Getting the Reporting Right: Improving PA's Lead Poisoning Surveillance Data Sharing

To ensure appropriate resources are directed to reduce the incidence of childhood lead exposure and poisoning, the Commonwealth annually publishes a Childhood Lead Surveillance report. The reports for 2016 and 2017 were released in December 2018. These reports provide useful raw data that show that nearly 10,000 children are still testing positive for lead poisoning annually. Most troubling is:

- Since the Flint water crisis, Pennsylvania hasn't made much progress in protecting children from the toxic effects of lead. In 2017, 9,325 children tested positive for lead poisoning; in 2015, that number was 9,643.
- Pennsylvania has the 2nd largest number of children testing positive for lead poisoning among states that reported to the CDC, and of the top 10 states with the most children poisoned, Pennsylvania ranks second worst for testing.

However, the reports don't tell us enough to fully inform decisions that can result in significantly more resources being deployed effectively to save children from the lifelong consequences of lead poisoning.

Key Findings

The latest Pennsylvania Department of Health Childhood Lead Surveillance Reports for 2016 and 2017 indicate that the Commonwealth must improve its collection and reporting of lead surveillance data to better inform policy and demonstrate adherence to best practices and legal requirements. Needed improvements include:

+ Reporting on data in a way that indicates if health care providers are following the Center for Disease Control and Prevention's (CDC) recommended lead screening protocol and if the state itself is complying with the legal mandate to ensure children on Medicaid and CHIP are tested appropriately.
+ Collecting and reporting data on the incidence of lead poisoning by race.
+ Providing data about the state's largest population centers where an overwhelming share of the children at risk and poisoned live.
+ Summarizing and comparing its data to inform policy makers and gauge the Commonwealth's progress.

public citizens for children + youth

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The Status of Childhood Lead Poisoning in Pennsylvania

+ Since the Flint water crisis, Pennsylvania hasn't made much progress in protecting children from the toxic effects of lead. In 2017, 9,325 children tested positive for lead poisoning; in 2015, that number was 9,643.

+ Pennsylvania has the 2nd largest number of children testing positive for lead poisoning among states that reported to the CDC, and of the top 10 states with the most children poisoned, Pennsylvania ranks second worst for testing.

+ Of the nearly 300,000 children in Pennsylvania under two years old, less than 30% were tested for exposure to lead even once in 2017.[1] No data is provided to indicate the share of children tested in accordance with the Centers for Medicare and Medicaid Services (CMS) protocol of two tests by the time a child is two years old.

+ For the approximately 850,000 children under six, the share of ever tested for lead is alarmingly low at 18.5%. Compared to 2016, an additional 5,579 children were tested, a less than 1% increase in the share tested.

+ 3,816 children two or under tested positive for lead poisoning in 2017. Fortunately, with slightly more children tested from 2016 to 2017, the number of young children testing positive for lead poisoning dropped by 343 children.

+ Both the share of children tested and share of children poisoned by lead was relatively consistent between urban and rural areas. Approximately 15% of the children in rural Pennsylvania were screened for lead exposure; nearly 4% tested positive for lead poisoning. In urban areas, just over 18.5% of children were tested and just shy of 5% tested positive.

+ The Commonwealth cannot identify the race of more than half of the children tested and it does not provide data on the race of children testing positive for lead poisoning. With respect to testing, where a child's race is known for 45% of all tests, 13% of the children were Black, less than 3% were Asian, 30% were White; there is no data for what share of children tested are Hispanic. For reference, low income children are at greatest risk of lead poisoning. In Pennsylvania Black children account for 37% of all poor children, 14% are Asian and 40% are Hispanic.[2]

+ 81% of children two or under who tested positive had blood lead levels of 5 to 9.9. Another 19.6% had levels between 10 and 19.9. The balance of the children, far less than 1%, tested positive with levels higher than 19.9.

+ Although research indicates that children on Medicaid and CHIP are at greatest risk of being poisoned by lead, no data is available in the Pennsylvania Department of Health's reporting on what share of children in these state-managed public insurance programs are tested and identified with elevated blood lead levels.

The Pennsylvania Department of Public Health is to be commended for its effort to improve the accuracy of childhood lead screening and incidence reporting. The 2016 and 2017 reports demonstrate that the Department is arduously improving its data collection efforts and making strides toward greater transparency.[3] However, significant improvement to the reporting can ensure that limited public funds are wisely spent to prevent lead poisoning and to care for all the children likely to be suffering the effects of exposure to one of the most harmful toxins for children.

Finding #1

Pennsylvania is not reporting on data in a way that indicates if health care providers are following the CDC recommended lead screening protocol or if the state itself is complying with the legal mandate to guarantee that children on Medicaid and CHIP are tested appropriately.

The Center for Disease Control and Prevention has found that lead exposure poses a significant threat to children.[4] Experts point out that "even small amounts of lead can cause very serious harm to the brain and other parts of the nervous system. Lead in a child's body can slow down growth and development, damage hearing and speech, cause behavior problems and make it harder to pay attention and learn."[5]

As a result of the risk that lead poses to young children, the Centers for Disease Control issued guidance that all children at risk of lead exposure should be screened at ages 1 and 2. This guidance is based on the research that finds that young children regularly put most things they find in their mouth and as a result infants and toddlers are more likely than other children to ingest the lead. Further, because the neurological system goes through rapid development in a child's first two years of life, even the smallest amount of lead has been found to have the potential to negatively effect that development.

Based on this CDC guidance, the federally funded Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit in Medicaid requires states as the administrators of these funds to comply with the CDC protocol.[6,7] States do so by requiring Medicaid health care providers to test children at least twice by their second birthday. Further, Pennsylvania also requires its CHIP providers to employ this testing protocol.[8] While private insurers are not required to cover the costs of such testing in Pennsylvania, the American Academy of Pediatrics recommends that all pediatricians follow this testing protocol and pediatricians are routinely paid for this service and the laboratory fees are also covered by the insurers.[9]

The state's most recent release of both the CY 2016 and CY 2017 Lead Surveillance Reports provides some data that helps us understand if children are being tested and what the rate of childhood lead poisoning might be. However, the state's approach to capturing and reporting the data is limited, and as result, it's not possible to accurately assess how well those protocols are being followed and worse yet whether our public health strategies are doing enough to protect children from being poisoned by lead.

Recommendation: PCCY recommends that the Pennsylvania Department of Health improve its reporting to demonstrate compliance with these protocols by:

> ***Recommendation #1: Report state and county level data on the share and number of young children tested for lead exposure in a cohort model, so that it's possible to asses if the CDC protocol of testing children twice before they are two is being followed. Provide the cohort data for all children and separately for children enrolled in Medicaid and CHIP.***

We recognized that parents and providers may not be able make all medical appointments before a child's second birthday. In practice health care appointments may slip. As such, to present a complete picture and to reflect on the ground experience with compliance, we recommend that this cohort approach follow a child until they turn three (36 months); doing so will present a more accurate picture of whether every child is being tested twice as the protocol requires. PCCY proposes a simple way to categorize the data as follows:

Report data on how many children are screened at both ages 1 and 2 for each birth cohort, including data specifically for children on Medicaid with the same approach used to present the CHIP data.

Total Birth Cohort			
Total Birth Cohort	Total Screened at age 1 (9 – 24 months)	Total Screened at age 2 (25 – 36 months)	Total Screened at ages 1 & 2
2015	X%	X%	X%
2014	X%	X%	X%
2013	X%	X%	X%

Medicaid Cohort			
Total Birth Cohort	Children on Medicaid Screened at age 1	Children on Medicaid Screened at age 2	Children on Medicaid Screened at ages 1 and 2
2015	X%	X%	X%
2014	X%	X%	X%
2013	X%	X%	X%

CHIP Cohort			
Total Birth Cohort	Children on CHIP Screened at age 1	Children on CHIP Screened at age 2	Children on CHIP Screened at ages 1 and 2
2015	X%	X%	X%
2014	X%	X%	X%
2013	X%	X%	X%

Recommendation #2: Further, we recommend that the report include similar cohort data detailing the screening and lead poisoning incidence for children on CHIP and Medicaid, disaggregated by each public insurance program. The Commonwealth spends nearly $29 billion in its Medicaid and CHIP programs.[10] In doing so the legislature and the public expect the Commonwealth and the providers and insurers it contracts with to screen children appropriately for lead exposure. By presenting the data by public insurance program, the taxpayers and lawmakers can better assess if their expectations are being met. Similarly, the Department of Human Services' oversight of its providers and insurers will be improved by annually disaggregating the state by Medicaid provider and CHIP insurer.

Recommendation #3: Report data on both the number of children who were newly poisoned each year and the total number that were poisoned each year for each age group. Lead tests are used to screen children and to conduct follow up on children previously diagnosed. Differentiating between these groups of children will allow policymakers to monitor changes among children newly diagnosed and the total number of poisoned children that exist in the population to apply best practices and the necessary resources to work towards reducing the condition.

Newly Poisoned Children					
Year		<3 years old	3 - 6 years old	7+ years old	Total
2016	Raw #				
2016	Percentage				
2015	Raw #				
2015	Percentage				

Total Poisoned Children					
Year		<3 years old	3 - 6 years old	7+ years old	Total
2016	Raw #				
2016	Percentage				
2015	Raw #				
2015	Percentage				

Finding #2

Pennsylvania is not adequately collecting data on the incidence of lead poisoning by race.

While lead does not discriminate, its harmful effects can have the same impact on children regardless of race. Yet national data indicates that low income and minority children are significantly more at risk of suffering from lead poisoning than their White counterparts.[11,12] With respect to the numbers and share of kids screened for lead, the Pennsylvania Department of Health reports indicated that the race of the child is known for only 45% of all lead screens. Of those screens where the race of child is known, 13% of the children tested are African American. Meanwhile, we know that the share of low-income children who are Black is nearly three times that rate, and Black children account for 42% of the children on Medicaid and CHIP.

Pennsylvania Child Ethnicity and Race				
	2017 Lead Screening Under Six[13]	Medicaid[14]	CHIP[15]	PA (from US Census)[16]
Hispanic/Latino	NA	17%	12.10%	7.30%
Not Hispanic/ Latino	NA	83%	76.7	76.5%
White alone	29%	53%	62%	82.10%
Black or African American	13%	27%	15.10%	11.90%
American Indian/ Alaska native	NA	<1%	0.20%	0.40%
Asian alone	2%	3%	4.20%	3.60%
Native Hawaiian & other	1%	<1%	0.10%	0.10%
Two or more races	NA	NA	1.10%	1.90%
Unknown	55%	NA	NA	NA

There may be several explanations for the under-representation of Black children in the screening data, including:

+ The other 55% of children where the race isn't known could be heavily concentrated with Black children.
+ If screening data was disaggregated by Medicaid and CHIP it might show that the Black children tested comprise a very large portion of the children at-risk evidenced by their enrollment in Medicaid or CHIP and therefore the Black children most at-risk are being screened.
+ Providers are doing a poor job ensuring Black children are being screened.

Equally troubling is the lack of data on the share of Asian American and Hispanic children.

Recommendation #4: Capture and report data on screening and BLL results by race for every child tested. Public health measures are most effective when public funds are deployed strategically and efficiently. A thorough presentation of the screening and incidence data by race will significantly improve outreach and prevention strategies.

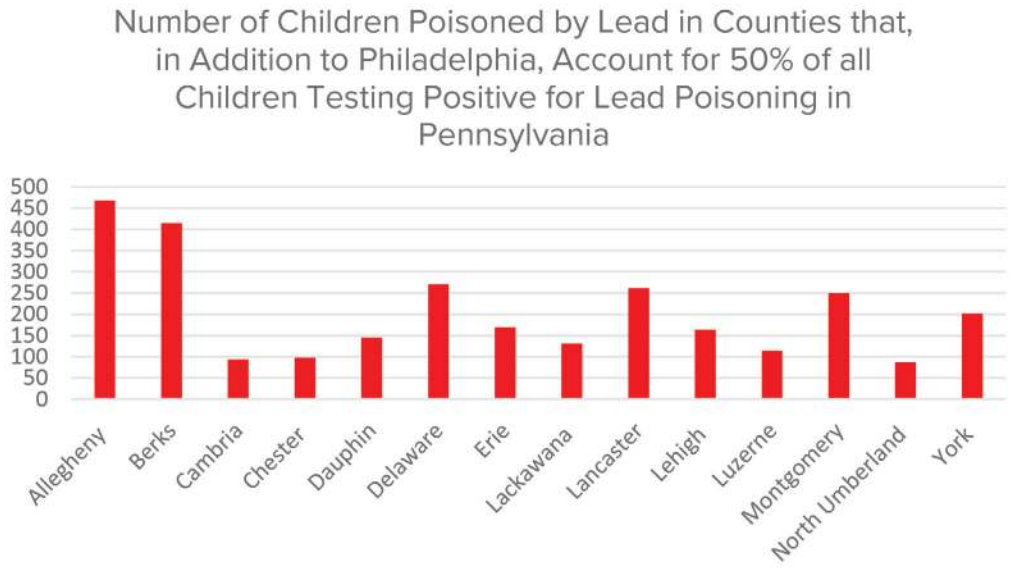
The new reporting structure begins to use available plotting tools to help the public, health care providers, lawmakers and others see where the state's hot spots are for

Finding #3

The Commonwealth's new reporting structure no longer includes the presentation of data regarding the Commonwealth's major cities; as a result the data about the state's largest population centers where an overwhelming share of the children at risk and poisoned live is no longer accessible.

the highest share of children being screened as well as the variance in the incidence of poisoning across the counties. More refined data plotting tools can improve the presentation significantly, but its noteworthy that the Department is increasing its use of data visualization tools to present information that can drive policy and action.

Fourteen of the state's 67 counties are home to more than 50% of the children testing positive for lead poisoning. It's likely that those children live in the large urban centers in these counties. If that is the case, and it's more apparent where the incidence of lead poisoning is occurring, improved outreach can be deployed to prevent more children from being poisoned.



Recommendation #5: The Department should continue to improve its use of data visualization tools and expand the geocoding and plotting of data in ways that deepen the understanding of where the high shares of children are being poisoned. The Department should also plot the data that shows where the incidence of poisoning is occurring in the cities within these hot spot counties.

Finding #4

The report provides no summary or national comparison of the data to inform policy makers, and it provides no trend information; as a result it's not possible to gauge the Commonwealth's progress.

While these reports indicate that the Commonwealth is upping its game with respect to ensuring the accuracy of its lead surveillance data, public reports with this level of detail issued by a entity charged with improving the public health of the Commonwealth should provide the public and lawmakers with a summary analysis of the data. For instance, the report never plainly states the following:

1. The number and share of children testing positive for lead poisoning. This data can be found by the reader adding up data shown on charts as far back as page 13 of the report.

2. The number and share of children tested once or the number/share tested in accordance with the CDC protocol. To extract this data, the reader has to sum data found in county-by-county data charts that have disaggregated totals starting on page 19.

The report also does not inform the reader about the trends. Policymakers and citizens need to know if the situation is getting better or worse for children in Pennsylvania. The presentation of trend data is a norm in public health as it drives the use of resources and decision making.

PCCY's comparison of two years of data released in these reports finds that in 2016, a total of 4,159 children under two were poisoned and in 2017 that number dropped to 3,816. That means that 343 fewer children who were tested for lead exposure in 2017 were poisoned compared to 2016. That's good news. It's a very small drop, but it shows that things are going in the right direction. The same trend can be found for children under six where 554 fewer children tested positive for lead poisoning in 2017 than in 2016.

Finally, we offer some additional data that could round out the report and ensure lawmakers, policymakers, health care providers and parents understand how well Pennsylvania is protecting its children compared to other states.

PCCY's review of this data finds: For at least two years in a row in 2015 and 2016 (the latest dates for which data is available), Pennsylvania has had the second largest number of children testing positive for lead poisoning among the 29 states required to report this data to the CDC.[17]

Alarmingly, among kids tested for lead, Pennsylvania has had the highest share of children poisoned at 6.9% and 6.7% in 2015 and 2016 respectively – more than twice the share of kids in New Jersey, New York and Massachusetts.

Pennsylvania has a high number and share of children harmed, yet tragically only a small share of Pennsylvania children are tested relative to the other top 10 states. Pennsylvania tested 16.3% and 16.9% of children in 2015 and 2016 respectively ranking ninth among the 10 states. Massachusetts tests the highest share of children (47.3% and 47.8% in 2015 and 2016 respectively), and if Pennsylvania tested at the same rate as Massachusetts, an astounding 14,000 children would be identified as poisoned – a number nearly double the maximum capacity of the Pennsylvania Farm Show Complex & Expo Center.

Since so few children are being tested, the grim concern persists regarding how many children have been harmed by lead but have gone undetected. Moreover, the source that poisoned them, likely deteriorated lead-based paint in their rental or owner-occupied home, also remains hidden, and therefore, in place to poison the next unwitting child exposed to it.

In 2016 Pennsylvania Ranked Second Among States Reporting to the CDC With the Highest Number of Children < 72 Months Old With Elevated Blood Lead Levels						
State	Total Population of Children <72 Months of Age	State Rank By Number of Children < 72 Months of Age	Percent of Children Tested <72 Months of Age in Total Population	State Rank By Percent of Children Tested in Total Population	Children < 72 Months of Age with Confirmed BLLs ≥ 5 µg/dL	State Rank By Number of Children with Elevated BLLs
New York	2,053,479	1	25.1	4	17,273	1
Pennsylvania	863,465	3	16.9	9	9,865	2
Ohio	841,179	4	19.1	8	8,805	3
Illinois	956,100	2	14.1	10	7,108	4
Massachusetts	438,438	8	47.8	1	6,853	5
Michigan	695,457	5	20.9	6	5,773	6
New Jersey	638,634	6	27.5	3	5,272	7
Wisconsin	413,384	9	21.2	5	5,043	8
Missouri	451,997	7	20.7	7	4,423	9
Connecticut	230,924	10	31.6	2	3,699	10

Closing

The Pennsylvania Department of Health's recently released 2016 and 2017 childhood lead poisoning surveillance reports provide critical data on the status of lead poisoning screening for the Commonwealth's youngest residents. These recent reports demonstrate the Department's commitment to providing regular, accurate data with an important focus on county level data. This screening data has great potential to tell the important story about the devastating, widespread impact of children's exposure to lead hazards that primarily occurs in the seeming 'safety' of their own homes. These children's stories are necessary to drive cost-effective policy change to ultimately create interventions that prevent them from being poisoned in the first place.

In this paper we've identified a number of ways that the Department's surveillance reports fall short of drawing a more complete and user-friendly picture – and of including critical measures that assess whether the state is in compliance with legal requirements. We've provided multiple recommendations to fill the gaps of missing data and to present the information in a more accessible and compelling manner. We know how to protect children from this injurious condition that robs them of their full potential and costs the state millions of dollars in health care, early intervention, special education and juvenile justice services. Better data will help build the public and political will for change.

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Public Citizens for Children and Youth (PCCY) serves as the leading child advocacy organization working to improve the lives and life chances of children in the region.

Through thoughtful and informed advocacy, community education, targeted service projects and budget analysis, PCCY watches out and speaks out for children and families. PCCY undertakes specific and focused projects in areas affecting the healthy growth and development of children, including child care, public education, child health, juvenile justice and child welfare.

Founded in 1980 as Philadelphia Citizens for Children and Youth, our name was changed in 2007 to better reflect our expanded work in the counties surrounding Philadelphia. PCCY remains a committed advocate and an independent watchdog for the well-being of all our children.

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Public Citizens for Children and Youth
990 Spring Garden Street
Suite 200
Philadelphia, PA 19123
215-563-5848