

Prometheus and the Patient

Epistemic Rights and Epistemic Duties

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A little about me

- PhD in medical informatics
- 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



My "mobile medical record"

Prometheus and the birth of civilization



- Gave the gifts of
 - Writing
 - Mathematics
 - Science
 - Fire
- In short...Civilization

Homer Warner and the birth of informatics



- Started as traditional cardiovascular researcher in the 1950s
- By the 1960s had started blending digital computers, engineering mathematics, and medicine to novel ends
- Had created a surgical ICU with extensive real-time physiological monitoring and data display

Homer Warner and the birth of informatics



At one bed there was a yellow light indicating something was wrong with the patient

There was a frustrated nurse. The monitor was telling her there was something wrong, there were physiological signals everywhere, but nothing was helping her know what she should do.



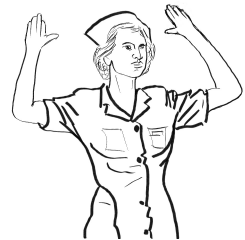
Homer Warner and the birth of informatics



Homer Warner: “[W]e’d overwhelmed her with information. We had all this data, but we didn’t know what it meant.”

Paul Clayton: “This nurse clearly needed help in the interpretation of the data...[I]t required that the computer have some medical knowledge.”¹

Birth of the HELP system.



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

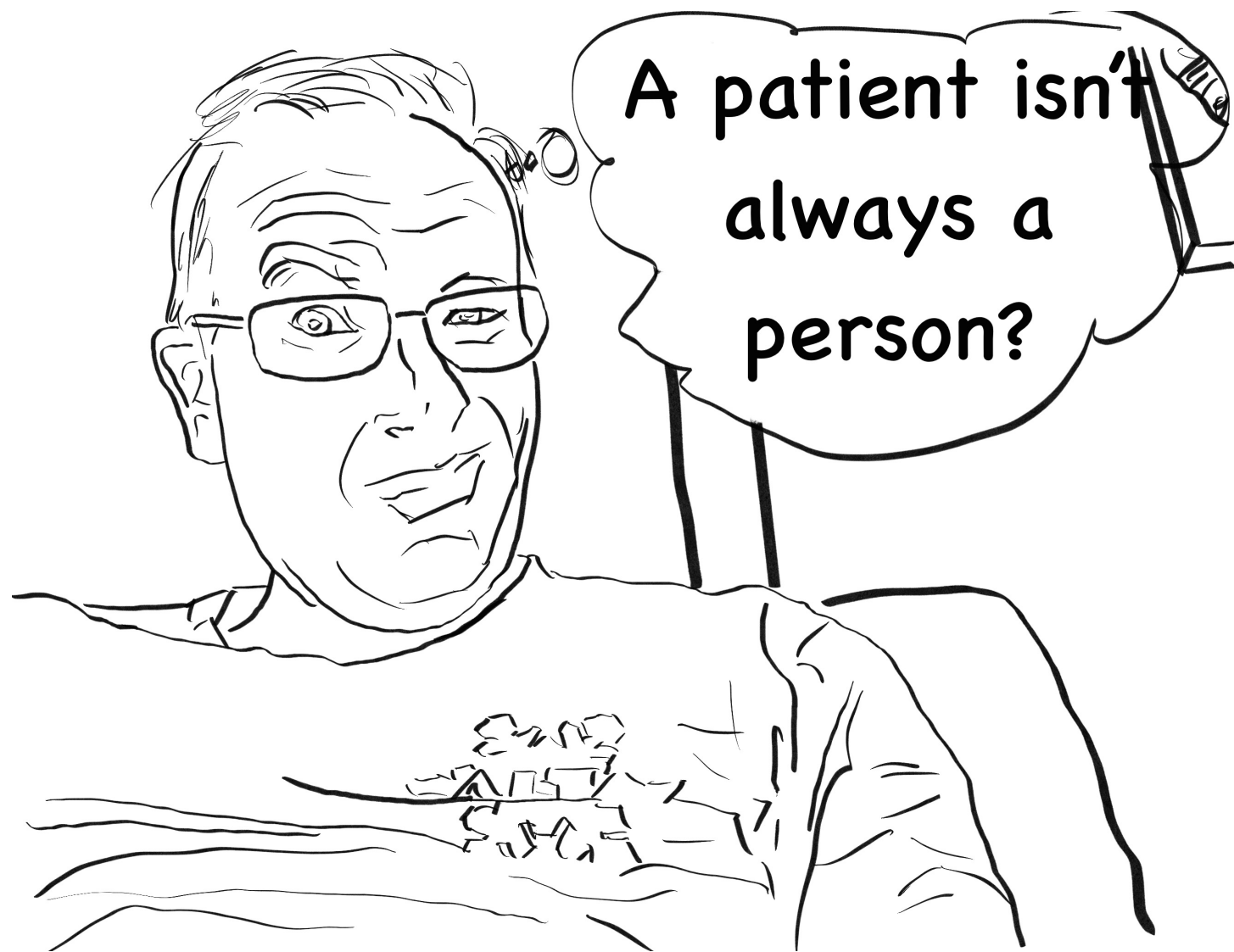
Thesis

1. Just as Prometheus gave humans the tools to create civilization, Warner, his peers, and their subsequent disciples, have given healthcare the tools to exercise epistemically informed care.
2. But just as the ICU nurse was provided data but not knowledge, today's patients
 - Might be provided data
 - But are unlikely to be provided knowledge to understand the data
3. Patients need more Promethean gifts to help them achieve **healthcare as persons**

Let's jump back and join Warner
and 1960's medicine

The 1964 annual meeting of the American Medical Association included a session titled

“The Patient as a Person”



A patient isn't
always a
person?

What is a person?

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

**A being with epistemic needs
and epistemic rights**

Philosophy Now
a magazine of ideas

JES

CATEGORIES

TAGS

SHOP

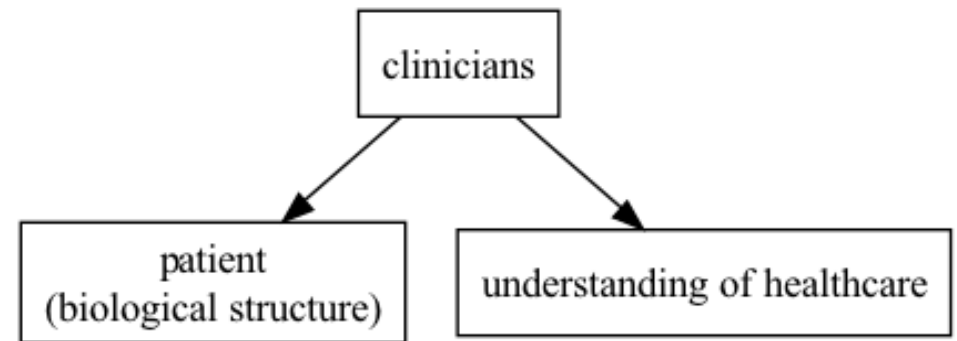
Question of the Month

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 entity generating signals (circa 1995 medical informatics education)*
- ***A ~~biological~~ structure 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

Current patient ecosystems fall short

- Patient health epistemic ecosystems tend to be
 - Monolithic
 - Simplistic
 - Unidirectional
- Do not support patients as persons
- Why?
 1. “Health” Incentives
 2. Epistemic Habits

“Health” incentives

What “health” is the healthcare system producing?

“Health” incentives

U. REINHARDT

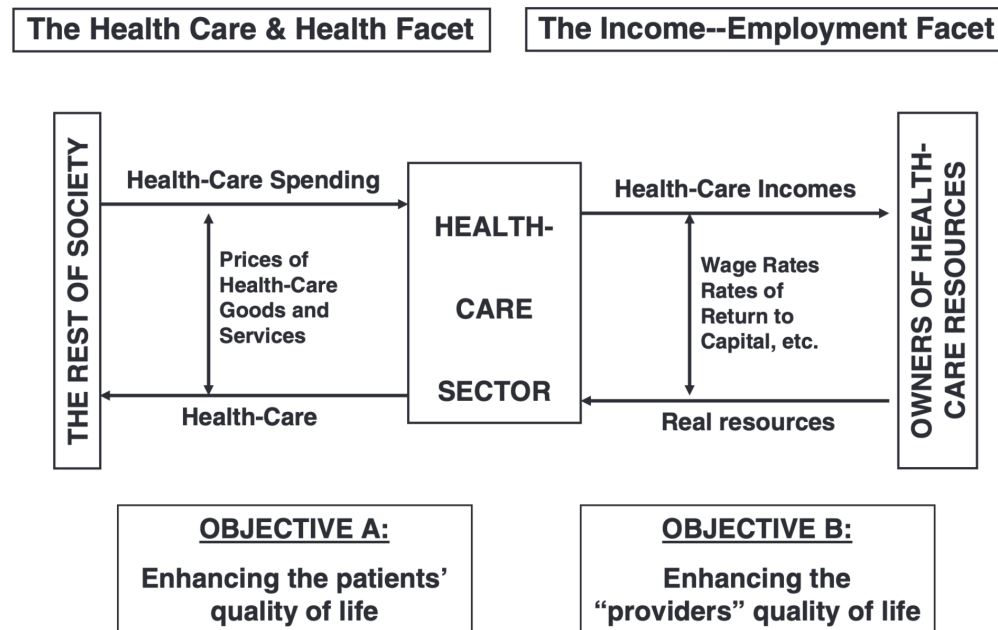


Figure 1. The terrain of the health care battle field

Example: “Financial Health”

- **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 [plastic surgeon] in relation to being further consulted by the plaintiff. It was legitimate for him to have this advantage and keep it for himself.”** (*Australian Health and Medical Law Reporter*)
 - Federal and state laws have since been passed to provide patients access to medical records (for a cost and long wait)

Example: “Status Health”



Miss•Treated
FIGHTING MISOGYNY IN THE MEDICAL
PROFESSION ONE STORY AT A TIME

[BLOG](#) [RESOURCES](#) [READING](#) [SHARE YOUR STORY](#)

5 Reasons My Google Search Is
Worth As Much As Your Medical
Degree

April 7, 2016

Purposeful flaws

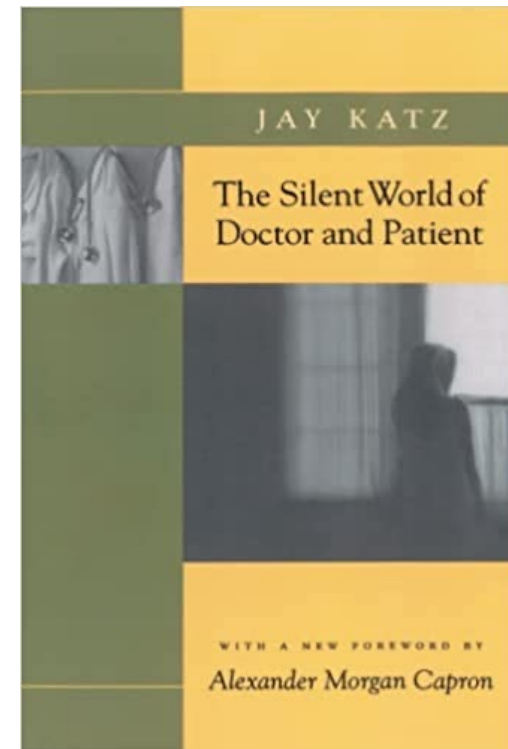
“[T]he flaws of the health care system and the **interest groups it caters to** can only exist to the degree that patients remain uninformed.”

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

Epistemic Habits

What are we trained to do?

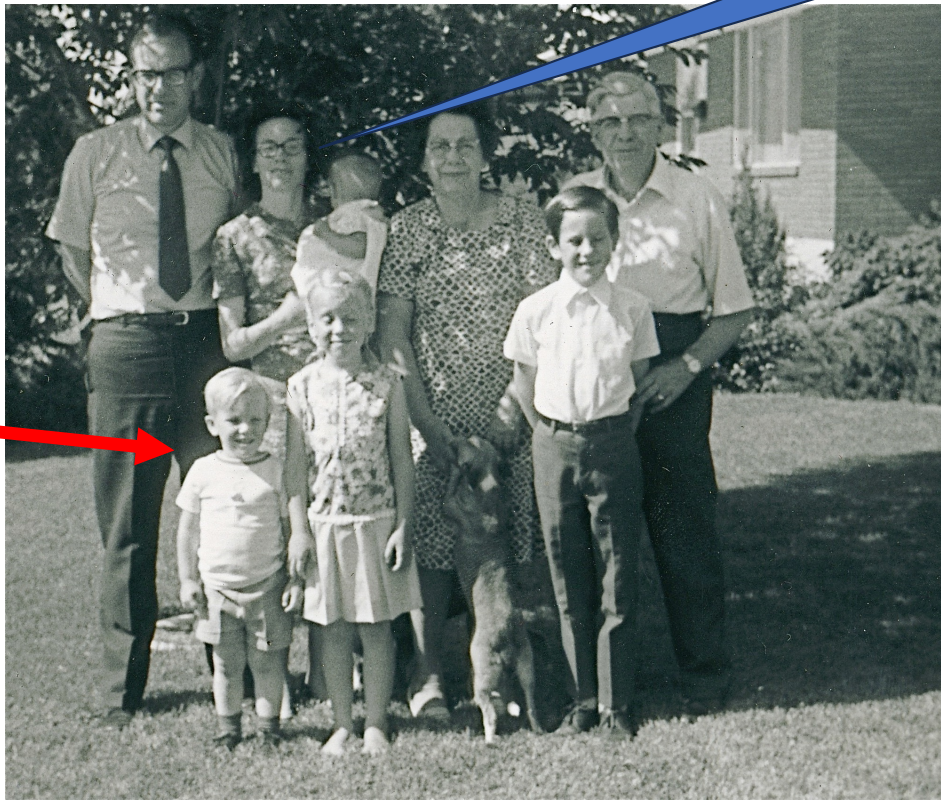
Jay Katz, M.D.'s 1984 diagnosis of medicine



It really was a pretty silent world

“They didn’t tell you much, and asked you even less, in 1976!”

Me *circa* 1971!



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
 - 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

Epistemic pressures since 1984

- Internal changes in medicine
 - Recognition of medical errors, quality, outcomes, etc.
- Expanding concepts of a citizen's epistemic rights
 - Right to know data being used to make decisions about them
- 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

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 (**testimonial justice!**)
 - Yet a non-understanding patient
 - *"Pre-eclampsia? I saw that on Downton Abbey!"*
 - She **does not understand** the seriousness of her condition (**hermeneutical injustice**)



Promethean gifts for the 21st Century patient

Facilitating healthcare for persons

Gift of timely epistemic resources



“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.”**

Hermeneutical injustice!

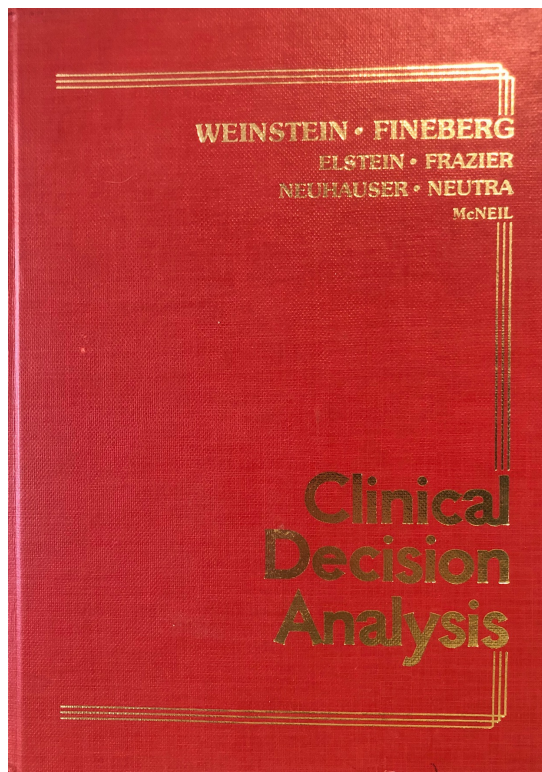
Gift of integrating patient generated data

- 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



Testimonial injustice!

Introducing Freeman Dyson



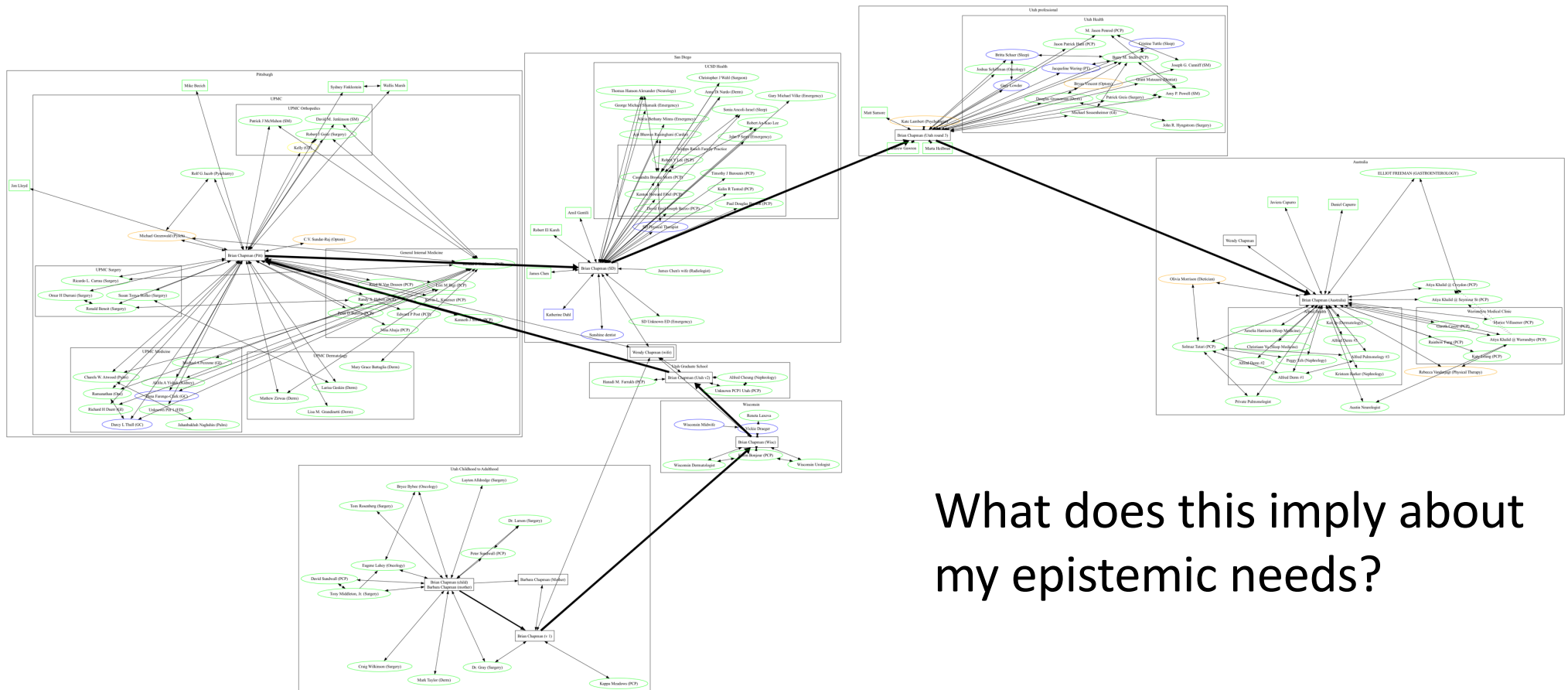
Patient facing decision support:

AKA “How can we help Angela be like Freeman?”

- Risks
 - Immediate delivery to her fetuses' development
 - Delayed delivery of her death
- Weighing her value of
 - Vaginal delivery
 - Clinicians value of rapid c-section



My mobility: My “immediate” healthcare network



What does this imply about my epistemic needs?

The gift of FAIR data



- Can I **find** my test result from X months/years ago to compare?
- Can I **access** my data while I'm at my appointment?
 - **Can I prove I'm a childhood cancer survivor?**
- Can my American data speak "Australian" (**interoperable**)?
- Can I **reuse** my data? That is, can I **compute** with my data?

These would not be “gifts” from a God

- But engineered solutions costing
 - Time
 - Money
 - Social capital
- Not healthcare processes, but **realizations of human rights**
- No right is meaningful without a corresponding duty

Epistemic right require epistemic duties

“All epistemic claim-rights correlate with epistemic duties.”

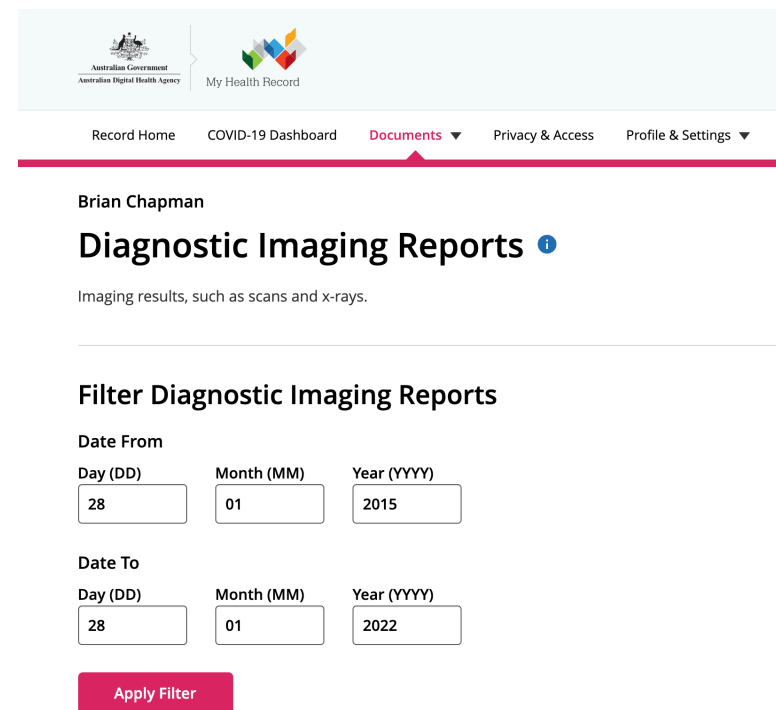
(Lani Watson, *The Right to Know: Epistemic Rights and Why We Need Them*)



Lani Watson

Australia's (mostly empty) My Health Record

- Addressed patient's rights to health data, but...
- **Did not assign a corresponding duty to providers to share**



The screenshot shows the Australian Government My Health Record interface. At the top, there is a navigation bar with the Australian Government logo and the My Health Record logo. Below the navigation bar, there are several menu items: Record Home, COVID-19 Dashboard, Documents (highlighted with a red underline), Privacy & Access, and Profile & Settings. The main content area displays the patient's name, Brian Chapman, and the title of the report, Diagnostic Imaging Reports, with an information icon. Below the title, there is a brief description: Imaging results, such as scans and x-rays. A section titled Filter Diagnostic Imaging Reports contains two date range filters. The first filter is for the date from 28/01/2015 to 28/01/2022. The second filter is for the date to 28/01/2022. An Apply Filter button is located at the bottom of the filter section.

Australian Government
Australian Digital Health Agency

My Health Record

Record Home COVID-19 Dashboard Documents Privacy & Access Profile & Settings

Brian Chapman

Diagnostic Imaging Reports ⓘ

Imaging results, such as scans and x-rays.

Filter Diagnostic Imaging Reports

Date From

Day (DD) Month (MM) Year (YYYY)

28 01 2015

Date To

Day (DD) Month (MM) Year (YYYY)

28 01 2022

Apply Filter

The duty to facilitate healthcare literacy

Example from the USA

- Legal expansion of patient rights AND increasingly specific epistemic duties
 - Health Insurance Portability and Accountability Act of 1996 (HIPAA)
 - Legal access to data
 - Health Information Technology for Economic and Clinical Health Act of 2009 (HITECH)
 - Access to health data in a digital and timely manner
 - 21st Century CURES Act 2016
 - Banning information blocking
- But are we simply replicating Warner's 1960s ICU?

Overwhelming patients with data without providing knowledge?

Not quite: Knowledge sharing

1996

PubMed
(Public Medline)

1998

Medline Plus

NLM's goal is to improve the national infrastructure that supports the public's access to electronic health information.

This infrastructure includes the intellectual organization, information technology, inter-institutional arrangements, and training that will be needed to ensure that all people in the [World] have a known, accessible, understandable, and affordable source of current, authoritative health information.

Future epistemic ecosystems

- Sharing computable knowledge linked to patient data
 - Facilitate **self-understanding**
 - Facilitate **self-decision making**
- Anticipate resistance
 - This will be technically difficult, but...
 - It disrupts Objective B of our dual health systems
 - Knowledge scarcity preserves economic value

U. REINHARDT

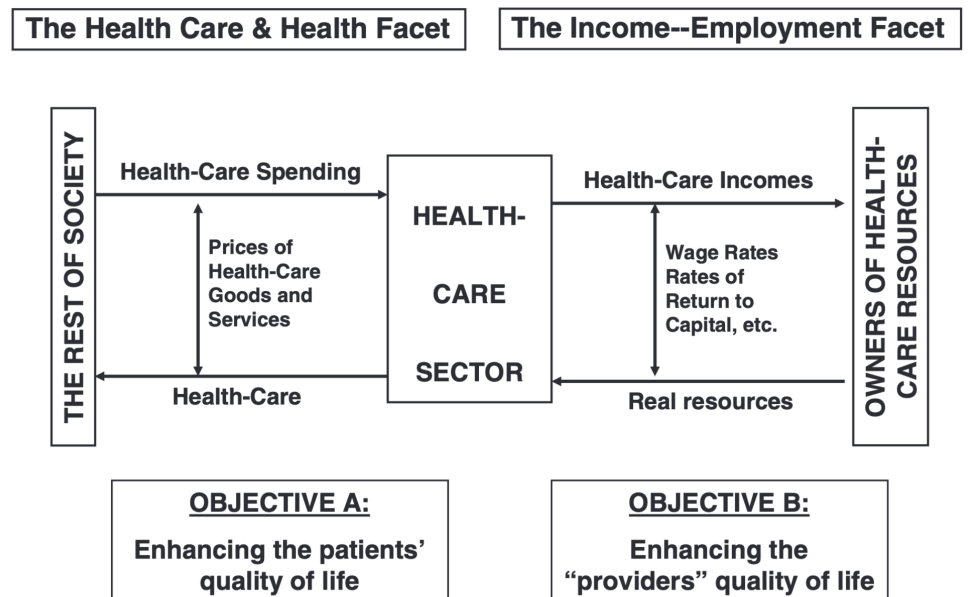


Figure 1. The terrain of the health care battle field

FHIR and other gifts

Progress towards patients as persons has been slow, but...

*“You can blow out a candle
But you can't blow out a fire
Once the flames begin to catch
The wind will blow it higher”
(Peter Gabriel “Biko”)*

