

CHS DATABASE CONFIDENTIALITY RULES

Researchers who are requesting Oregon Center for Health Statistics data sets (including all those who will use or have access to the requested data set) must agree to abide by the rules listed below.

1. Data may be used only for the purposes stated in the approved Data-use Agreement. Any changes in planned use of data must be submitted as a supplemental request and receive written approval from the State Registrar of the Oregon Center for Statistics, as well as the Oregon DHS-HS IRB where necessary.
2. Because researcher will have access to potentially identifiable individual record information that is confidential, protected by law and DHS Center for Health Statistics rules and policies, researcher must agree to assess the impact on privacy and confidentiality before releasing aggregated data. Identifiable information includes but is not limited to demographic identifier information, which will identify or may reasonably lead to the identification of one or more specific individuals. Therefore, outside research or study groups should abide by the same rules of confidentiality in reporting non-identified aggregates at the geographic level, where disclosure of detailed demographic information and medical information would make it possible to identify the person in local communities. Researchers should abide by the "10 and 50" rule mentioned in Policy 01-01-27 issued on January 1, 1999 by Oregon Department of Human Services, Health Division.
3. Researcher will protect confidentiality by keeping records and materials in a secure location with controlled access so that persons not connected with the study cannot access these records. Control of these records is to continue at the completion of the study by destroying the electronic files or listings.
4. Researcher will not attempt to link individual records from this data set with other information from any other data set without specific written permission or approval from the Oregon DHS-HS IRB. Linkage of information from multiple databases is a potential threat to confidentiality.
5. Prohibition against follow-up: The researcher will not perform any individual or family follow-up, and no data will be published or disclosed from which an individual can be identified except where permitted under ORS 432.119(2) or upon written authorization of the Oregon DHS-HS IRB.
6. Researcher will not release any individual record information either *in toto*, or in fragmented form, to any person or entity outside of the research team specifically related to the project described in the Data- use Agreement, without express written permission from the Oregon State Registrar.
7. Researcher understands that a breach of confidentiality would result in denial of all future

data set requests from the Oregon DHS Center for Health Statistics, as well as possible civil and/or criminal liability of the researcher. The Oregon DHS Center for Health Statistics has taken reasonable precautions to protect the identities of individual respondents providing information for this data set. Researchers will accept all liability for their use, disclosure, or revealing in any way of information that can be used to identify any individual person.

8. Researcher will ensure that the data set is destroyed after the purpose of the written request is fulfilled. Even after researchers no longer have access to the records of the Oregon DHS Center for Health Statistics, they should consider themselves bound by this document and must continue to maintain the confidentiality of information to which they previously had access.