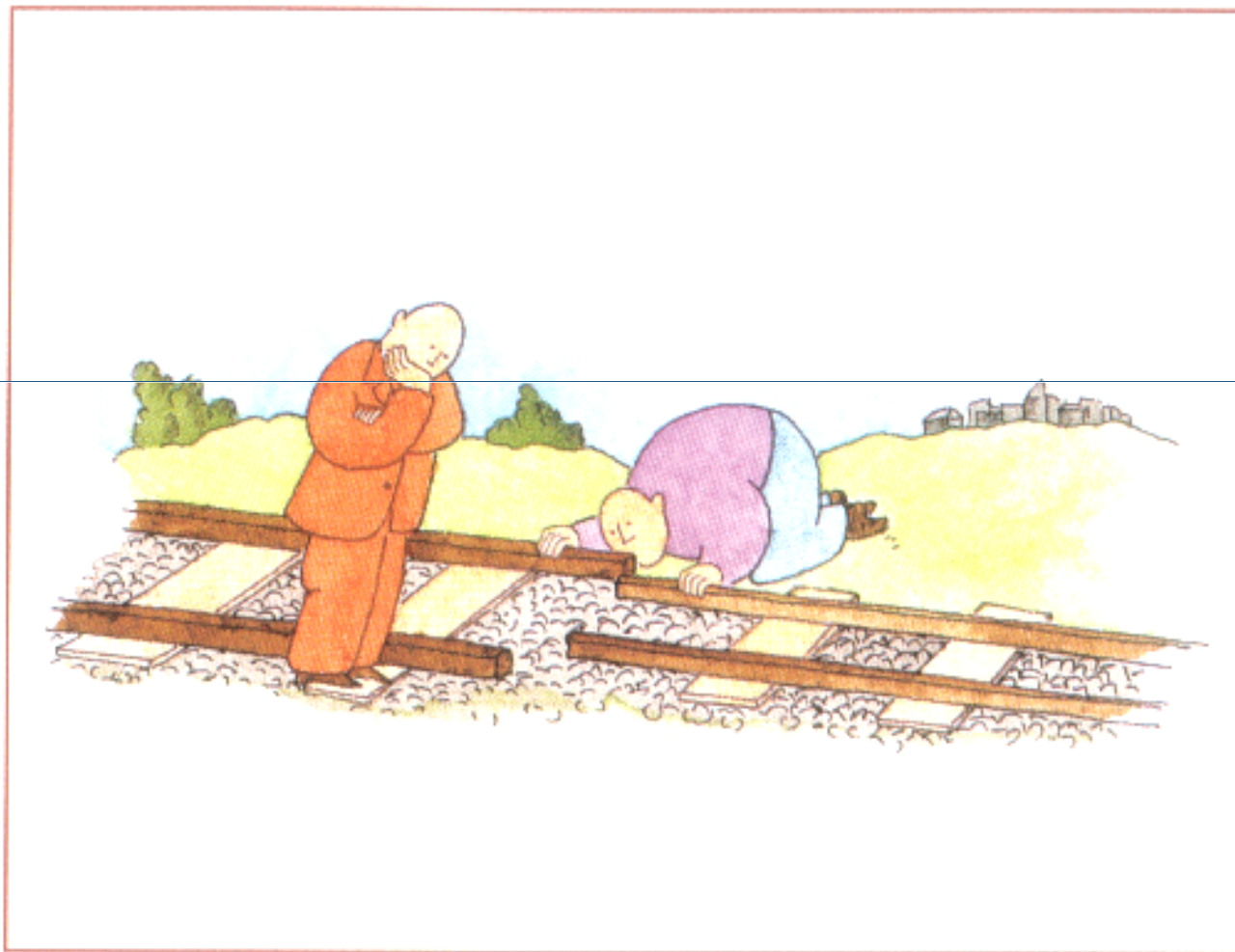# Personalized eHealth systems
Standardization work at ETSI

pHealth 2009 - The 6th international workshop on Wearable Micro and Nanosystems for Personalised Health in Oslo, Norway, 24-26 June 2009.

Francoise Petersen
APICA/ETSI Human Factors, eHealth
Francoise.Petersen@apica.com

Why standards?

What is an eHealth system?

❑ **eHealth systems include tools for**

  ➢ **health authorities and professionals,**
  ➢ **patients**
  ➢ **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
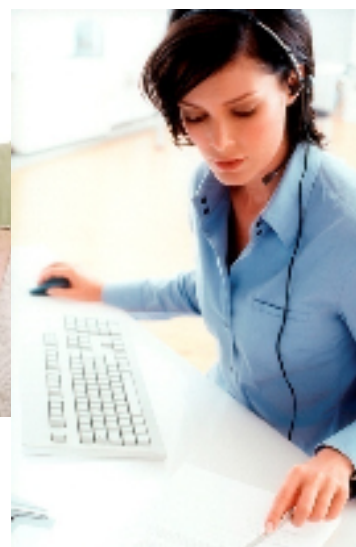
- ❑ **Not just in locations within the healthcare system**
- ❑ **Not just at home**
- ❑ **Not just at work**
- ❑ **But wherever the client may be - at home or abroad**

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. volume, colour**

  ➢ **user input methods e.g. tactile, voice, keyboard/mouse, switches, eye-tracking**

❑ **Fine-grained control of the sharing of sensitive information**

The benefits of personalization

❑ **A better user experience - in a range of situations**

❑ **Users can themselves tailor each system to their preferences**

❑ **Less user confusion, less risk of improper user handling, fewer errors**

❑ **Re-use of information and personalization parameters across e-Health systems**

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**

- ❑ **ETSI Human Factors, Specialist Task Force – STF342**
  - ➢ **ETSI Standard (ES) on standardized information and preferences**
  - ➢ **ETSI Technical Specification (TS) on architectural framework**

- ❑ **ETSI Human Factors and eHealth, STF352**
  - ➢ **ETSI Standard (ES) on standardized information and preferences in the eHealth domain**

Co-financed by the EC/EFTA in response to the EC's ICT Standardisation Work Programme

What can be in a user profile?

❑ **personal information**

❑ **extracts from the eHealth Record**

❑ **preferences and depending on time, activity, role, location**

❑ **context information**

❑ **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**

Profile categories

❑ **Normal profile**

❑ **Situation profiles**
  ➢ **e.g. "at the hospital", "at home", "at work"**
  ➢ **automatically activated, or**
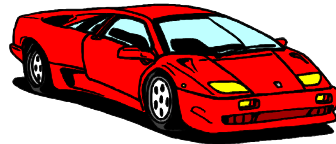 ➢ **manually activated**

❑ **Active profile**

Strongly related to ETSI work on ID

❑ **Current work on personalization emerged from previous ETSI work on a Universal Communications Identifier**

❑ **Also, ongoing ETSI work on Identity Management...**

Where is the profile data located?

EHR
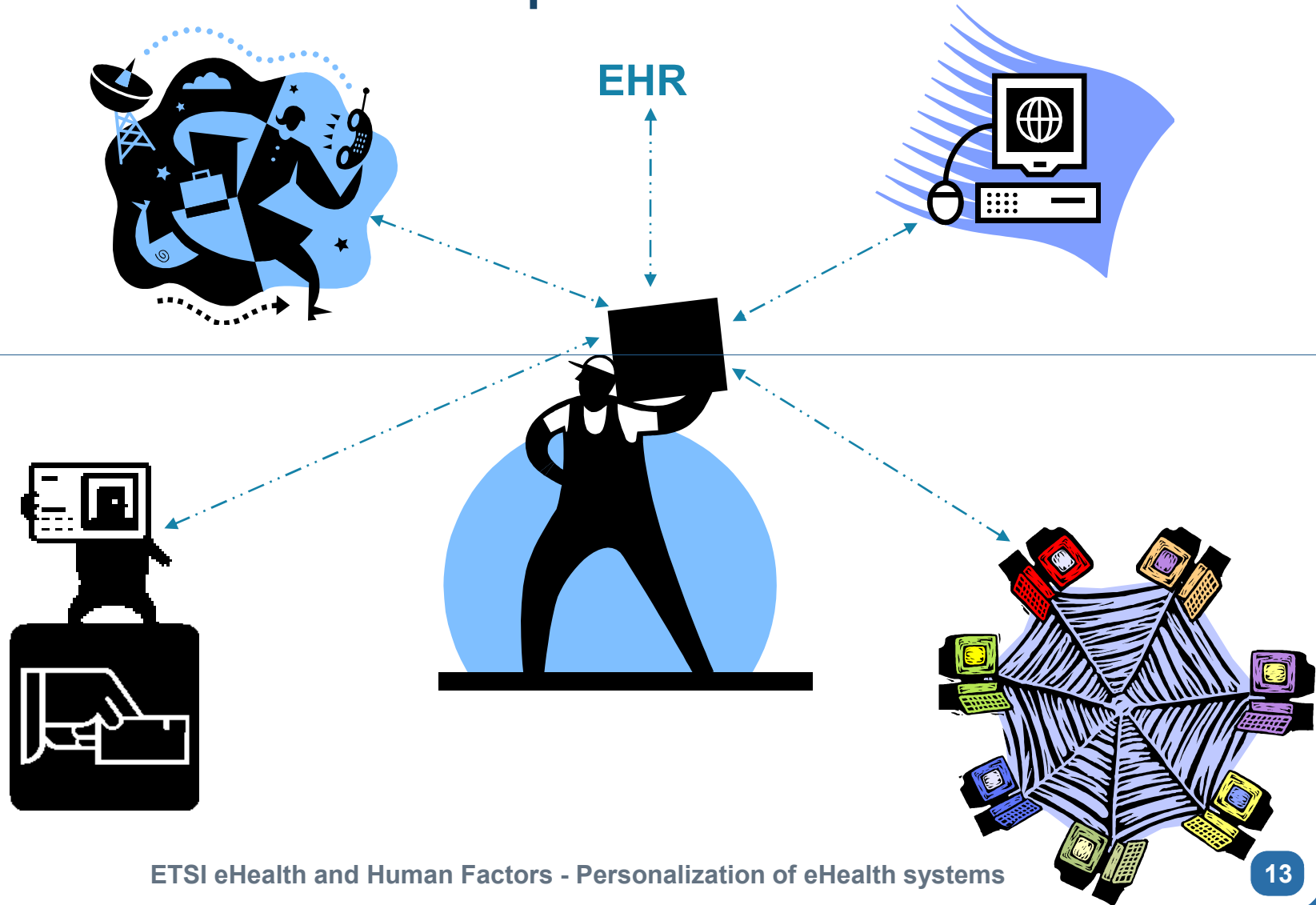
Sensors

- ❑ **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: system to monitor activity in a home**
  - ➢ **Video is usually considered to be more invasive**
- ❑ **Who can (not) access the data?**

Use of scenarios

❑ **MATCH project**

 ➢ **a collaboration among the Universities of Dundee, Edinburgh, Glasgow and Stirling (lead partner).**

❑ **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.**

 http://www.match-project.org.uk/main/main.html

❑ **Others?**

Thank you!
Information and communication

❑ **Web: http://portal.etsi.org/stfs/STF_HomePages/STF352/STF352.asp**
❑ **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**

More slides – just in case there is a demand for it…

What is ETSI?

- ❑ **ETSI, the European Telecommunication Standards Institute**
  - ➢ **active in all ICT areas**
  - ➢ **independent, non-profit, created in 1988**
  - ➢ **officially recognized and co-funded by the EU & EFTA**
  - ➢ ~~**offering direct participation of all members**~~
  - ➢ **more than 15,000 publications → all available for free!**

Use of Scenarios -
Example: 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!**

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**

Information sharing and privacy

❑ **Roles including:**
  ➢ **client**
  ➢ **carers – formal and informal**
  ➢ **relatives**

❑ **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.**

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)"

Overview - Profile Agent components

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        │  agent   │  │  agent   │  │ Watcher  │
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