

*Final Report
Experts Workshop*

Cultural diversity and disaggregation of statistical health information

*Quito, Ecuador
4 - 5 June 2002*



Pan American Health Organization
Regional Office of the
World Health Organization

Division of Health and Human Development
Program on Public Policy and Health

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Public Policies and Health Program



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Introduction

An experts workshop on cultural diversity and disaggregation of information was carried out in collaboration with the Ministry of Health of Ecuador; the Representative Office of the Pan American Health Organization (PAHO) in Ecuador; the Program on Organization and Management of Health Services, Division of Health Systems and Services Development, PAHO; and the Program on Public Policy and Health, Division of Health and Human Development, PAHO. The workshop was held in Quito, Ecuador, on 4–5 June 2002.

The event was part of a broader project aimed at helping to narrow the health gaps between different population groups in the Region of the Americas. Statistical data disaggregated by the variable "ethnic origin" will be a tool that can be used to monitor the situation of marginalized groups and also to develop health policies and systems that better reflect the needs and realities of these groups.

As one of the project's initial activities, the seminar-workshop sought to take advantage of the expertise and capacity that exist in some countries of the Region with a view to developing new methods for, and expanding



knowledge about, the collection, analysis, and dissemination of socioeconomic and health data based on ethnic origin.

Rationale

The collection and dissemination of data by ethnic origin are essential in order to identify, monitor, and progressively eliminate inequities in health status and access to health services. This information is critical to the effort to ensure that prevention, promotion, and treatment programs are effective and to establish binding norms that will make it possible to achieve equity.

The lack of high-quality, congruent data and analysis based on ethnic origin is a problem in the majority of the countries. The existence of information systems is vital for evidence-based decision-making, to achieve the proper allocation of limited resources, and to evaluate the effectiveness of interventions. The need to improve collection and analysis of data based on ethnic origin was affirmed in two recent international conferences.

In August 2001, the *United Nations World Conference against Racism, Racial Discrimination, Xenophobia, and Related Intolerance* urged the States "to collect, compile, analyze, disseminate and publish reliable statistical data at the national and local levels and undertake all other related measures which are necessary to assess regularly the situation of individuals and groups of individuals who are victims of racism, racial discrimination, xenophobia and related intolerance." In its Plan of Action, the Conference also recommended that "the information should take into account economic and social indicators, including, where appropriate, health and health status, infant and maternal mortality, life expectancy, literacy, education, employment, housing, land ownership, mental and physical health care, water, sanitation, energy and communications services"

In our Region, the *Plan of Action of the Third Summit of the Americas*, in April 2001, highlighted the need to "support the Health of Indigenous Peoples Initiative, promoted by PAHO, in assisting states and in consultation with indigenous peoples, to formulate integrated public policies and health systems that foster the health of indigenous peoples, in designing and implementing intercultural frameworks and models of care specifically aimed at addressing the health needs and priorities of these peoples, and in improving information collection, analysis and dissemination on the health and social conditions of these peoples, with particular emphasis on children."



The Plan of Action also identified the need to "promote the collection and publication of national statistics to generate information on the ethnic composition and socioeconomic characteristics of indigenous populations in order to define and evaluate the most appropriate policies to address their needs."

PAHO and the World Health Organization (WHO) are collaborating with the governments and with health sector authorities to fulfill the aforementioned resolutions, with the understanding that establishing indicators of health status and access to health services disaggregated by variables of ethnicity and race will help to promote evidence-based decision-making.

The goals of this project are to:

- 1) Improve data collection and analytic capacity
- 2) Generate new information that expands our collective knowledge of the health situation of indigenous populations and populations of African descent.

The first step in this process was the organization of a two-day meeting of experts for the purpose of reviewing different experiences in the Region with the collection of statistical information disaggregated by ethnic/racial origin.

Expected Results of the Workshop

The expected results were initially defined as follows:

- 1) Summary of country experiences with good data collection practices.
- 2) Recommendations for the development and application of methods for collecting and making more effective use of health information specific to populations of African descent and indigenous peoples.
- 3) Follow-up at the national level through the establishment of specific projects in selected countries that adopt and adapt the recommendations of the expert workshop with regard to inclusion of the variable of ethnic/racial origin in instruments for statistical data collection, and that expand their capacities for data collection and analysis.

Development of the Workshop

In March 2002, at a preparatory meeting in Mexico City, PAHO staff participated with Myrna Cunningham of Nicaragua and Manuel Cujilema of Ecuador in a detailed discussion of the workshop's development. It was agreed that Ecuador would be the venue for the proposed workshop, and that the Division on Nationalities and Peoples of the Ecuadorian Ministry of Health would extend the invitation on behalf of the host country. A total of 41 experts participated in the workshop, including representatives of national statistical institutes, statistics departments of ministries of health, and focal points for ethnic concerns within the health ministries of the selected countries (Brazil, Colombia, Ecuador, Honduras, Nicaragua, and Uruguay). Other participants included representatives from PAHO, the U.S. Census Bureau, the Latin American Information Agency (ALAI), the Inter-American Commission on Human Rights (IIDH), and Harvard University.

The workshop was organized in five panels in which the situations of the countries were explored. The program combined expert presentations with working group sessions.

The questions posed to the group of experts for discussion were as follows:

- 1) Why is it important to disaggregate statistical information by ethnic/racial origin? What are the costs and benefits of adopting this basic tool for policy design?
- 2) What problems may be encountered in the identification of people? How is ethnic origin identified? How is the question asked? How is the information registered?
- 3) What are the experiences with disaggregated collection of statistical data in the Region?
- 4) What are the experiences with disaggregation of health information by ethnic origin?
- 5) How can analyses of health information be improved through cross-tabulation of data by geographic origin and socioeconomic level?



Summary of Main Points of the Panels

Panel 1

Why is it important to disaggregate statistical information by ethnic/racial origin? What are the costs and benefits of adopting this basic tool for policy design?

Panelists: Irene León
Latin American Information Agency (ALAI)
Ecuador

Carlos Larrea
Harvard University
United States of America

Coordinator: Manuel Cujilema
Head of the Office on Indigenous Peoples
Ministry of Health
Ecuador

Irene León addressed the question by explaining the interest of governments in this subject, reflected in the results of the *United Nations World Conference against Racism, Racial Discrimination, Xenophobia, and Related Intolerance*.

In the Plan of Action approved by the Conference, countries are urged to design programs based on reliable statistical data, with the participation of the affected groups. Statistics are important because they reflect the magnitude of the problems and make it possible to construct indicators for monitoring.

The Conference called for the adoption of affirmative policies as a way of narrowing the existing social gaps, which disadvantage ethnic/racial minorities. Toward this end, it recommended taking into account "economic and social indicators, including ... health and health status, infant and maternal mortality," among others, and increasing access to basic social services.

As an example of the need to take affirmative actions, the speaker pointed to the case of Brazil, where it would take a hundred years to close the gap between Afro-Brazilians and the majority population but only ten years if positive measures were implemented.

The second presentation addressed two aspects of the importance of disaggregating statistical information by ethnic origin. Disaggregation makes it possible to construct empirical evidence on ethnic equity in health, and as a result promotes the design of policies to overcome the inequities.

Carlos Larrea analyzed information from the demography and health surveys (DHS) of selected countries (Bolivia, Brazil, Colombia, the Dominican Republic, Ecuador, Guatemala, Haiti, and Nicaragua). The first finding from this analysis is the weakness of the data collection instruments, since of



eight countries studied, four (Colombia, the Dominican Republic, Haiti, and Nicaragua) did not include any direct or indirect question on ethnicity. For those countries that did incorporate a variable on ethnicity (Bolivia, Brazil, Ecuador, and Guatemala), the speaker looked at the nutritional situations of the different ethnic groups. The results support the hypothesis that ethnic minorities are disadvantaged in relation to the majority population.

The conclusion was that more reliable results will be obtained by perfecting the design of the data collection instrument so as to facilitate the identification of people. Brazil and Guatemala are the countries with the most complete questionnaires.

The second conclusion of the panel was that the identification of gaps between populations of African-descent and the majority population in terms of their living and health conditions does not always correspond to the worst national situations. Rather, countries with identified gaps may simply have better information and analysis than other countries. The absence of information on ethnic groups does not necessarily indicate an absence of problems, but rather suggests that no means are available to correct the problems and as a result the problems will continue. One difficulty among others is the existence of different conceptual definitions of ethnic and racial groups within and between countries, limiting the possibilities for regional standardization.

Finally, it was proposed that, in addition to recommending that governments implement statistical programs designed to permit incorporation of the variable of ethnic/racial origin, steps be taken to promote the use of standardized forms that permit comparisons between countries. This can



help to avoid the tendency for those countries whose statistics are broken down by ethnic/racial group to appear to suffer from greater inequity than others.

Panel 2

What problems may be encountered in the identification of people? How is ethnic origin identified? How is the question asked? How is the information registered?

Panelists: John Long and Jorge del Pinal
U.S. Census Bureau
Washington, D.C.

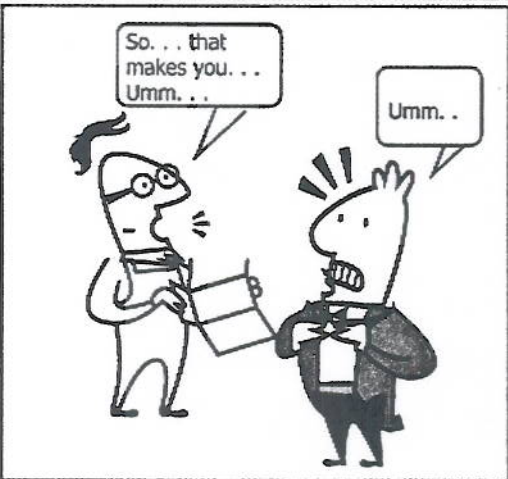
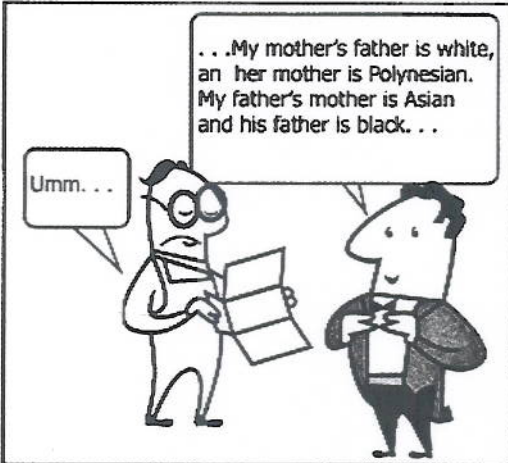
Diego Iturralde
Inter-American Institute of Human Rights (IIDH)
Costa Rica

Elsa Rodríguez de Bastides
Departamento Administrativo Nacional de Estadística
(DANE) Colombia

Coordinator: Rosa Carlina García
Division of Ethnic Affairs
Ministry of Health
Colombia

The representatives of the U.S. Census Bureau, John Long and Jorge del Pinal, presented experiences and lessons learned on the subject of self-identification. They began by pointing out that the census is a key instrument for statistical data collection and provides a basis for the correct definition and future projection of survey samples. They went on to discuss how the ethnic variable has been incorporated in censuses taken in the United States. The methods most often used to measure the ethnic variable are observation by the interviewer, self-recognition, and self-identification through symbolic or indirect questions, or through concrete questions such as those dealing with geographic location. However, the speakers explained that the criteria used in the U.S. census questionnaire, which currently incorporates concepts of race and ethnicity, vary in order to best capture members of the different

But, if it was such an easy question!



ethnic/racial groups. Hispanic or Latino origin is captured through a battery of questions that include ancestry/origin, maternal language, birthplace, citizenship of persons born abroad, and place of residence during the last five years. The reason that the language spoken is not used as a criterion is that when the question focuses on language, it risks missing some members of an ethnic group given that the youngest members of households typically speak English. In the case of bilingual respondents, if the interview is held in English the respondent will tend to say that his or her language is English, thus losing the information about the ethnic/racial origin of the family. As a result, it is recommended that the questionnaire be translated and administered in the original language of the respondent's family.

Other difficulties mentioned include the conceptual distinctions between ethnicity and race, the formulation of questions so that respondents are not offended, and the instructions given to interviewers. Interviewers must be trained.

The speakers also discussed continuing changes in the cultural profile of the population due to the intermixing of groups and the diversity of languages spoken. For example, in the United States an emerging group is known as "Mexican-Ricans"—persons of mixed Mexican and Puerto Rican descent.

In the second part of the panel, Diego Iturralde, drawing on his experience working in human rights,

offered some important observations on the discussion questions. He highlighted four points:

- 1. Varying scenarios.** The indigenous population of Latin America is 40 million strong, with more than 400 different peoples, including 200 in Brazil alone. Some of these groups have less than 1,000 members while others are very large, such as the Quechua with 2.5 million. A quarter of the indigenous population of Latin America lives in Mexico and another quarter in the Andes. There is also great variation in the ways these different peoples relate to the State. Some of the groups have had such relations for centuries, while in other cases relations are more recent.
- 2. The question of identity.** Another important issue is that of identity. Who adopts an identity? Is it the individual alone, or a collectivity that recognizes the identity through shared rituals? In cases where the collectivity assigns identity, the number of individual members of the community is irrelevant if the collectivity has been recognized by national authorities.
- 3. The language spoken.** The language the respondent speaks is another important factor in identifying his or her ethnic origin. Questions used to capture language should be varied, since language is a representation of the subject's culture. Asking for the respondent's maternal language is more useful in identifying people descended from the indigenous inhabitants of the country and less relevant for those of African descent. Furthermore, the question "What language do you speak?" should not be asked only in the dominant language of the country, because this could create confusion and influence the response. The interviewers should be bilingual
- 4. Territoriality.** In countries that have reservations for indigenous peoples, such as Brazil, Costa Rica, the United States, and others, the fact of land ownership solves the problem of identifying the members of these groups, for example the Aymara and the Yanomami. However, this conceptualization runs into a problem when a people inhabits a territory that is currently bisected by an international border. In such cases, it will be necessary to approach the issue differently.

Diego Iturralde proposed a focus on developing indicators in two or three areas that are defined with the participation of the affected population: for example, maternal and child health, gaps between indigenous groups and

others, etc. The next step is to define standards for the indicators, also in consultation with the affected groups. He suggested indicators of inclusion, of diversity, and of discrimination, such as:

- Fulfillment of commitments
- Legislation, policies, justice
- Institutional development
- Public investment
- Content covered in the education of health providers

The panel's third speaker was Elsa Rodríguez, of the DANE in Colombia, who explained that Colombia is a multiethnic and multicultural country. The 1993 census included a question about membership in an ethnic group based on self-recognition. Colombia's experience is interesting with regard to decoding the questions so that they could be interpreted by the various ethnic populations.

Based on a theoretically differentiated pattern, the census workers were given differentiated training in order to promote better comprehension of the questions. The results of the 1993 census indicate that the country has 81 indigenous groups, with a total indigenous population of more than 500,000 people.

With regard to the black population, the census counted only slightly over 500,000, but that is believed to be an underregistration. Other estimates yield figures between 26 percent and 30 percent of the country's total population.

Colombia has made great strides in adopting legal instruments for the recognition of ethnic groups. The current constitution makes special mention of indigenous and African-descent groups and defines the right to equal conditions.

Eighty-five percent of the indigenous people live on *resguardos* (collectively titled lands), and 80 percent of the Afro-Colombians counted by the census live in the collective territories of black communities. In the next census, possibly in October 2003, a question based on self-recognition will be asked: Do you consider yourself to be any one of the following six



choices—black, indigenous, *palenquero*, *raizale*¹, gypsy, or other? The DANE staff member added that Colombia is considering adopting a single form with the same questions for all population groups. Although the form will be in Spanish, an interpretation or translation of the questions and categories will be provided for indigenous respondents. The translation will not be simply literal, but also conceptual, including the adaptation of subjective questions. For example, in the section of the form that seeks information on housing, there may be different assessments of the adequacy or inadequacy of available services according to the ethnic/racial group. For some people a house with adobe walls might represent substandard living conditions, while for others it is the way their houses are traditionally built.

A concluding analysis of the different presentations revealed both similarities and differences in the experiences of the countries, which served as the basis for a set of general recommendations.

There was agreement that the external identification of racial/ethnic group by the interviewer can lead to the introduction of biases based on interviewer prejudices, as it does not take into account the respondent's self-concept; it should not, therefore, be used as the only means of identification. "Self-identification" was recommended, even though problems can arise when respondents avoid identifying themselves with certain groups because of discrimination. Another point of concurrence was that instead of asking the respondent's "ethnic origin," the question should be framed to ask about membership in specific groups, such as Aymara, Quechua, and so forth. This is complicated, however, by the fact that some countries have more than 40 nationalities and the list of possible choices would be very long. In other countries, Ecuador for example, the number is more manageable, and it would be feasible to list the names of nationalities on the data collection form. For the populations of African descent, this modality would not always be applicable. It was noted that the questions used to identify populations of African-descent and indigenous peoples cannot be the same. Finally, it was agreed that in addition to self-recognition or self-identification, identification based on geographic location is a valid alternative for the ethnic groups in some countries.

Another recommended way to approach this issue is through the question on "language spoken." Not all ethnic groups are bilingual or have an indigenous language.

The panel noted that, in general, the administrative records maintained by the ministries of health do not include the "ethnic origin" variable, despite the progress that has been made in identifying these groups through data collected in household surveys and population censuses.

¹*Palenqueros* are descendents of runaway slaves. *Raizales* live on the Colombian islands of San Andrés and Providencia; they are descendents of Caribbean islanders and speak an English-based Creole.

Panel 3

What are the experiences with collection of disaggregated statistical data in the Region?

- Panelists:*
- Max Ortega
Instituto Nacional de Estadística y Censos (INEC)
Ecuador
 - Josefa Blanco
Instituto Nacional de Estadística y Censos (INEC)
Nicaragua
 - Daniel Sucazes
Instituto Nacional de Estadística y Censos (INEC)
Nicaragua
- Coordinator:*
- Cristina Torres
Pan American Health Organization (PAHO/WHO)
Washington, D.C.

Max Ortega of INEC discussed the experience of **Ecuador**, emphasizing that the country needs disaggregated information, since without it there cannot be equity. The constitution of 1998 recognized Ecuador as a multiethnic state, but at that time there was not yet any reliable statistical information on this matter. With support from UNICEF, INEC developed the EMEDINHO 2000 survey, which disaggregates statistical data on the maternal and infant population at the regional, provincial, cantonal, neighborhood, and community levels, incorporating the ethnic variable (self-definition based on predefined alternatives and maternal language). The data were collected from a sample of 10,104 urban and rural households based on the 1990 census in 65 cities. Ecuador has 25 ethnic groups, both indigenous (4.2 million people, located mainly in the Sierra) and Afro-Ecuadorian (500,000 people, located along the coast and in the Andean Region). Additionally, other INEC surveys use maternal language to disaggregate the data they generate. Members of the indigenous communities have participated actively as interviewers.

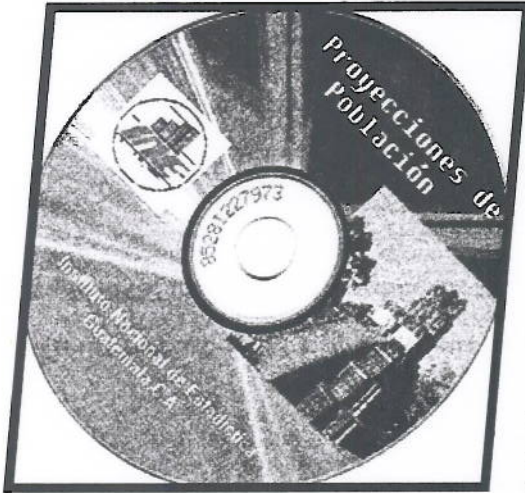
Based on this experience, the speaker suggested that PAHO:

- 1) Prepare a directory of existing statistical data sources, disaggregated at the local, national, and regional levels
- 2) Prepare the same for mortality and PYLL data systems
- 3) Prepare a manual on disaggregated and internationally comparable statistical data
- 4) Promote the disaggregation of data at the provincial, regional, and cantonal levels
- 5) Promote the inclusion of ethnic data in the ongoing consultation and hospitalization registries
- 6) Develop software to facilitate disaggregation at the local level
- 7) Promote and support training on methods of collection and analysis of disaggregated data
- 8) Promote the design of maps on the health situation and risk factors, using ethnic variables
- 9) Promote the diversification of statistical information on health
- 10) Promote the formation of user committees in order to coordinate the disaggregation systems with citizen participation.

Josefa Blanco of INEC **Nicaragua** reported on developments in her country. In Nicaragua the seventh population census of 1995 incorporated the maternal language as an ethnic variable so that the results would be disaggregated at the departmental, municipal, and urban/rural levels. The same was done with the ENNV 98 and 01 surveys (part of MECOVI), which had representativity at the national level and for groups of departments. The ENDESA 1998 and 2001 surveys (on health, housing, fertility, and work) used a sample of 13,398 households with urban/rural and departmental representativity. The 2005 census is currently being prepared, and the second phase of MECOVI (extending the survey by another four years) is also expected to provide support for national information systems.

Daniel Sucazes of INE **Uruguay** reported that his country has a lower level of development in comparison to the national experiences described so far. He noted that the indigenous populations of Uruguay were exterminated

during the colonial period; there is a small population of African descent, a legacy of the slavery era, and a small number of recent Asian immigrants. The 1908 census was the first to include a question on race. From the fourth census (1963) onward, questions on race are included. In 1996, responding to a proposal of the NGO *Mundo Afro*, a module on the race variable was incorporated in the continuing multipurpose survey, which is carried out



using very well trained interviewers. The survey covers a sample of 35,000 urban households. Recent results indicate a population of 26,300 blacks, 6,900 indigenous, 10,100 Asians, 145,000 mestizos (various types), and 2.6 million whites. The results indicate that Afro-Uruguayans fare worse than whites with regard to employment, education, and income. Black Uruguayan men have lower incomes than white women, who in turn are better off than black women. Manual labor occupations provide the main source of employment for the Afro population.

The majority of this group has only a primary education, while a secondary education is the norm among whites.

The discussion touched on the following topics:

- 1) Presence of ethnic variables in the DHS and ENDESA of Ecuador
- 2) The use of stigmatizing labels in the surveys and the need to consult the ethnic groups on this matter
- 3) The need for PAHO to promote the use of comparable data
- 4) The adoption of a system of indicators for the population of Nicaragua's Atlantic Coast
- 5) The lack of questions on ethnic group in the surveys carried out in Latin America
- 6) The urgent need to incorporate the ethnic variable into the surveys, as follow-up to the Durban resolutions
- 7) The need to determine the best way to capture the ethnicity of indigenous people and Afro-Latin Americans (similar or different questions,



complementary questions, batteries of questions, self-identification, dress, external observation, and others)

8) The incorporation of ethnic variables into ongoing health registries.

The presentations of this panel made clear that the questions used to identify people, including on survey questionnaires, whether based on dress, language spoken, maternal language, or self-perceived racial group, all have advantages and disadvantages, and that the questions cannot in themselves erase discrimination when it exists in a society. The designers of instruments should be careful not to strengthen such tendencies with questions that introduce biases, although they will be aware that if there is social discrimination against certain groups, this cannot be corrected merely by the way questions are asked. On the contrary, combating discrimination is a continuous process in which the society gradually raises consciousness through the analysis of information and puts in place policies to reduce the exclusion of the affected ethnic groups. It was emphasized that the identification of persons should be linked to the expectation that policies will be implemented to change the conditions that disadvantage them, ease their social exclusion, and facilitate their access to services.

A. USTED SE CONSIDERA:
Lee cada afirmativa y circule sólo el número que corresponda.

¿Mestizo? (andino + blanco).....	1
¿Indígena quechua o aymara?.....	2
¿Blanco o de origen europeo?.....	3
¿Negro o afroperuano?.....	4
¿Oriental o de origen asiático?.....	5
¿Indígena amazónico?.....	6
¿Otro?.....	7

Español

PARA PERSONAS DE 6 Y MAS AÑOS DE EDAD

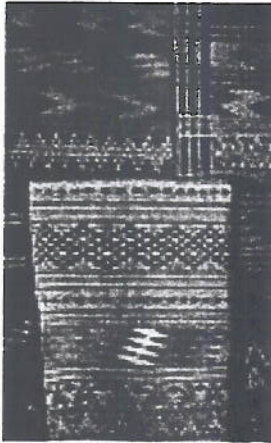
B. EL IDIOMA O LENGUA EN QUE APRENDIÓ A HABLAR EN SU NIÑEZ FUE:
Lee cada alternativa y circule sólo el número que corresponda.

¿Castellano?.....	1
¿Quechua?.....	2
¿Aymara?.....	3
¿Lengua amazónica?.....	4
¿Lengua extranjera?.....	5
¿Otra vernácula?.....	6

The experts noted that in household surveys, the design of the sample is as important as the definitions of the questions included in the questionnaire. The sample should include representatives of the ethnic/racial groups, so that the information from the sample, when projected to the population, can be used to gain a complete picture of the living conditions of these groups.

Panel 4

What are the experiences with disaggregation of health information by ethnic origin?



Panelists:

Enrique Morales
Director of Statistics
Ministry of Health, Nicaragua

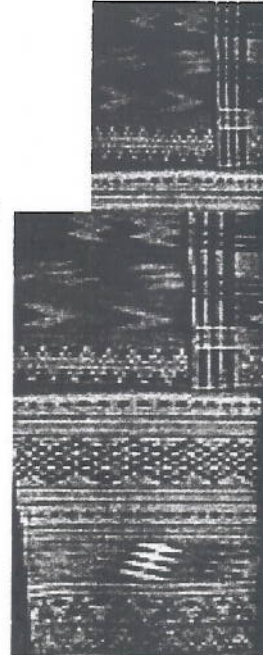
María Georgina Díaz
Chief of the Department of Statistics
Ministry of Health, Honduras

Iris Maresca
Director, Department of Statistics
Ministry of Health, Uruguay

Rosa Carlina García
Coordinator of Ethnic Affairs
Ministry of Health, Colombia

Coordinator:

Sandra Land
Pan American Health Organization
Washington, D.C.



Enrique Morales gave the presentation on **Nicaragua**. He reported that work on developing integrated health information systems began in 2000, and is currently underway in six SILAIS (comprehensive local health systems).

The ethnic groups are located in the poorer areas of the country. The information system can establish the geographic location of the ethnic populations.

The Ministry of Health maintains a network of services with 1,058 health units that report to the SILAIS. The general objective of the ministry's information system is to use information as a tool for management and support of the health services, with national and institutional coverage.

The system is designed to be comprehensive, covering service delivery, resources (human resources, financial resources, and medical supplies and equipment), and data on health problems.



Its functional scope covers strategic planning, outpatient care, hospital care, environmental services, supply services, financial resources, and human resources.

The following variables are included in the situational analysis: socioeconomic environment, population by municipality, reasons for outpatient consultations, reasons for emergency consultations, discharge diagnoses, causes of mortality, health indicators, basic sanitation, high-risk localities, and prioritization of health problems.

The planning is carried out annually, along with updating of the health situation analysis with process indicators. A number of challenges to implementation of the system have been identified, such as the acceptance of a new technology, personnel training, the cost of acquiring computers and technology, and the sustainability of the system.

It will soon be possible for the system to include variables on ethnic groups, based on the identification of their realities and recognizing their cultures and worldview. Moreover, in identifying disorders, the system will consider not only those recognized by the International Classification of Diseases (ICD) but also unclassified phenomena, for which the coding must reflect the criteria used by the communities in question and not the institutions.

María Georgina Díaz spoke about the experience of **Honduras**. She reported that the country has 1,172 units providing health services, distributed across the nine regions of the country.

A number of problems were identified in advance of the effort to build the health information system: excessive centralization of the information, a complex system with excessive data management requirements, lack of definition of the required information, little utilization of the information in decision-making, and duplication in information gathering. Data collection should be structured to respond to the needs of the different levels of the Ministry of Health, which means that it should yield reliable and updated statistics on population, users of services, production of services, and analysis of the health situation.

The general objective of the system is to have health information that is up-to-date, consistent, comprehensive, dynamic, and economical, and that permits timely decision-making and the monitoring of the health/disease process. Strategic lines are currently being developed for the system, such as the definition of indicators, automation of the system and development of the network, implementation of the units, capacity building for human resources, and strengthening of social participation.

To date, the health information system does not include the “ethnic origin” variable. It is possible that this variable could be incorporated in the near future. The censuses have included the question of ethnic origin, and this has yielded national statistics, disaggregated by ethnic group, in the areas that the census covers: housing, income, production, etc. The only effort to collect data on the socioeconomic conditions of the ethnic groups has been by the censuses, which have been designed to record the situation of respondents with regard to housing, occupation, income level, family composition, and level of education.

Iris Maresca reported that in **Uruguay** there has been a long evolution in the collection, processing, and analysis of vital statistics (deaths and births). There exists partial information on morbidity, but none of these data are disaggregated by the variable of “ethnic origin.” The speaker also reported that the institutions do not have a clear definition of this variable. There exist practically no health registries, with the exception of death certificates which do collect racial data and with which it has been possible to process information experimentally. Birth records do not include the ethnic variable, but it could be introduced easily if the political will existed in the country.

Finally, the speaker pointed out that vital statistics registries cannot possibly use the criterion of self-identification to answer the question on ethnic origin, since by their nature these registries require the intervention of third parties.

Rosa Carlina García presented the case of **Colombia**. The country is currently studying the provisions of Law 691 of 2001, which regulates the participation of ethnic groups in the General System of Social Security in Health. Work is underway to define a compulsory plan for indigenous health, with the formulation of a health care model for the regions where the indigenous and Afro-Colombian populations are concentrated. This would include the identification of procedures, attitudes, and practices that can be integrated in the process of regular public health care, especially with regard to promotion and prevention, without hindering the use of procedures of traditional medicine within these cultures. In this context, the health authorities have adopted an instrument known as the Individual Registry of Health Services Delivery (RIPS), which provides the basic minimum data set that the General System of Social Security in Health requires to carry out direction, regulation, and control and as support for the sale of services. It consists of three types of data: on identification of users, on the health services provided, and on the reasons for provision.

Within the framework of the General System of Social Security in Health, ethnic information is being integrated in health care registries through the inclusion of the "ethnic origin" variable. This is defined by asking the person to tell the health services to what population group he or she belongs, selecting from several alternatives: for example, mestizo or white; brown, mulatto, Afro, or black; indigenous or gypsy.

Panel 5

How can analyses of health information be improved through cross-tabulation of information by geographic origin and socioeconomic level?

Panelist: Bandeira Beato
Instituto Brasileiro de Geografia e Estatística (IBGE)
Brazil

The Brazilian experience was presented by Bandeira Beato. She reported that the censuses of 1872, 1890, 1940, 1950, 1960, 1980, 1991, and 2000 included a question on race, while the censuses of 1900, 1920, and 1970 did not include this question. The characterization of respondents was based mainly on self-definition, using predefined categories: white, brown, *preta*², and yellow. The census of 1991 expanded on these by introducing an additional category, "indigenous origin." The question was reworded as follows: "What is your race or color?" The response is by self-classification into one of the following categories: white, *preta*, brown, indigenous origin, and yellow. The 2000 census maintained these same categories.

Data from the censuses and from household surveys have provided a basis for questioning the myth of Brazilian racial democracy. The historical series offers evidence that social indicators have not shown a convergent trend when they are disaggregated by color or race. That is, socioeconomic advances resulting from universalistic social policies have not succeeded in closing the gaps between the indigenous populations and those of African-descent on the one hand and the white population on the other. This evidence has also provided grounds for the government's decisions to include affirmative action policies on the political and social agenda.

²*preta* is a term used for the Afro-Brazilian population.

The population of African descent in Brazil today numbers nearly 80 million. It is the second largest black population in the world and the largest outside Africa. Afro-Brazilians are most concentrated in the northeast and southeast regions, but in almost half the country's municipalities at least 50 percent of the population has African ancestry. Identification on the basis of geographic concentration permits rough estimates and analyses of the health conditions of the different ethnic/racial groups. Data from the household surveys on socioeconomic levels and living conditions, disaggregated by race/color, also make it possible to infer some aspects of the health situation.

REPUBLICA FEDERATIVA DO BRASIL
 MINISTÉRIO DA SAÚDE
 MUNICÍPIO DE SÃO PAULO
 SECRETARIA MUNICIPAL DA SAÚDE

SINAN
SISTEMA NACIONAL DE AGRAVOS
FICHA DE NOTIFICAÇÃO INVE
 (Pacientes com 13 anos)

Dados Gerais	1	Tipo de Notificação		2- Individual	
	3	Município de Notificação			
	4	Unidade de Saúde (ou outra fonte notificadora)			
Dados de Caso	5	Agravado			
		AIDS			
	7	Nome do Paciente			
	9	(ou) Idade	D - dias M - meses A - anos	10 Sexo M - Masculino F - Feminino I - Ignorado	
	11	Raça/Cor 1-Branca 2-Preta 3-Amarela 4-Preta 5-Indígena 6-Indefinido			
	13	Número do Cartão SUS		14	Nome da mãe

Many meetings at the country level have emphasized the importance of having data available on the Afro-Brazilian population to inform the design of policies. This point was made at a December 2001 meeting that examined national policy on the health of the black population as an equity issue, and recommended preparation of a minimum agenda for production and analysis of social health indicators that would incorporate new dimensions of the lives of poor and historically excluded people and communities. The Joint United Nations Programme on HIV/AIDS, meeting on 23 April 2002, also

strongly recommended introducing the variable of ethnic/racial origin in statistical information in order to strengthen quantitative/qualitative studies that seek to promote preventative and curative actions on HIV/AIDS. This group considered racism to be a vulnerability factor and proposed to investigate the effects of racial discrimination on the social conditions of the black population and their greater exposure to infection by the virus. The group also emphasized the need for the ethnic groups to participate in these processes.

Within a framework of human rights as central to human development, the enhancement of health databases, consistent with national commitments and international human rights treaties ratified by Brazil, should contribute to closing the health gaps by encouraging policies that promote ethnic/racial equity in health and full respect for these rights.

Working Groups

In order to facilitate the experts' discussion, a guide was prepared and was discussed concurrently by three working groups, which were formed to maintain a balance by country and by specialty.

Based on information presented in the panels on disaggregation of health information by ethnic origin, the guide asked each group to develop recommendations in response to the following questions:

- 1) What type of questions should be formulated in order to capture "ethnic/racial" origin in administrative records, surveys, and censuses?
- 2) What should the responsible institutions do to ensure that the collection and processing of this information by ethnic/racial group is as useful as possible?
- 3) What is needed from international technical cooperation in order to bring about introduction of the variable of "ethnic origin" or "ethnic/racial origin" in instruments for collection of health statistics, and to facilitate application of instruments containing these variables?

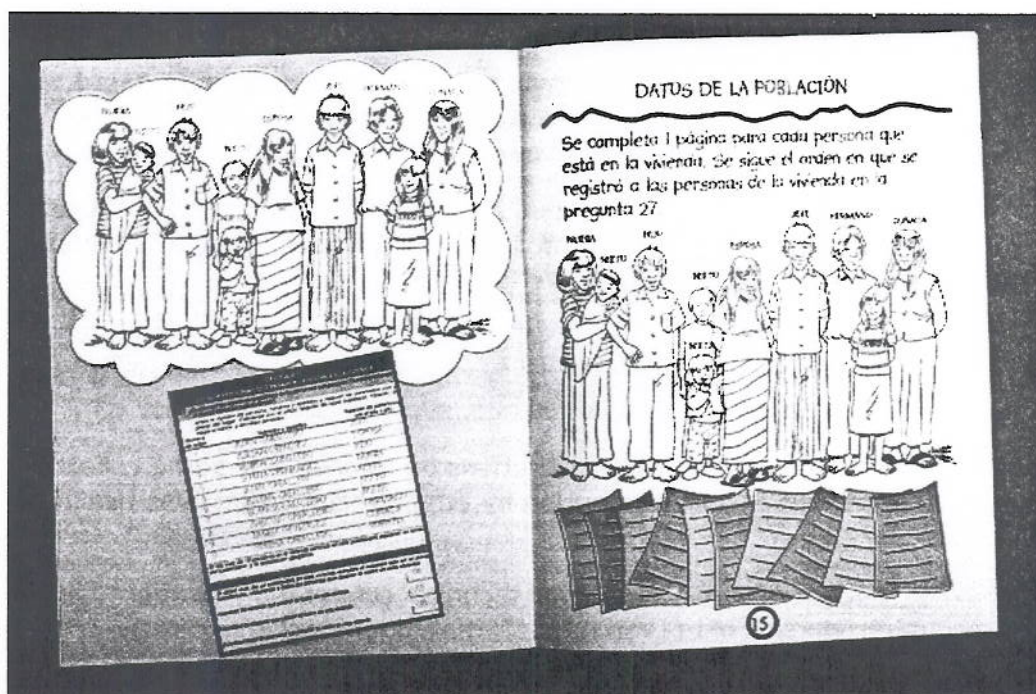
Reports of the working groups

Working Group 1

Rapporteur: Elsa Rodríguez

After discussing the questions in the guide, Group 1 offered the following recommendations:

In response to the first question—*What type of questions should be formulated in order to capture "ethnic/racial" origin in continuous registries, surveys, and censuses?*—the group suggested that the primary registry should contain a field for recording the group to which the person belongs. The variable can be called **CULTURAL DIVERSITY**, and should cover all population groups. Each country should determine how the question is asked, based on its



conditions and in consultation with the affected groups. The aim is not to create parallel statistical systems but to integrate this information into the national systems of statistics. The question should start with introduction of



the variable in its survey and census application and include other variables such as language, using the following questions as models: Which language do (or did) your mother and father speak? Do you speak the language of the group to which you belong? When you experience health problems, do you seek care from health facilities or health posts? From traditional medicine? From spiritual healers? From health promoters?

To question two—*What should the responsible institutions do to ensure that the collection and processing of this information by ethnic/racial group is as useful as possible?*—the group recommended that they work to raise awareness in the general population; facilitate joint research with the affected groups; examine traditional diagnostic systems and their classification of health problems, and investigate the extent to which these traditional diagnoses coincide with the International Classification of Diseases; develop training processes for health services personnel and for bilingual interviewers who gather information for censuses and surveys; and develop a system for feedback of information to the communities that provided it, based on dissemination, socialization, and management of information and its incorporation in health situation analyses based on living conditions.

To the third question—*What is needed from international technical cooperation in order to bring about introduction of the variable of "ethnic origin" or "ethnic/racial origin" in instruments for collection of health statistics, and to facilitate application of instruments containing these variables?*—the group recommended holding meetings of interested groups and experts for sharing experiences and monitoring the process; providing support for the collection, processing, dissemination, analysis, and use of the information; and promoting transfer of technologies, for example, designs for samples, data collection forms, and training manuals, and methods for processing, analysis, and dissemination of information.

Working Group 2

Rapporteur: Rosa Carlina García

In response to the first question in the discussion guide—*What type of questions should be formulated in order to capture "ethnic/racial" origin in continuous registries, surveys, and censuses?*—the working group proposed that as a general rule the word *race* should not be used. In order to avoid

racism, the variable should be called "ethnic origin," and the group recommended that four broad categories be adopted: white, black, indigenous, and other. The categories should be defined in accordance with the particular cultural characteristics of each country.

With regard to question two—*What should the responsible institutions do to ensure that the collection and processing of this information by ethnic/racial group is as useful as possible?*—the group suggested that variables be constructed with the participation of the ethnic groups; that instruments include the questions specifically needed to obtain the desired results; that information be collected with the participation of the subject group (as census-takers); and that inter-institutional coordination be encouraged in the different stages of the process, drawing on the expertise of institutions that maintain internal information systems (producing specific information) and know the subject ethnic groups.

In general, the working group emphasized the participation of the ethnic groups in all stages of the process, from the formulation of instruments through their application, the cross-tabulation of variables, and the final analysis.

To question three of the guide—*What is needed from international technical cooperation in order to bring about introduction of the variable of "ethnic origin" or "ethnic/racial origin" in instruments for collection of health statistics, and to facilitate application of instruments containing these variables?*—the group responded with the following suggestions:

That PAHO introduce within its own structure of country representative offices and in the information systems that it manages, information useful for analyzing the health situation of indigenous and African-descent ethnic groups, recognizing their traditional curative procedures and their worldview.

That PAHO issue a recommendation to governments encouraging them to move in this direction, paying special attention to training and sensitization of the ethnic groups themselves, of health professionals belonging to other groups, and of health professionals generally.

Within the realm of international technical cooperation, the working group also suggested the possible development of pilot projects in countries interested in this problem, which could help speed progress and raise awareness at different levels.



Working Group 3

Rapporteur: Daniel Sucazes

In order to answer the discussion questions in the guide, the working group reflected on the ideas set forth by the different speakers, and reached the following conclusions.

With regard to question one—*What type of questions should be formulated in order to capture "ethnic/racial" origin in continuous registries, surveys, and censuses?*—the group felt that it would be impossible to offer a general recommendation for the drafting of common questions to capture ethnic/racial origin in administrative records, sampling surveys, and censuses, because the countries present different specific features that can best be captured with instruments tailored to their needs, and because the questions should be asked in different ways depending upon the collection procedures used.

This group recommended that those in charge of gathering data be urged to consider, when writing the questions, the specific purposes for which the statistical information is being compiled, taking into account constitutional and legal mandates, as well as their practical possibility of execution.

The group also suggested taking into account the following criteria: (a) Self-recognition of membership in an ethnic/cultural group, a people, or a nation. The questions on self-recognition should proceed from the general to the specific. For example, persons who consider themselves members of an indigenous group would be asked to name the people or nation to which they belong, in a question with open response that permits coding in accordance with the objectives; this would lead to a dynamic process aimed at generating increasingly specific results. (b) Ask about the language spoken by the parents and the language spoken in the household, as well as about bilingualism. (c) Determine the territory of settlement of the people or nation in question, recognizing that these geographic limits will not necessarily coincide with political-administrative boundaries.

With respect to question two—*What should the responsible institutions do to ensure that the collection and processing of this information by ethnic/racial group is as useful as possible?*—the group recommended that they work in coordination with the public agencies in charge of ethnic/cultural affairs and with civil society organizations that represent the various ethnic groups and peoples.

For censuses and surveys, the working group advised asking the questions in the respondents' own languages when necessary and using translations that are more conceptual than literal. Interviewers should be recruited from among the target population groups, with nominations by local authorities. Also, it was recommended that the concepts be expressed in a way that takes into account cultural specificity.

With regard to question three— *What is needed from international technical cooperation in order to bring about introduction of the variable of "ethnic origin" or "ethnic/racial origin" in instruments for collection of health statistics, and to facilitate application of instruments containing these variables?*—the working group noted the need to encourage coordinated actions by the countries to carry out health assessments of binational peoples.

Another important need, according to the group, is to support efforts to recognize, systematize, and render operational the health systems of different cultures, as a part of the national systems.

The group believes that PAHO, with its experience, could share with the countries the progress being made toward these objectives in different settings and could sponsor horizontal relations of technical assistance and sharing of experiences.



List of Acronyms and Abbreviations

Acquired immunodeficiency syndrome	AIDS
Centro de Planificación y Estudios Sociales	CEPLAES (Ecuador)
Comprehensive local health systems	SILAIS
Confederación Nacional Afroecuatoriana	CNA
Conferencia de Nacionales Indígenas de Ecuador	CONAIE
Consejo de Desarrollo de las Nacionalidades y Pueblos del Ecuador	CODENPE
Corporación de Desarrollo de los Pueblos Afroecuatorianos	CODAE
Demographic and health surveys	DHS
Departamento Administrativo Nacional de Estadística	DANE (Colombia)
Encuesta de Demografía y Salud	ENDESA
Encuesta de Medición de Indicadores sobre la Niñez y los Hogares	EMEDINHO
Encuesta Demográfica y de Salud	ENDESA (Ecuador)
Encuesta Nacional de Niveles de Vida	ENNV (Nicaragua)
Federación de Indígenas Evangélicos	FEINE (Ecuador)
Federación Nacional de Organizaciones Campesinas e Indígenas	FENOCIN (Ecuador)
Fundación Ecuatoriana de Educación, Acción y Promoción de la Salud	FEDAEPS
Individual Registry of Health Services Delivery	RIPS
Instituto Brasileiro de Geografía e Estadística	IBGE
Instituto Nacional de Estadística	INE (Honduras)

Instituto Nacional de Estadística	INE (Uruguay)
Instituto Nacional de Estadística y Censos	INEC (Ecuador)
Instituto Nacional de Estadística y Censos	INEC (Nicaragua)
Inter-American Institute of Human Rights	IIDH
International Classification of Diseases	ICD
Latin American Information Agency	ALAI
Pan American Health Organization	PAHO
Potential years of life lost	PYLL
Program for the Improvement of Surveys and the Measurement of Living Conditions in Latin America and the Caribbean	MECOVI
Sistema Integrado de Indicadores Sociales del Ecuador	SIISE
United Nations Children's Fund	UNICEF
World Health Organization	WHO



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Agenda

Experts Workshop
**Cultural diversity
and disaggregation
of statistical health information**

*Quito, Ecuador
4-5 June 2002*

8:30 a.m. – 9:00 a.m. **Registration**

Tuesday 4

9:00 a.m. – 9:15 a.m. **Opening session**

Diego Victoria, PAHO/WHO Representative
Office, Ecuador

Patricio Jameriska, Minister of Health, Ecuador

9:15 a.m. – 9:45 a.m. **Panel 1:** Disaggregation of information by ethnic
origin: Why is it important? What can be done?

Panelists:

Carlos Larrea, Harvard University

Irene León
Representative of ALAI

Coordinator:

Manuel Cujilema, Ministry of Health, Ecuador

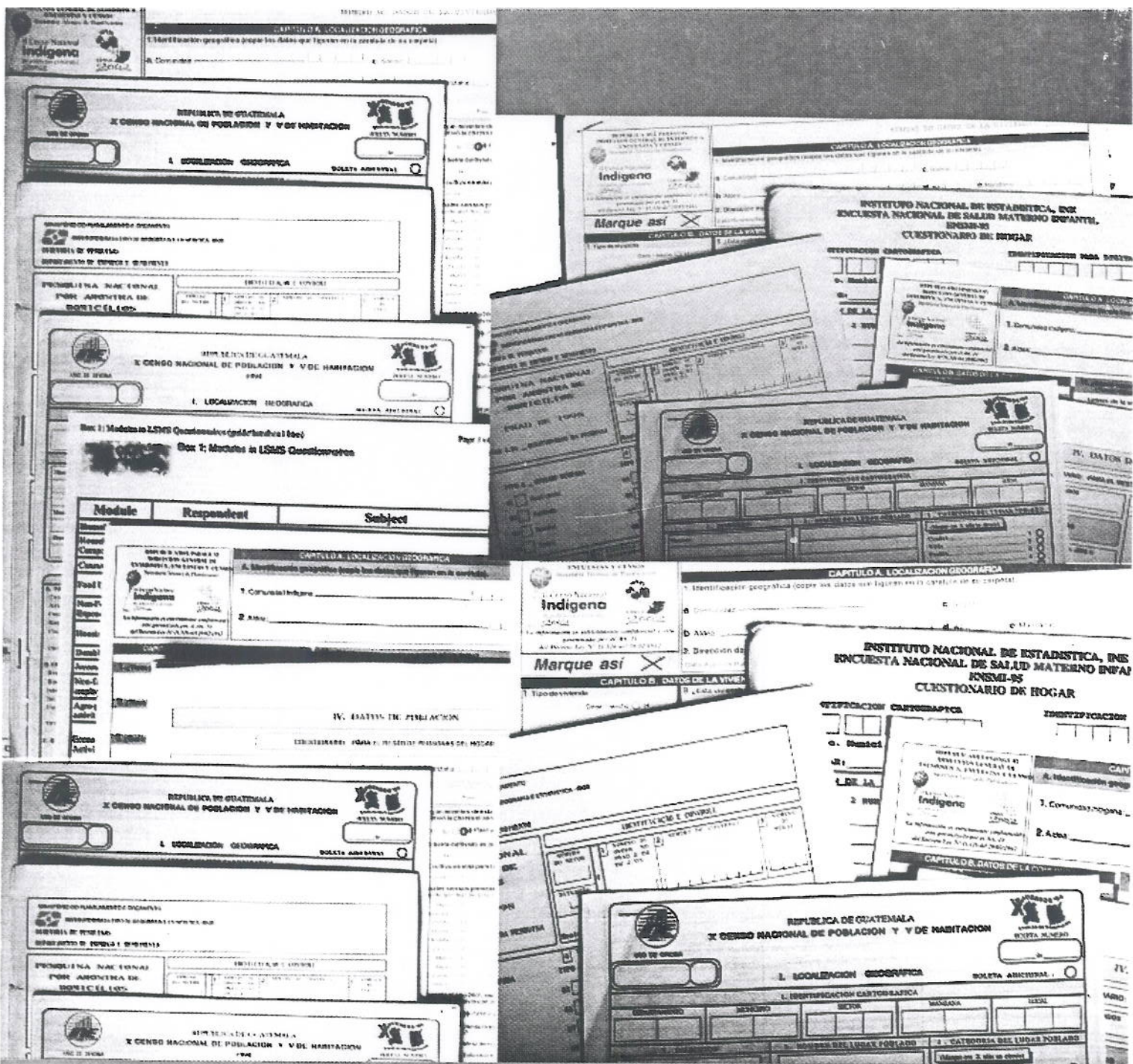
9:45 a.m. – 10:00 a.m. **Plenary discussion**

10:00 a.m. – 10:15 a.m. **Break**

-
- 10:15 a.m. – 12:30 p.m. **Panel 2:** How to identify and register ethnic origin: Problems of ethnic identification
- Panelists:**
John F. Long, U.S. Census Bureau
Jorge del Pinal, U.S. Census Bureau
Diego Iturralde, Inter-American Institute of Human Rights, Costa Rica
Elsa Rodríguez de Bastides, DANE, Colombia
- Coordinator:**
Rosa Carlina García, Ministry of Health
Colombia
- 12:30 p.m. – 2:00 p.m. **Lunch**
- 2:00 p.m. – 3:30 p.m. **Panel 3:** What experiences do we have with the disaggregated collection of statistical data in the Region?
- Panelists:**
Max Ortega, INEC, Ecuador
Josefa Blanco, INEC, Nicaragua
Daniel Sucazes, INE, Uruguay
- Coordinator:**
Cristina Torres, PAHO
- 3:30 p.m. – 3:45 p.m. **Break**
- 3:45 p.m. – 6:00 p.m. **Plenary session**

Wednesday 5

- 9:00 a.m. – 11:00 a.m. **Panel 4:** The national health information system
- Panelists:**
Rosa Carlina García, Ministry of Health, Colombia
María Georgina Díaz, Honduras
Enrique Morales, Nicaragua
Iris Maresca, Uruguay
- Coordinator:**
Sandra Land, PAHO
- 11:00 a.m. – 11:15 a.m. **Break**
- 11:15 a.m. – 12:30 p.m. **Panel 5:** How can geographical and socioeconomic proxies be used to complete the analysis of health information on ethnic minority and populations of African descent?
- Panelist:**
Lucila Bandeira Beato, IBGE, Brazil
- 12:30 p.m. – 2:00 p.m. **Lunch**
- 2:00 p.m. – 3:30 p.m. **Reports of the Working Groups**
Plenary presentation. Continuity of the groups and presentation of conclusions of the working groups: recommendations
- 3:30 p.m. – 3:45 p.m. **Break**
- 3:45 p.m. – 5:00 p.m. **Plenary discussion:** Areas for future cooperation
- Observations:** César Vieira, PAHO
- Coordinator:** Diego Victoria, PAHO/WHO
Representative Office, Ecuador
- 5:00 p.m. – 6:00 p.m. **Closing ceremony**
Special guests
-
-



Pan American Health Organization
 Regional office of the
 World Health Organization

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