TOWARDS BIOPROFILE A NEW CONCEPT OF ELECTRONIC HEALTH RECORD

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ABSTRACT

The challenge in Europe is of empowering a better healthcare system centred on citizen/patient needs. ICT is seen to "offer new possibilities for improving almost every aspect of healthcare, from making medical systems more powerful to providing better health information to everyone" [1]. Taking in account the numerous efforts to gather clinical information, there exists now some types of formats for storing and processing information for clinicians and researchers. Nowadays Health is much more than about samples to be tested or scans to be analyzed. Beyond that, it is necessary to take into account the whole environment conditioning of a person's health, including illness and sports. That leads to the need of having that information collected and stored so it can be usefully assessed, processed to support health and clinical decisions, and that's the path towards Bioprofile. The present study reflects the analysis and results concerning the roadmap towards creating a valuable personal Bioprofile inside Biopattern NoE.

Keywords: Electronic Health Records, Data Mining, Standards, Interoperability, bioprofile.

INTRODUCTION

The systematic utilization of new computational and technological resources has been spreading in healthcare environments. Information and Communications Technologies (ICT) are increasingly being applied into all healthcare processes and ambients, towards enabling a better handling and processing of information and knowledge. Nowadays, ICT take-up is even considered a reliable indicator of the level of development of a given healthcare system.

In particular, ICT has been used with the goal of creating health information records of a person. Such information records are typically known as EHR (Electronic Health Records) and contain information typically existent at the clinician's paper record including reports from consultation, diagnoses medication, doctor's notes and annexed exams like those from blood/urine analysis, ECG, EEG and many others. In recent years, there have been separate developments of different types of EHR, each with its own structure, some with the goal of having personal health data, others more focused in messaging and billing. There exists currently a number of EHR with names like GEHR, EPR, EMR… varying in some aspects but all with the purpose of storing Health Information in a digital support. The use of EHR has become a vital instrument in the digital healthcare environment and its use had been generalized. Health is no more an exclusivity of Hospitals and Clinical Centres but it is becoming more and more in the hands of people.

Need for highly interoperable systems

Healthcare is a cooperative endeavour with numerous points of contact between the patient and the health system. Systems therefore must be interoperable, allowing multiple users to see the record, and allowing information to be shared between health providers. Information must also be shareable between the software of different vendors.[2]

With the increasing adoption of EHR, it was identified by both research community and health professionals that additional information existed, which should be included in the so-called EHR that would enhance knowledge. Information such as life-style and travel would be of important value to correlate with the classical EHR information in providing a better and ample view on both a person's health, thus improving accuracy and responsiveness of heath practice, and on global community health, in this way identifying risk situations and overseeing health at a wider scale.

BIOPROFILE

The concept of Bioprofile is based on the idea of a lifelong sequence of information concerning factual events and reports relevant to a citizen's health. A biopattern is then basic information (pattern) that provides clues about underlying clinical evidence for diagnosis and treatment of diseases. Typically, it is derived from specific data types, e.g. genomics information and vital biosignals such as the EEG. A bioprofile might be seen as a personal 'fingerprint' that fuses together a person's current and past medical history, biopatterns and prognosis. It combines data, analysis and predications of possible susceptibility to diseases.

Furthermore the concept of a bioprofile will extend beyond the traditional information at paper or electronic health records as more valuable information will be included. With the growing interest of people in their personal health, the increased mobility of citizens and the growth of portable health devices, the paradigm of individual's health assessment and evaluation needs to be changed. The idea behind this new concept of health record takes both personal evolvement and other kinds of data that can be useful for health evaluation like travelling, habits, sports, addictions.. The challenge is then to include in the same personal health file,

information that complements the doctor's notes and clinical exams with data concerning travelling and lifestyle.

Bioprofiles will be dynamic, large and in stored in databases geographically distributed. With the ability to retrieve information from different locations there should be expected significant improvements in citizen's mobility as there exists some guarantee of cross border healthcare sustainability. Online access, analysis, remote diagnosis, prognosis and decision support capability will be needed.

In practical terms, the result will be the integration of a large set of information concerning one's health, including lifestyle information. The goal is to have the most complete collection of elements pieced together making a set of all exams and professional evaluation regarding a citizen's clinical history. Bioprofile will support a holistic view of the citizen's health, making use of available information technologies like Grid and other Web based services.

The functionalities of today's devices are enormous; one can have at the gymnasium or even at home a range of sports equipment that measure physiological values e.g. hearth rate, blood pressure and others. Also some of these equipments can estimate the rate of loss of calories and the result at the end of the exercise. Those values can not be seen with the same precision and accuracy of medical devices, but they can both give additional information that can help in identifying the reasons for determinate health status and to monitor the body response to exercise. On the other hand, it allows each person to contribute to his own health information and to provide information to clinicians thus enabling better health assessment.

MOTIVATIONS AND GOALS FOR A XEHR

"Europe increasingly suffers from lifestyle related diseases triggered by an unbalanced diet, physical inactivity, smoking or alcohol abuse. This means that citizens' health is, to a great extent, determined by individual choices on what people eat, smoke, drink and do". [3]

There are two main motivations that led to the development of a Bioprofile model. One is to involve the citizen in his/her personal health information gathering where the focus is to collect lifestyle information. The other is the need to build a valuable set of information that can be delivered to health professionals responsible for one's health, thus enabling better healthcare and a reduction in mistakes in heath practice.

Additional motivations might be enunciated for driving a need for bioprofiling, in particular:

- To comply with most of the information available to a patient.
- To allow information concerning different kinds of data to become contained in a single record.
- To combine clinical and genomic data in a single health record, a so called Bioprofile.
- To establish a data model that will allow research tools to operate with different kinds of data in a systematic way.
- To build a set of criteria to implement an extended EHR that becomes a bioprofile of a person.
- To allow prevention of deceases by feeding analysis tools to operate with bioprofile data
- To establish a temporal relation to actions and messages so that a bioprofile can be assembled.
- To be able to support help decision tools with a coherent bioprofile thus allowing correlation of different facts among personal Bioprofile.

A recent study conducted by *Eurostat* which evaluated how Europeans consider their lifestyle provides some facts and figures that support the need for a bioprofile. Considering the study report, we may wonder how such studies may benefit from bioprofile collection rather then street interviews. Furthermore we get the notion that people need more decision tools and more concrete facts in order to correctly evaluate lifestyle and its impact on health rather then suppositions:

"In 1999, 81% of EU citizens aged more than 15 thought that they led a healthy lifestyle. In Spain, France, Ireland, Belgium, Austria, Portugal and Germany more than 80% did so. Greece was the Member State with the lowest rate (64%) and also recorded the lowest percentage of people doing some exercise (19%), but had the highest share of smokers (45%) and people feeling stressed (72%).

Around three quarters of the EU population thought they ate a balanced diet. Only Italy (48%), Portugal (59%) and Greece (70%) recorded lower figures. As for sports, 78% of Luxemburgers and 76% of Finns exercised at least twice a week, compared with an EU average of 40%.

In Ireland, 52% of the population drank alcohol regularly in 1999, compared with 25% for the EU average. Denmark and the United Kingdom (both 44%) and the Netherlands (43%) also recorded high percentages, while the lowest were observed in Italy (12%) and Spain (19%).

The lowest proportions of smokers were found in Sweden (22%), Italy (27%) and Portugal (28%), while the lowest percentage of people feeling stressed was observed in Finland (27%), Sweden (30%), Denmark and Germany (both 32%). The EU averages were 34% and 38% respectively."[4]

The xEHR and the BIOPROFILE

The bioprofile is new and many activities are starting to develop around the concept. There are some efforts that, even with different names and concepts, are contributing to the assembly of a bioprofile. There are some ongoing case studies, like in Japan[5] and in Europe, mostly supported by the EC research programmes. Also it is important to note the development of some software products to cope with a person's interest for a bioprofile. Some software solutions in the market allow people to retrieve information concerning lifestyle and sports. At present, the information is only for personal use mostly to determine caloric balance and food and diet control.

One of Europe's top research priorities is to become world leader in specific areas of interest, in particular in those that might present high applicability and impact on economics and citizens wellbeing. Bioprofile presents health community with a mechanism to look further and deeper into the citizens' and communities health. Furthermore, impact on economics is expected by accurate diagnosis, seconded by pinpointed exams and prompt and effective treatment, but also by enhanced and early warning to citizens' health threats. It represents a step-further in a citizen-driven healthcare system where citizen takes an important and active role.

In this view, the European Commission funded the BIOPATTERN, a 4-year, Network of Excellence (NoE), project within the ICT for Health. It is a groundbreaking project that integrates key elements of European research to enable Europe to become a world leader in eHealth. The Grand Vision is to develop a pan-European, coherent and intelligent analysis of a citizen's bioprofile; to make the analysis of this bioprofile remotely accessible to patients and clinicians; and to exploit bioprofile to combat major diseases such as cancer and brain diseases.

The BIOPATTERN initiative proposes to provide novel computational intelligent techniques for biopattern analysis and a pan-European integrated, intelligent analysis of an individual's bioprofile. Information from distributed databases will be made available, securely, over the Internet to provide on-line algorithms, libraries and processing facilities for such analysis.

The design and implementation of a Bioprofile is ongoing within a subproject of the Biopattern Network of Excellence, SP33 xEHR/Bioprofile. There and other challenges ongoing in different subprojects that directly or by means of the used instruments or achieved results will contribute to the bioprofile. Within the Biopattern network, there are several subprojects that are studying Cancer and Brain deceases, making evaluations and data correlation. This type of research will produce results relevant to the assessment of decease, thus allowing the prediction and identification of potential threats to human health. Regarding the data itself and the efforts to gather information relevant to Biopattern project, there are three inter-related subprojects. The first is SP xEHR/Bioprofile, with the mission is to expand the traditional Electronic Health Record in order to contain more data later identified as lifestyle. The other two subprojects are Earlylife, which in essence studies fetal vital signs and has the goal to assess health status in the beginning of life before and after birth. The other is Bioprofiling over grid, which allows data to be gathered in a network thru GRID support.

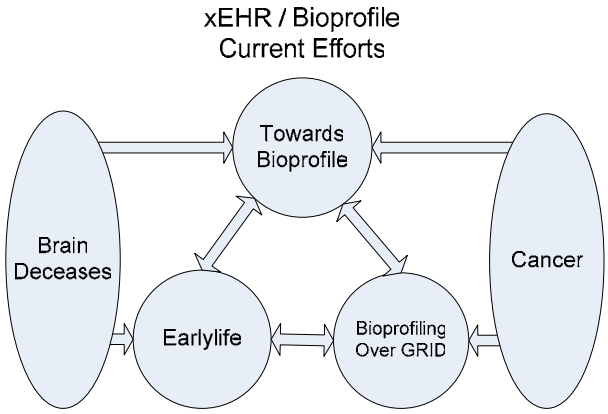

Fig. 1 Subprojects with contribution to Bioprofile

Extended EHR to support Bioprofile

The information contained in an electronic Health Record, such as those already in use, have much of the relevant information for one's health. To have a wider set of information it is necessary to handle the existing information and to enable the addition of non-clinical information.

The relevance of a bioprofile can be seen from the point of view of the clinicians but also from individuals that can have a closer control of their own health status. With the implementation of a bioprofile it is possible to develop and offer decision supporting tools that can evaluate, inform and even trigger alarms to request medical advice or support.

The implementation of a bioprofile will be based on existing EHR Standards. Those will be used for ongoing studies within the NoE. The next step will be to gather the indications of the Special Interest Groups based on targeted scenarios. Next the bioprofile will be tested out in an overall representative scenario application. Additional bioprofile needs and requirements will be driven continuously by addition of more scenarios.

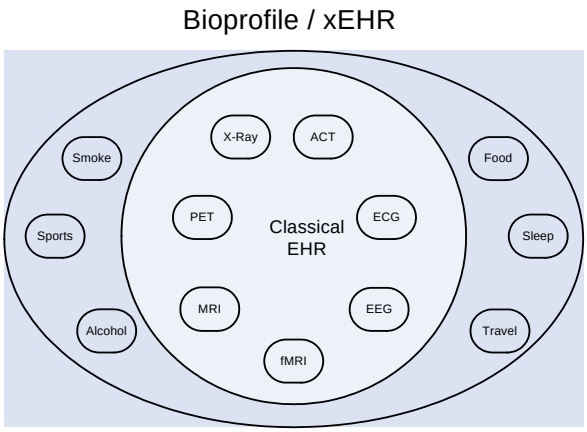

Fig. 2 - Extended EHR to support Bioprofile

In a simple way, one can refer to an xEHR as a traditional Electronic record enhanced with an upper level layer containing personal information, considered so far irrelevant.

For the implementation of a bioprofile to succeed, some technical advice is needed from those professionals working with specific disease, such as cancer or brain deceases in order to retrieve instructions concerning the information to be retrieved at a bioprofile. After those trials, it could be expanded to other kind of diseases but in the end, we expect that bioprofile information will be relevant to health status evaluation and not only to specific deceases.

BIOPROFILE SCENARIOS

Two possible approaches are local cases and pandemic questions.

Small scale scenario

A possible scenario for implementation can be considered for a better understanding. A man comes to the doctor; he says that in the last month he has dizziness, frequent headaches and some fever. The doctor makes some observation, measures blood pressure, hears heartbeat and looks for other symptoms. So he asks for other relevant issues concerning his lifestyle; if he lives in a rural area or near animals. The man says no, that he lives in the city and no contact with animals, also he suspects some food he ate some days ago. But for the doctor that makes no sense has he should have had a worse health pattern in the two or three days after eaten that food. So he looks for clues in the bioprofile of the person where she keeps up-to-date record of the proposed fields. In that consultation, he finds something very important that the person did not mention as he finds it irrelevant; four months ago he returned from a visit to the Congo in Africa. The doctor knows about a disease with that symptoms and exists in that region of Africa, carried by some mosquito. The fact that it takes some 3 or more months for the disease to incubate makes the doctor to take a closer look at the patient and sent the blood samples to a tropical medicine lab in order to search for the biomarkers of that decease. This case is a supposition, but it is an example how bioprofiling information could be used.

Large scale scenario

Obesity has become a problem of the current generation. The number of overweight adults and children has increased over the last years. Studies point to food problems as responsible for the problem.

"Over 200 million adults and some 14 million children in the EU are overweight or obese. And the situation is getting worse, particularly as regards children.
The basic problem is relatively easy to identify – a combination of unhealthy diets (too high in fat and sugar) usually coupled with a lack of physical activity."[6]

A national study can be carried out to identify the reasons for obesity among children with the section of a xEHR that has information concerning food ingestion. Following this studies, health advice and subsequent measures can be implemented in case studies to evaluate the consequences and then enforcing European laws.

RESULTS AND BENEFITS

The benefits resulting from this approach will be organized at three levels; at a personal level, concerning the benefits to each citizen regardless of whether they are a patient or not; at the clinical level, concerning the benefits to clinicians and institutions (e.g. in terms of efficiency and quality of work from this approach) and finally, the benefits to research.

Citizens

The more information available, the bigger is probability of a good diagnosis and early treatment. Individuals can benefit from the tools that can be used to trigger alarms regarding dangerous levels. It cannot substitute a doctor but it can recommend doctor consultation. Citizens can have more choice on the access to healthcare as personal files will not be so dependable of the institutions were the exams or interventions were made.

Clinicians/Health Institutions

Every health professional needs the most information available concerning each patient in order to perform the best of his skills. The gathering of information provided by the implementation of a bioprofile plus the additional information will give a valuable support to health professionals.

This would mean accurate diagnosis enabled by Decision Support Systems (DSS) that would help professionals to practice at their best backing-up their

decisions, by correlating information on real-time and displaying a set of warning and alerts to the professional.

Institutions will be able to deliver best practices and to provide a better health information model to it's patients. The interaction between citizens and institutions will be more relevant as the person can interact with the institutions. A personal device like a palm or a personal cell phone can be used by a person to store lifestyle information that a person, by he's decision, can provide to the institution files in order to complete his personal health record.

Healthcare Systems

Healthcare systems will have a great benefit from the implementation of information systems based on this kind of approach. The benefits are various and rely on a global improvement of health for citizens. As in commissioner Byrne's words, "We need to show that Europe is good for health. By increasingly putting EU policies at the service of good health, we bring Europe closer to its citizens and help them enjoy longer, happier, more productive lives."[3]

The collection of bioprofile information will allow citizens to get closer to health thus benefiting healthcare access and information.

Research activities

Research can benefit with such a system for two main reasons, one is the access to large amounts of data otherwise disperse and useless; the other is the possibility of having access without regards to undisclosed information as relevant parts can be accessed as separate pieces.

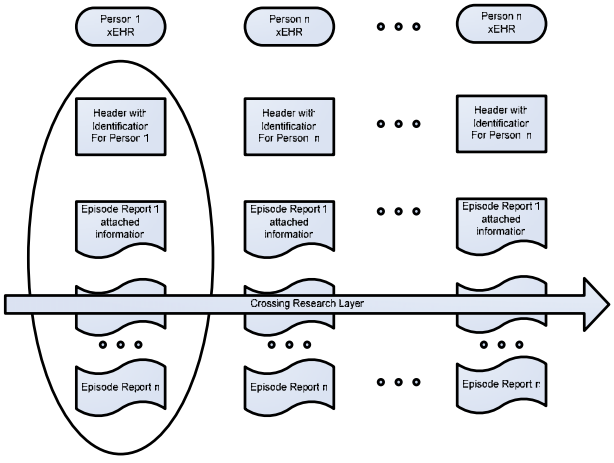

Fig. 3 - Bioprofile will allow crossing layers research

Many organizations are interested in anonymous mining of medical data and correlating the various medical parameters could lead to new conclusions and innovations. The research community would like to investigate and analyze the vast amount of existing clinical data, and find correlations between various diseases and medications, protocols and survival status, diseases and genomic, and so forth. [7]

BIOPROFILE ADOPTION

Many issue, other than technical ones, need to be cleared out and studied in order for a real bioprofile adoption to occur.

One important aspect of bioprofile is how to populate the bioprofile records with the valuable and relevant information. This may be a no-sense matter for cases like diabetes in which a log of the life-style event is almost mandatory for patients in order to continuously monitor their health, but this for sure not the case in general when a predictably healthy person has to regularly log its life-style events.

Another aspect is the implementation plan or guidelines that should/must be provided to healthcare responsible to enable them to take profit the full benefits of bioprofile and avoid pitfall in their path. Particular interest is on interoperability, in order for Europe's healthcare systems and specifically those enabling bioprofile, to integrate in support of a European healthcare environment.

Now, interesting new technologies are starting to evolve that can support the bioprofile. In particular, intelligent clothing could play an important role in continuously monitoring a person's health. As an example, some wear that could warn about stress condition or other, could also integrated logging capabilities that could then be downloaded into a person's health record to link the person's life-style with its own health condition.

CONCLUSIONS AND FUTURE WORK

The main conclusion from the current studies is that the development of a bioprofile seems to be very important for future improvements in healthcare from the point of view of the citizen's health information. The benefits range from improvement in healthcare to prevention of clinical error. It should also be important for European citizens lifestyle evaluation. We consider that even a small scale implementation of xEHR/Bioprofile could deliver very important results in terms of characterization of the population and disease evaluation thus driving research on new forms of diagnosis and treatment.

It is important to note that to have an updated model of xEHR it is necessary to make developments with the help of health professionals and citizens. In order to enable this interaction and further development it is extremely important in a near future to assemble a Biopattern community that will retrieve requests, assemble and disseminate new versions of a Bioprofile.

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