A Simple XML Framework for Health Data Exchange

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www.projecthdata.org

Background

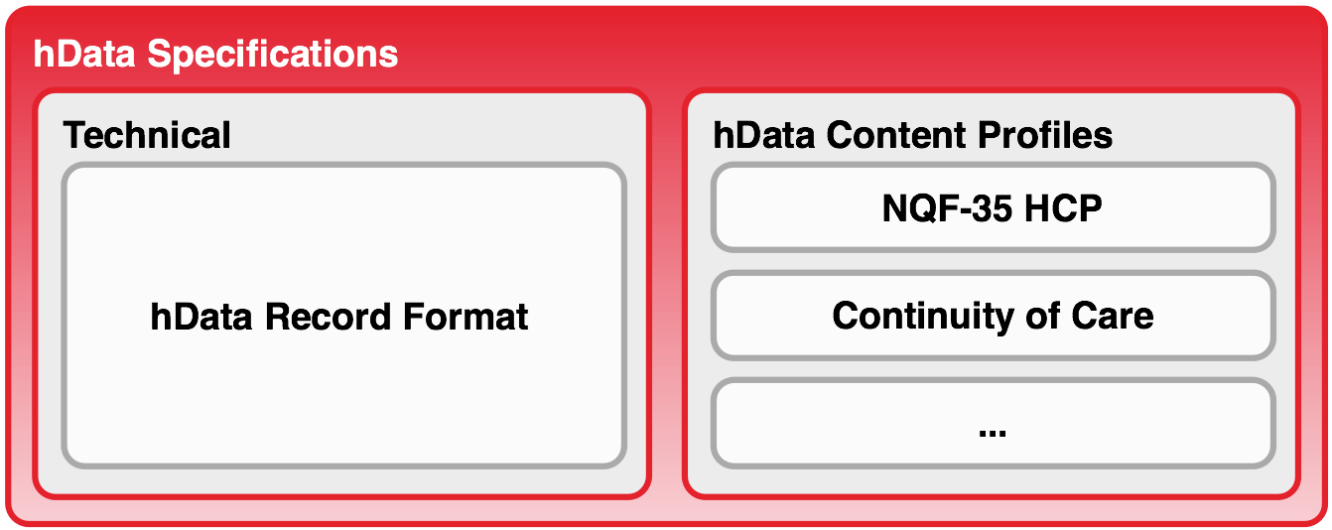
- EHR technologies are currently at the heart of the national U.S. Health Care debate
  - Promise of significantly improved efficiencies and cost savings
    - Fewer repeated tests and procedures
  - Improvements in the quality of care
    - Less communication errors
- EHR systems have been around since the 1960s
  - Massachusetts General Hospital MUMPS and Intermountain HELP system
  - Some current EHR systems still use MUMPS: Veterans Administration's VistA
  - There are over 100 "modern" EHR implementations
- Yet, adoption rates in the general medical community have been very low as of 2009:
  - Less than 11% of U.S. Hospitals have comprehensive EHR systems
  - Less than 18% of physicians have access to EHR systems
- Deployed EHR systems are often non-interoperable

Interoperability Issues with EHRs

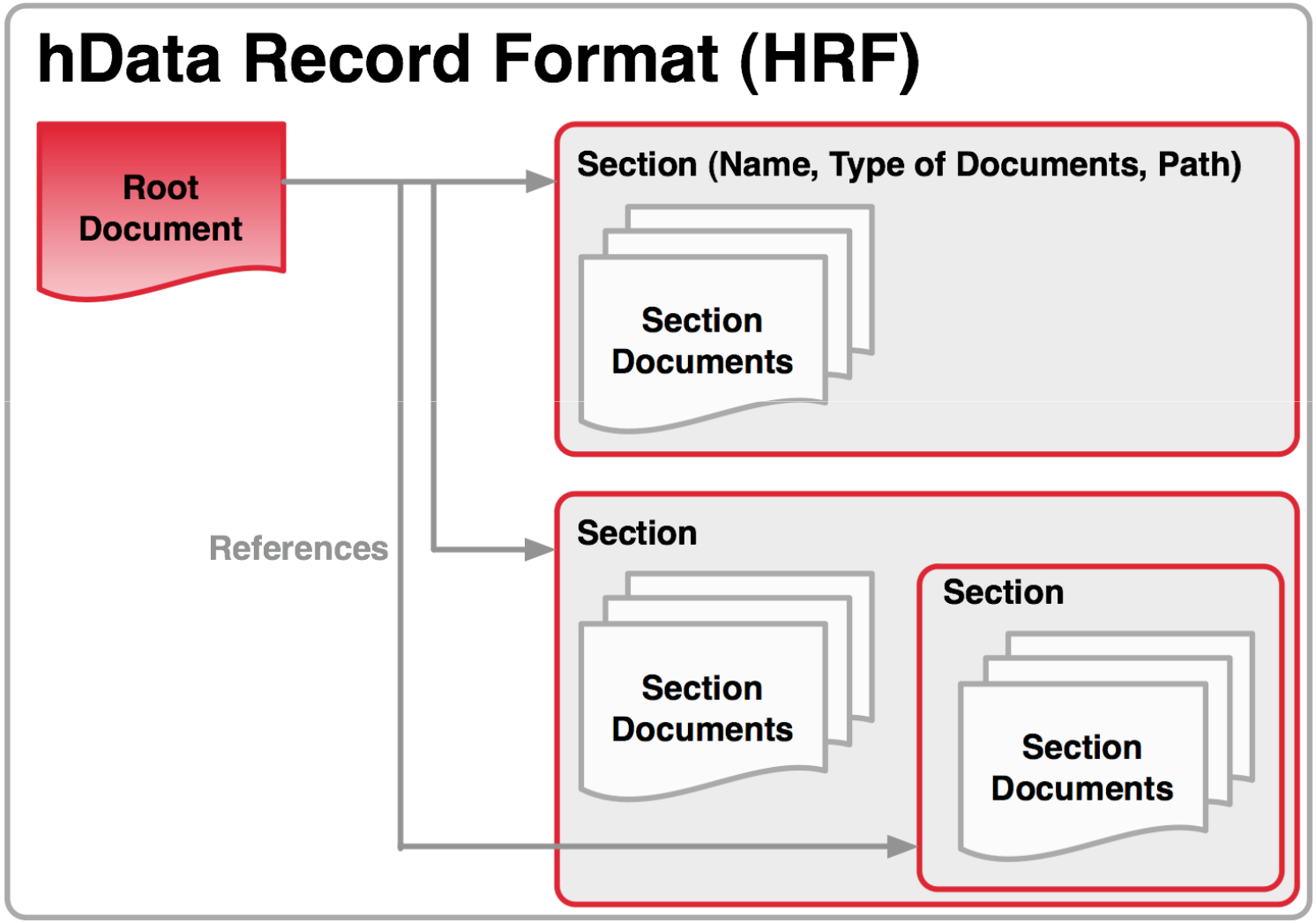
- Recent History
  - HL7 created the XML-based Clinical Document Architecture (CDA) in the late 1990s
  - Continuity of Care was an early use case
  - ASTM International adopted competing CCR standard
  - Reconciled as “Continuity of Care Document” (CCD)
  - HITSP continued reconcilation and profiled CCD as C32, now C80 & C83
- Current standards are difficult to use
  - Repeated use of overly abstract data structures
  - Underspecified implementation, including lack of a normative schema
  - Ambiguous data types
  - Steep and long learning curve
- Current standards and profiles lead to EHR Systems that cannot easily exchange interoperable data

Introducing hData

- hData is a new approach to EHR standards
  - Design approach: KISS
  - Strict separation of content and format: medical community defines the content, technical community defines the format
  - Machine and human readability of source XML is important
- Collection of linked, but standalone XML documents
  - MUST provide schema, so docs can be validated
  - Goal is to have small XML documents



HRF Abstract Structure



Root Document

- Contains necessary metadata for processing
  - Content description, including processing advice
  - Location of Sections
  - Basic information (Created, LastModified, etc.)

```
<root xmlns="http://projecthdata.org/hdata/schemas/2009/06/core">
  <documentId>c64e620d-f648-4531-9703-14b37afefc2c</documentId>
  <version>0.1</version>
  <created>2009-07-12-04:00</created>
  <lastModified>2009-07-12-04:00</lastModified>
  <extensions>
    <extension requirement="mandatory">
      http://projecthdata.org/hdata/schemas/2009/09/patient_information
    </extension>
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Extensions contain Types that MAY be within a single hData Record (HDR)

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Section can contain subsections

Serialization of an HDR

- Simplicity as a goal
  - Sections are represented by file system folders
  - Serialize individual XML documents into respective folders
  - The root documents goes into the base folder
  - Store the file hierarchy in a ZIP archive
- Common approach
  - Inspired by Open Document Format and JAR packaging
- Benefits
  - Easy to implement, well understood
  - XProc friendly (especially with Calabash extensions)

Web Representation

- HRF Structure maps naturally to URLs
  - Base URL identifies the record
  - Section paths map naturally to relative URLs
  - Section documents are of Content Type application/xml
- Section URLs resolve to Atom feeds
  - Default feed: contains section documents
  - Alternative feed: contains child sections

`http://example.com/hdata/patient1234/adversereactions/allergies/1.xml`

Record Identifier

Resolves into root document or user interface

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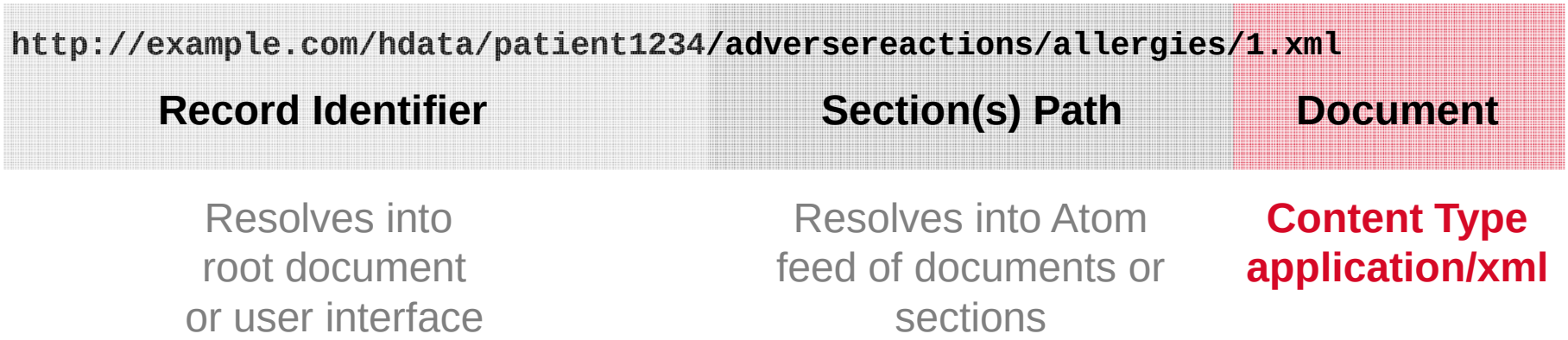


RESTful API

- All entities are subject to RESTful operations (GET, PUT, POST, DELETE)
  - Entire hData Record
  - Sections or child sections
  - Individual section documents
- Some operations may not be defined on a resource
  - For example: the root document may only be accessed by GET
- Only limited processing instructions are specified
  - For example
    - Section modification operations trigger an update to the root document
    - Extensions may be added or removed only on the hData Record resource
    - Audit log processing is not specified

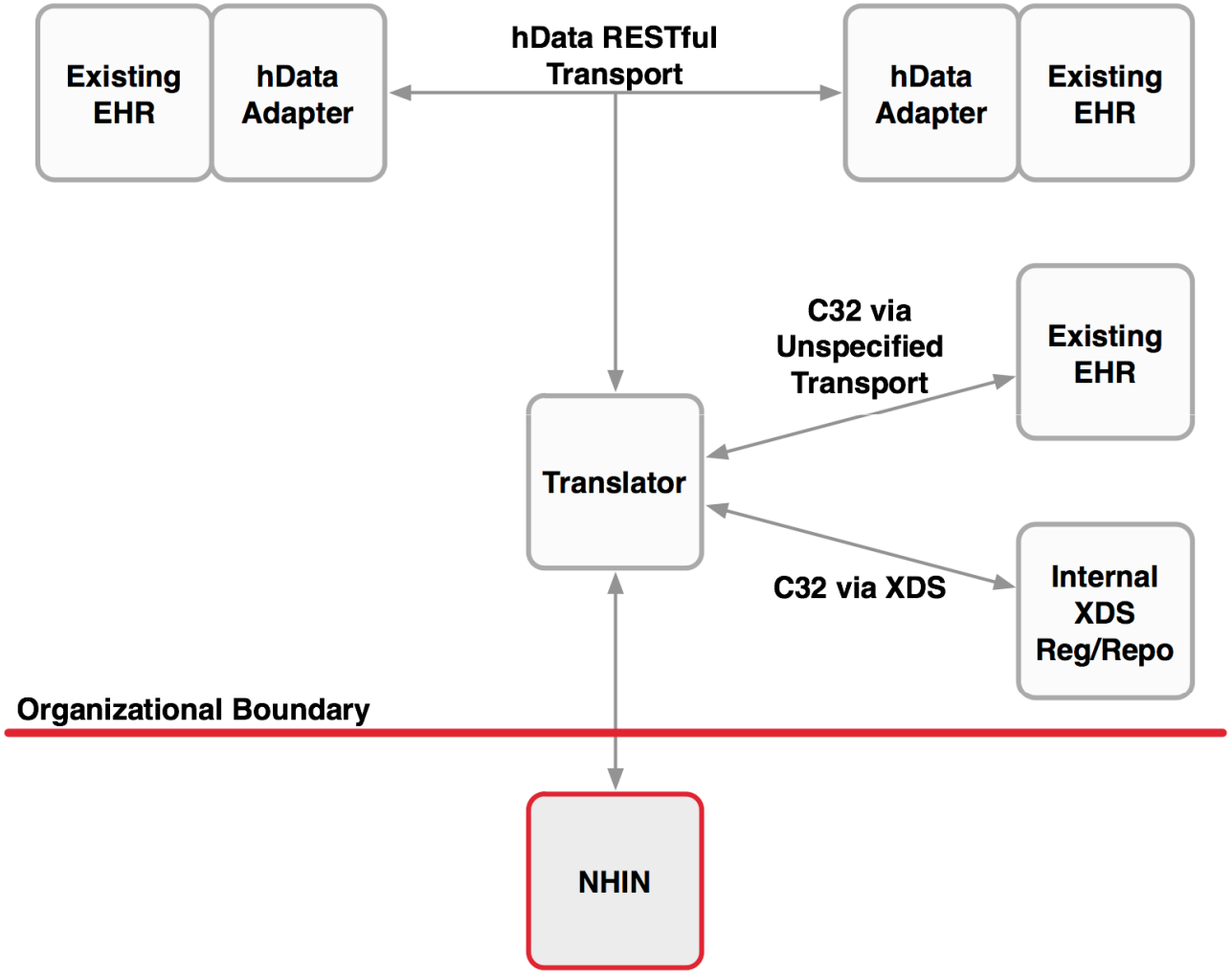
Departure from Tradition

- Traditional health records are a snapshot in time
  - Paper based: copy of current records are shipped
  - CDA-based EHRs: electronic representation of “point-in-time” records
  - Discrete information transmission through HL7 messages introduces additional complexities
- An hData Record is a living document
  - Once an hData Record resource location is known, services can subscribe to content feed
  - Automatic, timely updates and changes based on open standards
  - Service consumers can copy an entire hData Record information for “point-in-time” documentation purposes
- Subscription access can be cut off
  - For example: Patient changes specialist – no further access for that specialist to the patient’s hData Record is necessary

hData Content Profiles

- The hData Record Format only defines the data architecture and the exchange API of an hData Record
  - Technical community can modify the hData structures and protocols without interfering with the contents
- hData Content Profiles (HCPs) define the content
  - Section location
  - Section document types
  - HCPs are typically generated by the medical community, independent from the HRF
- An hData Record may conform to one or more HCPs
- All hData system implementations must implement the NQF-35 HCP
  - The National Quality Forum identified the 35 most important health data elements
  - The 35 data elements maps to 13 hData section document types
  - NQF-35 HCP conformance requirement limits “section and path proliferation”

hData Deployment and Integration

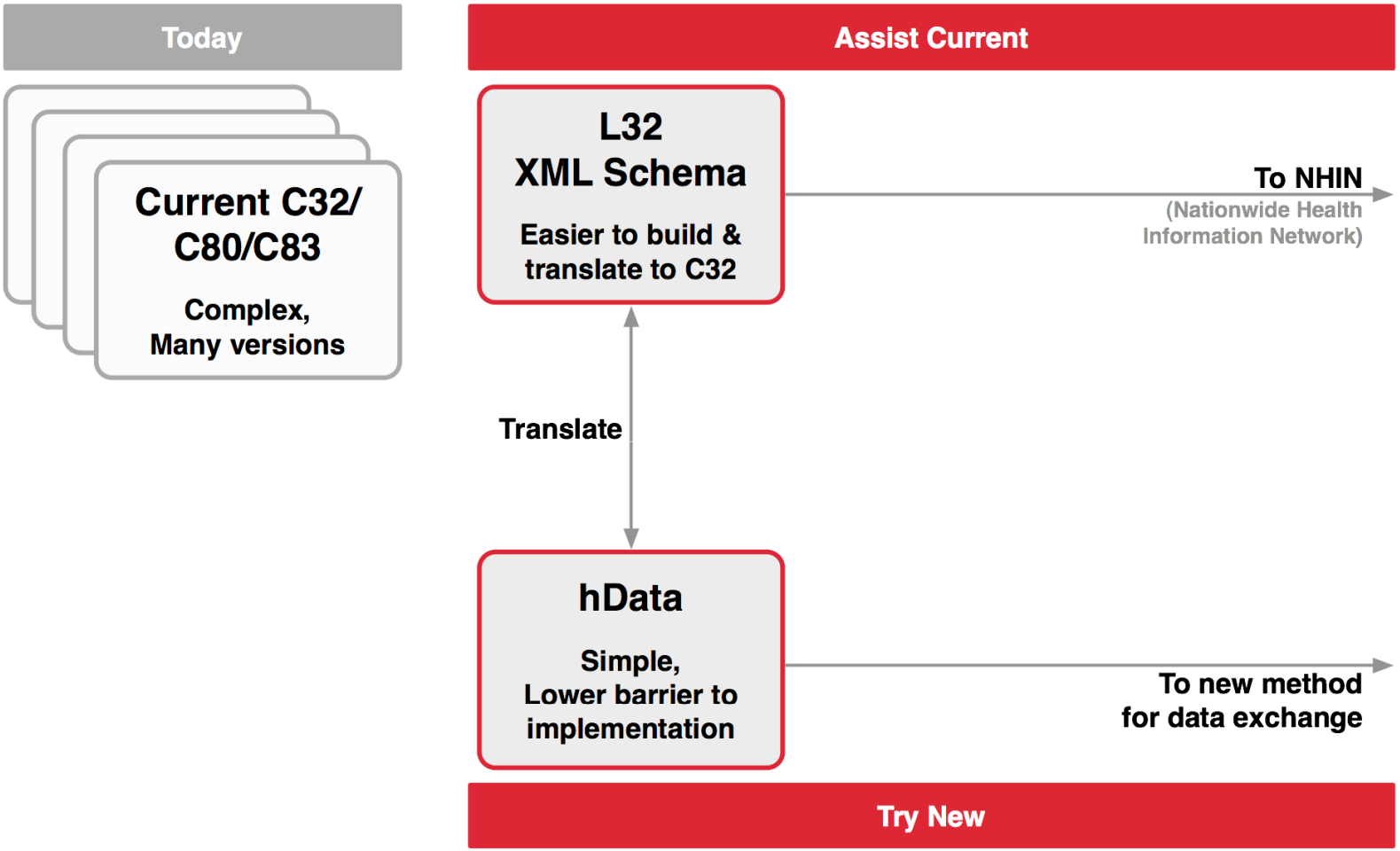


hData

Legacy Alignment: "Lightweight C32 Implementation"

- MITRE-funded initiative to develop an XML schema for C32-based documents
- Called L32 for "Lightweight C32 Implementation"
- Intended to be a single consistent, machine-interpretable implementation of the C32 (i.e., Continuity of Care) specification
- Results in HITSP/C32 compliant instance document
- Benefits
  - Provides a migration path from CDA-based document architecture
  - Restricts C32 further to assist processing
  - Allows conformance with U.S. EHR requirements
- Limitations
  - Retains complexities of CDA
  - Only addresses Continuity of Care content

Putting it together



Parallel approach offers alternatives to speed interoperability

The Road Ahead

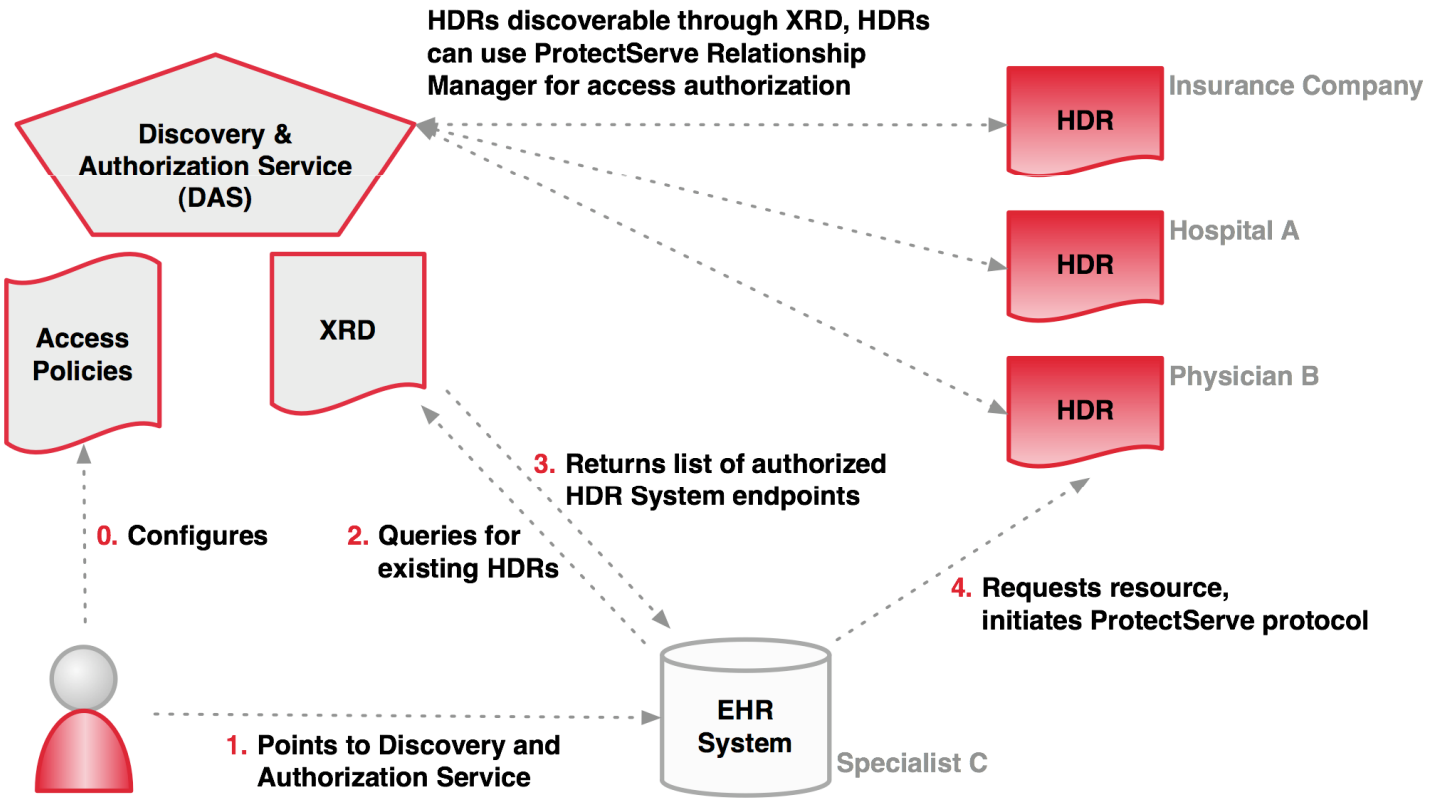
- Current hData specifications are focused on the data architecture and basic content vocabulary only
- For a full EHR technology deployment, critical components are missing:
  - Access Control
  - Identity and Privacy Management
  - Patient-centric Empowerment
- We are investigating potential solutions

Access Control, ID Mgmt, & Privacy

- Basic access control
  - Section path (= relative URL) based
  - Easy to implement
  - Coarse granularity – section documents are the unit of protection
  - May cause section proliferation (e.g., separation of behavioral records in separate tree)
- Privacy and Access Management
  - Looking at “ProtectServe”, a four-legged OAuth protection scheme which has been submitted to Kantara Initiative for standardization
  - Focus on protection of PII and HIPAA compliant profile
- Future requirements
  - Minimally: Section document based granularity
  - Ideally: XML node based access control
  - Problems are similar to MLS/CDS systems
  - Other ideas: signed section documents

Patient Empowerment

- Scenario: Patient sees a specialist for the first time and wants to authorize the specialist's EHR system to access different hData Records at PCP, hospital, etc.



Conclusions

C32

- Voluminous spec, repeated use of overly complex data structures
- Underspecified, including lack of normative schema
- Overly abstracted and ambiguous data types
- Steep and long learning curve
- No patient involvement in EHR management

hData

- Concise specification with strict separation of structure and content
- Commercial tools can validate and create instances
- Human and machine understandable terms
- Easy to learn and implement, accelerating innovation and reducing cost
- Patient-empowerment will enable patient-directed care and flexible delegation

Resources

- hData home page: http://www.projecthdata.org/
  - Current versions of the hData Specifications
    - hData Record Format
    - NQF-35 hData Content Profile
  - L32 information
- Feedback: talk@projecthdata.org

Questions?

Backup

C32 Examples

Section Identification

```
<component>
<section>
  <templateId root="2.16.840.1.113883.10.20.1.16"/> <!-- Vital signs section template -->
  <code code="8716-3" codeSystem="2.16.840.1.113883.6.1"/>
  <title>Vital Signs</title>
  <text>
    <table border="1" width="100%">
      <thead>
        <tr><th> </th><th>July 9, 2008</th></tr>
      </thead>
      <tbody>
        <tr><td>Circumference.occipital-frontal</td><td>43 cm</td></tr>
      </tbody>
    </table>
  </text>
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Pseudo-HTML

hData

```
<entry typeCode="DRIV">
  <organizer classCode="CLUSTER" moodCode="EVN">
    <templateId root="2.16.840.1.113883.10.20.1.35"/> <!-- Vital signs organizer template -->
    <id root="c6f88320-67ad-11db-bd13-0800200c9a66"/>
    <code code="46680005" codeSystem="2.16.840.1.113883.6.96"
          displayName="Vital signs"/>
    <statusCode code="completed"/>
    <effectiveTime value="200807091430"/>
    <component>
      <observation classCode="OBS" moodCode="EVN">
        <templateId root="2.16.840.1.113883.10.20.1.31"/> <!-- Result observation template -->
        <id root="c6f88321-67ad-11db-bd13-0800200c9a66"/>
        <code code="8287-5" codeSystem="2.16.840.1.113883.6.1"
              displayName="Circumference.occipital-frontal"/>
        <statusCode code="completed"/>
        <value xsi:type="PQ" value="43" unit="cm"/>
      </observation>
    </component>
  </organizer>
</entry>
```

Generic Data Containers