PCHRI2006

The Harvard Medical School Meeting on Personally
Controlled Health Record Infrastructure

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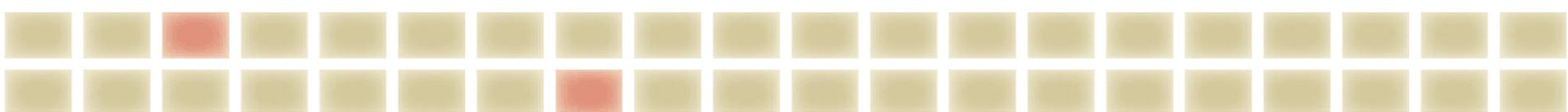School

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Working Track Summaries

From PCHRI 2006
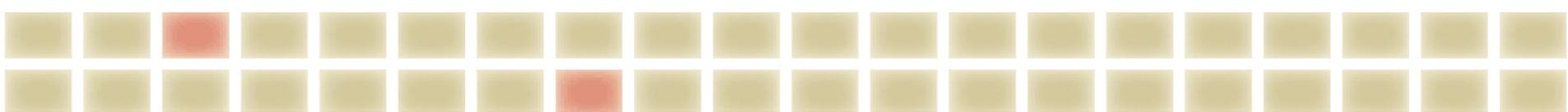## October 10th and 11th, 2006
Harvard Medical School

About the Conference

- October 10th and 11th, 2006 at the HMS Countway Library of Medicine
- 100 Leaders from Government, Academia and Industry discussing an ongoing infrastructure for Personally Controlled Health Records
- More information at http://www.pchri2006.org/

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About the Summaries

These summary slides were prepared by the participants during the PCHRI 2006 meeting. They have been slightly reorganized for easier reading. Each of the three tracks was originally asked to produce 2-3 slides summarizing areas of broad agreement and presenting unanswered questions.

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Track 1:
Business Models for Personally Controlled Health Records

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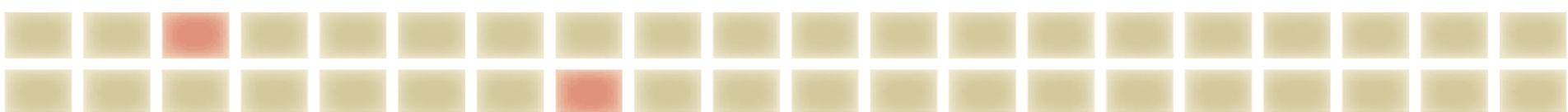
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"Liquid Data" Builds Businesses

- The value of PHR data will grow exponentially as more organizations have access to it, and the opportunity to build business models around it – there is a natural tipping point
  - The fundamental issue is not how to get consumers to demand the information and buy "records," but rather to facilitate "liquidity" of the data – if you create a benefit, people will connect with it
  - Consumers already perceive that their medical information exists in a "liquid form" and is freely exchanged between providers
  - Data liquidity is the underpinning to a viable market – liquidity is enabled by authentication
  - There are risk/benefit trade-offs to having medical data liquidity, and so far, people seem willing – at least in focus groups – to accept the reduction in privacy to save their lives, improve health
  - We need a "download" button on all sources of medical data
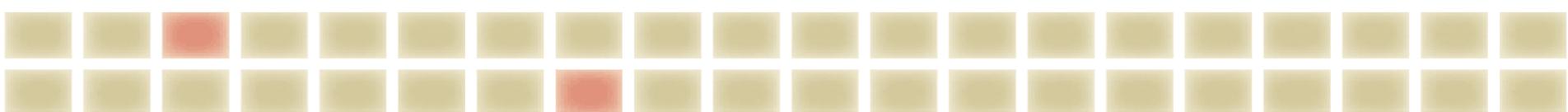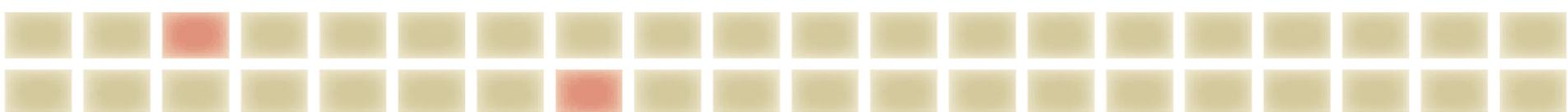
Business Models

- **Resolved**
  - We need an "easy button" –
  - Like any business, PHRs will succeed as a viable commercial strategy if they address a fundamental unmet need
  - Viable business models do exist right now for PHRs - 3rd party sponsored Tethered-PHRs
  - There is a likely emerging sub-group of consumers – enrollees in CDHPs – who have had the moral hazard of insurance removed – who may comprise the first consumer-paid PHR market
  - In a world with finite resources, the focus of on RHIOs may be better spent on enabling PHRs.

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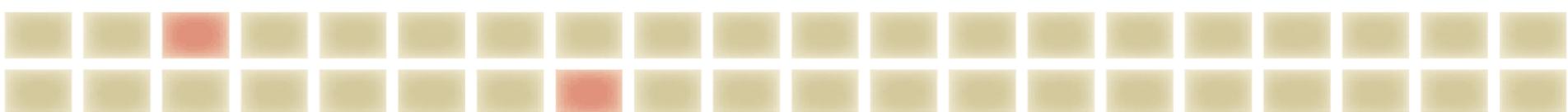
Business Models

- # Resolved
  - Standards are not the problem – technology is not the problem -
  - A critical path to enabling a market for PCHRs is to provide consumers an interest –ranging from the higher-order needs (I want to take care of my wife's health) to economic interests (I'd like to profit from providing access to my data)
  - For example - Enabling consumers to monetize their medical data, opting-in to allow third-parties, like clinical trials, to purchase their data
  - A PHR does not need to include eight distinct data sets – if your PBM offers you access to your medication history online, this is a PHR – maybe PHRs exist in more formats than we acknowledge
  - An incomplete record is better than no record – if it aggregates lab and medication data, which is all largely digital and online, that's a pretty good start
  - It may be naïve to think that the private sector can do this without government intervention – on some level – but then again, gov't make crowd out private sector innovation – everyone agrees to disagree on the right balance
  - PHRs could be the killer app for patient education – a truly scalable public health infrastructure

Business Models

- ## Unresolved

  - Role of academics as generators versus large employers as accelerators of innovation
  - There are challenges around the lack of consumer incentives to participate in PHRs, but also a lack of provider incentives to invest in the necessary infrastructure to feed a PHR – not clear which is the bigger problem – chicken or egg
  - What percentage of the population would have to be literate enough to create a "critical mass" of potential PCHR users as the basis of a viable commercial market – or even a grass-roots revolution.
  - The importance of workflow is undeniable in the adoption of HCIT in provider context – what is the importance of "life flow" in driving the adoption of PCHRs by consumers?
  - Are we missing a big opportunity because we are so quick to rally behind "personally controlled" health records? Is this really the ideal starting point from a business model perspective?
  - "C" may be inflammatory – is it really about control? Why presume they have no control? Perhaps it's sufficient to focus on patient centricity, rather than patient control. But will the patients accept it?

Business Models

- ## Barriers

  – To be "personally controlled" in is in the eyes of the beholder – do I get to chose my applications through which I see my data?

  – We can make statements that everyone agrees that it's a good idea but where's the evidence base?

  – Cleaning up HIPAA

  – The absence of a (HIPAA-compliant) "download" button from a sponsored PHR that allows the consumer to take their data with them to any "other" application

- ## Enablers

  – Gov't can take the lead by making key source of data available – CMS buys this and perhaps should make this a req for getting paid

  – The influence of large employers to drive transparency by providers (i.e., LeapFrog's impact on patient safety)

  – Use of a patient's PHR becoming a process quality measure – P4P – could be a carrot

  – But HIPAA has also been an enabler by standardizing the BA agreement, creating a baseline term sheet for compliance
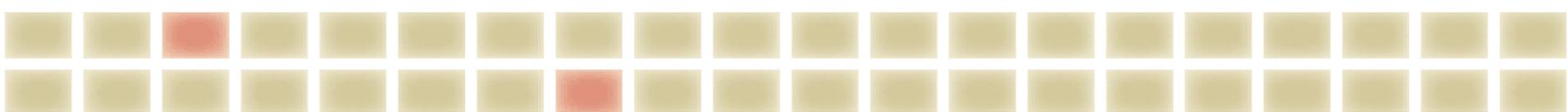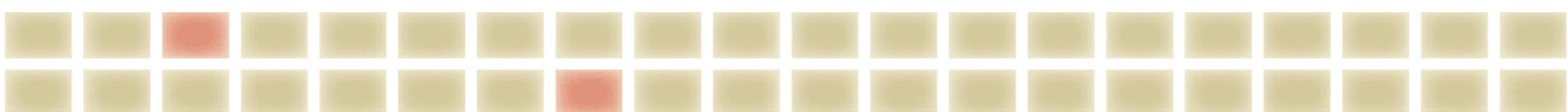
Track 2:
Societal Implications for Personally Controlled Health Records

Principles

- For adoption, look to consumer-recognized value
- "Control"
  - Separate control from ownership. Focus on uses ,rights, and functions
  - Dynamic, tunable, easy to use opt-in/opt-out (intelligent defaults)
  - Fine grained options for sharing
- Contents of the PCHR must have salience
  - the subset of data in the PCHR must be useful and in a useable form
- Impact on digital divide should be minimized
- Compatible with a range of business models

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Trust is Vital

- **Trust is a central component**
  - **Requires**
    - transparent rules, harmonizing privacy and autonomy interests with other interests
    - education component for physicians and patients
    - recognized authority involved—oversight, endorsement
    - Maintaining role of institutions (research, public health)
    - ongoing process for focusing on ELSI (Ethical, Legal and Social Issues)
      - Legislation
      - Regulation
      - Sealsof approval
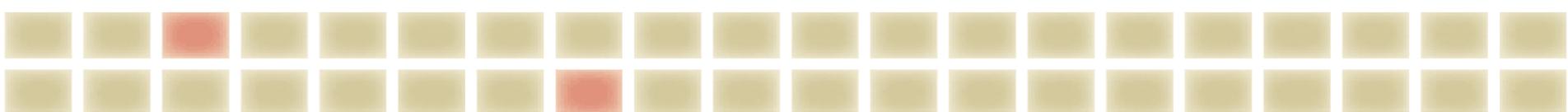   - Oversight board (The IOM?)
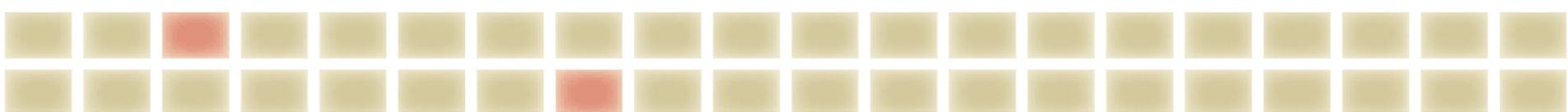
Infrastructure

- Support health care that is
  - Personalized, predictive, preemptive, participatory, preventive (Z^{++})
  - Safe, effective, efficacious, efficient empowering
    - By supporting tools for self-education, information management, activation, information sharing for clinical benefit, research, public health
  - Inclusive of diverse populations
- Accommodate unanticipated uses
- Has the following characteristics
  - Accessible (multiplatform), redundant, tolerant, flexible
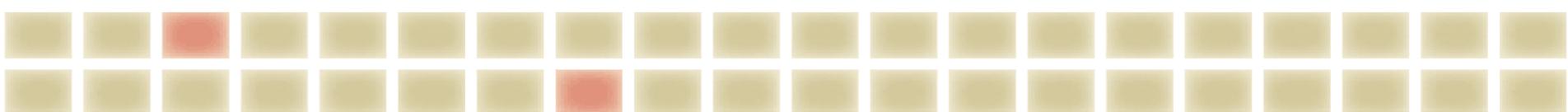
Recommendations

- Illustrate relevance through demonstration cases that get us a foothold and experience (Kapor 1%)
  - Consumer-centric—meeting true consumer demand.
  - Optimal use of existing resources; intersection of existing workflow (patient, provider) policy importance
  - Explore uptake, participation, denominator
  - Utility—infrastructure to support applications that meet consumer demand
  - Design to have an impact on health and measure impact on health and resource utilization
  - Build with feedback and iteration
- Focuses on moving data to patients & among systems/sources
  - Proxies or multiple users
- Consider the position of AHIC with respect to proposing legislation that would promote trust and adoption

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Track 3:
Standards & Technology for Personally Controlled Health Records

Definition of a PCHR

- PCHR includes a **irrevocable copy** [V] of all healthcare data that that is
  - Subsequent release of this copy is under patient control.
  - Same applies to all data contributed directly by patient.
  - Technology enabling rules of engagement
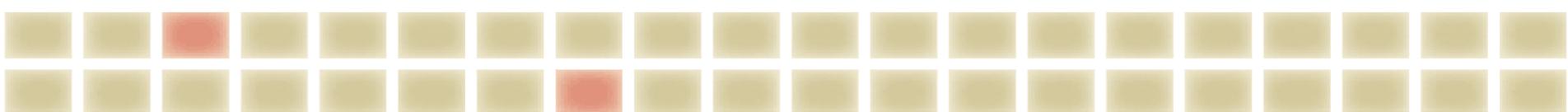
Further Consensus

- Avoid re-inventing stuff that works outside healthcare.
  - Encourage use of Semantic Web for KM in PCHRI
- **Identity** ± role :based access/release
  - Granularity in data release [photo site] PCHR can import messages from EMR and vice versa.
  - Subscription and/or single sign-on(=virtualization)
- Multiplicity of PCHR will be supported
- Need to elaborate use cases.
  - Include Bidirectional Public Health! Include research!
  - Revisit consumer empowerment use-case from HITSP.
- Audit trails: Minimal audit universe
  - Debate on whether audit trails should be interoperable
- Data in transit should be encrypted.
- Data encryption is too prescriptive: but it is safe practice.
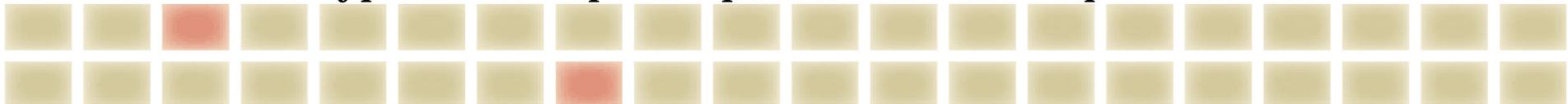
Unanswered

- How do you maintain continuity/cohesion/persistent memory of standards.

- Certification, Open Source code, licenses

- De-identification:
  - Needs to be specified: levels/characterized in ways that are used.
    - Specified with respect to given data types.