

Definitions

Aggregate data: data collected from individual-level records that have been combined for statistical or analytical purposes. In some instances, aggregate data may require suppression of small numbers to avoid the potential identification of individuals.

Cell suppression: a statistical method used to report aggregate data in tables that restricts or suppresses data to protect the identity and privacy of individuals.

Confidentiality Pledge: a written statement that certifies the individual's agreement to abide by the confidentiality restrictions specified in the written statement.

Data linkage: a method of combining data contained in two or more different files to relate significant health and other events for the same individual, organization, community, or other unit of analysis.

De-identified: information that does not identify an individual and with respect to which there is no reasonable basis to believe that the information can be used to identify an individual; therefore de-identified information is not individually identifiable health information and not protected health information.

DHSS data: all original DHSS-provided data elements, as well as those contained in all working copies, backup copies, and subsequently created data sets (electronic and paper copies).

Disclosure: the release, transfer, provision of, access to, or divulging in any other manner of information outside of the entity holding the information.

Encryption: the use of an algorithmic process to transform data into a form in which there is a low probability of assigning meaning without use of a confidential process or key.

Fee schedule: assessed fees for data and services provided.

Follow-back: refers to a method of collecting data that involves asking individuals to retrospectively report on important events or behavior related to such events. The event may be a personal event or an event involving someone close to the person providing data. Questions may be asked in-person, by phone, or on a survey instrument. The method may involve obtaining the individual's consent to participate when contacted, rather than having prior consent.

Generalizable: to emphasize the general character rather than specific details of, to formulate general principles or inferences from particulars.

Legitimate: conforming to or in accordance with generally accepted standards or principles governing research.

Minimum necessary: limiting unnecessary or inappropriate access to and disclosure of protected health information, including those used for research purposes, to the information reasonably necessary to accomplish the intended purpose.

Proper destruction: a method of disposal that would render the information unreadable and incapable of being reconstructed.

Protocol: the researcher's plan of a scientific study. A protocol includes a description of the research design or methods to be employed, the eligibility requirements for prospective subjects, the treatment regime(s) and the proposed methods of data analysis.

Record-level: person specific information or data that may or may not contain direct identifiers.

Re-release: releasing, sharing, or publishing DHSS-provided data or subsets of such data to any person or entity not directly identified in the study personnel section of the application or annual review form. Analytic tables, graphs, charts, or maps produced from DHSS-provided data for analytic purposes are allowable and not considered re-release.

Research: a systematic study designed to develop or contribute to generalizable knowledge.

Unauthorized disclosure: the dissemination, release, sharing or communication by any other means, of any confidential data or information to any person or entity not directly identified in the study personnel section of the application or annual review form.