# Health records in the cloud:

Possibilities and challenges

**Trial lecture by Saptarshi Purkayastha**
**PhD Candidate, NTNU**
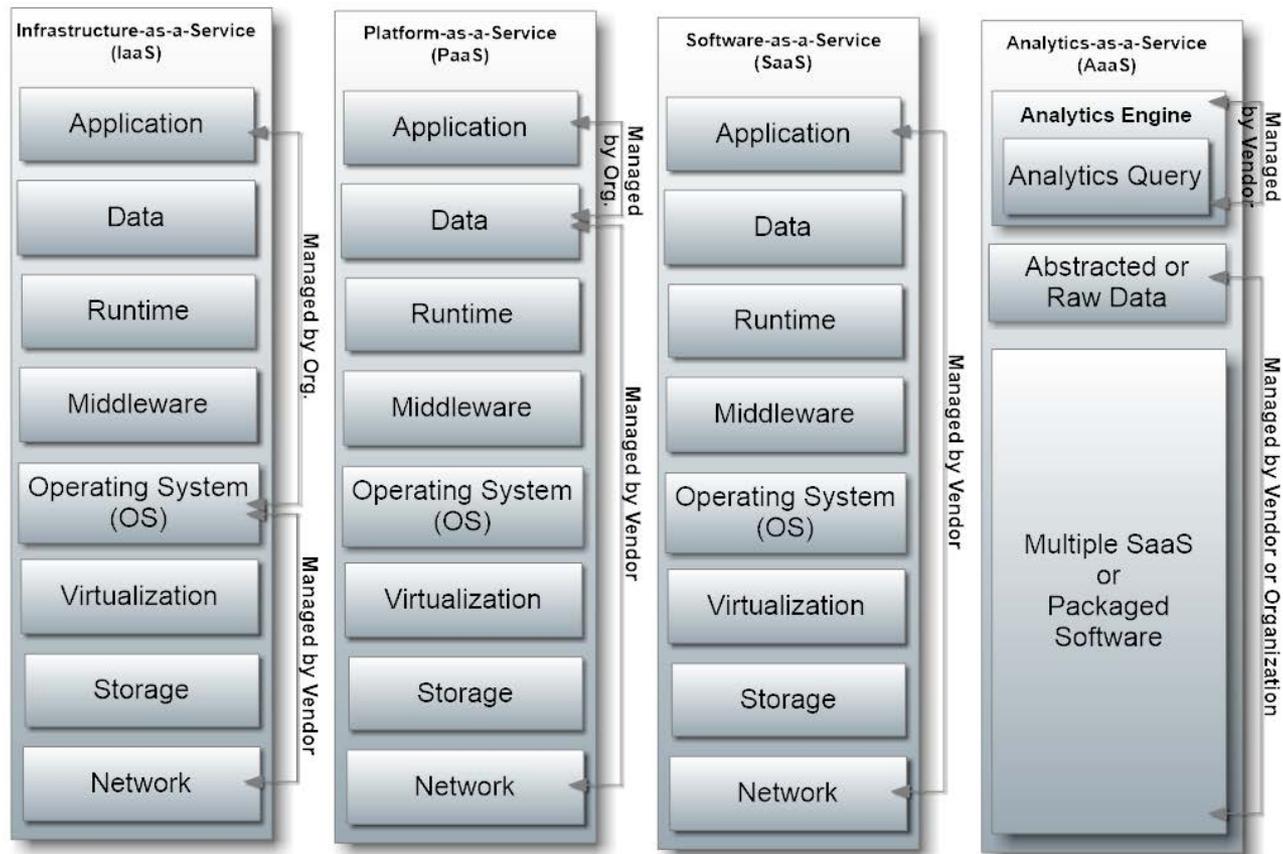**Visiting assistant professor, IUPUI**

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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)
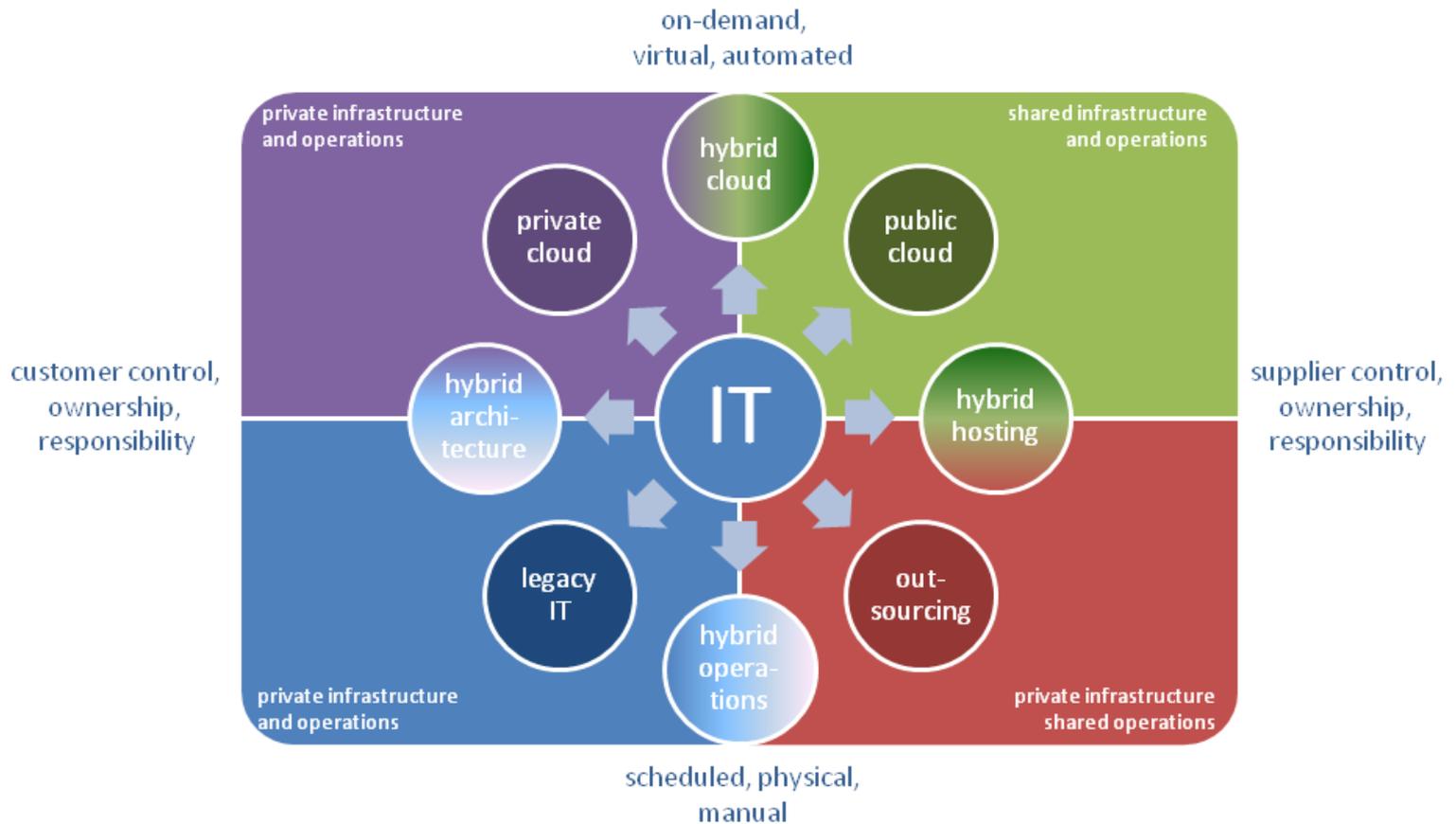  – Differential services: OS, platform (PaaS), database (DaaS)

# 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
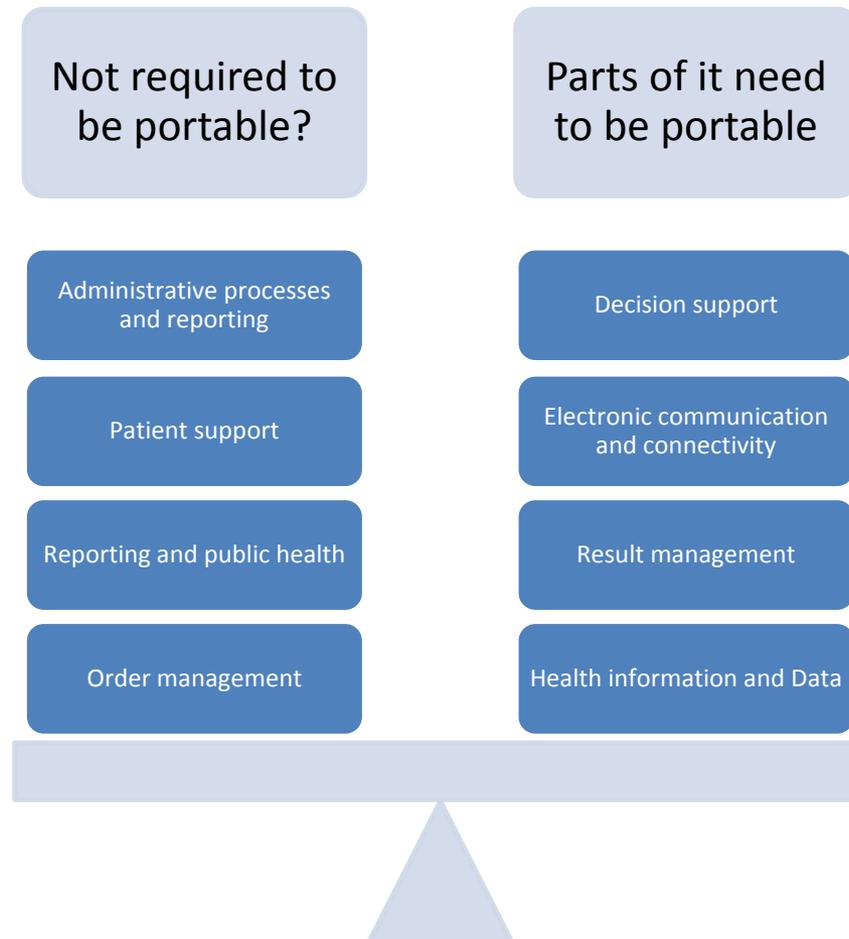
# Cloud computing types on ownership

# 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? | Parts of it need to be portable |
|---|---|
| Administrative processes and reporting | Decision support |
| Patient support | Electronic communication and connectivity |
| Reporting and public health | Result management |
| Order 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).

**Stages of Meaningful Use**

These objectives will evolve in three stages over the next five years:

| 2011-2012 | 2014 | 2016 |
|---|---|---|
| Stage 1 | Stage 2 | Stage 3 |
| Data capture and sharing | Advance clinical processes | Improved outcomes |

- HIPAA and similar regulations (Health Personnel Act, sec 42, 43, 44 in Norway) patient access to records is compulsary. 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



Source: Purkayastha et al. (2015) – IMIA Yearbook, 2015 (in press)
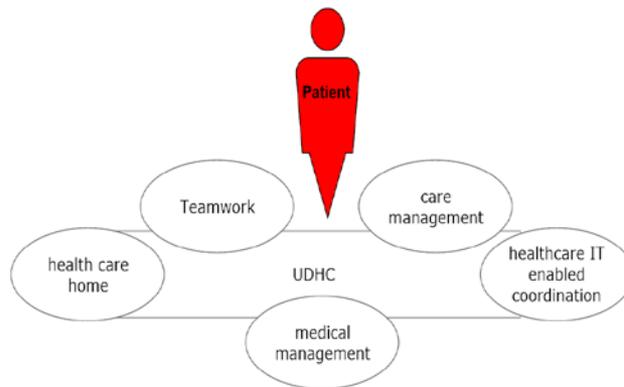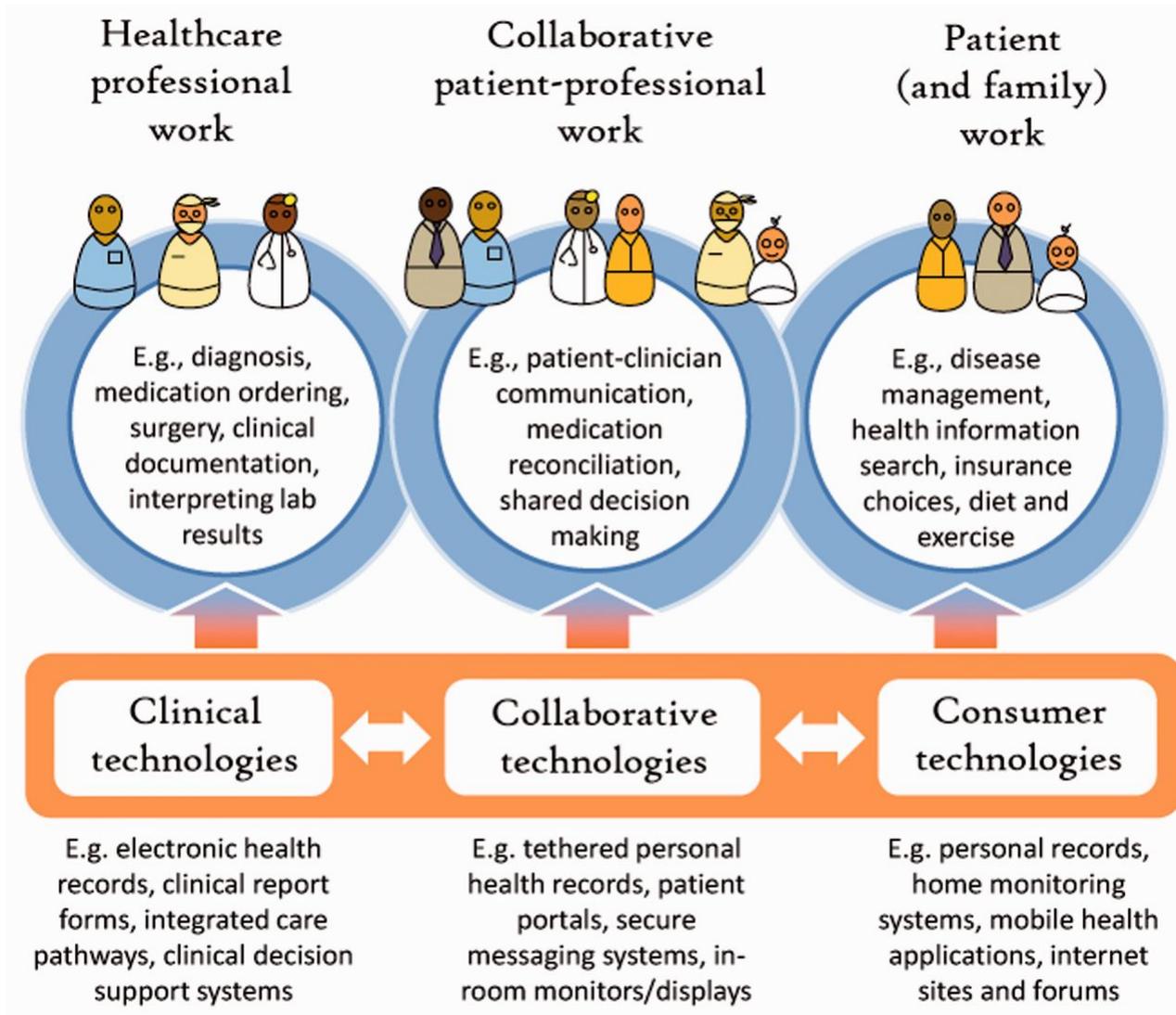
# Patient-work: a middle ground
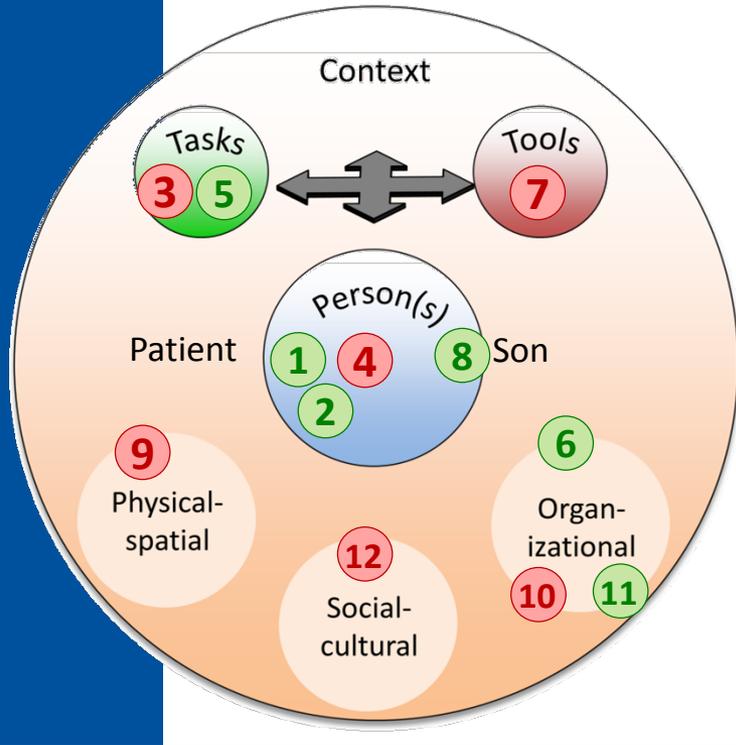


**①** Although she **knows** importance of exercise

**②** and is **motivated** to exercise,

**③** **walking is difficult** for the patient

**④** due to **physical impairment** and **fatigue**.

**⑤** However, she can **swim**

**⑥** and has **access** to an outdoor **community pool**.

**⑦** Although she **has no car**,

**⑧** her **son** drives her there in the summer.

**⑨** When the **weather gets cold**,

**⑩** this outdoor **pool is closed**.

**⑪** She does have **access to a local gym** w/ pool.

**⑫** 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.

**#** facilitating factor

**#** impeding factor

**Source: Holden et al. (2015) – JAMIA patient work framework**

# Infrastructure for patient-work



Healthcare professional work

Collaborative patient-professional work

Patient (and family) work

E.g., diagnosis, medication ordering, surgery, clinical documentation, interpreting lab results

E.g., patient-clinician communication, medication reconciliation, shared decision making

E.g., disease management, health information search, insurance choices, diet and exercise

Clinical technologies ↔ Collaborative technologies ↔ Consumer technologies

E.g. electronic health records, clinical report forms, integrated care pathways, clinical decision support systems

E.g. tethered personal health records, patient portals, secure messaging systems, in-room monitors/displays

E.g. personal records, home monitoring systems, mobile health applications, internet sites and forums

**Source: Valdez et al. (2015) – JAMIA (in press)**

# 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 loose 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 ubiqutous computing is another push to use the cloud.

- Even in low-resource settings – 20+ yrs of history of DHIS 2, deep pentration 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