Information systems and patients' empowerment around patients' pathways: the French and the Portuguese scenarios

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Abstract. In this work, the authors undertake a descriptive comparison of the French and Portuguese national information systems, especially related to recent developments towards patients' management of their own data.

It is clear that patients' participation in their health management is growing worldwide and that it is crucial for their wellbeing. On the other hand, the citizens' circulation in a professional or leisure context, may boost their use of international health information systems, as long as they are compatible with interoperability standards.

Nevertheless, some ethical considerations have to be explored, as well as information security issues. They constitute important challenges to tackle in the future with cooperation at a regional, national and European level.

Keywords. Information Systems, Electronic Health Records, Patients, Empowerment, Pathways, Privacy.

1. Introduction

The health-related information motivated a growing interest and therefore a high volume of works published worldwide on the subject, either in the press or in specialized literature and in scientific or healthcare fields.

There is the discussion of some global and shared perceptions about the benefits of patients' contributions to the management of the healthcare processes and of patients' interactions in the health information management. Accordingly, many systems are being improved towards the so called "patient empowerment".

In Portugal the Portal do Utente (Citizen Portal), officially launched in May 2012, constitutes a Personal Health Record area, offering patient online services as ebooking, recording and sharing of health data, and health education.

In France, the DMP (Personal Medical Record) [1]was launched in 2004. It met with many difficulties. It has been repositioned as a shared patient medical record. The introduction of the DMP correspond to implementation of the law of March 2002 on the Rights of patients and the Quality of the Health system including the concept of "health democracy" with the participation of the patients but also the challenges of data protection (medical confidentiality and privacy) without harming improvement of care.

The authors propose to compare different approaches of these issues in France and Portugal by placing them in the context of patient mobility within Europe.

2. Information management challenges around Healthcare Records in the two countries

In an economic context, often called global economy, national economies have to look for new ways for boosting productivity and competitiveness.

The rising cost of health care is seen as a common problem to the most advanced economies. The growing number of elderly, for example, creates needs that did not exist, either on the supply of care, or in the materials consumption. The development of certain diseases such as cancer or AIDS, in turn, have contributed to the pressure on health services. In response to these pressures, governments and the provision of health care entities are exploring new ways of working, allowing administrative and organizational structure of health care to be adapted to reduce costs while maintaining quality of care.

The increase in information exchange established national and internationally, between or within organizations, reveals a trend towards the establishment of a technological infrastructure that allows immediate communication at any time of day and in any properly equipped place for this purpose.

All the developed countries have roughly similar problems around Healthcare issues, particularly the imperative of mastering costs and improving quality of care betting on the implication of better informed patients and using new ICT devices. But many times the enthusiasm regarding the possibilities of the several ICT devices available for the patient, is not accompanied by the necessary consideration of the most sensitive aspects.

2.1. Portugal

The Portuguese population is nowadays esteemed in 10.380.838 people (Pordata, 2015) living on a territory of 91680 km². According to the Portuguese Instituto Nacional de Estatística (Statistics Portugal), in 2013 there were 226 hospitals in Portugal, 119 public hospitals and 107 private hospitals, and in 2012 there were 387 public clinics (2.3 family health and/or personalized healthcare units and 0.6 community care units per official clinic were reported).

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[1] In French: *Dossier Médical Personnel*.

The Portuguese *Plataforma de Dados de Saúde* (Health Data Platform) constitutes the national health record data sharing facility. Data are accessed through specific Portals, as the Citizen Portal, the Professional Portal, the Institutional Portal and the International Portal. As mentioned above, the Citizen Portal constitutes a Personal Health Record area, offering several patient online services, as ebooking, renewing patients' chronic or prolonged medication, personal emergency contacs, or health monitoring measurements (Weight, Height, Blood Sugar, Blood Pressure, Cholesterol, etc).

Until recently only 890.000 people were registered in the Citizen Portal, being the majority from urban regions (Lisbon and Porto). The governmental Department responsible for the Portal creation links the implementation difficulties to technological obstacles and also to legal restrictions, as far as the Portuguese Data Protection National Commission prevented the creation of a central health data repository due to confidentiality risks.

In 2011, the Conselho Nacional de Ética para as Ciências da Vida (National Council of Ethics for the Life Sciences) stated the main risks of health data hold in digital form :

 i. Information leakage, for fraudulent transfer of complete databases or deliberate intrusion of hackers in the pay of stakeholders (eg, entities that deal with assessment of disease risk or marketing communications);
 ii. Misuse of data for scientific research, with or without identity of the holders;
 iii. Illicit transfer of information, without respect for intellectual property or copyright;
 iv. Loss of confidentiality of individual data for illicit purposes or out of curiosity, for security failures difficult to prevent.

2.2. France

France is a more populated and large country than Portugal: 66 million inhabitants living on 550 000 km².

France has also a more centralized history of power than Portugal with the importance of the national State level. But there is also the great problem of "walls" or divisions :between Ministry of Health and Insurance organizations (collecting funds paid both by employees and by companies), and also between hospitals' sector and primary care sector, between public hospitals and private clinics, between the cure (physicians) and the care (nurses) and with other professions, between the social and medical sector, etc.

The great challenge is creating cooperation between all these levels with the particular role of interface organizations between primary care and hospitalization sector.

The other great specificity of the French Healthcare System is that of being quasi exclusively dedicated to care approach and not to a preventive approach. It is the consequence of an important choice in 1927 for primary care: that of paying doctors hen realized act [2] and then reimbursing the patients. During a long time there were no direct link between primary care doctors or GP's and the Health Insurance.

In 2010, as a consequence of the Law about Hospital, Patients, Healthcare and Territories were created the ARS : Regional Heathcare Agences managed by the State) and defined new Agencies : ASIP (Agency for Shared Information System in Healthcare) and ANAP (National Agency for Improvement of Performance in Health) [3].

The Isaac's report (2014) focuses about the opportunity of ICT to change the French Healthcare System from a curative to a preventive one with the development of patients' implication to a more predictive medicine responsabilizing them.

All these challenges are also essential in the discussion of the new Law Health about Health System in French Parliament since March 2015 with the challenge of a new step for "sanitary democracy" and empowerment of patients and that of mastering patients' pathways with ICT tools (with a "new" DMP now presented as "shared" and not "personal" and belonging to the patient and coordinated by the Health Insurance) and developing new cooperative interface organizations such as MAIA [4] or PAERPA [5] after Healthcare Networks and Pluriprofessions Houses and with the importance of Hospital at Home (HAD).

3. Shared Challenges for the two countries
The two systems roughly share a lot of important challenges.

3.1. The issue of data privacy with the Big data challenges
It's a main challenge with the development of a large amount of new data especially those of Big data obtained from a lot of new ways often not known by

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[2] In French : *paiement à l'acte*.

[3] In French, ASIP Santé : *Agence des Systèmes d'Information Partagés en Santé* ; ANAP : *Agence Nationale d'Aide à la Performance dans le secteur médico-social*.

[4] MAIA : In French, *Maisons pour l'Autonomie et l'Intégration des Malades d'Alzheimer*.

[5] PAERPA : *Personnes Agées en Risque de Perte d'Autonomie*, Health Pathways for Elderly : http://www.sante.gouv.fr/le-parcours-sante-des-aines-paerpa.html

the patients-citizens. It's the challenge between transparency and confidentiality of data linked with that of medical secret and responsibility in medical acts.
Nationwide or even worldwide certification criteria could contribute to more safe information systems, nevertheless there is always the human factor, which is not so deeply subject to an ethical control.

3.2. Mastering patients pathways
It is also a shared challenge linked with the interoperability of existing information systems with both technic and semantic aspects.
It is the idea of promoting a personal patients' pathway both in hospital sector and in primary care sector with the new idea of PPS in France: Personalized Plan for Cure [6].

3.3. New uses of Telemedicine
All this is linked of new uses of telemedicine not only to cure or do surgery but also to predict and pilot the patients' live with new devices linked for example to smartphones. Healthcare Networks especially those about diabetes are very interested in these in articulation with patient's associations: it's a new way of "sanitary democracy" and of co-production of services between patients and healthcare organizations. All these in mastering the tension between confidentiality and traceability.

3.4. The European perspective
All these new ways have also been experienced in the European level as for example in the Epsos Project (2008 - 2014) attempted to offer seamless healthcare to European citizens.

The epSOS working group, consisting of delegates from 26 countries, including clinical experts, defined the functional service related to the Patient Summary. A Patient Summary was defined as a "a standardized set of basic medical data that includes the most important clinical facts required to ensure safe and secure healthcare. This summarized version of the patient's medical data gives health professionals the essential information they need to provide care in the case of an unexpected or unscheduled medical situation (e.g. emergency or accident). Though this data is mainly intended to aid health professionals in providing unscheduled care, it can also be used to provide planned medical care (e.g. in the case of citizen movements or cross-organizational care paths)"[7].

Key goals are to improve the quality and safety of healthcare for citizens when travelling to another European country. Moreover, it concentrates on developing a practical eHealth framework and ICT infrastructure that enables secure access to patient health information among different European healthcare systems. In

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[6] In French : *Plan Personnalisé de Soins* (PPS).
[7] Retrieved from: http://www.epsos.eu/epsos-services/patient-summary.html

Portugal, for example, several public clinics contributed to the mentioned Project as a development of the national Health Data Platform. France participated in epSOS project through the Ministry of Health and ASIP Santé. France participation consisted particularly on the development of a pilot platform for sharing medical data within four French universities (Dijon, Paris X, Poitiers, Strasbourg) participating in the Erasmus program.

In the future, new projects will test cross-border eHealth services.

4. Conclusions

French and Portuguese Healthcare Systems have roughly the same challenges to cope. But the more little dimension of the Portugal gives another approach to the management of its Healthcare System: more focusing on proximity and cooperating with territorial decentralized institutions.

Both also cope with the imperative of better integrating patient's implication and responsibility and mastering the personal pathways with the main tension between confidentiality and traceability.

As stated by Ting Li and Thomas Slee, EHR systems are essential tools to help health care providers meet demands for quality enhancement, efficiency improvement, cost reduction, and error reduction. But, on the other hand, with the digitation of a growing number of personal medical records, patients have increasing concerns over information privacy, despite the visible benefits.

Health is always a competency of the national States. But French and Portuguese organizations participate in European projects which are the main prospect of evolution in the next years: not only for the mobility of citizens but for a management of the Healthcare issues at the European level.

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