Escape from the Past and the Present to the Future

Duke Nursing Students
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- Can you imagine a world in which all health systems use the same data elements and collect the same data for the same purposes and have agreements in place that permit sharing and access to data for research while protecting patient privacy?

Mirror, Mirror, 2021 Reflecting Poorly

	AUS	CAN	FRA	GER	NETH	NZ	NOR	SWE	SWIZ	UK	US
Overall	3	10	8	5	2	6	1	7	9	4	**11**
Access to care	8	9	7	3	1	5	2	8	10	4	**11**
Care process	6	4	10	9	3	1	8	11	7	5	2
Admin Efficiency	2	7	6	9	8	3	1	5	10	4	**11**
Equity	1	10	7	2	5	9	8	6	3	4	**11**
Health care outcomes	1	10	6	7	4	8	2	5	3	9	**11**

What's Wrong With The Present ?

- The present healthcare system is broken, and our approach to fixing it is flawed.
- We focus most frequently on the wrong problem.
- We focus on a single problem, and we are constrained by having to fit the solution into an existing system.
- We start with an assumed solution and attempt to solve the problem within the capabilities of whatever solution we have decided to use.
- We start with what we have and know, rather than looking for the best solution.

Why we are not solving problems?

- We spend much of our time and money doing work-arounds rather than facing the true hard problem.
- We tackle today's problem with tools from yesterday.
- We assume the barriers that currently exist are here to stay, and anything new we do must fit within those boundaries.
- We provide multiple different solutions then spend even more time in trying to harmonize the multiple solutions.
- We never look to see if someone else has solved the problem or are at least currently addressing it.

Life today

- Physician and nurse burnout are prevalent.
- There is little equity in health care today.
- Most popular EHR systems are aged (EPIC – 1976).
- New technology is not being used.
- Reimbursement drives what data is collected and how it is coded. Claims databases are used for observational research.

You can't get the perfect system by fixing today's system.

- The Galileo Project has as its objective to define the PERFECT <u>Health</u> System.
  - Health Care is a sub-component.
- The goal is not to address perceived problems of today, but to step into the future.
- Have held two "thinking aloud" Zoom sessions involving over 25 clinicians in 2020 and one additional session in 2021 with over 20 primarily Allied Health Staff
  - Invited initial thoughts shared in group
  - Divided into 5 breakout groups. Panelists were leaders of the breakout groups.
- Only constraints
  - Can't say "you can't do that because …"
  - Can't say "that's impossible"
  - No boundaries – no comment is out of scope.

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

Galileo Executive Committee

- James E Tcheng, MD
  Professor of Medicine, Interventional cardiologist

- Stephen Keir, DPh, MPH
  Professor in Neurosurgery

- Genie McPeek Hinz, MD, MS
  Associate CMIO

- Lori Orlando, MD, MHS, MMCi
  Professor of Medicine

- Vivian West, PhD, MBA, RN
  Associate Director, DCHI
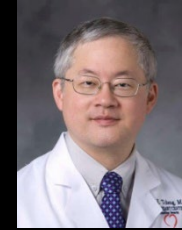
The first step toward perfect   PATIENT FIRST

- Without patients, we would not need a health care system.

- Therefore, patients should be the center piece of the perfect system.

- We must approach every function from that perspective.

- What should we do to provide the most value to the patient?

Perfect - for the patient

- There must be diversity, equity, and inclusion in health and health care.
- Access to care – whenever and wherever it is needed
- Service rendered cannot be influenced by what the insurance will pay but what is needed
- The appropriate medicine or treatment must be available to every person
- Health literacy is essential, therefore taught

More for the patient

- Patient navigation of the system should be enabled.
- Bring clinicians to patient, not patient to clinician.
- Mental Health should be an equal service.
- Virtual visits
- Home hospitalization whenever possible
- Once health system accepts a patient, it should accept full responsibility for that person

Digital Health and Patient Communication

- Every patient should have access to the Internet.
- Every patient should have a device capable of digital communication and interaction.
  - Smart phone
  - iPad
  - Computer
- Patient should have access to all their health data, delivered in an understandable language.

COMMUNITY

- The community engages in the health system.
- The community must accept equal responsibility for the patient with the health system.
- This responsibility means issues of transportation, access to health food, access to social events, access to parks for exercise, and provide person safety and health and education.

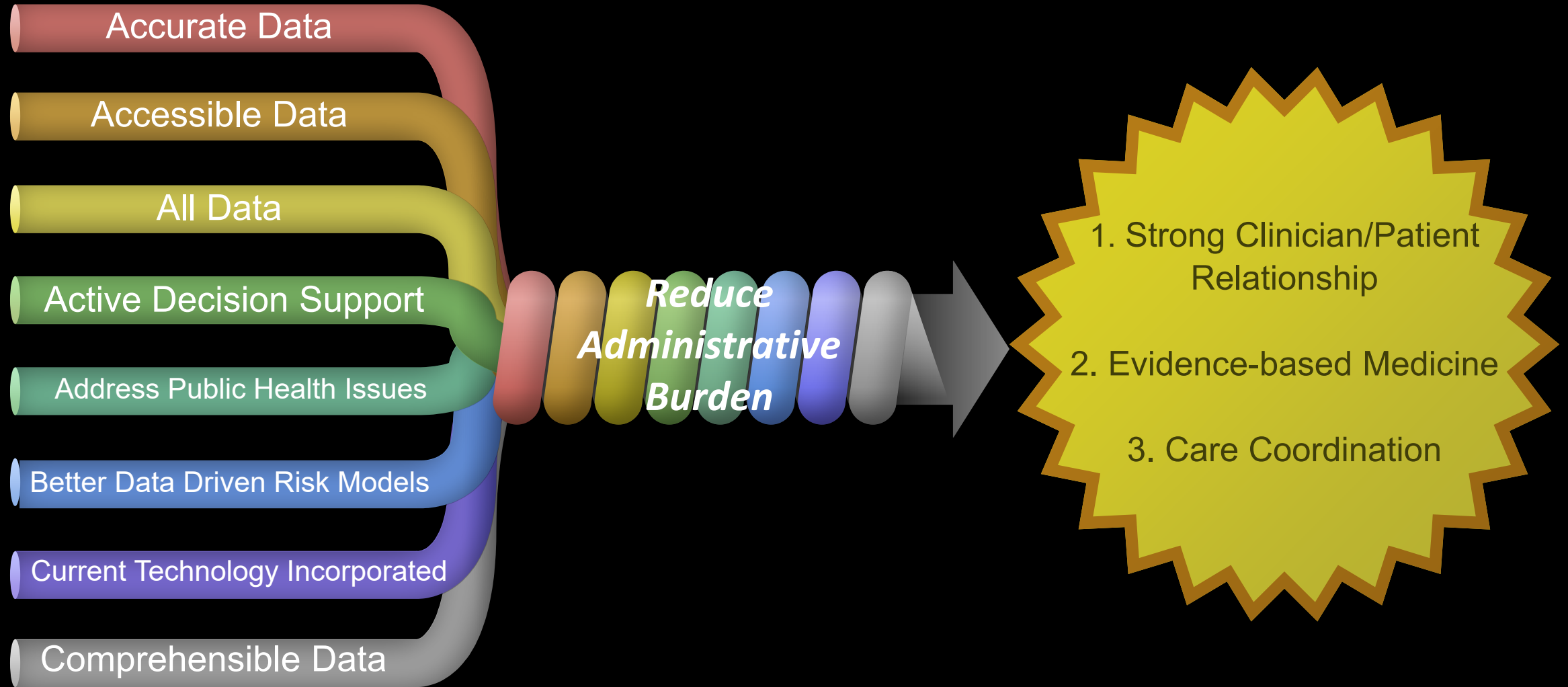# What is a perfect health system for clinicians?

- Access to any and all data about a patient.
- Longitudinal presentation of patient data, aggregated across all sources
- High quality and trustable data available when and where needed.
- Presentation of data as the clinician wants to see it.
- We all speak the same language – a seamless world of data.
- New forms of data capture – much data capture is automated.
- Use of AI to reduce finding the right data among Big Data.

GALILEO

- Accurate Data
- Accessible Data
- All Data
- Active Decision Support
- Address Public Health Issues
- Better Data Driven Risk Models
- Current Technology Incorporated
- Comprehensible Data

Reduce Administrative Burden

1. Strong Clinician/Patient Relationship

2. Evidence-based Medicine

3. Care Coordination

Source: James Tcheng, MD

Galileo Brainstorming Groups

- Physicians, PAs
- Allied Health Professionals
- Nurses, NPs, Midwives
- Older people
- Race minorities (together or separate)
- Disparities (economic, education)
- LGBTQ+
- Community Groups
- Rural communities

- Technical (IT and data scientists)
- Medical Students
- Teenagers
- Local public health groups
- Mothers with children, 5 yo
- Pregnant women
- Nursing home residents
- Clinical Workflow
- Mixed groups

Next Steps – 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
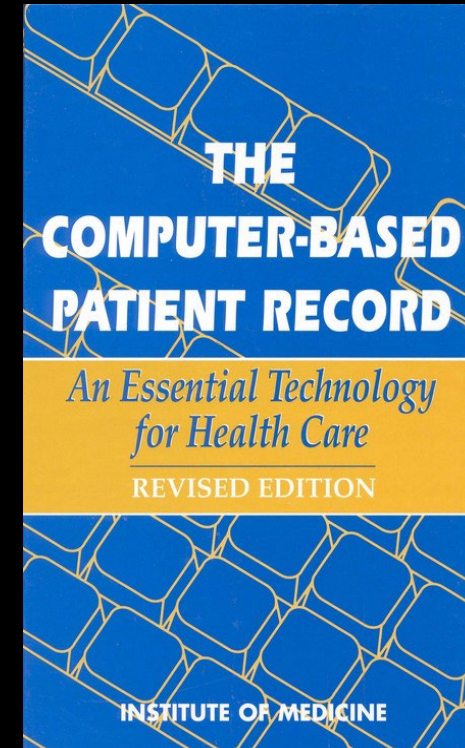- Propose technical changes: data store, data elements, cognitive-linked APIs

THE COMPUTER-BASED PATIENT RECORD
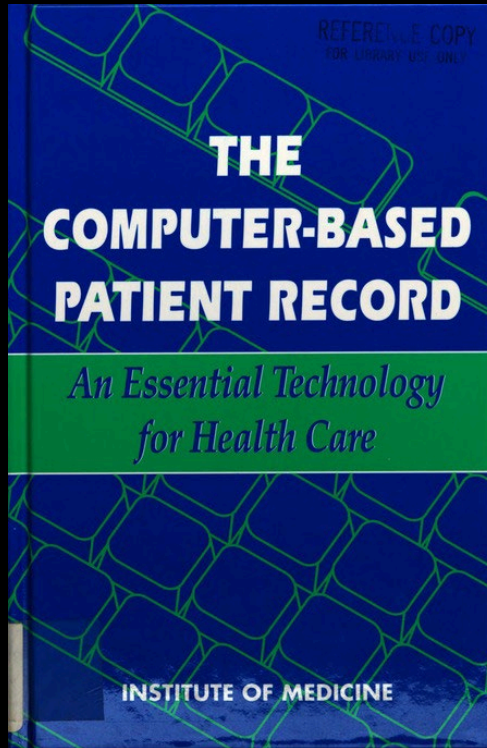
Published by the Institute of Medicine – now the National Academies of Medicine

1991

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.
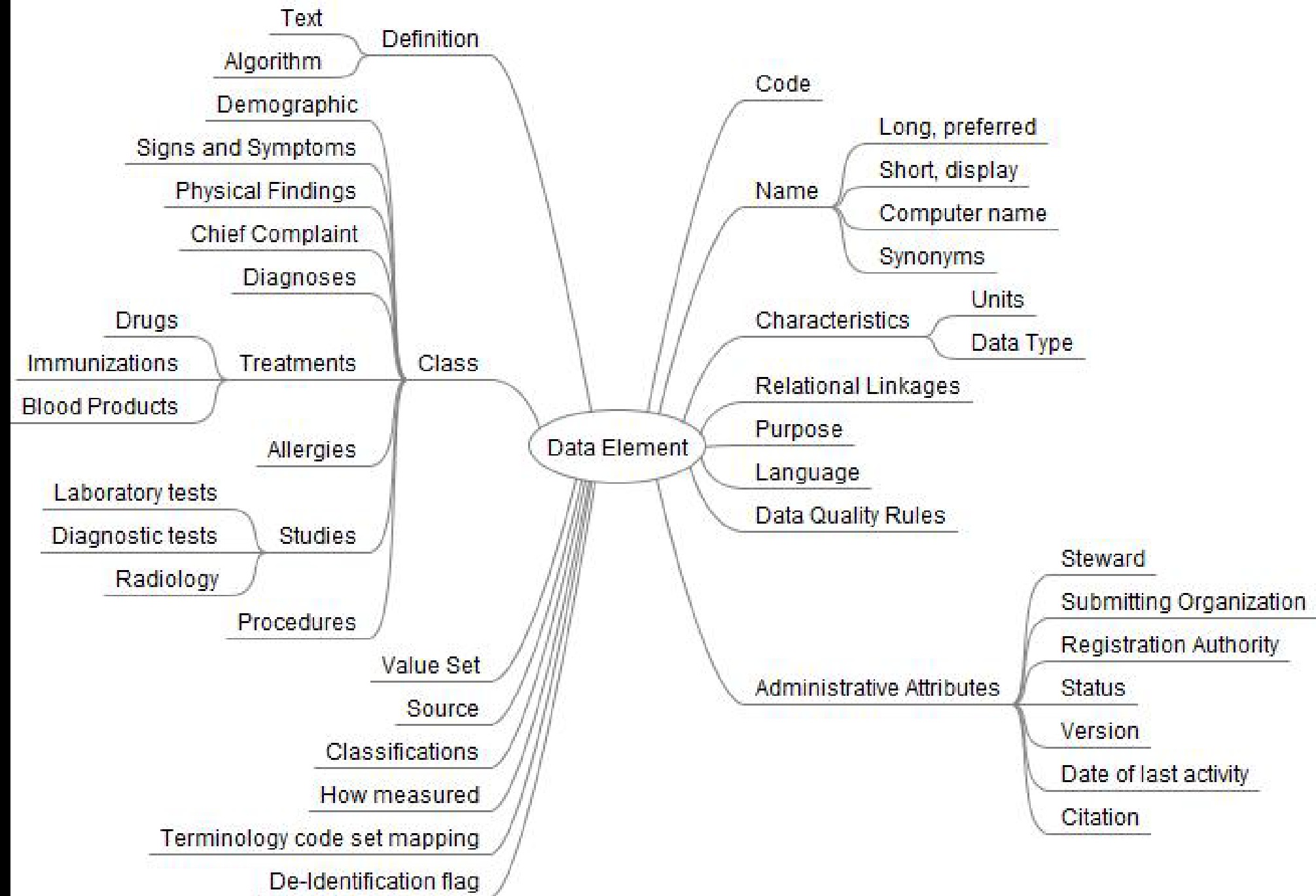
Data elements value enhanced

- 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
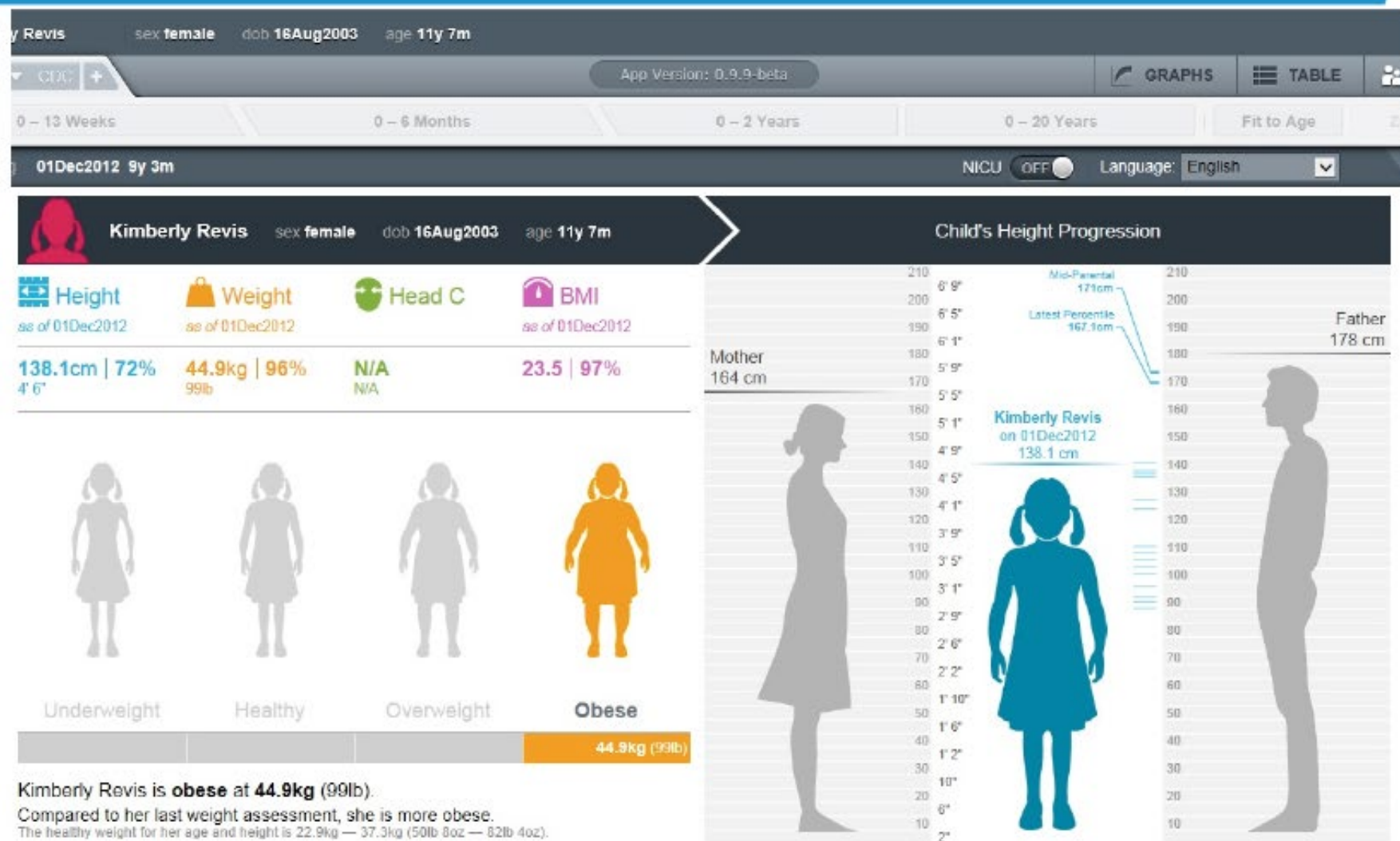
Examples of Cognitive APIs

- 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 of the future. What do you think?

Thank you!

Questions?