

BARRIERS ASSOCIATED WITH ACCESSING RECORDS OF THE DECEASED

A Glimpse into Real-World Access Barriers After Death

Scenario 1:

"I need a copy of my husband's medical records from his recent stay in the ICU. I just received a bill in the mail for over \$74,000, and I need to appeal it with the insurance company."

"The patient needs to sign a HIPAA form to authorize the record's release."

"My husband died in the ICU last month. I'm his wife of over 40 years and have been his advocate throughout his care. I need to take care of this bill."

"Ma'am, we can't do that because of HIPAA."

Scenario 2:

"I'd like to request a copy of my mother's medical records. Because of COVID-19 No Visitor Policies, I was unable to be at her side while she was at the hospital."

"We need a signed records request from the patient returned to our attention."

"My mother died from COVID-19. I need a copy of her records to understand what happened. No one called us with updates. We didn't know she was so sick. Please, I just need to understand her last days on this earth."

"Unfortunately, without a letter from an attorney, we can't release her records to you because of HIPAA."

Scenario 3:

A patient's life partner drops off a completed medical records request, a copy of the legal documentation authorizing them as the patient's personal representative, and a copy of the deceased's death certificate to the patient's physician's office.

The doctor's office denies the request "because of HIPAA," stating that the life partner was not the legal spouse or next of kin of the patient. Even with legal documentation authorizing them as the personal representative, the life partner is told they will need an attorney and a court order to get a copy of the deceased's medical records.

When Barriers to Access Extend After Death

Patients and their primary carepartners may face a wide range of barriers when attempting to access their medical records. Loved ones often encounter even steeper challenges when requesting access to records of the deceased. These barriers to access are significantly underreported. The AMA has curated resources and the following tips as guidance for physicians and practices to avoid HIPAA misunderstandings, prevent unnecessary burdens for both patients and practices when accessing a deceased patient's medical records, and prevent breakdowns in trust and communication between families, physicians, and practices, which may lead to additional trauma.

Health Insurance Portability and Accountability Act (HIPAA): In Life & Death

The [Health Insurance Portability and Accountability Act \(HIPAA\) Privacy Rule](#) (the Rule) establishes rules around how protected health information (PHI) is used, stored, and disclosed to ensure it is not wrongfully used or improperly accessed. HIPAA applies not only throughout a patient's life, but also protects an individual's PHI and right to privacy for [up to 50 years after the individual's death](#). Any medical records containing the PHI of individuals who have been deceased for more than 50 years fall outside of the Rule's protections. While the Rule offers protection for up to 50 years after the date of an individual's death, it does not require [mandatory medical records retention](#) and archiving for the corresponding 50-year time frame. All covered entities should refer to applicable State and other laws (i.e., military, tribal) defining the timing of required proper storage and destruction of such records.

Access After Death: The Designated Personal Representative

A patient's designated personal representative or legal executor of their estate has [a right by law to access and copy the deceased's medical records](#). To request access to the deceased's medical records, the designated personal representative or executor of the estate will typically need to present the following to establish proof of authorization:

- documentation verifying personal representative status or estate executorship;
- the patient's death certificate; and
- completed [medical records request form](#) (see [AMA Electronic Records Patient Access Playbook](#), Appendix D, p.91)

Note that each state has its own process and requirements for designating a person to assist an individual with medical decision making. That person may be known as different things across states (e.g., legal executor, power of attorney, health proxy, etc.) and may have varying scopes of power or authority. Physicians should understand at least some of the basics for the state in which they practice to help advise patients with questions about personal representatives for medical decision making.

All physicians, practices, and healthcare delivery organizations (HDOs) must be aware of socioeconomic, language, health, and digital literacy barriers that typically prevent individuals from legally appointing an executor of their estate. Traditionally marginalized communities and immigrant populations with limited English proficiency may not have equitable access to estate planning nor know about the importance of designating a personal representative. Similarly, individuals may not fully understand their rights to access a deceased patient's medical records under HIPAA.

Clinicians should recognize that both in these population settings and more broadly, there are typically three main barriers to patient's establishing personal representatives:

- Individuals may feel estate planning processes are for the wealthy, not "people like me."
- Individuals may not realize that designating a personal representative is about more than managing an estate or possessions.
- Many individuals cannot afford legal expertise to prepare the necessary paperwork to designate a personal representative.

Practices should consider seeking out resources in their patient population's communities to help patients with estate planning, such as legal aid, community health law projects, and medical legal partnerships. Ideally, these resources should be accessible to those of all incomes and those who speak languages other than English.

Clinicians may want to initiate conversations with their patients about establishing a personal representative, explaining that a representative can assist with care management and coordination both while the patient is alive and after their death. If a patient dies without naming a personal representative or executor, state laws often define a hierarchy as guidance based on an individual's relationship to the deceased patient. This hierarchy typically begins with an adult member of the immediate family, such as a spouse, parent, adult child, or sibling.

Barriers Associated with Accessing Records of the Deceased

If a patient has not designated a personal representative, covered entities and providers, using their professional judgment and acting in the patient's best interest, are permitted by the Rule to disclose only the PHI that is directly relevant to the individual's involvement in the patient's care, in compliance with [45 CFR 164.510\(b\)](#). This permitted disclosure is acceptable unless the patient, at any juncture before their death, explicitly expressed any objections about such sharing to the covered entity or physician.

Key Takeaways

- It is critically important to educate patients and their families proactively about the importance of designating a personal representative or executor of their estate in the event that a patient should be incapacitated or die. Point of care [educational materials](#), written at an appropriate health literacy and available in other languages, may help to bridge current existing informational gaps. The AMA has also developed an [End-of-Life Care CME module](#) to facilitate early discussions with patients.
- Health information management (HIM) professionals should be incorporated as an extension of the care team to help facilitate conversations and workflows to proactively obtain appropriate authorization in advance of an individual's incapacitation or death, where possible. HIM professionals should also assist in guiding personal representatives, primary carepartners, and family members through the complexities of requesting medical records of the deceased.
- Physician and their staff should refer to the [AMA Patient Records Electronic Access Playbook](#), Appendix D, p. 92, [Authorization for Use and Disclosure](#), and proactively encourage all patients to designate a person to receive their health information (line item 3) and to consider specifying that the authorization "persists after my death" as the "event", where applicable, the authorization expires (line item 5).
- Physicians, providers, and their HIM professionals must be educated to dispel HIPAA misinformation to prevent unnecessary information blocking and barriers to access, especially in the setting of actively grieving family and loved ones. Physicians, professionals, and supporting staff that may be at the interface of medical records requests of the deceased may benefit from basic training not only in what HIPAA allows and requires, but also in empathetic communication to improve encounters and prevent breakdowns in trust and communication during what may be a very tragic time during families' lives. The AMA has created an [Empathetic Listening CME module](#) to build trust and improve patient experience. Additional resources, including those offered by organizations like [Cleveland Clinic](#), can be found online.
- Designated personal representatives are typically required to present legal documentation authorizing the individual to act as a representative, a death certificate, and a signed [Patient Record Request Form](#) ([AMA Patient Records Electronic Access Playbook](#), Appendix D, p.91)
- Physicians and their staff must recognize that, in the event of a patient's death where a personal representative has not been legally designated, the Rule permits the disclosure of only the PHI that is directly relevant to the individual's involvement in the patient's care. While these disclosures are permitted (i.e., not required), it is critically important to recognize that physicians are not prohibited by HIPAA from sharing this information. Practices should view and process these requests with empathy, attempting to proceed as the patient would have wished.

Frequently Asked Questions (FAQs)

Why does a family member or primary carepartner/caregiver need to access the health information of the deceased?

There are many reasons that primary carepartners and families may need access to their deceased loved one's medical records:

- They may need access to address administrative issues with respect to billing, social security disability claims, worker's compensation, or life insurance policies.
- They may want to better understand their loved one's medical history, especially in the context of cancer, hereditary conditions, cardiac conditions, and other comorbidities.
- They may be interested in passing down medical records as part of their family legacy.
- They may need access to help with the grieving process.
- They may want to contribute records to ongoing clinical or scientific research, whether it is for COVID-19 or other diseases, like cancer or a rare disease.

Can records of patients who have been long-deceased for over 50 years be accessed for genealogy and hereditary research?

Yes. The Privacy Rule does not apply 50 years after the patient's death, and these records are no longer subject to the Privacy Rule. State laws may apply.

Are personal representatives and primary carepartners able to access electronic copies of a deceased patient's records?

Yes, personal representatives must be treated as the individual with respect to the Rule, as defined by the Rule in [Section 164.502\(g\)](#). However, there are instances where an individual has not expressly authorized another person to act on the individual's behalf. Persons who are involved in the individual's health care may be considered "carepartners" and, like family members, are permitted to have access to the deceased's PHI, as defined by the Rule in [45 CFR 164.510\(b\)](#). Since these individuals must be treated as the individuals, covered entities are required to provide the individual with access to the PHI in the form and format requested, if readily producible in that form and format, as per the Rule at [45 CFR 164.524\(c\)\(2\)\(i\)](#). In some instances, a carepartner's access to an individual's PHI is related to the carepartner's authority to act on the behalf of a living individual in making decisions related to health care. In instances where a carepartner's authority to act for the individual is limited or specific to particular health care decisions, the carepartner is to be treated as the individual only with respect to the PHI that is relevant to the representation.

Additional Resources On Accessing Medical Records of Deceased Patients

Journal of AHIMA: [Who Has Rights to a Deceased Patient's Records?](#)

HHS.gov: [Health Information of Deceased Individuals](#)

HHS.gov: [Personal Representatives: 45 CFR 164.502\(g\)](#)

HHS.gov: [Family and Friends](#)

HealthIT.gov [Resources and Tools for Consumers](#)

OCR: [A Patient's Guide to the HIPAA Privacy Rule](#)

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