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De-identification of Client and Participant Information and Use of Limited Data Sets

I. Purpose

The intent of this policy is to prescribe standards under which client and participant Protected Health Information (PHI) can be used and disclosed if information that can identify an individual has been removed or restricted to a limited data set. DHH staff and workforce members should refer to DHH Policy #72 (Public Information) prior to any use or disclosure of Protected Health Information. If the workforce member determines that there is a conflict between that policy and DHH HIPAA Privacy Policies, the workforce member must contact their supervisor prior to the use or disclosure. The supervisor shall then consult with the Privacy Officer and other appropriate DHH executive management.

II. Applicability

DHH's HIPAA Privacy Policies are applicable to DHH's workforce and its Business Associates.

III. Implementation

The implementation date of these policies is April 14, 2003.

IV. Definitions

The Definitions are included in the body of these policies.

V. Responsibilities

DHH's workforce and its Business Associates are responsible for assuring that DHH's HIPAA Privacy Policies are followed. The DHH Privacy Officer and the Program Privacy Officers are responsible for the implementation, resolution and enforcement of all aspects related to DHH HIPAA Privacy Policies.

VI. E x c e p t i o n s

The exceptions are listed in the policies.

VII. Policy: De-Identification of Client and Participant Information and Use of Limited Data Sets

- A. De-identified information is client or participant health information from which DHH or another entity has deleted, redacted, or blocked identifiers so that the remaining information cannot reasonably be used to identify an individual.
1. Unless otherwise restricted or prohibited by other Federal or State law, DHH can use and share health information as appropriate for the work of DHH, without further restriction if DHH or another entity has taken steps to de-identify the information consistent with the requirements and restrictions of policy in Section VII F.
 2. DHH may use or disclose a limited data set that meets the requirements of Section VII. H of this Policy, if DHH enters into a data use agreement with the limited data set recipient (or with the data source, if DHH will be the recipient of the limited data set) in accordance with the requirements of this Policy.
 3. DHH may disclose a limited data set only for the purposes of research, or nongovernmental public health purposes and must obtain a Data Use Agreement. However, unless DHH has obtained a limited data set that is subject to a data use agreement, DHH is not restricted to using a limited data set for its own activities or operations.
 4. If DHH knows of a pattern or activity or practice of the limited data set recipient that constitutes a material breach or violation of a data set agreement, DHH will take reasonable steps to cure the breach or end the violation and, if such steps are unsuccessful, DHH will discontinue disclosure of information to the recipient and report the problem to the United States Department of Health and Human Services (DHHS), Office for Civil Rights.

B. Requirements for De-Identification of Client Information

1. DHH may determine that client and participant information is sufficiently de-identified, and cannot be used to identify an individual, only if either a. or b. below have occurred:
 - a. A statistician or other person with appropriate knowledge of, and experience with, generally accepted statistical and scientific principles and methods for rendering information not individually identifiable has:
 1. Applied such principles and methods, and determined that the risk is minimal that the information could be used, alone or in combination with other reasonably available information, by a recipient of the information to identify the individual whose

information is being used; and

2. Documented the methods and results of the analysis that justify such a determination; or

b. DHH has ensured that:

The following identifiers of the individual or of relatives, employers, and household members of the individual are removed:

1. Names;
2. All geographic subdivisions smaller than a State, including street address, city, county, precinct, zip code, and their equivalent geographic codes. However, the initial three digits of a zip code may remain on the information if, according to current publicly-available data from the Bureau of the Census, the geographic unit formed by combining all zip codes with the same three initial digits contains more than 20,000 people; and the initial three digits for all such geographic unit containing 20,000 or fewer people is changed to 000;
3. All elements of dates (except year) for dates directly relating to an individual, including birth date, dates of admission and discharge from a health care facility, and date of death. For persons age 90 and older, all elements of dates (including year) that would indicate such age must be removed, except that such ages and elements may be aggregated into a single category of "age 90 or older;"
4. Telephone numbers;
5. Fax numbers;
6. Electronic mail addresses;
7. Social Security numbers;
8. Medical record numbers;
9. Health plan beneficiary numbers;
10. Account numbers;

11. Certificate or license numbers;
 12. Vehicle identifiers and serial numbers, including license plate numbers;
 13. Device identifiers and serial numbers;
 14. Web Universal Resource Locators (URLs);
 15. Internet Protocol (IP) address numbers;
 16. Biometric identifiers, including fingerprints and voiceprints;
 17. Full-face photographic images and any comparable images; and
 18. Any other unique identifying number, characteristic, or codes, except as permitted under Section 3, below, of this policy; and
- c. DHH has no actual knowledge that the information could be used alone or in combination with other information to identify an individual who is the subject of the information.
 - d. The DHH Privacy Officer will designate the statistician or other person referred to above, who may be either:
 1. A DHH employee;
 2. An employee of another governmental agency;
 3. An academic institution, or
 4. An outside contractor or consultant, subject to DHH contracting policy.

C. Re-Identification of De-Identified Information

DHH may assign a code or other means of record identification to allow information de-identified under this policy to be re-identified by DHH, except that:

1. The code or other means of record identification is not derived from or related to information about the individual and cannot otherwise be translated to identify the individual; and

2. DHH does not use or disclose the code or other means of record identification for any other purpose, and does not disclose the mechanism for re-identification.

D. Requirements For A Limited Data Set

A limited data set is information that excludes the following direct identifiers of the individual, or of relatives, employers or household members of the individual:

1. Names;
2. Postal address information, other than town or city, State and zip code;
3. Telephone numbers;
4. Fax numbers;
5. Electronic mail addresses;
6. Social Security numbers;
7. Medical record numbers;
8. Health plan beneficiary numbers (such as Medicaid Prime Numbers);
9. Account numbers;
10. Certificate/license numbers;
11. Vehicle identifiers and serial numbers, including license plate numbers;
12. Web Universal Resource Locators (URLs);
13. Internet Protocol (IP) address numbers;
14. Biometric identifiers, including finger and voice prints; and
15. Full-face photographic images and any comparable images.

E. Contents of Data Use Agreement

DHH may use or disclose a limited data set only if the entity receiving the limited data set enters into a written agreement with DHH that such entity will use or disclose the information only as specified in the written agreement.

A data use agreement between DHH and the recipient of the limited data set must:

1. Specify the permitted uses and disclosures of such information by the limited data set recipient. DHH may not use the agreement to authorize the limited data set recipient to use or further disclose the information in a manner that would violate the requirements of this Policy if done by DHH.
2. Specify who is permitted to use or receive the limited data set; and
3. Specify that the limited data set recipient will:
 - a. Not use or further disclose the information other than as specified in the data use agreement or as otherwise required by law;
 - b. Use appropriate safeguards to prevent use or disclosure of the information other than as specified in the data use agreement;
 - c. Report to DHH, if DHH is the source of the limited data set, if the recipient becomes aware of any use or disclosure of the information not specified in its data use agreement with DHH;
 - d. Ensure that any agents, including a subcontractor, to whom it provides the limited data set agrees to the same restrictions and conditions that apply to the limited data set recipient with respect to such information; and
 - e. Not identify the information or contact the individuals whose data is being disclosed.

Policies:

DHH Policy #17 - "General Privacy Policy"

DHH Policy #18 - "Client and Participant Privacy Rights"

DHH Policy #19 - "Use and Disclosures of Client or Participant Information"

DHH Policy #21- "Uses and Disclosures for External Research Requests, Internal Research Needs and Waiver of Privacy Rights for Research Purposes"

DHH Policy #22 - "Minimum Necessary Information"

DHH Policy #23 - "DHH Business Associate Relationships"

DHH Policy #24 - "Administrative, Technical, and Physical Safeguards"

DHH Policy #25 - "Enforcement, Sanctions, and Penalties for Violations of DHH HIPAA Privacy Policies"

Reference(s):

45 CFR 164.514

Contact(s):

State of Louisiana
Department of Health and Hospitals
Office of the Secretary
Privacy Office
P.O. Box 629
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