Harvard Medical School Meeting on Personally Controlled

Health Record Infrastructure

(PCHRI 2006)

Report to the AHIC Consumer Empowerment Workgroup

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About the Meeting

- October 10th and 11th, 2006 at the HMS Countway Library of Medicine, hosted by the Center for Biomedical Informatics

- 100 Leaders from Government, Academia and Industry discussing an ongoing infrastructure for Personally Controlled Health Records

- More information at http://www.pchri2006.org/

Selected Participants

- CMS
- CDC
- NIH
- NLM
- Social Security
- ONC

Plus Harvard University, HMS Center for Biomedical Informatics, MIT, The Center for Biomedical Innovation, Oregon Health Sciences University, Markle, Robert Wood Johnson, Stanford Medical School, Mass eHealth Collaborative, Reigenstrief, CareGroup, Mass Medical, AAFP…..

Agenda: Cross-Cutting Issues

1. Personal Control

2. Disruptive Technologies

3. Business Models

4. Data Liqudity

5. PHRs and HIEs

6. Technology: Friend or Foe?

1. The "PCHR"

- Personally *Controlled* Health Record
  - Control is about more than just access
  - *Not* welded to a single infrastructure
- A PCHR includes a **irrevocable copy** of all healthcare data
  - Subsequent release of this copy is under patient control
  - Same applies to all data contributed directly by patient
  - Technology enables the "rules of engagement"

Top level goals for PCHRs

- Enable a *single* point of access for patients to their PCHR, creating a "virtual medical home"

- Allow patients to control data flows through a health information exchange

- Establish a line of communication with patients

- Accommodate unanticipated uses

2. Business Models

- Consensus on a straightforward point: to encourage PHR adoption, consumers *MUST HAVE A COMPELLING INTEREST*
  - High order needs:
    - Take care of my wife's health
  - Economic interests:
    - I want to profit from my own data

- Workflow for EHRs, "Life Flow" for P(C)HRs?

3. Disruptive Technologies

From the keynote by Mitch Kapor:

Closed -> Open

Hierarchical, Centralized -> Decentralized, Coordinated

Islands -> Interoperability

- "If Open Systems are Nurtured, they dominate closed systems."

- "Build it and they will come – there will be unexpected entrepreneurial opportunities."

4. "Liquid Data" Builds Businesses

- The value of PHR data will grow exponentially along with its potential uses
  - The fundamental issue is not how to get consumers to demand information and buy "records," but rather to facilitate "liquidity" of the data
  - Consumers already perceive that their medical information exists in a "liquid form" and is freely exchanged between providers

- Risk/benefit trade-offs to medical data liquidity
  - People seem willing – at least in focus groups – to accept the reduction in privacy to save their lives or improve health

Underpinnings of Data Liquidity

- "Control"
  - Separate control from ownership & focus on uses and rights
  - Dynamic, easy to use opt-in/opt-out (with intelligent defaults)
  - Fine grained options for sharing

- Authentication (of data)
  - The value of information is based on its reliability

- Accessibility & Richness
  - We need a "download" button—for patients—on all sources of medical data

- Trust is a central component
  - Transparent rules, harmonizing privacy with other interests
  - Education component for physicians and patients
  - Ongoing process for focusing on ELSI (Ethical, Legal and Social Issues)
    - Legislation
    - Regulation
    - Seals of approval
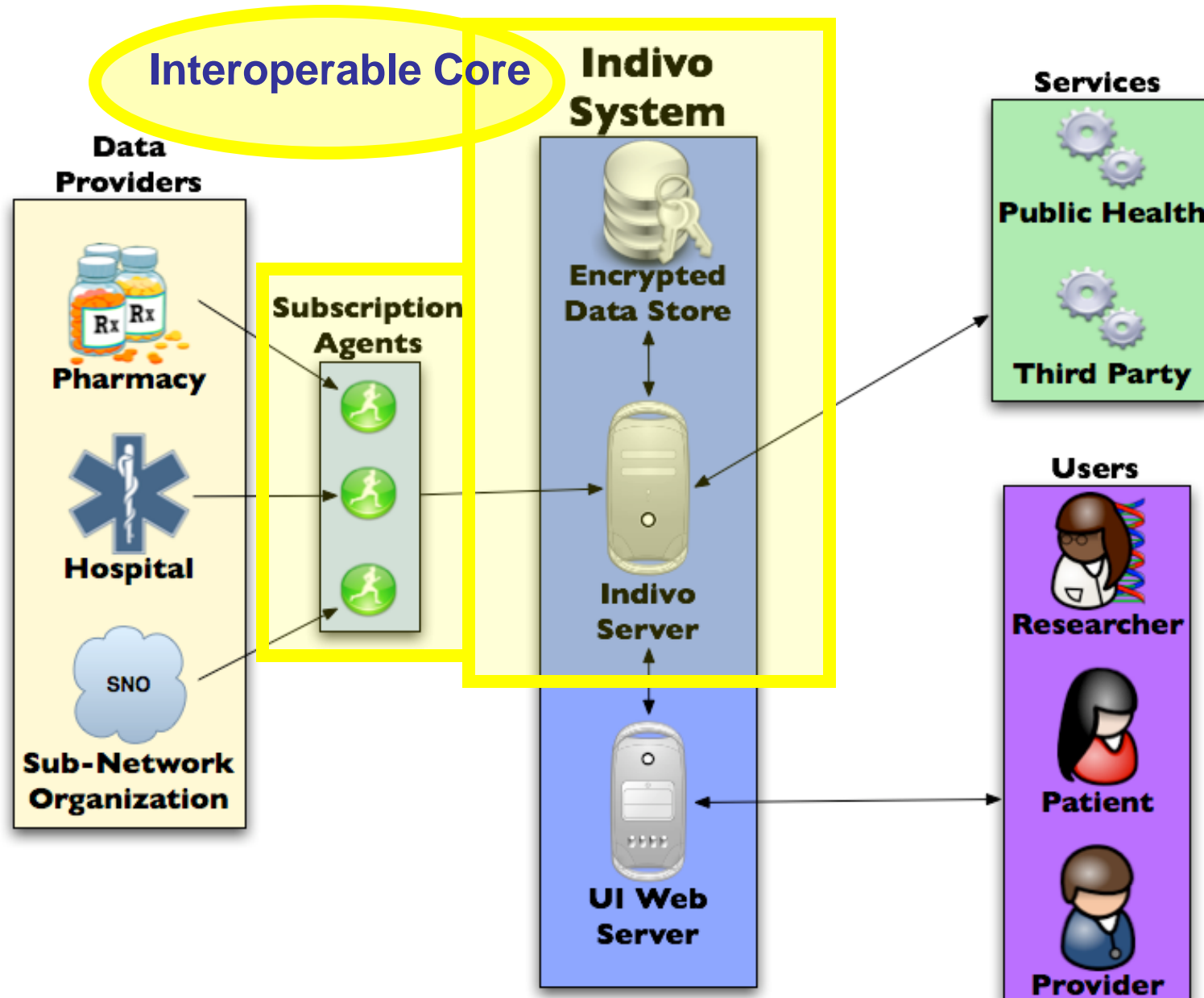   - Recognized oversight authority

5. PHRs and HIEs

- A PHR that isn't "welded" will contain pointers to multiple data sources.

- Is a PCHR the core of the health information exchange, or an element within it?
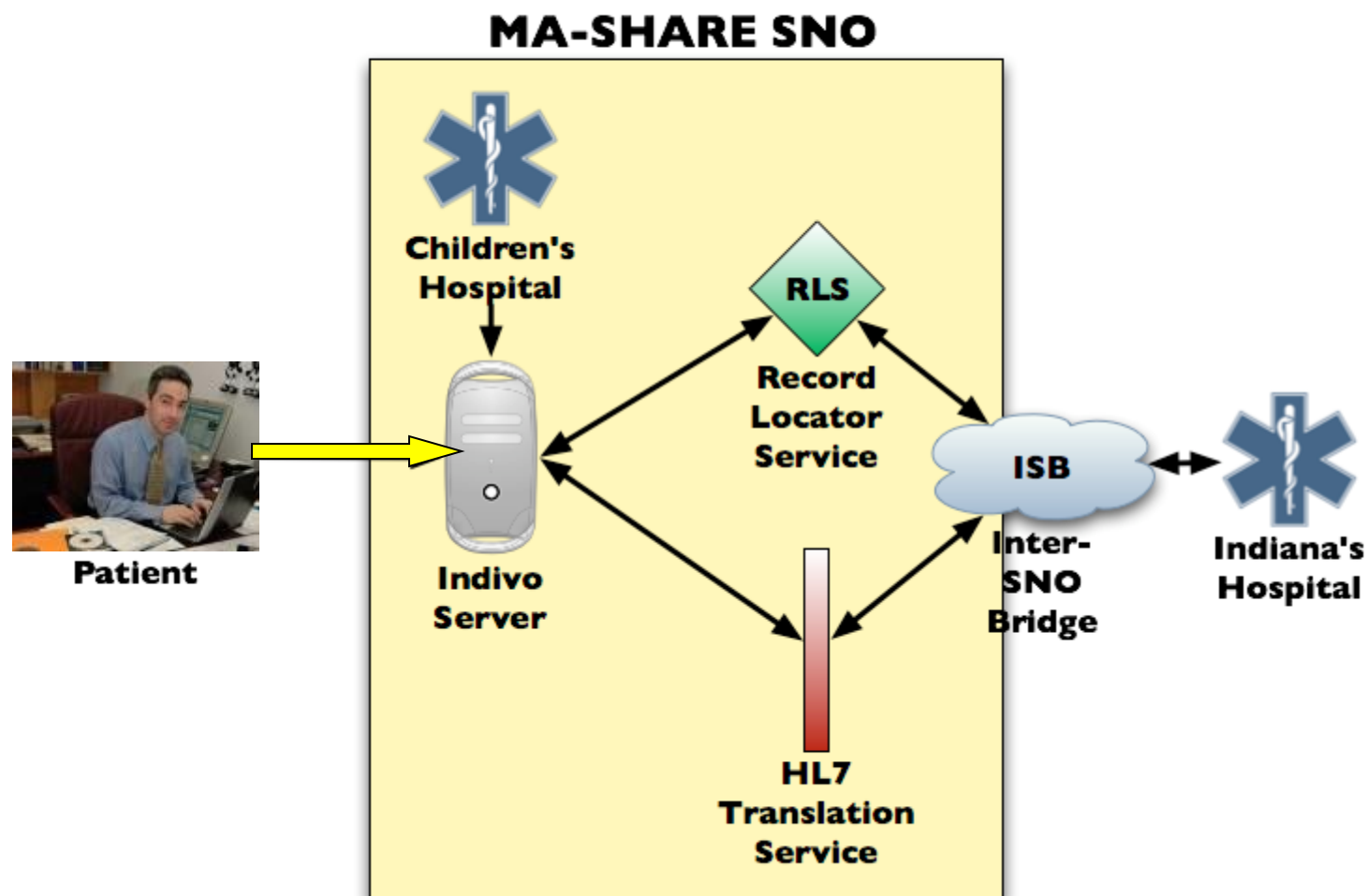
6. Technology is not the Problem

- Access control in online photo sharing works just fine!

- Other industries do a lot of R&D – don't reinvent the wheel

- For example, the "Semantic Web" technologies for knowledge management

Further (Technical) Consensus

- Audit trails should be simple and focused
  - Not sure about interoperability

- Data in transit should be encrypted
  - Encrypted stored data is a "safe" practice

- Define use cases for public health and research

Recommendations

- Promote openness in PHR platforms
- Prevent fragmentation through openness
- Don't crowd out innovation
  – Embrace policies that create and support platforms
- Rely on individual rights
  – Confront privacy head on by exercising individual rights to information
  – The patient is the integrator of his/her own medical record
  – Allow fine-grained opt in/opt out

Thank You!

www.pchri2006.org

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