



GUIDELINE FOR DE-IDENTIFICATION OF DATA FOR PUBLISHING/PRESENTATION

[OHSP Policy 901 Investigator Responsibilities](#) indicates that for research involving the use or disclosure of protected health information (PHI) the Investigator must ensure the protection of subjects' privacy and confidentiality and that the research is conducted in compliance with [Policy 702 HIPAA Privacy Rule](#). This includes at the end of the study when the Investigator is preparing to publish or present the data obtained and analyzed for the research study.

Subjects have a right to privacy and for the confidentiality of the data provided to be maintained when participating in research, and the Investigators are responsible for ensuring that the research data provided/collected is maintained in a confidential manner throughout the study. This includes during the conduct of the study, when the data is analyzed and prepared for publication/presentation, and when the study is closed. The approved protocol and consent form should describe how the data will be protected.

Preparing the Manuscript/Abstractⁱ

It is expected that research data will be published and/or presented in the aggregate. Identifiable data should not be included in a publication or presentation, including images or other pictures, unless it is essential for scientific purposes and the Investigator has obtained written consent from the subject and/or the subject's parent/guardian to publish the subject's identifiable data.

The journal may require a copy of the signed consent prior to publication, but another option may be to provide a written attestation by the Investigator that consent was obtained, rather than sending the signed consent to the journal to further protect the privacy of the subject.

When Raw Data is Required for Publication?

Many journals require disclosure of raw data as part of the publication process, often to support reproducibility and data sharing.ⁱⁱ Therefore, Investigators must be aware of the process of de-identification, by which identifiers are removed from research data, in order to protect the privacy of those subjects who agreed to participate in the research.

The HIPAA Privacy Ruleⁱⁱⁱ was designed to protect individually identifiable health information through permitting only certain uses and disclosures of PHI. The Privacy Rule permits a covered entity to de-identify individually identifiable data to allow the covered entity to use and disclose the de-identified information because it no longer identifies nor provides a reasonable basis to identify an individual. The Privacy Rule provides two de-identification methods: 1) a formal determination by a qualified expert or 2) the removal of specified individual identifiers, as well as, absence of actual knowledge by the covered entity that the remaining information could be used alone or in combination with other information to identify the individual. It is important to remember that these de-identification methods, even when properly applied, do not remove all risk, as there remains a possibility that de-identified data could be linked back to the identity of the subject to which it corresponds.ⁱⁱⁱ

When providing data for publication, the University of Rochester, requires de-identification of data, which means that the following 18 identifiers need to be removed from the data set before sending to the journal, , consistent with the URMCAffiliates HIPAA Policy and Procedure^{iv}:

- 1) Names
- 2) All geographic subdivisions smaller than a state, including street address, city, county, precinct, ZIP code, and their equivalent geocodes, except for the initial three digits of the ZIP code if, according to the current publicly available data from the Bureau of the Census: (a) The geographic unit formed by combining all ZIP codes with the same three initial digits contains more than 20,000 people; and (b) The initial three digits of a ZIP code for all such geographic units containing 20,000 or fewer people is changed to 000
- 3) All elements of dates (except year) for dates that are directly related to an individual, including birth date, admission date, discharge date, death date, and all ages over 89 and all elements of dates (including year) indicative of such age, except that such ages and elements may be aggregated into a single category of age 90 or older
- 4) Telephone numbers
- 5) Vehicle identifiers and serial numbers, including license plate numbers
- 6) Fax numbers
- 7) Device identifiers and serial numbers
- 8) Email addresses
- 9) Web Universal Resource Locators (URLs)
- 10) Social security numbers
- 11) Internet Protocol (IP) addresses
- 12) Medical record numbers
- 13) Biometric identifiers, including finger and voice prints
- 14) Health plan beneficiary numbers
- 15) Full-face photographs and any comparable images
- 16) Account numbers
- 17) Any other unique identifying number, characteristic, or code; and
- 18) Certificate/license numbers

Any questions on the process for de-identification and re-identification should be directed to the [HIPAA Privacy Officer or HIPAA Security Official for Research](#).

References

ⁱ Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals International Committee of Medical Journal Editors (ICMJE) www.icmje.org/icmje-recommendations.pdf

ⁱⁱ Principles of Transparency and Best Practice in Scholarly Publishing, the joint statement by the Committee on Publication Ethics (COPE), the Directory of Open Access Journals (DOAJ), the Open Access Scholarly Publishers Association (OASPA) and the World Association of Medical Editors (WAME) <https://oaspa.org/principles-of-transparency-and-best-practice-in-scholarly-publishing>

ⁱⁱⁱ Guidance Regarding Methods for De-identification of Protected Health Information in Accordance with the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule, www.hhs.gov/hipaa/for-professionals/privacy/special-topics/de-identification/index.html#rationale

^{iv} [P30 De-Identification of Protected Health Information](#) and [P25 Use or Disclosure of PHI for Research Activities - Procedures](#), section 5