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ACTIVITY REPORT

CONCLUSIONS AND RACCOMANDATIONS

Health Monitoring Systems in Europe:

Structures and Processes

Editors

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Executive summary

A Health Information System (HIS) is a crucial tool to support public health programs and policies designed to improve health in Europe. In order to work properly, a HIS needs to be effectively and efficiently managed. Cumbersome processes, structures performing blurred or useless tasks, gaps and overlaps in key activities and lack of an overall design substantially reduce the capability of the HIS to enhance decision-making processes and lead to healthier populations.

The present project analyzes the different Member States' (MS) HIS using a managerial approach in order to identify weaknesses and strengths as well as opportunities and threats. The specific objectives are to provide: a) a fully detailed organizational description in terms of structures, resources and processes of the different MS' HIS with particular reference to selected Surveillance Systems and Health Services Monitoring Systems; b) a comparative analysis with identification of major differences and similarities in the information systems; c) operative, feasible, sustainable recommendations for the implementation of the European Information System.

In order to understand how HIS works we studied how MS divide labor concerning HIS and how they coordinate different organizations and steps. The project concentrated on the regional and national levels. Each MS studied at least mortality and health determinants among Surveillance systems, and examined at least data transmission among HIS processes.

Strategy and tools used to analyze structures and processes included quantitative and qualitative methods. Organizational structures and networks were analyzed using organizational charts, i.e. diagrams graphically depicting authority and communication channels. Mandates, missions, functions, roles and strategies were studied by reviewing official documents, specific studies and legislations. A series of in-depth interviews with key informants, such as high officials (policy makers and top managers) and middle level officials (HIS managers, national and regional managers) were performed to examine coordination mechanisms and actual tasks carried out by each organization.

Results show that the design of HIS is frequently based just on technical considerations such as what data and information are needed by whom and too often ignores basic managerial principles. Symptoms of this problem are overlaps and gaps in activities, poor communication and conflict between organizations. Managerial root causes of these symptoms were identified in the following flaws:

- Mandates of organizations managing HIS are too vague and legislation sometimes emphasizes restricted access to databases instead of sharing data and knowledge among analysts,
- HIS related missions, visions and even strategic plans are frequently missing or lack focus, clear direction and alignment,
- Distribution of tasks among units responsible for data collection, analysis and diffusion is rather haphazard,
- Coordination mechanisms are too often absent or informal, therefore weak,
- Some key organizational processes are not designed as a whole, i.e. explicitly linking each step, and thus ignoring that their function is to serve customers, i.e. internal and external people that need relevant and timely data, information or knowledge.

Some countries have managed to confront such issues more effectively. In particular, two experiences can be considered as benchmarks, i.e. examples to be followed, by other EU countries: the Swedish HIS and the Irish HIS strategy.

A managerial perspective is crucial to a smooth functioning of any organization and system, including HIS. These are complex endeavors because deal with multiple dimensions of health status, determinants and services and are run by a set of organizations located at central, provincial and local level some of which are outside the health sector. Results of this analysis are of particular importance: first, they may help MS to improve HIS performance in terms of data, information and knowledge's timeliness, availability and usefulness; second, they can be used by the EU as an information tool in support of the development of an integrated European HIS.

Content

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Statements included in this document are the authors’ responsibility. Accounts of problems concerning HIS management, in no way are meant to denigrate individuals or organizations. On the opposite, the attempt is to identify specific issues and help managers and professionals to improve their managerial practices.
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Introduction

This paper discusses the Project titled “Health Monitoring: Structures and Processes” funded by the European Commission and assigned to the Veneto Region, Italy, specifically to one of its technical offices, the Reference Center of the Regional Epidemiological System (RC). The document has the following goals:

- to describe the project’s mandate, rationale, theoretical background, aim, objectives, strategy and research tools,
- to summarize the research’s results,
- to present recommendations for MS in order improve HIS management.

Mandate, Rationale and Theoretical Basis

This project’s aim inevitably derives from the **mandate** defined by the European Commission. Such mandate appears in the title of the project “Health Information Systems in Europe: Structures and Processes” and in the “Project objectives and action plans” which are outlined in the Community action program on Health Monitoring – Projects subsidized in 2001 by the European Commission, as follows:

“1. a fully detailed organizational description in terms of structures, resources and processes of the different Member States’ Health Information Systems (HIS) with particular reference to selected Surveillance Systems and Health Services Monitoring Systems,

2. a comparative analysis of the information collected as for point 1, in order to allow the identification of major differences and similarities in the information systems,

3. operative, feasible, sustainable recommendations for the implementation of the European Information System.”

The mandate provided participants with the endeavor’s rough boundaries but obviously such framework and the content within needed to be defined further. This was done elaborating the project’s rationale, rendering explicit its theoretical background and defining its aims and objectives. In the following pages this initiative’s rationale and theoretical basis are explained in some depth.

The HIS purpose is to provide quality, relevant and timely data, information and knowledge in order to support public health decision-making at local, regional, national and international level. Within each geographical location, HIS is a tool necessary to make decisions at strategic, control and operational level, to set directions, to monitor their implementation and evaluate their impact. The relationship between information and decisions works as follows: information represent one of the main basis for health decision-making processes, which, in turn, make possible sound decisions. Thus in order to improve decisions we need to improve both the decision-making process and the information which goes into it. This project focuses its attention on the latter aspect and in particular on the managerial arrangements that make possible to produce good quality information. The project's rationale is that the smooth functioning of a system (in our case the HIS) depends in no minor part on its management. The project's basic assumption is that a managerial analysis of HIS will help MS to improve their systems performance in terms of data, information and knowledge's timeliness, availability and usefulness. Further, better information quality and availability will hopefully lead to enhanced decision-making processes and finally healthier populations.

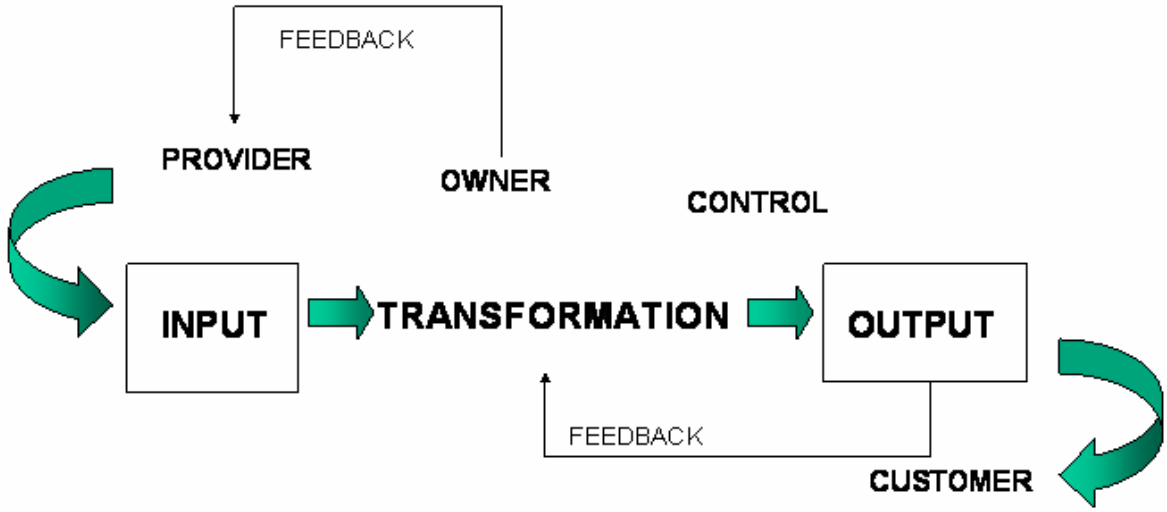
Managing the HIS means designing organizations capable of running the HIS' processes in an orderly way. Choosing the most relevant set of data and indicators, an up-to-date information technology and relevant statistical analysis, represent essential steps but are not sufficient to assure a functional HIS. If organizations responsible for HIS are designed and function ignoring basic principles of management what we get is a less than desirable situation pounded by problems such as blurred assignment of functions, cumbersome processes, tasks' gaps and overlaps and structures performing useless tasks.

In order to study HIS management we need a theoretical background from which we can draw useful concepts and frameworks, i.e. models, ways of organizing ideas and data. Models relevant to our effort derive from the theory of organizations, theory of communication, theory of public administration, the total quality management approach and public health. The following pages offer a brief overview of definitions, concepts and models relevant to our project, in order to build a shared language and

logic. In summary, management's basic ideas are presented and the same ideas are then applied to our topic, i.e. HIS management.

A **Health Information System** is an organized set of procedures for collecting, processing and disseminating information to assist decision-making at all levels in the health sector. **Data** are recorded facts, events, transactions (e.g. a diagnosis), **information** is data processed in such a way as to be useful (e.g. an incidence rate) and **knowledge** consists of interpretation of information, assignment of meaning (e.g. an epidemic has started). The opposite of knowledge is **uncertainty**, i.e. the difference between available and needed information. A **decision** is a choice between alternatives (e.g. treat cases or immunize contacts) and must be supported by knowledge. **Management** is getting things done through people, putting order in organizations and making them able to respond effectively to their environment's demands. **Organizations** are set of interdependent human beings with explicit aims and dedicated resources. A system view of organization identifies the following dimensions: inputs, processes, structures, outputs and the environment. **Inputs** are resources that contribute to the creation of outputs. **People** are the most important input, in particular because of their capabilities, mental models and motivations. **Processes** represent ways tasks are carried out, a set of steps converting resources into services or products. Processes are decisions, sequences of activities and information flows intended to achieve a specific result. Typical HIS processes include: data selection, gathering, quality control, distribution, collation, analysis, interpretation, dissemination and decision-making. **Structures** consists of distribution of authority and responsibilities among individuals, groups and units; in other words ways of grouping and coordinating tasks. In our case, relevant structures are units involved in HIS management within and outside the health sector, e.g. a National Statistics Office providing demographic data, a Communicable Diseases Surveillance Unit. **Outputs** are products, services and ideas resulting from the organization. **Strategy** represents the main directions, the key choices to deal successfully with the environment's demands and to achieve the organizational goals. The **environment** is everything outside the organization especially those conditions and organizations related to its goals and strategies. This project's focus is on processes and structures and to these concepts the following pages turn the attention.

Studying processes implies asking the following question: How does organization X do things? Each process has **providers** and customers. The former are people or organizations that carry out the tasks generating services, products or results. **Customers** are people or organizations that get a service, a product or a result. Providers and customers are both internal and external to an organization. An output of an organization (or a unit within an organization) represents the input of another one in a logical sequence to the point where the aim of a system is accomplished. Each component of the process must define and satisfy its own customers. Analyzing organizational problems in terms of providers and customers allows us to understand how one's own job is related to that of other individuals within and outside the organizational unit we belong to, i.e. the mutual dependency between units and organizations.



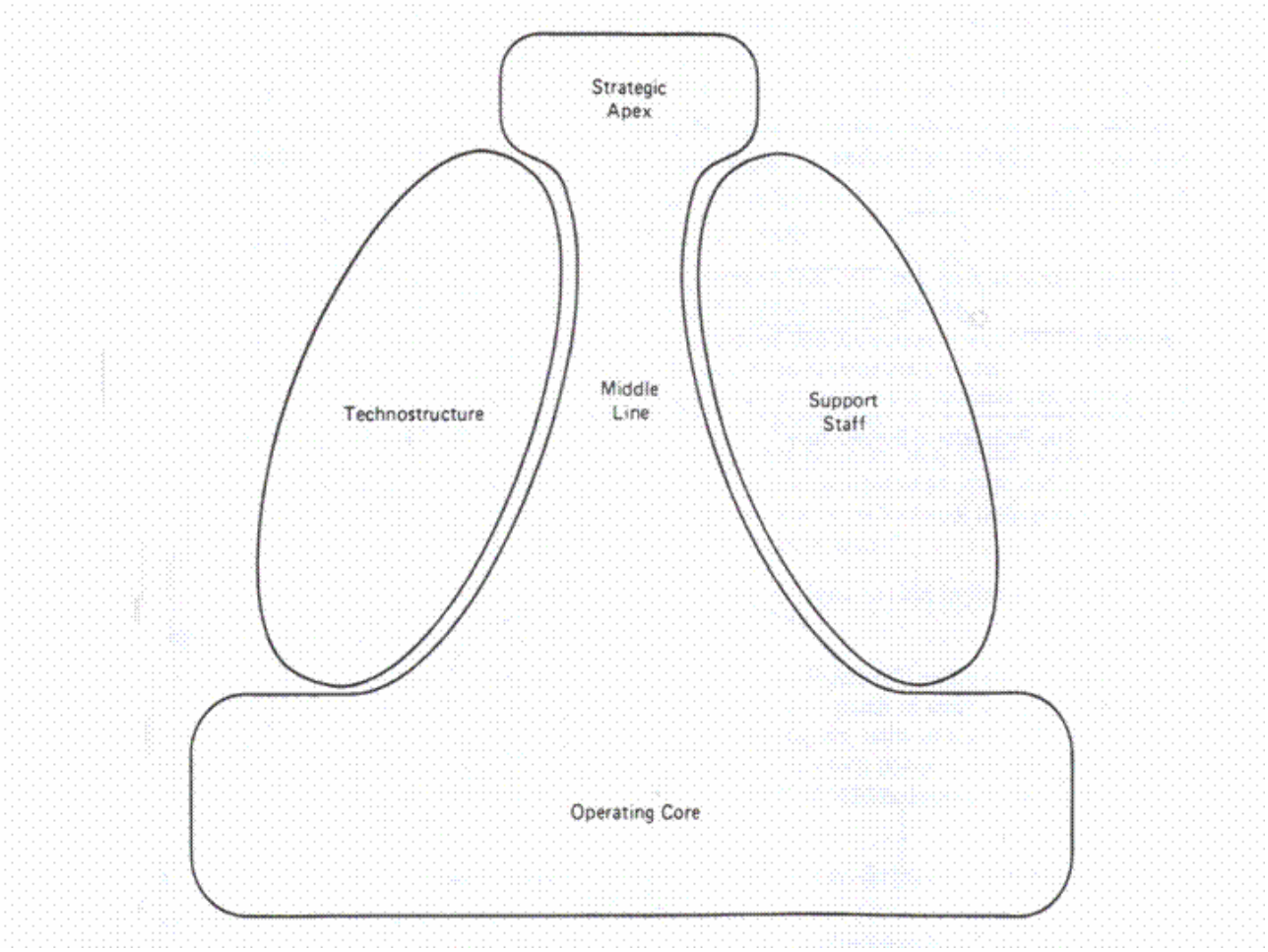
The key idea is that each of us, as an individual and as a group, depend on others who supply services and products necessary to perform our tasks. Analogously others depend on our products and services. Without a regular and coordinated flow, work becomes impossible or delayed or inaccurate. Analyzing organizational

problems in terms of processes allows to consider activities not as isolated fragments but as indivisible parts of a whole.

Next we tackle structures. Each organization faces the two following central issues: how to group labor (work processes) and how to coordinate it. Grouping labor implies creating structures, i.e. deciding about location of authority and responsibilities, assigning work to different organizations and units within the same organization. Grouping is indispensable in order to carry out specialized tasks, but grouping means also division of some work elements from others. Separation hinders communication and collaboration, therefore it is necessary to bring the different parts back together through coordination. When each part goes its own way, we do not get a system but a confusing set of disjointed, unrelated elements. How labor is grouped and assigned must be guided by some management principles which are discussed further on together with the research's findings.

The key idea is that each of us, as an individual and as a group, depend on others who supply services and products necessary to perform our tasks. Analogously others depend on our products and services. Without a regular and coordinated flow, work becomes impossible or delayed or inaccurate. Analyzing organizational problems in terms of processes allows to consider activities not as isolated fragments but as indivisible parts of a whole.

An important distinction within structures is between line and staff. Line refers to the hierarchical chain of command from the strategic apex through middle management to operations, i.e. production or services delivery. Staff refers to techno-structure and support staff. Techno-structure is composed of units defining standards, with an advisory role to line and therefore no authority. Typically HIS units fit into techno-structure. Support staff includes general services indispensable to the functioning of any organization, such as human and financial resources, maintenance and parking.



Source: Mintzberg H., Structures by five, Englewood Cliffs, NJ, Prentice Hall, 1979

In general, great emphasis is given to structures because these have to do with power and status and are usually visible, but other important elements of organizational success are processes, people, rewards and strategic directions.

In conclusion, the basic argument that justifies this project is that in order to understand how HIS work we need to study also organizations managing those systems. If organizations are designed ignoring basic principles of management we get defective systems, cumbersome processes, gaps, overlaps and structures performing blurred or useless tasks, in short we have poor performance.

Aim and objectives

This project's **aim** is to study HIS management. This aim implies to look at HIS structures and processes, i.e. at the anatomy and physiology of organizations managing it. Its objectives are:

- to describe selected HIS structures and processes from MS,
- to identify HIS management best practices in EU,
- to provide some tentative conclusions concerning the effect of organizational structures and processes on key dimensions of HIS output, such as availability, data quality, relevance and efficiency,
- to help policy-makers and public health officials to improve organizations managing HIS through recommendations.

This project's bottom line is that we are interested in the analysis of how our MS divide labor concerning HIS and how they coordinate different organizations and steps, because this represents a pre-condition for HIS management improvement.

In order to further clarify the project's aim, it is useful to specify what is left out of its boundaries. This project did not deal with

- HIS content, i.e. data, indicators, indexes,
- epidemiology, i.e. the distribution and causation of diseases,
- health services monitoring, i.e. inputs, outputs, outcomes and impact of policies and services.

The project develops applied research in order to offer practical recommendations, it does not deal with hypothesis' formulation and testing nor developing organizational theories concerning HIS in Europe. The applied approach is not in contrast with the use of models and theories, quite the opposite.

Opportunities and challenges

This project opened several **opportunities** because it might

- contribute to the development of a more solid HIS in Europe,
- allow participants to learn from each other and adopt solutions that have worked in other MS,
- provide knowledge useful to the harmonization of key dimensions of MS HIS and therefore improve comparability and exchange of information and knowledge,
- improve decision-making in the health sector,
- finally offer a small contribution to the strengthening of a better Europe. The European integration grows from huge enterprises such as the introduction of the

new currency but projects like this also contribute to the progressive integration of sectors, organizations and people.

Inevitably, this project posed also some **challenges**. Some of these were common to other similar initiatives in particular that participants are very busy with their main positions, have never worked together before and come from different cultures and professional backgrounds. A specific challenge to the project is the possibility that some participants might have not been inspired by the management perspective applied to HIS.

Strategy and Phases

Basic considerations about what was achievable given the available resources led to an early understanding by the group that it would be impossible and undesirable to study all HIS components, processes, structures and resources relevant to HIS management. The project's focus had to be circumscribed and several key issues concerning this aspect were discussed during the first two meetings. Those decisions are discussed in the following pages.

Project's participants decided to limit the analysis to specific levels of the health system. Among the possible options, i.e. local, regional, national and international (European Commission), team members decided to concentrate on the regional and national levels. Furthermore, the project examined in particular two components of the HIS: mortality surveillance and health determinants.

As far as HIS processes (data selection, gathering, quality control, distribution, collation, analysis, interpretation, dissemination, decision-making) are concerned, attention was focused in particular on

- Distribution, i.e. what are the policies, rules and standard operating procedures defining data and information flow and access ? Data flow and access are two crucial and interrelated aspects of HIS management, because if data and information do not circulate fast and reach the right units and individuals at the right time, HIS usefulness is considerably impaired,

- Interpretation, i.e. how is knowledge produced ? HIS is worthless until meaning relevant to decision-makers is attached to information,
- Dissemination, i.e. how is knowledge made available to decision makers, professionals and citizens ? Relevant meaning is valueless if does not reach potential users.

Less attention was paid to data collection (how are data collected, by whom, when, adhering to which procedures) and quality control (how are data reliability and accuracy ensured).

The group decided to study organizational units within and outside the health sector belonging both to techno-structure, e.g. health planning and HIS management units and to line, e.g. strategic apex and middle management. Managerial problems might originate from structures' and processes' design or functioning or both. Design refers to how processes and structures were meant to operate whereas functioning refers to their actual performance. The project intended to assess both these aspects.

The project was structured in several **phases**

I. Clarification of theoretical background,
II. Selection of objectives, strategies and products
III. Development of a work-plan
IV. Information gathering by MS
V. Comparison and integration of knowledge across MS
VI. Dissemination of findings and recommendations

The content of these phases was agreed during the project's first meeting and then was adjusted in the course of its development. The following pages describe what decisions were made in the course of the three meetings.

The first meeting was held in Brussels (March 1-2, 2002), with the aim of building consensus on project's objectives, strategies and products, developing a work-plan, agreeing on the time-frame and final products and getting participants to know each other. The meeting started with Perter Kramers who made a presentation on the major scope of the Health Monitoring Program and about the European Community Health Indicators (ECHI) program. Then, Tapani Piha, at the time official of the EU Health Monitoring Program, highlighted the importance of linking uncompleted works of the

previous HM framework with projects of the new framework. Roberto Gnesotto presented the rationale, aim and theoretical basis of the project. Some participants questioned the feasibility of the project and the relevance of its aims for the health information systems. Then Roberto Gnesotto presented the proposed strategy of the project discussing how to examine structures and processes of the HIS. Some participants said the project was unpractical and too ambitious. It followed a discussion of research tools and products of the project. Some participants felt it was difficult to study HIS from a managerial perspective since most of them were not trained in management; some of them felt not to have the skills to implement the project. The meeting was closed by a redefinition of proposed objectives and strategy and an agreement about the work-plan.

The second meeting was held in Venice (September 23-24, 2002) with the aim of sharing preliminary results on the evaluation of HIS performed in each MS and reach consensus on the next steps of the project. Henriette Chamouillet led the discussion in the first part of the meeting to clarify EC major needs relevant to the objectives of the project. She said the project's objective was not only to have a description of HIS in each MS and to analyze differences and similarities between them, but also to analyze the HIS as a whole. She recommended the project should also take into account previous initiatives of the Health Monitoring Program with particular reference to the ECHI project and related indicators. A series of discussions on the specific objectives and products of the project followed the presentations. After a brief brainstorming where participants could share ideas and comments on the prosecution of the project, the working group agreed to develop a framework prompt to direct each project leader in the writing of each MS report. Participants agreed that each MS was expected to develop a single report organized on the basis of the 4 categories of indicators identified by ECHI Project (Socio-economic Factors relevant to Health Status, Health Status, Determinants of Health and Health Systems). Each report would include a description of health information systems in terms of policies, legislations, plans, roles and responsibilities, organizational chart, processes and coordination mechanisms. Moreover, each MS was expected to identify key lessons through a SWOT analysis. A discussion about the final report containing a synthesis of each MS analysis closed the meeting.

The last meeting was held during May 2003 in Stockholm with the objectives to share and draw conclusions from the research findings, to agree on the final content and development of the project report.

Research methods and data sources

Processes' analysis require distinct approaches from the study of structures; therefore the two dimensions will be treated separately in the following pages. Describing a process means splitting an activity into its essential elements and uncovering their relationship. Flowcharts represent the best tools to describe processes, showing, through diagrams, the sequence of activities moving information or materials within an organization. Flowcharts also reveal time lags between steps, resources consumed by the process, outputs, (services and products), customers, (users of outputs) and the results, e.g. customers' level of satisfaction. The description of a process through a flowchart begins with the recognition of its borders, i.e. the beginning and the end. Next, intermediate steps are illustrated which include both activities and decisions. Processes can be described through different grades of detail, from a thorough analysis of minute steps to an overview of the essential activities. The latter is usually sufficient to identify main problems. To avoid being overwhelmed by the complexity of large phenomena, this project studied in particular, as mentioned before, two processes: access to data and production of knowledge. Another useful approach to the study of processes is the collection of opinions and HIS customers' level of satisfaction at various points in the sequence of activities and organizational levels.

On the other hand structures responsible for HIS management were diagnosed looking at their main dimensions, i.e. mandate, mission, vision, authority, responsibility, accountability and coordination tools. Furthermore organizational charts of key organizations, actual tasks carried out by each organization, vertical and lateral coordination mechanisms within and among organizations and organizational networks were considered.

Besides describing processes and structures relevant to HIS management, this project also applied some management techniques/concepts to the study of organizations'

structures, processes, and environments, in particular: responsibility map, SWOT, fit analysis and gap analysis. These are described together with the findings.

The information sources employed by the project included interviews with key informants and analysis of official documents. More in particular the sources used included:

- Analysis of official documents describing
    - mandates, missions, functions, roles and strategies,
    - HIS standard operating procedures, protocols and guide-lines,
- Analysis of HIS studies and recommendations,
- In depth semi-structured interviews with key informants, i.e. high officials (policy makers and top managers) and middle level officials (HIS managers, national and regional managers), (see Annex 1 for a sample questionnaire).

Findings

Findings are organized following the SWOT approach. SWOT, an acronym that stands for Strengths, Weaknesses, Opportunities and Threats, is a commonly applied managerial technique that directs attention toward internal aspects where an organization has assets and liabilities as well as toward the environment where an organization finds opportunities and threats. Strengths should be cultivated, weaknesses resolved, opportunities grasped and threats anticipated and overcome. This approach is useful also because it stresses the interface between an organization and its environment.

This chapter begins with an analysis of HIS common managerial weaknesses and then describes its strengths both through a summary list drawn from various MS and two experiences considered as benchmarks, i.e. examples to be followed, for other EU countries: the Swedish HIS and the Irish HIS strategy. Next the chapter takes into account opportunities and threats to HIS management and concludes briefly considering strengths and weaknesses of HIS content. The attempt is to put together recurrent themes in a short review, though it is clear that HIS managerial arrangements vary widely among MS.

Weaknesses

Weaknesses, i.e. main problems observed within organizations, are summarized under the headings of organizational symptoms, root causes and consequences. Frequently observed managerial **symptoms** are overlaps and gaps in activities, poor communication and conflict between organizations.

Organizational **root causes** of the above mentioned symptoms include:

- Mandates of organizations managing HIS are too vague and HIS related legislation sometimes emphasizes restricted access to databases instead of sharing data and knowledge among analysts,
- HIS related missions, visions, policies, strategic plans and procedures are frequently missing or lack focus, clear direction and alignment among them and with the environment,
- Assignment of tasks among units and organizations responsible for data collection, analysis and diffusion is rather haphazard and blurred. Different organizations' authority and responsibilities overlap,
- Some key organizational processes are designed as isolated elements, instead of parts of an overall system. Too frequently key steps are not explicitly linked to those preceding and following it and there is no overall coordinating role.

Consequences of HIS' poor governance are of three kinds:

- at the organizational level, these situation results in inefficiencies because the same tasks are carried out by different organizations, instead of each organization focusing on what knows and does best,
- at the output level, information and knowledge produced are too frequently late, unseen, unused or even plainly irrelevant,
- at the policy level, decision-makers have sometimes access to diverse or contradictory information. This compromises analysts credibility in front of both decision-makers and citizens and, more important, some strategies are not as informed as should and could be.

Symptoms, root causes and consequences are explored more deeply in the following pages.

Symptoms

Overlapping activities are manifestation of the fact that several organizations do the same work especially as far as analysis and interpretation is concerned. Gaps in activities are apparent in key areas of analysis; for example, socio-economic determinants of disease, home and palliative care, violence and disability surveillance are not covered by several MS.

Poor communication and conflict are frequent indications of less then ideal relationships between different organizations belonging or not to the health sector. Several analysts expressed frustration with the difficulty to access database from units managing them and some decision-maker expressed dissatisfaction with the lack of information or its marginal relevance. Different units and organizations fight in order to conquer space where they can present their analysis trying to anticipate and displace "competitors".

Organizational root causes

Mandate is the reason of being of an organization given from the authorizing environment, i.e. outside and above the organization. Organizational **mandates** are frequently too vague because use a bureaucratic language that does not clarify crucial technical aspects nor relationships with other complementary functions and organizations. This might in part be a consequence of professionals' marginal involvement in law making. Legislation sometimes emphasizes restricted access to databases instead of sharing data and knowledge among analysts. The principle of protecting the citizens' privacy takes over the need and the opportunity to use large databases to promote and protect public health and improve health services delivery. A further difficulty with mandates (but also with missions and plans) is that most surveillance attention is on communicable disease and the main causes of premature deaths and disability receive less attention of what they deserve.

Mission is the reason of being, developed inside the organization taking into account the mandate; it defines goals and content area with more precision and identifies customers needs and wants. Vision is the long term ideal future the organization aspires to. Strategic plans identify priorities, goals and ways to achieve them.

Mandates of HIS organizations are not always translated into **missions, visions and strategic plans** or the latter lack focus, clear direction and alignment among them and with the environment's demands. When HIS managers were asked to provide official documentation regarding their organization's mandate, mission and functions and to elaborate further on aspects not covered by those documents, such as accountability and coordination tools, some were not able to provide some of the requested information, nor to clearly articulate who their customers are, what products they expect and what is their level of satisfaction. In general, when asked to provide missions and visions, a typical answer offered by some managers was "everything is written in the law and we do not need to add anything to that". Though it is true that an organization can work effectively without explicitly devising mission and vision statements, if we add to this the frequent ambiguities of mandates, it is easy to end up with unclear roles and the above mentioned symptoms, i.e. organizational conflicts and tasks overlaps and gaps. Standard operating procedures are also frequently missing and this leads to uncertainty and improvisation in organizational behavior. The tendency to relay just on legislation without spell it out through mission statements, strategic plans and standard procedures is much more prevalent in southern European countries (e.g. Italy and Portugal) compared to the northern nations (e.g. Sweden, Finland).

Another root cause of malfunctioning is the rather haphazard and blurred **assignment of tasks** among units and organizations responsible for data collection, analysis and diffusion. Ambiguity of tasks division go with overlapping authority and responsibilities among different organizations. Authority is the power deriving from a formal position of approving or vetoing a key organizational decision. Responsibilities are tasks the organization must carry out in order to fulfill its functions.

A management tool that improves understanding of how functions are assigned to different organizations is the **Responsibility Map.** This is a matrix bringing together organizational structures, key activities and roles in decision-making. Possible roles of a structure include authority, responsibility, consultation (when a structure's opinion on a specific matter is required before the decision is made), implementation (when a structure has to transform a decision into reality) and information (when a structure is simply informed about a decision after that has been made). The responsibility map is

useful not only to analyze current situations but also to identify preferred states to be implemented. An example of responsibility map drawn from Veneto Region's data is presented in the following table.

RESPONSIBILITY MAP
TASKS, ORGANIZATIONAL UNITS AND ROLES:
CURRENT STATE RE MORTALITY ANALYSIS IN VENETO REGION

Organization / Tasks	MH	P	HP	PH	EPI	HR	ST	PD	OH	CR	HI	LH
Collection Coding Transm.	-	CON	CON	AURSP	INF	-					AU RSP	IMP
Analysis Interpret.	-	CON	CON	RSP	RSP	RSP	RSP	RSP	RSP	RSP		
Utilizat.	AU RSP	AU RSP	AU RSP									

Acronyms

MH Minister of Health
P Prevention
HP Health Planning
PH Public Health
EPI Epidemiology Center
OH Occupational Health
CR Cancer Registry
PD Pediatrics Department
HR Health Report Unit
ST Statistics Office
HI Health Information Unit
LH Local Health Unit

AU Authority
RSP Responsibility
IMP Implementation
CONS Consulted
INF Informed

The most important flaw is that responsibility to carry out mortality analysis is assigned at the same time to four units (highlighted in red): Public Health, Epidemiology Center,

Health Report Unit and Statistics Office. With the exception of the latter, all of them belong to the Health Sector. Moreover it was not clear if mortality analysis was a task included in the mandate of every unit or was added arbitrarily to routine work by some of them. Three other units, i.e. Occupational Health, Cancer Registry and Pediatrics Department, have the responsibility for mortality analysis specific to their areas. A principle of organizational design, i.e. one task should be carried out by one unit only, not by two or more[1], is missing.

A second problem is that the task "mortality analysis" does not reflect specialization, i.e. competence and expertise in the specific area of concern. Specifically the Statistics Unit is not staffed by multi-disciplinary personnel specialists in health sector. Obviously there is nothing wrong in assigning a task such mortality analysis to a Statistics Unit when this has relevant skills and there is no overlap with Public Health units. This is the case, for example, of Statistics Austria, the national statistical institute of Austria since 1829. Among its subsidiaries, there is the 32-member Advisory Board on Health Statistics, which brings together the main producers and users of health statistics at national level[2]. Otherwise it is confusing, inefficient and mortality analysis outputs become a thick set of tables with no interpretation nor explicit public health implications. Beyond mortality analysis, the problem of mismatching between skills and tasks is also frequently mentioned by MS particularly in the field of socio-economic determinants of health. Public Health units lacking social scientists have obvious difficulties in this area.

A third flaw revealed by this responsibility map is that Local Health Units do not have clear responsibility to carry out analysis at their level, but play a role essentially in data collection, coding and transmission. These units are not involved in data utilization and interpretation of results and therefore do not see the output of their work and the relevance of what they do.

[1] In some cases of vital or very complex tasks such as in aviation and reserach and development units, redundancy is deliberately chosen in organizational design. Inefficiency is compensated by the protection from possible breakdowns or missed opportunities with potential drastic consequences.

2 Besides statistics on mortality and causes of death, Statistics Austria produces the following annual analysis: cancer incidence, in-patients medical procedures as reported in hospital discharge and road traffic accidents. The same organization performs several surveys on health and related themes.

The responsibility map does not show a crucial managerial dimension, i.e. coordination mechanisms and to these now we turn our attention. Coordination mechanisms are management tools bringing together different units of the same organization or various organizations. Such tools can be vertical or lateral: the former include authority, policies, rules and standard operating procedures, planning and control systems, the latter are meetings, task forces, matrixes and networks. The most important weakness of HIS coordination mechanisms becomes apparent where organizations managing data distribution connect with units responsible for analysis, interpretation and dissemination. Although some task forces and formal agreements among this kind of organizations exist, frequently coordinating mechanisms are just informal, based on personal contacts, or absent. Weak formal connections, compounded by the absence of standard operating procedures and the ambiguity of work division, all contribute to open space for political games where access to data is sometimes used as a power tool, as a negotiable exchange. As a result, in Veneto health related databases are not easily accessible by public health analysts and researchers.

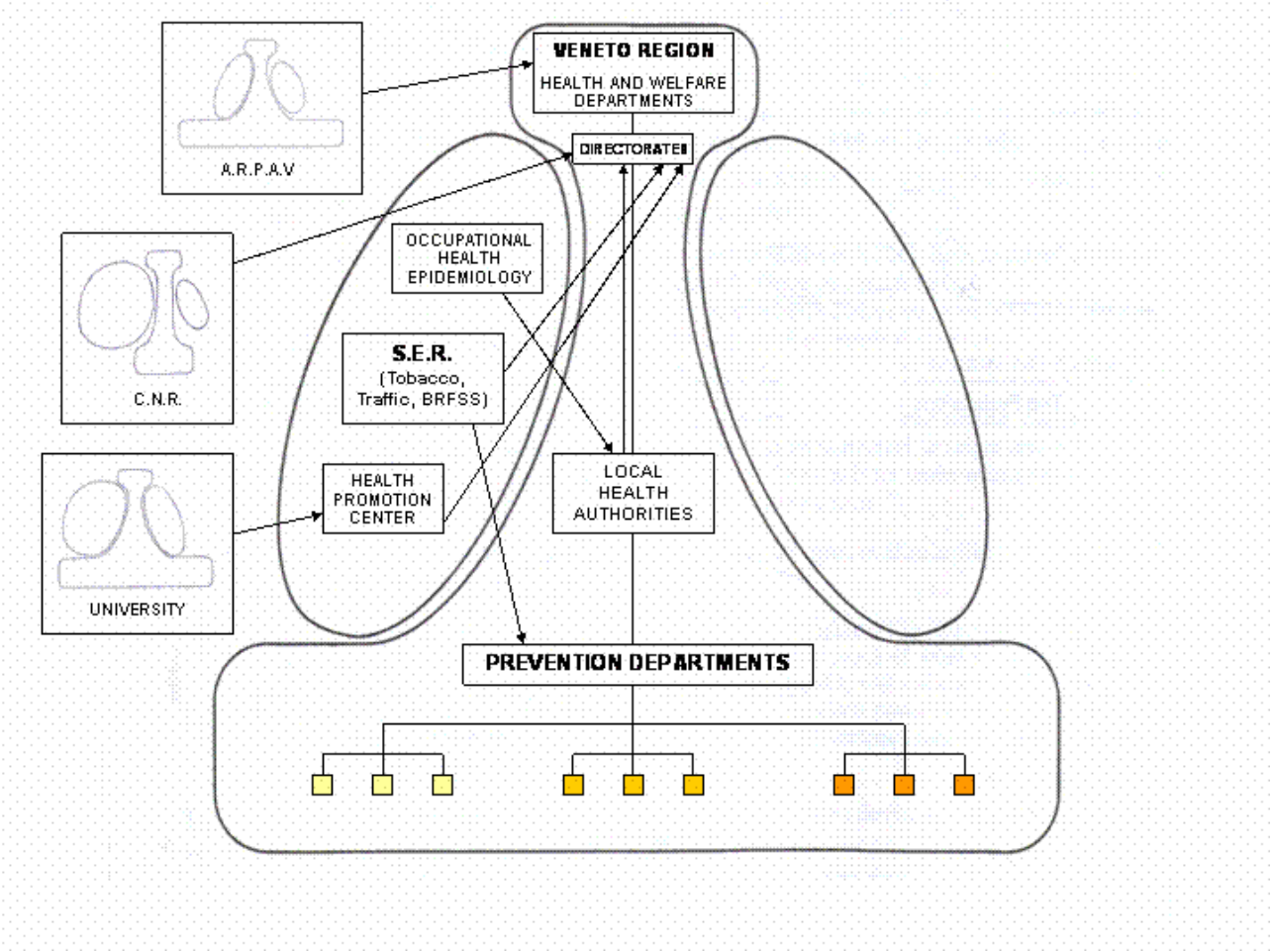
Weak coordinating mechanisms are also signs that some key organizational processes are designed as isolated pieces, without explicitly linking each step to those preceding and following it, overlooking the concept of provider and customer, i.e. internal and external people that need relevant and timely data, information or knowledge.

In summary vertical and lateral coordination mechanisms are insufficiently established at one critical point of the HIS processes: where databases move from Statistics Unit to Public Health Units. Although a criticism frequently moved against bureaucracies is the huge amount of rules and procedures, many of which supposedly outdated and useless, our findings show that in some public administrations the problem might be the opposite, i.e. lack of simple standard procedures such as flows of databases. The cost of this administrative gap is great.

The last weakness of HIS management considered here concerns the flow of knowledge from analysts to decision-makers. Organizational charts, i.e. diagrams graphically depicting authority and accountability, are useful in the study of this aspect

because they show what positions exist, how these are grouped, how formal authority controls them and the expected flow of advice from staff positions to the strategic apex of the organization.

The example shown refers again to Veneto Region; several organizations either belonging or not to the Regional public administration support public health decision-makers. The central portion of the figure represents the line from Regional top management to Prevention Departments of Local Health Authorities. Advice flows from different analysts to decision-makers following diverse paths: for example from the outside of the Regional structures directly to the top or through a staff unit acting as filter. Such complexity in the organizational relationships does not derive from an overall effort to design a network with an explicit purpose and logic, but from fragmented decisions made by several actors in different circumstances. This situation is not peculiar to Veneto Region, on the contrary is representative of several other HIS information flows.



ARPAV: Regional Environmental Agency

CNR: National Research Council

SER: Regional Epidemiological System

Consequences

As we anticipated above, consequences of HIS' poor governance are of three kinds:

- at the organizational level, waste, inefficiencies because the same tasks are carried out by different organizations, instead of each organization focusing on what knows and does best. Inefficiencies derive also from by-passing offices reluctant to provide databases, in order to purchase, from more collaborative units, data already in possession of the administration. Organizational waste originates also from time consuming informal data search. Ambiguities of mandates might lead organizations to carry out tasks different from those for which they were created. Another consequence of HIS unsatisfactory management is the slow responsiveness and limited adaptability of HIS to new health problems and rapid social changes.
- at the output level, consequences sometimes include late, unseen and unused information and knowledge, accumulation of data which is never analyzed and production of information without clear and relevant advise to policy-makers. An important shortfall of inadequate management are the missed opportunities of collating and analyzing available data for the formulation of prevention and care policies, for example data concerning special populations, such as elderly, disabled and immigrants, or data re voluntary traumas, such as domestic violence and attempted suicides episodes, which are used only for individual care in the absence of specific Health Information subsystems and units responsible for them. Missed opportunities for producing policy relevant knowledge derive also from poor integration of different data sources (eg. Hospital Discharges, Health Behaviors and Cancer incidence). Finally an unclear assignment of tasks might result also in poor feedback from one administrative level to a lower one.
- at the policy level, decision-makers have sometimes access to diverse or contradictory information. This compromises analysts credibility in front of both decision-makers and citizens and, more important, some strategies are not as informed as should and could be. If information produced by different sources is contradictory, decisions are just based on tradition, impressions or political

reasoning. Analysis irrelevant to policy also perpetuate the dominance of the biomedical model over the public health frame.

So far we emphasized defects in HIS management because as Japanese say “there is an opportunity in every mistake” and such opportunity cannot be grasped if the problem is not recognized. We now turn our attention to HIS management’s strengths, in particular to two success stories met during our investigation: the Irish HIS development strategy and the Swedish health registers system. These two experiences are considered benchmarks for other MS because have brilliantly confronted and solved critical aspects of HIS.

Strengths

This section starts with a concise list of sound managerial arrangements adopted by several MS, including Veneto Region. Organizational realities are always complex and by no means all drawbacks (or all assets) come together in the same body. The following strong points are mentioned because reflect reasoned choices by HIS managers and illustrate that managerial principles are both necessary and viable.

In short what the project shows is that in some MS

- division of labor is precisely assigned both between database managers and public health analysts and between analysts and policy makers,
- procedures including coordination mechanisms are well defined, the latter work properly especially around data collection, coding and quality control. Typical coordination mechanisms include National and Regional laws and regulations, formal procedures (e.g. manuals for codifiers), data quality control (e.g. a 20% random sample of death certificates), standard soft-wares, training and accreditation of personnel responsible for coding and regular meetings (Veneto Region),
- visibility of the whole HIS process from data gathering to knowledge creation, decision-making and feedback improves data reliability and utilization (e.g. MDs

filling death certificates see how their hospital and higher administrative levels produce and use knowledge),

- wide and integrated data-bases are promptly available to analysts,
- health sector units share data and analytical skills with non-health organizations, e.g. Insurance Institute and Occupational Health,
- some area of public health concern in EU countries are covered by new information subsystems managed by competent units, e.g. the Irish National Suicide Research Foundation has established a para suicide register and produces a multidisciplinary body of knowledge on the risks and protective factors associated with suicidal behavior,
- legislation gives specific mandate for communication of public health analysis, identification of public health priorities and formulation of strategies and programs are increasingly based on analysis, e.g. traffic traumas, tobacco and radon interventions.

Next, this section discusses two exemplary approaches to HIS management and planning in EU: the Irish HIS strategy and the Swedish health registers system.

The Irish HIS strategic plan as a benchmark for planning HIS in other EU countries

Among participating MS, Ireland has produced a strategic document concerning the overall development of HIS, titled *Health Information's Guiding principles. The health context of the National Health Information Strategy* and published as an interim paper by a Working Group of the Department of Health and Children in June 2001. The document sets out a "constitution" for the Irish HIS development, i.e. a number of key principles which should guide and govern health information strategy formulation and implementation. Principles were conceived for different steps in the HIS processes. For example a principle relevant to collection is "Persons who enter the data should ideally benefit from this data entry, either because they will use the data later on or because it will improve the quality of their work". A second principle, devised for the analysis phase, is "Information should be gathered and analyzed in ways which support its potential uses" and a third one, important for the dissemination step, is "Data should be made available as soon as is appropriate and possible and in appropriate formats with clear protocols governing the access to the data and confidentiality". Agreement, among main stakeholders, about governing ideas such as

those mentioned above represents a precondition for the sustainability of a major HIS revision implied by a strategic plan.

The document also explicitly considers on one hand general and health policy's implications for the National Health Information Strategy, such as the National Development Plan, the Program for Prosperity and Fairness, the National Anti-Poverty Strategy, the Action Plan for an Information Society and the National Health Strategy, and on the other hand the implications of information and communication technologies' evolution for the development of a National Health Information Strategy.

The document identifies the health information needs of key stakeholders, such as policy-makers, public health, hospital or health board managers, clinicians and citizens. For example, the information need of policymakers on equity, quality and accountability, of public health managers on inputs, access, activities and outcomes, of hospital administrators on waiting lists and of MS on clinical governance.

Furthermore the document makes use of the customer concept, recognizing that different users require different information and diverse dissemination channels. For example, the Department of Health and Children, health boards and other health agencies are identified as customers of the National Disease Surveillance Centre. The Irish strategy addresses the issue of HIS fragmentation, i.e. that some HIS components were established for one particular purpose and do not fully support the use of data for other aims. The plan devises approaches leading to a comprehensive HIS by integrating many of the existing data sources.

The document also underlines information gaps, especially in the area of health determinants and provides specific examples with possible solutions, for instance concerning inequalities in the occurrence of child accidents. The Irish Plan explicitly confronts the critical issue of using evidence to formulate policies and manage individual patients and of ensuring that every professional involved in the decision making process at all levels of the health services uses best available evidence when making decisions.

Among the infra-structural requirements of a health information strategy, the importance of information technology as a tool to facilitate collection, analysis, dissemination and use of health information, not as an end in itself, is emphasized. Finally the document recommends the definition of a vision of the role ICT will play in the health service together with middle and short term plans. In summary, the Guiding Principles document confronts in an orderly way key issues both intrinsic to the HIS and related to its information, socio-political and technological context.

The Swedish National Health Data System as a Benchmark of EU HIS

The Swedish HIS represents a successful example providing reliable, relevant and timely data, information and knowledge to support public health decision-making. This is based on a set of National Health Data Registers containing information on different public health topics and covering both sexes, all age groups, and all regions of the country. Such registers have adopted a personal identification number (PIN), which allows linkage of data on exposure or treatment from different sources to outcomes in health data registers. The registers include: the National Cancer Register, the Medical Birth and Malformation Register, the Hospital Discharge Register and the Causes of Death Register, The Medical Birth Register, The Acute Myocardial Infarction Register, The Abortion statistics (no personal identification number), Registration of sterilizations, of breast-feeding and of assisted reproduction, Injury statistics and EHLASS - The Swedish component of the European Home and Leisure Accident Surveillance System. Each Health Data Register is only allowed to contain information that is in accordance with the purpose of the register.

The national registers have been utilized to produce more than 1000 peer-reviewed articles focusing on different public health topics, for example residential radon exposure on lung cancer, effects of magnetic fields, trends in cancer survival and impact of cervical cancer screening. The Medical Birth Register has been used to analyze the risk of smoking during pregnancy, pregnancy outcome after the Chernobyl accident, associations between administration of vitamin K to newborns and childhood cancer, teenage pregnancy outcomes and effects on children born after in vitro fertilization.

The registers have been used both as isolated elements and also in combination with other registers or databanks. For example, social inequalities in health have been studied by linking health data registers with population censuses. The same approach has been used to study occupational risks. Other applications are risks of hormone replacement therapies, risk factors for cardiovascular diseases, sex differences in survival after myocardial infarction, and disease risks for vulnerable groups such as psychiatric patients, immigrants and single mothers. Some studies would have been impossible to conduct without national registers.

Many analysis were instrumental to support public health strategies and improve health in Sweden. A successful example of effective management of data in promoting health is the dissemination of information on breastfeeding since the early 1990s. Such effective use of data seems having contributed toward rising the frequency of breast-fed infants at six months from 51 percent to 72 percent.

Purposes and contents of the registers are defined and regulated by a series of laws and regulations which assign specific mandates to different organizations involved in databanks management. Roles and responsibilities of organizations carrying out data-related activities are clearly defined together with effective coordination mechanisms minimizing the risks of overlapping and inefficiency. The overall coordination of the registers is assigned to the National Board of Health and Welfare (NBHW) and its Epidemiology Center (EpC), a technical body which responds to the Ministry of Health. Two important functions of the NBHW are the supervision of medical care and social services in terms of quality, safety and individual rights and the evaluation and follow-up of social policy studies. The aim of the EpC is to describe, analyze and report on the distribution and development of health, diseases, social problems, utilization of health and social services and its determinants in different population groups within Sweden. The Center provides this kind of information to a large number of policy-makers in the Parliament and the Government, other public authorities, such as county councils and municipalities, but also researchers, the mass-media and the general public. In order to respond to its mandate, EpC collects and maintains epidemiological registers of high quality, publishes National public health and social reports, conducts research and co-

ordinates statistics within the areas of health and social services. The EpC is staffed just by about 50 people.

The Swedish HIS has worked out another important issue, i.e. division of labor between the National statistics office and Public Health Units. Statistics Sweden cooperates with the NBHW, that produces the official statistics on their behalf. Clear procedures concerning data flow between the different organizations involved ensure that databases are widely available to a variety of users including researchers and public health officials. One of the most important advantages of this system is that researchers do not have to collect data from scratch, and knowledge derived from the registers are readily available to national and local policy makers to formulate, implement and evaluate public health strategies.

Annually some 550 major orders and a large number of minor requests for data are processed from the registers. Data are freely available on the Internet through a user-friendly PC program and are updated annually. This program offers an extensive set of over 1.000 indicators on demographic and social conditions, mortality, morbidity, life styles, consumption of health-care, drug sales and other topics, available at national level and for all 21 counties and 289 municipalities. Many of these administrations use this program for planning and evaluation purposes.

The use of registers and data linkages has, inevitably, some disadvantages as well, such as the risk of doing harm to individuals who are registered. Despite such potential problem, after four decades of administering health data registers in Sweden, there is no known case of misuse or data leakage to unauthorized persons. Moreover, the benefits of the Swedish National Health Registers in improving knowledge and decision-making, resulting in effective strategies saving lives and improving health, outweigh the costs of being registered.

In conclusion, even if setting up a large number of health registers is not an option judged feasible by many MS, many lessons can be learned from the Swedish experience, because it shows how a number of difficult management issues that still represent stumbling blocks for some MS HIS can be resolved. Summarizing key aspects of the Swedish HIS, we can affirm that:

- Division of labor is clear cut,
- Coordinating tools and procedures are well-designed and serve well their purposes,
- Different organizations work in a collaborative way, for example the Epidemiology Center compiles health status analysis and Statistics Sweden contributes through the provision of reliable data,
- A very large amount of data is available to professionals to investigate an almost infinite set of health problems,
- A substantial set of indicators are freely available on the web to every administrative level,
- The protection of privacy is assured without limiting data linkage among registers,
- A relatively small group of multi-disciplinary professionals, capable to conduct public health analysis and with a clear mandate, build persuasive and credible arguments regarding public health problems' dimensions and potential solutions and communicate them to different actors, including policy-makers and the public,
- The organizational position of the EpC in proximity to the national Ministry of Health facilitates its interaction with policy-makers but at the same time preserves its analysts' professional autonomy.

Although it did not represent an area we planned to investigate, an issue that emerged from the interviews with key informants as well as from discussions among project's partners is the reality of organizations as socio-political systems. Viewing organizations as social and political realities means to reckon that human interactions, symbols and power are strong determinants of organizational behavior. This informal patterns of relationships i.e. the actual interactions between units and individuals have both positive and negative sides, such as mutual adaptation integrating formal lines of authority and communication or, on the opposite, sheer boycott of formal decisions. This project adopted a structural and systemic perspectives on organizations and would gain if completed by the political and human relations frames. The implication for improvement is that organizational structures and processes should be designed and adapted taking into considerations the current equilibrium and probable future scenarios.

Opportunities and threats

Several changes cross our societies and have strong implications for public health and therefore for HIS. In order to better understand and solve problematic aspects and build on strong dimensions internal to the organizations running HIS, we need also to look at the environment surrounding HIS. Today MS HIS faces a turbulent environment, where change is rapid, always challenging, sometimes threatening and sometimes opening up opportunities for improvement. Aspects especially worth mentioning include:

- Important immigration flows into some MS, bringing new needs,
- Emerging patterns in mature epidemics, e.g. the interaction between HIV/AIDS and tuberculosis, the progressive exposure of marginal population to HIV/AIDS,
- Epidemics of previously unknown diseases such as SARS with important health, economic and social impact,
- New climatic events, especially heat waves but also floods, with heavy health burdens, especially on the elderly and the health sector,
- Terrorist menace including biological, nuclear and chemical weapons,
- Low cost information technology able to manage large data bases, create linkages among different databases and organizations across countries, and connect data collectors and analysts,
- Information technology improving validity, reliability and data transfer speed (ex CATI),
- Financial constraints limiting investments in information technology and increasing conflicts and power games for control of resources,
- Adoption of a new reimbursement policy (DRGs),
- Decentralization policies within MS invest sub-national areas of much broader authority and responsibilities in the health sector, creating pressure to manage more effectively resources and programs, and to develop analysis capacity at Regional and local levels,
- Enlargement of EU political community to 10 more countries,
- Different methods of data collection and quality assurance across and within European countries,
- Effort by European Union toward the creation of an homogeneous HIS on public health problems currently not widely addressed across European countries,

- Progressive change in the dominant health determinant paradigm, from a bio-medical toward a comprehensive view of health, with a strong emphasis on socio-economic determinants of health,
- More mature democratic processes and structures leading to policy-makers' greater accountability, quicker responsiveness to citizens perceived needs and concerns, more pressing demands for better and broader information concerning health status, its determinants and the health sector,
- Some policy-makers might perceive the analysts role and products as undesirable pressures on their traditional prerogatives in the policy-making arena.

Finally, an aspect which clearly emerged from this project is the powerful influence of the administrative machine and broader societal structures on HIS management. For example, Belgium social, linguistic and political complexities are reflected in the intricacies of its HIS. Belgian is a federal state, which consists of 3 communities and 3 regions. As far as the HIS is concerned, the federal government and the 3 communities are the key players. Different types of data are collected at different levels with different methods, precluding their comparability. The federal level collects data about the health care system and supports surveillance networks of general practitioners and laboratories, registration of HIV infections and drug abuse. As our Belgian colleagues stated "The institutional complexity of the country hampers a global approach of the management of health data". These circumstances render Belgium HIS much more difficult to manage than, for instance, the homogeneous Dutch reality. Another example revealing the importance of cultural and historical factors influencing HIS comes from Germany where it is impossible to introduce a Personal Identifier, which would allow bringing together data from different sources, because data privacy protection has been given very high priority by legislation as a result of the German totalitarian experiences. Societal circumstances in which HIS are embedded might represent either a source of difficulty or a positive thrust and must taken into account when studying and improving HIS.

The above mentioned complexities and transformations underline the importance of adapting the HIS management to new realities. In the EU, HIS are managed by mature organizations, i.e. public administrations with a long history and traditionally facing fairly stable environments and predictable tasks. These characteristics called

for unambiguous division of labor and clear-cut policy, rules and standard operating procedures concerning the processing of data, information and knowledge. Nevertheless environmental turbulence relevant to HIS is now both great and unavoidable, and demands on public administration and societal expectations are higher than in the past. Therefore HIS structures and processes should be able to accommodate change without altering arrangements still valid. Only HIS which are managed rationally will have the capacity to adapt swiftly, anticipate and respond to the changes listed here or other occurring in the future. We conclude this chapter looking at weak and strong aspects of HIS content.

Strengths and weaknesses of MS' HIS content

Although HIS content is not at the center of this project's scope, our assumption is that this dimension depends in part on managerial arrangements. Some of the most frequently mentioned strengths and weaknesses of MS' HIS content are classified on the basis of the following four dimensions: availability, data quality, relevance and efficiency. First, definitions of such dimensions are given:

- Availability: accessible information to policy-makers, public health experts, researchers and the public at large regarding public health's problems,
- Data Quality: valid, reliable, timely information regarding public health's problems,
- Relevance: actionable information for public health's problems,
- Efficiency: reasonable cost per high quality and actionable information.

Availability

Strengths

- mortality, cancer incidence, Aids prevalence, rapid responsiveness of some systems (e.g. vitamin K and child cancer in Sweden);

Weaknesses

- difficult access to databases; insufficient data on social problems (social isolation, cocaine and ecstasy abuse), new groups (immigrants from developing countries), domestic violence, use of rear seat belts and child seats, disability data, abortion; use of ICD IX; record of only primary cause of death limits research on co-morbidities and other causes of death, i.e. no multiple causes of death, poor quality of occupation coding with many records 'unknown';

Data Quality

Strengths

- mortality, cancer incidence, Aids prevalence

Weaknesses

- inadequate validity and reliability re mortality data of some conditions: e.g. diabetes, traumas, traffic injuries collected by police, disability data, home care data
- data not originally collected for health reporting purposes, e.g. health insurances, statistical offices, hospitals

Relevance

Strengths

- cause and age specific standardized mortality rates; overall analysis of mortality trends with PH perspective; incidence of communicable diseases; attributable risk fraction for smoking and drinking and driving; detailed analysis of cancer mortality and incidence;

Weaknesses

- number of deaths by traffic traumas for each road, age and cause specific death rates per municipality with small populations

Efficiency

Strengths

- linked disease registries (cancer, cardiovascular diseases, traumas)

Weaknesses

- limited analysis of large databases, collection of useless data, incongruent timeliness between analysis and decision-making (too frequent analysis in relation to decision cycle).

Conclusion and next steps

The HIS is a crucial tool for supporting decision-making at the Health Systems' strategic, control and operational level, monitoring their implementation and evaluating their impact. The quality of HIS' output is in part determined by its managerial

arrangements. This project's rationale is that HIS works properly only if managed by organizations capable of running its processes in an orderly way.

This project's findings show that some HIS suffer from symptoms of ineffectiveness, inefficiency and organizational disorder. The root causes of some of these symptoms were traced to organizational arrangements, in particular ways organizational structures and processes managing HIS are designed and run. At the same time, our findings show that some MS, for example Sweden, have gone a long way toward clear assignments of HIS' responsibilities, smooth functioning of its processes, strong integration among its components, and successful influence of top decision-makers.

Environmental complexities and transformations accentuate the importance of adapting HIS management to new challenges. HIS structures and processes should be able to accommodate change in the health sector and in the society at large without altering arrangements still valid.

This project' effort at studying how MS divide labor concerning HIS and how they coordinate different organizations and steps, is not a mere intellectual exercise but represents a pre-condition for HIS management improvement. Results of this analysis are of particular importance because they may help MS to improve HIS performance in terms of data, information and knowledge's timeliness, availability and usefulness and also because they can be used by the EU as an information tool in support of the development of an integrated European HIS.

Our main recommendations are that decision-makers, administrators and professionals responsible for HIS, should identify symptoms of HIS malfunctioning, make explicit use of management tools to analyze them and consider the advantages of streamlining processes and redesigning structures. Organizational change is much more than simply rearranging boxes and lines of the organizational chart; such operation is never enough and, if conducted unskillfully can even be counterproductive. Principles of Total Quality Management can guide MS in their improvement efforts, grouping labor and coordinating its components in more rational ways. Participants of this project hope that it will contribute to better HIS management

and thus improve information quality and availability, health decision-making and, finally and most importantly, population health.

Possible next steps of another initiative continuing this effort might include a deeper analysis of other HIS components, besides those already studied, i.e. mortality and determinants of health. In particular it would be important to concentrate the attention on hospital discharges given the substantial proportion of the overall health expenditure deriving from this activity and the relevance of admissions information for hospital services management, prevention planning and integration of different care levels. In our aging societies, another critical dimension which deserves much more attention than today is the management of information on nursing homes and home care, including palliative care, and integrated social and health care. A further dimension to be studied further is the process of knowledge production and the link between HIS knowledge and decision making. Finally a didactic component could also be usefully added to the new project, so that lessons learned can be transferred to MS, including those not participating.

As mentioned before, the third objective of the original project, i.e. HIS management's improvement, was abandoned. A possible extension of this project could recuperate this goal, identifying solutions to main limitations of HIS managerial arrangements and recommending the formulation and implementation of strategies to institutionalize desired changes. Finally the enlargement of the EU to 10 more countries brings the opportunity to work together and learn from other countries' HIS problems and solutions and contribute to their integration into the European political and professional community.

Recommendations

The Work Plan 2003 of the Community Action in the field of Public Health 2003 to 2008 includes the continuation of the effort aimed at developing "a sustainable information system at EU level." In order to enhance the process of building such HIS, the Commission should look at HIS through a managerial perspective, among others, in order to identify current state's main shortcomings, outline preferred states and devise/implement/evaluate strategies able to accomplish desired results.

More specifically, the Commission should:

- facilitate identification, collection and diffusion of HIS management best practices such as the Swedish HIS's structures, processes, outputs and impact and the Irish HIS strategic plan,
- make available to MS diagnostic tools and techniques, such as SWOT analysis, responsibility maps, flowcharts and congruence analysis, useful in the identification of HIS malfunctioning symptoms, for example gaps and overlaps in activities, conflict and waste, and in the description and analysis of their managerial root causes,
- help MS in considering the advantages and the risks of streamlining processes and redesigning structures and making a choice between a do nothing, a strategic and a piecemeal approach to change HIS management,
- support MS in reviewing organizational missions and functions relevant to the achievement of HIS goals,
- assist MS in order to redesign structures congruent with key functions, i.e. key functions must be assigned to specific organizations or units, work should be assembled in such a way as to avoid gaps and overlaps, i.e. each task should be explicitly assigned to one unit and that task should be carried out by the responsible unit only, not by two or more,
- suggest standards to MS regarding staffing of structures, i.e. matching responsibilities with capable and experienced specialists in each specific area of concern,
- help MS to recognize the importance of organizational integration, i.e. linking different structures with coordination tools appropriate to the task and the proximity (or distance) between organizations, for example, task forces, permanent multi-organizational groups and strategic plans, standard operating procedures,
- provide MS with tools and techniques useful in streamlining processes i.e. eliminating activities that have a negative effect on the organization or the network, ensuring a smooth flow to the whole sequence, providing the appropriate resources and satisfying the customers,
- make sure MS institutionalize preferred structures and processes, i.e. ensure that change is absorbed by the appropriate organizations becoming routine,

- advise MS to involve organizational actors at each step so that the political dimension of change is taken into account, decisions are negotiated and the likelihood of their acceptance becomes higher because change's ownership becomes widespread. Changes of processes and structures should involve not only HIS top managers but also a large number of middle-managers and even professionals because these know the details of the situation and are able to provide useful solutions to the problems,
- grant support to MS through multi-country interdisciplinary meetings and consultation services,
- draw applicant countries' attention to the importance of adopting a managerial approach when improving their HIS, present the above-mentioned managerial tools and techniques adapting them to the specific circumstances and offer on-the-job training to develop appropriate skills, finally
- adopt analogous managerial principles when designing and assessing its own internal structures and processes and coordinating mechanisms with other international and national institutions, e.g. the networks of public health institutes and of health monitoring working parties.

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Annex 1

Guidelines for the interview to HIS key informants

Key informants should be chosen on the basis of their role in the organizations most involved in managing mortality and health determinants data. Management of surveillance implies the following 6 major tasks: Collection, Coding, Transmission, Analysis, Interpretation and Utilization. Ideally a total number of 12 key informants will be selected representing 3 categories each responsible for the following tasks:

A. collection, coding and transmission of data;
B. analysis and interpretation (knowledge);
C. utilization of knowledge (public health policies and strategies). The questionnaire included here refers to this category.

Before the interview, the interviewer should call each key informant outlining the project's major goals and contents and send to each participant a list of questions and topics to be covered in order to obtain their consent. All interviews have to be conducted face to face possibly in the interviewees' work environment. It is important to have some record of the main points of the interview and each key informant should provide permission for the interview tape-recording. Interviews should be taped so that interviewers can listen to them again and make notes. Interviewers will take notes during the interview also because informants being interviewed find note taking a compliment, communicating that you value what they have to say. It can be helpful to have another person listening to the interview to confirm that the interviewer understood them correctly. Establishing a rapport is crucial for the success of the interview. As a facilitator of the interview, use of active listening techniques such as nodding your head, saying "ah-ah", or "can you tell more about that?" will encourage key informants to talk more. It is critical that you do not impose your interpretations or perspectives.

The questions are semi-structured, with probing questions to elicit more information on issues of particular interest. A probe is used to encourage conversation without

influencing the answer. Two kinds of probe are used for open-ended questions. One is probing for clarity. The second is probing for clarity and additional information. Probing for clarity is used when respondents tend to answer in a general way, and to use general adjectives to describe situations and opinions. Probing for clarity is a matter of asking for a more specific response or explanation of a term (e.g. “What do you mean?” “Could you be more specific about”; “Could you tell me more”). Once a clear answer has been obtained, the interviewer should probe for additional responses to the question (Probing for completeness, i.e. additional information). The best way to do this is to repeat the substance of the question as part of a request for further information (“What else do you like?” “What other reasons do you have for.” During the conversation also the use of “Tell me more about that”, “Can you say it more clearly”, “I am sorry, I do not understand how that would work”, or “if I understand correctly, you are saying….” encourage the key informant to be more specific. The interviewer should continue probing for additional responses until the respondent indicates he/she has nothing else to say on the subject. Other probing techniques are five second pause; “I am sorry but I do not understand, would you explain me further?”, “Would you give me an example?”. Expressions such as “Is there anything else?” should be avoided because these can be easily answered with “no”. It may also give the impression that the interviewer is interested in closing the response and make the respondent feel as he/she is not really expected to provide further information. Nevertheless such phrase can be used as a final question to ensure that critical aspects have not been overlooked.

If you have been very good at establishing a good rapport, you may find it difficult to break off the interview. Beginning a summary of what key informants have said will help them to know things are winding down. Such summary is important because it gives the interviewer a chance to verify he/she has understood them. Interviewers may put what the key informants have said into their own words and may ask them if they have rephrased it correctly “Now let me see if I have understood you correctly. You are saying that…”. If they have misunderstood them they can give key informants a chance to correct them and clarify their position. As soon as possible after the interview, it is advisable to sit down and put thoughts on a paper, register key informant feelings, and anything else that seems relevant.

Key Informant Interview on Mortality Surveillance Systems in Europe (part C): utilization of knowledge (public health policies and strategies)

My name is _____ from the_____ _____. We are conducting a study on the Health Information Systems among European countries, and we would like to ask you a few questions about the Health Information System of your State/Region.

First, I would like to ask you a few questions about the organizations included in the health information system of your Region/State.

1. What do you think of the health status of the population living in your State/Region?

2. Describe briefly the mandate, mission and main functions of your organization in general (if necessary define *mandate* = reason of being of an organization given by the authorizing environment, i.e. outside and above the organization; *mission* = reason of being developed inside the organization taking into account the mandate. It defines goals and content area with more precision and identifies customer needs and wants; *functions* = core activities, i.e. services and products to be provided). **[Could we have a copy of a document describing these dimensions?]**

3. What do you think could be the main strengths and weaknesses of the health status and mortality information system of your State/Region? For example, is the information about health status and mortality accessible and timely? Is it relevant ?

4. Do you regularly use knowledge about mortality and health status to set priorities and to formulate and evaluate public health strategies and programs? Could you provide 2 or 3 examples of such utilization?

5. What do you suggest in order to improve the relevance of health status and mortality data analyses?

6. Is there anything else we should have talked about, but did not?