

90-590 MAINE HEALTH DATA ORGANIZATION

Chapter 730: INTERAGENCY REPORTING OF CANCER-INCIDENCE REGISTRY AND VITAL STATISTICS DATA

A joint rule with

**10-144 DEPARTMENT OF HEALTH AND HUMAN SERVICES
MAINE CENTER FOR DISEASE CONTROL AND PREVENTION - DATA,
RESEARCH AND VITAL STATISTICS**

Chapter 730: INTERAGENCY REPORTING OF CANCER-INCIDENCE REGISTRY AND VITAL STATISTICS DATA

SUMMARY: This joint rule provides for the reporting of cancer data and vital statistics data by the Department of Health and Human Services, Maine Center for Disease Control and Prevention; Data, Research, and Vital Statistics to the Maine Health Data Organization, pursuant to Public Law 2021, chapter 423.

The provisions include:

- Identification of the agencies involved and their reporting requirements;
 - Establishment of requirements for the content, format, method, and reporting periods for the data;
 - Data integration; and
 - Confidentiality.
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1. Definitions

Unless the context indicates otherwise, the following expressions shall have the following meanings:

- Department.** “Department” means the State of Maine, Department of Health and Human Services, Maine Center for Disease Control and Prevention.
- DRVS.** “DRVS” means the Data, Research, and Vital Statistics office within the Department.
- Encryption.** “Encryption” means the process of converting data to an unrecognizable form, in order to protect protected health information so that only authorized parties can view it. This includes data files and storage devices, as well as data transferred over wireless networks.
- Event.** “Event” means a birth, death, fetal death, marriage, divorce, annulment, or domestic partnership registration or termination.
- Identifying data.** “Identifying data” means the names and street addresses of the registrant(s) and other individuals named on or the subject of a report or record registered by the State

Registrar, including the date of birth and the month and day of the event. The year that an event occurred is not identifying data.

- F. **Interstate data exchange.** “Interstate data exchange” means a process whereby registration areas agree to exchange vital statistics data, reports and records or cancer diagnosis data with the state registrars of other states, territories, and neighboring countries where the individual resides.
- G. **Interstate exchange cancer cases.** “Interstate exchange cancer cases” means a cancer case in the Maine Cancer Registry where the only information on the cancer was received through interstate data exchange. There is no other report of the case submitted by any other institution.
- H. **MHDO.** “MHDO” means the Maine Health Data Organization.
- I. **Protected Health Information (PHI).** “Protected Health Information” includes identifying data and any individually identifiable health information (including any combination of data elements) that relates to the past, present, or future physical or mental health or condition of an individual; or the past, present or future payment for the provision of health care to an individual; and (a) identifies, directly or indirectly, an individual, or (b) with respect to which there is a reasonable basis to believe that the information can be used to identify an individual patient. PHI also includes individually identifiable registrant information.
- J. **Registrant.** “Registrant” means the individual(s) to whom the record pertains: the child named on a birth certificate, the decedent named on a death certificate, and the subject of cancer registry data.
- K. **Vital Records.** “Vital records” means reports of live birth, death, fetal death, marriage, and data related thereto which have been accepted for registration and incorporated into the official records from the system of vital statistics.
- L. **Vital Statistics Data.** “Vital statistics data” means the data derived from paper based or electronic vital records and reports.

2. Data Requirements and Exclusions

DRVS shall report Maine Cancer Registry data and data related to the registration of vital statistics, including identifying data or protected health information (PHI), to the MHDO, in accordance with this rule.

A. Cancer Registry Data Elements:

1. Reporting Facility/Physician
2. Registrant’s Name (first name, middle initial, last name, and, if applicable, maiden name)
3. Date of Birth
4. Address at Diagnosis; including
 - a. City or Town of Residence
 - b. County of Residence

- c. State of Residence
- d. Zip Code
5. Sex/Gender
6. Social Security Number, if available
7. Race
8. Attending Physician
9. Referring Physician
10. Date of Diagnosis
11. Topography of Cancer (ICD)
12. Morphology of Cancer (ICD)
13. Usual Occupation
14. Usual Industry
15. Stage of Disease at Diagnosis (AJCC coding system)
16. Patient's Mailing Address
17. Date of Admission
18. Laterality
19. Grade
20. Spanish/Hispanic Origin
21. Diagnostic Confirmation
22. Summary Stage
23. Date of First Course of Treatment (when available in the medical record)
24. Type of First Course of Treatment (when available in the medical record)

B. Vital Statistics Birth Data Elements:

1. Registrant's Name (first name, middle initial, last name, suffix and, if applicable, maiden name)
2. Date of Birth
3. Sex/Gender
4. Race
5. Hispanic Indicator
6. Event Location
 - a. City or Town
 - b. County
 - c. State
 - d. Zip Code
7. Registrant's Parent(s)
 - e. Last Name (including maiden name, if applicable/available)
 - f. First Name and Middle Initial
 - g. Date of Birth
 - h. Sex/Gender
 - i. Race
 - j. Hispanic Indicator
 - k. Residence City or Town
 - l. Residence County
 - m. Residence State
 - n. Residence Zip Code

C. Vital Statistics Death Data Elements:

1. Registrant's Name (first name, middle initial, last name, suffix and, if applicable, maiden name)
2. Date of Birth
3. Sex/Gender
4. Social Security Number
5. Race
6. Hispanic Indicator
7. Residence City or Town
8. Residence County
9. Residence State
10. Residence zip
11. Event Location
 - a. City or Town
 - b. County
 - c. State
 - d. Zip Code
12. Cause of death ICD-10 code

- D. Interstate Data Exchange Exclusions.** The Maine Cancer Registry is a signatory to the North American Association of Central Cancer Registries' National Interstate Data Exchange Agreement which prohibits re-release of interstate exchange only cases. Data which is from interstate exchange only cases will be excluded and not transferred to MHDO.

3. Filing Requirements

- A. File Format.** The file format will be an MHDO-provided template for each dataset. DRVS will use the current version of the appropriate template. The file format for DRVS will contain the data elements listed and described in subsections 2(A), 2(B), 2(C) and not excluded by 2(D). File naming conventions will be specified in the instructions included with each template.
- B. Filing Method.** Data files must be submitted via Secure File Transfer Protocol (SFTP). Files are required to be compressed and encrypted before uploading. This file-level encryption will ensure the confidentiality of all data that are submitted to the MHDO portal, not just individual fields.
- C. Filing Period.** DRVS will submit data sets to MHDO based on the following schedule:
1. Historic data from January 2015 to December 2021 will be submitted for births by April 30, 2022 and deaths by June 30, 2022 in yearly incremental files.
 2. Annually, birth files will be submitted by April 30th following the end of the calendar year and death files by June 30th.
 3. Annually, cancer incidence data will be submitted by April 30th for the diagnosis year that was submitted to the National Program on Cancer Registries in November of the prior year (e.g., by April 30, 2022 MHDO will receive diagnosis year 2019 data from MCR).

D. **Other Requirements.** The data reported will be assigned an MHDO identifier and becomes MHDO data.

4. **Confidentiality**

Information collected, processed and/or analyzed under this rule shall be subject to release to the public or retained as confidential information in accordance with 22 M.R.S. Chapter 1683 and 90-590 CMR Chapter 120 and this rule, unless prohibited by state or federal law.

STATUTORY AUTHORITY: 22 M.R.S. §§1406-A; 2706, sub-§2-A; and 8715-A; PL 2021, Chapter 423

EFFECTIVE DATE: December 14, 2021