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NESSI e-Health: Accelerating the Impact of ICT in the European e-Health Domain

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Abstract: NESSI e-Health is a working group of the NESSI Technology Platform. The main goal of this working group is to contribute to the identification and definition of a Specific Research Agenda (SRA) in the e-Health field for the coming years following NESSI guidelines. In this paper we present the main objectives of NESSI and of NESSI e-Health. We continue with the proposed methodology and we go then into the description itself of the group. We explain the main sub-domains to be explored and we illustrate this with a use case where all these sub-domains are tackle and how NESSI e-Health may contribute to foster the research in the different field. Finally we make a summary with the conclusions that may be obtained.

1. Introduction

ICT systems support and control many vital aspects of our lives. Moreover, this kind of systems has the potential to offer solutions for needs and challenges for a wide range of our daily life aspects. Health is among these mentioned aspects and the solutions are under the umbrella of what has been named eHealth applications and services.

NESSI e-Health [1] is a working group of the NESSI Technology Platform that aims to accelerate the impact of ICT technologies in Europe by addressing the emerging needs and the research and development challenges in the eHealth domain and ultimately providing relevant input to the NESSI SRA (Research Strategic Agenda) for the specific field.

NESSI e-Health is composed by very different institutions (big companies, SMEs, universities, etc.) that under the collaboration framework of the NESSI Technology Platform is intending to identify and define the future research areas within the e-health domain where NESSI technologies can be better exploited. NESSI e-Health will elaborate a roadmap where the current and future aspects would be considered in order to produce guidelines for the future research work, to be inlcuded in the NESSI SRA.

The working group has been created under NESSI Technology Platform umbrella to reach the required critical mass and participation of stakeholders to define such a roadmap. This initiative would join all the efforts from the different actors fostering the synergies among all of them.

The initial set of fields that NESSI e-Health working group will focus on has been identified as follows:

- Interoperability of Electronic Healthcare Records
- ePrescription
- Intelligent homecare monitoring
- Virtual Human

These identified sub-domains are the current hot spots in the health care research area and should be explored deeply in order to contribute to position Europe at the top positions in this specific research field. At this moment, most of the work done within this area had been carried out in the USA and it is necessary for Europe to be more active and present.

2. Objectives

The main goal of this paper is to present NESSI e-Health working group and to create awareness of the existence of such a group within the research community. It is also our aim to increase the interest on this initiative and to exchange with others their experience receiving very valuable feedback from different stakeholders.

The second objective of this paper is to obtain different opinions that may contribute to give the final shape to the group identifying other fields of interest that maybe are not given sufficient importance or are not present.

Thirdly, we would like to explain and show the identified need to have this initiative as a unique group and not as separate research groups. It is very important to realise that the efforts done would increase the total knowledge and the experience of all the actors involved improving the possibilities for further research and exploitation of NESSI technologies.

Finally, we also aim to explain identified research areas and to give a general overview of the technologies that the group is willing to address for each of the sub-domains.

3. Methodology

The methodology followed in the paper is divided in several parts: description of the proposed working group, presentation of specific sub-domains for the working group and application scenario. We conclude the paper with a set of conclusions obtained from the ongoing work of the group and the explanation within this paper.

In this section devoted to methodology, we would also like to make a general introduction about what we consider roadmaps and their potential for the research field as general consideration of the group methodology. Roadmaps are employed as decision aids to improve coordination of activities and resources in increasingly complex and uncertain environments. The classical road mapping methodology will be used in developing NESSI eHealth roadmap. In a road mapping process all of the alternative pathways going to a given objective is elaborated but more importantly road mapping helps narrow the field of requirements and possible solutions to those most likely to be pursued. It should be noted that implementability of a final roadmap is as important as its strategic value.

The common steps issued in road mapping are as follows:

- Analysis of the state of the art and user requirements in the domain
- Defining vision in the domain for the next five to ten years
- Analyzing the gap between state of the art and the vision
- Defining the roadmap - research challenges to be addressed for closing the gap

At this stage NESSI e-Health has just putted the basis to build this roadmap by defining a position paper in the area (to be approved by the governing bodies of NESSI) and having the e-Health working group approved within the NESSI Platform. In the coming months, as said previously, the group will be able to give the first results of its work.

4. NESSI e-Health: Description

In developing the roadmap for eHealth, NESSI will place specific importance to a set of issues that are described in the coming paragraphs. These issues are divided in two clear groups, one related to the finals users and the other one related to technical aspects.

On one hand the first set is related to aspects close to the final users (their expectations, willing, etc.). This group is of special interest for NESSI and also for the eHealth domain and it is composed by **Security, Privacy and Trust.** Within the health domain these issues are considered of high relevance for all the actors involved. Patients, general practitioners, specialised personnel, etc. expect that they can trust in the necessary functionality, quality, privacy, dependability and security. Moreover, for patients and doctors it is of vital importance the privacy of the data and the security of them.

Another very important aspect that is taken into account in NESSI is **Dependability.** Services for e-Health have to show a high dependability. QoS for the e-Health domain should be higher than for other applications, any failure is taken very seriously by the final customers. This parameter may mean a psychological barrier for final users because health is considered as the main important aspect in life by most of the people and nobody will accept to put it at risk unnecessarily.

On the other hand, there are sets of issues that are important from a technological point of view but are not perceived as relevant from the users' point of view. These aspects include for instance, **Open standards**: the NESSI community may contribute to the standardisation by integrating the different existing efforts. It is not NESSI business to create new standards but to help to make all the existing ones working together (in relation to all the possible aspects). Other aspect that is included in this group is the consideration of applications and services creation using **Open source**: having open source solutions for the e-Health services will be very helpful for wider acceptance of the involved technologies. NESSI will support efforts aimed to include this kind of solutions in the medical field.

To this point, all the mentioned characteristics are general and inherited from NESSI itself. In the coming section we present the specific sub-domains identify and the technical aspects that will become the focus of the main research for the e-Health working group.

4.1 General Conditions of NESSI e-Health Solutions

NESSI e-Health working groups will address four different sub domains but for all of them, the services created should be compliant with the three following criteria: **time scale**, **focus** and **intelligent ambient**.

Regarding the ***time scale***, it is necessary to conceive and design solutions, services and applications that help us to improve our quality of life since we born and during our whole life time, this is to say, they should be operational "*from womb to tomb*". The second common criteria is the ***focus*** of the solutions, all the services and solutions should be oriented to ***promotion and prevention*** for our health (although of course there will be many applications devoted to treatment of very different diseases). Finally, the third criterion is to foster the adoption of ***intelligent ambient*** for the e-Health domain. An appropriate balance has to be achieved between the perceived benefit of using the IT devices and e-services and the added effort to adhere these services. *Technology has to disappear* necessarily.

With these considerations in mind, the next section provides a more detailed description of the different sub-domains that have been identified by NESSI e-Health working group.

4.2 Specific Sub Domains for NESSI e-Health

NESSI e-Health group has decided to focus on an initial set of sub-domains where NESSI approach seems to be more efficient and applicable.

4.2.1 Interoperability of Electronic Healthcare Records

The Electronic Healthcare Record (EHR) is defined as "digitally stored health care information about an individual's lifetime with the purpose of supporting continuity of care, education and research, and ensuring confidentiality at all times".

Currently, this information is stored in all kinds of proprietary formats through a multitude of medical information systems available on the market. Typical formats include relational database tables; structured document-based storage in various formats and unstructured document storage such as digitized hardcopies maintained in a classical document management system. This results in a severe interoperability problem in the healthcare informatics domain.

There are Electronic Healthcare standards that are under development such as CEN EHRcom, HL7 Clinical Document Architecture (CDA) [2] and Integrating Healthcare Enterprise (IHE) [3] Cross Enterprise Document Sharing Architecture (XDS) to address the interoperability problem. Furthermore, there are several initiatives by the governments worldwide to share EHRs. Another important aspect of the interoperability of EHRs is the use of archetypes. However, interoperability of EHRs has not been achieved yet.

To achieve such interoperability, an EHR information system could be divided into different components where different standards may be applied. The main components being defined are:

- Content and structure standards (architecture)
- Clinical data recording (codification)
- Communication standards (messages format)
- Data security and authentication.

NESSI e-Health work in this area will start focused on the last two points that could be grouped under the "interoperable information transfer" concept. There are many institutions and organizations working on such "interoperability" as for instance ISO, HL7 or ANSI. Within Europe, the European Normalization Committee (CEN) is elaborating and finishing the standard EN13606, which is in process to become, within ISO framework, an international standard.

The main pillar where EN13606 standard is based on is the separation between information (something known about a specific entity of the domain – "John Doe has a fault in his septum atrial") and knowledge (wisdom accumulated through time and true for all the entities of the domain – "Septum atrial keeps human heart's atriums apart"). At clinical domain, knowledge is continuously evolving because it is increased or modified by collected evidences from daily practice. Most of the existing clinical information systems are not prepared to face changes at the knowledge domain and consequently they get quickly obsolete, which is one of the main reasons why e-Health systems have harvested little success until now. EN13606 standard manages this separation between information and knowledge by using a double model: the *reference model* and the *archetype model*.

The *reference model* represents the general characteristics of the components, how they are organized and their interaction with contextual information to satisfy the ethical and legal requirements of the record. An *archetype* is a ranked combination of components – classes – from the reference model, which is restricted by this archetype (giving its names, data accepted types, default values, etc.) to model the clinical concepts of the knowledge domain. These structures, though stable enough, can be modified or replaced by any other as clinical practice evolves, allowing the information system to keep operating because it works with the classes defined by the reference model.

The first set of tasks that has been identified by the working group for EHR area are the identification, specification and definition of the archetypes best representing data, describing concepts at all the different situations that will be studied in this e-Health

initiative, such as homecare environments. In order to work towards this aim it will be necessary the development, deployment and use of:

- Tools for **archetypes creation**. This task should be carried out by the clinical professionals who manage the knowledge of the domain. The development tools should offer facilities to handle such knowledge. These tools should work with ADL.
- Relationship with **terminologies** and **ontologies**. The archetypes must be based on terminologies that could be understood correctly in an automatic way by both the information systems and the humans. Semantic web and semantic services are new technologies fostering the development for this field.
- Creation of national and international **repositories**. The standard archetypes should be available to accomplish the semantic interoperability. It will be necessary to create these repositories offering the necessary mechanisms for adding new archetypes and generating new versions of the existent ones. These mechanisms must be easy to use by the clinical staff, since they are the main archetype users-group.
- **Query tools**. These tools should analyse the performed query in a semantic way, interacting with the archetype repositories, in order to recover the needed ones for: 1) composing the questions to the permanent storage system; 2) extracting the information; 3) and composing the proper answers.
- Tools for **automatic creation of applications** (introduction or visualisation of data) based on archetypes. It is the only way for the archetypes (and the templates based on them) to be able to develop all their potential. This way it would be possible to finally offer e-services interconnected with patients' electronic health record in an easy way.

To address some of these challenges, several technologies have been identified: 1) Systems able to work with the data structures defined in the standard. This implies developments in the field of the **permanent storage**. Working with relational databases might not be enough, it will be necessary to explore new possibilities: object oriented databases, XML, etc. 2) Tools to **validate** the extracts generated according to the standard to ensure we are able to represent the complex data structures defined in it. The best way to carry out these tools seems to be creating XML schemas. 3) The standard specification also defines security policies and rules for the access to the different record-sections.

4.2.2 ePrescription

Electronic prescribing refers to the use of computing devices to enter, modify, review, and output or communicate drug prescriptions. Ambulatory care errors are common and preventable; electronic prescribing can improve safety, quality, efficiency, and cost. However, at present, these potential benefits have not been fully realized. Electronic prescription systems have been implemented in a variety of levels ranging from systems with electronic drug references only with no prescribing capability to systems being able to handle basic supporting clinical data such as allergies, demographics, and formulary information, which can be used by the system to generate alerts. However the real benefit of electronic prescription systems will be achieved when they are supported by clinical decision support systems accessing the full EHR of a patient.

In relation to technologies to be used and/or investigated, there are lots of possibilities. At this early stage the working group has not identified yet the specific ones that seem more suitable. So far, the working group has identified the characteristics and performance that is expected from these technologies.

For ePrescription application, it is of crucial importance to guarantee the identity and role of the prescriber and the authenticity of the prescription document. Moreover,

confidentiality and integrity of the transmitted document, the identification of actors involved, etc. evaluates as successful or not the whole procedure.

Another technical requirements that is highly relevant for this service is the connectivity. All actors should be in direct or indirect communication in an easy way that fosters the understanding of all the parts. Without good connectivity among the parties it would be not possible to deploy the service with good quality.

There is also a technical challenge in the semantics area for ePrescription. A system that automatically can read prescription and identify the drug to be delivered to the user is required. To implement such a system, it is necessary to have identification codes for each drug, dosage, form, etc. This kind of system may result in an easier way to deliver drugs that will reduce drugs expenses.

Finally, in a federated environment such as that described above, private information about users (e.g. personal and health data) must be made accessible exclusively to those actors that require it and only when they require it. The systems must ensure that patients (and other actors) have control over how their personal and health information is distributed and over who has access to it. Moreover, these systems must also make the necessary provisions to comply with national privacy laws and EC privacy directives. In addition to technical measures, it is imperative that proper audit processes, implementing well known standards such as ISO17799, CoBIT or OSSTMM, are established to guarantee that patients can trust the systems in maintaining the privacy of their personal and health information.

4.2.3 Intelligent Homecare Monitoring

The medical practitioners at all levels are becoming more overloaded as the aging population of Europe increases. Information technology, combined with recent advances in networking, mobile communications and wireless medical sensor technologies offers a great potential to support healthcare professionals and to deliver health care services at a distance hence providing the opportunities to improve healthcare within Europe.

These services will be also central for the care of chronic patients. The integration with those other services for patient management and treatment protocols completes the picture of the e-services for chronic patients.

Technologies that will be studied for this application domain are on one hand those related to *semantic and web services* to support both information integration and knowledge extraction and knowledge management services. On the other hand it would be necessary to perform some research on *intelligent sensor network technology*, to acquire and actuate in real time with data from the physical and the behavioural/functional environment of the target individual. Networks that necessarily have to be: self-configurable, non-invasive/intrusive, easy to use, minimum user´ interactions (invisible), easy maintenance and low cost, moreover, it would be necessary to have a security layer for sensor networks, in order to avoid external tampering of the eHealth applications that rely on them. The sensors that would be considered may be placed directly in the patients or on other objects of their environment that may help somehow in their daily care (for instance sensors to control the food habits of the patient). Another category of sensors that would be studied are those related to posture and gesture recognition that may help to know in real time the situation of the patient.

As we are talking about home care we will focus on the existing challenges on this field. Currently, two interoperability barriers at home care services could be identified: 1) patient's collected information integration with healthcare information systems and 2) plug & play heterogeneous device operation at a PAN (Personal Area Network) or at a HAN (Home Area Network).

Focusing on the heterogeneous device integration, there is an applicable family of at-the-point-of-care medical-devices interoperability standards. They are ISO 11073/IEEE 1073,

also known as PoCMDC (Point of Care Medical Device Communication). The standard is adaptable to the home care requirements except some small modification and it provides a holistic solution from low level layers, even physical, to high level layers. The family of standards consists of four main groups:

- Transport (wired or wireless)
- General purpose services
- Device data.
- Network communication and gateway standards

Together with those main standards, specific application profiles are defined for each kind of device. The standard is currently being developed and still has a draft status.

4.2.4 Virtual Human

Virtual Human is the development of "in silico" models of human beings. In Silico means the modeling research done with the computers via computer simulation. Through a virtual human, normal and disease states can be simulated, as well as the effects of particular drugs on them, the components of interest are the drug, macromolecules, cells, organs and whole individuals. One of the gains is economical: testing drugs and treatments on virtual humans is much less expensive compared to conventional methods. Another reason is that the computer simulation may provide much more accurate results compared to testing drugs on rats and other animals. It is reported that 20% of the drugs that succeed in preliminary trials fail when doctors test them in large and this is too costly for the companies. However modeling human beings is complex and difficult since the science of the living things is not entirely understood. Biomedical and Pharmaceutical Technologies, probabilistic networks, dynamical systems, logics, simulation languages, database technologies for storing the whole knowledge base, grid technologies are the candidates to tackle the computational complexity of this modeling. Modeling virtual human is also in the focus of European Commission's current research plan.

The Virtual Human is an exploratory field where research and developments are brand new and in continuous update. NESSI e-Health working group is currently researching right now in identifying the related technologies that are applied to the specific field.

4.3 Why NESSI e-Health?

The motivation to create an e-Health group within the NESSI platform was directly related to the dimension of the research field that it is trying to address, and its direct connection to the NESSI technologies. The e-Health field and specially the four sub domains identified, requires of great research efforts following very different technology branches, even some times, the need to tackle the medicine field itself.

In order to obtain the maximum profit from the collaboration of very different institutions and research groups, it was necessary to create a specific working group within the global NESSI effort, which had a special focus on NESSI technologies and the healthcare market. The offered collaboration framework is optimum to put together all the needed groups to have the full added value chain for the e-Health applications: from basic research institutions to patients organisations and also industries (big companies and SMEs) that may finally deploy the services for the citizens.

5. Scenario

As far as the NESSI e-Health working group has defined its objectives and results as a roadmap for research, it is necessary to present a scenario where all the tackled aspects may be observed. The following text presents this scenario.

Mrs. Robinson lives in Graz, Austria, she is 68 years old and has two sons but she lives alone since four years ago that her husband died because of cancer. Due to this life circumstance, Mrs. Robinson has decided to collaborate with her hospital and doctor by entering a remote caring program and a virtual human research program. Once of her sons, Steven is the one in charge of the health care of Mrs. Robinson and he is also in charge of taking her to the doctor for periodic checking and to get the needed medication.

Last year, the doctor diagnosed Mrs. Robinson a cardiac arrhythmia and now she requires monthly controls for medication and also for signals measurements. During the last six months, these measurements have been done using a set of sensors that Mrs. Robinson herself can put on her body in the correct places. Thanks to this intelligent remote monitoring system the obtained signals are being visualise in real time by her doctor. Mrs. Robinson's doctor analyses the obtained information that is being received and detects a change in the reference values since the last time that she was monitored and he decides to make some changes in the medication that Mrs. Robinson is receiving.

Prior to take a final decision of changing her medication, the doctor opens here EHR in order to make sure that the new treatment will not affect her in a negative way due to other medical problems. Once that he checks that, he stores the new information making it available for other doctors and also for Mrs. Robinson's son can access the information and can be updated continuously.

Once that he updates the information, firstly he communicates the change to Mrs. Robinson and secondly he sends an ePrescription to Mrs. Robinson's house nearest pharmacy. This way, as soon as the pharmacy receives the new medicine they will phone Mrs. Robinson to let her know that it is ready. Mrs. Robinson then can decide just to go to the pharmacy when the medicine has arrived.

Apart from this, Mrs. Robinson collaborates with the Virtual Human research department. The stored data from the medical signals is used for the in silico simulations that are currently building models to treat arrhythmia using new drugs less invasive for the human body. Her doctor is making real good advances since he is using Mrs. Robinson medical signals because he is making new discoveries in the area.

Hopefully Mrs. Robinson will benefit from the results of her doctor research in the future and will enjoy a more independent life and three monthly or yearly revisions.

In this scenario we present how the four sub-domains of research affect the society and how the ethics, cultural and socio economic aspects should be considered in our research. The four areas addressed are the pillars for an independent live for all citizens and especially for the elderly. It is important to define the roadmap to include all the aspects that will enhance our quality of life. Of the proposed sub-domains, the base line for research in three of them can be identified easily, but for the Virtual Human this definition will be more complicated. We are at the moment when we can decide what we want to do within this field and which are the results that we would like to obtain from here.

Apart from the research field itself, the scenario presents other aspects that should be carefully considered as research areas for our work, namely:

Ethical issues: The work that we are intending to do includes a big component of ethical concerns. It is necessary to have volunteers that want to participate in the experiments and in the work. The way to recruit this people is by using authorisation forms that apart from the authorisation itself contain also data protection regulation information. It is necessary to ensure the data protection in order to make the user feel totally protected.

Cultural aspects: Any medical research needs to consider the cultural aspects. This is due to the fact that depending on the area, the cultural aspects and the history the methods to be applied may vary greatly.

Socio-economic aspects: Finally, it is crucial to be aware of the different socio-economic aspects that surround the patient. Depending mainly on the economic aspects and in the

social position the patients may claim to cover very different needs. It is our aim to make the proper findings to ensure the right classification of the detected needs. This classification may contribute to optimise the services provided by the health care systems covering all the needs and reducing the incurred costs.

6. Conclusions

The NESSI eHealth working group is aiming to create a research roadmap by involving all relevant stakeholders in Europe. The initial set of fields identified is the interoperability of Electronic Healthcare Records, ePrescription, Intelligent Homecare Monitoring and virtual human. A classical road mapping methodology will be used where the state-of-the-art will be surveyed, needs and challenges will be identified, a vision for the future will be created and finally a roadmap will be produced.

Technologies to be addressed within NESSI e-Health working group vary between application fields. However, the general characteristics of technologies used by NESSI include dependability, security, privacy and trust among other important aspects. Final users, i.e. patients and healthcare professionals, consider these parameters of vital importance and therefore are considered as such by the research teams working towards the achievement of NESSI technologies–based applications and services in line with them.

Other technical aspects relevant for the specific application domain are those related to connectivity and communication. NESSI e-Health working group will identify and explore the best combination possible for the different sub-domains. It is also very important to take into account open source and open domain solutions for the applications and services; NESSI e-Health working group is committed to give such solutions when possible.

Last but not least, the final objective of the NESSI e-Health working group is to raise the proper awareness and to reach the needed critical mass. All the experiences, comments and suggestions are welcome in our group. We are willing to define the research map for the coming years with the final goal to position Europe at the top of the research and also in the market to serve as many citizens as possible. In order to reach that goal the only possibility is to put together the sufficient knowledge and experience and to work together towards the same objective.

References

[1] www.nessi-europe.com

[2] HL7 EHR System Functional Model: A Major Development Towards Consensus on Electronic Health Record System Functionality. A White Paper. http://www.sanita.forumpa.it/documenti/0/100/140/148/EHR-SWhitePaper.pdf

[3] http://www.ihe.net