

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.