

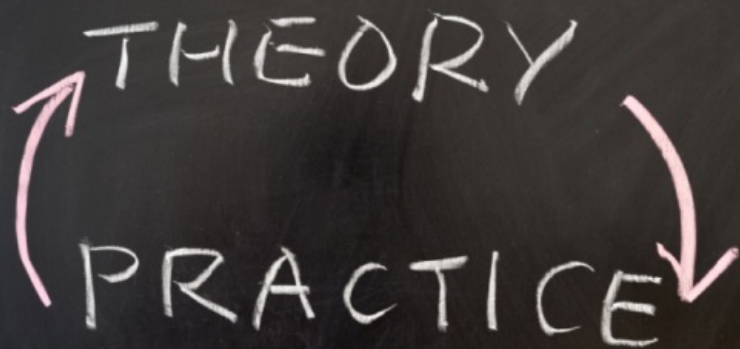


# Data Independence Day: Consumer Demand will Unlock Health Data

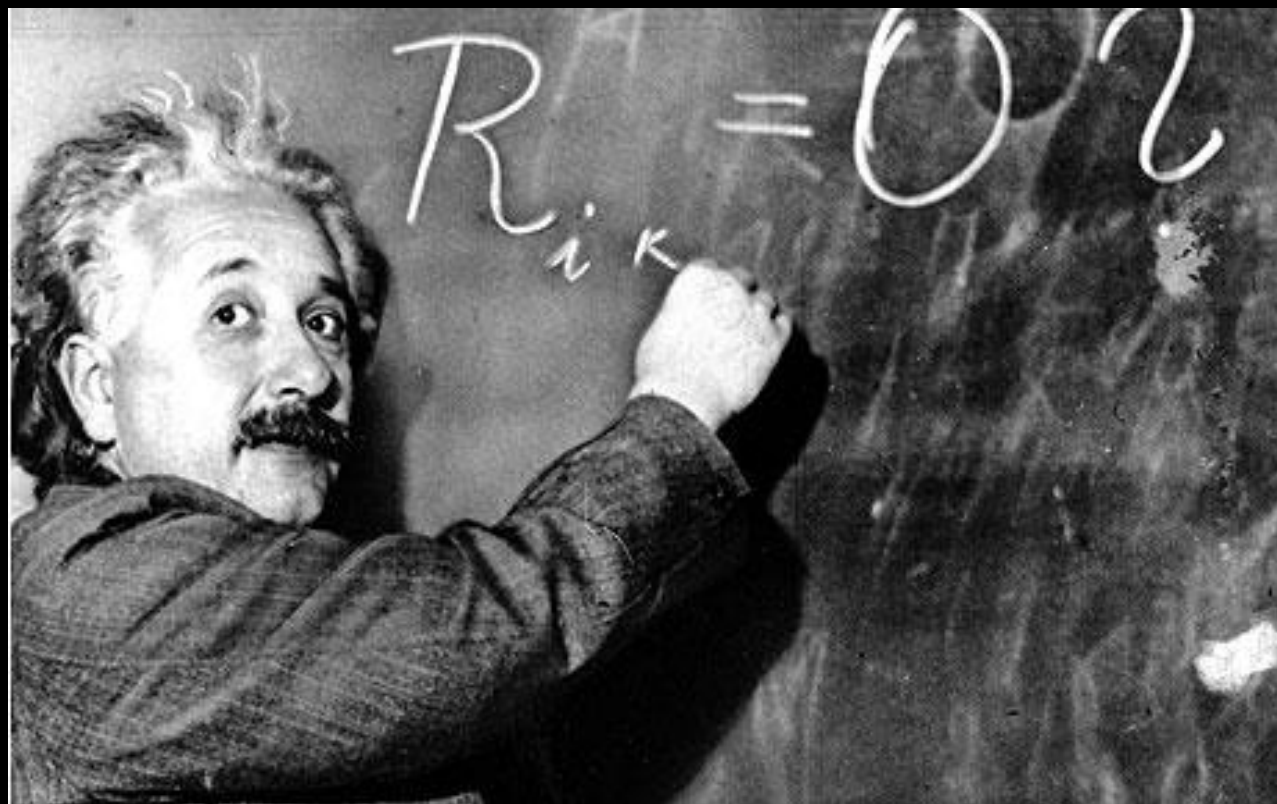
Christine Bechtal  
Christopher Boone  
Rebecca Coelius  
Farzad Mostashari  
Stephen Terry

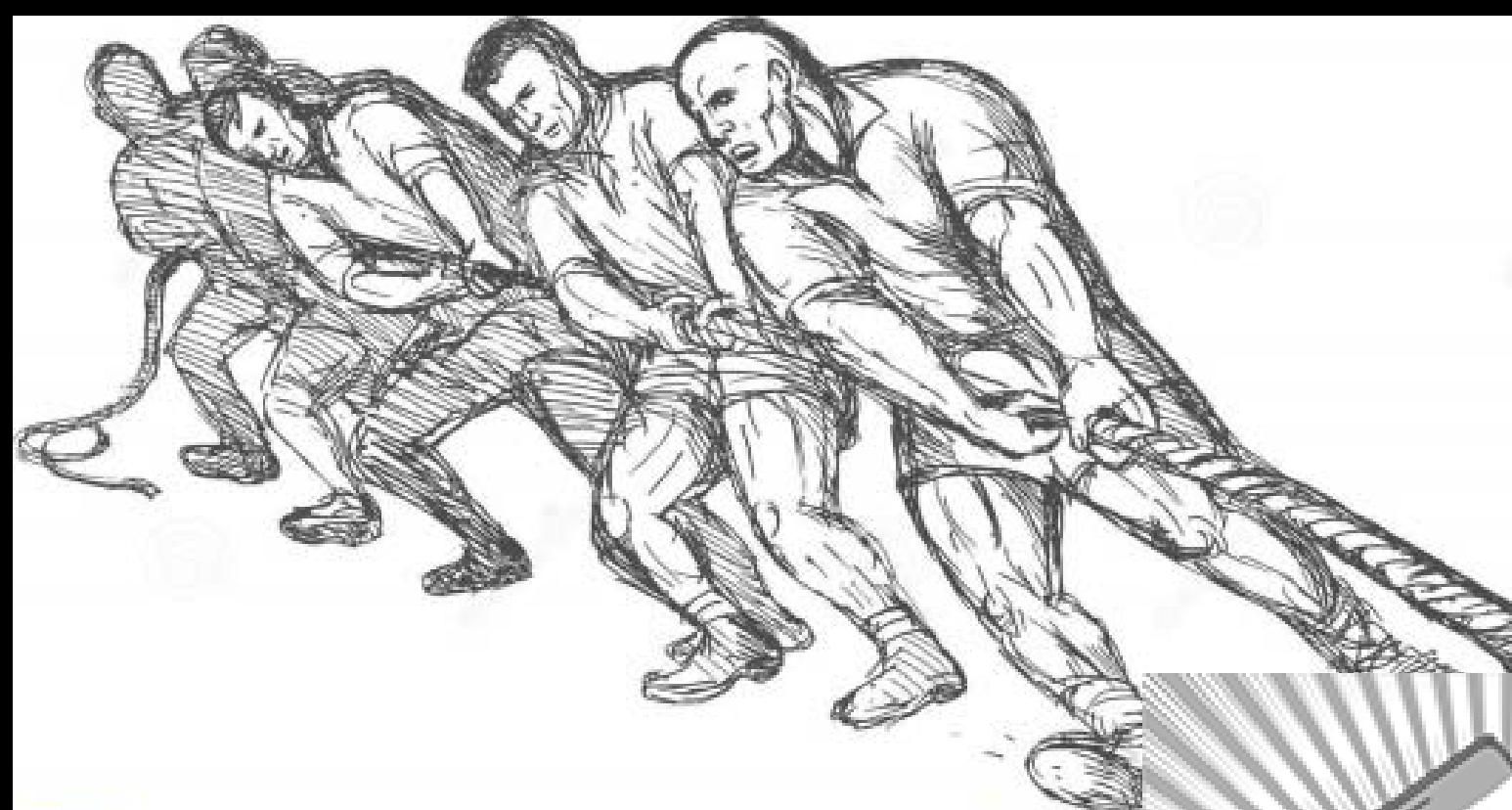


THEORY  
PRACTICE



A diagram on a chalkboard showing the words 'THEORY' and 'PRACTICE' in a vertical cycle. A red arrow points from 'PRACTICE' up to 'THEORY', and another red arrow points from 'THEORY' down to 'PRACTICE', forming a continuous loop.







GetMyHealthData

# READY, SET, TRACE!

## Ready to get your health data? Here's how:

- 1 Understand your legal rights to your health data.**
- 2 Choose what health information you want** (e.g., lab results, medication history, entire medical record) **and in what format** (e.g., paper, USB drive, CD-ROM).
- 3 Make the request.** Email, call, visit or use electronic tools to ask.
- 4 Once you get it, use your data.** Compile it, organize it, analyze it.
- 5 Tell us about it.** We want to hear from patients and families about their challenges and successes!

Download resources for each of these steps at **GetMyHealthData.org**.



## 3 STEPS TO GET YOUR HEALTH DATA



0:03 / 2:45





# HIPAA Fact Sheet: The P is for Portability

Key facts about patient requests for electronic health data



## ACCESS

**Patients have the right to electronic copies (e-copies) of their health records.**

If records are kept electronically, patients or their representatives can request an e-copy of their health data. In most cases, e-copies must be given to the patient within 30 days. Patients do not need to give a reason for their request. This information helps patients manage their own health and care for loved ones.

## FORMAT

**Patients can request their data in specific formats, if readily producible.**

Data can be in a structured format (CCDA, etc.) or read-only (PDF, etc.). Patients need structured data if they want to use a computer or mobile app to organize or analyze it. Providers are encouraged to help patients determine which electronic format best meets their needs.



## DELIVERY

**Providers**

HIPAA allows mainstream e-request. Prov may not be s A patient can health appli

**Providers can charge certain fees for e-copies of a patient's health records.**

Reasonable fees include the cost of labor to create the electronic file, cost of supplies (USB, etc.), and postage. Fees vary by state. Providers cannot charge for searching for or retrieving records. Federal law requires providers to recognize per-page fees for e-copies and cannot be denied their records because of fees.

AHIMA  
American Health Information  
Management Association

ANI

GetMyHealthData  
www.getmyhealthdata.org

GetMyHealthData

Get Your Data

Get Involved!

Blog

## Curiosity Got These Cats Their Health Data

by Elizabeth Brasington on March 17, 2016 under GetMyHealthData • Leave a comment [Edit]

-Elizabeth Brasington and Erin Mackay, GetMyHealthData

Cats have nine lives to figure out how to get their health data, but you don't have that kind of time. Here are 9 facts about digital health records from the curious cats that lived to tell the tale (or tail).

GetMyHealthData

Get Your Data

Get Involved!

Providers

The Latest

Tracer Stories

past. Get your health data electronically!

### Your Right to Request Your Health Data

Too often, consumers face barriers to getting their health information. You should know you have the right to:

- Ask to see and get a copy of your health information from most doctors, hospitals, and other health care providers such as pharmacies and nursing homes, as well as from your health insurance plan.
- Get either a paper or, if records are kept electronically, an electronic copy of your health information.

Learn more about your rights under HIPAA in the new guidance from the Department of Health and Human Services.

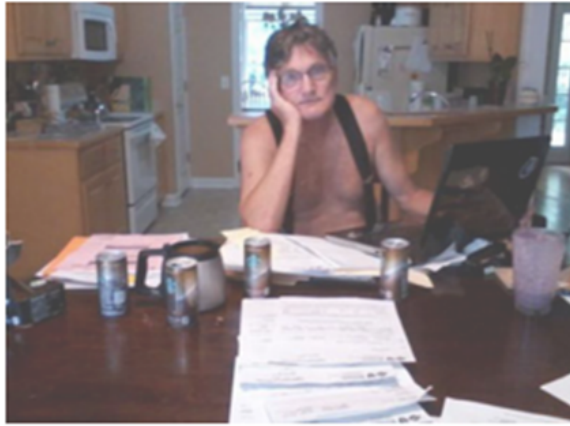
### Resources

- Right to Access Memo
- Your Health Information Privacy Rights
- Right to Access and Correct Your Health Information
- Your New Rights under HIPAA





## DAZED & CONFUSED



### Starbucks Required

"My attempt to reconcile three patient portals, CMS Blue Button data, and my Blue Cross health profile. Not an ad ...

[Read More](#)

## SHOW ME THE MONEY



### Ninety Dollars!

"I have not tried except for one instance where **they sent me a BILL for sending my records to my ...**

[Read More](#)

## FORMAT MATTERS



### Can't Open It

"Yes, I got my data! But... it came on a disc and my computer no longer has a disc drive so I ...

[Read More](#)

Four Killed



Alligator Wrestling in Colorado? A Draw for Thrill Seekers, and Critics



Debate Erupts in California Over Curriculum on India's History



U.S. Warns North Carolina That Transgender Bill Violates Civil Rights Laws



KNOXVILLE JOURNAL Teenager's Killing Inspires Memorials, but Not Gun Control



U.S.

## New Guidelines Nudge Doctors to Give Patients Access to Medical Records

By ROBERT PEAR JAN. 16, 2016



Christopher S. Moore with his son, Oliver, 4, who has a rare genetic disorder. Mr. Moore said he had difficulty getting Oliver's full medical records. Melissa Golden for The New York Times

### Download HIPAA Checklist

Free HIPAA Security Guide By ESET® Ten Steps For HIPAA Compliance.



WASHINGTON — The Obama administration is tearing down barriers that make it difficult for patients to get access to their own medical records, telling doctors and hospitals that in most cases they must provide copies of these records within 30 days of receiving a request.





Talayah Jackson @jacksononhealth · Oct 2

Requested your med records & felt like you were asking for Pentagon secrets? I have. Join @GetMyHealthData 's #Tracer chat - 10/6 at 2 pm ET



“Medical providers treat my data as if it were **top secret**. I understand their concern about revealing my data to third parties, but many are reluctant to reveal it to me...**How can I make informed decisions about my own health if I don't have information?**” -Adele Z.



# RELEASE OF INFORMATION DEPARTMENT

## Your Medical Records

770-810-8880

Open Monday - Friday, 8 A.M. - 4:30 P.M.

**CLOSED ON HOLIDAYS**

According to federal law, patients have the right to get copies of most medical records, whether they are paper copies, or electronic health records. Doctors' notes, medical test results, lab reports and billing information must be supplied to patients if they ask correctly.

The federal law that addresses medical records is called HIPAA, the Health Information Portability Accountability Act.

**\*Some results may be available through MyChart. Please see the MyChart Learn More page.**

**\*Third-party requesters please see frequently asked questions for authorization submission process.**

## HOW TO REQUEST YOUR MEDICAL RECORDS

## FYI: ACCESSING YOUR MEDICAL RECORDS & PERSONAL HEALTH INFORMATION

## FREQUENTLY ASKED QUESTIONS

“Getting records ( labs, etc.) are [the] total responsibility of patient, and offices seem **puzzled as to the repeated requests.** Practices in general...**respond begrudgingly to requests.**”-Richard M.





**Bray Patrick-Lake**

@BrayPatrickLake



Following

Here's my 100% worthless longitudinal [#health](#) record. [#Patients](#) need [#interoperable](#) [#EHR](#) today [@ONC\\_HealthIT](#)



RETWEETS

90

LIKES

80



8:31 AM - 19 Jun 2015



Reply to [@BrayPatrickLake](#) [@ONC\\_HealthIT](#)



**GetMyHealthData** [@GetMyHealthData](#) · 7 Jul 2015

[.@BrayPatrickLake](#) Wow, hope your computer has a CD drive! Great illustration of why eHealth [#data](#) so important [#GetMyHealthData](#)

“I attempted to get my data in an electronic file sent to my Direct address - the doctors’ admin staff did not understand. After some discussion, the best they could offer was a CD...

I received it shortly thereafter in the mail - it is a **47 page PDF of many things and of varying sizes and resolutions** - many super small images relative to the others, that I had to expand a thousand percent to read. **Incomplete at best.”** -Jeff T.

Bechtel, Christine

memorex™

Cool Colors  
CD-R  
52X 700MB 80min

Family HealthCare  
Medical Records  
5-4-15

## SHOW ME THE MONEY



### Charges Prohibitive

"I never got my records, as I found the charges prohibitive. I don't recall what they were, only that it ...

[Read More](#)

## SHOW ME THE MONEY

**EFFECTIVE July 7<sup>th</sup> 2015**

**PATIENTS REQUESTING MEDICAL RECORD**

PERSONAL/PRIVATE or PATIENT TRANSFER

Request for copies of Medical Records will be billed as followed:

Processing Fee	\$10.00 (Non Refundable)	Plus
No Charge	20 Pages or Less	
\$0.50	Per Page for the first 50 Pages	
\$0.25	per Page beyond 50 Pages	

- Duplicate requests will be billed according to D.C. Maryland and Virginia State Regulations
- Pre-Payment is required [redacted] will send you an Itemized Invoice
- Please Include your Check or Money Order made payable to [redacted] with a copy of Invoice.

Mail check or Money Order to:

### Stuck with the Bill

"The doctor charged the following for copies of my mom's medical records:

- First 50 pages \$0.50 per page
- Thereafter, \$0.25 ...

[Read More](#)

In Ohio, health-care providers can charge as much as \$3.07 per page for the first 10 pages of a person's paper or electronic medical records, 64 cents for pages 11 through 50 and 26 cents for any additional pages.



## Patient Portal Pricing

	Basic no cost to you	Gold \$125 a year	Platinum \$250 a year
<b>Appointment Services / Bill Pay</b>			
View Upcoming appointments	✓	✓	✓
Pay bills online	✓	✓	✓
Make appointments		✓	✓
View Appointment History		✓	✓
<b>Labs / Dictations</b>			
Last 60 days of labs / dictations	✓	✓	✓
All labs / All dictations		✓	✓
<b>Medications</b>			
Medication listing		✓	✓
Allergy listing		✓	✓
Free refill requests		✓	✓
<b>Clinical Data / Documents / Referral</b>			
Immunization history		✓	✓
Vitals history		✓	✓
Active problem list		✓	✓



**“I feel like I am in the twilight zone. It is 2016 and records cost \$293 and on top of that they are put on a CD... I may send a carrier pigeon to pay for this bill although I hear they are pretty costly. Thank you for giving me the hospital’s number. I’ll be sure to dial it on my rotary phone.” -Anonymous**





**GIVE ME MY**



**DATA!**



@GetMyHealthData

#FreeMyData

#DataExemplar





dont keep

CALM

the

struggle

is real

@GetMyHealthData

#FreeMyData

#DataExemplar



THE PRECISION MEDICINE INITIATIVE



GetMyHealthData

@GetMyHealthData

Gotta get a pic @WhiteHouse  
#PrecisionMedicine #WHChamps event!  
@Fridsma @aneeshchopra @MsWZ  
#GetMyHealthData



@GetMyHealthData

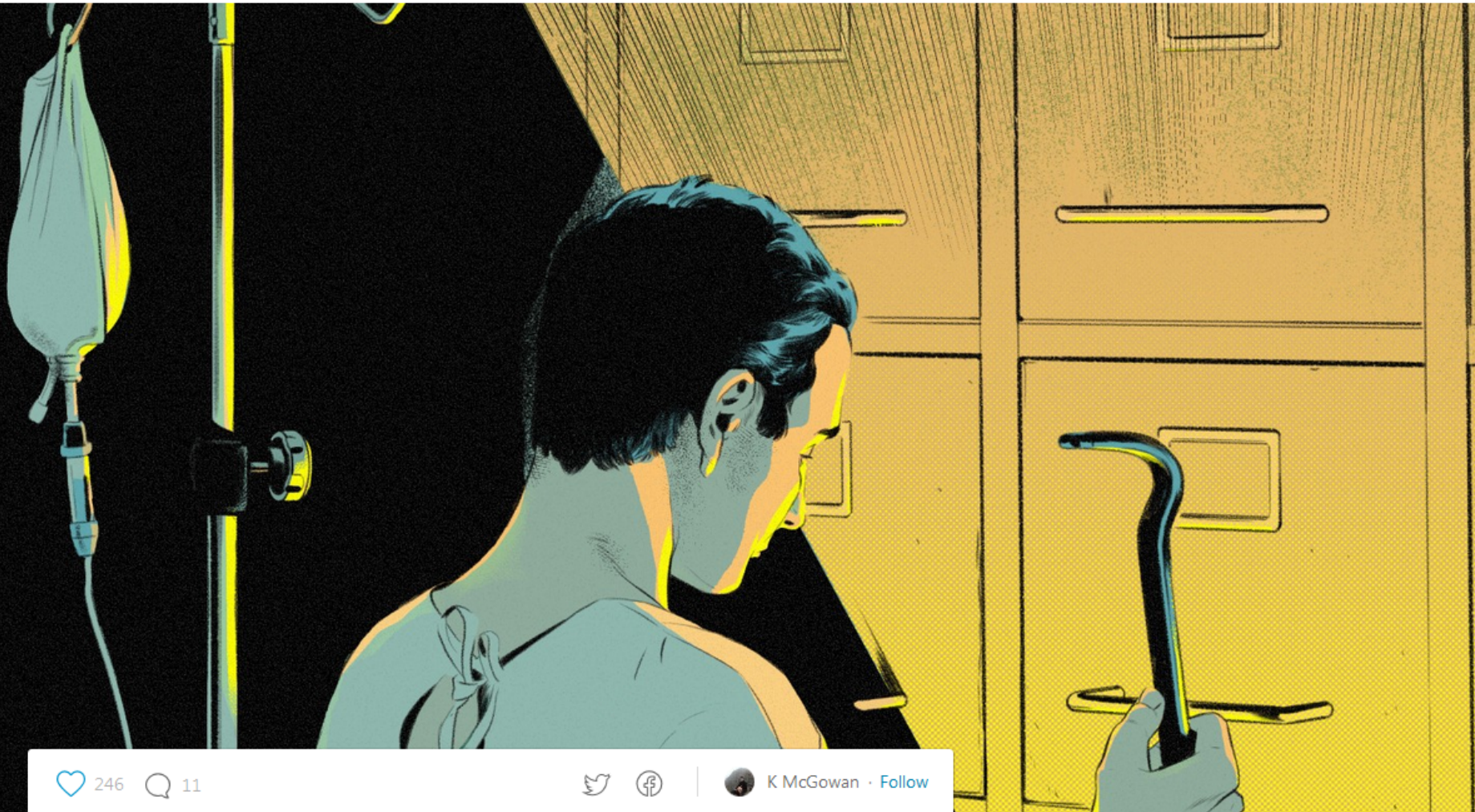
#FreeMyData

#DataExemplar



## Our Medical Data Must Become Free

Data generated by your body is routinely captured and sold by healthcare companies. Shouldn't you benefit from it, too?



246 11



K McGowan · Follow

@GetMyHealthData

#FreeMyData

#DataExemplar





GetMyHealthData