HIPAA Regulations and Sharing Sensitive Information About Clients With Dementia

Charlie Sabatino, ABA Commission on Law and Aging
Rachel Seeger, Office for Civil Rights, U.S. Dept. of Health & Human Services

National Alzheimer’s and Dementia Resource Center Webinar Series
September 27, 2017
Dementia complicates HIPAA issues because...

- Capacity to consent to disclosure becomes a common issue.

- Reliance on representatives and other interested parties is more common.

- Where there are no representatives or natural family or friends, health care providers may have to reveal PHI to a wider range of persons in a search for information on the patient’s family and personal history.
The HIPAA Landscape

**STATUTE (HIPAA)**
The Health Insurance Portability and Accountability Act of 1996, Public Law 104-191

**REGULATION**
Four Major Rules:

- **The Privacy Rule** (45 CFR Part 160 and Subparts A and E of Part 164)
- The Security Rule
- The Breach Notification Rule
- The Enforcement Rule
Covered Entity

1. A Health Care Provider (such as doctors, clinics, psychologists, dentists, chiropractors, nursing homes, home health agencies, pharmacies, and other professionals)

   ...who furnish, bill, or receive payment for, health care in the normal course of business

   ...but only if they transmit any information in an electronic form in connection with a transaction for which HHS has adopted a standard.
Covered Entity

2. A Health Plan. This includes Health insurance companies, HMOs, company health plans, government programs that pay for health care (such as Medicare, Medicaid), and the military and veterans health care programs.

3. A Health Care Clearinghouse. This includes entities that process nonstandard health information they receive from another entity.
**Individually Identifiable Health Information**

Information, including demographic data, that relates to past, present, or future:

- physical or mental health or condition,
- provision of health care to the individual, or
- payment for the provision of health care to the individual,

and that identifies the individual or for which there is a reasonable basis to believe it can be used to identify the individual.

This includes many common identifiers (e.g., name, address, birth date, Social Security number … even your weight….)
Protected Health Information (PHI)

Individually identifiable health information that is:

- transmitted by electronic media;
- maintained in electronic media; or
- transmitted or maintained in any other form or medium.

Several exceptions, most notably:

- disclosures about victims of abuse, neglect, or domestic violence; and
- uses and disclosures to avert a serious threat to health or safety.
**Personal Representative**

A person who has authority to act on behalf of an individual who is an adult or an emancipated minor in making decisions related to health care.

Includes:
- Agent under Health Care Power of Attorney (POA).
- Legally authorized default surrogate under state law.
- Guardian with health decisions authority.

A covered entity must, with some exceptions, treat a personal representative as the individual for purposes of the Privacy Rule.
HIPAA Disclosure Pathways

... to Individual’s Family & Friends

1. Recipient is a Personal Representative
2. There’s a written HIPAA Authorization
3. There’s a written Right of Access Direction
4. Discretionary Disclosures
HIPAA Disclosure Pathways

... to Individual’s Family & Friends

1. Recipient is a *Personal Representative*

Person has same right of access as the individual, absent special circumstances such as suspected abuse.
… to Individual’s Family & Friends

2. Written HIPAA Authorization

A permission to release used by providers. Privacy Rule provides specific elements that health care providers must include regarding scope, purpose, and duration.

<table>
<thead>
<tr>
<th>HIPAA AUTHORIZATION FORM</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I hereby authorize the use or disclosure of my protected health information as described below.</td>
</tr>
<tr>
<td>Individual: ___________________</td>
</tr>
<tr>
<td>Persons or organizations providing information: ___________________</td>
</tr>
<tr>
<td>Description of information to be disclosed (including dates of service): ___________________</td>
</tr>
<tr>
<td>Describe the purpose or intended use of information: ___________________</td>
</tr>
</tbody>
</table>

(Note: “at the request of the individual” is adequate if the individual initiated authorization without a stated purpose.)

2. COMPLETE THIS SECTION IF HEALTHCARE PROVIDER REQUESTED AUTHORIZATION. |
| Healthcare provider: Will the healthcare provider receive financial or in-kind compensation in exchange for using or disclosing the health information described above? Yes No |
| Individual: I understand that I get a copy of this form after I sign it. | initals: |

3. YES, YOU MAY DISCLOSE INFORMATION ABOUT ALCOHOL/SUBSTANCE ABUSE, HIV/AIDS, OR...
3. Right of Access Direction

Mandates release, absent special circumstances. Must be in writing, signed by the individual, and clearly identify the designated person and where to send the copy of protected health information.

No prescribed form. See sample in materials.
… to Individual’s Family & Friends

4. Discretionary Disclosures
   - If patient says okay,
   - If patient is present and does not object,
   - If patient is incapacitated or not present and provider determines, based on professional judgment that it’s in patient’s best interest. (Lots of discretion here!)
Discretionary Disclosures are limited to just the information that the person involved needs to know about the person’s care or payment.

HIPAA penalties primarily target failure to preserve privacy and security, not failures to disclose information.
OCR’s Access Guidance

HIPAA Right of Access Guidance

- Issued in two phases in early 2016
  - Comprehensive Fact Sheet
  - Series of FAQs
    - Scope
    - Form and Format and Manner of Access
    - Timeliness
    - Fees
    - Directing Copy to a Third Party, and Certain Other Topics
Designated record set broadly includes medical, payment, and other records used to make decisions about the individual

- Doesn’t matter how old the PHI is, where it is kept, or where it originated
- Includes clinical laboratory test reports and underlying information (including genomic information)
Very limited exclusions and grounds for denial

- For example, psychotherapy notes, information compiled for litigation, records not used to make decisions about individuals (e.g., certain business records) BUT underlying information remains accessible
- Covered entity may not require individual to provide rationale for request or deny based on rationale offered
- No denial for failure to pay for health care services
- Concerns that individual may not understand or be upset by the PHI not sufficient to deny access
Access – Requests for Access

- Covered entity may require written request
- Can be electronic
- Reasonable steps to verify identity
- **BUT** cannot create barrier to or unreasonably delay access
  - For example, cannot require individual to make separate trip to office to request access
Form and Format, Manner of Access

Individual has right to copy in form and format requested if “readily producible”

- If PHI maintained electronically, at least one type of electronic format must be accessible by individual
- Depends on capabilities, not willingness
- Includes requested mode of transmission/transfer of copy
  - Right to copy by e-mail (or mail), including unsecure e-mail if requested by individual (plus light warning about security risks)
  - Other modes if within capabilities of entity and mode would not present unacceptable security risks to PHI on entity’s systems
Access – Timeliness and Fees

- Access must be provided within 30 days (one 30-day extension permitted) BUT expectation that entities can respond much sooner
- **Limited** fees may be charged for copy
  - Reasonable, cost-based fee for labor for copying (and creating summary or explanation, if applicable); costs for supplies and postage
  - No search and retrieval or other costs, even if authorized by state law
  - Entities strongly encouraged to provide free copies
  - Must inform individual in advance of approximate fee
Third-Party Access to an Individual’s PHI

- Individuals’ right of access includes directing a covered entity to transmit PHI directly to another person, in writing, signed, designating the person and where to send a copy (45 CFR 164.524).
- Individuals may also authorize disclosures to third parties, whereby third parties initiate a request for the PHI on their own behalf if certain conditions are met (45 CFR 164.508).
Sharing Health Information With Family, Friends, and Caregivers Under HIPAA

• HIPAA sets rules for health care providers and health plans about who can look at and receive an individual’s health information, including family members, friends, and caregivers.
• The HIPAA Privacy Rule ensures that individuals have rights over their health information, including the right to get a copy of their information, make sure it’s correct, and know who has seen it.
When Health Information May be Shared

Under HIPAA, a health care provider may share information face to face, over the phone, or in writing. A health care provider or health plan may share relevant information if:

• A provider or plan has been given permission to share information by an individual or personal representative.

• The individual is present and does not object to sharing the information.

• The individual is not present or incapacitated, and the provider determines based on professional judgment that it’s in the person’s best interest.
What Happens if an Individual Wants Health Information Shared With Family, Friends, and Caregivers?

- HIPAA requires most doctors, nurses, hospitals, nursing homes, and other health care providers to protect the privacy and security of health information.

- However, if an individual does not object, a health care provider or health plan may share relevant information with family members, friends, and caregivers involved in health care or payment for health care in certain circumstances.
Examples

• An emergency room doctor may discuss an individual’s treatment in front of a friend when a friend is asked to come into the treatment room.

• A hospital may discuss a bill with an individual’s daughter who is with the patient and has a question about the charges if the individual does not object.

• A doctor may discuss the medication a patient needs to take with a health aide who has come with the patient to his or her appointment.

• A nurse may not discuss a patient’s condition with his or her brother if he or she tells the nurse not to.

• HIPAA also allows health care providers to give prescription drugs, medical supplies, x-rays, and other health care items to a family member, friend, or other person sent to pick them up.
What Happens When an Individual is Not Available for Permission?

A health care provider or health plan may also share relevant information if an individual is not present or cannot give permission when a health care provider or plan representative believes, based on professional judgment, that sharing the information is in the patient’s best interest.
Examples

- A patient has had emergency surgery and is still unconscious. The surgeon may tell a spouse about the patient’s condition, either in person or by phone, while he or she is unconscious.
- A doctor may discuss medications with a caregiver who calls a doctor with a question about the right dosage.
- A doctor may not tell a friend about a past medical problem that is unrelated to the patient’s current condition.
OCR’s new Right to Access Resources

OCR has launched a new consumer education campaign: https://www.hhs.gov/GetItCheckItUseIt

Access to your health information is your right

Get it. Check it. Use it.

Learn about HIPAA and your health information rights at: www.HHS.gov/GetItCheckItUseIt

Health Insurance Portability and Accountability Act
Information is key to making good health care decisions. Understand your health history to ask better questions and make healthier choices. Track your lab results and medications, get x-rays and other medical images, or share your information with a caregiver or a research program.
Clear and concise

- **Get it:** Covers Form and Format and Manner of Access, Time and Timeliness, Fees
- **Check it:** Check to make sure your health information is correct and complete
- **Use it:** Right to Third Party Access, including researcher.
HHS.gov/GetItCheckItUseIt

Clear and concise

• Links to Fact Sheets and FAQs
• Videos
• Poster
• Brochure
• Digital Ads and Banners
• Mobile Platform
• Link to Join All of Us
OCR has teamed up with the HHS Office of the National Coordinator for Health IT to create a series of three short, educational videos (in English and an option for Spanish captions) as well as an infographic to help individuals understand their right under HIPAA to access and receive a copy of their health information.

- Individual’s Right under HIPAA to Access their Health Information
- HIPAA Access Associated Fees and Timing
- HIPAA Access and Third Parties

[https://www.healthit.gov/access](https://www.healthit.gov/access)
Access: A Fundamental Right Under HIPAA

DID YOU KNOW?

- 8 in 10 individuals who have viewed their medical record online considered the information useful.¹
- 27% of individuals were unaware or didn’t believe they had a right to an electronic copy of their medical record.¹
- 41% of Americans have never even seen their health information.²
- HIPAA (Health Insurance Portability and Accountability Act of 1996) gives us the right to access our health information.
A Patient’s Guide: When Health Care Providers May Communicate About You with Your Family, Friends, or Others Involved In Your Care

A PATIENT’S GUIDE TO THE HIPAA PRIVACY RULE:

When Health Care Providers May Communicate About You with Your Family, Friends, or Others Involved In Your Care

U.S. Department of Health and Human Services • Office for Civil Rights

The U.S. Department of Health and Human Services (HHS) enforces the Federal privacy regulations commonly known as the HIPAA Privacy Rule (HIPAA). HIPAA requires most doctors, nurses, pharmacies, hospitals, nursing homes, and other health care providers to protect the privacy of your health information. Here is a list of common questions about HIPAA and when health care providers may discuss or share your health information with your family members, friends, or others involved in your care or payment for care.

COMMON QUESTIONS ABOUT HIPAA

1. If I do not object, can my health care provider share or discuss my health information with my family, friends, or others involved in my care or payment for my care?

Yes. As long as you do not object, your health care provider is allowed to share or discuss your health information with your family, friends, or others involved in your care or payment for your care. Your provider may ask your permission, may tell you he or she plans to discuss the information, and give you an opportunity to object, or may decide, using his or her professional judgment, that you should have the opportunity to object. In any
Access FAQs

- Scope
- Limited exceptions
- Form and format
- Timeliness
- Fees
- Right to an electronic copy of information in an Electronic Health Record (EHR)

https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/access/index.html
More Questions?

https://www.hhs.gov/hipaa

Sign up for the OCR Privacy & Security Listserv https://www.hhs.gov/hipaa/for-professionals/list-serve/