Successful Brazilian Experiences in the Field of Health Information

Final Report

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Executive Summary

This document presents the results of the Study of the Brazilian Health Information System, which undertook to record the history, structure, and use being made of health information so that this experience can be shared with other countries in the Americas.

Activities under the study were coordinated by a group of representatives from the Ministry of Health, including the Executive Secretariat, the SUS Department of Informatics (DATASUS), the Secretariat for Health Care, and the Secretariat for Health Surveillance, and the Pan American Health Organization (PAHO).

Over its history, the Brazilian health system has had experience with a number of different information systems, whether for managing epidemiologic information, compiling demographic data, monitoring service performance, or other purposes. To document the Brazilian experience as reliably as possible over the chosen period of time (the last 30 years), the coordinating group identified and assigned priority to three important components: (1) information systems that capture national demographic and health data pertaining to what might be termed the “lifeline”: birth, represented by the Live Birth Information System (SINASC), illness, with the System for the Reporting of Notifiable Conditions (SINAN) and the Hospital Information System (SIH), and death, with the Mortality Information System (SIM); (2) the recording, compilation, and dissemination of health information within the Unified Health System (through the SUS Department of Informatics – SUS/DATASUS); and (3) the initiative to develop a (possibly unique) process of interinstitutional coordination to identify information sources,
build and standardize indicators, and disseminate basic data, indicators, and health status assessments in an organized manner through the Interagency Health Information Network (RIPSA). For each of these three components – the information systems identified, the DATASUS experience, and the development of RIPSA – it was decided to adopt two approaches:

(1) an historical and conceptual approach, documenting the positive experiences, the systems’ limitations, their best practices, and lessons learned; and

(2) a qualitative and descriptive approach, supported by interviews and statements from key informants, with a view not only to creating a written record of the systems’ history but also helping to identify the systems’ principal applications, and their strengths and weaknesses from various perspectives (in addition, the responses were intended to include valuable suggestions on what would constitute an “ideal” system in the future).

For the first approach, a call was put out to the academic community, researchers, and technical personnel who had played an active role in the systems’ history to produce articles about the respective information systems and their experience with RIPSA and DATASUS. For the qualitative study, interviews were held with key informants representing the systems’ major users, such as health services managers in the three spheres of government (federal, state, and municipal), users in the academic area, managers of the systems being studied, and health advisers.
1. Introduction

Brazil’s Health Information System has developed in tandem with the major movements in the history of public health since the beginning of the twentieth century. During the first six decades, as programs were getting under way and specific actions were being taken to address collective health problems (challenges posed by such diseases as yellow fever, malaria, tuberculosis, poliomyelitis, and measles), information systems began to be created to meet the specific needs of these initiatives, each with a focus and perspective limited to the program area for which it was created.

In 1971, the Information Processing Nucleus was created within the Ministry of Health to support the management of information relating to the ministry’s activities, soon to be followed by the Health Information System (SIS) inaugurated in 1975 and a subsystem devoted to mortality data stemming from the adoption of a standardized declaration of death for the entire country.

In the latter part of the 1970s and the 1980s, Brazil went through a period of political excitement, awakening awareness of needs, and commitment to agreements for democratization and political and structural reform, culminating in promulgation of the present Brazilian Constitution in 1988, which has a chapter specifically devoted to health. The health reform movement was the main force behind these political growing pains and the framework within which technical and political guidelines were developed for addressing various issues, including information.

The evolution of health information systems in Brazil has closely paralleled the major transformations that have taken place in the structure, models of operation, and even the processes and managerial and monitoring mechanisms created in order to shift from a centralized structure to the decentralization that is
now in place. Numerous information systems and applications have been developed since the 1970s to address the changing and growing needs that have emerged from the organization, growth, and expanding responsibilities of agencies responsible for systems management in the three spheres of government: federal, state, and municipal. Thus, ever since its inception, Brazil’s information system has been in a constant state of evolution and technological upgrading, which has resulted in a high degree of complexity and variation among the different processes.

2. The Live Birth Information System (SINASC)

In 1973, responsibility for the information contained in the civil registry was officially vested in the Brazilian Institute of Geography and Statistics (IBGE), which was mandated to organize and systematize the processes for the collection and recording of data. At the time, the available information related to births was limited to a few demographic variables, and the only source of data was the local offices of the civil registry (notary public offices). The system failed to include a large number of births that were either never recorded at a local registry or else recorded at a later time.

The local registries were the sole source of information on live births until 1990, when the Ministry of Health created the Live Birth Information System (SINASC), which finally made it possible to reduce the rate of underreporting.

The data now being collected make it possible to provide information for setting health policy priorities and assessing both perinatal and neonatal care. Ever since the system was created, its decentralized nature has been an advantage because it has supported the consolidation of management at the local level. Electronic dissemination of information and ready access to the database by means
of a user-friendly tabulator have greatly increased the utilization of information. These factors have helped to ensure the high quality of the information system. At the same time, SINASC is undergoing constant assessment by a technical evaluation committee consisting of experts in information and surveillance from the Ministry of Health, the states, and the municipalities, as well as academic investigators.

There are still problems in the coverage of birth events in the country’s northern and northeastern regions, mainly in rural areas, especially those located far from any health services, where quality control is limited. Another area in need of attention is the review of information provided for the variables in the data fields: correction of errors in comprehension and interpretation; adjustment of descriptors that involve ethical, cultural, and/or legal issues; and the standardization of the civil records so that the entries are compatible with epidemiological data and biases are eliminated in the collection and analysis of information. Lack of full integration with other systems leads to duplication for some of the data being collected by SIH and SIM.

Since its inception, SINASC has been undergoing a process of planned implementation. It offers three major innovations compared with the civil registry. First, it is based on introduction of the compulsory declaration of live birth (DN), a basic standardized individual document that must now be used throughout the country. The second innovation has been the incorporation of new data elements into the system, including a series of headings related to the newborn, delivery, and characteristics of the mother, which provide important information for constructing indicators, setting priorities, and assessing maternal and child care. And third, the civil registry is no longer the sole source of information: the health establishments where infants are born now provide data as well, and through SINASC it is
possible to have information about births regardless of whether or not the child is registered.

The system grew quickly: within a few short years it was implemented in all the states of Brazil and decentralized at the level of the municipalities. In 1997, SINASC had more recorded births than the civil registry in all the regions of the country. Electronic dissemination of information and access to the database, together with a user-friendly tabulator, have greatly increased the utilization of information. The system is widely used in the three spheres of the Unified Health System. There has been emphasis on its application at the local level to construct epidemiologic indicators such as the prevalence of low birthweight, prematurity, cesarean sections, and births to teenage mothers. Mainly, however, it is used as a surveillance tool to collect information on high-risk newborns, and as such it has been implemented in a large number of municipalities throughout the country.

However, SINASC still has coverage problems in the country’s northern and northeastern regions, especially in rural areas and those located far from the health services, where quality control is limited. In addition, it needs to be more fully integrated with other systems such as the SIH and the SIM.

Some of the viable possibilities for improving the system include: electronic entry of the data for the declaration of live birth in the health services; consolidation of data at the level of the health unit and the municipality, thus strengthening epidemiologic surveillance; making the system more flexible to enable the municipalities and states to incorporate specific modules depending on their regional needs while still ensuring standardization at the national level; increased connectivity and integration with other systems of the Unified Health System (SUS) to prevent overlapping and duplication of information between the systems; and the creation of mechanisms for training professionals in the
municipalities and states to use the system as a tool for epidemiological surveillance.

3. System for the Reporting of Notifiable Conditions (SINAN)

The year 1990 saw creation of two entities within the Ministry of Health: the National Health Foundation (FUNASA), and the National Epidemiology Center (CENEPI). The latter agency was given two tasks: to encourage the use of epidemiological techniques and resources within the SUS; and to build a system for the reporting of notifiable conditions, which became SINAN.

SINAN was designed to contain two modules, one for reporting and the other for case investigation, both of them linked to a single record identifier. The first module was to contain basic information for identifying and locating the case, the suspected diagnosis, and an indication of the patient’s level of schooling. The second module was to include information relative to the epidemiological investigation of each case. Information from the first module would be submitted immediately, whereas the data in the second module would be transmitted later on.

Implementation of the system got under way in 1993 with the establishment of an upward flow of information generated at the local level. One of the challenges involved dealing with the differing practices and degrees of training and skill at the local and regional levels.

The system is based on the concept of a List of Compulsory Notifiable Diseases established at the federal level, including diseases of specific interest to the states, with the possibility of filling in any gaps that may be identified. It is intended to serve as a reference system for epidemiological surveillance activities.

However, the characteristics of some of the diseases or conditions, as well as some of the practices followed by the control programs, made it impossible to
apply this logic, since reporting of the case was linked to initiating an epidemiological investigation. This requirement added to the response time and made the system slow.

Also, the lack of information about the location of events in the less aggregated areas and services has limited SINAN’s usefulness for local managers and for analysis by health unit. Other challenges encountered during the implementation process were the loss of information in the course of migrating the data between different versions and systems, lack of integration of the development teams with the technical users, inadequate training of technical professionals in the use of data analysis tools such as TabWin, and inability to identify the codes submitted by the reporting units.

The effort to overcome these challenges led to standardization of criteria, information channels, and concepts, as well as the creation of a unified reporting form that nevertheless allows for flexibility and enables local users to include specific conditions, thus making it possible to meet needs arising from the decentralization of management while at the same time respecting established criteria and procedures.

A number of positive developments were also identified: the change in the level at which the report is recorded so that it is now done on an individual basis, expanded access to information, development of data entry software, standardization of case investigation forms while at the same time maintaining the individuality of each subsystem, and the possibility of introducing modules at the local level that will make it unnecessary to submit a report when no cases of a given disease have occurred in a particular locality.

Anticipated system upgrades include the implementation of SINAN-Net to respond to the demand for system input, increase the speed of information flow,
improve database security, facilitate routine operations, and meet the need for better operating routines and flagging software.

A planned user-friendly interface will help to improve the quality of data being entered on the reporting and case investigation forms. It is intended to decentralize the system to hospitals at the state and municipal levels, which will come to serve as notification sources.

4. Hospital Information System (SIH)

Concern about collecting and analyzing information on hospital production and payments contracted by the National Social Security Health Care Administration (INAMPS) resulted in the development of two systems in the 1970s that were precursors of today’s SIH.

A financial crisis in 1982 led to the establishment and implementation of an information system throughout the country in 1983, bringing together information from private hospitals either contracted by or working under an agreement with INAMPS, which was to serve as one of the elements in the plan for the reorganization of social security health care.

In 1991, following implementation of the Unified Health System and the transfer of INAMPS to the Ministry of Health, the system was renamed the Hospital Admissions (Information) System of the Unified Health System (SIH/SUS), with no change in the data entry procedures or document flow and processing.

Although the SIH still maintains some of the characteristics of the previous systems, it has undergone a number of upgrades to incorporate new technology and respond to changes in policy orientation. For example, the replacement of printed forms with diskettes in 1992 was followed in 1995 by the introduction of a series
of DATASUS applications – for example, the Financial Management Program (PGF) and the AIH Management System (SGAIH) – which have given SUS managers at the municipal and state level new control over invoices presented by their service providers.

The data collected by the SIH are used extensively for planning and management purposes, even though the information may have some limitations – mainly because the reason for developing and using the system was to control production, which can lead to distortions in the information fed to it due to differences in criteria and in the table of procedures. The system supports a variety of studies, both epidemiological and on services provided. Given its scope, flexibility, and rapid processing time, its broad potential should be enlisted to meet usage demands that go beyond the purpose for which it was initially developed.

This expanded usage will require further technical development and the provision of added tools that will allow the system to be accessed by different user groups. Some of the information collected is of excellent quality, such as the data on deaths, but there are still some technical and conceptual difficulties, as well as problems of standardization with respect to other systems, which affect how the conditions and principal cause for hospital admission are identified. With regard to retrieving information such as socioeconomic data about the patient and the identification of providers, the managers and researchers interviewed were in disagreement about the importance and usefulness of the data captured by the system.

Revision and updating of the tables of procedures will be an important factor in improving the quality of the information and reducing distortions. Since 2005, a process has been under way to review and standardize the tables of hospital and outpatient procedures, and it is expected to implement revised versions as part of
the decentralization process, which will allow information generated by the system to be processed by states and municipalities.

At the same time, changes in the network’s financing mechanisms, already implemented in new management contracts with the university hospitals, using global cost-based budgeting, reduce the risk of payment distortions. This certainly points to a line of development in the management process that is directly related to the system’s usage and characteristics.

5. Mortality Information System (SIM)

Created by the Ministry of Health in 1975, the Mortality Information System (SIM) is the oldest nationwide health information system. Up until then, the Brazilian Institute of Geography and Statistics (IBGE) had been responsible for the collection, processing, and dissemination of data on deaths. The implementation of SIM represented an approach to the handling of mortality data from the perspective of public health epidemiology and not merely the production of vital statistics. The first challenges at the time SIM was introduced were to create a unified model declaration of death for use throughout the country, to increase the system’s coverage, and to establish criteria for the information to be included in the declaration of death.

The last 10 years have seen major progress toward meeting these challenges. Among the factors that have contributed significantly to the system’s increased coverage, improvement in the quality of its data, and dissemination and use of the information produced are the following:

- the investment made by both the Ministry of Health and the State and Municipal Health Secretariats to populate the system with data and train the professionals involved in using the system;
the municipalization of health, which has facilitated increased involvement by local actors in improving the collection of information on mortality, filling in the declaration of death, and utilizing the information at the local level; and

- interventions with local offices of the civil registry, clandestine cemetery operations, health care professionals, hospitals, and medical examiner offices.

Even though significant progress has been made, SIM has both strengths and weaknesses. In particular, its strengths include: (1) steadily increasing coverage, such that since the year 2000 SIM has been reporting more deaths than were recorded in the civil registry; (2) improved quality of information, which can be measured by the reduction in the percentage of deaths due to ill-defined causes from 21.5% in 1980 to 13.3% in 2003; (3) growing recognition of the system as an important conduit for the production of health information; (4) thanks to advances in information technology, faster data and information processing and more rigorous control of data consistency using cross-checking software and a program for selecting the underlying cause of death (SCB), as well as development of the TabWin and TabNet programs, which make the tabulation of information fast and user-friendly, even via the Internet; (5) the facilitation of exchanges between professionals in the different management spheres of the health system (national, state, and municipal) and their greater involvement in the system; (6) its universal nature; (7) the wealth of information produced by the system; (8) decentralization of the system and assignment of responsibility to local managers, who are implementing measures to improve its quality such as active searches for deaths, creation of death investigation committees, and other strategies; (9) the growing use of mortality information for assessing the health situation, setting priorities,
and monitoring infant and maternal deaths, deaths from firearms and traffic accidents, etc.; and (10) progress in the timeliness of the information, thanks to the fact that it is being made available faster.

The system’s weaknesses include: (1) the quality of the physicians’ declaration of the cause of death; (2) the shortage of resources in the states and municipalities to further develop the system; (3) the high turnover rate and lack of training of professionals who are operating the system; and (4) the continuing high percentage of ill-defined causes of death, especially in the northern and northeastern regions.

To continue improving and refining SIM, the following steps are recommended: (1) intensify the training of professionals involved in the system; (2) continue raising awareness and enlisting the participation of professionals, managers, services, health counselors, civil registration offices, and medical councils at the regional and federal levels; and (3) promote the creation of new epidemiology units in hospitals and strengthen existing ones. In addition to training professionals and raising awareness about using SIM, it is essential to ensure that the states and especially the municipalities have the necessary material, technical, and technological conditions that allow them to manage the information systems fully and not merely collect data. The creation of Death Verification Services (SVOs) throughout the country, with legally established protocols and standards, is opening up the possibility of reducing the percentage of deaths for which the causes are ill-defined.
In 1990, with the introduction of administrative reform throughout the State, the National Social Security Health Care Administration (INAMPS) was transferred from the Ministry of Social Welfare to the Ministry of Health. As a result, it was necessary to create an information processing infrastructure to manage the INAMPS control and payment systems already agreed upon while at the same time developing new applications to support other actions in the area of health. A decree issued in 1991 created the Department of Informatics within the SUS (DATASUS).

In response to the need to improve the handling and tabulation of information in order to assess the health situation in the areas being studied, DATASUS developed a program that allowed for the tabulation of data on a personal computer, thus enabling the user to delineate the morbidity and mortality profile of the SUS client population. TabWin makes it possible to link these tabulations to a cartographic base and display the results graphically for a spatial evaluation. It also allows for consultation of relational databases and the creation of DBF files, and it has an interface for executing analysis routines using free statistical software which makes it possible to produce historical series, statistical functions, and visual displays of information using graphs and maps, as well as import data in XML and export data and maps in various formats. The program has been distributed at no cost since 1994, at first for the DOS environment (TabDOS), and since 1996, for Windows (TabWin).

As use of the Internet became widespread, TabWin was expanded into TabNet to allow for rapid tabulation of DBF files. The following requirements were taken into account in developing this software: (1) the program had to be fast
enough to tabulate large masses of data on low-cost servers; (2) the interface needed to be user-friendly with all the tabulation options accessible through a single menu, as with TabWin; and (3) the user should be able to save the tabulated date for use in TabWin, electronic spreadsheets, or other statistical analysis tools.

DATASUS has supported the State and Municipal Health Secretariats in implementing TabNet at their sites and promoting the decentralized dissemination of information based on local needs.

This program, as well as other similar products used in the health area, has been possible because the SUS information systems function at the national level, allowing for immediate generation of the most common tabulations using predefined files.

Through TabNet, DATASUS headquarters has amassed and makes available health information disaggregated down to the municipal level in the areas of health care, the health care network, epidemiology and morbidity, vital statistics, population and socioeconomic data, and financial information.

Since DATASUS was created, significant strides have been made in the dissemination of information. However, work still needs to be done to improve dissemination. The pending challenges include expanding and popularizing the media through which information is distributed, expanding the dissemination network, and developing policies and adopting measures for the dissemination of health information that are geared toward social empowerment.

7. Interagency Health Information Network (RIPSA)

The Interagency Health Information Network (RIPSA) was established in 1996 under a Ministry of Health directive with support from a technical cooperation agreement with the Pan American Health Organization (PAHO) in response to the
felt need for a collective effort to improve the availability of basic data, indicators, and analyses of health conditions and trends in Brazil in order to produce information suitable for the formulation, management, and assessment of public health policies and actions. The initiative is intended to support collective efforts involving the national institutions responsible for the production, analysis, and dissemination of health information.

After 10 years of operation, the RIPSA model has earned its reputation with government and academic institutions as a national reference point for the production and rating of indicators and as an effective means of promoting consensus on controversial issues in the area of health information. The value of this operational model was underscored in an assessment of the Basic Data Initiative in the Latin American context undertaken by PAHO in 2004.

There are still some major challenges to meet before it can be said that RIPSA’s final objectives have been fully achieved. This will entail a persistent effort to consolidate the results attained so far, along with the gradual introduction of behavioral and structural changes that will address the difficulties stemming from the political and administrative instability of the health sector in Brazil.

8. Final Remarks: General Characteristics of the Systems

It is important to emphasize that some of the characteristics mentioned above refer to all the health information systems in Brazil, which have been affected equally by the following circumstances:

Decentralization — Management of the information systems is shared between the three spheres of government: federal, state, and municipal. Decentralization broadens the scope of information production, improves the quality of data, and increases the likelihood that available information will be used at the local level to plan health actions and services in the state and municipal
spheres. However, there are still some difficulties with regard to the selection and maintenance of quality human resources in the states and municipios for the local production and analysis of data.

**Strategic role of DATASUS and RIPSA** — DATASUS enjoys the privilege of having access to data as well as the capacity to organize and integrate information systems. In addition to raw data, it offers programs for the organized collection of data and the development of epidemiological indicators. RIPSA, for its part, has become a nexus for the harmonized production of sectoral and extrasectoral data, both by discussing and analyzing the quality of the data and by systematizing information on the health indicators used in Brazil and disseminating a publication on them which also defines and explains the calculation procedures.

**Technological development** —. In recent years, developments in the field of informatics have played a key role in improving the flow of data, sharply reducing the time between the production and availability of information, and making access to it more democratic.

**Interoperability** — Although still in its incipient stage, a process is under way to expand the opportunities for communication between the various information systems.

**Improvement of data entered in the basic forms** — Even in the more fully developed systems such as SIM and SINASC, there is need to improve the data being entered in the two basic documents, the declaration of live birth and the declaration of death.

**Incorporation of private sector data** — This challenge is being addressed with the support of the National Supplementary Health Agency, which has implemented a strategy for assessing the quality of health care provided under
health plans and health insurance schemes. This strategy requires that information be produced on every procedure performed by professionals and institutions in the supplementary health system.

**Mechanisms for interaction between the federal, state, and municipal spheres (partnerships)** — The Unified Health System has management mechanisms for communicating among the three spheres of government — for example, bipartite intermanagerial commissions at the state level and a tripartite intermanagerial commission at the federal level — which define the strategies for implementation, organization, financing, and operation of the system. In this management model, information is valued as a basic input for the management and evaluation of health actions. However, the initiative faces major challenges.
1. Introduction: Health Information Systems in Brazil

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An understanding of the health information system in Brazil – its components, how it operates, and the ways in which it is being used – can be gained by taking a look at its origin, how it has evolved, and the current organizational structure within which it carries out actions to promote, protect, and restore health for the nation. This context will help to appreciate to scope and quality of the data generated, processed, and made available for such purposes as planning, management, evaluation, social monitoring, teaching, and research.

Historical, Legal, and Political Context

Over the last 30 years, considerable effort has been made to streamline the health sector in Brazil. At the beginning of this period it was nearly anarchic, with multiple actors in the three spheres of government largely uncoordinated and efforts being duplicated or triplicated in some areas while others were left unattended. From that, it has grown to become a systematic, structured organization that encompasses both the public and the private sector, working with the latter under a series of agreements.

The first initiative to address this issue was the enactment of Law 6,229, dated 17 July 1975, which created the National Health System. The law mainly spelled out activities such as the operation of health services in the states, territories, and the Federal District, and for the municipalities. The national health policy was to be formulated by the Ministry of Health and approved by the then

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Social Development Council. It was an attempt to organize a chaotic situation of health services delivery in Brazil. Little progress was made at that time, because at the federal level several different institutions were engaged in carrying out health actions – notably, the Ministries of Health, Social Welfare, Education, Culture, Interior, and Labor. It could be said that the Ministry of Health began to be formally characterized as the system’s mentor, although in reality this was not quite true. Also, that same year, the Health Information System (SIS) and a mortality subsystem were created within the Ministry of Health following the adoption of a standardized declaration of death for the entire country.

Thereafter, during the 1980s, several initiatives were undertaken to integrate services and streamline the delivery of health actions – for example: the Social Security medical reform, Integrated Health Actions, and the Unified Decentralized Health System. However, the country was still under an authoritarian regime and bold initiatives were not well received. At the end of the 1970s, however, an academic environment began to emerge, with open discussions about the health sector in Brazil which later took shape under the name of the health reform. The First Symposium on National Health Policy, held in 1979, laid down the principles that were later to be adopted by the Unified Health System – namely that: (1) health is a universal and inalienable right; (2) addressing the determinants of health is an intersectoral challenge; (3) the State is responsible for taking regulatory measures “to offset the more noxious effects of free enterprise in the area of health;” (4) policies should be directed toward decentralization, regionalization, and hierarchization; and (5) emphasis should be on participation by the people and social empowerment.[1]

Definitive steps were taken to lay down the principles and chart the practical course of the Health Reform at the VIII National Conference on Health held in
Brasília in March 1986, which was the culmination of preparatory meetings held in all the states and territories of Brazil. Among the topics debated were health as a right, reformulation of the national health system, and financing. It became evident at the conference that the health sector required fundamental changes that went far beyond administrative and financial reform; it needed to be reformulated from the ground up, based on a broadened concept of health itself and its corresponding institutional outreach, along with a review of all legislation pertaining to the promotion, protection, and restoration of health.\textsuperscript{[2],[3]}

Finally, convocation of the National Constituent Assembly gave strong momentum to the Health Reform movement, and indeed the assembly enshrined the basic principles defended by the proponents of the reform in the text of the new constitution in 1988.

The Unified Health System (SUS), created by the federal constitution in 1988, was later codified under two federal laws: the Organic Health Law of 1990 (Law 8,080), and Law 8,142 of 1990, the latter of which deals with social monitoring and health sector financing.\textsuperscript{[4],[5]}

The basic policy lines that guided organization of the Unified Health System were decentralization with unified management in each sphere of government; integrated health care, priority being placed on prevention without detracting from the importance of health care services and community participation.\textsuperscript{[4]} New and important actors emerged – the municipalities and the states – which came to play a key role even in the generation and use of the data needed by the country’s several health information subsystems.

With decentralization under way, consecrated by creation of the SUS, its harmonious operation was to depend on having the mechanisms for carrying on business between the three spheres of government. And thus a series of
intermanagerial commissions were established: a tripartite commission made up of representatives of the Ministry of Health, the National Council of State Secretaries of Health, and the National Council of Municipal Secretaries of Health; and, in addition, bipartite commissions in each state consisting of representatives of the State Health Secretariat and the State Council of Municipal Secretaries of Health. All major decisions are agreed upon in these commissions before they are implemented. The resulting agreements deal with the organization and operation of the system and the corresponding financing mechanisms. Decisions concerning the implementation and development of health information systems are also discussed and agreed upon in these commissions.

**Health Information Systems with National Coverage**

Traditionally, health information in Brazil has been fragmented, reflecting the compartmentalized activity of the sector’s various institutions.\(^6\,^7\) In the past, morbidity statistics mainly came from vertical services and programs, such as maternal and child health, health of schoolchildren, malaria, tuberculosis, leprosy, and polio. Several databases were in existence, and they reflected the scope and emphasis of each particular area. To a varying extent, there were problems with the coverage and quality of the information. Also, it was difficult to coordinate the information that the different sources produced. The result could sometimes be discouraging when information from different databases was compared. The inconsistencies reduced the possibility of being able to analyze the situation. Even though the data were plentiful, they were scattered in different sources and did not provide consistent and useful information to support decision-making.

Basically, the objective of information systems is to acquire knowledge to support the work of the services concerned. Even though morbidity information is the most useful for understanding the health of a population, mortality statistics are
easier to prepare and tend to be the first fairly reliable information to be made available. These statistics tell us what the people died of and give us an idea of what was going on in the population in terms of morbidity. In Brazil, prior to the 1970s, isolated efforts showed us something about our mortality statistics. As the quality of information tends to be better in the large cities than in the interior of the states, the first national information to be widely disseminated was the data on deaths in the capital cities of Brazil. For example, in 1944, the Federal Biostatistics Department in the National Health Department of the Ministry of Education and Health published a biostatistical yearbook containing mortality data by cause of death in 1929 and 1932.\[8\] After that, the Brazilian Institute of Geography and Statistics (IBGE) took on the task of publishing mortality data by cause of death in the municipios of the capital cities.

The 1970s saw a turning-point in the history of health statistics in Brazil. The change was due to two events in particular. First, the passage of Federal Law 6,015 in 1973 regulated the national civil registry and entrusted IBGE with responsibility for compiling statistics based on data from the registry. Every year IBGE publishes statistics on the births and deaths recorded throughout the country.

The second event was the National Meeting on Health Information Systems, held in 1975.\[1\] That same year, the Health Information System and its subsystem on mortality statistics was created within Ministry of Health. And indeed, several of the main health information systems that provide nationwide coverage were created in the latter half of the 1970s and the early 1980s.

Today, much of the information needed in order to understand the health situation of the population is being produced at the initiative of the Ministry of Health. Table 1 gives an overview of the main databases created in the last 30 years under the aegis of the Ministry of Health that are still in operation. There are
also supplementary information sources functioning outside the Ministry of Health that provide knowledge about the health of the population, and Table 2 gives summary information about some of the main databases in this category.

The four national databases most heavily used for assessing the health situation are presented below in greater detail as the subject of separate chapters in this collection.

**Mortality Information System (SIM)**

Based on several successful experiences, especially in Rio Grande do Sul and São Paulo, it was decided in 1975 to implement an epidemiological surveillance system at the national level. Accordingly, a model for the mortality information subsystem was developed, and the Ministry of Health proceeded to create the SIM. Also, a standard format was developed for the declaration of death, which was ultimately adopted throughout the country. Since that time, the Ministry of Health has been responsible for the nationwide collection and regular publication of data on mortality, and it has steadily improved the quality and coverage of this information.

**Live Birth Information System (SINASC)**

The Ministry of Health established SINASC in 1990 for the purpose of bringing together epidemiological information on all live births reported in the country. The system input document is the declaration of live birth, which is now standardized nationwide. The same declaration is filled in whether a delivery takes place in the hospital or at home, and it is useful for a number of purposes in addition to its statistical function. For example, it provides the physical location of the parturient mothers and the newborns, thus making it possible to plan specific health actions.
As in the case of SIM, the implementation of SINASC was gradual in the various federal units. Today, however, some municipalities are now reporting larger numbers of registered births than when the figures were being published by IBGE, based on data from the civil registry.

While information on mortality is useful in global assessments of the situation, planning, and the evaluation of actions and programs in the area, the SINASC information is more specific. It can be used to analyze and subsidize interventions related to the health of mothers and children such as pregnancy monitoring and care of newborns.

**System for the Reporting of Notifiable Conditions (SINAN)**

Epidemiological surveillance is the traditional way to apply epidemiology in the health services. One of the agenda items at the V National Health Conference in 1975 was the National Epidemiological Surveillance System\(^1\) and its enabling legislation, Law 6,259 of 1975.

The current system for the Reporting of Notifiable Conditions (SINAN) was gradually implemented starting in 1993. Its purpose is to collect, transmit, and disseminate data routinely generated by the epidemiological system in the three spheres of government: federal, state, and municipal. Its input comes mainly from reports of cases and investigations of diseases and conditions on the national list of compulsory reportable diseases, which is updated on a regular basis. The states and municipalities are allowed to include other major health problems in their respective regions, such as chickenpox in the state of Minas Gerais or diphyllobothriasis in São Paulo. A second form used to provide data to SINAN is the individual case investigation sheet, where the results of case investigations are recorded.
The SINAN data make it possible to conduct a dynamic investigation of a disease event in the population. SINAN can also help supply causal explanations for compulsory reportable conditions, as well as point out risks to which the population is exposed, thus contributing to a fuller understanding of epidemiological conditions in the geographical areas of the country.

**Hospital Information System (SIH)**

SIH was originally developed as a financial system to handle payments for in-hospital services. As an additional benefit, it is also used for epidemiological purposes. It was inaugurated in 1976 by the then National Social Security Institute (INSS). In 1986 it was extended to include philanthropic hospitals; in 1987 it was made available to universities and other teaching institutions; and in 1991, to public federal, state, and municipal hospitals. The basic input document is the Hospital Admission Authorization (AIH). It collects information on 60% to 70% of hospital admissions in the country within the Unified Health System.\(^9\) It does not include admissions to hospitals that are not connected to the SUS, the charges for which are paid for by health insurance or billed directly to the user. Since readmissions and transfers of patients to different hospitals cannot be identified, some cases may be counted twice.

**Interagency Health Information Network (RIPSA)**

RIPSA represents an effort to integrate the national databases. Started in 1996, at first it was a partnership of technicians from the Ministry of Health and PAHO. Its objective is to create a network of the agencies involved in the production and analysis of data of interest for health. In addition to the Ministry of Health and PAHO, its members now include the Brazilian Institute of Geography and Statistics (IBGE), the Institute for Applied Economic Research (IPEA), and
about 40 prestigious national technical and scientific institutions. The participating institutions are committed to making data available to the network on a regular schedule and agree to allow the information to be disseminated.

Every year information is tabulated on selected indicators so that users will constantly have new data on the health of the population. Because the information is being disseminated and used, it is constantly being refined.

RIPSA’s main objectives are: to identify institutions that produce information; to standardize, produce, and disseminate indicators in various areas (population, socioeconomic characteristics, mortality, morbidity, and coverage provided by health services and actions); and to contribute to and encourage analysis of the health situation and its trends.

RIPSA owes its success, after 10 years of operation, to a number of factors, including its prior experience with national databases and its collaboration with DATASUS, in which extensive effort was devoted to the development of programs such as TabWin to expand the utilization of national databases of interest for health. DATASUS is responsible for making information available through the Internet.

**Dissemination of Health Information**

Ever since creation of the Department of Informatics (DATASUS) within the Unified Health System in 1991, the dissemination of health information has been a goal, and this goal has been fulfilled through the free public distribution of health information and the tools that facilitate its use.

DATASUS has developed a simple, quick tool for tabulating data produced by the Unified Health System – namely, Tab, with versions available for DOS
(TabDOS), Windows (TabWin), and the Internet (TabNet). Almost all the national systems make their data available through TabNet.

To further facilitate the exchange of information, several products have been developed that bring information together from different databases – for example, the Health Information Notebook.

Nevertheless, there is still room for expansion in terms of access to information, ongoing training for local managers and health professionals in conducting analyses of the health situation at the local level, and support for and promotion of digital inclusion programs and the preparation of analyses geared to non-specialists.

The outlook for the health information sector in Brazil includes continued improvements in the national databases and increased integration between them to produce analyses of the situation and facilitate decision-making. This will call for emphasis on standardization, compatibilization, and further dissemination of health information in the three spheres of government.[6,7] It will also be important emphasize further analysis of information in order to provide knowledge and guidelines for a diversified public.
Chapter References

1 Cordeiro H. O Instituto de Medicina Social e a luta pela reforma sanitária: contribuição à história do SUS. *Physis* vol.14 (2) 343-62, 2004


9 RIPSA. Indicadores para a saúde no Brasil: conceitos e aplicações.
Table 1. Ministry of Health Information Systems

- **Mortality Information System (SIM)**
  Provides information on deaths by residence of the deceased. It is the oldest health information system currently in operation in the country. www.datasus.gov.br/catalogo/sim.htm or http://portal.saude.gov.br/portal/svs/area.cfm?id_area=460

- **Live Birth Information System (SINASC)**
  Provides epidemiological information on births reported throughout the country. www.datasus.gov.br/catalogo/sinasc.htm or http://portal.saude.gov.br/portal/svs/visualizar_texto.cfm?idtxt=21379

- **System for the Reporting of Notifiable Conditions (SINAN)**

- **Hospital Information System (SIH)**
  Stores data on hospital admissions in the Unified Health System. www.datasus.gov.br/catalogo/sih.htm

- **Outpatient Information System (SIA/SUS)**
  Responsible for capturing and processing of outpatient accounts in the SUS. Basic document is the *Boletim de Produção Ambulatorial* (BPA) [Outpatient Production Bulletin]. In 2005, about 2 billion laboratory tests were performed, 218 million at the high-complexity level. www.datasus.gov.br/catalogo/siasus.htm
• **Basic Care Information System (SIAB)**

  Collects data on basic care recorded by community agents or teams working for the Family Health Program (PSF).


• **National Immunization Program Information System (SI-PNI)**

  Reports numbers of persons vaccinated in the health units, movement of immunobiologics (stock, distribution, utilization, physical and technical losses), and notifications of adverse events; used in all the municipios in Brazil.

  [www.datasus.gov.br/catalogo/pni.htm](http://www.datasus.gov.br/catalogo/pni.htm)

• **Epidemiological Surveillance System (SIVEP)**

  Replaced the earlier Malaria Information System (SISMAL).

  [http://saude.gov.br/sivep_malaria](http://saude.gov.br/sivep_malaria)

• **SUS Human Resources Information System (SIRH/SUS)**

  Brings together data from various sources on employment, work force, training, job market for health professionals, etc., and disseminates consolidated information on the subject.


• **Public Health Budgets Information System (SIOPS)**

  Stores data on public income and expenditures on health services and actions.


• **Survey of Information on Beneficiaries of Private Health Insurance Plans**
Consolidates data on beneficiaries of health care plans or health insurance offered by private insurers.

Source: Adapted from RIPSA. *Indicadores para a saúde no Brasil: conceitos and aplicações*. Brasília, OPAS, 2002.
Table 2. Nationwide Information Systems or Databases that Supplement the Ministry of Health Information Systems

- **Population Census**
  Every 10 years the census of the Brazilian population is conducted to gather demographic and socioeconomic information about the people and data on the characteristics of their homes. In addition, a population count is taken halfway between censuses to update the data from the last full census. [www.ibge.gov.br](http://www.ibge.gov.br)

- **Civil Registry**
  The registry contains data on births, marriages, legal separations, and deaths recorded in local registries throughout the country. [www.ibge.gov.br/ibge/estatistica/populacao/registrocivil/default.shtm](http://www.ibge.gov.br/ibge/estatistica/populacao/registrocivil/default.shtm)

- **National Household Sampling Survey (PNAD)**
  Conducted annually during the intercensal periods in a representative sampling of the Brazilian population, this survey collects demographic and socioeconomic information about people and data on their homes. In 1998 and 2003, the PNAD included a supplement on health conditions. [www.ibge.gov.br/ibge/estatistica/populacao/trabalhorendimento/pnad/default.shtm](http://www.ibge.gov.br/ibge/estatistica/populacao/trabalhorendimento/pnad/default.shtm).

- **Survey on Medical and Health Care (AMS)**
• **National Basic Sanitation Survey (PNSB)**
  Conducted periodically (most recently in 1989 and 2000) to obtain data on water supply coverage, sanitary waste disposal, urban sanitation, and trash collection. [www.ibge.gov.br](http://www.ibge.gov.br).

• **Household Budget Survey (POF)**

• **Lifestyle Survey (PPV)**
  Conducted in 1996-1997 to obtain data on a number of characteristics such as nutrition, health, poverty, inequality, and the labor market: [www.ibge.gov.br](http://www.ibge.gov.br)

• **Monthly Employment Survey (PME)**
  Provides information on the labor market such as occupation of economically active persons, income, and possession of a signed worker identification card. [www.ibge.gov.br/ibge/estatistica/indicadores/trabalhoerendimento/pme/default.shtm](http://www.ibge.gov.br/ibge/estatistica/indicadores/trabalhoerendimento/pme/default.shtm).

• **Estimates and Projections**
  Based on census data and information from the sample surveys, IBGE makes projections of estimated population growth, birth and death rates, and fertility. [www.ibge.gov.br](http://www.ibge.gov.br) or [www.datasus.gov.br](http://www.datasus.gov.br).

• **Unified Social Security Benefits System (SUB)**
Contains information gathered by the Ministry of Social Welfare on the benefits (retirement, pension, aid, and others) granted and being paid to beneficiaries (MPAS). [www.dataprev.gov.br/](http://www.dataprev.gov.br/)

- **National Social Information Survey (CNIS)**
  
  Covers data on workers, employers, and employee contracts obtained from various sources. Internet: [www.dataprev.gov.br/](http://www.dataprev.gov.br/)

- **National Accounts System**
  
  Offers an overview of the economy, with data on production and consumption. [www.ibge.gov.br/ibge/dissemination/eventos/missao/informacoessociais.shtm](http://www.ibge.gov.br/ibge/dissemination/eventos/missao/informacoessociais.shtm)

Source: Adapted from RIPS A. *Indicadores para a saúde no Brazil: conceitos and aplicações*. Brasília, PAHO, 2002.
2. The Mortality Information System in Brazil: Conception, Implementation, and Evaluation

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Background

The usefulness of mortality statistics has been recognized for a very long time. Indeed, history shows that records have been kept for administrative purposes, especially to record the payment of taxes and military service, since the times of ancient Greece and Rome.

In 1662, Graunt, working in England, began to study causes of death as well as possible correlations between deaths and such variables as sex, age, place of residence, and meteorological and ecological conditions.

In the history of mortality records and information systems, another person who should be mentioned is William Farr, who at the end of the eighteenth century, also in England, worked to develop internationally standardized definitions of terminology related to vital events, the adoption of a uniform declaration of death, and classification of the causes of death.

In Brazil, the first government action regarding death records was the promulgation of Law 1,870 in 1814, which created a General Bureau of Statistics and charged it with handling data on births, marriages, and deaths. However, the requirement to record these events in the civil registry was not introduced until

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1888. This measure was followed by a series of legislative changes, but they did not substantially alter the spirit of the original laws.

The year 1938 saw creation of the Brazilian Institute of Geography and Statistics (IBGE), a federal agency working in collaboration with of the state departments of statistics responsible for collecting data within their territorial areas. Baldijão notes that in the 1970s IBGE began to produce a series of reports containing important information for the health sector. During that period, IBGE was put in charge of producing vital statistics for all of Brazil and instructed to rationalize data collection at the national level with the information recorded in the local offices of the civil registry. This made it possible to obtain more detailed and continuous data on vital events. Thus, since 1974 IBGE has been regularly publishing statistics based on data from the civil registry without, however, including the detailed causes of death.

In 1944 the Federal Biostatistics Service of the National Health Department under the Ministry of Education and Health published the Biostatistical Yearbook, which included data on mortality by cause of death in the capital cities of Brazil for the period 1929 to 1932. A few years later, IBGE published mortality data by causes, again only for the capital cities, but publication was still not on a regular basis.

Several steps were taken, mainly during the 1960s and 1970s, which may be characterized as “encouraging” in terms of raising awareness among the responsible authorities of the need to create a national mortality information system that would be of interest for the health sector. Some of the initiatives were:

- action taken by the Special Public Health Service Foundation (SESP) regarding studies on the registration of vital events and assessment of
their coverage, mainly in the northern and northeastern regions of the country;

- action taken by the School of Public Health of the University of São Paulo (USP) regarding:
  - inclusion of a course on the International Classification of Diseases (ICD) in the School’s curriculum starting in the 1960s; and

- creation of mortality information systems at the level of the states, and


By the early 1970s, all the elements were in place that would favor the implementation of a new mortality information system at the national level. All that was needed was the corresponding political decision, and this was provided in 1975 by the then Minister of Health, Dr. Paulo de Almeida Machado.

**Conception, Purpose, and Implementation**

In that year, the Ministry of Health, recognizing the need for mortality data to support specific actions and noting the examples that had already been set in some of the states, had the idea to create the Health Information System (SIS) with
A subsystem on mortality that would have wide-ranging coverage and reliable data. This was the first step.

A working group* was appointed in July of that year to develop the overall guidelines of the subsystem, starting first with a survey of the current status of the various versions of the declaration of death in the country. This survey revealed that there were forty-three models in use, all with different formats, numbers of copies, colors, and variables collected. Moreover, they were routed through many different channels before they arrived at the official agencies for publication (or not) of the statistics.

Based on what it found, the working group recommended that: (1) a uniform declaration of death should be adopted for use throughout the country, and it should follow the international standard proposed by WHO in 1948 for reporting the causes of death; (2) the document should be issued at the central level: the Ministry of Health should then distribute it to the State Health Secretariats, which in turn would be responsible for distribution to the municipalities; (3) the declaration of death should processed through a standardized document processing path; and (4) data processing should be done at the central level, based on the belief prevailing at the time that such actions should be centralized, on the operational difficulty of encoding the causes of death, and on the fact that the states or “federal units” did not have sufficient data processing equipment to make decentralization feasible.

In order to disseminate the new recommendations throughout the country and discuss their implementation with representatives from the states with a view

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to persuading them to participate, the Ministry of Health convened the first National Meeting on Health Information Systems in November of that same year. The participants at the meeting, held in Brasília, analyzed the health information situation in Brazil and the future outlook. A model nationwide declaration of death (designed to include fetal death) was presented and adopted for use by the Mortality Information Subsystem, and the channels through which the declaration would be processed were agreed upon, as well as the data to be tabulated, making it clear that, based on experience in the state of Rio Grande do Sul, each state or territory would be allowed to include additional data elements.

The meeting’s participants, which included, inter alia, technical personnel from the State Health Secretariats, agencies in the Ministry of Health and the Ministry of Social Welfare, the University of São Paulo School of Public Health and other universities, and IBGE, ended up formulating and approving a number of general proposals, objectives, and goals, in addition to specifying the role and responsibilities of the MS and the State Secretariats with regard to the system being created.

From this starting point, the Mortality Information System (SIM) soon began to be implemented throughout the country, with allowance for added categories in those states that already had some form of information system. Ample training material was produced, including a manual on entering data in the basic document and an operations manual for coding the data elements.

Part of the implementation process involved personnel training, which included sensitization of public health authorities, education of physicians on the importance of filling in the document correctly, and further training for those responsible for the processing and analysis of the data.

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Another important aspect was preparing personnel to code the causes of death, which became feasible in 1976 with creation of the Brazilian Center for the Classification of Diseases (CBCD) under an agreement between the Ministry of Health, PAHO, WHO, and the University of São Paulo.

This center was also designated the WHO Collaborating Center for the Classification of Diseases in Portuguese (while still known in Brazil as the Brazilian Center for the Classification of Diseases) and is now the WHO Collaborating Center for the Family of International Classifications of Diseases in Portuguese. According to its mandate published in the Federal Official Gazette (DOU), the center is responsible, inter alia, for promoting improvement in the quality of information contained in the declarations of death and for advising the Ministry of Health on activities related to promoting the International Classification of Diseases (ICD), as well as revisions thereof.

It is important to point out that, since its creation, the CBCD has collaborated substantially in the development of SIM, with actions ranging from raising awareness among health authorities so that they recognize the importance of mortality data and hence the need to implement the system, to the production of instructional materials aimed, among other things, at standardizing the use of terminology in this area and training specialized personnel.

Since its creation, SIM has been assigned to different Ministry of Health sectors as a result of changes within the ministry’s structure.

In 2003, under Decree 476 dated 9 June (Directive 1,929/GM of 9 October 2003, published in the Federal Official Gazette, vol. 197, on 10 October 2003, Section I, page 57 – see Annex 1), management of SIM was entrusted to the Health Secretariat Surveillance (SVS). Specifically, the decree states that the SVS is responsible for the final decision-making process regarding the overall objective
and specific purposes of an information system, ensuring that it fulfills the functions for which it was created. More specifically, it is responsible for deciding on the data elements, the channels of information, the checking of information, and the aggregation of data, in addition to ordering such changes as may be necessary.

**Description of the System**

**Basic Document: The Declaration of Death**

The adoption of a uniform format for the declaration of death has made it possible to standardize the manner in which the data relating to each death are reported and recorded throughout the country. As a result, it has facilitated the processing of information of interest to the health sector.

A declaration of death must be used both for deaths and for stillbirths, and for this reason a field has been added for specifying whether the type of death was fetal or non-fetal.

The declaration of death was originally created and approved in 1975, and in the intervening 30 years it has undergone modifications in terms of both reformulating some of the existing data elements to obtain more precise responses and introducing new ones that have turned out to be necessary.

Examples of some of the changes are:

- introduction of sequential numbering for the declaration (the final phase of being printed in 2007), to facilitate control of printing, distribution, collection, and recovery of the document;
- introduction of the data element “race/color;”
- introduction of data element 42 – i.e., the number of the declaration of live birth in the case of deaths in infants under one year of age – to link the death to data in SINASC, created in 1990;
- introduction of data elements 43 and 44, to help identify deaths (from any cause) in women of childbearing age who were pregnant at the time of death or had been pregnant during the year prior to the fatal event, with a view to detecting possible maternal causes;
- introduction of field VIII, “Deaths from External Causes,” including the requirement for a summary description of the event and the source of information for this description;
- change of the name of field VI from “Physician’s Certification” to “Conditions and Causes of Death,” to disabuse the physician of the impression that responsibility for this field begins and ends with him;
- inclusion of line “d” in Part I of the field “Conditions and Causes of Death” to bring it into alignment with the Tenth Revision of the International Classification of Diseases; and
- introduction of a column for coding the causes indicated in the Declaration, to be done in the secretariats responsible for this task.

The current format of the declaration is shown in Annex 2.

The model introduced in 1976 had two copies, while the present format has three copies in different colors, each of which goes through a different processing path. According to national law, the declaration of death must be signed by a physician and, in the case of an unnatural death, by a medical examiner following the autopsy, in compliance with the provisions contained in the Code of Medical Ethics.
**Document Processing Path**

Copies of the declaration are printed by the Ministry of Health and sent to the State Secretariats of Health for further distribution to the Municipal Secretariats of Health, which in turn pass them on to the health establishments, medical examiner offices, Death Verification Services, and the local civil registries.

Today it is the responsibility of the Municipal Health Secretariats to control distribution of copies to hospitals and physicians and see that they do not fall into the hands of funeral parlors. This last restriction is important, since in the past many funeral parlors have included among their services to families the provision of declarations of death that have been filled out (or merely signed in blank) by physicians who have not attended the decedent or even examined the body or spoken with the family. With the declarations signed in blank, the funeral parlors filled in the identifying fields and sometimes even the cause of death.

Under the previous system, initially, once the death was recorded with a notary at the local office of the civil registry as required under the Law on Public Records, the top copy was collected from the notaries’ offices once a week or once a month by the state agencies responsible for mortality statistics. There was also a time when it was allowed in some areas (especially where there was no civil registry coverage) to supplement this basic source by collecting data directly from hospitals, cemeteries, and health units. 7

This procedure changed in 1994 after the third copy of the declaration of death (DO) was introduced. Under the new arrangement, the copies are handled as follows:

The top copy (white) is collected from the health establishments and medical examiner offices in an active monthly search by the agencies responsible for mortality statistics (typically the Health Secretariats) or else submitted directly by
the health establishments. This copy ends up in the data processing center of the municipal or state health agency.

The second copy (yellow) is given to the family by the physician/health unit that prepared it so that the family can take it to the local civil registry office, where it is filed for future legal use.

The third copy (pink) remains in the reporting unit attached to the patient’s chart. When the death occurs at home and the declaration is provided by a private physician, the pink copy is also given to the family and follows the same path as the second copy.

These procedures may differ depending on the reporting unit. The document path is illustrated schematically in Annex 3.

**Important Concepts and Relevant Legislation**

When SIM was first established, it was considered essential to decide on certain basic concepts to be adopted nationwide, so that the resulting mortality statistics would be comparable and reliable. It is important to point out that in 1950 WHO published the definitions of all vital events to be used by its member countries. These definitions covered live births, fetal losses, deaths, and the underlying cause of death, and their dissemination was considered so important that the Ministry of Health printed the text on the back of the declaration of death.

Today these WHO definitions, which are also published in the 10th Revision of the International Classification of Diseases, appear on the back of each declaration of death.

With regard to the legislation referring to this matter, Law 6,015 of 31 December 1973, as amended by Law 6,216 of 30 June 1975, which remains in effect, states in its Article 77 that no burial shall take place without a certificate
from the civil registry corresponding to the place of death, said certificate to be a transcription of the recorded entry of the declaration of death by a physician, if such was present, or by two qualified persons who witnessed or verified the death.

It should be mentioned that implementation of SIM was not accompanied at the time by any legislation that required the use of the standardized document that had been decided on. That measure was not introduced until 2000, under Administrative Ruling 474 of 31 August 2000 (published in the Federal Official Gazette on 4 September 2000), later superseded by Administrative Rule 20, dated 3 October 2003 (published in the Federal Official Gazette, vol. 196, on 9 October 2003, Section I, page 71), which regulates the collection of data and the path and regularity of submissions of information on deaths and live births to the SIM and SINASC Health Information Systems (Annex 4). This administrative ruling, in Article 8, states that utilization of the declaration of death is compulsory in the entire country and is an indispensable requisite in order to record a death in the civil registry.

The requirement for the physician to provide the Declaration of Death is dictated by a decision of the Federal Council of Medicine through its Code of Medical Ethics and supplementary legislation. Of special note is Resolution 1,601 of 9 August 2000, which establishes important criteria in this regard. This regulation was amended and expanded to include several new provisions, the tenor of which are included in CFM Resolution 1,779 of 2005 (published in the Federal Official Gazette on 5 December 2005, Section I, page 121), which spells out the responsibility of the physician as provider of the declaration of death (Annex 5).

Care (PAB) throughout the country and calls for funds to be allocated exclusively to cover the cost of basic health care procedures and actions. This legislation is mentioned here because its Article 6 specifically states that the transfer of PAB funds shall be suspended if the Municipal Health Secretariat fails to supply information to the Health Information Systems, including SIM, for two consecutive months.

**Operational Procedures**

A review of SIM’s history shows that during the early years the top copy of the declaration of death, after being recorded at the local office of the civil registry, was supposed to be collected by the agencies responsible for statistics. The declaration forms were then sorted according to the municipality where the decedent resided and numbered sequentially for subsequent determination of the underlying cause of death. In preparation for electronic processing, each of the data elements was coded, and the codes were transcribed onto standardized spreadsheets. In some states, the data codes were noted directly on the declaration of death and no spreadsheet was used.

Up until the early 1990s, the data processing was done in the Ministry of Health’s Health Information Center in Brasília, since only the states with computerized services sent magnetic tapes with the data pre-checked. In the rest of the cases the data were run through flagging software to detect possible errors in filling in the declaration of death, selecting the underlying cause of death, entering the codes, or keying in the data. The validity of the codes was tested using cross-variables to detect any inconsistencies, for example, in cause of death, age, and sex.

Any errors found were listed and returned to the originating area for correction. With the progress in technology since then and the availability of
computers at the state and in some cases even the municipal levels, today such problems are handled locally. Ministry of Health/SVS Directive 20 of 3 October 2003 establishes the areas of responsibility at the state and municipal levels regarding the collection and analysis of mortality data.

Shortly after the CBCD became operational, its personnel contacted the WHO Collaborating Center for North America in Washington, DC, to learn about the system that has been in place there since 1976. Their system, Automated Classification of Medical Entities (ACME), which has been under development for a long time, electronically selects the underlying cause of death. The WHO center placed its technology at the disposal of CBCD, which in turn agreed to review and update all the decision tables so that they could be adapted for use in Brazil as appropriate. In 1983 the ACME system was installed at the São Paulo State System for Data Analysis (SEADE Foundation) under the supervision of CBCD, making Brazil the first country to use it outside the United States.

With the rapid spread of microcomputers, CBCD began to develop a computer-based program for automatic selection of the underlying cause of death. This was a slow and exacting process, undertaken in partnership with DATASUS. The program was tested at the end of the 1990s and has been undergoing steady improvement since then. The system, known as the Underlying Cause Selector (SCB), is heavily used and has already been incorporated into SIM. It is now regarded as a key factor in standardization of the selection of the underlying cause of death. Brazil succeeded in putting this system to practical use long before many other countries, including members of the European Union.

**Educational Materials**

As a fundamental and integral part of implementing SIM, the personnel responsible for the process started preparing instructional materials from the very
outset to support the standardization of criteria for all phases of the system. More recently, a new document, *Instruction Manual on Preparing the Declaration of Death*,\(^9\) was developed based on the changes in the design of the declaration of death and has become the definitive version, superseding all others.\(^9\) In addition, operating manuals have been prepared and distributed (www.saude.gov.br).

To help sensitize physicians about the importance of properly filling in the declaration of death, in 1979 the CBCD published the book *O Atestado de Óbito [The Declaration of Death]*, by Ruy Laurenti and M. Helena P. de Mello Jorge, which explains the medical, statistical, and juridical issues related to the declaration. Since then, the book has been updated from time to time to reflect the changes in the declaration of death format, definitions of events, and new legislation, and about 2,000 copies are distributed every year to physicians and medical students. The latest revised and updated edition appeared in December 2004.\(^{10}\)

This publication was the first in a series of CBCD publications, which have included such titles as the following:


- *O Atestado Médico Falso [The Invalid Medical Declaration]*, by Renato de Mello Jorge Silveira, first published in 1996 and reissued in 1999 and 2001.\(^{12}\)

The Quality of Information], by M. Helena P. de Mello Jorge, Ângela Maria Cascão, and Renato Carvalho Silva, first published in 2003 and reissued in 2005.¹³

The educational materials above have been supplemented with the following additional publications:

- Boletim do Centro Brasileiro de Classification de Doenças [Bulletin of the Brazilian Center for the Classification of Diseases]. Aware of the need to maintain ongoing contact with users of the International Classification of Diseases, the CBCD published the first issue of its Boletim in 1980, not only to establish ties with the coders but also to disseminate news and pertinent information about the ICD, orient and standardize the ways in which the coding is done, and clarify doubts about the coding of difficult cases. The Boletim has published articles on such cases, as well as on medical terminology, coding, selection of the underlying cause of death, and the application of international rules. In addition to being available in hardcopy, the Boletim is now posted on the CBCD Web site.¹⁴

- Manual de Treinamento: Codificação em Mortalidade [Training Manual: Mortality Coding]. The CBCD produced this manual for use in courses and briefings on the use of ICD for mortality coding. The manual includes all the pertinent training elements contained in Volume II of ICD (instruction manual), but these are presented using a more didactic and descriptive approach, with special reference to issues or aspects that apply specifically to Brazil.¹⁵

- International Classification of Diseases (ICD): Three revisions of the ICD have appeared during the period covered here: the Eighth
Revision, for 1977 and 1978; the Ninth Revision, 1979-1995; and the Tenth Revision, current since 1996. In addition to presenting the systematized list of diseases and conditions in the main body of the classification or supplementary classifications as part of their basic structure, these publications of the World Health Organization have provided a standard for the dissemination of concepts, definitions, and coding rules.\textsuperscript{6,16,17}

**Human Resources Development**

That a mortality information system has been created does not mean that it will work perfectly and do all that is expected of it satisfactorily. In addition to the having a framework of laws, ministerial directives, and relevant regulations, it is very important to have trained human resources to ensure that it works properly.

In the case of SIM, it is essential to ensure correct coding of the cause of death following the international recommendations set forth in the successive editions of the ICD. Training for this purpose is offered in courses on the application of the ICD to the coding of mortality given by the cause-of-death coders who have been with the CBCD since its inception.

For these courses, there are the standardized CBCD materials\textsuperscript{15} mentioned earlier as well as Volume II itself of ICD. The duration of the course is 60 to 80 hours at the introductory level and up to 20 hours for refresher courses.

WHO and its network of collaborating centers attach so much importance to training in use of the ICD for mortality coding that a committee (the Education Committee) was created to prepare standardized training materials for all the countries. The CBCD participates actively on this committee and, in response to a request, it has developed teaching materials, based on its experience, to be used for training at the international level.
In addition to these courses, CBCD promotes individualized training through electronic media, and it also responds to requests for the clarification of doubts – in most cases about coding but also with regard to SIM, and in particular the document processing path and correction of the SCB.

An important aspect of human resources development is the training of physicians to fill in the declaration of death correctly. This is accomplished through briefings, most of which are requested by the Municipal Secretariats of Health and also by hospitals, regional councils of medicine, and others.

**Advisory Committees**

As stated in the law, one of the objectives of the CBCD is to develop strategies for improving the quality of information provided in the declaration of death, as well as to advise the Ministry of Health on activities related to promotion of the ICD and its revisions, as mentioned above. Accordingly, ever since the early years of SIM, there has been a partnership with the CBCD and the University of São Paulo School of Public Health.

Also, throughout this period there has been a group of professionals knowledgeable in this area who have often been called upon for advice, consultation, and participation in joint projects even though they were not in the employ of the Ministry of Health.

In 1989 a Ministry of Health Advisory Group on Vital Statistics (GEVIMS) was created under Ministry of Health Directive 649/GM of 4 July 1989 (published in the DOU, vol. 126, on 5 July 1989). Over the next two years, this group gave priority to improving the quality of information on external causes of death and to the development of an information system on live births in Brazil, which led to the establishment of SINASC. GEVIMS held a national seminar on external causes of death in Brasília in November 1989, which brought together, in addition to its
own members, technical personnel from the Ministry of Health, representatives of the State Health Secretariats and medical examiners from all the states. The deliberations at this seminar provided the foundation for amendments to the layout of the declaration of death, including the addition of a specific field to be filled in by the medical examiner in the event of a death due to external causes, which has made it possible to study this type of mortality in greater depth.


The Statistics Produced

In 1984 the Ministry of Health began publication of the series *Estatísticas de Mortalidade Brazil* [*Mortality Statistics in Brazil*], which provided statistics on deaths in Brazil from 1977 to 1995 for the country as a whole and by regions, states, and capital cities, broken down by sex, age, cause, and domicile of the deceased, as well as by causes. The causes were categorized according to headings from the International Classification of Diseases CID (eighth revision, for data from 1977 and 1978, and the ninth revision, for data from 1979 to 1995) and also ICD-BR, a Brazilian adaptation of a list of presentations of death proposed by WHO.

This information, published in hardcopy, has also been disseminated on laser disk since 1990 (mortality statistics for 1979-1986), making it possible to obtain all the information on mortality in Brazil.
Today the Ministry of Health makes this information available for free on CD-ROM\textsuperscript{19} and also on the Internet (www.saude.gov.br). It covers about 1 million deaths per year and gives a good overview of the epidemiological picture of mortality in Brazil, especially in terms of sex, age, and cause of death. With regard to fetal deaths, the Ministry of Health is not yet working on the statistics, but the data are available.

**Evaluation of the System**

SIM was conceived with a view to filling the gaps in the civil registry, since it was in a position to cover events that had not been recorded in local notary offices, and to presenting an epidemiological profile of causes of death for the country as a whole and not just in the capital cities. However, the system was slow to get under way.

From the outset, it was a known fact that both the coverage and the quality of information were less than ideal. The first exercise, i.e., collecting and processing data for the year 1977, revealed that throughout much of the country only the capital cities had been covered, even though Brazil had nearly 4,000 municipalities (municipios) at the time. The areas most affected were in the north (Amazonas, Roraima, and Amapá), almost all of the northeast (Maranhão, Piauí, Ceará, Rio Grande do Norte, Paraíba, Alagoas, and Sergipe) and the state of Goiás in the Western Central Region. Even so, the Ministry of Health took the risk and published the data, and thus the first statistical yearbook, *Estatísticas de Mortalidade Brazil – 1977*, appeared in 1984.\textsuperscript{7}

At the time, the ministry pointed out that the tables for Brazil as a whole failed to state the magnitude of mortality in the country and that, for this reason, it had been recommended to use proportional mortality instead of calculation of coefficients. It was estimated that the data presented in the yearbook represented
approximately 65% of the total deaths in the country, which, calculated by indirect methods, in reality came to nearly 1 million.\(^7\)

With regard to the quality of the information, at the time attention was just beginning to be directed to questions of accuracy and clarity of the information being provided in the declaration of death and to the problem of deaths unattended by a physician.\(^7\)

Since then, successive evaluations have been undertaken by the Ministry of Health, the secretariats concerned, and independent academic researchers in an effort to measure the degree of reliability and the limitations of the information produced.

**Coverage**

**Geographic Coverage**

The geographic coverage of SIM is measured in each state or other political unit by the number of municipalities that report mortality on a regular basis,* the population covered by the system, and number of deaths reported by all the municipios and by those with regular notification during the period 1980-1995. The results show some interesting trends both for the country as a whole and for the regions. For example, the number of municipalities in Brazil has increased by 25%, but the proportion of those that report mortality on a regular basis has decreased by about 43% (Table 1).

At the same time, the proportion of population residing in municipalities that report data regularly has declined by about 27% (Table 2). As for the proportion of deaths reported by municipalities that provided mortality information on a regular

* That is, “municipios” that meet the following criteria: (1) they collect the declarations of death throughout the year; (2) they report at least 4 deaths per 1,000 population; and (3) they recognize a total number of deaths corresponding to at least 90% of the deaths recorded in the civil registry (SIM/SNBS/MS, published in CBCD 9:1, 1988).
basis during the period under study, when SIM was first implemented the reports represented 97.9% of the total number of deaths actually captured, but by 1995 the proportion had fallen to 77.4% (Table 3).

These figures show that in the newly created municipal designation (‘municipios’), in addition to the populations being very small, it is possible that SIM had not been fully implemented and that therefore its coverage needs to be improved.

Specifically, in those states that already had systems in place (São Paulo, Rio de Janeiro, and Rio Grande do Sul), coverage at the municipal level was already complete in 1980 and remained so throughout the period. In another example, however, it took SIM nine years to cover all the municipalities in the state of Goiás in the Western Central Region.

It is important to point out that the historical series being cited here was discontinuous, since the Ministry of Health suspended hardcopy publication of Estatísticas de Mortalidade and this method of evaluation was abandoned.

Table 1 – Number of Municipalities and Proportion (%) of Municipalities that Report Mortality Regularly, by Regions, Brazil, 1980-95

<table>
<thead>
<tr>
<th></th>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>%</td>
<td>Number</td>
<td>%</td>
</tr>
<tr>
<td>Northern</td>
<td>153</td>
<td>53.6</td>
<td>171</td>
<td>32.7</td>
</tr>
<tr>
<td>Northeastern</td>
<td>1,375</td>
<td>57.6</td>
<td>1,385</td>
<td>53.7</td>
</tr>
<tr>
<td>Southeastern</td>
<td>1,410</td>
<td>97.3</td>
<td>1,416</td>
<td>92.3</td>
</tr>
<tr>
<td>Southern</td>
<td>719</td>
<td>98.2</td>
<td>753</td>
<td>86.5</td>
</tr>
<tr>
<td>Western Central</td>
<td>334</td>
<td>38.9</td>
<td>367</td>
<td>51.5</td>
</tr>
<tr>
<td>Brazil</td>
<td>3,991</td>
<td>77.2</td>
<td>4,092</td>
<td>72.0</td>
</tr>
</tbody>
</table>

Table 2 – Proportion (%) of Regional Population Residing in Municipalities that Report Mortality Regularly, by Regions, Brazil, 1980-95

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern</td>
<td>78.4</td>
<td>69.9</td>
<td>40.3</td>
<td>21.1</td>
</tr>
<tr>
<td>Northeastern</td>
<td>68.2</td>
<td>64.0</td>
<td>46.1</td>
<td>36.8</td>
</tr>
<tr>
<td>Southeastern</td>
<td>99.2</td>
<td>98.2</td>
<td>86.3</td>
<td>87.2</td>
</tr>
<tr>
<td>Southern</td>
<td>99.5</td>
<td>90.0</td>
<td>74.6</td>
<td>77.1</td>
</tr>
<tr>
<td>Western Central</td>
<td>69.8</td>
<td>72.8</td>
<td>46.7</td>
<td>41.7</td>
</tr>
</tbody>
</table>

Brazil 87.3 83.8 67.2 63.4


Table 3 – Total Number of Deaths and Proportion (%) of Deaths from Municipalities that Report Mortality Regularly, by Regions, Brazil, 1980-95

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>%</td>
<td>Number</td>
<td>%</td>
</tr>
<tr>
<td>Northern</td>
<td>28,754</td>
<td>95.9</td>
<td>33,367</td>
<td>80.8</td>
</tr>
<tr>
<td>Northeastern</td>
<td>193,877</td>
<td>94.4</td>
<td>206,359</td>
<td>83.0</td>
</tr>
<tr>
<td>Southeastern</td>
<td>375,821</td>
<td>99.8</td>
<td>387,694</td>
<td>99.2</td>
</tr>
<tr>
<td>Southern</td>
<td>119,895</td>
<td>99.8</td>
<td>119,926</td>
<td>94.2</td>
</tr>
<tr>
<td>Western Central</td>
<td>32,380</td>
<td>90.5</td>
<td>40,885</td>
<td>82.5</td>
</tr>
</tbody>
</table>

Brazil 750,727 97.9 788,231 92.6 816,555 81.4 893,877 77.4

Source: MS, 1985; MS, 1988; MS, 1996; MS, 1998

Comparison with Data from the Civil Registry

The method traditionally used by SIM to assess its coverage is to compare its data with information from the civil registry (via IBGE), although it is recognized that the latter sources can also have lacunae, especially in the less developed regions of the country where the deceased are sometimes buried without an appropriate record of the death.
When SIM was created, it was thought that the new agency would eventually be able to capture a larger number of deaths than the civil registry, since it would be gathering its information from sources where the declaration of death was issued – mainly hospitals and medical examiners’ offices – and would therefore not need to rely on the civil registry to obtain this information. However, during the early years of SIM, it relied precisely on the civil registry as the source of its data. Since the civil registry information was incomplete, the total number of deaths captured by SIM always ended up being lower, not higher, than those in the civil registry (Table 4).

Up until 1995, despite having covered a large number of deaths and in some areas actually surpassing the number recorded by local notary offices, SIM had not yet achieved the totals captured by the civil registry and compiled by the IBGE. This situation was possibly due to the refusal of some of the local notary offices to transmit declarations of death to the health agencies, since they had a legal obligation to remit data to the IBGE (Law on Public Records, Art. 49) but not to the health agencies.20

This is the way matters stood at the end of the 1990s; but starting in 2000, SIM began to collect a larger number of deaths than those reported to the civil registry. In that year and the next three years, the absolute and relative differences were in SIM’s favor. This shift was possibly due to a change in the methodology used to collect the data.

In 1996, municipalization was advancing at a rapid pace in Brazil and analyses of coverage showed minor absolute differences versus the number of deaths being obtained from the local notary offices. Taking advantage of the new Tenth Revision of ICD, which went into effect in Brazil that same year, and taking as an example the flow of information established by SINASC, which collected
information from the declarations of live birth in the hospitals where the births were taking place, the National Committee on Mortality, an advisory body to SIM attached to the Ministry of Health, pointed out the need to change the document processing path for the declarations of death and have them collected directly from the hospitals. Training of personnel in this area was late getting started and slow to be implemented, which may explain why the increase in coverage only began to show up several years later, in 2000.

It is believed that as users grow to appreciate the value of the information and increasingly come to rely on it, SIM will eventually come close to capturing all the deaths that occur.

**Table 4 – Number of Deaths Captured by the Civil Registry System and by SIM, and Absolute and Relative Differences, Brazil, 1980-2004**

<table>
<thead>
<tr>
<th>Year</th>
<th>Civil Registry</th>
<th>SIM</th>
<th>Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>During the year</td>
<td>In the next year</td>
<td>Total</td>
</tr>
<tr>
<td>1980</td>
<td>809,213</td>
<td>6,232</td>
<td>815,445</td>
</tr>
<tr>
<td>1985</td>
<td>806,238</td>
<td>9,591</td>
<td>815,829</td>
</tr>
<tr>
<td>1990</td>
<td>847,639</td>
<td>12,347</td>
<td>859,986</td>
</tr>
<tr>
<td>1994</td>
<td>912,110</td>
<td>12,991</td>
<td>925,101</td>
</tr>
<tr>
<td>1998</td>
<td>936,885</td>
<td>15,064</td>
<td>951,949</td>
</tr>
<tr>
<td>2000</td>
<td>924,700</td>
<td>18,867</td>
<td>943,567</td>
</tr>
<tr>
<td>2001</td>
<td>928,345</td>
<td>21,698</td>
<td>950,043</td>
</tr>
<tr>
<td>2002</td>
<td>958,475</td>
<td>20,152</td>
<td>978,627</td>
</tr>
<tr>
<td>2003</td>
<td>974,440</td>
<td>19,215</td>
<td>993,655</td>
</tr>
<tr>
<td>2004</td>
<td>994,839</td>
<td>...</td>
<td>...</td>
</tr>
</tbody>
</table>


**Comparison with IBGE Estimated Deaths**

In an effort to pick up any gaps in the data from the civil registry and SIM, IBGE has been using demographic projections to estimate the total number of
deaths and deaths in infants under 1 year of age that hypothetically would have occurred in Brazil.\textsuperscript{21}

Since 1996, with creation of the Interagency Health Information Network (RIPSA), these estimates have been used as a reference point for assessing the achievements of SIM. RIPSA includes among its health indicators, “ratio of deaths reported by SIM versus indirect estimates,” with the idea that this figure might be a measure, albeit very broad, of the system’s coverage. This indicator can therefore be used to analyze geographic and longitudinal variations in the proportion of data collected by SIM with a view to checking its consistency. Thus it can serve as a test parameter for estimating underenumeration in the SIM database and as a criterion for using the SIM database in the direct calculation of indicators. Furthermore, it can contribute to the systems’ operational development by identifying critical areas that need further attention.\textsuperscript{22}

The data have been calculated retrospectively and are available starting with 1997 for total deaths and deaths in infants under 1 year old (Table 5).

Table 5 – Ratio of Total Deaths to Deaths in Infants under 1 Year Old Reported by SIM and Estimated by IBGE, by Region, Brazil, 1997/2000/2002

<table>
<thead>
<tr>
<th>Region</th>
<th>Total deaths</th>
<th>Deaths in infants &lt; 1 year old</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern</td>
<td>61.0</td>
<td>70.1</td>
</tr>
<tr>
<td>Northeastern</td>
<td>56.2</td>
<td>63.0</td>
</tr>
<tr>
<td>Southeastern</td>
<td>95.5</td>
<td>92.3</td>
</tr>
<tr>
<td>Southern</td>
<td>94.2</td>
<td>95.7</td>
</tr>
<tr>
<td>Western Central</td>
<td>85.4</td>
<td>84.9</td>
</tr>
<tr>
<td><strong>Brazil</strong></td>
<td><strong>80.0</strong></td>
<td><strong>81.9</strong></td>
</tr>
</tbody>
</table>

Some fluctuations can be seen, and the table shows that the ratios for total deaths are higher than they are for deaths in infants under 1 year of age. The data for 1997 show that coverage ranged from 56.2% in the northeast to 95.5% in the southeast, while the average for all of Brazil was 80%. By 2002 this ratio had exceeded 83%, but the southeast saw a decline. The situation with regard to capturing deaths in infants under 1 year of age had gotten worse in that the ratio had fallen even lower, a possible indication of lower coverage. Even in regions that should have good information, such as the southeast and the south, the situation is not acceptable, with the rate continuing to fall over time.

One may ask – and this is the doubt that arises – whether the estimates are realistic. How is it that coverage in the southeast was 105.2% in 1997 and five years later it is down to 80%? If we remember that these figures were calculated relative to the Censuses of 1980, 1991, and 2000, it may be that mortality had been overestimated, meaning that the current health situation has improved beyond what had been expected. Another important point has to do with infant mortality: bearing in mind the major effort being made by the health secretariats to reduce the level of these deaths, there is some evidence that they have been successful. It may be that the models used for the estimates failed to make sufficient allowance for the sharp downturn.

It is also important to keep in mind the limitations and imprecision inherent in the indirect techniques used to estimate the number of deaths. For example, there is the possibility already mentioned that in some cases this estimate, based on past trends, may fail to reflect new demographic patterns.
Use of the General Mortality Coefficient

It is a known fact that, regardless of the level of health of a given population, its general mortality coefficient should fall between 6 and 12 deaths per 1,000 inhabitants. If the population is younger or older, the value of the coefficient may be affected, but in most cases it will still fall within this range.\textsuperscript{23}

Up until 1990, the Ministry of Health had been considering 4 deaths per 1,000 inhabitants a minimum acceptable mortality coefficient for the country, and in that year the ministry raised the minimum to 6 deaths per thousand population.\textsuperscript{9}

It can be seen that the rates for Brazil since 1980 have hovered around 6 per 1,000, with minor fluctuations. The data for the various regions show that the northern, northeastern, and western central regions have much lower coefficients than the established minimum. On the other hand, in the southeast and the south the values are close to 6, and in some cases as high or higher than 7 per 1,000 inhabitants (Table 6).

<table>
<thead>
<tr>
<th>Year</th>
<th>Northern</th>
<th>Northeastern</th>
<th>South-eastern</th>
<th>Southern</th>
<th>Western Central</th>
<th>Brazil</th>
</tr>
</thead>
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<tr>
<td>1980</td>
<td>4.9</td>
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<td>7.3</td>
<td>6.3</td>
<td>4.3</td>
<td>6.3</td>
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<td>1985</td>
<td>4.6</td>
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<td>5.9</td>
<td>4.7</td>
<td>6.0</td>
</tr>
<tr>
<td>1990</td>
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<td>4.6</td>
<td>6.8</td>
<td>6.0</td>
<td>4.1</td>
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</tr>
<tr>
<td>1995</td>
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<td>6.2</td>
<td>4.9</td>
<td>5.8</td>
</tr>
<tr>
<td>2000</td>
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<td>4.8</td>
<td>6.4</td>
<td>6.1</td>
<td>4.7</td>
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<td>6.4</td>
<td>6.1</td>
<td>4.8</td>
<td>5.7</td>
</tr>
</tbody>
</table>


This is reason why RIPSA, in presenting the general mortality coefficient for Brazil, its regions, and its states and other federal units, specified that the indirect
method be used in calculating the estimated number of deaths as long as the SIM value was lower.\textsuperscript{22}

**Quality**

The quality of the information provided by the system’s data has been slowly but gradually improving. The information gaps due to data elements that were unknown or not filled in have become fewer in number, so that it is now possible to say that these proportions are steadily declining.

Analysis of the causes of death is affected by the large proportion of ill-defined causes, which distorts the relative picture of deaths due to all other causes.

Studies have been undertaken with a view to evaluating and dealing with these problems, but it has been difficult to incorporate the suggestions for improvement and many obstacles have been encountered. One problem is the physician, who in the final analysis is directly responsible for filling in the declaration of death, the system’s basic source of information. This explains, in part, the slowness with which the changes have come about.\textsuperscript{24}

**Identifying and Demographic Variables, and Flags for Possible Maternal Mortality**

**Sex and Age**

For the variables of sex and age, the frequency with which this information is unknown or simply “not filled in” has remained consistently low over time, so it can be said that this information is available for purposes of epidemiologic analysis.

Becker et al.\textsuperscript{25} reported in 1984 that for Brazil as a whole the age was unknown in 0.5% of the deaths in the capital cities and 1% of the deaths in the interior, ranging from 0.2% in the southeast to 2.8% in the western central region.
With regard to the sex, the proportions were even smaller, not exceeding 0.2% in 1984. In 1996, for Brazil as a whole, information on sex was unavailable in only 0.3% of deaths in general, with a slightly higher proportion for deaths in infants under 1 year old, and there were regional variations. That same year, the decedent’s age was unknown in 1.1% of the cases, and the figure was about the same in 2003. The low levels are explained primarily by the fact that the declaration of death is always filled out based on information from the patient’s documents.

**Race/Color**

This data field was added to the declaration of death in 1995, but it was only in 2000 that the Ministry of Health considered it possible to use this information, based on improved compliance. Since then, analysis of this variable has made it possible to study the estimated risk of dying for the white, black, and mulatto population in Brazil as a whole and in its regions. In 2003, it was determined that for 10.6% of all deaths this information was unknown, with the proportion ranging between 4.6% in the southern region and 21.8% in the northeastern region.26

**Pregnancy of Decedent**

The importance of data on maternal death is well known. However, it is also a fact that the causes of death associated with pregnancy, delivery, and the puerperium are among the most poorly reported causes on the declaration of death.27

With a view to improving the quality of data on maternal death, the 43rd World Health Assembly recommended in 1990 that countries consider including, in their declarations of death, questions regarding the presence of a pregnancy
either at the time of death or during the preceding year. This element was added to the country’s declaration of live birth by the Ministry of Health starting in 1995.

Laurenti, Mello Jorge, and Gotlieb, in a paper aimed at analyzing the information supplied on the declaration of death in this data field, reported a high proportion of absence of information (about 90%) in 1996 and 1997, with a slight decline from one year to the next. Another type of evaluation, this time based on cases classified as “maternal causes,” was to determine whether or not this field had been filled in. It was found that, of the 1,465 deaths due to maternal causes in 1996, and 1,776 in 1997, only 12.1% and 22.5%, respectively, included any notation as to whether the decedent was pregnant at the time of death, and only 18.6% and 22.8% provided any information about pregnancy during the year prior to the fatal event. In a few cases, the “no” box was checked, and in the rest the “unknown” option was marked, or else the field was not filled in at all. The authors conclude that, even though Brazil adopted the WHO proposal regarding introduction of this data element, the decision was not followed up with an information campaign or a specific pilot study working with physicians, mainly obstetricians, to get them to comply with the requirement to answer the newly included questions.

The declaration of death form currently used in Brazil has been amended to include this element, which appears in data fields 43 and 44.

Laurenti, Mello Jorge and Gotlieb, in a study of maternal mortality, reviewed 7,332 deaths in women of childbearing age in all the capitals of the Brazilian states during the first half of 2002 and found that information on this variable aimed at detecting deaths due to maternal causes had not been provided for in a high proportion of deaths of women who were in the pregnant-puerperal cycle. It would be expected that, for the 463 declarations of death of women in the
extended pregnant-puerperal cycle, all would have included responses to questions 43 and 44, since the women were or had been pregnant within the year prior to their death. However, information was supplied in only half the cases. The situation was even worse with regard to women whose causes of death were associated with pregnancy, delivery, and the puerperium: of 239 declarations of death, only 53.6% included responses to question 43 and 52.7% to question 44. Compared with the data from the authors’ earlier study, this was a reasonable improvement, but it is necessary to insist that adequate information be supplied on the declaration of death, as a number of authors have recommended, and, as a supplementary measure, to investigate cases and incorporate the additional information into the system.

**Problems with the Cause of Death**

In the analysis of causes of mortality, there is no question that deaths due to ill-defined causes represent a major gap in our knowledge of the distribution of deaths by causes. They also prevent the rational allocation of health resources based on epidemiological profiles, since this vague category can significantly alter the mortality rates for specific diseases. For these reasons, it is extremely important to study the problem.

**Deaths Due to Ill-Defined Causes**

Analysis of the causes classified in Chapter XVI of ICD-9 or Chapter XVIII of ICD-10 – in other words, those that consist of merely symptoms and signs, or ill-defined causes – brings out some interesting points. These chapters include not only physician-attended cases in which the physician was unable to determine the underlying cause of death (or the physician declared only a symptom or sign) but also cases that were not attended by a physician.
When the proportion of deaths due to ill-defined causes is high, some researchers have proposed redistributing the rest of the cases as a possible means of dealing with the problem. This methodology uses the proportional age distribution of cause-of-death codes in each of the chapters that cover well-defined causes, and this would appear to be an adequate solution. However, the approach has been questioned, and it is being increasingly regarded as unsatisfactory. The criticism is based on the assumptions inherent in the method, which field-testing has shown to be totally correct. Nevertheless, it is not recommended to use this methodology: When it is impossible to obtain a declaration of death correctly prepared by the physician, the policy should be to promote the investigation of doubtful cases with a view to refining the system and hence the health indicators that it generates.

A longitudinal analysis of the proportion of deaths due to ill-defined causes in Brazil as a whole and in the regions (Table 7) shows that up until the mid-1980s more than 20% of all the deaths captured by SIM fell under this heading. Approximately 10 years later, the proportion was down to about 18%, and in 2003, to 13%, which indicates that the figure is steadily declining. These results, although they are encouraging, hardly indicate that the problem has been resolved, because the latest figure still represents approximately 130,000 deaths in absolute numbers. Comparison of the proportions in the different regions of the country shows the northern and northeastern regions at one extreme and the southern and southeastern regions at the other. In the western central region, the figure has been steadily falling since 1990.

This decline is the result of efforts undertaken by the system’s managers in the three spheres of action: federal, state, and municipal. All the figures show that ill-defined causes could be more clearly specified, whether at the time the
declaration of death is prepared or later, as a task undertaken by the system, mainly at the local level.

This optimistic picture, however, is likely to be concealing an unacceptable reality. When the data from the states and other federal entities are examined separately, it can be seen that in some instances the proportions of ill-defined causes are lower than 10%, whereas in Maranhão and Paraíba they exceed 30%. Similarly, the state of São Paulo, which had a proportion of deaths due to ill-defined causes of only 6.4% in 2002, this figure conceals much higher proportions in some of its municípios – for example, São Vicente, which that same year had 27%. By the same token, the state of Rio de Janeiro had about 10%, while the municipality of Belfort Roxo had almost 30%.

Table 7 – Proportional Mortality (%) Due to Ill-Defined Causes, by Region, Brazil, 1980-2003

<table>
<thead>
<tr>
<th>Year</th>
<th>Northern</th>
<th>North-eastern</th>
<th>South-eastern</th>
<th>Southern</th>
<th>Western Central</th>
<th>Brazil</th>
</tr>
</thead>
<tbody>
<tr>
<td>1980</td>
<td>26.9</td>
<td>48.6</td>
<td>9.6</td>
<td>15.1</td>
<td>16.3</td>
<td>21.5</td>
</tr>
<tr>
<td>1985</td>
<td>27.5</td>
<td>46.9</td>
<td>9.5</td>
<td>13.5</td>
<td>18.6</td>
<td>21.1</td>
</tr>
<tr>
<td>1990</td>
<td>28.6</td>
<td>42.2</td>
<td>8.7</td>
<td>12.0</td>
<td>12.4</td>
<td>18.2</td>
</tr>
<tr>
<td>1995</td>
<td>25.7</td>
<td>34.4</td>
<td>9.7</td>
<td>9.4</td>
<td>13.3</td>
<td>16.2</td>
</tr>
<tr>
<td>2000</td>
<td>24.0</td>
<td>28.4</td>
<td>9.8</td>
<td>6.3</td>
<td>8.5</td>
<td>14.3</td>
</tr>
<tr>
<td>2003</td>
<td>21.2</td>
<td>25.9</td>
<td>8.9</td>
<td>6.7</td>
<td>5.7</td>
<td>13.3</td>
</tr>
</tbody>
</table>


The problem of ill-defined causes can only really be ameliorated – i.e., to reduce the high proportion relative to total deaths – when physicians start to submit more complete information about the causes, especially the underlying cause. It is essential that physicians know how to fill in the declaration of death correctly, listing the underlying cause and its complication in the proper spaces in Part I, and also declaring the contributing causes, if any, in Part II. Until this level is achieved,
it is suggested that the health secretariats uniformly encourage the investigation of at least those deaths that occur in hospitals. In 2002, even just considering those deaths labeled “not attended by a physician,” 22.8% of them occurred in hospitals or other health establishments.34

Deaths Not Attended by a Physician

Deaths not attended by a physician were already mentioned in the previous paragraphs, but given the magnitude of the phenomenon, the subject deserves special attention and further comment. In 1980, these cases did not amount to even 30% of all deaths due to ill-defined causes in Brazil. This low figure is probably accounted for by the fact that the information only refers to deaths that took place in the capital cities (the coverage available at the time the system was inaugurated). However, at the end of the 1980s the figure soared to 83%. This peak was followed by a gradual decline: by 1995 these deaths represented 65.9%, and by 2003, 53.3% of all deaths due to ill-defined causes. The pattern suggests that there may have been an increase in medical care coverage and that greater attention is being given to patients during their final illness. Another explanation might be that physicians have become more proficient at filling in their portion of the declaration of death.

It is interesting to note that in areas where the coverage of deaths has been low, as programs are implemented to improve the capture of data, the quality of information has tended to decline. The newly-entered cases tend to be deaths that were not certified by a physician or those in which, even though the declaration of death was signed by a physician, the patient did not receive medical care during the final illness. This will be the first time that quality has to be sacrificed in favor of increasing the number of deaths captured by the system.

Studies have shown that the indication “death not attended by a physician” does not necessarily mean that the patient was not receiving care. In reality, there
is a misunderstanding of the situation and the relationship between the response filled in for “cause of death” and the question posed in field 45: “Was the decedent attended during the illness that caused his or her death?” When this question is misinterpreted, the physician answers “no” because he or she understood that the question was asking whether the patient was being attended at the time of death. Investigations have shown that in not a few cases the declarations of death issued by the hospital showed a “no” answer in field 45 and “not attended by a physician” in the field corresponding to the cause, yet they were hospitalized patients who had charts with sufficient notations to prepare a complete declaration of death.

In an effort to improve the quality of mortality data, many Municipal Health Secretariats have created death verification services (SVOs). The goal of these services\(^\text{35}\) is to find out the cause of death in cases that were not attended by a physician and also in those cases where, even though they were attended by a physician, it was not possible to specify an exact diagnosis. In practice, however, it has turned out that quite often the SVO has been regarded by physicians and hospital administrators as the “supplier” of the declaration of death; in other words, cases that were attended by a physician and could have been readily diagnosed have been sent to the service without the cause filled in, merely bearing the notation “not attended by a physician.”

The Ministry of Health, through its Secretariat for Health Surveillance, is currently striving to encourage the creation of SVOs throughout Brazil.

**Deaths Due to External Causes of Undetermined Intent**

According to the international rules, when a death was caused by injury or the effect of some other external cause classified in Chapter XIX of the tenth revision of the ICD, the circumstances that gave rise to that situation must be selected as the underlying cause for tabulation and codification in Chapter XX.\(^6\)
This principle makes it clear that the underlying causes should always correspond to the external causes (circumstances) that gave rise to the injury and not to the injury as such.

The reasoning behind this concept is prevention: To have avoided the death, it would have been necessary at some point to cut off the chain of events between the cause that gave rise to the injury or poisoning (circumstances of the accident/violent act) and the death that ensued, and the best way to do that is to avoid the precipitating cause. It may be impossible to prevent a trauma, hemorrhage, burn, or poisoning, but it is possible to avoid a fall, fire, electric shock, or ingestion of a noxious substance.

Mello Jorge, Cascão, and Carvalho-Silva\textsuperscript{13} point out that medical examiners, when they fill in the declaration of death postmortem, often mention only the injuries observed and not the circumstances surrounding the accident or violent act that was responsible for the injuries.

In Brazil today, about 10\% of the deaths due to external causes fall within this category. While it is known that the deaths resulted from the injuries, lack of sufficient information makes it impossible to know whether the cause was an accident, homicide, or suicide. Nevertheless, the proportion of deaths in which the intent was undetermined has been on the decline. Between 1980 and 2003, the figure for the country as a whole dropped from 20.7\% to 8.8\%, with the northeastern and southeastern regions showing the highest rates (10\%) and the northern and western central regions the lowest (2.3\% and 3.1\%, respectively).

It can also be said, however, that the aggregated data not infrequently camouflage the real situation, as we saw with the deaths due to ill-defined causes. This was true, for example, in 1994, when the proportion of deaths due to
undetermined external causes for Brazil as a whole was about 12%, while the figure for the city of Rio de Janeiro was more than 54%.³²

Studies undertaken to evaluate SIM’s coverage of external causes have shed light on significant aspects of the situation. For example, Mello Jorge³⁶ and Drumond et al.³⁷ show in their studies that the medical examiners’ offices do in fact have the information that the health sector needs in order to clarify the underlying cause of death but fail to provide it in the declaration of death. Here again we see how it important it is for the physician – in this case the medical examiner – to fill in the declaration of death correctly. SIM managers at the different levels are urged to invest in methods to improve the quality of their data through further investigation. This a matter of information that is already available and which, if it is recovered, will help to improve the quality of data in the system.¹³ A study of Brazil’s municipalities conducted in 2000 showed that, after these cases were researched and the data incorporated, there were significant changes in the distribution of deaths due to external causes: homicides were actually five times greater than the number declared on the declarations of death; suicides were double; and traffic accidents increased 90% over the numbers previously reported.³² Thus, in order for the mortality statistics to show the true epidemiological picture in each locality, it is always necessary to investigate cases in which the declaration of death fails to show clearly whether the death was accidental or intentional. The investigation should be conducted by a credentialed professional working in cooperation with the medical examiner or police, and the causes should be recorded on a special form, not on the declaration of death. Instructions for this purpose, including how to incorporate the new data into the SIM database, are given in a publication prepared for this purpose by the CBCD.¹³
Deaths with an “Incomplete Diagnosis”

The term “incomplete diagnosis” applies to the underlying cause of death when the physician’s diagnosis on the declaration of death meets any of the following criteria: it is a consequence or complication of an underlying cause rather than the underlying cause itself; it refers to compromise of a given organ – for example, cardiopathy, hepatopathy, nephropathy – without specifying the disease; or it corresponds to the generic name of a disease without further qualification – for example, cancer.\(^{31,32}\)

Knowing that the cause of death was cardiac or renal failure, for example, or organ compromise such as cardiopathy is not enough information to be able to take adequate preventive action.

Such causes are found throughout all the chapters of the ICD and impair efforts to acquire information of good quality. An example is the case of septicemia, which is often declared the underlying cause. However, septicemia is never an underlying cause; it is always a complication, and often a terminal complication. But declaration of this cause artificially inflates figures on the frequency of deaths due to infectious diseases, when in fact septicemia can be a complication of a noninfectious primary disease or even an accident or violent act.

Mello Jorge, Gotlieb, and Laurenti\(^{31}\) demonstrated that it was possible to investigate and clarify 50% of the deaths in which the underlying cause was an incomplete diagnosis. For external causes, examples of an incomplete diagnosis would be a traffic accident in which the status of the victim and the circumstances of the accident are unknown, accidental exposure to unspecified factors, or falls not further specified, among others.

It is interesting to see that when these cases are clarified, the original epidemiological picture changes considerably. For example, deaths that were
presumed to be accidental may turn out to be intentional. Other studies have reached similar conclusions.

**Successful Experiences Aimed at Refining the SIM Database**

From the beginning, developers, users, researchers, and critics of health information in general and mortality data in particular have always been concerned about the completeness and accuracy of the data.

With regard to coverage, it has been considered that active searching for deaths, surveillance by the health secretariats, or correction based on comparison with other sources are valid measures to take in an effort to minimize underreporting of events, which is still taking place and still casts a shadow on the effectiveness of SIM.

On this point, Mello Jorge and Gotlieb refer to a joint study by SIM and SINASC that reviewed the surveys of deaths and live births and stillbirths undertaken by the Family Health Program through the Basic Care Information System (SIAB). The authors considered that the information from this system might be used for the purpose of increasing the coverage of vital statistics. Their paper, presented at the Second Meeting of Advisory Committees on Mortality and Live Births held in Brasília in September 2000, generated important contacts between technical personnel from the National Epidemiology Center (CENEPI) and those in charge of SIAB. It can be said, in fact, that their presentation was the stimulus for the project undertaken by the Ministry of Health that year, since the authors had urged the states to at least focus on capturing infant deaths in those municipalities where the number of deaths in infants under 1 year of age was greater in SIAB than in SIM. The results were promising in the sense that it was possible to incorporate a large number of deaths into the system.
With regard to improving the quality of information on the cause of death, assuming that it is possible to lower the proportion of ill-defined causes as a number of studies have shown, suggestions for standardized investigations to clarify the causes were prepared by the Technical Advisory Committee on Information Systems in 2004.34

As for external causes of undetermined intent, countless studies have shown that this information can be improved, even by checking news reports of accidents and violent acts published in the press.41,13

Studies undertaken so far by health/epidemiology services in the state or municipal secretariats have led to the introduction of routine procedures that have yielded improvements for the health information systems, especially SIM. It should be pointed out that these are not formal academic studies but rather studies of how the institutions have evolved, often prepared in partnership with other public agencies or private organizations. Some of these studies are innovative, and their results are reproducible and sustainable. It was possible to conduct these studies thanks to municipal action being carried out right where the events take place and are recorded, which is the right place to investigate and improve the quality of information.

A number of states and municipalities are developing methodologies to improve system coverage and the registration of causes of death. Only a few examples have been cited, and these were chosen because their results are published and can therefore serve as a reference for other areas that may wish to take avail themselves of these experiences.

- Program for the Improvement of Mortality Information, municipio of São Paulo (SP)41
Fetal Deaths

Despite the recognized importance of fetal deaths for the level of public health in general, the Ministry of Health has not been working with the data on a routine basis. Although information on fetal deaths has been available for more than 20 years, it has not been evaluated, and only a few studies have been done on quality of the data.\textsuperscript{11,48} Given the importance of this information for studies on fetal and perinatal mortality, it is recommended that its use be promoted so that RIPSA will become more involved. RIPSA’s role would be to raise awareness among the key actors and emphasize the need to use this information in the planning of local health interventions. It is only through constant use of these statistics that the data can be refined and their overall quality improved.

Future Outlook

There is no doubt that SIM has been making major strides in terms of both coverage and the quality of its data, but information on the underlying cause of death still leaves something to be desired. However, even in this area, there have been marked signs of improvement in the last two decades.
The goal for the future is to come as close as possible to 100% registration coverage and capture of deaths by SIM. With the trend toward municipalization, improving geographic coverage and refining the data are becoming easier. There has been considerable interest in the creation of SVOs, which would undoubtedly improve the quality of information and reduce the proportion of deaths due to ill-defined causes. At the same time, however, it is important to motivate municipal leaders as well, making them aware of the issue and providing them orientation in using mortality data to construct appropriate indicators that provide useful input for assessing the health situation at the local level. RIPSA has a fundamental role to play in this regard. Created in 1996, this network has been effectively meeting its objectives over the last 10 years, especially in terms of developing basic data and indicators that are consistent, up-to-date, broad in coverage, and readily available, and in coordinating with institutions that help to supply and cross-check the data.

Also, it is important for the managers of the information systems to take advantage of the successful experiences mentioned earlier and, if necessary, encourage the undertaking of investigations that will lead to refining the quality of their data.

Taking advantage of the technological advances now available, studies show the importance of linkages between databases: Almeida and Mello Jorge\textsuperscript{49} report on information from SIM and SINASC on the analysis of neonatal mortality; Bohland\textsuperscript{50} pooled data from SIM, SINASC, SIH, and SIAB with a view to improving the quality of information on deaths in women of childbearing age in Sergipe; Almeida,\textsuperscript{51} using RECLINK\textsuperscript{®}, also brought together data from SIM, SINASC, and SIH to study maternal deaths in Rio de Janeiro; and Aerts et al.,\textsuperscript{52} with a view to obtaining more complete information on birth defects in Porto Alegre (RS), drew upon data from SIM, SINASC, and Pra-Nenê, the database of
the Program for Health Surveillance of Children in the First Year of Life. All these studies show how this approach results in gaining more information.

It should be emphasized, however, that the physician is primarily responsible for the information generated from the declaration of death. Therefore, it is most important that medical education emphasize the real importance of filling in the declaration of death correctly and that physicians be trained in how to do so.

Thus it is foreseen that, with the concerted effort of all who are working in this sector, before long there will be adequate and integrated databases to support attainment of the objectives of the Unified Health System.
Chapter References

3. MELLO JORGE, M.H.P. Registro dos Eventos Vitais: sua importância in Saúde Pública, CBCD, 1990a (Série Divulgação no. 5).
12. SILVEIRA, RMJ O Atestado Médico Falso. São Paulo, CBCD, 2001 (Série Divulgação no 9).


Chapter Annexes

Ministry of Health Directive 1,929/GM of 9 October 2003
Declarations of Death (Form Currently Used in Brazil)
Declaration of Death – Document Processing Path
Ministry of Health/SVS Directive 20 of 3 October 2003
CFM Resolution 1,779 of December 2005
Ministry of Health Directive 1,929/GM of 9 October 2003
(Published in the DOU, vol. 197, on 10 October 2003, Section I, p. 57)
Regulates the responsibilities of the Secretariat for Health Surveillance and the Department of Informatics of the SUS with regard to the Mortality Information System (SIM), the Liver Birth Information System (SINASC), and the National System for the Reporting of Notifiable Conditions (SINAN).

THE MINISTER OF HEALTH, by authority granted to him,

Considering the responsibilities of the Ministry of Health as the managing agency of the SUS at the national level with respect to the development and maintenance of health information systems and guaranteeing access to its databases for managers and technical personnel in the sector and the population in general;

Considering the need to establish and formalize the responsibilities of the agencies of this Ministry in light of its recent reorganization,

RESOLVES:

Art. 1. To designate the Secretariat for Health Surveillance (SVS/MS) the managing agency of the following information systems:
   I. Mortality Information System (SIM);
   II. Live Birth Information System (SINASC);
   III. National System for the Reporting of Notifiable Conditions (SINAN),

Sole paragraph. The term managing agency is understood to mean the agency responsible for the final decision-making process regarding the overall objective and specific goals of an information system, ensuring that it fulfills the functions for which it was created, or specifically, it is responsible for deciding on the data elements, the channels of information, the checking of information, and the aggregation of data, in addition to ordering such changes as may be necessary.

Art. 2. It is incumbent upon the SVS/MS to provide such technical support to the Health Secretariats as may be necessary.

Art. 3. The Secretariat for Health Surveillance is hereby delegated the authority to issue the regulations for this directive.


Art. 5. This Directive shall enter into effect on the date that it is published.

HUMBERTO COSTA
Declaration of Death (Form Currently Used in Brazil)

Modelo da Declaração de Óbito
Declaration of Death – Document Processing Path

Information Processing Path for Hospital Deaths

HOSPITAL
DATA ENTRY
COPY 1 --> GOES TO --> HEALTH SECRETARIAT
COPY 2 --> HOSPITAL --> FAMILY
COPY 3 --> NOTARY FOR CIVIL REGISTRY --> RECORDATION

Information Processing Path for Deaths Due to Natural Causes
In Localities without a Physician

CIVIL REGISTRY
DATA ENTRY
COPY 1 --> GOES TO --> HEALTH SECRETARIAT
COPY 2 --> FILE
COPY 3 --> -- > HEALTH SECRETARIAT
MINISTÉRIO DA SAÚDE
SECRETARIA DE VIGILÂNCIA EM SAÚDE

PORTARIA Nº 20, DE 3 de outubro de 2003

Regulamenta a coleta de dados, fluxo e periodicidade de envio das informações sobre óbitos e nascidos vivos para os Sistemas de Informações em Saúde – SIM e Sinasc.

O Secretário de Vigilância em Saúde, no uso das atribuições que lhe confere o Decreto nº 4.726, de 9 de junho de 2003, e considerando a necessidade de regulamentar as rotinas de coleta de dados e envio das informações sobre óbitos e nascidos vivos ocorridos no País para os Sistemas de Informações em Saúde – SIM e Sinasc, resolve:

CAPÍTULO I
Das Disposições Iniciais

Art. 1º O conjunto de ações relativas a coleta e processamento de dados, fluxo e divulgação de informações sobre os óbitos ocorridos no País compõem o Sistema de Informações sobre Mortalidade–SIM.

Art. 2º O conjunto de ações relativas a coleta e processamento de dados, fluxo e divulgação de informações sobre os nascidos vivos ocorridos no País compõem o Sistema de Informações sobre Nascidos Vivos – Sinasc.

CAPÍTULO II
Das Competências

Art. 3º Compete à Secretaria de Vigilância em Saúde - SVS, como gestora dos Sistemas de Informações sobre Saúde – SIM e Sinasc, a nível nacional:
I – estabelecer diretrizes e normas técnicas;
II – consolidar os dados provenientes dos estados;
III – estabelecer prazos para o envio de dados pelo nível estadual;
IV – retroalimentar os dados para os integrantes do Sistema;
V – divulgar informações e análises epidemiológicas.

Art. 4º Compete aos Estados:
I – consolidar os dados provenientes das unidades notificadoras dos municípios por meio de processamento eletrônico;
II – estabelecer fluxos e prazos para o envio de dados pelo nível municipal;
II – remeter os dados ao nível federal, regularmente, dentro dos prazos estabelecidos nesta Portaria;

IV – analisar os dados;

V – retroalimentar os dados para as Secretarias Municipais de Saúde – SMS;

VI – divulgar informações e análises epidemiológicas; e

VII – normatizar aspectos técnicos em caráter complementar e atuação do nível Federal para o seu território.

Art. 5º Compete aos Municípios:

I – coletar e consolidar os dados provenientes das unidades notificantes;

II – enviar os dados, observados os fluxos e prazos estabelecidos pelos estados;

III – analisar os dados;

IV – retroalimentar os dados para as Unidades Notificadoras; e

V – divulgar informações e análises epidemiológicas.

Art. 6º Compete ao Distrito Federal, no que couber, as atribuições referentes a estados e municípios.

CAPÍTULO III
Dos Sistemas e Documentos-padrão

Seção I
Do Sistema Informatizado

Art. 7º Os sistemas informatizados, necessários ao processamento dos dados coletados pelos documentos-padrão, terão sob a responsabilidade do Departamento de Análise da Situação de Saúde – DASIS, a distribuição das versões atualizadas às Secretarias Estaduais de Saúde, que as repassarão para as Secretarias Municipais, bem como o treinamento para implantação e operação.

Seção II
Dos Documentos-padrão

Art. 8º Deverá ser utilizado o formulário da Declaração de Óbito – DO, constante no Anexo I desta Portaria, como documento padrão de uso obrigatório em todo o País, para a coleta dos dados sobre óbitos e indispensável para a lavratura, pelos Cartórios do Registro Civil, da Certidão de Óbito.

Art. 9º Deverá ser utilizado o formulário da Declaração de Nascidos Vivos – DN, constante do Anexo II desta Portaria, como documento padrão de uso obrigatório em todo o País, para a coleta dos dados sobre nascidos vivos, considerado como o documento hábil para os fins do inciso IV, do art. 10, da Lei nº 8.069, de 13 de julho de 1990.

Parágrafo único. O DASIS elaborará e divulgará as rotinas e procedimentos operacionais necessários ao preenchimento da DO e da DN.

Art. 10 A DO e a DN terão sua impressão, distribuição e controle sob a responsabilidade da SVS, que poderá delegar estas atividades às Secretarias Estaduais de Saúde.
§ 1º A DO e a DN serão impressas em três vias, conforme fotolito padronizado pela SVS que poderá ser fornecido às Secretarias Estaduais de Saúde, sempre que houver a delegação prevista neste artigo.

§ 2º Cabe ao DASIS, o controle da numeração que será utilizada nos formulários de ambos os sistemas.

§ 3º As Secretarias Estaduais de Saúde que receberem a delegação prevista neste artigo deverão solicitar ao DASIS, sempre que for necessária a impressão de novos formulários, a faixa numérica a ser utilizada.

Art. 11 As Secretarias Estaduais de Saúde ficarão responsáveis pela distribuição das DO e DN às Secretarias Municipais de Saúde e estabelecerão controle sobre a distribuição e utilização de cada um dos documentos-padrão, em sua esfera de gerenciamento dos sistemas.

§ 1º As Secretarias Municipais de Saúde ficarão responsáveis pelo fornecimento de formulários de DO para as Unidades Notificadoras, a seguir relacionadas:

I – Estabelecimentos de saúde;
II – Institutos Médicos Legais – IML;
III – Serviços de Verificação de Óbitos – SVO, e
IV – Cartórios de Registro Civil.

§ 3º É permitida a distribuição de formulários de DO a médicos cadastrados pelas Secretarias Estaduais ou Municipais de Saúde, vedada sua distribuição às empresas funerárias.

§ 4º As Secretarias Municipais de Saúde ficarão responsáveis pelo fornecimento de formulários de DN para as unidades notificadoras, a seguir relacionadas:

I – Estabelecimentos de Saúde, onde possam ocorrer partos; e
II – Cartórios de Registro Civil.

Seção III
Do Processamento dos Dados

Art. 12 Os dados constantes da DO e da DN deverão ser processados no Município onde ocorreu o evento.

Seção IV
Do Fluxo dos Documentos

Art. 17. No caso dos partos hospitalares, a DN será preenchida pela Unidade Notificadora e terá a seguinte destinação:

I – 1ª via: Secretaria Municipal de Saúde;
II – 2ª via: pai ou responsável legal, para ser utilizada na obtenção da Certidão de Nascimento junto ao Cartório do Registro Civil, o qual referirá o documento;
III – 3ª via: arquivo do unidade de saúde junto a outros registros hospitalares da puérpera.

Art. 18. No caso de partos domiciliares com assistência médica, a DN será preenchida pelo médico responsável que deverá dar a seguinte destinação:

I – 1ª via: Secretaria Municipal de Saúde;
II – 2ª via: pai ou responsável legal, para ser utilizada na obtenção da Certidão de Nascimento junto ao Cartório do Registro Civil, o qual referirá o documento;
III – 3ª via: pai ou responsável legal, para ser apresentada na primeira consulta em unidade de saúde.

Art. 19. No caso de partes domiciliares sem assistência médica, a DN deverá ser preenchida pelo Cartório de Registro Civil, mediante autorização dada em provimento da Corregedoria de Justiça do Estado e terá a seguinte destinação:
   I – 1ª via: Cartório de Registro Civil, até ser recolhida pela Secretaria Municipal de Saúde;
   II – 2ª via: pai ou responsável legal, para ser utilizada na obtenção da Certidão de nascimento junto ao Cartório de Registro Civil, o qual reterá o documento;
   III – 3ª via: pai ou responsável legal, para ser apresentada na primeira consulta na unidade de saúde.

Parágrafo único. As Secretarias Municipais de Saúde deverão utilizar-se dos meios disponíveis na busca ativa de casos não registrados, valendo-se inclusive, dos Agentes Comunitários de Saúde e partes tradicionais.

Art. 20. As Secretarias Estaduais de Saúde poderão adotar, em sua jurisdição, fluxos alternativos aos definidos nos artigos constantes desta Seção, após consulta e aprovação pela SVS.

CAPÍTULO V
Dos Prazos e Transferência dos Dados

Art. 21. As Secretarias Estaduais de Saúde remeterão, por meio eletrônico, os dados para o DASIS, consolidados trimestralmente, nos seguintes prazos:
   I – 1º trimestre: até 10 de abril;
   II – 2º trimestre: até 10 de julho;
   III – 3º trimestre: até 10 de outubro;
   IV – 4º trimestre: até 10 de janeiro do ano seguinte.

Parágrafo único. O fechamento do ano estatístico pela SVS deverá ocorrer até o dia 30 de junho de cada ano, relativamente aos dados do ano anterior.

Art. 22. Os arquivos enviados pelas Secretarias Estaduais de Saúde à SVS, deverão ser avaliados quanto à qualidade e integridade antes da realização da transferência.

Art. 23. É responsabilidade dos gestores nos três níveis a manutenção, integridade e confidencialidade das bases de dados do SIM e do Sinasc.

CAPÍTULO VI
Das Disposições Finais

Art. 24. A falta de alimentação de dados no Sistema de Informações sobre Mortalidade – SIM, e sobre Nascidos Vivos – Sinasc, por mais de 60 dias, ensejará a suspensão das transferências dos recursos do Piso de Atenção Básica PAB e o cancelamento da Certificação para Gestão das Ações de Epidemiologia e Controle de Doenças, bem como a consequente suspensão do repasse dos recursos do Teto Financeiro de Epidemiologia e Controle de Doenças – TFECD.

Art. 25. Ficam revogadas a Portaria nº 474, de 31 de agosto de 2000, publicada no DOU nº 171, Seção I, pág. 23 e 33, de 04 de setembro de 2000, Portaria nº 475, de 31 de agosto de 2000, publicada no DOU nº 171, Seção I, pág. 34 e 35, de 04
de setembro de 2000, republicada no DOU nº 4, Seção I, pág 109, de 07 de janeiro de 2002 e Portaria nº 627, de 05 de dezembro de 2001, publicada no DOU nº 238, Seção I, pág 118, de 14 de dezembro de 2001.


Jairhs Barbosa da Silva Junior

(*) Republicada por ter saído com incorreção, do original, no DOU de 07-10-2003, Seção I, pág 30.
CFM Resolution 1,779/2005

(Published in the Federal Official Gazette on 5 December 2005, Section I, p. 121)

Regulates the responsibility of the physician in providing information for

THE FEDERAL COUNCIL ON MEDICINE, by authority granted to it under Law 3,268 of 30
September 1957 and its enabling legislation, Decree 44,045 of 19 July 1958,

Considering the content of the following articles in the Code of Medical Ethics:

“Art. 14. The physician must make every effort to improve health conditions and the standards of medical
services and assume his or her share of responsibility for public health, sanitary education, and legislation
on the subject of health.

It is forbidden for the physician to:

Art. 39. Prescribe or make a declaration in secret or in a manner that is illegible, or to sign blank
prescription forms or blank medical certificates, declarations, or other documents.

Art. 44. Fail to cooperate with public health authorities or violate any legislation in effect.

Art. 110. Provide a medical declaration without having performed the professional act that justifies
making said declaration, or one that does not correspond to the truth.

Art. 112. Fail to attest to acts performed in the course of professional practice when requested by the
patient or legal guardian thereof.

Art. 114. Attest to a death that he or she has not personally verified, or the death of a patient that he or she
has not treated, except, in the latter case, when serving as a physician on duty or a substitute, or in the
case of an autopsy and verification by a medical examiner.

Art. 115. Fail to attest to the death of a patient whom he or she has been treating, except when there may
be indication of a violent death”;

and

Considering that:

The Declaration of Death is an integral part of medical care;

The Declaration of Death is an indispensable source of epidemiological data;

A natural death is caused by a disease or injury that initiated a succession of morbid events that directly
caused the death;

An unnatural death occurs as a result of violent external causes;

There is need to regulate the responsibility of the physician in providing the Declaration of Death,
and finally,

Considering the decisions reached in plenary session on 11 November 2005,
RESOLVES:

Art. 1. It is the responsibility of the physician who attested to the death to fill in the data required in the Declaration of Death.

Art. 2. When filling in the Declaration of Death, physicians shall abide by the following [criteria]:

1) Natural death:
   I. Death unattended by a physician:
      a) In localities with access to Death Verification Service (SVO):
         The Declaration of Death shall be provided by the physicians of the SVO;
      b) In localities without SVO:
         The Declaration of Death shall be provided by physicians in the public health service nearest to the place where the event occurred; and in their absence, by any local physician.

   II. Death attended by a physician:
      a) The Declaration of Death shall be provided, whenever possible, by the physician who had been providing medical care to the patient.
      b) The Declaration of Death for a hospitalized patient shall be provided by the attending physician, or in the absence thereof, by a substitute physician associated with the institution.
      c) The Declaration of Death for a patient undergoing outpatient treatment shall be provided by the physician designated by the institution that was providing the care, or by the SVO;
      d) The Declaration of Death for a patient receiving care at home (under the Family Health Program, home-based hospice, and other home care arrangement) shall be provided by the physician associated with the program in which the patient was enrolled, or by the SVO in the event the physician is unable to correlate the death with the clinical picture for which he or she had been following the patient.

2) Fetal death:

   In the event of a fetal death, the physicians attending the mother are required to provide the Declaration of Death when the gestational age is 20 or more weeks, or when the fetus has a bodyweight of 500 (five hundred) or more grams, or when the it measures 25 cm or longer.

3) Violent or unnatural deaths:

   The Declaration of Death shall necessarily be provided by the office of the Medical Examiner.

Sole paragraph. In localities that have only one (1) physician, that physician shall be responsible for providing the Declaration of Death.

Art. 3 This resolution shall enter into effect on the date of its publication, and it hereby revokes CFM Resolution 1,601/2000.

Brasília, DF, 11 November 2005

EDSON DE OLIVEIRA ANDRADE                        LÍVIA BARROS GARÇÂO
President                                    Secretary-General
3. **SINASC: An Evaluation of Progress**

Marcia Furquim de Almeida*

Gizelton Pereira Alencar*

Daniela Schoeps*

**Introduction**

Information on live births is indispensable for the management of health services. It is used both in the planning of delivery care for the mother and the unborn child and in the construction of health and demographic indicators such as infant, neonatal, and perinatal mortality rates as well as fertility and birth rates. Information about characteristics of gestation, delivery, and newborns is important in the assessment of care and in identifying specific needs – for example, knowledge about the rate of newborns at risk makes it possible to estimate the need for neonatal intensive care.

The traditional source of data on live births is the civil registry. However, since the 1940s, studies have shown that live births are undercounted because of underregistration of events.\(^1\) In the 1960s, a diagnostic study of national statistics indicated that there was dispersion and lack of standardization in the collection of data, as well as lack of regularity and uniformity in the reporting thereof, which has served as an impediment to planning activities. The strategy of centralizing the production of information has been adopted for the sake of refining and improving national statistics and also to facilitate electronic data processing at the beginning of the process of concentrating information at the level of federal management for the country as a whole.\(^2\)

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Law 6,015 of 1973 on Public Records laid down regulations for the registration of civil events in Brazil (the civil registry) and entrusted the Brazilian Institute of Geography and Statistics (IBGE) with responsibility for developing statistics based on these records. The law defined the data to be collected and established the information processing path, which called for filling in maps once a month showing the collection of data from the local offices of the civil registry, to be submitted once every three months to IBGE. The data were based on the verbal information usually provided by the father of the child at the time the birth is registered. Standardization of the source of data, the definition of variables, and the collection instrument, as well as the document processing path, has resulted in greater regularity and uniformity in vital statistics, but there continue to be problems of underregistration. The main purpose of the data collection system has been to regulate legally the registration of natural persons and provide the country with demographic information.

The fact that recordation fees are charged at the local offices of the civil registry is one of the factors that has contributed to underregistration, especially in the poorer areas of the country. The Constitution of 1988, with a view to guaranteeing the right to citizenship to all Brazilians, prohibited the collection of such fees to register a birth. However, there continued to be a charge for issuing the declaration of live birth because there was a loophole in the law: The law referred only to payment for entering the event in the civil registry. It was not until 10 December 1997 that Law 9,534 specified that no fee whatsoever may be charged for the registration of births.

The civil registry remained the only source of population data on live births until 1990, and thus the problems relating to the coverage of events persisted.
Research based on census data has shown that during the 1980s underregistration in Brazil as a whole was 22.6%.5

The need to establish a national health information system goes back to the late 1960s and early 1970s. In 1971, the Information Processing Nucleus was created in the Ministry of Health to support the implementation of an information system that would cover the work that the ministry does. The Mortality Information System (SIM) was created as a supplementary resource for the epidemiological surveillance information system. The creation of SIM represented an advance in the conception of information systems by introducing a standardized, partially precoded individual instrument for the collection of data – namely, the declaration of death (DO) – following guidelines proposed by the World Health Organization (WHO). This new type of information system brought positive results for the production of information: Data collection was standardized; errors due to transcribing data from the monthly collection maps were eliminated; and it became viable to initiate electronic data processing.2

The centralized approach to the production of information, originally adopted in an effort to refine and improve national statistics, was reinforced by the mainframe technology available at the time, as well as by the strong centralization of policy decision-making at the federal level under the military régime.2 Another, less decisive, factor was that centralization also offered a way to control the dissemination of information, which was another characteristic of that period in the country’s history.

Given the problems associated with capturing live births through the statistical system based on the civil registry, the São Paulo State System for Data Analysis (SEADE Foundation), which is responsible for statistics for that state, conducted a pilot project in 1980 to test the viability of obtaining data on births
through maternity services in the municipality (municipio) of Mogi das Cruzes in the metropolitan region of São Paulo. The conclusion was that it would be feasible to introduce an instrument for the collection of data in hospitals in order to obtain more detailed information on live births. The São Paulo State Health Secretariat created a working group with a view to proposing a standardized declaration of birth, bearing in mind the successful experience with implementation of the declaration of death and also the fact that declarations of birth in other countries make it possible to obtain information on live births both faster and in greater detail. Thus, a pilot project was undertaken in 1984 in five maternity services, each with different client profiles, in the município of São Paulo, and this initiative led to the conclusion that it would be viable to implement a specific instrument for the collection of data in hospitals.

**Conception and Purpose of SINASC**

At the end of the 1980s, the country’s process of redemocratization, implementation of the Unified Health System (SUS), and the decentralization of health actions added a new dimension and new actors to the health policy scene: the local/municipal sphere of action. This period also saw growth in computerization of the health services and the introduction of microcomputers, which gave further impetus to this process. The new scenario created a growing demand for decentralization of the production, dissemination, and analysis of health information.

It was within this social and political context that the Ministry of Health created an advisory group in 1989 to look at expanding, reformulating, and refining the process of producing and disseminating vital statistics (Ministry of Health Advisory Group on Vital Statistics or GEVIMS). Among the activities carried out by the group were a series of interinstitutional seminars that brought
together representatives of the Ministry of Health, IBGE, the state-level agencies responsible for the collection and production of data (the State Health Secretariats and the foundations associated with the secretariats in charge of state planning, including the SEADE Foundation in São Paulo and the João Pinheiro Foundation in Minas Gerais), DATASUS, educational and research institutions, and some of the municpios that were initiating the decentralized production of information under the umbrella of SIM. The diagnosis of the situation presented at this meeting showed the need for information on conditions of the newborn, gestation, and delivery, as well as maternal characteristics.\footnote{1} It was also pointed out that progress had been made in the capture of mortality information following the creation of SIM. These considerations led to a discussion about the need to create an information system on live births.\footnote{1}

The attendees also heard about international experiences in a number of countries where hospital records are the main source of data on live births and the birth is recorded by presenting a document produced by the health services – unlike Brazil, where the verbal information presented at the local office of the civil registry at the time of recordation is sufficient. Consideration was also given to the positive experience of SIM following introduction of the requirement to present the declaration of death, and how this has helped to improve information on mortality.\footnote{1}

Based on the GEVIMS diagnosis and the experiences reported, the participants decided on the need to implement an information system for live births, to be called SINASC. It was also agreed to introduce a declaration of live birth (DN) that would be standardized throughout Brazil and serve as the basic input document for SINASC. It was further agreed that the health services would be the main source of data for the system, since it was estimated that 85\% of all
births take place in institutions. The local offices of the civil registry would be a source of supplementary data in the case of home births.

The data fields to be included in the DN were also the subject of discussion and agreement by the representatives of all the units in the federation. It was decided to limit the number of data elements in order to allow for diversity between regions and also to increase the chances of adequate compliance by the health services in filling in the information. It was agreed that the data should be sufficient to allow the information to be used by both local and national decision-makers and to develop an epidemiological profile of live births. It was also decided that the data elements shared with the DO would be categorized in the same way so that information would be compatible between the two systems and allow for the development of specific indicators for the joint assessment of mother-and-child health conditions.

The fact that the system was conceived with the participation of all three spheres of the health system, IBGE, and academic and research institutions was fundamental to the success of this initiative, because it guaranteed wide-ranging discussion among the producers and potential users of this information system.

**Implementation of SINASC**

According to Solomon et al., implementation of an information system is a complex process that requires both technical and organizational capacity. These authors point out the importance of establishing a plan for its implementation, which should include the following steps: discussion of the new information system with the health community, estimation of the size of the database at the outset and in the next three or five years; clear definition of the type of events or cases to be collected; explanation of the data processing that will be required; and
development of a system for quality control of the data. Other important steps include identification of the institution responsible for the system and the source of data, and establishment of the document processing path.

**Identification of the Agency to Manage SINASC**

The National Epidemiology Center (CENEPI), working through the General Coordination for Health Information Analysis (CGAIS), was chosen to be responsible for the implementation of SINASC. Based on the recommendations of the interinstitutional seminars and with the collaboration of GEVIMS, the organizers proceeded to develop the DN, specify the document processing path for it within the system, and prepare an instruction manual on how to fill in the form. The task of estimating the size of the database was undertaken by CENEPI, which also took on the job of printing the documents that were to be distributed at the state level, to be passed on in turn to the municipalities. The identification of CENEPI as national manager of the system guaranteed its implementation, since at the time there was a heavy concentration of SUS financial resources at the national level.\(^{11}\) Having CENEPI in charge also reinforced the standardizing role of federal-level SUS operations, and the fact that it would be executing this role would guarantee standardization of the system.

The interinstitutional seminars promoted by CENEPI covered several steps in the planning process for implementing an information system: (a) the health services’ real need for information on live births was identified; (b) consideration was giving to conceiving a system with the support of the nation’s scientific and technical community; (c) progress was made toward definition of the event; (d) the source from which the data would be obtained was identified; (e) it was decided to adopt a standardized document for the collection of data; and (f) responsibilities were assigned in the federal, state, and municipal spheres of the system.
Definition of the Event

Solomon et al.\textsuperscript{10} consider that having a clear and precise definition of the event to be reported is one of the indispensable requisites for an ongoing registration system. Such a definition includes the standards for inclusion and exclusion of events and the legal criteria that need to be followed.

The definition of vital events is regulated by the 1973 Law on Public Records, which includes the WHO definition of a live birth: “Live birth refers to the complete expulsion or extraction from its mother of a product of conception, irrespective of the duration of the pregnancy, which, after such separation, breathes or shows any other evidence of life – e.g. beating of the heart, pulsation of the umbilical cord or definite movement of voluntary muscles – whether or not the umbilical cord has been cut or the placenta is attached. Each product of such a birth is considered live born.” [Up to this point the quote is the original English text.] In the case of a multiple pregnancy, a DN be filled out for each product of pregnancy, or in other words, for each live birth. [This sentence appears not to be in the definition.]\textsuperscript{12} Pursuant to this legislation, SINASC has adopted the foregoing definition of live birth and determined that all births in which vital signs are present, regardless or whether or not the product is viable, are to be captured by the system. Furthermore, the SINASC Manual of Procedures\textsuperscript{12} standardizes the destination of the three copies of the document and, in the event of any erasures or emendations, the cancellation thereof.

Identification of Source of the Data

In light of the small percentage of home births in Brazil, it was decided that health services would be the primary source of data for SINASC and that the civil registry would be a supplementary source of information on home births.\textsuperscript{12} This decision represented a gain, because annotating information on the characteristics
of the delivery, the mother, and the newborn on the patient’s chart is already part of the regular routine in the health services. The decision to have a DN filled in by the health services eliminated two earlier problems with statistics from the civil registry: (a) the fact that the verbal information is usually provided by a third party who did not participate directly in the event; and (b) the possibility of errors in the transcription of recorded information from the books at the local office of the civil registry to the monthly IBGE maps. Another important decision was that the DN can be filled in by any employee of the health service as long as he or she is duly identified.

The creation of SINASC received legal support with establishment of the Statute on Children and Adolescents under Law 8,069 of 13 July 1990. Its Chapter I, Article 10, paragraph iv specifies that hospitals and other health care establishments are required to provide a declaration of birth, which must include information regarding intercurrent circumstances during the delivery and development of the newborn.

**Processing the System’s Data**

DATASUS has developed an application to run on microcomputers that incorporates the latest electronic data processing technology. Based on the document processing path decided on for the system, the states would be responsible for collecting data from the municipios. Some of the municipalities that had already had experience in the decentralized production of mortality information, such as São Paulo and Ribeirão Preto, were made responsible for the production of SINASC data. The incorporation of data processing on microcomputers made for greatly increased speed in accessing information, which became another factor in the system’s success.
System Documentation

Another indispensable element in the creation of a new information system is documentation of the procedures to be followed, and this should be done prior to the implementation process.\textsuperscript{10,14} Thus, the standardized data collection document (the DN) was developed, the document processing path was established, and manuals on filling in the DN and operating a data processing system were prepared.\textsuperscript{15}

Declaration of Live Birth

The DN is a standardized, individually numbered document, designed by the system’s manager at the national level. The numbering is a mechanism for controlling its distribution. It comes in three copies: the top copy is retained by the health service where the birth took place and subsequently transmitted to the corresponding Municipal Health Secretariat; the second copy is given to the family for presentation at the local office of the civil registry,\textsuperscript{3} where the birth is recorded, and the office keeps this copy. The third copy is attached to the newborn’s medical chart in the health establishment where the birth took place.\textsuperscript{13}

The data fields on the DN are organized in blocks. In the most recent version (1999), Block I is supposed to be filled in by the local office of the civil registry at the time the birth is recorded, and it includes the following fields: name of newborn, registration code number, municipio in which the civil registry office is located, recordation date. Block II contains the data fields that identify the place where the birth occurred: name of the establishment, municipio, and state, plus the corresponding codes. Block III includes the data fields that refer to the characteristics of the mother: name, age, marital status, educational level, occupation, number of previous children still living or no longer living, and the mother’s address. Block IV is for data on gestation and delivery: duration of
gestation, type of pregnancy, type of delivery, and number of prenatal checkups. Block V is about the newborn: date and time of birth, sex, APGAR score, race/color, birthweight and, year of birth, and presence of congenital anomalies. Block VI is for identification of the mother and the newborn: right thumbprint of the mother and right footprint of the newborn. Block VII has fields for identifying the person responsible for filling in the form: name, position, identification number and issuing agency, and date. The data are precoded to facilitate electronic data processing.

Personnel Training and Implementation of SINASC

The training process for the implementation of SINASC was initiated by CENEPI in 1990, working through the General Coordination for Health Information Analysis (CGAIS) and in cooperation with the health information or epidemiological surveillance areas in the State Secretariats of Health. Operations training was a joint effort of CENEPI and DATASUS. It was decided the system would be implemented first in the state capitals because of the greater concentration of population, the availability of in-hospital medical care, and greater proximity to personnel responsible for training in the state secretariats, thus making it easier to spot and solve problems. The state of São Paulo implemented the system in all municipalities simultaneously. By the end of 1992, it was fully implemented in seven states and partially in place in all the rest but one.

Dissemination of Information

As part of the decentralization of health services under way, the plan for disseminating the information was predicated on having an analysis unit at the municipal level. This turned out to be the right approach because it meets the need
for information at the local level to support the planning of health interventions and the execution of programs in the area of maternal and child health.

Given the trend toward computerizing information in the health services, it was decided to disseminate information electronically, and DATASUS was entrusted with this challenge. Access to the SINASC database was granted through the Internet at <http://www.datasus.gov.br/>, and CD-ROMs were also made available. To facilitate access to the DATASUS database, the TabWin tabulator was developed to enable users to select data fields and cross-variables. The policy of allowing users to access the database directly, rather than just presenting predefined tables, was a technical response to the decentralization taking place in the health services, and indeed, the result has been the increased use of information, which is key to consolidating the system.

In 1997, following an evaluation which showed that a degree of stability had been achieved in the information produced by SINASC, it was decided to release national data for 1994, 1995, and 1996. There is a delay of two to three years in the dissemination of national information, which means that the data now available are for 2003. However, the generation of SINASC data is decentralized, which means that states and municipalities have more rapid access to the information they need in order to carry out their activities. As for the national data, the time delay appears to be about the same as for other countries – as it can be seen, for example, in the statistics on live births available at the headquarters of the National Center for Health Statistics.¹⁶

Changes and Refinements in SINASC and the Context of Health Information Systems in Brazil

The 1990s saw fervent discussion and proposals for improvement and refinement of the country’s health information systems. Various working units
were established at the initiative of the Ministry of Health, the Brazilian Association of Collective Health (ABRASCO), and the representative office of PAHO in Brazil, which included the participation of the scientific community, national players, and representatives of managers of the state and municipal health information systems.

A diagnosis of the information systems showed that the volume of data was high but that the major systems lacked standard criteria for entering the records, which was impairing compatibility and interoperability between the systems and leading to duplication of information. It became apparent that common definitions needed to be established for the registration of addresses in order to facilitate georeferencing the data. At the same time, there was progress in identifying the compulsory and supplementary information fields needed in order to make the systems compatible. The study pointed out the need to develop ethical criteria to regulate the collection, processing, dissemination, and use of information, as well as the importance of technical training in the execution of tasks in the information systems’ all three spheres of action.*

Creation of the Interagency Health Information Network (RIPSA) in 1996\(^1\) opened up an interinstitutional forum in which to discuss the systems and reach consensus on the calculation of health indicators with the participation of the scientific community and key players from the health information systems.

CENEPI created an Advisory Group on Information Systems, consisting of representatives from the health services’ three spheres of action plus technicians

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* Ministério da Saúde & ABRASCO. Uso e disseminação de informações em saúde – subsídios para elaboração de uma política de informações em saúde para o SUS, 1994 [document by the Ministry of Health and ABRASCO: Dissemination of health information – input for developing a policy on health information for the SUS, 1994]. The ABRASCO Technical Group on Health and Population Information (GTISP) promoted creation of the Working Unit on the Compatibilization of National Databases in 1997. That same year, RIPSA/PAHO created a committee on the subject and promoted creation of a working unit on the compatibilization of information systems and databases. Also that year, CENEPI created the Working Group on the Standardization of Health Information Systems to monitor the implementation of SINASC, evaluate the information, and propose refinements to SIM.
and researchers in epidemiology and demography, which was entrusted with monitoring SIM and SINASC and suggesting modifications in the document processing path, procedures, and tabulation of data. The group was designated a Consultative Council in 1999,\textsuperscript{15} and in 2004 it was given the title of Technical Advisory Committee.\textsuperscript{18}

During this period there was discussion of introducing of a universal SUS card, an initiative that will be important in making the information systems interoperable, but this concept has still not been fully implemented. There was also discussion of adopting a single common identification number, the civil identity registration card (RIC), which would facilitate linkage between the different information systems, but this concept was not implemented either.\textsuperscript{20}

The decentralization of epidemiological information systems was formalized under Integrated Partnership Programming for Epidemiology and Disease Control (PPI-ECD), which specified the responsibilities and financing mechanisms for the information system’s three spheres of action.\textsuperscript{21}

As a result of evaluations of SINASC and intense discussion of the information systems, especially in terms of the need to standardize the data fields and make them compatible, changes were introduced in some of the fields on the DN. A field was introduced for the name of the father and later withdrawn, even though studies have shown that neonatal mortality is higher in newborns for whom the name of the father has not been indicated.\textsuperscript{22}

Other fields introduced were marital status of the mother and identification of the mother and newborn by fingerprint and footprint, respectively, to meet legal requirements. In addition, some of the fields were changed with a view to capturing more precise epidemiological information – for example, the inclusion of more refined categories in reference to the duration of gestation and addition of the category “unknown” to the field indicating the infant’s sex. The field
corresponding to the mother’s education was changed to specify the number of years of schooling to make this information compatible with the population censuses and the Household Sampling Surveys (PNAD). There was concern about standardizing the fields for geographic and cadaster location with a view to ultimately georeferencing the data. The following fields were also introduced: occupation of the mother, race/color of the newborn, and presence of any congenital anomaly detected at birth. In the block referring to the person responsible for filling in the form, fields were introduced for position of the responsible individual and number and issuing agency of the identification card (Annex 1). In addition to reviewing the Manual of Procedures for the Declaration of Live Birth, CENEPI prepared the Manual of Procedures for SINASC, which formally specifies the responsibilities in the three spheres of action for the epidemiological information systems and standardizes the document (hospital and home births, Annexes 3 and 4), as well as the collection of data and procedures for transmitting the second copy in the event the family has lost the original. The introduction of these documents has made it possible to make changes aimed at better defining the event and further refining the document processing path.

In 2003, CENEPI was reorganized under Decree 4,726, dated 9 June 2003. Article 29 of this legislation created the Secretariat for Health Surveillance (SVS) and entrusted it, inter alia, with coordinating epidemiological information systems; coordinating activities related to promoting use of epidemiological methods throughout the SUS; providing technical advisory services and establishing cooperation with states, municipios, and the Federal District with a view to building up managerial capacity; and encouraging the introduction of new surveillance and disease control practices.
Evaluation of SINASC

Solomon et al.\textsuperscript{10} indicate that the following elements should be present as criteria for evaluating administrative records in the health area: (a) a plan of implementation; (b) adequate documentation; (c) quality control procedures; (d) procedures for defining/identifying cases/events; (e) clearly defined variables; (f) established collection procedures; (g) data processing; and (h) a defined policy on access to and dissemination of data. The implementation of SINASC met all these requirements except the one on quality control procedures. According to these authors, quality control procedures should be an integral part of the system and implemented during all the phases, with clear assignment of responsibility and a timetable for their execution.

The manual of procedures recommends that all fields of the DN be reviewed before the data are entered into the operational system at the municipal level.\textsuperscript{12} For some of the fields, there are mechanisms in place for controlling the data that are entered into the operational system – for example, age of the mother and birthweight. This system is automated: it generates a report of inconsistencies or absence of data and identifies DNs that need to be returned to the originating agencies for correction, both at the municipal level, when the data were entered there, and at the state level at the time of preliminary tabulation.\textsuperscript{12} However, these quality control measures are not enough.\textsuperscript{24}

SINASC’s routine procedures have not been subjected to very many evaluations. However, Ribeiro,\textsuperscript{25} in a study conducted in Ilhéus, noted a delay in receipt of DNs from the Municipal Health Secretariat and also a delay in entering the data, leading to a loss of documents. Also, a study conducted in São Paulo revealed difficulties in entering the data in some of the Municipal Health Secretariats, where the same personnel were also assigned to keying in documents for SIM, SINASC, and SINAN.\textsuperscript{26} In light of the heavy volume of live births in the
municipio of São Paulo, the Municipal Health Secretariat developed a standard procedure whereby the data from the DNs are entered at the hospitals and then sent on to the health coordinators in the various subprefectures of São Paulo. Standardization of this procedure speeded up the production of information and reduced the cost of transmitting the documents.

Evaluating an information system also means looking to see if mechanisms are in place to measure the capacity to capture/cover events and the quality of the information available, the latter in turn implying that quality control system is in place.

**Evaluation of Coverage of Events**

Table 1 gives the number of live births in Brazil captured by SINASC from 1994 to 2003, showing an increase of 18% during the period. However, this measure alone is insufficient. To evaluate the system’s coverage, the number of reported events may be compared against the data obtained by other information systems or the total estimated number of events, or techniques may even be developed that use data from the system itself.

It turns out that, since 1994, SINASC has captured more events than have been recorded in the civil registry in all the regions of the country except the southeast (Table 1), where the number of events recorded in the registry was larger up until 1997, due to delayed implementation of SINASC in the state of Minas Gerais. Table 1 also shows that the highest capture ratios for SINASC vis-à-vis the registry were in the northern and northeastern regions, where the problem of underregistration is greatest. According to an estimate by IBGE, under-registration in 2004 was on the order of 16% for the country as a whole. The highest rates were in the northern and northeastern regions, especially the states of Amazonas, Roraima, Pará, Maranhão, and Piauí, with figures of more than 30%.
Table 1. Number of Live Births Reported by SINASC and the Civil Registry and Proportion SINASC/Civil Registry, by Regions and Year, 1994-2003.

<table>
<thead>
<tr>
<th>Year</th>
<th>Source</th>
<th>Northern</th>
<th>Northeastern</th>
<th>Southeastern</th>
<th>Southern</th>
<th>Western Central</th>
<th>Brazil</th>
</tr>
</thead>
<tbody>
<tr>
<td>1994</td>
<td>SINASC</td>
<td>216978</td>
<td>617108</td>
<td>1074088</td>
<td>475727</td>
<td>187670</td>
<td>2571571</td>
</tr>
<tr>
<td></td>
<td>Civil Registry</td>
<td>125946</td>
<td>637341</td>
<td>1271303</td>
<td>459166</td>
<td>186949</td>
<td>2680705</td>
</tr>
<tr>
<td></td>
<td><em>Ratio</em></td>
<td>1.72</td>
<td>0.97</td>
<td>0.84</td>
<td>1.04</td>
<td>1.00</td>
<td>0.96</td>
</tr>
<tr>
<td>1995</td>
<td>SINASC</td>
<td>227013</td>
<td>732094</td>
<td>1140419</td>
<td>482965</td>
<td>242238</td>
<td>2824729</td>
</tr>
<tr>
<td></td>
<td>Civil Registry</td>
<td>115693</td>
<td>637456</td>
<td>1246645</td>
<td>441217</td>
<td>183522</td>
<td>2627443</td>
</tr>
<tr>
<td></td>
<td><em>Ratio</em></td>
<td>1.96</td>
<td>1.15</td>
<td>0.91</td>
<td>1.09</td>
<td>1.32</td>
<td>1.08</td>
</tr>
<tr>
<td>1996</td>
<td>SINASC</td>
<td>240251</td>
<td>787363</td>
<td>1199147</td>
<td>478879</td>
<td>239785</td>
<td>2945425</td>
</tr>
<tr>
<td></td>
<td>Civil Registry</td>
<td>149837</td>
<td>603081</td>
<td>1258600</td>
<td>424456</td>
<td>191297</td>
<td>2627271</td>
</tr>
<tr>
<td></td>
<td><em>Ratio</em></td>
<td>1.60</td>
<td>1.31</td>
<td>0.95</td>
<td>1.13</td>
<td>1.25</td>
<td>1.12</td>
</tr>
<tr>
<td>1997</td>
<td>SINASC</td>
<td>266332</td>
<td>887176</td>
<td>1305587</td>
<td>459039</td>
<td>238903</td>
<td>3148037</td>
</tr>
<tr>
<td></td>
<td>Civil Registry</td>
<td>150259</td>
<td>575508</td>
<td>1278502</td>
<td>427413</td>
<td>188831</td>
<td>2620513</td>
</tr>
<tr>
<td></td>
<td><em>Ratio</em></td>
<td>1.72</td>
<td>1.45</td>
<td>0.96</td>
<td>1.10</td>
<td>1.28</td>
<td>1.15</td>
</tr>
<tr>
<td>1998</td>
<td>SINASC</td>
<td>285229</td>
<td>915528</td>
<td>1351192</td>
<td>470326</td>
<td>234158</td>
<td>3256433</td>
</tr>
<tr>
<td></td>
<td>Civil Registry</td>
<td>193824</td>
<td>746009</td>
<td>1331484</td>
<td>454065</td>
<td>211456</td>
<td>2936838</td>
</tr>
<tr>
<td></td>
<td><em>Ratio</em></td>
<td>1.47</td>
<td>1.23</td>
<td>1.01</td>
<td>1.04</td>
<td>1.11</td>
<td>1.11</td>
</tr>
<tr>
<td>2000</td>
<td>SINASC</td>
<td>297078</td>
<td>926104</td>
<td>1306235</td>
<td>451009</td>
<td>232705</td>
<td>3206761</td>
</tr>
<tr>
<td></td>
<td>Civil Registry</td>
<td>197648</td>
<td>752185</td>
<td>1276836</td>
<td>430474</td>
<td>204510</td>
<td>2861653</td>
</tr>
<tr>
<td></td>
<td><em>Ratio</em></td>
<td>1.47</td>
<td>1.23</td>
<td>1.02</td>
<td>1.05</td>
<td>1.14</td>
<td>1.12</td>
</tr>
<tr>
<td>2001</td>
<td>SINASC</td>
<td>299388</td>
<td>942141</td>
<td>1230473</td>
<td>415957</td>
<td>227515</td>
<td>3115474</td>
</tr>
<tr>
<td></td>
<td>Civil Registry</td>
<td>212395</td>
<td>759816</td>
<td>1204605</td>
<td>397703</td>
<td>204708</td>
<td>2779227</td>
</tr>
<tr>
<td></td>
<td><em>Ratio</em></td>
<td>1.41</td>
<td>1.24</td>
<td>1.02</td>
<td>1.05</td>
<td>1.11</td>
<td>1.12</td>
</tr>
<tr>
<td>2002</td>
<td>SINASC</td>
<td>301208</td>
<td>929717</td>
<td>1195168</td>
<td>406116</td>
<td>227193</td>
<td>3059402</td>
</tr>
<tr>
<td></td>
<td>Civil Registry</td>
<td>222442</td>
<td>804418</td>
<td>1174804</td>
<td>391788</td>
<td>209516</td>
<td>2802968</td>
</tr>
<tr>
<td></td>
<td><em>Ratio</em></td>
<td>1.35</td>
<td>1.16</td>
<td>1.02</td>
<td>1.04</td>
<td>1.08</td>
<td>1.09</td>
</tr>
<tr>
<td>2003</td>
<td>SINASC</td>
<td>311335</td>
<td>930145</td>
<td>1181131</td>
<td>389675</td>
<td>225965</td>
<td>3038251</td>
</tr>
<tr>
<td></td>
<td>Civil Registry</td>
<td>233357</td>
<td>826533</td>
<td>1165103</td>
<td>376586</td>
<td>213028</td>
<td>2814617</td>
</tr>
<tr>
<td></td>
<td><em>Ratio</em></td>
<td>1.33</td>
<td>1.13</td>
<td>1.01</td>
<td>1.03</td>
<td>1.06</td>
<td>1.08</td>
</tr>
</tbody>
</table>

Source: MS/SVS/DASIS – SINASC (Live Birth Information System); IBGE, statistics from the Civil Registry, 2004.

Another way to evaluate coverage is to compare the data available in SINASC with the estimated number of live births. The RIPSA basic health indicators provide this information with an indicator that represents the ratio between reported and estimated live births (Table 2). It can be seen that SINASC coverage was about 89% for Brazil as a whole in 2002, and again the Northern and Northeastern regions had lower rates.
Table 2. Ratio (%) of Reported Versus Estimated Live Births, by Region, 1996-2002

<table>
<thead>
<tr>
<th>Region</th>
<th>1997</th>
<th>1998</th>
<th>1999</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern</td>
<td>74.38</td>
<td>75.55</td>
<td>79.60</td>
<td>79.85</td>
<td>80.99</td>
<td>80.42</td>
<td>89.62</td>
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<tr>
<td>Northeastern</td>
<td>73.55</td>
<td>77.32</td>
<td>80.23</td>
<td>80.72</td>
<td>81.92</td>
<td>80.62</td>
<td>90.56</td>
</tr>
<tr>
<td>Southeastern</td>
<td>94.58</td>
<td>100.20</td>
<td>102.82</td>
<td>98.74</td>
<td>92.24</td>
<td>89.14</td>
<td>111.42</td>
</tr>
<tr>
<td>Southern</td>
<td>102.42</td>
<td>99.94</td>
<td>102.50</td>
<td>98.14</td>
<td>90.52</td>
<td>88.32</td>
<td>114.34</td>
</tr>
<tr>
<td>Western Central</td>
<td>103.35</td>
<td>101.50</td>
<td>98.99</td>
<td>97.59</td>
<td>95.05</td>
<td>94.47</td>
<td>115.30</td>
</tr>
<tr>
<td>Brazil</td>
<td>87.33</td>
<td>90.31</td>
<td>92.80</td>
<td>90.79</td>
<td>87.70</td>
<td>85.72</td>
<td>103.05</td>
</tr>
</tbody>
</table>

Source: RIPSA-IDB 2003/IBGE and Ministry of Health/SVS – SINASC.

The data show that the values for this indicator fluctuate over time, especially in the southern and southeastern regions (Table 2), which have the lowest ratios between the number of events reported by SINASC and those in the civil registry (Table 1) and also the lowest rates of underregistration of births.29 There are two possible explanations for these fluctuations. The first is that the number of estimated live births has been virtually stable over time, since these deaths are calculated by indirect methods based on the population censuses and data from the Household Sampling Surveys (PNADs), and changes taking place during the intercensal period may be more difficult to capture. The second possible reason is the reduction in the absolute number of events reported by SINASC for the southeastern region (a decline of 1.3% per year, based on the exponential regression coefficient), the southern region (a drop of 3.4% per year), and the western central region (1.2% per year) (Figure 1). There has also been a downward trend in the number of births reported in the civil registry (Figure 2) in the southeastern region (a decline of 2% per year) and the southern region (2.6% per year), even considering that the rate may have been slightly affected by the fact that registration of births is free of charge, due to the low rate of underregistration in these regions. The data in the civil registry seem to confirm the downward trend in events observed by SINASC. However, more detailed studies are needed in order to know if there is a real drop in the number of live births.
Figure 1. Number of live births reported by SINASC, and the trend, by regions, 1997-2003.

Source: Ministry of Health/SVS – SINASC.
Note: Exponential regression was calculated for the period in question.

Figure 2. Number of live births reported by the civil registry, and the trend, by regions, 1997-2003.

Source: IBGE. Statistics from the Civil Registry.
Note: The exponential regression was obtained for the period in question.
The RIPSA committee on mortality and natality considers the number and frequency of queries and also the extent of coverage identify the states in which the direct method can be used to calculate the indicators (Acre, Amapá, and Roraima in the northern region; Pernambuco in the northeast; all the states in the southeastern region except Minas Gerais; and all the states in the southern region).\textsuperscript{30} Coverage of the SINASC systems is assessed by comparing SINASC figures with the number of live births estimated by IBGE.

SINASC coverage is lowest in the Northern and Northeastern regions,\textsuperscript{30} but Almeida and Alencar\textsuperscript{24} showed that there were also intraregional differences in the state of Piauí, where coverage of events was better in the capital than elsewhere in the state. It is possible to assume that similar patterns exist in other states in these regions, since the health services are mainly located in the capitals. The decision of PPI-ECD to require that the states and municipalities provide data for the information systems before they can receive resources has had a positive impact on the number of events captured by SINASC. For example, Table 3 shows birth rates by microregions in the state of Piauí. It can be seen that in 1996 the reporting of live births was low in several of the microregions, resulting in birth rates that were very different from reality. However, in 1999, the year in which PPI-ECD was inaugurated, improvements could be seen in identification of the mother’s place of residence and in the capture of events in the various microregions.

<table>
<thead>
<tr>
<th>Microregion</th>
<th>Live births</th>
<th>Population</th>
<th>GBR*</th>
<th>Live births</th>
<th>Population</th>
<th>GBR*</th>
<th>Live births</th>
<th>Population</th>
<th>GBR*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lower Parnaíba</td>
<td>6,209</td>
<td>294,346</td>
<td>21.09</td>
<td>4,899</td>
<td>298,301</td>
<td>16.42</td>
<td>6,259</td>
<td>310,253</td>
<td>20.17</td>
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<td>Coast</td>
<td>5,949</td>
<td>256,137</td>
<td>23.23</td>
<td>5,395</td>
<td>264,165</td>
<td>20.42</td>
<td>5,489</td>
<td>281,380</td>
<td>19.51</td>
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<td>Teresina</td>
<td>20,079</td>
<td>806,971</td>
<td>24.88</td>
<td>19,271</td>
<td>849,070</td>
<td>22.70</td>
<td>17,396</td>
<td>919,590</td>
<td>18.92</td>
</tr>
<tr>
<td>Campo Maior</td>
<td>4,171</td>
<td>203,645</td>
<td>20.48</td>
<td>2,691</td>
<td>203,612</td>
<td>13.22</td>
<td>3,871</td>
<td>212,045</td>
<td>18.26</td>
</tr>
<tr>
<td>Middle Parnaíba</td>
<td>2,129</td>
<td>121,667</td>
<td>17.50</td>
<td>2,097</td>
<td>123,185</td>
<td>17.02</td>
<td>2,037</td>
<td>127,372</td>
<td>15.99</td>
</tr>
<tr>
<td>Valença</td>
<td>28</td>
<td>97,243</td>
<td>0.29</td>
<td>1,226</td>
<td>96,836</td>
<td>12.66</td>
<td>1,628</td>
<td>104,971</td>
<td>15.51</td>
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<td>Upper Parnaíba</td>
<td>2</td>
<td>35,111</td>
<td>0.06</td>
<td>518</td>
<td>35,516</td>
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<td>795</td>
<td>37,703</td>
<td>21.09</td>
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<td>Bertolínia</td>
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<td>0.00</td>
<td>578</td>
<td>36,077</td>
<td>16.02</td>
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<td>38,435</td>
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<tr>
<td>Floriano</td>
<td>10</td>
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<td>2,229</td>
<td>116,001</td>
<td>19.22</td>
<td>2,203</td>
<td>120,268</td>
<td>18.32</td>
</tr>
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<td>1,172</td>
<td>74,243</td>
<td>15.79</td>
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<td>21.22</td>
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<td>114,518</td>
<td>0.02</td>
<td>1,391</td>
<td>114,034</td>
<td>12.20</td>
<td>2,265</td>
<td>124,093</td>
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<td>5</td>
<td>69,929</td>
<td>0.07</td>
<td>1,157</td>
<td>71,309</td>
<td>16.23</td>
<td>1,667</td>
<td>78,788</td>
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<td>Picos</td>
<td>9</td>
<td>173,183</td>
<td>0.05</td>
<td>3,111</td>
<td>176,305</td>
<td>17.65</td>
<td>3,328</td>
<td>189,999</td>
<td>17.52</td>
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<tr>
<td>Pio IX</td>
<td>4</td>
<td>50,708</td>
<td>0.08</td>
<td>738</td>
<td>49,659</td>
<td>14.86</td>
<td>907</td>
<td>52,881</td>
<td>17.15</td>
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<tr>
<td>A.M.Canindé</td>
<td>316</td>
<td>225,748</td>
<td>1.40</td>
<td>2,936</td>
<td>225,845</td>
<td>13.00</td>
<td>4,829</td>
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<td>Unknown</td>
<td>222</td>
<td>227</td>
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</tr>
</tbody>
</table>

Piauí 39142 2,673,085 14.64 49,436 2,734,158 18.08 49,436 2,734,158 18.08

* GBR = gross birth rate per 1,000 live births

Source: SVS-SINASC/ IBGE

Mello-Jorge and Gotlieb\textsuperscript{31} found that SIAB had managed to capture a few live births that had not been reported by SINASC. Based on these findings, a project was undertaken to integrate the data of SIM, SINASC, and SIAB by enlisting the participation of SVS, the Health Actions Secretariat (SAS), and state and municipal coordinations. One of the results of this project was the publication of a primer\textsuperscript{32} to guide community health agents working under the family health program to search actively for declarations of birth in the local offices of the civil registry, especially home births.

The SINASC documentation uses the WHO definition of live birth, which is clear in terms of the definition of the event to be reported and the fact that it does
no consider the viability of the newborn. However, it is not uncommon for a live birth to be registered and for the birth to be followed shortly thereafter by a death, as in the case of fetal deaths, which leads to overestimation of fetal mortality and underestimation of the number of live births.\(^{33,34}\) Pinheiro,\(^{35}\) in a study conducted in 2001 in the municipio of Ilhéus (Bahia), discovered that 48% of the neonatal deaths had been registered as fetal deaths – in other words, no DNAs had been prepared for these newborns. Another study, conducted in the southern area of the municipio of São Paulo,\(^{36}\) found this to be the case for 2.5% of the early neonatal deaths investigated.

Based on the definition of live birth adopted by SINASC, it is implicit that DNAs should be prepared for newborns who die immediately after delivery, but the fact that there is no explicit recommendation to do so may be contributing to the failure to report these events. This may be one of the reasons for the lower frequency of low birthweight (<1500g) observed in the north (0.7%) and northeast (0.9%) than in the southeast (1.3%) and south (1.2%) in 2002 (SINASC 2002). Silva et al.\(^{37}\) found a lower frequency of low birthweight in São Luis do Maranhão than in Ribeirão Preto (São Paulo state), and the possibility of lack of notification of the births was also suggested by these authors. However, more detailed studies are needed in order to determine whether the differences in the prevalence of low birthweight in the northern and northeastern regions are due to a reporting bias/systematic error\(^{38}\) or to risk factors that have not yet been identified.

**Assessment of Information Quality**

To assess the quality of information, it is necessary to look first at the completeness of the information available – that is, of the records already stored in the system, what proportion of them provide information versus those that are blank or contain the entry “Unknown.” The second type of assessment has to do
with the reliability or validity of the data recorded, which will provide a measure of their accuracy.38

Factors that have contributed to the quality of SINASC information include: the decision to use the right data source; application of the resulting information for programming health interventions at the local level; implementation of system routines based on the manual of procedures to ensure that the DN is filled in correctly; and the various studies 35-43 that have been conducted on the completeness of the data. Table 4 shows the gradual improvement in the completeness of SINASC information over time and the current high levels of completeness of the data in all the regions for all the variables in the system. Lack of information given for the data element “1-minute Apgar score” was higher than 10% in the northeastern region in 2003, suggesting that this assessment of newborns may not be practiced frequently in the region’s maternity services.

Table 4. Proportion of Failure to Supply Information, by Data Elements and by Regions, 1997 and 2003

<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>Age of the mother</td>
<td>2.80</td>
<td>0.21</td>
<td>4.73</td>
<td>0.39</td>
<td>1.07</td>
<td>0.10</td>
<td>0.87</td>
<td>0.05</td>
<td>1.59</td>
<td>0.09</td>
<td>2.23</td>
<td>0.19</td>
</tr>
<tr>
<td>Duration of gestation</td>
<td>1.25</td>
<td>0.28</td>
<td>5.17</td>
<td>1.27</td>
<td>4.40</td>
<td>1.43</td>
<td>1.16</td>
<td>0.21</td>
<td>2.32</td>
<td>0.75</td>
<td>3.67</td>
<td>1.06</td>
</tr>
<tr>
<td>Birthweight</td>
<td>1.18</td>
<td>1.22</td>
<td>2.75</td>
<td>1.12</td>
<td>1.49</td>
<td>0.51</td>
<td>0.47</td>
<td>0.11</td>
<td>0.53</td>
<td>0.14</td>
<td>1.57</td>
<td>0.69</td>
</tr>
<tr>
<td>Prenatal consultation</td>
<td>13.04</td>
<td>1.53</td>
<td>19.24</td>
<td>2.81</td>
<td>20.20</td>
<td>2.73</td>
<td>6.07</td>
<td>0.54</td>
<td>11.68</td>
<td>1.79</td>
<td>16.44</td>
<td>2.28</td>
</tr>
<tr>
<td>Type of delivery</td>
<td>0.36</td>
<td>0.09</td>
<td>1.06</td>
<td>0.34</td>
<td>1.35</td>
<td>0.48</td>
<td>0.24</td>
<td>0.03</td>
<td>0.34</td>
<td>0.09</td>
<td>0.93</td>
<td>0.31</td>
</tr>
<tr>
<td>Location</td>
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<td>0.00</td>
<td>0.16</td>
<td>0.01</td>
<td>0.61</td>
<td>0.03</td>
<td>0.09</td>
<td>0.00</td>
<td>0.05</td>
<td>0.00</td>
<td>0.32</td>
<td>0.01</td>
</tr>
<tr>
<td>Sex</td>
<td>0.19</td>
<td>0.17</td>
<td>0.31</td>
<td>0.26</td>
<td>0.12</td>
<td>0.09</td>
<td>0.02</td>
<td>0.01</td>
<td>0.18</td>
<td>0.10</td>
<td>0.17</td>
<td>0.14</td>
</tr>
<tr>
<td>1-minute Apgar score</td>
<td>11.20</td>
<td>6.97</td>
<td>33.07</td>
<td>17.7</td>
<td>10.56</td>
<td>4.53</td>
<td>5.90</td>
<td>1.22</td>
<td>12.86</td>
<td>3.84</td>
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<tr>
<td>Type of pregnancy</td>
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<td>0.06</td>
<td>1.54</td>
<td>0.3</td>
<td>1.15</td>
<td>0.26</td>
<td>0.27</td>
<td>0.02</td>
<td>0.51</td>
<td>0.09</td>
<td>1.01</td>
<td>0.21</td>
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<tr>
<td>Schooling of the mother*</td>
<td>79.36</td>
<td>0.02</td>
<td>72.18</td>
<td>0.05</td>
<td>75.90</td>
<td>0.03</td>
<td>77.59</td>
<td>0.01</td>
<td>76.17</td>
<td>0.02</td>
<td>75.46</td>
<td>0.03</td>
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<tr>
<td>Number of live children</td>
<td>23.83</td>
<td>1.02</td>
<td>27.99</td>
<td>0.34</td>
<td>15.96</td>
<td>6.91</td>
<td>9.15</td>
<td>0.23</td>
<td>27.68</td>
<td>1.59</td>
<td>19.81</td>
<td>3.04</td>
</tr>
</tbody>
</table>

* In 1997, this element was called “mother’s level of schooling,” and in 2003, “mother’s years of schooling.”
Source 2003: SVS/SINASC
As for the accuracy of the information recorded in the SINASC database, there are no routines in place for making this assessment. Instead, item-by-item evaluations have been undertaken through studies that compare the information in SINASC with information culled from patient charts\textsuperscript{39,44,45} or interviews with mothers of newborns.\textsuperscript{44,46,47}

The studies show that the information on sex, type of delivery, and birthweight recorded in the SINASC database is of excellent quality. With regard to the duration of gestation, it was noted that this variable tends to be underestimated for premature newborns (less than 37 weeks).\textsuperscript{44,46} The studies also show that determining the number of prenatal consultations is not always easy.\textsuperscript{44,47,48,49} Data on the socioeconomic situation of the mother (level/years of schooling, marital status) also leave something to be desired in terms of accuracy, possibly because of errors in recording this information on the hospital patient charts.\textsuperscript{44}

Almeida et al.,\textsuperscript{36} in a study conducted in the southern section of São Paulo municipality, found that the SINASC data on home births was underestimated. This situation may be due to the fact that not all the women who gave birth at home subsequently received care at a hospital, where the DN was filled out. These authors also suggested home births may be underestimated in rural areas of the country due to difficulties in capturing the event.

**Strengths of SINASC**

The establishment of SINASC was carried out according to a plan that met all the requirements of an implementation plan, and the system’s management meets nearly all the required operational criteria,\textsuperscript{10} which has ensured a high level of completeness of the information, as well as good quality of most of the data.
With the information that SINASC provides, it is possible, for example, to draw an epidemiological profile of newborns in the country based on such population data as low birthweight, preterm births, and proportion of cesarean deliveries; to assess differences and changes in the reproductive profile of women;\(^{50}\) to calculate health and demographic indicators; to put together the knowledge needed for setting priorities; and to assess the care being provided during delivery and to newborns.

Decentralization of production to the municipal level has made it possible to use the information to identify and carry out surveillance of newborns at risk and to support the work of the committees on infant and maternal mortality. Electronic dissemination of information and access to the database via a user-friendly tabulator has expanded the utilization SINASC information.\(^{51}\)

**Challenges Faced by SINASC**

SINASC still has problems with the coverage of events in the northern and northeastern regions. Despite active searching for home births, there are events that the system fails to capture, mainly in rural areas and in remote localities that are far from any health services. SINASC already has a few quality control routines, and there is need for more of these at all stages of the system in order to guarantee greater standardization of its procedures.

There is duplication of data in different information systems because births are registered not only with SINASC but also in the SIH database when the delivery is attended by the SUS; and if the newborn should fail to thrive, the event is recorded with SIM as an early neonatal death. There is information technology available to facilitate the interoperability of the systems, which would reduce costs and guarantee a higher quality of information. However, this issue is related to
other challenges that have already been identified, such as standardizing the concepts corresponding to the different data elements, or variables, in the information systems. This problem is not so easily solved, because it involves different cultures and practices in the health services, and it also entails additional operational costs. It should be noted, however, that Brazil is not alone in this situation: Several authors have cited similar problems in information systems in the United States\textsuperscript{52,53} and United Kingdom.\textsuperscript{54}

**Sustainability of SINASC**

The following factors have contributed to the sustainability of SINASC over time: (a) the decision to use the health services as the source of data for the system, since these services already routinely keep records on the variables included in the DN; (b) the fact that it is compulsory to present the DN in order to record a birth in the civil registry; (c) identification of the national agency responsible for managing the system; (c) the existence of a secure source of financing for the three spheres of system operation, with funding guaranteed by the PPI/ECD; (d) decentralization of the system, which has made for greater use of information produced at the local level; (e) dissemination of the databases, which has created widespread access to the information; (f) utilization of the information in the planning and evaluation of health services; and (g) extensive use of the data in studies on the epidemiological profile of mothers and newborns.

**Potential and Future Outlook**

An appraisal of SINASC would be incomplete without considering potential applications of the information produced and the future outlook for the system.
Potential Applications of SINASC Information

There is a wealth potential uses of SINASC information, and these opportunities have been the subject of a number of studies. Studies using SINASC information have been carried out in several regions and various municipalities with different characteristics to explore the epidemiological profile of live births (e.g., births to teenage mothers),\(^{55,56}\) the profile of access to delivery and newborn care,\(^{57,58}\) an evaluation of prenatal care,\(^{59}\) studies that show the risk factors for low birthweight,\(^{55}\) a possible link between type of delivery and the prevalence of low birthweight,\(^{60}\) and patterns of fertility in women.\(^{50}\) SINASC is the only source of demographic data on the prevalence of congenital anomalies. Although the completeness of this information could be improved,\(^ {38,44}\) it offers important potential applications in areas that are relatively unexplored.

Database linkage involves sharing the contents of two or more information systems. Standardization of the SINASC and SIM data elements has facilitated the linkage process and increased the potential for future studies, since it will be possible to identify risk factors for neonatal and infant mortality.\(^ {34,61,62,63}\) In addition to sharing data with SIM, there is the possibility of using other databases, such as linking up with databases on HIV/AIDS, as suggested in a study on HIV-infected pregnant women.\(^ {64}\)

Currently, several municipalities are using SINASC together with SIM to plan their surveillance actions – for example, surveillance of infant and maternal deaths or newborns at risk,\(^ {65,66}\) resulting in improved quality of the data.\(^ {51}\)

Future Outlook for SINASC

Changes in the titles of some of the data fields on the DN could help to improve the quality of information. “Age of the mother” could be changed to
“Date of birth,” to correct the problem of “rounding up” the age, and this information could easily be obtained from hospital patient charts. The mother’s place and date of birth are legally required for the civil registry and facilitate identification of the mother, as does the use of database linkage techniques. Inclusion of the mother’s place of birth might even make it possible to obtain demographic information.

The duration of gestation, or “gestational age,” is so important in assessing the viability of the newborn that in the United States the standard birth certificate records it as two different data elements: “Mother’s date of last menstruation” and “Gestational age in weeks.” In SINASC, this element is presented as a series of ranges (under 22; 22; 22-27; 28-31; 32-36; 37-41, and 42 weeks and over). In the United States, a similar change in the DN would make it possible to identify the births that present intrauterine growth retardation and calculate the lower level of survival, based on gestational age. Ribeiro conducted a test using a simplified version of the DN for home births and showed that the mothers had provided the date of last menstruation to the community health agents. This finding suggests that it will be easier to obtain this information in the hospitals at the time of delivery.

Information that is disseminated should have a release number, because corrections may subsequently be incorporated in the databases and system tables. The data tabulated using TabWin and distributed via the Internet and on CDs could have a release number. The SVS has set up a schedule of information release dates at several times during the year, which would allow for this type of control.

Linkage between SINASC and the birth data in the civil registry would make it possible to identify those places where the system has not had good captation and help to channel the direction of programs to improve the information. Also,
use of such a link would provide supplemental data, increase SINASC coverage, and improve the statistical estimates of births.

The information technology available is adequate to bring about improvements in SINASC’s operations. As a first step, the DNs could be filled in electronically in the health services, thus avoiding the step of having them filled in manually and they rekeyed into the system. The technology is already available to sign documents electronically, and Resolution 36 of 21 October 2004 approves regulations for the Homologation of Digital Certification Systems and Equipment within ICP-Brazil (ITI). Also, the technology is being used in Brazil by the Secretariat of Federal Income, and this application has made it possible to guarantee the integrity of the information on record.

A second step would be to make the system more flexible by incorporating models that could be converted to the standard system. This proposal is patterned after the United States live birth information system. In that country, there is a national standard that has been defined by consensus and is made available through the U.S. Centers for Disease Control and Prevention’s National Center for Health Statistics, but at the same time the states can define their local patterns, which are then converted to comply with the national standard. Ribeiro was able to test successfully a simplified SINASC module for the collection of data on home births in Ilhéus. It could be imagined that modules with even more data elements could be used as sentinels in hospitals of greater complexity.

A third step would be to increase the connectivity of existing information systems in the SUS, thus avoiding duplicate entries. For example, SIH software could be developed that would allow for the automatic issuance of a DN using data already recorded in the authorization for hospitalization.
Chapter References


14 Ministério da Saúde, ABRASCO. *Uso e disseminação de informações em saúde: subsídios para elaboração de uma política de informações em saúde para o SUS.* Brasília. 1994.


64 Cavalcante MS, Ramos Jr. AN, Pontes LRSK. Relacionamento de sistemas de informação em saúde: uma estratégia para otimizar a vigilância das gestantes infectadas pelo HIV. Epidemiologia e Serviços de Saúde 2005; 14(2): 127 - 133.


Chapter Annex I — Model Declaration of Live Births for Live Birth

Anexo I

Modelo da Declaração de Nascido Vivo

[Diagram of model declaration form]

ATENÇÃO: ESTE DOCUMENTO NÃO SUBSTIUÍ A CERTIDÃO DE NASCIMENTO
O Registro de Nascimento é obrigatório por lei.
Para registrar esta criança, o pai ou responsável deve levar este documento ao cartório do registro civil.
Chapter Annex II — Standardized Information Processing Path

NATIONAL EPIDEMIOLOGY CENTER (CENEPI) -- >
STATE HEALTH SECRETARIAT -- > DIRES
-- > MUNICIPAL HEALTH SECRETARIAT -- >
-- > HEALTH ESTABLISHMENT
-- > NOTARY FOR CIVIL REGISTRY

Note: When there was no Regional Health Directorate (DIRES) or equivalent.

Chapter Annex III — Information Processing Path – Declaration of Live Birth: Hospital Births

HOSPITAL
COPY 1 -- > PROCESSING AGENCY
COPY 2 -- > FAMILY -- > NOTARY
COPY 3 -- > HOSPITAL

Chapter Annex IIIa — Information Processing Path – Declaration of Live Birth: Home Births

HOME -- > NOTARY -- >
COPY 1 -- > PROCESSING UNIT
COPY 2 -- > NOTARY
COPY 3 -- > FAMILY -- > HEALTH UNIT

Chapter Annex IIIb — Information Processing Path – Declaration of Live Birth: Home Unit

HOME -- > HEALTH UNIT -- >
COPY 1 -- > PROCESSING UNIT
COPY 2 -- > FAMILY -- > CIVIL REGISTRY
COPY 3 -- > HEALTH UNIT
4. SUS Hospital Information System – SIH/SUS

Déa M. T. Carvalho*

Background

The evolution of the Hospital Information System of the Unified Health System (SIH/SUS), both before and after it acquired its present name in 1991, has closely paralleled the movements that have marked the history of public health reform in Brazil over the last 30 years, and in fact it is largely an outgrowth of these movements. This is understandable, because the information system has played a key role in the development and evaluation of policies related to the organization and financing of medical and hospital care in the public health system.

The SIH started out originally as a mechanism for handling payments for inpatient hospital services, implementing control measures, and auditing financial records. However, as the system began to provide more and more information about the services produced, it began to be used by both researchers and managers for other purposes. This trend is understandable, not only because of the large database available to the public covering hospitalizations in Brazil from 1983 up to the present, but also because of the wealth of individual records that link procedures to patient profiles. Since the International Classification of Diseases (ICD) is used for diagnoses, if the information is properly filled in, it can also be used for epidemiological purposes.

It should be pointed out that the SIH/SUS is not universal: it only covers hospitalizations in the public services network† – in other words, those financed

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* Executive Secretariat, Conselho Nacional de Secretários de Saúde [National Council of Secretaries of Health] (CONASS).
with government resources. Nevertheless, this coverage is quite extensive and is estimated to account for 70% to 80% of all hospitalizations. Currently, however, with the expansion of private insurance and group medical plans, the proportion of coverage now tends to vary by location and type of procedure, with SUS deliveries and other lower-cost procedures accounting for about 65% of all cases (see Table 4 below) and high-cost/high-complexity procedures, more than 90%, since they are not covered by these plans.

Like most payment systems, the predecessors of SIH were developed and implemented with a view to streamlining costs. According to Oliveira and Teixeira, adoption of the Social Security model as a means of offering universal benefits, with expansion of the medical services provided by the Social Security System to include additional groups of the population, has ended up favoring the private service producer at the expense of the services provided by Social Security. The payment modality adopted for the purchase of contracted medical services – i.e., service units – allows private producers to overcharge while delivering less medical care, and this is threatening the financial stability of the institution.

Thus, the National Hospital Accounts Control and Payments System (SNCPCH) was introduced in 1977. As accounts were paid, the software checked each bill presented by the contract hospital, item by item, against a fee schedule that established a ceiling depending on the nosology or medical procedure in question. Excess charges were automatically disallowed, and the bills had to be submitted to the hospital for justification and to the National Social Security Health Care Administration (INAMPS) for a manual technical review. The system

† Data for the years prior to 1991 include only admissions to hospitals contracted by or that have agreements with Social Security; excluding not only hospital services offered by INAMPS directly by also public hospital services offered by other Ministries, including the Ministry of Health, at the state and municipal levels.
was based on the Hospital Admission Guide (GIH) and the Table of Medical Fees for Professional Services, where values are expressed in service units (US).\textsuperscript{2}

Although most of the system was computerized, it still required the intervention of specialized professionals to carry out a series of manual tasks, ranging from preparation of the hospitals’ invoices to analysis of the data by physician reviewers. Among the challenges that arose were problems related to the unpredictability of hospital billing, and therefore the inability of INAMPS to control medical expenditures, as well disagreements between the providers and INAMPS on amounts that exceeded the fee schedule,\textsuperscript{2} not to mention frequent charges of fraud.

**Conception, Purpose, and Implementation**

In 1979, a technical committee was appointed to develop a new system that would be less complex and more precise. Presented for review in October 1980, the proposed new version was called the Social Security Medical and Hospital Care System (SAMHPS). According to Levcovitz and Pereira,\textsuperscript{2} it called for the payment of a fixed fee per procedure, based on the concept of average global values assigned to the procedures that the hospital care network was in a position to perform. The main instruments on which the system was based were a table of procedures with values set by the MPAS for professional services, hospital services, supplies and medication, and diagnostic and therapeutic support services,\textsuperscript{*} and a standardized form, the Authorization for Hospitalization (AIH). According to these authors, the system was still a prospective-type financing model,\textsuperscript{†} based on estimates of average costs applied to a given unit (case or procedure) based on a

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\textsuperscript{*} At the end of the 1990s these variables were reduced to apply only to professional services, hospital services, and diagnostic and therapeutic support services.

\textsuperscript{†} According to these authors, the prospective model is based on the assumption that the demographic and social variables of patients are homogeneous, as are the characteristics of the diagnoses and treatments. Thus, patients can be grouped according to these characteristics.\textsuperscript{2}
predefined calculation. The financial value established for each procedure was calculated from an analysis of accounts presented by the hospitals over a six-month period, and the table of procedures was based on WHO’s International Classification of Procedures in Medicine (ICPM).

The proposed system was discussed extensively with entities representing the service providers and associations of medical specialists before the final version was decided on. In 1981, a pilot version of SAMHPS was introduced in the municipality of Curitiba and eventually extended to the entire state of Paraná. This two-year experiment allowed time for debugging and adjustments in preparation for full-scale operation. In 1982, in response to the need to contain medical expenses during a serious financial crisis in the Social Security System, the Plan for the Reorganization of Social Security Health Care – known as the CONASP plan – called for implementation of SAMHPS throughout the country. And indeed, it went into effect in 1983 for the private hospitals under contract or agreement with INAMPS.

In 1991, after implementation of the Unified Health System and transfer of INAMPS to the Ministry of Health, SAMHPS was renamed the Hospital Admission System of the SUS (SIH/SUS) without undergoing any significant modification in its data entry forms of document processing path, which continued to be handled by the original team, DATAPREV, although it was transferred to the Ministry of Health and renamed DATASUS. The most notable change that occurred at that time was extension of the system to include public municipal, state, and federal hospitals – in the latter case, only those hospitals administered indirectly and those under the responsibility of other ministries.

Up until that time, public hospitals had been financed by irregular transfers of funds from their “maintenance” institutions – the Ministries of Health,
Education, and Social Security, and the State and Municipal Health Secretariats – based on amounts allocated in their global budgets. In the 1980s, movements to streamline the delivery of services in the public health system* were calling for decentralization of the management of these hospitals. And indeed, the health care services of INAMPS were transferred to the State Health Secretariats (SES) under SUDS Agreement 01/1988, while still maintaining the same financial management system. Soon thereafter, the administrators of public hospitals, complaining of the lack of freedom to allocate resources based on actual needs and the irregularity of their funding, requested that the prerogatives accorded to private hospitals be extended to them and that they be given monthly compensation equivalent to the services they produced and be allowed to use these funds as best they saw fit.

It was pointed out that extension of the private hospital financing methodology to include the public hospitals would increased productivity and offer the opportunity to obtain detailed information about services produced. These arguments were taken into account in the final decision. The new arrangement, which included changing the name of the SIH to the Hospital Information System of the SUS, was formalized under Basic Operational Order 01/1991.

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* These movements were led by Integrated Health Actions (AIS), working in conjunction with the CONASP Plan, in 1983-1986, and the Unified and Decentralized Health Systems (SUDS), from the time of their establishment under Decree 94,657, of July 1987, until actual implementation of the SUS in 1991.
Table 1. Milestones in the Evolution of the Hospital Information System
(Based on Levcovitz and Pereira, 1993)

- 1976 – Creation of the National Social Security and Social Welfare System (SINPAS) and the National Social Security Health Care Administration (INAMPS).
- 1979 – Beginning of studies to develop proposal for the Social Security Medical and Hospital Care System/Authorization for Hospitalization (SAMHPS/AIH).
- 1981 – Pilot implementation of SAMHPS/AIH in Curitiba (Paraná).
- 1983 – Dissemination of the SAMHPS/AIH documents and manuals, application of the first Table de Procedures and Values and initiation of expansion throughout the country.
- 1985 – New AIH form issued with preprinted serial control numbers.
- 1986 – SAMHPS/AIH extended to include philanthropic and charitable entities under a specific agreement; differentiated Results Valuation Index (IVH) for philanthropic hospitals and differentiated classification for high-complexity/high-cost procedures.
- 1987 – SAMHPS/AIH extended to include university and teaching hospitals. Steps initiated to transfer management of system operations to the State Health Secretariats (SES), with processing and payment of providers remaining centralized in INAMPS.
- 1988 (May) – Incorporation of payment for medical and surgical orthotic and prosthetic devices (OPM) into SAMHPS/AIH, with direct payment to the manufacturer/importer.
- 1988 (October) – Approval of the new Federal Constitution, which establishes the Unified Health System (SUS).
- 1990 – INAMPS transferred from the Ministry of Social Security and Social Welfare to the Ministry of Health, placing its administrative structure under the Secretariat for Health Care (SAS); approval of Laws 8,080 and 8,142, which regulate the organization and financing mechanisms of the SUS.
- 1991 – Issuance of SAS Ministerial Directives 15,16,17,18,19 and 20, with the effect of approving Basic Operational Order 01/91, which regulates the systematic financing of the SUS; renaming SAMHPS/AIH as SIH/SUS; extending SIH/SUS to all public hospitals; creating the Incentive for the Development of Teaching and Research in Health (FIDEPS); discontinuing IVH for university hospitals; and changing the system for the payment of orthotic and prosthetic devices (OPM).
System Description

In the 15 years since 1991, the original essence of SAMHPS has survived in SIH, even though it has undergone a number of changes both as policies have taken on new directions and as progress has been made in information technology. A good example of the latter is the replacement of the printed version of the authorization for hospitalization form with an electronic version on diskette in 1992.

Up until that time, the Ministry of Health would send out pads of prenumbered copies of document to hospitals or the State and Municipal Health Secretariats in amounts equivalent to 10% of the resident population based on the census or an updated estimate calculated by the Brazilian Institute of Geography and Statistics (IBGE). After the change to electronic format, the ministry only had to distribute software to the units participating in the network, followed up with periodic issues of the number series to be used. The fact that the information was being returned on diskette in a form that could be consolidated at any level enabled DATASUS to create a series of applications in 1995 that gave decision-makers in the state and municipal spheres of the SUS a new way to control the “bills” presented by their service providers – namely, the Financial Management Program (PGF) and the AIH Management System (SGAIH).

Nevertheless, there continue to be three types of AIH: AIH 7, the prenumbered hardcopy form, printed out by those Health Secretariats that still use it; AIH 1, similar to AIH 7 but recorded on magnetic medium; and AIH 5. The first two include the control number corresponding to the authorization for hospitalization, identifying information about the patient, a record of all the medical procedures and diagnostic and therapeutic services provided to the patient, and the ICD diagnostic code. AIH 5 (the “continuity” AIH) is used for psychiatric
or chronic patients after they have used up the maximum number of hospitalization days allowed under AIH 7 or 1 (in these cases, 45 days). It bears the same control number issued initially to the patient, the original date of admission that appears on the AIH 7 or 1, * and identifying information about the patient, and gives information about the continuity of his/her treatment. Thus, the number of times the patient was admitted to an institution, municipio, or state will differ from the number of AIHs paid if only the AIH 1 and 7 are presented.

Both the magnetic and hardcopy versions of the AIH consist of five separate blocks, which have remained basically unchanged over the years:

- AIH identification block, which gives the control number and name of the agency in charge of the network that issued the AIH document (the State or Municipal Health Secretariat or the physical or legal person authorized thereby);

- block containing the name of the issuing agency, patient identification (name, address, postal code (CEP), age, sex, Social Security affiliation, procedure authorized, name and DFP of physicians responsible for issuing the document and for hospitalization of the patient, type of admission (whether elective or emergency), fields to be filled out in the event of a death due to external causes, † and date the form was issued;

- block reserved for the medical auditor (authorizer) to record any procedures of a special nature that require payment in excess of the amount(s) established in the table, such as use of the ICU and special supplies, or any decision to change the procedure originally authorized, which can only be entered by the clinical director of the hospital;

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† Information related to external causes was further specified under Ministry of Health Directive 142/SAS of November 1997, in essence creating a sixth block.
- professional services block, containing detailed information on the medical procedures, examinations, and treatments undergone by the patient, as well as, in the case of contracted private entities, the CPF or CGC of the person who did so (Code 7 for physicians and Code 8 for businesses); and

- block reserved for the hospital, including its identification code (the CGC was replaced by the CNES code when this survey was implemented) and fields for recording admission and discharge dates, reason for discharge or record of death if applicable, the ICD codes for the principal and secondary reasons for admission to the hospital, and record of the main procedure performed if different from the one recorded in the first block.

Since the documents are primarily used for accounting purposes, it is compulsory to fill in all the blocks. Checking for consistency, such as compatibility of age and sex with the procedure, among others, was done manually at first and can now be done automatically at the time of data entry at all three levels of government and even at the level of the health care establishment. Other more basic types of checking, such as the comparison of procedures performed with the installed capacity and with specific credentials, were and continue to be done through the use of an inventory of health care establishments which has been an integral part of the system from the outset.

The Hospital Inventory Form (FCH), which was eliminated when the National Inventory of Health Establishments (SCNES)* went into effect in 2001, was extremely simple, especially when compared with other inventory forms,

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basically consisting of a unit identification module (CGC, name of the institution, name and CGC of the entity that supports it, legal nature, address, and banking information) and general characteristics, including number of beds per specialty, those available for use by the SUS, if necessary, and whether or not the institution has the credentials to perform high-complexity/high-cost procedures (SIPACS). Previously, these data had always been cross-checked manually by the health system manager.

The new National Inventory of Health Establishments (CNES) first emerged in 2000 as a proposal for the unification and replacement of several inventories being used by the national information systems under the Ministry of Health, and this unification and replacement was achieved upon effective implementation of CNES in August 2003. CNES is configured as an independent information system and includes data on the physical plant, human resources, equipment, diagnostic and therapeutic support services, and both outpatient and in-patient services provided by the health units. It covers all hospitals in the country, all outpatient services under the SUS, and even a large percentage of the outpatient services not associated with the SUS. In addition, it encompasses the database corresponding to the National Health Card carried by professionals who perform procedures and/or services under the SUS, each of whom is identified with a unique number, regardless of the location of his or her practice. Input of the system’s data is the responsibility of state and municipal health managers, and consequently there are significant variations in the quality of information provided, despite the length time it has been in operation.

* In addition to the SIH, the survey information was used by the Outpatient Information System (SIA), the Mortality Information System (SIM), the Live Birth Information System (SINASC), and the System for the Reporting of Notifiable Conditions (SINAN).
Even though decentralization of the health system has been gradually taking place since the end of the 1980s, the process gained momentum starting in 1994, which was also the time when the diskette version of the AIH was being implemented more effectively. At that time, the 1993 Basic Operating Regulations (NOB 1/1993) were in effect and called for direct automatic transfer of resources from the federal level to the other government spheres once they had earned managerial status. The states and municipalities that were considered to have achieved semi-full managerial status received all the resources to which they were entitled and took responsibility for the payment of their service providers, even though SIH processing continued to be centralized with DATASUS in the Ministry of Health.

Up until the end of the 1990s, the numerical series of AIHs were being distributed on a monthly basis to the State Health Secretariats based on the quantity stipulated for the state, which since the beginning of 1995 has been equivalent to 9%* of the resident population (estimated by IBGE) for the year, or 1/12 of 9% of the population for the month.

Following establishment of a funding cap on hospitalizations,† this limit was eventually relaxed at the state level but continued to be imposed at the national level. Either way, the State Health Secretariats were responsible for “redistributing” the funds, since the amount allocated for each municipality was determined, according to the 1996 Basic Operating Regulations, by the program budget previously agreed upon under Integrated Partnership Programming (PPI). The AIH numbered series were valid for four months – later reduced to three

* Prior to 1995, this figure was equivalent to about 10% of the resident population in a given year. The change was made because a large number of hospitalizations were observed in which, despite the severity of the case indicated by the diagnosis, the patient was being discharged in less than two days. This procedure was accompanied by inclusion of a series of procedures which existing technology was now allowing to be performed on a same-day basis in the Table of Procedures of the Outpatient Information System (SIA/SUS).
† SUS Basic Operating Regulations (NOB 1/1996).
months – after which they were no longer accepted by the system. This timing allowed for seasonal fluctuations in states where the seasonal occurrence of diseases has a significant effect on the number of hospital admissions.

The decision to release the numbers for use by the hospitals was and continues to be in the hands of the issuing agency. The numbers are assigned on a case-by-case basis, intended for specific patients upon presentation of a physician’s order for hospitalization that specifies the reason for each admission. The authorization that is issued includes, in addition to the control number (consisting of 10 digits as of 2006), information identifying the patient and the procedure authorized.* In cases of emergency in which the patient is hospitalized following care given in emergency services, the hospitals have 72 hours in which to request the authorization.

The hospitals enter the data regarding the hospitalization following the patient’s discharge, except in the case of long stays. At the end of the month, the data on the patients attended are sent to the Municipal Health Secretariat on diskette, CD-ROM, by e-mail, or by regular mail, as long as the mode of transmission is guaranteed to be secure. Once received at the Health Secretariat, the information is checked, any irregularities in the AIH are flagged, and the comments are sent back to the originating hospital and also to the SES, where the case is reviewed once again, the two sets of comments are consolidated, and those charges for which payment was authorized are then passed on to the Ministry of Health via the Internet.

* Specifically-designated individuals – for example, clinical directors – can authorize special procedures, a change from the authorized procedure, extension of the stay, use of the ICU, allowance for a companion, or any other expense that would exceed the initially authorized admission. They sign their name and CPF number in the data field corresponding to the Field Auditor Physician.
Cases that come under partnership agreements between managers in the three spheres of government follow a slightly different path. For cases in which the SES is the hospital’s managing agency, the information does not go through the SMS, and similarly, the Municipal Health Secretariats that have achieved semi-full
(NOB 01/93) or full managerial status with regard to the System (NOB/SUS 01/96), have been instructed to send their data directly to the Ministry of Health.

At DATASUS in the Ministry of Health the data are checked once again before preparing the bank tape, at which point values are assigned to the procedures performed and the items are consolidated according to service provider, with calculation of any pertinent discounts. The final payment order is issued by those states and municipalities that have managerial status to issue it, and otherwise by the Ministry of Health. In 2004, when all the states became full participants in management of the system, relationships with the service providers became the exclusive responsibility of the SESs and SMSs.

As already explained, SIH/SUS also had a module for checking entries against a hospital’s inventory. Every health unit had a Hospital Inventory Form (FCH), which it had to fill out in order to be accredited to the system, and the card was resubmitted whenever there was a change in the unit’s inventory of assets or a relevant managerial decision was taken. From the hospital, the form was sent to the agency responsible for managing the system, either the SES or the SMS, which certified the accuracy of the information supplied and made arrangements for the updates to be included in the national inventory. Only at that point was the hospital entitled to present an AIH for payment. Although the FCH was later replaced by information from the SCNES, the general concept in terms of checking against the hospital’s inventory remains the same.

In addition to SCNES, Lucas⁵ points out that the SIH needs to interface either directly or indirectly with a growing number of other information systems, as well as undertakings of the managing agencies, which it affects or is affected by. The information systems include the Inventory of Users (CNS), Integrated Partnership Programming (SIS/PPI), various regulatory systems (e.g., SISREG),

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and the federal-level Integrated Financial Administration System (SIAFI). As for other activities, the SIH is involved in programming the procedures performed by each establishment, taking into account the parameters of supply and demand, and in the monitoring, evaluation, and control of production. To a large extent, the temporal and geographic differences found in the SIH national database reflect the orchestration of all these factors by the responsible personnel in the three spheres of government. Typically, the northern and northeastern regions tend to have the most problems, and there can also be differences between the capital cities and the interior, and between one hospital and another even in the same municipality.

Since the mid-1990s, these databases, with their information on patient care, amounts paid, and inventory data on the health units, have been made widely available by DATASUS via the Internet, through the Ministry of Health Bulletin Board System, and, for a few years now, on CD-ROMs that are distributed every month (data on monthly production) and once a year (consolidated annual production). There are two kinds of files: one type shows the movement of all the data most used by managers and researchers, while the other, shorter version does not include data on professional services. Progress in information technology has made it increasingly easy to use and process the system’s data. Since 1995, DATASUS has been developing and refining tabulation tools for analyzing its data, starting with the DOS program TAB (no longer in use), followed by TabWin for Windows, and more recently TabNet for use on the Internet.*

It can be said that the information provided by the system basically continues to be the same despite a number of changes in the SIH over the years. Some of these changes have been minor, such as updating the payments schedule,

* TAB-DOS, developed in 1994, was disseminated on a CD of the Hospital Admissions Authorization System (SIH/SUS), a CD of the Mortality Information System (SIM), and a CD of the Outpatient Care Movement System (SIA/SUS). Starting in 1996, the Windows version, TabWin, was also distributed on CD-ROM. TabNet was made available to the general public starting in 1997.
the addition or deletion of procedures, and additions, deletions, and changes in accreditation, but others have been more extensive, such as the change in the collection of inventory data on the health care units.

The authorizations for specific procedures are constantly changing. Used originally as a tool for cost containment and control, more recently the SIH has become a mechanism for shaping policy (for example, in relation to quality of the procedures, to the extent that terms and conditions are established for granting the authorizations) and organizing the health care networks. Today there are 28 categories of special services* accepted by the SCNES, each corresponding to a different type of establishment: elder care, treatment of severe obesity, hearing health, oral health, eye care, mental health, workers’ health, cardiovascular health, long-term care, chronic pain, STD/AIDS, same-day hospital, home care, maternal and child care, nephrology, neurology, oncology, treatment of osteogenesis imperfecta, family planning, pneumology, burn center, rehabilitation, nutritional therapy, organ transplantation, traumatology and orthopedics, intensive care, urgent care, intermediate neonatal care, and video surgery. From time to time the tables used for cross-checking compatibility between the institution’s type of qualification and the procedures allowed are updated on the basis of directives.†

In 2004 a Ministry of Health proposal to decentralize SIH data processing‡ was presented for public comment and triggered intense discussion among representatives of the other spheres of government. The National Council of Secretaries of Health (CONASS), in its Technical Note 36/2004,6 clarified that full development of the system will be accomplished progressively, on a modular basis, incorporating some of the modules already used by the states and municipios, such

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* Directive 414/SAS of 11 August 2005. Before their use was more restricted, as they were considered components of the High-Complexity Procedures Information System (SIPAC).
† The last update was Directive 683/SAS of 12 December 2005.
as the Authorizing Module* and the Financial Module.† These modules are configured as independent applications, although they are fully compatible with one another. According to this Technical Note, the main differences between the proposed version, SIHD, and SIH, aside from decentralization of the process, were the following:

- The data field for the Medical Auditor will be increased from five to 10 lines to save having to issue a new AIH because of lack of sufficient space. Special procedures are introduced in a new field: Professional Acts and Other Procedures.
- AIHs that include as a diagnosis any disease that is required to be reported at the national or state level will be blocked and a report will be generated and sent to the epidemiological surveillance area for checking.
- The states shall be responsible for generating payment vouchers and other financial tasks, and for this purpose they shall be allowed to use the system that is available for their corresponding administrative area (SIAFEN, etc.), or else a module provided by DATASUS (compatible with the National Health Fund). DATASUS will no longer send payment vouchers to physical persons or establishments.

In 2005, upon completion of the first version of the Production Processing Module of the new decentralized system, or SIHD, as it came to be called, a pilot experiment was undertaken with the participation of four states and four

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* Authorizing Module – Addressed to the AIH and APAC issuing agencies identified by the manager as responsible for surveying the issuing agency, its authorizers, the numbered series, and the establishments under his management, supply the authorization number, replace the written/printed form, issue a receipt of the authorization, and compare the procedures authorized against those actually performed. This application was made available and standardized under Joint SE/SAS Directive 23 of 21 May 2004.
† Financial Module (SGIF ssoftware SGIF) – Receives the output of the Production Module and enables managers to apply discounts that are owed to their providers and issue a breakdown of the payment with gross amounts, discounts, and net amounts to be credited. Already developed, it can be used in states and municipios that do not have their own financial system.
municipalities. Effective implementation throughout the national territory was projected to take place in April 2006, even though most of the states and municipalities fully qualified to use the system had not successfully tested it. Once the information has been processed in the SESs and SMSs, it is to be sent to DATASUS (Receiving Module), which will continue to be responsible for its integration into the national database and for its dissemination.

Table 2. Major Milestones for the SIH (adapted from Gomes RM⁷)

<table>
<thead>
<tr>
<th>Year</th>
<th>Event Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1991</td>
<td>SAMHPS renamed SIH/SUS without any change in its characteristics: AIH is a prenumbered form; data entry, processing, and payment information centralized at the DATASUS level.</td>
</tr>
<tr>
<td>1992/94</td>
<td>AIH made available on diskette; data entry to be decentralized; State and Municipal Health Secretariats given new evaluation tools.</td>
</tr>
<tr>
<td>2001/03</td>
<td>Implementation of the National Inventory of Health Establishments; decentralization of the service provider inventory, superseding the FCH, and the SES and SMS are made responsible for its regular updating and maintenance.</td>
</tr>
<tr>
<td>2005/06</td>
<td>Decentralization of SIH data processing and the Financial Module.</td>
</tr>
</tbody>
</table>

Another change to be introduced simultaneously with the implementation of SIHD is a revision in the numbering of the AIH. Provision has been made, effective January 2006, for the number to be extended from 10 to 13 digits and to be generated by the State Health Secretariats. * A new, totally reorganized Table of Procedures is being prepared and will take into account both in-hospital and outpatient care as a step toward the goal of having a comprehensive view of the

disease prevention and treatment processes and a better gauge of outcomes from the various levels of complexity in the health care networks. It is expected to incorporate the new table by January 2007.

Evaluation of the System

One of the most frequent criticisms of the SIH is the quality of the data that it provides, stemming from fraud and manipulation on the part of the service providers. Actually, this is more a problem of the health system as a whole and not just the information system. According to Travassos, information systems have the potential of being more efficient at detecting fraudulent manipulation of hospital information. Much of the fraud in the Brazilian hospital system that has been chronicled in the country’s newspapers has been detected by using information available in the SIH/SUS. What persists is the ongoing inability of the government to implement more effective regulatory measures to guarantee the quality of its information and the care provided.

Every year, more changes are made in the system in response to feedback, with a view to improving physical and financial control, which at the same time will improve the quality of the data. Some of the changes made up through 1995 are listed in Table 1, and Annex III gives an update as of 2005. Studies carried out in the 1990s in Rio de Janeiro (RJ) and Maringá (Paraná) concluded that the information corresponding to a series of variables and selected criteria was reliable, and they even noted a downward trend in the frequency of hospitalizations for which the data were questionable. As the logic incorporated into the system has become more sophisticated in recent years, several other criticisms have been addressed as well, since most of the problems arise at the point of data entry. An
example is the use of tables to check compatibility between procedures and diagnoses starting in 2002.*

Although these steps have helped to improve morbidity coding based on the ICD, some issues still remain in this area. Again according to Travassos, the most serious problems associated with the quality of diagnostic information have to do with the precarious nature of the notes entered in the patient charts – the primary source of data for filling in the AIH form – and the coding process. This task is done in most hospitals by administrative personnel who have no training in how to do it.

An example is the 75 admissions in 1997 with a diagnosis of poliomyelitis, when the last confirmed case occurred in 1989 and WHO certified that polio was eradicated in Brazil in 1994. At the same time, it should be pointed out that the nature of this database has certain limitations: it consists of invoices for services provided, and these invoices cannot be amended once payment has been made. Unlike mortality and disease reporting systems, data in the SIH/SUS cannot be corrected, even after they have been investigated and errors in data entry or coding have been confirmed.

Nevertheless, Bittencourt et al., in their review of SIH applications in collective health, found a number of studies that used its information, or attempted to assess the use thereof, for the strengthening of epidemiological surveillance. Among the reasons cited for using this source were: the large volume of data, timeliness of the information, easy access, recognized shortcomings of statistics based on epidemiological reporting, and the need to expand strategies and practices for combating diseases. SIH information was used, for example, in a project to determine the disease burden in Brazil, in order to calculate the indicator

Disability-Adjusted Years of Life (DALY) lost due to a large number of conditions, diseases, and sequelae.9

Table 3. AIHs Rejected by Checking System and Not Paid, Brazil, 1995.

<table>
<thead>
<tr>
<th>Reason</th>
<th>No. AIHs rejected and not paid</th>
</tr>
</thead>
<tbody>
<tr>
<td>Charge presented twice</td>
<td>404,020</td>
</tr>
<tr>
<td>Length of patient stay incompatible with procedure</td>
<td>178,665</td>
</tr>
<tr>
<td>Charge submitted to the MS and semi-qualified municipios</td>
<td>78,886</td>
</tr>
<tr>
<td>Hospital not accredited under the SUS</td>
<td>61,413</td>
</tr>
<tr>
<td>Procedure charged for different from the one authorized</td>
<td>47,556</td>
</tr>
<tr>
<td>AIH number invalid or expired</td>
<td>40,246</td>
</tr>
<tr>
<td>Physician not accredited to provide care under SUS</td>
<td>37,733</td>
</tr>
<tr>
<td>Use of nonexistent beds</td>
<td>34,488</td>
</tr>
<tr>
<td>Admission without attending physician and/or without a description of the procedure</td>
<td>20,870</td>
</tr>
<tr>
<td>Hospital not authorized for high-complexity procedures</td>
<td>17,470</td>
</tr>
<tr>
<td>Use of supplies incompatible with procedure or excessive use of supplies</td>
<td>12,576</td>
</tr>
<tr>
<td>Inconsistency of admission/discharge dates</td>
<td>12,374</td>
</tr>
<tr>
<td>Nonexistent ICU beds or unauthorized use thereof</td>
<td>12,124</td>
</tr>
<tr>
<td>Procedure/diagnosis incompatible with sex</td>
<td>3,920</td>
</tr>
<tr>
<td>Improper charge for multiple surgeries</td>
<td>1,977</td>
</tr>
<tr>
<td>Rejections for 119 other reasons</td>
<td>65,649</td>
</tr>
<tr>
<td>TOTAL</td>
<td>1,029,940</td>
</tr>
</tbody>
</table>

Source: DATASUS / FNS / MS (1996).8
According to these authors, most of the published studies were undertaken to validate information generated by SIM, SINAN, and SINASC. With regard to SINASC and SIM, some of the studies pointed out that using the SIH could be a good strategy for capturing live births and finding clues in the investigation of maternal deaths in low-coverage areas. In the comparisons with SINAN, it was found that the SIH/SUS was not very helpful when it came to monitoring yellow fever, adult measles, tuberculous meningitis, or hepatitis A and B, or in yielding data that could be used in filling in the epidemiologic surveillance form in the case of hospital infections. On the other hand, the findings showed that the SIH/SUS offers great potential for monitoring pulmonary tuberculosis, leprosy, meningococcal meningitis, dengue, both visceral and cutaneous leishmaniasis, vaccine-preventable diseases, cholera, typhoid fever, and leptospirosis. An
important limitation to its use in epidemiology is that the condition being studied may not lead to hospitalization.

Table 4. Differences between Expected Number of Live Births, Totals Recorded by SINASC, and Deliveries Recorded by the SIH/SUS (by Place of Residence), Brazil and Regions, 2003

<table>
<thead>
<tr>
<th>Region</th>
<th>Estimated</th>
<th>SINASC</th>
<th>SIH/SUS</th>
<th>% SIH / estimated</th>
<th>% SIH / SINASC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern</td>
<td>387,136</td>
<td>311,335</td>
<td>245,460</td>
<td>63.40</td>
<td>78.84</td>
</tr>
<tr>
<td>Northeastern</td>
<td>1,153,740</td>
<td>930,145</td>
<td>793,269</td>
<td>68.76</td>
<td>85.28</td>
</tr>
<tr>
<td>Southeastern</td>
<td>1,325,029</td>
<td>1,181,131</td>
<td>784,930</td>
<td>59.24</td>
<td>66.46</td>
</tr>
<tr>
<td>Southern</td>
<td>441,208</td>
<td>389,675</td>
<td>272,546</td>
<td>61.77</td>
<td>69.94</td>
</tr>
<tr>
<td>Western Central</td>
<td>239,192</td>
<td>225,965</td>
<td>164,133</td>
<td>68.62</td>
<td>72.64</td>
</tr>
<tr>
<td>Brazil</td>
<td>3,544,390</td>
<td>3,038,251</td>
<td>2,261,513</td>
<td>63.81</td>
<td>74.43</td>
</tr>
</tbody>
</table>


Another limitation of the SIH is its coverage, estimated in 1998 at approximately 75% of actual hospitalizations, with variations between one state and another ranging from 57.3% in São Paulo to 94.6% in Roraima. It was possible to arrive at an up-to-date estimate of SIH coverage by comparing the number of normal and cesarean deliveries in its database with the estimates made by IBGE and also with the data provided by SINASC. The resulting figures, presented in Table 4, show that the system’s coverage in 2003 was about 65% of low- and average-complexity delivery hospitalizations in the country, ranging from 60% in the southeastern region to 70% in the northeastern region. Although it’s not possible to do a similar exercise for high-complexity procedures, given their high cost and limited coverage by private health insurance plans, it may be estimated that 90% of them are performed by the SUS, and would thus be found in the SIH database.
There are other issues that affect the coverage, and ultimately the quality, of SIH/SUS information, as well:

- The system does not identify readmissions and transfers from other hospitals, which means that the same patient could be counted twice or three times.

- Since the main purpose of the system is to pay for services with federal funds, its limitation in terms of the number of AIHs presented at the state level and the stipulated funding cap ceiling have a distinct impact on the number and nature of documents that end up being presented (see Table 3). Taking these limitations into account (a quantitative limitation equivalent to 9% of the resident population during the year and the maximum amount that can be spent, by state, as specified in the corresponding ministerial directives), managers at the state and municipal levels opt in most cases to charge for more expensive procedures and absorb the cost of the less expensive ones.

- The number of documents and the spending profile are largely dictated by the installed capacity and the profile of the service network in the local area, since it is impossible to pay for procedures for which there are no services available to perform them.

- There is a possibility of underregistration in the case of hospitals that work with a global budget, a situation that has been aggravated by the policy of the Ministry of Health to encourage contracts with teaching or philanthropic hospitals or very small hospitals, whose annual budgets are defined by their degree of insertion in the services network and by their performance in attaining specific goals.
The effect that policies can have on the system\textsuperscript{15} is illustrated by the decision to encourage a reduction in the proportion of cesarean deliveries in Brazil. Ministry of Health Directive 2,816/GM of 29 August 1998 limited the number of cesarean deliveries that would be paid for based on the proportion of such deliveries relative to all deliveries performed by each hospital within the system. From the figures in Table 5, it would appear that this policy met with quick success. Table 6, however, suggests a different scenario.
Table 5. Comparison between Proportions of Normal and Cesarean Deliveries Recorded by SIH/SUS in 1997 and 1999

<table>
<thead>
<tr>
<th>Region</th>
<th>1997</th>
<th>1999</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Normal deliveries</td>
<td>%</td>
</tr>
<tr>
<td>Northern</td>
<td>170,111</td>
<td>73.98</td>
</tr>
<tr>
<td>Northeastern</td>
<td>695,977</td>
<td>78.63</td>
</tr>
<tr>
<td>Southeastern</td>
<td>572,275</td>
<td>60.91</td>
</tr>
<tr>
<td>Southern</td>
<td>231,191</td>
<td>63.29</td>
</tr>
<tr>
<td>Western Central</td>
<td>106,450</td>
<td>57.48</td>
</tr>
<tr>
<td>Brazil</td>
<td>1,849,296</td>
<td>68.03</td>
</tr>
</tbody>
</table>


Table 6. Differences in Number of Normal and Cesarean Deliveries as Reported by SINASC and SIH/SUS (by Place of Residence), Brazil and Regions, 2003

<table>
<thead>
<tr>
<th>Region</th>
<th>SINASC</th>
<th>SIH/SUS</th>
<th>% SIH / SINASC</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Normal</td>
<td>Cesarean</td>
<td>Normal</td>
</tr>
<tr>
<td>Northern</td>
<td>219,936</td>
<td>91,125</td>
<td>188,261</td>
</tr>
<tr>
<td>Northeastern</td>
<td>661,840</td>
<td>265,108</td>
<td>620,745</td>
</tr>
<tr>
<td>Southeastern</td>
<td>600,549</td>
<td>574,959</td>
<td>544,053</td>
</tr>
<tr>
<td>Southern</td>
<td>210,358</td>
<td>179,193</td>
<td>193,190</td>
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<tr>
<td>Western Central</td>
<td>122,304</td>
<td>103,457</td>
<td>117,516</td>
</tr>
<tr>
<td>Brazil</td>
<td>1,814,987</td>
<td>1,213,842</td>
<td>1,664,680</td>
</tr>
<tr>
<td>%</td>
<td>59.92</td>
<td><strong>40.08</strong></td>
<td>73.61</td>
</tr>
</tbody>
</table>


In 2003, the percentages calculated on the basis of SIH data continued to remain within the limits specified in Ministerial Directive 2,816/98 et seq., which allowed the limit to be relaxed in the case of high-risk pregnancies. The
percentages gleaned from the SINASC data, and the comparison between the two, tell another story. It is highly unlikely that the practices financed by the public system are so different from those followed in the other hospitals that the SIH/SUS hospitals end up being responsible for 92% of the normal deliveries in the country, especially considering the coverage of the two systems (Table 3). Two hypotheses have been suggested to account for these numbers: either the procedure performed is intentionally misrepresented on the record by the service providers, or the cases to be recorded and paid for with federal funds are preselected by the managers.

This example shows how the data on hospitalizations can be compared with those in other databases to assess health sector public policies. Another frequent use of the SIH information is for appraisal of the performance of services in terms of effectiveness, adequacy, access, and efficiency. Because hospital deaths are well defined and correctly diagnosed, this has been the variable used most often in indicators that measure effectiveness. According to Bittencourt et al., even though there are conceptual and methodological aspects that need to be refined if hospital deaths are to be used as the indicator of quality of the care provided, studies of varying levels of analytical sophistication indicate that monitoring hospital deaths can be a discriminating criterion. For example, Guerra et al. detected a high occurrence of deaths in a elderly care clinic based on an analysis of gross monthly mortality rates* over time for both the clinic and hospitals with similar characteristics.

The absence of important clinical variables and details on the medical procedures performed limits the usefulness of the SIH in properly evaluating the treatment provided to patients with different conditions. However, it is possible to select a sample population of patients admitted for specific morbid conditions,

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* Monthly hospital mortality rate, calculated by dividing the number of deaths recorded on the AIHs during the month in question by the hospital’s total number of admissions during the same period (x 1,000).
which would allow for a more thorough analysis based on consulting the patient charts. In the articles cited by Bittencout et al., it was necessary to use sophisticated methodologies to evaluate SIH-based access. More simplified approaches have been attempted by technicians in the managing agencies using parameters established by the Ministry of Health, the SES, and/or the SMS to measure the quality of care.

**Table 7. Comparison between Costs for Procedures and Fees Established in the SIH/SUS Table (in R$ 1.00)**

<table>
<thead>
<tr>
<th>Procedure</th>
<th>Cost</th>
<th>SIH/SUS Table</th>
<th>% Table/Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Liver transplant</td>
<td>15,609.21</td>
<td>51,899.46</td>
<td>332.49</td>
</tr>
<tr>
<td>Kidney transplant - recipient (live donor)</td>
<td>5,533.75</td>
<td>14,828.17</td>
<td>267.96</td>
</tr>
<tr>
<td>Heart transplant</td>
<td>11,842.43</td>
<td>22,242.48</td>
<td>187.82</td>
</tr>
<tr>
<td>Surgical correction of congenital cardiopathy</td>
<td>3,751.19</td>
<td>4,813.35</td>
<td>128.32</td>
</tr>
<tr>
<td>Treatment of AIDS</td>
<td>2,537.53</td>
<td>1,407.39</td>
<td>55.46</td>
</tr>
<tr>
<td>Appendectomy</td>
<td>968.84</td>
<td>302.83</td>
<td>31.26</td>
</tr>
<tr>
<td>Cholecystectomy</td>
<td>1,948.67</td>
<td>455.04</td>
<td>23.35</td>
</tr>
<tr>
<td>Hypertensive crisis</td>
<td>662.52</td>
<td>120.05</td>
<td>18.12</td>
</tr>
</tbody>
</table>

Source: Extracted from the PLANISA study.

In efficiency evaluations, the SIH values of hospitalizations are frequently used as “costs,” even though they are actually expenditures. A study conducted by PLANISA in 2002 revealed large disparities between the real costs of procedures and those established in the SIH Table (Table 7), with the high-complexity procedures better remunerated that others. Of all the information provided by the system, expenditures such as care provided by the SUS are probably the ones that are monitored and analyzed the most by technicians in the health secretariats and the Ministry of Health, who examine them in terms of the services offered and
their utilization by age and sex in selected cuts of the area being studied. * Other indicators that are monitored include average length of stay in general and for specific causes; proportion of hospitalizations by selected cause or procedure; utilization of the ICU; and rate and index of use by age group (and/or sex, in general and by cause). 8 In most of these cases, allowance needs to be made for distortions in the services network (e.g., predominance of psychiatric institutions in certain municipalities).

**Possibilities and Future Outlook**

In general, the SIH is well accepted by service providers, technicians, and decision-makers in the managing agencies of the three spheres of government, in addition to being used by researchers and academics. There has been an impressive increase in the use of SIH information in the last ten years, largely attributable to development of the applications for tabulating and analyzing the data and to decentralization of the health system itself. At the same time, however, it is true that the SIH has not fully realized its potential because of some of the same problems that affect most if not all the health information systems in Brazil, most notably those having to do with the information infrastructure and culture.

- **Information and communication infrastructure** — Even though the situation is improving, in many parts of the country the idea still prevails that financial resources allocated for health should not be spent on computers. This perception is being overcome, not only thanks to the effective reduction in the cost of equipment and software but also because there is greater understanding of the benefits that can be achieved by using situation analyses as a basis for planning actions. Nevertheless, most of the

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* When TabNet is used, the breakdown can be by state, municipality, region, health region, microregion, or metropolitan region. At the local level, managers who have their own databases can designate a territory based on postal codes (CEP).
health care units and Municipal Health Secretariats do not have adequate equipment to meet their needs. The communication network is also deficient: in many municipios Internet access is only available via long distance dial-up.

- **Information culture** — Even though there has been notable improvement in understanding the importance of making use of information, little attention is being paid to the quality of the data at the time they are collected and entered in the record. This problem is probably related to the distance that remains between the professionals responsible for this activity and those who use the information for decision-making. Moreover, both the capacity to analyze the information in the three spheres of government, especially in the smaller municipalities, and the utilization of these analyses in decision-making may still be regarded as insufficient or unsatisfactory.

Despite these difficulties, the perception that the SIH plays an important role in the organization of the SUS itself has led to many overhauls and revisions of the system aimed at guaranteeing the availability of this essential information. With the new health sector regulations that will enter into effect following implementation of the management pacts for decentralized data processing, the SIH is about to face one of the most challenging periods in its long history.

In essence, the management pacts, announced in a ministerial directive in February 2006, models a health system based on mutual responsibility: both the managing agencies and the service-providing establishments assume responsibility for predefined health outcomes, but they are no longer subject to the imperative of monitoring the processes. There has been a recent trend to enter into target-based contracts with the hospitals in which remuneration is dissociated from the production of services. On the one hand, this may mean that the SIH, freed of its
original function, will be less subject to intentional omissions or altered data (fraudulent or not) in response to normative guidelines. On the other hand, recording the data may come to be seen as a nonessential exercise and adapting the establishments to use new versions of the system as an unnecessary expense. Other risks have to do with the management of entities at the subnational level, both with regard to capacity to handle the processing and in terms of commitment to maintain the databases and make timely submissions to the federal level.

Looking at the situation from a more optimistic perspective, it is possible that SIH will end up fully achieving its fervently sought goal of supplying reliable information. The fact is that several key initiatives are in line with this scenario.

- In 1999, a Ministry of Health directive* instructed all public and private hospital units located in the national territory, whether or not they were part of the SUS, to report to the Ministry of Health through their local SUS managing agency – the State Health Secretariat (SES) or Municipal Health Secretariat (SMS) – the occurrence of all hospitalizations regardless of the source of remuneration for services provided. In 2005, † the National Supplementary Health Agency (ANS), which is responsible for regulation of private health plans, issued a normative resolution introducing use of the Communication of Hospital Admission (CIH) to monitor care provided to beneficiaries of private health care plans. In practice, given the similarity between the AIH and the CIH, and because DATASUS is responsible for consolidating the databases for both instruments, this means that database coverage will be expanded to include all private hospitals that provide services under private plans and do not participate in the SUS.

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† Normative Resolution – RN 113 of 13 October 2005.
The Ministry of Health has taken important steps in the last five years toward integrating the various national information systems under its management. Implementation of the National Inventory of Health Establishments (CNES) and unification of the Table of Hospital and Outpatient Procedures mentioned above are examples of this effort. Other more technical initiatives currently under way include the establishment of parameters for communicating between systems and the creation of a repository of SUS tables. In addition, there is also the initiative to develop a national list of users and their basic information through the National Health Card (CNS). This system foresees assigning a unique number to each individual, which will be linked to his or her identifying data, to be used by all the health information systems. Among other advantages, its full implementation would make it possible to know the real extent of SUS coverage, have a profile of users, identify the bottlenecks in the service networks, and capture intermunicipal and interstate referrals. It is imperative that this project be carried forward and have the support of the majority of state and municipal managers.

It is possible to imagine a time in the future when the SIH is more than just a module in a truly “Unified Health Information System.” However, this vision will not become a reality overnight; it involves negotiation and building political consensus, and it means that policies will have to be compatible with practical technical possibilities. Until all this happens, it is essential to strive for constant improvement of the SIH/SUS and the maintenance of “internal consistency” and “congruity with current knowledge,” the importance of which are emphasized by Bittencourt et al. 10

* The number is already required for some of the SIH procedures, pursuant to Ministry of Health Directive 174/SAS of 14 May 2004.
Chapter References


3 Travassos C. O Sistema de Informações Hospitalares do Sistema Único de Saúde - SIH/SUS. Mimeo (s.l.). 1996.


12 Guerra HL, Barreto, SM, Uchôa E, Firmo JOA, Costa MFML. A morte de idosos na Clínica Santa Genoveva, Rio de Janeiro: um excesso de


**LAUDO PARA SOLICITAÇÃO DE INTERNAÇÃO AUTORIZAÇÃO HOSPITALAR**

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### LAUDO TÉCNICO E JUSTIFICATIVA DA INTERNAÇÃO

**TÉCNICOS QUE REALIZARAM A INTERNAÇÃO**

**RESULTADOS DE EXAMES DIAGNÓSTICOS (RESULTADOS DE EXAMES REALIZADOS):**

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**DIAGNÓSTICO INICIAL**

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### PROCEDIMENTO SOLTICITADO

**INSERÇÃO DE PROCEDIMENTO E TECNÓLOGIA**

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<th>DESCRIÇÃO</th>
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**INSERÇÃO DE PROCEDIMENTO E TECNÓLOGIA**

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**FREMENCER EM CASO DE CADERAS EXternas PACIENTES OU VIOLENCIAS**

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### AUTO AÇÃO

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### Observações

- **Assinatura**
- **Data**
- **Local**

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## ANEXO II

### LAUDO PARA SOLICITAÇÃO/AUTORIZAÇÃO DE PROCEDIMENTOS ESPECIAIS E OU MUDANÇA DE PROCEDIMENTO DE INTERNAÇÃO HOSPITALAR

### IDENTIFICAÇÃO DO ESTabelecimento

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### IDENTIFICAÇÃO DO PACIENTE

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### MODIFICAÇÃO DE PROCEDIMENTO

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### PROCEDIMENTOS ESPECIAIS

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### AUTORIZAÇÃO

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### IDENTIFICAÇÃO DO PROFISSIONAL SOLICITANTE

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### AUTORIZAÇÃO

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### ASSINATURA E CARIMBO

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### Reasons for Blocking or Canceling an AIH

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<tr>
<th>Reason Number</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>01</td>
<td>Dupl. Readmission, same ICD diagnosis &lt; 3 days</td>
</tr>
<tr>
<td>02</td>
<td>Dupl. Admission with overlapping time periods</td>
</tr>
<tr>
<td>03</td>
<td>Surgery related to initial clinical treatment</td>
</tr>
<tr>
<td>04</td>
<td>Clinical procedure stemming from or consequent to initial surgery</td>
</tr>
<tr>
<td>05</td>
<td>Dupl. Admission during same period while under Psychiatry</td>
</tr>
<tr>
<td>06</td>
<td>Dupl. Improper administrative discharge (&gt; 5 sp. procedures)</td>
</tr>
<tr>
<td>07</td>
<td>Obstetric procedure related to S/ average stay in initial procedure</td>
</tr>
<tr>
<td>08</td>
<td>Procedure not authorized</td>
</tr>
<tr>
<td>09</td>
<td>Dupl. Surgery or obstetric w/treatment /related reasons or S/ MP used up</td>
</tr>
<tr>
<td>10</td>
<td>Dupl. Surgery following clinical treatment, half of MP not used</td>
</tr>
<tr>
<td>11</td>
<td>Dupl. Mutually exclusive surgeries</td>
</tr>
<tr>
<td>12</td>
<td>Dupl. Procedures already included under another AIH in this processing</td>
</tr>
<tr>
<td>13</td>
<td>Dupl. records mutually incompatible</td>
</tr>
<tr>
<td>14</td>
<td>Dupl. discharge requested/death/transfer/self-discharge w/1 day/ procedure w/MP&gt;2 days = 1st attend.</td>
</tr>
<tr>
<td>15</td>
<td>Elective surgery. Not performed w/readmission within 15 days per procedure</td>
</tr>
<tr>
<td>16</td>
<td>Short stay unjustified</td>
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<td>17</td>
<td>Multiple surgery not characterized (same incision, same region, same pathology)</td>
</tr>
<tr>
<td>18</td>
<td>Dupl. Special procedure not justified</td>
</tr>
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<td>19</td>
<td>Special procedure not justified</td>
</tr>
<tr>
<td>20</td>
<td>Canceled elsewhere</td>
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<td>21</td>
<td>Polytrauma not characterized (same follow-up)</td>
</tr>
<tr>
<td>22</td>
<td>Polytrauma presented as multiple surgery</td>
</tr>
<tr>
<td>23</td>
<td>For auditing on patient chart</td>
</tr>
<tr>
<td>24</td>
<td>Incompatible information or records</td>
</tr>
<tr>
<td>25</td>
<td>To meet funding cap of manager</td>
</tr>
<tr>
<td>26</td>
<td>Adult procedure used for a child</td>
</tr>
<tr>
<td>27</td>
<td>Same-day hospital procedure</td>
</tr>
<tr>
<td>28</td>
<td>Discharge requested/death/transfer/self-discharge/1 day/ procedure w/MP&gt;2 days = 1st attend.</td>
</tr>
<tr>
<td>29</td>
<td>Long stay not permitted</td>
</tr>
<tr>
<td>30</td>
<td>Other reasons</td>
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</tbody>
</table>
Chapter Annex IV – Directives Related to Decentralization of the SIH

Directives in 2004
Directive 821/GM of 4 May 2004 - Decentralization of SIH
Directive 158 of 5 May 2004 – List of Special Procedures
Directive 23/SAS/SE - Authorizing Module

Directives in 2005
Directive 173 of 28 March 2005 - Table of Medical Procedures
Directive 276 of 1 June 2005 - Elective AIH
Directive 277 of 1 June 2005 - AIH Series
Directive 375/SAS of 4 July 2005 - Table of Medical Procedures
Directive 389 of 6 July 2004 - Request for CNS Number
Directive 567 of 13 October 2005 - Numbered Series for AIH Authorizations
Directive 586 of 24 October 2005 - Schedule Established
Directive 637 of 11 November 2005 – Change in Coding Structure of Issuing Agencies
Directive 675 of 1 December 2005 - Postponed Implementation of SIHS

Directives in 2006
Directive 98 of 14 February 2006 - Postponed Implementation of SIHD
Directive 99 of 14 February 2006 - Delivery Schedules: SIA, SIH, SIHD SCNES
5. Compulsory Reporting of Diseases and Conditions in Brazil: A Brief History of the Creation of the System for the Reporting of Notifiable Conditions (SINAN)

Wayner Vieira de Souza, PhD*
Carla Magda Allan Santos Domingues, MS. in Public Health **

Background
The practice of epidemiological surveillance as it is known today first appeared in Europe in the nineteenth century as part of the movement to organize public health. In the beginning, monitoring and control were limited to communicable diseases, and the source of information was the compulsory reporting of cases, based on lists of diseases and conditions of interest during a given period of time (Barata, 2005; Brant, 2001).

In Brazil, the first attempts to build an information system based on the reporting of diseases and conditions were influenced by the experience of combating malaria and yellow fever at the beginning of the twentieth century, as well as by the success of the Measles Eradication Campaign in the 1960s; the National Poliomyelitis Control Program, created in 1971; and the National Immunization Program (PNI), created in 1973 (Risi Júnior, 2003).

Up until 1973, data on the reports of diseases and conditions available for nationwide use were published in the Boletim Epidemiológico [Epidemiological Bulletin] of the Public Health Services Foundation (FSESP), which received and consolidated the data submitted by the State Health Secretariats, which in turn had come from the epidemiological surveillance units. Reporting was compulsory for

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diseases preventable by immunization, vector-borne diseases, tuberculosis, leprosy, human rabies, and, later, meningococcal disease (Risi Júnior, 2003).

In 1974, a restructuring of the Ministry of Health included creation of the National Secretariat for Basic Health Actions (SNABS), although coordination of the epidemiological surveillance system remained with FSESP (Risi Júnior, 2003).

The central topic of the V National Conference on Health, held in 1975, was discussion of the national health system and, in this context, the importance of the National Epidemiological Surveillance System (SNVE), coordinated by FSESP, was reaffirmed. SNVE was created under specific legislation (Law 6,259 of 1975 and Decree 78,231 of 1976) that made it compulsory to report communicable diseases and established the first national list of those for which reporting was required (Brasil, 2005; Paim, 1992).

In 1976, FSESP created a data processing center, which over the years has provided important support for the development, implementation, and operation of several national health information systems (Brasil, 1977).

In 1977 the Pan American Health Organization (PAHO) established the Expanded Program on Immunization (EPI) to address issues of vaccine coverage, distribution, storage, and conservation. The creation of this entity underscored the need for a national epidemiological surveillance program that would make it possible to assess results and the impact of actions taken. Vaccination and disease case reporting became routine activities in the basic health network, echoing the theme of the VI National Conference on Health (1977), which called for the incorporation of health services and emphasized basic health care, a position that was ratified by the International Conference on Primary Health Care held at Alma-Ata in 1978 (Risi Júnior, 2003; Paim, 1992).
In 1984, the First National Meeting on Teaching and Research in Epidemiology created the Epidemiology Committee of what is now the Brazilian Association of Collective Health (ABRASCO) (Barreto, 2002).

The National Health Foundation (FUNASA) was created in 1990 under Law 8,029 of 12 April 1990 as a result of merging FSESP with the Superintendency of Public Health Campaigns (SUCAM) (Brasil, 2001), a move that also incorporated the attributions of the former National Secretariat of Basic Health Actions (SNABS). Its enabling regulations were issued under Decree 100 of 16 April 1991 (Brasil, 1990).

This period also saw preparation of the first Overall Plan for the Development of Epidemiology in Brazil under the aegis of ABRASCO in 1989, and convocation of the First Brazilian Congress of Epidemiology in 1990 (Barreto, 2002; Paim, 1992).

In addition, in this same context, the National Epidemiology Center (CENEPI) was created as a directorate within the structure of FUNASA. In addition to inheriting some of the attributions of SNABS, CENEPI took on the goal from the outset of reducing the distance between scientific epidemiologists and those working in the services, and it encouraged the use of epidemiological techniques and resources within the context of the SUS (Barreto, 2002; Paim, 1992).

Implementation Process

At the beginning of the last decade of the twentieth century, with advanced computational resources available and a growing demand for useful and timely information to support epidemiological surveillance activity, it fell to CENEPI to
build an information system, to be called the System for the Reporting of Notifiable Conditions (SINAN).

The objective of this system was to standardize the collection and processing of data on notifiable conditions throughout the country so as to provide information for analyzing the morbidity profile and thus for decision-making at the municipal, state, and federal levels (Brito, 1993). The system’s hierarchy was to be patterned after the organization of the SUS, and it should be rapid and efficient enough to permit the analysis of health situations within a short period of time.

During 1991-1993 the processes of discussing, developing, and implementing SINAN got under way with support from the then newly created SUS Department of Informatics (DATASUS) and the Data Processing Enterprise of the Prefecture of Belo Horizonte (PROBADEL). In the meantime, heterogeneous implementation was taking place in the states and municipalities without any coordination or oversight by health managers in the three spheres of government.

The final set of data to be included in SINAN for each of the reportable conditions was decided on after discussions with the information coordinators and each of the specific coordinators, but with less participation than had been hoped for by the State and Municipal Health Secretariats. Over the years, records began to be kept regarding the investigation of conditions not on the national list of required reportable diseases without any criteria having been established for their inclusion or any standardized instruments developed for collecting data on the subject. This situation led to an excessive accumulation of data and hence to operational problems for the system.

Initially, SINAN had been conceived as two modules, one for reporting and the other for investigation, linked together by a unique record identifier. The first
module was supposed to contain basic information for identifying and locating the case along with the suspected disease and the patient’s level of schooling. The second module was to have pertinent information on the epidemiological investigation of each case, which would obviously be submitted to higher levels in the system, but at a later time, while the first module would be concerned with immediate notification. It was believed that with these two information paths it would be possible to achieve a system that could quickly consolidate the reported data and update data by incorporating information from the investigation, including any rejections of unconfirmed cases. However, the characteristics of some of the diseases or conditions, and in some cases even the practices introduced in the control programs, prevented this logic from being implemented, thus subjecting notification of the case to progress in the epidemiological investigation process (Brasil, 2006).

This turn of events prevented SINAN from being as rapid as had been hoped for. Moreover, capacity for consolidation and analysis at these levels varied from one place to another, closely paralleling the picture of deep regional differences in Brazil.

At the same time, several operational problems and issues in defining mechanisms for management and utilization were systematically interfering with the use of SINAN: failure to respond to requests at the different levels of the system, mainly in terms of timely monitoring of reported cases during epidemic periods and the lack of any mechanism for locating the events in sparsely populated areas of the country.

Nevertheless, since the implementation of SINAN, a path has been established for the individual reporting form, or basic collection document (see Annex): It starts at the local health services level, is sent to the regional offices of
the Municipal Health Secretariats, and then is transmitted to the central offices of these secretariats, and from there it goes to the State Health Secretariats, which are responsible for sending each state’s data to CENEPI (Brasil, 2006). Problems can arise at several points along the line, and may include: difficulties in the transmission of the data between any of the levels: unclear information in terms of the system’s primary objective; poor overall performance; conflicting information path and logic (e.g., chronic communicable/noncommunicable diseases and acute communicable/noncommunicable diseases); multiple system management (each technical area or program responsible for its particular aspect of SINAN); software limitations; nonstandardized tables; and failure to use prenumbered reporting sheets or routines for checking consistency and validation of the data (Carvalho, 1997).

Even while facing these problems, from the outset SINAN has incorporated the concept of a list of diseases for which reporting is required at the federal level while allowing for the inclusion of specific diseases of concern to particular states, thus filling a needed gap and establishing itself as a reference for epidemiological surveillance activities.

In light of the difficulties that were being encountered, starting in 1998 the use of SINAN was regulated under Ministry of Health Directive 1,882/GM of 18 December 1997, which made it compulsory for the municipalities, states, and Federal District to report their information regularly to the national database. The same directive also designated the Ministry of Health as national manager of SINAN.

In order to make the system more responsive to users’ needs and at the same time develop a new system that would expand capacity for carrying out surveillance activities and situation assessments in the three spheres of
government, CENEPI established a committee to confer on developing and perfecting the new version of SINAN (FUNASA Service Bulletin 12 of 20 March 1998). To ensure that the proposal was clearly delineated, the committee included personnel from user technical areas as well as DATASUS. This was the beginning of the “SINAN Windows” project, a partnership of CENEPI/FUNASA and DATASUS in which CENEPI was responsible for system design from the perspective of epidemiological surveillance, including the standardization of concepts and definition of the information path, instruments, and managerial reports, while DATASUS was responsible for producing software that should be workable at the various levels of complexity (LaGuardia, 2004).

The group greatly appreciated the input from the technical personnel, which was incorporated into epidemiological surveillance at the state and municipal levels, as well as public health professionals from academic institutions, all of which contributed to development of the proposal. In September 1998, a group was created to discuss this topic, called the Workshop on the Restructuring of SINAN, and its final report served as a guide for the standardization of concepts, definition of the information path, and the creation of forms for the collection of information, based on feedback from the implementation of SINAN-DOS in the different spheres of SUS management.

One of the problems identified was the lack of procedures for revising and correcting incorrect records, especially when it came to migrating the SINAN-DOS database to SINAN-Windows, since the only cases imported were those that had not been flagged for inconsistency, even if the inconsistencies applied to key data elements for identifying the case in SINAN-Windows (report number, date of report, municipality where the case was being treated, health unit), fields that are
required to be filled in, or information that had been questioned at the time of data entry.

The new SINAN-Windows software offered the following improvements, among others, over SINAN-DOS:

- increased number of system keys;
- inclusion of reports of acute and chronic conditions in a single database and generation of separate files for investigation data on each condition;
- improvement of routines for the detection of duplication, querying, transfers, and receipt, in response to comments from users;
- optimization of the routine for linking records on tuberculosis and leprosy to more than one entry in the system;
- inclusion of standardized output formats for the construction of indicators;
- interface with TabWin;
- possibility of identifying inconsistencies in the database;
- optimization of the querying routine so that the output of a given assessment can be saved in other applications; and
- inclusion of software for decentralizing the database.

**Current Situation**

The information systems available to the programs concerned with monitoring diseases and conditions in Brazil are SINAN, SINASC, SIM, and the Hospital Information System (SIH). Of these, SINAN is the one that has been used the most for epidemiological surveillance. However, trying to merge the functions of a reporting system with one designed to investigate cases has resulted in a sluggish
system with many information gaps, especially in terms of the location and autarchny of the cases, with information not being provided at a level of disaggregation compatible with the needs of the local health services.

The challenge not only for SINAN but also for the other health information systems in Brazil is to create a communication interface between them and stop treating them as legal registration systems, so that they will have the agility to trigger immediate responses and perform analyses on a timely basis.

Thus, it is fundamentally important to develop a health information system that produces integrated information in the different spheres of government that will be essential for use in planning, control, and execution, from the conception of health policies all the way to the direction of specific actions. By the same token, it is indispensable to define information pathways that combine different sources or different systems and which, at the same time, make institutional strengthening possible at the local level within the SUS context (Souza, 2003).

An example of how such a proposal would work can be seen in an analysis of an occurrence of tuberculosis in the municipio de Olinda (Pernambuco) during the period 1996-2000. A simple map of census tracts where there had been cases of retreatment for tuberculosis and/or families with more than one case of the disease during the period showed that 45% of all the cases reported were located in 28% of the demographic areas in question. This type of approach, combined with the possibility of visualizing the affected areas with the help of simplified geographic information systems, can be an important tool for the planning of interventions using rational resources (Souza, 2005).

Ten years after the implementation of SINAN, CENEPI ceased to exist and the Health Surveillance Secretariat (SVS/MS) was created within the Ministry of Health in June 2003. From its vantage point inside the Ministry of Health, the SVS
has been able to incorporate the experience and attributes of CENEPI, while at the same time moving forward with a set of new concepts that now guide health surveillance. It also serves as the managing agency for SINAN, the Mortality Information System (SIM) and the Live Birth Information System (SINASC).

Today, input for SINAN comes mainly from reports and investigations of cases of diseases and conditions that appear on the national list of required reportable diseases (LDNC), pursuant to Ministry of Health Directive 5/SVS of 21 February 2006, but the states and municipalities have the authority to include other public health issues that they consider to be important in their region. Surveillance is extended to the entire population residing in the country.

All the federal units use prenumbered collection instruments standardized by the Ministry of Health, which are specific for each required reportable condition. For leprosy and tuberculosis, case follow-up data are collected as well.

Printing, distribution, and control of the prenumbered reporting/investigation forms are the responsibility of the State Health Secretariat, and this responsibility can be delegated to the municipality.

The notification form has fields for the identification and location of the reporting establishment; identification, socioeconomic characteristics and place of residence of the patient; and identification of the condition being reported. The investigation form, in addition to the notification data, contains fields for the epidemiological history, clinical and laboratory data specific to each case, and a report on the conclusion of the investigation. The fields of the forms, as well as the characteristics of the corresponding variables in the databases, are described in the
The reporting units are usually services that provide care under the Unified Health System. All professionals, when practicing their profession, as well as those responsible for public and private health and teaching establishments, have the obligation to report any occurrence of a suspected or confirmed case of a condition appearing on the LNDC to the managers of the Unified Health System.

Although not yet completely adapted to the decentralization of health system actions, services, and management, SINAN can handle the collection, processing, storage, and analysis of data from the reporting units. However, responsibility for these duties depends on the management status of the municipio. If personal computers are not available in their units, the computerized system can be operated from the Municipal, State, and Regional Health Secretariats.

The reporting municipality must provide the system with data on cases detected in its area of coverage, regardless of whether or not the patients are residents of that municipality.

Depending on the need, SINAN data can be transferred either vertically or horizontally. Transfer is vertical when the objective is to transfer all the data that have been keyed in (with additions, modifications, and exclusions) to higher levels in the information system hierarchy, to permit aggregation and macroanalysis.

The purpose of horizontal transfer is to make the SINAN-Windows database on a particular condition or group of conditions available at the same hierarchical level (e.g., a technical area responsible for the surveillance of certain conditions) for the purpose of consultation and analysis.

Every week, the reporting unit transmits the information from the notification/investigation form (or, if it is computerized, the electronic data transfer file) to the Municipal Health Secretariats, which, in turn, transfer the files to the respective State Health Secretariat once a week. As of March 2006, SINAN was installed electronically in 3,800 municipalities (municipios).

Those municipalities that do not have the capacity to access SINAN electronically submit their notification/investigation forms to the State Health Secretariats, in accordance with the information path established in the particular state. Thus, the standardized collection instruments used by SINAN are available in all the municipal units of the country.

The State Health Secretariats transfer SINAN files to the Ministry of Health electronically every two weeks, in accordance with an annual schedule agreed upon between the SVS/MS and the State Secretariats.

All levels of the system share at least the responsibility to review the quality of the data (for duplication, fields incompletely filled in, and consistency of the data), perform epidemiological analyses, and disseminate information.

It is up to the first level of automation, usually the municipalities, or, if they do not have electronic data processing, the state level, to fill in the complete data, correct inconsistencies, link/discard duplications, and check records for rejection (Brasil, 2004).

The databases generated by the system are in GDB format. To analyze them using software such as SPSS, TabWin, and EPI Info, they need to be exported to DBF format. This procedure is done at all levels using one of the system’s own routines.
Systematic use of the decentralized system contributes to the democratization of information, giving all health professionals access to the information and making it available to the community. It is therefore an important instrument for providing assistance in health planning, setting intervention priorities, and evaluating the impact of interventions.

With a view to encouraging evaluation of the SINAN databases and calculating indicators for all users of the system, SVS has created a SINAN website at www.saude.gov.br/svs or www.saude.gov.br/SINANweb.

The following information is available on this site:

- Management reports: cases closed promptly and list of unclosed cases; and completeness of notification/investigation forms.
- Specific reports: AIDS; congenital syphilis; and tuberculosis.
- Documentation: data dictionaries; notification and investigation forms; instructions; manuals; and analysis to assess the quality of the database and construction of epidemiological and operational indicators.
- Production: follow-up of receipt of transfer files from each state.
- Database: use of the TabNet tool (under construction).

**Considerations and Future Outlook**

During the time from its implementation up to the present, SINAN has gone through major changes intended to improve its performance in order to meet health surveillance needs in the three spheres of government.

In this same spirit, SVS/MS, working with DATASUS, is developing a new application, SINAN-Net, which is attempting to modify the logic of information
production for purposes of analysis, making it available at ever more decentralized levels of the health system and assisting in the construction of geographically based epidemiological surveillance systems that will be attuned to what is going on around them in their area of action.

DATASUS, which is responsible for development of the system, hopes to develop a new set of upgrades to SINAN, incorporating responses to current requests and making the best use of available technology.

This new application will enable a municipality connected to the Internet to transmit data from the reporting form to the other spheres of government on a daily basis, thus making this information available in the three spheres of government within the shortest possible time.

Data from the investigation forms will only be transmitted after the investigation has been closed. Thus, the two stages will operate separately, which had been envisioned since the earliest versions of SINAN but never implemented.

Other routines, such as the return path, will be implemented in order to enable the municipality of residence to have all local cases in its database, regardless of where they were reported from.

The database, in turn, will be being prepared to allow for the georeferencing of reported cases, providing the states and municipios with tools for analyzing the spatial distribution of health events, broken down at different geographic levels.

With these new routines, it is hoped that their effective use will finally make it possible to have a dynamic diagnosis of the occurrence of an event in the population, provide causal explanations of the required reportable conditions, and point out risks to which the people are subjected, thus helping to portray the epidemiological reality of a given geographic area.
Chapter References


Barreto, Mauricio L. The role of epidemiology in the development of the National Health System in Brazil: background, foundation and prospects. Rev. bras. epidemiol., Nov. 2002, vol.5 suppl.1, p.4-17.


LaGuardia, Josué; Domingues, Carla MA; Carvalho, C; Lauermann, CR; Macario, E & Glatt, R. Sistema de Informação de Agravos de Notificação (SINAN): desafios no desenvolvimento de uma sistema de informação em saúde. Epidemiologia e Serviços de Saúde, 20004; 13(3): 135-147


6. Dissemination of Health Information: Experience of the SUS Department of Informatics (DATASUS)

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Background

Initiatives to disseminate information prior to the country’s redemocratization were limited to databases with access restricted to system managers and technical advisers to decision-making authorities, not only because of technological limitations at the time, but also, and mainly, because of an information policy that was dictated by “national security” interests and the corporate bias of institutions.

In the mid-1970s, the public health movement proposed a public health reform† and established the bases for what was to become the Unified Health System (SUS), thus generating a demand for detailed, up-to-date health information. These were also the early days of progress and expansion in tele-informatics, with remote access via terminals linked to mainframe databases, to be followed by the advent of microcomputer-based informatics, creating the possibility of decentralized databases.

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† “The Brazilian Public Health Reform was born out of the struggle against the dictatorship, based on the theme of Health and Democracy, and it gained substance in the universities, the labor movement, and in regional experiments in the organization of services. This social movement was consolidated at the VIII National Conference on Health in 1986, at which, for the first time, more than 5,000 representatives from all walks of society discussed a new model of health for Brazil. The result was to secure a guarantee in the Constitution, through a popular amendment, that health is the right of all citizens and a duty of the State.” Further information on the subject is provided in “Chapter Appendix,” under the heading “Note.”
The first development in the recent history of Brazilian efforts to build databases to capture and disseminate health information occurred in 1977, when the Ministry of Health, with a view to maintaining compatibility with other countries, standardized the registration of deaths in Brazil and created a computerized system for capturing the data, which it made available in a series of publications. At around that same time, the managers of the National Social Security Health Care Administration (INAMPS) asked the then-named Social Security Data Processing Enterprise (DATAPREV) for instruments that would support the planning and control of hospital production. The data collected served as the basis for the first initiatives to disseminate health information, though still for internal use by personnel engaged in the management of Social Security.

In 1980, perceiving the important role of information in management, DATAPREV, which by that time had a national network in place with access points in all the capital cities of Brazil, developed a preliminary application for the dissemination of information: the Integrated System for Statistical Processing of Strategic Series (SINTESE). This system brought together historic series from its files and other sources such as IBGE and added information such as dollar exchange and inflation rates in order to provide context for the data and allow for financial comparisons over time. The success of SINTESE grew beyond the walls of Social Security: DATAPREV, by providing training in the use of this application, turned it into one of the strategies for the development of professionals in the field of information.

Conception and Purpose of DATASUS

In 1990, with the administrative reform of the state, INAMPS was transferred from the Ministry of Social Welfare to the Ministry of Health, as called for by the Public Health Reform.² This move created the need for an information
processing infrastructure to maintain the control and payment systems for the INAMPS network of institutions with which it has agreements, a task which up until then had been the responsibility of DATAPREV, as well as to develop new applications to support other activities in the health area.

To define the new agency, an interministerial committee was created with representatives of DATAPREV, the Ministry of Health, and the federal government’s Secretariat for Administration. The new agency was to be national in scope, but it could not be a public enterprise, since institutions of that kind could no longer be created by governmental decision.

Varying ideas about the nature and mission of the new agency emerged from the discussions, and different alternatives were suggested for fitting it into the existing structure: (i) it could be attached to INAMPS as a data processing center (CPD), keeping it focused on maintaining the control and payment systems for the institutions with which INAMS has agreements; or (ii) it could be merged with the existing CPD in the Ministry of Health (under the direct ministry administration), which, in addition to restricting its administrative flexibility, could also hamper its mission to meet the ministry’s needs as well.

However, it was a third alternative that won out in the end, based on the conviction that the agency should support the entire Unified Health System – the three spheres of government (municipal, state, and federal), as well as the empowered society – and therefore have corresponding latitude and operational capacity. Thus, in the end it was placed under the National Health Foundation (FUNASA), an agency of national scope in the process of being created through a merger of two other agencies: the Ministry of Health’s Superintendancy of Public Health Campaigns (SUCAM), and Special Public Health Service Foundation (FSESP).
To start the transition process, a Health Systems Directorate was created within DATAPREV, with representatives in all the state capitals throughout the country. The new directorate included technical personnel involved in activities related to the INAMPS systems and supporting administrative staff. This was the first concrete step toward creation of the new agency.

**Implementation of DATASUS**

DATASUS was created as a department within FUNASA by amending the Provisional Measure that established the latter agency. The amendment called for the transfer of human and technical resources and equipment from the DATAPREV Health Systems Directorate to FUNASA, as well as the transfer of personnel and information processing resources from SUCAM and FSESP. Once approved, the Provisional Measure became Decree 100 of 16 April 1991, which created the SUS Department of Informatics (DATASUS).³

Negotiation of the transfer of human resources from DATAPREV to DATASUS involved a wide campaign of explanations and discussions with the employees of DATAPREV. Ultimately, nearly 1,500 people came to make up the roster of DATASUS civil servants located throughout the country, including systems analysts, specialists in organization and methods, programmers, administrative technicians, and data entry clerks.⁴ The entire team responsible for the development and maintenance of SINTESE was transferred to DATASUS, making it necessary to have a technical agreement between the two institutions for the maintenance and updating of Social Security data.

DATAPREV was not dismantled immediately. The products and services of DATASUS remained installed on the equipment of the institution of origin for approximately a year. In the process of building its new computing center,
DATASUS took on an INAMPS mainframe computer which still had database software installed on it that was compatible with multiple hardware platforms. The health information databases were transferred to this equipment, and databank querying was changed to SQL, thus creating a new culture in the institution (see details in the appendix). The technological reasoning behind this transition was to be independent of any one vendor, and this independence became possible in 1993 with the purchase of smaller, cheaper, and more efficient equipment on which it was possible to obtain the same results and significantly expand the choice of vendors. DATASUS was a pioneer in the public arena in deciding to adopt a downsizing strategy.

In early 1998, in light of the growing importance of DATASUS, one of the ideas that had previously been ruled out was to reappear on the political agenda: namely, linking DATASUS to direct administration. By a decision of the executive secretary of the Ministry of Health, a working group was created to assess the situation and come up with a proposal. The discussions turned around the nature of the entity (undersecretariat or department), incorporation of other areas of the ministry with similar activities, and redefinition of its mission, its responsibilities, and its sphere of action. As a result, DATASUS was placed directly under the Executive Secretariat in the Ministry of Health, incorporating the ministry’s General Coordination of Information Processing, and its mission was expanded to meet the needs of the Ministry and the SUS.

The Area of Dissemination

The dissemination of information, a practice previously embraced by DATAPREV, was emphasized by DATASUS from the outset and eventually translated into the free public distribution of health information and tools to facilitate its use.
With the advent of the personal computer (PC) and the DOS command interface, the dissemination of information began to take on new impetus, although initially the PCs coexisted with terminals still linked to the DATAPREV network.

The launching of Microsoft Windows led to the development of “SINTESE for Windows,” a new SINTESE interface which, by being much more user-friendly and incorporating new features, reduced the need for training courses and greatly increased the number of users and consultations.

On the other hand, the transfer of data from the INAMPS control systems continued to be dependent on DATAPREV, which was governed by a proprietary protocol, and severe bottlenecks were occurring due to the size of the files in transit and the physical limitations of transmission modalities at the time, even with the help of recently acquired compaction techniques. Introduction of the PC also popularized point-to-point communication via the telephone network. DATASUS began to use point-to-point connection for the transmission of its files, gradually becoming independent of the DATAPREV network infrastructure. This technology also led to widespread use of the Bulletin Board System (BBS). Two examples of the use of this technology platform are of special interest:

- creation of the Ministry of Health BBS (MS-BBS), managed by DATASUS, which permits the distribution and exchange of various types of files such as tables and programs, as well as messaging between users; and
- adoption of STM-400 (an Embratel communication system based on connecting PCs to a central server that manages mailboxes), by DATASUS and the Ministry of Health, which allowed for communication and the exchange of files, notices, and information among the nearly 120 units of FUNASA.
The microcomputer brought about a revolution in the processing and analysis of decentralized data. Growing awareness of the need to process and tabulate data in order to better assess the health situation in a given area led DATASUS to develop a fast and simple tool to perform tabulations on the PC using data from the information systems of SUS.

The resulting software was TAB, a PC-based program that made it possible to tabulate data from DBF files, which are the basic elements of the SUS information systems. TAB enables users to perform tabulations – for example, to delineate the morbidity and mortality profile of the population covered by the SUS. The program has been distributed free of charge since 1994, at first for the DOS environment (TabDOS), and since 1996 for Windows (TabWin).

TabWin is now able to link its tabulations to graphic features on a cartographic base, thus permitting spatial assessments. This capability became possible when map files provided by IBGE for the regions, states, and municipios of Brazil were included in the TabWin distribution package. Thus, users can map the variables resulting from their tabulations onto geographic areas, depending on their needs. With each new version of TabWin, DATASUS introduces new options, tailoring its potential to the needs of users while taking advantage of emerging technology.

With the advent of the worldwide Web, DATASUS made pioneering efforts to access the Internet via Alternex, the first non-academic provider in Brazil. Its next provider was Rede-Rio, of the National Research and Teaching Network (RNP), and later it contracted for access through Embratel, the telecommunications enterprise.

The early non-academic uses of the Internet in the SUS led to several notable developments: (i) e-mail became institutionalized as a means of communication
within DATASUS and the Ministry of Health; (ii) the Web site www.datasus.gov.br was developed, mainly for technicians in the health area; (iii) the National Health Information Network (RNIS) was created in 1996 as a resource for the financing of projects at the state level aimed at disseminating access to health databases and improving the quality of health information (ahead of its time, DATASUS modeled the policy that later came to be known as “digital inclusion” by suggesting that emphasis be placed on creating Internet access for the health secretariats and health councils; thus, RNIS took on the objective of integrating and disseminating health information by using the Internet to bring together the municípios of Brazil, facilitate access to and the exchange of health information, and thereby contribute to improved management, social monitoring, planning, and research by managers agents, and users of SUS; accordingly, Web sites were created in all the state health secretariats and about 90 municipal health secretariats, and the use e-mail was extended to the states and municipalities); and (iv) DATASUS launched the first health-oriented search engine in Brazil, AltaVista da Saúde [Health AltaVista], which made it possible to index the health-related sites that existed at the time.

Distribution of a CD-ROM containing the TabWin program along with data from the Hospital Admission System (SIH/SUS), the Outpatient Care System (SIA/SUS), and the Mortality Information System (SIM) served as a stimulus for standardizing the purchase of personal computers for the SUS network with a CD-ROM reader, making this new modality of disseminating information viable and expanding the use of TabWin in the SUS. In this way, the municipal and state secretariats acquired a powerful tool for tabulating their own data at no cost.

A new version of this application was developed in 2004 that implements an interface that makes it possible to consult relational databases. Thus, users can
create and catalogue their queries and execute them at any time, seeking up-to-date information in local or remote databases, all the time presented in the familiar TabWin environment. For most analyses, these new capabilities take the place of expensive off-the-shelf data warehouse tools. The new version also has an interface for executing free statistical software analysis schemes, making it possible to do perform operations on historical series, use statistical functions, and visualize information in the form of graphs, maps, etc., in addition to importing data in XML.

With the growth of the Worldwide Web, DATASUS managers decided to develop an application analogous to TabWin for the Internet (TabNet) to enable technical teams working for the Ministry of Health and the state and municipal secretariats of health to do rapid tabulations on files in DBF format, both within their Intranets and also on Internet sites. The developers of this tool were mindful of the requirements that it: (i) be fast enough to allow for the tabulation of large masses of data on low-cost servers (Intel line); (ii) have a simple interactive user interface with all the tabulation options listed on a single menu, similar to TabWin; and (iii) enable the user to save the tabulated data for use with TabWin in spreadsheets or other statistical analysis tools.

DATASUS has supported the state and municipal health secretariats in implementing TabNet at their work sites, in this way promoting the decentralized dissemination of information based on local needs. It has also supported different areas of the Ministry of Health in the organization of its data and in making the data available through TabNet, such as the DST/AIDS Coordination; the Health Surveillance Secretariat’s National Program for the Elimination of Leprosy; and the National Public Health Surveillance Agency, tabulating data from the national...
census of its workers, as well as institutions outside the area of health, such as the Rio de Janeiro Data and Information Center.

It has been possible to develop this program, as well as other health-related software products, because the SUS information systems are defined nationally, permitting the immediate generation of the more common tabulations based on predefined files. To use the tabulator productively, it is essential to know what data are available on SUS, where they can be obtained, and in what format. It is therefore indispensable to accompany the files with documentation if there is any chance that they will be tabulated, whether on CD-ROM or the Internet – as has been done, for example, on the DATASUS website, with technical notes alongside the tabulation options that describe the fields and indicators available.

As with most systems, the process of producing and disseminating information is directed first and foremost at meeting the needs of the system’s managers. Thus, the DATASUS policy on producing information was geared in the first place toward management of the SUS at the federal level, and only later toward providing information to support management of the state and municipal health services, propelled by municipalization, decentralization of the SUS, and the appeals from state and municipal health secretariats for more and better information for planning purposes and delivering health services to their populations. Activities to train managers and their advisers in the use of information continue to increase, while personnel turnover, technological advances, and changes in SUS operating standards constantly call for new briefings. In addition to the management data on the DATASUS website, epidemiological information has now been included.

At the time it was created, DATASUS was basically responsible for the Hospital Information System (SIH/SUS), the Outpatient Information System
(SIA/SUS), the Live Birth Information System (SINASC), the Mortality Information System (SIM), and System for the Reporting of Notifiable Conditions (SINAN). The creation of DATASUS made it possible to give priority to the health sector, and new systems began to be developed. In 1992, beta versions were developed for systems focused on hospital management and outpatient care: the Integrated Hospital Information System (HOSPUB) and Management of the Basic Outpatient Care Unit (SIGAB). With the development of new systems and the advent of the Internet, the information in the DATASUS databases is being made available on the Web. With due respect for privacy, it is understood that information on the following subjects is public and available on the Internet without any restricted access: care provided by the SUS to its citizens; morbidity, mortality, and births; and expenditures by the three SUS spheres of government. At the same time, identification of the patient, deceased, or newborn is password protected and only available to system managers, auditors, and legal authorities.

So that the Web sites do not become too large, the information available on the Internet is aggregated at the municipal level. More detailed information, without identifying the patients, can be obtained through a download from MS-BBS or on CD-ROM.

On the DATASUS Web site (www.datasus.gov.br) it is possible to obtain indicators and information on health and SUS financing, access to the latest versions of software applications and services, participate in discussion forums, etc. The health information is divided into: (i) health care; (ii) health care network; (iii) epidemiologic and morbidity data; (iv) vital statistics; and (v) demographic and socioeconomic data. Under financial information, data can be obtained on income and expenditures on health made by the states and municipalities, in
addition to expenditures made at the federal level in the form of direct payments to providers or transfers to other spheres of government.

For almost all the options, the user can select a time period or geographic area of interest (region, state, microregion, municipality, health region). The starting periods differ for each data set, depending on when the data started to be collected. It takes an average of three months after a hospital admission or outpatient consultation for the data to be available on the Internet, corresponding to the time needed for central processing of the data and generation of the files for dissemination.

Table 1 shows the information options available under the heading “Health Care.” The first option, "Hospitalizations by Specialty and Place of Admission,” gives the number of hospitalizations, the amounts to be paid for professional services rendered, diagnostic and therapeutic support, room charges, etc., as well as the average stay, number of deaths, and the hospital case-fatality rate. Different selection options are available, including locality of interest and specialty. The second and third options offer, in addition to the information under the previous item, the possibility of analysis by procedure performed. The item “Outpatient Service Production” gives information on the number of payments and amounts approved for outpatient care in the SUS, with a further breakdown that allows, among other options, selection by procedure performed and type of care (basic and non-basic). Under “Immunizations,” information can be obtained on the number of doses or immunizations applied, by age group and type of vaccine. “Family Health Program (PSF),” the last option in the group, provides information on the program’s coverage and the health and sanitary situation of the population covered.
Table 1. TabNet Information Groups Available under “Health Care”

<table>
<thead>
<tr>
<th>Information group</th>
<th>First year</th>
<th>Last period available</th>
<th>Updated</th>
<th>System source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospitalizations by specialty and place of admission</td>
<td>981</td>
<td>Jan/06</td>
<td>Monthly</td>
<td>MS / SIH/SUS</td>
</tr>
<tr>
<td>Hospital procedures by place of admission</td>
<td>992</td>
<td>Jan/06</td>
<td>Monthly</td>
<td>MS / SIH/SUS</td>
</tr>
<tr>
<td>Hospital procedures by place of residence</td>
<td>995</td>
<td>Jan/06</td>
<td>Monthly</td>
<td>MS / SIH/SUS</td>
</tr>
<tr>
<td>Outpatient service production</td>
<td>994</td>
<td>Nov/05</td>
<td>Monthly</td>
<td>MS / SIA-SUS</td>
</tr>
<tr>
<td>Immunizations</td>
<td>994</td>
<td>2005</td>
<td>Annually</td>
<td>MS / SI-PNI</td>
</tr>
<tr>
<td>Basic care – Family care</td>
<td>998</td>
<td>Jan/06</td>
<td>Monthly</td>
<td>MS / SIAB</td>
</tr>
</tbody>
</table>

Source: MS/DATASUS website, accessed 17 March 2006.

The segment entitled “Health Care Network” provides information on human and physical resources in the health units regardless of whether or not they are associated with the SUS. The hospitalization and outpatient care systems each have their own inventories, with identification of the hospital and outpatient care network corresponding exclusively to SUS, although this information ceased to be updated after July 2003, when the National Inventory of Health Establishments (CNES) went into effect. This new combined inventory includes information on physical area, human resources, equipment, and hospital and outpatient services of all hospital and outpatient care establishments associated with the SUS, plus all those that are not associated, including private establishments that provide the following services: clinical pathology, radiology, renal replacement therapy, radiation therapy, chemotherapy, hemotherapy, magnetic resonance imaging, nuclear medicine, interventional radiology, and computerized tomography. Individualized information is available by health unit, including number of beds, equipment, services provided per unit, and data on health professionals associated with SUS, who are identified by name, specialty, establishment with which they
are affiliated, and hourly fee for their services. This information group includes Medical and Public Health Care Research (AMS), produced by the Brazilian Institute of Geography and Statistics (IBGE), which conducts an annual inventory of public and private for-profit establishments that provide health services, both with and without hospitalization. However, the health unit is not identified, in keeping with the IBGE policy of keep this information confidential.

Table 2. TabNet Information Groups Available under “Health Care Network”

<table>
<thead>
<tr>
<th>Information group</th>
<th>First year</th>
<th>Last period available</th>
<th>Updated</th>
<th>System source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital network</td>
<td>1992</td>
<td>Jul/03</td>
<td>Monthly</td>
<td>MS / SIH/SUS</td>
</tr>
<tr>
<td>Outpatient network</td>
<td>1998</td>
<td>Jul/03</td>
<td>Monthly</td>
<td>MS / SIA-SUS</td>
</tr>
<tr>
<td>National Inventory of Health Establishments</td>
<td>2003</td>
<td>Mar/06</td>
<td>3 x week</td>
<td>MS / CNES</td>
</tr>
<tr>
<td>Medical and Public Health Care Research</td>
<td>1981</td>
<td>Jun/05</td>
<td>Annually</td>
<td>IBGE / AMS</td>
</tr>
</tbody>
</table>


The heading “Epidemiologic and Morbidity Data” groups together information on hospital morbidity, broken down by place or residence and place of admission. In Table 3, the starting periods differ because data on the patient’s residence only began to be included in 1995. The first options provide the same information as for “Health Care,” but with the possibility of selecting the main cause for admission based on the code from the International Classification of Diseases (ICD), available by age group or sex. An option recently added is to break down the morbidity data by external causes (Chapter XVII of the ICD), given their public health importance in Brazil. Information is also available on the occurrence of AIDS cases, with the possibility of monitoring them by year of notification or diagnosis and of selecting, among other options, the patient’s age group and type of exposure – homosexual, drugs, hemophilic, transfusion, vertical transmission, etc.
Other items of interest in this group are information on tests and specific surgeries for colon, uterus, and breast cancer, available by age group, and on the evolution and diagnostic assessment of cases of leprosy, with information, inter alia, on prevalence and incidence of the condition.

Table 3. TabNet Information Groups Available under “Epidemiologic and Morbidity Data”

<table>
<thead>
<tr>
<th>Information group</th>
<th>First year</th>
<th>Last period available</th>
<th>Updated</th>
<th>System source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospitalizations by specialty and place of admission</td>
<td>1984</td>
<td>Jan/06</td>
<td>Monthly</td>
<td>MS / SIH/SUS</td>
</tr>
<tr>
<td>Hospital procedures by place of admission</td>
<td>1995</td>
<td>Jan/06</td>
<td>Monthly</td>
<td>MS / SIH/SUS</td>
</tr>
<tr>
<td>Hospital morbidity by external causes and place of admission</td>
<td>1998</td>
<td>Jan/06</td>
<td>Monthly</td>
<td>MS / SIH/SUS</td>
</tr>
<tr>
<td>Hospital morbidity by external causes and place of residence</td>
<td>1998</td>
<td>Jan/06</td>
<td>Monthly</td>
<td>MS / SIH/SUS</td>
</tr>
<tr>
<td>AIDS</td>
<td>1980</td>
<td>2005</td>
<td>Annually</td>
<td>MS / SINAN</td>
</tr>
<tr>
<td>Cancer of the uterine cervix and breast</td>
<td>2000</td>
<td>Dec/05</td>
<td>Monthly</td>
<td>MS / SISCAM</td>
</tr>
<tr>
<td>Leprosy</td>
<td>1997</td>
<td>Dec/05</td>
<td>Monthly</td>
<td>MS / SINAN and MS / PNEH</td>
</tr>
<tr>
<td>Oral health</td>
<td>1996</td>
<td>1996</td>
<td>Every 10 yrs</td>
<td>MS / Epidemiologic Survey on Oral Health – Dental Caries</td>
</tr>
</tbody>
</table>


The “Vital Statistics” segment (Table 4) offers information on general mortality, which can be retrieved by place of occurrence or residence, age group, sex, and ICD chapter. This set also includes information on live births: length of gestation, type of delivery, birthweight, etc. More detailed information can be obtained on a CD-ROM distributed by the Ministry of Health’s Secretariat for Health Surveillance, which manages these two systems. The data run three years behind, a period that may be regarded as short, considering the size of the country and the inequalities in technical and technological development.
Table 4. TabNet Information Groups Available under “Vital Statistics”

<table>
<thead>
<tr>
<th>Information group</th>
<th>First year</th>
<th>Last period available</th>
<th>Updated</th>
<th>System source</th>
</tr>
</thead>
<tbody>
<tr>
<td>General mortality</td>
<td>1979</td>
<td>2003</td>
<td>Annually</td>
<td>MS / SIM</td>
</tr>
<tr>
<td>Live births</td>
<td>1994</td>
<td>2003</td>
<td>Annually</td>
<td>MS / SINASC</td>
</tr>
</tbody>
</table>


The heading “Financial Information” (Table 5) includes detailed information that makes it possible to follow the financing of the SUS. Under “SUS Resources,” one can see the amount spent by the SUS by municipios or providers, broken down by type of expenditure. The second option, “Public Health Budget Information System (SIOPS),” offers itemized breakdowns of income and expenditures on health at the municipal and state levels, as well as indicators such as total expenditure on health per inhabitant, percentage of resources applied to health, income from taxes and transfers, etc. The next information group shows federal expenditures on hospitalizations and payments to either hospitals or third parties, including net amounts to be paid. Under “Transfers to Municipios,” information can be obtained on federal transfers to the other spheres of government and federal payments made directly to health service providers. “Credits to Providers” shows breakdowns of federal payments to the health units, with amounts paid for hospital services, professional services, diagnostic and therapeutic services, etc., including the number of the bank order and date of payment. The final item refers to the information system used in association with the Payment Authorization Guide (GAP), which ceased to exist in 1997.
Table 5. TabNet Information Groups Available under “Financial Information”

<table>
<thead>
<tr>
<th>Information group</th>
<th>First year</th>
<th>Last period available</th>
<th>Updated</th>
<th>System source</th>
</tr>
</thead>
<tbody>
<tr>
<td>SUS resources</td>
<td>1996</td>
<td>Feb/06</td>
<td>Monthly</td>
<td>MS/SIH/SUS, MS/SIA-SUS, MS/Fundo Nacional de Saúde</td>
</tr>
<tr>
<td>Public Health Budget Information System</td>
<td>1998</td>
<td>2nd half of 2005</td>
<td>Twice a yr</td>
<td>MS/SIOPS</td>
</tr>
<tr>
<td>Database on hospitalizations</td>
<td>1992</td>
<td>Jan/06</td>
<td>Monthly</td>
<td>MS/SIH/SUS</td>
</tr>
<tr>
<td>Transfers to municipios</td>
<td>1998</td>
<td>Feb/06</td>
<td>Monthly</td>
<td>MS/Fundo Nacional de Saúde</td>
</tr>
<tr>
<td>Credit to providers</td>
<td>1996</td>
<td>Mar/06</td>
<td>Monthly</td>
<td>MS/SIH/SUS and MS/SIA-SUS</td>
</tr>
<tr>
<td>Information system for Payment Authorization Guide</td>
<td>1990</td>
<td>1997</td>
<td>Annually</td>
<td>MS/GAP</td>
</tr>
</tbody>
</table>


As it can be seen, there is a large amount of health information that is updated regularly and easily accessible. The problem is that it is contained in different databases and considerable effort is required to consolidate it so that it can be used to analyze the health situation in a given locality. To make access to this information easier, a few software products have been developed, in partnership with other institutions and public health specialists, that bring together information from different databases and place it at the disposal of health managers, the teaching and research community, and society in general.

Back in early 1991, DATAPREV’s Directorate of Health Systems Information prepared a list of potential SIS sources, describing the databases available in Brazil that could be of assistance in monitoring health issues in terms of basic health indicators; indicators of health policy, primary health care delivery/coverage, and health care delivery/coverage; and socioeconomic indicators. This initiative was followed by an expanded version in 1992, the product of a joint undertaking by FIOCRUZ and DATASUS, which was organized in the form of a directory: Diretório de Bases de Dados de Interesse da Saúde.
This guide was published the following year with an initial pressrun of 500 copies and reprinted shortly thereafter with another 3,000 copies, and a second edition was issued in 1997 with a pressrun of 1,500 copies.

With the spread and increasingly intensive use of the Internet and the availability of search engines, publication of the Diretório de Bases de Dados de Interesse da Saúde was discontinued. It had become clear that its main objectives – to provide references to existing national databases and information systems, and to facilitate access by researchers, professionals, and others interested in health – could now be met using faster and more dynamic resources and tools. In terms of information, these new resources and tools offered coverage and currency that could not be rivaled by the methods used to prepare the directory.

Since 1995, DATASUS has been looking for tools to deliver health information to users in a more structured manner. An example of this initiative is the publication Subsídios para análise [Analysis Aids] distributed to health managers at the state level and in the capital cities, as well as the health councilors in these spheres of government. Using maps and tables, this publication presents indicators such as hospitalization rates, expenditures on health, average cost of hospitalizations, and general hospital mortality rates, as well as historical series on the distribution and cost of hospitalizations and the distribution of hospitalizations by ICD chapter. It also shows the health regions that have the greatest variations in the selected indicators.

Also appearing during the period was the publication Indicadores Gerenciais e Qualitativos Básicos sobre a Assistência Hospitalar Prestada pelo SUS [Basic Managerial and Qualitative Indicators of Hospital Care Provided by the SUS], which presented a variety of different indicators – number of beds, bed occupancy
ratio, average stay, average cost per hospitalization, general hospital mortality, etc. – for the years 1993 and 1994, broken down by type of specialty (medical, pediatric, surgical, obstetric, psychiatric, tuberculosis, chronic and untreatable diseases, rehabilitation). This information was furnished by region and state or other federal unit.

As the Internet grew, these publications were discontinued, to be replaced, for example, by the *Caderno de Informação em Saúde* [Health Information Notebook], which brings together data and health indicators by selected geographic unit – the country as a whole, large regions, states, and municipalities – to facilitate comparisons and analysis. Applying TabNet to several databases, the *Caderno* makes information available on population, sanitation, the hospital and outpatient care network, hospital morbidity, births, mortality, immunizations, primary care, federal payments and transfers, and the public budget. These data and indicators are presented in the form of tables and graphs, some of them showing historical series. The information can be obtained from an online version, accessing the databases available through DATASUS, or as electronic spreadsheets that can be downloaded.

This application and other products aimed at the dissemination of indicators produced by the different databases, is one of the information groups under the heading of “Health Indicators” listed in Table 6. The first and second items refer to the two versions of the *Caderno*. The third item on the list is Basic Health Indicators and Data (IDB), a project of the Interagency Health Information Network (RIPSA) that brings together entities representative of the national technical and scientific communities involved in the production and analysis of data to make partnerships possible to provide information useful to understanding the reality of public health in Brazil and the trends thereof. The IDB correlates data
and indicators available for Brazil as a whole, large regions, states, metropolitan regions, and capital city municipios so that they can be tabulated, depending on the indicator, by sex, age group, and location of the household. Each indicator has a technical sheet with information on the underlying concepts and its applications, and in 2002 these sheets were assembled in a publication\textsuperscript{16} that is used by teachers of public health.

Table 6. TabNet Information Groups Available under “Health Indicators”

<table>
<thead>
<tr>
<th>Information group</th>
<th>First year</th>
<th>Last period available</th>
<th>Updated</th>
<th>System source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indicadores Municipais de Saúde</td>
<td>1994</td>
<td>2005</td>
<td>Annually</td>
<td>MS/SIH/SUS, MS/SIA-SUS, MS/Fundo Nacional de Saúde, MS/SIOPS, MS/SIM, MS/SINASC, MS/SI-PNI, MS/SISPACTO, IBGE/Censos, IBGE/Contagem da população and IBGE/Projeções intercensitárias.</td>
</tr>
<tr>
<td>Caderno de Information de Saúde [Health Information Notebook]</td>
<td>1994</td>
<td>2005</td>
<td>Annually</td>
<td>MS/SIH/SUS, MS/SIA-SUS, MS/Fundo Nacional de Saúde, MS/SIOPS, MS/SIM, MS/SINASC, MS/SI-PNI, MS/SISPACTO, IBGE/Censos, IBGE/Contagem da população and IBGE/Projeções intercensitárias.</td>
</tr>
<tr>
<td>Basic Health Indicators and Data (IDB) Indicators for the Basic Health Care Partnership [Yearbook of Health Statistics for Brazil]</td>
<td>1997</td>
<td>2004</td>
<td>Annually</td>
<td>RIPSÁ / IDB</td>
</tr>
<tr>
<td>Anuário Estatístico de Saúde do Brasil [Yearbook of Health Statistics for Brazil]</td>
<td>2001</td>
<td>2005</td>
<td>Annually</td>
<td>MS / SISPACTO</td>
</tr>
<tr>
<td></td>
<td>2001</td>
<td>-</td>
<td></td>
<td>MS/SIH/SUS, MS/SIA-SUS, MS/Fundo Nacional de Saúde, MS/SIOPS, MS/SIM, MS/SINASC, MS/SI-PNI, MS/SISPACTO, IBGE/Censos, IBGE/Contagem da população and IBGE/Projeções intercensitárias.</td>
</tr>
</tbody>
</table>


To follow the performance of the basic health care services and the health situation of the population, a partnership was created between the three spheres of government to develop a national instrument for monitoring and evaluating primary health care actions and services. Termed the Basic Health Care
Partnership, this instrument forms the basis for negotiating targets to be achieved by municipalities and states in the areas of children’s health, women’s health, control of hypertension, diabetes mellitus, tuberculosis, elimination of leprosy, and oral health. The basic health care indicators that are used, which have been defined by a directive, are periodically calculated by DATASUS and posted on its Website in a format similar to the Caderno, or Health Information Notebook.

In 2001 the Ministry of Health produced the Anuário Estatístico de Saúde do Brazil [Yearbook of Health Statistics for Brazil], using for this purpose the results of direct research or surveys of administrative records that give visibility to actions defined by public policies in the area of health. Its content took the IDB as a point of reference. The yearbook presents a collection of information on socioeconomic characteristics, organization of the health system, characteristics and dynamics of the population, its mortality and morbidity profiles and risk factors, the services network, and health actions, which together constitute important input for action and for dialogue between the sectors involved in implementation of the SUS. However, there has not yet been continuity in the realization of this initiative.

An historical review of the DATASUS technology, indicating the hardware and software that have been used and how they have impacted on the dissemination of information, is given as an appendix to this document.

**Evaluation of the Dissemination of Information**

In 2005, some 2,000 million outpatient procedures were performed, of which 218 million were high-complexity procedures, and there were approximately 12 million hospitalizations under the SUS. Roughly 1 million deaths and 3 million live births were registered in 2003. According to the CNES, as of March 2006 there were about 52,000 public health establishments and 74,000 private ones. In a country the size of Brazil, in which there are great inequalities in access to
technological resources and training, delivering the information produced by the different systems to each of the SUS establishments would be much more difficult without the tools developed by DATASUS, particularly those that take advantage of the Internet.

As noted earlier, the DATASUS Web site is mainly consulted by professional staff in the municipal health secretariats, personnel associated with the state secretariats, and universities requesting information related to the information systems or health area management and the execution of operational activities such as system downloads and data transfer. A profile of the users and their activities became evident from an on-site study\(^\text{21}\) conducted in 2002 over a period of 45 days with the participation of 1,015 respondents, including users from most of the states in Brazil. The majority were from the Southern and Southeastern regions of the country, which are the most affluent and highly developed. Only one small state in the Northern Region, Acre, did not participate in the study.

The results showed that usership closely paralleled the site’s objectives – i.e., to make information available to assist in the objective analysis of the health situation, decision-making based on real evidence, and the programming of health actions – unlike the purpose of the Ministry of Health Web site (www.saude.gov.br), which is to provide information to the population on its programs, publish recommendations, promote health campaigns and educational films, etc.

It was noted that about 50% of the users still had dial-up connections. This limitation is taken into account in the development of applications and resources offered on the Web site, thus enabling users with slower Internet connections to access the information they need in order to do their work.
In 2005, approximately 3 million operations were performed using TabNet. The largest proportion (21% of the tabulations) involved accessing demographic data, probably due to the fact that the first screen of the online version of the Caderno [Health Information Notebook] performs tabulations using these data (referred to as Municipal Indicators). Accessing data on basic health care, outpatient care, hospitalizations (mainly hospital morbidity), and mortality accounted for 10% to 14% of the TabNet operations. Tabulations using data from the IDB indicators on financing and live births represented 6% and 8% of the operations, respectively. The remaining tabulations accounted for less than 5% of the total.

Figure 1 shows the rising curve of TabNet operations, with declines during December through February (the time when many government workers take vacation because the schools are not in session) and in April and June 2005 (because of technical problems, it was not possible to obtain information properly during those months). The peaks in use of the Caderno probably correspond to updates made by DATASUS in the spreadsheets available for downloading and to use by managers in their partnership activities with the federal government. The steep rise corresponding to the online version of the Caderno (Municipal Indicators – accessed via the Ministry of Health Web site) may be a sign that users are migrating to the electronic spreadsheet version for this means of accessing information.
Figure 1. TabNet operations executed, 2000–2005.

Legend: Internet, via browser; Caderno queries; Municipal queries, MS Web site.
The scientific community is also making use of the information made available by DATASUS for their research and publications. A search of Google Scholar (http://scholar.google.com/schhp?hl=pt-BR) in February 2006 turned up 1,800 hits for DATASUS in published articles and technical reports.

However, despite the effort to make a broad array of information available for users to do their own tabulations, representatives of social empowerment are still not using the DATASUS Web site in the course of their work. They have mainly requested data on SUS financing, and the data available may be of assistance to them in overseeing expenditures made by SUS managers, but the technical language on the Web site may not be sufficiently clear for those who do not have a good command of the subject. The need to develop websites or specific products for members of the health councils was identified in meetings held with representatives of RNIS in 2000, as well as in the Workshop on Health Information for Social Empowerment held in 2003.22

Even though a lot remains to be done, the contribution that DATASUS has made to the dissemination of information for management activities, scientific research, and monitoring of the SUS is already recognized both national and internationally, especially because of its website. And indeed, WHO stated in 2000 that the DATASUS Web site is recognized as one of the best sources of local, state, and national health information in the world.23

The DATASUS initiatives to disseminate health information have always been based on the assumption that one of the department’s purposes is to provide needed information of good quality for the development of health. Nevertheless, the SUS has not actually had a formal policy on information and data processing. The only precedent is Ministerial Directive 118/GM of 1993,24 which in its Article 1 authorizes DATASUS to make health information available on one particular
system. Specifically, this directive states that “DATASUS, the Department of Informatics of the Unified Health System under the National Health Foundation, is authorized to place the information and data stored in the Hospital Information System (SIH/SUS) at the disposal of state and municipal health leaders, service providers, health professionals, and users in general.”

In 2003, DATASUS led the initiative to draft the formal National Policy on Information and Data Processing (PNIIS). The XII National Conference on Health, the first conference in this series to adopt the theme “Information and Communication in Health,” approved deliberations that reiterated the fundamentals of the PNIIS proposal in the following words: “The National Health Council, working together with the Ministry of Health, shall define strategies for drafting and implementing articulated policies on information, communication, continuing education, and mass education in the area of health for the three spheres of government, guaranteeing greater visibility for the lines of direction of the SUS and for health policy, actions, and resource utilization, with a view to expanding participation and social empowerment, and meeting the demands and expectations of society, thus making it possible to strengthen the democratization of all aspects of information and communication.”

Approval of the PNIIS amounted to important, explicit reinforcement of the DATASUS policy on the dissemination of information, giving the agency the means and assurance with which to take on its current challenges as well as those yet to arise in the future.

**Future Potential and Challenges**

According to WHO, a health information system is a mechanism for the collection, processing, analysis, and transmission of information needed in order to organize and operate health services, as well as for research and planning with a
view to controlling diseases. PAHO, in turn, views the health information system as a set of components (administrative structures, department of health statistics, health information units) acting in an integrated manner for the purpose of producing needed and timely information for implementing decision processes in the health services system.

Thus, the dissemination of information comes as the final stage in the process of developing an information system, after the data and information have already been defined, collected, stored, and processed. However, the target of dissemination should be kept in mind from the outset in defining the system and considering the need to integrate different databases to analyze the health situation and trends in specific localities.

It has been seen that the national systems have had problems integrating the databases and making them compatible. DATASUS has sought to reduce these problems through its initiatives to integrate different databases by offering tools such as TabWin, TabNet, and more recently the Caderno, or Health Information Notebook. The Caderno, for example, has been used by local managers in negotiating agreements between different spheres of government aimed at improving the health of the population. However, studies have shown that, for a number of reasons, the use of health information in decision-making is still insufficient in some municipalities and states.

An indispensable task in expanding the use of health information is the ongoing training of local managers and health professionals in how to access the universe of information and perform analysis of the health situation at the local level. This issue is of strategic importance, especially in light of the natural and systematic changes that occur in government. Along with this training, it is
important to encourage the installation of tools such as TabNet in the state health. Secretariats to give their managers more rapid access to the information they need.

The quality and coverage of existing information reflect the notable differences between our country’s regions. Regular use and analysis of the data will lead to improvement in the quality and flow of the information. Dissemination of the information plays an important role in this process, because it is through feedback, when the information is matched against reality, that discrepancies can be corrected so that the information can then be relied upon for decision-making.

Investments made by DATASUS in recent years to seek out and develop information resources, coupled with the adoption of policies on the dissemination of information, have created greater potential for access to data and health information. These efforts have been possible because of the large trove of information available in a single institution, which made it possible to organize the data similarly in all the systems and disseminate the information in a standardized form.

Nevertheless, there are still challenges to be overcome in order to improve the dissemination process. For example, there is need to broaden and popularize the means of distribution, expand the dissemination network, and develop policies and actions for the dissemination of health information that are aimed more directly at social empowerment.

Broadening the means of distribution can be achieved by making greater use of: (i) modern media technology as yet untapped (cellular networks, digital TV, etc.); (ii) technology already being used (Internet, print media, publications, pamphlets, primers, etc.); and (iii) other existing forms of dissemination that have not been fully explored, such as mobile service in vehicles and community
programs on radio, open TV, and cable, and campaigns, both nationwide and in specific health areas.22

It is also important to ensure the accessibility of the information, both to make it available to those who may have difficulty using the system, and to allow dissemination and information analysis tools to run under all hardware platforms and any kind of software, which is becoming increasingly diversified with the spread of freeware support programs. To widen the dissemination network, given the growing importance of the Internet as a vehicle for dissemination and communication, its expansion should be pursued through the support and promotion of digital inclusion programs for managerial, social empowerment, and health sector executor units, as well as citizens in general.

Developing policies and actions for the dissemination of health information aimed at social empowerment means reaching out to segments of the SUS that had not been contemplated previously: those who serve on the health councils. The information available in the form of indicators and tables are difficult to understand by lay users, who make up the majority on these councils. It is necessary to create, through partnerships with specialists and the social empowerment community, easily understandable language and analysis tools that will help the members of these councils to carry out the responsibilities with which they have been entrusted.

Since the databases cover the entire life cycle of the country’s citizens – birth, basic health care, immunization, outpatient care, hospitalization, and death, with links to specific health programs (hypertension, cancer of the breast and uterine cervix, leprosy, etc.) – the large volume of health information available in Brazil can undoubtedly be of assistance in appropriate decision-making, based on administrative and epidemiologic analysis.
The search for and adoption of information technologies that can be enlisted as tools in support of health information systems can help to encourage and support the utilization of information so that actions and services bring about improvements in the health of the Brazilian population.

Appendix — Historical Review of DATASUS Information Technology

During the time of DATAPREV, the predecessor of DATASUS, the health information systems resided on a Unisys mainframe platform and data transfer was accomplished using the National Package Network (RENPAC) linked to the Unisys proprietary poll/select protocol (half-duplex synchronous or asynchronous transmission with multipoint addressing). DATASUS then added to this hardware a Bull (Honeywell) computer that had belonged to INAMPS. This computer was running an Oracle Relational Database Management System, thanks to which DATASUS was able to transfer the health systems from the Unisys environment and become independent of DATAPREV. At that point the original query sets written in SQL Plus (Structured Query Language) were reconstructed, resulting in a broad in-house Oracle/SQL culture.

Next, the first predefined online query sets were developed for accessing the Database of Hospital Admission Authorizations (BDAIH) in order to query hospital movement. These sets were constructed in the query language processor QLP II with the capability of recovering data from a previous query, which made it possible to establish and control optimized topologies for accessing the datasets. QLP-Tx software was used to emulate a Unisys terminal on IBM PC-XT/AT-compatible microcomputers.

In 1993, RISC servers (Reduced Instruction Set Computers) were acquired, which needed fewer instructions and executed them at higher speeds. The
Oracle/SQL environment was retained and used as reserve software for running batch applications in Pro-Cobol and PL/SQL. This acquisition allowed for progress in data processing, reducing the time between the care provided and the availability of information about it, in addition to reducing the cost of equipment maintenance.

Responding to the need for health information, in 1994 DATASUS developed the TabDOS tabulator in Turbo Pascal, and with the advent of Windows, TabWin was developed in Borland Delphi.

In 1995, after the National Research and Teaching Network (RNP) was made available to non-academic institutions, Embratel offered to provide access to the commercial backbone of the Internet through the service provider GIX 49 (Global Internet Exchange). At around this time, CD-ROMs was starting to be mass-marketed, making it possible to port larger quantities of data and applications, and DATASUS decided to disseminate its data through this medium. The files were, and still are, distributed in DBF format, which is nonproprietary technology. Also at this time several programs were developed in Fox-DOS for executing the construction phases of the DBF files to be distributed (filtering, register correction, consistency testing, etc.). Also, support tools for this task were written in Borland Delphi – for example, the DBF file manipulator distributed on the CD-ROM, called VerDbf, which offers facilities for sorting, concatenating, and generating reports.

Also in 1995, DATASUS, in partnership with the WHO Collaborating Center for the Classification of Diseases (CBCD) at the School of Public Health, University of São Paulo, developed the System for Selection of the Underlying Cause of Death (SCB-10) in Prolog, with a view to speeding up and standardizing the process of selecting the underlying cause of death for incorporation in the Mortality Information System. The SCB-10 program has a knowledge base derived
from the ACME (Automated Classification of Medical Entities) decision tables, published in 1992 by the National Center for Health Statistics (NCHS), Hyattsville, MD, USA.

The first experiences connecting and interfacing between Windows clients and information servers such as http (Hypertext Transfer Protocol) were introduced in the standard CGI (Common Gateway Interface), usually implemented in Borland Delphi, and in IDC (Internet Database Connector) scripts with companion HTX templates. The online query sets were reprogrammed and expanded in Borland Delphi and IDC/HTX. Consolidation of knowledge from network and Web applications brought new approaches. The introduction of ASP, for example, solved the problem of different technologies configured on the same server.

In 2001, new conceptual development tools emerged in Brazil, such as RUP (Rational Unified Process), which is intended, through an object-oriented software engineering process, to guide the evolution of organizations that are developing software toward its objectives. RUP was taken into account during development of the Ministry of Health website (www.saude.gov.br) and also in the development of other systems under the responsibility of DATASUS.

In 2003, the federal government announced a policy of using freeware for its information systems. DATASUS is gradually adopting development tools such as PHP and MySQL databases, while retooling its applications so that they will run under the Linux operating system.

In line with current trends in information science, in 2005 DATASUS incorporated digital access into its website, with a tableless structure supported in CSS (Cascading Style Sheets) and TabWin. Always seeking to take advantage of the latest concepts in business intelligence and data warehousing, such as slice-and-dice, ranking, and query generation, it has added connection devices with
diverse platforms via SQL and has included an interface with the R Project for Statistical Computing environment, the latter having turned out to be extremely efficient in the generation of visual and numerical statistical simulations. TabWin makes it possible to import map files created using various geoprocessing programs such as ARC/Info, Atlas-GIS, EpiMap, MapInfo, Map Maker, and Garmin GPS, and it also allows for the exportation of tables generated in the following formats: HTML, XML, SPRING table, dBase III plus, Excel spreadsheet, SQL script, and CSV (comma-separated values).

DATASUS has been making an effort to offer distance learning, with courses on the utilization of TabWin and coding based on ICD, in addition to participating in the RNIS effort, which in 2001 completed a series of six distance education courses geared toward a national program for training specialists in health information. Soon a total of nine courses will be available, using the tool Moodle. Distance training has been shown to be an important tool, especially for a country the size of Brazil.

Note

The term “Public Health Reform” was used for the first time in Brazil in connection with the Italian public health reform. The expression was forgotten for a while and then resuscitated during the debates leading up to the VIII National Conference on Health when the expression was used to refer to the prevailing ideas regarding the changes and transformations that were believed to be necessary in the health area. These changes referred not just to the health system but to the entire health sector, introducing a new concept in which the final outcome was understood to be improved living conditions of the population as a whole. At the beginning of these debates, the movement for health reform did not have a specific name. It was simply a group of people who shared the same ideas regarding the field of health. At a meeting of the Pan American Health Organization in Brazil, these people, one of whom was Sergio Arouca, were referred to pejoratively as the “public health party.”
However, the group was not a party; it was a much larger mobilizing force, eventually becoming a broad movement for social action. In a master’s thesis mentored by Sergio Arouca in 1986, *Reviravolta na saúde: origem and articulation do movimento sanitário* [A New Direction in Health: Origin and Articulation of the Public Health Movement], the action of this group was referred to for the first time as a public health movement. Other names emerged as well, such as “public health reform movement.” In his book, *O dilema preventivista* [The Preventivist Dilemma], Arouca notes that any of these terms may be used.
Chapter References


27 Castro, RCF. Comunicação Científica na Área de Saúde Pública: 
**Perspectivas para a tomada de decisão em saúde baseada em 
conhecimento.** Doctoral thesis. Departamento de Prática de Saúde
Pública da Faculdade de Saúde Pública da Universidade de São

28 Moraes, I.H.S. et al. 1994. Utilização de Grandes Bancos de 
(orgs.) **Qualidade de vida: compromisso histórico da 
Epidemiologia.** Belo Horizonte: COOPMED Editora-Abrasco, 
Belo Horizonte-Rio de Janeiro.

29 Branco, M. A. F. **Sistemas de Informação em Saúde no nível 
local.** Cadernos de Saúde Pública, Rio de Janeiro - RJ, v. 12, n. 2, 

Available at 
http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1413-
March 2006.

7. The RIPSA Initiative: Ten Years of Evolution

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1. Background

The area of health information in Brazil presents a complicated picture with diversified purposes for production, dissemination, and utilization of data and information, resulting in multiple initiatives by different institutions involving the three spheres of the national health system and other sectors of the government, with the participation of teaching and research institutions as well.

The production of services in the health sector is constantly generating a large mass of data – with most data accessible via the Internet – which comes from information systems created by the federal government in order to meet specific technical and managerial needs. Increasingly, these systems had been overlapping one another over the decades, without any effort to rationalize the ways in which the data were collected with a view to making their records and variables compatible. The data being produced referred mainly to records on mortality, live births, reportable diseases, hospital and outpatient care, and, more recently, public budgets, health plans, and private health insurance.

With creation of the Unified Health System (SUS) in 1990, the delivery of health services was decentralized to the municipal sphere, causing an increase in the needs and requests for information for managing the sector. This made it increasingly necessary to change the dimensions of health information and restructure existing systems, making better use of existing information resources. And in fact, the law that established the SUS foresaw this need and created the National Health Information System (SNIS). 1

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Even so, for a number of reasons there continued to be overlapping central initiatives, which overloaded the services network with tasks related to recording, consolidating, and transmitting the information needed for technical and administrative purposes. Since the capacity to respond to these queries reflected the prevailing conditions in the different spheres of network management – socioeconomic, administrative, technical/operational – the quality and coverage of the information produced was spotty and unpredictable, making it difficult to interpret.

Other available sources of information are studies, research projects, and health surveys carried out under different initiatives. Of special note are the institutional and demographic studies conducted by the Brazilian Institute of Geography and Statistics (IBGE), including activities under an agreement with the Ministry of Health.²

There are also surveys and special studies promoted by the Ministry in collaboration with research institutions in the health sector, carried out under isolated technical initiatives that are not part of a comprehensive plan.

The fragmentation that exists is both the cause and the effect of the limited use made of available data in the sector’s decision-making processes. On the one hand, there are no objective political and administrative structural conditions that oblige health managers to give priority to producing systematically measured evidence as a basis for their actions. On the other hand, the sector’s technical areas have not attempted to develop methodologies for analyzing situations and trends that objectify health issues so as to provide tools for intra- and intersectoral decision-making. The result of this inertia is that initiatives in the area of information continue to be isolated and insufficient to influence the general health
process, while political decisions in the health sector tend to follow some other logic that does not involve the use of systematic information.

As it turns out, the main users of the data from the national health information systems are academic institutions. Despite the importance of their participation – and their valuable contributions toward improving the systems as such – it must be kept in mind that the main purpose of these tools is to support the management of the SUS, which has not yet become a full reality.

Another point to be considered is the need to improve technical and scientific output in the health field as a source of essential knowledge on which to base public policies and actions in the sector. Recent progress in development of the Virtual Health Library (BVS)\(^3\) is opening up promising new opportunities, such as the organization of information sources for decision-making and the development of methodologies for linking documentary and numerical databases in the national information systems.

These considerations led the Ministry of Health and the Pan American Health Organization (PAHO) to agree on the need for a collective effort to produce and make available information that is appropriate for the formulation, administration, and evaluation of public policies and actions in health. Thus, the Interagency Health Information Network (RIPSA) was created in 1996 by a Ministry of Health Directive\(^4\) under a cooperative agreement with PAHO.\(^5\) An important factor in bringing this about was the Regional Database Initiative, created by PAHO in 1995, with a view to enlisting national counterparts in the effort to document and disseminate information on the health situation and its trends.
2. Concept: Purpose, Objectives, and Strategies for Action

The initiative consists of supporting joint efforts involving national institutions responsible for the production, analysis, and dissemination of health information with a view to generating output of common interest. It is not an investment project or a program structure capable of taking measures that would override the institutional responsibilities of the participants.

The central ideas were developed in consultation with institutions engaged in strategic action in the information area: IBGE, the Institute of Applied Economic Research (IPEA), the Brazilian Association of Collective Health (ABRASCO), the SUS Department of Informatics (DATASUS), the Oswaldo Cruz Foundation (FIOCRUZ), the National Center of Epidemiology (CENEPI/FUNASA), the School of Public Health of the University of São Paulo (FSP/USP), and the São Paulo State Statistics and Data Analysis System (SEADE Foundation).

The initiative was conceived by the ministry and PAHO as a model of co-management action in which the participating institutions share the development of information products previously agreed upon, on the assumption that the process will not interfere with the institutions’ respective managerial dynamics. The network would operate in a condominium style, each member making the commitment to contribute with its own expertise toward the execution of a general working plan approved by the group of institutions as a whole. The common objective would be to rate the basic content of information on the health situation in the country and its progressive improvement. The network would be managed through a collegiate structure that would provide strategic orientation for technical production and for the intended interagency articulation.
According to the conception of RIPS A, the health decision-making process requires information that goes beyond the purview of the sector, since it is necessary to consider the conditioning and determining factors of health. Demographic, socioeconomic, and environmental information is usually produced in other spheres of government that are tied to the planning sector. Sectors such as education, social security, labor, and the environment, among others, have their own information systems that generate important input for understanding the health situation and its trends. Therefore, intersectoral coordination is one of the principles adopted for the composition and operation of the network.

Technical production within the network is focused on building a database of indicators that is regularly updated and improved, which needs to be configured so that it will provide a general panorama, as consistent as possible, of the health situation and its trends. For this purpose, the list of indicators must be limited, based on the “set of basic indicators” defined by PAHO.⁶

Certain niches for strategic action under the RIPSA umbrella were clearly established from the outset: (i) construction of a matrix of indicators, seen as a tool for unifying the network and providing an effective exercise in teamwork; (ii) selection of DATASUS as the shared residence of the database of indicators, regardless of the source; (iii) definition of the producing source of each indicator, based on the institution’s identification with the subject matter in question; and (iv) rating the indicators based on their shared attributes, thus ensuring overall consistency and uniformity.

Harmonious construction of the network implies well-established and systematic interinstitutional and interdisciplinary teamwork to oversee the development of activities, products, and events. This intention is made viable through joint processes – collegiate forums, committees, working groups – that are created for reviewing and updating the matrix of indicators, checking the
consistency and significance of the data and indicators disseminated each year, and maintaining the conceptual and methodological integrity of the indicators.

Considering that RIPSA mainly intends to serve the SUS at the national level, the Ministry of Health is naturally taking the lead in this process, while at the same time respecting the principle of collegiate deliberation on a consensual basis, which is fundamental to participation in the institutional network. That being the case, the technical and normative agencies of the Ministry of Health that are involved in the production, analysis, and dissemination of information are integral members of the network.

The partnership with PAHO was undertaken as a strategic element for ensuring the stability of the process, since PAHO has the status to mediate a collaborative effort of this nature. An international organization specialized in health and already thoroughly engaged in technical cooperation, PAHO has a mandate from the countries of the Western Hemisphere to promote the development of information in the area of health.

Based on these assumptions, RIPSA’s collaborative working mechanisms are implemented with resources defined in a cooperation agreement between the Ministry of Health and PAHO, through PAHO’s representation in Brazil. The member institutions cover the costs of their own activities, while RIPSA participates, through resources agreed upon, in bearing the cost of products being developed in accordance with its general plan of action.

3. Organization and Operation

The Ministry of Health directive that governs RIPSA sets forth its structure and operating mechanisms and places it under the coordination of the executive secretary of the ministry, who is responsible for articulating the program.
Following changes in the ministry’s direction and manner of action, the network has adjusted to new realities in the institutional context through successive revisions of the original directive.

The directive\textsuperscript{8} establishes that RIPSA shall be composed of: (i) the Ministry of Health agencies directly or indirectly responsible for the production of information and for the management of national health policies; (ii) other governmental and nongovernmental institutions representative of the technical, scientific, managerial, and social empowerment elements involved in the production, analysis, and dissemination of data of interest to health; and (iii) specialists of renowned expertise in matters of interest to RIPSA. The member institutions participate in the shared collaborative process through their representatives in the Network’s collegial forums and technical committees, which are:

\textbf{The Interagency Workshop (OTI) —} This is RIPSA’s principal collegial forum, which is entrusted with participative planning and technical direction of activities, and with advising the National Health Council in its area of specialization.\textsuperscript{9} The OTI brings together representatives of institutions concerned with the production, analysis, and dissemination of national data and information of interest for gaining an understanding of the health situation. It is expected to meet at least twice a year to review progress in its activities and approve the activities and products proposed by the Network’s secretariat for the following period. Between 1996 and March 2006, the OTI held a total of 13 meetings, the proceedings of which are available in the corresponding reports.

\textbf{Indicator Management Committees (CGI) —} These committees are responsible for continuously perfecting the databases through regular analysis and updates. There is a committee for each of the six categories of indicators in the
RIPSA matrix. This framework was established in order to maximize the institutions’ participation based on their respective areas of concentration. Each committee is coordinated by the institution which, based on consensus reach by the OTI, is considered most representative of the subject area: demographic indicators, IBGE; socioeconomic indicators, IPEA; mortality indicators, School of Public Health/University of São Paulo; morbidity and risk factors, Secretariat for Health Surveillance/MS; resources, Undersecretariat for Planning and Budget/MS; and coverage, Secretariat for Health Care/MS.

Committees on Interdisciplinary Topics (CTI) — Based on a proposal by OTI, these provisional committees have been created to explore methodological and operational issues related to the network’s products. Their composition depends on the particular issue, which may require the participation of institutional representatives and invited specialists. The work of each CTI is preceded by the preparation of a “basic schema,” terms of reference, which are submitted to the OTI for approval. Depending on the nature of the issue, the work of the CTI may require the support of ad hoc working groups.

Each committee’s final output is a report with a list of recommendations, which in turn serve as the basis for focused deliberations by the OTI leading to their implementation by the network’s secretariat and the member institutions of the OTI itself. Since the creation of RIPSA, a total of 16 such committees have been created, which have addressed a broad spectrum of issues in the field of health information. Details are available in the reports of the meetings.

Technical Secretariat — The Technical Secretariat is a team appointed by the executive secretary of the Ministry of Health to support the implementation of RIPSA activities and products, based on the Operational Plan for Products (POP) approved each year by the OTI. The composition of the Technical Secretariat has
varied considerably over the years in response to structural and functional changes in the Ministry of Health. Given its responsibility to promote the decisions recommended by the OTI and to turn them into reality, the Technical Secretariat is in fact the operational core of the network.

4. Basic Health Indicators and Data (IDB)

RIPSA’s matrix of basic indicators includes the title, definition, method of calculation, analysis categories, and the sources of data for each indicator. It is based on a document from the Government of Canada that defines and rates a set of community health indicators. The following criteria were followed in constructing the matrix: (i) relevance for understanding the health situation and its causes and consequences; (ii) validity for guiding policy decisions and supporting social empowerment through the SUS; (iii) appropriateness to the working processes inherent in health system management; and (iv) availability of national databases, information systems, or studies.

The matrix is the tool for producing the Basic Health Indicators and Data (IDB), which are consolidated by DATASUS on an electronic platform and made available via the Internet together with a tabulator (TabNet) that facilitates access by users. Initially, the plan was to have about 100 indicators, divided among the six subject areas. For each indicator, the data are broken down by geographic unit, age group, sex, and residential area (urban or rural). Other analysis categories may be accessed for determining indicators such as years of schooling, which is used as a proxy for social status. A synthesis of the data corresponding to the last year for which a report is made available is published as a printed pamphlet, illustrated with an annual theme.

For each indicator there is a rating sheet, downloadable from the databases, which is designed to help users understand the importance of the data disseminated
in the IDB. The sheet gives standardized information on the concept, interpretation, uses, limitations, sources, method of calculation, analysis categories available and suggested, and an interpreted table showing the potential use of the indicator.

Publication of the IDB began in 1998 with publication of the IDB-1997, both as a printed pamphlet and on the Internet. Since 1999, the database has been accessible using TabNet, and since 2001 data have been available for the municipalities corresponding to the state capitals. Since 2000, the pamphlet has been dedicated each year to a particular theme of importance for public health in Brazil. To date, the following themes have been featured: infant mortality, violence, women’s health, health of older persons, and public sanitation. IDB-2004 recaptured the historical series of indicators since the beginning of the 1990s to the extent that the data were available.

In addition to up-to-date databases available on the Internet and the printed brochure that appears annually, the health indicators for Brazil are also the subject of a RIPSA publication that seeks to integrate all the work that has been done and ensure conceptual unity for the process. This book, available both in hardcopy and on the Internet, has served as a reference for governmental and academic institutions interested in constructing and analyzing indicators in the area of health.

5. Other Network Topics and Products

The OTI recommendations for the fiscal year are consolidated in RIPSA’s POP, which lists products and tasks under way, and indicates the institutions responsible for carrying them out. Some are implemented by committees concerned with specific topics, which can be approached from new perspectives. The main themes addressed by RIPSA over the 10-year period are reviewed in the paragraphs that follow.
One of the network’s first initiatives was to analyze critical issues related to compatibility among the national databases on morbidity, mortality, live births, and health care. The outcome of this effort was the proposal of a detailed set of standards for the registration of basic categories (identification of the individual, place where care was provided, attending health professional, and event), which according to the Ministry of Health are shared in common by all the health information systems.¹³

Discrepancies among the data sources used in calculating the indicators of perinatal, infant, and maternal mortality, which gave rise to conflicts within the SUS in some of the states, were dealt with by creating a consistency index for data contained in administrative records.¹⁴ In the case of the Federal District, a field study promoted by RIPSA¹⁵ made it possible to resolve the impasse.

The heterogeneous nature of sectoral information on the relationships among health, health insurance, and employment was the subject of an exhaustive interdisciplinary analysis that resulted in a set of recommendations approved by the OTI. Among the products generated was a detailed study on the recording of employment and economic activity in the health information systems.¹⁶ The Ministry of Health has taken steps to initiate implementation of the recommendations based on results in sentinel pilot areas.

RIPSA has taken action to toward the standardization of clinical records, developing a set of essential information fields to be included in the patient’s online chart so that the variables can be integrated into health information¹⁷ based on a methodology that is open to participation via the Internet by those who are interested.

It was proposed to reformulate the Food and Nutrition Surveillance System (SISVAN), given the difficulties encountered in meeting the different needs for
information at the three levels of the SUS. One of the accomplishments was arriving at a technical consensus regarding indicators for breast-feeding, given the discrepancies in the historical data available.

To meet the demand for the *training of health information professionals*, RIPSA has proposed a comprehensive program for teaching institutions according to types of clientele and subject matter priorities, with the respective curricula and content. The proposed program was adopted by the technical area in the Ministry of Health.

An initiative referred to as the *Health Situation Forum*, based on municipal experiences in organizing information for purposes of SUS management and social monitoring, was undertaken with RIPSA support with a view to creating an application that would construct indicators automatically based on the national information systems, with parameters for their preliminary interpretation.

In response to a call from the IV Brazilian Congress of Epidemiology, RIPSA summoned the experience of its members to undertake the *analysis of spatial data in health* to standardize basic concepts and organize queries handled by IBGE and other agencies with geoprocessing technology. As a result, two well-received technical publications were produced which offered guiding principles for managers and professionals in the field of health.

The refinement of indicators for chronic degenerative diseases – a topic of growing importance in the SUS – was addressed by a committee of specialists who made recommendations for updating the RIPSA matrix. The same approach was adopted for the topic health of older persons, which resulted in a specific matrix of indicators accompanied by the corresponding rating sheets for analysis of this issue.
The need for an intersectoral approach to the topic accidents and violence, given their impact on the health services infrastructure, led to a joint analysis of existing information on this topic available from systems in the areas of health, transportation, and justice. This undertaking resulted in recommendations for improving the current indicators and a proposal for an expanded matrix to be used by professionals specializing in this subject area, with duly accepted indicators.26

Initial efforts to promote an analysis of RIPSA data led to a publication prepared jointly with IPEA on the consistency of the indicators for measuring and monitoring inequities in health in Brazil.27 Subsequent studies, supported by other partner institutions,28, 29, 30 provided useful information for decision-making in health. This RIPSA initiative also contributed toward putting together information on the health picture for the rest of the Americas.31 The subject of inequities in health was assigned to a committee, which did an in-depth analysis of the consistency of available data, and their findings provided input for the project “Atlas of Health Inequities in Brazil,” an initiative of the Ministry of Health.

With a view to encouraging the use of information in the decision-making process, RIPSA has been supporting the Ministry of Health in developing a model for monitoring the National Health Plan (PNS).32 Based on specially constructed indicators, it is intended to propose instruments for monitoring the health situation and implementation of the PNS.

Information on health and the environment is scattered in different sectors of the government. With RIPSA support, an intersectoral committee has been attempting to systematize content on the environmental determinants of human health through an inventory of the information systems and preparation of an analytical text on the current situation in the area.
6. Functional Evolution of the Network

RIPSA’s working dynamic is conditioned by the Ministry of Health management process, which in turn is influenced by frequent political, technical, and administrative changes that tend to generate new priorities and threaten the continuity of actions and projects. Between 1996 and 2006, the Ministry of Health was under the direction of eight different ministers, each of whom treated the area of information differently, with significant repercussions for the Technical Secretariat of the network.

Broadly speaking, the functional evolution of RIPSA can be broken down into five chronological phases, corresponding to the different ways in which the Technical Secretariat has fit into the ministry’s organizational structure. On more than one occasion, it has been necessary for other institutional partners in the network to intervene in order to keep activities on track.

The first phase corresponds to the conception and early days of RIPSA (1995-1996), during which the PAHO representation was in direct communication with the leadership in the Ministry of Health. This phase culminated in the first two meetings of the OTI, which were instrumental in development of the network’s conceptual frameworks and their formalization under a ministerial directive in which RIPSA was attached to the ministry’s executive secretariat.

During the second phase, from 1997 until May 2000, RIPSA was placed under a recently created office in the Ministry of Health called the Secretariat for Health Policy (SPS/MS), which had responsibility for directing national health policy. At first, the actions agreed upon under the previous administration continued to be carried out – most notably, building up the operational structure of the network, formalizing cooperation with PAHO, identifying member agencies, and creating the first two topic-focused committees. Despite some changes in
management in 1998 which slowed down the process, by the end of 1999 the first two IDB reports (1997 and 1998) had been prepared and there had been four meetings of the OTI.

The situation became critical in 2000, when the SPS/MS made a significant shift in direction and the RIPSA management model had to be adapted to the new circumstances. Coordination of the RIPSA Technical Secretariat ended up being informally transferred to the National Epidemiology Center in the National Health Foundation (CENEPI/FUNASA). The difficulties encountered during this third phase, which lasted until the second half of 2002, were offset by the valuable support that the CENEPI leadership gave to the network’s technical activities and to the expansion of its reputation, as it came to be recognized by professionals throughout the country. The 2001 and 2002 editions of the IDB appeared during this period, as well as important technical publications on rating the indicators, studies on inequities, and analyses of the health situation.

Despite this progress, the scattering of efforts and the informality of its direction compromised the course of development that RIPSA had started out on – namely, to serve as an interinstitutional strategy aimed at contributing to health sector management. This path was resumed in mid-2002, when new leadership in the ministry placed the network once again under the executive secretary. With this move, RIPSA embarked on its fourth phase, which emphasized rearticulation with support within the ministry and the participation of DATASUS, which at the time was separate.

In the meantime, the federal administration underwent major changes at the beginning of 2003, which included reformulation of the organizational structure and functions of the Ministry of Health. The new administration resumed discussions of national health information policy in the terms that had been
envisioned at the time the SUS was created. It was proposed to direct this policy through an “Information and Informatics Area of the SUS (AII/SUS),” which would include DATASUS. After several months of effort, the Technical Secretariat of RIPSA was reconstituted and its agenda was adapted to the new institutional context, following the OTI Plan.35 The IDB-2003 was completed, and a new plan was formulated for products and related resources.

Since the formal structure of AII/SUS had not actually been created, internal administrative difficulties gradually compounded, and eventually the concept was abandoned as a result of new administrative changes at the beginning of 2004. Responsibility for the information area was centralized in DATASUS, with the result that the Technical Secretariat of RIPSA was placed under this agency until the second half of 2005. DATASUS dropped the policy on information and informatics and gave up trying to develop the National Information System (SNIS) provided for in the SUS legislation. It continued to act as a provider of services and manager of information technology, with no tie-in to the objectives and processes of RIPSA.

Nevertheless, the network’s operating mechanisms continued to function.36 Thanks to other circumstances, it was intensely productive during the second half of 2004, which had a favorable effect on the work of the OTI.37 For a while, there was hope of revitalizing RIPSA, but this hope was dashed in early 2005 because of changes in the ministry’s executive secretariat that had a severe effect on coordination of the network.

Even broader changes occurred in July 2005, when the entire leadership of the Ministry of Health was replaced. The resulting arrangement was to mark the next and current phase of RIPSA. This time, the Technical Secretariat was attached to a special advisory office on information directly under the executive secretariat,
and starting in December of that year the network’s activities were resumed in full force. The ministerial directive corresponding on RIPSA was updated, the composition of the Technical Secretariat was revitalized, the OTI was convened, production of IDB-2005 was resumed, a strategic plan of action was developed, and an event was organized to commemorate the tenth anniversary of the network – all of this demonstrating the vitality of the process despite all the stumbling blocks encountered in its evolution.

The agenda for the near future calls for consolidating the gains achieved over the history of RIPSA, especially continued production of the IDB which has served to integrate the process and provide a foundation for the analytical publications and projects. New lines of action should be directed mainly toward: (i) developing standards for the representation of health information that facilitate interoperability of the systems and interpretation of the information; (ii) developing methodologies for analyzing information and preparing executive reports in support of decision-making processes in the SUS; (iii) promoting adoption of the RIPSA interinstitutional formula at the state level; and (iv) joining forces with the Virtual Health Library (BV S), with the support of technologies that constitute sources with which to build up health information and indicators.

7. Discussion

RIPSA is an experiment based on the reality of what the health sector in Brazil has been experiencing in recent decades, and of how the organization, production, and use of data and information fit into this picture. It is an initiative applied to Brazil’s very special circumstances, and as such, it deserves to be studied and reflected upon. The report that has been presented has sought to give an understanding of the complex institutional processes that enter into play in the development of an initiative of this kind.
Ever since federal health programs were introduced in the first half of the twentieth century to control specific diseases, the health sector has had difficulty developing an organizational model that combines the will and commitment of the central leadership with the need to respond to the unique characteristics of an immense and diverse country which, despite its history of centrism, has opted politically for a federative regime.

Even though decentralization began taking place in 1990, federal initiatives have continued to set priorities in the other areas of administration. Difficulties have continued to be encountered in taking these initiatives down to the sector’s operational level. It has been an even greater challenge to introduce health actions into an intersectoral government program in such a way that the determining factors of health are addressed and taken into the equation in their entirety.

There is absolutely no doubt that efficient use of information can contribute decisively to changing the way in which the health sector is managed, providing evidence for setting priorities, guiding the allocation of resources, suggesting synergetic actions toward a single objective, identifying interfaces for intersectoral planning, monitoring projects and activities, evaluating results, and disseminating information to users of different kinds. But the information that exists today is already a first step toward the goal that an abundance of data be available in the national databases and information systems throughout the public administration system.

The data being entered on an ongoing basis are now so massive that it has become a gargantuan task to sort and analyze them and, in the process, the systems themselves are tending to upstage their content, becoming more attractive for other purposes such as academic use. This situation is forcing managers to search for information from other sources, such as health surveys, which certainly have their
appropriate uses. However, these should be supplementary; they cannot take the place of overall planning of needs and resources, and especially, representation at the municipal and state level.

The best possible scenario for taking all these issues into account would be a public administration model with decision-making based on the use of information from a long-term perspective. In such a case, the preeminence of political demands would force the systems and databases to be streamlined in order to meet managerial needs. But this scenario is a little unrealistic, both for cultural reasons and because political circumstances dictate the transitory nature of management, which is forced to look for immediate results – and results that have an impact on public opinion. Thus it is only natural that managers will be reluctant to undertake a process that is so painstaking and has so little to show for it in the way of progress that is perceptible to society as a whole and not just those involved in information systems, databases, and technology.

RIPSA has emerged as an alternative model for addressing this challenge. It seeks to harness existing technical resources already in place in their institutions to produce, through successive approximations, contributions that will motivate health managers to use the information. By refraining from interfering in institutional organizational processes, the initiative builds on points of interest common to the principal agents involved, collectively defining objectives to be attained and products to be generated. Construction of the IDB is an objective that is clearly identified with this strategy, and it also has the advantage that it is part of an international proposal.

RIPSA’s innovative nature was pointed out in a review of PAHO cooperation in Brazil, which stressed its organic conception, implementation process, and sustainability. Along these same lines, a PAHO report differentiated
RIPSA from other similar experiences in Latin America, citing it as one of the most successful institutionalized examples of consensus, standardization, collection, coordination, and dissemination of information and indicators to different types of users via Internet access, bringing together national institutions responsible for the production and analysis of health data. In recent years, some of the Latin American countries have sought, on their own initiative, to draw inspiration from this model.

The greatest merit of RIPSA is its participative working process and its concrete result: a final product of recognized quality and usefulness – the IDB. This is why the network has survived for 10 years amid difficulties that sometimes threatened its very existence. An important factor in its success is that, from the beginning, it has enjoyed the participation of a select group of professionally recognized institutional representatives who have persevered in creating a working environment that gives priority to meeting objectives and targets, and is capable of overcoming difficulties that place their legitimate actions at risk.

RIPSA is based on a consensus among institutions that normally tend to focus their activities on meeting their own objectives, and it respects the work flow of its members. It does not exert any pressure that might interfere with the participation of key partners. Its principle is continuity of effort, with an eye toward opportunities to make proposals that can be viably executed.

Given the stumbling blocks that have been just described and the nature of the model itself, it is not surprising that after a decade RIPSA has not yet become fully engaged in the health decision-making process. So far, its contributions have been limited to isolated issues, such as the standardization of record formats in the health information systems. In this connection, it should be kept in mind that the instability of national management in the SUS means that this agency could
withdraw its support of the initiative at any time, even when it is at its peak momentum. Indeed, this very instability is reason for the creation and maintenance of the network.

RIPSA could not function without the solid bases provided by the Ministry of Health, the agency for which its products are essentially intended. The IDB, for example, would not be viable, nor would it have legitimacy, without the contributions of the ministry’s technical agencies. To begin with, the DATASUS staff technicians bear the burden of constructing and publishing the indicators and making the necessary arrangements with the agencies that produce the data. Other Ministry of Health offices are equally important for their normative role, their encouragement of SUS initiatives, or their technical competence in specific subject areas. One of these is the Secretariat for Health Surveillance (SVS), whose institutional mission is convergent with RIPSA’s purpose of analyzing the health situation.

The network’s real mainstay, however, is the continuing representation of its external partners, technically and administratively stable institutions that have a vested interest in the availability of reliable information. These partners look at RIPSA’s processes and products from a perspective that is less critical than that of governmental and academic users. The positions that they take carry weight in the management of health, lend technical rigor to procedures, and provide an element of moderation at times of impasse. One of the basic premises on which RIPSA rests is its intersectoral approach, which is ensured by the presence of such institutions as IBGE, IPEA, and the SEADE Foundation.

PAHO has played an important role in the development of RIPSA, providing support in the formulation of its initial proposal, accompanying its early days of implementation, and assisting in the development of an innovative cooperation
model. Taking advantage of its status as a neutral entity with a long tradition in the country but with certain distance from national political and administrative processes, PAHO has provided cooperation in the management of related resources, articulation with new authorities to ensure program continuity, support for the Technical Secretariat and other organizational entities, and technical documentation for the network. During the initial phase and at critical times in RIPSA’ history, PAHO has contributed its own resources in order to make the network’s products viable.

The importance of RIPSA comes through in the way it has handled sensitive issues, such as the selection of data sources for a given indicator, the interpretation of values found, the limitations of data produced, or the accuracy of the calculation method. For example, the network was able to develop consensus on the sensitive issue of the selection of infant mortality data for each state. Discrepancies between data from different sources have been dealt with satisfactorily, if need be through collaborative investigations promoted by RIPSA. These contributions have been transcendant in improving the availability, quality, and understandability of health data in Brazil, even for international comparisons.

The reports of meetings held under the RIPSA umbrella over its 10-year history show that approximately 450 technical experts have participated in sessions of the OTI, the Technical Secretariat, and the CGIs. This is a surprising number, since they represent between 40 and 50 institutions. Although this large number partly reflects the turnover of professionals in the health agencies – especially within the structure of the ministry – it also indicates the extent to which the values of RIPSA have spread among the technical personnel in the sector.

Another indication of the network’s influence is the academic literature in which it is cited. A preliminary survey on the Internet found 79 citations between
1999 and 2005 that featured RIPSA, consisting of published articles (39), master’s theses (11), doctoral dissertations (6), papers presented at conferences (6), books (4), technical meetings in the area of health (3), technical manuals (2), proposals (2), course materials (2), a Ministry of Health directory (1), a workshop (1), a monograph (1), and an unpublished paper (1).

In conclusion, RIPSA offers potential which, because of the circumstances of its development, has not be able to be fully explored. The current moment is favorable for certain priority lines of action, such as the development of new processes for analyzing the health situation, which could lead to objective interaction with its managers, other sectors of government, and society in general. The involvement of state-level participants in the SUS structure will be fundamental in order to induce municipal managers to give priority to the quality of registered data and the use of information in the delivery of health services.
Chapter References

1 Brasil. Law 8080, 19 September 1990, which established the SUS. Its Article 47 calls for the organization, within two years, of the National Health Information System.

2 IBGE. Study on Public Health Medical Care (AMS) and National Household Sampling Survey (PNAD), published in Suplemento Saúde and other supplements of health interest.

3 Latin American and Caribbean Center on Health Sciences Information (BIREME/PAHO). http://www.bireme.br/


7 Brazil, Pan American Public Health Office, supplementary amendment to the Basic Agreement for operation of the PAHO/WHO Area Office, signed on 16 March 2000, executed and implemented by Decree 3,594, 8 September 2000, published in the DOU on the following day.


15 Nogales Vasconcelos, AM. Aperfeiçoamento das estatísticas de nascimentos e óbitos no Distrito Federal: cobertura e qualidade das informações. Brasília, August 2003. 95 p. (mimeo)


Chapter References (Translation)

1 Brasil. Lei 8080, of 19 September 1990, which established this SUS. Article 47 contains provisions on the organization, within a period of two years, of the National Health Information System.

2 Brasil. IBGE. Pesquisa de Assistência Médico Sanitária (AMS) e Pesquisa Nacional por Amostra de Domicílios (PNAD) – suppl. Saúde, among other sections of health interest.

3 Centro Latino-Americano e do Caribe de Informação em Ciências da Saúde (Bireme/OPAS). [http://www.bireme.br/]


7 Brasil. Repartição Sanitária Pan-Americana. Ajuste Complementar ao Acordo Básico para funcionamento do Escritório de Área da OPAS/OMS, signed on 16.3.2000, to be executed and carried out pursuant to Decree 3,594 of 8.9.2000, published in the DOU on the following day.


RIPSA. Indicadores básicos para a saúde no Brasil: conceitos e aplicações. 298 páginas. OPAS. Brasília, 2002.


Sá Carvalho, Marília; Pina, Maria de Fátima; Santos, Simone Maria. Conceitos Básicos de Sistemas de Informações Geográficas e Cartografia Aplicados à Saúde. 124 p., illust. OPAS. Brasília, 2000.


Nunes A; Silva Santos, Jr; Barata, RB; Vianna, SM. Medindo as desigualdades em saúde no Brasil: Uma proposta de monitoramento. OPAS. Brasília, 2001.

Simões, CCS. Perfis de Saúde e de Mortalidade no Brasil: Uma análise de seus condicionantes em grupos populacionais específicos. OPAS. Brasília, 2002.


8. The Brazilian Experience in Health Information Systems: Interviews with Users and Managers

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General Considerations

With a view to strengthening health information systems, the MEASURE Evaluation project, supported by the Carolina Population Center, University of North Carolina, and mediated by the Latin American and Caribbean Regional Bureau (LAC) of the U.S. Agency for International Development (USAID), proposed conducting a study on information systems in Mexico based on the following points:

- performance of a diagnostic evaluation of the country’s information systems covering the last 20 years;
- discussion of the lessons learned, best experiences, and weaknesses of the systems; and
- development of a table showing the main components of an “ideal” information system for the next 10 or 15 years.

At the request of LAC and the Pan American Health Organization (PAHO), this project was extended to include Brazil, once these agencies realized that other countries could benefit from the discussions of the issues stemming from the fact

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that the two countries both had information systems in place but the two health system models were different – centralized in the case of Mexico, and decentralized in the case of Brazil.

The Study Design

The proposal to carry out this study was initially presented to FIOCRUZ in June 2005 by the Ministry of Health, DATASUS, and PAHO. It was divided into two parts:

- historical recollections written by key personnel about the systems, DATASUS, and RIPSA, with emphasis on the mission of each, the circumstances in which it was created, its scope, the actors and interests involved throughout its existence, legal aspects, early successes, and stumbling blocks encountered over the last 20 years, and of course, what they foresee for the future (the choice of these individuals was to take the following criteria into account: (i) participation in creation of the system or service about which they were invited to write; (ii) recognized achievements in development of the areas and topics being studied; and (iii) authorship of a study, evaluation, or thesis on any related subject); and

- historical recollections of key personnel known to have been involved in the systems as users or managers.

The fieldwork consisted of in-depth interviews, based on an outline previously prepared and discussed with the interviewees, for purposes of standardization.
Fieldwork

The objectives of the study had to be considered vis-à-vis the three months allowed for conducting it. If any methodological problems were to develop immediately, the overall objectives of the original project would have to be adjusted to the possibility of their being covered in the allotted space of time without affecting the main points of the study or the validity of the information obtained. In keeping with these guidelines, the following decisions were taken:

- The study would be qualitative in nature, supported by interviews and recorded recollections.
- It would not be possible to examine all the systems in the country, so the study would focus on three areas. The first area would cover four systems: (i) the Mortality Information System (SIM), (ii) the Live Births Information System (SINASC), (iii) the System for the Reporting of Notifiable Conditions (SINAN), and (iv) the Hospital Information System (SIH). A second area would examine DATASUS and the third area would look at the Interagency Health Information Network (RIPSA).
- The four systems were selected based on the fact that their coverage is national in scope and they are the most established and widely used. The choice of DATASUS is obvious, since it is the locus for the production of health information in the country. RIPSA was chosen because it is known for its efforts to create an information network.
- The fieldwork phase would have to be completed within 30 days.

- A total of 30 carefully selected individuals would be interviewed during the fieldwork phase.

- In selecting the respondents, it would be desirable for them not to be limited to the Brasília/Rio/São Paulo axis, where the largest number of public universities are university centers are located.

Two points were clear from the outset: first, that this exercise was not to be an evaluation of the country’s information systems over the last 20 years; and second, that in order to guarantee the respondents freedom of expression, the reports and the reports and analysis would only mention their profile to ensure their anonymity.

Profiles of the Respondents

The choice of respondents was made after drawing up a profile of what would be considered an “dream team” of persons working in the national information system in different capacities – to wit: each of the four systems, in order to function, has to deal with management at the three levels of the system: federal, state, and municipal. It is important to know about their experiences in implementing the systems. These are the professionals who are responsible for complying with the law in terms of receiving, analyzing, sending, and disseminating health data in the country at the three levels. Table 1 shows the distribution decided on by states. The federal level would be represented by professionals associated with the central level of the Ministry of Health and DATASUS.
Managerial Users of the Service

One of the factors associated with good performance of the health services is that the manager asks for and receives information from the systems to guide him in decision-making. Thus, it would be essential to hear from professionals involved in planning actions for an entire secretariat or for specific programs, who could clarify how the systems are used, what it is like to work with DATASUS, and the facilities and difficulties encountered (Table 1).

Academic Users

Individuals who are involved in lines of research and teaching that require constant access to data for the production of articles, theses, consultancies, and evaluations correspond to the group that probably use information from DATASUS and various other information systems the most for purposes of comparison with other systems. Once again, people were selected throughout the country, by line of research (Table 1).

Health Councilors

The Unified Health System has created Health Councils at all its levels of operation. The National Health Council is located in Brasília. As for the other levels, the survey of health councils in Brazil (Rasga & Escorel; 2005) identified about 5,500 such bodies. It was therefore felt to be important to hear their opinion about the data being provided by DATASUS, what use it is being put to, and its significance for SUS action in the area of social empowerment (Table 1).

Managers in DATASUS, the Secretariat for Health Surveillance, and Members of the Interagency Health Information Network (RIPSA)

The four types of respondents above were identified so that their views on DATASUS, SVS, and RIPSA could be elicited. It was considered important to interview professionals associated with these agencies in order to hear their
perceptions about health information policy in their country, the progress that has been made, the difficulties, and what opportunities may be opening up for the future. Also, it is important to know about their relationships with other users of the systems (Table 1).

**Table 1. Distribution of Respondents by Institutional Association and by State**

<table>
<thead>
<tr>
<th>State</th>
<th>National managers</th>
<th>State managers</th>
<th>Researchers</th>
<th>Councilors</th>
<th>PAHO</th>
<th>IBGE</th>
<th>Total</th>
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<tbody>
<tr>
<td>Federal District</td>
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<td>2</td>
<td>2</td>
<td>1</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td>Rio de Janeiro</td>
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<td>1</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>São Paulo</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td></td>
<td>5</td>
</tr>
<tr>
<td>Paraná</td>
<td>1</td>
<td>1</td>
<td>3</td>
<td></td>
<td></td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Santa Catarina</td>
<td>1</td>
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<td>1</td>
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<td>4</td>
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<tr>
<td>Rio Grande do Sul</td>
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<td>3</td>
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<tr>
<td>Pará</td>
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<tr>
<td>Paraíba</td>
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</tr>
<tr>
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<td><strong>7</strong></td>
<td><strong>5</strong></td>
<td><strong>6</strong></td>
<td><strong>2</strong></td>
<td><strong>1</strong></td>
<td><strong>28</strong></td>
</tr>
</tbody>
</table>

**Schedule of Interviews**

The interview schedules were defined as the nature of the study being undertaken became clearer. As said earlier, this undertaking was not to be an evaluation of systems, but rather a short-term qualitative study about the country’s information systems during the period corresponding to implementation of the SUS, without losing sight of what is revealed for the future. Using the terminology of Patton (2001), it can be said that it is a brief study of a “better practice,” rather than a “best practice.” We will return to this point later, but it is important to say that the decisions taken in selecting the interviewees and drawing up the schedule of visits gradually began to take shape once it was realized that this type of approach was going to be most suitable.
To find out if there were specific aspects that people were more interested in about the systems – for example, access – or if their concerns were more about the systems’ operation in general, two exploratory discussions were held with more than 15 people. These sessions were attended by individuals from FIOCRUZ; system users; personnel from the Ministry of Health, DATASUS, IBGE, and the University of Brasília; members of RIPSA; and the PAHO representative. The discussion referred to the four systems plus DATASUS and RIPSA. No one who might eventually be interviewed on any topic in the course of the study was allowed to participate in a discussion on a subject about which he or she might eventually be interviewed. In any case, once the respondents were selected, only the recollections of one of these persons, among the 30 who were participating, was considered indispensable.

Theses, articles, studies, recent reports, and information from the Internet containing analyses, evaluations, and relevant comments on the subject were consulted for orientation in preparing the scripts (Black, 2005; Glatt, 2004; Laguardia et al., 2004; Lessa. 2000; Mexico, 2005; Mota & Carvalho, 2003; Penchansky & Thomas, 1981; RIPSA, 2002; United Nations, 1994; Viacava, 2005). The studies on national cases, without exception, pointed to progress that had been made in the last decade, mainly with regard to data on live births and mortality, as well as to the effort undertaken by DATASUS to make the information available. But even these mentioned the need, for example, to improve data entry procedures. RIPSA, through its working groups, was able to systematize and disseminate a publication on health indicators being used in Brazil, defining budgets and calculation procedures. The strongest criticisms were directed toward the data provided by SINAN and AIH.
Exploratory reading and discussions showed that, both in order to achieve the study’s objectives and to meet the deadline, it would be advisable that, instead of the interviewees going into one or two aspects in depth, it would be better for them to do an overview, covering the implementation and operation of the systems from the standpoint of adequacy privacy and ethics, access, availability, reliability, relevance, acceptance, financial viability, scientific soundness, transparency, user confidence, efficiency, workplace, administration, personnel training, and other points mentioned in the recommendations of the United Nations (United Nations, 1994) and RIPSA (2002) and as was done in the studies of Black (2005) and Penchansky & Thomas, (1981).

There is a prevailing impression that Brazil used to be “worse” in this area, has “improved” in the last decade, and, unless certain measures are taken, could reach a point of stagnation in the next few years. Several proposals are being discussed and/or have been presented, and in the course of the discussions it was suggested that certain actions could be taken which would lead to greater progress. The coordinators of the present study thought that this was an opportunity to hear from people with different interests and find out their points of agreement and disagreement about the impact of these systems and their usefulness in decision-making, academic research, and keeping society in general informed. Therefore, the interviews are focused more on general processes. The expectation was that discussions about “what works,” “what needs to be improved,” and how the future is perceived may point the way to more focused studies. These were the thoughts in mind when the interview scripts were prepared (Annex I – Interview Scripts).

An Experiment that Works

In the evaluation of public social policies there is a constant demand for qualified information, reliable evidence, lists of “lessons learned” and “best
practices.” The expectation is that the evaluation exercise will not be merely theoretical, that it will be useful for decision-making, training, and gaining information about specific sectors of society. Even though this study is not entirely a qualitative evaluation, it does share this expectation, as well as some of the difficulties that arise when an attempt is made, in the case of social phenomena, to establish valid correlations between interventions and the effects observed (Pawson, 2002). Although establishing causal relationships in this sphere through discrete variables alone may lack sufficient explanatory power, on the other hand, the classical, highly explicative approaches used in the social sciences require time and in-depth analysis – factors which are often incompatible with grasping and understanding certain institutional and political processes.

Despite difficulties in the last 15 or 20 years, progress has been made: there has been a marked growth in qualitative studies on such issues as equity, technological innovation, social inclusion, the workforce, decision-making, human resources development, etc. – in other words, areas in which the proposals and actions are almost always multistrategic, intersectoral, and interinstitutional, with marked interaction between national and local levels (Barnes et al., 2003; Patton, 2001; Pawson & Tilley, 1997; Pawson, 2002; Sullivan et al. 2002).

Gradual methodological progress has been made by developing approaches that allowed for rapid identification/focalization of topics, more appropriate use of results obtained from basic research, relaxation of procedures through triangulation of methods, use of software created to disaggregate certain occurrences, advances in case study (mainly for the study of results) and, especially, progress in compared qualitative analysis (Dixon-Wood, 2004). These approaches and procedures are versatile to the extent that they can be adapted to quantitative analysis, leaving aside the old arguments of quality versus quantity.
Of the various theories and models of approach that have been created, some have been shown to be particularly useful in the evaluation of public policies – for example, theory of change and action theory. These studies focus on articulations between the factors necessary in order for a program to work (inputs), the implementation of activities and processes, the products offered in a given period of time (outputs), the short- medium-, and long-term outcomes, and the impact. An effort is made to analyze the mechanisms that contribute to introducing, implementing, altering, or rejecting specific proposals within various institutions, systems, and geographical areas, which can range from the local and regional levels to the national level. Emphasis is on “what works” and “wicked issues,” according to Barnes, et al. (2003) and Sullivan, et al. (2002).

This type of evaluation can have different objectives. It is called *summative* when it focuses on the effectiveness of a program, and when the objective is explicitly to improve a program, it is called *formative* (Patton, 2001). Outside Brazil, where there are a large number of scientific publications, the results of action research and formative and summative evaluations tend to appear in journals aimed at stakeholders and decision-makers.

Proper contextualization of the phenomenon to be analyzed is fundamental in these theories, and in this connection attention turns to *realistic analysis*, which is much less formal than other approaches in the social sciences that are based on inductive analysis. It gives priority to practice, and to the lessons derived therefrom (Mark et al., 2000), and, since the epistemological limits are unknown, it is extremely useful in the understanding of specific *constructs* created by individuals. The explanatory structure of the realistic analysis is centered on the configuration with which it is dealing in that moment, making it possible to understand the deep implications of the context in relation to the program, not only in the conditions of
its implementation, but fundamentally in the changes wrought during the process, the going beyond the analytical limits of an evaluation based solely on the observable effects and impacts of the intervention (Bodstein, 2004; Denis & Champagne, 1997; Pawson & Tilley, 1997). The epistemological challenge exists because, from the point of view of complexity and the many theories that sustain it, there are multiple perspectives and many interests involved in any human action, and therefore, practical implications regarding its validity, objectivity, and reliability need to be taken into consideration.

According to Miles and Huberman (1994), the realism of analysis does not contradict the axiom that knowledge is constructed historically and socially, nor does it overlook the importance of the subjective or the phenomenological, or of meanings. For these authors, analysis is focused on a given point – a process – a case that is at the center of events and which, once it is understood, may come to provide a causal description of the factors in play. The realistic analysis requires both a referential explanation and evidence that each element or event is an intrinsic part of the things that happened or are happening.

Therein lies the value that is given to surveys and solid information on the conduct of programs and policies, some of them purely descriptive and others requiring more complex artifices, such as the construction of tables or logic models, exploratory studies, rapid opinion studies with groups involved, reading focused on official and unofficial documents, etc. It is the type of analysis that has the objective of knowing that vast area between the ideal of “how it should be done” and the reality of “how it is being done.” It starts from the idea that the logic that underlies a project can be studied from various prisms, and one of them, undoubtedly, stems from an empirical logic which, even though modest in the affirmation of certainty, helps to discriminate between requests that are more or
less plausible, identify premises, and test opposing hypotheses. The aforecited criteria of validity, reliability, and objectivity are guaranteed by the rigor and transparency which each phase of the study is undertaken, and by the field work and collection of data that go into the final report (Patton, 2001).

The notions of “lessons learned” and “best practices” come from analysis of these concrete cases. Obtaining a reasonable and plausible picture of how things happened and are happening, it is possible to better understand to what degree a given program, model, or action actually does what it proposed to do. Thus a certain structural fatalism – though not entirely referential and socio-theoretical – is avoided, which makes it possible for factors that were previously invisible to be observed and taken into account.

Thus, we believe that this study offers a realistic analysis insofar as the country’s information systems are concerned. It is partial, because it is not a complete evaluation. It is almost an exploratory study, based on readings in the literature and recollections of key figures. Some of the individuals helped to create the systems, others administer them, and others use them – or should use them – heavily. The results obtained may constitute an approximation of a realistic analysis. The interview scripts covered both strengths and weaknesses, with a view to eliciting what these people thought had been accomplished, what was learned, what turned out right, and what is expected for the future.

Brazil, given its historical configuration and its institutional and organizational arrangements, is facing the challenge of modernization along with the processes of democratization, citizen empowerment, and strengthening of a public sector that really cares about the public. Perhaps it is not yet time to speak of best practices, but certainly there are several better practices being developed.
that deserve to be recorded.* There is need for successive, well-structured studies, even if some of them are only partial, to disseminate knowledge on the use and operation of programs and systems in order to then be able to speak in terms of transference and generalization.

**Section References**


Black, C. et al., 2005. Data, Data, Everywhere...: Improving access to population health and health services research data in Canada. Centre for Health Services and Policy Research


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* "(The) former director of ... Kellogg Foundation and I (discussed) the deteriorating meaningfulness of (...) ‘lessons learned’ and ‘best practice’ (..). applied to any kind of insight, evidentially based or not. (...) We began thinking about what would constitute ‘high quality lessons learned’ (...) (They should be) (...) supported by research on use, theories about diffusion of innovation and change, practitioner wisdom, cross-case analyses of use, the profession’s articulation of standards and expert testimony... [These are] principles extrapolated from multiple sources” (Patton, 2001; 565-566)


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Internet consultation
DATASUS website
Ministry of Health website
Epidemiological Surveillance website

**National Live Birth Information System (SINASC)**

*A system that is part of a bureaucracy is just a cabinet in the living-room, whereas a well-conceived system has life, and it can change peoples’ lives.*

– *A municipal manager*

Development of the National Live Birth Information System (SINASC), established in 1991, was focused on creation of a system that would allow both for the collection of information and for its processing as demographic and epidemiologic data. It should be capable of producing quantitative information about the health of the mother and the newborn, and also disclose aspects of perinatal care.

Since SINASC was implemented gradually on a state-by-state basis starting in 1989, its data at the national level are considered more reliable starting in 1997. According to one municipal manager, “SINASC makes it possible to monitor indicators such as postneonatal mortality and teen pregnancies that are social and public health risks affecting the population as a whole, thus justifying the application of preventive policies.”
From the perspective of the federal manager, ever since its conception, SINASC had been proposed as a simple system for the collection of information, so that only a few data elements needed to appear on the collection form, the declaration of live birth (DN). It was intended to have processing decentralized at the state or municipal level.

The experience of some of the municipalities, such as Mogi das Cruzes in the state of São Paulo and Porto Alegre in Rio Grande do Sul, which had already had information systems on live births in place since the 1980s, served as the basis for its design. In Porto Alegre, the system was used for epidemiological surveillance and data were being collected on birthweight, gestational age, and age of the mother, while the system in Mogi das Cruzes was handling information that was more demographic in nature and variables such as birthweight and gestational age were not being recorded.

One of the municipal managers commented that SINASC had started out very strong at the national level with good quality and more data elements on the form than the earlier system had. But once the form was introduced in three copies, one of them to be delivered to the mother, it became an official document to be used in registering the child’s birth. According to this manager, the idea of using a computerized system from the start, with the possibility of “constructing an epidemiological profile for the entire country, makes this system much better,” and the use of “a single unified document allows for the comparability of data.”

For this manager, the problem of direct supervision of the collection of data in maternity services had been a concern ever since SINASC was introduced in his municipality.

Decentralization is a strong characteristic of the system, which, as a municipal manager pointed out, was introduced at a time in the evolution of health
policy in Brazil when the decentralization movement was getting under way. Some of the municipalities had already assumed tasks related to epidemiological surveillance and the health information systems which had previously been the exclusive responsibility of the states. Thus, SINASC not only tapped into the experiences and needs of the municipalities but was introduced already with a design that envisaged decentralization and municipalization in the flow of consolidation and evaluation of the data collected. He added that decentralized implantation of SINASC would have helped the municipalities to begin to manage their own health information.

A manager at the state level, in turn, defends the need for this process to reach the level of the maternity services so that the consolidation of data can be increasingly decentralized and the data obtained by SINASC can contribute to the surveillance of conditions associated with maternal and child health. Accordingly, this manager argues that more and more municipalities, and even hospital units, should be trained to analyze and consolidate the data from the DN. This decentralization would allow for more prompt identification of at-risk situations for newborns at the local level and make it possible for preventive and curative measures to be taken. As a national information system, SINASC is able to keep information and indicators more up to date with a speed that outpaces even the developed countries, but consolidation at the state and federal levels does not allow for this aspect of health surveillance.

Along this same line, the municipal manager also said “it is ridiculous for the federal government to manage the information system because they are too far from the place where the information is being reported.” For him, “If the municipal manager were made responsible for the quality of what he does, our systems would be producing much better information.” In other words: “It will always be more
difficult for the federal level to check and correct information that is incomplete or incorrect."

On the other hand, both the municipal and the state-level managers recognized that there is need for a place were the data from the municipalities are cross-checked, duplication is weeded out, and the municipalities of residence for the births are corrected. For the state-level manager, this should be the responsibility of the state health secretariats: “An agency is needed that will regulate or centralize this, make these corrections, and return the data to the municipios. In the case of SINASC, it should be the State Health Secretariats.” The municipal manager pointed out that matching up data from SINASC and SIM as far as matters such as addresses are concerned involves more than one municipality. For the federal manager, corrections of residence and place of birth, when done by the ministry at the time of consolidating data from all the states, will be made available in real time with the data processing system.

The municipal manager also thought that the state health secretariats should “train the municipios so that they are able to carry out the activities for which they are responsible, but the critical mass for doing this is lacking at the state level.”

For a municipal manager, since the beginning, implementation of the system in his or her municipality has consisted of ongoing evaluation of the data entered in the hospitals. There are two phases that are supervised: the first is collection of the forms in the hospitals by municipal health secretariat (SMS) technicians (nursing auxiliaries), who in this way maintain direct contact with the professionals in the maternity services, and the second phase is entering the data in the system by the same technicians who collected the forms in the hospitals. This strategy is similar to the processing and analysis of information provided by the professionals who fill in the DNs. The supervision and evaluation also includes a quality control
system that systematically reviews the cases by consulting the hospital patient charts. When the patient charts do not match up, they are checked against the public records, which work in partnership with the SMS, making it possible to compare the data supplied on the DN with what appears in the civil registry. To help make these professionals aware of the importance of the information they are providing, direct contact is made and feedback provided on the information collected in that hospital.

One of the characteristics of SINASC is that the DN is not usually filled in by physicians. This task falls more often to nurses or nursing auxiliaries. **Continuity of the teams** is seen as essential in order to guarantee the quality of the information. For the managers, the identification, screening, and training of the personnel in the hospitals who are responsible for filling in the DNs is a matter of the utmost importance. One of the practices noted is “sending a table to all the hospitals to encourage improvement, showing that the percentage ‘unknowns’ varies greatly from one hospital to another.”

Another characteristic of the DN is the **ease with which it can be filled in** and the **continuity of the same collection form** over time. For the municipal manager: “These documents have to have a certain stability, they have to be engraved in your soul. To fill in a document properly, it has to be engraved in your soul, and it will only get there after it has been used for a long time. For this to happen, it can’t be long, it can’t be nitpicky; it has to be easy and fast.”

The managers’ comments frequently refer to the high **quality** of the SINASC data. The only reservation had to do with the northern and northeastern regions. With regard to **completeness**, a best practice that was cited was the development of a careful evaluation system and the correction of information recorded incorrectly or indicated as “unknown,” which happens in sources across
the board: the hospitals, the offices of the public registry, physicians’ patient charts, home visits, etc. For this municipal manager: “You need to know if it is a problem in filling in the document, or if it is truly impossible to find out the information.” This manager emphasizes the fundamental role of the municipal team that works with the SINASC information, primarily in the sense of being able to qualify the information filled in by the hospitals, and secondly, being able to transform this information into a real happenings, through health surveillance actions and evaluation of the quality of the services provided by the prenatal health posts and the maternity services. Another example of a best practice is the fact that the hospital assumes responsibility for incomplete recording of the information “because if we were not able to identify who that infant was who was at risk, it was because the hospitals had not helped us in this mission, and they have to know that if a death occurs, they are part of the history of that death.”

In the opinion of the federal manager, in filling in the SINASC data fields, “the states, on average, do quite well, especially when compared with the situation with SIM.” However, there still are gaps, largely due to the high turnover of professionals. Along with the problem of training the professionals, there still are difficulties in filling in the SINASC data fields due to errors of misunderstanding and misinterpretation, as well as problems related to ethical, cultural, and/or legal questions, and the need to match the data in the civil registry with the epidemiological information, which can produce biases in the collection and analysis of the information. Over the development of SINASC, some of the data elements were altered in the way they are presented on the forms, and some were eliminated entirely. Most of the changes occurred in 1999, which compromised analysis of the data that year.
The state-level manager attributes the high quality of the information to the fact that most of the data fields are precoded, and according to the federal manager, it is because there are no legal implications related to filling in the data, as is the case with the underlying external causes of death in SIM.

In the course of developing the system, problems were identified in relation to filling in some of the data fields due to difficulty understanding the question and in others due to ethical, cultural, and legal problems. For the federal manager, an example of difficulty understanding the question is the way education is presented, which after 1999 has been reported as number of years of schooling. Also, errors of interpretation occur in the case of number of live children, in which case the response sometimes includes the current gestation. The number of prenatal consultations can pose problems because the mother may not understand what a prenatal consultation consists of. There is also low reliability in the case of race/color, according to the municipal manager, who considers that this information should refer to the skin color of the mother and not the newborn. Other data elements, such as type of delivery and length of gestation, have been changed because they did not meet technical requirements. With regard to the type of delivery, information about the use of forceps was eliminated, leaving only the categories “vaginal delivery” or “cesarean delivery.” Ethical, cultural, or legal problems in filling in the forms were also mentioned by the federal manager, as in the case of information about abortion, which was eliminated in 1999, and marital status, which, for legal reasons, given that the DN is required for the civil registry, could not be replaced with “in a permanent union,” which would have been more meaningful from the epidemiological standpoint. The infant’s footprint has been misinterpreted, and in some cases confused with the heel prick test. The managers at the state and municipal levels cited difficulties in capturing
information on **congenital malformations** in the newborn at the time of collecting data for the DN. This generated the need to cross-check the information against the mortality system. The same municipal manager felt that eliminating information on abortion made it more difficult to “differentiate between fetal death and stillbirth.”

In the view of the municipal manager, it is necessary to distinguish between problems in filling out the forms that are due to an intrinsic inability to collect the correct information, as for example, the race/color of the newborn, and errors stemming from problems associated with how the element is presented on the form, as in the case of schooling, in which it is necessary and possible to invest in improving the information. On the other hand, he disagreed with the exclusion of low-reliability variables when their exclusion may be masking some type of risk, as in the case of abortion. This manager also considered that the small number of SINASC data elements helps to guarantee the quality of the information, and he agreed with the federal manager on not adding any new data elements to the DN.

**With regard to coverage**, one of the first points that was brought up has to do with the level of commitment of local technicians to the objectives of the system: “There is a relationship of **direct commitment** on the part of the technicians who work with the system, and this relationship is only established when there is municipal management. SINASC has an information team, and this team never allows anything or anyone to place SINASC at risk. I believe it is because of this relationship that the data are good, not only here, but in many other places.” This level of commitment was noted several times: “The people who work with SINASC know that when a child is born the health service has to know that this child exists in order to guarantee that he or she receives quality care; it’s about citizenship.”
As a result of this active search for births in the services and the offices of the public registry, yet another best practice was cited in this municipality: notification of the Child Protection Council when children are identified whose birth has not been recorded in the civil registry. “It is SINASC that finds out when children’s births have not been registered, because their people check the SINASC data against the data in the offices of the civil registry. Every month the databases are cross-checked and the infants that have not been registered are identified. The Child Protection Council is then notified so that it can find these families and initiate the registration process.”

In the view of the state-level manager, SINASC has had good coverage ever since it was introduced because the data are collected directly in the hospitals. This good coverage has meant that the SINASC is ahead of the IBGE. Accordingly, in eight of the country’s states the SINASC data on live births is used to calculate infant mortality.

The reduction in the number of births registered by SINASC, especially in the southern and southeastern regions, reflects, according to the federal manager, a real reduction in fertility and not a decline in the system’s coverage. Although problems still remain with regard to coverage in the northern and northeastern regions, this coverage is slowly increasing. The federal manager also pointed out that SINASC coverage includes information from the private sector.

Even though it is now in place throughout the national territory, SINASC gives the municipalities the authority to decide on their own document processing path. According to the federal manager, the forms are distributed by the Ministry of Health using a manual system based on the average number of births in each state. Starting in 2006, new software was added to control distribution of the forms automatically.
The processing path recommended by the Ministry of Health for collection of the data starts with filling in the DN in the hospitals and transmitting the data on diskette to the SMS, which then analyzes the information, consolidates it, and sends it to the state. The state, in turn, checks the data, consolidates it, and sends it to the Ministry of Health. According to the federal manager, “No one is obligated to follow this processing path, even though it is recommended and spelled out in the directive this way. There are states that do it some other way, and they have the autonomy to do that. There are three copies: the first one stays where the data are recorded, which is in the state secretariat; the second one is to be taken by the parents to the civil registry office for recordation; and the third one stays on file in the hospital, attached to the patient chart of the newborn.”.

It has been decided at the federal level, through a directive, that the state health secretariats have to send in their data every four months, and the states have been complying. As a result, there has been less of a lag between the time of collection and dissemination of the data.

There are states in which the DNs are transmitted from the civil registry to the central level, which processes the statistics and consolidates them with information from the municipal health secretariats and then sends them back to the state secretariat and the Ministry of Health. In the case of the municipality of the manager interviewed, the municipal secretariat has developed software to transfer the data from the DNs submitted by the hospitals, sending them simultaneously to the state secretariat and the Ministry of Health: “We simply export it to the ministry; we enter the data using our own software.” Unlike the version used by SINASC, this software includes the address and is linked to a cadaster office that can check the information provided on the DN. This locally used program also allows for coding of the variables so that it is possible to control the quality if the
filled-in data. This program can locate the child and the region where the family lives, which makes it possible to carry out health surveillance, including a home visit if necessary.

According to the municipal manager, the dissemination of municipal data is done by the SMS through an epidemiological bulletin that presents them in an easily understandable format, with specifics broken down by each health region of the city. In this way, the information becomes a tool for evaluating health actions and services in each area. In addition, reports are published with data for each hospital, plus supporting material to aid health district managers with data on their particular areas. Another form of dissemination is the creation of a map with the distribution of births and their associated conditions in the different regions of the city, which is presented to the trade unions and municipal health councils. Consultation of DATASUS and RIPSA publications to respond to various types of technical requests in the secretariat were cited as additional ways in which the data are used.

Similar practices were also reported by the state-level manager. In his state, the agency responsible for the state’s statistics brings together the information from the municipalities, consolidates it, and transmits it to the state health secretariat, which then returns the information to the regional directorates, from where it is sent back to the municipalities. Because of gaps in this document processing path, one system was created to consolidate and disseminate the data for access by the general public and a separate one that allows municipal managers to access their own database with a password. In addition to the traditional indicators, this system generates others such as a social responsibility index and a child vulnerability index, which are used to orient regional public policy.
The federal manager periodically disseminates the data on CD-ROM and in regular official publications. Confidential data are carefully protected in the database maintained by the ministry, with restricted access, and even with the new software about to be introduced, this confidentiality is assured. For the most part, the data have been used extensively by researchers and professionals in the health services for scientific studies and papers to be presented at conferences.

As an example of a situation in which the use of SINASC data was important for the organization of health surveillance and the orientation and planning of management, the municipal manager reports that “we needed to set up teams in the Family Health Program (PSF), and with SINASC we were able to see what areas had the largest number of births and teenage mothers, where the pockets of infant mortality were located, and where post-neonatal mortality was highest.”

As for tools available for tabulating and analyzing the data, the federal manager considers that the construction of indicators and tabulations was greatly facilitated by tools made available by DATASUS such as TabWin. The criticisms of TabNet and TabWin are unfounded, he says; they do not take into account the progress that has been made, or else they stem from failure to inform people about the resources that are available. He goes on to note that “before, when you wanted a tabulation, you had to wait in line. With TabWin, you can do any tabulation you want. I am one of its biggest fans.” The municipal manager agrees with these statements, but he thinks that “people without any knowledge of epidemiology or statistics may have some difficulty using these tools.”

On the development of qualified human resources, it was reported, among the best practices cited, that “there is a growing corps of qualified technical personnel in the secretariats. We have people who can handle the information
systems, who work with these systems bearing in mind that they are a source of data for research.” It was admitted, however, that that is not the situation everywhere in the country and much still remains to be done to train health professionals to handle and analyze the data presented by the information systems: “people don’t know how to use them – people don’t know how to access the IDB; they don’t know to access a record; they don’t understand what to do with the form. This is a training problem.”

It is recognized that team continuity is fundamental to guaranteeing the quality of the information (municipal manager), and it is acknowledged that the high turnover of professionals who fill in the forms in the hospital services and those who consolidate the data in the municipios and the states is one of the reasons for the problems in filling in the forms and interpretation of the information (federal manager).

With regard to the lag in disseminating the information by the central level, the municipal manager considers that the Ministry of Health is slow to close out its databases compared with IBGE and other countries. However, according to the state and municipal managers, “our system is very good, totally different from the developed countries … we have a lag of four years, and now 2004 is almost closed. Considering the international picture, this is very good.”

Some of the strengths of SINASC identified by the respondents are:

- good coverage and good quality of SINASC information, owed to the talent and effort of the technicians who produce it (in the words of a municipal manager, most of “Brazil’s regions have technical personnel who are deeply dedicated to producing reliable information, from the collection of data to analysis and dissemination of the information. ... I believe that our data are
closer to reality that the estimates produced by IBGE”);

- excellent qualifications of the professionals in the Ministry of Health and RIPSA also appeared in the respondents’ statements;

- the strategy being adopted by the Ministry of Health to decentralize SINASC to the state health secretariats;

- coverage and quality of the data make it possible to generate reliable indicators for planning and evaluation in the field of maternal and child health;

- convening of EXPOEPI, which has enjoyed increasingly larger participation by professionals from the health secretariats, allowing for the exchange of experiences and sharing of information about best practices;

- existence of a Technical Evaluation Committee, made up of technical personnel from the Ministry of Health, state and municipal managers of SINASC, researchers from the universities, and technicians from DATASUS, who follow the system’s development, identify problems, and propose solutions.

- linkage of SINASC with data in the Mortality Information System, which has made for better analysis of health and living conditions.

- creation of the Department of Health Information Systems Monitoring (DASIS) at the federal level, which is responsible for monitoring the quality of health information; and

- cooperation with the Council for the Protection of Children and Adolescents when an unregistered child is identified.
Weaknesses cited included:

- problems with filling in the address, which is sometimes reported incompletely or incorrectly by the person accompanying the pregnant mother at the time the patient chart is set up (managers are concerned that personnel in the services may not be sufficiently aware of the importance of this information for surveillance purposes);

- turnover of professionals in the services and insufficient training for those who fill in the DN and consolidate the data, which affects the quality of the information collected;

- limited dissemination of the information and low utilization of the data at the local level as a tool for health surveillance, which is still the case in some of the cities, especially the large urban centers;

- low system coverage in the northern and northeastern regions; and

- lack of administrative guidelines for handling legal issues involving the use of civil registry documents and the declaration of death.

Recommendations made by the users included:

- invest in the training of professionals working in the services as well as in qualification of the teams;

- decentralize collection to services that use the Internet and promote differentiated access for the different levels of management (for hospitals, for entering and consulting their data, and for the federal level, for example, allow access to the network at any time);

- monitor coverage and the quality of data more closely in the northern and northeastern regions;
- create, at the federal level, a Department of Health Information Systems Monitoring (DASIS), to be responsible for monitoring the quality of health information; and
- continue to work with the Council for the Protection of Children and Adolescents when an unregistered child is identified.

System for the Reporting of Notifiable Conditions (SINAN)

_It does not make any sense for the municipality to produce information and only for it to be passed up to the state or the federal level.... We have to insist on recommending that the municipality becomes the manager of information, so that it can do epidemiological analysis._

— A federal manager.

_The information system by itself is nothing. We, the people, are a big part of the information system._

— A municipal manager

The System for the Reporting of Notification Conditions (SINAN) was originally considered a system that “should be integrated some day,” even though it had always operated as a series of modular subsystems. What comes through in the interviews of people in managerial positions is that all the efforts to perfect it have been and are being directed toward making it a modular system, rather than an integrated but unworkable whole. The approach seems to be taking shape is that the various subsystems follow the same standards, use the same concepts, and work with a minimal set of data elements that are shared by all even if they are not part of a single unified database.

The respondents were unanimous that progress has been made in this information system in recent years, but its main characteristic – i.e., the fact that it
is a series of separate systems – continues to be cited as a source of difficulties that need to be overcome.

One of the managers at the federal level delineated three distinct phases in the evolution of the system since the 1990s:

- the phase when the system was allowed to be used for all notifiable diseases conditions;
- the phase that corresponded to effective implementation in all the states and other units of the federation; and
- the phase of decentralization to the health units.

From the operational standpoint, the system has had three phases as well:
DOS → Windows → NET

In the course of these developments, there were a few challenges that had to be faced: (a) loss of information in the process of migrating the data; (b) lack of coordination between system developers and the technical areas; (c) the need to train professionals in the technical area to use the data analysis tools, e.g., TabWin; and (d) clarification of the codes provided by the reporting units.

According to one of the managers at the federal level of the system, “the [recent] reorganization that involved the standardization of criteria, processing paths, concepts, and the universal standardized reporting form” provided an opportunity to deal with some of the bottlenecks in the system’s operation. Another federal-level manager pointed out that this standardization does not prevent the municipal and state levels from adding other data elements and even new conditions, as long as the established criteria and procedures are respected. An example of the flexibility afforded by the reorganization is the addition in 2006 of
more than nine new conditions in the areas of worker’s health, spotted fever, and specific reporting for syphilis in pregnant women.

Another proposal for improving the system – still planned for 2006 – is the introduction of SINAN/Net, given that SINAN/Windows is now obsolete because of the growing volume of information. This change is expected to speed up the flow of information, provide better database security, meet the needs of most operating routines, and facilitate checking and debugging. The more user-friendly interface will also ensure improved quality of the responses in filling out the notification and investigation forms. Also, decentralization of the system will be extended to hospitals at the state and municipal levels, which will become the reporting sources.

None of the respondents was against decentralization when seen as a basic principle of the Unified Health System, but putting it into operation still poses specific problems for the information systems. Hence, there are different points of view, depending on one’s perspective. Managers at the federal and state levels felt that the quality of information suffers with decentralization because it is harder for personnel at the local level to properly investigate reported cases, and when they do undertake such investigations the process is slow because of the time elapsed between the notification and confirmation of cases. In the words of a state-level manager, “the more decentralized, the better the coverage, and the worse it gets in terms of [quality of] the information.”

One of the federal-level managers recognized that “it is really the responsibility of the municipality” and it is up to the municipality to do the job correctly, but a frequent user of the system stressed that the importance of confirming and closing the cases should not become an obsession at the local level. He thinks it is better to know that there are “approximately X cases” than not to
hear about any of them. He adds, however, that this does not mean that the opposite of being obsessive is to inundate the system with an exaggerated number of poorly closed cases. Instead, what should be done is to build indicators that reflect the quality of the data and estimate the coverage – for example, one such indicator might be “number of confirmed cases based on a positive or negative laboratory result.”

It is a complex picture in which legal rulings are not sufficient to overcome the impasse created by the fact that there is no definition of the cases (confirmed and not confirmed) that supposed to be recorded, which has led to various interpretations. Thus, some places send in all reported cases while others submit only the cases that were confirmed. Some of the subsystems, such as the ones for AIDS and leishmaniasis, specify that only the confirmed cases should be recorded, but this definition does not apply to the other conditions.

Those at the local level recognize the need to have an overview of the national situation in terms of the incidence of required reportable diseases, and they understand that they have to provide the best possible information to the federal level, and this reinforces the obsessive tendency mentioned above. By the same token, for the manager at the federal level, “it doesn’t make sense for the municipality to be just a conduit of information to the state and federal levels. The municipality has to be the manager of the information, it has to do epidemiological analysis.” Seen from this perspective, the treatment given at the local level is positive, since it comes from the idea that the quality of information improves when the local level is able to do the analysis.

As one of the municipal managers said, “I think that we at the local level are the ones who should be analyzing the local database. But to do this, I have to have my database here. I have to analyze it – that is, weed out duplicates, analyze the
data, do case surveys, cross-match the variables.” In part, this need on the part of the local level comes from the fact that the data are not sent back to the municipalities except in the case of the AIDS subsystem. It is to be hoped that the desire to “hold onto the data” in order to process it better and maintain the local databases may be met once SINAN/Net has been introduced, which will guarantee that all levels have access to the information.

The user pointed out the importance of having a low-cost software tool making a descriptive analysis of the data, and felt that TabWin has filled this role. He wondered: “If there is no computer in the local secretariat, how is someone going to consult TabNet? If he consults it, he can’t find anything out because he doesn’t know how to manipulate it. His has dial-up, not high-speed Internet.” For him, this situation has to do with the size of the municipality, since the very small ones “don’t necessarily have to work with the large databases,” given the low frequency of events. At the other extreme are the large capitals cities, such as Rio, São Paulo, Belo Horizonte, and Recife that have human and computational resources as well as the possibility of partnering with teaching and research institutions that give them even greater processing and analytical power. According to him, “in the middle of the road there are some 3,000 municipalities that are potential users of TabWin. This is the universe of people, the municipalities, that need to look at the health situation through the prism of indicators, that are at least minimally computerized, and that have access to the data.”

Even with analysis of data at the local level, according to this same user, there are indicators with regard to certain conditions reported to SINAN, such as case-fatality and survival rates, that are important for managers and can be constructed based on supplementary information from other systems such as SIM (deaths) and the SIH (hospitalizations).
The decentralization process, which transfers responsibility for notification to the hospitals in an effort to increase the capillarity of the system, will have to deal with problems of quality unless it is accompanied by an adequate human resources development program.

The respondents all agreed that there are differences between the subsystems in terms of the quality of the information – i.e., the degree of **coverage** and **completeness** of the records – depending on the type of condition, geographical location, and period when it occurred. For example, congenital syphilis and maternal syphilis and HIV infection during pregnancy are well known to be underreported. Notification is directly related to the quality of epidemiological surveillance and health care, as well as the degree of coordination between them.

The question of **underreporting** needs to be addressed. According to the federal manager, “every technical area needs to be organizing a strategy, as part of their surveillance activity, for improving the capture of information.” One strategy, which is not being used enough, is routine searching for unreported cases based on information available in other systems. These same technical areas are also responsible for seeing that the reporting forms are properly and completely filled in.

Several measures have been taken to make health system managers more aware of the importance of the **quality in their reported data**. In the case of the Minimum Basic Care (PAB) program, the threat of suspension of fund transfers when a municipality fails to provide information to the system for two consecutive months may be producing mixed results: on the one hand, it creates awareness of the importance of the information system; but on the other hand, some people suspect that it encourages laxity in terms of the quality of reporting. In the opinion of the federal manager, the introduction of certain indicators that utilize SINAN
information for Integrated Partnership Programming (PPI) – for example, the proportion of cases promptly closed – has been shown to be a more effective alternative for improving the quality of information. From what this manager says, it may be inferred that incentive-based practices are more effective in improving information quality than those that are based on penalties.

One of the users recommended case-finding, tie-ins between the provision of resources and notification, encouragement of negative reporting, and financial incentives when it can be demonstrated that the data are being used in the planning and evaluation of health actions. The municipal manager was also concerned about insufficient negative notification, noting that there is “low negative reporting ... people forget ... it’s more difficult.”

The federal-level manager is concerned about cases of diseases that must be reported immediately. They are often reported by telephone but then not recorded in SINAN because personnel in the municipality think that they have been “relieved of their obligation to report to the system.” According to this same manager, another problem that needs to be addressed is the notification of outbreaks, in which cases are aggregated and reported as a group. SINAN does not have the logic to handle this format; each record refers to one single case. For this respondent, “the outbreak module has been useful for diseases that are not required to be reported and occur only sporadically.”

The uncertainty of reporting by the private sector is also considered to add to the problem. Underreporting is especially common for certain conditions – for example, sexually transmitted diseases.

Decentralization has increased the problem of duplicate records because a case reported by the municipio where the patient resides may also be reported by a different municipio where care is provided. Despite the introduction of cross-
checking software to prevent this from happening, in the case of chronic diseases, for which obtaining medication is tied to notification, duplication continues to occur, both when patients move to a different município and when they are receiving medication in more than one municipality. On the other hand, since the SINAN reporting units are not standardized, this can also be a cause for duplication of records within the same município.

Ever since the system first began to operate, there has been discussion about which **data elements should be considered for inclusion in the form**. One federal-level manager referred to the ongoing tension between “the megalomania of each technical area that wants to include everything in the form versus what is really necessary for the actions to be carried out.” Currently a large number of data elements are being routinely collected, and they are having a negative impact on the quality of the information being filled in. The municipal manager suggested that it might be necessary to **standardize** the tables containing addresses and the names of institutions.

The inclusion of **social variables** – race, education, occupation – on the form does not mean that the information is being properly reported. Managers at both the federal and municipal levels said that there has been difficulty filling in the field labeled “occupation,” and the municipal manager believes that the “education” field poses problems as well. No one mentioned race.

According to the municipal manager, there is need for **ongoing training** in the services to improve the quality of reporting, even in areas where good results can be seen. The federal manager agreed and pointed out that “the high turnover of professionals has necessitated major training activities from time to time.”

For the local-level manager, for example, the hospital resident physician is the ideal person to report cases, but the rotational nature of the medical residence
program means that there is frequent turnover. It is hoped that the epidemiological surveillance nuclei in the hospitals can introduce a culture of notification in this environment, training not only the residents but other professionals as well.

According to one of the managers, “the main source of available data is [still] the Epidemiological Bulletin published by the Ministry of Health,” and “the only subsystem that has been making its databases available on the Internet for some years now is SINAN-AIDS.” It was mentioned that in Rio Grande do Sul data are disseminated in epidemiological bulletins published by the state. Today, according to another federal manager, “if a manager wanted to compare his data with those in another state, he would have to go to Brasilia.” For this person, the Bulletin will cease to be his preferred place to find information once SINAN-NET is introduced.

From the statements made by the respondents, it appears that there is a fair amount of consensus as to the “what was done right” and “what is working” in SINAN:

- It is a system that has gone from a condensed set of data at the central level to the present situation in which access is available on a case-by-case basis.
- Access has ceased to be restricted; it is more democratic.
- The introduction of SINAN-NET is expected to help improve the flow of notification, speed up the transmission of information, reduce problems of underregistration, and make it easier for different users to tabulate and analyze data.
- The case investigation forms have been standardized, which will permit communication between different subsystems of SINAN as well as
other systems (SIM, SINASC, SIH) and allow for the use of software tools such as RECLINK®.

- The system is increasingly able to identify cases recorded in one subsystem and compare them with data in another – for example, tuberculosis and AIDS.

- Some of the installations were cited as being especially efficient: at the municipal level, Porto Alegre, Belo Horizonte, Goiânia, and Curitiba, and the state level, Alagoas, the Federal District, Maranhão, Mato Grosso do Sul, Pará, Pernambuco, São Paulo, and Rondônia. There are various factors that make these particular municipalities stand out, but the main one seems to be that they give importance to information as a public policy tool. This understanding is translated into support for epidemiological surveillance, planning actions, human resources development, allocation of informatics resources, and cooperation with the different levels of the health system (these fit in well with SINAN).

- It can be said that the most successful example of SINAN in recent years has been its AIDS subsystem, for its coverage, completeness of information, and availability of data through epidemiological bulletins and the Internet.

**Mortality Information System (SIM)**

SIM is the oldest national health information system still in operation in Brazil. Instituted by the Ministry of Health in 1975 and computerized starting in 1979, SIM came into being as part of the initiative to implement the World Health Organization Reference Center for the Classification of Diseases in Portuguese, based at School of Public Health (FSP), University of São Paulo. The expectation
was that this center would support studies on mortality, especially in connection with the International Classification of Diseases (ICD), and that it would contribute both to new revisions of the ICD and to the training of personnel to work as coders.

Creation of the reference center received strong support from the World Health Organization (WHO) and the Pan American Health Organization (PAHO), particularly for the Inter-American Investigation of Mortality in Childhood, which involved a group of professors and researchers from FSP as well as counterparts in several other countries of the Americas. In Brazil, this study was carried out in three municipalities (São Paulo, Ribeirão Preto, and Recife), and it involved investigating a sampling of deaths in children under 5 years of age based on official birth and death records and interviews with health professionals and families. The results of this study revealed the sizable underregistration of deaths and the lack of uniformity in the sources of data on mortality – in other words, the fact that there was no single unified declaration of death for all of Brazil.

It should be pointed out that at that time the entire process of collecting, consolidating, and disseminating data on births and deaths was the responsibility of IBGE, and the data were based on the records kept in the local civil registry offices. Neither the Ministry of Health nor any of the rest of the government health sector had any involvement to speak of in this process.

It was only starting in 1975, when a group of highly qualified professionals associated with the reference center at FSP/USP and other Brazilian institutions were invited to join forces with the Ministry of Health, that institutional conditions were created for the establishment of SIM at the national level.

One of the respondents emphasized that SIM represented a new concept in the approach to mortality because it ceased to be regarded as only being of interest
for demographic and population studies and was being looked at from the perspective of epidemiology:

“From the point of view of the Ministry of Health, it practically didn’t exist. Of course, the IBGE collected the number of births and deaths from the local offices of the civil registry – that was the classic routine. But we began to see it: the main user of mortality data is always going to be the Ministry of Health.” (Interview 1)

“The mortality information system for the city of São Paulo (PROAIM) was a pioneering initiative. It regarded death as an epidemiological event, even though in the state of São Paulo it was being treated as a demographic event. Death represented an exit from the population. And then PROAIM comes along, adding the perspective of epidemiological surveillance. A death is no longer a number subtracted from the population stock, it is an epidemiological case. It has a name, an address, and a cause, and if it has a cause, it is necessary to see what that cause is, and see if anything can be done with the information. And this is going to be a reason for organizing the system, making diagnoses of the situation. It’s going to make a whole lot of things happen in our work. That’s what people were thinking at the time.” (Interview 4)

Two tasks were given priority when SIM was established. The first was to create a single model for the declaration of death for use throughout the country, since death records were not standardized at the time.

“And thus, SIM, the Mortality Information System, was created, and its big contribution at that time was to institute a model declaration of death that was standardized throughout the country.” (Interview 1)
The second task was to address the high rate of underregistration of deaths in order to broaden the system’s coverage. For this purpose, according to the respondents, a major campaign was undertaken to raise awareness among personnel involved in the system: secretaries of health, health professionals and physicians in particular, regional councils of medicine, local offices of the civil registry, and others. All the respondents mentioned that, in addition to this process of raising awareness, there was also a massive investment in training professionals on how to fill in the death certificate and about the quality of the information provided.

Suffice it to say that, given the diverse realities existing in Brazil, the implantation of SIM was not homogeneous throughout the country in terms of either the rate at which it was implemented in the different regions and states or the coverage of the system. As Viacava (2005) has pointed out, the social inequalities in Brazil are reflected not only in the performance of the health system but also in the recording and reporting of vital events.

Difficulties in filling in the declaration, inadequate technical qualifications, a poorly defined path for transmitting information, and the existence of clandestine cemeteries are examples of the initial hurdles encountered that called for different strategies depending on each local situation.

The support of WHO and PAHO, the commitment of resources by the Ministry of Health, and involvement on the part of professionals and managers were cited in the interviews as fundamental elements in the implantation and subsequent development of SIM in Brazil.

The respondents recognized that currently the monitoring of mortality information by the Ministry of Health is much more rigorous than it was in the
The early years of SIM, and major advances have been made in the system’s coverage, the quality of the data, and dissemination of the information produced.

The respondents were unanimous in citing the advances made in the system’s coverage since it was first instituted. As is well known, when SIM was initially introduced, there was a high percentage of underregistration of deaths, especially in the northern and northeastern regions of the country. However, gradually, one step at a time, the system managed to advance significantly in terms of its coverage, attaining an average for the country as a whole of 84% in 2003, with lows of under 60% in some of the states of the Northeastern region and levels of over 90% in the southern, southeastern, and western central regions (figures based on demographic estimates, Mansano, 2004; Viacava, 2005).

Even recognizing the lingering problems in the northern and northeastern regions, the respondents emphasized the progress that has been made in the system’s coverage even in these areas:

“Quantitatively, the system’s main challenge has always been coverage in the northern and the northeastern regions, but even so, the levels have greatly increased in these states.” (Interview 1)

“In terms of coverage, there is no doubt that it is much better today.” (Interview 2)

One concern that came through in some of the interviews was the tendency to overestimate the underregistration of deaths in certain parts of the country. The perception of this trend stems from the fact that the method of calculating the rate of underregistration is based on long-term demographic estimates, which do not capture the rapid changes that have been taking place recently in fertility rates,
increased life expectancy, and availability of health services, among other factors that directly impact the mortality profile.

“What is our problem now? It is the parameter for evaluating underregistration. Because today our parameter is the estimates prepared by IBGE. The ideal would be to have an external parameter, and that external parameter would be the IBGE estimate. But the estimate has problems. It covers a very long period, all the way to 2030, and this means that it incorporates factors from the past. This can generate a lag. These trends are usually overestimated.” (Interview 5)

Various attempts have been made to revise this process, both in the Ministry of Health and in different states and municipalities. These are mentioned in the following statements.

“The underregistration of deaths in this state is low. It is low because the following indicator is used: I have to set a standard mortality rate for the municipalities. Those that have fewer than 4 deaths per 1,000 population are the ones that have underregistration. Now, if I do not set this standard, I run the risk of miscalculating the underregistration.” (Interview 2)

“Everyone complains about IBGE. But IBGE has its specific objectives. What business do I have taking an estimate that they use for something else and then complaining about it? It’s up to us to do our own estimates, geared to our own needs. Can I keep on using IBGE? Sure I can. But let’s make our own estimates. For mortality, we have created a different parameter, suggested by Célia Landmann in the study she coordinated on infant death. We extrapolate this parameter for deaths in general. The parameter that has been suggested is mortality per municipality. For our municipality, the mortality coefficient of less than 4
suggested by SIM would mean that coverage is low. This is one of the parameters used to control the model when it comes to coverage.” (Interview 5)

With regard to information quality, it was also unanimous among the respondents that significant advances have been made in filling in the declaration of death since the establishment of SIM. However, several of them pointed out that this improvement was not the same in all the states, nor was it the same for all the data elements in the DO. The main problem, according to the respondents, is the high percentage of ill-defined causes of death.

“Today, our biggest challenge is to reduce the ill-defined causes. Take the northeast, for example, where the proportion is 20% to 30%.” (Interview 2)

“Well, maybe it’s more correct to say that one of the main problems is still the diagnosis – mainly the ill-defined causes given as a diagnosis of the cause of death. There is no question, this is a very serious problem, but the situation has been getting better over time. Today the proportion of ill-defined causes of death in Brazil as a whole is around 13%. In some states, however, it is as high as 30%. Certainly SIM has improved in this regard, but there is still room for more improvement.” (Interview 5)

Some of the factors that have contributed to the high levels of deaths to ill-defined causes were cited in the interviews: difficulties related to the qualifications of professional coders responsible for entering the underlying cause of death in different parts of the country (limited training and high turnover of professional employees, among others).

“Often the municipalities have no coding capability at all. You can see that in certain municipalities there is a high turnover of personnel. That can really be a problem, can’t it? When you have a coder, invest in training this coder, and then he
or she moves on to a better job. There you are, without that coder that you have been working with and all that effort has gone to waste.” (Interview 3)

According to the respondents’ statements, the introduction of SIM computer software for selecting the underlying cause created a higher level of confidence in the quality of this information, since the system goes through an elaborate logical sequence in selecting the underlying cause of death. At the same time, however, this software did not do away with the need to train professional coders.

“Today, at least we have greater confidence because the program has software that selects the underlying cause. Before that, it was the coder who made the decision. Now the system works this way: you enter the data and the program applies the rules. Even so, it’s still just a computer system. ... You have to key in the code filling in the lines exactly the way the physician wrote them and then put in the correct code. Otherwise the system doesn’t work! You have to do everything just right for it, and if you put in the lines just right, it will select the cause. And then on the side it opens a window saying what it has just done, and that such-and-such condition leads to so-and-so. ... I always say that I would feel extremely frustrated to be doing something there, and the system goes and chooses a cause, and I have no idea why it’s choosing what it does. ... and only someone who really knows about the subject can make an intelligent correction to improve the system.” (Interview 2)

There were some references to possible weaknesses in the software for selecting the underlying cause. It was emphasized that the program is based on a table developed in North America, where the epidemiological profile is quite different from the Brazilian, so that it could be generating differences in the interpretation of the underlying cause. The quote below addresses this question.
“The program for coding the underlying cause has some faults: it consults a table to find out, for example, whether hypertension leads to infarct. The machine doesn’t know, so it consults a table. If there is any error of interpretation in this table ... this table is an American table, which has a given logic. There are diseases that occur here, for example associated with infection or malnutrition, that are different for us. Take diarrhea. For us, it is always infectious. For them, no.” (Interview 2)

The lack of physicians’ knowledge about, and training in, filling in the forms were factors emphasized by almost all the respondents. Another factor that they cited was the limited interest in and importance given by some professionals to the process of filling in the DO, which is often regarded as merely a bureaucratic procedure.

“The attitude of professionals is that paperwork is a nuisance; reading the manual is even worse. Nobody likes it.” (Interview 2)

Ill-defined causes are especially high for deaths occurring in emergency services and hospitals during stays of less than 24 hours. There is a mentality that if a physician wasn’t following the decedent previously, it is more prudent to merely record the symptoms and signs or state that the causes could not be determined – which is a mistake.

“There is a legend in this country that if the patient died in the hospital without being there 24 hours, it is not appropriate to declare the death.” (Interview 1)

“There’s this problem in the emergency services, that they treat the case as if a person who dies there was already a cadaver when he or she arrived. In this case, it’s impossible to determine the cause of death unless the family brings along some
kind of documentation. But I say that part I of the declaration, on lines “a” and “b” under “cause of death,” you can say that you don’t know and that the cause is undetermined. But then you can use part II and give the probable cause. Because if the person arrives in the unit and you provide some care, ... to get the ball rolling, you have a hypothesis. ... It’s common for the resident on duty, if he wasn’t following the patient, to say that the cause could not be determined.” (Interview 2)

With regard to other data elements used by SIM, there was a general impression among the respondents that the quality of information has improved and the number of blank entries has declined for almost all the fields.

Some of the respondents said that the most common omissions have to do with the data elements **medical care provided, laboratory confirmation of the diagnosis**, and **surgery performed** (fields 45, 46 and 47). Other respondents mentioned omission of the **place of death** in the case of violent deaths on public roadways, which requires careful epidemiological investigation on the part of the physician filling in the declaration.

“What isn’t filled in properly? Cases of violence on public roadways. No one fills in those cases because they require the person filling in the form to go and find out the information. The person died on the road, run over by a vehicle – died right there. The person filling in the declaration is not going to go chasing after that information. Yes, what is difficult for us is analyzing violent deaths and the place where they occurred.” (Interview 5)

In deaths among women of childbearing age, the variables indicative of **maternal death** (fields 43 and 44) are as ones that are often left blank. As for the fields referring deaths in infants under 1 year of age (fields 33 and 42), the respondents were divided in their perception of whether or not there has been an improvement. While some of them emphasized that there has indeed been
improvement in these fields, others considered that these variables are among the ones most frequently omitted on the DO.

Among the so-called social variables, the respondents pointed to improvements in filling in the fields “race/color” and “schooling.” The variable “occupation” was cited as having low reliability, given the extensive list of occupational categories and the different interpretations that are given, which, according to the respondents, raises the question of whether this field should be subject to revision or suppressed entirely.

The respondents confirmed that there are differences in the quality of information between the public and private health sectors. Although this question has not been studied in detail, the respondents’ accumulated experience in the management and/or use of SIM suggests that the quality is better in the answers filled in by the public sector. This may be due to the predominant mentality of procedure-based billing in the private sector, with epidemiological information relegated to the background. The creation of epidemiological nuclei in the public hospitals was pointed out as a factor contributing to the improved quality of information.

In the opinion of the respondents, many factors have contributed to the progress of SIM, both in relation to coverage and in terms of the quality of information. Investments made by the Ministry of Health and the State and Municipal Health Secretariats in training the professionals involved in the system, from the collection of information up to the final processing phase, have made a fundamental difference. The respondents emphasized that, more than showing how the system works, this training has been concerned with raising awareness, getting the professionals involved in the system, and showing them the
importance of mortality information and the different ways in which it can be used for management, timely intervention, and the evaluation of health actions.

“Another strategy for improving the quality of information is to work with the municipios on training. ... There we can talk about filling in the fields, ill-defined causes, all the variables, and so on. Because it’s not just the fact that there was a death; it becomes a question of the age, sex, place of residence, all the variables together. We can take advantage of this training to show that this is what we do with the DO, not just go there and tell people that they have to fill in the blanks.” (Interview 2)

“We talked a lot with the medical professionals about filling in the declaration of death and the importance that they give to it. Then we would go on a little about mortality statistics, what the mortality information is like in that hospital, showing the percentage, for example, and explaining that that was actually a little piece in the overall picture of quality care. That gave them something to think about.” (Interview 3)

Progress in the municipalization of health was also cited as an important factor in improvement of the system, because it has made for increased involvement of local managers in the production, utilization, and dissemination of health information. To the extent that the local level has assumed more responsibility for sectoral management, health information has taken on new importance in light of its role in decision-making.

“I am for closer ties between the mortality system and the physicians. The closer the link between those who record the information and those who use and organize it – the ‘information managers’ – the more you are going to have quality information.” (Interview 3)
Before, the municipalities merely fed the data to the health information systems, but with **decentralization**, they came to be responsible for the organization and management of these systems, with resulting benefits for the quality of the information. Many municipalities, with support from the state health secretariats, have taken on the task of investigating deaths, depending on the priorities of each locality, adopting various strategies for improving the system, and have had satisfactory results.

“Let’s talk about improving quality. In the beginning, we developed a search for ill-defined causes in cases that were suspected of being from AIDS or maternal death. Then we developed software that automatically generated letters to physicians to investigate any suspicion regarding an ill-defined cause. ... What were these letters like? They were addressed to a particular physician. They referred to a particular death, saying where it had occurred and on what date, and we asked for the underlying cause of the death. The letter contained a direct question and it was mailed out with a complete explanation. A sample clinical case was enclosed with instructions on how to fill in the blanks corresponding to that case. Also enclosed was a response sheet with the name of the person and the hospital already filled in. The physician had two choices: report the clinical case in detail, or fill in a new Declaration of Death and send it back. ... We have had very positive feedback from this.” (Interview 4)

Among the **successful experiences** in terms of improvements in filling in the DO, the respondents cited interventions with the local offices of the civil registry, clandestine cemeteries, professionals, hospitals, and medical examiner offices – in other words, all the sectors involved in the primary collection of information.
One point that often came up in the statements is getting professionals involved in SIM. The building of an esprit de corps – pointing out shortcomings, seeking solutions, and investing in the full-scale operation of SIM – is crucial to its progress.

“Because we, many of the municipalities in the country, have succeeded in getting others to jump on the bandwagon ... this is improving a lot, and people are enthusiastic. They’re having a ball.” (Interview 1)

“This has also generated a movement in which people are starting to study the mortality information system, to recognize it and work with it. We have had several people who, based on our initiatives, have joined the ranks of those already working in the municipios and the state and are writing theses about it.” (Interview 5)

Proposals and strategies for overcoming the remaining problems in coverage and quality of the information have been implemented in various places, in some cases isolated initiatives and in other cases joint undertakings bringing together municipalities, state health secretariats, and the Ministry of Health.

One of these approaches has been to intensify the training of professionals and make this an ongoing process. There is no doubt that full-scale operation of SIM depends on the quality of the information filled in on the DO, which in turn requires that professionals be trained to do this.

Another strategy adopted in some of the states is setting targets for reduction of the percentage of ill-defined causes in the intermanagerial partnership agreements, such as Integrated Partnership Programming (PPI) and the Basic Health Care Pact, among others. Here, the steering and regulating role of the Ministry of Health is essential for attaining these targets.
The creation of Death Verification Services (SVOs) is another strategy that may help to reduce the number of ill-defined causes. Their implementation and operation depends on establishing protocols, document processing paths, and routines, which need to be defined through some legal apparatus in order to standardize actions and avoid having to investigate cases that could have been handled in the hospital unit where the death occurred.

It’s also important to report on a project being coordinated by the Ministry of Health which is aimed specifically at reducing ill-defined causes. The following excerpt from one of the interviews gives a good idea of its overall direction.

“This project for reducing ill-defined causes is being carried out through a local team effort – an undertaking with the community. It involves the Ministry of Health, to have access to the declaration of death and records on the care that was given. They are involving public attorneys as well as physicians and medical and nursing councils. Most of the states have not yet gotten involved in the project. Where there is a university and a school of medicine, you have the record linked to the school, which also helps to train the students. There are none so far in the capital cities. Thus we have a project that offers the basic skeleton, which provides for the financing and costing of this service. We are going to implement several of them in the capital cities, working with the Federal Council on Medicine. Because it has to be standardized. Everything is about negotiating the standards and procedures for the DO.” (Interview 5)

The implementation of a new DO format, foreseen for 2006, opens up the possibility of refining some of the fields to make the information compatible with other databases and creating more opportunities for constructing and utilizing information on mortality based on the health care and management needs of the SUS.
The collection of data, the document processing path, and schedule for sending mortality information to SIM is regulated by FUNASA/MS Directive 474 of 31 August 2000. According to these regulations, the data are collected by the Municipal or State Health Secretariats from health care establishments and local offices of the Civil Registry. Then the data from the DOs are coded, keyed in, and sent to the Health Surveillance Secretariat (SVS) in the Ministry of Health. It is the job of the SVS to consolidate the data and make it available to the DATASUS Department of Information Processing.

As for the uniform implementation of SIM nationwide, there used to be quite a long delay between the when the data were collected and when they were disseminated by the Ministry of Health (about six years). Some of the respondents remember that at the time the system was not computerized as it is today and there were large differences between the states in terms of submission rate and degree of difficulty they were encountering in collecting the data on deaths, coding them, and sending them to the Ministry of Health. Also at that time, checking and assessment for consistency of the information was centralized in the Ministry with only a few exceptions. When there was any inconsistency in the database, the DO was returned to the state health secretariat, which then investigated and corrected the information. This took a long time. The statement below gives an idea of the early difficulties.

“The problem in the beginning was that we had to maintain the information system at the central level. When if some of the states are sending data and others aren’t, when are you going to close out the statistics? ... There wasn’t any computer – computers were just beginning to be used – and we made a consistency table. ... We had one for causes, one for age, and one for sex. When there was any inconsistency, the Ministry returned the information to the state, which
sometimes... Now let’s assume that the person died on the 1st of May. By the time the information reached the ministry it would June or July. By August it was keyed in. Sometimes the information had to be sent back for further investigation, then months later, depending on the inconsistency, the physician did not find anything out. Sometimes the information only arrived in the ministry a year later.” (Interview 1)

Thus, in the opinion of the respondents, the decentralization and computerization of the system greatly speeded up the transmission of data and organization of the document processing path. Currently, many municipalities are responsible not only for the collection of data but also for its management and evaluation. Thus, in the case of inconsistencies, the municipal health secretariats, or even the state secretariats, identify these inconsistencies and make the revision before sending the data to the Ministry of Health. With this change, the time between the collection of data and dissemination of the information nationwide has been reduced considerably, to about three years. This interval was still considered long for some of the respondents. Others felt that the delay is quite similar to the situation in other countries, as far as health information is concerned.

“The delay in the dissemination of SIM results is a fairly frequent complaint. But I think that we are a lot better. It used to be five, six, seven years. I think that today Brazil is within the expected gap. It’s the same thing in other major countries. Look: I receive statistics regularly from the Scandinavian countries, the United States, and from Argentina, too. In May or June of this year I received the latest publication from the Scandinavian countries. The date of the publication is 2005, and the data are from 2001, some from 2002. It’s the same thing in the United States.” (Interview 1)
Another question that came up in the interviews has to do with the compatibility between the time lag in the information and the uses for which it is being put. Some of the respondents said that mortality information is very valuable for assessing trends in the health situation and that for this reason it offers potential input for public policy-making, both in the health area and in other sectors. Its usefulness as a sentinel event linked to health surveillance actions carried out at the municipal level, where access to local mortality information is available more quickly, doesn’t depend on processing at the federal level. In order to speed the system up, some states have made information available within as little as a year, with the proviso that it is still subject to review.

“We also have to keep in mind that dissemination at the state level and later by the federal level is for working with a historical series. In other words, for surveillance, the municipio can have data within a week if it wants. We even recommend that the information be collected weekly. Now if they don’t do this because they don’t have a vehicle or for whatever reason, that’s not the point. But this is the time lapse at the level of the municipality, and it’s there that they need to have the information for surveillance purposes. This immediate information is not about the death itself but rather about the report that it occurred. Then the municipality has this information if it wants it; because that’s where it’s being collected. Regardless of whether the processing of the information is centralized or not, the collection takes place in the municipality, and we keep telling them this. You don’t need to have a computer in order to have data and generate the information. The municipality needs to understand this first; it can’t afford to wait until someone dies to figure this out. The point of mortality information is to see a trend, a profile. It is very helpful for this” (Interview 2).
“One of the functions of SIM is to provide mortality information that is reliable and of good quality, so that it can assist in guiding policies in the sense of preventing or reducing health damages. The system serves as the base. It’s not that the system itself is going to provide the information. The data have to be processed, worked on, so that data become information. Of course morbidity is extremely important... Mortality is the end of the line. But it serves very effectively as a warning that things have gotten so bad that they are generating a large number of deaths. So I defend this role of providing the necessary support so that we can analyze trends and mortality situations, and in this way help to shape public policy.” (Interview 5)

One aspect to be considered with regard to procedures for transmitting and consolidating mortality data is the fact that in some of the states the management of SIM has been decentralized to the municipalities while in others it is under state administration. Although the respondents have said how much municipalization has enabled SIM to make progress, some of their statements emphasize the need for this process to be implanted in at least minimally adequate conditions in order to preserve and improve the quality of the system. The existence and assignment of trained professionals to run the system, especially coders, along with implementation of a local supervision process, were cited as indispensable conditions for decentralization to the municipios.

“My argument is that, in order to decentralize mortality information, I have to have a team that is able to code the underlying cause of death. Otherwise, I run the risk of losing information quality.” (Interview 2)

“The degree of involvement in the system is going to depend on each place and each organization... For example, Rio Grande do Sul decentralized everything. Now all the municipalities key in the DO, collect them in the hospitals and from
the doctors, then they key it in; everything. In Bahia it’s different. Some municipalities, the larger ones, key in everything, and the smaller ones key in part of it, but they don’t code in the cause of death. That coding is only done in the state health secretariat. Because they understand that the municipalities don’t have coders yet, they don’t have people who are sufficiently trained to enter a code based on what has been described.” (Interview 5)

The situation in the municipality of São Paulo is worth mentioning. For some time, this municipality has been producing information on mortality, investigating deaths, and working to improve the coverage and quality of the system. In addition to all this process of collecting and checking the data, the institution officially recognized by the Ministry of Health as manager of SIM for the entire state is the State System for Data Analysis (SEADE Foundation), an agency tied to the secretariat of planning for the São Paulo state government.

“Now, just imagine how irrational the system is in the state if São Paulo! PROAIM has a golden, highly refined database, with ongoing investigations by the medical examiner and the SVO for toxicology and so on. ... Then the parallel PROAIM system takes its golden database, sends it to SEADE, and SEADE takes its own information and transcribes it into this other database, instead of taking the PROAIM database and incorporating it into their system. It’s absurd! It’s absurd what happens in the state of São Paulo.” (Interview 4)

Several of the respondents noted that the decentralization of SIM had not reduced the role of the state health secretariats or even the Ministry of Health in management of the system. According to Mota & Carvalho (1997), the decentralization of health actions and services should include sharing the responsibility for health information between the levels of government, which does not mean merely shifting systems under federal or state management to the local
level. Thus, the responsibilities assumed by the municipalities for the organization and management of the information systems should be integrated with the state and national systems. Even though in many states the state health secretariats no longer do the collection, transcription of the DOs, and coding, these secretariats still have a fundamental role to play in preparing professionals, monitoring and evaluating the quality of information and reviewing the data, overseeing regional management of the system, and supervising and supporting the process in the municipios under their jurisdiction.

There is an expectation in the Ministry of Health that the installation of new software for the processing of SIM data will give the ministry greater control over the information flow within the system.

“Now the new system is going to improve control. We are going to have a map of all the machines that process the DOs. We are going to have much better control of the distribution. ... Every state has its own organization. With the new system, we are going to increase control. We are going to know where something came from, where it’s going, and on what machine it was keyed in – with the new system, that is. ... This is going to go all the way to the municipalities, to know where the data went and how much went to each place and on what machines they are being keyed in. We are going to have greater control now with the new system. Today, I have no way of controlling anything. In 2006 we are going to know everything. But in general, there has not been any complaint about the document processing path, no complaint.” (Interview 5)

The statement of one of the respondents suggests the need for greater clarity in defining the roles of the agencies associated with SIM at the federal level in order to avoid disputes and conflicts and to expand cooperation.
“I think there was a management problem at the national level. I don’t know how it is today because things got very confusing: what roles were of DATASUS, the secretariat, national census, and so on. I think that the coordinator of the system is the secretariat of surveillance and health. Because I think that any information system should be managed from the standpoint of the sector that needs it the most. To me, DATASUS is the disseminating organ of the system. That’s only logical, because its an informatics thing. ... But it can’t be the manager of the information. For example, sometimes it publishes things about the WHO International Classification of Diseases, which is complicated.” (Interview 3)

All the respondents without exception recognized that significant progress has been made in the operation of SIM since its early days, especially in the last decade. This progress has taken place in the following areas, among others:

- increased coverage of the system and reduction in the underregistration of deaths;
- improved quality of data entered in the declarations of death, with fewer omissions and a lower proportion of ill-defined causes;
- greater appreciation of the value of health information in general and information on mortality in particular as support for decision-making based on health needs;
- greater involvement on the part of various groups and institutions in the production and dissemination of information; and
- improved processing speed and faster nationwide dissemination of information on mortality.

One factor that was emphasized in the interviews was the effect of implementation of the SUS and decentralization of the sector. The assumption of
responsibility for managing the local health systems by the municipalities thrust information into the spotlight as a basic tool for managing the sector and evaluating the effectiveness of health actions. Thus, the local level, which previously only collected the declarations of death, came to recognize the importance of this information for making decisions in the health area and began to push for its improvement. The fact that municipal managers are investing in the training of professionals to operate the system and even in acquiring the necessary infrastructure to install and develop it shows how much priority is being given to health information in the government health agenda.

“In terms of the underlying cause of death, we can clearly see that there has been an interesting connection between decentralization and the quality of information.” (Interview 3)

“PROAIM was given top priority in municipal management within the SUS. The SUS understood that PROAIM was its mortality system, and PROAIM was beginning to qualify their analyses, too ... PROAIM would go to the databases and look up meningitis. It was studying meningitis. It would take the infant deaths in the northern region of the city ... and begin to answer the questions being asked in the health services. And then the SUS began to take shape and create a decentralized level, which was asking for information. ... It followed the development of the SUS itself over those 15 years. ... The information system was always being pulled along by these political changes. ... All this has healed. Even in the matter of the ill-defined causes we are seeing an improvement here in Brazil.” (Interview 4)

“For me, what has changed is that information is on the manager’s agenda, and it didn’t used to be. Today municipal managers are more concerned about ensuring that they have the structure to make the system work. ... So today you
have more support for the structure part than you used to. Contracting technical people: today many places have expanded and hired more people. They have invested in training. Many states in the northeast have yet to meet the targets. They have invested a lot. They have invested within a significant picture.” (Interview 5)

There has also been **strengthening of basic health care** since the mid-1990s. The introduction of the Family Health Program (PSF) was mentioned in the interviews as a strategy that has resulted in improvements in the coverage and quality of the SIM information, especially with the introduction of management mechanisms involving partnerships between the different levels of government (municipal, state, and national). Some of the respondents recognized, however, that the potential of basic health care for improving information has not yet been fully explored.

“I think the PSF is a very important strategy for improving information. I don’t think it is has been used very much for this. ... I believe there is still a lot of room for the improvement of information through basic health care. In other words, in the municipalities that have broad coverage, the quality of information still leaves something to be desired.” (Interview 3)

“The recent policy of investing in basic health care has had a positive impact. It is on the manager’s agenda. Previously, this was only a problem for the people who were taking care of the information. Today, the manager has made it his problem as well, that he has to answer to within the partnerships. He has to answer to the fact that he didn’t meet such-and-such target, and what happened. He could be penalized in some way.” (Interview 5)

“I think the PPI has been a step forward. It was a step forward to give the information problem to the manager. Because it didn’t used to be his problem. It was down there in fifth place. Today, it’s at the top of his list. It is in each state’s
PPI, in health surveillance, in basic health care. ... It’s what gets him mobilized. So yes, I think it was positive.” (Interview 5)

The steering role of the Ministry of Health, whether through the partnership mechanisms with the states and municipios or through technical support – that is, the development of specific projects to improve the quality of information and reduce underregistration in specific localities – was mentioned in several of the statements.

It’s true that progress has not taken place to the same degree in all the municipalities of the country. Differences in terms of financial resources and technical training, and even of involvement of the municipal managers in the information system, affect the pace and scope of SIM’s development.

“Paraíba saw a big investment this year. Now Piauí is investing a lot, hiring people. Then there are states that I think are never going to get going. One of them, I think, is Maranhão. Some of the states don’t answer. Others have gotten mobilized and are responding. ... The municipality of São Paulo is a pioneer. They have created a structure. Then you have Porto Alegre, since São Paulo got started in the 1990s. Everyone is a little inspired by the work in São Paulo. Recife even got an award for the work they have done, in the field of violence. Infant death plays a big role in information politics. And one of the states that impresses me the most is Mato Grosso do Sul.” (Interview 5)

One aspect that appears to be key to improving the system, in the opinion of the respondents, is the committed engagement of professionals from different academic backgrounds and with different ties to SIM. These “information activists” have played a major role in getting the system deeply embedded in the politics of health at the different levels, spreading the word about the importance of
health information for the planning, management, and evaluation of actions, and creating an organizational culture that appreciates the value of quality information.

Even though progress has been significant, it is necessary to also recognize that certain problems and difficulties persist in some parts of Brazil. A reflection of the country’s social and regional inequalities, problems such as the nonexistence of medical professionals in certain areas or hard-to-reach localities, difficulties in retaining professionals, especially trained coders, are recurrent in certain regions, and addressing them is a challenge that calls for both creativity and customization to local realities.

The interviews revealed a wide range of possibilities for the utilization of SIM information in terms of both mortality studies in different parts of the country and management of the SUS itself at its different levels of operation.

Within the Ministry of Health, mortality information has been used mainly for the analysis of infant and maternal mortality, and also to establish a mortality profile of the major causes of death. Currently there are plans in the ministry to go more deeply into mortality in some specific projects, two of which are of particular interest. The first is a study on inequalities in health based on the causes most notably associated with inequality, such as tuberculosis, leprosy, and homicide. The other study proposes to correlate diabetes, hemodialysis, complications, survival, and mortality.

Another issue, then, is the importance of these studies for managerial decision-making, to support the policy-making process, and in assessing possible results and impacts of these policies.

At the level of the states and municipios, SIM has made it possible to carry out analyses of mortality with a view to developing health surveillance actions in
the broadest sense and supporting health management and decision-making. Here too, the most common studies have to do with infant and maternal mortality, in which tests that have involved cross-checking against information from other systems such as SINASC, SIH, and IBGE have been promising. Other mortality studies have been undertaken at the state and municipal level, often as a management priority. These include analyses of presumably avoidable deaths, early mortality, violence, chronic diseases, etc.

Mortality information is now being studied from the perspective of geographical distribution, and geoprocessing is being used in some of the municipios. This trend poses the challenge of constructing indicators that are capable of measuring specific local realities.

Even though some of the states and municipios are using mortality data in creative ways, the respondents still tend to think that there is need for the states and municipalities to work harder on analyses that will help them in their practice of health surveillance.

In all these studies, one of the main aspects that has been addressed is **consistency of the data and quality of the records**. The general impression is that the quality the data provided on the DO has greatly improved in recent years.

Among the respondents there is a noticeable concern about **socioeconomic information**, which is needed for more in-depth analyses of equity in health based on patterns of mortality in different population groups.

Of the social variables covered by SIM, the one that has improved the most in terms of quality of the data provided, according to the respondents, is race/color. This improvement may be related to the visibility this topic has gained thanks to recent debates in Brazil over public policies on behalf of the black population.
The variable “occupation” still poses problems in terms of the answers provided. Some of the respondents indicated the need to update the list of occupations used by SIM. Others stressed the lack of standardization of this variable, which has led to different interpretations of the same occupation. Another data element that poses problems is schooling.

The respondents welcomed the introduction of fields in the DO that support the investigation of maternal death. However, much of the time these fields are left blank.

Problems in the quality of the information have a direct impact on mortality calculations, especially in the case of maternal and infant mortality. In eight of the 27 states of Brazil, where the quality of information on mortality and live births is good, it is already possible to calculate infant mortality using the direct method using data from SIM and SINASC. According to the respondents, this represents significant progress for the country’s information systems, since calculating infant mortality on the basis of estimates alone fails to take into account recent demographic changes and progress in the health sector, leading to overestimated rates. Increasingly, municipal and state managers are wanting to meet the necessary criteria so that they can use the direct procedure. The respondents agreed that extension of the use of direct calculation of infant mortality depends basically on improving coverage and the quality of data entered on the DO. They believe that this is a possibility in the medium term, but it will require a massive investment in improving mortality information.

“I think we need to get over this mania that says that Brazil doesn’t have data. Brazil has a lot of data, and for the most part the quality of the information is on a par with that of other countries where it’s classic to use statistical data [for these calculations], such as England.” (Interview 1)
The respondents were unanimous that the introduction of TabWin and TabNet had allowed for unprecedented progress in the availability of information on mortality in Brazil. Internet access to the database and the possibility for the user to make whatever tabulations he wants, without the need for heavy technological resources, are the major benefits that have come from the introduction of these two software packages. In addition to democratizing information, these applications have made for progress in capturing feedback for the system.

Some of the respondents cited the difficulties still faced by certain states and municipios, especially in the northern and northeastern regions of the country, in gaining access to the information because they do not have the computer infrastructure to operate the system.

There are stories of validating experiences in disseminating information produced at the local level in many of the states and municipios. These experiences generally share the perspective that health information should be of good quality and accessible to the largest number of people in the shortest time possible. Thus, in some localities, information still subject to review is already made available and regular bulletins are issued containing the information produced. It is worth pointing out that when they manage their own information systems, states and municipalities do not have to wait for information to be made available by the Ministry of Health unless they are interested in a comparative analysis or information on deaths that occur elsewhere in the country.

The Ministry of Health, for its part, is concerned with making the information available efficiently and on a timely bases. In addition to the software mentioned above, which is available on CD-ROM and on the DATASUS Web site,
the ministry has invested in publishing compilations and bulletins to disseminate health information.

An issue that came up in one of the interviews has to do with the problem of identifying the different sources of health information within the Ministry of Health, which makes it difficult to gain access to the information produced. This is how the respondent explained his concern.

“In Brazil, no standards for dissemination have been established. They put out the information, but no one follows the standard. That makes it difficult. I would look for some things in DATASUS, others had to be gotten from the ministry. Get it here; get it there. They never knew exactly what was where or how to get it.” (Interview 3)

**Strengths and Weaknesses of SIM**

In general, the respondents’ opinions of SIM were very favorable. The following strengths of the system were emphasized:

- increased coverage;
- improvement of information quality;
- visibility of the system as an important channel for the production of health information;
- use of advances in information technology for faster processing of the data and availability of the information, as well as more rigorous control of the consistency of data through cross-checking software;
- exchanges among professionals at the different levels of management in the health system (national, state, and municipal) and their involvement in the system;
- its universal nature;
- the wealth of information produced by the system; and
- decentralization of the system with responsibility assumed by the local manager.

Among the weaknesses, the following were mentioned:

- quality of the declaration of the cause of death by physicians;
- scarcity of resources in the states and municipalities for developing the system; and
- insufficient training and ongoing upgrading of professionals in the use of the system.

**Suggestions/Recommendations of the Respondents**

Considering that the system’s coverage and the quality of information are the two main issues that are hampering the consolidation and further development of SIM, several strategies were suggested by the respondents for improving the system, some of them inspired by trial initiatives in the municipios and states, and even in the national setting.

In the first place, it’s important to mention once again the need to step up the training of professionals involved in the system, from the physician responsible for filling in the DO to the coders and all the way up to the management level. This training should not only be included in the medical curriculum but also be an ongoing process that reaches out to include professionals already in the health services.

Another strategy that was suggested has to do with raising awareness and involving professionals, managers, personnel in the services, health councilors,
notaries in the offices of the civil registry, and members of the regional and federal councils of medicine – in other words, everyone who has anything to do with the system. The creation of epidemiological nuclei in hospitals has had an impact on the quality of information.

Along with the training and consciousness-raising of professionals involved in the operation of SIM, it is indispensable to provide the states and, even more important, the municipios with the materials, techniques, and technology they need in order to manage the information systems and not merely collect the data. It is a matter of giving concrete validity to the concept of shared management of the system, which means creating the structures and incentives so that the municipios themselves can produce the information needed for the decisions that are essential for local management of the health services.

Also, the creation of death verification services (SVOs) throughout the country, with legally established protocols and standards, opens up the possibility of reducing the percentage of deaths due to ill-defined causes.

One aspect that deserves to be emphasized is the difficulties posed by the country’s vast territory, the sheer number of federative entities (26 states, the Federal District, and more than 5,500 municipalities), and the sharp social inequalities, all of which have to be faced in order to operate a system of such broad scope. The main challenge is to establish a system that is uniform nationwide, does not reinforce existing inequalities, and is able to make room for progress through experiences at the local level.

Without any doubt, vesting responsibility in the managers at all levels is vitally important to the system’s progress, and the building of partnerships has proved to be promising for the improvement of health information.
One aspect that has been disappointing in recent years has been the articulation of health information as a health policy priority. There is still need to demonstrate its importance for understanding health needs and supporting the process of formulating, implementing, managing, and evaluating public interventions in the health field.

**Hospital Information System (SIH)**

*What happens is that people form the basic assumption that payment systems are not reliable. This has been turned into a veritable truth.*

— A state-level manager

Many criticisms have been leveled at the information system over the years: tensions and conflicts over the Hospital Admission Authorization form (AIH) and the payment system have unfairly impugned the entire information system. According to the statement of an respondent who is an academic professional “the people who were critical of the payment system ... were criticizing the SIH-SUS and this may have undermined the process of refining and upgrading the AIH,” which was introduced in the early 1980s.

This same view – referred to several times in the interviews as “the prejudice against the billing system” – may have held back its use as an epidemiological tool. According to a state-level manager, the system has been improving, and today it has broad enough coverage for its epidemiological usefulness to be considered, although there are still areas that need to be improved.

The difficulties that have given rise to the criticisms can be traced to the system’s origins. A manager at the federal level reports that the SIH was inspired by a system being used in the state of Paraná, which was extended to the rest of the country and given the name Social Security Hospital and Medical Care System.
(SAHMPS). Its input data were drawn from the AIH. “Since the system was tied to payments, it was very easy to tweak the information in order not to jeopardize payment.”

The model used in Paraná, which used an input document called the Hospital Account, required considerable manual effort to review the accounts (about 30%), and this did not inspire confidence because the system allowed for distortions. Thus, the SAHMPS proposal was to create a transparent information system that negotiated the charges in advance, thereby reducing the volume of information and increasing the level of confidence and safety. That way, “all the parties involved would know the amount of the charges, the standards, and the criteria.” According to another federal manager, a series of control factors were introduced, such as the fee schedule for everything, fees paid per procedure or service provided, fixed payment to hospitals, length of stay, etc. Even so, this led to such situations as “holding onto the patient” in order to make more money. Still, this was the start of more transparent negotiations and “fees that were close to reality, based on records of historical series, for lack of a better method.” However, according to the same manager, this form of calculation “didn’t work because it was not based on technical needs but rather on the amount of money available.”

In the 1990s, following creation of the Unified Health System (SUS), the hospital payments system changed its name and was referred to as the SIH. According to the respondents, it was very difficult, starting from the beginning, to implement a flagging system, given the large volume of accounts and the high rate at which they were rejected, since if one of the accounts from a given hospital was rejected, all the others were as well. This manager reported that “in the beginning, any questionable entries that were flagged were regarded as danger signs. ... In reality they were nothing but flags – they weren’t supposed to be blocked, just
investigated as departures from the norm. But the system simply went on to block them” and then the distortions began to occur because the only accounts that were paid were those that were within the established ranges.

While lauding the broad expansion in **coverage** that the SIH has seen in the last 10 to 15 years, one user said that there are still some problems in both coverage and data entry due to the special nature of the information system, in which payments are based on procedures. Also, the SIH was originally limited to admissions in the privately contracted hospital network of the SUS and only recently began to include the public network. Another drawback is that the way in which the financing of services has evolved in Brazil has led to the creation of situations that distort the data referring to hospitalizations in the public system. Examples are the imposition of funding caps on the municipalities and hospital units, the creation of public hospital foundations, and supplementary payments for procedures from the municipios. The respondent said that he does not know the system’s exact current coverage or whether or not there are local variations. According to one researcher, “The worst part is that today no one knows how to estimate the coverage, or how it varies, and even worse, whether or not the proportion of underreporting varies greatly between one municipality and another, which probably happens. So this may be introducing non-systematic errors in the data and no one knows how to assess this. ... In other words, the policies of recent decades have also introduced problems of this kind in the system.”

The inclusion of public sector hospitals happened gradually, starting in the 1990s, with the creation of the SUS. The university hospitals were first, followed by the municipal, then the state and the federal ones. These latter filled in the AIH forms for information purposes but not for payment.
According to the state-level manager, “At first the system covered 80% of the population, but today the proportion is probably only 40% to 50%. Many people have left the system” with the expansion of the market of health insurance plans. More recently, he went on to say, “we are capturing ... data of better quality, with more awareness of the need for accuracy, but less data, fewer hospitalizations.”

Brazil produces 1 million hospitalizations per month that are submitted to DATASUS for purposes of undergoing a disallowance process. A portion of them are definitively removed from the databases, and the rest remain in a separate database and information about them is released. Some of them that were disallowed because of the funding cap are presented again in subsequent months.

To get around these difficulties and find out the degree of underregistration, one user suggested using the information obtained from the National Household Sampling Surveys (PNADs).

An academic user reported that several studies have shown that there are problems in the quality of information in the SIH, which vary depending on the time, place, legal status of the provider, and certain specific fields in the AIH form. These problems in quality interfere with research and epidemiological analysis and in the use of SIH data for planning and monitoring health actions. The creativity seen when the system first began to operate got bogged down by the increasing technical complexity of the health care system: “The system is a living thing that should reflect the dynamics of society. It should be flexible and be constantly updated so that the quality of the information isn’t lost.”

Since the system is designed for billing, the information provided in fields that are unrelated to billing may be less reliable. An example is the primary and secondary diagnoses, which are essential if the SIH is to be used for surveillance
and analysis of the health situation. According to the state-level manager, “The person who is capturing the data is the biller... There are one or two of them in every hospital. It’s a job that needs to be done. ... The biller belongs to a different world that has nothing to do with information science, the world of informatics.”

The federal manager pointed out that there are companies specialized in doing this job, which “is not a good thing.” These companies “know how to take advantage of loopholes in the directives, such as daily charges for the person accompanying the patient, longer stays, etc. This is carefully studied by the companies. The smaller hospitals find it to their advantage to contract them. This is not a desirable thing, but it exists. ... The companies guarantee that they will increase the hospital’s billing by 30%. They already have an idea what can be grafted on, and it’s very difficult to detect in an audit unless each line item is checked, one by one. The audit has to be done there on the spot, in the municipality ... There aren’t enough people to do this.”

The quality of information is also affected by the funding cap imposed at the various levels of service management, which has become yet another variable to distort the system, according to a federal manager. For example, a high-complexity hospital will tend to give preference to more expensive procedures for billing purposes.

A federal manager also mentioned the importance of **regularly reviewing the SIH tables of procedures**, which, according to him, is not being done adequately: “They update the tables by simply tacking on new things. ... Up until recently, you couldn’t hospitalize a patient with AIDS because there were no procedures for patients with AIDS. ... The system is absolutely alive; it needs to be adjusted all the time.” One academic user added that there are “procedures that... greatly downgrade the quality of information. ... From the standpoint of using this
database, the information on procedures, whether for epidemiology or for evaluation, is lousy information.”

One of the academic users cited conceptual problems relating to the principal and secondary diagnoses that are undermining the quality and completeness of the information. In his words: “The principal diagnosis, whether entered at the time of admission or at discharge, could be what best explains the reason why the patient was hospitalized, yet it usually happens that a patient will have more than one diagnosis. ... Even the terminology in the AIH manual is profoundly ambiguous. This is an area that needs to be developed conceptually.”

According to the state-level manager, the very fact that there is discussion about filling in the diagnosis fields is already a step toward improving quality. When the tenth revision of the International Classification of Diseases (ICD) went into effect, people had to be trained to enter the codes in the system, and this made it more suitable for epidemiological use.

Regarding the addition of a secondary diagnosis, one state-level manager wondered whether “more quantity ... might end up compromising the quality of the information.” In his opinion, he would prefer to invest in further details of the diagnoses, both the primary and the secondary, for which fields have already been recommended to be filled in.

One of the health sector policies for the allocation of resources, Integrated Partnership Programming (PPI), works as an incentive to improve the quality of the AIH, since some of the indicators that it uses are generated by the SIH. According to a state-level manager, “in terms of planning management, it is very good. It is completely structured, and it could be used.”
One thing that has indirectly helped to improve the system is the need to accurately enter the postal code (CEP) corresponding the municipality of residence and the municipality of the hospital unit, which is required for the PPI. The managers emphasized that with this requirement, all the municipalities in Brazil are poring over their databases, making sure their CEP codes are correct.

The state-level manager cited the need to refine some of the variables better in order to improve the quality of the system – for example, the reason for the charge and the nature of the hospitalization. He also suggests that, by articulating the SIH with other systems such as SIM and SINASC, it would be possible to gain a broader picture of some of the issues such as violence, maternal death, and reproductive health. Another suggestion is to consider the SIH a subsystem that supplements SINAN – for example on congenital syphilis, tuberculosis, and flaccid paralysis.

An academic respondent said that there is already consensus on the high reliability in the variables that refer to mortality, especially maternal and early neonatal mortality. In these cases, the AIH is a good estimator of mortality because most deaths occur in hospitals. One difficulty arises when the patient dies while being treated in an emergency unit: the death is listed on the DO as having occurred in the health service, yet the patient was not admitted to the hospital and no AIH was generated. Given the conceptual differences between the principal diagnosis (the reason for which the patient was hospitalized) and the underlying cause of death (the diagnosis on record in SIM), it is necessary to pay close attention in analyses that rely on both systems.

As for new data elements to be included, the respondent mentioned the need to include socioeconomic variables. He recalled that up until the creation of the SUS, the AIH included fields for occupation and social security status, which
were removed. Today the system does not have any information on this, which is “a serious limitation, because there are issues about inequality and discrimination ... that are fundamental for the study of quality.”

Even though the inclusion of these data elements is mentioned in Directive 3,947/GM of 25 November 1998, which lists the obligatory and elective variables, this view is not shared by the managers. One of them suggests that the problem would be resolved by instituting a SUS identification card that included information on the domicile as well as socioeconomic variables. According to him, “if you are identifying people, you have attributes for them that translate into their socioeconomic status. This information doesn’t have to be on the AIH; it can be on the card. Why just collect socioeconomic data for people in hospitals? If socioeconomic attributes are important, then we should have them for the entire user population.”

Another reason cited for not including these variables is that they are not permanent: “They depend on the social context ... and the stage in the person’s life. [What should be done is] take samplings in the hospitals, which would stratify the hospitalized clientele and capture the socioeconomic data.” Another suggestion from these managers was to use the socioeconomic information that exists in other systems.

A data element that was considered important by one of the academic users was identification of the provider – that is, more precise information about the professionals directly involved in providing care, a field that could be used for evaluating the quality of the care provided.

With regard to the information processing path, each hospital delivers a diskette, prepared using an installed program, to its municipal secretariat, which checks the data and makes it compatible and then delivers it to the health region.
Currently, in the municipalities that have full managerial status, “the cross-checking system is decentralized, but it is still up to DATASUS to set the standards and issue the guidelines.” One of the state-level managers reported that the checking and flagging are done “in the [full managerial status] municipality itself. If it passes this step, then it goes out directly. Nothing is rejected unless it’s rejected at the federal level.”

One of the managers at the federal level felt that the decentralization to be provided for in the new Decentralized Hospital Information System (SIHD) is important, since “the information going back from the central level to the municipalities will then be only a reduced file (RD), closed. The challenge to see that the person who produced the data is also the one who analyzes it, bills it, and makes use of it, all one and the same.”

By the end of the year the SIHD will be fully in place [some passages refer to it as already in place], which will make it possible to decentralize processing of the AIHs to the state or municipal health secretariats. When the information is received from the hospitals in their area on CD-ROM or diskette or as an electronic file, the system checks the data, calculates the lump sums to be paid, and transmits the necessary reports to local management. The local database incorporates the updated information along with a historical list of previous items handled. This has to be done every month. Once the information is processed, the SIHD sends it to the central system so that central management can issue reports, perform audits, and provide information to the Ministry of Health. For the financial calculations and payments, files containing the gross calculated amounts are sent to the SGIF (http://www.saude.sp.gov.br/portal/7743d2f5c0a8012200bf053f936944b6.htm).

It is hoped that with introduction of the SIHD, the decentralization process will be refined. According to the statement of one of the developers behind the
concept, “during the process of constructing the application, there was extensive discussion about the billing process, the consistency logic being built in, and capturing the data.” Thus two serious problems were dealt with: the delivery of information on all the hospitalizations, and the skills profile of the professional who is providing data to the system, who ceases to be a “biller” and becomes a health professional. With this, the quality of information should begin to improve, since it should be easier to “catch mistakes and see problems in capturing and producing the data. You receive the data, open up the system, analyze it, work with it directly. It is not just a point along the production line. The person communicates with the producer of the data, questions him, sits down with him, gets an explanation for the data.”

Some of the successful experiences are already headed in this direction – for example, in such municipalities as Aracaju, Curitiba, and São Paulo. One of the federal managers recalled that in Aracaju the Health Financial Information Management System (GIS) is used in the outpatient services, and the procedures are recorded directly by the attending professionals without any intermediary. This manager thinks that, in the case of the AIH, the Integrated Hospital Environment Information Processing System (HOPUB) developed by DATASUS is an alternative worth exploring.

A state-level manager noted that “there is no autonomy yet, even in the states with full managerial status, for them to run the system and make payments. They still have to go through DATASUS.” This manager warned that it has happened in some of the municipalities with full managerial status that “they try to pass off their social responsibilities in the area of health to other municipalities. ...
It’s an unfortunate situation. In the end, the citizens themselves are passed off as well. We don’t want this. This is a situation that needs to be looked into very carefully. You can’t decentralize without limit. It wouldn’t be a bad idea to undertake some transverse actions aimed at getting back control.”

With regard to making the SIH data available, one of the academic users considered that availability is good both from the perspective of access and the formats, and that this is one of the strengths of the system. With regard to dissemination procedures, the respondent emphasized that he had noted progress with some of the formats used for disseminating SIH data, including incorporation of some new fields in the consolidated summary. However, effective use of the system depends on being able to control its known limitations, for example those related to coverage. This same view was expressed by a federal manager: “availability of data: It’s already a fact, quite a bit of progress has been made, but I have some reservations, and they have to do with the proper entry of data.”

There was consensus among the respondents on the importance of developing tabulation software like TabWin and TabNet, which make it possible to analyze data at the local level and even help to generate the PPI indicators. One of the respondents thought that effective use of these programs presupposes knowledge about the structure of the database, which means that the user has to understand it “from the point where the information is captured, including all the quirks that that entails, all the way up to consolidating and exporting the information.” During trainings it was clear that the people who were getting the most out of training were “the ones who had need for a particular set of information and who understood that that information could be produced using the data that were in that database.” An academic user reiterated the need to train local
managers, recognizing that “it’s not easy to use the data to formulate a response, to make policy and monitor its results.”

With decentralization came changes in the document processing path, the manner of collection, and the profile of users who were adding to the use of the SIH at the local level, which tended to intensify after introduction of the SIHD, in the words of a state-level manager. For him, there have already been successful experiences in the most developed centers in the country which show that the hospitals are capable of making a “more refined” use of the databases, bearing in mind that they contain information on all the hospitalizations processed within the SIH structure without the “billing bias.”

According to this same source, it would be up to RIPSA to construct a set of rigorously devised indicators that could be used at the local level, similar to what is already being done for the large metropolitan areas the state capitals. These indicators should be disseminated by DATASUS via the Internet.

Another initiative that has been being developed by DATASUS is the construction of a database broken down by state and municipio that contains all the information and tools necessary to calculate the indicators according to the definitions proposed by RIPSA.

One of the state-level managers stressed that the information disseminated by DATASUS using TabWin and TabNet “is very helpful, fundamental ... just that it needs to be more recent. Some of it is up to date, but most of it is four years behind.” According to the respondent, with this information it is possible to analyze, for example, mortality by municipality of residence, available hospital beds per inhabitant, average cost of hospitalizations, consultations per inhabitant, etc. Analysis of this information can yield “a profile of the municipio you are going to visit, and you can get to know a little more about aspects of basic health
care or hospital issues.” Mention was also made of the contribution of the *Cadernos de Informação em Saúde* [Health Information Notebooks], which, “the way they are organized, they help a lot” because they make it possible to monitor the level of financial investment made by the states and municipalities in fulfillment of prevailing legislation (Amendment 29).

From the statements made by the respondents, it may be deduced that the health councils make limited use of the information and the press makes only sporadic use of it, focusing almost always on situations in which there have been complaints. In this context of disinformation, the public at large does not go back to the data available on the Internet. No mention was made of nongovernmental organizations using this information, or of schools doing so in the primary or secondary grades.

One of the academic users did not think that researchers or managers had difficulty accessing the system or using the data. This use has had an important effect on improving the system itself. However, the respondent cited the lack of effective and efficient ongoing mechanisms for monitoring and auditing the quality of the data, which has made it necessary to introduce regular exercises to audit the information system (visits to the in-hospital services and sampling of the patients’ charts), apart from other audits more geared to issues about payment and reimbursement for services performed – in other words, fraud detection. However, despite the problems mentioned, one of the strengths indicated by this user was the ongoing commitment of the DATASUS professionals who work with the AIH.

Today, audits are based on management and not on hospitalizations as such – in other words, they look at the overall picture of mortality indicators, control of fund transfers, and effective utilization of the funds. However, in cases of complaints or for clarifications involving hospitalizations, the Office of the
Corregidor General of the Union (CGU) can bring in professional health auditors. In this regard, the data that are available are insufficient because of the six-month time lag, which is considered too long for auditing purposes. This means that the auditors have to go to the municipios and states to have access to the information on the AIHs.

There is agreement between the auditors and the academic users on the need to invest in training in order to improve performance in this area at the municipal level. According to one of the auditors, “The auditing systems in some of the municipalities are still extremely inefficient.” One of the obstacles identified at the central level is that the office that coordinates the SIH is the Secretariat for Health Care (SAS), whereas auditing has always been under the SUS National Auditing Department (DENASUS). Because of this situation, “auditors’ reports are not fed back into the system; in the SAS [the tendency is to deal with problems by issuing] directives,” which is seen as no more than a palliative solution.

**Strengths**

- Since its inception, the SIH has been characterized by the simplicity and creativity with which it addresses a complex issue, since it is based on a payments system. It has served well in replacing the service unit, and it has become a modern system.

- Despite its lack of universality, it is quite a robust system because the data obtained through the AIH correspond to at least 70% of all hospital activity, equivalent to 11 million hospitalizations per year.

- It is the only system that provides information with a two-month turnaround. It offers information in real time in the case of many conditions – hepatitis, for example, and maternal death, showing where
the deaths are occurring. This helps in decision-making and auditing and exemplifies how the SIH, despite being regarded as primarily a billing system, can be used in health surveillance.

- The SIH is considered a very good system in terms of management and planning, since it is heavily used. In this regard, PPI has provided a strong incentive for improving the quality of the SIH.

- The system has contributed to hospital management itself, since providers have been obliged to systematize their data, and today they are better informed about such issues as length of stay, complications, billing, etc.

- Upcoming improvements to the system will soon make it possible to retrieve the AIH with the name of the patient using a restricted password. The patient’s name is not openly available, but the auditing services will have access to it. This will also give the user increased control over the cost and quality of the services provided.

- The system was ahead of its time, introducing almost 20 years earlier some of the aspects that have come to characterize the payments system currently used by health plan operators. Some of these companies also work with tables of procedures, while others use the table produced by the Brazilian Medical Association or have developed packages tied to the SUS.

- It has the capacity to incorporate major changes, such as the recent University Hospital Pact, which is a break from its primary function of being a payments system. Thus, there is a continuing demand for the AIH to be filled in completely, since it is becoming a tool for
monitoring hospitalizations.

Weaknesses

- The changes introduced in the payment system have led to a situation in which it is no longer possible to assess the degree of the system’s coverage.
- The system has become more complex, and the improvements have not been accompanied by quality control.
- It was conceived as a payment information system, and it still has too many data fields. There is excessive detail, due to the need to cover all payments.
- A serious problem is caused by the dichotomy between the person who collects the data, typically known as the “biller,” and those who use the information, especially the short version.
- Insufficient training is given to the professionals who collect the data.
- Several directives have been issued on the same subject. Some of them are old and should be rescinded, and there should be new ones to replace them, but that hasn’t been done yet. These problems affect municipal and state operations.
- The system allows the municipalities to carry out some practices that end up turning the AIH into a sort of coin that pays for some of the professionals’ salaries.

Proposals

- Legal instruments are needed to oblige the private sector not under an agreement with the SUS to regularly and accurately provide a
minimum of diagnostic information and dates of hospitalization.

- Although tools already exist for identifying the same person in different databases by name, the ideal is to have a **unified system for capturing data** “to enable the health surveillance professionals, the programmer, and the planner to use the databases simultaneously and not have to consult them one at a time.”

- A **single standardized table of procedures** should be adopted in coordination with the Hospital Information System and the Outpatient Information System.

- **Information should not be tied to billing.** The information system should contain all the information on hospitalizations separate from the billing data, so that it can become an even better tool for health surveillance. Agreement needs to be reached so that the states and the providers share data on all their hospitalizations.

- **Hospitals need to computerize even more,** so that it is no longer just the administrative personnel but also the health professionals who are feeding data to the system and everything is captured electronically.

- Thought could be given to **creating a sampling system** – that is, an information system for capturing samples, without any characteristic excluded. This would not only make use of the information more viable but also have an impact on the set of data currently being captured by the system.

- **Provisional data could be made available.** There is no need for the information to be complete before it is made available.

- **Use of the SIH for health surveillance and planning** could be
promoted more actively, redirecting and further expanding use of the database not only as an auditing tool but also an epidemiological reading and a mechanism for planning and disseminating information.

- Consideration should be given to **articulating with other databases and entities outside the sector**. There is already an initiative under way in São Paulo (Project DW-Saúde) that intends to supply the São Paulo State Health Secretariat with management information obtained through the integration of data from various isolated data sources, which will be centralized and organized so that users (managers) can easily retrieve extracts from complex analytical reports that contain managerial information of use in decision-making.

- Ideally, it would be a system that would capture **essential data** through a set of variables, based on patient charts, that would be sufficient to easily gain an overview of the health reality in the country, including health care, births, deaths, and maternal health.

- The system could be **simplified so that coverage could be expanded to include the private sector** not under an agreement with the SUS. This would involve rethinking and simplifying the system so that it would be easier to understand the entire payment process and become feasible to affiliate with the private sector.

**Dissemination of Data by DATASUS**

The trajectory of DATASUS follows along between the unfolding of DATAPREV and the emerging organizational needs of the SUS. Two key moments mark its identity. The first was the creation in 1990 of a Directorate of Information Processing within the SUS, under the National Health Foundation...
(FUNASA), whose principal activity consisted of processing the AIH. The second key moment was its transfer in 1997 to the executive secretariat in the Ministry of Health.

This initial history, while seeing the system’s shift in emphasis from social security to health information in general, was also characterized by vagueness in terms of its responsibilities. The respondents referred to constant confusion during those times, and even today it tends to be defined as a department or informatics enterprise within the Ministry of Health rather than as an information organ for the SUS. Other confusion has been inherited and is still being felt around its complete departure from FUNASA, a matter that has left some doubt as to what the responsibilities of DATASUS actually are and where it actually fits within the organizational structure.

Nevertheless, as one of the respondents points out, the transfer to the executive secretariat put DATASUS in a better institutional position to undertake broad actions in terms of organizing and standardizing the information system for the SUS in the full context of decentralization:

“Placement within the National Health Foundation was an expedient at the time. The transfer to the executive secretariat of the Ministry of Health placed it in a better institutional position to carry out a mission, mainly that of standardizing and organizing the health information system. At the National Health Foundation there were two ongoing debates. The first was whether we were part of the foundation or the SUS, and this was never really settled. The second, which went on for several years, was over the transfer of its activities to the states and municipalities as part of municipalization.” (EP02)

More clearly defining the responsibilities of DATASUS is an important step toward the more effective development of its activities, which historically
have been tied to the SUS. They can be better understood today if unreasonable expectations are challenged and at the same time a “strategic role” for DATASUS is more clearly identified. Both of these points will be addressed further below. With regard to its growing organic relationship with the SUS (which was never assumed, much less guaranteed, by its move to the executive secretariat), in reality the basic issues for DATASUS go back to its articulation within the decentralization movement and the establishment of a policy on information dissemination.

Behind the **policy on information dissemination** and the approach to dissemination as a political issue lies the historical backdrop of public health reform and the redemocratization of the country, which took root in the Constitution of 1988 and permeated the formulation of a national health undertaking. It is therefore appropriate to raise two key questions: What is the purpose of health information, and to whom is it addressed? For DATASUS, dissemination of information has been one of its main issues, which has not been solved by the fallacious binarism that counterposes the political and the technical dimensions. On the contrary, these dimensions are radically integrated, the one potentiating the other, while still retaining their specific aspects.

Technical resources at the time DATASUS was created severely limited dissemination, despite the belief that information should be made public as a means of diminishing the power that so easily concentrates around those who consider it privileged. Referring to this period in its history when technological resources were scarce and major efforts were being made to disseminate information, one of the respondents said:

“At the time, microcomputer technology was in its infancy and there were virtually no large-capacity media available. The Internet was still far in the future.
Communications were very closed, but even so, we began to work on this. Some opportunities were available for dissemination: via diskette or through the national packages network, which was another alternative. The Internet only began to appear in 1995, and we were pioneers in using it this. Before that, we used BBS. Alternatives began to emerge, and several things came along for us at just the right time. For example, when use of the CD-ROM began to spread, we already had the databases prepared for distribution. When the BBS got so it couldn’t handle any more, the Internet came along and we were able to make an immense leap forward” (EP01)

It’s interesting to notice that technological advances came along in step with emphasis on the political importance of disseminating information, creating resources that would make this goal viable. By the same token, we can say that the political emphasis on the importance of disseminating information favored the formulation of legal frameworks for a policy on dissemination. On this point, the comments of one of the respondents, referring to the DATAPREV period, are quite illuminating:

“At the time, the only thing we were doing was processing the AIH, and only a few institutions managed to have access to the data. I got started on a policy of dissemination. Up until then, the prevailing view, even in the Ministry of Health, was that DATAPREV was a service provider and the information belonged to INAMPS. Only INAMPS could authorize its use and dissemination. This view only changed with the arrival of Gilson Carvalho from Ribeirão Preto in the Secretariat of Health Care. We got him to agree to a directive, which the minister signed, that changed the process. As I understood it, the information didn’t belong to INAMPS but rather to the SUS and society as a whole. He turned the process around. Instead of our needing an authorization from INAMPS to distribute
information, we now had the obligation to distribute this information to the managers of the SUS, the health councils, and society at large, and moreover, to provide technical assistance to those users, so that they could better understand the information and use it in managing the SUS. This was in 1991 or 1992. At that time DATASUS became responsible not only for collecting but also for disseminating information. Law 8,080 only says that state and municipal managers have access to DATASUS information; it doesn’t say how. The new directive turned this logic on its head. Essentially, it was a cultural change in which you were no longer the owner of the information, because the information was now under the direction of INAMPS and later the secretariat for health care. In a moment of clarity, we were able to reverse this, and from then on our obstacles were only technical ones.” (EP02)

This situation was corroborated by another respondent, who meanwhile emphasized that dissemination is constantly faced with setbacks that restrict it and place public information at the service of private interests. Legal frameworks exist, and they are important. However, making them work in reality means constantly being on the alert and taking political action to implement them and see that they are complied with. In the words of one of the respondents:

“Going back a little, one of the biggest problems for a while was convincing INAMPS at the time that the information was public, and that ‘sitting on it’ was nothing more than a power play. Then at a certain point we managed to get the then minister to sign a directive saying it was public. From then on it was possible to work on dissemination. But then the sentiment began to turn back again, with people wanting to hold onto the data. There are places that still hold onto their data. A false policy of dissemination developed where only people’s friends got to receive it. It turned into a bargaining chip: I’ll give you data, if you give me
something. Look how good I am. I give you data, now write something nice about me. And this wasn’t just in the health field. The health field is different from other areas because of its complementarity, but this was happening everywhere. Information being used as power. There will always be this conflict. We will always have to keep up the fight.” (EP01)

It should be pointed out that this practice of appropriating public data for private use is not restricted to the health sector. It can occur in relations between the states and the municipalities, and between the municipalities and the councils. However, one way to look at this problem is to realize that the more the information is being disseminated, the more the demand will grow and people will be aware of dissemination, which works in favor of the process.

Indeed, wide dissemination plays a fundamental role not only in the constitution of DATASUS and its political perspective on information, but also in the process of decentralizing the SUS.

The respondents pointed out that the dissemination of information strengthened and potentiated the efforts to decentralize the SUS, through alliances with local managers and the development of human and technological resources for the collection, production, and analysis of data, and most of all, its day-to-day use in management. In speaking about the dissemination movement, which he had participated in from the beginning, one of the respondents said:

“This movement was linked to decentralization of the SUS, and this enabled us to adopt a technology by means of which the states and municipios could analyze their own data. We took advantage of the revolution in media and informatics, and as part of this new direction, we began to develop technology to enable technical personnel in the state and municipal health secretariats and from the academic world to also retrieve and analyze data.” (EP02)
Moreover, by strengthening a local culture in which information is involved in everyday management, the return for DATASUS is that the data are of better quality. Moreover, a climate is created for developing alternatives and innovations which, at the local level, means developing systems and routines independently that are original and appropriate for the context, sometimes even superior to the systems proposed by the federal sphere. A sign of this movement can be seen in the increased coverage of the data: “Once the system was decentralized, coverage increased. Data were being captured close to where the events were occurring, and with decentralization to the municipalities, this coverage became much more complete.” (EP01)

Decentralization of the system also put more power behind the policy for the dissemination of information. It not only led to improved coverage of the data, but also, as mentioned before, to improvements in everyday management. This achievement had an impact on the management itself of the SUS as it is today. This view was reinforced by one of the respondents:

“I think that administration of the SUS, as it is today, would not be viable without the information that is available. Today the system is managed with much more information than it had 15 years ago, and it is gradually making its way into the day-to-day work of health professionals at all levels. In fact, decentralization was made viable by the restructuring of this information system. We decentralized, and we didn’t lose the information.” (EP02)

Being able to feed the data back for management and the services is indeed a fundamental point in favor of dissemination, even as an element of sustainability and quality of local data, with involvement of the main actors in the information systems. In this regard, one of the respondents said:
“It’s a problem with dissemination that the information doesn’t always reach the people it should. The biggest problem in dissemination is to get the data back to the person who generated it, closing the loop, so that it reaches the physician who is doing all that paperwork and doesn’t know if it’s going to serve any purpose.” (EP01)

Nevertheless, decentralization poses challenges for standardization and compatibility of the data and pulls DATASUS in two directions, between being a central entity, an actor with a strategic, privileged national role in the information field, and yet not centralizing the system. There are two points here: just as there is no point in producing information if it is not disseminated, understood, and applied at the various levels of management, it also becomes problematic to develop systems that are not sufficiently compatible.

A prevailing view among the respondents about this issue is that to implement a single unified information system would be a step backward. One of the disadvantages of such a supposed general, all-encompassing system intended to adequately cover the entire country is that it would do away with one of the richest characteristics of the national information field – namely, the variety of local solutions tailored to specific contexts, which increase coverage and help to improve the quality of the data. The discussion rests on qualifying what is meant by “standardization” and “compatibility” in the highly diversified Brazilian context. On the other hand, it is also true that a multiplicity of poorly integrated subsystems reduces the operability of the system as a whole.

The interviews made it clear that the problem of compatibility did not mean that the programs or operations had to be standardized. The central point would be standardized coding and data transfer in a manner that protects communication. This is what the respondents had to say:
“The issue of standardization has to do with the interfaces, not the operations. For example, the mortality information system does not have to run under the same program in every locality. The programs can keep their particular features. The city of São Paulo has developed a parallel system because they operate in a different manner, but they have to enter the site twice, once according to the standard (which in their case is not the national but the state standard) and once the way they want to. What’s important is that the interface of the system that’s running there and the interface that the state or the ministry is receiving on is the same, and that it’s well defined. This is not true of the operations. You can offer them a way of operating, but if the states and the municipalities don’t want it, they can do something else, using more or less resources.” (EP01)

“If we focused more on setting standards and not on setting fixed patterns, there would be no limit for the agencies to develop their own departmental systems. It would be even more successful to the extent that you are placing development closer to the user. It’s important to understand that DATASUS is a Department of Information and Informatics, with focus on organization of the health information system. This issue is being discussed right now in the Ministry of Health.” (EP02)

From this picture it can be inferred that the respondents see DATASUS as playing a strategic role (and this is corroborated by interviews with the health councilors). The primary feature of this “strategic role” is expressed in the tension of DATASUS being a central organ in a context of decentralization, but this contradiction has been the wellspring of its achievement. Instead of performing a generalizing and controlling role of centralization and standardization, DATASUS can be seen as an agency that has been given special authority to organize and integrate information systems, facilitate with legitimacy, make decisions, and take
action. Considering this strategic role to be performed, the placement of DATASUS in the executive secretariat of the Ministry of Health seems appropriate to one of the respondents:

“For me, the rationale for DATASUS to be in the executive secretariat of the Ministry of Health is based on the fact that it can take part in a process of organizing and integrating the information systems. To do this, you need to be in a central position, with institutional legitimacy. But this idea of providing services suggests a logic that would have DATASUS implementing, for example, a program on hypertension or diabetes. Then the job of DATASUS is to recommend the system and have it implemented.” (EP02)

However, the other respondent disagreed that this was the appropriate place for DATASUS, since institutionally, being under the Ministry of Health, it is subject to federal impositions that oblige it to follow certain rules of operation that run counter to the principle of negotiation and partnership with the other levels of management. According to him, for DATASUS to be able to carry out its strategic role in organizing and integrating information systems it should be an independent body, such as a foundation, or an autonomous institute. In any case, the main issue in this important debate is to safeguard the autonomy of DATASUS in its capacity to support working processes, in organizing the system rather than in executing specific tasks.

Thus, it is important to protect DATASUS against being assigned mistaken roles leading to expectations that it can resolve serious structural problems in the public health sector – that the information system will be a panacea. On this point, one of the respondents said:

“The information system is being sold as the solution to do a bunch of things that it doesn’t do. No hospital care information system is going to solve a problem
that goes back to the physician, or the physician who wasn’t there when he should have been, or the unavailability of supplies that should have been procured.” (EP01)

Inappropriate expectations of DATASUS end up burdening its routine with ambitious plans to cover data that it is not feasible to collect in the services, as well as creating problems in the evaluation of its activities. DATASUS is faced with many other challenges that are inherent in a growing system that is open to the general public, not to mention the challenge of being caught up in the context of major national issues.

**Main Difficulties Cited**

Since this was a survey on DATASUS, naturally the data and their quality were recurring topics during the interviews. One of the problems mentioned was the **protection of privacy**, which is an impediment for certain interested parties, especially the academic users. With the increasing inclusion of new social variables, there is greater risk of directly or indirectly identifying patients treated by the SUS, which is a violation of their basic rights. Added to this concern is the issue of **not overloading the collection forms** or procedures. These limitations run the risk of frustrating important users of the information systems, the academic sector, whose research often redounds in benefits for the information field itself. It is therefore a delicate balance and seemingly paradoxical situation because it involves imposing necessary limits on the production and release of information which in fact is in the interest of the people and contributes to the sustainability of the systems.

“The matter of privacy is a fundamental issue. We receive an enormous volume of request for identified information, and we have to exercise discipline. Before, we used to take the micro-data, remove the patient’s identification number,
name, and address, and distribute it. Now if you want to make the effort, you can put it together by geographical area, etc. We have had requests from several different areas – mainly users doing academic research for the government – who want the identifying information for all the AIHs, including the name and address. We ask them what they want it for, and they say that it’s for a study already approved by their institution’s ethics committee. … For the time being, we are not distributing anything. There has to be legislation on this. We have already had people from outside breaking into the DATASUS computer to see the data. If we stand our ground, they say we are being too bureaucratic, that we have the data, and since he is manager of the place, he needs the information. In reality, what they want to do would be violating the patient’s right to privacy.” (EP02)

As the respondents have indicated, the **demand to include new data elements**, despite the problems that this would entail for the information systems and collection at the local level, comes not just from the academic researchers but also from the central level, as pointed out by one of the respondents:

“I never see anyone at the central level giving information away, even if it can’t be used, and at the same time there is always pressure to keep collecting new data. The new data are collected, and in principle, they would be important. Take the discussion over occupation or economic activity. It’s a four-digit classification. Is the professional who records a hospital admission or a death competent to classify the “occupation” field? Who is it who knows how to record these four digits? The physician has a blank space where he writes down the profession. Then there’s the coder who classifies the occupation and puts it into four digits. For that I need a trained interviewer who interacts with the informant until the occupation is properly classified. In the current process, the quality of this type of information
will never be very good. In the meantime, there’s no way you can reduce this. Four digits is very little; what we need is six, but they won’t give it to us.” (EP02)

This point is directly related to the issue of the **reliable quality** of the data, especially when they are collected at the end of the line in the information systems. The main point is the limitations in terms of availability of the data and the training of those who fill in the forms and enter the data. As we pointed out before with regard to dissemination, getting the information back to those who produced the data in the first place and renewing the involvement of these actors in the system is a fundamental strategy for combating underreporting and inadequate data entry. Adding length and complexity to the collection forms makes it more difficult to get data at the local level, as noted by one of the respondents:

“But that’s the same thing that is being asked to be done all over again, and the person is not going to get any return on the effort he makes. There’s no point in starting to ask for more things. You’re not going to get new information; you’re going to lose information. You go there with a huge long form that is complicated to fill in, like some of the long forms they have, and those poor people in God-knows-where at the end of the world have to fill them in. It’s almost impossible.” (EP01)

The primary examples of this point are the data on mortality and the impressive number of **deaths due to ill-defined causes**. In the regard, the respondent wondered, however, if this was more than just a problem in the information system, and rather, that it might be reflecting the consequences of problems with quality health care and the rights of the people:

“What I am saying is not a matter of the quality of the data. It has to do with the quality of health management. Take the mortality system, for example. The information on the cause of death. We have an average of 25% of the declarations
with ill-defined causes – more or less. Is this an error in the system? No. This comes from the end of the line. The people who are not being taken care of. If Maranhão has 50% of the ill-defined causes, the health care in Maranhão is lousy. This is an indicator of the poor quality of care, not an indicator that the system is bad. There’s no point in insisting that the information system is bad, the quality of the data is bad, when there’s a problem at the source. The physician has 15 minutes to see the patient. Is he going to spend 10 minutes filling in a form or sitting at the computer? He is not there to fill in forms. He is there to take care of the patient. The physician earns R$2.50 for a 15-minute appointment. Is he going to waste his time filling in a form? No, this isn’t a problem of the information system, it’s a problem of the health care system. And it’s a problem with the people, too. The fact that the death or the birth hasn’t been recorded is a problem that goes far beyond the information system.” (EP01)

Another problem with the quality of the data comes from excessive cross-checking of the information, which favors distortions. As one of the respondents said:

“For example, if you set up a cross-check between the procedure and the diagnosis, instead of entering both pieces of information, you create a table of links and only accept certain diagnoses for those procedures. What happens then? The bill is rejected. If the hospital has a limit of 10 C-sections, he does as many as he is allowed to do, and the rest he charges as if they were normal deliveries. I keep thinking that reality has changed, when in fact I have only disqualified my information system by excessive flagging. More cross-checking at the collection point does not mean that the quality of the information is better. It can mean just the opposite. So the question is: Are we going to build a huge amount of cross-
checking into the network, or are we going to lose information and possibly distort medical practice?”(EP02)

One of the points emphasized regarding the problem of data quality was the need for greater care in collecting it. One of the most serious problems is the scant training and support given to the actors involved in managing and more fully developing information solutions. It may also be due to excessive criticism of the information or the procedures – the language, understanding, and appropriateness of which are beyond the actors who are working on the systems in the field. An issue that comes up clearly for one of the respondents is the distance that still exists between DATASUS and the local levels:

“We keep the people at arm’s length. I think we are much more inclined to respond to the central level and are forgetting the people at the day-to-day level, who are looking to information processing for some other kind of solution. Maybe we can’t even do this directly, but rather create conditions so that this process of introducing information into the services takes its own natural course. I think we are very distant from the operational level of the system.” (EP02)

An issue of concern that weighs on the overall situation is training. In addition to it being insufficient, there is the problem of personnel turnover. To a certain extent, this issue is inherent in the very fact of political succession, which affects all spheres of government. Even today, the end of an administration can represent a change in entire teams and even specialized technicians. The most serious consequence is interruption of projects and successful or promising initiatives that always seem to be at risk when a new administration takes over. One of the respondents was very emphatic on this point:

“We go to all the trouble of training people, and two years later everybody changes and we have to start all over again. It is an unending job. Everywhere, at
all levels, even in the townships, there is a turnover every four years, and in the states, too. Not to mention the changes in between. It’s not just the mayor or a secretary who are new: sometimes the entire team changes and no one is left at all. And we’re lucky if they don’t take the computer home with them as well. At the federal level they don’t take the computers home because the databases are too big. But when that happens there’s also the huge job of reconstructing what had already been created before. This happens in every public office. And then you walk in and they say: “Let’s do something new, something really revolutionary.” (EP01)

Subcontracting also poses new problems in terms of discontinuity and personnel turnover. This point seems to be related to the increase in financial resources, which has led to more temporary contracts at the expense of appropriate investments in permanent teams that can give long-term support to institutional policies and projects of interest to the national health information system. One of the respondents illustrated this picture:

“Today our budget stands at R$200 million. It has gone up tenfold. This is a lot of money to spend on informatics. Apparently this windfall has given rise to a wave of third-party contracts. I believe we have lost control over efficiency in the rush to obtain results without spending the time to set the standards, establish objectives, or invest in integration. But while our financial resources have grown impressively, our human resources have not kept pace with this growth. In fact, there has been a loss of human resources because you always lose people to the market. This happens in any institution. It’s good for the professional who leaves to make more money, but we are seeing an aging of the staff, and if the losses are replaced at all, it is done through third-party contracts. The way I see it, any institution that has an area devoted to informatics needs to have a permanent team. There really isn’t this binary option of either doing things internally or contracting
out. You have to have a balance. You need to have a few permanent people who know the working process of the organization and represent the organization in all the contracts that are farmed out. If you start using subcontracts without having a permanent core of people to oversee what is being done, you are taking a risk. That’s what happened with us. We spent a fortune on third-party contracts and when the time came to incorporate the work done under these contracts, we ran into all kinds of difficulties and could not take advantage of the results.” (EP02)

The main difficulties and challenges for DATASUS seem to stem from expansion of the national health information system itself. Items that will continue to rank high on the DATASUS agenda include: improving the quality of the data, striving for better coverage, protecting the privacy of citizens, reaching out to the local level, training, more upgrading, and support for the creation of solutions. Meanwhile, alternatives are being visualized, or are already under way, that point to promising roads ahead and illustrate the major progress that has been made so far.

**Alternatives and Progress**

The mere existence of a national health information system for the Unified Health System is already progress in itself, especially because of its characteristics. It is a system that makes a large quantity of information openly available, both for management and for social empowerment, as part of a policy of dissemination. For this purpose it has legal frameworks that protect the public status of the information, and the fact that there is a ministerial directive to this effect is in itself an important step forward. To date there is no parallel in the other national sectors. And this progress is getting even more of a boost by making the data available on the Internet for free consultation. Despite the difficulties mentioned and the reservations with regard to certain collection forms and routines, the information
systems exist. They are up and running. They provide a basis for new approaches that can be taken toward expansion and redirection, and they can serve as a reference for other sectors.

Their importance is recognized among management and academic professionals, as well as social empowerment actors. Their information provides the basis for working documents, more informed oversight against fraud, well-founded planning, lines of action, and new knowledge that can redound to the benefit of the system itself. Therefore, to the extent that the national system reaches out more to the local users at the end of the line in the day-to-day services and leads to social empowerment, new alternatives can be created that are more appropriate and yield better results. The strengthening of training is also an important alternative for refining the collection of data, stimulating its expanded use, and implementing local systems tailored to the needs of the states, as well as developing the national system.

Continuing to invest in recognizing these local differences without losing sight of the national identity may be an important direction for DATASUS to take in the next decade. The flexibility of the systems, with the creation of tools to handle the data such as TabWin and TabNet, and their plasticity have already led to indispensable advances in the field of health information. However, moving forward depends on having greater technical capacity and engaging in further dialogue with the users. In the end, the point is for DATASUS to avoid bureaucratizing information or becoming merely a data warehouse, and for it to find its place within the dynamic ongoing flux of events.

**Interagency Health Information Network (RIPSA)**

Created in 1996 as a joint initiative of the Ministry of Health and the PAHO/WHO representative office in Brazil with the aim of developing
interinstitutional coordination to make basic data, indicators, and analyses of the health situation and its trends in Brazil available to the public in an organized and comprehensive manner, the Interagency Health Information Network (RIPSA) has been working since its inception on building up the capacity to formulate, coordinate, manage, and implement public policies and actions aimed at improving the population’s quality of health and quality of life.

RIPSA was the outgrowth of a diagnosis by a group of specialists in the Ministry of Health and PAHO/WHO that identified a “maze of problems” and “critical bottlenecks” in the area of health. Among these “bottlenecks,” the issue of information comes to the fore in practically all the surveys that discussed aspects to be overcome. This diagnosis coincided with PAHO’s role in Brazil of taking action at strategic and structural points that are hindering development of the Unified Health System (SUS), and this mission led to the actions that created RIPSA.

The initial idea for the Network was promoted by two areas of representation: public institutions and academia. Among the public institutions were the Ministry of Health, the Brazilian Institute of Geography and Statistics (IBGE), DATASUS, the São Paulo State System for Data Analysis (SEADE Foundation), and the Institute for Applied Economic Research (IPEA). On the academic side was the School of Public Health of the University of São Paulo, the Oswaldo Cruz Foundation (FIOCRUZ), and the Brazilian Association of Collective Health (ABRASCO). According to the respondents, RIPSA grew because having information was always the objective of these institutions and the individuals who helped to mobilize the project.

The situation surrounding the birth of RIPSA coincided with the end of inflation and a reasonably stable economy following implementation of the “Plano Real” economic restructuring plan. This context significantly increased the state’s
capacity to start planning again. The original document that delineates the objectives of RIPSA proposed the creation of a network through which the agencies could coordinate their efforts. The respondents referred to the fact that the Minister of Health at the time, Adib Jatene, was “obsessed with information,” and his presence greatly facilitated the first steps toward the creation of RIPSA.

The initiative also marked the beginning of a new mode of action for PAHO in Brazil. RIPSA proposed a new “framework for joint action,” since up until then the organization had relied on the mechanism of transferring funds to organizations in the countries for the development of specific projects. With the advent of RIPSA, PAHO became a co-manager of actions being carried out, a position that was defended at the time by Armando Lopes Escavino as a more modern style of cooperation. This approach was very helpful in the first steps taken toward the creation of RIPSA. The fact that the meetings were convened jointly by the Ministry of Health and PAHO gave the initiative a higher profile. In addition, PAHO provided a work space in which representatives from the institutions could feel free to speak up, raise issues, question concepts, and even challenge data produced by the executive branch, with a view to creating a process that would lead to standards for the quality of information.

There was disagreement about the ideal location for the RIPSA nucleus. Some of the statements said that, even though PAHO offered several advantages at the beginning – “an unrivaled space for negotiation,” “an impressive capacity to convene participants,” and “greater freedom to speak out” – it does not have a tradition of continuity for this type of initiative. Moreover, the Ministry of Health is responsible for national direction of the SUS, and for this reason the Ministry’s executive secretariat is the most logical place to insert the RIPSA coordination. Also, the idea is for the country to be in charge of the process; PAHO cannot
assume the coordination role because there are times when some of the policies need to be questioned firmly, which would put PAHO in an awkward position as an international organization. In the view of other respondents, however, PAHO is in fact the ideal location for RIPSA, because it has more experience and the capacity to minimize disagreements. Those who held this view pointed out that in the Ministry of Health the turnover of personnel and constant repositioning of RIPSA within its structure interrupt the continuity of the network’s activities. Moreover, with RIPSA installed on PAHO premises, competition between the institutions would be avoided, since PAHO is regarded as “neutral territory,” while at the same time it is recognized by the participating institutions.

In the view of the respondents, **RIPSA would have greater authority** if it were effectively integrated into the process of decision-making on public policy, which is not yet the case. In the opinion of one of the respondents, it would be useful to create a sort of “intelligence agency” that intervened in setting policy. He believes that the institutions involved in the network have had significant authority since the beginning with regard to both its coordination and the Interagency Workshop (OTI). However, some of the respondents felt that this “force” in RIPSA comes more from the people serving on the OTI and than the institutions as such. The offices have extremely competent technical personnel who understand the problems associated with both the generation and use of health information. RIPSA is entirely an interagency process, and each member who is invited to participate in a particular group brings a strong background and leadership in that specific field.

The network flourishes, according to some of the participants, because “it is not owned by any one institution.” It expresses itself through the OTI, the members of which represent their institutions – for example, the Councils of State and
Municipal Secretaries of Health (CONASS and CONASEMS). As the SUS grows, the OTI incorporates new actors, who deliberate on actions that are ultimately become ministerial directives. However, this process cannot be implemented without addressing and overcoming internal resistance “from the owners of the databases in the Ministry of Health, the Ministry of Labor, the Ministry of Social Welfare.”

Much of the information is outside the domain of the Ministry of Health – for example, data on traffic accidents, environmental cleanup, and workplace accidents. Thus it’s necessary to create specific groups to work with these Ministries to establish a common language so that this information will be useful both for the agency that uses it regularly and also for the health area.

The topic-focused groups that meet during the OTIs have grown “surprisingly”: Their efforts have resulted in the creation of instruments, directives, and resolutions. Technical personnel from the different ministries feel that their work is appreciated when they are invited to explain their systems – and possibly adapt them in order to help the health system build a new public policy culture. In the rich process of creating these groups, the main objective is to make the various databases compatible so that the information systems can communicate, which is essential for the development of a good health information system. Through RIPSA, for the first time there is communication between the ministries of health, labor, social welfare, and justice. Previously, there had been no incentive for these institutions and their databases to work together as nuclei for intersectoral action. RIPSA has ushered in a phase in which information is of interest not only to those for whom a system has been physically installed but to those who use other systems as well.
After the administrations of Health Ministers Adib Jatene and Carlos Albuquerque, from whom RIPSA received significant support, the network’s nucleus was transferred from the ministry’s executive secretariat to its secretariat for policy, and then later to the National Health Foundation (FUNASA). This process weakened RIPSA, whose participants became unclear as to who was actually coordinating its technical nucleus. By that time the network had grown in importance, and this inspired some of the authorities assuming new responsibilities in the ministry to take advantage of its strategic position to reinforce their own status in the government structure. This trend caused the technical coordination in the Ministry of Health to lose some of its substance and clarity, while at the same time the position of DATASUS was beginning to weaken as well.

In the 10 years of the network’s existence, according to some of the respondents, it has failed to create a strategic intersectoral management sector within the SUS. Another shortcoming pointed out is the need for more analysis and use of the information. The only example of an intersectoral initiative is the Interinstitutional Workers’ Health Executive Group (GEISTAT), created during the administration of Itamar Franco, when Jamil Haddad was health minister, which remains in operation to this day. Initiatives of this kind would have been clearly encouraged if the SUS had acted more like a system and less like a mere service focused exclusively on health, failing to take into account decisions made in other sectors that affect the health of the population, as mandated in the Constitution. The only structure in the SUS that makes provision for this is the National Health Council, which has organized intersectoral committees. It is necessary to create groups similar to GEISAT in other areas as well – for example, the environment, which would bring together the Ministry of Environment, the Institute of Environment and Renewable Natural Resources (IBAMA), FUNASA,
and FIOCRUZ – to draw up shared strategies and public policy interventions based on existing information.

Respondents also pointed to the need to **improve the quality of information** offered by some of the existing systems, citing the example of SIM. The way to achieve this would be to create an interinstitutional team that would be responsible for this task exclusively.

As for the purposes of RIPSA, the entities that participate actively have clarity about its vision. However, even though a Ministerial directive has set deadlines to make the different systems compatible, the Ministry of Health has lacked the capacity and leadership to keep the various groups organized. This happens because the ministry has been reluctant to make a commitment to an intersectoral approach. It has preferred to act within the narrower limits of health and has resisted seeing health as the outcome of policies made outside the sector – for example, minimum wage, various aspects of economic policy, income distribution, housing policy, etc. Even though this broader view of health is written into the Constitution, the Ministry does not have an internal organization that embraces this logic.

The interviews indicate that the Ministry of Health has not given priority to the creation of a “structural nucleus” or “technical management” of RIPSA within the ministry itself. Failure to clearly identify the “technical manager” responsible for preparing the agenda of the OTI, together with the constantly shifting position of the network and its representatives within the ministry, has led to a loss in continuity of the initiatives that are needed in order to meet the founding goals of RIPSA.

Despite these difficulties, however, the day-to-day commitment of several RIPSA technicians and member institutions has resulted in producing its most
important achievement, namely the **Basic Health Indicators and Data for Brazil (IDB)**. The goal behind this initiative is to publish information of high quality after it has been subjected to systematic scrutiny by groups that analyze and critique it. The first indicator to be created was infant mortality, and other indicators have followed the same methodology. In addition, RIPSA produces reports on specific areas, such as infant mortality, generating summary documents which, in addition to the information, include warnings on defects that still exist with regard to the particular variable. In this way, RIPSA became a working tool both for public policy planners and for the National Congress or any segment of society that is interested in the particular subject.

The process of judging the data has met with **reservations on the part of some of the institutions**, since there is concern that it might generate criticisms that expose authorities or place PAHO itself in an awkward position. The strategy that has been adopted is to point out gaps in the definition of existing data elements as the occasion arises and at the same time propose joint actions and build strategies for improvement when all parties are included and prepared to assume responsibility for attaining the objective of improving that data element. Knowing that those who are making the suggestions are serious, committed, and have the competency to do so helps in building an environment that is propitious for making progress.

Once a given document has been prepared, it is submitted to the public authorities and their technicians for comment. The next step is to go to the minister in the respective area to try to get the initiative on his agenda. This **strategy is intended to initiate a change the direction of policy**. Without it, RIPSA would be having signs of “materials fatigue,” since all it does is make data compatible. It doesn’t recommend policy or any changes in the process – in fact, it even has
difficulty rectifying the sources of information. It has prestige and recognition, but it does not actually change policy. To overcome this, RIPSA is currently (in 2006) creating an interagency analysis group to implement a preliminary model for situation studies. The first step is a report on the context based on what has been prospected.

After 10 years, the members of RIPSA have quite a clear general understanding of its purposes, despite the tentative participation of some of its member institutions. This general understanding creates the necessary conditions for solidifying the concept of RIPSA as a formulator of policy, but the logic behind this has been undermined, mainly because of “institutional fatigue” for the reasons mentioned.

Today most of the institutions and people attend the conferences convened by the RIPSA, despite the uneven participation of member institutions in the studies presented. The delegation of the Ministry of Health, which is always present, has a high turnover rate, which weakens its representation and means that it is always “starting all over again.” This was pointed out as “a serious limitation.”

In addition, the action of the Ministry of Health is not what it should be, given that health information is a priority of the government. There appears to be a hesitation on the part of the ministry to express opinions or criticisms or share experiences in a process that includes the participation of CONASS and CONASEMS. Such an attitude would create the ideal environment for a health information policy in which RIPSA would be the instrument for its conception.

With regard to the participation of important agencies such as IBGE, the experience of RIPSA shows that IBGE a source that can be referred to for household sampling. It has the capacity to mobilize structures to do this at opportune times, and it gets the best results out of this process. Even though
institutions tend to have a culture of working in isolation, this is not the case with IBGE. One of the respondents urged stronger ties between IBGE and the Ministry of Health through an interinstitutional team that involves the academic sector.

The example of IBGE reinforces the thesis that other agencies should participate in RIPSA, in order to be able to work with important data on such issues as violence (today still restricted to the Ministry of Justice and other civil institutions, such as “Viva Rio” and the Violence Nucleus of the University of São Paulo), policies for older adults, and the changing labor market. This effort could lead to the formation of a specific committee or even a working group. Other important areas that are related to health include traffic, labor, and the environment. IPEA, which is nominally a member, was mentioned as an agency that could be included more actively in the RIPSA undertaking.

With regard to the working groups (GTs) and interagency workshops (OTIs), their tasks are quite specific in nature, with some groups more technically oriented and others more politically oriented. The group on infant mortality, for example, is very concerned about the quality of information, the origin of the data, and the extent of coverage. On the other hand, the group concerned with occupational health is looking into how public policies can be effective in the workplace, and therefore inclines more toward a political and strategic dynamic. Thus, RIPSA brings together both technical focus and political action.

In the opinion of some of the respondents, from the strategic perspective, after 10 years RIPSA as an institution has become a little “long in the tooth,” but not as a concept, since it continues to play an important role. The best proof of this is that, compared with the initiatives that have been implemented in other countries of Latin America, the concept of an organization with the purposes that the network upholds remains unique. The closest example, in terms of effort to
improve the quality of data and having a role in planning, is the case of Cuba, which, in moving toward decentralization, is using the set of basic indicators both at the national level and in the provinces and municipalities. Also, Argentina and Chile are investing in improving the quality of their information systems. However, none of these countries has developed anything like RIPSA, which is an important innovation. Before, each institution went in its own separate direction. Today there is a convergence of efforts.

The importance of RIPSA can also be measured by the fact that it exists in the organizational context, operates, coordinates actions, and proposes measures within the SUS. This evidence belies critical awareness of the need to improve the production of information within the organizations. Proof that RIPSA represents progress can also be seen in the knowledge that it is viable and that it can happen without major investments, simply the articulated, combined forces of its member institutions. A third measure of its importance is the indicators that it has produced under the IDB, including definition of what each indicator is, how it is constructed, and what purpose it serves. Finally, RIPSA has brought together a group of indicators that have served both to improve public management and to support academic research, including master’s and doctoral theses based on reliable, up-to-date information that can be cross-checked, with historical series available on the Internet since 1996.

The respondents considered that RIPSA has a strategic function, despite the fact that only some of its objectives have been fully met. The first of these objectives is “establish a set of basic data and indicators that are consistent, up-to-date, broad in coverage, and easy to access,” and the fact is that they been made widely available. This objective was achieved not only because the data were available, but also because the institutions defined targets to be met. Over the
years, the databases have become increasingly consistent and the quality of information has been improved.

The second objective is “articulate institutions that are contributing to the provision and critiquing of data and indicators, as well as the analysis of information.” The respondents confirmed that there already is strong articulation, but they said that it could be even stronger. One of the problems cited was the fact that many of the institutions have a shortage of personnel, as some of the staff have retired or left for other reasons and have not been replaced.

The third objective is “implement support mechanisms for improving the production of data and information.” In the area of vital statistics, a working group on compatibility was created to see if IBGE and the Ministry of Health could try to integrate their databases. Since the end of 2004, work has been under way on the declaration of live birth (DN) and the declaration of death (DO). The expectation is that the two systems will converge in the near or medium term.

The fourth objective is “promote consensus on concepts, methods, and criteria for the utilization of databases.” The opinion of the respondents is that there was never a lack of consensus. Nevertheless, in the last two years there have been more exchanges and stepped-up common efforts to improve the quality of data, which still needs to be worked on.

The fifth objective is “promote exchanges with other subsystems specialized in information on public administration.” The establishment of a working group on compatibility reflects the effort to break down the barrier that has existed between the systems, fed by a “corporate culture” in the negative sense.

The sixth and final objective is “contribute to the study of relatively unexplored topics or issues of recognized importance for understanding the health
picture in Brazil.” RIPSA has fulfilled this objective, having made progress in the analysis of information and the systematic use of situation studies and trends as a tool for decision-making.

This logic of planning public policy would have been received more encouragement if the National Health Information System (SINIS) had in fact been implemented, as provided for in the Organic Law. This system would be established under the aegis of an intersectoral policy committee and would reinforce the view that health is the outcome of a variety of sectoral policies. With the advent of SINIS, it will be possible to investigate and answer questions that are beyond the capacity of the administrative information now available because of either low coverage or poor quality. The initiative’s success will be more easily achieved with the endorsement of the “head” of the national statistical system, IBGE.

With regard to the way in which RIPSA operates, the respondents stated that the General Commission on Coordination has changed its direction from the way in which it was initially conceived. As for the other entities – the OTIs, Committees on Interdisciplinary Topics (CTIs), Indicator Management Committees (CGIs), and the technical secretariat – greater clarity is needed with regard to their roles, since these groups have been conceived under differing terms. For example, the group that analyzes the database on hunger is different from the one that is concerned with refining statistics and databases on mortality. The first group works with a mass of information that it assesses and analyzes, consults commissions, sees the possibility of improving the situation, and returns to the original concept. The other group develops measures and strategies for achieving better performance. One has to do with the administration and management of the system; the other is concerned with technological improvement of the system. Still,
the interagency approach remains, because it is the basis of RIPSA. Some are of the opinion that when a new committee is created to analyze a specific problem, it is merely an advisory group that analyzes the situation, gives its report, and then ceases to exist, as in the case of the outbreak of cholera, or when there is a contradiction to be resolved between specific sets of data.

With regard to the Committees on Interdisciplinary Topics, their contribution is focused on refining the indicators, explaining shared concepts, harmonizing, identifying critical points of realization, and proposing seminars to implement actions of the Ministry of Health, offering working methods and technology for dealing with particular issues. The respondents were in favor of increasing the number of these committees.

An important initiative that has not been implemented in RIPSA’s 10 years of existence is the development of IDBs for the states. The respondents who tried to account for this situation pointed to the reluctance of the states to lose control over their information – and their concern that it might be manipulated. It is believed, however, that if the idea of state IDBs is actively promoted, organized sectors will get involved. Since not all the states have adequately trained technical teams (except for states in the western central, southern, and southeastern regions), it is necessary to move with caution, creating an advisory group of technical teams to help implement the IDBs, since there are significant limitations with regard to the quality of data outside the regions mentioned. This effort would have a positive impact on the quality of national data. As the entire country becomes part of this process, some of the indirect techniques that are still being used will fall by the wayside as data on population and mortality and birth rates become accessible by direct calculation.
The greatest contribution of the IDB, according to the respondents, is that RIPSA has had the courage to define indicators that are considered important and make them available for national analysis without any restrictions. In addition, the initiative has created critical awareness that the use of data should be carefully considered before it is disseminated as truth. To this end, there are specific groups dedicated to analyzing what the data represent; they serve as a filter that includes analysis, quality control, and responsibility for the source. Another contribution of the IDB has been the broad dissemination of data in academic circles, where it has raised critical awareness. Still, this effort has yet to be transformed into information as such, a step that goes beyond the data itself.

The respondents indicate that there is no monitoring of the use of data, nor is there a forum for this. At most, comments and suggestions are received, as well as feedback from academic users. They point out the key role played by academic users in this regard. As for the health services, their opinion is that health workers make very little use of the IDB because when they look at the data they have to think about it, and health professionals don’t have time for that. When it comes to managers, the legislative bodies, and institutions in civil society, the data need to be translated into information, even for use in communication processes, in order for these segments to understand it and ultimately question it. Once they are able to question it, they are then in a position to provide feedback to refine and improve the information.

In the effort to refine and improve the data, there are times when the producer of the data finds himself “watching over it.” The solution in this situation is to bring in the producer as a participant on the committee that is doing the evaluation, incorporating him into the critiquing process. Using this approach creates mechanisms within RIPSA itself for critiquing and reaching consensus.
The respondents felt that the **indicator rating form** slated for discussion by the agencies is a “very good” idea, since it will give even more importance to the data and comments about them. Still on the subject of quality control, one of the problems identified is the fact that Brazil has areas where coverage is still precarious and uneven. The use of averages hides the real situation regarding certain indicators and specific localities in a country that is highly heterogeneous. On top of this reality, local managers tend to believe they are doing a good job and that *their* indicators are more or less acceptable. These discrepancies influence the very use of information as a management tool. If the indicator “infant mortality” becomes the indicator that measures progress, a declining indicator shows the positive effects of public management, but the same indicator can also show the negative effects. Ideally, indirect techniques should be being phased out and replaced with direct calculation, and RIPSA can help to accomplish this. It has been done in other Latin American countries, notably Costa Rica and Chile.

In regard to the RIPSA products and their **dissemination**, the respondents consider that they are being widely distributed, even being made available on the Internet. In addition, all the municipal managers receive the IDB publications. However, there is no control over which municipal authority is receiving the publication or the use being made of it. There was agreement that strategies are needed such as the promotion of workshops in which national examples are reviewed in order to get states and municipios to participate in the discussions.

On the importance of disseminating data on the national reality to the general population, all agreed that this is important as a means of getting citizens involved and as part of the education process. For this purpose, it is essential to “translate” the RIPSA data into **language that is accessible to the everyone**, so that people will be aware of what is happening in their country. Using the data in
schools and getting students to do projects on the health situation in the country were also cited as activities that should be encouraged, as well as enlisting the media much in the way that IBGE does when it releases the Household Sampling Surveys.

According to the interviews, the schools of medicine are using the IDBs as materials for analysis, and the data have been the topic of debates in conferences on epidemiology, at which RIPSA has been present since 1998, as well as conferences of the National Association of Demographers.

For the future, efforts should focus on the prevention of duplication and overlapping systems through the effective implementation of SINIS, which would be responsible for breaking down the barriers between the systems and bringing together SIM, SINASC, SINAN, and the SIH in a single unified system. SIM, for example, could still be an information system, but it would not be isolated. With SINIS it will be possible to better define the content and the models to be used in each of these systems. Minister Carlos Albuquerque has signed a directive mandating that the systems be made compatible, which is a requirement of the National Health Council. The SINIS proposal calls for bringing together the basic nuclei of global and specific information so that the entire system has access to this information through user-friendly software developed specifically for this purpose. Like the Unified Health System, the information system will be unified, in keeping with the philosophy of the Brazilian health system.

The respondents also pointed out the need to formulate a policy on analysis of the health situation, its trends, and the future outlook, which would bring to the fore the debate over major national and state surveys and place this issue high on the agenda, including the points at which information is a “critical node.” As
part of this debate, population-based surveys could be proposed and specific questions could be asked about improving the data of the administrative systems.
9. Final Comments

A study has been conducted of the principal health information systems in Brazil. The last 30 years have seen the creation and development of information systems with the purpose of offering better conditions for the planning, management, and evaluation of health programs and services as data become available on the health of the population that are national in scope and of reliable quality. It is a refinement process that develops over time. There are still imperfections and difficulties to be overcome. However, a lot of progress has been made in this time, both in the opportunity to have access to data and in the expansion of its coverage and the quality of the information offered. During this period, Brazil’s health care system has gone through a deep transformation, mainly in the sense of decentralizing its management and thus bringing in new actors who are producing and using the data. At the same time, technological development in the field of informatics has allowed for major progress in the recording, processing, and dissemination of data.

This diagnosis has included the presentation and discussion of the current strengths and weaknesses of the different systems and the lessons that have been learned that will lead to improvement of their quality and greater commitment on the part of the different actors involved in generating and analyzing the data. Finally, suggestions and proposals are offered for improving the information systems, increasing their coverage, and making them more practical, efficient, and reliable.

The country’s four main information systems were analyzed: the Mortality Information System (SIM); the Live Birth Information System (SINASC); System for the Reporting of Notifiable Conditions (SINAN); and the Hospital Information
System (SIH). In addition to these systems, the study evaluated DATASUS, the country’s main structure for disseminating health information, and the Interagency Health Information Network (RIPSA), which promotes a shared environment for discussing the different systems and the quality of information and brings together institutions in the health field as well as other sectors of society involved in the production of demographic, social, and economic data.

Some of the characteristics that were analyzed refer to the systems as a whole.

1. **Decentralization.** The management of information systems now takes place in three spheres of government: federal, state, and municipal. Decentralization has increased the scope of data generation and use. However, there are still some difficulties with regard to the recruitment and maintenance of high-quality human resources in the more peripheral areas for the local production and analysis of data.

2. **The strategic roles of DATASUS and RIPSA.** DATASUS is an agency that has been given special authority to disseminate data and to organize and integrate information systems. In addition to raw data, it offers programs for organized tabulation and the preparation of epidemiological indicators. RIPSA, in turn, has become the space for the harmonization of data production both within and outside the health sector through debate and discussion of data quality, preparing and distributing a publication on health indicators used in Brazil which defines the indicators and the procedures for calculating them.

3. The **technological development** that has occurred in recent years in the area of informatics has contributed decisively to improving the flow of data,
substantially reducing the time between data production and availability of information and at the same time democratically expanding its accessibility.

4. **Interoperability** is still in the early stages. A process is being developed that seeks to expand communication possibilities between the various information systems that now exist, both through applications that allow for linkage between the systems and through the development of virtual environments that contain information from all the systems (data warehousing).

5. **Improvement of the data entered in the basic forms.** Even with the more developed systems such as SIM and SINASC, there is need to improve the quality of the data entered in the basic collection forms, i.e., the declaration of live birth and the declaration of death.

6. **Incorporation of data from the private sector.** This is a challenge that is being addressed with support from the National Supplementary Health Agency, which is adopting reporting requirements for medical and hospital procedures for private health plans and insurance schemes.

**Mortality Information System (SIM)**

Implementation of Mortality Information System introduced a new paradigm in the use of data on deaths in Brazil. Information that used to be used exclusively for demographic studies could now be approached from the epidemiological perspective. SIM has contributed to improving the diagnosis of the national health situation. Development of a single uniform declaration of death (DO) for nationwide use has undoubtedly been a fundamental milestone in the system’s development.
In an effort to reduce the high percentage of underregistration of deaths and increase the coverage of the system, an intense campaign was undertaken to raise awareness among those involved in the system, including state health secretaries, health professionals and physicians in particular, regional medical councils, notaries, and others. Also, a massive investment was made in training professionals how to correctly fill in the data fields in the DO and to understand the importance of the quality of the information they provide. An information processing path for the DOs was standardized and institutionalized, and different strategic measures were taken, depending on local realities, to reduce burials in clandestine cemeteries. The system has gradually managed to make significant progress in terms of coverage, reaching a national average of 84% in 2003, with variations ranging from less than 60% in some of the states in the northeastern region to 90% in the southern, southeastern, and western central regions. In the northern and northeastern regions, despite improvements in recent years, the system still has not attained satisfactory coverage in some of the states.

In parallel, there have been significant improvements in filling in the DO since the implementation of SIM. This improvement, however, has not been felt to the same degree in all the states or in all the data fields of the DO. The main problem is the high percentage of deaths due to ill-defined causes, which can be related to the shortage of physicians in many localities, low levels of schooling and high turnover of personnel trained to enter codes for the underlying cause of death in different parts of the country, and also to physicians’ lack of interest, inadequate training, and insufficient awareness of the importance of filling in the data correctly on the DO. Many physicians still regard filling in the DO as mere red tape. The introduction of a SIM computerized program to automatically select the underlying cause has given more confidence in the quality of this information,
to the extent that the system is able to complete the entire logical sequence for selecting the underlying cause. However, this application does not eliminate the need for ongoing training of professional coders.

Other frequent omissions in filling in the data involve the fields on medical care given, laboratory confirmation of the diagnosis, and performance of surgery.

Progress in the municipalization of health has also been an important factor in the system’s improvement. It has made for greater involvement on the part of local managers in the production, utilization, and dissemination of health information, as opposed to just feeding data into the system, bearing in mind its importance in decision-making. Many municipalities have begun to investigate deaths, depending on local priorities, and to adopt strategies for improving the system, with satisfactory results. Municipalization has greatly increased the system’s turnaround in processing and disseminating information on mortality in Brazil.

National Live Birth Information System (SINASC)

SINASC was established with a view to creating a system that would allow the collection and processing of data for both demographic and epidemiological purposes, the latter providing qualitative information on health of the mother and the newborn as well as disclosing aspects of perinatal care. It was implemented gradually, on state at a time. From the outset it used a single standard form for collecting the data: the declaration of live birth (DN), the processing of which was decentralized to the states and municipalities. The DN is issued in three copies: the top copy is retained by the health service where the delivery took place and later sent to the municipal health secretariat; the second copy is given to the family and
presented at the local office of the civil registry; and the third copy is kept with the newborn’s patient chart.

The coverage of SINASC is better than that of SIM. The estimated number of live births captured corresponds to a coverage level of 89% to 115%. As with SIM, coverage is lowest in the northern and northeastern regions. An extremely important strategy has been the requirement that it be filled out under the terms of Integrated Partnership Programming and integrated into the health surveillance system in order to improve the coverage of births.

One of the characteristics of SINASC is that the DN is not usually filled in by physicians. This is usually done by nursing auxiliaries. The quality of the data entered is relatively good for most of the data elements, with an excellent level of completeness. There are problems of reliability with the following data elements: mother’s place of residence, mother’s level of schooling, number of prenatal consultations, race/color of the newborn, and presence of congenital anomalies.

Many research studies have been based on SINASC data, such as births to teenage mothers, profile of access to delivery and newborn care, evaluation of prenatal care, risk factors for low birthweight, and fertility patterns in women, among others. Linkage with SIM data has allowed for better analyses of health and living conditions.

**System for the Reporting of Notifiable Conditions (SINAN)**

SINAN was originally conceived as an integrated system, but it has a modular structure and has always operated as a set of subsystems. Three stages may be recognized in the development of SINAN: use of the system for all notifiable diseases and conditions; effective implementation in all the states; and decentralization to the health units as reporting sources. From the technical
standpoint, it was originally a DOS system, then upgraded to Windows, and has now been adapted for Internet use.

Decentralization has significantly increased coverage, but in the beginning, especially, the quality of the information tended to degrade because at the local level it was more difficult to properly investigate all the cases, and when they were investigated the results were very slow because of the delay between notification and confirmation of cases.

The lack of a clear definition of what should be reported under the heading of suspected and confirmed cases allowed for varying interpretations. Some of the municipalities submit all the cases that are reported, and others only send in the confirmed cases. Some of the subsystems, such as the ones for AIDS and leishmaniasis, have decided that only confirmed cases should be recorded, but this rule does not apply to the other conditions.

The quality of the subsystems varies with regard to degree of coverage and completeness of the records depending on the type of disease or condition, geographical location, and time of occurrence. For example, congenital syphilis and maternal syphilis and HIV infection during pregnancy are well known to be underreported.

Several measures have been taken to make health system managers more aware of the importance of quality of their reported data. In the case of the Minimum Basic Care (PAB) program, the threat of suspension of fund transfers when a municipality fails to provide data to the system for two consecutive months has created greater awareness of the importance of the reporting system, but on the other hand it is suspected that this mechanism has encouraged laxity in terms of the quality of reporting. The introduction of indicators that utilize SINAN information for Integrated Partnership Programming, such as the proportion of cases closed on
a timely basis, has been an effective alternative for improving the quality of information. The use of incentives has been much more successful in improving the quality of information than resorting to penalties.

In the case of diseases that must be reported immediately, it often happens that notification is given by telephone and does not get recorded in SINAN because personnel in the municipio think that they have met its obligation to report to the system. Another problem that needs to be better handled is the notification of outbreaks, in which the cases are aggregated and reported as a group. However, SINAN does not have the logic to handle this format, since each record corresponds to one individual case. Another problem is the uncertain nature of reporting by the private sector. Underreporting is especially common for certain conditions, such as sexually transmitted diseases.

Decentralization has increased the duplication of records, because a case reported by the municipality where the patient resides may also be reported by a different municipality where care is provided. Despite the introduction of cross-checking software to prevent this from happening, in the case of chronic diseases, for which obtaining medication is tied to notification, duplication continues to occur, both when patients move to a different municipio and when they are receiving medication in more than one municipio. Another cause of duplicated records rests within SINAN itself, when the reporting units are not standardized within the same municipality. On the other hand, since the SINAN reporting units are not standardized, this can also be a cause for duplication of records within the same municipality.

Currently a large number of variables are being routinely collected, and their large number is having a negative impact on the quality of the information being entered.
The main source of available data is still the Epidemiological Bulletin published by the Ministry of Health, and the only subsystem that has been making its databases available on the Internet for some years now is SINAN-AIDS. The bulletin will cease to be the preferred place to find information once SINAN-NET is introduced.

Some of the municipalities and states have been more competent in the production of SINAN data. There are various factors that make these particular places stand out, but the main one seems to be that they give importance to the information as a tool of public policy. This understanding is translated into support for epidemiological surveillance, planning actions, human resources development, allocation of informatics resources, and cooperation with the different levels of the health system.

It can be said that the most successful example of SINAN in recent years has been its AIDS subsystem, for its coverage, completeness of information, and availability of data through epidemiological bulletins and the Internet.

**Hospital Information System (SIH)**

Many of the criticisms against the SIH over the years have stemmed from tensions and conflicts over the Hospital Admission Authorization (AIH) and the hospital payment system. Prejudice against the billing system may have held back its use as an epidemiological tool. Although there are still areas that need to be improved, the system has been getting better, and today it has broad enough coverage for its epidemiological usefulness to be considered.

It was very difficult, starting from the beginning, to implement a flagging system, given the large volume of accounts and the high rate at which they were rejected, since if one of the accounts from a given hospital was rejected, all the
others were as well. Brazil produces 1 million hospitalizations per month that are submitted to DATASUS for purposes of undergoing a disallowance process. A portion of them are definitively removed from the databases.

While the SIH has seen major growth in its coverage over the last 10 to 15 years, there are still some problems in both coverage and data entry due to the special nature of the information system, in which payments are based on procedures. Also, the SIH was originally limited to admissions in the privately contracted hospital network of the SUS and only recently began to include the public network. Another drawback is that the way in which the financing of services has evolved in Brazil has led to the creation of situations that distort the data referring to hospitalizations in the public system. Examples are the imposition of funding caps on the municipios and hospital units, the creation of public hospital foundations, and supplementary payments for procedures from the municipios.

By the end of the year the Decentralized Hospital Information System (SIHD) will be in place, which will make it possible to decentralize processing of the AIHs to the state or municipal health secretariats. On receiving information from the hospitals in the area on CD-ROM or diskette or by electronic file, the system checks the data, calculates the lump sums to be paid, and transmits the necessary reports to local management.

**DATASUS**

DATASUS is the great disseminator of health information. It is an agency with special authority which it can use to organize and integrate information systems, facilitate with legitimacy, make decisions, and take action.

The mere existence of a national health information system for the Unified Health System is already progress in itself, especially because of its characteristics.
It is a system that makes a large quantity of information openly available, both for management and for social empowerment, as part of a policy of dissemination. For this purpose it has legal frameworks that protect the public status of the information. To date there is no parallel in the other national sectors. Its progress is being potentiated by making the data available on the Internet for free consultation. Despite the difficulties mentioned and the reservations with regard to certain collection instruments and routines, the information systems exist. They are up and running. They provide a basis for new approaches that can be taken toward expansion and redirection, and they can serve as a reference for other sectors. Their information provides the basis for working documents, more informed oversight against fraud, well-founded planning, lines of action, and new knowledge that can redound to the benefit of the system itself.

The flexibility of the systems, with the creation of tools to handle the data such as TabWin and TabNet, and their plasticity have already led to indispensable advances in the field of health information.

**Interagency Health Information Network (RIPSA)**

RIPSA was created with the aim of developing interinstitutional coordination to make basic data, indicators, and analyses of the health situation and its trends in Brazil available to the public in an organized and comprehensive manner. Its main task is to build the capacity to formulate, coordinate, manage, and implement public policies and actions aimed at improving the population’s quality of health and quality of life.

RIPSA’s main objective is to make the various databases compatible so that the information systems can communicate, which is essential for the development of a good health information system. Through RIPSA, for the first time there is communication among the ministries of health, labor, social welfare, and justice.
Previously, there had been no incentive for these institutions and their databases to work together as nuclei for intersectoral action. RIPSA has ushered in a phase in which information is of interest not only to those for whom a system has been physically installed but to those who use other systems as well.

The most important achievement of RIPSA is the **Basic Health Indicators and Data for Brazil (IDB)**. The goal behind this initiative is to publish data of high quality after it has been subjected to systematic scrutiny by groups that analyze and critique the information. The first indicator to be created was infant mortality, and other indicators have followed the same methodology. In addition, RIPSA produces reports on specific areas, such as infant mortality, generating summary documents which, in addition to the information, include warnings on defects that still exist with regard to the particular data element. In this way, RIPSA became a working tool both for public policy planners and for the National Congress or any segment of society that is interested in the particular subject.

RIPSA has fostered the development of critical awareness regarding the need to improve and refine the production of information within its participating organizations.

Finally, RIPSA has also promoted the effort to prevent duplication and overlapping systems through effective implementation of the National Health Information System (SINIS), which would be responsible for breaking down the barriers between SIM, SINASC, SINAN, and the SIH.
Annex I — Scripts for the Interviews

Script for the Live Birth Information System (SINASC)

Note: In reporting on SINASC, the respondent may or may not mention other national systems. Note down what he says and the examples he gives. Welcome any publication, brochure, report, or other materials that he wants to share. If he makes any drawing or chart (flowchart, organizational chart, etc.), ask if he can give it to you are try to copy it. In conducting the interview, bear in mind the status of the respondent: system manager or in-service, academic, or Health Council user.

1. Initial Phase

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<tr>
<th>Facts/Dimensions/Variables</th>
<th>In the Interview</th>
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<tr>
<td>Implemented gradually by the Ministry of Health since 1990.</td>
<td>The information offered by the respondent is relevant if he can explain, from personal experience, how the system worked in the beginning, the problems that were overcome, how they were overcome, etc.</td>
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<td>Improvement in quality noted starting in 1996.</td>
<td>It is significant if the respondent spontaneously indicates that the quality of the data has allowed the figures to be used as the denominator in direct calculations of infant mortality.</td>
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What is important to extract here, if possible, is information that helps to describe the system during its early years and thus provides information for developing a better practice; for younger respondents or those who are not familiar with the events of the period, it is not important to insist. Don’t push for exact dates; let the information flow naturally.
2. Procedures for Filling in the Declaration of Birth (DN)

Note: Have in hand a copy of the publication *Indicadores Básicos para a Saúde no Brazil/RIPSA*, (p. 268 – Sistema de Informações sobre Nascidos Vivos) [Basic Health Indicators in Brazil/RIPSA; Live Birth Information System] and the flowchart for hospital and home births in *Sistemas de Informação em Saúde* (Mota & Carvalho, p. 512).

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<tr>
<td>According to FUNASA/MS Directive 475 of 31 August 2000, published on 4 September 2000, which regulates the collection of data, the document processing path, and the schedule for submitting information on live births to SINASC:</td>
<td>Respondent to comment on:</td>
</tr>
<tr>
<td>• The basic document is the Declaration of Live Birth (DN), which is standardized nationwide and distributed by the MS in 3 copies. For deliveries in hospitals and other health institutions, the top copy of the DN should be filled in and sent to the corresponding Secretariat of Health. In the case of home births, communicating this information is the responsibility of the local office of the Civil Registry.</td>
<td>♦ Observations about these procedures.</td>
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<td>It is estimated that SINASC currently covers 93% of all live births in the country, greatly exceeding the births recorded in the Civil Registry. Coverage in the Northern and Northeastern regions is 75%.</td>
<td>♦ Any criticisms regarding the most frequent problems; especially, comments referring to the field “birth attended or not”, as well as data entry done within and outside the services.</td>
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<td>♦ Discuss, in general terms, progress and difficulties in filling in the fields (maternal age, previous children, number of dead children, skin color, schooling of the mother, occupation of the mother, marital status of the mother, etc.); don’t forget that this will be explored in depth in Section 5 of the outline.</td>
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<td></td>
<td>♦ With regard to the gap between coverage and actual events, what efforts are being made to overcome the problem in his area of action, what strategies are being used, what other systems are being enlisted (estimates, data from the services—mainly in the case of managers).</td>
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<tr>
<td></td>
<td>♦ What has improved in recent years.</td>
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<td></td>
<td>♦ Proposals under way, already submitted, places where they were sent.</td>
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If the respondent indicates that he is unaware of the procedures involved in filling in the data, continue the interview but inform the coordinators.
3. Procedures for Transmitting and Consolidating the Data on Live Births

Note: Have available a copy of the publication *Indicadores Básicos para a Saúde no Brazil/RIPS*, (p. 268 – Sistema de Informações sobre Nascidos Vivos) [Basic Health Indicators in Brazil/RIPS; Live Birth Information System] and the flowchart for hospital and home births in *Sistemas de Informação em Saúde* (Mota & Carvalho, p. 512).

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| According to FUNASA/MS Directive 475 of 31 August 2000, published on 4 September 2000, which regulates the collection of data, the document processing path, and the schedule for submitting information on live births to SINASC:  
• The Declarations of Birth are consolidated by the State Health Secretariats, which send them electronically to the SVS.  
The system’s database is available on CD-ROM and the Internet (with a delay: in 2005 the data available were for 2002). | Respondent to comment on:  
♦ What he thinks about this procedure in general.  
♦ Pay special attention his views on the action taken by the institutions or other entities in the system  
♦ Given the existing difficulties (slowness of the system, among others), find out if the respondent is open to other forms of calculation for research or decision-making in the areas of planning and epidemiological surveillance. |

If the respondent indicates that he is unaware of the procedures involved in filling in the data, continue the interview but inform the coordinators.
4. Considerations regarding the System’s Operation in the Last Decade

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<th>Facts/Dimensions/Variables</th>
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<tr>
<td>In the last decade there have been improvements in the system’s operation due to <em>specific factors</em>:</td>
<td>♦ Try to find out if the respondent is inclined to admit that there has been a “change for the better”; either way, probe the arguments offered by the respondent; note the factors cited that have contributed to the change (or the status quo):</td>
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<tr>
<td>• Changes in the document processing path</td>
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<tr>
<td>• Decentralized monitoring of the system</td>
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<td>• Existence of a health policy that has given priority to basic care</td>
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<td>The improvements have not affected all parts or the country evenly. States in the Northern and Northeastern regions still have problems that date from before the period in question. Data from the capital cities tend to be better than from other cities in the states.</td>
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<td>♦ If the respondent admits that things are beginning to “improve,” try to find out the factors that he associates with the phenomenon and when he thinks the improvement will be more tangible.</td>
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<td></td>
<td>♦ Try to identify the specific points at which the “improvement” is occurring (in the system as a whole, only in relation to certain types of deaths, etc.) while bearing in mind the position occupied by the respondent (manager; in-service, academic, or Health Council user).</td>
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</tbody>
</table>

If we are working with the concept of *better practice*, this is the part of the interview where we will be able to obtain information on:

♦ Awareness on the part of the respondent of changes in general in SINASC and any changes in the place/region/state where he lives and works with regard to the registration of attended and unattended births.

♦ The factors which, according to the respondent, have contributed to improvement, or not, of the system, which should be categorized, for example, as political or technical; responsibilities of the local, state, and national levels; decision-making that has benefited the system in terms of stewardship (resource management, human resources, relations with the private sector, technological innovations, etc.).

♦ At what point in the recent past does he place the time at which changes began to occur. This will give more substance to the term “recent period.”

♦ If the respondent is from a place that has not been following the relative success occurring in the rest of the country, it is possible that he may mention plans for the future that are already in place elsewhere, but let him talk about them and don’t interrupt the flow of the interview.
5. The SINASC Variables

Note: Have available a copy of the document *Estrutura do SINASC para o CD-ROM* [The SINASC Structure for CD-ROM]

<table>
<thead>
<tr>
<th>Facts/Dimensions/Variables</th>
<th>In the Interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>The TabWin and CD-ROM versions have the following data elements:</td>
<td>Respondent to comment (note the position occupied by respondent: academic, public service, Health Council):</td>
</tr>
<tr>
<td>• Age of the mother – Race</td>
<td>• Use habitually made of the information.</td>
</tr>
<tr>
<td>• Marital status of the mother – Schooling of the mother – Occupation of the mother</td>
<td>• Type of difficulties encountered in working with the data elements (Are they easy to understand? Do they help to interpret the data? What do you think about how the data are updated? Are the data elements sufficient for constructing the indicators that are needed?)</td>
</tr>
<tr>
<td>• Place of residence/municipio</td>
<td>• Find out if the respondent is familiar with the forms developed by RIPSA; if so, whether they are consulted; points of agreement and disagreement between them.</td>
</tr>
<tr>
<td>• Place of occurrence/municipio</td>
<td>• Any criticisms regarding the most frequent omissions on the part of the services, the professionals, the public sector, the private sector, etc.</td>
</tr>
<tr>
<td>• Number of live children – Number of dead children</td>
<td>• What has improved in recent years.</td>
</tr>
<tr>
<td>• Weeks of gestation – Type of pregnancy – Type of delivery</td>
<td>• Proposals under way, already submitted, places where they were sent.</td>
</tr>
<tr>
<td>• Number of prenatal consultations</td>
<td></td>
</tr>
<tr>
<td>• Date of the birth</td>
<td></td>
</tr>
<tr>
<td>• Apgar score (1-5) – Birthweight</td>
<td></td>
</tr>
<tr>
<td>• Race/Color</td>
<td></td>
</tr>
<tr>
<td>• Code for congenital malformation or chromosomal anomaly</td>
<td></td>
</tr>
</tbody>
</table>

More and more researchers are asking for socioeconomic information in order to do analyses by different population groups and thus monitor patterns in these groups. Respondent’s remarks regarding difficulties in filling in the social variables vis-à-vis the biological ones; what has improved and what needs to be improved.

In seven states of Brazil it is already possible to calculate infant mortality by the direct method, taking SIM and SINASC into consideration (RIPSA’s Committee on Mortality has recommended that the states achieve 90% coverage in SINASC and 80% in SIM). This possibility has created increasing demands from municipal and state-level managers who want to be given the means to apply the same procedure in their local operations. Find out if the respondent knows about this and has an opinion on the subject. Consider this information valid.

Determine the level of “optimism” (It won’t be long ...) or “pessimism” (It’s still quite a way off...) of the respondent on the possibility that use of the direct method will be expanded (It won’t be long ...) or (That’s still pretty far down the road...) .

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This part of the interview should provide information of a more technical nature, as well as insight into the use and management of the system’s information. The interviewer should be even more conscious of the position occupied by the respondent (system manager or in-service, academic, or Health Council user). His experience as a professional is fundamental in validating the project and it is therefore necessary that the successes, lapses, and recommendations he mentions be explored and recorded.

6. Procedures for Disseminating Data on Live Births

Note: Have available a copy of the publication Indicadores Básicos para a Saúde no Brazil/RIPSA (p. 268 – Sistema de Informações sobre Nascidos Vivos) [Basic Health Indicators in Brazil/RIPSA].

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<tr>
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<tr>
<td>DATASUS website: <a href="http://www.datasus.gov.br">www.datasus.gov.br</a></td>
<td>Respondent to comment on how the data are made available/disseminated:</td>
</tr>
<tr>
<td>CD-ROM distributed by SVS and on the Internet: <a href="http://www.funasa.gov.br/sis/sis03_sinasc.htm">http://www.funasa.gov.br/sis/sis03_sinasc.htm</a></td>
<td>♦ How the data are used; if they are not used, find out why; what does the respondent think of the indicators that are available.</td>
</tr>
<tr>
<td>DATASUS has developed software which allows for data to be tabulated in compact formats that do not require users to have a lot of technological resources. TabWin was considered a qualitative leap in the 1990s in terms of access. Currently the tabulator TabNet is being used to generate information and maps (on the Internet).</td>
<td>♦ Positive aspects, bearing in mind both the quality of the information and how easy it is to access using the TAB software, etc.</td>
</tr>
<tr>
<td>If the respondent indicates that he is unaware of the procedures involved in filling in the data, continue the interview but inform the coordinators.</td>
<td>♦ Negative aspects, bearing in mind both the quality of the information and the difficulties encountered in step-by-step searching.</td>
</tr>
<tr>
<td></td>
<td>♦ Try to find out if TabWin and TabNet are used equally, regardless of the type of user.</td>
</tr>
<tr>
<td></td>
<td>♦ What needs to be done, what the respondent thinks could already be being done, what can be done in the near future (5 years).</td>
</tr>
</tbody>
</table>
7. Strengths and Weaknesses; Views of Other Professionals

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<td>The system’s strengths</td>
<td>If this has not been made clear yet in the interview, try to find out the respondent’s opinion. Make sure you really understood the point (whether it has to do with sectoral policy, the stage of the country’s development, human resources, funding, technological innovation, etc.).</td>
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<td>Impressions regarding the needs and actions of the following:</td>
<td>Bearing in mind the position occupied by the respondent, try to find out:  ♦ How he perceives the needs of his colleagues and the other professionals who use the system.  ♦ What the differences are between use of the information for different purposes (service, decision-making, research).  ♦ How much of a contribution each type of professional has already made and/or can make to improve the system.</td>
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<td>Academic users</td>
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</tr>
<tr>
<td>Managers</td>
<td></td>
</tr>
<tr>
<td>Councils</td>
<td></td>
</tr>
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8. If the Respondent Addresses More General Considerations

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<td>The U.S. National Research Council (2001) has referred to some difficulties encountered in that country’s system:</td>
<td>If the respondent starts to talk about other systems or general considerations, the notes at the left may be relevant.</td>
</tr>
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<td>♦ Overlapping and duplication of data, and hence inefficiency in the production of information</td>
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<tr>
<td>♦ Limited access to data generated by the private sector</td>
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<tr>
<td>♦ Fragmentation in the collection of data and lack of standardization of terminology and definitions of the variables, making it difficult to compare data from different sources and to communicate between databases</td>
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<tr>
<td>♦ Problems in dissemination to health professionals</td>
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</tr>
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<td>♦ Lack of an overall policy that defines procedures for the collection of data and dissemination of information</td>
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<tr>
<td>♦ Limited capacity of the databases to generate information for the local level or for population subgroups</td>
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</tr>
<tr>
<td>♦ Limited capacity of the information systems to allow for longitudinal monitoring with a view to integrating the processes of disease prevention and treatment and the results on the health levels of the population</td>
<td></td>
</tr>
</tbody>
</table>
Script for System for the Reporting of Notifiable Conditions (SINAN)

Note: In reporting on SINAN, the respondent may or may not mention other national systems. Note down what he says and the examples he gives. Welcome any publication, brochure, report, or other materials that he wants to share. If he makes any drawing or chart (flowchart, organizational chart, etc.), ask if he can give it to you or try to copy it. In conducting the interview, bear in mind the status of the respondent: system manager or in-service, academic, or Health Council user.
## 1. Initial Phase

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<td>In 1975, the law that instituted the National Epidemiological Surveillance System also made it compulsory for the Health Units to report cases of certain diseases every week. The data were consolidated by the State Health Secretariat and then send by aerogram to the Ministry of Health.*</td>
<td>♦ The history of how SINAN developed is relevant, because many of the problems that exist today are due to its conception and the way in which it functions. The respondent may remember proposals and discussions, and it is important to capture his thoughts on the matter.</td>
</tr>
<tr>
<td>The System for Compulsory Notification of Diseases (SNCD) has always had problems of underreporting and limited availability of information morbidity in the country. The form used for collecting the information was vague, without details about the fundamental variables, and therefore it did not encourage surveillance at the local level. This led to the creation of several parallel systems at the different levels: local, state, and national.*</td>
<td></td>
</tr>
<tr>
<td>During the period 1990-1993, with technical support from DATASUS and the Municipal Prefecture of Belo Horizonte (PRODABEL), the Ministry of Health created and gradually implemented SINAN. In 1998 CENEPI – which is now SVS – revamped its collection forms, document processing paths, and software, as well as strategies for immediate implementation throughout the country.*</td>
<td></td>
</tr>
<tr>
<td>Currently the computerized system is installed and running in 3,800 municipios. The other municipios use standardized collection forms and their data are processed at the next higher level in the hierarchy that is equipped to do so.</td>
<td></td>
</tr>
<tr>
<td>The system has seen constant changes. It follows a different logic than the other systems, because it is not a single unified system but rather a group of systems on different diseases that were always managed vertically.</td>
<td></td>
</tr>
</tbody>
</table>

What is important to extract here, if possible, is information that helps to explain the complexity of this system within the prevailing model in the country. Apparently it is not considered a “better practice” in its entirety but only in terms of some of its parts. In this sense, it is relevant for us to know what the respondent thinks about this.

* The information contained in these paragraphs was taken from Sistemas de Informação em Saúde e a Vigilância Epidemiológica [Health Information Systems and Epidemiological Surveillance] (pp. 9-10).
2. Procedures for Filling in Data for SINAN

Note: Have available a copy of the publication *Indicadores Básicos para a Saúde no Brazil/RIPSA* [Basic Health Indicators in Brazil/RIPSA], which contains information SINAN on p. 268, and the flowchart on the SINAN flow of forms and information in *Sistemas de Informação em Saúde e a Vigilância Epidemiológica* [Health Information Systems and Epidemiological Surveillance] (p. 12).

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<tbody>
<tr>
<td><strong>SINAN’s objective is to collect, transmit, and disseminate data generated routinely by the epidemiological surveillance system in the three spheres of government to support research and analysis of information reportable diseases.</strong> Conceived as a modular computerized system starting at the local level, it can be used in the health units. According to FUNASA/MS Directive 073 of 9 March 1998, which regulates the collection of data, the document processing path, and the schedule for submitting information on live births to SINAN:</td>
<td>Respondent to comment on:</td>
</tr>
<tr>
<td></td>
<td>♦ General observations about the modular format used at the level of the health units;</td>
</tr>
<tr>
<td></td>
<td>♦ Any criticisms regarding the most frequent problems with special attention to comments about filling in the FIN and FII;</td>
</tr>
<tr>
<td></td>
<td>♦ Discuss, in general terms, progress and difficulties in filling in the fields, bearing in mind the specific nature of the condition; pay special attention to compulsory notifiable diseases, chronic degenerative diseases, and work-related accidents.</td>
</tr>
<tr>
<td></td>
<td>♦ With regard to the gap between coverage and actual events, what efforts are being made to overcome the problem in his area of action, what strategies are being used, what other systems are being enlisted (estimates, data from the services—mainly in the case of managers)</td>
</tr>
<tr>
<td></td>
<td>♦ What has improved in recent years.</td>
</tr>
<tr>
<td></td>
<td>♦ Proposals under way, already submitted, places where they were sent.</td>
</tr>
<tr>
<td>Some of SINAN’s component systems have good coverage because the patients receive free medication and therefore their condition is required to be reported (the case of AIDS, leprosy, and tuberculosis), but this is not true for other conditions.</td>
<td></td>
</tr>
</tbody>
</table>

If the respondent indicates that he is unaware of the procedures involved in filling in the data, continue the interview but inform the coordinators.

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If the respondent indicates that he is unaware of the procedures involved in filling in the data, continue the interview but inform the coordinators.
3. Procedures for Transmitting and Consolidating the Data on Notifiable Conditions

Note: Have available a copy of the publication *Indicadores Básicos para a Saúde no Brazil/RIPSA* [Basic Health Indicators in Brazil/RIPSA] (p. 268) and the flowchart on the SINAN flow of forms and information in *Sistemas de Informação em Saúde e a Vigilância Epidemiológica* [Health Information Systems and Epidemiological Surveillance] (p. 12).

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<tbody>
<tr>
<td>According to FUNASA/MS Directive 073 of 9 March 1998, which regulates the collection of data, the document processing path, and the schedule for submitting information on live births to SINAN:</td>
<td>Respondent to comment on:</td>
</tr>
<tr>
<td>• At the national level, SVS processes the data, which shall be submitted by the State Health Secretariats every 2 weeks, between the 1st and 3rd day and between the 15th and 17th day of each month.</td>
<td>♦ Ask the respondent to think about the procedure in general. Pay special attention to views on the action and role of institutions and other entities involved, bearing in mind the three levels of government: local, state, and national.</td>
</tr>
<tr>
<td></td>
<td>♦ Given the existing difficulties (slowness of the system, delayed dissemination of data relative to the time when the event occurred, etc.), try to find out if the respondent is doing research or making decisions in the areas of planning or epidemiological surveillance; what access he has to SVS to obtain data before they are officially released.</td>
</tr>
<tr>
<td></td>
<td>If the respondent indicates that he is unaware of the procedures involved in filling in the data, continue the interview but inform the coordinators.</td>
</tr>
</tbody>
</table>
4. Considerations regarding the System’s Operation in the Last Decade

<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>In the last decade there have been improvements in the system’s operation due to specific factors:</td>
<td>Try to find out if the respondent is inclined to admit that there has been a “change for the better”; either way, probe the arguments offered by the respondent; note the factors cited that have contributed to the change (or the status quo):</td>
</tr>
<tr>
<td>• Changes in the document processing path</td>
<td>- Factors related to policies and their implementation (priority given to basic health care);</td>
</tr>
<tr>
<td>• Decentralized monitoring of the system</td>
<td>- The mission of particular agencies;</td>
</tr>
<tr>
<td>• Existence of a health policy that has given priority to basic care</td>
<td>- The capacity and profile of managers, and the latitude that they are given;</td>
</tr>
<tr>
<td>The improvements have not affected all parts or the country evenly. States in the Northern and Northeastern regions still have problems that date from before the period in question. Data from the capital cities tend to be better than from other cities in the states.</td>
<td>- Stewardship (flows, monitoring, relationship with the private sector);</td>
</tr>
<tr>
<td></td>
<td>- Technical factors.</td>
</tr>
</tbody>
</table>

If we are working with the concept of better practice, this is the part of the interview where we will be able to obtain information on:

- Awareness on the part of the respondent of how SINAN operates in general and of any changes in the place/region/state where he lives and works.
- The factors which, according to the respondent, have contributed to improvement, or not, of the system, which should be categorized, for example, as political or technical; responsibilities of the local, state, and national levels; decision-making that has benefited the system in terms of stewardship (resource management, human resources, relations with the private sector, technological innovations, etc.).
- At what point in the recent past does he place the time at which changes began to occur, This will give more substance to the term “recent period.”
- If the respondent is from a place that has not been following the relative success occurring in the rest of the country, it is possible that he may mention plans for the future that are already in place elsewhere, but let him talk about them and don’t interrupt the flow of the interview.
5. The SINAN Variables

Note: Have in hand the document extracted from the SINAN website, which has a list of the compulsory notifiable conditions.

<table>
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<tbody>
<tr>
<td>Unlike the other systems, in which consistency can be checked before the information is sent to another sphere of government, the need for immediate action means that in the case of SINAN, the data are sent in as quickly as possible; they can be double-checked later. *</td>
<td>Respondent to comment (note the position occupied by respondent: academic, public service, Health Council):</td>
</tr>
<tr>
<td>It is claimed that in all instances the data provided by SINAN are consolidated and analyzed and that feedback is given to the previous levels, in addition to redistribution of the data to the locality where the patient whose case was reported resides. *</td>
<td>- Use habitually made of the information.</td>
</tr>
<tr>
<td>According to the SINAN website, its objectives are:</td>
<td></td>
</tr>
<tr>
<td>- Make a dynamic diagnosis of an event that occurs in the population;</td>
<td></td>
</tr>
<tr>
<td>- Monitor the health of the population;</td>
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<tr>
<td>- Anticipate the occurrence of events;</td>
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<td>- Provide assistance is explaining the cause of events;</td>
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<tr>
<td>- Point out risks to which people may be subjected;</td>
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<tr>
<td>- Assist in health planning;</td>
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<tr>
<td>- Set priorities for intervention;</td>
<td></td>
</tr>
<tr>
<td>- Assess the impact of interventions.</td>
<td></td>
</tr>
<tr>
<td>SINAN also handles negative reporting, i.e., notification of the non-occurrence of compulsory notifiable diseases. Immediate notification is required for the following: 11 types of conditions, even if they are only suspected; 3 types of conditions that must be confirmed; and 4 categories of events regarded as outbreaks or aggregations of cases or deaths.</td>
<td>Respondent’s remarks regarding difficulties in filling in the social variables vis-à-vis the biological ones; what has improved and what needs to be improved.</td>
</tr>
<tr>
<td>More and more researchers are asking for socioeconomic information in order to do analyses by different population groups and thus monitor patterns in these groups.</td>
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<td>This part of the interview should provide information of a more technical nature, as well as insight into the use and management of the system’s information. The interviewer should be even more conscious of the position occupied by the respondent (system manager or in-service, academic, or Health Council user). His experience as a professional is fundamental in validating the project and is it is therefore necessary that the successes, lapses, and recommendations he mentions be explored and recorded.</td>
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6. Procedures for Disseminating Data on Notifiable Conditions

**Note:** Have in hand the document extracted from the SINAN website, which has a list of the compulsory notifiable conditions.

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<tr>
<td>The system’s database is not available on the Internet; SVS checks the data against information obtained from other sources and disseminates the relevant information in the Boletim Epidemiológico: <a href="http://funasa.gov.br/sis/sis03%5ESINAN.htm">http://funasa.gov.br/sis/sis03^SINAN.htm</a></td>
<td>Respondent to comment on how the data are made available/disseminated:</td>
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<td>♦ How the data are used; if they are not used, find out why; what does the respondent think of the indicators that are available.</td>
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If the respondent indicates that he is unaware of the procedures involved in filling in the data, continue the interview but inform the coordinators.
7. Strengths and Weaknesses; Views of Other Professionals

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<td>Bearing in mind the position occupied by the respondent, try to find out:  ♦ How he perceives the needs of his colleagues and the other professionals who use the system.  ♦ What the differences are between use of the information for different purposes (service, decision-making, research).  ♦ How much of a contribution each type of professional has already made and/or can make to improve the system.</td>
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Script for the Mortality Information System (SIM)

Note: In reporting on SIM, the respondent may or may not mention other national systems. Note down what he says and the examples he gives. Welcome any publication, brochure, report, or other materials that he wants to share. If he makes any drawing or chart (flowchart, organizational chart, etc.), ask if he can give it to you or try to copy it. In conducting the interview, bear in mind the status of the respondent: system manager or in-service, academic, or Health Council user.

1. Initial Phase

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</tr>
</thead>
<tbody>
<tr>
<td>Created by the Ministry of Health in 1975.</td>
<td>The information offered by the respondent is relevant if he can explain, from personal experience, how the system worked in the beginning, the problems that were overcome, how they were overcome, etc.</td>
</tr>
<tr>
<td>Implemented in 1977.</td>
<td></td>
</tr>
<tr>
<td>Established nationwide 1979.</td>
<td></td>
</tr>
</tbody>
</table>

What is important to extract here, if possible, is information that helps to describe the system during its early years and thus provides information for developing a better practice; for younger respondents or those who are not familiar with the events of the period, it is not important to insist. Don’t push for exact dates; let the information flow naturally.
2. Procedures for Filling in the Declaration of Death (DO)


<table>
<thead>
<tr>
<th>Facts/Dimensions/Variables</th>
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</tr>
</thead>
<tbody>
<tr>
<td>According to FUNASA/MS Directive 474 of 31 August 2000, which regulates the collection of data, the document processing path, and the schedule for submitting information deaths to SIM:</td>
<td></td>
</tr>
<tr>
<td>✷ The basic document is the Declaration of Death (DO), which is standardized nationwide and distributed by the MS in 3 copies. The DO should be filled in by the physician; in places where there is no physician, it is filled in by the local office of the Civil Registry before 2 witnesses. This document is indispensable in order to obtain the Death Certificate from the Civil Registry and for burial.</td>
<td></td>
</tr>
<tr>
<td>With regard to underregistration, in the 1990s, 71.4% of the deaths were reported, and in 2002 the figure was 83.2%. The greatest difficulties are encountered in the Northern and Northeastern regions. The proportion of deaths due to ill-defined causes is approximately 14%.</td>
<td></td>
</tr>
<tr>
<td>Respondent to comment on:</td>
<td></td>
</tr>
<tr>
<td>✷ Observations about these procedures.</td>
<td></td>
</tr>
<tr>
<td>✷ Any criticisms regarding the most frequent problems; especially, comments referring to hospital and non-hospital deaths, as well as how the physician is filling in the data.</td>
<td></td>
</tr>
<tr>
<td>✷ Discuss, in general terms, progress and difficulties in filling in the fields other than the cause of death (maternal age, attended by a physician).</td>
<td></td>
</tr>
<tr>
<td>✷ Discuss progress and difficulties in mortality information other than infant mortality.</td>
<td></td>
</tr>
<tr>
<td>✷ With regard to the underregistration, what efforts are being made to overcome the problem in his area of action, what strategies are being used, what other systems are being enlisted (SIH, for example, or other data services—mainly in the case of managers).</td>
<td></td>
</tr>
<tr>
<td>✷ What has improved in recent years.</td>
<td></td>
</tr>
<tr>
<td>✷ Proposals under way, already submitted, places where they were sent.</td>
<td></td>
</tr>
</tbody>
</table>

If the respondent indicates that he is unaware of the procedures involved in filling in the data, continue the interview but inform the coordinators.
3. Procedures for Transmitting and Consolidating the Data on Mortality


<table>
<thead>
<tr>
<th>Facts/Dimensions/Variables</th>
<th>In the Interview</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>According to FUNASA/MS Directive 474 of 31 August 2000, published on 4 September 2000, which regulates the collection of data, the document processing path, and the schedule for submitting information deaths to SIM:</strong></td>
<td>Respondent to comment on:</td>
</tr>
<tr>
<td>• The Declarations of Death are collected by the State or Municipal Health Secretariats from health establishments or local offices of the Civil Registry, coded, and keyed into the computer system.</td>
<td>✦ What he thinks about this procedure in general.</td>
</tr>
<tr>
<td>• SVS/FUNASA consolidates the data and makes them available to the SUS/DATASUS Information Processing Department.</td>
<td>✦ Pay special attention his views on the action taken by the institutions or other entities in the system</td>
</tr>
<tr>
<td>The time lag between the year the event occurred and its dissemination is 3 years in SIM.</td>
<td>✦ Given the existing difficulties (slowness of the system, among others), find out if the respondent is open to other forms of calculation for research or decision-making in the areas of planning and epidemiological surveillance.</td>
</tr>
</tbody>
</table>

If the respondent indicates that he is unaware of the procedures involved in filling in the data, continue the interview but inform the coordinators.
4. Considerations regarding the System’s Operation in the Last Decade

<table>
<thead>
<tr>
<th>Facts/Dimensions/Variables</th>
<th>In the Interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>In the last decade there have been improvements in the system’s operation due to specific factors:</td>
<td>♦ Try to find out if the respondent is inclined to admit that there has been a &quot;change for the better&quot;; either way, probe the arguments offered by the respondent; note the factors cited that have contributed to the change (or the status quo):</td>
</tr>
<tr>
<td>• Changes in the document processing path</td>
<td>▪ Factors related to policies and their implementation (priority given to basic health care);</td>
</tr>
<tr>
<td>• Decentralized monitoring of the system</td>
<td>▪ The mission of particular agencies;</td>
</tr>
<tr>
<td>• Existence of a health policy that has given priority to basic care</td>
<td>▪ The capacity and profile of managers, and the latitude that they are given;</td>
</tr>
<tr>
<td>The improvements have not affected all parts or the country evenly. States in the Northern and Northeastern regions still have problems that date from before the period in question. Data from the capital cities tend to be better than from other cities in the states.</td>
<td>▪ Stewardship (flows, monitoring, relationship with the private sector);</td>
</tr>
<tr>
<td>Even though there is little communication between the databases (including SIM), data on mortality are important for epidemiological assessments.</td>
<td>▪ Technical factors.</td>
</tr>
</tbody>
</table>

♦ If the respondent admits that things are beginning to “improve,” try to find out the factors that he associates with the phenomenon and when he thinks the improvement will be more tangible.

♦ Try to identify the specific points at which the “improvement” is occurring (in the system as a whole, only in relation to certain types of deaths, etc.) while bearing in mind the position occupied by the respondent (manager; in-service, academic, or Health Council user).

♦ If the respondent admits that things are beginning to “improve,” try to find out the factors that he associates with the phenomenon and when he thinks the improvement will be more tangible.

If we are working with the concept of better practice, this is the part of the interview where we will be able to obtain information on:

♦ Awareness on the part of the respondent of changes in general in SINASC and any changes in the place/region/state where he lives and works with regard to the extent of coverage and the proportion of deaths due to ill-defined causes.

♦ The factors which, according to the respondent, have contributed to improvement, or not, of the system, which should be categorized, for example, as political or technical; responsibilities of the local, state, and national levels; decision-making that has benefited the system in terms of stewardship (resource management, human resources, relations with the private sector, technological innovations, etc.).

♦ At what point in the recent past does he place the time at which changes began to occur, This will give more substance to the term “recent period.”

♦ If the respondent is from a place that has not been following the relative success occurring in the rest of the country, it is possible that he may mention plans for the future that are already in place elsewhere, but let him talk about them and don’t interrupt the flow of the interview.
5. The SIM Data Elements

**Note:** Have in hand a copy of the publication *Manual de procedimentos sobre Mortalidade*, 1999 [Manual of Procedures on Mortality, 1999].

<table>
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</thead>
<tbody>
<tr>
<td>The CD-ROM version of SIM has the following data elements:</td>
<td>Respondent to comment (note the position occupied by respondent: academic, public service, Health Council):</td>
</tr>
<tr>
<td>• Age – Sex – Race</td>
<td>• Use habitually made of the information.</td>
</tr>
<tr>
<td>• Marital status – Schooling – Occupation</td>
<td>• Type of difficulties encountered in working with the data elements (Are they easy to understand? Do they help to interpret the data? What other interpretation should be included?)</td>
</tr>
<tr>
<td>• Place of birth</td>
<td>• Any criticisms regarding the most frequent omissions on the part of the services, the professionals, the public sector, the private sector, etc.</td>
</tr>
<tr>
<td>• Place of residence/municipio</td>
<td>• What has improved in recent years.</td>
</tr>
<tr>
<td>• Place of occurrence/municipio</td>
<td>• Proposals under way, already submitted, places where they were sent.</td>
</tr>
<tr>
<td>• Specific information fetal deaths and deaths in infants under 1 year of age</td>
<td></td>
</tr>
<tr>
<td>• Underlying cause of death according to the ICD</td>
<td></td>
</tr>
<tr>
<td>• Circumstances of the death</td>
<td></td>
</tr>
<tr>
<td>• Attended by physician or not</td>
<td></td>
</tr>
<tr>
<td>• Results of tests, surgery, and necropsy</td>
<td></td>
</tr>
<tr>
<td>• Work-related accident</td>
<td></td>
</tr>
</tbody>
</table>

More and more researchers are asking for socioeconomic information in order to do analyze mortality by different population groups and thus explore analyses related to equity in health. The only way to analyze inequalities and access to services is through the geography of cases attended, births, and deaths.

Respondent’s remarks regarding difficulties in filling in the social variables vis-à-vis the biological ones; what has improved and what needs to be improved.

In seven states of Brazil it is already possible to calculate infant mortality by the direct method, taking SIM and SINASC into consideration (RIPSA’s Committee on Mortality has recommended that the states achieve 90% coverage in SINASC and 80% in SIM).

This possibility has created increasing demands from municipal and state-level managers who want to be given the means to apply the same procedure in their local operations.

Find out if the respondent knows about this and has an opinion the subject. Consider this information valid.

Determine the level of “optimism” (It won’t be long ...) or “pessimism” (It’s still quite a way off...) of the respondent on the possibility that use of the direct method will be expanded (It won’t be long ...) or (That’s still pretty far down the road...).
This part of the interview should provide information of a more technical nature, as well as insight into the use and management of the system’s information. The interviewer should be even more conscious of the position occupied by the respondent (system manager or in-service, academic, or Health Council user). His experience as a professional is fundamental in validating the project and is it is therefore necessary that the successes, lapses, and recommendations he mentions be explored and recorded.

6. Procedures for Disseminating Data on Mortality


<table>
<thead>
<tr>
<th>Facts/Dimensions/Variables</th>
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</tr>
</thead>
<tbody>
<tr>
<td>DATASUS website: <a href="http://www.datasus.gov.br">www.datasus.gov.br</a> CD-ROM distributed by SVS</td>
<td>Respondent to comment on how the data are made available/disseminated:</td>
</tr>
<tr>
<td>DATASUS has developed software which allows for data to be tabulated in compact formats that do not require users to have a lot of technological resources. TabWin was considered a qualitative leap in the 1990s in terms of access. Currently the tabulator TabNet is being used to generate information and maps (on the Internet).</td>
<td>♦ How the data are used; if they are not used, find out why; what does the respondent think of the indicators that are available.</td>
</tr>
<tr>
<td></td>
<td>♦ Positive aspects, bearing in mind both the quality of the information and how easy it is to access using the TAB software, etc.</td>
</tr>
<tr>
<td></td>
<td>♦ Negative aspects, bearing in mind both the quality of the information and the difficulties encountered in step-by-step searching.</td>
</tr>
<tr>
<td></td>
<td>♦ What needs to be done, what the respondent thinks could already be being done, what can be done in the near future (5 years).</td>
</tr>
</tbody>
</table>

If the respondent indicates that he is unaware of the procedures involved in filling in the data, continue the interview but inform the coordinators.
### 7. Strengths and Weaknesses; Views of Other Professionals

<table>
<thead>
<tr>
<th>Facts/dimensions/variables</th>
<th>In the interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>The system’s strengths</td>
<td>If this has not been made clear yet in the interview, try to find out the respondent’s opinion. Make sure you really understood the point (whether it has to do with sectoral policy, the stage of the country’s development, human resources, funding, technological innovation, etc.).</td>
</tr>
<tr>
<td>The system’s weaknesses</td>
<td>If this has not been made clear yet in the interview, try to find out the respondent’s opinion. Make sure you really understood the point (whether it has to do with sectoral policy, the stage of the country’s development, human resources, funding, technological innovation, etc.).</td>
</tr>
<tr>
<td>Impressions regarding the needs and actions of the following: In-service users Academic users Managers Councils</td>
<td>Bearing in mind the position occupied by the respondent, try to find out: ♦ How he perceives the needs of his colleagues and the other professionals who use the system. ♦ What the differences are between use of the information for different purposes (service, decision-making, research). ♦ How much of a contribution each type of professional has already made and/or can make to improve the system.</td>
</tr>
</tbody>
</table>
8. If the Respondent Addresses More General Considerations

<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>The U.S. National Research Council (2001) has referred to some difficulties encountered in that country’s system:</td>
<td>If the respondent starts to talk about other systems or general considerations, the notes at the left may be relevant.</td>
</tr>
<tr>
<td>♦ Overlapping and duplication of data, and hence inefficiency in the production of information</td>
<td></td>
</tr>
<tr>
<td>♦ Limited access to data generated by the private sector</td>
<td></td>
</tr>
<tr>
<td>♦ Fragmentation in the collection of data and lack of standardization of terminology and definitions of the data elements, making it difficult to compare data from different sources and to communicate between databases</td>
<td></td>
</tr>
<tr>
<td>♦ Problems in dissemination to health professionals</td>
<td></td>
</tr>
<tr>
<td>♦ Lack of an overall policy that defines procedures for the collection of data and dissemination of information</td>
<td></td>
</tr>
<tr>
<td>♦ Limited capacity of the databases to generate information for the local level or for population subgroups</td>
<td></td>
</tr>
<tr>
<td>♦ Limited capacity of the information systems to allow for longitudinal monitoring with a view to integrating the processes of disease prevention and treatment and the results on the health levels of the population</td>
<td></td>
</tr>
</tbody>
</table>
Script for the Hospital Information System (SIH)

Note: In reporting on the SIH, the respondent may or may not mention other national systems. Note down what he says and the examples he gives. Welcome any publication, brochure, report, or other materials that he wants to share. If he makes any drawing or chart (flowchart, organizational chart, etc.), ask if he can give it to you are try to copy it. In conducting the interview, bear in mind the status of the respondent: system manager or in-service, academic, or Health Council user.

1. Initial Phase and Development

<table>
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<tbody>
<tr>
<td>In 1976 the National Social Security Institute (INPS) established the National Hospital Payment Control and Accounts System. In 1983 the Hospital Admission Guide was created as an instrument for collecting data and later named the Hospital Admission Authorization (AIH). It is a system created primarily to process hospital accounts and permit the monitoring of costs and auditing. In the 1990s, when the Ministry of Health assumed responsibility for medical care, the system took on the function of generating information and became the Hospital Information System (SIH). The system was gradually decentralized, and starting in 1994, data processing was passed on to the State Health Secretariats, and later the Municipal Health Secretariats took over full management.* Every month the MS distributes numbered AIH forms to the State Health Secretariats, in a predetermined number (9% of the resident population as calculated by IBGE). Thus, the number of forms received every month by each state is ( \frac{1}{12} ) of 9% of its population.** The state then redistributes the forms to each municipio as specified in the Integrated Partnership Programming (PPI) agreement. The numbered forms are valid for 4 months, after which the system automatically rejects them.**</td>
<td></td>
</tr>
<tr>
<td>The history of how the SIH developed is relevant because many of the problems that exist today are due to its conception. The respondent may be able to recall the proposals and discussions, and it is important to capture what he has to say.</td>
<td></td>
</tr>
</tbody>
</table>
What is important to extract here, if possible, is information that helps to explain the complexity of this system within the prevailing model in the country, and in this sense, it is important to know what the respondent thinks about this.

* The information contained in these paragraphs was taken from the publication Sistemas de Informação em Saúde [Health Information Systems] (Mota & Carvalho, p. 14).

** The information contained in these paragraphs was taken from Sistemas de Informação em Saúde e a Vigilância Epidemiológica [Health Information Systems and Epidemiological Surveillance] (p. 13).
2. Procedures for Filling in Data for the SIH

Note: Have in hand the following publications: *Indicadores Básicos para a Saúde no Brazil/RIPS*, (p. 184, Proporção de Internações Hospitalares (SUS) por Grupos de Causa; p. 269, Sistemas de Informação Hospitalares (SIH/SUS)) [Basic Health Indicators in Brazil/RIPS; Proportion of SUS Hospitalizations by Groups of Causes, and Hospital Information Systems] and *Sistemas de Informação em Saúde and a Vigilância Epidemiológica* (p. 14, Esquema of the Fluxo Básico de Autorizações de Internação Hospitalar (AIH)) [Health Information Systems and Epidemiological Surveillance; Basic Processing Path for Hospital Admission Authorizations (AIH)].

<table>
<thead>
<tr>
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</tr>
</thead>
</table>
| As originally conceived, SIH did not incorporate epidemiological logic; it was merely a device for handling the payments for hospitalizations in contract hospitals and later philanthropic, university, and public hospitals. Hospitalizations in the private sector paid for directly by the patient or covered by health insurance plans were not included in the system. The information covers about 70% of hospitalizations in the country, and its form includes a place to enter the ICD code corresponding to the cause for admission, which, if properly filled in, can be used for epidemiological purposes in some of the states and municípios. | Respondent to comment on:  
♦ Any criticisms regarding the most frequent problems.  
♦ Discuss, in general terms, progress and difficulties in filling in the data, bearing in mind the type of hospital  
♦ With regard to the fact that coverage does not include hospitalizations in the private sector, direct payment, and health insurance plans, what efforts are being made to overcome the problem in his area of action, what strategies are being used, what other systems are being enlisted (estimates, data from the services—mainly in the case of managers).  
♦ What has improved in recent years.  
♦ Proposals under way, already submitted, places where they were sent. |

If the respondent indicates that he is unaware of the procedures involved in filling in the data, continue the interview but inform the coordinators.
3. Procedures for Transmitting and Consolidating the Data on Hospitalizations

Note: Have in hand the following publications: *Indicadores Básicos para a Saúde no Brazil/RIPSA*, (p. 184, Proporção de Internações Hospitalares (SUS) por Grupos de Causa, and p. 269, Sistemas de Informação Hospitalares (SIH/SUS)) [Basic Health Indicators in Brazil/RIPSA; Proportion of SUS Hospitalizations by Groups of Causes, and Hospital Information Systems] and *Sistemas de Informação em Saúde and a Vigilância Epidemilogica* (p. 14, Esquema of the Fluxo Básico de Autorizações de Internação Hospitalar (AIH)) [Health Information Systems and Epidemiological Surveillance; Basic Processing Path of Hospital Admission Authorizations (AIH)].

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<tbody>
<tr>
<td>The AIH is filled in by the hospital and submitted once a month electronically to the municipal and/or state SUS manager, depending on the management level for processing at the national level. When the same patient is admitted or transferred to another hospital within the services covered by the system, these admissions are not identified separately, which results in cumulative counts. Accounts for persons with the same name are lumped together when they are presented. They are then verified and separated out by the manager the following month, as appropriate.</td>
<td>Respondent to comment on: ♦ What he thinks about this procedure in general, his ideas on how the validity of the information is affected by such aspects as calculation of the ceiling; underestimation caused by items disallowed; forms calculated differently (university hospitals and those operating under a budget), lack of information about the private system not under contract with the SUS. ♦ Given the existing difficulties (differences in filling in the data depending on the hospital, cumulative counting, seasonal occurrence of diseases vis-à-vis the fixed quota in the number series of the AIH, etc.) try to find out how the respondent goes about doing research or decision-making in the areas of planning and epidemiological surveillance. ♦ Ideas the respondent may have on improvements that can be made in the future.</td>
</tr>
</tbody>
</table>

If the respondent indicates that he is unaware of the procedures involved in filling in the data, continue the interview but inform the coordinators.
4. Considerations regarding the System’s Operation in the Last Decade

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<th>Facts/Dimensions/Variables</th>
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<tr>
<td>In the last decade there have been improvements in the system’s operation due to specific factors:</td>
<td></td>
</tr>
<tr>
<td>• Changes in the document processing path</td>
<td></td>
</tr>
<tr>
<td>• Decentralized monitoring of the system</td>
<td></td>
</tr>
<tr>
<td>• Existence of a health policy that includes other hospitals outside of the system.</td>
<td></td>
</tr>
<tr>
<td>As with the other information systems, the Northern and Northeastern regions still have more problems. Differences between capital cities and the interior also occur, and there are variations from one hospital to another and even within the same municipio.</td>
<td></td>
</tr>
<tr>
<td>♦ Try to find out if the respondent is inclined to admit that there has been a “change for the better”; either way, probe the arguments offered by the respondent; note the factors cited that have contributed to the change (or the status quo):</td>
<td></td>
</tr>
<tr>
<td>▪ Factors related to policies and their implementation;</td>
<td></td>
</tr>
<tr>
<td>▪ The specific nature of hospital care;</td>
<td></td>
</tr>
<tr>
<td>▪ The capacity and profile of managers, and the latitude that they are given;</td>
<td></td>
</tr>
<tr>
<td>▪ Stewardship (flows, monitoring, relationship with the private sector);</td>
<td></td>
</tr>
<tr>
<td>▪ Technical factors.</td>
<td></td>
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<tr>
<td>♦ If the respondent admits that things are beginning to “improve,” try to find out the factors that he associates with the phenomenon and when he thinks the improvement will be more tangible.</td>
<td></td>
</tr>
<tr>
<td>♦ Try to understand to what he attributes this “improvement” is occurring (in the system as a whole or only in relation to certain aspects, certain hospitals, or certain states or municipios, while bearing in mind the position occupied by the respondent (manager; in-service, academic, or Health Council user).</td>
<td></td>
</tr>
<tr>
<td>♦ If we are working with the concept of better practice, this is the part of the interview where we will be able to obtain information on:</td>
<td></td>
</tr>
<tr>
<td>♦ Awareness on the part of the respondent of changes in general in SINASC and any changes in the place/region/state where he lives and works.</td>
<td></td>
</tr>
<tr>
<td>♦ The factors which, according to the respondent, have contributed to improvement, or not, of the system should be categorized, for example, as political or technical; responsibilities of the local, state, and national levels; decision-making that has benefited the system in terms of stewardship (resource management, human resources, relations with the private sector, technological innovations, etc.).</td>
<td></td>
</tr>
<tr>
<td>♦ At what point in the recent past does he place the time at which changes began to occur, This will give more substance to the term “recent period.”</td>
<td></td>
</tr>
<tr>
<td>♦ If the respondent is from a place that has not been following the relative success occurring in the rest of the country, it is possible that he may mention plans for the future that are already in place elsewhere, but let him talk about them and don’t interrupt the flow of the interview.</td>
<td></td>
</tr>
</tbody>
</table>

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5. The SIH Variables

Note: Have in hand a copy of the document *Diccionário de variáveis da AIH (mensal and reduzido)* [Dictionary of AIH Variables: Monthly and Short Version].

<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>The monthly instrument represents the “movement” and contains all the data; the short version does not show data on professional services. The data elements on which information is requested are as follows:</td>
<td>• Respondent to comment (note the position occupied by respondent: academic, public service, Health Council):</td>
</tr>
<tr>
<td>♦ Code of state or federal unit under which the hospital operates – Hospital survey identification number – AIH identification according to type</td>
<td>• Use habitually made of the information.</td>
</tr>
<tr>
<td>♦ Patient ID number (CEP) – Municipio of residence – Age – Sex – Nationality – Schooling</td>
<td>• Instrument use more often: monthly or annual?</td>
</tr>
<tr>
<td>♦ Number of children</td>
<td>• Views on updating of the data.</td>
</tr>
<tr>
<td>♦ Admission to ICU: ICU days during month of admission – ICU days during month of discharge – Total ICU days – Types of ICU care used</td>
<td>• Try to find out if the respondent thinks that the current data elements are sufficient for constructing the indicators needed.</td>
</tr>
<tr>
<td>♦ Similar data for intermediate care</td>
<td>• Try to find out what the respondent thinks about some of the recurring issues. Examples: When hospital deaths due to a given cause are compared between SIM and the SIH, sometimes the level of correspondence is quite low. To what extent is it possible to rely on the diagnoses (per ICD-10)? To what extent is it possible to rely on the information generated by the procedures for which hospital admission is authorized – in other words, on the diagnosis at the time of admission?</td>
</tr>
<tr>
<td>♦ Procedures performed</td>
<td>• Type of difficulties most frequently encountered. What is being done to overcome and weigh the distortions in the service network?</td>
</tr>
<tr>
<td>♦ Rate charged (in RS) for hospital services – professional services – auxiliary diagnostic and therapeutic services – newborn care – orthotic and prosthetic devices – blood – tomography and MRI paid to third parties, not prorated – transplants (including cost of OR, organ extraction, examination of the cadaver, auditory assessment [2], examination of the transplanttee) – obstetric analgesics – first pediatric consultation</td>
<td>• What is being done to overcome and weigh the distortions in the service network?</td>
</tr>
<tr>
<td>♦ Fallopian tubes tied, cesarean section w/ tubes tied and vasectomy – Types of contraceptives used – Indicator of at-risk pregnancy – Enrollment number corresponding to pregnant woman in prenatal program</td>
<td>• What has improved in recent years? Find out if the respondent knows of any state of municipio that could be considered a model.</td>
</tr>
<tr>
<td>♦ Date of admission – Date of departure – Length of stay (days) – Departure due to death – subsequent to AIH for long-term stay</td>
<td>• Proposals under way, already submitted, places where they were sent.</td>
</tr>
<tr>
<td>♦ Primary diagnosis per ICD – Secondary diagnosis per ICD</td>
<td><strong>More and more researchers are asking for socioeconomic information in order to do analyze mortality by different population groups and thus explore analyses related to equity in health. The only way to analyze inequalities and access to services is through the geography of cases attended, births, and deaths.</strong></td>
</tr>
<tr>
<td>♦ Reason for charge per Table – Nature of hospital affiliation with SUS per Table – Type of pregnancy – Code of municipio in which hospital is located</td>
<td>Respondent’s remarks regarding difficulties in filling in the social variables vis-à-vis the biological ones; what has improved and what needs to be improved.</td>
</tr>
<tr>
<td>♦ Nature of admission per Table – Number of professional service points in this AIH</td>
<td></td>
</tr>
<tr>
<td>♦ Identification number (CPF) of the auditor</td>
<td></td>
</tr>
<tr>
<td>♦ Flag indicating that the patient on the AIH has the same name as another patient</td>
<td></td>
</tr>
</tbody>
</table>

This part of the interview should provide information of a more technical nature, as well as insight into the use and management of the system’s information. The interviewer should be even more conscious of the position occupied by the respondent (system manager or in-service, academic, or Health Council user). His experience as a professional is fundamental in validating the project and is it is therefore necessary that the successes, lapses, and recommendations he mentions be explored and recorded.

* The information contained in these paragraphs was taken from *Sistemas de Informação em Saúde e a Vigilância Epidemiológica* [Health Information Systems and Epidemiological Surveillance] (pp. 9-10).
6. Procedures for Disseminating Data on Hospitalizations

Note: Have in hand the following publications: *Indicadores Básicos para a Saúde no Brasil/RIPSA*, (p. 184, Proporção de Internações Hospitalares (SUS) por Grupos de Causa; p. 269, Sistemas de Informação Hospitalares (SIH/SUS)) [Basic Health Indicators in Brazil/RIPSA; Proportion of SUS Hospitalizations by Groups of Causes, and Hospital Information Systems] and *Sistemas de Informação em Saúde and a Vigilância Epidemiológica* (p. 14, Esquema do Fluxo Básico de Autorizações de Internação Epidemiológica (AIH)) [Health Information Systems and Epidemiological Surveillance; Basic Processing Path of Hospital Admission Authorizations (AIH)]

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<thead>
<tr>
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<tr>
<td>The system makes data available regularly after 2 months from the date of admission on a monthly CD-ROM or the Internet: <a href="http://dtr2001.saude.gov.br/sas">http://dtr2001.saude.gov.br/sas</a> <a href="http://www.datasus.gov.br/catalogo/sihsus.htm">http://www.datasus.gov.br/catalogo/sihsus.htm</a></td>
<td>Respondent to comment on how the data are made available/disseminated:</td>
</tr>
<tr>
<td>Indicators available:</td>
<td>♦ How the data are used; if they are not used, find out why; what does the respondent think of the indicators that are available.</td>
</tr>
<tr>
<td>• Average length of stay, in general or by specific cause</td>
<td>♦ Positive aspects, bearing in mind both the quality of the information and how easy it is to access using the TAB software, etc.</td>
</tr>
<tr>
<td>• Average cost per hospitalization, in general or by specific cause</td>
<td>♦ Negative aspects, bearing in mind both the quality of the information and the difficulties encountered in step-by-step searching.</td>
</tr>
<tr>
<td>• Proportion of admissions by cause or procedure selected</td>
<td>♦ What needs to be done, what the respondent thinks could already be being done, what can be done in the near future (5 years).</td>
</tr>
<tr>
<td>• Use of the ICU</td>
<td></td>
</tr>
<tr>
<td>• Hospital death rate, in general, by specific cause, or by specific procedure</td>
<td></td>
</tr>
<tr>
<td>Managers show growing interest in the following indicators:</td>
<td></td>
</tr>
<tr>
<td>• Ratio of population relative to paid AIHs, total cost of hospitalization, and days of hospitalization by sex and/or age group</td>
<td></td>
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<tr>
<td>• Rate of utilization, in general or by cause, by sex and/or age group</td>
<td></td>
</tr>
<tr>
<td>• Index of hospitalization, in general or by cause, by sex and/or age group</td>
<td></td>
</tr>
<tr>
<td>• Index of expenditure on hospitalization, in general or by cause, by sex and/or age group</td>
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</table>
7. Strengths and Weaknesses; Views of Other Professionals

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<tbody>
<tr>
<td>The system’s strengths</td>
<td>If this has not been made clear yet in the interview, try to find out the respondent’s opinion. Make sure you really understood the point (whether it has to do with sectoral policy, the stage of the country’s development, human resources, funding, technological innovation, etc.).</td>
</tr>
<tr>
<td>The system’s weaknesses</td>
<td>If this has not been made clear yet in the interview, try to find out the respondent’s opinion. Make sure you really understood the point (whether it has to do with sectoral policy, the stage of the country’s development, human resources, funding, technological innovation, etc.).</td>
</tr>
</tbody>
</table>

Impressions regarding the needs and actions of the following:
- In-service users
- Academic users
- Managers
- Councils

Bearing in mind the position occupied by the respondent, try to find out:
- How he perceives the needs of his colleagues and the other professionals who use the system.
- What the differences are between use of the information for different purposes (service, decision-making, research).
- How much of a contribution each type of professional has already made and/or can make to improve the system.
8. If the Respondent Addresses More General Considerations

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<td>The U.S. National Research Council (2001) has referred to some difficulties encountered in that country’s system:</td>
<td></td>
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<td>♦ Overlapping and duplication of data, and hence inefficiency in the production of information</td>
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<td>♦ Lack of an overall policy that defines procedures for the collection of data and dissemination of information</td>
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<tr>
<td>♦ Limited capacity of the databases to generate information for the local level or for population subgroups</td>
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<tr>
<td>♦ Limited capacity of the information systems to allow for longitudinal monitoring with a view to integrating the processes of disease prevention and treatment and the results on the health levels of the population</td>
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</table>

If the respondent starts to talk about other systems or general considerations, the notes at the left may be relevant.
**Script for the Informatics Department of SUS/DATASUS**

**Note:** In reporting on DATASUS, the respondent may or may not mention other national systems. Note down what he says and the examples he gives. Welcome any publication, brochure, report, or other materials that he wants to share. If he makes any drawing or chart (flowchart, organizational chart, etc.), ask if he can give it to you are try to copy it. In conducting the interview, bear in mind the position that the respondent occupies in DATASUS.

**Note:** Have in hand the document from the DATASUS website and remember that the interview is not concerned with DATASUS in all its capabilities but only with aspects related to health information (Hospital and Epidemiological Information, Health Establishment Survey, SIOPS, and the Health Information Caderno, IDB Brazil).

**Note:** Don’t forget to focus as closely as you can on each of the systems being studied in this project: SIM, SINASC, SINAN, and SIH.
### 1. Initial Phase and Development in the Last Decade

#### Facts/Dimensions/Variables

According to Decree 2,477 of 28 January 1998, DATASUS was attached to the Executive Secretariat of the Ministry of Health.

Over recent decades DATASUS has made enormous progress in making existing information available, making it possible for any interested user to access and tabulate data.

TabDOS was the first version of the tabulation software to be offered, and in the last decade it has evolved to become TabWin and TabNet.

The systems have gradually started to review their information, the first one being SIM, followed by SINASC, SIH, SIA, SIAB, etc. Given the nature of SINAN, which actually brings several systems together, some of the information that it depends on has a constant lag between the date it is made available and the date of the event. It does not exist in TAB format.

A concept behind DATASUS, in terms of the development of tools for the use of information systems is unique in that it gives the user a wide range of freedom in the combination and presentation of data elements.

#### In the Interview

Try to find out:

- How the health information system functioned in the beginning, problems that were overcome, and how they were overcome.
- If the place where DATASUS is located in the government structure is the most effective for its task of making data available, any agreement or disagreement on this point (Is it in an ideal place?)
- Authority, responsibility and degree of autonomy invested (what it has and what it should have).
- Whether, in general and bearing in mind the resources it has, the Health Information sector has been able to meet its objectives, and in what way may it have fallen short.

Over recent decades DATASUS has made enormous progress in making existing information available, making it possible for any interested user to access and tabulate data.

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A concept behind DATASUS, in terms of the development of tools for the use of information systems is unique in that it gives the user a wide range of freedom in the combination and presentation of data elements.

In the interview, explore issues around this aspect of the model:

- The advantages that it offers
- Any criticisms that have arisen
- Try to find out what exists today, in concrete terms, that would not exist if DATASUS had not made this effort to make data available.
- Try to find out the respondent’s opinion on a point that often comes up – namely, whether making data available on the Internet broken down by municipio may have improved the quality of data entered and the reporting done through the various instruments that feed the systems, or whether it may have given false results to health managers at the local level.
- Try to find out if there is a sense of a strategic role being played by this sector of DATASUS in the sense of redirecting the statistical system, promoting cooperation between different agencies, and transforming data into information of use for the health sector and for the country, thus expanding opportunities for social empowerment.
2. Information Made Available by DATASUS

<table>
<thead>
<tr>
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<tbody>
<tr>
<td>On the Internet, the following health information is provided by DATASUS:</td>
<td></td>
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<tr>
<td>• Hospital information</td>
<td></td>
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<tr>
<td>• Epidemiological information</td>
<td></td>
</tr>
<tr>
<td>• National Survey of Health Establishments</td>
<td></td>
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<tr>
<td>• Public Health Budgets Information System (SIOPS)</td>
<td></td>
</tr>
<tr>
<td>• Health Information Notebook (<em>Caderno</em>)</td>
<td></td>
</tr>
<tr>
<td>• Basic Health Indicators and Data for Brazil (IDB)</td>
<td>Try to find out:</td>
</tr>
<tr>
<td></td>
<td>• Who decides what to include, what to keep, and what to discard of the information that is available. Get the respondent to focus on each of the systems being covered in this study: SIM, SINASC, SINAN and SIH.</td>
</tr>
<tr>
<td></td>
<td>• Where and how “quality control” is achieved in the data being received.</td>
</tr>
<tr>
<td></td>
<td>• Whether there is any protocol, procedure, or strategy used to decide which variables are consistent and can be disseminated.</td>
</tr>
<tr>
<td></td>
<td>• Whether it is possible to introduce a checking system.</td>
</tr>
<tr>
<td></td>
<td>• Progress resulting from these practices.</td>
</tr>
<tr>
<td></td>
<td>• Remaining problems (updating, inclusion of social variables).</td>
</tr>
<tr>
<td></td>
<td>• What can be expected in the immediate future.</td>
</tr>
<tr>
<td></td>
<td>• Whether the DATASUS General Coordination is aware of the role that health information can play.</td>
</tr>
</tbody>
</table>
3. Strategic Role of an Agency Like DATASUS in the Health Information Sector

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<td>The growing interest of many countries in enlisting their statistics system to improve the quality of management and monitor the health situation has led to discussions and proposals for action.</td>
<td></td>
</tr>
<tr>
<td>In the United States, the National Committee on Vital and Health Statistics, a body entrusted with advising the Department of Health and Human Services, sponsored a national consultation on health sector policy in the area of its activities, and the resulting document emphasized the importance of specifying:</td>
<td></td>
</tr>
<tr>
<td>• Needs for information in the 21st century;</td>
<td></td>
</tr>
<tr>
<td>• The conceptual framework for achieving greater significance;</td>
<td></td>
</tr>
<tr>
<td>• More effective procedures for collecting, storing, and communicating information with a view to ensuring its high quality;</td>
<td></td>
</tr>
<tr>
<td>• Ways to protect the safety, confidentiality, and privacy of information so that it can be safely used in promoting the health of the population.</td>
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</tr>
<tr>
<td>The document also proposes the creation of a Council for Health Information Planning that would have broad latitude and relative autonomy and would include non-public sectors.</td>
<td></td>
</tr>
<tr>
<td>In Australia, for example, there is an agreement between two principal agencies, the Australian Bureau of Statistics (ABS) and the Australian Institute for Health and Welfare (AIHW), under which the necessary mechanisms will be adopted for collection, quality control, and dissemination of health information.</td>
<td></td>
</tr>
<tr>
<td>Pay attention throughout the interview to see if the respondent mentioned one or more points related to the text at the left.</td>
<td></td>
</tr>
<tr>
<td>When you get to this point in the interview, do not ask direct questions, simply try to understand if the respondent has a strategic vision for DATASUS within the information sector.</td>
<td></td>
</tr>
</tbody>
</table>
4. If the Respondent Addresses More General Considerations

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5. Strengths and Weaknesses; Views of Other Professionals

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</tr>
</thead>
</table>
| Strengths of the DATASUS Health Information sector            | If this has not been made clear yet in the interview, try to find out the respondent’s opinion.  
Make sure you really understood the point (whether it has to do with sectoral policy, the stage of the country’s development, human resources, funding, technological innovation, etc.). |
| Weaknesses of the DATASUS Health Information sector           | If this has not been made clear yet in the interview, try to find out the respondent’s opinion.  
Make sure you really understood the point (whether it has to do with sectoral policy, the stage of the country’s development, human resources, funding, technological innovation, etc.). |
| Impressions regarding the needs and actions of the following:| Bearing in mind the position occupied by the respondent, try to find out:  
♦ How he perceives the needs of his colleagues and the other professionals who use the system.  
♦ What the differences are between use of the information for different purposes (service, decision-making, research).  
♦ How much of a contribution each type of professional has already made and/or can make to improve the system. |
| In-service users                                              |                                                                                 |
| Academic users                                               |                                                                                 |
| Managers                                                     |                                                                                 |
| Councils                                                     |                                                                                 |
**Script for the Interagency Health Information Network (RIPSA)**

Note: In reporting on RIPSA, the respondent may or may not mention other national systems. Note down what he says and the examples he gives. Welcome any publication, brochure, report, or other materials that he wants to share. If he makes any drawing or chart (flowchart, organizational chart, etc.), ask if he can give it to you or try to copy it. In conducting the interview, bear in mind the position that the respondent occupies in RIPSA.

Note: Have in hand a copy of the publication *Indicadores Básicos para a Saúde no Brasil/RIPSA*, (pp. 12-19 – Conceitos and Aplicações) [Basic Health Indicators in Brazil/RIPSA; Concepts and Applications].

| RIPSA became a formal entity under Directive MS/GM 2,390 of 11 December 1996, subsequently updated by Directive MS/GM 820 of 25 June 1997 and Directive MS/GM 443 of 26 April 2000. Its purpose is to promote the effective and timely availability of basic data, indicators, and analyses of health conditions and trends, with a view to perfecting the capacity to formulate, manage, and evaluate relevant public policies and actions. | Try to find out:
- The institutions, groups, and individuals that worked together to create RIPSA.
- Since it was created, what has been RIPSA’s place in the government structure – any agreement or disagreement on this point (Is it in an ideal place?).
- Authority, responsibility and degree of autonomy invested in RIPSA (what it has and what it should have).
- Whether the respondent has an idea how it should function.
- Whether, in general and bearing in mind the resources it has, the Health Information sector has been able to meet its objectives, and in what way may it have fallen short. |
| Composition of the Network: 40 entities, which represent national technical and scientific institutions, agencies, and groups involved in the production and analysis of data (information producers in the strict sense, health system managers, and science and technology groups), which are committed to partnering to perfect information of common interest. | Try to find out, in the opinion of the respondent:
- If there is full understanding of the role of RIPSA on the part of its member systems.
- If all the members attend the general meetings.
- If they all participate in RIPSA activities.
- The degree to which there is real institutional participation.
- How the Ministry of Health has fulfilled its role through its various agencies involved.
- How much participation there has been by large agencies such as the IBGE.
- Any other agencies that should be participating.
- If their participation is specific in nature (for example, for some of the Working Groups and Interagency Workshops, it is more technical in nature, while for others it is more political, etc.).
- Who else should be included. |
Considering the initiatives of other countries in Latin America, the concept of an organization with objectives and a structure such as RIPSA is seen by many to be unique. In the interview, try to find out if this view is unanimous, and if so, what the characteristics of RIPSA that make it so special.

Try to find out what exists today, in concrete terms, that would not exist if RIPSA had not undertaken the actions that it has, whether at the organizational level or in its way of operating, coordinating actions, proposing technical measures (approaches to calculation and standardization, for example), creating forums for debate, etc.

Try to find out if RIPSA is seen to be playing a strategic role in the sense of redirecting the statistical system, promoting cooperation between different agencies, and transforming data into information of use for the health sector and for the country.

Objectives of RIPSA:
- Establish sets of basic data and indicators that are consistent, up to date, comprehensive, and widely available.
- Bring together institutions that work to provide and check data and indicators, and to analyze information.
- Implement supporting mechanisms for improving the production of data and information.
- Promote consensus on concepts, methods, and criteria for the utilization of databases.
- Promote exchanges with other subsystems specialized in information for public administration.
- Contribute to the study of aspects that are relatively unexplored or of recognized importance for understanding the public health picture in Brazil.

Try to find out which of all of RIPSA’s objectives, is producing the best results and why.

Try to find out if RIPSA has contributed, or is in a position to contribute in the future, to improvements or future improvements in the production of data – from collection up to dissemination – in Brazil.

Try to find out about progress that has been made toward having an information network in place that is capable of improving comparisons and planning actions and analysis linked to the occurrence of events.

RIPSA operates through the following commissions or working groups:
- General Coordinating Commission
- Interagency Workshops (OTIs)
- Committees on Interdisciplinary Topics (CTIs)
- Indicator Management Committees (CGIs)
- Technical Secretariat
- An indicator matrix
- Operational Plan for Products (POP)
- Shared database and indicators

Try to find out which the respondent thinks about this manner of operation and the results achieved so far.

Try to find out about proposals for future undertakings.

Try to find out if some of the major issues raised at the national or even the state level should be discussed by the RIPSA working groups.
RIPSA regularly publishes Basic Health Indicators and Data (IDB) for conducting analyses and preparing reports on the health situation and its trends. About 108 indicators have been formulated by the RIPSA working groups, including the following:

- Demographic factors
- Socioeconomic factors
- Mortality
- Morbidity and risk factors
- Resources
- Coverage

**Comments on the IDB:**
- The contribution they have made
- Whether there is follow-up on their use
- Main difficulties that have been overcome
- How disagreements have been handled; consensus mechanisms that have been used.
- What needs to be improved

RIPSA felt the need for an instrument that would provide technical guidelines, and the OTI proposed a form, to be discussed by the member agencies for rating the indicators, which includes the following headings, each of which is defined:

- Definition of the concept
- Interpretation
- Uses
- Limitations
- Sources
- Calculation method
- Suggested categories for analysis
- Statistical data and observations

Try to find out the current status of the indicator ratings proposed by the OTI.

Dissemination of the products developed assumes prior consultation with partners and the protection of intellectual property rights.

Comments about the products developed and the dissemination they have been given.
Access to the data by the general population.