

Looking Ahead: Data, Systems & People Standards



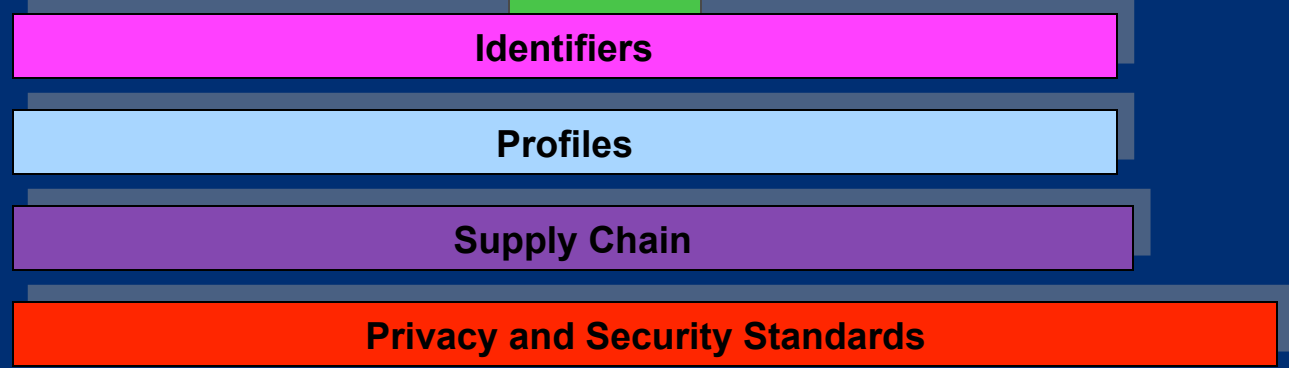
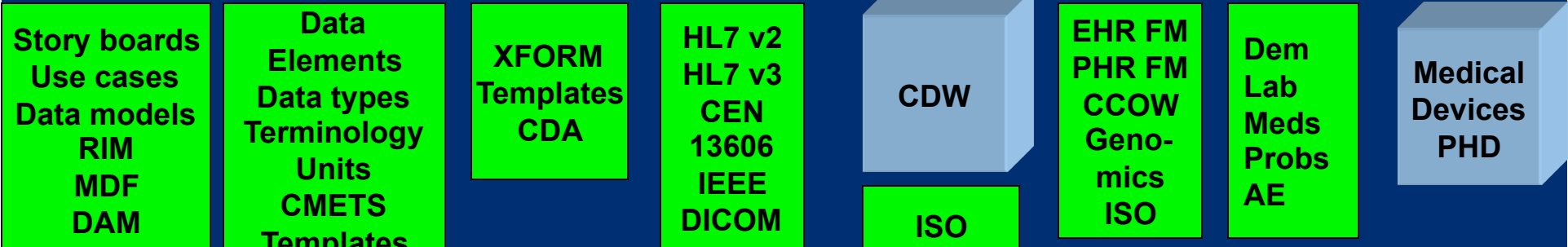
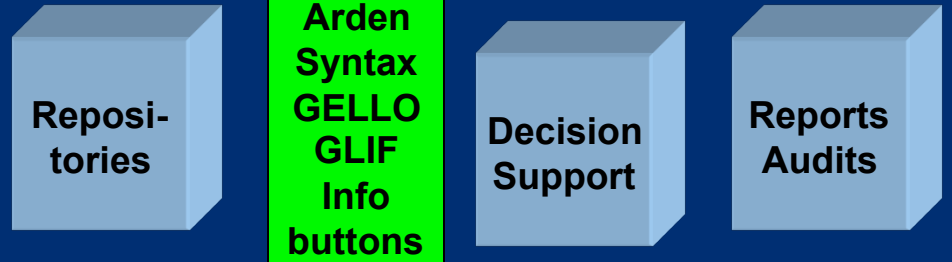
Duke Center for Health Informatics



If God created the earth in six days ...

then why are we still struggling with HIT standards after 25 years???

ISO, CEN, HL7, CDISC, DICOM,
IEEE, IHTSDO, LOINC, GS1,
IHE, NCPDP, X12, openEHR,
WHO/ICD, ...



- Patient-centric
 - Aggregation
 - Data transport
 - Merger
 - Standards
- Sharing
 - Query
 - Transport

What can we learn from history?

- Early work focused on a specific problem – we know what we wanted to do and we knew the customer – us.
- We knew the environment and we optimized the standard to perform in that environment.
- The solution was straight forward, simple, easy to understand, and easy to implement.
- Over 95% of US hospitals use v2; most state HIE will use v2
- V2 supports local, enabled interoperability
- Then the world became complicated. We became academic, creating complex standards based on models forgetting what users will need and us..
- In fact, we have difficulty in understanding who the user is.

Jumping ahead

- The creation of today's standards are isolated from the domains and persons who will be using the standards.
- Development is too fragmented, too technologically focused, too siloed.
- Groups creating standards have not been sensitive to the changing landscape and to what new problems we need to solve.
- We have not engaged the experts in the domain we are addressing.
- There has been an increasing disconnect between SDOs and what the using community really needs.

Wherein lies the solution?

- Understanding what standards are needed and what they should do means an integrated merger with the vision and goals of the future of health care.
- Standards must be part of the merging environments in the fields of biomolecular informatics, clinical research informatics, patient care informatics, community informatics, public health informatics and population health informatics; and, of course, person informatics crosses all domains.
- We technologists need to learn to listen and find the problem to be solved, not biased by the way it is now done as a result of the available tools.

What we've missed

- We look at only one part of the problem, and the disconnect makes the brilliant solutions meaningless.
- Examples
 - HIE aggregates data on the basis that providers will use data from sources other than recreating the data. Do you believe that will happen without standards to guarantee quality, integrity and trust?
 - Brilliantly architected systems to support exploitation of clinical databases fails to associate data with the encounter
 - System designed for consumer interaction fails to recognize that consumers have no access to the system

So back to the real world

- A problem that is not solved remains a problem.
- Many of the problems are solvable, but we must break a few eggs. What exists is the most difficult barrier to overcome in introducing new concepts.
- Too often the first concepts, first design, first architecture dominates what can happen in the future.
- How do we overcome momentum biased by money, competitive advantages, existing system, and customer reluctance to change?
- Two easy examples
 - Unique, ubiquitous personal identifier
 - Language

Quotes from *The Unfolding of Language* – *The evolution of mankind's greatest Invention*

- Compared to language, all other inventions pale in significance since everything we have ever achieved depends on language.
- Language influences the ability to learn, the ability to describe, the ability to understand, the ability to remember, and the ability to communicate effectively.
- In health care environment, we use terminologies invented for other purposes, and we use mapping as a solution.
- Languages are developed independently by all the communities now attempting to come together.
- We have forgotten the Bible story of Babel.

A Healthcare Language

- Structured data vs free text
 - Where does structure stop and free text begin
- Increased emphasis on Natural Language Processing
- Publicity of IBM's Watson on Jeopardy
- Today's language is ambiguous
 - 67 definitions of unstable angina
 - 12 definitions of myocardial infarction

How do we tip the scales?

- The creator of standards must develop a new philosophy. They need to recognize that where we started is not where we need to be.
- If I asked you “What is the first thing that comes to mind when I say standards, what would you say?”
- The answer should be a deeper understanding of what we are trying to achieve.
- How can we engage with this HIE project to approach seamless care?
- HL7 has created a new task force called Fresh Look to take a new look at where HL7 needs to go. Part of that is a focus on the data.

Another problem to solve - Privacy

- Privacy is a pendulum that serves best when it sits in the middle – not to either extreme.
- Release of data should never damage the patient.
- Non-release of data should never prevent appropriate care. Overly restrictions could harm both patient and provider.
- There is a societal responsibility to share data.
- We need to make finding patients for clinical trials easier, and we need to make patient consent easier.

Issues with the EHR

- EHR Architecture will unlikely be standardized – it will be proprietary. We need to insure that we know what data is included and where it is stored.
- EHR storage should be independent of collection, presentation and use.
- Data should not be stored in packets and folders, but as specific data items. Presentations may do packaging.
- EHR should be designed around use – not input.

What will the future bring?

- We have used work-arounds for over twenty years – such as mapping among terminologies, redundant collecting of data, errors in aggregation of data.
- Solving these problems would expand what could be accomplished faster and at less cost.
- Requires a clear definition of the problem – start there, not with the technology.
- Requires a commitment and a compromise from all players
- Enter a Brave New World!