From NST to NSE +
Patients Online Access to their EPR

Monika A. Johansen
Head of department
From NST to NSE
About NST

We were:
• 100 -120 employees working with e-Health and telemedicine
• 44 researchers (27 PhD’s/ 8. Professors), 40 project managers and 10 developers
• Multidisciplinary background
• National advisory unit on telemedicine (and e-health) since 1999.
• WHO collaboration centre since 2002.
• Master of telemedicine/e-health at UiT since 2005
• 11 EU projects
• More than 100 national projects

Results 2013
• 89 scientific publications
• 8 public defences of dissertation
• Centre for research based innovation
From NST to NSE: Background

• On one side: NST had fulfilled its mission – knowledge on the use of telemedicine was nationwide. No need for NST.

• On the other side: NST had 44 researchers (of which 27 PhDs and 8 Professors), and e-competence developed over 20 years.

⇒ Use the competence in a national research and analysis centre for e-health.
  • Norwegian Centre for e-Health Research (NSE) was established 1. January 2016.
A knowledge institution for e-health

The Norwegian Ministry of Health and Care Services vision:

The Norwegian Centre for E-health Research shall provide and curate a complete overview on e-health, grounded on experience and knowledge, to be used in the fulfillment of the national goals.
NSE’s strategic areas

- The health record of the future
- Personal systems and connected care (Self-management, m-health ..)
- Health data availability and analysis (Secondary use of data)
- Patient pathways and models for integrated care
- Effects of national services
Budget

• 2016 total budget at 78,3 million NOK:
  • 35,9 MNOK from the Norwegian Ministry of Health and Care Services
  • 4 MNOK from the Northern Norway Regional Health Authority.
  • 38,4 MNOK from external research grants

• In 2016 the budget complies:
  • 52 man-years
  • 60 persons
  • mainly researchers
Patients Online Access to their EPR

Developing and Implementing Patients’ Full-scale Electronic Access to their Health Record
Tove SØRENSEN\textsuperscript{a}, Monika A. JOHANSEN\textsuperscript{a,b},
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\textsuperscript{b}Telemedicine and E-health Research Group, Arctic University of Norway
The paper report on the participatory design process leading to the full-scale service of digital access to the EHR for the inhabitants of Northern Norway
Tar makta over egen behandling

En av helsebransjes mest fascinerende utviklinger er at mange mennesker i dag selv blir ansvarlig for egen helse i en global og digital verd. Dette gjelder ikke bare i USA, men også i Norge. Dette bildet viser en eldre dame på en laptop, tolken av en påvirkning av teknologi.

**Jeg har vært heldig som har fått være testpatient.**

**ZE-0421**

En artikkel har blitt avløst av maleriet. Denne texten er utgitt som ei av månedens buffetstoler, og den er også publicert av DIPS ASA. Nr. 2-2015.

Avslutt fullskjerm
Patients Online
Access to their EPR

In Norway:

- EHR is fully established
- The patient - both the object and the owner of the health record.
- The patient - acknowledged as a legitimate and important partner in their own health care process.
- Since 2001, patients has had the right by law to access their health record [1].
- In 2013 a White Paper stated that patients should have digital access [2].
- In 2011, a national health portal, Helsenorge.no, was established to accommodate digital patient services
The patient portal Helsenorge.no: Make use of an unique identification and authentication method via a national ID portal, providing secure access to health information.
Dokumentoversikt

På denne siden får du innsyn i pasientjournal ved sykehusene i vårt helseregion. Mer om innsyn i pasientjournal.


Selv om det er dokumenter du ikke ser på?

Selv om du ikke finner seg i pasientjournalen nå?

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## The Journal Documents

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How much information is provided?

Norway’s Northern Health Region: *As much as possible - as soon as possible*

All documents in the hospital EPR available in digital format, inc. psychiatry, as soon as they are approved (signed), to patients from 16 years (children under 12), except:

- Documents not compatible with EPJ/PAS and documents in a format not supported, e.g. test-results, X-rays
- Health professionals can exempt transparency, according to the Norwegian Patient Right Act, § 5.1 by indicating this in the EHR-system.
How much information is provided?

The Western Health Region: Nearly the same as in the Northern Norway Health Region, but they do not provide:
  • Access logs
  • Five psychiatry departments are not included
  • Three days delay on referrals for children and youths in psychiatry

The South-Eastern Health Region:
  • First region that started this service
  • Only available for some hospitals (OUS og Sykehuset Østfold),
  • Only provide some specific documents
  • Aim to provide more journal records in near future.

The Central Norway Health Region:
  • Buying new EPR system for both primary and specialist health care
Studies we have conducted – and methods:

1. **Patients’ requirements**: Surveys (2011-12): Who ask for access to the patient journal, and what do they plan to use it for?

2. **Patients’ attitude and experiences regarding use of the Internet for health purposes**: Survey 2013 - more than 1000 respondents

3. **Experiences from piloting and using the services**: User tests, interviews and surveys (2014-2015) - more than 300 respondents
1. Results: Patients’ requirements

- 76% would like to receive their journal in electronic format
- 87% planned to share it with others
- Most patients requested their journal as they would like to learn more about their diagnosis and treatment.
- Patients would like to check who had accessed their journal
2. Results: Patients’ attitude and experiences regarding use of the Internet for health purposes -> e-health in Norway 2013

- A total of 78% had used the Internet for one or more health related areas.
- 44% of the population wish to communicate with their doctor via the Internet, e-mail or sms.
- Important facilities when choosing a GP:
  - online scheduling of appointments (55%)
  - e-prescription (53%),
  - e-mail communication (36%)
  - digital access to EHR (30%)
3. Results: Experiences from piloting and using the services
About the service in general

Q: In general, we found that the service functioned as expected.

99% will use the service again, in the future

87% will recommend it to others
Understanding the content (1/2)

Q: I understood most of what I read.

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n=245

91% understood most content of their EHR
Q: I found it hard to understand all medical terminology.

Half of the patients found it hard to understand all medical terminology (51%) while as many as 23% had no trouble at all.
Summary & conclusion

• No question about the rationale of the service: Patients want online access. Patients have the right to access. The issue is how; technically, organisational and political

• Step-by-step approach; dialogue and striving for consensus, acknowledging that the system is – and will be - changing along with the users’ feedback

• Timing: A secure patient portal, political will and patient empowerment to a new level
Workshop: Patients’ digital access to their health record: A service for all?

- 14 November
- **Who** should have access?
- **What** type of journal documents should be provided?
THANK YOU FOR YOUR ATTENTION

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