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# Standardization work on personalized eHealth systems

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*Abstract*— **For widespread adoption of eHealth, and to achieve eInclusion and eAccessibility, eHealth systems must be tailored to each individual user's needs and preferences. Many eHealth products and services contain adjustable parameter settings, but they are specific to each product and unrelated to each other. This paper describes ongoing work to establish standards and guidelines for personalization of eHealth systems, taking into account the needs of all users, both clients and caregivers. The standard builds on a generic 'user profile', which stores data about the users, their preferences and their context. This profile can then be used by eHealth services and devices to ensure a user experience tailored to each person. The work surveys relevant areas of personalization, like identity management, profile management etc, addressing in depth those aspects of personalization that are specific to eHealth: User capabilities, care provider roles and functions, health related information, and confidentiality measures.**

## I. Introduction

THE design of healthcare and eHealth services has traditionally had a strong focus on the clinical perspective of the client as patient. However, there is an increasing demand for new solutions such as the migration to self-managed care. This will allow increased client mobility, helping to sustain normal daily activities such as professional life, family life and hobbies [1]. The eHealth services will therefore need to adapt to the users (including patients and carers). As specified in several IETF standards, the user's preferences may vary according to the current profile such as location [2], type of places [3], activities [4], and even mood [4]. A possible extension of these IETF standards could include further details related to the eHealth area.

This paper describes published and ongoing work within the Human Factors and eHealth Technical Bodies of the European Telecommunications Standards Institute (ETSI), to achieve eHealth systems personalized to meet individual users' requirements [5], [6]. The overall objective is to ensure that personal health and care systems adapt to the user in a uniform way, thereby enabling independent living, and making them safer, easier to deploy, and more trustworthy. In addition, the work will enable eHealth service and device providers to reach larger user segments more easily and more quickly.

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## II. The need for standardization

Currently, the range of preferences and values that can be set by users is not consistent between eHealth services. Therefore, it is difficult or impossible to transfer settings for one particular device or service to another device or service, in a way that ensures the same user experience. With the aim of providing enhanced eHealth services, it would be better if:

- Different devices or services of the same type had consistent parameter types with similar value ranges producing identical effects. For example, for preferences like 'loud volume' or 'large text' to be useful, users wish them to always result in the same standardized user experiences.
- Settings in one proprietary form on one device or service could be converted to settings in another proprietary form on a similar device or service from a different supplier.

In order to achieve the best user experience, there is a need to ensure interoperability of services, devices and the users' preferences defined in their profiles. The realization of this objective depends on standardization of personalization preferences related to eHealth and the ways in which these are expressed. There is also a need for standardizing an architecture that supports this concept.

## III. Past and ongoing ETSI standardization activities

To achieve easy personalization of eHealth systems, user understandable terms need to map to technical descriptions that have universal applicability across a wide range of services and devices. This depends on standardization of preferences and on the ways in which these are expressed. ETSI has described a concept and developed guidelines [7]

relevant to users and their needs to manage their profiles for personalization of services and terminals.

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. To achieve these goals, two ETSI Specialist Task Forces (STFs) have been set up: STF342 [8] which specifies general user preferences and an architecture supporting personalization, and STF352 [9] which specifies eHealth specific preferences. Three ETSI deliverables will be provided as the output of this work:

- An ETSI Standard on general standardized preferences (including settings, values and operations) related to personalization and user profile management;
- An ETSI Standard on eHealth specific standardized preferences;
- A Technical Specification on architectural issues related to networks, terminals, SmartCards etc.

As part of the work, the projects are collecting input from end-users and their representatives, including clients and care givers (formal and informal).

## IV. eHEALTH PERSONALIZATION ISSUES

### A. *Privacy of eHealth information*

eHealth information is probably the most personal and sensitive information that a person makes available in an electronic form. Therefore the privacy of this information is of the highest importance if trust in eHealth systems is to be established and maintained. People's trust that the privacy of their eHealth information is being appropriately handled can only be achieved if they feel confident that their eHealth information is only made available to appropriate people in appropriate circumstances. This implies the need to be able to:

- authenticate the identity of a person accessing an eHealth user profile;
- confirm that the role of the person accessing information from the eHealth user profile is appropriate to the type of information being accessed.

The rules for disclosing health related data may depend not only on the data themselves, but on several context parameters, like the health condition, the geographical location, the person's age, the marital status, the dependency status, and of course on the status of the person/system that requires access to the data. These parameters need to be classified in a standardized way.

### B. *Roles*

In order to manage privacy, there is a need to handle different 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.

For the appropriateness of roles to be confirmed it will be necessary to establish a very detailed set of eHealth related roles (e.g. the client's personal doctor, a parent, or a nurse assigned to emergency services) and then to ensure that a person's eHealth profile contains an accurate record of their eHealth related role. The extensive existing ETSI work on a Universal Communications Identifier (UCI), listed in [10], will be used as input to the current work about reliable ways of authenticating the identity of a person accessing an eHealth profile.

It is essential that the solution proposed by the current work defines a common framework for eHealth user profile information. A mechanism for applying access policies is needed such that the same eHealth profile information can result in a range of different outcomes according to the policies that are applied and personal preferences. The relationship between a client and a carer or a health professional is likely to be complex, affected by local legal and common practice policies. Being able to correctly mirror current acceptable practice in terms of eHealth policies will be critical to establishing eHealth systems that are trusted by the public.

It is already clear that for each attribute in a user profile it will be necessary to state who has the right to view or modify the information. This requirement indicates that one of the many outstanding features that will need to be agreed across national borders is:

- a classification of roles related to eHealth;
- ideally, a worldwide method for certifying that particular people or organizational roles belong to a particular eHealth role.

### C. *eHealth System environment*

An increasing amount of eHealth data are collected by sensors worn by the user or placed in the environment. Furthermore, processing capabilities make it possible to combine data about an individual to infer meaningful conclusions about the individual's health condition and even mental status. Clearly such data is or should be accessible for personalization, and their use should follow rules adapted to the individual. Other factors that will be investigated will include:

- language and cultural issues that can occur when information stored in eHealth profiles is being accessed by a person from a language and cultural background different from that of the environment in which the profile was created;
- the need to provide contact information for key eHealth related people within the profile e.g. whom to contact in emergency;
- context information that indicates the current status of the eHealth client e.g. in hospital, travelling;
- devices and services related to the profile e.g. pacemaker, alarm system, realtime blood pressure monitoring service, service to remind the client to take medicine;
- access to the medical data in an eHealth record;
- classification of information related to:
    - how sensitive the information is (the caution that must be given to its release);
    - whether access to the information could, in some circumstances, be life critical;
    - the recency of the information (e.g. date the information was added to the profile or when it was last amended);
    - the certainty of the information (e.g. is it fact, the opinion of a health professional, the client's own opinion).

### D. *Supporting architecture*

The architectural framework for personalization that is being developed in this work will support the concepts described in EG 202 325 [7]. Some of the functionality could be implemented in the network, in terminals and in SmartCards. New generations of SmartCards (e.g. (U)SIMs) can hold an increasing amount of profile data and have processing capability, which makes them useful for implementation of the profile concept. Also other means such as USB sticks and RFID (Radio-frequency identification) can be useful. In order for a profile to be effective, there is a need for entities to:

- store and retrieve the profile data from multiple profile storage locations;
- process the profile data and initiate achievement of the behaviour encoded in the profile rules;
- activate and de-activate context dependent profiles in the appropriate circumstances.

### E. *Scenarios*

In order to illustrate the varied and complex issues associated with eHealth profiles, the ETSI work will supply scenarios and examples of ways in which application of the proposals for eHealth profiles will benefit the effective delivery of eHealth services. This can include scenarios such as a person receiving appropriate emergency care because of the ability to automatically access critical eHealth information via their profile. The work will also refer to published and ongoing work in the area.

## V. CONCLUSION

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 will become part of a totally new era with radically enhanced eHealth services.


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