Health Data Standards: An Enabling Component in Quality Care Systems

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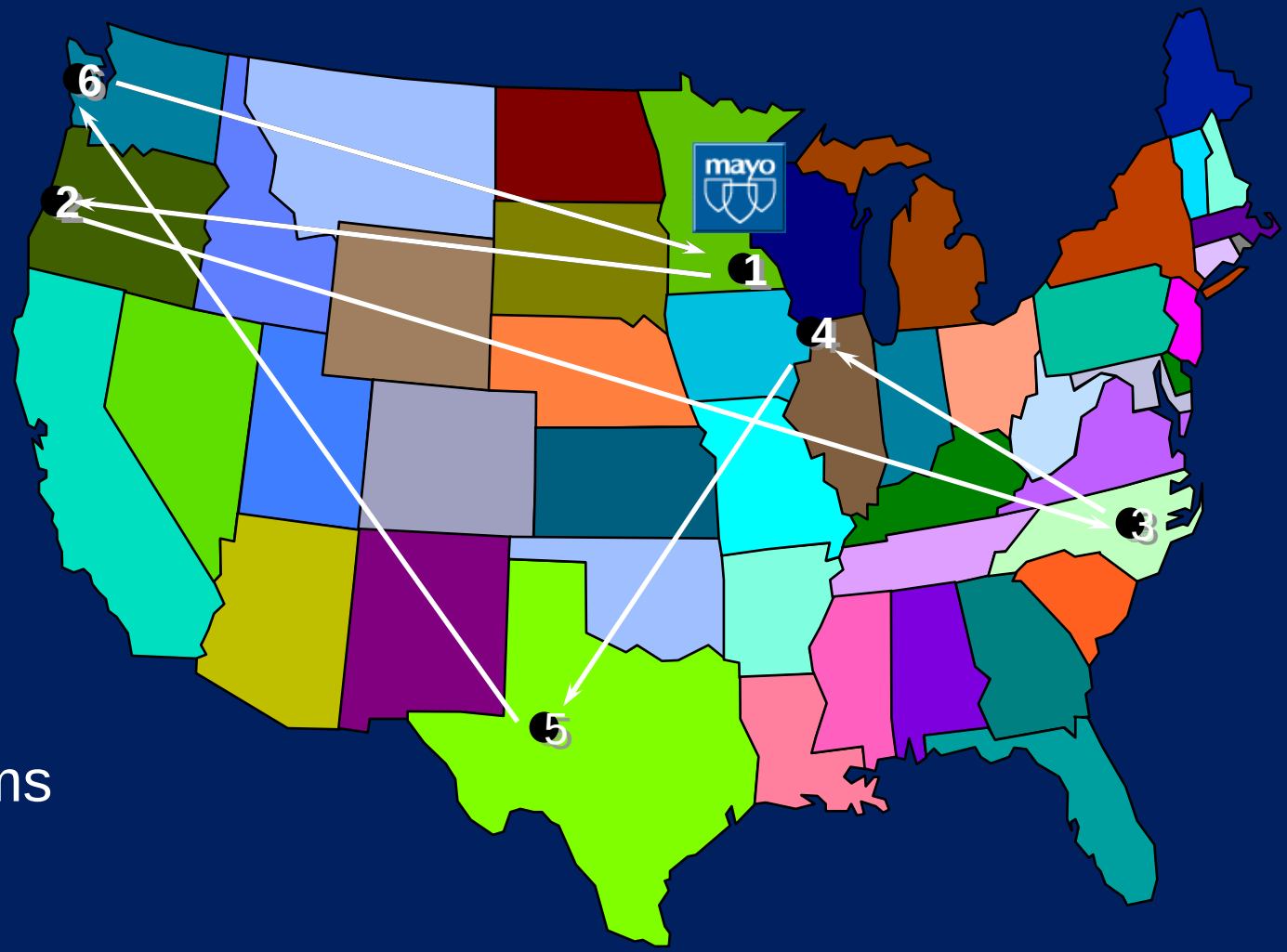
20-year Episode of Chronic Illness: the story of Jerry, a diabetic



- 6 sites
- 8 systems

From Dr. Paul Carpenter, Mayo

A Mother's Dilemma

Source: President's Commission on Systemic Interoperability

Melissa Santini's two-year old son, Rocco, has six doctors and counting. When he was 10 months old, Rocco developed severe digestive problems. Since that time, he has been referred to several specialists. After exhaustive and repeated testing, doctors have ruled out certain diseases – but no one has been able to diagnose Rocco's condition which continues unabated.

Melissa is at the breaking point. She carries around an expandable file full of Rocco's x-rays and test results. Every time Rocco goes to a new doctor or new medical facility, she has to repeat the litany of his medical care and fill out the same forms numerous times while trying to hang onto two-year-old Rocco and another energetic four-year-old son. With the incredible volume of information she has been forced to memorize, she can barely remember what happened with Rocco just last week, let alone recount the chronology of his entire medical history.

continued

She cannot understand why all this information is not available on one digital record, or why she has to fill out the same paper forms every time she takes Rocco in for an appointment. She is incensed that in today's world, a nurse writes Rocco's weight on a yellow sticky note and loses it before it gets entered into his paper chart. She wants to be able to access her son's medical test results on line, rather than wait for days for a doctor to call her back.

She is also concerned that her son has to repeat tests. "They referred us to a pediatric GI doctor, and he basically did all the same tests that the other doctor just did. I had to wait another two or three weeks for him to retest all of the things that had just been tested, even though I had copies of them that I had to pay for from my pediatrician's office. That just made me furious." She is concerned that there's no way for all the doctors to get together to review all the medical records. She is livid … and her son is not getting better.

RHIO Example

Patient presents with chest pain at the Emergency Room of Baptist Hospital in Memphis, Tennessee. Baptist Memorial Hospital participates in the MidSouth eHealth Alliance, an AHRQ demonstration Regional Health Alliance through which data is available from other health care facilities (specifically Emergency Departments) within the region. The ER physician accesses the patient's electronic medical record and notes that the patient was seen just two days before at the Methodist Le Bonheur Healthcare system. There the patient had undergone cardiac testing in which all the findings were negative. The ER physician first, did not redo the tests, treated the problem as non-cardiac, and reassured the patient. The result was immediate response and appropriate treatment, non-redundant testing, and a considerable savings in cost.

Incidentally, the Christ Community Health System doesn't have EHRs, but its 4 clinics and mobile van send limited data to the RHIO and use the RHIO as their EHR.

Current Concerns

- Patient safety – increased concerns related to prescription drug errors
- Demand for better quality – only 54% receive appropriate care
- Cost containment resulting from unnecessary and redundant tests
- Public health including health surveillance and handling health problems in natural disasters
- Accommodating an aging and mobile population including effective management of chronic disease
- Consumer sophistication and involvement in their own health; consumer dissatisfaction and lack of trust in current health system
- Increasing importance of secondary uses of data – translational medicine

Healthcare Indicators

	Expenditures per capita	Life expectancy at age 60	Preventable deaths per 100,000 pop.	Access Problems	5 Yr. survival breast cancer	MI 30 day hospital mortality	Deaths from surgical or medical mishaps per 100,000 pop
Australia	$2,876	18.2	88	34	80	8.8	0.4
Canada	$3,165	17.7	92	26	82	12	0.5
France	$3,159	18.4	**75**	n/a	79.7	**8**	0.5
Germany	$3,005	17.5	106	28	**78**	11.9	0.6
Japan	$2,249	19.6	81	n/a	79	10.3	**0.2**
New Zealand	**$2,083**	17.1	109	38	79	10.9	n/a
UK	$2,546	16.9	**130**	**13**	80	11	0.5
US	**$6,102**	**16.6**	115	**51**	**88.9**	**14.8**	**0.7**

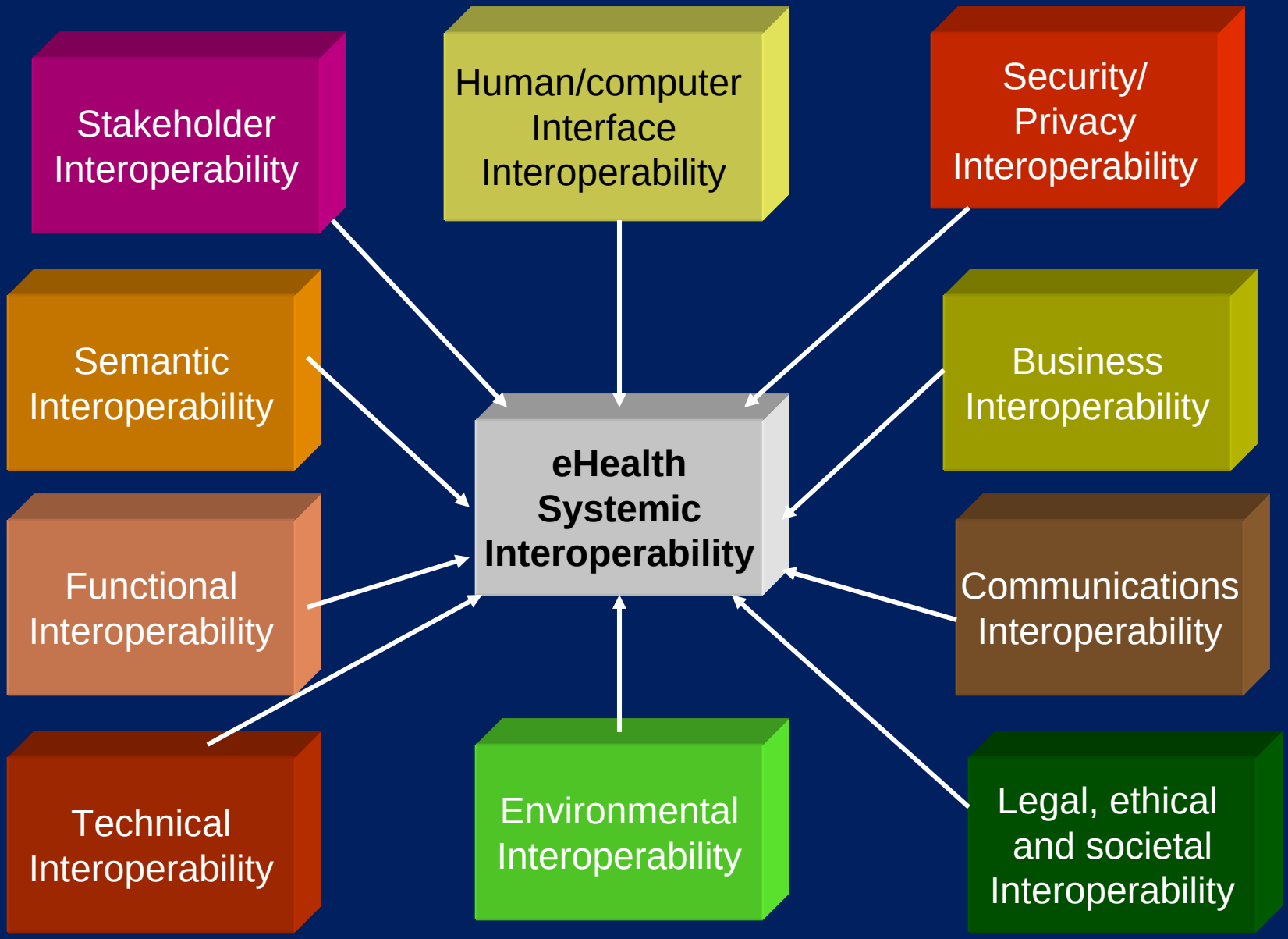
Source: BMJ

Solution requires …

- Data at point of care
  - Complete, aggregated, timely, trustworthy, unambiguous, reusable, logically accessible
- Knowledge at point of care
  - Evidence-based, up-to-date, computer-usable
- Processes and work flow
  - Effectively and efficiently combine data with knowledge to enable optimal human decision making
  - Monitor decisions and results and provide safety checks, feedback and recommendations
  - Integrate data collection, presentation and decision support transparently into care delivery process

Putting it all together requires :

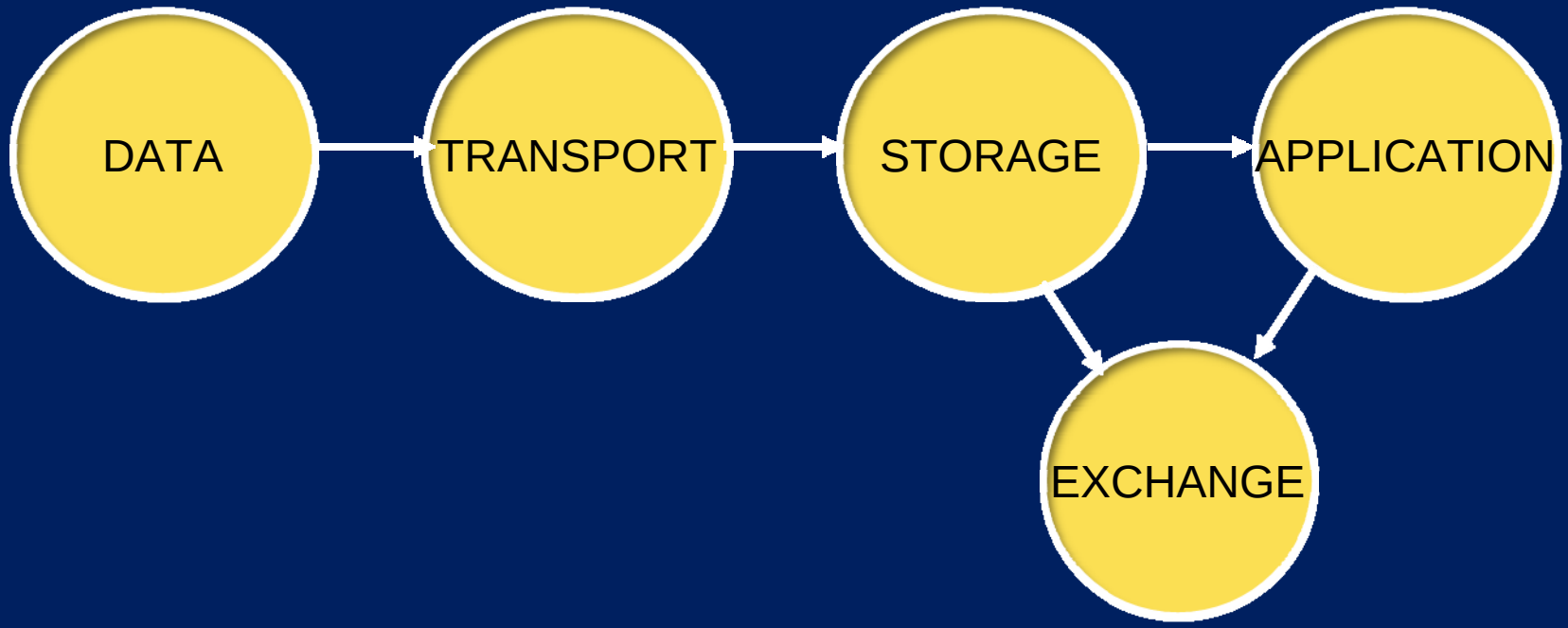
- A common vision, a common goal, a common process
- Working together with all stakeholders
- Collaborative efforts with effective resource utilization
- Interoperability …
- Standards …


Stakeholder Interoperability
Human/computer Interface Interoperability
Security/ Privacy Interoperability
Semantic Interoperability
eHealth Systemic Interoperability
Business Interoperability
Functional Interoperability
Communications Interoperability
Technical Interoperability
Environmental Interoperability
Legal, ethical and societal Interoperability

Stakeholder Interoperability

- The stakeholders must include all persons who are involved in all processes associated with a given task.
- The usual list includes providers, vendors, payers, consultants, government, and consumers.
- Who has been left out?
  - Suppliers, regulators, employers, informaticians, knowledge brokers, commercial laboratories, device manufacturers…
- For example, consider who all might be involved in the process of ordering a lab test, getting the specimen, process the test, reporting the results and storing the results as part of an EHR.

Interoperability



Semantic Interoperability

- The basic element for semantic interoperability is the data element with all of its attributes
- Attributes include a unique code, a name (ontology, terminology, vocabulary, nomenclature, classification), a precise and unambiguous definition, data type, units, a value set, synonyms, other functional attributes depending on the nature of the data element
- Important are both content and syntax of data element.

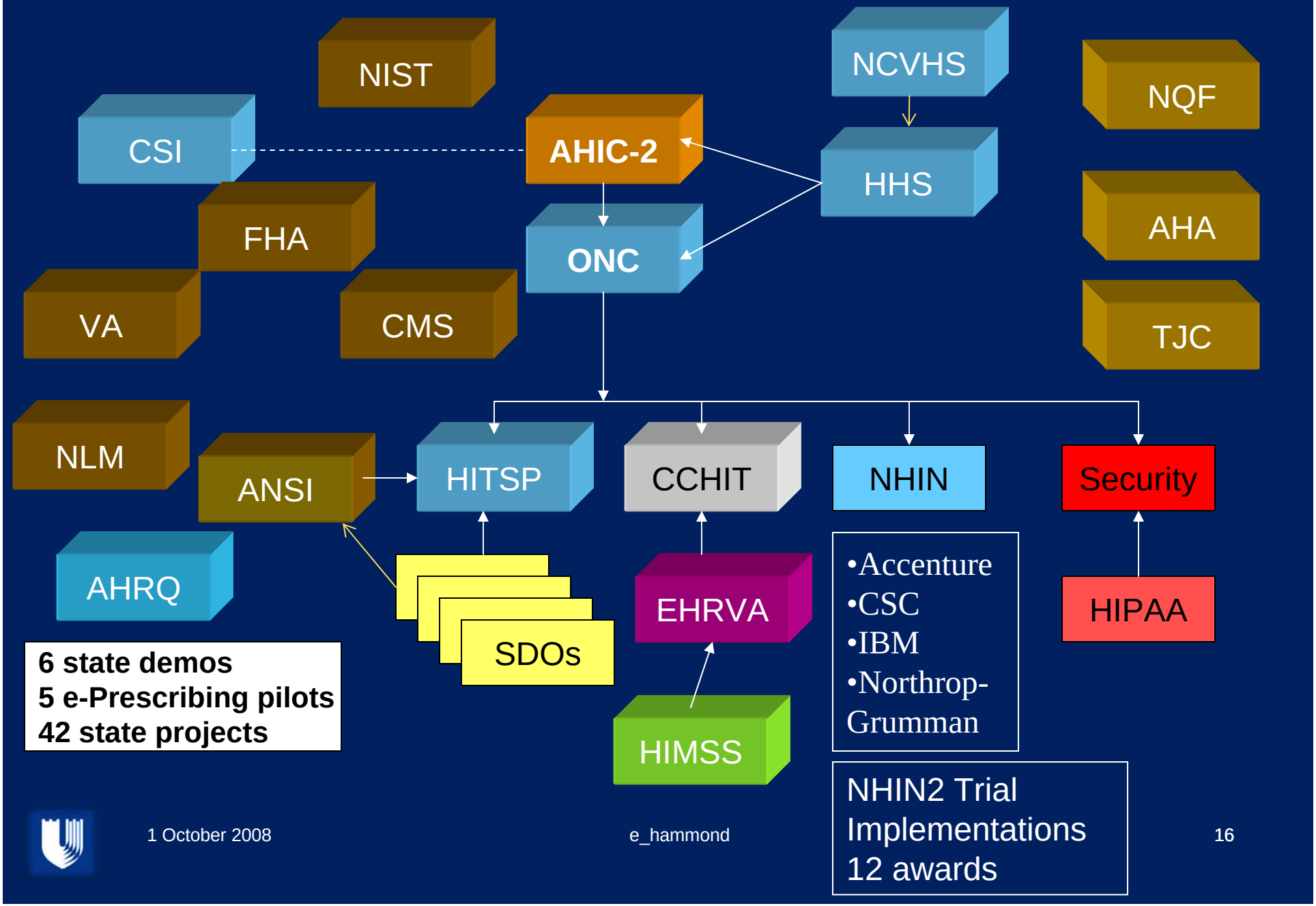
Semantic Interoperability

- Reference Information Model: defines all data items, entities, acts, roles and relationships. [ISO/HL7 RIM is a global standard.] [CEN 13606]
- Data models [BRIDG (CDISC, caBIG, HL7), CEN, ISO]
- Templates [HL7]
- Archetypes [openEHR, CEN 13606]
- Common Message Element Type [HL7]
- Clinical Statements [HL7]
- Detailed Clinical Models [HL7]
- Clinical Document Architecture [HL7]
- Continuity of Care Record [ASTM]
- Continuity of Care Document [HL7/ASTM]
- Structured Documents [DICOM]

Other Standards

- Transport Standards (data, audio, images, waveforms) (HL7, CEN, DICOM, ISO, ASTM)
- Communication Standards (W3C, IETF, IEC, ITU)
- Security and Privacy Standards (Authentication, Digital Signature)
- EHR Content, Architecture and Functional Requirements (HL7); Certification (CCHIT)
- Decision Support including Research protocols and guideline specifications, InfoButtons (HL7)
- Medical devices, barcodes, geographical standards (GIS)
- Patient identifiers, provider identifiers, profiles for data interchange (XDS)
- Implementation guides, tool sets

What is the infrastructure in the United States?



So, where are we?

- Technology is adequate to move ahead.
- Standards are adequate to move ahead.
- Healthcare system contains adequate money to move ahead.
- Public and private interest for solving problem is at all time high.
- Pressures are high, and the reasons are all right.

Why are we still stuck?

- Failure to cooperate and collaborate; competition is high.
- Leadership fails to lead. Leaders fail to make tough decisions.
- Vision is not shared; products are not shared.
- Stakeholder community does not look beyond its own borders for solution. No one does their homework.
- Too much concern about who will pay for it and who will own it.
- It takes more than we have been willing to give.

What the future might bring

- An EHR designed to take full advantage of technology and embraces new concepts
- Push technology that delivers what the provider needs in form, time, content, and based on the next event
- Dashboard presentations based on closed loop systems. Heads-up displays; instant awareness.
- Providers not only accept EHR but change the way they practice medicine (a necessity)
- Connectivity and completeness
- Enables accessibility wherever the patient is
- Reusability
- Establish and track metrics for health outcomes, quality of care, performance, access, disparities, and efficiency
- Permits projection for resource requirements for health care