

Atención Primaria

www.elsevier.es/ap



SCIENTIFIC ARTICLES

Medical ontology for treatment of clinical data from children and youth

José P. Lousado^{a,*}, Vitor Rodrigues^b, Nuno Costa^c, Ruben Carvalho^c,
Carlos Albuquerque^c, Vitor Franco^d

^aESTGL-Polytechnic Institute of Viseu, CI&DETS, Portugal

^bUniversity of Trás-os-Montes e Alto Douro, Vila Real's Nursing Superior School, Portugal

^cHealth School-Polytechnic Institute of Viseu, CI&DETS, Portugal

^dUniversity of Évora

KEYWORDS

Data Security;
Ethic in Health;
Health Information
Systems;
Ontologies

Abstract The use of information technologies in the field of biomedical data management has grown considerably and is today one of the main fields of use of these technologies. There are several advantages arising either to an individual's health or to public health, particularly because access to clinical data become available anywhere access via the Internet or individual health card. This card will contain personal data accessible from a terminal card reader, identical to the citizen card. This work focuses on the development of an ontology of universal data structure so that the information is accessible and organized in the same way, regardless of the system that use them. In this context there is the need to incorporate security mechanisms, the respect of ethical principles underlying the management and maintenance of clinical data, ensuring maximum confidentiality.

To develop the proposed ontology, for the treatment of clinical data of children and youth is used as reference bulletin health in Portugal. Using this structure, it follows the clear and unambiguous identification of the fields required for registration of clinical information, standardized in a relational model. To ensure the confidentiality of data, identification of the individual is only the number of national health system and are not recorded on the card personal data such as name, address or contact forms.

© 2013 Elsevier España, S.L. All rights reserved.

MISIJ project funded by FCT- Monitoring health indicators in children and adolescents: Impact of health education- Reference PTDC/ CPE-CED/103313/2008- and CI&DETS FCT- PEstOE/CED/UI4016/2011

*Correspondence author.

E-mail: jlousado@estgl.ipv.pt (J.P. Lousado).

Introduction

There is no question that, nowadays, any society in the world is permeated by the so called “society of knowledge, which brings implications to the organizations and to the people that are a part of them, making them (people and organizations) to be ‘alive’ and in constant learning.¹

It’s a fact that nowadays every health organization uses information systems as an indispensable tool to its own management,² being the ones that most suffer, in the past few years, most modifications.³

It is also true that in the health sector (hospitality care, and primary health care), information is very complex, since there are many professionals groups engaged, besides that the motivation and the formation of the several health professionals for the use of technologies of information, might not be the best, ally to the fact that the health care is a sector with great demands in available information. However, the part of the information systems in this area is crucial, because, although it incorporates technological innovation, facilitates the inherent processes to the organizations functionality and promote an effective communication between every intervenient,⁴ facilitates the access to the patients information and the sharing of information between health professionals, they offer information that backs up decision, and encourage the research.⁵

In the particular area of health care the information systems, establish their own performance in 3 levels:⁶

- By the citizen level, where it can access its own information and the national health service;
- By the level of the health professionals, which can rapidly and have secure access to all the patients information.
- By the level of managers and politicians, in a way they can access the management information in useful time.

We know that information systems play an important role in the management of health costs and improving the quality of the provision of health care, but we also know that the information of health or disease of the patients are strictly personal and confidential. And any transfer of information through technology involves actual and potential risks and may, ultimately, the information “fall into the wrong hands” and thus compromise the privacy of the patient.⁷

You need to know what are the appropriate uses for health information systems, who should use these systems, what benefits and risks that information systems have for patients and whether information systems can change the relationship of health professionals-patients.⁸⁻¹⁰

In Portugal, namely in September 2011, the National Council of Ethics for the Life Sciences (CNECV) prepared an opinion on health information and the records of this information in electronic support and the respective accesses and uses. The CNECV drafted 15 recommendations, which protrude through 8, 14 and 15, respectively.¹¹

- That health data, while sensitive data relating to personal intimacy, are reserved and subject to duty of confidentiality;

- That one should seek to sensitize health professionals to the notion that the computer can be an aid to good relationship with patients and with other professionals and service users;
- The creation of “Electronic Health Record” informatics super-structure... should deserve special attention in order to identify the ethical issues relevant to their creation and operation.

Based on the text above and the importance of information systems in health, it is described a system that has as main objective, to allow access and registration of clinical data remotely, through the creation of an electronic health card, the Personal Patient Card (PPC).

The use of information systems for the health sector is not new. For several years, many researchers have been examining the matter, having developed methodologies sensitive issues related with the security and confidentiality of clinical data.¹²

On the issues of privacy, security and data, several authors have expressed concern with the fact that these are likely to be recorded in databases on servers or personal computers. These could be accessible to many people, and could lead to the disclosure of personal data with a high degree of commitment of the security and confidentiality of data. Therefore, there is great interest among some groups in society, in obtaining that information, whether for research or commercial purposes, which may break the trust between patient and doctor, hindering the proper evaluation of symptoms and diseases manifested by the patient as well as the violation of ethical principles.¹³⁻¹⁵

More recently, the European Union member states have passed laws on data protection in particular by Directive 95/46/CE on data protection, which sets the rules on personal data privacy and the ethical and deontological principles that should be followed by health professionals. In this regard, also aligned countries like the U.S.A., Canada, Australia and Japan One of the key principles behind the european directive is that the information must be kept in a personal way, just as long as necessary, for the purposes for which it is intended.¹⁶

Several problems have been reported, including the lack of security and confidentiality of data in case the same is lost, registering venereal or infectious diseases that could be a factor of exclusion, having been already implemented many security mechanisms to minimize the effects, especially in terms of digital certificates, Public Key Infrastructure (PKI), Healthcare Professional Card (HPC) and Patient Data Card (PDC) among others.¹⁷

In this work, we describe an ontology for treatment of clinical data, particularly for the control of risk factors such as obesity, eating habits, etc., Which follow the principles of European directives regarding the protection and safety data and has been asked to look the Portuguese National Commission for Data Protection. This work is part of project “Monitoring health indicators in children and adolescents: Impact of health education”, with data being collected, processed statistically to identify and flag predictors of risk for the health of citizens, such as diabetes, obesity, hemophilia, allergies, among others, that will accessible through the PPC.

Modeling and system conception

The system has provided the interaction of several actors, from the patient to the doctor. Early in the process, a new medical consultation, it is checked for the PPC. If the patient already have the PPC, then starts a new record, and immediately extracted historical information of the patient, or else, it will be created a new record and PPC will be provided later. Thus, the physician will tracking and monitoring the progress of patients, particularly with regard to risk factors. After the observation and collection of new data relating to the patient, they are saved in the database being sent a report of the development of patient data. Note that is expected in monitoring risk factors, the statistical processing of the data for scientific purposes, the project noted above.

The whole process, from the beginning to the end will be recorded in the system so that the system can be audited, ensuring equal treatment, the length of ethical and deontological duty of all health professionals. For the process to be implemented secure authentication mechanisms, both for the patient and for the health professionals who have access to patient data present in the PPC as well as in the database (Fig. 1).

The database is hosted on a dedicated server, in Polytechnic Institute of Viseu, accessible through Web Services or via web portal that will be developed specifically to support the platform.

To ensure the security and confidentiality of data, identification of patients is done only based on the number of user of the Portuguese National Health Service.

The system can be extended to other uses, including emergency services, through the scanning of a QR Code printed on the PPC, which will allow healthcare professionals using a Smartphone or tablet with internet connection, instantly have access to patient history. This access will be

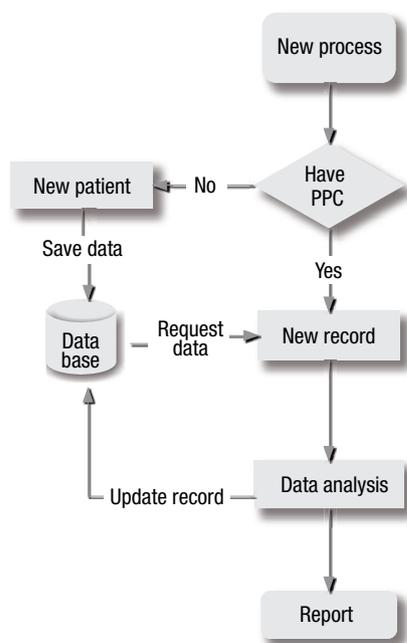


Figure 1 System Workflow.

possible through authentication of healthcare professionals, so this must have credentials that will allow the access to the information (Table 1).

The entity “Patient” is used to store patient data that does not identify clearly where it will be registered only the county, civil parish, district and nationality, since these are revealed important data for the statistical processing. It is important to note that almost all the fields are mandatory, except for fields “RiskFactors” and “photoLink.”

The last, can however be very useful in immediate recognition of a patient, along with other field, “signsIdentity” used to register signals or identification marks of the patient, including facial signals, limbs, scars, etc.

The entity “Consultation”, allows recording all consultations in patient observation, where they could be routine visits or an emergency.

Considering that we intend to apply statistical and data analysis algorithms, it is recommended that all fields are

Table 1 System entities that define the proposed ontology for the patient and consultation than supports database model

Entity: Patient	
Field	Description
HNSNumber	Health national Service number of patient
Birthdate	The birthdate to compute age of patient
Nationality	Define the country where was born
CivilParish	Identify the local where the patient lives
Municipality	identification of county
District	identification of the district
Password	Secret key login
BloodGroup	The Blood Group of patient : A+/-, B+/-, AB+/- or O+/-
RiskFactors	Text field for description of risk factors observed in consultations
PhotoLink	Path for photography
SignsIdentity	Special signs from patient, scars, hair and eyes color among others particular signs
Entity: Consultation	
Field	Description
HNSNumber	Health national Service number of patient
dtConsultation	Date of consultation
Height	Height of patient
Weight	Weight of patient
WaistPerimeter	Waist perimeter
MaxPressure	Systolic pressure
MinPressure	Diastolic pressure
CephalicPerimeter	Perimeter observed in consultation
Remarks	Remarks about consultation
ConsType	Consultation type (scheduled or not scheduled)

filled in, so that all fields except the field “remarks” are required.

The data model should consider other entities which facilitate the task essentially of who will enter data, such as diseases, a register entity for the physicians and other entity that allows recording all activity in the system.

Application Scenarios

It is intended that the public target, in this first phase, are children and young people of the county, for monitoring and control of risk factors such as obesity and the propensity for some diseases such as diabetes and cardiovascular disease. It is expected that in a year we can analyze the data of the 500 children and young people to trace the patient profile in this age group, including the identification of risk factors, dietary habits and the relationship between several measures taken.

Parallel to this data collection, the system is prepared for interactive data collection, patients who are marked, with interconnection to the health centers of the coverage area, particularly in monitoring and registration of food typology.

The whole process, in the case of children and adolescents, necessarily requires a parental consent, and the processing of these data is uniquely for research purposes, without direct identification of the patient. Statistical analysis will draw the different profiles with the identification of factors that have a higher propensity to contract some diseases.

After collecting these data are processed and analyzed statistically. The use of data mining algorithms can later reveal certain food associations, habits and other behaviors (physical inactivity, lack of sports, smoking, etc...) in the determination of risk factors.

Several techniques will be used, such as data samples classification in order to construct decision trees identifying the rules that will create the template. This method may prove to be very important in the classification of new cases, where the immediate application of the model, had made a prediction for specific risks.

Other techniques to be implemented, use hierarchical clustering methods, such as single link, complete link, group average among others, which group together the data, establishing a relationship of cause/effect of the several factors.

In the scenarios envisaged for use, connecting to the service via the mobile platform, can actually make the difference.

After validation of the health professional, are displayed basic information, some of them listed in the PPC which serve as confirmation the identity of the patient, such as photo and the number of health service. In this panel, the health professional can immediately register a new event (scheduled consultation or emergency) or use other options, such as access to the detailed history of the consultations held by the patient.

Conclusion

As part of a more ambitious project, the portal, in its different fields will certainly contribute to improving quality

of life, adjusting them to healthier behavior, including the discovery of hidden knowledge in the databases, using statistical and data mining algorithms.

The process and the tools included in system concept, in addition to the research component patent since its conception, takes on great importance for parents and health professionals, who may follow the process of evolution of certain risk factors in children and adolescents, making it much closer, all stakeholders in the process.

The process can easily be extended at a later stage to schools where health professionals in collaboration with teachers, that a particular stage of life of the children (over 4 years and older) accompanying them, will be more sensitized of certain behaviors enhancers risk factors, namely for the observation of daily eating habits, and behavior.

The availability of the platform, integrated in services provided as a tool for the mobile platform, taking advantage of the latest technologies incorporated in these devices will revolutionize the concept of access to support services and monitoring health, so hopefully that might be adopted by health professionals, both regionally and nationally, and internationally, since the system will be available for access via the Internet.

Conflict of interests

The authors declare that there are no conflicts of interests.

Acknowledgements

Project MISIJ funded by FCT (PTDC/CPE-CED/103313/2008) and CI&DETS FCT (PEstOE/CED/UI4016/2011).

References

- Rodrigues V, Nogueira F, Granjo C. What Implications do Information Systems Have for the Restructuring of Health Organizations? In: Proceedings book of the IASK International Conference Global Management. 2007. p. 284-9.
- Johnson CW. Why did that happen? Exploring the proliferation of barely usable software in healthcare systems. *Quality & safety in health care* [Internet]. 2006 [cited 2013 Mar 28];15 Suppl 1:i76-81. Available from: http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=2464864&tool=pmcentrez&render_type=abstract
- Thomas AR, Urquhart C. NHS Wales e-library portal evaluation Report for Informing Healthcare Strategy Implementation Programme Department of Information Studies University of Wales Aberystwyth. 2006.
- Rodrigues V. Sistemas de Informação em Saúde. In: Lopes V, Rodrigues V, Coelho E, Monteiro MJ, editors. *Promoção da Saúde e Actividade Física: Contributos para o Desenvolvimento Humano*. CIDESD/UTAD; 2010. p. 512-22.
- Gao F, Li M, Clarke S. Knowledge, management, and knowledge management in business operations. *Journal of Knowledge Management* [Internet]. 2008 [cited 2013 Mar 5];12:3-17. Available from: <http://www.emeraldinsight.com/10.1108/13673270810859479>
- Sheffield J. Inquiry in health knowledge management. *Journal of Knowledge Management* [Internet]. 2008 [cited 2013 Mar 6];

- 12:160-72. Available from: <http://www.emeraldinsight.com/10.1108/13673270810884327>
7. Fichman RG. The Role of Information Systems in Healthcare : Current Research and Future Trends. 2011;22:419-28.
 8. Marckmann G, Goodman KW. Introduction: Ethics of Information Technology in Health Care. 2006;5:2-5.
 9. José E, Rezende C, Barros C, Tavares EC. Ética e telessaúde : reflexões para uma prática segura. 2010;28:58-65.
 10. Antonio J, Castillejo P. Atención Primaria Telemedicina , una herramienta también para el médico de familia Telemedicine, also a tool for the Family Doctor. 2013;45.
 11. CNEV. Parecer n.º 60-sobre informação de saúde e registos informáticos de saúde [Internet]. Conselho Nacional de Ética para as Ciências da Vida. 2011; Available from: http://www.cneqv.pt/admin/files/data/docs/1318269169_CNECV_P_60_2011_10.10.11.pdf
 12. Skiba LW. Patient retained records--the health identity card. The Journal of the Royal College of General Practitioners. 1984;34:104-6.
 13. Coleman V. Why patients should keep their own records. Journal of Medical Ethics. 1984;10:27-8.
 14. Cushman R. Information and medical ethics: protecting patient privacy [Internet]. Ieee Technology And Society Magazine. 1996;15:32-9. Available from: http://ieeexplore.ieee.org/xpl/freeabs_all.jsp?arnumber=536299
 15. Meyer H. Protecting Privacy in Computerized Medical Information. JAMA: The Journal of the American Medical... [Internet]. 1994 [cited 2013 Jan 22]; Available from: <http://jama.ama-assn.org/content/271/19/1549.2.short>
 16. Burnap PR, Spasić I, Gray WA, Hilton JC, Rana OF, Elwyn G. Protecting Patient Privacy in Distributed Collaborative Healthcare Environments by Retaining Access Control of Shared Information. 2012 p. 490-7.
 17. Costa C, Oliveira J. A new concept for an integrated Healthcare Access Model. Studies in health... [Internet]. 2003 [cited 2013 Jan 22]; Available from: <http://www.google.com/books?hl=pt-PT&lr=&id=i0KEzajbRUIc&oi=fnd&pg=PA101&dq=electronic+card+carlos+costa&ots=MUoTfvfKna&sig=u4c8XfIWcN9vyPPlapwfWkRldnY>
 18. Armbrust M, Fox A, Griffith R. A view of cloud computing. Communications of the ... [Internet]. 2010 [cited 2013 Jan 23]; Available from: <http://dl.acm.org/citation.cfm?id=1721672>
 19. Ograph B, Morgens Y. Cloud computing. Communications of the ACM [Internet]. 2008 [cited 2013 Jan 23]; Available from: <http://dosen.narotama.ac.id/wp-content/uploads/2012/01/news-cloud-computing.pdf>