Travel Health Informatics and Telehealth

Selected Papers from EFMI Special Topic Conference
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Foreword

Humankind always wanted to invent devices for enhancing their natural abilities; we built cranes for lifting heavier objects, created cars and planes for going faster and phones for better communication, discovered drugs for better healthcare, invented computers to support all our intellectual activities and so on. All these are making our lives easier. And, what is remarkable, the rate of development in these directions is higher and higher and the development in one area is merely dragging all the others.

We see now that one of the major characteristics of the present time is the "increased people's mobility". Indeed, we travel; we travel a lot. We travel to see family and friends, we travel for business, we even work temporarily in a different place, we travel for conferences - like this one, we travel for pleasure, as tourists, and so on. But, what about our health problems during these travels? Can we provide the proper care? Can we assure the continuity of care? There are several components of healthcare supply that can benefit of the newest achievements in the field of health and biomedical informatics.

What has been done in this field? Which are the solutions? Who and how? These are the questions which look for an answer from our colleagues who were invited to, or sent their opinions to be presented at the 9th EFMI Special Topic Conference, Antalya, 12-15 November 2009, organized jointly with the TurkMIA National Conference on Medical and Health Informatics.

The place was very well chosen - Antalya area is famous as a wonderful touristic spot on European maps, and Turkey, as a full member of the European Federation of Medical Informatics and a candidate country for EU has made important steps to align to European standards in the field.

Let's resume the idea that the development in one area is closely related, bidirectionally, to the progress in all neighboring areas (and not only them!). This is visible also in the contents of our conference. It was not easy to classify all the papers; some papers covered general areas, with applicability in several directions.

Traditionally, for the Special Topic Conferences, two or three EFMI Working Groups, the closest to the conference topic, are invited to organize special sessions. For this edition the invited WGs were: IDR - Health Informatics for Disabled and Rehabilitation, EHR - Electronic Health Record and PPD - Personal Portable Devices. Besides the three sessions organized by them, we organized other three sessions with selected submitted papers: Telehealth, Cross-Border Health Information Transfer and Inter-Regional Co-operation.

All papers have been peer reviewed and we thank the reviewers for their work and the sponsors for their support. We hope that all the participants at the STC 2009 will find here valuable information and will contribute to further development of Health and Biomedical Informatics in Europe - the major target of EFMI.

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From Patient-Initiated Exchange (PIX) to Traveler's Electronic Health Record Template (TrEHRT)

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Extended Abstract

We are facing a world with fast-paced technological evolution as well as accelerated aging population. Today's travelers often carry several electronic devises personally. Among these devises, mobile phones and/or smart phones have to be the most popular item no matter the nature of the trip. Ironically, there are other things more travelers start to bring to their travel like their medical conditions and medications. We envision that a portable electronic personal health summary that stores an essential data set of health information in a mobile phone will be a useful tool for travelers nowadays. It provides convenient access to their own medical record any time, anywhere. Therefore an international collaborative project TET/ TrEHRT (Traveler's Electronic Health Record Template) was initiated three years ago [*] by delegates from APAMI (Asia Pacific Association for Medical Informatics), EFMI (European Federation on Medical Informatics) and AMIA (American Medical Informatics Association) and later supported by IMIA (International Medical Informatics Association).

       The purpose of the TrEHRT is to create an interoperable electronic health summary template specifically for travelers. TrEHRT can benefit travelers with planned or unplanned health care needs during travel. A TrEHRT is a standard XML format file that includes an essential medical information crucial to travelers' own health care needs and may also be used for public health data gathering during epidemic. It contains basic demographic data, current medical conditions, present & recent medication history, allergy history as well as recent travel history…etc. Coding system for items such as diagnosis, medications and lab tests will be used as much as possible and multi-lingual support for major international languages should be available with certain translational capability.

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Building something like TrEHRT and making it available to most travelers around the world is not a trivial job. Even with the software pieces implemented, there is still problem with availability of the original medical record data. Although it is always possible for a traveler to enter her/his own medical data, it would much more convenient and much less error-prone if this data can be downloaded directly from the source of of the medical record, i.e., from the EHR of health care organizations (HCOs) that served this traveler before she/he commenced the trip. Unfortunately, it has been a well known problem that HCOs do not share their EHR, not with one another and, sometimes, not with the patient her/himself.

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[*] The TrEHRT Project was initiated within the Trilateral Convention (2007) signed by the presidents of the following organizations:
- George Mihalas- EFMI – European Federation for Medical Informatics
- Don Detmer – AMIA – American Medical Informatics Association
- Yu-Chuan Jack Li – APAMI – Asia-Pacific Association of Medical Informatics
and supported by:
- Reinhold Haux – IMIA – International Medical Informatics Association.

INFORMATICS FOR THE DISABLED AND REHABILITATION

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The Application of Information and other Technologies to Improve the Mobility of Blind, Visually Impaired and Deafblind People

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Abstract: This paper considers the application of information and other technologies to improving the mobility of blind, visually impaired and deafblind people. A number of proposals for new technical solutions are presented. These proposals originated out of research carried out by the author in seven different countries. The research methodology is presented and some preliminary results with particular reference to the factors that affect mobility are discussed, while noting that the formal analysis of the research has not yet been completed. The paper is introduced by a brief discussion of the classification of different travel aids.

Keywords: Travel aids, environmental information, information technology, end-users, interviews.

1. Introduction

The ability to travel (independently) is very important for participation in all aspects of modern life, including work and leisure activities. However, much of the information provided to support travel is visual, putting blind and visually impaired people at a disadvantage. Therefore, many blind or visually impaired people need some sort of aid in order to travel safely and in comfort. Although many of them are confident and experienced 'travellers', significant numbers of blind and visually impaired people feel unable to go out without a guide, implying the existence of significant barriers to independent travel. Blind and visually impaired people who also have some degree of hearing or other impairment generally experience even greater barriers to independent travel. Although not all these barriers can be overcome through the application of information and other technologies, these technologies do have a potentially important role

However, despite the potential of modern technology, the most popular aids are still the long cane and the guide dog. A large number of high tech travel aids have been developed, but very few are actually used by significant numbers of blind and visually impaired people. There is also still only limited understanding of how blind and visually impaired people use travel aids and environmental and other information to support independent travel.

There are a number of different ways of classifying mobility devices [1, 2], with several devices in most categories:

- Primary and secondary aids based respectively on whether the device can be used on its own or is used to supplement another 'primary' device.
- Device functionality, including obstacle avoidance, object finding, environmental accessibility, route following and providing information on facilities and landmarks. Some devices are multifunctional.
- The technology used to obtain the environmental information, including ultra-sonic, infrared, camera, satellite technology (currently generally global positioning system (GPS)) and mobile phone technology.
- The way information is provided to the user: tactile (generally by vibration), speech, sounds of varying loudness and pitch, and musical tones.
- How the device is carried, including attached or integrated into a cane, otherwise in the hand, in a pocket, in a backpack

2. Empirical Research by the Author

2.1 Methodology

Research was carried out by the author to determine the mobility and travel experiences of blind and visually impaired people, the problems and barriers encountered and the need for new travel aids and more accessible environments, as well as their spatial knowledge and means of learning new routes [3]. Data was obtained from semi-structured interviews with blind, visually impaired and deafblind people, technical visits to observe recently developed technologies and devices and those still under development, observation of mobility and orientation training and interviews with trainers and teachers. In the interviews respondents were treated as experts on their own experiences and requirements. A semi-structured approach was chosen, since this both provides enough structure to ensure that all the topics of interest are covered and has sufficient flexibility to enable issues raised by the interviewee to be explored and the balance of time spent on different topics to be varied. In addition, the semi-structured approach increases the likelihood of the interviewee discussing their own experiences, opinions and preferences rather than reflecting back those of the researcher.

Interviewees were initially asked to introduce themselves and to talk about their lives, activities, interests, visual impairment and the role of travel in their lives. Topics arising from this introduction were then explored in more detail. Other topics covered included:

- The use of travel aids
- Orientation and mobility training
- Public transport
- Buildings and urban environments
- Description of a route and a familiar room or other space
- Spatial representations
- Learning new routes
- Landmarks used and any changes in them due to changes in vision/visual impairment.
- Any changes over time in their experiences of getting around
- Attitudes and support from family, friends and the local community
- Education and employment
- Interests.

The last two items were included in order to have a better understanding of the experiences, background and context of the interviewees, as well as the factors that could affect successful independent travel. For instance, education in a special or mainstream school may effect the opportunities for mobility training at an early age and

participation in some games and sports can lead to the development of spatial skills and sport can also develop movement skills.

Contacts for interviews were obtained through organisations of blind, visually impaired and deafblind people, as well as via researchers working with them. All interviews took place in the language of the interviewee. Interpreters were not used other than for a small number of interviews with deafblind people using contact or visual sign language. Interviews took place in the office of an organisation, another convenient location for the interviewee or by telephone and had very varying lengths of between 30 minutes and three and a half hours, depending on a number of factors, including the issues that arose and the amount of time the interviewee had available. To date 38 interviews have taken place in France, 66 in Poland, 33 in the UK with further interviews planned, 91 in Italy, 47 in Spain and eight in Tunisia, as well as a technical visit to the Czech Republic. The people interviewed are very varied with regard to age, education, occupation, type of visual impairment and age of onset and degree of independent mobility.

The sample has a good gender balance, and includes people from ethnic minorities, as well as people with both hearing and visual impairments and people with both visual and physical impairments, including two deafblind wheelchair users.

2.2 Preliminary Observations: Factors that Affect Successful Mobility

Since the formal analysis of the interviews has not yet taken place, the following discussion is preliminary and may be modified later. In addition statistics are not yet available and therefore imprecise terminology, such as 'a high percentage' or 'over half' will be used. However, the preliminary examination of the research indicates that the following factors are important in improving the mobility of blind and visually impaired people. These factors will first be listed and then briefly discussed.

- Access to information in audio and/or tactile format. In the case of visually impaired people accessible visual information is also important.
- Uncluttered urban environments, particularly pavements which are clear of obstacles.
- Good public transport, including in rural areas.
- Access to mobility training from an early age.
- The opportunity and encouragement to explore the (local) environment.
- Positive attitudes by other people and encouragement to be independent.
- Self image and motivation.

  Access to information, including the following, is crucial for successful travel:
- Public transport routes, times and prices as well as the information required to locate bus and tram stops and railway and underground stations.
- The locations of a range of facilities, including public offices, leisure centres, sports facilities, health centres and workplaces.
- Routes from the home and workplace to a number of different locations and between these locations.
- Obstacles and other dangers to be avoided.
- Street names.
- The location of pedestrian crossings.
- Warning signs of potential danger.

Without information of this type, travellers have little chance of reaching a desired destination and could suffer injury, for instance through falls or stepping in front of fast moving vehicles. Much of this information is presented in a visual format or generally obtained through vision by sighted people. Therefore, visually impaired and blind people

required equivalent information to be presented to them in a format they can use, whether tactile, audio or an accessible visual format for visually impaired people.

Urban environments: A high proportion of the interviewees mentioned problems due to cluttered urban environments, street furniture and vehicles (cars, motorbikes and bicycles) parked on the pavements, as well as restaurant and cafe terraces. This presents an increasingly difficult and dangerous environment for blind and visually impaired people to navigate. In addition, while some of these obstacles, such as litter bins and roads signs are in fixed though difficult to navigate positions, others, such as parked cars, change their position from day to day. This makes it difficult for blind and visually impaired people to use prior knowledge to anticipate and help them avoid obstacles. There is therefore a need to clear urban environments, particularly pavements, of clutter. This should include moving road signs, poles, waste paper baskets and other street furniture to the side of the pavement, heavily fining cars for parking on the pavement and improved and more frequent cycle parking to discourage parking on the pavement.

Public transport: Blind and visually impaired people require public transport in order to be able to travel more than a few kilometres. This is particularly important for people who live a distance from friends, family, sources of employment and facilities. When transport is not available and there is nothing to do within walking distance, there is little motivation to go out and people can easily become trapped in the home or totally dependent on the availability of a sighted person to go anywhere.

Formal orientation and mobility training by qualified instructors has only become available in most countries relatively recently [4]. Preliminary analysis of the research indicates that younger people have generally had some formal orientation and mobility training, with details depending on a number of factors, including what is available locally. Older people who were blind from an early age generally have not had training in their youth, but some of them have had later, generally fairly brief, formal training. Many of the older respondents have had training in (residential) schools for the blind on a more informal basis, as well as some opportunities to learn skills from older students. Interviews with orientation and mobility instructors indicate an increasing tendency to introduce training and the use of small canes or 'pre-canes' to very young children in the form of play. Some instructors provide training to people with significant differences in day and night vision, for instance those with retinitis pigmentosa, both during daylight and after dark. Since my research indicates that many people in this category do not go out at night, this is clearly important. There are also some indications that people who have had orientation and mobility training and started to use a long cane at a young age are less likely to experience shame and embarrassment about using a long cane. These negative feelings were a problem for many of my respondents, even those whose active involvement in organisations for blind people could have been expected to lead them to have more positive attitudes.

In some cases, this led to respondents only going out with a sighted guide and, in others, more collisions and less safe mobility than would have occurred with a cane. There was also some evidence that the respondents with the best and most confident mobility were often those who had had early opportunities and encouragement to explore the environment or go out on their own. To do this safely early orientation and mobility training is frequently required. It seems likely that exploration of the environment from an early age will frequently improve confidence and spatial understanding, with associated improvements in wayfinding and orientation. This will then generally lead to good independent mobility.

Attitudes: Blind and visually impaired people, just as sighted people, are sensitive to and influenced by the attitudes and expectations of other people. Therefore, negative or inappropriate attitudes can present a barrier to independent travel. In particular, parents, spouses and other family members are often overprotective. While this overprotection arises from good intentions and love and concern about the blind or visually impaired child or other family member, its impact can be suffocating and lead to virtual

imprisonment in the home or the person only going out accompanied. In my research I encountered examples of young blind people who had to move to a fairly distant city in order to escape parental overprotection and gain independence and older blind people who were only able to go out on their own after the death of an overprotective close family member. Equally, expectations that blind and visually impaired people should only go about accompanied and have little to contribute to society act as barriers to independent travel, fulfilment of potential and participation in society, to the detriment of both the blind person and society as a whole. On the other hand, a change in thinking away from these negative views and low opinions to an acceptance of blind and visually impaired people as ordinary productive members of society would probably have a positive impact on their mobility and independence.

My research with both blind and visually impaired people and orientation and mobility instructors indicates the importance for independence of being able to ask for and receiving appropriate help. Therefore, the proposed change in attitudes should be accompanied by a willingness to offer assistance when required and the ability to recognise that blind and visually impaired people are entitled to determine for themselves when they do and do not wish assistance. In addition, assistance, particularly by family and friends, should be aimed at encouraging independence, rather than doing things for the blind or visually impaired person.

Self-image and self acceptance are equally important to the attitudes of other people in promoting independence and positive life experiences. However, there is frequently a relationship between self-image and the attitudes of other people, with negative attitudes by society to a particular social group frequently leading to a negative self-image. Thus acceptance of blind and visual impaired people and recognition of their ability to contribute to society are likely to promote a positive self-image and self acceptance by blind and visually impaired people. In the absence of this, a strong desire for independence and the willingness to persevere to overcome difficulties will be necessary to overcome low expectations by society, overprotectiveness and any shame or reluctance to use a long cane or other travel aids.

While information technology could be used to support information and awareness campaigns, it is in the area of access to information in a tactile and/or audio format that the introduction of new solutions based on information and other technologies is particularly relevant. Therefore, the remainder of the paper will focus on this subject.

3 Access to Information

Where possible, information should be made accessible in tactile, audio and high visibility formats. Tactile information is required for accessibility by deafblind people, whereas many blind and visually impaired people have a preference for audio information for, for example, street names. However, a few respondents had encountered and liked the use of Braille indications of street names on the poles of traffic lights. High visibility formats include large high contrast lettering at below eye level and the use of colour contrast stripes, which are most commonly yellow, to draw attention to, for instance, stairs and the edges of railway and underground platforms.

In order to carry out navigation and wayfinding functions it is necessary to locate either the user or a particular point in the environment. This has led to the development of two distinct approaches based on information technology, though in practice they have overlapping functionality:

- Satellite navigation, currently global positioning systems (GPS), which locate the user.
- Environmental information beacons, which locate a point in space.

GPS [5] uses the signal emitted by the 24 US military satellites in fixed orbits round the earth to identify locations. This signal is received by a small handheld GPS receiver

with an antenna, either as a stand-alone device or incorporated into a mobile phone or PDA. The distance to the satellites is calculated by measuring the time difference between sending a signal and receiving it back. Triangulation using the signals from three satellites can be used to calculate the location of the receiver anywhere on earth, using digital mapping software. Knowledge about this location can then be used to provide the user with information about a wide range of facilities, called points of interest, using digital mapping software.

An environmental information beacon contains a transponder with a stored message, a receiver and signal processing. In the case of an active device, the transponder constantly broadcasts the message in a format that is imperceptible to humans. The user's infrared, or radio frequency receiver or radio frequency identification device (RFID) reader then receives the message, decodes it and outputs it to the user, generally as a speech signal. In the case of a passive device, the stored signal is activated when a signal is transmitted by a user handheld device. A signal is then sent to this device or a loudspeaker situated close to the transponder, decoded and played, generally as a speech signal. In many cases the signal is directional and increases in strength as the user approaches the beacon, and thereby acts as a guide to the associated facility. The message generally identifies the facility and may also provide additional information about it. In the vicinity of the beacon, the user can receive other active signals, such as warnings about escalators or road works. They can also transmit a signal to activate other functions, such as audio indications at traffic lights or level crossing or send a request to the driver of a train approaching a station platform to open the doors when the train stops or for a shop assistant to come to that particular location to provide assistance.

Both GPS and environmental information beacons are examples of location based services [6] which use information and other technologies to provide information about a particular location. The difference in functionality of the two different technologies is largely a consequence of two factors:

• The fact that GPS generally have a digital mapping software and a central processing unit, whereas environmental information beacons do not.

• Differences in the information that can be related to a known user location and a known environmental location as the user moves.

Therefore, for instance, an environmental information beacon is able to accurately direct the user to the door of a particular facility, such as a shop or hospital. GPS cannot generally currently do this, as its accuracy is about five to 20 metres. However, the digital mapping software and central processing unit can be used together with knowledge of the user's current location to carry out a variety of navigation and information functions, which generally include the following:

• Simulation of a route in advance of a journey.

• A database of points of interest which can be searched. Additional points of interest can be added and shared with other users. Many blind travellers use this feature to determine when they are approaching their bus or train stop.

• Real time (audio) instructions to enable the user to follow a route to a particular destination, generally with some degree of customisation of the format of the information.

Environmental information beacons would be able to carry out these functions if provided with digital mapping software and a central processing unit which they currently lack. However, currently information beacons can be used to support navigation to a destination if laid out along a route with an appropriate distance between beacons. On the other hand information beacons can be used both inside and outside and are not particularly affected by climatic conditions, whereas GPS function best in wide open spaces and in climatic conditions without rain or high wind.

Users of GPS systems have greater control over the information provided, though installing a large number of points of interest would be time consuming. However, the costs of GPS for blind people are quite high. For instance, the Trekker Breeze is about 530 euros and the Trekker GPS 1250 euros, compared to 90-150 euros for several models of the Garmin and Tom Tom GPS for sighted users. Installation of information beacons is generally dependent on local government and/or private organisations and they currently have relatively limited distribution, mainly confined to a few countries, including USA, Czech Republic, UK and France. Information beacon receivers are generally considerably simpler than GPS ones, though this is largely due to the fact that information beacons generally provide fewer and less complex functions than GPS. However, they have the disadvantage of each system using a different type of receiver, giving an urgent need for standardisation to enable blind travellers to access this type of information wherever it is available**.** This is particularly important when the receivers are also used to activate audio traffic light signals. Currently both environmental beacons and GPS provide audio output, but could, in principle, also provide Braille or other tactile output.

In addition to GPS which locate the user and environmental information beacons which locate a point in space, hybrid systems are now being developed, which combine a GPS to locate the user and a beacon to locate a point in space. Existing developments are still at the prototype or trial installation stage. However, this approach has considerable potential, as long as care is used in the design to ensure that accessing this wide functionality does not require a complicated user interface.

4. Proposals for New Technical Solutions

One of the aims of the research was to obtain ideas for new technical solutions to support and facilitate travel. A number of ideas resulted from the research, some suggested directly by respondents and others resulting from my reflections on their ideas or the technical visits. A number of the proposals for new technical solutions which use information technology arising from the research will be listed here and then discussed.

They include the following:

- A lightweight portable tactile interface that is compatible with and can be integrated into a large number of existing devices
- A receiver/reader that can access all or the majority of existing environmental information beacons plus standards for the development of new systems for compatibility with this device.
- A combined environmental information system and GPS
- A virtual or robotic guide
- A three dimensional virtual or real model of the local environment
- A route advice system
- An obstacle avoidance device on a mobile phone
- Interactive talking and Braille foreign language phrase books, dictionaries and translation devices.

4.1 Lightweight Portable Tactile Interface

A lightweight portable tactile interface could be used both to make travel support technologies accessible to deafblind people and to provide information to blind peole that does not interfere with accessing environmental sounds. The range of different communication strategies, including speech, sign language, contact sign language, deafblind manual alphabets, Tadoma and finger Braille [7] make it very difficult develop a unique interface which works for all deafblind people.

A prototype device to support communication using finger Braille has been developed in Japan [7] and prototype devices have also been developed to support communication between a deafblind person using the UK [8, 9] or US [10, 11] deafblind manual alphabets and a hearing and sighted person. A device supporting communication between a hearing and sighted person and a deafblind person using the US manual alphabet has been commercialised, but is unfortunately expensive [12, 13]. The Braille communication device called the Deaf-Blind Communicator has recently been developed by Humanware [14], but is unfortunately very expensive. It comprises two portable components: a BrailleNote mPower and a mobile phone with visual display and qwerty keyboard. The deafblind person inputs Braille messages to the BrailleNote and they are output on the phone screen. The hearing and sighted person enters messages on the phone qwerty keyboard and they are output to the BrailleNote. The device can be used for face-to-face conversation, to send text messages and to make text phone calls. It also provides internet access and email.

4.2 Universal Receiver/Reader for Environmental Information Beacons

A number of different environmental information beacons have been developed with a range of different functionalities. However, other than the joint receiver for the RNIB REACT and InfraVoice systems [15], there has been no consideration of the need for users to access different systems of environmental information beacons using a single receiver. This would enable users to access information from environmental information beacons when they travel. It would also enable information beacons with different functionalities to be used to complement each other, as is already the case with the REACT and InfraVoice Systems, where the InfraVoice system supports finding a particular location or choice of routes at a junction and the REACT system provides information about a particularly facility [15]. While there would be in benefits in the design of an optimised system of environmental information beacons to become the default standard for all future installations, this is unlikely to happen: researchers and developers will continue to promote their own systems and there has already been a certain amount or even considerable investment in some of these systems. Existing systems, some of which have additional transport functions, include Remote Infrared Audible Signs (Talking Signs), RNIB React, InfraVoice, the Czech system of information beacons, Actitam, Blind Orientation System, Easy Walker and Noppa Personal Navigation System.

Therefore there is a need for the development of standards to ensure that the full functionality of any future systems of environmental information beacons can be accessed using the universal receiver/reader, as well as with the system specific receiver or reader. While development of the universal receiver and the full design specifications will require involvement of end-users, the following design principles can be stated:

- Inclusion of infrared and radio frequency receivers and an RFID reader, as well as possibly also a GPS receiver.
- Light weight and pocket sized, with the option to wear round the neck.
- Easy and intuitive to use.
- A relatively small number of controls, which are easy to distinguish using either vision or touch.

4.3 Combined Information System and GPS

As discussed in Section 3, both GPS and environmental information beacons aim to provide information which can be used to support navigation and wayfinding. However, while both technical approaches provide useful functionality, they also have disadvantages. While a number of systems that combine the two approaches are under

development, for instance the Sesamonet system in Italy [16], the Noppa system in Finland [17, 18] and the *mTransVIP* system in Poland [19], they do not have the full range of possible and desirable functionality. In addition, the different systems have not been designed so that they can all be accessed by one receiver. However, while improving functionality, it is important that the device is easy and intuitive to use. This will probably require two levels of functions, so that the more complicated functions provided for experienced users do not complicate access to the basic functions.

Design principles should include the following:

- A lightweight, easily portable receiver, including a central processing unit, GPS, infrared and radio frequency receivers and an RFID reader. This receiver should have a combination of speech input and a small number of push buttons and be designed to be easy and intuitive to use.
- Choice of speech/audio and tactile output or, alternatively two versions, with speech tactile output respectively. There should be a choice of receiving audio output on the integrated loudspeaker or on earpiece with ear hanger, designed to reduce interference with environmental noise [15].
- Compatibility with existing systems of environmental information beacons.
- A wide range of navigation, location information, alerting and transport functions. The different functions should be easy to access, with the most frequently used functions available through a one to three word speech command. The choice of what functions to include should involve detailed examination of existing GPS, environmental information beacons and hybrid systems, as well as consultation with end users.

4.4 Robotic or Virtual Guide

Guide dogs can give users a greater sense of security and allow them to travel safely with less need for concentration and less fatigue, as well as to walk faster than long cane users. However, they have the disadvantage of requiring considerable care and attention and some potential users are afraid of or do not like dogs. Since guide dogs are living beings, they cannot just be left in the corner and ignored like a long cane. The aim of a virtual or robotic guide is a device with the advantages, but not the disadvantages of a guide dog [20], as well as providing additional functionality, such as reading road signs.

From my research some blind and visually impaired people, who are uncomfortable, embarrassed or ashamed of using a long cane, find a guide dog acceptable and consider that people react differently to a blind person with a guide dog and a cane. Research would be required to determine whether a robotic guide would be equally acceptable to this group of people.

The robotic guide would be designed to function analogously to a real guide and choose a path which avoids obstacles. The user would follow the movement of the robotic guide, analogously to following a real guide. Development of a robotic guide would require the following modules:

- Obstacle detection: this would probably use digital (video) camera technology. Incorporating the camera into the top or head of the robotic guide would facilitate the detection of high-up or overhanging obstacles.
- Calculation of a clear path of sufficient width for both the user and robotic guide to pass without making contact with obstacles or leaving the pavement.
- Independent movement of the robotic guide
- Navigation, wayfinding and object identification.

In the current state of technological development, designing a robotic guide which is able to detect obstacles and follow a clear path is feasible. A number of different types of robotic devices have also been designed which give powered movement. Although nothing like a large moving robotic guide has been developed, there are a number of

different mobile robots, including robots that play soccer and have fast and flexible movement [21, 22], as well as a small robotic dog [23] that is able to dance. A prototype moving robotic navigation and obstacle avoidance device, called the Robotic Guide [24], has been developed. It comprises high-tech computer parts on a mobile base and is able to read radio frequency identification (RFID) tags which localise the robot. The user selects a target location in for instance a store or an airport, and the robot provides navigation information to the user. At the destination the robot is able to help the user locate particular products on the shelf.

In principle it would be possible to give the robotic guide a wide range of navigation, wayfinding and object identification functions. This would probably require a combination of technologies, including GPS module, infrared transmitter and reader, Bluetooth module, barcode reader and an RFID tag reader. Satisfactory performance and reasonable appearance are both probably going to require a fairly large guide. While the option of folding or otherwise reducing the size of the robotic guide could be investigated, this would need to be easy to carry out by touch, fairly fast and the unfolded or otherwise reassembled guide would need to be both very stable and rigid.

A possible solution to this problem would be the use of a virtual guide. This would have the same functionality as a real guide dog or robotic guide, but comprise a computer programme on a portable computing device and provide haptic feedback to users of the clear path to follow. The system would comprise four modules as in the case of a robotic guide. However, in this case the digital (video) camera would have to be held by the user or attached to them in a way that ensured that the image was not disturbed by the user's movements and the appearance of the user with the camera was acceptable. Attaching the camera to the user would have the advantage of leaving their hands free. The calculation of a clear path would be similar to in the robot case. However, rather than allowing for the robotic guide, the algorithm would need to allow for a certain amount of free space on other side of the user to take account of delays in responding to the haptic signal or a lack of precision. Experimentation with end-users would be required to determine the amount of free space required.

The greatest difference would be in the third module. Instead of a module to support independent movement by the robotic guide, a module to provide haptic feedback to the end-user would be required. This is also the area where proof or feasibility of concept research is most essential before further development is carried out to determine whether and to what extent users are able to follow a clear path using only the information provided by haptic feedback. Additionally, research will be required on the best means to provide this haptic feedback to the end-user and the relationship between the haptic feedback and the free path direction of movement.

4.5 Virtual or Real 3-Dimensional Model with a Telephone Help-line

A telephone help line for blind and visually impaired people in combination with information relayed from a camera is already being operated by the Czech Organisation of Blind People Sons [25] and a Polish prototype system, called MicroLook, is under development [26]. The Czech service is able to use the information provided by the camera to direct a blind person round road works or when they become disoriented and provide information on a range of facilities and services. However, it is small scale, with only two operators. This raises the question of how a larger scale service of this type could best be funded. User interaction with the help line as well as their ability to move in difficult surroundings without requiring the assistance of the help line could be improved by the provision of three dimensional tactile information about the local environment.

Possible options for doing this include a three dimensional real model or virtual model with haptic feedback of the local environment. This could be used to provide users with a three dimensional 'snapshot' of the location at the current time. Since the

user would explore the model using touch, the model would need to avoid excessive detail and too high a number of different features, which would make it unreadable.

In the case of a virtual model, information from one or more digital cameras would be used to generate a three dimensional computer model of the local environment on a PDA or future generation mobile phone with high computing capacity. A number of mini motors would then generate a pattern of forces corresponding to this virtual model. The user would explore the pattern of forces corresponding to the virtual model using haptic gloves on both hands which would enable them to touch, enclose and follow the contours of the virtual model, analogously to exploring a real object.

With regards to realisation, it is clearly much easier to regularly update a computer program which generates a virtual model and provides haptic feedback than a 'real' three dimensional model. However, in the case of a virtual system, in addition to programming, it would be necessary to develop a whole hand haptic interface, since current haptic interfaces are based on point interaction. Research will also be required to determine whether interaction with the virtual model provides users with sufficient information to understand their real environment. In the case of a real model considerable research will be required to determine appropriate materials, which are sufficiently plastic to allow the model to be regularly and speedily updated but which are structurally stable, can provide sufficient granularity of detail and result in models which are easy to explore and interpret via touch.

Portability will clearly be an important factor in the design of the system and it may be feasible for the real model to be collapsed in some way when not in use to be put in a pocket. There are tradeoffs between size of the model and the extent of the local environment that can be shown, but also restrictions on the volume that can easily be explored with two hands.

4.6 Route Advice System

One of the main difficulties encountered by blind and visually impaired people when travelling is obtaining information on the location and times of public transport. In addition, they frequently also experience difficulties in finding the appropriate platform or stop. One suggested solution is a talking (and tactile) route advice system to be provided initially in underground, bus and train stations and eventually also at bus and tram stops.

The system would tell users how to reach a particular destination which could be input as a street address, public building or facility or public transport stop or station. The information provided would include the bus, train and/or tram lines to take and where to change, as well as clear route descriptions in simple language of how to find both the initial stop or platform and any intermediate stops or platforms at which the user need to change public transport vehicle or mode. There are currently on-line information systems, such as www.transportdirect.info and www.travelinescotland .com, which provide public transport information, including, in some cases, to a street address. However, these systems do not tell users how to reach the stop or station or the route to take when changing public transport vehicle or mode.

To be most effective the route information system should be combined with tactile guidelines and environmental information beacons with both speech and Braille output. The combined system would enable blind, visually impaired and deafblind people to travel more independently and to find their transport vehicle without requiring assistance or asking for information. However, the system should be used to supplement and complement existing assistance systems at railway and other stations rather than replace them.

This should be part of a general principle of support to disabled people being available in the form of both technical aids and human assistance, with users able to choose which option best meets their needs in a given circumstance. In addition,

however well designed an aid is, it should not be assumed that all potential users will be able to use it or that it will meet all their requirements in all circumstances. In particular, many blind and visually impaired travellers may prefer to obtain assistance rather than use possibly unfamiliar technical aids in order to find their way in busy and unfamiliar railway stations.

4.7 Obstacle Avoidance Device on a Mobile Phone

My interviews indicate that a number of blind and visually impaired people who could benefit from using a long cane are either delaying using a cane or do not use one at all due to feelings of embarrassment and lack of acceptance of their visual impairment. Sometimes this is the sole reason and sometimes there are also other factors. Due to the growing strength of the disabled people's movement, anti-discrimination legislation and increasing awareness of disabled people, attitudes to disabled people in many countries are changing. While this change is by no means complete and it has not yet reached many parts of the world, as it strengths and spreads it will have a positive impact on the self-image and self-acceptance of disabled people, including blind and visually impaired people. In addition both individual and group support should be provided to help blind and other disabled people improve their self-image.

However, it is likely that in the short term many blind and visually impaired people will continue to find use of a long cane unacceptable. One solution would be the development of obstacle avoidance software which can be used on a mobile phone. Since most mobile phones now include a camera, but not infrared or ultrasonic sensors or a laser, this would indicate the use of digital camera technology for obstacle detection. It is possible that in some cases the increased confidence resulting from using obstacle avoidance functions incorporated into a mobile phone would lead to a significant improvement in the user's confidence and independence.

Ideally, the device should act as a primary mobility device i.e. provide sufficient information to the user on obstacle locations to enable obstacle avoidance and safe mobility without the need for a supplementary device. However, a device of this type would lead to improved safety and mobility compared to the current situation of no device user even if this did not prove feasible. Existing pocket-size devices include the Tom Pouce and Télétact [27] and mini guide [28] and are designed to be used in conjunction with a long cane. While the mini guide is easy to use, the Tom Pouce and Télétact are aimed at blind and visually impaired people with good mobility and orientation skills and require training. Since the user group for the proposed device are unlikely to seek training, it should be very easy and intuitive to use.

4.8 Interactive Foreign Language Phrase Books, Dictionaries and Translation Devices

Lack of knowledge of the local language makes travel more difficult for all travellers. However, it poses particular problems for blind and visually impaired people, since for them asking for information or help from passers-by, public transport personnel and shopkeepers amongst others, is an essential strategy for independent travel. In addition, information from, for instance, street signs is not available to them in an accessible form. There is therefore a need for interactive electronic talking and Braille foreign language resources, including phrase books, dictionaries and translation devices, with correct natural sounding pronunciation in both languages. Thus the materials would support travel abroad by enabling blind and visually impaired people who do not know the local language to ask for help and information. Device design would need to consider how to best support users in understanding the answers they receive, which is frequently a more difficult problem than working out how to ask for information or help. While a number of talking dictionaries have been developed, they generally have the problem of using

the same voice synthesiser for both languages. There is also a lack of talking phrase books.

5. Conclusions

This paper has discussed proposals for new technical solutions to support independent travel for blind and visually impaired people. These proposals are introduced by a brief presentation of the methodology and some of the initial observations arising from empirical research carried out by the author in seven different countries. The aims of this research include increased understanding of the difficulties and barriers to independent travel encountered by blind and visually impaired people and the development of proposals for technical and other solutions to support independent travel.

Since the formal analysis has not yet been concluded, it is only possible to make preliminary observations, some of which may later be modified. Some of these preliminary observations are presented in the paper in the form of discussions of some of the factors which lead to improved mobility for blind and visually impaired people and how their needs for information can best be met, including a brief of comparison of GPS and audio information beacons.

I would be interested to hear from both researchers and blind and visually impaired people interested in collaborating on the further development of some of the proposals presented in this paper.

Acknowledgements

References

[1]   Hersh MA and Johnson MA. Mobility – an overview. In Hersh MA and Johnson MA, eds. *Assistive Technology for Visually Impaired and Blind People*, Springer Verlag, 978-1-84628-866-1, 2008, p. 167-208.
[2]   Hersh MA and Johnson MA. On modelling assistive technology systems part I: modelling framework. *Technology and Disability*, 2008, 20(3), 193-215.
[3]   Hersh MA. Designing assistive technology to support independent travel for blind and visually impaired people *CVHI '09*, Wrocław, 2009.
[4]   Neustadt N and LaGrow SJ. The development of the profession of orientation and mobility around the world. In: Blasch BB ,Wiener WR and Welsch RL. F*oundations of Orientation and Mobility*, American Foundation for the Blind, New York, 1997.
[5]   May M and LaPierre C (2008c). Accessible global positioning system (GPS) and related orientation technologies. In: M.A. Hersh MA and M.A. Johnson MA, eds. *Assistive Technology for Visually Impaired and Blind People*, Springer Verlag, 978-1-84628-866-1, 2008, p. 251-288.
[6]   Steiniger S, Neun M and Edwardes A. Foundations of Location Based Services, Lesson 1, CartouCHe, *Lecture Notes on LBS*, V. 1.0, undated.
[7]   Sakai T. Toward barrier-free broadcasting, NHK (Japan Broadcasting Corporation), 2001, http://www.nhk.or.jp/strl/publica/bt/en/re0006.html, accessed 2006.
[8]   Hersh MA and Worrall K. Design issues in the development of communication devices for deafblind people, *IEEE Symposium on Assistive Technology*, Glasgow, Scotland, 2003.
[9]   Hersh MA, Worrall K and Johnson MA. Survey of AT for deafblind people: state of the art and new developments, *AAATE*, Dublin, Ireland, 2003.

[10] Jaffe DL. Evolution of mechanical fingerspelling hands for people who are deaf-blind, clinical report, *Journal of Rehabilitation Research and Development,* 1994, 31(3), 236-244.

[11] Jaffe DL, Schwandt DF and Anderson JH. Technology transfer of the Ralph fingerspelling hand, in *Conf. Intellectual Property in the VA: Changes, Challenges, and Collaborations*, 2001.

[12] Kramer J. Communication system for deaf, deaf-blind and non-vocal individuals using instrumented gloves, U.S. Patent 5,047,952, Virtual Technologies, 1991.

[13] Kramer J and Leifer L. The talking glove: an expressive and receptive verbal communication aid for the deaf, deaf-blind and nonvocal, *SIGCAPH Newsletter*, 1988, 39, 12-16.

[14] http://www.humanware.com/en-united_kingdom/products/blindness/deafblind_communicator/_details /id_118/deafblind_communicator.html, accessed 1.10.09.

[15] Whitney G, Keith S and Wilson J. The production and evaluation of ajoint receiver for the RNIB REACT and InfraVoice speaking signs beacons, Middlesex University, http://www.cs.mdx.ac.uk/research/idc/papers/IDC-TR-2004-003.pdf, 2004, accessed 15.9.09.

[16] SesamoNet Secure and safe mobility network, ec.europa.eu/dgs/jrc/downloads/jrc_sesamonet_flyer_en.pdf, undated, accessed 10.9.09

[17] Koskinen S and Virtanen A. Navigation system for the visually impaired based on an information server concept, *Mobile Venue ´04*, Athens, 2004.

[18] Virtanen A and Koskinen S. Personal navigation and information system for users of public transport, http://virtual.vtt.fi/virtual/noppa/noppaeng.htm, undated, accessed 9.9.09.

[19] Jelonek J and Erdmann M. MTRANSVIP – the system facilitating visually impaired people an unassisted use of urban traffic, *CVHI '09*, Wrocław, Poland, 2009.

[20] Whitmarsh, L. (2005). The benefits of guide dog ownership, *Vis. Impairment Res*, vol. 7, pp. 27-42.

[21] Kim, D-H and Kim J-H. A real-time limit-cycle navigation method for fast mobile robots and its application to robot soccer. *Robotics and Autonomous Systems*, 2003, 42(1), 17-30.

[22] Ogino, M,Katoh Y, Aono M, Asada M and Hosoda K. (2004). Reinforcement learning of humanoid rhythmic walking parameters based on visual information *Advanced Robotics*, 2004, 18(7), 677–697.

[23] Kopaczek P. private communication, 2004.

[24] Robot guide dog picks up where man's best friend leaves off, Newswise, http://www.newswise.com/articles/view/501688, 2005, accessed 24.9.09.

[25] Bresnicky B. Private communication, 2009.

[26] Kulczak L and Pasterny H. Micro Look: travel information system for blind people, presented at *CVHI '09*, Wrocław, Poland, 2009.

[27] Farcy R and Damaschini R. Guidance - Assist systems for the blind. *Proc. of the EBIOS* Amsterdam. 2000.

[28] The miniguide ultrasonic mobility aid, http://www.gdp-research.com.au/minig_1.htm#DESCR_A, undated, accessed 30.9.09.

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Retrospective Altruism and TransientCooperation in Accessibility Mapping

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Abstract: A central agency attempting to collect detailed accessibility information for users with different and constantly evolving needs and preferences faces a practically insurmountable challenge. Inspired by the social web revolution, the OurWay concept of a collaborative route planner was created a few years ago. Its main contribution is to let users share subjective opinions about accessibility by rating segments of routes suggested by the system. It is now time to review the concept, and draw on different fields of research to highlight challenges, experiences and outlook for this approach to harvesting accessibility information. The concept seems feasible, although it works not because users engage in active cooperation and with the explicit desire to help each other, rather it works by producing feedback as a *by-product* of navigation. When faced with an obstacle, users provide feedback to get an alternative route, and this accumulated feedback is what helps provide improved routes to subsequent users. I introduce two terms, *Retrospective Altruism* (RA) and *Transient Cooperation* (TC), to further illustrate the type of cooperation we observed when studying OurWay. The contribution of this paper is three-fold: 1) A presentation of what seems to be a viable concept for accessibility mapping, 2) our preliminary experiences with use of the system, including RA and TC, and 3) a brief survey of other fields experiencing related types of challenges with regard to trust and credibility with user generated content.

1. Introduction

Collecting huge amounts of detailed, subjective information is nearly impossible without involving the end user. Base map data from big vendors is primarily targeted towards car usage, and there is little or no focus on other user groups with different needs, such as bicyclists, baby-strolling parents or people in wheelchairs or visually impaired users. The more closely one looks at the needs and preferences of individuals, the more one realizes that one size does not necessarily fit all, even within (falsely) presumed homogeneous groups, e.g. wheelchair users. In fact, this might also be true for car drivers, although the rules and regulations governing roads and the car as an proxy to the environment helps a bit. Consider being an avid bird watcher or to have an intrinsic fear of tunnels. Your car navigator won't really help you here, despite route alternatives such as "scenic routes" and "shortest time".

And consider for a moment the humongous task of collecting all the required information to cater for bespoke routes based on individual needs and preferences. It is one thing to collect data for "normal" car navigation (and it is financially viable, too), it is something completely different to collect information according to an open-ended, ever-changing and subjective specification.

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Accessibility information is detailed and personal, not a general purpose, objective set of measurements. Initiatives to standardize types of accessibility measurement are well-meant, however at some detail the system is bound to break down as a consequence of the vast amount of information to be harvested by selected and trained members of the community, and the attempt to fit this information into rigid and ontology-based schemes.

Traditionally, accessibility information has been provided by central authorities, e.g. interest organizations such as the Norwegian Association of Disabled (Norges Handicapforbund).

They have been the trusted source of (amongst many other things) accessibility information, and have run a number of projects to collect and disseminate this information to its users. Interestingly, they often (if not always) rely on selected members of their community to collect and verify information on the local and specialized level.

The OurWay concept tries to solve parts of this dilemma by involving end users as central contributors of information. Crowd sourcing has its challenges, perhaps most noticeably when it comes to trust and credibility. At the very least, this is often the main concern of the authorities that once had a monopoly on collecting and disseminating information. The main problem though, might not be that information is created at the edges of the network, by the end users. Although this requires thoughtful consideration when reading and applying acquired information, this is not something unique to user generated content. As Douglas Adams so adequately puts it in his 1999 essay *How to Stop Worrying and Learn to Love the Internet*:

> Working out the social politics of who you can trust and why is, quite literally, what a very large part of our brain has evolved to do. For some batty reason we turn off this natural skepticism when we see things in any medium which require a lot of work or resources to work in, or in which we can't easily answer back – like newspapers, television or granite. Hence "carved in stone". What should concern us is not that we can't take what we read on the internet on trust – of course you can't, it's just people talking – but that we ever got into the dangerous habit of believing what we read in the newspapers or saw on the TV – a mistake that no one who has met an actual journalist would ever make [1].

And while we can be fairly certain that basic map data from a national provider is reliable for everyday use, the same cannot be said e.g. for accessibility data only partially collected, outdated and stale. Not only because of the sheer amount of information to be collected, but also the temporal aspects of such information and the subjective nature of accessibility.

This introduction presents the motivation for user-driven accessibility mapping, and the reminder of this paper is laid out as follows: Section 2. reviews some related fields where user generated content is applied, and I point to similar challenges and remedies with regard to trust and credibility. The OurWay concept is reviewed in Section 3., and Section 4. reviews the understanding of cooperation, and places TC and RA in a theoretical context. Finally, Section 5. contains a brief discussions and suggests themes for future research on the OurWay concept.

2. Related fields of work

Five years after the first Web 2.0 conference held by O'Reilly Media and MediaLive, user contributed information is found everywhere. In the blogosphere, statusphere, discussion forums, encyclopedias, street maps and health information systems to name a

few. It is hardly surprising that all of these areas share some challenges, especially concerning trustworthiness and credibility of information.

The recurring theme is that the traditional model which alludes to credibility through authority is put to the test when users are involved as active, and in some cases, the main contributors to the information flow. Concerns about trust, credibility and sharing of information and experiences is of course not unique to health informatics (or any other discipline). Here's a brief look at two other fields and how they are discussing the same issue.

2.1. Geomatics

The OpenStreetMap[2] project was started by Steve Coast in 2004, motivated by the fact that the Ordnance Survey, Britain's national mapping agency, charged so much for their content that it prevented ordinary people and organizations to make creative use of it. Since then, more than 100.000 individuals have contributed to make an impressive worldwide geowiki [9]. Both the coverage and accuracy [3] and credibility [7] of Volunteered Geographic Information (VGI) [8] have been studied, and provide an interesting background for discussing related issues in the field of health informatics.

Flanagin [7] argues that local knowledge is best found, identified, and described by locals. This applies in an obvious way to accessibility information. The collaborative route planner is itself (at least when discussed in the context of use by disabled users) in the cross between geomatics and health informatics.

2.2. Collaborative writing

The most well-known collaborative undertaking on the web is probably Wikipedia. It has built-in features (watch lists, history pages, discussion pages etc) that allows for ad hoc peer review w and community engagement. A cornerstone of Wikipedia is the principle that all articles should be written from a neutral point of view (NPOV)[3].

However this is not necessarily a desired feature or goal for a collaborative accessibility mapping approach. Here, a multi-faceted, subjective view of the world is encouraged, and the challenges become how to identify, associate with and trust the providers of accessibility ratings that meets one's own needs.

When there is much controversy around a theme on Wikipedia, so called edit-wars can break out, whereby sections of text are rapidly changed from one version to another to reflect different points of view. At IBM, Viegás [17] has demonstrated tools and techniques for visualizing page edits over time (history flow), a concept that could also be applied to changes in accessibility ratings (or rather, opposing views among users in a group or between groups) in collaborative accessibility mapping.

Two current projects that aims to raise the public awareness about the trustworthiness of Wikipedia articles are WikiDashboard [16] and the WikiTrust [2] initiatives. Wiki- Dashboard provides an easy-to-navigate overview of article editors, number of edits, and history for each article and editor. In WikiTrust, each word in a Wikipedia article is color coded with respect to the trust value assigned to it, based on metrics that takes the authors computed reputation and the history of the text into account.

Finally, the work of Priedhorsky et al. on the impact of damage and types of damage in Wikipedia articles is worth mentioning [15]. It provides a thorough set of tools and metrics for understanding just how vulnerable Wikipedia articles are to erroneous edits, and on how rapidly most of the damage is corrected by the community.

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[2] http://openstreetmap.org/
[3] http://en.wikipedia.org/wiki/NPOV

In the field of Health Informatics, Moturu et al. outlines challenges of trust and credibility with the advent of health applications inspired by theWeb2.0 revolution [14]. The challenges and remedies outlined here are more specifically addressed within Health Informatics, however the underlying challenges are shared across many fields, including those mentioned above.

3. OurWay overview

3.1. The OurWay concept

The OurWay concept is simple. It consists of a route planning server containing the geographical network (roads, paths, corridors etc), and a routing algorithm (Weighted shortest path) which takes into account user supplied ratings on route segments according to accessibility. The OurWay concept differs from traditional accessibility mapping efforts in two important ways:

- End users create and share accessibility information with their peers instantly, and are not passive consumers of centrally provided information.
- The information collected is simply a subjective rating (good, uncomfortable or inaccessible), as opposed to a more rigorous and objective measurement approach based on ontologies.

In our experiments, we have used relatively homogeneous groups of people, although the concept includes ideas for multiple (self-identified) groups of people who share information with each others just by the very fact that they're members of the same group. We created a prototype implementation of the OurWay concept that runs on a mobile phone. The prototype presents the user with a map and the ability to ask for a route to take them from place A to place B. The suggested route is rendered on top of a base map. The user follows the route just as a car driver follows a route on a car navigation system.

By allowing end users to rate segments of the route (and request alternative routes based on these ratings), the system "learns" about obstacles and tries to avoid these in new route suggestions. It is key to keep this process as unobtrusive as possible, and in the earliest version of the prototype we used a five degree Likert scale for accessibility ranging from "impossible" to "excellent". We have since made it even simpler, by using a three degree Likert scale where the user can choose between *inaccessible, uncomfortable* and *good* when providing feedback to the system.

It is worth mentioning that the only time the user really *has* to provide feedback (if they decide to play by the "rules", i.e. choose to use the navigator) is when they encounter an absolute obstacle, say for instance when facing a staircase when using a wheelchair. To continue using the system, they must rate the route segment where the obstacle is found, and if required they can ask for an alternative route from their current location. In fact, the only predictable type of rating from the users is *inaccessible*, the use of uncomfortable is not used often (or consequently), and *good* is seldom if ever used.

I'm not arguing that the traditionally detailed and objective information is of no use, I'm simply pointing to the fact that collecting this level of detailed information is an extremely resource demanding endeavor, and one that is likely to have severe limitations with regards to coverage and update cycles. Indeed, the OurWay approach does not attempt to capture why something is accessible or not, this is left to the users and groups discretion. This is comparable to how tagging of images on Flickr or bookmarks on delicious is a free form of content meta-data, yet yields tremendous opportunities for individuals looking for pictures or links they have an interest in.

3.2. Feasibility

In our first round of OurWay experiments, we wanted to see if the concept itself seemed viable, and whether mobile internet and GPS technology had reached a maturity that made OurWay seem like a worth-wile approach. Our findings in this respect were positive, and we also found that the routes *converged* quickly, that is, relatively few ratings (and thus few users) were necessary for the system to provide obstacle-free route suggestions [11].

We later identified three possible usages that could benefit from the OurWay concept: *Route finding, Surveying and Accessibility verification* [10] . Route finding is the primary application of the concept, and forms the basis of our research so far. Using OurWay as a surveying tool, say in a campaign setting, would most likely produce different dynamics with regards to collaboration and motivation.

We have since looked at how users relate to the route planner and the way in which they provide feedback during use. An indoors experiment was conducted where users were to solve a set of pre-determined navigational tasks in our campus building. The users were video recorded and briefed after each task. Our findings made clear that feedback from users did not come primarily at instances when they wanted to actively share experiences with others, but rather as a *by-product* of using the navigator. Especially in the case of absolute obstacles, as in the example given above [12].

The by-product-of-use type of feedback is so prominent that it might be worthwhile replacing the three degree Likert scale with one button for the user to request an alternative route. Keeping in mind that this is mostly relevant for the end users, and not necessarily for the surveyors, campaign users or other user groups. I acknowledge that our studies so far have been limited in size, however this has allowed us to focus on detail and do in-depth interviews with participants that have provided us with insight which I present in the next section.

4. Cooperation

Through our studies we have looked at how the users relate to the tools and technology, and how they relate to each other. To describe this in a context, I want to start with a short introduction to important work on groups and cooperation. This is by no means an extensive evaluation of previous work, but it helps frame the discussion of how we interpret the usage patterns displayed by the participants in the OurWay studies. They are also mentioned because they promise to form a solid basis for understanding user actions in more full-scale deployments of the OurWay concept.

4.1. Communities of Practice

Coming from the work by social scientists to understand learning processes, the term *Communities of Practice* (CoP) refers to ways in which apprentices learn from taking part in a communities that share a common goal [18]. To quote Etienne Wenger, one of the originators of the term:

> Communities of practice are groups of people who share a concern or a passion for something they do and learn how to do it better as they interact regularly. [4]

Later, Lave and Wenger described situated learning in CoP's as Legitimate Peripheral Participation, LPP [13]. The main contribution of LPP is an understanding of

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[4] http://www.ewenger.com/theory/

how the learning process gradually turns an apprentice into an expert. Starting out with important although non-critical tasks, the apprentice is introduced to the Community of Practice.

Step by step, the importance of the tasks and the responsibility is increased, until the apprentice has acquired expert skills within the community.

There are several reasons why the OurWay end users (the route finders) cannot be considered a Community of Practice. Firstly, there is no established practice, or a pronounced community. In fact, there are no experts that can take on apprentices. How this would play out over time is difficult say, however what interests me is the type of invisible cooperation that takes place in our current tests of the concept. That said, looking at the type of usage we envision for *surveyors* and *verifiers* of accessibility information it is easier to apply the insight from CoP.

4.2. Communities of Interest

Building on Communities of Practice, Gerhard Fischer has introduced the term *Communities of Interest* (CoI) to focus on cross-domain collaboration [6]. The main concern here is the communication between groups from different domains, the challenges introduced by different cultures and vocabularies and how to capture this in knowledge management systems.

Communities of Interest often have a more temporal nature than Communities of Practice. CoP's are typically long-lived (although not static), and the learning that takes place within the community can take a long time.

The temporal and cross-community aspects of CoI makes it an interesting candidate for shedding light on the OurWay users. Again, this is perhaps more applicable to interaction between the different types of stakeholders involved in accessibility mapping. The problem remains, however, that it is difficult to use for understanding interaction between the end users.

4.3. Social Navigation of Information Space

Dourish and Chalmers introduced the concept of social navigation in 1994. They described it as .

> ... navigation towards a cluster of people or navigation because other people have looked at something [5].

Social navigation takes an information centric approach, whereby information left behind by users because of their activities form 'places' where people interact. Sharing of information then, is not (necessarily) a result of participation in a Community of Practice, rather it is a by-product of use, which might well be without any thought for other users.

Social navigation of information uses the way we navigate in the real world, e.g. by visiting restaurants with many customers and avoiding the ones without them, as a metaphor for navigating information places on the web. This way of thinking about interaction fits very well with the way users of OurWay share their experiences. They leave traces of their use, which in turn is used (behind the scenes) to provide better quality routes for other users. Curiously, OurWay takes the metaphor of navigation back to the physical world— it is tempting to dub it *Sociogeographic Navigation of Information*.

Paul Dourish describes Social navigation of information as a type of awareness system, with some significant differences compared to "traditional" CSCW awareness technologies. The information can be aggregated over time from the use of many different users, which means that communicating awareness can be asynchronous. The

decoupling of the activity that produces the information and the situation in which this information is used (perhaps as part of an aggregate) poses challenges to the design of these systems, e.g. for presentation of awareness information [4]. The OurWay concept also differs slightly from these ideas, by the fact that it is the *removal* of obstacles, not identification of non-obstacles which is key to the concept.

This insight provided by Dourish and others can help in the design of future implementations of the OurWay concept, which up till now has not focused on the communication of awareness information (the aggregated ratings). Rather, only the consequence of aggregated ratings, i.e. the suggested route, has been provided to the user.

4.4. Transient cooperation

Social navigation of information describes systems, technology and use that facilitate sharing of awareness information across time and space. The type of cooperation that takes place between the users of such a system (including the OurWay concept) is what I refer to as *Transient Cooperation*:

Transient Cooperation is a form of cooperation which does not require an existing community, or explicit participation other than a shared benefit from use. The interaction is asynchronous and limited in time, and the users might be unaware of their cooperators or the benefit they have from cooperation.

This is a phenomenon we have observed during tests of the OurWay concept. Users with different backgrounds, goals, preferences and needs are brought together through the use of an OurWay prototype system to solve navigational tasks. The users typically quickly disengage from the idea of "the others", and focus on solving their own task at hand.

One could argue, of course, that the design of the OurWay prototype does not encourage or invite to more explicit cooperation between the users. If we were to follow the design ideas for awareness coming out of the CSCW community, we might well be able to inspire more direct cooperation between users. The interesting point, however, is the observation that despite the lack of outspoken cooperation, the system works and improves over time.

4.5. Retrospective altruism

When preparing participants in our indoor exercises, we presented them with the OurWay concept, and told them they were part of a group of people who would all share and benefit from each other's annotations.

Very quickly, however, most users "forget" the other users, tend to adopt the navigational tasks we gave them as their own, and focus almost exclusively on solving the task at hand. This leads to some interesting behavior, such as one user tricking the system into providing an alternative route by tagging a closed door as inaccessible. We often see users ignoring the opportunity of rating a door sill as uncomfortable even though they really have to struggle to pass it.

Thus, our participants are, with few exceptions, using the navigation system in an egoistic fashion. They are seldom concerned about other users, and usually annotate only when they have to in order to get an alternative route around an absolute obstacle.

During in-depth interviews, however, they are often convinced that they were in-fact concerned citizens and did have other users in mind during use. Even when confronted with video evidence that shows their self-centered activity they will maintain that they did reflect on other users and their potential benefits during annotation. This phenomenon is what I have called *Retrospective Altruism*:

Retrospective Altruism describes the tension between selfish activities that takes place at one time, and the attempt (or desire) to describe those very same activities as altruistically motivated at a later time.

This observed phenomena can be helpful in the design of future implementations of the OurWay concept. Most users seem to *want* to appear as concerned citizens, and this might be an argument for visualization of aggregated ratings, users etc. in order to help them achieve that. The tensions in the Retrospective Altruism phenomena is anyhow a potential for improving the collaboration of and awareness shared between users of the system.

5. Discussion and conclusion

The OurWay concept of collaborative accessibility mapping seems promising. Our studies range from a technology-centered proof-of-concept to user-centered evaluations of use, and our results suggests that it forms a solid base for further exploration of "Accessibility 2.0".

The concept separates from the rigid, objective and detailed accessibility measurement approach which is the hallmark of centralized, authority-controlled information collection and dissemination. The end user is closest to the experience (geographical or accessibility-wise), and functions as a "citizen sensor" to use a term from the field of VGI.

Segment rating as a by-product of navigation takes us back fifteen years to the ideas of Social Navigation of Information Space. Since then, mobile phones have become powerful computers with embedded location technology, which gives us the opportunity to bring the navigation metaphor back into the physical world. OurWay is a simple, almost to the point of being naive, approach to the challenge of collecting accessibility information. It seems to work, and it works in ways predicted by the CSCW community in the mid 1990's.

We observe that users tend to behave selfishly and how the concept works despite of the selfishness. Users are not actively engaging in cooperation, nevertheless they do cooperate through the shared use of a navigational system. I use the term *Transient Cooperation* to describe this phenomena . I have dubbed the way users tend to apply post-hoc rationalization to describe their selfish actions as altruistically motivated *Retrospective Altruism*. Within these two terms lies a great potential for enhancing future implementations of the OurWay concept to foster trust, credibility and cooperation.

The issue of trust and credibility is central to widespread deployment of the OurWay concept, as it is for any system which utilizes user generated content for decision making. The consequences of errors might be different across applications in different domains, however the general problem is shared amongst many fields of work, and there is plenty of published material to learn from.

We don't know much about how the OurWay concept scales if released to consumers. On the other hand, the centralized model has its own challenges with regard to scale. We look forward to testing the OurWay concept over a longer period of time, across many users in different user groups.

Acknowledgements

References

[1]   D. Adams. How to Stop Worrying and Learn to Love the Internet, 1999.

[2]   B. Adler, J. Benterou, K. Chatterjee, L. De Alfaro, I. Pye, and V. Raman. Assigning trust to wikipedia content. In WikiSym 4 rd Intl Symposium on Wikis, 2008.

[3]   A. Ather. A Quality Analysis of OpenStreetMap Data. Master's thesis, 2009.

[4]   P. Dourish. Where the footprints lead: tracking down other roles for social navigation. Springer-Verlag London, UK, 1999.

[5]   P. Dourish and M. Chalmers. Running Out of Space: Models of Information Navigation. Short paper presented at HCI, 94, 1994.

[6]   G. Fischer. Communities of Interest: Learning through the Interaction of Multiple Knowledge Systems. In 24th Annual Information Systems Research Seminar In Scandinavia (IRIS'24), Ulvik, Norway, pages 1–14, 2001.

[7]   A. Flanagin and M. Metzger. The credibility of volunteered geographic information. GeoJournal, 72(3):137–148, 2008.

[8]   M. Goodchild. Citizens as sensors: the world of volunteered geography. GeoJournal, 69(4):211–221, 2007.

[9]   M. M. Haklay and P. Weber. Openstreetmap: User-generated street maps. Pervasive Computing, IEEE, 7(4):12–18, Oct.-Dec. 2008.

[10]   H. Holone and G. Misund. People Helping Computers Helping People: Navigation For People With Mobility Problems By Sharing Accessibility Annotations. In ICCHP. Springer, 2008.

[11]   H. Holone, G. Misund, and H. Holmstedt. Users are doing it for themselves: Pedestrian navigation with user generated content. pages 91–99, Sept. 2007.

[12]   H. Holone, G. Misund, H. Tolsby, and S. Kristoffersen. Aspects of personal navigation with collaborative user feedback. In Proceedings of the 5th Nordic conference on Human computer interaction: building bridges, pages 182–191. ACM New York, NY, USA, 2008.

[13]   J. Lave and E. Wenger. Situated learning: Legitimate peripheral participation. Cambridge University Press, 1991.

[14]   S. Moturu, H. Liu, and W. Johnson. Trust Evaluation in Health Information on the World Wide Web. In Conference proceedings:... Annual International Conference of the IEEE Engineering in Medicine and Biology Society. IEEE Engineering in Medicine and Biology Society. Conference, volume 1, page 1525, 2008.

[15]   R. Priedhorsky, J. Chen, S. T. K. Lam, K. Panciera, L. Terveen, and J. Riedl. Creating, destroying, and restoring value in wikipedia. In GROUP '07: Proceedings of the 2007 international ACM conference on Supporting group work, pages 259–268, New York, NY, USA, 2007. ACM.

[16]   B. Suh, E. Chi, A. Kittur, and B. Pendleton. Lifting the veil: improving accountability and social transparency in Wikipedia with wikidashboard. 2008.

[17]   F. Viégas, M. Wattenberg, and K. Dave. Studying cooperation and conflict between authors with history flow visualizations. Proceedings of SIGCHI, pages 575–582, 2004.

[18]   E. Wenger. Communities of Practice: learning, meaning, and identity. Cambridge University Press, 1999.

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Refinement of an ICT Based NeuroRehabilitation System Employing Telemedicine, Haptics, 3D-visualization and Serious-games

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Abstract: The aim of this research and development is to construct a home based rehabilitation system primarily for persons with motor and cognitive sequel after stroke. The rehabilitation method is based on virtual reality (computer generated environments and objects). A kinematic (movement documenting) assessment instrument and a number of "serious games" with stereoscopic 3D visualization and haptics (a robotic arm with a track stick, which mediates a feeling of touch and force feedback / proprioception) has been developed. Assessment and rehabi-litation / training is at present carried out by the motor activity of the hand and arm as well as cognitive functions such as primary memory and neglect (left sided attention deficit). The scenario is that the patient sits in front of a computer monitor and holds a haptic stick with which he/she performs different games / exercises. The pattern of movement is detected and analyzed continuously. This gives an objective quantitative and qualitative measure of the patient's progress and will give decision support for choice of suitable exercises as well as individually adapted adjustment of difficult and complexity based on the individual's needs.

Key Words: Haptics, Rehabilitation, Stroke, Telemedicine, Virtual Reality

1. Introduction

Stroke is a cerebrovascular catastrophe, and the most common cause of neurological disability. Recent estimates indicate that stroke-related disability-adjusted life years (DALYs), a measure of overall disease burden accounting for disease-related years of life lost and years lived with disability, were 38 million in 1990 worldwide and may increase to 61 million in 2020 [1]. Further, these estimates suggest that stroke will be the fourth leading cause of disability as measured by DALYs lost by 2030. Caregivers of stroke survivors with chronic disability may have increased stress, fatigue, somatic symptoms, and decreased emotional well-being [2, 3]. Furthermore, the economic burden of stroke is substantial [4].

The increasing costs of providing healthcare services to a stroke/ageing population and changing pattern of use of hospital resources, i.e. fall in the average length of stay,

are shifting the focus of care from hospital to home or nearby community centres [5]. This current trend of cost containment in health care has prompted a search for modern methods of providing quality care. A modern telemedicine communication technique has the potential to improve and prolong the contact with the patient after being discharged. Evidently telemedicine systems minimise the barrier of distance, and makes it possible to be able to conduct evaluation and rehabilitation program at rural locations, at great distance from the clinic [6].

In this paper we will describe a telemedicine system which addresses the challenge of home-based training regarding 1) motivational issues, 2) personalized training programs, 3) long distances between clinic and home and 4) cost-effective training support from the clinic. In particular, we will provide tools to support coaching patients and monitoring their progress on distance. The system is currently being tested in an on-going study. The aim of the system is to deliver games in the form of a solution that aids rehabilitation in all its phases: 1) at the hospital, 2) at rehabilitation centers, and 3) at home.

2. Material and methods

The study was carried out in a rural area in Sweden, i.e. NU Hospital Group Area. Mednet (Inst. for Biomedicine) and Department of Clinical Neuroscience and Rehabilitation (Inst. for Institute of Neuroscience and Physiology), both at the Sahlgrenska Academy at the University of Gothenburg, and the company Curictus AB have developed a novel assessment and treatment method for stroke rehabilitation, securing a continuous chain of care and rehabilitation.

2.1. The telemedicine system

The telemedicine equipment (Figure 1) consists of a semi-immersive workbench (www.curictus. com) with a haptic interaction device [7]. The environment provides a wide range of activities through a library of 3D games. The games are steered with the haptic device, which gives force feedback such as feeling the force from throwing a ball or touching a surface. The work bench is placed in a user's home. Data, such as logs of the user activities and performance is sent to a central computer, to be assessed by the rehabilitation personnel in charge of the patient.

Figure 1-Telemedicine system

2.2. Motivational issues: providing engaging activities

A central component of the rehabilitation systems is the library of games, intended to be simultaneously entertaining for the patient and beneficial for rehabilitation. These engaging activities (Figure 2, an example) train certain movements so that the patient can perform their daily training exercises in a stimulating environment.
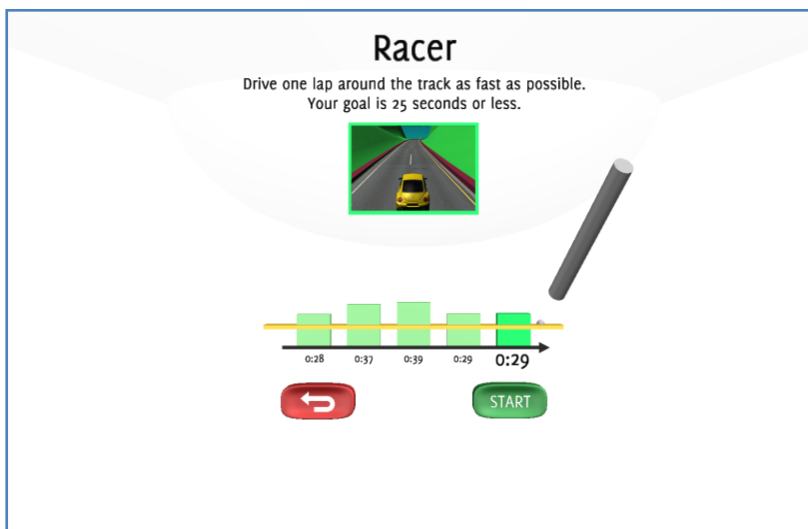
Figure 2-Supination/pronation exercise

Since the consequences of a stroke vary greatly among different user's, the system is designed to be modular so that users can use games specifically designed to deliver physical training of arm/hand movements, as well as cognitive training, according to their individual rehabilitation needs. The user will also be able to participate in common activities, and communicate with each other as well as family and friends.

2.3. Tools to support home-based rehabilitation

In order to support home-based rehabilitation, we provide additional tools to support therapy on distance: a Patient Care Management System was developed and a video-conferencing setup was added to the setup.

2.4. Personalized training program

After clinical examination which measures the ability to perform activities of daily living, and tests to assess the fine and gross motor function of the upper extremity, as well as the movement pattern and kinematic variables of the hand, an individual training program is established. The clinic supplies the user with the portable telemedicine system at the time of the discharge from the hospital. Back at their home the user will be able to exercise freely at their own suitable time and in a familiar environment. At specific exercise hours the therapist monitors and coaches the user from a distance. Follow-up of results is performed by the therapist, and evaluated in relation to the training goals: Tailoring the exercises for the individual user, training progresses with continuous difficulty adjustments and changes in treatment activities. Training outcome is also visualized to the user and discussed in a user ― therapist audio/video session.

3. Results

3.1. Patient Care Management System

The patient care management system is a server that acts as a front-end to the game library, patient database system and training systems. From the patient care management system, staff can observe and graph patient's progress, prescribe games to be played by each patient and communicate (using audio and video links) with users as shown in Figure 3.

Data stored in the database includes:

- Results of each game, number of times run, performance for each run
- Raw hand movement data (x, y, z, yaw, pitch, roll and button press information), captured at 1000Hz and resample to 60Hz, for every run
- Game events time stamped to match the raw hand movement data movement
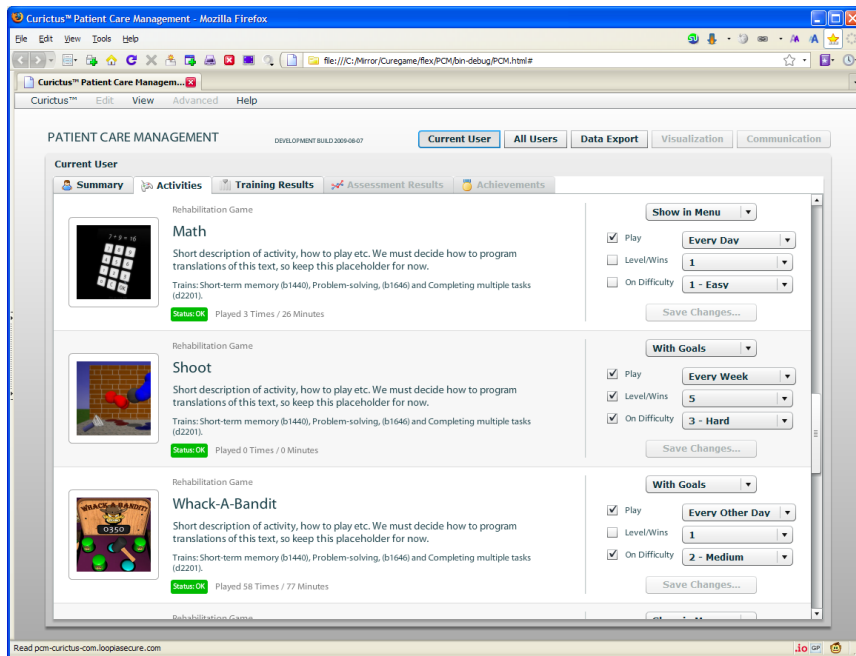
Figure 3-Prototype of the Patient Care Management System

The patient's activities and accomplishments over time can be viewed in a calendar where game played, times, frequency of training, and play statistics can be explored in an interactive manner. In Figure 4, training results for one user is shown (in Swedish).
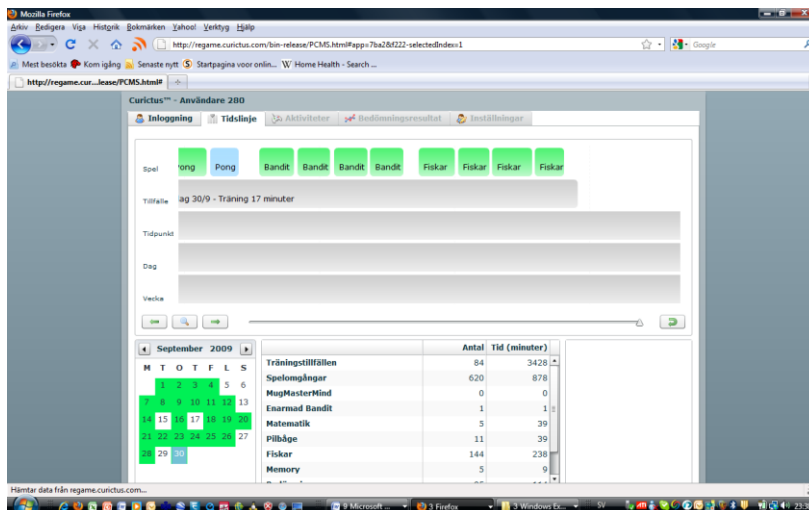
*Figure 4- Training results for one user, i.e. results of each
game; number of times run and performance for each run.*

The rehabilitation central will have bidirectional contact with the home-based units for collection of daily assessments, game allocation and tuning of difficulty. The patient's activity record is primarily designed to support distance meeting between the therapist and the patient.

3.2. e-Coaching the patient at home

The video conference system we are using is of-the-shelf software (Marratech) which we have customized to suit this particular usage.

Figure 5 shows a screen shot of a video conference meeting, where the large left area contains the user activity calendar, and the large video screen is the person you are talking too. All participants in the meeting have small video screens below, and the participants can talk and both can point at and discuss the common work area to the left. However, it is the therapist who will normally interact with the user activity calendar.
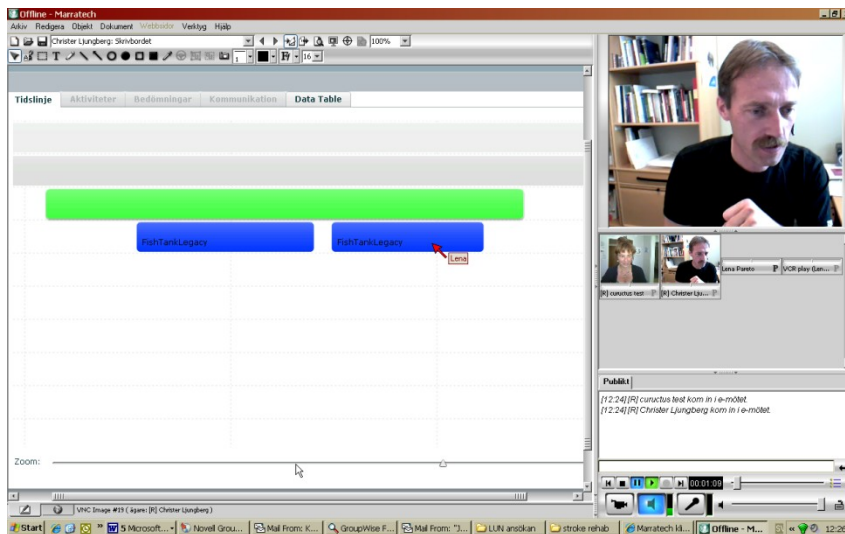
Figure 5 – e-Coaching screen shot

3.3. Costs

Stroke is associated with high cost, at the hospital but also for the community and proxies. Placing telemedicine equipment with haptics in the user's home is a cost. Aspects of costs will therefore be taken into consideration (contacts with health care personnel, the amount of time with home assistance, a personal assistant or aid from an informal caregiver). We will also record the costs for assistive devices, home modifications and medications.

4. Discussion

We have initiated testing of a fully deployed rehabilitation organisation with clinical evaluation systems that have bidirectional contact with the home-based units, for collection of daily assessments, game allocation and tuning of difficulty, and audiovisual communication between therapists and users.

Previous studies have shown that the system is motivational and has benefits beyond real life training [8, 9]. Variation of activities and levels are vital due to patients' varying abilities and taste. In particular the combination of challenging cognitive activities which encouraged motor training is considered useful [9]. The audiovisual communication between therapists and patients is enhanced by providing the interactive user activity calendar as a boundary object to support the dialogue. The purpose of a boundary object is to have a common point of reference and a mutual object to discuss around, which is particular important for distance communication [10]. It shows what, how and when the patient have played since last week or over the entire training period, and the therapist can walk the patient through and discuss things of interests.

Currently we are testing a Clinical Decision Support Systems (CDSSs) to supporting treatment planning and a taxonomy to communicate ideas between medical professionals and game designers [11]. We use a model to support the design, analysis, and comparison of games through the use of game design patterns [12]. This will enable a certain exercise and its related patterns to be identified in the taxonomy. Good rehabilitation today should be based on the World Health Organization's ICF model

[13], which provides a multi-perspective approach to the classification of functioning and disability as an interactive and evolutionary process. The possibilities of implementing a connection to medical terminology, i.e. the ICF model and game patterns should be explored [6].

Modern e-Health technologies may function as a communication port regarding stroke rehabilitation, and also have the potential to become a health care portal in the community. Such a portal has the potential to improve the quality of life for elderly people with physical and mental impairments as well as for their care giving relatives. From a economic point of view, rehabilitation through a telemedicine service system promise cost reduction in health service delivery and it could therefore be proposed as an opportune strategy for saving resources, not only regarding stroke patients by rehabilitation in their homes or at community centres, but also in a broader way effecting the post-hospital health care services as a whole. Thus the efficiency of the system may significantly contribute to lower costs in the health care system. The increase in efficiency will result in cost-benefits for council and entirely new grounds for coworkers and persons with stroke.

5. Conclusion

We have designed and implemented an e-health system for stroke rehabilitation. Our proposed system will enable many persons with stroke to prolong their rehabilitation period. This can probably also minimizes the economic impact of stroke on society. This solution is also able to monitor every tiny movement made by the patient while using the system, which can be recorded and sent back to the hospital. Such data is invaluable in not only monitoring the patients progress, but in creating a knowledge-base of persons with stroke.

Acknowledgement

References

[1]   Lopez, A.D., et al. Global and regional burden of disease and risk factors, 2001: systematic analysis of population health data. *Lancet* 2006: 367(9524): 1747-57.
[2]   Forsberg-Warleby, G., Moller A, and Blomstrand C. Psychological well-being of spouses of stroke patients during the first year after stroke. *Clin Rehabil* 2004: 18(4): 430-7.
[3]   Forsberg-Warleby, G., Moller A, and Blomstrand C. Life satisfaction in spouses of patients with stroke during the first year after stroke. *J Rehabil Med* 2004: 36(1): 4-11.
[4]   Palmer, A.J., et al. Overview of costs of stroke from published, incidence-based studies spanning 16 industrialized countries. *Curr Med Res Opin* 2005: 21(1): 19-26.
[5]   Zhu, H.F., et al.. Impact of a stroke unit on length of hospital stay and in-hospital case fatality. *Stroke*, 2009: 40(1): 18-23.
[6]   Krupinski, E., et al. Research recommendations for the American telemedicine association. *Telemed J E Health* 2006: 12(5): 579-89.
[7]   Broeren, J., et al. Rehabilitation after stroke using virtual reality, haptics (force feedback) and telemedicine. Stud Health. *Technol Inform* 2006: 124: 51-6.
[8]   Broeren, J., et al. Virtual rehabilitation in an activity centre for community-dwelling persons with stroke. The possibilities of 3-dimensional computer games. *Cerebrovasc Dis* 2008; 26(3): 289-96.

[9] Pareto, L., et al. Virtual reality, haptics and post-stroke rehabilitation in practical therapy. http://www.icdvrat.reading.ac.uk/2008/papers/ICDVRAT2008_S06_N04_Pareto_et_al.pdf. Last accessed: 16th September 2009.

[10] Østerlund, C. The Materiality of Communicative Practices: The boundaries and objects of an emergency room genre. *Scandinavian Journal of Information Systems* 2008: 20(1): 7-40.

[11] Goude,D., Bjork S. and Rydmark M. Game design in virtual reality systems for stroke rehabilitation. *Stud Health Technol Inform* 2007: 125: 146-8.

[12] Björk, S., Lundgren S, and Holopainen J. Game Design Patterns. http://www.cs.chalmers.se/~lundsus/bjork_et_al_game_design_patterns.pdf. Last accessed: 16th September 2009.

[13] World Health Organization. International Classification of Functioning, Disability and Health: ICF. 2001. http://www.who.int/classifications/icf/en. Last accessed: 16th September 2009.

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Telemedicine Systems for Delivering Patient-specific Motor and Cognitive Rehabilitation

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Abstrac: *In this paper we illustrate the Neurological Rehabilitation (NR) Concept of the EU project MyHeart, funded by the European Union from 2004 to 2008. The concept is especially devoted to supporting post-stroke treatment. We describe how it is structured and how technologies are leveraged to support both motor rehabilitation and speech/cognitive training. The architecture allows assisted training both at the clinic and at home, after discharge from the intensive care unit. Both promising results and issues, collected during the first evaluation phase, will be discussed.*

Keywords: Computer-based rehabilitation, motor rehabilitation, cognitive rehabilitation.

1. Introduction

Recovery from a stroke begins in the acute unit and it is articulated into a series of intensive and extensive rehabilitation protocols. Despite the protocols variability, there is nowadays a common trend, in clinical medicine, to shorten hospitalization and foster homecare [1]. The reason is both to cut costs and improve quality of life. The aim of MyHeart's Product Concept NR is to support patients in the performance of speech and motor therapy, both when they are still hospitalized, and after discharge, at home [2,3]. Patients eligible for the service must be in stable clinical condition and show mild motor impairment and/or aphasia with no other cognitive impairment that could impact on the system's use.

Liability constraints of Italian hospitals impose that IT-based rehabilitation does not replace conventional therapy. Therefore, at the hospital, exercise performed with the system is in addition to the conventional one, resulting in a more intensive, hopefully more effective, program. This could lead to an earlier discharge. After discharge, patients could find the same rehabilitation device at home or at long stay ward, thus continuing exercises with the help of their caregivers. This helps the so-called "continuity of care".

In the following sections the service built within Concept NR will be described, in terms of its architecture, technology used and first experimental results.

2. The system architecture
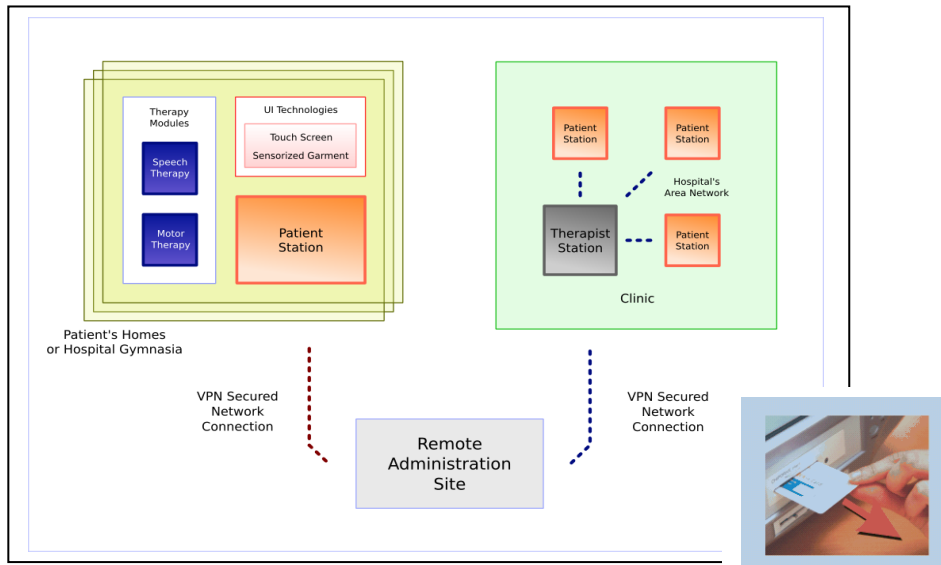
Figure 1 – The telemedicine platform used within the MyHeart project. Patient's identification occurs via a personal card (right bottom)

Figure 1 shows a simplified view of the system technical architecture. The infrastructure is based on EvoCare, a solution developed by Dr Hein GmbH , that was a partner in the MyHeart consortium. The main components are one server, and a number of users' workstations, connected by a secure network. Users may be physicians, physiotherapists, speech therapists and, of course, patients. Medical personnel use the therapists' stations to administer their assigned patients, prescribe exercises, and review their performance. Performances are reported in terms of percentage of correct exercises and time to execute them. Moreover, temporal trends are shown to appreciate the patients' progress. Protocols can be updated, re-formulated and sent to patients according to the course of the rehabilitation. Patients use the patients' stations which support the rehabilitation exercises. Patients' identities are recognized via personal "check-in cards." Once inserted, the exercise protocol (prepared by physicians) and messages are downloaded automatically at the patient's site. The server acts as the repository for exercise prescriptions, results, and messages.

From the technical point of view, specific exercises, including speech therapy and motor therapy, are realized by a "plug-in" mechanism. Each plug-in implements all activities required by the specific type of exercise: it is responsible for providing configuration screens, support the execution of the actual exercise, provide appropriate feedback to the patient, and store the results. It also supports browsing and summarization of the results for the therapist to review.

3. The technology

3.1. Speech therapy module

A quite standard Speech Therapy system is based on the EvoLing software, still developed by Dr. Hein GmbH. It includes an extensive set of exercises, each promoting one ability: to recognize words, phonemes, graphemes, and pictures. Semantic and orthographic information is considered in order to build exercises with an adapting degree of difficulty.

A more innovative system has been developed using another platform, namely E-Prime®, provided by Psychology Software Tools [3]. We integrated the basic platform with a wide database of stimuli, relationships among stimuli and hierarchic classification. In order to personalize the exercises on the basis of users' preferences and ability, we introduced a patient database able to manage not only personal data but also her/his profile (clinical information, education, hobbies, etc.), and performances in terms of correct answers and execution time. Our repository, implemented by MS Access (Figure 2), contains now about five thousand nouns, divided in different semantic categories (foods, animals, sports, objects, etc), and about one thousand verbs. At the moment two thousand stimuli have associated the corresponding sound and half of them also the corresponding image.
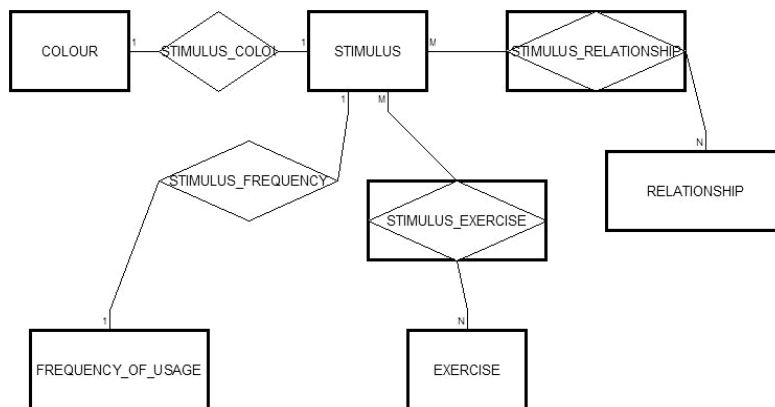
Figure 2 – The Entity-Relationship Diagram of the stimuli DataBse for speech therapy.

The core tables are "Stimulus", "Stimulus_Exercise" and "Stimulus_Relationship" while the others one represent encoding tables.

Each row in "Stimulus" table describes a stimulus characterized by the following attributes: ID, Description, Length, Frequency of usage in the Italian setting, Colour, Image file, and Sound file.

The stimulus' ID is a hierarchic code, that allows retrieving the hierarchical relationship among the stimuli through dot-separated numbers. For example the "IS-A" between carnivorous and mammal is represented by the two codes 19.1.7 and 19.1 respectively.

"Stimulus_Relationship" table contains the relationships among our stimuli. For example, in the "COMPOSED_BY" relationship, "magazine" is in association with "paper". As another example, "dark" is in association with "light" in the "OPPOSITE" relationship.

"Stimulus_Exercise" table specifies which stimuli can be used for each exercise. A stimulus is suitable for a particular exercise on the basis its properties like the presence of the corresponding image, the association with a particular relationship, and so on.

Figure 3 shows some interactions with cognitive rehabilitation exercises.
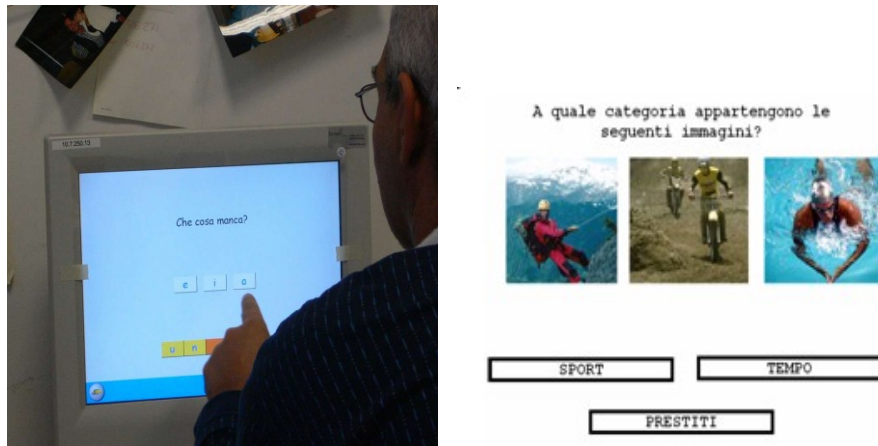
Figure 3 - Two different types of cognitive exercises: the right one is based on the stimuli hierarchy

3.2. Motor therapy module

Motor therapy exploits innovative components. When sitting at their station, patients wear a special sensorized garment, plugged into a portable electronics box (figure 4). Motion recognition is based on strain sensor technology, directly printed on garments. Conductive elastomers are polymer-based materials which exhibit electrical conductivity. Sensing stripes are thin and can be printed by cheap industrial processes; they do not alter the mechanical properties of the fabric (Lycra in our case) and they are stable and non-toxic. The same material is used for connecting wires between sensors and the readout electronics (see Figure 4 again). In the current version of garments, the sensing stripes are put on patches sewn onto the garment.

Before starting the self-exercise session, a brief calibration phase is necessary, during which the patient, with the help of a caregiver or a therapist, performs at least two correct movements, that will be considered as reference "templates" and will be compared with the subsequent movements that patient will perform alone. In other words, this session allows the system to learn such movements and store the corresponding reference paths. After calibration (lasting 1-3 minutes on the average), the motion recognition software is started; it provides real-time feedback on the progress and accuracy of exercises by means of clear symbols such as colored bars and a smiling/frowning face, as shown in Figure 5. The movements have to be repeated until the assigned number of repetitions are performed, or a timeout expires. A traffic light icon shows when to start a new repetition (Figure 5, right).
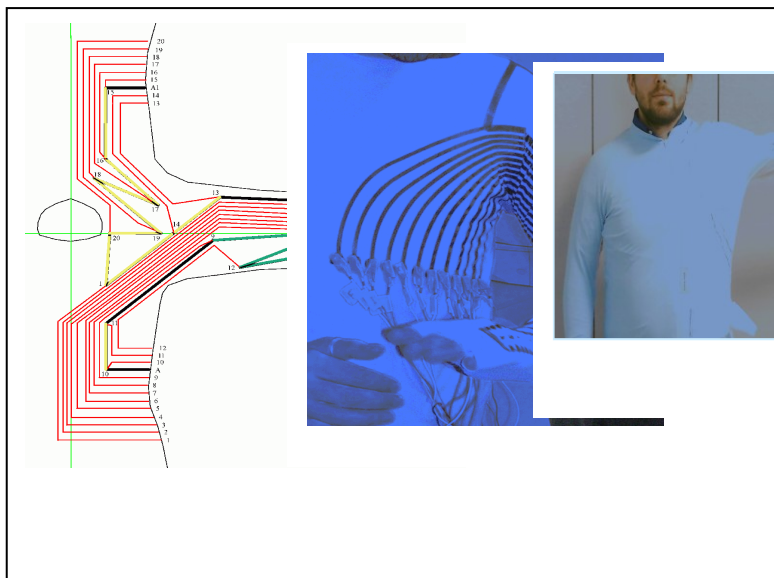
*Figure 4 - The sensor printing design, the prototype and the final
version of garment. No wire is visible and the portable electronics is
hidden in the pocket*
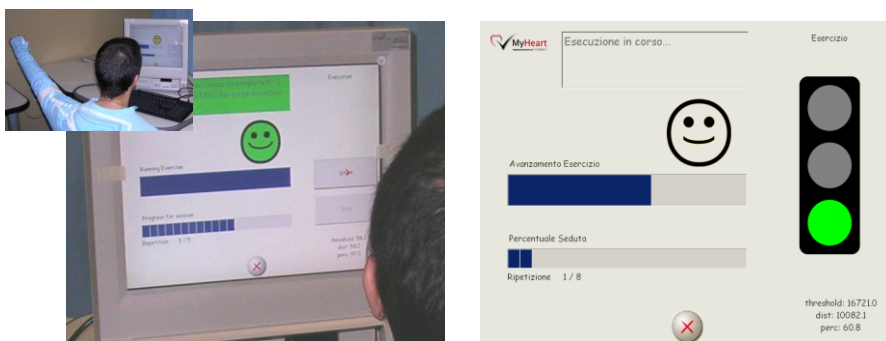
*Figure 5 - The interface is very simple, in order that also aphasic patient do not get
confused.*

3.3. Movement recognition

When signals from body movement are acquired, they are processed in order to verify
the correct execution of the rehabilitation exercise. Since there is no direct
correspondence between the fabric stretch values at various points of the garment and
biomechanical parameters or like angles between limb segments, posture classification
was tackled via machine-learning based algorithms. Therefore, every repetition is
classified evaluating the similarity with the above mentioned templates or reference
path. Some reference paths correspond to well-known, deficit-related exercises, like

adduction, abduction, rotation, extension, etc. Other exercises may be tailored to the specific patients, in particular functional movements like combing, eating, brushing, etc.

The machine learning approach to movement recognition is an important research topic by itself, be-cause strain sensors are affected by various sources of uncertainty, which make the recovery of limb positions from sensor readings less than straightforward. The accuracy of classification is affected by the dynamic nature of the task. Smeared sensors produce velocity-dependent artifacts; therefore, the recognition accuracy is impaired when limbs are moving. In addition, patients wear the garment each time in a different way, and also within the same session the garment may slightly move. Also, one is interested in the closeness of a movement path to a reference, not just to detect a limited set of basic positions.

4. Results

The NR system underwent a small-scale study to assess user satisfaction and gather initial measures and feedback. Preliminary qualitative and quantitative results for both motor and speech therapy were obtained from the first thirteen and twenty patients enrolled, respectively.

About motor therapy, the preliminary laboratory evaluation with voluntary subjects [4] showed an overall efficiency on movement recognition of 91%, while the patients' satisfaction was measured by administrating a questionnaire (Table I).

Table 1 - Patients' interview results

QUESTION	Agree	Neutral	Disagree
Do you like using the PC?	8	3	2
Are the exercises easy to understand?	9	3	1
Is the PC difficult to use?	6	4	3
Do you easily understand the screen?	2	7	4
Is the program useful?	8	3	2
Do you get bored?	2	4	7
Do you feel less cared for?	1	4	8
Would you use it at home?	6	5	2
Do you feel improved?	6	4	3
How would you prefer to continue the treatment?	therapist +system 6	neutral 3	therapist only 4

An important benefit of this kind of systems is the possibility of documenting the rehabilitation results by quantitative measures, that often are lacking in this medical area. As an example, we report a graph (Figure 6) showing the progress of a patient on speech therapy. It is very clear, at a glance, that this patient is improving, because with increasing difficulty level, both the answers correctness and the reaction time is improving. Figure 6 refers to an individual patient: unfortunately, we don't have, at present, enough patients to provide statistical results on the computerised treatment benefit.
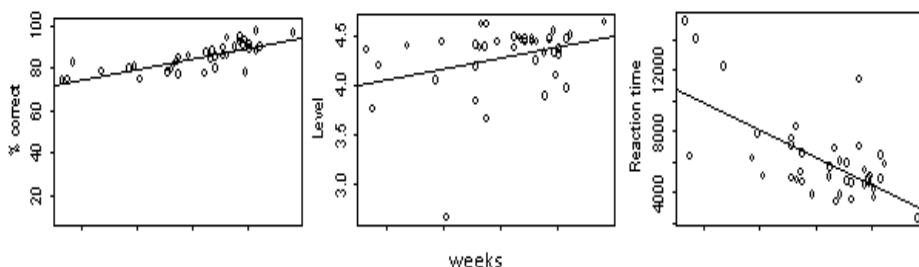
Figure 6. Weekly progress of a patient under speech therapy: from left to right, the percentage of correct answers, the difficulty level of the proposed exercises, and the time to answer (ms).

5. Conclusion

The integrated nature of the NR system is intended to support a multidisciplinary, telemedicine-based approach to rehabilitation. The benefits of IT-based aids are supported by current beliefs on rehabilitation, e.g. those expressed in the SPREAD guidelines [5]. First of all, long term rehabilitation programmes are considered beneficial for the recovery process, but cost is very high. IT technologies are a promising solution for providing long-term rehabilitation at lower costs. At the same time, early discharge is recommended for patients with less severe disability. The system allows for early discharge while still being monitored remotely.

Finally, the concept addresses a frequently-reported issue, i.e. lack of quantitative measures on the progress of rehabilitation. The diffusion of computerized monitored rehabilitation aids may increase the objectivity of practice and allow for quantitative progress evaluation and therapy comparisons.

Acknowledgments

References

[1] Kwakkel G, "Impact of intensity of practice after stroke: issues for consideration," Disability and rehabilitation, vol. 28, no. 13-14, pp. 823–830, 2006

[2] Giorgino T, Tormene P, Cattani B, Pistarini C, Quaglini S.Remote support for stroke rehabilitation: MyHeart's "neurological rehabilitation" concept. Stud Health Technol Inform. 2007;129(Pt 1):92-6.

[3] Giorgino T, Tormene P, Lorussi F, De Rossi D, Quaglini S Sensor evaluation for wearable strain gauges in neurological rehabilitation. IEEE Trans Neural Syst Rehabil Eng. 2009 Aug;17(4):409-15.

[4] Giorgino T, Tormene P, Maggioni G, Capozzi D, Quaglini S, Pistarini C.Assessment of sensorized garments as a flexible support to self-administered post-stroke physical rehabilitation. Eur J Phys Rehabil Med. 2009 Mar;45(1):75-84.

[5] Inzitari D, "The Italian Guidelines for stroke prevention. The Stroke Prevention and Educational Awareness Diffusion (SPREAD) Collaboration," Neurological sciences: official journal of the Italian Neurological Society and of the Italian Society of Clinical Neurophysiology, vol. 21, no. 1, pp. 5–12, Feb 2000.

ELECTRONIC HEALTH RECORDS AND STANDARDS

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Security Infrastructure Services for Patient Managed Lifelong Health Record

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Abstract:. Modern health care requires in many cases information about patients that exceeds what an organization-based EHR managed by one service provider can offer. Services like pro-active prevention and health prediction require in many case information covering the whole person's life. Research and other secondary use also needs longitudinal personal health information. The lifelong health record is an answer to those needs. In this paper we discuss on how and to what extent the legal lifelong EHR and its counterpart the personal health (PHR) record can be managed by the data subject. Infrastructural security services needed to enable for the data subject to control his/her own lifelong health information are discussed. Expanded sets of principles and requirements essential for managing the use of PHRs in ubiquitous health environment are also discussed.

Key Words: Security infrastructure, security services, lifelong EHR, PHR, information management, ubiquitous health.

1. Introduction

The definition of an Electronic Health Record varies in different countries. A number of definitions for the term "EHR" exists worldwide, and there is rarely an internationally accepted EHR definition. Differences reflect different shades of meaning between different countries and organisations. Two widely used definitions for the EHR are:

- A comprehensive, structured set of clinical, demographic, environmental, social, and financial data and information in electronic form documenting the healthcare given to a single individual [1], and
- A longitudinal collection (e.g. produced by encounters in one or more care settings) of personal health information of a single individual, entered or accepted by a healthcare provider, and stored electronically [2].

We also have to mention Regulated/Legal Health Records. AHIMA (American Health Information Management Association) defines that the legal health record is "generated at or for a healthcare organisation as its business records, and is the record that would be released upon request".

Typically, one single EHR does not cover all lifetime health information of a person. Instead, it includes information entered by service providers working for one service provider organisation. Therefore, terms as GP-record, primary health care record, occupational care record and hospital record are widely used.

The Lifelong EHR has many names. It has been called a virtual EHR, a longitudinal EHR, and a logical EHR or even a birth to grave record. In this paper, the lifelong EHR has two meanings. First it is a physical or virtual combination of all institutional EHRs created by different service providers during a person's lifetime. Secondly it is a

personal health record (PHR) which provides a complete and accurate summary of the health and medical history of an individual [3].

In this paper we first analyse how and for what extent the patient can manage his lifelong regulated EHR. We also develop principles and rules for security services which the data subject needs for trusted management of his PHR.

2. The legal lifelong EHR

The legal lifelong EHR contains information entered by health professionals or medical devices. The stewardship of this kind of information belongs to a health professional or to the service provider organization. Patients have limited possibility to control the record within the limits of national legislations.

Technically, the Lifelong EHR can be a single physical record, a distributed (e.g. virtual) or logical record. In most of cases, a person has used many geographically distributed services during his life time, and also has many separate service provider centric EHRs which together form the virtual lifelong EHR. The lifelong EHR can also be a set of linked documents. In modern health care, very seldom a single service provider or service provider organisation has got the responsibility and has the capability to manage the lifelong virtual EHR.

In many cases, the virtual lifelong EHR is created by linking separate service provider centric EHRs on-the-fly [4]. Linking has been done both at regional and at national level using suitable middleware services. Examples of this kind of architectures are the NHS Care Record Service together with its summary part SPINE and the Dutch national record switching service. There are also many regional middleware solutions with this kind of record linking ability [5].

It is also possible to store the lifelong EHR or links (common meta-data) into a personal portable device (e.g. smart card, mobile phone, USB-memory stick or implanted chip), and use the portable device together with middleware service to create, and control the use of, the virtual lifelong EHR.

Shabo has proposed an independent health record bank model for lifelong EHRs. In his model, a private "record bank" organisation is managing the use of the legal lifelong EHR on the behalf of service providers or the government [4].

3. Security Infrastructure

The term information infrastructure traditionally refers to the communications networks and associated software that support interactions among people and organizations. It also describes the physical hardware and software to interconnect computer systems and users.

In the modern ICT world, the infrastructure can be understood in many ways. Infrastructure services can comprise hardware services such as networks and storages, or infrastructure software. In Service Oriented Infrastructure (SOI), the infrastructure enables that all applications can operate to deliver business value to the end users. Typical infrastructure services in SOI enable resource sharing, application integration, communications and collaboration. Infrastructure services can be also virtualized. The Infrastructure as a Service (IaaS) model offers a virtualized platform as a service.

Blobel [6] has defined that infrastructural security services are services which facilitate secure communications in a large scale involving mutual distrustful users. Based on his definition infrastructural security services are: registration, certificate handling, directories, card issuing key management and naming. Generally we can say

that in health care settings security infrastructure services link all kind of EHRs, different users and computer systems, and the data subject in trusted way.

It has been discussed already that the lifelong EHR can be centralised, distributed or portable, and it is used in many different platforms and information architectures. Instead of defining architecture and platform dependent security services, we therefore concentrate in this paper to the definition of security principles which enable the data subject to manage his/her legal lifelong EHR or personal health record.

4. The management of the lifelong EHR

Information management means the organization of, and the control over, structure, processing and delivery of information including collection, processing, storing and dissemination [7]. It means also handling, supervision, or control of the use of information.

Health information management (HIM) is the "discipline that focuses on health care data and the management of health care information, regardless of the medium and format". This management includes content management, quality management and the management of security and privacy protection.

Thinking of the data subject's management of lifelong EHR, we have to ask how and to what extent he or she can manage the use and access of the lifelong EHR? There are many rules and regulations limiting this.

The "ownership" of EHRs is not clearly or uniformly defined in most countries, but we can say that organisations controlling and managing legal EHRs act as stewards. It is also the responsibility of the EHR system to ensure that only those persons, processes and entities having the right to access records can do it. Furthermore, health data can be used only for purposes it has been collected; and no further processing of data for other purposes is allowed without informed consent of the subject of care or specific national legislation.

Typically a national law, decree or guideline defines that the service provider or service provider organisation has got responsibilities for managing organisational EHRs [3]. All EHRs should be managed according to national regulations and ethical principles (e.g. the HIPAA act, EU-Directive 95 or the Act on the Freedom of Information). This means that EHRs remain in the legal custody of the provider created them. In the case the lifelong EHR is a single physical record under the control of one service provider, it will be managed using some principles and rules relevant for organisation centric EHRs.

The virtual lifelong EHR requires some kind of link or metadata service, and therefore its management is more complicated. In this case, the management is shared between local record authorities and the organisation managing the common part or common meta-information. The centralised part is managed typically by a governmental organisation or a public-private operator, but local EHRs are managed by service provider organisation [4], [8].

The lifelong EHR can be also stored into a personal portable device such as a smart card, mobile phone, personal portable device, CD/DVD, a USB stick or into an implanted smart device. In this case, the device holder can have full or partial control over the stored information.

In the case of the legal lifelong EHR its management and control is regulated and in most cases done by a governmental organisation. The data subject has limited control over this process. In all cases the data subject has no control over the content and quality of his legal EHRs.

4.1. Data subject's rights to control the lifelong EHR

Present principles used for the management of the EHRs are developed to restrict the use and make necessary information available for health professionals. Rules are built on ethical principles and national regulations. Widely accepted and used principles for the management of the EHR are:
- The use of the content of the EHR should be purpose limited,
- Consent/opt-out should be used for controlling the access and disclose of the record,
- The content of the EHR cannot be changed after it has been signed,
- Information collection should be limited (e.g. only information needed for the care can be collected),
- Patient-doctor relationship is needed for access to, and use of the record,
- Only persons participating to the care have permission to access the record,
- Secondary use of the content of the EHR is enabled only by legislation or patient's explicit consent, usually after pseudonymization of the record,
- The access to the record should be limited by roles and duties, and
- Health professionals should have the "break the class" possibility.

Because the legal lifelong EHR has the same status as a single EHR, it is managed using same principles discussed above.

In many countries, the data subject (e.g. the patient) has got some rights to control the use and disclose of his/her regulated health information. Typically, he or she can
- Use consent documents to limit the access and use of the EHR,
- Use opt-out principle to restrict the visibility or use of the record,
- Access to his own lifelong EHR or to some parts of it, and
- Access to the disclosure log of his/her EHR.

It is also possible that the patient can assign temporal access rights to other health professionals or persons (e.g. a family doctor, next to kin).

The data subject has no right to control the content of the EHR or delete some parts of it. He/she cannot control the preservation of EHRs, and has limited right to be aware who is using the record and for what purposes. The data subject has also no right to control which organisational EHRs are linked to his lifelong EHR, and where links are stored. In many countries there are also specific regulations enabling the use of EHRs without patient control.

5. Security Infrastructures for the management of the lifelong EHR

Management principles discussed in the previous chapter are realised using different kind of platforms, infrastructural and value added security service [6]. Both governmental and commercial solutions are in use. Independent of the architecture used for the lifelong EHR the following security services are needed:
- Patient authentication and authorization,
- Access control services,
- Consent and opt-out management services,
- Communication security services, and
- Audit-log services.

The distributed EHR architecture requires more complicated security infrastructure because it is necessary to manage both the linking of EHRs (e.g. the security of common meta-information or master-index repository) and distributed EHRs.

5.1. National platforms for the lifelong EHR

The Finnish National EHR communication architecture is an example of a governmental data bank solution. It is built on top of the centralised eArchive (e.g. the data bank). It is a repository which can create virtual lifelong EHRs for all citizens [8]. The whole lifelong EHR or selected parts of it can be disclosed by the eArchive after automatic, rule-based verification of access or disclose request. Patients have got limited rights to control how their lifelong EHR or parts of it are disclosed. Any disclosure requires an explicit consent, and using additional opt-out service the patient can hide selected parts of one EHR in such a way that it cannot be disclosed. The national architecture includes an infrastructural consent management service. Patients can use this service to change any time personal consents and opt-outs using the Internet. Another meaningful security service is the patient-doctor certificate. Any data disclosure from eArchive requires this certificate (or there is a specific legislation enabling disclosure). Patients are identified and authenticated with the help of the national CA-service which is also a part of the Finnish security infrastructure.

The UK Spine and Record Service is an example of distributed EHR model with centralised governmental meta-directory. In this solution, patients can use their opt-out to restrict the use of distributed EHRs.

The Swiss model for on-the-fly virtual lifelong EHR uses Health Insurance Cards (PDC) for both the creation and for control of the virtual EHR. The infrastructure includes patient identification and certification services, e-signature and data encryption services and PKI services. Patient can lock personal emergency data by a PIN. The Swiss platform supports also card to card authorization (e.g. authorization from patient card to health professional card [10].

The German Electronic Health Card (eGK) is another example where smart cards are used to enable the patient to control the distribution of personal clinical information stored on the card or in the network [11].

The newest development has been Internet based data banks. The Google Health is one of the commercial health data banks available [9]. It offers a possibility for an individual to collect personal EHRs, store them in an Internet repository, and create in this way a lifelong EHR which is a copy the of person's legal EHRs. The Google Health offers individuals accounts and the possibility to define which persons can share stored EHRs. Google Health has also defined its own security policy which is not compliant to HIPAA rules, however [9].

Newest platforms are moving from static rules to the use of infrastructural policy-based access control services [6]. This enables patients to define their own security polices for the controlling their EHRs. Policy federation services can be also part of this kind of solution.

6. The Personal Health record

The Personal Health Record (PHR) has many definitions. It is widely accepted that PHRs enable individuals to manage a lifelong view of their personal health information. AHIMA has defined PHRs in the following way "An electronic universally available, lifelong resource of health information needed by individuals to make health decisions. Individuals own and manage the information in the PHR, which comes from healthcare providers and the individual. The PHR is maintained in a secure and private environment, with the individual determining rights of access" [12].

The Personal Health Record is furthermore a repository that is initiated and maintained by an individual; it is separate from legal EHRs and it does not replace them.

The PHR can be also a combination of individual's personal health and welfare related information (e.g. PHR) and the copy of person's legal lifelong EHR [13].

Similar platforms developed for the management of lifelong legal EHRs can be used to realize the PHR. The Internet is a common platform for PHRs, but also smart portable personal devices can be used. Internet based Google Health is an example of a commercial PHR platform. It stores all individual's health information in one place and enables securely sharing of information with a family member, doctors or caregivers [9].

6.1. Security principles for the management of the PHR

AMIA has defined that every person should have control over their PHRs, i.e., all secondary uses of PHR data must be controlled by the consumer, except as required by law [13]. Ball has defined the following requirements for managing the PHR [14]**:**
- The individual should have the control of his/her PHR,
- PHRs are accessible from anyplace at any time,
- PHRs are private and secure,
- Persons can see who entered each piece of data,
- The PHR offers easy exchange of information across the health care system.

For trusted management of the PHR by the data subject, more granular principles and rules are needed. The data subject who is managing his/her PHR should have the possibility to:
- Limit the use of the PHR by purpose, context, obligations, and to specific parts of the record (e.g. restrict the use of genetic data),
- Control at granular level that is using the PHR's information,
- Limit the use based on personal obligations, preferences and restrictions,
- Limit the data disclosure,
- Limit which part of information is archived and for how long period,
- Trigger the anonymisation of data,
- Control of semantic mappings,
- Control over personal profiling,
- Control modifications, copying and deleting of the data,
- Control the delegation of access permissions,
- Be aware of the environment and its security features where the PHR is used and Federate of personal access rights.

Security service should support all kind of personal obligations including event-driven obligations, short/long term obligations, obligations contextual or unrelated to the access.

7. Related work

Dynamic context- and content-aware security services for the security management of multi-source and heterogeneous information have been proposed by many researchers. Georgiadis is proposing an active access control system that supports context-based permission activation [15]. Giuri has specified a set of security policies where permissions on systems objects may depend on the content itself [16]. Kumar has developed a model for context sensitivity in RBAC [17]. Li has developed a Person-Centric Context Aware System Architecture where users are the owners of their personal information and have the control of how their information will be used by others [18]. Zhang is also proposing a Context-Aware Dynamic Access Control Service system for pervasive applications. [19]. Adam has developed a Content Based Authorization model where privileges are divided into browsing privileges and authoring privileges [20].

Covington is proposing a Context-Aware Security Architecture for Emerging Health Applications (CASA) [21].

Based on research done it is clear that a person-centric, dynamic, context- and content-aware infrastructure is needed for the management of PHRs. In following chapters we develop the generic requirements discussed to more health specific and more granular ones.

8. Security requirements for the management of PHRs in ubiquitous environment

In the near future we live in ubiquitous and pervasive information space. It is characterized by heterogeneous information and distributed computing. The preventive, predictive, pre-emptive, dynamic and networked eHealth is one of the major services available and used in this ubiquitous information space. The pervasive health paradigm gives us lifelong view to persons' health and wellness. To be effective, pervasive health requires that person's lifelong EHR and other health and welfare related information (e.g. the PHR) is available from anywhere on 24h/7d basis. Despite the technology and architecture used in ubiquitous environment, it is necessary that the infrastructure is able to manage the trusted use of the information and enable the on-the-fly control of personal information by the data subject.

Infrastructure used for managing and controlling the use of PHRs should support all principles and requirements defined in chapter 6.1. The infrastructure should enable to the data subject to manage the use and disclose of all parts of the PHR dynamically. More exactly it should support:

1. Dynamic, flexible on-demand authentication of users and entities,
2. Context- and purpose-aware access and disclosure of objects of the PHR,
3. Defining and modifying at granular level security policies dynamically, modifying permissions, setting restrictions and constraints connected to use the PHR or any part of it,
4. Policy-, purpose-, context- and content-based access requests,
5. The use of dynamic context-aware authorization and access control mechanism with fine-grained contextual constraints. It should dynamically grant and adapt permissions to users according to current context,
6. The on-the-fly modification of permissions according to the changes in the environment, and
7. Filtering the viewed information depending on the context of the user.

In addition to the aforementioned principles, the infrastructure should enable the data subject to dynamically control context and purpose of the use of his/her PHR as well as control/restrict the linking of objects of the PHR. The PHR should be aware of the context of the subject of data, users, application and the environment.

The PHR will be used in different jurisdictions. Regulatory and legal frameworks in different countries can provide varying degree of protection of privacy. The "adequacy" of protection can remain open to interpretation [3]. Therefore, the infrastructure should support dynamic policy and conflict negotiations in the case users, services and subject of data have different policies and regulations.

9. Discussion

The use of the legal lifelong EHR is regulated and controlled by rules developed for organisation centric EHRs. The common policy for organisational EHRs has been that records are under the control of health professionals, service provider organisations or they are controlled by the government. This means that patients and individuals have limited rights to manage and control their EHRs. Present security infrastructures are also planned for the management of local use and access. Even infrastructures developed for cross-organisational sharing of EHRs are built on those old principles.

The need for secondary use of EHRs and PHRs is increasing and there are also needs for cross-border sharing of EHRs. In consequence, records are communicated and used outside traditional and trusted health care settings. Therefore, the data subject needs more power to control who, how, for what purposes and where his/her records is used.

The content of Internet-based PHRs is available globally. Its potential users are health professionals, the data subject, autonomous computer systems, persons/organizations authorized by the data subject and different kind of secondary users. The PHR can be accessed anywhere using smart personal portable devices. The PHR can also communicate with environmental sensor and surveillance networks. In this ubiquitous environment, the data subject should have full control over content and use of his PHR. Present principles and infrastructure developed for the management of legal EHRs cannot offer sufficient possibilities for the data subject to manage his/her PHRs. Detailed principles and rules as well as new dynamic person-centric and context-aware security services are needed for guiding the use of PHRs . In this paper, we have made a proposal for those principles and developed requirements for security services needed.

One possible response to the needs discussed is the development of an infrastructural policy-based security services with policy negotiation abilities. But infrastructural security services alone are insufficient to facilitate the data subject's full control over his/her personal health information. It is also necessary that the information structure of lifelong EHRs and PHRs includes rich security-related meta-information (e.g. granular security policies) which is used by the interface to control access to, and use of, PHRs and lifelong EHRs.

Acknowledgment

References

[1] www.astm.org/COMMIT/E31

[2] HINA, A Health Information Network for Australia, Commonwealth of Australia. National Electronic Health Record Taskforce. ISBN 0 642 44668 7. July 2000.

[3] ISO/TS 21457-1 Health Informatics – Security requirements for archiving of electronic health records – Part1: Principles and requirements, 2008.

[4] Shabo A, A Global Socio-economic-medico-legal Model for Sustainability of Longitudinal Electronic Health Records, Part1 and Part 2, Methods Inf Med 3/2006 and 5/2006.

[5] Harno K, Ruotsalainen P, Nykänen P and Kopra K, Evolution of Health Information Exchange between Healthcare Providers, International Journal on Advances-in-Life-Sciences, 2009.

[6] Blobel B, Analysis, Design and Implementation of Secure and Interoperable Distributed Health Information Systems, Studies in Health technology and Informatics, 89, Amsterdam, IOS Press, 2002.

[7] en.wikipedia.org/wiki/Information_management.

[8] P. Ruotsalainen, Finland's Strategy and Implementation of Citizens' Access to Health Information, Medical care Compunetics 5, IOS Press 2008.

[9] https://www.google.com/health.

[10] Stendlin P, The Swiss Architecture for Health Insurance Cards (PDC), IT security for e-health, London 4th Sept, 2009.

[11] Pharow P, Blobel B and Hildebrand C, How Can the German Electronic Health Card Support Patient's Role in Care Management, In: Bos L et al. (Edrs) Medical and Care Compunetics 5, 386-401, Studies in Health Technology and Informatics 137, Amsterdam, IOS Press, 2008.

[12] AHIMA, The Transformative Potential of Integrated Personal Health Records, Discussion Draft— September 2006.

[13] AMIA and AHIMA, The Value of Personal Health Records – A Joint Position Statement for Consumers of Health Care, In: Bos L et al. (Edrs) Medical and Care Compunetics 5, 402-406 Studies in Health Technology and Informatics 137, Amsterdam, IOS Press, 2008.

[14] Ball MJ, Costin MY and Lehmann C, The Personal Health Record: Consumers Banking on Their Health. In: Blobel B, Pharow P, Nerlich M (Edrs.) eHealth: Combining Health Telematics, Telemedicine, Biomedical Engineering and Bioinformatics to the Edge, Global Experts Summit Textbook, 35-46, Studies in Health Technology and Informatics 134, Amsterdam, IOS Press, 2008.

[15] Georgiadis C, Flexible Team-Based Access Control Using Contexts, SACMAT'01, May 3-4, 2001, Canutillo, USA.

[16] Guiri L and Iglio P, Role Templates for Content-Based Access Control, In Proceedings of the Second ACM Workshop on Role Based Access Control (RBAC 97), Virginia, USA, 1997.

[17] Kumar A, Karnik N, Chafle G, IBM, India Research Laboratory, India.

[18] Li W, Kilander F and Jansson G, Towards a Person-Centric Context Aware System, Swedish Royal Institute of Technology, Sweden, liwei@dsv.su.se.

[19] Zhang G, Context-aware Dynamic Access Control for Pervasive Applications,

www.caip.rutgers.edu/papers.

[20] Adam N, Atluri V, Bertino E and Ferrari E, A Content Based Authorization Model for Digital Libraries, IEEE Transactions on Knowledge and data Engineering, 14 (2), March/April 2002.

[21] Covington M, et al., A Context -Aware Security Architecture for Emerging Applications. In *Proceedings of the Annual Computer Security Applications Conference*, pages 249-260, Las Vegas, NV, USA December 2002.

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Spatial Electronic Health Record for the epidemiological clinical data

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Abstract: The present work aims to describe a methodological schema for the development of an Electronic Health Record (EHR) that can be potentially used as a statistical analysis tool for accidents, linking these records with geographical databases and techniques of Geographic Information Systems (GIS). The current work describes the development of an EHR in which demographic and clinical data are analyzed and combined dynamically. This model provides statistical data as well as graphical representation of data in order to provide information in regard to a series of parameters related with accidents. Moreover, registered data such as the geographic area of the accidents can be exploited to conduct further geographical epidemiological analysis. This fact will lead to a better understanding of the dynamic parameters of health. The role of geographical information in the health sector with the use of GIS systems is supported with the use of the spatial analysis as well as with relevant supportive tools. A suitably designed pseudo-GIS system can potentially indicate geographical areas that run through future danger for increased prevalence of accidents. Consequently, it can contribute to the better understanding of the health status of local study populations enabling healthcare interventions. It can also be used for the improvement of problematic infrastructures which could potentially lead to increased number of accidents.

1. Introduction

Hospitals have a long road ahead to adoption of electronic health records with main functions: Order entry, Results management, Electronic health information/data capture, Administrative processes. Larger hospitals were further along in EHR adoption than were mid-sized or small hospitals and non rural hospitals were slightly further along than were rural hospitals. For these reason, it is crucial to develop an efficient, real-time EHR environment for monitoring and analyzing epidemiological changes, introducing healthcare policies.

Electronic health record systems hold the promise to address the two most crucial challenges to the healthcare system: controlling costs and improving quality. An electronic health record is a digital collection of a patient's medical history and could include items like diagnosed medical conditions, prescribed medications, vital signs, immunizations, lab results, and personnel characteristics like age and weight.

Moreover geography plays a major role in understanding the dynamics of health, and the causes and spread of disease. The classic public health triad composed of man, agent/vehicle and environment emphasizes the importance of geographic location

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(environment or space where we live) in health and disease. Interactions within this triad can also change with time.

The main idea behind this work is the implementation of a real-time EHR environment, leading to epidemiological analysis combining geographical information for the evaluation of the healthcare sectors. Statistical analysis and graphical presentation tools have been included inside the system, for the analysis of the clinical data. Due to this geographical information, spatial databases could be used to support the proposed system. Main characteristic of these databases is the capability of managing large collections of relatively simple geometric objects (maps). The main application driving research in spatial database systems are GIS. For that reason, a GIS system has been develop to target resources for disease prevention by highlighting areas with significantly high rates, and to predict which areas might be at future risk and which may benefit most from future local population screening. GIS provide the capability to perform two types of spatial analysis that could not be performed without GIS: finding areas of high disease incidence that can be labeled as statistically significant and worthy of further investigation, and examining the spatial relationship between disease incidence and information that is geo-referenced differently from the disease data.

2. Introduction to Electronic Health Record (EHR)

Electronic health (e-Health) has become a very important area of focus and activity in multiple domains, such as health promotion, health care and maintenance, public health, medical science, health service, data management, image processing, telecommunication, wireless network, and operational research. A carefully designed Health Information System which includes various fields related with the health of injured could be used as a tool for the extraction of statistical information regarding their health. In 2004 the Utrecht study [1] combined the traditional epidemiological studies with the strength of the Electronic Health Record that is being kept in Primary Health Care Facilities. Such a reformed Information System could be based not only on health data fields, but also on secondary information that may be correlated with specific health conditions. Thus it can be used as a tool for the research and the fulfillment of epidemiological studies by extracting the data from the Information System. The development of a unique Electronic Health Record for the registration of patients injured by accidents aims to be used as a tool for the surveillance of various parameters concerning the specified population, as well as for the extraction of epidemiologic information from the database of the EHR.

The EHR, as defined by the Medical Records Institute, is electronically maintained information about an individual's lifetime health condition and health care. A comprehensive EHR at the point of care could be created by aggregating and sharing data among all sites at which patient receives care, as well as with data supplied by the patient. To share and use data from multiple institutions, data must be built upon common words (data elements and terminology), structures, and organizations (interoperability). The EHR has the ability to generate a complete record of a clinical patient encounter, as well as supporting other care-related activities directly or indirectly via interface - including evidence-based decision support, quality management, and outcomes reporting" (Figure 1).
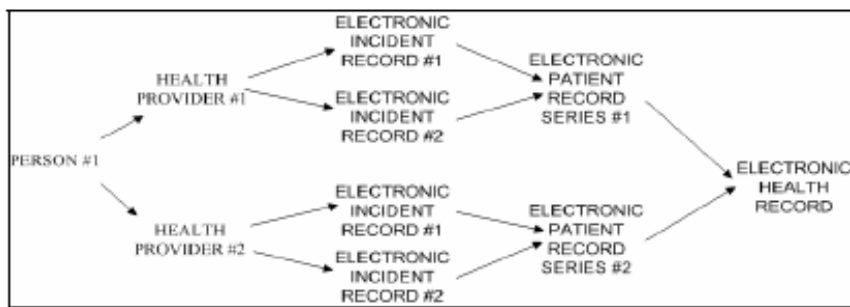
Figure 1. Creation of an electronic health record

3. Methodology

A health information system for the epidemiological study takes into account specific parameters that are related with accident types. All fields that have been included into the system either health or patient related have been standardized and given a specific range of values to select from. The health and other related fields of the database have been structure in a way that ensures that every time is a new entry, the system labels this entry with an appropriate number code that will be used for the statistical functions of the system.

Every database table used as reference table to given values to other tables contains a non auto-number primary key (identifier) that has been set by the database designer. The key values of these fields are identical to the desired coding of the values that will be used for statistics. Normalization of the databases is performed keeping in mind how exactly we intended to utilize the data.

The database application that has been used for the development of the EHR build based on Microsoft Access 2007, which is considered as an all in one solution for Database and User Interface environment development. The fields included in the EHR are based on the handwritten patient data that is being collected in a Greek Island hospital. The system holds all the personal and medical information of each patient. Although the rules of minimizing data redundancy suggest that the information should be split into different tables.

The sections of information have been split into 3 Categories: the Demographics information of the patients, which are Name, Surname, Age, Gender, Home Address, and Place of Birth. The second section involves the health record like Medical Interventions, Blood Test, Diagnosis and Other Examinations. The sub sections regarding the health record includes a list of Diagnostics which takes values from an additional table with the International Classification of Diseases ver.10 (ICD10), the Blood Test with the fields Date of Exam as well as an additional 17 fields of relevant blood test results (i.e. Ht, Blood Sugar, K, Na, etc) and the Medical Interventions with the fields: Date of Intervention, Description of Intervention. Finally, the third section includes the Admissions which are the Date of Admission, Date of Exit, Days of Stay, Accident Type, Place of Accident, Loss of Consciousness (Yes-No), Comments.

The fields of interest that have been selected for further exploration consist of the following pairs:

- Age-Days of Admission
- Diagnosis-Type of Accident,
- Blood test results-Age,
- Type of Accident-Days of Admission
- Type of Accident-Admission to Athens

The above sections of information are organized into the Information system accordingly. The manipulation of the collected information includes descriptive statistics (mean, mode, standard deviation) and non-parametric statistical test (Pearson chi-squared). These tests have been incorporated into the system through an integral user interface. The correlation of the specified variables is performed in database-level by the transformation of the various correlation test function into SQL code (Figure 2).
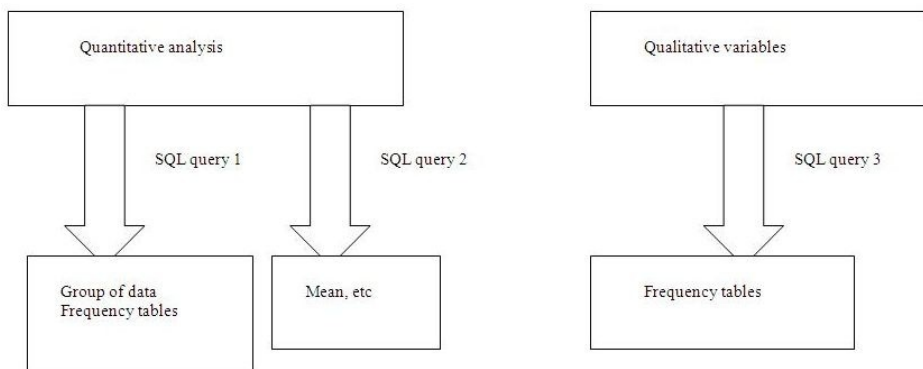
Figure 2. Descriptive statistics of quantitative and qualitative variable

SQL stands for Structured Query Language. It is standard interactive and programming language for programming interactive communication with databases through a Database Management System (DB MS). Using SQL, one can retrieve data from a database, create database, and database objects, add data, modify data, and perform more complex functions. The SQL system is acceptable by database programmers, thus minimizing compatibility issues and enabling the easy exchange of information among different systems. The correlation of the specified variables is performed in database level by the transformation of the various correlation test function into SQL.

The user interface of the system provides (Figure 2): the Electronic Health Record, the graphical presentation of the collected data through of forms which provide access to the diagrams that were described above, and the dynamic graphical presentation of certain health and demographic parameters in a a series map of the island of Samos, which depicts the values of these parameters in the various areas of the island.
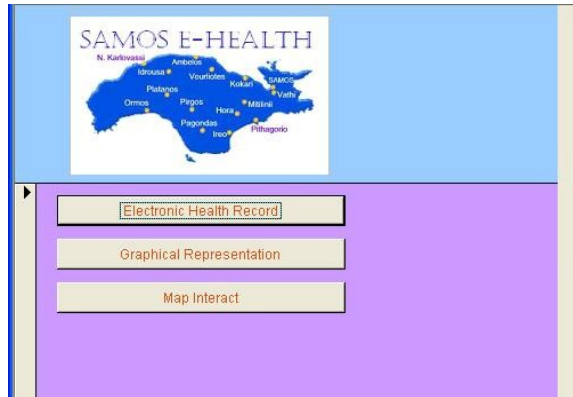
Figure 3. Startup screen of the Information System

The Electronic health record incorporates all given options through a single screen, which provides access to all patient data (Figure 3). The form is split into two parts. The above area contains the demographic data of the patient (Patient ID, Surname, First Name, Age, Gender, Home Address, and Place of Birth).

Figure 4. The Electronic Health Record Form

The bottom area includes the admission data of the patient that has been selected (Date of admission, Date of Exit, Days of Stay to the hospital, Type of Accident, Area of Accident, Admission to Athens, Loss of Consciousness). The diagrams are being updated automatically after each modification of the patient data. The diagrams appear in Visual Basic forms, which can be accessed through the unified Electronic Health Record environment (Figures 2).
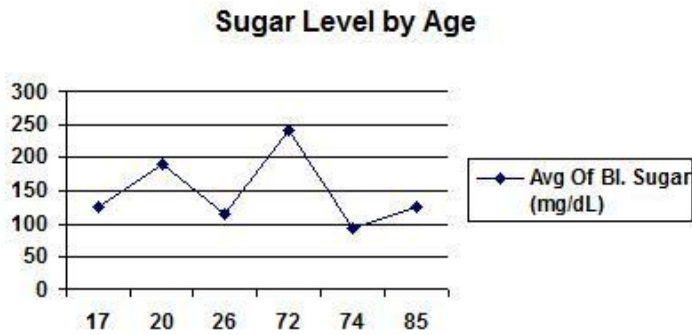
Figure 5. Blood Sugar Level by Age

Presentation of demographic and health information of the patient population could be provided through a pseudo-GIS interactive map of the Samos Island. Geographical Information System (GIS) is a system of hardware, software, data, and people to collect, store, analyze, manipulate, model, visualize, and disseminating information about specific areas [6-9]. Geographical Information Systems (GIS) can be used to undertake spatial analysis, quantitative representation and modeling of spatial data; making them fit for population analyses which uses attribute data about humans in order to get the size of population, its composition, characteristics, and how they are and will be spatially distributed. Data are normally collected at the point level (individuals) but it is always available spatial entities (e.g. administrative units) to allow tabulations according to various data characteristics and demographic analysis using statistical techniques. GIS, with its spatially referenced data and spatial analysis tools can provide solutions to display 2D or 3D spatial data [10-12].The interactive maps have been created by using links behind each map area. Each link enables the execution of a specific query that refers to the selected area (Figure 3).
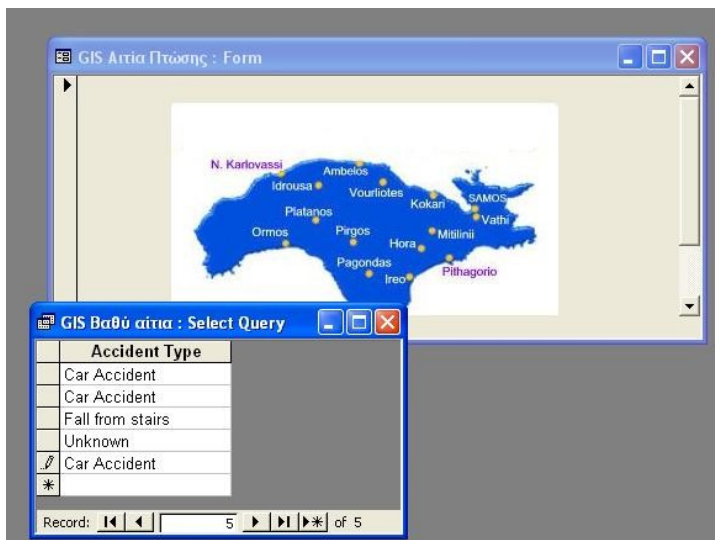
Figure 6. GIS: Accident type by Area of Accident

4. Conclusions

The main purpose of this work is to develop an effective real-time Electronic Health Record (EHR), for the storing and analyzing of clinical data, combined spatial Databases and GIS techniques. Combination of these functions graphical presentation could be used for monitoring diseases mapping as well as healthcare management policies. These monitoring results could be used as pilot directions for the spatial epidemiological analysis taking advantage geographical information for understanding the dynamics of health.

Statistical analysis and graphical presentation tools (based on spatial Databases) have been included inside the system, for the analysis of the clinical data. Main characteristic of these databases is the capability of managing large collections of relatively simple geometric objects (maps). Finally, a pseudo-GIS system has been develop to target resources for disease to predict which areas might be at future risk and which may benefit most from future local population screening.

Reference

[1] Grobee D, Hoes A, Verheij T, Schrijvers A, van Ameijden E, Numans M. The Utrecht Health Project: Optimization of routine healthcare data for research. European Journal of Epidemiology. 2005; 20: 285-87.

[2] Majeed A. Sources, uses, strengths and limitations of data collected in primary care in England. Health Stat Q. 2004;21: 5-14.

[3] Thiru K, Donnan P, Sullivan F. A validated logistic regression model to identify coronary heart disease patients within primary care databases in the United Kingdom. AMIA AnnuSymp Proc. 2003; 1030.

[4] Mansson J, Nilsson G, Bjorkelund C, Strender LE. Collection and retrieval of structured clinical data from electronic patient records in general practice. A first-phase study to create a health care database for research and quality assessment. Scandinavian Journal of Primary Health Care. 2004; 22(1): 6-10.

[5] Fuke D, Hunt J, Siemenczuk J, Estoup M, Carroll M, Payne N, Touchette D. Cholesterol management of patients with diabetes in a primary care practice- based research network. Am J Manag Care. 2004; 10 (2 Pt 2): 130-6.

[6] Harris, B. (1989), Beyond Geographic Information Systems: Computers and the Planning Professional, Journal of the American Planning Association, 55, 85-90.

[7] Harris, B. and Batty M. (1993). Location Models, Geographic Information and Planning Support Systems. Journal of Planning Education and Research, 12; 184-198.

[8] Klosterman, R. E. (1997). Planning Support Systems: A New Perspective on Computer-Aided Planning. Journal of Planning Education and Research 17, no. 1: 45-54.

[9] Klosterman, R. E. (1999). The What if? collaborative planning support system. Environment and Planning B 26: 393-408.

[10] Chou, Y. (1997). Exploring Spatial Analysis in Geographic Information Systems. Santa Fe, OnWord Press

[11] DeMers N. M. (2000) Fundamentals of Geographic information system, Wiley and sons, New York, USA

[12] Tomlin, C. D. (1990). Geographic Information Systems and Cartographic Modeling. New Jersey: Prentice Hill.

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Biometrics in the Health Sector: Lights and Shadows of a Sophisticated Technology

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Abstract. Biometric technologies are retained an important tool in the field of eHealth and telemedicine, as a valid alternative to pin and password in accessing the patients' electronic data. The scenario is fairly new because just recently the availability of high speed networks and increasingly less expensive storage media, has made it possible to store very large volumes of data accessible also from remote locations. On the other hand, medical data are unanimously considered very sensitive, therefore requiring sophisticated security technology to prevent undeserved access to the information. The biometric technologies are proving to be highly useful in significantly increase the security of transactions bur, at the same time, may present some complex aspects that should be carefully considered and evaluated. The present paper aims to analyze some of these critical points with particular reference to the context of eHealth and telemedicine. As a matter of fact, the applications in the medical sector, and in particular those concerning some categories of users such as the elderly patients, require a special level of attention due to the problems connected to the ageing.

Keywords. Biometrics, Security, eHealth, Telemedicine, Accessibility, Ageing

1. Introduction

The experience gained so far in the brief but intense history of eHealth and telemedicine has clearly shown that the problems connected with the personal data protection may represent a factor particularly critical.

If patients are not confident that their information is acquired, transmitted and stored in a secure and confidential way, they will probably not be keen to reveal accurate and complete information. If health-care providers are not confident that the organization responsible for the management of the records will keep them secure and confidential, they will probably limit the disclosure of data. In both cases, these limitations of trust lead to inferior health care [1].

In these last years the technologies based on the biometric recognition have been proposed as an innovative and affordable tool for Identity Management procedures adopted for the secure access to medical data.

As a matter of fact, the technologies based on biometric recognition have reached a very high level of affordability and, on the other hand, it is a diffused opinion that the possibility given to patients to access their own medical data on the basis of credentials

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based on a physical or behavioral characteristics may improve significantly the level of security and confidentiality of the transactions.

Provided that several logistic and legal aspects linked to the "biometric" access to medical data, such as the management of the emergency cases or the delegation of authority to a third party, have to be still completely cleared, new issues, highlighted by the first massive real-world applications based on biometrics, are emerging as particularly critical moving the attention of the research community from the technology aspects to the legal and social contexts of biometrics.

In particular, a strong attention is actually devoted to the accessibility problems which take into a right account the well establish fact that, because of several factors, the biometric recognition can't be used by all.

Other than various evident physical or behavioral impairments that may make difficult or impossible the use of a biometric system, the term "biometric disability" indicates various factors that may strongly impact, at different levels, on the performances of a biometric system.

In some cases the "biometric disability" may be linked to the age of the users and this is particularly relevant considering that the population of the health-care systems is generally composed of a high percentage of elderly patients.

In discussing these points of complexity related to the accessibility and usability contexts, for the sake of brevity, the present paper will consider only three biometric technologies (recognition of fingerprints, iris and face). They should be considered the most popular also in the light of their usage in the new electronic documents and for the automated immigration procedures.

The remaining part of this paper is organized as follows: Section 2 introduces the biometric technologies highlighting the intersections with the eHealth and telemedicine contexts; Section 3 analyzes some critical points of biometric technologies, both conventional as related to specific categories of users; Finally, section 4 focuses on the conclusions and on the possible future continuation of the research.

2. Biometrics

Biometrics (biometric recognition) is defined as the automated recognition of individuals based on their behavioral and biological characteristics [2].

The main characteristics measured are face, fingerprints, hand geometry, handwriting, iris, retinal, vein, and voice. Other modalities are in various stages of development and assessment and, among these, the analysis of the different hand's vascular patterns seem very promising and are rapidly becoming popular.

Biometrics is becoming the foundation of an extensive array of highly secure identification and personal verification solutions [2] and may be considered the pivot of innovative eHealth Identity Management architectures in which the pins and passwords may be complemented or even, in some cases, replaced by the evaluation of the behavioral and/or physical characteristics of the users.

The research on the capabilities of biometrics in eHealth and Telemedicine is boosted by the recent availability and adoption of standards for the exchange of diagnostic images and by the significant decrease of data storage costs linked to the high increase of data transfer rates.

Several research or pilot programs, many of them developed in the framework of the European Community, have suggested the creation of centralized or distributed archives of patients' medical data.

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[2] In the context of the standardization (ISO/IEC JTC1 SC37 "Biometrics"), "Individual" is restricted in scope to humans.

The secure access to such massive medical information, considered to be very sensitive data, represents a very critical factor and the use of biometrics has undoubtedly a strong appeal thanks to its ability of increasing the security and confidentiality of the accesses.

3. Critical Points

Although all the advantages offered, the biometric technologies, as it is well known, present some critical points.

Some of these are related to the essence itself of biometrics, other are linked to other parameters as it will be shown in the next sections of this paper.

3.1. Traditional sources of errors

Uncertainty in the precision of acquiring and comparing biometric data raises risks of different kinds associated with false acceptance and false rejection of biometric credentials. False acceptance has the more significant impact—if a user who has not enrolled biometric data is ever authenticated, this represents a serious breakdown in the security of the overall system. On the other hand, false rejection is more of an inconvenience for the individual—they have correctly enrolled data, but the device has not authenticated them for some reason. The degree of uncertainty varies between devices for the same type of biometric data and between different types of biometrics [5]. The two parameters which measure the two probabilities of errors are respectively the False Acceptance Ratio (FAR) and the False Reject Ratio (FRR).

3.2. Some sources of errors depending on specific technologies

3.2.1. Fingerprint

Users need to have clean and naked fingers. This demand could lead to potentially dangerous delays in time-critical situations, especially in intensive care [4].

Moreover, it has been evidenced that certain work activities involving contact of fingers with special abrading or chemical agents can alter the papillary reliefs of fingertips with possible implications for biometric technologies based on fingerprint recognition.

3.2.2. Iris recognition

Atropine drops (or other medical drugs) may be used to dilate the pupil. Dilating drops work on one of two principles: they either stimulate the iris muscle that opens the pupil (the dilator), or prevent action of the iris muscle that closes the pupil (the sphincter).

A dilated pupil reduces the chord of the iris and therefore adds a degree of difficulty to the biometric recognition.

3.2.3. Face recognition

Every change in the face aspect of a user may be reflected by a certain amount of error in recognition. With particular reference to the health sector, various pathologies, such as, for example, the Bell's palsy, may pose a problem to face recognition biometric system.

3.2.4. Age related errors

As premised in the introduction, it is particularly significant that, for many biometric technologies, the best performances are reached in a specific range of the users' age.

Leaving out the various physical, societal and ethical problems related to the acquisition of the biometric characteristics from children, in general terms, it can be stated that the difficulties in using a biometric recognition, increase with the age of the users due to the natural "evolution" of the body.

For example, elderly generally experiment a thinning of the papillary reliefs and an increased dryness of the skin. This may represent a problem for biometric system based on fingerprint recognition [3].

Even the iris, which is a biometric feature generally considered to be unchanging over the time, can lead to recognition errors if the user is subject to eye surgery. For example, cataract removal, an operation relatively common for elderly, requires the user to register again in a biometric system because it is possible that the iris characteristics have been altered significantly by the operation.

Due to different motivations based on the ageing process of the face skin muscles and structure, also the methods based on biometric recognition of face may become critical for elderly.

4. Conclusions

Biometric technologies can represent an important support in accessing to medical data in the contexts of eHealth or telemedicine.

However, the adoption of the biometric technologies which offers the indisputable advantage of increasing the level of security of the transactions, (a factor of primary importance in the medical data management), should be carefully evaluated in terms of a correct consideration of the various parameters that characterize the application.

In particular, if such parameter is the age of the users and the population of the users is is characterized by a considerable number of elderly subjects, it should be considered that the level of complexity of the biometric application increases according to a mathematical law which, in general terms, is a function of the age of the users.

It should anyway evidenced that the studies on the biometric applications concerning disomogeneuos and fragmented population of users are still in a first stage and only the real-world applications will probably provide valid and useful answers.

At the same time there is no doubt that such studies, with specific reference to massive applications, are mandatory to evaluate the limits of the biometric recognition based on a single factor and the capabilities offered by other approaches such as multibiometrics.

References

[1]   Savastano M, Hovsto A, Pharow P and Blobel B, *Identity-management factors in e-health and telemedicine applications*, Journal of Telemedicine and Telecare 2008; 14: 386–388 DOI: 10.1258/jtt.2008.007014

[2]   http://www.biometrics.org/introduction.php (last accessed 11.10.09)

[3]   Roizenblatt R, Schor P, Dante F, Roizenblatt J and Belfort Jr R, *Iris recognition as a biometric method after cataract surgery*, available at http://www.biomedical-engineering-online.com/content/3/1/2 (last accessed 11.10.09)

[4]   http://www.ehealtheurope.net/news/3387/austrian_hospitals_get_fingerprint_biometrics (Last accessed 11.10.09)

[5]   http://encyclopedia.jrank.org/articles/pages/6557/Biometrics-Security.html (last accessed 11.09.09)

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[3] This issue is well known to the biometric system which advice to avoid to acquire the fingerprints of the elderly users. This rule is applied also in some massive immigration procedures based on biometrics.

PERSONAL PORTABLE DEVICES

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EFMI Working Group PPD on Personal Portable Devices:
History and Evolution, Mission and Vision

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Abstract. The healthcare and welfare systems all over the world are aiming at actively involving patients and health professionals into the provision of healthcare and welfare services. Especially citizens shall be entitled to take over a higher level of responsibility for their own health status. Applied and convenient technologies like, e.g., Internet, notebooks, and mobile phones enable citizens to actively participate in treatment and rehabilitation regardless whether they are at home or abroad. It's not any longer just data cards in healthcare; it's an ongoing and standard-based personalization of all health services including the application of portable devices, sensors, and actuators including extended communication network features. This stipulates the personalized health approach as it offers the chance for practicing high quality wireless personalized shared care. The seamless path from smart cards and similar tokens to personalized portable mobile devices tackles aspects like the personal health advisors, RFID technology, Near Field Communication, the Electronic Health Record (EHR), chips, and smart objects. It is important to identify criteria and factors determining the application of such personalized devices in a safely and wirelessly operated healthcare and welfare of today and tomorrow. These ongoing processes enforced the paradigm shift from cards to secure wireless devices to mobile sensors, and the citizen's acceptance of underlying technologies. The EFMI Working Group "Personal Portable Devices (PPD)" aims at supporting and guiding the paradigm shift on a European level collaborating with domain-specific associations, federations, and institutions world-wide, and liaising with Standards Developing Organizations (SDO) for introducing new technical approaches and standardization activities as well as supporting emerging implementations in the PPD domain.

Keywords. eHealth, pHealth, device, wireless service, sensor, interoperability, personalization, user profile.

1. Introduction

Cards have widely been used in healthcare and welfare applications for more than 40 years. Seriously taking an increasing mobility of both patients and data into account, such portable "devices" have long been considered the best choice for the citizens (in terms of the ID functionality) and patients (in terms of access to their medical data) regardless whether being at home or abroad. Many countries in Europe and beyond still plan the nation-wide introduction of reader-dependent (contact) and reader-independent (contactless) patient data cards with or without medical data, respectively. It has indeed been a long way from the invention of cards in the late 1960s to a new generation of personal portable devices supporting Europe on its way to a united and healthier continent. Those PPD can be personal devices in possession of patient or citizen; they

can be personalized devices bearing personal information of their holder, or they can even be personalizable devices bearing ID-related information whenever required.

Mobile phones including health-related functionality are well-known and well-applied for different purposes in many countries. Sensors and sensor networks already applied in various industry domains (like power plants, natural oil and natural gas production) can and shall help providing both health services to individuals (personal health) and collect personal and patient-related medical information [1]. Personal portable (wireless) devices (PPD) are more and more going to play an important role in the context of modern Health Information Systems and the pathway towards the future moving the "wireless patient" into the center of all processes in the healthcare and welfare sector [2]. A standard-based personalization of these services is a pre-requisite for guaranteeing a seamless access to, and provision of care for all.

2. The History of EFMI WG PPD

The EFMI Working Group (WG) "Personal Portable Devices (PPD)" was established in December 2003 under its previous name WG "CARDS" with the aim of continuing the most relevant activities of the former eEurope Smart Card Initiative (eESC) and its "TrailBlazer 11 (TB1)" on "Health Cards". The TB11 documents are now hosted by the WG, although they now enjoy a status that is more one of historical reference than forward-looking and "trail-blazing" as they were when first written.

WG CARDS aims were to be a European competence center to watch relevant ongoing activities and to provide knowledge to policy makers, architect designers, and developers involved in the deployment of cards-based projects in Europe and beyond. Many such projects took advantage of the information and knowledge that the WG offered. The scope of projects varied from localized implementations, national initiatives through to international.

During the WG's first few years there was a strong focus on the smart card as, at that time, it offered, relative to other approaches available at the time, a convenient and low risk mechanism to needs such as personal identification, proof of entitlement, data portability and transfer. The healthcare environment for such technologies was, and still is, a very challenging one especially when compared, for example, to the transport environment. Smart-card based ticketing is now so extensive used that it is hard to imagine the time when the majority of issued tickets were hand-written; in this time, a manual ticket inspection was the only option. But the result of an error in transcribing or reading a travel ticket is unlikely to cause loss of life – a possible and tragic outcome of such an error in a typical situation in the medical domain.

Progress on implementing card-based healthcare systems proceeded at a cautious pace. Some countries made a positive decision not to implement at all; others addressed care administration and finance only. Many countries are still scheduling the introduction of patient cards on a national level. The European Health Insurance Card (EHIC) has been introduced in almost all EU countries, and its electronic successor, the eEHIC, is being addressed in standardisation and EU's political decision making. Cards are rarely used in the actual delivery of healthcare.

Cards, whether bearing only a magnetic stripe, a data-storage chip, on-board processor, contactless technology or any combination thereof had found their place; and by 2007 the smart card was no longer a novel and innovative solution. The smart card was tried and tested; its role was well defined; implementations were sufficiently advanced; and knowledge of the strengths and limitations of smart card technology was widespread [3]. Initial limitations of on-card memory capacity and processing power were rapidly being overcome with advent of ever smaller yet more powerful chips. The need for an international centre of knowledge was diminished [4].

In parallel, and never in the scope of the previous WG CARDS, were innovations in computer-readable "tags" on physical items. Such technologies include: Optical Character Recognition (OCR); Magnetic Ink; linear then 2-dimensional Barcodes and other glyphs such as coloured matrix codes; RFID (radio frequency identification) tags, and related Near Field Communication (NFC) solutions.

Here is the convergence: the RFID tag is little more than a contactless smartcard without the plastic; and a 2007 smart card could boast more memory and more processing power than a personal desktop computer from the previous decade.

3. The Evolution from CARDS to PPD

In the beginning of 2007, the strategy for WG CARDS was clear: evolve ahead of the technical capability, and therefore the application domains, of the "portable computer". In healthcare and welfare, these application domains cover administration and delivery of care and services. Delivery of care encompasses monitoring of patients receiving care and, ever-increasingly reaching towards the lower end of the risk spectrum, those merely at risk of needing care.

At the same time, the care and service delivery paradigm moved from an organization-centered to a person-centered approach. The patient was put in the center of any care-related procedure. Along with that, patients and increasingly also citizens were asked to take over a higher level of responsibility with regard to their own health status. This paradigm shift included new aspects of wellness, life style, and dietary recommendations rather than just focusing on the pure treatment of persons currently being a patient [5].
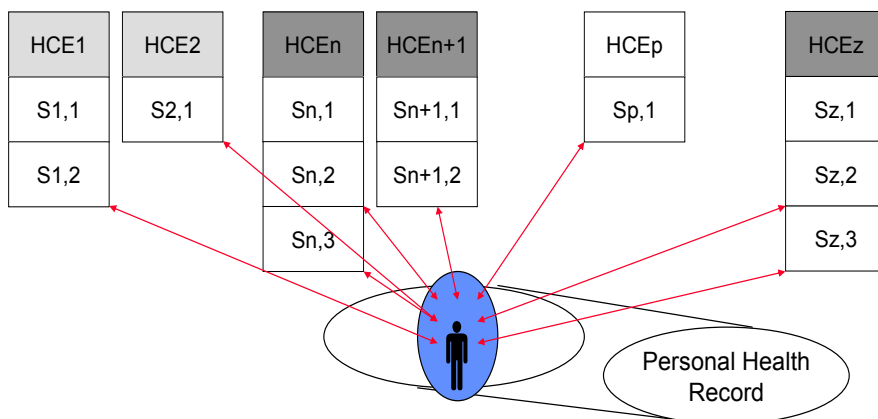
Figure 1. The Personal Health Approach [5]

Evolution is not, however, accomplished in a single transformation. Many steps are needed to go from simple cards to advanced medical devices [6].

For example, an intermediate step could be the appropriate use of intelligent devices as personal health and wellness advisers. The technology could include an RFID-based drug sensor device, implanted smart sensors, and a nano-computer. Such chip-based solutions enable pro-active care and build a component of what might be called cyber-health. New generation personalized electronic identity gadgets allow the proven concept of universal personal electronic access control tools for healthcare and welfare services.

It is also easy to envisage how combining "in/on-body" devices with personal electronic healthcare record (PHR) system and graphical interactive user interfaces would expedite symptom reporting and diagnosis and enable data exchange with patient records held by healthcare providers [7].

Even if other application domains may have already used and applied this kind of technology for their own purposes, these futuristic healthcare and welfare scenarios are just those – they are futuristic.

The WG CARDS needed to find a realistic but future-looking focus; and a future-proof name. This name is WG "Personal Portable Device (PPD)"; the focus is on managing identity and entitlement aspects in healthcare and welfare without leaving technological trends behind. In other words – cards and card-related projects are still in the focus of the WG. This paradigm shift towards a device-related approach required new collaboration activities and new liaisons as well.
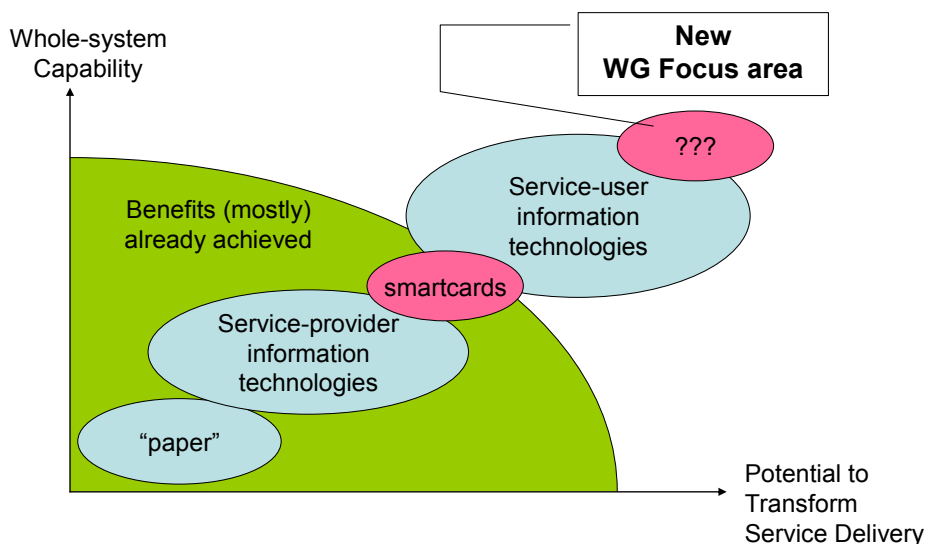
Figure 2. Technological Paradigms and WG Focus

4. The New Mission of WG PPD

The new mission of the EFMI WG PPD after 2007 was to focus open-mindedly on the technology needed to support Identity Management (IdM) and Entitlement Management (EnM) in healthcare and welfare. This technology approach goes far beyond traditional card-related use cases without leaving the domain of health cards behind. Cards and tokens are more and more part of a personal and personalized portable device.

Identity Management includes services necessary to establish relevant personal details that might include: full personal identity, personal ("account") identification or personal entitlement. The delivery of person-related and safe healthcare and welfare services includes various services necessary for the administration and the provision of all care services (primary acute care, secondary care and tertiary care whether in care establishments, in the home or mobile). Ambient Assistive Living as a domain shall in this respect be tackled by the WG activities. Respective devices need to actively support all these application areas, and introduces new horizons for patients while being abroad regardless whether as a businessperson or on vacation.

Such portable and personalized devices in healthcare and welfare do not have one single purpose only. Devices can act as value tokens, data carriers, and many more things, often anonymously. The range of purposes is as broad as processes involved in the delivery and administration of care services. Where personal devices are used in the delivery of care they are being used in situations where the patient's life may depend upon the availability, integrity and accuracy of information stored on them or accessed using data stored on them. The WG recognises situations where the person needing care is not able to directly and personally participate in the identity management process (through, e.g., permanent or temporary physical or mental incapacity) or where their portable personalised token is not usable (e.g. the token is missing or destroyed, or remote computers are not available).

A comprehensive usage of intelligent portable personalized tokens and related devices for Identity Management requires a high level of awareness, confidence, and acceptance among all addressed stakeholders and communities (patients, citizens, health professionals) by their active involvement and empowerment.

The WG therefore orients on different technologies including mobile ones for such intelligent portable personalized tokens and their use to enable proportionate validation of personal details in all situations where health or welfare care is needed, or where related services are needed to provide. The active support of mobility is thus a key success factor in a society that is mainly based on the flexibility of persons and data.

The WG PPD members consider that it is vital to provide authoritative guidance on the type and content of information stored (and processed) on such a token compared to that held on a remote computer. This addresses security and safety alike, and requires an active collaboration with organizations, institutions, and working groups inside and outside of EFMI that focus their work on the respective aspects.

The WG PPD recognizes that there are many options for the form-factor of such a portable personalized token (and device) for their use in secure Identity Management applications such as mobile phone, smartcard, USB sticks, RFID tag embedded in a personal item, and NFC technology, etc.

As the addressed topics require advanced interfacing with other experts, the WG PPD foresees and actively supports a close cooperation with other EFMI WGs in the domains of Security, Safety and Ethics, Electronic Health Records, Human Factors, Nursing, Primary Care, and others. The WG furthermore aims at generally interacting with other organization and groups in the domain of mobile portable devices (not currently addressed by any other EFMI WG).

This kind of active collaboration and exchange of information is needed to be presented to both WG members and interested parties. WG PPD has therefore been actively involved in the preparation of various workshops, seminars, and sessions that have addressed the WG-relevant topics.

5. Current Activities of WG PPD

As the new branding and purpose of the WG needed to be established, the WG organized several dissemination activities during the course of 2008 and 2009. This has mainly been done in two ways.

Firstly, the WG distributed relevant calls for contributions for events related to PPD aspects, and invited the WG members and any other interested party to submit papers, posters, and demonstrations reflecting WG PPD as an active contributor and a supporter of the respective event. Several members submitted their publications to the various events identified, and informed the WG chairpersons about additional events in the focus of the WG.

On the other hand, active members of the WG were directly contacted by the WG Chair and Co-Chair during 2009. Supported by these members, the WG PPD proposed a

series of domain-related sessions, seminars, workshops and other promotion activities to several events related to PPD aspects.

EFMI WG PPD submitted a proposal for organising a seminar at the pHealth 2009 workshop in Oslo, Norway, as a joint activity with ISO/IEC JTC1 SGSN and ETSI TF HF. Attracting more than 200 attendees, pHealth 2009 focused on the application of personalized health services. The PPD/SGSN seminar offered 7 different presentations on various aspects of PPD-related health services but also basic services like personalization and general aspects like ethical questions and the human factor in a technology-oriented healthcare and welfare domain. More than 70 attendees intensively discussed with the speakers and chairpersons about the presented aspects, and about 40 of the attendees signed in for an interests' list with the purpose of informing about future events in the domain, and with the aim of getting them interested in a future EFMI WG PPD membership.

In terms of a permanent promotion of the WG PPD aims, goals, objectives, and achieved results, the next dissemination activity initiated and prepared by WG PPD took in Sarajevo, Bosnia & Herzegovina, during the 2009 Medical Informatics Europe conference (MIE 2009). After the successful workshop in Göteborg in 2008 [8], WG PPD provided for MIE 2009 a three-hour workshop on the topic of "Portable Devices, Sensors and Networks: Wireless Personalized eHealth Services" with 5 invited speeches jointly organized with members of ETSI STF 352. The presentations given addressed the various topics of the current WG PPD work. The attendees again intensively discussed the topics and generally provided positive feedback with regard to current activities and future plans.

For STC 2009 in Antalya, Turkey, WG PPD submitted the proposal for an invited session on "Personalised Portable Devices for Travelers" with 4 invited speeches addressing various aspects of PPD application ranging from the paradigm shift and its consequences to personal health advisers to the aspect of personalization and personal profiles to the underlying technology of GSM. The session has been jointly organized by the EFMI WG PPD members, members from ETSI STF 352, and a number of ISO/IEC JTC1 SGSN representatives.

6. The STC Session Topics

The requirements for safe and high quality care as well as efficiency and productivity of health systems under the well-known constraining conditions are expected to be realized by increasingly distributed and specialized health services that become strongly oriented on the actual personal health status and the needs of the subject of care. Those health services are provided independent of time, localization, and distribution of resources in a highly communicative and collaborative way called eHealth. Personal health regardless whether at home or abroad must be supported by mobile computing for ubiquitous communication, by pervasive computing for comprehensive and pervasive care as well as autonomic computing for adaptive personalized system design enabling ubiquitous care altogether [5].

Future ICT makes it possible to collect any kind of personalized information. This information is considered a combination of a person's legal electronic health record, information collected by a body sensor network (BSN) from motes, life-style information, location information, social care information, sleep data and signals received by implanted nano-sensors. This group of devices makes it possible at any time to collect, store, transfer, and process information about personal health and wellness in any environment, even in such a way that the person may not even be able to recognize the ongoing data collection and processing which is a security and privacy threat. The information produced by such a PPDs is a necessary enabler for pHealth and a personal advisor for behavior, lifestyle, wellness, and medical decision support. From other side it

also creates certain security and privacy protection needs along with a set of ethical questions. Even in the future ubiquitous pHealth environment is it necessary that the person is always aware of who has used or disclosed personal information when, why and what kind of information exactly. Because the pHealth environment is very dynamic, it is also necessary that the subject of information has a possibility to dynamically control at a fine-grained level the use and disclose of information collected via the PPDs. The related new security, safety, and privacy protection requirements need to clearly be addressed in advance.

As the domain of personal health is to be addressed, personalization and effective user profile management will be critical to the uptake of eHealth systems towards personalized portable health service provision. Adapting an eHealth system to the individual user is very essential for making the system safe and easy to deploy and to use as an effective support to independent living. Personalization can thus enhance the user's trust in the system, and make it more readily accepted. It can range from simply setting an alarm volume according to the user's hearing abilities and the ambient noise level, to the complex tailoring of the user's entire eHealth environment. The personalization is achieved by maintaining and updating a user profile which depends on, and is dynamically adapted to, the user's context, general and special preferences, physical and mental abilities, and other relevant parameters. The profile can then be used by eHealth services and devices to ensure a uniform user experience irrespective of context. The unique approach to achieve the goals of personalized eHealth systems is the combination of three important areas: standardization of ICT, human factors, and eHealth services.

Applying personal portable devices to travelers and their specific health needs always requires a technology that guarantees the necessary level of communication. GSM technology can assist in making the lives of citizens healthier and safer. Especially when traveling, the benefits of a cellular technology combined with monitoring can be utilized to the full potential. Optimized care is no longer bound to the home but can continue during travels. The doctor is virtually available whenever and wherever medical support is needed. Continuous technological innovation like the miniaturization of cellular technology and the digitalization of medical technology makes a machine-to-machine connection perfect for a use in the healthcare and welfare domain. When mobility becomes a key requirement, GSM based solutions can provide the answer. Over the past years, the number of wireless solutions in the medical field has grown significantly. Mobile health (mHealth) devices have meanwhile reached a maturity level well above the pilot phase, and the solutions are proven and simple to implement.

7. The Vision of PPD Application

In longer term, the WG PPD activities need to have an influence on the technologies applied to the healthcare and welfare domain in terms of personal portable devices. National, European, and international organizations such as -among others- the World Health Organization (WHO), the International Medical Informatics Association (IMIA), and the Administration for Children and Families (ACF) within the US Department on Health and Human Services (HHS) shall additionally be invited to collaborate with the WG PPD, and to widen the scope of the WG.

Liaisons have already been established with Standards Developing Organizations (SDO), like ISO TC 215, CEN TC 251, ICAO, ISO/IEC JTC 1, and others [9]. Specific emphasis shall be given to a liaison with ETSI in general and their task force on "Human Factors" in particular [10].

For 2010, WG PPD has planned various similar activities inviting not only WG members and liaison partners but also presenters from domains related to PPD aspects. This might lead to a revision of the current WG PPD mission statement according to future trends not only in terms of technology. It also encompasses a variety of legal and

ethical aspects important to rise while looking forward to an Information Society, and an IT-based 21st century world.

Based on the new mission statement, the 2015 vision of the WG is to begin to embrace the personal portable devices needed for care delivery in preventive and remedial situations. This will encompass all of the foundation work – the considerations on micro and nano processors applied on "cards" started in TB11 in the late 1990s; the work on their evolution and application in healthcare as championed and spearheaded by WG CARDS from 2003; and as will be accomplished by the WG PPD of the turn of this decade on Identity Management.

Acknowledgement

References

[1]   Pharow P, Blobel B: Mobile Health Requires Mobile Security – Challenges, Solutions, and Standardization. In: Andersen S.K., Klein G.O., Schulz S., Arts J., Mazzoleni M.C. (Edrs.): eHealth Beyond the Horizon – Get IT There. Proceedings of MIE 2008. Series Studies in Health Technology and Informatics, Vol. 136. IOS Press, Amsterdam, Berlin, Oxford, Tokyo, Washington 2008

[2]   Cheshire P: "Ambient Technology in Care Services" – the Role of PPDs. World eID 2006, Sophia Antipolis, September 2006

[3]   Pharow P, Blobel B: Electronic Health Cards and Respective Health Network Security Requirements. In: Engelbrecht R, Geissbuhler A, Lovis Ch, Mihalas G (Edrs.): Connecting Medical Informatics and Bio-Informatics. Proceedings of MIE 2005, 403-408. Series Studies in Health Technology and Informatics, Vol. 116, IOS Press, Amsterdam, Berlin, Oxford, Tokyo, Washington DC 2005

[4]   Pharow P, Blobel B, Engel E: Cards in Health Telematics Applications - Tool or Token. In: Blobel B, Pharow P, Zvarova J, Lopez DM (Edrs.): eHealth: Combining Health Telematics, Telemedicine, Biomedical Engineering and Bioinformatics to the Edge - CeHR Conference Proceedings 2007, pp. 41-48. IOS Press, Amsterdam, and AKA GmbH, Berlin, 2008

[5]   Blobel B: Introduction into Advanced eHealth – The Personal Health Challenge. In: Blobel B, Pharow P, Nerlich M (Edrs.): eHealth: Combining Health Telematics, Telemedicine, Biomedical Engineering and Bioinformatics to the Edge – The Global Experts Summit Textbook. Series "Studies in Health Technology and Informatics", Vol. 134. IOS Press Amsterdam, Berlin, Oxford, Tokyo, Washington, DC, 2008.

[6]   Hovsto A, Pharow P, Blobel B: How to Achieve Sustainability in Advanced eHealth Sensor-based Systems. Conference Proceedings 13th International ITA Workshop, Kraków, June, 2008. http://www.itw2008.pl/papers/ITW2008proceedings.pdf

[7]   Blobel B, Pharow P, Norgall T. How to Enhance Integrated Care towards the Personal Health Paradigm? In: Kuhn KA, Warren JR, Leong T-Z (Edrs.): MEDINFO 2007, pp. 172-176. IOS Press Amsterdam, Berlin, Oxford, Tokyo, Washington, DC, 2007.

[8]   Pharow P, Blobel B: Mobile Health Requires Mobile Security – Challenges, Solutions, and Standardization. In: S. K. Andersen, G. O. Klein, S. Schulz, J. Arts, M. C. Mazzoleni (Edrs.): eHealth Beyond the Horizon – Get IT There. Proceedings of MIE 2008, pp. 697-702. Series Studies in Health Technology and Informatics, Vol. 136, IOS Press, Amsterdam, Berlin, Oxford, Tokyo, Washington 2008

[9]   ISO/IEC JTC1 SGSN: Creating Ubiquitous Services with Sensor networks. Working Document SGSN N059

[10]   ETSI EG 202 325: 2005, Human Factors (HF); User Profile Management, ETSI, Sophia-Antipolis, 2005

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More than Cards – The Application of Personalized Portable Devices Supporting Travelers Needs

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Abstract. Modern health care systems all over the globe aim at involving health professionals and citizens into the care processes offering health service provision in any place at any time. Citizens are thus entitled to take over more responsibility for their own health status including aspects of wellness, lifestyle, and dietary recommendations. Technologies like the Internet, mobile phones, sensors, actuators, etc. enable patients to actively participate in healthcare treatment and rehabilitation as well as monitoring processes regardless where they are located – at home or abroad. Guaranteeing availability and security/safety of such services, there is a need for a standard-based personalization including the application of portable devices, sensors and actuators stipulating the personalized health approach. This approach offers a real chance for practicing high quality wireless personalized shared care. The application of personal portable devices combined with access to sensor networks aims at identifying criteria/factors determining the application of such personalized devices, sensors, and actuators for wireless networked healthcare and welfare service provision. The topics to address in this paper are based on experiences from national, EU, and international projects, emerging standardization activities, and existing and emerging routine implementations in the domain of personal or personalized healthcare and welfare.

Keywords. eHealth, pHealth, device, wireless service, sensor, interoperability, personalization, user profile.

1. Introduction

Cards have indeed been widely used in the healthcare and welfare domain for about 40 years. Many countries are still planning the introduction of ID cards and patient data cards. The European Health Insurance Card (EHIC) is being introduced in almost all countries within the EU; its successor called the electronic EHIC (eEHIC) is under standardization. However, cards and other security tokens are just single access pieces of rather complex solutions. They need specific readers and infrastructures; they need their related devices. It has been quite a long way from the early 1980s plastic cards to the 1990s chip cards and chips to the 21st century personalized portable devices being just at the horizon. Mobile phones are well-known and well-applied already for various healthcare and welfare purposes in many countries around the world [1].

Cards are able to bear administrative data (access rights, attributes) and medical information (e.g. a basic set of emergency data, allergies, vaccination and immunization

records, specific disease records like diabetes). But they are always limited with respect to their storing capacity and their processing power.

Sensors and sensor networks help providing mobile or portable health services and collect patient-related medical information virtually in any situation. Such personalized portable (wireless) devices (PPD) play an important role in the context of modern Health Information Systems (HIS) and for the pathway towards what may be called the "wirelessly connected patient". Applying them, devices are on the one hand considered to be security tokens bearing keys and pointers to access information stored in networks. On the other hand, such devices can even bear an extract of an Electronic Health Record (EHR) or a Personal Health Record (PHR).

In addition to traditional healthcare and welfare approaches, new requirements arise from the establishment of portable wireless devices including sensors. Specific networks for such sensors shall be implemented for data capturing and data analysis. Solutions from industrial domains like transportation can be adopted and adapted to personal health service scenarios. Sensors need to store not only raw data but also the variance of data outside some predefined levels as these data items may sometimes indicate a very specific and individual health situation.

Analogue to traffic lights, patients' status can be divided into "green", "yellow" and "red". Collected data thus may lead to initiating alarms in "red light" situations of serious health problems. Otherwise, data continuously collected, stored, and pre-processed shall be transferred only upon request, e.g. once in 24 hours as a summary report being later transferred into the patient's EHR or PHR.

Advanced standardization both from a technical and an administrative perspective is underway allowing the achievement of a significant level of harmonization and interoperability of solutions nationally, in Europe, and worldwide [2].

2. Personalization of Health Services

Personal Health (pHealth) requires personalization procedures. This is true in terms of personal profiles as well as in terms of the personalization of devices. pHealth mainly focuses on personalized health service provision and sees citizens in the center. Wearable technologies for personalized health like related portable devices (cards, chips, tokens, mobile phones, sensors, actuators, etc.) are considered first line communication tools [3] for travelers as well as for handicapped citizens at home. These devices can hold medical/clinical data and provide:

- Identification management, personalization, access control, insurance, reimbursement, and entitlement [4];
- Security, privacy, trust, and trustworthiness of health service delivery by allowing advanced standardized privilege management and access control measures partly controlled by the device holder;
- Secure and reliable access to vital signs (parameter data) in routine use as well as in case of emergency regardless of the location of the citizen and the medical unit (monitoring center, hospital, emergency vehicle, etc.);
- Quality of care by providing stakeholders with up-to-date personal health data from everywhere anytime.

Patients increasingly expect to continue their lives in an everyday environment (home, work, vacation, etc.) rather than being hospitalized. The technical and procedural measures of pHealth can support this move to the personal realm, provided the systems can be personalized to fit the needs of patients and carers. Personalization can enhance the user's trust in the system, and make it more readily accepted. Standardized information and preferences need to be stored and made available to eHealth systems [5]. An underlying architecture is needed to manage the respective user profiles. Especially for the health-related needs of travelers, this infrastructure needs to guarantee a convenient

and secure access to information (data, knowledge, etc.) in every place at any time [6], [7].

3. The Processing Infrastructure Services

Personal portable devices including sensors/actuators and related sensor networks in modern healthcare application have great potentials in providing personalized services for chronic disease management, disease monitoring, personal wellness monitoring and physical fitness tracking. The shared processing environment, in which the raw device and sensor data usually are collected, aggregated, processed, and comprised into real high-level context information on the physical conditions of the individual and the current environmental conditions. Such infrastructure should therefore carefully be designed and developed in order to meet the challenges in sensor networks from both the networking and information sensing perspective.

Specific requirements on such kind of information processing based on nano and micro technologies appear to be taken into account when physical entities in modern healthcare application evolve from chip cards to smart cards to intelligent chips to portable devices. The majority of data carried in smart cards, such as personal identification, allergy and disease records, are manually recorded and stored. This leaves room for errors and misinterpretations. Contrary, portable devices and related networks can provide real, physical patient-related information which is collected and pre-processed automatically. The infrastructural services thus need to be resource-efficient in order to comprehensively provide correct, reliable, and completely compiled data for a seamless support of personalized healthcare and welfare services technically based on wireless network facilities like, e.g. GSM.

The pure measurement of sensor and device data is definitely not the ultimate goal of sensor networks. Usable information or even pre-processed knowledge including a basic level of decision support is expected to be obtained from the information processing. In such devices and sensors connected to networks, the processing of information needs to be applied in a shared, collaborative and distributed way (supporting the paradigm of shared care) in order to meet existing and emerging challenges, such as constrained resources of mobile and wireless devices, incomplete and inconsistent information from individual sensors, reliable and correct information gaining, and integrated service providing probably under non-ideal environmental conditions, like noise, interference and unstable communication links. Other conditions like a changing behavior of an individual while physically exercising have to be taken into account as well.

4. PPD Applications Aspects

Personalization, roles and role management as well as the process of collaboratively storing, collecting, and processing information are aspects to successfully be addressed before applying personal portable devices, sensors, actuators, and other medical equipment including the underlying wireless network functionality to the human user in hospitals, monitoring organizations, or citizens' personal environment including citizens residing or temporarily living in other countries (e.g. for business trips, on vacation, or for temporary work).

Various applications, application domains, medical use cases and scenarios in real life and key science fields support the paradigm shift from large (and often static) medical devices (mainly implemented in large institutions) to the world of flexible, mobile nano and micro technology applied either close to the human body, or even inside the body. Challenging aspects of such applications but also aspects addressing security, safety, privacy, quality, etc. will be highlighted in the following.

4.1 Health Service Security and Privacy in future pHealth

The paradigm change from present paternalistic disease management focused an organization-centered healthcare is under way. Major targets of the next generation eHealth are an early detection of diseases and changes in functionality, prediction and pro-active prevention of diseases. In 2020 ubiquitous care is expected to be reality in secondary, primary and personal care settings including temporary setting like, e.g., while being on vacation. Pro-active prevention and (personal) health and wellness prediction services require much wider information than what is collected and available today. Pre-emptive health care services require device-based knowledge of individual's normal functions in order to provide early detection.

The future ubiquitous ICT makes it possible to collect any kind of personal information meaning a combination of person's legal health record, information collected by BSN (Body Sensor Network) from motes, life-style information, location information, social care and welfare information, sleeping data and signals received by various implanted nano-sensors. Typical sources of this information are intelligent ambient analyzers, wearable and implanted sensing systems, e.g. the family of personal portable devices (PPD) applied in pHealth.

Such a PPD makes it possible to collect, transfer and process personal health and wellness related information any time and in any environment, even in such a way that the person is not aware of the ongoing data collection and processing. Especially citizens traveling to foreign countries do not want to be bothered and disturbed by such an information collection but they want their data to be collected and fused. The information collected and pre-processed by various PPDs is thus a necessary enabler for pHealth. On the other hand, it obviously creates new security and privacy protection needs. Even in the future ubiquitous pHealth environment it is necessary that the person is always aware of who has used the personal information, when, why and what information is used or disclosed, and for what purpose. Even in emergency situations when people immediately need medical treatment, the access to those personal data stored in a PPD shall be logged, and shall be traceable later on.

Because the pHealth environment is a very dynamic one with changing medical partners depending on the country of residence and the countries of designation (e.g. when traveling), it is necessary that the subject of information has always a possibility to dynamically control at fine grain level the use and disclose of information collected via his/her PPDs. The successful application and use of PPDs in pHealth applications sets up new requirements both for the security infrastructure and the information models used with PPDs.

4.2 NFC Mobile Phones for Health Service Personalization

One important aspect of applying nano and micro technology to the domain of healthcare and welfare in general and to the pHealth domain in particular, reflects the utilization of recent RFID, NFC and ZigBee technologies in the large scale eID systems [8].
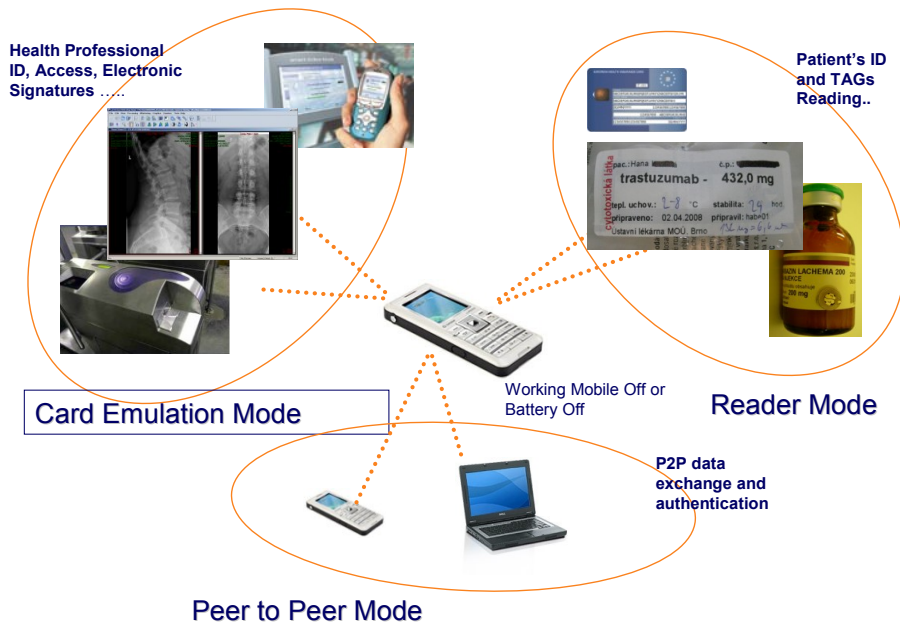
Figure 1. Examples for NFC Applications.

4.3. Current Status

It is to be seen that the contactless identification of subjects interconnected into large systems, the remote management of identities, and the sophisticated data mining creates together rather risky environment in terms of irregular practices. The (very feasible) misuse of administrative information pieces like identities and authorization but also the misuse of, in this case, medical and clinical data of individuals generates huge concerns about appropriate means of privacy protection and next justification of investment into the new technologies at all.

The eHealth stakeholders are not health professionals and patients/insurees/citizens only. More and more, other objects have to be identified, such as remedies, equipment in hospitals regardless whether large or small, biological samples and tissues, and cyto-toxic drugs up to robots servicing patients. Non-deterministic solutions, fuzzy logic and correlations on the base of artificial intelligence are used for data mining, decision making, profiling and monitoring.

System integrators offering the infrastructure or the platform for personalized health services have to precisely distinguish how to deal with different identified objects. The regulatory base for managing human identities is much more developed than those regulations dealing with things.

Rules for identification of self-assembling mechanisms do not yet exist, despite those "revivals" are already utilized in practice. These mechanisms bear very private data to access. In this context, an NFC handset seems to be an important tool enabling GSM connectivity and on-site secure and free-of-charge communication with the sensors disseminated in the human's personal environment.

4.4. Challenges for pHealth

In the following, recent means and tools of identification in the range from RFID tags towards NFC mobile handsets shall shortly be described. The utilization of these means differs in relation to the identified subject. Examples are given for management of human identities. Add-on explanation is given on the first outcome from large integrated project (e.g. FP7 ICT CP Robotic Evolutionary Self-Programming and Self-Assembling Organisms). The organization of one of the authors provides identification of those robots done by means of RFID technology ("Ubisense") which enables accurate in-door localization. Furthermore, the participating organization ensures mutual communication of the robots on ZigBee platform.

In the eHealth domain, the direct utilization is foreseen for panic buttons (bring the security for professionals or e.g. management of selected "swarm" of patients) or prompt localization of emergency health equipment in health care settings enabling the application of this technology also to the domain of pHealth as such.

Figure 2. Examples for RFID and SWARM Applications.

4.4. Intelligent Transportation System Services

The approach of Intelligent Transport Systems (ITS) is a global development to deploy technology in transport infrastructures, vehicles and vessels to make transport and travel cleaner, more efficient, safer and more secure. The underlying sensor networks influence a wide range of technological areas, market segments, and domains.

The ITS approach utilizes combinations of computers, communication networks as well as new positioning and automation technologies that collect and generate data in order to relieve traffic congestion, to ensure safety and to protect the environment, while providing transport related services and applications [9].
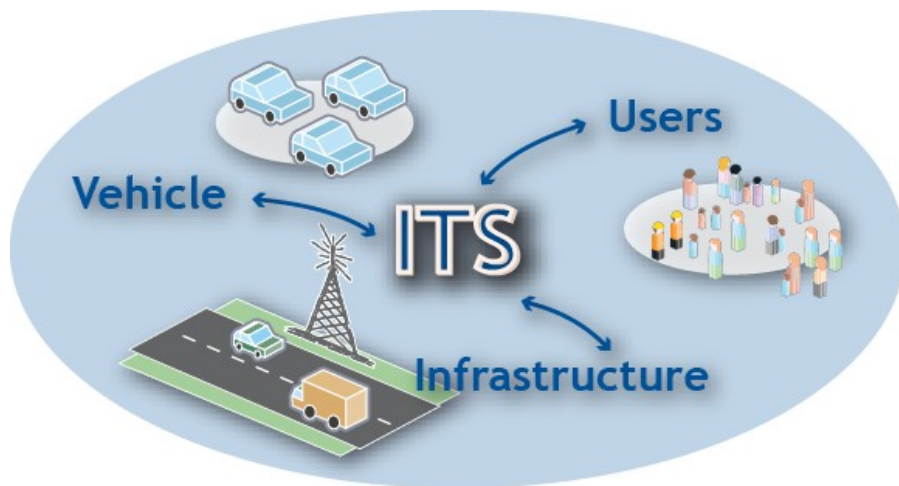
Figure 3. ITS Applications in Various Domains.

The approach aims at solving problems of traffic congestion with the help of large centralized computers and communication systems. Today, such transportation systems use decentralized ICT in both infrastructure and vehicles in an effort to manage factors that need to interact, such as vehicles, drivers, freight and routes. Systems are normally used to improve traffic flow, to increase the efficiency of freight and public transportation and to reduce accidents, pollution, and fuel consumption.

A vital use for ITS is the improvement of road safety for instance through emergency notification systems, collision avoidance systems, but also through automatic traffic enforcement. Today, ITS define a global development to exploit new technology in the transport domain. To be effective, ITS needs a certain level of interoperability, for example, between cars of different brands and different communication platforms, and when a car travels from one country to another. They can also promote the development and deployment of ITS and thereby reduce costs [10].

As a special aspect of tracking the position of vehicles and in parallel as a bridge between the road safety aspect and the aspects of healthcare and welfare, ITS can help identifying the position of vehicles transporting tissues, organs, blood bag, drugs, medical equipment, and other goods important for health services delivery.

In terms of pHealth applications for citizens/patients/traveler regardless whether being at home and abroad, ITS aims at comprehensively facilitating and managing the appropriate interaction of

- Emergency vehicles which can be located, identified, assessed and controlled using ITS;
- Human users (e.g. drivers, passengers, commuters), who employ ITS for navigation, entertainment, travel information and their monitoring capabilities;
- Roadside elements (infrastructure), for which ITS can provide monitoring, detection, response, control, road management and administrative functions;
- External information which may be provided to the ITS by telematics services or other service providers and vice versa (may include emergency and breakdown calls and remote diagnostics);
- Localization of users (patients at risk but also citizens who want to be informed on case of emergency of either the environment or other persons (relatives, children, etc.).

Addressing the domain of healthcare and welfare in general and the provision of personalized health services in particular, ITS can actively contribute to creating an environment that really provides Ambient Assisted Living (AAL). The same sensors, actuators, and sensor networks applied for road safety can be applied for increasing the

safety of citizens in general and of patients (patients at risk, patients recovering from serious diseases, chronically ill patients, pregnant women, elderly, etc.) at home and abroad in particular.
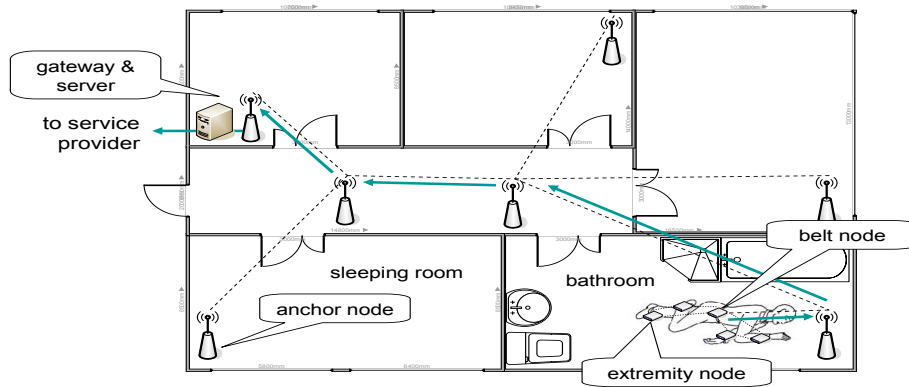
Figure 4. Sensor Networks in a pHealth Environment.

Additionally, such sensor networks help actively supporting people traveling around the globe regardless whether on business or on leisure. The same chronically ill patient and the same patient recovering, e.g., from stroke while going for an active recreation and rehabilitation in a foreign country can use the ITS-based technology for processing vitals signs in every situation anytime. The sensor as part of a Body Sensor Network (BSN), a Body Area Network (BAN) or a Wireless Body Area Network (WBAN) collect the vital signs, a processing unit indicates whether or not the vitals signs show an emergency status.

5. Conclusions

Personalized portable devices, sensors and actuators as well as the underlying mobile wireless networks enable personal and even personalized health service provision regardless of location and time. Applications from other domains stimulate the respective paradigm shift in the healthcare and welfare domain. The paradigm shift from health cards bearing identity-related data, administrative data, and partly also medical/clinical data to personalized portable devices and sensor/actuator networks for providing personal health services regardless of an individual's current location addressed not only technical, medical, and organizational aspects. Legal, ethical, and standardization aspects of portable devices and sensor networks need to be mentioned in this respect, and need to actively be pursued as well.

Facilitated by various domain experts contributing their different views on the topics of interest, the application of PPD and related networks for seamlessly providing personalized health services independent of location and time allows a comprehensive look into the present and the near future of health service provision supported by devices of any technology, any kind and any size either directly applied to the human body, or placed even inside the body.

A system dedicated to support such a personal health service provision can help the users (citizens/travelers/patients) to live an independent life in their normal environment at home, at work, while driving, while traveling, out doing errands or any kind of sport. As a consequence, the users' context will be much more variable than when the client is institutionalized. Especially for travelers, both the access to personal information and the collection of vital signs is of high importance in this respect.

Since the appropriate reaction in one context can be ineffective or even detrimental in another context, the pHealth system registers or enquires about the users' context

when necessary, and acts according to context needs. This is what pHealth is all about. And it is not science fiction, it is becoming reality. But despite of amazing supportive technical tools now available, the human factors of travelers and the face-to-face communication even in a foreign country with a doctor speaking a foreign language remain a must in health care.

The domain of personalizing health service provision includes the proper and seamless application of devices, sensors, and actuators. Components are available by now; others are thinkable or even realizable in the near future. It is important to address the progress in this domain from the standpoint of the next steps on the pathway to personal health service provision actively supported by devices, sensors, actuators, and the underlying wireless infrastructure regardless whether applied remotely or close to the human body.

The progress in the field of applied personal and personalized portable (wirelessly connected) devices is not only a progress for citizens; it is especially a progress for the travelers. Patients traveling to foreign countries for recreation or rehabilitation purposes may speed up their process of recovery. Patients with chronic diseases (asthma, diabetes, or with dialysis needs) are able to enjoy their vacation as they know there is an ongoing monitoring, and an alarm is set in terms of an emergency case. All these aspects became and become possible when PPDs are in place and can seamlessly be applied to persons in need.

References

[1]   Cheshire P: "Ambient Technology in Care Services" – the Role of PPDs. World eID 2006, Sophia Antipolis, September 2006.

[2]   Pharow P, Blobel B: Mobile Health Requires Mobile Security – Challenges, Solutions, and Standardization. In: Andersen S.K., Klein G.O., Schulz S., Arts J., Mazzoleni M.C. (Edrs.): eHealth Beyond the Horizon – Get IT There. Proceedings of MIE 2008. Series Studies in Health Technology and Informatics, Vol. 136. IOS Press, Amsterdam, Berlin, Oxford, Tokyo, Washington 2008.

[3]   Blobel B, Pharow P, Norgall T. How to Enhance Integrated Care towards the Personal Health Paradigm? In: Kuhn KA, Warren JR, Leong T-Z (Edrs.): MEDINFO 2007, pp. 172-176. IOS Press Amsterdam, Berlin, Oxford, Tokyo, Washington, DC, 2007.

[4]   European Telecommunications Standards Institute (ETSI), http://www.etsi.org.

[5]   User Profile Management: ETSI Specialist task force 342. http://portal.etsi.org/STFs/STF_HomePages/ STF342/STF342.asp (last accessed: May 14th, 2009).

[6]   eHealth User Profiles: ETSI Specialist task force 352. http://portal.etsi.org/STFs/STF_HomePages/ STF352/STF352.asp (last accessed: May 14th, 2009).

[7]   ETSI EG 202 325: 2005, Human Factors (HF); User Profile Management, ETSI, Sophia-Antipolis.

[8]   .Draft Standard for Smart Transducer Interface for Sensors and Actuators – Transducers to Radio Frequency Identification (RFID) Systems Communication Protocols and transducer Electronic Data Sheet Formats. IEEE P1451.7.

[9]   Hovsto A, Pharow P, Blobel B: How to Achieve Sustainability in Advanced eHealth Sensor-based Systems. Conference Proceedings 13th International ITA Workshop, Kraków, June, 2008. http://www.itw2008.pl/papers/ITW2008proceedings.pdf.

[10] ISO/IEC JTC1 SGSN: Creating Ubiquitous Services with Sensor networks. Document SGSN N059.

[11] ETSI Specialist Task Forces, http://portal.etsi.org/stfs/process/ home.asp.

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An Architectural Framework for the Personalization of eHealth Devices and Services

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Abstract: Adapting an eHealth system to the individual user helps to ensure that the system is safe and easy to deploy and use as an effective support to independent living. Personalization can thus enhance the user's trust in the system, and make it more readily accepted. There are two main categories of eHealth users - the client, whose health and well-being is monitored, and the carer, the (group of) person(s) acting in the role of a health facilitator. As care is moving out from institutional care to independent living, the focus is on the needs of both formal and informal carers. Personalization for a client can range from simply setting an alarm volume according to the user's hearing abilities and the ambient noise level, to the complex tailoring of the user's entire eHealth environment. Personalization is achieved by maintaining and updating a user profile, which depends on and is dynamically adapted to the user's context, general preferences, physical and mental abilities, and other relevant parameters. The profile can then be used by eHealth services and devices to ensure a uniform user experience irrespective of context in a range of situations such as when the person is at home, at work and when travelling. This paper describes standardization work at the Human Factors and eHealth Technical Bodies of the European Telecommunications Standards Institute (ETSI).

Keywords. Medical Informatics; Personalization; User profiles, Standardization

1. Introduction

People increasingly expect to continue their lives in an everyday environment (home, work, etc.) rather than being institutionalized. eHealth can support this move to the personal realm, provided the systems can be personalized to fit the needs of patients and carers. Personalization can enhance the user's trust in the system, and make it more readily accepted. Standardized information and preferences need to be stored in user profiles and made available to eHealth systems. An underlying architecture is needed to manage the respective user profiles. This paper describes work on eHealth personalization including standardized information and preferences and an architectural framework where personalization can be integrated into Next Generation Networks. The Human Factors and eHealth Technical Bodies of the European Telecommunications Standards Institute (ETSI) have created two specialist task forces, STF 342 [1] which specifies an architecture for personalization [2] and standardized user preferences and information in general [3] (not particularly related to eHealth), and STF 352 [4] which standardizes the information and preferences for personalization of eHealth systems in

particular [5] for all people belonging to any eHealth role (e.g. client, carer).

The personalization is achieved by maintaining and updating a user profile, which depends on and is dynamically adapted, to the people's context, general preferences, physical and cognitive abilities, and other relevant parameters. The profile can then be used by eHealth services and devices to ensure a uniform user experience irrespective of context. The work builds on the personalization and user profile concept described in the ETSI guide EG 202 325 [6].

2. Focus on Users' Needs

There are two main categories of eHealth equipment and service users - the client, whose health and well-being is monitored, and the carer, the (group of) person(s) acting in the role of a health facilitator. As care is moving out from institutional care to domestic environments in support of independent living, both formal and informal carers need to be addressed.

One of the most important aspects of eHealth is that people should feel comfortable with the eHealth services provided to them. This implies that eHealth services should fit with their´ lifestyle and preferences. Unless some mechanism allows them to personalize their eHealth experience, a one-size-fits-all solution must be provided that will only meet the precise requirements of a very small proportion of potential clients.

An eHealth system can help the clients to lead an independent life in their normal environment at home, at work, driving, when out doing errands or sport. As a consequence, the clients' context will be much more variable than when institutionalized. Since the appropriate reaction in one context can be ineffective or even detrimental in another context, the eHealth system should register or enquire about the client's context, and act according to the context needs.

In order to focus on people's needs in any eHealth role, the personalization projects conducted interviews, collected inputs and met stakeholders at a range of events. The Design for All approach has been adopted in the work. It means that accessibility is considered as something that can benefit people whether or not they have disabilities. The work is contributing to a standard that will provide a selection of preferences, referring to the various subsections of the standard which can be useful for people in a specific situation or for people with disabilities.

3. eHealth Services Supporting Multicultural Information and Communication

With enlargement of the European Union, citizens will come from an ever-increasing range of countries each of which may have a range of different cultures and languages. They will also encounter many more languages and cultures in different contexts such as health, business and leisure become increasingly global. The number of tourists and immigrant workers who use non-European languages will also increase within those countries. Therefore, the range of cultures and languages that must be supported in European communication and information services will need to grow significantly.

Even when language and cultural factors are considered, it will probably never be practical to present services in variants suitable for every language and cultural variation. With the objective to provide a solution to this, the ETSI Guidelines EG 202 421 "Multicultural and language aspects of multimedia communications" [7] proposes various means to ensure that the most appropriate version of a service interaction is delivered to each service user in any eHealth role. It also proposes ways in which everyone can be offered a cultural variant of a service best matched to their preferences and abilities, even when their preferred cultural variant is unsupported. Achieving this will require a means to determine a person's range of cultural preferences and abilities, a standard way to store

them, and a means for services to access them so that the most culturally compatible service variant can be provided to the user.

Instead of frequently having to choose language options, users should be able to define their cultural preferences and capabilities only once in their user profile. This would enable devices, services and people they wish to communicate with, access to their preferences in order to provide content and services presented in a way that suit their needs. A language preference set in a user profile should be capable of being overridden by the user at any time. The user profile concept provides the users with a means to define their language and cultural options in a flexible way that meets their requirements in a range of situations and roles. The most flexible solution for defining language preferences is to have the ability to define rules in a user profile.

The work on personalization and user profiles specifies multicultural preferences such as spoken language, written language, simple text, symbols, currency, automatic spelling and grammar check, automatic spelling checker language, auto-completion mode language. Whenever it is relevant, other standards are referred to, such as ISO 639-3 [8] for defining languages.

4. Profile Categories and User Roles

Profiles may contain many individual data items (information, preferences and rules). The values of these items will either not change or change very infrequently and some may be individually changed by the user whereas other will not be changed by the user (e.g. extracts from the Electronic Health Record which cannot be changed by the client). However, the maximum benefit of user profiles will only occur if the values of multiple profile items can be simultaneously changed in a predictable way according to the current situation in which the user is.

Furthermore, this benefit will be greatest when these multiple changes occur without user intervention as the result of a user profile rule being triggered in response to a change of situation. The Active Profile provides the user's information, preferences and rules applicable at a given time. The Active Profile gets its values from the Normal Profile and the Situation Profiles. The Normal Profile defines the profile data that will be applied even when no specific user-defined situation applies. Many profile data defined in the Normal Profile will also be applied when a specific user-defined situation applies, unless it is over-ridden by another value specified in the Situation profile e.g. "At Home", "At the Hospital", "Out".

When identifying the capabilities of a profile system a person may exploit, it is necessary to define a number of different roles the person may have. A typical person using the profile system will have at least two roles – the "user" role and the "administrator" role. Their capabilities are:

- User: use of the person's own profiles, including activation or deactivation of profiles. It is likely that some people, for instance very young children, would only be allowed (e.g. by parents) the user role.
- Administrator: definition of profiles or modification of existing ones; definition of access rights.

Some people will have a role in managing another person's profile (e.g. a parent may manage the profiles of their children or a carer may help a client to manage their profile). In these circumstances, such people will have an administrator role for a profile that is not directly associated with them. In addition to these two basic profile related roles, there is a need to identify roles within the eHealth domain, such as the most basic roles:

- Client: The individual receiving the eHealth service. The client's use of the eHealth service can be to support independent living and/or for the care of his or her own health and wellbeing.
- Carer: Individuals providing health or social care to the client. Both professional and informal carers are included in this category. Informal carers

may be in a range of categories such as relatives, neighbors, friends or volunteers providing care for the person in need. There is a need for further role subdivision.

Security, privacy, authentication, and authorization based on advanced personalization and its related roles and the role management are important aspects to take into account. Another important factor to consider before successfully applying personal portable devices, sensors, actuators, and other medical equipment including the underlying network functionality to the human user is the collaborative environment for processing the information collected, stored, pre-processed, and transmitted.

5. Architectural Overview

5.1 Functional Entities

The User Profile Management (UPM) system consists of five functional entities: User Interface Agent, Processing Agent, Activation Agent, Storage Agent and Context Watcher, as shown in Figure 1, and explained in more detail in the following subsections.
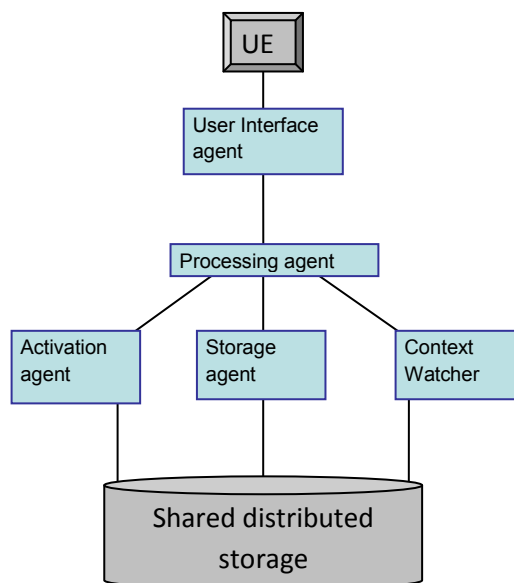
Figure 1. Architectural overview

5.2 User Interface Agent

The purpose of the User Interface agent is to provide the interface to the end-user's UE (User Equipment) for viewing and editing and controlling the activation of their profiles. This includes:

- Ensure that only legitimate end users (in their role of user profile users or user profile administrator) have access to appropriate UPM functionalities.
- Select information to display to the user.

- Allow users to edit their profiles (normal profile and situation profiles).
- Allow preferences related to the UPM system itself to be edited.
- Adapt system model to user view (e.g. displaying, editing, providing notifications) and vice versa.
- Provide end users with different degree of flexibility in managing their profiles, by enabling or disabling access to some functionality.
- Allow user profile users to manually activate and deactivate situation profiles, thus (temporarily) inhibit automatic changes to situation profiles.

5.3 Processing Agent

The purpose of the profile processing agent is to process profile and context data and initiate achievement of the behavior encoded in the profile rules. The profile processing agent is responsible for ensuring that all the operations required by the profile rules are carried out.

The profile processing agent implements an evaluation engine functionality, used to:

- determine which situation profile will be automatically activated/deactivated
- how conflicts are solved
- provide feedback to the profile administrator when defining new profiles or modifying existing ones.

The processing agent normally subscribes to the context watcher for changes in the values of context variables for processing the automatic activation/deactivation of profiles.

5.4 Activation Agent

The profile activation agent is responsible for taking the changes identified by the processing agent and applying those changes to the relevant services and devices. It is also responsible for informing the processing agent and thus initiating a recovery procedure if the activation is not successfully achieved. The activation agent may act as a client for the Common Profile Storage (CPS, as described below).

5.5 Storage Agent

The storage agent is responsible for answering any query by the profile processing agent by storing and retrieving situation profiles, rules, templates and any other metadata defined in the UPM system. It ensures that user profile data is kept consistent by exploiting synchronization and transaction integrity mechanisms. It ensures the requested levels of privacy required by the UPM system users and administrators by exploiting data access control mechanisms. The storage agent may act as a client for the shared distributed storage. The "shared distributed storage" could be implemented in a TISPAN Next Generation Networks (NGN) architecture. When the architecture is implemented in distributed systems, the storage agent, the activation agent and the context watcher do not interface directly to network functions/services, applications and devices, but use external functional entities, such as Common Profile Storage (CPS) [9] to perform such a task.

5.6 Context Watcher

The context watcher is initially used by the processing agent to discover which profile information and preferences are available to the UPM system (per user profile user), and

the range of values allowed for those information and preferences. It also informs the processing agent about which context information can be used in context variables and is responsible for keeping the correct mapping to each context source. The context watcher may obtain context information from context sources by using either a subscription mechanism or a query mechanism.

The context watcher is also involved in automatic activation and deactivation of situation profiles. As soon as it detects a change in at least one context variable, the context watcher notifies the processing agent which may initiate an automatic activation procedure. The context watcher may act as a client for the shared distributed storage.

5.7 Shared Distributed Storage

In a typical profile management scenario, there are multiple profile storage locations. Many of these locations will not store the total profile but only components that apply to a device, an application, a network function or service. Different locations may have different persistence and priority levels. Although the user profile data is distributed amongst devices, applications and services, ideally, all profile data should always be available, over all networks, from all supported devices and services, including fixed and mobile services allowing service continuity and optimal user experience.

The purpose of the shared distributed storage [9] is to guarantee a uniform view of profile data by providing an abstraction of the profile data independent from:

- the physical location where they reside;
- the different data formats in which they are expressed;
- the different protocols used to retrieve them;
- and keeping a mapping to the locations where such data can be found.

6. Related Work

The work on the ETSI Standard (ES) on standardized information and preferences is as much as possible, where relevant, referring to other standards such as those from W3C [10], ISO [9], Internet Mail Consortium's vCard [11], and IETF [12].

The work on personalization and user profiles emerged from earlier ETSI work on a Universal Communications Identifier which is a unique identifier of the user rather than a range of identifiers of the many of communication devices or services (e.g. numbers of fixed phone at home/work, mobile phones, fax and email addresses). Not only will this new Universal Communications Identifier [13], [14] solve the problem of coping with the increasing number of identifiers; it will allow the person you are communicating with to be clearly identified in a way that the user can trust. The Universal Communications Identifier concept has been developed based on an analysis of users' needs and an architectural framework within the Next Generations Network (NGN) has been developed by ETSI [15]. In order to make new and advanced information and communication services and devices a success, it has been recognized that it is essential to perform standardization work on personalization and user profile management, which will be beneficial for a whole range of new and advanced information and communication services, whether used together with the Universal Communications Identifier or other identifiers.

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The cooperation with the Wireless World Research Forum (WWRF) work on personalization and user profiles [16] has been very useful for our work.

7. About ETSI

European Telecommunications Standards Institute (ETSI) produces globally-applicable standards for Information and Communications Technologies (ICT), including fixed, mobile, radio, converged, broadcast and internet technologies and is officially recognized by the European Commission as a European Standards Organization. ETSI is a not-for-profit organization whose 720+ ETSI member companies and organizations benefit from direct participation and are drawn from 60+ countries worldwide. For more information, please visit: www.etsi.org.

7.1 About ETSI Specialist Task Forces (STF)

STFs are teams of highly-skilled experts working together over a pre-defined period to draft an ETSI standard under the technical guidance of an ETSI Technical Body and with the support of the ETSI Secretariat. The task of the STFs is to accelerate the standardization process in areas of strategic importance and in response to urgent market needs. For more information, please visit: http://portal.etsi.org/stfs/process/home.asp.

7.2 About STFs Funded by EC/EFTA

The work carried out here is co-financed by the EC/EFTA in response to the EC's ICT Standardization Work Programme.

8. Conclusion

Context sensitive personalization utilizing user profiles is essential for achieving personalized eHealth services and devices for all users. Standardization in this area and adoption of these standards, as explained in this paper, is necessary to ensure compatibility between a range of eHealth services and devices. Further work is recommended for the development and evaluation of templates for various situations, especially for the use by people with impairments in order to optimize the accessibility of personalized eHealth systems.

Acknowledgments

References

[1] ETSI STF342 web page, http://portal.etsi.org/stfs/STF_HomePages/STF342/STF342.asp.
[2] Draft ETSI TS 102 747: Human Factors (HF): Personalization and User Profile Management: Architectural Framework.
[3] Draft ETSI ES 202 746: Human Factors (HF); Personalization and User Profile Management; User Profile Preferences and Information
[4] ETSI STF352 web page, http://portal.etsi.org/stfs/STF_HomePages/STF352/STF352.asp.
[5] Draft ETSI ES 202 642: Human Factors (HF), eHealth; Personalization of eHealth systems
[6] ETSI EG 202 325: Human Factors (HF); User Profile Management.
[7] ETSI EG 202 421: Human Factors (HF); Multicultural and language aspects of multimedia communications.
[8] ISO 639-3: "Codes for the representation of names of languages - Part 3: Alpha-3 code for comprehensive coverage of languages
[9] 3GPP TR 32.808: "Telecommunication management; Study of Common Profile Storage (CPS) Framework of User Data for network services and management".
[10] W3C Cascading Style Sheets, http://www.w3.org/Style/CSS/
[11] Internet Mail Consortium vCard standard, http://www.imc.org/pdi/
[12] IETF, RPID: Rich Presence Extensions to the Presence Information Data Format (PIDF), RFC 4480
[13] ETSI EG 202 249: "Universal Communications Identifier (UCI); Guidelines on the usability of UCI based systems", http://pda.etsi.org/pda/queryform.asp.
[14] ETSI EG 202 067: "Universal Communications Identifier (UCI); System framework".
[15] ETSI EG 284 004: "Telecommunications and Internet converged Services and Protocols for Advanced Networking (TISPAN); Incorporating Universal Communications Identifier (UCI) support into the specification of Next Generation Networks (NGN)".
[16] The WWRF Outlook Visions and research directions for the Wireless World, User Profiles, Personalization and Privacy, ISSN 1662-615X

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Personal Portable Device – a Health Advisor for Travelers

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Abstract. Personal portable devices offer many benefits to travelers. With the help of such a device the traveler can monitoring his/her health status, get alerts and advice, and use it to remotely access health services and applications. The smart personal portable device can include various records such as the traveler's personal medications and vaccination record, and it is possible to even store the whole Electronic Health Recond into such a device. Networked personal portable devices offer also benefits for health professional because the health service provider can access the traveler's remote health records. Smart personal portable devices can be context-aware and give proposals and alarms based on context information. In this paper we are analyzing benefits of different kind of personal portable devices for travelers. Examples of practical device-based solutions are discussed as well as the remaining challenges. A generalized architecture for personal health services using personal portable devices is also proposed.

Keywords. Personal portable device, personal health system, health advisor, health monitoring.

1. Introduction

Tourism is a global business and a rapidly expanding business area. All kind of people from businesspersons to backpackers are traveling around the globe. This means that an increasing number of people having personal health problem and needing continuous medication are visiting rural areas and extreme places. People are also traveling to places where communicable diseases are common. In many touristic places there is neither the Internet access nor any mobile networks available, and it is difficult to find urgent high quality medical help or advice from there.

The expanding number of travelers means also more accidents and emergency cases where acute health services are required. Tourists not speaking the local language will meet medical professionals in foreign countries, and they may experience many cultural problems which makes it rather complicated to get an appropriate health advice or ambulatory care. From the other viewpoint, the local health professional working in traveler's destination country needs relevant, reliable, and useful information of the visitors and their current health problems, their physical and mental condition, and their medications. The personal portable device (PPD) is a new promising tool designed and applied to help travelers in situations where they experience different kinds of healthcare and welfare problems.

2. The Personal Portable Device

Personal portable devices have nowadays many names. They are sometimes referred to as personal organizers or personal digital assistants (PDA). In this paper we define that the PPD is a lightweight electronic device but not a PC. It can be a simple mobile phone like the typical wireless communication tool, an access tool to the Internet, a personal database, or an intelligent multifunctional personal advisor. The PPD can also be a wearable micro/nano device and even an implanted smart chip. Sensors and actuators on the one hand and the PPD on the other hand are in many cases connected to each other to form a personal health system (PHS).

The PPD as such can have quite limited storage capacity and processing power; or it can be a smart device having the capacity of a stand-alone PC [1]. Smart PPDs have the ability to notify, inform, and make recommendations. The PPD can also be an educator and an expert giving health-related advice and offering wellness and lifestyle options. Some PPDs are a part of the body area network (BAN) or the wireless BAN (WBAN). Using modem nano-technologies, a PPD can include even a personal laboratory (a lab-on-a-chip), and it can control personal actuators.

In this paper we are aiming at classifying the PPD family, and in this respect we have identified four different groups. The PPD can be:
- A one way communication device,
- A security devices,
- An independent smart device which has the ability to make autonomous decision and control actuators, and
- A device for monitoring and transferring information (e.g. vital signs) collected from the user and sent to an external information system.

Technically there is a large variety of PPD forms and types. The PPD can be a USB stick, a smart card, a mobile phone, or even an implanted smart chip. It can be a stand-alone device, or act as an embedded part of an intelligent information system or network. Most advanced PPDs are also aware of the environment and its characteristics where they are used. This kind of PPDs can collect and monitor individual's parameters and vital signs, and can send them via a network to the data controller or the monitoring unit / center.

3. Personal Portable Health Devices

PPDs are already used for different kind of healthcare and wellness related purposes. Depending of their intelligence and communication capacity, the personal portable health device can:
- Include parts of individual's lifelong EHR,
- Be aware of the environment where it is used, give warnings and proposals for health management,
- Monitor person's vital signs and conditions, and make early warnings,
- Be linked via the Internet and/or mobile networks to external health services,
- Include links to person's remote EHRs, and
- Be a security tool enabling the person to manage the use of his/her distributed health information.

There are many commercial healthcare and wellness oriented PPDs that are available by now. An alarm wristband with one button is an example of a simple one way communication device. Another more advanced PPD is the Verichip which is developed for emergency health applications [2].

The category of independent smart PPDs is wide. Some of them have limited intelligence as the BodyBugg with motion sensors [3]. More intelligent PPDs can

monitor and log the person's vital signs for supervising their health status [4]. This kind of PPD has typically necessary knowledge, decision support, and intelligence imbedded, but they can also use external knowledge to get a second opinion from the telemonitoring center or a nearby hospital.

PPDs targeted for monitoring purposes are equipped with sensors and network connectivity. Those PPDs monitor individual's personal health and wellness information, and send the collected (and often compressed) information to an external IT system (e.g. to the monitoring system of a hospital, to an emergency clinic, directly to the family doctor, and to a remote database). The majority of all these PPDs have been developed for the management of chronic diseases. A typical system developed for monitoring individual's health parameters using PPDs is shown in figure 1.
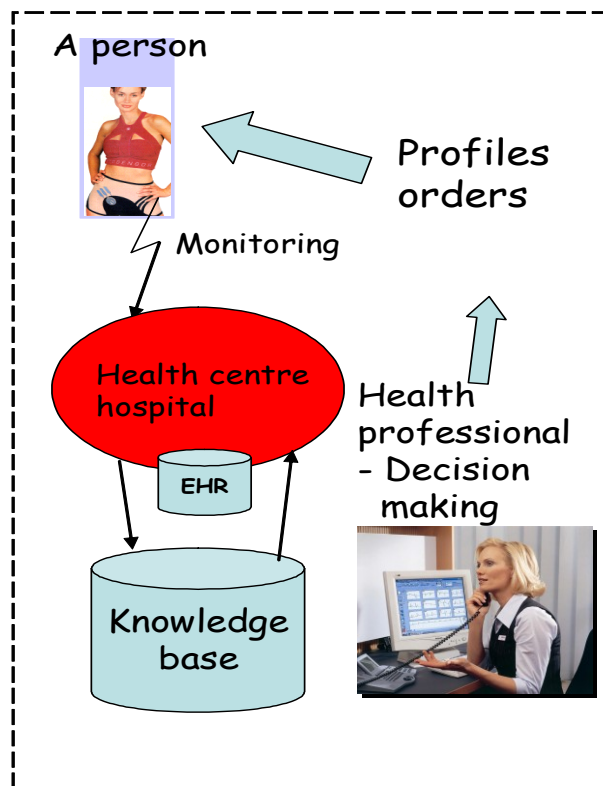
Figure 1. Health monitoring system using PPD

Practical examples of this kind of installation are the Cardio-online [5] and the Google health with sensors [6].

4. PPDs and the Personal Health System

The personal health system (PHS) using PPDs can either be built over traditional healthcare services, or it can be a system which is usually managed and controled by the person itself.

Many large scale architectures have been proposed for the application of a PHS includung PPDs. Ruotsalainen proposed a multilayer architecture where the personal domain includes sensors, the body area network (BAN), and smart personal devices [7].

In this model, the personal domain is connected to existing private and public health services. The Fraunhofer Institute IBMT in Germany has developed a platform for the "Mobile Health Assistant" [8]. Martinez has developed a virtual health platform for medical tourism [9]. A generalized model for the PHS applying smart PPDs is shown in Figure 2.
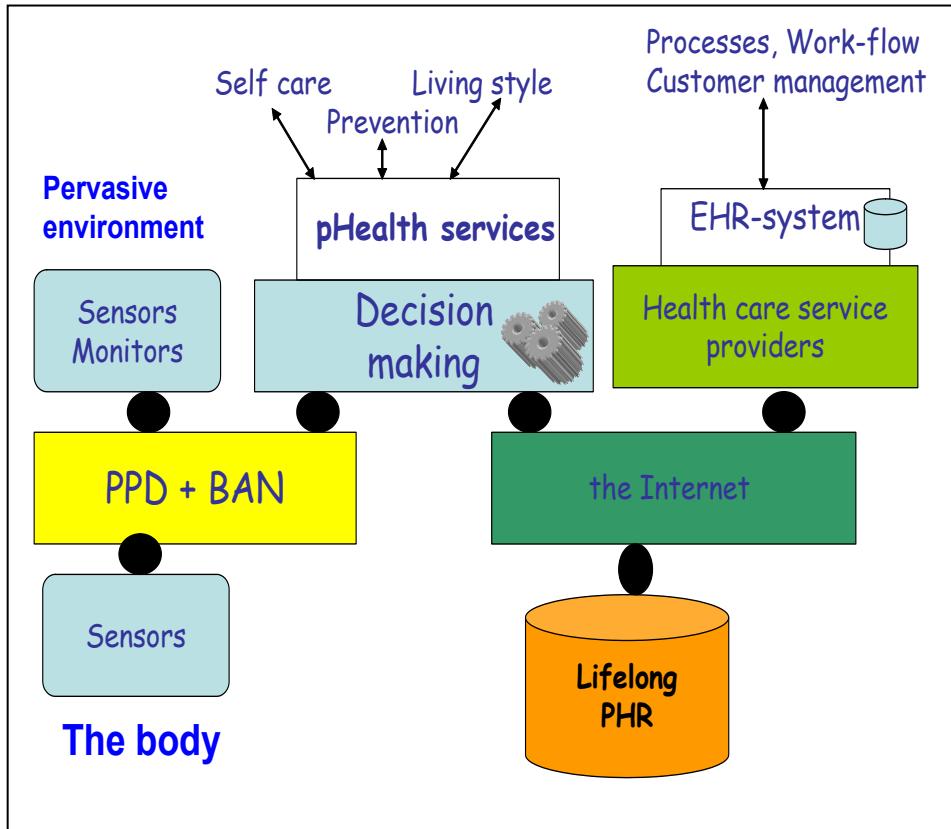
Figure 2. A general model for the PHS with a smart PPD

5. Autonomous Personal Portable Health Devices

The smart autonomous PPD is a stand-alone device with sensors and local intelligence for decision making. In many cases it has also developed communication ability. With the help of sensors, this kind of PPD can measure individual's personal health parameters and vital signs. It can also be aware of the context (e.g. the environment) where the person is located. Using embedded intelligence (e.g. AI and decision making), this PPD can make context-aware reminders and proposals, and can even change the state of person's activators. Smart autonomous PPDs typically include individual's personal health profiles which are controled, updated and changed) by the person itself. For this type of PPD, personalization services are needed. Autonomous PPDs can also ask advice outside the person's domain, like asking for a second opinion or downloading new knowledge from external knowledge bases [1].

A prctical example of smart autonomous health PPDs is the PICO-1 device. It offers accurate FEV1 and PEF measurement for people suffering from asthmatic diseases. It includes software to control the quality of the blow, storage for measurements, and

personal profiles. Using embedded intelligence, this PPD can give alerts and calculate trends [10].

Autonomous PPDs are not controlled by any health professional or health service organization, but they can transfer information to a healthcare system under the control of the individual.

6. Travelers and PPDs

Usually, citizens in general and patients in particular rely on the permanent availability of medical support and medical advice. Personal health addresses the provision of health services in any place at any time. This is true not only for the citizens' working and living environment but increasingly also while being abroad for various purposes.

Travelers using PPDs can thus get many health benefits. Travelers have different kind of health related needs starting from just to be informed of health risks of the area they are visiting (e.g. communicable diseases, severe weather conditions influencing the vital status, dust and pollution) to the need for a scheduled medical support and treatment (e.g. for dialysis patients being on vacation) to the provision of emergency healthcare services. The community of chronically ill travelers can monitor and control their health condition, and check for example if there is a need to change their medication with or without contacting their local or family doctor. Furthermore the traveler can use his/her PPDs for emergency calls and for the access to cross-border health service.

Autonomous PPDs are specifically important for rural and remote areas as travelers can use this type of PPD anywhere even in places where no communication network is available. The local physician can use clinical information which is stored in the PPD (e.g. medication and vaccination data) as a professional and knowledge-based support in decision making. Autonomous PPDs can also work as a personal health advisor and educator.

A stand-alone PPD can nowadays easily contain a minimum emergency data set (e.g. contact addresses, permanent medication, allergies and links to person's EHR). The present storage capacity of smart chips makes it possible to even store a person's whole lifelong PHR into the PPD. Based on enhancing technologies in the nano and micro domain and on decreasing costs of wireless communication, the role of any type of PPD will even increase in the near few years.

In the future, PPDs can include person's multilingual emergency record or even the whole EHR. Future context-aware PPDs can understand health risks caused by the environment and give early warning for the traveler at any time.

PPDs used for monitoring require network connection between it and the controller. It is also necessary that the service is available in traveler's home country in a way that a citizen just needs one single PPD or one set of PPDs wherever he or she might reside or be. Therefore PPDs targeted for monitoring (telemonitoring, disease monitoring, lifestyle and wellness monitoring, etc.) are especially suitable for travelers having diseases which need continuous monitoring and control.

7. Discussion and Conclusion

The ongoing paradigm shift from organization-centric healthcare and welfare systems to the person-centered approach, as well as the introduction of portable IT-based devices for disease and health management, diagnosis, treatment, and monitoring offers a complete series of new mobile personalized health services provided to citizens in need wherever and whenever.

Supporting the growing mobility of persons and data, personal portable devices (PPD) applied for the provision of healthcare and welfare services play an important role emphasizing citizens in general and patients in particular to take on their role as a partner in healthcare and welfare processes, and as an individual being responsible for his/her own health status.

Both PPDs targeted for monitoring and autonomous PPDs offer many advantages for travelers. They make it easy for the traveler to monitor and control his/her health status at any time anywhere. The information storage and communication capacity of PPDs helps medical professional in designation countries in clinical decision making. They help travelers to get medical advice in a designation country by accessing his or her EHR or PHR. Still, there are a few problems to be solved.

- The lack of communication networks can prevent monitoring and consultation.
- Information stored into the PPD or accessed via networks can be difficult to use because of language problems.
- There is a lack of common semantics and classification which can produce problems for health professionals of foreign countries.
- The lack of standardized messages can prevent the communication.
- The lack of local technology can prevent to use PPD's information, and
- Health professionals in designation countries may not be educated enough to use smart PPDs.

A question not less meaningful than those raised before is the one about trust and trustworthiness. It is important to address to what extent a health professional and a citizen/ patient can trust the administrative and medical/clinical information stored into the PPD. The PPD needs to be a trustworthy device because without a proof of the origin, authenticity, and integrity (including roles and rules on how to access a PPD) PPD's data can not be used as qualified clinical data by the health professional.

Technologies like electronic signatures and electronic watermarks offer solution to this problem, but they still need complicated security services which are not commonly available (and even not legally applicable) in all countries of interest. The monitoring approach also raises the question of privacy especially if the PDD is able to provide context-aware information and supports decision making processes.

In spite of all the challenges and problems left, PPDs offer useful possibilities for travelers to manage their health status and their wellness requirements during their trips regardless whether short-term or long-term, and regardless whether on business or on vacation. PPDs used with trust and confidence will help also health professionals in the management of travelers' care.

The majority of underlying mobile and processing technologies for a PPD applied to travelers and their specific health-related needs are already in place. Let's make adequate use of them, and let's take care of the respective privacy and ethical aspects while remotely accessing sensitive person-related information.

References

[1] P. Ruotsalainen*, Intelligent chips - Personal health advisers in pervasive information space*, pHealth 2009, 24-26 June 2009, Oslo Norway.
[2] VeriChip Corporation, Delray Beach, Florida,www.verichipcorp.com/
[3] 24 Hour Fitness USA, Inc.,www.bodybugg.com.
[4] http://www.iis.fraunhofer.de/EN/bf/med/proj/sensave.jsp.
[5] ec.europa.eu/information_society/eeurope/.../smits2.ppt
[6] S. Ohlsson, From sensors to Google health, pHealth 2009, 24-26 June 2009, Oslo Norway.
[7] P. Ruotsalainen ans H.Pohjonen, European Security Framework for Healthcare, Studies in Health Technology and Informatics 96, Advanced Health Telematics and Telemedicine, The Magdeburg Expert Summit Textbook, IOS Press 2003.
[8] http://ec.europa.eu/information_society/events/phs2007/docs/slides/phs2007-kiefer-s1a.pdf.

[9]   D. Martinez etc.al, Virtual Health Platforms for Medical Tourism, Advanced Health Telematics and Telemedicine, Medical and Care Compunetics 5, ISO Press.

[10] Feffaris Respiratory Ltd., www.ferrarisrespiratory.com.

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Using GSM Technology for a Healthier and Safer Life of Travelers

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Abstract. Apart from mobile phones, GSM technologies have successfully been implemented in various industries. By deploying so called machine-to-machine (M2M) solutions, assets or people are connected with monitoring centers, business processes are improved and new services enabled. These proven solutions can easily be transferred into the mobile health (mHealth) arena. In this domain, they play an important role in making life healthier and safer, especially for travelers where mobility is essential. The paper will focus on representative wireless M2M solutions and services in the fields of Ambient Assisted Living, telemonitoring, and fitness monitoring. Key elements of a complete end-to-end M2M solution will be explained. In addition, benefits will be quantified and the major challenges and pitfalls will be outlined.

Keywords. Society, eHealth, mHealth, mobile health devices, wireless health, GSM, Machine-to-machine communication (M2M), Ambient Assisted Living (AAL), telemonitoring, fitness monitoring

1. Introduction

One billion adults in the world are overweight. 860 million chronic disease patients are accounting for 75-85% of total healthcare spending. 600 million people are at an age of 60 years and above. These are just facts related to the future challenges of healthcare and welfare [1]. Actually, these facts put an enormous pressure on the healthcare sector in general and on public expenditure for healthcare in particular. At the same time people have an increased demand for a healthy and high-quality life. Although some people suffer from certain diseases or medical handicaps they want to continue their lives independently and with peace of mind. These and others are the main drivers for new healthcare solutions, such as mobile health or mHealth [2].

At the same time - and as "Wired Magazine" pointed out it in their July 2009 issue ("Living by numbers") - there is a trend towards fitness monitoring of vital data [3]. Besides heart rate monitors which transmit training data onto web based platforms, the Nike+ wireless sensor system is a prominent example for training systems [4].

Of course, both health and fitness monitoring requirements do not have to stop at the doorstep as they are also relevant for people travelling abroad, and even more so. This is where the need for truly mobile solutions arises which is currently best met by the use of cellular based machine-to-machine (M2M) technology.

2. Machine-to-Machine (M2M) Technology Overview

This paper focuses on cellular based M2M technology. Therefore, the following chapters describe representative wireless M2M solutions, their evolution and benefits. Key elements of complete end-to-end M2M solutions will be explained.

2.1. Representative Wireless M2M Solutions and Services

Apart from mobile phones, the basic technologies of the global system for mobile communication (GSM) have been implemented successfully in various industries. They are used to connect assets or people with monitoring centers, to improve processes, and to enable new services. Mobile Network Operators (MNOs) can leverage their existing mobile infrastructure to address the emerging healthcare and welfare domain by providing applied services for the growing mHealth market.

Today, many applications and services in the facility management segment, in the transportation sector, in the logistics area, etc. benefit from the use of innovative M2M communication. Regardless whether it is the consumption data from power meters or the location and speed information gathered from on-board-units in fleet-management solutions, these existing large scale deployments can be leveraged as a proven blue print for medical solutions. The basic processes are quite comparable; challenges like data security and privacy have already been successfully mastered in M2M solutions like point of sale (POS) terminals and automated teller machines (ATMs). Quality requirements in the medical sector like extreme reliability and full manufacturing traceability are also quite similar to the automotive industry where M2M is widely applied today. Mobile health solutions can be implemented using familiar TCP/IP and SSL encryption, and GSM based solutions can take advantage of inherent security mechanisms and the quality of service (QoS).

2.2. Evolution of M2M

M2M technology has evolved from basic telemetry, mainly used by large companies. Many of these early M2M applications used wired communications and did fulfill the very basic purpose of transmitting data, but there are a few shortcomings left [5]:
- Proprietary systems, no standardization;
- Limited mobility;
- High installation and maintenance efforts, and
- Limited flexibility.

In the past decade there has been an enormous progress in the Information and Communication Technology (ICT) industry that allowed for the utilization of M2M applications on a large scale. Such M2M solutions are often based on wireless technologies. Originally developed for consumers, technologies like GSM, WLAN, and Bluetooth were enhanced and further developed for industrial purposes – resulting in the following benefits [5]:
- Low installation efforts;
- High level of mobility;
- Economies of scale can be reached through the utilization of widespread standards, and
- High level of availability, reliability and security.

GSM cellular technology plays a key role for an M2M network due to economies of scale, based on the appropriate level of coverage and the worldwide adoption of the standard. Truly mobile applications are possible through cell-handover and roaming.

2.3. Key Elements of a Complete End-to-End M2M Solution

If data has to be transmitted over larger distances, the cellular network infrastructure of a mobile network operator (MNO) is often used. Alternatively, local communication infrastructures can be set up, but M2M communication based on cellular networks has the great benefit of inherent security mechanisms and built-in Quality of Service (QoS).
So called M2M Application Platforms (Middleware) between the communication network and the IT center provide a trustworthy and secure exchange of information. The M2M application platform provides for instance SIM management and passes the

data onto the backend IT system (an Enterprise Resource Planning (ERP) system, a health care service center, etc.) in the desired or required data or message format. The application evaluates the data and can trigger necessary actions, e.g. based on individual pre-defined thresholds.
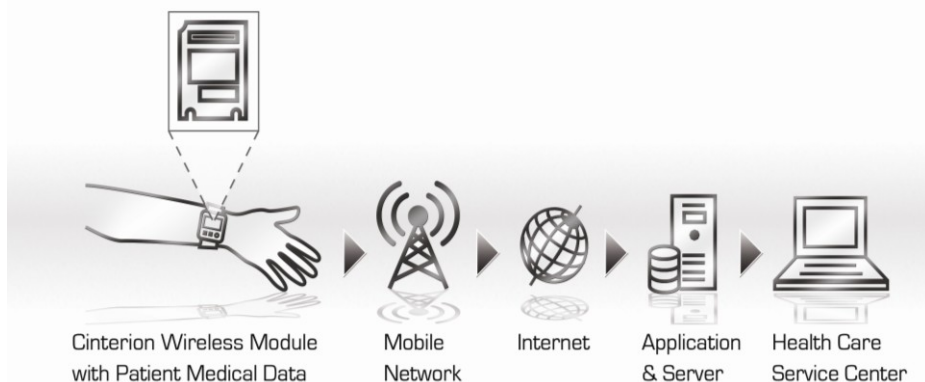
Figure 1. Typical M2M Solution Architecture (Source: Cinterion Wireless Modules GmbH).

Core components of a typical M2M solution comprise of a communication unit (wireless module) to transmit the data, the communication network (GSM/3G cellular mobile network) that can transmit data through secure channels via the Internet, an application server (IT infrastructure), and the service center itself (e.g. the medical telemonitoring center).

It is of great importance to align the individual components of an M2M solution based on an end-to-end system view to effectively minimize the total cost of ownership. When choosing the optimal communication technology (e.g. ISDN, DSL, Ethernet, GSM, Bluetooth), parameters like availability, mobility requirements and installation efforts have to be taken into consideration as they need to be analyzed carefully. For medical consumer applications additional parameters like weight, battery life and standby time are crucial. The latter can be addressed by built-in intelligent power management of wireless M2M modules.

3. mHealth Solutions –Viable for Travelers through M2M

The majority of portable medical devices today work as individual units; they monitor and report single sets of results for only one specific aspect and purpose of patient health. Doctors and nurses need to compile a complete picture of patient's wellbeing out of all these single pieces. But wouldn't it be better if medical professionals could avoid compiling and analyzing disparate data, and instead focus precious time and attention on caring the patient? Indeed, it would.

Fortunately, the healthcare industry has realized this inefficiency and is moving towards a system in which connected devices monitor, aggregate, visualize, and manage medical data on web-based platforms. These new systems allow quick and easy access to medical data and deliver a clear and complete picture of all aspects of a patient's health without ignoring the very important aspects of security, safety, and privacy of patient and medical professional.

Web-based platforms that perform this task can be connected by many different technologies but the most efficient method is basing it on the intelligent use of wireless modules and applied M2M technology. Wireless modules reliably communicate vital information (e.g. vital signs of a citizen) over cellular networks, eliminating the need for

expensive and time consuming fixed land-line communication installation. M2M technology improves patient mobility and avoids the pitfalls of competing technology's limited distance and inconsistent performance. This is especially important for travelers regardless whether on a business or leisure trip. A complete recording of vital parameters is possible without holidays usually being a kind of "white spot".

In the healthcare sector, M2M based communication is for instance used to monitor patient compliance during medication treatment (pill reminder) or to support the efficient mobile monitoring of elderly or chronic disease patients through wearable "health monitors" (Chronic Care Management / Ambient Assisted Living) regardless whether being at home or abroad. By means of telemonitoring, the consulting doctor can monitor the patient's health status and wellbeing efficiently. He can immediately react in case of emergencies to avoid expensive hospitalization, and this monitoring is performed without limiting the patient in his or her mobility. Telemonitoring based on M2M provides increased convenience and significantly reduces cost at the same time. Given the ever increasing pressure on resources in the healthcare and welfare sector, the cost saving aspects will increase in their importance in the future.

Especially in case of diabetes and other chronic diseases, telemonitoring can be very beneficial for the patient, as these diseases cannot be healed but only managed. Without treatment and regular control the patient suffers from a high risk of complications. This is because continuous monitoring is required to avoid thresholds to exceed, and quick action is required when thresholds are exceeded. Telemonitoring can thus provide good assistance in this field. GSM technology can effectively ensure the continuity of care and the access to health services for travelers regardless where they are and what they actually do.

3.1. Drivers, demand and requirements for Mobile Health (mHealth) solutions

The requirements on mHealth solutions are diverse:
- Cost-efficient to reduce cost pressure from public health care sector and make it affordable to a large group of people;
- Easy to install and to use in order to allow also not technically educated people to use the solution;
- Secure to meet privacy concern of users;
- High quality and reliable to work when needed (in case of an emergency).

The requirements mentioned above can be effectively catered for by the intelligent use of M2M technology.

3.2. How to Connect Medical Devices to the Mobile World?

How can personal portable medical and wellness devices be connected to the mobile world today?
- Step 1 – Standalone medical devices: Application running on the single device only;
- Step 2 – GSM Connectivity through external mobile phones connected via Bluetooth to medical sensors;
- Step 3 – GSM Connectivity through external dedicated terminals connected via short-range or cable to medical sensors;
- Step 4 – fully integrated/embedded GSM solutions with ease of use, high mobility, cost and power optimized.

To connect such medical devices to the mobile world even faster than before and to improve the time to market, companies like Cinterion Wireless Modules offer design-in support for module integration which involves antenna design, power management and GSM related certification pre-tests, e.g. for CE, FCC, AT&T approvals Also regarding the choice of SIM card and tariff, there is dedicated support available [8]. The current

development of standards in the area of personal health and wellness solutions is adding to the overall momentum. One of the most notable industry associations in this regard is the Continua Health Alliance (CHA), a coalition comprising more than 200 member companies dedicated to establishing interoperability of systems [1]. Another initiative has been launched by the GSMA in the Embedded Mobile Initiative [9].

4. Main Application Fields: Ambient Assisted Living and Telemonitoring

4.1. M2M Telemonitoring and Ambient Assisted Living

M2M technology can extend the reach of ambient assisted living (AAL) homecare systems to any location where wireless coverage is available — and it's easy to use and install! With M2M telemetry monitoring, also known as telemonitoring, mobile wireless sensor systems can remotely monitor and communicate a patient's vital parameters, whether at home or on the go. Telemonitoring devices can automatically call for help in real time when needed, which allows for faster reaction times and can ultimately help save lives. An example of an established home monitoring product would be for instance the German pacemaker and ICD manufacturer Biotronik. Their CardioMessenger® product can "automatically send medical and technical information from your heart to your attending physician. This enables him or her to keep an eye on you even when you are far away, and to evaluate your condition based on accurate and up-to-date clinical data" [7].

4.2. Better Chronic Care Management

Regular health monitoring is crucial for patients with chronic diseases which can worsen slowly over time without symptoms until the moment when suddenly a critical threshold is reached. Suddenly, life threatening conditions can arise that result in serious illness and expensive hospitalization. With enabled telemonitoring devices, experts can conveniently detect the smallest variation in vital statistics before serious conditions occur. Telemonitoring thus enables earlier detection and treatment [6]. Such handy personal portable medical devices improve the quality of care provided and save medical costs, prevent hospitalization and potentially save lives. This type of disease management is applied to diabetes, COPD (chronic obstructive pulmonary disease), and CHF (chronic heart failure), among others. Medical telemonitoring solutions are efficient and cost-effective tools for the treatment and prevention of chronic diseases as well as in the rehabilitation process [6].

5. Benefits

5.1. Improved Medical Care Quality through Remote Monitoring

M2M enabled mobile sensors for ECG (aka EKG), blood pressure, blood sugar, blood oxygen, and other vital parameters are connected to a patient to consistently monitor and transmit crucial health information to be automatically or manually reviewed by healthcare service providers. When medical parameters and vital statistics are measured more frequently and during real life activities from grocery shopping to exercising to socializing, a more complete health profile can be captured. This enables better treatment and improved overall wellbeing for the citizen while being a patient, and it reduces costs for the patient and healthcare provider alike.

5.2. Secure and Highly Reliable Applications

Machine-to-machine technology serves all medical industry requirements from small form factor modules easily integrated in existing connected solutions to scalable platform modules for use in gateways without the need for additional processors. Wireless GSM enabled medical monitoring solutions are extremely easy to use and free of the constraints of fixed line networks - allowing complete mobility for both patient and device, and guaranteeing a simplified installation when compared to complicated wired solutions.

With appropriate M2M technology, medical devices and applications are more robust; vital patient data can be transmitted securely utilizing the latest encryption technologies. End-to-end data security is effectively supported by inherent security mechanisms of today's cellular networks. M2M technology utilizes regulated frequency bands, which is one of the differentiating benefits of cellular technology as opposed to WiFi.

M2M technology is also flexible and highly reliable for seamless, always-on worldwide communications making truly global healthcare solutions a reality which is essential especially for frequent travelers.

5.3. Benefits for Patients, Service Providers, and the Public Healthcare Sector

Generally, new mHealth systems allow quick and easy access to medical data and deliver a comprehensive picture of *all* aspects of a patient's health.

mHealth solutions extend the reach of a typical ambient assisted living (AAL) homecare systems to any location where GSM wireless coverage is available, for instance in parks and recreation areas, in a nearby restaurant, or in remote rural areas in developing countries.

The application of remote patient monitoring (RPM) can significantly improve life for elderly people, high-risk or chronic disease patients but also pregnant women, since worsening medical conditions can be transmitted to the nearest emergency center immediately. When traveling, a patient can be connected to a tele-medical center at home which could then coordinate necessary further steps, and negotiate these steps with local authorities, health centers, hospitals, etc.

Mobile Network Operators (MNOs) are well positioned to address this emerging and promising market. As result they can leverage existing infrastructure, offer new services resulting in increased revenues and customer satisfaction and loyalty. Actually, the MNO can bundle the mHealth service with other services and increase competitive advantage.

For the public healthcare sector, mHealth has the great potential to reduce cost. There are significant savings possible when reducing the number of days people have to be hospitalized. Regular health monitoring is important especially for patients at risk and patients with chronic diseases which parameters can worsen slowly over time without symptoms. With the application of specific telemonitoring devices, the health center experts can easily detect even the smallest variation within the given range of the patient's vital statistics before a serious situation may occur. Telemedical and telemonitoring solutions thus help improving the quality of care provision, the access to care services, and it helps saving the enormous costs for today's medical treatment and rehabilitation, among others.

Health insurance companies have conducted studies about the potential savings that can be realized when telemonitoring is applied for the treatment of chronic diseases. The costs could be reduced by more than 50%, e.g. by avoiding hospitalization. At the same time, the quality of care is improved. And the savings potential is indeed enormous, as the cost for the treatment of chronic diseases already accounts for more than two thirds of total healthcare expenditure.

5.4. Challenges

From a medical perspective, the reimbursement issue of mHealth services remains a challenge. On the other hand, cellular roaming costs can still be prohibitive with some providers; some are already on the way to a "global" SIM card and offer management platforms that cater for the specific needs. Taking the overall costs of emergency or preventive treatment of a patient at risk in the specialized hospital into account, communication costs of a personal portable medical monitoring device represent just a very small amount of money compared with the hospitalization costs.

5.5. New Services and Business Models

Mobile Health (mHealth) and the application of wireless modules in the fast-growing domain of healthcare and welfare can provide answers to challenges that healthcare providers are facing today. Optimized integrated mobile care can improve cost efficiency through shorter hospital stays, optimized productivity for medical staff and doctors, and improved quality of medical services at the same time. Businesses in this emerging market can extend and enhance their range of services and increase benefits for end users, to gain clear competitive advantages in this quickly evolving business landscape.

6. Conclusion and Summary

GSM technology can assist in making the lives of elderly, chronic care patients, and patients at risk healthier and safer. Especially when travelling, the benefits of a cellular technology combined with vital signs monitoring can be utilized to the full potential. Optimized care is no longer bound to the home but can continue during travels. The doctor is virtually "always just around the corner". Continuous technological innovation like the miniaturization of cellular technology and the digitalization of medical technology makes M2M perfect for a use in the healthcare and welfare domain. When mobility becomes a key requirement (like in the case of travelers), GSM based M2M solutions can provide the answer.

Various innovative devices can improve the everyday lives of citizens by providing higher security (based on standards) and a higher quality of life. By integrating connectivity through cellular technology into these personal portable devices, their added values can be even greater. M2M communication enables the Internet of things, and devices can continuously send and receive information via the mobile network independent of time and place. Over the past decade, the number of wireless solutions in the medical field has grown significantly. M2M mobile health (mHealth) devices have meanwhile reached a maturity level well past the pilot phase, and the solutions are proven and simple to implement. However, the market for mHealth solutions is just at the beginning. Current standardization efforts will nurture future growth. Let's step up, let's actively contribute to the progress of personal portable wireless medical devices of the next generation.

Cinterion products are carrier approved and used for a variety of solutions including remote maintenance and control; metering; payment systems; industrial PDAs; routers and gateways; security systems; health care; automotive and eToll; tracking and tracing; environmental monitoring and more.

For more information, please visit: http://www.cinterion.com/health

References

[1] Davis, R. Continua Health Alliance Overview Presentation http://www.continuaalliance .org/static/cms_workspace/Continua_Overview_Presention_v13_9.pdf Last accessed: 29th Sept. 2009

[2] Pharow, P. et al. Der Weg von eHealth zu mHealth – Komplexe Funktionale und Sicherheit-sanforderungen in der Welt mobiler medizinischer Geräte. In: Schreier, G. et al. *eHealth2008 – Medical Informatics meets eHealth*. Österreichische Computer Gesellschaft, Wien, 2008.

[3] Wolf, G. Know Thyself: Tracking Every Facet of Life, from Sleep to Mood to Pain, 24/7/365. http://www.wired.com/medtech/health/magazine/17-07/lbnp_knowthyself. Last accessed: 22nd June 2009.

[4] McClusky, M. The Nike Experiment: How the Shoe Giant Unleashed the Power of Personal Metrics. http://www.wired.com/medtech/health/magazine/17-07/lbnp_nike. Last accessed: 22nd June 2009.

[5] Sauter, M. GSM Technologie ermöglicht kabellose Machine-to-Machine (M2M) Anwendungen. In: Wollert, F., ed. *Wireless Technologies Kongress 2007*. Berlin. Akademische Verlagsgesellschaft Aka GmbH, 2007, p. 176-180

[6] Braun, G. et al. Telemonitoring von Gesundheits- und Vitaldaten – Ökonomischer und qualitativer Nutzen bei chronischen Erkrankungen. In: *Ambient Assisted Living : Technologien, Anwendungen ; Tagungsbandbeiträge*. VDE Verlag GmbH, Berlin, 2009

[7] BIOTRONIK Home Monitoring®. http://www.biotronik.de/en/de/1222. Last accessed: 28th Sept. 2009

[8] Cinterion Wireless Modules. Test Laboratories. http://cinterion.com/test_labs/articles/testing.html. Last accessed: 28th September 2009

[9] GSM Association: Embedded Mobile Initiative – Market Opportunity. http://www.gsmworld.com/our-work/mobile_broadband/embedded_mobile/market_opportunity.htm. Last accessed: 28th Sept. 2009.

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Communication and Mobility: Using Standards for Continuity of Care

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Abstract. European healthcare is changing The increased movement of the citizen asks for administrative changes, but also for patient records that can be accessed ubiquitously in real time and also across borders. New technologies offer new approaches and possibilities. This paper outlines the changes of developments in the health sector brought upon by ICT. It demonstrates present initiatives towards European eHealth cross-border solutions regarding different levels of interoperability such as semantics, technical requirements, organizational and security related requirements. The project ByMedConnect is given as an example for implementing standardized solutions for overcoming limiting factors and ensuring an interoperable solution supporting continuity of care. Challenges on a future user-friendly European eHealth solution are discussed.

Keywords. eHealth, electronic healthcare record, EHR, interoperability, standard, cross-border healthcare

1. Introduction

Electronic support of health care known as eHealth is able to improve the access to clinical data, knowledge and information and to enhance the quality of services and working conditions offered. eHealth supports mobility. It allows patients to access appropriate health resources based on equal opportunity and informed choice. Information and communication technologies (ICT) support networking between human beings, institutions and health information systems -also across borders. Smart and safe communication of data, information and knowledge will remain main development issues in the next decade as networks are crossing regional and national boundaries. There are several national initiatives in Europe which are not harmonized so far.

In 2008 the European Commission issued a recommendation on cross-border interoperability of the electronic healthcare record (EHR) [1]. It states that in order to achieve interoperability "Member States are invited to undertake actions at five levels, namely the overall political, the organizational, the technical, the semantic and the level of education and awareness rising".

At the same time a large scale project, called epSOS (European Patients Smart Open Services) [2] involving 12 Member States (and many Health Ministries) aiming to support the implementation of cross-border healthcare was initiated.

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Many other National and European projects have helped advancing interoperability in different sectors of eHealth, e.g. TrustHealth [3] and SEISMED [4] in security, DIABCARD [5], NETCA@RDS [6] and ARTEMIS [7] developed technical and semantic solutions for communication, TOSCA [8] showed feasible solutions for tele-health, Bit4Health [9] demonstrated ways towards an eHealth architecture.

2. Health Information Systems

Health information systems are developed for different purposes using a variety of technologies. They might be supporting administration or even decision support. The scope of functions provided and the way they are implemented depend on the health care area. Primary care in mostly all countries is visit oriented with treatment time usually restricted to few minutes. This minimizes the amount of data which are documented per visit.

In secondary and tertiary care larger systems were developed; these support logistics and patient management. They are episode oriented and at their core are ADT (Admission-Discharge-Transfer) and financial management. The systems serve as an administrative basis for departmental and service systems such as laboratory and radiology.

While presently healthcare systems and medical services evolve around the patient-doctor relationship, in the near future this correlation will be just one part of a more holistic approach. eHealth needs to be seen being a framework of compliance with privacy issues, healthcare centers, home-monitoring, and results being used for research. Social services are in many countries getting linked to health services.

Today health data communication is usually limited to one institution or to regional doctor networks. Most countries lack communication between the different health care institutions, e.g. hospitals and primary care. Some of the reasons are technical problems and missing standards and/or the insufficient application of existing standards.

Missing common terminology is another hindrance in communication, even more so when communication concerns institutions or physicians in different countries.

The DIABCARD project [5], which aimed at improving communication in diabetes care, was one of the first projects to demonstrate an interoperable solution. Its dataset was based on the standardized European Emergency Data Set [10] and on a "Diabetes dataset" developed and agreed by European physicians of the EASD (European Association for Studying Diabetes). Chip card technology was used for communicating data between physicians. A dedicated card interface module ensured the independence of the solution from specific cards and card readers. DIABCARD was implemented in Austria, Greece, Italy, Spain, France and Germany. The follow-up project ByMedCard - Health across Borders adapted and implemented the DIABCARD concept for citizens travelling between Germany and Hungary.

Increased mobility of the citizens asks for administrative changes, but also for patient records that can be accessed ubiquitously in real time and also across borders. Thorough and adequate administrative changes are required.

EpSOS [2] aims to develop a practical eHealth framework and an ICT infrastructure that will ensure secure access to patient health information, particularly with respect to basic patient summaries and ePrescriptions between different European healthcare systems. NETC@RDS [6] has been working towards the establishment of new improved health care administration services for mobile citizens across the EU.

3. Standardization

Healthcare information is presently still very fragmented with proprietary medical information systems using individual interfaces, data protection solutions and even terminology. In contrast mobility requires interoperability which has to enable the exchange of clinical data between computer based applications, even for cross-border communication.

Modern technology supports mobility: the internet enables fast and –almost-ubiquitous access and is to be seen as a main platform for the future. Trusted portable devices like a mobile phone, a smart card or other devices such as USB sticks can complement it for reliable identification and authentication of users. Safe communication between sender and receiver relies on confidentiality, authenticity, data integrity and accountability.

The information needed to treat the patient as well as security functions will have to be available in the preferred language of the health professional. Under strict security conditions, authorized healthcare personnel will be able to read and write information locally or remote. This requires interoperability on different levels:

- Semantics ensuring common definition and understanding of the content;
- Technical enabling the use of different environments in order to integrate the different applications;
- Organisational requiring the understanding of legislation, regulation and other policies as well as governance models;
- Security making sure of a trustful environment.

A number of ISO and CEN standards have been published to advance these goals. They range from requirements on protocols, devices and architectures to service infrastructures. Unfortunately, they are often neither known nor used. The BioHealth project (Security and Identity Management Standards in eHealth including Biometrics) [12] has been analyzing reasons for this and has at the same time tried successfully to provide ways to enable SMEs to get information on eHealth standards to help them decide – backed by an online Standards' Repository - whether a specific standard would be of help to them or not. The project was exemplified on security standards in eHealth.

A main step towards interoperability of healthcare related data and the development of eHealth platforms were decision 189, 190, 191 on the European Health Insurance Card (EHIC) [6], which is used to proof the citizen's entitlement to health treatment in any EU Member State. As an additional measure the European Commission issued Mandate 403 (M/403) [12] to the three European Standards Organizations (CEN, CENELEC, and ETSI) in order to provide a consistent set of standards to address the needs of European eHealth provision.

Amongst others digital identity is a major issue. This can be defined as a collection of digital information on one subject. It is needed to link different electronic data to one person, e.g. a person's health insurance number to his lab data in order to store these in the person's health record. Digital identity serves different purposes: identification, authentication, and assurance. It consists of a set of attributes, e.g. characteristic habits, preferences or traits plus an identifier which can be real or anonymous.

Management of digital identities (eID) is a very complex area. eIDs need to be allocated not only to human beings but to all principals and even to specific items. eID of replicable things and robots which are used for automated operation of patients have to be envisioned in the near future. Several projects and activities work towards to overcoming barriers in the digital identity sector and to finding ways on eID management.

4. Supporting Continuity of Care

The Continuity of Care Record (CCR) [13] is a basic data set of the most relevant facts about a patient's health status, covering one or more episodes or visits. These may be documented by a GP, a specialist, a hospital physician or a nurse during treatment in order to enable other health professionals caring for a patient to readily access a summary of relevant information. It includes identifying data, information about the patient's health status (e.g. anamnesis, allergies, risks, problems, medications, operations) and basic data about insurance, care documentation and care plans. The CCR is represented in XML, a structured electronic format. The CCR is meant to address the information needs for continuity of care from one health professional to another. As it contains only selected, relevant portions of a patient's health record it provides a perfect data source for treatment across borders.
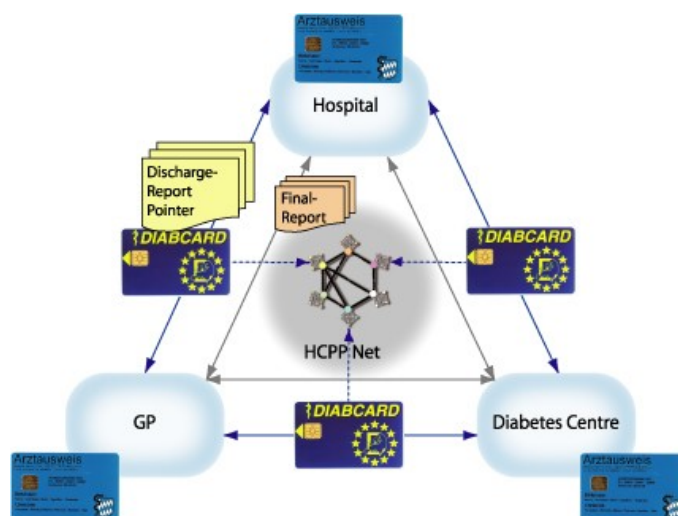
Figure 1. Secure communication network between physicians in hospital and primary care using professional cards (Arztausweis) and the DIABCARD smart card.

The physician originating the CCR transmits it to the co-treating practitioner. This approach already proofed applicable in the DIABCARD system where a smart card was used as communication tool. The XML structure contains also links which point to selected documents of the patient's EHR. The documents are located on a specific server and can be accessed by authorized physicians using the Health Care Professional Protocol (HCPP) [14] via internet.

The ASTM standard CCR has been introduced in the USA in more than 100 health care systems. Microsoft's Health Vault and Google's concept for healthcare support have implemented this standard. Another variant is CCD, the CCR is translated into an electronic document conforming it to the HL7 CDA [15] concept. Solutions for patient centered administration of the CCR by use of mobile phones are available.

In the ByMedConnect [16] project the pragmatic and limited approach of the CCR is complemented by the more comprehensive standard ISO 13606 – Electronic Health Record Communication [17]. It consists of various parts and proposes an advanced architecture to deal with the heterogeneous systems existing in the medical domain. It defines a reference model for the EHR that specifies the common building blocks, and introduces Archetypes [18] as a formal model of real clinical concepts that lay the basis for interoperable semantically sound data exchange. Currently tools are developed that enable the clinicians themselves to define these universal models in an international

collaborative approach [19]. Archetypes created can then be published in a repository for sharing and reusing them within inter-institutional and inter -sectoral communication . The use of archetypes is an important step towards semantic interoperable EHRs that are portable (via institutional / regional boundaries), precise (e.g. terminology binding), accessible (individual queries + decision support) and durable (life-long record).
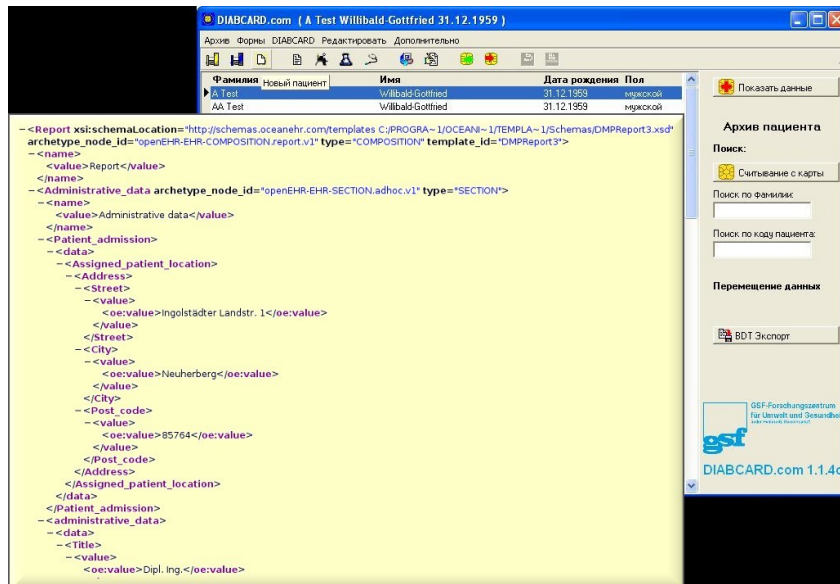
Figure 2. Export of data in ISO 13606 compatible format out of the Russian version of the disease management software DIABCARDcom

Archetype based data exchange has the potential to fill the gap of lacking communication capabilities between heterogeneous systems. The standard for EHR communication has recently been published for international use at ISO, e.g. a Japanese version is ready for implementation. The standardization activities are supported by the EUROREC Institute [20] and the OpenEHR Foundation [21].

5. Conclusion

In future healthcare will be different. The benefits of eHealth are apparent. For many years the Member States and the European Commission have been supporting projects enhancing the quality of care by ICT. The present technological developments -building on the results and achievements of those early initiatives- are pointing towards patient-centered health care supported by anytime-anywhere access to health information and enabling instantaneous connections to clinical support. Presently eHealth is at a crucial point; many initiatives towards European eHealth solutions have been initiated and are ongoing as has been shown in the preceding chapters. These solutions still need to be proved applicable, feasible, usable, acceptable and useful.

The success of eHealth will depend on the acceptance by all users. This means that a comprehensive European eHealth strategy needs to be developed. eHealth offers large business opportunities and it has the potential to drive innovation. This necessitates the development of new products and high investment costs. A clear political commitment towards the financing is required.

eHealth requires accessibility of new technologies and e-literacy. The European population is aging. This means, on the one hand, large opportunities towards the support of the elderly, but, on the other hand, challenges like creating awareness and

technology education in the elderly have to be met. In a European cross-border scenario legal barriers such as the contradiction of national legal requirements, and of national laws impacting identity have to be overcome without neglecting social barriers such as the culture of distrust or the fear of loss of anonymity. eHealth relies on the trust in the system by all stakeholders. This keeps data protection, privacy, security and also ethical issues high on the agenda.

Acknowledgement

References

[1]   Commission Recommendation of 2 July 2008 on cross-border interoperability of electronic health record systems (notified under document number C(2008) 3282)

[2]   epSOS- European Patients Smart Open Services; http://www.epsos.eu (last accessed 24-09-09)

[3]   Blobel, Bernd (2000) The European TrustHealth Project experiences with implementing a security infrastructure. International Journal of Medical Informatics 60 (2), S. 193-201.

[4]   SEISMED - Secure Environment for Information Systems in Medicine; http://ehto.org/aim/volume2/seismed.html (last accessed 24-09-09)

[5]   DIABCARD

[6]   NETCA@RDS -A step towards the electronic European Health Insurance Card; http://netcards-project.com (last accessed 24-09-09)

[7]   ARTEMIS- Building interoperability into medical information systems; http://istresults.cordis.europa.eu/index.cfm/section/news/Tpl/article/BrowsingType/Features/ID/79928 (last accessed 24-09-09)

[8]   TOSCA- Tele-Ophthalmological Services - Citizen-centred Applications; http://www.ist-world.org/ProjectDetails.aspx?ProjectId=525f09f393a64657a6c645111f3fc278 (last accessed 24-09-09)

[9]   Blobel, Bernd (2005) Die Implementierung von bIT4health im Spiegel der europäischen Initiativen sowie der fortgeschrittenen Programme anderer Länder. In: Steyer, Günter und Tolxdorff, Thomas, (eds.) bit for bit - Halbzeit auf dem Weg zur Telematikinfrastruktur: TELEMED 2005 - Telematik im Gesundheitswesen. Akad. Verl.-Ges., Berlin, S. 88-95. ISBN 3-89838-064-5

[10] European Emergency Data Set – NETLINK Requirements for Interoperability; http://www.sesam-vitale.fr/netlink/netlink_requirements_for_interoperabilityv21.pdf (last accessed 24-09-09)

[11] BioHealth - Security and Identity Management Standards in eHealth including Biometrics; http://www.bio-health.eu (last accessed 24-09-09)

[12] M/403 EN; http://ec.europa.eu/enterprise/standards_policy/action_plan/doc/mandate_m403en.pdf (last accessed 24-09-09)

[13] Continuity of Care Record (CCR) Standard - Resource Site; http://www.ccrstandard.com (last accessed 24-09-09)

[14] ByMedCard - Health-Care-Professionals-Protocol (HCPP); http://www.stmugv.bayern.de/krankenhaus/telemedizin/projekte_detail.htm?ID=AAxpv0ps7BE2AiIRuFTDJA%3D%3D (last accessed 24-09-09)

[15] HL7book – CDA Resource Page; http://hl7book.net/index.php?title=CDA (last accessed 24-09-09)

[16] ISO 13606-Part 1:2008, http://www.iso.org/iso/catalogue_detail.htm?csnumber=40784 (last accessed 24-09-09)

[17] ByMedConnect - Improving communication by linking domains thus fostering integrated healthcare in Bavaria; http://www.bymedconnect.de (last accessed 24-09-09)

[18] ISO 13606-Part 2:2008, http://www.iso.org/iso/iso_catalogue/catalogue_tc/catalogue_detail.htm?csnumber=50119 (last accessed 24-09-09)

[19] openEHR Clinical Knowledge Manager; http://www.openehr.org/knowledge (last accessed 24-09-09

[20] EuroRec Institute; http://www.eurorec.org (last accessed 24-09-09)

[21] openEHR Foundation; http://www.openehr.org (last accessed 24-09-09)

Using Remote Patient Monitoring for the Long Term Management of Chronic Disease

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Abstract: We describe our experiences of using remote patient monitoring to support the long term management and clinical intervention in patients with chronic disease. Within the project we developed new algorithms to determine from vital signs collected on a daily basis, those patients requiring clinical investigation for their condition. Our aim was for patients to achieve and sustain clinically recommended values for parameters. In our study, the telemonitoring prompted clinical intervention in 37% of patients. Our approach proved particularly effective for the newly diagnosed, and for those with long term issues of management.

Keywords: Telehealth; Remote Patient Monitoring; Chronic Disease Management

1. Introduction

It is estimated that there are over 17 ½ million people living with a long term condition in the UK, accounting for over 80% of GP consultations. With an aging society these numbers are only set to increase further [1]. Evidence has shown that even relatively small reductions in blood pressure in those with hypertension and blood glucose in diabetes mellitus can reduce their clinical risk significantly [2, 3]. It is vital that healthcare services are able to provide these gains for patients at an affordable cost. Remote Patient Monitoring (RPM) has been identified as a potential tool to manage this demand for health care [4]. To date there have been many projects that have evaluated the technology [5], however most have concentrated on detecting and managing the acute exacerbations that arise from chronic disease (particularly CHF) rather than determine effective ways to manage long term the condition itself. This study aims to develop and evaluate methods that exploit both RPM in the patients' homes and protocol-based clinical interventions to achieve sustained improvement in disease measurements for three long-term conditions: chronic heart failure (CHF); Type 2 diabetes mellitus; and essential hypertension.

2. Methods

Our study was based in Chorleywood Health Centre, a medium sized general practice to the NW of London. From a total population of 6000 registered patients, 724 were

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determined to have CHF; type II diabetes mellitus; and essential hypertension, some having two or more. 173 were chosen randomly and invited to take part in the study. Of these 51 accepted the invitation to participate in the study.

Each participant was provided with an RPM unit for a 12 week period, the study having three such cohorts over a nine month period. We had a further set of 3 patients having the equipment for the entire nine month period and a set of 3 patients with no equipment. We used a commercial RPM system (Care Companion, AMD Telecare, North Chelmsford, MA, USA) that consisted of a unit with a touch screen device to allow manual entry of certain data (glucose) and attached peripheral devices to measure automatically appropriate medical values. Those with CHF were given weighing scales, SpO2, and BP unit; those with Diabetes a glucometer; and those with Hypertension a BP unit. Each participant was asked to enter daily physiological measurements. Targets were set for each group based on best practice guidelines [6, 7]: BP of 140/85mmHG for non diabetic patients and 130/80mmHG for patients with diabetes, HbA1c of 7% (8.6 mmol/L). CHF was managed by monitoring weight, BP and SpO2 for significant change.

The data was sent via the participant's telephone line to a server held at the Health Centre and could be accessed and viewed via a website. A chart of the data was created for each patient and this was hyperlinked into the EPR (electronic patient record). The primary healthcare team reviewed each patient whose data lay beyond the threshold defined by our intervention algorithm at regular case conferences and clinical interventions were agreed.

3. Intervention Protocol

We developed a sophisticated personalised automated intervention algorithm within the project to improve the accuracy with which patients requiring intervention were recognized compared to existing systems based on a simple threshold. The specific goals were to reduce the number of false positive indications and to adapt automatically when a clinical intervention was made so that no further indications were given until sufficient time had elapsed for the intervention to take effect.

Our approach was to smooth the raw data by using a median filter over 3 days, which is effective at removing outlier values. We then wished to apply an adaptive threshold that was based on the patient's data, responded to an intervention and would eventually provide an indication should the patient data remain above the long term target value.

Such an adaptive threshold can be achieved by applying an exponential curve having an initial value that is 2 standard deviations above the current value (calculated from patients existing data), and decaying over a 14 day period to the long term target value. The threshold is seen to model well changes in the data when the patient responded to an intervention. The threshold also remained responsive to sudden changes resulting acute exacerbation.

The algorithm is shown applied to a hypertensive patient in figure 1 where the final target is set at 140/85. The smooth curves indicate the boundaries within which the data should lie to achieve best clinical outcome as described in the Map of Medicine [8]. To avoid needless triggers and alarms the boundaries are adjusted upward at the beginning of monitoring and after the introduction of an intervention, the value being set to 2 standard deviations above the current value.

A case conference run with the doctors and nurses of the team reviews the collected data and the clinical notes. Data is observed on a daily basis but unless swings are extreme, data is reported on a weekly basis and reviewed for possible intervention every two weeks. Figure 1 shows the successful addition of a calcium blocker to better control the systolic blood pressure.

BP - HYP2 - ID 1029
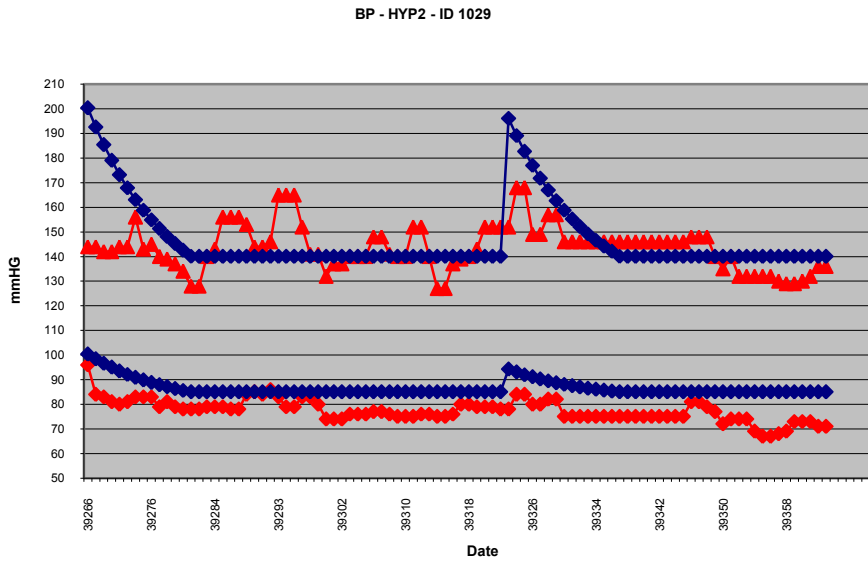
Figure 1. Personalized automated intervention protocol for a hypertensive patient with successful addition of a calcium blocker to better control the systolic blood pressure

Figure 2 shows a diabetic patient unwilling to accept her newly diagnosed diabetes and treatment until there is eventual control of the blood sugar following repeated intervention and education.

Blood Sugar - DB1 - ID 1011
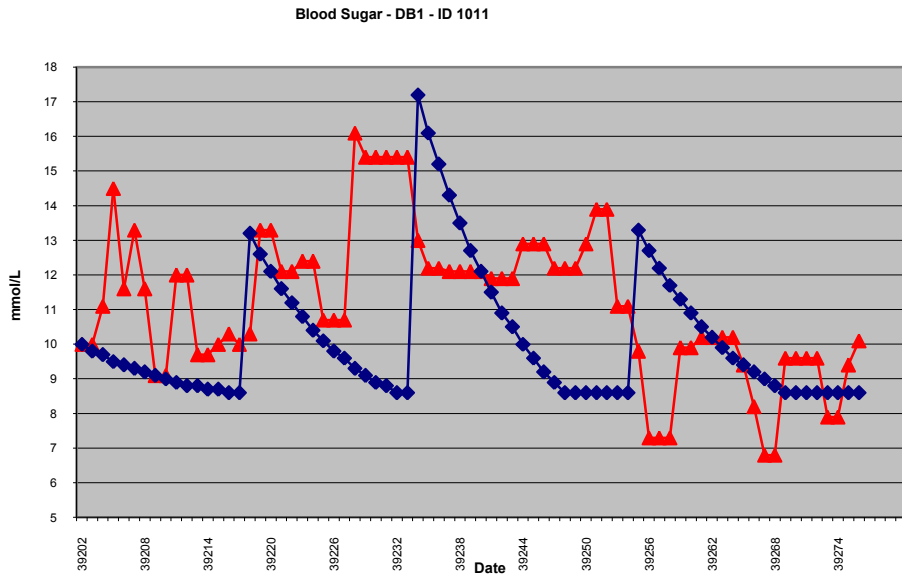
Figure 2. Personalized automated intervention protocol for a newly diagnosed diabetic patient

Figure 3 shows the daily blood glucose readings for a patient known to have long term management issues of diabetes. On each clinical intervention, the threshold is reset to a value higher than the current value and it can be seen to reduce back to the target

value over a 14 day period. The patient refused nursing advice to rotate his injection site, his persistence with one site being due to his difficulty in coping when in his wheel chair – he is disabled because of a diabetic neuropathy – and his faith in his private diabetologist. Observing his results changed his thinking. The dose of insulin was then increased. The final change was to introduce Metformin.
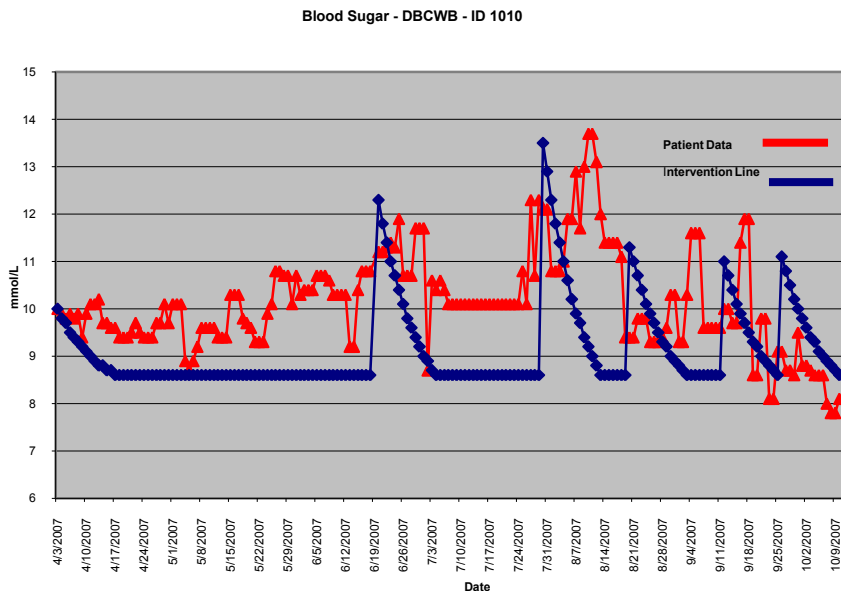
Figure 3. Personalized automated intervention protocol for a diabetic patient having long term management issues and requiring repeated intervention

4. Preliminary Results

After 6 months of the study, 2 cohorts have each completed the 12 week trial, giving data on 29 patients (mean age 70, 17 female). 11 patients had essential hypertension as their primary long term condition, 8 had chronic heart failure, 7 had type II diabetes mellitus, 2 had chronic heart failure and type II diabetes mellitus, and 1 had all three conditions. 9 participants withdrew from the study before they were due to be given the RPM units because of clinical or social reasons and further participants were recruited to replace. None withdrew during monitoring.

The algorithm has prompted clinical intervention in 11 patients (37% of the patients): of these 64% were in the CHF group, 18% in the Hypertensive group and 18% in the diabetes group. The average time elapsed before first intervention was 47 days (SD 21). Primarily these interventions (72%) resulted in changes to medication and health advice, however one hypertensive patient was referred for a pace maker after the discovery of a bradycardia due to heart block, and one CHF patient had two emergency hospital admissions during the 12 week period. These interventions have resulted in a mean shift reduction of 12mmHG Systolic and 2mmHG Diastolic in the hypertensive group.

5. Discussion

The personalized threshold algorithm was developed to be based on the patient's data, clinical target values and clinical interventions so that it might easily be applied automatically within a RPM system. When linked to their primary healthcare team, the need for clinical intervention is easily recognized and thus provides better and earlier disease management. Limiting the amount of time required to review the data by both reducing the number of alerts and filtering out those patients not requiring intervention contains work load and makes adoption of the system more likely.

Results suggest that 4 weeks is sufficient time in which to recognize a need to intervene clinically and that in 12 weeks it is possible to intervene enough to affect a change toward target. This reduces both the disruption of patients' lives and the cost of the service because the equipment can be reused quickly.

In the UK, the GMS contract has made general practice the key organization to care for chronic disease. But the clinical question remains – on whom and when should we intervene? A single occasional measure of a physiological parameter might fail to reveal poor care and deterioration in a patient's illness. A clinical response to a single reading of blood pressure can lead to excessive dosages and harm. In contrast in this study, clinical interventions were agreed upon by the team and carried out by both nurses and doctors in their clinics and in the patients' homes. The value of RPM was established quickly in the minds of the team as the results were reviewed and made any additional clinical work acceptable. In answering clinical questions further clinical tests were needed: blood tests; ECGs recorded; ambulatory ECG and blood pressure recordings made; and referrals arranged. The combination of technology and clinical skills possible in general practice was proven to be effective in responding to the data.

6. Conclusion

RPM used with automated personalized intervention algorithms and a clinical protocol was found to be very effective in the long term management of patients with chronic disease in this primary care setting. It was particularly effective in the case of newly diagnosed patients, patients needing change in medication, those unwilling to comply, and those with poor long term control, as it supported an aggressive targeted strategy for intervention. By improving the intervention algorithm, fewer false positive patients were detected, giving the users confidence to act on the information.

By shifting the focus of care away from managing acute exacerbations, clinicians can use RPM to recognize those of their patients who would most benefit from monitoring. The clinical information provided by RPM allows both healthcare professional and patient to confront issues together and resolve difficulties. Awareness of the physiological measurements and learning their value from the clinical team empowers patients in gaining self-determination in understanding and managing their own illness resulting in benefits for themselves, their healthcare professionals, and the health economy.

References

[1]   DOH, Improving Chronic Disease Management, 2004, Available at:
      http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_40
      75214 (last accessed 3 April 2008)

[2]   Prospective Studies Collaboration, Age-specific relevance of usual blood pressure to vascular mortality:
      a meta-analysis of individual data for one million adults in 61 prospective studies, The Lancet 2002;
      360: 1903-1913

[3]   Stratton IM, Adler AI, Andrew H, Neil W, Mathews DR, Manley SE, Cull CA, Hadden D, Turner RC,
      Holman RR. Association of glycaemia with macrovascular and microvascular complications of type 2
      diabetes (UKPDS 35): prospective observational study, British Medical Journal 2000; 321: 405-412

[4]   Barlow J, Singh D, Bayer S, Curry R. A systematic review of the benefits of home telecare for frail
      elderly people and those with long-term conditions, Journal of Telemedicine and Telecare 2007;13:172-
      179

[5]   Bensink M, Hailey D, Wootton R. A systematic review of successes and failures in home telehealth:
      preliminary results, Journal of Telemedicine and Telecare 2006; 12 (Suppl. 3): S3:8-16

[6]   Williams B, Poulter NR, Brown MJ, Davis M, McInnes GT, Potter JF, Sever PS, MCG Thom S.
      Guidelines for management of hypertension: report of the fourth working party of the British
      Hypertension Society 2004 – BHS IV, Journal of Human Hypertension, 2004; 18: 139-185

[7]   McIntosh A, Hutchinson A, Home PD, Brown F, Bruce A, Damerell A, Davis R, Field R, Frost G,
      Marshall S, Roddick J, Tesfave S, Withers H, Suckling R, Smith S, Griffin S, Kaltenthaler E, Peters J,
      Feder G. Clinical Guidelines and evidence review for Type 2 diabetes: management of blood glucose,
      Sheffield: ScHARR, University of Sheffield, 2001

[8]   Map of Medicine. Available at http://www.mapofmedicine.com/ (last accessed 23 Septermber 2009)

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Developing a Standard for Personal Health Devices based on 11073

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Abstract: This paper describes the process and outcome of the efforts to develop a new standard for Personal Health Data (PHD) based on the existing 11073 family of standards for medical devices. It identifies the requirements for a standard that is to be applied to small devices with limited resources of processor, memory and power and that will use short range wireless technology. It describes how existing components of 11073, such the Domain Information Model and nomenclature have been used and adapted to create the new standard. Currently the base protocol and specialization standards for9 devices have been produced with a further seven in development. Devices based on the standards are now being released.

Keywords: Standards; Personal Health Devices; Telehealth

1. Introduction

The 11073 family of standards for medical devices [1, 2, 3] has existed for many years but its use has been limited. This has variously been explained, but that it was designed for plug and play for intensive care unit (ICU) devices has been a major influence. Such devices normally are mains powered, are connected to wired networks and have high quality processing capability. The protocol, based on OSI, is often criticized as being heavyweight and complex. In its current form, it did not appear appropriate to be used as the basis of a new standard for personal health data (PHD) devices. However, with the expected rapid increase in the demand for health devices in the home with capability to communicate results, a standard capable of operating in this environment is essential.

The 11073 family of standards is partitioned into a set of standards covering the many aspects of communicating the semantics of medical data from device to manager. This includes a Domain Information Model (DIM), nomenclature, device specializations, device behaviour, communication transports, and communication protocol. The 11073 family of standards has also acted as an umbrella for medical device standards.

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2. Background

2.1. The IEEE 11073 PHD Working Group

The IEEE 11073 PHD Working Group (WG) was established to develop a new medical standard that would be used for the typical PHD device. It was accepted that any new standard would need to be implemented within the limited resources of such devices. It was also expected that the standard would align with current developments in the Bluetooth SIG and USB SIG to develop health profiles. The work group set itself the task to develop a common base protocol that will work with an initial set of six device specializations (pulse oximeter, pulse/heart rate, blood pressure, thermometer, weighing scale and glucose).

The group currently consists of 97 members from 51 organizations, with 56% from USA, 22% from Far East and 22% from Europe. It has weekly telephone conference calls and meets every 2-3 months as face to face meeting.

2.2. The Standards Process

Initially four proposals were submitted to the group for consideration as a basis for the standard. However no one proposal satisfied all the requirements and a process to develop a combined proposal was adopted. This included identifying a template of a set of minimum requirements, a set of preferred requirements, and a set of mandatory behaviour. Proposals were compared and strengths of each identified to inform the final proposal.

The final proposal was mainly based on the 11073 standard but included important changes to accommodate the resource requirements of PHD devices and to incorporate advantageous characteristics of the other protocols.

3. The Protocol

3.1. Protocol Overview

The work of the IEEE PHD 11073 is defined by the framework as shown in figure 1. The overall task is concerned with defining the protocol at layer 7. The transports which provide layers 1-6 are defined elsewhere and are outside the scope of the work of the group, although there is close liaison with groups such as Bluetooth SIG to ensure compatibility. However note that the group has set an objective to make the protocol transport agnostic.

The existing 11073 standard uses OSI layer 7 and utilizes existing functionality of CMISE and ROSE. It was quickly apparent that an optimized exchange protocol was required. This would provide the same functionality as OSI layer 7, but implement it in a lightweight fashion, eliminating any redundant features, and be fully defined in the new standard 20601, which would simplify implementation.
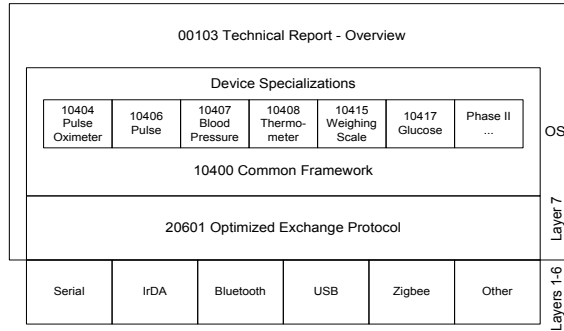
Figure 1. Overview of the IEEE PHD 11073 Framework

3.2. Domain Information Model (DIM)

The existing DIM of 11073 was used, but it was simplified for PHD devices by constraining the scope of the model and restricting and flattening the hierarchy, figure 2. Abstract Syntax Notation (ASN.1) is used to describe the model, and this may also form the basis of definitions of data structures for other languages.
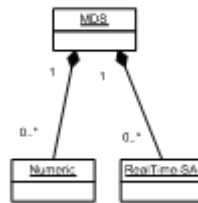
Figure 2. Optimized PHD DIM

The current optimized DIM for the PHD has three objects; the Medical Device System (MDS), the Numeric and the Real Time Sampled Array (RT-SA). The MDS has as attributes all the information pertaining to the device and its operational status, such as unique device ID, device configuration, and time functions. Attributes also contain product specification in text form. Attributes may be determined by using the GET method defined in 20601.

Numeric objects relate to the physiological parameters and have as attributes the mechanism to obtain an observed value and its status such as units and the timestamp. The numeric object is defined to permit intermittent observations to be reported. Observations may be reported using four methods: the manager may make a specific request for currently available data; the manager may request data to be reported as they become available for a specified time; the manager may request data to be reported as they become available for an unbounded period of time; the agent may send an unsolicited observation. The RT-SA is optimized to report an array of observed values as a single data transmission, which reduces protocol overhead and would be used for real time streams with high data rate and requiring low latency, such as the plesythmogram.

The protocol is further optimized by allowing for fixed and variable format of data transmission (figure 3). In variable format, each observation carries its attribute ID, the length of the entry and the numeric value. If a stream of observations is established, each having the same attributes, then the common attributes can be defined in advance of the transmission so that only the values need to be reported each time. This is common attribute list is defined as the Observed-Value-Map is applied to each set of values

reported and will reduce the transmission burden. The idea is further extended to the concept of defining standard devices with standard configuration. In this case there may be no need to define the Observed-Value-Map in advance, so reducing transmission burden during association further. A device may define itself as supporting extended functionality and use the variable format to allow flexibility.
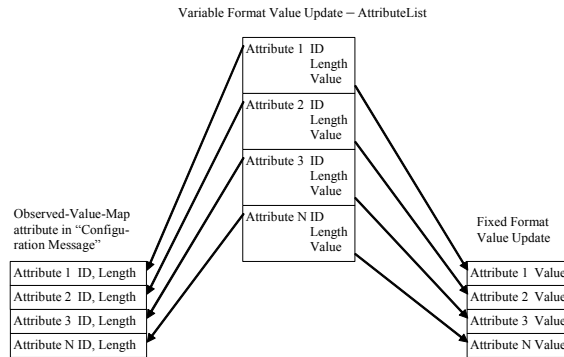
Figure 3. Fixed and Variable Data Formats

The Medical Device Encoding Rules (MDER) [3] is used to convert ASN.1 structures to binary transmissions, and this has been augmented within PHD to provide further optimized data types. Although essentially the same as DER, they apply some optimizations to the protocol by having fixed size coding and removing some of the features, and so aligns with the needs of PHD devices. Note that network byte order is big endian.

3.3. Communication Model

The transport layer has been assumed to appear as a point to point link and provide a byte serial stream and matches the connection-oriented models of the proposed transports. It is further assumed that whenever the transport indicates a connection, the state machine (figure 4) moves to the connected state and the agent is placed in the unassociated state. The agent will initiate the association between itself and the manager by issuing an association request and will enter the associating state. The association request will contain configuration ID and allow the manager to determine if it should accept the request and if it already has configuration information from an earlier association. If the manager does not have configuration information it must request that configuration information is sent by the agent prior to entering the operating state. The configuration information sent by the agent will include information on the objects in the device and a handle number by which they may be accessed. This step is bypassed if the configuration is already known and assumed unchanged. Manager and agent will then enter the operating state. An association release and its response will take manager and agent back to the unassociated state, and this is the preferred method to disconnect devices.
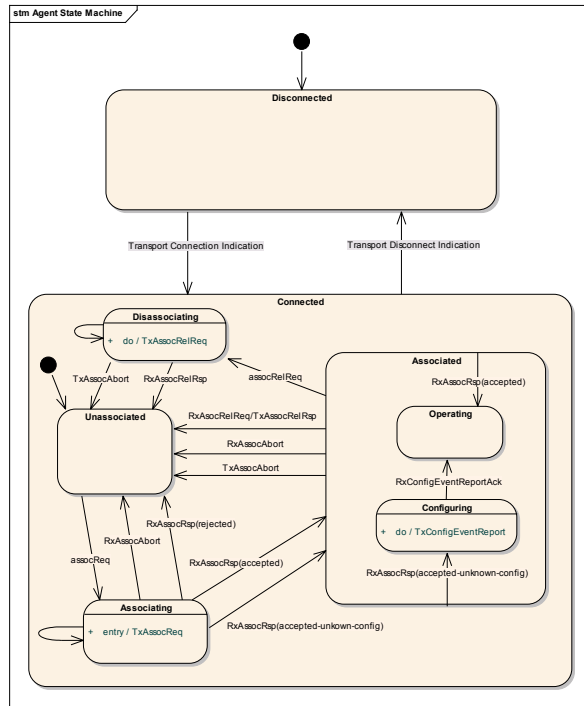
Figure 4. Association State Machine

4. Progress

The IEEE PHD WG has now produced to standard the base protocol and methodology (11073-20601-2008) and the specialization standard for specific devices. Other specializations are in development, table 1.

Table 1. The Standards

Standard	Device	Status
-10101	Nomenclature	Standard
-10201	Domain Information Model	Standard
-10404	Pulse Oximeter	Standard
-10406	Basic ECG (1 to 3 lead)	In development
-10407	Blood Pressure	Standard
-10408	Thermometer	Standard
-10415	Weighing Scale	Stnadard
-10417	Glucose Meter	Stnadard
-10418	INR	In development
-10419	Insulin Pump	In development
-10420	Body Composition Analyzer	In development
-10421	Peak Flow	In development
-10441	Cardiovascular	Standard
-10442	Strength Fitness	Standard
-10443	Physical Activity Monitor	In development
-10471	Independent Living Hub	Standard
-10472	Medication Monitor	In development
-20601	Personal Health Devices	Standard

5. Conclusion

The IEEE PHD WG has focused on producing a protocol for medical devices that is optimized for low capability agents that have limited resources of processing power, memory and power for communication. It has reduced the size and complexity of the existing 11073 standard by reducing the data transmission sizes through defining a lightweight application layer, removing the session and presentation layers of OSI, and making assumptions of the transport layer. The DIM has been constrained and its hierarchy flattened to create simplified models more appropriate to PHD devices. An optimized reconnection protocol can remove the need to transmit the configuration of an agent already known to a manager or for standard devices. The protocol aligns with the existing DIM and utilizes the existing nomenclature to leverage the 11073 standards and to provide a framework for extensibility.

Acknowledgments

References

[1] ISO/IEEE 11073-10101: Health informatics — Point-of-care medical device communication — Part 10101: Nomenclature. First edition 2004-12-15.
[2] ISO/IEEE 11073-10201: Health informatics — Point-of-care medical device communication — Part 10201: Domain information model. First edition 2004-12-15.
[3] ISO/IEEE 11073-20101: Health informatics — Point-of-care medical device communication — Part 20101: Application Profiles – Base Standard. First edition 2004-12-15.

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Lessons learned: Implementing the EN13606 EHR standard the need for a European Semantic Interoperability Infrastructure Framework

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Abstract. ERS, a Dutch company, is involved in marketing and deploying an EHR product based on the European and International standard CEN/ISO EN13606. A unique feature is that the EN13606 is based on the Two Level Modeling principle; meaning that there is a complete separation between responsibilities between the IT-domain and all Health Knowledge domains. During the last two years we learned a lot. In this presentation we want to share with you our real-life experiences. Topics to be discussed: Features and gains, Modeling Archetypes, Involvement of professional societies, Standardization, Role of ontologism, Intellectual Property Rights issues and Licensing, European / National Procurement, Quality assurance and a possible role of EuroRec (European Institute for Health Records)
The consequences for National and European projects will be presented and discussed.
From the lessons learned we would like to contribute to National and European projects dealing with seamless semantic interoperability.

Keywords. EHR, EN13606, standardization, implementation, Semantic Interoperability Infrastructure

1. Introduction

EN13606 EHR-com [1] is a European (since 2006) and ISO standard for the Electronic Health Record Communication. It is the result of almost 20 years of European and Australian Research and Developments. European standards play a regulated role in the European Common Market for free transport of goods, people, money and services. To that end European standards development is based on European Directives (98-34 and 98-48) [2].

The EN13606 standards shares with HL7 [3] messages the fact that it helps to define transports of data between separate IT-systems. It differs with the HL7 standards because the point of departure is that it describes how data and information is stored, retrieved and exchanged in and between ideal 'virtual' systems. In other words it defines how data and information should be documented and is painstakingly implementing archiving requirements. since it is based on an ISO document 18308 "Requirements for EHR architectures". [4]

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An outstanding feature of EHR-systems based on EN13606 is that it provides a complete separation between the responsibilities for on one hand the IT providers and on the other hand all healthcare knowledge domains. This feature is called the Two Level Modeling Approach.

ERS is a Dutch company that during the last couple of years is marketing an Integrated Care EHR with 4 Generic standards based Engines for: Presentation, Rules, Integration/Migration and Documentation. The Documentation Engine is based on the EN13606 specification.

Because of our implementation efforts we (and our customers and partners) encountered several obstacles that have to be addressed in order to enable seamless semantic interoperability. This article describes the obstacles and possible ways forward.

Our experiences indicate that the EN13606 and EHR-systems based on it provide all that is needed at the technical IT-level. Our conclusion is that we need at the non IT-technical level a European Semantic Interoperability Infrastructure.

2. The European/ISO EHR standard

The EN13606 standard has 5 parts.

2.1. Reference Model

This is a model that describes how clinical facts can be documented in a patient safe privacy respecting way. This model is very stable and the result of 20 years of R&D.

*Open*EHR (a not-for-profit) foundation [5] produced and published an implementable specification of part one.

2.2. Archetype Model

This is a model that describes how to produce archetypes.

Archetypes allow healthcare providers to define what (and how it) needs to be documented in for instance the case of a Blood pressure observation. Healthcare will have to produce libraries of archetypes defining the information content of their field of expertise.

A unique feature of the EN13606 is that systems that conform to this standard can implement seamlessly any archetype defined in seconds without a resource (time and money) intensive implementation process as is required by HL7 messages.

A second unique feature is that each archetype produced is implemented immediately in conformant EHR-systems without any need to write new software or test software.

2.3. Terminology

This part contains several internal classifications used by the standard.

2.4. Patient Mandate

This part describes how the patient is able to express who has access to what data and information.

2.5. Implementation Guide

This part describes how the standard can be implemented in order to send and receive between systems.

3. The European Semantic Interoperability Infrastructure

The European Project 'Semantic Health' [6] provided an authoritative detailed report. Archetypes according to the "Semantic Health" project play an important role. They classify EHR-systems using Archetypes at level three (the highest) of semantic interoperability.

For seamless (cross border) communication between EHR-systems all must rely on a common infrastructure with semantic services.

Part 1 of the EHR standard (the Reference Model) must be implemented in EHR-systems for maximal utility. Part 1 provides the generic structure (syntax) to store, retrieve and archive information in its proper context.

Seamless integration needs a set of shared codes from coding systems (reference terminologies) and translations into other languages. Codes can be considered words from a dictionary.

Using syntax and a dictionary with words, correct sentences can be constructed. In a particular context only certain phrases are used by humans for communication and therefore make sense. Archetypes and Templates based on the EN13606 allow to record in a defined context such sensical common phrases. Each clinical specialty will have to produce and agree on its common phrases they need in order to document their provision of healthcare. Recently a possible co-operation between CEN/ISO and HL7 opened up: ISO accepted a New Work Item Proposal to work on Detailed Clinical Models (DCM) [7]. These DCM's can be considered to define the clinical content in a more neutral way such that subsequently can be used to produce EN13606 archetypes and be used in HL7 messages and HL7 CDA documents.

The Reference Model, the archetypes and coding systems contain many definitions based on our knowledge about the real world. Ontologists play an important role to help define in a correct and computer interpretable way the definitions we use. Without correct definitions computer reasoning, clinical decision support, re-use of existing stored information cannot be performed in an n efficient and patient safe way.

Finally it is absolutely necessary that all aspects mentioned, and that are part of the European Semantic Interoperability Infrastructure, need to be quality assured.

In order to create European, National and regional seamless semantic interoperability it is essential that on all these levels a Semantic Interoperability Infrastructure is in place.

To create at all these levels a functioning semantic infrastructure, a lot of expertise and knowledge is needed. It is very likely that it is beyond the possibilities for each region or Member State to provide the resources needed (money, expertise and knowledge). 23 Languages and many cultures have to be bridged.

4. Features and gains

It is obvious that an EHR-system using standards based Generic Engines has unique features: it creates flexibility, seamless integration and exchange, re-use of information, etc.

Experiences in Spain [personal communication] show that using the EN13606 it is possible to create a functional shared Patient Summary between two hospitals within a period of 2 weeks.

Clinicians in and outside the Netherlands indicate that they like the extreme flexibility and re-use of information for research, and reporting, the ordering and the clinical decision support.

IT-departments like the fact that existing IT-systems can be integrated and migrated; that the need for database conversions and data loss is strongly diminished; that less resource intensive message connections have to be maintained.

Hospital Management appreciates the possibilities of re-use of information for reporting.

5. Lessons learned: Modeling Archetypes

Clinical communities will start to model their information needs as DCM's/Archetypes. Cross healthcare domain, cross border, semantic interoperability needs common patterns to model the same type of topic in the same way. The present EN13606 does not prescribe these needed common patterns. Future work will be needed to define and standardize these documentation patterns.

Most of the work done on archetype modeling was based on limited clinical experiences in the UK and Australia. *Open*EHR played an important role in demonstrating the EN13606 Archetype approach by providing a community and open source tools, but also introduced IPR problems that now hamper the commercial uptake. In the present phase real life production ripe quality assured archetype libraries are needed. Tools provided by *open*EHR no longer prove to be sufficient. A new generation of tooling is necessary, that accommodates the results of the lessons learned and go beyond the present openEHR-tools, that deploy the Reference Model in a hardcoded way. In particular we need DCM tools trained clinicians/nurses can use, which output can be used in the EN13606 and HL7 worlds. The New Work Item Proposal in ISO will produce the requirements needed for the new versions of DCM/Archetype tooling.

After the production of DCM's/Archetypes these artifacts must be maintained and published in order to be shared by all. Together with codes form coding systems they are the essential linking pin for semantic interoperability.

6. Lessons learned: Involvement of Professional Societies

Each sector of the health knowledge domain will be responsible for the production of their information requirements expressed as DCM's/Archetypes. At the levels of regions, Member States and Europe these consensus processes have to be instituted. So far the archetype libraries have been produced on an ad-hoc basis in projects many times as a volunteer effort. This is not sustainable in the future. It is obvious that sound European, National, and regional semantic infrastructure needs resources (money) to train and involve clinical communities.

7. Lessons learned: Standardization

European technical standards play a regulated role in the European Common Market for free transport of goods, people, money and services. To that end European standards development is based on European Directives (98-34 and 98-48) [2].

Healthcare is changing rapidly. Formal National Standard Development Organizations (NSDO's) produce stable technical specifications and are not geared to include rapid changes healthcare needs.

This will have consequences for the effective scope of Mandate M/304 [8] issued by the European Commission, since new specific types of public and open standardization bodies are needed to rapidly and flexibly, produce, translate and publish DCM's/Archetypes at regional, National and International levels in all European languages and cultures.

8. Lessons learned: Role of Ontologies

So far terms defined in EN13606 (and *open*EHR) were done in isolation and without proper ontological support. The same can be said about classifications, vocabularies and terminologies. In a pragmatic way clinicians and IT-experts were involved and made mistakes that hamper patient-safe semantic interoperability by means of incorrect or ambiguous definitions. In this way reasoning by computers cannot executed in a patient-safe way. Clinical decision support, re-use of information will be difficult or impossible, or dangerous, even.

In the HL7 Reference Information Model but also in the *open*EHR definitions of basic terms there are serious problems with definitions used [9], [10]. A recent example is the difference between the meaning of the term 'symptom' as used in English speaking countries and the European continent. Or the way *open*EHR defined and interprets 'Observation', 'Evaluation', 'Instruction' and 'Action'.

It is imperative that all elements, needed for a European Semantic Interoperability Infrastructure as described in §2 get an ontological sound foundation.

9. Lessons learned: Intellectual Property Rights and Licenses

In the European Semantic Interoperability Infrastructure DCM's, Archetypes, coding systems and ontologies will have to play an essential pivotal role. They must be shared by all in order to create seamless patient safe interoperability.

OpenEHR is a not-for-profit foundation owned by two legal entities only: University College of London and Ocean Informatics from Australia). Open*EHR* publishes the implementable specification of EN13606 part one for academic (non-commercial) use. In addition openEHR facilitates healthcare providers in communities to produce and publish archetypes under *open*EHR Intellectual Property Rights (IPR). The conditions for commercial use of the specification and artifacts are still under debate by the *open*EHR foundation. The IPR in the *open*EHR domain are at this moment fully owned by two legal entities; *open*EHR is NOT publicly owned. These facts are perceived to create legal uncertainty by our clients (hospitals). The result is that our clients and partners will not publish their archetypes and DCM's via *open*EHR, or transfer their IPR to *open*EHR, and ask us for guarantees that all archetypes used are free of IPR constraints. The present *open*EHR IP and licensing policy is not supporting commercial uptake of products based on the EN13606.

A study into the specifics of IP ownership and needed licensing schemata is needed within the European Semantic Interoperability Infrastructure.

10. European procurement

The European Community has as its main goal the creation of one economic market for the free movement of goods, money, persons and services. To this end there are (among others) European Directives that that govern procurement. [11]

The European/ISO EN13606 makes possible EHR-systems with unique features like: extreme flexibility, re-use of information for research and reporting, reduction of needed resources for implementation. It facilitates innovation of the healthcare delivery process.

ERS, as a company that brings to the market an Integrated Care EHR based on this innovative EHR standard, encountered serious difficulties responding to Request for Proposal (or Information) in procurement processes, when not partnering with qualifying partners. All Requests demanded full working applications, a certain company turnover for a number of years or a number of successful installations but they never demand compliance with European/ISO standards.

As a young company with an innovative product we never comply with these types of demands on ourselves, although on the technical level we more than any other felt very qualified.

Only one conclusion is possible: the present European procurement process executed by organizations favors old, existing, products and makes the introduction of new innovative products based on European standards impossible.

11. Lessons learned: Quality Assurance in the European context

Seamless semantic interoperability between entities in one region or country but also cross-border need to have in place a (European) Semantic Interoperability Infrastructure and EHR-applications that conform to the European/ISO EHR-standard and this Infrastructure. It is imperative that the Infrastructure and EHR-systems are able to show compliance to a series of requirements and show this by means of certificates. Only in this way minimal levels of privacy and patient-safety can be secured.

At the regional, national and European level intertwined interdependent Quality Assurance processes need to be in place. European and National legislation can secure the basic functioning for the free movement of health information as a serve in Europe.

For some time the European Commission is working on European legislation. After last year's Recommendation [12] work is underway for a European Directive.

We feel that this is the only way to create a level playing field for new innovative standards based IT companies selling EHR software.

For many years the European Institute for Health Records (EuroRec)[13] is working on National and European quality criteria for EHR-systems and European/National/Regional testing and certification. To this end they cooperate worldwide with relevant organizations. In the (near) future EuroRec is capable to perform an important role in the Quality Assurance of EHR-systems and the European Semantic Interoperability Infrastructure as European Agency involved with the execution/implementation of the relevant European Directives.

12. Conclusions

- European Governance of Semantic Interoperability is a necessity in order to have patient-safe and privacy respecting cross-border exchange of information in cross-border care in Europe and to create a competitive European market for EHR-system solutions of high quality that are able to serve the requirements of healthcare now and in the future.

- Semantic Interoperability is complex and exceeding the financial capacities and available expertise in even the big European Member states. The problem of Semantic Interoperability is compounded in Europe by the fact that there are more than 23 language and cultural barriers that have to be bridged.

- At the European level a new standing organization, holding public IP and proper licensing schemata, with secure longterm funding is needed, that is responsible for the European controlled production, maintenance and publication of Detailed Clinical Models (Archetypes), coding systems and supporting ontologies plus all the needed quality assurance.

- The new standing (non-technical) organisation producing DCM's and Archetypes will impact the scope of the European Standardization Mandate M304.

- This European organization will have to coordinate (not replace) all existing relevant actors in the field of International Semantic Interoperability in their existing natural roles.
  Of prime importance will be the involvement at the national and European levels of citizens (patients) and healthcare domain experts.

- A European Governance of Semantic Interoperability can only be reached as a European joint effort when based in the European Community political and legal framework with the aim to have free movement of goods, persons, money and services.

References

All references were checked and found to be correct on 21 September 2009.

[1]   CEN/tc251 EN13606 EHR-com, http://www.cen.eu/
[2]   http://ec.europa.eu/enterprise/standards_policy/general_framework/index.htm
[3]   http://www.hl7.org
[4]   http://www.iso.org/iso/catalogue_detail.htm?csnumber=33397
[5]   http://www.openehr.org
[6]   http://www.semantichealth.org/
[7]   http://detailedclinicalmodels.org/wiki/index.php?title=Main_Page
[8]   http://ec.europa.eu/enterprise/standards_policy/action_plan/doc/mandate_m403en.pdf
[9]   http://hl7-watch.blogspot.com/
[10]   W. Ceusters, Post-hoc interpretation of mutually incoherent information models: the role and benefits of realism-based ontology. EuroRec symposium 2009, Sarajevo. http://www.eurorec.org/files/filesPu blic/eurorec2009/ceusters.ppt
[11]   http://europa.eu/publicprocurement/index_en.htm
[12]   http://www.eurorec.org/whoarewe/recommandations.cfm
[13]   http://www.eurorec.org

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Considerations in Evaluating Devices for Personal Health Records

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Abstract: The need for a portable physical device for storing the Personal Health Records (PHR) is examined as an extension and as a derivative of the need for Electronics Medical Records (EMR), specially in situations (e.g. travelling) where on-line connectivity might not be available. Different approaches of 'who manage the PHR data' are presented and the role of the PHR device in the various scenarios is analyzed. Several personal portable memory devices are examined as possible alternatives for storing the PHR, based on practical considerations and market researchs results. Several 'real' implementations of credit card size, secure USB Flash Drive as the device for PHR are presented and the experience and conclusions are analyzed. Advanced USB flash drive technologies are presented, enabling, in addition of storing the data, activating from the device some software informatics applications such as integration with EMR systems, using interoperable standard software systems. Conclusions based on experience gathered from several PHR implementations in Europe and the USA are presented which demonstrate the advantage of the credit card size USB flash drive, enabling users to keep securely their entire medical history in their wallet.

Keywords*:* Personal Health Records; PHR; USB Flash Drive, UFD, Medical Records, Informatics, Interoperability, credit card size UFD

1. Introduction

The possible benefits of Personal Health Records (PHR) are quite accepted today, however there are still debates on the preferred methods and technologies for it, and some controversial opinions about the required privacy and security level. Some vendors are already offering Web based PHR services, for example Google Health [1] and Microsoft Health Vault [2], although some consumer organizations are concerned about the patient privacy of those services.

This article examines the need for user/patient physical device in addition to web based (or central server) PHR (and not instead of it).

For evaluating such need, we start from the basic question of 'Why PHR'. Then checking if physical device is required for fulfilling the PHR basic needs.
Next we evaluate the advantages of portable USB Flash Memory Drive (UFD) as the physical device for PHR, and the last step is to check if credit card size UFD could be the optimal personal device for PHR.

Based on discussions with service providers and accumulated experience from pilots with real user made in Europe and the USA we examine practical considerations and priorities of implementing PHR for target groups.

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2. Why PHR?

Some of the basic expected benefits of PHR are presented below.

1. PHR can save lives – for example in emergency situations (road, travel or other accidents, hart attack etc.) especially when travelling to foreign countries, and especially if the user has allergies, consume medicines or has history of medical procedures. When every second is important and taking the right decision is critical, such information if provided on time to first responders and to the emergency room can avoid wrong medicines or wrong medical treatment, which could save the patient life.
2. PHR can improve health care quality. It can be the basis for decisions support – based on full medical history. Doctors can diagnose the current patient status based on the full medical history. Medical tests such as X-Rays or MRI stored in the PHR can include not only the conclusions but also the full 'raw data'. Specialist Doctor will be able to re-examine the X-ray picture taken long ago, maybe for re-evaluating the patient status.
3. PHR can save health care cost. For example: avoid medical test duplications (not to mention that avoiding redundant tests could contribute to the patient safety and convenience). Some statistics [3] shows that about 30% of the medical tests (in the examined hospitals in the USA) might not be needed if the results of previous tests were available.
4. Hospitals can save time and efforts needed to type (or write) the patient details, and avoid errors, by just copy the digital data from the device to their database.
5. PHR can help the patient to take more responsibility – 'empowering the patient' – become more aware and active in keeping healthy life style, be more active and involved in health care and healing processes, be able to understand its own medical situation, add data of self tests (like temperature, blood pressure etc.). For that, a very convenience access to the PHR is needed, even in situations, like travelling, that internet is not available.

3. Why physical device For PHR?

If we re-examine the reasons for PHR, it may lead to the conclusion that physical PHR device have' (in addition to the web based PHR system) is at least 'nice to and in some cases a 'must' in order for benefiting PHR. For example:

1. PHR for **life saving** especially in emergencies. In such situations, Internet might not always be available (for downloading the patient PHR stored in a remote server) . A copy of the PHR, kept on a memory device carried by the patient in a way that first responders can find it and easily read it using any available PC – could solve the problem.
2. PHR can **improve health care quality**…. By enabling to the doctors that have to make medical decisions immediate access to the patient's medical tests history: X-Ray's, MRI etc. However, X-Rays and MRI images might include hundreds of Mega Bytes (MB). Downloading it from the Internet might take too long for a Doctor to wait. For example: even with fast Internet of 10 Mega bits per second (Mb/s) it might take about 160 seconds (2.5 minutes) to download X-Ray image of 200MB, while the same image could be downloaded in about 10-15 seconds from a typical USB memory device.
3. More than that, not every doctor has in their PC software for presenting X-Ray images (such as DIACOM). Again, with USB device as a platform for the PHR data – this problem can be easily solved, since, due to the large memory size of the USB device, it can not only contain the medical data but also the software tools enabling

to see the data. For example: the DIACOM software application enabling to see the X-Rays 'raw data' picture stored.

4. Why USB Flash Drive as the Physical device for PHR?

Comparing USB [4] Flash Drive (UFD) with other possible alternative devices (such as 'smart card') we find some strong advantages to prefer the USB device:

1. The large memory size per device which is today up to many (16, 32 and even 256) Giga Bytes (GB). Practically there is probably no need today for more than 8 or 16GB, which can include all the medical history and tests' row data such as text, images, and even voices and video clips (for Ultra-Sound tests, monitors etc.)
2. The fast data transfer – today the standard 'Read' speed is about 15-20 MB/s, while the theoretical limit of the existing standard USB 2.0 is 60 MB/s and the coming new standard of USB 3.0 enable downloading speed of about 800MB/s – means that the 200MB image can be downloaded in less than a second.
3. No need for special 'readers' for USB Flash Drive. USB connector is available today in almost every computer used by doctors, hospitals etc. and it's just 'plug and play' to most common OS (operating systems) including Windows, Macintosh and Linux.
4. More than that, not only the data can easily be retrieved, but the device can contain some software applications needed to view the data (such as DIACOM), and run those application from the USB device, with no need for installation on the PC. Application can be 'Auto-run' from the device, means – upon connecting the device to the PC, the application can start automatically – big advantage to busy doctors. Applications can be more than just viewing the data. They can also do some data processing, taking advantage on having access to all the medical history. For example: application for checking medicine interactions – each new medication subscribed by the doctor can be automatically checked for interactions and possible problems based on the data of all other medications, the demographics data of the patient (adult, chilled, gender etc.), allergies etc.
5. Security for such application can rely on the hardware security (see below) and/or security of virtual machine as described in [5].

     Regarding security and privacy protection (in case the device got lost etc.) needed for the medical data according to regulations such as HIPPA [6]- advanced USB device can include today very high level of data security such as encryption, password protection for assure customer's privacy and even PKI (Public Key Infrastructure) [7] for encryption, authentication and digital signatures. The hardware security can be closed to the level of 'smart card', including key pair generation, random number generator, PKI algorithm performed inside the hardware (the secret key is never exported), and even performing the hash functions inside the hardware (better than smart card, where the hash is calculated in the computer, enable to Trojan horses resides in the computer to exploit it for manipulating the data signed by the smart card).

5. Why Credit Card size UFD for PHR?

Today very small size UFD are available in many form factors. However, being a device that has to be carried by the user all the time (for being available in case of emergency, or not forgotten when visiting a doctor), too small might not necessarily be the best choice.   Another point is that the user should consider it as a valuable object. Comparing Credit Card size UFD (CCsUFD) with other form factors of UFD for PHR shows some advantages to CCsUFD device. For example:

1. Card is kept in the wallet.
   o Easily found by first responders (in Emergencies)
   o safe and available
   o Doesn't get lost, forgotten or misplaced
2. People are used to Medical Card [8]. So the move from the situation today to USB based PHR will be smoother.

CCsUFD enable large double sided area for printing necessary information such as:
   o User's personal details and picture (including some non-sensitive medical information like: blood type, allergies etc.)
   o Operation instructions
   o Branding capabilities

6. Additional considerations

- Advanced security for better medical data privacy. This should include symmetric and asymmetric (PKI) encryption and authentication.
- Read and write restrictions. Some require that only authorised medical personal can write into the device, no-one can delete medical data that was written into the device, and only the user has the possibility to grant right to read personal data (whole or part of it).
- Having different type of memory sectors such as: CD-Rom type for storing the application, which allows also 'Auto-run' functionality (for starting the application automatically upon inserting the device into the USB port. Read-write part which include security access (e.g. password) for allow read or write into this sector. 'Hidden area' part, which is not visible to the Operating System.
- Rigidity of the device: such device should survive for at least 3 years before replacement in the wallet environment (for example: bending flexibility, allowing sitting on the wallet).
- Whether and water proof device (preferably a device that can survive washing machine)
- Printing capabilities of the user information (text and colour pictures).
- Cost considerations. This might be linked to the question to whom the device is provided: is it to the whole population or to some segments that might need it most urgently, like: people suffering from chronically diseases, pregnant women, babies etc.

7. Example of Credit Card size UFD used for PHR

Below we present in Figure 1 and Figure 2 some examples of CCsUFD used for PHR in Europe and the USA (some of the cards are with plastic USB connector, some with metal USB connector, and in some the connector has a 'cover').

Figure 1. Example of Credit Card size UFD used for PHR in Europe

Figure 2. Example of Credit Card size UFD used for PHR in the USA

8. Who manages the Medical Data?

One extreme approach is that the data is fully managed by the health care system. This approach – which is more common in Europe, mainly for elderly people, assumes that in order to enable Doctors rely on the PHR data, only approved medical personal are allowed to enter the data to the PHR. Meaning that the patient is not allowed to enter data. The patient has the right to decide who will be able to see his/her data.

When the CCsUFD is used, the patient is only a 'carrier' of the card. However – by giving the card to the Doctor, the patient give the Doctor the right to see the data.

In such approach, it's good that the CCsUFD can have the memory divided into several sectors. One of them can be a 'secure' sector into which only the approved medical personal can enter data. However, since sometimes un-approved personal (for example – a Doctor in another country) might provide some medical treatment, and in order not to lose this data, those personal can enter this data to another sector of the memory (dedicated to 'pending' medical data). When the patient is back home, he/she can visit their family practitioner (an 'approved' doctor), who can decide if to move those medical records to the 'secure' sector.

The other extreme approach is that the data belongs to the patient, who also manages the medical data. This is part of 'empowering' the patient, who has full control on the data. This approach is more common in some populations in the USA, who also more concerned about the privacy of their medical data, and feel enough confidence to check (using data from the Internet and other sources) their doctors advices and decisions.

In this approach, the patient might prefer to have the PHR data in a physical device that he/she can fully control. In some such scenarios, there is a copy of the medical data in a central server (which is good for backup, in case the device is lost), but the data there can encrypted with the key known only to the patient.

In many cases, the PHR systems are developed to the majority of the population, which might be between those two extremes.

For downloading the medical data into the card, some interface to other medical databases is needed. For that the device might include software 'connector' applications for interoperability. Another approach might be to use interconnection software which can interconnect between the device to medical databases.

Acknowledgments

References

[1.]   http://www.google.com/intl/iw/health/about/
[2.]   http://www.healthvault.com/
[3.]   http://www.ncbi.nlm.nih.gov/pubmed/9576410
[4.]   http://www.usb.org/home
[5.]   http://www.ssddfj.org/papers/SSDDFJ_V1_1_Bem_Huebner.pdf
[6.]   http://www.legalarchiver.org/hipaa.htm
[7.]   http://www.sun.com/blueprints/0801/publickey.pdf
[8.]   http://www.ehealthnews.eu/content/view/1595/27/

CROSS BORDER HEALTH INFORMATICS

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Responsibility Agreements for the Control of Personal Information Across Borders: Issues & Questions

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Abstract: In today's mobile world people expect that their relevant health information will be made available for treatment wherever they may be. This means that personal health information must routinely be disclosed outside the person's home jurisdiction and often where data protection legislation is approached differently. While these arrangements are not new, it is the scale and scope of the interoperability and the increasing mobility of individuals requiring health services which forces this problem to the forefront today. The transfer of information begins a process which contains risk. Lack of consistency in language and definitions also create challenges. How can we get to solutions rather than describe more problems? Work is required to describe successes, create process to manage agreements, to document basic principles and create standard requirements, to communicate and learn from others.

Keywords: trans-border data flow, inter-jurisdictional, information sharing, information sharing agreement, responsibility agreements, data protection, mobile ehealth, EHR

1. The main issue

Patients expect that their relevant health information will be made available for treatment. While they do not expect that every jurisdiction will know everything about them, they do expect that the right information will be available in the right place when needed. Someone who considers themselves a reasonable individual who provided information in one setting would expect that it would be used for a consistent purpose in another wherever practicable, even if the use is not spelled out. This expectation is higher the closer the person or patient is to their home jurisdiction, however the expectation in today's globally mobile world is that health information should be available wherever needed, as readily as is financial information.

Information Sharing Agreements have been created in the past for specific but limited information flow. Billing for health services delivered outside a patient's home jurisdiction have been managed by agreements for many years. Ministries of Health and private payers have managed their information flow under contracts which described services, permitted purposes, and requirements for control, audit, monitoring and response to privacy or security breach.

While these arrangements are not new, it is the scale and scope of the interoperability and the increasing mobility of individuals requiring health services which forces this problem to the forefront today. People travel more; they travel for work, for vacations; as part of retirement they may split their residency between two or

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more areas; they travel to other jurisdictions specifically for health care. To make information available outside the person's home jurisdiction, where the laws, policies, practices are different requires that the cooperating parties agree to rules about how information will be managed and protected. Canada is in the process of developing a pan-Canadian EHR or interoperable EHR (iEHR) to address the need for information support for healthcare.[2]

The transfer of information begins a process which contains risk. It is the activity of lessening that risk to an acceptable level for both the discloser and the acceptor, all the while ensuring that there is no negative impact on the patient, that presents the challenge. Governments are typically risk averse. They must be seen to be taking a strong measure of care over their citizens, and their citizens' data. The agreement to share information, while not creating additional privacy risk for the citizen-patient, is key but means that a number of factors must be worked through to enable the flow. There are a number of labels given to such agreements but an overall descriptive label might be to term them "*Responsibility Agreements*".

2. How can we deal with the Legislative Challenges and Variation?

Where legislation to protect information collection, use and disclosure is stronger, or even different from one jurisdiction to another, the resulting detailed legal mapping of legislative requirements can be onerous. In addition, the legislation itself is open to interpretation often until (under Common Law) a case has been brought, and a precedent set. Lawyers have difficulty making a clear recommendation in the absence of precedent.

Where no law exists it can take time to create law which will truly enable what is intended while protecting citizens and governments from unintended consequences. Until it is tested new law can be difficult to interpret and difficult to understand how it should be applied. Old law which has been tested will usually no longer fit the present circumstances.

Given the fast pace of change in information technology and the change in business relationships in the health system it is not surprising that currently law which can control inter-jurisdictional information flows in a consistent, understandable and efficient fashion without creating thousands of bi-lateral information sharing agreements is not in place.

For example, *The BC Freedom of Information and Protection of Privacy Act* prohibits the disclosure of personal information outside Canada without the consent of the individual. This prohibition does not exist in other Canadian jurisdictions but this legal requirement must be met in any arrangement under which data is disclosed to any other entity, foreign or Canadian. Other jurisdictions however, have difficulty agreeing to uphold this requirement as it can mean significant change to their operational processes.

European Union (EU) law allows personal data to flow outside the EU only if there is an adequate level of protection in the country of destination or if a number of specific exceptions apply. On 20 December 2001, the European Commission recognised that the Canadian Personal Information Protection and Electronic Documents Act (PIPED Act) provide adequate protection for certain personal data transferred from the EU to Canada. This allows EU operators to send certain personal data to recipients in Canada subject to the Canadian Act, without additional safeguards being needed to meet the requirements of the EU Data Protection Directive. Without such an act, transfers to countries without a substantially similar data protection act, must meet specific contract clause requirements, applied contract by contract.

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[2]http://www.infoway-inforoute.ca/lang-en/about-ehr/what-is-ehr

The Canadian Act, does not apply to government organisations to which the Federal Privacy Act applies or that are subject to public sector privacy legislation at the provincial level. Similarly, it does not apply to non-profit and charitable organisations unless they engage in activities of a commercial nature such as the bartering and selling of donor's lists. However, some Canadian provinces have gone a step further and created private sector privacy legislation covering all bodies which are not covered by their public sector act.

If the recipient jurisdiction is not subject to a substantially similar Act, then adequate safeguards must be put in place before the data can leave the European Union. One way to do this is to enter into a standard contract. One such set of contractual clauses has already been approved by the European Commission. It allows importers voluntarily to undertake to abide by the standard in the Canadian Act even though the Act does not apply to them. This approach ensures that the same standard applies throughout Canada. When the Canadian Government recognises a provincial law as being substantially similar to PIPED Act Commission decisions are then adapted to reflect this.

In BC where the information is disclosed outside Canada to a third party for processing, the Canadian organisation must have the individual's consent. If the information is being transferred for processing purposes, the organisation is required to ensure that the foreign organisation is bound by the same requirements that would apply were it operating in Canada. This can be accomplished by a contract or other legal agreement between the parties which stipulates that the foreign organisation must abide by the requirements of the Act. It can also include the stipulation that the foreign organisation be subject to an independent audit to verify its compliance. Legally compliant privacy schedules for use in Health IT vendor contracts have been created, implemented and applied consistently – where there was organizational agreement to do so.

An issue arising out of inter-jurisdictional information disclosure is that there may be potential privacy risks posed by anti-terrorism legislation in a foreign country. This could mean, for example, that a foreign law could circumvent restrictions or caveats imposed by the disclosing organization on further use or disclosure of personal information. Many foreign countries have anti-terrorism laws and security measures that contain powers similar to those of the USA PATRIOT Act. In such cases, a jurisdiction may wish to impose added conditions on the recipient, such as segregating the shared data from its other records or advising the disclosure whenever the information is to be disclosed under foreign law, if that is possible.

A multi-perspective approach to the issues can help. Typically privacy experts focus on sound ethical and legal principles, and their outputs as principles and policies are rigorous, but at times some feel that they disconnected to the human and organisational context in which their principles need to operate with the added difficulty of reaching precision. However, those principles eventually have to be turned into rules that can be applied by people and by contracts, with consistency and precision, reliably, within the complexity of health care.

Lawyer's outputs can sometimes seem to be disconnected from contemporary requirements. What the law presently defines is not automatically what is needed: good legal assessments should compare what is pre-defined with what is now needed, whereas privacy lawyers seem only interested in what is permitted, which is usually designed to enable business of the past.

Computer scientists, on the other hand, develop precise mechanisms to implement security that also seem at times disconnected to the human and organisational context, but sometimes with limited understanding of the ethical and legal principles which their policies have to reflect.

Part of the problem is that the policy work is required in order to allow the technology to be implemented. Technology standards organizations can't declare policy,

but without policy it is difficult to know what technology is necessary. We have been building the technology standards based on policies that we have run across in practice. Mostly this is limited to a small set of reasonable mainstream policies.

In addition cultural variations play a large role in the difficulty to reach agreement and differences in process creates challenges as well. Some initiatives have foundered because they attempted to begin the process of working out details rather than beginning with business requirements and basic principles. Doing so leaves one to translate details on how something is to take place, backwards into principles BUT often without actually putting them into words. When we do that we are paying the lawyers to try to put words to our beliefs and it can be very expensive.

3. Content Challenges

Once we have agreed to basic principles and we begin on the content, we at least know what our differences are. Often our issues as human beings will be about saving face or avoiding political and other risk. Good managers know that a loss of trust can affect our other business dealings. It will take political will to subsume the political level within reason and rationality, before real action takes place.

ISAs range widely in the degree of complexity and detail they contain. Some are simple, and address only the importance of confidentiality and the controls to support it ,such as password principles. Some additionally incorporate the concept of Acceptable Use. Some meet every detail of legal requirements including rights to audit, monitor and have control over data out of the organization's custody.

Lack of consistency in language and definitions creates a challenge. Stakeholders must get together and agree on what terms mean. Without that, communication cannot take place and the work cannot move forward.

The laws which govern data protection all apply to an organization, in which a single person may be made responsible legally for stewardship of data. However, the nature of healthcare is about delivering integrated services to a functionally integrated human being – and usually by integrated team of care providers. The integration of services and thus the need for integrated data cannot work with the information silos and program silos of the past. And yet we create a privacy vulnerability by sharing and integrating the data needed to do the job. This would imply that our fear of integrating data should be balanced by rational approach to risk mitigation.

At present we have created bigger silos, but they are still silos. If we build information systems to what is legal rather than what business requires we will not have served the patient nor the health system. While we may need better ISAs we need more than that; we need an approach that says we know how to share data about the person to the right provider and in a secure way and to be able to trust the system that does so.

4. How do we get to solutions rather than describe more problems?

- Work is required to inventory and describe those initiatives where consistent, simple solutions have been found.
- Work is required to create a process for managing agreements so that thousands of bi-lateral agreements are not created
- Work is required to agree to the basic principles and content so that a set of standard clauses can be applied.
- Leadership and will is required to ensure that special interest agendas do not prevent the process from moving forward.

- Examples need to be communicated so that we can learn from the success of others.
- Timing is important. The problem will not be solved until it has to be. Until organizations and jurisdictions require a solution and cannot move forward without one, discussions about the ideal, rather than the possible will continue.

References

[1.] COMMISSION DECISION of 20 December 2001 pursuant to Directive 95/46/EC of the European Parliament and of the Council on the adequate protection of personal data provided by the Canadian Personal Information Protection and Electronic Documents Act (notified under document number C(2001) 4539) (2002/2/EC)

[2.] http://ec.europa.eu/justice_home Frequently Asked Questions on the Commission's adequacy finding on the Canadian Personal Information Protection and Electronic Documents Act

[3.] Opinion 7/2001 on the Draft Commission Decision (version 31 August 2001) on Standard Contractual Clauses for the transfer of Personal Data to data processors established in third countries under Article 26(4) of Directive 95/46 5061/01/EN/Final WP47

[4.] Circle of Care, Sharing Personal Health Information for Health-Care Purposes, Ann Cavokian Ph.D., Information and Privacy Commissioner, Ontario, Canada www.ipc.on.ca

[5.] Office of the B.C. Information and Privacy Commissioner, Privacy Guide for Personal Information Exchange Agreements (undated) www.oipc.bc.ca

[6.] Guide for developing personal information Sharing Agreements, Revised October 2003, Access and Privacy Services, Alberta.

[7.] Report of the Information & Privacy Commissioner/Ontario Review of the Canadian Institute for Health Information: A Prescribed Entity under the Personal Health Information Protection Act, Ann Cavoukian, Ph.D., Commissioner

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The Role of International Nomenclatures and Standards in Travel Shared Health Care

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Abstract. The paper describes several classification systems that should support travel shared health care. Among the most important we can rank SNOMED CT, ICD-10, LOINC and others. The increasing number of classification systems and nomenclatures requires designing of various conversion tools for transfer between main classification systems and for recording of relations among terms in these systems. Extensive ontologies and semantic networks are modeled for information transfer among various databases. Metathesauri are designed to monitor and connect information from various heterogeneous sources. UMLS is the most extensive project nowadays. The analysis of suitability and usability of individual terminological thesauri has been started by mapping of clinical contents of the Minimal Data Model for Cardiology (MDMC) to various terminological classification systems. Close co-operation with physicians is essential for solving mapping problems. We have compared also how well attributes of MDMC are recorded in textual medical reports and in medical reports recorded by means of the ADAMEK software application.

Keywords. Medical Informatics; Classification Systems; Shared Health Care

1. Introduction

Travel shared health care is the need for the open society of the 21st century. Nowadays healthcare systems in Europe and other economically developed countries are going through the process of a significant transmission. From the central controlled healthcare, they are going to process controlled or shared health care with the aim to reach personalized health care. Moreover, the development of new ways of providing health information, data and knowledge is accompanied with major advances in information and communication technologies. New technologies speed up an exchange and use of data and knowledge and eliminate geographical and time barriers. These technologies influence the health care and traditional ways how to work with data and knowledge. New requirements to collect data in health care efficiently are based on an electronic health record (EHR). The need to structure collected data and knowledge embedded to any EHR system and to remove or minimize information stored as free text is evident.

Medical reports show that insufficient standardization of medical terminology presents one of the prevailing problems in processing of any kind of medical-related data. More than ten synonyms may often be found for a single medical term. And even more significant problem arises when the "synonyms" are not fully semantically equivalent or when they are generally understood in different ways. Usage of such synonyms in scientific terminology leads to inaccuracy and misunderstanding. Various

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classification systems, nomenclatures, thesauri and ontologies have been developed as a result of common endeavour directed to the unification of medical terminology. Unfortunately, the fact that there are more than one hundred of incompatible systems brings complications. The necessity of software tools supporting conversion between major classification systems and recording relations among terms in heterogeneous sources became obvious. Moreover, the most research in this area has been carried for English language. Apparently the most extensive project addressing these issues is the Unified Medical Language System (UMLS) [1], [2], [3]. Further we will show for the field of cardiology the difference between usability of information stored in free text medical record and stored by structured EHR.

2. Classification Systems and Nomenclatures

Classification systems are coding systems based on creating classes. The classes form aggregated terms, which correspond, at least, in one classification attribute. The classes of a classification must cover totally the defined field and they must not overlap. The formation of classification systems has been motivated mostly by their practical usability in registration, sorting, and statistical processing of medical information. The first interest has been to register incidence of diseases and causes of deaths. Further we describe the most important classification systems and nomenclatures.

2.1. ICD

The foundation of the ICD- International Classification of Diseases [4], [5] was laid by William Farr in the year 1855. The World Health Organization took it over in the year 1948. At that time it was its 6th revision. The basic drawback of ICD lies in its lower level of hierarchy. ICD is convenient for purposes of diagnosis statistics but not for further coding of complex medical information as e.g. terms for symptoms and therapies are missing. The last revision made an effort to classify in as much detail as possible (instead of the first digit there is a letter from the Latin alphabet, further places are digits). Since 1994 the 10th revision of ICD is in use and it contains 22 chapters.

2.2. SNOMED

The acronym SNOMED stands for Systematized NOmenclature of MEDicine. SNOMED was published for the first time in the year 1965. It is a detailed reference terminology based on coding. It consists of more than 300 thousands of terms referring to healthcare and it enables to use medical information whenever and wherever it is needed. SNOMED provides a "common language" enabling a consistent way of acquiring, sharing, and collecting healthcare data from various clinical groups among which we can rank nursing, medicine, laboratory, pharmacies, and veterinary medicine. This classification system is used in more than 40 countries worldwide. SNOMED enables to describe any situations in medicine by means of 11 axes. Individual terms are determined by an abbreviation of a dimension followed by a hierarchical numerical code.

2.3. SNOMED CT

SNOMED Clinical Terms (SNOMED CT) [6], [7], [8] originated from two terminologies: SNOMED RT and Clinical Terms Version 3 (Read Codes CTV3). SNOMED CT represents the Systematized Nomenclature of Medicine Reference Terminology developed by the College of American Pathologists. It serves as a common

reference terminology for gathering and acquiring health data recorded by organizations or individuals. The Clinical Terms Version 3 was developed by the United Kingdom's National Health Service in the year 1980 as a mechanism for storing structured information on primary care in Great Britain.

These two terminologies united in the year 1999 and a highly complex terminology SNOMED CT arose. Around 50 physicians, nurses, assistants, pharmacists, computer professionals, and other health professionals from the USA and Great Britain participate in its development. Special terminological groups were created for specific terminological fields, such as nursing or pharmacy. SNOMED CT covers 364 400 health terms, 984 000 English descriptions and synonyms, and 1 450 000 semantic relations.

Among fields of SNOMED CT belong finding, procedure and intervention, observable entity, body structure, organism, substance, pharmaceutical/biological product, specimen, physical object, physical force, events, environments and geographical locations, social context, context-dependent categories, staging and scales, attribute, and qualifier value. Nowadays we can meet with American, British, Spanish, and German versions of SNOMED CT.

2.4. MeSH

Medical **S**ubject **H**eadings (MeSH) [9], [10] is a vocabulary controlled by the National Library of Medicine (NLM) in the USA. It is composed of terms, which denominate keywords hierarchically and this hierarchy helps with searching on various levels of specificity. Keywords are arranged not only alphabetically but also hierarchically. On the most general level there are broad terms such as "anatomy" or "mental diseases". NLM uses MeSH for indexing of papers from 4600 world best biomedical journals for the MEDLINE/PubMED® database. MeSH is used also for a database cataloguing books, documents, and audiovisual materials. Each bibliographical reference is connected with a class of terms in the MeSH classification system. Searching inquiries use also the MeSH vocabulary to find papers with required topics. The MeSH vocabulary is updated continuously and it is also controlled by specialists creating it. They collect new terms appearing in scientific literature or in the arising fields of research. They define these terms in the frame of the contents of the existing vocabulary and they recommend their adding to the MeSH vocabulary. There exists also the Czech translation of MeSH. Unfortunately, the Czech translation is not complete and its quality is very low.

2.5. LOINC®

The **L**ogical **O**bservations **I**dentifiers, **N**ames, **C**odes - LOINC® [11], [12] classification system is a clinical terminology, which is important for laboratory tests and laboratory results. In the year 1999 the HL7 organization accepted LOINC® as a preferred coding system for names of laboratory tests and clinical observations. This classification system contains more than 30 000 various terms. The mapping programme called the Regenstrief LOINC Mapping Assistant (RELMATM) helps with mapping of local codes of various tests to the LOINC codes.

Currently, there are more than one hundred of various classification systems. These are for example AI/RHEUM; Alternative Billing Concepts; Alcohol and Other Drug Thesaurus; Beth Israel Vocabulary; Canonical Clinical Problem Statement System Current Dental Terminology 2005 (CDT-5); COSTAR; Medical Entities Dictionary; Physicians' Current Procedural Terminology; International Classification of Primary Care; McMaster University Epidemiology Terms; Physicians' Current Procedural Terminology; CRISP Thesaurus; COSTART; Diseases Database; DSM-III-R; DSM-IV; DXplain; Gene Ontology; HCPCS Version of Current Dental Terminology 2005 (CDT-5), 5; Healthcare Common Procedure Coding System; Home Health Care Classification;

Health Level Seven Vocabulary; Master Drug Data Base; Medical Dictionary for Regulatory Activities Terminology (MedDRA); MEDLINE; Multum MediSource Lexicon; and many others.

3. Tools for Sharing Information from More Sources

The increasing number of classification systems and nomenclatures requires designing of various conversion tools for transfer between main classification systems and for recording of relations among terms in these systems. Extensive ontologies and semantic networks are modeled for information transfer among various databases. Metathesauri are designed to monitor and connect information from various heterogeneous sources. UMLS is the most extensive project nowadays.

3.1. UMLS

The Unified Medical Language System (UMLS) was initiated in the year 1986 in the National Library of Medicine in the USA as a "long-term R&D project". UMLS knowledge sources are universal. It means they are not optimized for individual applications. UMLS contains more than 730 000 biomedical terms from more than 50 biomedical thesauruses. It is an intelligent automated system, which "understands" biomedical terms and their relations and it uses this understanding for reading and organization of information from machine processed sources. Its aim is to compensate terminological and coding differences of these non-homogeneous systems and also language varieties of users. It is a multilingual thesaurus of classification systems such as MeSH, ICD, DSM, SNOMED and others on a high-capacity medium, which enables to transfer coded terms among various classification systems.

UMLS is based on three knowledge sources: Metathesaurus®, Semantic Network, and SPECIALIST Lexicon. The Semantic Network contains information about semantic types and their relations. The SPECIALIST Lexicon records syntactic, morphologic, and orthographic information of each word or a term.

The UMLS Metathesaurus is an extensive, multi-purpose, and multilingual database. It contains information about biomedical, healthcare and their relative terms, their various expressions and relations among them. The UMLS Metathesaurus has been developed from electronic versions of many various thesauruses, classifications or collections of codes, such as SNOMED, MeSH, AOD, Read Codes, ICD-10, and others. The main aim is to connect alternative expressions of the same terms and to identify useful relations among various terms. If thesauruses use the same expressions for different terms, then both meanings are present in the Metathesaurus and we can also see which meaning is used in which thesaurus. If the same term is used in different hierarchical contexts in various thesauruses, then the Metathesaurus keeps all these hierarchies. The Metathesurus does not give one consistent view but it keeps many views, which are present in source thesauruses.

The computer application providing Internet access to knowledge and relative sources is called the UMLS Knowledge Source Server. Its aim is to make UMLS data accessible to users.

The most important for our work from the point of view of the first analysis of usability of these classification systems for needs of clinical contents description of some systems used in healthcare in the Czech Republic is to find out whether a given term appears in the SNOMED CT classification system and to find out its identification number in this system. This and possibly identifiers in other systems can be later used in modeling of archetypes – basic building blocks of electronic health records.

4. Standardization of Clinical Contents

The analysis of suitability and usability of individual terminological thesauri has been started by mapping of clinical contents of the Minimal Data Model for Cardiology (MDMC) [13] to various terminological classification systems. MDMC is a set of approximately 150 attributes, their mutual relations, integrity restrictions, units, etc. Prominent professionals in the field of Czech cardiology agreed on these attributes as on the basic data necessary for an examination of a patient in cardiology.

During the analysis we have found out that approximately 85 % of MDMC attributes are included in, at least, one classification system. Most of them (more than 50 %) are included in the SNOMED CT system. Attributes, from the point of view of possibilities of their mapping to standard coding systems, can be classified in the following way:

- Trouble-free attributes – i.e. attributes, which can be mapped in a direct way, so only one possibility of mapping exists, possibly there are only synonyms with exactly same meanings and therefore the same classification code (e.g. patient first name, current smoker, motility, height of a patient, etc.).
- Partially problematic attributes – i.e. attributes, which can be mapped in a way that there are several possibilities of mapping to different synonyms, which differ slightly in their meanings and usually in their classification codes (e.g. ischemic cerebro-vascular stroke, angina pectoris, hypertension, congestive cardiac failure, etc.).
- Attributes with a too small granularity, i.e. attributes describing certain characteristics on a too general level so that classification systems contain only terms of a narrower meaning (e.g. e-mail in MDMC versus e-mail to work / e-mail to home / e-mail of a physician and so on in classification systems).
- Attributes with a too big granularity, i.e. attributes describing certain characteristics on such a narrow level so that classification systems contain only a term of a more general meaning (e.g. symmetrical pulse of carotids, etc.).
- Attributes, which cannot be found in classification systems, e.g. dyslipidemy, etc.
- Selected attributes of the MDMC coded by SNOMED CT are shown in Table 1.

Table 1. Selected attributes of MDMC coded by means of SNOMED CT

Attributes of MDMC (in Czech)	English equivalent	SNOMED CT (Concept ID)
alergie na léky	Drug allergy (disorder)	416098002
	Allergic reaction to drug (disorder)	416093006
hypertenze	essential hypertension (disorder)	59621000
	High blood pressure (&essential hypertension)	194757006
	Essential hypertension NOS (disorder)	266228004
ischemická choroba srdeční	Ischemic heart disease (disorder)	414545008
dušnost	Asthma (disorder)	187687003
bolest na hrudi	Dull chest pain (finding)	3368006
palpitace	(Palpitations) or (awareness of heartbeat) or (fluttering of heart)	161965005
otoky	Swelling or edema (finding)	248477007
synkopa	Syncope (disorder)	271594007
klaudikace	Claudication (finding)	275520000
hmotnost	On examination - weight NOS (finding)	162770007
	Height and weight (observable entity)	162879003
výška	Body height measure (observable entity)	50373000
tělesná teplota	Body temperature finding	105723007
	Body temperature (observable entity)	276535009
obvod pasu	Abdominal girth measurement	48094003
dechová frekvence	respiratory rate (observable entity)	86290005

Close cooperation with physicians is essential for solving of such mapping problems. It is often needed to choose the right synonym substituting a certain technical term. It is necessary to do it very carefully not to lose information or not to misinterpret it. In case it is not possible to do it without any lost of information, the better way is to describe a non-coded term by means of a set of several coded terms, possibly with showing mutual semantic relations. If this is not possible, we can polemize with specialists whether these "indescribable" terms (attributes) can be replaced by other more equivalent or more standard ones. In special cases it is possible to add a certain term to an upcoming new version of a certain coding system. In case it is not possible to use any of the above-mentioned possibilities of solving mapping problems, it is necessary to cope with the fact that mapping will never be 100%. The insufficient mapping process limits the interoperability of heterogeneous systems used for various purposes in healthcare. Restricted interoperability is often inevitable from the very root of the problem, e.g. insufficient harmonization of clinical contents of heterogeneous systems of electronic health records.

We developed a structured electronic health record ADAMEK based on MDMC for an outpatient department of the Municipal hospital in Caslav. We analyzed 1118 of medical reports generated by ADAMEK application according to MDMC attributes as well as 27 free text medical reports on cardiology patients stored in hospital information system directly.

In all medical reports generated by ADAMEK, in 100 %, these MDMC attributes were recorded: *drug allergy, aneurysm of aorta, angina pectoris, chest pain, swelling of lower limbs, asthma, left ventricular hypertrophy, myocardial infarction, other allergies, cough after ACE inhibitors, claudication, silent myocardial ischemia, systolic pressure, type of DM treatment.*

If we compare how individual attributes are recorded in free text medical reports of the hospital and in ADAMEK medical reports, we reach the following results, see table 2. *Drug allergy* is recorded in free text medical reports in 22.2 %, in the ADAMEK application in all, e.g. 100 % of reports. The answer whether a patient suffers or not from *aneurysm of aorta* has been recorded in all reports from the ADAMEK application but in none of textual medical reports. Questions about *chest pain* have been recorded in all medical reports using the ADAMEK application but only 37.0 % of free text medical reports include remarks on chest pain. The *level of stress* has been recorded in 96.2 % of the ADAMEK medical reports, in free text reports it was only in 11.1 %.

Table 2. Percentage of recorded values of the selected MDMC attributes in 1118 ADAMEK medical reports and in 27 free text medical reports

MDMC attribute	ADAMEK medical reports	free text medical reports	free text medical reports – 95% confidence interval	
	n=1118	n=27	lower limit	upper limit
drug allergy	100.0 %	22.2 %	8.6 %	42.3 %
aneurysm of aorta	100.0 %	0.0 %	0.0 %	12.8 %
angina pectoris	100.0 %	0.0 %	0.0 %	12.8 %
chest pain	100.0 %	37.0 %	19.4 %	57.6 %
level of stress	96.2 %	11.1%	2.4 %	29.2 %
total cholesterol	83.4 %	70.4 %	49.8 %	86.2 %
diabetes mellitus	95.9 %	40.7 %	22.4 %	61.2 %
asthma	100.0 %	55.6 %	35.3 %	74.5 %
physical load in job	94.8 %	11.1 %	2.4 %	29.2 %
glycaemia	77.6 %	51.9 %	32.0 %	71.3 %
HDL cholesterol	82.0 %	66.7 %	46.0 %	83.5 %
weight	97.9 %	96.3 %	81.0 %	99.9 %
hypertension	95.3 %	70.4 %	49.8 %	86.2 %
myocardial infarction	100.0 %	14.8 %	4.2 %	33.7 %
PQ interval	89.1 %	62.9 %	42.4 %	80.6 %
other allergies	100.0 %	18.5 %	6.3 %	38.1 %

claudication	100.0 %	3.7 %	0.9 %	19.0 %
smoker	96.5 %	66.7 %	46.0 %	83.5 %
body temperature	14.9 %	0.0 %	0.0 %	12.8 %
triacylglycerols	82.4 %	44.4 %	25.5 %	64.7 %

The same percentage was reached in the attribute physical load in job, in the ADAMEK application it was in 94.8 %. Total cholesterol has been recorded in 83.4 % of the ADAMEK medical reports, in free text reports it was 70.4 %. Presence or absence of diabetes mellitus was recorded in the software application in 95.9 %, in the free text reports it was 40.7 %. Glycaemia was recorded in 77.6 % of reports from the ADAMEK application and in 51.9 % in free text medical reports. Cholesterol was recorded in 917 reports of the software application, which is 82.0 %, while in free text medical reports we can meet with this attribute recorded only in 66.7 % of analyzed reports. Both kinds of reports are the closest in weight that is recorded in the ADAMEK application in 97.9 % of medical reports and in 96.3 % of free text medical reports. Presence or absence of hypertension can be met in 95.3 % of the ADAMEK reports, while only in 70.4 % of free text reports. A big difference can be found in left ventricular hypertrophy. It is recorded in all medical reports from the ADAMEK application but only in 11.1 % of free text medical reports. Another big difference is e.g. in the menopause attribute that is recorded in 96.9 % of reports from the ADAMEK application but only in 7.4 % of free text medical reports. The PQ interval is recorded by means of the software application in 89.1 % and in 62.9 % in free text medical reports. Similarly the QRS interval is in ADAMEK medical reports recorded in 89.5 % and in 66.7 % in free text medical reports.

From this analysis it is clear that by means of the software application ADAMEK a higher number of attributes is recorded. We can conclude that while recording results of examinations by means of a free text a lot of attributes is left unrecorded. There may be several reasons for that. Physicians do not have a strictly given skeleton according which they should proceed and it can happen that they may forget some attributes. In software applications it is not possible because if physicians forget to fill in the given attribute, the application will not let them to continue. Another reason why some attributes are not recorded may be the fact that physicians from the previous attributes know that the next attribute cannot be present and that is the reason why they do not ask about it and they do not record it. But from the free text medical report we do not know whether these missing attributes have been checked or whether they have been deduced by physicians on the basis of previous knowledge.

5. Conclusions

Usage of international classification systems, e.g. SNOMED CT, LOINC etc., is the first and essential step towards interoperability of heterogeneous healthcare records. Sufficient semantic interoperability is a basis for shared health care, which leads to efficiency in health care, to financial savings and to reduction of patients' stress.

Standardised clinical terminology would bring advantages to physicians, patients, administrators, software developers and payers. Standardised clinical terminology would help providers of travel shared health care because it would give them more easily accessible and complete pieces of information, which belong to the health care process and it would lead to better care of patients.

Acknowledgments

References

[1.] http://www.nlm.nih.gov/pubs/factsheets/umls.html
[2.] Han S-B., Choi J.: The comparative study on concept representation between the UMLS and the clinical terms in Korean Medical Records. International Journal of Medical Informatics (2005) 74, pp. 67-76
[3.] Campbell J.R., Olivek D.E., Shortliffe: UMLS: towards a collaborative approach for solving terminologic problems, J.Am. Med. Inform. Assoc. 5 (1998) , pp. 12-16
[4.] http://www.who.int/classifications/icd/en/
[5.] Stausberg J., Lehmann N., Kaczmarek D., Stein M.: Reliability of diagnose coding with ICD-10. International Journal of Medical Informatics 77 (2008), pp. 50-57
[6.] [http://www.ihtsdo.org/snomed-ct/
[7.] http://www.nlm.nih.gov/research/umls/Snomed/snomed_main.html
[8.] The International Health Terminology Standards Development Organization: SNOMED Clinical Terms® User Guide. January 2008 International Release.
[9.] http://www.nlm.nih.gov/mesh/
[10.] Gault Lora V., Schultz M.: Variations in Medical Subject Headings (MeSH) mapping: from the natural language of patron terms to the controlled vocabulary of mapped lists. J Med Libr Assoc. 2002 April; 90(2): pp. 173–180
[11.] http://www.regenstrief.org/medinformatics/loinc/
[12.] Khan A. N., Griffith S. P., Moore C., Russell D., Rosario A. C., Jr., Bertolli J.: Standardizing Laboratory Data by Mapping to LOINC. J Am Med Inform Assoc. 2006 May–Jun; 13(3): pp. 353–355
[13.] Tomečková M.: Minimal data model for cardiology (in Czech). Cor et Vasa, 2002, Vol. 44, No. 4 Suppl., p. 123

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How can we improve the communication quality between doctor and foreign patient?

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Abstract. The circulation of labor force and with the effect of globalization;, today there are societies contain different cultures. Language is one of the biggest hindrances that people from different cultures confront with. Language barrier appears when two people with no common language try to communicate. Doctor-patient relationship is the first place where the common language barriers should be got through. In the first section of this article; culture, and as an element of it, language will be examined. In the second part, communication problems of the patients with no local language and doctors that do not know the mother tongue of the patients will be evaluated and the solutions developed will be evaluated. In the third part, the events that the foreign patients and medical institutions are faced with will be modeled with the help of interviews made with the health staff from 3 private and 2 public hospitals operating in Turkey. Faced problems are modeled from the view of Director of Quality Department, Head of Nursing Department, Emergency Doctor(M.D), Emergency Nurses, Staff of Public Relation Medical Director(M.D), Manager of Human Resources, Hospital Director(M.D), Professor of Physical Medicine and Rehabilitation. In the fourth part, the problems of a Greek patient in a private hospital will be evaluated according to case study method. In the last part, the method proposed to come over the language barrier will be introduced.

Keywords. Language barrier, culture, foreign patient, communication problems

1. Introduction

While traveling is getting easier and migration is taking place frequently, cultural differences and communication problems have emerged as a new problem of today. The most important case communication is inevitable for a non-speaker of the native language is being a patient. Some undesirable outcomes may occur if the patient can not give the correct information.

With the recent migrations in the western countries such as Germany, France, USA, Canada, UK, Holland the number of non-speakers of the native language has become noteworthy. In Turkey, there is also an increase in the number of foreign patients with the real estate sales to the foreigners in the places such as Antalya and Bodrum. On the other hand, highly qualified healthcare professionals and competitive pricing increased the share of health tourism in the whole tourism income (http://www.medicaltourisminturkey.org).

On the ground of the importance of communication, according to various resources, 80% of the medical mistakes are caused by giving incorrect information [13,8]. Having gained more and more importance recently, foreign patient-doctor communication and

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the gaps it has, will be evaluated with the view of knowledge management, and finally, the method developed to prevent the incorrect information translation will be introduced.

2. Literature Review

Foreign patients do not know the local language and therefore the language of the doctor is analyzed in detail. [1,2,10,14] In the basis of this study, lies the increase in the number of the non-speakers of the language of migrated country. For example in USA, 18% of people older than 5 years speak another language at their home (U.S. Census Bureau 2002: QT-P16, cited in Lee 2003:3). This information takes place in the article of Alexander and friends (2009) that contains interesting data about the non-speakers of native language:

"In Geneva, Switzerland, 43% of the population is foreign born and about 25% of the population speaks a language other than French at home.".

2.1. Culture

Edward Tylor's definition is cited as the first definition of culture[15]. Tylor(1903/1988) defines as "culture or civilization, taken in its wide ethnographic sense, is that complex whole which includes knowledge, belief, art, morals, law, custom, and other capabilities and habits acquired by man as a member of society".As one of the famous authors who has decoded the most about his studies on culture, Hofstede (2005:4) defines culture as "the collective programming of the mind which distinguishes the members of one group or category of people from another". According to these definitions, language is critical for both underlined words. "Capabilities" are built by interpretation of language. "Collective programming of mind" programming codes are generated by language. We can say that culture is created by language.

The effects of culture on health care are similar to those of language. For example in Turkey (strong uncertainty avoidance and collectivist culture) women are willing to be consulted to a woman obstetrician (H2 hospital Director of Quality Department), in USA (weak uncertainty avoidance and individualist) there is no such problems. According Collins et al. (2002, cited in Lee 2003:5):

"Effective communication between patient and doctor is critical to good medical outcomes."

So a woman patient form a different culture may affect the medical outcomes. In literature, several paper [2,6] use language and culture interchangeable but in this paper we will use the language as creator of culture.

2.2. Developed Methods To Pass Trough The Language Barrier

Information transfer (communication) between a patient and a doctor is generated in two ways. If the patient and the doctor speak the same language and their cultures are close to each other the transfer is established directly. If there are differences in the language and the culture of patient and doctor, a proxy is used. Followings are the proxies developed in the situation if the patients do not know the local language:

1. Going to hospital with a friend or relative who knows local language and using him or her as translator. In the deep interviews done with medical sector workers, most of the foreigners live in Turkey use this method, but if the friend or relative in the role of translator does not know the local language so much then some problems may emerge.

2. Interpreter establishes the communication between patient and doctor. This method is specially used in private health care enterprises in Turkey. Because of

cost, increasing effects, interpreters are not chosen by patients who have no good economic welfare. In many countries the language requirements of interpreters are not defined, and non-medical professional interpreters are used widely. In the study of Karliner et al.(2007) "professional interpreters are associated with improved clinical care more than is use of ad hoc interpreters, and professional interpreters appear to increase the quality of clinical care for limited English proficiency(LEP) patients to approach or equal that for patient without language barriers." Also many studies showed that professional interpreters who do not know the culture of the patient may offend the patient and the patient may lose confidence [3] .-

3.   Translation of those who are not medical staff. This type of translation is more common among immigrants. Because of large numbers of Turks living in Germany, it is quite probable to find non-medical staff that knows Turkish in the hospital.

4.   If the medical staff knows foreign language. The manager of public hospital and the managers of H1 and H2 hospitals said that the most important communication problem of medical sector is medical staffs without foreign language.

Table 1 –Types of interpreters used, according to specific foreign languages in health institutions[2:page 3]

Language	Professional interpreters (%)	Untrained volunteers (%)	Bilingual employees (%)	Patients' relatives/ friends (%)	Clinician speaks patient's language (%)	Chi-square	p Value
Tamil ($N = 65$)	39	18	6	37	0	43.6	<0.001
Albanian ($N = 99$)	37	15	19	28	0	67.3	<0.001
Bosnian ($N = 91$)	37	15	21	25	1	74.6	<0.001
Serbian ($N = 101$)	36	15	22	27	1	67.9	<0.001
Croatian ($N = 101$)	35	14	26	25	1	71.9	<0.001
Turkish ($N = 91$)	28	12	30	30	0	61.5	<0.001
Arabic ($N = 100$)	23	9	44	24	0	125.3	<0.001
Portuguese ($N = 98$)	6	2	70	16	5	207.3	<0.001
Spanish ($N = 107$)	5	2	55	16	21	138.8	<0.001

Table 2 –Assessment of quality of different types of interpreters in health institutions[2: page 4]

	Professional interpreters ($n = 99$)	Untrained volunteers ($n = 99$)	Bilingual staff ($n = 99$)	Patients' relatives/ friends ($n = 99$)
Poor (%)	0	1.4	2.0	12.5
Satisfactory (%)	6.1	14.3	30.8	56.8
Good (%)	31.7	37.1	60.4	22.7
Excellent (%)	41.5	7.1	3.3	4.5
Do not know (%)	20.7	40	3.3	3.4
Chi-square	22.7	43.3	119.5	85.1
p Value	<0.001	<0.001	<0.001	<0.001

In these studies low content rates of the patients can be seen. The most satisfactory method is bilingual staff and the least one is translation of relatives/friends of the patient.

3. Data and Method

The aim of this paper is to improve communication quality between doctor and foreign patient. The research question is How can we improve the communication quality between doctor and foreign patient? Yin (1994) defined a case study as "an empirical inquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident." Kohn(1997) states that "Yin suggests the methodology may actually be more powerful for explanatory purposes in its ability to answer questions of how and why". In this paper by the definition of case study methods and the structure of the research question. Semi-structured interviews and observations are used for data collection and case study method is used for analyzing data.

3.1. Selecting Cases

In Turkey there are 5 types of hospital. H1 private and multi branch, H2 private unique branch, H3 private, multi branch and foundation supported ,H4 public hospital, H5 university hospital. Cluster sampling method is used because population is heterogeneous. The population is first divided into separate groups of elements which is called as clusters, H1, H2, H3, H4, H5. A sampling from the hospitals in service in different cities, eager to provide data and known as the best in their cluster, is generated. As some hospitals demanded during the negotiations, the clusters they belong to are mentioned instead of their names.

Table 3 –Hospital Characteristics in each Cluster

| Cluster	Total Staff (approximately)	Total Branch	Is there a department for foreign patient?	Informant
H1	7500	17	Y	Hospital Director(M.D), Professor of Physical Medicine and Rehabilitation
H2	450	1	N	Director of Quality Department, Head of Nursing Department, Emergency Doctor(M.D), Emergency Nurse, Senior Staff of Public Relation
H3	800	4	N	Medical Director(M.D), Manager of Human Resources
H4	1600	1	N	Head of Nursing Department, Emergency Doctor(M.D), Emergency Nurse,
H5	More than 10.000	1	N	Emergency Doctor1(M.D), Emergency Doctor2(M.D),

3.2. Problems with patients who do not know Turkish

In some regions of Turkey, there are people who do not know the native language. We see that usually a relative or a friend of the patient help the communication as a translator (H1 Professor of Physical Medicine and Rehabilitation).

During the deep interviews with H3 Medical Director, he says:

"Citizens from the eastern region of our country, and immigrants from Iraq, Afghanistan, and Africa come to hospital when they are ill, with a relative or a friend of them; and we intervene the patients with the translation of these people."

The process goes on in two ways for the non-citizen patients. If the patient can speak English; as the public relations, nurses or the doctor can, the communication is established with the help of staff. But if the patient speaks a language other than the staff can do, then a translator is required.
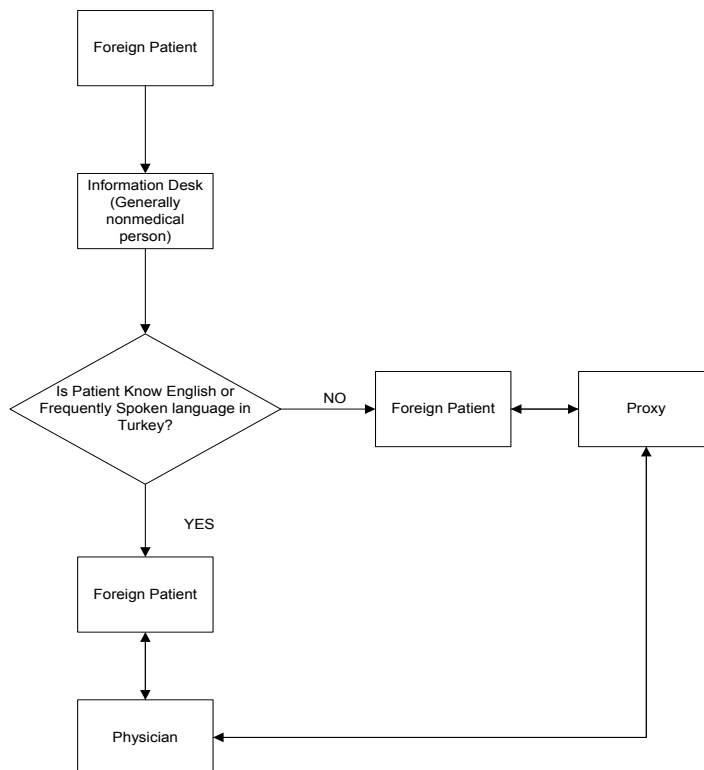
Figure 1. A Flowchart of the Current State of Foreign Patients

Hospital Director in H1 hospital stated that:

"The number of our foreign patients that become ill in Turkey is less than the patients that was ill before coming to Turkey. We sent our doctors to other countries and enable them to meet doctors working in clinics and hospitals. In the next step, foreign doctor sends his/her patient to us. Before the patient arrives, we get the tests and diagnosis applied to the patient. We meet the patient at the airport and accommodate the patient according to his/her economic welfare. All the transportation and other needs of the patient are met by our department established for this purpose. Taking into consideration the countries most foreign patients come from, we employ that staffs who know their language.

Because the number of foreign patients in H1 hospital is more than other private and public hospitals, many applications were developed in accordance with the needs. For example, if the patient gets lost anywhere in the hospital and shows the card given to him/her to any hospital employee the problem is solved.

"In the frame of JCI accreditation, the patients and employee are not asked to identify themselves according to their room number. For the probability of being lost in the hospital mostly used sentences takes place in Turkish and in the language of the patient. When patient shows his or her need in own language, the Turkish translation takes place under it then the communication is established."

In H2, H3, H4, H5 hospitals, patients usually come after they get ill in Turkey.

Quality manager of H2 hospital:

"Our patients usually come us after an illness in Turkey or according to the recommendation of their acquaintance who were satisfied from our service. Among our patients, there is a group which establishes contact with us before they come to examination and shows the previous cure documents, and the other group comes without any plan or foreknowledge."

In 2007 the distribution of the foreign patients came to H2 hospital is as follows:
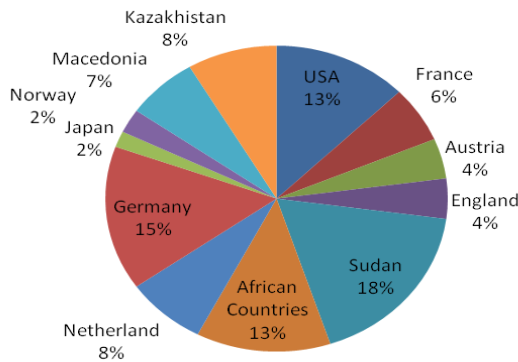

Figure 2 Distribution of Foreign Patients per Country

Many demographic features of the patients are: 64% are men and 36% women. 52% paid cash, 26% used assurance and 21% cured for free by the hospital. Foreign patient level in all hospitals is about 1%.

If we consider the graphic which Hofstede (2005:191) has drawn according to the cultures of the countries;

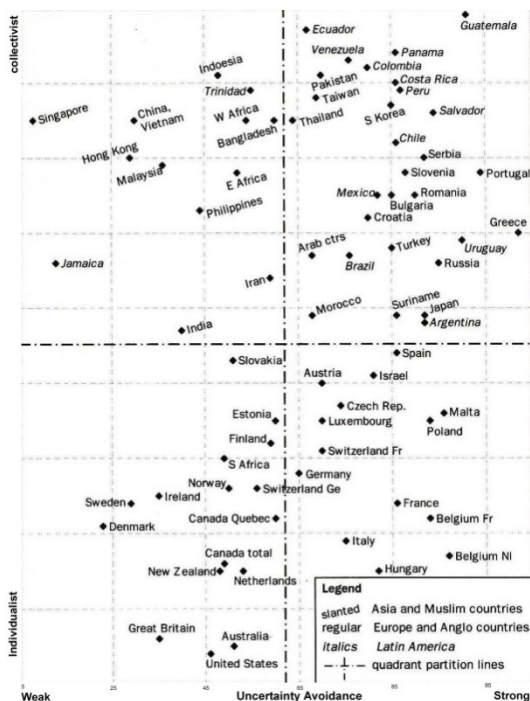**Figure 3.** Uncertainty Avoidance versus Individualism

The patients coming to H2 hospital take place in all four areas. These patients took service in 15 different departments. In communication with these patients, proxies were used.

In 2007 H1 hospital's foreign patients came from 69 different countries such as Afghanistan, Argentina, Germany, Angola, Albania, Austria, Azerbaijan, Kazakhstan,

Russia, UK, USA, Canada, Finland, Czech Republic, India, Iraq, Iran, Vietnam, Uruguay shortly all quadrants of Hofstede's culture dimensions.

In literature LEP (limited English proficiency) concept is used but limited Turkish proficiency, limited Arabic proficiency, limited Chinese proficiency are also problem. When we look at the problems about the culture and language, the cases in USA and Europe countries are common for all countries and should be solved in all countries.

In mostly used method, using proxy, the main problem is the transfer of the knowledge. Knowledge changes while transferring from one place to another, so knowledge cannot be transferred but translated.

For example; in communication with simultaneous translation the question of Turk doctor "Neyin var?" is translated as "what is wrong?"or "obligation" word is used. But the purpose here is to ask "What seems your chief complaint today?" In the article of Holden et al (2004) which includes usual examples, the following part takes place:

"For example, Japanese speakers of English are influenced by the notions of politeness. Rather than categorically refusing a request, Japanese might say: 'I'll think about it' (which means "there is no way I am going to do anything about it.'; or, often with a great sucking of breath between clenched teeth: 'That's very difficult', meaning that something is a sheer impossibility."

3.3. Specific Situation

Patient Name: Y.S.
Year : 2008
Age: 48
Nationality : Greece

"The patient comes to Bursa because of the dead of a friend of him. He goes to emergency with stomach ache. He is alone. The patient speaks English and Greek. After he turns to information desk, he is taken to the emergency doctor. The emergency doctor knows only Turkish. A professional interpreter is called. Patient tells the interpreter that when he first comes to the emergency he could not express himself to the hospital employee and he needs immediate cure. In addition, he says that he was depressed even before the therapy and if he didn't have to, he would not come to a Turkish doctor."(Interpreter, H2 hospital Emergency Doctor (M.D), Emergency Nurse, Senior Staff of Public Relation).

As we can understand from these expressions the patient has a negative point of view against Turkey because of the dreary events between Turkey and Greece in the past. This point of view is considered as a code given form the society he lived since his childhood [18] As the patient has to wait despite the emergency, he uses accusatory expressions.

He says that "the doctor in the emergency is young and inexperienced".

That the translator is easy-going and that he mentions the negative behaviors of the patient after the examination has been an important factor in the success of the treatment.

"After the therapy blood test and abdominal USG are demanded. Then gastroenteritis is diagnosed and his prescription was filled." (Emergency Doctor)

"After making a good bargain, patient lowers the price and pays in cash."(H2 Director of Quality Department)

Because of the proximity of a less individualist society and relatively low prices in Turkey, the patients says that he also has a tooth ache and wants to see the therapy room for teeth. After seeing the room he takes a tooth therapy, as well.

4. Solution

In this article we stated that knowledge is translated not transferred. Culler (1982) states that "every understanding is a misunderstanding."[4]. If every understanding is a misunderstanding then communication between different cultures using different proxies is a distorted understanding. To establish the communication in mother language gains importance. "Communication between physicians and patients is fundamental for medical care."(Joos et al.1996, cited in Lee et al. 2003).

The solutions are developed in a way that the patients take less time of the proxies. Physician reads the report in his/her own language both audibly and visually, and may also provide videos and audios in the language of the patient[5,19].

The method developed in the scope of this article is a little more different. Native speaker doctors prepared the questions for diagnosis in their own language as well as the answers to such questions. Until the diagnosis the patient chooses the questions in own language then physician and patient gets the printouts in their own languages.

The forgotten point in the developed audio and video based system is, while answering physician's question without the system patient uses own language and physician does not understand. Videos are important in one-way communication as giving information about how the test will be done like as urine test.

How can we solve communication problems between foreign patient and doctor? Can XML be a solution?

XML is defined by the W3C:

"Extensible Markup Language (XML) is a simple, very flexible text format .Originally designed to meet the challenges of large-scale electronic publishing, XML is also playing an increasingly important role in the exchange of a wide variety of data on the Web and elsewhere" (http://www.w3.org/XML)

We can use xml for information transfer from one language to another one. We use transfer because native speaker doctors prepared the questions for diagnosis in their own language as well as the answers to such questions. Foreign patient and doctor use software in their own language, culture and words.

Foreign patient and doctor information transfer process can be modeled as below:
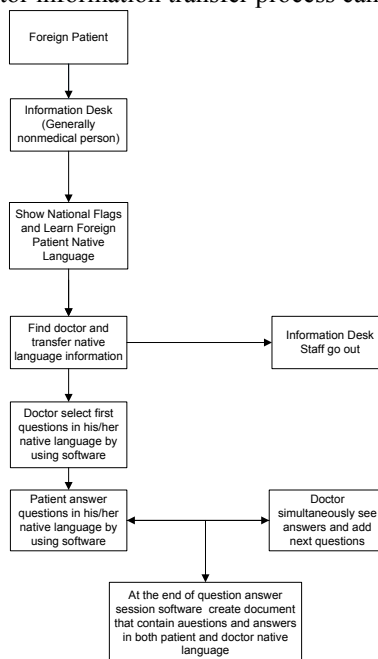
Figure 4. Foreign Patient and Doctor Information Transfer Process

Both foreign patient and the doctor can see every question in their native language and culture.

4.1. Software

This software can support all languages. When we add a new language program XML file is extending.

Figure 5. Foreign Patient Guide Supported Language

When we add a new language it will be located in this section:

```
<DesteklenenDillerstr>
  <string>en</string>
  <string>de</string>
  <string>tr</string>
  <string>fr</string>
          .
  <string>new language code</string>
</DesteklenenDillerstr>
```

I have only migraine data for testing software in Turkish, French, German and English languages. Let's think that our doctor is a Turk and patient is a French native speaker.

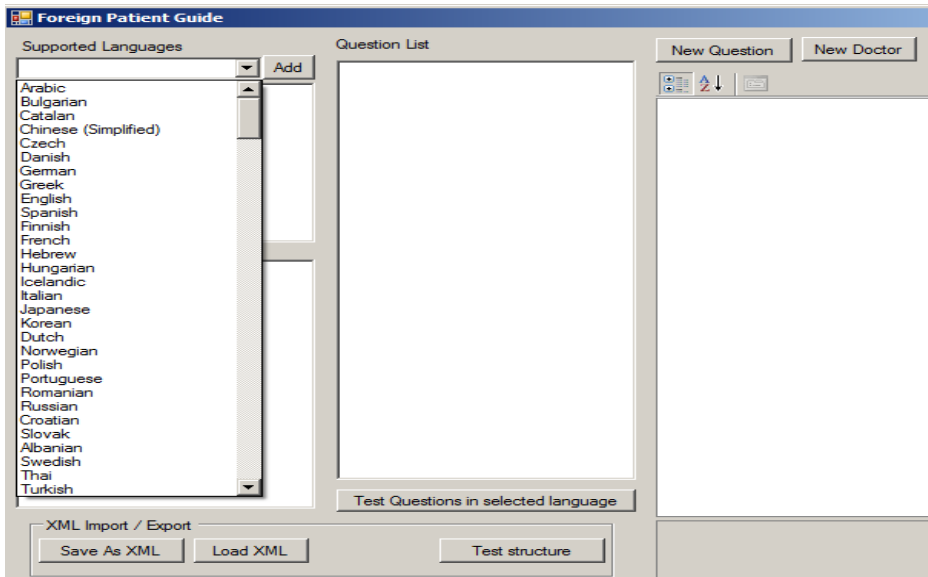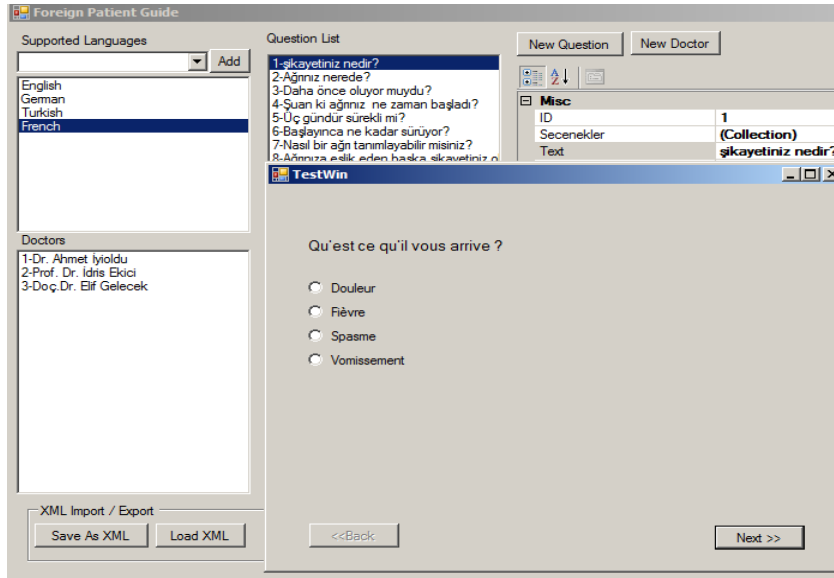**Figure 6.** Patient screen for French native speaker

Doctor select question in his/her native language "şikayetiniz nedir?" and patient see this question in his native language "Qu'est ce qu'il vous arrive ?".

```
<Soru Text="şikayetiniz nedir?" ID="1">
  <Texts>
    <DictItem Text="What seems your chief complaint today?  ">
      <Culture CultureStr="en" />
    </DictItem>
    <DictItem Text="Şikayetiniz nedir?">
      <Culture CultureStr="tr" />
    </DictItem>
    <DictItem Text="Welche Beschwerden haben Sie?">
      <Culture CultureStr="de" />
    </DictItem>
    <DictItem Text="Qu'est ce qu'il vous arrive ? ">
      <Culture CultureStr="fr" />
    </DictItem>
  </Texts>
```

CultureStr for doctor is "tr" and for patient is "fr". If we add a new language this section will be extend. <DictItem Text="In new language "> and <Culture CultureStr="New language code" />. Screen shot:
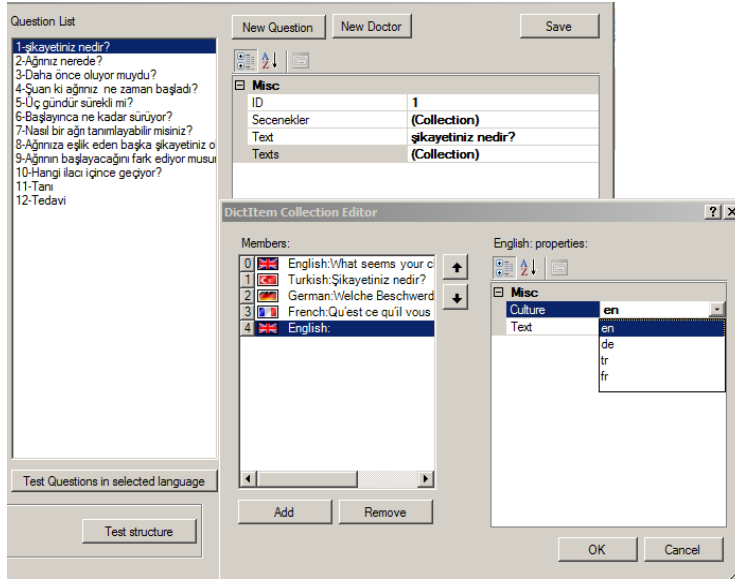
Figure 7. Foreign Patient Guide Item Collection Editor Screen

5. Conclusion

Translations done by ad hoc interpreters and professional interpreters who do not know patient's culture are equivalent according to the transfer of the knowledge but are not equal. Because of this, these are the translation of knowledge rather than transfer of knowledge. Our solution can be a solution for knowledge transfer problems and limited all language proficiency. What we need is only questions for every complaint, what doctor is asking to their patients. It is not easy but if we do this, a visit to a foreign country will be much safe and a patient will have a chance to chose his/her doctor in which country he/she wishes.

Every understanding may be a misunderstanding because what we understand may be different from what is said by others. We understand equivalent of what said by others, not equal. By this project we are trying to extend understanding. As we mentioned before according to varied resources 80% of the medical mistakes are caused by wrong information (wrong information transfer). If we extend enough equivalent it will be nearly equal, at this point medical mistakes will decrease.

References

[1]   Alexander B., Perneger TV., Bovier PA., Loutan L., and Stalder H. Improving communication between physicians and patients who speak a foreign landuage. *British Journal of General Practice* 2003: 53: 541-546

[2]   Alexander B. and Hudelson P. Communicating With Foreign Language- Speaking Patients: Is Access to Professional Interpreters Enough? *Journal of Travel Medicine* 2009: 1-6

[3]   Collins KS., Hughes DL., Doty MM., Ives BL., Edwards JN., and Tenney K. Diverse Communities, Common Concerns: Assessing Health Care Quality for Minority Americans. Findings from the Commonwealth Fund 2001 Health Care Quality Survey. New York: Commonwealth Fund.

[4]   Culler J. On Deconstruction, New York: Cornel University Press 1982.

[5]   Galvez E and Stronks A (2007) "*Hospitals, Language, and Culture*" Joint Commusion International(http://www.jointcommission.org/NR/rdonlyres/E64E5E89-5734-4D1D-BB4D-C4AC-D4BF-8BD3/0/hlc_paper.pdf Last accessed Agust 2009)

[6]   Gale DD. Cultural Sensitivity Beyond Ethnicity: A Universal Precautions Model. *The Internet Journal of Allied Health Sciences and Practice* 2006:4(1):1-5

[7]   Holden NJ. and Kortzfleisch HFOV. Why Cross- Cultural Knowledge Transfer is a Form of Translation in More Ways Than You Think. Knowledge and Process Management 2004: 11(2): 127-136

[8]   Joint Commition International. http://www.jointcommission.org/SentinelEvents/SentinelEventAlert/sea_25.htm Last accessed: June 2008

[9]   Joos SK., Hickam DH., Gordon GH., and Baker LH. 1996. Effects of Physician Communication Intervention on Patient Care Outcomes. *Journal of General Internal Medicine* 11(3): 147:155

[10] Karliner LS.,JAcops AE, Chen AH and Mutha S. Do Professional Interpreters Improve Clinical Care for Patients with Limited English Profeciency? A Systematic Review of the Literature. *Health Service Research* 2007: 42(2): 727-754

[11] Kohn LT. Methods in Case Study Analysis(Panel discussion conducted at the 1996 meeting of the Association for Health Services Research) 1997.

[12] Lee SM. A Review of Language and Other Communication Barriers in Health Care. Office of Public Health and Science 2003.

[13] Packard, C.Finding Links between Healthcare Safety, Communication, and Cultural Norms and Assumptions. *Carle Selected Papers* 2009 Vol.50 No.2 : 55-58 (http://www.carleconnect.com/CSP/CSP%20Fall_Winter%2007/13.Packard.pdf Last accessed Agust 2009)

[14] Perloff RM., Bonder B., Ray GB., and Ray EB. Doctor-Patient Communication, Cultural Competence, and Minority Health. *American Behavioral Scientist* 2006: 49(6): 835-852

[15] Vatrapu R., and Suthers D. "Culture and Computers: A Review of the Concept of Culture and Implications for Intercultural Collaborative Online Learning. *IWIC 2007*: 260-275

[16] Hofstede G. And Hofstede GJ. Cultures and Organizations Software of the Mind. McGraw-Hill. 2005

[17] Yin, R.K.*Case Study Research, Design and Methods,* 2nd ed. Newbury Park, Sage Publications, 1994.

[18] Hostede G.and Hofstede GJ. Cultures and Organizations: Software of the Mind, Second Edition, McGraw-Hill, New York, 2005.

[19] http://pgsi.com (Last accessed Agust 2009)

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Integrated Care Delivery – A Challenge Which Can Cross Many Borders

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Abstract. Many governments have introduced strategies to reform their health care system, and many have advocated to take a patient centred approach. The Dutch ministry of health not only discussed such an approach, but also did manage to introduce it in the health care system. In the nineties the stakeholders launched the paradigm shift by the introduction of the health issue based DBC system. The government adopted the patient centred approach for changing the funding of hospitals. The next step is the use of the DBC concept for contracting chronic care arrangements based on care standards defined by providers and patients. A vital element in this approach is the semantic interoperability of systems supporting the integrated care delivery. So one of the objectives of the implementation is to adopt common standards for clinical parameters. By using Detailed Clinical Models to describe these parameters a sound base is created to exchange information at the patient level. By integrating these parameter definitions in the care standard it adds to the potential to be applied in other countries and so to help concepts cross borders, not only of health care settings, but also between countries. Time will tell how much time it will take to create a Schengen for health care concepts in Europe.

1. The Paradigm shift of health care delivery

In the nineties a remarkable event took place in the Dutch health care system. The publication of the Biesheuvel report on modernisation of the Dutch hospital system was that event. The advice to change to a new way of curative, acute care delivery aimed at providing integrated care focused on the health issue of the patient. The proposal was the result of negotiation between the major stakeholders in the health arena: the clinicians, the hospitals and the insurance companies. The Dutch ministry of health was not involved in this process. The approach was to focus on the health issue of the patient from the referral to the hospital until the end of the treatment episode. The core of the solution was to move to a more health product oriented approach, in which hospitals contract care with health insurers based on price and quality. A process of change started to gradually move in some years from an inflexible budgeting system to a system of contracting care products.

1.1 Designing the hospital products

The first step was the quest for the definition of the health issue based products of the hospital, as DRG's could not be used as they only define health care products delivered during an inpatient episode. The " Product Typering" project of the major stakeholders, managed by Laurens Baas resulted in the concept of the Diagnosis Treatment Combination, the DBC. The DBC concept was elaborated 1996 by a team of Urologists. They designed the clinical parameters to be used to " describe" the care given to a patient, via four axes: type of referral, the care request, the diagnosis and the treatment. Urologists in 6 hospitals,

which illustrated the potential of the approach, ran a pilot both from a clinical point of view as for defining care products to be used for contracting care. The next step was a national test for all urologists in 1998-9. As the DBC code was defined as the combination of the four axes, the test resulted in over 1000 different DBC combinations, only for Urology. During the evaluation the 22 care product clusters were defined, which were clinical relevant and homogeneous for costs. These were the real care products, the DBC's, but this result was neglected, when the process was started to use the DBC approach for all specialties in the DBC2003 project aimed at implementing DBC system in all Dutch hospitals in 2003.

1.2 The DBC introduction in hospitals

The adoption of a health issue oriented approach required a major change in the documentation of the care delivery. The DBC 2003 project focused on the different types of changes involved in the shift to a patient centred care product approach. One of the major tasks was to introduce a health issue oriented registration in all hospitals for all specialties. This was necessary to be able to define the DBC care products, as no national registration existed and the new DBC's should be medical relevant and cost homogenous. As changes in common practice are always very hard to manage and difficult to implement, over 40 pilot hospitals were funded by the ministry of health to start collecting DBC information by patient health issue episode. Based on these data the first version of the DBC "products" was designed and implemented in all Dutch hospitals in February 2005. For 10 % of hospital production contracting was introduced for the B list of DBC's. The introduction of the new system has yielded many positive results, like vanishing waiting lists, increasing debates within hospitals between management and medical specialists on how to deliver better and patient focused clinical care. These results exceeded the problems with the introduction, like cash flow problems first with hospitals and later for health insurers, the interpretation of the rules of opening and closing of health episodes. Since 2005 the percentage of contracting has risen to over 30 % and will be raised to more than 50 % in the coming two years. The introduction has not been easy, but it has dramatically changed the health care delivery scene in hospitals for all involved both providers and patients. Only in 2006 the clustering approach introduced by the urologists was the base for a restructuring of the DBC system introducing the ICD 10 Classification to integrate the care products of the 28 different specialties. The new DBC version will be implemented in hospitals in 2011.

2. Introducing the DBC concept for Chronic Care

2.1. The ZonMw Diabetes Ketenzorg project 2007-2008

The new century, which increased the worries of the growing numbers of baby boomers to become pensioners and requiring more care in the near future. Many studies created an awareness of a crisis in the making due to rising numbers of citizens at risk of getting chronic diseases and actually being diagnosed with such a disease. When the organisation of care providers and Patient organisations agreed on the " care standard" for high quality Diabetes care and it turned out that only 30 % of Diabetes patients was treated according to the standard a start was made with a process to come to structural change. The introduction of the DBC system for hospitals was a driver for applying the same concept for longitudinal chronic care. For contracting chronic care multidisciplinary care arrangements was needed In 2006 a test started with contracting Diabetes care based on the care standard between Care groups, a legal entity of multidisciplinary care providers and health insurers. The research project managed by the National ZonMw organisation selected 10 care groups, which were granted to test the new way of delivering integrated care to patients based on an integrated,

personalised health plan for each patient. The aim of the project was to test if the way the care was organised had any influence on the results of the care delivered. But an important side effect of the project was the test of a care funding model which was base don standards for good Diabetes care and contracted with **one** partner, who took the responsibility for providing good and effective care to meet the specific needs of patients.

Although many problems were faced the project was very successful and created an enormous offspring in different directions.

As care standards were the base for this development, many provider groups and patient organisations started to develop care standard for chronic diseases like COPD, Cardio Vascular Risk management, Heart failure, Depression, and Cystic Fibrosis to name a few. This was the tool for health care funding for the near future, so join forces and start working and find consensus. A new driver for multidisciplinary teamwork was born.

2.2 The Chronic Care Policy 2008

The ministry prepared a policy for a programmatic approach to manage chronic diseases with a couple of " policy letters" to the Dutch parliament. The first was sent to parliament in July 2008 on a new policy on chronic care, followed by the introduction of the concept of the Keten DBC funding strategy for 4 major Chronic Diseases in December 2008. In the course of 2009 the new dimension of the health product funding was further elaborated. As the new approach was silo killing it required structural changes in the reimbursement of general practitioners. This took some time, but only last week the minister of Health, Ab Klink managed to pass the Chronic Care Funding arrangements through parliament. The new approach of multidisciplinary organised chronic care was supported broadly by parliament; it was only the speed of implementation that caused some discussion. As of the 1st of January 2010 it is allowed to contract the multidisciplinary delivery of preventive care for Diabetes and Cardio Vascular Risk management base don Keten DBC contracts. A major breakthrough in healthcare delivery as general practitioners, medical specialists and patients will be working closely together. The " Rubicon" has passed, and a new era of health care delivery has been initiated. The new policy is introduced on voluntary basis, but it must be possible to contract these care standards. A process has been started to support the introduction of the KetenDBC's in the health care scene.

2.3 The care standard

Essential in the new policy is the care standard as agreed upon by providers and patients as base for the organisation of the care delivery and funding arrangements. Care standards have been developed for a range of conditions by close collaboration of stakeholders. As the care standards have been chosen to be the object for health care funding, the interest to develop care standards has increased nearly exponential.

The ministry has taken the initiative to create a coordination platform to work on a standard for care standards. This has been done expeditiously and has resulted in a draft standard of care standards. The care standard focuses on the individual patient and describes good chronic care from indexed prevention to care related prevention for those who have been diagnosed with the disease.

2.4 The Integrated care standard

Having a care standard is one step, but the implementation adds other dimensions. It requires a structure to deliver care by multiple care providers in close collaboration with

patients. As a contractor is needed to contract care with the health insurer, the introduction of new coalitions in the health care arena has been seen. These new arrangements are multidisciplinary of origin and break through the existing silos. An important dimension of the new approach is the integrated care plan, which is created and monitored for each patient participating in the disease management program. This can only be organised if the care providers all are able to a share the use of the integrated care plan of the patient, and the patient as part of the care team can contribute as well. As patients will live longer they will face multiple diseases, so the treatment plan should be able to manage complex situations.
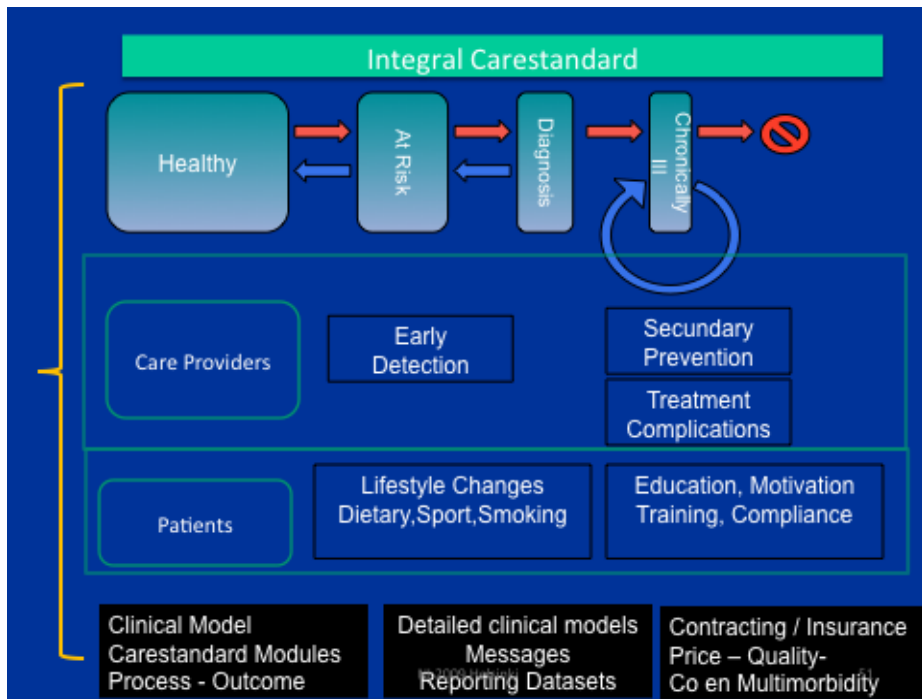
To enable the support of a multi morbidity patient sharing semantic interoperability is mandatory for IT systems used by care providers and patients. After some discussions the following solution was adopted, each care standard will have some annexes focused on specific implementation issues. Some are related to the formal procedures related to the use of the care standard for contracting, but other annexes focus on specific implementation aspects like the contracting and billing requirements. But the most interesting from IT point of view is the annex devoted to the definition of the parameters used within the care standard. A Detailed Clinical Model, the intermediary between the CEN Archetypes and the HL7 Clinical Documents, will describe each parameter. This annex will be based on work done by health care providers and NICTIZ for the eDiabetes project and will further be developed in close collaboration with the Dutch IT industry. Another annex will focus on the requirements for the functionality of IT systems to support disease management for chronic diseases.

3. Conclusion

As of January 2010 contracting for two care standards will be introduced in the Dutch health care market. A new step in the process of change, which started in 1994 leading

to, a higher quality of care and more focus on an active involvement of patients in their care process.

The integrated care standard concept is developed for the Dutch health care market it has the potential to cross national borders. The detailed clinical models contribute any way to facilitate this process.

References

[1]   The DBC System, Ministry of Health, DBC Onderhoud
[2]   The NDF, diabetes zorgstandaard, 2003, 2007 Netherlands
[3]   Archetypes for HL7 CDA Documents, Eric. Browne, October 2008
[4]   Diabetes Ketenzorg, ZonMw project 2006-2008
[5]   eDiabetes, a NICTIZ project 2009
[6]   The Detailed Clinical Model foundation

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What Tourist Guides Must Know About Medical Informatics

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Abstract: This paper shows why it is necessary to use some topics from medical informatics in tourist guiding. Tourist guides must have solid knowledge of computer literacy, but more over they have to be well informed about EHR and telehealth. That is the only way to be good guides to their travellers, to be helpful and efficient in the case of any traveller's health accident. In such a manner they will make a trip as a really nice and unforgettable experience.

Key Words: Medical Informatics; Tourist guides; EHR; Telehealth

1. Introduction

The good description of eligible relation between health and travelling assumes: "To be healthy during your travel activities is usually a question of common sense only if you initially devote additional attention to precautions relating to travel safety and reliability. Therefore, a small change in your behaviour can make your trip a valuable, exciting and healthy experience." [1].

New threats to health security arise every day more and more so this idyllic relation between health and travelling has changed. Today we are all in the new situation where our health is at risk. Dr. Margaret Chan, Director General of World Health Organization (WHO) mentioned in her speech: "We live in a world where threats to health arise from the speed and volume of air travel, the way we produce and trade food, the way we use and misuse antibiotics, and the way we manage the environment. All of these activities affect one of the greatest direct threats to health security: outbreaks of emerging and epidemic-prone diseases. Outbreaks are unique public health events because of their ability to cross national borders, undetected and undeterred. … All nations are at risk. This universal vulnerability creates a need for collective defences and for shared responsibility in making these defences work. … On the positive side, our world's electronic transparency has made it difficult for any country to hide an outbreak. News will always seep out and be picked up." [2].

The knowledge about health safety is anticipated from all tourist professionals, but tourist guides are in a special situation. While travelling they are constantly in immediate contact with passengers and must solve their eventual health problems as well. In this paper the authors, well experienced in both medical informatics and tourist guiding want to expose good advantages of efficient blending of those two unexpectedly allied topics.

2. Principal acquirements from Health Informatics for tourist guides

Today computer literacy is anticipated from everybody and tourist guides are not exceptions and must have elementary knowledge about using information and computer technology (ICT). Tourist guides must be very well informed about all recommendations about health conditions in the country they are visiting with their group. International organizations as WHO [3], [4] [5], WTO (World Trade Organization) [6], UNWTO (World Tourism Organization) [7], [8], [9] and some governmental institutional agencies [10] give a lot of very detailed, precise and practical instructions about travelling to all destinations worldwide, especially concerning health risks assessment and health services. Those recommendations are mostly intended to be helpful to tourists, but tourist guides must be informed about all these things better than their travellers. If not, how will they help them.

There are two inevitable topics in tourist guides' elementary knowledge about Medical Informatics: Electronic Health Records (EHR) and Telehealth.

On the web page of HIMSS (Healthcare Information and Management Systems Society) there is a definition of EHR [11]: „The Electronic Health Record (EHR) is a longitudinal electronic record of patient health information generated by one or more encounters in any care delivery setting. Included in this information are patient demographics, progress notes, problems, medications, vital signs, past medical history, immunizations, laboratory data and radiology reports."

It is completely clear that tourist guides are not expected to know data from travellers EHR.

However, it is very expected that tourist guides know:
o   If traveller has EHR.
o   How to reach traveller's EHR. It has to be reachable in both senses: in the moment and on the place where the traveller needs it, as well as where to find it.
o   How to find some solution in case of problems in getting the traveller's EHR.

It is a very important part; so various kinds of troubles in looking for EHR could be expected. In foreign, especially far away, countries the language problem is inevitable, very often travellers depend on guide's help. Different habits, different names, different concepts are sources of many misunderstandings and troubles. Tourist guides have to know how to overcome them.

Telehealth, also known as telemedicine, is the remote provision of health care services enabled by technology. A continuum of successful telehealth applications have been demonstrated over the last twenty years, ranging from the transmission of digital photographs and patient histories for diagnostic consultation to remote monitoring of physiologic data for chronic disease management, to interactive patient physical examination using medical video endoscopes and ultrasound over high-definition videoconferencing links. The common tie among these varied applications is that technology is used to improve access to health care services independent of geography.

There are two primary operational modes of telehealth:
o   real-time or synchronous
o   deferred or asynchronous, or store-and-forward.

In real-time telehealth, a telecommunications link allows instantaneous interaction. Video-conferencing equipment is one of the most common forms of synchronous

telemedicine. Peripheral devices can also be attached to computers or the video-conferencing equipment which can provide aid in interactive examination. With the availability of better and cheaper communication channels, direct two-way audio and video streaming between centres through computers is leading to lower costs.

In deferred telehealth, data (such as digital photographs) are captured locally at the patient's site, then temporarily stored or cached for transfer at a later time, either via a secure web server, encrypted e-mail, specially-designed store-and-forward software or electronic health record. The consulting provider then reviews the stored data and makes diagnosis, treatment and planning recommendations that are electronically transferred or faxed back to the referring provider [12], [13].

Such a detailed description of telehealth time shows important role of tourist guides' elementary knowledge about telehealth.

Tourist guides must be able to:
o To find out the possibility of telehealth services for their travellers.
o To obtain the best possible quality of telehealth services.
o To overcome, as in the case of EHR, all misunderstandings, language problems, cultural verities coming from differences among traveller's country and hosting country.

Heretofore we described the necessities of elementary knowledge about medical informatics in standard tourist guiding of adult persons healthy before trip and some possible situation which could occur. Everything starts to be more complex in tourist guiding of children, senior tourists or dealing with medical tourism[14] so popular last years. In those cases tourist guides must be much more experienced and have much bigger knowledge in everything, and medical informatics as well.

Especially telehealth can improve quality, efficiency and customer service in medical tourism applications by better coordination of care between providers in patients' home and foreign countries, enhanced preoperative and postoperative care, and optimizing patient and family member travel. It is expected that in the case of medical tourism tourist guides are more educated in medical subjects. Maybe it is a better solution to have basic medical education and to get additional knowledge in tourist matters.

3. Conclusion remarks

Good computer literacy and elementary knowledge about Medical Informatics is inevitable to be a good tourist guide.

During the tourist trip in every moment, all day long tourist guides are available to all their travellers. When something happens to a particular traveller, guide must be especially focused on him, the rest of group is postponed till the moment the situation with affected traveller is under control and acceptable. In the event of health accident the reaction and help of tourist guide must be extremely quick. Good knowledge of some topics in Medical Informatics would be an enormous help.

There are two very important benefits: our affected traveller will be taken care of in the best way and the rest of the group will feel safe with a qualified tourist guide.

It is said that tourist guides are available to all travellers all the time during the trip. However, tourist guides are all the time negotiators among travellers and new surroundings. In the case of health accident tourist guide is the only negotiator between

the traveller and local physician. Tourist guide could sometimes even be the negotiator among local physician and traveller's GP or some health institutions, and than every acquirement helps a lot.

Nowadays tourist guides are good enough in computer literacy and use ICT in everyday life and for tourist matters. A big progress happened in using ICT and it is visible in tourist guides' better education and awareness.

Authors' experience is that tourist guides are not educated in any specific subject of Medical Informatics interesting for their job. They mostly don't know what Medical Informatics is and why it is important to know basic elements in their professional carrier. These subjects must become a part of professional education of tourist guides.

Moreover, authors' suggestion is that EFMI takes in consideration the establishing of Working Group for Medical Informatics in tourism.

References

[1]   Travel Medicine Program (2008), www.phac-aspc.gc.ca/tmp-pmv/travel/advice_e.html/
[2]   Chan M.: World Health Day debate on International health Security (2007), www.who.int/
[3]   Invest in Health, Build Safer Future, (2007), Genève, WHO, www.who.int/
[4]   International Travel and health, (2009) Genève, WHO, www.who.int/
[5]   Main health Security Challenges in the WHO European Region (2009) Genève, WHO, www.who.int/
[6]   Worksheets for Implementing Quality Supporting Systems in Local Tourism Destinations, (2001), Madrid, WTO, www.wto.org
[7]   Health Threats related to International Security (2007), UNWTO, www.unwto.org
[8]   Support to creating and maintaining safe environments for world tourism and monitoring tourism-associated risks, (2006), www.wto.org/
[9]   Crisis Guidelines for Tourism Industry, Madrid, UNWTO, (2006), www.unwto.org/
[10]   Seven Tips for Responsible Travel (Traveller), ISTM, (2007), http://www.istm.org
[11]   Electronic Health Record. http://www.himss.org/ASP/topics_ehr.asp , last accessed: September 2009.
[12]   Brown N., Telemedicine Coming of Age, (2005), http://tie.telemed.org/articles/article.asp?path=telemed101&article=tmcoming_nb_tie96.xml
[13]   http://www.telemedicine.com/whatis.html
[14]   Simmons S.C., Burdick A.E.: The Role of telehealth in Medical Tourism. Published on line Aug 4, 2009. http://www.medicaltourismmag.com/detail.php?Req=230&issue=11

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INTER-REGIONAL
CO-OPERATION

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Macedonian Integrated Health Information System – Deployment Issues

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Abstract. Macedonian Integrated Health Information System strategy is determined by Strategy for the Development of Macedonian Integrated Health Information System. The primary aim of Macedonian Integrated Health Information System development strategy is to recommend the necessary actions to rectify present deficiencies in health information systems and to put in place the frameworks to ensure the optimal development and utilization of Integrated Health Information System and related requirements and specifications. National healthcare ICT implementation strategy components are accented: purpose of the ICT implementation strategy, information principles, need and ICT enablement in domains of patients, healthcare professionals, policy-makers and managers and public. Based on the determinants, the key to successful implementation of ICT is a strong and universally accepted strategy. A mid and long term ICT strategy is necessary to achieve such goal. Two organizational levels have been established – ministerial and project levels. General architecture of Macedonian Integrated Health Information System and its implementation as well as national ICT environmental accelerations for national primary healthcare ICT environmental accelerators for health ICT implementations are presented.

Keywords. ICT healthcare implementation strategy, healthcare functional requirements, healthcare standards, electronic health record, integrated healthcare, agent based software technology, healthcare computer, communication network, healthcare implementation.

1. Introduction

Conceptual design of national healthcare information system has been based on following documents:

- Strategy for the Development of Macedonian Integrated Health Information System
- eEurope Action Plans: 2000, 2002, 2005
- Health Action Plans – Guidance (2008)
- An action plan for a European e-Health Area (COM 2004-356 final)
- EU eHealth Strategy

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2. Project organization and management

2.1. Preparatory stage of the project, process of procurement and in the IHIS[2] pilot

- Ministerial Level: Advisory team to Minister of Health with representatives from healthcare system.
- Project Levels: Project teams, selected implementation team representatives in first locations.

2.2. The implementation stage of the project Primary health information system

Ministerial Level: During the implementation stage of the project there are two bodies: Supervisory board and Project Management Unit. Supervisory board has a task of business sponsorship of the project and supervising completion of project milestones. It is consisted of highest officials from Ministry of Health, Health Insurance Fund (both directors), Institute for Public Health (director) and high level representative from supplier of the PHIS. Project Management Unit (PMU)[3] has a task of operational management of PHIS implementation. Its head is project manager – coordinator and project manager both appointed by the minister and members are representatives on the operational level from Ministry, Health Insurance Fund, Institute for Public Health, Medical Chamber, World Bank experts and suppliers. PMU and its members are free to use outside experts opinions.

3. The Requirements and Functional Specifications

3.1. National Requirements

The strategic national requirement for the IHIS is to enable necessary tools to speed up reform of health system and to maintain improvement of the health status of the Macedonian population of all backgrounds and all ages.
Underlying principles or values of the Macedonian health strategy are
- Equity, which means that the whole population has timely financial and geographical access to an agreed package of health services.
- Shared responsibility for health between government, public and private health care providers, non-governmental organizations, and citizens.
- Social health insurance, creating solidarity between sick and healthy, poor and rich, and young and old.

The goal of better health for patients will be achieved by:
- Easier access to health services
- Transparency in waiting lists and doctor appointment scheduling
- Public and transparent standards for health systems and easy access to information
- Electronic documents instead of paper documents
- Defined and implemented medical guidelines
- Benefits for health professional will be achieved by:
- Less administration and paperwork
- Focus on patient
- Easy access to all patient's medical data
- Results of specialist treatments are easily accessible

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[2] IHIS = Intergrated Health Information System
[3] PMU = Project Management Unit

- E-prescriptions and e-appointment – doctors can manage their time and focus more on patient
- Electronic medical guidelines for doctors
- Avoidance of repeating same treatments

Benefits for health institutions (ministry, health insurance fund and public health institutes) will be achieved by:

- Avoidance of repeating same treatments
- Unified coding lists
- Control of expenses and procurement in the health system
- Real time management of drugs prescription and prescription of orthopedic devices
- Real time access patient activities in the system
- Public health efficiency improvement through exact data
- Real time trend following
- Simulation effect of future laws and measures on the health system

3.2. International Requirements

Functional and technological regional and international interoperability of National Health Systems, focused to meet EU eHealth goals in order to serve any requirement for Integrated Health Information System of non-resident during his/her stay in Macedonia

3.3. Functional Specifications

A comprehensive, affordable and efficient web based software for Primary Health Care doctor's offices and Health homes, web based software for hospitals and for registers for public health institutions, offering all the advantages of modern technology and allowing the doctor to provide excellent care for the patients with easy and quick processing of data for all purposes: medical, analytics, insurers..

Complete. HIS software family does support all relevant areas in the health system and consist of: Medicus.Net.IHIS (GPs and specialists), SPP.IHIS (hospitals), E-Prescription.IHIS (Pharmacies), SJ.Org.IHIS (central site, registers, and EPR, HIF and NIHP), Pub. HIS (E-Health Portal) and S.EHR.IHIS.

3.4. Integrated Health Information System - High Level Functional Specifications – Central Information System

The Central Information System contains:

- ***Healthcare information system management***: health insurance management, patient management, electronic health documentation management, extended communications management, health information system reporting management;
- ***Clinical Information System Management:*** service management, data access and protection management, clinical documentation management, health related registers management, communication system, clinical data management, "virtual" electronic health and electronic medical record management;
- ***Administrative and business support***: support preparing and issuing electronic invoices for patients which are paying for services fully or partly by themselves, Global registration management, health insurance database management, personal ID-management, national MKB-10 classification system, drug, pills, orthopaedic supplement list management, list of services and procedures;
- ***Privacy and security management***: fully supports accessing patient records and archives in central EHR/EPR database directly from inside of application user interface, with possibility of instant access to EPR and EHR data including clinical

data and medical documentation (referrals, results, reports etc.) interchange via HDAC.

- ***Technical and technological integration with the:*** Health Insurance Fund and Ministry of Health;

3.5. Integrated Health Information System - High Level Functional Specifications – Client Information System.

The Client Information System contains:

- ***Health Professional***: fully support working with patients, referring patients to other specialist or hospital with automated results/reports/opinions interchange via HDAC central database (EHR) according to predefined rules and information flow management procedures and data normalization standards.
- ***Health and Medical Supporting services***: support drug prescription support, with fully e-Prescription module of operation supported, including automated support for efficient drug selection using medical guidelines, treatment management and chronic diseases routine prescribing support.
- ***Patient oriented services***: Encounter registration and waiting room management, Patient identification, Authentication and administration services, Patient related medical documentation (laboratory, images, other), task list, procedures and memos;
- ***Patient Management:*** General Demographic Patient Data, Health insurance related data, Patient Health Data (Anamnesis, Risk factors, Allergies, Medical treatments, Health Problems, Chronic deceases,), Patient Medical Data, Vaccinations, Administrative document issued, Illnesses;

3.6. Integrated Health Information System - High Level Functional Specifications – Central Services

The Central Services consist of:

- Health and Medical Supporting services: Health documentation management, Clinical documentation management, Decease Related Drugs Recommendations, Drug Retrieval;
- Components of Central Information System: Core Networked Healthcare Repositories4 (Population, Health Insurance, Public Health, Health Financials) along with acting Application Service Providers - ASPs (Primary Healthcare, Public Health, Health Insurance, Health Professional Associations):
- Contextual Portals: Portal for Health Professionals and Public Portal. Portal implementation provides autonomy of professional functionalities and contextually "glue» enables all stakeholders in constant and mutual interactions.

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4 With respective data, process and knowledge interdependencies

4. General Architecture of Macedonian Integrated Health Information System

4.1. Overview

Figure 1. Functional overview of Macedonian Integrated Health Information System

Health Data & Application Center as a central location will functionally have architecture that will be able to fulfill all current requirements as well as to be scalable for future extensions. Figure 1 shows functional architecture of the IHIS

This approach to architecture will enable optimal usage of networking resources according to the level of traffic and security needed.

Centralized architecture will be functionally divided into two groups of servers in order to achieve load balancing, high availability and high reliability in order not to have single point of failure but also there are resources on the central location that are able to take part of the functions of parts that could fail even in cluster work mode.

Therefore GPs and hospitals will have their entry application point on cluster of Enterprise Servers that will act as Application servers and will access relational database on another pair of Enterprise Servers that will be again in cluster.

As seen from Picture 1 and descriptions, the solution is designed for mission critical operations (high availability and high reliability). At the same time hardware and software are completely scalable enabling national level roll-out and future upgrades in hardware and software functionality.

The Portal solution is divided into health professional portal and public portal.

NIHP, central registers and central coding tables will be stored on central clusters that will have Application servers and will access central databases.

Central interfaces will be implemented for data interchange between existing software solutions (primarily HIF information system) and new IHIS solution.

Web based architecture and centralized maintenance ensures outstanding cost effectiveness and low maintenance overhead, both in financial terms and human resources. This architecture also enables quick and easy deployment, at the same time providing the user with a familiar and intuitive user interface – the Web.

4.2. Macedonian Model of Electronic Health Record

Digitally stored health care information about an individual's lifetime with the purpose of supporting continuity of care, education and research, and enduring confidentiality at all times.

- EHR architecture
  - o Capture faithfully the original meaning intended by the author of a record entry or set of entries;
  - o Provide a framework appropriate to the needs of professionals and enterprises to analyze and interpret EHRs on an individual or population basis;
  - o Support the safe and relevant communication of EHR entries between professionals working on different sites, whilst respecting the privacy wishes of individual patients.
- Significant standard attributes and capabilities of EHR
  - o *Medical content:* Patient medical history
  - o *Legal and regulatory compliance:* limit access only to authorized persons
  - o Billing and reimbursement
  - o *Communication and synchronization:* accessed and (if the user is authorized) updated
  - o *Longevity:* not only for the life of the patient, but ideally beyond
- EHR content
  - o Identification component
  - o General data component
  - o Care component
  - o Prevention component

4.3. National Health Smart Card

National health smart card in being deployed for health professionals in the first phase and then it will be deployed to all Macedonian citizens that have health insurance.

Health smart card will have digital signatory as well as a health data. All cards will be the same with the different roles as follows:

- For professional usage - health professional role for secure access to patient data, with security components;
- For citizen's/patient's usage - Insured patient's role which includes: administrative data, medical data and security components.

Acknowledgments

References

[1] COM (2004) 356, e-Health - making healthcare better for European citizens: An action plan for a European e-Health Area, Brussels, 2004-04-30
[2] "Crossing the Quality Chasm: A New Health System for the 21st Century", Institute of Medicine (IOM), 2001, ISBN 0-309-07280-8
[3] S.Fox, Internet Health Resources, Pew Internet and American Life Project, July 2003
[4] eSEEurope Agenda for the Development of the Information Society, Stability Pact for South Eastern Europe, [Online] http://www.stabilitypact.org/e-see/esee.pdf, accessed July 2004
[5] Electronic health records: a guide for clinicians and administrators By Jerome H. Carter
[6] Strategy for the Development of Macedonian Integrated Health Information System.

Computer Based Program for Quality Assessment of Family Medicine Teams based on Accreditation Standards

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Abstract. In order to speed up and simplify the self assessment and external assessment process, provide better overview and access to Accreditation Standards for Family Medicine Teams and better assessment documents archiving, Agency for healthcare quality and accreditation in Federation of Bosnia and Herzegovina (AKAZ) has developed self assessment and externals assessment software for family medicine teams. This article presents the development of standardized software for self and external evaluation of quality of service in family medicine, as well as plans for the future development of this software package.

Keywords. family medicine, accreditation, healthcare quality, software development

1. Introduction

Agency for healthcare quality and accreditation in Federation of Bosnia and Herzegovina (AKAZ) is authorized body in the field of healthcare quality and safety improvement and accreditation of healthcare institutions (1). Besides accreditation standards for hospitals (2) and primary health care centers (3), AKAZ has also developed accreditation standards for family medicine teams (4, 5). In order to speed up and simplify the self assessment and external assessment process, provide better overview and access to accreditation standards and better assessment documents archiving, AKAZ has developed self assessment and externals assessment software for family medicine teams.

2. Structure of accreditation standards

The standards have hierarchical structure comprising of 7 chapters or topics with 35 standards, their 161 criteria (both quantitative and qualitative) and number of sub criteria. Criteria are divided into three groups: basic, advanced and terminal. Similarly, the accreditation status family medicine team can achieve, can be basic, advanced and terminal accreditation. Beside mentioned, each criterion has its own measure components – sub criteria (quantitative or qualitative), thus accreditation standards structure being hierarchical with four levels: 1. Chapter (or topic); 2. Standard; 3. Criterion; 4. Sub criterion/Indicator. Criteria carry certain amount of points which is

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shared among its sub criteria/indicators. Sub criteria/indicators can be independent or interconnected for the purpose of assessment, and also can carry bonus points.

Family medicine team members (doctors and nurses), accreditation process facilitators, external assessors, accreditation board members and AKAZ personnel were identified as potential users. Information needs of each group as well as methods of entering, viewing, using, sharing and storing of those information were also taken into consideration. Based on accreditation standards structure and needs of different potential users, it was concluded that software backbone should be a database containing all accreditation standards, self assessment and external assessment details.

3. Databases for comprising accreditation standards

We decided to create relational database comprising of four tables containing data about chapters (topics), data about each standard, basic data about each criterion and data about individual sub criteria/indicators as well as data about self assessment and external assessment, respectively. Unique identifier (primary key) was designated for every table. For table Chapters it was chapter's number, for table Standards – standard's number, for table Criteria – criterion's number, and for table Sub criteria primary key was automatically generated number. In addition, in tables Standards, Criteria and Sub criteria, foreign keys (fields linked to primary keys of hierarchically higher tables) were designated. Because this was the first version of database, for simple design mechanism and straightforward user interface, we decided to utilize Microsoft® Access 2000. We created three MS Access files: one containing tables with data and relations (relational database), and the other two containing forms, queries and links on tables from the first file. The other two files acted as user interface, one for family medicine team's self assessment, and the other for external assessment. It was planned to provide family medicine teams with a two files – database and self assessment user interface. After the self assessment and before the external assessment, family medicine team would submit the database to AKAZ. Then, the database would be forwarded to the external assessor along with the external assessment user interface. It would enable external assessor to have insight into the self assessment results and to enter the external assessment findings. After the external assessment is done, automatically generated reports are printed and submitted to AKAZ along with the database.

Self assessment user interface is linked to database and contains several SQL queries for accreditation points summing by different levels of criteria, as well as several forms and sub forms for viewing and navigation trough chapters, standards, criteria, sub criteria/indicators, and entering self assessment data.

External assessment user interface is somewhat similar to the one for self assessment, yet more complex. It is linked to the database too, and contains several SQL queries for accreditation points summing by three levels of criteria, as well as several forms and sub forms for displaying and navigation trough chapters, standards, criteria, sub criteria/indicators, and entering data from external assessment. It also automatically generates three types of printable reports on external assessment.

4. Databases indicators assessment

After the development the software was tested during the project of WHO and AKAZ "Quality Improvement and Accreditation Program Based on Accreditation Standards for Family Medicine and Performance Indicators in Two Cantons – Tuzla and Posavina" . The database and the self assessment interface were installed on nine family medicine teams' computers. Members of nine teams (doctors and nurses) were provided with basic

training and support by telephone in case of unclear issues concerning the use of software. During one month all teams have done self assessment according the accreditation standards using the software and submitted their databases to AKAZ. During that period of time none of the users reported any error in the software functioning or any major difficulties in using it. On contrary, majority said that the software has been of great help and had very stimulating effect because they were able to follow their progress during the self assessment in any moment.

After reviewing of self assessments, AKAZ concluded that seven of the nine teams met the conditions for external assessment. Two external assessors were designated to every of the seven teams. External assessors were provided with teams' databases and external assessment user interfaces. External assessment lasted for two days (17th and 18th of November 2008). For the purpose of external assessment external assessors used the software installed on their laptop computers. After completion of assessment they submitted the databases and printed reports to AKAZ. None of the external assessors has reported neither any errors in software functioning nor any difficulties in using it. All fourteen external assessors gave very positive comments on software and stressed the fact that the software has greatly eased their work during the external assessment of family medicine teams.

Data from all gathered databases AKAZ has imported into specially created database for analyzing and archiving. Preliminary results obtained by the analysis suggested that all seven family medicine teams could achieve basic level of accreditation. Rating of family medicine teams based on number of accreditation points was also determined, and all the results were forwarded to the Board which considers assessment reports and gives the final decision on accreditation. Further on, database of all self assessments and external assessments made possible analysis of overall fulfillment of all individual sub criteria/indicators and corresponding remarks given by family medicine teams' members, facilitators and external assessors. Thus, identification of certain difficulties of some sub criteria/indicators fulfillment and need for their revision was made possible.

In meanwhile one limitation of the software was identified – prerequisite that appropriate version of MS Access is installed on user's computer. In some cases that will not be practicable or it will require additional cost for purchase of MS Access application. In order to overcome the identified limitation, AKAZ plans further development utilizing the MS Visual Basic 2008 Express Edition tool for development of user interface linked to existing MS Access database. Software created in this way would eliminate the need for having MS Access installed on user computer. Further on, AKAZ also plans development of web based application which would allow online registration of family medicine teams, their online self assessment, and immediate feedback in the means of benchmarking, i.e. comparison against other family medicine teams. Bringing the spirit of competition into accreditation process, this could, further stimulate teams in their struggle for healthcare quality improvement. On the other hand, AKAZ would have a better and immediate insight in self assessments of teams who entered the accreditation process.

5. Conclusion

During this project we came to conclusion that software for self assessment and external assessment is ideal for accreditation standards distribution, their overview by the family medicine team members, their self assessment and external assessment.

REFERENCES

[1]   Bosna i Hercegovina. Zakon o sistemu poboljšanja kvaliteta, sigurnosti i o akreditaciji u zdravstvu. Službene novine Federacije BiH 59/05.

[2]   Ridanovic Z, et al. Akreditacijski standardi za bolnice. Sarajevo: Avicena; 2005.

[3]   Ridanovic Z, Nakas B, Cepo M, et al. Akreditacijski standardi za dom zdravlja. Sarajevo: Avicena; 2005. p. 17-177.

[4]   Ridanovic Z, Nakas B, Ceric K, et al. Akreditacijski standardi za timove porodicne/obiteljske medicine. Sarajevo: Avicena; 2005. p. 15-44.

[5]   Ridanovic Z, Akreditacijski standardi za timove porodicne/ obiteljske medicine. Sarajevo: AKAZ; 2008.

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Improving Quality of Medical Care Using an Integrated Healthcare Information System

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Abstract. The research objectives are to analyze the requirements of an integrated informatical healthcare system and develop new means to improve the quality of healthcare at a national level. As we've all seen, Internet technology has become a dominant factor in business, academia, and healthcare, therefore the software architecture, design patterns and framework has been built for the complexities and challenges of the Web. Our model of IT Infrastructure is an independent integrated medical information system implementing a unique patient healthcare record in the setting of GPs, specialists and hospital healthcare system in Romania, built on a central database with a secure online interface. Setting: over 700 Romanian Healthcare Providers are using our model implemented in ICMed. Population: data was available for over 1000000 patients as of 2009. Requirements for an integrated healthcare IT system were analysed from the perspective of recent trends in IT technology and healthcare, European legislation, pharmaceutical industry, research developments and Romanian e-health policies. Recent trends emphasise two major directions: 1.) Quality management including assisted medical decision, error-proofing mechanisms, pharmacovigilance and adverse events handling and, 2.) Patient-physician shared electronic health records at a national and international level. Requirements for these features include a centralized health record integrating all medical data, methods to safeguard data security and confidentiality and flexible user interfaces to improve acceptance and reduce errors in a complex system. E-source is another development particularly useful for the pharmaceutical industry.

Keywords. Patient Healthcare Record, Quality Management, Web

1. Introduction

The structure of modern healthcare systems involves integrating a variety of healthcare providers, starting with GPs and continuing with specialists in the outpatient setting and hospital inpatient setting as well as laboratory and pharmacy units. Our mission is to remove one obstacle - the high cost and complexity of clinical information software and IT Infrastructure. By leveraging the global resource network of healthcare institutions, universities, vendors and individuals, we design and build a high quality medical informatics system for GPs and Clinics seeking a low cost solution.

Quality management in medical healthcare is a complex task. Medical errors occur frequently and can cause substantial morbidity, mortality and costs [1,2]. Preventing these errors necessitates some challenging activities, insofar as even measuring adverse events is faced with difficulty [3,4]. Incomplete medical records, workload and time

limitations, complex medical tasks, poor user interfaces and many other factors contribute to this high rate of medical errors.

The gateway to a patient's medical record is centred on the general practitioner. Shortcomings in the healthcare stem therefore often directly or indirectly from limitation in the primary health setting. Previous studies have shown a significant variation in physician performance, poor performance being associated with advanced age [5,6], level of clinical experience [7], availability of continuous medical education and numerous other factors. General strategies have been proposed to improve the quality of medical care [8], including various campaigns by the Institute of Healthcare Improvement [9], The Six Sigma Way [10], Evidence Based Medicine-specific methods and a continuous medical education.

Measuring outcomes is one of the most important aspects during any quality assessment. The NHS compiled a set of outcome measures to guide the reimbursement of General Practitioners in the UK and to foster the development of high quality primary medical care. [11]

Analysing outcomes in the primary healthcare is however hampered by the low mortality in this setting, the long time spans that need to be followed, and the very heterogeneous population of patients and diseases. As a consequence, a medical informatics system capturing all the relevant information over lengthy periods of time offers a clear advantage over peer reviews and auditing strategies.

ICmed is a healthcare IT system that integrates all major medical players using a unique patient record. It was developed initially around primary healthcare providers and was later extended towards outpatient specialty and inpatient hospital care, as well as integration with local medical laboratories and pharmacies.

The objective of this study was to analyse future trends in the development of medical information systems and use this knowledge to improve our model of medical IT framework. Further, we analysed the usage pattern of the model in primary healthcare setting in order to verify the adequacy of this IT system in monitoring physicians' performance in the primary healthcare setting.

2. Materials and Methods

Two authors searched the medical literature and the medical legislation in various European countries and the US for recent advances and developments in the medical field. This study was centred on corroborating these requirements with actual medical data collected from healthcare providers using our model of integrated healthcare IT system and with technical challenges posed by these requirements.

Initially, the model was centred on primary healthcare, being later extended to cover both outpatient specialty and inpatient care. This framework is widely used by healthcare providers in Romania.

Standardized data is collected using a secure web interface and stored in a central relational database hosted by a national data centre. The system fulfils the Romanian legal requirements for data safety and privacy. Healthcare Providers using this system have granted access to the collected data for anonymous usage statistics.

The online version of ICmed using a centralized database became operational in 2007. Prior data was stored locally and was not used in this analysis. For the purpose of this analysis we used data collected up to February 2009, as well as more detailed data from an older snapshot of the database from 2008. The latter comprised only data within the primary healthcare setting, a detailed analysis presented elsewhere [12]. There was a steady database growth during the last 3 months of roughly 20% per month, equivalent to an average rate of 100000 subjects per month.

Study population: The examined population comprised more than 1000000 people entered into the database as of early February 2009. We analysed during a previous

study the ICMed usage patterns in the primary health setting during the December 2007 – October 2008 time frame on a sample of 476,761 subjects out of a population of slightly above 500000. Relevant demographic data was extracted from this database and was further analysed as shown below.

Setting: A number of 745 healthcare providers were actively using the database in February 2009 in contrast to 359 primary healthcare providers at the beginning of November 2008.

Definitions: A patient was defined as a person having at least one medical contact with the primary healthcare system during the study period.

Demographics: The population served by the model was largely comprised of people living in urban areas (87%), compared to 8% in rural areas. Data was missing for 5% of the sample, most likely representing rural areas. There was a slight female preponderance (53% vs. 47%) (see Tables 1 and 2).

Table 1. Demographic data of the whole population and of the subgroup of persons who had an encounter with the primary healthcare system (patients).

	Total	**Patients**	**p**
Gender			< 2E-16
M	47 %	42 %	
F	53 %	58 %	
Location			< 2E-16
Urban	87 %	87 %	
Rural	8 %	13 %	
NA	5 %	0 %	
County			< 2E-16
Timis	35 %	73 %	
Arad	18 %	17 %	
Other	47 %	10 %	
Total	476,761	100,029	

Table 2. Number of patient records per month and per physician.

	Total	**Sep.**	**Oct.**	**Increase**
Median	472	238	342	42%
95 %	3.300	700	773	10 %
Max	4.848	972	1.112	14 %
Total	261.435	47.744	66.306	39%

Timis County (35%) and Arad County (18%) were best represented in the initial sample, with slightly lower prevalence during the second period (see Table 3).

Table 3. Patient characteristics. Patient distribution split over counties.

County	Aug.	Sep.	Oct.	Total (thousand)
Timis	23.3	31.0	37.2	190.0
Arad	6.7	11.1	18.0	44.0
Other	3.7	5.9	11.7	28.5
Total	33.8	47.7	66.3	261.4
Number of visits per patient				
Median	1	1	1	2
95 %	2	2	2	7
Max	16	13	13	53

The remaining 47% of people entered in this database are living in one of the 39 remaining Romanian counties. This IT Framework covers 28% of the general population in Timis County and 25% of the Arad County population. There were only minimal differences between the 2 time frames, with a slightly greater proportion of subjects living outside Timis County in the February 2009 sample.

3. Results

Technological trends: We identified a number of major medical technological trends during our research. One major area of development involves quality management, which can be further subdivided into a number of overlapping fields:

- Assisted medical decision;
- Error-proofing mechanisms;
- Pharmacovigilance and adverse events;
- And other features related to quality management.

And a second major area of development involves sharing medical data between healthcare providers and between the patient and the clinician using shared electronic health records. We will discuss both trends separately; nonetheless, there is a degree of overlap between these two trends.

Improving healthcare quality: Medical professionals repetitively request identical information during each patient visit to a different healthcare provider. This repetitive data is likely to be incomplete and to contain various errors.

A unique patient record offers major advantages in this area, because every healthcare provider operates on the same set of data and is able to refine this set of data in time, therefore maintaining a high quality patient record.

Similarly, health professionals are less likely to spend large amounts of time on eliciting missing information, focusing instead on active problems and tasks.

In order to maintain a single instance of a complete patient healthcare record, all healthcare providers have to work using a single record for a given patient. Our model was implemented using a central database, therefore maintaining a unique patient healthcare record for any given patient.

The second advantage of the online interface stems from the great flexibility of the web-layout (see Figure 1). Graphical user interfaces can be created using ergonomic principles and addressing usability concerns, including methods to integrate medical reasoning pathways. This last issue provides important advanced error-proofing mechanisms [12].

Figure 1. ICMed Graphical User Interface using modern web technologies.

Having a complete patient record, with all underlying diseases and medical interventions greatly expands the possibilities to recognise adverse events, drug interactions, contraindications and provide a sound way to pharmacovigilance.

Sharing medical information: The online design using a centralized database allows full sharing of every aspect of the medical information between healthcare professionals. Extending this feature to patient-physician shared health records is feasible, though major obstacles remain pertaining to authentication and rights management. Romanian legislation is either missing or ambiguous in this respect.

As a last analysed trend; although eSource plays only a niche role, being largely confined to the pharmaceutical industry, it offers great potential for the future. The fine granularity in the ICMed database, combined with a standardized terminology and sensible default values, make our model's data very interesting for clinical studies.

4. Discussion

A unique, central patient healthcare record offers major advantages. However, a number of technical limitations have to be overcome: maintaining the confidentiality and the security of the medical data is the most important issue. This IT Framework uses a secured online interface, an authentication being requested from each medical professional. Although this issue is technically solvable, a more fundamental concern arises from unauthorized request of patient data for patient not attending a particular healthcare provider. Limiting access to patient data for only those patients that actually did attend the healthcare provider is a challenge for any system implementing health data exchange and is therefore not limited to the online database architecture.

The usage of standardized coding systems (ATC, ICD10), allows advanced methods of pharmacovigilance. Although WHO-DRL (MEDRA) and SNOMED add a more detailed description of drugs and medical terms, they are not free to use, and there are no Romanian translations of these systems. Our model already implements a detailed drugs database covering every single drug registered in Romania, putting therefore advanced analysis possibilities into this framework.

5. Conclusions

Our model offers a flexible framework to integrate all healthcare providers using a centralized database with online access. This architecture offers completely new opportunities in quality management. Extending this model into additional areas necessitates addressing further issues, including continuous security improvements and advances in the pertinent legislation.

References

[1] J.M. Aranaz-Andres, C. Aibar-Remon, J. Vitaller-Murillo, P. Ruiz-Lopez, R. Limon-Ramirez, E. Terol-Garcia, the ENEAS work group, Incidence of adverse events related to healthcare in Spain: results of the Spanish National Study of Adverse Events. J. Epidemiol. Community Health 62 (2008), 1022-1029.

[2] S.N. Weingart, R.M. Wilson, R.W. Gibberd, B. Harrison, Epidemiology of medical error, BMJ 320 (2000), 774-777.

[3] P. Michel, J.L. Quenon, A.M de Sarasqueta, O Scemama, Comparison of 3 methods for estimating rates of adverse events and rates of preventable adverse events in acute care hospitals, BMJ 328 (2004), 199.

[4] R.A. Hayward, T.P. Hofer, Estimating hospital deaths due to medical errors: preventability is in the eye of the reviewer, JAMA 286 (2001), 415-420.

[5] R. McAuley, W. Paul, G. Morrison, et al., Five-year results of the peer assessment program of the College of Physicians and Surgeons of Ontario, CMAJ 143 (1990), 1193-1199.

[6] A. Charles, H. Britt, L. Valenti, The independent effect of age of general practitioner on clinical practice, MJA 185 (2) (2006), 105-109.

[7] N.K. Choudhry, R.H. Fletcher, S.B. Soumerai, Systematic review: the relationship between clinical experience and quality of healthcare, Ann Intern Med 142 (2005), 260-273.

[8] T. Bodenheimer, The American Healthcare System. The Movement for Improved Quality in Healthcare, New Eng J Med 340 (1999), 488-492.

[9] J.L. Reinertsen, M. Bisognano, M.D. Pugh, Seven Leadership Leverage Points for Organization-Level Improvement in Healthcare (Second Edition), Massachusetts: Institute for Healthcare Improvement, Cambridge, 2008 (Available on www.ihi.org).

[10] J.O. Westgard, Six Sigma Quality Design and Control (Second Edition). Westgard QC, Inc, 2006.

[11] NHS Employers and the General Practitioners Committee, Quality and Outcomes Framework guidance for GMS contract 2008/09. Delivering investment in general practice, 2008.

[12] N.G. Leveson, System Safety Engineering: Back To The Future, available online from http://sunnyday.mit.edu/book2.pdf .

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Exploring the Adoption of Technology Driven Services in the Health Care Industry

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Abstract: Users of health information systems cannot benefit from them in a full capacity unless they can use them comfortably. Behavior of these adopters is influenced by various factors related to technology characteristics, user characteristics, social environment and organizational environment in the adoption process. This paper explores determinants of Health Information Service adoption among users and analyzes relationship of these determinants with the behavior of the user.

1. Introduction

With the rapid development of telecommunication systems, intelligent monitoring and control systems have become the major application areas of telemedicine. Such applications include 'Smart homes' for telecare by means of movement detectors, oxymeters, tensiometers and various other devices [1], a ring-sensor that monitors patient's blood oxygen saturation [2] and a web based electrocardiogram monitoring application facilitating collection, analysis and storage of patient data [3]. Many different devices and techniques are used to collect more accurate patient information. A spoken dialogue system was designed by Giorgino et al [4] to test the reliability of a speech recognition system. Finally, compared to traditional patient care, telemedicine systems provide many benefits to the physicians and patients. Brink et al [5] found electronic health information and monitoring systems help physicians in early detection of occurring head and neck cancer problems. Telemedicine systems are reported to reduce number of clinic visits significantly [6].

Effort expectancy defined as "the degree of ease associated with the use of the system" [7] is one of the factors related to service characteristics. The more users think that the service is complex to use, the slower their adoption is. Also, compatibility , which is defined as "the degree to which an innovation is perceived as being consistent with the existing practices, values, needs and experiences of the health care professional" influences acceptance of information and communication technologies in the case of occupational therapists [8]. Besides, availability, quality and value of the information provided by the service are other important characteristics [9]. In addition, some of the adoption factors are related to individual characteristics. Chen et al [10] studied user specific characteristics such as age, educational level, and job experience to explore the intention of nurses towards web-based learning. Also, user satisfaction which is defined as "the overall evaluation of a user's experience in using the system and the

potential impact of the system", significantly influences adoption process [11]. Moreover, users' intrinsic motivation about adoption and perceptions about ease of use are influenced by satisfaction of user with medical care [12]. Apart from service and users, adoption is influenced by the organizational, environmental or external characteristics as well. Rewarding and financial incentives were found to accelerate adoption of computerized physician order entry with clinical decision support systems [13].

2. Research Methodology

Prior to the study, a health information service prototype was developed for patients and their health care providers. The service was designed to

- Collect patient data via various devices like stethoscope, treadmill, bascule, mobile phone
- Support collecting patient information and transmitting to the health care providers
- Facilitate the early detection of health problems by means of monitoring patient data

Qualitative research method was applied in the study in order to analyze the topic and to take advantage of interviewees' creative ideas and experiences. Semi structured open-ended questions were asked to the potential users, physicians and nurses. A home based telemonitoring service was designed for obesity and diabetic patients. The service mainly consisted of;

- Hypothetical devices that were capable of sending data via bluetooth technology
- Prototype of the patients' application developed for mobile devices to collect information about patient.
- Prototype of the physicians' application developed for mobile devices to get patient information.
- Prototype of the PC application installed in the desktop computer of the physicians to monitor patient status
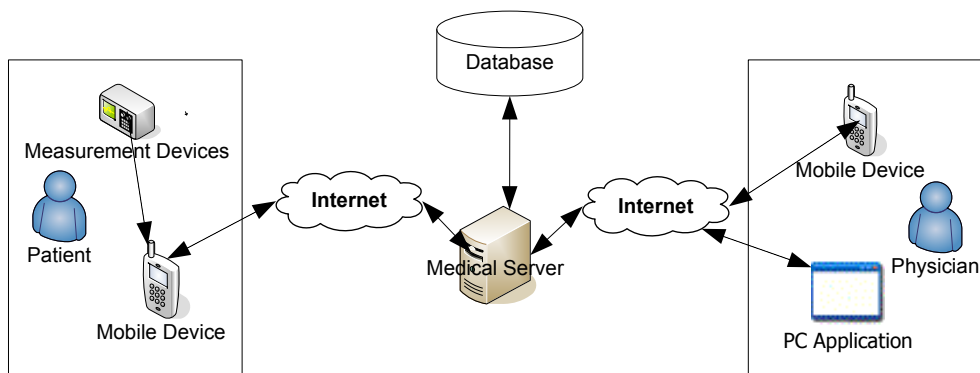- A medical server in order to store and manage patient data collected from various sources

Figure 1. Proposed Service

The proposed system also has reminder services for both patients and physicians. If the patient takes medicine at regular times, the service warns him/her when medicine time comes. Also, if the patient does not enter any information at a specific time period,

the service warns him/her to enter. Moreover, physicians can define reminders based on specific patient data.

3. Results

3.1. Service Characteristics

Service characteristics should match with the user needs and requirements for better performance and effortless adoption [14].

Content - Potential users attempt to use services that meet their needs and requirements. So, required information content differs based on doctors' area of specialization and patients' disease types in the case of health information services. As an example, general surgery doctors need cardio information and diabetic patients show concern for blood glucose level. Users think that appropriate, comprehensive and quality content improve the usefulness of the service. Relationship between content quality and usefulness is also supported in the literature [15].

Cost - One of the major predictors of behavior intention to use an IS system is the perceived cost [16]. Tung et al [17] defined cost as the monetary expense for using the electronic information system. It negatively affects the adoption of the service. Based on the participants' comments, it can be said that the more costly the service, the less people prefer to use it. So, the findings about the cost were parallel with the literature [17].

Sound Quality –The sound used in the mobile device to communicate with the patient/physician was mechanical male voice. Most of the participants disliked the voice and they proposed to use a voice like a human one. So, participants are more comfortable with a non-mechanical female voice in the conversation with mobile device.

Security – There is no doubt that security affects the adoption of IT services [18]. Security is the condition of protecting user specific data against others.

Mobility - Users can benefit from a mobile service anywhere at any time. According to Kleinrock [19], two of the well-known dimensions of mobility are time and place independence. What participants said about the mobility also supports these findings. Especially, doctors pay more attention to the mobility characteristics of the service in the adoption process because they can reach patient data even if they were outside of the hospital. Mobility affects usefulness of the service in a positive way. So, mobile applications were found more useful by the potential users because users can use these applications whenever they need.

Time Factor - Time factor is a person's belief about the expense of time while interacting with the service and response time of the service about patient status. If entering data to the service takes up long time, users prefer seeing the doctor instead of using the service. Biermann et al [20] also found that 30% of the patients prefer entering extra data to a system if it is not time-consuming. Participants emphasized that time expense is a significant factor that affects adoption of users. So, designers should develop services that do not require much usage time. Users do not prefer to spend much time while using the service.

3.2. User Characteristics

Health Status – in some health conditions, like chronic illness, patients need more health care than normal conditions. Although Wilson and Lankton [12] did not find strong relationship between patients' health care need and intention to use provider-delivered e-health, participants in the study prefer to use e-health service if they catch a disease.

Age - Behavior of the user toward a computer usage is also influenced by the age of the user [21]. Chen et al [10] studied age as a determinant of intention of nurses toward web based learning. Others examined age as a moderator variable in the technology adoption context [22, 7]. In the study, it was found that both potential users and doctors considered age as a factor that affects effortless use of the service. It is a general belief that aged people would have difficulties while adopting or using a technological device.

Users' Time Constraint – Participants think that people who do not have enough time to visit a doctor may prefer to use the service. So, in addition to service related time factors like quick data entry and rapid response, users' time limitations also affects attitude of users toward using health services.

3.3 Intermediary Characteristics

Usefulness - Usefulness is the key determinant of attitude in the technology acceptance research field. Davis [23] defined usefulness as "the degree to which a person believes that using a particular system would enhance his or her job performance." and found that usefulness is the strongest predictor of behavioral intention. Many researches support Davis' findings about usefulness [24, 7]. Venkatesh et al [7] called usefulness as performance expectancy and defined it as "the degree to which an individual believes that using the system will help him or her to attain gains in job performance". There were many comments about usefulness of the service. So, it can be said that health information service users pay great attention to how the service would improve their job performance. These findings are in parallel with the previous research findings [23, 24, 7].

Ease of Use - Perceived ease of use (EoU) defined as "the degree to which a person believes that using a particular system would be free of effort" is one of the core constructs in TAM [23]. Significant effect of EoU on behavior intention was also confirmed by many other researches [24, 25]. Moreover, comments of potential users about the EoU supported these findings.

3.4. Social Influence

Social influence contains three main constructs: subjective norms defined as "The person's perception that most people who are important to him think he should or should not perform the behavior in question [26]", social factors which is "The individual's internalization of the reference group's subjective culture, and specific interpersonal agreements that the individual has made with others, in specific social situations [27]" and image defined like "The degree to which use of an innovation is perceived to enhance one's image or status in one's social system." [7, 28].

3.5. Facilitating Conditions

User Guidance - In the previous studies facilitating conditions were found significant when they were examined with intermediary variables like age or experience. For example, it was found that they only matter for older users [7]. However, in the research participants did not mention about the age or other variables while talking about the facilitating conditions. They indicated that all of the users need some help to use the service.

4. Conclusions

This article contends that health information service adoption decisions of users are influenced by service characteristics like cost, content, sound quality, security, mobility, and time factor; user characteristics namely health status, age and users' time constraint; social factors and facilitating conditions like user guidance. In line with previous technology adoption studies, usefulness and ease of use are found two significant determinants of user behavior.

References

[1] Rialle V., Lamy JB, Noury N, and Bajolle L. Telemonitoring of patients at home: a software agent approach. Computer Methods and Programs in Biomedicine 2003: 72: 257-268.

[2] Yang BH, and Rhee S. Development of the ring sensor for healthcare automation. Robotics and Autonomous Systems 2000: 30: 273-281.

[3] Magrabi F, Lovell NH, and Celle BG. A web-based approach for electrocardiogram monitoring in the home. International Journal of Medical Informatics 1999: 54: 145–153.

[4] Giorgino T, Azzini I, Rognonia C, Quaglinia S, Stefanelli M, Gretter R, and Falavigna D. Automated spoken dialogue system for hypertensive patient home management. International Journal of Medical Informatics 2005: 74: 159-167.

[5] Brink JL, Moorman PW, Boer MF, Pruyn JFA, Verwoerd CDA, and Bemmel JH. Involving the patient: A prospective study on use, appreciation and effectiveness of an information system in head and neck cancer care. International Journal of Medical Informatics 2005: 74: 839-849.

[6] Chae YM, Lee JH, Ho SH, Kim HJ, Jun KH, and Won, J.U. Patient satisfaction with telemedicine in home health services for the elderly. International Journal of Medical Informatics 2001: 61:167–173.

[7] Venkatesh V, Morris MG, Davis GB, and Davis FD. User acceptance of information technology: toward a unified view. MIS Quarterly 2003: 27 (3): 425–478.

[8] Schaper LK, and Pervan GP. ICT and OTs: A model of information and communication technology acceptance and utilization by occupational therapists. International Journal of Medical Informatics 2003: 71: 103–115.

[9] Aubert BA, and Hamel G. Adoption of smart cards in the medical sector: the Canadian experience. Social Science & Medicine 2001: 53: 879–894.

[10] Chen IJ, Yang KF, Tang FI, Huang CH, and Yu S. Applying the technology acceptance model to explore public health nurses' intentions towards web-based learning: A cross-sectional questionnaire survey. International Journal of Nursing Studies 2008: 45 (6): 869-878.

[11] Yusof M.M., Kuljis J., Papazafeiropoulou A., & Stergioulas L.K., 2008. An evaluation framework for Health Information Systems: human, organization and technology-fit factors (HOT-fit). International Journal of Medical Informatics, 77, pp.386-398.

[12] Wilson EV, and Lankton NK. Modeling patients' acceptance of provider-delivered e-health. Journal of the American Medical Informatics Association 2004: [11(4): 241-248.

[13] Simon JS, Rundall TG, and Shortell SM. Adoption of Order Entry with Decision Support for Chronic Care by Physician Organizations. Journal of the American Medical Informatics Association 2007: 14: 432– 439.

[14] Goodhue DL. Understanding user evaluations of information systems. Management Science 1995: 41: 1827-1844.

[15] Ozen Ç, and Basoglu N. Impact of man-machine interaction factors on enterprise resource planning (ERP) software design. Proceedings of Portland International Conference for Management of Engineering and Technology'06 2006: 2335-2341.

[16] Mathieson K, Peacock E, and Chin WW. Extending the technology acceptance model: the influence of perceived user resources. The DATA BASE for Advances in Information Systems 2001: 32 (3): 86-112.

[17] Tung FC, Chang SC, and Chou CM. An extension of trust and TAM model with IDT in the adoption of the electronic logistics information system in HIS in the medical industry. International Journal of Medical Informatics 2008: 77: 324-335.

[18] [18] Cheng TCE, Lam DYC, and Yeung ACL. Adoption of internet banking: an empirical study in Hong Kong. Decision Support Systems 2006: 42: 1558–1572.

[19] [19] Kleinrock L. Nomadicity: anytime, anywhere in a disconnected world, Mobile Networks and Applications. Mobile Networks and Applications 1996: 1 (4): 351-357.

[20] [20] Biermann E, Dietrich W, Rihl J, and Standl E. Are there time and cost savings by using telemanagement for patients on intensified insulin therapy: A randomised, controlled trial. Computer Methods and Programs in Biomedicine 2002: 69: 137–146.

[21] Liu JE, Pothiban L, Lu Z, and Khamphonsiri T. Computer knowledge, attitudes, and skills of nurses in People's Hospital of Beijing Medical University. Computers in Nursing 2000: 18 (4): 197–206.

[22] Chau PYK, and Hu PJH. Investigating healthcare professionals' decisions to accept telemedicine technology: an empirical test of competing theories. Information & Management 2002: 39: 297–311.

[23] Davis FD. Perceived Usefulness, Perceived Ease of Use, and User Acceptance of Information Technology. MIS Quarterly 1989: 13 (3): 319-339.

[24] Taylor S, and Todd P. Assessing IT Usage: The Role of Prior Experience. MIS Quarterly 1995: 19 (4): 561-570.

[25] Venkatesh V, and Davis FD. A Theoretical Extension of the Technology Acceptance Model: Four Longitudinal Field Studies. Management Science 2000: 45 (2): 186-204.

[26] Ajzen I. The Theory of Planned Behavior. Organizational Behavior and Human Decision Processes 1991:50 (2): 179-211.

[27] Thompson RL, Higgins CA, and Howell JM. Personal Computing: Toward a Conceptual Model of Utilization. MIS Quarterly 1991: 15 (1): 124-143.

[28] Moore GC, and Benbasat I. Development of an Instrument to Measure the Perceptions of Adopting an Information Technology Innovation. Information Systems Research 1991: 2 (3): 192-222.

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Tele-Education As Method Of Medical Education

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Abstract. Development of computer networks and introduction and application of new technologies in all aspects of human activity needs to be followed by universities in their transformation on how to approach scientific, research, and education teaching curricula. Development and increased use of distance learning (DL) over the past decade have clearly shown the potential and efficiency of information technology applied in education. Use of information technology in medical education is where medical informatics takes its place as important scientific discipline which ensures benefit from IT in teaching and learning process involved. Definition of telemedicine as „use of technologies based on health care delivered on distance" covers areas such as electronic health, tele-health (eHealth), telematics, but also tele-education. Web based medical education today is offered in different forms, from online lectures, online exams, web based continuous education programs, use of electronic libraries, online medical and scientific databases etc. Our Department of Medical Informatics has taken many steps to introduce distance learning in medical curricula, from organizing professional-scientific events (congresses, workshop etc), organizing first tele-exam at the faculty and among first at the university, to offering on line lectures and online education material at the Department's website (www. unsamedinfo.org). Distance learning in medical education, as well telemedicine, significantly influence health care in general and are shaping the future model of medical practice. Basic computer and networks skills must be a part of all future medical curricula. The impact of technical equipment on patient-doctor relation-ship must be taken into account, and doctors have to be trained and prepared for diagnosing on consulting patients by use of IT. Telemedicine requires special approach in certain medical fields – tele-consultation should be introduced to the curricula, tele-surgery, tele-radiology etc. Telemedicine and distance learning are best suited for medical education and doctor-to-doctor consultation, the first contact between doctor and a patient should stay face-to-face when possible. In this paper, we present the results of the project Introduction and Implementation of Distance learning at the Medical Faculty of University of Sarajevo and compare it with the following expected outcomes: development and integration of information technology in medical education; creation of flexible infrastructure to enable access to e-learning to all students and teaching staff; improvement of digital literacy of academic population; ensuring high educational standards to students and teaching staff; helping medical staff to develop „life-long learning" approach in work ane education.

Keywords. medical education, distance learning, medical informatics, e-learning.

1. Distance learning - definition and description

Distance learning is conventionally defined as: any educational or learning process or system in which the teacher and instructor are separated geographically or in time from his or her students; or in which students are separated from other students or educational

resources (1,2,3). The most important factor which influences the changes occurring in education has been the installation and development of the Internet and electronic multimedia techniques. Distance learning does not preclude traditional learning processes; frequently it is used in conjunction with in-person classroom or professional training procedures and practices.

Pedagogical and organizational improvements have fundamental importance. It is in use both interaction teacher-student and interaction student-student. Phases of synchronized and synchronized learning are combined. Individual and group works are also combined. If all these forms are involved in educational process, they mutually supplement each other, as a last resort. Traditional education as well as contemporary education is supported by informatics technologies in unique system of flexible education. In order to use advantages of flexible education, it is necessary to combine different forms of learning, during the preparation phase and development of every educational course in appropriate way.

Distance learning is not simply a set infrastructure, but rather a concept of learning that incorporates different technologies and learning media. Within the province, different video, audio and computer tele-conferencing systems, along with Computer Based Training, Computer Managed Instructional systems and other media are being integrated technologically, instructionally and organizationally. The tele-education concept crosses all jurisdictions among institutions both within and outside the province, public and private, at any level of education, to anywhere including institutions, workplaces and the home. Tele-education, tele-teaching, tele-training, tele-mentoring, and tele-accreditation have been clearly demonstrated and are now common practice.

2. Advantages and disadvantages of distance learning

Distance learning compared to traditional way of learning had many its advantages as well as disadvantages. Some of the main advantages of distance learning are:
- the economical factor,
- student has 24 hour access to needed information,
- he/she is given the opportunity to learn the subject in his/hers own time and speed,
- he/she can access learning material independently of place or time,
- he/she is given the opportunity to learn how to work independently,
- using e-mail or chat rooms he/she is able to contact professor or his/hers assistant if there are any questions or confusions regarding lectures; etc. (2,3).
- Fundamental advantages of flexible education in terms of classical education are:
- more efficiency;
- increase capacities of educational institutions;
- education can be easily adopted to the needs of education on-the-job;
- costs of educational process are smaller;
- it is possible to distribute the education uniformly, thus the new educational programs are available for fields outside of educational and economic centers;
- it enables the possibility of access to the foreign educational resources to the various institutions;
- superior quality of the knowledge gained.

Many critics consider that using e-mail or chat rooms to obtain contact with the professor is actually the main disadvantage of this system of learning. Question arises whether this way of professor-student communication is helpful to students because face-to-face contact is missing as well as the opportunity of student-professor relationship building.

3. Distance learning in medical curriculum at Medical Faculty, University of Sarajevo

In October 2003, University of Sarajevo began with Distance learning education, opening University Distance Learning Centre. Opening the University Distance Learning Centre, as coordination body and leader in all activities in connection to Distance learning, has provided opportunity for development and growth of this kind of lifelong education.

In relation to above project conducted by the University Tele-information Centre (UTIC) and as continuation of two-year project Possibilities of introduction of Distance learning in Medical curriculum, the Cantonal Ministry approved and supported a new project; Introduction and implementation of Distance learning in medicine. Platform for the course of distance learning is achieved in collaboration with UTIC. University Tele-information Centre, established as part of University of Sarajevo and first ISP in B&H in 1996 (UTIC). It is scientific-organizational unit of the University of Sarajevo for improvement of scientific-research work and through UTIC members of the University can be gathered in the unique computer-communication structure. Objectives of UTIC are:

- to connect members of the University of Sarajevo with similar institution in the country and abroad due to more efficient use of scientific, research and educational resources,
- use of educational data bases and other information for the needs of the University and its members,
- development and integration of informatics computer technologies in education,
- creation of flexible infrastructure which will enable e-Learning to be accessible to all students and University staff,
- improvement of general digital literacy of academic population,
- development of top quality educational content which could be integrated in the actual European processes of e-Learning revolution.

With their help centre for distance learning, "LUCIS CENTRUM", is created (Figure 1). We hope that this is just a beginning step towards improvements of the B&H education system and that this project will serve as an indicator towards that future.
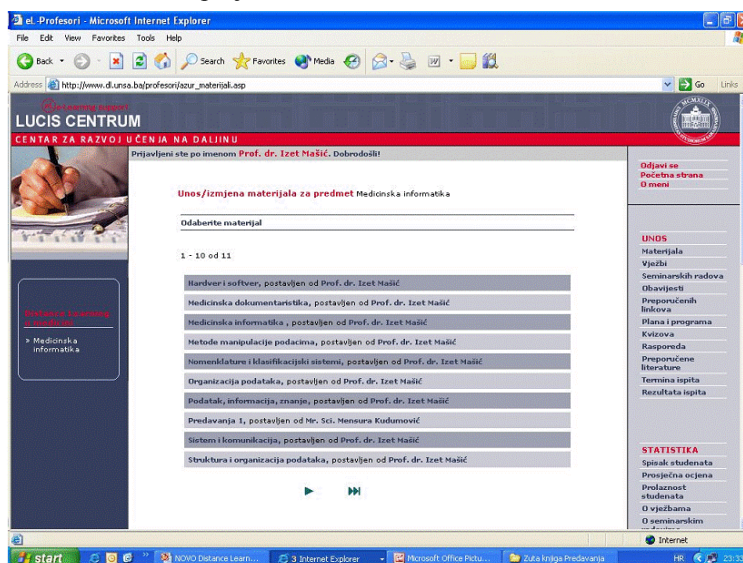

Figure 1. Uploaded materials for subject Medical Informatics at the web page of Lucis Centrum of University of Sarajevo.

On UTIC web site, seven students enrolled from Medical faculty, for the subject Medical Informatics are able to learn from the distance location. So far, teaching staff uploaded eleven lectures at the web site:

1. Hardware and software,
2. Medical documentations,
3. Medical informatics,
4. Methods of data manipulation,
5. Nomenclatures and classification systems,
6. Data organization,
7. Data, information and knowledge,
8. Lectures 1,
9. System and communication,
10. Structure and data organization, and
11. Expert systems.

Beside the materials it is possible to upload and download the following:

1. practical works,
2. seminar work,
3. information,
4. recommended links,
5. plan and programs,
6. quiz,
7. schedule,
8. recommended readings,
9. examination schedule, and
10. examination results.

Basically software application has two interfaces: teacher and student interface. Access from any of these is very simple and fast (1,2,3).

4. Education content of distance learning

Lecture contents will be presented in our virtual classroom. In our case, learning material from the subject of medical informatics, and later, hopefully from other medical subjects, will be available on web site, www.e-learning.ba (Figure 2).

In this "classroom," learning materials, power point lecture presentations as well as practice exercises with step-by-step instructions, are easily accessible to students. Moreover, on this web site, students will be able to find subject relating literature as well as English version of the presentations. To access this information requires only one click on a download option as well as one second patience depending on student's internet speed connection. In short, our virtual classroom gives students the opportunity to access needed information, at any time, and in any place without having to be bound to the classroom.

Figure 2. Content of Medical Informatics page at at the web page of Lucis Centrum of University of Sarajevo.

Using these simple navigations, maximal efficiency and fast access to needed material is possible.

As we can see on the Figure 3, all links are in chronological order according to the plan and program of the lecture as well as practice (materials, practical works, seminar work, information, recommended links, plan and programs, quiz, schedule, recommended readings, registration to examination, and examination results).

Special attention is given to the link "kvizovi" (quiz). In order for the student to check his/hers progress (to test his/hers knowledge of the lecture he/she studied), every lecture is followed by quizzes. Quiz questions are multiple choice questions and they are based on the lecture content. After every quiz, student receives "feedback" regarding his/hers progress. Results are given in terms percentages (one needs 51% right answers to pass the quiz). On this way student has absolutely control over his/her work.

5. Our experiences of Advantages and disadvantages of distance learning in medical education process

In many universities across B&H students' contact with professors are almost impossible (unless one needs to orally take the exam), due to many professors other jobs or responsibilities; students are mainly able to communicate with professor's assistants. Moreover, thru traditional way of teaching, during the lectures, students from their professors obtain mostly the information which they can find in the literature or on the internet. Rarely, there is student-professor interaction or lecture discussion during the class. From this one can conclude that an ambitious student using tele-education will experience minimum lose.

We live in "Age of Information". These technologies are changing the way we perceive the world, how we think and communicate with another. Established cultures are being transformed and new cultures are forming. New virtual environment affects the way we build our sense of who we are. Some characteristics of the Internet with which are people in B&H know a little are:

- large volume of users and potential users,
- lack of physical boundaries which allows for the manipulation of time and space,
- information can be accessed in a concurrent fashion using different media,
- concept of redundancy.

In the virtual environment we are applying for information in a way that is expanding our senses and one must to take into account that experience is occurring in the context of the virtual environment. Information without a context has no meaning.

The greatest progress was made in the area of tele-education and distance learning in B&H. Distance learning does not preclude traditional learning processes; frequently it is used in conjunction with in-person classroom or professional training procedures and practices. Distance learning is used for self-education, tests, services and for the examinations in medicine, i.e. in terms of self-education and individual examination services. The possibility to work in the exercise mode will image files and questions is an attractive way for self-education (12,13,14,15).

Very first serious initiative was generated by World University Service of Austria (WUS Austria) in B&H. During 2002 and 2003 WUS Austria, through its programs, Distance learning 2002 and Distance learning 2003 year, supported the development of the educational processes at B&H universities. At Medical faculty of University of Sarajevo at Chair for Medical informatics since 2002 is in progress realization of the project named: "Possibilities of introducing of distance learning in medical curriculum", approved by the Federal and the Cantonal ministry of science and education. The purpose of the project is to facilitate improvement of educational process at biomedical faculties, applying contemporary educational methods, methodologies and information technologies in accordance with strategy and goals proclaimed by Bologna declaration. Pilot project was realized during school years 2003-2005, theoretical and practical education of subject Medical informatics are adapted to the new concepts of education using world trends of education from the distance. One group of students was included in the project finalized by electronic exam registration and electronic exam on 20 June 2005, at Medical faculty in Sarajevo.

Figure 3. Web sites of Chair for Medical Informatics, the University Tele-information Centre of University of Sarajevo, and Chair for Family Medicine at Medical faculty of University of Sarajevo.
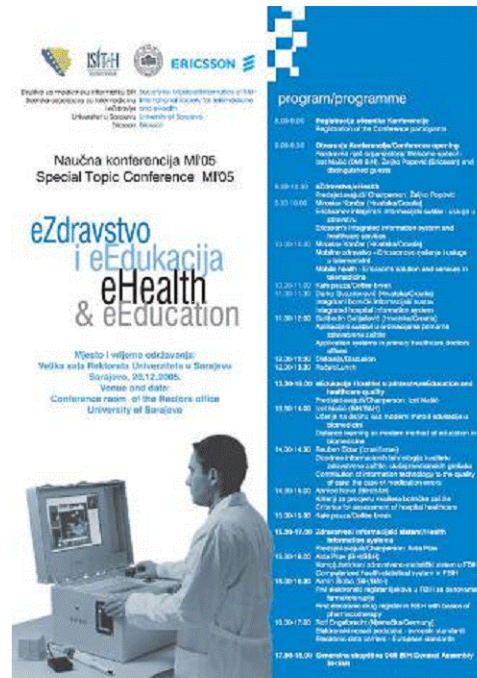
Figure 4. Special Topic Conference – e-Health and e-Education.

Distance learning in medicine has impact on telemedicine and practicing medicine as well. Basic skills of the use of computers and networks must be a part of all future medical curricula. The impact of technical equipment between patient and the doctor must be understood, and the situation where the diagnosis based on live voice or picture is different from a normal doctor-patient contact. In some areas telemedicine requires unique techniques. Tele-robotically discipline guaranties differ from what surgeons normally learn. Telemedicine, and distance learning as a prerequisite for it, is lest suited for doctor-to-doctor consultation, and the first contact to a doctor should always be a face-to-face consultation (15).

6. Conclusions

Distance learning in medicine has impact on telemedicine and practicing medicine as well. Basic skills of the use of computers and networks must be a part of all future medical curricula. The impact of technical equipment between patient and the doctor must be understood, and the situation where the diagnosis based on live voice or picture is different from a normal doctor-patient contact (10). In some areas telemedicine requires unique techniques. Tele-robotical guaranties differ from what surgeons normally learn. Telemedicine, and distance learning as a prerequisite for it, is lest suited for doctor-to-doctor consultation, and the first contact to a doctor should always be a face-to-face consultation.

Expected outcomes of the project Introduction and Implementation of Distance learning in medicine are:

- development and integration of informatics-computer technologies in medical education,
- creation of flexible infrastructure which will enable access to e-Learning by all students and teaching staff,

- improvement of digital literacy of academic population,
- ensure high educational standards to students and teaching staff, and
- to help medical staff to develop "Lifelong learning way of life".

The health sector is one of the most evident potential beneficiaries of the Internet revolution and World Wide Web resource in the present and in the future, when the tools now available and the system's reliability and efficacy as a whole will be further incremented and improved.

REFERENCES

[1] Mašić I, Novo A, Kudumović M, Mašić Z. Edukacija iz Medicinske informatike na medicinskim fakultetima u BiH. AIM, 2005; 13(1): 3-8.

[2] Masic I, Novo A, Kudumovic M, Masic Z. E-learning at Medical Faculty of University of Sarajevo. AIM; 2005; 13(3): 132-5.

[3] Masic Z, Novo A, Masic I, Kudumovic M, Toromanovic S, Rama A, Dzananovic A, Bander I, Masic M, Guso E, Balta E. Distance Learning at Biomedical Faculties in Bosnia and Herzegovina. Connecting Medical Informatics and Bio-Informatics. Procedings of MIE 2005 (editors: Engelbrecht R, Geissbuhler A, Lovis C, Mihalas G). IOS Press, 2005: 267-72.

[4] Engelbrecht R, Ingenerf J, Reiner J. Educational standards - terminologies used. Stud Health Technol Inform. 2004;109:95-113.

[5] Masic I, Ramic-Catak A, Kudumovic M, Pasic E. Distance learning in the medical education in B&H: E-Health & Education Proceedings, Zagreb, 2002: 17.

[6] Masic I, Bilalovic N, Karcic S, Kudumovic M, Pasic E. Telemedicine and telematic in B&H in the war and Post war Times. European Journal of Medical Research, 2002; 7(supl.1): 47.

[7] Hovenga J. Bricknell L. Current and Future Trends in Teaching and Learning. Stud Health Technol Inform. 2004;109:131-142.

[8] Mantas J. Future Trends in Health Informatics – Theoretical and practical. Stud Health Technol Inform. 2004;109:114-127.

[9] Mantas J. Comparative educational systems. Stud Health Technol Inform. 2004;109:8-17.

[10] Sosa-Iudicissa M, Oliveri N, Gamboa CA, Roberts J. Internet, Telematics and Health. IOS Press, 1997; 36: 5-53.

[11] UTIC Univerzitetski tele-informatički centar (UTIC) (in Bosnian) [homepage on the Internet]. Available from URL: www.utic.net.ba. Accessed: June 10, 2009.

[12] Zimitat C. Designing effective on-line continuing medical education. Med Teach. 2001;23:117-122.

[13] Harden RM, Hart IR. Centre for Medical Education, University of Dundee, UK. An international virtual medical school (IVIMEDS): the future for medical education? Med Teach. 2002;24:261-7.

[14] Harden RM. A new vision for distance learning and continuing medical education. J Contin Educ Health Prof. 2005;25:43-51.

[15] Mašić I, Riđanović Z. Informacijske tehnolgije u medicini i zdravstvu; AIM. 1995; 3: 5-8.

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