literature, including the production of countries in the Region;
- *Publication catalogues*: collections of books and monographs from libraries of the Region; catalogue of books in press; catalogue of health scientific audiovisuals; and catalogue of serial health science publications. These catalogues are essential for the establishment of procurement policies and the cooperative use of health sciences publications, complementing the bibliographic databases by announcing the collections location;
- *Cooperative access service to documents in electronic format (SCAD)*: it is a cooperative service with the objective of providing access to documents through the Internet to any library or professional. The request, payment and reception of the document can be done electronically. SCAD ensures not only efficient and universal access to scientific literature, but also to documents produced by Ministries, Secretariats and other institutions. SCAD will guarantee access to the electronic version of documents and scientific articles in less than 48 hours;
- *Electronic publication system on line*: The Scientific Electronic Library Online (SciELO) consists in the electronic publication of journals produced in the Region. The system today is limited to scientific journals from Brazil, Chile, and Mexico. Further to the expansion of participating countries, the SciELO methodology will be used for publishing full texts in electronic format of books, monographs, governmental and non-governmental documents, thesis, epidemiological bulletins, legislation, congress annals, and manuals, among others. The electronic publication of databases for numerical health indicators, chemical substances, health technologies, etc. will also be included;
- *Cooperative consortium for access to journals in electronic format*: it consists in establishing and operating consortia between libraries and information centers for their joint subscription to international journals in electronic format. Establishing agreements for reducing the cost of access to health services, libraries, and documentation centers in the Internet is included;
- *Selective dissemination of health information to different users*: It consists in establishing a service for the selective dissemination of information via E-mail and/or

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*PUSH*, which permits automatic dispatch of the latest available information to users, in accordance with thematic profiles of specific interest. Support for professional inter-consulting systems through *chat-rooms* is included;

- *Up-to-date directories* of institutions, specialists and health events in the Region;
- *Directed information sources*, with regard to content and form, decision-making processes at all levels—including authorities, politicians, health services managers, health professionals and different population segments;
- *Support information sources* for courses on health education in different formats and purposes;
- *Products and services* designed for communication and direct exchange of news, doubts, solutions, experiences, etc., to and among the users through discussion lists, video conferences, etc.;
- *Health information locator (LIS)*: With the massive dissemination of the Internet use, an ever-increasing difficulty in identifying the sources of reliable information is noticed. LIS is the response to the necessity to identify, certify, and select those sources and at the same time allows fast and efficient access to them. Specifically, LIS is the operation of a catalogue of health resources available in the Internet, registered in accordance to quality patterns as defined by a network of cooperating centers.

Construction and development of the VHL incorporating this information sources complex constitutes a new model or paradigm for treatment of scientific and technical health information, and represents a substantial change in the organization and operation mode of national and regional scientific and technical information systems. The VHL decentralized construction will allow these systems to master the new information and communication technology.

## **X. IMPLEMENTATION OF *DECIDES***

*DECIDES* technical cooperation strategy is made viable in practice by projects with precise results, timetable, and a geographical space defined for its operation. Although the countries belonging to this space will profit more directly, the use of modern communications technology opens the possibility for other countries in the Region to benefit from these initiatives since, once the information is placed in the Internet, it automatically spreads its advantages to all countries and users. There are two *DECIDES* projects currently in preparation: *DECIDES/MERCOSUR* and *DECIDES/US-Mexico Border*.

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*DECIDES/MERCOSUR*: The regional integration initiatives constitute a privileged environment for the development of *DECIDES* given the coincidence of objective cooperation among countries and the implementation of mechanisms that make viable this cooperation. In the case of MERCOSUR (expanded to Chile and Bolivia), its workgroup-11 —devoted to health activities—and the Specialized Meeting of Science and Technology (RECyT)—aimed at promoting the scientific and technology development of the member countries— are the principal institutions related to *DECIDES*. MERCOSUR also has the MERCOCIUDADES project made up of nearly 50 cities of the Region whose objective is to promote cooperation among them in various sectors that are in line with the objectives of the CISOL component.

*DECIDES/US-Mexico Border*: The US-Mexico border has specific characteristics with regard to health and health care, which requires a coordinated effort between both countries. For this reason, PAHO has established an office in El Paso, Texas, directed to promoting cooperation among USA and Mexico. This region has several universities and research institutions, some of which are PAHO/WHO Collaborating Centers, as well as bilateral organizations and an exchange program between sister cities. All this, plus the funding agencies interest to promote social development programs in this region, create a very favorable condition for the implementation of *DECIDES*.

These two projects and others that ultimately will be prepared to make *DECIDES* viable share elements already cited such as AGENDA, REDIISAL and CISOL components; utilization of the VHL common space; intensive use of modern communication, and information technology; creation of exchange networks and others. These projects are planned for a period of four years. At the end of this period, the networks of collaborating institutions will be capable of assuming management of the different intervention areas, supported and coordinated by BIREME. BIREME, in turn, will have developed the mechanisms required to manage the additional workload derived from the expansion of its operations.