DATA CONCERNS AND CHALLENGES IN HEALTH: NETWORKS, INFORMATION SYSTEMS AND ELECTRONIC RECORDS

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ABSTRACT

Since the beginning of the 1980's most industrialized countries have had to cope with the problem of managing the costs of their Health care systems and particularly the costs of hospitalization. The development of information technologies accelerated by the Internet have led to responses that depend greatly on the better management of information. Health care is entering the Information Society: the rise of networks is a key aspect of our Knowledge and Information Society.
With information and services developments that allow for greater involvement of the patient, Health data and more particularly medical data represent a very important economic and social concern. This paper analyzes the rise of networks within the Health field from the French experience in Healthcare Networks and compares it with that of the United States, Canada, the United Kingdom and Spain. Then we outline the special properties of Health data: its personal, sensitive and confidential nature as well as how it needs to conform to particular legislation. Finally we study the use of these data, the essential role of Information and Communication Systems with its key element, the patient's Electronic Health Record, in promoting new practices based on information sharing and the quality of data. This marks the beginning of huge changes.

Keywords: Networks, Information and Communication Systems, Electronic Health Records, Health, Information sharing, Data quality.

1   INTRODUCTION

In developed countries, the post-industrial society is both a "Networked Society" (Castells, 1996/2001), a Services Society and an Information and Knowledge Society. With the expansion of the Welfare State, Health expenditures have become more and more important. In 2002, they exceeded 14% of the GDP in the United States, 10.5% in France, Germany and Canada, and reached 7.5% in the United Kingdom and Spain. Various reforms have been tried but no country appears to be really satisfied with its Health system (Glouberman & Mintzberg, 2001). Shortell, Gillies, Anderson, Morgan Erickson & Mitchell (1996) have pointed out the imperative of overcoming fragmentation and *Remaking Health Care in America*. In France, the crisis of the summer of 2003 and the significant deficits of National Health Insurance has made the questions of Health even more explosive. The United Kingdom wants a new start for its National Health Service (NHS) and speaks about a "New NHS". Significant reforms are also underway in Germany, the Netherlands, Spain, Switzerland, Italy and Canada.

Internet technologies have accelerated the development of the ICT (Information and Communication Technologies) in Health sector. "Health in networks" (Bourret, 2003) constitutes a major aspect of our "Networked Society" with specialized services for customers whose loyalty must be developed. Information management is gradually becoming a major factor of quality and efficiency (cost effectiveness) in Health systems. The quality of the care is closely connected with the quality of the Health data.

In this article, we will highlight the progressive development of a networked Health service, mainly by analyzing the French experiments in Healthcare Networks and the rise of the role of the patient-consumers. We will then show how the control of information constitutes a major element in the quality of the Health services. We will analyze the special nature of Health data before pointing out the central role of Information and Communication Systems (ICS) and of their fundamental element the Electronic Health Record (EHR) in supporting new

cooperative practices focused on patients who are more demanding and more proactive healthwise and the prospect for major changes that this implies.

2   NETWORKS IN HEALTH AND THE RISE OF THE ROLE OF THE PATIENT-CONSUMER

As early as 1971, Japan set the course for its national goal of becoming an Information Society by the year 2000. In France 1978, the Nora & Minc report considered the "computerization" of French society as the preferred means of successfully emerging from the crisis affecting the Western world since 1973 (Nora & Minc, 1978). In March 2000, the European Union declared as a strategic goal for 2010 to "become the most competitive and dynamic knowledge economy of the world". But the reality is less triumphant. Particularly in the Health care field where, in spite of dramatically increased expenses, inequalities have grown, not only in terms of geography or income, but also in access to information.

The way the Health systems work is often criticized. The compartmentalization of activities is often highlighted, particularly in France, between *Caisse Nationale d'Assurance Maladie des Travailleurs Salariés*: National Health Insurance Office (CNAMTS) and the different departments of the Ministry of Health, between hospitals being dominant and called "hospital-centrism" and primary care, between specialists and general practitioners, and within the hospital structures, between doctors and other professions (especially nurses). The patient is torn between the often rival services of public or private hospitals and between different professions: specialists, general practitioners, nurses… In countries with National Health Systems such as the United Kingdom or Spain, the huge majority of specialist doctors are located in the public hospitals. This is not the case in France. As in the US, autonomous physicians dominate ambulatory Health care in France, however access constitutes the most striking difference between the two systems, with 16% of the US population without Health insurance (Dutton, 2002). At the hospital level, often considered as the symbol of the Fordian-Keynesian interventionist State in Europe, Glouberman & Mintzberg (2001) make the distinction between four separate worlds symbolized by the four Cs: Cure, which relies on physicians; Care, which depends on nurses; Control and administration, which is entrusted to managers; Community, involving boards and trustees. These four worlds correspond to four sets of activities and four states of mind which work in isolation. Shortell et al (1996) outline the excessive fragmentation of the US Health system and the imperative to integrate its various components.

Medicine is evolving, relying more and more on technical and medical innovation. The length of patient hospitalization has been continually decreasing. The public hospital has became a technical resource. Medicine has changed, patients too. They have became more demanding consumers playing a more active role in their health and are not afraid to change doctors. Thanks to the Internet they are often better informed than many general practitioners especially for rare illnesses. In the US, patients can create their own medical record on the Internet. The number of patients' associations has increased. In France, patients have created their own Internet site for rare illnesses (Orphanet). In the United Kingdom, Spain, Canada, the Scandinavian countries and more recently in France**,** thanks to the March 4, 2002 *Loi sur les Droits des malades et la qualité du système de santé:* Law on Sick People's Rights and the Quality of the Health System (Journal Officiel, 2002)*,* the patient's role has been recognized and enhanced. Expecting more, patients often demand "perfect health" (Sfez, 2001) forcing doctors to focus on results and not just on demands for the means. Patients are also becoming older and suffering from multiple pathologies which in turn affects Health costs. In a constantly changing world, Larrasquet (1999) highlighted the importance of integrating networks and project management concepts to better understand the complexity of the Health field, thus ensuring complementary knowledge and action.

Health networks and resorting to informatics have quickly become the preferred means to both master Health expenses and to improve service quality. In the beginning of the 1980's, Canada, in particular Quebec, chose a "computerized outpatient care shift" (*virage ambulatoire informatisé*) and the development of networks between Health organizations, mainly hospitals, seeking efficiency (cost effectiveness) with the undeclared goal of transferring part of hospital Health expenses to primary care (Carré & Lacroix, 2001). In the US, the Health Maintenance Organizations (HMOs) have invested in outstanding Information Systems to improve coherent, continual care coordination.

The United Kingdom has made the data processing improvement and shifting responsibility to the patients and their families the main basis of a "New NHS" (National Health Service). Thus they have transferred management responsibilities to the new Primary Care Trusts (PCTs) which buy the hospital services and clinics. Prime Minister Tony Blair has clearly defined the goal: "The challenge for the NHS is to harness the information revolution and use it to benefit patients" (*Information for Health*, 1998). The NHS Plan aims to develop a vision of a "service designed around the patient". The report *Information for Health* defined the broad aims of the long term plan (1998-2005), making improved circulation of information the major foundations of a modern NHS. Similar solutions have also been developed in Australia and in the city-state Singapore, which defines itself as a "knowledge based economy".

Since January 2002, Health in Spain is managed by the 17 autonomous communities (regions). Spanish Catalonia assumed this transfer of responsibility as early as 1983. The autonomous Catalan government (the *Generalitat*), responsible for the organization of public Health (the *Servei Català de la Salut* became *CatSalut*), relies on a networked system of management (*Xarxa sanitària d'utilizació pública de Catalunya*) consisting of 3 main levels. The first level consists of 360 primary care centers (CAP: *Centres d'Atenció Primària,*), the second level the different local hospitals and finally the excellence centers in Barcelona form the third level. The major element of this policy of Health networks is the new *CatSalut* Information System (CatSalut, n.d.) which should be operational by the end of 2004. *CatSalut* has also developed a call center for all of Spanish Catalonia: *Sanitat Respon*. In Spain, as in the United Kingdom, the long term goal is to offer the services of a global online administration, and not only in the Health field, to all its citizens (*The strategic plan of CatSalut*, 2002).

As a rather distant extension of the Nora & Minc report, the new Georges Pompidou public Hospital (Paris) has been conceived as a paperless networked hospital. The global context within which this networked Health system exists has evolved. Even in France, the interventionist state is withdrawing. In 1994, with the winds of neo-liberal change blowing from the Anglo-Saxon world, the Bangemann report advised allowing competition between private firms to help Europe to achieve the goal of becoming a Global Information Society (Bangemann, 1994). Mrs. Thatcher had already privatized British Telecom. In France, a part of the France Télécom was privatized in 1998. At the same time, during the establishment of the R.S.S. (*Réseau Santé Social*: Social Health Network) France opted to use the private operator Cegetel-Vivendi for a limited time until October 2004 mainly to transmit electronic claim forms used in paying for medical treatment (particular at the primary care level).

All the Health networking solutions reflect the uniqueness of each national Health system. Since the mid 1920s, France has chosen a so called "liberal" system for primary care, relying mainly on the patients' direct access to physicians, specialists and hospitals and on payment by service and not by global capitation (an annual set price per patient as is mainly the case in the British NHS, Spain, etc…). Unfortunately, liberalism also means individualism**,** and French medicine is known to be one of the worst systems for working collectively compared to other Western countries. To limit the disadvantages of compartmentalization (Health Insurance/Health Ministry; primary care/hospital; hospitals/clinics; physicians/other professions; general practitioners/specialists) and to curb the problems of its Health system, France has tried an experimental type of Healthcare Networks (*réseaux de santé*) since the mid 1980s.

Some think Healthcare Networks originated before 1914 with the establishment of coordinated structures for tuberculosis care. But their main development dates from the 1980s. They promote the necessity of a holistic view of the patient placed at the very center of the networked organization. Healthcare Networks encourage collective responsibility and collegiality (as opposed to hospital hierarchies). They mostly favor continuity and coordination of care: the promotion of non-hierarchical practices based on better information sharing and developing new relationships between patients (who have assumed a more active role in their health) and the different practitioners. While staying focused on the patient, Health Networks must also integrate the interests of and coordinate the actions of the four main groups of actors i.e. care institutions, physicians, social institutions, territorial authorities.

Healthcare Networks developed in the 1980s follow two very different approaches. The first approach originated from general practitioners facing the emergence of AIDS who had to invent new ways of coordinating with the hospitals and chemists. They were true Healthcare Networks (integrating not only the medical but also psychological and social aspects of treatment). The second approach was promoted by managers who wanted to adopt the methods of the HMOs and that of American Managed Care to better control costs. In this case, we talk about coordinated care networks (*réseaux de soins coordonnés*). The edicts (*ordonnances*) of April 1996 favored experimentation with the Managed Care type of networks, which allows tariff innovations (Bourret, Laurent & Scarbonchi, 2001). In the past each component of Healthcare Networks has received specific financing (one for primary care outside hospital/another for care in hospital). Since October 2002, global financing of the Healthcare Networks (and not just for separate activities) is possible.

Healthcare Networks are very different. Today roughly 2000 exist in France, some very structured with different employees, while others are not even formalized by a charter or an association. Networks have developed to answer various needs e.g. pathologies (Aids, cancer, mental health, diabetes, asthma, hepatitis C…) or specific populations (drug addicts, those at risk, those needing palliative care). In March 2002, legislators wanted to use networks as the preferred way to improve the French Health System by integrating the two approaches within the same geographical area.

The future of Healthcare Networks depends on the emergence of new cooperative practices. Their first challenges are communication (building trust and relationships between the partners) and the management of information from a sharing and data quality perspective.

The Information System constitutes the network's nervous system. Both distinct from its environment yet interacting with it, it contributes to the management of daily operations from the main perspective of monitoring the continuity and traceability of patient pathways. However, it must also provide data on operational and

evaluation (assessment) indicators to achieve real strategic management of the network. The Information System is the backbone of a Healthcare Network and is an essential tool for its evaluation.

In France Healthcare Networks have an important opportunity to improve the efficiency and quality of the Health System. Other countries have developed their own approaches. In the United Kingdom, particularly in the London area, there are two examples: the Children and Young People's Healthcare Network centered on the St Mary and Great Ormond Street Hospital and the Tuberculosis Healthcare Network in Greater London.

3   INFORMATION CONTROL AND MANAGEMENT AS A MAJOR FACTOR IN IMPROVING CARE SERVICES

According to a recent survey by the Institute of Medicine (IOM) (Blendon, DesRoches, Brodie, Benson, Rosen, Schneider, Altman, Zapert, Herrmann & Steffenson, 2002), medical mistakes could explain 50,000 to 100,000 deaths a year in American hospitals, a much higher number than road accident deaths. Possible explanations for this are: overworked staff (particularly nurses), lack of communication and poor management of information problems, physicians acting in an isolated way (too little team work). According to this study, better information management is the preliminary step in the improving a Health organization's results. Internet technologies combined with better communication practices offer new opportunities for a more human influence in medicine and not just more technical or specialized medicine. Many experts agree with these recommendations. For example, according to the French Fieschi's report (2003): "the quality of care is dependent on the use of information management tools".

The development of Internet technologies has further increased the manner in which information factors improve the quality of care. A broad view must be taken when considering the future of Health in an Information Society. For Silber (2003), eHealth does not only involve the use of Web and Internet technologies but also all interconnected Medical Informatics (of which a central component is the Electronic Health Record) and telemedicine. There also exists the challenge of mHealth (mobile), especially for elderly people (remote surveillance ...).

According to McGinnis (2002), Health Informatics includes various categories, covering both Health data and informatics tools:
- clinical data management,
- decision support systems,
- technical and hardware issues,
- database structures and constraints,
- autonomous smart devices, focused on shared values
- standards for communication language used between healthcare providers,
- data exchange language standards for communication between healthcare devices
- legal and ethical considerations
- telemedicine
- patient centered computing

Shortell et al (1996) sum up the main goal with a patient's comment: "I want to know what's done to me is really needed and is done as efficiently as possible". According to Shortell et al, for that to be achieved in the United States it is imperative "to accomplish the transformation of an effective community healthcare management system by the integration of finance, human resources, strategic planning, total quality management and information systems to build an integrated and continuum care from primary care, to acute care, restorative care and maintenance care". According to Glouberman & Mintzberg (2001) in hospitals, the central component of the healthcare system, four worlds exist: cure (doctors), care (nurses), control (managers), community (trustees), with four sets of activities, four organizational structures, four unreconciled mindsets and "so long as they remain disconnected, nothing fundamental will change". The main concern is to make the actors or groups of actors with different motivations, and often opposite interests, work together to promote, by new cooperative practices, a collective culture focused on shared representations and values.

France must overcome another handicap pointed out by the Fieschi report. For a lot of important officials, particularly hospital directors, the management of information is above all a cost and an administrative obligation. Unlike a lot of Anglo-Saxon managers, they don't have a strategic view of using information. Information is not only a cost but participates in the global improvement of efficiency in Health care. It creates value and must be profitable (providing returns on investments within 3 or 4 years).

One of the major factors in the improving the quality of Healthcare is through sharing and managing the information. Inspired by PDCA (Plan – Do – Check- Act) or the Deming circle in Quality Management, we propose an "informational kaizen" (or continuous improvement loop as illustrated in Figure 1):
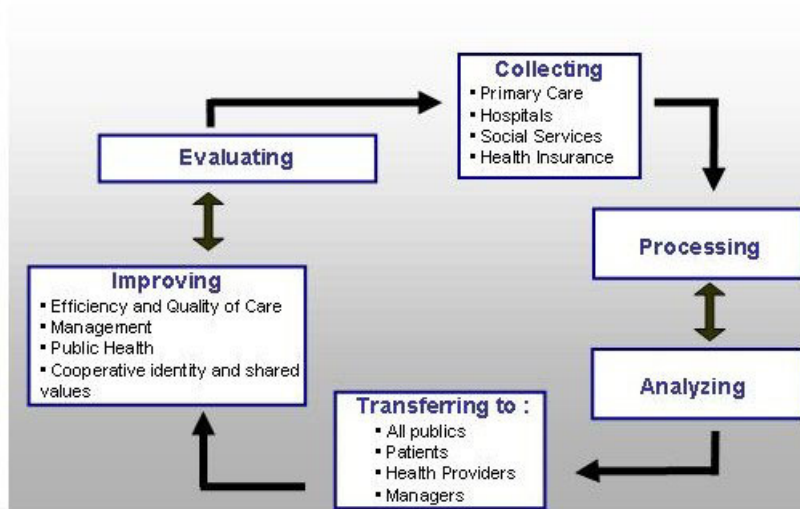
Figure 1. Improving Healthcare Services by Information Sharing and better Data Quality

Health data comes from various sources and can have very different uses as can be illustrated the next diagram (Figure 2):
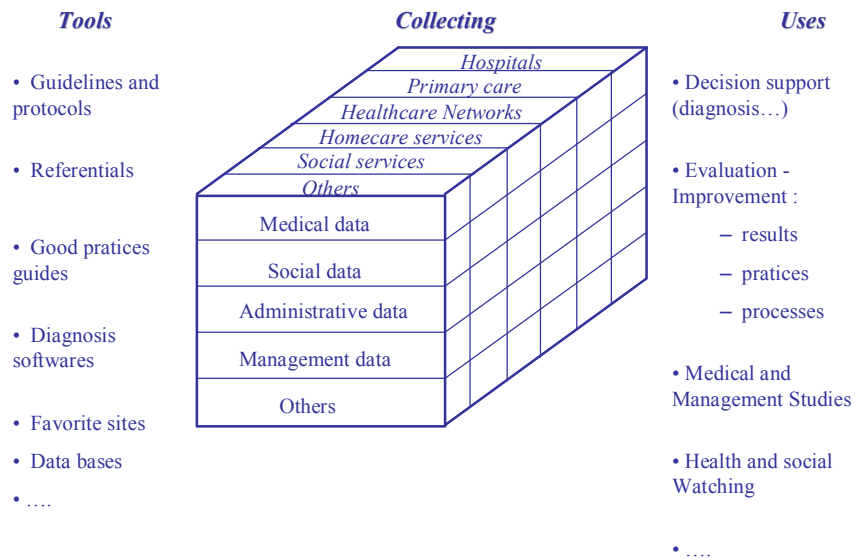
Figure 2. Sources and uses of Health Data

Telemedicine

Telemedicine constitutes a particularly promising sector in future medical activities. It is both a tool, a source of data and a data user. Beuscart (2000) finds: "Telemedicine consists of communication between professionals to increase expertise, know how or sharing capabilities". He distinguishes between the various application fields: telediagnosis (services/distant institutions and patients), telestaff (collaboration and coordination between health providers), telemonitoring, remote surveillance, and telesurgery, which is the more focused upon aspect of

telemedicine. To achieve interoperability between systems and data, telemedicine needs the management of multimedia (paper, sound, image) and multinorm data. In France, for example, since 1994, the telemedicine mission of the Paris Hospital Organization (*Assistance Publique – Hôpitaux de Paris*) since 1994 provides multimedia data via TELIF (Telif Gateway, n.d.), a telemedicine program for neuro-surgical and neuro-medical emergencies in the Paris area. Telemedicine is a major tool for very large countries with scattered populations such as Canada, Australia or the Scandinavian countries.

Websites

The explosion of the Internet has led to the development of an enormous number of websites in the Health domain. Currently, there are over 100,000 sites linked to Health issues in the world. Approximately 800 million people use the Internet in the world. About 70% of American Internet searchers are for Health related sites. The NIH websites (such as, Medline from the National Library of Medicine, which has been available online since 1997) are by far the most visited Health sites in the world with 6 million visitors per month, 3.2 million of which are American. The online NHS Direct received 500,000 visitors in January 2003 searching for British Health information.

In Canada, the Canadian Health Network (CHN) (CHN Gateway, n.d.), or in French (Québec), *Réseau canadien de la santé* (RCS) is a leading service of Health Canada (*Santé Canada*) and the major Health organization across the country for providing the Canadian people Health information they can trust. Rouen University-Hospital in France is known in French speaking Internet circles for CISMeF. Its website (CISMeF Gateway, n.d.), created in 1995, receives 500,000 visitors per month. Patients' associations have also created their own sites. Orphanet (Orphanet Gateway, n.d.) is a multilingual European gateway, linked to 200 patient associations dedicated to rare diseases and supported by the French National Health Research Institute (INSERM) and funds from the European Commission.

4   SPECIFIC ASPECTS OF HEALTH AND MEDICAL DATA

With the development of information and services, Health data represents a very important economic and social concern. Health data and particularly medical data are not ordinary data. They have a huge specificity.

4.1 Sensitive data

According to the European directive of October 1995 (that protects personal data and also favors its transfer within the European Union), Health data is considered "sensitive" data. In France, as early as 1978, in an effort to protect citizens from possible abuse of its medical information (unauthorized files), legislators enacted the Informatics and Freedom or Data Protection Act (*Loi Informatique et Libertés*) and the *Commission Nationale de l'Informatique et des Libertés* (CNIL) (CNIL Gateway, n.d.) to control its application. The United Kingdom adapted its national legislation to the European directive in October 1998. France and Germany have not completed this adaptation. France began the legislative process in January 2002. The European directive strengthens the protection of a person's rights. It introduces the notion of personal data which represent any data that allows a person to be identified. Permission for its use depends on the goals of the collecting organization (research, general interest) and on the nature of the collected data.

Each country has its own idea about what constitutes sensitive data and public liberties. In the USA, Congress called on the Health and Human Services Department (HHS) to protect patient privacy as part of the Health Insurance Portability and Accountability Act (HIPAA) of 1996 (Office for Civil Liberties – HIPAA, n.d.). The first-ever federal privacy standards to protect patients' medical records and other health information provided to health plans, doctors, hospitals and other health care providers took effect on April 2003. Developed by the HHS, these new standards provide patients with access to their medical records and more control over how their personal medical information is used and disclosed. They represent a uniform, federal level protection of privacy for consumers across the country. Particular State laws that provide additional protection to consumers are not affected by this new rule.

The United Kingdom is very much concerned about the protection of an individual's freedom. There are no identity cards nor national cards for the National Health Service (NHS). In the United States, they have more freedom to use Health data and consequently more risk of leaks. But different ideas about what constitutes sensitive data at the various stages of life also exist: for young people in employment, medical and Health data related to employers or insurance organizations are sensitive; for older people, especially in case of social

services, income data and data on their property are sensitive data. Not all people are equally concerned. In March 2003, a Harris Interactive survey (Taylor, 2003) made a distinction among adults in America: there exist "privacy fundamentalists" (26%), "privacy pragmatists" (64% compared to 54% in 1994) and "privacy unconcerned" (10% compared to 22% in 1994). Sixty-nine percent of adults agree that "consumers have lost all control in information collected and used by companies" but 53% disagree that "existing laws and organizational practices provide a reasonable level of protection for the consumer today".

Sensitive data implies the need for special security safeguards. The risk of malicious actions and handling errors cannot be excluded and sensitive data can be involuntarily divulged (Bettelheim, 2000). However globally, electronic mailing is safer than letters and faxes for the transmission of data. The major difficulty is actually knowing how to reconcile two relatively contradictory imperatives: availability and confidentiality, or in other words, to reconcile accessibility and the security of data.

A very important issue is that of **access** to sensitive data.
In France, decrees relating to access to personal information held by professionals and Health institutions were published in April 2002 (Legifrance, n.d.). There are very precise about the obligations of Health institutions but do not solve the main problem of what data the patient has access to. There actually exists a great difference between the two kinds of data associated with patients: raw multimedia data and physicians comments. These comments also constitute one of the physicians' working tools. Should patients have access to all this data, that is to say to the processed information (physicians' comments) or only to the raw data? However without the intervention of physicians there is no medical data, this intervention transforms raw data into value added medical data.

The issue of the access to medical data cannot be dissociated from the issue of their **ownership**. As for access the question is complex. Which data does the patient own: the raw or processed data? The borderline between data that belongs to the physician and data belonging to the patient is even more complex in cooperative organizations such as Healthcare Networks.

Data ownership can be defined by three juridical elements: the *usus*, the *fructus* and the *abusus.* The *usus* is the right to use a possession. The *fructus* is the ability to get a commercial profit from one's own health data, directly or indirectly. The *abusus* gives its owner the right to give up his possession and to completely or partly destroy it. It is imperative to define more precisely the nature of the patient's right of ownership of his data. To let the patient have free access to his medical data at least implies control over preventing him from deleting or modifying the health data without a professional's explicit advice.

The notion of **consent** is also a determining factor. In France, the patient has the right to allow or refuse a professional to consult his medical record. But here too, the issue is not simple. Will this permission be explicit (written) or implicit (which is possible if there is no clearly expressed opposition)? The issue does not concern only private physicians but also all institutions managing Health data such as hospitals and Health Insurance offices, insurance companies, mutual societies, etc…

With our consumer and litigious society especially in the Health field, the linked issues of ownership and access to personal data are very important. The risk of leaks is huge. If they are communicated to the patient, the physicians' personal comments can be turned against them and then they will be reluctant to write anything in the medical records or these records will have two parts: one that can be communicated to the patient and the other that cannot be. Therefore a happy medium must be found. Some countries such as the United Kingdom or Spain emphasize the essential role of summaries or abstracts that are given to patients, especially in the hospitals.

The issues of access to and ownership of Health data cannot be dissociated from the issue of data **storage**. This leads to new roles such as that of the "information lawyer" or "data host", in French: *hébergeur*, this last term having been recognized by the law of March 4th 2002 (Journal Officiel, 2002). So the patients' medical data progressively slips from the hands of physicians to those of intermediaries. This gives rise to other issues such as office security and systems maintenance, and more importantly, the issue of payment for services (and even more when this service is said to be free!). What is the real use of the data collected? The French Gros report (2002) underlines that the new function of "data host" must be strictly controlled not only at the national or European level but, with the increasing use of Internet technology, by international agreement.

The use of Health data also involves **ethical** issues associated with increased information sharing. It brings us to the key issue of responsibility in the use of shared data and shared medical confidentiality. In France, the physicians retain individual responsibility. The concepts of responsibility and shared medical confidentiality necessary for treatment are at the heart of these debates because sharing information and shared diagnosis imply a shared medical responsibility with the prospect of huge legal problems.

4.2   Data Quality

Data quality is the most important factor of information management. As outlined in *An Information Strategy for the modern NHS*: "Better care for patients and improved health for everyone depend on the availability of good information, accessible, when and where it is needed" (*Information for Health*, 1998). Without reliable data there is no possibility of improving quality in healthcare. Wang (1998) has defined Information Quality in terms of both Categories (Intrinsic, Accessibility, Contextual and Representational) and Dimensions (Objectivity, believability, relevancy, timeliness, value-added, completeness, interpretability ….). According to recent surveys of patient records in Paris hospitals, errors in data (wrong identification, wrong data capture, documents not in the right patients' records …) were found in 20 – 30% of the records!

It is only with the physician's intervention that data becomes medical data. A major difficulty is to manage the borderline between general data and medical data. Raw health data without the benefit of the physician's intervention is worth little. But this kind of physician's intervention (data capture and validation) implies financial questions. Nowadays in France it is not a recognized act as it is in Belgium.

The quality of information on web sites is yet another issue. It is really very uneven. The French association of Engineers (*Centrale Santé*) has proposed the following evaluation criteria for web sites (*Net Scoring*) :
-   Credibility (99 points): identification of sources, the creation of an editorial board, identification of conflicts of interest, the existence of meta-data, the existence of a site administrator
-   Content (87 points): accuracy, source quotations, navigability, the quality of the search engine, omissions and exclusions …
-   Hyperlinks (45 points)
-   Site design (21 points)
-   Interactivity (18 points)
-   Quantitative aspects (12 points): site use …
-   Ethical aspects (18 points): liability, independence, secret, confidentiality …
-   Accessibility (12 points): index quotations and research engine quotation … (Centrale Santé, n.d.)

Institutions have also defined types of good behavior. In June 2001, a workshop of the European Commission measured quality along the following lines:

-   the transparency and honesty of the distributed information,
-   explicit sources,
-   respect for privacy,
-   maintenance and updating,
-   responsibility of the authors,
-   availability of data (Qualited criteria for health related websites, n.d.).

The British NHS project DISCERN (DISCERN Gateway, n.d.) and the Swiss project Health On the Net (HON) (HON Gateway, n.d.) point out the following good practices:

-   all medical advice is only given by specialized and qualified staff,
-   the information disseminated on the site aims at improving but not replacing the existing relationship between physician and patient,
-   sources must be quoted,
-   the financial support behind the web site must be identified (advertising).

It is essential to sharpen the discernment of users mainly by creating local advice centers to guide them. The State can also create its own websites. This is the choice of NHS Scotland (program SHOW: Scottish Health On the Web) (SHOW Gateway, n.d.) and of the Canadian Health Network *(Réseau Canadien de la Santé*) a priority of Health Canada (*Santé Canada)* (CHN Gateway, n.d.). The NHS also has the same idea. These programs are generally linked to other activities, such as educating the public in health (prevention) and about responsibility, as seen in the Health Education Board of Scotland (HEBS) become Health Scotland (Health Scotland Gateway, n.d.).

Cybermedicine constitutes another aspect of e-health. In Denmark teleconsulting is very commonly used. In France, teleconsulting without having met the sick person is illegal. The problem is that there is a fine line between delivering general information on a particular medical problem and a consultation that could lead to establishing a remote diagnosis. France is also reluctant to engage in the electronic pharmaceutical business but it will be bypassed by international usage: the pharmaceutical e-business products is very important in the US.

Telemedicine data also has its special aspects (from surgery to remote monitoring). The College of Physicians in Quebec – *Collège des Médecins du Québec* has defined six main parameters for this data: availability, integrity, confidentiality of the data, identification of the users, the non repudiation of transactions, traceability (*Collège des Médecins du Québec*, n.d.).

Patient health data obtained by call centers are not very helpful. NHS Direct records the health data of patients that call in but the information is not integrated into electronic national health records. On the one hand, it has not been authenticated by physicians. On the other hand, patients who call do not have to be identified: they can choose to remain anonymous.

Management and validation issues arise with the uncontrolled **increase of Health data**. The issues of data pertinence and data selection is still further accentuated by new ways of obtaining data such as through portable personal micro-computers, cellular phones or PDA (Personal Digital Assistant) .

There are huge **data cemeteries**. Much information which could improve care quality is not used, especially because of the incompatibility between materials and databases. For example, in France there are considerable interoperability issues between the Health Insurance system (CNAMTS) and the hospitals, as each hospital has its own information system! The enormous volume of collected data is not efficiently utilized for the strategic management of the French Health system as it is in countries like the United Kingdom or Spanish Catalonia. The French Health system is often referred to as blind or short sighted. Risk management does not exist in France. Health institutions are not care purchasers but only blind payers without control. The Program for Medicalization of Information Systems (PMSI) of the hospitals allows the Regional Agencies of Hospitalization (ARH) to calculate a Synthetic Activity Sign (ISA) which tries to measure the productivity of the establishment. An important change will be the activity tariffs (*tarification à l'activité)*: hospitals will be financed according to their activities and not from a global budget. With its capitation system, the NHS only has to reimburse the private sector for a few medical activities and so the management of administrative data is very much simplified. Another problem is the **purpose** behind data collection. In France, the Health Insurance system (CNAMTS) collects data with the view of managing reimbursement to patients or health professions (physicians, chemists …). The data can only legally be stored for two years. Its storage for a longer period of time and, more importantly, its use in controlling Health professions (especially physicians) is much debated and legally questionable.

5   NEW TOOLS FOR COOPERATIVE PRACTICES CENTERED ON PATIENTS: INFORMATION & COMMUNICATION SYSTEMS AND SHARED ELECTRONIC HEALTH RECORDS

In the Health field data have many uses in the building of new, cooperative and integrated patient-centered practices (Figure 3):
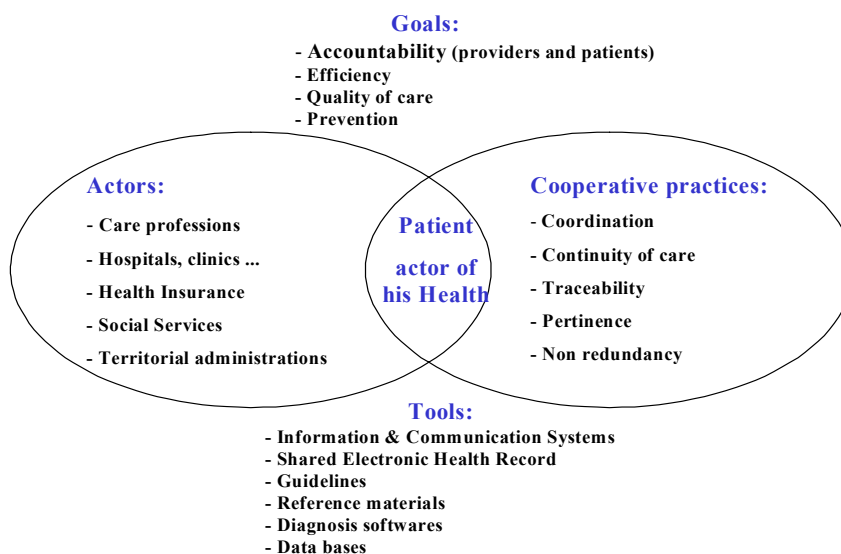

Goals:
- **Accountability (providers and patients)**
- **Efficiency**
- **Quality of care**
- **Prevention**

Actors:
- **Care professions**
- **Hospitals, clinics ...**
- **Health Insurance**
- **Social Services**
- **Territorial administrations**

Patient actor of his Health

Cooperative practices:
- **Coordination**
- **Continuity of care**
- **Traceability**
- **Pertinence**
- **Non redundancy**

Tools:
- **Information & Communication Systems**
- **Shared Electronic Health Record**
- **Guidelines**
- **Reference materials**
- **Diagnosis softwares**
- **Data bases**

Figure 3. New Practices centered on Patients

According to Stefanacci (2001) medical errors are due to a failure in knowledge, communication or process. Such errors can largely be avoided thanks to the use of technology and access to electronic medical records. Grimson & Hasselbring (2000) claim that: "The present inability to share information across systems and between care organizations … represents one of the major impediments to progress toward sharing care and cost containment". The notions of the interoperability of tools and data, traceability, continuity of care converge towards the idea of monitoring patient pathways in the Health systems in order to improve not only the quality of care but also to reduce costs (non redundant services and coherence). The main tools are Information Systems and Electronic Health Records. The notion of "patient pathways", a form of management by processes (reengineering methods), is a central one from the perspective of networked Health. But this is not easy with patients with multiple pathologies, in particular older people. For Ammenwerth, Brender, Nykänen, Prokosch, Rigby & Talmon (2004), the use of modern information and communication technology offers tremendous opportunities to improve health care. However, there are also hazards associated with information technology in health care.

5.1   Information and Communication Systems

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. Now, all Health organizations use Information Systems but their levels of development are very unequal and various problems exist. For example, Kaiser Permanente's computer system, the biggest American HMO, a non profit organization (which covers 8.2 million people) has coped with problems of data integrity, accuracy and privacy particularly in its information technology center in Walnut Creek (California): for example bad data in medical databases, sending emails containing sensitive medical information to the wrong people, sending wrong medication to patients ….

We need to maintain a broad vision when considering the future of Healthcare Networks and Information and Communication Systems. They are both tools for improving communication, and, in the case of Networks, a tool for transmission of information. The most structured networks have computerized systems: computers in networks, associated software (to help diagnosis and prescription), databases, peripherals, but also physical processes, a means of transportation and human operators. The human dimension of the relationship is as essential as the information and data dimensions. It must not only manage information (store and transmit it) but also help to improve the users' relationships and capabilities. Shortell et al (1996) desire "participating systems", i.e. Information and Communication Systems. The majority of networks actually widely depend on paper supports: charters, booklets, reports, meeting-accounts… The Information and Communication Systems contribute a lot to the structure and the development of Healthcare Networks. It is the main support of a policy of communication and training. The Information and Communication Systems must favor the emergence of new less hierarchical and more cooperative practices. The setting up of processes (patient pathways, good practice guides, reference materials) are an essential element of coordination, continuity (continuous and seamless) and quality of care thanks to traceability and information sharing. Information and Communication Systems are at the heart of a Total Quality and Certification Policy, especially with the development of ISO 9000 standard in Health organizations.

The management of competence, when it favors the keeping and the transmission of knowledge is another major factor that determines the quality of Healthcare Networks. It cannot be dissociated from a training policy, not only of Health providers but also of patients (prevention, observance). Once again the Information and Communication System is the main tool in this.

The Information and Communication System acts as a communication tool among the network members, monitoring the daily performance of the networks (indicators) and alarm signals. To achieve optimal operational capacity it must overcome numerous challenges to ensure both the availability and confidentiality of especially sensitive personal data: not only solving the problems of the interoperability between multimedia and multinorm data (Internet technologies being essential) but also between its different subsystems: the management software in medical offices, patients' shared records, call centers, telemedicine ... (Salzano & Bourret, 2003). The linking up of information constitutes a major concern.

The everyday operation of a Healthcare Network is an attempt to develop cooperative medical practices, mainly between the primary care physicians who generally work outside the hospital and hospitals with their different departments. The first challenge concerns transfers of information. It is at the heart of managing patient pathways and in coordinating medical decisions. The hospital is at the centre of the main part of these data transfers.

Numerous attempts at normalisation exist. These standards are frequently based on formal models, described in UML (Unified Modeling Language), which model the actors, the roles, the acts and the practices. The challenge is interoperability between the various tools.

Generally composed of different, vertical, obsolete and unconnected applications, hospital Information Systems are also frequently confined to the administrative domain. Currently they do not provide value added health data. The development of interoperability frameworks is imperative. An approach using existing documents seems the most suitable. The entire future of health systems depends on this investment in interoperability without producing new constraints. It solves the key issue of an integrated electronic health record.

New organizations such as Healthcare Networks must be submitted to evaluation with a view to improvement linked with Project Management and Total Quality Management Methods. Their Information and Communication Systems must be able to collect the necessary data and follow up the results of the quality indicators of given services. Healthcare Network 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 evaluation object, the complexity of the evaluation project with its multitude of stakeholders and the motivation behind the evaluation. These examples are only some of the challenges facing the organizational and social evaluation of computer-supported cooperative work (CSCW) systems that support complex communication. They also highlight the importance of evaluation: "Evaluation is a means to assess the quality, value, effects and impacts 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" (Ammenwerth et al, 2004).

5.2   The Electronic Health Record

The Patient Electronic Health Record (EHR) is a key enabler of eHealth ("Aspects of eHealth", *The IPTS Report*, 2004) and a major component of Health Information Systems. Two main visions of EHR exist. The first older one views EHR as an electronic safe; it is often connected with the idea of a standardized EHR. The second view, which is more recent and more innovative, has emerged with the Internet technologies: the shared EHR.

In February 2003, Kaiser Permanente highlighted the electronic medical record as the key element of a policy of improving the quality and efficiency of its care (Kaiser Permanente Gateway; Computerworld). It should be ready for use at the beginning of 2005 (10 States, 11,000 physicians, 8.2 million members). In May 2004, a new office was created in the US Ministry of Health: the office of National Health Information Technology Coordination. All Americans are to have a standardized record planned for 2010. Within the framework of the *National Programme for Information Technology for the NHS*, the implementation of a national Electronic Health Record is a priority of the British NHS with the ideal of a record for life (ERDIP project*: Electronic Record Development and Implementation Programmme*) (ERDIP, n.d.). It should be operational by 2008. There is no vision of imposing a very structured and rigid framework but to privilege rather a way to facilitate data sharing, systems interoperability, interfaces and meta-data standards. Doctors' access rights and patients' consents are also important. 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, according to the Fieschi report, attempts to create a single structured record have failed over the last 20 years. Kuhn & Giuse (2001) also recommend choosing a much more pragmatic approach to developing 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 regional and be patient-centered by supporting a global vision of his health; they should be interoperable and evolutionary with two essential objectives: to facilitate data sharing and to collect data of a suitable quality for monitoring patient pathways (continuity and traceability) in all parts of the Health systems. In Spring 2004, the new Health Minister, Ph. Douste-Blazy declared that the Patient Electronic Health Record is a central tool in improving the French Health system and for meeting the challenges of coordination, transparency and quality of care (Ministère Santé Gateway, n.d.).

The main advantage of the EHR shared approach by documents (EHR is made up of documents and also include links to documents at remote sites) is that data deposits remain in the sites where they are collected: this would solve a lot of problems about data ownership and data transfer. It seems particularly suitable for Health Networks, especially networks between hospitals and primary care.

Challenges for the shared EHR also involve meta-data and ontology definitions but also challenges of interoperability and data quality as for Information and Communication Systems.

With the idea of sharing data for improving the quality of care, federal initiatives have already begun, with, in particular, the FNEHAD (*Fédération Nationale des Etablissements d'Hospitalisation à Domicile*: National Federation of Home Care Organizations) project in connection with the CNAMTS (Fnehad Gateway, n.d.).

Obviously, developing a shared Health Electronic Record is a major element in establishing a collective identity and representing all the viewpoints of each Health actor. But it can also create other problems of compartmentalization.

There are huge differences in the use of Electronic Health Records across Europe. According to the European Commission (Silber, 2003), in 2002, almost half of the internet connected general practitioners (48%) in the European Union use an EHR (Electronic Health Record). But huge differences exist: 95% of internet connected GPs use one in Denmark, 90% in Sweden. The use is more limited in Spain (35%), Greece (27%) and France (17%). In Europe, attempts to transfer electronic record data between different countries have occurred. The European Commission supports an experiment managed by the French operator Thalès between the Vic General Hospital (Spanish Catalonia) and a laboratory of Thalès society in Geneva (Switzerland).

In the United States, patients can build their own medical record on the Internet and have it managed by specific firms. But how reliable is the medical information in this record? Can this record be used by physicians who would then assume responsibility for medical care on the basis of information contained in this record?

A medical record is also an artifact where multiple stories about patients and about organizations exist. It transforms the living body of the patient into a juxtaposition of organs, parameters, views, rows of numbers, graphs and all sorts of data (Berg & Bowker, 1997).

5.3   National Health Cards

The patient's global identification in every component of the Health System constitutes a key issue. Thus, the issue of a patient's medical record cannot be separated from that of National Health Cards. If they are not only administrative cards but contain emergency data (allergies, main health episodes ...) as well as meta-data and pointer functions, National Health Cards could constitute a preferential way of accessing the EHR. In France, there is the *Carte Vitale* set up by the *Caisse Nationale d'Assurance Maladie - CNAMTS* (National Health Insurance Office). At the moment, it only enables the transmission of electronic health forms for payment claims (*feuilles de soins électroniques*). Its creation highlights the distinctiveness of the French system where there is separation of Health Insurance (CNAMTS) from the Health Ministry (which manages hospitals). Private physicians are paid for each action and not according to a capitation system, such as in the United Kingdom or in Spain. Today the *Carte Vitale*'s use announced as "the electronic medical passport" is accepted by a majority of physicians. But it is only an administrative support for rapid reimbursement and not a means of payment or a Health Card. The addition of a medical component has been expected since 1996.

In Spain, the Health card of Catalonian *CatSalut* does not possess medical data. In Quebec (Canada), the *Carte Soleil* created by the *Régie d'Assurance Maladie du Québec* - RAMQ (Quebec Health Insurance Office), should soon include emergency medical data thanks to a double authentication procedure (by patient and Health professional). In Germany, the national Health Card project gave way to strong controversy.

The main stumbling block concerns the identifiers. In France, the CNIL is totally opposed to the use of a single identifier for each citizen.

In Europe we must also harmonizing national and European Cards. The idea of an European Health Card goes back to 1978. A report on this subject was given to the European Parliament in 1996. It aims to make care easier when people travel within the European Union. The project was validated by the European Council of Barcelona on March 2002. It is comprised of two elements: one for rapid reimbursement and the other for emergency medical data. A preliminary card with only little administrative data is expected for the end of 2004. But there exist important impediments. The healthcare field remains determined only by individual National policy and not by a European-wide one. For reasons of public liberty, the United Kingdom has no national identity card and resolutely avoids participating in this project.

Information and Communication Systems and Electronic Health Record constitute essential tools in supporting the affirmation of new cooperative practices. The development of reference materials, guidelines, good practice frameworks, diagnosis softwares (Figure 3) is essential. This same diagram lists various cooperative uses of the data provided by these tools of information sharing. They are centered on the patient: diagnosis, traceability of care without redundancy, improving prevention, the development of responsibilities. They also allow improved management (efficiency) and the strategic running of networked organizations including health surveillance procedures.

The setting up of networks within Health fields contributes to the creation of knowledge. According to the terminology suggested by Nunamaker, Briggs, De Vreede & Sprague (2001), the management of Health data transforms it into information, knowledge and strategic support (wisdom). Information sharing contributes to the

enhancement of the knowledge and capabilities of all the partner organizations (i.e. their intellectual bandwidth). Information and Communication Systems must have the capability to transfer knowledge to the different units of the networked organizations.

Thus, the concept of networked organizations in Health relies on the global logic of managing and valuing information. It blurs the boundaries between existing professions in the Health field, particularly between nurses and doctors. These boundaries between professions are specific to individual countries. The role of nurses is much more developed in the United Kingdom (which makes them the pivotal in primary care) as opposed to France. In the United Kingdom, nurses manage and direct patients who call NHS Direct, the leading telephone service of the NHS which provides health information on a 24-hour nurse run telephone helpline. The construction of networks in Health also supports the development of many professions and service companies (often quite transitory) centered on information and communication: for example information managers, coordinators of Healthcare networks, webmasters in the Health field, administrators of data warehouses …

6   THE BEGINNING OF GREAT CHANGES

The term "computer" made its first appearance in a Medline abstract only 40 years ago. Since then, Information and Communication Technologies have modified medical and surgical practices. The rapid diffusion of the Internet constitutes a new step and favors patient's empowerment within the global context of an information society and its transition from production logic to service logic for patients who have now become "customers". Advances in Health systems depend more and more on cooperative practices and the sharing of information and data. These inescapable advances present both opportunities and risks.

On the one hand, we have pointed out all the positive aspects of networked Health. Better use of information (information sharing and quality) must favor continuity, traceability of care and also cost cutting (by reducing redundancy and improving efficiency). On the other hand, the multiplicity of information can lead to disinformation. The patient, who is now a better informed and more active consumer remains insufficiently guided in the complex world of Health. Medicine is becoming less human, the family practitioner is disappearing, everything is becoming more technical. Patient is torn between hospital departments and various physicians. Dematerialization of documents (electronic documents) also deprives the patient of his usual marks with paper documents.

The development of networked Health is too often described only in technical terms with the dominance of the Information Systems. Ellul denounced the "technician society" (1990). Some Healthcare Networks in France and some HMOs in the United States because of old legacy systems and not distributed systems almost perished through informatics. The healthcare industry's archaic information technology is also a major cause of runaway costs (Warner, 2004). Management is measurement. But according to Mintzberg (2001), an "efficiency obsession" based on a quantitative vision centered only on cost control also constitutes a significant risk. The construction of networks in the Health field must take into account technical constraints (mainly data-processing) and, thus, economic and legal constraints but must not therefore neglect the integral and human relationships.

As underlined by Van der Lei (2002): "applying information and communication technology (ICT) to a medical domain is not merely adding a new technique, it radically changes processes in that domain". He highlights the necessity of analyzing "feedback mechanisms". In fact all advances are double edged. Good practice guides can improve the quality of doctors' services by standardizing practices through a form of "customization"; i.e. the standardization of the traditional actions, thus saving time which can then be used to personalize services (particularly for discussion and listening) for better management of difficult cases. With the development of a culture of litigation in Health and the consumerism of patients who now require results and not only good practices, comes the need to protect doctors from potential lawsuits (through the use of the good protocol). This is one of the insurance companies' conditions of approval. At the same time, they unquestionably contribute to a certain "Taylorization" of traditionally very intellectual professions, which largely explains the discomfort of General Practitioners, particularly in France.

For Shortell et al (1996), building new delivery systems depends on the ability to achieve "mass customization" which is very closely linked to the concept of "holographic" organization. Mass customization involves developing services to meet the unique needs of each patient, using relatively standard support functions, and to coordinate care to maintain continuity of treatment for all the patients. The essence of a "holistic" or "holographic" organization is the ability to embed the "whole" into each "part". The "whole" represents the global system and the caregiver "customizes" the services to meet the needs of "each" patient. Health Networks constitute a significant example of using possible "holographic" organization to manage changes and complexity.

The overall context has rapidly evolved. Such is the case for the national State, even in France. Decisions on Health should not rely solely on market price. For example, American HMOs have submitted to strong cost competition at the expense of quality care. The State must play a major role even in the USA (Stiglitz, 2003). Even in the country of free enterprise, citizens have asked for State's intervention; the Health Insurance Portability and Accountability Act (HIPAA) was voted for in 1996. In Europe, a "new" State is emerging with special roles: to provide incentives, assessments, guarantees of national asset, and so on … The notion of evaluation (assessment) in the Health field is essential (Kimberly & Minville, 2001). It can be highlighted with examples such as the National Institute for Clinical Excellence (NICE) in the United Kingdom or the *Agence Nationale pour l'Accréditation et l'Évaluation en Santé (ANAES* - National Agency for Accreditation and Assessment in Health) in France. Another use of data, from a strategic national perspective is to facilitate health watch, for example after the controversy about the French Institute of Health Watch (*Institut de Veille Sanitaire*) concerning elderly people's deaths during the summer of 2003. This "new" State must favor normalization in the interoperability of computerized tools, help to strengthen cooperative solutions such as French Healthcare Networks, favor initiatives to improve data acquisition (such as the coding of actions and pathologies expected in France since 1993); forbid coding on the basis of nominative data; guarantee respect for an individual's rights while preserving the confidentiality of the medical record; avoid commercial uncontrolled use of patients' Health data; play a role in regulation establishing and safeguards; and provide accreditation of the web site hosts and guidelines about the information quality of Internet sites.

Particularly in Europe, but also in Canada and even in the USA, this " new" State must find its position when facing the emergence of regional powers. In the United Kingdom, Scottish, Welsh and Northern Ireland NHS also exist. Since April 2002, the NHS has transferred important responsibilities to PCTs and Health Authorities (*Shifting the balance of power within the NHS*, 2001) but with strong control by the national government nonetheless (in French: *déconcentration*). In Spain, since January 2002, Healthcare is dependent on all 17 Autonomous Communities, each of which have their own specific Health policies. In France, decentralization laws were voted for in 1982 and since March 2003, the State Constitution mentions "decentralized management". *Agences Régionales de l'Hospitalisation* or Regional Health Boards for Hospitals (ARH) were created in the 22 regions but they still depend on the national government. Offices such as *Observatoires Régionaux de Santé*: Regional Health Observatories (ORS) or *Union Régionale des Caisses d'Assurance Maladie*: Regional Coordination of Health Insurance Services (URCAM) which manage a lot of Health data have been created since 1996. Now the creation of ARSs (Regional Health Agencies) by extending ARHs to Health Insurance seems to be the goal.

7   CONCLUSION

Medicine, patients and the general context in which Healthcare is managed have changed. We are only at the beginning of great changes produced by the convergence of information technologies, network managed organizations and specialization within Health. The rise of networks is a response to the complexity of Health systems. The efficient and responsible use of information technologies may improve coordination and continuity of care. It changes professional practices and the behavior of both patients and professionals. The main challenge is to harmonize, standardize and personalize care for the patient. An essential aspect of this is to maintain confidence between the Health professional, his/her patient and the Health organizations.
Health data is strongly specific and personal. In an era of globalization, the State must always play a major role in regulation, protecting the interests and ensuring the equal access to health services for all its citizens. Developing a culture of information sharing and data quality (as a result of the use of specific tools such as Information and Communication Systems or Electronic Health Records) is essential in changing attitudes when building a collective mindset by integrating the views of all the actors during the reconstruction of Health systems. The main goal is the management of diversity so as to create a group-oriented culture and develop more efficient, integrated quality driven organizations, in other words: "building community" (Shortell et al, 1996).
The management of information and the use of data are at the heart of all the challenges facing our Society of Information, Knowledge and Networks, especially in the Health field. Raghupathi & Tan (2002) have highlighted the challenges of Information Technology in Health Care: "granting ready access to data warehouses full of patient-care and insurance records, as well as critical medical information, they help management cut costs and remote physicians work collaboratively".

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