



# PA NEDSS, ACHD & You FAQs

## **What is PA NEDSS?**

PA NEDSS is the Pennsylvania National Electronic Disease Surveillance System. It is the Pennsylvania Department of Health's (PA DOH) state data system that is used for the reporting of diseases and investigating findings on a 24/7 basis. It is a secure, on-line tool that provides a means of compiling and analyzing information on diseases and other health issues. Reporting agencies include healthcare facilities, physicians, laboratories, and more.

As just one example, and the relevant one in this instance, the results of any blood tests for lead of any child in the Commonwealth must be reported to the PA DOH. The laboratory performing the test(s) input the data into the PA NEDSS database, typically through an electronic data interchange.

## **How is PA NEDSS used by Allegheny County?**

The Allegheny County Health Department (ACHD), using a code, is able to extract county-specific lead test data that can help ACHD see what's going on in the county as it relates to trends. Just last year, there were over 20,000 county-specific blood lead records input into PA NEDSS. ACHD can extract data for certain blood lead levels so that remedial action can be taken, and resources provided, as appropriate to those children and families. The data has also been used as a basis for ACHD's lead reports.

## **When did ACHD realize the agency was not receiving correct data?**

In December 2018, PA DOH released its 2016 and 2017 lead reports. When comparing the numbers, there was a clear difference. Staff began pouring through the reports and data and quickly identified a systemic error, as well as discrepancies in how data was being input that impacted ACHD's numbers.

## **So, what does that mean?**

Data being input by providers was not being provided in a consistent way. Because of that, it affected how the data was subsequently reported out. Instead of a key piece of information – whether a test was venous or capillary – being part of the data report, that information was instead found in the comments section. Because ACHD reports only search for specimen type, any report missing this designation was not included in the ACHD data that was extracted.

Although the systemic error affected reporting, ACHD housing inspectors get the information in real time about the children with levels of 10ug/dL and above so if the information was missing for these children, ACHD's lead inspectors called the doctor to verify the type of blood lead test and followed up accordingly.

## **Has this error resulted in children not being treated, or lead exposure not being addressed?**

No. For all individual children, the results of the blood lead level tests would have been provided directly to the treating physician for appropriate follow-up.

As noted, ACHD housing inspectors got the information in real time from PA NEDSS about the children with levels of 10 ug/dL and above and If the information was missing for these children, ACHD's lead inspectors called the doctor to verify the type of blood lead test and followed up accordingly.

ACHD worked with the state to revise the data extraction code and identify all children with confirmed levels of 5-9.9 ug/dL, that were missed since June 2018 (the point at which ACHD began lead investigations for this population). ACHD staff contacted the families of all these children to ensure that they have follow-up blood tests if the last test was older than three months. If follow-up tests were elevated, a home investigation to identify the source of lead will be conducted. ACHD staff has also offered home investigations to those whose test was less than three months old. All of this work has been accomplished since finding the error.

### **Is this going to continue to happen?**

The county has rigorously reviewed data for this time period to ensure the issue has been resolved. With the corrected extraction code, the needed data should be available to ACHD. ACHD has also worked with PA DOH to make sure results are comparable. ACHD also worked with the laboratories that were inputting the data in different forms to correct the error going forward.

It is important to note that PA DOH is continuously improving so it is possible that additional changes could happen in the future. ACHD will stay in close contact with PA DOH to make sure that these changes are reflected in future extractions.

### **Why are there still minor differences in the state and county data?**

ACHD only reports information on venous tests since these are the children that are eligible to receive investigation for lead exposure. while PA DOH reports data on venous tests and also on double capillaries for CDC reporting purposes.

### **Is ACHD still making progress on addressing lead level cases in the county?**

While the numbers of children exposed are somewhat higher, the rates of exposed children continue to demonstrate a downward trend. The new data has been posted on the ACHD website.

### **Did ACHD share this information with everyone?**

ACHD staff immediately reached out to the PA DOH to discuss the issue and work cooperatively with the department to correct the systemic errors. Once laboratories that were inputting information were identified, the department also reached out to those entities to try to address the input errors. Those conversations have been ongoing.

Additionally, ACHD has reached out to all impacted families not already identified and has worked closely with partners including Women for a Healthy Environment, Conservation Consultants Inc, and Allies for Children to work through the issue and solutions, and to ensure that nothing was overlooked in the response.

### **Is this all that ACHD is doing about elevated blood lead levels, and lead exposure?**

ACHD and its partners are committed to decreasing lead exposure through primary prevention and intervention. To date, those efforts include passing a universal lead testing ordinance; following children who have been tested by linking testing data to birth certificate data; leading a Lead Task Force to produce recommendations; producing the first annual childhood blood lead report; implementing blood lead testing at three Health Department sites; providing educational materials to families in multiple languages; working on a model ordinance for lead-safe lead-free housing; and obtaining funding to expand capacity for investigation and to support the community lead coalition.