

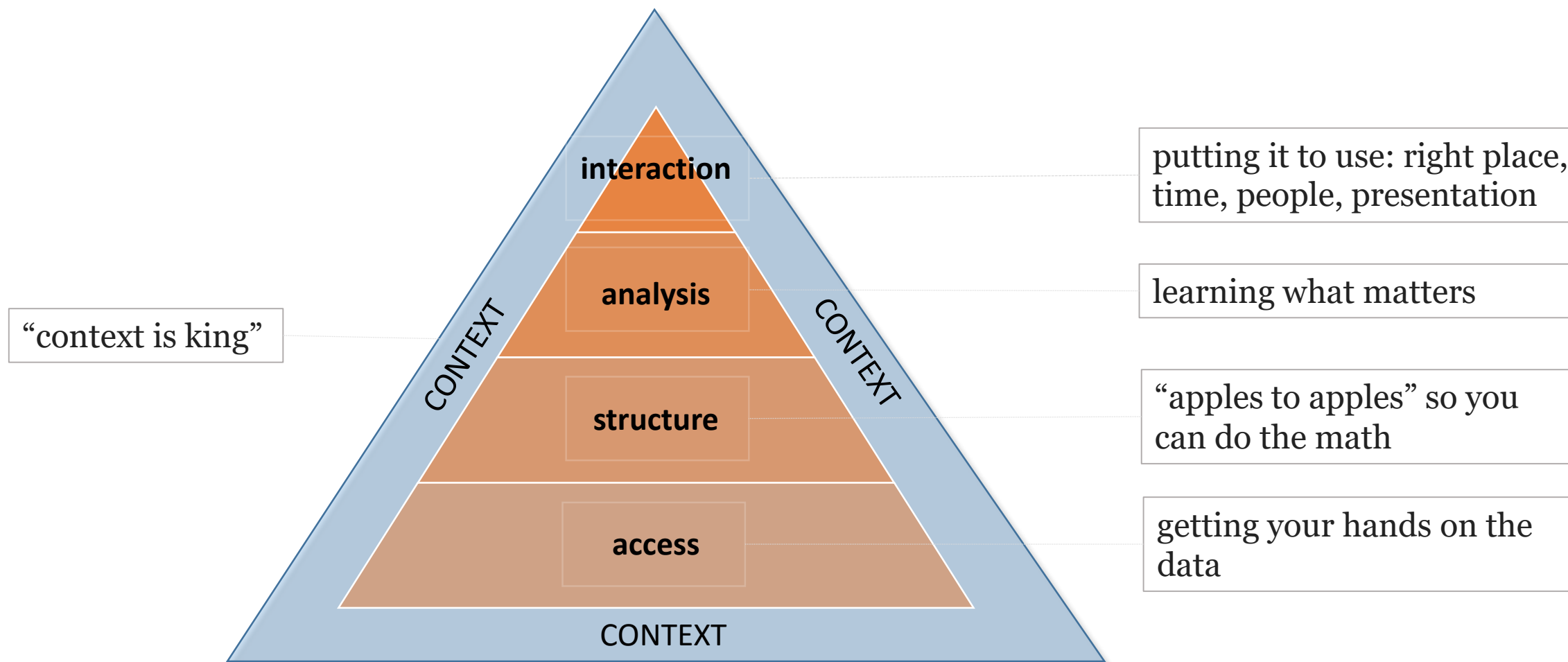
Data Trends

Dr Gareth Kantor

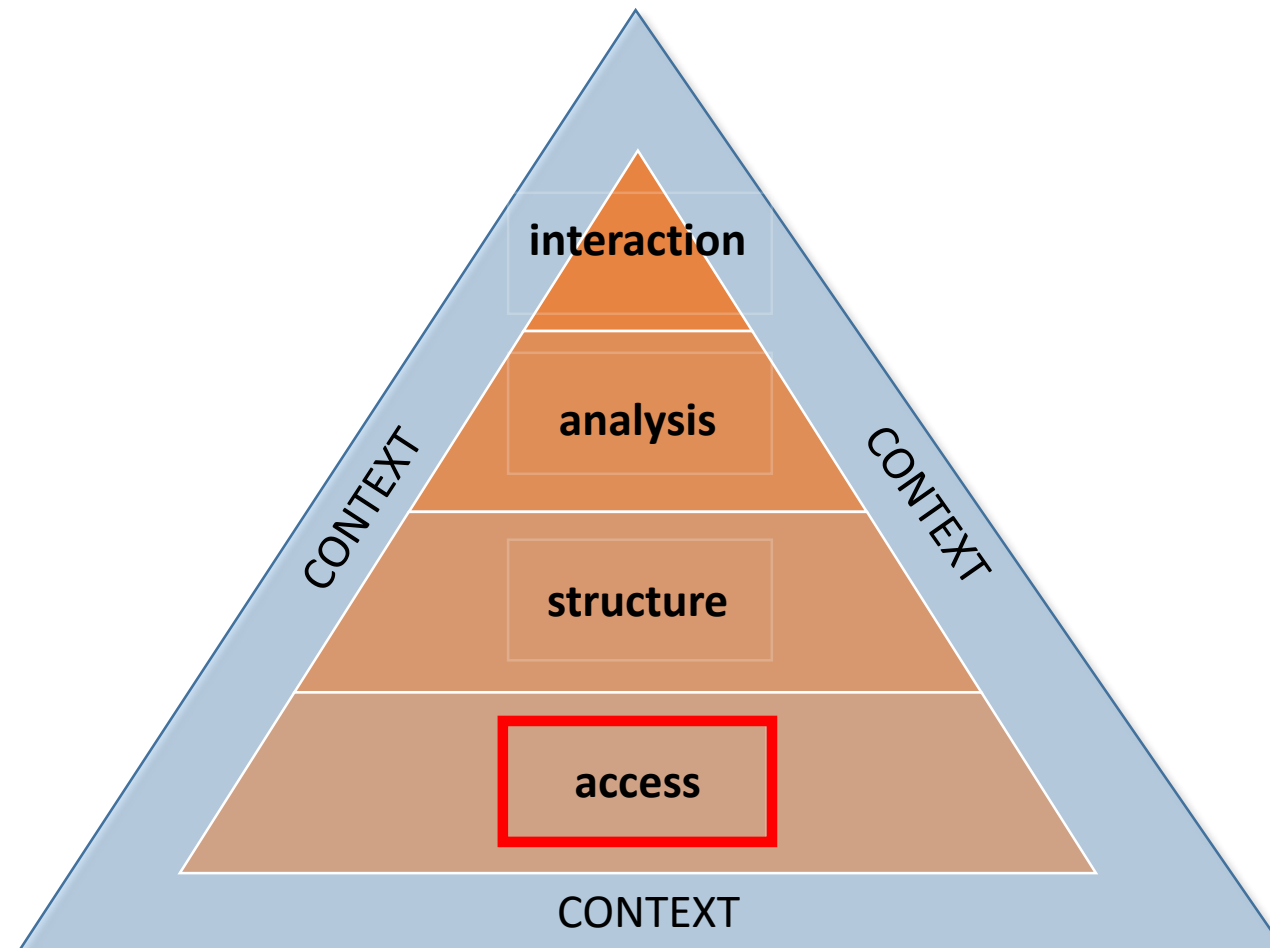
April 2016

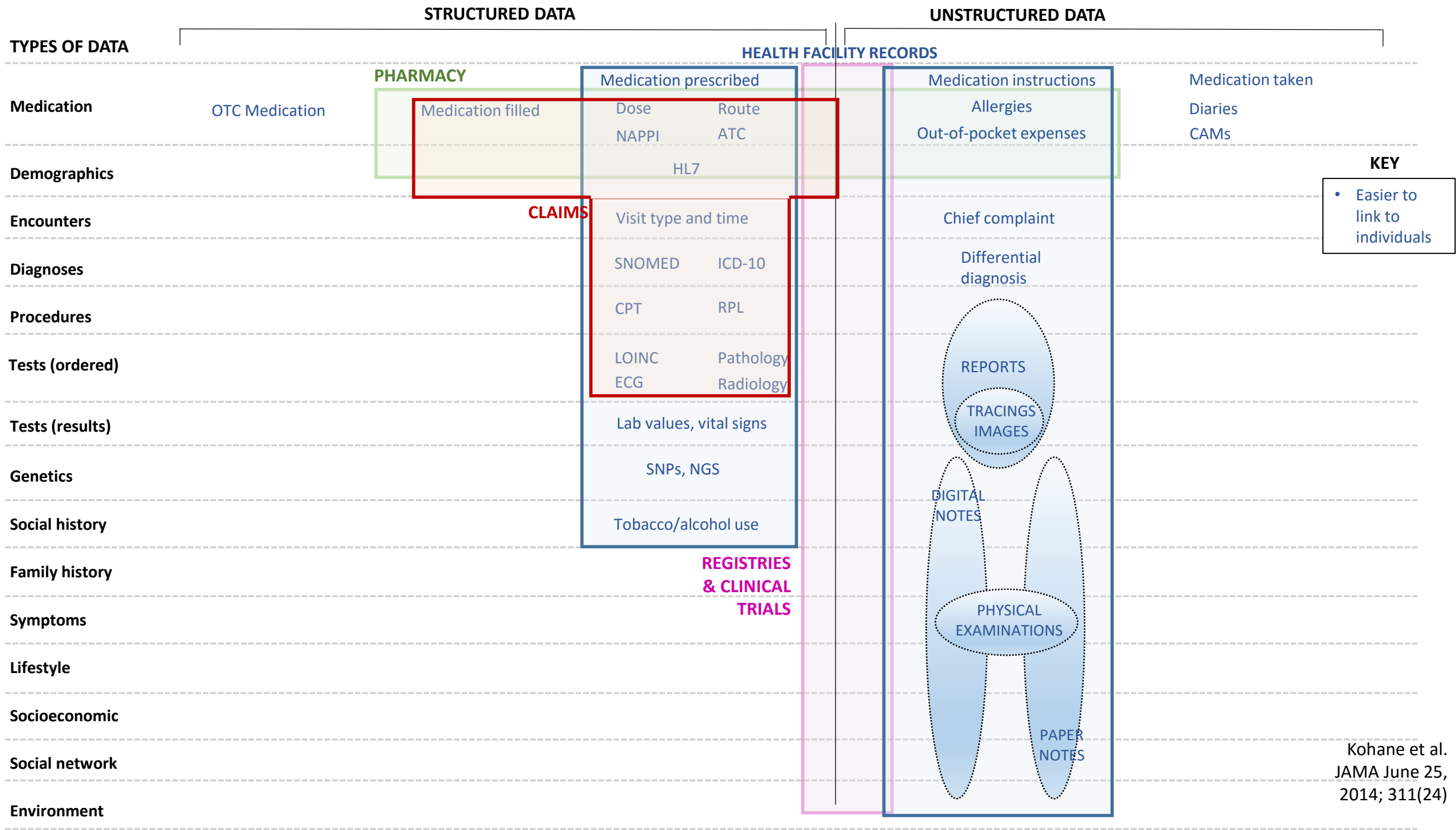


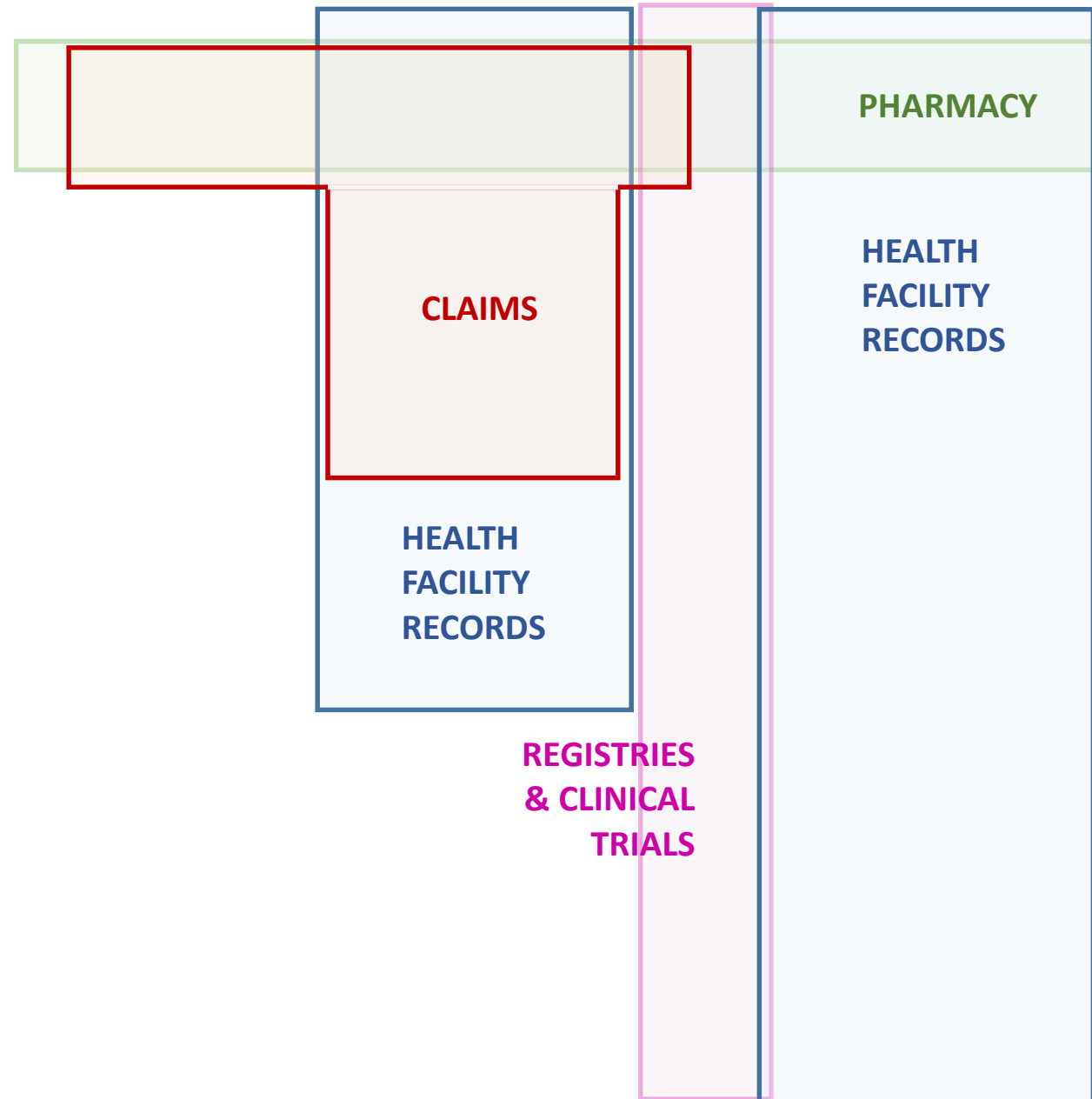
“Data thinking in health care”

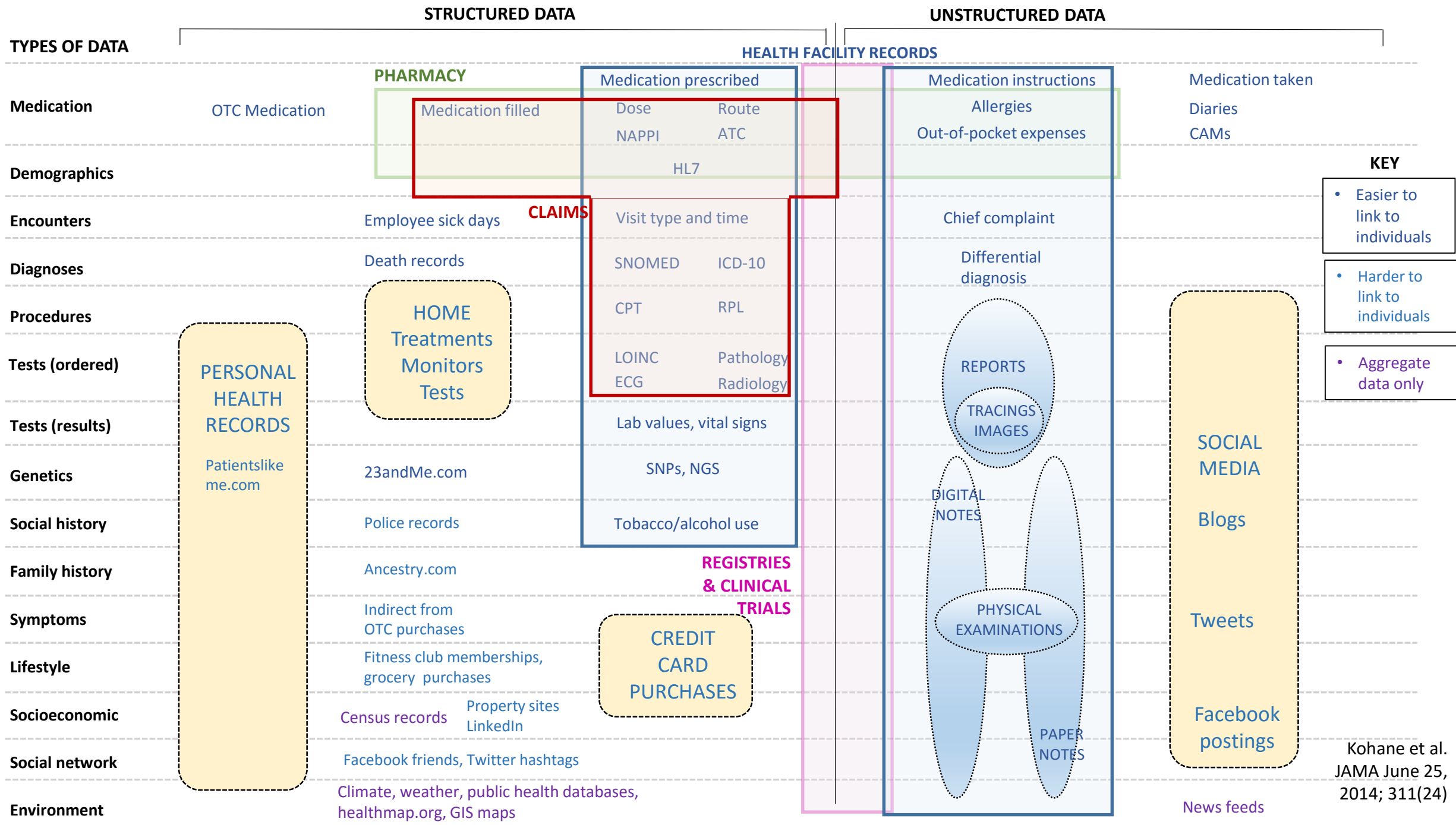


Adapted from LEONARD D’AVOLIO www.cyft.com



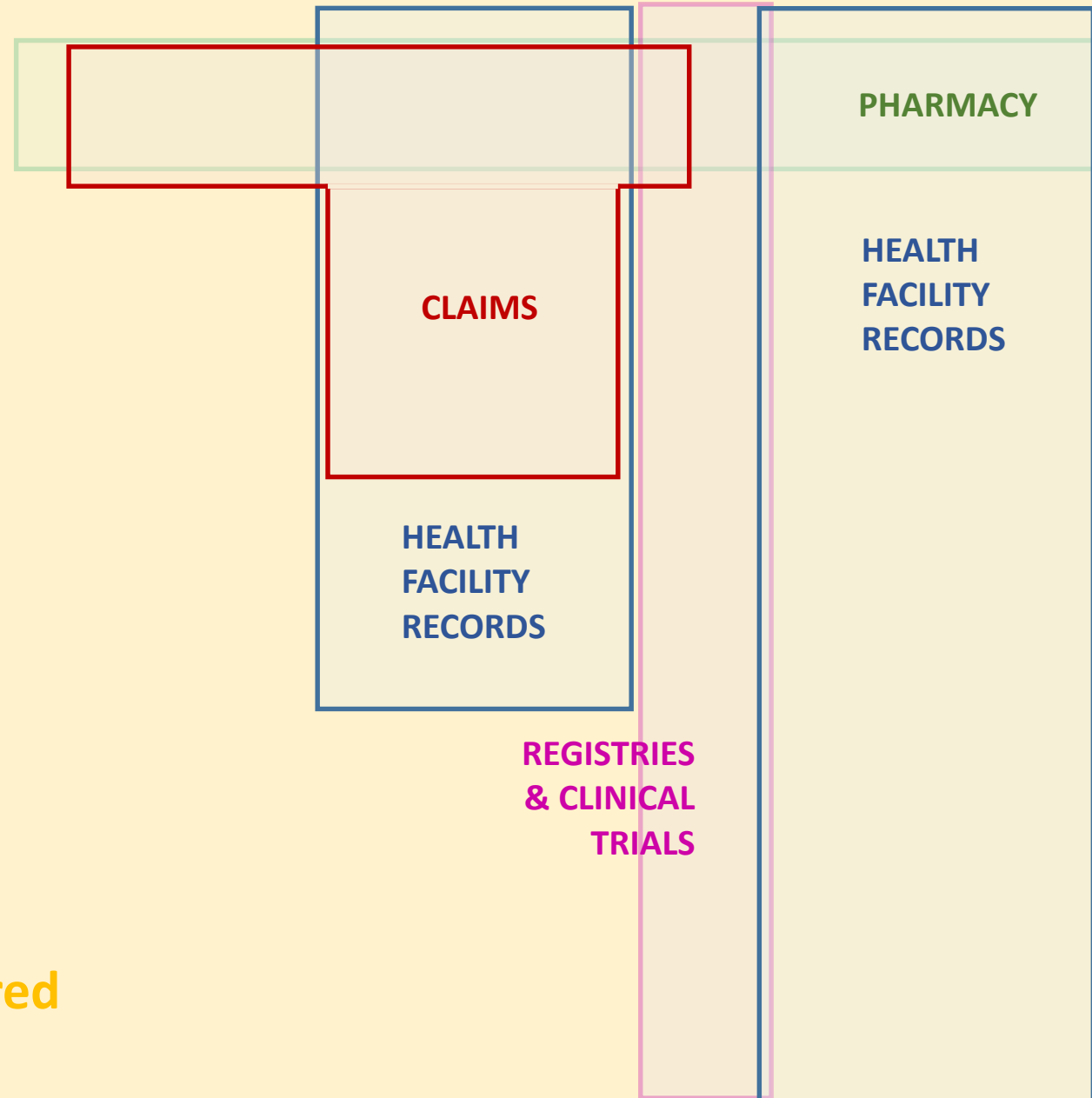






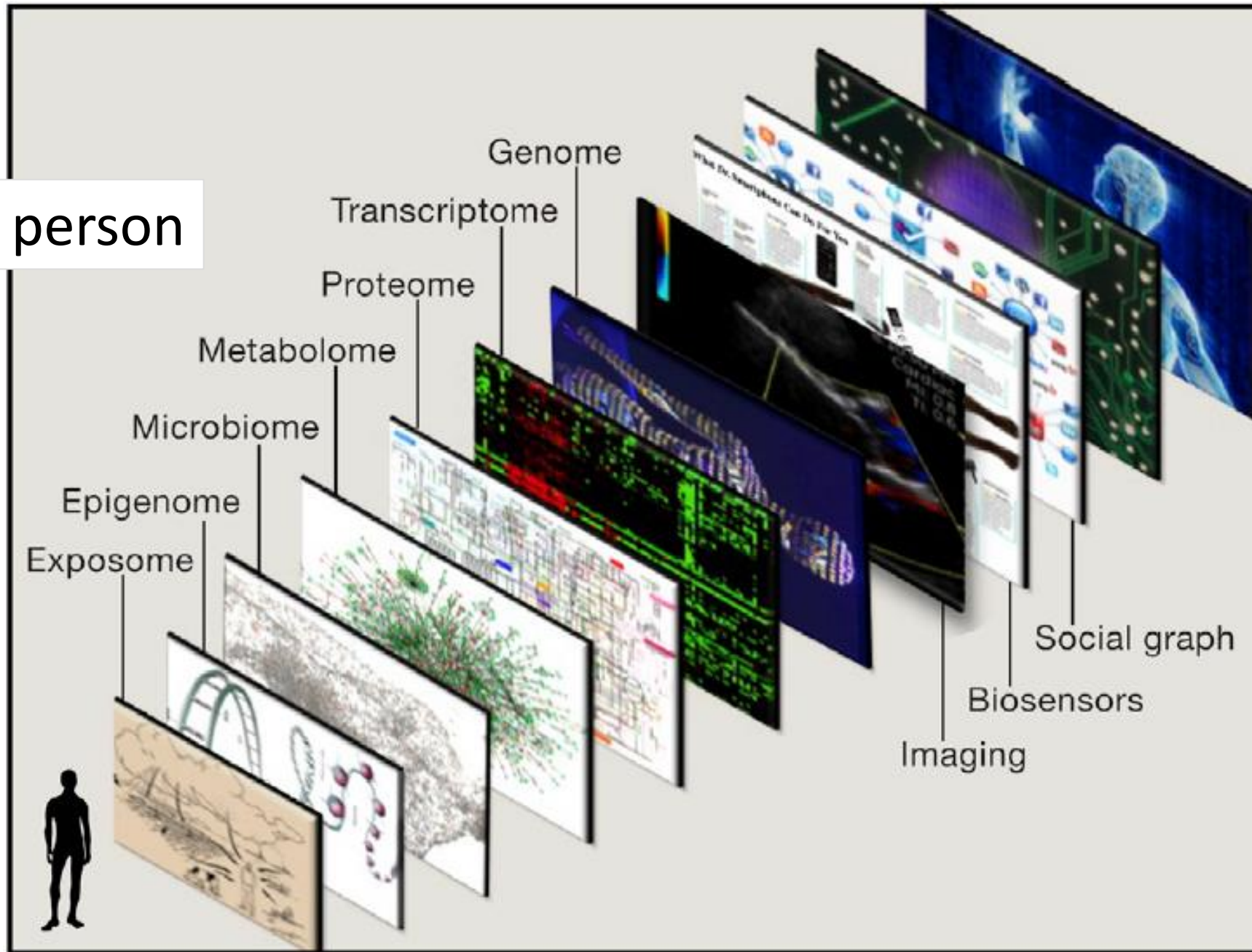
**MUCH
MORE
DATA !!**

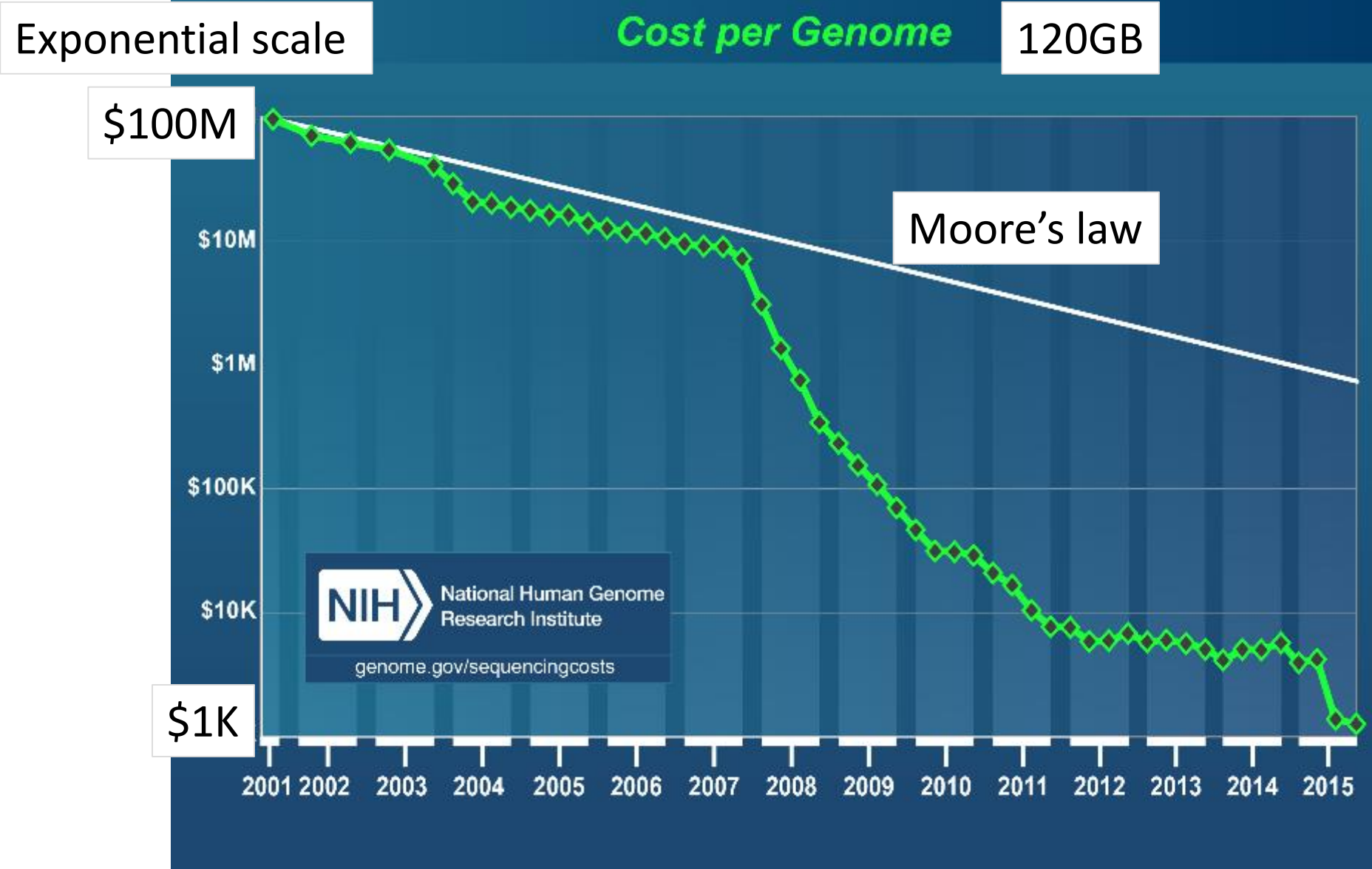
**80-90%
unstructured**



System LEVELS

Individual person





Gigabyte	10 ⁶ bytes
Terabyte	10 ¹² bytes
Petabyte	10 ¹⁵ bytes
Zettabyte	10 ²¹ bytes

2012 worldwide digital healthcare data ~500 petabytes

= 1 billion laptops

“Storage is cheap”

Wearables

Five themes in 2016:

- 1. Beyond step counting**
- 2. Better design**
- 3. Smart clothing**
- 4. Advancing sensor technology**
- 5. Reimbursement constraints**

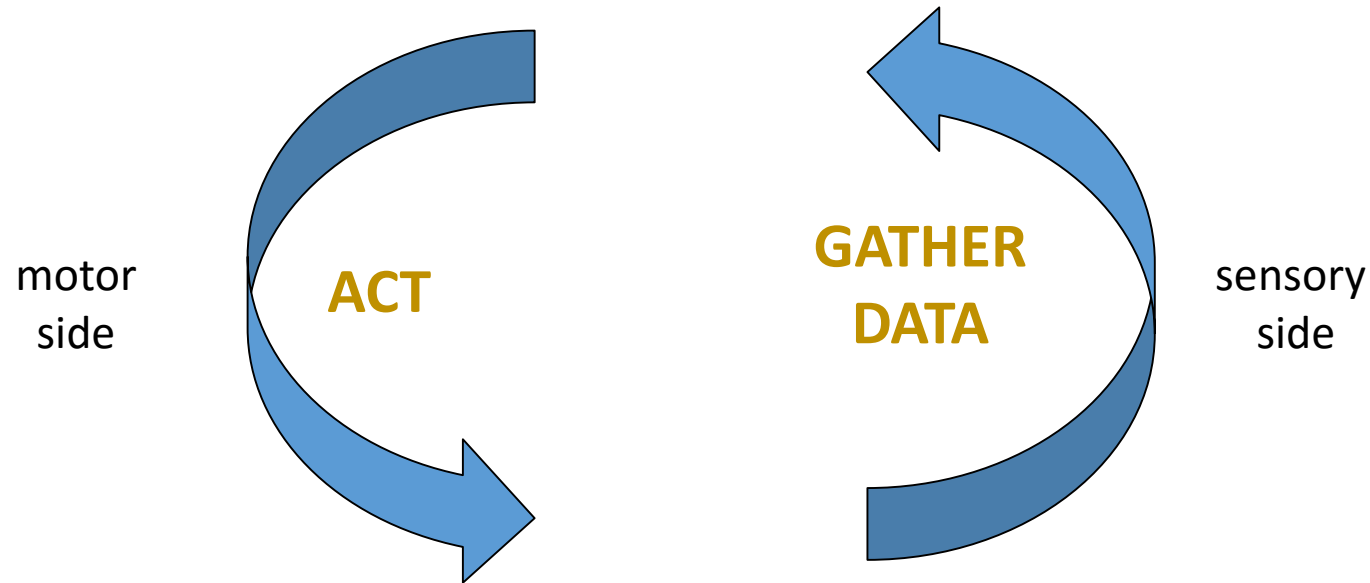
Wearables Weekly

Gillian Christie gchristie@thevitalitygroup.com.



Photo: John Tlumacki. The Boston Globe

The reflex arc of patient care



“All the barriers to medical informatics hopes are on the sensory side.
- computers can’t know everything the provider does”

Clem McDonald, MD - NLM - 3/3/2013. HIMSS Physician Health IT Symposium

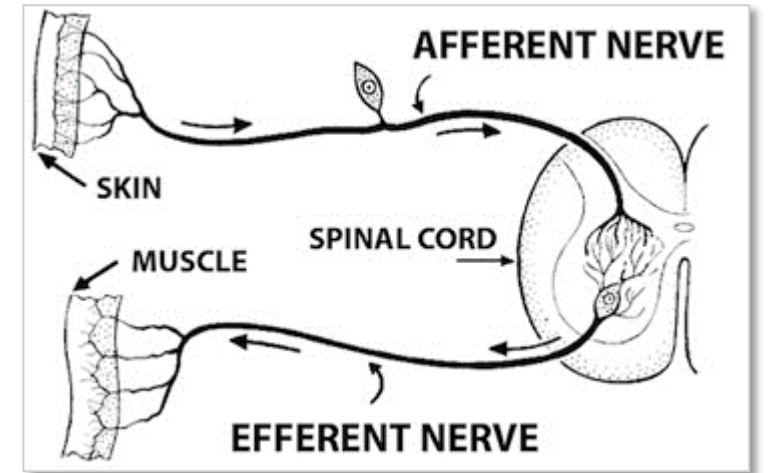


Photo: <http://www.ucchartingsolutions.com/>

Dominance of mobile devices

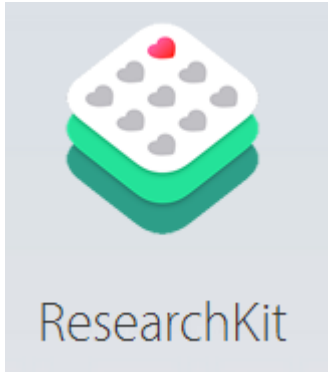
“mobile devices will become the predominant means by which patients interact with BIDMC. Your phone will be the **repository of your medical record**, the means by which you **collaborate with your provider**, and the vehicle for **submission of data to your care team**.”

“The desktop is dead.
The phone is the future.”

John Halamka, CIO, Beth Israel Deaconess Medical Center



DIY cellphone. David Mellis MIT



EpiWatch
Johns Hopkins University



mPower
University of Rochester, Sage Bionetworks



Autism & Beyond
Duke University, University of Cape Town



“We’ve gone as far as we can with traditional research. Now we have technology in our pockets that lets us go even further.”

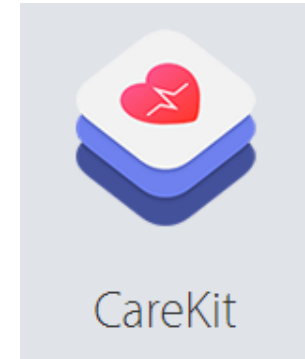
Dr. Helen Link Egger,
Duke University Medical Center

“We’re trying to bring care to patients, wherever they are, right on their phone”.

Dr. Ray Dorsey,
University of Rochester

- simple integration of devices in the home
- collection of patient questionnaires
- bidirectional exchange of care plans

Dr John Halamka
Beth Israel Deaconess



Chronic conditions care app
Beth Israel Deaconess Medical Center



Diabetes care app
One Drop



Postsurgical care app
Texas Medical Center

The more you know about your health,
the better you can look after it.

Open data & transparency

HealthData.gov

Unleashing the Power of Data and Innovation To Improve Health

“dedicated to making high value health data more accessible to entrepreneurs, researchers, and policy makers in the hopes of better health outcomes for all”

SHINING A LIGHT

Safer Health Care Through Transparency

<http://www.npsf.org>



The NEW ENGLAND
JOURNAL of MEDICINE

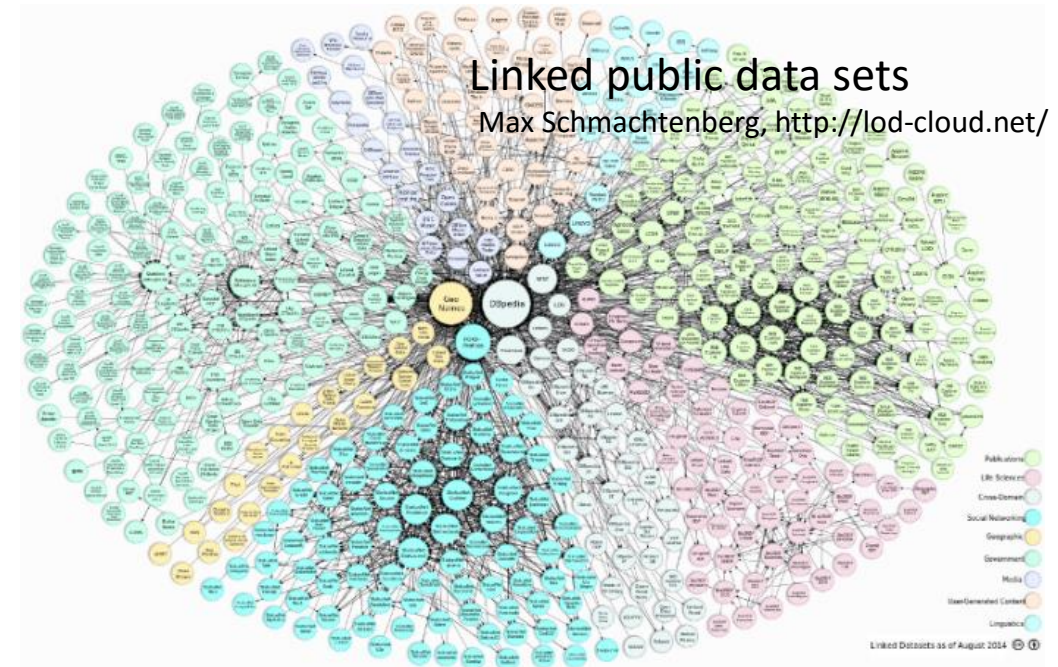
EDITORIAL

Data Sharing

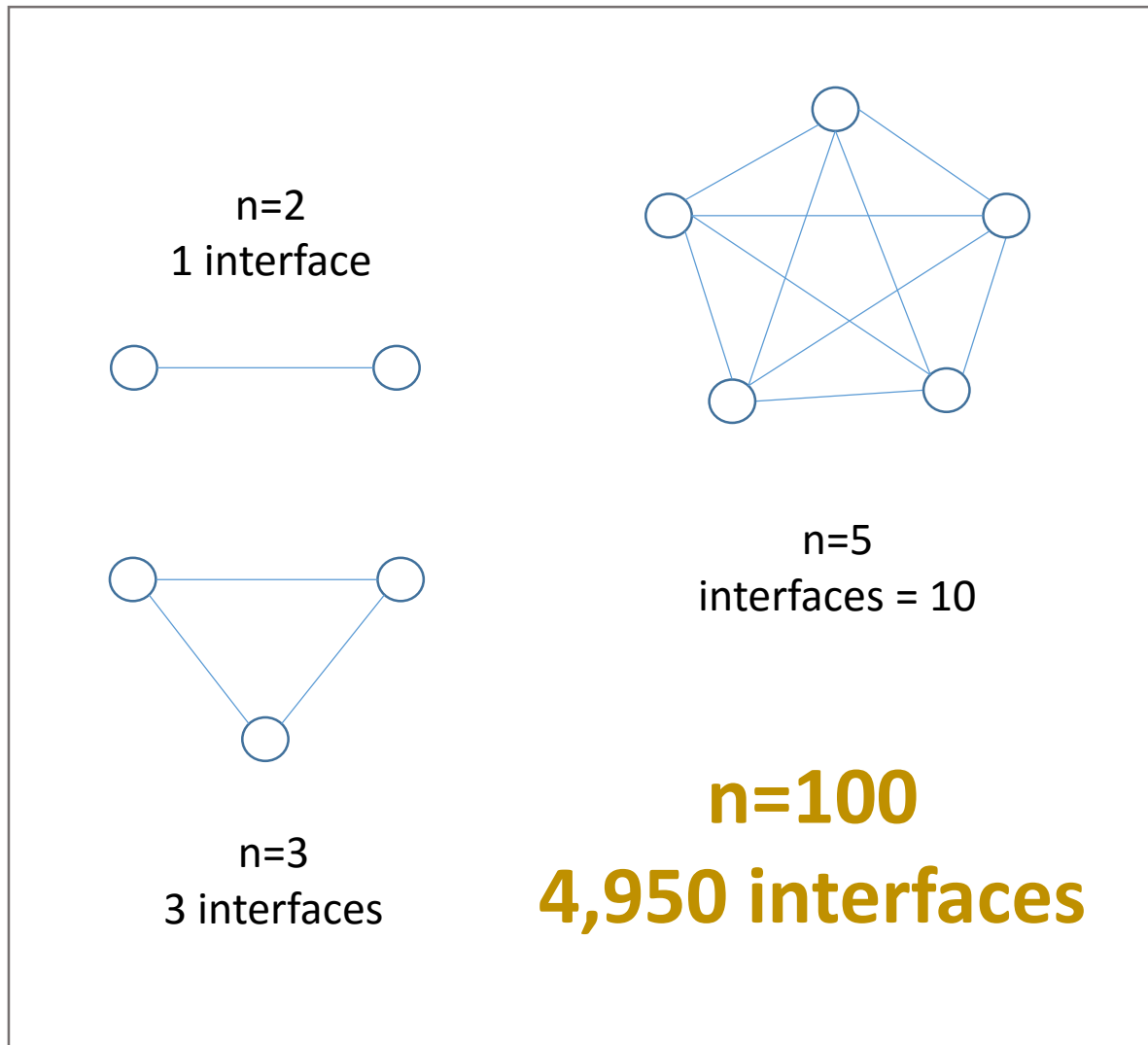
“research parasites”

Dan L. Longo, M.D., and Jeffrey M. Drazen, M.D.

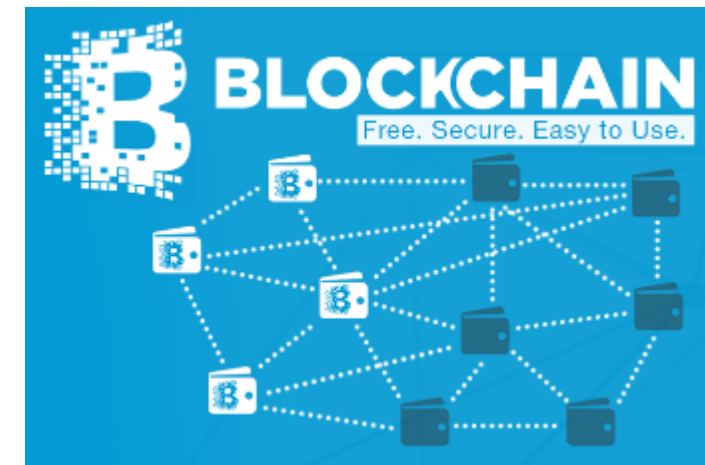
N Engl J Med 2016; 374:276-277 | January 21, 2016 | DOI: 10.1056/NEJMe1516564



<http://southafrica.opendataforafrica.org/>

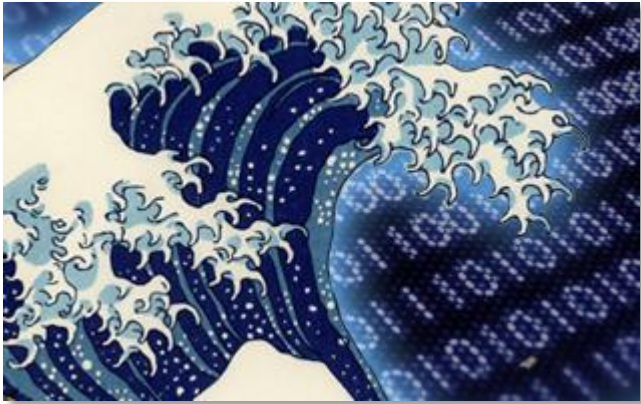


“A permissionless distributed database that maintains a continuously-growing list of transaction records hardened against tampering and revision”.



A solution for federated data and security/authentication – with nobody “in charge”

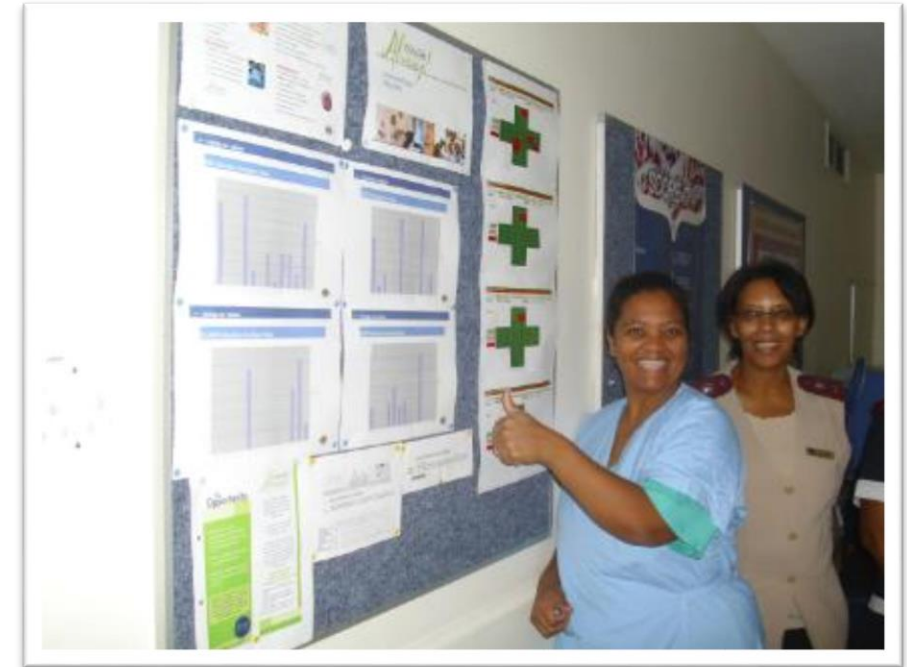
The data tsunami



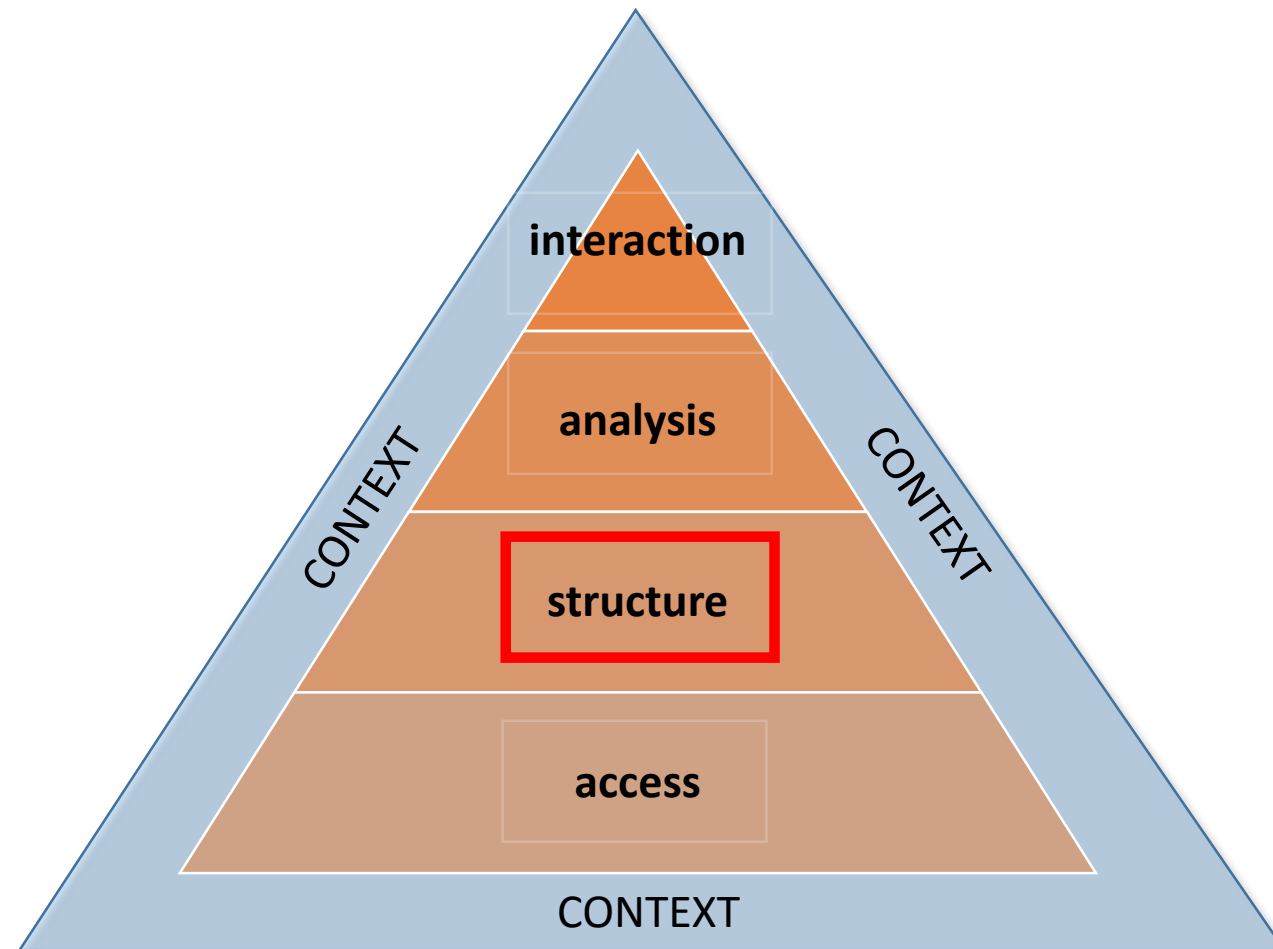
Doctors and their private hospital records



Simple, useful data



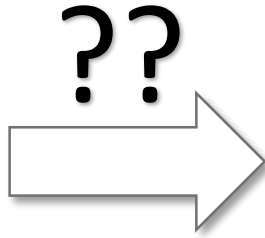
		1	2		
		3	4		
		5	6		
7	8	9	10	11	12
13	14	15	16	17	18
19	20	21	22	23	24
		25	26		
		27	28		
		29	30	31	



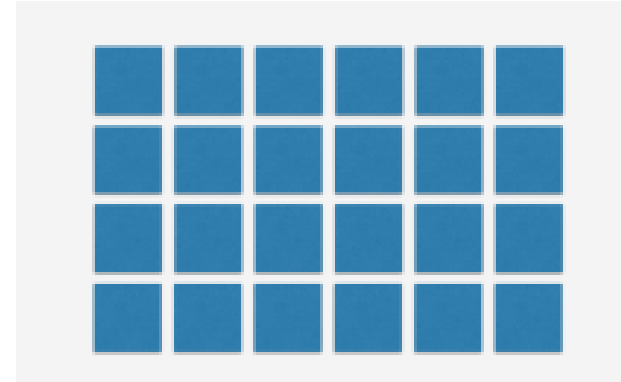
unstructured



What you find in the “wild”
e.g. text, images, audio,
video



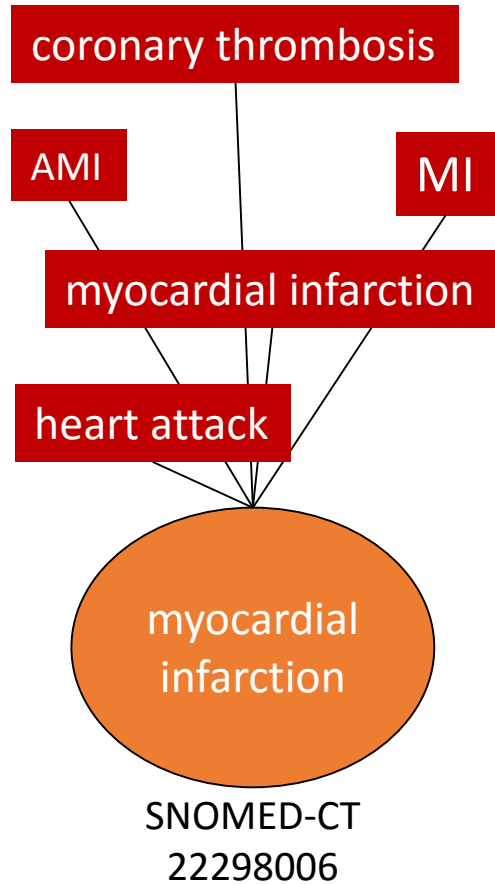
structured



What you find in a database
(typically)

ICD-10
CPT/CCSA
NAPPI
DICOM
CCDA
etc

Semantic interoperability



“data liquidity”
vs data lock-in
vendor lock-in



Application interoperability



Fast Health Interoperability Resources

Enables the **exchange** of clinical, administrative, public health and research data.

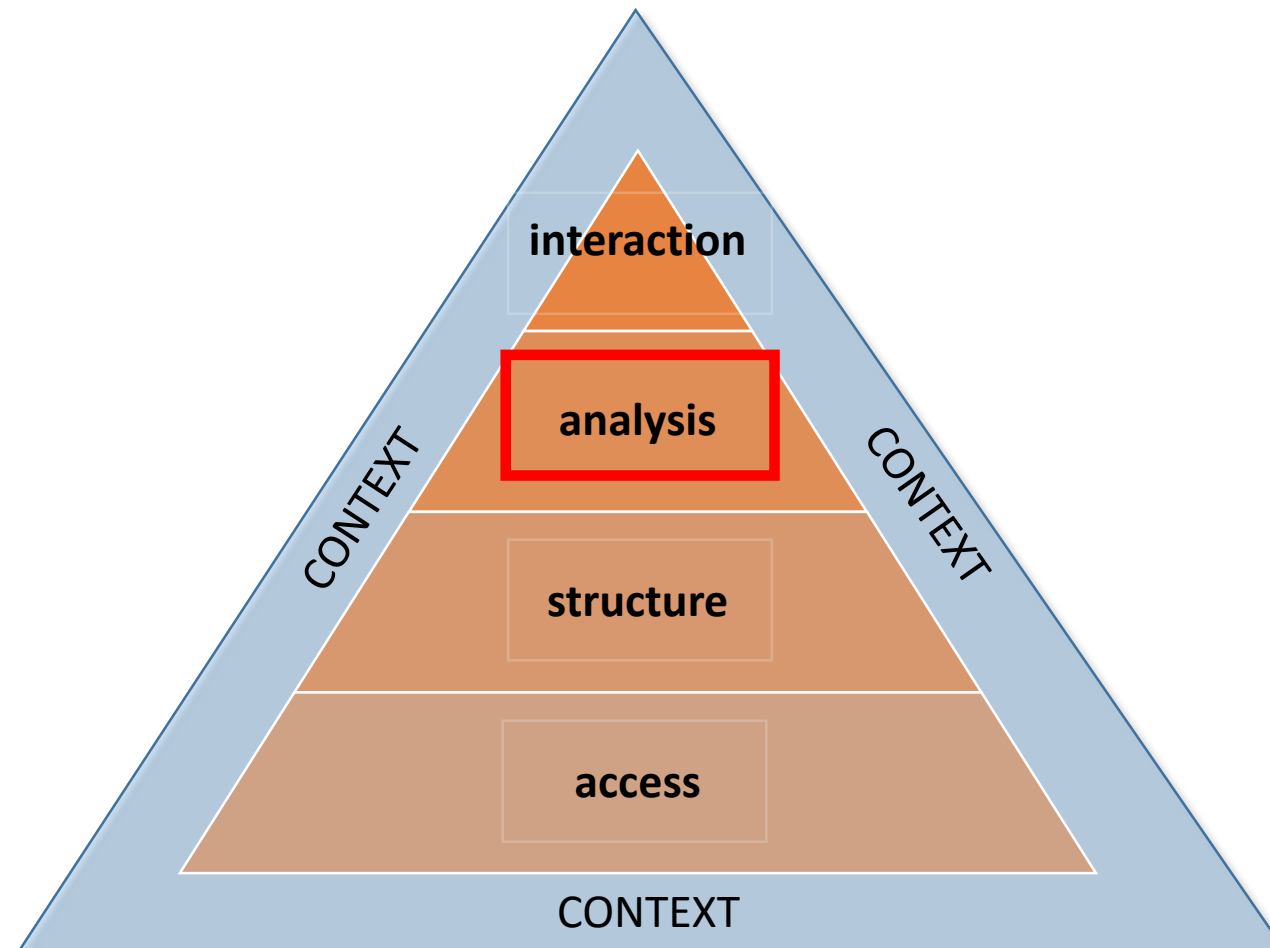
For use world-wide in a **wide variety of contexts**, including in-patient, ambulatory care, acute care, long-term care, community care, allied health, etc.



Open, standards-based technology platform

Enables innovators to create **apps** that seamlessly and securely run across the healthcare system for patients, doctors, and healthcare practitioners to improve clinical care, research, and public health.

Electronic health records (EHR) and **data warehouses** support the SMART standard



Ask the right questions...

Are we improving?

Are we achieving?

Are we meeting the needs of our patients (customers)?

Have we had a good day or a bad day (week/month/year)?

Measure what matters...

- Individual health outcomes
- Population health
- Per capita cost

Learning Healthcare System

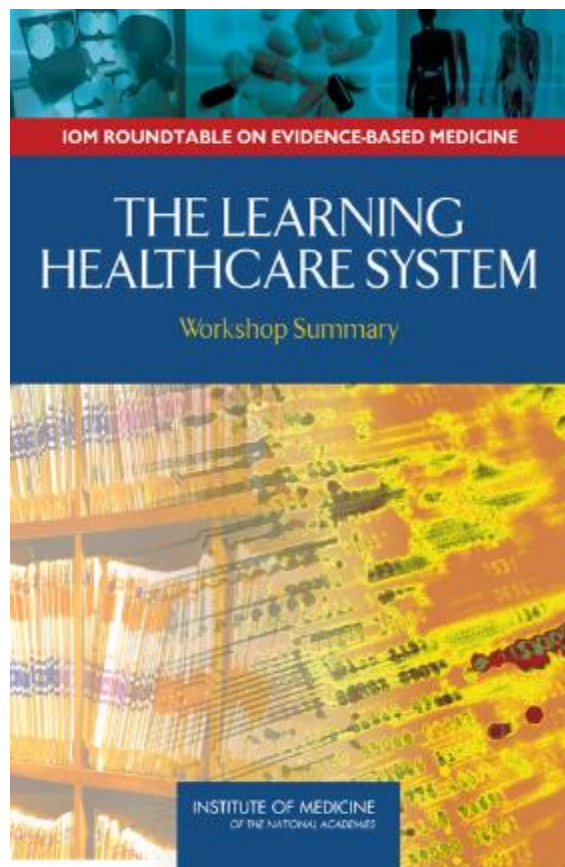
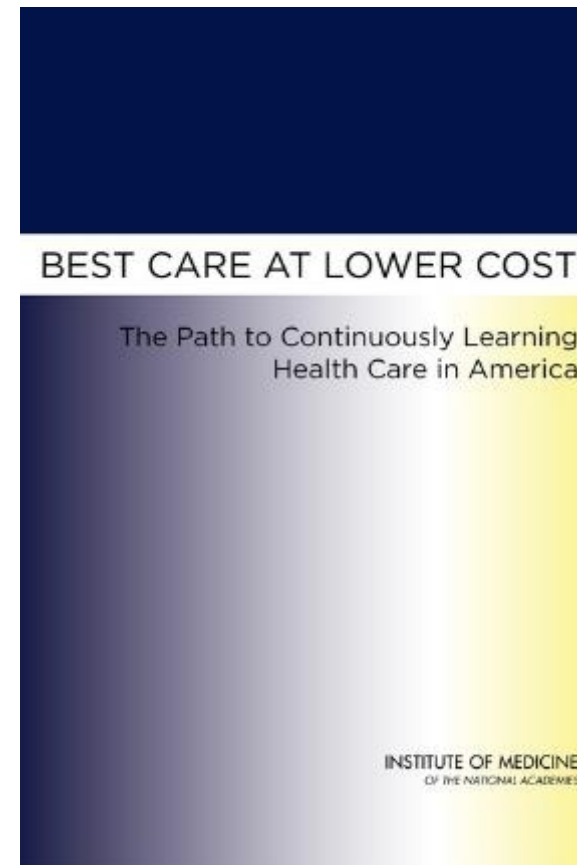
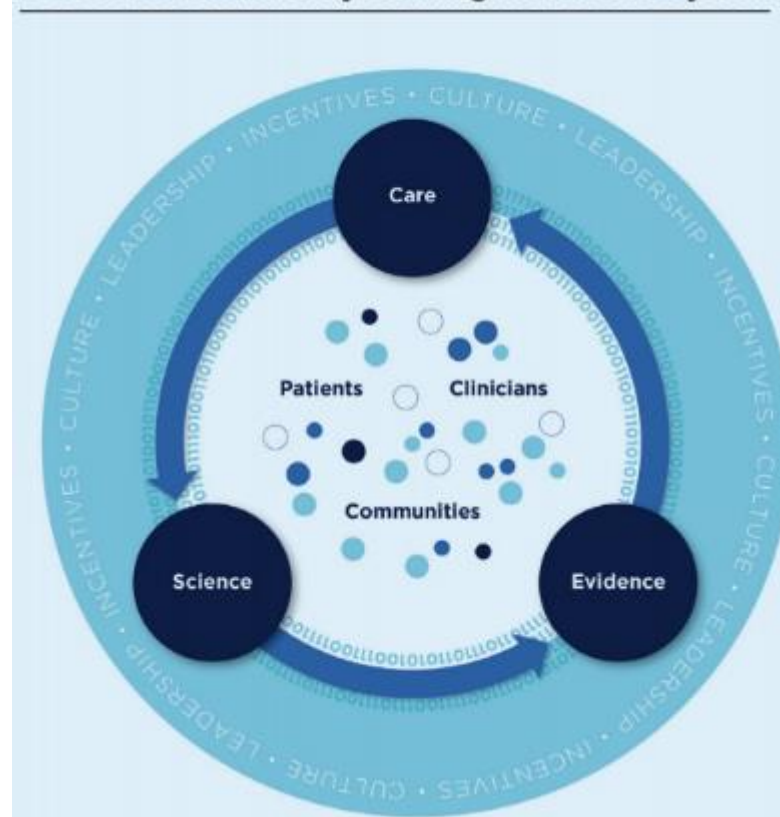
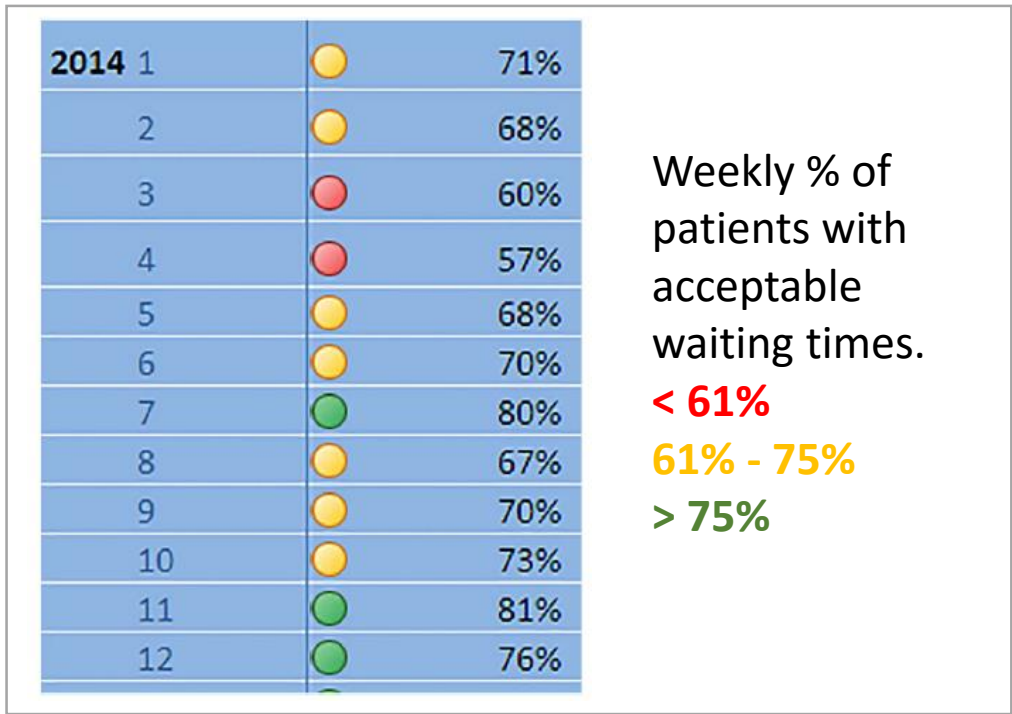
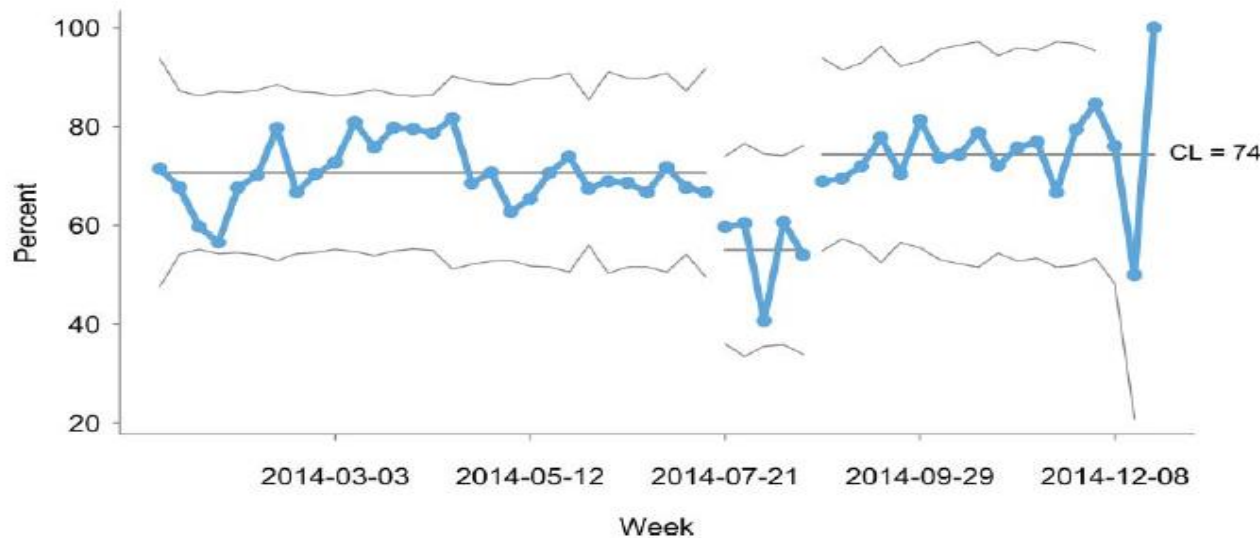
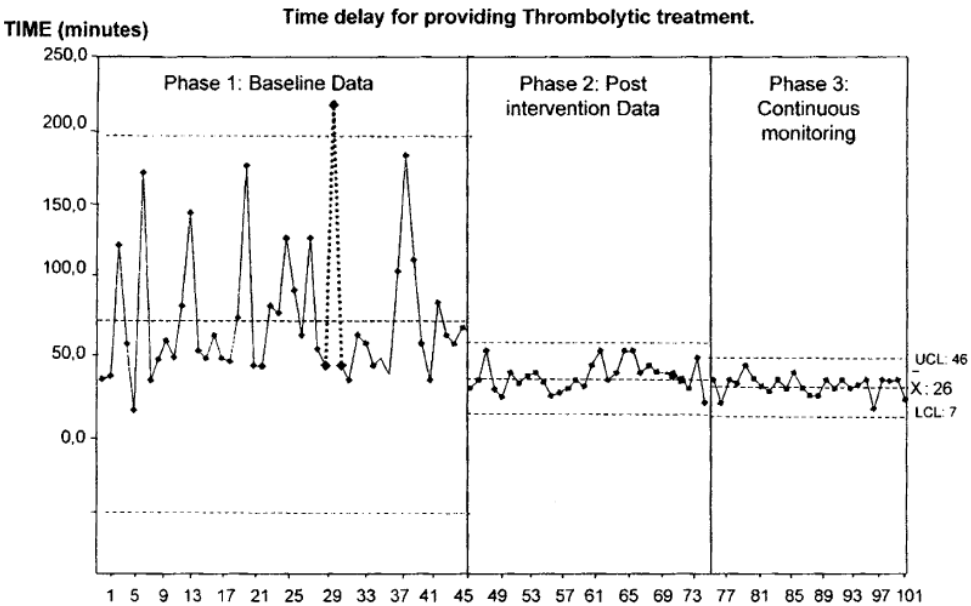
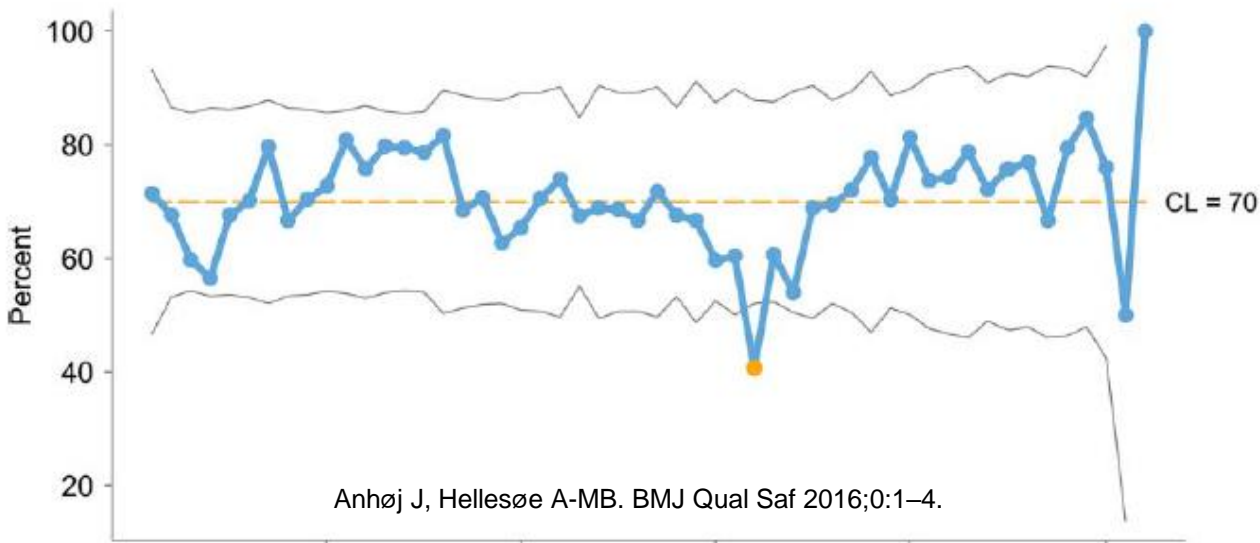


FIGURE: A Continuously Learning Health Care System

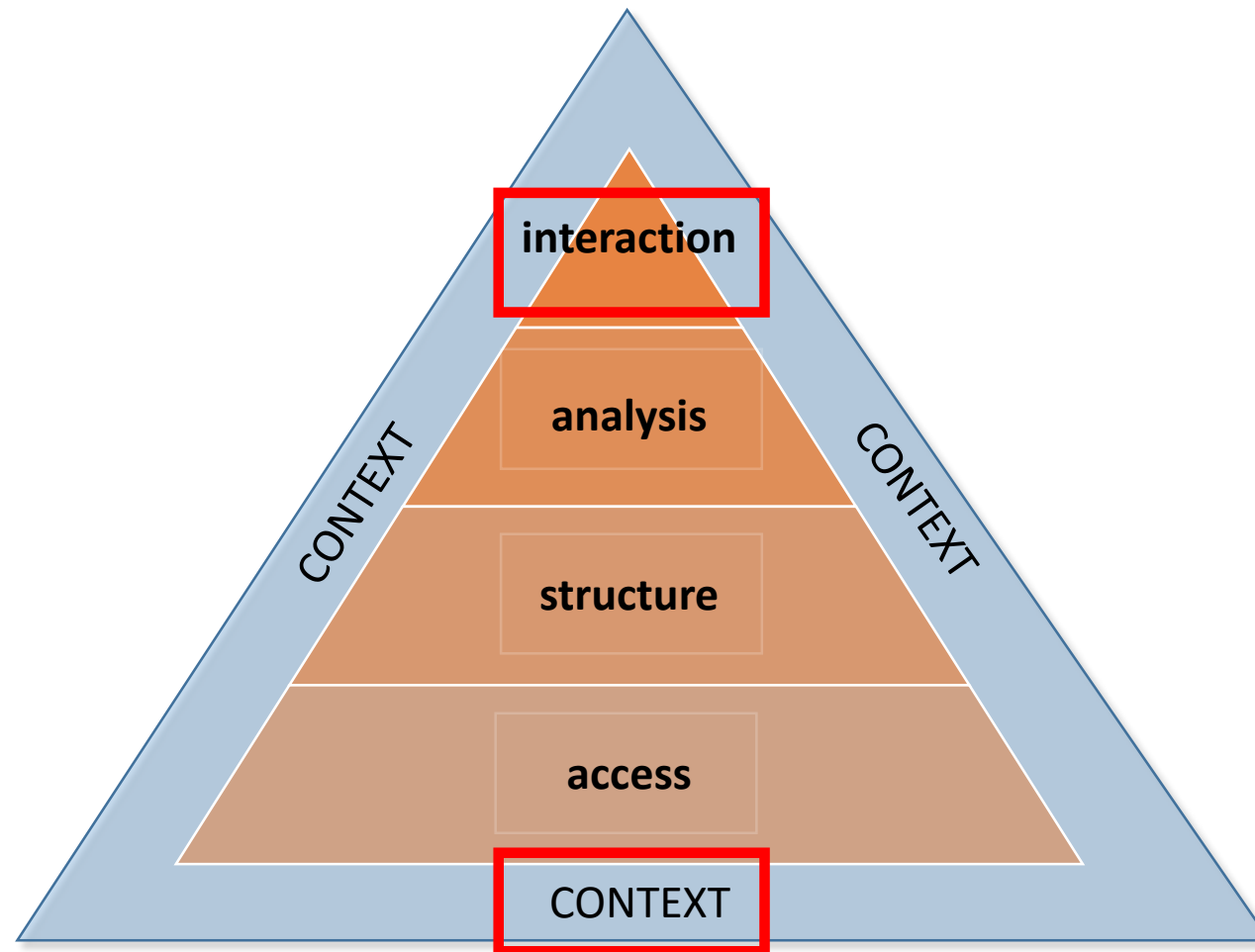




% of patients with acceptable waiting times:
 special cause variation



Three time periods, each showing common cause variation

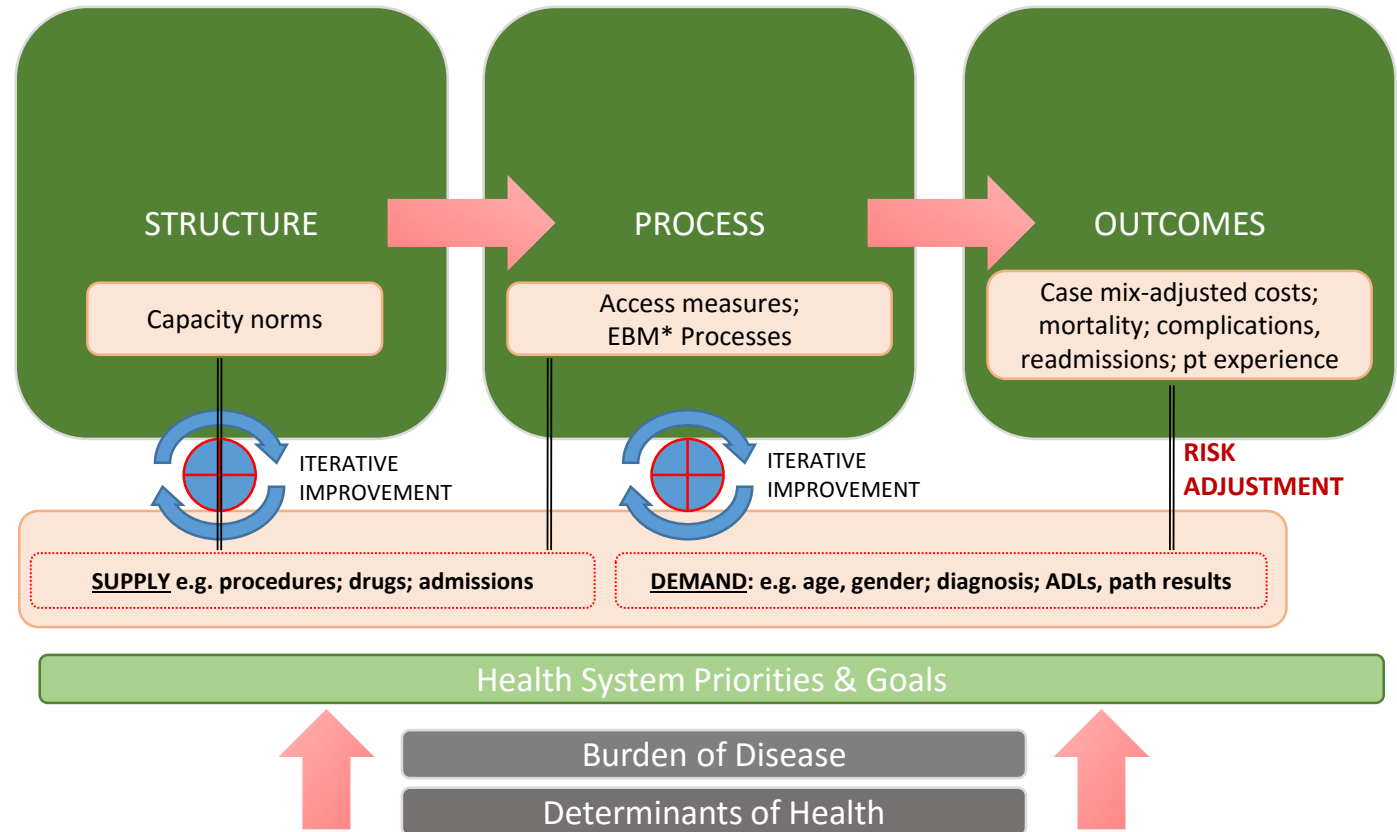


System LEVELS

Entire System

Demand for **value**
Improvement
Accountability/**transparency**
e.g. CC / HMI

Patients at the centre
Co-production of health

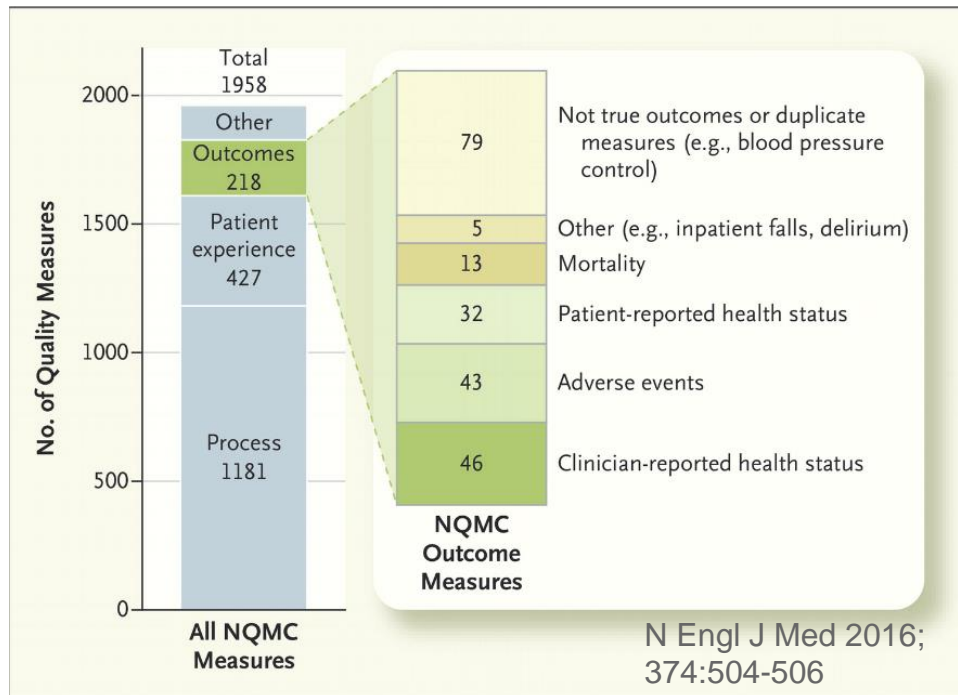


= Measurement

*EBM = Evidence-based medicine

“Measure what matters”

1958 measures; only 218 outcomes



Definitive, standardized, quality measurement sets focused on outcomes

International Consortium for Health Outcomes Measurement's Standardized Outcome Sets.*			
Standard Sets Complete			Under Consideration for 2016 and Beyond
2013	2014	2015 (Final Approval Pending)	
1. Localized prostate cancer	5. Parkinson's disease	13. Breast cancer	22. End-stage renal failure
2. Lower back pain	6. Cleft lip and palate	14. Dementia	23. Oral health
3. Coronary artery disease	7. Stroke	15. Frail elderly	24. Brain tumors
4. Cataracts	8. Hip and knee osteoarthritis	16. Heart failure	25. Drug and alcohol addiction
	9. Macular degeneration	17. Pregnancy and childbirth	26. Bipolar disorder
	10. Lung cancer	18. Colorectal cancer	27. Burns
	11. Depression and anxiety	19. Overactive bladder	28. Melanoma
	12. Advanced prostate cancer	20. Craniofacial microsomia	29. Head and neck cancer
		21. Inflammatory bowel disease	30. Pediatric oncology (conditions to be determined)
			31. Rheumatoid arthritis
			32. Liver transplantation
			33. Congenital hand malformations
			34. Chronic rhinosinusitis
			35. Congenital hemolytic anemia
			36. Rotator cuff disease
			37. Malaria

* The standard outcomes sets completed or pending in the first 3 years cover conditions accounting for 45% of the global burden of disease.

- Many patients with > 1 condition
- Measurement patient centered vs disease-centered
- Process measurement still NB; processes get outcomes
- Huge burden of measurement for public reporting

Data trends - summarising...

1. Huge amount of new data, more coming; some basics missing; not enough sharing
2. Data needs structure (e.g. linking to an individual), analysis (thinking is still required) and interaction
3. Start where we are – existing data, even simple stuff
4. Distinguish (expensive) hype/hope/fantasy from practical/useful
5. Bring the focus back to patients e.g. patient reported data – including outcomes!
6. Need clarity and constancy of purpose i.e. a better healthcare system



Gartner Hype Cycle for Emerging Technologies 2015

thanks

