Security and personalized eHealth systems

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What is an eHealth system?

- eHealth systems include tools for health authorities and professionals as well as personalized health systems for patients (including formal and informal carers)

- including the process of curative or preventative care, contributing thereby to the person's well-being.
eHealth system users can be very diverse

- Including such widely differing categories such as people with disabilities and very old or young people.
Situations where eHealth services need to be delivered can be equally diverse:

- Not just in locations within the healthcare system
- Not just at home
- Not just at work
- But wherever the client may be - at home or abroad
Other challenges

The client of an e-Health system may:
- not be particularly computer literate
- have a physical and/or mental impairment
- mental impairment may compromise understanding of security implications

Many of today’s e-Health systems:
- handle sensitive data that requires protective measures – a major privacy challenge
- are tailored to a professional user
- are difficult for a client to understand
- are combined with other (e-Health) systems
- may require special setup procedures
What can be personalized?

- Standardizing personalization and the user experience of e-Health systems related to:
  - the degree of user control
  - user perception related parameters e.g. audio volume, use of colour
  - user input methods e.g. tactile, voice, keyboard/mouse, switches, eye-tracking

- Fine-grained control of the sharing of sensitive information

- Standardizing the meaning and scale of personalization parameters:
  - terms for medical concepts that can be understood by non-medical people (e.g. by both clients and carers)
  - the handling of particularly sensitive data
Information sharing and privacy

- As users become more aware of privacy issues, there is
  - an increasing need for user acceptance of personalized services
  - a demand for solutions allowing them to be in control of their profile content.
- If profile content is made available to the wrong people, then users will lose confidence.
- Too restricted access to profile content should be avoided,
  - as it may reduce the usability and the number of available services.
- Roles including:
  - client
  - carers – formal and informal
  - relatives
Privacy settings should change if others are present!

HIV level increased – contact your doctor immediately!
The benefits of personalization

- Re-use of personalization parameters across e-Health systems
- Users can themselves tailor each system to their preferences
- Less user confusion, less risk of improper user handling, fewer errors

In summary:
Easier adoption of e-Health systems
More control of security/privacy issues
ETSI work on personalization and user profiles

- EG 202 325 published 2005
  - Concept and guidelines

- New Specialist Task Force – ETSI Human Factors STF342
  - ETSI Standard (ES) on standardized personalization objects
  - ETSI Technical Specification (TS) on architectural framework

- New Specialist Task Force – ETSI Human Factors and eHealth STF352
  - ETSI Standard (ES) on standardized personalization objects in the eHealth domain

Co-financed by the EC/EFTA in response to the EC’s ICT Standardisation Work Programme
What is in a User Profile?

- personal information
- preferences and depending on time, activity, role, location
- context information
- pointers to extracts from the user’s eHealth Record
- rules
  - automatically activate a situation dependent profile that allows the eHealth services to be adapted to suit the current situation
- specific security related obligations and preferences related to the above
World Class Standards

Privacy issues depending on where profile data is located

ETSI eHealth and Human Factors - Personalization of eHealth systems
Access to Electronic Health Record

- **General access safeguards**
  - “apart from the patient himself – only those healthcare professionals/authorized personnel of healthcare institutions who presently are involved in the patient’s treatment may have access” (ref.)

- **Special access safeguards by involvement of the patient**
  - “If feasible and if possible” … “the patient should be given the chance to prevent access to his EHR data if he so chooses”. (ref.)

- **Relevant also for the eHealth profile?**

Ref. see “Working Document on the processing of personal data relating to health" in electronic health records (EHR)”
Sensors

- Sensors can be related to the person
  - What sensors are practical – e.g. anything worn might not be worn
- Sensors can be related to the environment
  - What sensors are acceptable – e.g. video and privacy
- Example: PIR based system to monitor activity in a home
  - Video is usually considered to be more invasive
- Who can (not) access the data?
Scenario: Bert goes to the Bookies

- Bert and his care issues
  - 75 year old male living alone
  - Route to bookies includes an underpass where dim light disorientates him
  - Concerned that the route is unsafe
  - Concerned that because he has COPD (Chronic Obstructive Pulmonary Disease) and that he can’t run from trouble in the underpass
  - Smoker, and has been for 60 years

- Those who care about Bert
  - Jim, friend, living next door
  - Alice, daughter, living an hour away
  - Bert’s doctor
  - Bert’s social worker
Privacy and profile related issues

- Bert
  - Navigation aid might help Bert to feel confident to go to Bookies
  - Self management strategy for giving up smoking and taking COPD drugs
- Jim, Bert’s friend
  - Did Bert make it to the Bookies?
- Bert’s social worker
  - Did Bert make it to the Bookies?
- Bert’s doctor
  - Has Bert given up smoking?
  - Is he taking his medication?
- Alice, Bert’s daughter
  - Has Bert given up smoking, if not he will be ineligible for medical care!
Who we are

Specialist Task Force 352:  
Personalization of eHealth systems by using eHealth User Profiles

Who we are:

Team Members:  
Mike Pluke  
Torbjorn Sund  
Françoise Petersen (STF leader)

Why we do it:
Thank you!
Information and communication

- **Email:** Francoise.Petersen@etsi.org

Do you want to:
- receive the newsletters from our STF (about once a month, or when relevant)?
- discuss personalization and user profiles with a wider group? If so welcome to use our mail list
  STF352_CONSULTATION@LIST.ETSI.ORG
    - Subscribe at: [http://list.etsi.org/STF352_CONSULTATION.html](http://list.etsi.org/STF352_CONSULTATION.html)