2.1 Clinical Data

What is Biomedical and Health Informatics? - http://informatics.health/
William Hersh, MD, FACMI, FAMIA, FIAHSI

What are clinical data?

- A datum is a single observation
- Clinical data are the collection of observations about a patient
  - Example from John Halamka from Personal Genomes Project
- Each datum about a patient has a minimum of four elements:
  - the patient (Bill Hersh)
  - the attribute (heart rate)
  - the value of the attribute (50 beats per minute)
  - the time of the observation (9:00 am on 7/1/1990 – many ways to record dates!)

Types of clinical data

- Structured or discrete
  - Numerical measurements – blood pressure, temperature, lab values
  - Coded data – selection from a controlled terminology system
  - Recorded signals – ECG, EEG
  - Images – radiographs, photographs, etc.
- Unstructured or documents
  - Narrative – documents typically generated by clinicians
  - Other textual documents

Uses of clinical data

- Form basis of historical record
- Support communication among providers
- Anticipate future health problems
- Record standard preventive measures
- Coding and billing
- Provide a legal record
- Support clinical research

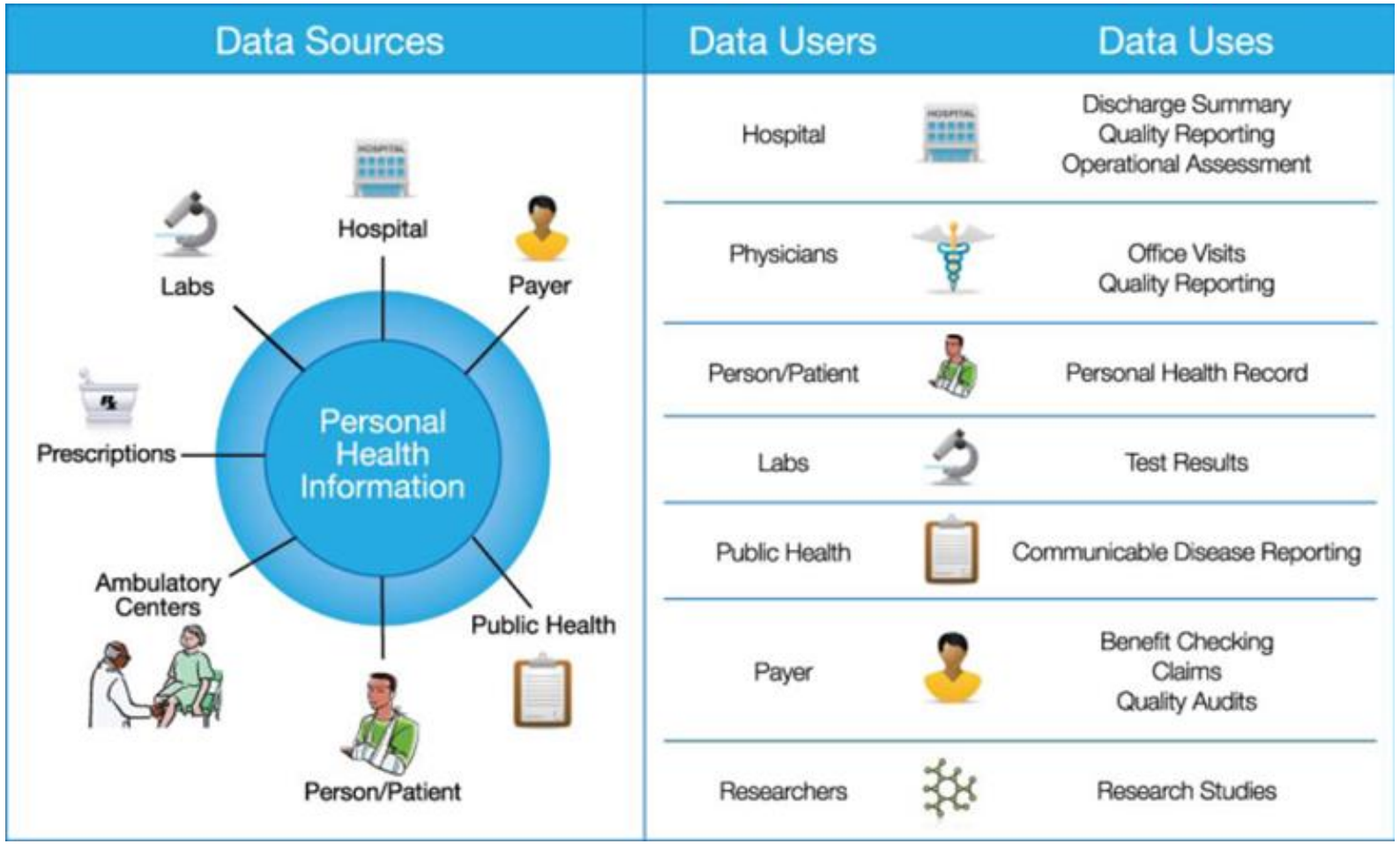
Types of clinical data documents

- History and physical (H&P) – initial assessment by a clinician
- Progress notes – update of progress by primary, consulting, and ancillary providers
- Reports – by specialists, ancillary providers
- Typical paper chart maintained all patient notes in chronological order, sometimes separated into different components

Assessment of a stable patient

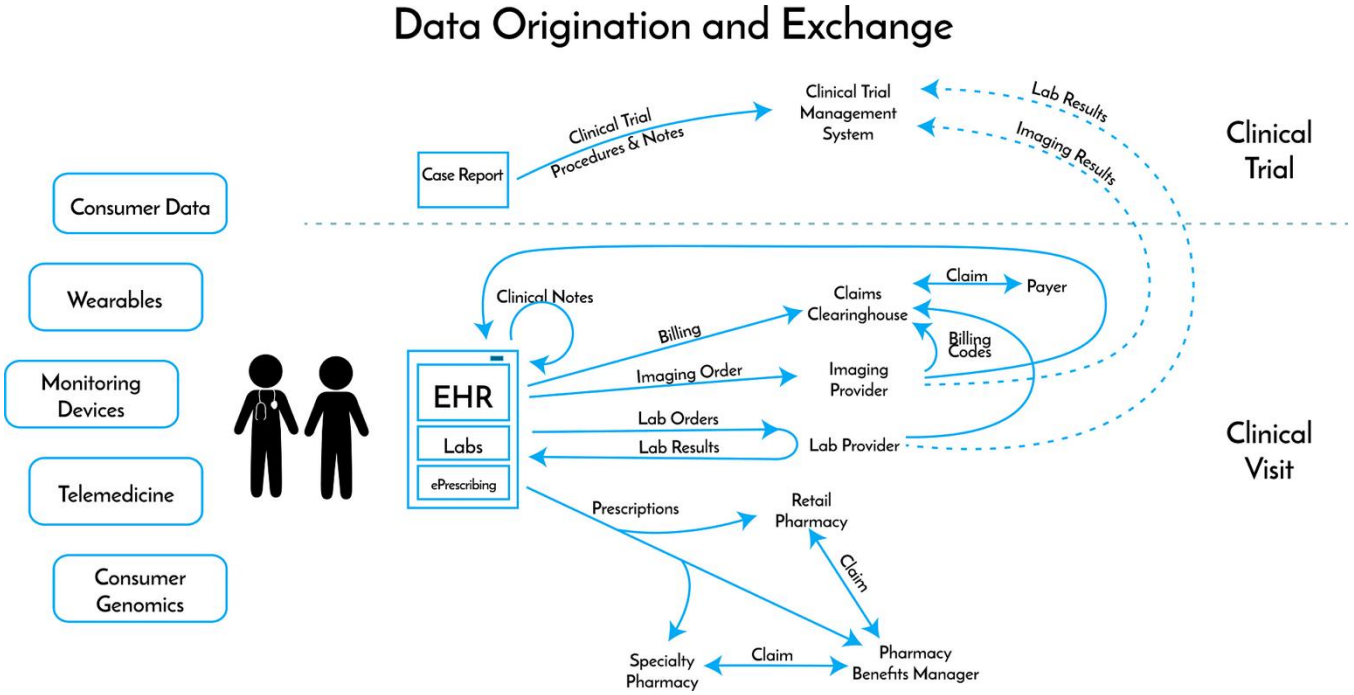
- Chief complaint
- History of the present illness
- Past medical history
- Social history
- Family history
- Review of systems
- Physical examination
- Testing – lab, x-ray, other
- Assessment and plan

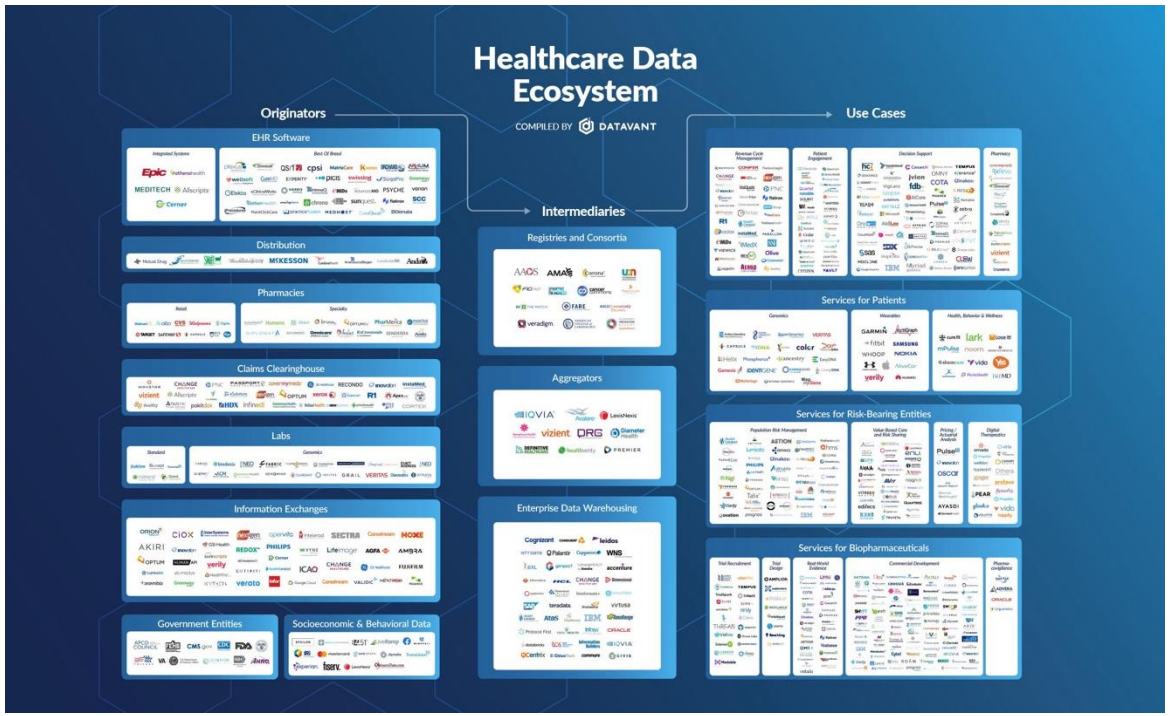
Many sources, users, and uses of clinical data (NCVHS, 2009)



OHSU

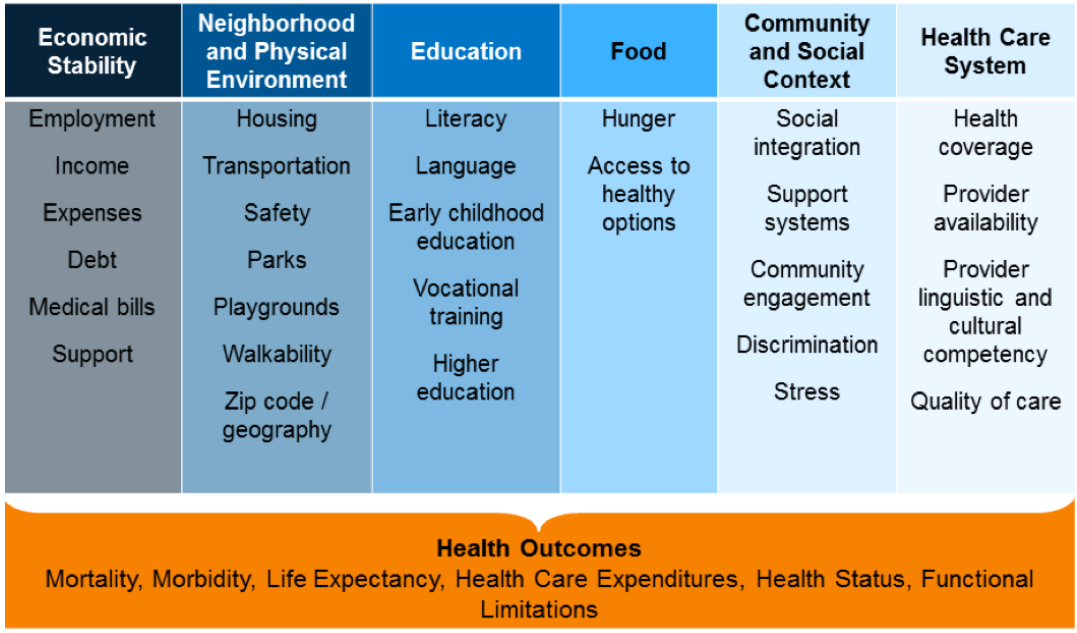
Health data ecosystem (May, 2022)





Social determinants/drivers of health (SDOH) (Artiga, 2018)

- Challenges for collecting (Chunara, 2024)
  - Creating culturally-appropriate measures of multi-level social determinants
  - Modeling complex, multifactorial causal pathways
  - Data capturing long period of action for distal factors
- Collection and use may be improved by (DesRoches, 2024)
  - Trusting patient-clinician relationships
  - Greater transparency in how data will be used
  - Targeted uses
- Can be implemented for use in a biopsychosocial model in EHR template (Rieger, 2023)
  - Patient perspectives and mental health
  - Expanded social history
  - Impact on patient care



Domains	Relevant content areas
Patient perspectives and goals	Patient understanding of health, perceived control, health goals, advance care planning
Mental health	Mental health conditions (depression, anxiety, etc), cognitive impairment
Behavioral health	Medication adherence, exercise, nutrition, substance use
Social support	Primary relationships, caregiver availability/capacity, domestic abuse, community relationships
Living environment and resources	Financial resources, insurance status, acce healthcare, housing, food security, transpor
Functional status	ADLs, IADLs, education, occupation, mobility devices
Biomedical information	Chronic and acute medical conditions

Some complications of data

- Circumstances of observation – e.g., how was heart rate taken? pulse? ECG?
- Uncertainty – how accurate is patient reporting, measurement, device?
- Time – what level of specificity do we need?
- Imprecision vs. inaccuracy

Special populations and types of data – children

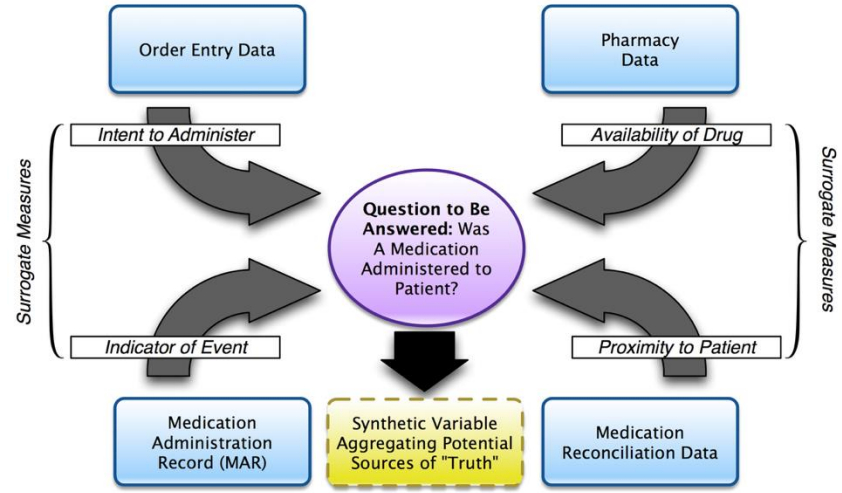
- Critical functions include (Dufendach, 2015; O'Donnell, 2020)
  - Tracking of well-child visits
  - Support for anthropometric analysis
  - Immunization tracking and forecasting
  - Weight-based drug dosing
- Challenges for use of data (Dufendach, 2024)
  - Immunization management
  - Growth and development
  - Social drivers of health tracking
  - Clinical decision support for different sizes and weights
  - Patient identification
  - Privacy
  - Other care situations, e.g., adoption, protective custody, etc.

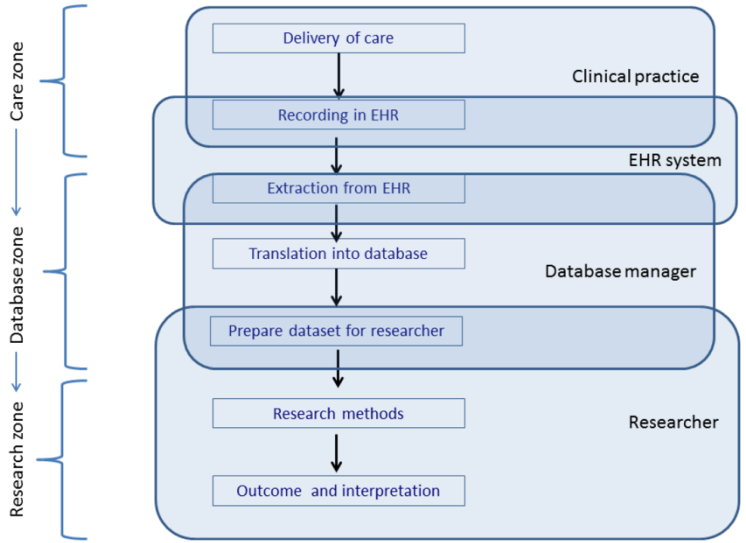
Coding of clinical data

- Historically performed by a Clinical Coding Specialist (CCS)
- Major purpose has historically been for reimbursement (Scott, 2013; Basch, 2018)
- A core issue in biomedical informatics has been how to generate and use coded data for other purposes
- Trade-offs
  - Standardization of language vs. freedom of expression
  - Time to narrate vs. code
- Other difficulties
  - Creating and maintaining coding systems
  - Structuring coding systems to capture meaning

Other complications, especially for re-use of clinical data

- May be (Hersh, 2013)
  - Inaccurate
  - Incomplete
  - Transformed in ways that undermine meaning
  - Unrecoverable
  - Of unknown provenance
  - Of insufficient granularity
  - Incompatible with research protocols
- Many steps in capture and transformation for analytics and research, all potentially subject to error (Verheij, 2018)





Ambiguity in verbal probabilities (Andreadis, 2021)

Verbal probability term	Number of studies	Average numeric estimate, random effects model (%)	95% CI (%)	Minimum sample average (%)*	Maximum sample average (%)*	Range of individual estimates (%)†
Rare(ly)	7	10.00	[7.99, 12.01]	7.0	21	0–80
Rare-severe event	3	10.06	[5.45, 14.68]	6.3	34.8	–
Rare-mild event	3	14.14	[7.88, 20.40]	9.6	39.3	–
Uncommon	4	17.64	[13.19, 22.09]	13.3	22.9	0–90
Unlikely	6	17.71	[14.86, 20.55]	13.3	27	0–85
Common-severe event	3	43.08	[40.27, 45.88]	41.9	45.6	–
Possible(ly)	6	43.28	[36.66, 49.89]	36.9	62	–
Common-mild event	3	50.47	[45.59, 55.34]	48	58	–
Common	6	58.73	[50.40, 67.06]	34.2	70.5	10–100
Very common	3	60.10	[42.36, 77.85]	38.5	71.6	5–100
Probable(ly)	5	69.87	[67.07, 72.67]	66	73.9	20–100
Likely	6	71.87	[69.90, 73.84]	66	94	–
Usual(ly)	3	75.38	[71.53, 79.23]	72	78	–
Very likely	3	84.30	[79.43, 89.17]	75.2	93	20–100

OHSU

Use of stigmatizing language

- Negative and positive categories (Park, 2021)
- Found in 2.5% of all H&P notes, higher for (Himmelstein, 2022)
  - Patients with diabetes, substance abuse, and chronic pain
  - Non-Hispanic black patients
- Negative descriptors 2.5 times more likely for black patients in H&P notes (Sun, 2022)

Categories	Definitions	Examples[b]
Questioning credibility	Implication of physician disbelief of patient reports of their own experience or behaviors	• He insists the pain is behind his knee. • He claims that nicotine patches don't work for him. • I listed several fictitious medication names and she reported she was taking them, and that she takes "whatever is written there"
Disapproval	Highlights poor reasoning, decision-making, or self-care, usually in a way that conveys the patient is unreasonable	• Reports that if she were to fall, she would just "lay there" until someone found her • He was adamant that he does not have prostate cancer because his "bowels are working fine." • Counseled that there is no evidence for this, but patient has strong beliefs. • She is adamant that she cannot perform any kind of exercise due to pain and will not change her diet.
Stereotyping	Quoting African American Vernacular English	• Chief complaint - "I stay tired" • Reports that the bandage got "a li'l wet"
	Quoting incorrect grammar or unsophisticated terms	• States that the lesion "busted open" • Reports she was unable to fill prescription for the "sugar pill"
Difficult patient	Inclusion of details with questionable clinical significance that depict the patient as belligerent or otherwise suggests that the physician is annoyed	• She persevered on the fact that "a lot of stuff is going on at home with my family" but that "you wouldn't understand." • I informed her that this is unlikely to be helped by antibiotics and talked about smoking cessation with her. She said she will ask her 'sinus doctor' for antibiotics.
Unilateral Decisions	Language that emphasizes physician authority over patient	• She was told to discontinue... • I have instructed him to...

How to overcome stigmatizing language in EHR

- Many current conventions of charting can be racist and should be overcome, e.g., (Williams, 2023)
  - Mentioning race routinely in first line of note
  - Using race as proxy for genetics and/or social determinants of health
- Many descriptions of pregnant and birthing people lead to unintended meanings and bias, e.g., (Barcelona, 2023)
  - Failure to progress – state cervical dilatation over number of hours
  - Geriatric pregnancy – state age
  - Incompetent cervix – state cervical measure
  - Patients refuses or claims – opts not to or reports

Also need effective “stewardship” of data

- Ensuring the “knowledgeable and appropriate” use of data from individuals’ personal health information (NCVHS, 2009)
- Maintaining the patient’s story in the record (Vigilante, 2018; Gantzer, 2020) – even if EHRs can make that difficult (Kommer, 2018)