1st International Workshop on

Personalisation for e-Health

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Preface

The past years have witnessed unprecedented levels of investment in the e-Health sector, both in terms of research effort, and in terms of funding, as well as a great public interest. e-Health can be broadly defined as the application of IT (especially Internet technologies) to improve the access, efficiency, effectiveness and quality of any processes (clinical and business alike) related to health care. In the e-Health vision, intelligent systems would, for example, enable:

– citizens to take more control of their well-being, by accessing personalised and qualified health information, both medical and pedagogical, and accessing appropriate medical care from their homes;
– health professionals to manage their activity more efficiently, by receiving relevant and timely updates; and
– teams of health professionals to work together more effectively, coordinating their activities, sharing their knowledge about the patients they are collectively taking care of, and ensuring the best coordinated care is provided.

The 1st International Workshop on Personalisation for e-Health focuses on the many aspects of personalisation for health delivery, related to e-Health environments. The 11 papers presented, from 7 countries, approach the problem from diverse perspectives, such as knowledge engineering, multi agent systems, natural language processing, cognitive modelling, human factors, mobile computing, as well as public health and medical informatics, and they promise to offer an interesting and lively workshop, with engaging discussions.

June 2005

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Handheld Computing Devices in a Surgical Ward. Advantages on Clinical Information Sharing

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Abstract. At the Campus Bio-Medico University of Rome we have been using wireless networks and portable devices for more than three years to improve the quality of service. In this paper we describe the design of an application for handheld devices created to support the activity of the surgical ward, where daily documentation and maintenance of medical record quality is a crucial issue. We tested the introduction of handheld computers in medical records keeping and in communication among the surgical staff, ensuring coordination of activities and knowledge sharing about their patients. Remarkable issues were represented by: context-aware interaction, personalization of content management and interface design.

Keywords: mobile computing, adaptive interface, interaction-centered application, tailored decision support

1 Introduction

Patient data management is an area in which the risk of errors is high and in which PDAs may play a significant role [6, 10–12]. In a surgical ward, clinical information must be constantly and rapidly shared among the whole staff (physicians and nurses). The paper documentation (PPR, Paper patient record) is inadequate to support the task of providing fast and reliable decision elements. The PDA, allowing ubiquitous and consistent access to patient data, could help physicians take more precise, rapid and secure decisions.

In this paper we describe the design of an application for handheld devices created to support the activity of the surgical ward. Our hypothesis was that the use of handheld devices could enhance communication and quality of health records: physicians could improve their access to information by wireless connected PDAs, so that patient data could be available wherever decisions are taken.

After an accurate analysis of the staffs needs, we realized that content and presentation should be properly designed and not simply adapted for the PDA.
starting from PC based solutions. Before solving problems due to some limitations of handheld devices (small screen, difficulties in writing and reading, short battery duration, etc.) we faced the importance of creating patterns: in order to convert the written note into EPR (Electronic patient record), we needed a structure. Therefore we converted the paper records kept by the staff from unstructured to structured data. We studied their daily recordings and created a paper form. Later on we produced an electronic prototype with context-aware presentation of data and where reading and writing were made easier through an adaptable interface. Some staff members tested the prototype for two months and we were able to improve it. Afterwards, the first version of the programme was released.

The solutions adopted are strictly connected to the needs of the staff, such as communication: we can therefore say that the design is not only user-centered, but interaction-centered.

In paragraph 2 we describe the project, starting from the analysis of users needs up to solutions adopted and interface design; some interesting issues concerning context awareness are described in paragraph 2.4.3; after presenting the results (paragraph 3), we tried to compare our work with the other teams’ experiences.

2 The Project: an interaction-centered design

Campus Bio-Medico University of Rome, was a proper environment for our project: (i) the coexistence of the School of Medicine and the Bioengineering department in the same institution and building; (ii) the availability of a University Hospital with 15 wards (124 beds), intensive care units and a day-hospital unit.

The collaboration between bioengineers and surgeons began in May 2004: after the initial analysis and the software development, each member of the team received a PDA to allow rapid annotations of clinical data sharing them through a wireless LAN. In September 2004, the first phase ended and we collected feedback for a new implementation. The programme was modified and we started a second phase on the 1st March 2005.

2.1 Analysis

After getting introduced with the general surgical ward, we focused on the interaction activity. Our investigations concentrated on what each staff member’s task: activities, content and behaviour.

Composed by seven surgeons and six residents, the surgical ward staff at Campus Bio-Medico takes care of: general surgical ward patients (15 to 20); out patients clinic (30 hours per week); surgical interventions (30 hours per week); diagnostic day hospital.

Surgeons, despite their other duties, are ultimately responsible for the correctness and completeness of medical records. However, senior surgeons may be
more involved in teaching, research and surgical activities than patient care, in which they are helped by residents. These ones, on the other hand, need the support of a senior, who controls their determinations, on the basis of clinical and instrumental data. The key elements in clinical work, particularly for constant postoperative monitoring are patients data recording and updating, and their rapid and precise knowledge sharing.

The normal activities of data recording are concerned with: patient history; physical examination; ongoing therapy (drugs); diagnostic/therapeutic workup (laboratory exams, X-ray exams, endoscopic exams etc); scheduled surgery.

The data set concerning a patient is normally compiled in different steps (Fig. 1):

1. a morning briefing between physicians and nurses takes place in the office;
2. handwritten notes are taken during daily rounds on a paper sheet over a wooden tablet;
3. events or changes in health condition are subsequently entered into the hospital database;
4. the entire body of information is summarized in a cumulative report at the time of patient discharge from the hospital.

Each step depends on the physicians time resources, experience and routine to paperwork. The most important part of the clinical work is accomplished in the ward, but not all the notes written down during the visits are present on the patient record. These data are normally written on a paper sheet over a wooden tablet, which can be updated many times during the day, until the sheet is unreadable and is changed with a new one. The wooden tablet is a picture of the situation in the ward in a specific moment; sometimes it can be richer than the official clinical document, where some information are recorded only on patient discharge. This procedure causes the physicians a heavy burden for data transcription.

Fig. 1. Data management in surgery ward
2.2 Methodology and content management

The analysts assisted more times at the morning briefing among physicians and nurses and followed the surgery staff during the round.

Three kinds of information interweave in the daily recordings: the ward management (who is in which bed); the surgical programme (who is to be operated); the monitoring of patient in postoperative period.

In order to achieve a valuable result in a short time, we tried to convert the written note and studied the paper recordings of the surgical ward staff. In table 1 we list the information normally gathered for each bed.

<table>
<thead>
<tr>
<th>patient</th>
<th>hospital</th>
<th>surgical intervention</th>
<th>postoperative monitoring</th>
</tr>
</thead>
<tbody>
<tr>
<td>name</td>
<td>admission date</td>
<td>procedure</td>
<td>physiologic parameters:</td>
</tr>
<tr>
<td>surname</td>
<td>date of discharge</td>
<td>date of surgical intervention</td>
<td>blood pressure;</td>
</tr>
<tr>
<td>date of birth</td>
<td>(if the surgical intervention has already been performed, number of post-operative day)</td>
<td>body temperature etc.;</td>
<td>diet;</td>
</tr>
<tr>
<td>age</td>
<td></td>
<td></td>
<td>ileus or gas canalization;</td>
</tr>
<tr>
<td>diagnosis</td>
<td></td>
<td></td>
<td>diet;</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

At first we studied the notes and created a paper form, with the most frequent options. Later on we converted this data model into a presentation layout for PDA, with some adjustments (see later).

Some members of the staff tested the system for two months. They gave us all the necessary feedback to improve the application. During this phase we modified the application to register a good level of satisfaction. We therefore proceeded in extending the test to the whole staff.

Even though the physicians normally use computers, they did not receive enthusiastically the PDA. They enhanced problems such as difficulties in learning a new system, doubts concerning the relative advantage of this system (is it faster than writing and reading data on the wooden tablet?), technical problems like wireless connection performance and power supply, doubts concerning the user interface (few predefined options and only small text boxes).

2.3 Hardware infrastructure and software development

The hardware infrastructure was already installed at Campus Bio-Medico University of Rome, where many doctoral works and researches have been focused on wireless technology and the use of handheld devices for clinical records. The most important was HISS (Hospital Information System for Students), a project carried out in 2003-2004 under the financial support of Hewlett-Packard [3–5],
which enabled students of medicine, nursing and dietetics to use wireless mobile devices while practising in all the wards.

Using the same SQL database server of the HISS project, with the possibility to record XML structured data, we developed a whole ASP.NET application. We added some tables to the existing DB, in order to distinguish the surgical notes from other information concerning patients' data recorded in other wards.

2.4 Interface design

PDAs are not able to manage complete electronic medical records or display complex graphic information, but they have been identified by users as excellent tools for managing clinical information and accessing it at the point of care. Nevertheless PDAs do have some limitations, due to reduced screen dimensions and uncomfortable systems of data entry, which can cause some difficulties in reading and writing. We tried to overcome these problems with solutions tailored on the needs of the staff.

**Interface design: information display.** In comparison to paper, PDAs can show only part of the information. We converted this 'bias' into an advantage, since we were forced to further systematize the contents already converted on the paper from unstructured to structured data. The more synthetic way of presenting the contents made patient data communication easier and faster.

The surgical notes were divided into more pages with a hierarchical structure: (i) the notes concerning all the ward; (ii) synthetic information concerning each patient; (iii) detailed notes on the problems of a single patient.

When we browse through the notes, the patient personal information (name, surname and date of birth) is always present, so that we know to whom the notes are referred. The structure of these pages has been designed to put in evidence relevant information.

1. in each page of notes, the screen is divided in two parts: the upper part, evidenced in gray, is destined to reading; the lower part presents **RadioButtons** for further data entry (Fig. 2.a);
2. the order in which items are displayed may depend on users preferences (in some cases, i.e. for diagnosis or surgical interventions, the order of records is inverted, so that the last is at the beginning, Fig. 2.b);
3. in case of more complex notes, only the last record is visible, while the previous can been seen accessing the archive through a button at the end of the note (Fig. 2.c).

**Interface design: data entry.** Patients personal information come directly from the admission database of the hospital information system. In the HISS project users could find this information by selecting of the number of floor of the hospital and bed. A copy the data contained in the admission database was
then exported into a table of the HISS database and it was associated with all the recordings concerning that patient. We extended the search function giving the surgeons the possibility to search the information by department (displaying names, surnames and dates of births of all the patients of the surgical ward) or directly by name of the patient. This multiple choice is useful since the same data can be seen: (1) inside the context (the ward), or separately (the single patient); (2) knowing or not knowing the name of the patient.

After importing personal data from the hospital system, the users can insert data concerning: (i) diagnosis; (ii) surgical intervention; (iii) post-operative monitoring.

In comparison to paper recordings, the electronic patient record has the advantage of inserting automatically some information: the date and time of data entry, the name of author of data entry. This system is studied to enhance communication among surgeons since whoever reads the notes can trace back to the author and knows at what time the patient has been visited.

A further effort was spent to obtain a flexible structure of notes through dynamically created forms, whose layout can change depending on the quantity and quality of information inserted. For instance, some windows are opened only if you need it. In this way we tried to avoid too long pages and, at the same time, to harmonize hierarchical structure and navigability.

Data entry was also simplified by using predefined options. However, in many cases, on specific request of the staff, we also gave the opportunity to insert free notes in text boxes of different sizes. For example, for the indication of the diagnosis and surgical interventions, the surgeons preferred free text notes.
to ICD9-CM codification (which is used in the final document). In the HISS project we had developed a system to search for a disease into the wide database of ICD9-CM. But the surgeons did not like this function and wanted to be free to write whatever they wanted. However, at the end of the stay in hospital of a patient, they are compelled to write ICD9-CM codes for administrative purposes. Therefore some of them envisage an application for converting the plain text into ICD9-CM codes. As the codes are related to financial reimbursement by the Regional Health Authorities, errors in their attribution may lead to serious economical failures. We are aware that the typical Italian physician is not keen on using any codification at all and this behaviour causes some problems in Hospital Information Systems.

**Personalization.** The contents were personalized following different criteria:

- different relevant information is displayed depending on the user (physician or a nurse);
- since the surgical team is divided in two groups, each member of one group can visualize first the patients that are followed by his group and then the others;
- each user can save his interface view-state, so that when he goes back to work after a pause (or even the day after) he can start exactly from the point he was at the moment of stopping;
- each user can decide if he wants to work on-line or off-line.

**Context awareness.** We created an interface that dynamically adapts to the screen size: if the system is accessed through a pocket PC the dimensions of the pages are automatically resized to fit in the limited window, and the information to be displayed is reduced. A larger amount of information is available when the application is opened on a desktop PC. The two devices are used in different contexts. During the morning briefing among physicians and nurses the base for further recordings is compiled at a desktop PC in the office (this is the most massive part of data entry and it is done using a keyboard and a 17" screen). Afterwards, moving through the ward, data are just updated using the handheld devices. Each physicians can visualize the entire ward or only the patients he is taking care of, using a function similar to the ‘favourite’ links in a browser.

Besides working on-line the surgeons can also download the data they need and work at home, at university or in any other areas of the Campus not reached by the wireless LAN. When they return to the wireless enabled area they can synchronize the data. We studied three different ways of synchronization:

1. when the physician enters the wireless covered area, the synchronization starts automatically;
2. when the physician enters the wireless covered area, a pop-up windows on his display asks if he wants to synchronize;
3. entering the wireless covered area, the physician can open Active Sync (the programme which allows data synchronization between desktop PC and PDA) and send the data to the central database.
The third way was preferred by surgeons, since they claimed that sometimes the data are downloaded only for personal studies and they don’t want neither the database to be automatically updated nor been asked for synchronization. Only when they really want to synchronize, they would issue the command.

3 Results

For the first months the PDA was used by some members of the staff, while others continued to write on the ‘wooden tablet’. The comparison between electronic and paper records showed that undoubtedly handheld computers can improve both quantitatively and qualitatively the medical record. The information collected with PDA is more concise and precise. The possibility of modifying the notes allows an ordered flow of data, where all the data of postoperative monitoring are present, except the really unessential facts. Furthermore, in case of a double recording of the same piece of evidence, the note can also be eliminated. As can be seen in Fig. 3, the electronic record is at the same time more accurate and more synthetic than the one on the paper.

Eventually even the more reluctant members of the staff accepted to use the PDA, not only in consideration of the advantages we have described, but also taking into account the possibility of getting ubiquitous access to lab, endoscopy and other tests, to the outpatient database, to medical references and manuals, etc. They were able to communicate every kind of data not only to the other members of the staff, but also to the nurses and to other departments of the hospital such as admission, maintenance, etc.
4 Related works

There are many works in literature reporting of the use of PDA in healthcare environments. Most of them are concerned with administrative and organizational task and only few concentrate on clinical work.

For example, in [8] the focus is on empowering mobiles devices, by extending the instant messaging paradigm, to recognize the context (location, timing, role) in which hospital workers perform their tasks. Reference [7] describes an application middleware for immediate high-quality multimedia communications in a hospital: by integrating a multimedia framework with an event-based notification system, the authors obtain a platform that can provide seamless, context-sensitive communications, which can adapt to users location. With "Bedside Florence" [13] nurses are able to electronically record notes and vital parameters such as blood pressure and body temperature right at the bed of a patient.

The WARD-IN-HAND project [1] proposes as key elements "hands-free" interfaces through the use of voice and pen-based human-computer interaction and the use of widely available hardware and software to reduce costs.

Even rarer are investigations on interaction process inside a surgical ward. A study by Lapinsky et al. [6], using focus group analysis of PDA users, found that patient-care data management by handheld device was not considered valuable, unless it is integrated into the hospital computer system. However, the long-term goal of integrating e-prescribing, physicians’ notes, radiology, and laboratory handheld capacities for physicians in outpatient clinics as well as in hospitals will dramatically improve functionality [9].

5 Future developments

After the introduction of PDAs, we monitored the staff. Our next goal is to monitor the patient in order to understand whether the electronic record can improve the quality of care into the hospital. Two groups of patients will be monitored: the follow-up of the first one will be done in the traditional way (paper); the other one with PDA. We want to know if a more precise and faster way of communicating can prevent postoperative problems and to which extent it is possible to predict them.

Furthermore, analysing PDAs recordings we can assess standard procedures, so that the physician has also a tailored decision support in his activity.

Last, but not least, we want to know if the trainees take advantage of the use of handheld devices. Already the HISS project investigated the issues of handheld devices in a learning environment. In this case we want to go far beyond and see if students can be best prepared to future professional activity.
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References

Authoring and Generation of Tailored Preoperative Patient Education Materials

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1 Introduction

In reconstructive surgery, multiple interventions during one surgical episode are common. Each intervention must be explained, its intended and potential consequences articulated, and informed consent of the patient secured. Although the pre-surgical encounter between the patient and the surgeon is the opportunity to accomplish this, it is essential that the patient be given educational materials to complement and augment face-to-face exchange. This is virtually impossible to do well with brochures, because many combinations of procedures are possible, different patients have different concerns, and patients have varying levels of literacy and knowledge. In the extreme, a patient would either be given a set of brochures selected from hundreds of variants, or every patient could be given the same set of brochures without regard for differing needs. Neither of these scenarios is tractable or acceptable.

We propose a solution allowing divergence from the generic, static, preoperative information brochure to one that is customized for every individual patient regardless of the complexity of the surgical intervention. This solution will require reformulation, extension, and optimization of an existing Natural Language tailoring engine and creation of a database of educational modules pertaining to each subcomponent of a given surgical intervention. A key outcome of this research will be an authoring tool that will assist surgeons in entering the text content that will be assembled into coherent material by the tailoring engine.

This research will provide important tools to assist in patient-centric healthcare: a means of shaping complex information so that it is more relevant and personalized, a mechanism for assisting in the achievement of informed consent to procedures, a method that has been shown to improve patient engagement and compliance with medical regimens, and a technique for complementing and reinforcing the information communicated during the pre-surgical encounter. The authoring tool and tailoring engine will form a robust architecture to allow providers to expand the educational scope beyond reconstructive surgery to all forms of medical intervention, surgical or otherwise.
2 The Importance of Tailoring in Patient Education

2.1 The Problem with Current Patient Education Materials

Present-day health-education and patient-information material is often limited in its effectiveness by the need to address it to a wide audience. What is generally produced is either a minimal, generic document that contains only the information common to everyone, or a maximal document that tries to provide all the information that might be relevant to someone (and hence much that is irrelevant to many). But material that contains irrelevant information, or omits relevant information, or that for any other reason just doesn’t seem to be addressed to the particular reader is likely to be discounted or ignored, with consequent problems in motivation for compliance with medical regimens, health-related lifestyle improvements, and so on.

However, recent experiments suggest that health-education material can be much more effective if it is customized for the individual reader in accordance with their medical conditions, demographic variables, personality profile, or other relevant factors. For example, Strecher and colleagues sent unsolicited leaflets to patients of family practices on topics such as giving up smoking [24], improving dietary behaviour [6], or having a mammogram [23]. In each study, the ‘tailored’ leaflets were found to have a significantly greater effect on the patients’ behaviour than ‘generic’ leaflets had upon patients in a control group.

This kind of customization involves much more than just producing each brochure or leaflet in half a dozen different versions for different audiences. Rather, the number of different combinations of factors can easily be in the tens or hundreds of thousands (as in the studies cited in the previous paragraph). While not all distinct combinations might need distinct customizations, it is nonetheless impossible to produce and distribute, in advance of need, the large number of different editions of each publication that is entailed by individual tailoring of health information.

Recently, researchers in Natural Language Generation have begun to apply methods from Artificial Intelligence and Computational Linguistics to develop automated systems for tailoring health information to individual patients ([4], [7], [20], [3], [21]). The HealthDoc Project (1994–1999) [12] developed a method for generating tailored documents based on a new paradigm for Natural Language Generation—‘generation-by-selection-and-repair’—in which new documents are created from a pre-existing ‘master document’ which contains all the pieces of text that might be needed in tailoring a version of the document for any particular audience. Selections from the master document are made for both content and form, and then are automatically post-edited—‘repaired’—for form, style, and coherence.

In a realistic and usable implementation, the HealthDoc approach requires a sophisticated authoring tool to assist the writer, and a sentence planner (cf. [26]) that would undertake to repair and polish the selected text—we can’t expect the average technical writer to pre-compile all the possible combinations in advance. To develop such a system, a number of research issues need to be addressed: representation of the master document; authoring and knowledge-based document management; and sentence planning for automated post-editing.
2.2 The Potential Solution: Natural Language Generation

The creation of the input material for Natural Language Generation systems is a problem for all generation systems, including our selection-and-repair paradigm. The concept of ‘preparing’ a database, knowledge base, or other resource for natural language generation has been used by other researchers—for example, O’Donnell et al [17] manually incorporate in the generator’s database additional information (including a taxonomic organization of the types used in the database) that will be used to ensure coherent and high-quality text. This idea led us to adopt the authoring of a ‘database’ of reusable text (i.e., the master document) as the basis for the paradigm of generation-by-selection-and-repair.

Other approaches to natural language authoring have been developed (e.g., [13], [19]), and Brun et al [5] point to an ‘an emerging paradigm of “natural language authoring”’ (p.25) which they contrast to the (pure) natural language generation approach as one in which ‘the semantic input is provided interactively by a person rather than by a program accessing digital knowledge presentations’ (p. 25). Scott et al [22] present a solution to the problem of authoring input for language generation systems in which the user operates directly upon a knowledge model from which the final output text will subsequently be generated.

Our approach to authoring for natural language generation systems falls somewhere between the paradigm described by Brun et al and that of classic language generation: as others do with authoring-based systems, we allow a user to enter the exact textual input that will later be used in generating new texts ([18] [14]), but we are also dealing with authoring of input at a deeper level of linguistic representation ([15], [1], [2]), as is typical of Natural Language Generation systems.

A focus in the original HealthDoc Project was on the development of authoring tools that would be used by a professional programmer or computational linguist to automate the preparation of input specifications for a document generation system at the deep level of linguistic representation needed for the subsequent process of textual repair. For authoring in health situations, however, typically the authoring is accomplished through the interaction of the health professional with a ‘knowledge engineer’, someone trained in structured knowledge acquisition. Our intent is to design a system, based on our paradigm of Natural Language Generation by selection-and-reassembly, strategic planning, knowledge structuring, and a formal model of learning, which interacts directly with the surgeon to allow entry of purpose-specific and patient-specific textual variations in ordinary English which will then be selected, processed, and assembled by our tailoring engine into readable, patient-specific, educational material.

2.3 The Need for Tailored Patient Education in Reconstructive Surgery

Modern reconstructive plastic surgery has evolved into a highly complex field aimed at restoration of patient form and function. The surgical solution to a given reconstructive problem may require grafts of various types (skin, bone, and tendon) combined with tissue-mobilizing procedures (flaps) from among dozens of potential locations on the body. Each reconstruction will have different implications for aesthetics, function, rehabilitation, recovery, and potential complications, all of which must be reviewed with the patient preoperatively.
The fraction of this information that is actually retained by the patient after the consultation is consistently rather small. In many surgical specialties, brochures, Internet websites, and other forms of ‘take-home’ educational materials are frequently used to supplement the surgeon-patient consultation and enhance patient retention of information. However, such solutions have proven impractical for much of reconstructive plastic surgery due to the sheer number of techniques available and their frequent need to be performed in combinations. The complexity of the surgical procedure and the variety of options that need to be considered in tailoring documentation to the individual patient make the creation of appropriate material a combinatorially explosive process. Figure 1 illustrates the complexity inherent in choosing among the surgical options available in breast reconstruction.

Fig. 1. Decision tree of surgical options in breast reconstruction

Although preoperative information brochures have documented value for patient education, a library of static documents would be difficult to establish if it were to encompass all reconstructive surgical alternatives. For a patient undergoing a multistep procedure, a handful of brochures would be required, which would lack cohesiveness, and would likely be very confusing. Consequently, existing preoperative information
brochures are only available for the most common reconstructive surgical procedures and must, by necessity, remain generic in nature to ensure applicability to all patients.

Creation of a tailored information document, customized for every individual patient would potentially increase relevance and effectiveness of the educational material. The tailoring process would permit inclusion, exclusion and/or modification of educational information based on a variety of criteria, including the surgical procedure(s) being performed, impact of adjuvant therapies, medical co-morbidities, and potentially any other factor deemed significant. Although no amount of supplemental documentation can replace the surgeon-patient dialogue with which informed consent is obtained, it is well-documented that only a small fraction of the information communicated in this process is actually retained by the patient. Reference material for review by patient, friends, and significant others would have great value in the preoperative, perioperative, and postoperative stages if this information could be tailored to the individual patient. This observation is supported by recent work in patient education attesting to the potential value of increasing patient involvement in the surgery decision through patient-centred methods [25] and using quality information brochures to improve surgeon-patient communication [16].

We are developing a system for generating preoperative patient education materials that allows divergence from the generic, static, preoperative information brochure to one that tailors the text to every individual patient regardless of the complexity of the surgical intervention. The components of this system will consist of a Natural Language Generation tailoring system, content authoring environment, and creation of a database of educational modules pertaining to each subcomponent of a given surgical intervention.

3 Components of a Tailoring System for Reconstructive Surgery

Creation of a corpus of textual variants. We are creating a corpus of textual variants that will be used in generating tailored educational materials for reconstructive breast surgery by a process of selection and reassembly using the HealthDoc model of document generation. Beginning with the initial generic content, we are applying a formal organizational structure that mirrors the stages of the surgical procedure. Each component of the surgical procedure will then be broken down into subcomponents for which textual variants will be created based on various patient modifiers.

The subcomponents, called content modules, include: technical summary, preoperative workup, postoperative course, sequelae, complications, discharge planning, recovery, and rehabilitation. Patient modifiers include: timing of reconstruction, mastectomy type, radiation treatment, smoking, obesity, diabetes, and other comorbidities. The textual variants will initially be entered manually by a programmer into our master-document format and subsequently authored by a patient-education writer using the prototype authoring tool being developed.

An authoring tool to guide health care providers. In previous work in the original HealthDoc Project, we developed several authoring tools ([15], [18], [1]) for the creation of text variants that could be represented in the master-document format and
used to generate customized documents by the tailoring engine. However, none of these tools was geared to the domain expert; rather, they were intended for a programmer or computational linguist who would specify the content at a deep level of linguistic representation required to do syntactic and semantic repair of reassembled text. We are developing an authoring environment for health-care providers that will guide surgeons to directly enter the text variants in ordinary English that will then be used to create the tailored educational material.

Although the earlier authoring tools could be used to enter text at various levels of linguistic representation, there was no ‘knowledge-level’ modelling for knowledge acquisition to support the generation of tailored educational materials. At the knowledge level of authoring tailored content, the physician would be guided through the process of considering the concerns of the various stakeholders (e.g., surgeons, patients, hospital) with regard to tailoring the educational material. For example, the surgeon may be primarily concerned with communicating information that will ensure patient compliance with the recommended treatment and that will lead to favourable outcomes; the patient may be most concerned with the variations in risks and complications associated with the different treatment options. The authoring tool should therefore ideally embody a cognitive model that aids the physician in mapping out these complementary, and sometimes contradictory, high-level concerns. Yang [27] has developed a design methodology for an authoring tool that uses a Constructivist model of patient-centred learning to guide the physician through the process of creating the master-document framework.

The Constructivist approach [11] assumes that learners construct their own knowledge from their experiences and that the educator is only the knowledge provider. Yang has applied Constructivist theory to develop a patient-education model and design a knowledge acquisition framework which could assist health professionals in organizing their domain knowledge prior to the writing of the actual textual content. A key contribution of a Constructivist model to the HealthDoc methodology would be in guiding the author to construct the underlying discourse structure of the master document.

With the original HealthDoc authoring tools, the emphasis was on providing the author with a means of entering textual variations, specifying the conditions under which each variation should be selected, and annotating the master document with information needed for later automated repairs. However, it was assumed that the author would use his knowledge of the application domain to organize the pieces of text into a coherent master-document structure. Knowledge about the discourse structure was left implicit, to be managed mentally (and differently) by each individual author. As an example, an author might enter the following text and variations on the topic of the two types of diabetes:

(1) There are two main types of diabetes. One type is insulin-dependent, also known as type I diabetes, and the other is non–insulin-dependent, also called type II diabetes.

(2) The condition that you have is insulin-dependent diabetes. (variation 1) The condition that you have is non–insulin-dependent diabetes. (variation 2)
Insulin-dependent and non–insulin-dependent diabetes are different disorders, so that the causes, short-term effects, and treatments for the two types differ. However, both types can cause the same long-term health problems.

4) With insulin-dependent diabetes, your body makes little or no insulin. *(variation 1)* With non-insulin-dependent diabetes, your body makes insulin, but can’t use it well. *(variation 2)*

The underlying discourse structure of this passage of text can be characterized as follows:

– Define the two types of diabetes.
– Identify the patient’s type of diabetes.
– Compare the types.
– Contrast the types.

However, the elements of this discourse structure would not have been made apparent during the authoring process. Also, the author would not have been able to indicate that a similar pattern of statements *(define, identify, compare, contrast)* could be applied in constructing other topics of text.

In contrast, Yang’s knowledge level of modelling could guide the creation of the master document according to pre-defined discourse structures that model the interaction between physician and patient. Her Constructivist model⁴ tells us that addressing patient concerns (about pain, risks, complications, etc.) should be the basis for the information provided by the physician. An authoring tool incorporating this type of knowledge would therefore have an explicit ‘addressConcerns’ rhetorical model that would be used in constructing a topic passage. For example, the topic passage for each concern might have the following elements:

– Identify the concern.
– Describe the concern.
– Address how patient should handle the concern.

The (generic) text for the concern of pain might therefore be entered as follows:

5) You may feel severe pain. *(Identify concern.)*

6) The pain or discomfort will be felt in the breast area or abdominal site. Soreness and swelling are often part of your body’s reaction to the trauma of surgery. *(Describe concern.)*

7) You should not perform lifting activities or anything that involves the muscles in the breast area or abdominal site. This will cause additional pain and prevent the healing of your wound. *(Address handling of concern.)*

⁴ Other learning models might also be used at the knowledge level of modelling the master document.
A Natural Language Generation tailoring engine. The current HealthDoc tailoring engine will be the software kernel of our proposed Natural Language Generation tailoring system. We have now replaced our original ‘homegrown’ document design language [8] with a standard document description language (XML). Master documents containing personalized health information for various domains (e.g., skin care and smoking cessation) have been prepared and marked up with XML tags and attributes. These tagged conditional documents have then been processed through an XSL transformation that produces a presentation-ready and print-ready, highly customized document using the PHP Hypertext Preprocessor. This software can now enable visualizations of tailored versions of any content in our master-document format as either a Web presentation or in paper form.

Our earlier work in the HealthDoc Project demonstrated that complex, stylistically polished texts can be crafted from pre-existing texts represented in an appropriate ‘master-document’ format. We are continuing the development of the ‘generation-by-selection-and-repair’ paradigm, with particular emphasis on the architectural issues involved in text-to-text generation systems. Our long-term goal is to continue to develop our theory of automated text repair, and test it by implementing repair algorithms that recognize and revise various infelicities in ill-formed texts. One approach to the automated detection of ‘repair patterns’ that we plan to investigate is the combination of pattern-based methods from classical rhetorical theory (e.g., [10]) with n-gram language models.

4 Conclusions

Our goal in this research is to develop natural language software tools, specifically an authoring tool and Natural Language Generation tailoring system, to automatically generate tailored patient education for patients choosing among the plethora of options involved in reconstructive breast surgery. The benefits of enhanced preoperative education have been established in the literature, and serve as the basis for many of the predicted benefits listed below:

- A single, comprehensive source of educational materials.
- Less conflicting information than might be associated with multiple educational brochures in multistep surgical procedures, assuming these materials even exist.
- A better-informed patient: Decreased perioperative anxiety; fewer and less serious complications; faster recovery and rehabilitation; enhanced recognition of postoperative complications, because of the ability to include more specific information tailored to each of the surgical subcomponents.
- Better patient outcomes: fewer and less serious complications, etc.
- Less time required in perioperative discussions ensuring that information is communicated.

Future applications of the results of this research would be the extensions of content to other procedures and surgical subspecialties. The intended robustness of theory and technology will also allow extension beyond that of surgical intervention, potentially to any medical treatment involving multiple modalities requiring cohesion of educational content (e.g., medical and radiation oncology)
Acknowledgements

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References

The HOMEY project: a telemedicine service for hypertensive patients

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Abstract. This paper deals with the opportunities and challenges of "intelligent dialogue" technologies in the context of medical applications and, more specifically, home care. The system focuses on an automated, telephone-based home monitoring service for chronic hypertensive patients. A remarkable point in the development of systems that are going to communicate with patients is the promotion of compliant behaviors. In the case of hypertension, we refer to the compliance with the prescribed treatment. To this concern, a number of cognitive theories have been recently proposed to account for the willingness to change our own behavior, that is more and more considered the key issue for disease prevention. In our system, the dialogue is personalized according to these theories, taking into account the patient's actual condition and the clinical practice guidelines on hypertension management. The system has been tested through a clinical trial involving patients from two Italian hospitals. Results show a blood pressure decrease in the group of patients exploiting the Homey service.

1 Introduction

Advances in Information and Communication Technologies open the possibility for widespread use of novel human-computer interfaces. Among them there are interfaces based on automated speech recognition (ASR) [1,2,3]. In general, an automated dialogue system is a complex software installed in a workstation, called “telephony platform”, connected to a telephone number (sometime toll-free). When a call comes in, the computer is able to answer and talk to the caller through a natural dialog and a synthesized voice. The machine is also able to comprehend the user's answers, provided in natural language. In this way a conversation takes place on the telephone line between computer and patient. The automatic dialogue, besides the limitation due to the fact that on one side there's merely "a machine" rather than a human, can never-
theless serve and autonomously solve simple and routinely tasks. In fields other than healthcare, such systems are able to provide common services, for example train table information, road conditions, and room reservation. In the healthcare field they can book laboratory tests, or collect clinical information from patients, directly from their home, or wherever a phone can be employed (including mobile phones). Some examples already exist, for smoking cessation [4], physical activity enhancement [5], and severe disease monitoring [6,7]. See also [8] and [9] for interesting reviews.

2 The Homey Project

The European Union, with a funding for research activities within the Health Care for Citizens programme, gave birth to the HOMEY project in year 2001. As mentioned, the project goal is building dialogue systems, which will provide easier and more efficient communication between specialist health centres and patients affected by a chronic disease.

Far from willing to interfere with the direct relationship between physician and patient, or other caregivers, introduction of these technologies aims at improving the flow and availability of information at the point of care. The actual system has been developed in collaboration with specialists in hypertension care from various Italian hospitals (IRCCS Policlinico San Matteo in Pavia, Hospital Careggi in Florence, and Hospital Sacco in Milan).

2.1 Background and Motivation

Several clinical studies pointed out that home monitoring has the potential of increasing health outcomes, granting at the same time cost savings for the national health system. This remarkable feat is especially attractive in western countries, where public investors are pushing towards a more effective use of money in the healthcare services [10]. Prevention of cardiovascular diseases, often caused by hypertension, is one of the means for saving very high future costs. Models for behaviour change highlight the importance of being conscious of the benefit that will be gained by modifying one's own behaviour. The ability to convey messages in a way which is effective and convincing has been taken into consideration by theories of behaviour adoption. The most prominent ones are the Social Cognitive Theory [11], the Health Action Process Approach [12], and the Trans-Theoretical Model [13].

Recently the importance of understanding cardiovascular risk has been strongly stressed in medical literature. British Heart Foundation periodically publishes fact-files, which are compiled with a wide spectrum of doctors to reflect current opinions. Fact-file number 10/2002 [14] reviews evidence about how cardiovascular risk is consistently underestimated by the population. It argues that better risk communication is crucial to the adoption of behaviours which reduce risk: stopping smoking, low-fat diet, increased physical activity and taking medications as prescribed. A patient’s feeling of being in control over the potential development of a coronary heart disease is generated by two components: (1) response efficacy, i.e. the knowledge that
the actions taken have the potential to improve health, and (2) self-efficacy, i.e. feeling confident in one’s ability to adopt the risk-reducing behaviour. Therefore, risk communication involves imparting information about risk, how to reduce that risk, and ensuring that patients have confidence in their ability to change their behaviour. These are the intentions of the developed dialogue for hypertensive patients.

2.2 The Clinical Problem

Hypertension is a chronic disease whose care requires, among other factors, attention to healthy life habits and care in monitoring of blood pressure values, weight and heart rate. Numerous clinical tests, in fact, proved that long-term elevated blood pressure values remarkably increase the probability of serious damage of important body organs, mainly heart and brain, causing illnesses such as stroke and myocardial infarction. Hypertension affects a large fraction of European adult population: according to recent estimates, as high as 40%. Luckily, drugs available to reduce blood pressure are numerous and effective. Unluckily, there is low compliance to both drug prescription by general practitioners (GPs) and assumption by patients.

Specialist centres have an outstanding role in the care process of the disease. In these centres, physicians are able to apply the latest best-practice care procedures (according to internationally accepted guidelines), adapting them to the specific patient. An effective care, however, requires that doctors are timely informed of the health status of their patients: for example, they should know the blood pressure values, whether side effects occurred, and also whether patients were compliant with the prescribed therapy and life style. Therapy, in fact, often comprises of both, drugs and life style modifications, such as doing more physical exercise, following a diet and ceasing to smoke.

Higher quality of interaction between physician and patient, and the information exchange between the two, are therefore essential for the effective care of hypertension and other chronic diseases. Unfortunately, organizational and economic constraints lead to few patient encounters, normally once or twice every year. In these encounters, a blood pressure Holter test should be prescribed, i.e. the automatic collection of blood pressure values for 24 hours, through a simple, non invasive device.

The low frequency of control visits has some bad consequences: these patients in general take one or more drugs, and early detection of side effects may be impaired; patients feel "abandoned" by the healthcare system, and this affect their therapy compliance; some of them stop the pharmacological treatment without advising medical experts; with no close monitoring, they are also less willing to maintain a good life style.

The dialogue system which Homey partners have developed serves this purpose: to enable doctors and patients to continuously exchange information on health conditions, and to have this information flow happening in a simple and timely way, even during the time gap between their physical encounters.
3 The Technological Solution

The above mentioned functionality is illustrated in Figure 1. Since patients are in general over 60, simplicity is assured by the use of the telephone, which is easy to use and highly diffused (the service is accessible from the mobile too). The use of a dialogue system replaces the need of using specialized computer-based tools, sometimes complicated for patients to use, and at the same time grants that the precious information collected is organized and stored, and not lost, for example, in loose notes. Thanks to the use of a common telephone, information is immediately transferred to the care centre, where doctors are able to evaluate it and decide, when necessary, suitable changes to make the therapy more effective. To be useful, a data collection system must also organize the data acquired and present it in order to be easily interpreted, and therefore support the physician's decision process. In our case, this simplicity hides the adoption of innovative technologies, gathered not only from research on human speech recognition and automatic creation of natural language dialogues, but also on the intelligent use of electronic patient records (EPR). In the Homey system the technologies are integrated with an EPR system, able to store demographic data, disease history, outcomes of previous visits and laboratory tests, and, above all, blood pressure values and side effects possibly reported by patients. Such data are recorded and stored, for each patient, both whether it comes from the physician's visit, or self-reported by the patient via the dialogue system by telephone. As shown in Figure 2, the physician looking at the patients' data can see whether information comes from telephone or from direct encounters: in fact, the latter case is indicated by an icon with a person writing on the PC, while in the former the telephone icon appears. Moreover, the icon represents either a flawless or a broken telephone, meaning that the call has been closed in the correct way, or some exceptions occurred leading an unexpected call closure, respectively. This is very important to give data the correct reliability.

Such features, however, are not all of the functions of the dialogue system: technology innovation in this telemedicine project led us to realize a system that generates a dialogue tailored to every single patient. Data stored in the EPR, together with the history of calls made by a patient, are accounted for by the system. Reasoning on that, it is able to formulate a different dialogue on a case-by-case basis; the dialogue is generated run time, depending on the specific condition of the patient, prescribed
drugs, side effects, and his/her life style. Suggestions are generated in agreement with international guidelines about hypertension management [15]. The dialogue, however automatic, is therefore adaptive: its internal workings take into account both the information contained in the clinical records, the data coming from the ongoing conversation, and the medical knowledge coded in the guidelines.

3.1 The Dialogue Generation

The system interprets a dialogue description written in a high language level, which specifies the spoken interaction: which steps to take, what questions are to be asked to the user and what possible utterances are allow in reply. The user is first authenticated with a numeric password. Then, the dialog engine interprets a state vector which represents the patient's health state and other associated information. The system presents the caller with a series of questions (also known as prompts), dealing with specific aspects of the patient's health state and behaviour. The questions are organised by topic in "contexts". The contexts implemented in the current version (of course they can be increased to improve the extent of the conversation) are:

- Service identification,
- Patient identification,
- Patient compliance assessment,
- Patient health status understanding.
• Educational advices
• Quantitative data acquisition,
• Possible side effects investigation,
• Life style investigation,
• Planning of next patient actions,
• dialogue conclusion

It is worthwhile noting that not all the contexts and questions are necessarily activated at each call. In fact, the adaptivity features modify the flow of the call depending on the specific patient.

Speech recognition and dialogue interpretation technologies we used in our application are provided by SPINET system (Speech Into Enriched Text). The system, developed by ITC-Irst research Institute, provides both the engine which performs the actual recognition on the sampled audio signal, and the dialogue manager [16]. The system speaks to the caller via a synthetic voice, which does not suffer the limitation of prerecorded prompts, restricted to fixed sentences. The voice is created at run time by a commercial text-to-speech software (we used "Silvana", from the Actor system, licensed by Loquendo). The telephony platform used was ContaCT, licensed by Retek SpA.

3.1.1 Examples of dialogue

The dialogue system we developed leverages two advances in dialog technology, as it is not only adaptive but also mixed initiative. Such a dialogue try to mimic the behaviour of a telephone answerer, whose counterpart may anticipate answers to questions that have not been formulated yet. For example:

System: Please tell me your heart rate
Patient: I don't know it, I know my pressure: systolic is 130 and diastolic is 92
System: So, you did not measure heart rate, but you have 130 over 92 as blood pressure, can you confirm?
Patient: Yes

As an example of adaptation, we consider a 65 years old patient that shows high blood pressure values in spite of a prescribed treatment. In this case there is the suspect of low compliance, thus the patient is reminded to take the prescribed drugs and follow the suggestion for a healthier life style.

System: Please tell me your blood pressure values
Patient: I have a systolic pressure of 160 and diastolic is 100
System: So, you have 160 over 100, it's high, can you confirm?
Patient: Yes
System: Are you still swimming two times a week?
Patient: Yes, I do
System: Are you still smoking?
Patient: Yes., 5 cigarettes per day
System: You should stop smoking.
System: I remind you that you have to take your BetaBlocker pill in the morning, after the blood pressure measurement

Patient: Yes

System: I want to inform you about a risk that you have: considering next 10 years, you have a certain risk of suffering from stroke or myocardial infarction; this probability is more than double, with respect to other people. But if you try complying more with your drug therapy and healthy habits, keeping your blood pressure levels above 140/90, you can reduce this risk, and you are expected to live without problems much more than 10 years.

Another facility that the system embeds is that a physician, after looking at the patient's data entered by telephone, can write a text through the EPR interface, and this text will be voice-synthesised to the patient during his/her next call. In this way, the patient may receive a much tailored suggestion by his physician and in the same time he will feel reassured, because he has the evidence that "someone on the other side" is periodically monitoring his data.

4 System Validation

A motivation for the adoption of the system is that its use will prove economically viable and beneficial to the collaborating parties. Clinical evidence suggests that careful monitoring and self-monitoring of hypertensive patients can have a beneficial impact not only on the allocation of resources in hospitals, but also on the actual health condition of subjects, and their motivation to change behaviours in favour of healthier habits [17].

To verify this hypothesis for our proposed system, we collaborated with the caregivers to design a randomized controlled clinical trial. About 300 patients, after being informed of the scope of the study, have been enrolled. They were randomly assigned to either a control group (patients treated conventionally) or a treatment group (patients using the telephone-based system). The groups size ratio was 1:1, stratified by sex. Full details for this study, including considerations on the clinical perspective, are given in reference [18], while results are shown in Table 1. As a guide to read Table 1, medical experts agree that the Holter measurement (i.e. the average values over the 24 hours) is more reliable than the single, ambulatory measurement, because the latter is affected by some biases: first, it is well known that blood pressure is highly variable during the day; second, there is the "white uniform" effect, that in many patients causes a temporary increase of blood pressure.

About the absolute value of blood pressure difference, the reader must be aware that, according to the most recent clinical evidence, also a few decrease (5-7 mmHg) is highly effective in reducing cardiovascular risk.

Table 1. Results of the controlled randomised clinical trial
<table>
<thead>
<tr>
<th></th>
<th>Traditional treatment group</th>
<th>Homey service group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(Systolic/Dyastolic, mmHg)</td>
<td>(Systolic/Dyastolic, mmHg)</td>
</tr>
<tr>
<td>Ambulatory measurement</td>
<td>141/91</td>
<td>139/91</td>
</tr>
<tr>
<td>Holter measurement</td>
<td>141/90</td>
<td>141/85</td>
</tr>
<tr>
<td>Enrollment</td>
<td>130/87</td>
<td>128/83</td>
</tr>
<tr>
<td>Follow-up</td>
<td>128/86</td>
<td>125/75</td>
</tr>
<tr>
<td>Blood pressure decrease</td>
<td>11/4</td>
<td>11/8</td>
</tr>
<tr>
<td></td>
<td>13/4</td>
<td>16/10</td>
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</tbody>
</table>

Values under the column “Ambulatory” are blood pressure values measured by physicians in a clinical settings, those under “Holter” show average values of 24-hour monitoring (the latter are considered by physicians the most reliable measures). For each measurement type, figures at trial start (Enrolment) and end (Follow-up) are quoted. Patients using the spoken dialog system (treatment group) on the average show a slightly better control of their ambulatory blood pressure values with respect to the control group. The decrease of Holter measure is much more evident. Both groups exhibit a statistically significant decrease in blood pressure with respect to enrolment. All figures quote systolic/diastolic blood pressures.

5 Conclusion

The present work illustrates an automatic dialogue system, with particular reference to the reasons why these systems are especially relevant for individualized patient monitoring. We applied this technology in the medical domain of hypertension, but it is worth stressing that it can be adapted to the most part of chronic disorders, when patients’ treatment develops at home. The acceptance of our dialogue system among patients was very satisfactory, as it is confirmed by the fact that, months after the trial’s conclusion, a remarkable fraction of the patients originally enrolled is still using it to periodically report their data. Up to now only the effectiveness of the system on the health outcome has been estimated. Future direction of the study will include an economic evaluation, considering the fraction of patients requiring hospitalisation and additional treatment to cure side effects.

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User Modeling for Tailored Genomic e-Health Information

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Abstract. GenIE, a prototype intelligent system currently under development, is intended to assist genetic counselors by creating editable first drafts of genetic counseling information tailored for their clients. In this paper we describe GenIE’s approach to constructing the normative component of a genomic user model, a model of the patient’s genomic health. Also we describe future plans to include patient-tailored interactive graphics for conveying risk information in electronic documents drafted by the system.

1 Introduction

We are developing GenIE, a prototype intelligent system intended to assist genetic counselors by creating editable first drafts of genetic counseling patient letters. In the USA, genetic counselors meet with clients to explain, e.g., genetic testing, inheritance of genetic disorders, and risks of multifactorial diseases such as cancer. The client may be a genetics patient or parent/guardian of the patient. In current practice, the information and clinical services provided to the client/patient are summarized by the counselor in the patient letter, a one- to two-page tailored print document [1].

GenIE will create a first draft of this type of letter using natural language generation (NLG) techniques [2, 3]. The genetic counselor will provide information about a patient’s case (such as symptoms, test results, and diagnosis) through GenIE’s graphical user interface. (It may be possible to acquire some patient information from medical records as well.) The system will create a user model from this information and a generic domain model on genomic health. By user model we mean a model of the patient’s genomic health, including genomic information about family members. A letter will be synthesized by applying linguistic knowledge on standard topics, organization and writing styles for this genre [4, 5]. A document editor will present the synthesized first draft for review and editing by the counselor.

One intended benefit of GenIE is to save the genetic counselor time by partially automating the letter writing process. In current practice, genetic counselors have limited time available for letter writing, and thus may use “cut-and-paste” methods to reuse pieces of previously written letters. Time constraints on members of this profession are not likely to lessen. As information about human genetics has increased at a rapid pace in recent years, so have genetic testing options; this is likely to increase demand for the
services of genetic counselors. In addition, GenIE might be useful as an educational tool to help physicians learn how to communicate with patients on genetics-related problems. (Note, however, GenIE’s role is not to perform decision-support functions, but to help explain the medical experts’ beliefs and reasoning to a lay audience.)

Documents drafted by GenIE could be presented (after being reviewed by the counselor) to their audience electronically, which would enable written text to be augmented with graphics for low-literacy and low-numeracy recipients. Although in current clinical practice visual aids (e.g., [6]) may be used at the client meeting, it is not feasible for today’s writers to include tailored graphics in patient letters. Thus, in addition to the goal of generating written text, we are currently investigating generation of tailored interactive graphics to help explain probability-related information in patient documents presented electronically.

2 Genomic User Model

GenIE’s user model will integrate two components, one which we term an affective component and the other a normative component. The affective component represents variables relating to the client’s appraisal of issues represented in the normative component [7]. The focus of this paper, the normative component of the user model, integrates generic genomic health information with evidence and expert judgments about the client’s case. In this section, we describe the creation and structure of the normative component of the user model.

2.1 Corpus Project

The normative part of the user model is constructed by updating a generic genomic health domain model with patient-specific information. The design of the domain model has been informed by an encoded corpus of twenty-one genetic counseling patient letters. The letters were encoded by members of our project using a coding scheme we developed for representing the biomedical content in genetics counseling letters [8]. The coding scheme provides a small set of tags (History, Genotype, Mutation-event, Biochemistry, Physiology, Symptom, Test Result, Probability, Karyotype, and Complication), the first eight of which were formally evaluated and shown to have very good intercoder reliability [8]. These tags are used to annotate phrases in a letter referring to causally or probabilistically related concepts. These concepts may be viewed as variables in a Bayesian network (BN) model [9, 10] of a letter’s biomedical content. For example, a sentence from a letter published in [1] followed by its encoding is shown in Figure 1. (The term proband in genetics refers to the person of interest in a genetic study, in this case, a child patient.)
Philip was diagnosed as having a pseudoarthrosis of the left tibia and also several café-au-lait spots both of which are features of neurofibromatosis.

Philip was diagnosed as having `<symptom-3.1/proband` a pseudoarthrosis`>` of the left tibia and also `<symptom-3.2/proband` several café-au-lait spots`>` both of which are features of `<genotype-3/proband` neurofibromatosis`>`.

**Figure 1.** Sentence from patient letter in original and in encoded form.

2.2 Genomic Domain Model

Generalizing from cases modeled in the encoded corpus, we constructed BN graphs representing several genetic disorders. (Since we are not experts in clinical genetics, reference books were sometimes consulted for clarification.) A corpus-based approach to design is being used so that the domain model will represent the biomedical concepts and reasoning of the genetic counselor at the level presented in the letters, i.e., at a level of detail designed for a lay audience. From the encoded letters, we determined relevant variables (of the types defined in the coding scheme), their domains, and network topology needed to represent a disorder. However, to implement the domain model as a functioning BN would require acquiring the full conditional probability tables for each BN variable. Since it is not our goal to provide decision-support capabilities, the domain model is not required to compute probabilities. Thus, to avoid the cost of acquiring numeric probabilities, we decided to implement the domain model as a qualitative probabilistic network (or QPN) [11, 12]. A QPN is an abstraction of a BN where qualitative constraints are specified instead of probability distributions.

Qualitative constraints for the domain model are specified in terms of the relations of qualitative influence, product synergy, and additive synergy as defined in [11, 12]. Types of qualitative constraints characterizing the domain of clinical genetics seen in our corpus include the following [13]:

- Arcs in a BN represent positive and negative qualitative influence. An example of positive qualitative influence is the relationship between genotype and symptom, i.e., a genotype with one or two abnormal alleles may cause a certain symptom.
- An example of negative product synergy is the relation of two genetic disorders to a symptom, i.e., where they are assumed to represent mutually exclusive possible causes of the symptom. Negative product synergy licenses a kind of intercausal reasoning (sometimes called explaining away). Another example of negative product synergy is inheritance of an autosomal dominant disorder. (Autosomal dominant disorders are caused by having one abnormal allele.) Since a child inherits two alleles, one from each parent, if a child has an autosomal dominant disorder then increasing belief that one parent is a carrier of the abnormal allele explains away (reduces) belief that the other parent is the carrier.
Autosomal recessive inheritance illustrates zero product synergy. (Autosomal recessive disorders result when both alleles of a gene are abnormal.) Zero product synergy does not permit explaining away.

The combined effect of a treatment and a genetic disorder on some symptom can be defined in terms of negative additive synergy, i.e., the treatment may diminish the effect of the disorder.

Figure 2 shows part of a domain model for Neurofibromatosis 1 (NF) constructed from the letter published in [1]. As shown in the model, the genotype for NF (G3) may cause symptoms of pseudoarthrosis (S3.1) and/or café-au-lait spots (S3.2). NF is an autosomal dominant disorder. Either parent may have transmitted the abnormal allele to the proband (G3). If the mother or father had inherited the mutation (G24.1 or G24.2, respectively), then that parent might present symptoms of NF (S24.2 or S24.3, respectively). However, another possibility is that the mother or father experienced a mutation event (M26.1 or M26.2, respectively) that affected the reproductive cell of that parent (G26.4 or G26.5, respectively) that contributed DNA to the child (G3). (In that case, the parent carrying the mutation would not present symptoms.) All arcs in the figure represent positive qualitative influence. The four possible causes of G3 are shown in a relation of negative product synergy (denoted by X-) to G3.

2.3 User Model Creation and Use

The normative component of a user model is created by updating the generic domain model with information about a specific patient’s case, including relevant information on family members. GenIE’s graphical user interface presents the genetic counselor with a pedigree tool for diagramming a patient’s family tree, as shown in Figure 3. The graphical user interface also enables the counselor to set the values (with probability estimates) of history, symptom, test result, and genotype variables for any member of the family tree, as shown in Figure 4. For example, the generic domain model shown in Figure 2 could be updated from information entered through the graphical user interface to represent a patient who has pseudoarthrosis and café-au-lait spots (updating S3.1 and S3.2) and whose most likely diagnosis is NF (updating G3). In addition, the genetic counselor could enter the information that neither parent has symptoms of NF (updating S24.2 and S24.3), and (therefore) it is not likely that they have inherited NF (updating G24.1 and G24.2).
Qualitative constraints may be applied to provide the natural language generator with derived information needed to draft a patient-tailored letter. For example, an explanation for why it is believed likely that one of the parents has germline NF can be derived from the beliefs that the proband has NF and that the proband’s NF mutation must have been inherited, but that it is unlikely that either parent has inherited NF; thus, by elimination, one of the parents must have germline NF. Alternatively, if the generic domain model were updated to represent a case where the mother also has symptoms of NF, then the user model could help the natural language generator provide the following explanation: since she presents symptoms, it is likely that the mother has inherited NF, which she could have transmitted to her child. (Thus, belief in the other three possible sources of the child’s NF mutation would be explained away.)

GenIE’s NLG component has not been implemented yet. However, Figure 5 shows a prototype graphical user interface for the document editor that would enable the writer to review and edit the first drafts created by GenIE.
3  Tailored Interactive Graphics

In genetic counseling, much of the information to be presented involves probability. Effective presentation of probability information to a lay audience faces numerous problems identified in the field of health risk communication (see, e.g., [14]). In addi-
tion to the goal of generating written documents for clinical genetics clients, we are interested in augmenting the text with computer graphics in order to address these problems.

As a starting point, we have designed a tailored interactive graphic that can be added to a generated document to illustrate simple autosomal inheritance. This is sometimes illustrated in genetics textbooks or counseling aids [6] with static pedigree diagrams representing the parents and four potential offspring, each illustrating a different possible combination of the two alleles from the parents. Such diagrams have several limitations. First, they are not tailored for a particular patient. Second, they do not convey pictorially the magnitude of the risk for and against a particular outcome. Third, they are subject to the fallacy of non-independent events. For example, a client who is told there is a 25% risk of having a child with a certain genetic disorder may mistakenly think that since she has had three children so far and none are affected then her next child will be affected.

Figure 5. Editor for revising drafted letters in GenIE prototype under development. (Note: letter was drafted by a human author in order to demonstrate editing tools.)

As a starting point, we have designed a tailored interactive graphic that can be added to a generated document to illustrate simple autosomal inheritance. This is sometimes illustrated in genetics textbooks or counseling aids [6] with static pedigree diagrams representing the parents and four potential offspring, each illustrating a different possible combination of the two alleles from the parents. Such diagrams have several limitations. First, they are not tailored for a particular patient. Second, they do not convey pictorially the magnitude of the risk for and against a particular outcome. Third, they are subject to the fallacy of non-independent events. For example, a client who is told there is a 25% risk of having a child with a certain genetic disorder may mistakenly think that since she has had three children so far and none are affected then her next child will be affected.
We have designed and implemented an applet to address these problems. The applet presents two “wheels of fortune”, one for each parent (Figure 6). The graphic is tailored by being initialized with the number of abnormal alleles (0, 1, or 2) in each parent’s genotype according to the user model. (However, the user is able to reset the number of mutated alleles in a parent’s genotype to explore other scenarios.) The magnitude of the probability that a parent will contribute a mutated allele to the child’s genotype, and the complementary probability that the parent will not contribute a mutated allele, is depicted by dividing each wheel into two sections depicting the likelihood of the two possible outcomes.

The probabilistic nature of inheritance is conveyed through user-controlled animation. Each time the user presses a button (labeled Spin in Figure 6), the two wheels appear to spin and the applet randomly chooses the result of the spin (conveyed pictorially as the part of the wheel landing under a pointer). By running the animation several times, the user can see the non-deterministic nature of the outcome. In future work, we will evaluate the effectiveness of the applet.

![Inheritance Demonstration](image.png)

**Figure 6.** Screenshot of risk communication applet.
4 Related Work

MIGRAINE generated patient-tailored interactive explanations about migraine using information collected from the user (the patient) [15]. The HealthDoc project generated patient-tailored health-education documents using the medical record as user (reader) model [16]. The OPADE project generated user-adapted explanations of drug prescriptions for users with different information needs, e.g., the patient or the patient’s healthcare provider [17]. Although these systems used patient data, they did not represent it in a way that supported reasoning about the relationships between medical problems and diagnosis or treatment, as in our user model.

5 Summary

We are currently developing GenIE, a prototype intelligent system intended to assist genetic counselors by creating editable first drafts of tailored genetic counseling patient letters. In this paper, we described the normative component of GenIE’s user model, a model of the patient’s genomic health. This part of the user model is created by updating a generic genomic domain model, implemented as a qualitative probabilistic network, with beliefs about the patient and the patient’s family provided by the genetic counselor. This kind of user model supports derivation of qualitative inferences about the patient. In addition to its role in text generation, the user model will provide information for tailoring graphics for future versions of GenIE presenting documents in electronic media. In this paper we described a tailored interactive visual aid that we have developed to augment written material on inheritance risks.

Acknowledgments

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A Web-based System to Monitor and Predict Healthcare Activity

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Abstract. The UK National Health Service is subject to variation in demand for medical services, particularly during the winter. Such variations can cause major problems for the management of services to patients. This paper describes System Watch, a real-time system to assist with healthcare planning in NHS Scotland.

1. Introduction

‘System Watch’ monitors and predicts health service activity in real-time across Scotland via a web-based interface. Real-time information is available on: hospital emergency activity (subdivided into medical and surgical specialties), rates of infectious illness, and on ambulance emergency call-outs. Predictions are provided of numbers of emergency admissions and of bed occupancy. In addition to producing information on activity, System Watch also identifies vulnerable groups of patients admitted to hospital for whom intervention may be beneficial, for example repeated emergency admissions in elderly patients. Details of such patients are sent automatically to a hospital clinician who assesses whether the patient’s care can be managed differently to help prevent future re-admissions. Information on the website is updated immediately in response to new data and data may be submitted as frequently as a user requires.

2. User Consultation

System Watch was designed following consultation with potential users and other groups with an interest in monitoring healthcare activity and identifying patients with particular health attributes. Groups consulted included: Ayrshire and Arran Health Board who expressed a particular interest in the project during its early stages and agreed to pilot its use, the Scottish Centre for Infection and Environmental Health (SCIEH), the Performance Management Division of the Scottish Executive Health Department (SEHD), NHS24 (Scottish out of hours telephone service) and the Met Office who had started a project with similar aims to System Watch in England [1].
Discussions with these groups established that there was a role for a system bringing together real time data from several areas of the health service. The groups agreed to collaborate on the development of System Watch and where appropriate to make data available.

3. Data

A wide range of potential data sources were considered relating to: the acute sector, primary care, social services, prescriptions, local monitoring systems, weather and air pollution. Ideal sources of data were those that were available both historically, to allow predictive modeling, and also in real-time. (The term ‘real-time’ is used here to mean up-to-date rather than ‘as soon as recorded’, i.e. there is not a continuous feed of data.) Obtaining real-time data was often a limitation and several data sources that may otherwise have been useful could not be included. Table 1 summarizes the data that were eventually made available to the project and each source of data considered is described below.

Table 1. Project Data

<table>
<thead>
<tr>
<th>Data</th>
<th>Extent of Historical Data</th>
<th>‘Real-Time’ Availability</th>
<th>Used by System Watch?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital admissions</td>
<td>1981-2002</td>
<td>Individual records sent weekly</td>
<td>Yes</td>
</tr>
<tr>
<td>Flu rates</td>
<td>1992-date</td>
<td>Weekly by health board</td>
<td>Yes</td>
</tr>
<tr>
<td>NHS24</td>
<td>Dependent on area - earliest from 2003</td>
<td>Individual records sent weekly</td>
<td>Yes</td>
</tr>
<tr>
<td>999 call-outs</td>
<td>1999-date</td>
<td>Weekly call-out frequencies by health board</td>
<td>Yes</td>
</tr>
<tr>
<td>Local monitoring information</td>
<td>Weekly updates of local monitoring information for some health boards</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Weather</td>
<td>1981- date by health board</td>
<td>Available but not set up</td>
<td>No</td>
</tr>
<tr>
<td>Air Pollution</td>
<td>Earliest 1993 Dependent on area</td>
<td>Available but not set up</td>
<td>No</td>
</tr>
</tbody>
</table>
4. Predicting Activity

Poisson regression models have been used to model daily frequencies of admission and bed numbers [6]. Two types of prediction are produced. Model 1 is constructed using historical data from 1981 but weighted more heavily towards recent years. It fits week of the year (calculated from 1st January), day of the week and public holidays. No account is taken of real-time information and the predictions can be calculated for any time into the future. Model 2 includes the same factors as Model 1 and additionally real-time information on hospital admissions and rates of flu. This model predicts daily activity for three weeks ahead and is updated each time new data are received. Separate models were fitted for each of the 12 mainland health boards because patterns varied between areas and no advantage was gained from modeling all health boards in a single model. Hospital predictions were based on scaled down health board models because local decisions (e.g. a ward closure) could not be reflected in the model. All models were refitted regularly to take into account the latest additions to the historical dataset of hospital admissions. Results obtained from the models were found to be sufficiently accurate to be used in the bed management process [7].

Figure 1 is an example graph showing daily numbers of admissions to Edinburgh Royal Infirmary along with predictions. The triangular line shows observed bed occupancy figures, the diamond line is fitted using Model 1 and is referred to as a ‘Seasonal’ prediction giving a prediction for an indefinite period ahead, and the square line is fitted using Model 2 and gives short term predictions for three weeks ahead taking into account real-time data. Past predictions are also included to give users an idea of their expected accuracy. Each graph is accompanied by a table showing the values plotted with 95% confidence intervals for predictions.

Graphs of weekly totals, routine admissions, by specialty type and for individual hospitals are also available. In a typical health board with four hospitals 360 graphs would be updated each time new data are received. Flu rates, ambulance emergency call-outs and NHS 24 symptom frequencies are also displayed via separate links, although predictions are not yet provided for these statistics.

[Figure 1. Example graph from website showing daily admissions in Edinburgh Royal Infirmary]
5. Implementation

The information generated is made available via a web-based interface to give easy and immediate access to all users. It has been designed so that updates can be carried out at any time in response to new data being received. This gives control to users over how frequently information is updated for their area, for example during a pressure period it is likely that a hospital will choose to send data more frequently.

Providing information in real-time is a major feature of System Watch and it is important that the update process functions reliably and that any problems can be quickly rectified. Problems so far have included: errors with transferring data, server downtime, computer hardware problems, downtime of web servers, FTP and email problems.

6. Generating Information on Individual Patients

So far the role of System Watch as a planning aid to monitor and predict activity has been described. However, the availability of real-time patient-level data also allows information to be generated on individual patients. Vulnerable groups of patients can be identified (e.g. those experiencing multiple admissions), up-to-date patient histories can be requested by drawing from historical patient record databases, and predictions of the risk of various patient ‘events’ can be formed (e.g. risk following a procedure, risk of becoming repeatedly admitted to hospital, probability of requiring a procedure in patients referred to a clinic, probably of not attending a clinic appointment). Such knowledge can aid clinicians and other healthcare professionals in making decisions about an individual patient’s care. One example is the Evercare model of care for at-risk older people used in the US and currently piloted in the UK [8,9] to coordinate care in community-based settings and in nursing homes.

A scheme to identify elderly patients who are repeatedly admitted to hospital has been set up within System Watch. Details of any patient aged over 80 admitted to hospital more than three times in a year are automatically emailed to a hospital clinician. The patients are then reviewed and discussed with the patient’s GP who, if necessary, makes changes to their care. Although this information could be obtained manually from hospital notes, it is not routine practice for clinicians to check patients’ admission histories. Three health boards are participating in a pilot study using this approach [10]. There is also the potential to identify other groups of patients, for example identifying repeated admissions for self harm or in young children.

A feature has been built into System Watch to allow users to request details of a patient’s history of admissions to Scottish hospitals. Patients are identified by either their hospital case reference number or their Scottish community health index (CHI) number, and their history can be made available immediately to hospital staff via a secure web file transfer system. However, this feature has yet to be implemented as patient confidentiality issues must be considered.
7. Discussion

System Watch has demonstrated the feasibility of monitoring and predicting activity in real-time, and to derive, process and feed back information on individual patients. There are however several ways in which its scope can be extended: making more real-time data available and with a greater frequency, improving the accuracy of predictions, and by generating more diverse information on individual patients.

During the next few years it is expected that real-time information from electronic GP systems, results of laboratory tests, details of prescriptions received, out-patient clinic and accident and emergency attendances will become available to System Watch. At present the project relies on the co-operation of data providers to carry out manual extracts of data and analysts to initiate updates upon its receipt. An automated process to both extract and send data on a daily basis and to update the website is planned. This would reduce errors in the data extraction and update process and would lead to a more up-to-date system.

Historical records are maintained at ISD covering many areas of healthcare (e.g. hospital out-patient clinic attendances, birth, maternity, cancer, mental health, genetic abnormalities, etc) and provide a rich source data on patients. Interfaces are planned to access this information automatically on request. The availability of historical information combined with real-time information could form a basis for an integrated care record.

Vulnerable groups of patients are at present identified to hospital clinicians by email. However, in some situations it may be more appropriate to use other means, such as a mobile device. Such devices could also be used to request and receive patient information during consultations where there is no computer access, for example during home visits or by ambulance staff. It is also possible to arrange for a chosen patient contact to be automatically informed by email or mobile phone when the patient is admitted to hospital.

Forming predictions for individual patients is an area ripe for further development in healthcare. One example is described by Oniscu et al. [12] where survival of patients listed for renal transplant is predicted based on their co-morbidity and whether or not they receive a transplant. Other potential applications are: risk following a procedure, risk of becoming repeatedly admitted to hospital, probability of requiring a procedure in patients referred to a clinic, probably of not attending for an appointment, risk of abuse in children. Predictions can be generated automatically and flags provided if risk for a patient exceeds a particular level. However, such predictive approaches need to be constructed in consultation with clinicians to ensure that they have a practical use.

When making patient-level information available, patient confidentiality is an important consideration and procedures for obtaining the required permissions need to be put in place. Correct linkage of records is also important. This can be achieved with a high level of accuracy when the CHI number (Community Health Index) is attached to a record. There is currently an initiative in Scotland to attach the CHI number to all electronic medical records and encourage its use.

Readers with access to NHSNet can access the website at http://www.show.scot.nhs.uk/systemwatch using login: system and password: watch.
References

Personalised training tool using Virtual Reality

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1 Introduction

A few, largely preventable, risk factors account for most of the world’s disease burden. These are high cholesterol, high blood pressure, obesity, smoking and alcohol. Chronic diseases are the major cause of death and disability worldwide, and increasingly affect people from countries all over the world [1]. Guidelines on diet, physical activity and health serve two important purposes: to guide policy makers and to educate consumers, healthy or ill, about healthy lifestyles. In order to motivate and create adherence to prevention programmes it is highly recommended to stress the importance of lifestyle-health relationship. And it is also essential to analyse how to formulate these programmes and what information they should convey. The strategies drafted by the international institutions competent in the matter stress the importance to increase the overall awareness and understanding of the influences of diet and physical activity on health and of the positive impact of preventive interventions.

The work presented in this paper contributes partially to solve this situation by using one of the most effective strategies: the prevention, through the procedure of education. A tool based on virtual 3D technologies for the Internet [2], using X3D, a powerful and extensible open file format standard for 3D visual effects, has been developed creating an e-learning system, that includes interactive and immersion advantages, key for the success of these systems.

2 Materials and methods

The main advantage of the tool developed is the delivering of personalised information in an environment adapted to the user. This personalisation is performed by taking into account the user’s needs, preferences and motivation. To do so, a structured questionnaire about nutritional, statistical, physical activity and motivational data was developed with the help of professionals. The questionnaire is presented in different parts, grouped into: registration, statistical, nutritional and physical exercise and, finally, motivation. After choosing the identification data, statistical, nutritional and physical exercise forms are prompted. Finally, motivational data are requested. All applicable questions need to be answered. After the data are collected, the user profile is stored in the database. Each group of questions has a specific objective: the statistical questions classify the users by age, gender, health status, ICT knowledge or profession. Nutritional questions enquire if the users are vegetarian or if it is common that they often eat out in order to allow, for instance, the creation of customised diets. Motivational questions are related to the importance the users give to their self-care through the lifestyle adopted up to the moment or the intentions to incorporate healthier attitudes in the future. The goal of these ques-
tions is to place the user into a motivation status according to the “Stages of Change” methodology [3] which sets the characteristics of each state and the motivational techniques to be used for citizens positioned in each of them. To carry out the personalisation we selected a number of dimensions that affect the lifestyle of individuals. From a significant number they were reduced down to: age, illness, motivation and self-efficacy. According to these factors, we analysed which of them affected the information provided (i.e. tone, format and content). Afterwards, the data “in the user profile” is matched against these factors and the information is presented accordingly. This was decided with the help of specialists. The following stage is to categorise users into different training groups so that training is provided in a structured and personalised manner. To summarise, the following characteristics are considered:

- type of actor: Healthcare professional, ICT system administrator, patient, Healthy Citizens/support groups, etc
- skills: knowledge on ICT, knowledge on health and education
- consumers attitude and motivation: using ICT devices and caring about their health
- social background: age, cultural background and accessibility to ICT and education

In Figure 1, each circle represents one of these features. Being “inside” a circle means having that feature and on the other hand, being “outside” represents a lack of that ability. Each intersection has its own features and lacks so it shows specific needs in order to train and motivate the users. By placing users in the zones (A, B, C, etc) we classify them into training groups. Table 1 describes the characteristics of the different training groups.

![Fig.1. Training features: classification of users Based on the methodology developed for the e-User project [4]](image)

After identifying the characteristics of the training group, we matched the groups against the dimensions explained previously: type of actor, skills, motivation and social background in order to develop a truly personalised training tool. Besides, a lot of effort was put into analysing the expected training outcomes. Before the beginning of the session a survey is handed out in order to know:

- Statistical details: age, gender, disabilities
- Education and ICT education: fields of study, degrees earned, computer literacy
- Cultural background: language, place of origin, traditions, sensitive subjects
- Employment background: experience, time in current job, relationships with other participants
- Motivation: attitudes towards self care, the use of new technologies, status of health, etc
• Expectations: reasons for attending the course, expected results.

<table>
<thead>
<tr>
<th>TYPE</th>
<th>DESCRIPTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>User of platform: the target to achieve in this case is to maintain the user in the current situation (access, competences and motivation on ICT and health).</td>
</tr>
<tr>
<td>B</td>
<td>Lack of motivation on health but access and competence given, most likely from user experience at work or from basic education. Good competence in ICT. Focus should be given to make aware of self-care benefits.</td>
</tr>
<tr>
<td>C</td>
<td>Access and motivation on health given, but lack of competence. Traditional target for ICT training measures, high probability of success of such measures.</td>
</tr>
<tr>
<td>D</td>
<td>Only access given, but neither competence nor motivation on health. Severe barriers exist before online services will be used. Likely to apply for many older persons who live in households together with their children who provide the access.</td>
</tr>
<tr>
<td>E</td>
<td>Only access is missing. The bottleneck here is infrastructural equipment, which may need to be provided by the state as in the case of free public Internet access points. Also applies to many disabled who need special devices and services to access mainstream computer applications. The use of mobile (easy-to-use) equipment could be an approach here.</td>
</tr>
<tr>
<td>F</td>
<td>Only competence given, most likely from basic education. Motivation on the self-care process benefits is likely to be the bottleneck here.</td>
</tr>
<tr>
<td>G</td>
<td>Only motivation on health exists. Applies for parts of the poor population who show a strong commitment to society, but lack the means to gain competence and access to the Net. ICT training and mobile equipment could be a solution here.</td>
</tr>
</tbody>
</table>

Table 1. Training group characteristics

Furthermore, three different levels are then taken into account to perform the personalisation:

• The content of the information provided is adapted to the users’ needs
• The environment is personalised according to the user preferences
• The tone in which the information is presented, that depends strongly on the user’s state of motivation.

In this sense, only relevant information in the appropriate mode (direct, indirect, soft, etc.) is delivered to the user through a scenario accordingly personalised (avatar, colours, links, etc.). This personalization is performed by applying several rules, which allow the system to infer the content, the environment and the tone to be applied to each instance of the different profiles.

The tool is integrated in an e-learning environment which is interactive and immersive. X3D allows the description of a virtual world in XML format by means of predefined tags. The scenarios are virtual worlds that simulate a real daily world. A training activity in the system consists of an Internet multimedia session that shows personalised information by means of an attractive visual interface.

3. Results

In addition, the tool implemented has been developed to present the following features:

• To be visual and interactive
• To be integrated in an e-learning system
To offer personalised information in form and content

A training activity consists of an Internet multimedia session that shows personalised information by means of an attractive visual interface. The personalisation of the scenarios involves, presenting different information (links, articles, recipes, sport videos, etc.) to each user profile. In order to perform the personalisation, the system accesses the database and extracts the model files stored. Adapting the information includes not only the content but also the form (i.e. tone in which it is presented). This depends strongly on the user motivation state [12] to follow advice and to adopt changes to a healthier lifestyle, identified in the profiling stage.

The tool has been tested with a number of users to check whether the tool and the information provided suited the users’ needs. A survey was handed out for completion after the first training session in order to measure their satisfaction with the system. The survey is structured in different parts, related to the adaptability of the contents, the appropriateness of the relation between the scenarios and the information showed in each of them, the choice of Virtual Reality as the interface and the usability of the global tool. Statistical data were also collected, such as the age, the profession or the computer knowledge level.

The sample was formed by 52 citizens and covered people from a large range of ages (18, >60) and different occupations (medical, technical and other). The results of the survey indicate that 72% agree with the high potential of e-learning systems. This percentage is similar for every age range. However, Virtual Reality is valued quite negatively among people over 46 (35%) opposed to the students and technical professionals (70%). The usability of the tool is ranked positively (75%), although it is stated that users would like to see a more dynamic application. Furthermore, 80% of the users state that the relation between the scenarios developed and the information provided in each of them was tailored to their needs and the contents were marked as a good educational tool to adopt a healthy lifestyle. Figure 2 shows the system appearance.

4. Discussion

4.1 Quality healthcare information

It has been long argued that the Internet can potentially support consistent and effective health promotion and disease prevention strategies to both the health care provider and the patient [6]. The existence of easily accessible clinical and patient information resources provided by the use of these tools will likely change, the traditional clinician-patient relationship as both parties use information resources to educate and inform themselves and each other about diagnosis therapy, and prognosis [7]. Moreover, reasons for the growth of the consumer’s online health information-seeking include the development of participative consumer-oriented healthcare models, the growth of health information that makes any one clinician incapable of keeping pace, cost-containment effort that reduce clinicians’ time with patients and raise concern about access to “best” care, emphasis on self-care and prevention, and ageing population with increased healthcare needs, and increased approaches to health care [8].

Furthermore, concerns about the quality of healthcare information found on the web let to the focus of one “Healthy People 2010’s” health communication objective, “quality of Internet health information sources”, as public health officials recognise that “the potential for harm from inaccurate information is significant” [10]. Quality of health information found on the Internet should be subjected to the same standards as traditional information, including source and message characteristics, as well as adaptability to targeted
audiences. Therefore, personalised healthcare information, continuous patient supervision by medical doctors and certificated healthcare information is fundamental to promote and effectively enhance the patient’s healthcare process.

Fig 2. The system appearance.

4.2 Personalisation and motivation to achieve results

Healthcare professionals stress the importance of motivation and determination in order to stick to a plan to lead a healthy lifestyle. There are numerous studies that analyse the motivation to lead a certain conduct or treatment and analyse the change of behaviour depending on the individual’s attitudes: the basis is the Self-Determination theory [9, 11]. As results depend on the motivation of the individual (UCLA Center for Human Nutrition, 1996) [12], one of the goals of our tool is to provide information that motivates the users and takes them through the different stages of motivation described in the model called “Stages of Change”.

The new healthcare delivery process models tend to be citizen/patient centred, that are respectful of the individual preferences, needs and place information and training at the heart of the healthcare delivery strategies [12]. People should have better access to trusted sources for the information they need, tailored to their individual requirements.

To conclude, the tool developed provides certified information and achieves personalisation by considering different dimensions of people’s lifestyle and filtering the information according to:

- Who the user is: a Healthcare professional, a Citizen, etc.
- What the user needs: different information or services the user may need
- Where the user is: considering different scenarios, including “on the move”
- How the user needs the service: considering different type of devices

Moreover, we believe that the tool developed provides an enhanced mechanism to train the user in the management of personalised information to promote a healthier lifestyle. Although human interaction should not be avoided [13], the support of an Internet tool is
key to access information personalised, certified and motivates the user [14]. In conclusion, the tool developed is a significant improvement to empower citizens to evolve in the self-care process providing them more control over their own lives.

5. Conclusions

An interactive and visual tool has been developed and integrated in an e-learning system that offers personalised information about healthy lifestyles. We consider that this is a very interesting research line due to the increase of e-learning systems and the importance of having access to quality information related to health. Joining both in the same system provides citizens with a way to obtain information to be responsible for their own health. Moreover, the implemented tool adds a motivational feature with the aim of making users feel taking control of their own self-care.

Our intention is to focus on a more dynamic tool, so that the promotion for adherence to therapies and compliance matches the dynamic lifestyle of the users. Besides, we feel that a new dimension should be included: the idea of “self-confidence” or “self-efficacy”. Our research will go in this direction.

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References

Evaluating how users interact with NHS Direct Online

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Abstract. Evaluating the NHS Direct Online website presents some challenges and therefore a number of evaluation methods and approaches are utilized by NHS Direct. This paper presents one approach, web log analysis, to explore how users interact with the NHS Direct Online website. Focusing on one health topic, MRSA for one-day’s website visits, proved informative and highlighted a number of interesting questions about the user interaction with the MRSA topic and about navigation on the website. The findings show 242 visits to the Methicillin-resistant staphylococcus aureus (MRSA) topic, the PDF or print pages were visited 9 times on the day, and therefore, it may be assumed that the MRSA topic was viewed in an apparently logical sequence. For the remaining visits to the website, some visits achieved quite good coverage of the MRSA topic, however, none of the visits followed any of the logical sequences hypothesized for viewing health information content.

1 Introduction

NHS Direct provides the main health advice and information service for the NHS for patients and the public. The NHS Direct telephone service has handled more than 25 million telephone calls since its inception as a pilot project six years ago, and the NHS Direct website (www.nhsdirect.nhs.uk) has received around 19 million visits since it was launched in December 1999. The NHS Direct self-help guide will soon have been delivered to 18 million households in England as part of the Thomson Local directory, and NHS Direct Interactive, a digital satellite health information channel, is now available to some 7.5 million homes.

NHS Direct New Media is the directorate within NHS Direct with responsibility for provision of the digital health information platforms such as the website, NHS Direct Interactive (health information channel on digital television) the printed self-help guide and the Online Enquiry Service. The purpose of providing a range of health information platforms is to ensure that information about health care, treatment, self-care and healthy lifestyles is accessible to a diverse population in respect of their health needs for information.

The NHS Direct website had over 6 million visitors during 2003/4. The health information provision on the website includes:

1. A self-help guide to treating common health problems at home;
2. An encyclopaedia covering hundreds of health topics, with links to other quality assured health websites;
3. Information on the choice of treatments available for 60 different conditions;
4. Frequently asked questions;
5. Hot topics on the latest health issues;
6. A searchable database of local health services e.g. GPs, dentists, pharmacies;
7. A contact us section of the website
8. An online email service for requesting health information (Online Enquiry Service).

Every time a user links up to a website, the server keeps track of all the actions in the web log file. The web logs provide details about file requests to a server and the server response to those requests. The type of data that can be collected depends on how it has been set up and defined by the technical staff. Log files can contain an enormous amount of data that may be irrelevant to what is required for the analysis; therefore, extraction methods for relevant data are required.

In a health information environment collecting and analysing the web logs could potentially provide information about the numbers of people coming to the site, the health topics of importance to the public and what aspects of the health topic they are viewing.

2 Literature Review

2.1 Using the Internet for health information

Health information is considered fundamental for promoting patient choice, informed consent, shared decision-making and self-care. The Internet plays a crucial role in UK government proposals to provide more information to create a more informed patient population\(^1\). The NHS Plan, published in July 2000, made a commitment for patients to “have far greater information about how they can look after their own health and about local health services” and that “patients will be helped to navigate the maze of health information through the development of NHS Direct New Media, digital television, and NHS Direct information points in key public places”\(^2\). Providing better information has been identified as one of the key methods of improving patient experience by understanding what people want in terms of information and ensuring that the information is there when, where and how they want it with the expectation that good quality information forms the basis for patients to make informed choices about their care.

Increasing numbers of consumers are using the Internet to support their healthcare\(^3\). Worldwide there are over 6.75 million health-related internet searches carried out every day, representing approximately 5% of all internet searches\(^4\). The Internet is increasingly playing a role in lay help-seeking behaviour, with many clinic-based surveys showing that patients are using the internet in relation to specific health consultations\(^5\). People consult the internet both for themselves, and on behalf of families and friends\(^7\). It is well known that
patients may not have all their questions answered in traditional health encounters. It is possible that internet health services are able to help those who for whatever reason are unable to have their questions answered in a formal health setting.

### 2.2. Methicillin-resistant staphylococcus aureus (MRSA)

Some microorganisms, referred to as pathogens, cause infection when they gain access to body tissues, establish themselves, multiply and cause an adverse reaction. Certain parts of the body have a natural flora or commensal population of microbes, which are harmless in the area they normally inhabit but may set up an infection elsewhere in the body. Bacterial resistance to antibiotics may be intrinsic or acquired. Intrinsic resistance is associated with a natural property of the organism, whereas acquired resistance arises either from mutation in sensitive cell populations or by the resistance from one cell to another. Staphylococcus aureus is commonly present on skin and mucous membranes. The most common site of colonization is the nose, 20-30% of the general population are carriers’ of staphlococci. Some staphylococci aureus organisms have acquired resistance to antibiotics primarily because of the frequent and sometimes injudicious use of antimicrobial therapy. Mild, moderate and serious infections due to MRSA involving soft tissues, bones and joints, postoperative wounds, urinary tracts and lungs have been reported. Autoinfection is responsible for approximately one third of infections due to this organism. However, the most important mode of spread for MRSA is probably contact transmission by the hands of health care professionals. Worldwide staphylococcal infection is a major form of acquired sepsis in hospitals and is responsible for outbreaks in hospitals. It is for this reason that MRSA has a high profile with the public and with the popular press. Phrases such as ‘hospital super bug’ have appeared in alarmist media stories. Therefore, there is a need for the public to be able to access good quality research-based information about the prevention, causes, symptoms and treatment of MRSA.

### 2.3 Web log analysis

There is a paucity of published research or professional papers about web log analysis. However, what there is can generally be found in the computer science literature and rarely relates to health websites. Nicholas et al 2004 evaluated the NHS Direct New Media website and undertook a web log file analysis. The main outcome from the study was the development of useful theoretical concepts relating to how the public generally search for health information on the Internet; concepts such as ‘promiscuous users’, formulated for those who visited a combination of websites, which included the NHS Direct website. The authors reported that site penetration search sessions lasted approximately five minutes and approximately three quarters (74%) of user sessions featured three or fewer pages, 20% contained between 4 and 10 and 6% featured 10 or more pages. The potential of web log analysis has, of course, been recognised in commercial settings where the aim is to have an understanding of how the website is used to subsequently increase the visitors to the website and this is where the commercial software companies are finding a niche.
3 Study design and methods

The purpose of the study is to develop a web log analysis approach that would enable the exploration of how users interact with the NHS Direct Online website.

The objectives of the study are to:

1. Develop an approach to web log analysis that will enable the NHS Direct New Media web logs to be analysed in a meaningful and informative way.

2. Establish an approach to extracting, truncating and analysing the data from NHS Direct New Media web logs.

3. Develop an awareness of the navigation and health information seeking behaviour of users accessing MRSA information web page on the NHS Direct New Media website.

3.1 Time period of the study

A Monday, 4th October 2004, was identified for data collection for this study for a number of reasons; first, the volume of website traffic is generally highest on Mondays. Second, there were no uncharacteristic changes to the volume of website traffic due to; the operation of the servers, which were fully operational, there were no adverse MRSA media stories and there was no additional website activity related to MRSA, such as a ‘Hot Topic’, which presents topics of interest that are for a particular time under public scrutiny.

3.2 Description and processing of the data

To cope with the amount of daily visitors to the website NHS Direct New Media uses three servers. In order to manage a vast amount of data this study proposes to process and analyse one day’s log file data. Even exploring one day’s activity from three servers for the website comprised over 121MB. These large data files were transferred to SPSS and data truncation methods were used, according to accepted web log analysis conventions, to reduce the data to visits to the website.

The variables used to identify a visit to the website by a computer or computer network visit are; time, IP address and user browser and operating system characteristics. Confining the analysis to the visits within a topic area increases confidence of identifying the linked pages, rather than identifying the associated pages across many hundreds of health topics, which is the usual web log analysis approach.

4 Discussion of findings

MRSA was the 15th most frequently visited health topic on 4th October 2004, comprising 242 visits, which reflects the general public health concern with MRSA. The most popular time for accessing MRSA information was between the
hours of 7pm and 10pm. 56.1% (n=137) only visited one page during their visit and of those 86.1% visited the introductory page. It is interesting to reflect on this finding; do the majority of people only search for broad introductory level information and not have any interest in the causes, symptoms, treatment and prevention of MRSA or are the links from this page to other aspects of the topic information navigationally difficult to find. The site penetration data of 74% visiting 3 or fewer pages in the Nicholas et al (2004) study cannot be compared to the data in this study which explores topic penetration. The concept of site penetration is the number of pages it would take to get through to useful information. However, in the current study the user has already penetrated the website to a health topic and therefore, this concept was not directly applicable.

Health information in its written form is commonly presented according to an accepted public health structure. This structure appears to logically support the step-by-step development of comprehension of the health topic under examination and comprises:

- Introduction
- Causes
- Symptoms
- Treatment
- Prevention

On the website, the various sections of the health information topic are presented in the top central bar, which is meant to be indicate that content should be accessed in the order from left to right, in the following order:

- Introduction
- Symptoms
- Causes
- Treatment
- Prevention

This structure varies slightly from the usual written structure and symptoms appear before causes. It is possible that visitors to the website did not recognise that the information sections are meant to be accessed from left to right across the bar and therefore, may read the sections from the top line to the bottom line and in this case the order would be:

- Introduction
- Treatment
- Symptoms
- Prevention
- Causes

Although some visits showed relatively good coverage of all sections of the content of MRSA on the website, none of the visits, with the exception of the visits viewing the PDF/print pages, searched for MRSA health information according to any of the possible hypothesized pathways presented above. This
poses a question about the impact of health information, in respect of the visitor increasing their knowledge and gaining a comprehensive understanding of the health topic, if the visitor is not following the usually accepted structure of health information. It may be that searching for health information on a website is fundamentally different in nature to written information and visitors access it in a much more unsystematic way. An additional question would be, if the navigational bar at the top of the page, which contains the information sections of the topic, does in fact help visitors to search for health information in a way that is meaningful for them. Further research would be required to understand the complex issue of how visitors search for information on a health website and to identify if there should be increased signposting to information, which guides the visitor through a logical journey to the various sections of the health topic. Nine print or PDF pages viewed indicates that all the topic information was accessed, possibly to be viewed at the visitors leisure or with friends/family/colleagues when offline. Therefore, it may be considered that all the MRSA information was viewed on these occasions in a logical order and this is a positive outcome for NHS Direct New Media.

References

e-Health Portal and SNOMED for a more personalized integrated EHR

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1. Changes and challenges
The healthcare industry has gone and is still going through profound changes. Those changes raise new challenges and to address them, the technological approach to the electronic health record (EHR) must be reviewed accordingly.

1.1 Ambulatory care
One of the most profound change seen in many countries around the world is a shift from an hospital based healthcare system to a more ambulatory system with home care, day care clinics, same day surgery,… We are now treating patients in ways that were thought impossible a few years ago. It is now possible for a patient to come to the hospital in the morning, have his coronarography and be home at night! You can also have your intravenous antibiotics at home or have adjustment to your anticoagulation regimen on an out patient basis.
With those changes we saw the advent of collaborative care and the challenge of assuming the continuity of care in a now very distributed environment with a multidisciplinary approach and more mobile health professionals. As a result, access to information, efficient communications and knowledge transmission are more important than ever so the care team can work together in a coordinated fashion.

1.2 Chronic diseases management
The incidence of chronic diseases is rising in part due to the aging of the population and more efficient treatment. They are also more complex with multi-organ involvement. With chronic diseases, our management aims at stabilizing the patient and keeping him in that state but also slowing/stopping more functional deterioration and preventing more complications. To achieve those goals it is mandatory to have a high level of coordination in the care team but also to actively involve the patient himself.
The challenges are the same one of the ambulatory care setting but this time the patient must also be an active part of the care team. As such, he must be able to enter information in his own medical record (ex: blood pressure 3 times a day, daily weight, fluid intake,… but also access information tailored for his clinical condition or communicate with the care team.

1.3 Knowledge management
The healthcare sector is one of the most information driven industry and the amount of information that must be dealt with on a regular basis is growing every day. Also with
the advent of the Internet, access to information is more and more easy. It is now usual to have a patient coming to his appointment with printed documents that he found on the Internet.

The challenges secondary to the explosion of information and their easy access are mainly related to quality of this information and information overload prevention.

1.4 Classical EHR approach

Most of the EHR that are available on the market today are not patient-centered but rather ‘hospital-centered’. As such they were not design to address easily the challenges raised by the new paradigms found in the healthcare sector those days. One of the consequences is that the care activities delivered outside the hospital walls are difficult to integrate or not at all. Another major consequence is that no tools or functionalities are available to integrate the patient as an active member of the care team or care team members that are not hospital based.

So to address those new cognitive needs, workflow and knowledge/information life cycle, a new approach must be considered.

2. e-Health Portal: a technological approach tailored for a personalized HER

2.1 Architecture

An e-Health Portal is a composite application that can integrate multiple different clinical applications and make them look as one integrated EHR with one single sign-on (Fig. 1). It is a very modular and scalable solution. The architecture is very versatile and personalization is one of its strengths.

![Fig. 1 e-Health Portal Architecture](image)
2. Patient and community integration

It is now possible to find on the market e-Health Portal that integrates a community and a patient portal. This holistic approach makes it possible to actively involve them more actively in the healthcare system. Having their own space, it is possible to integrate tools and information that are tailored for their particular needs. Most of the products find on the market today make it possible for the patient to enter clinical information in his own record that are sent to a data base and with rules integration, have alerts send to a health professional based on his care management plan (fig. 2). Communication tools are also integrated to support multidirectional messaging between them and the care team. That way, patients can have their own personalised EHR. Community portal are more generic or can be tailored for a specific disease.

3. SNOMED: the key for tailored information and knowledge management

3.1 Unstructured Information

One of the major problems in the healthcare sector is that the majority of important information is still in the form of free text (medical history, nurse notes, … ). In this format, this information is extremely difficult to manage on a large scale and cannot be considered in a clinical decision support system (CDSS).

3.2 SNOMED driven personalized knowledge/information management and decision support systems

SNOMED is a systematized nomenclature of medical terminology and concepts. With it, it is possible to encode medical information in free text and have this information in a standardized format for exchange and processing by machines. We can find on the market at least one automatic encoder that is integrated in a word processing software (Fig. 3).

With the incorporation of this tool in a portal, it is now possible to think that we can encode medical information found in free text and have them used by CDSS or to trig-
ger a search for information tailored for a particular patient. By extension, the same can be applied for patient and also the triggering of guidelines and protocols can also be programmed based on the input from the encoder.

![SNOMED Automatic Text Encoding](image)

Fig. 3 SNOMED Automatic Text Encoding

4. **Research integration: accelerating the knowledge turnover**

Another problem found in healthcare is the time it takes for the positive results of a research study to be used by the care team for actual patient care. To address this specific problem, we will test next autumn a new approach by incorporating general practitioners in the research team. Through a portal, they will be informed about actual and potential projects, enroll their patients and enter the research information. In exchange, they will be able to access continuous medical education tailored for their needs and access/communicate with a specialist to help them in the management of their patients. Since they will be involved from the beginning in the research project, it will be easy for them to transfer the research results in their own practice in a very rapid and efficient way.

5. **Conclusions**

Major changes in the healthcare sector have raised some interesting challenges. To address them, one of the best tools available in the market today is e-Health Portal. e-Health Portal has the technology to integrate disparate systems and give synergy to information coming from various sources. They can also integrate the community and the patients in a more active and personalized way.
Intersecting electronic decision support with user modelling in a web-based consumer decision aid for colorectal cancer screening

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Abstract. Colorectal cancer (CRC) is one of the most common types of cancer. However, its associated mortality can be ameliorated through effective screening tests dependent on high uptake and adherence within a target population of older adults. This paper describes a developmental process to deliver specific tailored information via the web to assist individuals in making a decision to undertake screening. This decision aid aims to adopt behavioural theories to define the psychosocial variables within a user model; such a model could then be utilised to individualise tailored information to initiate and sustain a decision to undertake CRC screening.

1 Introduction

Colorectal cancer is one of the three most common cancers of Europe, North America, Northern Africa, Western Asia, South Eastern Asia and Australia [1]. In the United States, in 2003 it was predicted to account for 10% of all cancer-related deaths [2]. Similarly in the EU, CRC accounted for 13% of new cancer cases and ~10% of cancer deaths in 2004 [3]. In Australia CRC was responsible for 14% of cancer deaths for the year 1990 [4] and is the most prevalent form of newly diagnosed cancer [5]. Despite the prevalence of CRC, research suggests that only 20 to 40% of people in the targeted age group (50/55 to 75 years) actually screen by testing for faecal blood. Moreover, this low uptake level for screening occurs despite the fact that the most commonly used faecal tests, the faecal immunochemical test (FIT) for blood in faeces and the faecal occult blood test (FOBT, non-specific chemical detection) are easy to use, safe and inexpensive [6,7]. Tests are effective with trials indicating a 23% reduction in mortality, as well as favourable shifts towards earlier stage distribution of colorectal cancers in screening groups [8]. Other screening modalities, such as colonoscopies are also effective [9,10,11]. Trials suggest that, implementing biennial screening (and even annual screening) could reduce CRC mortality by 20% over 10
years; dependent on high uptake and adherence to regular screening. Communicating the need for CRC screening and the effectiveness of the screening tests available to the target group is thus a clearly demonstrated need. Paper based delivery of screening messages has improved uptake [14] but a need remains to test whether electronic delivery can achieve similar or improved uptake rates. The potential advantages of web-based delivery include the ability to present information in a way that is more easily navigable than paper; a capacity to use context to enhance relevance through tailoring on key variables, and the ability to provide instantaneous internet enactment of a decision to avoid difficulties that are attached to procrastination i.e. online test ordering or physician booking.

Previous work demonstrates the effectiveness of screening decision aids through improving knowledge, reducing decisional conflict and stimulating more active decision making [15]. Research suggests that this effectiveness is enhanced when information is tailored to an individual and their needs; tailored print communications are read, remembered and perceived as more relevant than non-tailored materials [16]. Recent meta-analyses comparing web- and non-web information interventions show enhanced outcomes among individuals using web-based interventions, in areas of knowledge and targeted behaviour change [17]. The web delivery of tailored information therefore poses unique development challenges; impacting on a user base and their acceptance of information systems that aim to influence screening behaviours using educational and behavioural interventions. This relates to an intended user base of age 50 years and older, with a limited but burgeoning literacy in both computer and internet technologies; ~29% of Australians aged 60 and over are reported as having used a computer in the last 12 months (2003 as reference year), 32% and 42% of those aged 55 to 64 have accessed the internet from home or from any site respectively [13].

The aim of this randomised clinical trial in development, is to determine the effectiveness of tailored electronic information delivery compared to paper-based delivery, focusing on outcomes including screening behaviour (participation, change in stage of readiness to screen), screening modality (FIT/FOBT or colonoscopy), and satisfaction with screening decision, information and delivery mode.

2 Methods

Development of the computerised decision aid will be based on behavioural theory including locus of control, risk perception, self-efficacy, response efficacy and the Precaution Adoption Process Model. It would reflect an individual’s set of behavioural determinants that may require change to initiate and sustain the process of CRC screening. The ability to deliver a targeted behavioural intervention to older adults is predicated on achieving an understanding of a community who are presumed to have not benefited from the internet “dividend” (i.e. those that may not have internet literacy), the potential age biases that exist in provisioning of such information [19], and the optimal manner for presenting information to those with
cognitive (e.g. memory) and other impairments [20]. Before developing the web resource it is important to achieve an understanding of factors that describe willingness and motivation to access internet technologies by this cohort of users [21]. The technology of user modeling provides a means of delivering a tailored mix of educational content directed at an individual’s specific motivation, beliefs, knowledge and other determinants that affect behaviour. A survey will be conducted in order to identify and measure individual determinants associated with CRC screening beliefs and behaviours and outcomes from this will be used to inform decision support frameworks and an individual’s user model. Stage of change (readiness to screen) will also be measured at this point. Frameworks are required to be developed which address the granularity of these user models, impacted against the modes of data acquisition, to develop user models i.e. the value of “tailoring” surveys versus alternate acquisition through end user information system observations. A successful software system implementation would reflect characteristics of interpersonal communication; verbal interactivity equivalence within the individualised user model to act in the capacity of a pedagogical tool [18].

A variety of sources will be used for creating and assessing applicability of educational content and feedback messages (including focus groups, domain experts, the literature, and American Cancer Society plus Australian National Health & Medical Research Council (NHMRC) guidelines). This information will be used to develop text that describes the nature of and risk factors for CRC, the value of screening, and descriptions of testing procedures and the implications of test outcomes. Information will be personalised on the basis of name and basic personal characteristics, and also tailored to meet the specific informational needs of each user.

3 Outcome measures

Outcomes will be compared between the paper and electronic modes. The study will be powered so as to effectively compare screening uptake, but a range of additional outcomes will be included. These consist of:

- Intention to undertake screening and the screening test selected,
- Appropriateness of screening test selected as determined by comparison to clinical guidelines,
- Participant satisfaction with their decision and decision-making process,
- Satisfaction with the information provided and the mode of its delivery,
- Anxiety caused by the intervention,
- Decisional conflict, and,
- Cost effectiveness of the electronic process.

References

A Mobile Agent Approach for Ubiquitous and Personalized eHealth Information Systems

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Abstract. The past years have witnessed a heavy investment and research in the eHealth sector. The work of medical practitioners at all levels is becoming more information intensive as sophisticated medical equipment and computer applications are more widely used. At the same time, the demands of the patients / citizens are increasing due to the innovative medical and scientific advances. Digital technologies are becoming more important in health management aiming to reduce the cost and to deliver health care services at a distance. In addition, the Internet is increasingly used by citizens to obtain medical information, therefore it is critical that the Web-based eHealth content and services are developed efficiently, complying with the established quality criteria and being available for all in an adaptive and personalized manner delivered by multiple and ubiquitous delivery channels. In this context, the aim of this paper is to argue that in the face of the existing systems and platforms diversity and information sparsity, mobile agent technologies can provide the base for ubiquitous, transparent, secure, interoperable, and integrated eHealth information systems for the provision of adapted and personalized sustainable services to the citizens.

1 Introduction

During the last few years several initiatives (public and private) were undertaken addressing different applications of mobile and ubiquitous eHealth issues, ranging from doctor mobility (remote access to medical data), to patient mobility (remote monitoring of vital signals, tele-consultation, mobile medical record, wearable medical sensors) up to web based medical data access. Nevertheless, the scope of these initiatives was focused and the different approaches were designed in an ad-hoc way. As a result, it is not possible to integrate the different technological innovations and services into an integrated system. Many issues that are crucial for the deployment of an integrated ubiquitous mobile health system were not addressed, like for example social and economic aspects, changes in medical work practices and even standardization of technologies and integration with existing medical information systems. It is for these reasons that most of the technological innovations were either rejected by the market or their scope and usage remained limited. Following the improvement of the wireless transmission technologies, the primary objective of many researches today, realizing the ubiquitous mobile health problem, is to design and implement integrated ubiquitous eHealth mobile services systems and platforms emphasizing on the aforementioned issues.

The aim of this paper is to realize the common challenges and implications of the current eHealth environment. Special emphasis will be placed on the emergence of the wireless and mobile technologies and advancements in the specific area and how this affect the designing and development of ubiquitous information systems for the provision of eHealth adaptive and personalized services. Eventually, the mobile agents paradigm will be presented,
examining its characteristics, arguing that it could effectively be used for the composition of such personalized, multi-modal, and interoperable component-based eHealth information systems for sustainable services provision satisfying the growing citizens’ demands.

2 The eHealth Sector – Current Trends and Implications

Today’s information age is accelerating at quantum speed. Advances such as the Internet and high-speed networks have propelled the never-ending quest for information. An infinite amount of information is being created and accessed by people around the globe everyday. However, healthcare today remains one of the most information intensive and least automated of all industries. Nevertheless, European Commission through its eEurope 2005 Action Plan has drawn some specific innovative guidelines and objectives for advancing the current eHealth situation. These include the creation and dissemination of electronic health cards, the set up of European-wide information networks of public health data, and the provision of online personalized health services through intelligent information systems to the citizens. Moreover, another vital consideration is the standardization of the different pertinent elements (in cooperation with the various standardization bodies like ETSI, ITU, CEN / CENELEC, ISO), defining communication and transmission protocols and interfaces that will allow the systems to work in an interoperable, coherent and cohesive way.

3 The Mobility Emergence – Towards the mHealth Reality

The mHealth could be considered as a new kind of front-end access to public services with specific capabilities of delivering on demand real time information. Nowadays, as an integral part of eHealth, many governments should start offering eHealth services via a variety of service delivery channels apart from the Web. One of this mobile service delivery channels is mobile telephony. This channel becomes more relevant considering the much faster growth of mobile penetration rate compared to desktop based Internet access. The mobile phone is now pervasive and is used in every human activity, private, business and governmental. While penetration levels are likely to continue to increase, the most significant future development will be the growth of mobile broadband services, as the potential provided by third generation mobile (3G) and its enhancements, as well by other wireless technologies, including RLAN, satellite and others, is realized. The dissemination of these technologies represents a paradigm shift that will enable the emergence of new data services, combing the benefits of broadband with mobility [1].

Moreover, the needs of mobile users differ significantly from those of desktop users. Getting personalized information “anytime, anywhere and anyhow” is not an easy task. Such applications should be characterized by flexibility, accessibility, context-awareness, quality and security in a ubiquitous interoperable manner in order to provide the citizens with quality on demand information (services). User interfaces must now be friendlier enabling active involvement (information acquisition), giving control to the citizen and provide easier means of navigation supported by the small screens of the mobile devices and enable adaptation of hypermedia, multi-media, and multi-modal intelligent and personalized user interfaces [2]. However, mobility applications can suffer from a handful of noteworthy problems. These could be summarized into: local mobility, limited mobility, closed mobility and interrupted mobility.

To overcome these problems intelligent techniques have to be implemented to enable the development of adaptive and mobile Web-based systems [2] that will enhance the more direct and personalized eHealth services delivery. Fundamental characteristics should include openness, high connectivity speed, reliability, availability, context-awareness, broadband connection, interoperability, transparency and scalability, expandability, effectiveness, efficiency, personalization, security and privacy [3, 4].
4 The Web Personalization Imperative

4.1 User Service Requirements and Delivery

To get the right information at the right time and the right place is not so easy for the citizens. The eHealth sector working at its front or back office, it has encountered in several times and occasions the particular problem. Citizens’ interaction with the services has to be improved, and a serious analysis of user requirements in the area of eHealth has to be undertaken, documented and furthermore analyzed taking into consideration its multi-application to the various delivery channels and devices in order to design effective and personalized eHealth information systems that will provide quality eHealth services. This paper presents, based on studies conducted [5, 6, 7], some of the user (citizen) requirements and arguments anticipated. They could be clearly distinguished into: (a) General User Service Requirements (flexibility: anyhow, anytime, anywhere; accessibility; quality; and security), and (b) Requirements for a Friendly and Effective User Interaction (information acquisition; system controllability; navigation; versatility; errors handling; and personalization).

4.2 Challenges in the Adaptive and Personalized eHealth Design

The "Mobile" generation is now extending the basis of the adaptation by adding models of context such as location, time, computing platform and bandwidth to the classic user model and exploring the use of known adaptation technologies to adapt to both an individual user and a context of their work. Now, by user needs it is implied both, the thematic preferences as well as the characteristics of his mobile device, the device profile. Therefore, adaptive personalization here is concerned with the negotiation of user requirements and device abilities. Although one-to-one service provision may be a functionality of the distant future, user segmentation is a very valuable step in the right direction. User segmentation means that the population is subdivided (ideally per service or group of related services), into more or less homogeneous, mutually exclusive subsets of users who share an interest in the service. The subdivisions are based on one or more user characteristics. These could be demographic characteristics, socio-economic characteristics, psychographic characteristics, or individual physical and psychological characteristics. The issue of personalization is a rather complex one with many aspects and viewpoints that need to be analyzed and resolved. Some of these issues become even more complicated once viewed from a moving user’s perspective, in other words when constraints of mobile channels and devices are involved. Such issues include, but are not limited to, the following: what content to present to the user, how to show the content to the user, how to ensure the user’s privacy, or how to create a global personalization scheme [8].

4.3 A Mobile Agent Approach for Web Personalization

There are a number of different approaches and architectures that have been implemented in building eHealth information systems, each one of which with different strengths and weaknesses. This paper will be focused on the intelligent mobile agent approach, since the mobility dimension is henceforth incorporated, and therefore needs as to locate the required information, on time, under any circumstances are considered vital. Agents are processes with the aim of performing tasks for their users, usually with autonomy, playing the role of personal assistants [8, 9]. Agents usually solve common problems users experience on the Web such as personal history, shortcuts, page watching and traffic lights [10]. Some of the agents’ main characteristics could be distinguished according to their abilities used and according to the tasks
they execute. The former include characteristics such as intelligence, social capacity and mobility; while the latter classify the agents into information filtering agents, information retrieval agents, recommendation agents, agents for electronic market, and agents for network management [9]. Furthermore, several mobile agent platforms could be proposed in order to base the development of an efficient mobile eHealth information system. These could be broadly categorized as Java and non-Java based ones. The main reason that the particular approach of intelligent mobile agents is proposed for a given wireless environment is that they are being identified by some specific capabilities that could enable the more efficient implementation of the adaptive and personalized eHealth information systems. These advantages of the intelligent mobile agents are focused upon: Reduction of the network load, overcoming network latency, asynchronous and autonomous execution, and dynamic adaptation.

5 Conclusion

In conclusion, this paper presented the current eHealth sector situation in further realization of the technological environment divergence and citizens’ disorientation, due to, in the former case ad-hoc development of systems, while in the latter sparsity of information. The growing demands of the citizens for “anytime, anywhere and anyhow” information (services) delivery as well as the mobility and wireless platforms and devices emergence, intensified the imposition of the development of common standards and protocols as well as technologies that could be used for the design of interoperable, ubiquitous, secure, adaptive, personalized and transparent m- and eHealth information systems. Eventually, in the face of the mobile Health reality the mobile agents paradigm has been examined arguing that it could serve the core technology for the development of the aforementioned systems.

References

Changing notions of trust and compliance: their implications for personalisation of eHealth systems for maternity care

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1 Introduction

The past decade or so has shown two parallel phenomena: the organic, non-planned growth of the Web and its communities, and the design of a future world of eHealth, including study of how eHealth applications aimed at the public can be personalised. We discuss the influence of the former on the latter.

There is a large and lively collection of resources and online communities relating to pregnancy and birth. This is an interesting case study for issues of trust and compliance in particular because many of the issues that arise are highly controversial, with usual practices and advice differing systematically between countries (e.g., the US and the UK) and between professional groups (e.g., midwives and obstetricians), as well as unsystematically between individual practitioners.

Traditionally, both doctors and patients expect that the doctor will tell the patient what to do, and that the patient will trust the doctor and comply with instructions. Interestingly, although [3] discusses the fact that non-compliance may be a deliberate decision, it does not explicitly discuss cases where the patient may have made a judgement about the advice itself. For example, it mentions that a patient might take less than the prescribed dose of a drug because the patient fears side effects, but it does not mention that a patient might take a lower dose because they know that a different dose was used in a relevant clinical trial.

The UK government report Changing Childbirth[2] recommended that the maternity services should become more woman-centred: one result of this is the oft-occurring phrase “informed choice” (rather than informed consent, or compliance) to describe the ideal role to be played by the pregnant woman. In practice, however, a traditional compliance model still holds sway. For example Stapleton et al. write [4]: “We observed a strong hierarchy within the maternity services, with obstetricians at the top, midwives and health professionals other than doctors in the middle, and pregnant women at the bottom”. They conclude: “The hierarchical power structures within the maternity services, and the framing of information in favour of particular options, ensured compliance with the "right" choice." (my emphasis).

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2 Nature of today’s resources

Web sites range from the sites of medical research journals, to one giving the complete text of Enkin et al.’s classic book on evidence-based care, “Effective care in pregnancy and childbirth” (http://www.maternitywise.org/guide/about.html), to many frankly paternalistic sites (“Your doctor will decide...”).

Usenet newsgroups The main relevant newsgroup is misc.kids.pregnancy (mkp). It has relatively high traffic (hundreds of messages per day). A small number (say 5-25, depending on definition) of “resident experts” (mostly not health professionals) regularly answer questions and provide references to sources of information, including abstracts of medical research papers. There are many less regular posters. The group has a US bias, but members worldwide. There is topic drift and off-topic argument, but not so much as to swamp the on-topic posts. Posts contain a mixture of support, chat and factual/scientific traffic. Any new study reported in the press is discussed (and often criticised in a scientifically literate manner) on this group. Someone who reads this group over months in preparation for and during pregnancy will be aware in advance of many of the issues on which she has to make choices, and will often be aware of controversies that she might not otherwise encounter. She is likely to recognise the fact, if a health professional gives her only one side of a story.

A typical example thread is that headed “Amniocentesis - cons/pros”, which began on February 25 2005, and amassed over 60 followups in the next week. It included scientific and statistical discussion of what amniocentesis can and can’t show; emotional and moral discussion of the pros and cons of choosing amniocentesis (including a subthread on whether a post-amniocentesis miscarriage should be considered murder!). It also included some information on practices in different countries concerning when amniocentesis is offered/recommended.

Mailing lists for professionals Yahoo group ukmidwifery1 and an obstetricians’ mailing list2 are both available to laypeople. Comparing these two is a stark demonstration of the systematic differences in approach between obstetrics and midwifery. We may take VBAC, vaginal birth after caesarean, as an example. Some obstetricians believe that after a woman has had a caesarean section, all subsequent births should also be by caesarean section. Others (and most midwives?) vehemently disagree. Both sides claim to have studies to back up their arguments. ukmidwifery members regularly support and inform women seeking VBAC; indeed a recurring theme on the list is to bemoan the current caesarean rate, which most members of the list consider to be inexcusably high. On OBGYNL, by contrast, a typical recent post on the subject (http://forums.obgyn.net/ob-gyn-l/OBGYNL.0503/0303.html), in a thread entitled “Those crazy VBACs”, included the phrase “If I were allowing VBACs”. Awareness of such conflicts is likely to decrease a woman’s trust in any single professional’s unsupported opinion.

1 http://health.groups.yahoo.com/group/ukmidwifery/
2 http://forums.obgyn.net/ob-gyn-l/
3 Effects on trust and compliance

The Web has made access to research and pedagogical information dramatically easier. It has also made available qualitatively new sources of information. People can now hear about the advice given by other people’s healthcare providers worldwide, share experiences, and even eavesdrop on heated discussion among health care professionals. Moreover, the large membership of the available fora makes it possible to form an impression of the consensus or lack of it on an issue.

In this context trust in any one practitioner is likely to be provisional. Compliance is also at issue. For example, screening for gestational diabetes is routine in the USA, but there is a controversy over whether this is appropriate: one school of thought is that gestational diabetes is a misnomer. Misc.kids.pregnancy regularly hears from people about to undergo this screening who are advised on how to “beat the test”. Inevitably, some posters exclaim that it would be better to refuse consent to the test than to subvert it, and others explain that their providers are so insistent that they should have the screening that to refuse would be intolerably awkward, so that they prefer to take the test and pass by hook or by crook! That is, a woman makes her own choice of what to comply with, resting on the authority of what other practitioners advise in similar circumstances. This has obvious risks and benefits.

Health practitioners’ attitudes to people seeking health information online can be instructive. Almost all profess to believe that people should take responsibility for their own health. Nevertheless, there is a stereotype of the informed patient as a non-compliant hypochondriac nuisance. For example, Harris Interactive’s Healthcare News [5] characterises all those who ever go online for health information as “cyberchondriacs”. ([5] reports that 74% of all those online have at some point looked for healthcare information online, and that most of those do so using a portal or search engine, not by starting at a specialist site.)

4 Implications for eHealth systems

In the light of access to this conflicting information, it is unlikely that the internet literate user of an eHealth system can be given one viewpoint and expected to trust it implicitly, even if it is backed up with argument. EHealth systems will need to acknowledge opposing viewpoints and explain explicitly why a conclusion has been reached. This has been done to a limited extent: [1] is a good example.

Will a system ever be able to credibly claim to be viewpoint-free: will obstetricians and (radical) midwives ever be able to agree on the information and advice presented? Certain documents (NICE guidelines (http://www.nice.org.uk), MIDIRS Informed Choice leaflets (http://www.midirs.org) are already developed with this aim: however, anecdotally their development tends to be fraught.

Personalisation How may relevant eHealth systems be personalised? Most obviously, by taking account of previous medical and obstetric history, such as parity. However, we have already mentioned the VBAC controversy. If space permitted, we could cite many more, such as whether to intervene in a longer-than-average pregnancy, or when to encourage home birth.
A more ambitious use of personalisation might be to start by getting a general picture of someone’s ideal birth, and use that to give tailored relevant information. For example, someone whose ideal birth is in hospital with as little pain as possible might be given different advice to someone who prefers to avoid drugs and sees pain as positive. Exactly how to do this would need to be carefully considered, because naturally any system would have to present the risks and benefits of any given option honestly. A different slant on the same information might be justified, however. For example, one might offer information on labour positions that are often found helpful to both groups, but introduce the information differently. The potential drug-free home-birther might be told:

“People who prefer to avoid using drugs for pain control often say that finding good positions for labour is important to them. Some positions which are often found helpful are ...”

whereas the hospital pain-minimiser might be told:

“Even people who plan to use epidural anaesthesia should consider alternative methods of pain control, because there are many reasons why an epidural might not be available immediately. [link: What reasons are there?] What position you are in can make a big difference to how much pain you perceive. Some positions which are often found helpful are ...”

Possibly such matters, having more to do with the mother’s comfort than with life and death, would be less daunting to address initially.

5 Conclusion

This short, preliminary paper has aimed to open debate on trust and compliance in situations where people have easy access to information about controversies and different viewpoints. eHealth systems aimed at pregnant women need to co-exist with online resources and communities and elicit trust in this environment.

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