**Section 1010.60 Data Dissemination**

a) The Department will provide facilities the opportunity to review the Consumer Guide to Health Care (Guide) prior to public release. The entire report will be made available to each facility on the Department's secure web server for review before publication. This review period will end 15 working days after the availability date of the review material. During the review period, each facility may submit written comments concerning its report content to the Department. Comments shall be submitted on facility letterhead and shall be signed by the administrator or designee. All comments received by the Department will be kept on file. No comments will be accepted after the end of the review period and no changes to the content of the Guide will be accepted. If any facility or the Department finds erroneous or incomplete data in the Guide, these data will be identified and footnoted prior to publication. If the Department makes an error in the preparation or presentation of the Guide, the error will be corrected.

b) Limited Data Product and Report requests approved by the Department shall result in the creation of the minimum necessary data set from the population of data elements available to the requester and accompanying data use agreement covering access, usage, distribution and confidentiality of the data.

1) The Department, in accordance with Section 2310-33 of the Department of Public Health Powers and Duties Law of the Civil Administrative Code of Illinois, will charge fees to the requesting entity for providing access to data files or producing studies, data products or analyses of data. A schedule of fees for standard and custom datasets and products according to category of purchaser is presented in Section 1010.70 of this Part. In determining fees, the Department will consider all of the following:

A) Type of data and specified usage;

B) Record count and computer time required;

C) Access fees for computer time;

D) Staff time expended to process the request; and

E) Handling and shipping charges.

2) All requests for data files, data products, aggregations or reports containing limited data elements shall be made in writing to the Department using Department forms available at https://dph.illinois.gov/content/dam/soi/en/web/idph/files/forms/formsoppsdischarge-data-request-form.pdf. All data obtained from the Department shall be used solely for the purpose identified by the requesting entity and for use by the requesting entity. The scope and term of this usage will be detailed in a data use agreement specific to each request. Use of the data for any other purpose shall require a separate and specific written request, approval, and data use agreement.

3) When the Department prepares facility-specific data, reports or comparative analyses for public release, affected facilities will be given the opportunity to review and comment on the data, studies or reports and their content prior to release to the public. Facilities will be provided access to the entire report on the Department's secure web server for review prior to publication. The review period will end 15 working days after the availability date of the review material. While no changes to previously submitted data will be accepted, the Department will accept written comments and explanations from facilities during the review period. The Department will keep these comments and explanations on file and, as appropriate and reasonable, will incorporate them into the text description of the published report, study or analysis. If a Department error is found in the publication, the error will be corrected.

c) De-identified Data Files and Reports

1) Public use data files, reports and studies based on information submitted by hospitals and ambulatory surgical treatment centers shall contain de-identified data and shall comply with State and federal law, including, but not limited to, the Gramm-Leach-Bliley Act and the HIPAA privacy regulations.

2) All requests for public use files or special compilations, reports, studies or analyses derived from public use files shall be made in writing to the Department, with forms available at https://dph.illinois.gov/content/dam/soi/en/web/idph/files/forms/formsoppsdischarge-data-request-form.pdf. The release of data related to an approved public use data request shall not require a detailed data request form or comprehensive data use agreement. However, each request will be evaluated and, if necessary, will require a signed data use agreement appropriate to the content of the data requested. The data use agreement will include, but not be limited to, restrictions on patient identification and sale or release of the data to third parties.

3) Facility syndromic surveillance data submitted to the Department may be used for epidemiological investigation or other disease intervention activities of the Department or local health department. Investigation shall include obtaining laboratory and clinical data necessary for case ascertainment. Findings of the investigation shall be used to institute control measures to minimize or reduce the risk of disease spread or to reduce exposures in a public health emergency event recognized or declared by local, State, or federal authorities.

4) Syndromic surveillance data will be released for local health departments and the Centers for Disease Control and Prevention, consistent with the Department of Public Health Act and the Control of Communicable Diseases Code and used for monitoring public health. Release will be through secure transfer of data and accessed by approved software tools for data analysis.

5) Release of aggregate, de-identified syndromic surveillance data is permitted only by the Department or local health department of the jurisdiction that the data describes.

6) Release of syndromic surveillance data to individuals or entities other than the public health agencies identified requires a data use agreement. A data request form to initiate the process will be made available publicly at https://redcap.dph.illinois.gov/surveys/?s=MAPECL9E73. Any release of syndromic surveillance data must be consistent with the Department of Public Health Act and Health Statistics Act. Only the Department can review and approve the release of visit-level syndromic surveillance data to a third party.

7) Facility user access is permitted only for data specific to the user's facility or health care system. Any sharing of data across facilities will require an agreement between the facilities and provided to the Department or due to provisions in applicable administrative rules (such as for extensively drug-resistant organism (XDRO) data or data for the Prescription Monitoring Program (PMP)). Aggregate data at the State level may be shared with facility users, but aggregate level of visits to facilities at the county level may not be shared with facility users.

8) The Department will *not release any syndromic data or information obtained pursuant to this* Part *to any individuals or entities for purposes other than the protection of the public health.* Release will be through secure transfer of data and accessed by approved software tools for data analysis.

A) *All access to data by the Department, reports made to the Department, the identity of or facts that would tend to lead to the identity of the individual who is the subject of the report, and the identity of or facts that would tend to lead to the identity of the author of the report, the author being an individual or the reporting facility, in the case of syndromic surveillance, shall be strictly confidential, are not subject to inspection or dissemination, and shall be used only for public health purposes by the Department, local public health authorities, or the Centers for Disease Control and Prevention.*

B) *Entities or individuals submitting reports or providing access to the Department shall not be held liable for the release of information or confidential data to the Department in accordance with this subsection.* (Section 2(h)(i)(C) of the Department of Public Health Act) [20 ILCS 2305/2(h)(i)(C)]

d) Patient Confidentiality and Data Security

1) *Patient name, address,* any part of the *Social Security number,* *unique patient identifier based on the last four digits of the patient's Social Security number*, *or any other* *data* *that the Department believes could be used to determine the identity of an individual patient shall be stored and processed in the most secure manner possible*. (Section 4-2(d)(4) of the Act) Only authorized staff will have access to these data, with all computers and databases secured by password. Only computers located in controlled Department work sites will allow access to these data.

2) Patient name, address, and any part of the Social Security number will not be released publicly. These data may be used to link discharge data or syndromic surveillance with other data sets internal or external to the Department, with linkage results released under guidelines of appropriate Department controls. The patient name, address, and any part of the Social Security number will not be released as part of these linkage results. The Department will evaluate any request for access to any or all of these three specific identifiers by authorized staff of other Illinois State agencies, local health departments, or approved research project participants individually. Evaluation criteria include need and security of patient confidentiality. The unique patient identifier may be released to State agencies, local health departments and approved data requesters using appropriate guidelines.

(Source: Amended at 47 Ill. Reg. 4017, effective March 10, 2023)