Democratization of healthcare through self-monitoring technologies

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***Abstract*— The burden on our healthcare systems is ever increasing with people living longer and requiring more support. Technologies can help ease the strain. One important aspect in health management is prevention enabled by self-monitoring and, eventually, self-understanding one's lifestyle through building supportive, interactive and engaging systems. This paper outlines a system aimed at empowering users with a better understanding of how their lifestyles can impact their wellbeing by using a context-based story-telling approach. While this work is still in its early phases, we believe that a lot of promise is shown through the current development status as well as our system design. Our initial findings show that available user data generated through our daily activities can reveal a wealth of information related to our lifestyles and provide support in implementing changes.**

Keywords- preventive healthcare, self-understanding

I. Introduction

Healthcare is an important issue in societies as well as in research, and prevention, enabled by increased self-awareness, is part of the process, as emphasized in reports from the World Health Organization (WHO) [1] and UK's National Health Services [2]. According to WHO estimates, 75% of the total world population lives with one chronic condition and 50% with two or more [2]. Increased self-awareness is essential, as about 75% of all chronic patients are low risk and, with proper lifestyle changes, they could better manage their diseases and avoid further deterioration.

We believe that technologies are crucial for empowering individuals with more information about their health and the effects their lifestyle choices have on their wellbeing by enabling self-monitoring, self-awareness and self-understanding. Recent technological developments allow for using and building more reliable, unobtrusive and affordable self-monitoring systems. For example, fitness-related self-monitoring is becoming increasingly popular with several available commercial systems combining physiological sensors and various visualization methods to help people better understand their body's reaction to exercising. However, we are interested in more than just the physical aspects of our lives and we believe that by collecting and correlating easily available information we generate through our usage of computing devices we can provide a more objective overview of our daily experiences. Human perception and acceptance is also continuously changing, as younger generations get more used to having technology around, digitally recoding their lives, and sharing it. To better understand our vision for the system described in this paper, we introduce a motivating usage scenario. The system presented in the scenario is part of the UK-funded PAL project (http://www.palproject.org.uk), focusing on self-monitoring systems for preventive and reactive healthcare.

Mary is 55 and she had heart surgery 3 months ago. The operation was a success and she is recovering well but her doctor advised her to take it slow and pay more attention to her lifestyle. To make it easier, Mary is using the PAL system, which can record various activity data from personal devices and correlate all information into a daily story view, so that she can see how certain activities performed during the day impact her physiological state, especially her heart condition. The system helps her remember what happened during the day and allows her to record her own thoughts regarding the events as well as her reactions. For example, the other evening Mary tried to figure out why she felt unusually tired. By using the PAL system, she could see that she had lots of meetings and skipped lunch. One meeting was especially demanding, as her colleague George kept interrupting her presentation, as usual, which annoyed her. The system not only helps her to better understand her own behavior, but also allows her to access some of the information when she talks to her doctor so together they could identify potential risk factors.

Our work is strongly motivated and influenced by the Calm Computing vision described by Weiser and Seely Brown in [3], where technologies can enrich our lives by seamlessly capturing what goes on at the *periphery (*outside our attention focus) and bringing it to the *centre* (what we are attuned to) when needed. Various work in affective computing (described by Picard in [4]), persuasive technologies (described by Fogg in [5]), and context awareness (as defined by Dey and Abowd in [6]) offer further insights into supporting self-understanding through self-monitoring and, ultimately, driving lifestyle changes. Our view regarding the user's role within the system is very well represented by Shneiderman in [7], with systems empowering people instead of replacing them, and users being not only consumers of information, but also part of the information gathering and processing. Interesting work was performed by Affective Diary [8] project with its focus on creating emotion-informed user-friendly visualizations of collected data. The user studies conducted in this work show that people like to reflect on their daily activities, much as they would do with a diary, and they can become quite attached to it as it provides them with a better understanding of what happened and why.

PERVASIVEHEALTH 2010, March 22-25, Munchen, Germany

DOI 10.4108/ICST.PERVASIVEHEALTH2010.8884

The contribution of our paper lies in presenting the development and initial data collection and validation of a system that exploits accessible data in order to support self-understanding. The key issues in our system focus on gathering relevant user information, managing and interpreting it and present it to the user through interactive and intuitive interfaces. With this work, we aim to create solutions that allow people to better understand and manage their own health and wellbeing.

II. SYSTEM DESIGN: AN AGENT VIEW

Building a system as described in our scenario brings various challenges. We cluster these challenges around three main areas of information flow. This categorization will also be used throughout the rest of the paper.

Information gathering: (a) Determine what information is relevant; (b) Find a balance between too much and too little data, i.e., having lots of data requires considerable effort spent on gathering as well as processing while not enough data might render the system useless; (c) Find appropriate sources for data by taking into account what is acceptable for users in terms of integrating the system into their lives, e.g., what is acceptable to wear, to collect, and how much would the system cost; (d) Allow users to control what is collected; (e) Allow users to add new data into the system.

Information processing: (a) Strike a balance between too much and too little processing: users might derive unexpected information if the system allows them access to lower level data; (b) Create a dynamic and flexible model to represent the information collected as well as new information derived through processing and user involvement; (c) Involve the user in the information processing: users often possess more information about a situation than is available to the system.

Information presentation: (a) Find appropriate paradigms for showing a wealth of information through simple and easy to understand interfaces; (b) Allow users to interact with the system, either for controlling it, for querying and examining the information, or for adding new information; (c) Allow users to understand how data was processed, i.e., what lower level information was used for deriving higher level information.

The ultimate challenge is to build a system that has a positive impact on people's lives by allowing them to better understand and manage their wellbeing. In this paper, we describe the system we have been building to support such applications. Figure 1 presents a multi-agent view of our system following the information lifecycle. The *Data Gathering Agent* abstracts all modules that collect input data from the various sources. Currently, the data is collected asynchronously through various means (e.g., Bluetooth, USB, IP, etc.) as our present scenarios focus mainly on the reflective aspect: looking back and seeing what happened during a certain time period. The *Data Transformation Agent* performs various operations on input data available in various formats and in multiple local storages, such as: data conversion (e.g., from bytes to values), data categorization, data filtering, data storing into MySQL database, database optimization (for time and space), and data model management. The operations are governed by the *Database Model* containing information about the structure of the database. The user database is currently centralized to better address potential security and privacy concerns that come with the sensitivity of the collected data as well as fit the single user centric view of the current system.

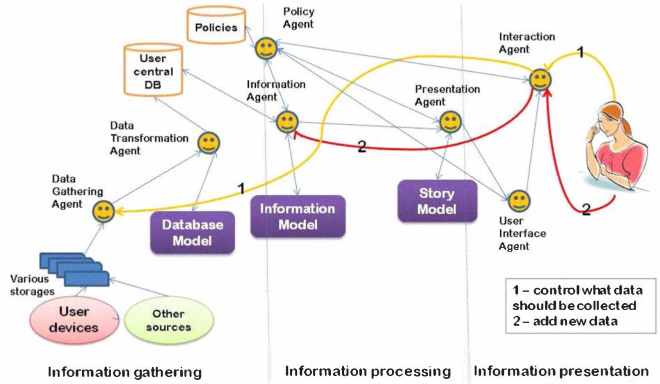

Figure 1. Multi-agent system view

Once data is collected into the central database it is processed by various specialized modules, grouped under the *Information Agent* abstraction. Various types of information processing are envisioned, such as *filtering* in order to discard useless or faulty information, *aggregation* of two or more types of data and *interpretation* of existing information in order to create higher-level concepts. New information created through these processing means is added to the *Information Model.* The *Presentation Agent* has the role of assembling information in a user-friendly format, according to the *Story Model* (see Section IV). The *User Interface Agent* is responsible for creating various information visualizations. As the system is envisioned as being highly interactive, the *User Interface Agent* and *Interaction Agent* need to work together in order to (1) allow the user to see and manage what is being collected; (2) allow the user to query for specific information ;(3) allow the user to add new information as either annotations to existing data or new data altogether; (4) take into account certain device capabilities, especially for scenarios that involve remote access to the system; (5) determine what is the best way to interact with a user in case of reactive assistive scenarios, e.g., when the system needs to warn the user about something. It is important to note that Figure 1 includes a larger scope than currently addressed in our implementation, as it also reflects other work planned in the PAL project, such as incorporating privacy policies into all information-related transactions and capturing user concerns through direct and indirect interactions. The *Policy Agent* is responsible for managing policies related to information usage, as well as various user preferences, and will become increasingly important once other information usages involving external parties (as described in the scenario) are added to the system.

III. SYSTEM IMPLEMENTATION AND EXAMPLE

In this section, we describe the information we are collecting as well as what the collection platform entails. It is important to highlight that our choice of collected information and input sources was dictated by: (1) the intended application space (support for users' self-monitoring and self-understanding); (2) enabling both static and mobile scenarios

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http://dx.doi.org/10.4108/ICST.PERVASIVEHEALTH2010.8884

spanning various spaces and situations; (3) the focus on widely available technologies (PCs, laptops and mobile phones) and (4) using reliable, and unobtrusive physiological sensing systems. Figure 2 shows what information is currently collected from which input sources. The system can collect information from both physical (raw data) and logical sensors (interpreted data). As shown, we currently use: a Garmin ForeRunner 305 wristwatch-like device used for fitness-related monitoring, providing heart rate and GPS-related information as raw as well as interpreted data; a mobile phone running the NORS platform [9], a Java-based sensing platform that allows collection of data from the phone and from attached BT-enabled sensors, and an Alive Heart Monitor - small wearable sensing device developed by Alive Technologies. PC data collection is performed through a commercial activity monitoring platform. Additional information is obtained on-demand from external email and calendar servers. Figure 2 lists all data collected from the various input sources.

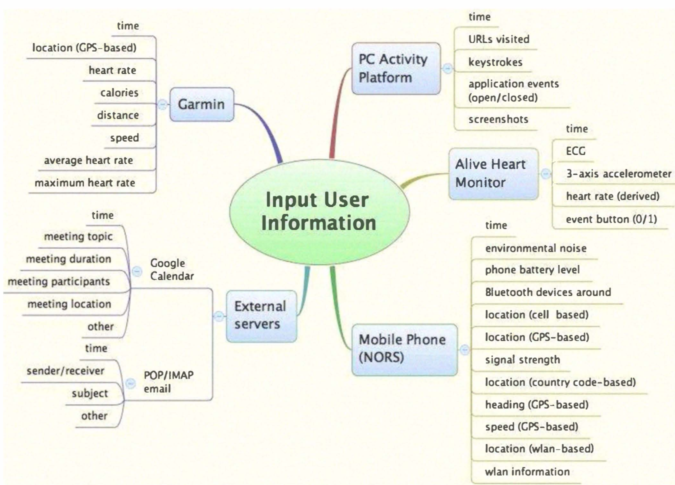

Figure 2. Input sources and collected information

In order to better exemplify the potential of our system we present a small experiment recorded during writing this paper. During one hour we recorded available data from the PC, mobile phone, and the Alive Heart Monitor. From all the data collected, we chose two graphs representing ECG, heart rate, accelerometer (X, Y, and Z), and event button (Figure 3) as well as applications used and keystrokes counting (Figure 4). We can see in Figure 3 that there is very often a correlation between increased ECG activity and accelerometer data, i.e., ECG data indicates increased movement. Furthermore, we can see that the event button was pressed twice, when the user considered that something interesting happened or was about to happen. The event button was pressed a second time at around 15:36:42 (circled) and looking at Figure 4 we can see that it corresponds to an increased number of keystrokes. Looking at what application was used at that moment we can see that the paper's window was active, suggesting a more productive paper writing phase. Using such data, we can also determine if the user takes sufficient breaks, which is especially important during paper writing. Data recorded can be interpreted and correlated in various ways and used for various purposes including user's wellbeing.

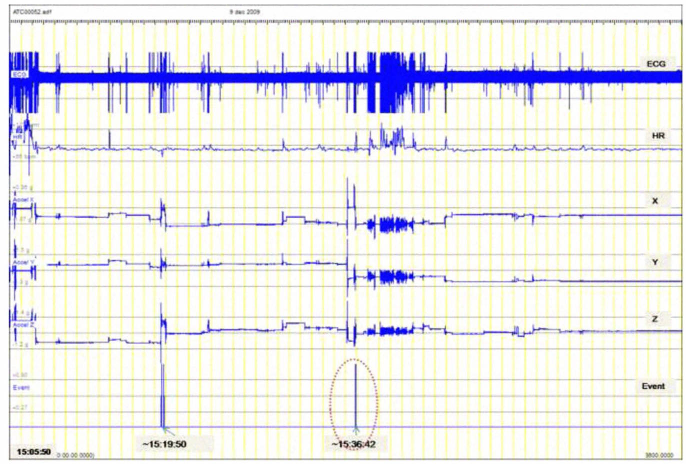

Figure 3. Data recorded by Alive Heart Monitor

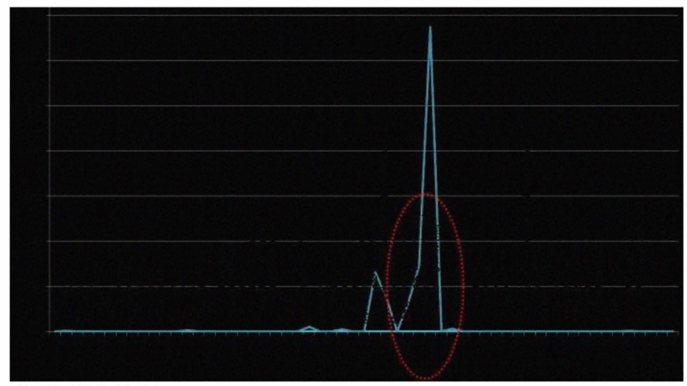

Figure 4. Keystrokes and applications used

An important issue in our implementation is the existence of various formats and synching methods used by our data sources, which requires a considerable effort when building the data gathering part of our system. Standardization efforts in the health area should improve some of these issues. Battery lifetime is also important. Although the Alive Heart Monitor can record for a few days before recharging is required, the Garmin device as well as the mobile phone needs a daily recharge when GPS is recorded. Furthermore, time correlation is an issue when using multiple devices as their clocks can differ from a few seconds to a few minutes. Special care needs to be taken in keeping them synchronized.

In our experiments, we have been focusing on a single user in various situations such as at home, at work, or on the go. Our preliminary findings show (1) that it is unrealistic to assume that people would wear or even remember to switch on devices all the time (e.g., Garmin requires an explicit Start/Stop action) (2) the incentive of using such system depends on how eventful the day is expected to be (3) that attaching wearable electronics such as a heart monitor belt is still not comfortable enough to allow for permanent data collection (4) the accuracy of data highly depends on where and how the sensors are placed, a person's posture or movement.

IV. ONGOING WORK: FROM SENSORS TO USERS

The collected information allows understanding of user's *physical context* (e.g., location obtained through various types

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of sensors and at different granularity levels), *social context* (obtained from sensors, e.g., Bluetooth, or from communication data, e.g., emails, calendar), *emotional & physiological context* (obtained through ECG and heart rate monitoring), *mental context* (interest derived through web activity, applications used, keyword-based filtering of keystrokes, screenshots), *activity context* (from accelerometer data or applications used), and *environmental context* (noise level, battery levels, signal strength, etc.) which can play an important role in healthcare-related applications. An appropriate balance has to be found between having too much abstraction and allowing transparency. Allowing end user access to certain unprocessed or lightly processed data can also generate abstractions that a system designer might not have considered or could not even consider due to incomplete or hard to access information. For example, in our scenario, the system can realize that Mary's heart rate increased, her voice pitch raised and deduct that she was getting angry. However, Mary's status could also be a reaction to an increase in room temperature or to being in a crowded environment rather than anger. Some other hidden parameters can have an impact on her emotional status (current or even historical, such as previous experiences related to people present, etc.) and in such situations it would be better to just show to the user through the interface that something unusual happened at a certain moment during the day (e.g., based on her heart rate and voice pitch changes) and let her deduct what exactly happened and why, by allowing access to other collected information (e.g., who else was there, what else happened around the same time, etc.).

Our exploration of interactive information systems and natural ways of presenting life experiences led us to *stories* as a means of relating information to humans. Stories offer a way of organizing information as collections of meaningful events brought together either by following a timeline or a certain topic or character, as described by Bruner in [10]. In our system, we plan to explore this type of information presentation from simple to more complex structures enabled by a modeling process that takes information from the *Information Model* and arranges it into a story-based representation, according to the *Story Model*.

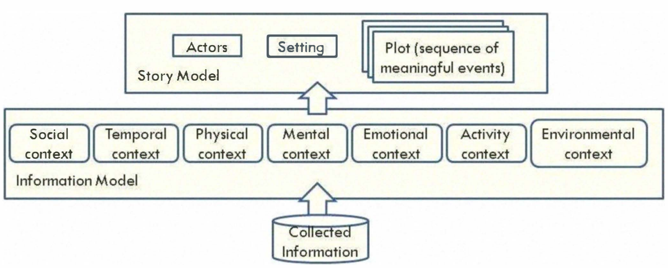

Figure 5. Relations between context and story structures

Stories are formulated as a sequence of meaningful events with collected information forming these events. For that, the *Presentation Agent* and the *Information Agent* collaboratively determine what could be "meaningful". Such event is described through the scenarios: Mary's meeting, her presentation and her increased heart rate. Through zoom-in functionalities, Mary has access to other related information. She can see notes she previously added to the event, as well as add some more (e.g., explain why she thinks she felt so stressed during a certain meeting). The annotated information becomes part of the story and will be available to her when she reflects on the information in the future. This makes the story evolve in a subjective, human way, as perception of feelings and explanations can change based on remembering or forgetting things. Also important to note is that the story can change depending on what the user is most interested in (e.g., emotional state vs. spatial movement), as well as based on end users' identities and their relation to the main user (i.e., the one that most of the collected data refers to). Furthermore, we plan to explore adding persuasion features into the model, especially when a lifestyle change is desired.

V. CONCLUSIONS

In this paper, we presented the motivation, design, and current implementation of a system designed to support people in self-monitoring and self-understanding within preventive healthcare scenarios. Our work is divided into three distinct phases, the first being the selection of the input data, the design and development of the data gathering platform and initial tests, which this paper presented. We are currently embarking into the next phases, concerning data analysis, processing, modeling, and visualization as well as evaluating the applicability and usefulness of such system. Central to our approach is the presentation of data within a certain story through an interactive modeling process evolving over time based on information processing provided by the system and the users. Such modeling process allows users to become engaged with the system and enable access to lower level data that was used by the system to build up the story presented.

We believe that the first results regarding our system's potential are promising and we intend to further evaluate and report its usefulness in various situations and with multiple users, in order to better understand how such systems can support people in managing their lifestyle and their wellbeing.

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Digital Object Identifier: 10.4108/ICST.PERVASIVEHEALTH2010.8884
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