

# DATA FOR DECISION MAKING IN NETWORKED HEALTH

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## ABSTRACT

*Today's developed countries are networked societies, with strong specificities in the Health field. Health costs have strongly increased. Indeed, governments, local powers, public and private health or insurance organizations face difficult choices: they need the most specific and valuable data available.*

*Data for Decision Making in Networked Health is necessary at 3 levels: between patients and physicians and within the organizations (micro), within the organizations (meso) and in regional powers or governments (macro) and with 3 major content dimensions: quality, ethics, economics (effectiveness). We point out some specific tools of e-Health Information Systems: EHR (Electronic Health Record), portals and call centers. Then we analyze the main issues about data for Decision Making in Networked Health: information sharing, coordination and evaluation. Lastly we use an Information System perspective to analyze ways of improving interoperability at the core of each context, and of advancing from one context to another.*

**Keywords:** decision making, health networked organizations, information system, interoperability

## 1 INTRODUCTION

In developed countries, nowadays we live in a networked society: a society of information, knowledge and services (Castells, 1996), with strong specificities in the Health field (Bourret, 2003, Silber, 2003). The World Health Organization (WHO) has outlined the importance of information for improving health for all. However, financial resources remain limited. Health costs represent 11% of GNP in France, Germany, Switzerland and Canada, 14% in the USA, and 7.5% in Spain and the United Kingdom. Governments, local powers, health or insurance organizations therefore face difficult choices in terms of opportunities and priorities, and for that they need specific and valuable data.

Firstly, this paper provide a comprehensive overview of our networked society and the appointment of ICT (Information and Communication Technologies) and Health (in other words e-Health) in a perspective of needs and uses at the micro, meso, and macro levels. We point out the main challenges of development of Nationwide Health Information Network both in the US, UK and France. Then we analyze the main issues about data for Decision Making in Networked Health: coordination and evaluation.

In the last sections, we use an Information System perspective to investigate the three interoperability layers (micro, meso and macro). We analyze the requirements and challenges to design an interoperability global architecture which supports different kinds of interactions; then we focus on the harmonization efforts provided at several levels. Finally, we identify common methodological and engineering issues.

## 2 NEEDS AND USES OF HEALTH DATA IN A NETWORKED SOCIETY

Palier (2005) has shown that health system reforms are divided into four main objectives that tend to be contradictory. These four objectives are: equal access to treatment, financial viability (efficiency), the quality of treatments, and the liberty of actors (patients and health professionals). Each reform must strike a balance between the different objectives. Glouberman and Mintzberg (2001) have pointed out four separate worlds functioning within the hospital: that of doctors, of nurses, of managers and of the board of directors. These categories become particularly important between town medicine and the hospital, and this is especially the case in France. Indeed, a recent study has shown that such separations in France, assimilated to non-quality, account for 15% of total health system costs (Coulomb, MEDEC 2005). In the USA, Wennberg, Fisher & Skinner (2002) estimate that between 20-30% of health care spending is for treatment that do not improve health status, are redundant or are not appropriate for the patient's condition.

Dranove (2003) has furthered the discussion by outlining the evolution of medicine from traditional systems, centered on autonomous physicians through government planning efforts, to managed care organizations. Today's networked society is characterized by information, knowledge and services alike. Castells speaks of a "networked society" and, along with Aoyama, points out the importance of "information professions", which include roughly 50% of the workers in the US: doctors, nurses ... (Gadrey, 2003). But it is not only information and informatics, so Miège (2004) speaks about "informationnalisation" to tackle with the new communication standards and the social logics linked to this evolution.

The challenges faced are primarily those of costs mastering (effectiveness), followed by those of quality improvement. Governments, local powers, health or insurance organisations (public or private) must make difficult choices in terms of opportunity and priority. The Networked Information Society has strong specificities in the Health sector. These include sensitive data (privacy) and twin challenges both for organization management, quality of care and relations between all the levels (micro, meso, macro) as well as between the different actors, such as care & health insurance organizations, and health professions (doctors, nurses, etc.) state and local powers, and of course, patients, a role of increasing importance. This is why they need specific and reliable data for decision making.

We now turn to an analysis of the data requirements for coordination through information sharing. On the one hand, Le Coadic (1999) has distinguished 3 levels in Information Science: "building" information, "communication" of the information (processes), and "uses" of information. Data management for decision making in networked health corresponds to these 3 levels. On the other hand, data in an "information needs" perspective is necessary at 3 other levels. These include the level between patients and physicians or within organizations themselves (micro), the level within the organizations themselves or between the Health Organizations (public or private hospitals, Health Insurance ...) or the meso level, and finally, the level between regional powers or governments (macro). This in turn includes 3 major content dimensions: quality, ethics, and economics (effectiveness).

According to the American Medical Association, "Managed Care" is the overall unity of systems and techniques used by delivered care organizations, management organizations, and health insurance for checking the quality, access, use, costs and prices of healthcare services for a particular population. Managed Care is a global perspective of coordination, traceability for mastering costs and checking health providers. Managed Care is mainly concerned by the first two levels. In the USA, Health Maintenance Organizations (HMOs) are among the most relevant realizations of Managed Care (MCO: Managed Care Organizations). In Spanish Catalonia, CatSalut, the public Health Purchaser, may be considered a non-profit HMO, whereas in the UK, the new Primary Care Trusts (PCTs) are also public health purchasers.

In an OECD (Organisation for Economic Co-operation and Development, 2004) report to health ministers, entitled *Towards High-Performing Health Systems* (2004), this challenge has been clearly highlighted: "Health systems should invest in automated health-data systems, including electronic medical records and systems to automate medication orders in hospitals. Better systems for recording and tracking data on patients, health and health care are needed to make major improvements in the quality of care" (OECD Website, n.d.). Each country has experimented its way. In the United Kingdom, according to a report for the Prime Minister Blair entitled *Information for Health*: "The challenge for the NHS (National Health Service) is to harness the Information revolution and use it to benefit patients" (Burns, Information for Health, 1998).

During the last twenty years, most developed countries (except France, where an "hospitalocentrist" perspective has always prevailed) have bet on ambulatory care (primary care). Such has been the case in Canada with Quebec's *Centres Locaux de Services Communautaires* (CLSC) and the "electronic ambulatory shift" (*virage ambulatoire informatisé*), in Spain, with Catalonia's *Centres d'Atencio Primària* (CAP), and more recently in the United Kingdom, with the Primary Care Trusts (Crisp, 2002). Nevertheless, in France, a necessity has emerged for greater interface between Hospitals and primary care doctors with Healthcare Networks.

## 2.1 The Micro Level

At this first level, information requirements concern the relationship between patients and physicians, between physicians and other professionals or within an hospital department. Medical errors represent a strong challenge (Stefanacci, 2001): in the USA, they would explain 50 000 to 100 000 deaths every year (Blendon, DesRoches, Brodie, Benson, Rosen, Schneider, Altman, Zapert, Herrmann & Steffenson, 2002). According to Cordonnier, 30% of medical errors came from poor information management and especially from patient's identifiers (Le Beux & Boullier, 2001). The everyday mission of Healthcare Networked Organizations is an attempt to develop cooperative medical practices, mainly among the primary care physicians who generally work outside the hospital and hospitals with their different departments. The first challenge concerns transfers of information. The hospital is often at the centre of a lot of these data transfers.

At the beginning of the 1980s, American HMOs focused especially on Information Systems for checking the continuity of care and, more importantly, limiting the redundancy of services and cutting costs. The Information System is a key tool both for managing the everyday performance of the organizations (indicators) and for watching emergency (alarm signals). It is at the heart of managing the continuum of patient pathways, and in coordinating medical decisions in both primary care (micro level) and in the hospitals (see meso level). But this Information System is also basic for transferring and sharing strategic information between all the various components of the whole Health Systems. So the development of interoperability frameworks is imperative. The key element of eHealth (Boden, Braun, Cabrera, Constantelou, Da Costa, Karounou, Ligtoet, Monteagudo, Redondo, Rodriguez & Skulimowski, 2004) as a major component of Health Information Systems is the Patient Electronic Health Record (EHR). Interesting integrated regional achievements exist, for example in Quebec (Canada) or in Andalucia (Spain).

The big American HMO Kaiser Permanente (10 States, 11,000 physicians, 8.2 million members) highlighted the electronic medical record for improving the quality and efficiency of care with implementation deadlines during 2005 (Kaiser Permanente, n.d.). In the USA, the EHR (Electronic Health Record) for all Americans is a Federal priority. In April 2004, President Bush called Americans to be covered by interoperable electronic health records within ten years and he established a National Coordinator for Health Information Technology within US Department of Health and Human Services (HHS). In July 2004, HHS released the Framework for Strategic Action: *The Decade of Health Information Technology: Delivering Consumer-centric and Information-rich Health Care* (U.S. Department of Health and Human Services, Office of the National Coordinator for Health Information Technology, 2005). In September 2005, for The Government Reform Committee: "Bringing the IT (Information Technology) Revolution to Healthcare" is "The Last Frontier" (Government Reform Committee, 2005). In the UK, the implementation of a national Electronic Health Record is a priority of the British NHS with the goal of a record for life (ERDIP project: *Electronic Record Development and Implementation Programme*) (ERDIP, n.d.). It should be operational by 2008. The crucial issue of who stores the data contained in these Health records is not closed. Will the NHS store the data itself via the new Primary Care Trusts or will it be entrusted to private companies?

In France, attempts to create a single structured record have failed over the last 20 years. The Fieschi report (2003) recommend choosing a much more pragmatic approach to develop Health Information Systems (and not only Hospital Information Systems) starting with the data available in the existing information systems (hospital, private clinics, Healthcare Networks, doctors teams ...). These new Information Systems should be patient-centered and probably managed at the regional level. With the Health Insurance Reform of August 2004, the Patient Electronic Health Record managed by the *médecin traitant* (a French version of the GP gatekeeper) became a central tool both for containing costs and improving the quality of care (Ministère Santé, n.d.).

Other aspects of e-health are those of patients' information and orientation on the healthcare systems. We must point out the main successes of call centers managed by nurses: in the United Kingdom, NHS Direct (6 million calls in 2003) and in Spanish Catalonia, Sanitat Respon, created in the Barcelona area in 2001, and progressively extended to the whole of Spanish Catalonia (500 000 calls in 2004). This has proved a good manner to cope with the problem of managing emergencies.

Another important aspect of decision-making within Health Networked Organizations is the offer of medical information to both professionals and to patients. This information would concern new techniques, drugs, events, etc. This is the main role of websites (portals) with the development of new professions of specialized webmasters. It is vital for them to choose reliable information and links (they rely information filtered on the responsibility of the HNO). There exist a lot of specialized sites for professionals. For a wider public, we must also point out the contribution of Scotland's SHOW (Scottish Health on the Web) and of Canada's Health Network (*Santé Canada*).

The emergence of new professions in the information field: "Information Technology Professions" (Denning, 2001) have strong specificities in Health field. But there also exist new professions and outgrowths of very old professions, such as nurses by skills or competencies hybridization, especially medical, management, information and communication competencies. We have pointed out new professions in French Healthcare Networks: "coordinators" and "evaluators" (Bourret, 2003). New professions have also emerged that with specializations in coordination and communication activities, such as nurses case managers in Quebec (Canada) who watch for the patients' continuum of care (appointments ...) mainly in hospitals.

## 2.2 The Meso Level

The "meso level" is that of Health Organisations (public or private hospitals, Health Insurance etc.). This level includes two important issues for managing patients' global care: traceability and patients' pathways and managing the organizations themselves.

The first aspect joins the “micro” level through the EHR perspective. The second point is an Information System perspective in special needs: managing Health Care Organizations. An important evolution has taken place in France: from January 2005 onward, over a likely period of 8 years, hospitals, like private companies, will cease to be financed by global budgets, and will rather be financed by resources directly linked with their activities (T2A: *Tarification à l'Activité*) using data of PMSI (*Programme de Médicalisation des Systèmes d'Information*). Long term success will mean a real revolution in the management of both public and private French hospitals. It will also mean drastic changes for the use of information in such organizations, with greater emphasis on competition and productivity, such as in the British “quasi market” of hospitals and PCT since 2002. One important aspect of transferring and using data among organizations within a “meso” level perspective is that of Telemedicine. Telemedicine is mediatized, especially as telesurgery or telediagnosis, but also with experiments in home telewatching. Managing reliable multimedia data is an important part of this emerging e-health activity.

Dranove (2000) notes that, in America nowadays, MCO often stands for “managed *cost* organizations” (without considering quality) rather than for “Managed *care* organizations”. Patients can regain confidence in the medical system by becoming customers, shopping around for the best managed care plans and the best providers. The patients must seek and act on information about the best care available. For the patient, better data is necessary for competition between MCOs. Market forces can enable patients to obtain the highest quality care at low prices. Several hurdles must be overcome through substantial improvements in health care data. Dranove argues that “we need better outcome measures and must be able to link patient-level medical records across providers”.

## 2.3 Macro Level

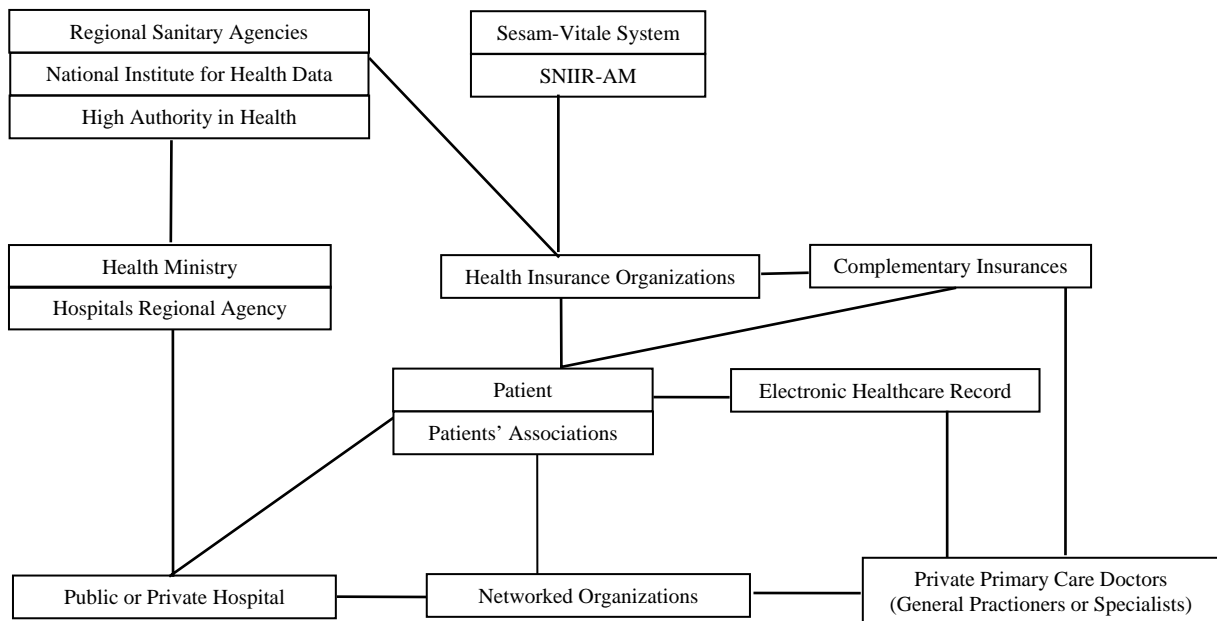
Over the last twenty years, everywhere, States have developed a logic of experiment and contractualisation. Data is necessary to evaluate results and measure gaps with objectives targets.

For regional powers or State Health Systems at the “macro” level, data is required for various uses:

- First, the evaluation perspective which is at the interface between “meso” and “macro” levels with the data production for the evaluation of “meso” health providers organizations (hospitals ...) are required for uses by Health or Insurance purchasers (States, regional powers such in Spanish Catalonia, American HMOs, French Health Insurance, British PCTs ...) with data for special indicators.
- To plan the evolution of establishments (public or private hospitals). This includes the creation or closing of establishments, as in France Regional Plans for Organizing Care, SROS (*Schémas Régionaux d'Organisation Sanitaire*) or sanitary maps. It also includes the links with territory planning challenges as well as the problem of competition and, consequently, important coordination needs between state and regional levels.
- For Sanitary Watch to foresee Public Health problems and help to decision making: for example in the long run, data from French *Observatoires Régionaux de Santé (ORS)* and, in the short run, to react immediately in case of emergencies such as disease or extreme weather, and its consequences on weak individuals (note the French problem during the Summer heatwave of 2003, with 15.000 deaths among the elderly).

The 3 levels are interconnected: the success of global Health Information Systems policies mainly depends on the quality of these interconnections: in other words, coordination and challenges of metadata, or information about information. For example, as described in Nakache (2003), the Data Warehouse project, called *Système National d'Information Inter-Régimes de l'Assurance Maladie (SNIIR-AM)*, aims at supporting the French National Health Insurance to select the intervention domains and to take into account numerous problems: financial, medical, social, accounts, public health and political. As this Data Warehouse covers the entire population (62 million persons), it has been considered as one of the biggest in the world. Information sources are provided by multiple databases concerning health professionals, establishments, patients and delivered care. France hopes to create a National Institute of Health Data, to coordinate the management of patient data, and especially that of SNIIR-AM.

The interconnection issues in the French Health System have become more problematic due to the needs of data for reimbursement, with French specificity of paying professionals for each individual act and then reimbursing the patients by very different Health Insurance organizations. These issues represent the main challenges tackled at different levels:



**Figure 1:** The complexity of the French Health System

The Information System of the hospitals must be reorganized and interconnected via the “2007 Hospital Programme”. They must also be interfaced with the EHR and with a new version of the “Sesam Vitale” card. The card, which has been aimed for completion by 2006, should contain not only administrative data but also health emergency data and pointers functions for both hospitals and Health Insurance Organizations.

In the United Kingdom, the ambitious “Information for Health” Programme has the same goals, but without the reimbursement aspects. Consequently the UK Programme does not include the same consents and access challenges linked to the French case, where activities are paid in act and subsequently reimbursed.

In the United States, the Electronic Health Record for all Americans promised by President Bush within ten years is connected with a Nationwide Health Information Network (NHIN) Project. Firstly, from November 2004 to March 2005, the Office of the National Coordinator for Health Information Technology (ONC) released a Request for Information (RFI) to learn how interoperability of health information could be achieved through a NHIN (U.S. Department of Health and Human Services, Office of the National Coordinator for Health Information Technology, 2005). Four possible NHIN governance models emerged: a Federal Government entity, Federations of RHIOs (Regional Health Information Organizations), State Government Sponsored Federation of RHIOs or local Public-Private Collaborative Entities. The more common NHIN definition is a “network of networks” built on the Internet but there is also advocates of “central national database” or of a “system of legacy systems”. The information must be available nationwide, be secure, exchanged in a patient-centric manner, governed by privacy and access control policies, with local or regional coordination, supporting a rapid translation of scientific knowledge into daily practices. According to them, RHIOs do not store information but are the trusted agent for data exchanges in a region, the providers storing the data on their own legacy systems.

Actually as suggested by Morin & Le Moigne (2003), the complexity of health systems must be broached through global and converging approach or “dialogique” and “hologrammatique” approach. For us this converging approach consists in putting together the three different levels of analysis (micro, meso, macro).

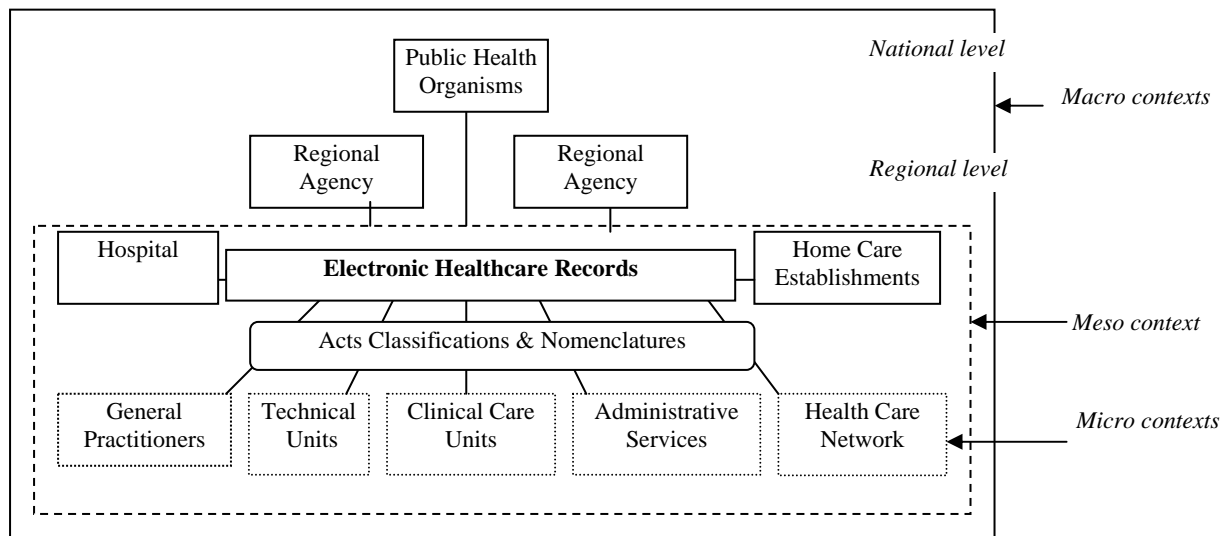
### 3 AN INFORMATION SYSTEM PERSPECTIVE TO INTERPRET MICRO, MESO AND MACRO CONTEXTS

In this section, we interpret micro, meso and macro contexts within an Information System (IS) perspective. We then analyze the challenges and engineering issues at stake in improving interoperability at the interior of each context and in advancing from one context to another. Finally, we provide an overview of the harmonization efforts concerning norms and technologies in the domains of interoperability and security, in order to facilitate these evolutions.

In order to analyze possible approaches to developing decision services for health domain organizations, we consider the interoperability requirements at stake. In the US, ONC considers interoperability as a “key

component to interconnect”. According to them, interoperability is “the ability to exchange patient health information among clinicians and other authorized entities in a timely manner and under consistent security, privacy and other protections” (U.S. Department of Health and Human Services, Office of the National Coordinator for Health Information Technology, 2005). Health organizations differ with respect to the contexts in which they operate and the computer-supported cooperation level they aim at reaching. We consider the micro, meso and macro contexts as granularity levels, with different kinds of interactions and different heterogeneity problems, as illustrated by Figure 2:

- In the Micro context, interactions are based on internal healthcare delivery processes and artifacts, such as administrative, diagnostic and clinical data, for a medical department or a GP.
- The Meso context extends the previous context by allowing interactions between several health departments and GPs.
- The Macro context supports wide interactions between the health centers of a shared region, or public, financial supporters, universities, institutions, health agencies and organisms, which may be public or private, national or international.



**Figure 2.** The EHR structuring element for all contexts

In general, IS are classified in accordance with their main objectives, whether transactional or decisional. These objectives are mainly to support the organizations in either the care delivery process or in the decisional process. With respect to these classifications, the IS of the micro and meso contexts are transactional, whereas the IS of the macro context are decisional. However, due to the decision potential within the EHR, the meso context may be simultaneously considered as transactional and decisional.

Although not all of these contexts are partitioned, they must nevertheless be able to interoperate, consolidate and aggregate information from one level to another.

Heterogeneity between IS of the micro context generates several conflicts that must be resolved in order to build cooperative IS in the meso and macro contexts.

## 4 MAIN STAKES FOR DECISION MAKING: COORDINATION AND EVALUATION CHALLENGES

### 4.1 Health Information Specificity

A principal goal of Information Systems is that of producing reliable data for decision making. But what exactly is meant by the “right” information? Glouberman and Mintzberg (2001) have pointed out the difficulty of “managing through measurement”. Indeed, a successful liver transplantation does not have the same meaning for the surgeon, nurses, or administrators, for example, when a cancer from 5 years prior returns, or when the liver is slowly rejected. So Glouberman and Mintzberg want to outline the risks in managing through raw numbers only, without any qualitative perspective.

Health Data is very different from other data. From as early as 1978 in France, legislators enacted the Informatics and Freedom or Data Protection Act (*Loi Informatique et Libertés*) in an effort to protect citizens from possible abuse (Legifrance, n.d.). The *Commission Nationale de l'Informatique et des Libertés* (CNIL) (CNIL, n.d.) was subsequently founded to control its application. The European directive of October 1995, protecting personal data and favoring its transfer within the European Union, considers Health data as “sensitive” data. The United Kingdom adapted its national legislation to the European directive in October 1998. France did not complete this adaptation until August 2004. This European directive strengthens the protection of a person’s rights. Personal data represent any data allowing a person to be identified. Permission for its use depends on the goals of the collecting organization (research, general interest). In the US, for the *Summary of NationWide Health Information Network*, a NHIN should be patient-centric with sufficient safeguards to protect the privacy of personal health information. In the US, the protection of patient privacy rests mainly on the Health Insurance Portability and Accountability Act (HIPAA) of 1996 (Office for Civil Liberties – HIPAA, n.d.). But there are also no fewer than 25 specific Federal laws as potentially applicable to the implementation of a NHIN: HIPAA of 1996 of course, Disabilities Act, Antitrust laws, Drug Enforcement Agency regulations, Family Education Rights and Privacy Act (FERPA), Employee Retirement Income Security Act (ERISA), Freedom of Information Act, Medical malpractice, Medicare Modernization Act of 2003, Medicaid payment, Physician self-referral law (Stark law)... The first-ever federal privacy standards took effect on April 2003. Particular State laws that provide additional protection to consumers are not affected by this new rule. States’ law disparities and also international laws must be also examined (U.S. Department of Health and Human Services, Office of the National Coordinator for Health Information Technology, 2005).

Access to sensitive data is very important. In Canada, The Quebec Access Commission Information (*Commission d'Accès à l'Information du Québec*) takes particular care in managing consent and privacy protection. In France, some decrees regarding access to personal information were published in April 2002 (Legifrance, n.d.). While they are very precise about the obligations of Health institutions, they do not solve the main problem of what data the patient does or can have access to. The issue of access to medical data cannot be dissociated from the issue of data ownership. Does the patient “own” raw or processed data? There are also important challenges at stake for identity providers, in the domains of authorization access management and cryptographic issues. In France, the law of March 2002 speaks about health data warehouses (in French: *hébergeur*). However, 3 years later, applications decrees have still not been applied by the government.

In the US, managing patients’ consents and correctly identifying patients by linking individuals to their information is a key consideration for NHIN development. There exists a passionate debate between the advocates of a unique national patient identifier to ensure the stored information in the right record and its retrieval for the right patient to a second group strongly opposed than such a unique identifier would threaten patients’ privacy and a third group supporting a more pragmatic approach where patients would be more concerned in managing their consents. They speak about an algorithmic patients’ identifier instead of a national patient identifier. Other major privacy considerations have been highlighted for a NHIN:

- health record ownership: who should own the patient’s health record ? who maintains it ? what constitutes it ? which medical providers should have access to the record in whole or in part ?
- debate between an “opt-in model” insisting on patient’s active consent versus an “opt-out model” presuming patient’s consent, with the key issues about duration of the rights of disclosure and the example of an unconscious patient in an emergency room (U.S. Department of Health and Human Services, Office of the National Coordinator for Health Information Technology, 2005).

## 4.2 Coordination: From Information Sharing ...

For Grimson, Grimson & Hasselbring (2000): “The present inability to share information across systems and between care organisations represents one of the major impediments to progress toward shared care and cost containment”. Glouberman and Mintzberg (2001) have pointed out the compartmentalization of four different hospital worlds: cure (physicians), care (nurses), administration (managers) and collectivity (board). There also exist further difficulties within the community. So we are faced with two different coordination challenges. There are challenges within the hospital, and also within community services. These are challenges for cutting across the four “specialized curtains”, which are:

- the “acute” curtain (that between hospital and community or primary care)
- the “cure” curtain (between cure and care in the hospitals)
- the “medical” or scientific curtain between physicians (specialists and general practitioners) and the other health professionals (nurses, psychologists ...)

- and finally the “professional” curtain between health professionals and “alternate” practices (chiropractors, acupuncturists ...).

So the main challenges to the Health field concern semantic interoperability (see next sections) between various legacy information systems, such as hospitals, doctors, British Primary Care Trusts, Health Maintenance Organizations in USA or Health Insurance in France, and companies. This is related to the shared use of knowledge, and information exchanged from disparate systems through the shared Electronic Health Records.

There exist various interesting achievements in Quebec (Canada) and in Andalusia (Spain). The Laval region in Quebec (Canada) has developed an innovative Information System which interconnects Hospitals and Local Sanitary Centres (*Centres Locaux de Soins Communautaires*: CLSC) in order to regulate patients’ flows in relation with nurses’ case managers in the hospitals (Sicotte, Moreault, Lehoux & Farand, 2004).

The projects of the *Junta de Andalusia* (Spanish regional power) seem to be the most integrated. The main goal of *Salud Andalusia Digital* is a global integration of all the technologies and systems dedicated to citizens and aiming at the improvement of access, transparency and efficiency through different achievements. Firstly a single identification tool: the “sanitary card” (*Tarjeta Sanitaria*) provides access to all the computerized clinical history of the patient. At the same time, the informatization of the whole network of primary care (1038 centres) has been achieved, as well as informatization of the Telemedicine Network connecting rural districts to reference hospitals. The first health users’ database in Spain containing information of all the Andalusian citizens has also been implemented. The *Receta XXI* Project will permit chronic patients to directly obtain drugs without having to return regularly to doctors for prescription renewal. The Systems and Technologies Management Center (*Centro de Gestión de Sistemas y Tecnologías*: CEGES) manage all the integrated systems and works all year long, 24 hours a day (Junta de Andalusia, n.d.).

In France, the Fieschi report (2003) pleads for Regional Information Systems. This is not only the case for public or private hospitals’ IS, but also includes the integration of data from primary care level and health insurance organizations.

### 4.3 ... To Organized Care Delivery Systems ...

But developing a Nationwide Health Information Network (NHIN) is one thing: it is only an essential tool. Its key success depends on the creation of new services or products such as disease management services (U.S. Department of Health and Human Services, Office of the National Coordinator for Health Information Technology, 2005). A part of the RSS (*Réseau Santé Social*) relative failure in France is being only a transferring data network for Health Insurance without ceating value added services to medical professions and patients.

Interesting achievements already exist to cope with the core challenge of using information and communication technologies for the improvement of healthcare services for citizens, patients and clients. In a situation of limited resources, the imperative of collaboration for improving productivity is ultimately the same in public systems (national or regional systems) as in the United Kingdom, France, Spain, and Canada, or in more private systems such as the American HMOs.

As examples of projects concerning hospital centered networks with interoperable IS supporting administrative, diagnostic and clinical data exchanges, through an Internet based middleware, we will cite in Italy the SPERIGEST project (Benassi, Bravar, Carpeggiani, Macerata, & Donato, 2002) at the Pisa Hospital, and in Greece the European PICNIC (Professional and Citizen Networks for Integrated Healthcare) (Tsiknakis, Katehakis & Orphanoudakis, 2002) project for a health regional network.

In France, for instance, public hospital and healthcare parties of the Nord-Pas-de-Calais region have been developing from 1998 an experimental project of a hospital centered network to exchange in real time messages and documents between the multiple parties involved in the care delivery. Today, the technical solution, based on complementary components, is completely validated. In the French Franche-Comté region, a portal federating sixteen health care networks constitutes one of the few examples of an electronic health care record implementation ensuring coherence at a regional level (Lehalle, 2003). In the next sections (§5), we will mention some Information Systems challenges and issues for these ambitious projects.

Glouberman & Mintzberg (2001) have pointed out the key challenge of collaborative management of the entire system. This is the challenge of creating comprehensiveness (universality, portability, and accessibility) “beyond markets and hierarchies”. To achieve this vital goal, they insist on social ownership, appropriate scale, involved leadership, collaborative networks with the main issues of reconnecting care, cure, control and community.

This is also the key challenge outlined by Shortell, Gillies, Anderson, Morgan Erickson & Mitchell (1996) for whom “Remaking Health Care in America” is about “ building an effective community health care management



system” through an “integrated ” and “organized” delivery system. For that, the quality and efficient management of data for improving decision making is a “determining” factor.

#### 4.4 ... In a framework of continuous evaluation

Finally all systems of public and private insurance face a basic separation between providers and purchasers of health, based on contracts. Public systems (i.e. French Health Insurance, CatSalut in Spanish Catalonia, British PCTs, etc.) or private systems (i.e. American HMOs, private insurance in France such as AXA, etc.) purchase specific services at a contract price from providers: hospitals, primary care teams, private doctors, health networks ... according to specific requirements and constraints.

Consequently the purchaser wants to evaluate the quality of the service. According to Lievre (2002) we can analyze the relationship between goals, outcomes and means in a Health System or in a Delivered Organization as represented in the following “Evaluation Triangle”:



**Figure 3:** The Evaluation Triangle

Health Organizations’ evaluation for improvements is linked to Project Management and Total Quality Management methods (Wang, 1998). Their Information and Communication Systems must be capable of collecting the necessary data and following up results of quality indicators of given services. Healthcare Organization evaluation is, broadly speaking, an evaluation of their Information Systems.

Ammenwerth, Gräber, Herrmann, Bürkle & König (2003) point out three main problem areas in the evaluation of Health Information Systems: the complexity of the object of evaluation and of the evaluation project, along with its multitude of stakeholders, and the motivation behind the evaluation. These are only some examples of the challenges facing organizational and social evaluations of Computer Supported Cooperative Work systems (CSCW) that support complex communication. In another paper, Ammenwerth, Brender, Nykänen, Prokosch, Rigby & Talmon (2004) highlight the importance of evaluation: “Evaluation is a means to assess the quality, value, effects and impact of information technology and applications in the health care environment, to improve health information applications, and to enable the emergence of an evidence-based health informatics profession and practice”.

Potential methods to measure the success of a NHIN, in other words its evaluation, are under debate. The respondents distinguished two phases: short-term measures linked to process activities and rather quantitative (number of users, volume of transactions) and longer-term measures linked to outcomes (improvement of patients’ health, safety of the care, value added of health care) rather qualitative (U.S. Department of Health and Human Services, Office of the National Coordinator for Health Information Technology, 2005).

The principal data management challenges that remain to be tackled by Health Networked Organizations are those of interoperability and security.

## 5 CHALLENGES AND ISSUES TO IMPROVE THE INTEROPERABILITY AT THE INTERIOR OF EACH CONTEXT AND TO GROW UP FROM A CONTEXT TO ANOTHER

## 5.1 Challenges

Walker, Pan, Johnston, Adler-Milstein, Bates & Middleton (2005) estimated a net savings from national implementation of fully standardized interoperability between providers and other organizations to approximatively 5% of the US health care spendings in 2003.

According to the NHIN Summary, the concept of interoperability has various meanings such as: uniform business processes, controlled medical terminology, communication protocols, reference implementations, data standards allowing data exchange (U.S. Department of Health and Human Services, Office of the National Coordinator for Health Information Technology, 2005).

The Information System of a Health Networked Organization must be understood as a complex system within a global environment. It is characterized by complex legal and professional frameworks, multiple actors, and a wide production of heterogeneous systems, which are undertaken without any common objective and distributed throughout different organizational structures. They have highly disparate initial automation levels, such that in a fragmented context there is no real collaboration. Due to social and economical pressures and to technological advances, the automation levels tend to increase towards higher levels, which may be classified as communicative, collective, coordinated or concerted (Hichney, Dean & Nunamaker, 1999).

In accordance with the framework of the Computer Supported Cooperative Work, and the main Information Systems Engineering paradigms, two problems need to be solved simultaneously, in order to specify and develop cooperative applications with increased interoperability levels and approaches (Salzano 2002, Salzano & Bourret 2003). These two problems are:

- to reconsider legacy systems and to modernize them through a deep reengineering of their work processes to improve the information sharing. For that, new processes must be created to satisfy interoperability requirements
- to make interoperable modernized systems, thanks to a component based architecture.

So in the US, the integration of legacy systems within a NHIN is identified as a “key issue” and a lot of respondents to the surveys suggested a backwards compatibility plan for all legacy systems. Another debate is that of a document-oriented approach versus a coded and structured data approach of the NHIN.

## 5.2 Issues in terms of harmonisation efforts

Many respondents of the NHIN Request for Information considered standards as the critical element of interoperability: terminology/coding standards, markup standards and information about the data characteristics, security standards and network-interaction standards (U.S. Department of Health and Human Services, Office of the National Coordinator for Health Information Technology, 2005).

Following a progressive approach, health organizations firstly plan to facilitate communication between several points of treatment, then expand and secure these services, finally develop common services and concepts (semantic interoperability), structured on the electronic healthcare record. The legacy systems have been developed following standards and recommendations that are not always compatible. Firstly, they have to interact through a communication infrastructure in order to share Electronic Health Records (HER). These may be structured and accessed in different ways, according to time, problems, or organization. In France, for exemple, the micro or meso level of the GP tools are compared to the EHR. Very few GP tools (like Axilog by France Telecom Group, or Crossway Ville, by Cegedim Logiciels Médicaux) end up integrating new recommendations about the shared medical record on a network (structured data, exchanges, traceability, opposability, etc.).

Before addressing the very critical problem of semantic interoperability, we must first confront the obstacle of attaining the technical interoperability needed for exchanging health information.

Important harmonization efforts are established in the communication area, to build a synthesis between:

- the standards XML, MIME and ebXML, recommended by the World Wide Web Consortium (W3C) (World Wide Web Consortium, n.d.)
- the American or international health domain de facto standards :
  - HPRIM, *Harmonie et Promotion de l'Informatique Médicale*, largely used by the software providers community for laboratories, clinics and GP exchanges (HPRIM, n.d.)
  - DICOM, Digital Imaging and Communication in Medicine, largely supported in the numerical medical imaging domain) (DICOM, n.d.)
  - HL7, Health Level Seven, defining the protocol for exchanging clinical data between diverse healthcare information systems (HL7, n.d.)

- the European pre-norm 13606 provided by the European Committee of Normalization (CEN/TC 251), based on the exchanges models (CEN/TC251, 1997). Moreover, a modular architecture (HISA) has been designed by the CEN/TC251 to bring interoperability between both legacy and future information systems in a healthcare environment, for patients' treatments and management purposes. This framework contains three cooperative layers (applications, middleware and physical) providing generic common services (GCS) and healthcare specific services (HCS).

The harmonization of the establishments' IS through the normalization process is a governmental priority for many developed countries. In France, for example, several Public Interest Groups (*Groupement d'Intérêt Public*, GIP) have been created:

- the GMSIH (Hospitals' Information Systems Modernization Group) GIP (GMSIH, 2005) participates in the harmonization, interoperability, opening and security of the health establishments' IS. To do so, it collects users' experiences and requirements, and participates in European normalization and specification groups. It diffuses norms, standards, and studies to facilitate their integration in the operational solutions of care establishments and software editors.
- the Health Professionals' Card (HPC, in French '*Carte de Professionnels de Santé*' or CPS) GIP (CPS 2005), established in 1993, develops and promotes the use of the HPC or "CPS" throughout the electronic applications of the French Health care sector. It is a Certification Authority to certify the solutions answering the security requirements of health data exchanges and sharing (professionals' authentication, respect of the patients' private life, etc.). The State, medical orders, primary and complementary reimbursement institutions, the GMSIH, users representing associations, are members of this GIP.

The synergy of all these actors (institutional, public and private) in the interoperability arena, make the users strongly determined to require more harmonized software products. It helps minimize gaps between fragmented care and global health services, by reducing the gap between micro and macro levels.

This analysis could be generalized to several contexts, in Europe or USA. The NHIN Request for Information pointed out the necessity of harmonizing redundant standards and identifying missing standards both for public and private interests such as standards from the Consolidated Health Informatics CHI initiative and the Medicare Prescription Drug Improvement and Modernization Act of 2003 (MMA). Another idea is that of a not-for-profit group or public-private partnership such as the Internet Corporation for Assigned Names and Numbers (ICANN) (U.S. Department of Health and Human Services, Office of the National Coordinator for Health Information Technology, 2005).

## 6 CONCLUSION

We have examined the information needs for effective decision-making in the health arena at the micro, meso and macro levels. We then examined the coordination challenges and activity evaluation obstacles at stake. Afterwards, such as the respondents of the US request for information for a Nationwide Health Information Network (NHIN), we considered interoperability among Information Systems as a fundamental requirement for the decision making process. Despite the differences between possible approaches to achieving interoperability in the three contexts (micro, meso and macro), we identify some common principles, which concern:

- *methodological recommendations*, to establish priorities among external or internal interactions while enlarging information services progressively, in a global quality framework.
- *engineering aspects*, including the requirements elicitation (quality of services, solutions and partnerships having to be planned), the design of a flexible, component-based architecture, and the uses of information and communication technologies, particularly the Internet.

With the *virage ambulatoire informatisé* (ambulatory computerized shift), consisting in fact behind the speech about patients' autonomy and responsibility in mastering costs by transferring them from hospital to primary care and above all to patients and their families, Carré & Lacroix (2001) and Miège (2004) pointed out the development of social logics and new communicational standards behind the use of ICT. Stiglitz (2003) highlighted the key issues of Health in the future of developed countries.

We are only at the beginning of great changes. The key challenges of managing Health data: securing privacy, mastering costs, have been identified in the US NHIN project. But Information Networks, Information Systems, EHR and Data are only tools. The main goal is to improve the patient's health and the quality of care through better mastery of information management. As explained by US patient in a waiting room: "I want to know what's done to me is really needed and is done as efficiently as possible" (Shortell, Gillies, Anderson, Morgan Erickson & Mitchell, 1996).

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