Telemedicine and E-Health

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Abstract—In the process of healthcare digital data management, the generation of good-quality data is just the first half of the process, the second half belonging to e-Health and Telemedicine. This consists in archiving, protecting, querying—to report, to answer specific questions and to do data mining—and letting the various actors to operate normally also from a distance, even mobile, with no differences. The wideness and the differences of the user interests, even on a same data set; the high efforts needed in preparing standards for letting both machines to be interoperable and humans to mutually understand each other, as well as within their inner circle; the evergreen communication battle between increasing data granularity, for a better description, and using even overlapping acronyms, for saving time; the still open debate about sensitive data, eventually to be kept hidden, and their practicalities of disclosure, as needed by an emergency physician; the information noise a too-many-data situation might generate, and the uncertainty typically belonging to most of the diagnostic process; the still high speed of the ICT products and technology market evolution and the need to keep the valuable healthcare data readable for periods of several decades; the needs in both continuing and curricular education programs: even though we leave in an about-post internet era, all of those still ask for high quality research.

I. INTRODUCTION

As any good history would have a future, at least a near future, let us open this contribution to the celebration of the XX anniversary mentioning some activity lines, in the area of Telemedicine and e-Health, on their way at the Politecnico di Milano.

– on February 16 and 17, 2011, a Consensus Conference will be held on “Quality issues in the Life-long Personal Medical Record”. A couple of years ago, the Italian Government made the decision to push towards the adoption of a Life-long Personal Health Record (PHR). The general, but thoughtful, purpose was to let the digital personal health-related data and documents effectively accessible, and shared among the credited actor profiles. For such an achievement, a collection phase and an editorial phase should be done, first and properly. Today, despite the lack of an operative agreed reference model, even abroad, about half of the Italian Regions started to experiment the Life-long PHR, variously defined and implemented. The Consensus Seminar would offer an opportunity of cooperated evaluation of such recent past, as well as of common envisaging of the near future. The organized collection of developed-on-the-field experiences, the scientific insights—too often neglected—on specific multidisciplinary issues, the needed interaction between top-level actors—clinical, health, and technological—active in the Governance arena: these are the basis through which the Consensus Seminar would contribute to build a more global and sustainable quality of the Life-long PHR. A number of scientific issues are on the ground for such a subject. Security and privacy, interoperability among machines and the lexicons used by the several user profiles, data and versus documents, and the not-to-be-forgotten evergreen balance between effectiveness and completeness: all of these can be major examples. The overall approach for academics being to try to give help to the dialogue between the ICT manufacturers and the healthcare governance.

– Since some years, usually in May, the Annual Report on ICT in Healthcare will be released by the Observatory Services of the School of Management, to shed light on the diffusion of ICT applications in healthcare organizations and the issues related to their governance (Fig.1). These Services came to manage some thirty reports per year, mainly on regular basis. The observatory on Technologies for the disabled is also cared, while several others are focused on areas to whom Bioengineering is not far from. ICT, healthcare market insights and advising the whole-public ICT company serving the entire Lombardia Region are examples.

– Serving for the role of database outsource advisor, service designer and data manager, the Cefriel, will serve the “New Healthcare Networks” programs of the Regione Lombardia. Cefriel formerly a Consorti job, for some one-Master-after-Master programs, which was one of the activities since the Cefriel beginning.
In e-health, as in biomedicine in general, numerous questions can be addressed only by comprehensively searching different types of data that are inherently ordered, or are associated with ranked confidence values. The Bio-Search Computing project, part of the five year Search Computing project funded by the European Research Council, is being developed at the Department of Electronics and Information (DEI) of the Politecnico di Milano, to support the integration of the results of eHealth search engines with other data and computational resources. A prototype implementation, publicly available at http://www.search-computing.org/UIDemoBio/, demonstrates a case study of the use of a search computing platform to describe well known bioinformatics resources as search services, and carry out comprehensive analyses over the resulting integrated services (Masseroli et al., 2010). In particular, this makes explicit how different ranked data can be integrated in a way that takes account of the ranked results from different types of data and analyses. In so doing, the prototype illustrates the use of ranking as a first class citizen for data integration in the e-health and life sciences, and identifies open issues for further investigation.

- At MOX, which is a Laboratory of the Department of Mathematics, they started an impressive research: to try to obtain clinically-oriented validation by doing data mining on the administrative data, provided by the Healthcare Services of the Regione Lombardia, as they pay for the diagnosis and therapy services delivered to all the 9.5 million citizens of the Lombardia Region.

Now, after such an introduction, let us go back, at that beginning of 20 years ago. We do this by outlining some evident changes occurred over the recent decades.

II. WE DID IT

We did books (Fig. 2a). The first one was published in 1992 by the major Italian publisher of medical books (Pinciroli, 1992). Mainly contributed by the computer science full-professor colleagues, it came after long discussions, where their question was: “why a general informatics textbook would not be enough, also for the medical area?” And the given answer was: “I easily agree with you for the concepts, but the examples, they do have to come from the specific arena, which is Medicine and Healthcare”. And we still believe in such an answering approach. Later on the Internet era arrived. It arrived for all of us. So the paradigm changed. Even for the computer science colleagues. For the Biomedical Engineering students, the risk on an un-sufficient background in the newly named e-Health arena started to arise. In the meanwhile, some Medical Informatics basics became more recognized to belong to such corpus of knowledge. As it happens also in the historically stabilized Math courses taken by every freshmen, the corpus glue was not the impossible similarity among medically-oriented building blocks. Instead it was their complementarities in view of a major target. So the book on “Elements of BioMedical Informatics” came, published in the 2005 (Pinciroli and Masseroli, 2005). In its user-oriented but still informatics-structured chapters, the introduction and the evaluation-oriented concluding remarks were written for every reader, MD included, while the central part was for engineering students. The table of content of the third book, titled “e-Health Applications”, published in the 2009, come from the e-Health field and practices (Pinciroli and Bonacina, 2009). It includes descriptions of informatics packages developed just because Medicine was needing them. DICOM, UMLS, HL7, SNOMED are major examples. Then it describes cases of products and service. Booking, registration procedures for new drugs, biometrics, and several more are the chapter titles. Detailed table of contents of the two more recent books can be reached at www.ehealth.polimi.it website.

We did a large-scale DataBase (DB) for Cardiology Project (Fig 2b). Shortly after the beginning of the Personal Computer (PC) era, about twenty years ago, high expectations were born within the communities of several medical specialties. A more effective patient management looked to be at hand thanks to a new generation of DBMS, ready to be used within the PC environment, with a flexibility – on the clinical targets – impossible to obtain from the centralized, usually mainframe-based, hospital IT devices and systems. A challenging, and lately un-implementable, scenario was to consider a number of geographically distributed but clinically similar hospital
departments, to whom give the same software package, in such a way they would cooperate and group patient populations easily reaching the tens of thousands. As the worldwide known matured and respected Framingham Study, published on the best scientific journals, collected a population of less than ten thousands, the new PC+DBMS based scenario was quite promising, and the Italian branch of Bayer agreed in supporting a varied campaign for the cardiology and hypertension area. They started the “Informatics Services for Cardiology Project”. Packages for ambulatory medical record, with drug dictionaries and drug-to-drug interactions embedded, were set up, with the cooperation of the major Italian cardiology scientific societies giving their help in the wished performances design, as well as in the testing phase (Pinciroli et al., 1992). A number of meetings with the clinicians were held around Italy for collecting practical advices and recommendations while showing the prototypes of the packages. Later on, pursuing the distribution of the packages only in the occasion of practical-training short courses, I took around Italy, to some thirty destinations, a travelling classroom. It consisted of some 30 portable PC. At an invited audience consisting of both the department heads and their departmental persons in charge for the IT application uses, the packages and their user manuals were given by Bayer, under the patronage of most of the cardiology community. This action made a true step ahead the cooperative environments of the Italian cardiologists, as these were also widely technically assisted and scientifically promoted at the European level. After some time it came out that all this technological and organizational effort was not enough for having the cooperation arising in practice. The quite easier than before as assembling of numerous populations, as a must towards prestigious publication sites of observational studies, did not leverage a wider cooperative activity among the clinical departments, even if they appreciated the overall project and the Bayer sponsoring action, which later on discontinued the program, also for avoiding emerging conflicts with the chief information officer at the various hospitals, which were – and still are today – the manager in charge of the institutional information system. Its targets often conflicts with cooperative inter-institutional studies, any will be their promoter: a scientific medical society, a
drug company, the healthcare governance of a geographical region or of an insurance company.

We did the Visible Human Dataset – Milano Mirror Site (Fig. 2c). In the middle of the 90’s, the story began because my students took more than two weeks for downloading one hundred slices – one hundred only, over the 1800 hundred total - of the NIH-NLM supported and just ready Visible Human Dataset (Ackerman et al., 1995). From those slices I would have selected the heart volume - it would have been a true one, and not just a geometrical model – to visualize the results of a model describing the propagation of the heart electrical activity. All that effort requested by our downloading, so limited in respect to the overall anatomy archive, which came to be the most detailed ever built up over the centuries, took me to open a dialogue with NLM. The dialogue landed to the opening of the Visible Human Dataset – Milano Mirror Site, serving the Visible Human Dataset data users of the entire continental Europe. Having the contract signed between NLM and the Politecnico di Milano, it came out that the 65 GBytes of the entire archive would have been better managed by the Cilea Interuniversity Consortium, as 12 GBytes were the overall storage capacity available to us at the Politecnico inner computer centre. The sponsors - Bracco, Hewlett-Packard and Agilent Technologies, Ilation and Telecom Italia, - came easily, prestigious and generous, to support the Digital Anatomy era opening. The computer system only was priced around the 250 millions of Italian Lire, equivalent to 125 thousand Euro at its beginning. All the previous numbers to make easier the comprehensive comparison with the present 1 thousand Euro of a notebook with a storage capacity of some 500 GBytes. The comparison tells two hundred and fifty times less in money, for having ten times more in memory, and the other improvements in clock speed, in communication bandwidth and in mobile possibility to be added. All of these changes simply unbelievable to image, just 15 years ago. Opened on February 19, 1997, the Visible Human Dataset – Milano Mirror Site gave its good services not only to the European, mainly research-oriented community. The interactions with the academic anatomists were many, as well with Anatomy itself, as a corpus of truly 3D practical knowledge, facing for its first time a serious reason to move towards the computer methods and devices arena. By the time being, the overall advancements of the machines making “bio-images” let the already “digital” anatomy, become both “in vivo” and “multimodal”, where for example CT and PET data are fused in view of positioning and functional coordinated targets.

At Medinfo 2004 we did a lot. Medinfo 2004, the three-yearly world congress of Medical Informatics, took place in San Francisco – California, from 4th to 11th of September 2004; organized by the International Medical Informatics Association (IMIA, http://www.imia.org/). The American Medical Informatics Association (AMIA, http://www.amia.org/) was in charge of the congress organization. The Politecnico di Milano gave evidence of a strong scientific participation with 12 contributions presented during the congress. In general 70% of contributions submitted to the Medinfo call for papers are not accepted and not supposed to be presented during the congress days. The 12 contributions – scientific papers and tutorial – submitted by Politecnico di Milano were all accepted. This substantiates the leading position of the Italian University at the world level. The Tutorial – one of the accepted contributions – was about bioinformatics. The title was “Effective Use of Human Genome Public Web Databases via Customized Data Warehousing and Mining”, it was presented by Marco Masseroli, a professor of “Laboratory of Medical Informatics and Distributed Systems” at the Bioengineering Department. The tutorial dealt with the effective use of genome data banks and presented a software prototype developed by the Laboratory of Medical Informatics and Telemedicine of the Bioengineering department. The developed application allows the automatic exploration in a simultaneous way – over different data banks located in several institutions – of biomolecular data organized in categories. The other scientific contributions presented by the Politecnico of Milano were about different thematic areas: knowledge management for new drug submission by pharma-industries; telemedicine infrastructure for ENI’s offshore; new approach for querying and retrieving biomedical data from heterogeneous sources; packages for information management from micro array; data mining in recent biomedical research; medical informatics applications for dentistry. More information was provided about the II level Master in eHealth offered by Politecnico di Milano as an interesting program for the post-degree vocational training. The Medinfo 2004 exhibition had the "University Row", this included numerous stands of Universities and Research Centers working in Medical informatics and Telemedicine at international level. The Politecnico di Milano, the only European University present at the congress with an academic booth, showed its educational offer and its research activities in the Biomedical and eHealth fields. Other academic booth were: Harvard-MIT Training Program in Biomedical Informatics just in front of Politecnico’s booth, besides Stanford University School of Medicine and Columbia University, then Mayo College of Medicine/University of Minnesota, Oregon Health & Science University, University of Alabama at Birmingham, University of Colorado Health Sciences Center School of Nursing, University of Missouri-Columbia, University of Texas School of Health Information, University of Utah e University of Washington, University of Sydney. The
educational offer of Politecnico di Milano was one of the most complete at international level. It is composed by the Bachelor in Bioengineering (three years); Master of Science in Bioengineering (two years); PhD in Biomedical Engineering; II level Master in eHealth (one year) organized in cooperation with Cefriel – the ICT Center of Excellence For Research, Innovation, Education of the Politecnico di Milano; post-diploma degree for “Medical informatics technician” (Fig. 2d).

III. FROM HOSPITAL AND HEALTHCARE INFORMATION SYSTEMS THE SCENARIO HAD MOVED TO E-HEALTH

Observing how often the word e-Health is used nowadays, not only where up to a couple of decades ago we were using Hospital and Healthcare Information Systems (H&HIS), we would be pushed to understand if such a terminological change has occurred mainly for fashion, or for more serious reasons, any they may be (Fig. 2e). The possible reasons may be singled out by focusing major changes and persistence in the BioMedical Informatics arena. We propose the following observations.

The regular preparation of reports (reporting), the performing of search to be never repeated (search), and the doing of data mining for answering well perceived but still unstructured question (data mining): such three major targets in using computers have stayed evergreen over the decades. This was a persistence. But other remarkable changes have occurred. (a) Let start with the present expectations about the “anywhere anytime anyhow” concepts and practices. Having our notebook, anywhere we will be, connected, without wires, via a USB key, to the information system of our hospital, is now considered quite normal. This comes from the “C” part of the “ICT” acronym, where the “I” gives more flexibility to the “C”, and the “C” provides more usability to the “I”, in such a way that it has become practically impossible to separate one each other of them. (b) The capacity of digital memory devices increased of several order of magnitude, even making the cost to decrease dramatically. Also the clock speed increased a lot. Memory sizes of terabytes are now commonly available, whereas only some years ago the maximum capacity was of kilobyte. In addition, the Central Processing Unit’s (CPU’s) clock frequency has sped up from Mega Hertz to Giga Hertz, and, thanks to the current common parallel and multi-core architectures, processors are able to sustain a computational load that only some years ago was unthinkable. So the efforts of those times for high savings in execution time and in memory engagerements – would we remember MUMPS ? – , by the time being make most of us smiling. (c) After more than a decade of fearing the digital divide, worrying about its negative influences on the healthcare field, now we can observe the presence of somehow not negligible and often significant digital inclusion. Mainly thanks to home-banking, to buying travel tickets and supermarket items while at home, to keeping in good standing the family pictures archive, to wide-spread of “intelligent” mobile phones, within the multigenerational family, now we see a level of digital culture that was really absent two decades ago. In addition, when someone in the family goes sick, this culture is ready to be used, even if under some specific guidance and limits. (d) The “man-machine interface” problems are not at all that hard as they were at those times. The TCP/IP protocol made the Internet concept successful in the everyday practice, even at dummies environments. Indeed, we started to face the noise of too much information and too many data, too often from unfaithful sources. (e) Biometrical sciences and technologies are now more understood, but the worries about privacy still delay they generalized wide spreading. Some big failures of geographical healthcare information systems have occurred too, in such a way to raise some serious doubts in our capability to provide effective data protection over long and continuous time periods. (f) At too many hospital departments the medical record is still on paper, while about all of its data, which are coming from machines, are generated digitally. Evident cases are the pathology laboratory, whose data are sometime downloaded at home via internet, and the department of bio-images, where there are not so many films around anymore, and images are given to the patients on CD-ROM regularly.

Did we focus contents relevant enough to say that the terminological frequency change from H&HIS to e-Health is not just a question of fashion, but it is supported by significant evolution? We would say yes. To the point to support effectively some services inspired by the more and more needed approach frequently told as “patient centered”, where the “Personalized Health Informatics” has started its first steps, with a fast grow up.

According to a definition focused by Eysenbach, “e-health is an emerging field of medical informatics, referring to the organization and delivery of health services and information using the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a new way of working, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology” (Eysenbach, 2001). The e-Health, which is to have some major impacts on the work of clinicians / healthcare practitioners, health care administrators, researchers, and on the experience of patients. However there are still many problems to solve along the way, such as “ownership” of data, privacy issues, interface designs and access policies for different user types.
IV. PERSONALIZED HEALTH INFORMATICS IS NEXT

We face an increasing understanding that centrally managed healthcare systems are not able, alone, to coordinate all the aspects of a full evaluation of patient’s clinical state (Jaen et al., 2010). From here, the development of a more “patient-centered” view arises. This makes also e-Health to be more focused, which is named “Personalized healthcare (pHealth)”, which frequently implies the participation of the patient also in the management of personal digital healthcare documents. Personalized Health Informatics (PHI or Consumer Health Informatics) can be defined as the set of web-based tools in which the patient is the central element of services devoted to promote and ameliorate health (Eysenbach, 2000, 2008). PHI provides platform of services to maintain, enhance, and restore an individual's health, leveraging the growing power and sophistication of mobile computing and communication devices and the expanding capabilities of wireless networks (Lacal, 2006).

Within pHealth research, we can identify two complementary action lines. The first one focuses the system side. It is about what services a healthcare system offers for making health more personalized to the patients. The second one focuses the patient side. It does the attempt to make the patient more actively –but sustainably – involved for the higher effectiveness of its health care.

A. The Institutional Action line: the case of Lombardia Region

The region of Lombardia, located in the north of Italy, is one of Italy’s twenty administrative regions. Like as every Italian Region, the regional government (of Regione Lombardia) is directly responsible for healthcare delivery. With around 9.5 million inhabitants, it presents about 16% of the Italian population. In 2000, against the background of a growing demand and limited resources, the Lombardia Region began the introduction of a local Hospital Information System (HIS) in each hospital and the implementation of a regional network. Lombardia adopted a “non-invasive” approach, respecting the independence of the region’s hospitals and integrating already existing local systems rather than replacing them. In order to create new services on the regional level for both citizens and healthcare professionals, such as an electronic Health Record (EHR) and ePrescribing, it was necessary for health care provider organizations such as hospitals to have a local information system. The Lombardia Region supported the integration of almost all existing systems from a technology perspective, providing an enabler for information sharing and exchange (EHR IMPACT, 2010).

In the Lombardia Region, there are 150 thousand Health & Social Care Operators, 7,700 General Practitioners and Pediatricians, 2,500 Pharmacies and fifteen Healthcare Local Units. In addition, there are 34 Public Healthcare Services Suppliers (29 Public Hospital and 5 Public Medical Research Institutes). Further, over 2500 Private Healthcare Services Suppliers are available, too (SVILUPPO CRS, 2010).

Following the European Netlink project, the Lombardia launched its Regional Service Card and Healthcare and Social Service Information System (Carta Regionale dei Servizi della Lombardia – Sistema Informativo Socio Sanitario, CRS-SISS) in 2000 (CRS Lombardia, 2010). The project’s goals were to introduce greater efficacy and efficiency in the distribution of health care services through:

– the improvement of services to citizens by reducing the “distance” between citizens and healthcare organizations;
– the planning, management and re-distribution of health care resources;
– the reduction of information latency within the system;
– the establishment of a ‘standard’ of access to telecommunications services with the necessary prerequisites of security, interoperability and compatibility; and
– the completion of connections that would include not only health care services but also other public services in the region (e.g. automobile taxes, garbage collection & removal service, heating system's maintenance schedule)

The CRS-SISS project main streams are:

Development of Healthcare Extranet as main instrument of innovation and integration framework among all actors. This line has the following

– creation of new services at regional level for Citizens and HC Professionals (Electronic Health Record)
– creation of a large technological infrastructure
– implementation of an integrated regional information
system
- Development of Internal Information Systems for Healthcare Organizations’ (e.g. Hospitals and Healthcare Local Units) promoting features such as:
  - central data base and clinical data repository (administrative data, service codes, …)
  - solutions for clinical management of patients
  - application for integration of Organization’s Information Systems through an integration middleware

The CRS-SISS project Main Results are (SVILUPPO CRS, 2010):
- About 9.5 millions CRS delivered
- About 94% General Practitioners and Pediatricians in the Network.
- 100% Pharmacies in the Network
- All Healthcare Local Units and Public Hospitals of the Region have been integrated
- Public Hospitals are generating events, reports and clinical documents, digitally signed, into EHR to share data with other operators
- Oncology Lombardia Network and Rare Diseases Networks available
- Choice and revocation of GP and pediatricians available on line.

B. The Patient-at-home Action Line: the case of Historia Medica Familiae Digitalis

Despite the wide spreading of information and communication technologies is taking to an internet connection in every home, and implementation of nationwide health information network digital clinical data continue to reside in hospital and healthcare provider’s offices. Further, more and more patients ask to access their record online (Halamka et al., 2008).

When an online access to medical documents is not available, patients must visit hospital department to access their data and ask for a paper-based copy of clinical documents (Halamka et al., 2008). Due to an augmented sense of responsibility towards their healthcare, patients/citizens have developed complex strategies to storage, organize and manage their healthcare documents at home (Moen and Brennan, 2005): just-in-time, just-at-hand, just-in-case, just-because. In designing and developing patient-centered health applications designers and developers should to consider those strategies and make them available in market products (Demiris et al., 2008).

At present, a number of healthcare clinical data are receivable at home in digital format. For example we can access the web site of the hospital where we made a lab test and download the report in electronic format, e.g. as a pdf file. In addition, Hospital Diagnostic Services give us the results of magnetic resonance examination on a CD-ROM, containing hundreds of images. This great result was unthinkable to obtain if based on films of the exam.

The personal control on data, the information sharing, system safety and flexibility are the most important features that a system for healthcare document management should have, from user’s point of view (Civan et al., 2006). Another crucial element is the level of Information and Communication Technology (ICT) skill, that, if low, as in the case of older people, can be the basis of the so-called “digital divide” (Kim et al., 2005; Kim et al., 2009). In the multigenerational family, essentially composed by Grandparents, Parents, and Children, the middle generation (parents) always took care of the healthcare documents of the entire family. The family environment is characterized by single members, each of them with a personal clinical history, but sharing for instance the family history, the living environment, the lifestyle, the involvement in events related to a single member that could affect the entire familiar nucleus (Bonacina et al., 2010). In fact, it has been recently shown how the family history is one of the cheapest and easily obtainable methods to monitor the risk of pathologies, either genetics or environmental (Feero, 2010; Feero et al., 2008). In addition, the present level of ICT skills of the middle generation is a step towards the “digital inclusion” of weakest generations, who also most need sanitary assistance.

We proposed a system, “Historia Medica Familiae Digitalis”, that provides an easy compilation and effective visualization of the clinical data concerning family members in a secure and controlled environment (Bonacina et al., 2010). This system is a particular case of PHR where some problematic aspects of the PHR implementations have been considered and answered. The most important aspect relates to the reliability of entered data. We proposed the idea of the Matching Evaluator, a healthcare professional who remotely checks the information entered by the user. This procedure ensures the quality of entered data, at least in the correspondence between uploaded exams and labeling information. In addition, this approach enhances information security, being all the health-related family data locally stored on the user’s personal computer (Bonacina et al., 2010).

C. Upcoming Innovation Scenarios

As products of the management of the medical record at the personal and the family level arrive, such as Personal Health Record (PHR) and Personal Controlled Health Record (PCHR), they would include features for the management and the monitoring of the drug (medication) administration process. To this purpose, these systems have to include features for the assumption schedule generation, also in graphical form, drug assumption registration, and so on. Appropriate medication administration represents a key factor for recovery a healthy state; however, some risks could be arising during drug therapy. For hospitalized patients, adverse events that include infections, adverse drug events (ADE), injurious falls, and surgical complications affect patient safety, after patient discharge
too. Computerized methods can contribute to detect adverse events. A computerized monitoring system to detect ADEs in outpatient settings by searching in the electronic medical records also applying data mining techniques is presented in (Honigman et al., 2001). Further, patient education is another significant element for appropriate medication administration. An illustrated medication schedule devoted to low literacy patient implementing pill cards, as low health literacy is a risk factor for medication non-adherence, is presented in (Kripalani et al., 2007). When the number of drugs to assume concurrently increases, the possibility of medication errors, drug-drug interactions, and ADEs increases (Fulton and Allen, 2005). Usually in a multigenerational family environment, the middle generation takes care of drug administration for children and elderly people. Then, the development of a system for the monitoring of medication administration can account on the diffusion of common used electronic device. An example is the bar code reader that allows reading the barcode printed onto each drug package. While bar-code medication administration is an effective technology to prevent medication errors and has been diffusing in different institutions (Cochran et al., 2007; Poon et al., 2005), no researches have been devoted to the application of this technology to medication administration at home environment. We modeled the environment for the drug administration at home settings for a multigenerational family group and designed a monitoring system for helping the personal management of drugs in a safe way, considering the drug acquisition at the pharmacy, the automatic generation of assumption schedules for each family member, the check of single events of medication administration. We also considered in the model the use of common electronic devices such as barcode readers (Bonacina, 2008). The development of a software system for safe drug administration in a Home (personal or family) environment can help to identify drug-drug interactions, ADEs, and other problems related to drug medications. To this purpose we hypothesized that a proper connection from home to the central server of Healthcare Service provider (assessed available) to inquiry drugs databases and drug-drug interactions databases was available; a connection to the central server of Healthcare Service provider (assessed available) to inquiry electronic medical dictionary also regarding pathological and physiological condition was available.

V. NEEDED RESEARCH INSIGHTS ABOUT BUILDING BLOCKS AND SERVICES IN IMPLEMENTING PHI APPLICATIONS

A. Towards a shared definition of “Fascicolo Sanitario Elettronico” - FSE

The Italian Government has recently promoted the “Fascicolo Sanitario Elettronico” (FSE). It is a Citizen-Centered Electronic Medical Record. In other words, there is a generalized, also institutional, expectation of strong results on FSE implementation, aiming to give the same opportunities to all citizens from all Italian Regions. While a common and agreed detailed definition is under study at governmental level, guidelines about data treatment and privacy have been released (Garante per la Protezione dei Dati Personali, 2009).

B. Towards a Medical Ontology for the Family

Healthcare is a complex environment where the communication occurs between different actors, such as clinicians, doctors, nurses, and patients. The communication deals with complex and interconnected concepts, and is often affected by uncertainty, in the sense that education degree, domain knowledge, environment, and skills held by the involved actors - senders and receivers - affect the message tailoring. Therefore, the dissemination and use of patient- and consumer-centered health record systems face with some barriers. One of them is the consumer’s low health literacy which leads to discrepancy in understanding medical concepts and affects therapy adherence, even more when patients are elders. We described some approaches for understanding the best working architecture for carrying out the necessary analysis of the correspondence between the medical vocabulary of the consumer/family and that of the doctor, in the Italian language (Bonacina and Pinciroli, 2009a). In the household, we considered four medical areas as follows: a) "Pregnancy and the Newborn", b) "Emergency Care at Home", c) "Paediatrics", d) "Geriatrics" (for the outpatient). We developed ontologies for the a), b), c) and d) areas in Italian or English. In addition, for the Geriatrics domain we developed a lexicon connector to find correspondences between the medical vocabulary of the consumer and that of the doctor (Bonacina and Pinciroli, 2010). Then, we carried out tests of bi-directional matching between the family’s and the doctor’s medical lexicons within the a), b), c), and d) areas (Bonacina and Pinciroli, 2009a).

C. Characterizations of the ongoing Family Medical Lexicon

To present health information using consumer-familiar terms in PHI applications, we designed and implemented a tool able to infer about the knowledge level and use of medical lexicon inside Italian families (Bonacina and Pinciroli, 2009b). We considered different potential sources of medical lexicon before made our choice. First, medical TV serials can be a source of lexicon, but they do not generate any electronic textual files; second, family medical encyclopedias may be good tools for teaching, but do they describe what is learned?; third, the Internet world, as it is, is unreliable, while medical supplements of some important newspapers are probably suitable.

Usually the healthcare pages of some important newspapers are both addressed to common citizens and
VI. PROBLEMS RELATED TO BUSINESS MODELS FOR PHI APPLICATIONS DIFFUSION

Scientific literature published about a number of projects demonstrating the possible usefulness of personalized both health informatics applications and personal health records. On the other hand, there are so many products on the shelf (Marchionini et al., 2007), but no one can be named the leader.

Among the qualities that affect the success and lifetime of a software product there are the set of available useful capabilities, the friendless of user interfaces, however the adopted business model is another heavy aspect. Barriers in creating and maintaining a health record for families or individuals that need assistance can be summarized as it follows: (1) the ability of computer use - at the present family “middle” generation holds these skills; (2) quality of entered data requires that a medical professional verify the electronic medical record filled in by the consumer/patient; (3) the life-long medical record requires that evolutionary maintenance of PHR systems is the same as for others software system; (4) privacy of health data requires that there is not information sharing with other family members, unless some policies and agreements have been defined; (5) Costs of the service depends on the kind of national health systems: country having socialized medicine, or not.

For PHI applications, we hypothesized three different business models, as it follows:

- Model 1: the PHI application can be delivered as a CD-ROM attached to a weekly magazine. In this case, the training on application use is on the family own, also making available a toll free number for help. About costs, the publisher of the magazine should maintain a call-center service.

- Model 2: Can the PHI software applications be included into Microsoft Office-like Suites? At present, Office Suite consists in nine applications and some tools: the “classical” ones, such as Word, Excel, PowerPoint, Access, Outlook, Publisher, and the newer ones, such as Groove, InfoPath, OneNote. Then into Office Tools a number of specific application are available, e.g. “Document Imaging”, “Document Scanning” and “Picture Manager”. Though, a Family Health Record application can be implemented using the available building blocks of Office Suite and should be ease to realize for Microsoft software development staffs. For marketing reasons, an additional fully Family Health Record application may be distributed at no extra costs.

- Model 3: The PHI software application can be viewed as the last leaf toward the family of the Regione Lombardia network, supplied by “Lombardia Informatica” which is the health ICT provider and implementer of CRS-SISS Project of the Lombardia Region described above.

The issue of PHR systems business models is an element that “Historia Medica Familiae Digitalis” prototype (Bonacina et al., 2010) shares with other PHR systems. The most obvious possible solution is that payers are the primary beneficiaries, therefore the consumer or the patient. However, this approach seems not to be feasible, at least at present. Perhaps the most likely solution is to integrate the family health record in a software package for health data management supported by healthcare providers, following the “business model 3”. For instance, in a country like Italy or UK, where there is socialized medicine, healthcare provider could include the family PHR service in the National Health System. Costs of the proposed system must include the payment for the validation of user-entered data by medical personnel (“Matching Evaluator” or family doctor too) in addition to the usual costs for the service maintenance.

VII. CONCLUSIONS

Again, “as any good History would have a future, at least a near future”, let us close this contribution to the celebration of the XX anniversary mentioning few key-words, in the area of Telemedicine and e-Health, we are working around at the Politecnico di Milano. “iPad world” and “Avatar” are a couple of really intriguing technological tools waiting for serious and useful research for their proper allocation in the medical arena. To be added to “Medical and Healthcare Informatics”, the adjectives “Consumer” and “Personalized” will drive much of the upcoming research. Also the “Life-long Personal Health Record” will generate similar effects, according to its action lines, both institutional and patient-at-home. “Data noise”, “dematerialization”, “access policies”, “digital signature”, “responsibility remapping”, and more: all of this makes a good “arrivederci” to the XXX anniversary, in ten years from now.

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