



# ANOMALOUS HEALTH INCIDENT (AHI) DEPARTMENT OF DEFENSE (DOD) PATIENT REGISTRY FAQs



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### **What is the patient registry?**

The Department of Defense Trauma Registry (DoDTR) is a web-based data collection tool that captures and documents, in electronic format, information about the demographics, injury-producing incident, diagnosis and treatment, and outcome of injuries sustained by US/Non-US military and US/Non-US civilian personnel in wartime and peacetime from the point of injury (POI) to final disposition. The DoDTR supports US military performance improvement initiatives with global collection and aggregation of casualty care epidemiology, treatments, and outcomes (JTS, n.d.; OSD, 2022).

### **What is the purpose of the AHI registry?**

The purpose of the AHI registry is to collect patient medical data related to reported health incidents for the purpose of analysis so that knowledge and characteristics of these incidents can be expanded for further advancements in the diagnosis, treatment, and outcomes of AHI-affected individuals (OSD, 2022).

### **Will participation in the registry affect my medical care?**

Your decision to participate or to decline participation in the registry will have no impact on your medical care.

### **If I consent or decline to be in the registry, can I change my mind later?**

Yes, you have the right to consent, or withdraw consent, at any time.

### **Will my Agency or Department know I consented into the registry?**

We will not publish the names of individuals who choose to participate, nor will your participation be indicated to your home agency, unless your agency specifies that it is a requirement.

### **What information will be included in the registry?**

The data collected in the AHI Registry includes your name as it appears in your electronic medical record, your demographic information, the precipitating event (the narrative of what happened when you first experienced symptoms), a description of the symptoms, and any diagnosis or treatment, as well as outcomes of the AHI patient (OSD, 2022).

### **Where will my information be stored?**

Your information/data will be stored on a secure server; privileged access to the AHI registry is restricted to Joint Trauma System (JTS) personnel. The registry is housed within a DoD approved military system, which only grants access to those personnel who support the AHI registry within the Joint Trauma System.

### **How long will my information be stored?**

Information will be stored indefinitely while the registry is maintained.

### **How will my information be protected in the registry?**

Your information will be protected in the registry by a secured firewall with access requirements including restriction to a DoD network, registry account approved computer access card (CAC) certificates, and autonomous role-based password controls.



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## How can I ensure that my information is correct?

Patients are able to check the accuracy of their information through the electronic health record patient portal.

## Who will see my information in the registry?

Your data/records are confidential to the extent permitted by law and only personnel on a need-to-know basis will have access to your personal identifying information (PII). Unless a requesting Agency/organization has approval through the DHA Privacy and Civil Liberties Office, we will not share your data. If approved, a requestor would not see your PII or data elements that could point to or identify you; these data elements would be redacted, and your identifiers will be removed in all reports. All reasonable efforts will be made to keep the personal information private and confidential, but absolute confidentiality cannot be guaranteed. Data collected are used solely for analysis (OSD, 2022).

## Can my information be shared from the registry?

PII and personal health information (PHI) can only be shared with researchers that receive an approved Data Sharing Agreement (DSA) from DHA's Privacy and Civil Liberties office. A DSA is an administrative control used by DHA to document that the requested use of data is in compliance with all federal laws and DOD policies.

The DSA documents the responsibilities of the requestors, including the government sponsor and applicant/recipient. The DSA also confirms that DHA data will be used as permitted or required, and it exercises administrative, technical, and physical safeguards to protect the privacy of PHI, as required by the Health Insurance Portability and Accountability Act (HIPAA). The DSA determines the HIPAA-defined category of data intended for use (i.e., protected health information, a limited data set, or de-identified PHI). HIPAA permits a covered entity to use or disclose a limited data set for research, public health, or health care operations purposes. The DSA also maintains records to confirm compliance in case of an investigation.

## Is this a one-time data pull or will my information be continuously uploaded into the registry?

Your information will be drawn from medical records and entered into the JTS DoD AHI registry. JTS personnel will collect information up to one year after your initial evaluation. Additional information beyond one year may be gathered by request.

## Is my information de-identified or will it be attributable to me?

Research data may be released with an approved DSA from the DHA's Privacy and Civil Liberties office. However, your identifiers will be removed from reporting prior to sharing. De-identified data can also be released to other federal agencies through an approved Institutional Review Board (IRB) research protocol (OSD, 2022).

## How are individuals included in the registry?

Any participating Department of Agency, to include the Department of Defense, has a Memorandum of Agreement (MOA) with the Defense Health Agency (DHA). That MOA requests permission from the referring Agency to allow their employee to be included in the patient registry. The DHA will also request permission from the individual to include them in the patient registry as well.

## References

1. Joint Trauma System (JTS) (N.D.) The Department of Defense Center of Excellence for Trauma: Registries. <https://jts.health.mil/index.cfm/data/registries>
2. Office of Secretary of Defense (OSD) (August 2022). Defense Health Agency Form 245. <https://dpcl.dod.mil/Portals/49/Documents/Privacy/SORNs/DHA/EDHA-07.pdf>