Missouri Environmental Public Health Tracking (EPHT) Network

Metadata Record

Childhood Lead Testing Data

Description
Citation
Title: Missouri Childhood Blood Lead Testing Data for calendar years 2001 - 2009. **Originators:** Missouri EPHT Program **Publication date:** 03/08/2011
Description
Abstract: Childhood blood lead testing data for Missouri children less than six years old for 2001-2009, according to the specifications of the Indicator Template and the Content Domain. More information regarding the creation of this indicator can be found in the *Missouri EPHT Data and Statistical Guide* available at http://www.health.mo.gov/living/environment/epht/index.php. **Purpose:** This dataset is required by the Centers for Disease Control and Prevention for submission to the EPHT Network. **Supplemental information:** This dataset was extracted from the Missouri Health Strategic Architectures and Information Cooperative (MOHSAIC) system. MOHSAIC is a transactional application that provides a centralized and integrated database for the entry, update, and retrieval of information from a client-centered record. It is a population-based registry containing a record for all children born in Missouri since January 1, 1994 and individuals who have received services at local public health agencies or WIC clinics. All blood lead testing, case management and risk assessment data is located in MOHSAIC. It is a .Net application with an Oracle backend.
Point of Contact
Person: Missouri EPHT Program Manager **Organization:** Missouri Department of Health and Senior Services Division of Community and Public Health Section for Environmental Public Health Bureau of Environmental Epidemiology **Phone:** 573-751-6102 **Fax:** 573-751-6041 **Telecommunications Device or Teletypewriter (TDD/TTY) phone:** 800-669-8819 **Email:** EPHTN@health.mo.gov

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County: Cole County

Address type: Physical
Address: 930 Wildwood Drive
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State or Province: MO
Postal code: 65109
County: Cole County

Data Type

Native dataset environment: The file was created using Microsoft Access 2007, SAS 9.2 and Excel 2007 in a Windows environment residing on a network of IBM servers.

Time Period of Data

Beginning date: 01/01/2001
Ending date: 12/31/2009
Currentness reference: Time Period End Date

Status

Data status: Complete

Update frequency: Annually

Key Words

Theme: Health
Keywords: childhood blood lead exposure, childhood blood lead testing, childhood blood lead poisoning, lead poisoning, blood lead, elevated, lead, blood, poisoning, tested, child, 029, Missouri, MO
Keyword thesaurus: None

Theme: Health
Keywords: testing rates
Keyword thesaurus: Lead vocabulary - CDC

Place: Location
Keywords: 029, Missouri, MO
Keyword thesaurus: FIPS 5-2 (State)

Data Access Constraints

Access constraints: Access to the records within this dataset requires permission from the Missouri Department of Health and Senior Services, Bureau Environmental Epidemiology (BEE). To request record level data (whether identified or de-identified) for research, a principal investigator must submit a completed Application for Research Purposes.

More information on obtaining permission to view and/or use this dataset is available at http://www.health.mo.gov/data/policies.php.

Use constraints: Missouri State Statutes and Code of Regulations allow for the release of data by the Missouri Department of Health and Senior Services; however, patient level records are not public information, and may be shared only with other public health authorities, a public health authority exception in 701.326.4 RSMo., or researchers of a health study if they abide by the same confidentiality restrictions required by the Department of Health and Senior Services under sections 192.067 and 701.328, RSMo.

The Missouri Department of Health and Senior Services and other public health authorities are authorized to utilize data and information for epidemiologic studies and for surveillance. Non-Missouri residents should contact the Missouri Department of Health and Senior Services for specific statues, rules, and regulations that may affect the release and/or use of data. The below listed statues apply to Missouri residents only.

- 192.067(1), RSMo, the department, for purposes of conducting epidemiological studies to be used in promoting and safeguarding the health of the citizens of Missouri … is authorized to receive information from patient medical records.
- 192.067(2), RSMo, Medical information…may be released by the department only in a statistical aggregate form that precludes and prevents the identification of patient, physician, or medical facility except that medical information may be shared with other public health authorities and coinvestigators of a health study if they abide by the same confidentiality restrictions required of the department of health and senior services… The department of health and senior services, public health authorities and coinvestigators shall use the information collected only for the purposes provided …
- 192.665(9), RSMo, "Patient abstract data", data submitted by hospitals which includes but is not limited to date of birth, sex, race, zip code, county of residence, admission date, discharge date, principal and other diagnoses, including external causes, principal and other procedures, procedure dates, total billed charges, disposition of the patient and expected source of payment with sources categorized according to Medicare, Medicaid, other government, workers' compensation, all commercial payors coded with a common code, self-pay, no charge and other.
- 192.667(7), RSMo, Information obtained by the department under the provisions of section 192.665 and this section shall not be public information…The department of health and senior services may authorize the use of the data by other research organizations pursuant to the provisions of section 192.067… The department shall not release data in a form which could be used to identify a patient. Any violation of this subsection is a class A misdemeanor.
- 19 CSR 10-33.010 Reporting Patient Abstract Data by Hospitals and Ambulatory Surgical Centers: (1)(A) Coinvestigator means any person or organization that

applies to the department to be a coinvestigator of an epidemiological study; (C) Epidemiological study means research using patient abstract data to understand, promote or safeguard the health of a defined population. No marketing study or study designed to use data on a specific provider shall be considered an epidemiological study; (M) Public health authority means a federal, state or local governmental agency which has as its mission and responsibility the promotion and safeguarding of the public's health.

- 19 CSR 10-33.010 Reporting Patient Abstract Data by Hospitals and Ambulatory Surgical Centers: (12) Any person may apply to the department to be a coinvestigator of an epidemiological study using patient abstract data. A research protocol shall be submitted which includes all of the following: (A) A description of the proposed study; (B) The purpose of the study; (C) A description of the data elements needed for the study; (D) A description of a tape or a report if either is required; (E) A statement indicating whether the study protocol has been reviewed and approved by an institutional review board; (F) A description of data security procedures, including who shall have access to the data; and (G) A description of the proposed use and release of the data.
- 19 CSR 10-33.010 Reporting Patient Abstract Data by Hospitals and Ambulatory Surgical Centers: (13) The director of the department shall appoint a data release advisory committee composed of three (3) persons representing the health care industry and three (3) persons representing researchers and consumers. The advisory committee shall review all research protocols of persons applying to be a coinvestigator of an epidemiological study using patient abstract data. The advisory committee shall make a recommendation to the director whether the coinvestigator protocol should be accepted, accepted with conditions, or rejected. The committee shall consider: (A) The review made by the staff of the department; (B) Whether the proposed study meets the definition of an epidemiological study; (C) The potential for the coinvestigator or any other person to use the data for nonepidemiological purposes; (D) The professional expertise of the applicant to conduct the study; (E) The appropriateness of the proposed study design; (F) The willingness and ability of the applicant to protect the identity of any patient, physician or provider; and (G) The data security measures and final disposition of the data proposed.
- 19 CSR 10-33.010 Reporting Patient Abstract Data by Hospitals and Ambulatory Surgical Centers: (14) The coinvestigator shall agree to the confidentiality, security and release of data requirements imposed by the department and shall agree to the review and oversight requirements imposed by the department.
- 19 CSR 10-33.010 Reporting Patient Abstract Data by Hospitals and Ambulatory Surgical Centers: (15) Data released to the coinvestigator shall not be rereleased in any form by the coinvestigator without the prior authorization of the department. Authorization for subsequent release of the data shall be considered only if the proposed release does not identify a patient, physician or provider.
- 19 CSR 10-33.010 Reporting Patient Abstract Data by Hospitals and Ambulatory

Surgical Centers: (16) The following data elements permit identification of a patient, physician or provider, and are not to be rereleased by a coinvestigator: patient name; patient Social Security number; any datum which applies to fewer than three (3) patients, physicians or providers; physician number; provider number; and a quantity figure if one (1) entity contributes more than sixty percent (60%) of the amount.

- 19 CSR 10-33.010 Reporting Patient Abstract Data by Hospitals and Ambulatory Surgical Centers: (17) The department shall release only those patient abstract data elements to the coinvestigator which the department determines are essential to the study. The Unique Physician Identification Number (UPIN) associated with any patient abstract data shall not be released to any coinvestigator. If the research being conducted by a coinvestigator requires a physician number, the department may create a unique number which is not the UPIN. The department shall not provide information which links the unique number to the name of the physician.
- 19 CSR 10-33.010 Reporting Patient Abstract Data by Hospitals and Ambulatory Surgical Centers: (18) No epidemiological study conducted with a coinvestigator shall be approved unless the department determines that: (A) The epidemiological study has public benefit sufficient to warrant the department to expend resources necessary to oversee the project with the coinvestigator; (B) The department has sufficient resources available to oversee the project with the coinvestigator; and (C) The data release advisory committee reviewed the study and the director of the department authorized approval.
- 19 CSR 10-33.010 Reporting Patient Abstract Data by Hospitals and Ambulatory Surgical Centers: (19) Public health authorities and coinvestigators receiving data shall be informed by the department of the penalty for violating section 192.067, RSMo.

Missouri State Statutes and Code of Regulations allow for the release of record level vital records data by the Missouri Department of Health and Senior Services. The below listed statutes only apply to vital events occurring within Missouri's borders. The records of vital events that occur to Missouri residents in other states are the property of the state where the events take place.

- 193.045.2(4), RSMo, authorizes the state registrar to provide to the state or local health agencies copies of or data derived from certificates and reports required under sections 193.005 to 193.325, deemed necessary for state or local health planning and program activities…such copies or data shall remain the property of the department and the uses made of them shall be governed by the state registrar.
- 193.245(1), RSMo, the department to disclose upon request, a listing of persons who are born or who die on a particular date, but no information from the record other than the name and date of such birth or death shall be disclosed.
- 193.245(2), RSMo, allows the department to authorize disclosure of information

contained in vital records for legitimate research purposes.

- 193.255.4, RSMo, authorizes the state registrar, upon request by federal, state, local and other public or private agencies, to furnish copies or data of any other vital statistics… for statistical or administrative purposes upon such terms or conditions as may be prescribed by regulation, provided that such copies or data shall not be used for purposes other than those for which they were requested unless so authorized by the state registrar.
- 19 CSR 10-10.090 Access to Vital Records: (1) (B) 3. No data shall be furnished from records for research purposes until the state registrar of vital records has received and approved a formal request for the research project. (1) (B) 2. The term research means a systematic study designed to develop or contribute to generalizable knowledge. The term generalizable means to emphasize the general character rather than specific details of, to formulate general principles or inferences from particulars. (1) (D) authorizes the state registrar or the local custodian – when deemed in the public interest and not for purposes of commercial solicitation or private gain – to furnish copies of records or data from records to public agencies administrating health, welfare, safety, law enforcement, education or public assistance programs and to private agencies approved by the state registrar.
- Under section 610.035, RSMo, the department is prohibited from disclosing any Social Security number of a living person unless such disclosure is permitted by federal law, federal regulation or state law. Section 208.120, RSMo prohibits the department from disclosing any information obtained by them in the discharge of their official duties relative to the identity of applicants for or recipients of benefits or the contents of any records (e.g., Medicaid, Food Stamps). Public assistance information can be provided on de-identified records only.
- 45 C.F.R. Part 160 and Part 164. Vital Records requestors for research or administrative purposes will only be provided access to the minimum information necessary to achieve their specific research or administrative requests. Requestors are prohibited from disclosing any information that would identify a person and are also prohibited from the re-release of the data provided.

How should this dataset be used?

Use of this data is restricted for statistical reporting and analysis only.

How should this dataset not be used?

Do not attempt to learn the identity of any person included in the data. Do not disclose or make use of the identity of any person or establishment discovered inadvertently and report the discovery to:

Missouri EPHT Program Manager
Bureau of Environmental Epidemiology
P.O. Box 570
Jefferson City, MO 65102-0570

Phone: 573-751-6102
Email: EPHTN@health.mo.gov

Can it be linked to other datasets?

Do not combine this data with other data for the purpose of matching records to identify individuals. Do not disclose or make use of the identity of any person or establishment discovered inadvertently and report the discovery to:

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Can these data be used for commercial purposes?

No.

Can these data be used to form a basis for additional health studies or some remediation actions?

Possibly, please refer to application and review procedures for using Missouri's Health Data at http://www.health.mo.gov/data/policies.php.

What are the constraints for data interpretation?

Do not imply or state, either in written or oral form, that interpretations based on the data are those of the original data sources, the Missouri State Government, the Missouri Department of Health and Senior Services, or the Centers for Disease Control and Prevention unless the data user and data sources are formally collaborating and have received written permission to do so. Acknowledge, in all reports or presentations based on these data, the original source of the data, the Missouri Department of Health and Senior Services, and the Centers for Disease Control and Prevention.

Data Security Information

Security classification system: Contains small numbers which may allow indirect identification of patients, physicians or providers.

Security classification: Restricted

Security handling: Data must be stored on secure server. Additional security measures may be required. Specific security measures are available at http://www.health.mo.gov/data/policies.php.

Spatial Reference Information

Spatial Domain

Bounding Coordinates

In Unprojected coordinates (geographic)

Boundary	Coordinate
West	-95.774699999999996 (latitude)
East	-89.098842000000005 (latitude)
North	40.613639999999997 (longitude)
South	35.995479000000003 (longitude)

Data Structure and Attribute Information

Overview

Entity and attribute overview: These data include records of resident Missouri children less than six years of age who were tested for the presence of lead in their blood. The file contains data for all 115 jurisdictions within Missouri.

Fields included in the data set are health outcome (childhood blood lead test), state of residence, county of residence, test year, test month, age group, sex, race, whether race/ethnicity reported, ethnicity, number of monthly events, number of average daily events, number of monthly minimum daily events, number of monthly maximum daily events.

The dataset includes blood lead testing data for children less than six years of age by calendar years 2001-2009 and were developed from MOHSAIC files for 2001-2009.

Entity and attribute detailed citation: http://health.mo.gov/living/environment/lead/index.php

Data Quality and Accuracy Information

General

Logical consistency report: Zip codes are compared to state and county codes to determine consistency of geocoding.

Completeness report: Completeness percents on the source files from which the childhood blood lead testing file was produced, for selected items, are as follows:

- Principal diagnosis: 99.9 percent complete for 2000-2009 discharge years.
- Patient name (used for unduplicating): 90-99 percent complete depending on year.
- Social Security Number (used for unduplicating): 80 percent all years.
- Race: 98 percent complete all years.
- Sex: 99.999 percent complete all years.
- Age: 99.9 percent complete all years.
- County of residence: 99.9 percent complete all years.
- Test date: 99.999 percent complete all years.

- Zip code of residence: 99.9 percent complete all years.
- State of residence: 99.99 percent complete all years.
- Ethnicity: collected as part of race item in 2000, as separate item beginning in 2001; probably underreported.
- Testing counts with zeros indicate no results matching the specific blood lead level criteria for that county and cohort year.

Data Source and Process Information

Process Steps

Process step information

Process Step 1

Process description: Data extracted from MOHSAIC (Missouri Health Strategic Architectures and Information Cooperative) database using Microsoft Access 2007.
Process date: 09/19/2010

Process Step 2

Process description: Individual data tables for the calendar years from 2000 - 2009 were combined into one table using SAS 9.2.
Process date: 09/19/2010

Process Step 3

Process description: The combined data set was analyzed and compiled using SAS 9.2 in conjunction with the data requirements described in Centers for Disease Control and Prevention Recommendations for Nationally Consistent Data and Measures within the Environmental Public Health Tracking Network , version 1.3, p.52-56, the Lead Data Dictionary (10/8/2009) and Lead How-to Guide (10/8/2009). More information on these documents can be located in the Missouri Data and Statistical Guide available at http://www.health.mo.gov/living/environment/epht/index.php.
Process date: 09/29/2010

Process Step 4

Process description: SAS file forwarded to the Missouri Office of Information, Information Technology Services Division to be added to Missouri IBIS System for specialized query tool creation.
Process date: 09/29/2010

Process Step 5

Process description: Metadata record created for the dataset using the EPHT Metadata Creation Tool., version 1.1.
Process date: 03/10/2011

Process Step 6

Process description: Missouri Metadata record created for the dataset using the Missouri EPHT Metadata Record format then converted to .pdf. The creation of a Missouri Metadata record is completed to assist users by offering the record in a format compatible with electronic reading devices and smart phones.

Process date: 06/01/2011

Data Distribution Information

General

Resource description: XML file

Distribution liability: These data were provided by the Missouri Department of Health and Senior Services; the findings and conclusions based on these data are the sole responsibility of the author(s) of the study.

Although every effort has been made to ensure the accuracy of the material contained in this dataset and the Missouri EPHT Network Portal, complete accuracy cannot be guaranteed. The Missouri Department of Health and Senior Services is not responsible for any errors or misprints contained herein and cannot accept any responsibility whatsoever for loss or damage occasioned or claimed to have been occasioned, in part or in full, as a consequence of any person acting, or refraining from acting, as a result of a matter contained within the Missouri EPHT Network Portal.

Distribution Point of Contact

Person: Missouri EPHT Program Manager
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Bureau of Environmental Epidemiology

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Custom Order Process

Custom order process: To request record level data (whether identified or de-identified) for research, a principal investigator must submit a completed Application for Data for Research Purposes. The application requires detailed information about the study protocol, justification for all data elements requested (each data element must be related to the hypotheses), and measures to ensure the confidentiality and security of the data. All information must be clear, consistent and specific. General descriptions do not allow accurate assessment of the value of the study or the need for the data items. Release of data from vital records and/or the Patient Abstract System by the Missouri Department of Health and Senior Services is granted to an agency/institution for the sole purpose of the research project described in the protocol application. The applicant will be required to complete and sign an Agreement for Oversight. All persons that will have access to the data must be listed in the application and will be required to sign Confidentiality Pledge prior to being granted access to the study data.

It is the principal investigator's responsibility to design a valid study that would make a contribution to public health, and it is not the department's role to help refine a faulty study or a poorly described study until it meets generally acceptable scientific standards. Protocols of this nature will be rejected and further processing of such applications will be discontinued. An application will be immediately rejected if it is determined that 1) it does not clearly describe a well-designed research or epidemiologic study, 2) the data will be used for commercial or marketing purposes, or private gain, 3) being a co-investigator would overburden the department, or 4) there is reason to believe that confidentiality of the data would be jeopardized by its release.

Researchers interested in obtaining DHSS data should first familiarize themselves with the data sets prior to designing their studies (see Data and Surveillance Systems at http://health.mo.gov/data/index.php). Only those data elements related to the hypotheses and necessary for the study should be requested. The principal investigator will be notified of any discrepancy between the list of data elements requested in the research protocol and those determined by DHSS staff to be needed.

Contact information may be found at http://health.mo.gov/living/environment/lead/index.php.

PLEASE NOTE: Research proposals involving Patient Abstract System data are also reviewed by an independent Data Release Advisory Committee (DRAC) and submitted to the Department of Health & Senior Services (DHSS), Institutional Review Board (IRB) for review, prior to final study approval determination.

If the study/project involves linkage with another data set or contact with family, next-of-kin or acquaintance, DHSS IRB approval is required. A request for identifiable record level data for living subjects (e.g., birth records) shall also require approval by the DHSS IRB. Requests for de-identified files do not require approval by the DHSS IRB.

In addition to the protocol application, the following forms must also be completed for DHSS IRB review and approval (when applicable):

- Abstract of Protocol
- IRB Form 1 'Request for Review of Research Protocol'
- Protocol Template
- Checklist for Submission of Research/Study Protocols

If a study does not involve DRAC and/or DHSS IRB review, we suggest submitting a completed application at least two-to-three months prior to when data will be needed. Studies involving DRAC and/or DHSS IRB review generally require a longer review period, so we suggest submitting the completed application and IRB packet at least four-to-five months prior to when data will be needed. Protocol applications are reviewed on an 'as time permits' basis between other priority projects. The complexity of the requested data sets and the number of priority projects may impact the response time. Please plan accordingly.

Regardless of the duration of the study/project, approval is only for one year at a time. Annual review is required for each study for as long as Department data are held.

More information on obtaining a custom created dataset is available at http://www.health.mo.gov/data/policies.php

Metadata Reference
Metadata Date
Last updated: 01/13/2011
Metadata Point of Contact
Person: Missouri EPHT Program Manager **Organization:** Missouri Department of Health and Senior Services Division of Community and Public Health Section for Environmental Public Health Bureau of Environmental Epidemiology **Phone:** 573-751-6102 **Fax:** 573-751-6041 **Telecommunications Device or Teletypewriter (TDD/TTY) phone:** 800-669-8819 **Email:** EPHTN@health.mo.gov

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Metadata Access Constraints

Access constraints: None
Use constraints: None

Metadata Standards

Standard name: FGDC Content Standard for Geospatial Metadata