**Section 845.65 Provision of Data**

a) Only aggregated medical data from which it is impossible to identify any patient, reporting entity, or primary caregiver, shall be made available via an annual lead poisoning surveillance report drafted by the Department.

b) All requests by researchers for confidential data shall be submitted in writing to the Department. The request shall include a study protocol that contains: objectives of the research; rationale for the research, including scientific literature justifying the current proposal; overall study methods, including copies of forms, questionnaires, and consent forms used to contact facilities, physicians or study subjects; methods for documenting compliance with Department of Health and Human Services − Protection of Identity – Research Subjects; 42 CFR 2a.4(a) through (j), 2a.6(a) and (b), 2a.7(a) and (b)(1); methods for processing data; storage and security measures taken to ensure confidentiality of patient identifying information; time frame of the study; a description of the funding source of the study (e.g., federal contract); the curriculum vitae of the principal investigator; and a list of collaborators. In addition, the research request must specify what patient identifying information is needed and how the information will be used. Identifying information is defined as any information, collection, or groups of data from which the identity of the patient or reporting entity to which it relates may be discerned, e.g., name, address or ID number.

c) Upon request, the Department shall disclose individual patient or reporting entity information to the reporting entity that originally supplied that information to the Department.

d) By written reciprocating agreement, the Department may disclose individual patient information concerning residents of another state to the Childhood Lead Poisoning Prevention Program in the individual's state of residence only if the recipient of the information is legally required to hold the information in confidence and provides protection from disclosure of patient identifying information equivalent to the protection afforded by the Medical Studies Act.

e) The identity of any person (or any group of facts that tends to lead to the identity of any person) whose blood test result is submitted to the Illinois Childhood Lead Poisoning Prevention Program is confidential and shall not be open to public inspection or dissemination. This information shall not be available for disclosure, inspection or copying under the Freedom of Information Act or the State Records Act. All information for specific research purposes may be released in accordance with procedures established by the Department in this Section.

f) The patient identifying information submitted to the Department by those entities required to submit information under the Act and this Part is to be used in the course of medical study under the Medical Studies Act and is privileged from disclosure by the Medical Studies Act.

(Source: Amended at 43 Ill. Reg. 2440, effective February 8, 2019)