



The Duke / Pew Charitable Trusts Common Healthcare Data Interoperability Project

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DukeHealth



The Transformation of Healthcare ...

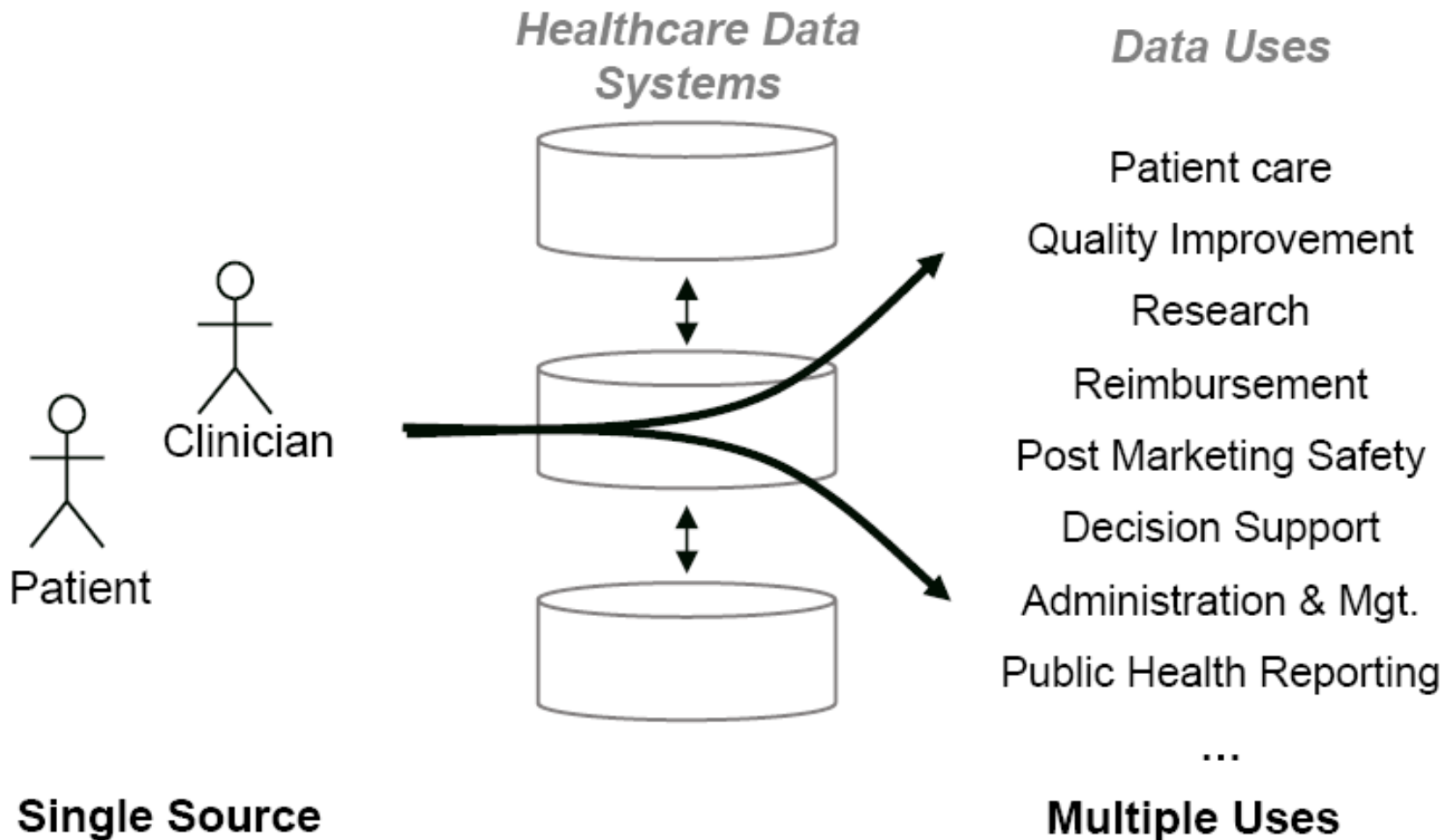
What's the Common Denominator?



Clinical documentation
Administrative reporting
Quality and performance
Registry submission
Analytics
Big Data
Machine learning
Etc.

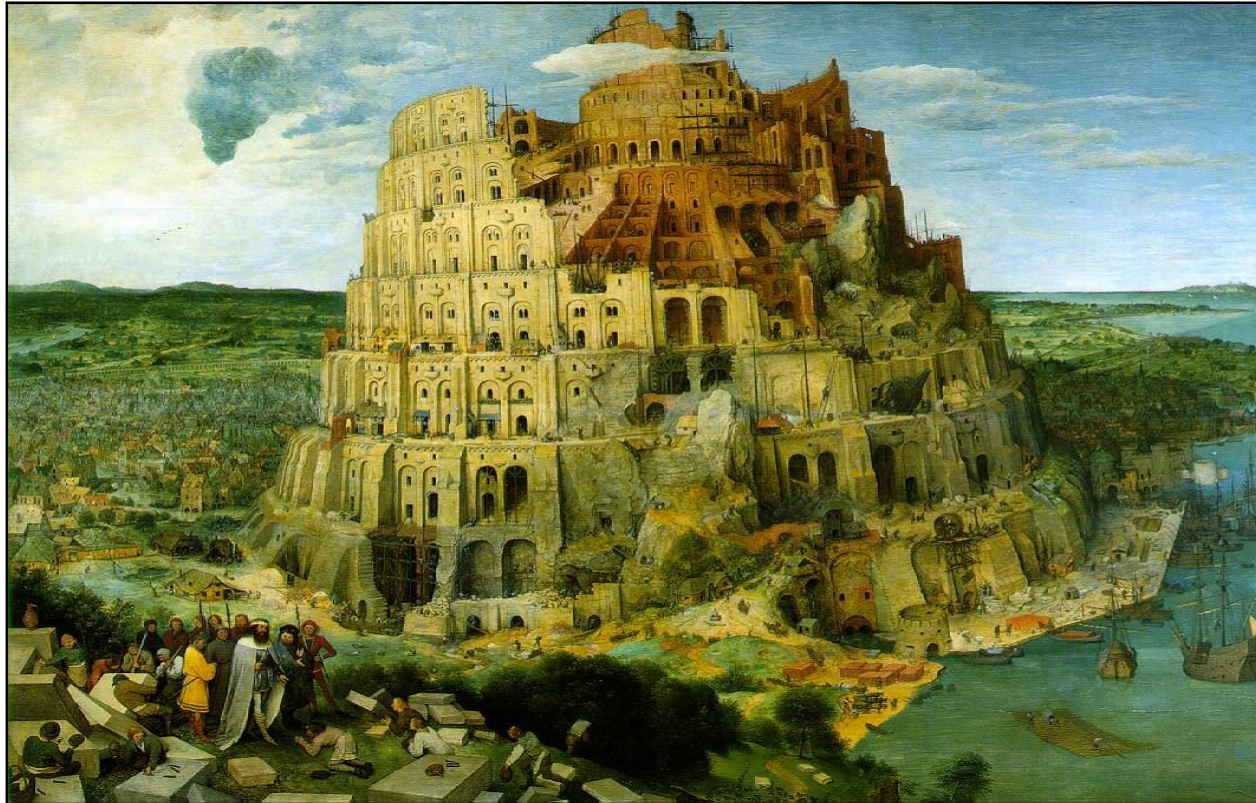


Exchange, Use, and Reuse of Data Requires Shared Data Definitions (including semantics)





THE Foundational Issue



Tower of Babel

Pieter Bruegel the Elder and Pieter Bruegel the Younger, 1563



Common Healthcare Data Interoperability Project

Improving the Interoperability of Healthcare Data

- **Aim 1:** To compare the CRFs of ≥ 20 registries & identify data elements that are common (>50% prevalence) across those registries
- **Aim 2:** To characterize the data elements in the context of healthcare data standards and other predicate work
- **Aim 3:** To produce an implementation guide that catalyzes the governance, structural, operational, and technical transformations needed to implement a common clinical data element set across registries, followed by EHI and national data models

Supported by funding from The Pew Charitable Trusts



US Core Data for Interoperability (USCDI)

<https://www.healthit.gov/sites/default/files/draft-uscdi.pdf>

Table 1: Draft USCDI Version 1 Data Classes

Draft USCDI Version 1 Data Classes	
1. Patient name	2. Sex (birth sex)
3. Date of Birth	4. Preferred Language
5. Race	6. Ethnicity
7. Smoking Status	8. Laboratory tests
9. Laboratory values/results	10. Vital signs
11. Problems	12. Medications
13. Medication Allergies	14. Health concerns
15. Care Team members	16. Assessment and plan of treatment
17. Immunizations	18. Procedures
19. Unique device identifier(s) for a patient's implantable device(s)	20. Goals
21. Provenance	22. Clinical Notes

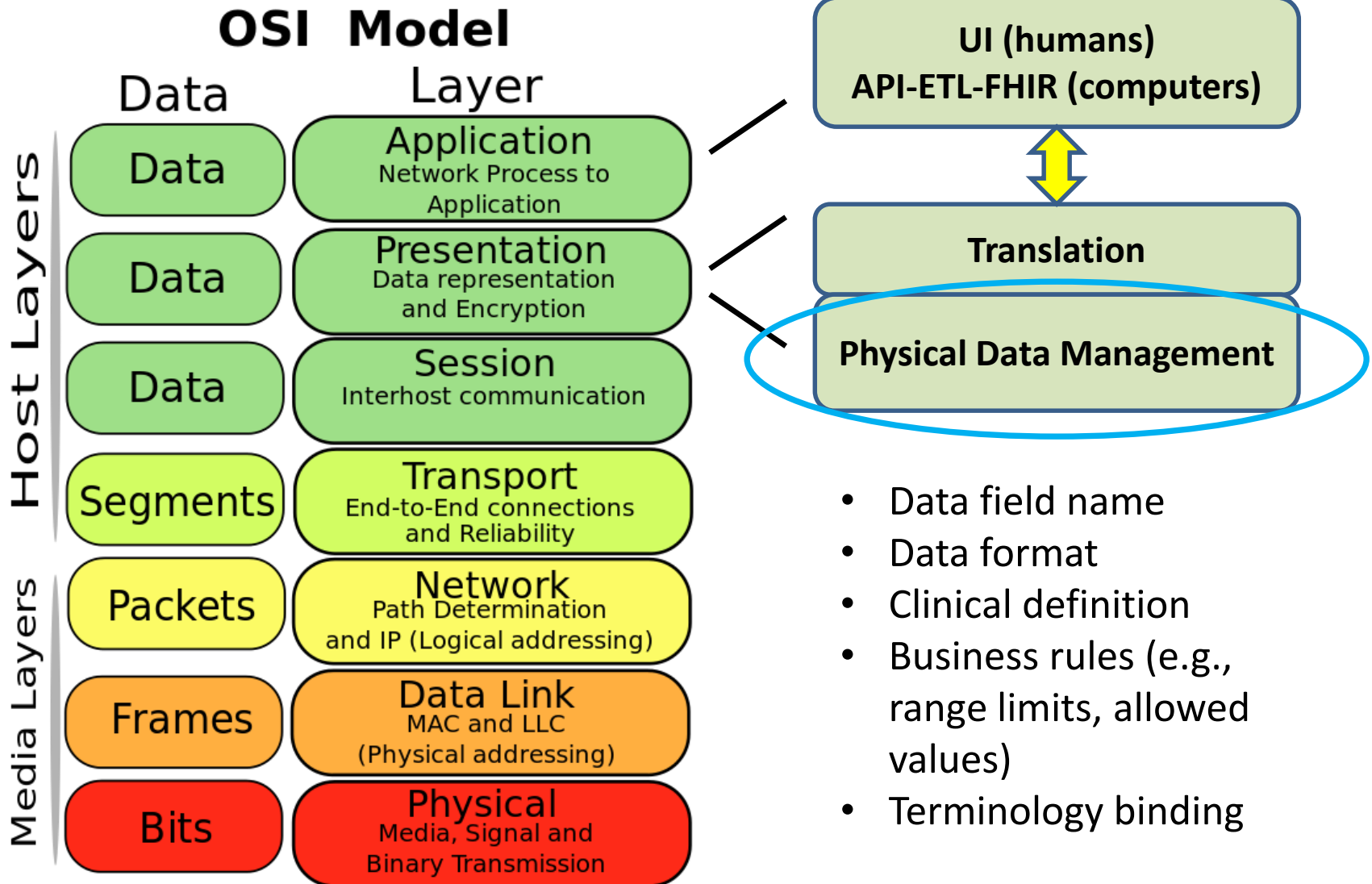


Common Clinical Data Elements

Clinical concepts shared across clinical, research, and regulatory contexts NOT unique to a discipline, are captured as data, and already have bindings to standardized terminologies:

- Demographics, administrative data (ONC)
- Vital signs, tobacco use history (ONC)
- Procedure codes (CPT)
- Laboratory data (LOINC)
- Medications (RxNorm)
- UDI and reference device data (GUDID)

Native, Interoperable Data Standardization



- Data field name
- Data format
- Clinical definition
- Business rules (e.g., range limits, allowed values)
- Terminology binding



Key CDE Metadata

Question or prompt
May have associated controlled terminology

Value, result or answer
May have associated controlled terminology

HCV status:

The diagram shows a black rectangular box containing the text 'HCV status:' followed by a white rectangular input field with a thin black border. Two thin grey lines originate from the top corners of the input field and extend upwards and outwards to the text labels 'Question or prompt' and 'Value, result or answer' respectively.

1. Clinical concept label (e.g., human prompt for CRF, data entry screen)
2. Db field label (all caps, no spaces, underscores only, limited chars ...)
3. Clinical definition of the concept, synonyms thereof
4. Data type / format (e.g., free text, constrained list, integer, ...)
5. Allowed values (aka permissible values = value set; VSAC?)
6. Allowed values definitions
7. Business rules (e.g., range / edit checks, consistency, validation)
8. SDO binding(s)
9. Published reference(s)



ONC

- Common Clinical Dataset - USCDI
- Interoperability Standards Advisory

NIH / NLM ...

- VSAC repository
- CDE repository

FDA

- MDEpiNet, CRNs, Women's Health
- Regulatory use cases
- Global coordination
- Demonstration via projects

EHI Vendors

- EHR, other HIT systems
- Structured reporting

The Playbook - Content

- **General (core) CDEs**
 - Domain-specific CDEs
 - UDI: GUDID, AUDI
 - Outcomes: AHRQ
-
- Data models
 - Patient ID, matching
 - Data aggregation
 - Distributed analysis

HL7-CIC, CIIC, CIMI ...

- The Playbook: Process for CDE modeling
- Tooling, repository of logical CDE models
- Registry domain analysis modeling

NEST / NESTcc

- Coordination of medical devices

DCRI / Academia

- Need for CDEs
- Academic publishing

Professional Societies

- Registries
- Domain-specific CDEs
- Structured data capture

NQRN Registries on FHIR

- Environmental scan
- ID / spec of general (core) CDEs
- Demonstration / implementation



Data standards are like toothbrushes:

Everybody agrees we need them, but nobody wants to use anyone else's.

Various attributions



Common Healthcare Data Interoperability Project

- **Request 1:** provide CRFs and corresponding data dictionaries to the DCRI team (Rebecca Wilgus, James Tcheng) *(anonymized & confidential)*
- **Request 2:** attend follow-up meeting at Pew in Washington, DC (August 21) to review findings
- **Request 3:** work with your IT team to plan for implementation of the work product (implementation guide)

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