

*VA short Welcome!*

Clinical Databases and Digital  
Health Technology to Build a  
Learning Health System  
and Patient Centered Care



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- Clinical Databases **Subject**
  - Patients data in a data bank
- Digital Health Technology
  - Software to collect analyse and send the data
  - Visual displays for easy understanding
  - Devices – body monitors and mobile
- ...to Build a Learning Health System
  - learn about patients – what causes ill health, what improved services, research
- and Patient Centered Care
  - Using the patient data in consultations

# Subject

- Patient register
  - data bank storing your clinical data and others
- Uses
- Issues
- Questions to you about your registers and systems
- If time: learning health system

Questions: 1 = Yes; 2 = No; 3 = Other

- I have entered-in data about my health on a web site
- I know who has access to this data
- The web site told me who has access
- The web site asked my permission to give my data to specified other
- I know who has access to data my physician records about me
- This is different for veterans (Kaiser?)

# John's CVS 'flue jab

- *Cannot show scan of agreement*
- We are covered by strict HIPAA regulations about who has access.
- Those with access can do what they like with your data – we have no control over them

# Issues

- Control and privacy one issue in using patient registries
  - Changing attitudes and laws
    - 2011 google health, 2012 facebook, 2013 NSA
- Affects our research
- May slow or speed developments in health care

# Agenda

- Patient registries
  - explanation in English
- Examples of uses
  - Enabled services, real time low cost research, service improvement
- Future creation and use of patient registries

# The problem – digital reflects real

world fragmentation in care

- Each physician own business with own EMR

–most do not connect with others (2014)

- Can't see others treatments and assessment

= We have to repeat our story, optimal care less likely

## Problem 1: Unconnected

# Problems – underuse of patient clinical data

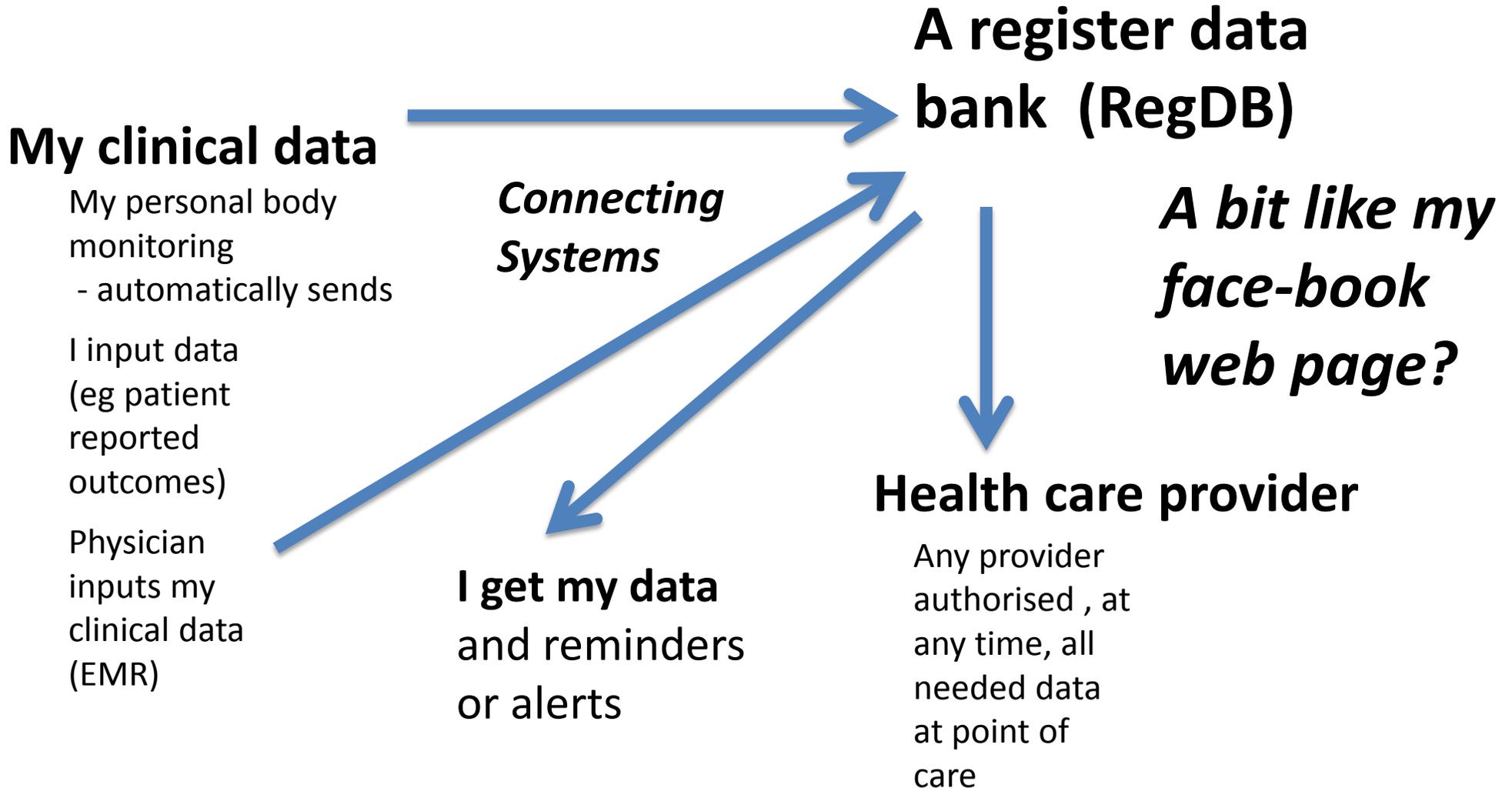
- EMR under-developed for intelligent support
  - reminders and alerts, effective treatments for patients like me, best practice guidance
  - Systems not scanning EMRs for best practice and risks
- Body monitors and our assessments not contributing data to care or research

# NEXT - Basic idea

– for 12 year olds

# Understanding clinical data flows and storage

T



# Patient Registers - Types

- All patients with one disease or treatment (“Focused register”)
  - In nation, region, health system, one physicians patients
- All patients, all clinical data (comprehensive patient register)

# Explanation

- EMR “feeds” register, & receives register services
- Physician / patient access register in consultation  
= “Smart registers” give alternative to EMR
  - Give “service add ons”
- “smart register services” deliver patient data or analyses over time – shows time trends
  - Physician or patient can request real time analysis
- <http://www.srq.n.nu/>, research

# Example of real time analysis (“smart register” services)

Chart shows user can ask eg show a) cost of medications, b) patient reported outcomes.

Physician or patient can request real time analysis

- <http://www.srq.n.nu/>, research

# Example 1: Swedish Hip Registry

- 35 yrs old

Data:

- Patient demographics
- Procedure/treatment
- Clinical outcomes
- PROs

(cannot show web site or examples)

# How the register improved outcomes

- Reduced reoperation rate 10times
- Converge on 6 miin protheses
- Two standard operations
- Happened voluntarily

just by yearly reports

and presentation at annual conference

Allowed considerable other research

Future – relate to patient genome profiles

US \$24 bln costs for replacement/repair  
Could avoid \$2 bln

Other registers – Treatments, and disease based

- Eg Diabetes Register 95% all departments of medicine 75% of all PHCs

# The other swedish registries

BCG estimate 10yr 1: 10 ROI

Sweden increased funding 5 fold

- Biggest improvements from public data
- Both poor & high performers show significant improvements.
- Success = quality data; transparency; and physician involvement

# One contributor to Q/cost performance

- Cannot show graph – shows sweden highest on OECD quality index – middle of range on 9% GNP

# Swedish international comparisons initiative

- You can see this on [Stefan Larsson: What doctors can learn from each other](#)

<http://itunes.com/apps/tedconferences/ted>

# ICHOM Initiative

## Consortium of Health Outcomes Measurement ICHOM

- <http://www.ichom.org/project/low-back-pain/>
- <http://www.ichom.org/medical-conditions/>
- <http://www.ichom.org/>

# Points from example 1

- For you what is significant from this?
  - Could it work here?
- Patient reported outcome
- Patient confidence
- Patient benefit
- Time for data to influence practice
- Did not need financial incentives
- Relevance to other treatments/diseases

# Swedish Rheumatoid Arthritis Registry and co-care • learning health system

## 2) Arthritis co-care supported by clinical data system

Patient enters data (cannot show picture of tablet)

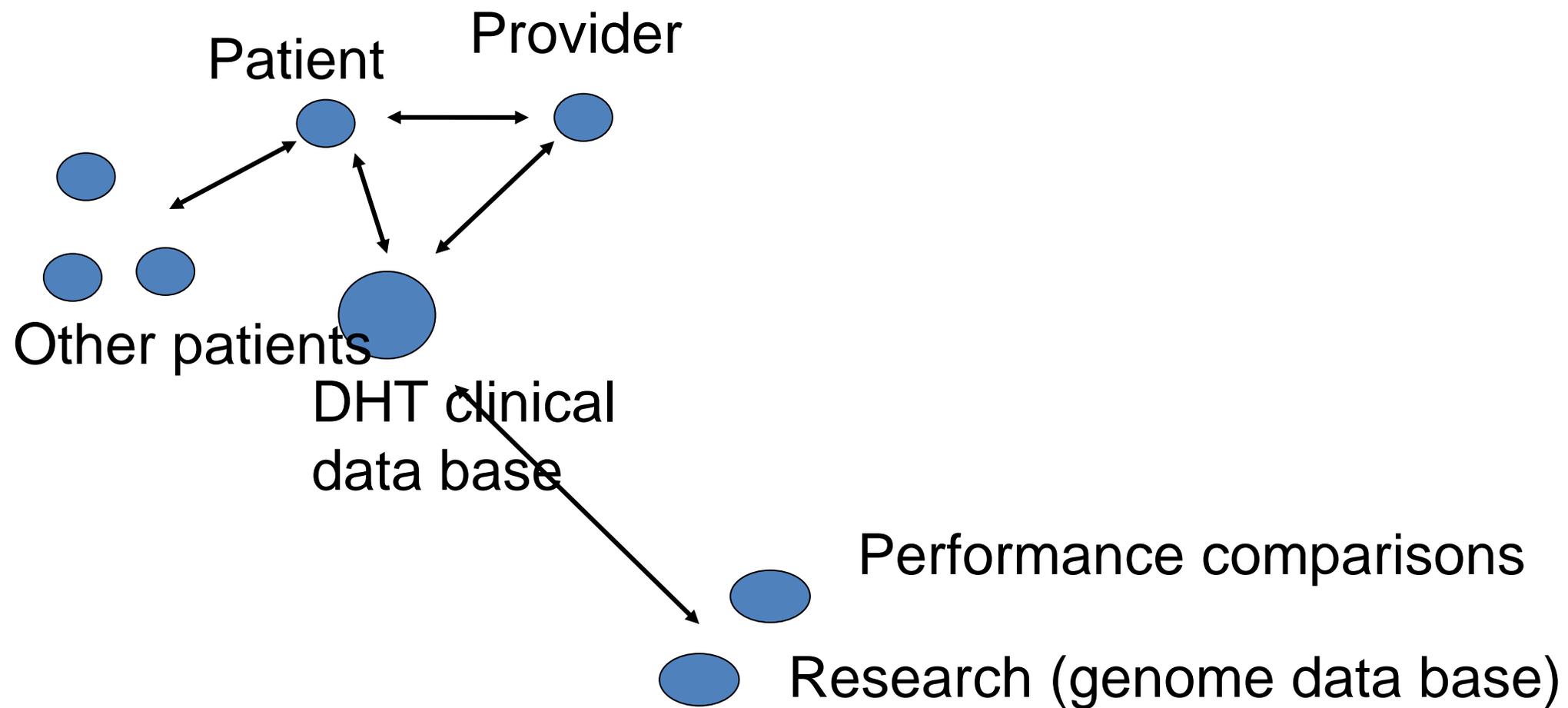
<http://www.srq.n.nu/films>

- <http://healthstories.se/?p=13> 1.51
- <http://www.srq.n.nu/films> 1.51
- 1.51
- [/films](#) 1.51

- Then: Clinical data base. **presents trends** in treatment and patient-reported disease score

Cannot show visual display

- <http://healthstories.se/?p=13> 1.51
- <http://www.srq.n.nu/films> 1.51



# Questions      KI/DTI/RWJ study

- Will empowerment of arthritis registry work with others?

## Challenges adopting model in USA

- EMR proprietary – abstract data from EMR for registry?
- Exchange upload data
- Physician uptake
- De identified patient data in separate system – no ownership issues?
- <http://217.76.63.11:8080/rareg/>

# Points from example 2

- For you, what is significant from this?
  - Could it work here?

**Register enabled services** direct to patient and physician

–At point of care

- Enables but does not ensure SDM/co-care
- Physicians need training for SDM

- Service direct to patient at home

# Points from example 2

- Visual presentation under-developed
- Can less-literate patients benefit?
  - Use for other patient diseases/groups?
  - **Platform** for connecting users

# Example 3:

## C3N

# Example 3: Cicinatti C3N model

- IBD Register is part of national network

<http://c3nproject.org/>

- C3N = internet platform for patients, providers and researchers to work together to improve care

## Network-based production for health?

- 1. Focus on outcome
- 2. Build community
- 3. Effective use of technology
- 4. Learning system – System science, QI, qualitative research, clinical research

- EMR individual patient data
- Patient-entered data
- Monitoring “Always on Software”
- Linked data bases with patient identifier
- Patient groups contributing

# Patients like me – to July 2012

- PatientsLikeMe members have shared...
  - 4,029,661 [symptom reports about 7,338 symptoms](#)
  - 548,650 [treatment histories about 12,838 treatments](#)
- Data reflected back to you to learn from,  
“Long tail Research”
- Over 5 years [published 27 studies](#), & shared aggregated data with eg [researchers behind ALS Untangled](#).

# Patients contributing to comparative effectiveness research

## PCORnet

18 Patient-Powered Research Networks (PPRNs) run

& governed by groups of patients and their partners

particular condition

interested in sharing health information and

participating in research;

# Points from example 3

- Register-related “platform”
- For you what is significant from this?
  - Could it work here?
- Register part of Web site “Forum” for partnerships
- Enables but does not ensure partnerships
  - More likely because of close community and values
  - Use for other patient diseases/groups?

# Questions Yes No Other

- I can name a patient register I know of
- I have some idea where it gets the data from
- I have used register data in my research
- I know the rules about research access and use
- I need to know more about this in the future

# HIPAA

Get written authorization from subjects before their personal health information can be used

- Or demonstrate that research meets requirements that exempt written authorization,
- such as the use of information that is not individually identifiable (eg the birth date or social security number must be removed).
- Get consent using on-line tool -later

# Future

# Future creation and use of patient register & register enabled

## services

- Privacy control, access, security
- Inequities of health – increase or decrease
- Software robots
- Research
- Improvement & learning health system

# Example : patient access to heart data

- Implanted defibrillator
- beats too fast or slow, zaps back to normal.
- Constant data collection  
“ relayed through the physician to ensure proper interpretation and explanation” FDA

# Example : patient access to heart data

- At checkup found defective – surgery

“. "If I had been able to follow my own reports, I would not have walked around for an entire year with a potentially dangerous problem,"

Different with apps - iPhone and sleep-monitoring app - "There is no real law that protects that data."

# Privacy

- 20 focus groups
- should have control over whether and how “their” data are shared and used (Schneider 2009)
- 75% OK for research if consent asked

# Privacy

- IOM recent
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# Your newborn

- Blood spot specimen
- Blood stored by state departments of health
- Case against Texas DoH for not seeking consent led to 5m destroyed.
- Initiative to seek consent



# “Private Access” – set preferences

- Private Access, <https://www.privateaccess.info>.

# Inequalities?

- Data allows research to identify
  - Inequalities in health
  - differential risks of different patient subgroups
- Long term decrease?
- Short-term increase?: use of data and services by low literacy patients and low income physicians

# Interventions to enable patient to make more use

- Talking Touchscreen has Health LiTT
- <http://www.healthlitt.org>
- measure of health literacy
  - Can be self-administered (Eng or Spanish) uses sound, text, and images.
  - Cover health- and insurance-related topics and informed consent.

# Summary

- Digital data and systems will transform healthcare
  - Patient self-care, provider support, feedback about outcomes of service changes, real time research.
- Benefits slowed
  - by uptake assistance and delays in updating regulations and reimbursement
- Urgent research: privacy, inequities

# Questions to you

- We use this register..
- Patients consent or what told
- Rules for access by research and others
- 5 years – what different?

To follow – learning health system

- Learning health system concept

- Data from EMR and registries
- Real-time research
  - Breaks down boundaries
- Networks for co-care, co-research, co-design

One definition focuses on patient-researcher partnerships as key feature

- 94 % of U.S. adult social media users with health conditions strongly endorse sharing their health data anonymously to help improve health care.
- 76 percent of American social media users with a medical condition believe that data from their personal health record potentially could be used without their knowledge.

# Significance - Learning health system

- Check impact of changes on patient outcomes and costs
- Health system use EMR data and other data in different ways:
  - Check for indicators of adverse events (safe-care Kaiser)
  - Natural linguistic programming and structure records
  - Software trawl data for patterns
  - Real time research and comparisons

Privacy

Physicians protective

Connecting systems

Physician practice change to enable patient participation

Costs

Unskilled design and implementation

Safety

Increases disparities? – less educated patients

# For us as patient

Faster benefits

Is our data being used for purposes we may not like?

Who owns clinical data streamed from monitors?

## Heart Gadgets Test Privacy-Law Limits

- <http://online.wsj.com/news/articles/SB1000142405297020393700457807882087474407>

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# The practicalities

Privacy

Physicians protective

Connecting systems

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# For us as patient

Faster benefits

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# Conclusions

- How John and others benefitted from 35 years of Hip register
- Other Swedish registries
- Expansion of funding and ROI
- Sweden international comparison initiative
- Swedish Arthritis register empowers patients
- Transfer to USA?
- Learning health system

Your part in making  
the future?

# Questions to you?

- Surprises?
- If you put in PRO, who owns the data
  - Your monitoring data – who owns and has control of access?
- Would not work here?
- Want to know more about?

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- <http://online.wsj.com/news/articles/SB10001424052970203937004578078820874744076>
- Who owns the rights to a patient's digital footprint and who should control that information? WSJ's Linda Blake reports. 6

# Resources

- HIPAA Privacy Rule, <http://www.hhs.gov/ocr/privacy/hipaa/administrative/privacyrule/index.html>.
- Assessment Center, a free online research management tool that helps researchers create study-specific Web sites for securely capturing participant data (available at <http://www.assessmentcenter.net>)

EDM forum <http://www.edm-forum.org/home>

SRQ 2013 Swedish quality register web site <http://www.srq.n.nu/>, accessed 26 jan 2014. SRQ secretariat web site allows real time analyses by users through web site: <http://217.76.63.11:8080/rareg/>

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# Conclusions

*Each person write down and then share in the group:*

1. This was new or surprising, for me...
2. The most useful idea for my work was...
3. What I would like to find out more about...