



@chapmanbe

## The varieties of healthcare experience: Pluralism, informatics, and consumer empowerment

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Brian E. Chapman, Ph.D.

A/Professor and Professional Patient





## A little bit about me...

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- I have a PhD in Medical Informatics



## ...but I'm foremost a patient

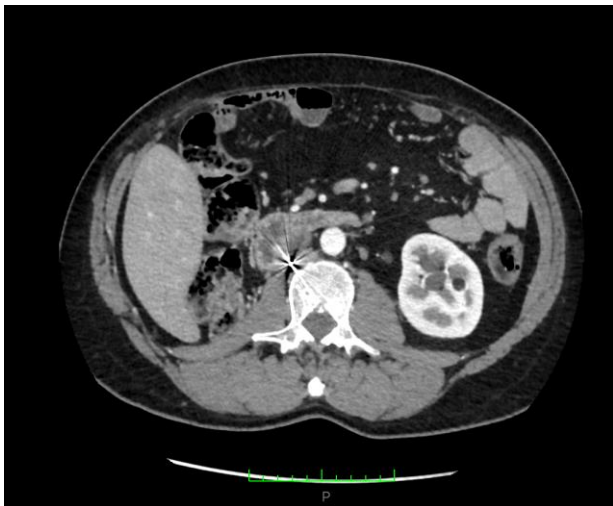
- 4-time cancer survivor
  - Two childhood cancers (1976, 1983)
- 6 abdominal surgeries
  - 4 emergencies
- 4 orthopedic surgeries
- 2 “not-otherwise-categorized” surgeries
- Advanced peritonitis
- Gangrenous strangulated bowel
- And all the chronic issues that result from the acute ones!



My “mobile medical record”



## I make no claim to be representative



#SNOMEDCT/722149000

#SNOMEDCT/443869003

#SNOMEDCT/192681000119104

#SNOMEDCT/21897009

#SNOMEDCT/269579005

#SNOMEDCT/269581007

...



## I make no claim to be representative

**Salt Lake City, Utah**  
The Church of Jesus Christ of Latter-day Saints  
Church Hospital System  
225 8th Avenue, Salt Lake City, Utah

**EARL W. CHAPMAN**  
ADDRESS: SALT LAKE CITY, UTAH  
TELEPHONE: 266-  
HUSBAND  
SALT LAKE COUNTY WATER CONSERVANCY DISTRICT  
OFFICE MANAGER  
DATE: 5/24/68  
PATIENT AGE: 30 SEX: F

**H.S. SANDERS, M.D.**  
PHYSICIAN  
ADMITTING: MATERNITY  
FINAL

PATIENT ID: 1150045  
DISCHARGED: 5/24/68 3:40PM  
ADMITTED: 5/24/68  
INSURANCE: 5724768  
GROUP: 585  
CONTRACT: 32.00  
DATE: 5/24/68  
ROOM NO.: 585  
TYPE: 15A  
RATE: \$

Pharmacy	Laboratory	X-Ray	Op. & Del. Room	Central Supply	Blood Bank	Intensive Care	Daily Service Charge	Miscellaneous Charges	Payments	Date	Balance Dr.
Amount	Code	Amount	Code	Amount	Code	Amount	Code	Amount	Code	Amount	Code
3.75	106	4.50	229	60.00	2402					MAY 28 68	111.50
										MAY 25 68	164.25
										MAY 26 68	0.00
										MAY 27 68	55.00
										Pd 6-2-68	
										CX #215	

**Holy Cross Hospital**  
LABORATORY  
1045 EAST 1st SOUTH  
SALT LAKE CITY, UTAH 84102

**Chapman, Brian E.**  
ADDRESS: 206/B 2296382  
DATE: 4/7/76  
CLINICAL DIAGNOSIS: Right Renal Tumor  
A.W. Middleton, Jr., M.D.  
TISSUE SITE AND LOCATION: Rt Kidney  
PATHOLOGIC DIAGNOSIS: Wilms's tumor of right kidney (see micro for margins).  
CODE: 6  
RML/mf

**PATHOLOGISTS**  
CYRIL FULLMER, M.D. STANLEY L. GIBSON, M.D.  
BRUCE LLOYD, M.D. SAROF N. KULKARNI, M.D.  
E. MYRON LAUB, M.D.

GROSS:  
The specimen labelled "right kidney," consists of a kidney and subcutaneous tissues weighing 283 grams. The kidney has been opened and reveals a large yellow centrally located tumor measuring 6 cm. in diameter. There is a maximum of 12 mm. of renal





## Abraham Heschel

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"Prayer is  
meaningless unless  
it is subversive..."





## Abraham Heschel Brian Chapman

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"A keynote is  
meaningless unless it  
is subversive..."





## "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"
  - Abraham Heschel was invited to speak





**"I assert that  
every patient is  
in fact a  
person!"**





# MEDINFO23

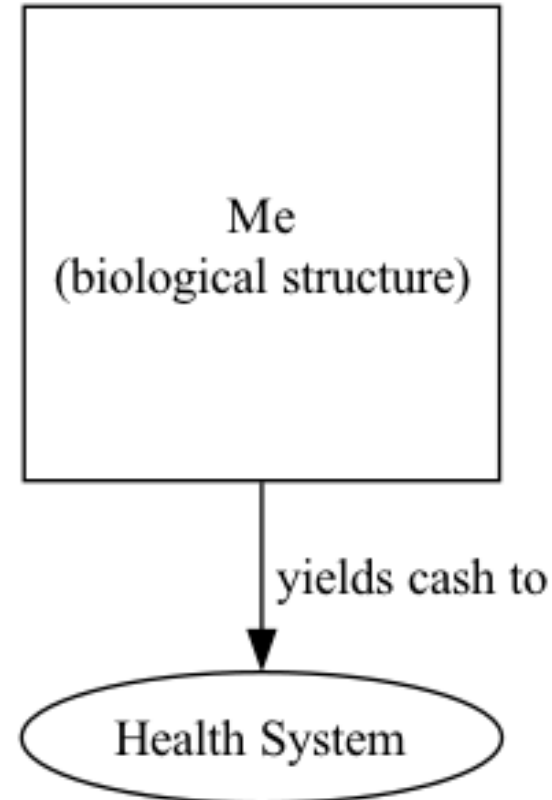
8 – 12 JULY 2023 | SYDNEY, AUSTRALIA





## What is a patient?

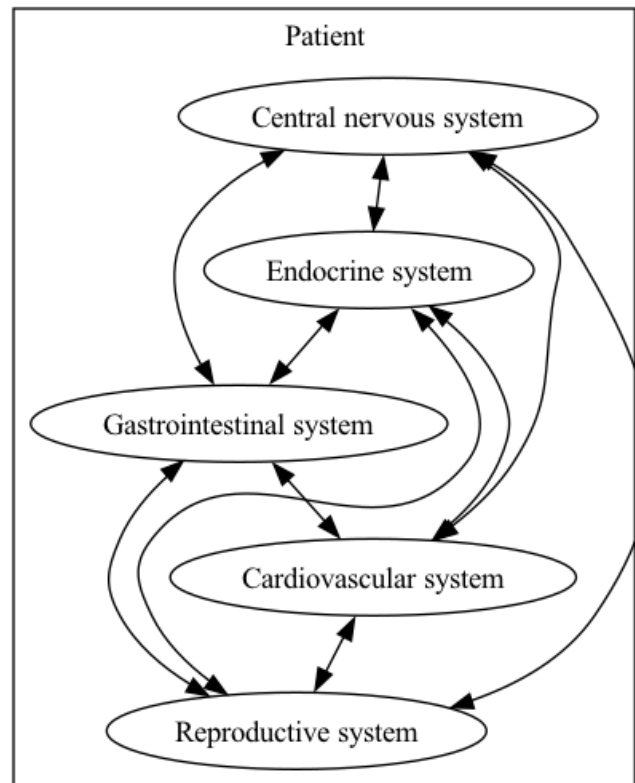
- "A biological structure yielding cash"  
~ *Uwe Reinhardt*





## What is a patient?

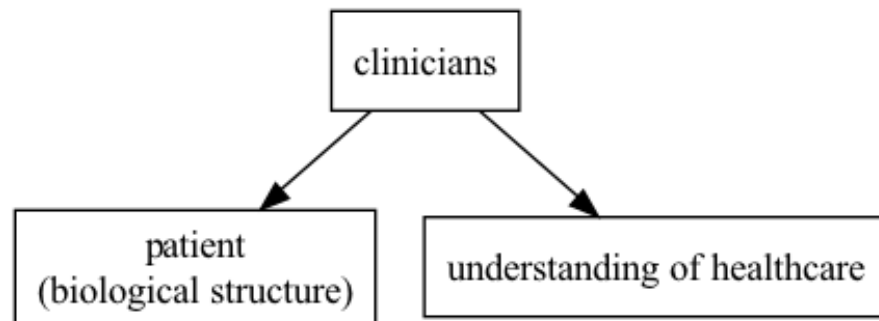
- "A biological structure yielding cash"  
~ *Uwe Reinhardt*
- A biological structure reducible to interconnected but distinct physiological systems





## What is a patient?

- “A biological structure yielding cash”  
~ *Uwe Reinhardt*
- A biological structure reducible to interconnected but distinct physiological systems
- *A biological structure that cannot understand its medical care*







# Philosophy *Now*

a magazine of ideas

JES

CATEGORIES

TAGS

SHOP

**Question of the Month**

# What is a Person?



## What is a person?

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

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

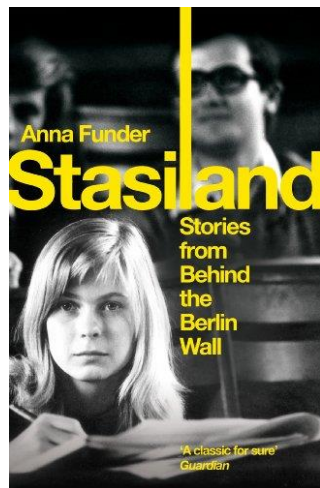


## Epistemic rights

- 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



## Think about healthcare through these lenses



Hermeneutical Injustice



Testimonial Injustice

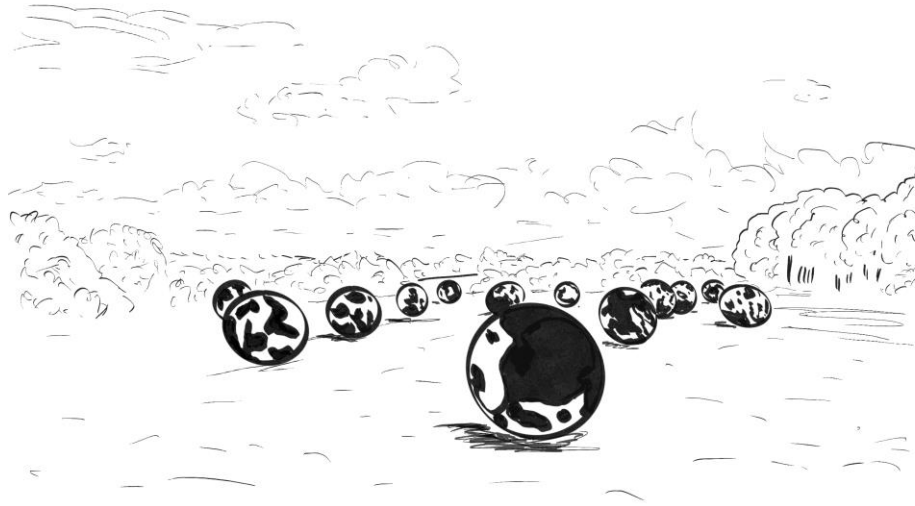


## Physicists are famous for studying cows...





...but only if they are spheres



And apparently only if they are Holsteins





## Healthcare is often prone to simplification too

"All patients are spheres!"

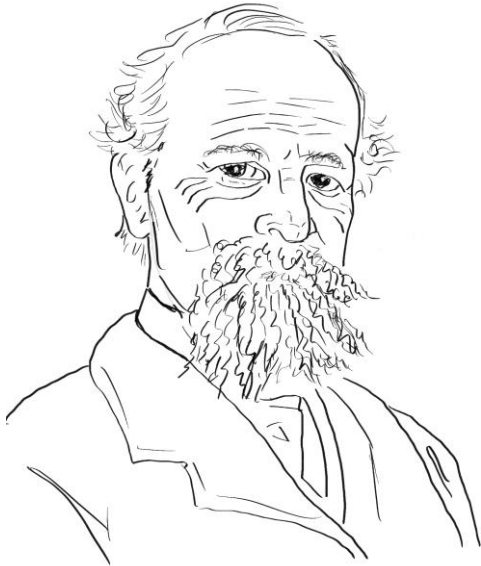
Not "biological spheres"  
(good custody)

But "information spheres!"  
(poor liberty)





## William James on Health Informatics



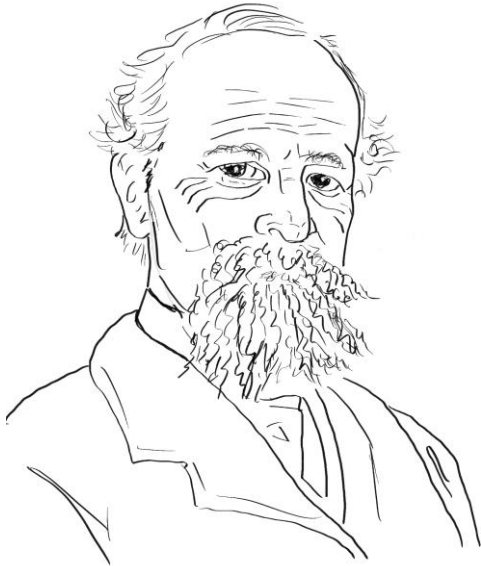
"Dought it, indeed, to be assumed that the lives of all men should show identical **[health information]** elements? In other words, is the existence of so many **[patient]** types and sects and creeds regrettable?

"To these questions I answer 'No' emphatically."



## William James on Health Informatics

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"And my reason is that I do not see how it is possible that creatures in such different positions and with such different powers as human individuals are, should have exactly the same functions and the same duties."



## William James on Health Informatics

"If an Emerson were *forced* to be a Wesley, or a Moody forced to be a Whitman, the total human consciousness of [healthcare] would suffer."





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Yet...



## Whether I'm a monitoring patient







## Or a blunting patient





## Whether I'm happy to be on the sideline





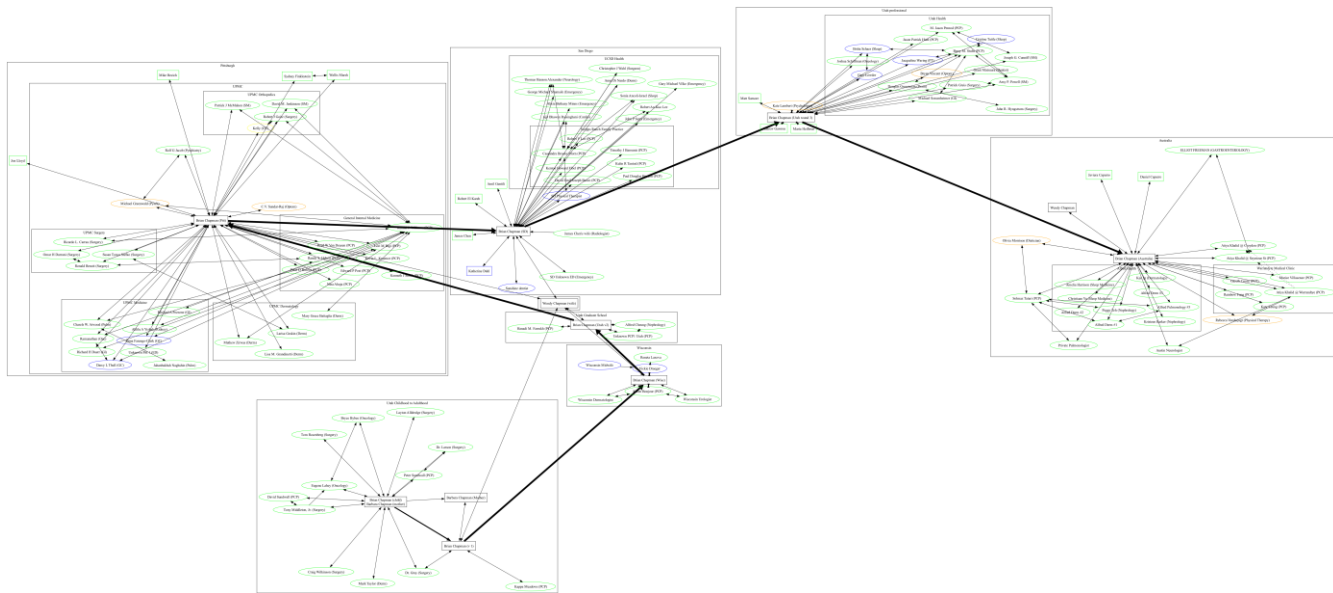
## Or I want to be in the middle of the team

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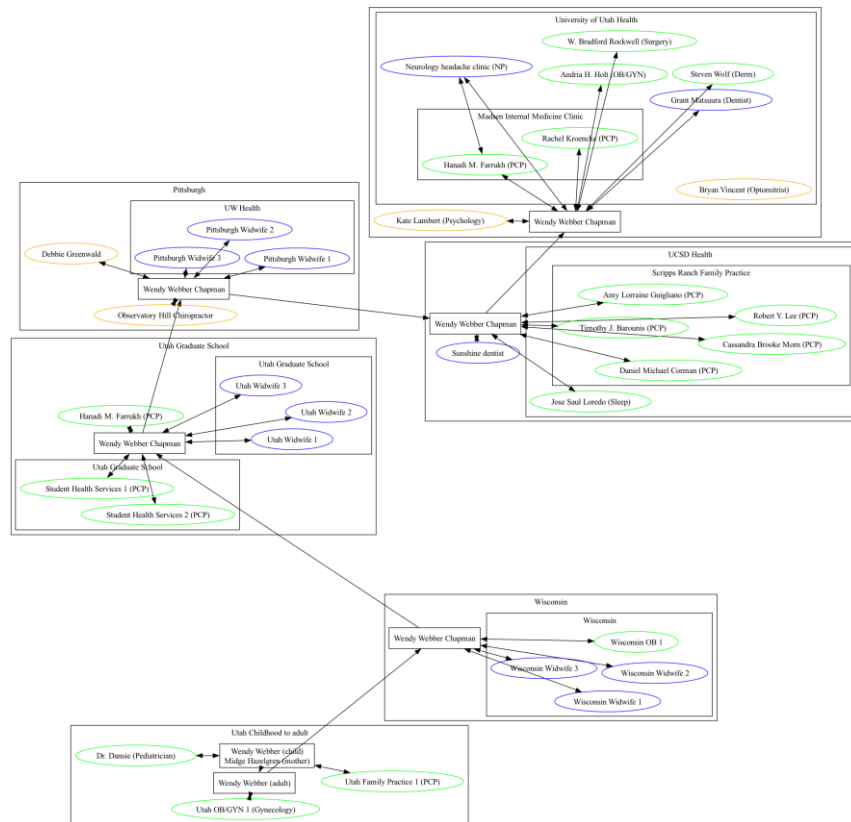




Whether my  
network of care  
is large...



## ...or small(er)





We are all given the same (limited)  
health information tools!

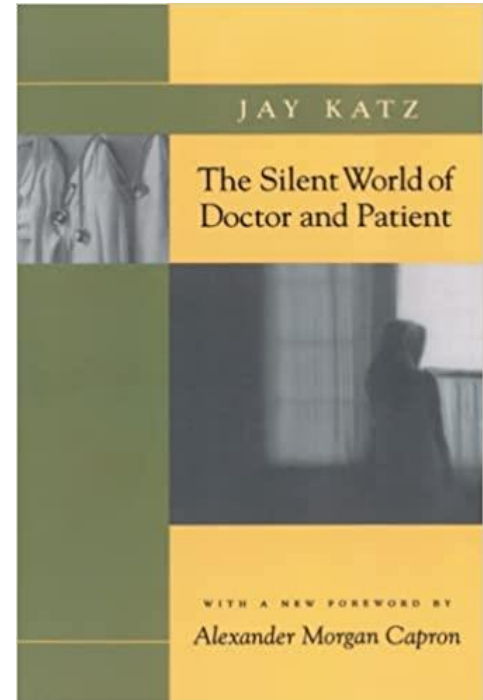




# Why?



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



# MEDINFO23

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"They didn't tell you much in 1976!"

Me!





## 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
  - All patients are spheres!



## 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
  - All patients are "information spheres"!

**Informatics has largely inherited these same problems from medicine**



## Epistemic pressures since 1980

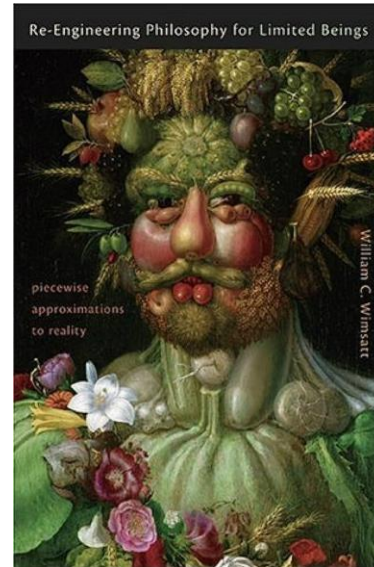
- Internal changes in medicine
  - Medical errors, quality, outcomes, etc.
- Expanding concepts of a person's human rights
- Expanding recognition of patient as person
  - Values distinct from clinicians
  - Capacities



## 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")



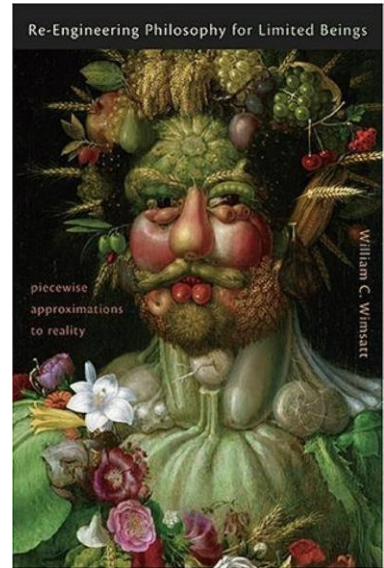




## Patients can be critical information redundancies

"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")





## Larry Weed

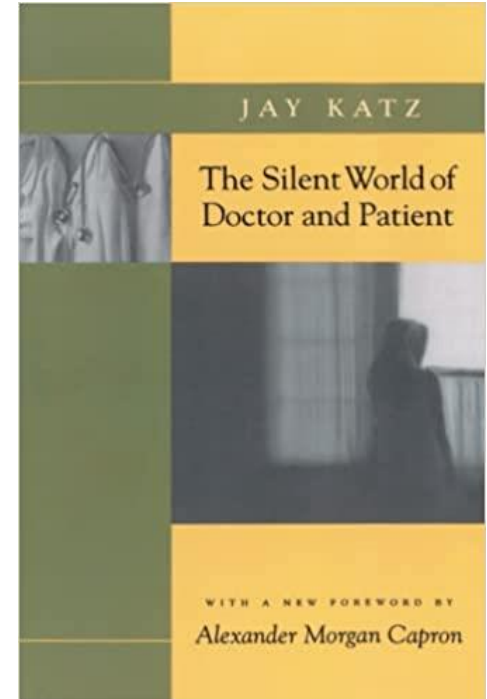


*"Until ...patients...working directly from their own records are the rule instead of the exception, we cannot seriously attack the fragmentation of care in today's specialty clinics and wards."*

(Lawrence L. Weed, *Knowledge Couplers*)

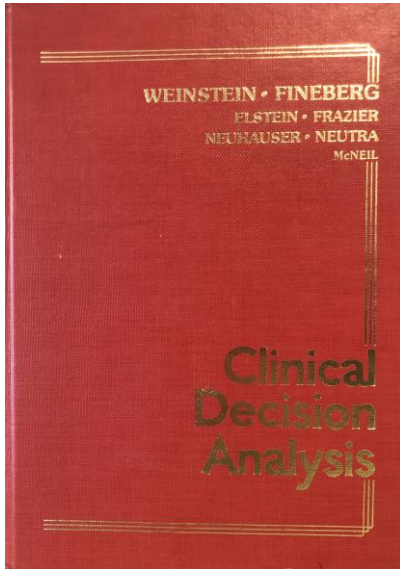


"To recognize others fully requires not only an appreciation of their limitations but their capacities as well. Physicians have shown a keen sensitivity to patients' decision-making limitations but *considerable insensitivity to their capacities to decide.*"





## "Capacities to decide": Freeman Dyson





## "Capacities to decide": the "not very well educated"



"'Tell me who is going home today.' The nurse volunteered the name of a middle aged woman who had had lupus for ten years....I asked the patient to tell me all about each of her problems. She knew very little about the medical problems.



## "Capacities to decide": Larry Weed, M.D.



**House staff:**

"We never give patients their records."

"We do not have the time to give the medicines that way. It would not be safe to leave her with them unattended. She is on many powerful drugs."

"The patient is not very well educated, and I do not think she could do all the things your questions imply."



## "capacities to decide": Larry Weed, M.D.



"But," I said, "you said she is going home this afternoon. She lives alone. At 2 pm you will put her in a wheelchair, give her a paper bag full of drugs, and send her out the door. Are you going home with her?"

"No. Is her management at home our problem?"

"You just said she could not handle it. Who will do it? The patient may not seem well educated or very bright to you, but *what could be more unintelligent than what you are doing?*"





## Universal needs of diverse patients

- Both the brilliant, well-educated Freeman Dyson and the “not very well educated” lupus patient of Weed’s story—as widely different as they are—are autonomous agents that *must* act on their own.
- At the very least as soon as the exit the hospital/clinic doors



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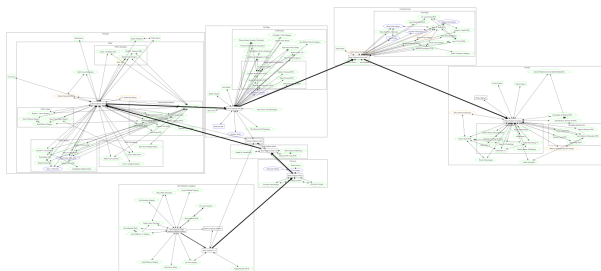
# A personal perspective on epistemic injustices in healthcare



## 21<sup>st</sup> Century Epistemic Injustice:

To me, providing data only as  
paper/PDF is an injustice

Is my data FAIR?





## 21<sup>st</sup> Century Epistemic Injustice



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

Lack of information during in-patient care  
hermeneutical injustice

Are we listening to  
Angela's data?



Ignored patient generated data in out-patient visits  
Testimonial injustice



## Hermeneutical Injustice: How we get to know



My Health Record



Other pathology reports are available to access 7 days after upload, allowing time for your healthcare provider to review and discuss the results with you. You will be able to see the report in your record but won't be able to open the document during this 7-day period.



## Hermeneutical Injustice: How we get to know

"Reading [medical diagnoses and prognoses] in the medical portal has been an empowering thing for me ... *there was something that has been disempowering about having a doctor tell me.*"

(<https://momastery.com/blog/we-can-do-hard-things-ep-215/>)

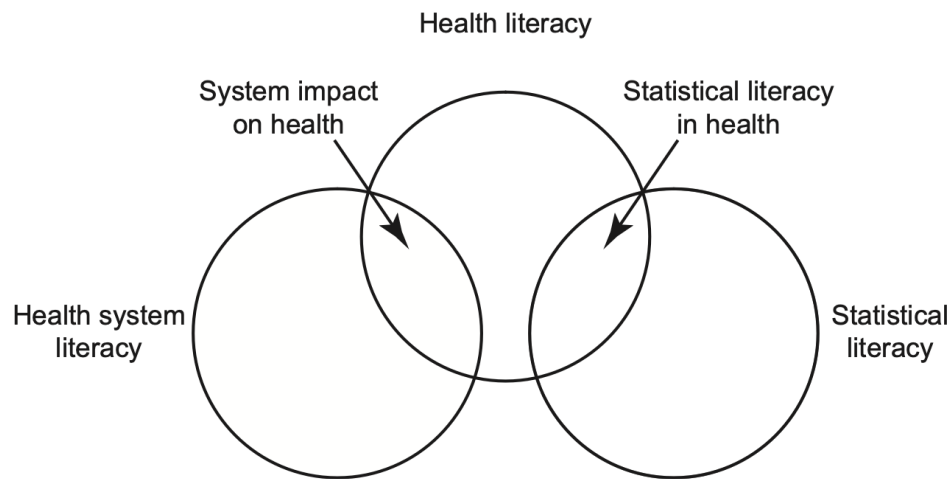


@andreagibson



## 21<sup>st</sup> Century Epistemic Injustice

Not educating citizens for basic literacies necessary for healthcare





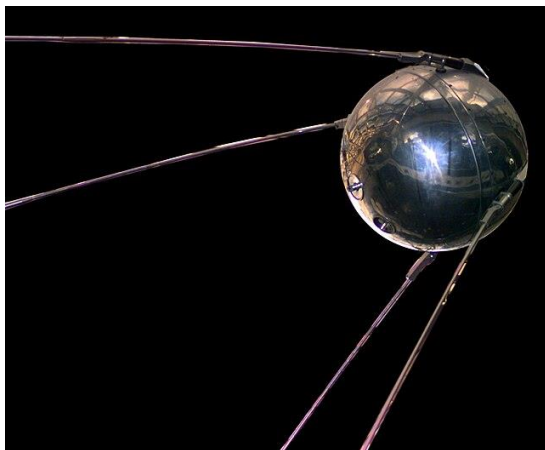


“Patients’ health illiteracy is, in part, a consequence of how the health care system has been set up. Conversely, the flaws of the health care system and the interest groups it caters to can only exist to the degree that patients remain uninformed.”

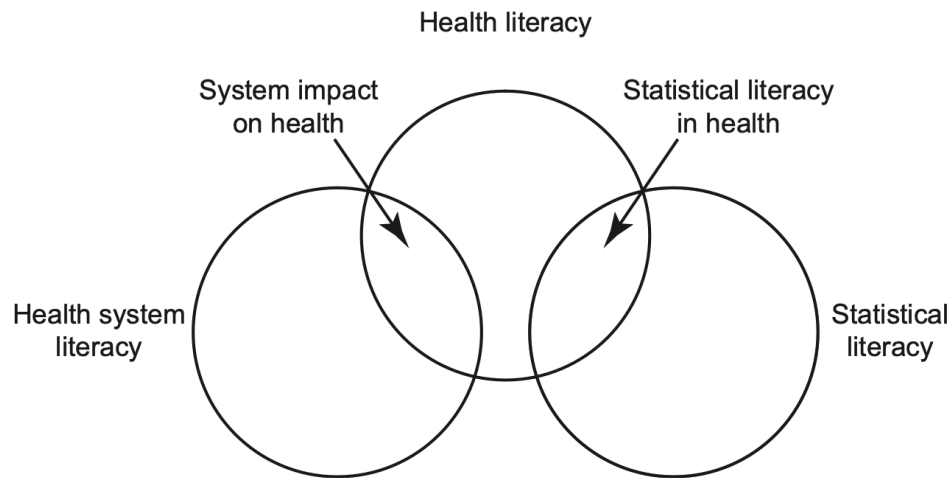
Markus A. Feufel, et al. in ***Better Doctors, Better Patients, Better Decisions: Envisioning Health Care 2020***



## 21<sup>st</sup> Century Epistemic Injustice



Germany: Science Kids





## Patients *are* indeed (wildly variable) persons

- Health systems commit epistemic injustices when they
- Decide for the patient how the patient can interact (or not) with their data
- Do not provide mechanisms for patients to utilize their own data
- Do not provide tools (digital or otherwise) for patients to understand their data





## Way back in 1973

The month I started kindergarten!

### 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



## Have some imagination!

- Treat patients as 21<sup>st</sup> Century persons
  - Give them the data!
- Eliminate monolithic solutions where patients are merely guests
- Create a marketplace of solutions—James' variety of "sects and creeds"—that patients can pick to match their incredible inherent information variety

MANCHESTER  
1824  
The University of Manchester

Case study:  
Remote Monitoring of Rheumatoid Arthritis

