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**Human Factors (HF);
Personalization of eHealth systems
by using eHealth user profiles (eHealth)**

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Foreword

This ETSI Standard (ES) has been produced by ETSI Technical Committee Human Factors (HF), and is now submitted for the ETSI standards Membership Approval Procedure.

Intended readers of the present document are:

- eHealth service providers;

- device manufacturers;

- software developers;

- researchers.

Introduction

Adapting an eHealth system to the individual user is essential for making it safe and easy to deploy and to use as an effective support to independent living. Personalization can thus enhance the user's trust in the eHealth systems, and make them more readily accepted. Personalization 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 environment, including the eHealth services and devices.

The present document specifies a standard for personalization of eHealth systems. The personalization is achieved by maintaining and updating the user profile, consisting of a set of user related information, preferences and rules. The user profile depends on and is dynamically adapted to the user's context, preferences, physical and mental abilities, and other relevant parameters. The profile can then be used by eHealth systems to ensure an uniform user experience. The standard builds on the personalization and user profile concept described in EG 202 325 [i.1]. The generic personalization architectural framework is described in TS 102 747 [2] and the preferences for a wide range of services and devices (not particularly related to eHealth) are described in ES 202 746 [1].

The Design for All approach has been adopted in the present document. It means that accessibility is considered as something that can benefit people whether or not they have disabilities.

The URI root is upm-ns, identified by xmlns:upm-ns=http://uri.etsi.org/upm. The additional namespace which is health specific (xmlns:health-ns in the list below) has been specified in the present document. The other additional namespaces listed below are common with those listed in ES 202 746 [1].

Additional namespaces are:

- xmlns:profile-management-ns=http://uri.etsi.org/upm/profile-management;

- xmlns:personal-information-ns=http://uri.etsi.org/upm/personal-information;

- xmlns:connectivity-preferences-ns=http://uri.etsi.org/upm/connectivity-preferences;

- xmlns:interaction-preferences-ns=http://uri.etsi.org/upm/interaction- preferences;

- xmlns:notifications-ns=http://uri.etsi.org/upm/interaction-preferences/notifications;

- xmlns:communication-handling-ns=http://uri.etsi.org/upm/communication-handling;

- xmlns:consume-content-ns=http://uri.etsi.org/upm/consume-content;

- xmlns:way-finding-ns=http://uri.etsi.org/upm/way-finding;

- xmlns:health-ns=http://uri.etsi.org/upm/health.

# 1	Scope

The present document provides a standard relevant to management of user profiles for personalisation of eHealth systems and services according to users' preferences and needs. Personalization of eHealth systems includes personalization of the eHealth information and interaction. It specifies standardized elements of profiles including information and preferences.

Profile aspects within the scope of the present document are:

- those provided for the primary benefit of the end-user;

- those where the end-user has rights to manage the profile contents;

- those where the end-user has the right to have a dialogue with the information owning stakeholder.

# 2	References

References are either specific (identified by date of publication and/or edition number or version number) or non-specific. For specific references, only the cited version applies. For non-specific references, the latest version of the reference document (including any amendments) applies.

Referenced documents which are not found to be publicly available in the expected location might be found at http://docbox.etsi.org/Reference.

NOTE:	While any hyperlinks included in this clause were valid at the time of publication ETSI cannot guarantee their long term validity.

## 2.1	Normative references

The following referenced documents are necessary for the application of the present document.

[1]	ETSI ES 202 746: "Human Factors (HF); Personalization and User Profile Management; User Profile Preferences and Information".

[2]	ETSI TS 102 747: "Human Factors (HF); Personalization and User Profile Management; Architectural Framework".

[3]	IETF RFC 4480: "RPID: Rich Presence Extensions to the Presence Information Data Format (PIDF)".

[4]	CLDR: "Unicode Common Locale Data Repository", "measurement-unit" supplemental data.

NOTE:	See http://cldr.unicode.org/.

[5]	ISO 80000-1:2009: "Quantities and units - Part 1: General".

[6]	vCard: The Electronic Business Card, Version 2.1.

NOTE:	See: http://www.imc.org/pdi/vcard-21.txt.

[7]	ETSI TS 102 334 (all parts): "Network Address Book on fixed network".

[8]	XML Schema Part 2: Datatypes Second Edition (October 2004).

NOTE:	See http://www.w3.org/TR/xmlschema-2/.

2.2 Informative references

The following referenced documents are not necessary for the application of the present document but they assist the user with regard to a particular subject area.

[i.1]   ETSI EG 202 325: "Human Factors (HF); User Profile Management".

[i.2]   ETSI EG 202 421: "Human Factors (HF); Multicultural and language aspects of multimedia communications".

[i.3]   ETSI SR 002 564 (V2.0.0): "Applicability of existing ETSI and ETSI/3GPP deliverables to eHealth".

[i.4]   eHealth Ministerial Declaration: "The Contribution of ICT to Health. Ministerial Conference and Exhibition"; Brussels, 22-23 May 2003.

NOTE: Available at:
http://ec.europa.eu/information_society/eeurope/ehealth/conference/2003/doc/min_dec_22_may_03.pdf.

[i.5]   WHO: "International Classification of Diseases (ICD)".

NOTE: Available at: www.who.int.

[i.6]   WHO: "International Classification of Functioning, Disability and Health (ICF)".

[i.7]   WHO: "International Classification of Health Interventions (ICHI)".

[i.8]   WHO: "Guidelines on the use of International Nonproprietary Names (INNs) for Pharmaceutical Substances".

[i.9]   Oh H, Rizo C, Enkin M, Jadad A: What Is eHealth (3): "A Systematic Review of Published Definitions", J Med Internet Res 2005;7(1):e1.

NOTE: See http://www.jmir.org/2005/1/e1/.

[i.10]   Eysenbach G. "What is e-health?" J Med Internet Res 2001 Jun 18;3(2):e20.

NOTE: See http://www.jmir.org/2001/2/e20/.

[i.11]   Mitchell J. "From telehealth to e-health: The unstoppable rise of e-health", Canberra, Australia: Commonwealth Department of Communications, Information Technology and the Arts (DOCITA); 1999.

[i.12]   "Integrating Community Equipment Services (ICES)" (January 2005): "Telecare".

[i.13]   Doughty, K., Cameron, K. and Garner, P. (1996): "Three generations of telecare of the elderly" Journal of Telemedicine and Telecare 2(2): 71-80.

[i.14]   ISO 215: "Documentation - Presentation of contributions to periodicals and other serials".

3   Definitions and abbreviations

3.1   Definitions

For the purposes of the present document, the following terms and definitions apply:

accessibility: ensuring that all sectors of the community have equal access to communications and online information

administrator: person who defines profiles with profile data

NOTE: Also known as profile administrator.

carer: individual who provides health or social care to the client

   NOTE: Both professional and informal carers are included in this category.

client: individual receiving the eHealth service, to support independent living and/or using eHealth services for the care of his or her own health and wellbeing

eHealth service provider: provider of eHealth services to a group of people

formal carers: professional providing care for the client

health/care professionals: professionals (e.g. clinicians, doctors, occupational therapists, social workers) involved in the assessment of clients and delivery of more specialist care than that provided by carers

informal carers: relatives, neighbours, friends or volunteers providing care for the client

profile: set of user related information, preferences, rules and settings which affects the way in which a user experiences terminals, devices and services

   NOTE: The use of the word profile in the present document implies user profile unless otherwise stated.

profile provider: entity (e.g. company such as a service provider, organisation such as a special interest or affinity organization) that provide profiles and associated services

rule: statement that can be interpreted by the profile system to produce or limit an action

state: aspect of users and their devices and services

template: set of rules and settings provided by an entity as a starting point for the user for the creation of their profiles

usability: extent to which a product can be used by specific users to achieve specific goals with effectiveness, efficiency and satisfaction in a specified context of use

user: person using ICT services

user profile: See profile.

3.2   Abbreviations

For the purposes of the present document, the following abbreviations apply:

ACR-NEMA	American College of Radiology - National Electrical Manufacturers Association
ADL	Activities of Daily Living
CEN	Comité Européen de Normalization
COPD	Chronic Obstructive Pulmonary Disease
DICOM	Digital Imaging and Communications in Medicine
EAACI	European Academy of Allergy and Clinical Immunology
EHR	Electronic Health Record
FIC	Family of International Classifications
HL7	Health Level 7
ICHI	International Classification of Health Interventions
ICT	Information and Communications Technology
IDR	Informatics for the Disabled and Rehabilitation
IFIP	International Federation for Information Processing
IHE	Integrating the Healthcare Enterprise
NLU	Natural Language Understanding
NPS	Nomenclature for allergy Position Statement
PCI	Primary Care Informatics
PHR	Personal Health Record
PPD	Personal Portable Devices
SDO	Standards Developing Organization
SFC	Scottish Funding Council
UPM	User Profile Management
WAO	World Allergy Organization

WG	Working Group
WHO	World Health Organization

4 Overview of the personalization and profile concept

4.1 Introduction

For the convenience of the reader, this clause provides an brief overview of the personalization and user profile concept as described in more detail in EG 202 325 [i.1]. Further information can also be found in ES 202 746 [1] which provides standardized user profile preferences and information. The personalization and user profile Architectural Framework is described in [2] (not restricted to eHealth personalization). The present document concentrates on the eHealth aspects of the user profile. From now on in the present document, the term "profile" will be used with the meaning "user profile".

4.2 What is a profile?

A profile contains details of the user and their personal requirements in a form that can be used by a system to deliver the required behaviours. When users wish to have the behaviour of devices or services personalized to their requirements, a profile will be required for:

- storing information, preferences and rules;

- making the information and preferences available to services/devices and when relevant also to other people.

Users require the data to be stored in a secure manner with user agreed levels of privacy applied to the availability and distribution of that data.

In the present document, the profile is often referred as if it is a single functional entity. However, parts of this profile may be distributed amongst a number of storage locations that include the user's services and devices. There may also be copies of profile data stored in devices or services and in a centralized location. Wherever the data is stored, the profile system will ensure that the data is synchronized when relevant. When new devices are acquired, factory set information and preferences may be updated by information and preferences copied from equivalent data that is already in the user's profile.

Major factors of the profile concept described in the present document, that distinguish them from profiles described in many other sources, are:

- the primary purpose of the profiles are to offer benefits to users;

- profiles contain information that allows users to configure services and devices to meet their individual needs;

- most of the data in the profile is considered to be owned by the user;

- the user can view all of the information in their profile in a form that is designed to be easy to understand;

- much of the information in the profile is intended to be applicable to a wide range of services and devices that are associated with the user;

- the user is usually able to modify most of the information in the profile (examples of exceptions when someone cannot modify information in the profile is when a child who might not be allowed to change most of the data, as their parents might have decided to configure the profile for them or clients who ask a carer to update the profile on their behalf).

4.3   Organization of the profile content

In general, a profile contains [1]:

- Information: data about or related to the user (e.g. name, address).

- Preferences: choices made by the user about a given parameter that will define or modify the system behaviour. More complex preferences can be expressed in the form of rules (see below).

  NOTE: When something is considered essential to the user, it would be more appropriate if a preference is instead called a "need" (e.g. a blind user sets the modality to "sound"). However, for simplification, in the present document the word "preference" is used.

- Rules: statements that can be automatically interpreted in order to define or modify the system behaviour. These rules may:

  - express complex preferences;

  - activate or de-activate situation profiles.

More specifically, the profile is organized into several blocks. The major organisational units of the profile are:

- Personal information: data about or related to the user (e.g. name, address, location).

- Human centred preferences: These are the overall preferences that might apply across the user's usage of a wide variety of different devices and services.

  As these preferences are not mapped precisely to specific features of services and devices, they may be presented in ways that must be interpreted before they can be used as the definition for a precise setting for a service or device feature.

- Service/device category related information and preferences: The information and preferences in this clause are related to service categories (e.g. Communications services), further sub-categories of the service category (e.g. Realtime communication), and specific services/devices.

Information and preferences need to be associated with a scope, which includes:

- (groups of) services;

- (groups of) devices;

- (groups of) people (e.g. entries in an address book).

- A scope may be very narrow (e.g. one specific service) or very broad (e.g. preferred language for all my services).

The values of the profile information and preferences in the profile will be either:

- directly set by the user (or by someone else on behalf of the user);

- read from other profile information (e.g. from devices or services);

- set as the result of a rule that is contained in the user's profile.

Further details on the profile content for services and devices in general (not restricted to eHealth services) is described in ES 202 746 [1] on "User Profile Preferences and Information".

4.4   Profile extensions

4.4.1   Proprietary profile extensions

Because of the limited of standardization of the features of eHealth related services and devices, it is not possible to define a full set of standardized profile data related to these. However, the profile may still contain information and preferences related to these as proprietary profile extensions. As stated in ES 202 746 [1], in addition to profile data items as defined and listed in the present document, it is possible for eHealth service developers and device manufactures to include proprietary profile data items in the profile which shall be identifiable as proprietary (e.g. specify the company and/or product identifier for which the proprietary information and preferences are intended for). Proprietary profile extensions are outside the scope of the present document.

4.4.2   Additional standardized information and preferences

In addition to profile data items as defined and listed in the present document, it is expected that there will be a need for future additional standardized information and preferences, for which new versions of the present standard may be developed.

4.5   Templates

Profiles can contain a very large number of settings and preferences which would be difficult to set up unaided. When users first create profile specifications, the creation task can be greatly simplified if the profile specifications are created from templates. The template provides a set of rules and settings that act as a starting point for users when creating their profiles, and these can be further amended by the user to suit their individual needs. Templates can be provided to the user from a number of different sources. Typically, templates would be used to create a personal default profile specification. Some templates for creating typical situation profiles would then also be provided. The use of templates will typically be in combination with a wizard guiding the user while defining their profile.

There may be parameters for which defaults are not appropriate and where the profile system will force the user to set their own value e.g. where it might result in a potentially dangerous health condition or if it is legally required for the user to make an explicit decision for themselves. When prompting the user for a value, the profile agent may:

- request explicit user input;

- propose a range of options from which the user will have to chose one;

- propose a value to accept or reject and give the user a mechanism to specify an alternative value if they reject the proposed value.

Further information and guidelines on templates can be found in clause 9 of EG 202 325 [i.1].

4.6   Profiles and user views

4.6.1   Situations, context and the scope object

Users move between situations throughout the day (e.g. at home, driving, working), and also users may change depending on their specific health condition. In each of these situations, users may have different needs for how they would like their ICT resources arranged. Wherever a user wishes to have different behaviour from their ICT it will first be necessary to identify criteria that uniquely define the situation. These criteria are captured as rules that defines when a Scope object is active (i.e. when it is isActive method evaluates to TRUE). Hence the user concept of a "situation" is represented in the profile system by a Scope object.

4.7   Context information

The profile system should be provided with any relevant information that can affect the behaviour of the system. This is called context information.

Examples of the context information include:

- the status of the services to which the user is subscribed;

- the status of the user's devices;

- the location of the user;

- other presence information;

- network conditions.

Context information will often be addressed in rules. The profile system can request context information or receive notification of changes, based upon a subscription. The activation of Scope object will be determined by rules involving context information. TS 102 747 [2] describes a "Context Watcher" application that is responsible for managing the acquisition of context information from the various sources (e.g. sensors, devices, services). There are two fundamental options for how this context information may be obtained:

- Polling: where the Context Watcher periodically requests updated context information from the source;

- On update: where the context source sends updated context information to the Context Watcher when a change has occurred to that context information. The information would normally be sent immediately the change has occurred at the source, but a degree of latency in sending this information may occur.

The choice about the frequency at which context information is requested from a source is the responsibility of the profile management system. The choice about when a change of context information is notified to the profile management system is the responsibility of the device, service or sensor system that is the source of the context information. In both cases, the ideal aim is to adjust the frequency of context information updating to match the perceived significance of the context information in terms of its importance and its urgency. Where context information is used to control profile behaviour in ways that are not very important or very urgent, the profile management system can be set to poll for this information quite infrequently.

Although frequent polling may place an unnecessary load on the communication channel used to acquire the updates (which may also have an associated cost), for context information that may be needed to determine states that have a very important or urgent significance in terms of the control of the profile, frequent polling will be what is required. Some eHealth situations may be associated with outcomes that will cause discomfort or danger for the user. The health status of a user may change very frequently and sometimes rapidly, and as a consequence, the associated context information will therefore need to be polled very frequently to track those changes. Sources that provide context information to a user profile management system will need to provide context updates more frequently and with less latency under similar circumstances.

The "situations" that users define, or generic situation profiles that profile providers make available to profile user, will relate to a situation that has some meaningful significance to the user. Users would normally be aware that they are in a situation as the core features that define the situation would be very obvious to the user (e.g. the location that they are in, the services that they are using or the time of day). So most user defined situations will be visible, predictable and generally slow to change.

In contrast, there may be many instances in the eHealth domain where there is a need for a sudden change to the settings of profile data to immediately reflect the entry into a health state which the user was not able to predict and of which the user may be totally unaware. For example, in cases where body-worn sensors detect that one of the user's physiological measures has exceeded a threshold value it may be necessary to change items in the profile and alert a care worker or emergency service even if the user has not detected that they have reached this critical state. Alternatively, where a user has a health condition where they experience significant changes in sensory ability (e.g. fatigue related loss of visual acuity), the system should respond to ensure that services being used are adjusted accordingly.

So, unlike normal user-defined situations, these health events will be neither visible, predictable nor slow to change. However it is still possible for Scope objects to be defined that correspond to these eHealth states and for the corresponding profile behaviour to be handled using the standard user profile handling procedures built into the architecture.

What is different in many health related states is that they will not be fully understood by the ordinary user and the ordinary user will not be able to determine how the profile should be modified as a result of entering that state. As such, these health states do not fit the criteria for normal situation profiles and therefore it would usually be inappropriate to allow the user to interact with the Scope objects associated with these states in the same way that they would be able to interact with the Scope objects associated with "situation profiles" (as described in clause 4.6.1). In particular, the states associated with many eHealth related Scope objects would not appear in the menu that contains user selectable "situation profiles" and users would not be asked if they wish to accept or reject the changes that would be made to the profile. In practice, it is likely that many Scope objects and corresponding Profile-Item-Attributes objects would be administered by a health professional or specialized health provision service provider.

Because the user may not be aware of the health state change that has occurred, they should be informed about why what may appear to be random changes to the profile and alerting actions have happened. Users should be informed in a way that they are likely to understand and taking into account the fact that they may well be unable to fully understand the technically correct explanation of the cause that triggered the changes they observe.

Context information may also be used in a rule associated with a profile data item that will cause the value of that profile data item to continuously change according to a function that the rule represents. Alternatively, continuous change of the value of a profile data item may be under the control of a system external to the user profile management system (but which may itself use the same context information used by the user profile management system). In both these cases, the dynamically changing profile data items will be associated with an eHealth related Scope object that may be permanently activated or itself controlled by context related behaviours that are independent of those that are causing the profile data item's value to continuously change.

4.8 Generic profile architecture

The personalization is achieved by maintaining and updating a profile, which depends on and is dynamically adapted, to the people's context, general preferences, physical and cognitive performance, and other relevant parameters. The profile can then be made available and used by eHealth services and devices to ensure a uniform user experience taking context into account. Whereas the profile is considered as if it is a single data entity, in practice parts of this profile (profile components) may be distributed amongst a number of storage locations that include the user's services and devices and the data is synchronized between them. It is recognised that not all devices and services have user personalisation parameters that can be set externally, and there are also devices and services that handle profiles in a proprietary way. The architectural framework is further described in TS 102 747 [2].

5   Model

5.1   General user profile model

The eHealth system model builds on and extends the user profile system model which is specified in figure 5.2.1 of ES 202 746 [1].
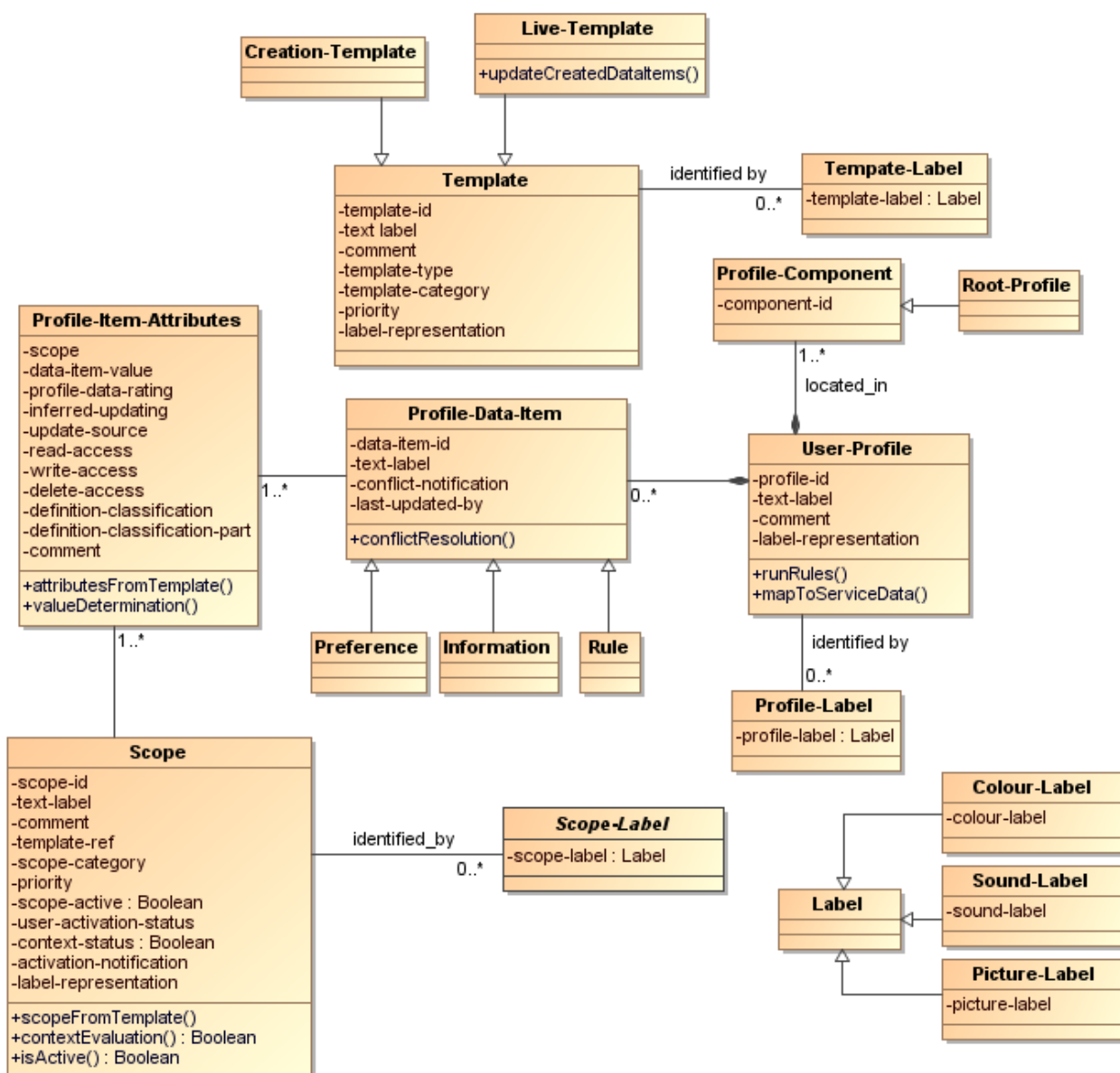
Figure 5.1.1: UPM system model from ES 202 746 [1] with extensions

The object of central importance is the "User-Profile". The profile contains a number of "Profile-Data-Item" that can be either of type "Preference", "Information" or "Rule". The "User-Profile" defines the UPM user's specific personalization requirements at any time.

Another object of crucial importance is the Scope object. Each Scope object relates to a pre-defined state of the UPM system, including the state of external context information provided by the context watcher described in TS 102 747 [2]. When this pre-defined state of the system occurs, the scope-active attribute of the Scope object is set to "true".

Some of these Scope objects relate to states of the system that have significant meaning to the UPM user. Such states of the UPM system are described in user terms as "situations" and the Scope object becomes a link to the system behaviour behind the user's view of a "situation". Situations may be explicitly defined by UPM administrators or, more typically, they will be partially pre-defined in the form of Template objects.

Other Scope objects will pre-exist, or be created by the UPM system, in order to identify other states of the UPM system that are required to successfully achieve the behaviour desired by the UPM user. Those Scope objects that are not intended to be visible to users as "Situation Profiles" will have their scope-category attribute set to "system". A very important Scope is the "normal" Scope that is always active. UPM user's would experience this as the normal state of the UPM system and could be given a view of their profile in this state called a "Normal Profile".

Each Profile-Data-Item has a number of associated attributes, including the actual value of the data item. These attributes of a Profile-Data-Item are encapsulated as the attributes of the Profile-Item-Attributes object. As a result of the progressively variable needs of the individual user, the values may need to change progressively rather than instantly. Therefore, the data-item-value can either be a fixed single value or it can be dynamically assigned by a rule or by and external source in order to set its value in a way that depends on elements in the particular context. Normally we expect the user profile system to be easy to configure to the user so the configuring of progressive behaviour could ideally be provided by a 3rd party (e.g. in templates).

The required behaviour of the UPM system and the UPM user's devices and services may be different depending on the context, and in particular in different "situations". To achieve this objective, the values of any or all of the attributes represented in a Profile-Item-Attributes object may need to differ according to the current Scope. This required behaviour is achieved by allowing a separate Profile-Item-Attributes object to be defined for each Scope object, with the first attribute of the Profile-Item-Attributes object identifying the Scope with which the Profile-Item-Attributes object is associated (the scope attribute).

There will always be one Profile-Item-Attributes object that is associated with the "normal" Scope and defines the behaviour of the UPM system when no other "situations" occur (i.e. no other Scopes are active).

Rules, preferences and information data items will sometimes need to refer to entities such as devices, services and people (represented as address book entries). In addition it will also be necessary to refer to groups which may contain any of these other types of entity. Figure 5.1.2 shows how all of these objects (Address-Book-Entry, Device, Service, Group) can be generalized into the Addressable-Entity class.
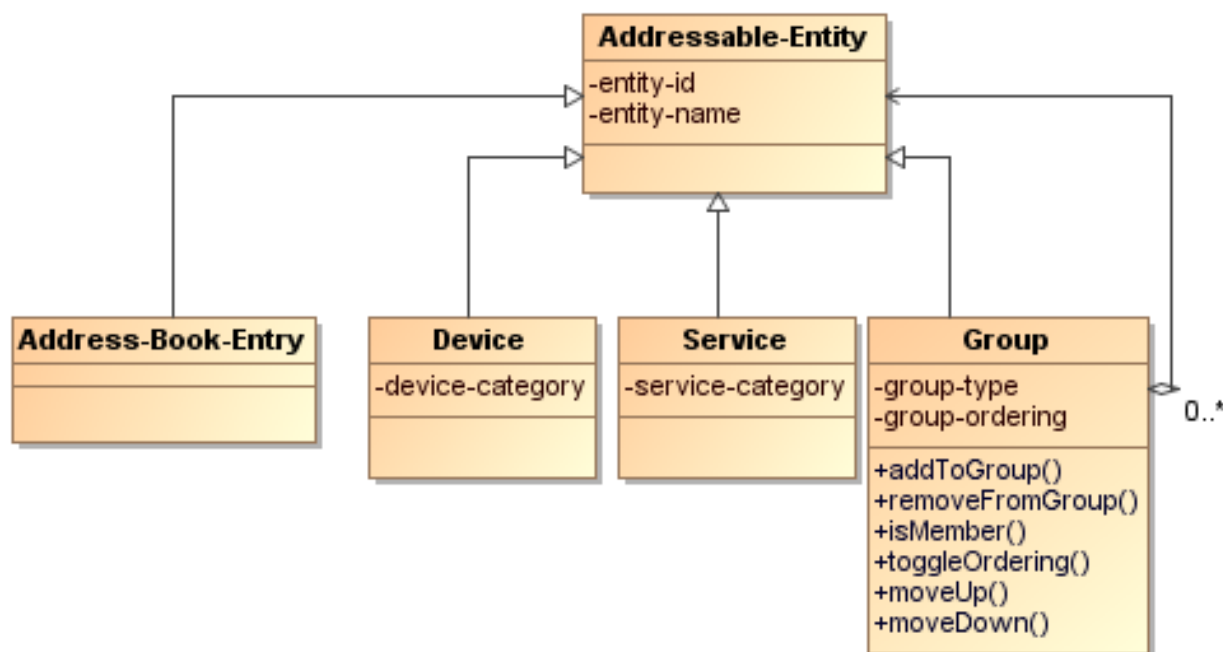
Figure 5.1.2: Addressable entity model from ES 202 746 [1] with extensions

The model in figure 5.1.2 allows a range of different entities, including groups, to be referred to in rules, preferences and information.

In order to help identify the eHealth category that an address book entry belongs to, a note has been added at the bottom of table 8.2.1 suggesting that a domain-specific-role and an externally-defined-role fields are added to address book entries. This would be of benefit when address book entries are referred to in rules, preferences and information. These fields could therefore be of benefit when assessing the likely accuracy of the data that has been updated by a person who is in the user's address book.

5.2   Extensions to the model

5.2.1   Introduction

As a result of investigating eHealth scenarios, some extensions to the profile system model which is specified in ES 202 746 [1] (figure 5.1.2) have been made.

5.2.2   Services and device

ES 202 746 [1] identifies the fact that the user profile management system can get access to a range of services and devices. There could be a range of services related to eHealth such as self help groups and those dealing with exercise. In the scope of eHealth, there are two major service categories external to the profile; the PHR and the EHR. The user profile does not provide access control to those services as it is the responsibility of the services. The Addressable-Entity class is modelled in figure 5.1.2.

It should be noted that the user profile do not provide access control to external services, which is particularly important services such as PHR or EHR.

The service and device categories can be used by rules to determine the priority of one service or device over another.

Table 5.2.2.1: Extension to Addressable-Entity class in ES 202 746 [1]

Field name	Extension to Addressable-Entity class
service category	**Description:** Specifies the category of a service. **UID:** profile-management-ns:Addressable-Entity/service-category **Instances:** unordered-list **Type:** enumeration **Value range:** tele-communication, PHR, EHR, preventative-care, formal-care, self-care, social-support, emergency, assistive, formally-managed, self-managed, information, other **Default value:** other **Technical information:** *tele-communication*: service used for tele-communication (e.g. mobile phone call); *PHR*: Personal Health Record; *EHR*: Electronic Health Record; *preventative-care*: service and actions aimed at preserving well-being or preventing or reducing the risk of unwanted health conditions; *formal-care*: service supporting care normally provided by care professionals; *self-care*: service supporting care done by the clients themselves to deal with their health and wellness; *social-support*: service supporting communication with other people; *emergency*: service intended for use in situations of risk for the client; *assistive*: service typically intended for use by people with disabilities but can also be useful for other people; *externally-managed*: service managed by carers (formal or informal); *self-managed*: service managed by the client; *information*: service providing information; *other*: service that do not fall into the above listed categories.

Table 5.2.2.2: Extension to Addressable-Entity class in ES 202 746 [1]

Field name	Extension to Addressable-Entity class
device category	**Description:** Specifies the category of a device. **UID:** profile-management-ns:Addressable-Entity/device-category **Instances:** unordered-list **Type:** enumeration **Value range:** telecommunication, measuring, emergency, assistive, medical-device, formally-managed, self-managed, other **Default value:** other **Technical information:** *telecommunication*: device intended for use of telecommunication services (e.g. mobile phone); *measuring*: device for measuring; *emergency*: device intended for use in emergency situations; *assistive*: device typically intended for use by people with disabilities but can also be useful for other people; *medical-device*: device used for medical purposes; *externally-managed*: device managed by carers (formal or informal); *self-managed*: device managed by the client; *other*: device that do not fall into the above listed categories.

5.2.3   Reference to alternative definitions and classifications

The present document identifies a single definitive standard for data items whenever possible. However, in some circumstances it is not possible to refer to a single standard in the present document (e.g. because local regulation or preference may dictate which definitions and classifications should be used). Therefore the present document provides the option to specify both a profile data items value and the definition and classification that specifies that profile data item, and which part of that standard that defines contents of the profile data item. This is an extension to Profile-Item-Attributes class as specified in ES 202 746 [1].

It is recommended that standardized terms are used when applicable. It is recognized that other standards (national and/or local) may be used. In practice, this can only be useful if a translation service is used.

The recommended syntax for specifying what definition and classification is used, should ideally be unique and as useful as possible, so useful options would be to specify them as namespaces or as a URI, but other alternatives may be considered.

Table 5.2.3.1: Extensions to Profile-Item-Attributes class in ES 202 746 [1]

Field name	Extensions to Profile-Item-Attributes class
definition classification	**Description:** Specifies classification and standard that a profile data item value refers to. **UID:** profile-management-ns:Profile-Item-Attributes/definition-classification **Instances:** one **Type:** string
definition classification part	**Description:** Specifies which part of the classification and standard that a profile data item value refers to. **UID:** profile-management-ns:Profile-Item-Attributes/classification-part **Instances:** one **Type:** string

5.2.4 Further extensions to Profile-Item-Attributes class

A "comment" field has been added to the profile-item-attribute class to allow the user to provide some explanatory text to accompany the current value of the profile data item.

As explained at the end of clause 4.7, the value of a profile item attributes object may be:

- a fixed value set by the user or by a template (described in ES 202 746 [1]);

- it may vary according to a behaviour specified in a rule;

- or its value may be (dynamically) set by a device or service.

In order to incorporate this extended behaviour, an additional valueDetermination method for the profile-item-attributes class is specified in table 5.2.4.1.

Table 5.2.4.1 also contains a description of the attributesFromTemplate method which was not described in ES 202 746 [1].

Table 5.2.4.1: Further extensions to Profile-Item-Attributes class in ES 202 746 [1]

Field name	Extensions to Profile-Item-Attributes class
comment	**Description:** The user can write a *comment* providing additional information related to the Profile-Data-Item. **UID:** profile-management-ns:Profile-Item-Attributes/comment **Instances:** one **Type:** string
Profile-Item-Attributes method: attributesFromTemplate()	**Description:** This method is run when the Profile-Item-Attributes object is created and sets the values of the attributes of the Profile-Item-Attributes object to those specified in the template who's template-id is the parameter specified in the invocation of the method. **UID:** profile-management-ns:Profile-Item-Attributes/attributesFromTemplate
Profile–Item-Attributes method: valueDetermination()	**Description:** This method sets the data-item-value after having checked that it is allowed to be set (e.g. checking that source trying to set the value is according to the user's preferences as specified in update-source). **UID:** profile-management-ns:Profile-Item-Attributes/valueDetermination

6 Stakeholders and their healthcare roles

6.1 Stakeholders

There are a variety of different stakeholders that have an interest in an eHealth User Profile. These are outlined below. Access to eHealth services need to be adapted to context and other people taking into account the risk of misunderstandings due to differences in language, culture, religion, etc.

The following are some of the most important stakeholders in most eHealth situations:

- **client:** This category of stakeholder covers those who are using health/care devices and services themselves to address a health or care need that they themselves have The category of stakeholder is characterised by having a wide range of expertise in health and care, ranging from very little expertise to being very expert. In many cases these stakeholders will have little or no training in care or health, so they will not be trained to understand data/information being delivered by health and care devices or services. It is important that they can specify the appropriate level of detail conveyed by devices and services that matches their expertise in health and care, and that the information conveyed from eHealth devices and services is presented in a way that they can comprehend.

- In general the default expectation is that a user defines and modifies the contents the user profile. In the context of eHealth however, it is probable that significant eHealth elements of the profile invoked by a user will not be populated by them. Profile parameters may come from sources such as devices and services used by the client. Important elements of the profile will almost certainly be set by professional carers. This therefore has implications for the way that profiles administration is managed by and on behalf of the clients.

- Normally it would be expected that the behaviour of a profile user in any given situation would not vary significantly, so the profile content could remain comparatively static whilst continuing to present the correct profile parameters to the systems and services being accessed by the profile user/owner. In the context of eHealth however, the patient may change in terms of their own behaviour or the way that they need a service or device to respond to them. This change may be quite pronounced and may be quite rapid. Examples could include becoming tired, losing concentration, mood swings, change in dexterity or strength or change in a health condition.

- This therefore has implications for the way that the services and devices should respond to the changes in the behaviour and needs of the clients. If the response is not sufficiently sensitive, the devices and services will become unusable by the client. If the response is too sensitive, the client may respond to the changing device or service behaviour, causing additional changes in the profile content or situational profile behaviour, with the result that the client could find themselves, perhaps without even realising it, "fighting" with the profile, device and services.

- **informal carers:** This category of stakeholder provides care in a wide variety of situations in a non-professional capacity. They may have a wide range of competences based on thorough through to little or no training in the health and care issues of the individual(s) that they are involved with, but they may have training in the use of the health/care services and devices. It is important that they can specify the appropriate level of detail conveyed by devices and services that matches their expertise in health and care, and that the information conveyed from eHealth devices and services is presented in a way that they can comprehend.

- **health/care professional:** A health/care professional is trained to handle health/care data and information, to recommend or perform treatments/therapies, and to use health/care services and devices. This category of stakeholders includes clinicians and doctors, occupational and other therapist, social worker and domiciliary (home) care workers (delivering care to people in their own homes e.g. washing, dressing, going to and getting out of bed and a range of practical/domestic tasks).

  - The care professionals will have a professional competence in their specific area of health and care, but within this category of stakeholder there will be a very broad range of needs for different ways of presenting the same health and care information. These needs will range from simple alerts on a mobile device to complex charts and tables showing trends and supporting data. It should not, however, be assumed that all professional carers will need or can use rich representations of data even if it could be made available to them. These stakeholders will need to be able to specify the richness of the data/information that they use and the most appropriate representation of the data/information.

- **eHealth service and device provider:** An organisation that offers eHealth services and/or devices to a range of stakeholders. The services provided may or may not involve service specific devices. The eHealth service provider can typically be classified according to one of the following organisational options:

  - public sector body (e.g. a local health authority) which has purchased a telecare system or a health/medical device from a manufacturer and uses it to provide an eHealth service to its citizens. In general, services and devices must be properly calibrated, provided and operated within the constraints of appropriate regulations and usage standards;

  - a private sector company or charity, which has been contracted by the authority to provide an eHealth service (but who are independent of the local authority). In general, services and devices must be properly calibrated, provided and operated within the constraints of appropriate regulations and usage standards;

  - a private sector company which offers eHealth services directly to subscribing customers. Devices provided by this service provider may not be required to be approved by a regulatory authority or formally calibrated.

There are frequently very strong associations between stakeholders and the roles described in clause 7.5. However, the allocation of roles to stakeholders can vary significantly from country to country and even from region to region within a country. This variation is often made even more complex due to historically changing patterns of funding for both medical and non-medical care services, with an often complex mix of publicly or privately funded care.

The interaction with an eHealth user profile for this category of stakeholder is centered on the provision of services and devices, and the associated profile to other stakeholders. In this sense, it is the responsibility of these stakeholders to ensure that the profiles that govern the access to the eHealth services and devices provide the correct range of usage parameters to suit the interest and health/care training/competencies of the variety of other stakeholders accessing or mediating access to the services and devices.

profile provider: An entity, such as a company, that provides the profile and associated services is called a profile provider. The profile provider may offer different versions of profile tools that are designed with respect to the context of use for different users, tasks, equipment and the physical and social environments. In addition to profile tools, the profile provider may also offer 3rd party services for administrating the profiles. Different types of profile providers include:

- Profile provider providing the whole profile or a major part of the profile: the profile data may be distributed at different locations, or reside at one centralized location. Profile providers should be offered a means, under control of the user's profile system and therefore the user, of synchronizing their part of the profile with other parts of the profile. The level of availability should be guaranteed.

- Device or service specific profile providers: a device manufacturer, a device, or a service provider may provide a profile, related to the particular device or service (e.g. of an eHealth service).

- Self providers: where users set up their own environment, providing their entire profile, or parts of it. The level of availability of such profiles cannot be guaranteed as the availability of the device or service which hosts the profile is unknown.

For further details on profile providers, see [i.1].

It is possible to define other stakeholders such as health/care manager, care mediator, health/care service and device funders regulators and policy makers. However, their relationship to user profiles is sufficiently distant that we have chosen to not address them in the present document.

7   Profile management information and preferences

7.1   Addressable entities and group

This clause specifies addressable entities and group. It builds on and extends the Addressable entity and group specified in ES 202 746 [1]. Rules, preferences and information data items will sometimes need to refer to entities such as devices, services and people (represented as address book entries). It can be useful for example in rules used for filtering criteria or for specific situations such as emergency situations. In addition it will also be necessary to refer to groups which may contain any of these other types of entity. Groups are also used for storing and finding contact information in a way that allows them to be more easily found and addressed.

The following profile data items, specified in ES 202 746 [1], are relevant for eHealth purposes:

- Group method: addToGroup:
  Description: a method that controls the addition of new members to a Group object

  UID: upm-ns:Group/addToGroup

- Group method: removeFromGroup():
  Description: a method that controls the removal of members from a Group object

  UID: upm-ns:Group/removeFromGroup

- Group method:isMember():
  Description: a method that evaluates to TRUE if the supplied argument of the method is a member of the Group object.

  UID: upm-ns:Group/isMember

Table 7.1.1: Extensions to Group class in ES 202 746 [1]

Field name	Extensions to Group class
group type	**From ES 202 746 [1]** **General description:** *group type* enables special types of groups to be identified. **UID:** profile-management-ns:Group/group-type **Instances:** one **Type:** enumeration **Value range:** unclassified, whitelist, blacklist **Default value:** unclassified **eHealth extension to the value range of the Group class (in ES 202 746 [1])** **Description:** *group type* enables special types of groups to be identified. Some of the values in the value range below are identical to those in *role*. Users can always define their own group names. This is done in Adressable-Entity.entity-name. The purpose of "group type" is to provide some commonly known names of groups in order to allow for example the option (for organizations or profile providers) to provide pre-defined rules in templates or for other people to be able to more easily find contact information for contacts within these groups (e.g. in an emergency situation). **Value range:** emergency-contact, doctor, dentist, care-provider, hospital, health-center, care-facility, insurance, client, formal-carer, informal-carer
group ordering	**Description:** *group ordering* specifies if the members of the group are ordered or unordered. An ordered group could for example be used for specifying a priority of contacts from the most important to the least important. **UID:** profile-management-ns:Group/group-ordering **Instances:** one **Type:** enumeration **Value range:** ordered, unordered **Default value:** unordered
Group method: toggleOrdering()	**Description:** *toggleOrdering* is a method that sets the group to be toggled between ordered or unordered list. **UID:** profile-management-ns:Group/toggleOrdering
Group method: moveUp()	**Description:** *moveUp* is a method that moves members of a Group object up one step of the list of members to create a user defined order. **UID:** profile-management-ns:Group/moveUp
Group method: moveDown()	**Description:** *moveDown* is a method that moves members of a Group object down one step of the list of members to create a user defined order. **UID:** profile-management-ns:Group/moveDown

7.2   Profile related information and preferences

7.2.1   Priority levels

In order to avoid that the same preference is addressed in two (or more) situation profiles causing an conflicts, there is a priority level associated with each situation profile, and if relevant on individual preferences. The value of the preference with the highest priority will be chosen. Users may have both eHealth related profiles, and non-eHealth related profiles. eHealth related profiles (although not those related to wellness/sports) may be considered to be more important than non-eHealth related profiles. The emergency profile has the highest priority. The topic of avoiding conflicts and resolution of conflicts from a general point of view (not just eHealth profiles) is further described in TS 102 747 [2].

The following profile data items, specified in ES 202 746 [1], are relevant for eHealth purposes.

7.3   Requirements for information sharing and privacy

7.3.1   Privacy of information held in electronic health records

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 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.

The most sensitive eHealth related information will normally be the information held in Electronic Health Records (EHRs) or Personal Health Records (PHRs). The management of data in EHRs and PHRs, including issues related to managing the privacy of the data within these records will be the responsibility of the organisation hosting the eHealth information.

Due to the vulnerability of data transmitted on the internet and stored on the web, companies or organizations that set up web portals for health and/or provide health advice on the internet should pay particular attention to privacy rights and the confidentiality of client data. Several advisory codes of conduct for web portals have been published, e.g. [i.12].

Maintaining privacy and confidentiality helps create a sense of trust between the client and the eHealth service provider. Other factors that affect trust are: ethics; legal aspects; availability and reliability; integrity and safety, all of which are covered in other parts of the present document.

7.3.2   Privacy of information stored in a user profile

Where a service that host eHealth information related to the user permits the user to view and make local copies of the data, this data may be added to the user's user profile. It will be the responsibility of the service that hosts the eHealth information to ensure that the exchange of information with the user profile management system is done in a secure and privacy protecting way.

Where a user profile contains eHealth information that has been copied from an electronic health record, it is the responsibility of the profile user to create rules that permit this information to be shared with other parties according to privacy requirements that the user judges to be appropriate. If this copied eHealth information is subsequently shared with other parties in ways that the user considers to be inappropriate, the responsibility for this unintended behaviour is not in any way the responsibility of the organisation that hosted the record from which this information was copied. To avoid the risk that such unintended sharing will occur, the sharing of copied eHealth information under the direct control of the user profile management system should be discouraged for eHealth information that may be considered sensitive in nature. Such discouragement may be indicated to the user by means of general warnings cautioning the user about directly sharing this copied information.

The responsibility for the privacy of the data in an eHealth user profile is a potentially problematic area, as the contents of a user profile may not only not have been supplied or entered by the user (but by a health professional, informal carer, service or device) nor may the data be properly understood by the user, nor indeed may the possible use and consequences of the use of the profile be understood by the user. This is important in the context of eHealth as inappropriate or incorrect data may have serious consequences for the user. Different local regulatory frameworks across across the European Union and beyond, might govern these issues and it is therefore not possible to standardize any solution.

TS 102 747 [2] describes the privacy control mechanisms associated with the user profile management system.

7.3.3   Information acquisition and sharing

One of the key aspects that will determine the success of eHealth profiles is that the profiles contain information that is of relevance to various different eHealth situations. It is not only important that all the relevant information is available in a profile, but also that it is accurate and up-to-date.

Some information may be provided by the user, so that, subject to issues of ageing of the information, it can be assumed that the user is able to provide relevant and accurate information. Other information may be copied directly from sources that already contain accurate and up-to-date information and preferences. These sources could include services such as Electronic Health Records (EHRs) and Personal Health Records (PHRs) and devices which have already been used for some time and which might therefore be (partly) personalized.

It will be the responsibility of the organisations managing an external service to enforce an appropriate privacy policy in relation to the sharing of that information with other people or services. The user profile management system shall not be able to change the privacy policies of other services. The issues that are specific to this situation are the enforcement of access rights that are consistent with the privacy protection and data integrity objectives associated with that data. This also applies to the copying of information into the user profile management system.

The control of what information the user is allowed to copy from a service will be controlled by the service provider and the user profile will only be able to specify which subset of the allowed information the user wishes to copy. The importance of ensuring that the service has ultimate control over what information the user profile management system may copy is especially important for EHR and PHR systems where the information may be very sensitive.

Where information has been copied from a service into the user profile, the service provider can no longer be considered to be responsible for how the information in the profile is used. The responsibility for the sharing the copied information with other people or services becomes the sole responsibility of the user.

In some cases it may be appropriate to keep the information and context data synchronized between the profile a service. Synchronization of UPM systems is described in TS 102 747 [2].

A more complex situation is when the information in the profile is not directly obtainable from a single location but must be derived from multiple sources of data such as a number of different sensors. In these cases it is necessary to have a rule that identifies how these multiple sources of data are to be combined and how the information that is written into the profile may be modified according to the current context. Clause 7.4 gives a further description of the access to information stored in other sources.

7.3.4   Validation of profile data items

The majority of the preferences in a profile are defined exclusively by the profile user and can thus be accepted as a true statement of what the user's wants. However information in a profile could come from several sources and, if the validity of the information is of importance to the person or service accessing the profile, it may be necessary to check the validity of items of profile data. In the Profile-Item-Attributes object there is the last-updated-by (see table 7.4.1) attribute which can be used for validation of the validity of data. The validation methods that can be used may vary between different data items and can range from person to person verification between a representative of the source organisation and the person accessing the profile to an automatic verification process involving digital certificates.

7.3.5   Accreditation of profile read/write access

The eHealth roles will typically need to be certified by a trusted (regulation) authority (e.g. on an international, national, local and/or organizational level). In addition, there is a need for a secure authentication system to verify that the asserted role is an authentic representation of the actual role of the profile user. Read/write access can be assigned to individuals (on the basis of individual identities) and/or roles. The management of access rights may be assigned to a system that is not a part of the core user profile system.

7.4   Sources

During set-up of the profile, information and preferences will be gathered from services and devices in order to populate the profile. In cases where for example, a telehealth system realises that the user's performance in a particular attribute (e.g. strength or dexterity) is below normal on a specific day, it could inform the profile and then the profile could update the particular profile data item so that other services/devices will be personalized according to that information/preference. It can be expected that this updating could occur considerably more frequently with eHealth conditions than with non-eHealth conditions.

The following profile data items, specified in ES 202 746 [1], are relevant for eHealth purposes:

- inferred updating :
  Description: inferred updating concerns adaptive personalization. If inferred updating has the value yes or confirmation, then the system is enabled to update the profile automatically depending on factors such as the context, how the user is using devices and services.

  UID: upm-ns:Profile-Item-Attributes/inferred-updating

- priority:
  Description: priority is used in the determination of the correct Profile-Item-Attributes instance to use to set the data-item-value of a Profile-Data-Item (when the scope-validity of two or more Scope objects referenced by a Profile-Data-Item are simultaneously TRUE).

  UID: upm-ns:Scope/priority

The last-updated-by (specified in table 7.4.1) replaces both update-source-category and update-source-identity which are specified in ES 202 746 [1].The last-updated-by provides more information, such as name and role of the entity, of the entity that has updated the profile-data-item (compared to update-source-category and update-source-identity).

Table 7.4.1: last-updated-by replaces update-source-category and update-source-identity in Profile-Data-Item in ES 202 746 [1]

Field name	last-updated-by
last updated by	**Description:** *last updated by* specifies the entity that last set the value of the profile data item. **UID:** profile-management-ns:Profile-Data-Item/last-updated-by **Instances:** one **Type:** anyURI **Technical specification:** Last updated will be a URI that is either: -the Profile-id of the user's profile if the data-item-value was last updated by the user -the data-item-id of the rule that updated the data-item-value if it was last updated by a rule -the entity-id of the Addressable-Entity that updated the data-item-value if it was last updated by an Addressable-Entity.

7.5 Roles

This clause informs about different roles. For each of the roles, they may be one or both of the profile user role and the administrator role, as described below in clause 7.5.1. Individuals may have different roles in different contexts.

7.5.1 Profile system roles

- **Profile user role -** A person is in a user role when they are using their existing profiles, including activation or deactivation of their profiles. It is likely that some people, for instance very young children, would only be allowed the user role.

- **Profile administrator role** - A person needs to be in an administrator role to define new situation dependent profiles or to modify existing profiles. The most straightforward case is that the same person is in a user role most of the time and may be in an administrator role when there is a need to create a new profile or update existing ones.

  - It should be emphasised that in general, the user is likely to be the principle administrator for their profile, it is very likely that significant elements of the eHealth related profile data will be administered by someone else on behalf of the user, but not be administered directly by the user. This has significant implications for data privacy and accountability for the accuracy of the data and it is used by devices and services that act in response to the user profile contents.

  - For further details on the administrator role, see EG 202 325 on User Profile Management [i.1].

  - Further details on administrator and user roles is described in the TS specifying the architectural framework for user profile management TS 102 747 [2].

NOTE: A person addressed in the present document, whether in a user role or in an administrator role, is most often called "user" in the present document.

7.5.2   eHealth related roles and sharing of profile data

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.

Many users may wish to share selected information from their profile during an emergency situation. As the user has entered such information into the profile with the express wish that it may be shared with other entities (devices, services or people) according to rules that they specify, there should be no contravention of data privacy laws in sharing this data. For an emergency situation there may be two forms of constraint relating to the sharing of that information. These are:

Context: The issue here is in determining if the current situation is an emergency that would justify the sharing of the emergency-related information.

Role: The issue that needs to be solved here is to reliably determine whether the entity with which the information is being shared is an appropriate person according to their (eHealth) role. Where the person or system requiring the information has a "role" specification in their profile that matches the roles specified in the profile user's rules, there should be no problem. The problems will arise where the person or system requesting the information has no "role" specified in their profile or where the role is appropriate but does not match an item in the user's rule.

Where it is not possible to resolve the above issues, the user should always be provided with the option of overriding any rule controlled sharing and be allowed to share information with a specific person that they choose.

Some of the roles mentioned below form the standardized eHealth roles. In order to provide a more finely granulated roles, some additional roles can be externally defined.

The access right preferences can be specified in the profile by the following mechanisms:

*   The Scope method:contextEvaluation described in table 7.5.2.1 and Scope class in ES 202 746 [1] is used to define a rule which specifies the details about the access such as who, which role and under which conditions the profile data item(s) can be accessed

*   Table 8.2.1 specifies both predefined roles and externally defined roles which are useful in rules for specifying which roles can access profile data item(s).

*   Table 7.5.2.2 specifies read/write/delete access which are extensions to Profile-Item-Attributes class in ES 202 746 [1]

*   Table 7.5.2.3 update source specifies the user's preference of what/who is allowed to update the data-item-value.

The Scope method:contextEvaluation described in Scope class in ES 202 746 [1], is amended in table 7.5.2.1, with an example describing how role can be used to set context-status to TRUE

The following specifies the user's preference of what/who is allowed to update the data-item-value.

Table 7.5.2.1: Extension to Scope class in ES 202 746 [1]

Field name	Extension to Scope class
Scope method: contextEvaluation()	**Description:** a Boolean expression involving context data that evaluates that data to see whether they meet the requirements specified for the scope object and then sets the value of the context-status attribute. EXAMPLE 1: for a context object that represents an "At Home" situation, the context-evaluation expression could be: WHEN (location==GPS.pos.home) OR (WiFi_SSID==myHomeWiFi) THEN context-status := TRUE EXAMPLE 2: Another use of Scope is for allowing other people to update the profile. When a medical professional wishes to update a Profile-Data-Item the following rule would be relevant: WHEN (role== medical-professional) THEN context-status := TRUE **UID:** profile-management-ns:Scope/contextEvaluation

**Table 7.5.2.2: Sharing preferences for further extensions to
Profile-Item-Attributes class in ES 202 746 [1]**

Field name	Sharing preferences for further extensions to the Profile-Item-Attributes class and to the Scope class
read access	**Description**: *read access* is used to express the user's wishes for how a Profile-Data-Item can be shared regarding the read access. **UID**: profile-management-ns:Profile-Item-Attributes/read-access **Instances**: unordered-list **Type**: enumeration **Value range**: share, confirmation, do-not-share **Default value:** do-not-share **Technical specification**: *share*: The Profile-Data-Item can be read without confirmation needed . *confirmation*: the system will ask the user if the Profile-Data-Item Can be read by the specified addressable-entity, and then the user can answer "yes" or "no". *do-not-share*: the Profile-Data-Item cannot be read by other than rules within the profile system.
write access	**Description**: *write access* is used to express the user's wishes for how a profile data item should be shared regarding the write access. **UID**: profile-management-ns:Profile-Item-Attributes/write-access **Instances**: unordered-list **Type**: enumeration **Value range**: share, confirmation, do-not-share **Default value:** do-not-share **Technical specification**: *share*: The Profile-Data-Item can be written without confirmation needed . *confirmation*: the system will ask the user if the Profile-Data-Item Can be written by the specified addressable-entity, and then the user can answer "yes" or "no". *do-not-share*: the Profile-Data-Item cannot be written by other than rules within the profile system.
delete access	**Description**: *delete access* is used to express the user's wishes for how a profile data item should be shared regarding the delete access. **UID**: profile-management-ns:Profile-Item-Attributes/delete-access **Instances**: unordered-list **Type**: enumeration **Value range**: share, confirmation, do-not-share **Default value:** do-not-share **Technical specification**: *share*: The Profile-Data-Item can be deleted without confirmation needed . *confirmation*: the system will ask the user if the Profile-Data-Item Can be deleted by the specified addressable-entity, and then the user can answer "yes" or "no". *do-not-share*: the Profile-Data-Item cannot be deleted by other than rules within the profile system.

**Table 7.5.2.3: Sharing preferences for further extensions to
Profile-Item-Attributes class in ES 202 746 [1]**

Field name	Sharing preferences for further extensions to Profile-Item-Attributes class
update source	**Description:** *update source* specifies the user's preference of what/who is allowed to update the data-item-value. **UID:** profile-management-ns:Profile-Item-Attributes/update-source **Instances:** 1..n **Type:** anyURI **Technical specification:** Update source will be a URI that is either: - the Profile-id of the user's profile if the user is responsible for updating the data-item-value - the data-item-id of a rule if a rule is responsible for updating the data-item-value - the entity-id of an Addressable-Entity if an Addressable-Entity is responsible for updating the data-item-value

8   Client related information

8.1   Introduction

Descriptive information is about or related to the user such as the user's name and address. Such information can be useful in different situations when the user wishes to provide information to various services or other people (e.g. when booking a meeting with a doctor), without having to type it in each time. Some of this information may not be applicable for processing by profile rules and is most likely to be intended for identification and transmission to other people or services, according to the user's privacy requirements.

8.2   Personal information

There will be personal information in a profile that is not uniquely eHealth specific and is described in ES 202 746 [1], (e.g. name and contact information). In the eHealth context there is information such as roles, allergies, disability, contact person (e.g. who to contact in different situations, such as in everyday life, in case of an emergency).

The following profile data items, specified in ES 202 746 [1], are relevant for eHealth purposes:

- vCard version:
  Description: vCard version specifies the version of the vCard standard supported by the personal information listed in this table.

  UID: personal-information-ns:vcard-version

- last revision:
  Description: last revision specifies the date when the personal information was last updated. The last revision is a requirement of TS 102 334 [7], for the passing of address book entries within an NGN. All information passed must have this parameter specified as it indicates the recency of the information.

  UID: personal-information-ns:last-revision

- name:
  Description: if the name type is present, then its value is a structured representation of the name of the person.

  UID: personal-information-ns:name

- formatted name:
  Description: if the formatted name type is present, then its value is the displayable, presentation text associated with the source for the vCard.

  UID: personal-information-ns:formatted-name

- nickname:
  Description: nickname specifies a descriptive name given instead of or in addition to the one belonging to a person, place, or thing. It can also be used to specify a familiar form of a proper name specified by personal-information-ns:name or personal-information-ns:formatted-name.

  UID: personal-information-ns:nickname

- display name:
  Description: display name specifies the alias name to be shown in the user interface. Also known as nickname. It may contain multiple display names, but only if they are labelled with different language' attributes (xml:lang). This allows, for example, a Korean-speaking person to display their name in different languages.

  UID: personal-information-ns:display-name

- UCI label:
  Description: The label Universal Communications Identifier (UCI).

  UID: personal-information-ns:X-ETSI-UCI-label

- UCI additional data:
  Description: Universal Communications Identifier (UCI).

  UID: personal-information-ns:X-ETSI-UCI-AdditionalData

- telephone number:
  Description: telephone number value is specified in a canonical form in order to specify an unambiguous presentation of the globally unique telephone endpoint".

  UID: personal-information-ns:telephone-number

- e-mail:
  Description: e-mail specifies the electronic mail address for communication with the object the vCard represents".

  UID: personal-information-ns:email

- URL:
  Description: URL specifies a resource (e.g. web page) that the user has specified.

  UID: personal-information-ns:URL

- photo:
  Description: photo specifies a URI pointing to an image (icon) representing the Person.

  UID: personal-information-ns:photo

- address:
  Description: address specifies the extended address of a postal address.

  UID: personal-information-ns:address

- birthplace:
  Description: birthplace specifies the birthplace.

  UID: personal-information-ns:birthplace

- bday:
  Description: bday specifies the birthday.

  UID: personal-information-ns:bday

In ES 202 746 [1], "role" is replaced by "vCard role". The reason is that it is convenient to use the more generic word "role" in for example rules, for the three types of roles listed in table 8.2.1.

Table 8.2.1: Role related extensions to personal information in ES 202 746 [1]

Field name	Role related extensions to personal information
vCard role	**"vCard role" as defined below replaces "role" in ES 202 746 [**1**]:** **Description:** *vCard role* specifies the person's role as specified by the vCard standard [6]. **UID**: personal-information-ns:vCard-role **Reference to a standard:** vCard [6] - ROLE **Instances:** unordered-list
domain specific role	**Description**: *domain specific role* specifies the person's role in a specialised domain (e.g. in eHealth). These roles are in addition to any roles specified in the *role* field and can be referred to in rules, preferences and information. **UID**: personal-information-ns:domain-specific-role **Instances**: unordered-list **Type**: enumeration **Value range**: client, medical-professional, formal-carer, informal-carer, emergency-personnel, service-device-provider, unclassified **Default value:** unclassified **Technical specification**: *client* : Individual receiving the eHealth service, to support independent living and/or using eHealth services for the care of his or her own health and wellbeing; *medical-professional*: A medical professional (e.g. clinician, doctor) is involved in the assessment of clients and delivery of one or more medical roles. The medical professional will have a qualification that entitles them to perform various medical roles. They may also perform other non-medical roles such as performing some non-medical care roles. *formal-carer*: A care professional (e.g. occupational therapist, social worker) is involved in the assessment of clients and delivery of one or more non-medical care roles. The care professional will have a qualification that entitles them to perform various care roles. *informal-carer*: A non-care professional (e.g. family member) is involved in the care of the client. *emergency-personnel*: A professional intervening in an emergency situation. *service-device-provider*: A professional responsible for installing and configuring a service /device according to the parameters in a users profile. *unclassified*: role is not classified. **Related field:** *role, externally-defined-role*
externally defined role	**Description**: An *externally defined role* may be specified by an external source, for example on a national level. These are in a form defined by the <source> organisation. These roles are in addition to any roles specified in the *role* field. **UID**: personal-information-ns:externally-defined-role **Instances**: 1..n **Type**: string **Technical specification**: of the form <source>:<externally specified role> Where <source> is defining where to find the specified role. It could for example be a name-space. **Related field:** *role, domain-specific-role*
NOTE 1:	Where possible, a domain-specific-role field and an externally-defined-role field should be added to address book entrie.
NOTE 2:	The more generic name "role" shall be possible to be used in rules. When "role" is used in rules, it replaces any of vCard-role, domain-specific-role and externally-defined-role. When the name "role" is used, the value range shall be a superset of the value ranges for vCard-role, domain-specific-role and externally-defined-role. The roles specified by the external source, that is specified by externally-defined-role, are of type enumeration. For roles, a method (for example named GetRole) shall return any role where the type shall be "enumeration" whether it is "role", "domain-specific-role" or "externally-defined role" (which solves the issue that externally-defined-role is of type string).s in order that these can be can be referred to in rules, preferences and information.

Table 8.2.2: Personal information

Field name	Personal information
gender	**Description:** Specifies the gender. **UID:** personal-information-ns:gender **Instances:** one **Type:** enumeration **Value range:** male, female, partly-female-male, do-not-specify
about me	**Description:** *about me* is a short description about the user's health condition/interest intended to be displayed at eHealth discussion groups. **(**Example: "I have diabetes and wish to connect with other diabetes sufferers".). **UID:** personal-information-ns:about-me **Instances:** 0..n **Type:** string

8.3 Health information

The present document identifies a single definitive standard for data items whenever possible. However, in some circumstances, for example the profile data items specified in table 8.3.1, it is not possible to refer to a single standard (e.g. because local regulation or preference may dictate which definitions and classifications should be used). Therefore the present document provides the option to specify both a profile data items value and the definition and classification that specifies that profile data item, and which part of that standard that defines contents of the profile data item. For further details on this topic, see clause 5.2.3. It is also possible to associate a comment (see table 5.2.4.1) related to the profile data item value, which could provide additional information in free text.

Table 8.3.1: Basic health related information

Field name	Basic health related information
disease	**Description:** Specifies diseases and related health problems. **UID:** health-ns:disease **Instances:** unordered-list **Type:** string **Related field**: *Definition-classification* *Definition-classification-part*
functioning disability health	**Description:** Specifies functioning, disability and health. **UID:** health-ns:functioning-disability-health **Instances:** unordered-list **Type:** string **Related field**: *Definition-classification* *Definition-classification-part*
health interventions	**Description:** Specifies health interventions. **UID:** health-ns:health-interventions **Instances:** unordered-list **Type:** string **Related field**: *Definition-classification* *Definition-classification-part*
medications	**Description:** Specifies medications. **UID:** health-ns:medications **Instances:** unordered-list **Type:** string **Related field**: *Definition-classification* *Definition-classification-part*

Field name	Basic health related information
active medical implant	**Description:** Specifies an active medical implant (e.g. a heart pacemaker). **UID:** health-ns:active-medical-implant **Instances:** unordered-list **Type:** string **Related field**: *Definition-classification* *Definition-classification-part*
passive medical implant	**Description:** Specifies a passive medical implant (e.g. a Vital Signs Implant). **UID:** health-ns:passive-medical-implant **Instances:** unordered-list **Type:** string **Related field**: *Definition-classification* *Definition-classification-part*
assistive technology	**Description:** Specifies assistive technology (e.g. wheel chair, Braille output device, hearing aid). **UID:** health-ns: assistive-technology **Instances:** unordered-list **Type:** string **Related field**: *Definition-classification* *Definition-classification-part*
allergies	**Description:** Specifies allergies. **UID:** health-ns:allergies **Instances:** unordered-list **Type:** string **Related field**: *Definition-classification* *Definition-classification-part*
vaccinations	**Description:** Specifies vaccinations. **UID:** health-ns:vaccinations **Instances:** unordered-list **Type:** string **Related field**: *Definition-classification* *Definition-classification-part*
blood type	**Description:** Specifies the blood type. **UID:** health-ns:blood-type **Instances:** one **Type:** string **Related field**: *Definition-classification* *Definition-classification-part*
user height value	**Description:** Specifies the value of the user's height. This can be useful for example for fitness and wellbeing services. It is stored in the profile in meters, according to the International System of Units (SI units) [5]. **UID:** health-ns:user-height-value **Instances:** one **Type:** decimal **Related field**: user-height-unit
user weight value	**Description:** Specifies the value of the user's weight. This can be useful for example for fitness and wellbeing services, emergency services (e.g. for extra heavy people bigger ambulance). It is stored in the profile in kg, according to the International System of Units (SI units) [5]. **UID:** upm-ns:interaction-preferences-ns:user-weight-value **Instances:** one **Type:** decimal **Related field**: user-weight-unit

Table 8.3.2: Unit preferences for input and display purposes

Field name	Unit preferences for input and display purposes
length	**Description:** length specifies how to show and enter length units (e.g. meter, foot). **UID:** upm-ns:interaction-preferences-ns:length **Reference to standard:** Unicode CLDR "measurement-unit" [4] supplemental data **Instances:** one **Type:** enumeration **Value range:** metric, US, UK
weight	**Description:** *weight* specifies how to show and enter weight units (e.g. kg, stone). **UID:** upm-ns:interaction-preferences-ns:weight **Reference to standard:** Unicode CLDR "measurement-unit" [4] supplemental data **Instances:** one **Type:** enumeration **Value range:** metric, US, UK

9   Situation and context related information

9.1   Introduction

Situations, location, context are mentioned in [1]. These can be addressed in rules, and can also be useful for informing other people.

9.2   Highlevel health condition

Table 9.2.1: Highlevel health condition

Field name	Highlevel health condition
highlevel health condition	**Description:** Specifies a highlevel description of the health condition. This is not intended to give detailed information about the current and precise health status of the person, but it is intended to be used in the creation of rules or for informing other people such relatives and friends. **UID:** health-ns:highlevel-health-condition **Instances:** one **Type:** enumeration **Value range:** well, mild-condition, stronger-condition, emergency **Technical specification**: *well*: the person is feeling well; *mild-condition*: with a condition but not strongly affecting the person; *stronger-condition*: with a condition and it is strongly affecting the person; *emergency*: in emergency.

9.3   Place types and locations

The following profile data items, specified in ES 202 746 [1], are relevant for eHealth purposes:

- location type:
  Description: location type describes the type of place a person is currently at.

  UID: upm-ns:location-type

- place property:
  Description: place property describes properties of the place the person is currently at.

  UID: upm-ns:place-property

- entity location geopriv:
  Description: entity location geopriv provides information about the location of a person or a device.

  UID: upm-ns:entity-location-geopriv

- entity location gps:
  Description: entity location gps provides information about the location of a person or a device.

  UID: upm-ns:entity-location-gps

9.4   Mood and activity

Some care treatments may require the client to self assess their current state, feeling(s) or activity. In addition, some can be detected by sensors. For certain medical conditions, the set of mood options from which the client can choose may be matched to the typical mood states associated with this condition.

It may be possible to monitor aspects of mood and activity and then map them to values of the mood and activity data items in table 9.4.1. However, the options provided by the mood and activity elements of RFC 4480 [3] were not primarily designed for eHealth purposes and it may be difficult to make suitable mappings between measured values and the mood and/or activity options.

Mood and activity profile data items could be used for example in rules that alert people such as carers if a specific mood or activity is active or non-active, or can be used to select an appropriate situation profile.

Table 9.4.1: Mood and activity

Field name	Mood and activity
mood	**Description:** *mood* describes the mood of the person. **UID:** personal-information-ns:mood **Reference to a standard:** RFC 4480 [3] - Mood Element **Instances:** unordered-list **Type:** enumeration **Value range:** as in RFC 4480 [3] - Mood Element and in addition the following: dizzy, nauseous, in-pain, hypersensitive.
activity	**Description:** *activity* describes what the person is currently doing, expressed as an enumeration of activity-describing elements. A person can be engaged in multiple activities at the same time, e.g., traveling and having a meal. **UID:** personal-information-ns:activity **Reference to a standard:** RFC 4480 [3] - Activities Element **Instances:** unordered-list **Type:** enumeration **Value range:** as in RFC 4480 [3] - Activities Element and in addition the following: inactive, in-bed, in-shower-bath, walking, undergoing-treatment.

10   Service and device category related information and preferences

10.1   Introduction

There are information and preferences specified in ES 202 746 [1] which are intended for any service and also for eHealth purposes. Some categories with could be configured by standardized information and preferences in a user profile are:

- Connectivity preferences;

- Interaction and user interfaces;

- General interaction preferences;

- Interaction modality;

- Multicultural aspects;

- Visual preferences;

- Audio preferences;

- Tactile/haptic and device related preferences;

- Date and time preferences;

- Notifications and alerts.

This comprehensive set of options could be applied to a wide range of eHealth services including:

- remote consultations (e.g. using video conference system);

- assistive technologies;

- information systems;

    - information services for clients such as Personal Health Record (PHR) systems,

    - information about the user to share with others such as Personal Health Record (PHR) systems,

    - information services carer to client such as web portal of the hospital or clinic,

    - information services client to carer such as Personal Health Record (PHR) systems,

    - information services within health care provision such as Electronic Health Record (EHR) systems,

    - information for Self-Care,

    - information about available Care Services,

    - information about Care Support Groups & Services.

- care needs monitoring technologies;

- supportive such as reminder and alarm/alert systems;

- preventative;

- treatment giving.

Many devices may have a number of configurable features which can be automatically set by reading a user profile and they can also be useful for providing information, (e.g. contextual information) to the profile system. Example categories of devices that could be configured (or provide information) include:

- assistive devices;

- monitoring devices;

- treatment giving equipment;

- wellbeing equipment.

In addition to the information and preferences as specified in ES 202 746 [1] and in previous clauses of the present document, there are some service/device specific information and preferences which are specified in the following clauses.

10.2   Video preferences

Some of the above mentioned services could use video conferencing. To ensure optimized video conferencing, the following preferences could be defined:

The following profile data items, specified in ES 202 746 [1], are relevant for eHealth purposes:

- video zoom:
  Description: video zoom specifies the preferred video appearance.

  UID: interaction-preferences-ns:video-zoom

In addition, video quality is specified.

Table 10.2.1: Video preferences

Field name	Video preferences
video quality	**Description:** *video quality* specifies the preferred video quality, within the subscription. **UID:** interaction-preferences-ns:video-quality **Instances:** one **Type:** enumeration **Value range:** low, medium, high, highest **Default value:** device-service-default

10.3   Numeric output

Some people may have a preference for displaying numeric information in graphs or charts (e.g. people who are innumerate), whereas other people might prefer numbers (e.g. because of compatibility with their assistive devices). Where services provide alternatives, the following preference would be of benefit.

Table 10.3.1: Numeric output

Field name	Numeric output
numeric output	**Description:** *numeric output* specifies how the information is presented. **UID:** interaction-preferences-ns:numeric-output **Instances:** unordered-list **Type:** enumeration **Value range:** number, text, symbol, table, graph-chart **Default value:** device-service-default

10.3.1   Notifications and alerts

This clause describes the notification and alert in a service/device independent way and extends the "alert and notification" preferences as specified in ES 202 746 [1], using the Notification-Preference class.

**Table 10.3.1.1: Threshold based alert as extension to
Notification-Preference class in ES 202 746 [1]**

Field name	Threshold based alerts as extension to Notification-Preference class
threshold variable	**Description:** *threshold variable* specifies which variable will result in an alert or notification is given when a particular threshold is given. **UID:** notifications-ns:Notification-Preference/threshold-variable **Instances:** one **Type:** any type of measurement unit which is defined by the service.
threshold direction	**Description:** *threshold variable* specifies which variable will result in an alert or notification is given when a particular threshold is given. **Description:** *threshold* specifies which is the threshold when an alert or notification is given. **UID:** notifications-ns:Notification-Preference/threshold-direction **Instances:** one **Type:** enumeration **Value range:** greater-or-equal, less-or-equal
threshold value	**Description:** *threshold variable* specifies which variable will result in an alert or notification is given when a particular threshold is given. **Description:** *threshold* specifies which is the threshold when an alert or notification is given. **UID:** notifications-ns:Notification-Preference/threshold-value **Instances:** one **Type:** decimal

10.4   Usability and accessibility

Usability and accessibility issues must be taken into account. Annex B of ES 202 746 [1] presents the preferences relevant to people with disabilities.

Annex A (informative):
Profile content specification

A.1   Structure of profile items

The profile item specification are presented in tables as described below. These are exactly the same as in ES 202 746 [1].

Table A.1.1: <group of information and preferences>

Field name	Specifications	*<name of table>*
<name>	**Description:** <free text description> **UID:** <unique ID> **Reference to standard:** < standard> "[n]" - <part of standard> **Instances:** <express the number of possible values which can be chosen by the user> **Type:** <type> **Value range:** <value range> **Unit:** (e.g. percentage, pixels) **Default value:** <default value(s)> **Technical specification:** <free text description providing further details and technical information> **Related field:** <specifies relationship to other field(s).>	

NOTE 1: The display name in the user interface of the services and devices do not need to be the same as the <name> in the present document.

NOTE 2: The display name in the profile tool is recommended to be the same as, or similar to the <name> (or translation from English to any language) in the present document, in order to ensure that the user understands what information and preferences they have defined in their profile (also when changing profile provider and profile tool).

A.2   Description

Freetext description of the preference.

A.3   UID

Unique ID.

A.4   Reference to standards

Reference to standards. When there is a reference to standards, then some of the other fields might not be filled in.

A.5   Instances

Instances express the number of values which can be chosen by the user. Different services/devices may have different requirement on instances for a given setting related to that particular service/device. The instances given in the present document is an indication which is most relevant for the widest range of services/devices.

The values are: one, ordered-list, unordered-list. In an ordered-list, the first item has the highest significance (e.g. most preferred).

A.6 Type

Types are described in further detail in W3C XML Schema [8].

A.7 Value range

EXAMPLE: 1..10.

In practice, the user interface would probably express the standard in the human value range. The present document, does not provide the mappings between these values (e.g. low, medium, high) and technical values in this area as the human value range is a relative value range rather than a precise technical value, which also depends on the service/device.

A.8 Default value

Profile providers will provide a set of default values to help the user getting a good starting point when creating their profiles. The "default value" is a recommendation to profile providers for the value to set for a preference. However, profile providers may choose an alternative value. When the value "device-service-default" is specified, that means that the profile will not change the value in the service/device. A "device-service-default" is either representing the service/device default as a factory default, or the value that has been set by the user prior to the use of the user profile system.

A.9 Technical specification

Provides further details and technical information.

A.10 Related field

Specifies relationship to field(s).

Annex B (informative):
Background

B.1   eHealth and telecare

There is a multitude of definitions of eHealth [i.9], emphasizing to various degree health, technology and business aspects. The most commonly cited definitions on the Internet is "(eHealth) … refers to health services and information delivered or enhanced through the Internet and related technologies" [i.10] and "the combined use of electronic communication and information technology in the health sector" [i.11]. A similar definition is proposed by the European Commission: "e-Health refers to the use of modern information and communication technologies to meet needs of citizens, patients, healthcare professionals, healthcare providers, as well as policy makers" [i.4]. In the ETSI document [i.3] the following is added: "eHealth systems include tools for health authorities and professionals as well as personalized health systems for patients (individuals) and citizens (community)". Health in this context refers to the process of curative or preventative care, contributing thereby to the person's well-being.

Telecare implies an aspect of communication, remote consultation or remote monitoring, with a person in need of care at one end of the line (the "client"), and at the other end a health professional, a relative, a neighbour, (collectively denoted the "carer"), an alarm centre or even a computerized system. Telecare should be distinguished from telemedicine, which involves health professionals at both ends of the communication line [i.2]. Telecare usually implies that the client can go on living at home, whereas previously he/she would have to be hospitalized or institutionalized. Telecare thus has obvious and important benefits: It frees resources in the health system, enables independent living for the client, acts to reassure the client, warn about and prevent accidents, and give relief to relatives and informal carers.

Doughty [i.13] defines three generations of telecare. The first generation consists of very basic systems, dependent on the service user to trigger an alarm and alert the carer of the need for assistance. They are often referred to as Personal and Emergency Response Systems or Personal Alarm Systems. Telecommunication links are used to send the alarm to the carer. These first generation systems are still the most commonly used as they are cheaper and easier to install and use than newer generation systems.

Second generation systems introduced sensors to provide continuous monitoring and raise alarms. This takes the reliance away from the service user having to trigger an alarm. Examples of such alarms are flood sensor alarms and temperature sensor alarms as well as client monitoring systems such as fall detectors. These alarms will in general be triggered when a threshold condition is reached, e.g. if the flood sensor records a certain level of water or if the temperature sensor detects a low temperature in the dwelling. While these sensors reduce the reliance on users to flag alerts, they still do not provide a carer much information about the health condition of the service user.

The third and most recent generation of telecare aims to predict care needs by anticipating changes that could lead to loss of well being before they occur or result in long term damage. It aims to provide more contextualized information about the occupant for a carer. Health and well-being data is collected using a range of sensors that monitor the occupant as required. The sensor data is then analysed and presented to stakeholders in context so as to contribute richer data into the "dialogue of care". The sensors that are used can vary from system to system, but many will focus on collecting data related to the users Activities of Daily Living (ADLs) and data important to the medical condition(s) affecting the service user. As the focus shifts from purely functional and medical sensing, carers can gain insights into the general well being and the specific conditions of interest in the care of home dwelling people, and the people themselves can understand their situation better and engage more actively in their own self-care.

The importance of telecare for home dwelling people is illustrated in figure B.1.1. Changes in health or well-being, if left undetected or unattended, will result in loss of quality of life, and ultimately loss of independence. Acute episodes inevitably cause damage that can have lasting consequences. The prediction, or at least detection of changes that could result in an acute episode is therefore vital, particularly when home dwellers are somewhat socially isolated and live alone.
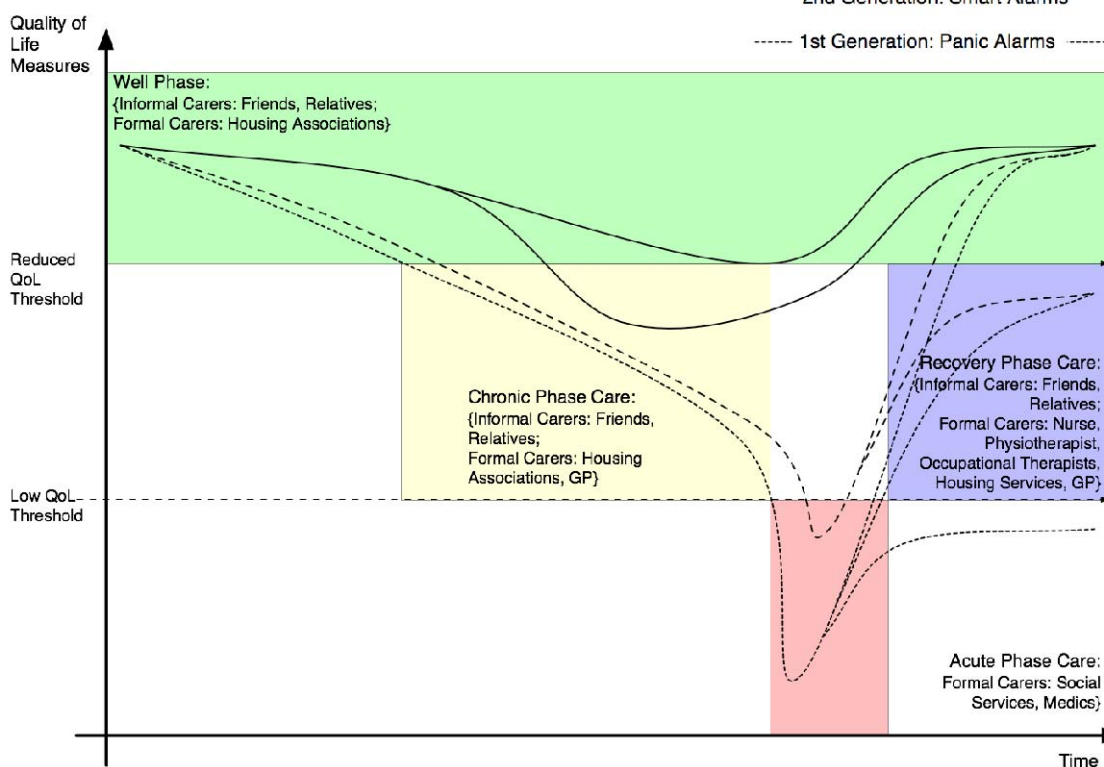
Figure B.1.1

Independent living also implies, however, social interaction, including travelling abroad. Any care that occurs at home must follow the person as they leave the home, otherwise they cannot function independently and as they chose. Whilst it may be possible to access care services remotely, it's also important that local care services can provide support as required. Both the access to care services, and the local delivery of care services depend on the profile of the user's requirements and usage characteristics being available and enabled.

B.2   eHealth standardization

Standardization within health and eHealth has traditionally been oriented mostly towards the needs of the medical profession: Hospital information systems, storage and exchange of diagnostic information, exchange and interpretation of sensor data, etc, but later initiatives are also more directly concerned with the needs of the client and end user. In the following a non-exhaustive selection and brief overview of standardization activities relevant for eHealth is given.

ISO, International Organization for Standardisation. ISO Technical Committee TC 215 deals specifically with health informatics, with the following scope: "Standardization in the field of information for health, and Health Information and Communications Technology (ICT) to achieve compatibility and interoperability between independent systems". It is organized in the following Working Groups (WG):

- WG1 Data structure. Definitions, frameworks, models, templates and data sets.

- WG2 Data interchange of clinical and administrative messages.

- WG3 Semantic content: Concept and knowledge representation.

- WG4 Security: Confidentiality, availability, integrity, accountability, management.

- WG5 Health cards.

- WG6 Pharmacy.

- WG7 Devices.

- WG8 Business requirements for an Electronic Health Record.

None of the above WGs deal specifically with personalization issues. WG5 (Health cards) will have future relevance as a carrier of information related to user preferences, but until now the focus of WG5 (as well as that of several national health card deployments) has been towards the needs of the medical profession and of the insurance companies.

CEN, Comité Européen de Normalization. CEN Technical Committee TC 251 is the body within Europe mandated to develop standards for Health Informatics. It has four working groups that mirror closely (except for the number) WG1 to WG5 in ISO 215 [i.14].

SNOMED, Systematized Nomenclature of Human Medicine is an organization that deals specifically with health terminology and classification standards, mainly targeting a common terminology for diagnosis and treatments. (SNOMED CT - Systematised Nomenclature of Medicine Clinical Terms). SNOMED CT is used in more than 50 countries and it is included by a number of standards setting organizations to promote consistent use of the terminology. Examples include HL7 and ISO (SNOMED developers participate in the ISO Technical Advisory Working Group on Health Concept Representation ISO TC 215 WG3).

World Health Organization's International Classification of Diseases (ICD) [i.5], contains information on diagnosis and health condition. *WHO's International Classification of Functioning*, Disability and Health (ICF) [i.6], is a classification of the health components of functioning and disability. The ICD and ICF constitute the core classifications in the WHO Family of International Classifications (WHO-FIC). Another important classification is the International Classification of Health Interventions (ICHI) [i.7]. The WHO document "Guidelines on the use of International Nonproprietary Names (INNs) for Pharmaceutical Substances" [i.8] provides the recommendations and guidelines that identify pharmaceutical substances or active pharmaceutical ingredients by a globally recognized code.

HL7, Health Level 7 is an ANSI accredited US Standards Developing Organization (SDO) that provides "standards for interoperability that improve care delivery, optimize workflow, reduce ambiguity and enhance knowledge transfer" (http://www.hl7.org/). The organization deals mostly with the information exchange between the patient record in the hospital and external institutions.

IHE, Integrating the Healthcare Enterprise provides guidelines about how to implement and configure healthcare systems so that they can exchange data in a structured way. It is a cross-industrial attempt to integrate the plethora of information and computer systems that are found in a hospital.

EFMI, European Federation for Medical Informatics is a very active and independent organization dealing with all aspects of ICT within the health sector (http://www.helmholtz-muenchen.de/ibmi/efmi/). It organizes the yearly MIE conference which attracts a large and highly skilled audience. EFMI has several working groups relevant for personalization within eHealth:

- WG Personal Portable Devices (PPD), dealing with the deployment of projects related to devices like cards, tokens, and similar technologies in the domain of healthcare and welfare. One of the group's focus areas is described as a "vision of personalised, portable device technology applications in advanced Identity and Personal Data Management".

- WG Informatics for the Disabled and Rehabilitation (IDR). The group's focus is mainly technical/industrial, targeting accessibility and usability for the disabled.

- WG Natural Language Understanding (NLU). The group mainly aims to act as a point of contact for researchers within its field of interest.

- WG Primary Care Informatics (PCI), aiming amongst others to "promote research and development to develop a core generalisable theory for primary care informatics"

IMIA, International Medical Informatics Association has its origins in IFIP (International Federation for Information Processing), and collaborates closely with WHO. Several IMIA working groups have relevance for personalization:

- WG 02, Consumer Health Informatics. The group "is concerned with electronic information related to health care available to the public (e.g. Internet, wireless, standalone electronic media)". Its main focus is towards the use of health resources on the internet.

- WG Human Factors Engineering for Healthcare Informatics. One of its goals is to "coordinate studies and actions in the healthcare domain and to develop standardization initiatives for usability studies and user-centered design".

- WG Smart Homes and Ambient Assisted Living, targeting "the study and promotion of research and development in the area of smart homes and ambient assisted living applications".

DICOM, Digital Imaging and Communications in Medicine is the name of a family of standards established and maintained by ACR-NEMA (American College of Radiology - National Electrical Manufacturers Association). In addition to dealing with medical imaging and images, the DICOM standard also targets related information needed for correct data interpretation, such as patient and contextual data.

UMLS is an ontology aimed to facilitate the development of computer systems that behave as if they "understand" the meaning of the language of biomedicine and health.

WAO is the World Allergy Organization. The WAO provides a nomenclature which is an update of the EAACI NPS. The WAO nomenclature is designed to be used independently of target organ or patient age group, and is based on the mechanisms which initiate and mediate allergic reactions. As knowledge about basic causes and mechanisms improves, WAO will continue to review the nomenclature to optimize global communication about allergic diseases.

ITU-T Study Group 16 (SG16) addresses the evolution of advanced digital telecommunication techniques has enabled the development of multimedia systems to support e-health applications, in particular in the area of telemedicine.

Annex C (informative):
Scenarios

This annex contains scenarios which illustrate how users can personalize their services and devices. The scenarios will highlight some interesting concepts and are not intended to illustrate all alternative solutions. At the beginning of each scenario, there is list of issues that are covered in the scenario.

MATCH Tele-Care Scenarios: The scenarios being used in this annex come from work being done in the MATCH project. The project is funded by the SFC (Scottish Funding Council) under grant reference HR04016.

The project is exploring the role of technology in:

- maintaining the independence of those receiving social and health care at home;

- improving their quality of life;

- enhancing the care they receive at home;

- easing the burden on their carers.

The project is a collaboration among the Universities of Dundee, Edinburgh, Glasgow and Stirling (lead partner). Details of the project can be found at http://www.match-project.org.uk/main/main.html.

# C.1	Bert going to the bookies

This scenario is from the MATCH project [http://www.match-project.org.uk/main/main.html].

Bert is a single man aged 75, he lives alone on the outskirts of a large city near to a local cluster of shops.

He has a daughter Alice who visits once a month as she lives about an hour and a half drive away. Alice is aged 37 and lives with her husband Dave and her two children Jennifer (2) and Josh(6). Bert's next-door neighbour Jim is a close friend aged 57 living with his with wife.

Bert has become apprehensive about negotiating the underpass on his normal route to the bookies, as he does not see well in dim lighting and tends to become disorientated. Bert has also been a smoker for 60 years and as a result suffers from COPD (http://www.priory.com/cmol/copd.htm). This is exacerbated on exertion, and as a result Bert is concerned that he would not be able to handle a run in with an unscrupulous character in the dim light of the underpass. As a result his trips to the bookie are taking longer and becoming less frequent.

Over time the system would learn the pattern of Bert's Friday trips to the bookies. Once a model of this behaviour had been established the system would notice an increase in duration of the trips and reduction in the frequency associated with Bert's apprehensions. From knowledge held in the system about Bert's know conditions, a conclusion that the journey is becoming problematic at the underpass would be proposed, in the first case to Bert perhaps suggesting alternate route. If the problem persists the system would alert an appropriate person in this case possibly Jim or Alice, advising them a problem may exist.

Table C.1.1: Analysis of the scenario "Bert Goes to the Bookies"

Stakeholder	Relationship to Client	eHealth Profile
Bert (Client)		Uses a tele-health monitoring package to check his COPD and his behaviour that is affected by his COPD. Sets the behaviour of devices and services based on his COPD, so that they communicate data back to him in ways that he can comprehend.
Alice (Informal Carer)	Daughter, with an interest in Bert's well being. They have agreed that she can know his tele-health data, and his smoking behaviour.	Has a profile that allows access to Bert's individual data delivered from an eHealth service, and sets the way that the data is presented to her so that she can understand how Bert's COPD is changing. (Is it responding to treatment or is it getting worse).
Jim (Informal Carer)	Bert's best friend who wants to be sure that Bert is getting to the bookies, because this is an indication that Bert is well. Jim gets a text message as an alert if Bert does not go to the bookies after several days.	Has a profile that sets the mobile phone to present the alert according to the his preferences, taking into account the prevailing conditions (indoors, outdoors).
Social Worker (Formal Carer)	A social worker is involved in Bert's case because he must stop smoking before he can have oxygen at home. Recommends the equipment that Bert should have at home so that Alice and Jim can be alerted to Bert's situation.	Has a profile that allows access to cases of personal data delivered by tele-health services, including Bert's. The profile is also set to show the trends in the condition of Bert and the other clients at various levels of detail.
Community Matron (Formal Carer)	Visits Bert to provide some treatments for his COPD and to take health measurements. Monitors Bert's health data gathered from home health monitoring systems and home activity systems remotely.	Has a profile that allows access to cases of personal data delivered by tele-health services, including Bert's. The profile is also set to show the trends in the condition of Bert and the other clients at various levels of detail. Has various profiles that determine how the mobile equipment taken on home visits is configured according to specific user preferences.
General Practitioner (Formal Carer)	Has Bert attend regular consultations in order to check the progress of his COPD. Monitors Bert's health data gathered from home health monitoring systems and home activity systems remotely in order to be able to assess if the therapies and medicines are having the desired effect on Bert's behaviour. Recommends the equipment that Bert should use at home to monitor his COPD.	Has a profile that allows access to cases of personal data delivered by tele-health services, including Bert's. The profile is also set to show the trends in the condition of Bert and the other clients at various levels of detail, contextualised with the medical care programmes that Bert is under. Has various profiles that determine how the equipment in the surgery is configured according to specific user preferences.
Device & Service Developer/Provider	Indirect relationship. Provide devices and services that meet the functional needs of people with Bert's conditions, and may have an interest in ensuring that the systems are usable and useful for all relevant stakeholders.	Provide user profile structures that can qualify the behaviours of the devices and services.
Policy Makers	Indirect relationship. Is interested to gather statistics about Bert and all other service and device users in order to ensure that resources are targeted to need.	Has a profile that allows access to the anonymised statistics of service and device usage, with some contextual information to interpret the statistics.
Funders	Indirect relationship. Is interested to gather statistics about Bert and all other service and device users in order to ensure that resources are available for those with needs.	Has a profile that allows access to the anonymised statistics of service and device usage, with some contextual information to interpret the statistics.

C.2   Sally has early onset of dementia

This scenario is from the MATCH project [http://www.match-project.org.uk/main/main.html].

Sally is a 59 year old woman living with her husband. She started to have dementia 2 years ago. Her husband is quite supportive. He is working 3 days a week. Sally has a community psychiatric nurse regularly visiting every 2 weeks. She is also attending the hospital twice a week. A chiropodist comes every fortnight to do Sally's feet. As a treat, Sally has reflexology once a month.

Symptoms: She can recognize faces but not necessary remember names. Sometimes she remembers who you are but not always. She remembers family members but when she meets a new person she takes quite a long time to remember who you are. She can easily forget an appointment, for example, a doctor's appointment. She is able to take her medicine in the morning, lunch and evening because the package is properly labelled.

She can go around the town alone. She can do the shopping but she needs a list to remember the thing that she needs to buy. However her husband does the shopping most of the times. A sweet tooth and a family history of the disease led to Sally developing adult-onset diabetes when she was 50. Sally isn't very mobile anymore: She had a hip replacement operation, and nine months ago, she was hospitalised because she broke her femur when she tripped over a cable in her living room.

June sees her GP every month or so; there is always something worrying her. She also goes for regular blood sugar checks. June is still receiving regular physiotherapy for her broken leg. Apart from church and Bingo, TV and radio are her main interests, and the telly is constantly on.

She doesn't have any problem with meals; she usually has a good breakfast and dinner with her husband. In addition she can make a cup of tea, prepare vegetables, sandwiches and meat safely. However she can't exactly remember where the things are; she has to open every drawer to find the things so it takes more time to prepare food. After using items she finds it difficult to put them back. She can remember obvious things like milk goes in the fridge but she can't remember where to put a pan.

When she is getting ready in the morning she finds it difficult to decide what to wear because she can't remember what she wore the day before.

She is trying not to show her problem to other people as a kind of defence mechanism. When she is in a familiar environment she is fine but when she is taken to new places she becomes anxious and panics, so her symptoms of forgetfulness get worse, and she starts asking the same questions over again.

The system would combine sensor monitoring information and a multimodal reminder (video and voice recognition) that interacts with Sally to help remember her appointments, find items, what item to buy, what to wear, etc.

Table C.2.1: Analysis of the scenario "Sally has early onset of dementia"

Stakeholder	Relationship to Client	eHealth Profile
Sally (Client)		Uses a tele-health monitoring package to check her safe use of spaces such as kitchens, to ensure that she is adhering to mobility therapy following her hip replacement, and to monitor her diabetes and her associated eating habits. Sets the behaviour of devices and services based on her various conditions, so that they communicate data back to him in ways that he can comprehend. Has a variety of devices in the home, including a TV based information interface and services to support shopping and reminders on mobile devices for when she is alone shopping or socialising away from home.

Stakeholder	Relationship to Client	eHealth Profile
Bob (Informal Carer)	Husband, with an interest in Sally's well being. They have agreed that he can know her tele-health data, and the associated lifestyle data.	Has a profile that allows access to Sally's individual data delivered from an eHealth service, and sets the way that the data is presented to him so that he can understand how Sally's various conditions are changing. (Is it responding to treatment or is it getting worse). Has wide access to Sally's data in anticipation of her increasing forgetfulness, and is trialling movement tracking service based on mobile phones.
Community Psychiatric Nurse (Formal Carer)	Visits Sally to provide some treatments for mobility, diabetes and to take health measurements. Monitors Sally's health data gathered from home health monitoring systems and home activity systems remotely.	Has a profile that allows access to cases of personal data delivered by tele-health services, including Sally's. The profile is also set to show the trends in the condition of Sally and the other clients at various levels of detail. Has various profiles that determine how the mobile equipment taken on home visits is configured according to specific user preferences.
General Practitioner (Formal Carer)	Has Sally attend regular consultations in order to check the progress of her various conditions. Monitors Sally's health data gathered from home health monitoring systems and home activity systems remotely in order to be able to assess if the therapies and medicines are having the desired effect on her behaviour. Recommends the equipment that Sally should use at home to monitor her various conditions.	Has a profile that allows access to cases of personal data delivered by tele-health services, including Sally's. The profile is also set to show the trends in the condition of Sally and the other clients at various levels of detail, contextualised with the medical care programmes that Sally is under. Has various profiles that determine how the equipment in the surgery is configured according to specific user preferences.
Hospital based medical and care specialists (Formal Carer)	Have Sally attend regular consultations in order to check the progress of her various conditions. Monitor Sally's health data gathered from home health monitoring systems and home activity systems remotely in order to be able to assess if the therapies and medicines are having the desired effect on her behaviour. Recommend the equipment that Sally should use at home to monitor her various conditions.	Have profiles that allow access to cases of personal data delivered by tele-health services, including Sally's. The profiles are also set to show the trends in the condition of Sally and the other clients at various levels of detail, contextualised with the medical care programmes that Sally is under. Have various profiles that determine how the equipment in the hospital are configured according to specific user preferences. Some of the profiles are set centrally to accommodate the cohort of professionals in the various teams at the hospital.
Device & Service Developer/Provider	Indirect relationship. Provide devices and services that meet the functional needs of people with Bert's conditions, and may have an interest in ensuring that the systems are usable and useful for all relevant stakeholders.	Provide user profile structures that can qualify the behaviours of the devices and services.
Policy Makers	Indirect relationship. Is interested to gather statistics about Bert and all other service and device users in order to ensure that resources are targeted to need.	Has a profile that allows access to the anonymised statistics of service and device usage, with some contextual information to interpret the statistics.
Funders	Indirect relationship. Is interested to gather statistics about Bert and all other service and device users in order to ensure that resources are available for those with needs.	Has a profile that allows access to the anonymised statistics of service and device usage, with some contextual information to interpret the statistics.

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