ICT for Healthcare, Selfcare and Prevention

Challenges, Opportunities and Trends

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Foto: Fröken Fokus

3 Areas of Health Informatics

- Patient-Centred Information Systems
- Health-enabling and Ambient Assistive Technologies
- Decision Support

CIS and EHR

Vision: To provide clinical information systems that adapt to changing healthcare environments

Today: Numerous systems are in use but clinician acceptance varies, interfaces are not open and the systems do not support patient-centered delivery of care

Tomorrow: Current and new CIS and EHR technology will help to provide international standards for interoperable applications that use health, social, economic, behavioral, and environmental data to communicate, interpret, and act intelligently upon complex healthcare information to foster precision medicine and a learning health system.

Challenges: Usability, Visualization, Interoperability, Data integration

Opportunities: Precision medicine and learning health system

Gardner RM. Clinical Information Systems – From Yesterday to Tomorrow. Yearb Med Inform 2016;Suppl1:S62-75

Evans RS. Clinical Electronic Health Records: Then, Now, and in the Future. Yearb Med Inform 2016;Suppl1:S48-61

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Patient-centred information systems

”Patient-centred care = Care that is guided by the individual patient’s needs, preferences and values”

Gerteis M, Edgman-Levitan S, Daley J, Delbanco TL (Eds).
Through the Patient's Eyes: Understanding and Promoting Patient-Centered Care.
Wiley, 1993 1st ed

https://www.cartus.com/en/blog/one-size-does-not-fit-all/

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Dimensions of PCC (from Gerteis et al)

(1) respect for patients' values, preferences, and expressed needs;

(2) coordination and integration of care;

(3) information, communication, and education;

(4) Physical comfort;

(5) emotional support—relieving fear and anxiety; and

(6) involvement of family and friends.

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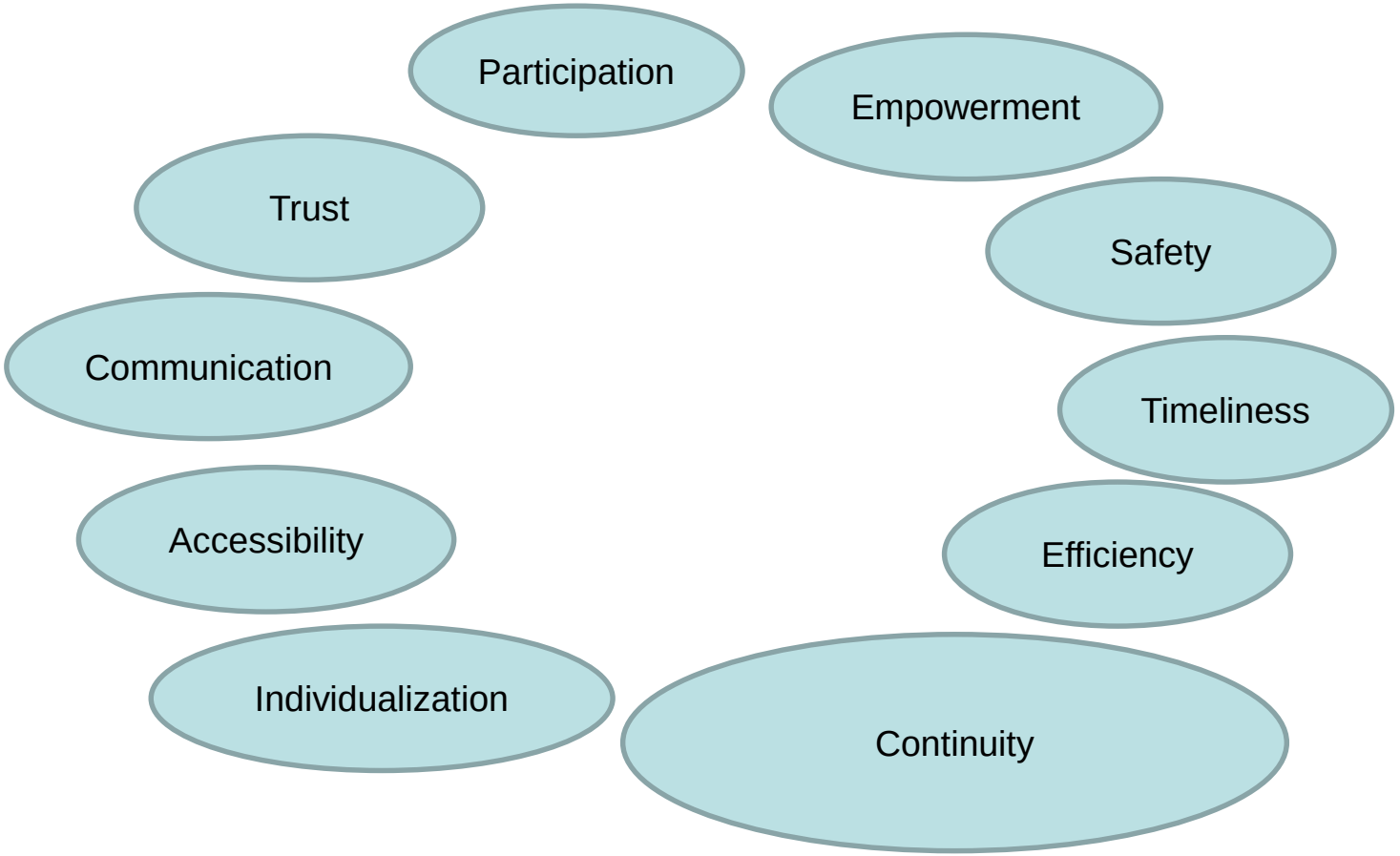
What is of value for patients?



Final report VIP-PA (Visualising patient-centred process- and business models for e-services in health and social care)
http://ki.se/ki/jsp/polopoly.jsp?d=36739&l=sv

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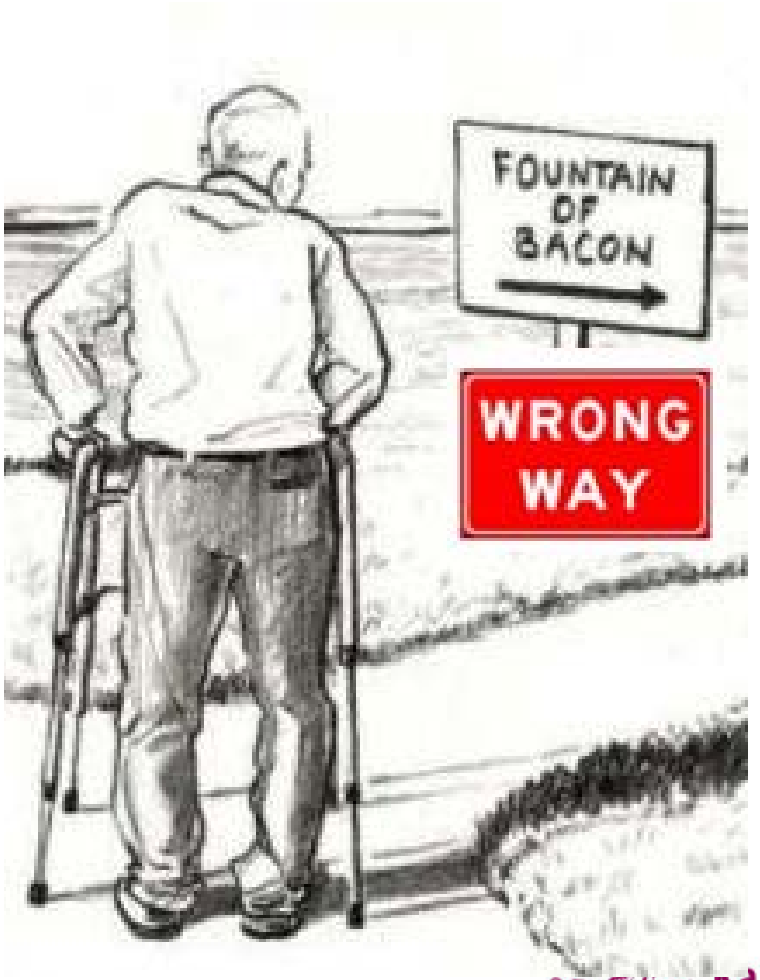
Foto: Fröken Fokus

Meet Oscar: Patient is not Just a Patient

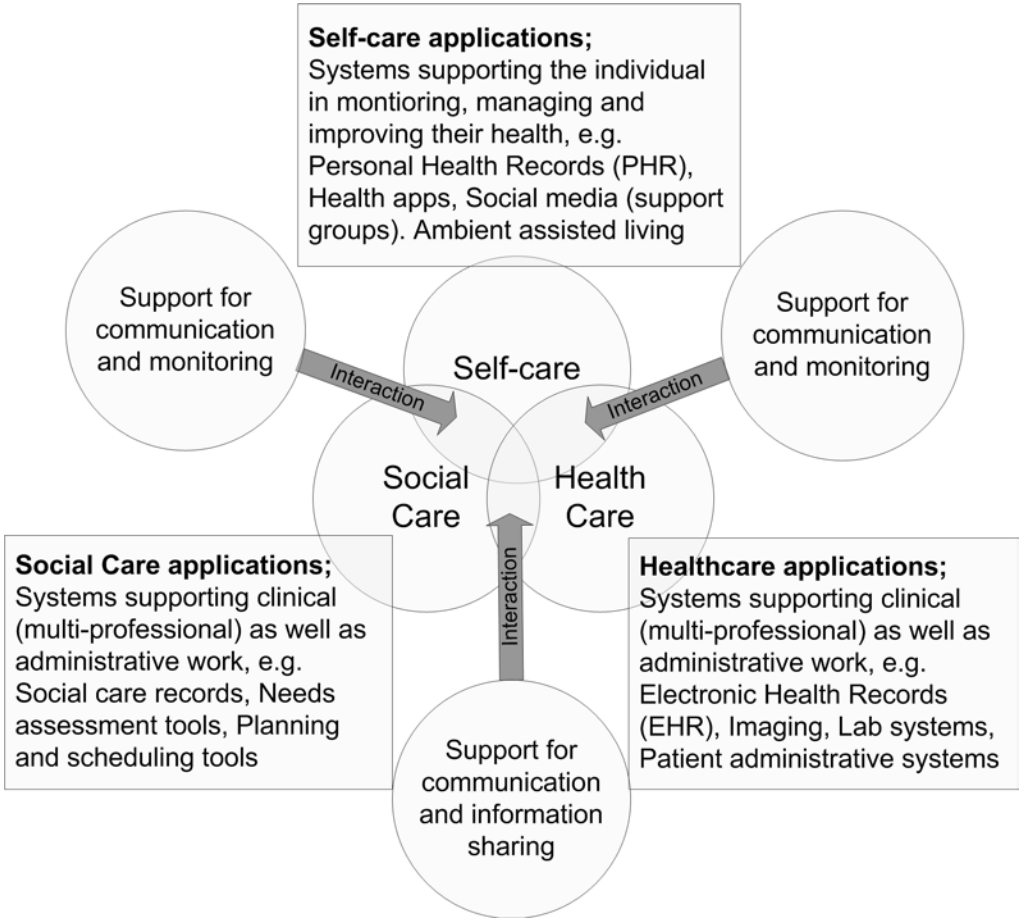
- **Our agenda for Oscar:**
  - Medication adherence
  - Come to follow-up appointments
  - Improved self-monitoring
  - Participation in PT
  - Nutritious food choices and increased calories
  - Living Will
  - Participate in Shared Decision-Making
- **Oscar's agenda for Oscar:**
  - Grieving for his wife
  - Transportation
  - Managing Rx side effects
  - Seeing his grandchildren
  - Reducing knee pain



Slide by Pei-Yun (Sabrina) Hsueh, IBM Research, New York

Foto: Fröken Fokus

How can informatics facilitate PCC?



Contextual framework for integrated eCare.
(Adapted from [Hägglund et al., 2012]).

- Elderly Home Care
- National citizen e-services
- Chronic Care
- Maternity Care

Isolated and un-coordinated information processes need to be visualised and shared with the patient in a consistent and comprehensible way.

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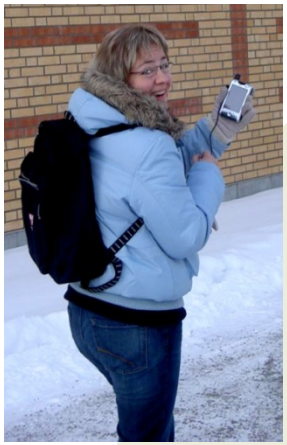
Foto: Fröken Fokus

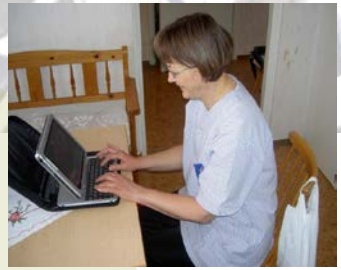
Old@Home

http://www.medsci.uu.se/mie/projects/closecare



Home helper in action

Reads, writes and communicates!

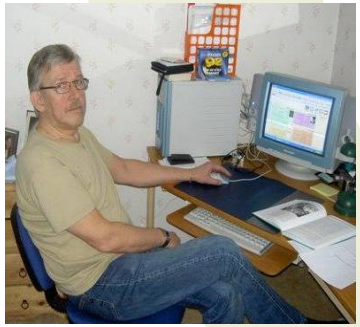


District nurse at a patient's home

Gets online information!

Patient in his home

Participates and feels safe!



Relative

Participates and is updated!

General practitioner

Reads up to date information!

Hägglund M, Scandurra I, Moström D, Koch S. Bridging the Gap – a Virtual Health Record for Integrated Home Care, International Journal of Integrated Care Vol. 7, 2007

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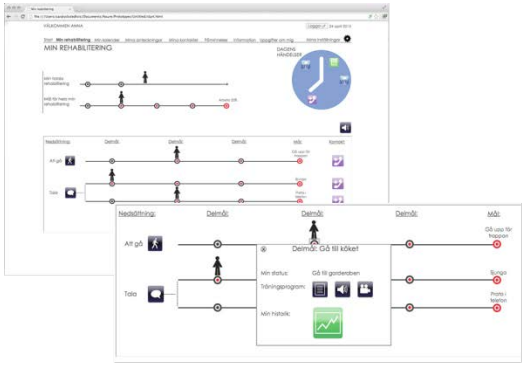
Foto: Fröken Fokus

Collaborative Stroke Care



Nadia Davoody, HIC

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My Care Pathways (2011-2013)

Financial support: VINNOVA
Project leader: Nina Lundberg, SLL
Research leader: Sabine Koch, KI

- Visualisation of care pathways:
  - Stroke - Stockholm
  - Lungcancer - Stockholm
  - Hip surgery – Skåne region
  - Heart diseases - Västra Götalands 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 organisations
- Stimulate third parties to develop new products

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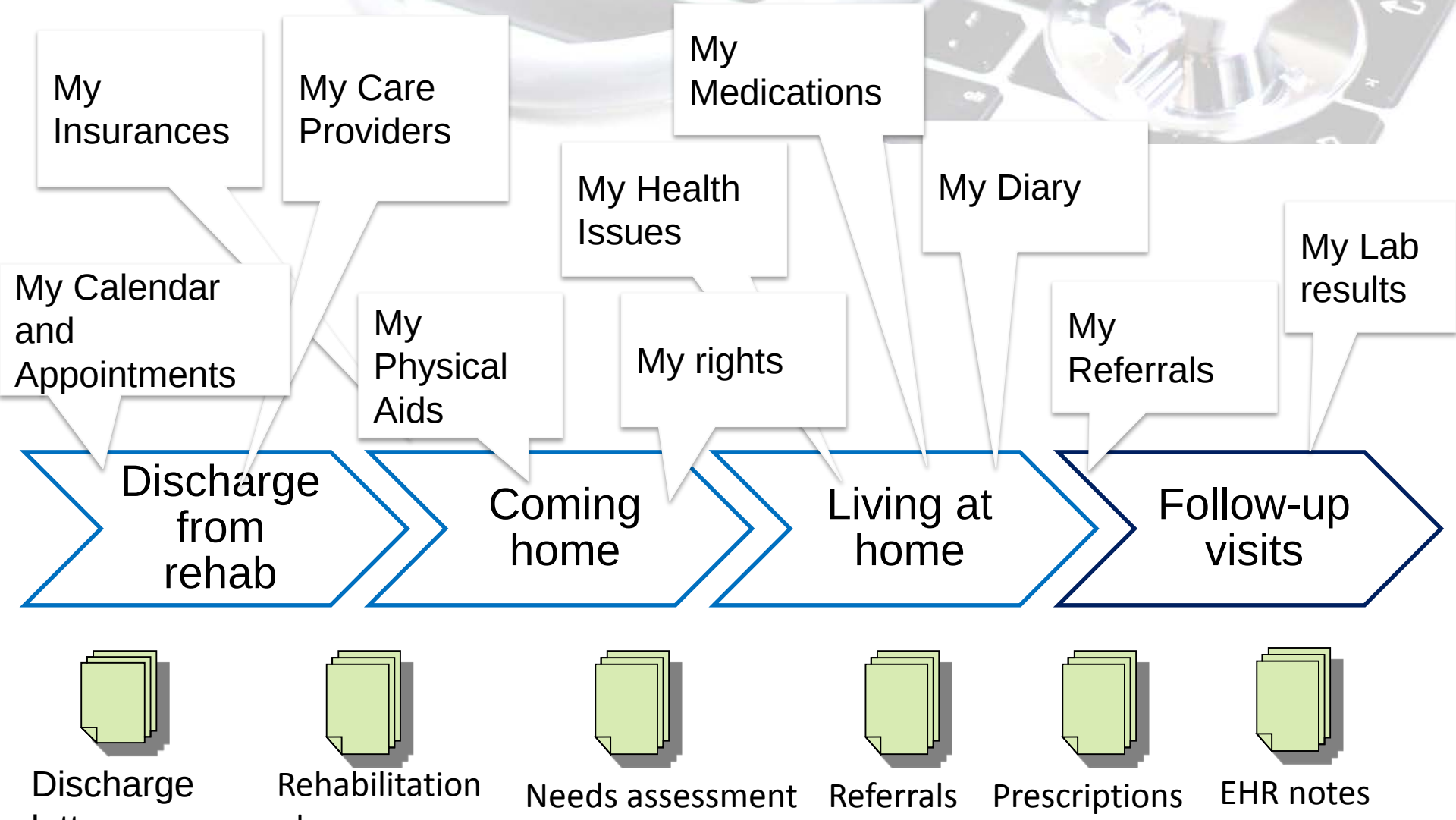
Foto: Fröken Fokus



Sabine Koch, 180618

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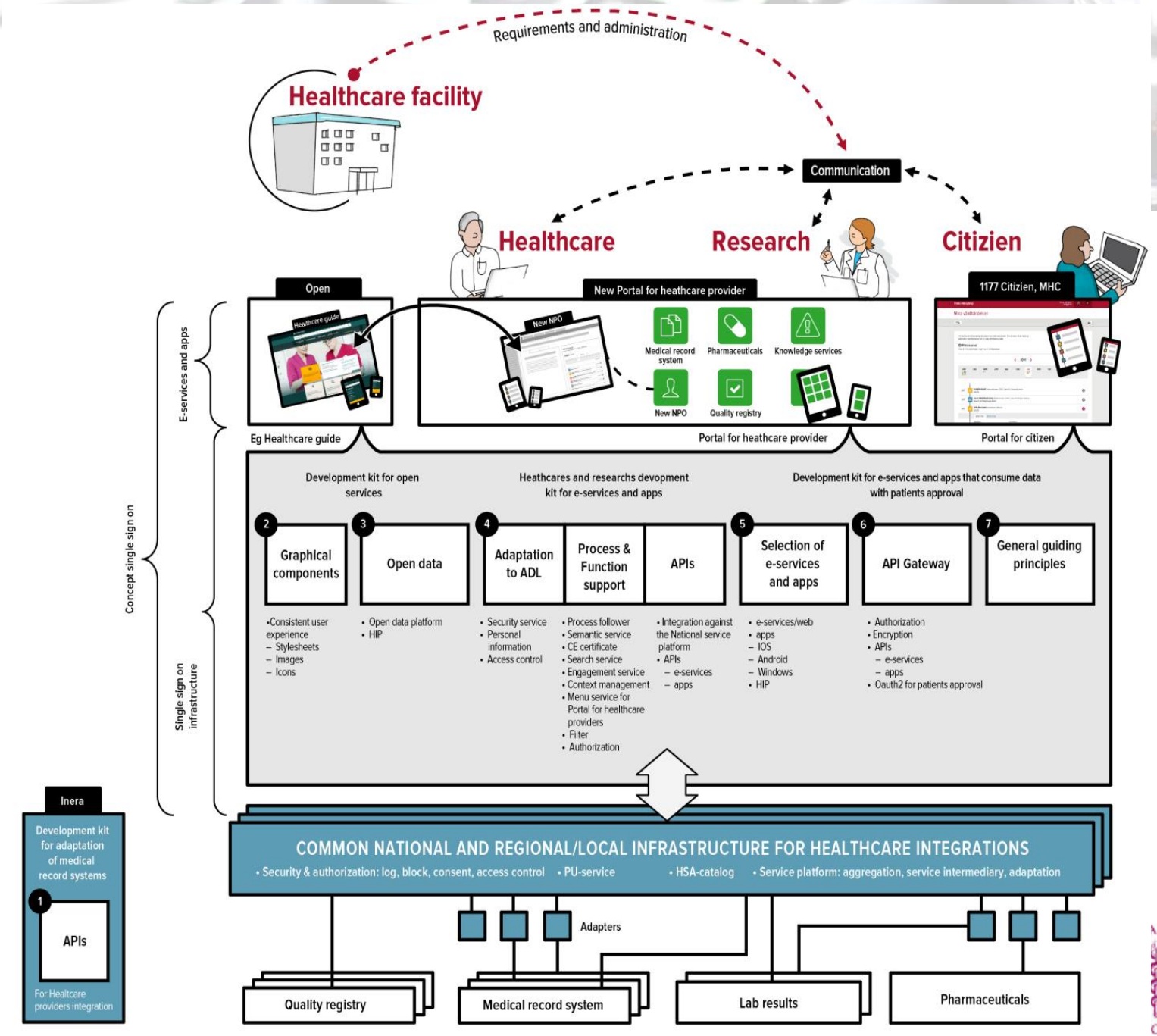
Foto: Fröken Fokus

Project principles

- Open source
- Reuse
- Use existing standards
- Make use of existing open health data
- Comply with existing regulations

Foto: Fröken Fokus



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The Swedish virtual portal for patients/citizens

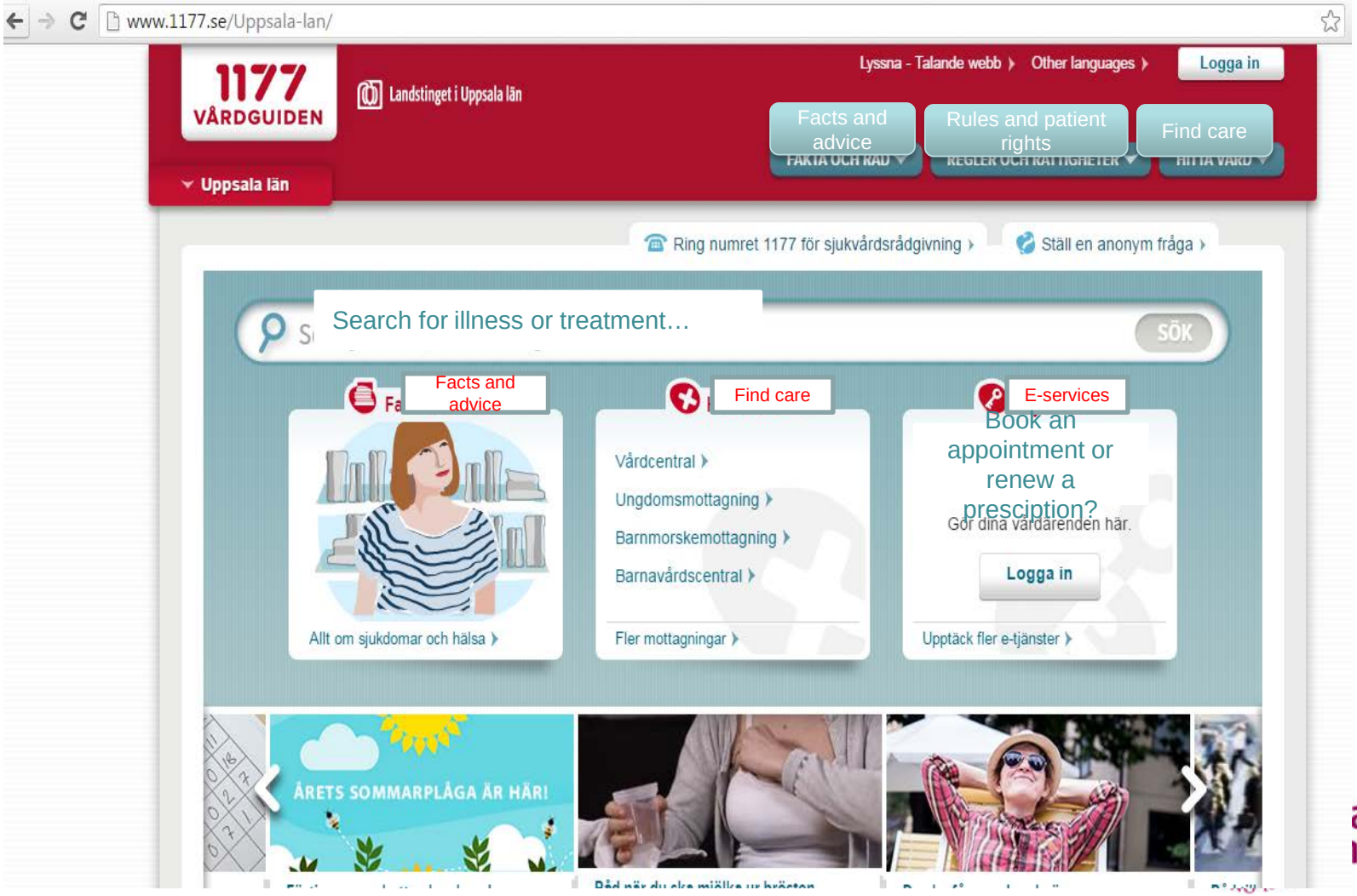

Foto: Fröken Fokus

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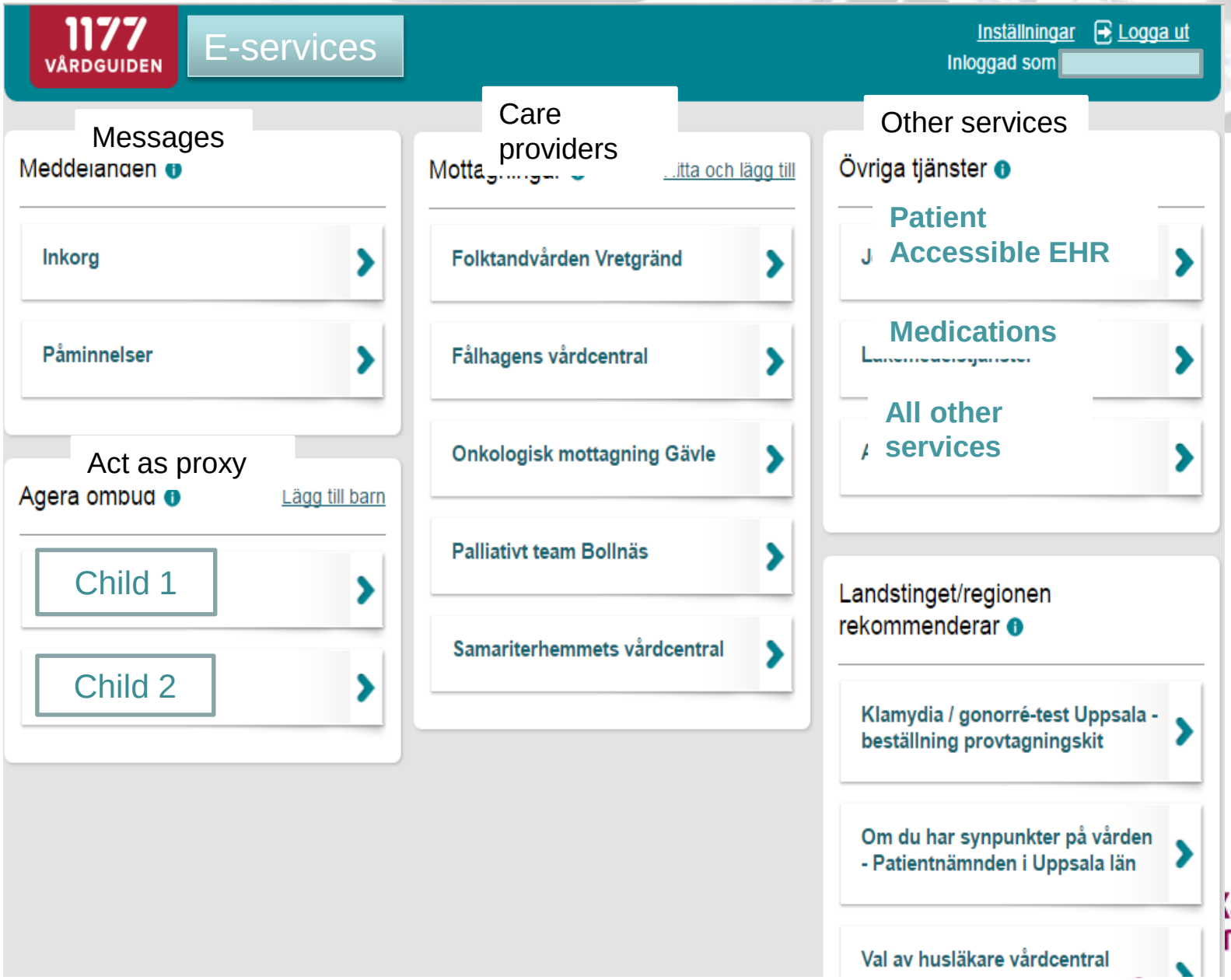
1177 VÅRDGUIDEN
E-services
Inställningar
Logga ut
Inloggad som
Messages
Meddelanden
Inkorg
Påminnelser
Act as proxy
Agera ombud
Lägg till barn
Child 1
Child 2
Care providers
Folktandvården Vretgränd
Fålhagens vårdcentral
Onkologisk mottagning Gävle
Palliativt team Bollnäs
Samariterhemmets vårdcentral
Other services
Övriga tjänster
Patient Accessible EHR
Medications
All other services
Landstinget/regionen rekommenderar
Klamydia / gonorré-test Uppsala - beställning provtagningskit
Om du har synpunkter på vården - Patientnämnden i Uppsala län
Val av husläkare vårdcentral

Foto: Fröken Fokus

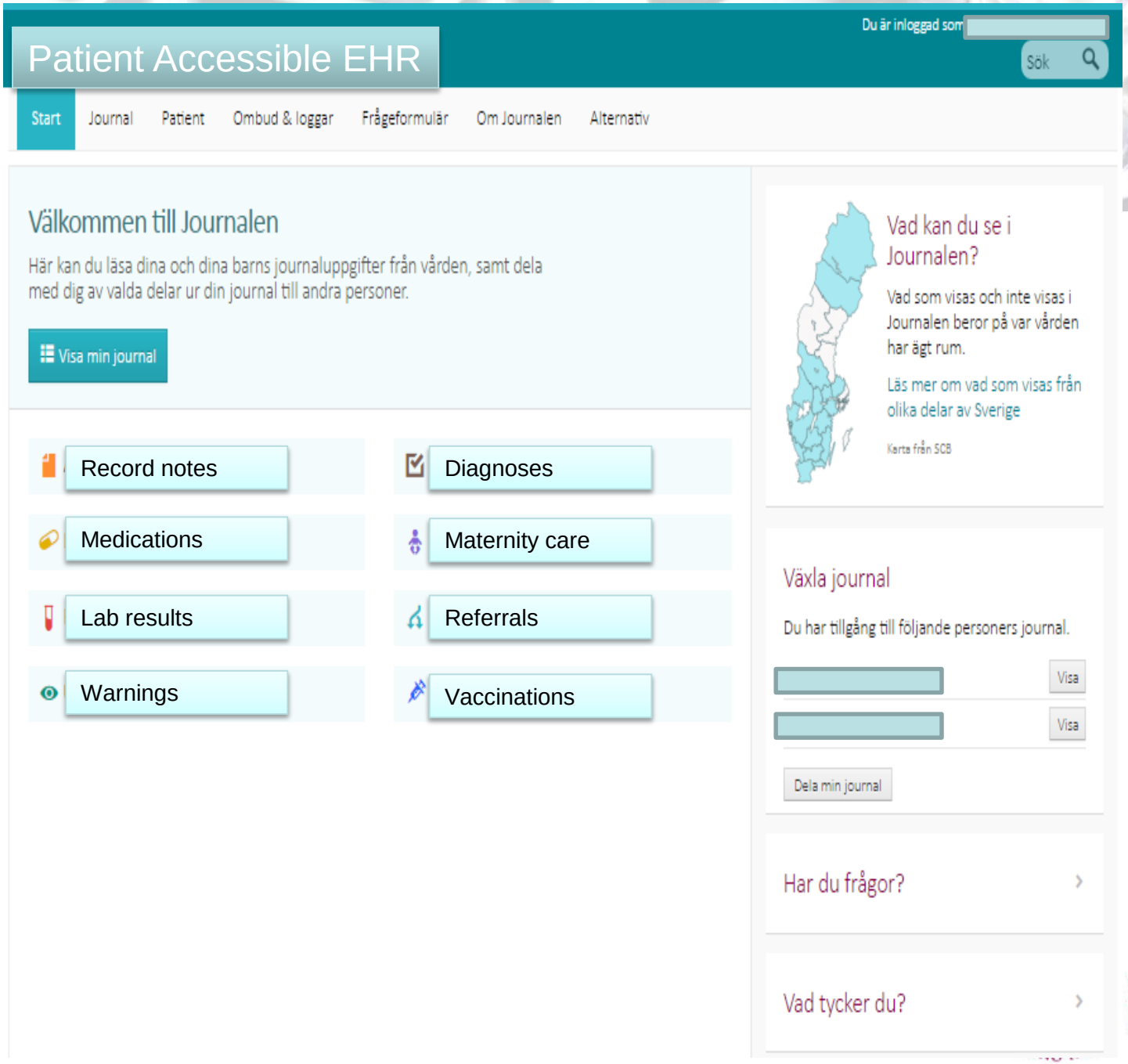

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Foto: Fröken Fokus

Patient Accessible EHR

Journalöversikt — Record overview

I tidslinjen ser du alla tillgängliga uppgifter ur din journal, i tidsordning med det nyaste överst. Klicka på en rad för att se mer detaljer om den. Saknar du någon uppgift?

Vad innebär Nytt/Ovidimerat och Nytt/Osignerat?

Tidslinje | Kalender | Filtrera | Skriv ut

Listan visas filtrerad på datum, från 2013-12-01 till 2016-03-31

23 mar 2016	Besök	Samariterhemmets vårdcentral
17 mar 2016	MIRENA	Samariterhemmets vårdcentral
25 feb 2016	Konsultremiss	Fålhagens vårdcentral
22 feb 2016	Besök	Fålhagens vårdcentral
	Diagnos	Fålhagens vårdcentral
15 feb 2016	Administrativ	Fålhagens vårdcentral

Foto: Fröken Fokus

What are barriers to adoption of patient centered informatics tools?

Main issue	Action needed	Pitfalls	Possible solution
Absence of provider coordination and process owner	Harmonisation at policy level; Coordinated service provision at strategic management level	Lack of stakeholder involvement	Harmonise at the care professional level within the care providing teams
Uncoordinated involvement of several actors and disruptive information chain	Support collaboration between different actors through informatics to achieve continuity of care	Patient perspective lacking in process descriptions; Agreed processes and specifications are missing or not detailed enough	Describe care processes / scenarios of use and standardise their information content; Patient journey mapping

Koch S, Hägglund M, Scandurra S. **Informatics and Socio-technical Challenges when Designing Solutions for Integrated eCare**. in: Meyer I, Müller S, Kubitschke L. Achieving Effective Integrated E-Care Beyond the Silos. IGI Global, June 2014

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Foto: Fröken Fokus

What are barriers to adoption of patient centered informatics tools?

Main issue	Action needed	Pitfalls	Possible solution
Lack of a common picture between different users	Elicit the needs of ALL users	Diverging and conflicting user needs are elicited	Agree on common principles,; Apply collaborative methods for user needs elicitation and work analysis
System development leads to replacement of existing routines without extra value	Describe future care processes / scenarios of use and estimate their value	Pre-definition of all processes is not possible; Change management is not taken into account	Identify intersection and touch points and define shared data sets; Make changes explicit and agree upon them

Koch S, Hägglund M, Scandurra S. **Informatics and Socio-technical Challenges when Designing Solutions for Integrated eCare**. in: Meyer I, Müller S, Kubitschke L. Achieving Effective Integrated E-Care Beyond the Silos. IGI Global, June 2014

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Foto: Fröken Fokus

What are barriers to adoption of patient centered informatics tools?

Main issue	Reason	Action needed
Insufficient use of collaborative IT support	Insufficient usability	Increase usability
	Lack of incentives	Create incentives for use
	Lack of education	Educate users
	Physician resistance	Prepare for change management

Koch S, Hägglund M, Scandurra S. **Informatics and Socio-technical Challenges when Designing Solutions for Integrated eCare**. in: Meyer I, Müller S, Kubitschke L. Achieving Effective Integrated E-Care Beyond the Silos. IGI Global, June 2014

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Foto: Fröken Fokus

Lessons learnt

- Stakeholder involvement is mandatory
- Development is driven by local (technical) prerequisites & existing legacy systems
- Risk for digital divide and health inequalities

Decision support

Vision: CDS is viewed as an essential component of a Learning Health System where a virtuous cycle is created from data generation, to aggregation, analysis, knowledge creation, knowledge dissemination and use, and ongoing measurement for continuous feedback and refinement

Today: CDS that are implemented in practice are essentially rule-based; more traditional rule-based knowledge base is rapidly being complemented by knowledge resulting from using data mining techniques for discovery

Tomorrow: the clinical encounter between a clinician and a patient will be supported by a wide variety of cognitive aides to support diagnosis, treatment, care-coordination, surveillance and prevention, and health maintenance or wellness.

Challenges: CDS systems must provide a rationale or explanation to the end-user for the recommendation proposed with an assessment of certainty or confidence in the recommendation.

Opportunities: Precision medicine

Middleton B, Sittig DF, Wright A. Clinical Decision Support: a 25 Year Retrospective and a 25 Year Vision. Yearb Med Inform 2016;Suppl1:S103-116

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Grand Challenges for CDS

- Improve the effectiveness of CDS interventions
  - Improve the human-computer interface
  - Summarize patient-level information
  - Prioritize and filter recommendations to the user
  - Combine recommendations for patients with co-morbidities
  - Use free-text information to drive clinical decision support
- Create new CDS interventions
  - Prioritize CDS content development and implementation
  - Mine large clinical databases to create new CDS
- Disseminate existing CDS knowledge and interventions
  - Disseminate best practices in CDS design, development and implementation
  - Create an architecture for sharing executable CDS modules and services
  - Create Internet-accessible CDS repositories

(Sittig, 2008)

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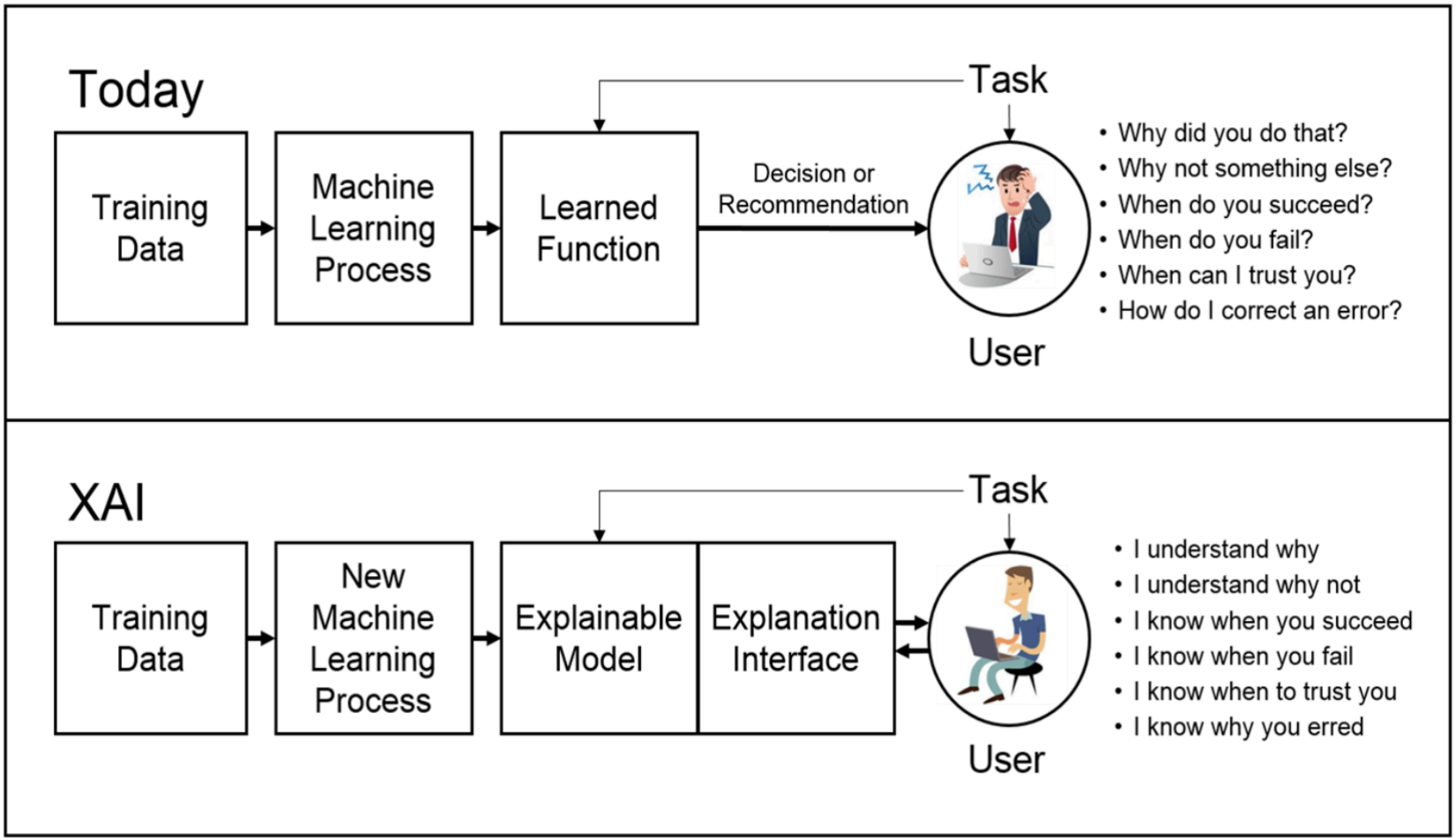
Foto: Fröken Fokus

Why are CDSS not used?

- Lack of trust
  - On the knowledge base
  - On system reasoning
- Lack of integration with EHR
- Lack of integration with work processes
- Deficiencies in the Human-Computer Interface

Explainable AI



Slide credit: DARPA XAI

Foto: Fröken Fokus

Lessons learnt

- Incentives need to be aligned
- Standardized clinical terminology and ontology needed
- Knowledge maintenance is crucial
- Explanatory CDS is mandatory

Health-enabling and Ambient Assistive Technologies

- 1995 first elderly home care project in New South Wales (Celler et al)

Vision: Ambient use of sensor-based information and communication technologies, aiming at contributing to a person's health and health care as well as to her or his quality of life.

Today: aging patients, who live alone, can now be monitored 24/7 by sensor networks; Analysis techniques are still in their infancy; limited generalizability and usefulness of some of the analyses and models reported in the literature; patients are becoming the main drivers in the collection of sensor data (quantified self-movement).

Tomorrow: H-E&AAT will be used for population screening; patients with chronic diseases use them continuously to track their health or temporarily to achieve a specific aim, e.g. adjustment of medication; Sensors will become capable of measuring medically relevant parameters unobtrusively and non-invasively

Challenges: proof of diagnostic relevance and therapeutic efficacy is still lacking

Opportunities: to close the loop between research in health-enabling and ambient assistive technologies and the practice of health care and safe living

Haux R, Koch S, Lovell NH, Marschollek M, Nakashima N, Wolf KH. Health-Enabling and Ambient Assistive Technologies: Past, Present, Future. Yearb Med Inform 2016;Suppl1:S76-91

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Foto: Fröken Fokus

Lessons learnt

- overly-optimistic results in light of small sample sizes
- impact studies for diagnostic relevance and therapeutic efficacy are still missing

Consumer Health Informatics

- 1993 Conference by Tom Ferguson et al

Vision: Patients will be in charge of their own health care using informatics tools

Today: Patient engagement and shared-decision making through online communities, social media, portals and PHRs

Tomorrow: personalized information source and decision aid to facilitate tailored monitoring of wellness, disease prevention, and treatment for informed and engaged consumers

Challenges: Health literacy and digital divide

Opportunities: Precision medicine

Demiris G. Consumer Health Informatics: Past, Present, and Future of a Rapidly Evolving Domain. Yearb Med Inform 2016;Suppl1:S42-47

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e(mpowered)-Patients

Hugo Campos
Programming his ICD
(implantable cardioverter defibrillator)

Emily Kramer-Golinkoff
Managing advanced stage cystic fibrosis

Dana Lewis
creator of the “Do-It-Yourself Pancreas System” (#DIYPS) to manage her diabetes

Christian Farman
Managing self dialysis

To manage my Parkinson’s disease I spend 1 hour in neurological healthcare and 8765 hours in selfcare per year

Sara Riggare,
(im)patient,
entrepreneur &
PhD student

Foto: Fröken Fokus

Lessons learnt

- Clinicians might be reluctant to receive large amounts of data
- Improved data analytics needed
- Improved data visualization needed for patients and clinicians

Foto: Fröken Fokus

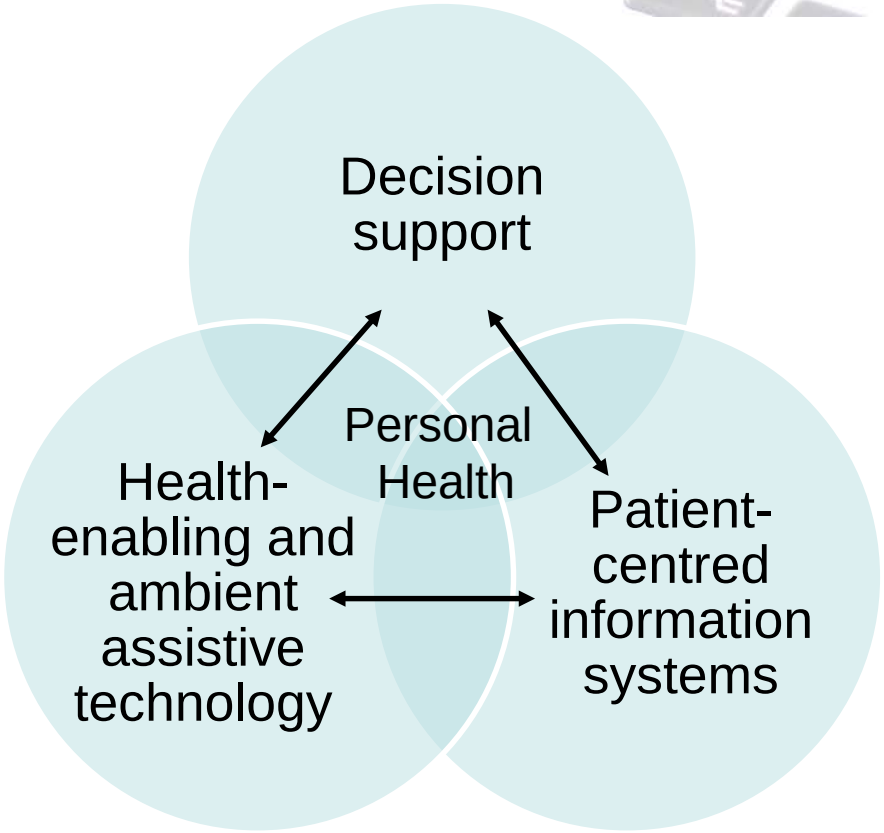

Foto: Fröken Fokus

Conclusion

“The health informatics community needs to find ways to build data models to systematically extract and link data along the continuum of care including their contexts and deliver the results according to research agendas that are driven by patient needs.”

Koch S. Health Informatics in Sweden – a personal view. IJBH 2017; 5(2):29–32

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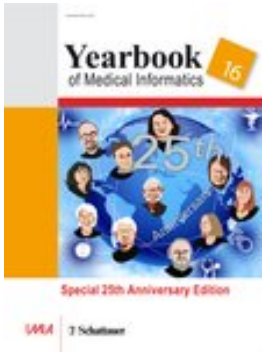
Want to read more?

IMIA International Medical Informatics Association

www.imia.org



Yearbook of Medical Informatics (open access)
Especially the 25th Anniversary Edition, 2016

https://www.thieme-connect.com/products/ejournals/issue/10.1055/s-008-39301

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Submit your research

MEDINFO 2019, 26-30 Aug, Lyon, France

Submission deadline: Nov 12, 2018

http://www.medinfo-lyon.org/en/

Methods of Information in Medicine – impact factor journal publishing new methodological informatics approaches in biomedicine and healthcare https://www.thieme-connect.com/products/ejournals/journal/10.1055/s-00035037

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Questions?

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