



ALASKA TRAUMA REGISTRY RELEASE OF INFORMATION POLICY

INTRODUCTION

The purpose of the Release of Information Policy is to establish guidelines for the release of data from the Alaska Trauma Registry to individuals or organizations requesting information pursuant to the provisions of 7 AAC 26.745 TRAUMA REGISTRY which provides in part: (b) The Trauma System Review Committee shall keep Trauma Registry Data confidential in accordance with AS 18.23.030 except that (3) reports on trauma registry data, not including patient identifiers, physician identifiers, or hospital identifiers, may be provided to epidemiologists, health planners, medical researchers, or other interested persons to study causes, severity, demographics and outcomes of injuries, or for other purposes of studying the epidemiology of injuries or emergency medical services and trauma system issues.

In sharing trauma registry information, it is the intent of the Trauma System Review Committee that

1. patient, facility, health care provider, and service confidentiality be protected
2. legitimate and responsible use of trauma registry data for the purposes of promoting public health research, public health education, injury prevention, and peer review be insured, and
3. trauma registry data is represented accurately and without prejudice to an individual or institution.

PROCEDURE

Information requests will be put into one of two categories and considered as outlined below.

1. As established by the Trauma System Review Committee, participating trauma registry hospitals and ambulance services may request reports or information under 7 AAC 26.745. Customized reports or information will be provided to individuals or institutions requesting information pertaining to themselves to include privileged and nonprivileged data and information; privileged data or information is defined as any data or information identifying an individual patient, physician, hospital, or prehospital care provider, and acquired in the performance of activities of the Alaska Trauma Registry program.
2. A recognized and known legitimate individual or organization requesting nonprivileged data or information from the trauma registry for the purpose of promoting public health research or public health education will be provided the requested information by the Trauma Registry Database Manager. The Trauma Registry Database Manager may require that the requestor submit his/her request in writing and provide proof of requester legitimacy. Nonprivileged data or information is defined as any data or information that does not identify an individual patient, physician, hospital, or prehospital care provider, and data or information that constitutes a limited data set under 45 C.F.R. 164.514(e). Release of information may be contingent upon signature of the following agreement:

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ALASKA TRAUMA REGISTRY DATA UTILIZATION AGREEMENT

The Trauma Program of the Alaska Department of Health and Social Services, Division of Public Health, places the following conditions on the acceptance and utilization of data from the Alaska Trauma Registry:

1. Ownership of the data will remain with the Alaska Department of Health and Social Services, Division of Public Health, Section of Emergency Programs/Trauma Program (ADHSS/DPH/EP/TP).
2. Applicant will have access to the “raw” data that has been sent for research and analysis. No other person will have access to the data unless for technical support and with ADHSS/DPH/EP/TP approval. Upon completion of the proposed research project in the application, the “raw” data will be deleted, and transmittal copies destroyed.
3. Access to the data file will be protected by a security system that requires the user to provide at least one password.
4. Release of nonaggregate data to any other individual or agency without the express permission of the ADHSS/DPH/EP/TP is prohibited. If given permission, recipient will ensure that the individual or agency agrees to the same restrictions and conditions that apply to the recipient with respect to the data.
5. The recipient will commit to protecting the identity of trauma registry patients, ambulance services, and hospitals. (Although we do not give names, in some communities, the dates, age, sex, race and place of injury occurrence are sufficient to identify an individual or service.) No use will be made of the identity of a person, service or hospital discovered inadvertently.
6. The recipient will comply with all statutes and regulations related to the protection of patient-identifiable information, including HIPAA privacy and security regulations. An agency using the data will ensure minimum use and provide for personal sanctions against an individual who violates the regulations regarding disclosure.
7. The recipient shall immediately report to ADHSS/DPH/EP/TP any use or disclosure of the data not provided for by its data utilization agreement of which it becomes aware.
8. Data will not be linked to any data set with individually identifiable records.
9. The recipient will submit to the ADHSS/DPH/EP/TP a signed Alaska Trauma Registry confidentiality statement.
10. The data may only be used for studies of a public health nature.
11. The recipient will allow the ADHSS/DPH/EP/TP and the Trauma System Review Committee prepublication review of conclusions based upon data from the trauma registry. (This is to insure correct interpretation of the contents of the database.) If disagreement exists, the recipient will allow the Trauma System Review Committee the opportunity to include their comment within the published document. Acknowledgement is to be given to the ADHSS/DPH/EP/TP as the source of data in any publications, articles or studies that are prepared or published.
12. The recipient will not identify the data or contact the individuals represented in the data.

STUDY PROPOSAL

The study proposal will include objectives, methods, study population of interest, and specific elements needed from the trauma registry. The requestor must inform the Trauma Registry Database Manager of any changes to the study design or changes in the estimation of time for project completion.

DUTIES OF THE TRAUMA SYSTEM REVIEW COMMITTEE

The Trauma System Review Committee will be available to make final determinations on requests for information from the trauma registry. An information request review by the Trauma Registry Database Manager may be accomplished by circulation of the proposal to committee members.

DUTIES OF THE TRAUMA REGISTRY DATABASE MANAGER

The Trauma Registry Database Manger will:

1. Prepare requested reports to participating hospitals or ambulance service
2. Answer legitimate requests for non-privileged data by recognized individuals
3. Reject inappropriate requests
4. Work with requestors and Trauma System Review Committee members on requests
5. Report all information requests, as requested by the Trauma System Review Committee, during regularly scheduled meetings by presenting short summaries of information provided.

CONFIDENTIALITY

Any and all release of information pursuant to this policy shall be expressly subject to the provisions of AS 18.23.030 (a), which provides that such information shall be held in confidence and is not subject to subpoena or discovery. Such released information shall be used solely for research/investigation purposes, and shall have any patient, provider and facility identifying information redacted. Those persons or institutions who receive any information pursuant to this policy shall be required to sign and return a confidentiality agreement that forbids re-disclosure of released information, except for the described purposes of study or research pursuant to the provisions of 7 AAC 26.745.

RESEARCH APPLICATION
(To be filled out by applicant)

Upon approval by the Trauma Registry Database Manager, and/or the Trauma Program Manager, and/or Trauma System Review Committee; the Trauma Registry has up to 30 business-days (excluding weekends and holidays), to complete a data request. Depending upon the complexity of the data request, more complex requests could lengthen this time period. This time period has the potential to be expedited for less complex data requests.

Please complete the following for data release.

Name _____
Agency _____
Address _____

City _____ State _____ ZIP _____
Phone Number _____
Fax Number _____
Email _____
Project Title: _____
Expected time of completion _____
Person receiving data transfer _____

I have read and agree to the above conditions for the use of data from the Alaska Trauma Registry of the ADHSS/DPH/EP/TP.

Signature _____ Date _____
(Print Name) _____

PLEASE ATTACH A COPY OF THE STUDY PROPOSAL

1. Objective
2. Methods
3. Population of interest
4. Years of interest
5. Data elements of interest





ALASKA TRAUMA REGISTRY CONFIDENTIALITY STATEMENT

I understand and agree that in the performance of my role on a steering or review committee or board or group; or as an employee of Southern Region Emergency Medical Services Council, Inc.; or as an employee of ADHSS/DPH/EP/TP; or as an employee of a participating hospital or prehospital service; or as a trauma registry manager, trauma registrar, or data entry clerk; or as a professional services contractor for the Department of Health and Social Services; or as a recipient of trauma registry data, I must maintain and safeguard the confidentiality of privileged Alaska Trauma Registry data and information. I understand that privileged data and information is defined as:

"Data and information generated and/or acquired by the Alaska Trauma Registry Program which identifies an individual patient, practitioner, or facility; written or recorded records of any trauma registry steering or review committee sessions, data collection staff meeting, or any regularly constituted committee of the Alaska Trauma Registry Program; data and information generated and/or acquired in the administration of the Alaska Trauma Registry Program; any personal knowledge of any representative or employee of the Alaska Trauma Registry Program who can identify an individual patient, practitioner, or facility."

Further, I understand that violation of the Alaska Trauma System Confidentiality Policy may result in legal action.

In order that we may exchange data from time to time which otherwise may be considered of a confidential nature, the undersigned agrees to abide by the following statement:

"Any data or information identifying an individual patient, physician, hospital, or prehospital care provider, and acquired by either party in the performance of activities of the Alaska Trauma Registry project shall be held in strict confidence and shall not be disclosed to any person or legal entity without the prior written consent of the other party."

DATE

(SIGNATURE)

(PRINT NAME)

(TITLE)