A Brief Look at the Past, the Present, and the Future in Health Informatics.

W. Ed Hammond, PhD, FACMI, FHL7, FAIMBE, FIMIA, FIAHSI
Duke Center for Health Informatics
Clinical & Translational Science Institute
Duke School of Medicine

Duke's Contributions to Informatics

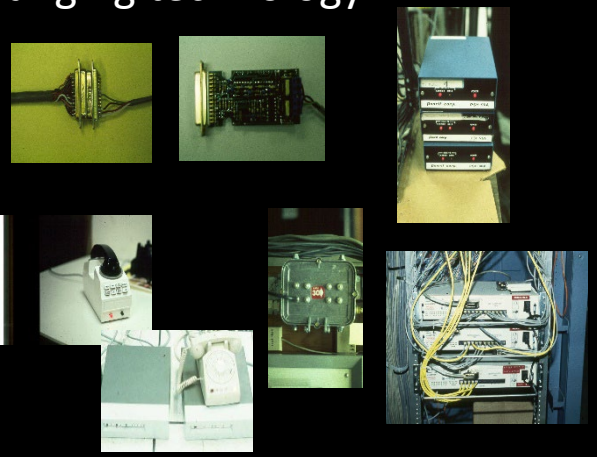
- One of first research databanks for patients with Coronary Heart Disease (MIRU)
- Developed programming language - Gemisch
- One of the first electronic health records – 1969
  - The Medical Record (TMR) – 1975
- Hospital Information System (DHIS) – 1974
  - Most licenses sold of any HIS
- MAPS – data transport program between systems
- DEMPO – Duke's first e-mail system
- IAIMS Consortium begun at Duke
- One of 1st NLM Informatics Training Grants

PDP 12 Digital Computer Corp

- 4K Main Memory
- 12 bit words
- 330K DEC Tapes

Teletype
110 baud
10 characters/second

Changing technology



Development of TMR

1970 Automated HP
1971 OB Prenatal Record
1973 Appointment System
1974 Ambulatory Care
1975 TMR Structure defined
1978 TMR Ambulatory
1981 Nephrology

1981 !st Non Duke Site
1983 Cardiology Databank
1984 Inpatient System implemented
1986 The Laboratory System
1987 TMR/DHIS linkages implemented
1988 OB record converted to TMR
1988 SICU bedside project
1989 Multicounty OB database

1990 Bone Marrow
1990 Rheumatology

1991 Accounts Receivable
1991 OB Inpatient

1991 OB/FMC tightly coupled linkage
1992 Reservation System
1992 Bone Marrow Outpatient

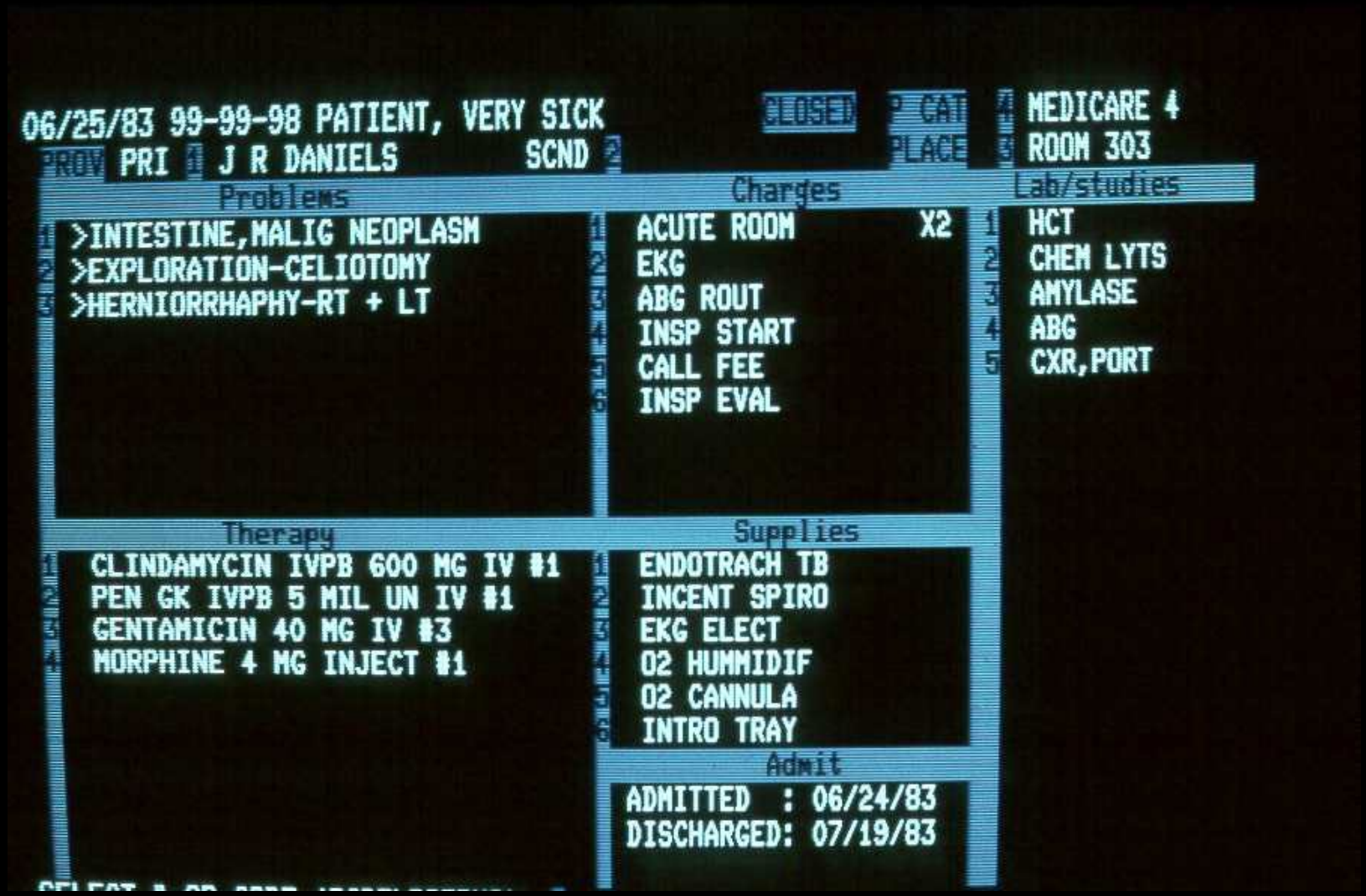
1992 Physician Order Entry
1992 HL7 Interfaces
1993 Insurance Workstation
1995 Web-based TMR
1996 E-mail laboratory
1997 E&M Guidelines
1998 New Generation TMR

Clinical Focus

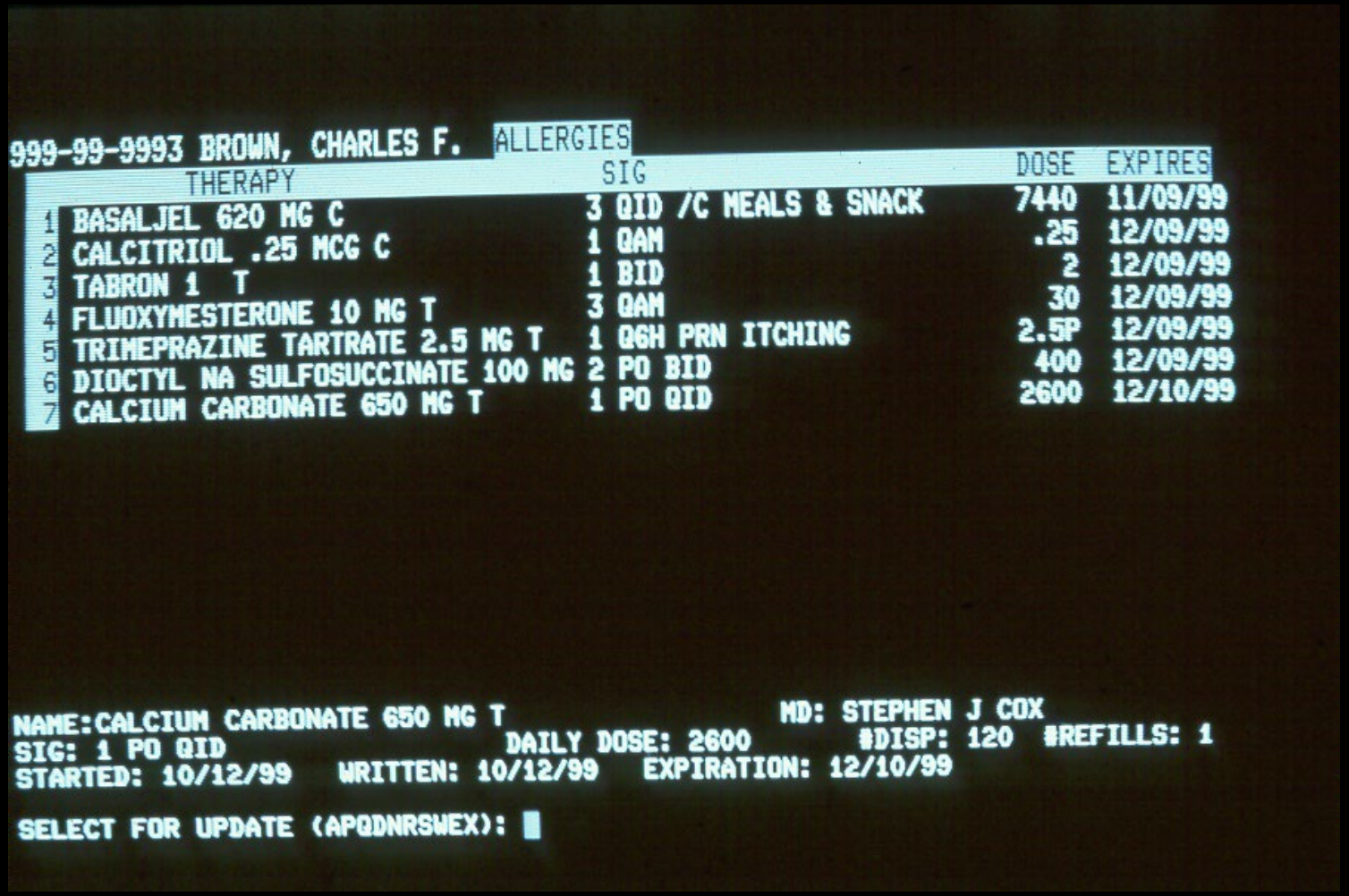
999-99-9912 PATIENT: VERY SICK **PROBLEM LIST**

NO.	ONSET	RESOLVED	(* INDICATES ACTIVE PROBLEM)
1	??/??/??		* Glomerulonephritis-Memb - BX 09/79
2	03/??/81		* Nephrotic Syndrome
3	11/??/79	03/04/84	Steroid Administration
4	??/??/85		* Hypertension - Diastolic
5	??/??/??		* Prostatic Hypertrophy (Benign)
6	03/??/81		* Renal Obstructive Disease
7	06/04/79	06/04/83	Transurethral Prostatectomy
8	12/26/88		* Renal Failure (Chronic)
9	07/10/88		* Gortex Placement
10	02/02/89		* Dialysis Therapy
11	04/??/89		* Access Revision
12	04/15/89		* Kidney Transplant (Related)
13	05/14/89		* Graft Rejection (Acute)

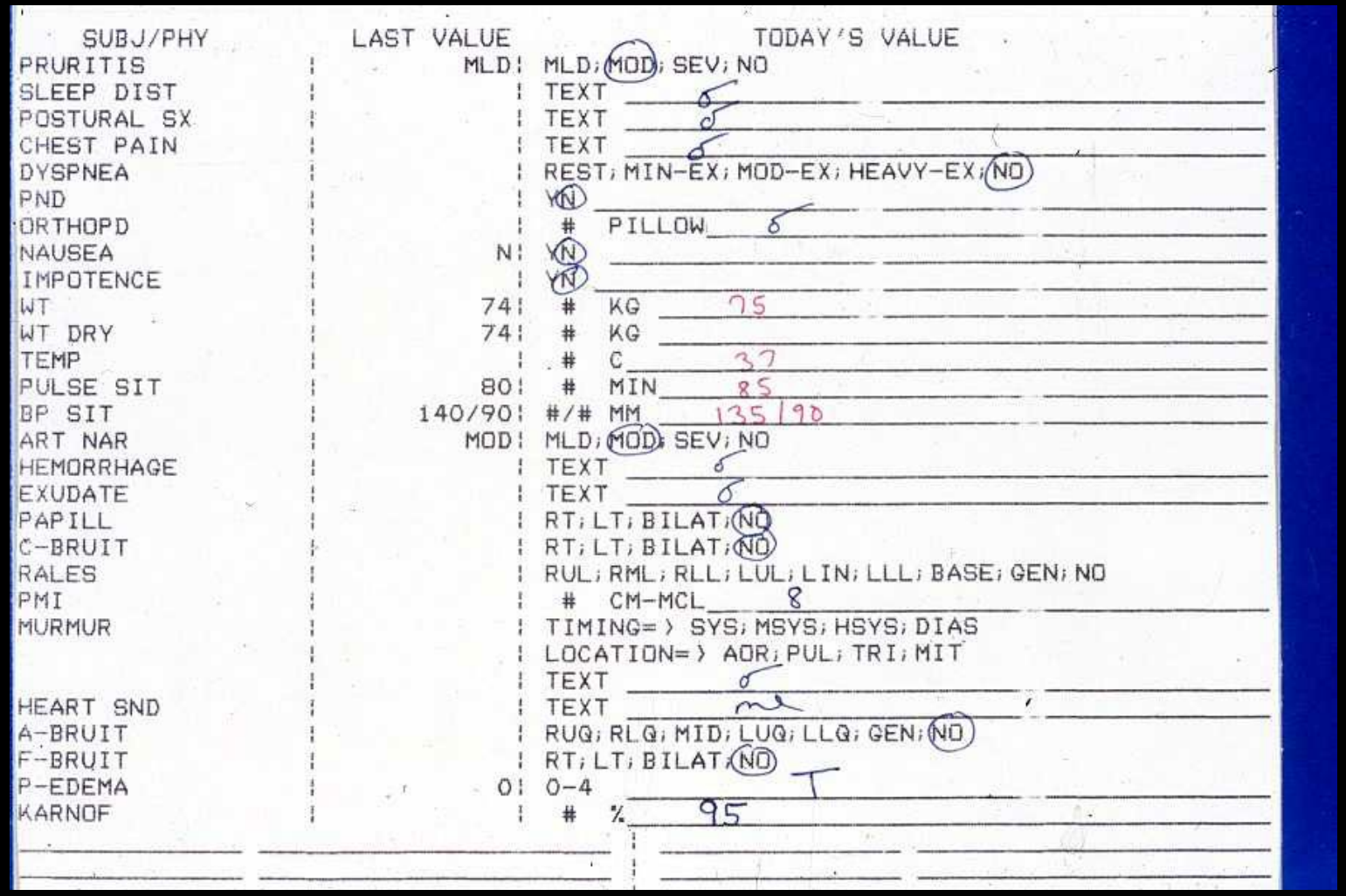
Practice Management



Renal Direct Entry



Renal Encounter Entry Form



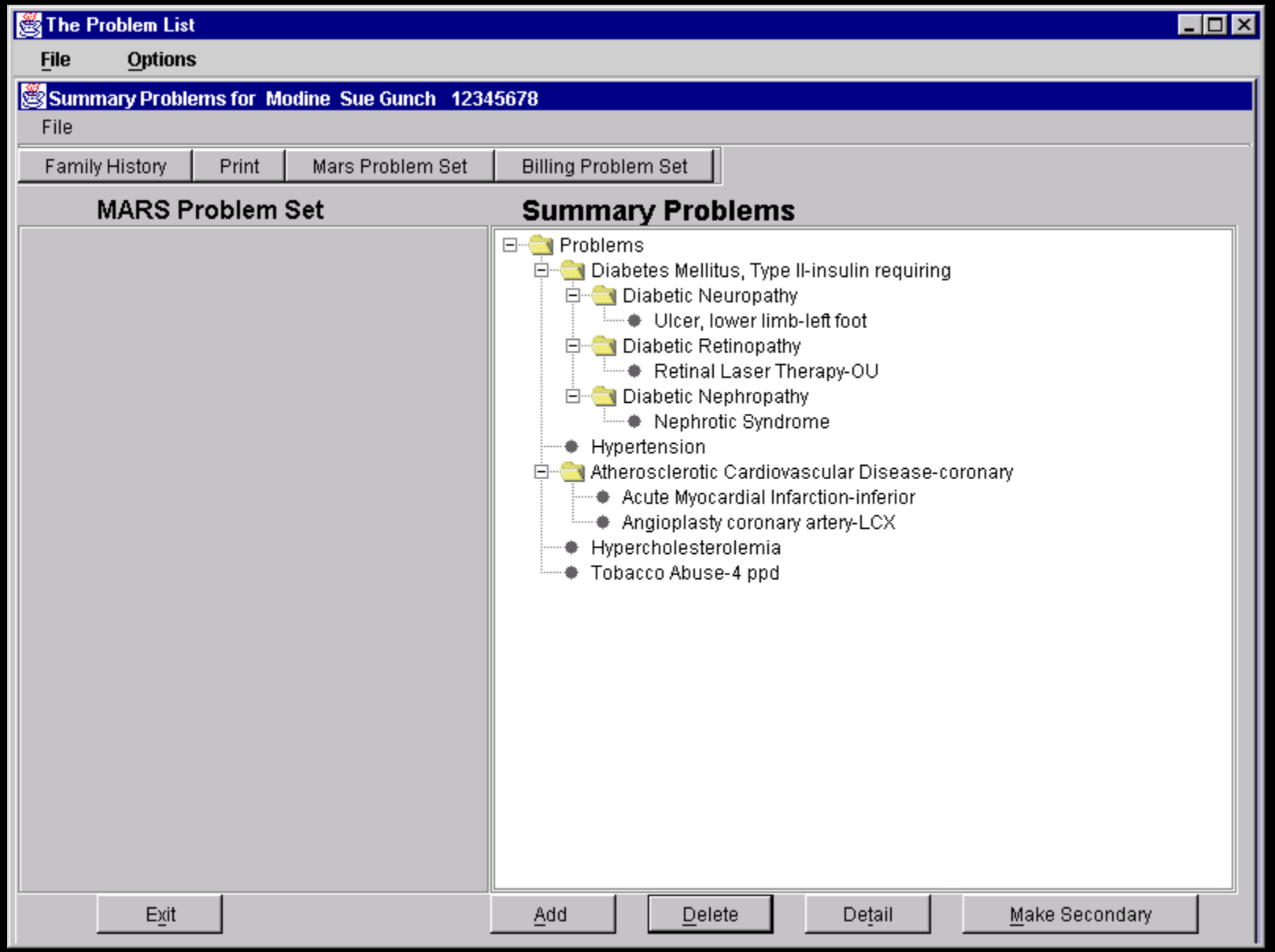
SUBJ/PHY	LAST VALUE	TODAY'S VALUE
PRURITIS	MLD	MLD; (MOD); SEV; NO
SLEEP DIST		TEXT ⟋
POSTURAL SX		TEXT ⟋
CHEST PAIN		TEXT ⟋
DYSPNEA		REST; MIN-EX; MOD-EX; HEAVY-EX; (NO)
PND		Y(N)
ORTHOPD		# PILLOW ⟋
NAUSEA	N	Y(N)
IMPOTENCE		Y(N)
WT	74	# KG 75
WT DRY	74	# KG
TEMP		# C 37
PULSE SIT	80	# MIN 85
BP SIT	140/90	#/# MM 135/90
ART NAR	MOD	MLD; (MOD); SEV; NO
HEMORRHAGE		TEXT ⟋
EXUDATE		TEXT ⟋
PAPILL		RT; LT; BILAT; (NO)
C-BRUIT		RT; LT; BILAT; (NO)
RALES		RUL; RML; RLL; LUL; LIN; LLL; BASE; GEN; NO
PMI		# CM-MCL 8
MURMUR		TIMING=> SYS; MSYS; HSYS; DIAS
		LOCATION=> AOR; PUL; TRI; MIT
		TEXT ⟋
HEART SND		TEXT ⟋
A-BRUIT		RUQ; RLQ; MID; LUQ; LLQ; GEN; (NO)
F-BRUIT		RT; LT; BILAT; (NO)
P-EDEMA	0	0-4 T
KARNOF		# % 95

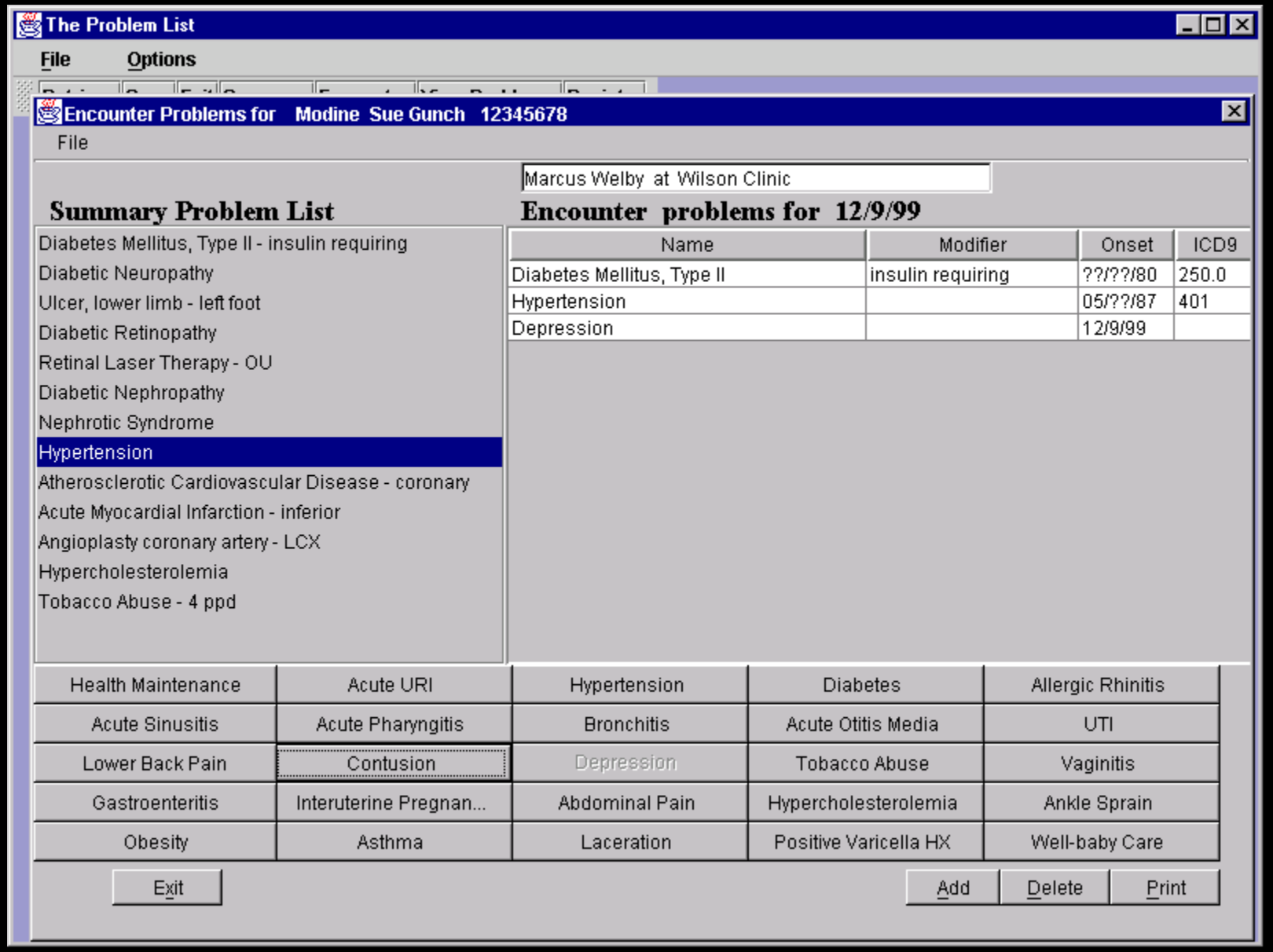
Dictionary of Metadata

- data element definitions
- vocabulary and external code sets
- physical resources
- data capture protocols
- billing algorithms
- decision support rules
- work flow rules
- information flow
- linkages
- report generation
- drug-drug interactions
- people and places
- security

Implications for Medical Informatics

- Critical mass of functionality
- Visible benefit
- Partnership within development teams
- Ability to maintain and evolve
- Ability to prototype and later incorporate
- Ability to accommodate preferences
- Open interfaces
- Scalability


The Problem List
File
Options
Summary Problems for Modine Sue Gunch 12345678
File
Family History
Print
Mars Problem Set
Billing Problem Set
MARS Problem Set
Summary Problems
Problems
Diabetes Mellitus, Type II-insulin requiring
Diabetic Neuropathy
Ulcer, lower limb-left foot
Diabetic Retinopathy
Retinal Laser Therapy-OU
Diabetic Nephropathy
Nephrotic Syndrome
Hypertension
Atherosclerotic Cardiovascular Disease-coronary
Acute Myocardial Infarction-inferior
Angioplasty coronary artery-LCX
Hypercholesterolemia
Tobacco Abuse-4 ppd
Exit
Add
Delete
Detail
Make Secondary


The Problem List
File
Options
Encounter Problems for Modine Sue Gunch 12345678
File
Marcus Welby at Wilson Clinic
Summary Problem List
Encounter problems for 12/9/99
Diabetes Mellitus, Type II - insulin requiring
Diabetic Neuropathy
Ulcer, lower limb - left foot
Diabetic Retinopathy
Retinal Laser Therapy - OU
Diabetic Nephropathy
Nephrotic Syndrome
Hypertension
Atherosclerotic Cardiovascular Disease - coronary
Acute Myocardial Infarction - inferior
Angioplasty coronary artery - LCX
Hypercholesterolemia
Tobacco Abuse - 4 ppd
Name
Modifier
Onset
ICD9
Diabetes Mellitus, Type II
insulin requiring
??/??/80
250.0
Hypertension
05/??/87
401
Depression
12/9/99
Health Maintenance
Acute URI
Hypertension
Diabetes
Allergic Rhinitis
Acute Sinusitis
Acute Pharyngitis
Bronchitis
Acute Otitis Media
UTI
Lower Back Pain
Contusion
Depression
Tobacco Abuse
Vaginitis
Gastroenteritis
Interuterine Pregnan...
Abdominal Pain
Hypercholesterolemia
Ankle Sprain
Obesity
Asthma
Laceration
Positive Varicella HX
Well-baby Care
Exit
Add
Delete
Print

The Healthcare System Is Broken!

- Lack of communication
  - Between clinicians
  - Between clinicians and patients
- Health care workers burnout
- Aged technology

- Lack of interoperability
- Systems are siloed
- Systems are out of date
- Medical errors are the 3rd leading cause of death (2020)

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

Source: Eric C. Schneider et al., *Mirror, Mirror 2021 — Reflecting Poorly: Health Care in the U.S. Compared to Other High-Income Countries* (Commonwealth Fund, Aug. 2021). https://doi.org/10.26099/01DV-H208

The present

- Hospital dominated
- Hospital Information Systems
- Higher revenues with sicker people
- Most care delivered in hospitals and clinics
- Reimbursement drives everything.
- Clinical data largely unstructured, poor quality, incomplete and inconsistent.
- Local terminologies dominant.

Why we are not solving problems

- We assume the barriers that currently exist are here to stay, and anything new we do must fit within those boundaries.
- We spend much of our time and money doing work-arounds rather than face the true problem.
- We are not willing to attack the really hard problems.
- We tackle today's problems with tools from yesterday.
- We provide multiple different solutions then spend even more time in trying to harmonize the multiple solutions.
- We start with what we know and have, rather than looking for the best solution.

More bumps

- We focus on a specific problem rather than looking at that problem within a total environment.
- We start with an assumed solution and attempt to solve the problem within the capabilities of whatever solution we have decided to use.
- We never look to see if someone else has solved the problem or are at least currently addressing it.
- We provide multiple different solutions then spend even more time in trying to harmonize the multiple solutions.
- We start with what we know and have, rather than looking for the best solution.
- We ignore the hard problems.

For the first time in generations, life expectancy has plateaued and is declining. Much of this rising mortality is attributable to determinants of health not readily addressed by the health care system.

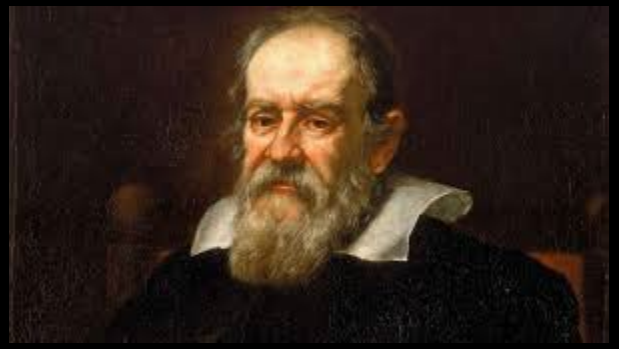
Karen DeSalvo

Life today

- Physician and nurse burnout are prevalent.
- There is no 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.

What is the Galileo Project?



- The Galileo Project is to define the PERFECT Health System.
- Health Care is a sub-component.
- The goal is not to address perceived problems of today, but to step into the future.
- Invited 24 clinicians to participate to a “thinking aloud” Zoom session on September 10, 2020. We have repeated this process with two more groups.
- Can’t say you can’t do that.
- Can’t say that’s impossible.
- We want the perfect system with no constraints.

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

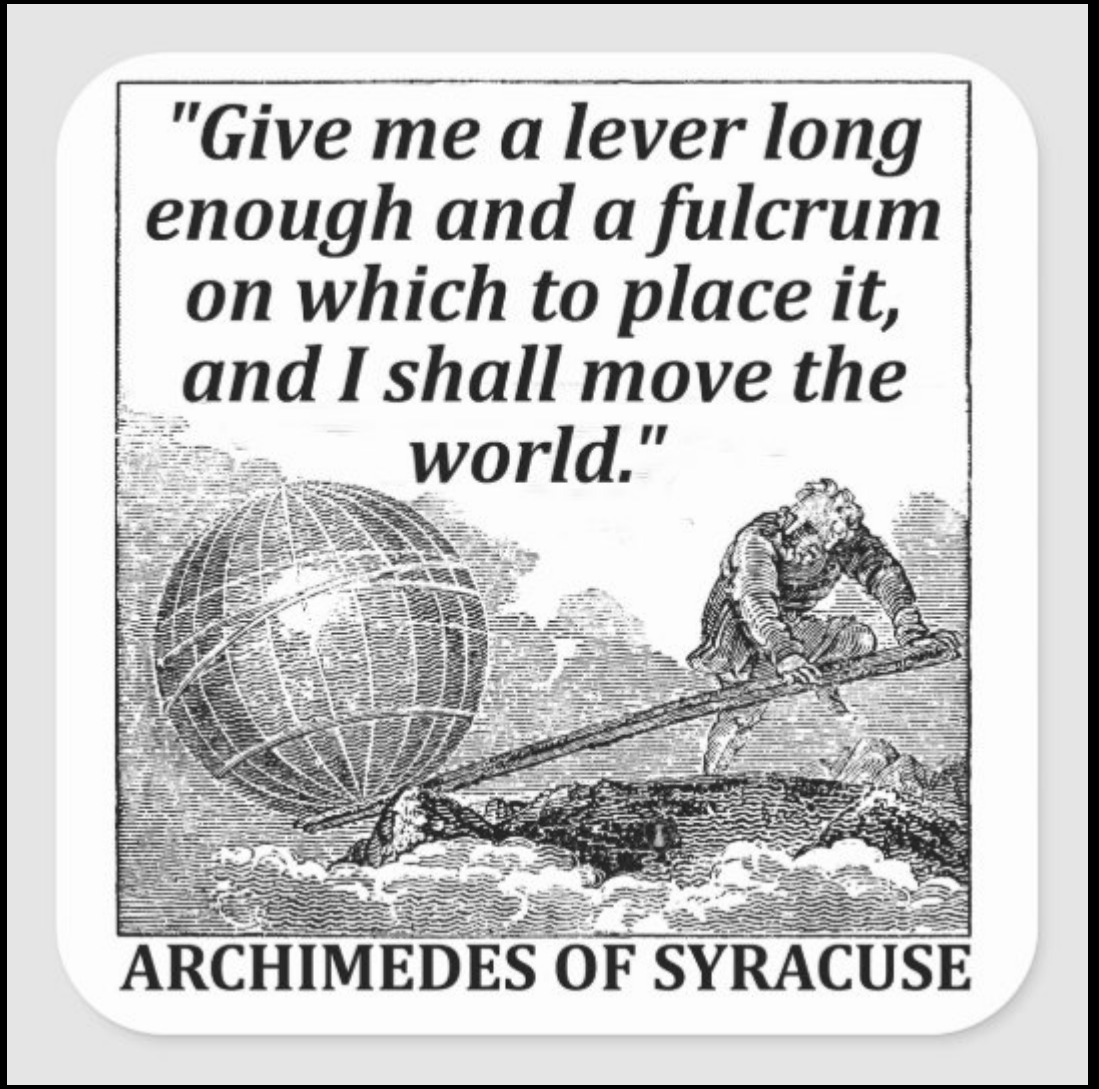
- There must be equity in health and health care.
- Access to care – whenever and wherever it is needed
- Service rendered cannot be influenced by what the insurance will pay but what is needed
- The appropriate medicine or treatment must be available to every person
- Health literacy is essential, therefore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

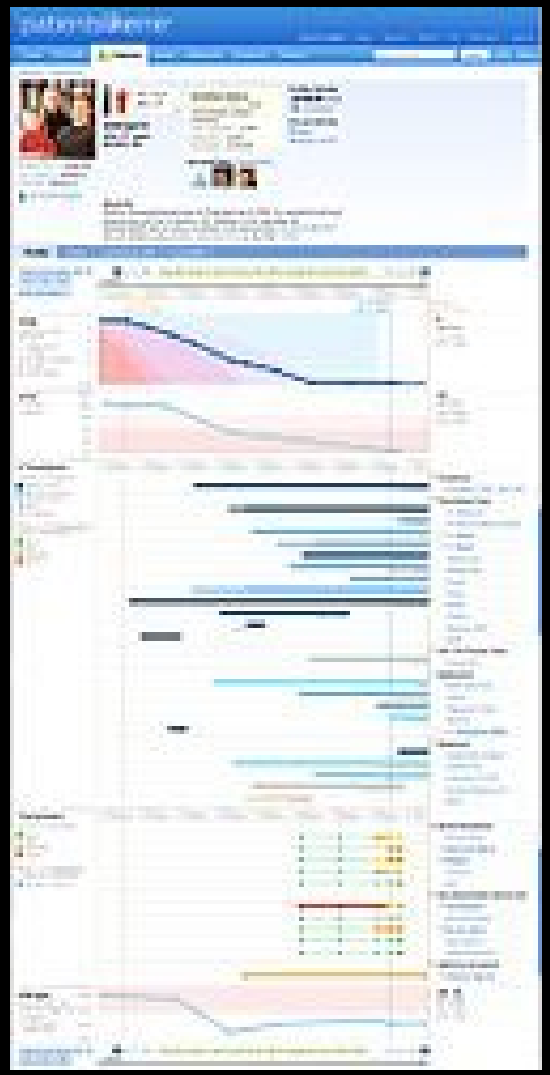
The Archimedes Project

- Collect comments from patients of “bad” things that have happened to them in the health care environment.
- Use NLP and data analytics to classify comments.
- Design the perfect system to resolve all these issues.
- Patients are the lever to push acceptance of the perfect health system.



New Voices …

- Patients, consumers, citizens or what ever we wish to call them are have an influence in health and health care.
- “Googling” has opened the knowledge and understanding of disease for the non-professional to change the communication between physician and patient.
- Shifting care outside traditional settings
- Data collected and analyzed in real time becomes more responsive.
- Patients want to push this data back into their EHR.



Patient Communication

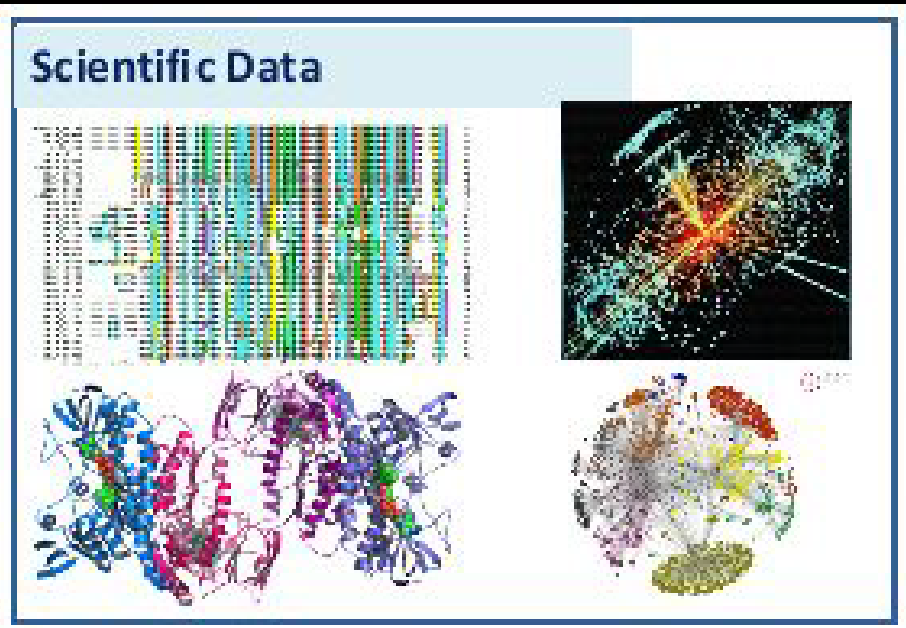
- Every patient should have access to the Internet.
- Every patient should have a device capable of digital communication and interaction.
  - Smart phone
  - iPad
  - Computer
- Patient should have access to all their health data.

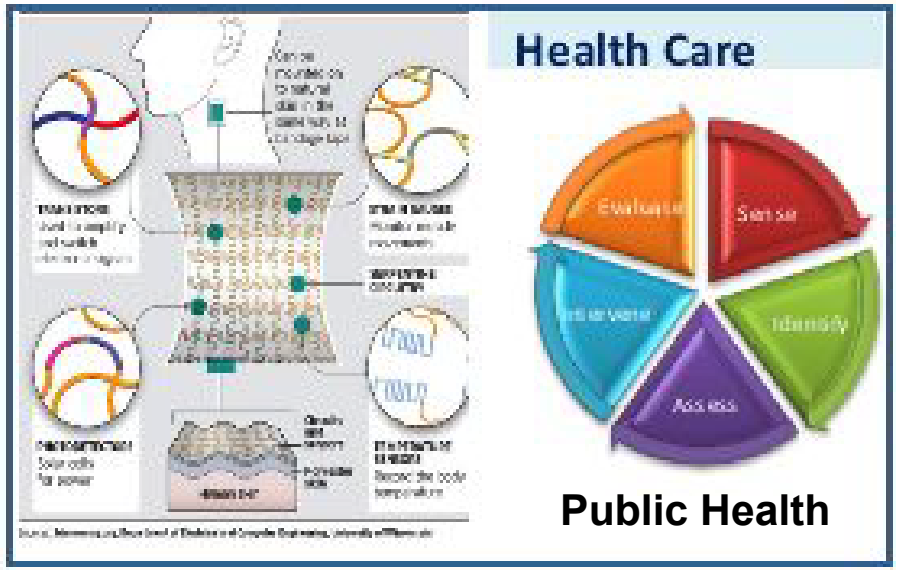
Community

- 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.

The clinical environment

Today everything is a source of data





REQUIRES

- Data Liquidity
- Data Sharing
- Data Standards

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.

The Human Metric Project

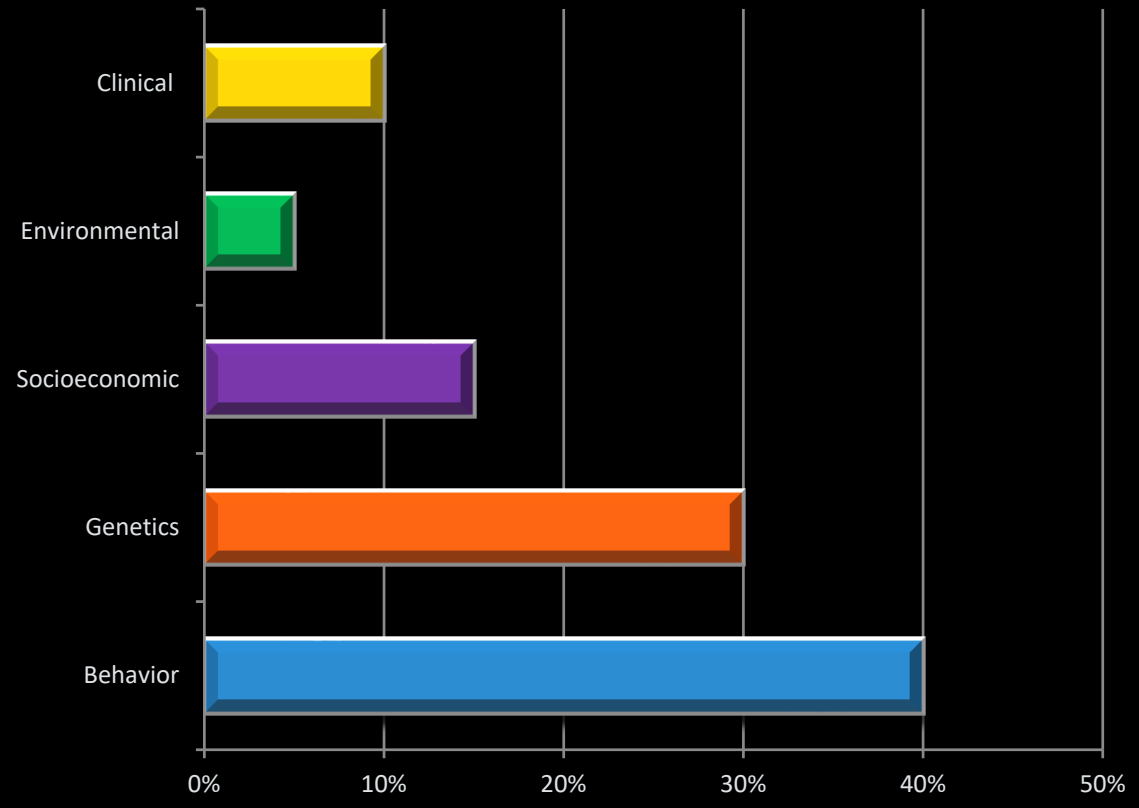
- If we knew everything about a person, could we do a more optimal job of guiding an individual to a high quality and a longest possible length of life? That is the basis of the human metric project.
- But this project is more than that. It identifies the types of data we must collect – clinical, behavioral, social determinants of health, economic, geospatial, genomic, and environment.
- It addresses first issues of common and consistent data elements, including ta common language. It addresses how data is collected. It addresses how data is used. It addresses various packaging of data.

The Basic Requirements

- Data Element – atomic level terms with rich attributes
- Data models – building complex structures from data elements such as blood pressure, heart murmurs
- Data sets – grouping of data elements for specific purposes
  - Phenotypes
  - Risk models
  - Knowledge models
  - Registries
  - Care plans

New kinds of data

Social Determinants of Health



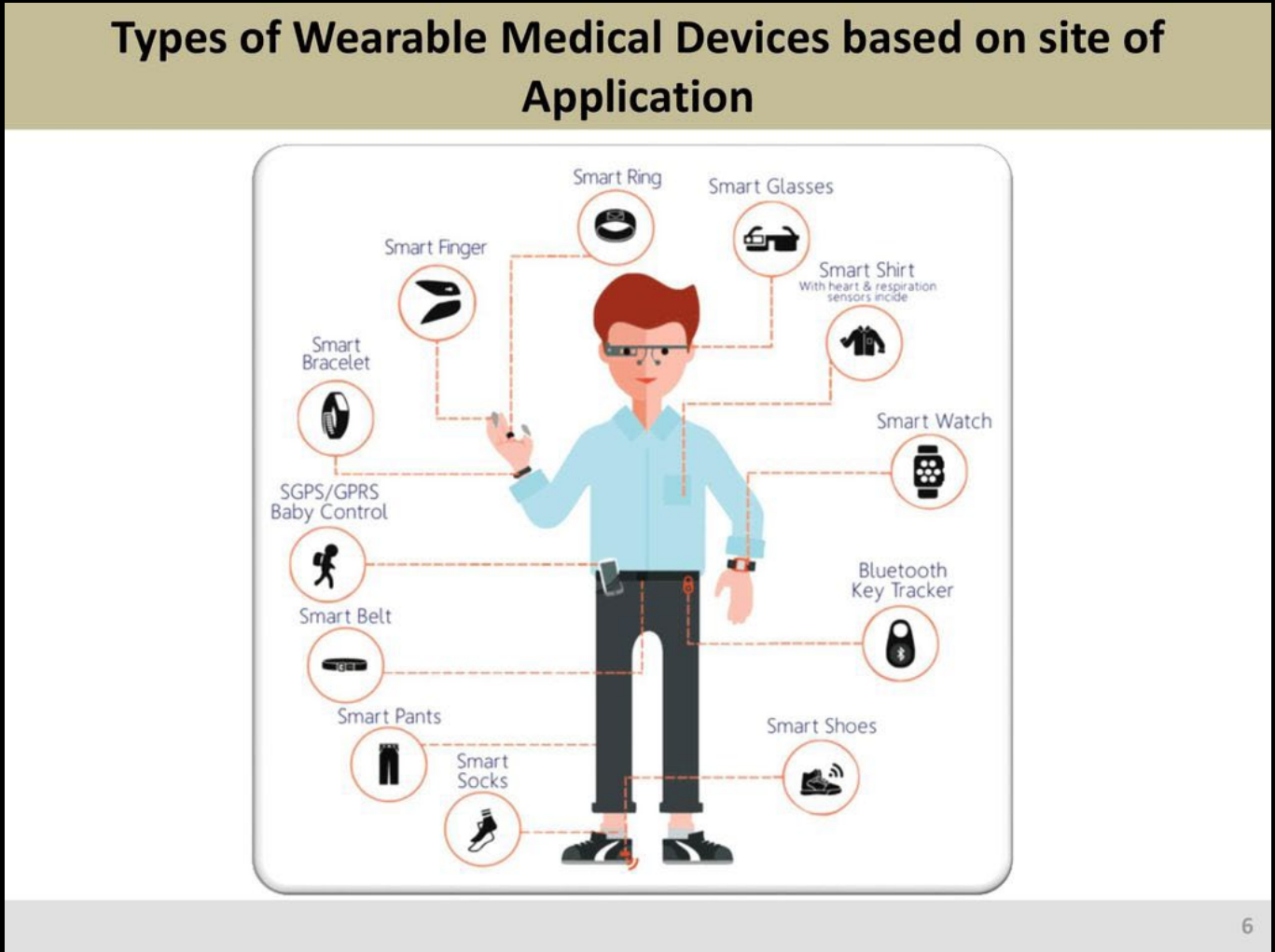
Impact on quality and length of life

Mobile Devices

- The ubiquity of smart phones has changed communications between and among groups. A virtual visit will replace an office visit.
- Wearable sensors will give real time data about the person resulting in early interventions.
- Smart phone apps can be used for data collection by text, check boxes, and photographs with sufficient resolution to make clinical diagnoses in many areas such as dermatology.
- Smart phones can be used for education, behavior modification, and more.

Brick and mortar institutions will be replaced by virtual healthcare systems.

Wearable Sensors



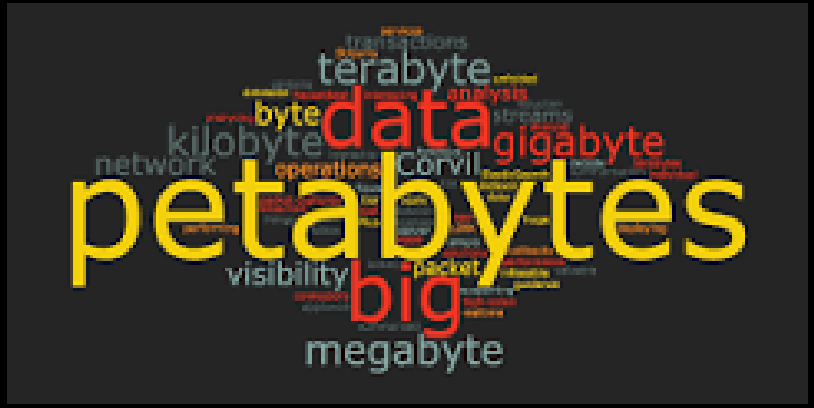
- Real time data, all the time
- Sense instant change in condition
- Earlier intervention
- Appropriate intervention

The New EHR

- Supports multiple use of data rather than secondary use.
- All data related to the patient is stored in a single virtual container labeled data box.
- Data box performs REST services – Create, read, update, delete
- Data storage is independent of data use.
- 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

Big Data and Its Impact

- Big Data is a consequence of more things that create data and more initiatives to merge data.
- For a single patient, we are talking about petabytes of data; for a aggregated database of multiple patients, we are talking about exabytes or more.
- Computable knowledge is an award of Big Data.
- Requires new and innovative methods of analyses to create new knowledge
- NoSQL databases making their appearances to provide higher speed necessary for analyses.



In 2017, we created 44 zettabytes of new data daily.

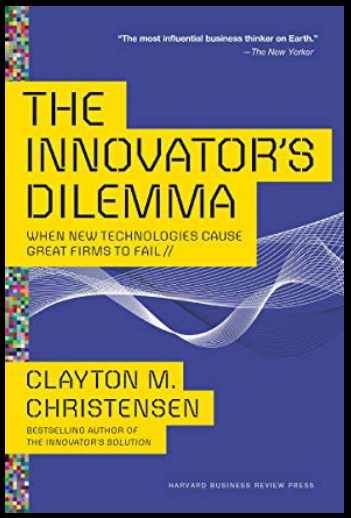
Decision Making

- The amount of data and the kinds of data influencing health and health care has far exceeded the ability of the human brain to make fact based decisions.
- Therefore, most health care decisions will be made by computers and executed directly without human engagement.

Perfect requires

- Universal Person Identifier
- Unique and atomic data elements creating a common data model
- Consistency in how data collected, how represented
- Increased data quality and trust
- Quality checked with data entry
- Document identification
- Common templates
- Common transport

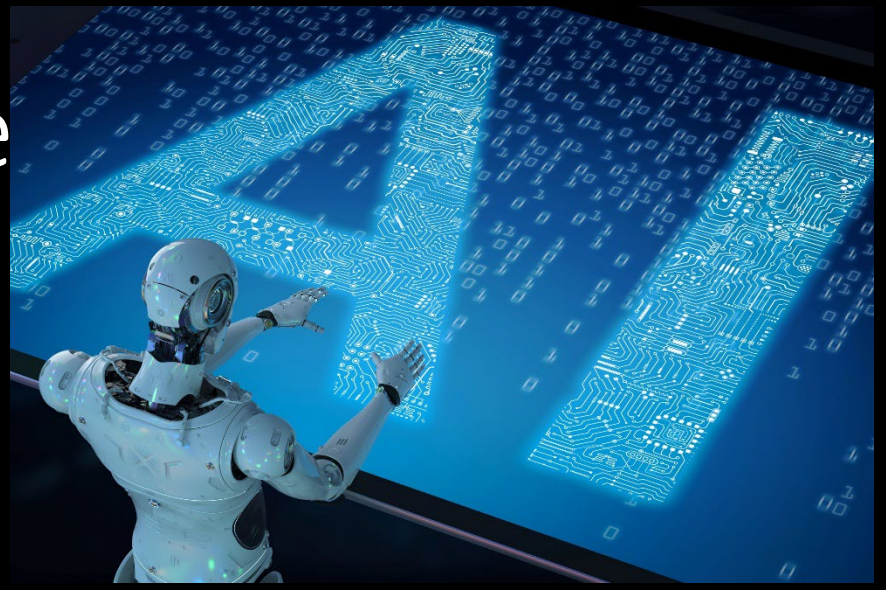
Disruptive Innovation Makes Perfect

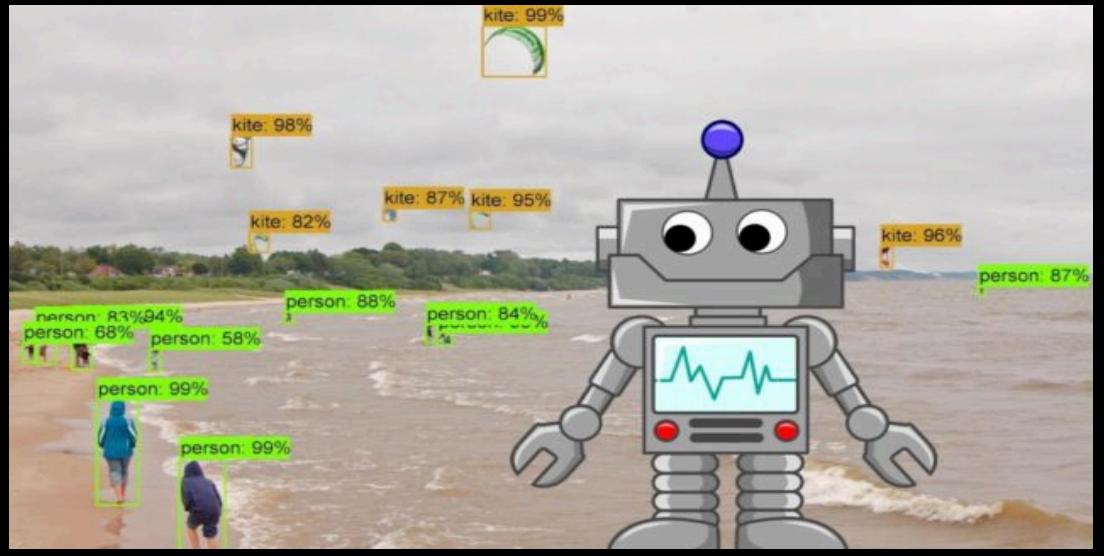


- Integration of images and enhanced use
- Biomarkers and genomics
- Enhanced registries – automated population of registries
- Automated Clinical Trials, Observational Clinical Trials, Pragmatic Clinical Trials
- Partnered iAPPs to tell a complete story
- Perfect provides the right data for the right patient to the right clinician at the right time for the right reason.

The Second Machine Age

- Cognitive Computing
- Machine Learning
- Deep Learning
- Artificial Intelligence





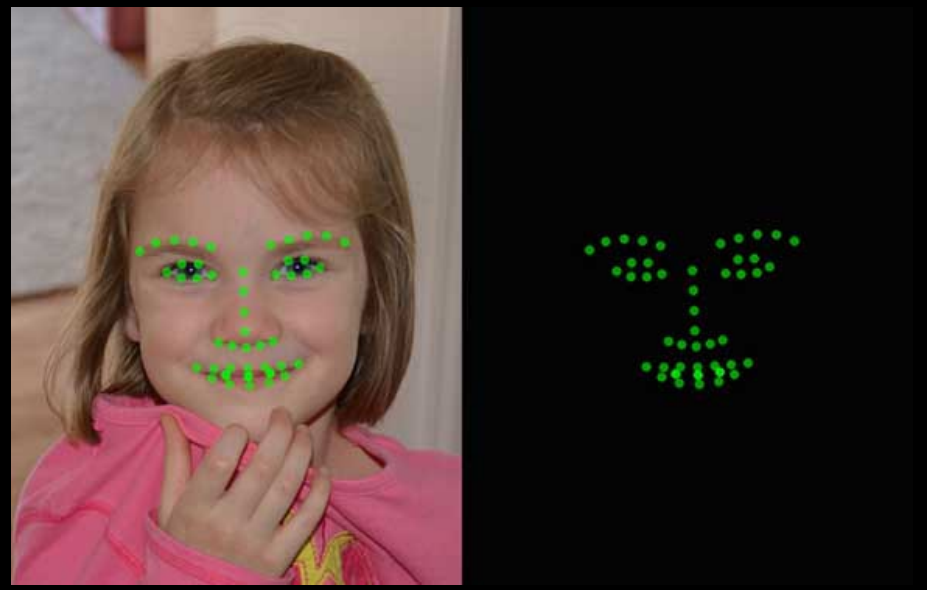
So, what can we expect?

- "Soon, it will be hard to imagine a doctor's visit, or a hospital stay that doesn't incorporate AI in numerous ways. With healthy clinical evidence, we'll see AI become more mainstream in various clinical settings, creating a positive feedback loop of more evidence-based research and use in the field. In addition, AI and ambient sensing technology will help re-humanize medicine by allowing doctors to focus less on paperwork and administrative functions, and more on patient care.

Pete Durlach, senior vice president for healthcare strategy and new business development at Nuance.

Some projects at Duke

- Autism
- Patterns in electronic health records
- Management of opioids
- Medication management
- Ophthalmology
- Radiology
- Exercise physiology
- FORGE
- Duke Institute for Health Innovation

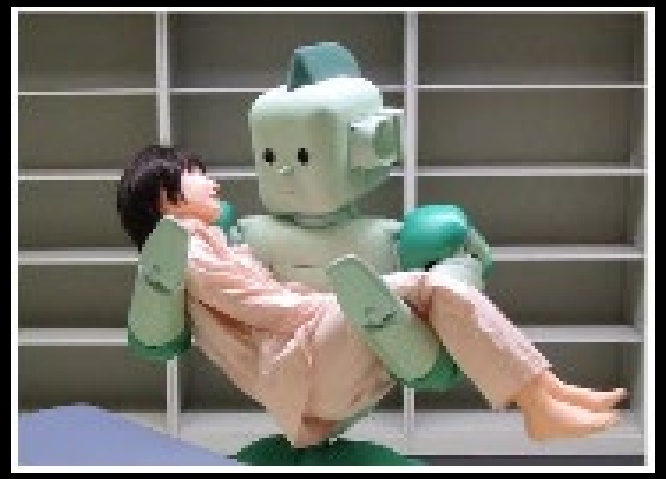


AI Models

- AI models are being built in healthcare management and risk assessment
  - Understanding capacity for volume of patient visits in offices
  - Predicting patients who are at highest risk of re-hospitalization
  - Understanding different levels of risk in patients with chronic disease
  - Identify patients of high risk of progression of kidney disease
  - High risk of complications of diabetes
  - High risk of having complications after surgeries

Source: Dr. Marroquin, UPMC

Robots and Avatars



Perfect and the future

- Society should demand the perfect system.
- Can we make the changes necessary to enable the perfect system?
- How much will the transition cost?
- Should it be global?
- Who will be the leaders?