

# **An Individual's Right to Access and Obtain Their Health Information Under HIPAA**

## **Moderator**

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## **Panelists**

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# Objectives

- Discuss how the HIPAA right of access enables individuals to become more involved in their care
- Review key components of the HIPAA access right, including individuals' ability to direct a copy of their health information to a third party, including a researcher
- Suggest ways to integrate aspects of the access right into medical practice

# HIPAA Right of Access

- HIPAA provides individuals and their personal representatives with a legal, enforceable right to see and receive copies, upon request, of their health information
- Most healthcare providers, health plans, and business associates that maintain the health information must provide individuals with access



# HIPAA Privacy Rule Overview

- Effective April 14, 2003 – right of access<sup>[a]</sup>
- Who must comply?
  - **Covered entities**<sup>[b]</sup>
    - Most healthcare providers who transmit data electronically
    - Health plans
    - Healthcare clearinghouses
  - **Business associates**<sup>[c]</sup>
    - Any person or organization that functions on behalf of a covered entity that involves use or disclosure of identifiable health information
    - Examples: billing, coding, analytics, electronic health record vendor

a. HHS. Health Information Privacy. HIPAA for professionals. <https://www.hhs.gov/hipaa/for-professionals>;

b. HHS. Health Information Privacy. Covered entities and business associates. <https://www.hhs.gov/hipaa/for-professionals/covered-entities/index.html>; c. HHS. Health Information Privacy Business associates.

<https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/business-associates/index.html>.

# HIPAA Privacy Rule Overview (cont)

## Goals

- **Provide strong federal protections for privacy rights**
  - Patients should understand that the goal is to protect them
  - Ensure that individuals trust in the privacy and security of their health information
- **Encourage open communication with providers**
- **Make sure that the right information is flowing to the right people at the right time**
  - Make sure staff interacting with patients have the ability to explain the goals of HIPAA

# HIPAA Education

**Remember that patients may come from countries where completing a government form may not be in their best interest, yet they still desire to share their health information**

- Instructing the front staff about how to educate patients will decrease patients' angst and mistrust of the provider
- Do provide support services for translation



# What Is Protected Health Information (PHI)?

Information that

- Relates to
  - The individual's past, present, or future physical or mental health or condition
  - The provision of health care to an individual
  - Past, present, or future payment for the provision of health care to the individual
- And
  - Identifies the individual, or
  - There is a reasonable basis to believe it can be used to identify the individual



# Benefits of Providing Individuals Access to Their Data

- Increases people's engagement in their care
- Improves overall patient experience/CAHPS score
- Makes patients more aware of their condition
- Prepares patients better for office visits
- Seeing their healthcare information in writing motivates patients to improve their self-care and aids their decision making about what additional care is required
- Checking their own records makes it easier for patients to remember to schedule a follow-up appointment
- Sharing records with other providers is easier for patients when they have access to the records themselves

# Key Aspects of the HIPAA Right of Access

- Scope of information and request procedures
- Form, format, and manner of access
- Timeliness
- Fees
- Directing copy to a third party

# Scope of Information and Request Procedures

- The right to access applies to all information in a **“designated record set,”** which broadly includes medical, payment, and other records used to make decisions about individuals
  - EVERYTHING in the electronic health record
  - Patient notes
  - Medications
  - Lab results
  - X-rays
  - Procedure and discharge notes
- It does not matter how old the information is, where it is kept, or where it originated

HHS. Health Information Privacy. Individuals' right under HIPAA to access their health information.  
<https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/access>.

HHS. Health Information Privacy. HHS strengthens patients' right to access lab test reports.  
<https://www.hhs.gov/hipaa/for-professionals/special-topics/clia/index.html>.



# Scope of Information and Request Procedures (cont)

- **There are very limited exclusions from the right to access**
  - Psychotherapy notes that are kept separate from the patient's other records
  - PHI compiled for litigation
    - BUT underlying PHI is required to remain accessible
  - Records not used to make decisions about individuals
- **Not sufficient to deny access**
  - Failure to pay for healthcare services
  - Concerns that individual may not understand the PHI or be upset by it

HHS. Health Information Privacy. Individuals' right under HIPAA to access their health information.

<https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/access>.

HHS. Health Information Privacy. HIPAA privacy rule and sharing information related to mental health.

<https://www.hhs.gov/hipaa/for-professionals/special-topics/mental-health/index.html>.



# Request Procedures

- **An individual or their personal representative can request their health information at any time, for any reason**
  - You may require a written request, and it can be electronic
  - Required: verify identity of requesting individual
- **Procedures cannot create a barrier to, or unreasonably delay, an individual's access**
  - Example: cannot require individuals to mail an access request or make a separate trip to the office to request access
  - Providers are encouraged to offer multiple options for requesting access and obtaining the information

# Form, Format, and Manner of Access

**An individual has the right to receive a copy of PHI in the form and format requested if “readily producible”**

- Depends on the entity’s capabilities, not its willingness
- If information is maintained electronically, at least 1 type of electronic format must be accessible by the individual
- The individual has a right to specify the mode of transmission or transfer
  - Has a right to receive information by email (or mail), including unsecure email if requested by individual (give light warning about security risks)
  - Other modes: accommodate request if within capabilities of entity and the mode would not present unacceptable security risks to PHI on the entity’s systems

# Form, Format, and Manner of Access (cont)

- The provider must give the patient access even if the provider knows the patient is planning to do something with the data that may not be in their best interest
- The patient has the right to choose what to do with their data, such as putting it online or using a consumer application with poor security



# Timeliness and Fees

- Access must be provided within 30 days
  - One 30-day extension is permitted
  - Providers are expected to respond much sooner if possible
- Limited fees may be charged
  - Reasonable, cost-based fee for labor for copying, or creating summary or explanation
  - If applicable, cost of supplies and postage
- No fee is allowed for search and retrieval or other costs, even if authorized by state law



# Timeliness and Fees (cont)

- Individuals must be informed in advance of approximate fee
- Providers are strongly encouraged to provide free copies
- Educate office staff, including those answering the phone and doctors receiving such texts, to document all requests in a central place
  - Document the date the request was made

# Directing PHI to Third Party

- **An individual has the right to have the entity directly transmit PHI to a third party of the individual's choice**
- **Examples of third parties**
  - Primary care physician
  - Friend, family member, or caregiver
  - Mobile health application
  - Research institution
- **A signed, written request from the individual is required** (can be virtual)
- **The requirements are the same as for providing access directly to the individual** (eg, fee limitations, form and format, timeliness)

HHS. Health Information Privacy. Individuals' right under HIPAA to access their health information. <https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/access>.

HHS. Health Information Privacy. Research. <https://www.hhs.gov/hipaa/for-professionals/special-topics/research/index.html>.

# Directing PHI to Third Party (cont)

- **Requests for mobile health applications will grow with adoption of health IT**
  - Prepare now for the wave of mobile health applications
- **The third party can be a researcher**
  - For example, individuals participating in the *All of Us Research Program* (formerly The Precision Medicine Initiative [PMI] Cohort Program) can share their data online with this important initiative or with other clinical trials



# Directing PHI to Third Party (cont)

- The third-party transfer may be to a competitor and may be repeated multiple times
- The fact that a hospital just asked for a patient's information, and that information was sent to the hospital, does not mean the patient cannot later ask for PHI to be sent to the same entity or another entity
- **Resources are at issue in any center**
  - It is not all right to suggest that the patient get medical information from the hospital just because the hospital can better defray the cost



# HIPAA Access Educational Tools

## OCR's Fact Sheet & Frequently Asked Questions:

*Individuals' Right Under HIPAA to Access their Health Information 45 CFR § 164.524 and Questions and Answers About HIPAA's Access Right*

- <http://www.hhs.gov/hipaa/for-professionals/privacy/guidance/access/index.html>

## HHS consumer-facing videos and infographic: *Your Rights Under HIPAA*

- <http://www.hhs.gov/hipaa/for-individuals/guidance-materials-for-consumers/index.html>

## HIMSS Privacy & Security Toolkit

- <http://www.himss.org/library/healthcare-privacy-security/toolkit>

# HIPAA Access: Key Messages

- **With few exceptions, individuals and their personal representatives can access and receive a copy of their health information in medical records or other records used to make decisions about the individuals**
  - In the form and format that individuals request
  - As long as providers can produce it that way
- **If an entity maintains the requested health information electronically, it must offer individuals access in at least 1 type of electronic format**
- **Providers cannot have unreasonable measures in place**

# HIPAA Access: Key Messages (cont)

- Providers should produce the information no later than 30 days from the date of request
- If a fee is charged for copies, the fee must be limited
- Providers are encouraged to supply copies free of charge and to respond to requests as soon as possible



# HIPAA Access: Key Messages (cont)

A patient can direct a provider to send a copy of their health information to a third party, including:

- A mobile app
- A family member
- A researcher for medical research



# Abbreviations

CAHPS = Consumer Assessment of Healthcare Providers and Systems

FHIR = Fast Healthcare Interoperability Resources

HIMSS = Healthcare Information and Management Systems Society

HIPAA = Health Insurance Portability and Accountability Act

IT = information technology

PHI = protected health information