Changes to the Privacy Rule of HIPAA
Update for Society of American Archivists
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Background and Dates

• 1996 - Health Insurance Portability and Accountability Act (HIPAA) adopted by Congress
• April 14, 2003 - Privacy Rule of HIPAA goes into effect
• July 2010 - OCR proposes changes to the Privacy Rule as a result of the HITECH ACT
• January 25, 2013 - OCR publishes its final rule to implement the privacy and enforcement provisions of the HITECH Act and modifies the HIPAA Privacy, Security and Enforcement rules issued under HIPAA
• March 26, 2013 - Effective date
• September 23, 2013 – Compliance date
• September 23, 2014 – Deadline for covered entities revise existing Business Associate Agreements
Who is covered by HIPAA and the changes in HIPAA?

• Covered Entity - A health plan, a health care clearinghouse, or a health care provider who transmits health information in electronic form in connection with a transaction for which HHS has adopted a standard.

• Business Associates of Covered Entities - A person or entity that performs certain functions or activities that involve the use or disclosure of protected health information on behalf of, or provides services to, a covered entity.
Definition: Protected Health Information

• PHI is individually identifiable health information transmitted or maintained in any form or medium (electronic, oral, or paper) by a covered entity or its business associates, excluding certain educational and employment records and excluding information on those individuals who have been deceased for longer than 50 years.
Change in the Definition of Decedent PHI

• Between April 14, 2003 and March 25, 2013, Protected Health Information of decedents was defined as being protected by HIPAA in perpetuity.

• Starting March 26, 2013, PHI no longer includes health information of individuals who have been deceased for over 50 years, i.e., those who died before March 26, 1963.

• New definition lifts protection for individually identifiable health information of those known to be deceased for 50+ years.

• HHS declined to designate a date from record creation when records would be presumed to relate to individuals deceased 50+ years.
Information may still be protected by State Medical Records Statutes

HIPAA does not define the term “Medical Record”

Consult with legal counsel regarding what categories of information and formats would be considered part of the state law’s definition of a “medical record” and how institutional policy applies that definition.

Medical records traditionally include:

• Unit medical record, whether paper or electronic, usually held by hospital medical records office or other provider based centralized filing systems
• Other records used to make health care decisions about the individual patient
Other HIPAA Changes: GINA and Sale of PHI

• Genetic Information Nondiscrimination Act of 2008 (GINA)
  – Clarifies that genetic information is health information under the Privacy Rule.
  – “Genetic information” includes information about genetic tests and about diseases and disorders manifested in an individual’s family member (i.e., family health history).

• Sale of PHI
  – Covered Entity may no longer receive any direct or indirect remuneration in exchange for PHI without prior patient/personal representative authorization.
  – Exceptions include:
    • to provide an individual with a copy of their own record
    • Research
    • Under those exceptions, remuneration is limited to the reasonable cost to provide the PHI
Other HIPAA Changes: Disclosure about a Decedent to Family Members and Others Involved in Care

• Final Rule permits Covered Entities to disclose a decedent’s PHI to family members and to others who were involved in the care or payment for care of the decedent prior to death, unless doing so is inconsistent with any prior expressed preference of the decedent that is known to the Covered Entity.

• The Final Rule did not address comments submitted by archivists asking whether the permitted disclosures to family members could be extended to requests from genealogists for information about family members who have been deceased for less than 50 years.

• Absent confirmation from HHS, it is safer to assume that this provision does not extend to medical genealogy requests.

• Assume this is limited to requests involving the health of the patient during the period immediately surrounding death.
Is the information Individually Identifiable Health Information? [Health information containing any of the 18 specified HIPAA identifiers]

No

Legally permitted to disclose

Yes

Did the information come from a medical record?

No

Is the individual deceased for more than 50 years?

Yes

Legally permitted to disclose

No

HIPAA requirements to disclose

Yes

Is the individual deceased for more than 50 years?

No

HIPAA requirements and Maryland Law requirements to disclose

No

Meet Maryland law requirements to disclose

Yes

Policy Considerations

[• Should attempt to honor any limitations or refusal from a personal representative of which we are aware.]

[• Others?]
Determining if an individual subject of PHI has been deceased for more than 50 years

Is the death date known?

Yes

Less than 50 years ago

Not covered by HIPAA

More than 50 years ago

Covered by HIPAA

No

Determine the age of the subject at the date of record creation.

Determine how old the subject would have been 50 years ago.

Less than 70 years old

Individual is likely to have been alive 50 years ago.

Information about this individual is still likely protected by HIPAA

Between 70 to 85 years old

Individual may have been alive 50 years ago.

Information about this individual may still be protected by HIPAA

Between 85 to 100 years old

Likelihood that the individual was alive 50 years ago decreases.

Information about this individual is of decreased likelihood to be protected by HIPAA

Between 100 to 115 years old

Individual unlikely to have been alive 50 years ago

Information about this individual is unlikely to be protected by HIPAA

Over 115 years old

Individual would have been deceased 50 years ago

Information about this individual is highly unlikely to be protected by HIPAA

Decision tree prepared by Phoebe Evans Letocha, Collections Management Archivist, Johns Hopkins Medical Institutions, 5/14/2013