The Informatics Rebellion and the Patient Experience

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How did I end up in biomedical informatics?



Portrait of the Instructor as an Angry Young Man

- Trauma of 1976 made me interested in
 - Medicine
 - Mathematics (common for childhood trauma victims)
- Traumas of 1983-1985 made me sick of sick people
- Randomness (this is an important ingredient of my message) of growing up in the "hometown" of BMI

The "Husband" Speaks

"Knowledge is Power. France is Bacon": Tackling medicine's paternalism problem

AKA "The Unnamed Coconspirator #1 Speaks"



What I would really like to talk about



What I will talk about

- Motivate you to think about informatics as a radical enterprise
- Encourage you to think about the big picture in what you are embarking on
 - What does it mean to be human and how does my research relate to the inherent needs and constraints of humanness
 - What is the philosophy of your career?
- Entice you to think about the individual patient as a topic worthy of study

Career advice slide (CAS)

•Make sure there is a big intersection between what you do and what you really care about? If you were in my University of Melbourne "Digital Transformation of Health" class...

"Lecture 1: Informatics as Rebellion"

Science as Rebellion

"The common element [of science] is rebellion against the restrictions imposed by the locally prevailing culture...."



Science as Rebellion

"If science ceases to be a rebellion against authority, then it does not deserve the talents of our brightest children."



Does healthcare need a rebellion?

Braithwaite et al. BMC Medicine

https://doi.org/10.1186/s12916-020-01563-4

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The three numbers you need to know about healthcare: the 60-30-10 Challenge

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Hazards of health care



Leape, CDC 2003

Jeffrey Braithwaite^{1*}⁽⁰⁾, Paul Glasziou²⁽⁰⁾ and Johanna Westbrook³⁽⁰⁾

Abstract

Background: Healthcare represents a paradox. While change is everywhere, performance has flatlined: 60% of care on average is in line with evidence or consensus based guidelines; 30% is some form of waste or of low value, and 10% is harm, the 60-30-10 Challenge has persisted for three decades.

Main body: Current top down or chain-logic strategies to address this problem, based essentially on linear models of change and relying on policies, hierarchies, and standardisation, have proven insufficient. Instead, we need to marry ideas drawn from complexity science and continuous improvement with proposals for creating a deep learning health system. This dynamic learning model has the potential to assemble relevant information including patients' histories, and clinical, patient, laboratory, and cost data for improved decision-making in real time, or close to real time. If we get it right, the learning health system will contribute to care being more evidence-based and less wasteful and harmful. It will need a purpose-designed digital backbone and infrastructure, apply artificial intelligence to support diagnosis and treatment options, harness genomic and other new data types, and create informed discussions of options between patients, families, and clinicians. While there will be many variants of the model, learning health systems will need to spread, and be encouraged to do so, principally through diffusion of innovation models and local adaptations.

Conclusion: Deep learning systems can enable us to better exploit expanding health datasets including traditional and newer forms of big and smaller-scale data, e.g. genomics and cost information, and incorporate patient preferences into decision-making. As we envisage it, a deep learning system will support healthcare's desire to continually improve, and make gains on the 60-30-10 dimensions. All modern health systems are awash with data, but it is only recently that we have been able to bring this together, operationalised, and turned into useful information by which to make more intelligent, timely decisions than in the past.

Keywords: Learning health system, Complexity, Complexity science, Change, Evidence-based care, Clinical networks, Quality of care, Patient safety, Policy, Healthcare systems

Franklin: Dyson's Ideal Scientist Rebel



"[Franklin] combined better than anyone else the qualities of a great scientist and a great rebel. As a scientist, without formal education or inherited wealth, he beat the learned aristocrats of Europe at their own game....

"Franklin's triumph as a rebel resulted from the fact that his rebellion was not impulsive but was carefully thought out over many years."

Franklin: Dyson's Ideal Scientist Rebel



"Franklin became a rebel only when he judged the time to be ripe and the costs to be acceptable. As a rebel he remained a conservative, aiming not to destroy but to preserve as much as possible of the established order of society."

Homer Warner: Rebellion Against Ignorance



- "When I finished medical school, I thought I knew everything. But when I finished my internship, I realized I didn't know anything, and I didn't want to be in that state."
- Went to pursue PhD in physiology at the University of Minnesota
- Curiosity a healthy response to ignorance

"I took a class while I was doing this work with diagnostic cardiology. . . in what they called advanced engineering math. It really wasn't advanced at all. For me, it was very advanced, but it was differential equations. . . .[The teacher] was excellent. He just had all kinds of interesting illustrations of the principles he was teaching."



New York Times

"One day, he talked about Fourier analysis. I was very interested in that, because of dealing with arterial pressure waveforms. So I went home, and I bought a threefoot-long [about a meter] slide rule with trigonometric functions on it. I spent one night analyzing a single heartbeat into its harmonic components, and convinced myself that I understood how to do that."



New York Times

"A few days later, he talked about another technique, which he called a **"transfer function,"** which was able to use signals representing both the input and the output signals from a system, and said you could mathematically characterize such a system. **So I thought, 'I'll try that.'**"



New York Times

- An engineering friend Robert Stephenson pointed out an article by Robert S. Ledley and Lee B. Lusted about using probabilities and logic to make medical diagnosis.
- "Let's try that."
- Bayesian diagnosis of congenital heart problems
 - AMA 1961: First paper describing computeraided decision support with real patient data
 - Moved Warner to a broader research area



Robert Stephenson

3 July 1959, Volume 130, Number 3366

Reasoning Foundations of Medical Diagnosis

Symbolic logic, probability, and value theory aid our understanding of how physicians reason.

Robert S. Ledley and Lee B. Lusted

ance are the ones who do remember and consider the most possibilities."

SCIENCE

Computers are especially suited to help the physician collect and process clinical information and remind him of diagnoses which he may have overlooked. In many cases computers may be as simple as a set of hand-sorted cards, whereas in other cases the use of a largescale digital electronic computer may be indicated. There are other ways in which computers may serve the physician, and some of these are suggested in this paper. For example, medical students might find the computer an important aid in learning the methods of differential diagnosis. But to use the computer thus we must understand how the physician makes a medical diagnosis. This, then, brings us to the subject of our investigaWhat predicts the paper that will be recognized as foundational 10 years from now?



JAMES A. EVANS

- What predicts next year's paper?
 - Essentially doing what everyone else is doing this year
- What predicts the foundational paper 10 years from now?
 - Co-authorship of authors at same institution and different departments
 - Random merging of topics (spouses, soccer teams, church, etc.)

"Designing Diversity for Sustained Innovation with James Evans"

What was my random encounter?



"Plato and Pythagoras stand nearer to modern physical science than does Aristotle....**The practical counsel to be derived from Pythagoras, is to measure, and thus to express quality in terms of numerically determined quantity.**"

~Alfred North Whitehead, Science and the Modern World

CAS

- •Create opportunities for random encounters in your life
 - Don't just hunker down in your cubicles or home offices

Homer Warner: Rebellion Against Ignorance



- By the mid 1960s Homer had built a post-surgical ICU with exhaustive computerized monitoring of patients
- Extensive real-time physiological monitoring and data display
- One confused nurse

Homer Warner: Rebellion Against Ignorance



"It was clear to him that just providing data and displaying...may not be an adequate solution....**This nurse clearly needed help in the interpretation of the data...[I]**t required that the **computer have some medical knowledge.** They needed to build some intelligence into the system."¹

Birth of the HELP system!

1. Am Med Inform Assoc 1995 Mar-Apr;2(2):137-42. doi: 10.1136/jamia.1995.95261907.

Larry Weed: Rebellion Against Clinical Chaos



- Began his academic career with a dual appointment at Yale in Pharmacology (basic science) and Medicine (clinical care)
- Contrast the systemic, thoughtful, welldocumented peer review nature of science
- To the chaotic, poorly documented, multitasking world of clinical practice

"As a scientist, you have a very specific project. That's your research. You work on it and work on it, and you finally get it written up. You get it published in a journal. The scientist works under a disciplined system of review and publication of his work. A physician works in a chaotic system of keeping and organizing data and has no systematic review and correction of his daily work."

Larry Weed: Rebellion Against Clinical Chaos



- Reinvented medical documentation
- SOAP Notes/Problem Oriented Medical Record

Larry Weed: The Mobile Rebel



• Why in the world move from Yale University to Eastern Maine Medical Center in Bangor, Maine?

Larry Weed: The Mobile Rebel



- Why in the world move from Yale University to Eastern Maine Medical Center in Bangor, Maine?
- Actually implement a change in how medicine is practiced

CAS

•Leverage the unique opportunities where you are at. Realistically work with the unique limitations of where you are at.

Larry Weed—The Caustic Rebel

Others on Larry Weed

- "He doesn't suffer fools gladly. He's a totally consistent personality--this is a delight to those of us who find him inspiring, and tedious to those who wish he would go away." (Don Detmer)
- "He never read Dale Carnegie's How to Win Friends and Influence People" (Uwe Reinhardt)
- "Dr. Weed could be a prickly ambassador for his ideas....and went a few steps beyond tough love in telling doctors about their limitations." (New York Times)

Larry Weed on medicine

- "You all went to medical school. Your capacity for self-deception is beyond belief."
- "The unaided human mind is not a reliable instrument for this processing of information in the solution of patients' problems. Yet medical education and licensure permit physicians to try exactly that."
- "Psychologists proved in the 50's that doctors cannot do their job."
- "The problem with the field of medicine is you can't do what the patients think you're supposed to be doing."

Larry Weed: The Eloquent Rebel

• Nobody that I have read has provided a more elegant, persuasive argument for why informatics needs to be integral to modern healthcare than Larry Weed.

What was Larry Weed's random encounter?

 I'm not sure, but Francis Bacon's <u>"Idols of the</u> <u>Mind"</u> must be a candidate



Were they rebels in the mold of Franklin?





Weed, probably not

Warner, yes

The Informatics Legacy

Aftermath of revolutions are usually bad

"It dawned on me...that virtually every major successful revolution ended by creating a state more powerful than the one it overthrew, a state that in turn was able to extract more resources from and exercise more control over the very populations it was designed to serve."

(James C. Scott, Two Cheers for Anarchism)

games C. Scott

Informatics Legacy in 2023: The Bad





USA VA Research Symposium 2022

"Top Failures of BMI Community"

- "Inability to convince vendors of EHR system to make them open and accessible for research and evaluation."
- "allowing the deployment of artificial intelligence based clinical decision support by vendors with minimal evaluation."
- "Not enough exchange of ideas and not much collaboration on very largescale projects."

- "Inability to create a brand for itself."
- "Inability to explain what we do to decision-makers and healthcare providers."
- "Inability to move on to new hypotheses after the old ones have failed multiple times!"

Top Failures of BMI Community

- "Failure to recognize the cost of data capture and the invention of systems that require care givers input that they don't have the time to enter. So the systems die"
- "Lack of a truly semantically interoperable standard for data/messaging; Rigorous evaluation of solutions to determine real impact and optimal implementation methods."
- "Loss of heart and minds of physicians through EHRs and Meaningful Use."

- "Interoperability; Clinician burnout due to technology;"
- "Not having made more progress in dissemination of decision support, devoting too much effort elsewhere."
- "The current state of the electronic health record. The fault goes far beyond the international biomedical informatics community, however."
- "HL7 v3"

Children!



- "Why are you losing your hair?"
- "Why is Mom so much more successful than you?"




"No matter where you are in your career, you always need a mentor."

Lisa Cannon-Albright (@ Zhao in downtown Pittsburgh circa 2009)

The Patient Experience

The patient as agent

Informatics and the patient experience

- Keep in mind Warner and Weeds rebellion in the clinical realm
 - Ignorance
 - Chaos
- I want you to remember the nurse in Warner's ICU
 - Initially Warner was sharing data but not knowledge

"What it really amounted to is, **we'd overwhelmed her with information.** We had all this data, but we didn't know what it meant."

What do you need for time travel? A time machine or just moving to Australia?



Deseret News

Visit Victoria

Australia circa 2019

- DSL internet connections!
- Fragmented healthcare delivery
- Physical film for radiology studies
 - Orthopedic surgeon #2: ("Digital radiology is terrible!")
- And little to no patient access to data

March							
Mon	Tue	Wed	Thu	Fri	Sat	Sun	
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					
Phases of the Moon: 6:● 13:● 22:● 29:○ Holidays and Observances: 21: Harmony Day							
nonays and observances. 21. namony Day							

Calendar for March 2021 (Australia)

Australia granted early vaccine access to healthcare workers and "at risk" individuals

- Doctor: "Are you a healthcare worker?"
- Me: "No. I'm a childhood cancer survivor!"



Created by Luis Prado from the Noun Project

"Can you Prove that!"



Created by Andrew Doane from the Noun Project

"I can show you my scars."



My "mobile medical record"



How many of you could "prove" a medical event/condition from 45 years ago?

I could!



	Chapman, Brian E.	76-2536	
Holy Cross Hospital	ADDRESS 206/B 2296382	4/7/76	
LABORATORY	CLINICAL DIAGNOSIS Right Renal Tumor	A.W.Middleton, Jr.	
1045 EAST 1st SOUTH SALT LAKE CITY, UTAH 84102	TISSUE SITE AND LOCATION Rt Kidney		
PATHOLOGY REPORT	Wilms's tumor of right kidney(see margins).	micro for 6	
PATHOLOGISTS			
CYRIL FULLMER, M.D. STANLEY L. GIBBON, M.D. BRUCE ILOYD, M.D. SAROJ N. KULKARNI, M.D. R. MYRON LAUB, M.D.		RML/mf	
GROSS:			

The specimen labelled "right kidney," consists of a kidney and subcutaneous tissues weighing 285 grams. The kidney has been opened and reveals a large yellow centrally revertie times measuring 6 cm. in diameter. There is a maximum of 12 mm. of renal

Am I an exception? Well, you are an informaticist. Of course you have your data. In 1976 I had no legal It's different in right outside of the USA. litigation to access my medical record



Exceptionally cute, maybe!

Consider this 1977 Editorial

One might also ask why a patient would want to see his or her medical record anyway...

More likely reason might be a kind of morbid curiosity on the part of a patient. There are such patients, [GASP]...

[maybe they have] dissatisfaction with the physician.

Let a patient see the record and...

- They'll look things up at the library
- They might pass judgment on the doctor and treatment
- They might sue
- They will see our uncertainty
- They'll misunderstand

Patient's Access to Physician's Records West J Med. 1977 Sep;127(3):237-8.

Way back in 1973

The month I started kindergarten!

SOUNDING BOARD

GIVING THE PATIENT HIS MEDICAL RECORD: A PROPOSAL TO IMPROVE THE SYSTEM



1st day of kindergarten 1973



Giving the Patient His Medical Record: A Proposal to Improve the System

Budd N. Shenkin, M.D., and David C. Warner, Ph.D.

We propose that legislation be passed to require that a complete and unexpurgated copy of all medical records, both inpatient and outpatient, be issued routinely and automatically to patients as soon as the services provided are recorded

Benefit for Patients

- The record would serve as an educational tool. **Patients would consult books**...
- Eventually, increased knowledge would lead to more appropriate utilization of physicians.
- patients to participate in their own care.
- Free patients to choose and change physicians.
- Patients would also be able to make better judgments about their physicians, and to differentiate legitimate physicians from quacks.

Benefit for Physicians

- decentralized peer review...[providing a] clear incentive to practice highquality medicine
- provide physicians new opportunities to learn.
- provide a more 'longitudinal' view of a patient, and physicians would appreciate better (and treat better) the course of a disease.

Access to Medical Data in the USA

- •1996: HIPAA
- 2009: HITECH
- 2016: 21st Century Cures Act
 - Information blocking rules 2022
 - 50 years after NEJM article!

Why such a slow journey?

- 1. Economics
- 2. Lack of duties to share
 - 1. HIPAA provided rights
 - 2. 21st Century Cures provided duties
- 3. Failure to see patients as persons

Everything follows the money

• Money is to voltage as information is to current



Every dollar spent on health care services is someone else's earned income

Economics: Evidence from Australia

- Breen v Williams High Court Decision, 1996
 - Patient wanted copies of medical records in order to join class action lawsuit in the USA for breast implant manufacturer (1977)
- "The Court held that the collection and **retention of the data was an economic advantage to the defendant in relation to being further consulted by the plaintiff.** It was legitimate for him to have this advantage and keep it for himself. It would be markedly unfair if any patient could decide to cease consulting a doctor and to consult another and be entitled to give the new medical adviser everything that the doctor had on record." (Australian Health and Medical Law Reporter)
 - Australian Medical Association argued that medical records are copyrighted
 - Federal and state laws have been passed to provide means for patients to access their medical records but no duties for healthcare to provide the data

Duties

"All epistemic claim-rights correlate with epistemic duties. Consequently, the allocation of epistemic claimrights is tied to the allocation of epistemic duties." (Lani Watson, *The Right to Know: Epistemic Rights and Why We Need Them*)



Lani Watson

My Australian Health Data Experience

- I have a right to my data! I have a government provided personal health record!
- But a lack of duties imposed on clinicians leads to
- A lack of data in my personal health record



1964 AMA Annual Meeting Session: "The Patient as a Person"

"physicians who plan to attend are encouraged to bring their wives, and doctors in the San Francisco area are also encouraged to invite their clergymen"





What is a patient?

- "A biological structure yielding cash"
 ~ Uwe Reinhardt
- A biological entity generating signals (circa 1995 medical informatics education)
- A biological structure that cannot directly understand its medical care



And what are a patient's information needs?

What is a person?

- A being with
 - Imagination
 - Values
 - Agency (decision making)

A being with epistemic needs and epistemic rights

Epistemic rights

- Rights to
 - Data, information, knowledge, and understanding, particularly related to our selves
 - Sharing of our knowledge
- Epistemic injustices
 - Hermeneutical injustices—Impeding self understanding
 - Testimonial injustices Impeding self advocacy

Think about healthcare through these lenses







Hermeneutical Injustice

Testimonial Injustice

Jay Katz, M.D.'s 1980 diagnosis of medicine





What was healthcare like in 1976?

- My mother signed no consent forms
- My mother was not informed of the risks of surgery to chemotherapy
- My mother was not told I had been enrolled in a randomized clinical trial
 - Options of chemotherapy or radiation therapy were not discussed
- It was, in short, a fairly silent world

Jay Katz's diagnosis of medicine

- 1. Modern medicine diverged from the openness of science and adopted uncritically ancient medicine's dictum of not disclosing
- 2. Clinicians' transference of their own uncomfortableness with uncertainty to patients
- 3. Undervaluing patients as persons with values and capabilities

Informatics has largely inherited these same problems from medicine

There are always exceptions: Larry Weed



"Until ...*patients...working directly from their own records are the rule instead of the exception*, we cannot seriously attack the fragmentation of care in todays's specialty clinics and wards."

(Lawrence L. Weed, Knowledge Couplers)

Epistemic pressures since 1980

- Internal changes in medicine
 - Medical errors, quality, outcomes, etc.
- Expanding concepts of a person's human rights
- Expanding recognition of patient as person
 - Values distinct from clinicians
 - Capacities

The three numbers you need to know about healthcare: the 60-30-10 Challenge

Jeffrey Braithwaite^{1*}0, Paul Glasziou²0 and Johanna Westbrook³0

Abstract

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Main body: Current top down or chain-logic strategies to address this problem, based essentially on linear models of change and relying on policies, hierarchies, and standardisation, have proven insufficient. Instead, we need to marry ideas drawn from complexity science and continuous improvement with proposals for creating a deep learning health system. This dynamic learning model has the potential to assemble relevant information including patients' histories, and clinical, patient, laboratory, and cost data for improved decision-making in real time, or close to real time. If we get it right, the learning health system will contribute to care being more evidence-based and less wasteful and harmful. It will need a purpose-designed digital backbone and infrastructure, apply artificial informed discussions of options between patients, families, and clinicians. While there will be many variants of the model, learning health systems will need to spread, and be encouraged to do so, principally through diffusion of innovation models and local adaptations.

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Patients are valuable for metabolizing error

"We are *error-prone* and *error tolerant*—errors are unavoidable in the fabric of our lives.... Cognitively speaking, we metabolize mistakes!"

(William C. Wimsatt, "Normative Idealizations versus the Metabolism of Error")



Patients can be critical sources of information redundancies

"Our adaptive mechanisms must be capable of detecting and responding to—nay, feeding on—errors at different levels and across varied contexts, and *exploiting parallelisms and redundancies*."

(William C. Wimsatt, "Normative Idealizations versus the Metabolism of Error")



"To recognize others fully requires not only an appreciation of their limitations but their capacities as well. Physicians have shown a keen sensitivity to patients' decision-making limitations but *considerable insensitivity to their capacities to decide.*"



"Capacities to decide": Freeman Dyson





Epistemic Rights: A Framework for Thinking About Patients and Informatics





Epistemic Injustice: Angela



Is Angela's data available when she needs/has a right to understand?



Are we listening to Angela's data?



Lack of information during in-patient care **hermeneutical injustice**

Ignored patient generated data in out-patient visits **Testimonial injustice**

My "immediate" healthcare network



21st Century Epistemic Injustice:

Are you providing me data in a **FAIR** format?

- Findable
- Accessible
- Interoperable
- Reusable





How FAIR is my data?

- Australia MyHealthRecord: F
- UCSD MyChart: B+
- UPMC MyChart: D+/C-
- Utah MyChart: B-



Better Doctors, Better Patients, Better Decisions

Envisioning Health Care 2020

Control by Gerd Gigerenzer and J. A. Muir Gray



STRÜNGMANN FORUM REPORTS

21st Century Systemic Epistemic Injustice

Not educating citizens for basic literacies necessary for healthcare



From Better Doctors, Better Patients, Better Decisions: Envisioning Health Care 2020

"Patients' health illiteracy is, in part, a consequence of how the health care system has been set up. Conversely, the flaws of the health care system and the interest groups it caters to can only exist to the degree that patients remain uninformed."

Markus A. Feufel, et al. in *Better Doctors, Better Patients, Better Decisions: Envisioning Health Care 2020*

CAS: What do you want out of your career?



Alfred North Whitehead

"Centuries, sometimes thousands of years, have to elapse before thought can capture action."

(Alfred North Whitehead *Adventures of Ideas*, p. 55)

CAS: What do you want out of your career?



"[W]e shall be respected for our accomplishments, not our titles." ("Computer Scientist as Toolsmith")

Fred Brooks

CAS: What do you want out of your career?



Apsley Cherry-Garrard

"If you march your Winter Journeys you will have your reward, so long as all you want is a penguin's egg."

(The Worst Journey in the World)