

# HIPAA: A 20<sup>th</sup> Anniversary

*How far have we come?  
A Conversation with NYS Health  
Foundation*

Christine Bechtel

November 7, 2016

\* How does HIPAA fare in the Information Age According to Consumers?

\* Where do we need to go next?

Overview



# Get My Health Data

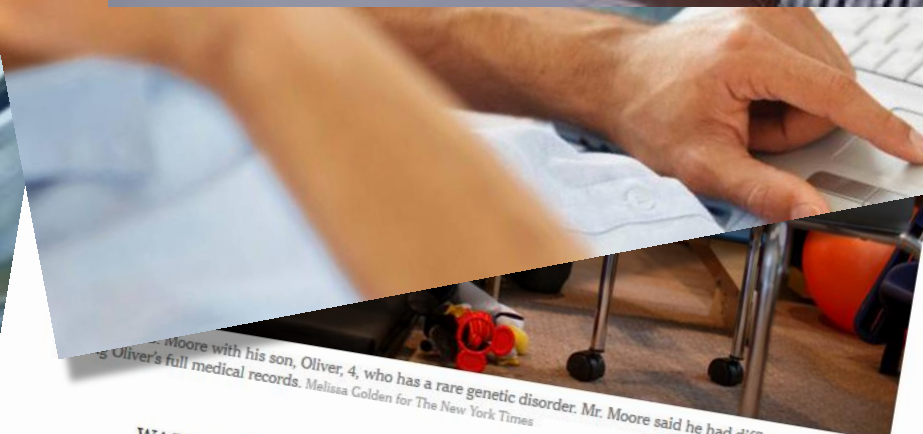


# Health Datapalooza

*A theory is born*

June 2, 2015





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

WASHINGTON — The Obama administration is tearing down barriers that  
make it difficult for patients to get access to their medical records, by  
telling doctors and hospitals to make it easier for patients to get their  
these records.



and



# 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](https://www.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 can email patients a copy of their records.**

HIPAA allows providers to send a main stream email account (Gmail request. Providers should advise may not be secure, and patients A patient can also request other health applications.



## COST

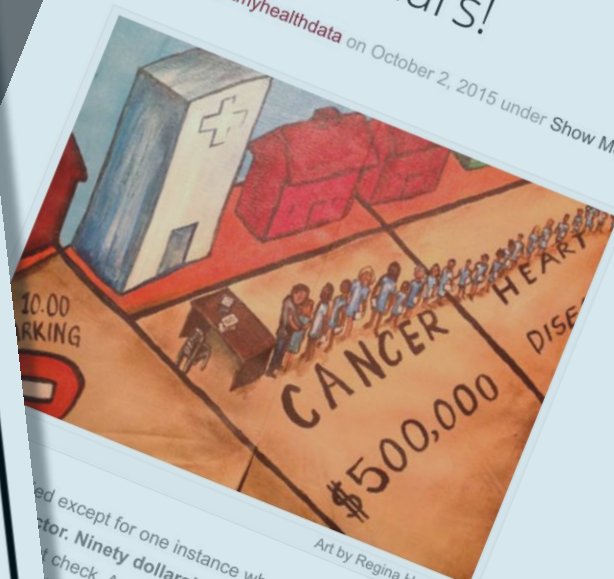
**Providers can charge certain fees for electronic copies of a patient's records.**

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



# Ninety Dollars!

by [getmyhealthdata](#) on October 2, 2015 under Show Me the Money - Leave a comment



[Get Your Data](#)

[Get Involved!](#)

[Providers](#)

[The Latest](#)

[Tracer Stories](#)

## 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:

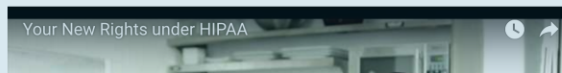
- Ask to see and get a copy of your health information from most doctors, hospitals, and other health care providers such as pharmacies and nursing homes, as well as from your health insurance plan.
- Get either a paper or, if records are kept electronically, an electronic copy of your health information.

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](#)

Your New Rights under HIPAA






# What To Do With Your Data

Almost every other industry – banking, travel, retail, and education – gives customers powerful tools to manage their lives online. Good news- that’s increasingly true in health care- all you need is your data!

The products below are featured because each of them openly shared information with us about their policies and practices. All report that they allow you to compile your records in one place, and they don’t release your personal health data. We **do not endorse any single product**, nor do we have any financial relationships with these organizations. We are providing you with clear information so you can make the best choice for you. You should always do your own research on each product, including how much they cost and what other users have to say, but these are good starting places:

Search:

	USE MODEL PRIVACY NOTICE	DOESN'T RELEASE PERSONAL DATA	OFFER DIRECT ADDRESS	DATA PORTABILITY
 <b>ACTIVDOCTORS ONLINE</b> Activ Doctors Online		X	X	X
 <b>Andaman7</b> Andaman7		X	X	
 <b>better.</b>		X		X

## App Details

### Model Privacy Notice

The model notice was developed by the federal government and works just like a nutrition label. It is a standardized format for communicating privacy and security policies in a clear, concise manner.

### Direct Address

Some of these apps offer what’s called a Direct email address. Direct works just like email but has extra security features built in to help protect health information. This is one way you can ask your doctor to send your data directly to an app, for those that offer this feature. To learn more about Direct for consumers, read [this article](#).

### Release Personal Health Data

Most organizations that create apps are not

## Share Your Experience

### Tell Us What Happened!

A key part of this national effort is to learn from the successes they are having in the real world. You will help us create tools and resources for consumers to get their health information.

First, we need to know: have you successfully retrieved your health information?

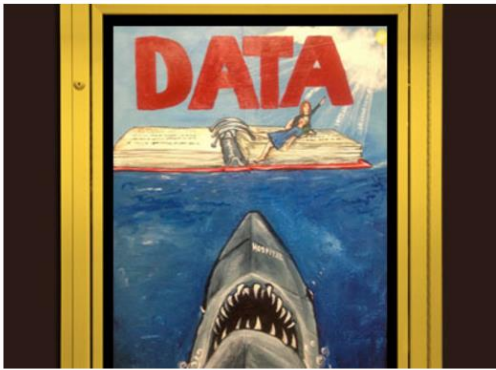
**Yes!** I got my data.

**No.** I was unable to retrieve my data.

**Not Yet,** but I hope to receive it. Federal law allows providers 30 days to process your request. Please give us your email address so we can follow up in about 30 days.



## 📁 CULTURE CLASH

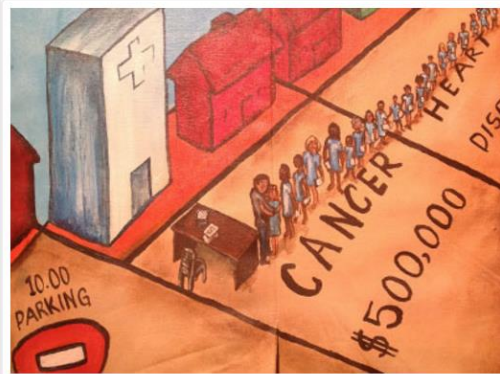


### Handicapped

"I was recently hospitalized and was so frustrated as to how disparate and unavailable my records were for the staff ...

[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](#)

## 📁 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](#)

# Key Themes:

- ▶ Culture
- ▶ Format and Delivery

## ▶ Fees

"I was recently hospitalized and was so frustrated as to how disparate and unorganized the records were for the staff

[Read More](#)

## Ninety Dollars!

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

[Read More](#)

## Starbucks Required

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

[Read More](#)

# Culture:

# Data is for Doctors.



COMMUNITY  
RADIOLOGY  
ASSOCIATES

MRN: 2295816S



MR Lumbar Spine W  
spine (05-18-2016)

**For physicians only**

To view your patients' images and reports online visit:

[www.CommunityRadiologyConnect.com](http://www.CommunityRadiologyConnect.com)

This CD contains confidential patient information, if you are not the intended recipient of this information, or if you believe that you have received it in error, please destroy the CD and contact us at 888-601-0943.



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.

“Getting records (labs, etc.) is the responsibility of the patient, and offices seem **puzzled as to the repeated requests.**

Practices in general....**respond begrudgingly** to requests.” –Richard M.

“Getting information out of [*Hospital Name*] is enough to put you back in [the *Hospital*].”



# 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**



**Bray Patrick-Lake**

@BrayPatrickLake



Following

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



RETWEETS LIKES

90 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

# Format & Delivery:

## PDFs + CDs = the New Paper

# Format not negotiable? What about my app? Regular email?

Please send SHC request to:

Stanford Healthcare  
Associated Internal Medicine  
350 30th Street, Suite 320  
Oakland, Ca 94609

Fax UHA Requests to: (510) 342-0081

AUTHORIZATION • DISCLOSURE OF HEALTH INFORMATION

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## SECTION D:

You would like this information released in the following format:

- Paper Copy       Encrypted CD/DVD \*       Electronic PDF File  
(Patient requests only)

You would like this information released via the following method:

- Mail    Fax (see below)    Pick up in person (date) \_\_\_\_\_    Secure Email (see below)  
(Patient requests only)

If Fax, provide Fax number: \_\_\_\_\_

If Email, provide Email address: \_\_\_\_\_

[Redacted]

*If file is too large for email,  
mail is fine.*

SECTION E: Please indicate the reason you would like your health information released.

- Check here if you are the patient and you do not want to provide the reason.  
 Check here if the release is not to the patient and provide the reason for the release here:

## SECTION F:

*\*Please send in Consolidated Clinical Document Architecture (C-CDA) or Continuity of Care Record (CCR) format if available.*

“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.

# Most Common Delivery Options :



# Fees.

## 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
- 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 [redacted] for copies of my mom's records:

- First 50 pages \$0.
- Thereafter, ...

[Read More](#)

## Bah Humbug

"Merry Xmas to me? I just paid \$148.96 to access a e-copy (PDF) of my medical record."-A. S ...

[Read More](#)

Surpri\$e amounts

## SHOW ME THE MONEY



SHOW ME THE MONEY

Find Invoices | Review Invoices | Pay Your Invoices

Invoice # : [redacted]  
Invoice Total : \$148.96  
Patient Name : [redacted]  
Balance Due : \$148.96  
This is the total amount due for this invoice.  
Payment Amount : \$148.96  
Full payment is required. Do you want to continue?

Merry Xmas to me? I just paid \$148.96 to access a e-copy (PDF) of my medical record from @HealthPort\_Tech. You, Christine Bechtel, Sara and 6 others

## 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](#)

# 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**



# Consumer Usability:



“My attempt to reconcile three patient portals, CMS Blue Button data, and my Blue Cross health profile. Not an ad for Starbucks, just required a lot of caffeine to handle!” —*Jeff H.*

It's not that simple... even when you get your data!



“I gave up - it would have taken hundreds of clicks, and all I'd get is a **TOTALLY DISORGANIZED** and unusable **PILE** of separate files. Give me my **INFORMATION**, in a form I can use - not some crap pile of bytes! This is **DISEMPOWERING** to patients.”





# Opportunities

- ▶ Close the gap/chasm between policy and practice
  - ▶ Partner with patients to redesign workflow and consumer experience
- ▶ Double down on sparking *provider* demand
- ▶ Connect HIM department with patient portals
- ▶ “A receipt with every encounter”
- ▶ Create a culture where data viewed as a critical tool for consumers to manage health, care

DATA!

# We All Want Better Health, Better Care

Better health and care requires **changes** in...  
How patients are **cared** for.  
How care is **paid** for.  
How patients are **engaged**.

*Farzad Mostashari, MD, MPH*  
*Former National Coordinator of Health IT*



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