User-centred design to create Patient-centred IT
Agenda Lecture 3 – UCD and Patient-centred IT

Usability in Health Informatics

Introduction – HI / MI

User Centred Design

Guidelines

The usability standard

UCD methods

Importance of evaluation

The Case: OLD@HOME

Assignment Q&A
RECAP and a look ahead!

- What was, according to you, the most important of last lecture, #2?

- Talk to your neighbour about your ideas of
  - HI/MI? Eg. how do HI/MI support care?
  - Usability in Health informatics
  - The usability standard

- What do you already know of User-centred (systems) design?
We are trying to create good and secure care

- Health informatics is an important tool

Not only for clinicians
  - Other professions
  - Patients & relatives

Not only for diseases
  - Maintain health
  - Prevention
We are trying to create good and secure care
Vision for good eHealth / 7 R:s + 1

- Right care professional can – with an easy operation - get
- Right information about the
- Right patient at the
- Right place in the
- Right amount, presented in a
- Right way, adapted to
- Right situation

To support a good patient meeting and cooperation between different care actors.

And, the information should be registered only once and with little effort and time consumption.
Healthcare supported by a HCI framework

- It is **crucial to involve users** in the development… …We’ve said that for a long time…

- **How** to involve the users, and how to work with them effectively & efficiently is still not clear…

- Based on Human-Computer Interaction Science

- **Users, Usability and User Centred Development**
  - Usability standard ISO 9241-11
  - User analysis (context/usage analysis)
  - User centred design-methods (OLD@HOME)
  - **Usability evaluations** (DOME)

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Usability standard ISO 9241-11 in practice

Based on this standard we can assess how

- **effective**, [do the users reach their goals?]  
- **efficient** and  [resources spent in reaching goal..?]  
- **satisfactory** [are they satisfied when doing that?]

A product is,  
in order to be considered as having good usability for:

- A specific group of **users**
- performing specific **tasks**
- in a specified **environment/context**
Usability – which questions to ask?

- To whom?
- In which situation? In which context?
- Solving which task?
Human Centred design processes for interactive systems

“User Centred Design is a process focusing on usability throughout the entire development process and further throughout the system life cycle.” (Gulliksen 2003)
“**User centred design** emphasizes that the purpose of the system is to serve the user, not to use a specific technology, not to be an elegant piece of programming. The needs of the users should dominate the design of the interface, and the needs of the interface should dominate the design of the rest of the system”. (Norman 1986)

“For me, **User Centred Design** is an iterative process whose goal is the development of usable systems, achieved through involvement of potential users of a system in system design.“

“**User Centred Design** captures a commitment the usability community supports – that you must involve users in system design – while leaving fairly open how this is accomplished.” (Karat 1997)
Socio-technical approach

Berg (1999) advocates for the socio-technical approach as development of ICT needs to

- emphasize **social, organizational, professional** and other **contextual** considerations
- in order to improve the staff’s individual and organizational work situations.
- A socio-technical approach elucidates the various perspectives on healthcare.
- **AND** it emphasizes the need to address **cooperative work processes** rather than discrete tasks for individuals.
“The focus of PD is not only the improvement of the information system, but also the empowerment of workers so they can codetermine the development of the information system and of their workplace” (Clement and Besselaar 1993)
Cooperative Work

- Cooperative work (CSCW)
  - Arbetsprocessen i vårdelen!
- Cooperative design ~ PD
- Common ground
  - Interdisciplinary groups
  - Contextual design
  - Language - definitions

- Multi-stakeholder Involvement
    - Recommended Practice for Architectural description of software-intensive Systems
### System development team building

<table>
<thead>
<tr>
<th>Customer Representative</th>
<th>Analyst</th>
<th>Developer</th>
<th>Tester</th>
<th>Project Lead</th>
<th>Coach</th>
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<tr>
<td>Directs the Business</td>
<td>Applies Complementary Techniques</td>
<td>Shapes Enterprise Systems</td>
<td>Leads Large-Scale Testing Efforts</td>
<td>Manages Programs</td>
<td>Coaches new coaches</td>
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<td>Actively Manages Scope</td>
<td>Adapts Techniques</td>
<td>Shapes Systems</td>
<td>Plans Testing</td>
<td>Manages Small Projects</td>
<td>Formalizes and invents Techniques</td>
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<tr>
<td>Ambassador User</td>
<td>Facilitates Discussions</td>
<td>Designs Interfaces &amp; Interactions</td>
<td>Leads Testing</td>
<td>Manages Large Projects</td>
<td>Adapts Techniques</td>
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<tr>
<td>Project Advisor</td>
<td>Builds Models</td>
<td>Designs Internals Of Elements</td>
<td>Specifies Test Cases</td>
<td>Provides Effective Team Leadership</td>
<td>Coaches Techniques</td>
</tr>
<tr>
<td>Subject Matter Expert</td>
<td>Clearly Describes What’s Needed</td>
<td>Writes Good Code</td>
<td>Executes Tests</td>
<td>Plans and Tracks Progress</td>
<td>Articulates Techniques</td>
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Define potential *specific* user groups

- **Composition** - age, gender, number, language, education, disabilities
- **Training** and experiences – background, domain knowledge, computer experience
- **Support** and tools – first line support, training, documentation
- **Usage** of the application - how often, how long, mandatory (or not)

for a *specific* use situation
Examine the usage situation

External factors affect usage and can potentially lead to failure
How do we find the right problem?

- Deep understanding of the clinical environment
- Focus on the need – not on the solution!
- Consider all aspects of product development
  - Technical development costs are only a small part…
  - Regulatory restrictions, intellectual property, reimbursement model, Quality management
- You cannot afford to fail at a late stage:

   **Fail fast!**

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Objective: Elicit users’ needs in inter-/intra professional work

Results: Method $\rightarrow$ supports ”points of intersection”
$\rightarrow$ transfer of user needs to system spec

Pre-seminar work

Thematic Seminar Series

Iterative prototyping

Care professionals and researchers

Inter- and Intra-professional Working groups

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Theme perspectives and groups

Thematic Seminar Series

1. Project start up – introduction – all stakeholders
2. Current work situation – inter-professional
3. Organization – inter-professional
4. Info. & communication handling
5. Technical workshop – all stakeholders
6. Future work perspective – inter-professional
7. Current work scenarios - intra-professional
8. Current work scenarios – inter-professional
9. Detailed analysis of information needs
10. Future work scenarios - intra-professional
11. Future work scenarios – inter-professional
12. Visualization of future work scenarios

Pre-seminar Work

Multi-disciplinary work

Iterative Sketching/Prototyping

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The MdTS method – in short

Multi-disciplinary Thematic Seminars
Collaborative design method for interdisciplinary working groups
- Specification of future work scenarios
- Iterative prototyping, use of use cases
  → Support communication between different professions
  → Enhance transfer of user needs to detailed system specifications

1) **Pre-seminar work**: Field studies, observations, interviews, questionnaires
  → tacit knowledge and gain an understanding that is useful for the ICT development.

2) **Thematic Seminar Series**: the dominating part during the user needs analysis. Different themes/perspectives are used to gather info from different user groups – inter- and intraprofessional seminars
  _between_ the different professional groups and _within_ the groups.
  → Entire organization is participating in the req. gathering.
  → Agree on what is important to create.

3) **Iterative prototyping** is applied to improve today’s work situations → future work situations (a realistic way).

   2 parts:  **Holistic perspective** → common ground, understanding for each others’ work.
   **Detailed perspective** → to reach to details, separate sessions are needed.

**Iteration benefits**: **New ideas** from the experiences of the others…
  → improved work processes

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The Heuristics (Design Principles)

1. Visibility of system status
2. Match between system and the real world
3. User control and freedom
4. Consistency and standards
5. Aesthetic and minimalist design
6. Recognition rather than recall
7. Flexibility and efficiency of use
8. Error prevention
9. Help users recognize, and recover from errors
10. Help and documentation

(Nielsen, Heuristic evaluation, 1994)
Patient-centred care? Patient-centred IT?

- Patient-centeredness of healthcare is a well-established and non-controversial quality characteristic ensuring that care should be respectful of and responsive to
  - individual patient preferences, needs, and values,
  - and ensuring that patient values guide all clinical decisions.

- Many initiatives provide patients with access to health information and other services from a healthcare perspective, rather than a patient-perspective
  - what information is available to provide to patients - rather than what they actually want
  - and what information healthcare professionals want to monitor - rather than what the patients want to tell their healthcare professionals.

Do not look at the patient...

...look in the same direction as the patient!
Bridge the sector gaps → Intersection points

- Contextual framework for integrated eCare - from Hägglund M et al. 2012.
UCD for Patient centred IT

- Design of an eHealth service should be based on
  - an explicit understanding of the patient,
  - the patient’s health-related tasks/activities and environments.

- not only limited to the interaction with healthcare,
  - a deep understanding - of where and how the patients are to use the system.

- Patients are involved throughout design and development.
  - Make sure to recruit and actively involve real patient representatives throughout the design process.
  - The design is driven and refined by patient-centered evaluation.
  - It is imperative to perform formative evaluations with patients to ensure that the proposed eHealth solutions meet their needs.

- The design addresses the whole patient experience.
  - Take into consideration how this eHealth system fits into the patient’s entire healthcare journey. Do not focus exclusively on the health objectives deemed important from a healthcare professional perspective; consider the needs and preferences of the patients who will actually use/or be part of/ the system.
Conclusion – a patient’s “journey” mapping

- Active patient participation in development of eHealth is crucial
- \(\rightarrow\) by translating the human-centered design concepts to **patient-centered design guidelines** can be an important way to adapt design processes accordingly.
- Use patient journey mapping to **visualize** and **discuss** the interaction points:

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SAFETY PARTICIPATION AVAILABILITY

ICT-based services for enhanced home healthcare of the Swedish elderly!
Problems today

- Increasing elderly population
- Limited resources
- Limited access to information
  - EHR
  - Prescription List
  - Discharge notes
  - Care plan
- No support for POC documentation
- No support for sharing information
- Lack of coordination
- Lack of participation of patients and relatives
Communication/Interaction points in home care

- Actors in Swedish homecare of older people (with communication flows) – adapted from (Koch et al., 2005)

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Old@Home

- **Virtual Health Record (VHR)**
  - Immediate and ubiquitous access to patient-oriented data
  - Different views for different user groups (Nurses, Home helpers, GP’s, patients & relatives)

- **Mobile access**
  - Different technical solutions
  - Support for POC documentation

- **Integration**
  - Access to information from different feeder systems

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Informatics and socio-technical challenges when designing for integrated eCare
The Integration Architecture

Feeder systems:
- Daily notes and Care plan
- Home help service personnel (HHS)
- Medical record
- General practitioner (GP)
- Nurse record and Care plan
- District Nurse (DN)

Information broker (BizTalk Server):
- XML

Mapping:
- Ideal XML

Mediator Database:
- Online synchronization of data

VPR:
- SQL CE database
- Offline access to data
- PDA application for the HHS
- Webb application with views for the DN and GP
- Patient Portal for the patients and their relatives

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Home helpers
Read, write, communicate!

Nurse
Has access when working in the field!

Elderly at home
Feel safe and participate!

Relatives
Participate in the care process and are updated!

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Physician
 Reads updated info!
Some OLD@HOME design solutions

**Objective:** Design User Interfaces from the specific demands

**Results:** Show HOW design solutions meet the demands

Avoid Cognitive Overload
- Prioritized information
- Context dependent work spaces
- Quick overview

Origin of Information
- Colour coding
Ex: Design of Prescription list

"Visualization and Interaction Design Solutions to Address Specific Demands in Shared Home Care"
Virtual health record – web

<table>
<thead>
<tr>
<th>Allmänt</th>
<th>Anamnes</th>
<th>Status</th>
<th>Vårdplan</th>
<th>Anteckningar</th>
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### Praktiskauppgifter
- **Färdväg:** tredje huset till höger, gröna knutar, rött staket.
- **Portcod:** 1234
- **Nyckel:** nr 20
- **Bor med:** Kajsa Andersson
- **Upplysning:** Upplysningar får endast lämnas till barnbarnet (ej hans barn, är osams).

### Komihåg
Öppna inte fönstren. OBS ny omläggning samt nytt omläggningsmaterial, läs vårdplanen, /VF 20090314

### Tillfällig information
- **CareOf:** Maria Hägglund
- **Gatuadress:** Djäknegatan 17-450
- **Postnummer:** 75423
- **Postort:** Uppsala
- **Telefon:** 018-510117
- **Mobil:** 070 425 0297
- **Giltig period:** v. 22
- **Annan ort:** År på kanarieöarna v. 16
### Web VHR: Med. anamnesis

#### Verner Wikman - 19190102-7712

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<th>Angina pectoris, insulinbehandlad diabetes Typ II, hypertoni</th>
<th>2005-03-28</th>
<th>LL</th>
<th>Primärvårdsläkare</th>
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</thead>
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<tr>
<td>Allergi Penicillin</td>
<td>2006-03-14</td>
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<td>Primärvårdsläkare</td>
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#### Första som är skrivet under:
- **Tidigare sjukdom**
- **Socialt**
- **Aktuellt**
- **Status**

#### Anamnes
- **Hela sammanställn.**

#### Senaste som är skrivet under:
- **Tidigare sjukdom**

#### Ladda sidan på nytt ...

---

**Första sökorden:**

- **2005-03-08, JF**

  **Nuv sjd** Angina pectoris, insulinbehandlad diabetes typ II, hypertoni

  **Aktuellt** Fungerar bra hemma med hemtjänst 2 ggr/dag samt nattpatrull. Dotter besöker honom några ggr per vecka. Beskriver rörelsesmåtor i benet, som han vill ha någon ny medicin emot. Något trög i magen, vill ha nytt recept på Laktipex. Sitter inne mest hela

- **2005-03-08, JF**

- **Status**

  **Status**

  **Hjärta** - Renellhundet och avlägsnat cirka 70, utan blivud
VHR for Home help service - PDA
**Web patient portal**

### Egna länkar

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### Lägg till länk

### Egen information

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<th>Cigge Citron</th>
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<tr>
<td>Tele.Hem</td>
<td>0650 12221</td>
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<tr>
<td>Gatuadress</td>
<td>kasköplan 3, vån 2</td>
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<tr>
<td>Postnummer</td>
<td>82441</td>
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<tr>
<td>Postort</td>
<td>Hudiksvall</td>
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### Kontaktperson Htj

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<th>Namn</th>
<th>Ingela Möller</th>
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</tr>
<tr>
<td>Telefon</td>
<td>0650 556538</td>
</tr>
<tr>
<td>Mobil</td>
<td>070 2699590</td>
</tr>
<tr>
<td>Epost</td>
<td><a href="mailto:ingela.moller@hudiksvall.se">ingela.moller@hudiksvall.se</a></td>
</tr>
<tr>
<td>Arbetsplats</td>
<td>Håsta hemtjänstområde och äldreboende</td>
</tr>
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</table>

### Närstående

<table>
<thead>
<tr>
<th>Namn</th>
<th>Malin Citron</th>
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<tr>
<td>Relation</td>
<td>dotter</td>
</tr>
<tr>
<td>Namn</td>
<td>Tobako Citron</td>
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<td>son</td>
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<tr>
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<td><a href="mailto:Tobako@telia.com">Tobako@telia.com</a></td>
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### Ansvarig DSK

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<th>Viveca Fryklund</th>
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<tr>
<td>Telefon</td>
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<tr>
<td>Epost</td>
<td><a href="mailto:hudiksvall.se@hudiksvall.se">hudiksvall.se@hudiksvall.se</a></td>
</tr>
</tbody>
</table>
Lessons learned → Patient-centred IT

It’s not about technology

... but

- how to take advantage of it
- how to organize healthcare delivery in a smart(er) way
- and how to reimburse it

”Right information in the right place to right person at the right time” - and in the right format
Partners in the OLD@HOME project

Research

Institutes, universities

Public sector

Society

Companies

Industry

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Assignment

- A small project, assignment, to be performed in groups of 4-5 persons.

- HANDS-ON: To analyse an existing system, evaluate its usability and suggest preliminary solutions to usability problems.
  - or.....

- LITERATURE STUDY: To investigate, by literature studies etc., some interesting facts related to the use of IT in medicine or healthcare.

- Start early, i.e. now!!!

- In both types of assignments, the focus should be on usability, design of the user interface and the benefit for the healthcare professionals and/or for the patients. You are supposed to spend one week working time per person for the assignment (~40 hours).
Assignment, logistics

- **Step 1:** Form groups of 5 persons. This should be done **latest Monday Nov 4.** Each group should send an (one) email to Bengt Göransson (Bengt.Goransson@it.uu.se) and Isabella Scandurra (Isabella.Scandurra@it.uu.se) latest Nov 4, with a list of the group members’ names. Write “Medical Informatics” on the subject line.

- **Step 2:** You must specify your assignment and get an approval before starting the assignment work. Also here, write an email to Bengt.Goransson@it.uu.se & Isabella.Scandurra@it.uu.se and specify your assignment, the application area, contact persons and a few lines about how you plan to perform your assignment project.

You will get a reply with an OK or some advice how to proceed. This should be done **latest Monday Nov 11.**
Assignment Q & A

- Teams?
- Topics?
  - Specify your assignment
  - the application area,
  - contact persons and
  - Project plan (how to perform the assignment)
List of Suggestions for your assignment

- Hands-on projects

**Hands-on work r/t IT-development phases in eHealth development**

- Mobile interface design of personal EHRs
  - Students chose design tools and degree of mockup/prototype level.

- Use of personas to evaluate current version of Sustains
  - Access to your personal EHR is needed
  - Students need to select appropriate evaluation method and
  - Create personas, or possibly use Evry’s personas?

- Create an online feedback (Sustains /eRecord) to improve user engagement
  - In Sweden? In other countries?
  - Compare to other domains’ (eg. Banking) design regarding content and design
  - Discuss constraints and design issues to succeed in improvement?
    - Describe needed workflow (both in system and in organization) to satisfy “public users”

- Evaluate consumer health products and suggest improvements
  - Aftonbladet Health, RunKeeper…
  - Patient wearables and other gadgets

- Your own patient experiences: Private Health data in relation to Personal EHRs provided by the Healthcare organisation – which data belongs where and why?
  - Specific patient groups (org) or your own data and needs - Initial contact with CeHis/mina vårdkontakter?
List of Suggestions for your assignment

- Literature studies 1/2
  - 2 LUL as a Customer-projects

Literature studies – as ROOM FOR IMPROVEMENT (search pubmed etc)

- RCT studies in eHealth where other evaluations methods could have been used…
- User Centred Design – when, where, how and why is it used in eHealth? In relation to the UCD standard and methodology – do the projects follow the standard or..?
- Who publish failures in eHealth (uni/healthcare org/industry?) and what kind of failures – what can we learn?
  - National/international perspectives
  - Socialstyrelsens Lex Maria for MI/MT deviations
- Ethical and legal issues regarding accessible EHRs internationally
  - How do others do? Based on what? (search pubmed, EU-sites etc)
- Patient empowerment r/t public eHealth systems
  - definitions by EPF and application in practice?
- Progress in Europe/globally/ regarding Patient access to EHR?
  - Different countries’ eHealth strategies and current status regarding work towards patient access.
  - Literature + interviews – what they say and what they do…

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List of Suggestions for your assignment

- Literature studies 2/2

**Interview/Literature studies – as ROOM FOR IMPROVEMENT (search pubmed etc)**

- Virtual communities in healthcare (patientslikeme, quantifyself and others)
  - Who are they, how are the communities built, how do they work..? aims and objectives? improvement suggestions?

- Clinical apps (often consumer/self-management) in relation to patient empowerment?
  - Do clinical apps work as patient empowerment tools?

- Consumer empowerment via Health Apps in **Public health**
  - Stop smoking, chronic diseases; get fit, lose weight…- How do this work IRL?

- Physicians (or Med.Stud’s) views on Patient-related eHealth and its impact on Patients, Physicians and their relationships. (Interviews required in Swedish?)
  - EU study on communication via e-mail exists, extend that study to include attitudes, respect and relationships etc.

- Review of /mobile/ Health applications related to /Mobile/ UC Design Guidelines
  - To what extent do they follow the guidelines? Effects related to that?

- International comparisons – how to take care of patient’s interests (differences in Europe)? Different patient organisations’ point of view (interviews?)

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List of Suggestions for your assignment

- Literature studies
  - 2 LUL as a Customer-projects

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List of Suggestions for your assignment

- 2 LUL as a Customer-projects – Swedish speaking persons are mandatory
  Deliverables: graphs/diagrams and oral presentation + report.

How is the clinical data used by the users?

- Statistical analyses of the Sustains/Cosmic data out of .xls documentation (Sept 2013)
  - Which patients are using the system, when? Where? How often?
  - What do they want to know? Control the logs? Change access?
  - Do they read other’s records? Children? Elderly?

Examine patients’ general knowledge of Sustains/eRecords and if they use/have entered the JPN that is accessible in Uppsala (LUL).

- Data collection = 4 questions (do you know.. If yes, have you accessed, age/gender?)
  - Outside Primary care units/hospital entrances: 3 days/student: and 2 studenter/entrance.

- → 2 groups are out collecting in 3 days → visiting 6 care units
  - Requirement: to get as many answers as possible.

- Try to compare with the data in Sustains: Did your presence changed the behaviour?
  - if your interviews made patients/people go and access their personal EHR?

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Assignment – hand in and presentation

The presentation of your assignment work must be made both **orally** and in **written form**.

- The written report will normally be approx. 6-10 pages.
- Send the written report by mail to Bengt Göransson (Bengt.Goransson@it.uu.se) and Isabella Scandurra (Isabella.Scandurra@it.uu.se) no later than **Monday Dec 9, 13.00**
- The oral presentation is specified in the course schedule (**Wednesday December 11**).
  - Plan for 10 minutes presentation of your work and 5 minutes for questions
  - It’s mandatory to stay during all presentations, not just your own group.
- There is also a written examination which takes place on Wednesday December 11.
- The projects that have LUL (County Council of Uppsala) as a customer need to present their work at a special “LUL occasion”. **To be announced.**
The written report – outline suggestions

- **Abstract** – Short summary.
- **Background** – Describe the application area and the system you study.
- **Problem description** – Describe the problem you find outgoing from the users’ perspective.
- **Describe the system** under study in more detail.
- **Analysis** - Describe the method, the analysis and the results. This should be related to usability issues.
- Describe your **ideas for improvements** of the system, how the usability problems could be solved. Give some preliminary descriptions of what the solution could look like. Motivate and try to evaluate your ideas.
- **Discussion**. – For instance: Potential different solutions or things you could have done alternatively. Knowledge you gained during the work that is worth bringing forward.
- **Conclusion** – a short section describing your most important findings.
- **References** – interviews as well as other sources should be stated.
Lecture materials

- Building usability into health informatics (Isabella’s thesis, 2008)
  http://publications.uu.se/abstract.xsql?dbid=8403

- Sharing is Caring – integrating Health information Systems to Support Patient-centred Shared Homecare (Maria Hägglund’s thesis, 2009)
  http://uu.diva-portal.org/smash/record.jsf?searchId=1&pid=diva2:173112

- Traceability in Healthcare innovation – maintaining the relations between needs and solutions. (Madelene Larsson, 2013).

- Supporting Citizen-Centered Care for Seniors Experiences from Two Swedish Research Projects (Hägglund, M., Scandurra, I. & Koch, S. 2012)
  - IEEE Computer Based Medical Systems 2012, Rome, Italy 20-22 June

- User-Centered Design for Patient-Centered eHealth (Abstract, Maria Hägglund)


- Key principles for user-centred systems design (Gulliksen et al)
Important books and articles on HCI methodology

- Cooperative design perspectives on 20 years with the Scandinavian IT Design Model, Bødker, S., Ehn, P., Sjögren, D., & Sundblad, Y. (2000). Design vs. Design, NordiCHI.

- Methodological Review (Kushniruk & Patel)


Articles: Examples from Scandurra’s method, results and evaluations


- Participatory design with Seniors: Design of future services and iterative refinements of interactive eHealth Services for old citizens. Journal of Medicine 2.0 vol 2 (2)


- Evaluation of OLD@HOME Virtual Health Record: Staff opinions of the system and satisfaction with work. Journal of Telemedicine and eHealth, 2009;15(1) 53-61

- From user needs to system specifications: MdTS as collaborative design method for development of health information systems. Journal of Biomedical Informatics, 2008: 41 (4) 557-569


- Visualization and interaction design solutions to address specific demands in shared home care. Stud Health Tech Inf, Vol 124, 2006, 71-76


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