

CHAPTER 21
CENTRAL REGISTRY FOR
BRAIN AND SPINAL CORD INJURIES

641—21.1(135) Purpose. This chapter describes the central registry for brain and spinal cord injuries.

641—21.2(135) Definitions. For the purpose of these rules, the following definitions shall apply:

“*Acute injury*” means an injury for which a person has been continuously hospitalized since recognition of that injury.

“*Agency*” means Iowa department of public health.

“*Brain injury*” means any clinically evident brain damage resulting from trauma or anoxia which temporarily or permanently impairs a person’s physical or cognitive functions.

“*Hospital*” means hospital as defined by the department of inspections and appeals in Iowa Code section 135B.1.

“*Physical agent*” means mechanical energy transmitted from a living or nonliving vector to humans.

“*Reportable case*” means a person who is admitted or transferred to a hospital with a diagnosis of acute traumatic brain or spinal cord injury or a person who is pronounced dead in the emergency department of a hospital with an acute traumatic brain or spinal cord injury.

“*Spinal cord injury*” means any acute, traumatic lesion of the neural elements in the spinal canal, resulting in any degree of sensory deficit, motor deficit, or bladder/bowel dysfunction.

641—21.3(135) Reportable injuries. The brain and spinal cord injuries listed below are required to be reported to the Iowa Department of Public Health, Division of Health Protection, Lucas State Office Building, Des Moines, Iowa 50319-0075, as part of a statewide population-based registry.

21.3(1) Reportable cases of brain injuries are those that are identified by the following codes from the International Classification of Diseases, 9th Revision, Clinical Modification:

- a. 348.1 (resulting from physical agents)
- b. 800.00–800.99—Fracture of vault of skull.
- c. 801.00–801.99—Fracture of base of skull.
- d. 803.00–803.99—Other and unqualified skull fractures.
- e. 804.00–804.99—Multiple fractures involving skull or face with other bones.
- f. 850.00–850.99—Concussion.
- g. 851.00–851.99—Cerebral laceration and contusion.
- h. 852.00–852.59—Subarachnoid, subdural, and extradural hemorrhage, following injury.
- i. 853.00–853.19—Other and unspecified intracranial hemorrhage following injury.
- j. 854.00–854.19—Intracranial injury of other and unspecified nature.
- k. 994.1—Drowning and other nonfatal submersion.
- l. 994.7—Asphyxiation and strangulation.

21.3(2) Reportable cases of spinal cord injuries are those that are identified by the following codes from the International Classification of Diseases, 9th Revision, Clinical Modification:

- a. 806.00–806.9—Fracture of vertebral column with spinal cord injury.
- b. 952.00–952.9—Spinal cord injury without evidence of spinal bone injury.

641—21.4(135) Who reports and under what circumstances. Hospitals treating, transferring, or having pronounced dead any person determined to have sustained a reportable case of traumatic brain or spinal cord injury are required to submit information as identified by the agency.

641—21.5(135) Method and frequency of reporting.

21.5(1) Hospitals shall report, electronically or on a paper form prescribed or approved by the agency, the required information for any reportable case of traumatic brain or spinal cord injury within 45 days after the end of the quarter during which the patient was discharged, transferred to another acute care hospital, or pronounced dead in the emergency department.

21.5(2) Reports that are submitted electronically shall meet the data quality, format, and timeliness standards prescribed by the agency which are described in the manual, available from the agency, for completing the brain and spinal cord injury registry reporting form.

641—21.6(135) Confidentiality.

21.6(1) The agency shall maintain the confidentiality of all submitted registry reports of traumatic brain and spinal cord injuries and shall not release reports, or any information which can be associated with a particular individual, unless the release is in compliance with the provisions of subrule 21.6(2).

21.6(2) A registry report of a traumatic brain or spinal cord injury that is submitted to the agency that can be associated with a particular individual shall be released as follows:

a. To the particular individual upon receipt of a written request signed by the particular individual and suitable identification presented in person to an employee designated by the agency.

b. If the particular individual is a minor, to a parent or attorney of the particular individual upon receipt of a written request signed by a parent or attorney of the individual and of a certified copy of the birth certificate and suitable identification presented to an employee designated by the agency.

c. If the particular individual has a court-appointed guardian or if the particular individual is deceased, to the court-appointed guardian or to the executor or administrator of the particular individual's estate upon receipt of a written request signed by the court-appointed guardian, executor, or administrator, and of a certified copy of the order or decree which appoints the guardian, executor, or administrator, and of suitable identification presented to an employee designated by the agency.

d. To an attorney or other person who is designated by the particular individual upon receipt of a written request signed by the particular individual and suitable identification presented to an employee designated by the agency.

e. To an authorized representative of a study or research project that shall be reviewed by a scientific advisory panel and approved by the director of public health. The director of the agency shall appoint a scientific advisory panel of no less than three scientists or public health staff to review research proposals for which the release of information that identifies an individual who is reported to have a traumatic brain or spinal cord injury is required.

f. The release of information for research that identifies individuals with traumatic brain or spinal cord injuries shall be subject to the terms and conditions set by the agency. Such study or research project keeps the identifying information confidential and privileged. A formal memorandum of agreement signed by an authorized representative of the agency and the director of the research project shall include provisions that the data provided by the agency shall not be copied for retention, resold, or otherwise provided to another person or organization and will be returned to the agency upon completion of the study.

g. The agency may transmit transcripts or copies of reported cases to state or national traumatic brain and spinal cord injury registries when the reports relate to residents of other states or countries. The agreement shall require that the transcripts or records be used for statistical purposes only and that the identity of reported cases shall not be released.

641—21.7(135) Quality assurance. For the purpose of ensuring the completeness and quality of submitted data, each hospital may allow the agency inspection of parts of patient's medical reports as necessary to verify or clarify these data by signing an agreement. The agency's authorized representative may enter the facility, obtain the information, and report it in the appropriate form. Prior to inspecting

the records, this agency shall work with the hospital to determine a time and date agreeable to both parties.

These rules are intended to implement Iowa Code section 135.22 as amended by 1994 Iowa Acts, House File 2145.

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