

Technological Changes for a Perfect Health System

September 19, 2022

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Galileo Mission

We seek to describe the perfect health system, one that is realizable, fosters innovation, and enables individuals to attain their highest quality of life.



Galileo Vision

- **Will focus on the patient as the most important component**
- **Will be diverse, equitable, and inclusive**
- **Will meet patients at their points of need**
- **Will have input from all identifiable groups of persons**
- **Will enable the building of healthy communities**
- **Will recognize the need to act locally while thinking globally**
- **Will be affordable to all persons**
- **Will use technology in appropriate, affordable, and effective ways**

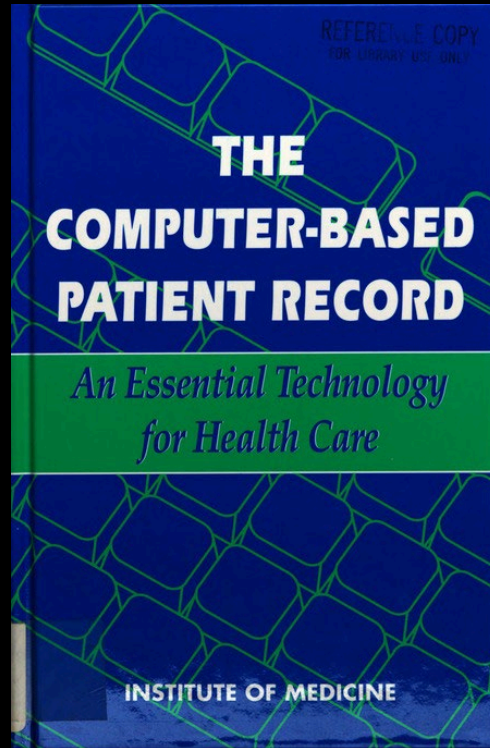


Next Steps – defined 10 things to do this year

- Write a summary paper covering all we have learned from the interviews
- Creating a website for sharing presentations, interviews, and other material
- Summary seminar with all previous participants to update
- Interview at least 4 new groups
- Propose technical changes: data store, data elements, cognitive-linked APIs

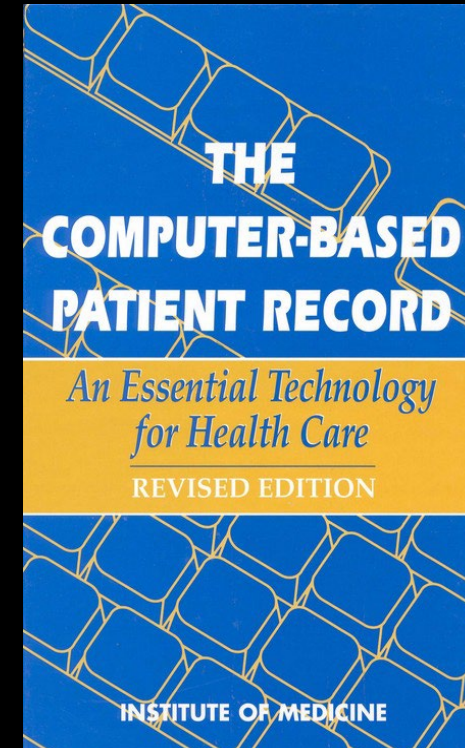


THE COMPUTER-BASED PATIENT RECORD



1991

Published by the
Institute of Medicine –
now the National
Academies of Medicine



1997



Requirements for Computer-based Patient Record

- Support patient care and improve quality
- Enhance productivity of health practitioners
- Reduce administrative costs
- Support clinical and health services research
- Accommodate future developments in health care technology, policy, management, and finance
- Insure patient data confidentiality

Today's EHR has not met these expectations!



Different Users Have Different Requirements

- Primary care –manage different aspects of the case
- Specialists – focus on specific diseases
- Chief resident – focus on teaching during rounds
- Pharmacy’s view – focus on medications
- Dietitian view – support diet and nutrition
- Security department – identifies security risks
- Accounting department – focus on what should be charged
- Research view – access to data without violating patient privacy
- Policy makers – reporting views to prepare reports relating to privacy



EHR Was Doomed From The Start

- Systems were designed by computer engineers with little input from the medical community.
- Systems designed exclusively for inpatient systems.
- Systems were very expensive and only large hospitals could afford them.
- Systems focused on service functions not using data for improving patient care.
- Laboratory systems were developed separately with separate databases.
- Financial systems were developed separately with their own databases.
- Patient management systems largely duplicated the patient chart.
- Architectural framework has remained unchanged. Systems have evolved from the beginning, not restarted.



Proposal for change

- Replace the current EHR model
- Adopt a single common set of data elements
 - Single data element for each concept with a unique definition
 - Rich set of attributes for each data element
 - Attributes include computable knowledge for data elements
 - Build structures based on atomic data elements
- Functional and cognizant-based application program interfaces (API)



Different approaches to data storage

- All data about a patient is stored in a single data cell.
 - Clinical, genomic, behavior, social, economic, environment, family history
 - May contain multiple databases, but data is managed by knowing precisely where data is located.
 - Instantly knowing if data element exists.
- Data is stored as data – not as a function of use.
- All functionality for using the data is external to the data cell.
- Interaction with the data is through Representational State Transfer (REST) – Create, Read, Update, Delete



Making data work

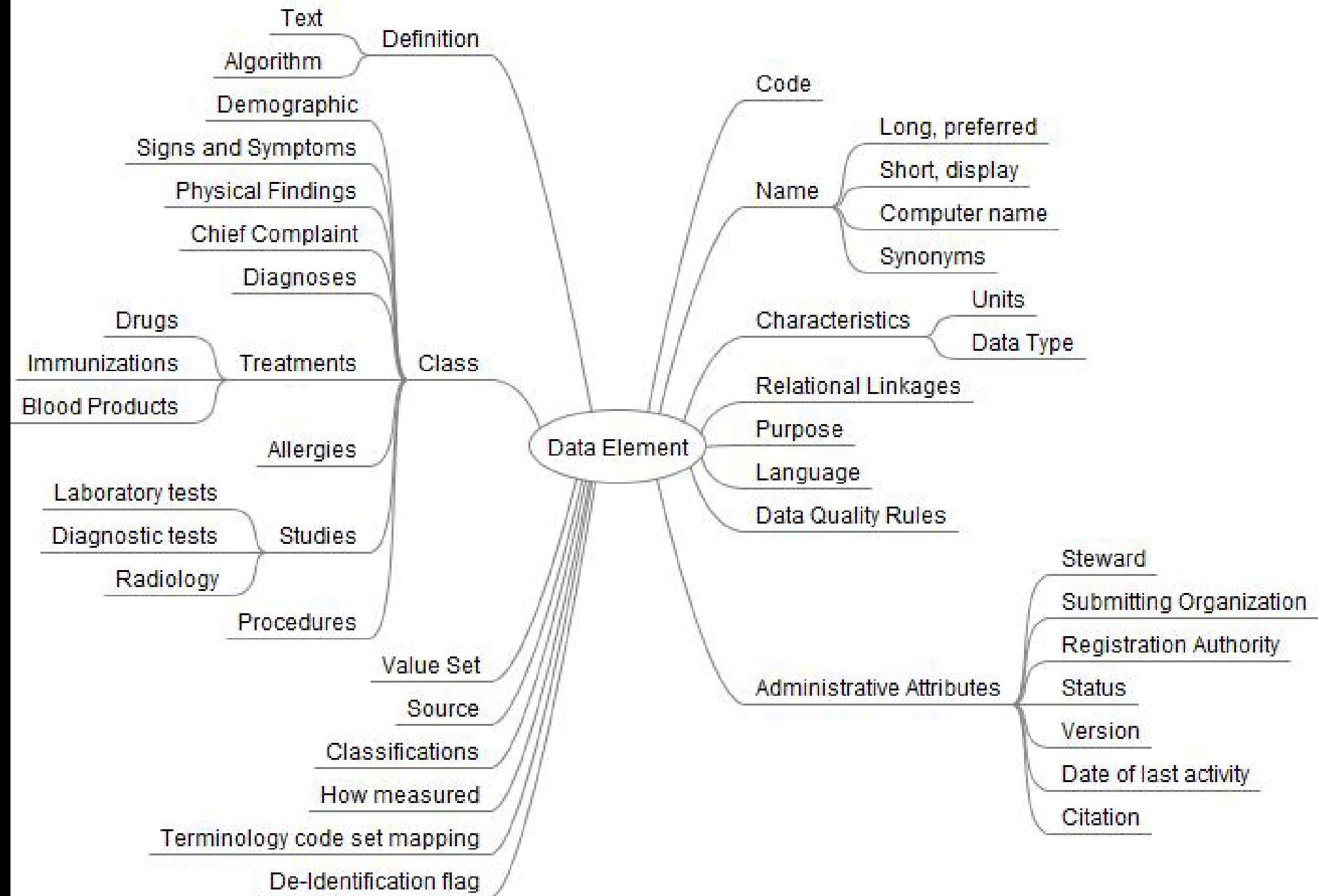
- There are so many common data models, they are uncommon.
- Mapping between common data models is wasted energy. Mapping always results in a loss of information.
- Data sharing and data aggregation are becoming mandatory in health care.
- Goal is a single, common set of data elements with a rich set of attributes used nationally and, perhaps, internationally.
- Attributes provide an opportunity to add computable knowledge and controls to data. Examples include ontology, linkages, decision support links, quality assurance, risk factors, phenotypes, and management data.



Doing the impossible

- HL7/FHIR and OHDSI/OMOP have entered an agreement to create a common set of data elements and a common data model.
- PCORI has now joined the group working on a common set of data elements.
- ONC is supportive of the idea, and we are looking to integrate USCDI.
- Other groups we plan to recruit include CDISC, NLM VSEC, CMS, CDC, FDA, CMS, LOINC, SNOMED, CodeX, i2b2/ACT, caDSR, others
- We are proposing using the Clinical Societies as the doorway to creating data elements and being the stewards of data elements.





Data elements value enhanced



- Create structured sets of data elements into larger groupings
 - Simple cases such as blood pressure, heart murmurs, BMI
 - More complex sets such as an echocardiogram, cardiopulmonary exercise testing
 - Structures to capture complex phenomena yet are easy to work with
 - Functional sets such as well baby work-up, pediatric growth, kidney function, maternal health
 - Phenotypes – diagnostic, treatment, monitoring
 - Tracking Covid patients (and others) across time and space
 - Registries
 - Computable knowledge built into the data element
 - Any defined purpose for a standardized grouping of data elements



Use of data

- Use functionality is performed independently by functional apps.
 - Permits keeping up with new technology and new requirements
 - Allows specialization of data presentation and use
 - Enables competitive market
- Supports query-based interactions: pull over push
- Permits cognitive use of the data through Application Program Interfaces (API)
- HL7 International[®] SMART on FHIR[®] provides a standard for developing these APIs.



SMART[®]

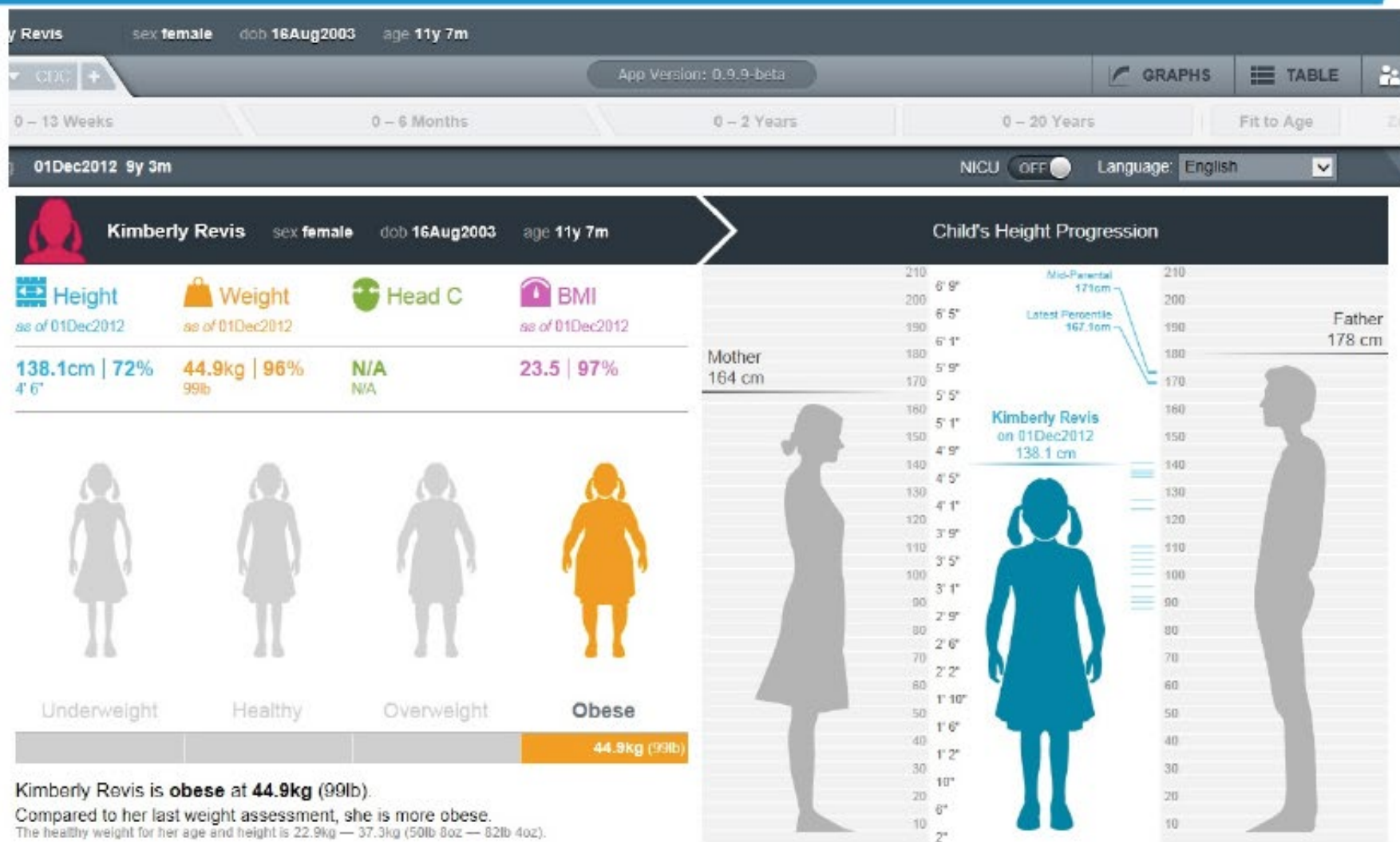


- Enables vendors to create apps that seamlessly and securely run across healthcare systems
- Defines a health data layer that builds on FHIR and resource definitions
- Applies set of profiles used to express meds, problems, labs and other clinical data
- Patients, clinicians, others can draw on library of apps to improve clinical care , research, and public health



Pediatric growth chart – innovative parent's view

- Custom view optimized for communication with parents and child
- Visually project height in terms of parent's height
- Print copy for parents, or email via portal



Examples of Cognitive APIs

- Functional and productive problem list
 - Problem list can drive activities and clinical behavior
- Support or do documentation
- Link different types of data in innovative ways
- Use phenotypes to drive effective use of knowledge along with patient data to reduce uncertainty and aid decision-making
- Change passive data storage to innovative partnerships in patient care



What does this mean to the health system?

- Access to more data of higher quality and consistency establishing trust.
- Receiving data from clinical trials directly and automated.
- Increasing use of AI with decisions and contact directly involving patients new regulations and responsibilities.
- New tools to more quickly make decisions?
- Constant vigilance to make sure regulations enhance and not limit of delay advances in health and health care.
- You are the experts. What do you think?



DISCUSSION

This work is supported in part by the Duke Clinical and Translational Science Award, NIH Award UL1TR002553.

