

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

A/Prof Brian E. Chapman

University of Melbourne

A little bit about me...

- 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!

...And...

- I have a PhD in Medical Informatics

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](#)

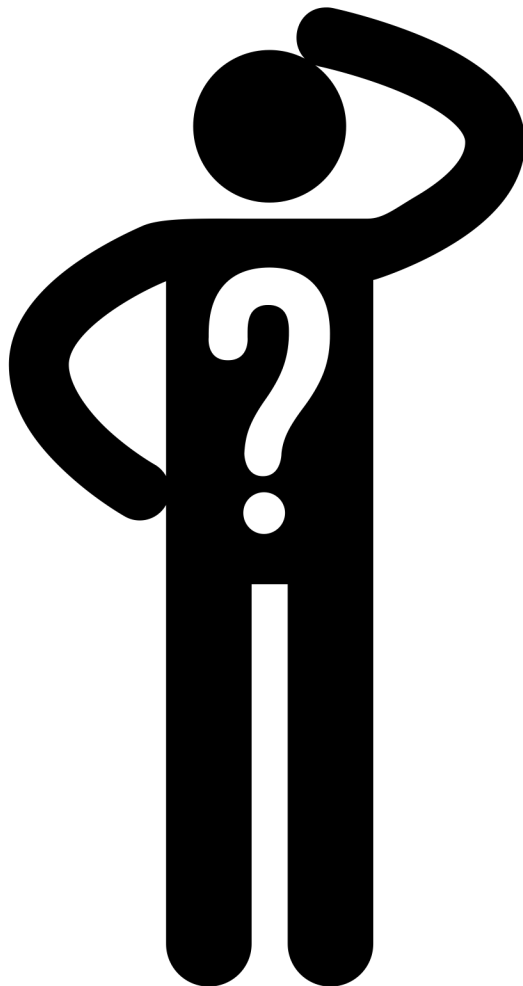
“Why are you here?”

“I’m a childhood
cancer survivor!”



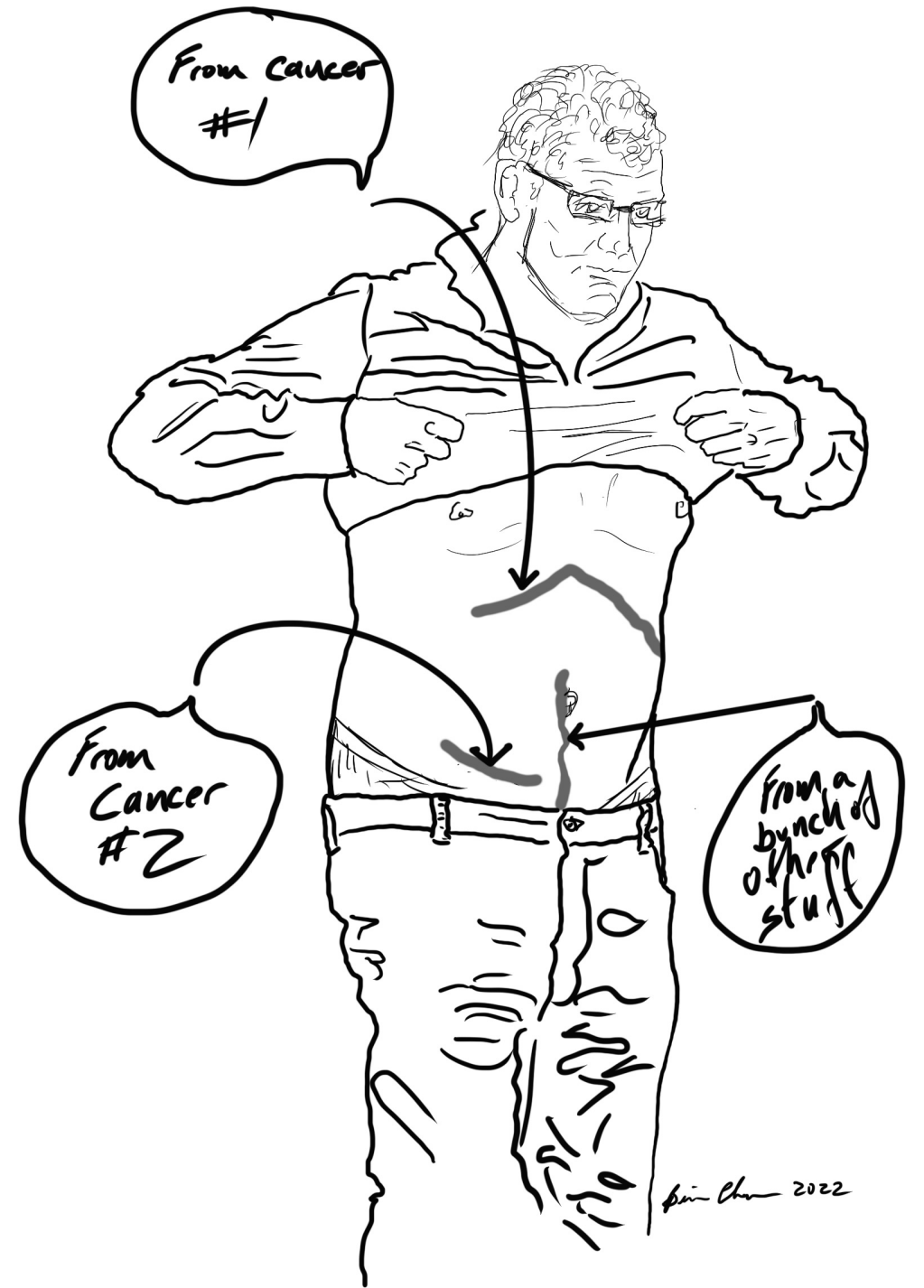
**Created by Luis Prado
from the Noun Project**

“Prove it!”

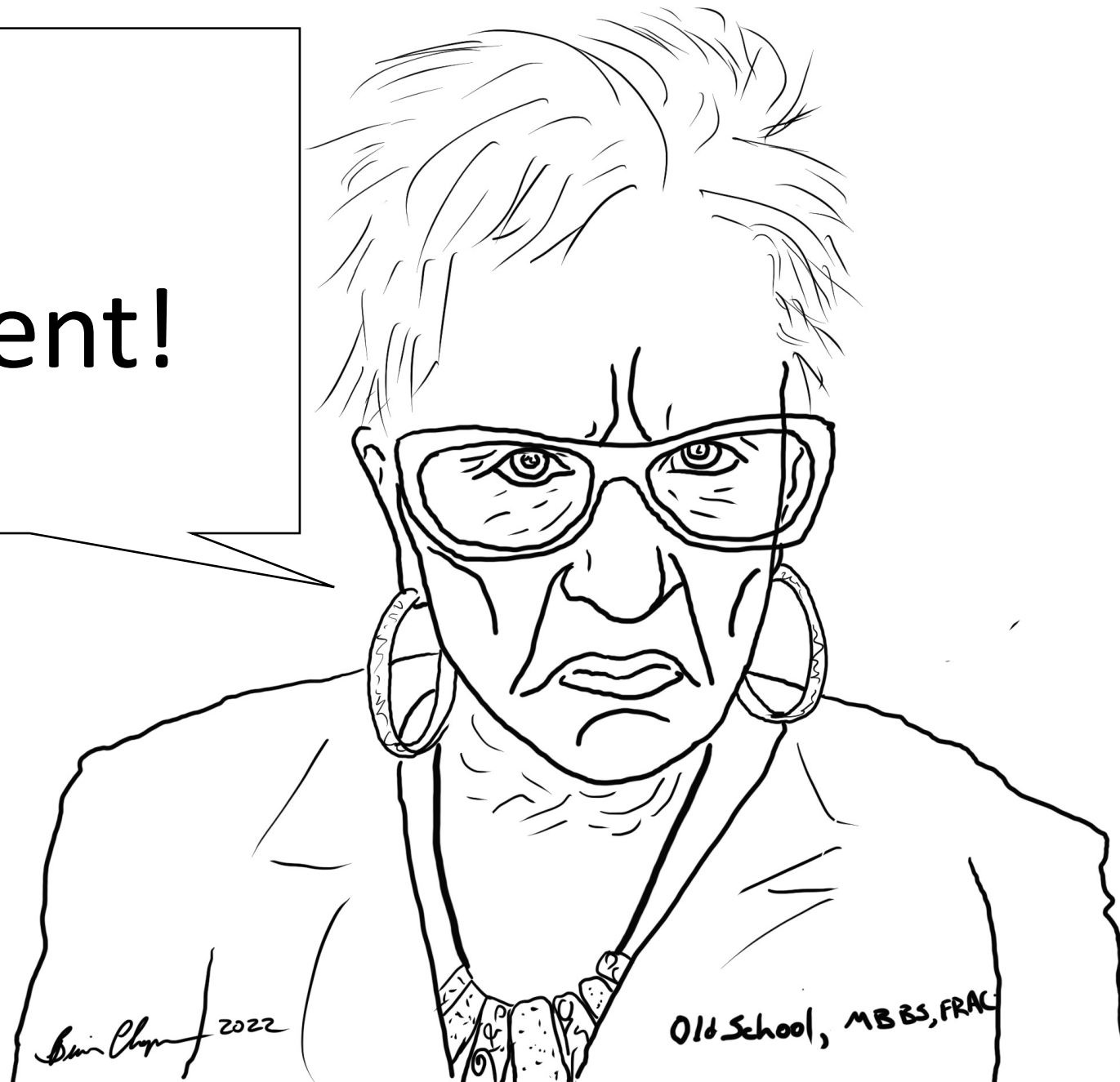


**Created by Andrew Doane
from the Noun Project**

"I can show you my scars."




Not
sufficient!



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



 <p>Holy Cross Hospital LABORATORY 1045 EAST 1st SOUTH SALT LAKE CITY, UTAH 84102</p> <p>PATHOLOGY REPORT</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	CODE 6
PATHOLOGIC DIAGNOSIS Wilms's tumor of right kidney(see micro for margins).		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 necrotic 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!

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...

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

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



Misunderstanding

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





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

What is a patient anyway?

- 2009

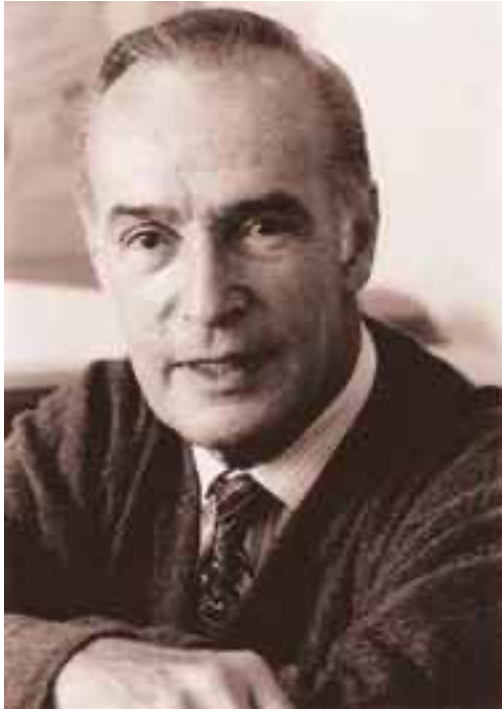
“A biological structure yielding cash” ~ *Uwe Reinhardt*

- 1977

Someone who would misunderstand their medical record

- 1989

Someone who uses “everyday language” for medical problems



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?'

Example

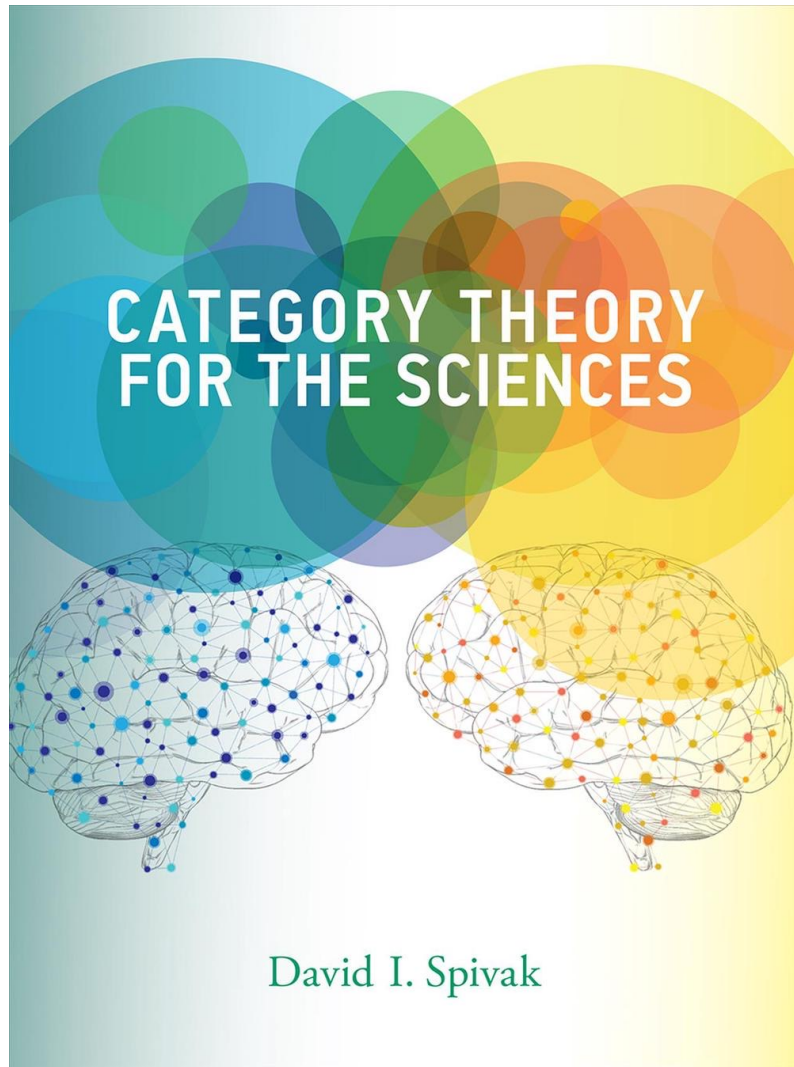
2020 Daniel develops severe pain and goes to a nearby academic medical center.



“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.

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.

Eliminate the knowledge wars!



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



Eric Topol ✓

@EricTopol

physician-scientist, author, editor
drerictopol.com

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>

Let's Jump Ahead in time to 2019



[Deseret News](#)



[Visit Victoria](#)

Past Visits

1 Year Ago

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

View notes

View After Visit Summary®

JUL 5 Nurse Visit Huntsman Cancer Clinic 2C 2019

View After Visit Summary®

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

View notes

View After Visit Summary®

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

View notes

View After Visit Summary®

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

View notes

View After Visit Summary®

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

View After Visit Summary®

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

View notes

View After Visit Summary®

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

View notes

View After Visit Summary®

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

View notes

FEB 15 Nurse Visit Huntsman Cancer Clinic 2C 2019

Test Results table with columns: Test, Ordered By, Date. Includes various lab tests like Hepatic Function Panel, Lipid Panel, etc.

There are no more test results available.

Back to the home page

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

Patients Love Communicating via Portals!



Jacqueline

Colon

04/9/2019

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

Unable to Contact

03/26/2019

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



, MD

Wow!

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

Month (MM)
Year (YYYY)

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

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	Manage Access
28-Jun-2021	FULL BLOOD EXAMINATION (Hematology)	Dorevitch Pathology	DR ATIYA KHALID	Final ID: 21-31790417-FBE-0	Manage Access
28-Jun-2021	GENERAL BIOCHEMISTRY (Chemistry)	Dorevitch Pathology	DR ATIYA KHALID	Final ID: 21-31790417-MBI-0	Manage Access
28-Jun-2021	HBA1C (GLYCATED HB) (Chemistry)	Dorevitch Pathology	DR ATIYA KHALID	Final ID: 21-31790417-GHB-0	Manage Access
28-Jun-2021	LIPID STUDIES (Chemistry)	Dorevitch Pathology	DR ATIYA KHALID	Final ID: 21-31790417-LIP-0	Manage Access



Jan Chen 2022





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.

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

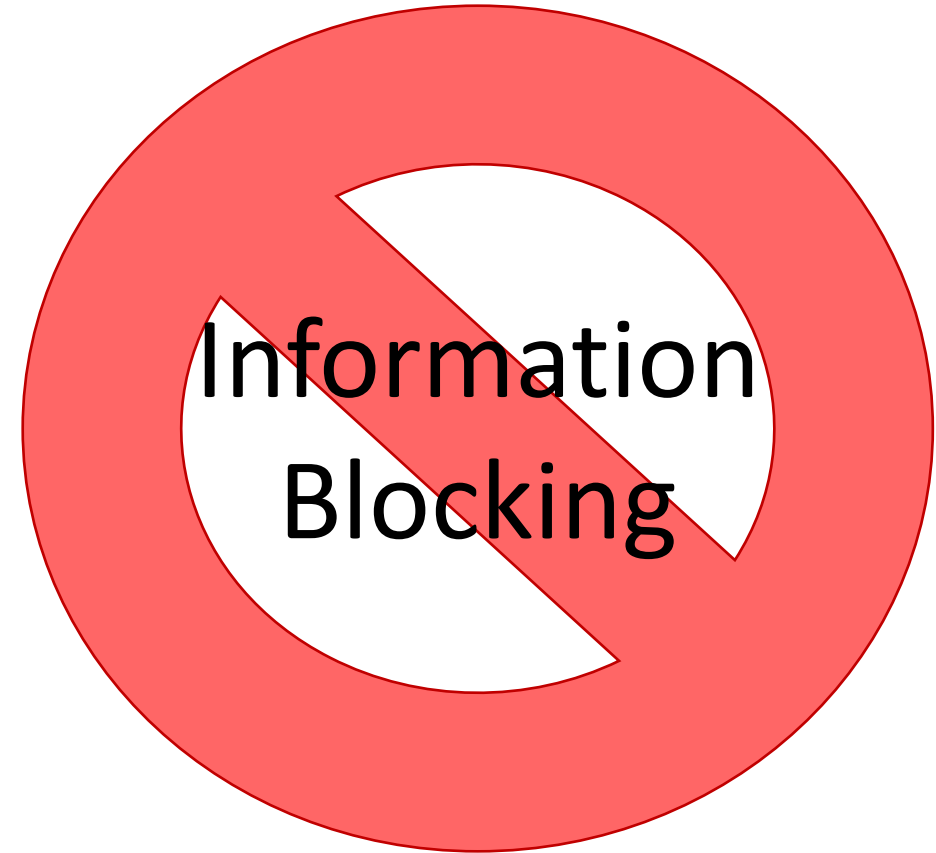
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 - Health Information Technology for Economic and Clinical Health Act of 2009 (HITECH)
 - 21st Century CURES Act 2016

Knowledge is power!

21st 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.

“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....”





Ben Chen 2022



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.

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

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\[1:ITTOO\]2.0.CO;2](https://doi.org/10.2344/0003-3006(2006)53[1:ITTOO]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 ↗](#))”

MEMBERSHIP



MEMBERSHIP

[Consulting and Education](#) [Tools and Resources](#) [Publications and Alerts](#) [Er](#)

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

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.

5 Rights of Decision Support

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



IC
Und

MAKE
FHIR
NOT
PAPER

IT'S
MY DATA
I PAID
FOR IT

Knowledge
is
Power

22
E
2

Sun Chen 2022