Health records in the cloud:
Possibilities and challenges

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What is the cloud?

• Cloud computing is a paradigm for serving computing as a utility or a service.

• Water, electricity, gas, telephony and then computing as a 5th utility (Buyya et al., 2009).

• Started as providing «infrastructure» as a service (IaaS).

• Instead of having local infrastructure and components, the cloud model exploits another entity’s servers, software that are provided as services.

• But how is this different from colocation? i.e. Renting rack space in someone’s data center. Or buying monthly server hosting.

• The difference is:
  – Flexibility: in terms of pricing, availability and access
  – Business model: Computing by the hour, by the power (computing)
  – Differential services: OS, platform (PaaS), database (DaaS)
Cloud computing models

- **IaaS** – Amazon EC2
- **PaaS** – Salesforce, Facebook games/apps
- **SaaS** – Google docs

Source: Purkayastha & Braa (2013) - Big Data Analytics for developing countries—Using the Cloud for Operational BI in Health
Cloud computing types on ownership

Managing The Cloud

Cloud computing types:
- Private cloud: customer control, ownership, responsibility
- Public cloud: supplier control, ownership, responsibility
- Hybrid cloud: on-demand, virtual, automated
- Hybrid architecture
- Hybrid operations
- Hybrid hosting
- Outsourcing

Cloud computing operations:
- Private infrastructure and operations
- Shared infrastructure and operations
- Scheduled, physical, manual
Electronic health records

• Health records are stored electronically in information systems known as EHR/EMR systems.

• All medical history, sometimes including family disease history or health condition related entries.

• Continuity of care, disaster situations are the most cited reasons for exchange of EHR (NCHS, 2009)

• But what information do you need in continuity of care? Think about HL7 CDA (Clinical document architecture) documents with templates for OP Visit, Discharge summary etc.

• Full EHR contains non-health data, like social security numbers (ID), bank/payment details (billing), employment details (insurance).
Core features: EMR/EHR systems

- IOM 8 core features of EMR/EHR
- Selecting which records are important to share with caregivers to make decisions

Not required to be portable?
- Administrative processes and reporting
- Patient support
- Reporting and public health
- Order management

Parts of it need to be portable
- Decision support
- Electronic communication and connectivity
- Result management
- Health information and Data
Patient centered care coordination

- Focus to move away from EHR away from provider-only or provider owned record to patient-owned, provider managed.

- Patient centered outcome research institute (PCORI) is a huge funding mechanism in the US to change the direction. Involve patients in their own care and be part of the clinical research that will be funded.

- Another fairly interesting legislation in the US is Meaningful use. The creation of funding of EHR and Health information exchanges (HIE).

- HIPAA and similar regulations (Health Personnel Act, sec 42, 43, 44 in Norway) patient access to records is compulsory. Also contains patient opt-in/opt-out rules (sec 25, 45)

- In what way does it change care provisioning? Do patients have the capability? Yet to be fully understood because of the limited evidence on patient involvement
Switching care providers – Choice

• Owning and being able to carry records gives patients the freedom to choose providers and share information with the providers

• But this is different from *personal health records*. Personal health records is a combination of patient-generated health records as well as provider-generated health records

• Can patients in low-resource settings, with low health literacy and limited number of providers, make a choice?

• Is patient centered care realistic in such settings?
Patient narratives or more

- Another way to look at EHR is narratives from patient results in «empathy» from the provider (Price et al., 2006).

- Patientslikeme and other narratives sharing portals are a validity challenge for EBM and may result in creating hyperchondriacs.

- Patient-generated data - activity monitors, exercise and diet data and its integration with EHR systems.

- *From dyadic ties to information infrastructures...* (IMIA YB, in press), where we highlight a case of using cloud for care coordination by hosting de-identified records – clinician social network, EBM, building case records in BMJ

Although she knows importance of exercise and is motivated to exercise, walking is difficult for the patient due to physical impairment and fatigue. However, she can swim and has access to an outdoor community pool. Although she has no car, her son drives her there in the summer. When the weather gets cold, this outdoor pool is closed. She does have access to a local gym w/ pool. However, she chooses not to go there because the gym’s other patrons tend to be younger and she is self-conscious about what they will think when they see all her surgical scars.

Source: Holden et al. (2015) – JAMIA patient work framework
Infrastructure for patient-work

In the cloud – What situations

- Beyond care coordination – where else?
- Backup – during disaster situations
- Accessibility – available in different situations

- As a provider, do you want to ‘let go’ of your patient? Do you want to lose business?
- Indiana HIE (IHIE) is an example of successful patient repository – INPC, where competing providers share information
Security

- Adequate laws to control sharing of the records and action that can be taken on inappropriate access to records
- A number of cases in the US on incorrect access. But in most cases the HHS levies punitive action on the provider or health care organization.
- Very limited, but have been cases of «private cause of action». This is interesting from the patient-centered point-of-view
- Providers who provide care, or in certain cases, where patient has given informed consent, health records can be shared with researchers
- At what level should information be de-identified? For how long should data be kept in record. Lifetime care record is one suggestion.
Privacy and ethical considerations

• Closely related to who has access to information, but more importantly if the patient has consented to use of their health data.

• Health data banks are used for profitable purposes by pharma companies.

• Health records such as genetic data can be used to preempt diseases and avoid giving a health plan.

• Ethical questions about cloning, organ creation using genetic data.
Other systems in the cloud

- Word processing – Google docs (TM) moved to cloud.
- File storage on the cloud – from contracts to IP
- Email – gmail reads every email text and shows ads
- Facebook – all personal travel, trips, friends, shopping, behavior etc.
- Paga Web – bluegarden – 20% of all Nordic payslips

- Are these any less sensitive? Or more sensitive?
Inevitable?

- Direction in which services are moving, more and more in the cloud. The move to mobile and ubiquitous computing is another push to use the cloud.

- Even in low-resource settings – 20+ yrs of history of DHIS 2, deep penetration of mobile in the social fabric.

- Organizational capabilities, with limited technology skills are enhanced by using the capabilities of cloud computing providers to manage technology.

- Sharing resources better for environment. Elastic services allow sharing computing resources.

- Balancing computing load while heavy traffic or high-load computation is required