

DEPARTMENT OF HEALTH AND HUMAN SERVICES
BUREAU OF EPIDEMIOLOGY AND POPULATION HEALTH
LIFECOURSE EPIDEMIOLOGY AND GENOMICS DIVISION
MANDATORY REPORTING OF AMYOTROPHIC LATERAL SCLEROSIS
CASES

(By authority conferred on the department of health and human services by sections 2226, 2233, and 5111 of the public health code, 1978 PA 368, MCL 333.2226, 333.2233, and 333.5111)

R 330.101 Definitions.

Rule 1. (1) As used in these rules:

(a) "ALS" or "Amyotrophic Lateral Sclerosis" or "Lou Gehrig's disease" means a uniformly fatal disease with the average life span of 2 to 5 years following diagnosis, manifested as a progressive neurodegenerative disease.

(b) "ALS case abstraction form" means the form prescribed by the department to report the required reportable information for individuals with ALS and conditions related to ALS.

(c) "Code" means the public health code, 1978 PA 368, MCL 333.1101 to 333.25211.

(d) "Conditions related to ALS" means diseases that manifest similarly to ALS, including the following:

(i) Progressive muscular atrophy.

(ii) Primary lateral sclerosis.

(iii) Flail arm.

(iv) Flail leg.

(e) "Department" means the department of health and human services.

(f) "Health professional" means an individual licensed under article 15 of the code, MCL 333.16101 to 333.18838, to work as a physician, a physician's assistant, or a nurse practitioner.

(g) "Public health investigation" means the collection of medical, epidemiologic, exposure, and other information to determine the cause of illness or disability, which is used to determine appropriate actions to prevent or mitigate additional illness or disability.

(h) "Report" means documents or data containing health information provided to the department consistent with these rules.

(2) A term defined in the act has the same meaning when used in these rules.

History: 2025 MR 10, Eff. May 15, 2025.

R 330.102 Reportable Information.

Rule 2. (1) Health professionals and health facilities must provide reports in a format that ensures the inclusion of the following information, as applicable:

(a) If available, all of the following information, with respect to the patient, must be provided:

- (i) Reporting facility name.
- (ii) Reporting facility type or source, including hospital, clinic, or death records.
- (iii) Medical record number.
- (iv) Last and first name and middle initial.
- (v) Birth date.
- (vi) Death date, if applicable.
- (vii) Sex.
- (viii) Race.
- (ix) Ethnicity.

(x) The primary diagnosis indicating ALS or a condition related to ALS, including the diagnostic code.

- (xi) Date of diagnosis.
- (xii) Current residential address.
- (xiii) Telephone number.
- (xiv) Email address.

(b) Upon receipt of a report, the department may request the collection of the following information, in addition to information specified in subdivision (a) of this subrule, if available:

- (i) City, state, and country of birthplace.
- (ii) Location of disease onset, if known.
- (iii) Current occupation.
- (iv) Military veteran status.
- (v) Military branch of service, if applicable.
- (vi) Duration of military service, if applicable.
- (vii) Location of military service, if applicable.
- (viii) Date of symptoms onset.
- (ix) Family history of ALS.
- (x) Family history of dementia.

(xi) Family history of psychiatric illness such as depression, bipolar disorder, or schizophrenia.

(xii) Secondary neurological diagnosis such as frontotemporal dementia, if applicable.

(xiii) Site of onset of progressive weakness if known, including, but not limited to the following:

- (A) Bulbar.
- (B) Truncal.
- (C) Generalized.
- (D) Respiratory.
- (E) Upper limb.
- (F) Lower limb.

(c) Name, address, telephone number, email address, and other contact information of the health professional who diagnosed or treated the patient.

(d) Name, address, telephone number, email address, and other contact information of the reporting health professional or health facility.

(2) Reports submitted in electronic or physical format must meet data quality, format, and timeliness standards prescribed by the department.

History: 2025 MR 10, Eff. May 15, 2025.

R 330.103 Reporting responsibilities.

Rule 3. (1) Following the effective date of these rules, health professionals and health facilities must submit the reports, as described in R 330.102, within 3 months of diagnosis.

(2) Health professionals and health facilities may be asked by the department to provide follow-up information on individuals for the variables in R 330.102(1)(b) within 6 months after the follow-up.

(3) Health professionals and health facilities must submit the report required in R 330.102 when requested by the department. Additional reports may be made by health professionals and health facilities in the absence of a departmental request.

(4) Nothing in this rule relieves a health professional or health facility from reporting to another entity as required by state, federal, or local statutes or regulations or in accordance with accepted standard of practice, except that reporting in compliance with this rule satisfies the reporting requirements of the code.

History: 2025 MR 10, Eff. May 15, 2025.

R 330.104 Investigation and quality assurance.

Rule 4. (1) The department shall consult with local health departments in the development of procedures for processing ALS reports and conducting follow-up investigations to ensure an efficient, non-duplicative, and effective public health response.

(2) The department may make requests for individual medical and epidemiologic information to validate the completeness and accuracy of reports. Individuals or organizations that receive such requests must provide the information sought to the department promptly, no later than 30 days after the request is made.

History: 2025 MR 10, Eff. May 15, 2025.

R 330.105 Confidentiality of reports.

Rule 5. (1) To the maximum extent allowed by law, reports and health information collected under these rules are not public records and are exempt from disclosure under the freedom of information act, 1976 PA 442, MCL 15.231 to 15.246.

(2) Reports and any health information collected under these rules are medical records for the purpose of section 13(1)(l) of the freedom of information act, 1976 PA 442, MCL 15.243.

(3) Medical and epidemiological information that identifies an individual and that is gathered in connection with an investigation is confidential and is not open to public inspection, except as provided in subrule (5) of this rule. All individuals in possession of reports and records collected under these rules shall maintain the confidentiality of reports, records, and data pertaining to testing, diagnosis, care, treatment, reporting, and research, and shall not reveal the identity of any individual.

(4) Medical and epidemiological information that is released to a legislative body must not contain information that identifies a specific individual.

(5) Information collected under this rule must be used for epidemiologic investigation and evaluation and the department and local health departments may release reports or information under any of the following conditions:

(a) If the department has received written consent from the individual, or from the individual's legal guardian.

(b) As necessary for the department to carry out its duties under sections 2221(2) and 2637(1) of the code, MCL 333.2221 and 333.2637.

(c) If necessary for the purpose of research designed to contribute to generalizable knowledge, with documented approval by the department's institutional review board.

History: 2025 MR 10, Eff. May 15, 2025.