Cancer Patients Accessing their Online Medical Records

Hanife Rexhepi
Informatics Research Centre, University of Skövde, Sweden
”Nätjournal kan vara farlig”

Landstinget i Uppsala är först i Europa med att lägga ut alla patier. Men både läkare och myndigheter varnar för att patientsäkerheten provsvar görs tillgängliga.

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Det finns ett starkt politiskt tryck att utveckla it-användningen i sjukvården. Dels för att effektivisera vården, dels för att stärka patienternas ställning.

– Många av it-lösningarna borde ha varit på plats för 20–30 år sedan. Och det är klart att patienterna ska ha sina journaler tillgängliga på nätet. Det viktiga är att tekniskt lösa sekretessfrågorna så att inte arbetsgivare eller försäkringsbolag kan ta del av innehållet, säger Johan...

Nätjournal kan bli Lexbaseskandal

Politikerna i Landstinget Västmanland beslöt i höstast att låta alla patienter i länet få journaler på nätet via personlig inloggning.

Ett första försök startades i Uppsala län för drygt ett år sedan utan diskussion med läkar- och sjukköterskefacken.

Reumatikerförbundet:
Vi patienter vill ha nätjournaler

Anne Carlsson
ordförande, Reumatikerförbundet

Journaler på nätet stärker patienternas makt i vården


Stoppa nätjournalerna!

Björn Andersson
universitetssjukhusöverläkare, docent, medicinkliniken, Sahlgrenska universitetssjukhuset/Sahlgrenska, Göteborg
bjorn.andersson@vgregion.se
• Deployment of Online Medical records and E-health services (DOME)
• Interview study with cancer patients
• Questions
Deployment of Online Medical records and E-health services (DOME)

Goal
To build and disseminate knowledge about the implementation and use of medical records online and other eHealth services and is based on studies of e-health projects

Idea autumn 2011
Start june 2012

Uppsala university
University of Skövde
Lunds university

Action research
SUSTAINS
National implementation

Vinnova, Sweden’s innovation Agency, Uppsala Universitet and 30 co-financiers
A Multidisciplinary Research Project

Senior researchers from different areas:
- Information Management
- Human Computer Interaction
- IT and work environment
- Management studies
- Business studies
- Healthcare Informatics

Qualitative and Quantitative:
- Information technology
- Medicine
- Information Security
- Organization theory
- Engineering Education
- Medical informatics
Research in three different areas

A. Patients and Relatives

B. Professionals and Management

C. Development and Deployment
Studies in WPA - Patients and Relatives

1. Survey - patients requesting their paper-based Medical Records
2. Survey - patients who have experience of accessing their Online Medical Records - pilot project
3. Interview study - patients from department of Oncology
4. Interview and observation study of patients understanding when reading their Online Medical Records
5. Follow-up survey to patients who read their paper-based Medical Records
6. Survey and interview study with patients accessing their Online Medical Records
Studies in WPA - Patients and Relatives

Autumn of 2012, County Council of Uppsala (LUL) gave all patients over 18 years of age access to their EMR:
- appointment bookings
- medical notes
- drug prescriptions
- medical lab results
- diagnoses
- referrals
- access log

Resistance and fear

Seriously ill patients access

Women’s Protection Unit
Psychiatry
Interview study

• 15 + 15 patients
• Ethical vetting/ assessment of the research
• Voluntary participation
• Cooperation with the department of oncology - information sheet
• Semi-structured interviews (45-60 min)
• Transcribed
• Thematic analysis

Please note: All images are from “clip art” and have nothing to do with the study
Cancer Patients Accessing their Online Medical Records
Why cancer patients are reading their medical record online?

- Curious
- Increased understanding
- Control (well being)
- Access test results - Reduce anxiety
- Have I understood the information correct
- Suspects inaccuracies
The importance of accessing Online Medical Records

Preparation ➔ improved communication & increased participation

"Memory support"

Reduced waiting times – Access to information when and where it is needed

Safety
The importance of accessing Online Medical Records

Can create a feeling of safety

“Accessing test results, it is a tremendous difference, it really means a lot to me. To get the information at once so you do not have to wait. It's so difficult to wait, whether it is bad or good news, it's very good to know”
What is your opinion on accessing information that may be worrying?

14 of 15 patients want to access all type of information, including worrying information.
“If we can manage to have all these cancer diseases and to live with it, then we can handle reading about it”
Access to worrying information

“I'd rather sit and cry at home and fix myself in the head so I can get back on track, rather than sitting in front of a doctor, choked without the ability to ask questions”
The majority experience improved relationship:

- The opportunity to prepare for the meeting →
- improved communication and increased feeling of safety and empowerment
All patients perceive that they understand the contents in the EMR even if they do not understand specific medical words.

The majority of patients have not been upset by reading the EMR.

Six of fifteen patients have found inaccuracies in the EMR.

- No one has made a request for an correction – do not want to bother
- Sees it as an opportunity to correct errors
Cancer Patients Accessing their Online Medical Records - Overview

- All patients want to read unsigned medical notes
- They are positive about the possibility of sharing information with relatives
  - only one patient has shared the information
- The patients trust that the service maintains a high level of security
In conclusion….

- Patients are positive to Online Medical Records
- Allowing full access to medical records increased satisfaction without much effect on anxiety
- Providing access to medical records seems to reduces emotional distress and enhance ability to:
  - understand the own medical condition and
  - to follow the own care process
Cancer Patients who have not read their Online Medical Records
A majority of the patients want to take part of information, even if it is worrying/disturbing

“I want to know and understand everything”

“The news are disturbing no matter how you get them”
Questions?

Hanife Rexhepi
PhD student in healthcare informatics
Informatics Research Centre,
University of Skövde, Sweden
Hanife.Rexhepi@his.se