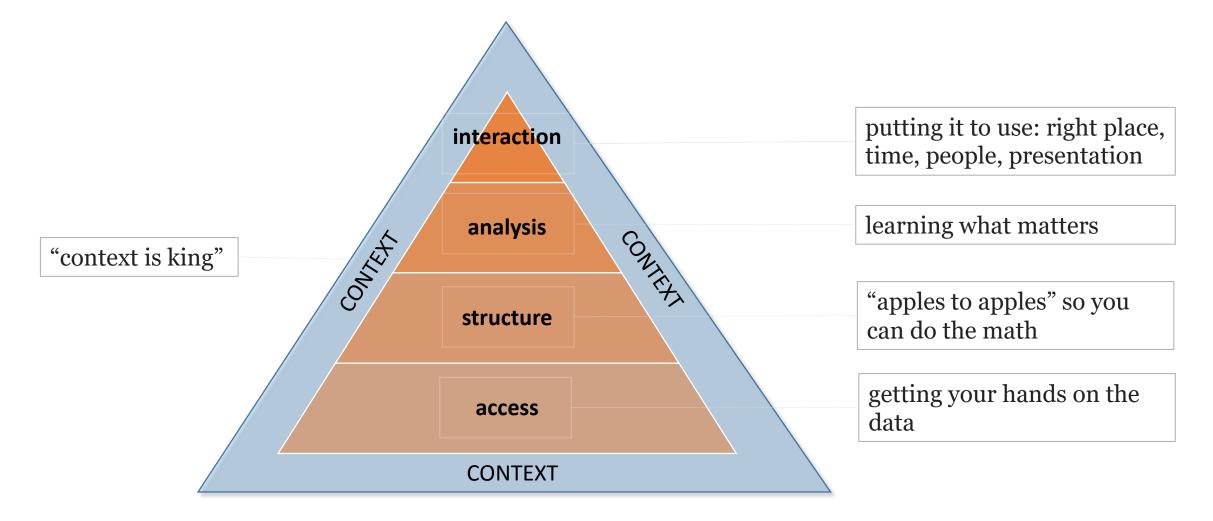
# Data Trends

Dr Gareth Kantor April 2016



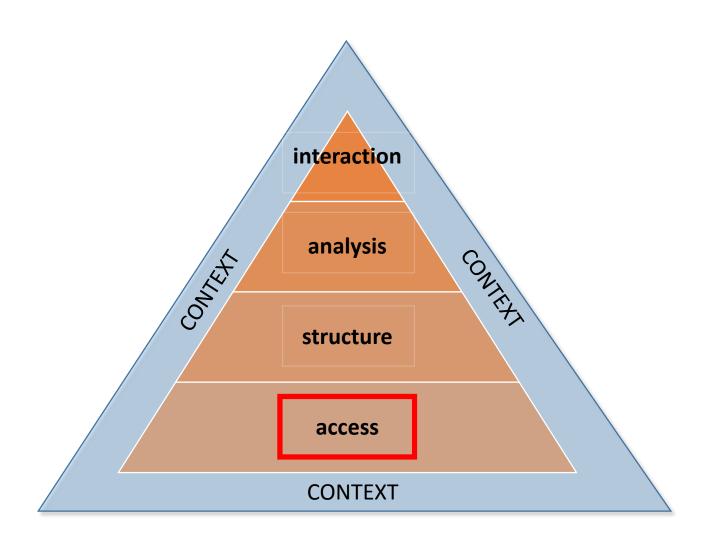
## "Data thinking in health care"



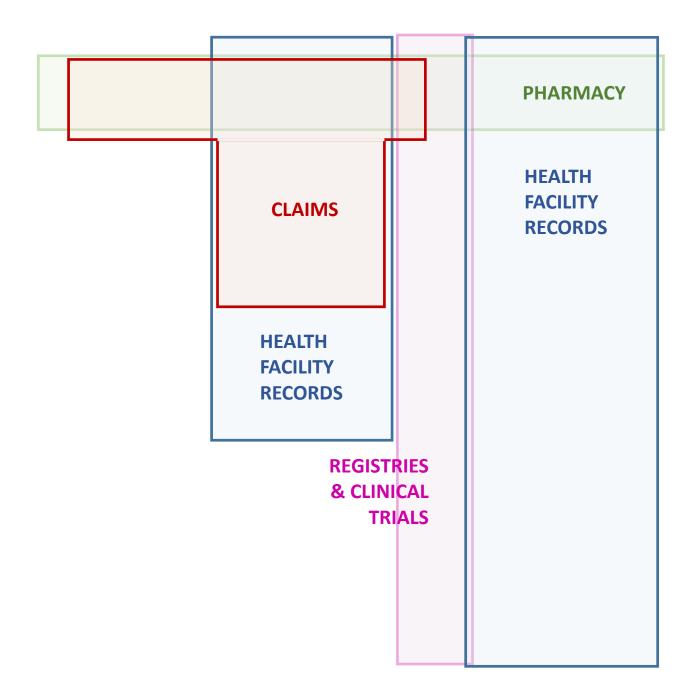


Adapted from LEONARD D'AVOLIO www.cyft.com

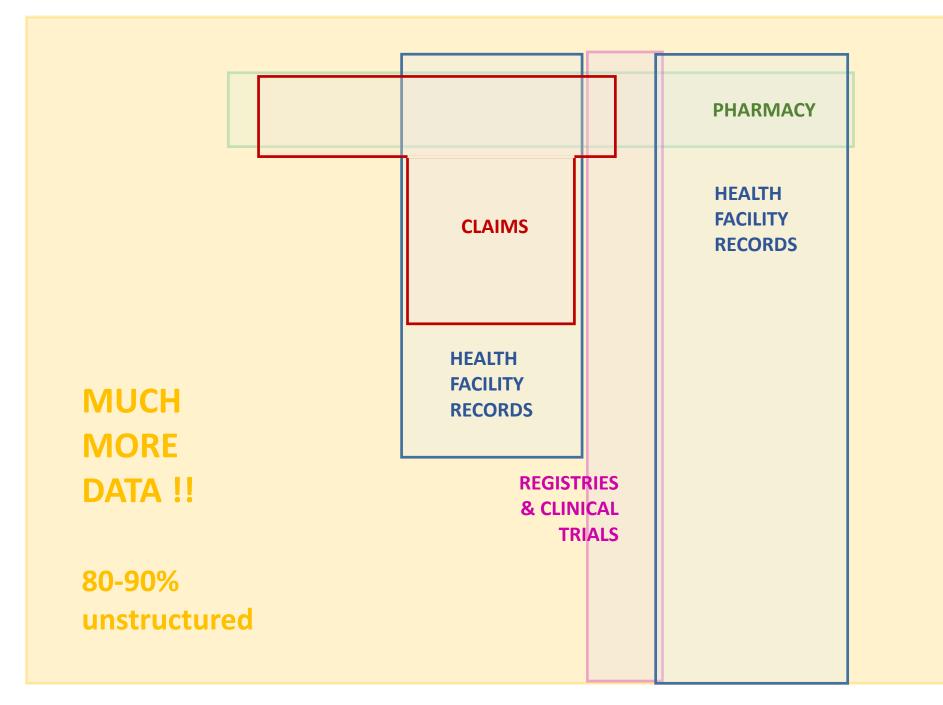


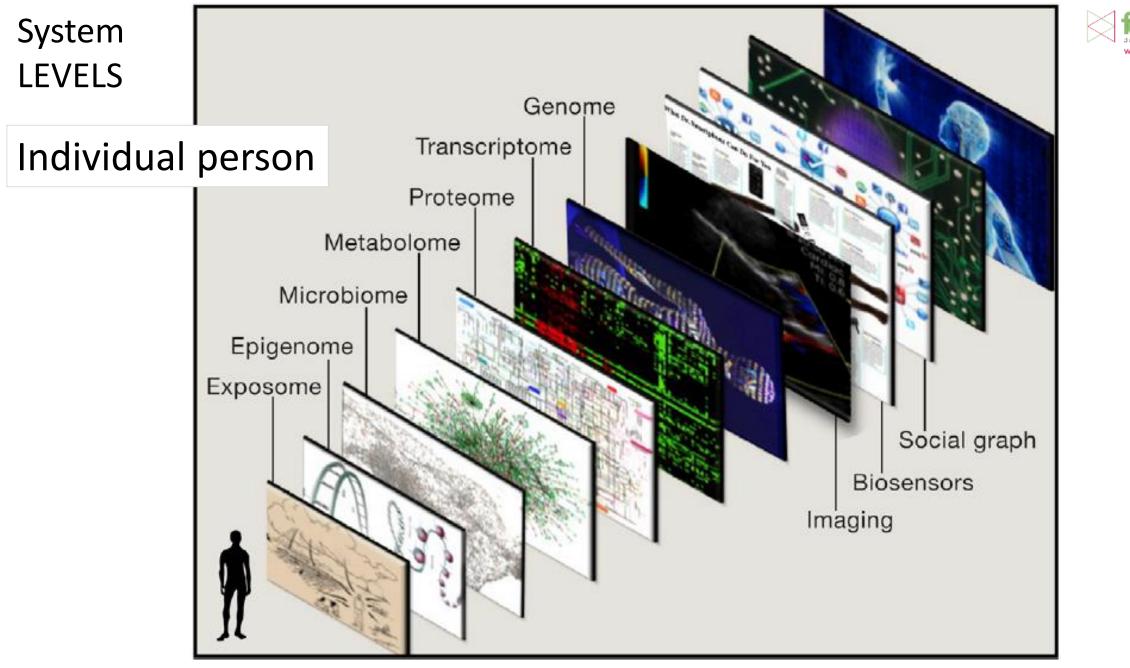


		STRUCTURED DATA	A	UNSTRUCTURED DATA		
TYPES OF DATA		HEALTH FACILITY RECORDS				
	PHARMACY		Medication prescribed	Medication instructions	Medication taken	
Medication	OTC Medication	Medication filled	Dose Route	Allergies	Diaries	
			NAPPI ATC	Out-of-pocket expenses	CAMs	
Demographics			HL7		КЕҮ	
Encounters		CLAIR	As Visit type and time	Chief complaint	Easier to     link to	
					individuals	
Diagnoses			SNOMED ICD-10	Differential diagnosis		
Procedures			CPT RPL			
Tests (ordered)			LOINC Pathology	REPORTS		
			ECG Radiology			
ests (results)		Lab values, vital signs				
Genetics			SNPs, NGS			
				DIGITĂL		
Social history			Tobacco/alcohol use	NOTES		
Family history			REGISTRIES & CLINICAL			
Symptoms			TRIALS	PHYSICAL EXAMINATIONS		
Lifestyle						
Socioeconomic						
				PAPER	12 - h	
Social network				NOTES	Kohane et a JAMA June 2	
					2014; 311(24	
Environment						

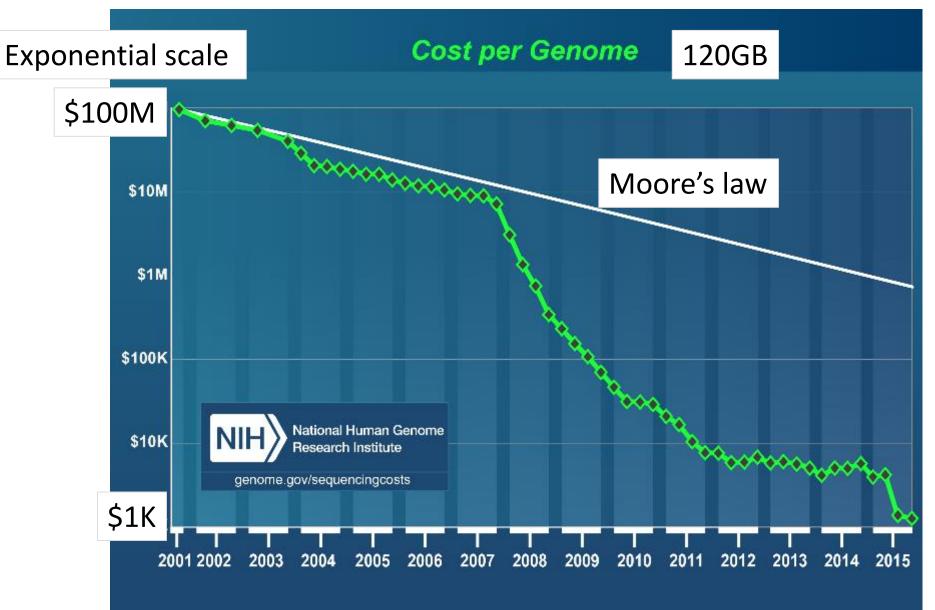


		STRUCTURED DATA	A	UNSTRUCTURED DATA		
TYPES OF DATA			HEALTH FACILI	TY RECORDS		
		PHARMACY			Medication taken	
Medication	OTC Medicatio	on Medication filled	Dose Route	Allergies	Diaries	
			ΝΑΡΡΙ ΑΤΟ	Out-of-pocket expenses	CAMs	
Demographics			HL7		KEY	
Encounters		Employee sick days	Visit type and time	Chief complaint	Easier to     link to     individuals	
Diagnoses		Death records	SNOMED ICD-10	Differential diagnosis	Harder to	
Procedures		HOME Treatments	CPT RPL		link to individuals	
Tests (ordered)	PERSONAL	Monitors	LOINC Pathology ECG Radiology	REPORTS	Aggregate     data apply	
	HEALTH	Tests			data only	
Tests (results)	RECORDS	·	Lab values, vital signs	IMAGES	SOCIAL	
Genetics	Patientslike me.com	23andMe.com	SNPs, NGS	DIGITAL	MEDIA	
Social history		Police records	Tobacco/alcohol use	NOTES	Blogs	
Family history		Ancestry.com	REGISTRIES & CLINICAL			
Symptoms		Indirect from OTC purchases	CREDIT	PHYSICAL EXAMINATIONS	Tweets	
Lifestyle		Fitness club memberships, grocery purchases	CARD PURCHASES			
Socioeconomic		Census records Property sites LinkedIn	FUNCIASES	PAPER	Facebook	
Social network		Facebook friends, Twitter hashtag	<sup>72</sup>	NOTES	postings JAMA June 25	
Environment	×/	Climate, weather, public health d healthmap.org, GIS maps	latabases,		News feeds 2014; 311(24	





Topol E. Individualized Medicine from Prewomb to Tomb. Cell 157 (2014): 241–253





Gigabyte	10 <sup>6</sup> bytes
Terabyte	10 <sup>12</sup> bytes
Petabyte	10 <sup>15</sup> bytes
Zettabyte	10 <sup>21</sup> 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

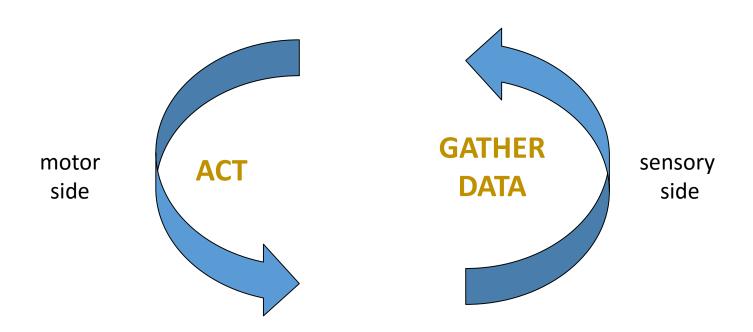
Wearables Weekly

Gillian Christie <u>gchristie@thevitalitygroup.com</u>.



Photo: John Tlumacki. The Boston Globe

## The reflex arc of patient care



AFFERENT NERVE SKIN MUSCLE EFFERENT NERVE

"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."



DIY cellphone. David Mellis MIT

John Halamka, CIO, Beth Israel Deaconess Medical Center



ResearchKit



EpiWatch

mPower

Johns Hopkins University

Autism & Beyond Duke University, University of Cape Town

University of Rochester, Sage Bionetworks



"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 CareKit





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



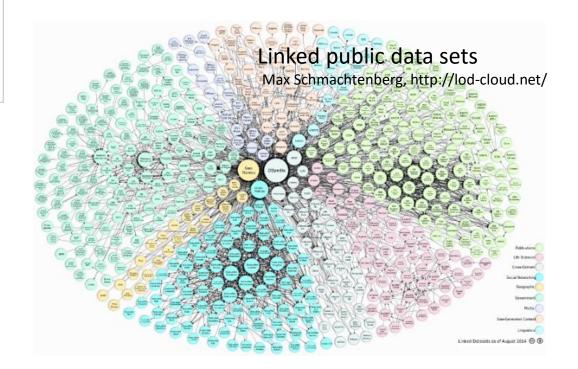
#### The NEW ENGLAND JOURNAL of MEDICINE

"research parasites"

#### EDITORIAL

#### Data Sharing

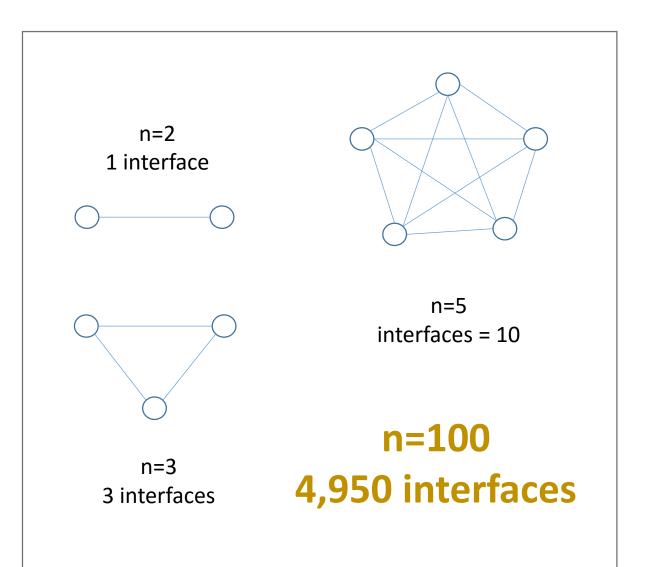
Dan L. Longo, M.D., and Jeffrey M. Drazen, M.D. N Engl J Med 2016; 374:276-277 | January 21, 2016 | DOI: 10.1056/NEJMe1516564



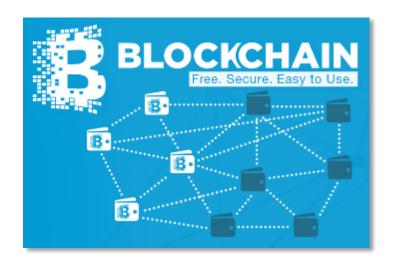


http://southafrica.opendataforafrica.org/





"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

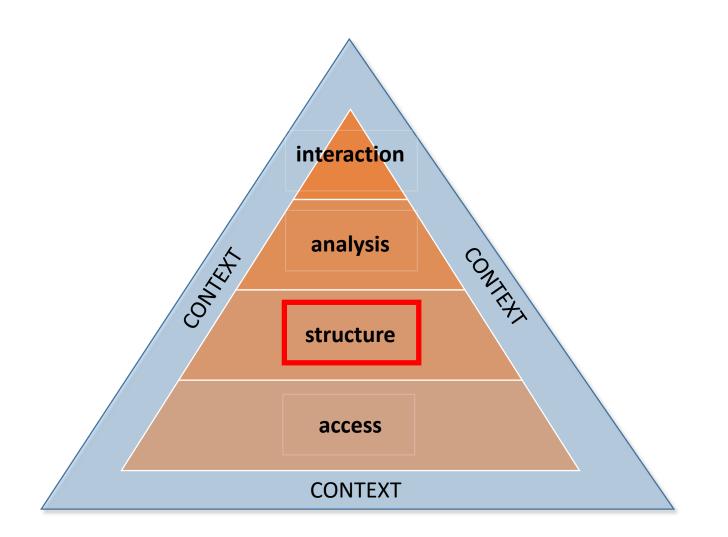


#### Simple, useful data



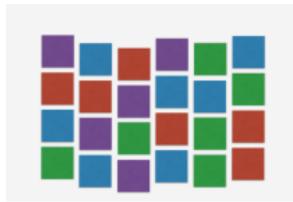
		1		2		
		з		4		
		5		6		
7	8	9		10	11	12
	14	15		16	17	18
19	20	21		22	23	24
		25		26		
		27				
		2.9	30	31		

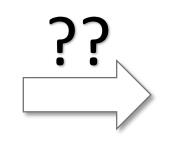


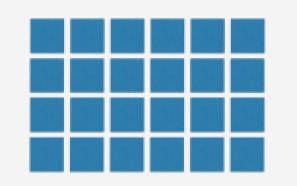


### unstructured







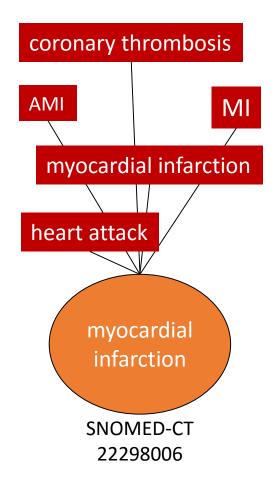


What you find in the "wild" e.g. text, images, audio, video What you find in a database (typically)

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.

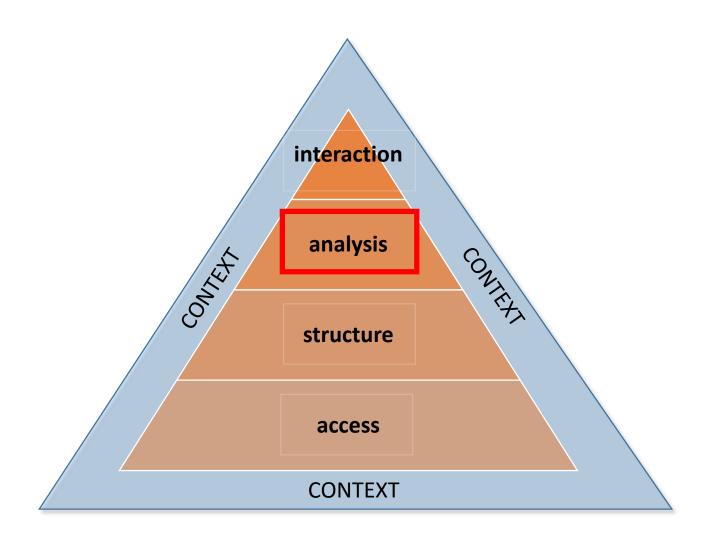


#### **Open, standards-based technology** platform

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...

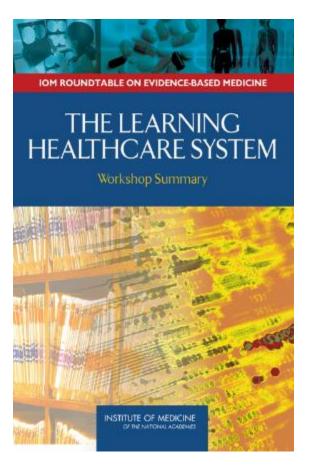
Are we improving? Are we achieving? Are we meeting the needs of our patients (customers)? Have we had a good day or a bad day (week/month/year)?

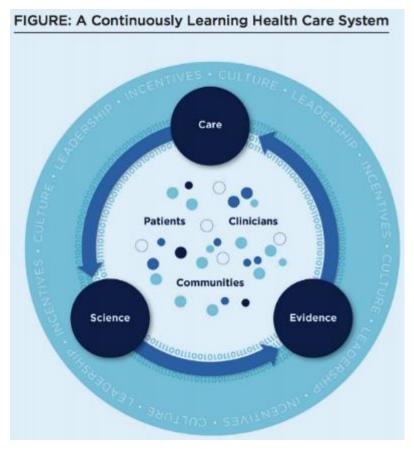
### Measure what matters...

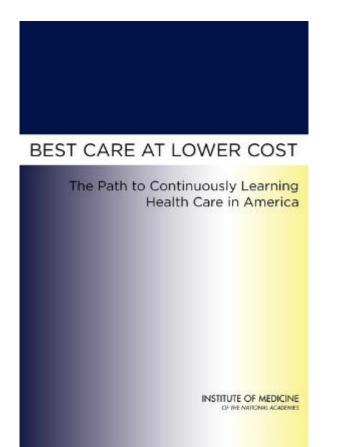
- Individual health outcomes
- Population health
- Per capita cost



### Learning Healthcare System



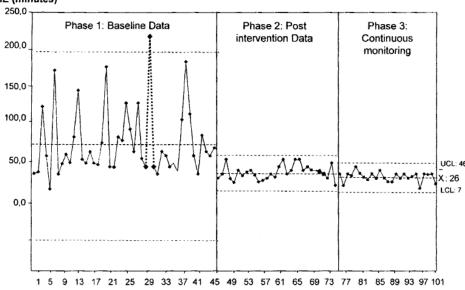




2014 1	$\bigcirc$	71%	
2	$\bigcirc$	68%	
3	0	60%	Weekly
4	0	57%	patients
5	$\bigcirc$	68%	accepta
6	$\bigcirc$	70%	waiting
7	0	80%	<b>&lt; 61%</b>
8	0	67%	61% - 7
9	$\bigcirc$	70%	> 75%
10	0	73%	
11	$\bigcirc$	81%	
12	0	76%	

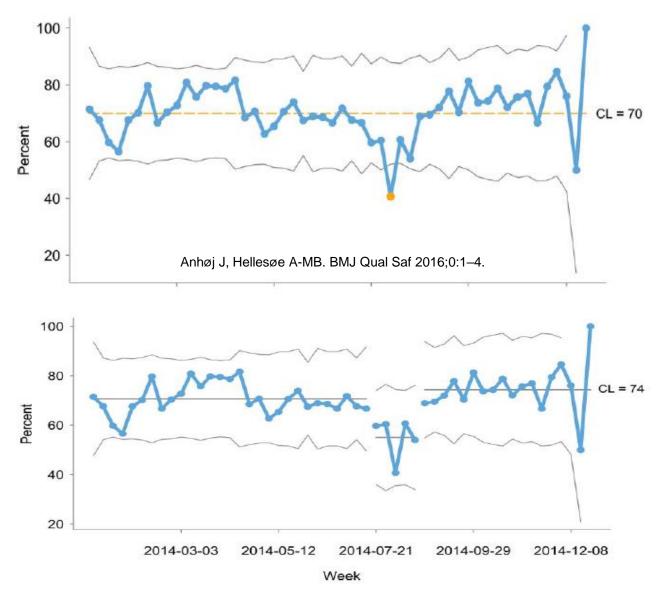
of vith nes.

TIME (minutes)



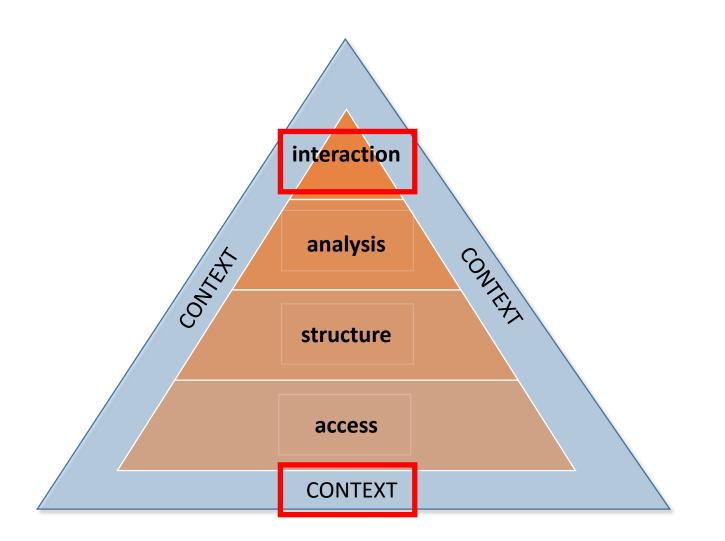
Q Manage Health Care Vol. 13, No. 1, pp. 17–32

% of patients with acceptable waiting times: special cause variation



Three time periods, each showing common cause variation





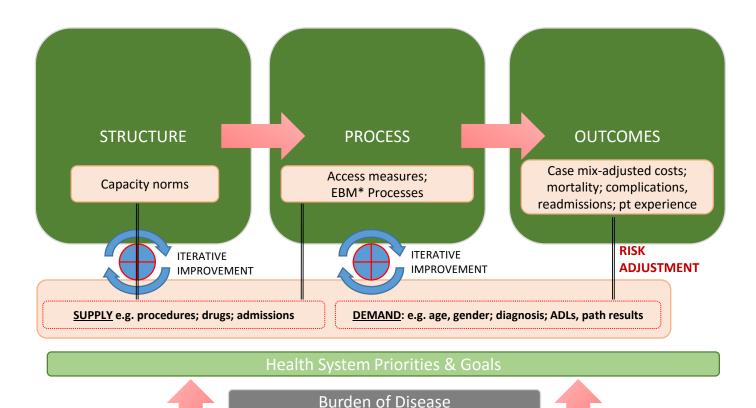


#### System LEVELS

### Entire System

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

Patients at the centre Co-production of health



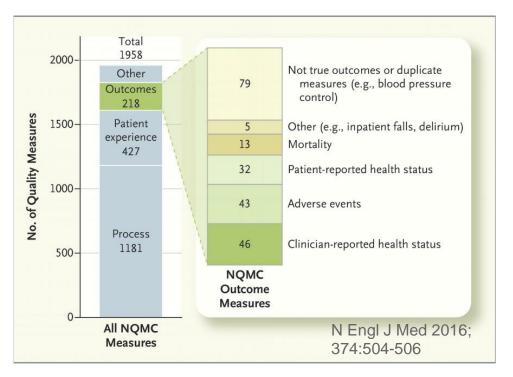
Determinants of Health

= Measurement

\*EBM = Evidence-based medicine

#### "Measure what matters"

#### 1958 measures; only 218 outcomes



#### Definitive, standardized, quality measurement sets focused on outcomes

	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	<ol> <li>Pediatric oncology (conditions to b determined)</li> </ol>
			31. Rheumatoid arthritis
	0.14		32. Liver transplantation
# ICH	ON		<ol> <li>Congenital hand malformations</li> </ol>
			34. Chronic rhinosinusitis
			35. Congenital hemolytic anemia
			36. Rotator cuff disease
			37. Malaria

- 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

