

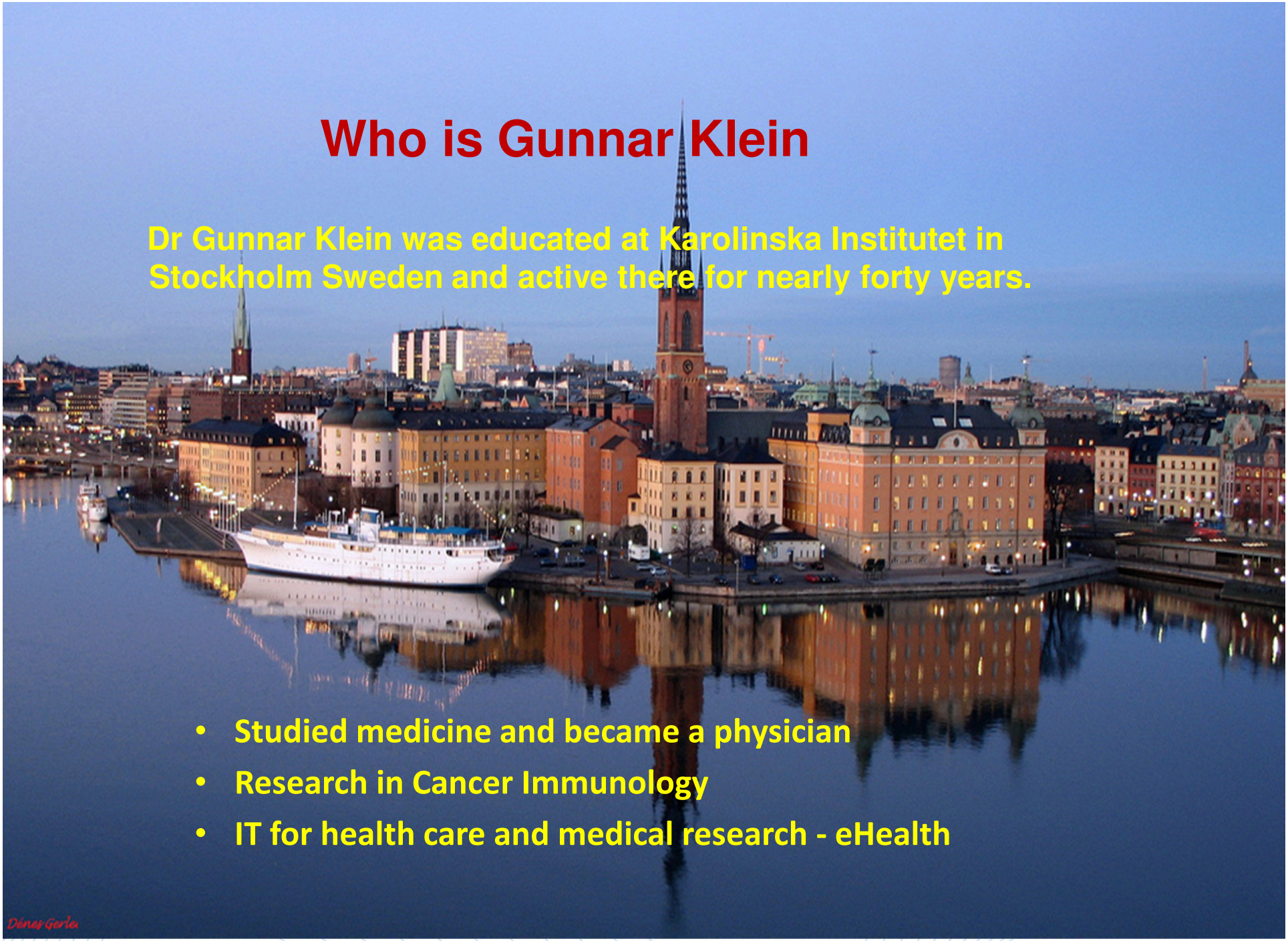
Primary Care Physician
Meeting the Cyberpatient

Gunnar O Klein, M.D. Ph.D.

Professor of Informatics/eHealth in Örebro, Sweden

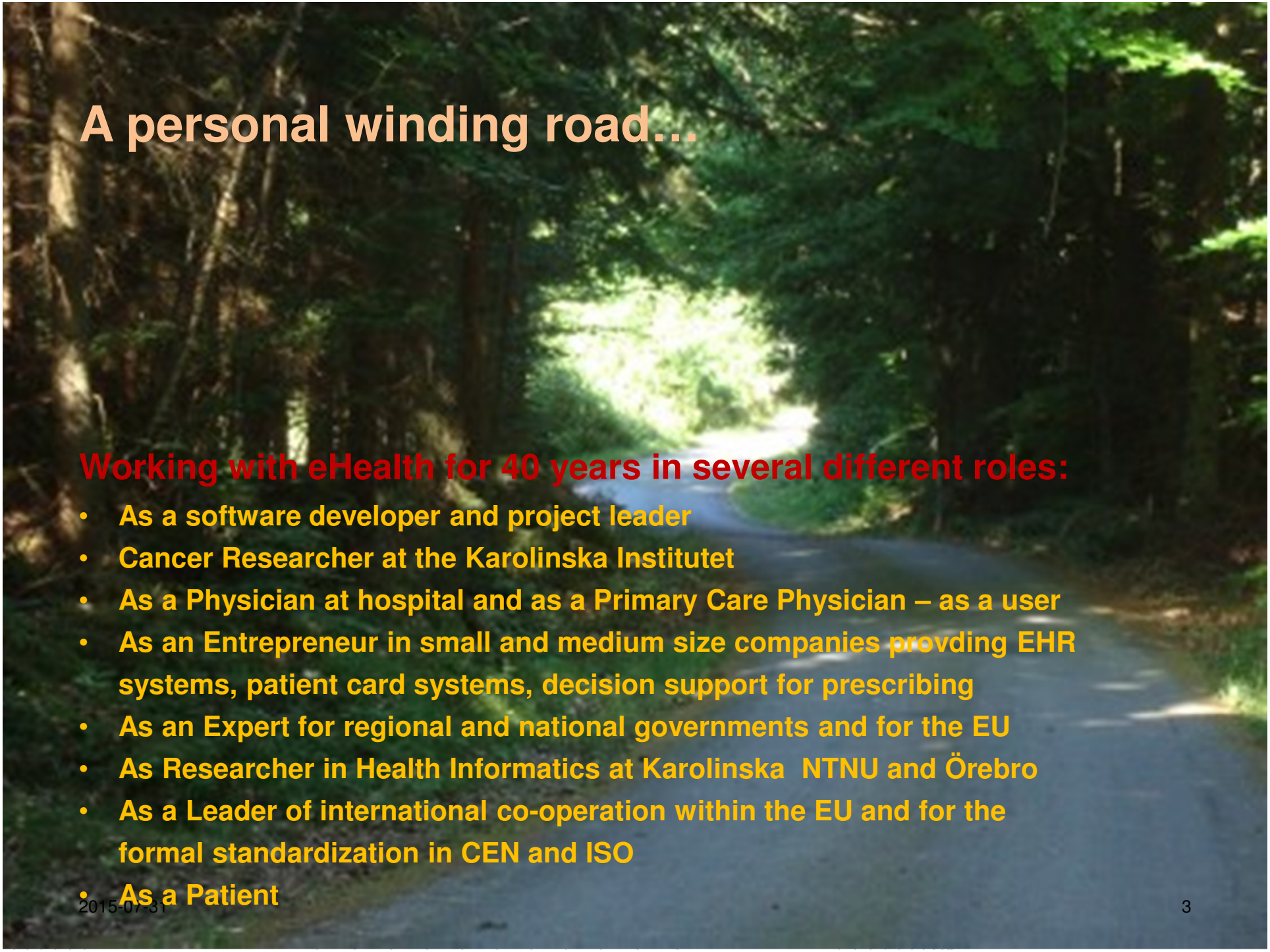
Keynote Lecture in Valencia 2015-07-28

Who is Gunnar Klein



Dr Gunnar Klein was educated at Karolinska Institutet in Stockholm Sweden and active there for nearly forty years.

- Studied medicine and became a physician
- Research in Cancer Immunology
- IT for health care and medical research - eHealth



A personal winding road…

Working with eHealth for 40 years in several different roles:

- As a software developer and project leader
- Cancer Researcher at the Karolinska Institutet
- As a Physician at hospital and as a Primary Care Physician – as a user
- As an Entrepreneur in small and medium size companies provding EHR systems, patient card systems, decision support for prescribing
- As an Expert for regional and national governments and for the EU
- As Researcher in Health Informatics at Karolinska NTNU and Örebro
- As a Leader of international co-operation within the EU and for the formal standardization in CEN and ISO
- As a Patient

Content

- The new patient-physician role play when the world of knowledge is available a click away for both parties.
- New ways of interaction between patients/citizens and the health care providers with a special focus on patient reporting of outcome measures
- The support of patients with chronic diseases like AIDS in lesser resourced countries using mHealth techniques with a special view at Mozambique
- Different technical and organizational approaches to communicate between patients and physicians
- The effects of patients having access to their health records online.

A Communicating Health System - a vision for eHealth

- All patient information is made available for continous care wherever the patient meets care
- Knowledge based systems are interacting with patient data
- Effective co-operation between professionals
- Active patients are a part
- eLearning for professionals and citizens
- All patient cases can be used to generate new knowledge

Changing the role of the doctor from:

The one who knows to

a wise guide to knowledge

- All the medical knowledge of the world is just a click away for the capable patients (and their next of kin)


I'VE ALREADY GOT A DIAGNOSIS FROM HOMEDOC.COM...BUT I THOUGHT I'D SEE YOU FOR A SECOND OPINION!
FRAN
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An example from my practice ...

Liza had

- anisokori (different size pupils)
- pupillotomi (did not react to light)
- photofobia
- absence of reflexes in arms and legs
- headache
- fainting
- exanthema in half of the body (only left)
- numbness

After two months with specialists at the university hospital

- No diagnose, no improvement
- The patient uses Google with a few of the symtoms and finds a patient association in Australia for

Adies syndrome

I knew nothing about this

- Not in the disease classification ICD-10
- Not on the internet pages usually used
- However, the scientific database Pubmed from NLM showed a few scientific articles about this
- Sex weeks after. The Neurologist at the University Hospital (who got the articles from me) agrees.

Some lessons

- While many of the patients have common problems we know about and for which there are national and local guidelines quite a few have rare diseases
- Medical science is international – only 1 % is Norwegian. Doctor's need to search knowledege internationally
- Many patients do that already


McHUMOR by T. McCracken
"Off hand, I'd say you're suffering from an arrow through your head, but just to play it safe, I'm ordering a bunch of tests."

New ways of interaction between patients/citizens and the health care providers

mHealth – a buzzword with many meanings

- There exists a large number (>125 000) apps, commercial and some altruístic for patients to download
  - Mainly to deal with their health problems (alone)
- There are also good apps for the doctor
- Apps can also be used for steering and co-ordination of professional health work. Not the least in lesser resourced countries – e.g. Reporting of provided services for AIDS and TB programs in Africa
- **Let's focus on patients interacting with professional care using ther mobile**

Why?

- Because the patients likes it – Sure !
- Because it strengthens the patients

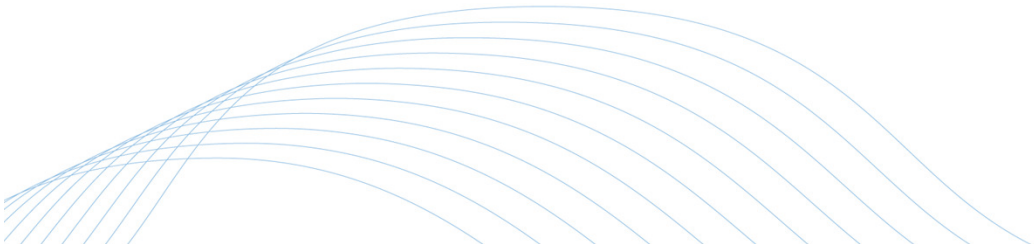
  «Patient Empowerment»

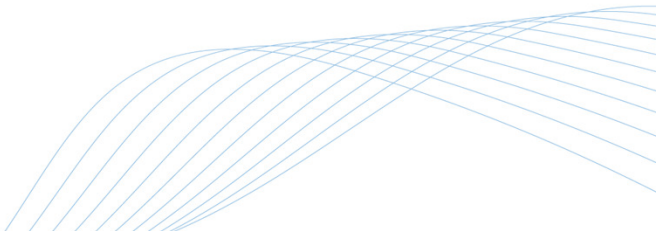
- But there is a lot more ...

Why are mobiles used today in the interaction between patients and care?

- Guide to finding the right care and make appointments
- Get reminders
- Ordering new prescriptions
- Reading «their» case notes from the doctor’s record

Towards a new kind of dialogue that touches upon the core of medicine





In traditional care

- **Before the visit we know nothing about the current state and needs of the patient**
- We ask them when they come
- We measure things, eg blood preassure
- We come up with a diagnosis and a treatment plan, perhaps a prognosis – It will probably be better soon (especially if you take this medication)

- **Then we forget the patient**
  (at least until next time)
  - The patient may come back and tell us what happened – maybe very badly ...

The new partnership



«It takes two to tango»
British Medical Journal 1999

- **The one that is carrying the shoe knows best where it hurts**
- Let us start to ask patients how they are really feeeling – when they are experiencing it – before and after visists to the doctor

- **Stop guessing!**

- Why not recieving good information in a structured way from the world's greatest expert on my health – myself?

Patient reporting - some applications

a) Investigation of changing symptoms to clarify type of problem, frequency and degree over time
It can be an aid for diagnosis but more often to assess different types of therapy

b) To document the progress. There are many diseases witha great potential for improvement without therapy (which possibly only adds risks)
This can give doctor and patient a sense of security. «It actually goes well».
But also when things do not go well. An intervention may be needed, new investigations (lab, imaging etc) or therapy

c) Data from the patient may automatically trigger a health professional with the right decision support systems

Patient reporting – more applications

d) To try out an individualised therapy. Choice of drug, dosage etc.
   After each change a series of measurements are made with patient reported data that is jointly evaluated by doctor and patient

e) To try out effective treatments on groups
   Focus is on statistics and not on individual – Clinical Research.
   «Patient Reported Outcome Measures - PROM»

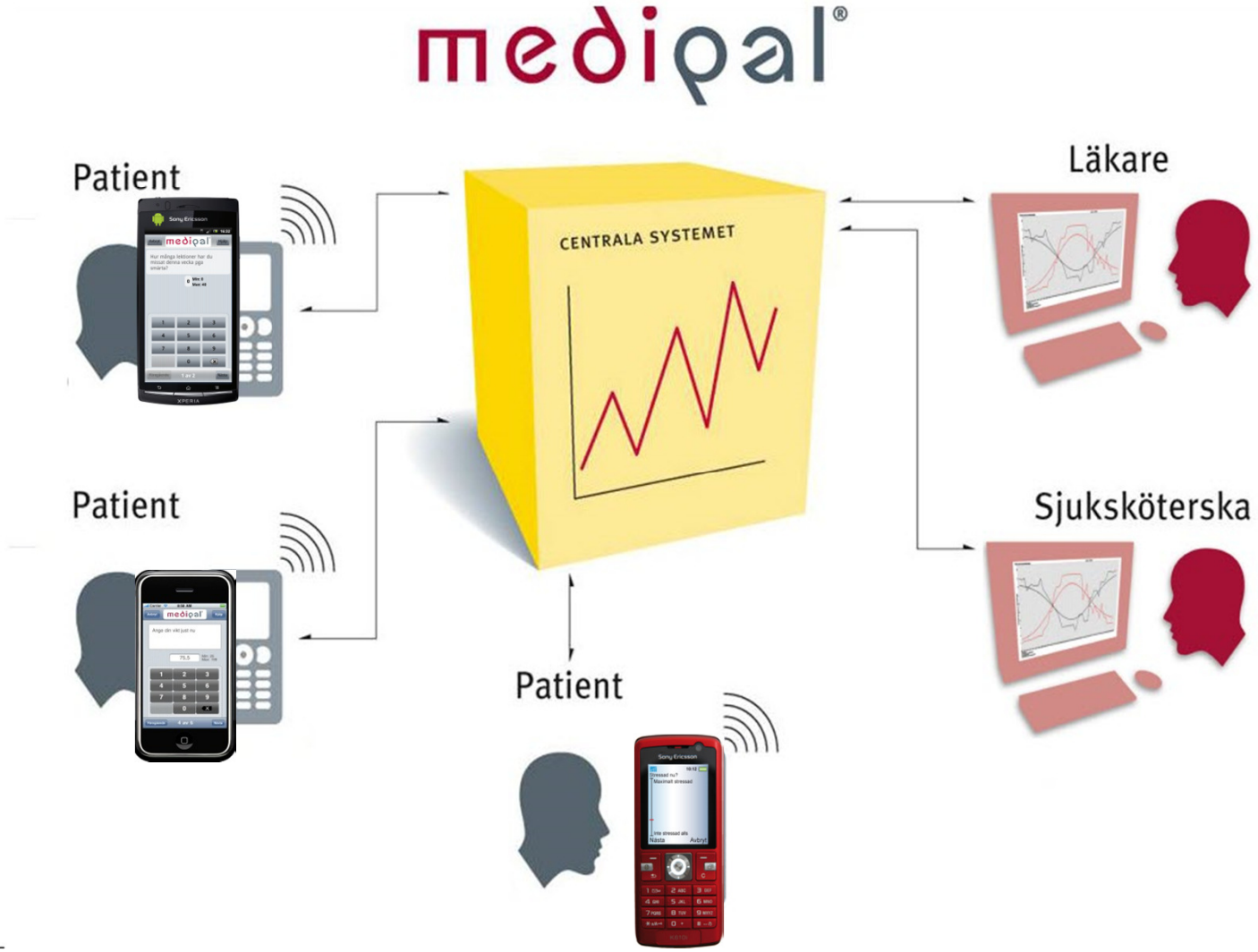
f) Quality Management
   The purpose may be to compare different units, differerent staff, therapies etc. Please observe that patient experience (satisfaction) can also be in focus.

Some chronic diseases where patient reporting over internet has been demonstrated

- **Asthma and COPD**
- **Diabetes**
- **Rheumatoid arthritis**
- **Parkinson**
- **Migraine**
- **Pain**
- **Obesity**
- **Inflammatory bowel diseases**

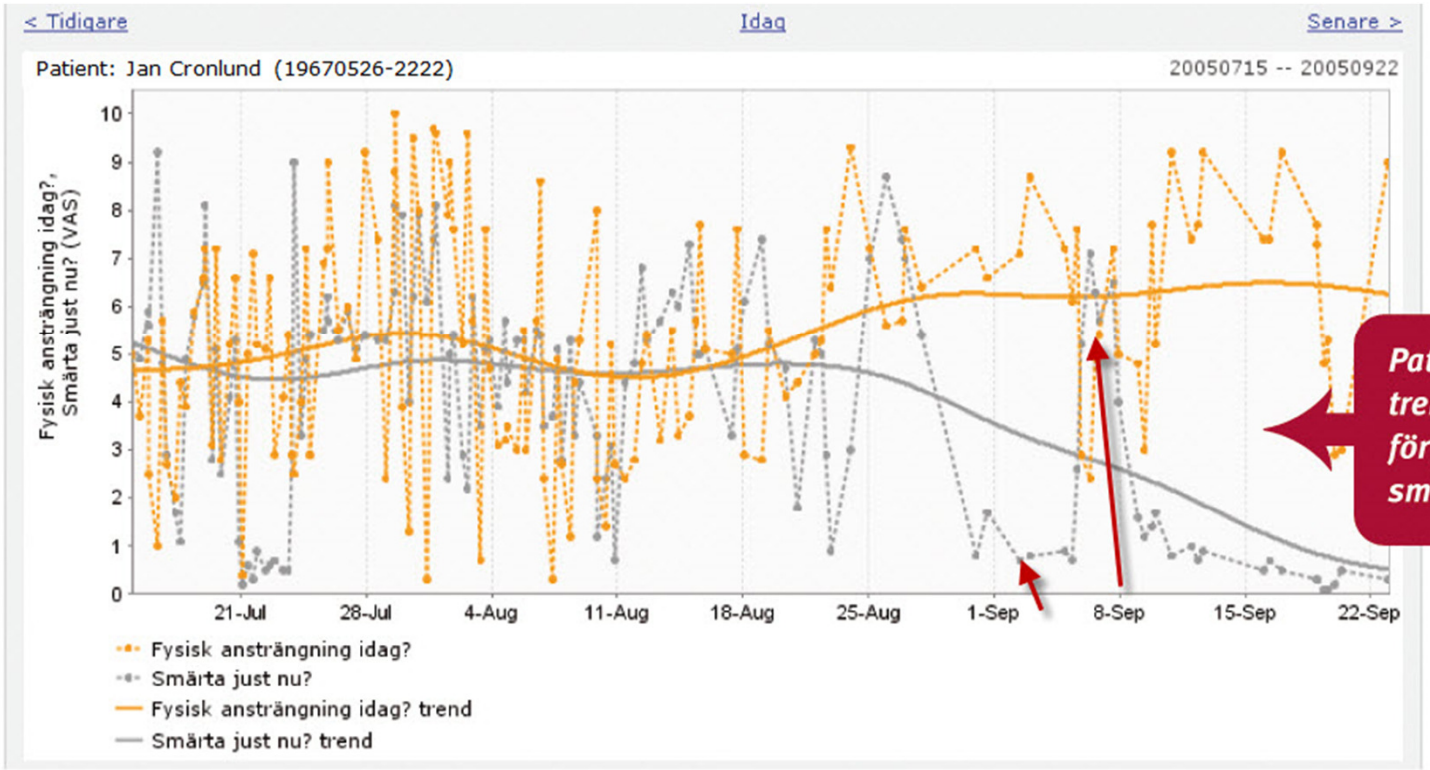
For some of this closed solutions have been developed with a pharmaceutical company

A Swedish company has a general system for patient reporting



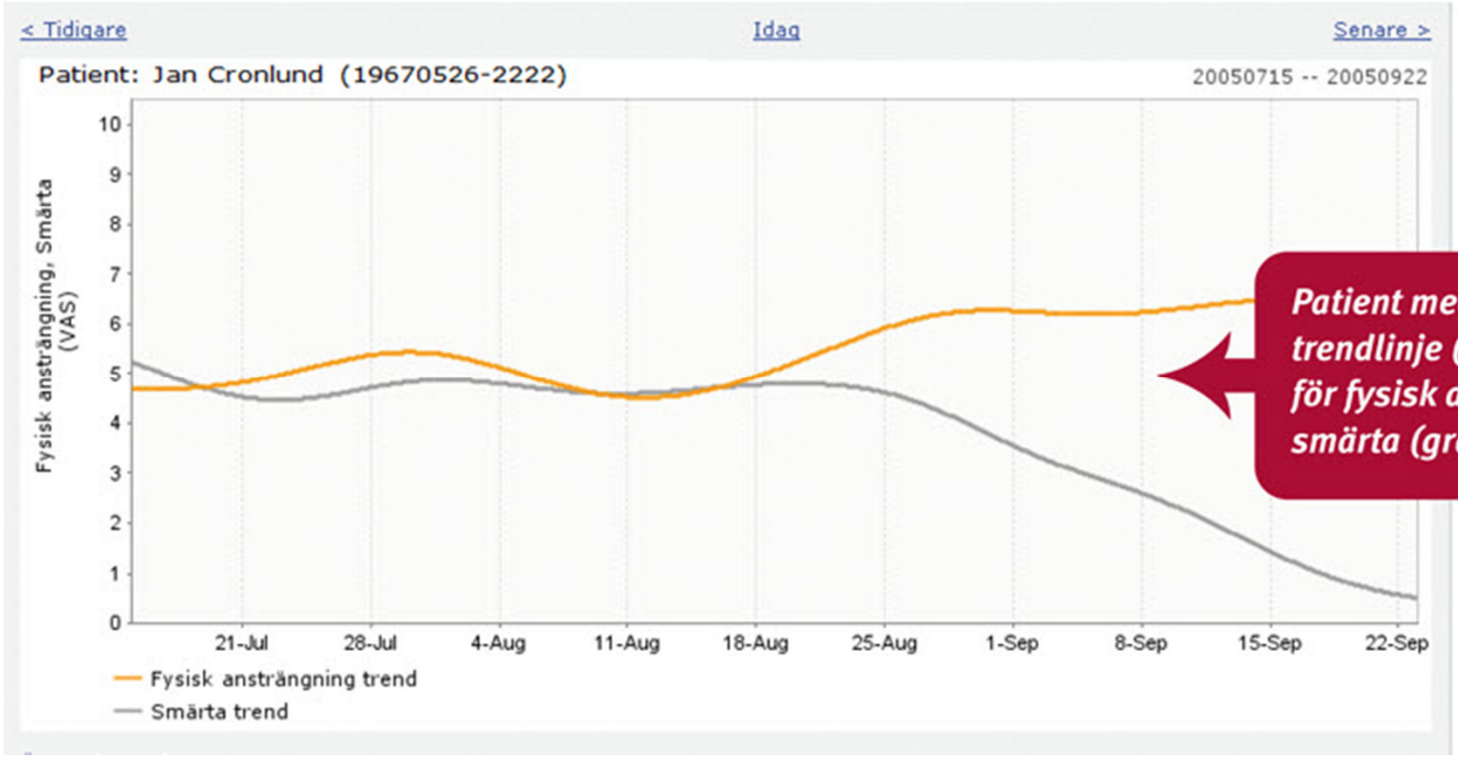
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Example: Patient with neuropathic pain. Dose adjustment



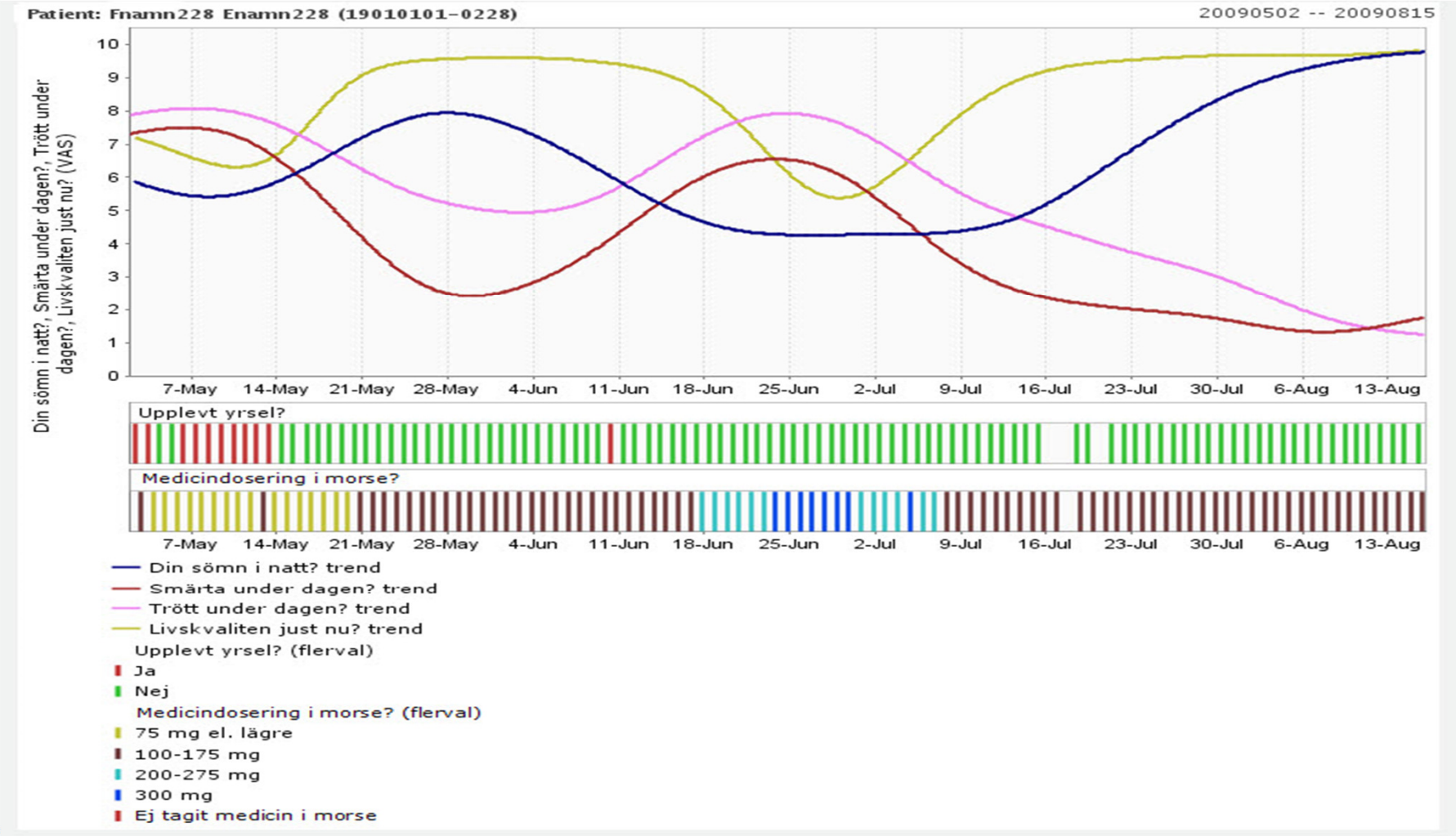
Patient med neuropatisk smärta; trendlinje (rullande medelvärde) för fysisk aktivitet (gul) respektive smärta (grå) under doshöjning.

Trendlines visualises effects

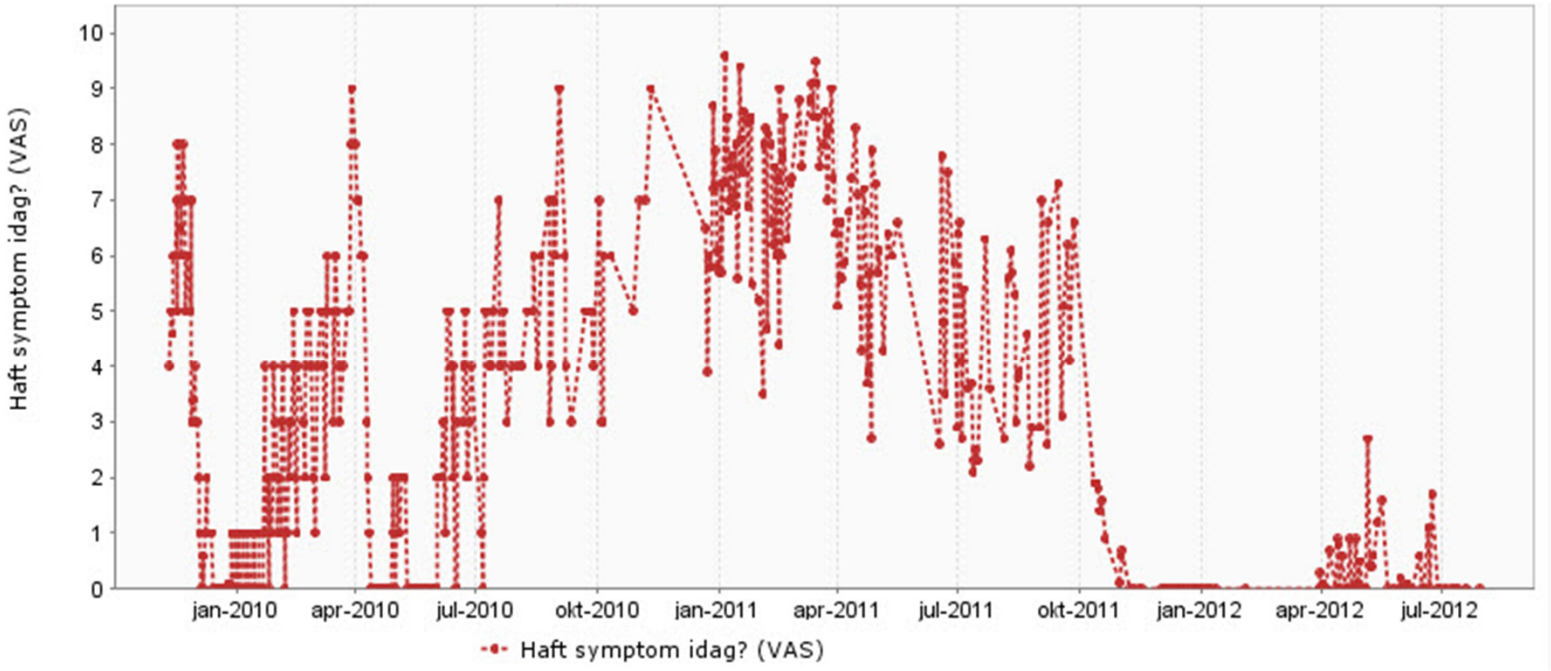


Patient med neuropatisk smärta; trendlinje (rullande medelvärde) för fysisk aktivitet (gul) respektive smärta (grå) efter doshöjning.

Patient with chronic pain – Registration of drug use, dizziness, pain, sleep, quality of life, fatigue

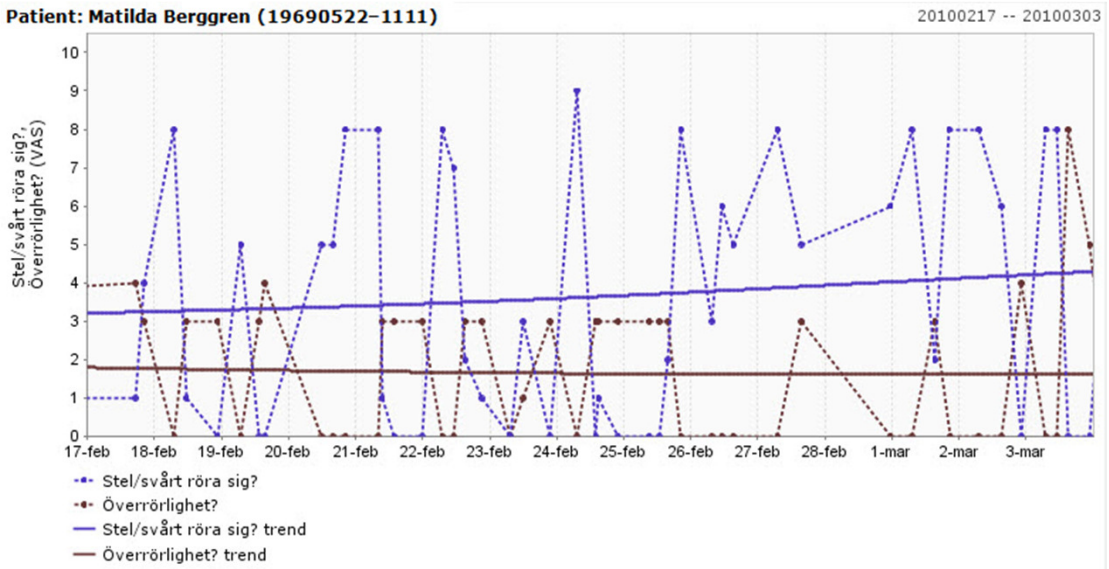


Patient with narkolepsis and kataplexia

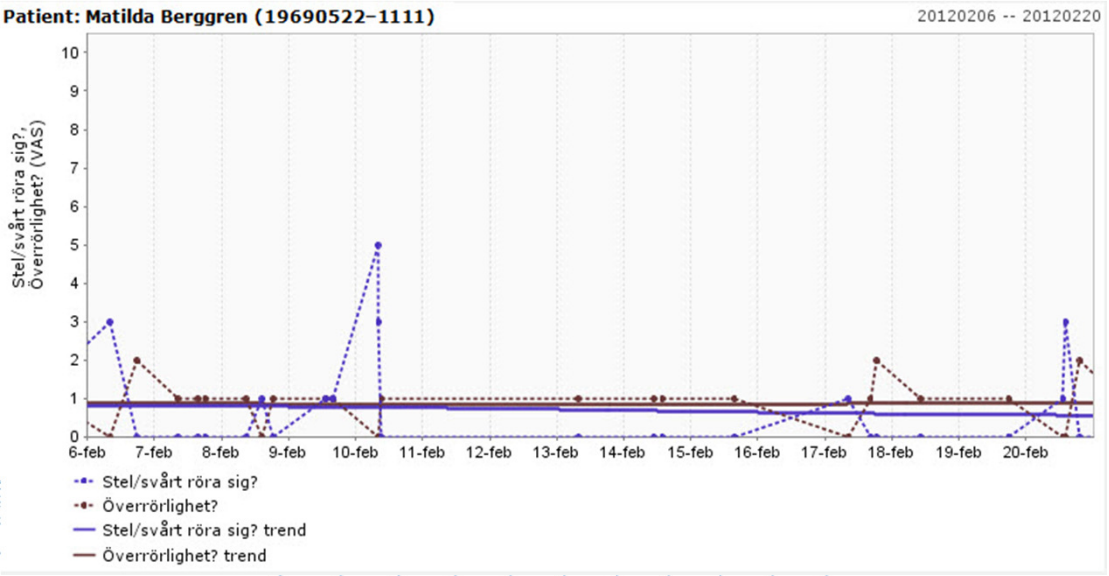


"*This information was crucial to find the right treatment says the neurologist Dr* Christian Carlström, Stockholm

Evaluation of motility with a Parkinson patient



without Duodopa



with Duodopa

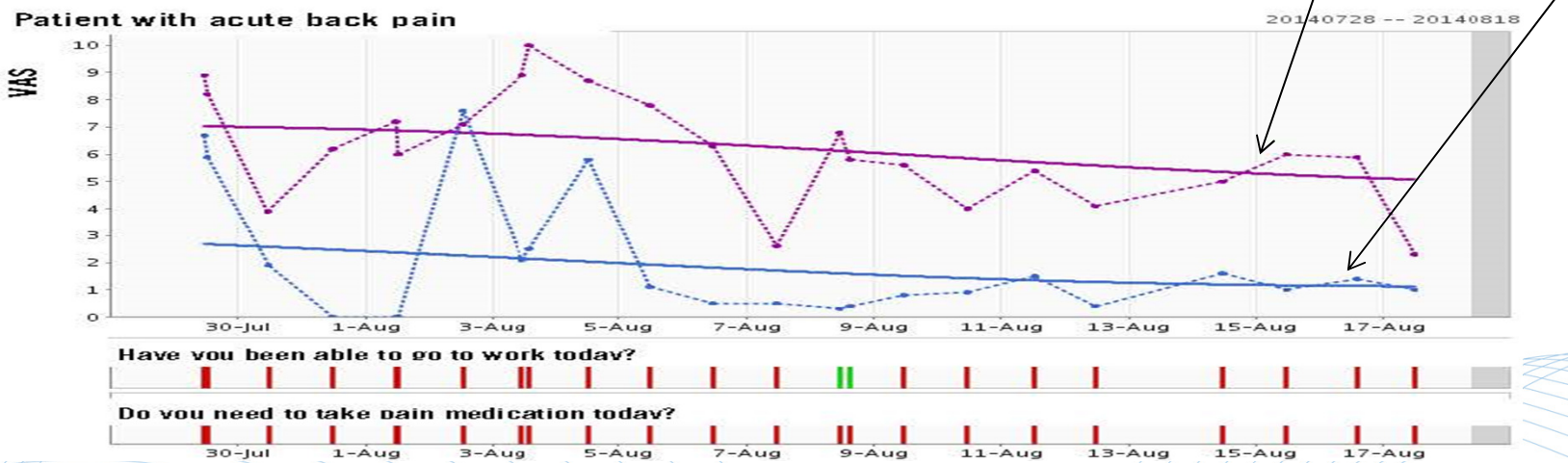
Patient reporting in primary care

In a pilot project I developed three questionaires for patients with:

- Acute back pain
- Knee injury
- Foot injury



Pain walking and at rest



In Mozambique to fight AIDS and TB

The SMSaúde system was designed as a web based application with integration to the local EHR system with the purpose of improving the care for HIV and Tuberculosis infected patients using GSM Short Message Services to send motivation and education messages including reminders to patients about the importance of taking their medication and to come to regular check-ups at the health centre.





There are so many possibilities

- In different clinical specialties with appropriate questions for the problem at hand
- Pain and recovery after surgery and anesthesia Ongoing studies
- But also in primary care for common problems like pain in the musculoskeletal system or acute infections – not the least with small children (with patients reporting)
- We shall not forget psychiatric diseases where simple questionaires and bilateral communication tools have a great possibility besides more advanced internet psychiatry

Some challenges

- Studies of patient doctor interaction
- Design processes with usability evaluations
- What are the optimal visual interfaces?
- Ethics and information security
- How do you integrate the patient moile in regional and national infrastructures for eHealth?
- When does this “medicine” work best?

Different technical and organizational approaches to communicate between patients and physicians

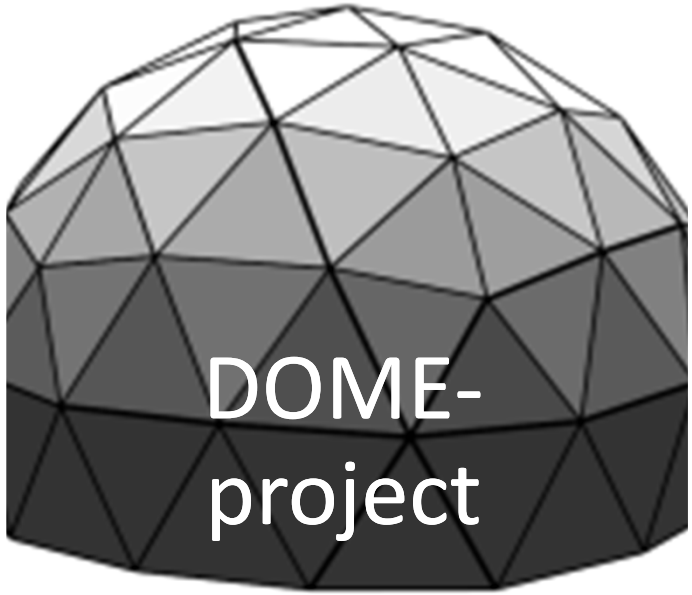
- Dependent on general organization of health care
- Telephone services culture
- Personal two-way email
- Institution based web portals
  - National and regional initiatives
- Patient controlled web based repositiories
- Patient carried devices with record copies
- Patient apps

The new patients read their records

Blessing or Hell

A heated debate

Deployment of Online Medical records and E-health services (DOME)



Uppsala university

University of Skövde

Lund university

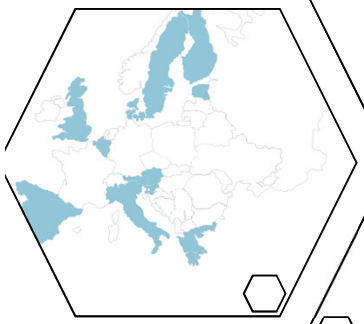
Örebro university



Aim: To build and disseminate knowledge about the implementation and use of health records online and other eHealth services.

THE COUNTY PILOT: UPPSALA

SUSTAINS: Support USers To Access INformation and Services

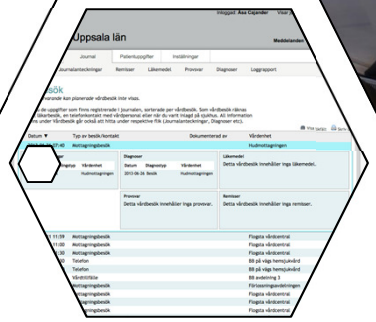


EU project coordinated by Uppsala county Council (2012-2014)

European Commission

16 parts in 11 countries in Europe

Nov. 2012 launch of online system SUSTAINS



Today > 80 000 users in Uppsala

Deployment of different public eHealth services for the citizen



sustains

Research in three different areas



A. Patients and Relatives



B. Professionals and Management



C. Development and Deployment

Effects from Primary Care Pilot 1997-2012

Solo family practice, 2250 listed patients, EHR since 1995.
Patient portal 2002-2011 → 492 patients had online access

From care professionals' point of views (2011)

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

The importance of accessing Online Medical Records



improved communication & increased participation → Preparation

”Memory support”

Reduced waiting times –

Access to information when and where it is needed

Can create a feeling of safety

Cancer Patients Accessing their Online Medical Records - Overview

- All patients perceive that they understand the contents in the EHR 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

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"


The road to better health goes through research in health informatics – and innovative uses of technology also in primary care
A bridge to the future
It starts now!