Experiences of Novel eHealth Services for Patients – Pros, Cons and Future Challenges

22 August 2013, 10.30-12.00
Medinfo 2013 – Workshop on eHealth
#EHR4U

Organizers:
Isabella Scandurra  Uppsala University,
Rose-Mharie Åhlfeldt  University of Skövde,
Maria Hägglund  Karolinska Institutet, Sweden
1st session: Current studies

- Welcome & WS structure
- The process of patient empowerment measurement in SUSTAINS - W. Atzori
- Clinical use of a Patient EHR portal in Primary Care – a long term study - T. Ålander
- Overview of e-patient centered services in Estonia - K. Podošvilev

2nd session: Future challenges

- Can healthcare match the informed patient’s knowledge? Can patients take on new responsibilities? – B. Eklund
- The Northern Light – Intro plan of SUSTAINS in NLL – I.Scandurra
- My care pathways – National services that allow patients to follow, own and manage their care processes - M. Hägglund
- Concluding remarks

The goal of the DOME project

* To produce and disseminate knowledge about adaption and use of medical records online and other eHealth services aiming to benefit both patients and healthcare organizations

Scientific studies

PhD projects

Development of internal constellation

Development of external constellation and dissemination of results

www.it.uu.se/research/hci/dome
The process of patient empowerment measurement in SUSTAINS

Walter Atzori - European Patient Forum

Outline

* SUSTAINS project
* Assessing patient perspective and outcomes
* A framework for patient empowerment
* Methodology and Methods
* Limitations and challenges
• 3 year project (ICT PSP Pilot B) deployed in 11 European regions

• Supporting the implementation of Key Action 13 of the Digital Agenda for Europe

• Making the online access by citizens/patients to their Electronic Health Records (EHR) a reality

• Pure online access is complemented with a rich basket of e-services making it possible for patients and citizens to interact with HCPs

• The common denominator in terms of usage is that they are all designed to be used by the citizens/patients provided they have access to the Internet

• It is not a R&D nor a pilot project, but a deployment of already mature services and applications

Medinfo 2013 #EHR4U  The process of patient empowerment measures in SUSTAINS
Patient empowering potential of eHealth services (eHealth ERA project):

* **Category 1:** eHealth information tools and services for citizens/patients focusing on the electronic provision of health and wellness information to citizens.

* **Category 2:** eHealth management support tools and services for citizens/patients focusing on applications which allow citizens to interface with health service providers electronically in order to better support their use of health services. Patient accessible EHR, ePrescriptions (etc.).

* **Category 3:** eHealth homecare and telemedicine tools and services for chronically ill citizens (patients) focusing on applications that allow citizens who are receiving healthcare to be supported in their personal environment, whether fixed or mobile, outside traditional healthcare facilities, e.g. telemedicine.

The process of patient empowerment measures in SUSTAINS
<table>
<thead>
<tr>
<th>Administrative services</th>
<th>UPPSALA</th>
<th>VENETO</th>
<th>ARAGON</th>
<th>PAIVASCO</th>
<th>ESTONIA</th>
<th>SCOTLAND</th>
<th>CENTRAL GREECE</th>
<th>SYDDANMARK</th>
<th>NORBOTTEN</th>
<th>SOUTH KARELIA</th>
<th>SLOVENIA</th>
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<tbody>
<tr>
<td>Book or rebook a consultation/diagnostic exam</td>
<td>X</td>
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<td>Pay a service fee</td>
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<td>Change GP (when moving or similar)</td>
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<td>Consult audit trail</td>
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<td>Access to health insurance data</td>
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<tr>
<td>Access to the data of health services costs</td>
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<td>X</td>
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<tr>
<td>Delegation of access</td>
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<td>X</td>
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<td>X</td>
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<tr>
<td>Mask sensitive data</td>
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<td>X</td>
<td>X</td>
<td>X</td>
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<td>X</td>
<td>X</td>
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<td>X</td>
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<tr>
<td>Track referrals</td>
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<td>X</td>
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<tr>
<td>Notification services</td>
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<td>X</td>
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<td>X</td>
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<tr>
<td>Consent for the export of EHR data to the epSOS Patient Summary</td>
<td>X</td>
<td></td>
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</tr>
</tbody>
</table>

The process of patient empowerment measures in SUSTAINS
# Clinical services

<table>
<thead>
<tr>
<th>Clinical services</th>
<th>UPSALA</th>
<th>VENETO</th>
<th>ARAGON</th>
<th>PAISVASCO</th>
<th>ESTONIA</th>
<th>SCOTLAND</th>
<th>CENTRAL GREECE</th>
<th>SYDDANMARK</th>
<th>NORBOTTEN</th>
<th>SOUTH KARELIA</th>
<th>SLOVENIA</th>
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</thead>
<tbody>
<tr>
<td>Examine the EHR</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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</tr>
<tr>
<td>Ask a question to a physician/nurse</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X^4</td>
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<td>X</td>
<td>X</td>
<td>X^3</td>
<td>X</td>
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<td>X</td>
</tr>
<tr>
<td>Fill out a Health Declaration Form</td>
<td>X</td>
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<td>X</td>
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<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<tr>
<td>Print out drug and lab list before travelling abroad or outside their region</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Patient’s input into EHR</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<td>X</td>
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<tr>
<td>Integration of data relating to patient’s self-monitoring</td>
<td>X</td>
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<td>X</td>
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<td>X</td>
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<td>X</td>
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<tr>
<td>Decision support</td>
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</tbody>
</table>

Clinical services Table

The process of patient empowerment measures in SUSTAINS
3 objectives

The ultimate goal of SUSTAINS is not to provide citizens with access to EHR, but through that access we are aiming at:

- Fostering the **empowerment of patients** through a more active role of citizens and patients in the management of their health condition *(Patient outcomes)*

- Fostering more efficient and continuous contact between the patient and the professionals to achieve **optimal medical results** *(Clinical outcomes)*

- Contributing to making healthcare systems **more efficient and sustainable** *(Economic outcomes)*
Patient empowerment
Identified as primary outcome for this project:

Patients’ having the ability to: a) understand health information b) make an effective use of it to inform sound health decisions in the context of everyday life, c) and participate in a meaningful way in health-related decision-making in an equal partnership with health professionals.

(SUSTAINS definition of patient empowerment)
Methodology

Defining a framework for patient empowerment measurement:

• Literature review
• Integration of outcomes of user requirement process
• Development of a model of empowerment applicable to patient accessible EHR

Methods used to conduct the assessment:

• **Quantitative:** Patient Empowerment Survey (panel data, baseline and follow up after 1 year of service usage)
• **Quantitative:** Focus groups with a representative sample of service users in 2014
Empowerment model

- **Patient knowledge**: Link between patient and his/her understanding and use of health information
- **Patient control**: Relationship between the patient and the management of his/her condition
- **Patient participation**: Relationship between patient and health professionals

Support from health professionals leads to meaningful patient involvement in health.
Sustains PES

Patient knowledge

9. How much of the health information that you receive from health professionals **during face-to-face visits** do you understand?

<table>
<thead>
<tr>
<th>Score</th>
<th>1 (none)</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10 (all)</th>
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<tbody>
<tr>
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</tbody>
</table>

Unable to respond

Patient control

19. Do you take your **medication** exactly as prescribed?

<table>
<thead>
<tr>
<th>Score</th>
<th>1 (not at all)</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10 (entirely)</th>
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</tbody>
</table>

Unable to respond

Patient participation

22. Do you **think of questions in advance** that you want to ask your doctor during face-to-face consultations?

<table>
<thead>
<tr>
<th>Score</th>
<th>1 (never)</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10 (every time)</th>
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<tbody>
<tr>
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</tbody>
</table>

Unable to respond

25. To what extent do you feel **able to draw your health professionals’ attention** to the issues that are a priority for you?

<table>
<thead>
<tr>
<th>Score</th>
<th>1 (not at all)</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10 (entirely)</th>
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</tbody>
</table>

Unable to respond

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The process of patient empowerment measures in SUSTAINS
# Expected Users and Sample Size

<table>
<thead>
<tr>
<th>Region</th>
<th>Expected number of users</th>
<th>Sample size (confidence level = 95% confidence interval = 4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Uppsala County</td>
<td>25,000</td>
<td>586</td>
</tr>
<tr>
<td>Veneto</td>
<td>10,000</td>
<td>566</td>
</tr>
<tr>
<td>Aragon</td>
<td>5,000</td>
<td>536</td>
</tr>
<tr>
<td>Pais Vasco</td>
<td>27,000</td>
<td>587</td>
</tr>
<tr>
<td>Estonia</td>
<td>40,000</td>
<td>591</td>
</tr>
<tr>
<td>Scotland</td>
<td>500</td>
<td>273</td>
</tr>
<tr>
<td>Central Greece</td>
<td>500</td>
<td>273</td>
</tr>
<tr>
<td>Syddanmark</td>
<td>10,000</td>
<td>566</td>
</tr>
<tr>
<td>County of Norbotten</td>
<td>1,500</td>
<td>429</td>
</tr>
<tr>
<td>South Karelia</td>
<td>6,750</td>
<td>551</td>
</tr>
<tr>
<td>Slovenia</td>
<td>20,000</td>
<td>583</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>146,250</strong></td>
<td><strong>5,541</strong></td>
</tr>
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</table>
Questions & Answers
• We are not aiming at scientific evidence (we are at deployment stage)

• We have no control on who is actually using the SUSTAINS services - making use of quantitative methods more challenging

• We are faced with huge diversities across regions

• SUSTAINS targets citizens at large regardless of whether they have a chronic disease

• Assessment of patient empowerment would require longer follow-up than what allowed by a EU project - especially to assess impact on those not using the services regularly
Clinical use of a patient EHR portal in primary care – a long term study:

Ture Ålander – Ture Ålander Praktik

* Uppsala University, Sweden
  Department of Public Health and Caring Sciences
  ture@tapraktik.se
  www.tapraktik.se

Clinical use of a patient EHR portal in primary care – a long term study: Ture Ålander – Ture Ålander Praktik

* Uppsala University, Sweden
  Department of Public Health and Caring Sciences
  ture@tapraktik.se
  www.tapraktik.se
The new health care account, in Uppsala 2002

Background

Citizen with a HCA

Message system

Sustains system

Internet

time
password

Info Medix

Academic hospital

Family practice

ProfDoc journal

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Dr Ålander
Patients have access to their previous contacts, booking, fees, personal data, sick leave, documents from the hospital, laboratory results, prescribed medicines, doctor’s notes, diagnosis, adverse reactions, hospital contacts, message system, pharmaceutical and medical dictionary.
Setting


492 patients chose a HCA and had online access to their EMR between 2002-2011.

Lessons learned

2002-2003 278 patients; 133 F (46y), 145 M (47 y)
93 patients made 227 accessses until aug-2003

Find useful: 49% yes, 35% not so much, 0% not useful
Log in problem: 96% no problem, 4% some
Security concerns: 84% none, 16% don´t know, 0% yes
Text understandable: 75% yes, 21% some difficulties
Showed EMR to another person: 86% no, 14% yes
Patients most valued e-service

2011, n=55

<table>
<thead>
<tr>
<th>Rank</th>
<th>E-Health service</th>
<th>Index</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>Laboratory findings, doctor notes</td>
<td>63</td>
</tr>
<tr>
<td>2</td>
<td>Diagnoses</td>
<td>57</td>
</tr>
<tr>
<td>3</td>
<td>Communication</td>
<td>45</td>
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<td>4</td>
<td>Hospital contacts</td>
<td>32</td>
</tr>
<tr>
<td>5</td>
<td>Medical info</td>
<td>31</td>
</tr>
</tbody>
</table>

68% want to get back the HCA back to a great extent
22% would like to change family doctor to get a HCA
Questions & Answers
Doctors' experience

• More accurate notes
• No problem with extra phone calls, emails
• Less work with lab reports
• Better informed patients- improve consultation
• No legal concerns
Pros

• Clinical study
• Longest follow up study – 9 years
• All adult patients were addressed
• Comparable data- same doctor/patients
Cons

- Only one test center
- Hospital care not included
- Internet not so spread at study start
  2005: 89% mobile phone, 77% Internet access
Future challenges

• Involve health care providers
• Improve user interface - apps
• Improve messaging – patient reports, health status, questionnaires
• Improve translation

Thank you!
Overview of patient centered e-services in Estonia

Kelli Podošvilev – East Tallinn Central Hospital

- Experience of National Health Information System – access to country-wide HIS Patient Portal
- Hospital experience – patients access to all their medical data and on-line booking services by using East Tallinn Central Hospital information systems’ patient portal called iPatient.
Background

- Estonian National Health Information System (HIS) became accessible at the beginning of 2009.
- The development and maintenance of the HIS is regulated by the Health Information System Act (Act).
- The access to HIS and iPatient portal is secured by using
  - the electronic identity card (ID-card) or Mobile-ID (www.id.ee)
  - data exchange layer x-road (www.ria.ee)
Background

• The **optout** system is used:
  • there is no need for the patients consent while sending the data to the HIS;
  • all healthcare providers must send data to HIS;
  • patients can deny access to their medical data gathered to the HIS.
Background

• Patients have on-line access to all their health data in HIS
  • they can declare intentions and preferences
  • monitor logs
• One of the largest hospitals in Estonia - East Tallinn Central Hospital - opened its health information system to the patients.
• Patients had access by using iPatient portal since the end of 2007.
• Patients had access to all of their medical data, incl images.
Current status

• The growth of patient portals’ use has been slow but it is growing steadily.
• The total number of medical documents in HIS is 10 618 185
• The total number of patients having documents 1 131 369 persons (87% of the population);
• The population in Estonia is 1,3 million inhabitants
• The main users of the health care information are younger females (age group 20-40) - the non traditional group of patients of the hospital. Other age groups are following.
• However the data also shows that men are less interested in viewing their health data.
Current status

Unique patients using Patient Portal and iPatient in a year

- **2009:**
  - Patient Portal: 2490
  - iPatient: 13144

- **2010:**
  - Patient Portal: 19535
  - iPatient: 22280

- **2011:**
  - Patient Portal: 22786
  - iPatient: 26425

- **2012:**
  - Patient Portal: 26425
  - iPatient: 31520

*2012 Patient Portal data Jan – Aug 2012

Overview of patient centered e-services in Estonia

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Current status

Logins by age and sex in 2012

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Overview of patient centered e-services in Estonia
 Pros

• Enable patients to view all their health data gathered to the HIS or to the hospitals´ database
• Easy and secure access by using ID-card or Mobile-ID solutions
• Optout - all healthcare providers must send data to HIS, however patients have the right to close their own data
Cons

• Focus on health data
  • Not to the „sub-services“ like online-booking, managing personal data etc
  • Patients are mainly interested in health data
• Standardisation
  • Only standardised data should be gathered to the HIS
  • Better cooperation with health care providers to clarify the significance of standardised data (f.e. to create services)
Future challenges

• To attract more patients to view their health data
  • Different age groups, male patients
• To create services
  • So far health data is gathered to the HIS and hospital database but it is important to use this data to create new services
• Enabling patients to fill in their health data (home monitoring, side effects of the drugs, etc)
Lessons learned

• Patients are interested in having on-line access to their health data and monitor ones’ health status.
• Feedback shows that when patients do not have access to their health data they contact service provider - „as they must periodically or before doctors’ appointment view their test results.“
• Health data should be easily and securely accessible to the patients
• It should not be concentrated on: „What happens if a patient sees health data before doctor...“
• It is important constantly to inform patients about possibilities to view their health data and to support them actively inform their physicians that they know how to use their health data.
BREAK

... 5 minutes ...
Can the IKEA concept be implemented in Health Care?

Benny Eklund – County Council of Uppsala

* Леонид Рогозов Leonid Rogozov
* BMJ 2009;339:b4965
Background

- Long story of self service in Health Care
- New legislation 2008
- Test project for 8 years
- EU funded project started Jan 2012
- Launch of service November last year
Current status

Antal unika användare


0 7500 15000 22500 30000
Questions & Answers
Pros

Better utilisation of both patient and relatives as new resource in Health Care production
Very early decision on highest level in organisation
Future challenges

- More patient input possible
- More adaption to specialities in Health Care
- Patient statements as willingness to donate organs
- Possibilities of masking and control of others access
Lessons learned

Dont expect to be accepted from the very first day
The Northern Light - introduction plan of SUSTAINS

Maria Jansson – County Council of Norrbotten

* County Council of Norrbotten, Sweden
Background

The county of Norrbotten

- **Area:** 98,911 km²
  - 25% of Sweden’s total area
- **Population:** 248,422
  - 2.6% of Sweden’s population
  - Most sparsely populated area of the EU
    - 2,51 Inhabitants/km²
- **Long distances** = High demands for care delivery
  - ICT solutions are prioritized
  - 9/10 inhabitants have broadband connection
Background

Building on previous ICT-projects

* Web based Clinic-specific services for citizens
  * Book meetings with professionals (video. Mail, chat etc)
    * Attachments of information (documents, photos, recorded videos)
  * Storage of own monitored data and the information is also accessible for the healthcare personnel
  * Access to personal prescribed ordination, training programs (video) etc
Current status

* Working to make SUSTAINS services national initiatives (5 regions: NLL, LUL, Jkp, SLL, Skåne)
* Planning for testing patient access to EHR
  * System development performed, test with patients during this autumn R/T Personal Health Account (PHR)
* Anchoring: Information and communication process within the County Council
* Investigating the regulatory framework that Uppsala has applied, what does it mean for the County Council of Norrbotten?
Questions & Answers
Pros

• Anchoring process is imperative
• National initiative strengthens the solutions; will be based on gathered previous knowledge
• Will learn from others – e.g.
  • EU-project and
  • a National level
Cons

Time consuming

• It takes time to work together nationally (which is also positive)
• Takes time to implement changes in the EHR – they need to be planned in the ’VAS’ development process
• New work processes for the staff in order to follow the regulatory framework
Future challenges

• Implementing all changes in our EHR system VAS
• Continue to develop distance-spanning healthcare solutions:
  • Add other information necessary for NLL
  • Involve issues related to ICT literacy, culture, language etc
• Change of mindset amongst professionals
Lessons learned

• Finding the right competences (even though you find the people…)
  • → increase the competence on long term basis
  • → service contracts are standardized
• Laws and regulations and interpretation of those
  (the County Councils can interpret differently…)
  • Strive to avoid different care delivery in the same country
  • → Use a Lowest Common Denominator
My Care Pathways (Mina Vårdflöden)

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Maria Hägglund – My care pathways
About the project

* Visualization of care pathways/processes
  * Stroke - Stockholm
  * Lung cancer - Stockholm
  * Hip surgery – Skåne region

* Develop methods and guidelines that describe the process to develop further care pathways and support services
  * In co-production between research, public sector, industry and patient organizations

* Platform for innovative development of eHealth services
  * Stimulate third parties to develop new products
  * Open platform and Software Development Kit
  * Business models
Methods used

- Understanding the differences – timing it right!
- Active patient involvement
  - Personas
  - Scenarios
  - Prototyping
- Open platform and Software Development Kit enables innovative solutions
Current status

* Prototyping and testing
Questions & Answers
Key challenges

Legal issues
• Should patients have access to all information immediately?
• Origin of information affects legal constraints
• Ethical considerations

Organizational issues
• Changed roles
• Changed responsibilities
• How do we engage clinicians?
• Socio-technical development

Usability issues
• Functional and cognitive disabilities
• The digital divide

Business-model issues
• Ownership
• Accessibility
• Financing

Interoperability issues
• Semantic interoperability
• Terminologies
• Presenting information from diverse sources in one consistent view

Maria Hägglund – My care pathways
Lessons learnt

* Involve the patients!
  * Understand their journeys – listen to their stories
  * Identify needs
  * Patients are not a homogeneous group
* Get healthcare professionals/organizations onboard
  * True usefulness comes when collaboration is supported
Concluding remarks
Thank you all for your participation!

The discussions will continue on Twitter: #EHR4U