

Data Use Agreement

Oregon Health Authority
Public Health Division
Injury and Violence Prevention Program
OTR Data Team
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****For Official Use Only****

Date received:

Request number:

DATA REQUEST CONTACT INFORMATION

Organization name:	
Organization address:	
Primary contact person (PI or manager)	
Telephone number:	
FAX Number:	
Email address:	

DATA REQUEST INFORMATION: The Oregon Trauma Registry (OTR) can provide data to researchers. The users of data or recipient(s) cannot identify the information or contact individuals.

Specify which year(s) of data are needed:

File format in which to provide database: Excel CSV Other format:

CONTACT INFORMATION

Study contact person:

STUDY DESCRIPTION

Length of study:

Start date:	
End date:	

List all study personnel (include names of staff, their roles, and affiliation working under). Data recipient(s) will not use or disclose the information other than permitted by the agreement or otherwise required by law. :

Name(s) starting with Principle Investigator/Manager	Role(s)	Affiliation

Provide a description of the study (include the name of the funder, study aims, and anticipated outcomes):

Specify data needs (include variables, needs for analysis, and how you will analyze the data – logistic regression, etc.):

Please identify variables needed from these lists in your description

Oregon Trauma Registry (OTR):

[https://public.health.oregon.gov/ProviderPartnerResources/EMSTraumaSystems/TraumaSystems/Documents/Oregon%20Trauma%20Registry%20Data%20Dictionary%20\(Abstract%20Manual\).pdf](https://public.health.oregon.gov/ProviderPartnerResources/EMSTraumaSystems/TraumaSystems/Documents/Oregon%20Trauma%20Registry%20Data%20Dictionary%20(Abstract%20Manual).pdf)

More information regarding the process and details on obtaining and using OTR data can be found at:

<https://public.health.oregon.gov/ProviderPartnerResources/EMSTraumaSystems/TraumaSystems/Pages/data.aspx>

Describe plans to secure data (such as encryption, passwords, locked files, etc.). Data recipient(s) must report to the covered entity any uses or disclosures in violation of the agreement of which the recipient becomes aware:

Will laptops or mobile devices be used? If so, describe how you will protect data from loss or unauthorized access:

If you connect remotely please describe the security controls you will use to secure the data:

Describe plans to destroy data after study ends:

Describe plans for dissemination of results, including reporting back to the Oregon OTR Data Team:

Provide any additional information about the use of the data:

DATA USER CONFIDENTIALITY AGREEMENT

I certify that I have read and agree to abide by the Confidentiality Rules on the attached sheets following the signature(s). (Please sign below.)

_____ Principal Investigator / Manager	_____ Printed Name	_____ Date
_____ Individual user with access to data	_____ Printed Name	_____ Date
_____ Individual user with access to data	_____ Printed Name	_____ Date
_____ Individual user with access to data	_____ Printed Name	_____ Date

Internal Use Only	
Date of program review request:	
Date of project review:	
Section manager final approval signature:	
Date of manager signature	

RESTRICTIONS AND CONDITIONS OF USE:

Investigators (including all those who will use or have access to the requested data set) who are requesting Oregon Trauma Registry (OTR) data must agree to abide by the rules listed below.

1. Data may be used only for the purposes stated in the attached Data Use Agreement. Any changes in planned use and/or access to data must be written as a supplemental request and receive written approval from the OTR Data Team, as well as the Oregon OHA-HS IRB where necessary.
2. Researcher must agree to assess the impact on privacy and confidentiality before releasing aggregated data. 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.
3. Researcher will ensure that any agents, including a subcontractor, to whom it provides the OTR data set agrees to the same restrictions and conditions that apply to the recipient with respect to the OTR data released.
4. Access to and small number suppression of each OTR data set will be determined by the Oregon OHA OTR Data Team. OHA will determine guidelines for small numbers suppression in collaboration with researchers. Rates, counts and other statistical reporting of OTR data may be suppressed in the output when the count or the population in the denominator is less than a certain threshold. Rates, counts and other statistical reporting that could be used to identify a health care provider, ambulance service medical transportation agency or health care facility must also be suppressed. If through manipulation of the data users are able to reconstruct the suppressed data they will, nevertheless, abide by the small numbers guidelines.
5. Researcher will protect confidentiality by using appropriate safeguards to prevent use or disclosure of the OTR data by a third party or other than as specified in the Data Use Agreement (e.g. use a password protected screensaver when possible, store data on encrypted memory, and keeping laptops, 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.
6. 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 OHA-HS IRB. Linkage of information from multiple databases is a potential threat to confidentiality.
7. Researcher will make no effort to determine the identity of individuals from the OTR data released. Identity discovered inadvertently is a breach of confidentiality and should be reported to the OTR Coordinator immediately. Researcher will notify the OTR Research Analyst if the researcher becomes aware of any use or disclosure of the Oregon OTR data not specified in the Data Use Agreement.
8. 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 OHA-HS IRB.

9. 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 Epidemiologist.
10. Before publishing any Oregon OTR data, researcher must notify the OTR Research Analyst and provide a copy of the data to be published. Published data will include appropriate data source citations. The researcher's organization should be cited as the source of interpretations of the data.
11. Researcher understands that a breach of confidentiality would result in denial of all future data set requests from the OTR Data Team, as well as possible civil and/or criminal liability of the researcher. The OTR Data Team 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.
12. Researcher will ensure that the data set is destroyed after the purpose of the written request is fulfilled and will provide the OTR Research Analyst with a written confirmation that the data has been destroyed. Even after researchers no longer have access to the records of the Oregon EMS, they should consider themselves bound by this document and must continue to maintain the confidentiality of information to which they previously had access.

Oregon Revised Statute from 2015 Legislative Session:

The statute governs any release of information from the Oregon Trauma Registry:

Relating to use of information related to trauma injury; amending ORS 431.623 and 431.635.

SECTION 1. ORS 431.623 is amended to read: 431.623.

(1) The Emergency Medical Services and Trauma Systems Program is created within the Oregon Health Authority for the [purpose of] following purposes:

- (a) Administering and regulating ambulances[.];
- (b) Training and licensing emergency medical services providers[.];
- (c) Establishing and maintaining emergency medical systems, including trauma systems[.]; and
- (d) Maintaining the Oregon Trauma Registry[, as necessary] for purposes related to trauma reimbursement, system quality assurance and [ensuring] cost efficiency.

(2) [For purposes of ORS 431.575 to 431.619 and ORS chapter 682,] The duties vested in the authority under ORS 431.575 to 431.619 and ORS chapter 682 shall be performed by the [Emergency Medical Services and Trauma Systems] program.

(3) The program shall be administered by a director.

(4) [With moneys transferred to the program by ORS 442.625,] The director of the program shall apply [those] moneys transferred to the program under ORS 442.625 to:

- (a) Developing state and regional standards of care;
- (b) Developing a statewide educational curriculum to teach standards of care;
- (c) Implementing quality improvement programs;
- (d) Creating a statewide data system for prehospital care; and
- (e) Providing ancillary services to enhance [Oregon's] this state's emergency medical service system.

(5) The director of the program shall adopt rules for the Oregon Trauma Registry[, establishing:]. Rules adopted under this subsection

must establish:

- (a) The information that must be reported by trauma centers to the program for inclusion in the Oregon Trauma Registry;
- (b) The form and frequency of reporting information under paragraph (a) of this subsection; and
- (c) Procedures and standards for the administration of the Oregon Trauma Registry.
- (6) The director of the program may adopt rules establishing, from information maintained in the Oregon Trauma Registry, a registry of information related to brain injury trauma.

SECTION 2. ORS 431.635 is amended to read:431.635.

(1) As used in this section, “individually identifiable information” means:

- (a) Individually identifiable health information as that term is defined in ORS 179.505; and
- (b) Information that could be used to identify a health care provider, ambulance service medical transportation agency or health care facility.

(2) Notwithstanding ORS 431.627, individually identifiable information may be released from the Oregon Trauma Registry:

(a) For use in executive session to conduct specific case reviews by:

- (A) The State Trauma Advisory Board or any area trauma advisory board;
- (B) The State Emergency Medical Service Committee; or
- (C) The Emergency Medical Services for Children Advisory Committee.

(b) To the Oregon Health Authority for purposes related to the administration of public health programs, including:

- (A) The establishment of a registry of information related to brain injury trauma as described in ORS 431.623 (6); and
- (B) The performance of epidemiological investigations of the causes of and risk factors associated with trauma injuries.

[(b)] (c) [For quality assurance or quality improvement purposes] To an emergency medical services provider or a designated trauma center for purposes related to quality of service assurance and improvement, if the information is related to the treatment of an individual by the provider or center.

(d) To the Department of Human Services for purposes related to enabling the department to plan for and provide services to individuals adversely affected by trauma injuries, if the department agrees to use the information only for the purposes described in this paragraph and to maintain the confidentiality of the information.

[(c)] (e) To a person conducting research [only] if:

- (A) An institutional review board has approved the research in accordance with 45 C.F.R. part 46; and
- (B) The person agrees to maintain the confidentiality of the information.

(3) The Oregon Health Authority may release only the minimum amount of individually identifiable information necessary to carry out the purposes for which [it] the information is released under this section.