HEALTH INFORMATION SYSTEM

REPORT FROM PORTUGAL

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Abbreviations List:

RHA – Regional Health Administrations
PC – Psychiatric Census
DHRM – Department for Human Resources and Modernization
GDH – General Directorate of Health
HDG – Homogenous Diagnose Groups
GP – General Practitioner
HIS – Health Information System
HM – Health Minister
CFMI – Ministry of Health's Computer and Financial Management Institute
SP – Sentinel Physicians
NHI – National Health Institute
NHS – National Health Survey
NIS – National Institute of Statistics
AR – Autonomous Regions
ROR – Regional Oncology Records
NHS – National Health Service
LMI – Legal Medicine Institute
ISTS – Information Systems' Technical Secretariate

ARS – Administrações Regionais de Saúde
CP – Censo Psiquiátrico
DRHM – Departamento de Recursos Humanos e Modernização
DGS – Direcção-Geral da Saúde
GDH – Grupos de Diagnóstico Homogéneos
MF - Médico de Família
SIS - Sistema de Informação da Saúde
MS - Ministro da Saúde
IGIF – Instituto de Gestão Informática e Financeira do Ministério da Saúde
MS – Médicos-Sentinela
INS - Instituto Nacional de Saúde
INS - Inquérito Nacional de Saúde
INE - Instituto Nacional de Estatística
RA – Regiões Autónomas
ROR – Registos Oncológicos Regionais
SNS – Serviço Nacional de Saúde
IML – Instituto de Medicina Legal
SETESI – Secretariado Técnico para os Sistemas de Informação

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Abstract

The data necessary to the making of this project were obtained via a consultation of several legal and normative documents, and of other bibliographical sources. These sources were complemented with interviews to keys informers that are related to the various processes of coordination, recollection, transmission and analysis.

In Portugal, there is not a coordinating legislation nor an explicit strategy for the development and coordination of the Health Information System. The Health Information System has as legislative basis the Health Statute Law, the several organic laws of the Departments of the Ministry of Health. The key exceptions to this are the Information Systems related to Mortality (a joint responsibility of the National Institute of Statistics and of the General Directorate of Health) and to Transmissible Diseases of Mandatory Notification.

The Systems related to socio-economical and demographic statistics, of the responsibility of the National Institute of Statistics, have grounds on both this Institute's own legislation and on specific legislation for each area.

Mortality statistics, although exhaustive, have deficient quality, and the information production is excessively slow to have effectiveness in terms of short-term Public Health Policies.

The Information System for Transmissible Diseases of Mandatory Notification, despite the fact that it in general presents a sub-notification of unknown dimensions, has been responsive in relation to some diseases, thus allowing the occurrence of adequate interventions in an useful time span.

Information Systems related to the Health System performance are in general exhaustive, however the use of them by decision-making organs is not always sufficiently extensive and its connection to the Epidemiological surveillance systems is deficient or even null.

The main problems with the Health Information System are the lack of a strategic vision, insufficient quality control mechanisms, difficulties in coordination, slowness on information production, lack of access in relation to some of its components, and little adequacy to epidemiological surveillance needs.

The changes that are occurring on the National Health Service, mainly with the business management strategies that are being implemented in some hospitals, brings increased coordination difficulties but it simultaneously raises political needs to obtain a greater control and effectiveness of the information system. In this way, if the Health reform may be able to be a source of threats on one hand, it is also an opportunity for the reform of the Health Information System.

Description and Analysis of the System

HIS Policies, including legislation, and plans

The health system is based on a National Health Service, with Health Centres, where the GP's work, and Hospitals. The NHS depends directly from the Ministry of Health and is divided into five Health Regions – North, Center, Lisbon and Tagus Valley, Alentejo and Algarve – and two Autonomous Regions, Madeira and Azores. Portugal is not a federative State, but it has two autonomous Regions. These hold their own specific competences in the Health area, although on general terms there are not great differences between the NHS on the Continental territory and in the Autonomous Regions.

In the Continental territory the Health Region's Administration Boards are nominated by the Minister of Health, and in the Autonomous Regions the NHS is coordinated by their respective Regional Health Secretaries, chosen by the President of each of the Autonomous Regions Government.

The main organisms of the Ministry of Health are:

- The General Directorate of Health
- The Ministry of Health's Computer and Financial Management Institute
- The Department for Modernization and Health Resources
- The General Directorate for Installations and Health Equipments
- The National Institute of Pharmacy and Medication
- The Dr. Ricardo Jorge National Health Institute
- The National Institute for Medical Emergency
- The Portuguese Blood Institute
- The General Health Inspection

In Portugal, there is no statute law solely related to HIS. The several components of HIS have legal support in laws not specifically made for HIS. A great part of the HIS subsystems derives from generic information-related functions that appear in the organic laws for the several departments of the Ministry of Health and the NHS.

Parts of the information subsystems have legal support, not on laws, but in normative documentation.

The main exception concerns the health statistics published by NIS, who have specific legislation, particularly when it comes to mortality statistics.

The chief legal documents who support HIS are the organic laws for the central Health Ministry departments, namely the GDH, IGIF / CFMI, INSA, the law that established the Health Regions in the NHS, and the Health Statute Law.

There is not a formal policy for HIS, however the need for it has been recognized; a model for HIS has been in discussion for about a year already, and some documentation about it has been already produced in order to support that discussion.

In this context, a Technical Secretariate for Information Systems was created, in the dependence of the High-Commissioner for Health and coordinated by the Service Director for Information and Analysis of the GDH, with the objectives of proposing a strategy for the HIS, and of establishing a place of coordination for the several organisms of the Ministry of Health who have responsibilities in the HIS.

In the meantime, the Technical Secretariate for Information Systems is inactive and political facts suggest that the position of High Commissioner is either to be extinct or its functions will be profoundly changed in nature.

Roles and responsibilities

Involved in the HIS are several entities specific to the Health system (GHD / DGS, NHI / INS, CFMI / IGIF, DHRM / DRHM, ROR, RHA / ARS, AR / RA) and also others outside the Health System (NIS / INE, Scientific Societies, Sentinel Physicians).

Population and socio-economic factors relevant to health status

In Portugal, INS is responsible for the elaboration of demographic and socio-economic statistics.

Once every decade, on the years ending in 1, the General Population and Residential Census is made. On the years between these censuses, the NIS produces population estimates.

Health status

Mortality

Mortality statistics come to life out of the collaboration between GDH and the NIS. NIS is the holder of the database while GDH is, by law, the entity delegated by the NIS in order to produce death causes codification.

The death certificate is, by law, defined and designed by the GDH.

The mortality statistics system also includes the Civil Records Conservatories.

The physician that certifies the obit hands the DC (death certificate / certificado de óbito) to the deceased's family, in practice to the funeral houses, who delivers them to the Civil Records conservatories; they then transcribe it into an obit form and fill it in with the demographic and socio-economic data pertaining to the deceased. This form goes then to NIS who inserts the data onto a database and sends the form to GDH. After making the codification of death causes, GDH resends the form to NIS who then inserts on the database that death causes codification.

NIS produces the simpler statistics (absolute numbers) while GDH publishes both raw and adjusted mortality rates.

Morbidity

The Health Information Survey is currently done by the National Observatory of Health, located on INSA, without any set schedule. So far, three Health Surveys were made.

Cancer Statistics

Cancer statistics are coordinated by the Oncology Register, who in practice splits into three ROR (North, Centre and South). It is intended for the OR to be systematic, obtaining data from hospitals (clinical and laboratorial) and from GP's. The ROR are located in the Oncology Institutes (there are three of them: on the north, centre and south). The data is sent by physicians (from the hospitals or GP's) or by anatomo-pathology laboratories either through a hardcopy form or electronically transmitted.

Mental Health Statistics

GDH makes, without a set schedule, the Psychiatric Census, already on its third edition, the last one during 2001. That Psychiatric Census was carried out during a week, comprising public, private and religious institutions. The Census does not comprise psychiatrists and psychologist's offices.

The Psychiatric Census intends to characterize the patients who in the space of one week seeked an appointment or a psychiatric emergency service, or who were institutionalised in a psychiatric infirmary.

The last Psychiatric Census was the only one who engaged general hospitals with Psychiatry services along with private and religious institutions.

Transmissible diseases of mandatory notification

Since 1927, there is a set system for the survey of transmissible diseases; its information system is controlled by GDH. All physicians are required to report the occurrence of a group of transmissible diseases. The list of diseases to report is updated with some regularity; its last update was made on January 2001.

The report is sent to the county health authority that, besides coordinating the first intervention, sends, if necessary, a copy to the regional health authority and to GDH.

All cases outlined in the list of transmissible diseases of mandatory notification have a set case definition for its notification.

The entire system is set on clinical report, with the exception of the meningococcemia disease, that since 2002 has a component of laboratorial report.

Sentinel-Physicians

SP is a network of voluntary GP who reports a number of diseases that change with some regularity. Though independent, they are actually coordinated by the ONSA.

SP are the basic clinical structure for influenza surveillance.

Determinants of Health

The information related to a great part of the socio-economic and educational determinants of health is produced by NHI and obtained via its periodical inquiries and through the General Population Census. NIS publishes periodically statistics related to the economical situation, unemployment, education, etc..

NIS also publishes healthcare related statistics that include public services (its data provided by the Ministry of Health) and private services (data provided by inquiries).

Information systems related to environmental determinants are of the responsibility of GDH (domestic and recreational water supply) and of the Ministry of Environment (water and air quality and noise).

HIS does not comprise other determinants and the available information comes from specific surveys.

Health System

GDH is responsible for the information system related to the production of NHS services (hospitals and health centres).

The information system related with vaccination is of the responsibility of the GDH. This system is exhaustive and it allows the detection of children without adequate vaccination coverage in accordance to the directives (Guidelines) of the National Vaccination Plan.

In regard to primary health care, that part of the information system contains data related to the number of professionals (physicians, nurses, technicians and others), and number of appointments in relation to age group, gender, and medical specialties. It also supplies information about the use of diagnose exams.

In regard to hospitals, it supplies information related to appointments, internments, emergencies, surgical activity and complementary diagnose exams.

The information system related to homogenous diagnose groups is of the responsibility of the CFMI / IGIF. It supplies information about the internments and, although it has not been the initial objective, it also supplies information about the motives of internments. It also supplies important information about costs for pathology and by procedure. This database is shared by CFMI and GDH. Though not exclusively, CFMI supplies information of a more economical ground while GDH occupies itself of the epidemiological part.

The financial information system is the responsibility of CFMI, who gets the information from the Health Regions.

Coordination Mechanisms

Some IS subsystems have quite strong inter-organization coordination mechanisms between them. Namely, the information system related to mortality. The two responsible institutions (GDH and NIS) have permanent contact mechanisms between them, in at least a weekly basis. On the other hand, the NIS also has its own permanent coordination mechanisms with the Civil Record Conservatories.

Two of the institutions important in the mortality system are the Legal Medicine Institute and the Hospitals. Coordination with these institutions is more complex, with difficulties arising mainly with the hospitals. In the case of LMI there has been a reinforcement in coordination, with periodical information about obits subject to a medico-legal autopsy being available from at least two regional LMI centres.

In relation to the system of transmissible diseases of mandatory notification, the coordination with regional and local health authorities is good, although it needs to be reinforced in some respects.

In a general fashion, the several subsystems have satisfactory vertical coordination mechanisms, although insufficient. The main problem lies in the coordination mechanisms between institutions that are not vertically related, as is the case between the GDH and the CFMI / IGIF. In this particular case, the coordination mechanisms are quite insufficient, with the GDH limited to receiving only the copies of the databases related to the HDG / GDH.

One of the objectives of the creation of the ISTS / SETESI was the establishment of a coordinating organ for the HIS. However, it still hasn't been able to institute coordination mechanisms able to perform that in effectiveness.

SWOT Analysis

	Strengths	Weaknesses	Opportunities	Threats
Mortality	.Exhaustive .Adequate coordination mechanism	.Excess of mortality by ill-defined signs and symptoms .Poor quality of the death certificate .Insufficient number of autopsies .The information chain is slow, not allowing quick and adequate responses in order to comply to Public Health needs	.Improvement of the electronical communication systems .New quality control mechanisms introduced in 2001	.Changes on the GDH Organic Law .Low sensibility by the part of politicians to mortality related problems
Transmissible Diseases	.Sensitive on some diseases (i.e.: mumps, meningococcic meningitis .Good coverage on tuberculosis .Sufficient quality control system based on Health authorities	.Sub-notification of most of the diseases .Diseases with ridiculous notification figures (i.e.: sexually transmissible diseases) .Excessively slow communication .Inexistence of laboratorial notification for most diseases	.Possible improvement of electronical communication systems .Creation of Regional Public Health Centres .Alterations on the transmissible diseases of mandatory notification List and introduction of laboratorial basis notification .Introduction of laboratorial notification of meningococcic meningitis in the scope of SARA	.Low sensibility on the part of physicians for the notification
GDH	.Exhaustiveness	.Deficient quality (variables that are insufficiently filled and minimal quality control mechanisms)	.Introduction of the CID 10	.New hospital management models

Sentinel-Physicians	.Voluntariness and commitment .Influenza surveillance system	.No national representativity .Poorly substantial surveys		.Lack of motivation of GP's for lack of official support
ROR	.National coverage	.Significant delays on data sending	.Greater sensibility from the executive organs in regard to cancer problems	.Lack of motivation from both the physicians and the services .Insufficient resources .Three regional records without methodological consolidation
Health System	.Coverage of all the Hospitals and Health Centres	.Slowness on some of the processes, which prevents its use, in effectiveness, on epidemiological surveillance	.New necessities imposed by the development of the NHS	.Introduction of new models of business management on Public Hospitals