

Health and Human Services Privacy Act Regulations

Federal Law: Health and Human Services (HHS) Privacy Act Regulations

Citation: [5 U.S.C. § 552a](#); [45 C.F.R. Part 5b](#)

The HHS Privacy Act Regulations implement the requirements of the Privacy Act of 1974 for HHS.

THE LAW

What does the law do?

The Department of Health and Human Services (HHS) Privacy Act Regulations implement the requirements of the [Privacy Act of 1974](#) for HHS. The HHS Privacy Act Regulations protect records and systems of records maintained by components of HHS. Records are protected by the HHS Privacy Act Regulations if they [can be retrieved from a records system by using a personal identifier](#).

To whom does the law apply?

The HHS Privacy Act Regulations apply to [all components of HHS](#) as well as certain non-federal entities that carry out federal functions, [HHS contractors](#), and advisory committees and councils.

How is “identifiable” information defined?

The HHS Privacy Act Regulations define a “record” as a collection or grouping of information about a living individual that [“contains his name, or an identifying number, symbol, or other identifying particular assigned to the individual, such as a finger or voice print or a photograph.”](#)

SHARING OF IDENTIFIABLE DATA

Does this law allow identifiable data to be shared?

A record can be disclosed if the subject of the record [consents in writing](#) to its release. A record can also be disclosed [without consent](#) in the following situations: 1) disclosures to HHS officers and employees who have a need for the record to perform their duties; 2) disclosures required by the Freedom of Information Act; 3) routine uses listed in the [notice](#) for the system of records; 4) disclosures to the Bureau of the Census; 5) disclosures for statistical research or reporting; 6) disclosures to the National Archives of the United States (if there is sufficient historical or other value to warrant preservation); 7) disclosures to another government agency for a civil or criminal law enforcement activity that is authorized by law; 8) disclosures to an individual if there is a compelling circumstance affecting the health or safety of any individual; 9) disclosures to Congress;

10) disclosures to the Comptroller General; and 11) disclosures pursuant to a court order. [HHS officials have some discretion to grant access to record systems that are exempted from the HHS Privacy Act Regulations.](#)

Among who?

[Pursuant to specific regulatory requirements](#), records protected by the HHS Privacy Act Regulations can be disclosed to HHS officers, employees, and contractors, the US Census Bureau, the National Archives, other government agencies, Congress, the Comptroller General, and other individuals (under specific circumstances).

What are the prerequisites and conditions?

HHS must keep an [accounting](#) of certain record disclosures. Permitted routine uses of protected records will be listed in a [notice](#) pertaining to a system of records. Disclosures for statistical research or reporting require a written assurance that restricts the information to authorized uses, and records cannot be transferred in a form that identifies a subject individual. Disclosure relating to circumstances affecting health or safety require giving notice to a subject individual. The HHS Privacy Act Regulations specifically [exempt many record systems](#) from specific regulatory requirements.

SHARING OF DE-IDENTIFIED DATA

Does this law allow de-identified information to be shared?

The HHS Privacy Act Regulations specifically require that records disclosed for statistical research or reporting be transmitted in a form that does not identify a subject individual. Moreover, the HHS Privacy Act Regulations protect “records” from disclosure, which by [definition](#) include identifiable elements, such as a name or identifying number. Consequently, information that does not contain identifiers would not be protected by the HHS Privacy Act Regulations.

Does this law define de-identification or standards to render the data de-identified?

The HHS Privacy Act Regulations do not contain specific standards to render a record legally de-identifiable. However, the regulatory definition of a “record” requires some identifier, such as a name, identifying number, or other identifying particular (e.g., photo, finger or voice print). Consequently, removal of these identifiers would likely be necessary to legally render a record non-identifiable.

DATA SHARING IMPLICATIONS FOR PUBLIC HEALTH

Does this law support data sharing to improve the health of communities?

The HHS Privacy Act Regulations permit several broad categories of permissible disclosures, and provide HHS components with flexibility to make disclosures that can support public health activities. For example, the HHS Privacy Act Regulations permit disclosures for “routine uses,” and several HHS components have [designated](#) public health or research uses as a routine uses for various HHS records systems.

How does this law hinder data sharing to improve the health of communities?

The HHS Privacy Act Regulations lack a specific exception permitting disclosures for public health uses. Consequently, disclosures intended to promote community health must meet the requirements of another disclosure provision.

Does this law establish prerequisites, conditions, or limitations for data sharing, not previously identified?

The HHS Privacy Act Regulations place [restrictions](#) on the records that HHS components can maintain (e.g., records relevant and necessary to accomplish legally authorized function).

What other terms apply to sharing this data?

HHS components can issue [supplementary regulations](#) to comply with other statutory requirements that are inconsistent with the HHS Privacy Act Regulations or to meet particular needs of the other HHS programs. Some HHS records are subject to regulatory requirements of [other agencies](#) (e.g., personnel records are subject to Civil Service Commission regulations). The HHS Privacy Act Regulations do not apply to HHS grantees that administer federally funded programs. The written consent of subjects to disclose their records must comply with regulatory requirements, and a broad [blanket consent](#) is not permitted.

What remedies or solutions might be employed to support data sharing while complying with this law?

Many HHS components have designated public health and research uses as “routine uses” of various HHS record systems. Accordingly, these records can be disclosed for these purposes under the [routine use exception](#).

What ethical considerations apply to the exercise of discretion to share data under this law?

HHS oversees a variety of records systems governed by the [Privacy Act](#). The ethical considerations for using an HHS record system will be different depending on the specific record system and the characteristics of the subjects of the records.

Additional Information relating to the Privacy Act of 1974 can be found [here](#) and information relating to the HHS Privacy Act Regulations can be found [here](#).

SUPPORTERS



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This document was developed by Cason Schmit, Research Assistant Professor, Texas A&M University and reviewed by Jennifer Bernstein, Deputy Director, Mid-States Region of The Network for Public Health Law. The Network for Public Health Law provides information and technical assistance on issues related to public health. The legal information and assistance provided in this document does not constitute legal advice or legal representation. For legal advice, please consult specific legal counsel. October, 2018