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A Robust Health Data Infrastructure

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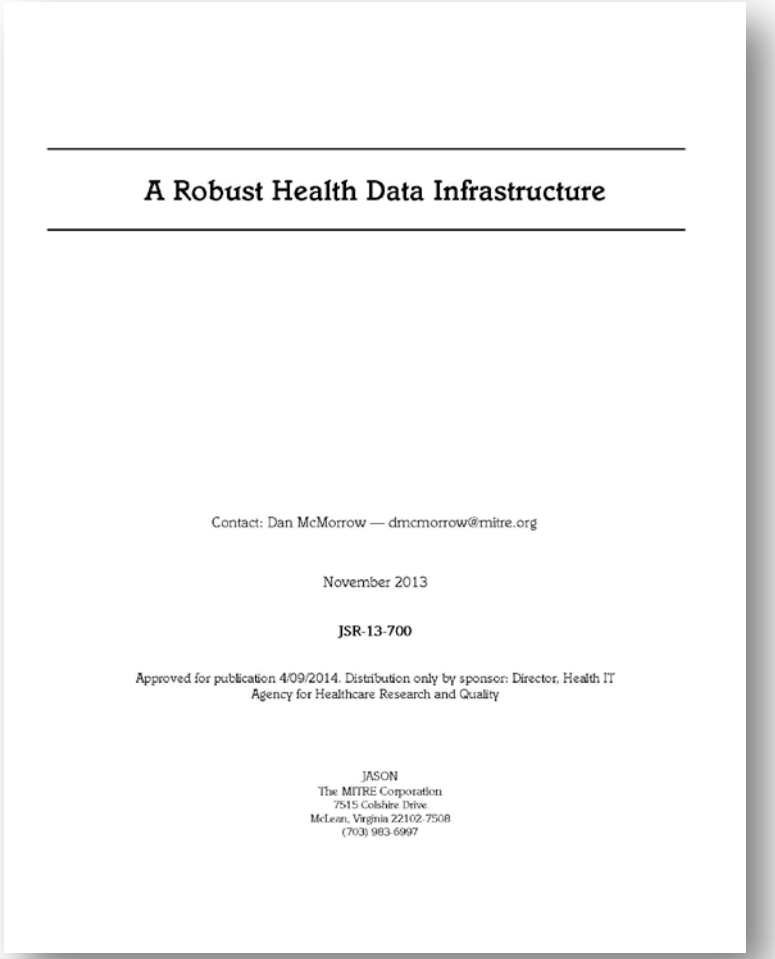
About the report

- Sponsored by AHRQ in collaboration with ONC and the Robert Wood Johnson Foundation
- JASON is an independent scientific group that provides consulting services to the US government on matters of science and technology. It was established in 1959.



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Study Charge

- How can **complex data handling techniques** and **Internet-based technologies** be applied to health care to promote the development of **real-time integrated datasets** at a scale seen in other industries?
- How can the various users of health data in the **clinical research and public health** communities be presented with **tailored and highly specific data views in near real time** based on routinely collected health data?
- As health data grows from megabits to gigabits per individual, what **fine-grained analytics** should be made available to **patients and health care providers** to guide health care decisions?
- What **fundamental data management capabilities** are needed to support potential future requirements in an open-ended manner?
- What are the **national security consequences** of not addressing comprehensive health data opportunities in clinical research and public health?

Briefing Organizations

Arizona State University	The Broad Institute	Cornell University	Deloitte
Digitalmill	HIMSS	IBM	Kaiser Permanente
Microsoft	National Quality Forum	Stanford University	UC Davis
UC San Diego	University of Iowa	Vanderbilt University	The White House

Challenges identified

- Federation
- Jurisdiction
- Scalability
- User interface
- Interdisciplinary
- Front loaded cost
- Payer
- Business Model
- Exchange concept
- Data security
- Data integrity
- Access and curation
- Consent
- Intellectual property
- Legal liability

Key Findings

- The current lack of interoperability among data resources for EHRs is a major impediment to the unencumbered exchange of health information and the development of a robust health data infrastructure.
- Interoperability issues can be resolved only by establishing a comprehensive, transparent, and overarching software **architecture** for health information.
- The twin goals of improved health care and lowered health care costs will be realized only if health-related data can be used in the public interest, for both clinical practice and biomedical research.
- That will require implementing technical solutions that both protect patient privacy and enable data integration across patients.

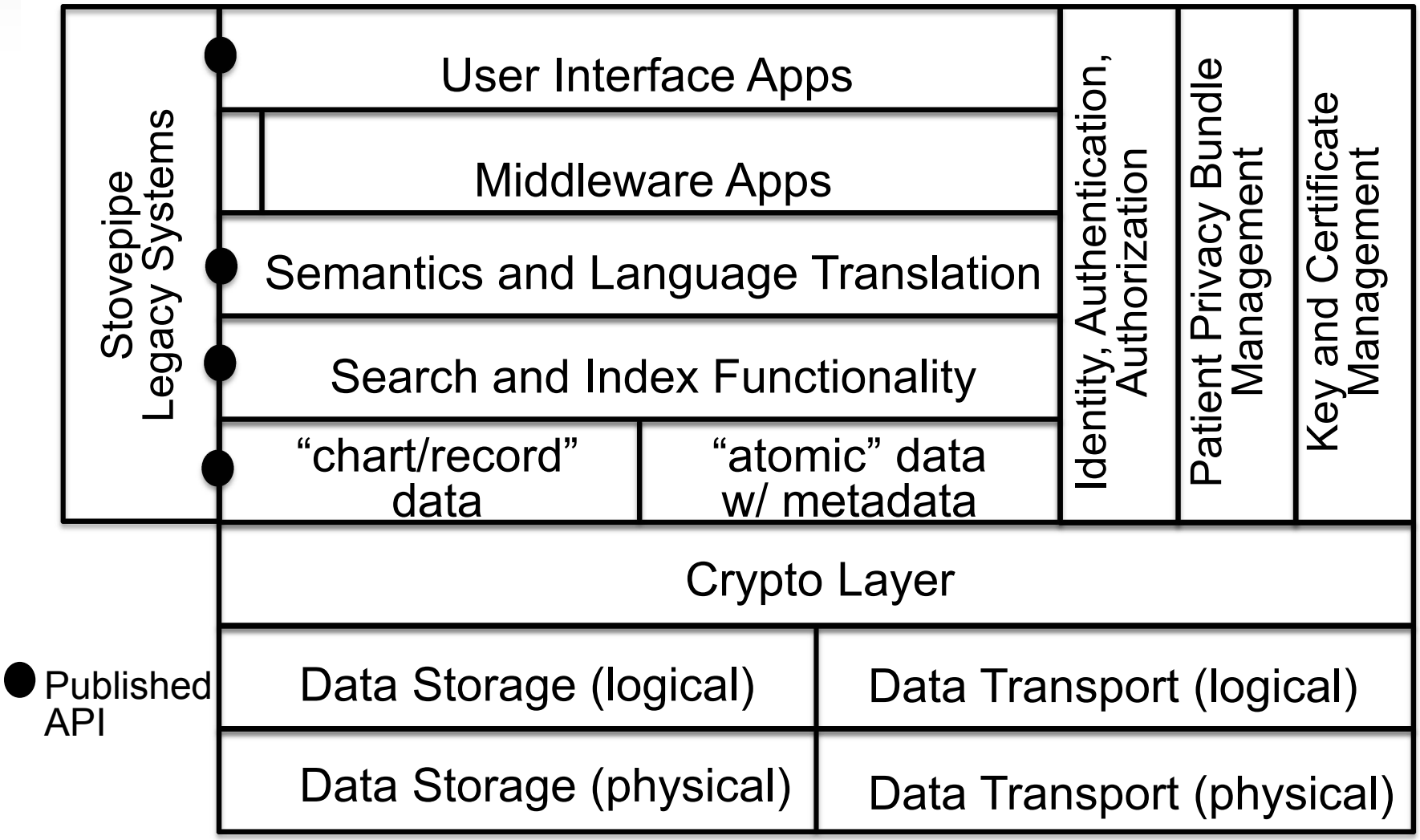
Software Architecture

- For the purposes of this report, a software architecture defines a set of interfaces and interactions among the major components of a software system that ensures specified functionality.

Health IT Architecture Principles

- The patient owns his or her data
- Be agnostic as to the type, scale, platform, and storage location of the data
- Use published APIs and open standards, interfaces and protocols
- Encrypt data at rest and in transit
- Separate key management from data management
- Include metadata, context, and provenance of the data
- Represent the data as atomic data with associated metadata
- Follow the robustness principle: "*Be liberal in what you accept, and conservative in what you send.*"
- Provides a migration path from legacy EHR systems

Example Architecture



Patient Privacy and Risk Management

- A patient privacy bundle is a collection of fine-grained settings of default permission and inheritance settings for access privileges to electronic health data.
  - Both atomic data and metadata must be associated with permissions
  - The patient controls access by electing a privacy bundle
- A fine-grained permission system is flexible, and can accommodate many different types of security policies
- The choice of a patient privacy bundle implies an assumption of different levels of risk by the patient in return for different benefits for themselves and society

Recommendations (selected)

- Within 12 months, ONC should define an overarching software architecture for the health data infrastructure.

- EHR vendors should be required to develop and publish APIs that support the architecture of the health data infrastructure.

Topics for Discussion

- ONC should define an architecture this year.
- Patient privacy and related risk management should be addressed by the use of patient privacy bundles.
- The architecture should be supported by openly developed, published and tested APIs.