

# Throw Some More Rights on the Barbie

## *A View from Down Under on Epistemic Rights and Informatics*

A/Prof Brian E. Chapman

Javiera Martinez-Gutierrez

Megan Prictor

University of Melbourne



# “Knowledge is Power. France is Bacon”: *Tackling medicine’s paternalism problem*

A/Prof Brian E. Chapman

University of Melbourne



# Punk Informatics: Technology Evolutions and Empowerment of a Do-It-Yourself Health Professional



# Our Australian Adventure

**Associate Dean of Digital Health and Informatics**



Prof

**Wendy Chapman**

Ad & Centre Dir, Digital Transformation Of Health  
Medicine, Dentistry and Health Sciences

A/Prof



**Brian Chapman**

Associate Prof Health & Biomedical Informatics

Medical Education

→ AKA What are we going to do with the spouse?



# My qualifications for medical Education?

- 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 qualifications for medical Education?

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  - 4 emergencies
- 4 orthopedic surgeries
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- Advanced peritonitis
- Gangrenous strangulated bowel
- And all the chronic issues that result from the acute ones!
- PhD Medical Informatics

# Erik Meijer: The Vegetarian Butcher



# Chapman Duo Strategy for Understanding Australian HealthCare

## **Wendy Chapman: Top Down**

- Meet with CEOs of hospitals
- Sit on boards of national organizations
- Talk with government and industry leaders

## **Brian Chapman: Bottom Up**

- Pick a GP
- See specialists
  - Pay large fees for private practice
  - Wait long time for public practice
- Get radiology exams



I had urgent medical needs



# Timing is Everything

- October 1, 2019
  - I arrive in Australia
- January 29, 2020
  - I watch Nadal lose to Thiem in AO
- February 24, 2020
  - I Start at the University of Melbourne
- March 3, 2020
  - I teach my first class
- 25 January 2020
  - First COVID-19 case confirmed in Australia
- 15 Mar 2020
  - Victoria declares a state of emergency
- 20 March 2020
  - University confirms first case
- 23 March 2020
  - Campus shuts down

## Dennis Parker's Informed Observation



“Going to  
Australia is like  
going back in  
time 20 years.”

Australia 20 Years Behind?

- **Exhibit #1**

- Our first internet option was...

## Australia 20 Years Behind?

- **Exhibit #1**
  - Our first internet option was...
  - DSL

Australia 20 Years Behind?

- **Exhibit #2**

- My first radiology study resulted in...

Australia 20 Years Behind?

- **Exhibit #2**

- My first radiology study resulted in...

- Physical films!

# Australia's Health System: a 10000 m view

## Government Roles

### **State Responsibilities**

- Public Health
- Hospital/Specialist Care

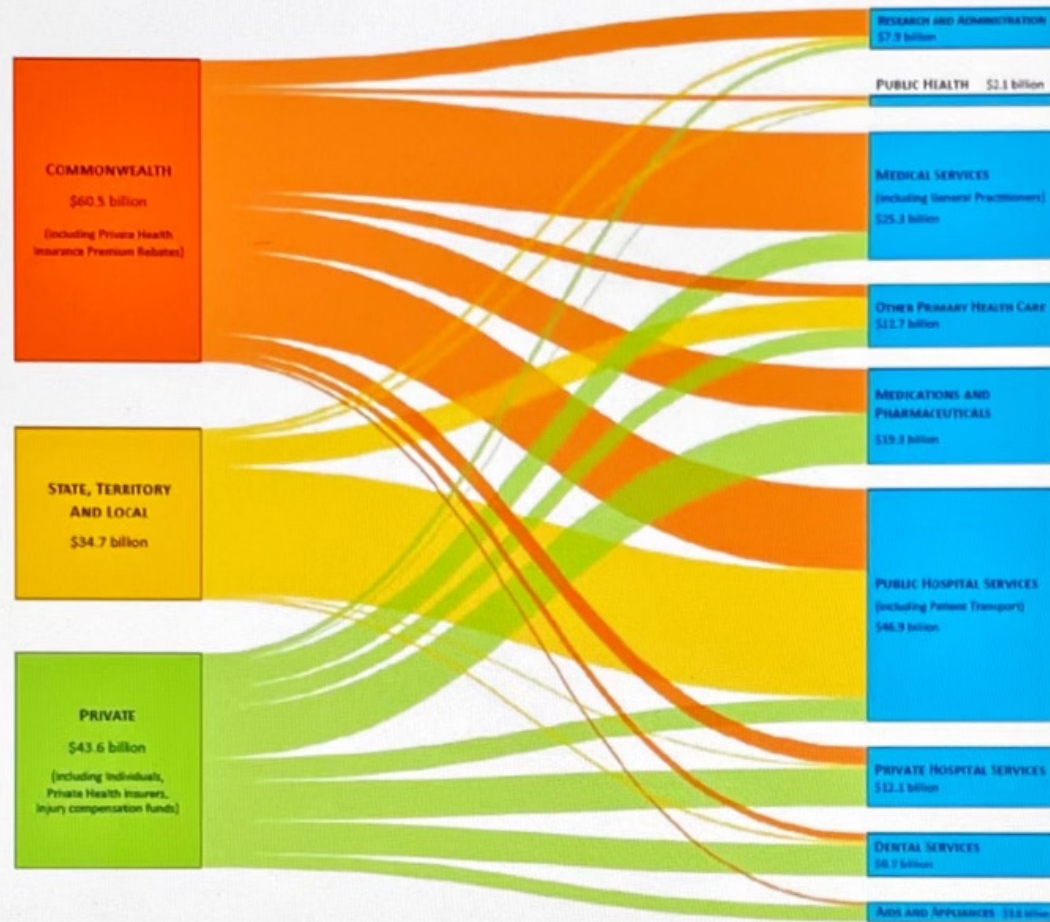
### **Federal Responsibilities**

- General Practice
- Long-term Care

**All taxation is Federal!**



Figure 1: Funding flows in Australia's health care arrangements 2012-13<sup>97</sup>



Source: Department of Health

# Australia Has Two Health Systems

## **Public System**

- GP
  - “Bulk Billing”
  - “Non Bulk Billing”
  - Fee for service payment system
- Specialist/Hospital Care
  - Nephrology ~4 month wait
  - Dermatology ~4 month wait
  - Sleep medicine ~13 month wait

## **Private System**

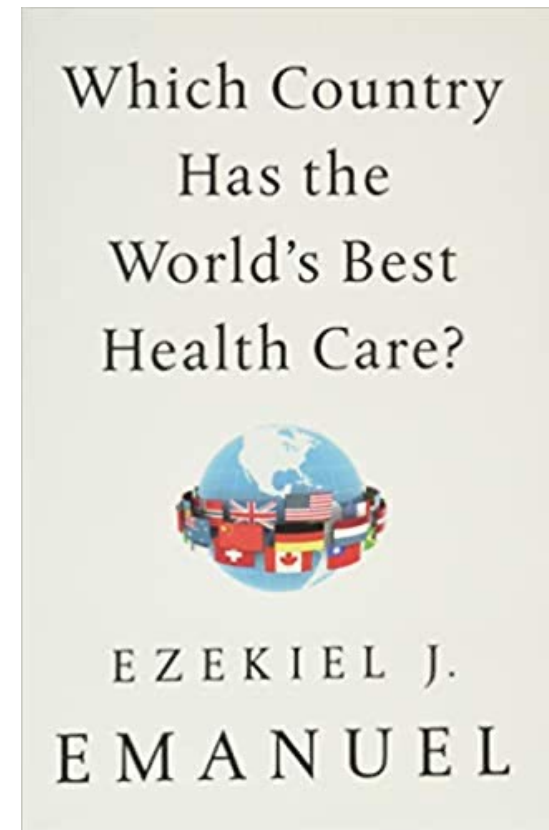
- Penalties for high income earners not having private insurance
- Competes with (intended to reduce pressure on) public system
- Electives vs Serious medicine



# What is Australia's (Victoria's) Informatics Eco-system

- Long record of EMRs and research registries in general practice
  - **National**
- A largely failed attempt to create a centralized Patient medical Record (My Health Record)
  - **National**
- A well-intentioned but underfunded attempt to implement EMRs in state hospitals
  - **State**
  - \$270M (AUD) for the entire state (17 hospitals)
  - No adoption or
  - Skeletal adoption

What are some challenges for Australia's health system?



- “**First, there is poor coordination across the continuum of care** arising from how care is financed....This creates significant barriers to care coordination and drives cost growth. No single payer is responsible for the entire continuum of care.”
- “The 2nd challenge is linked to the care coordination: **Australia lacks robust health systems research to drive quality improvement or cost cutting.** The quality of care in private hospitals is essentially a black box. Private payers have no economic incentive to conduct health systems research.”
- “Third, **waiting lists...are quite long.** Physicians—especially surgeons—have no incentive to reduce them.”

- “Fourth, there are **biases in favor of wealthy Australians**. Although the Medicare system is universal and progressively financed, wealthier Australians have built-in financial advantages.”
- “Finally, the **urban-rural maldistribution of resources is especially acute.**”

# Top three impressions



1. It's good to see that high complexity care happens at public hospitals. That gives me the peace of mind that if you get really sick, you will be taken care of and won't depend on your ability to pay. **For most mundane stuff it's a matter of figuring out how things work.**

2. **I am shocked that patients cannot access their data, any of it**, not lab results, images, nothing. Even when they have the IT infrastructure for it with MyHealthRecord.

3. GPs are small businesses and it will be impossible to change how they work without changing the funding system. But they seem to be convinced that it's about the amount of funding and never discuss the mechanisms or getting rid of fee for service.



# My Top Three Impressions

- Caveat: My experience of the US health system has been through integrated academic health systems (UPMC, UCSD, Utah)
- Australia “feels” more expensive
- A heavier decision burden was placed on me, while at the same time it was harder to get data
- Healthcare communication was a failure to communicate





Data

Understanding

Information

Knowledge

# Calendar for March 2021 (Australia)

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](#)

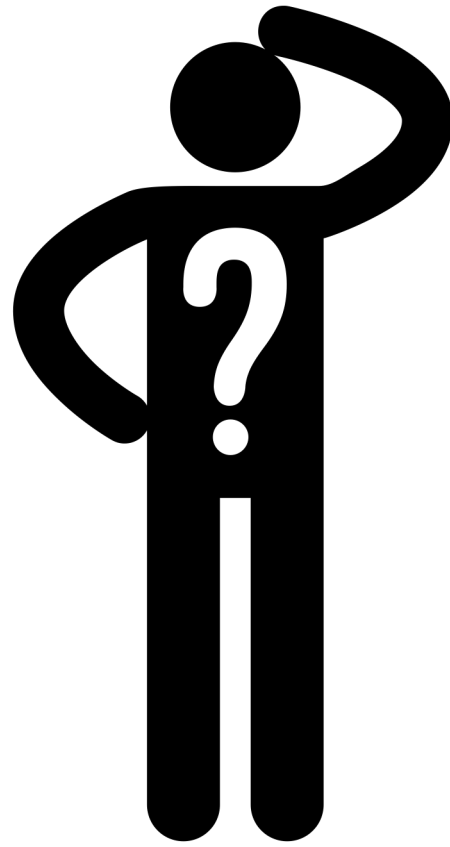
“Why are you here?”

“I’m a  
childhood  
cancer  
survivor!”



Created by Luis Prado  
from the Noun Project

**“Prove it!”**



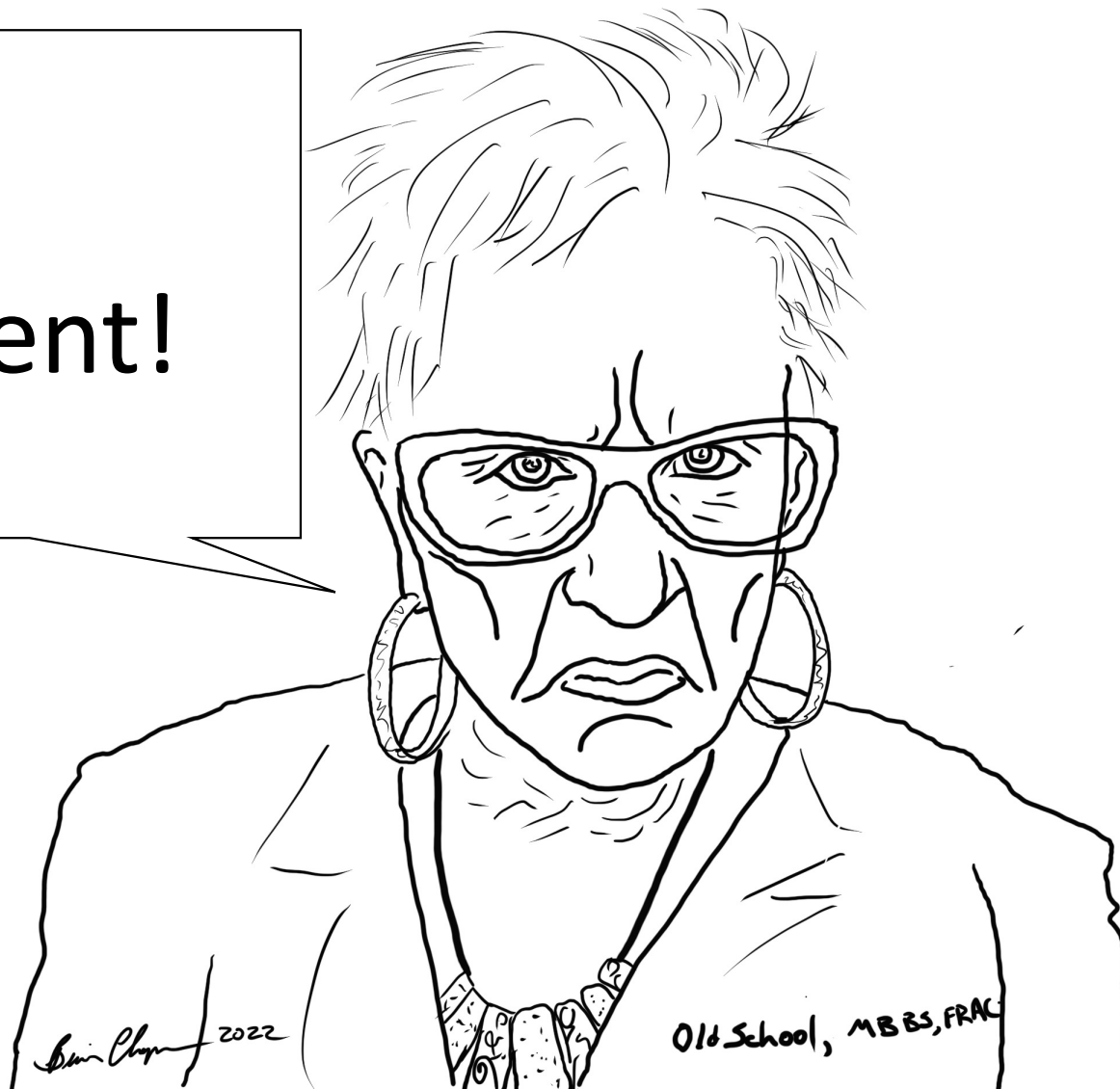
**Created by Andrew Doane  
from the Noun Project**

"I can show you my scars."





Not  
sufficient!




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

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

Nearly impossible in Australia.



 <p><b>Holy Cross Hospital</b> <b>LABORATORY</b> 1045 EAST 1st SOUTH SALT LAKE CITY, UTAH 84102</p> <p><b>PATHOLOGY REPORT</b></p> <p><u>PATHOLOGISTS</u> CYRIL FULLMER, M.D.      STANLEY L. GIBBON, M.D. BRUCE LLOYD, M.D.      SAROJ N. KULKARNI, M.D. R. MYRON LAUB, M.D.</p>	Chapman, Brian E.	76-2536
	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

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 located tumor measuring 6 cm. in diameter. There is a maximum of 12 mm. of renal

# Am I an exception?

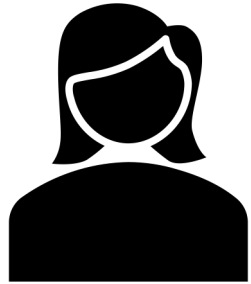


Well, you are an  
informaticist. Of  
course you have  
your data.



Exceptionally cute, maybe!

# Am I an exception?



In 1976 I had no legal right outside of litigation to access my medical record

Well, you are an informaticist. Of course you have your data.

It's different in the USA.



*Exceptionally cute, maybe!*



“You are sooooo  
American!”

What does that mean?



**Created by Andrew Doane  
from the Noun Project**





“I just meant your accent...But it also seems Americans think they have more rights than we Australians think we have.”

# 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.

# Consider this 1977 Editorial

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

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[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

# Two Types of Epistemic Injustices

- Testimonial injustices:
  - patient is prevented from contributing their knowledge and experience to the healthcare processes
- Hermeneutical injustices:
  - patient is prevented from understanding their disease and treatment.
- There is a correlative epistemic injury to clinicians who must practice without the optimal epistemic contribution of patients.

# Hermeneutical Injustice

- I think this captures me

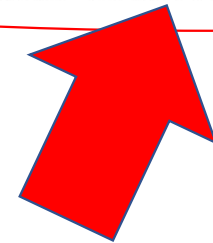
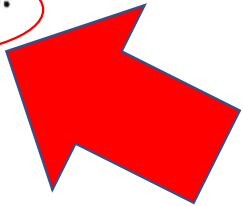
**Morbidly  
curious patient**



# My Poster Patient for Hermeneutical Injustice

I am a 44-year survivor of a Wilms' tumor. I was diagnosed when I was two and treated with surgery, chemotherapy, and radiation. Since I was so young, I have no memories of these events, and what I know is essentially limited to what my parents have told me. Unfortunately, my parents have now both passed away. When I went to get the records from the hospital where I was treated, I was told that they no longer exist. Subsequent to my treatment I have developed multiple health problems, some of which I understand to be related to my childhood treatments.

I told her this



# 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.** We were never there for 'rounds' so we didn't get to see the Dr assess the twins daily. Rounds happened early in the morning. I would spend 11am to 11pm at the nicu. Rudi joined me when he would get off work. I would have preferred daily Dr notes. 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.”

# Knowledge is Power!

Those who control what we know, or think we know, exert an influence on our lives that is **often as dangerous as it is imperceptible.**

Lani Watson, Ph.D.  
*Epistemic Rights*





What is a patient anyway?

1977

Someone who would misunderstand  
their medical record



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

# Misunderstanding

I didn't need access to my medical records to misunderstand aspects of my medical care!



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

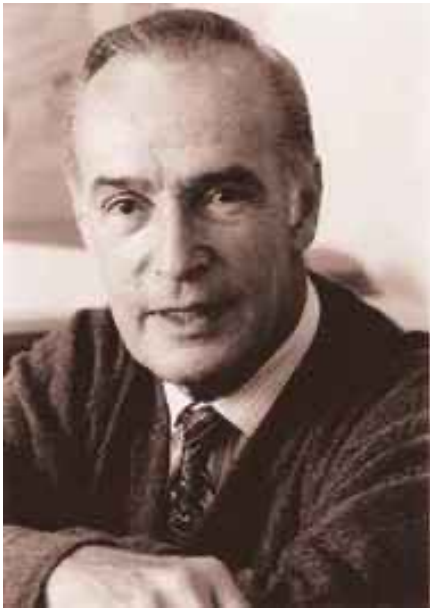
“Survey research from the USA, shows that, compared with their counterparts, patients who are older, in poorer health, persons with fewer years of formal education, minorities, and those whose first language is not English, are significantly more likely to report that **open notes boost their recall, understanding, and engagement in their care plan.**”

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

“In surveys from Sweden and the USA, around 98% of surveyed patients with experience of the practice believed open notes are a good idea or reported they wanted access to continue. For example, in a large scale survey research of over 22000 patients in the USA, Walker *et al* found that **only a small minority—3% and 5%—of patients reported being very confused or more anxious by what they read.**”

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

“Analysing survey results, Salmi *et al* found that 98% (n=3366) of patients with a cancer diagnosis who read their visit notes agreed open notes was a ‘good idea’ compared with 70% (n=70) of oncology clinicians who had opened their notes. More starkly, **only 4% (n=131) of oncology patients reported finding their notes confusing**, compared with 36% (n=44) of oncology clinicians who believed their patients would find the notes ‘more confusing than helpful’ and 27% (n=33) who did not know if patients found notes confusing.”



Morton Hunt, NY Times

My wife described her symptoms to one specialist in medically precise terms, to which he smarmily replied: 'Let's not use fancy words. Why don't you just call things by their everyday names?'



My wife described her symptoms to  
one specialist in medically precise

**Testimonial injustice**

names?



Morton Hunt, NY Times



What is a patient anyway?

1989

Someone who uses “everyday language” for  
medical problems

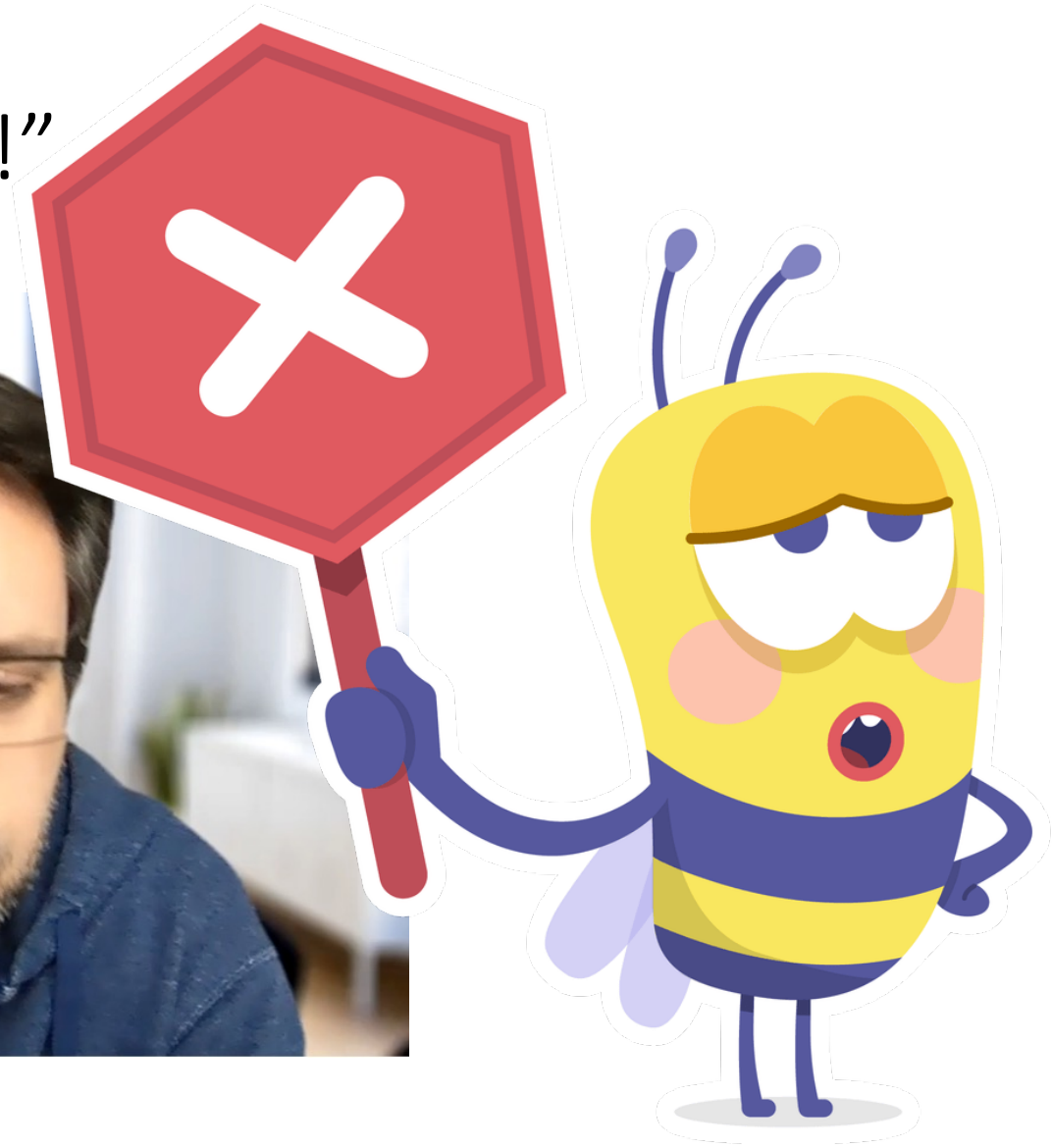
# Example

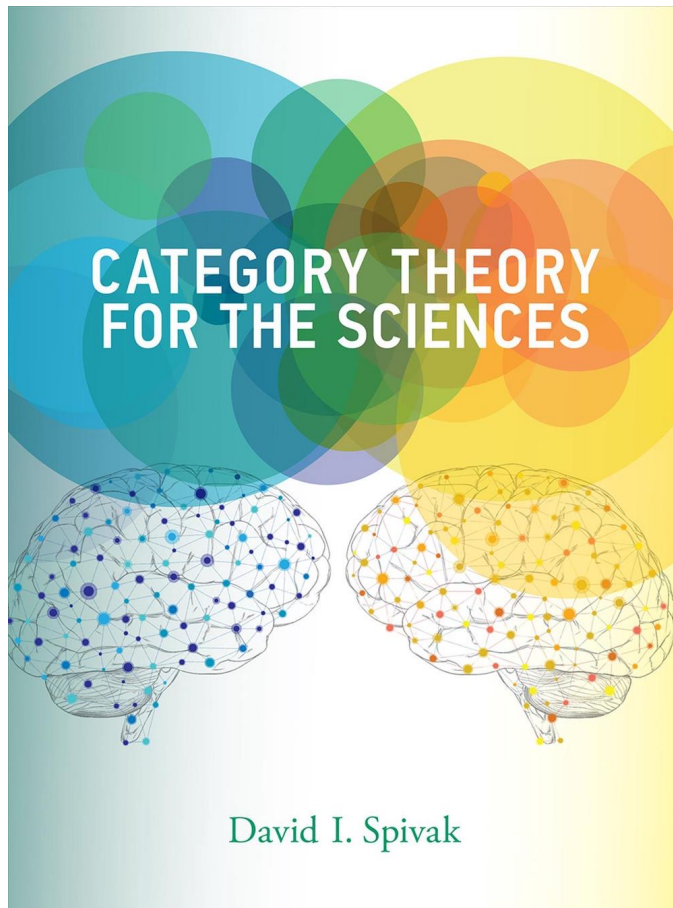
2020 Daniel develops severe pain and goes to a nearby academic medical center.



“I have a renal colic.”

“Don’t use fancy words!”



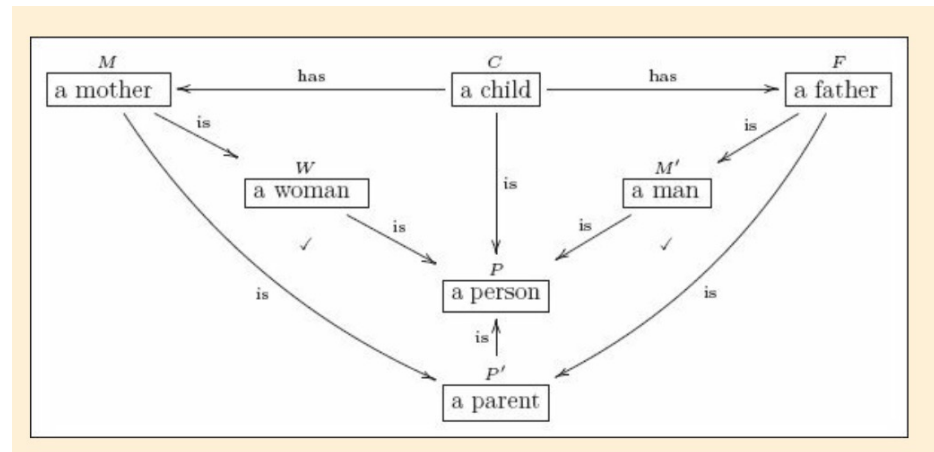
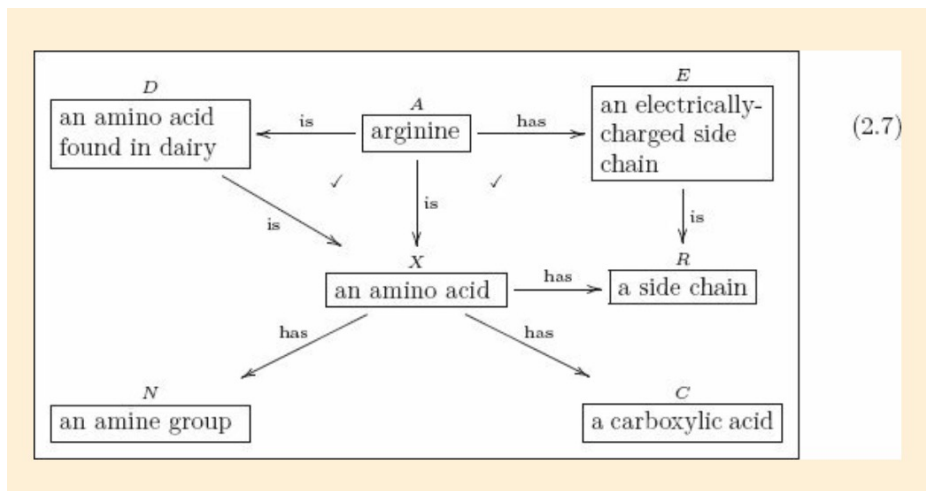


Defining an ontology log (OLOG) for a patient  
“An aspect of a thing  $x$  is a way of viewing it”

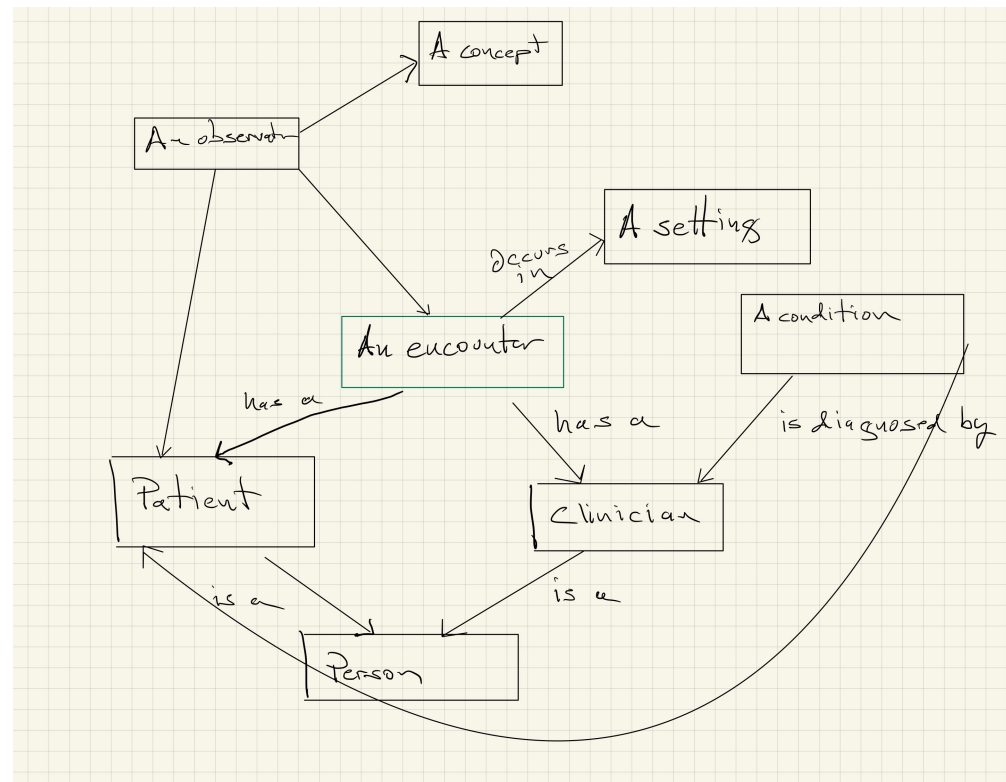
- An aspect that every  $x$  [patient] has
- Don't want to lose patients!

**Brian's Definition:** A patient is an individual that has entered into a transactional relationship with another individual or group of individuals who is (are) legally authorized, with consent of the individual, to take clinical actions (e.g. prescribe, offer medical advice, take therapeutic actions) on the patient's behalf.

# Example Ologs



# What is a patient anyway?



# Eliminate the knowledge wars!



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

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

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

*April 7, 2016*



Eliminate the knowledge wars!



**Testimonial injustice**

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

April 7, 2016

# Let's Jump Ahead in time to 2019



[Deseret News](#)



[Visit Victoria](#)



Menu



### Past Visits

1 Year Ago

**AUG** Office Visit  
**12** Bryan Vincent, OD  
 Moran Eye Center Ophthalmology  
 2019

[View notes](#)

[View After Visit Summary\\*](#)

**JUL** Nurse Visit  
**5** Huntsman Cancer Clinic 2C  
 2019

[View After Visit Summary\\*](#)

**JUL** Office Visit  
**5** Douglas Grossman, MD  
 Huntsman Cancer Clinic 2C Dermatology  
 2019

[View notes](#)

[View After Visit Summary\\*](#)

**MAY** Dental Visit  
**15** Mandy Biesinger, RDH  
 Faculty Practice Dental  
 2019

[View notes](#)

[View After Visit Summary\\*](#)

**APR** Office Visit  
**16** Douglas Grossman, MD  
 Huntsman Cancer Clinic 2C Dermatology  
 2019

[View notes](#)

[View After Visit Summary\\*](#)

**APR** Hospital Outpatient Visit  
**10** Michael Sossenheimer, MD  
 University Hospital Endoscopy  
 2019

[View After Visit Summary\\*](#)

**APR** Office Visit  
**2** Patrick Greis, MD  
 University Orthopaedic Clinic A  
 2019

[View notes](#)

[View After Visit Summary\\*](#)

**MAR** Office Visit  
**18** Barry M Stults, MD  
 Madsen Internal Medicine  
 2019

[View notes](#)

[View After Visit Summary\\*](#)

**MAR** Office Visit  
**7** Jacqueline Waring, PT  
 University Orthopaedic Sports Medicine  
 2019

[View notes](#)

**FEB** Nurse Visit  
**15** Huntsman Cancer Clinic 2C  
 2019

**Test Results**

11 of 14 healthy posts your test results in MyChart within hours of being finalized. This means you may be seeing your results before your provider has reviewed them.

Please note: These test results could include sensitive information. Examples include results related to a cancer diagnosis, genetic testing or the gender of your baby in a fetal ultrasound. If you are not comfortable using this information before you have discussed your results with your provider, please wait to view them.

Test	Ordered By	Date
Hepatic Function Panel	Douglas Grossman, MD	JUL 5, 2019
Surgical Pathology Tissue	Michael Sossenheimer, MD	Apr 10, 2019
Prostate Specific Antigen, Total	Barry M Stults, MD	Mar 18, 2019
Expanded Hepatic Function Panel	Douglas Grossman, MD	FEB 15, 2019
MR KNEE W/ CONT CT	Amy P Fawcett, MD	Jan 25, 2019
MR KNEE 3 VIEWS BILATERAL	Barry M Stults, MD	Jan 15, 2019
Lipid Panel	Barry M Stults, MD	Jan 11, 2019
Sedimentation Rate, Westergren (ESR)	Barry M Stults, MD	Jan 11, 2019
Basic Metabolic Panel	Douglas Grossman, MD	Dec 16, 2018
Expanded Hepatic Function Panel	Douglas Grossman, MD	Dec 14, 2018
CBC with Platelet Count	Barry M Stults, MD	Sep 25, 2018
Comprehensive Metabolic Panel	Barry M Stults, MD	Sep 21, 2018
Estimated Glomerular Filtration Rate	Barry M Stults, MD	Sep 18, 2018
CBC with Platelet Count	Barry M Stults, MD	Aug 15, 2018
Lipid Panel	Barry M Stults, MD	Aug 11, 2018
Prostate Specific Antigen, Total	Barry M Stults, MD	Aug 11, 2018
Basic Metabolic Panel	Barry M Stults, MD	Aug 11, 2018
Hepatitis B Virus Surface Antibody	Barry M Stults, MD	Aug 11, 2018
Estimated Glomerular Filtration Rate	Barry M Stults, MD	Aug 11, 2018
LDL Cholesterol, Direct	Barry M Stults, MD	Aug 11, 2018
Expanded ECG Lead ECG	Barry M Stults, MD	Nov 10, 2017
MR SHOULDER 2 OR MORE VIEWS LT	Barry M Stults, MD	Nov 10, 2017
Basic Metabolic Panel	Barry M Stults, MD	Nov 10, 2017
Lipid Panel	Barry M Stults, MD	Nov 10, 2017
Estimated Glomerular Filtration Rate	Barry M Stults, MD	Nov 10, 2017
Hepatic Function Panel	Barry M Stults, MD	Aug 7, 2017
Hepatitis B Virus Surface Antibody	Barry M Stults, MD	JUL 20, 2017
Hepatitis A Virus Antibody, IgM	Barry M Stults, MD	JUL 20, 2017
Comprehensive Metabolic Panel	Barry M Stults, MD	JUL 18, 2017
Estimated Glomerular Filtration Rate	Barry M Stults, MD	JUL 18, 2017
DERMATOLOGY/IMMUNOGEN TESTING	John R Myrneson, MD	Dec 20, 2016
Basic Metabolic Panel	Barry M Stults, MD	Dec 12, 2016
Lipid Panel	Barry M Stults, MD	Dec 12, 2016
DERMATOLOGY/IMMUNOGEN TESTING	Douglas Grossman, MD	Dec 2, 2016
Basic Metabolic Panel	Barry M Stults, MD	Sep 13, 2016
Lipid Panel	Barry M Stults, MD	Sep 13, 2016
Estimated Glomerular Filtration Rate	Barry M Stults, MD	Sep 13, 2016
Uric Acid, Spot	Barry M Stults, MD	Apr 27, 2015
Lipid Panel	Barry M Stults, MD	Apr 27, 2015
Comprehensive Metabolic Panel	Barry M Stults, MD	Apr 27, 2015
C-Reactive Protein, High Sensitivity	Barry M Stults, MD	Apr 27, 2015
Estimated Glomerular Filtration Rate	Barry M Stults, MD	Apr 27, 2015
US NECK OR THYROID	Jason P Hunt, MD	Jun 4, 2014
X-ray of lower and sacral spine, 2 or 3 views	Joseph C Cantrell, DO	Nov 11, 2013
X-ray of middle spine, 3 views	Joseph C Cantrell, DO	Nov 11, 2013
X-ray of shoulder, minimum of 2 views	Amy P Fawcett, MD	Nov 11, 2013
X-ray of knee, 3 views	Amy P Fawcett, MD	Nov 11, 2013
Albumin-Creatinine Ratio, Urine	Barry M Stults, MD	Oct 29, 2013
URINALYSIS WITH REFLEX TO CULTURE	Barry M Stults, MD	Oct 29, 2013
Lipid Panel	Barry M Stults, MD	Oct 29, 2013
ULTRASON EX VENA THROMBOSIS QUAD	M Jason Perrett, MD	Oct 8, 2013
Chest X-ray	M Jason Perrett, MD	Oct 8, 2013
Estimated Glomerular Filtration Rate	M Jason Perrett, MD	Oct 8, 2013
Triglycerin I	M Jason Perrett, MD	Oct 8, 2013
Sedimentation Rate, Westergren (ESR)	M Jason Perrett, MD	Oct 8, 2013
CBC with Platelet Count	M Jason Perrett, MD	Oct 8, 2013
Comprehensive Metabolic Panel	M Jason Perrett, MD	Oct 8, 2013

There are no more test results available.

[Back to the home page](#)



- Menu
- Appointments/Admissions
- Messages
- Test Results
- Schedule an Appointment

### Visit Records

Select the visits you'd like to view, download, or send. You can select a single visit or multiple visits using the options below. Your Lucy Summary is also available.

- Single visit
  - Date range
  - All visits
  - Lucy summary
- Office Visit with Bryan Vincent, OD** Monday August 12, 2019  
Moran Eye Center Ophthalmology
  - Nurse Visit with Hc** Friday July 05, 2019  
Huntsman Cancer Clinic 2C
  - Office Visit with Douglas Grossman, MD** Friday July 05, 2019  
Huntsman Cancer Clinic 2C Dermatology
  - Dental Visit with Mandy Biesinger, RDH** Wednesday May 15, 2019  
Faculty Practice Dental
  - Office Visit with Douglas Grossman, MD** Tuesday April 16, 2019  
Huntsman Cancer Clinic 2C Dermatology
  - Hospital Outpatient Visit with Michael Sossenheimer, MD** Wednesday April 10, 2019  
University Hospital Endoscopy
  - Office Visit with Patrick Greis, MD** Tuesday April 02, 2019  
University Orthopaedic Clinic A
  - Office Visit with Barry M Stults, MD** Monday March 18, 2019  
Madsen Internal Medicine
  - Office Visit with Jacqueline Waring, PT** Thursday March 07, 2019  
University Orthopaedic Sports Medicine
  - Nurse Visit with Hc** Friday February 15, 2019  
Huntsman Cancer Clinic 2C

# Patients Love Communicating via Portals!



**Jacqueline**

04/9/2019

Colon

Thank you for scheduling your procedure with University of Utah Health Care! Your appointment is scheduled ...



checking in

PT

04/3/2019

Hi Brian, I've been thinking about you and wondering how you're doing. I see that you had an appointment w...



**Stephanie**

03/26/2019

Unable to Contact

March 25, 2019 Dear Brian, Our records indicate that Dr. Stults has referred you to see Orthopaedics for addi



Wow!

, MD

03/9/2019

Brian, Will see you soon. Barry

## Event Summaries

Information about healthcare events or consultations.

### Filter Event Summaries

Display documents from

All dates

### Information on Event Summaries

No information is available.



## Diagnostic Imaging Reports

Such as scans and x-rays.

### Diagnostic Imaging Reports

Date To

Day (DD)

28

Month (MM)

01

Year (YYYY)

2015

Month (MM)

01

Year (YYYY)

2022

Apply Filter

Apply Filter

[Expand for more filtering options](#)

### Information on Pathology Reports

Specimen Collected Date	Pathology Test Name	Pathology Organisation	Requester	Status	Action
17-Sep-2021	PWL HISTOPATHOLOGY (Surgical Pathology)	Dorevitch Pathology	DR RAINBOW FUNG	Final ID: 21-34638883-PWH-0	<a href="#">Manage Access</a>
28-Jun-2021	FULL BLOOD EXAMINATION (Hematology)	Dorevitch Pathology	DR ATIYA KHALID	Final ID: 21-31790417-FBE-0	<a href="#">Manage Access</a>
28-Jun-2021	GENERAL BIOCHEMISTRY (Chemistry)	Dorevitch Pathology	DR ATIYA KHALID	Final ID: 21-31790417-MBI-0	<a href="#">Manage Access</a>
28-Jun-2021	HBA1C (GLYCATED HB) (Chemistry)	Dorevitch Pathology	DR ATIYA KHALID	Final ID: 21-31790417-GHB-0	<a href="#">Manage Access</a>
28-Jun-2021	LIPID STUDIES (Chemistry)	Dorevitch Pathology	DR ATIYA KHALID	Final ID: 21-31790417-LIP-0	<a href="#">Manage Access</a>





The NEW ENGLAND  
JOURNAL of MEDICINE

# 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 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.





**Eric Topol** ✓  
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It's your body  
You paid for it

It is worth more than any other type of data

It's being widely sold, stolen and hacked. And you don't know it.

It's full of mistakes, that keep getting copied and pasted, that you can't edit

You are/will be generating more of it, but it's homeless

Your medical privacy is precious

The only way it can be made secure is to be decentralized

It is legally owned by doctors and hospitals

Hospitals won't or can't share your data ("information blocking")

Your doctor (>65%) won't give you a copy of your office notes

You are far more apt to share your data than your doctor

You'd like to share it for medical research, but you can't get it

You have seen many providers in your life; no health system/insurer has all your data

Essentially no one (in the US) has all their medical data from birth throughout their life

Your EHR was designed to maximize billing, not to help your health

You are more engaged and have better outcomes when you have your data

Doctors who have given full access to their patients' data make this their routine

It requires comprehensive, continuous, seamless updating

Access or "control" of your data is not adequate

~10% of medical scans are unnecessarily duplicated d/t inaccessibility

You can handle the truth

You need to own your data; it should be a civil right

It could save your life

<https://twitter.com/erictopol/status/917038007139438592>

# Transactional?



The NEW ENGLAND  
JOURNAL of MEDICINE

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

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

Human Rights without Laws  
imposing Duties (Penalties)  
is just “Talk about Rights”

---

# Progress

- Expanding recognition that patients are humans and thus have human rights
  - Epistemic rights: rights to data, information, knowledge, and understanding
- Digital technologies eliminated many of the logistic barriers
- Three Federal laws
  - Health Insurance Portability and Accountability Act of 1996 (HIPAA)
  - Health Information Technology for Economic and Clinical Health Act of 2009 (HITECH)
  - 21st Century CURES Act 2016

# Progress

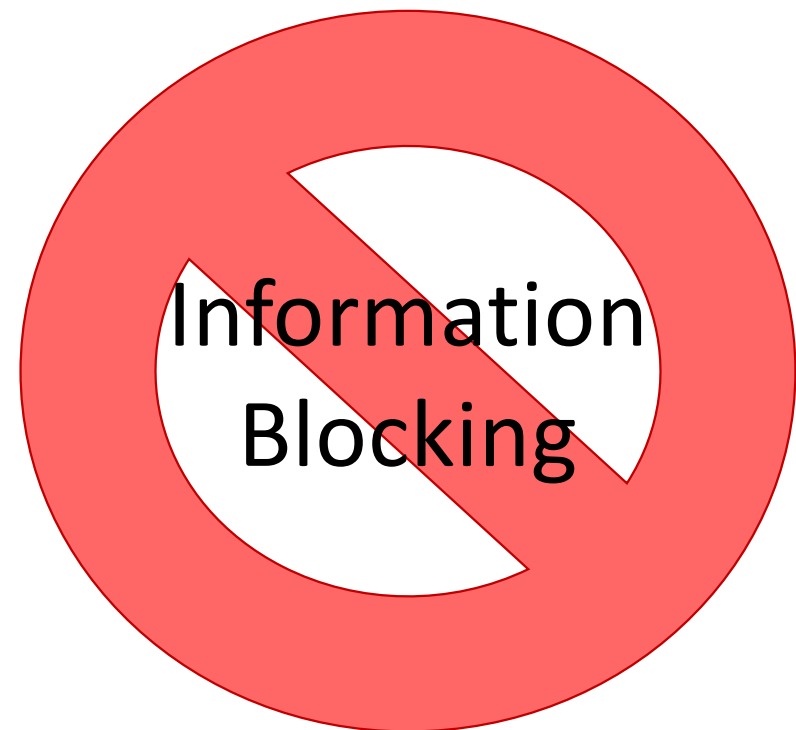
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  - Health Information Technology for Economic and Clinical Health Act of 2009 (HITECH)
  - 21st Century CURES Act 2016

Knowledge is power!

# 21<sup>st</sup> Century CURES Act

Patients can electronically access all of their electronic health information, structured and/or unstructured, at no cost.

And at the same time as the clinician



# Extension of a Larger Movement

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.

What is the state of rights  
and laws in Australia?

---



# It is complex

“The legislative framework now protecting both the privacy of patient information and simultaneously the use of, and access to, that information by healthcare consumers and others is increasingly **becoming more complex.**” ([Essentials of Law for Health Professionals](#))

**Implication: I’m probably going to make a mess of this.**

# What is the Law in 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)
- “There is no common law right of patients in Australia to access their medical records as the record is ‘owned’ by the doctor/healthcare institution.” (Megan Prictor)
- “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*)
- AMA argued that medical records are copyrighted
- **Federal and state laws have been passed to provide means for patients to access their medical records**

What is a patient anyway?

“A biological  
structure  
yielding cash”



*Uwe Reinhardt (2009)*

## **Fiduciary:**

*An individual in whom another has placed the utmost trust and confidence to manage and protect property or money. The relationship wherein one person has an obligation to act for another's benefit. ([The free Legal Dictionary](#))*

- “If doctors were under a fiduciary duty to their patients [as in Canada (USA?)], patients might be entitled to access to all the information in their medical records but there is no general fiduciary duty in Australia.”

What is a doctor anyway?



# Recall Emanuel's Observation about Australia

**“[T]here is poor coordination across the continuum of care.”**

- Elevates the importance of patient access to data

# Recall Capurro's Observation about Australia

**“GPs are small businesses [i.e. a *LOT* of stand-alone clinics]and it will be impossible to change how they work without changing the funding system [not likely].”**

- Elevates the importance of patient access to data

# “Pushing Against Ignorance”

“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.”





# No Rights without Corresponding Duties

“If a patient has a claim-right to know X, then someone along the line must be assigned the correlative epistemic duty to not merely provide them with access to their medical data, but to ensure that they come to know.... In fact, it seems likely that there is a **right to understand X** (not merely to know X), in many important cases....”



### Patient Rights

- A patient needs the right to **access** data/information
- A patient needs the right to **understand** their data
- A patient needs the right to **use** their data

### Informatics Duties

- Patient portals/Patient Controlled Medical Records
- Sharing knowledge with data
- Providing data/knowledge in interoperable, digital manner





David Edmonds, Ph.D.  
Oxford Uehiro Centre for Practical Ethics

“I think it is a great sin to not write in an accessible fashion when you can write in an accessible fashion.”

# Dirty Secret:

Medical language is not always understandable within medicine!

[Anesth Prog](#), 2006 Spring; 53(1): 1–2.  
doi: [10.2344/0003-3006\(2006\)53\[1:TTTTOO\]2.0.CO;2](https://doi.org/10.2344/0003-3006(2006)53[1:TTTTOO]2.0.CO;2)

PMCID: PMC1586860  
PMID: [16722276](https://pubmed.ncbi.nlm.nih.gov/16722276/)

## IT'S TIME TO THROW OUT OLD-FASHIONED LATIN ABBREVIATIONS

[Joel M Weaver](#), DDS, PhD

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An Australian study looking at the use of abbreviations in discharge summaries at the Royal Melbourne Hospital concluded

“The 80 discharge summaries contained 840 different abbreviations used on 6269 occasions. Of all words, 20.1% were abbreviations. Of the 6269 occasions of shorthand, 6.8% were categorised as ‘Understood but inappropriate and/or ambiguous’ or ‘Unknown’ (category 3 or 4), equating to 1.4% of all words, and an average of 5.4 words per discharge summary. ([Overview of shorthand medical glossary \(OMG\) study](#) [↗](#))”



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RECOMMENDATIONS

## List of Error-Prone Abbreviations

February 5, 2021

Institute for Safe Medication Practices  
An ECRI Affiliate

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RECOMMENDATIONS

## List of Confused Drug Names

February 28, 2019

# Language can impact care



## Do Words Matter? Stigmatizing Language and the Transmission of Bias in the Medical Record

*Anna P. Goddu, MSc<sup>1</sup>, Katie J. O'Connor, BA<sup>1</sup>, Sophie Lanzkron, MD, MHS<sup>2</sup>, Mustapha O. Saheed, MD<sup>3</sup>, Somnath Saha, MD, MPH<sup>4,5</sup>, Monica E. Peek, MD, MPH, MSc<sup>6</sup>, Carlton Haywood, Jr., PhD, MA<sup>2</sup>, and Mary Catherine Beach, MD, MPH<sup>1</sup>*

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JAMA  
Network | **Open**<sup>™</sup>

Original Investigation | Ethics

## Physician Use of Stigmatizing Language in Patient Medical Records

Jenny Park; Somnath Saha, MD, MPH; Brant Chee, PhD; Janiece Taylor, RN, PhD; Mary Catherine Beach, MD, MPH

JAMA  
Network | **Open**<sup>™</sup>

Original Investigation | Health Policy

## Examination of Stigmatizing Language in the Electronic Health Record

Gracie Himmelstein, MD; David Bates, MD, MS; Li Zhou, MD, PhD

# Language can impact care



## Do Words Matter? Stigmatizing Language and the Transmission of Bias in the Medical Record

*Anna P. Goddu, MSc<sup>1</sup>, Katie J. O'Connor, BA<sup>1</sup>, Sophie Lanzkron, MD, MHS<sup>2</sup>, Mustapha O. Saheed, MD<sup>3</sup>, Somnath Saha, MD, MPH<sup>4,5</sup>, Monica E. Peek, MD, MPH, MSc<sup>6</sup>, Carlton Haywood, Jr., PhD, MA<sup>2</sup>, and Mary Catherine Beach, MD, MPH<sup>1</sup>*

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“Exposure to the stigmatizing language note was associated with more negative attitudes towards the patient (20.6 stigmatizing vs. 25.6 neutral,  $p < 0.001$ ). Furthermore, reading the stigmatizing language note was associated with less aggressive management of the patient’s pain (5.56 stigmatizing vs. 6.22 neutral,  $p = 0.003$ ).

# Time to Rethink Medical Language

“But **words** plainly force and overrule the understanding, and **throw all into confusion** and lead men away into numberless empty controversies and idle fancies.”

(FRANCIS BACON *NOVUM ORGANUM SCIENTIARUM*)





# Time to Rethink Medical Language



“Even though Whitehead repeatedly acknowledges the limitations of language—describing it as “elliptical,” “incomplete and fragmentary”—he never despairs that the linguistic medium poses insurmountable barriers to what philosophy can investigate (PR, 13; AI, 226). He instead treats **language as a tool capable of recalibration.**”

(Nicholas Gaskill. *The Lure of Whitehead*.  
University of Minnesota Press)

# Time to Rethink Medical Language

- “It is a great sin to not use structured documentation when you can use structured documentation.”
  - Concept-based representations like SNOMED can have consumer synonyms, images, language translations, etc.
- How do you maximize your documentation for the whole team, including the patient who is the “team leader”?
- Why is our English medical language filled with, I claim, unnecessarily esoteric Latin, Greek, German?
- Must begin this in medical school with teaching documentation in a coherent, principled based manner

# Promoting Informed Choice: Transforming Health Care To Dispense Knowledge for Decision Making

Patients need good information to make good choices, but supplying that needed information is not something that physicians and hospitals do well. Among the great ironies of the modern health care system is how poorly it delivers knowledge at a time when society enjoys unprecedented access to information. [Patients] can obtain so many facts with the click of a button yet must struggle to gather well-tailored information about their clinical options or ways to care for their own health. Consumers encounter a system designed to deliver the material commodities of care (such as tests and drugs) but not knowledge.

*Ann Intern Med.* 2005;143:293-300.

# Patients are Clinical Decision Makers

1. The right information:
2. to the right person: including clinicians, patients and their caretakers;
3. in the right format:
4. through the right channel:
5. at the right time in workflow:

- Who should be my GP?
- Should I transfer my mother to a different hospital?
- What medications have I been prescribed?
- What surgeon has lower infection rates?

# The Patient and the Pedestal

*Patients are all important!*



# The Patient and the Pedestal

“Patient-centered care” without patient data/knowledge access is mere marketing

“Patient-led care” without patient data/knowledge access/control is a lie



Calling for a Revolution

# My Revolution

- Not just talking about epistemic rights
- Legal recognition of epistemic rights
- Informatics facilitation of epistemic rights
- Informatics facilitation of patient-led healthcare



IC  
Und  
MAKE  
FHIR  
NOT  
PAPER

IT'S  
MY DATA  
I PAID  
FOR IT

Knowledge  
is  
Power

232  
E  
23

Sam Chen 2022

