

The Latest on Patient Privacy Rights: Consumers and Electronic Access to Health Data



Christine Bechtel, MA
President
Bechtel Health



Patrice Sminkey
Chief Executive Officer
Commission for Case Manager Certification (CCMC)



PATHWAY TO DISCOVERY FOR THE PROFESSIONAL CASE MANAGER

Agenda

- Welcome and Introductions
- Learning Objectives
- **Patrice Sminkey**, CEO, the Commission
- **Christine Bechtel**, President, Bechtel Health
- Question and Answer Session



PATHWAY TO DISCOVERY FOR THE PROFESSIONAL CASE MANAGER

Audience Notes

- There is no call-in number for today's event. Audio is by streaming only. Please use your computer speakers, or you may prefer to use headphones. There is a troubleshooting guide in the tab to the left of your screen. Please refresh your screen if slides don't appear to advance.
- Please use the "chat" feature below the slides to ask questions throughout the presentations. We will pose questions after the presentation and will address as many as time permits.
- A recording of today's session will be posted within one week to the Commission's website, www.ccmcertification.org
- One continuing education credit is available for today's webinar only to those who registered in advance and are participating today.



PATHWAY TO DISCOVERY FOR THE PROFESSIONAL CASE MANAGER

Learning Objectives Overview

After the webinar, participants will be able to:

1. Describe the new HIPAA right of electronic access and understand how an institution can help or hinder these rights.
2. Discuss strategies for helping patients to make meaningful use of their own health data.
3. Demonstrate understanding of why patients want their health data and the impact it has on health status, care planning and care coordination.

CM Learning network[®]



PATHWAY TO DISCOVERY FOR THE PROFESSIONAL CASE MANAGER

Introduction



Patrice Sminkey
Chief Executive Officer
Commission for Case Manager Certification

- Webinars
- Certification Workshops
- Issue Briefs
- Speaker's Bureau



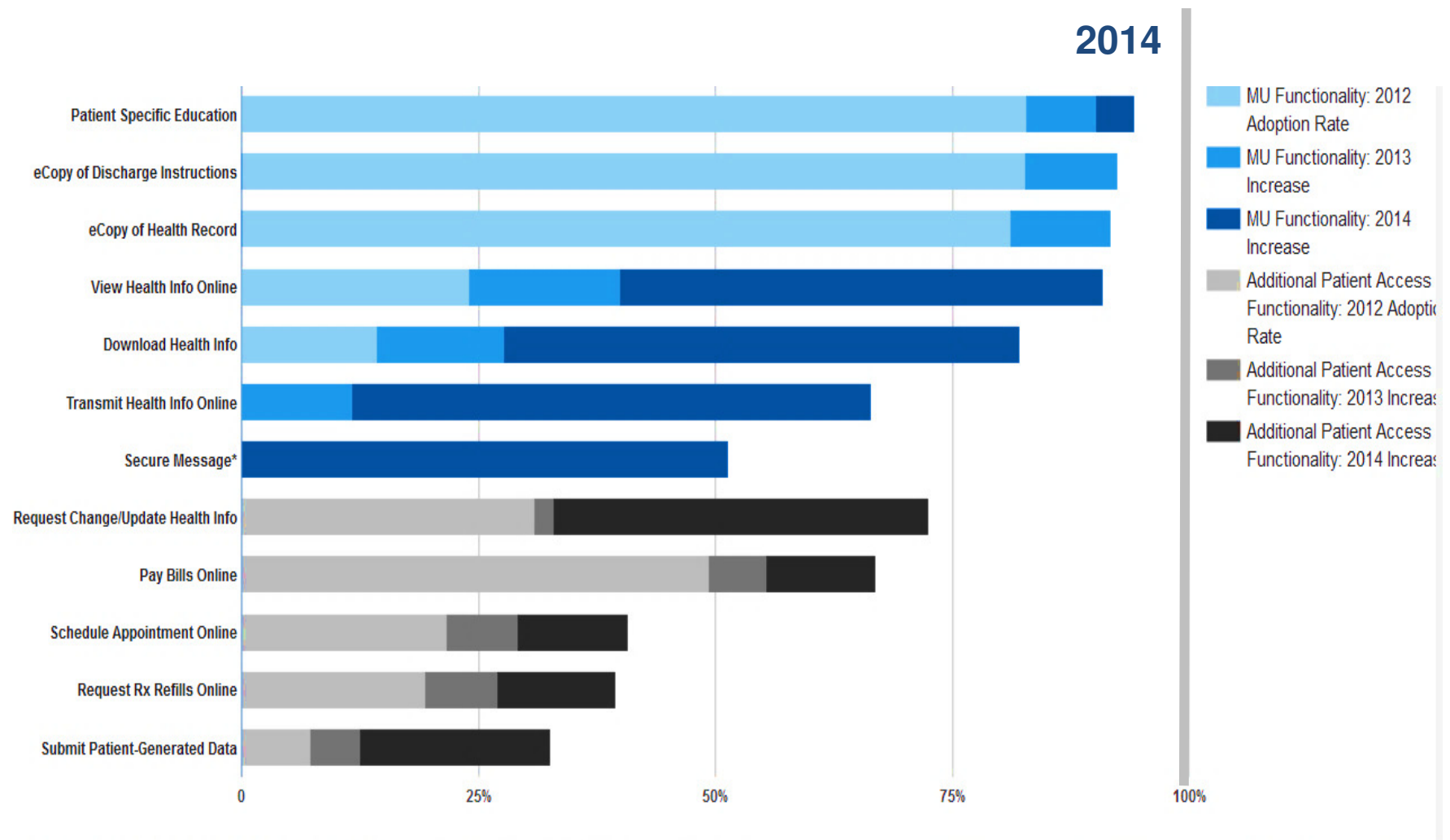
PACE[™]
Pre-Approved Continuing Education



CareManagement
OFFICIAL JOURNAL OF THE ACADEMY OF CERTIFIED CASE MANAGERS

www.ccmcertification.org

EHRs: Increasing Focus on Patient Engagement



Office of the National Coordinator for Health Information Technology. 'U.S. Hospital Adoption of Patient Engagement Functionalities,' Health IT Quick-Stat #24. dashboard.healthit.gov/quickstats/pages/FIG-Hospital-Adoption-of-Patient-Engagement-Functionalities.php. October 2015.

2016: Enhanced patient access to records

Transforming Health IT [Top Health IT Trends >>](#)

Privacy & Security

HHS unveils new tools to help patients understand privacy rules under HIPAA

Federal agency says people too often face obstacles to accessing their health information.

HHS Office for Civil Rights issues guidance on patient rights to data under HIPAA

OCR Director Jocelyn Samuels: 'Far too often individuals face obstacles to accessing their health information'

January 8, 2016 | By Katie Dvorak

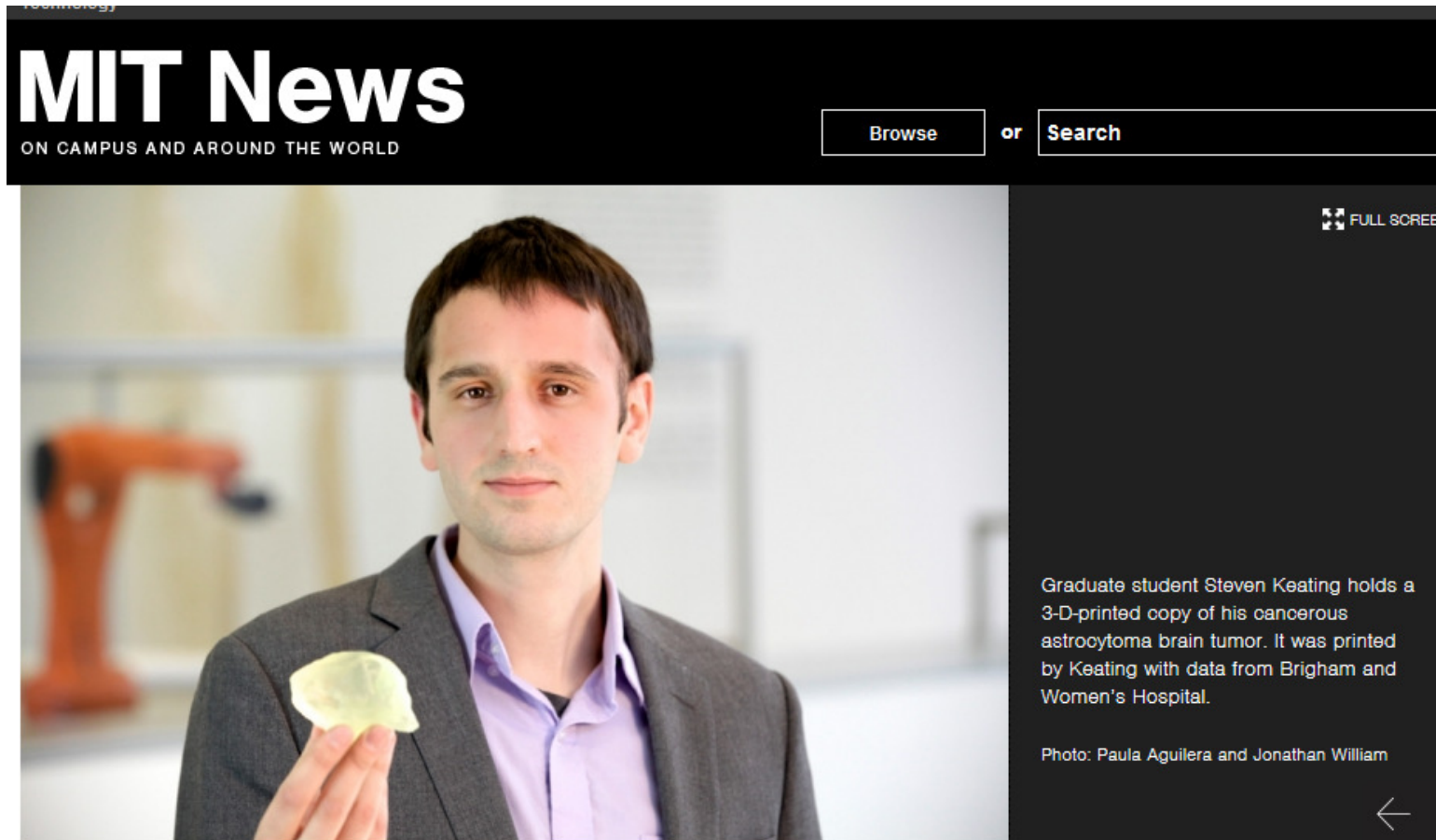


Patient Advocates Commend HHS' New HIPAA Guidance on Patients' Rights to Their Health Data

by Staff Writer 01/11/2016 0 Comments



Why it matters



Cerebral curiosity

Graduate student Steven Keating takes a problem-solving approach to his brain cancer.



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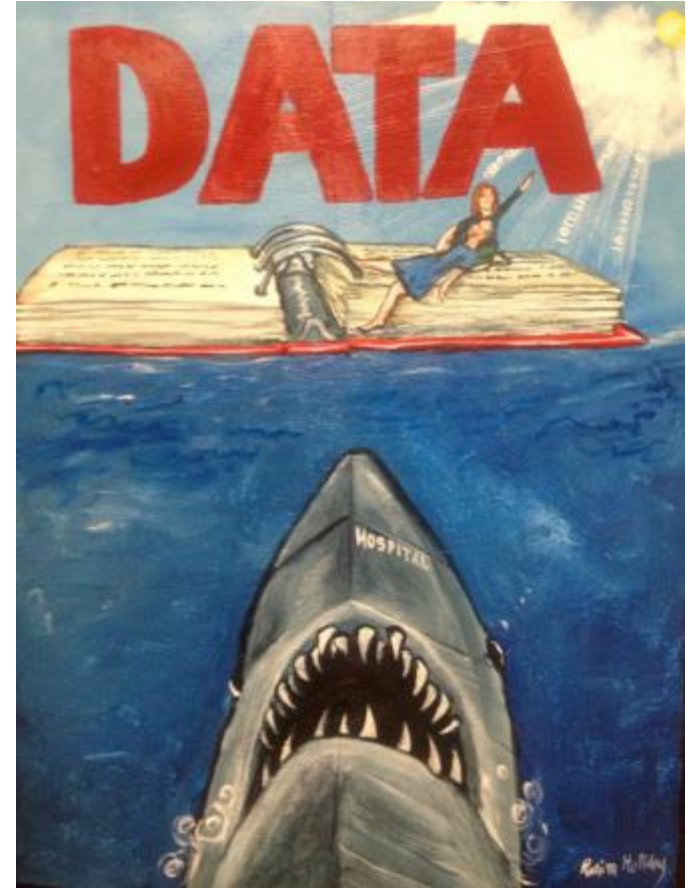
The Latest on Patient Privacy Rights: Consumers and Electronic Access to Health Data



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Bechtel Health

The Latest on Patient Privacy Rights:

Consumers and Electronic Access to Health Data



Christine Bechtel
Coordinator
GetMyHealthData Campaign



About Us:



- A consumer-led, **national campaign** to help patients get access to their electronic health data and troubleshoot problems along the way.
- We provide resources for **patients and providers**, based on consumer reports of their experiences
 - AKA: Tracers
- **Coordinated** by the National Partnership for Women & Families, in **collaboration** with
 - health, consumer and technology groups;
 - individual advocates and experts.
- **Funded** by the Robert Wood Johnson Foundation and individual donors



Overview of Core Strategies



- **Showcase the problems and successes in today's system: #Tracers**
 - Volunteers who want their health data, are willing to make a HIPAA request, and tell us about the results.
- **Problem solve for and with consumers: #Helpers**
 - Individuals & Organizations who lend their services, resources, or expertise to support the Tracers or advance campaign goals
- **Enable data utility, privacy & security: #Tech**
 - Guidance for consumers on what to do with the data – keep it safe, make it useful.
- **Create a better environment: #Policy**
 - Advocating for policies that liberate data and make it safe, secure and useful.
- **Foster consumer demand and provider awareness: #Comms**
 - Raise awareness (consumers & providers) about the value of health data, how to request it, how to respond to requests appropriately.

Today's Agenda

Surgeon,
oncologist,
radiologist,
different forms.
Argh!!
-Martha M., WA

- **Electronic access:** A right, and the right thing to do:
 - Benefits of access to consumers
 - Legal rights overview
- Little Known **Facts** about the Right of Electronic Access
- The **Wild West** – what patients experience today
- You can help! **Resources...**
- Q&A



Patients Speak



Engaging Patients and Families: How Consumers Value and Use Health IT

DECEMBER 2014



1875 Connecticut Avenue, NW | Suite 400 | Washington, DC 20009
202.860.1800 | www.nationalpartnership.org



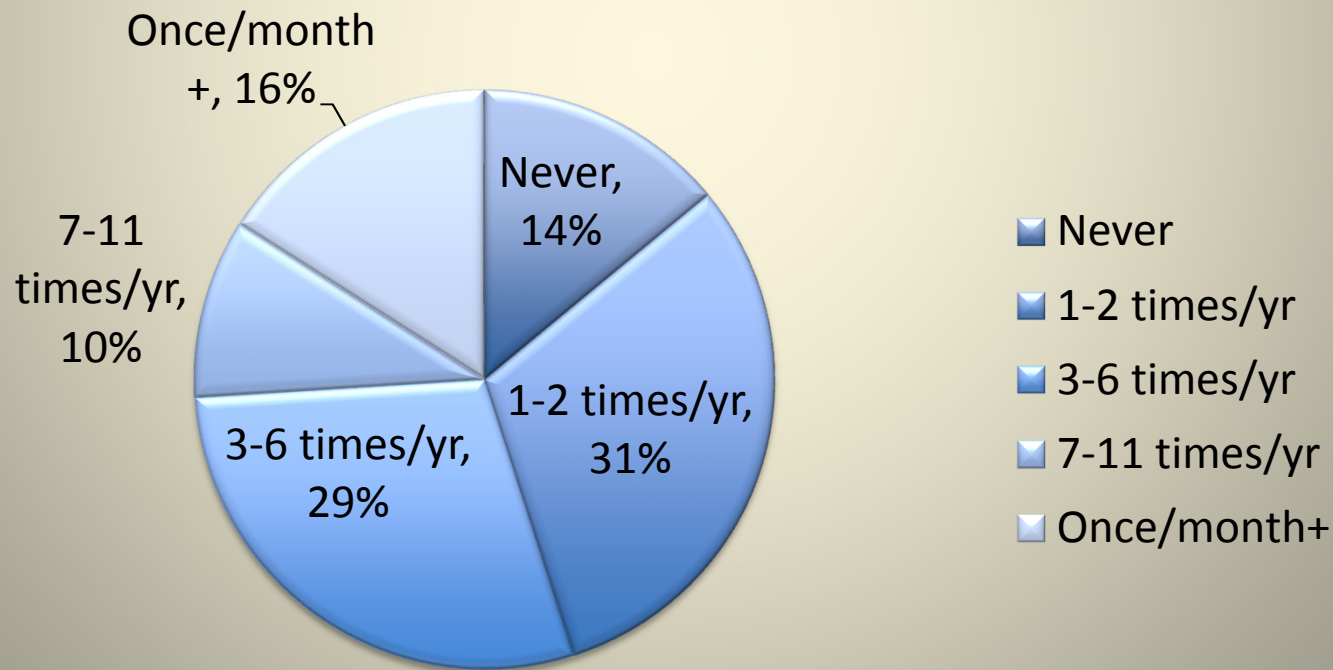
- Conducted at the fifth anniversary of the HITECH Act
- Respondents who have a main doctor and know if the doctor uses paper or electronic records:
 - 1192 EHR respondents
 - 853 paper respondents
- Harris Poll conducted a nationally representative online survey in April-May 2014
- Full report available at:
www.NationalPartnership.org/PatientsSpeak

Do Patients Want Online Access? ...Uh, yeah!



- Among respondents with online access, 86% use it at least once a year.
- Even among paper respondents, 64% say online access is important.

Use of Online Access



55% use online access 3 or more times a year!

Why Online Access is important to patients...



Which of the following activities would you do with online access to your health information?

[Base = All qualified respondents (n=2045)]



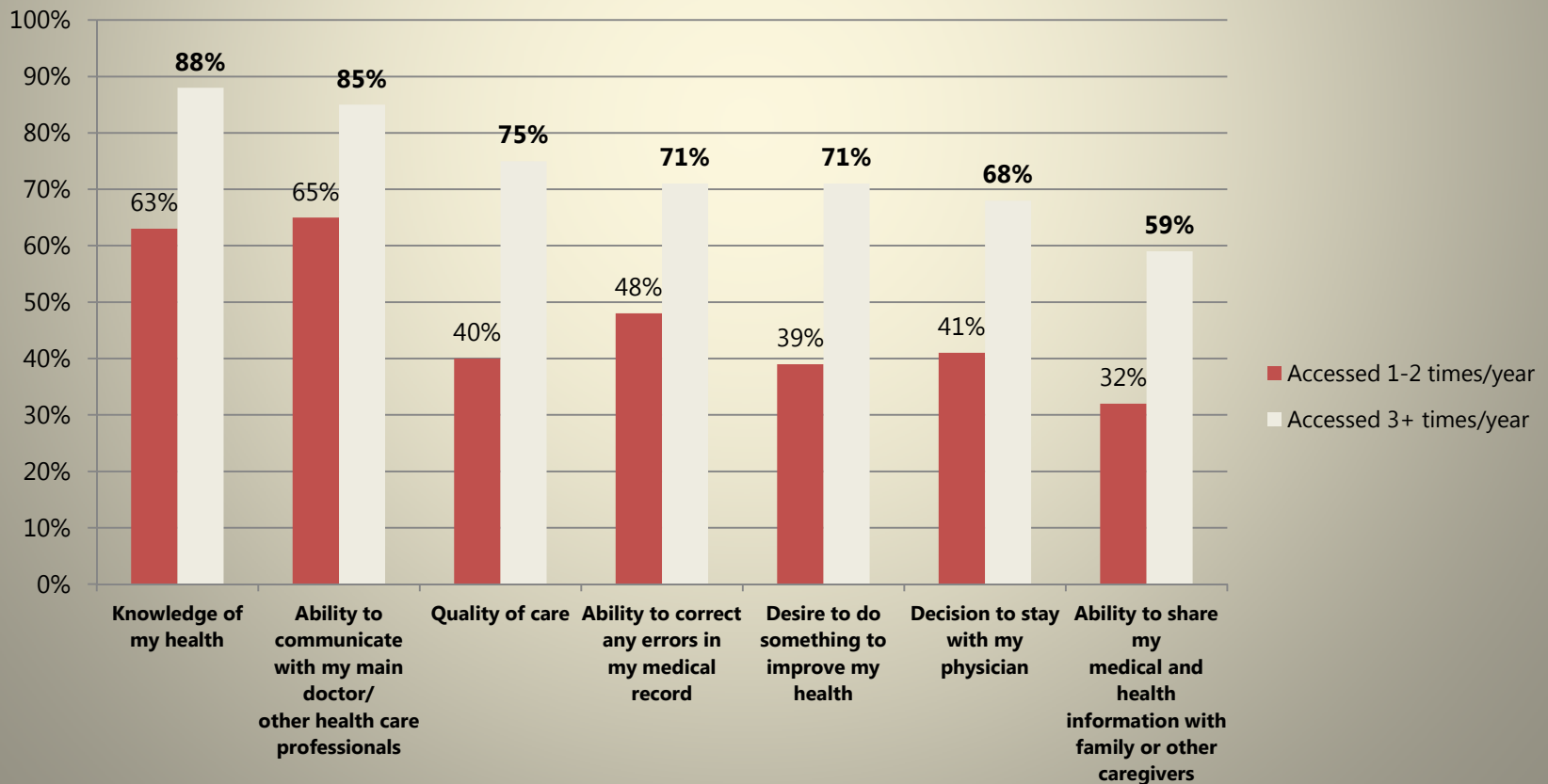
More Online Access Leads to Better Care

My whole team
on same page!

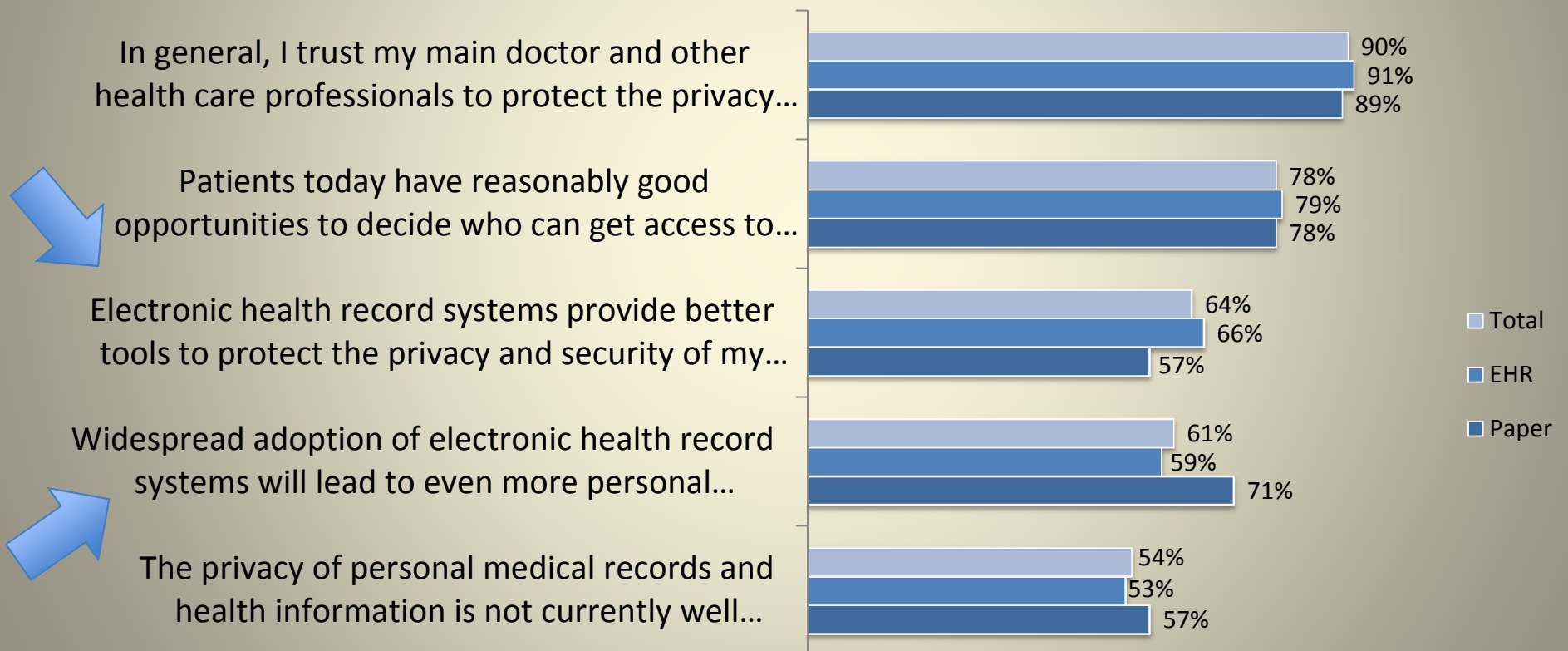
Marjorie M., CA

Online Access to Health Information: Positive Impacts More Frequent Access = Greater Benefit

[Base = Accessed EHRs online (n=492): 1-2 times/year (n=187); 3+ times/year (n=305)]



How do consumers feel about privacy?

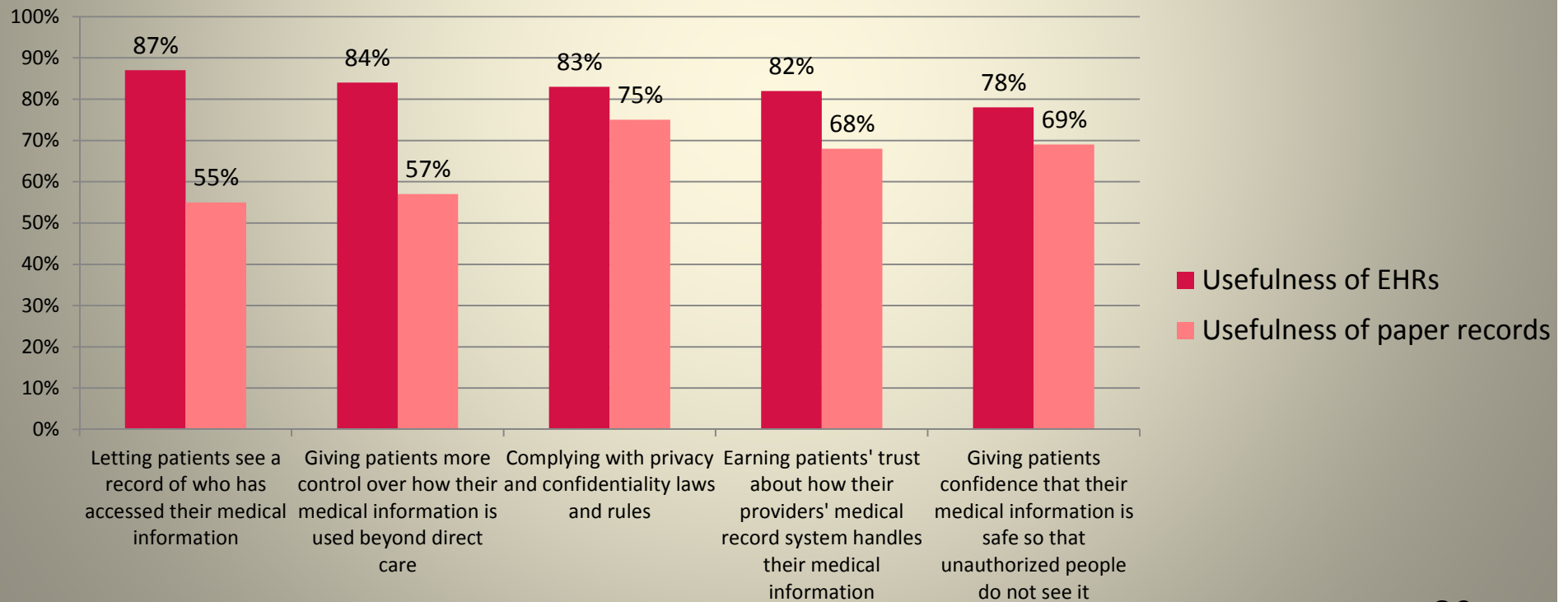


Patients Find EHRs More Useful in Protecting Privacy



EHR and Paper Patients Alike Find EHRs Significantly More Useful and Protective of Privacy Across Key Domains

[Base = All qualified respondents: (n=2,045)]



How do consumers feel about online access and privacy?



Those who use online access more frequently (3+ times per year) have **significantly greater trust** that their providers will protect their privacy and other patient rights:

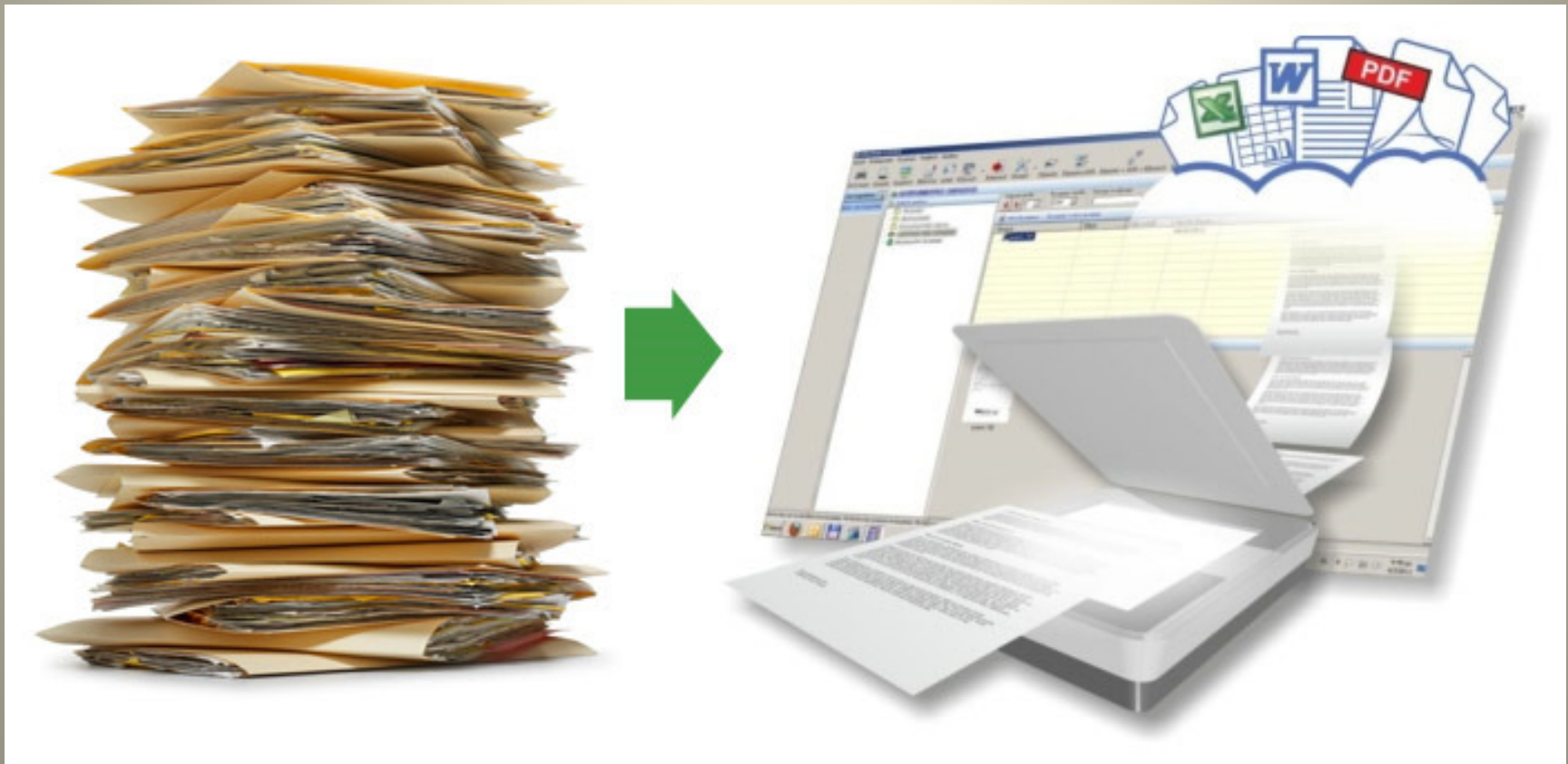
- 84 percent trusting “completely” or “a lot,” compared with 69 percent.

So what does all this mean?



- Patients want online access
 - It enhances trust
- They want to health data in important, new ways
 - Apps, portals, etc.
- They have some concerns about EHRs and privacy.
- Those who use health data say they are more engaged, motivated to do something about their health.

Information Technology (IT) has finally come to health care...



Thanks HITECH Act!!!



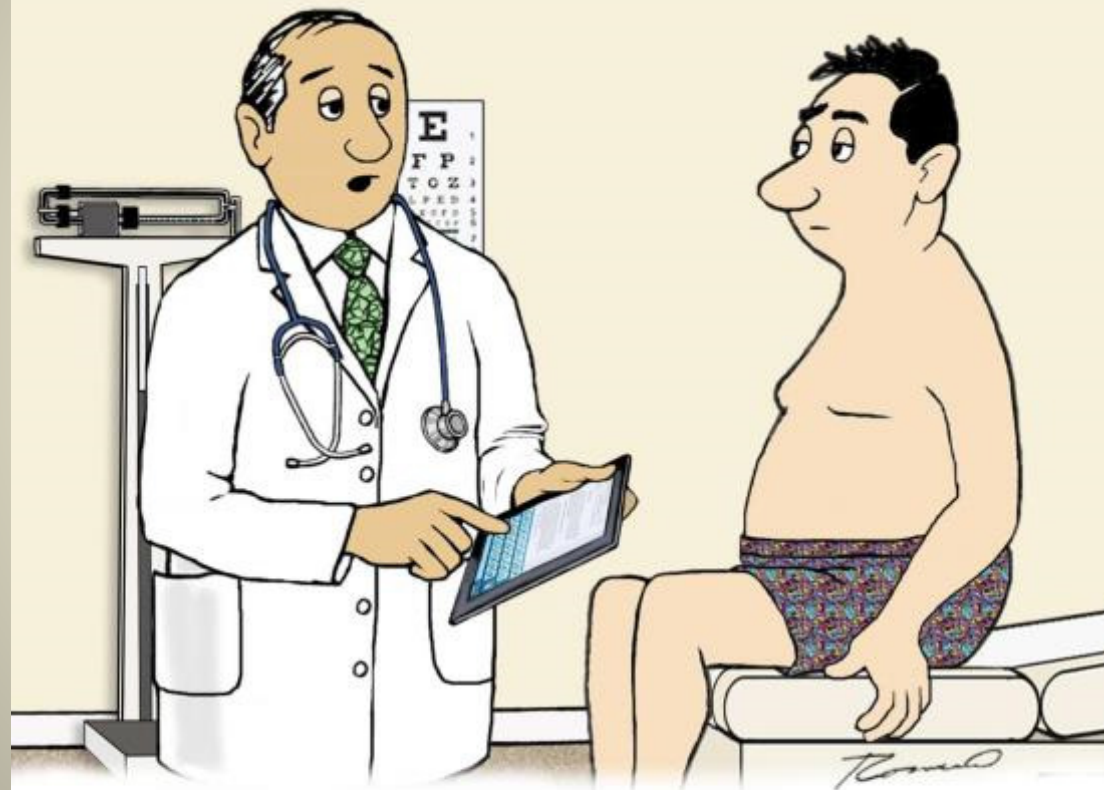
- In 2009, HITECH Act created “**Meaningful Use EHR Incentive Program**”
- Most providers now have an EHR – so they hold electronic data.
 - More than 8 in 10 physicians have some form of EHR (ONC Dashboard)
 - 95% of hospitals have adopted certified EHR under Meaningful Use (ONC)
- As part of this program, many providers and hospitals created **patient portals and/or can produce structured Summary of Care Documents**
 - Including ability for patients to “view, download or transmit” their health information in a computable format
- Most also have the ability so send email, create PDFs, etc.

HITECH also created a new HIPAA Right of Electronic Access



- The Health Insurance Portability and Accountability Act (HIPAA) was amended in 2009 to ensure that patients have a legal right to an electronic copy of their medical record.
 - If the provider can produce data electronically.
- Regulations implementing this right were finalized in 2013
- New clarifying guidance just issued by the Office of Civil Rights January 7th, 2016

Growing pains.....



"According to your HIPAA release form
I can't share anything with you."

Right of Electronic Access: As a patient, you can....



- HIPAA **right to request** an eCopy:
 - If the information can be produced electronically, patients can request it that way.
 - Including X-rays and images
- If their records are **paper**, patients can still request an **eCopy**, such as a scanned-in PDF. If the provider can technically do it they must.
 - But they don't have to buy special equipment.
- Patients can request the data be in a certain **format** (CCDA, CCR, PDF, XLS, etc.) – human or machine readable, or both
 - If the record can technically be generated in this format, it must be.
 - OCR : **Not a matter of willingness; it's a matter of capability.**
 - If format cannot be readily produced, must come to agreed upon alternative. (and if no agreement possible, revert to paper).

Right of Electronic Access:



- OCR also says that “Where the Covered Entity is providing electronic copy, we also expect the copy to be in machine readable form to the extent possible, consistent with the request.”
 - Again, providers don’t have to be ready for every electronic format
 - But do need to know what they are capable of and not (capable vs. willing)
- If the provider is using “Certified EHR” (e.g., Meaningful Use EHR, then electronic copy is readily producible.
- Provider can also offer the patient eCopy via Meaningful Use EHR patient portal, if the patient agrees/desires.
 - Doesn’t cover all the information in the HIPAA “designated record set” but is typically a fairly comprehensive record of care.

Right of Electronic Access:



- **Delivery:**

- Patients can negotiate delivery mechanisms, including: Unsecure email, secure email, regular mail, in person pick up, sent to an app, USB stick, CD ROM, etc.
- If provider can technically do it, and it poses no undue security risk **to their systems**, they must honor the request. Even if there is risk to the patient's data. Entity not responsible for disclosures resulting from insecure transmission if patient requested it.

- **Timeliness:**

- HIPAA sets records request timeline of 30 days with one extension if needed.
- OCR clarified: 30 day window is really for old, archived, not readily available info. Expect that if requests can be met sooner with electronically available info, 30 days is an “outer limit.”

Right of Electronic Access:



- **Fees:**

- Reasonable, cost-based:
 - Labor for copying PHI
 - Supplies for creating copy
 - Postage, if mailed
- Does not include*
 - Verification
 - Documentation
 - Search/retrieval
 - Maintaining systems
 - Recouping capital
 - Other costs

- Should per-page fees apply to electronically produced data?
We say no. Guidance forthcoming.

Given the positive impact health data has on patients' care and outcomes, GetMyHealthData believes it's a best practice to charge no fees – at least for the first annual copy of health data.

NEW RESOURCE!



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 patient's records to a mainstream email account (Gmail, etc.) at the patient's request. Providers should advise patients that traditional email may not be secure, and patients can decide to accept this risk. A patient can also request other methods, such as mobile health applications.

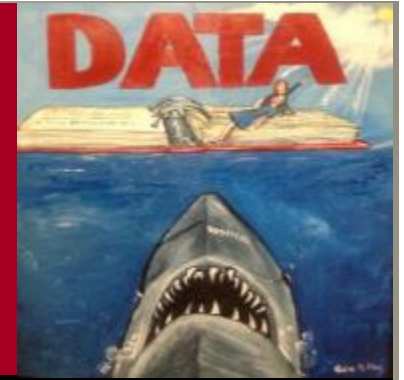
COST

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.



Tracer Patients.... Anyone can do it!



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.



What We're Learning...



- **Bright Spots**
 - Patient Portals – popular, but not perfect
- **Dazed & Confused**
 - Federal access policies may be in place but implementation highly variable
 - Request process overly complicated; too many ways it can go wrong
- **Culture Clash**
 - Many providers lack workflow for eCopies or are unaware of right of electronic access
 - Culture of resistance still the norm
- **Format Matters**
 - Data received is not always useful!
- **Show Me the Money**
 - Fees are barriers; lack of transparency

What We're Learning: Record Requests can be Costly



The screenshot shows the HealthPort website interface. At the top, there is a navigation bar with "Find Invoices", "Review Invoices", and "Pay Your Invoices". Below this, there is a form with the following fields:

- 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?

At the bottom of the form, there are "Cancel X" and "Yes »" buttons.

Below the screenshot is a tweet from a user (profile picture of a woman) dated 23 Dec 2015. The tweet text reads: "Merry Xmas to me? I just paid \$148.96 to access a e-copy (PDF) of my medical record from @HealthPort_Tech." The tweet also shows "You, Christine Bechtel, Sara and 6 others" and interaction icons for reply, retweet (3), and like (2).

What We're Learning: Format Matters

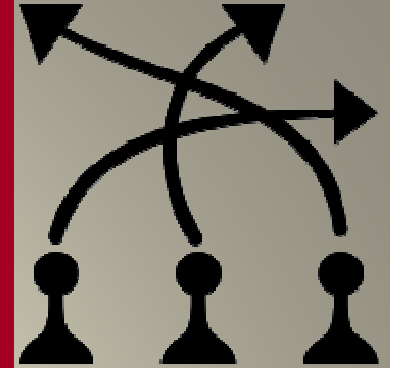


"I attempted to get my data from my primary care doc in an electronic file sent to my Direct address. After some discussion, the best they could offer was a CD... it is a 47 page PDF of many things and of varying sizes and resolutions...**Incomplete at best.** Nothing readable or computable in blue button or any other format."

"I have two binders and 8 discs. Swell."



What We're Learning: Culture of Resistance



“**Offices seem puzzled** [by patients asking for their data]. Practices in general have no email capabilities with patients, and respond begrudgingly to requests.”

One Georgia health system tells patients they can get their records “***If they ask correctly.***”

“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. Listen up! It’s my body, my health. I have the right to all relevant medical information. **How can I make informed decisions about my own health if I don’t have information?**”

⚠ 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](#)

📁 FORMAT MATTERS

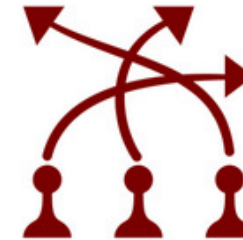


2 binders, 6 Discs

"Two binders, 6 discs, 4 patient portals, and still no longitudinal health record." —B.P. Lake ...

[Read More](#)

🏠 DAZED & CONFUSED

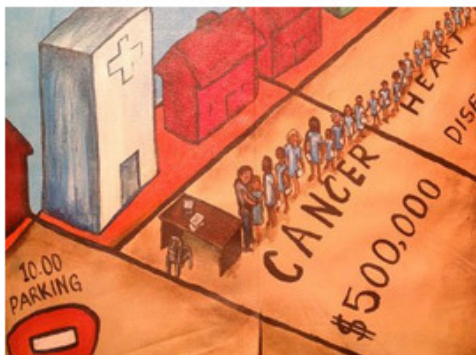


Still Waiting

"I have had various medical problems off and on my entire adult life and due to being an army wife ...

[Read More](#)

💰 SHOW ME THE MONEY



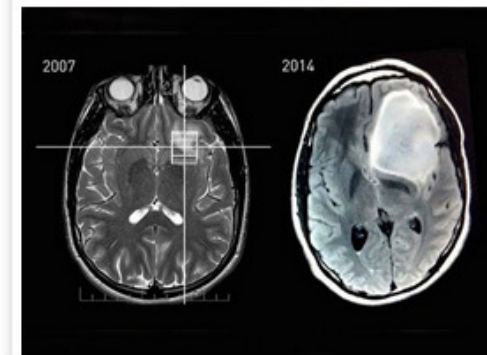
Ninety Dollars!

☀ BRIGHT SPOTS



Reports in Hand

☀ BRIGHT SPOTS



Clinical Data Came Quick

Troubleshooting & Provider Resources



Tips and resources to navigate common roadblocks to requests for your health data available at:

<https://getmyhealthdata.org/home/troubleshooting/>

<https://getmyhealthdata.org/provider-resources/>

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AHIMA | ANI | GetMyHealthData | www.getmyhealthdata.org

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Key Actions for Case Managers



1. Be a **Tracer** yourself.
2. Promote and leverage **online access** to health information in patient and family engagement, care coordination.
 - Understand what's possible, including view, download, transmit
3. Bring together the **records request staff with the health IT staff**
 - How do we meet requests in my organization? How can we do better? Are we giving patients the data they need and can use?
4. Use the Infographic
5. Give us feedback!

Contact Us:

christine@getmyhealthdata.org

www.getmyhealthdata.org



Question and Answer Session



Christine Bechtel, MA
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Commission for Case Manager Certification

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www.ccmcertification.org



Thank you!

- Please fill out the survey after today's session
- Those who signed up for continuing education will receive an evaluation from the Commission.
- A recording of today's webinar and slides will be available in one week at <http://ccmcertification.org>

