An Architectural Framework for the Personalization of eHealth Devices and Services

Françoise PETERSEN [a], Nick HINE [b], Antonella FRISIELLO [c] and Mike PLUKE [d]
[a] *Apica/European Telecommunications Standards Institute (ETSI), Sophia-Antipolis, France*
[b] *University of Dundee, Dundee, United Kingdom*
[c] *ISMB, Turin, Italy*
[d] *Castle Consult, Ipswich, United Kingdom*

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

Keywords. Medical Informatics; Personalization; User profiles, Standardization

1. Introduction

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

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

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

2. Focus on Users' Needs

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

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

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

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

3. eHealth Services Supporting Multicultural Information and Communication

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

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

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

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

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

4. Profile Categories and User Roles

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

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

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

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

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

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

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

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

5. Architectural Overview

5.1 Functional Entities

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

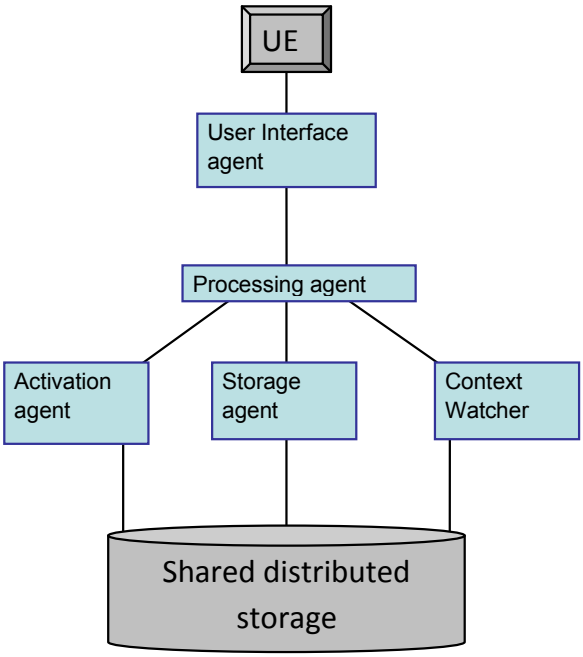

Figure 1. Architectural overview

5.2 User Interface Agent

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

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

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

5.3 Processing Agent

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

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

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

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

5.4 Activation Agent

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

5.5 Storage Agent

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

5.6 Context Watcher

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

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

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

5.7 Shared Distributed Storage

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

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

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

6. Related Work

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

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

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

7. About ETSI

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

7.1 About ETSI Specialist Task Forces (STF)

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

7.2 About STFs Funded by EC/EFTA

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

8. Conclusion

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

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Address for Correspondence

Françoise PETERSEN
Apica/European Telecommunications Standards Institute (ETSI), Sophia-Antipolis, France
francoise.petersen@apica.com