January 2021

2019 Blood Lead Surveillance System Assessment

Final Report

Acknowledgments

This work was supported by the Council of State and Territorial Epidemiologists, through Centers for Disease Control and Prevention (CDC) cooperative agreement number, NU38OT000297-01-00. Its contents are solely the responsibility of the authors and do not represent the official views of CDC.

We sincerely appreciate the state and local health departments for participating and would like to extend a special thank you to the four states who pilot tested the assessment.

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Executive Summary

In July 2019, the Council of State and Territorial Epidemiologists (CSTE) requested state epidemiologists in all 50 states, and their equivalents in Washington DC and New York City answer a set of questions in an online assessment about their child and adult blood lead surveillance systems. The purpose of the assessment was to collect information about the functionality and utility of blood lead (BL) surveillance systems at the state level, with a focus on identifying challenges and opportunities for integrating child and adult surveillance systems. All 52 jurisdictions completed the assessment, although some did not answer all questions.

Key findings:

- Child BL surveillance systems are in place in all 52 jurisdictions, and adult systems are in place in 38 (73%), based on laboratory reporting of blood lead test results.
- Twenty-five percent of the child systems use the CDC-developed Healthy Homes and Lead Poisoning Surveillance System (HHLPSS) application for data management, and 17 (33%) have incorporated their BL surveillance into their jurisdiction's communicable disease system (e.g. 'NBS", "Maven").
    - Seventeen percent use a different data management system for information about case follow-up (e.g. nursing case management).
- Over 60% of the laboratory reports are transmitted in HL7 to the child systems.
- Sixty percent of the jurisdictions use the data to identify clusters of children exposed to the same source of lead.
- Forty-four percent of the adult surveillance systems are integrated into the same system as their child system.
    - Of the 23 integrated systems, 11 (48%) are integrated into their jurisdiction's communicable disease surveillance system and four (17%) into HHLPSS.
- Fourteen (50%) of the jurisdictions with integrated systems noted that a benefit of the integrated system is its utility for identifying "take-home" lead exposures.
- Thirty-five percent of the adult programs said they would consider using a data application that integrates child and adult BL data if it were available, of which 92% noted they would need funding to do this.
- The child and adult programs identified many limitations to their systems.
- Twenty-five of the 52 jurisdictions (48%) said they would be willing to participate in a workgroup to develop requirements for a child-adult integrated data management system.

Recommendations:

- Convene a workgroup to develop detailed requirements for an integrated data management system.
- Convene communities of practice to identify strategies for incorporating adult and child BL surveillance into existing communicable disease systems.
- Increase funding for child and adult surveillance systems to promote surveillance system integration.

Introduction

Background

Public health agencies at the state and local level have been monitoring lead exposure in children and adults by collection and analysis of blood lead test results reported by laboratories for more than 30 years. Many of these agencies have received funding and technical assistance from the Centers for Disease Control and Prevention's (CDC) National Center for Environmental Health (NCEH) and the National Institute for Occupational Safety and Health (NIOSH) to support building and maintaining surveillance systems based on laboratory reporting. Deidentified surveillance data are provided by many states and some large jurisdictions to NCEH (for children) and NIOSH (for adults) for compilation in databases that are used for data summaries posted on the web[1, 2] and in surveillance reports.[3,4] These data have been critical for identifying state and national trends in the incidence of lead exposure; at-risk groups; and new, existing, and re-emerging lead exposure hazards.[5,6,7,8 9]

Legal authorities to conduct surveillance based on mandated reporting of selected health conditions are a state public health function.[10] States have implemented a variety of data management systems for reportable infectious and non-infectious conditions. CDC has provided support for communicable disease surveillance by developing a product called the National Electronic Disease Surveillance System (NEDSS)-based system,[11] which has been adopted in 23 states. Commercial companies have also developed products that have been adopted by some states.[12] In the 1990s, NCEH developed a data management system for blood lead laboratory reports called "Systematic Tracking of Elevated Lead Levels and Remediation" (STELLAR). NCEH replaced STELLAR in 2010 with a product called Healthy Homes and Lead Poisoning Surveillance System ("HHLPSS"), which is a childhood lead poisoning prevention program at the state and local level to collect and manage data on screening of children for toxicity, identification and confirmation of cases, medical management of cases, and investigation and abatement of lead hazards. HHLPSS includes additional functionality allowing for expanded collection and tracking of non-paint lead hazards, provision of healthy homes data collection tools and reports, importing electronic laboratory records in HL7 format, and provision of a centralized state-based surveillance repository.[13] Some states elected to develop their own data management systems rather than use HHLPSS, including some that added a lead module to their communicable disease system and some that developed custom applications for lead. NIOSH has not developed a data management system for the state programs it works with under its "Adult Blood Lead Epidemiology and Surveillance" (ABLES) program,[14] and thus, all state ABLES programs have developed their own systems.

This diversity of blood lead surveillance systems presents some limitations for program improvement for blood lead surveillance across the United States. First, the separate systems for child and adult surveillance limit the ability of public health to describe the full spectrum of lead exposure within a state and across the US population. It is difficult to discern across these distinct population groups potential sources of exposure such as

take-home lead, maternal-child lead exposures, and clusters of exposure to non-paint lead sources (e.g. imported spices) affecting adult and child family members. Parents or other family members employed in lead-related industries (e.g., battery manufacturing, construction) may take lead dust home on their skin, hair, clothes, or tools and expose their children. In addition, pregnant and breastfeeding women may pass lead to their unborn baby or breastfeeding infant.[15] A surveillance system that integrates child and adult BL reports is likely to be more efficient, save on resources, meet national data standards, and allow for linkages between child and adult exposures in order for programs to more easily identify lead exposure clusters involving both children and adults.

Because of the diversity of systems development and management, there is an opportunity for some state programs to learn from other programs that have addressed surveillance system challenges and/or determined more cost-effective data management strategies. To date, there has been no systematic assessment of state child and adult blood lead surveillance systems to identify existing data management systems, including their strengths and limitations.

Purpose

The purpose of this project is to support blood lead health surveillance and build epidemiologic capacity in state and local public health agencies by conducting a national assessment on the functionality and utility of blood lead surveillance systems at the state level, with a focus on identifying challenges and opportunities for integrating child and adult surveillance systems. CSTE was awarded funding through a CDC cooperative agreement to develop and conduct the national assessment of blood lead surveillance systems. This report summarizes the methods for developing the assessment tool and administering the assessment, the results of the assessment, and significant findings and recommendations based on the assessment results.

Methods

Assessment Development and Distribution

The CSTE blood lead surveillance system assessment was developed in collaboration with a CSTE consultant with expertise in child and adult blood lead surveillance and a workgroup representing NCEH, NIOSH, and several state members of CSTE's environmental and occupational health subcommittees. In addition, input was provided by attendees at two sessions during the 2019 CSTE Annual Conference in Raleigh, North Carolina.

The assessment requested information on the modes of transmission of blood lead laboratory test reports into the child and adult surveillance systems (e.g. spreadsheet, electronically in HL7 format), the types of data management systems used by child and adult programs, whether the child and adult reports were managed in the same data

application or separate ones, the benefits and problems when child and adult data were managed in the same system, the major limitations of each system, and efforts to correct the limitations. The assessment asked whether states would consider using an integrated data management system if one should become available; and if no, why not.

The jurisdictions were also asked if their systems collected information about the pregnancy status of women, whether they had manual or automated systems for identifying clusters of children and adults, whether the child and adult programs did joint exposure investigations; and if yes, how the data were managed for these investigations.

The assessment consisted of 27 mostly closed-ended questions (yes/no or checklists), and 20 open-ended sub-questions asking for additional information related to central questions. A copy of the questionnaire is in Appendix 1. Results were collected using a web-based assessment tool. Skip patterns were used to account for the fact that some states do surveillance for children and adults using the same data application, some do surveillance for children and adults in different data applications, and some states do not do blood lead surveillance for adults.

The assessment was pilot tested by four CSTE subcommittee members. Following edits based on the pilot, it was distributed by CSTE staff, via email with a link to the assessment, on July 10, 2019, to the State Epidemiologists or their equivalents in 52 jurisdictions: the 50 states plus New York City and Washington DC (hereafter, all will be referred to as “jurisdictions”). The principal investigators and project managers for NCEH-funded child lead poisoning prevention programs and NIOSH-funded ABLES project managers were copied on the email to the State Epidemiologists.

Instructions to the recipients noted that assessment responses were confidential and that results would be released only in a form that would not identify specific jurisdictions. The recipients were asked to provide one response per jurisdiction, combining responses from child and adult programs, but they were instructed that separate responses were acceptable.

Non-responding jurisdictions and those where only the child or the adult part of the assessment was completed were followed up by email and telephone at least twice to request completion. Data collection closed on August 15, 2019.

Data cleaning and analysis

Each completed assessment was reviewed to identify inconsistencies and contradictions between answers. Jurisdictions were called to clarify their answers where needed. Corrections were made based on the review and follow-up telephone calls. For the jurisdictions that responded from their child and adult programs separately, CSTE combined the two responses into one after reconciling differences as needed.

Answers to open-ended questions (e.g. “describe the case investigation data system”) were prepared for inclusion in this report by editing for clarity and elimination of information that would identify the respondent’s jurisdiction. Where multiple jurisdictions provided similar answers in text fields, categories were created so summary statistics could be generated.

Each jurisdiction was assigned one of four geographic regions of the country based on the U.S. Census definition.[16]

Descriptive statistics from the assessment were generated using Excel. Tables with summary numbers are included in the results section that follows and the narratives provided in responses to open-ended questions are included as lists in Appendix 2.

Results

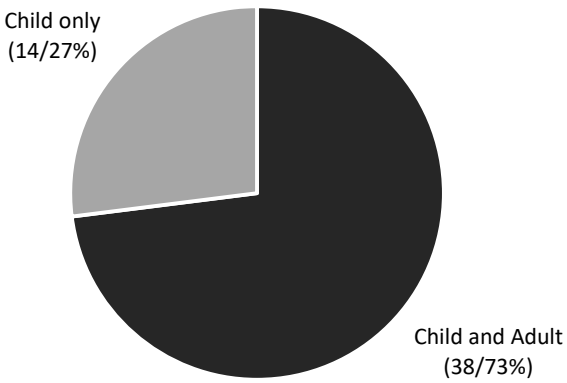
Response rate

All 52 jurisdictions completed the assessment, including responses from child and adult programs where there were both programs, for a response rate of 100%. Adult and child responses from six (12%) jurisdictions were submitted separately.

Distribution of child and adult systems

All jurisdictions indicated they had a child surveillance system, and 38 (73.1%) of the jurisdictions indicated that they also had an adult surveillance system (Figure 1).

Figure 1: Number/percent of the 52 jurisdictions with child and adult systems



Laboratory reporting

All respondents indicated that laboratories reported blood lead test results.

Laboratories reported all tests regardless of age in 46 (88.5%) jurisdictions, five (9.6%) reported tests with age specifications for adults and/or children, including three (5.7%) jurisdictions that only had reporting for children (Table 1).

Table 1: Number and percent of 52 jurisdictions with age definitions for BL laboratory reporting

LABORATORY REPORTING AGE DEFINITION	N	%
All blood lead tests regardless of age	46	88.5
BL tests of children only: no age specified	1	1.9
BL tests of children only: age specified *0-6 years* *Up to age 18 years*	2 *1* *1*	3.8
BL tests specified for children and adults *Child <6 years; adult =>15 years* *Child <6 years; adult =>16 years*	3 *1* *2*	5.8
Total	52	100

Child data management systems

Respondents were asked to identify their child data management system from a list of five data management application types to choose from and an “other” option. They were asked to provide a description if they checked “other”.

Thirteen (25%) of the 52 jurisdictions responded that they use the CDC-developed, web-based data management platform HHLPSS. HHLPSS was used by almost half (n=8, 47.1%) of the jurisdictions in the South, compared to between one (7.7%) and three (25%) in the other three geographic regions.

Seventeen (32.7%) of the states indicated that they had incorporated their child lead surveillance system into their data system used for surveillance of communicable diseases (CD), including eight (15.4%) into their NEDSS Base System (NBS) and nine (17.3%) into another custom or commercial product (e.g.) product, including six that named Maven[17] as the product. Seventeen jurisdictions (32.7%) either developed their own web-based application or used Access or another relational database (Table 2).

Of the five jurisdictions that checked “other”, two (3.8%) indicated that they used STELLAR (Appendix 2 Table A2-1).

Table 2: Child lead surveillance data management system types in the 52 jurisdictions by geographic region (Appendix 3 Table A3-1)

DATA MANAGEMENT SYSTEM TYPE	MIDWEST STATES		NORTHEAST STATES		SOUTHERN STATES		WESTERN STATES		TOTAL	
	N	%	N	%	N	%	N	%	N	%
A custom web-based application developed by your state for blood lead reports	3	25.0	5	50.0	2	11.8	1	7.7	11	21.2
Access or another relational database	1	8.3	1	10.0	1	5.9	3	23.1	6	11.5
CDC's HHLPSS application	3	25.0	1	10.0	8	47.1	1	7.7	13	25.0
Incorporated as a module into your CD's NEDSS based system (NBS)	2	16.7	1	10.0	2	11.8	3	23.1	8	15.4
Incorporated into another electronic CD data application	2	16.7	0	0.0	3	17.6	4	30.8	9	17.3
Other	1	8.3	2	20.0	1	5.9	1	7.7	5	9.6
Total	12	100.0	10	100.0	17	100.1*	13	100.1*	52	100.0

*Percentages do not total 100% due to rounding

Transmission of laboratory reports to child surveillance systems

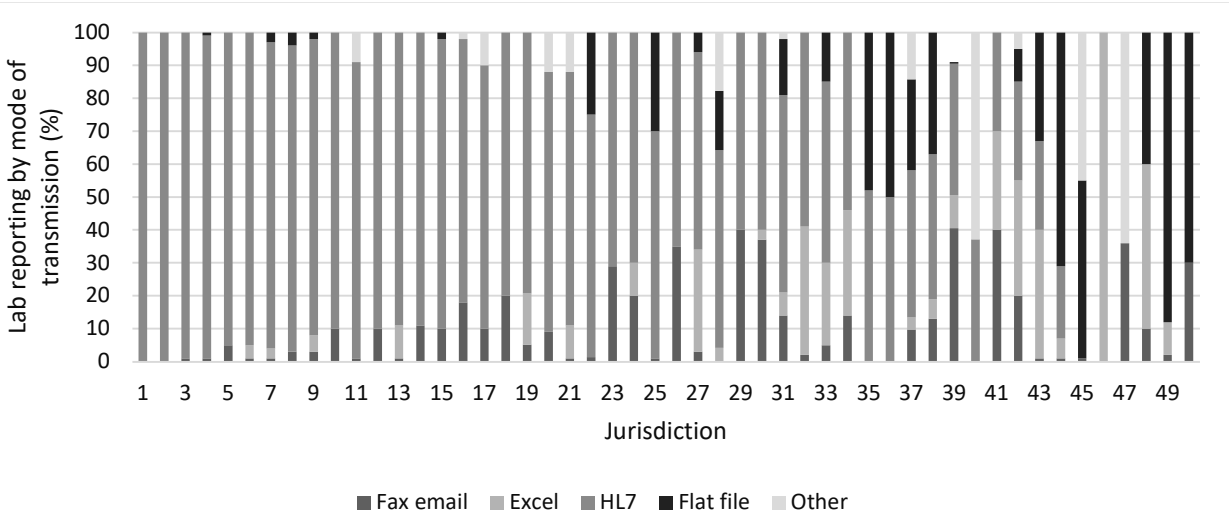
The respondents were asked to estimate the percent of laboratory reports that were transmitted into the system by four defined modes and an "other" option. Fifty (96.2%) of the 52 jurisdictions gave estimates (All but one jurisdiction's estimates added up to 100%). On average, 61.3% of laboratory data were transmitted electronically in the Health Level Seven (HL7) standard for the transfer of clinical data, whereas other transmission modes were much lower on average. There were wide ranges for most transmission modes (Table 3). Figure 2 illustrates, for each of the 50 respondents, the percentage of reports that come in each mode, arranged by percent transmitting in HL7 (in grey), with Jurisdiction 1 having the greatest percent transmitting in HL7 and jurisdictions 45-50 not receiving any reports in HL7; HL7 predominates for the majority of jurisdictions.

The narratives of transmission modes described by the nine jurisdictions that included an estimated percent for “other” is in Table A2-2 in Appendix 2.

Table 3: The range, average, and median for the percent of BL reports transmitted to the child surveillance system by mode of transmission (50 jurisdictions)

BL LAB REPORT TRANSMISSION MODE	RANGE %	AVERAGE %	MEDIAN %
Fax or email	0 – 40	10.5	3.0
Excel	0 – 100	9.7	0
HL7	0 – 100	61.3	60.0
Flat file	0 – 88	13.0	0
Other	0 – 64	5.1	0

Figure 2: Percent lab reporting by mode of transmission for each jurisdiction (1–50)



Data systems for child case investigation

The respondents were asked if they used the same data application for data related to case investigations of children with elevated blood lead levels as they used for management of the data from BL reports. Forty (76.9%) of the 52 jurisdictions reported using the same data application for case management as for laboratory reporting, nine (17.3%) used a different application, two (3.8%) noted that the state child program did not collect case management information from the local health departments that did case management, and one (1.9%) jurisdiction noted they do not do case management.

Eight (88.9%) of the nine jurisdictions with different applications for case management identified the type of application used. Three (33.3%) used spreadsheets. Notably, one (11.1%) jurisdiction that reported using an Access database for laboratory reports used

STELLAR for case management, and another state that has a custom web-based lab reporting data system reported using HHLPSS for case management (Table 4).

Table 4: Data management systems used for case investigation data (52 jurisdictions)

CASE INVESTIGATION DATA SYSTEM	N	%
Same as lab surveillance (System type)	40	76.9
Different from lab surveillance (System type)	9	17.3
Spreadsheet	*3*	
Access	*1*	
STELLAR	*1*	
CDC's HHLPSS	*1*	
Maven	*1*	
State communicable disease system	*1*	
System type not provided	*1*	
Done at local level and data not collected by state	2	3.8
Not applicable - jurisdiction does not do	1	1.9
Total	52	99.9*

*Percentages do not total 100% due to rounding

Identification of clusters of lead exposure in children

Respondents were asked if they used their surveillance system to identify clusters of children exposed to the same source of lead. One jurisdiction skipped this question. Of the 51 respondents, 31 (60.8%) answered “yes” (Table 5). Jurisdictions in the South and Northeast were more likely than the other two regions to identify clusters.

Table 5: Number/percent of 51 jurisdictions that use their surveillance system to identify clusters of lead exposure among children, grouped by geographic region

CLUSTERS IDENTIFIED	MIDWEST		NORTHEAST		SOUTH		WEST		TOTAL	
	N	%	N	%	N	%	N	%	N	%
Yes	4	36.4	7	70.0	13	76.5	7	53.8	31	60.8
No	7	63.6	2	20.0	4	23.5	5	38.5	18	35.3
Unknown	0	0.0	1	10.0	0	0.0	1	7.7	2	3.9
Total	11	100.0	10	100.0	17	100.0	13	100.0	51	100.0

Those answering “yes” were asked to describe how they did this. Table A2-3 in Appendix 2 lists the information provided by the 28 jurisdictions that answered this question, which varied considerably. Fifteen (53.6%) of the 28 respondents described automated or manual matching of addresses, four (14.3%) by other data analyses, two (7.1%) by linking household members including siblings, and the remaining seven (25.0%) by other or unspecified methods.

Limitations of child surveillance system

Respondents were asked to identify limitations in their child surveillance system by checking any from a list of 16 specified limitations plus an “other” option. If they checked “other” they were asked to describe the “other”.

Fifty (96.2%) checked at least one limitation, and the remaining two left all limitations questions blank. On average, 4.8 limitations were identified per jurisdiction with a range of one to 15 limitations. The two leading limitations were: “No algorithm to identify clusters” (n=28, 56%) and “limited pre-set queries for generating reports” (n=23, 46%). The most frequently identified limitations in HHLPSS jurisdictions were: “limited pre-set queries for generating reports” (n=10, 83.3%) and “time consuming for users to update data” (n=7, 53.8%). The most frequently checked limitations of users of other applications were: “no algorithms to identify clusters” (n=24, 63.2%) and “address geocoding and/or mapping functions not available” (n=18, 47.4%) (Table 6). Appendix 4 shows the limitations types for each of the applications separately rather than grouping by HHLPSS and all others combined.

Table A2-4 in Appendix 2 lists the descriptions provided by the 15 jurisdictions that checked “other” limitations.

Table 6: Number/percent of limitations types: HHLPSS and other child data management systems users (50 jurisdictions)

LIMITATION TYPE	HHLPSS SYSTEM (N=12)		ALL OTHER SYSTEMS (N=38)		TOTAL (N=50)	
	N	%	N	%	N	%
Expensive to maintain	3	25.0	12	31.6	15	30.0
Budget limitations prevent improvements	0	0.0	14	36.8	14	28.0
Requires a lot of staff time to support user help desk	3	25.0	11	28.9	14	28.0
Difficult to get database application problems fixed	6	50.0	10	26.3	16	32.0
Difficult for users to learn	1	8.3	6	15.8	7	14.0
Time consuming for users to update data	7	58.3	7	18.4	14	28.0
Exposure coding systems doesn't capture all sources of exposure	3	25.0	12	31.6	15	30.0
Address geocoding and/or mapping functions not available	1	8.3	18	47.4	19	38.0
No algorithms to identify potential clusters	4	33.3	24	63.2	28	56.0
National data standards not met for some variables	0	0.0	8	21.1	8	16.0

Variables important for child surveillance missing	2	16.7	11	28.9	13	26.0
Limited pre-set queries for generating reports	10	83.3	13	34.2	23	46.0
Queries for generating reports do not meet all state needs	6	50.0	10	26.3	16	32.0
Custom queries difficult/impossible to conduct	4	33.3	8	21.1	12	24.0
Difficult to export data to excel or another format	0	0.0	6	15.8	6	12.0
Difficult to export data for reporting to CDC	1	8.3	6	15.8	7	14.0
Other	2	16.7	13	34.2	15	30.0

Respondents were asked to identify which of the listed limitations had the greatest impact on the operation of their program in an open-ended question. Forty-four (88%) of the 50 jurisdictions that checked at least one limitation answered this question, including seven that identified two rather than one leading limitation for a total of 51 leading limitations. Table A2-5 in Appendix 2 provides the responses, grouped into categories: data queries/data analysis (19.6%), data entry/data management (19.6%), database functionality (23.5%), funding/staffing (15.7%), and other/unknown (11.8%).

Thirty-seven (74.0%) of the 50 jurisdictions answered yes to the question: “Were they making efforts to address identified limitations?” Thirty-five (94.5%) of the 37 jurisdictions that indicated they were making efforts identified in response to an open-ended question on what they were doing: seven (20%) were exploring or planning for a new data system. Other responses were varied (Appendix 2, Table A2-6).

Adult blood lead surveillance programs

Thirty-eight (73.1%) of the 52 jurisdictions indicated that they had an adult surveillance program. The highest percentage of jurisdictions in the West (12 of 13 or 92.3%) had adult programs, and the lowest percentage was in the South (10 of 17 or 41.2%) (Table 7).

Table 7: Number/percent of 52 jurisdictions with adult surveillance programs by geographic region

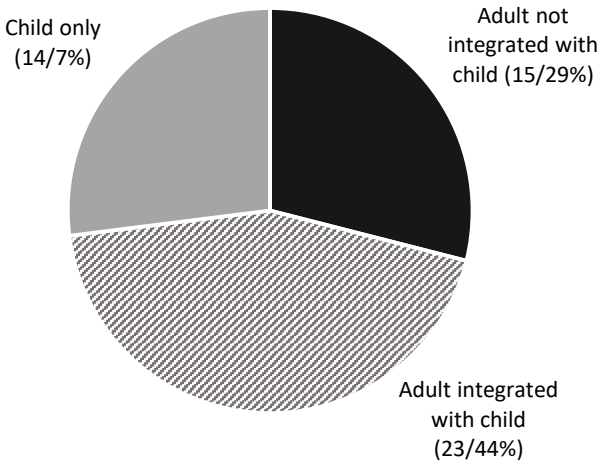
ADULT PROGRAM	MIDWEST		NORTHEAST		SOUTH		WEST		TOTAL	
	N	%	N	%	N	%	N	%	N	%
Yes	8	66.7	8	80.0	7	41.2	12	92.3	38	73.1
No	4	33.3	2	20.0	10	58.8	1	7.7	14	26.9
Total	12	100.0	10	100.0	17	100.0	13	100.0	52	100.0

Adult data management systems

The 38 respondents with adult programs were asked if they used the same system as the child blood lead system (hereafter referred to as an integrated system) or a different system. Twenty-three (60.5%) responded that they had an integrated system, and 15 (39.5%) were separate.

Figure 3 illustrates the proportion of the 52 jurisdictions by whether they had an adult system that is integrated with their child system, a system that is not integrated, or only a child system and no adult system.

Figure 3: Number/percent of 52 jurisdictions with integrated adult/child surveillance programs



The 15 jurisdictions with unintegrated adult systems were asked to identify what data management system they used. Access was the most common system for the 15 unintegrated systems (eight or 53.3%), followed by a custom web-based application (five or 33.3%). For data systems for jurisdictions with integrated systems, which were identified by matching the adult jurisdiction with the answer to the question by the jurisdiction's child program, nearly the majority (n=11, 47.8%) were integrated with one of the jurisdiction's communicable disease systems (NBS: six or 26.1% and other CD system: five or 21.7%). Four (17.4%) jurisdictions integrated adult with child in the HHLPSS application (Table 8).

Table 8: Number/percent of 38 jurisdictions' adult data management system types, by integration status with child systems

DATA MANAGEMENT TYPE	NOT INTEGRATED WITH CHILD		INTEGRATED WITH CHILD		TOTAL	
	N	%	N	%	N	%
A web based custom application developed by your state for blood lead reports	5	33.3	3	13.0	8	21.1
Access or another relational database	8	53.3	3	13.0	11	28.9
CDC's HHLPSS application	0	0.0	4	17.4	4	10.5
Excel or another spreadsheet system	1	6.7	0	0.0	1	2.6
Incorporated as a module into your NEDSS based system (NBS) for communicable disease	0	0.0	6	26.1	6	15.8
Incorporated as a module into another electronic communicable disease surveillance data application (custom or commercial e.g. MAVEN)	0	0.0	5	21.7	5	13.2
Other	1	6.7	2	8.7	3	7.9
Total	15	100.0	23	99.9*	38	100.0

* Percentages do not total 100% due to rounding

Modes of transmission of laboratory reports to the 15 non-integrated adult data management systems

The 15 non-integrated jurisdictions were asked if the adult blood lead reports were transmitted as an export from the child system or not, and their modes of transmission. Six (40%) of the 15 non-integrated adult systems received blood lead reports as an export from the child system. Table 9a indicates the ranges, averages, and medians for the percent of reports by each transmission mode for the jurisdictions that receive reports from the child system, and table 9b is the same data for the jurisdictions that do not. Two of the six receiving files from the child system received all of them via HL7, one by flat file, and the other three received all of their files by other systems. The three jurisdictions that indicated an "other" mode of transmission identified the modes as "secure file transfer", "in-house-software", and "SAS query from child then manual data entry". Two of the nine not receiving reports through the child system received 100% via fax/email, six received between 88 and 99% via HL7, and one received flat files.

Table 9a: Range, average, and median percent of reports transmitted to adult surveillance system by each mode of transmission – six systems that receive reports as export from child system

MODE OF REPORT TRANSMISSION	RANGE OF % TRANSMITTED	AVERAGE % TRANSMITTED	MEDIAN % TRANSMITTED
Adult fax email	0.0 – 5.0	1.5	0.0
Excel	0.0	0.0	0.0
HL7	0.0 – 100.0	49.8	0.0
Flat file	0.0 – 100.0	20.0	0.0
Other	0.0 – 100.0	58.0	90.0

Table 9b: Range, average, and median percent of reports transmitted to adult surveillance system by each mode of transmission – nine system that receive do not receive reports from child system

MODE OF REPORT TRANSMISSION	RANGE OF % TRANSMITTED	AVERAGE % TRANSMITTED	MEDIAN % TRANSMITTED
Adult fax email	0.5 – 100.0	27.5	10.0
Excel	0.0 – 5.0	0.6	0.0
HL7	0.0 – 99.0	51.9	85.0
Flat file	0.0 – 90.0	20.0	0.0

Modifications made to the child data system to integrate adult system

The 23 jurisdictions that had integrated data systems were asked in an open-ended question what modifications were made to include adult data, such as name of employer. Twenty (87%) of the 23 jurisdictions provided answers, including nine (45.9%) that described variables that were added or modified, three (15.0%) that described changes in database functionality, one (5%) that described multiple modifications, five (25.0%) that described other and unclear modifications, and two (10.0%) that noted no modifications had been made (Appendix 2 Table A2-7).

Data sharing agreements

The 23 jurisdictions with integrated systems were asked if they had needed to establish written data sharing agreements in order to integrate the adult data with the child data system. Only two (10%) indicated data sharing agreements were needed.

Benefits and problems with the integrated system

The 23 jurisdictions with integrated systems were asked to describe (1) the benefits of the child/adult integrated system and (2) problems encountered in managing adult data within the integrated system as open-ended questions.

Two of the 23 jurisdictions left the benefits question unanswered. The 21 (91.3%) jurisdictions answering the question identified a total of 28 benefits, including 11 (39.3%) related to surveillance system administration, 14 (50.0%) related to identifying take-home clusters of exposures, and three (10.7%) with other comments. Table A2-8 in Appendix 2 provides the narrative from each of the jurisdictions for this question.

Eighteen (78.3%) of the 23 jurisdictions provided a description of problems encountered when managing adults: four (22.2%) stated there were no problems, and 14 (77.7%) each identified one problem. Six (35.3%) problems were related to database functionality, three (17.6%) were related to data reporting, and for two (11.6%), the nature of the problem was unclear. Table A2-9 in Appendix 2 provides the narrative description from each of the jurisdictions for this question.

Collection of information about pregnancy status of tested women

Adult system respondents were asked if their data system collected pregnancy status of tested women, and, if yes, to describe what was collected as an open-ended question. One of the 38 jurisdictions left this question blank. As shown in Table 10, 22 (59.5%) of the jurisdictions said yes.

Table 10: Number/percent of 37 jurisdictions that collect pregnancy status of tested women

PREGNANCY STATUS COLLECTED	N	%
Yes	22	59.5
No	13	35.1
Unknown	2	5.4
Total	37	100.0

The narrative descriptions of information collected regarding pregnancy status provided by 17 (77.2%) of the 22 jurisdictions answering yes were diverse and varied in level of detail (Appendix 2, Table A2-10).

Linking children and adults with same exposure

Respondents were asked if they had a manual or automated method to link children and adults who may have had the same lead exposure. Two (5.3%) of the 38 respondents left this question blank. Eighteen (50%) of the responding jurisdictions indicated that they had methods to make this link (Table 11a).

Table 11a: Number/percent of 36 jurisdictions with adult programs that have methods for linking adults and children with the same potential exposure

METHOD FOR LINKING CHILDREN AND ADULTS?	TOTAL	
	N	%
Yes	18	50.0
No	18	50.0
Total	36	100.0

Of the eighteen jurisdictions indicating that they had methods for linking adults and children, six (33.3%) had automated systems to do the linkages, 11 (61.1%) did linkages manually, and whether the linkage was manual or automated was not specified by one jurisdiction. Table A2-11 in Appendix 2 provides the narrative descriptions of linkage methods.

Joint blood lead exposure investigations

The 38 jurisdictions with adult programs were asked if they had worked with their child programs on joint blood lead exposure investigations. Thirty-seven (97.3%) of the 38 jurisdictions answered this question, and 24 (64.9%) said they had joint exposure investigations with their child programs.

Table 11b: Number/percent of 37 jurisdictions with adult programs that worked on joint blood lead exposure investigations

ADULT/CHILD PROGRAM JOINT EXPOSURE INVESTIGATIONS	N	%
Yes	24	64.9
No	13	35.1
Total	37	100.0

The 24 jurisdictions that said they collaborated on investigations with their child programs answered an open-ended question about how they collaborated and shared data. Thirteen (54.2%) noted that this happened because the child and adult programs were in the same program, and the others described a variety of collaborations (Appendix 2, Table A2-12).

The 24 jurisdictions were asked who had access to the data during the joint investigations. All answered the question, but responses are not included in the Appendix either because they included identifying information that could not be redacted or the responses were too general to be informative (e.g. “everyone” or “both programs”).

Twenty-two (91.7%) of the 24 jurisdictions listed the variables they use to link child and adult cases (Appendix 2 Table A2-13); almost three quarters (17 or 72.7%) linked using address, often in combination with other variables.

Twenty-one (87.5%) of the 24 jurisdictions answered the question: what would have made the data sharing and coordination process work better? Fifteen (71.4%) described data functionality or variables needs, such as the need for a single system (Appendix A2-14).

Ten (41.6%) of the 24 jurisdictions provided useful information to the question: What data that are not available in your system would have improved the exposure investigation? A variety of missing data elements were identified, including exposure source, employer name, occupation, pregnancy status, and others (Table A2-15).

Limitations

The respondents were asked about the limitations to their adult surveillance system with a checklist of 17 options that were almost the same as the list for the child programs. Thirty-six (94.7%) of the 38 adult program respondents answered this question. The three leading limitations were: “no algorithms to identify clusters” (48.6%) (which was also the leading child limitation), “variables important to adult surveillance missing” (45.7%) and, “difficult to get database problems fixed” (42.9%) (Table 12).

Table 12: Number/percent of 36 jurisdictions identifying limitations to adult surveillance system

LIMITATION TYPE	N	%
Expensive to maintain	8	22.9
Budget limitations prevent improvements	11	31.4
Requires a lot of staff time to support user help desk	12	34.3
Difficult to get database application problems fixed	15	42.9
Difficult for users to learn	3	8.6
Time consuming for users to update data	8	22.9
Exposure coding systems don’t capture all sources of exposure	8	22.9
No algorithms to identify potential clusters	17	48.6
Address geocoding and/or mapping functions not available	14	40.0
National data standards not met for some variables	7	20.0
Variables important for adult surveillance missing	16	45.7
Limited pre-set queries for generating reports	11	31.4
Queries for generating reports do not meet all state needs	7	20.0
Custom queries difficult/impossible to conduct	7	20.0
Difficult to export data to excel or other format	2	5.7
Difficult to export data for reporting to NIOSH	1	2.9
Other	10	28.6

Nine of the ten jurisdictions checking “other” limitation described the limitation. Three (33.3%) each identified issues with variables and resources. One described many issues (Appendix 2, Table A2-16).

Respondents were asked to identify the leading limitation in their adult system among all identified in the checklist as an open-ended question. Thirty-two (88.9%) of the 36 jurisdictions checking at least one limitation responded, with 11 (34.4%) identifying issues related to database functionality (e.g. difficult to get database application problems fixed), seven (21.9%) related to staffing and funding, and 10 (31.3%) related to missing variables (Appendix 2, Table A2-17).

The 16 respondents that identified missing variables for adult surveillance were asked to list the missing variables. Fourteen (87.5%) of the 16 responded. One said “many”, and one said “none”. One listed “pregnancy status only”. The remaining 11 listed employer, exposure, and occupation-related variables, plus some demographic variables (Table A2-18).

The respondents were asked if efforts were underway to address these limitations. All thirty-six jurisdictions that identified limitations responded, and 22 (61.1%) answered yes (Table 13).

Table 13: Number/percent of 36 jurisdictions indicating if efforts were underway to address limitations

EFFORTS UNDERWAY TO ADDRESS LIMITATIONS	N	%
Yes	22	61.1
No	10	27.8
Unknown	4	11.1
Total	36	100.0

They were then asked in an open-ended question what efforts were underway to address these limitations; or, if efforts were not underway, then why not. Twenty-three jurisdictions provided responses: five (21.7%) were in the process of building a new system, two (8.7%) noted they were making changes in budget/staffing, four (17.4%) were addressing data reporting issues, and eight (34.8%) were making changes in database functionality (Appendix 2 Table A2-19).

Interest in an integrated data application

The 38 adult jurisdictions were asked if they would consider using a data application that integrates child and adult blood lead data if it were available. Thirty-seven (97.3%) of the 38 jurisdictions responded, including 13 (35.1%) said yes, three (8.1%) said no, and 13 (35.1%) said it was unnecessary because they already had an integrated system. All the 13 integrated jurisdictions said unnecessary, and two (13.3%) of the unintegrated systems said no (Table 14).

Table 14: Number/percent of 37 adult jurisdictions that would consider an integrated data application by unintegrated and integrated jurisdictions

CONSIDER USING INTEGRATED SYSTEM?	UNINTEGRATED JURISDICTIONS		INTEGRATED JURISDICTIONS		TOTAL	
	N	%	N	%	N	%
Yes	7	46.7	6	27.3	13	35.1
No	3	20.0	0	0.0	3	8.1
Unnecessary: we already have an integrated surveillance system that meets our needs	0	0.0	13	59.1	13	35.1
Unknown	5	33.3	3	13.6	8	21.6
Total	15	100.0	22	100.0	37	99.9*

*Percentages do not total 100% due to rounding

Those who answered yes were asked what would have to be in place for the jurisdiction to consider a change with three specified options and an "other" option; they were instructed to check all that applied. Twelve (92.3%) of the 13 jurisdictions checked at least one option. Almost all (11; 91.7%) indicated a need for funding (Table 15).

Table 15: Elements identified as needing to be in place to consider an integrated system (12 jurisdictions)

ELEMENT	N	% OF 12 JURISDICTIONS
Funding	11	91.7
Meeting state's IT requirements	9	75.0
Meeting our blood lead data requirements	7	58.3
Other	1	8.3

Seven of the nine (77.8%) jurisdictions indicating that the system would need to meet the state's IT requirements gave some examples of those requirements. They are listed in Appendix 2 Table A2-20.

In a follow-up question that asked the amount of funding that would be needed, only one of the 11 indicating funding provided an estimate: "$45,000–$50,000 annual maintenance including state data center charges".

The three indicating they would not be interested were asked to identify why not from a checklist of six options. One of the three jurisdictions answered, checking the option: "Likely to be very difficult and time consuming to get approval from state's Information Technology program".

Participation in a workgroup to develop integrated system requirements

All 52 jurisdictions were asked if someone from their child and/or adult program would be willing to participate in a workgroup to develop requirements for an integrated system, and, if yes, asked to provide contact information. Fifty-one (98.1%) answered the question; 25 (49%) said yes, and all 25 provided names and contact information.

Concluding comments from the jurisdictions

The 52 jurisdictions were asked to add any additional comments that would help determine the feasibility of and requirements for developing an integrated data application. Twelve (23.1%) jurisdictions provided comments as listed in Appendix 2, Table A2-21.

Discussion

All 52 surveyed jurisdictions—50 states plus Washington DC and New York City—completed the assessment, although a few did not answer every question.

The assessment showed that all 50 states plus Washington DC and New York City have child blood lead surveillance systems. Forty-four (88%) are funded by CDC-NCEH (A. Ettinger, personal communication, October 7, 2019). Only one jurisdiction indicated that they collect the laboratory data but do not do follow-up case investigations. Thirty-eight (73.1%) of the 52 surveyed jurisdictions also have adult surveillance systems; NIOSH provides support to 26 (68.4%) of them (R. Tsai, personal communication, September 19, 2019).

Respondents identified various data management systems in place both for child and adult programs, with the HHLPSS application and systems shared with communicable disease predominating, but no one system type included more than a quarter of the jurisdictions for child and more than about 30% for adults. STELLAR was still used in three jurisdictions (two for all surveillance and one just for case investigation data), even though NCEH has not supported the use of this desktop application for 10 years.

Eight (15.4%) of the 52 used NBS for child lead surveillance. Another 15 states in the country use NBS for communicable disease surveillance but without a lead module. Early on in NBS development at CDC, there was a plan to include the development of a lead Program Area Module (PAM), but that plan was not implemented. It might have made it easier for NBS jurisdictions to add their own lead modules had the lead PAM been developed.

Twenty-three (60%) of the adult systems were integrated into their child systems. Again, there was no single data management system used among these jurisdictions with adult/child integrated systems.

Almost all child and adult programs identified a variety of limitations in their systems, the frequency of which varied depending on which data system was in use. Lack of an algorithm for identifying clusters was the most frequently cited limitation for both child and adult systems. Fourteen percent of child programs and 25% of adult programs were somewhere in the process of considering or developing new data systems as a solution to limitations, including two new applications that are going to go live this year.

Fifteen percent of child programs and 31% of adult program jurisdictions noted funding and staffing as their leading surveillance system limitations, and 92% of the jurisdictions indicating that they would consider adopting an integrated system but indicated they would need funding to do that.

Given the diversity of data systems in place, it is not likely that the development of one prototype for an integrated system would be the only solution to the goal of having integrated child-adult systems in place nationwide.

At the same time, the diversity of systems provides opportunities to develop and promote best practices, so for example, NBS jurisdictions who have added a lead module for adults and/or children would have valuable information for other jurisdictions already using or considering using NBS for lead.

Manual or automated methods for identifying exposure clusters and/or take-home lead exposure are already in place in 60% of the child programs and 50% of adult programs but, many rely on manual matching of addresses and related information. Fifty-six percent noted that a lack of algorithms to identify clusters in the data system was a limitation of their system. The ones indicating that they have developed automated systems to do this could be an excellent resource for jurisdictions that would like to do the same.

CSTE has the names and contact information from 25 of the 52 jurisdictions who would be willing to participate in workgroups to address all these issues. CSTE can obtain their permission to release their names so they could be contacted about workgroups.

There are several limitations to this assessment that should be noted.

First, two jurisdictions did not answer a considerable number of questions, and it is unknown whether they chose not to answer those questions, for whatever reason, or they started the assessment but did not come back to finish it.

Second, it was challenging to summarize the narratives provided in response to the many open-ended questions. On the other hand, the narratives provided a depth of details that should be useful when developing requirements for improvements to existing surveillance systems.

Third, it should be noted that CDC-NCEH funds eight large cities and counties that were not included in the assessment, and it is unknown whether the results from this assessment would have been representative of their responses.

In addition, it is important to note what this assessment did not do. It was not designed to be a detailed requirements-gathering assessment in the IT project management sense. It also was not an assessment of data workflow, each jurisdiction's data system functionality, or each system's program components. All of these issues would require a more in-depth assessment.

Recommendations

First, a workgroup could be convened to develop detailed requirements for an integrated system.

Second, communities of practice workgroups could be developed for each of the different applications already in use in multiple jurisdictions to identify and promote best practices.

It would potentially be helpful to obtain advice from subject matter experts in public health informatics. Organizations with this type of expertise include the Public Health Informatics Institute[18] and Altarum Institute.[19]

In addition, it could be useful to discuss surveillance systems limitations and opportunities with companies that have developed products used by multiple state communicable surveillance disease systems, like Conduent, which developed Maven.

Additional funding for all jurisdictions for child and adult blood lead surveillance would help promote blood lead surveillance system improvements and integration of child and adult surveillance systems.

References

1. Centers for Disease Control and Prevention. Blood Lead Surveillance Data. (2019, July 30). Retrieved from https://www.cdc.gov/nceh/lead/data/surveillance-data.htm

2. Centers for Disease Control and Prevention. Childhood Lead Poisoning. (n.d.). Retrieved from https://ephtracking.cdc.gov/showChildhoodLeadPoisoning.action

3. Raymond J, Brown MJ. Childhood Blood Lead Levels in Children Aged <5 years – United States, 2009-2014. MMWR Surveill Summ 2017; 66(No.SS-3):1-10. DOI: http://dx.doi.org/10.15585/mmwr.ss6603a1

4. Alarcon WA. Elevated Blood Lead Levels Among Employed Adults – United States, 1994-2013. MMWR Morb Mortal Wkly Rep 2016; 63:59-65. DOI: http://dx.doi.org/10.15585/mmwr.mm6355a5

5. Kennedy C, Yard E, Dignam T, et al Blood lead levels among children aged <6 years —Flint, Michigan, 2013-2016. MMWR Morb Mortal Wkly Rep. 2016;65(25):650–654.

6. Angelon-Gaetz KA, Klaus C, Chaudhry EA, Bean DK. Lead in Spices, Herbal Remedies, and Ceremonial Powders Sampled from Home Investigations for Children with Elevated Blood Lead Levels — North Carolina, 2011–2018. MMWR Morb Mortal Wkly Rep 2018;67:1290–1294. DOI: http://dx.doi.org/10.15585/mmwr.mm6746a2

7. Centers for Disease Control and Prevention. Lead poisoning associated with ayurvedic medications--five states, 2000-2003.MMWR Morb Mortal Wkly Rep. 2004 Jul 9;53(26):582-4.

8. Materna B, NIOSH. Occupational and Take-Home Lead Poisoning Associated with Restoring Chemically Stripped Furniture — California, 1998 Morbidity and Mortality Weekly Report: April 06, 2001: 50(13):246-248

9. Ettinger A, Leonard ML, Mason, J. CDC's Lead Poisoning Prevention Program: A Long-standing Responsibility and Commitment to Protect Children From Lead Exposure, J Public Health Manag Pract. 2019. January/February; 25 (1-suppl), S5–S12

10. Smith PF[1], Hadler JL, Stanbury M, Rolfs RT, Hopkins RS; CSTE Surveillance Strategy Group.
"Blueprint version 2.0": updating public health surveillance for the 21st century. J Public Health Manag Pract. 2013 May-Jun;19(3):231-9. doi: 10.1097/PHH.0b013e318262906e.

11. Centers for Disease Control and Prevention. NBS. (2019, December 2). Retrieved from https://www.cdc.gov/nbs/

12. Public Health Informatics Institute. (2013). *Electronic Disease Surveillance System (EDSS) Vendor Analysis*,. Decatur, GA: Public Health Informatics Institute.

13. Centers for Disease Control and Prevention. Lead - HHLPSS Data Management Platform. (2019, July 30). Retrieved from https://www.cdc.gov/nceh/lead/data/hhlpss.htm

14. Centers for Disease Control and Prevention. Adult Blood Lead Epidemiology and Surveillance (ABLES) - NIOSH Workplace Safety and Health Topic. (2018, May 11). Retrieved from https://www.cdc.gov/niosh/topics/ables/default.html

15. Egan KB, Tsai R, Chuke SO. Integrating Childhood and Adult Blood Lead Surveillance to Improve Identification and Intervention Efforts. 2019. J Public Health Manag Pract. January/February 19 (25) S98–S104. doi: 10.1097/PHH.0000000000000872
16. U.S. Census Bureau Geography Division (n.d.). Retrieved from https://www2.census.gov/geo/pdfs/maps-data/maps/reference/us_regdiv.pdf
17. Disease Surveillance and Outbreak Management System. (n.d.). Retrieved from https://www.conduent.com/solution/public-health-technology/disease-surveillance-system/
18. PHII. (2020). Retrieved from https://www.phii.org/
19. Altarum. (2020). Retrieved from http://altarum.org/

Appendix 1: Assessment Questions

The Council of State and Territorial Epidemiologists (CSTE) is conducting an assessment of state-based blood lead surveillance systems and is asking your state (or jurisdiction) to respond.

The goal of the assessment is to understand the potential opportunities and challenges for integration of the child and adult blood lead surveillance systems into one system at the state (or jurisdictional) level. An integrated system would manage child and adult blood lead data in one application that would have, for example, the same interface, same data elements and coding schema, and the same data input and export features. An integrated system is likely to be more efficient, save on resources, meet national data standards, and allow for linkages between child and adult exposures in order for programs to more easily identify lead exposure clusters involving both children and adults (for example, take-home lead, exposures from a lead-contaminated imported food, remedy, or cosmetic).

Your responses will be confidential and shared only in de-identified, aggregate form. CSTE will not release state-specific information in any reports unless otherwise requested and approved by the state(s). Please click here to begin the assessment and submit your responses by **close of business on July 24th**. It should take approximately 20 minutes to complete.

For questions, please contact Alesha Thompson (athompson@cste.org)

Guidelines for completing this assessment:

This assessment is being sent to managers for child and adult blood lead surveillance programs based on information available from CDC's National Center for Environmental Health (NCEH) and National Institute for Occupational Safety and Health (NIOSH). Contact information was not available from CDC for states without CDC-funded lead surveillance programs, and, therefore, for these states, the assessment is being sent to the State Epidemiologist. Ideally, states with child and adult lead surveillance systems will collaborate to provide one response to the assessment for their jurisdiction.

If any part of your current surveillance system is in the process of migrating to a new system, please answer the following questions in relation to the new system, even if that system is still under development.

This assessment response is being submitted by:

- ○ Name _____
- ○ Title _____
- ○ Program _____
- ○ Name of Agency _____
- ○ State/Jurisdiction _____
- ○ Email _____
- ○ Phone _____

Check one:

- ○ It is a response from the child blood lead surveillance program only
- ○ It is a response from the adult blood lead surveillance program only
- ○ It is a combined response from the child and adult blood lead surveillance programs
- ○ It is a response from a program other than lead surveillance (Please specify program) _____

1. Do laboratories (including clinical and point-of-care laboratories) report blood lead test results to your state?

- ○ Yes
- ○ No
- ○ Unknown

Display This Question:

If 1. Are laboratories required to report blood lead test results to your state? = Yes

1a. What is/are the age range(s) for reportable blood lead test results? (Check all that apply)

- ○ All blood lead levels, regardless of patient age
- ○ Children, no age range specified
- ○ Children, specify age range _____
- ○ Adults, no age range specified
- ○ Adults, specify age range _____

2. How do laboratories report blood lead lab test results for children? (Check all that apply and estimate the percent of lab test results that come from each source per year - should add up to 100%)

Note: Adult data is addressed starting in question 9

Individual lab reports by Fax or US mail: _____
Excel spreadsheets: _____
Electronic Lab Reports (ELR) in HL7: _____
Flat file (e.g. CSV, tab delimited): _____
Other (Please describe): _____
Unknown: _____

Total: _____

3. What data management system does your state use to manage the laboratory reports for children?

- ○ CDC's HHLPSS application ("Healthy Homes and Lead Poisoning Surveillance System")
- ○ A custom web-based application developed by your state for blood lead reports
- ○ Access or another relational database
- ○ Incorporated as a module into your NEDSS based system (NBS) for communicable disease
- ○ Incorporated as a module into another electronic communicable disease surveillance data application (custom or commercial e.g. MAVEN)
- ○ Other
- ○ Unknown

Display This Question:

If 3. What data management system does your state use for child blood lead surveillance? = Incorporated as a module into another electronic communicable disease surveillance data application (custom or commercial e.g. MAVEN)

3a. Please provide the name of your application:

_____

Display This Question:

If 3. What data management system does your state use for child blood lead surveillance? = A custom web-based application developed by your state for blood lead reports

Or 3. What data management system does your state use for child blood lead surveillance? = Access or another relational database

Or 3. What data management system does your state use for child blood lead surveillance? = Other

3b. Please describe your data management system:

_____

4. Is the previously referenced lead surveillance data management system used to collect case investigation and intervention data on children, in addition to managing the laboratory report data?

- ○ Yes
- ○ No
- ○ Unknown

Display This Question:

If 4. Is the previously referenced lead surveillance data management system used to collect case inv... = No

4a. Describe the case investigation/intervention data system

_____

5. Is the surveillance system used to identify clusters of lead exposure among children (e.g., multiple children in the same household)?

- ○ Yes
- ○ No
- ○ Unknown

Display This Question:

If 5. Is the surveillance system used to identify clusters of lead exposure among children (e.g., mu... = Yes

5a. Please describe how clusters are identified:

_____

6. What are the limitations of your child blood lead data system, if any (check all that apply)

- [ ] Expensive to maintain (e.g. server costs).
- [ ] Program budget limitations prevent improvements/modernization
- [ ] Requires a lot of staff time to maintain and provide Help Desk support to users
- [ ] Difficult and/or time consuming to get database application problems fixed when they are identified
- [ ] Difficult for users to learn the system
- [ ] Time-consuming for users to do data updates
- [ ] Exposure coding system does not capture all potential sources of lead exposure
- [ ] No algorithms to identify potential clusters related to a single source of exposure (e.g. take-home lead for an occupationally or environmentally exposed adult, consumption of an imported food or remedy).
- [ ] Automated address geocoding and/or mapping functions are not available
- [ ] National data standards are not met for some variables
- [ ] Variables important for child lead surveillance are missing
- [ ] Limited pre-set queries for generating reports
- [ ] Queries for generating reports do not meet all state data analysis needs
- [ ] Custom queries are difficult or impossible to conduct
- [ ] Difficult to export data to Excel or other format for uses in the state
- [ ] Difficult to export data for reporting to CDC

☐ Other (Please describe)

☐ Unknown

Display This Question:

If 6. What are the limitations of your child blood lead data system, if any (check all that apply) = Variables important for child lead surveillance are missing

6a. Please state missing variables:

_____

7. Which one of the above limitations has the greatest impact on the effective operation of your child blood lead surveillance program, if known?

_____

8. Are efforts underway in the state to address any of these limitations?

○ Yes

○ No

○ Unknown

Display This Question:

If 8. Are efforts underway in the state to address any of these limitations? = Yes

Or 8. Are efforts underway in the state to address any of these limitations? = No

8a. Please describe

_____

9. Does your jurisdiction have an adult blood lead surveillance program in operation or in the planning stages?

- ○ Yes
- ○ No
- ○ Unknown

Skip To: 26 If 9. Does your jurisdiction have an adult blood lead surveillance program in operation or in the pl... != Yes

10. Is the data application used for adult surveillance the same application as used for child blood lead surveillance (identified in q 3)?

- ○ Yes
- ○ No

Skip To: 15 If 10. Is the data application used for adult surveillance the same application as used for child bl... = Yes

11. Do all adult blood lead test results reported by laboratories go into the same data application as child blood lead test results before being exported to the adult surveillance system?

- ○ Yes
- ○ No
- ○ Unknown

Display This Question:

If 11. Do all adult blood lead test results reported by laboratories go into the same data applicati... = No

Or 11. Do all adult blood lead test results reported by laboratories go into the same data applicati... = Unknown

12. How do laboratories report adult lead lab test results for adults? (check all that apply and estimate the percent of lab test results from each source per year – should add up to 100%)

Individual lab reports by Fax or US mail: _____
Excel spreadsheets: _____
Electronic Lab Reports (ELR) in HL7: _____
Flat file (e.g. CSV, tab delimited): _____
Other (describe): _____
Unknown: _____

Total: _____

Display This Question:

If 11. Do all adult blood lead test results reported by laboratories go into the same data applicati... = Yes

13. How are adult blood lead test results imported or transferred from the child data management system into the adult blood lead data management system (check all that apply and estimate percent for each method)?

Individual lab reports by Fax or US mail: _____
Excel spreadsheets: _____
Electronic Lab Reports (ELR) in HL7: _____
Flat file (e.g. CSV, tab delimited): _____
Other (describe): _____
Unknown: _____

Total: _____

14. What data management system does your state use for adult blood lead data?

- ○ A web based custom application developed by your state for blood lead reports
- ○ Access or another relational database
- ○ Excel or another spreadsheet system
- ○ Unknown

Display This Question:

If 14. What data management system does your state use for adult blood lead data? = A web based custom application developed by your state for blood lead reports

Or 14. What data management system does your state use for adult blood lead data? = Access or another relational database

14a. Please describe your data management system:

_____

Display This Question:

If 10. Is the data application used for adult surveillance the same application as used for child bl... = Yes

15. What modifications did you make to the data application to include adult level information (e.g. name of employer)?

_____

Display This Question:

If 10. Is the data application used for adult surveillance the same application as used for child bl... = Yes

16. Did you need to establish written data sharing agreements between your child and adult programs in order to use the same data application?

- ○ Yes
- ○ No
- ○ Unknown

Display This Question:

If 10. Is the data application used for adult surveillance the same application as used for child bl... = Yes

17. Describe benefits of the child/adult integrated system

_____

Display This Question:

If 10. Is the data application used for adult surveillance the same application as used for child bl... = Yes

18. Describe problems you have encountered managing adult data within the integrated system:

_____

19. Is pregnancy status of women captured in the database?

- ○ Yes
- ○ No
- ○ Unknown

Display This Question:

If 19. Is pregnancy status of women collected in the database? = Yes

19a. What information is collected?

_____

20. Do you have a manual or automated system set up to link children with blood lead test results to adults with blood lead test results who may have had the same lead exposure (e.g. occupationally- or hobby-exposed adult to their children)?

- ○ Yes
- ○ No
- ○ Unknown

Display This Question:

If 20. Do you have a manual or automated system set up to link children with blood lead test results... = Yes

20a. Describe how the system does this (e.g. manual or automated address matching or geocoding)

_____

21. Have your child and adult blood lead programs worked on joint blood lead exposure investigation?

- ○ Yes
- ○ No
- ○ Unknown

Display This Question:

If 21. Have your child and adult blood lead programs worked on joint blood lead exposure investigation? = Yes

21a. How did you collaborate and share data?

_____

Display This Question:

If 21. Have your child and adult blood lead programs worked on joint blood lead exposure investigation? = Yes

21b. Who had access to the data during the investigation?

_____

Display This Question:

If 21. Have your child and adult blood lead programs worked on joint blood lead exposure investigation? = Yes

21c. What variables, if any, did you use to link child and adult cases?

_____

Display This Question:

If 21. Have your child and adult blood lead programs worked on joint blood lead exposure investigation? = Yes

21d. What would have made the data sharing and coordination process work better?

_____

Display This Question:

If 21. Have your child and adult blood lead programs worked on joint blood lead exposure investigation? = Yes

21e. What data that are not available in your system would have improved the exposure investigation?

_____

22. What are the limitations of the data application for adult surveillance, if any (check all that apply)

- [ ] Expensive to maintain (e.g. server costs).
- [ ] Program budget limitations prevent improvements/modernization
- [ ] Requires a lot of staff time to maintain and provide Help Desk support to users
- [ ] Difficult and/or time consuming to get database application problems fixed when they are identified
- [ ] Difficult for users to learn the system
- [ ] Time-consuming for users to do data updates
- [ ] Exposure coding system does not capture all potential sources of lead exposure
- [ ] No algorithms to identify potential clusters related to a single source of exposure (e.g. the same employer, take-home lead for an occupationally or environmentally exposed adult, consumption of a home remedy or contaminated food).
- [ ] Automated address geocoding and/or mapping functions are not available
- [ ] National data standards are not met for some variables
- [ ] Variables important for adult lead surveillance are missing
- [ ] Has limited pre-set queries for generating reports
- [ ] Queries for generating reports do not meet all state data analysis needs
- [ ] Custom queries are difficult or impossible to conduct
- [ ] Difficult to export data to Excel or other format for uses in the state

- [ ] Difficult to export data for reporting to NIOSH
- [ ] Other (describe) _____
- [ ] Unknown

Display This Question:

If 22. What are the limitations of the data application for adult surveillance, if any (check all th... = Variables important for adult lead surveillance are missing

22a. Please state the missing variables:

_____

23. Which one of the above limitations has the greatest impact on the effective operation of your adult blood lead blood lead surveillance program?

_____

24. Are efforts underway to address any of these limitations (check all that apply)?

- ○ Yes
- ○ No
- ○ Unknown

Display This Question:

If 24. Are efforts underway to address any of these limitations (check all that apply)? != Unknown

24a. Please describe:

_____

25. If a data application that integrates child and adult blood lead surveillance becomes available, would your state/jurisdiction consider using this?

- ○ Unnecessary: we already have an integrated surveillance system that meets our needs
- ○ Yes
- ○ No
- ○ Unknown

Display This Question:

If 25. If a data application that integrates child and adult blood lead surveillance becomes availab... = Yes

25a. If yes, what would have to be in place for the state to consider a change? (check all that apply)

- ☐ Funding Other (Estimate initial conversion/installation and annual maintenance costs, if possible)
- ☐ Meeting the state's office of technology requirements (e.g., security)
- ☐ Meeting the state's blood lead data requirements
- ☐ Other (Please describe)

_____

Display This Question:

If 25a. If yes, what would have to be in place for the state to consider a change? (check all that a... = Funding Other (Estimate initial conversion/installation and annual maintenance costs, if possible)

Please estimate initial conversion/installation and annual maintenance costs if possible:

_____

Display This Question:

If 25a. If yes, what would have to be in place for the state to consider a change? (check all that a... = Meeting the state's blood lead data requirements

25b. Please give some examples: (e.g., must be able to upload lab reports from spreadsheets as well as electronic HL7 messages, must have automated system to assign latitude/longitude coordinates to addresses))

_____

Display This Question:

If 25. If a data application that integrates child and adult blood lead surveillance becomes availab... = No

25a. If no, why not? (check all that apply)

- ☐ An integrated system is not necessary for our current needs
- ☐ Costs for conversion are prohibitive
- ☐ Costs for maintenance are too high
- ☐ Incompatible with current organization of child and adult blood lead surveillance programs in our jurisdiction
- ☐ Likely to be very difficult and time consuming to get approval from state's Information Technology program
- ☐ Other (describe) _____
- ☐ Unknown

26. Would you or someone from your child and/or adult program be willing to participate in a workgroup to develop specific and detailed requirements for an integrated child and adult blood lead surveillance data application?

- ○ Yes
- ○ No
- ○ Unknown

Display This Question:

If 26. Would you or someone from your child and/or adult program be willing to participate in a work... = Yes

26a. If yes, please provide the preferred contact information below

- ○ Name _____
- ○ Email _____
- ○ Job Title/Position _____

27. Please add any additional comments that would help determine the feasibility of and requirements for developing an integrated child and adult surveillance data application.

_____

You have reached the end of the Blood Lead Assessment. Please advance the page in order to submit your department's response. Upon submission, you will be re-directed to the CSTE webpage.

End of Block: Default Question Block

Appendix 2: Tables with Narratives from Open-ended Questions

Table A2-1: "Other" case management data systems for jurisdictions that use a different system from the system used for laboratory reports (5 jurisdictions)

CDC STELLAR
STELLAR- MS DOS SYSTEM
Excel. lab reports come into NEDSS system (40% excel; 60% HL7) and then exported to lead Excel system via spreadsheets.
We use a legacy data management system that combines blood lead registry data with case investigation data as well as environmental intervention and enforcement data. It was developed using Powerbuilder and has a SQL Server database backend
We use a custom version of CDC's HHLPSS. We modified an early version of CDC's HHLPSS and customized it to our state's lead laws and rules.

Table A2-2: Transmission modes for laboratory reports described in "other" transmission mode (9 jurisdictions)

Web-based Application
Mail
Direct entry into system
Manual entry through web portal
5.3% downloaded from a reference lab's external website; 8.8% sent in an Excel file that is not in discrete data fields- requires SAS coding to process
Web Form (15.0%); proprietary format and formats with multiple records per line (2.8%)
In-house online application for point-of-care devices.
Providers submit a fixed width text file through a secure electronic health information exchange that is converted to a DBF file and processed automatically into our database.
Electronic Non-HL7 format

Table A2-3: Jurisdictions' cluster identification methods (28 jurisdictions)

CLUSTER IDENTIFICATION METHODS CATEGORY	CLUSTER IDENTIFICATION METHODS NARRATIVE	N	%
Manual or automated address matching		15	53.6
	By manually matching similar addresses; also it is sometimes noted in the received patient files.		
	Case managers notice cases reside at the same address and link them manually.		
	Addresses of children with elevated blood lead levels from Maven are mapped using GIS		

	The system is able to track multiple children at the same address or one child at a different address over time.		
	Each child and unit specific address is assigned a unique ID which are related and stored in a data table. The application provides relational views so that any child living at the unique address is visible along with his/her corresponding blood lead levels at that address. The application also tracks the address history for a child so that all addresses the child resided in can be viewed. Furthermore, any case related activities are visible through a related case view.		
	Clusters are identified using GIS mapping.		
	They can be linked by address		
	Based on geocoded address and apartment number		
	Each address tracks associated children and adults. Clusters can easily be identified due to the link between addresses and patients.		
	Based on residential address. For new or potential cases, we look to see other individuals associated with that address in our system.		
	Address match for family members. specific geospatial analysis.		
	In routine reports of address and all BLL >5 at that location		
	Staff reviewing workflow queues in the data system identify some clusters through recognition of similar names and addresses. The system does not automatically link/associated cases to one another.		
	Clusters are identified by assessing common addresses and by ordering provider.		
	When there are multiple lead poisoned children at one address, they are linked through the same address record in HHLPSS.		
Through data analysis		4	14.3
	Clusters are identified through analysis of data collected in HHLPSS.		
	Cluster detection algorithm run against reports; during investigation by epidemiologists; reports from providers		
	SAS reporting - rates, combined with other risks indicators in sub county geographies.		
	Data is downloaded from the system, cleaned, and analyzed using statistical and spatial analysis.		
By identifying siblings/members of same household		2	7.1
	Identified as Sibling		

	Multiple children can be linked to the same household and siblings can be linked to siblings		
Other and unspecified methods			
	Matching demographics by case or by phone interview.	7	25.0
	The data management system automates processing of all blood lead levels (positive and negative) that results in the creation of a patient profile and associates all results with that profile without any user intervention. All cases associated with a cluster are connected using a function in the data system that is also used as a tool to connect cases of reportable disease by epidemiological risks like common food, sexual contact, household contact or other risk factor. This allows any county to view the relationships between cases of reportable disease. In addition to this feature, all cases associated with a cluster are tracked using the system's Outbreak Module feature. The Outbreak Module provides a standardized system for managing outbreak investigations. Epidemiologists, nurses, disease investigators and others can use the Outbreak Module to create detailed surveys used to interview cases/patients, update outbreak information as it is collected, analyze data collected, prepare an outbreak summary report and even report the outbreak/cluster to the state health office.		
	By state, jurisdiction (county), city, Zip code, age, socioeconomics		
	Can pull line lists by specific time frames, by jurisdiction, review trends overtime.		
	Clusters are identified through medical case managers and environmental investigation. Clusters/outbreaks are assigned an outbreak number and can be reviewed and managed by the investigator or Epidemiologist by the unique identifier.		
	Clusters are identified manually only for occupationally-linked cases.		
	No statistical software is used. We don't get many elevated reports so clusters are obvious		
Total		28	100

Table A2-4: "Other" limitations of the child system (15 jurisdictions)

Any associated address information is not linked to individual test result.
Canned reports do not capture all the needs of the program

Case management functionality lacking
Difficult to deduplicate addresses
Inability to track houses and addresses independently from cases and patients (no address database).
Local data are not in sync with the system used by the state (NBS)
Only 3 labs feed directly into the system. Every other lab has to be standardized through manual processing, which takes a lot of staff time.
Some ELRs are missing key variables; e.g., address
System getting old(er), looking at potential replacement with one that betters address future meaningful use requirements.
The Access is an old system that while reliable is not adequately documented and needs to be replaced. But it does meet most of our needs.
The current surveillance system does not lend itself to the structure in which lead is handled within the state. We effectively have 150+ persons who handle lead cases and the system is not made to support their activities.
We are not in a position to answer many of these questions until we have more experience with the new application, beginning on September 2019. The first 6 are more of an unknown than the remaining boxes, many of which we have tried to address in our development phase, but it is too soon for us to answer these accurately.
Unfunded by either CDC or state
No staff assigned to this activity and no funding is available.
Lack of support at national level for public health informatics in blood lead surveillance programs. A workgroup that involves the states should be created for any changes to data standards and to facilitate state collaboration. Difficult to cross train due to data being received in multiple formats and timelines. Current information system is not fully supported by state IT. Inability to link family members and properties within the information system. Local public health cannot access the information system. All communication with local public health is done by email or phone. No automated work queues or alerts for case management. All data must be manually entered or manually batch uploaded. Home risk assessment data is entered by a separate unit in the health department and data is stored as a Word document, not individual data fields.

Table A2-5: Limitation that has the greatest impact on surveillance system operation (51 limitations from 44 jurisdictions)

LIMITATION CATEGORY	LIMITATION WITH GREATEST IMPACT NARRATIVE	N	%
Data queries/data analysis		10	19.6
	Limited pre-set queries		
	Queries for generating reports do not meet all state data analysis needs		
	limited pre-set queries would create false associations		
	no queries system exists		

	Lack of useful queries supplied with the application		
	No algorithms to identify potential clusters.		
	No algorithms to identify potential clusters related to a single source of exposure		
	No algorithms for clusters, and inadequate data from adult blood lead reports to link parents with children for occupational exposure investigations.		
	The associated address information is not linked to individual test result presents the greatest impact.		
	Pre-set queries are limited ad do not meet state or local data analysis needs		
Data entry/data management		10	19.6
	High level of manual data updates/ data entry		
	Difficult to deduplicate addresses because it takes time to clean up child and property cases.		
	Time consuming for users to do data updates		
	Time-consuming for users to do data updates		
	The manual standardization of labs that don't come directly into the system.		
	Blood lead data received from clinics/Dr.'s offices, hospitals, etc., that utilize the point-of-care machines are not automated into the data system (faxes, etc.) and need to be hand entered into a spreadsheet.		
	Historical addresses were not recorded correctly in our system.		
	All data must be manually entered to manually batch uploaded.		
	Time-consuming for users to do data updates		
	Time-consuming to enter/update data		
Database functionality			
	The inability to output the data as reports or flat files.	12	23.5
	Difficult to get database problems fixed in a timely manner when identified that can severely limit the functions of the database		
	Automated address validation and geocoding.		
	Outdated electronic lab importing abilities		
	Data received and uploaded in multiple formats and timelines makes it difficult to cross train.		

	Difficult and/or time consuming to get database application problems fixed when they are identified;		
	Difficult to export data reporting to CDC		
	Automated mapping/geocoding		
	Geocoding		
	HHLPSS currently has limited case management functionality which is highly dependent on manual input by users. Previous surveillance system automated certain case management functions allowing case manager to focus on other areas of concern.		
	It takes too long to get system issues fixed by CDC and pre-set queries are limited and do not meet state or local data analysis needs		
	Not syncing data with the state office for other jurisdictions		
Missing variables		5	9.8
	Insurance Status/Type		
	Missing variables		
	Missing exposure variables		
	In depth information on lead source is missing from our data.		
	All sources of exposure cannot be captured.		
Funding/staffing		8	15.7
	Current database is not fully supported by state IT.		
	Program budget limitations slowing improvements and enhancements.		
	Staff time limitations		
	Staff time limitations for development, maintenance and training.		
	Unfunded by either CDC or state		
	Program budget limitations preventing improvements/modernization.		
	Staff time to maintain.		
	Funding		
Other/unknown		6	11.8
	The current database does not fully support the work of jurisdiction's many lead case managers.		
	Unknown		

	Our current system uses a programming language that is no longer widely used, and as such it is difficult to maintain and enhance		
	n/a		
	Unknown		
	None		
Total		51	100.0

Table A2-6: Efforts to address identified surveillance system limitations (35 jurisdictions)

EFFORT CATEGORY	EFFORT NARRATIVE	N	%
Exploring or building new data system		7	20
	Building an in-house lead database that will address all aforementioned limitations.		
	Switching to NBS, but NBS will have its own limitations.		
	Have an active project to implement Maven by 2021. We hired an informatics staff to assist with standardizing reporting and HL7 onboarding. We may also explore storing risk assessment data as individual data fields rather than Word documents.		
	We are developing an integrated backend application to automate the receipt, processing and management of incoming data. We are also developing a process to ensure consistency and integrity of data across databases		
	Exploring the creation of a new data system to support public health and environmental services for children exposed to lead. An improved data system will support enhanced case management services, lead hazard evaluations and a more robust reporting system for data analyses.		
	Exploring potential software replacements, but only casually looking now because we are currently in the process of replacing the Immunization system.		
	We are in the process of identifying qualified vendors for a new redesigned lead registry		
Other efforts to address limitations		28	80
	We are trying to get a handle on these variables to try to collect more in-depth information.		
	Working with our informatics group, that maintains the data system receiving blood lead reports to create an easier option for point-of-care users to upload their blood lead data.		

	Standardized reporting template is being implemented among reporting labs and clinics.		
	Evaluating whether or not we can pay a contractor to develop message mapping guides and adding the variable field to database.		
	Linking statewide data is complex		
	Provide education and training for providers on what and when to report lead exposure cases		
	Developing and testing spreadsheet for providers to send electronic reporting		
	We have coordinated with other states to modify and refine our NBS system.		
	In Fall 2019, the Lead Poisoning Prevention Program will be revising and streamlining the lead poisoning risk factor data collection screens to capture risk factor data that are more relevant to the program and its constituents.		
	Add some functions to help generate reports		
	The state is working with Conduent (Maven) to ensure a more timely response to database issues		
	We are able to generate reports needed from a data download from HHLPSS. We are considering incorporating reports in Tableau		
	State users report issues/problems to the CDC team, and the CDC team will try to fix these issues in the next released version of HHLPSS.		
	We are slowly improving documentation of the system and leverage capabilities of the new blood lead module within our immunization registry.		
	Testing functionality of current HHLPSS database.		
	Working with a vendor to perform a high-level overview of the CLPPP surveillance systems. Recommendations are being made to improve processes and procedures		
	Making a new NBS page for lead investigations that will make it easier to edit questions and create custom reports		
	Exploring many different options in NBS. We have had to create our own separate master address table outside of NBS,		
	We conduct manual tracking of cases as well as with HHLPSS system and compare		
	Data analysis processes are being reviewed to ensure needs of program are met		

	1) State is working with commercial labs to get HL7 data to feed directly into the system 2) We provide webinars for users to learn the system 3) Though geocoder is old, it is periodically updated 4) We have a relationship with Medicaid that allows us to fill in missing data 5) When time allows, we contact clinics and labs for missing information		
	IT is working to address noted concerns.		
	Work is on-going to develop/test/strengthen algorithms to link child cases with adults.		
	Assessing our current activities for blood lead with the idea of applying for CDC funding during the next grant cycle.		
	In house IT support has been successful in creating needed reports.		
	Case investigation forms and NBS are being updated to incorporate a much broader range of variables. As well, the system is being assessed for inclusion of geocoding for all records.		
	Hired a full time position to manage system		
	We notify CDC when we identify bugs in the HHLPSS system but we can't fix them. We're developing more custom queries for reports that are not pre-set in HHLPSS.		
Total		35	100.0

Table A2-7: Modifications to child systems to include adult information (20 jurisdictions)

MODIFICATION CATEGORIES	MODIFICATION NARRATIVE	N	%
Variables added or modified		9	45.0
	Added variables associated with adults (e.g., OSHA involved in investigation, testing part of employee program, etc.)		
	Child and adult blood lead data have always been in the same information system. Employer and pregnancy information is currently stored in a note field. However, this is a work around until we are able to implement Maven.		
	Employer information, employee job description, hobby related information, and take-home lead exposure in children.		
	Had to add fields to capture employer, NAICS, COC, work-relatedness, non-occupational activity.		
	NAICS code variable, employer, and work relatedness		

	occupation		
	Since employer could not be recorded, input employer and occupation data into a guardian field.		
	We utilize the provider field for occupational information. We have to generate custom reports to evaluated adult information		
	No modifications were made to the current database. We simply changed the way we map adult test to capture employer information. Employer is recorded as the ordering facility for occupational lead tests.		
Database functions		3	15.0
	CDC HHLPSS application includes adult level monitoring. Adults =>10 ug/dL with occ expo exported to an Access database for case management.		
	Child cases open with a BLL >=5 mcg/dL Adult cases open at a level of 25 mcg/dL		
	Edit rhapsody route to all all positive lead ELR into NBS, regardless of age.		
Multiple modifications listed		1	5.0
	a. We had to add fields to accommodate data collected for adults and work-relatedness to include follow-up interviews with workers and employers and documentation of follow up b. We had to add a special data table for new employers and link it in a special way to every new blood lead. Adding Census CIC codes was a huge challenge along with NAICS because of the numerous subcategories of codes available in the Census coding system. c. We had to design special reports unique to program. d. We had to design unique follow up, to-do lists/queries for adult lead that would allow us to id cases that had missing information and or needed follow up interventions. e. We chose to add fields related to take-home lead exposure in childhood lead. Adult lead can see these cases using a workflow or query that contains cases. Adult lead then conducts follow up with parent. f. We chose to construct special tables for pregnant women that were screened for lead. This is not finished. Adult lead keeps these cases separate in analysis of adult lead cases.		
Other and unclear		5	25.0
	Ability to track all ages and may include adult and child specific data such as employer and parent/guardian as examples.		

	All blood lead tests are reportable to the state regardless of age and are sent from laboratories analyzing the blood samples to the states' data system.		
	some lab reports have name of employer, many do not		
	We can accept employer information in ELR files, but can accept additional exposure information in an electronic questionnaire within our version of HHLPSS		
	There are individual investigation forms for adult and child cases, each containing relevant variables.		
None		2	10.0
	No modifications made.		
	None. Original data application (Access) has always included both adult & child. NBS will also include both.		
Total		20	100.0

Table A2-8: Benefits to a merged data system (28 benefits listed by 21 jurisdictions)

BENEFITS CATEGORY	BENEFIT NARRATIVE	N	%
Benefits to surveillance system administration		11	39.3
	Only one data system to learn/maintain for both state & local staff,		
	Data entry is exactly the same.		
	One system to view blood lead tests and case follow-up information		
	Similar data management protocols.		
	One repository to house data.		
	Standardized data storage.		
	Streamlines the process for our lead program.		

	Primary one is that childhood lead is the gatekeeper of commercial and ELR lab data. They have experience formatting the electronic commercial lab data for kids, that will now apply to adults. Labs will send all data to them and they will upload into the new database. Consolidating this makes sense, especially since labs can send child and adult lead together. In working so close it has become clear where our programs overlap. It's not a lot, but in these select instances: take home lead exposure and use of pregnant woman data. Childhood lead also can communicate using the data system, cases with no DOB that they would like our help with, and we can assign the cases back to them is if it is a child. I guess there is some advantage in maintaining one system vs two, there is only one IT support team needed; however, with that said our tech consultation and monitoring of the system is heavy, we meet once a week likely for the life of the program. Overall, transitioning to a web-based system will eventually save a lot of data entry time for adult lead and minimize staffing costs. With that said, it is cost prohibitive and does not make sense to have 2 separate web-based systems for childhood and adult lead.		
	all cases are in one system so users only need to learn one system.		
	this integrated only in that the both adult and child info in NEDSS is on same spreadsheet		
	Less time consuming to convert adult data into another format for import into the old surveillance database.		
Identifying take home and clusters of exposures		14	50.0
	Reducing take home lead exposure and reporting		
	Better able to identify take-home lead exposure.		
	We are able to identify potential cases of take home lead to children when we manually match adults addresses to children's.		
	This would help to simplify the workload. Clusters could be identified better in households and in the community. If someone is exposed as a child and then moves to an adult age they would still be monitored in the same system.		
	One program administers the child and adult blood lead surveillance system so it is ideal to have all data in one information system. When we implement Maven, we will be able to link child and parent records, we may see more benefits in identifying exposures and offering resources.		

	Our system is particularly useful in epi-linking adult and child lead poisoning cases. The Epi-Link function is used as a tool to connect cases of reportable disease by epidemiological risks like common food, sexual contact, household contact, or other risk factor. This allows any county to view the relationships between cases of lead poisoning. The Epi-Link Results screen shows all current case-to-case relationships for that patient case. There may be other case-to-case relationships for a given person/patient because they are case, and not person, specific. This tool helps in monitoring adult and child blood lead levels associated with take-home lead poisoning to prevent further increase.		
	It has been helpful in identifying take-home exposures.		
	Identify take home exposure and common exposure sources.		
	It's been helpful for the adult lead program in terms of making the case to employers that occupational exposures go beyond the adults.		
	The single system supports use by integrated investigation staff and allows the identification of clusters involving both adult and child cases.		
	We have the ability to identify possible take-home work lead exposures of children.		
	It can assist in identifying guardians of children.		
	Follow children into adulthood, identifying take-home exposures, household clusters.		
	Allows identification of linked cases.		
Other comments		3	10.7
	Integrated systems allow us to look at all lead data in a more meaningful way and allows us to separate child and adult tests as needed.		
	Consistency		
	It is an integrated system, which should be the goal of all surveillance programs to reduce siloed systems and resources		
Total		28	100

Table A2-9: Problems encountered managing adult data within the integrated system (18 jurisdictions)

PROBLEM CATEGORY	PROBLEMS NARRATIVE	N	%
Database functionality		6	33.3
	Forgot to ensure that an elevated blood lead level did not trigger an open lead case - case management staff were confused (and reports to them complicated) when adults started appearing in notifications of an elevated "child";		
	Geocoding/address matching is not automatic, and only done ad-hoc. This leads to duplicates and difficulty identifying people in the same household.		
	The fields in HHLPSS do not include all information that we would like to see.		
	Cannot list employer addresses in HHLPSS, can't easily pull a report of employers and see all associated adults.		
	All of our ELR blood lead tests come in as "Child" and must be manually changed to "Adult", which is extremely time-consuming.		
	The new system is not as nimble to extract data from vs MS Access. Overall, judgement of new functionality is pending since the adult lead system will not go live until August 2019.		
Data reporting		3	16.7
	Incomplete data from reporters such as missing date of birth to differentiate adult from child.		
	Missing address data for some ELRs.		
	We cannot think of any problems managing adult and child data in the same information system. Our current major issues are that employer information is not always captured and/or sent by the provider and pregnancy information is not included in the ELR HL7 2.5.1 message specification.		
Other problems		2	11.1
	Local health departments are supposed to manage child cases. While the state program is supposed to manage the adult cases. This causes some confusion. Local health departments *forget* and initiate cases and they don't always tell the state program.		
	sharing PPI between adult PCP and child PCP. Obtaining consent can slow the process		
Unclear		3	16.7
	Communication between programs		

	The frequency of testing of adults who work in lead related occupations and tracking that with their occupation and potential for work relatedness in the exposure.		
	NA		
No problems		4	22.2
	No problems specifically related to integration.		
	None		
	None		
	none		
Total		18	100.0

Table A2-10 Information collected in the data system about pregnancy status of tested women (17 jurisdictions)

"Is patient pregnant" Y/N/U
A yes of no if the women is pregnant.
Check box for pregnancy status
Just current pregnancy status.
Pregnant or not
Documented in comment fields in HHLPSS: name, address, age
If sex = 'female' and patient complete voluntary blood lead test form or is successfully contacted for interview, ABLES asks if they are pregnant or planning to attempt pregnancy.
In addition to the blood lead level and the risk factor data associated with her blood lead level, if a woman is pregnant, her due date is collected.
Labs may check a "pregnant at draw" box in their reports (not sure how complete this field is). If our staff find out while investigating source of exposure that a patient was pregnant, we add this info to the record & notify our child lead program.
None. The current database does have a variable for capturing pregnancy status but this is not a variable reported by commercial labs.
Pregnancy information is captured in a notes field and not a discrete data field. Pregnancy status is not included in the current ELR HL7 2.5.1 message specification. To collect this information, we generate a monthly list of women of childbearing age with an EBLL and call the women's providers to ask if they are pregnant.
pregnancy, gestation if known
Pregnant? Breastfeeding?
Same NIOSH required variables as all other adults.
Unfortunately, not much other than "reason for screening = prenatal" (if known) all other pregnancy data must go into notes which are not useful for analyses or any kind of follow-up.

When conducting an adult exposure questionnaire, information about the pregnancy status of any household member can be collected in our version of HHLPSS.
1) If female, are you pregnant? 2) Is anyone pregnant in your household?

Table A2-11: Manual or automated systems to link adult and child cases (18 jurisdictions)

MANUAL OR AUTOMATED SYSTEMS TO LINK ADULT AND CHILD CASES	LINKAGE NARRATIVE	N	%
Automated		6	33.3
	System set-up is in progress for monthly match of geocoded addresses of last year's adults with BLL >=5 to all of last year's children. Roll-out expected fall 2019.		
	Through geocoded addresses and storage of identifiers that are present in each data management system		
	HHLPSS has association feature as well as relationship association feature		
	All cases associated with a household cluster or take-home lead are connected using the epi-link function in our database. The Epi-Link function is used as a tool to connect cases of reportable disease by epidemiological risks like common food, sexual contact, household contact, or other risk factor. This allows any county to view the relationships between cases of reportable disease. The Epi-Link Results screen shows all current case-to-case relationships for that patient case. There may be other case-to-case relationships for a given person/patient because they are case, and not person, specific. The epi-link tool is specifically useful for tracking and monitoring take-home lead poisoning cases in children.		
	We manually name and/or address match and record the employer, and then are able to run a report or look at a workflow to identify potential links to occupational exposure. When ABLES is fully integrated into our new system we will be able to link the adult to the child using a dropdown picklist from a field about children.		
	address matching algorithm.		
Manual linkage		11	61.1
	For Adults there is an interview for results of =>25 µg/dL and during the interview there are questions pertaining to whether they have children <6 in their household. If the answer to this question is yes there is a referral back to		

	the childhood lead program. This is only done for adult take home lead exposure		
	If the Child Lead Program finds that an adult in the home has an occupation which might cause take-home lead exposures, then they refer that information to the adult lead program. It is then manually entered into our adult system.		
	If patient completes voluntary blood lead test form or is successfully contacted for interview, they are asked if they have children in the home under 6yo. If 'yes', ABLES shares adult patient information with childhood program to attempt manual matching.		
	manual		
	Manual matching		
	We only do this as needed. For instance, if a child has an unknown cause the childhood lead program can search address and see if an adult also has an EBLL.		
	Automated geocoding of addresses provides info on current residents and previous residents; there is also a manual way to add "contacts" as in identify a parent or sibling etc. but it's cumbersome		
	cases are manually related		
	Manual can create an outbreak and link applicable cases		
	The system allows you to manually link cases.		
	Manual-- we can add on outbreak number to link cases.		
Unknown if manual or automated		1	5.6
	They would be linked if they are associated with the same residential address only.		
Total		18	100.0

Table A2-12: Collaborations and data sharing for joint child/adult exposure investigations (24 jurisdictions)

COLLABORATION CATEGORY	COLLABORATION NARRATIVE	N	%
Same program/staff		13	54.2
	Child and adult blood lead are managed by one program.		
	In our state, the childhood and adult lead programs are the same program.		
	In the same unit		
	It is typically the same staff doing the work on both.		
	Same bureau, same system.		

	The two programs are together.		
	same program (same staff)		
	Not necessary. The programs are exactly the same people and database.		
	We are one program. However, we do collaborate with OSHA consultation program to offer education		
	Our state's adult and child lead programs are one in the same and data are maintained in the same database. The adult program contacts adults with elevated blood lead levels greater than or equal to 10 Î¼g/dL and shares information with the child program.		
	I have a access to both childhood and adult lab reports		
	If the Child Lead Program finds that an adult in the home has an occupation which might cause take-home lead exposures, then they refer that information to the adult lead program.		
Other types of collaborations		11	45.8
	Informally as needed by investigation		
	Joint blood lead exposure investigations are periodic but not frequent. Childhood program alerts Adult lead to single or group child exposure and suspected occupational source using a to-do list or workflow in database. Adult lead can see all fields in a child case, but not alter for the most part. Adult lead sends follow up prevention information to parents/guardians and documents this in child case. If there are 2 or more children involved, adult lead contacts the employer and discusses exposure prevention and typically asks for on-site visit. We refer cases to OSHA if the employer is not compliant or childhood exposure cases persist. We get local county health departments involved for leverage with employers if necessary. Data is not shared a lot. If we need to describe a problem or trends, data is manually extracted, summarized in tables or graphs and shared via email. Our database is not nimble enough to do this on its own, at least not yet. The original intent of the database template we use was for managing insurance data.		
	Meetings, use of same databases		
	Most of our collaborations center around contaminated product use that is impacting the blood lead levels of the parent and children. We also collaborate on pregnant women cases.		
	Our adult lead manager also participates in the childhood program and has access to HHLPSS		
	Phone calls and emails to discuss exposure and investigation status. ABLES provided a copy of the completed questionnaire and provider information.		

	The case data is available to anyone in the jurisdiction (i.e. county) who has access to the lead module. So they can see adult and child cases. You can also make other people "contacts" with a case. So, for example, if there are a number of people who are in the same household they can be made "contacts" and it's easy to see who they are, whether they are a case and any blood lead tests they have received.		
	The most frequent collaboration is when the occupational health surveillance unit interviews an adult with an EBLL to determine if it is a work-related exposure and determines there are children present in the home. The OHS unit refers the address/name to the childhood lead program (CLP). Much less frequently, CLP has reached out when a child age 16 and 17 has an EBLL or suspected exposure of take-home lead from a parental occupational exposure.		
	We collaborate through in-person meetings, by telephone. Both Childhood and Adult Lead Programs have access to the data so sharing is easily performed as we can both go into the MAVEN system and view data.		
	We have done a few joint investigations, e.g. firing range where both kids & adults were exposed, take-home exposure cases.		
	We shared the results of adult blood lead and child blood lead data analysis and the sharing of findings allowed us to identify similar clusters between adult blood lead and child blood lead cases.		
Total		24	100.0

Table A2-13: Data linkage variables for joint exposure investigations (22 jurisdictions)

LINKAGE VARIABLES CATEGORY	LINKAGE VARIABLES NARRATIVE	N	%
Includes address		16	72.7
	what variables were used to link child and adult during exposure invest		
	name, address and birthdate		
	Once we have shared address/name for referral we have not linked the cases formally		
	Unique identifiers, addresses, and demographics		
	Adult name, address, phone number, DOB, Guardian Info.		
	Home address, first and last names, DOB		
	Last name and addresses		
	Address information		

	Address, Last Name		
	For ongoing project, linking on probabilistic match of address. Previous investigations simply got child contacts from the adults themselves.		
	A child's EBBL may trigger additional testing for family members. We can use addresses to search through records, but often if multiple family members have an EBLL, we will be made aware of the situation by the clinic or local public health.		
	Addresses, parent or guardian names		
	1. Child's address at time of test. We need to check that date of address is around the same time as the address that we have for the employee. 2. Child's Last name (less reliable) 3. We also have an Occupational Exposure “Definite" field and a space to designate Company name. Both are manually entered, based on positive environmental lab results 4. We also have an Occupational Exposure “Possible" field and a space to designate Company name. Both are manually entered, based on information from interviews. If the company name matches and there is no other information, we can link a child based on this.		
	Address, last name, etc.		
	Address, name.		
	Address and jurisdiction.		
	Address and guardian information that is received with blood lead tests on children.		
Other linkages		6	27.3
	CountyExp		
	Manual link based on knowledge from the cases.		
	Integrated demographic info that is auto loaded from birth data supplied by Vital Records. Manual look-ups in Medicaid for other parent-child links.		
	Cases are not automatically linked		
	Home visit and screening data is used connected to adult blood lead data. Linking is done without the use of the current database.		
	Links between adults and children is not an automated process. Most of the time the connections are made based on the outcome of either an adult or a child case investigation. For example, through the child case investigation we get the father's name. We look it up and find that he has test results (and often is a case). At that point we make the link between the two cases.		
Total		22	100.0

Table A2-14: "What would have made the data sharing and coordination process work better for joint exposure investigations" (21 jurisdictions)

DATA SHARING/COORDINATION CATEGORY	DATA SHARING/COORDINATION NARRATIVE	N	%
Data variables/functionality changes		15	71.4
	A combined database with all environmental investigation information; a designated group of individuals for case review		
	A database better suited for linking data and capturing adult related lead exposures.		
	A well-integrated single system		
	Automated address geocoding or matching.		
	Case notes in same system		
	Databases that "talk to" each other		
	Having a single system that combines both registries		
	HHLPSS to be modified to include all adult and occupation information		
	If local public health could access our database (special permissions).		
	It would be great if there was the system could automatically link cases based on street address information. This is something that has been on the "wish list" for awhile.		
	same database		
	System users can currently only see the cases occurring in their jurisdiction, should that view be expanded it could enhance coordination. Summary reports would also be useful.		
	The adult lead data may not have a home address, so it might be difficult in some cases to confirm that the person with a lead test is the same one as referred by the Child Lead Program. And some adults do not provide a full date of birth to Child Lead or agree that their personal information may be shared.		
	We don't need to share that much. Some function to link kids to parents automatically would be nice, but this would be difficult in the current system.		
	we need a formal lead data system instead of just having the info on an excel spreadsheet		

Other or none		6	28.6
	Better Social Services - Medicaid integration.		
	It perfected sufficed as is.		
	N/A		
	NA		
	None		
	Nothing		
Total		21	100.0

Table A2-15: Missing variables related to joint exposure investigations (11 jurisdictions)

Exposure source. Also, increased testing of children statewide.
For Adult data = names and dates of birth of children of employees, street address For Childhood data = street address
Home address; Employer and/or occupations of all adults in the home; hobbies, i.e. indoor target shooting
Missing address information and the absence of a master address index are barriers.
Nothing stands out as lacking. Pregnancy status at time of blood lead test report would be helpful. Occupation would also be helpful. Nevertheless, we follow up with individuals and health care providers to
Occupation and employer information for adults
Physicians observations and findings.
Reason for blood lead draw/test is not reported. Accurate contact information with each blood lead test would improve our contact rates.
The ability to capture exposures in discrete data fields.
We cannot look for children who share the same home address & see if they have been tested.

Table A2-16: "Other" limitations of the adult system (9 jurisdictions)

OTHER LIMITATION TYPE	OTHER LIMITATION NARRATIVE	N	%
Database variables		3	33.3
	Census occupational codes are not captured in Merlin.		
	Limited information from reporters		
	It is difficult to call each adult or their provider to understand what their exposure to lead is. Very time consuming.		
Database functionality		2	22.2

	No link between Adult and Child for common Lead exposure		
	Issues with linking certain variables (if more than one blood lead test or home address)		
Resources		3	33.3
	The adult lead programs does not have any budget.		
	We are about to convert to a new system with some improvements built in, but this has been a long time in coming (requiring substantial resources)		
	We receive no funding for Adult Blood		
Multiple		1	11.1
	Same as child surveillance limitations. Lack of support at national level for public health informatics in blood lead surveillance programs. A workgroup that involves the states should be created for any changes to data standards and to facilitate state collaboration. Difficult to cross train due to data being received in multiple formats and timelines. Current information system is not fully supported by state IT. Inability to link family members and properties within the information system. Local public health cannot access the information system. All communication with local public health is done by email or phone. No automated work queues or alerts for case management. All data must be manually entered or manually batch uploaded. Home risk assessment data is entered by a separate unit in the health department and data is stored as a Word document, not individual data fields.		
Total		9	99.9*

*Percentages do not total 100% due to rounding

Table A2-17: Leading adult surveillance system limitation (32 jurisdictions)

LEADING LIMITATION CATEGORY	LEADING LIMITATION NARRATIVE	N	%
Database functionality		11	34.4
	De-duplication of repeat cases with incorrect spelling of names/DOB requires manual merging of cases which is time consuming		
	Difficult and/or time consuming to get database application problems fixed when they are identified		
	Difficult to get application problems fixed as it's an in-house system. We redesigned the system for HL7 feed and incorporated updated QA/reporting features. This is difficult to maintain with no IT staff.		

	Difficult to get database problems fixed when they are identified.		
	Inability to automatically link a child Lead exposure to possible Adult take home Lead source.		
	server problems create slow system processing.		
	Our database is currently only set up to incorporate BLLs of 10+ but for national surveillance purposes we need to incorporate 5+		
	Queries for generating reports do not meet all state data needs		
	query system and address geocoding system		
	System getting old(er), looking at potential replacement with one that betters address future meaningful use requirements.		
	The missing variables are not the issue. It is gathering the data for the variables that is time consuming because they are not added in the reporting system to the state.		
Funding/staffing		7	21.9
	funding		
	Funding and missing variables.		
	I think the resource-intensive effort to identify employers and industries, or for non-occ cases, the source of lead exposure, is our biggest challenge in additional to the very large volume of reports. We cannot obtain this info for reports <10 ug/dL so for these lower levels we cannot say if they are occ or non-occ. We really cannot describe the overall picture of BLLs, just what we know about those at or above 10 on which we can obtain lead exposure info.		
	No funding		
	Requires a lot of staff time to maintain and enhance		
	Staff time limitations for maintenance, development and training		
	Will continue to include the need [i.e., system expensive to maintain] in all requests for funding		
Missing variables		10	31.3
	Census occupational codes are not captured. Some national data variables are not captured (for e.g, country of birth)		
	Due to the missing variables listed above, we have to export the data set to Excel, manually code the information, and call clinics to collect missing information. This makes the ABLES summary a tedious process.		
	important variables for adult lead surveillance are missing		
	Lack of addresses for some ELRs and geocoding.		
	Limited information from reporters		

	Missing exposure variables & time-consuming to enter/update data.		
	Missing variables include adult sources		
	Pregnancy Status		
	The missing address is the most limiting to our program.		
	The missing adult variables require work arounds which require considerable staff time and effort to input and maintain.		
Other/unknown		4	12.5
	No state laws requiring and low voluntary reporting of employer name or contact; industry; occupation; source, nature, or details of exposure.		
	None		
	N/A		
	Unknown		
Total		32	100.1*

*Percentages do not total 100% due to rounding

Table A2-18: Missing variables in adult systems (14 jurisdictions)

Occupation, Employer and addresses (demographical information).
Missing variables include adult sources of exposure and occupation/employer.
Industry codes
We have a work-related variable but a choice for "both" is missing (been waiting for it for years); also have an issue with differing race variables
Employer information and NAICS codes, whether the exposure was work or hobby related, pregnancy status.
All exposure source variables missing from Access--exposure is an open text field.
Employer, employer addresses, occupation - All would need to be able to be associated with a blood lead test and not just the patient in case employer/occupation changes.
Though we have a field for employer info, it is often not completed by labs & substantial resources are needed to fill in missing info. We also have to code employer's industry which is resource-intensive. There may be other variables that would be helpful (I'm filling in for epi who retired abruptly)
As reported by labs, adult test reports do not contain employer name or contact; industry; occupation; source, nature, or details of exposure.
StateRep2, StateExp, CountyExp, Status, Ethnicity, Race, WorkRel, NAICS Year, NAICS, COC Year, COC, Process

Employer, occupation and home address variables are there but they are often not populated by the healthcare providers.
Pregnancy status
Many
None

Table A2-19: Efforts to address identified limitations in adult systems (23 jurisdictions)

CATEGORIES OF LIMITATIONS ADDRESSED	ADDRESS LIMITATIONS NARRATIVE	N	%
Budget/staffing		2	8.7
	When we hire our new occupational health epi - these items will get addressed.		
	Will continue to include the need [for more funding] in all requests for funding		
Data reporting		4	17.4
	The system is set up to merge based on DOB, address, etc but the lab data submitted often has many data entry errors in personal information resulting in staff having to merge manually.		
	Actively working with reporters to improve the quality of the reported data.		
	Working to modify reporting requirements associated with adult lead tests. Working to identify and access other sources of these data.		
	The state is working to make lead exposure a state reportable disease		
Data system functionality		8	34.8
	ABLES program has been working since June 2019 to make the database smaller and more simplified. The database is not running faster		
	Adult lead staff is currently working with IT staff to resolves ongoing issues.		
	CDC HHLPSS and NIOSH are collaborating on ways to update HHLPSS with mandatory adult data required by NIOSH.		
	IT staff work on errors and constantly maintain and address problems when they are identified		

	We are developing an integrated backend application to automate the receipt, processing and management of incoming data. We are also developing a process to ensure consistency and integrity of data across databases		
	Working with Conduent [Maven]on specific issues and also to improve their overall responsiveness.		
	We are currently working with HIV/STD/HAP to reformat the HL7s according to our specifications after they changed their system. We are also looking at other possible systems to consider for future use.		
	We have custom reports made from a download of HHLPSS data.		
Exploring or building a new system			
	A new in-house lead database is being created.	5	21.7
	Exploring potential software replacements, but only casually looking now because we are currently in the process of replacing the Immunization system.		
	Have an active project to implement Maven by 2021 which will include data fields for the missing variables. We hired an informatics staff to assist with standardizing reporting and HL7 onboarding. We may also explore storing risk assessment data as individual data fields rather than Word documents.		
	Switch to NBS.		
	We're hoping our new system will streamline some aspects. Also need to fill key positions (program chief, lead epi) before we can address improving the system.		
No efforts underway		3	13.0
	No		
	No funding available to improve/enhance the adult blood lead surveillance and missing variables.		
	None are underway.		
Other		1	4.3
	We are trying to look at a better system of keeping track of adults but calling providers on each case is still an barrier.		
Total		23	99.9*

*Percentages do not total 100% due to rounding

Table A2-20: Examples of the state's blood lead requirements that would need to be met to consider an integrated system (7 jurisdictions)

Must be able to upload HL7 messages; must have automated assignment of latitude/longitude coordinates to addresses; must have ability to collect all NIOSH/ABLES required variables; must have a migration package that will allow us to bring historic adult data into the new system.
Ability to link adult cases and children together. HL7 Importing. Advanced reporting out of the application that would meet all grant reporting requirements
Must be able to track case management and environmental services, and need to be able to query easily for reports
Must be able to add attachments/PDF documents, do direct data entry, upload a variety of file formats, customize/add variables
Be able to bi-directional interface with Vital Records, Immunizations, Chronic, etc.
HL7 and able to upload from spreadsheets, manual option for mail entries.
An upgrade to HHLPSS that has all fields and needed information for adult exposure

Table A2-21: Other comments (12 jurisdictions)

Childhood Lead will continue to use HHLPSS. No ABLES program but use NBS to store adult BLLs reported electronically by labs and submit to NIOSH.
For the adult, lead is included in a heavy metal poisoning Registry which also includes arsenic, cadmium and mercury.
Too soon for the pediatric lead program to effectively evaluate our new application and the potential for building and expanding on its core functionality to cover other work-flow and programs; however, it was designed to provide robust flexibility and configuration with potential for incorporating other needs. The adult lead program stated that the following would need to be in place to consider an integrated application: 1) funding (estimate initial conversion/installation and annual maintenance costs), 2) must meet state's office of technology requirements, 3) must meet state's blood lead data requirements, 4) must meet operational requirements of both programs. In addition, it must be able to accept HL7 messages, have a secure connection, must be automatic with no manual interactions, must be able to run standard and custom reports, and must be web-based and accessible from anywhere.
Labs and clinics using LeadCare machines report results via fax (manual input), Email (electronically uploaded), and the online portal (electronically uploaded). Lab results are electronically uploaded via HL7. I am uncertain of the percentage breakdown among these input methods. Our database development team would be better able to provide this information.

Meets Meaningful Use requirements! Ability to integrate with other programs, shares common demographic components.
Our system collects all blood lead levels no matter the age.
Need a budget support
NIOSH ceased funding for our ABLES program. We continue to monitor high adult blood leads and pass data along to our state's workplace safety program. We periodically link with childhood blood lead data. But counts of work-related elevated blood leads are low and thus we cannot justify applying significant resources to better integrate the child and adult blood lead surveillance and have little interest in doing so.
Several years were spent by our programs to accept inbound HL7 data, bring HHLPSS online, and update our adult data system. The new application would have to offer significant functional advantages for us to convert to an integrated system.
The CDC already offers HHLPSS and NEDSS. We are unsure how this solution would be different or better than what is already offered. HHLPSS, NEDSS, and Maven are already sufficient options for information systems. Forming a collaborative state workgroup with state representation and informatics subject matter experts to update standards, identify solutions, and collaborate may be a better use of resources.
The feasibility of integrating the current state system and the developing surveillance data application.
Our state's Environmental Public Health Tracking Program is currently acting as a data steward for conducting adult lead surveillance. The Tracking program and National Network should be consulted as to best practices for data collection and reporting.
This would be difficult for us since our HL7s also contain other heavy metals (arsenic, cadmium, mercury) and carbon monoxide tests. We track all of these so any system that we use must be able to process those tests as well.
understand that right now we are doing the absolute minimum
We are mandated by our agency (DOH)to use the MAVEN system with all other notifiable conditions. They will not support separate surveillance systems. ABLES is not in DOH and therefore uses its own system (Access) for adults
We don't believe siloing the data system is going to help health departments. We think a better approach would be to have integrated tools that will enhance the capacity to identity clusters, enhance ELR or ECR, or establish ways to communicate across systems.

Appendix 3: United State Census Bureau Regions

Table A3-1: Four Statistical Regions of United States Census Bureau

Region 1: Northeast	Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont, New Jersey, New York, and Pennsylvania
Region 2: Midwest	Illinois, Indiana, Michigan, Ohio, Wisconsin, Iowa, Kansas, Minnesota, Missouri, Nebraska, North Dakota, and South Dakota
Region 3: South	Delaware, Florida, Georgia, Maryland, North Carolina, South Carolina, Virginia, District of Columbia, West Virginia, Alabama, Kentucky, Mississippi, Tennessee, Arkansas, Louisiana, Oklahoma, and Texas
Region 4: West	Arizona, Colorado, Idaho, Montana, Nevada, New Mexico, Utah, Wyoming, Alaska, California, Hawaii, Oregon, and Washington

Appendix 4: Limitation Types by Child Data Management Systems

Table A4-1: Number/percent of limitation types by child data management systems

LIMITATION TYPE	CUSTOM WEB-BASED APP (N=11)		ACCESS OR ANOTHER RELATIONAL DATABASE (N=6)		HHLPSS (N=12)		INCORPORATED INTO ELECTRONIC COMMUNICABLE DISEASE SURVEILLANCE DATA APP NOT NEDSS (N=9)		INCORPORATED AS A MODULE INTO NEDSS BASED SYSTEM (NBS) FOR COMMUNICABLE DISEASE (N=8)		OTHER (N=4)		TOTAL (N=50)	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Expensive to maintain	3	27.3	1	16.7	3	25.0	4	44.4	2	25.0	2	50.0	15	30.0
Budget limitations prevent improvements	5	45.5	3	50.0	0	0.0	2	22.2	1	12.5	3	75.0	14	28.0
Requires a lot of staff time to support user help desk	1	9.1	2	33.3	3	25.0	5	55.6	1	12.5	2	50.0	14	28.0
Difficult to get database application problems fixed	3	27.3	2	33.3	6	50.0	2	22.2	1	12.5	2	50.0	16	32.0
Difficult for users to learn	1	9.1	1	16.7	1	8.3	2	22.2	0	0.0	2	50.0	7	14.0
Time consuming for users to update data	2	18.2	4	66.7	7	58.3	0	0.0	0	0.0	1	25.0	14	28.0
Exposure coding systems doesn't capture all sources of exposure	2	18.2	4	66.7	3	25.0	3	33.3	2	25.0	1	25.0	15	30.0
Address geocoding and/or mapping functions not available	3	27.3	4	66.7	1	8.3	3	33.3	6	75.0	2	50.0	19	38.0
No algorithms to identify potential clusters	4	36.4	6	100.0	4	33.3	6	66.7	6	75.0	2	50.0	28	56.0
National data standards not met for some variables	1	9.1	2	33.3	0	0.0	0	0.0	3	37.5	2	50.0	8	16.0
Variables important for child surveillance missing	2	18.2	5	83.3	2	16.7	1	11.1	1	12.5	2	50.0	13	26.0
Limited pre-set queries for generating reports	3	27.3	3	50.0	10	83.3	2	22.2	2	25.0	3	75.0	23	46.0

Queries for generating reports do not meet all state needs	5	45.5	1	16.7	6	50.0	1	11.1	1	12.5	2	50.0	16	32.0
Custom queries difficult/impossible to conduct	2	18.2		0.0	4	33.3	2	22.2	2	25.0	2	50.0	12	24.0
Difficult to export data to excel or other format	2	18.2	1	16.7	0	0.0	0	0.0	1	12.5	2	50.0	6	12.0
Difficult to export data for reporting to CDC	1	9.1	1	16.7	1	8.3	2	22.2	1	12.5	1	25.0	7	14.0
Other	4	36.4	3	50.0	2	16.7	2	22.2	3	37.5	1	25.0	15	30.0