

# Health information systems

## Introduction

From the moment when the political model for health protection established by the Spanish Constitution took shape in 1986 as the National Health System<sup>59</sup>, its conceptual framework has included universal coverage, equity, comprehensive healthcare, efficiency and quality. The assignation of the principal responsibilities in terms of planning, management and evaluation of its services to the autonomous communities defines its decentralized character while also converging with the principle of solidarity between regions so that social and territorial imbalances can be overcome.

A model of health services of this nature must rely on effective measures of cohesion which can sustain this character of being a *system*, in the sense of a group of related entities and activities, which pursue specific objectives for the protection of the health of the population residing in Spain.

One of these elements is the Health Information System (HIS-NHS), considered an essential instrument for the operational cohesion and guaranteed quality which the National Health System requires<sup>60</sup>.

The creation of the Health Information Institute in 2003 as an organ of the Ministry of Health and Consumers' Affairs with the responsibility for developing and maintaining the HIS-NHS is a demonstration of the firm commitment of the Spanish parliament to guarantee the availability of reciprocal information and communication between the health administration of the state and the autonomous communities.

## The Health Information System of the NHS: development and maintenance strategy

The HIS-NHS is one of the crucial elements in the bid to overcome the challenges posed by the complex organizational situation of the National Health System and the demands for more and better information about the public health services which are being made by the citizens, whether in the role of patients, professionals or the health administrations themselves.

59 Act 14/1986, General Health.

60 Act 16/2003, of Cohesion and Quality in the National Health System.

This was the wording under which its construction was begun in 2004 on the foundation of unquestionable technical credibility and neutrality within the National Health System. Its acceptance among the users of the service could only be obtained by means of enormous input from the generators and users of the information in its development, and a permanent effort towards transparency.

Obviously the HIS-NHS had to be loaded with data, taking advantage of the existing health statistics which provided a wealth of information about the level of health, resources, activities, expenditure and some results. However, these were all organized, in essence, as a descriptive repertoire of statistical operations which were independent of each other. While they did provide a lot of useful data, there were serious limitations when it came to evaluating the objectives of the National Health System.

For this reason it was felt that the HIS-NHS should evolve towards the handling of information rather than the handling of data, and it would then generate the facts that the different clients required: in first place, the public which is constantly better informed and more demanding as regards its health and which has increased expectations of the quality of the services; secondly there are the medical personnel who are more and more involved in the management of resources and committed to making scientific advances available as far as resources allow; and finally the health authorities who, in a context of limited resources, have to juggle efficiency and quality with the aim of achieving a good level of health and satisfy the expectations of the public and the professionals.

In keeping with this purpose, the strategy for developing the HIS-NHS, which was presented to the Interterritorial Board by the Institute of Health Information in 2004, was founded on the management of content from the viewpoint of a comprehensive healthcare service, making information available on the protected population, services and standards, human and material resources, activities undertaken, pharmacy and health products, financing, results obtained and the expectations and opinions of the public.

To achieve all this and to redirect the existing statistics so that this information could be incorporated, new statistics would be needed to cover the information that was lacking. This was the case in primary care, specialized outpatient care or the mental health of the population, among others.

Other criteria established for the development of the HIS-NHS were the use of explicit methods which offered technical rigour and enabled the distribution of reliable, appropriate, up-to-date information to meet the needs of the different users.

Even so, the indispensable requirement for reaching these goals lay in engaging the real involvement of the agents of the Health System in the

process. To achieve this, the Ministry of Health and Consumers' Affairs and the autonomous communities have worked closely together in the development of the HIS-NHS. The Sub-committee on Information Systems, which is made up of the representatives of the Ministry and the Health Departments with responsibilities in this area, is the development forum to update and advance the existing information systems and discuss proposals for the improvement of information, although these are always submitted to the Interterritorial Board for approval.

## The Health Information System of the National Health System in 2007 (HIS-NHS)

The situation in 2007 reveals considerable advances in the quality, quantity and relevance of the information available on health and the health service in Spain.

The series of improvements which have been applied to the existing health statistics and the opening of new sub-systems of information, a term which is intended to go beyond the limited concept of *statistics*, reveal a panorama which can be considered optimistic.

### The processes of obtaining and analysing the information

Our knowledge of the characteristics and distribution of morbidity perceived by the Spanish population and other health-related habits and behaviour have improved and been brought up-to-date in 2007 through the *National Health Survey* which was carried out in 2006<sup>61</sup>. It also explores the ways in which the population uses the health services, and relates all these characteristics to each other and a series of personal, demographic and territorial variables.

This survey, which the Ministry of Health and Consumers' Affairs began in 1987, had maintained a stable range of content over the years, but the transformations in terms of health protection, service provision, epidemiological patterns, technology and other factors, prompted the survey to adapt to the new circumstances in health and in society. To achieve this, it was decided to review and update some of the aspects of the survey without interrupting its historical progression. A priority in this review has been to reinforce the survey as an instrument for the detection and measurement

61 The National Health Survey is carried out by the Ministry of Health and Consumers' Affairs, dates from 1987 and is produced with the collaboration of the National Statistics Institute.

of health inequalities, especially in relation with gender and social class. It also incorporated dimensions which have not previously been explored in relation with public health, as in the case of mental health, and the determinants of health in relation with the physical and social environment. Similarly, there has been a reformulation of certain questions to begin the process of adapting the survey to the requirements of the European Health Survey Project. Other sections of this report show some of the results of this survey.

The years 2006 and 2007 have seen the start of the *Primary Care Information System* (SIAP) which covers the resources and services available, and the organization of these. A catalogue of primary care centres has been drawn up and the criteria for collecting data at this first level of care have been agreed with the autonomous communities, to become available in 2008. The time frame in which this information system should reach its stage of maximum development is estimated to be in four years, and one of its principle landmarks is the analysis of the care process. The computerisation of medical records, with standard criteria for using the content, is considered to be a tool which facilitates this project.

The information system for *waiting lists* (HIS-WL) went into operation in 2004 with the information on surgical waiting lists from 2003. It therefore had five years of data consisting of nine readings at six-monthly intervals, the coherence and stability of which supports the appropriateness of the methodology employed.

The autonomous communities have made a significant effort to improve their information systems, applying a common methodology which enables them to obtain figures for the National Health System through aggregation and handling of compatible data. Obtaining this information for the whole country can be considered an achievement, because despite the concern that most of the health systems which resemble ours have shown over their waiting lists, very few of them have managed to obtain and publish this data on a national scale. If, as in the case of Spain, the country has also engaged upon the complete decentralization of its health services, achieving this level of detail is an immense source of satisfaction for the possibilities it affords for improvements and transparency in the public service.

The publication of this information is carried out in accordance with the terms agreed by the Interterritorial Board of the National Health System. The Ministry of Health and Consumers' Affairs releases the aggregate figures for the national level and each autonomous community takes responsibility for publishing the information which refers to its own territory.

Since January 2005, the Ministry of Health and Consumers' Affairs also has a system necessary for compiling and handling the data on waiting lists provided by *external consultants and diagnostic tests*.

With reference to external consultants, while not all the autonomous communities possess this system of information, it has been possible since December 2006 to offer an approximation of the situation in the National Health System as a whole based on its larger numbers, drawn from the data provided by the 15 health departments. As regards the diagnostic tests, although the data from 13 health services have been collected, it is not possible to offer information on the indicators with sufficient guarantees of reliability, given the variability of this data and indicators among the autonomous communities and the different level of precision of these.

It is therefore necessary in the case of these two sub-systems to complete their development and improve the base of the information systems which the autonomous communities use in creating these statistics.

Work has been done on extending the range of the *minimum basic data set (MBDS)* to include hospital admissions, both in terms of other services (outpatient care for day surgery and day hospital), and other types of centres so that all activity, whether public or private, can be included. In both cases, the availability of data is very far advanced (table 57).

The new model and the axes for the analysis of hospital admissions in the NHS are currently in development. They combine a series of operational and quality indicators for hospitals based on data contained in the admissions register (MBDS). An application in a web page enables consultation of the results and adjustments for the variables and references points for improved performance.

A pilot scheme for the establishment of new statistics in medical institutions with inpatient facilities (ESCRI) is also under way which will provide information on structure, activity and expenses in Spanish hospitals, created in consensus with the autonomous communities and statistics users. The objective is to adapt the contents to the new models of organization. The new variables to be analysed have been prepared for both hospitals and centres for specialised care.

The *National Death Index (NDI)* was set up in 2006 and contains the personal data of each and every death included in the civil registers across the country from 1987 to the present, which means there are 7 million entries at the disposition of the health sector.

Its purpose is to provide data for the information systems used to deal with patient management, health administration and control, maintenance of data on diseases, public health monitoring, obtaining statistics and the carrying out of epidemiological studies or medical research.

The personal data included in the NDI can be released, for the purposes mentioned previously, to public health centres or establishments which provide treatments, public health administrations and public research centres. It should be noted that they contain no information relating to the cause of death, which may limit their usefulness in some studies.

**TABLE 57. Causes of hospitalisation in the National Health System, 2007**

Chapter	Women		Men	
	Percentage	Cases	Percentage	Cases
Infectious diseases and parasites	1.57	30,028	2.62	43,775
Neoplasia	8.05	154,301	10.43	174,519
Endocrine, Nutrition and Metabolic disorders, and Immune system disorders	1.93	36,998	1.62	27,151
Diseases of the blood and haematopoietic organs	0.96	18,346	1.00	16,817
Mental disease	1.75	33,612	2.46	41,241
Disorders of the nervous system and sense organs	2.98	57,026	3.34	55,901
Diseases of the circulatory system	11.13	213,159	16.77	280,644
Diseases of respiratory system	7.94	152,182	14.42	241,295
Diseases of the digestive system	9.67	185,343	14.77	247,148
Diseases of the genitourinary system	6.18	118,368	5.45	91,196
Complications in pregnancy, birth and post-natal period	25.87	495,626	-	-
Diseases of the skin and subcutaneous tissues	0.84	16,017	1.19	19,963
Diseases of the muscular and skeletal apparatus and of the connective tissue	5.42	103,750	4.74	79,387
Congenital anomalies	0.69	13,193	1.16	19,382
Conditions originating in the perinatal period	1.45	27,853	2.04	34,075
Poorly defined symptoms, signs and conditions	3.57	68,451	5.06	84,660
Injuries and intoxications	7.11	136,248	9.38	156,973
Annex: supplementary classification of factors influencing conditions of health and contact with health services	2.36	45,248	2.88	48,200
Others	0.52	10,042	0.68	11,344
<b>Total</b>		<b>1,915,791</b>		<b>1,673,671</b>

For the sake of these statistics, the National Health System includes public hospitals, hospitals in the network of public use and hospitals with substitute contracts. Psychiatric hospitals and long-stay hospitals are excluded.

Source: Ministry of Health and Consumers' Affairs. Register of Hospital Admissions (MBDS), 2006.

The *Health barometer*, an annual nationwide study, reveals the opinion that the general public holds on health services. The conclusions are of great interest in establishing the priorities of the health administrations and in creating the corresponding health policies.

The Barometer has a permanent section on the operation of the system which is repeated in each edition of the survey, and a variable part which is aimed at exploring questions of current concern. The 2007 edition explored the level of confidence in the work of the health professionals and an evaluation of the errors related with health services. There has also been an investigation into the use of services in autonomous communities other than one's own and the opportunity to have access to clinical information from any point within the health system.

The results of 2007, in general, reflect a positive opinion as regards the different elements that form part of the analysis every year, the evaluation of the operation of the system, evaluation of the public health services in primary care and outpatient treatment for specialised care and hospitalisation, waiting lists and the rational use of medicines.

67.4 % of the general public are of the opinion that the National Health System functions correctly; only 4.7 % feel that it should be completely overhauled. Almost 27 % of the public think that some important changes are needed in order for the system to improve (table 58).

**TABLE 58. The general public and the health service, 2007**

Positive opinion	67.4 %
Needs fundamental changes	26.9 %
Needs complete overhaul	4.7 %
NC	1.1 %

NC, No Comment. From the Ministry of Health and Consumers' Affairs-CIS.  
Data extracted from the health barometer 2007.

As regards the changes that have occurred in the last five years in the services rendered by the NHS, the most common opinion expressed in 2007 was that primary care, outpatient care and hospitalisation have all improved (table 59).

**TABLE 59. Opinion on the evolution of services, 2007**

	Primary care (%)	External consultations (%)	Hospitalisation (%)
Has improved	47.4	40.5	42.3
No change	40.3	41.1	39.8
Has worsened	5.9	6.9	6.4
NC	6.4	11.4	11.4

NC, No Comment From the Ministry of Health and Consumers' Affairs-CIS.  
Data extracted from the health barometer 2007.

## Associating information

The construction of the *key indicators of the National Health System* during 2006 and their presentation before the Interterritorial Board in December 2007 has been one of the most notable achievements of the HIS-NHS as it represents the first prioritised data set which includes the aspects held to be most relevant for health and the Spanish health system.

The first project for the integration of indicators was based on 4 main subjects of analysis: population, health conditions, determinants and the health system, with the latter including the aspects of accessibility, resources, use, quality and results of care.

The *selection of indicators* has been carried out by consensus between the health administrations represented in the *Interterritorial Board of the National Health System*, which approved an initial list of 110 indicators in its plenary session in March 2007. In the full session of the Interterritorial Board of the 12<sup>th</sup> of December 2007, the first database was delivered to the heads of the health departments of the autonomous communities.

The methodological framework of reference was the ECHI (European Community Health Indicators) project of the European Commission. The indicators were related to *population, the state of health and its determinants, the availability of resources, the activity, quality, cost and public satisfaction.*

It included widely used indicators, both in our own system and in those of neighbouring countries, and indicators aligned with the proposed lines of work that different international organisms were developing (Eurostat, DG Sanco [General Management of Health and Protection of the Consumer], WHO and OECD). Indicators derived from the health strategies of the NHS approved by the Interterritorial Board were also included.

As its general criteria, the data was *available in aggregate form for the whole NHS and broken down for each autonomous community.* It is a rule now that the gender perspective must also be included in the construction of the indicators.

The database which was built for the distribution of the data uses a software application of the WHO which has been adapted for Spain. The data proceeds, in every instance, from *official sources of statistics.*

## Plan for access to the data and distribution of the information

The application of the principles of transparency, accessibility and quality to the Information System of the National Health System means that the data and information collected and prepared by the Ministry of Health



and Consumers' Affairs are published regularly and at established times, ensuring that there is minimal lag between their production and distribution, using provisional data and information, keeping to public timetables and the most appropriate formats which will permit their integration, study and analysis.

A calendar has been created on the web page of the Ministry which publicizes the forecasts and important dates in the *publishing of data*. There is a channel of communication permanently open for consultation and messages on these subjects via email.

The following documents have been placed at the public's disposal in 2007:

- An update of the series Death by cause. Spain and Autonomous Communities, 1981-2004.
- Register of Hospital Admissions, NHS. Weight of the Diagnosis Groups. 2005
- National results of the Statistics for Medical Institutions with Inpatient Facilities (ESCRI), 2005.
- National results and by autonomous community of the Statistics for Medical Institutions with Inpatient Facilities (ESCRI), (publication online of the final results).
- Register of Hospital Admissions, NHS. National Regulation 2006.
- National Hospital Catalogue, 2007.
- Catalogue of primary care centres, 2007
- Update of the series on resources and population of the SIAP, 2004-2006.
- Update of the operational reports SIAP, 2006.
- Surgical waiting lists and for outpatient care at the 31<sup>st</sup> of December 2006.
- Surgical waiting lists and for outpatient care at the 30<sup>th</sup> of June 2007.
- Public health spending statistics, 2005 (advance).
- Health barometer 2006.
- Health barometer. Historic series, main variables, 1995-2006.
- National Death Index, updated to the 1<sup>st</sup> of October 2007.
- Maintenance of the consultation application for the electronic publication of CIE-9-MC, 5<sup>th</sup> edition.
- National Health Survey in Spain 2006-2007. National results and by autonomous community.
- Analysis of health spending in Spain. Working group on public health spending. Ministry of Economy and Finance, Ministry of Health and autonomous communities.
- Code Bulletin 27. Addendum for 2008. Technical Unit of CIE-9-MC.

To *improve care for the public and specialist users* it is also possible to receive free of charge, on demand, the general information and exploitation of data and information which the Ministry of Health and Consumers' Affairs produces.

All requests received through any media (in person, telephone, fax, post or email) are always answered from the email address: [informacionsanitaria@msc.es](mailto:informacionsanitaria@msc.es)

The collection of data provided by the health services of the autonomous communities, the Ministry of Health and Consumers' Affairs and other sources, whether national or international, represent significant added value when they share a logical and structured format. It provides us with a "bank" of data for the field of healthcare which has enormous potential for research and analysis.

The supply of all this *microdata* which is freely available for research through download from the web page of the Ministry of Health is one of the objectives which the Institute of Health Information has been working on, and it is expected that the data from the National Health Survey, the specialised care information system and the health barometer can be accessed directly in 2008. As has already been described, direct access to the National Death Index is available in controlled conditions only for public organisms and institutions.

The compliance with the calendars for release, publication in appropriate physical media, systematic response to the needs of the users and direct access to files of microdata are priorities. The optimisation of these processes and storage of the bank of data of the NHS in a central deposit, as has been indicated above, and the corresponding development of tools for the web page for interactive consultations are also transcendental elements.

## Collaboration with international organisms

The presence and the image of the Spanish National Health System in the area of international health information has been strengthened in recent years through the annual update and improvement of the Eurostat, WHO and OECD databases, along with the corresponding metadata which improves the capacity for interpretation and comparisons. The Institute of Health Information is an active participant in the meetings of the DG Sanco Network of Authorities Responsible for Information Systems, the health group of the OECD and the area of social and health statistics of Eurostat.

## Dynamic information

Besides what has been conceived carefully as the Information System of the NHS, it is engaged in another area of activity that goes beyond the mere statistical function of the former.

It is the standardisation, management and exchange of information vital for the development of the activity of the NHS, such as the identification of users and regulated access to clinical information.

For the first of these, the correct identification of each person, there is a *database of the population covered by the National Health System*. This database combines the different databases of the individual health card from the autonomous communities and is an instrument of administrative data exchange and insurance management of use across all the health services. It is a guarantee for the citizens that they can receive treatment from the NHS in all areas.

Each autonomous community is responsible for handling the entries in this shared database, which also contains data from Social Security and the Ministry of Justice.

Thirteen autonomous communities and Ingesa (Ceuta and Melilla) use this system at present. Andalusia and the Valencian Community are in the testing stage, Catalonia in the pre-testing stage and the Basque Country began to work on its incorporation in June 2007.

It is expected that all of the autonomous communities will be able to exchange data from their health cards through this tool in 2008 and the first quarter of 2009.

As regards the *access to clinical information*, a model to permit inter-operational capacity between different health establishments of the NHS has been agreed and designed during 2007 which will allow any citizen to access their clinical information when they require attention. This will have a positive effect on the quality of healthcare, on the work of the qualified personnel and on the efficiency of the system.

To achieve this, the Institute of Health Information of the Ministry of Health has defined, with the support of scientific bodies and other experts, the criteria for normal operational demands for clinical histories within the National Health System and the reports which are normally used in clinical practice.

This criteria, together with the model of inter-operational capacity have been reviewed and approved by the departments of health of all the autonomous communities, being approved finally by the Interterritorial Board of the National Health System in its session of the 10<sup>th</sup> of September 2007, to carry out a pilot scheme for the exchange system in 2008.

The framework of the Plan Avanza during 2006-2007 has been useful in reinforcing these projects. All of the autonomous communities, including Ingesa, have participated in the online health project, an initiative that was foreseen in the Avanza Plan and developed through a negotiated framework between the Ministries of Health and Consumers' Affairs, Industry and Tourism and Commerce.

The total amount of investment in information and communication technology by the National Health System has been €252,133,705, a quantity that was distributed in direct proportion to the populations of the different territories for execution in 2006 and 2007. Of this total volume, the amount provided by the state administration is 141,000,000 euros, while the remaining amount of 111,133,705 is raised from the group of Health Administrations.

Finally, the participation of Spain along with 12 other members of the European Union in a project for the exchange of clinical information of European citizens living in other countries, known as *Large Scale Pilots (e-prescription and patient summary)* as part of the *European initiative e-Health*. The Ministry of Health and Consumers' Affairs, with three autonomous communities (Andalusia, Castile-La Mancha and Catalonia) have taken part as beneficiaries in the project and the proposal has been presented, and is pending final approval from the European Commission.