Standard for Personalized eHealth Services ⋆

Torbjørn Sund[1], Nick Hine[2], Francoise Petersen[3] and Mike Pluke[4]

[1] Telenor R&I, Fornebu, N-1331 Norway

[2] University of Dundee, DD1 4HN U.K.

Apica, Biot, France

[4] Castle Consulting Ltd., Ipswich, U.K.

Abstract. Stimulated by the rapid development in ICT, wireless communication and sensor development, patient care is moving out of the institution and into the personal realm. The move requires that eHealth systems should be tailored to the user, including personalization and adaptation to user context. This paper describes ongoing work to establish a standard for such personalization. The standard builds on the user's preferences and current situation, which together define the current user profile. This profile can then be used by eHealth services and devices to ensure a user experience tailored to each person and situation. The work surveys relevant areas of personalization, like identity management, profile management etc, addressing those aspects of personalization that are specific to eHealth: user capabilities, care provider roles and functions, health related information, and confidentiality measures.

1 Introduction

eHealth enables patient care to move out of the hospital and into the personal realm. The transformation is facilitated by the rapid development in mobile, wireless technologies and sensors, and it helps people to lead an independent life outside of institutions [1].

However, the move towards personalized health care means that people who are not particularly trained in the use of ICT will deal with complex equipment, which may be life critical, and which may contain confidential and vulnerable information. Equipment and services for personal health care therefore must be highly adaptable, and it must be possible for the user to personalize the equipment to accommodate his or her individual mental and physical capabilities [2]. Furthermore, since the equipment will be used in varied environments it should also adapt easily to the user's current context.

Clearly, standardization is needed for these important user aspects of eHealth systems. Firstly, standardization will ensure that personalization is handled similarly and predictably in different eHealth systems. Secondly, it will enable different systems to exchange user preference data, thereby freeing the user from repetitive, tedious and

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error-prone input of preferences. Thirdly, standardization will reduce the possibility of potentially dangerous misunderstandings. To achieve these goals, the Human Factors and eHealth Technical Bodies of the European Telecommunications Standards Institute (ETSI) have created two specialist task forces, STF342 [3] which specifies an architecture for personalization and user preferences in general, and STF352 [4] which standardizes the personalization of eHealth systems in particular. The current paper reports on the on-going work of the latter.

2 Methods

For the purpose of this work, users of eHealth equipment and services are classified in two main groups: The eHealth *client* whose health and well-being is monitored, and the *carer*, the person or group of persons acting in the role of a health worker. The current work deals with the eHealth client, and considers how the client's *preferences* and dynamic *context* are mapped to a particular user *profile*.

2.1 User Preferences

The User Perspective. The standard being developed will recommend a uniform way of specifying preferences, both in terms of what can be specified, how they should be specified, and what effect they should have on system behaviour. Currently, the preferences that can be selected by the client of an eHealth equipment or service are not standardized, and value ranges and effect upon system behaviour are not consistent. For example, preferences like "loud volume" or "large font" should always result in the same and standardized user experience.

The Carer Perspective. The information about the eHealth client that is supplied to a carer must be adapted to the carer's competence and professional level. However, the carer may not be educated in either health or ICT. He or she can be a neighbour, relative, social worker, house assistant or even (in case of emergency) a random passer-by. The eHealth system therefore must have a way of classifying the carer, and use this to map the client's profile data to terms that are readily understood by the carer.

As an example, the eHealth system may have recorded that the client is deuteranomalous. Most people will not understand this, so unless specifically asked for the medical term, the system should supply the common term of red/green blindness instead.

The Engineering View. When preferences are specified according to a common nomenclature, it will be possible for systems to exchange user preference data without the intervention of the client. Thus new installations of eHealth equipment can immediately be adapted to the user, and the user is relieved of having to go through much of the current tedious and sometimes difficult installation procedures.

2.2 User Context

An eHealth system can help the client to lead an independent life in his/her normal environment. However, being free to roam about, the client's context will be much more variable than when the client is institutionalized. Since the appropriate reaction in one context can be ineffective or even detrimental in another context, the eHealth system should register and adapt to the client's context when necessary.

It would be futile to try and standardize the almost uncountable number of possible different contexts. However, the standard aims to supply a framework for specifying and classifying those context variables that may have an effect upon the client's health and well-being, and the possible consequence for eHealth system behaviour.

2.3 User Profile

The user's detailed context will be highly variable and too complex to be useful as direct input to an eHealth system. We therefore introduce the concept of a "situation", which is defined by the state of a number of relevant context variables. For example, a "Sleeping at Home" situation could be defined by the state of sensors in the home that detect that the client is in the bedroom and not moving [5, 6]. Well-being related situations such as "Normal", "Stressed" and "In Need of Assistance" could be defined by the state of sensors worn on the client's body [7]. Each situation will have a corresponding user profile, which should be used by the eHealth system to adapt its behaviour correspondingly. This would include calls to medical assistance in the case of emergency or "Need of Assistance".

3 Results

This paper reports on on-going work in the STF352. It builds on a large knowledge base on personalization, human factors, context and privacy issues; applying and adapting results from these fields to the field of eHealth.

3.1 Personalization Issues

ETSI has described a concept and developed guidelines relevant to users and their needs to manage their profiles for personalization of services and devices [8]. For a single product or service it may be difficult for a user to manage all of the information needed in their profile. Primarily the users need to understand how their profile affects their eHealth services. They will need to view and update the content in their profile. In addition they should be informed when other entities access their eHealth profile.

Concerning the information that an eHealth system has about a user, personalization is an issue both for the carer and the person being cared for, both during the search for information about a person's illness or medical status, and when this information is applied for selection of treatment and medication. At the same time, the user should be able to choose and personalize what information shall be related to which carer and under what circumstances.

3.2 Privacy of eHealth Information

Maintaining the privacy of health information is of the highest importance, so it should only be made available to appropriate people depending on the circumstance. This implies the need to be able to authenticate the identity of a person accessing an eHealth user profile, and to confirm that the role of the person is appropriate to the type of information being accessed.

The rules for disclosing health related data may depend not only on the data itself, but on several context parameters, like the health condition, the geographical location, the person's age, the dependency status, and of course on the status of the person/system that requires access to the data. The standard will specify rules for classifying and accessing such parameters.

3.3 Roles

In order to manage privacy, for each attribute in a user profile it will be necessary to state who has the right to view or modify the information. Such rights should be tied to roles. Roles embrace those of health personnel, formal and informal carers and telecare agents. Some roles may be mutually exclusive, others may be complimentary, and one person may have different roles in different situations. A standard for classification of roles related to eHealth personalization is therefore needed, and will be included in our work.

Also needed is an internationally agreed upon system for certifying the role of a particular person. For the appropriateness of roles to be confirmed it will thus be necessary to ensure that a person's eHealth profile contains an accurate record of their eHealth related role. The extensive ETSI work on a Universal Communications Identifier (UCI) [9] will be used as input (among others) to the current work, thereby ensuring a reliable way to authenticate the identity of a person accessing an eHealth profile.

eHealth roles identified in our work comprise the following: Doctor, carer, informal carer, care mediator, emergency service, client and client administrator. For each of these roles, there will be different ways of characterizing the user, different views of the eHealth system, and different access rules.

3.4 System Architecture

A general model for user profile management is being proposed by the ETSI project team STF342. Our results will be used to extend this model into the eHealth domain. In the model, it is suggested that maintaining and updating the user profile according to preferences and context should be performed by a Profile Agent. The architecture of the Profile Agent including possible connections with external systems is depicted in Figure 1.

Although profile data may distributed among several devices and services, to ensure consistent behaviour the data should be managed from a single location. This is the purpose of the *Profile Storage Agent*, which will handle storage and retrieval of profile data from multiple profile storage locations, each one storing only components that apply to a particular device or service. Ideally, profile data should always be available,

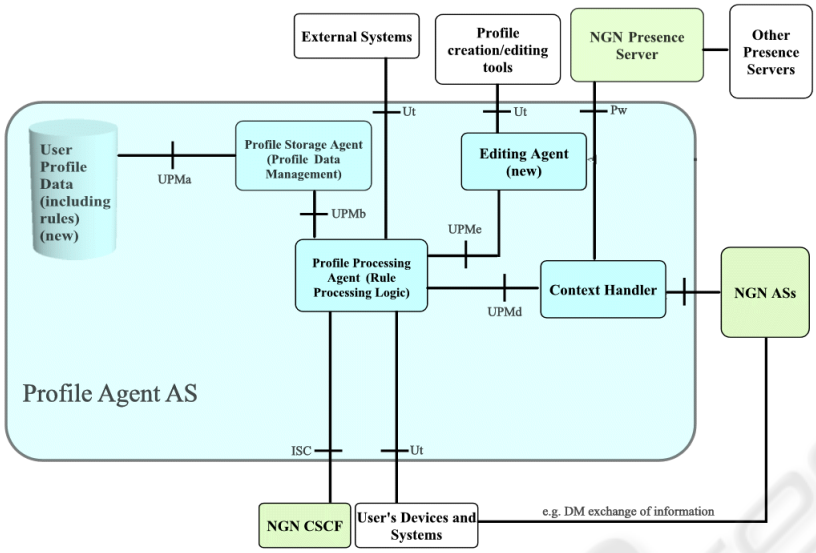

Fig. 1. Proposed architecture of a user profile agent.

over all networks, from all supported devices and services. Consistency may be ensured by synchronization of data and by employing transaction security.

The *Profile Processing Agent* will process the profile data and initiate achievement of the behaviour encoded in profile rules. The Profile Processing Agent is responsible for ensuring that all the operations required by the profile rules are carried out, and it will need to initiate operations on a variety of devices and services referred to in the profile.

The Profile Processing Agent can be further subdivided into an *Evaluation Engine*, which evaluates which preferences need to be updated when state variables have changed, and an *Execution Engine* responsible for distributing the updated preferences to the relevant devices and services. For efficiency and effectiveness some of the functionality of the Execution Engine may be distributed on the relevant devices and services.

The *Editing Agent* implements the user interface for viewing and editing profiles, and the *Context Handler* will provide information about the user's context to the Profile Processing Agent. It is anticipated that much of the user context data will be provided by functions implemented in the user's mobile terminal and by services in the network.

3.5 Related Work on Personalization

Personalization of computer systems is an active research field, with many on-going research projects both within and outside of Europe. Some of these projects relevant for the current work are mentioned in the following, but the list is far from exhaustive.

IST-SMS. (Simple Mobile Services) is a project which has developed and implemented a special SIM card able to store sensitive profile data, identity information and digital

certificates. The SIM offers also a digital signatures service which is useful during electronic transactions whenever the identity of the user (not of the service provider) has to be proved or data consistency has to be verified.

IST-SPICE. (Service Platform for Innovative Communication Environment) [11] researches in and develops intelligent service platform solutions for user profile and context information management and anticipatory middleware functionality in the domain of context aware service platforms.

MAGNET. (My personal Adaptive Global NET) [12] has its emphasis on user-centricity, personalization and personal networking. The objective is to improve the quality of life for the end-user by introducing new technologies more adapted to the user. MAGNET research focuses on environments to become smarter, more responsive, and more accommodating to the needs of the individual without jeopardizing privacy and security.

4 Conclusions

Personalization will be critical to the uptake and success of new and advanced eHealth services. Based on the ETSI standardization work in this area, the future ICT services and devices may become part of a totally new era with radically enhanced eHealth services.

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