



Description of the National Health Information System in Romania

**Results of a participative evaluation conducted
in June 2003**

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ABSTRACT

This assessment of the National Health Information System (NHIS) in Romania was conducted as part of a project of the WHO Regional Office for Europe. Its goal is to enable a better use of information in decision-making, while holding into account the other factors influencing decisions. The methodology was developed with the authors in June 2003 and is currently being tested in the Czech Republic, Denmark, Hungary and Poland. Semi-structured interviews of key-informants at the highest level, both decision-makers and professionals working in the field of health information, were performed by a Romanian team, with the support of WHO. Special attention was given to the processes taking place at sub-national level. The project aims at building capacities in health information at country level, and serving as a basis for reviewing and strengthening NHIS; as a result, this system could be a better instrument for good governance, responsive to the needs of modern Public Health as expressed by different audiences and initiatives.

Keywords

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Executive summary

Since the profound political changes of the 1990s, the health care system and the health insurance system have gone through a series of successive reforms. Numerous reorientations are still ongoing which deeply influence the structure and functioning of the Health Information System (HIS) struggling to keep up with decreasing staff and increasing requests for data and information. Unfortunately, the difficulties of the HIS only reflect that of the health system.

The Romanian HIS is characterized by the coexistence of a traditional system already in place and a multitude of new information flows which emerged to meet the specific needs of the health care reform implementation. This system collects an oversized volume of data, while being rather unresponsive to modern Public Health information needs. However, only a small fraction of the data is actually used for decision-making and for the evaluation of the health system performance. There is no information flow 'downwards', for instance in the form of feed-back to data producers.

Presently, the health information system in Romania consists of three parallel sub-systems:

- The first, led by the Ministry of Health and the National Institute of Statistics, which represents the formal statistical system;
- The second, led by National Health Insurance House, focusing on the monitoring of expenditures for the delivery of health services;
- The third containing a multitude of smaller information channels linked to national health programmes that are practically independent from one another. Each of these circuits is coordinated by a different institution or facility, depending on the purpose of each programme.

There is a high degree of data fragmentation with communication between and within the three sub-systems minimal or even nonexistent. Each of the leading institutions exerts exclusivity over their data which are accessible only for a fee. Software, formats, definitions, standards and supports used for reporting are different both between and within sub-systems. Repeated changes of software complicate data storage and processing. The reporting periodicity varies between sub-systems. Electronic reporting and transmission is non-existent. Data producers – hospitals, family physicians and departments from the District Public Health Directorate – have to comply with double or triple reporting in formats and software which are not compatible.

In terms of content, even though data are collected on health status and 'positive' topics such as wellbeing, in practice only data on diseases are analysed and processed into information. Data and information on the causes of disease are scarce and incomplete, in particular for chronic diseases. Routine data on lifestyles and health determinants are not collected, or very irregularly. Data are already aggregated at district level; access to disaggregated or individual data is difficult, for instance concerning providers' activity and costs per activity, where there is no possibility of obtaining individual data.

There are no organized quality control and quality assurance mechanisms. Data is often inappropriate, insufficiently processed and utilized, sometimes even breaking confidentiality regulations.

The lack of targeted analysis and objective-oriented interpretation of the data are among the weakest points of the HIS. Public health reports are still constructed around the production of traditional lengthy statistical tables on a limited number of topics compared to the bulk of data which is collected, with no multivariate analysis, insufficient construction of indicators, and no

dissemination plan. The range of information products is extremely limited, with poor presentation of the data.

At all levels, the Romanian HIS suffers from a shortage of qualified professionals. Recruiting and retaining skilled specialists is difficult, due to unattractive remuneration and obsolete data collection methods. This results in a loss of motivation and interest in the work. The lack of purpose for data collection, in conjunction with the lack of feed-back, leads to poor data quality. Much of the HIS relies heavily on data provided by primary care providers, which are especially at risk of losing interest: the large share of their time dedicated to filling forms distracts them from their main responsibility of patient care, and they have limited power for decision-making whatever the data indicate.

However, the Romanian system retains the following strengths:

- It reflects the advances in the health system reform, with new information flows and reporting created towards the National Health Insurance House and the national health programmes in order to meet new needs;
- There is a strong tradition of reporting, with the necessary infrastructure already in place for generating, transmitting and processing the data and time series available over 50 years;
- Some of the main demographic and health indicators are based on standardized formats which allow comparability over time and space;
- The richness of the data and information which could potentially be used to support decision-making, although decisions in health policy are often taken on the basis of criteria other than data.

1. Context of the WHO/EURO project

Health Information is essential to good governance. As such, the HIS has a central function in the health system of a country¹. Decision-makers use information at facility level, district level and national level, in order to design and monitor policies, to evaluate the impact of interventions, and to choose budget priorities for the delivery of services. Advocacy groups, donors, researchers, and media reporters are also increasingly interested in accurate and reliable data on health issues. These different users may have conflicting needs.

The Division of Health Information, Evidence and Communication at WHO/EURO started a project in 2003 aimed at assessing and strengthening the HIS in Member States by using an agreed methodology. Understanding the system better will enable WHO and other intergovernmental agencies to identify countries' needs for support in health information, and to advise them on the best solutions to improve the quality and relevance of the data they produce.

The **objectives** of the project are:

1. To describe the NHIS, including the flow of data, the links between the different institutions dealing with health data and information, and the legislation in this area;
2. To define the current and potential users of health information and the means to disseminate health information to them in a meaningful manner;
3. To identify gaps and problems (duplication, delays, etc.) in the production, validation, analysis, interpretation and/or dissemination phases, with attention to the national and district levels;
4. To recommend solutions to strengthen the NHIS, as well as the network of public health institutions and health decision-makers interested in health information.

This approach is based on **building capacities** in the country itself, by having a local team responsible for conducting the project in the country with WHO/EURO's help and support. This should **empower** the local health professionals to implement appropriate changes. The **exchange of experiences across countries** is also a strong focus of the project.

2. Methods

Individual semi-structured interviews were conducted in Romanian with 26 key-informants (Annex 1). They lasted 60 to 90 minutes, and all but three took place at the Institute of Public Health in Bucharest. WHO advisers participated in 20 interviews during a three-day visit. The confidentiality of individual responses was ensured to the interviewees at all stages of the process (no taping, no individual quotations in the reports). The key-informants represented the

¹ The Health Information System is a dynamic and flexible infrastructure for the monitoring of health activities, active at the national or sub-national level, comprising the persons, values, legislation, inter-institutional relationships, technology and standards for the collection, processing, storage, transmission, display, dissemination, and access of information from complementary sources for use, analysis, interpretation and sharing by all professional and lay users within and outside the health sector

The Health System "consists of all people and actions whose primary purpose is to promote, improve, restore or maintain health" (World Health Report 2000). The Health Information System is a component of the Health System, along with curative, preventive and palliative health services; pharmaceuticals; home care; and public health activities (such as health promotion and disease prevention, environment and safety improvement). The Health *Care* System is therefore a narrower concept than the Health System.

main organizations, which are producers or users of health information, at national and district levels, as well as inside and outside the health system. Special efforts were made to include decision-makers at the highest possible level.

A questionnaire has been developed on the basis of a WHO proposal covering:

- a description of the mission of the institution;
- the flow of data and information during the phases of collection, processing, analysis and dissemination to users;
- the quality control and quality assurance procedures;
- the legislative framework of health data or information;
- the use of data and information in support of policy and decision-making;
- the use of the databases and information produced by WHO and other international institutions or organizations.

Information from the interviews was complemented by a review of official documents and legislative texts.

3. The health system

The health system in Romania after the Second World War was a Semashko model of State-financed health system. Its characteristics were the following: the necessary funds for all activities within the health system were provided entirely by the State, which was the exclusive owner of all material resources; the health services for the whole population were delivered by the State. This system was based on the principles of centralized planning, rigid management and State monopoly. Thus, the health care system created by the Ministry of Health was integrated, centralized, State-controlled through taxes and with limited freedom of option, although accessible to all.

The process of reform of the health system in Romania started in 1990. The problems of the health system were identified through a diagnostic study funded and developed by the World Bank (150 million US\$) in the framework of the project “Healthy Romania” during 1992 and 1993. This study made a number of recommendations:

- the creation of an independent, decentralized and self-administrated national public health insurance fund;
- the creation of alternative private health insurance funds;
- the decentralization of the health services;
- the shift of emphasis towards the primary health services;
- the autonomy of the hospitals in utilization of the resources;
- the development and implementation of an accreditation system for health care providers, both institutions and staff.

As a result of this proposal, the transition towards a social health insurance system, more decentralized, pluralistic and with contractual relationships between the insurance Funds and health services providers, began in 1994.

Presently, the right to health care in Romania is guaranteed by the Constitution. The Law No. 145/1999 **On Social Health Insurance** was passed on 1 January 1999. The principles of the health system based on social insurance are solidarity, the freedom of choice of services provider by

the insured, the competition between providers, the quality assurance of the services, the respect of the patient and the guarantee of the confidentiality of the medical examination.

This law stipulates the establishment of the Social Health Insurance Fund, fed by the contributions of the insured persons and physical or legal bodies that employ paid staff, by subventions from the State's budget as well as the local budgets, and by other sources. The National Health Insurance House that distributes the funds collected to all District Health Insurance Houses administrates the Social Health Insurance Fund.

The White Chart of Governance (December 2000) stipulates the following strategic objectives of the reform:

- Unifying the legislative and organizational framework;
- Implementing the social health insurance system;
- Decentralizing the health system, by strengthening the role of local authorities, professional associations, financing institutions, communities, etc.;
- Diversifying the mechanisms of financial resources generation;
- Paying services based on efficiency and quality of medical performance;
- Improving the accessibility of health care services;
- Shifting the emphasis from hospital care to ambulatory services;
- Improving the quality of health care services;
- Stimulating the privatization;
- Introducing the competition between providers.

The White Chart also specifies the following principles for health policy:

- Equity assurance in access to health care services;
- Universal health services coverage of all individuals;
- Solidarity in services financing;
- Stimulation of the provision of efficient and effective health services;
- Provision of health services adapted to the needs;
- Health professional autonomy;
- Collaboration of health care services with other sectors that influence upon the health status.

The implementation of the health system reform has undergone different rhythms: advances, stagnation, regression, resets and restarts. The political changes, following elections have reflected into the way of implementing the health system reform. The inconsistency in health system reforming has lead to the present crisis of the system, which is the greatest and the deepest crisis experienced by the Romanian health system.

4. The health information system

The White Chart of Governance defines the information system as the main provider of information in support of decision-making in health policy at both central and local levels as well as for result evaluation. In the last years, as a result of the reform in the health care system, a number of hierarchical structures and actors have emerged: the Ministry of Health with its subordinated institutions, the National Health Insurance House, hospitals, private medical offices, Institutes of Public Health, Institutes of Medical Research and Education. Each of these institutions owns a more or less complex information system over which it has exclusivity. The

consequences are double reporting, as well as incoherence of some definitions and coding. For example, the format in which data are requested by the District Health Insurance Houses does not consider the current national regulations and WHO requests, thus, the same indicator reported through two different channels will have two different values. Lately, some measures have been taken in order to correct this situation. *These measures need further reinforcement through tight and permanent regulations, possibly in the shape of a standardization institution, common to the Ministry of Health, the National Institute of Statistics, the National Health Insurance House, the College of Physicians of Romania and other interested parties.*

The implementation of an efficient HIS is a necessary, beneficial and obligatory process. Since 1990, the development of an information system in reporting and processing of health related data at national and district level has been a matter of permanent concern.

In this regard, the Ministry of Health has been the beneficiary of "Healthy Romania Project" funded by the World Bank. Some 250 servers, 750 workstations and other equipment were installed in all districts, during 1998 and 1999. One first important result of the project was the improvement of communications through Internet connections and e-mail facilities. Direct lines between the Ministry of Health and the National Centre for Health Statistics and between the Ministry of Health and each District Health Insurance Houses were established. The web page of the Ministry of Health has been constructed and it represents an important source of legislative and statistical information as well as other important information of public interest. Software for databases, resources management and other medical software have been produced and installed in the Ministry of Health, National Centre of Health Statistics and Public Health Directorates from Neamt District. The implementation of information system projects has taken place under difficult and complex conditions because 1998 and 1999 were transition years for the health system in Romania, involving a multitude of major changes in the organization and functioning of the system, as for example the development of the health insurance system or restructuring of the local public health authorities at district level.

At the same time, other pilot projects of HIS in hospitals and outpatient departments have been developed within the framework of health programs funded from national and international sources. Presently, these projects need evaluation. Many Information Technology (IT) specialists and other information professionals, already trained in using the new software, have left their positions for better remunerated ones, which led, together with the repeated reductions of the staff, to serious deficiencies in implementing the HIS, as shown in the White Chart.

At the end of 2000, other important projects were carried out: the Information System of Health Insurance (still not finalized), as well as HIS for other areas of health care such as health care units, professional associations, educational institutions, research, providers, etc. These information systems have different functions and different owners of the equipment, software and data, therefore different responsible persons are exploiting and maintaining the applications. *The development of protocols for common use of standards and databases interfaces for two-way transition is necessary in order to prevent inconsistencies in reporting, the losses of data sources and multiple requests of the same data. There is also a need for a concerted action to develop a strategy for the HIS and for the establishment of permanent working groups for standardization.*

The HIS should be harmonized with the strategies of national information system and with the regulations issued by the National Institute of Statistics, by the Ministry of Communications and IT as well as by the other international organizations with which there is a permanent data exchange.

At the beginning of 2004, the Ministry of Health, together with the Ministry of Communications and IT, will initiate a unitary information system, “Health Insurance House – Providers – District Public Health Directorate”, which will be finalized with the introduction of the “health card” and the “unique identification of the insured”. This will constitute a powerful information system, which will allow a clearer picture of the health system.

5. Legislative framework

5.1. The legislation in the context of the health system reform

The fluctuations in the implementation of the health system reform had a reflection on the legislation. Each electoral mandate has resulted in modifications of the legislation. As a result, an excessive number of legislative papers (laws, government decisions and orders of the minister) are issued and repeatedly and subsequently amended. For example, in the field of health, 37 legislative papers were issued during 2000, 81 papers in 2001 and 106 in 2002.

The legislation has supported the Government and the Ministry’s health policy objectives, which are stipulated in the governmental strategy. In order to shorten the period of time between the generation of a law proposal and the actual adoption, many regulations are applied through ordinances, emergency ordinances of the Government or by orders of the Ministry of Health.

During the last years, special attention has been paid to the harmonization of the Romanian health legislation to the European Union (EU) legislation in the light of Romania’s accession to the EU.

The main areas of legislation covered are:

- The implementation of the health insurance system;
- The establishment of the institutions' roles, functions and relations in the health system, within the EU accession context;
- The management of the National Statistical Data Fund, including the health system data fund.

The list of general and specific legislation on information system (Annex 2), including the HIS, is not exhaustive. It only comprises the most recent and relevant legislative papers that coordinate the activities related to information flow within the health system or related to the health system.

The legislation contains a number of general principles applicable to the management of any type of data, including health data.

5.2. General principles stipulated in the legislation

- Responsibilities of the State institutions in the collection, storage and analysis of data on health determinants with the objective of creating the national database;
- Definition of the information flow;
- Guarantee and protection of the fundamental rights of individuals;
- Necessity of data security assurance;
- Definition of the areas and the conditions of data processing and data use;
- Accessibility of the decision-makers to existent data and information;
- Patient confidentiality;
- Data confidentiality;

- Right of the person, patient and population to both general and health-related information;
- Regulations concerning specific diseases that represent a public health problem.

Strengths

- The legislation is published in the Official Gazette ("Monitorul Oficial" – the official publication of the Romanian Parliament) and is enforced either immediately after the date of publication or after a well-defined length of time. Thus, the legislation is made available to the community, both to juridical bodies and individuals. The legislative papers referring to the health area are published on the Internet, some on the Ministry of Health's site with a delay of 2 – 4 months, others on the Internet pages of some public or private institutions;
- Romania is in the process of harmonization to the EU legislation. Where legislative papers and standards are concerned, the WHO recommendations are followed;
- The statement of general principles to be respected in data management;
- The mention of the organizations and institutions involved in health related data and information management and the relations between them;
- The general principles stipulated in the legislation on data and information are in conformity with international legislation in the field.

Weaknesses

- The large number of legislative papers with repeated subsequent modifications;
- The lack of control and of quality assurance mechanisms;
- Excessive precaution in law enforcement, particularly in the sense of limitation of access to health data and information for the professionals;
- Conflicts between confidentiality requirements and the general practitioner's obligation to report their activities;
- The methodological norms for the application of law are published with a long delay;
- Anything that is not in a law is not done (overemphasis of the legislative drive of action).

6. Participants in the health information system

6.1. Main organizations inside the health system

The organizations participating in the data and information exchange were identified based on the analysis of the legislation as well as information flow of health data and information. Part of these organizations are subordinated, coordinated or under the authority of the Ministry of Health. Also, some other participants in the information exchange, pertaining to the network of other ministries (e.g. Ministry of Justice, Ministry of Administration and Internal Affairs, Ministry of National Defence, etc.) belong to the health system, but they are independent from the Ministry of Health. The main organizations in health information flow are the following:

The Ministry of Health itself (formerly *Ministry of Health and Family* from January 2000 to June 2003) is an active participant in the exchange of health information. Its mission is to implement the governmental strategy and policy in the fields of health assurance and health care reforms. The attributions of the Ministry of Health in the area of health information are to organize the information systems in health care, in public health, and in data reporting from the medical units for the assessment of the population health status, to analyze and evaluate periodically the health status indicators and the medical units performance criteria and to deliver

periodical reports on health status of the population to the government. ***The General Direction of Health Care*** coordinates the entire health care activity: emergency, curative, rehabilitation, occupational, delivered through both public and private units, as well as sportive health care and forensic medicine. This direction coordinates the health programmes in the field. There is a separate team that deals with maternal and child health. ***The General Direction of Public Health and State Sanitary Inspection*** coordinates and exerts control over the public health activities, health promotion and preventive medicine. This direction coordinates the public health programmes in the field. ***The General Direction of Budget and Acquisition*** establishes the grounds for necessary financial resources for population health care and supervises their utilization.

A. Institutions subordinated, under the authority or coordinated by the Ministry of Health

1. ***National Centre for Health Statistics (NCHS)***'s main attribution is the organization of the information system for health care activities, the elaboration of indicators to evaluate the health status of the population, the efficiency of medical network activity and the provision of technical and methodological assistance to the statistical departments at district level. The NCHS develops the primary recording system and supervises in the field the health statistical activity executed by the District Public Health Directorates and by different medical units in data collection, control, storage and transmission. If needed, the NCHS designs and develops studies in the areas of demography, performance assessment, needs in health care technology and primary prevention. At the same time, it is responsible for the training of the staff working in the statistical offices of the District Public Health Directorates and in hospitals. The NCHS writes regular reports on the main aspects of the population health status and sends them to the decision-makers. NCHS is directly subordinated to the Ministry of Health. It routinely exchanges information with all the District Public Health Directorates, the National Institute of Statistics, the National Health Insurance House, the College of Physicians from Romania and collaborates with international institutions such as WHO, UNICEF and the EU.
2. ***District Public Health Directorate (DPHD)***. The Public Health Directorates of the 41 districts and of Bucharest Municipality are decentralized units of the Ministry of Health. They represent the public health authority at local level. They implement the strategy of the Ministry of Health, i.e. the national policies and public health programmes, the activities of preventive medicine and sanitary state inspections, the monitoring of the health status and organization of health statistics, as well as the planning and development of financial investments from the State budget in the health sector. They organize the statistical information collection and processing and write the reports delivered to the Ministry of Health and to the local authorities. The Office of Statistics of the DPHD organizes the database at district level, checks and encodes the data for entry to the database. It participates in implementing the information system in the hospitals and other medical units. The Office of Statistics from DPHD is methodologically subordinated to the Ministry of Health and to the National Centre for Health Statistics.
3. ***Institutes and Centres of Public Health*** ensure the scientific grounds for the health policy and for the strategies in the area of prevention, promoting and preserving health. They develop public health studies, elaborate norms and methodologies, produce reports and coordinate some of the public health programmes ([Annex 3](#)).
4. ***Medical Health Care Institutes*** ([Annex 3](#)) are medical inpatient units of public utility. They are legal entities and public institutions providing tertiary health care services (preventive, curative and recovery). They also perform the methodological coordination and the national implementation of the health programmes, which include monitoring certain categories of

patients, screening activities and the development of national and/or local registries for the diseases identified as public health problems.

5. ***National Health Insurance House (NHIH)*** is an autonomous public institution of national interest. It is a legal entity that assures the unitary functioning of the social health insurance system throughout Romania. NHIH is coordinated by the Ministry of Health who manages and administrates the social health insurance system in order to implement its health policies and programmes. The president of the NHIH is a State secretary at the Ministry of Health. The NHIH establishes the general strategy of the health care system, administrates and exerts control together with its territorial health insurance houses, over the use of social health insurance funds. In the field of information, the NHIH ensures the organization and functioning of the unitary and integrated information system to record the insured persons and for the administration of the social health insurance fund. The Ministry of Health establishes the reporting indicators regarding the activity and health status based on proposals from the NHIH and the College of Physicians. The NHIH also consults the College of Pharmacists and the Order of Nurses. It coordinates the District Health Insurance Houses, the Health Insurance House of Bucharest Municipality, and the two separate Health Insurance Houses of the Ministry of Public Work, Transports and Housing, and of Defence, Public Security, National Security and Magistrates. The NHIH comprises Health Insurance Houses of the 42 districts.
6. ***District Health Insurance House (DHIH)*** is a public institution. It is a legal entity with its own budget subordinated to NHIH. DHIH collects the contributions and manages the approved budget, assuring the functioning of the social health insurance system at local level. The attributions in the field of information ensure the organization of unique, integrated information system for recording the insured persons and for management and administration of the social insurance fund at district level. It has the right to develop, according to its own problems, needs and interests, its procedures of data collection and reporting. DHIH collaborates with all other DHIH, District Colleges of Physicians, Pharmacists and Order of Nurses and has contractual relationships with all health services providers.
7. ***National Institutes of Research-Development*** conduct scientific research, technological development, consultancy, methodological coordination and continuous medical education.

B. Health care services and products providers that have contractual relationships with DHIH

1. ***Hospitals*** are medical units with beds, of public utility. They are public or legal private facilities providing health care services (preventive, curative, recovery and palliative). Optionally, specialized ambulatory care may be offered within the hospital's structure. The hospital has contractual relationships with the DHIH, respectively with the Health Insurance House of Bucharest Municipality or with the two independent Health Insurance Houses. At the same time, the hospital is subordinated to both the District Public Health Directorate and the Ministry of Health. Some aspects of the hospital functioning also subordinate the hospital to the local authority, the City Hall.
2. ***Outpatient departments, ambulatory care departments or diagnostic centres*** are units with or without legal entity. They are private or public units providing preventive, curative, recovery and emergency specialized health care services. They are either integrated within the hospital's structure or independent units.
3. ***Medical offices*** are units with or without legal entity. They are private or public units providing preventive, curative, recovery and emergency health care services. The health care services are delivered by general practitioners, family physicians, specialized physicians and

other types of personnel, both medical and non-medical (biologists, chemists, psychologists, physicists, etc.).

4. **Family physicians** are graduates of Medical Faculties, accredited and authorized to deliver health care within primary health services for the patients enrolled on their lists. They have annual contracts with the District Health Insurance House, which stipulate the obligation of transmitting data and information to the District Public Health Directorate (**Framework contract in the primary health care for 2003**, article 1, paragraph 1, letters “n” and “o”). Family physicians collaborate with other health care providers also contracted by the Health Insurance House, such as specialized outpatient departments, hospitals, laboratories, etc. They receive methodological assistance by the College of Physicians.
5. **Pharmacies**, with or without legal entity, provide public or private pharmaceutical services.

C. Independent organizations

1. **College of Physicians**. This professional association has as main objective the safeguarding, control and surveillance of the practice of the medical profession, as well as the enforcement of the laws and regulations pertaining to the professional exercise.
2. **College of Pharmacists** is the equivalent association for pharmacists, with similar attributions.
3. **Order of Nurses** is the equivalent association for nurses, with similar attributions.
4. **Two Health Insurance Houses** are independent of the Ministry of Health: one for the Ministry of Public Work, Transports and Housing, and the second one, for the employees of Defence, Public Security, National Security and Magistrates. Their position is similar to a District Health Insurance House.

6.2. Main organizations outside the health system

1. **National Institute of Statistics (NIS)** is the specialized organism of the central public administration, with direct subordination to the government and financed through the state budget. It is the organizer and the coordinator of the national statistical data and it is authorized to establish the system of statistical indicators in every domain, terminology, classifications, methodologies and technologies in order to obtain fully objective data and statistical research assurance. The attributions of the National Institute of Statistics include: the organization and coordination of the data collection (process, analysis, and dissemination), the development and updating the demographic, economic, legislative and financial national datasets, the development and maintenance of the national statistical database, the production of specific statistical tools and the exploitation of the statistical information system, the interpretation and dissemination of statistical studies and analyses to the general public and to public authorities, and the coordination of statistical research, especially on the social and economic situation. The NIS coordinates the statistical activities of all data producers, the centres and statistical offices, for the development of national data fund. At the same time, the NIS cooperates with all Ministries, central institutions, bodies and agencies in developing the national statistical information system and cooperates with other national statistical institutions in order to develop a sustainable statistical system and to assure the comparability of statistical data with other countries and the EU.
2. **Ministry of Agriculture, Forests, Waters and Environment** organizes the activities of integrated monitoring of the environment; elaborates and publishes information and reports on environment status, establishes the pollution factors, develops and assures the standards for agricultural and alimentary products and food safety. It also develops specific indicators for the national statistics in the field, in collaboration with the National Institute of Statistics.

3. **Ministry of Labour, Social Solidarity and Family** develops the methodologies, norms, standards and indicators concerning workplaces safety and security. It develops the prevention policies in the fields of safety and security in relation with occupational risk factors develops the strategies for workplace injuries and occupational diseases prevention, elaborates and develops the information system in the fields of labour, social solidarity and family policies.
4. **Ministry of Transport, Constructions and Tourism** organizes the activity for developing its own statistical data in the field of transports, housing, building and tourism, thus participating in the national and international information system.
5. **Institute of Quality of Life** performs studies and research in the field of social sciences. It elaborates the instruments for the diagnosis of quality of life, poverty and social development, and analyses social policies: anti-poverty, housing, rural development and in the field of education.

6.3. International organizations interested in the health information

Health data and information are produced and/or used by a number of international organizations, which provide technical assistance and financial support in studies and surveys comprising population health:

1. **WHO Liaison Office** - Romania's collaboration with WHO started in June 1948. Since 1990, the EUROHEALTH programme has formed the basis for WHO's collaboration with the Romanian Ministry of Health. It aims at supporting the national efforts towards health development and sustainability in line with the European HEALTH 21 strategy. Collaborative agreements between EURO and Ministry of Health were established according to the priority areas identified at country level for which the Ministry requested EURO's support. For the period of 2002–2003, a Biennial Collaborative Agreement for "Mother and child health", "Communicable diseases", "Mental Health", "Drug abuse", and "Health technology and pharmaceuticals" has been agreed and carried out. Other programmes and activities carried out through WHO Liaison Office in Romania include: Child and adolescent health and development, Food safety, Health impact assessment methods and strategies, Mental Health, The European Observatory on Health Systems and Policies, Pharmaceuticals and Water and Sanitation.
2. **The World Bank**, present in Romania since 1991, has a portfolio of 30 projects (21 are ongoing). Through its loans, technical assistance, and policy consultancy, the Bank supports a number of programmes that aim at reducing poverty, improving living conditions, strengthening the social security network, increasing the investments in health, education and rural development, protecting the environment, supporting structural reforms, increasing the efficiency of the legislative system and of the public administration.
3. **United States Agency for International Development (USAID)** – the American governmental agency implements in Romania a programme centred on the development of the private sector, democratic governance and health since 1990. The health programmes aiming at child welfare and maternal health have the objectives of decreasing the number of institutionalized children and increasing the access to integrated services of better quality.
4. **United Nations Children's Fund (UNICEF)** – the representative office for Romania and Moldova has been active in Bucharest since 1991. The national programme 2000–2004 for Romania has three components: child protection, maternal and child health and education for health. This programme reflects UNICEF's global mission: developing better conditions in which all children,

including the most vulnerable and marginalized ones, can grow in a safe environment that can meet all their developmental needs in full accordance with their rights.

The general organizational chart of the participating actors in the health-related data and information is presented in Figure 1. Two grouping criteria are used:

- The level: national, sub-national and local (the sources of primary data).
- Their position in relation to the health system: inside or outside.

Figure 1: Organizational chart of health information flow

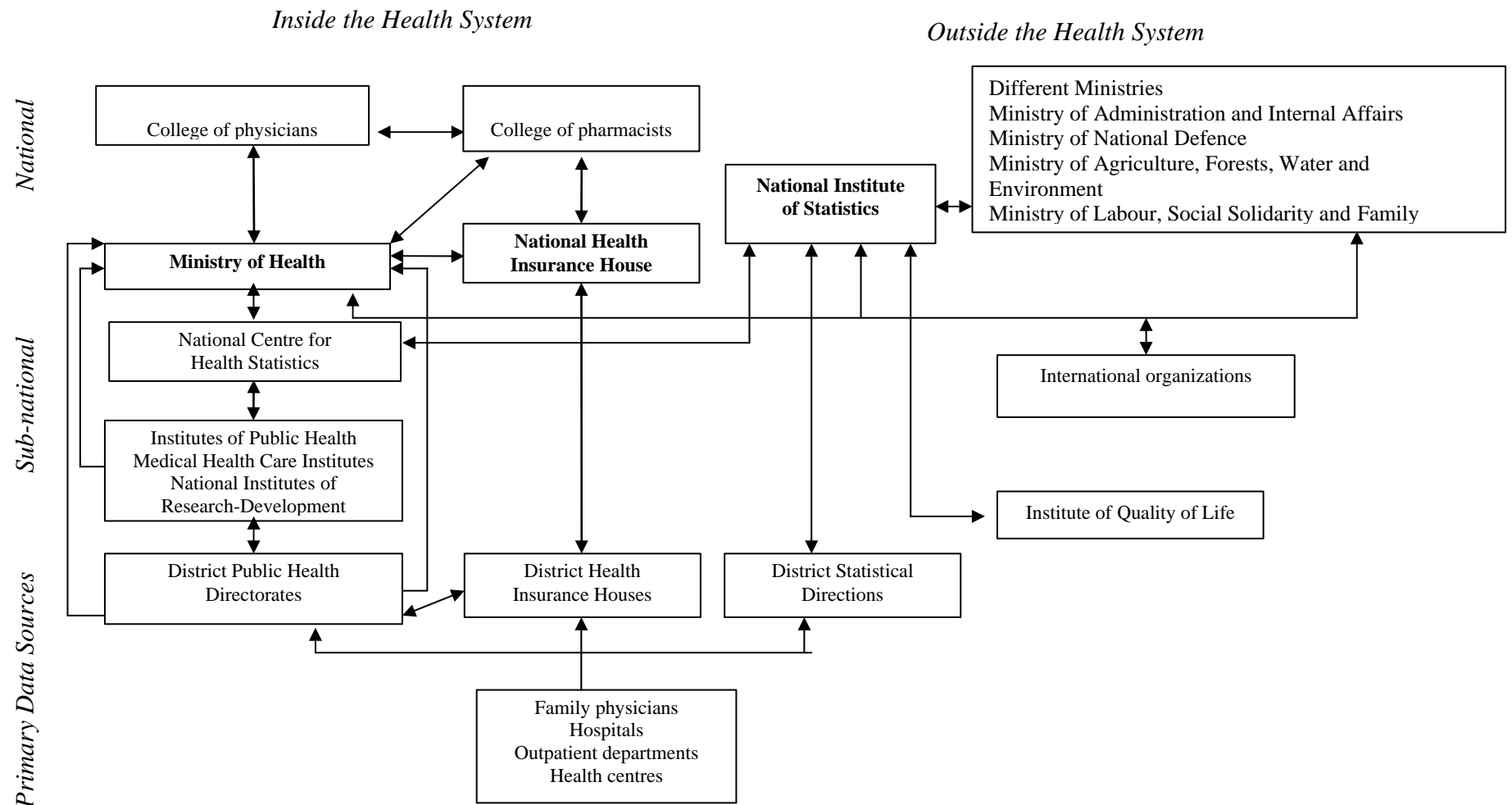


Table 1: Health data and information sources

Type of data	Primary data source	Intermediary destination	Final destination
Routine data	Health care providers from health system	District Public Health Directorates District Statistical Directions District Health Insurance Houses	Ministry of Health National Health Insurance House National Institute of Statistics
Data and information for monitoring and evaluation of national health programmes and sub-programmes	Health care providers from health system involved in the National Health Programmes	District Public Health Directorates District Health Insurance Houses	Ministry of Health National Health Insurance House Institutes of Public Health and Medical Health Care Institutes that are national programmes coordinators
Surveys and special studies	Various national and international organizations	-	Ministry of Health National Health Insurance House National Institute of Statistics

7. Data and information sources

The data and information related to health and its determinants are produced from three main sources (Table 1):

1. ***Routine data collection from the NHIS.*** This channel has a specific component for the health sector and a component outside of the health sector. Data are provided systematically, in most of the cases on traditional statistical format and at pre-determined intervals of time. The data flow to the National Institute of Statistics and to the National Centre for Health Statistics is carried out in conformity with the Ordinance of Government of Romania No.9/1992 **On organization of the official statistics** (Annex 3).

For the health sector, the primary data sources are:

- Providers of health services (family physicians, hospitals, diagnostic centres, institutes, etc.) under their contract with health insurance houses.
- Institutions and organizations which provide health services but are directly subordinated to the Ministry of Health. Some of these also hold a contract with the health insurance houses.

These providers send specific data and information in a larger amount and in a much more detailed way than requested by the National Institute of Statistics. The National Centre for Health Statistics and National Health Insurance House are using these data to evaluate the performance of various health organizations, for resources allocation and for the identification of health problems. Some other data are passively reported based only on historical tradition.

2. ***Data and information for the monitoring and evaluation of national health programmes and sub-programmes.*** This type of data production is specific to the health sector. In this case, the data and information are reported at different time intervals (monthly, quarterly or annually) as specified through orders of the Minister or methodological norms. Through this channel, the data are supplied by health services providers to the National Centre for Health Statistics, to the Institutes of Public Health involved into national health programmes and to the District Health Insurance Houses.
3. ***Ad hoc surveys and special studies.*** This type of data production is common to all sectors. These activities are developed without a pre-determined periodicity. The subjects of these activities are determined by the needs or interests of various beneficiaries. In these situations, standard formats are rarely used.

8. The flow of routine data and information within the health system

Data and information generated within the health system resulting from the first two sources above are currently structured in three relatively independent flows. These flows are:

1. ***Information flow to the Ministry of Health.*** This first circuit (presented in Figure 2) belongs to the Ministry of Health and District Public Health Directorates, which took over the old system and collects data at district level.
2. ***Information flow to the National Health Insurance House.*** This second circuit belongs to the National Health Insurance House. It was created to meet mainly the needs of health insurance houses. It is primarily centred on the evaluation of providers' activity.

3. ***Information flow towards national health programmes managed by the Ministry of Health*** represents the third circuit. The Law 100/1998 **On public health assistance**, through introduction of financing system based on national health programmes, has lead to the creation of this third information flow needed to monitor the national health programmes and sub-programmes.

The following detailed description of each information flow presents the main institutions which receive, process and report on health data. The primary sources of data (family physicians, outpatient departments and hospitals) are presented in a separate chapter, as they are common to all three information flows.

8.1. Information flow to the Ministry of Health

The present HIS has been in place for 50 years. Until the Law of social health insurance became effective in 1999, the health information flow has functioned on territorial principle. Each medical unit had a specific assigned territory and was providing health care services for residents of that territory.

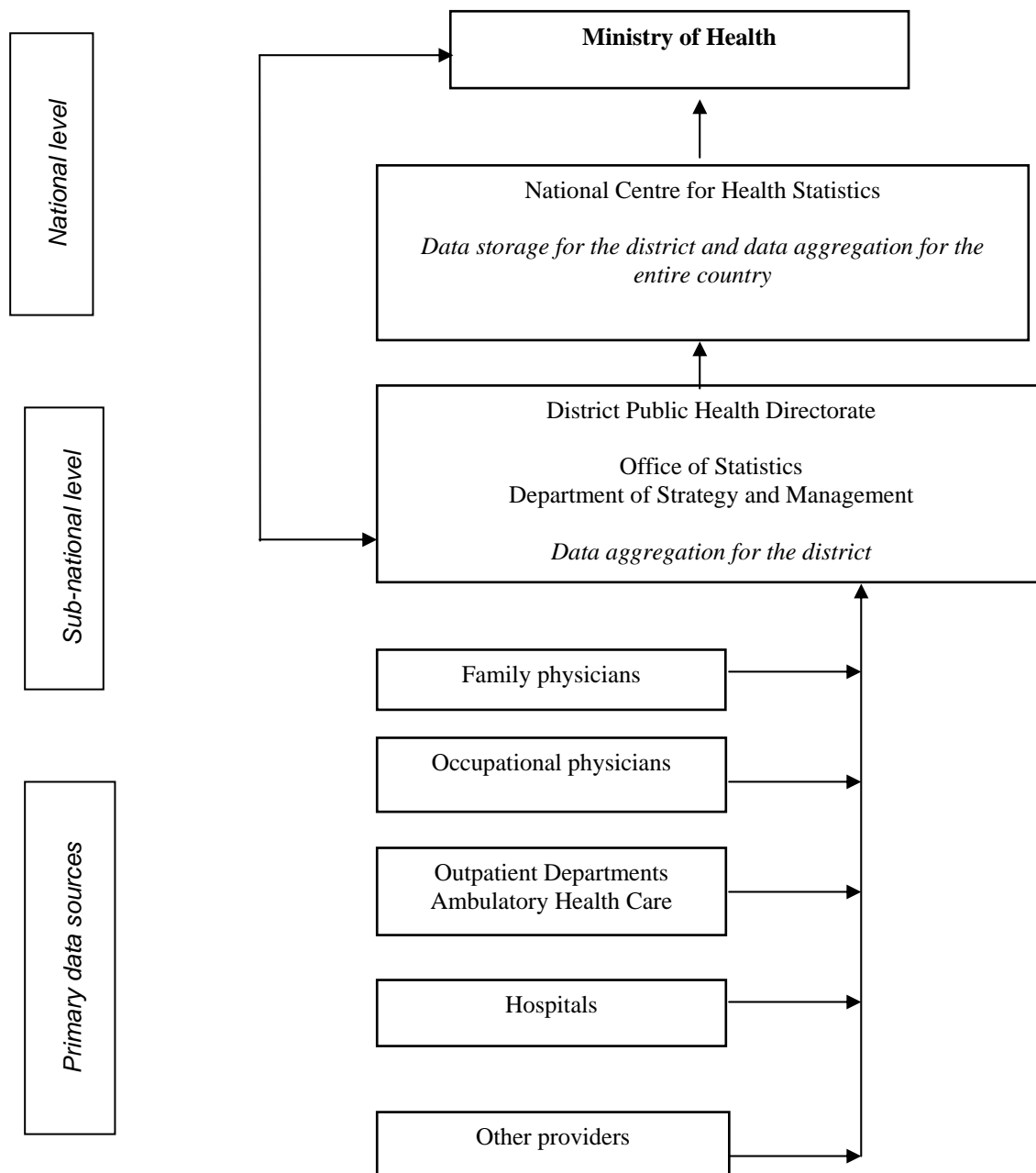
The District Public Health Directorates collect data and information from all providers of health care services which have an agreement with the District Health Insurance Houses. According to the Law of social health insurance, all patients registered on family physicians lists, regardless of their place of residence, receive health care, as well as contracted specialized institutions (outpatient department and units with beds). Thus, the territoriality principle is discontinued. Therefore, clear data are available on a population that receives medical care at the family physician level but also, after adjustments, on the whole population at district level.

The information flow towards the Ministry of Health is a centralized system, having pyramidal design and with pronounced directive characteristics (Figure 2).

Strengths

- Availability of long time series;
- Richness of data and information;
- Comparability in space and time due to consistent templates over the last 40 years;
- Existence of a reporting tradition;
- Presence of the infrastructure with trained personnel and pre-existent channels of transmission.

Figure 2: The main information flow led by Ministry of Health



Weaknesses

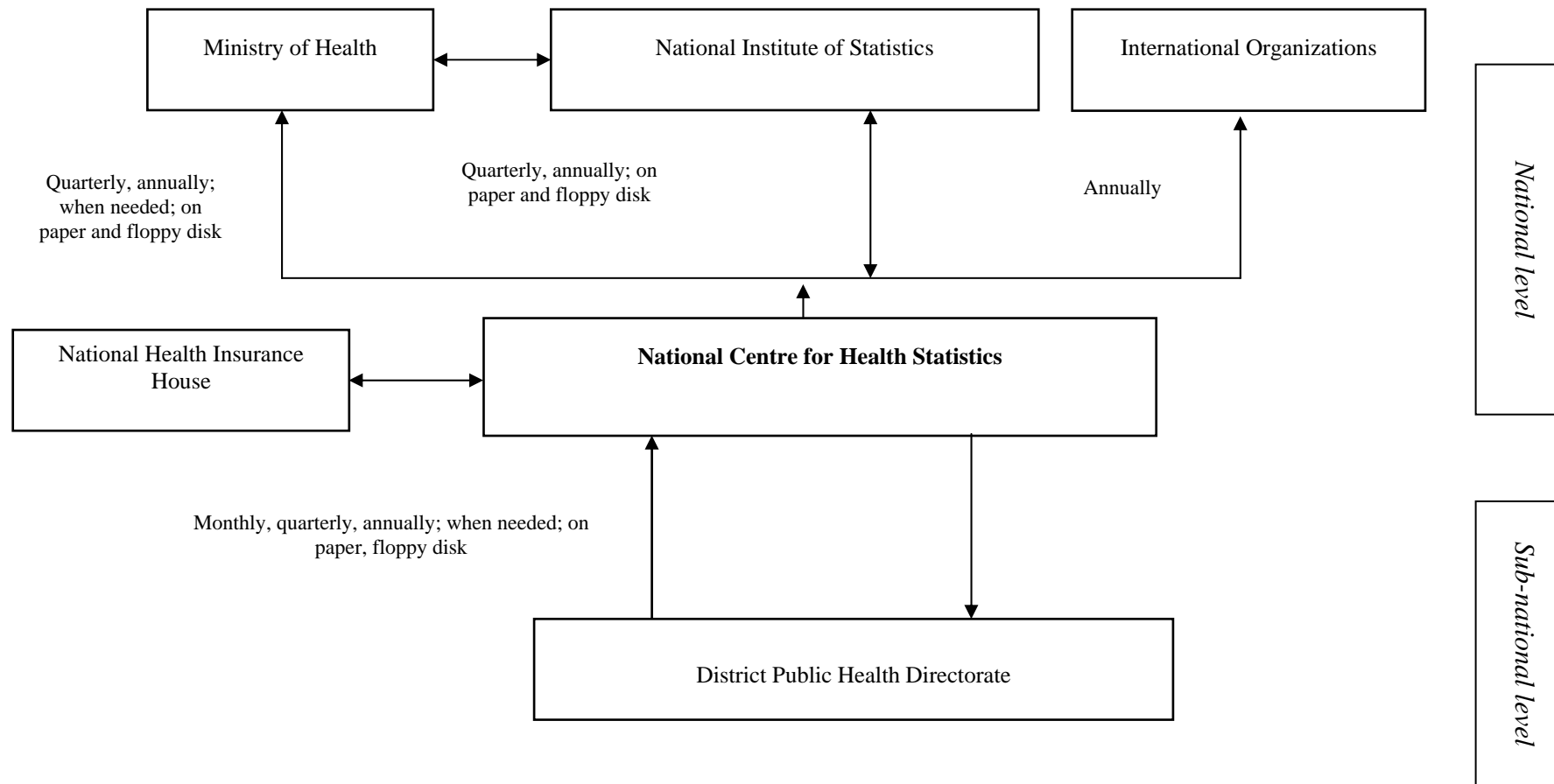
- Lack of standard definitions (except the definitions of demographic events and case definitions for some communicable diseases);
- Aggregation at district level;
- Lack of quality control and quality assurance mechanisms;
- Complete lack of standards to allow comparability and compatibility with other data;
- Reporting on paper and floppy disk;
- Absence of a national electronic network for data and information transmission;
- One-way circulation of data and information only: from source to the centre. Local centres do not have access to non-aggregated data from the system (lack of feed-back);
- Low degree of data processing;
- Potential risk of generating and circulating discordant or unreliable data (lack of validity);
- Under-estimation of certain diseases. Examples are provided in Annex 4.

The National Centre for Health Statistics (NCHS) is the main contributor to the information flow to the Ministry of Health. It receives routine data and information from all District Public Health Directorates and the Public Health Directorate of Bucharest Municipality (Figure 3). Data and information are received on paper, floppy disk and e-mail. The templates are standardized; some of them were updated after 1990.

National Centre for Health Statistics collects, stores, processes and analyses the routine data. For this purpose, it uses various databases, particularly FoxPro and MS Excel. The software for analysis is written in different programming languages.

National Centre for Health Statistics sends data and information to:

- Ministry of Health and its different Directions for routine periodic information;
- District Public Health Directorates;
- National Statistics Institute for updating the data on natural movement of the population and health care units' performance assessment;
- International institutions with regular collaboration, such as WHO.

Figure 3: Position of the National Centre for Health Statistics in the health information flow

Data and information **dissemination** is done through the following publications:

- **Health Statistics Year Book** contains comprehensive data and information with long chronological series: data are comparable and the reporting system is practically the same since the 1950s. Unfortunately, there is a rather long latency between data collection and publication: the publication containing the data of the previous year is released in September-October. Data are aggregated at both district and country level and are presented in table format. Interpretation and analysis are rarely produced;
- **Bulletins** are biannual or annual publications with well-defined themes, such as communicable diseases, natural movements of the population, health care services utilization, etc. The published data are provisional. Only 100–150 copies are printed and actually, they reach only the national decision-makers and directors of District Public Health Directorates;
- **Periodicals** are usually annual publications on well-defined themes such as “Maternal mortality”, “Infant mortality”, “Medical inpatient units”, “Radiological procedures”, “Occupational morbidity”, “Morbidity with temporary work incapacity”, “Balneology services” and others. These publications have the advantage of detailing a specific problem but usually, the data processing is simplistic (calculation of rates, indices), sometimes standardization methods are used.

The main users of data from the health system are institutions and organizations within the health system and in the international organizations.

Use of data and information in decision-making: at local level, the data and information are used mainly for intervention in the situation of acute or crisis events and to a lesser extend, for developing health strategies or policies. The relation between data and decision is often inverted: the decision is made based on other criteria and the justification for the already made decision is searched afterwards among the information.

Strengths

- Comprehensiveness of data and information, in long chronological series (approximately 50 years), comparable in time and territorial units, particularly for demographic events;
- On-line access to the web page, containing demographic data on legal population, deaths, mortality, birth rate, natural growth and infant mortality, in MS Excel format. The Web page also contains Data Presentation System (DPS) programme of WHO for its Member States, providing adjusted mortality per district, residence area and gender;
- The large number of publications containing data and information from the health system (over ten per year).

Weaknesses

- No national health information electronic network;
- Data aggregated at district level;
- No automatic quality control of data other than logical checks (exclusion of absurd data);
- No modular databases, no on-line storage and no possibility of rapid updating;
- Too many software used for storage and processing; each module has its own processing type;
- Long latency of publication until the final results (6–8 months after the end of previous year);

- Limited amount of copies of the Year Book (250 copies in 2002), which reduces the number of interested persons having access. In practice, the Year Book reaches only the District Public Health Directorate level.

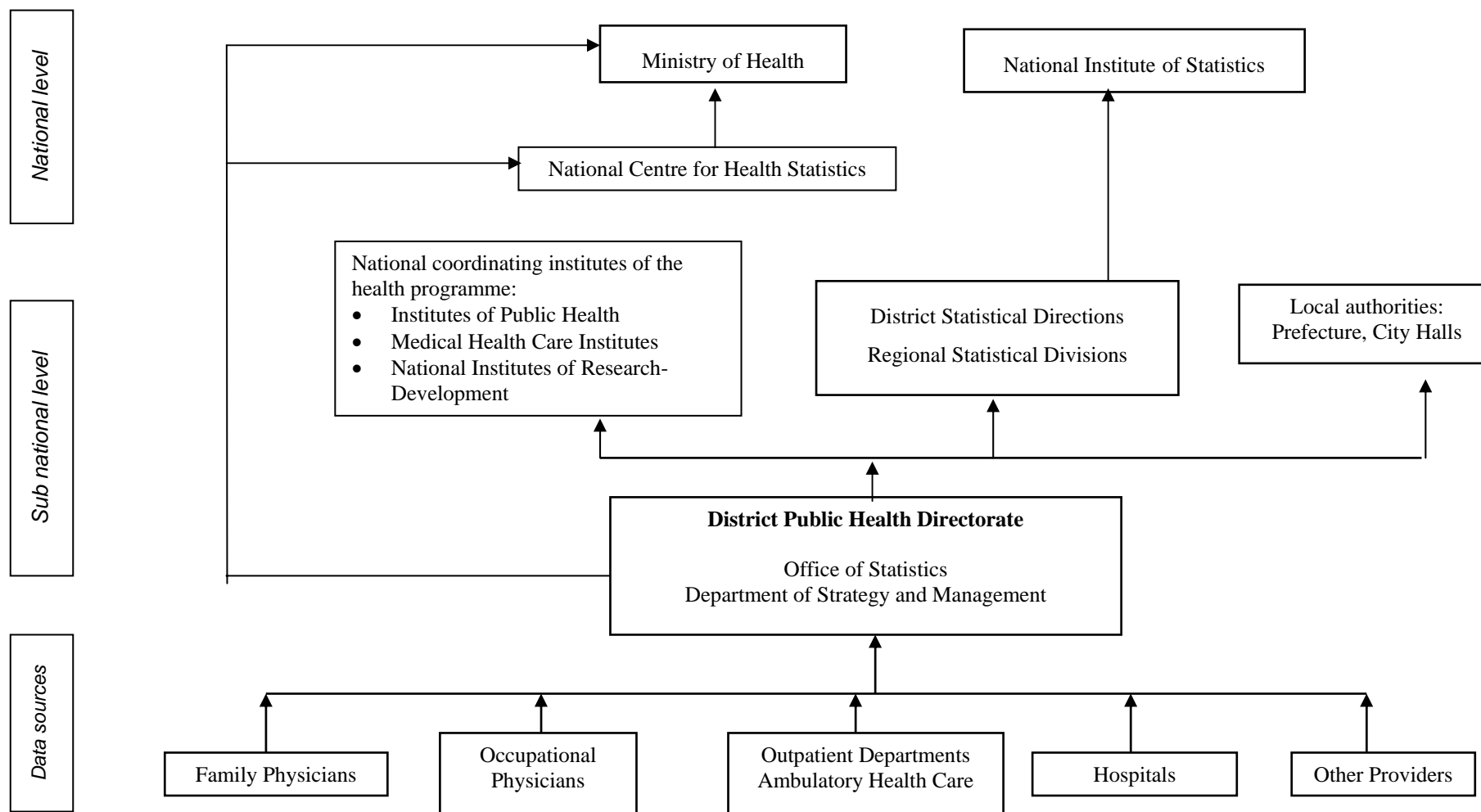
Recommendations

- Use of specific methods for identification and prioritizing of health problems, health status inequalities (territorial, gender and age groups) or of vulnerable groups in view of a better use of existing data;
- Production of a health status report illustrated with many more graphs would be useful to decision-makers and would allow a better understanding of the problems;
- Free access to public data is stipulated in the law. Yet, in practice, there is an excessive prudence in providing access to health data, even with a fee;
- Lack of minimal mandatory technical standards at national level for computer security against non-authorized access to non-aggregated data;
- Lack of minimal mandatory technical standards at national level for information protection against accidents in the storage and processing system.

The District Public Health Directorate (DPHD). The *Office of Statistics and Information* is at the centre of the data and information flow within the DPHD (Figure 4). A medical doctor leads the bureau, full-time or part-time. In some cases, he/she is a public health and health care management specialist or just holds a competence degree in this specialty. Depending on local particularities, an extra medical doctor, one to three employees with undergraduate education level and one IT professional can be added to the team. Each bureau is equipped with at least one computer. Since July 2003, the situation has changed. The Order of the Minister of Health No. 664/2003 modifies the structure of the DPHDs (previously approved through Order No. 120/2001). The Office of Statistics and Information changed its title into *Office of Statistics*. Meanwhile, the hierarchical subordination has changed, resulting in staff reduction while the attributions of the office remained the same.

The Department of Strategy and Management from the DPHD has attributions in the management of national health programmes at the district level. Data sets, rates and specific indicators for each sub-programme were developed to monitor the progress. The reports are analyzed and reviewed annually on the occasion of the budget approval.

Figure 4: Position of the District Public Health Directorate in the health information flow



Data exchange: the DPHD receives data from all health care providers who have a contract with the Health Insurance House (presented in Figure 4) and from all departments within the directorate's structure (i.e. food hygiene, environmental hygiene, scholar hygiene, etc.). In Romania, the number of providers is important. For example, in 2001, there were approximately 11 000 family physicians, 442 hospitals, 249 occupational dispensaries, 62 polyclinics. This leads to a large number of reports received by the office (for example in District of Brasov, approximately 400 family physicians and 14 hospitals with their outpatient departments sent their report to the statistical office). Most of the time, the reports are received monthly. The quarterly and annually requested reports are fewer and some of them (particularly the quarterly ones) are the compilation of monthly data. The format is a template and the support is paper, floppy disk or e-mail.

The data transmitted to the DPHD are:

- Demographics;
- Morbidity (information on communicable and some non-communicable diseases considered as Public Health problems);
- Assessment of providers' performance.

All health care providers from each category supply the same type of data. This mechanism facilitates on one hand the gathering of a large volume of data and information but has the following drawbacks:

- The large number of providers results in deficiencies of data quality;
- The professional training in data collection, coding and transmission is difficult;
- The volume of work to process the data retrieved in the office is large.

The data **storage and management** activities run by the bureau of statistics are:

- Logical check of data;
- Encoding of the causes of death;
- Centralization and aggregation of data at district level;
- Development of the district database;
- Update of the district database;
- Processing and analyzing the data according to local needs.

The databases are usually written in FoxPro and MS Excel. The databases used are not modular and there is no possibility of on-line access. The transfer between databases is done manually. The quality assurance/quality control mechanisms are limited only to logical check.

The Office of Statistics **sends** data and information to:

- The National Centre for Health Statistics: monthly, quarterly and annually on paper, floppy disk and e-mail;
- The Ministry of Health: only exceptionally and only in the situation of some specific communicable diseases or epidemics outbreak (by phone, e-mail or on paper);
- The District Statistical Direction or Regional Statistical Division; from there, the data are sent to the National Institute of Statistics. The flow of data referring to the natural movements of population is two-way: the demographic events are recorded at the place of their occurrence but they are measured in relation to the main place of residence of the individual involved in the event;

- Local authorities (prefecture, City Halls, district and local councils): the type and quantity of data and information varies from one district to another and from simple current information to analysis of the main aspects of the health status of the population in special situations;
- Institutes that are national coordinators for health programmes and sub-programmes through the department of strategy and management they belong to;
- Different categories of the general public, particularly in the situation of crisis events or requests from media representatives.

Strengths

- Comprehensiveness of data and information, in long chronological series (approximately 50 years);
- Non-aggregated data going down to provider level;
- Routine of reporting;
- Powerful channels of data transmission;
- Trained staff in data collection, coding, processing and analysis;
- Computer resources.

Weaknesses

- Complete lack of data on health-related behaviours, habits and lifestyles;
- The data analysis is insufficient and scarce. Most of the time, it is limited to the presentation of a table with absolute numbers, set of rates and indicators in chronological series, at district and country level. Comments to these figures are rarely inserted;
- Insufficient staff for the large volume of work;
- Frequent changes in hierarchical subordination;
- Unclear reference population – at town or city level;
- Frequent changes of software.

Recommendation

The identification of a small number of well trained, morally and/or materially co-interested providers, that own a computer and adequate software also connected to a database network, would allow getting valid data in real time.

8.2. Information flow to the National Health Insurance House

This information flow was created along with the implementation of the Law no. 145/1997 **On Social Health Insurance**. This law has led to the creation of other hierarchical structures and actors, in addition to the Ministry of Health and its subordinated institutions: the National Health Insurance House and the District Health Insurance Houses, health care services providers, research institutes, etc. Each of these structures owns a more or less complex information system, on which they exert their exclusivity.

The flow towards the National Health Insurance House is presented in Figure 5.

Strengths

- Allows computing the number and types of services delivered;
- Allows the reimbursement of the services and the computation of expenditures;
- Serves as a basis to estimate the demand of services and the balance between demand and offer;
- Supplies data for resources allocation to meet the demand (health services planning).

Weaknesses

- Lack of compatible and unified software for data reporting. Each District Health Insurance House created its own software system, using different programming language which makes the data inter-comparability and communication difficult;
- The reported data reflect the high degree of bureaucracy in Romania. The monthly reported data by each family physician are excessive and take approximately three working days each month for completion of reporting files. Each family physician is requested to personally submit the reports at the contracting District Health Insurance Houses headquarters;
- Overburden of the family physician, creating discouragement, taking their time from direct patient care and jeopardizing the quality of the data;
- Frequent changes of physicians' lists of patients, which further increases the volume of paper work;
- Communication with family physicians is difficult due to the large number of providers in each district on one hand, and to the scarce provision of computers in the family physicians' offices on the other hand;
- No national electronic information network for family physicians. There is only one network comprising approximately 100 family physicians that are involved in an internationally financed project. This project aims at monitoring the family physician's activity and owns a mini network. Each member of the project has a personal computer and uses the same software. This software has not been approved by the National Health Insurance House to be the unitary software for all family physicians;
- Data are transmitted on paper and/or floppy disks.
- Few data on health status are included in this data exchange, which main purpose is the administrative control of both physicians and patients' use of public resources;
- Health care service providers do not share information.

The National Health Insurance House (NHIH)

Data exchange: the NHIH is the main contributor to this flow of data. It receives statistical reporting from all the District Health Insurance Houses (Figure 5).

The Emergency Ordinance No. 838/2002 **On the organization and functioning of the health insurance system** stipulates the right and the obligations of each insured person to be informed by the Health Insurance House at least once a year about the services he/she is entitled to. The ordinance does not expressly mention the obligations concerning the confidentiality of personal data. The respect for the confidentiality of data is stipulated within the framework contract between various providers and the Health Insurance House. Under these conditions, contradiction arises between the House and the providers. The Health Insurance House, with the purpose of controlling expenditures, requests from providers a dataset that allows easy identification of the insured.

The **strengths and weaknesses** are the same as those identified for the information flow towards the National Health Insurance Houses.

The District Health Insurance House (DHIH)

Data exchange: the DHIH receives and processes data and information from all health services providers and sends data and information to the National Health Insurance Houses and to other beneficiaries upon request.

8.3. Links between the Ministry of Health and the National Health Insurance Houses regarding health information

The general diagram of the information flow towards the Ministry of Health and towards the National Health Insurance Houses are shown in Figure 5 is a combination of two information flows.

Strengths

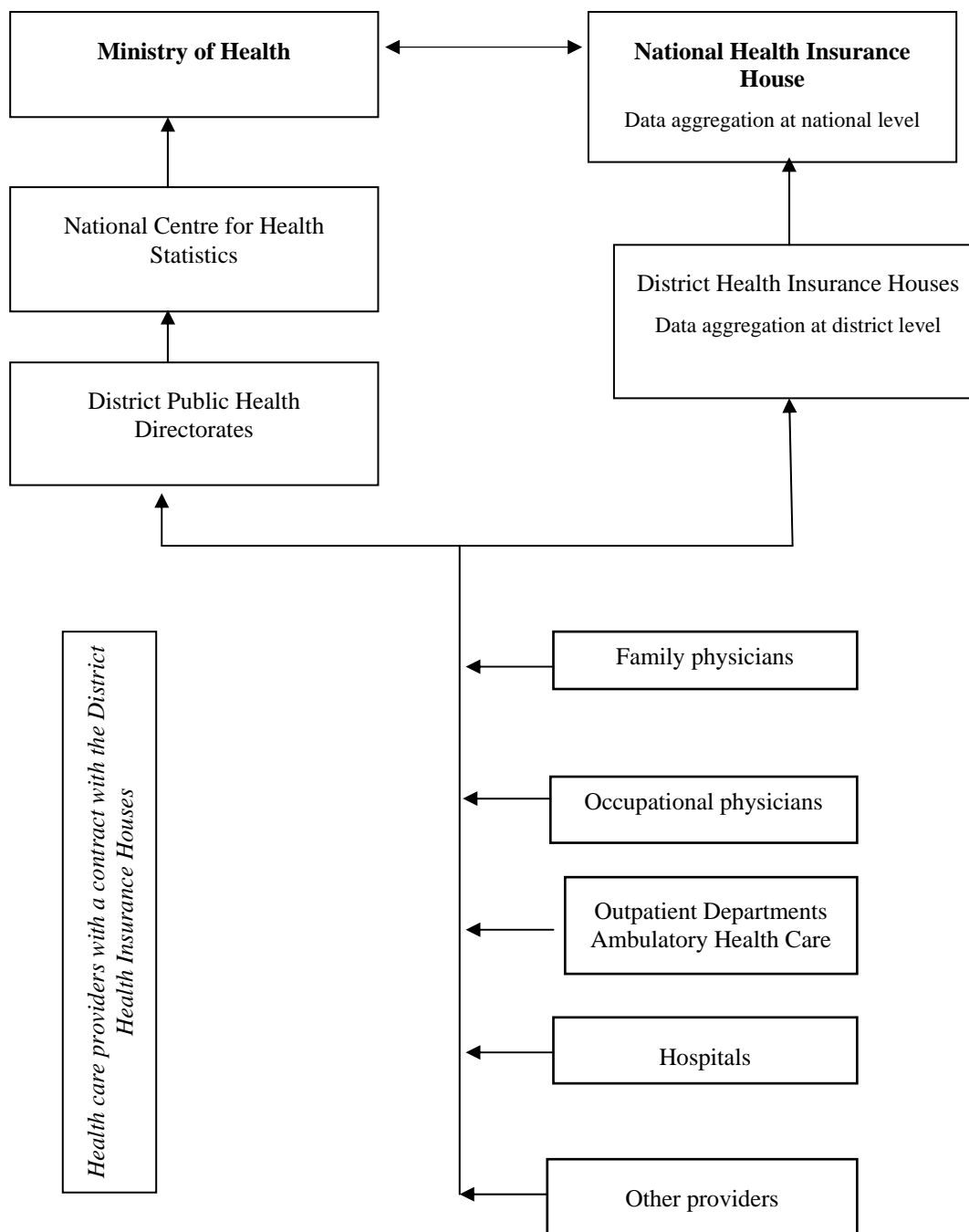
- Meet the principal perceived needs of these two main organizations for decision-making;
- Monitor the activity of health care providers;
- Allow the monitoring of expenditures within certain limits.

Weaknesses

- Two parallel information flows resulting in double reporting and incoherence in definitions and coding. As a result, the same indicator reported through two different channels has two different values;
- The health care providers contract with the DHIH, but they are not subordinated to the District Public Health Directorates;
- The large number of health care providers within a district (hundreds), especially family physicians, involves a heavy administrative load.

It is of importance to note that the health care providers from the private sector, who do not have a contract with health insurance houses, do not provide data or information to the health system.

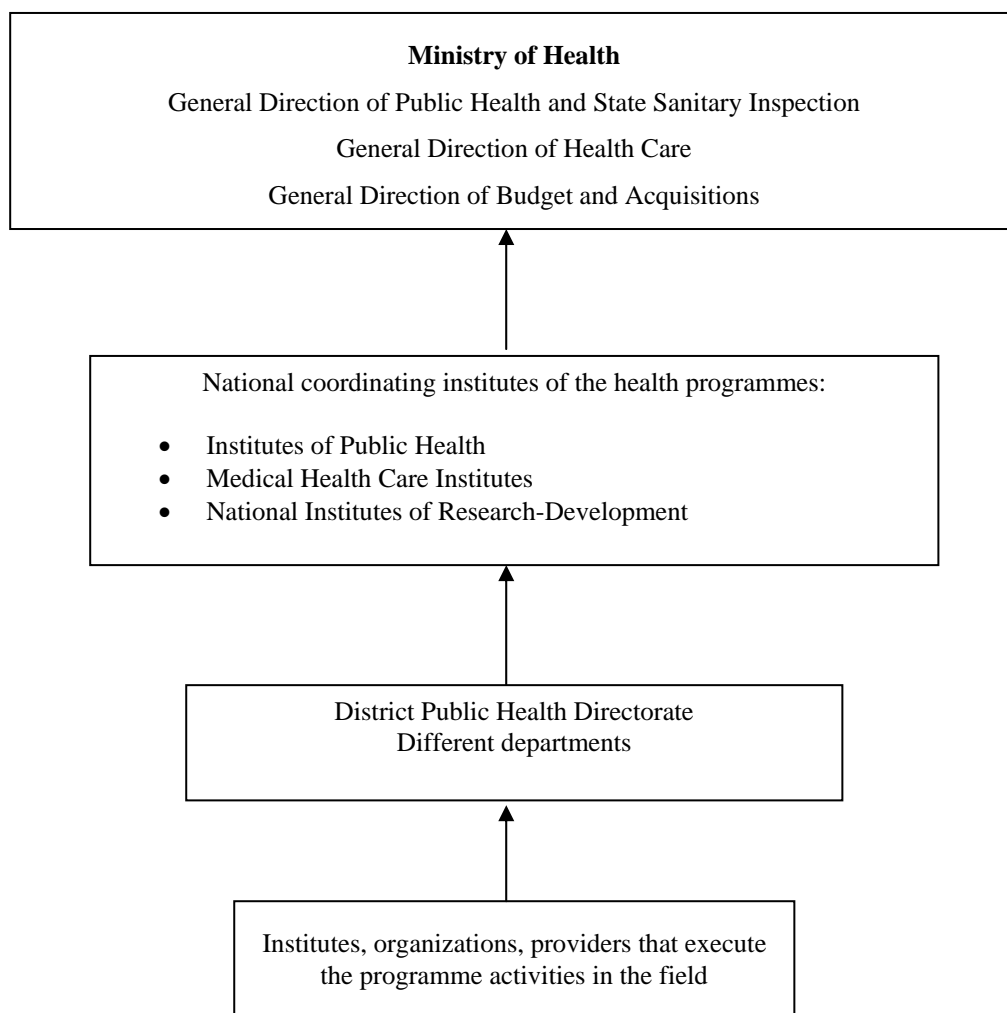
Figure 5: The transmission channels for data produced by health care service providers—family physicians, outpatient departments and hospitals



8.4. Information flow towards National Health Programmes managed by the Ministry of Health

In 2003, the Romanian health system had four ongoing national health programmes. They were coordinated by the Ministry of Health through the General Direction of Public Health and State Sanitary Inspection, the General Direction of Health Care and the General Direction of Budget and Acquisition. Each national health programme consists in over 40 sub-programmes. Each of them operates with continuously improved and modified specific data flows. The degree of the development and implementation of the information flow varies greatly between sub-programmes. The generic diagram is presented in Figure 6.

Figure 6: Information flow for National Health Programmes



The great number of sub-programmes and the variety of related information flows preclude an exhaustive presentation. For illustration, we present the information flows related to three national health sub-programs.

The information flow related to the “Evaluation of health status and environmental risk factors” sub-programme from the “Community public health programme” national health programme:

This national public health sub-programme is managed by the General Direction of Public Health and State Sanitary Inspection of the Ministry of Health. The Institute of Public Health in Bucharest is the national coordinator through a secretariat. The programme contains four main objectives with over 40 activities. These objectives are:

1. Health protection and prevention of the diseases associated with environmental risk factors;
2. Evaluation of effects of environmental factors on the health status of children and youth in collectivities;
3. Health protection and prevention of diseases associated with occupational risk factors;
4. Monitoring of population health status and demographic surveillance.

At the end of each year, a report is written on sub-programmes in relation to the health status of the community at district, regional (four historical and geographical regions, attributed to one of the four Institutes of Public Health) and national levels.

The four objectives are nationally coordinated by one of the four regional Institutes of Public Health. The coordinating institute develops the standard methodology, which is thereafter implemented by each District Public Health Directorates. In this context, along with the reporting, the execution of the activities and the financial monitoring (information sent to the Ministry of Health quarterly), the actual results (of laboratory measurements, of the surveys, etc.) are sent to the coordinating regional institute. Data and information are sent on paper and by fax but rarely by e-mail. The detailed extended synthesis is sent to the Ministry of Health and short information is brought up to the attention of local authorities, the media, interested non-governmental organizations, etc.

The information flow within the sub-programme “Evaluation of health status and environmental risk factors” is presented in Figure 7.

Evaluation indicators for sub-programme “Evaluation health status and environmental risk factors”. There are three types of indicators, each with different periodicity.

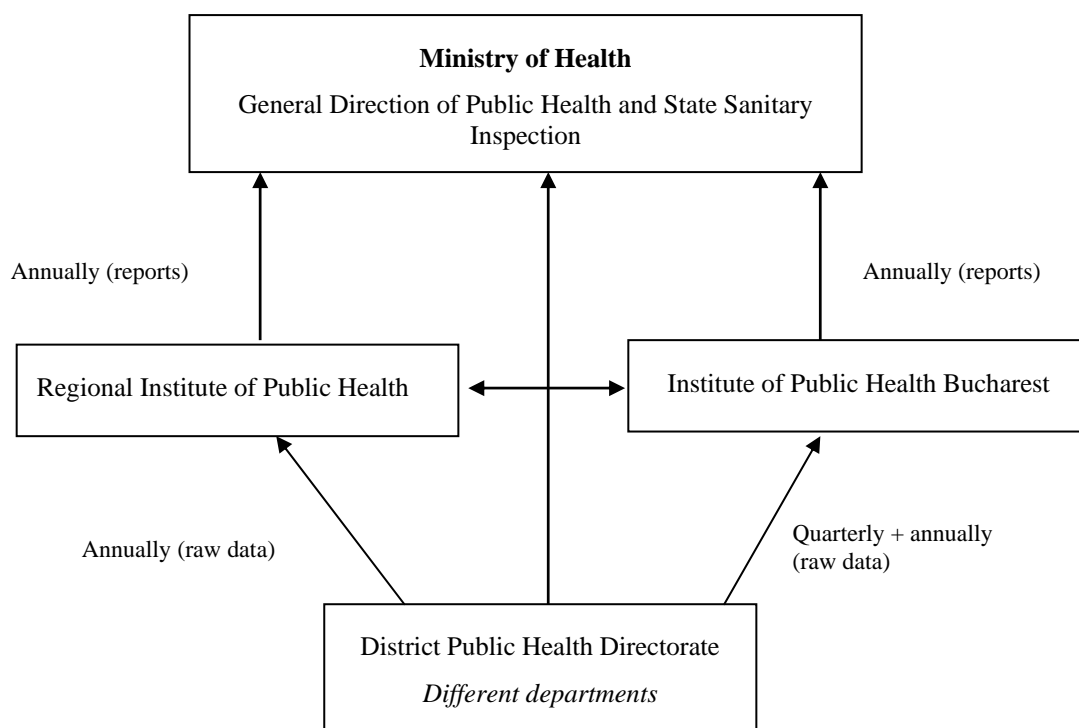
Outcomes indicators are sent annually. They refer to reduction of risk factors and of the frequency of related diseases. These data are included in the annual reports.

Process indicators are sent quarterly and refer to the number of specific activities in the monitoring and evaluation of risk factors, and their effects on health (including studies).

Cost/efficiency indicators are sent quarterly and refer to mean cost per activity.

Data referring to process and efficiency indicators are stored, processed and analyzed at the Institute of Public Health in Bucharest.

Figure 7: The information flow within the sub-programme "Evaluation health status and environmental risk factors"



Strengths

- Especially conceived for monitoring the impact of environmental risk factors on the health status;
- Requires national reports on the frequency of environmental risk factors;
- Data collection is following standard methodologies for each risk factor;
- Data covers the entire country;
- Stipulates the obligatory dissemination of the results to the decision-makers outside and inside the health system.

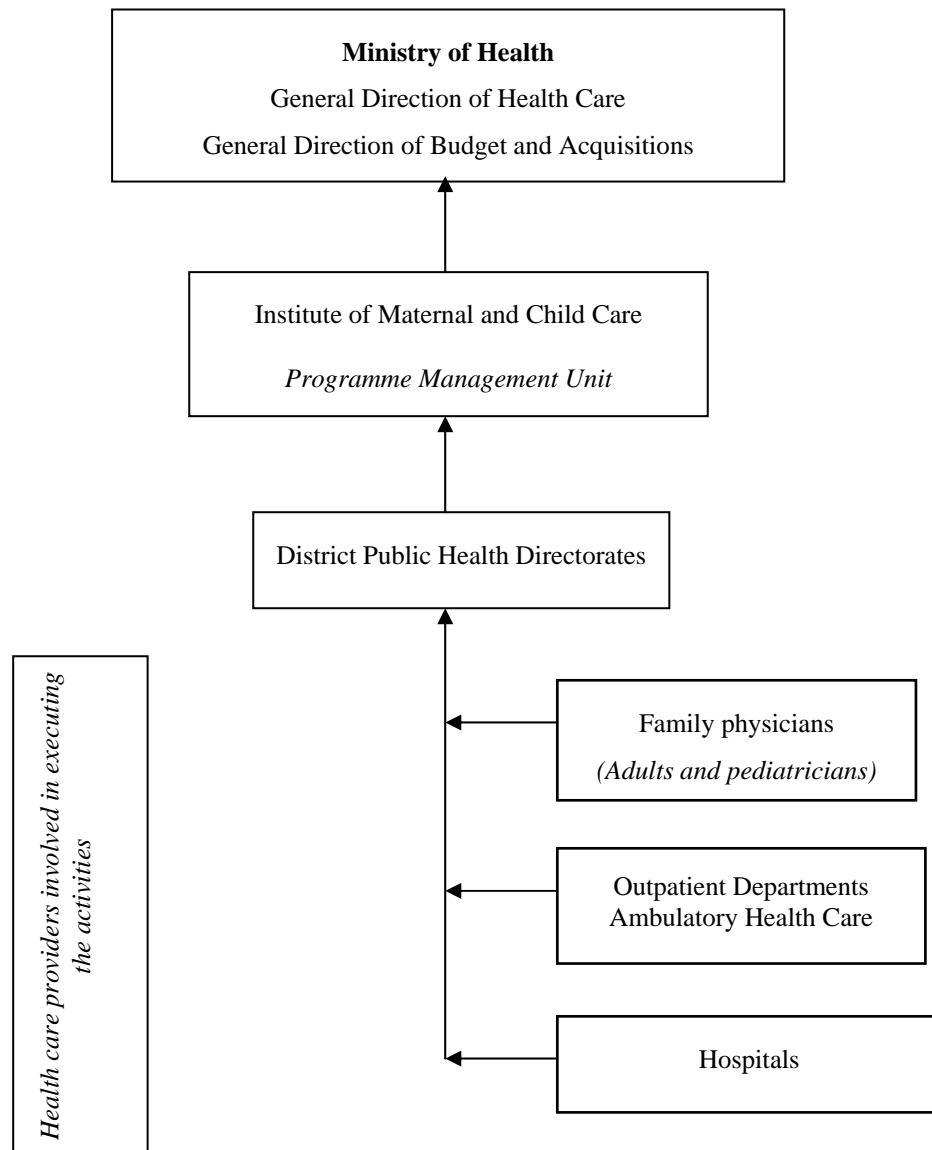
Weaknesses

- No unitary methodology for the calculation of average cost per activity, therefore data transmitted from the districts cannot be compared;
- Great latency between data collection and completion of the reports (about 6 months);
- No national electronic network;
- Data are transmitted by fax, e-mail and post (on paper);
- No quality control of data.
- Each of the 42 activities has a different way of data storage. Therefore, there are more than 42 independent databases, one or more for each risk factor; the modules are not compatible, reducing the possibilities of linkage and comparison.

The information flow related to the “Maternal and child health” national health programme:

The national coordinator of this national health programme is the Institute of Maternal and Child Care, which includes the programme management unit (with all 19 component sub-programmes for 2003). The information flow of the programme is presented in Figure 8.

Figure 8: Information flow towards the "Maternal and child health" national health programme



Strengths

- Data and information requested were designed according to programme or sub-programmes monitoring needs;
- Standardized data collection, which allows comparability between regions.

Weaknesses

- Large volume of requested and managed data;
- Additional non-paid activity for health care services providers;
- No national electronic network; data are transmitted on floppy disk, by e-mail or by fax;
- No quality control of data;
- Some of the data requested to monitor expenditures threaten the medical confidentiality (for each person who is given free medication through the programme, the full name, personal identification – ID – numeric code, address and diagnosis are requested);
- The current conception of the system does not allow the longitudinal follow-up of the patient.

The information flow related to the "Tuberculosis Control" sub-programme from the Community public health programme:

This national health programme is coordinated by the Institute of Pneumology. The information flow for recording the tuberculosis cases is presented in Figure 9.

The territorial dispensaries evaluate monthly all patients who completed 12 months of treatment. The information flow is the same as for the recording of the new cases.

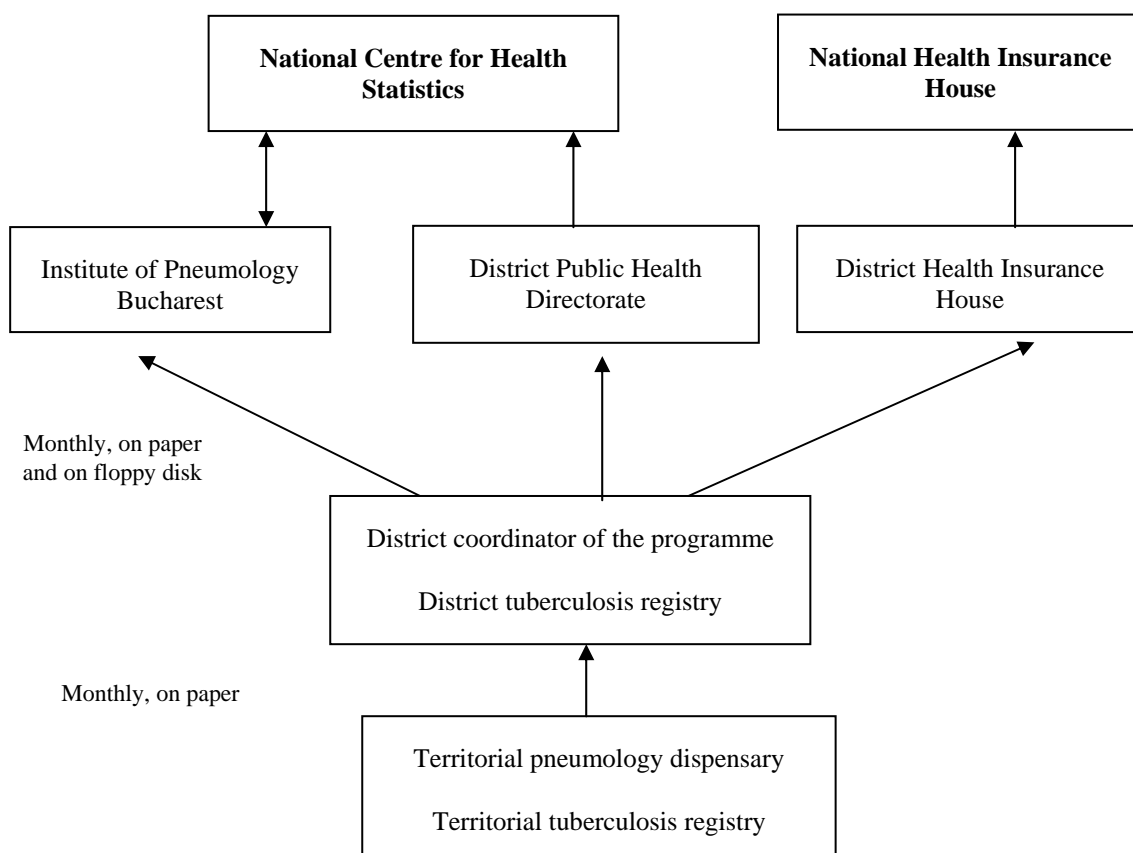
Strengths

- Clear case definitions included in the programme;
- Feeds into the national tuberculosis registry, based on the district registries;
- The existence of the specific network involved in the programme, with experience and continuity in developing the programme;
- Respect of data confidentiality;
- All district pneumology dispensaries have computers and use the same software (EpiInfo, free of charge is used for data storage). They also have e-mail subscriptions;
- The documents used for recording, storage and transmission are standardized, throughout the country and compatible with international recommendations (WHO, EU);
- In the process of integration with the European surveillance system.

Weaknesses

- Insufficient staff. Staff insufficiently trained in the field of database management;
- Partial control of quality of data and only at central level;
- Data transmission on paper, floppy disk and e-mail;
- Although the format is unique, data are transmitted to three beneficiaries: the District Public Health Directorates, the District Health Insurance Houses and the Institute of Pneumology.

Figure 9: Data flow within the national health sub-programme for "Tuberculosis Control"



9. The primary sources of health data and information

The primary sources of data are common to the three main information flows towards the Ministry of Health, the National Health Insurance House and national health programmes managed by the Ministry of Health. These primary sources are health services providers: hospitals, out-patients units and family physicians.

Hospitals

In conformity with the Law on Hospitals, Law No. 270/2003, within the structure of the district hospital, the *Department of Statistics* is responsible for data collection and transmission. In all other types of hospitals, there are groups in charge of this task.

The departments of statistics of university and district hospitals are equipped with computers. For all other types of hospital, the resources depend on local possibilities. The activity of departments of statistics is coordinated by a medical doctor, clinician, employed by the hospital. For this supplementary activity, the coordinator is sometimes not remunerated or receives a symbolic fee. In the department, there are also undergraduates employed by the hospital. The unattractive remuneration makes it rather difficult to hire and retain experienced IT professionals. Compared to the volume of work, the staff and the available skills are insufficient.

Data sharing

The hospital sends data and information in three directions: to the District Public Health Directorates, to the District Health Insurance House and for some national health programmes, to the institutes or organizations which are national coordinators, as presented in Figure 10.

The data sent to the District Directorate of Statistics continue the existing chronological series, sometimes duplicating, in different format, the flow towards the Health Insurance Houses or the ones connected to the Diagnostic Related Group (DRG). It is the case of the number of patients discharged from hospital, mean length of stay, services delivered by laboratories, etc.

The data and information sent to the District Health Insurance Houses have a pronounced economic character (costs per wards, departments). These are related to the DRG system for performance assessment and resources allocation.

The financing "*per case*" system has been introduced in the hospitals on 1st January 2003, within the reform of the health system. The coding of hospital discharge data was implemented in all the Romanian hospitals. Moreover, the diagnosis coding ICD-10 (the four characters version and electronic retrieval of "Minimum Patient's Data Set" using the DRG application) and the new "General Clinical Record" of the patient were implemented. All these have completely changed the flow of information produced by the hospitals. The data are sent on monthly basis both to the Health Insurance House and to the National Centre for Health Statistics. One or two medical doctors from the hospital were nominated as DRG respondents. They receive assistance from the DRG consultant in the District Public Health Directorate and are trained by the project coordinators at the Institute of Health Research-Development, the National Centre for Health Statistics and the National Health Insurance House.

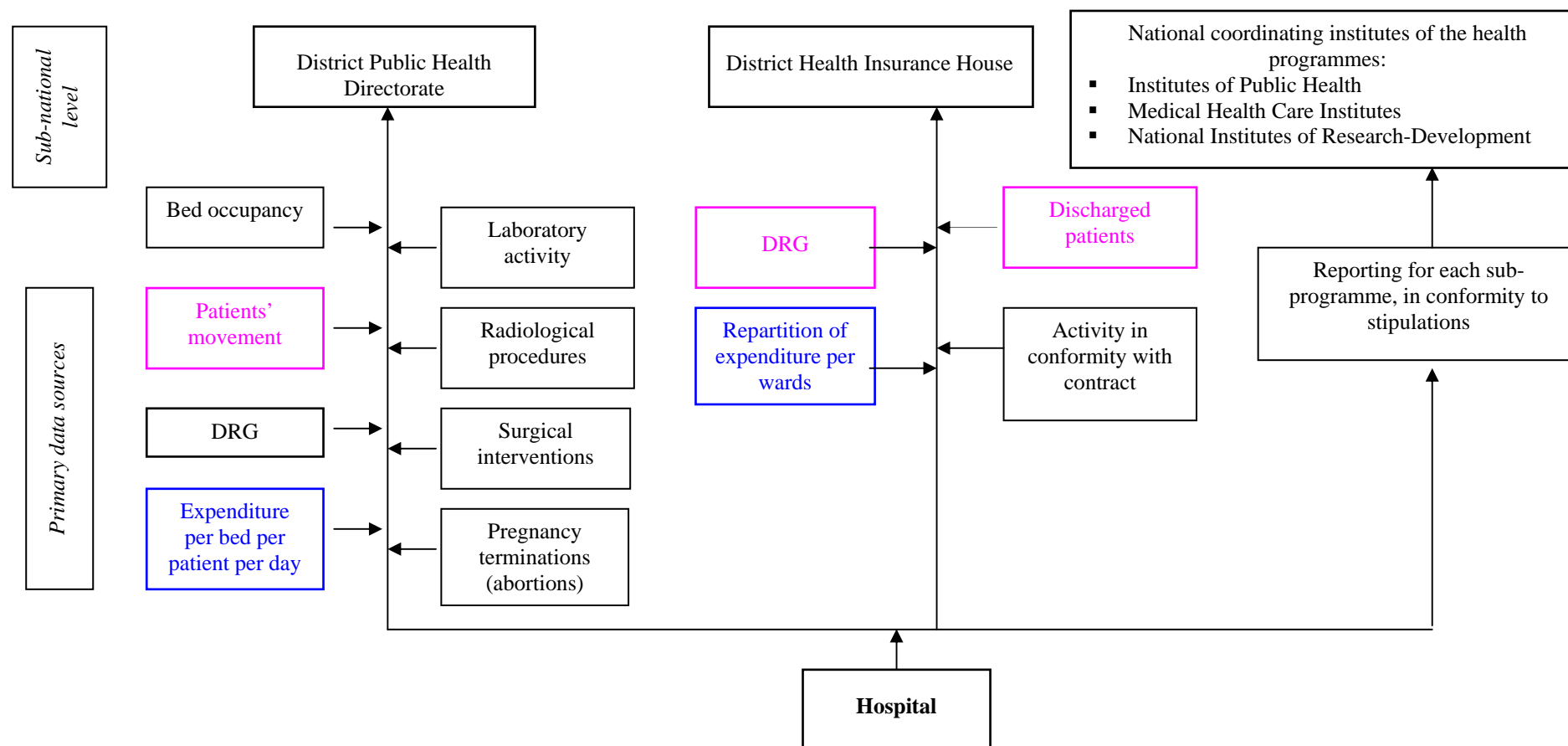
The software used in data collection and transmission are produced by different companies. They generally use the same principles, but unfortunately, they are neither compatible nor standardized. They are written in different programming languages. The outputs are the same. The type of software that hospitals purchase depends on their financial resources. The introduction of the financing mechanism based on resolved case, starting in 2004, will require a harmonization of the information flow new needs.

The feedback on the data is received only in the case of inconsistencies in reporting, for verification and correction. There is no on-line access to the database containing the results of data from DRG system.

Strengths

- The HIS supports the reform of resources allocation to the hospital, according to the complexity of admitted cases and health care services offer, thus replacing the historical criteria in resources allocation;
- Minimal data set on patients is established by law allowing the evaluation of case complexity and utilization of health services;
- Department of health statistics already established.

Figure 10: Position of the hospital in the health information flow



Note: The same colour represents same data sent in different directions under different formats.

Weaknesses

- Data and information reported in three different directions, under three different formats;
- Multiple software;
- Double subordination to both, health system and local public authority;
- Lack of staff and insufficient training of the personnel in the statistics department;
- Scarce intranet networks in the hospitals;
- Lack of intercommunication of information between family physicians, out-patient units and hospitals, which makes the follow-up of the patient difficult within the system.

Outpatient department

The outpatient department provides specialized health services. The organization chart contains one or two persons with medium education who cover data collection and reporting for activity evaluation and some aspects of health status monitoring, as presented in Figure 11.

In the situation of a specialized outpatient department integrated in the hospital, the hospital reports for the outpatient department also goes through the same channels. The observations made for the hospitals apply to the outpatient departments as well, regardless of it being independent or a component of the hospital.

Strengths

- The main data source for some health programmes or sub-programmes, such as tuberculosis, sexually transmitted diseases, diabetes, malignant tumours and mental diseases.

Weaknesses

- Triple reporting of data and information in three different directions, under three different formats;
- The existent data are used mainly for service reimbursement;
- Lack of intercommunication of information between family physician, outpatient units and hospital, which makes the follow-up of the patient difficult within the system.

Family Physicians

Data and information collected and transmitted

The family physicians run their activity in an office that they rent from the State. Resources are limited and the computers are either owned by the family physicians or were donated through various projects.

As presented in Figure 12, the family physicians send data to:

- The District Public Health Directorates, the Office for Statistics: data related to some aspects of the health status of the patients or on activities of primary or secondary prevention of certain diseases;
- The District Health Insurance House: the data pertain to the characteristics of the patients and the activity in the office. Data are mainly used for economic purposes (per capita and fee for service financing in conformity with contractual stipulations), but also for performance assessment of family physicians and evaluation of their relationships with other specialized health services provider.

The activity of the family physician as data source is presented in Figure 12.

In 1997, the National Society of Family Medicine and General Medicine has initiated the “Sentinel dispensaries network” programme. This programme was continued by the National Centre for Family Medicine Studies. The objective of this programme was to develop an information system for data collection in the primary health care in order to obtain the real picture of this important sector of health care. The sentinel dispensary network became operational at the beginning of 2000, with the financial support of the Dutch Government, which donated 100 computers. Hundred physicians throughout the country are now using the "Medins" software for data entry. The data are transmitted on-line through the "Medins" software onto the network's site.

Strengths

- One of the main primary data sources;
- Increased number of family physicians' offices with PC equipment;
- Increased number of family physicians who perceived the need of providing quality data to the HIS and are aware of the need for reliable data;
- Introduction of the educational curricula of family physicians modules of basic informatics and health statistics.

Weaknesses

- Lack of inter-communication between family physician, outpatient units and hospital, which complicates follow-up of the patient throughout the health care system (seamless chain of care);
- Sending data and information to two beneficiaries with conflicting requirements, for example vaccinations, records of pregnant women, records of some chronic diseases: data and information transmitted to District Public Health Directorates are entered into a template used countrywide, whereas each District Health Insurance House designs its own recording and reporting template following the recommendations of the National Health Insurance House. The data and information are sent on paper for the District Public Health Directorates and on both paper and floppy disk for the District Health Insurance Houses;
- Large volume of data and information are requested, mostly on a monthly basis, but also requested quarterly and annually;
- The data storage is done on paper files, but also on floppy disk and/or computer when the physician has access to one;
- Although the framework contract stipulates that the data on health care services delivered to patients should be confidential, this is not done in practice due to the requirements of the control exerted by the Health Insurance Houses. The Health Insurance Houses request, for example, for some categories of patients, along with numeric personal ID number, the full name, address, diagnosis and the prescribed treatment. These data allow the easy identification of patient and breaks the confidentiality of individual data;
- Although data are collected at individual level, their aggregation at District Health Insurance Houses level takes the “episode” of the delivered service as the unit of analysis. Each visit to the physician is considered as an independent “episode”. Thus, the patient cannot be followed longitudinally, and the number of patients recorded over a period of time is unknown. Only the sum of services delivered within a period of time can be analysed, regardless of the beneficiary.

Figure 11: The position of the specialized outpatient department in the health information flow

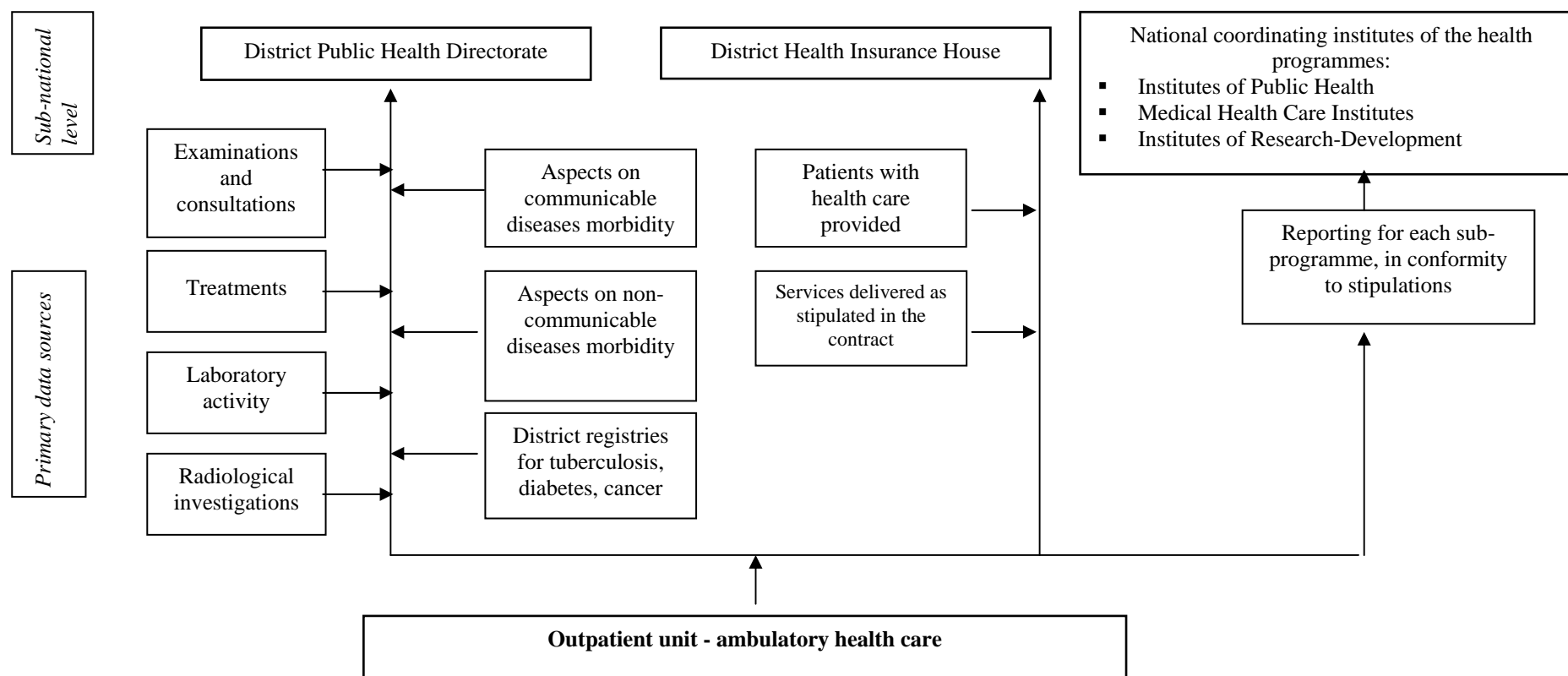
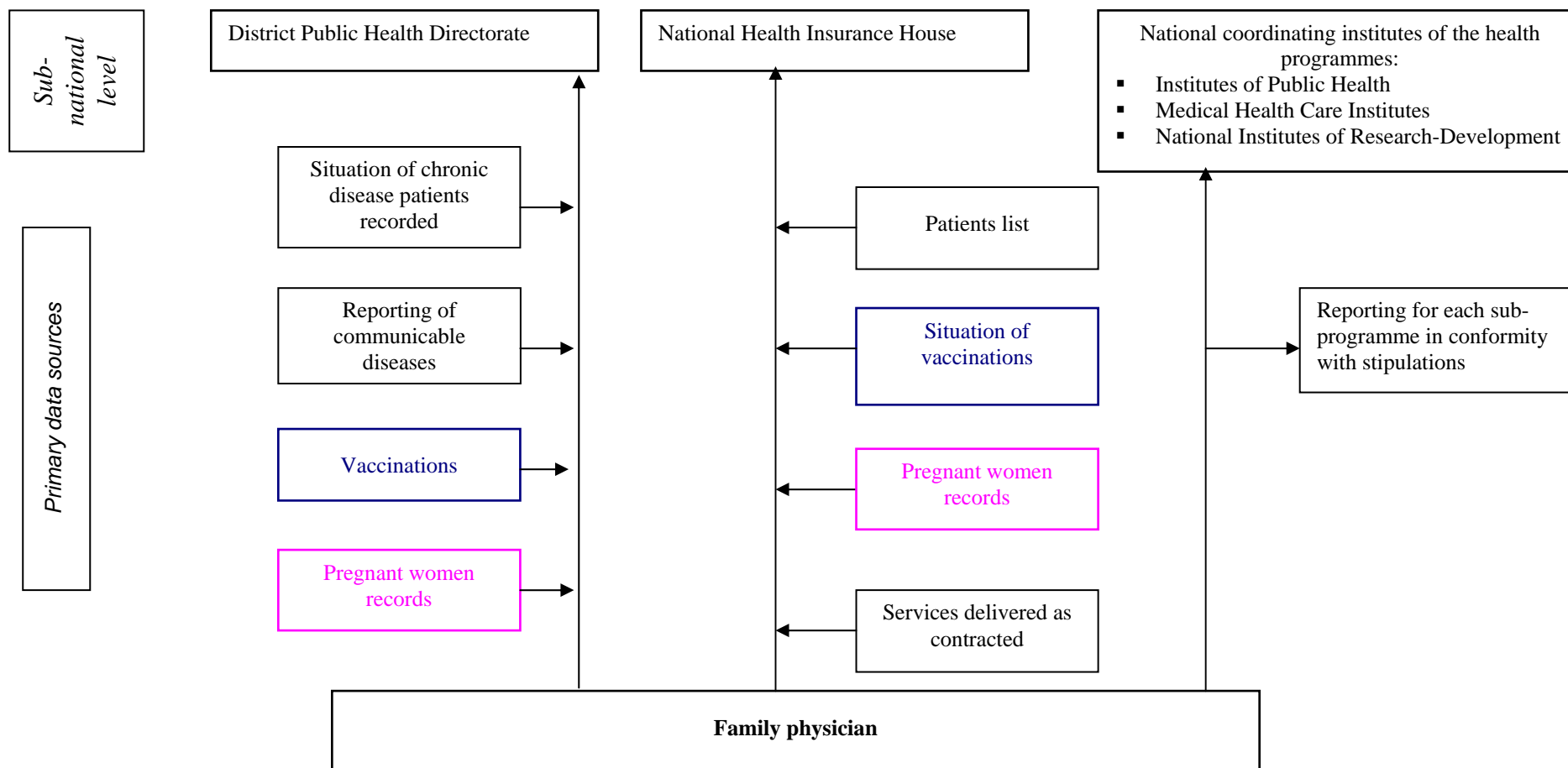


Figure 12: The position of the family physician in the information flow



Note: same colour represents same data sent in different directions under different formats.

10. The flow of routine data and information outside the health system

The National Institute of Statistics (NIS)

The NIS is the main organization in this circuit.

Data exchange: The data and information from the health system are received through two channels:

- Ministry of Health's National Centre for Health Statistics;
- All District Public Health Directorates via the District Directorate of Statistics as presented in Figures 1, 4 and 13.

This is a two-way data exchange.

The databases are generally in ORACLE. Some micro databases are also in Visual FoxPro. The quality control and quality assurance are performed through logical check at data entry and during data processing through correlation and verification of data coherence, evaluation of responses rates in the surveys.

Along with routine data and information, the NIS conducts health surveys generally with methodological and financial support from institutions as a part of international programmes, such as PHARE programmes, and supported by EUROSTAT, the Italian National Statistics Institute, the National Institute of Statistics and Economic Studies from Paris, etc.

Presently, most of surveys are integrated in the PHARE project that covers the majority of the costs. It consists of several modules such as:

- Modernization of statistical data dissemination system;
- Continuous professional training survey;
- Health interview survey;
- Budget survey;
- Living conditions survey;
- Family budget survey;
- Multifunctional sample of territorial zones, master sample;
- Strengthening of documentation services;
- Improvement of environmental statistics compliance;
- National survey on child activity.

Most of these modules contain data on population health status and health determinants: acknowledged and self reported morbidity, lifestyles (nutrition, alcohol consumption, tobacco use and physical activity), environmental factors (housing, noise), satisfaction on delivered health services, monthly expenses for health, etc.

The “Family Budget Survey” is being conducted annually since 1996. In the chapter referring to out-of-pocket family expenses, the health expenditure (money spent for health aside from health insurance) is separately identified. The survey includes data on self-reported morbidity.

Strengths

- Availability of 4-5 years of surveys;
- Representative sample for the entire country and for the households from all eight geographic development regions;
- Standardized methodology, comparability of data over the years;
- Inclusion of the only individual data available on some health determinants, such as family income, housing, food consumption, characteristics of the head of the family;

Weaknesses

- The interviews are performed by persons without medical training and data are self-reported.

Reports based on this survey include “private expenditure for health” (financed by UNICEF and the Centre for Health Policies and Services; have been published in Romanian and English), “Health status of the population from Romania”, “Living conditions of population from Romania”, “Coordinates of life standard in Romania” and “Income and consumption of the population in 2000”.

The "Health interview survey" of self-reported health status was conducted for the first time in 2000, in a sample of 1000 households (3000 persons). It is planned to be conducted every five years. This expensive survey receives external financial support. The report is entitled “Health Status of Population in Romania”.

Strengths

- Data flows are well established;
- Long temporal data series, comparable in time and space;
- Compatible databases, SQL type, modular;
- Sampling and pooling techniques very well set;
- Monthly reporting of data to decision-makers. These reports are published on the Internet as well;
- Rich web page, containing all products. The access to the materials on the web page is free of charge;
- Many of the questionnaires of the ongoing survey are downloadable from the web page.

Weaknesses

- Quality assurance/quality control – no double check, just logical check at entry;
- Most of the data are aggregated at district level;
- Understaffing for the large volume of work;
- Latency between generation and publication (at least 6 months);
- On-line data and information on the web page are in text or .pdf format and cannot be directly retrieved from database.

Publications of the National Institute of Statistics:

The census of the population and dwellings, 2002: the partial results of the census were released in March 2002. The census data are available on the Internet in .pdf format and on CD-Rom.

Bulletins are published monthly, quarterly and annually in brochures and are also available on the Internet in .pdf format.

Strengths

- Standardized data retrieval;
- Long chronological series.

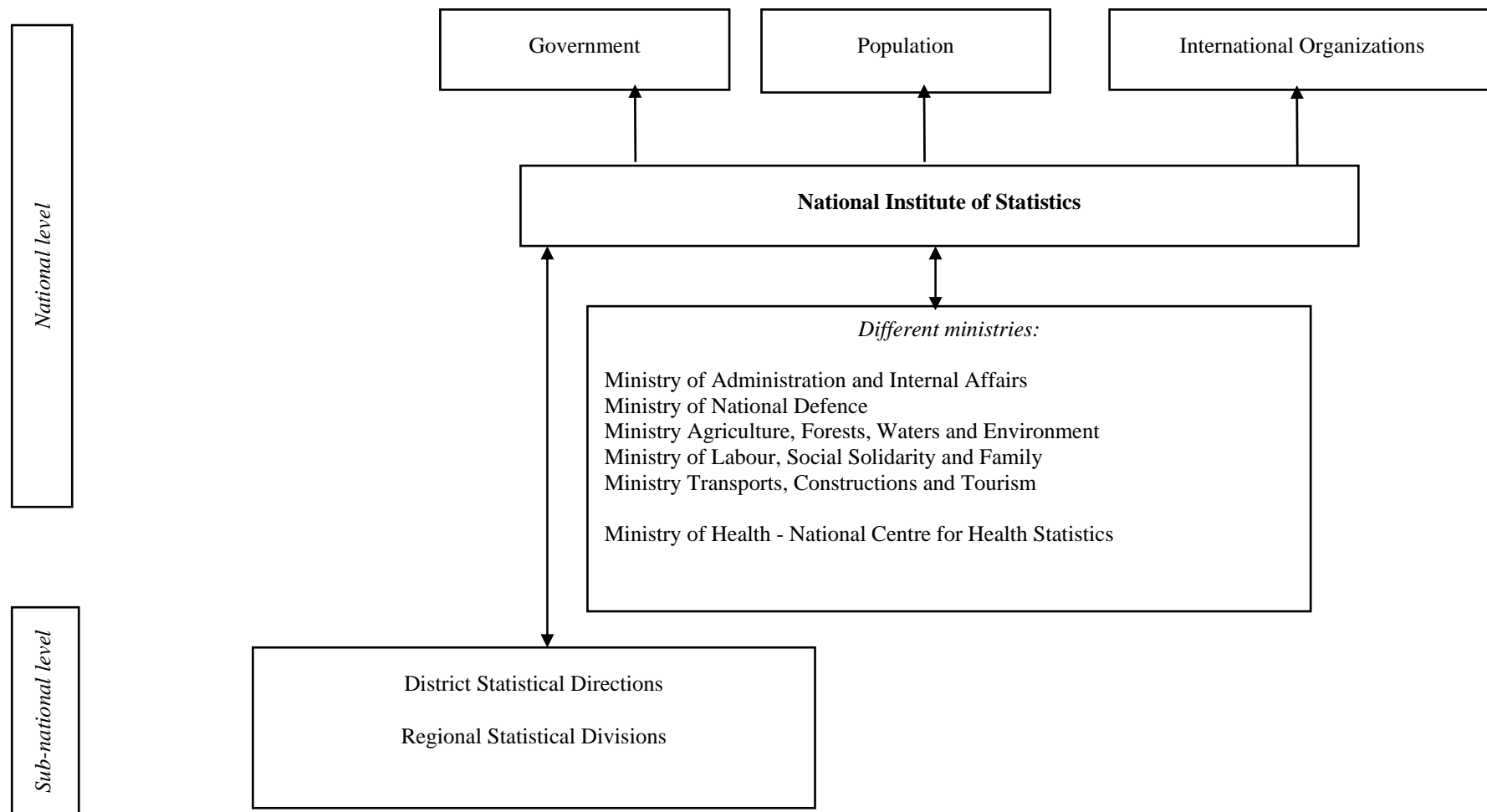
Weaknesses

- Long latency (the year book containing data for previous year are released in August–September of the following year);
- Published data are aggregated at district level;
- Limited accessibility to non-aggregated data (usually through financial mechanisms).

Statistical Year Book of Romania has special chapters on “Population”, “Health” and “Finances” which contain data and information on health status and some health determinants as housing, income, expenses and consumption, education, culture, etc. The Yearbook is published in book and is also available both on the Internet in .pdf format and on CD-Rom.

The chapter “Public health and social assistance” contains data on the network of health care, social units and their territorial distribution, the number and structure of the health professionals, the activity of medical units and its staff, and health status of the population.

Figure 13: The position of the National Institute of Statistics in the health information flow



11. Data and information from surveys, special studies and research

These sources of data are used by institutions inside and outside the health system. Under the conditions of chronic sub-financing in the health system, large-scale studies are scarce. These studies are often developed with methodological and financial support from international organizations such as World Bank, EU (through its programmes PHARE, Tempus, Socrate, PECO, Copernicus, FP5, FP6, etc.), WHO, UNICEF, USAID and others.

The access of users is generally limited to official publications, with a fee for ad hoc data extractions. The costs are usually high for Romanian institutions, particularly if access to non-aggregated data is requested.

Health status surveys

The Ministry of Health conducted health status surveys in 1959, 1964, 1977, 1983, 1989, and 1997, through the National Centre for Health Statistics. All these surveys were based on representative samples of the country population as well as the historical and geographical regions. The aim of these surveys was to gain information on prevalence of some chronic diseases and symptoms in the population. The data collected and the results of the last four surveys are comparable. They combine the results of the interviews with the clinical examination performed by family physicians and with the anthropometric and laboratory measurements.

In 1994, a survey on lifestyles and self-reported morbidity in the population was conducted. The data were representative for the country's population over 15 years of age.

One health problem in Romania, identified by international organizations using published data, was **reproductive health**. Three studies were conducted: national study on population reproduction (1993 and 1999) and the study on reproductive health in youth (1996). The studies were conducted in partnerships between Romania and the Centre for Diseases Control (USA), USAID, UNFPA and UNICEF.

The results of these studies were published and disseminated to the main categories of decision-makers. Some were also published in scientific papers and magazines.

12. Use of health information and databases developed by international organizations

The answers retrieved through the interviews showed that Romanian specialists scarcely use the databases developed by international organizations, although the necessary infrastructure is available (computers and Internet connection). A notable exception is the "Health for All Database" developed by WHO/EURO, consulted especially by the public health specialists. Friendly interface and free access facilitate its use.

Fee request for accessing the databases represents a barrier in data and information utilization.

13. Recommendations and Conclusion

The recommendations can be grouped under 14 categories:

1. *Setting up concerted actions for developing a Strategy of Health Information System and planning the **Health Information System Reform** and its implementation in the context of the Health System Reform:*

The HIS should become more coherent, efficient and powerful, by rationalizing data collection, expanding some of the existing data collection systems, but also by decreasing the volume of reported data and improving their utilization.

Among possible methods to conduct the HIS reform, the creation of small working groups (no more than 10 participants) on the main health topics/programmes which should be documented and monitored in the HIS, under the leadership of a Steering Committee, has yielded interesting results in Finland (reform of the Health Information System 2002-2003). Prioritizing activities would then be the responsibility of the Steering Committee, possibly with external support of international organizations such as WHO. It is not advisable to try and implement too many tasks, given the national budget limitations and the relatively weak political support.

The NHIS must be geared towards monitoring the national health policies while being harmonized with the strategies of the National Information System and with the regulations issued by the National Institute of Statistics, by the Ministry of Communication and Information Technology, as well as by those of international organizations with which there is a regular data exchange.

Requests of data from international agencies must have a subsidiary position relatively to health information needs of the country.

2. *Nominating a **coordinating organization** to ensure the coherence of the HIS system, redefining and distributing responsibilities among existing institutions:*

This will lead to greater efficiency in data collection by relieving current actors from double or triple reporting. Methods include data sharing and the use of data transfer agreements and protocols, as well as common concepts and standards to ensure data quality. Modifying the type of data, the collection method, or the level at which they are collected, will have a deep impact on the roles and responsibilities of the different actors. The mandate of the Steering Committee must be broad enough to allow for such major changes, for the sake of reducing the volume of data and simplifying it, while respecting the mission of each institution.

3. *Developing an **integrated HIS with a distributed structure** which coordinates between the different modules and flows:*

The NHIS review process revealed that each information flow has been developed in different directions because each was designed to meet specific needs imposed by the structure and the function of each flow. The striving to unify them into a unique integrated system with a monolithic structure confounds the component institutions. A modern HIS, more responsive to the public health information needs, requires the development of an integrated system with an interfaced and interconnected modular structure, with an emphasis on defining and designing the interfaces between the modules. This system will link the three

existing channels. It will assure intercommunication of data sets between institutions as well as the integrity of the data. This will improve the utilization of existing data and diminish the loss of presently collected data. A modular interfaced solution for HIS assures that the system is flexible and adapted to new requirements.

4. *Developing a **health information portal with a data bank of indicators**, with all data producing organizations as the main data sources:*

Developing a national electronic network of health and health-related data and information is the overall aim. This will allow online access to data with a low level of aggregation, respecting the confidentiality of individual data. The formats of the on-line data should allow their import and transfer into software that can process and analyze data according to various needs.

5. *Strengthening of the **co-operation capacity and partnership** between the Ministry of Health, the National Institute for Statistics, the National Health Insurance House, the Ministry of Communication and the Information Technology:*

This partnership is essential for the elaboration of the Strategy of Health Information System, the development and implementation of the Health Information System Reform. This co-operation would ensure the coordination of the HIS development, its proper and comprehensive functioning, access to accurate and timely data, as well as the maintenance of databases and registries. In addition, this collaboration is an important mean of ensuring data security, enabling linkages between databases and data sets as well as facilitating the exchange and implementation of knowledge into policy and practice.

6. *Promoting the simplified and supportive **legislative framework** to the HIS:*

Legislative incentives play a major role in Romania. It is important to complement the legislation, currently resulting in more or less well accepted obligations, by the construction of a strong common interest for data quality across institutions. Common use of the same data should be a strong incentive. There is a need for a simplified and powerful legislation in order to facilitate data collection and use. Public health data are a public good, and as such they should be free of charge for all producers and most users of the health system. There might be exceptionally fees for processing ad hoc data on specific requests. The creation of a legal framework for on-line access to data and information is needed, to enable and facilitate the free access to quality data with enforcement of confidentiality aspects.

7. *Establishing **national standards** to assure comparability and compatibility of data and information across various component institutions:*

Without standards, there can be no effective development of the information system. The development and the implementation of national standards of data definitions and for communication between computer systems will assure achievement of the feasibility of the entire HIS by: a) facilitating the sharing and the use of health information in the data collection and integration phase; b) permitting the comparability of results over time and location in the analysis and interpretation phase; c) expressing results in unambiguous terms in dissemination phase. The elaboration of national standards implies: 1) adopting standards for data: case definitions, coding and classification standards, defining the minimum set of variables to collect; 2) development of standards for electronic integration, for information technology and for communication, including health information exchange; 3) development

of quality standards for evaluation of data sources and for data information and dissemination; 4) development of consistent analysis methodologies.

8. *Defining the **content and periodicity** of the data and information, concentrating on what is useful and relevant for the stewardship function of the health system:*

The oversized volume of data collected by Romanian HIS, insufficiently used in decision-making, requires major refocusing. This implies defining more precisely who the users of the data are, identifying their needs and for which purposes the data are collected (monitoring and surveillance, planning, delivery of services, evaluation of interventions, administration, quality of care, resources availability and use, advocacy, fundraising, research, policy). The lists of relevant indicators as well as the data sources to feed into them are country-specific. However, WHO/EURO can provide advice, as well as facilitate the exchange of experiences with other countries.

9. *Introducing **quality control and quality assurance mechanisms** including automated validity checks and evaluation methods:*

There is a need for improving the quality of data entry and processing at all levels of the HIS. Methods and guidelines need to be developed and implemented for periodic and routine assessment of data quality in specific databases. Another important issue concerns the development of outcome validation and evaluation of different components of the HIS.

10. *Identifying and designing the appropriate **information technology support** and software applications which are necessary to make databases accessible and compatible to share data and to disseminate information products:*

This requires development of data warehouses, data marts and data-retrieval tools, as well as technology and applications for improved data exchanges, transfer and linkage across the systems.

11. *Defining the **expertise** that should be created or developed:*

Skills in data interpretation, reporting and dissemination need to be expanded, so that data become information and knowledge useful for decision-makers and health professionals. This can be achieved through training, seminars and recruitment in Public Health Institutions. Basic, post-graduate and ongoing education programmes in epidemiological and statistical methods, data management, and Public Health communication, are major areas for development.

12. *Promoting innovation and the use of data:*

This can be done by encouraging individual or institutional initiatives to collect and share data more efficiently, and by removing financial and technical obstacles to the use of data. Different types of products should be developed for the various target audiences with emphasis on short synthesis geared towards the current and future issues on the political agenda.

13. *Assuring the **sustainability** of a proper functioning of the HIS at national and local levels:*

Understaffing, unattractive salaries and obsolete data collection methods are major drawbacks to the effectiveness of the NHIS in Romania. Key issues of sustainability of the HIS are the provision of adequate human and financial resources, implying a significant budget increase for all relevant institutions. Improvement and provision of technological base of the HIS are one other important requirement. In addition, provision of the means and training to fully use the new technologies as well as the development of legislation and policy framework that pertain to the HIS are substantial components of sustainability. Strong collaboration between the Ministry of Health, the National Institute for Statistics, the National Health Insurance House, the Ministry of Communication and Information Technology and Ministry of Finance can play an important role in this aspect.

14. *Setting in place a **continuous mechanism for the assessment of the health information needs** rather than a one-time exercise, in order to respond to the rapidly evolving needs of the population and of the health system:*

This document is a starting point, but a detailed assessment of the NHIS must be conducted by the Romanian institutions themselves. Decision makers, specialists in health and other areas as well as authorities at the local and national levels perceive a great need for Health Information products in relevant, accessible and timely formats.

The above-mentioned Steering Committee could nominate a project leader or a group of core people who would follow-up the implementation of the priorities according to an agreed-upon action plan and evaluate the effectiveness of the changes.

However, the major challenges in Romania are to motivate Public Health professionals and decision-makers and to advocate for the importance of using health information and evidence in policy. It requires going beyond the present conflicting driving forces, and identifying a respected leader who can conduct the changes. The Ministry of Health could and should play a central role in reviewing and strengthening the NHIS, but other Ministries and institutions could also take the lead. Intersectoral links will need to be created along the way, since health is crucial to all aspects of development in Romania.

Annex 1

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Annex 2

List of interviewed key-informants

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Note: The representatives of the Ministry of Labour, Social Solidarity and Family could not participate.

* Interviewed without the presence of WHO representatives

Annex 3

Legislation

General legislation on information system, including the health information system

1. The Ordinance of the Government of Romania No. 9/1992, amended with the Law No. 311/2002 **On the organization of the official statistics** stipulates in article 3 (1) the principles of the public statistics: autonomy, confidentiality, transparency, specialization, proportional representation and statistical deontology. The National Institute of Statistics is the organizer and coordinator of the national statistical data fund. The stipulations in the law are obligatory for both individual and legal bodies, active in Romania. The scope of national statistics is to provide arguments and data in support of decision-making, policy-making, public opinion information and transmission of statistical data to international organizations in conformity with the official commitments of the Romanian State (article 1;1). This law also comprises the conditions of statistical data collection, processing and transmission.
2. The Law No. 677/2001 **On protection of the individuals, concerning personal data processing and the free circulation of these data**. The law has as main scope guaranteeing and protecting the fundamental rights and liberties of individuals, especially the right to private life. The first part of the law defines the following terms: personal data, personal data processing, storage and record system of personal data. This part of the law lists the categories of special data (health data is among them) for which free circulation is prohibited. The article 9 refers to exceptions in processing health data of the person.
3. The Law No. 86/2000 **For ratification of the Convention on access to information, public participation to decision-making and access to justice in environmental-related matters**, signed in Aarhus, Denmark, on 25 June 1998. The law stipulates the right of the population to obtain information related to the main determinants of health, both environmental and occupational.

Specific legislation for health information system

4. The Law No. 100/1998 **On public health assistance** regulates the entire public health activity. The law stipulates the attributions of different institutions involved in generating, retrieving, processing and using health data. This law contains articles concerning regulation on data and information management, as shown below. The article 12, paragraph (h), stipulates that the Ministry of Health “organizes the HIS in the field of public health assistance and the framework of data reporting in order to provide information on health status of the population” and paragraph (i) stipulates that available data are used “for periodical reporting issued for Government information on health status of the population”. The periodicity is not defined. The National Centre for Health Statistics is the specialized institution subordinated to the Ministry of Health, which is responsible for the organization of information system of health care activities (according to article No.11 in the Law). This institution is financed through state budget. Based on the methodologies elaborated by the National Centre for Health Statistics, “the District Public Health Directorates organize statistical information collection and processing, prepare the reports provided to the Ministry of Health and to the local authorities, according to the law statements, with respect to the confidentiality of data on individuals” (article 20). The confidentiality of data is also stated in article 30, and has to be respected at all levels: data collection, storage and processing.

5. Decision of the Government of Romania No. 22 from 2001 **On organization and functioning of the Ministry of Health and Family** details the attributions assigned to the Ministry in the area of information system. This was modified by Decision of Government No. 743, 8 July 2003 **On function of the Ministry of Health**. As stated in article 3, paragraph 9, the Ministry of Health “organizes the information system in the area of public health care and the framework of reporting by the medical units for identification of the health status of the population, analyses and evaluates periodically the health status indicators and the performance criteria for medical institutions”.
6. Order of Minister of Health and Family No. 120/2001 **On approval of the organization and functioning regulation of the District Public Health Directorate**, modified by Order of Minister of Health, No. 664, 9 July 2003 **On the approval of the structure of the Public Health Directorate**. The attributions assigned to the Public Health Directorates in relation with medical statistical information collection, storage and processing were fulfilled through the statistical and information office appointed in the organization chart and directly subordinated to the director. Since July 2003, the bureau has changed into a department and is released from direct subordination to the director. This change has had negative implications especially in terms of staff reductions. Chapter 1 contains in details the attributions assigned to the department: data collection from primary records, according to requests from the National Centre for Health Statistics, reporting, hierarchical and functional relations with other compartments from within the Public Health Directorate and with other institutions, both medical and from outside the health system (the National Institute of Statistics). The main activity of the statistics department is to organize and manage the database at county (district) level.
7. Order of the Health Ministry No. 868/2001 **On approval of the Methodology of establishment of the Unique Registry of nurses**. The Unique Registry of nurses represents a database containing records of all nurses licensed to practice. The records are centralized and updated at the Ministry of Health and at the Order of Nurses of Romania.
8. Order of the Minister of Health and Family No.1022/2002 **On pricing the services for a fee delivered by the National Centre for Health Statistics upon request from both individual and juridical bodies**. This order contains the list of all services that can be delivered and their prices. The order does not specify whether the fees apply to all requesters from within and outside the health system, whether they apply to all types of statistical data or only to the data that imply more sophisticated statistical processing.
9. Law No. 145/1997 the **Law of Social Health Insurance and Emergency Ordinance No. 150/2002 On organization and functioning the social health insurance system**. In section 3 named “Attributions of the insurance houses”, the article 64 (k) states as obligatory “the assurance of the organization of the information and unique integrated information system for the insured records and for management and administration of the fund”. The indicators used in data reporting within the health insurance system are unitary and are settled by the Ministry of Health at the proposal of National Health Insurance House and College of Physicians.
10. **The Constitution of the National Health Insurance House** approved through the Order of the National Health Insurance House No. 37/2001. In conformity with article 5, point 31, the National House “assures the necessary statistical recording for the specific activity of the social health insurance fund and collaborates with institutions with similar attributions in the field of statistics”. Within this framework, the National Health Insurance House has created its own system of reporting.

11. The Law No. 270/2003 the **Law on Hospitals**. The article. 10 states that the department of statistics is part of the organizational structure of the hospital. The article 31 states the obligation of the hospital to store, process and transfer information concerning its activity, in conformity with the regulations approved by the Ministry of Health. The hospital also has the obligation to supply the data to the District Public Health Directorate and to the insurance house. Equally, the hospital is responsible to ensure the data security on both, written and electronic documents, in conformity with the current legislation.
12. The Order of Minister of Health and Family No. 798/2002 **On the introduction in all hospitals the template of the "general clinical record of the patient"**.
13. The Order of Minister of Health and Family No. 29/2003 **On introducing the electronic minimum data set collection in Romanian hospitals** - the scope of this order is to introduce the "DRG National" application, recommending the organization or re-organization of the information statistics structure at each hospital level. This structure has as main task the generation of the necessary data in electronic format to introduce the DRG system in hospital financing. The institutions involved are the Ministry of Health and Family, the National Health Insurance House, the National Centre for Health Statistics, the National Institute of Research-Development in Public Health, the District Public Health Directorates and the hospitals.
14. The regular **Orders of Ministry of Health and Family and National Health Insurance House** for the adoption of the health sub-programmes and methodological norms of financing, reporting and indicators control are issued annually.
15. **The annual framework contracts between family physicians and insurance houses** stipulate the obligatory reporting to the insurance house, as well as to the District Public Health Directorates. The collaboration convention between Ministry of Health and National Health Insurance House for data exchange.
16. The Law No. 46/2003 **On patient's rights**. The law details two fundamental rights of the patient: the right to have information concerning the available medical services, the ways of using such services, their own health status, possible treatment, risks for health, etc. (articles 4–20), and the right to confidentiality of information and private life (articles 21–25) – the data are confidential both, during the lifetime of the patient, as well after his/her death. The confidential information can be used only in conformity with the law or the patient's consent. The exceptions refer to the situations when the patient represents a danger to him or her own self or to public health.
17. The Order of Minister of Health No. 8/2000 **On operative information in epidemiological and hygiene matters** specifies the types of events that the District Public Health Directorates report by telephone to the Ministry of Health, the direction of Preventive Medicine (currently the General Direction of Public Health) and to the territorial institutes of public health, as well as their status (the moment in time and frequency). A separate chapter contains the types of events and their status, that have to be reported by the family physicians, medical centres, hospitals outpatient department, regardless their affiliation to the public or private sector.
18. The Ordinance of the Government of Romania No. 53/2000 **On obligatory diseases reporting and vaccination**. The physicians, regardless of their organizational form within public or private sector, have the obligation to report all communicable and some non-communicable diseases, in conformity with the methodological norms of the Ministry of Health. The physicians from the

public sector comply with this reporting system, but this does not happen with the physicians from the private sector of health care. The data flows from private sector are not yet clearly defined.

19. The Order of Minister of Health and Family No. 141/2002 **On the organization of the national network of communicable diseases surveillance and control** – the annex 1 of the order stipulates the attributions and responsibilities of the institutions and units comprised in the network of communicable diseases survey and control. The reporting, transmission (transfer), process and analysis involve the following institutions: private or public primary health care units, specialized health care units, non-governmental organizations with authorized activity for health services in the area of communicable diseases survey and control, District Public Health Directorates, institutes of public health, the Institute of Communicable Diseases, the Institute of Pneumology, the National Institute of Haematology, the specialized network for sexually transmitted diseases.
20. The Order of Minister of Health and Family No. 91/2002 **On approval of “the National Programme of Tuberculosis Control 2001-2005”** specifies the case definitions (according to the WHO recommendations) used in the tuberculosis registry for different categories of patients (chapter 5), the format of various documents bearing information (annex no. 1–15) and their circuit (chapter 7).
21. The Order of Minister of Health and Family No. 871/2002 **On nominal reporting of patients with cancer and the record of cancer cases.** The differentiation between district and institutional cancer registries is made for the first time in Romania. The district registries are of highest importance for public health sector (particularly in elaborating, implementing and evaluating the national oncology programme). Both district and institutional registries are needed for public health planning. The national cancer registry is maintained by the National Centre for Health Statistics.

The order states the data generation, data flow, primary records (diagnosis, reporting, transmission, recording and out-recording the patients with cancer). Each oncology medical office and family physician office has the special records registry, the template of patient with cancer record, and the statistical record of the patient with cancer ONC 1 (of entering the records) and ONC 2 (of out-records). In its present conception, the registry is only partially compatible with the registry recommended by IARC. The differences are particularly in the chapter referring to the diagnostic modality and diagnostic coding. The diagnostic coding does not use the ICD–ONC coding system. The following institutions are involved in the implementation of the order: the Ministry of Health and Family (General Direction of Medical Care), the National Centre for Health Statistics, the Institutes of Oncology of Bucharest and Cluj, the DPHDs.

22. The Order No. 889/1998 **On introduction of the HIV reporting system and approval of the methodology** - the order contains the case definitions (according to the WHO recommendations), the information bearer documents and their flow.

The diagnostic, reporting and storage of data on occupational diseases are stipulated in the Law No. 90/1996 **On Occupational Safety and General Norms of Occupational Security from 2002.**

Annex 4

List of Institutes and Centres of Public Health, Medical Health Care Institutes and National Institutes of Research-Development subordinated to the Ministry of Health

These institutes are active participants as health-related data and information producers and users.

	Name of the institution	The national programme coordinated or in whose implementation participates
	Institutes and Centres of Public Health	
1	Institute of Public Health Bucharest	Evaluation of the health status and risk factors Survey of communicable diseases
2	Institute of Public Health Cluj Napoca	Evaluation of the health status and risk factors Survey of communicable diseases
3	Institute of Public Health Iasi	Evaluation of the health status and risk factors Survey of communicable diseases
4	Institute of Public Health Timisoara	Evaluation of the health status and risk factors Survey of communicable diseases
5	Centres of Public Health Targu Mures and Sibiu	Evaluation of the health status and risk factors Survey of communicable diseases
	National Institutes of Research-Development	
1	National Institute of Research-Development in Microbiology and Immunology "I. Cantacuzino"	Survey of communicable diseases
2	National Institute of Research-Development in Public Health	Implementation of the new resources allocation system based on DRG Health promotion and Education for Health
	Medical Health Care Institutes	
1	Institute for Maternal and child care	National programme of maternal and child health with all 19 sub-programmes
2	Institute of Communicable Diseases "Matei Bals"	HIV/AIDS infections survey
3	Institute of Pneumology "Marius Nasta"	Tuberculosis control
4	National Institute of Transfusion Haematology	Haematology and transfusion safety Prevention and control of haemophilia and thalassaemia
5	Institute of Cardiovascular Diseases Bucharest	Prevention and control of cardio-vascular diseases
6	Institute of Oncology Bucharest	Prevention and control in cancerous pathology
7	Institute of Cerebrovascular Bucharest	Prevention and early diagnosis in neurological diseases
8	Institute of Diabetes, Nutrition and Metabolic Diseases Bucharest	Prevention and control of nutrition diseases
9	Clinical Hospital of Psychiatry Bucharest	Prophylaxis of psychiatric and psycho-social pathology
10	Clinical Emergency Hospital "St. Ioan" Bucharest	Prevention in nephrologic pathology and dialysis
11	Institute of Endocrinology Bucharest	Prevention in endocrine pathology

Annex 5

The example of the frequency of chronic diseases in the population

The number of cases of disease reported by the health care services compared to the number of diagnostics reported in the population following a medical examination (data retrieved through an interview survey performed by National Centre for Health Statistics) leads to the situation illustrated in the following table.

Discrepancy between diagnoses known by the patients as a result of a medical examination and diagnoses obtained from medical records of family physicians

Diagnosis	Number of patients with diagnoses , Health Examination Survey (A)	Number of patients with diagnoses, medical records of family physicians (B)	Percentage (B/A) ×100
Hypertension	2 713 894	891 074	32.83
Ischemic cardiac diseases	2 127 106	547 729	25.74
Cardiovascular diseases	311 731	101 634	32.60
Ulcer	825 170	179 600	21.76
Chronic hepatitis and cirrhosis	550 114	12 241	21.85
Cor pulmonae	550 000	31 887	5.79
Diabetes mellitus	348 405	255 188	73.24
Anaemia	730 485	75 809	10.37

Source: Ionescu, T. Chronic Diseases Public Health Priority in Romania, 2001, NCHS. Bucharest. Romania.

This discrepancy can be explained on one hand by the lack of communication between the family physicians and the specialists from outpatient-departments and hospitals, and, on the other hand, by the patient bypassing the primary medicine, in the sense that he/she will approach directly the outpatient-department or the hospital. The whole population is not enrolled on family physicians lists; therefore, the pathology of the unregistered group is unknown and not included into the family physician's reports.

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