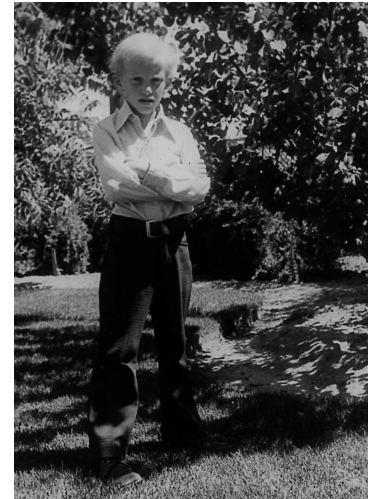


# Sharing is Caring: A Patient Perspective

Brian E. Chapman, Ph.D.  
University of Melbourne



Beginning of 2<sup>nd</sup> Grade



End of 2<sup>nd</sup> Grade

# A little about me

- PhD in medical informatics
- Privilege of teaching many practicing clinicians in Melbourne
  - Including Carl Kuschel
- Long-term patient
  - 4-time cancer survivor
    - Two childhood cancers (1976, 1983)
  - 12+ surgeries
    - 4 emergencies
  - Advanced peritonitis
  - Gangrenous strangulated bowel
  - Many resulting chronic issues!
- View the patient experience through the lens of medical informatics
  - Moving to Australia has given me lots of opportunities to compare/contrast

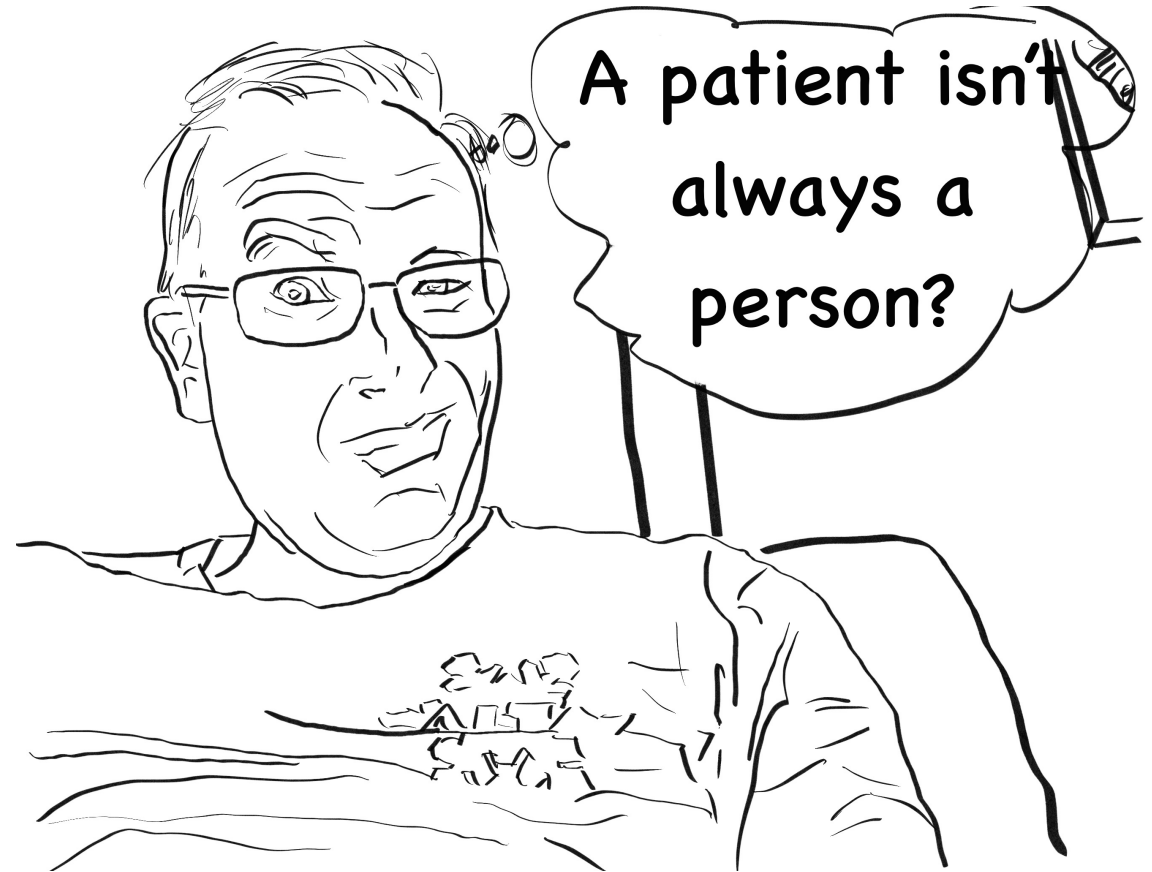


My "mobile medical record"

# “The Patient as a Person”

- Part of the American Medical Association 1964 annual meeting in San Francisco
  - “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”

It was a different era!



# What is a person?

- A biological structure with
  - Imagination
  - Knowledge/understanding
  - Values
  - Agency (decision making)

## A being with epistemic needs and epistemic rights

Data and information are the ingredients of knowing, understanding, agency

**Philosophy Now**  
a magazine of ideas

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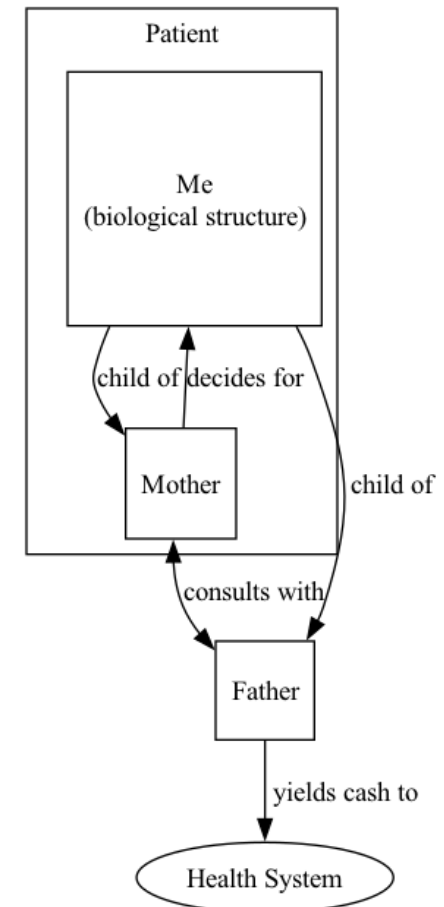
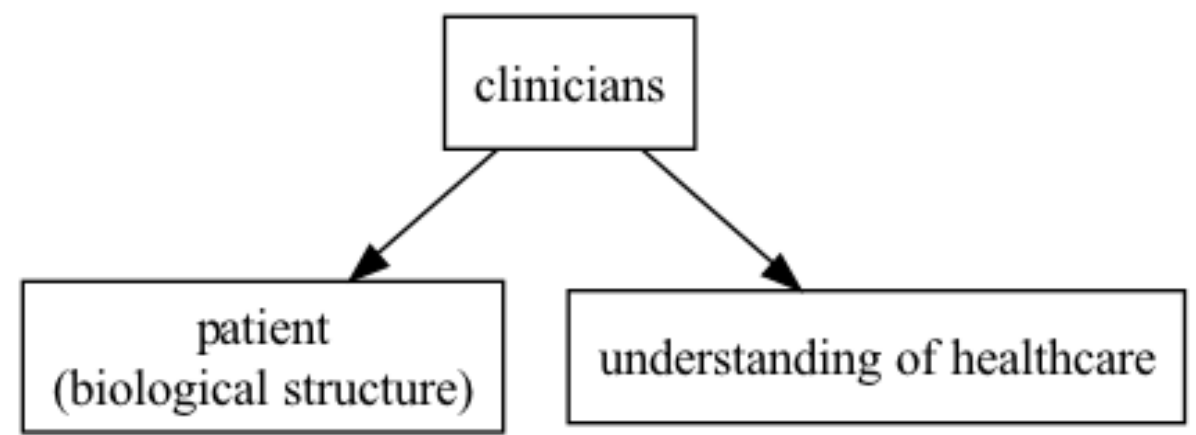
**Question of the Month**

## What is a Person?

*“It would be wonderful if we could definitely say what a person is so that all the world would agree. But we cannot.”*

# What is a patient?

- “A biological structure yielding cash”  
~ *Uwe Reinhardt*
- *A biological structure generating signals (circa 1995 medical informatics education)*
- ***A biological structure (network?) that cannot understand its medical care (traditional healthcare model)***



# Epistemic rights

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

# For a patient to be a person

- Patients must be able to acquire knowledge, express values, and exercise agency within the context of their care
- To deliver healthcare to persons, healthcare systems must
  - create epistemic ecosystems free of epistemic injustices
  - Ecosystems must help patients to
    - Understand their care and circumstances
    - Advocate for their care and circumstances

# Medical Exceptionalism: Not sharing



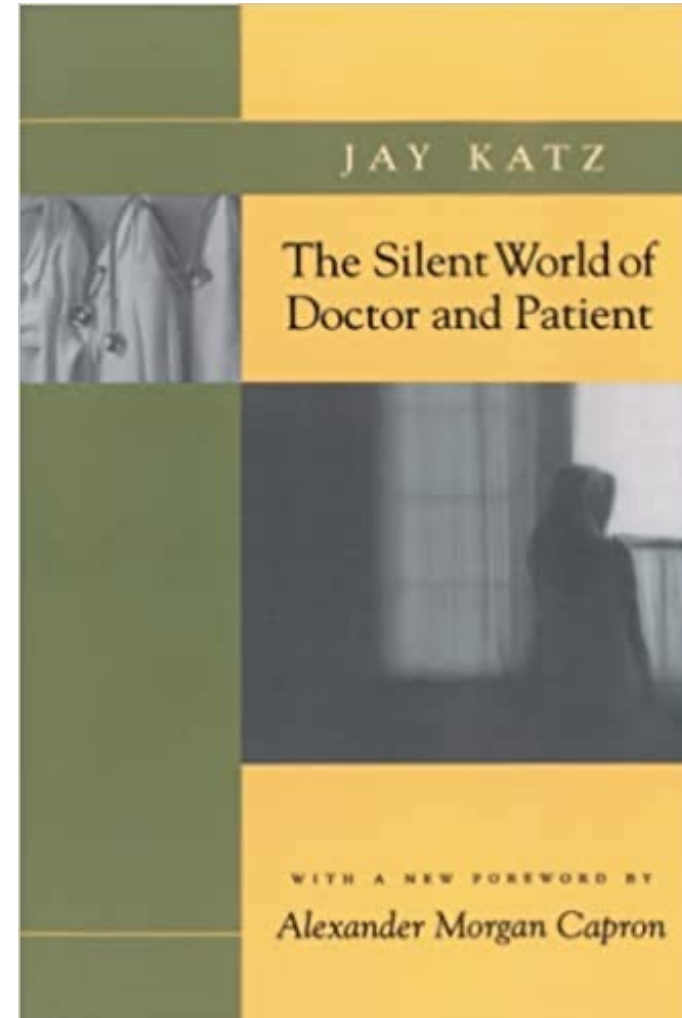
The NEW ENGLAND  
JOURNAL of MEDICINE

1973

“In most exchanges in society a purchased product becomes the property of the purchaser, who is then free to evaluate the product on his own, have it evaluated by experts and choose freely among suppliers for any further services.”



# Jay Katz, M.D.'s 1984 diagnosis of medicine



# Jay Katz's diagnosis of medicine

## Origins of Epistemic habits

1. Modern medicine diverged from the openness of science and adopted uncritically ancient medicine's dictum of not disclosing
  - Habits of silence
2. Clinicians' own uncomfortableness with uncertainty compels them to hide uncertainty from patients
  - Habits of deception
3. Medicine undervalues patients as being persons with distinct values and capabilities
  - Habits of paternalism

“They didn’t tell you much  
in 1976!”



Me!

# The silent world of 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 silent world

# 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.

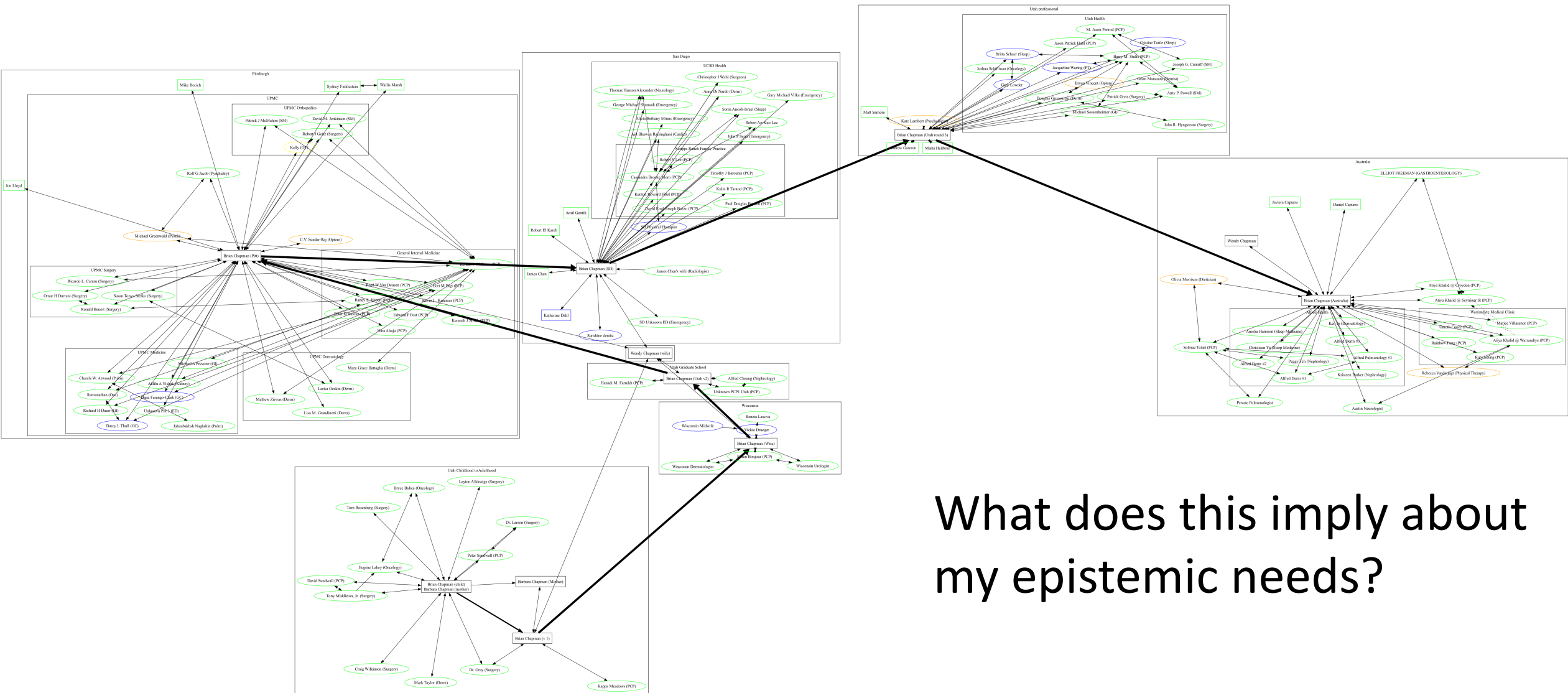
## Let a patient see the record and...

- 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

# Epistemic pressures since 1984

- Expanding concepts of a citizen's epistemic rights
  - Right to know data being used to make decisions about them
- Internal changes in medicine
  - Recognition of medical errors, quality, outcomes, etc.
- Expanding recognition of patients as persons
  - Values distinct from clinicians
    - What is good for the doctor is not necessarily good for the patient
  - Obligation to be responsible participants
- Increasing chronic care
- Increasing patient mobility

# My mobility: My “immediate” healthcare network



What does this imply about my epistemic needs?

# Some personal Australian medical experiences

- “Do you have a previous imaging study?”
- “Did they notice this lesion?”
- “Has it grown?”





# Access to my health data

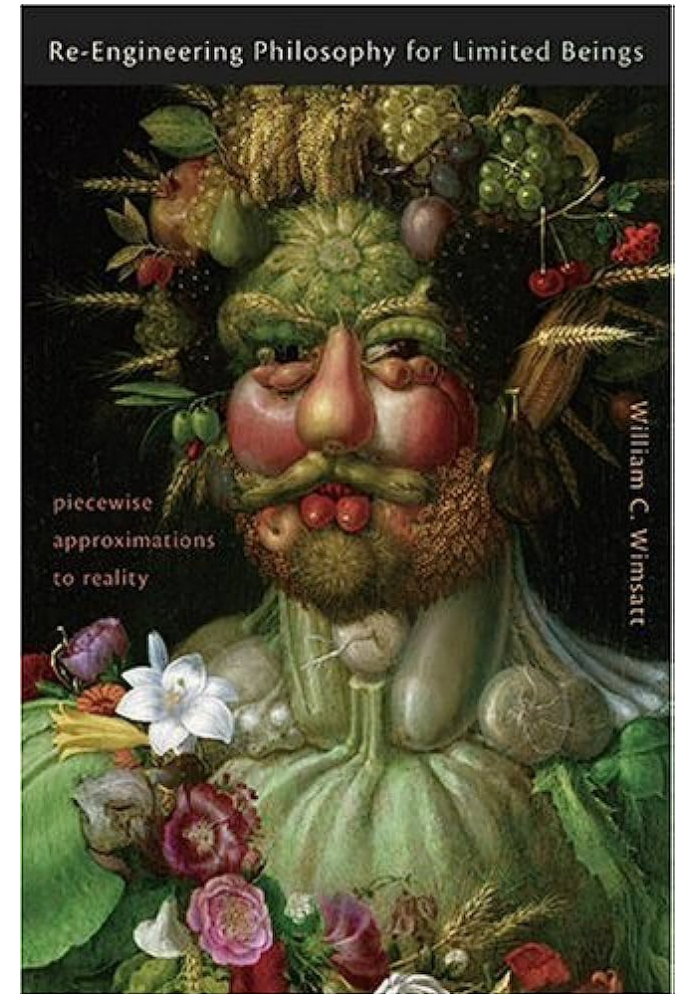
- Hermeneutical Justice (understand my healthcare)
- Testimonial justice (Advocate for my care)
  - I'm not a blank slate
  - I bring the evidence of my past care with me to my Australian GPs
- Difficult to achieve continuity of care without me being in possession of my data
  - I see a lot of different providers

Communication in healthcare is noisy!

# 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!*”

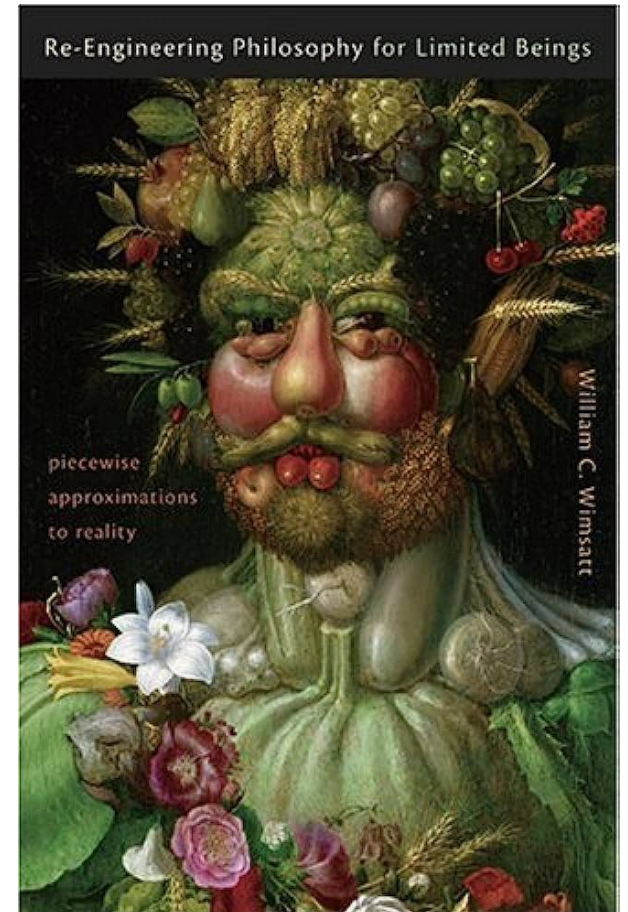
(William C. Wimsatt, “Normative Idealizations versus the Metabolism of Error”)



Patients can be critical 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”)



# Metabolizing error: Common example

*Hello,*

*I've noticed that there is an error in my allergies. In the portal I have an allergy listed as "erythromycin". This should be "azithromycin" which was first documented on 23-03-2011 at the University of California, San Diego, Medical Center.*

*Thanks,*

*Brian*

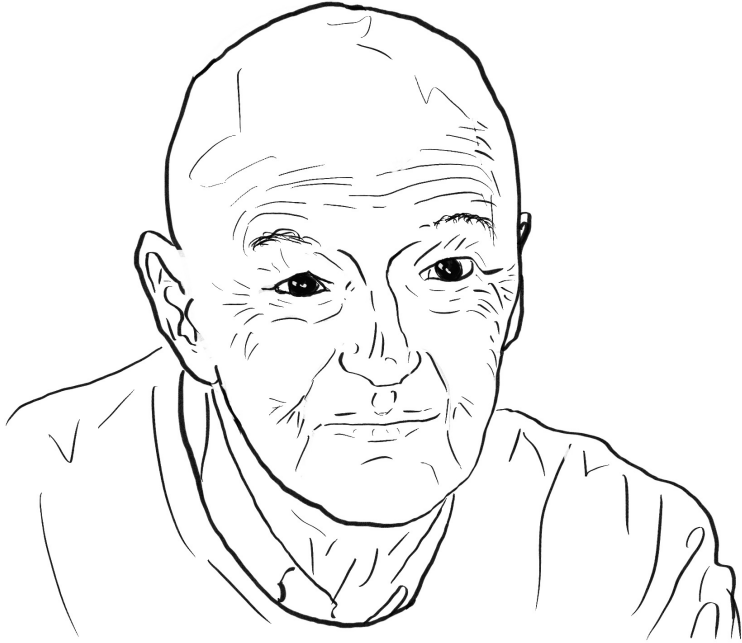
*Good afternoon Brian,*

*We have been advised by our Pharmacy department that patient's allergies/reactions should be entered on discussion with the doctor or pharmacist on admission or in clinic. Otherwise, you may discuss this directly with the Medication Safety Lead of our Pharmacy department on (03) xxxx yyyy.*

*Kind regards,*

*Patient Portal Support Team*

# 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 today’s specialty clinics and wards.”**

(Lawrence L. Weed, *Knowledge Couplers*)

*"[Larry Weed] is one of the giants of the last 500 years in medical thinking."*

# Introducing Angela circa 2018

- Well educated (BS/MS)
- Worked in an academic health system
- An engaged patient
  - She uses her patient portal
  - She monitors chronic conditions



# Introducing Angela circa 2018

- High risk first pregnancy (twins)
- Epistemically complex patient
  - She's texting her perinatologist
  - She's reviewing scientific literature
  - She's instructing the nurses on how to measure her blood pressure (William Wimsatt cheers! **testimonial justice!**)





# Introducing Angela circa 2018

- High risk first pregnancy (twins)
- Epistemically complex patient
  - Yet a non-understanding patient
    - *“Pre-eclampsia? I saw that on Downton Abbey!”*
  - She **does not understand** the seriousness of her condition (**hermeneutical injustice**)
  - Ignores symptoms



“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*

# Hermeneutical Injustice



“I would get mixed msgs from nurses vs Drs at the nicu. The nurses stressed how much you had to proactively advocate. **We also rarely saw the Dr. In the 6 weeks we were in the nicu they arranged one meeting...**The info we received was from nurses and felt like we were getting it through the grapevine. **When they were released from the nicu we were given 30 ish pages of discharge notes.**”

This would no longer be allowed in the USA!

# Testimonial Injustice

- Upon discharge, Angela told to carefully monitor babies' "inputs" and "outputs"
- Buys an app for that
- Dutifully entered all the data into the app
- All the data were then ignored by the clinicians

If you want to hear more from Angela:



# Way back in 1973: Advocating for Sharing

The month I started kindergarten!

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## **SOUNDING BOARD**

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

Predicted a health information services marketplace



1<sup>st</sup> day of kindergarten 1973

## 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 could better 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 high-quality 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.

# “Patients, clinicians and open notes: information blocking as a case of epistemic injustice”

- Who benefits most?
  - Older patients
  - Patients with poorer health,
  - Less educated patients
  - Minorities
  - Non-native language speakers
- Only 3-5% of patients reported being confused, anxious, etc. by notes

# Francis Bacon: Knowledge is Power



Lard\_Baron · 11 yr. ago · *edited 10 yr. ago* 🏆 3 💡 🦴 🗨️ 5 & 12 More



When I was young my father said to me:

"Knowledge is Power....Francis Bacon"

I understood it as "Knowledge is power, France is Bacon".

For more than a decade I wondered over the meaning of the second part and what was the surreal linkage between the two? If I said the quote to someone, "Knowledge is power, France is Bacon" they nodded knowingly. Or someone might say, "Knowledge is power" and I'd finish the quote "France is Bacon" and they wouldn't look at me like I'd said something very odd but thoughtfully agree. I did ask a teacher what did "Knowledge is power, France is bacon" mean and got a full 10 minute explanation of the Knowledge is power bit but nothing on "France is bacon". When I prompted further explanation by saying "France is Bacon?" in a questioning tone I just got a "yes". at 12 I didn't have the confidence to press it further. I just accepted it as something I'd never understand.

It wasn't until years later I saw it written down that the penny dropped.

↑ 3.9k ↓ Give Award Share Report Save



# Ignorance keeps patients from being people

“The other side of the [knowledge is power] coin is less pithy but no less significant: **ignorance disempowers.** It limits our ability to make the everyday decisions of our lives, as well as the decisions that change our lives in important ways.”

(Lani Watson)



# Sharing is caring!



# Sharing is essential for patients to be persons



Thank you!