



# PTOS Data Application/Overview, Proposal, Fees and Data Use Agreement

2019

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# **Pennsylvania Trauma Outcome Study (PTOS) Research Data Application and Agreement**

## **I. Overview**

Thank you for your interest in obtaining data from the Pennsylvania Trauma Systems Foundation (PTSF) Statewide Trauma Registry Database (PTOS). The PTOS contains data submitted by Pennsylvania trauma centers that are accredited by PTSF (“Accredited Trauma Centers”) since 1986 and is regarded as one of the best trauma databases in the United States in terms of the quality and value of the data. PTSF and its staff manage and ensure the integrity of the database through a variety of automatic and manual data processing steps in addition to assuring ongoing training requirements for Accredited Trauma Center registrars to assure quality data abstraction and submission.

PTOS data is made available to researchers, providers, payers, government agencies and others to facilitate trauma systems research and trauma outcomes studies and ultimately to improve trauma care in the Commonwealth of Pennsylvania and beyond. The data is provided by Accredited Trauma Center staff who are trained by PTSF staff to assure quality data abstraction and submission based on training modules developed by PTSF.

Research data is provided in three ways:

1. Basic – includes all elements in the PTOS database for a one to five-year period commencing with the year prior to the date of approval of the application.
2. Customized – data is given for specific data elements only as specifically requested by the applicant for a one to five-year period commencing with the year prior to the date of approval of the application.
3. Standard Reports
  - a. Trauma Center Pursuit Feasibility Report - this report is a standard report created for hospitals performing analyses as they consider trauma center accreditation. See Appendix B for contents of this report.

### **General Requirements:**

1. If the data is being used for a specific research study:
  - a. Complete the attached data application. Proposals are subject to review and approval by the PTSF Research Committee with available mentoring by the committee.
  - b. Provide a signature of support from the Trauma Medical Director if the research is being conducted by staff at an Accredited Trauma Center. This is not required for out of state researchers not affiliated with an Accredited Trauma Center.
  - c. Provide a letter from the Internal Review Board (IRB) showing evidence of review and support specific to the study.
  - d. Within two years of receiving data submit a research abstract to PTSF. Additionally, you may be asked to present your abstract at the PTSF annual fall conference at the PTSF Research Committee’s discretion.
2. If the data is being used by a College/University for the purposes of general querying on behalf of students with research questions that are undefined at the time of the request:
  - a. Include the intended use of the data, including by way of example, for students in your classes who are studying public health.

- b. As research questions are defined, submit them to PTSF for review by the PTSF Research Committee.
  - c. Prior to the submission of any research data analysis for presentation and/or publication, submit to the PTSF Research Committee for review and ultimate approval by the PTSF Board of Directors.
3. Note in the application the type of data being requested and applicable fees.
4. Sign the PTOS Data Use Agreement acknowledging terms and conditions.

## **II. PTOS Data Fees**

### **Data Use Categories**

Fees are charged for data based on the type of organization the Requestor represents. The following categories provide a general fee structure and conditions. The amount of fees, their categories, and any conditions may be changed at any time at the discretion of the PTSF Board of Directors.

- Commercial - any corporation, coalition, association, consultant, organization or individual that requests PTOS data for commercial purposes (e.g., for profit), including the use of the data to develop a commercial software product or for reimbursable data analysis services. The data may be used by the entity or individual for their own purposes or on behalf of a client, including a software vendor or pharmaceutical company.
- Non-Commercial - any corporation, coalition, association, consultant, organization or individual that requests PTOS data for non-commercial purposes (i.e., not for profit) to use internally for their own purposes, including, for instance, the development of non-commercial software and non-reimbursable data analysis services. This can include, but is not limited to hospitals and other health care providers, purchasers, insurers, interest groups, consumers, researchers at non-PTSF accredited hospitals, and colleges/universities. The data may be used by the entity or individual for their own purposes or on behalf of a client as long as the entity or individual is not reimbursed for the service.
- Accredited Trauma Center - a PTSF accredited trauma center.
- PTSF Partners – any organization that carries a seat on the PTSF Board of Directors or a State Government agency.

### **Types of Data Sets**

1. Basic– includes all elements in the PTOS database for a one to five-year period commencing with the year prior to the date of approval of the application.
2. Customized – data is given for specific data elements only as specifically requested by the applicant for a one to five-year period commencing with the year prior to the date of approval of the application.
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## Data Fees

Data Sets	Commercial	Non-Commercial	PA Accredited Trauma Center	PTSF Partner
Basic	\$10,000 for one to five-year period commencing with the year prior to the date of approval of the application plus \$5,000/yr. annual usage fee after first year (includes a yearly data update).	\$1000 for one to five-year period commencing with the year prior to the date of approval of the application plus 500/yr. annual usage fee after first year (includes a yearly data update).	Waived	Waived
Customized	\$5000 for initial data request for one to five-year period commencing with the year prior to the date of approval of the application.	\$500 for initial data request for one to five-year period commencing with the year prior to the date of approval of the application.  Hourly rates will apply for data requests taking more than one hour of staff time. See rates below.	Waived	Waived
Trauma Center Pursuit Feasibility Report	n/a	\$1,000.00	n/a	n/a
Hourly Rates for additional Queries/ Reports	\$1000/hr. charged at one-hour increments.	\$200/hr. charged at one-hour increments.	Waived	Waived

Questions? Please contact Juliet Altenburg at the Pennsylvania Trauma Systems Foundation at (717) 697-5512 ext. 102 or [jaltenburg@ptsf.org](mailto:jaltenburg@ptsf.org).

### III. PTOS Data Application: Contact Information

**Name of Primary Contact**

**Organization:**

**Phone Number:**

**Email Address:**

**Preferred Mailing Address:**

FEE CATEGORY ACKNOWLEDGEMENT (check appropriate category)

PA Accredited Trauma Center

PA Government

Non-Commercial

Commercial

DATA SET (check appropriate category)

Basic

Customized

Trauma Center Pursuit Feasibility Report: Please note that for this data set completion of a PTOS research proposal (page 7) is not required. A completed PTOS Data Use Agreement; (Appendix A) in addition to Appendix B is needed prior to PTSF processing your request.

PTSF makes small research grants available to approved applicants at its discretion. This study will be automatically considered for the annual research grant unless the box below is checked.

**DO NOT consider this Application for the PTSF Research Grant**

**PTOS Data Application: Research Proposal**  
*For Completion by Organizations using PTOS for research*

Name of Principle Investigator:

Title

Organization:

Contact Information:

Title of Proposal:

Calendar years the data should be queried for:

Purpose/Specific Aims (limit to one page): Concisely state the intended purpose and scope of the proposed project. Present the rationale for your project. Clearly specify the research questions, hypothesis, or system components this research is designed to answer. References are suggested.

Methodology and Timetable: Clearly specify the patient population being requested. Be sure to include age ranges and/or applicable diagnosis or procedure codes. Include the proposed timetable for the study/project. Discuss the plans for analysis/interpretation of the data.

Dissemination: Specify where and when the research is expected to be presented or published.

Third Party Disclosure: Identify any third party to whom you will, or for whom there is a possibility that you may, disclose the research and/or the data, e.g., a sponsor, a co-researcher, etc.

**IV. APPENDIX A:  
PTOS Data Use Agreement  
Terms and Conditions for the Use of PTOS**

This Data Use Agreement ("Agreement") governs the disclosure and use of data from Pennsylvania Trauma Systems Foundation ("PTSF") Statewide Trauma Registry Database ("PTOS"). Any organization requesting data from the PTOS database ("Requestor") must sign and submit this Agreement with the PTOS Application as a precondition for approval. Upon approval of the Application, the Requestor must comply with the following terms and conditions at all times:

- A. This Agreement incorporates the terms and conditions set forth in the PTOS Data Application/Overview, Proposal, and Fees and any policy, guidance or instruction provided by PTSF related to the PTOS database.
- B. The Principle Investigator identified in the Application will be the primary responsible party on behalf of Requestor.
- C. All correspondence will be directed to the Primary Contact as listed on the Application.
- D. Requestor is responsible for its compliance, including by its employees, directors, managers, subcontractors, agents and volunteers, with the terms and conditions of this Agreement at all times to the exclusion of any other party, regardless of such party's role in sponsoring or funding the research.
- E. The topic/planned use of data at all times must have direct relevance and applicability to a trauma patient or evaluation of the trauma system.
- F. The data may be used to support any phase/aspect of a study/project but not for purposes that have not been approved by PTSF, including by way of example, use in an expert report in litigation.
- G. PTSF contains data provided by Accredited Trauma Centers whose staff is trained by PTSF staff to assure quality data abstraction and submission based on training modules developed by PTSF. However, PTSF makes no representation, guarantee or warranty, express or implied, that the data are error-free or that other parties will agree with the results of any research using the data. PTSF is not responsible or liable for the results or consequences of its use.
- H. The following disclaimer must be used for any research published utilizing PTOS data:

THESE DATA WERE PROVIDED BY THE PENNSYLVANIA TRAUMA  
SYSTEMS FOUNDATION, MECHANICSBURG, PA. THE FOUNDATION  
SPECIFICALLY DISCLAIMS RESPONSIBILITY FOR ANY ANALYSES,  
INTERPRETATIONS, OR CONCLUSIONS.

- I. Published studies utilizing PTOS must be shared with PTSF and logged into the research area of the PTSF website.
- J. Requestor recognizes that data obtained from the PTOS database is highly confidential. PTOS data may only be used as described in the Application as approved by PTSF, and may not be shared with any third party, including by way of example to an affiliated entity



in the same health system, except with written consent from PTSF. The data will be stored, maintained and used only in a secure environment, e.g., at all times on encrypted information systems based on industry-standard encryption standards.

- K. PTSF reserves the right to approve or deny a request for data at its discretion and to modify fees at any time.
- L. Requestor will destroy the data following the conclusion of the PTSF-approved or project described in the Proposal, provided that if Requestor believes that destruction is not feasible, it will request permission in writing from PTSF to maintain the data, and state in its request why destruction is not feasible and how it will ensure that the data will remain confidential. PTSF shall review such request and approve or deny it in its sole discretion. At any time PTSF may request from Requestor a written update on whether the data was destroyed and if not destroyed how its confidentiality is being maintained.
- M. Requestor will be fully responsible for the costs related to a breach of the data in violation of federal or state law or this Agreement, or any other violation of this Agreement.
- N. Requestor acknowledges that data elements in the data and the software that supports the PTOS database or such data elements may be proprietary to PTSF, a vendor or another third party, and Requestor agrees to not use, and to prohibit third parties with whom it discloses the data from using, any such data elements or software for any other purpose other than as permitted under this Agreement. Requestor further agrees not to disassemble, decompile, or otherwise reverse-engineer any such data elements or software and also will prohibit others from doing so.
- O. Requestor will indemnify, defend, and hold harmless PTSF, including any employees, contractors, directors, officers, agents, or volunteers, including individuals who serve on the PTSF Research Committee and other committees, and the Accredited Trauma Centers that provide data to PTOS from any or all claims and losses accruing to any person, organization, or other legal entity as a result of violation of this Agreement.
- P. Requestor will report any actual or suspected violation or apparent violation of any term of this Agreement to PTSF without unreasonable delay and in no case later than thirty (30) calendar days of becoming aware of the violation or apparent violation.
- Q. Any violation of the terms of this Agreement, as determined by PTSF, shall be grounds for immediate termination of this Agreement, and PTSF shall determine in its sole discretion what corrective actions if any shall be undertaken including but not limited to providing notice of the termination or violation to affected parties and prohibiting Requestor from receiving PTOS data in the future.
- R. In the event that PTSF terminates this Agreement due to a violation, PTSF may direct that Requestor immediately return all copies of the data or reports provided by PTSF without refund of fees.
- S. PTSF reserves the right to pursue any claim against Requestor for violation of this Agreement as permitted under law, including in equity or for damages.

- T. No person may release PTOS data in response to a subpoena or court order without immediate, written notification to PTSF of such potential release. PTSF reserves the right to respond and/or intervene in order the protection of the data.

I, the undersigned, certify that the statements in this proposal are true and complete. I accept the obligation to comply with the terms and conditions of the access and use of data from the PTSF PTOS Database as set forth in this PTOS Data Use Agreement.

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Signature (Principal Investigator)

Date

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Signature (Trauma Medical Director,  
if requestor is from accredited trauma center  
and using data for trauma research purposes)

Date

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Signature (Pennsylvania Trauma Systems Foundation)

Date

## APPENDIX B

### Trauma Center Pursuit Feasibility Report

The purpose of this report is to support hospitals in conducting feasibility studies as they consider pursuing trauma center accreditation.

Data that is part of the report is in the table below including the value of each data element.

Please answer the following list of questions so that PTSF can process your request. Data will be queried from one full calendar year of the year prior to the request.

1. Names of surrounding counties from catchment area from which data should be queried:
  
2. Zip Codes of patient residence from catchment area from which data should be queried:
  
3. Names of hospitals from catchment area from which data should be queried for #6 in table below.
  
4. Please list any data not contained in this appendix that you would like to receive. (Note: Data above and beyond elements listed in this appendix will incur an hourly staff fee further described on page 5.)

Data Element	Value of information
1. County(s) of injury	
2. Zip Code of Residence	
3. Patient Age	
4. Number of patients taken directly from scene to a PA trauma center	<ul style="list-style-type: none"> <li>• Shows volume of trauma in counties surrounding hospital that are cared for elsewhere.</li> <li>• Based on level of pursuit can serve as an indicator of how volume may increase as a result of accreditation.</li> </ul>
5. Number of transfers out to a PA trauma center from requestor's hospital, including name of receiving trauma center	<ul style="list-style-type: none"> <li>• Can serve to show the volume and acuity of patients that may not require transfer based on level of trauma center accreditation.</li> <li>• Can serve to show where the majority of patients are transferred and thereby the hospital that is best suited to act as a mentor to a pursuing hospital.</li> </ul>
6. Number of transfers out to a PA trauma center from other hospitals within catchment area. (Referring hospital names not given.)	<ul style="list-style-type: none"> <li>• Can serve as an indicator of the volume of trauma patients cared for at surrounding hospitals that are not trauma centers.</li> </ul>
7. Trauma patient hospital Length of Stay of requesting (referring) hospital	Serves as an indicator for whether patient transfer is currently being conducted in a timely fashion.

<b>Data Element</b>	<b>Value of information</b>
8. Discharge disposition of trauma patient your hospital transferred to a trauma center.	Can help hospital determine the ultimate severity of injury of the transferred patient.
9. Primary Cause of injury (ICD-10 Mechanism of Injury) Codes	Causes of injury can help guide injury prevention efforts in your community!
10. ICD 10 Diagnosis Codes	
11. Procedure codes (Procedures done in requesting/referring hospital AND/OR at receiving trauma center patient was transferred to.)	Often transferring hospitals delay transfer to do diagnostic studies. This query will help you see whether studies were duplicated at the receiving hospital.
12. ISS Score (Injury Severity Score which dictates severity of injury. Zero is no injury. A score of 75 is highest degree of injury. ISS > 15 typically is indicates injury requiring care at a trauma center.)	
13. Payer Classification Category (Insurance category of patient. PTSF does not collect information related to billing charges.)	Can be valuable in assessing financial reimbursement for trauma patients.