

REPORT TO THE PRESIDENT
REALIZING THE FULL POTENTIAL OF
HEALTH INFORMATION TECHNOLOGY
TO IMPROVE HEALTHCARE
FOR AMERICANS:
THE PATH FORWARD

Executive Office of the President
President's Council of Advisors
on Science and Technology

December 2010



The PCAST Report: What, Why, How, When and *Really?*

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Redwood Mednet 2011
15 July 2011
Santa Rosa, CA

<http://www.whitehouse.gov/sites/default/files/microsites/ostp/pcast-health-it-report.pdf>

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Gartner

Arthur C. Clarke's Three Laws of Predictions

- When a distinguished but elderly scientist states that something is possible, he is almost certainly right. When he states that something is impossible, he is very probably wrong.
- The only way of discovering the limits of the possible is to venture a little way past them into the impossible.
- Any sufficiently advanced technology is indistinguishable from magic.



"Hazards of Prophecy: The Failure of Imagination", in *Profiles of the Future* (1962)

Wes' Corollary to Art's 3rd Law

- When constrained to a time frame, all magical thinking coming from distinguished but elderly scientists is indistinguishable from sufficiently advanced technology.

or

- The road to hell is littered with the bodies of technology experts that were going to fix healthcare.

PCAST Report: WHY?

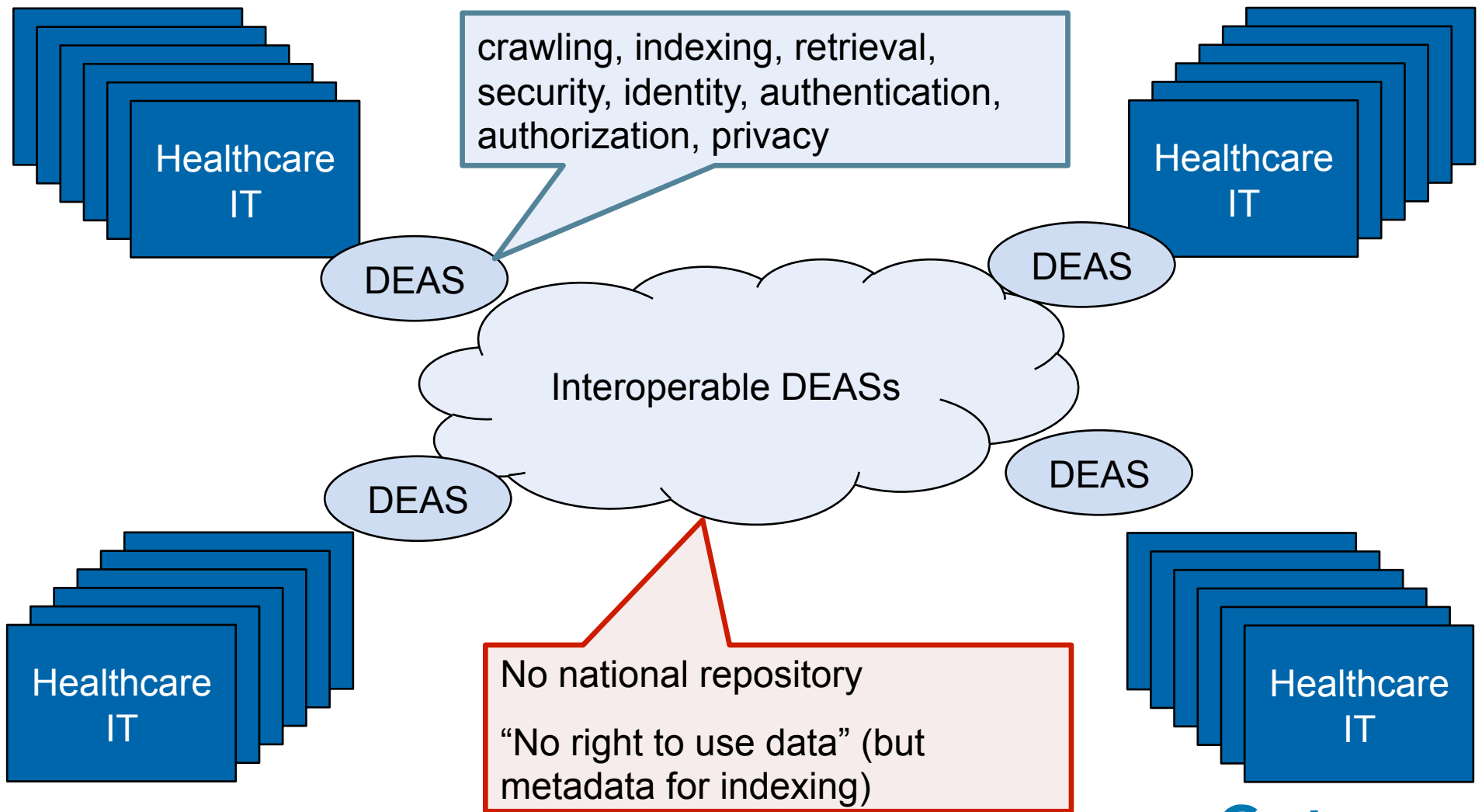
“Despite success stories from some early adopters, the current level of IT use in healthcare is uninspiring. Recent initiatives, particularly by ONC, are shifting the incentives and may stimulate substantial EHR adoption. *But a substantial advance and concentrated focus are needed to develop a scalable, national health IT infrastructure.* New technologies can assist in taking the required steps.” (p. 38; emphasis added.)

Described in terms of “use cases”

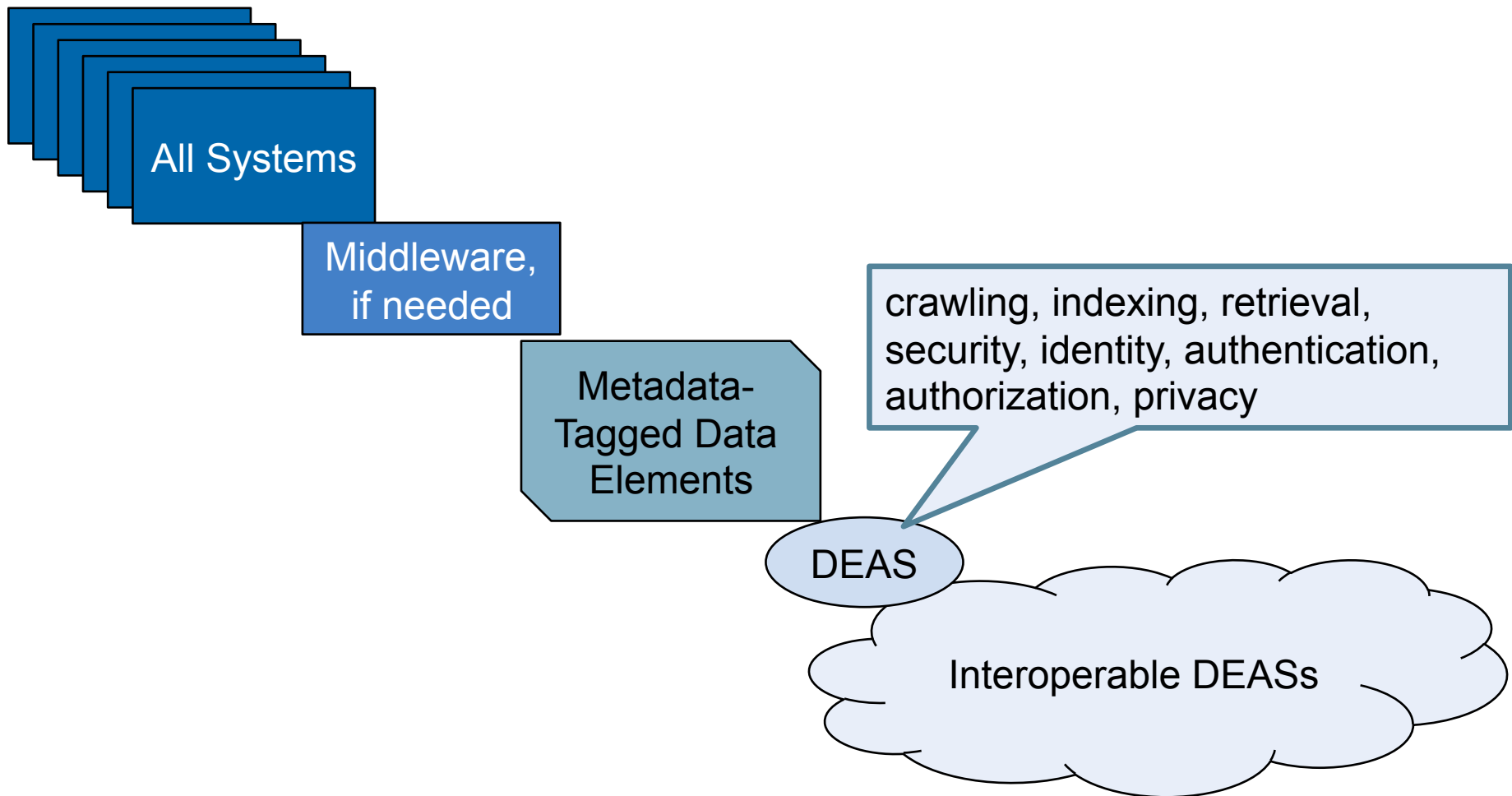
Observations on the Use Cases

- No mention of tapping the available data (even if anonymized) for discovery of
 - Rare adverse events
 - Research cohorts
 - Other forms of medical learning
- Consistent patient consent might overcome this but also may create a bias on reported data.
- Supporting, consistent legislation may be needed
- No mention of artificial intelligence, “bots” and other latent possibilities in healthcare IT
- No mention of home or carried monitors, which are potentially more demanding on patient ID
- At best, hints at disseminating medical knowledge

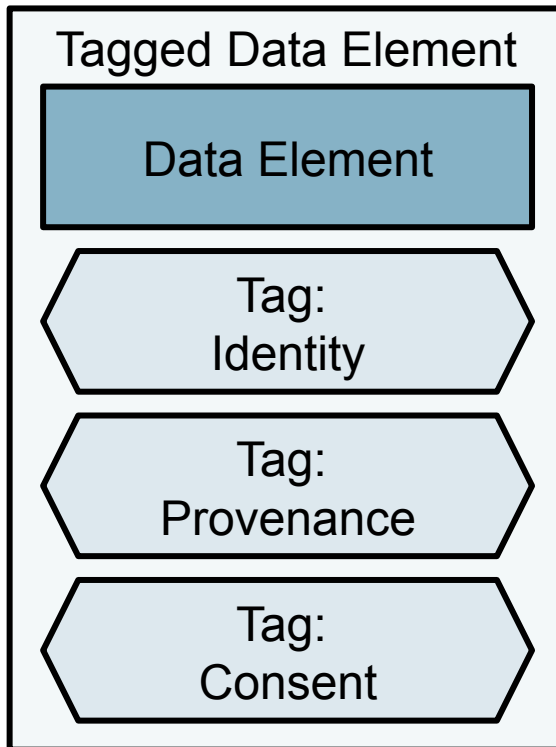
The PCAST Vision Health IT Infrastructure



The PCAST Vision – Metadata Tagged Data Elements



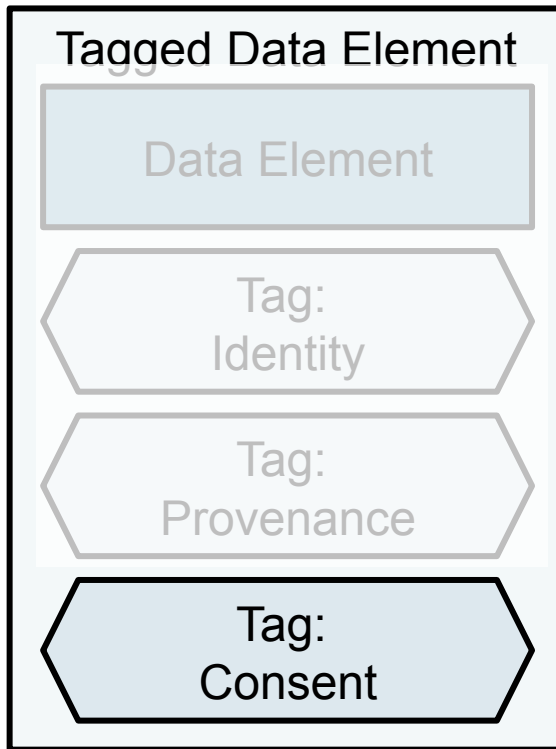
The PCAST Vision – Metadata Tagged Data Elements



- Types of tags
 - **Identity:**
 - identifiers and demographic information to support probabilistic match (no universal health ID)
 - Remove to “anonymize”
 - Identify the content of data element (but not values)
 - **Provenance:** source of information
 - **Consent:** Patient consent assertions
- Benefits of tagging
 - Supports use for many purposes
 - Tag language is extensible, can evolve over time
 - New data element types can be added at any time (formats independent of tags)

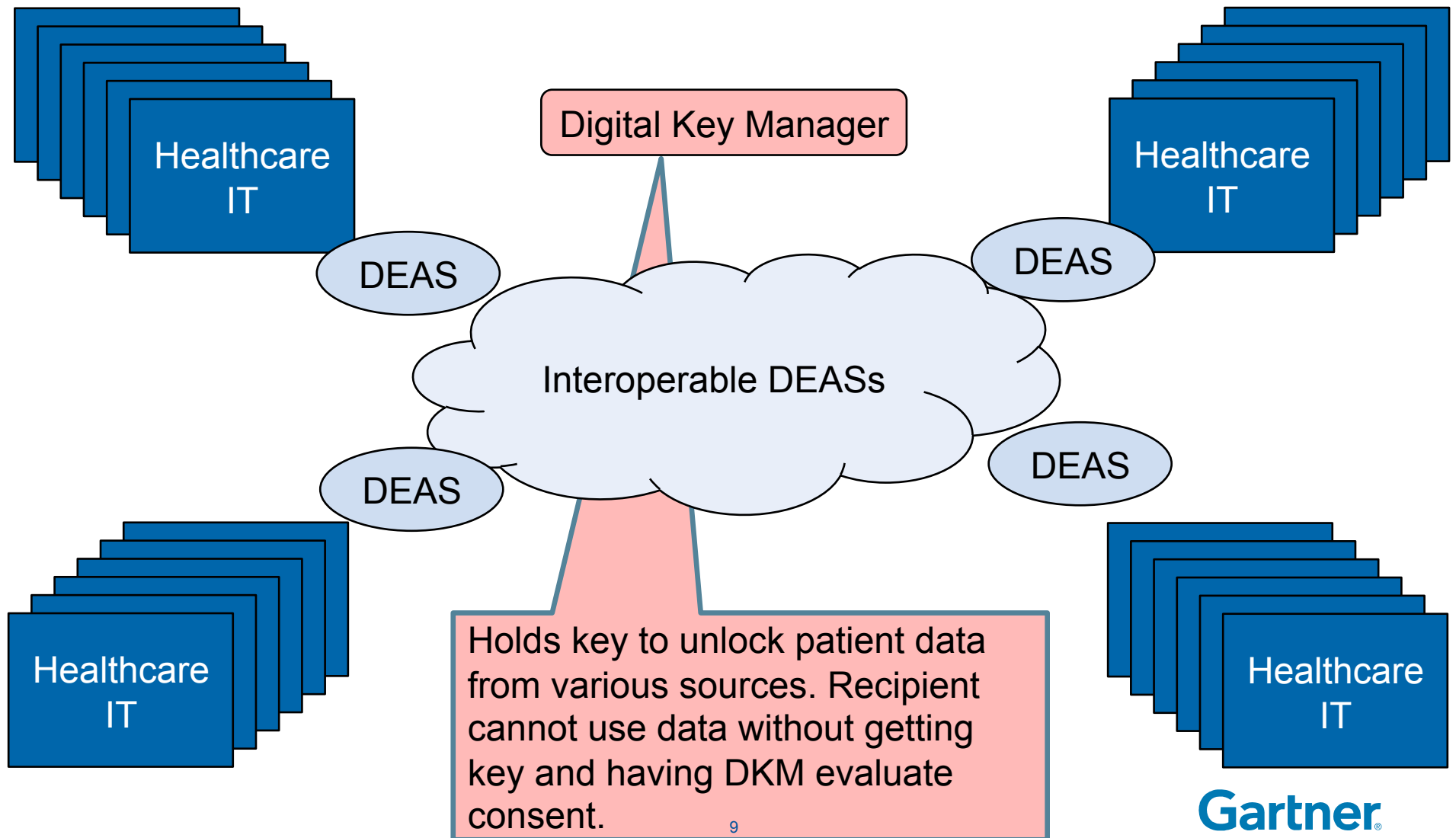
The PCAST Vision

Representative Consent Tags



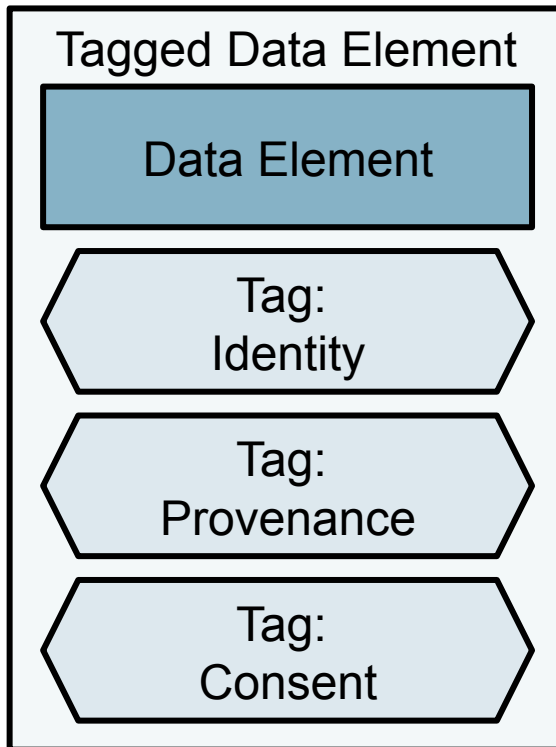
- Possible types of consent qualifications
 - Purpose of request
 - Role of requestor
 - Identity of requestor?
- Type of Consent
 - Allow retrieval
 - Allow anonymized retrievals (aggregate only)
- Indexing consent
 - Index on data element type
 - Index on data element contents

The PCAST Health IT Infrastructure Includes Separate Digital Key Managers



“Data Architecture for the 21st Century”

Separate Key Exchange



- Encryption key per data element
- Recipient receives data in encrypted form
- Recipient then asks a consent manager agent for the keys necessary to unlock the data elements received
- Consent manager has no data, only tags
- DEAS and other intermediaries have no ability to unlock data (unless they have indexing consent)
- There is a potential path to revocable consent here

Universal Exchange Language

- The most important standard
- Probably an XML variant
- Is the format for the element and its tags
- Some of the authors clearly believe that this should be a re-do, i.e., simpler than current data format standards

Issue: Push vs. Search/Request

- Some use cases require “pushing” data
- PCAST report does not explicitly address this requirement
- Observations:
 - Most of the security and integrity requirements associated with requesting data are applicable to “push”
 - Universal exchange language and most tags equally applicable to “push”
 - Consent is generally determined for the entire push; in many cases it is not reasonable to say “here is the “data, but you can’t unlock it.”

Issue: Retained data

- Some of the authors envisioned that data would be pulled from the source each time it was needed, not retained by recipient
- Such an approach would ensure consistent application of consent data
- This is a non-starter
- The mechanisms and standards described in the PCAST report do not rely on the assumption

Issue: Separate Key Exchange

- Has the potential to simplify one of the thorniest issues in HIE.
- Many issues to be worked out for data that is part of the care process, shared between providers if this is to use the same infrastructure.
- Significant patient education issues.
- Application of digital rights management has demonstrated scalability, but is far less complex than the proposed approach, if the patient is to have granular control over the release of data.
- Only proof point for more complex consent issues relate to national security intelligence issue; control over operators of systems is more direct.

Pluses and Minuses

- + Knocks ONC out of a strict year-by-year incremental approach to standards.
- + Challenges the complexity of WS-* interfaces, which have fallen out of favor for new efforts.
- + New thinking about UEL has the potential to stimulate simplified approaches to clinical data standards, such as the “HL7 Fresh Look.”
- + UEL work can proceed independently of work on digital rights management and policy.
- Equating privacy to consent risks creating a workable technology that still inhibits patients from sharing data.
- PCAST impression that semantics of clinical care can be dramatically simplified remains to be proven.
- Not a viable replacement for current MU standards through 2015.
- Does not address the necessary infrastructure for vetted provider identity and public key infrastructure