

STATE COMMITTEE OF PUBLIC HEALTH
BUREAU OF HEALTH PROMOTION AND INFORMATION
ADMINISTRATIVE CODE

CHAPTER 420-2-4
ALABAMA HEAD AND SPINAL CORD INJURY REGISTRY

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420-2-4-.01 General Provisions.

This chapter applies to the reporting of head and/or spinal cord injury to the Alabama Head and Spinal Cord Injury Registry (AHSCIR or Registry).

Author: Teresa S. Pells, M.P.H., Stephen Wilson, B.S., NRP

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420-2-4-.02 Definitions.

(1) "Accuracy" means the correctness of data reported on head and spinal cord injury cases submitted to the AHSCIR.

(2) "Advisory Council" means the council appointed by the State Health Officer consisting of health care professionals, university representatives, appropriate state agencies, persons or family members of persons with head and spinal cord injuries, and other interested parties from various health associations.

(3) "AHSCIR" means a database created by state law to collect information about head and spinal cord injuries. The AHSCIR is housed in the Office of Emergency Medical Services (OEMS). Data from the trauma system may be included in the AHSCIR.

(4) "Board" or "State Board of Health" means the Board of Health of the State of Alabama as defined by §22-2-1, Code of Ala. 1975, or the State Health Officer, or his or her designee, when acting for the Board.

(5) "Clinical Records" means any record, hard copy or patient abstract, containing information which could lead to the identification of head and spinal cord injury patients, head and spinal cord injury diagnosis or treatment facilities, independent clinical laboratories, or health care providers.

(6) "Clinical Information" means any information which could lead to the identification of head and spinal cord injury patients, head and spinal cord injury diagnosis or treatment facilities, or health care providers.

(7) "Completeness" means the complete reporting of all confirmed cases of head and/or spinal cord injury as well as all required data fields.

(8) "Data Acquisition Manual" means the manual developed by the AHSCIR which specifies the rules and guidelines used when abstracting a confirmed head and/or spinal cord injury case to be reported.

(9) "Death Match" means the matching of confirmed cases of head and/or spinal cord injuries reported to the central registry with a listing of deceased individuals.

(10) "Electronic Data Submission" means transferring data from a computer used by a reporting entity to a database server specified by the AHSCIR.

(11) "Head and/or Spinal Cord Injury Patient" means any person who is undergoing diagnosis or treatment for head and/or spinal cord injury.

(12) "Health Care Facilities" means all public, private, federal or military hospitals, or any other facilities where head and spinal cord injury cases are diagnosed or treated.

(13) "Institutional Review Board (IRB)" means the members selected by the State Health Officer to examine proposed research projects and ensure that research procedures will respect and protect persons who are research subjects, maximize benefits, and minimize any potential harm or risk.

(14) "Office of Emergency Medical Services (OEMS)" means the subdivision of the Department charged with the enforcement and administration of these rules.

(15) "Spinal Cord Injury" means occurrence of an acute traumatic lesion of neural elements in the spinal canal (spinal cord and

Cauda equina), resulting in temporary or permanent sensory deficit, motor deficit, or bowel or bladder dysfunction.

(16) "Statistical Data" means collected aggregate data which does not lead to the identification of head and spinal cord injury patients, diagnosis or treatment facilities, or health care providers.

(17) "Timeliness" means the reporting of all confirmed cases of head and spinal cord injuries within 90 days of diagnosis or admission to an acute care hospital.

(18) "Traumatic Brain Injury or Head Injury" means an occurrence of injury to the head that is documented in a medical record, with one or more of the following conditions attributed to head injury:

(a) Observed or self-reported decreased level of consciousness.

(b) Amnesia.

(c) Skull fracture.

(d) Objective neurological or neuropsychological abnormality.

(e) Diagnosed intracranial lesion.

(f) As an occurrence of death resulting from trauma, with head injury listed on the death certificate, autopsy report, or medical examiner's report in the sequence of conditions that resulted in death.

This definition applies to an acquired injury to the brain. This term does not include brain dysfunction caused by congenital or degenerative disorders, nor birth trauma, but may include brain injuries caused by anoxia due to near drowning.

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420-2-4-.03 Reporting Date And Submission.

(1) All confirmed cases of head and/or spinal cord injuries diagnosed or treated and admitted to acute care hospital facilities in the state shall be reported via electronic submission to the AHSCIR preferably within 30 days but no longer than 90 days of admission or diagnosis as prescribed by these rules.

(2) The reporting facility is solely responsible for providing complete and accurate data as required in the AHSCIR Data Acquisition Manual. If data do not meet established quality of data standards in any or all of three areas: completeness, accuracy, and timeliness, the reporting facility will respond to queries from the OEMS and submit original and/or corrected data. If this measure is necessary, then notification shall be sent to the facility in the form of a letter regarding specific discrepancies in the data. The facility shall reply within 60 days and resubmit the data. No fees shall be charged to facilities to implement these rules.

(3) If the health care facility fails to report in the prescribed format, the State Health Officer's authorized representative shall be permitted access to all records which would identify confirmed cases of head and/or spinal cord injury.

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420-2-4-.04 Data To Be Reported.

(1) All confirmed cases of head and/or spinal cord injury with the following International Classification of Diseases, Tenth Revision, Clinical Modification (ICD-10-CM)* diagnostic codes as a primary and/or secondary diagnosis must be reported:

Traumatic Brain Injury

	Begin With	End With	
S01	S01.00X - S01.05X S01.80X - S01.95X	A	Open Wound
S02	S02.3XX	A or B	Fracture of Skull and Facial Bones
S04	S04.02X - S04.049	A	Injury to Optic Chiasm and Optic Tract
S06	S06.0X0 - S06.9X	A	Intracranial Injury
S07	S07.0XX - S07.9XX	A	Crushing Injury of Head
S08	S08.89X	A	Avulsion and Traumatic Amputation of Part of Head
S09		A	

	Begin With	End With	
	S09.8XXA - S09.90X		Other and NOS Injury of Head
T74	T74.4XX	A	Shaken Infant Syndrome

Spinal Cord Injury

	Begin With	End With	
S12	S12.000 - S12.9XX	A or B	Fracture of Cervical Vertebra and Other Parts of Neck
S13	S13.0XX	A	Traumatic Rupture of Cervical Intervertebral Disc
S14	S14.0XX - S14.9XX	A	Injury of Nerves and Spinal Cord at Neck Level
S17	S17.0XX - S17.9XX	A	Crushing Injury of Neck
S24	S24.0XX - S24.9XX	A	Injury of Nerves and Spinal Cord at Thorax Level
S32	S32.000 - S32.059	A or B	Fracture of Lumbar Spine and Pelvis
S34	S34.01X - S34.9XX	A	Injury Lumbar/ Sacral Spinal Cord and Nerves

*May also use International Classification of Diseases, Tenth Revision, Clinical Modification (ICD-10-CM) or any other current version as appropriate.

(2) A report shall also be given for each subsequent head and/or spinal cord injury diagnosed in an individual. If it cannot be decided whether a case should be reported, the OEMS should be contacted for guidance.

(3) All electronically submitted reports of confirmed cases of head and/or spinal cord injury shall include but not be limited to the data items listed in the AHSCIR Data Acquisition Manual.

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420-2-4-.05 Quality Control.

(1) All health care facilities shall permit periodic quality control reviews by OEMS staff including case finding, abstracting, coding, and data submission processing. The OEMS shall provide at least 15 days' notice to a facility when OEMS seeks access to information on site at a facility.

(a) All health care facilities shall perform quality control reviews including case finding, abstracting, coding, and data submission processing. Health care facilities shall submit quality control data to OEMS upon request.

(2) The OEMS will ensure the provision of head and spinal cord injury registry training and consultation.

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420-2-4-.06 Referrals.

(1) The OEMS will facilitate referring of persons who sustain head and/or spinal cord injuries by sharing registry data with the Alabama Department of Rehabilitation Services (ADRS).

(2) The OEMS will submit data to the ADRS based on an Interagency Agreement between the two agencies.

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420-2-4-.07 Confidentiality.

(1) The clinical records of individual patients submitted to the AHSCIR shall be confidential and shall not be public records open to inspection. Only state personnel authorized by the State Health Officer and other individuals authorized by the State Health Officer or designee shall have access to the records. All individuals with access to patient information shall be made aware of the privileged and confidential nature of all information submitted to the AHSCIR.

(2) The information contained in the clinical records of individual patients submitted to the AHSCIR shall be password protected, therefore, only personnel authorized by the OEMS staff to access the system involved in maintaining patient information shall be able to do so.

(3) Clinical information from the AHSCIR may be disclosed in the following circumstances when authorized by the State Health Officer or designee:

(a) Information may be disclosed in response to a subpoena or a valid court order.

(b) Information may be disclosed as provided in the Access to Information for Research Purposes section of these rules.

(c) Information may be released to a participating hospital to confirm a death match if the hospital has an agreement with the Center for Health Statistics to allow release of this information.

(d) Statistical information and data based on client information may be released by the OEMS so long as no information identifying an individual patient or facility is released.

(4) Photocopying or other reproduction of any clinical records or reports in the possession of the OEMS containing identifying information, except as may be required in the conduct of the official business of the OEMS, is prohibited.

(5) Any legible documents such as computer printouts, or photocopies of any documents containing identifying information, shall also be considered confidential material while in active use and shall be destroyed by shredding immediately upon termination of their use by the AHSCIR.

(6) Follow-up information submitted shall be retained indefinitely by the AHSCIR.

(7) Patient-specific data may be exchanged with any other clinical facility for the purpose of obtaining information necessary to complete a case record. This data shall not be further disclosed by that agency or facility.

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420-2-4-.08 Access To Information For Research Purposes.

(1) The OEMS may release statistical data only to a person or agency for the following purposes:

- (a) Medical research or education.
- (b) Epidemiologic studies.
- (c) Health education.
- (d) Health planning or administration.
- (e) Required statistical reports necessary for publication of an annual report.
- (f) Publication of the AHSCIR annual report.
- (g) Other statistical reports not previously produced and/or published by written request for research, information, or education.

(2) A medical researcher may request the release of clinical records from the AHSCIR by the submission of a written research proposal to the registry containing the following information:

- (a) Purpose of the research.
- (b) Research design.
- (c) Proposed benefits to be derived from such research.
- (d) A statement of compliance with all applicable state and federal requirements regarding the confidentiality of patient records.
- (e) A completed application to the Alabama Department of Public Health (ADPH) Institutional Review Board (IRB) for release of confidential data.
- (f) If the research is to be credited toward a degree to the researcher, or if the research is being otherwise conducted by an institution of higher learning, the proposal shall contain a statement signed by the dean of the school, or designee, declaring that the proposed research is in compliance with all applicable research standards of the institution.

(3) The clinical records or reports of the individual patient may be disclosed to research staff for the purpose of medical research, provided that the registry has determined that:

(a) Disclosure of this information is deemed necessary to accomplish the purposes of the research.

(b) The research warrants the risk to the individual patient of the potential disclosure of their medical records.

(c) Adequate safeguards to protect the clinical records or identifying information are established and maintained.

(4) For the purposes of these rules, research is defined as any systematic investigation designed to answer a defined scientific question that requires collection and analysis of data in order to develop or contribute to generalizable knowledge. A researcher is defined as the primary investigator or project director.

(5) The OEMS shall submit all research proposals to the ADPH IRB in determining whether to release information as provided in this rule. The consideration of all research proposals shall conform to the established ADPH IRB policy.

(6) Any copies of reports or records provided to the researcher remain under the ownership of the OEMS and shall be returned to the OEMS upon termination of the research to be destroyed. Upon completion of the study, the researcher shall submit one copy of the completed research paper to the OEMS. The OEMS shall transmit the paper to the IRB for review, to be returned to the AHSCIR for filing. If the committee deems the research to be of importance to the practicing physicians of the state, then the committee may recommend, with the concurrence of the researcher, the research agency or institution, that the abstract of the research be published.

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420-2-4-.09 Assistance And Consultation For Public Health Work.

(1) The OEMS shall provide assistance and consultation for public health work.

(2) The OEMS shall provide consultation for any agency, facility, or organization actively engaged in the effort to reduce the incidence of head and/or spinal cord injuries, whether through direct service to, or the education of, head and spinal cord injury patients and their families, the public, or the medical professions in accordance with the provisions of these rules and the availability of staff time and resources.

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