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Presentation slides HEC / MIE 2016

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HIBA - Taking Health Information Behaviour into Account: implications of a neglected element for successful implementation of consumer health technologies on older adults

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Deployment of Online Medical records and E-health services (DOME) [View project](#)

Patient Empowerment Meets Concerns for Patients

A Study of Patient Accessible
Electronic Health Records in Sweden

Christiane Grünloh, KTH Stockholm & TH Köln
Hanife Rexhepi, University of Skövde
Åsa Cajander, Uppsala University
Rose-Mharie Åhlfeld, University of Skövde
Gunilla Myreteg, Örebro University
Isto Huvila, Uppsala & Åbo Akademi University



Christiane Grünloh, Hanife Rexhepi

@c_gruenloh

@Hanife_Rexhepi

@DOMEprojekt

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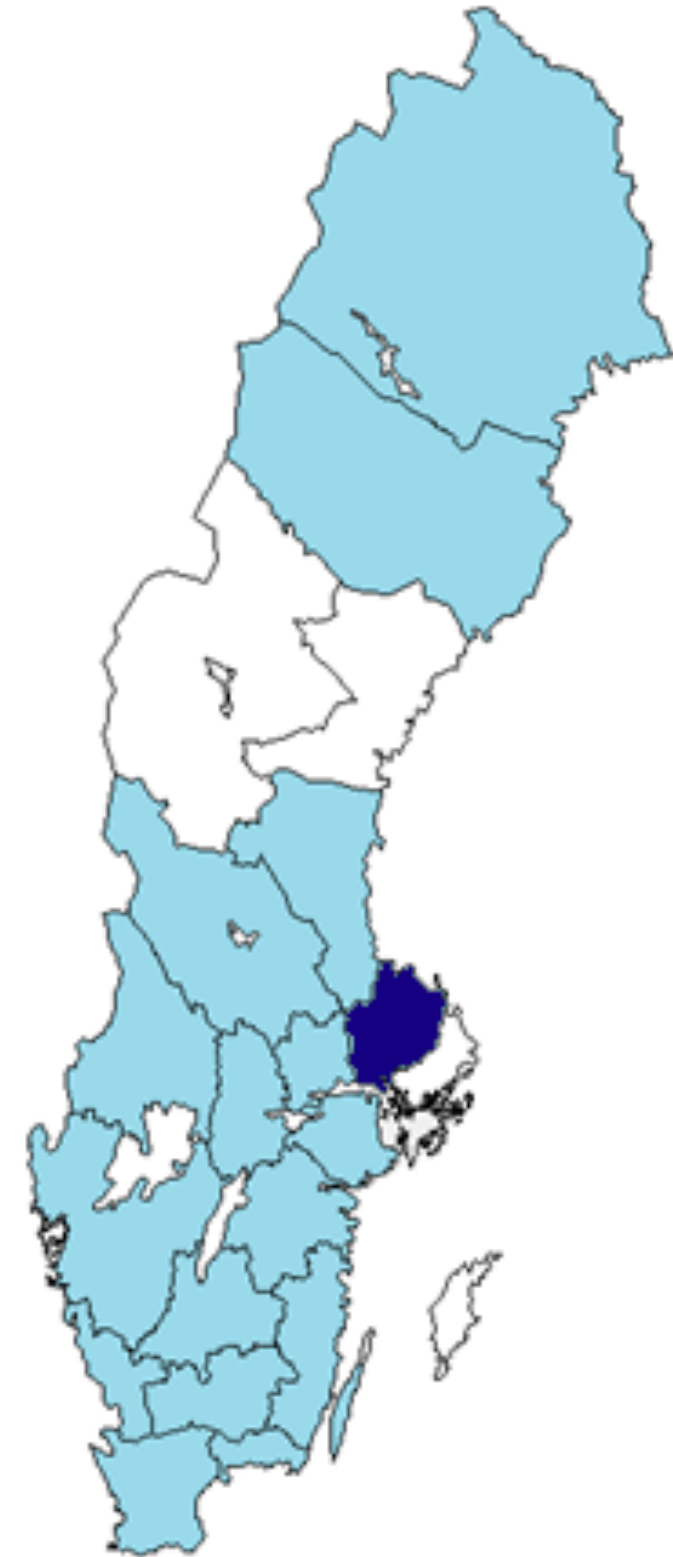
GMDS & DGEpi & IEA-EEF annual meeting,
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Journalen

- 2012: County Council of Uppsala gave patients access to their EHR

- appointment booking
- medical notes
- drug prescription
- lab results
- diagnoses
- referrals
- access log

- Secure login e-ID
- 16 counties included today, more will follow
- DOME: **D**eployment of **O**nline **M**edical Records and **E**-health service



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@c_gruenloh

@Hanife_Rexhepi

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Journalöversikt » Journalen

https://externlulservices.lul.se/JournalCategories/JournalOverview

Du är inloggad som

Sök

StartJournalPatientOmbud & loggarOm Journalen

ÖversiktAnteckningarDiagnoserLäkemedelProvsvärRemisserUppmärksamhetssignalerVaccinationer

Du ser information för ~~Journalen~~ ~~Journalen~~ ~~Journalen~~ Här kan du växla journal.

Journalöversikt

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

Idag

25 maj 2016

Du har inga händelser idag.

18 maj 2016

Besök

Nytt/Osignerat

Logopedmottagningen

Diagnos

Nytt/Osignerat

Logopedmottagningen

17 maj 2016

Diagnos

Nytt/Osignerat

Onkologmottagningen

16 maj 2016

Blod-, urin- eller annat vätskeprov

Nytt/Ovidimerat

Onkologmottagningen

4 maj 2016

Besök

Logopedmottagningen

Diagnos

Logopedmottagningen

28 apr 2016

Besök

Logopedmottagningen

Diagnos

Logopedmottagningen

21 apr 2016

Besök

Logopedmottagningen

Diagnos

Logopedmottagningen

Blod-, urin- eller annat vätskeprov

Svaret skickat till ~~Journalen~~ ~~Journalen~~ (Läkare) på Onkologmottagningen 2016-05-16

Nytt/Ovidimerat:

Detta provsvar är nyare än 14 dagar, vilket innebär att vårdpersonalen kanske inte hunnit kontakta dig om innehållet.

Om referensvärden i provsvar

Analys	Resultat	Referensintervall
P--ASAT	0,25 ukat/L	0,25-0,75
P--ALAT	0,15 ukat/L	0,15-1,10
P--Magnesium	0,70 mmol/L	0,70-0,95
Pt--eGFR (Krea)	110 mL/min/1,73	60-110
P--Kreatinin	105 umol/L	60-105
P--Bilirubin	1 umol/L	5-25

Electronic Health Record (EHR): Journalen

Motivation

"Nätjournal can be dangerous"

...all patient records are accessible to all doctors in the network. This could lead to a situation where a doctor in one hospital can see the records of a patient in another hospital without the patient's consent.

...the patient's records are accessible to all doctors in the network. This could lead to a situation where a doctor in one hospital can see the records of a patient in another hospital without the patient's consent.

Records online strengthens the power of the patients in care

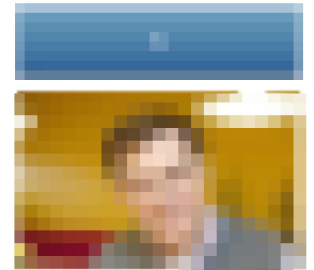
Healthcare. There is a significant increase in the power of the patient in the digital age. The patient is now able to access their own records and share them with their doctor. This is a significant change in the way healthcare is delivered.

Published February 10, 2014 06:00

Nätjournal can be Lexbaseskandal

Patients in the Lexbaseskandal have been told to stop using the network. The network is now being used to store patient records.

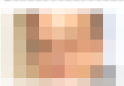
...the patient's records are accessible to all doctors in the network. This could lead to a situation where a doctor in one hospital can see the records of a patient in another hospital without the patient's consent.



Cite
2014; 111: CUHX
Läkartidningen 16-17 / 2014
Läkartidningen.se 2014-04-15

DEBATE

Stop nätjournalerna!



DAGENS
Medicin

DEBATE

"Nätjournaler is a democratic tool!"

...the patient's records are accessible to all doctors in the network. This could lead to a situation where a doctor in one hospital can see the records of a patient in another hospital without the patient's consent.

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Interview study



- 12 physicians
(onco, ortho, emergency, internal)
- 15+15 patients from oncology
- 6-12 months after the launch
- Ethical Approval
- Semi-structured interviews (45-60 min)
- Transcribed
- Thematic analysis



Results



reading before
physician

receiving bad news
(unprepared,
without physician
present)

suspected
diagnosis

medical
terms

Anxiety



Results



reading before
physician

receiving bad news
(unprepared,
without physician
present)

suspected
diagnosis

medical
terms

Anxiety

preferred bad news
through "Journalen"
instead of waiting

partial understanding
not seen as
problematic

direct access to test
results reduces
anxiety

want to have a
choice how to
receive news



Results



Anxiety

increased
phone calls

more questions
during visits

changing way
of writing

demand changes of
inaccuracies / errors

Workload



Results



Anxiety

increased
phone calls

more questions
during visits

changing way
of writing

demand changes of
inaccuracies / errors

Workload

no calls
due to lack of
understanding

ask at next visit,
friends, look online

no calls / requests to
demand corrections

don't want to be a
burden



Results



Anxiety

Workload

Usefulness

no usefulness due to
assumed lack of
understanding

no usefulness due to
assumed anxiety



Results



Anxiety

Workload

Usefulness

no usefulness due to
assumed lack of
understanding

no usefulness due to
assumed anxiety

prepare for the
next visit

enhanced shared
decision making

memory aid

increased understanding of
their health condition

information in
timely manner

increased sense of
control

Conclusion

- Physicians' expectations and patients' experiences were different --> perceived usefulness differed accordingly
- Physicians' expectations based on general assumptions about patients' capabilities and their lack of medical knowledge
- Patients had not experienced the negative aspects of online access anticipated by physicians
 - online access to medical records did not generate substantial anxiety, concerns or increased phone calls
 - Patients respectful of physicians' time
- Patients perceived access to their online medical records as central to their coping with their disease



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Limitations & Future Work

- Number of participants
- Actual experience of physicians
- Follow-up interview study with physicians & nurses
- National patient survey
implemented in *Journalen* (> 580.000 users)



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Questions?



Christiane Grünloh

PhD Student

KTH Royal Institute of Technology
School of Computer Science and Communication, Sweden

TH Köln University of Applied Sciences, Germany
christiane.gruenloh@th-koeln.de



Hanife Rexhepi

PhD Student

University of Skövde School of Humanities and Informatics, Sweden
hanife.rexhepi@his.se



Christiane Grünloh, Hanife Rexhepi

@c_gruenloh

@Hanife_Rexhepi

@DOMEprojekt

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