INITIATIVE ON THE HEALTH OF INDIGENOUS PEOPLES

TOWARD A COMPREHENSIVE APPROACH TO HEALTH
Guidelines for Research with Indigenous Peoples

WORKING GROUP ON RESEARCH
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This document, produced by the first working group on research with indigenous peoples, is a preliminary proposal in searching for a comprehensive concept of health, proposing useful methodologies and techniques, and identifying priorities in research with indigenous peoples. Readers will enrich these proposals with their own contributions based on their theoretical and practical experience. In this context, the Pan American Health Organization, as a technical cooperation agency, is committed to promoting opportunities for thought that will systematize the information to achieve the general well-being of the indigenous peoples of the Region.

Note: Please complete the charts attached to this document: Data bank on researchers and research centers, and mail them to us the following address: Pan American Health Organization, 525 23rd Street, N.W. Washington, D.C. 20037. USA - Telephone: (202)974-3214 And-mail: landsand@ paho.org http://www.paho.org

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1. BACKGROUND

1.1 General Context

The First Hemispheric Working Meeting on the Health of Indigenous Peoples, held in Winnipeg, Canada in April 1993 for the first time defined the principles and made specific recommendations for work in health with the indigenous peoples of the Region based on respect for and revitalization of the culture of these peoples. However, with the admission of the People's Republic of China to the United Nations system in 1971, consideration had already begun to be given on an international level to cultural issues and the possibility of applying health programs based on a harmonious relationship between traditional medicine and western medicine. "Other healing methods," such as those used in India, the rest of Asia, Africa and Latin America were recognized and information on them disseminated (Ref:1).

In 1976, the Working Group for Promotion and Advances in Traditional Medicine was created within the World Health Organization (WHO). In 1978 at the WHO Conference in Alma-Ata, USSR, as well as within PAHO in the 1970s and 1980s, emphasis was placed on primary health care as a priority in the developing countries, with the affirmation that "...with the support of formal health systems, the agents of Traditional Medicine can become important allies in organizing efforts to improve community health ..." (WHO and UNICEF 1978:33). This proposal was welcomed with greater enthusiasm by the Asian and African countries than by those in the Region of the Americas.

Recent years have seen initiatives in different countries of the Americas for improving the living conditions and health status of indigenous peoples. Meetings have been held to share experiences. Two important events were the First Continental Meeting, Five Hundred Years of Indigenous Resistance," which was held in Quito, Ecuador in 1990, and the Continental Campaign, 500 Years of Indigenous, Black, and Popular Resistance, held in Estelí, Nicaragua in October 1992. PAHO has provided cooperation to several of these initiatives at various times.

Several countries have signed agreements, laws, and resolutions at the national, subregional, and regional level. These have been drawn up with enthusiasm for favoring indigenous peoples. Unfortunately, many of these agreements have not been ratified and the large majority of them have not been put into effect:

Principal International Agreements
• On 10 December 1948, the Universal Declaration of Human Rights was issued, based on the principles of equity, equality, and freedom.
• On 7 June 1989, Convention 169 on Indigenous and Tribal Peoples in Independent Countries of the International Labor Organization (ILO) was approved. This is the first document that includes the notion of people considered collectively whose principal collective right is territory, understood as the set of natural, geographic, cultural, mythical and religious resources that make up their world view and ensure their survival.
• In June 1992, in light of the appearance of new social movements, including indigenous and ethnic-cultural movements, The Earth Summit was held wherein "Nations recognized the need to recognize that indigenous populations have values, territory, traditional knowledge and the right to subsistence; they recognized their ecological and agricultural knowledge as vital for the promotion of sustainable development."
• On 26 July 1992, at the Second Ibero-American Summit of Heads of State and Government, 19 countries signed the Agreement Establishing the Fund for the Development of the Indigenous Peoples of Latin America and the Caribbean, whose general objective is to "support the processes of self-development of indigenous peoples, communities and organizations in Latin America and the Caribbean and to guide the actions, strategies, and the Indigenous Peoples' own autonomous organizational forms at all levels."
• In 1993, thanks to the efforts of the indigenous peoples themselves in promoting human rights, conservation of the environment, development, education and health, the United Nations General Assembly proclaimed the year 1993 as "International Year of the Indigenous Populations of the World." In 1994, in Vienna, during the United Nations Conference on Human Rights, it was recommended that the International Year become the "International Decade of the Indigenous Populations of the World" (1994 - 2004) and it was suggested that a permanent forum on the subject be established.

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- In April 1993, the First Hemispheric Working Meeting on the Health of Indigenous Peoples was held in Winnipeg, Canada. In consultation with representatives from these peoples, the Meeting defined the principles for developing and putting into operation the Initiative on the Health of Indigenous Peoples of the Americas. The principles established at the Winnipeg Meeting were ratified at the subregional workshops in Santa Cruz, Bolivia and Quetzaltenango, Guatemala in 1994. These principles are:
. Need for a comprehensive health approach
. Right to self-determination
. Respect for and revitalization of indigenous cultures
. Reciprocity in relations
. Right to systematic participation

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- The recommendations of the First Hemispheric Working Meeting culminated with the approval of Resolution V at the XXXVII Meeting of the Directing Council of PAHO, on 28 September 1993. Resolution V reflects the political will of the Member Governments of the Pan American Health Organization in the sense of promoting the Initiative on the Health of Indigenous Peoples of the Americas and gives a mandate to the Secretariat of PAHO to promote the Initiative.

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- In 1994, in view of the difficulties faced by the health sector, the Summit of the Americas was held. Its Plan of Action contains the resolution on "equitable access to basic health services" and an agenda that includes reaffirmation of the resolutions of the World Summit for Children of 1990, the Nariño Agreement of 1994 and the 1994 Conference on Population and Development to reduce infant mortality by one-third and maternal mortality by one-half by the year 2000. This was in addition to the commitment to develop, in accordance with mechanisms defined by each country, reforms designed to reach the targets of child, maternal and reproductive health; universal and non-discriminatory access to basic health services; care for the poor, the disabled and indigenous populations; a more solid public health infrastructure; alternatives for financing, administration and delivery of services; quality assurance and greater participation from agencies and NGOs.

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(1) Convention 169 on Indigenous Tribal Peoples in Independent Countries 1989 - Regional Office of ILO for Latin America and the Caribbean, 4th, Updated edition: November 1992.
(2) "Project for the creation of the Fund for Development of Indigenous Peoples in Latin America and the Caribbean" - Documents Series No. 1.

1.2 Initiative on the Health of Indigenous Peoples: 1995-1998 Plan of Action

The Initiative on the Health of Indigenous Peoples of the Americas emerged in September 1993 to support the attainment of the goal of health for all under the principle of equity and as a result of joint efforts of representatives from the Governments of the Region, nongovernmental

organizations, indigenous organizations and indigenous peoples of the Americas. The principles and recommendations for developing the Initiative and putting it into operation were defined at the First Hemispheric Working Meeting on the Health of Indigenous Peoples held in Winnipeg, Canada and were ratified under Resolution V adopted by the Directing Council of PAHO in September 1993 (HSS/SILOS-34), and by the Subregional workshops held in Santa Cruz, Bolivia and Quetzaltenango, Guatemala in 1994.

In response to the mandate of Resolution V and considering the complexity of the indigenous problem, the Pan American Health Organization is promoting the initial actions, in which the Member States are committed to discovering how to adapt health services to the values and practices of their indigenous peoples, while recovers and disseminates indigenous knowledge of prevention and disease cure and health promotion.

In May 1995, in consultation with indigenous representatives and the Member Governments, under the terms of the recommendations from the Winnipeg Meeting, the Subregional workshops and the stipulations of Resolution V, PAHO developed a broad working plan known as: *1995-1998 PAHO/WHO Plan of Action for Promoting the Initiative on the Health of Indigenous Peoples of the Americas*. The plan has identified four lines of action: plans, policies, processes, national and local human resources; projects for priority problems and vulnerable populations; development and strengthening of traditional health systems; and coordination, promotion, dissemination and exchange of scientific and technical information. It also presents a general view of the background, goals, schedule of activities, and expected outcomes for the Decade of Indigenous Peoples of the World, for 1998, as well as for each year up to 1998.

Due to the complexity of the indigenous problem and the need to give just and specific treatment to each country and indigenous group in the Region, the Initiative has been designed to be taken up in different phases. The approximation phase that will lead to knowledge that is more adequate and closer to each reality has begun with Panama, Honduras, Nicaragua, Colombia, Ecuador, Bolivia, and Chile. It continues with Guatemala, Mexico, Peru and Venezuela and then with Argentina, Belize, Brazil, El Salvador, Guyana, Paraguay, and Suriname but does not overlook the remaining countries.

In making the Initiative operational, at the internal level PAHO –both at Headquarters and in the Representative Offices– is promoting an interprogramatic process of joint work among the divisions and programs of the Organization, coordinated by the Unit for Organization and Provision of Services of the Division of Health Systems and Services Development (HSP/HSO). At the external level, PAHO has assumed its role as facilitator and coordinator for establishing a multidisciplinary, intersectoral and interinstitutional process of reciprocal cooperation among the actors involved in improving the living and health conditions of the peoples of the Region, placing priority on the participation of indigenous peoples through their representatives.

The concrete shape that these processes take will determine the effect of plans, policies, projects, and training programs that are appropriate, realistic, viable and sustainable; the establishment of real priorities in the field of indigenous health based on real data; and the structuring of a health system which is accessible, efficient and effective for the entire population of

the Americas. In this context, research has a preponderant role as the challenge is to achieve the consolidation of these processes without interfering in the dynamics of life of indigenous peoples, to find the proper methodology, to call for the equal participation of all actors, and to work on firm bases provided by in-depth knowledge of the real conditions of indigenous peoples and their communities.

1.3 Research on the Initiative on the Health of Indigenous Peoples

Both the Winnipeg Meeting and the subsequent workshops reiterated the need to prioritize research as an alternative for learning and shared knowledge among the peoples of the Region. The workshops also indicated the urgency of undertaking a systematic, participatory and collaborative process of research to identify priority areas, methodologies, guidelines, and indicators based on the actual living and health conditions in which the indigenous peoples are evolving.

This conceptual proposal and the recommendations specified herein are the product of the working group on "Research: Guidelines, methodologies and training programs with indigenous communities," held on 29 and 30 November and 1 December 1995 within the framework of the Initiative on the Health of Indigenous Peoples of the Americas. The working group had contributions from 7 researchers in different sectors, 3 of whom were indigenous, and from the Focal Points of the Initiative in several Regional Programs. The objectives of the working group were:

- To analyze research trends in the Region and their contribution to the process toward comprehensive well-being of indigenous peoples.

- To identify priority areas that should be addressed in research with indigenous communities, and the strategies for implementing projects in these areas.

- To discuss aspects related to methodology, indicators and codes of ethics in different types of research (epidemiological, operational, participatory, collaborative, ethnographic) in indigenous communities.

- To obtain proposals with regard to guidelines for research on methodology, regulation of intellectual property and establishment of codes of ethics for research with indigenous populations and the practice of traditional medicine, including medicinal plants and programs for training in research.

2. GENERAL TRENDS IN RESEARCH WITH INDIGENOUS PEOPLES

The social, economic, political, and cultural changes of the last decade have notably influenced the state of health and well-being of most countries in the Americas. Indigenous peoples are not isolated nor do they constitute a self-contained group. They are part of the dynamics of the Region and as a result their problems depend to a great extent on the historical, social, cultural, political and economic reality of the entire society. Based on available estimates and sources, the indigenous population of the Americas is approximately 42 million people distributed in some 400 ethnic groups; this would represent about 6% of the continent's population and somewhat less than 10% of the population of Latin America and the Caribbean (HSS/SILOS - 34). Although these percentages may vary throughout the continent, the historical importance of indigenous peoples is unquestionable.

As part of the world process of change, the countries of the Region have been redirected toward globalization of the economy, communications and many services, with neoliberal and state modernization policies, overlooking the multi-ethnic nature of their populations. Will indigenous peoples be able to survive the globalization process? Will traditional community ties be strong enough to confront the shocks of a free market that is so cold, exact and impersonal? Can the necessary changes be made in the Americas so that marginal groups will be part of national societies, with effective application of the much-touted constitutional rights of multiculturism? Can indigenous peoples survive in areas where the most important strategic natural resources are located? Can they preserve their genetic heritage and biodiversity under the pressures of finding and producing new therapies? (Cunningham, 1996 Ref:2).

Around the mid-1980s, the prevailing notion was that macroeconomic balance was the fundamental condition for development and that inflationary processes had their greatest effects on those with lower incomes. To this was added pressure on the public sector to eliminate expenditures allocated to serve the population sector that was not poor and to increase its efficiency in producing services. Faced with this situation, several countries established emergency or social investment funds to mitigate the effects that the crisis and adjustment programs had on the most vulnerable social groups. The funds, which operate with quite a lot of autonomy, were conceived as a complement to a public sector whose ability to perform was being questioned (Ref: 3).

Reality showed that economic growth alone did not result in increased equity, nor did the mere redistribution of wealth lead automatically to economic growth. The idea was resurrected that an appropriate distribution of the benefits of economic growth, reflected in improvements in the living conditions of the population, was what distinguished an economy that is growing from one that is developing. This new perspective has been expressed in the commitments undertaken at recent international summits on children, the environment, population and social development, as well as at the Summit of the Americas, formulating overall guidelines and solutions for overcoming the unequal conditions in which significant population groups live. The correct implementation of these recommendations should be based on joint research with the full participation of indigenous peoples (Ref:3).

Research related to indigenous peoples has always been carried out in terms of "others" and has thus probably been included within anthropology. The emphasis has been on studying the "exotic" characteristics of these peoples, as a curiosity, the value of which became greater during the second half of this century while the number of indigenous peoples was declining and those who remained were trapped in the crushing wave of acculturation. The principal areas of research became studies aimed at looking for mechanisms to assimilate indigenous peoples within the flow of the dominant society. An example of this was the *indigenista* school that predominated in Mexico and the United States in the 1960s (Ortiz 1984: 78-81). However, although some indigenous populations tried to integrate themselves, the dominant society resisted accepting them fully, pointing to their "otherness" as an obstacle to their full participation. The resistance of indigenous populations and their decision to continue existing as "different" and "differentiated" cultures and societies is the fundamental element in the "persistence" of indigenous peoples in the continent.

Numerous studies on medicinal plants, most of them removed from the cultural context of the ethnic groups, were produced in the 1970s and 1980s. The communities, almost in their entirety, did not participate in the results obtained, much less in the economic benefits that much of that research has reported. The 1980s and 1990s have put the indigenous peoples on notice as the forces of globalization have incorporated them all without distinction as parts of the large blocks of economic society.

Like many other minority groups, indigenous populations have found the opportunity to question their insertion in the new world order. The topic of cultural identity has become the principal subject of research, especially in terms of its economic, political and cultural determinants (Benjamín and Tiessen 1994:252-261 and Fields 1994:232-248). In this context, an important effect of the emphasis on cultural identity has been the increasing numbers of indigenous people who have slowly taken the initiative in their own research (Stavenhagen 1994; 77-80, Watanabe 1995: 25-46, and Warren 1994:81-86), occupying a space previously dominated by non-indigenous people. By doing so, they have turned the bogeyman of "otherness" upon its head. They now seek to determine the agenda of research about themselves, what to study, how, and who will do the research. The presence of indigenous professionals who assert the needs of their peoples will produce a new and vitalizing element in research.

The participation of the communities, their leaders, advice from elders, traditional therapists in the process of research –from the start of any research proposal– will be a very important factor in recovering the confidence of these peoples in the agencies, organizations, institutions and people with research proposals that involve them.

3. TOWARD A COMPREHENSIVE CONCEPT OF HEALTH

3.1 Health Sector Reform

Many countries in the Americas are embarked on processes that involve some type of reform in their health sector. The subject of equity is central in most of the initiatives under way, although in many cases it is only stated as an intention. In general, the processes of reform have set themselves the objectives of achieving a better level of health for the entire population, equitable access to health care and better quality and greater efficiency in systems and services (Ref:3).

Expanded health system coverage refers both to providing services to social groups currently without access or with limited access to such services and to including new benefits that were lacking in the portfolio of services provided. The first case emphasizes coverage for poor populations in urban peripheries or rural areas, mothers and children, indigenous populations and temporary workers. The second case involves attending to emerging problems related to demographic and epidemiological changes. Added to this is the globalization of standards of service consumption and new possibilities for services opened up by technological development in health (Ref:3).

As indigenous populations are one of the most marginalized sectors of society and those most affected by emerging diseases, the challenge to Health Sector Reform is to find a response consistent with the sociocultural reality of these peoples. The place of health in this new research agenda is essential. Social and cultural well-being cannot exist without physical well-being, which itself is threatened by lack of access to existing services, malnutrition caused by the dismantling of the food production system and the destruction of the means of survival. High rates of morbidity and mortality due to several diseases have put some peoples at risk of extinction, especially those who are few in number. The determination of the epidemiological profile of these peoples at the regional, national and local level will trace their living conditions and health; the priority is to be capable of expressing their real needs.

3.2 Health as Harmonious Coexistence

3.2.1 *Different Perspectives in the Approach to Health*

Great resistance from civilian society in general and from health professionals in particular to knowledge about and comprehension of the culture of indigenous peoples has led to a strengthening of negative stereotypes about these peoples. The large majority of health programs have tried to indiscriminately promote changes in the behavior and lives of indigenous peoples as part of proposals for "improving their health." The spiritual dimension of healing, which is so essential, has not been taken into account.

In the context of the Americas, overcoming stereotypes and knowledge and dissemination of indigenous values as "protectors of health" will determine valid solutions for these peoples. Health is not the exclusive result of services provided to individuals or communities, but also depends on policies adopted by the different sectors of the governmental structure.

For the indigenous world, disease is conceived of as interference with normal social behavior and the individual's ability to work. Problems or imbalances in the supernatural sphere, in the body, the emotions, and the social or physical environment are some of the causes that explain the presence of disease. Indigenous culture interweaves disease with the maintenance of physical, psychic and spiritual balance and with religion and social relations.

In this process, we thus detect the presence of very different perspectives in the approach to health. The situation worsens with problems such as the lack of consensus among actors within each country and the cooperation agencies regarding the content and nature of proposals to improve indigenous health and political viability which requires great leadership and negotiating capacity as well as immediate adjustment to changing circumstances; the lack of continuity in the actors responsible for promoting processes, directing the respective studies and negotiating proposals; technical complexity that sometimes makes it difficult to obtain enough social support to overcome the resistance of those who oppose change because they lack adequate knowledge regarding the benefits of the alternative proposals; insufficient attention to community participation in processes. These are several of the problems facing the processes for improving the living and health conditions of indigenous peoples (Ref:3). The search for greater community participation, consistent with growing democratization in the Region, will make way for cooperative and indigenous solutions to the health problems of the Americas, where the voice of indigenous peoples should be considered.

3.2.2 *Strengthening Indigenous Peoples*

The criteria most commonly used to characterize the indigenous population have been the language spoken, self-identification and geographic concentration (territoriality). A combination of these criteria is needed. Regarding self-identification, the acculturation variable has great significance. However, it must be pointed out that the sense of belonging to a group is subject to different stages in an individual's life. Usually, while adolescents reject ethnicity, adults recover their sense of belonging and identify themselves as part of a group. The indicators of acculturation, of return and of revitalization are very important. There are peoples who have lost the language and others who have recovered it. In Peru and Paraguay, a high percentage of the non-indigenous population speaks the native languages, Quechua and Guarani. In Mexico, the indigenous population has grown because self-identification has increased. To the extent that there are processes that recognize the contributions of the indigenous population and its culture, denial of indigenous identity will decrease.

It is not difficult to identify valid indicators when the culture and life of the people are known. What the "elders" think is related to life and the protective aspects of health and constitutes guidelines for establishing variables.

In Winnipeg, there was debate regarding the scope of the term "indigenous" and the connotations of its use. The consensus was that "indigenous" peoples are those who recognize themselves as such. In addition, ILO Convention No. 169 on Indigenous and Tribal Peoples (1989) recognizes as "indigenous populations," sectors distinguished from the national community, "... peoples in independent countries, considered indigenous populations because they descend from populations that inhabited the country or a geographical region to which the country belongs, at the time of conquest, colonization or the establishment of the current state borders and that, whatever their legal status, retain all or a part of their own social, economic, cultural and political institutions." (Convention No. 169, Article 1).

The Initiative on the Health of Indigenous Peoples assumes these concepts and the commitment to promote, as is stipulated in its principles, the systematic participation of indigenous representatives in any proposal involving their people and reciprocity in the relations among the various actors in the process directed to the comprehensive well-being of these peoples. In addition, under Resolution V, the governments of the Region commit themselves to facilitating the establishment or strengthening of a high-level technical commission or other mechanism of consensus, as appropriate, with the participation of leaders and representatives of indigenous peoples, for the formulation of policies and strategies and the development of activities in the areas of health and the environment for the benefit of specific indigenous populations (HSS/SILOS-34, Resolution V). With these premises, within the context of explicit recognition of multiculturalism as a constitutional mandate, respect for the multiculturalism of the nations, the reassessment of indigenous knowledge, the strengthening of the uniqueness of their own cultures, the goal should be that indigenous peoples again take control of the course of their own lives, of which health is only a part.

The challenge presented by lack of adequate and sufficient knowledge and information regarding the health of indigenous peoples in face of the mandate to act and achieve immediate effects, requires participatory planning and operational research, through a participatory process of planning -action-reflection-action as a strategy for generating knowledge and adequate information while activities are being carried out. Research as a tool to support the community will help in implementing solutions based on ancestral knowledge and will strengthen local organization based on the decision-making and management of indigenous peoples.

As long as power is concentrated in the non-indigenous world, it is impossible to speak of equity. The strengthening of their capacity as people will lead indigenous peoples to generate their own discussion of their problems and solutions. It is important to identify and promote positive factors that protect community and family health and have made it possible for communities to survive and in some areas to maintain health levels similar to those of more advantaged sectors. The ultimate purpose of addressing these problems jointly and proposing improvements is not to help the indigenous peoples but rather to help each other so as to achieve health for all (SILOS-34).

The processes through which indigenous peoples have lived provide a 503-year history of extermination, abuse, exploitation, colonialism, discrimination, abandonment, and neglect that have left a mark on their living conditions and their position within society. In the Region, their struggle to maintain their culture and identity and to recover their land, territory and rights has been

continuous, leading to a process that has strengthened indigenous organizations and peoples. A respectful accompaniment to these processes is a priority.

3.2.3 *Toward a Concept of Health as Harmonious Coexistence*

The comprehensive approach to health in research with indigenous peoples should consider a conceptual and epistemological perspective. According to the World Health Organization, health is defined as biological, psychological and social well-being. The concept of health, as such, does not exist among indigenous peoples. For them, health is a collective matter. Well-being is harmony among all elements that make up health, it is the right to one's own understanding and control over one's life, and the human being's right to "harmonious coexistence with nature, with oneself and with others, directed to comprehensive well-being, to fullness and spiritual, individual and social tranquility." (definition of a group of indigenous peoples from the province of Bolivar, Ecuador). The comprehensive and holistic nature of the definition are concepts that have always been present among indigenous peoples, colored by the essence of the multi-ethnicity and multiculturalism of these peoples.

Setting priorities in health from a perspective that is foreign to the reality of indigenous peoples leads to fragmentation of problems and solutions and overlooks their world view, the historical processes of the society and why these peoples occupy the place they do within the current social structure. Indigenous populations have a different way of analyzing and prioritizing. They define problems in terms of processes and not in terms of problems. For example, migration, alcoholism, domestic violence, drug abuse and the use of weapons are defined as serious problems, while infant mortality may be seen as a less serious problem, if the direct effects on the community are considered.

However, in the current context of the social structure and changes in the Region, who is going to determine priorities in the work with indigenous peoples and what is their participation going to be? Complex historical and social processes include many variables that require a different conceptualization. How are we going to overcome theoretical prejudices? How are the social problems of indigenous peoples analyzed? The western perspective has put too much emphasis on specific problems, forgetting the process and the context demanded by the holistic analysis of the indigenous world view. Acculturation, the loss of territory, family relations, social issues, problems of the ecosystem: these are problems that lead us to think that we must expand the systems of analysis and promote identification of an alternative paradigm other than that imposed by the dominant culture.

Indigenous populations do not live in isolated communities. For the majority, their daily lives take place in two worlds. Changes in the Region, historical and recent diasporas and migrations among the indigenous populations have not been given sufficient consideration. These processes, exacerbated by economic crises, armed conflicts, the impact of the labor market and civil wars, are not individual processes. They are political processes that have implications in different areas. In this panorama, some questions arise. How can we facilitate the maintenance of their culture by taking advantage of their own mechanisms which have led them to survive as peoples? How do we provide a real response to their needs and problems under these new circumstances?

How are the changes of globalization and modernization affecting different groups, particularly indigenous groups? Are more social problems being created with the proposed solutions? Nobody has analyzed these processes from the point of view of indigenous peoples. In the context of Health Sector Reform, what will happen to the indigenous peoples with respect to epidemiological transitions, chronic diseases, and risk factors versus factors "protecting health" that are specific to these communities?

4. PRIORITY ASPECTS

4.1 Sensitization Process

Discrimination in many countries of the Region is part of the life of the society. This "daily life" aspect would seem to have made it appear "normal." The scale of artificial prestige as a result of colonization put the indigenous population in the lowest position. Subsequently, the absence of policies favoring them, has not only condemned them to the situation of poverty and abandonment in which they live but which has pointed them out as being "responsible" for remaining in those conditions, thus giving rise to negative stereotypes, the use of pejorative adjectives regarding everything associated with the indigenous culture, and mistreatment that reaches the point of being institutionalized discrimination. The alienation caused by such adverse conditions has led many indigenous peoples to deny their roots and their ancestors. Acculturation has become a debilitating factor for these peoples.

The need for sensitization and promotion of the self-assessment of the proposals under way at all levels is an urgent task. The Pan American Health Organization, as a technical cooperation agency, has a fundamental role. Its presence in the Region through the Representative Offices facilitates the creation of opportunities to promote consensus-building among the different sectors of the country.

The establishment of an ongoing process of intercultural education and self-instruction, and thus a reassessment of these peoples both at the formal and informal levels, will make it possible to learn about the immense cultural reserve that has survived despite such negative conditions.

In this sensitization campaign, the role of governments, the communications media, civilian society and the indigenous peoples themselves is fundamental. Recognition of the multi-ethnic and multi-cultural nature of the populations in the countries of the Americas under the Constitution of each country would establish the legal framework for implementing plans and programs consistent with the characteristics of the population. The recognition of differences as a resource would lead to the need to know more about the cultures with which we are living. The promotion of seminars to discuss topics concerning the living and health conditions of indigenous peoples as well as the processes that concern society in general would open up room for thought where the representatives of these peoples themselves would explain their situation and/or position and present and receive proposals for solutions and joint work.

The dissemination of international agreements that favor the indigenous peoples of the world and the Region; the dissemination of technical information to channel the direct work at decision-making levels as well as information accessible to the population in general, the dissemination of the principles and lines of work that govern the task of indigenous health within the framework of the Initiative on the Health of Indigenous Peoples of the Americas and its evolution, presents an opportunity to learn about and contribute to the proposals of the Pan American Health Organization and contribute to the process of sensitization in the Region.

4.2 Retrieving Information

4.2.1 *Reassessment of Indigenous Knowledge*

The tendency to consider indigenous knowledge as unscientific has meant that the standards of scientific knowledge from the western point of view prevail in the academic arena. In many cases, the program of studies, the approach to indigenous subjects and the analysis of these problems have overlooked the sociocultural context of these peoples. The search for a paradigm that complements the proposals of both indigenous and non-indigenous learning is necessary.

Within the communities there is a reserve of accumulated knowledge to which the indigenous populations themselves have limited access. The study of the process of producing and utilizing knowledge about these peoples would be framed within the requirements of what is called scientific. Recognition that the contribution that indigenous knowledge has made to the preservation of nature, the environment and life itself –not only that of the indigenous peoples but also the population in general– would support a reassessment of indigenous cultures.

The challenge is to know how to use western knowledge for the well-being of indigenous peoples and under what circumstances indigenous knowledge or western knowledge is more appropriate. The two forms of knowledge are not antithetical and access to both would make them complementary.

As a preliminary step for this joint work, we should all be able to "speak the same language." The fact that one belongs to this or that world, allows one to better to understand the problem of their world, and this, rather than being a difficulty, should become an advantage. By establishing a simultaneous and operational process of inter-cultural and multi-directional learning and training, we would succeed in learning, understanding, including and respecting what is different from our world. We would be capable of producing learning and adequate information while we act "–of learning by doing–" and of systematically recovering knowledge and information produced by experience "learning from what has been done and what is being done."

4.2.2 *Retrieving Information*

There is usually agreement about considering Latin America and the Caribbean as a multi-ethnic and multi-cultural grouping. Despite the numerical importance of the indigenous population in the Americas, not all countries have compiled information in this regard. In the 1980s, only 9 of the 35 countries in the Region included information on the indigenous population in their censuses or household surveys. In general, information from official sources in the countries of the Americas and the Caribbean, except for information on epidemic outbreaks or special studies, has utilized changing definitions or has simply omitted the ethnic qualifier in national population censuses, as well as in ongoing registries of births, deaths and migrations (Ref:4). Available national data are homogenized and obscure the reality of the indigenous populations, to such an extent that, as in the case of the Caribbean, these peoples do not enter into social assistance programs, or as in the case of Argentina, the Tehuelche and Aoki Ken ethnic groups are in danger of becoming extinct and there are no policies that favor them. If we recognize that indigenous peoples have specific problems and specific inalienable rights, the lack of data has been one of the excuses at decision-

making levels for doing nothing to improve their situation. The information available in the Pan American Health Organization is also incomplete.

Data and information from secondary sources, on the other hand, demonstrate that the level of health and nutrition among the indigenous populations of the Americas is several times lower than national averages and in some regions reaches alarming extremes (HSS/SILOS-34). Although it is true that the formation of a data bank has political implications, and mistrust has been produced by negative experiences, it is possible that some indigenous organizations are opposed to the acquisition of data with regard to their peoples. It is also true that the lack of data makes it difficult to monitor, supervise and evaluate projects, programs, plans and proposals that involve indigenous peoples. Above all, it slows down the visualization of the problems that oppress these populations and the formulation of policies that respond to the real needs of these peoples. In this context, the formation of a data base implies joint work by the different sectors and disciplines and especially the systematic participation of the representatives of indigenous peoples in the Region.

The limited availability of documented and systematized experiences also hinders the dissemination and utilization of the lessons learned locally, nationally and regionally. In this respect, we should emphasize the importance of data at the local level to indicate the peculiarities and/or similarities of peoples. Several border peoples are split among nationalities. When we refer to indigenous peoples, the national borders of the republics are subject to change. An ethnic map would be supplemented with an epidemiological map and would complete the picture of the health and living conditions of indigenous peoples. Multi-country efforts would provide dynamism in achieving the comprehensive well-being of these peoples.

The Pan American Health Organization has accumulated experience in the area of recording and evaluating levels of health and living conditions in almost all countries in the Region. This would be strengthened by establishing appropriate mechanisms for collecting and utilizing the information with the perspective and the support of indigenous organizations and communities. The complexity of the indigenous problem and the lack of sufficient resources, making it impossible to address each and every urgent need of these peoples, require a search for alternatives so that existing resources can be better utilized, avoiding duplication of efforts and promoting a process of mutual learning based on experiences in the Region.

4.3 Training of Indigenous Researchers and a Code of Ethics

As long as the formulation of policies, the management of projects, the preparation of projects, etc., are elements foreign to indigenous populations, these tasks will remain in the hands of non-indigenous people. As long as the non-indigenous world is unaware of the alternatives of ancestral knowledge and the alternatives offered by conceptualization based on the indigenous world view, this collaboration of the two worlds will not have firm bases. Often, the researcher, whether indigenous or not, who works with indigenous peoples has been underestimated. The presence of indigenous researchers in the work of the Initiative demands equal rights and responsibilities as well as some changes in the approach of the research process.

The dynamic of indigenous peoples is different, time has a different connotation, the agricultural calendar and holidays mark essential elements that should be respected. The absence of basic services, limited accessibility to the communities, difficulties due to climate according to the time of year, etc., do not enter into the logic of western urgency which demands strict adherence to timetables. Although consideration of these differences does not mean decreasing the rigorousness of requirements and standards, planning for research with indigenous peoples must take into account the overall context of this world.

With regard to requirements for access to resources for research and information related to topics of interest and guidelines, the Pan American Health Organization has published, through the Program of Research and Technological Developments in Health of the Division of Health in Development, the "Manual on Policies, Standards and Procedures" (March, 1994) and the document: "Areas, Lines and Priority Subjects of Research." The dissemination of these and other similar publications would make room for thought, allow for receiving new ideas and complement the existing information.

With regard to intellectual property and research involving human beings, there are internationally accepted regulations. However, when these aspects refer to indigenous peoples, there are no specific regulations that respond to the specific nature of these peoples. Many negative experiences have created mistrust and misgiving among the representatives of indigenous peoples who, in light of the absence of standards that support them, consider warding off any sector that seeks to work with them as their only option.

The collective sense of indigenous peoples requires defining standards that are consistent with their idiosyncrasies. In indigenous communities, there are codes of ethics that have survived from generation to generation, where the roles of the community's members and confidentiality are essential. How would one proceed in the case of a communicable disease in a community where there are certain standards involving female or male roles? What information provided to the researcher can be divulged? Which subjects can been discussed collectively? Can the researcher violate an ethical standard of the community if he/she disseminates specific information? An understanding of these codes for formulating specific standards in research with indigenous peoples should become clear in daily work with these peoples.

Intellectual property as a collective right has taken on importance not only in research on medicinal plants, but also in studies aimed at recovering medical practices, practices for preserving the environment and practices that support studies on biodiversity. It is urgent the accessibility and dissemination of published material on the formulation to regulate both the intellectual and material benefits obtained from the knowledge acquired.

The analysis of the impact of proposals with indigenous peoples should include the formulation of the proposals. Successful projects that fail to publish negative results and even damage to the community caused during the course of the project are not rare: acculturation, destruction of the environment, alteration of the population dynamics, dependency, etc.

The Pan American Health Organization, as part of its program to support research, has given priority to the work of organizations and institutions whose lines of action and philosophy agree with those of the Organization. However, recognizing the gaps that exist in terms of standards of ethics for research with indigenous peoples, it will give priority to discussion leading to the formulation of standards based on the rights and the differences of indigenous peoples in the Region.

4.4 Specific Cases

4.4.1 *Infectious Diseases: Malaria*

In the Americas there are still groups in which both the incidence of and mortality from preventable diseases is high. Malaria is endemic in many tropical regions of the world. Of the 740.3 million inhabitants in the Americas, 665.6 million live in areas that are sometimes considered suitable for the transmission of malaria. It is the indigenous groups that have suffered the worst consequences. In 1991, a study in 16 indigenous towns in the Yanomami area was carried out in Brazil. The study examined 18,140 people. The most important diseases were malaria (357.9 cases per 1,000 of population) and intestinal parasitic diseases (117.5 cases per 1,000 of population). These, together with acute respiratory infections (104.2 per 1,000 of population), represented about 60% of the total diagnoses.

How can these groups which do not utilize the western knowledge that society has accepted as good teach us principles and practices that are beneficial, even for our survival as a species, if they themselves are at risk of becoming extinct? When proposing that we learn about and disseminate indigenous knowledge, who will be the real beneficiaries of this research?

Social prejudices and stereotypes hamper the work with indigenous peoples. In the evaluation of a malaria program in the Amazon region of Colombia and Venezuela, the indigenous population was described as "incapable of learning." During conversations with the indigenous leaders, it was discovered that their people knew the disease and distinguished it from other febrile diseases. However, the extraction of blood requested for the malaria diagnosis had a profound cultural connotation and hence this procedure was rejected. In a local survey carried out by William Millike of Kew Gardens, on cultivable and non-cultivable species used by the indigenous yanomami population in the Amazon region, 80 species of plants used for treating fever in general, including malaria, were identified (Ref:5). At the levels concerned with available treatments, research and health policies, there is a need to question and reformulate fundamental concepts on health systems. Such a reformulation would recognize the capacity of indigenous knowledge to support and, in some cases, lead in the search for effective treatments and methods of dispensing these in the control of endemic and tropical diseases.

The solution of urgent problems identified with the communities has as a real priority the understanding of problems in their context by the people who are going to work with indigenous peoples. It is necessary to go beyond a specific definition of health which, instead of following a predominantly western paradigm, includes and respects other equally valid concepts in health, and in the particular case of malaria as a specific disease, in its diagnosis, monitoring and treatment. Indeed, many of the approaches used in "alternative" or "complementary" medicine in North America, Western Europe and Australia have their origins in the ancient, traditional forms of health care.

In populations with access to western medicine, treatment against malaria varies from region to region and even from country to country. However, some common aspects have been identified in terms of the medication used. Conventional anti-malarial drugs are usually expensive, difficult to obtain locally and sometimes ineffective. Some strains of plasmodium falciparum have developed resistance to chloroquine (Ref:5).

In areas where the population does not have access to western medicine, traditional medicine presents alternatives. Several ethnobotanical research studies have documented the effectiveness of treatments based on medicinal plants. Many plants such as qinghaosu (*Artemisia annua*) from which artemisinin, a drug used in China and Vietnam to combat malaria, is derived, have been used for hundreds of years. Traditional treatments can not only provide a reliable alternative in view of the scarcity and lack of biomedical treatments, but they can provide the essentially cultural and spiritual connotation in local communities. Through direct participation with local peoples to provide precise understanding of how malaria is viewed and consequently how it can be treated, this disease can be eradicated. This area of knowledge has been overlooked until now (Ref:5).

Research on medicinal plants that act to control vectors, such as the work carried out in Ethiopia and Uganda on the use of *phytolacca dodecandra* in the control of schistosomiasis and other water-borne parasitic diseases, offers important new directions with regard to prevention. Academic emphasis and the distribution of resources must be re-balanced in research that relates exclusively to the isolation of the active ingredients of plants. In vivo and in vitro studies would thus be a second step after medicinal plants have been identified in the field, together with information on the preparation of medicines, cultivation method, and cultural values.

To ensure the sustainability of natural health care and alternatives based on medicinal plants for future generations, policies need to address the fundamental interaction between health and biodiversity. This will require new bilateral and multilateral investments in the conservation and cultivation of medicinal plants. It will require strengthening –and in some countries, creating– policies and an organizational infrastructure for developing traditional medicine. Finally, it will require the generation of new and profitable research methodologies together with national policies to guarantee safety and effectiveness (Ref:5).

In recognition of the validity of the alternatives presented by traditional medicine, consideration should also be given to a systematic exchange of knowledge among shamans, healers and herbalists to promote communication among indigenous groups, to document and disseminate experiences in the complementary work of medical systems and, where appropiate, to codify knowledge to make it available to all.

4.4.2 *Reproductive Health*

Reproductive health as a part of comprehensive well-being is part of the community concept of balancing the individual with nature, society, family and himself or herself and responds to a community ideology currently confronting large problems (Ref: 6). High rates of maternal and child morbidity and mortality, discrimination, the lack of opportunities for improvements for indigenous women and men, and violence are examples of the deterioration of reproductive health, in the broadest sense of the concept, among indigenous peoples.

During the 1990s, a cycle of conferences, particularly the Fourth World Conference on Women (Beijing, 1995), the World Summit on Social Development (Copenhagen, 1995), the International Conference on Population and Development (Cairo, 1994) and the World Conference on Human Rights (Vienna, 1993), as well as the Convention on the rights of children, the Convention on elimination of all forms of discrimination against women and the Declaration on the elimination of violence against women culminated in a progressive and ambitious program to achieve social equality, justice, development and peace (Ref:7).

In substance, the International Conference on Population and Development and the Fourth World Conference on Women established that health and reproductive sexual rights are fundamental for human rights and development. Although the subject of reproductive health in terms of indigenous problems was discussed in several countries in preparatory meetings for these conferences, due attention was not given to the voice of indigenous women and men in the establishment of resolutions.

The incipient representativeness of indigenous peoples in Cairo, Beijing and other international meetings, as well as negative experiences in regard to reproductive health and the implementation of family planning programs, deepen the misgivings that hinder the implementation of a joint work process (De Souza, 1995 and Hartman, 1995). In this document it is important to present a summary of what was established at Cairo and Beijing as an invitation to the different sectors to make room for consideration wherein indigenous peoples have decision-making power.

The International Conference on Population and Development and the Fourth World Conference on Women, echoing other international agreements, supported basic concepts that should transform the process of policy formulation in this area:

- *Health and sexual and reproductive rights*, especially a woman's fundamental right to assume control over and make decisions concerning her body and sexuality, are an integral part of development and human rights.

- *Good sexual and reproductive health*, beyond the emphasis on demography and family planning, is a precondition for achieving socioeconomic progress and sustainable development. Ensuring universal access to a broad range of information and sexual and reproductive health services, especially for women and adolescents, should be a priority goal of national programs.

- *Population policies and family planning programs should support the principles of voluntary and informed choice* and should not impose coercive measures that violate fundamental human rights, especially those of women.

- *The integration of a gender perspective in all policies, programs and activities* is essential for improving their impact and for better utilization of available resources. Incorporating a gender perspective does not necessarily require a great financial investment, since it is based on changes in behavior and attitude. However, the results are a very economic solution for addressing many problems in health care as well as the obstacles impeding socioeconomic development in general.

- *Association with civilian society*, especially with nongovernmental organizations specializing in the area of sexual and reproductive health and with women's groups, should become an integral element of governmental policies and the planning, implementation and supervision of programs. The contributions and innovative and economic initiatives of nongovernmental groups have been recognized in many cases as models that should be copied.

Although aspects related to health and sexual and reproductive rights may often be controversial and delicate subjects, the international community has recognized that they can no longer be overlooked (Ref:7). For the Pan American Health Organization, the Reproductive Health approach with indigenous peoples is a priority. It is thus important to know the position of these peoples and particularly that of indigenous women regarding this subject. Promoting greater opportunity for communities to participate in the planning, implementation and execution of Reproductive Health proposals will determine their control over available funds and their responsibility for the monitoring, supervision and evaluation of such projects, ensuring that the priority of Reproductive Health programs is to protect women, men and children.

5. PROPOSED METHODOLOGY

5.1 Research Within a Process of Change

Health is a good that is not equally distributed, regardless of whether the individual is indigenous or not. Distribution is related to "opportunities of life", where someone was born, who their parents were, etc. As a result, it is important to understand how to maximize distribution without forgetting the influence that policies in different public arenas, not only the health sector, have in this area. When we propose research we must first of all analyze how the process and results of the research are going to influence the living conditions of indigenous peoples.

In general research proposals and the approach to the community, in particular, create expectations. When obtaining information and knowledge about the community's situation, we are not sure that those who make the decisions will actually take the information into account. The credibility of the researcher is at stake. Involving the different sectors present in the community will ensure that responsibilities are shared from the outset of the proposals.

In this context, research should be understood as the production of knowledge that will contribute to the solution of problems. It should be applicable and it should make optimum use of available local resources as a process that leads to a schedule of achievements (Ref: 8).

There are five stages in this process:

1. *Presenting a fact to the eyes of the world*. For example, the moment when people talk about domestic violence, or discrimination, or the existence of beneficial techniques in indigenous knowledge, is already a success. In this stage, it is not going to be a change of the policies but the sensitization of the civil society by the dissemination of the subject will promote better knowledge of it, and will lead to the second stage of this process.

2. *Generating debate on a subject*. This leads to more research projects, since it creates concern and promotes interest about the subject.

3. *Presenting negative facts to the public*. This can limit harmful policies.

4. *Presenting results that promote change in the programs of current policies*. This is the concrete contribution of research.

5. *Developing new policies.* As the goal of the effective utilization of research.

The documentation and presentation of local problems specific to indigenous communities, in the native language when appropriate, or in simple language, will contribute to the community's self-knowledge about problems and to shared analysis for structuring an alternative epidemiology with variables applicable to specific contexts, so as to become the support for formulating policies according to the needs of these peoples.

Recognition of the diversity of indigenous peoples brings with it the need to formulate proposals that respond to situations and contexts that vary from country to country, from region to region and from people to people. In this sense, research, provided with adequate methodology, is a potential tool for change that will help to generate responses as varied and various as the situations and peoples requiring them. The need to incorporate the comprehensive approach in research with indigenous peoples implies mutual collaboration between epidemiological methodology and sociological and anthropological methodology both in their quantitative and qualitative approach, so as to ensure that the voice of the community will provide content and structure to the analysis of problems within recognized scientific frameworks.

The majority tendency to express scientific matters in statistical terms has ignored the scientific validity of qualitative methodology, and the description of preliminary steps of gaining knowledge about the community and establishing a relationship of trust, as part of the research methodology with indigenous peoples. Given the need to obtain information that describes the real conditions of these peoples, the following questions arise: How should the necessary data be obtained? What types of data are important and which are the most appropriate indicators?

The "demystification" of research will make it accessible to people whose education is not so specialized. One of the important premises is to train people in the communities to generate local data and put in the hands of the community the health diagnosis in order to promote the program implementation, identification of priorities, solutions and indicators of both impact and evaluation.

The frame of reference for research should understand the conceptual model and the social model, depending on the branch of science proposing the research. Consideration should also be given to the prejudices that the researcher and those on his team may have and the context that often makes them explicit.

5.2 **Rapid Evaluation Techniques**

The participatory process of planning -action-reflection-action of the operational research, corresponds methodologically to a combination of strategies technics/methodologies, that includes: approximation and knowledge strategies of the community, specific intervention strategies in accordance with the case or problem, strategies of communication and of feedback in the knowledge and solution generation. In this process the community will recover its management capacity and will become a true participatory and co-responsible entity of its well-being.

The research methodology currently has quantitative and qualitative techniques, whose usefulness has been proven in different areas. In the particular case of research with indigenous peoples we recognize the limitations that present each one of them individually.

In the present document we present a description of the rapid evaluation techniques with the courage to promote the reflection in the search and development of alternatives which are new

and/or complementary, valid and feasible in the joint work with the indigenous peoples in particular contexts.

a. *Key informants:* This is a select group of 25-50 people who should have knowledge and experience in the subject to be investigated and be open to answering questionnaires. The identification of these people is not based on probability but rather on the researcher's criterion. The direct interview is used only to obtain the essential elements.

b. *Focus Group:* This is a group of 8 to 12 people, the ideal number is 8, whose dynamic resembles a group interview where the role of the moderator is key. The moderator, who is in turn the researcher who will present the conclusions, should be a very able person, capable of maintaining the group's interest and of obtaining ideas, suggestions, and conclusions without influencing the participants. The results obtained are used for comparison with those of the key informants. Focus groups are useful for discussion of the beliefs, attitudes, and culture, for obtaining the popular consensus on some subjects and represent a tool for gaining knowledge of disadvantaged populations. In indigenous communities, focus groups should be organized by indigenous leaders, as a mechanism to promote acceptance of proposals that grow out of the process.

c. *Community interviews:* These are direct interviews conducted in the community in public meetings. They address specific or current subjects, for example, cholera, and lead to discussion.

d. *Direct observation of the universe of action:* In direct observation, it is necessary to prepare "observation forms" where the data that one wishes to obtain are organized methodically. To minimize the influence of personal prejudices when applying this technique, the participation of a team of researchers is preferable.

e. *Informal Surveys:* In an informal survey, 25 to 50 people freely answer questions about themselves in their own words. It is not a probability sample but a group of people directly affected by a specific problem. For example, in an epidemic the informants are parents of children who have suffered from the disease.

Rapid epidemiological surveys are based on an adaptation of standard epidemiological techniques. Some of the techniques for rapid epidemiological evaluation are sampling within a limited geographical area, techniques for sampling closed groups, evaluation and monitoring of risk factors.

5.2.1 ***Limitations***

Rapid evaluation techniques are useful, less expensive, rapid, less complex and generate ideas and recommendations. They are flexible and scientifically accepted. They do, however, have limitations. Regarding their reliability and validity, unless a sample is randomly selected, it cannot be representative. The selection of the sample and the data obtained can be influenced by the researcher's prejudices, personal preferences or the points of view of the observer or interviewer.

Validity depends to a great extent on the researcher's ability and their knowledge of the culture and the community.

These techniques generate qualitative and quantitative data. The qualitative data are often difficult to record, code and analyze objectively. If the sample is not representative, generalization is not possible and can be detrimental when decisions to intervene are involved. Usually, those responsible for decision-making prefer to make their decisions on the basis of quantitative data. However, qualitative data obtained through appropriate methodology, make the quantitative data more specific and put them into context.

5.2.2 *Usefulness of these Techniques*

These techniques are useful:

- When descriptions or qualitative data are sufficient for decision-making. For example, in the case of an epidemic or a catastrophe, or when seeking to implement some programs. For example, provision of water.

- For understanding attitudes about an intervention program or a program in progress, in order to obtain opinions as to whether the current work should be continued or not.

- When the quantitative figures need to be interpreted. For example, if 25% of the population is not using a service and we want to know why.

- When the fundamental objective is to develop suggestions and recommendations.

- When we want to identify guidelines to develop questionnaires, proposals, or hypotheses for more comprehensive studies.

5.2.3 *Selecting People*

The selection of people is carried out according to the matter involved. For example, if we wish to know the opinion of adolescents on a specific subject, the group cannot be made up of people of any age. If there are tensions between different sectors, the sectors involved in the conflict cannot participate in the same group if we want to work toward resolving the conflict. The clarity of the objectives for forming a focus group, knowledge of the problem involved, and the researcher's impartiality, ethics and ability to identify the appropriate people are fundamental.

Rapid evaluation techniques are a powerful methodology and observation the best method for learning. When generating knowledge, we should suggest hypotheses that sometimes challenge prior truth.

Understanding the data obtained and understanding it in depth is a process that demands patience. Opening up the possibility of positions that are less academic but equally valid would

supplement the available methodology and would identify specific alternatives in research with indigenous peoples.

6. RESOURCES AND MANAGEMENT

The complexity of the problems of indigenous peoples and the precarious living and health conditions of these peoples exceed available resources. The economic crisis affecting the Region has reached all levels, with the result that access to resources is increasingly difficult, particularly for activities with groups that are always marginalized. Paradoxically, the changes and currents that the Region is going through proclaim equity.

As in other aspects, the almost non-existent power of the indigenous world is translated into a lack of knowledge about its reality and real capabilities, hindering resource mobilization. An approach based on mutual knowledge and respectful dialogue between the two worlds will dissipate misgivings and the fear of "losing power" to the less powerful. The promotion of pluralistic, interdisciplinary and intersectoral agencies with decision-making powers, wherein the principal actors are representatives of indigenous peoples, is essential. This will make it possible to prepare realistic proposals that avoid the duplication of efforts and promote coordination among different organizations, better utilization of available resources, and monitoring, supervision and evaluation in terms of local, national, subregional or regional plans.

In this context, the experience of institutions such as the International Development Research Center (IDRC), which openly support innovative proposals in research with indigenous peoples and the training of researchers in this field, is fundamental.

Although the Pan American Health Organization, because of its prestige, technical capability and presence in the Region, has been the depository and conduit for resources from various financial sources, this mechanism should not be considered a requirement for obtaining resources. The local, national, subregional and regional levels and indigenous peoples themselves should share responsibility for this search and thus for the management of resources.

It is essential to strengthen indigenous organizations for their efficient and effective management of resources. The Initiative on the Health of Indigenous Peoples of the Americas, following the explicit mandate of Resolution V, and the stipulations of the 1995 - 1998 PAHO/WHO Strategic and Programmatic Orientations, is promoting this strengthening by placing priority on the training of indigenous leaders, the participation of indigenous representatives in the review of documents and projects, and the hiring of indigenous people for the Organization's work with these peoples. In addition, consistent with the importance of the comprehensive approach to health, it has initiated an interprogram process of support and development of proposals for mobilizing resources.

7. RECOMMENDATIONS

The recommendations presented below seek to make a contribution toward implementation of the comprehensive health approach within the framework of the Initiative on the Health of Indigenous Peoples of the Americas with respect to research:

1. The Pan American Health Organization, through the Initiative on the Health of Indigenous Peoples, presents an integrating proposal in accordance with the fundamental aspects of indigenous peoples. As a result, the recommendation is made to promote the preparation of joint, multidisciplinary and intersectoral work based on the communication, coordination and dissemination of information, ensuring the participation of indigenous organizations and communities, so that the bases have an active role and shared responsibility in identifying priorities in research, seeking resources, formulating proposals, and monitoring, supervision and evaluating them.

2. Knowledge of the process that research has followed with indigenous peoples and the human resources available is indispensable. The recommendation is thus made to:

   a. promote within countries and/or subregions the analysis of research on the subject of the health of indigenous peoples so as to be able to identify its strengths and weaknesses and its conceptual framework and, based on the conclusions, to determine priorities for the future;

   b. set up a data bank on indigenous researchers and institutions involved in research with indigenous peoples which have indigenous people among their professionals.

3. Since the absence of specific information on the living and health conditions of indigenous peoples contributes toward their being ostracized from the mainstream and disregarded in health policies and makes it difficult to quantify the impact of proposals and projects within these communities, it is recommended that:

   a. the analysis of the conditions of indigenous peoples not be based on national data;

   b. PAHO promotes the formation of a data bank and its analysis at the country level so as to describe the conditions of indigenous peoples both at the national and local level and if possible, by indigenous communities, through its national offices, together with the Ministry of Health and indigenous organizations;

   c. PAHO promotes the inclusion of the ethnic variable and gender in the information systems of the countries;

   d. the identification of alternative variables in the analysis of living and health conditions of indigenous peoples be promoted.

4. Because indigenous peoples are not an isolated entity in the general dynamic of the Region, it is recommended that any proposal for research be framed in this context, taking into account sociocultural aspects.

5. Negative experiences produced by imposed research have contributed to the mistrust of indigenous peoples. It is thus recommended that:

   a. all research projects with indigenous peoples include an assessment of their impact on the environment as well as on the health and culture of these peoples;

   b. consultation with indigenous representatives about this subject be promoted.

6. Recognizing the validity of indigenous knowledge and its practices, the holistic approach and the effect of indigenous therapists, the recommendation is made to:

   a. determine the guidelines to be followed with regard to the dissemination and exchange of knowledge among indigenous therapists;

   b. follow a process of research on indigenous medical systems and their practices in the field of comprehensive health as conducted by indigenous peoples, their formal and traditional authorities (representatives, members of the counsel of elders) and human resources in indigenous health;

   c. suggest proposals for research comprehensively, avoiding considering isolated aspects of indigenous culture and the habitat in which these peoples evolve, for example, studies of medicinal plants outside the cultural context. All this should be done using methods that do not threaten the safety of individuals, the community, and the environment.

7. As indigenous peoples are the absolute owners of their knowledge, it is essential that the establishment of official standards be promoted to favor these peoples in terms of intellectual property rights and the benefits obtained from research.

8. Recognizing that the dynamic of indigenous peoples is different, it is recommended that these differences be considered in planning research and in aspects involving the hiring of researchers.

9. Given the lack of knowledge regarding the reality of indigenous peoples, it is recommended that the Pan American Health Organization promote a sensitization campaign at all levels, including the use of communications media, the participation of civilian society and the training of local resources in research.

10. Lack of information regarding the requirements for access to financing has hindered the participation of indigenous researchers in the submission of proposals for their peoples. It is thus recommended that the information available on this subject be disseminated.

11. Recognizing the need for systematic, egalitarian participation of indigenous organizations, it is recommended that:

    a. indigenous organizations with presence at the regional as well as subregional, national and local levels be strengthened;

    b. contacts and exchange of experiences among indigenous representatives at the regional level be promoted;

12. In recognition of the need to establish an intercultural education process, it is recommended that:

    a. the information available on research regarding western and indigenous knowledge be codified in such a way that it is accessible to all;

    b. the participation of indigenous representatives at national and international meetings addressing subjects that involve them as well as those covering general subjects be promoted;

    c. the incorporation of intercultural knowledge in the program of studies in schools for human resources training in research be promoted.

13. Considering that meetings of this type promote thought and the exchange of experiences, it is recommended that they be promoted as a preliminary step for setting up an advisory group on research with indigenous peoples.

14. Considering that the principal actors involved in the subject dealt with in the research working group are indigenous peoples, it is recommended that the document produced by the research working group be distributed to the different indigenous organizations of the country, recognizing that it included indigenous participants and that these peoples were represented in the working group.

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Agenda: Working Group on Research with Indigenous Peoples

First day:	**Research and Researchers in the Region**
08:30	Presentation of participants
09:00	Objectives, expectations and methodology of the Meeting. **Dr. Sandra Land**
09:15	Research in the Initiative on the Health of Indigenous Peoples. **Dr. Rocío Rojas.**
09:30	Current Research Trends in the Region (including reference to the practice of Traditional Medicine). **Dr. Joseph Palacio**
10:30	Coffee
10:45	Principal obstacles in the research project with indigenous peoples. **Dr. Anwar Islam**.
12:30	Luncheon
14:00	Priority Areas in research with indigenous peoples. **Mrs. Wara Aldarete**
15:15	Coffee
15:30	Need for research on the Health of Indigenous Peoples in areas such as:
	a. Communicable diseases, including vector-borne diseases. **Dr. Fabio Zicker**.
16:30	b. Reproductive Health. **Mrs. Isabel Hernández**.
Second day:	**Research Methodologies with Indigenous Peoples**
08:30	Efficiency and usefulness of the methodologies available in research with indigenous peoples. **Mrs. Alice Pineda.**
10:30	Coffee
10:45	Alternative Methodologies according to type of research (epidemiological, operational, participatory, collaborative, ethnographic). **Mrs. Wara Aldarete**.
12:30	Luncheon
14:00	Methodology concerning the comprehensive approach to the health of indigenous peoples and their medical knowledge, and with respect to their health problems (chronic diseases, physical disability, mental health, violence, sexually transmitted diseases, AIDS, etc.). **Dr. Joseph Palacio.**
16:00	Coffee
16:15	Methodologies in the approach to specific areas: Rapid evaluation techniques, preparation of protocols, preparation of questionnaires, identification of appropriate indicators, identification of suitable mechanisms for communication, preparation of training programs in research, etc. **Dr. Anwar Islam.**
Third Day:	**Legislation, Ethics and Research**
08:30	The international codes of ethics in research with indigenous peoples (regulation of intellectual property)
09:30	Sources of financing in research with indigenous peoples Grant program - PAHO. **Dr. Rebecca de los Ríos**
10:30	Coffee
10:45	Proposals
12:30	Luncheon
14:00	Proposals
16:00	Coffee
16:15	Presentation of relevant conclusions. Closing session.

November 1995

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Presentations of Participants

- **Dr. Anwar Islam**
  Focus Groups: A tool for qualitative research, Ottawa, Canada, 1995

- **Alice Pineda**
  Efficiency and utility of the methodologies available in research with indigenous peoples

- **Isabel Hernández**
  Reproductive Health with indigenous peoples in the Latin America

- **Wara Aldarete**
  Research with indigenous peoples: Priority areas or significant topics?

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2. Resolution V, 1993.

3. Desarrollo y Fortalecimiento de los Sistemas Locales de Salud. Salud de los Pueblos Indígenas, 1993. PAHO/HSS/SILOS-34.

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6. Incorporación del enfoque de género en los Programas de la OPS para la promoción de la salud de los pueblos indígenas, PAHO/HDW/95-002, Washington, D.C., 1995.

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15. Ruiz Magda, Bodnar Y., El carácter multiétnico de Colombia y sus implicaciones censales. Document presented at the Workshop Seminar "Investigación Sociodemográfica contemporánea de pueblos indígenas", Santa Cruz, Bolivia, 1993.

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