2017 Newborn Screening Annual Report

November 2018

Prepared by
Disease Control and Health Statistics |
Office of Newborn Screening

Washington State Department of Health

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Contents

Executive Summary

This report is presented in accordance with Revised Code of Washington (RCW) 70.83.080 and Washington Administrative Code (WAC) 246-650-040, which require the Department of Health to produce an annual newborn screening report for the State Board of Health (SBOH) and the general public. This report summarizes data for the period January 1, 2017, through December 31, 2017.

The Newborn Screening Program (NBS) tests all infants born in Washington for 28 treatable but potentially deadly or disabling disorders that the SBOH has specified in WAC Chapter 246-650.

During 2017 there were 87,234 infants born in Washington. An additional 437 babies born out-of-state received one or more newborn screens in Washington.

Infants Identified with a Disorder

The Newborn Screening Program identified 203[1] infants born in 2017 with one of the 28 disorders on the screening panel. Among these infants, 113 were affected with a severe form of one of the disorders and were quickly referred to appropriate preventive care systems before they suffered irreversible damage from their conditions. The other 90 infants were identified with a condition that required treatment or close monitoring[2].

An additional 1,410 infants were identified with hemoglobin abnormalities that, while not directly harmful, can have important implications for future reproductive choices for the infants and their parents. In these cases, the infants' health care providers were notified of the findings and their implications, and were provided a list of resources to help families understand how the findings might impact them.

Performance Data

Timely collection and submittal of newborn specimens are necessary because early detection and clinical intervention are critical to effectively treating many conditions the tests detect. State law requires that initial newborn specimens must be collected no later than 48 hours following birth. For all Washington births in 2017—including hospitals, birth centers, and home births—98.3 percent of initial specimens were collected within this timeframe, a slight improvement of 0.1 percentage points over the previous reporting period (January 1, 2016 – December 31, 2016).

State law also requires initial newborn specimens to be received at the State Public Health Laboratories within 72 hours of collection. During 2017, 89.7 percent of specimens were received within the required timeframe. This was a slight increase of 0.5 percentage points from the previous reporting period (January 1, 2016 – December 31, 2016).

State law requires health care providers to notify NBS of the date they communicated the need for diagnostic testing to the parent or guardian. During 2017, 57.2 percent of the required notifications were received by the program. This was an increase of 6.5 percentage points from the previous reporting period (January 1, 2016 – December 31, 2016).

[1] Excludes four infants not detected through newborn screening (one with congenital adrenal hyperplasia, two with mild congenital hypothyroidism, and one with cystic fibrosis). Excludes two infants with congenital hypothyroidism that were born out-of-state.

[2] This number includes mild forms of the disorders on the required newborn screening panel and a small number of non-panel conditions identified through the screening process

Program Overview

Newborn screening is a population-based, preventive public health program conducted in every state and in many countries throughout the world. It enables early identification of selected disorders that, without detection and treatment, can lead to permanent mental and physical damage or death in affected children. The goal of newborn screening is to help prevent developmental impairments (such as mental disability and neurological deficits), delayed physical growth, severe illness, and death through early detection and intervention.

Across the United States, there are variations in the disorders for which each state screens. Appendix A includes a list of the national Recommended Uniform Screening Panel (RUSP) and includes the disorders screened on the Washington State screening panel. The Washington State Board of Health adds conditions to the newborn screening panel only after careful consideration of the following criteria:

1. **Available Screening Technology**: Sensitive, specific, and timely tests are available that can be adapted to mass screening[3].
2. **Diagnostic Testing and Treatment Available**: Accurate diagnostic tests, medical expertise, and effective treatment are available for evaluation and care of all infants identified with the condition.
3. **Prevention Potential and Medical Rationale**: The newborn identification of the condition allows early diagnosis and intervention. Important considerations:
    - There is sufficient time between birth and onset of irreversible harm to allow for diagnosis and intervention.
    - The benefits of detecting and treating early onset forms of the condition (within one year of life) balance the impact of detecting late onset forms of the condition.
    - Newborn screening is not appropriate for conditions only present in adulthood.
4. **Public Health Rationale**: Nature of the condition justifies population-based screening rather than risk-based screening or other approaches.
5. **Cost-Benefit/Cost–Effectiveness**: The outcomes outweigh the costs of screening. All outcomes, both positive and negative, need to be considered in the analysis. Important considerations to be included in the economic analysis include:
    - The prevalence of the condition among newborns.
    - The positive and negative predictive values of the screening and diagnostic tests.
    - Variability of clinical presentation by those who have the condition.
    - The impact of ambiguous results—for example, the emotional and economic impact on the family and medical system.
    - Adverse effects or unintended consequences of screening.

A history of the conditions added to the Washington panel is shown in Appendix B. More information regarding the criteria can be found on the Board of Health's newborn screening criteria website.

[3] Sensitivity is the ability of the test to accurately find babies who are affected with a certain newborn screening disorder. Specificity is the ability of the test to accurately find babies who are not affected.

Newborn Screening System

Successful newborn screening requires collaboration among the Newborn Screening Program, health care facilities (hospitals, clinics, laboratories, and birth centers), health care providers (pediatricians, family practice physicians, nurse practitioners, and midwives), and families of newborns. It is a coordinated system of screening services comprised of laboratory, follow-up, and support staff.

Responsibilities of the Washington State Newborn Screening Program:

- Perform rapid, efficient screening of children born in the state for the disorders required by state regulation (WAC 246-650).
- Verify each newborn has had access to screening and, if not, take action to assure screening is available.
- Provide appropriate follow-up and recommendations to health care providers for newborns with abnormal screening test results to facilitate prompt diagnostic and treatment services.
- Consult with health care providers regarding test implications and recommend follow-up actions.
- Perform long-term follow-up and tracking of affected children to evaluate outcomes of the program, improve effectiveness, and promote continued access to appropriate specialty health care.
- Collect, analyze, and disseminate data on newborn screening requirements, including cost effectiveness of the system and health outcomes.
- Provide technical assistance and education regarding all components of newborn screening to hospitals, health care professionals, families of affected children, and the general public.

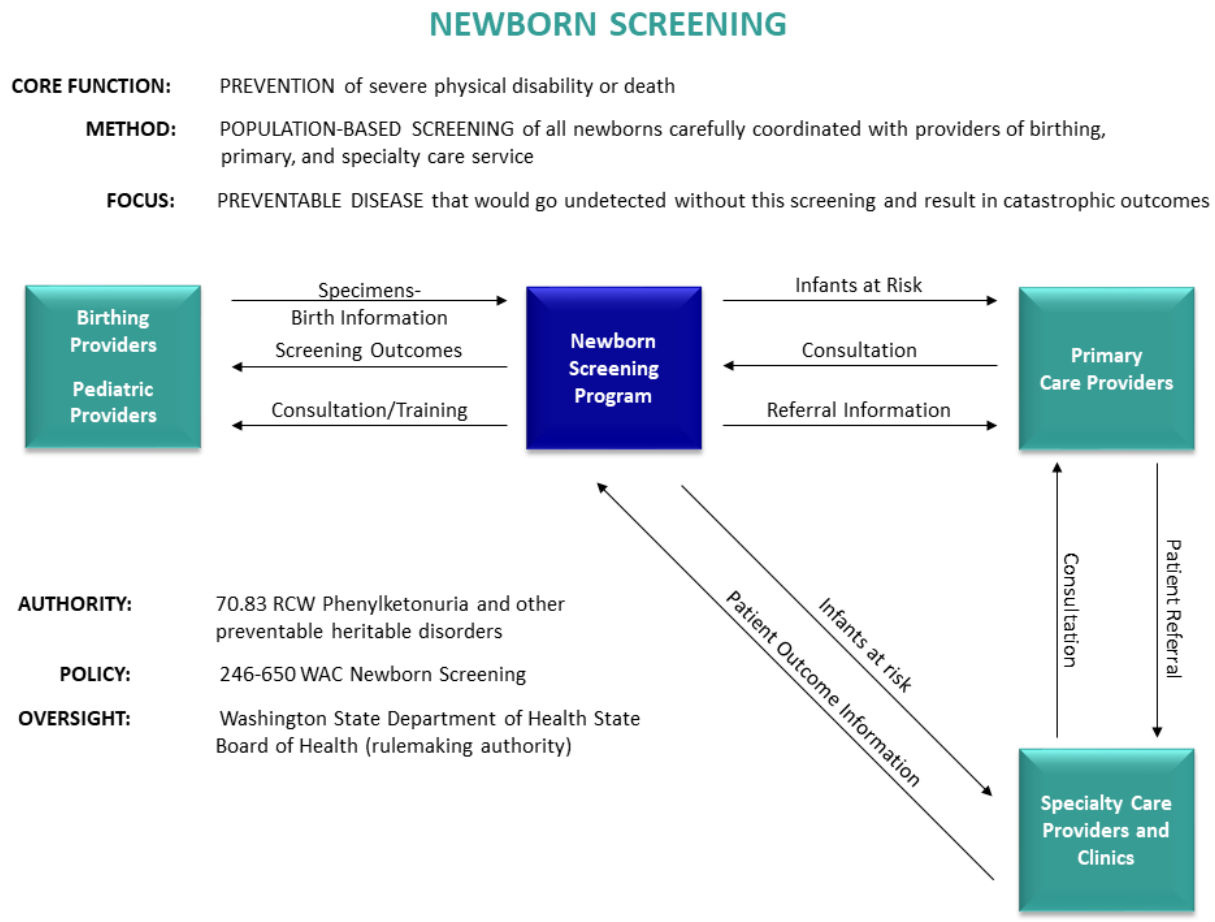
Responsibilities of the health care facilities and providers:

- Collect and send specimens to the state laboratory within the required timeframes (RCW 70.83.020).
- Provide proper collection, labeling, and handling of newborn screening specimens.
- Document the screening status of each infant.
- Quickly respond to information and specimen requests from the Newborn Screening Program (NBS).
- Ensure prompt follow-up on infants requiring further testing to rule out or confirm a diagnosis.
- Provide parent education about newborn screening and refer for diagnostic and clinical care services as needed.
- When required, report to NBS the date the parent/guardian was notified of the need for further diagnostic testing.

Responsibilities of the families:

- Receive education from their health care provider about the newborn screening tests that will be performed on their infant and ask questions if they have any.
- Report to their health care provider the presence of a family history of any screened or unscreened disorder.
- Respond quickly to requests from the health care provider or Department of Health (department) for repeat screening.
- Cooperate with health care providers and institutions when required for follow-up.

These interdependencies and synergies are illustrated in the following graphic.



Screening Costs

The department's cost to operate the program (including laboratory testing, monitoring to assure adequate screening for all infants, follow-up of all abnormal findings, education, and evaluation) is covered through a fee charged for each infant through the facility that collected the initial specimen. During 2017, this charge was $76.10 for each child. This fee is typically covered by insurance and other third-party payers. In return, the state's health care system realizes significant savings by avoiding the costs of lifetime treatment for disabling conditions.

In addition to the screening fee, a separate charge of $8.40 per birth was collected during this period to support specialty clinic care for infants diagnosed through newborn screening. This clinic subsidy fee funds clinics with expertise to consult with parents and providers on the rare conditions detected.

Quality Assurance and Development Activities

In 2017, the Washington State Newborn Screening Program participated in several new educational activities. Partnering with Western States Genetics Collaborative, it helped administer a survey at Savvy Family Expo to new and expecting parents to gauge their attitudes towards latent and late-onset conditions that could be added to the state newborn screening panels. The program hosted an informational booth at Baby Fest and Baby Bump two expos in the Seattle area for expecting and new parents. It also began providing live web-based trainings to expand outreach to health care professionals.

To augment general training for specimen collection and reporting, the NBS program provides outreach and education to Washington State hospitals and other providers regarding their responsibility for specimen collection, specimen transit, and parent notification. The Newborn Screening Program sends quarterly reports on the performance of hospitals and health care providers in meeting these responsibilities, along with an itemized list of any instances where these requirements were not met. The program also ensures every baby born in the state receives newborn screening by comparing birth data with specimens received. The program investigates all instances where an infant does not appear to have a newborn screening specimen.

Additionally, NBS sends quarterly quality reports to all submitters – hospitals, midwives, clinics and outpatient laboratories. These quality reports detail performance of the facility at collecting good quality specimens and completing the collection cards accurately. With the implementation of these reports, there has been a significant improvement in the statewide demographic error rate (see Table 7).

Newborn Screening Operations

The Newborn Screening Laboratory expansion project broke ground in January 2017. The expansion of the laboratory will increase lab capacity and accommodate the addition of new conditions and testing platforms. The additional laboratory space includes a room for the tandem mass spectrometers and a new DNA testing suite. Additionally, the project includes high-density storage, expanded stock room and additional office space. The project is expected to be complete in November 2018.

Newborn Screening New Conditions

In April 2017, the Newborn Screening Technical Advisory Committee began reviewing two lysosomal storage disorders for addition to the newborn screening panel: Pompe disease[4] and Mucopolysaccharidosis type-I[5] (MPS-I). Both conditions are on the national Recommended Uniform Screening Panel (RUSP – see Appendix A). The advisory committee reviewed the first four screening criteria and asked NBS to complete a benefit-cost analysis for each condition. The committee reconvened on June 28, 2017, to review the fifth criteria of cost benefit/cost effectiveness. During the August 10, 2017, State Board of Health meeting, the Board voted unanimously to add both conditions to the newborn screening panel. The next steps for implementation include updating the Washington Administrative Code and securing funding from the legislature to increase the newborn screening fee. Pending approval of funding, testing for the new conditions is expected to start in the fall of 2019.

[4] Pompe disease is a lysosomal storage disorder (LSD) characterized by progressive neurodegeneration that results in muscle weakness, cardiac, and respiratory failure and often death, if not detected and treated early in life.
[5] MPS-I is a lysosomal storage disorder (LSD) characterized by progressive skeletal and joint disease, and neurodegeneration that results in physical deformities, cognitive delays, and often death if not detected and treated early in life.

2017 Performance Data

Collection and Transit Performance

During the 2014 Legislative Session, a revision was made to Chapter 70.83 RCW to specify both collection and transit times for initial newborn screening specimens. Previously, the law required collecting a specimen prior to discharge from the hospital with no other specific requirements for collection and submission; the Newborn Screening Program (NBS) provided guidelines to out-of-hospital providers. The new requirements apply to all hospitals and birthing providers throughout the state.

Under the rule revision, each hospital or health care provider attending a birth outside a hospital is required to collect and transport specimens to the State Public Health Laboratories (PHL) within specified timeframes. These requirements ensure timely testing and diagnostic treatment for the protection of newborns.

Specimen Collection	Initial specimens must be collected no later than 48 hours following birth. It is recommended that initial specimens are collected between 18 and 48 hours following birth. For all Washington births in 2017—including hospitals, birth centers, and home births—98.3 percent of initial specimens were collected within the required timeframe.
Transit Performance	Initial specimens must be received by the State PHL within 72 hours of collection (excluding days that the laboratory is closed – Sundays and Thanksgiving). For all Washington births in 2017—including hospitals, birth centers, and home births—89.7 percent of initial specimens were received within this timeframe.

The following tables indicate both aggregate and individual submitter performance in meeting these requirements. Table 3 depicts the annual compliance measures by birth facility type for both specimen collection and transit compliance. Since the revision of the NBS law, there has been little change in the overall specimen collection compliance; however, almost 20 percent of babies born out-of-hospital have their initial specimen collected after 48 hours of age. This delay in specimen collection is often due to the logistics of a home birth, where birth attendants leave the home shortly after birth and often do not return until day three of life – missing the optimal window for specimen collection.

In 2017, hospitals slightly improved their aggregate transit time compliance by 0.5 percentage points to reach 90.7 percent compliance. The NBS program plans to collect data on hospital specimen transport methods during 2019 to identify strategies for improvement. In 2017 only 65.7 percent of out-of-hospital births had their initial specimens reach the laboratory within 72 hours of collection. This population relies heavily on the United States Postal Service for specimen transport. This difference is further exacerbated by geography with only 44.9 percent of out-of-hospital specimens from Eastern Washington meeting the transit time requirements (see Appendix D), highlighting a need for this community to have access to alternative methods of specimen transport. Overall, there was little change in compliance from 2016 to 2017. Further detail on hospital performance by birth volume and geographic location can be found in the appendices.

Table 1: Specimen Collection Compliance by Birth Facility

Births January 1, 2017 - December 31, 2017

Each hospital or health care provider attending a birth outside of a hospital is required to collect and transport specimens to the State Public Health Laboratories (PHL) within specified timeframes (70.83.020 RCW). These requirements ensure timely testing and diagnostic treatment for the protection of newborns. The timeframes for specimen collection and transport are:

1) Initial specimen collected no later than 48 hours following birth
2) Initial specimen received by State PHL within 72 hours of collection (excluding Sundays and Thanksgiving)

Facility of Birth	City	Eligible Infants	1) Collection Compliance
Newport Hospital	Newport	92	100%
North Valley Hospital	Tonasket	83	100%
Whitman Hospital and Medical Center	Colfax	32	100%
St Clare Hospital	Lakewood	4	100%
Summit Pacific Medical Center	Elma	4	100%
EvergreenHealth - Monroe	Monroe	2	100%
Klickitat Valley Hospital	Goldendale	2	100%
Lincoln Hospital	Davenport	1	100%
Willapa Harbor Hospital	South Bend	1	100%
Yakima Regional Medical Center	Yakima	1	100%
Madigan Army Medical Center	Joint Base Lewis-McChord	1,939	99.9%
Swedish - Issaquah	Issaquah	1,623	99.8%
Sunnyside Community Hospital	Sunnyside	522	99.8%
Prosser Memorial Hospital	Prosser	381	99.7%
Kadlec Regional Medical Center	Richland	2,798	99.6%
Virginia Mason Memorial	Yakima	2,563	99.6%
Good Samaritan Hospital - MultiCare	Puyallup	2,280	99.6%
Providence St Peter Hospital	Olympia	2,090	99.6%
Holy Family Hospital - Providence	Spokane	1,225	99.6%
EvergreenHealth Kirkland	Kirkland	4,596	99.5%
Overlake Medical Center	Bellevue	3,687	99.5%
Swedish - Edmonds	Edmonds	1,370	99.5%
Swedish - Ballard	Seattle	1,122	99.5%
Northwest Hospital - UW Medicine	Seattle	1,080	99.5%
Legacy Salmon Creek Medical Center	Vancouver	3,422	99.4%
Auburn Medical Center - MultiCare	Auburn	1,214	99.4%
St Joseph Hospital PeaceHealth - Bellingham	Bellingham	2,004	99.3%
Highline Medical Center	Burien	982	99.3%
Providence Centralia Hospital	Centralia	683	99.3%
Pullman Regional Hospital	Pullman	422	99.3%
Harrison Medical Center	Bremerton	1,953	99.2%
Trios Health Hospital	Kennewick	1,439	99.2%
Deaconess Hospital - MultiCare	Spokane	1,427	99.2%

Table 1: Specimen Collection Compliance by Birth Facility (cont.)

Facility of Birth	City	Eligible Infants	1) Collection Compliance
Skagit Valley Hospital	Mount Vernon	989	99.2%
St Joseph Medical Center - Tacoma	Tacoma	4,235	99.1%
Sacred Heart Medical Center - Providence	Spokane	3,104	99.1%
Naval Hospital - Bremerton	Bremerton	527	99.1%
Swedish - First Hill	Seattle	7,532	99.0%
Providence Everett Regional Medical Center	Everett	4,706	99.0%
Valley Medical Center - UW Medicine	Renton	3,736	99.0%
Valley Hospital	Spokane	708	99.0%
Toppenish Community Hospital	Toppenish	404	99.0%
St John Medical Center - PeaceHealth	Longview	812	98.8%
St Francis Hospital	Federal Way	1,275	98.5%
Tacoma General Hospital - MultiCare	Tacoma	2,916	98.4%
Central Washington Hospital/Confluence Health	Wenatchee	1,339	98.4%
Naval Hospital - Oak Harbor	Oak Harbor	183	98.4%
Island Hospital	Anacortes	481	98.3%
Capital Medical Center	Olympia	662	98.2%
Grays Harbor Community Hospital	Aberdeen	442	98.2%
St Elizabeth Hospital	Enumclaw	335	98.2%
Othello Community Hospital	Othello	480	98.1%
PeaceHealth Southwest Medical Center	Vancouver	2,062	97.9%
Kittitas Valley Healthcare	Ellensburg	324	97.8%
Forks Community Hospital	Forks	46	97.8%
Mason General Hospital	Shelton	256	97.3%
University of Washington Medical Center	Seattle	1,927	97.2%
WhidbeyHealth Medical Center	Coupeville	214	97.2%
Coulee Medical Center	Grand Coulee	69	97.1%
Three Rivers Hospital	Brewster	93	96.8%
Cascade Valley Hospital	Arlington	155	96.1%
Mount Carmel Hospital - Providence	Colville	217	95.9%
Olympic Medical Center	Port Angeles	501	95.8%
St Mary Medical Center - Providence	Walla Walla	687	95.5%
Mid-Valley Hospital	Omak	229	95.2%
Lake Chelan Community Hospital	Chelan	95	93.7%
Samaritan Healthcare	Moses Lake	1,026	93.6%
Jefferson Healthcare	Port Townsend	113	92.0%
All Hospital Births	**Statewide**	**83,924**	**98.9%**
All Out-of-Hospital Births	**Statewide**	**3,151**	**80.6%**
All Washington State Births	**Statewide**	**87,234**	**98.3%**

Table 2: Specimen Transit Compliance by Birth Facility

Births January 1, 2017 - December 31, 2017

Each hospital or health care provider attending a birth outside of a hospital is required to collect and transport specimens to the State Public Health Laboratories (PHL) within specified timeframes (70.83.020 RCW). These requirements ensure timely testing and diagnostic treatment for the protection of newborns. The timeframes for specimen collection and transport are:

1) Initial specimen collected no later than 48 hours following birth
2) Initial specimen received by State PHL within 72 hours of collection (excluding Sundays and Thanksgiving)

Facility of Birth	City	Eligible Infants	2) Transit Compliance
St Clare Hospital	Lakewood	4	100%
EvergreenHealth - Monroe	Monroe	2	100%
Lincoln Hospital	Davenport	1	100%
Willapa Harbor Hospital	South Bend	1	100%
Yakima Regional Medical Center	Yakima	1	100%
EvergreenHealth Kirkland	Kirkland	4,596	99.7%
Northwest Hospital - UW Medicine	Seattle	1,080	99.7%
Swedish - First Hill	Seattle	7,532	99.4%
Swedish - Issaquah	Issaquah	1,623	99.0%
Swedish - Ballard	Seattle	1,122	98.9%
Overlake Medical Center	Bellevue	3,687	98.7%
Harrison Medical Center	Bremerton	1,953	98.5%
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Central Washington Hospital/Confluence Health	Wenatchee	1,339	95.9%
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PeaceHealth Southwest Medical Center	Vancouver	2,062	95.0%
Toppenish Community Hospital	Toppenish	404	94.8%

Table 2: Specimen Transit Compliance by Birth Facility (cont.)

Facility of Birth	City	Eligible Infants	2) Transit Compliance
St Mary Medical Center - Providence	Walla Walla	687	94.0%
Whitman Hospital and Medical Center	Colfax	32	93.8%
Valley Hospital	Spokane	708	92.8%
Samaritan Healthcare	Moses Lake	1,026	92.2%
Mount Carmel Hospital - Providence	Colville	217	92.2%
Madigan Army Medical Center	Joint Base Lewis-McChord	1,939	91.0%
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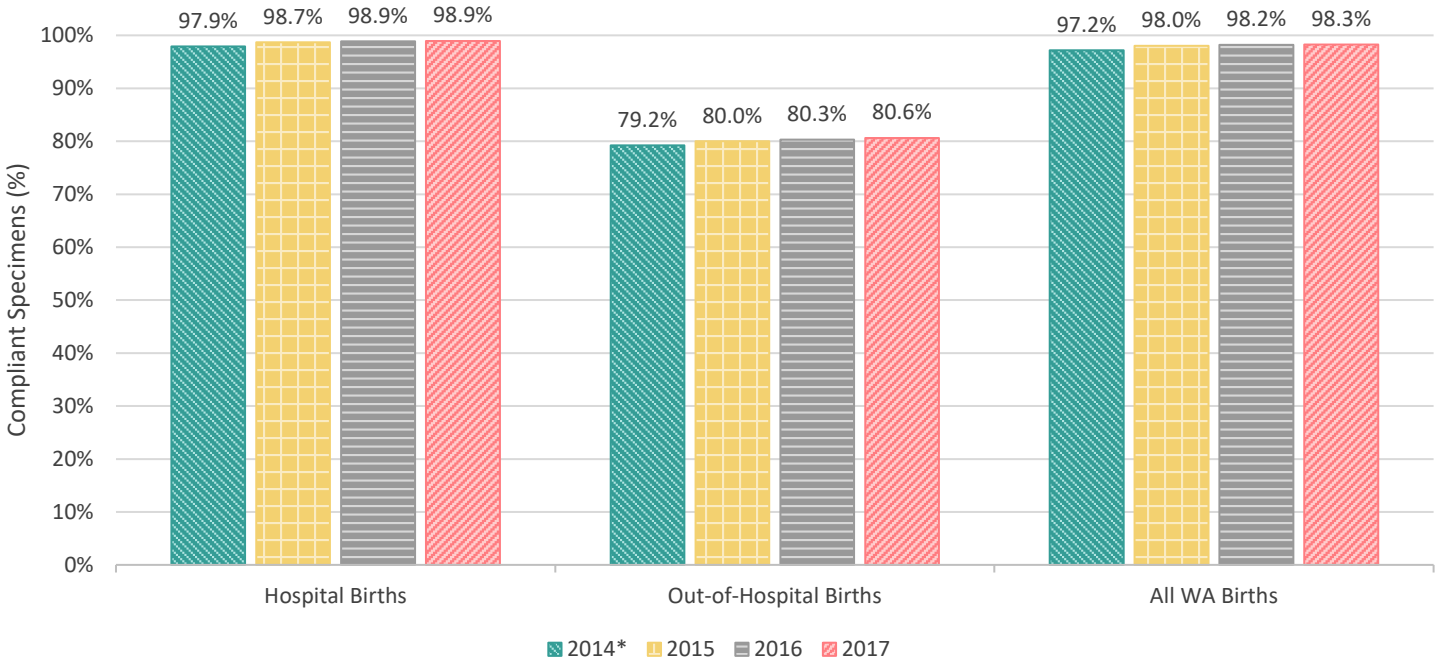
Mid-Valley Hospital	Omak	229	72.5%
Olympic Medical Center	Port Angeles	501	72.3%
Lake Chelan Community Hospital	Chelan	95	66.3%
Kadlec Regional Medical Center	Richland	2,798	60.1%
Three Rivers Hospital	Brewster	93	58.1%
Mason General Hospital	Shelton	256	57.8%
Cascade Valley Hospital	Arlington	155	55.5%
Summit Pacific Medical Center	Elma	4	50.0%
Klickitat Valley Hospital	Goldendale	2	50.0%
Providence Centralia Hospital	Centralia	683	47.1%
Jefferson Healthcare	Port Townsend	113	45.1%
Othello Community Hospital	Othello	480	44.0%
Providence St Peter Hospital	Olympia	2,090	41.1%
Coulee Medical Center	Grand Coulee	69	36.2%
Grays Harbor Community Hospital	Aberdeen	442	33.5%
Prosser Memorial Hospital	Prosser	381	25.2%
All Hospital Births	**Statewide**	**83,924**	**90.7%**
All Out-of-Hospital Births	**Statewide**	**3,151**	**65.7%**
All Washington State Births	**Statewide**	**87,234**	**89.7%**

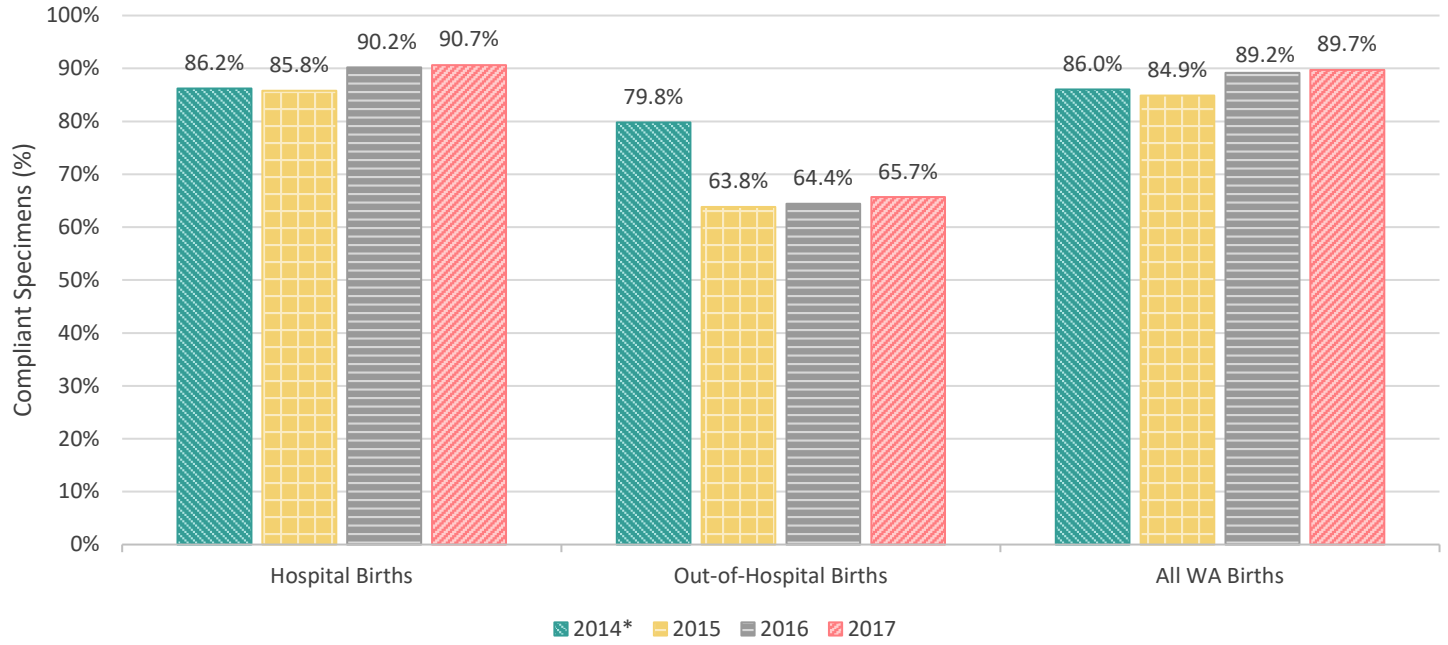
Table 3: Annual Compliance Measures

Born July 1, 2014 - December 31, 2017

Annual Age at Collection (AAC) Compliance - Birth Facility Type



Annual Transit Time (TT) Compliance - Birth Facility Type



*Includes data from July 1, 2014- December 31, 2014

Specimen Quality Indicators and Performance

The Newborn Screening Program tracks and records the quality of specimens received at the laboratory from all submitters. Each quality measure is tracked and reported quarterly to submitters to ensure the best possible testing results. The program provides guidance when errors occur, and offers onsite training for staff as needed and upon request.

Specimen quality measures include information on the number and type of unsatisfactory specimens received and the frequency of incomplete or incorrect demographic information submitted with specimens. Collecting good quality specimens and completing the demographics accurately on the specimen card are critical to the timely identification of babies with newborn screening conditions. These measures assist hospitals in identifying areas for training or improvement.

Unsatisfactory Specimens	Some specimens are considered unsatisfactory due to the quality of specimen collection or handling. In these cases, another specimen must be obtained to complete screening, which could delay diagnosis and treatment of an affected infant or cause undue hardship for the parents. Overall, 2.5 percent of specimens submitted were classified as unsatisfactory for the year. See Key 1: Unsatisfactory Specimen Descriptions, at the end of this report.
Demographic Errors on Specimens Cards	Key demographic fields are necessary for interpreting newborn screening results and for identifying the infant. Specimens with invalid or missing demographic information could delay diagnosis and treatment of an affected infant. During the 12-month period, 12.0 percent of specimen cards submitted had one or more demographic errors.

The following tables provide performance statistics in aggregate (Table 4) and by submitter (Table 5 and Table 6) for the year ending December 31, 2017.

Table 7 depicts the annual quality measures. There has been an increase in the percentage of unsatisfactory specimens submitted by hospitals and clinics and laboratories, while birth centers and midwives showed improvement in specimen collection. This may be attributed to high staff turnover rates in medical facilities and highlights an area for targeted education and outreach. As in previous years, the most common specimen collection errors are Layered (too much blood) or Incomplete Saturation (not enough blood) see Appendix F.

The improvement in the demographic error rate for birth centers, midwives, clinics and laboratories from 2016 to 2017 can be attributed to increased education on demographic errors through the expansion of the quarterly reports, which include a detailed guide on how to complete the NBS form. Statewide, there was an improvement in completion of demographic fields affecting newborn screening results; particularly there were 3,580 fewer specimens missing birth time and 2,899 fewer specimens missing collection time than in 2016. More detailed information regarding quality measures can be found in the appendices.

Table 4: Unsatisfactory Specimens & Demographic Errors Report

Table 5: Unsatisfactory Specimens by Submitting Facility

Table 6: Demographic Error Rates by Submitting Facility

Table 7: Annual Quality Measures

Appendix F: Unsatisfactory Specimens

Appendix G: Demographic Errors on Specimen Cards

Table 4: Unsatisfactory Specimens & Demographic Errors Report
Received January 1, 2017 - December 31, 2017

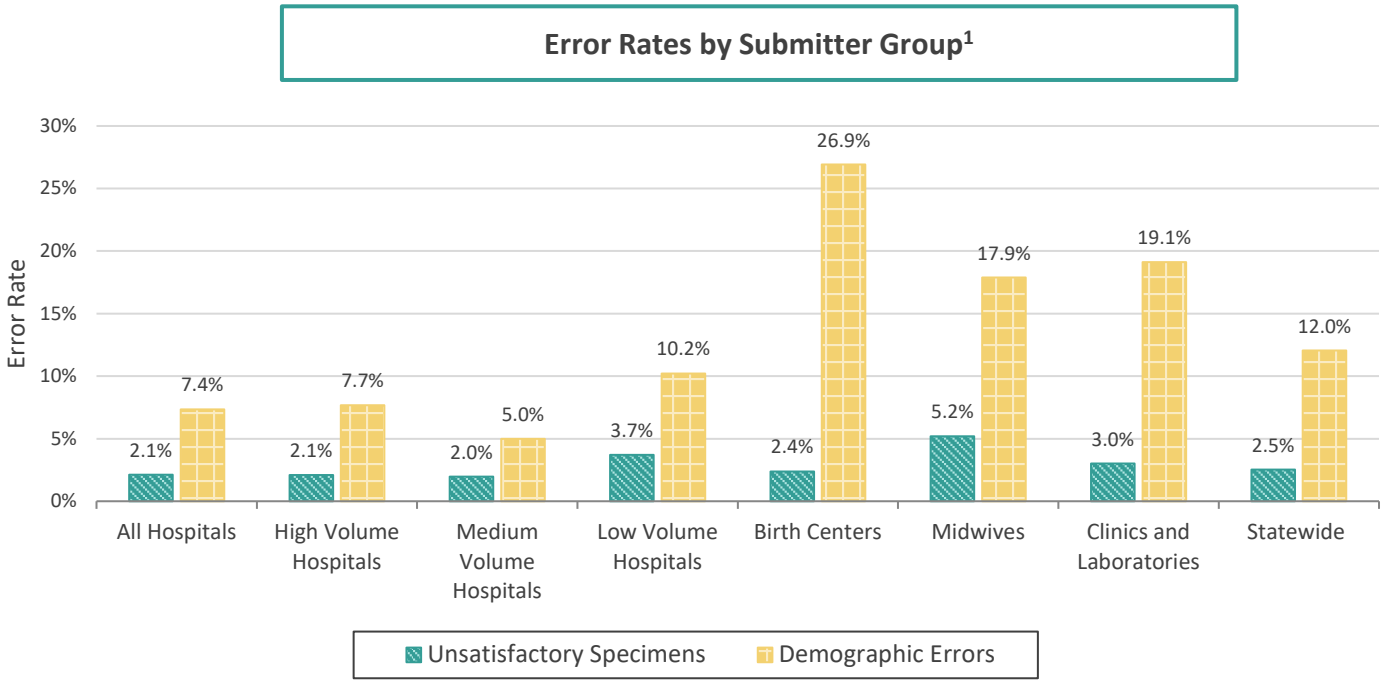
Unsatisfactory Specimens

Some specimens are considered unsatisfactory due to the quality of specimen collection or handling. These specimens are tested for extreme values but another specimen must be obtained to complete screening. The need to obtain a repeat specimen could delay diagnosis and treatment of an affected infant.

Demographic Errors

Some specimens arrive with missing or invalid demographic information. Key demographic fields are necessary for interpreting newborn screening results and for identifying the infant. Missing or invalid information can delay screening results and could delay diagnosis and treatment of an affected infant.

Submitter Group[1]	Total Specimens	Unsatisfactory Specimens[2]		Demographic Errors	
		Total	Error Rate	Total[3]	Error Rate
All Hospital Specimens	**102,286**	**2,176**	**2.1%**	**7,520**	**7.4%**
High Volume Hospitals	85,112	1,789	2.1%	6,524	7.7%
Medium Volume Hospitals	14,483	287	2.0%	721	5.0%
Low Volume Hospitals	2,691	100	3.7%	275	10.2%
All Birth Center Specimens	**754**	**18**	**2.4%**	**203**	**26.9%**
All Midwife Specimens	**4,719**	**245**	**5.2%**	**844**	**17.9%**
All Clinic and Laboratory Specimens	**62,407**	**1,885**	**3.0%**	**11,924**	**19.1%**
Statewide	**170,166**	**4,324**	**2.5%**	**20,491**	**12.0%**



[1] See Key 2: Hospital Volume for hospital volume category definitions.
[2] See Key 1: Unsatisfactory Specimen Descriptions for descriptions and causes of unsatisfactory specimens.
[3] Includes specimen cards with one or more missing or invalid demographic fields.

Table 5: Unsatisfactory Specimens by Submitting Facility
Received January 1, 2017 - December 31, 2017

Unsatisfactory Specimens

Some specimens are considered unsatisfactory due to the quality of specimen collection or handling. These specimens are tested for extreme values but another specimen must be obtained to complete screening. The need to obtain a repeat specimen could delay diagnosis and treatment of an affected infant.

Submitting Facility	City	Total Specimens	Unsat Specimen[1] Error Rate
Three Rivers Hospital	Brewster	151	0%
Lincoln Hospital	Davenport	28	0%
Kaiser Permanente WA - Capitol Hill	Seattle	14	0%
St Joseph Hospital Providence - Chewelah	Chewelah	10	0%
Willapa Harbor Hospital	South Bend	2	0%
Swedish - Cherry Hill	Seattle	1	0%
Lourdes Medical Center	Pasco	1	0%
Yakima Regional Medical Center	Yakima	1	0%
East Adams Rural Hospital	Ritzville	1	0%
Ferry County Memorial Hospital	Republic	1	0%
Fairchild Air Force Base - 92nd Medical Group	Fairchild AFB	1	0%
St Mary Medical Center - Providence	Walla Walla	701	0.3%
Naval Hospital - Bremerton	Bremerton	1,137	0.4%
Mason General Hospital	Shelton	269	0.4%
Legacy Salmon Creek Medical Center	Vancouver	3,668	0.7%
Harrison Medical Center	Bremerton	2,135	0.8%
Madigan Army Medical Center	Joint Base Lewis-McChord	3,977	0.9%
Kadlec Regional Medical Center	Richland	3,286	0.9%
Good Samaritan Hospital - MultiCare	Puyallup	2,372	0.9%
Northwest Hospital - UW Medicine	Seattle	1,584	0.9%
PeaceHealth Southwest Medical Center	Vancouver	2,303	1.0%
St John Medical Center - PeaceHealth	Longview	863	1.0%
Olympic Medical Center	Port Angeles	948	1.1%
Jefferson Healthcare	Port Townsend	185	1.1%
Samaritan Healthcare	Moses Lake	1,053	1.2%
Sacred Heart Medical Center - Providence	Spokane	4,625	1.3%
Holy Family Hospital - Providence	Spokane	1,424	1.3%
Valley Hospital	Spokane	976	1.3%
Naval Hospital - Oak Harbor	Oak Harbor	454	1.3%
Providence Everett Regional Medical Center	Everett	5,172	1.4%
Island Hospital	Anacortes	694	1.4%
Pullman Regional Hospital	Pullman	433	1.4%

Table 5: Unsatisfactory Specimens by Submitting Facility (cont.)

Submitting Facility	City	Total Specimens	Unsat Specimen[1] Error Rate
Deaconess Hospital - MultiCare	Spokane	1,847	1.5%
St Francis Hospital	Federal Way	1,496	1.5%
Capital Medical Center	Olympia	664	1.5%
Overlake Medical Center	Bellevue	3,861	1.6%
Skagit Valley Hospital	Mount Vernon	1,013	1.6%
Toppenish Community Hospital	Toppenish	678	1.6%
Virginia Mason Memorial	Yakima	4,319	1.8%
WhidbeyHealth Medical Center	Coupeville	387	1.8%
Swedish - First Hill	Seattle	8,531	1.9%
Swedish - Issaquah	Issaquah	1,685	1.9%
Seattle Children's Hospital	Seattle	806	1.9%
Lake Chelan Community Hospital	Chelan	161	1.9%
Newport Hospital	Newport	159	1.9%
St Joseph Medical Center - Tacoma	Tacoma	4,997	2.0%
North Valley Hospital	Tonasket	102	2.0%
Central Washington Hospital/Confluence Health	Wenatchee	1,365	2.1%
Swedish - Ballard	Seattle	1,229	2.1%
Prosser Memorial Hospital	Prosser	526	2.1%
Grays Harbor Community Hospital	Aberdeen	429	2.1%
EvergreenHealth - Monroe	Monroe	47	2.1%
EvergreenHealth Kirkland	Kirkland	4,966	2.2%
St Joseph Hospital PeaceHealth - Bellingham	Bellingham	2,077	2.2%
St Elizabeth Hospital	Enumclaw	439	2.3%
Tacoma General Hospital - MultiCare	Tacoma	3,737	2.4%
Swedish - Edmonds	Edmonds	1,962	2.5%
Highline Medical Center	Burien	1,026	2.5%
Sunnyside Community Hospital	Sunnyside	889	2.6%
Mid-Valley Hospital	Omak	231	2.6%
Trios Health Hospital	Kennewick	1,510	2.8%
Valley Medical Center - UW Medicine	Renton	4,007	2.9%
Kittitas Valley Healthcare	Ellensburg	340	2.9%
Whitman Hospital and Medical Center	Colfax	63	3.2%
Virginia Mason Hospital	Seattle	30	3.3%
Othello Community Hospital	Othello	807	3.5%
Harborview Medical Center - UW Medicine	Seattle	112	3.6%
Forks Community Hospital	Forks	109	3.7%
Coulee Medical Center	Grand Coulee	129	5.4%
Summit Pacific Medical Center	Elma	51	5.9%

Table 5: Unsatisfactory Specimens by Submitting Facility (cont.)

Submitting Facility	City	Total Specimens	Unsat Specimen[1] Error Rate
Providence St Peter Hospital	Olympia	2,329	6.7%
Auburn Medical Center - MultiCare	Auburn	1,234	7.1%
Providence Centralia Hospital	Centralia	697	7.5%
Mount Carmel Hospital - Providence	Colville	241	8.3%
Cascade Valley Hospital	Arlington	206	9.2%
University of Washington Medical Center	Seattle	2,277	10.1%
Mary Bridge Children's Hospital - MultiCare	Tacoma	29	24.1%
Columbia Basin Hospital	Ephrata	4	25.0%
Walla Walla General Hospital	Walla Walla	9	33.3%
Lewis County Hospital	Morton	3	33.3%
All Hospital Specimens	**Statewide**	**102,286**	**2.1%**
Non-Hospital Specimens	**Statewide**	**67,880**	**3.2%**
All Birth Center Specimens	Statewide	754	2.4%
All Midwife Specimens	Statewide	4,719	5.2%
All Clinic and Laboratory Specimens	Statewide	62,407	3.0%
All Washington State Births	**Statewide**	**170,166**	**2.5%**

[1] See Key 1: Unsatisfactory Specimen Descriptions for descriptions and causes of unsatisfactory specimens.

Table 6: Demographic Error Rates by Submitting Facility
Received January 1, 2017 - December 31, 2017

Demographic Errors

Some specimens arrive with missing or invalid demographic information. Key demographic fields are necessary for interpreting newborn screening results and for identifying the infant. Missing or invalid information can delay screening results and could delay diagnosis and treatment of an affected infant.

Submitting Facility	City	Total Specimens	Demographic Error Rate[1]
Lewis County Hospital	Morton	3	0%
Willapa Harbor Hospital	South Bend	2	0%
Swedish - Cherry Hill	Seattle	1	0%
Lourdes Medical Center	Pasco	1	0%
Yakima Regional Medical Center	Yakima	1	0%
East Adams Rural Hospital	Ritzville	1	0%
Ferry County Memorial Hospital	Republic	1	0%
Fairchild Air Force Base - 92nd Medical Group	Fairchild AFB	1	0%
Three Rivers Hospital	Brewster	151	1.3%
North Valley Hospital	Tonasket	102	2.0%
EvergreenHealth Kirkland	Kirkland	4,966	2.4%
Virginia Mason Memorial	Yakima	4,319	2.6%
Holy Family Hospital - Providence	Spokane	1,424	2.6%
Olympic Medical Center	Port Angeles	948	2.6%
Naval Hospital - Bremerton	Bremerton	1,137	2.7%
Forks Community Hospital	Forks	109	2.8%
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Othello Community Hospital	Othello	807	3.1%
Newport Hospital	Newport	159	3.1%
Coulee Medical Center	Grand Coulee	129	3.1%
Samaritan Healthcare	Moses Lake	1,053	3.4%
Northwest Hospital - UW Medicine	Seattle	1,584	3.9%
Sunnyside Community Hospital	Sunnyside	889	3.9%
Overlake Medical Center	Bellevue	3,861	4.0%
Valley Hospital	Spokane	976	4.0%
Swedish - Edmonds	Edmonds	1,962	4.2%
Skagit Valley Hospital	Mount Vernon	1,013	4.2%
Island Hospital	Anacortes	694	4.2%
Swedish - Issaquah	Issaquah	1,685	4.5%
Swedish - Ballard	Seattle	1,229	4.5%
Highline Medical Center	Burien	1,026	4.6%
Kadlec Regional Medical Center	Richland	3,286	4.7%

Table 6: Demographic Error Rates by Submitting Facility (cont.)

Submitting Facility	City	Total Specimens	Demographic Error Rate[1]
Providence St Peter Hospital	Olympia	2,329	4.7%
St Joseph Hospital PeaceHealth - Bellingham	Bellingham	2,077	4.7%
St John Medical Center - PeaceHealth	Longview	863	4.9%
Toppenish Community Hospital	Toppenish	678	4.9%
St Francis Hospital	Federal Way	1,496	5.2%
St Mary Medical Center - Providence	Walla Walla	701	5.3%
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Providence Centralia Hospital	Centralia	697	6.7%
Virginia Mason Hospital	Seattle	30	6.7%
Deaconess Hospital - MultiCare	Spokane	1,847	7.1%
Kaiser Permanente WA - Capitol Hill	Seattle	14	7.1%
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Jefferson Healthcare	Port Townsend	185	10.8%
Cascade Valley Hospital	Arlington	206	11.2%
Naval Hospital - Oak Harbor	Oak Harbor	454	11.7%
PeaceHealth Southwest Medical Center	Vancouver	2,303	13.2%

Table 6: Demographic Error Rates by Submitting Facility (cont.)

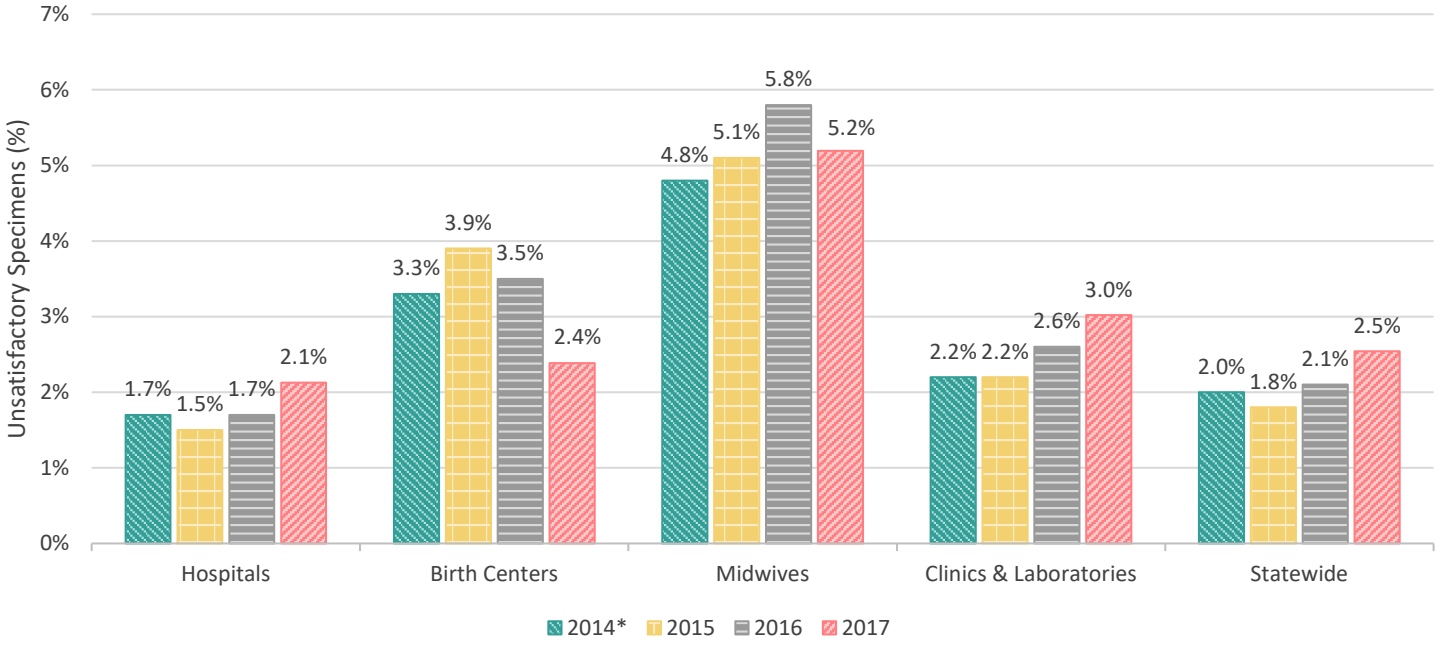
Submitting Facility	City	Total Specimens	Demographic Error Rate[1]
Mid-Valley Hospital	Omak	231	13.9%
Summit Pacific Medical Center	Elma	51	15.7%
Mount Carmel Hospital - Providence	Colville	241	15.8%
Walla Walla General Hospital	Walla Walla	9	22.2%
EvergreenHealth - Monroe	Monroe	47	23.4%
Columbia Basin Hospital	Ephrata	4	25.0%
Swedish - First Hill	Seattle	8,531	26.1%
Harborview Medical Center - UW Medicine	Seattle	112	28.6%
Mary Bridge Children's Hospital - MultiCare	Tacoma	29	31.0%
Lincoln Hospital	Davenport	28	35.7%
All Hospital Specimens	**Statewide**	**102,286**	**7.7%**
Non-Hospital Specimens	**Statewide**	**67,880**	**19.1%**
All Birth Center Specimens	Statewide	754	26.9%
All Midwife Specimens	Statewide	4,719	17.9%
All Clinic and Laboratory Specimens	Statewide	62,407	19.1%
All Washington State Births	**Statewide**	**170,166**	**12.0%**

[1] Includes specimen cards with one or more missing or invalid demographic fields.

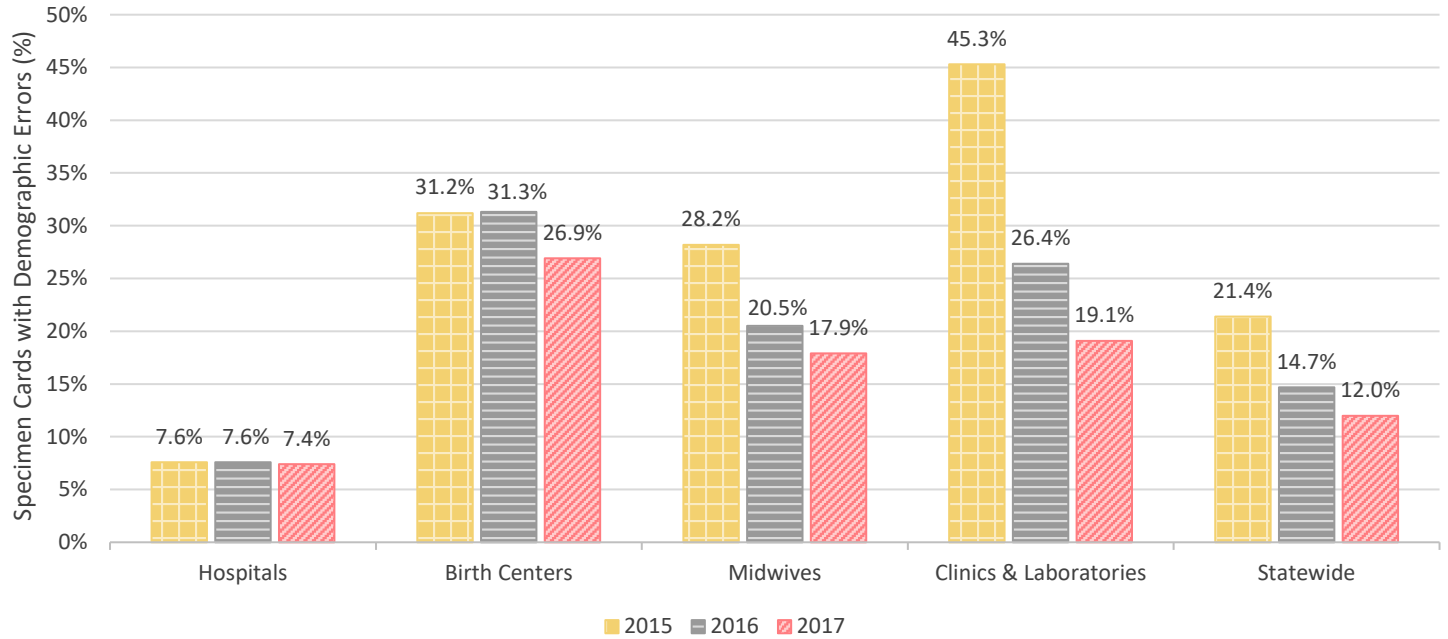
Table 7: Annual Quality Measures

Received July 1, 2014 - December 31, 2017

Annual Unsatisfactory Specimen[1] Rate - Submitting Facility Type



Annual Demographic Error Rate[2] - Submitting Facility Type



*Includes data from July 1, 2014- December 31, 2014. Demographic error rates were calculated differently in 2014 and are not included.

[1] See Key 1: Unsatisfactory Specimen Descriptions for descriptions and causes of unsatisfactory specimens.

[2] Includes specimen cards with one or more missing or invalid demographic fields.

Parent Notification

When screening results indicate an infant requires further diagnostic testing and evaluation, the Newborn Screening Program contacts the infant's health care provider with disorder-specific recommendations. The provider is then responsible for informing the parents.

Referrals are classified into two types:

Standard Referrals	Due to the potential severity of the condition, clinical evaluation and diagnostic testing should be done immediately. Parents should be notified the same day as the referral. For standard referrals, 51.1 percent of the required notifications were reported to the department. Of the reported notifications, 68.5 percent reported that parents were notified the same day as the referral.
Non-urgent Referrals	Diagnostic testing and evaluation should be done as soon as possible. For non-urgent referrals, 61.3 percent of the required notifications were reported to the department. Of the reported notifications, 83.1 percent reported that parents were notified within three days of the referral.

The following Table 8 details the timeliness of parent notification by their health care provider in 2017.

Table 9 shows the annual parent notification measures, including the percent of required notifications reported to the department and the percent of on-time parent notifications. In 2017, 57.2 percent of the required notifications were reported to the department (an increase of 6.5 percent from the previous year). Of the reported notifications, 77.7 percent of parents were notified of the need for diagnostic testing and evaluation in the recommended timeframe. This difference highlights the need for better education of health care providers regarding their responsibility to notify parents in a timely manner and then report that notification to the department. Anecdotally, very few referral notification forms are returned for infants in the Neonatal Intensive Care Unit (NICU) or Special Care Nursery. For infants who are not in the hospital at the time of the referral, our plan is to be more active in obtaining this information by contacting the health care provider if the referral notification form is not returned.

Table 8: Timeliness of Parent Notification by Health Care Providers

Births January 1, 2017 - December 31, 2017

When screening results indicate an infant requires diagnostic testing and evaluation, the Newborn Screening Program contacts the infant's health care provider with disorder-specific recommendations. The provider is then responsible for informing the parents. Health care providers are required to notify the Newborn Screening Program of the date they communicated the need for diagnostic testing to the parent or guardian (70.83.070 RCW). Referrals are classified into two types:

Standard Referrals

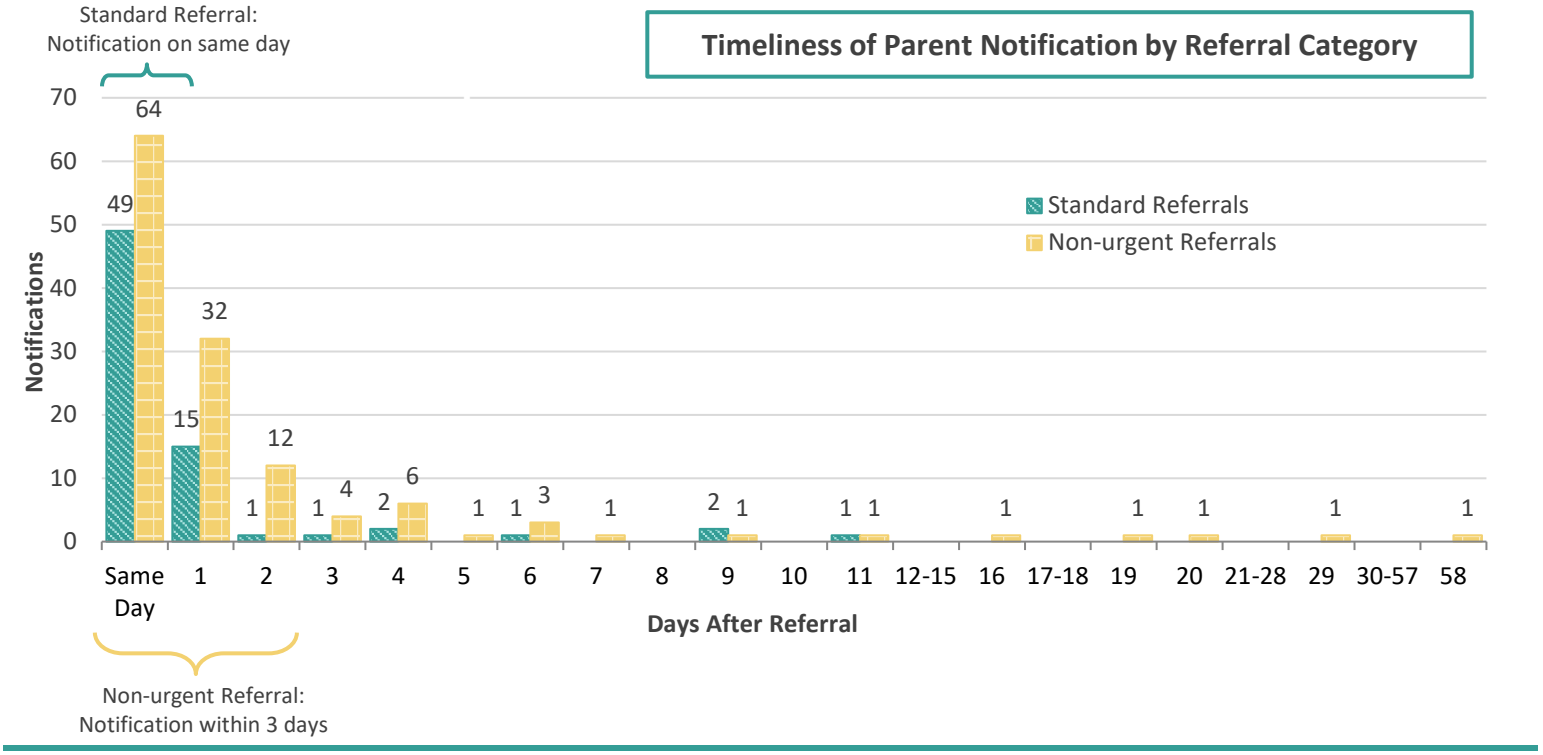
Due to the potential severity of the condition clinical evaluation and diagnostic testing should be done immediately. Parents should be notified the same day as the referral.

Non-urgent Referrals

Diagnostic testing and evaluation should be done as soon as possible. Parents should also be notified as soon as possible, ideally within three days of the referral.

Newborn Screening Referral Category	Infants Referred for Diagnostic Testing		Health Care Provider Reported Date of Parent Notification		On-time Parent Notification	
	Total	Percent	Total	Percent	Total	Percent
Standard Referral	141	39.9%	72	51.1%	49	68.1%
Non-urgent Referral	212	60.1%	130	61.3%	108	83.1%
All Referrals	**353***	**100%**	**202**	**57.2%**	**157**	**77.7%**

*Excludes 27 instances where the health care provider began diagnostic testing prior to screening results based on family history, prenatal diagnosis, or clinical symptoms.



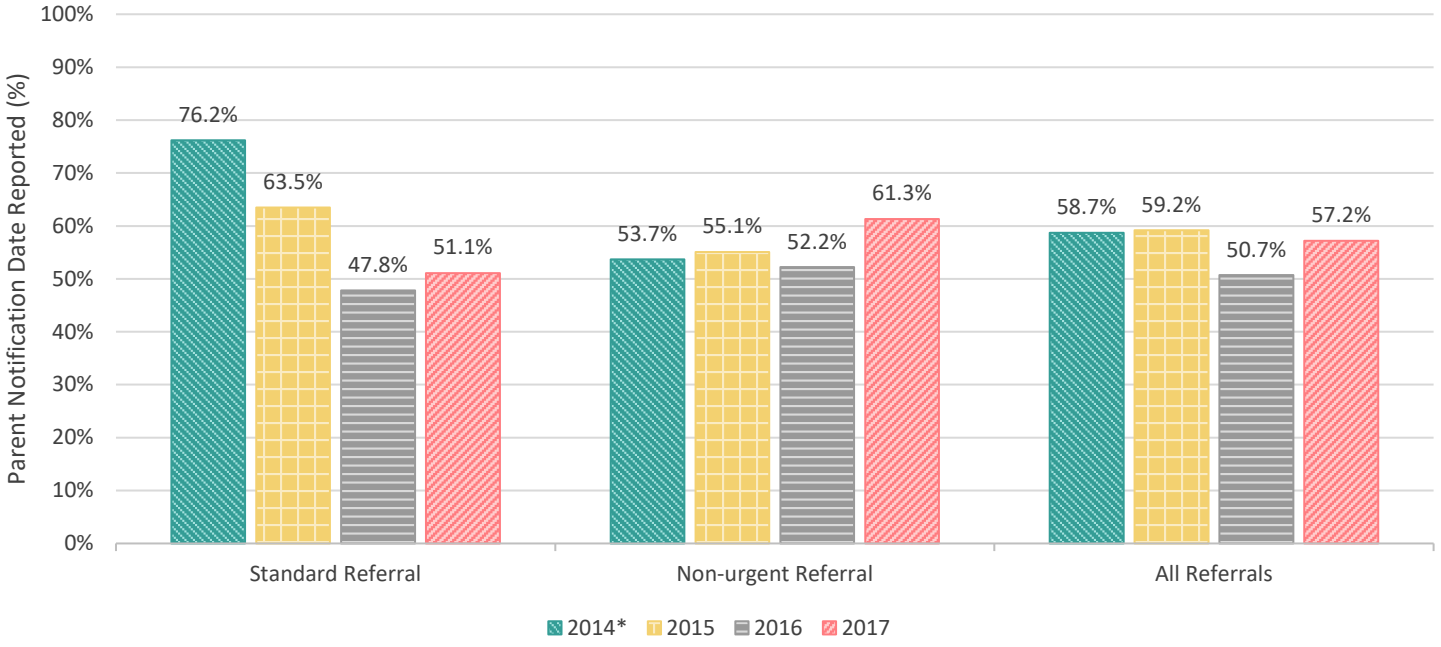
Disorders included in Standard Referrals: Congenital adrenal hyperplasia (CAH), Congenital hypothyroidism (CH), Cystic Fibrosis (CF), Glutaric acidemia type I (GA-I), Galactosemia (GALT), Isovaleric acidemia (IVA), Maple syrup urine disease (MSUD), Medium chain acyl-CoA dehydrogenase (MCAD) deficiency, Methylmalonic acidemias (MMA)/Propionic acidemia, Phenylketonuria (PKU), Severe combined immunodeficiency (SCID), and Very long-chain acyl-CoA dehydrogenase (VLCAD) deficiency.

Disorders included in Non-urgent Referrals: Congenital adrenal hyperplasia (CAH), Cystic fibrosis (CF), Mild congenital hypothyroidism (CH), Carnitine uptake defect (CUD), Homocystinuria (HCY), Hemoglobinopathies (HB), 3-hydroxy-3-methyglutaric aciduria (HMG)/ Multiple carboxylase deficiency (MCD), Isovaleric acidemia (IVA), Methylmalonic acidemias (MMA)/Propionic acidemia, and Severe combined immunodeficiency (SCID).

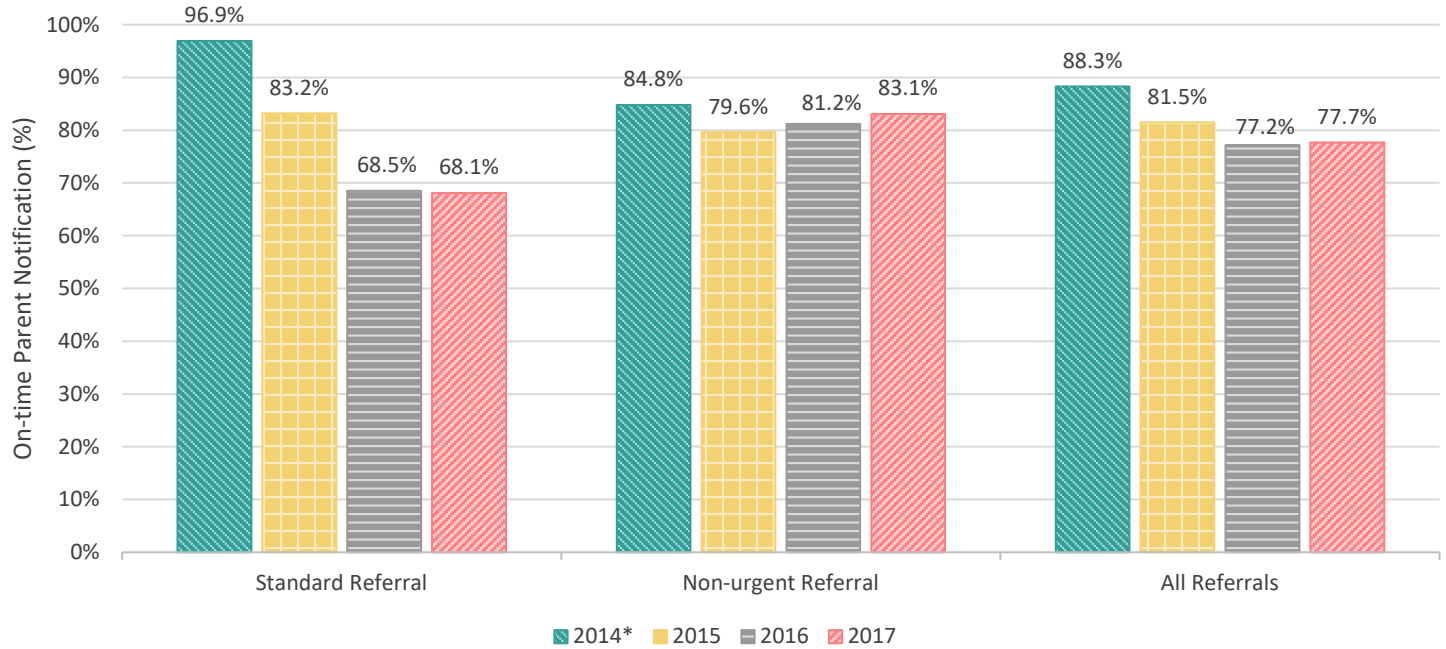
Table 9: Annual Parent Notification Measures

Received July 1, 2014 - December 31, 2017

Annual Parent Notification Reported - Referral Category[1]



Annual On-time Parent Notification - Referral Category[1]



*Includes data from July 1, 2014- December 31, 2014.

[1] **Standard Referrals:** Due to the potential severity of the condition clinical evaluation and diagnostic testing should be done immediately. Parents should be notified the same day as the referral. **Non-urgent Referrals:** Diagnostic testing and evaluation should be done as soon as possible, ideally within three days of the referral.

Newborn Screening Disorders Detected

The following is a brief description of the disorders identified through the Newborn Screening Program and abbreviations used throughout the report. Statistics on each of the disorders are included in the tables following the descriptions of the conditions.

Amino acid disorders (AA): disorders of metabolism characterized by the body's inability to correctly process amino acids or the inability to process the ammonia that is released during the breakdown of amino acids. The accumulation of amino acids, ammonia or other by-products may cause severe complications including intellectual disabilities, coma, seizures, and possibly death. Early detection and treatment can prevent most or all of these consequences. Disorders are:

- Argininosuccinic acidemia (ASA)
- Citrullinemia (CIT)
- Homocystinuria (HCY)
- Maple syrup urine disease (MSUD)
- Phenylketonuria (PKU)
- Tyrosinemia type I (TYR I)

Biotinidase deficiency (BIO): deficiency of the enzyme that affects normal recycling of biotin, one of the B vitamins. If untreated, a severe deficiency of biotin can result in metabolic crisis, coma, and death. Treatment with biotin can prevent all symptoms.

Congenital adrenal hyperplasia (CAH): excessive production of androgenic hormones due to a defect in the pathway that converts cholesterol into the hormone cortisol. The most common defect, and the primary target of our screening, is deficiency of the enzyme 21-hydroxylase. Deficiency of this enzyme accounts for approximately 95 percent of all cases of CAH. If untreated, CAH can lead to an imbalance in the body's concentration of salts which in turn can rapidly lead to shock and death. It also causes excessive masculinization and extremely premature sexual maturation. Treatment consists of providing cortisol which normalizes hormone production. Proper treatment prevents death and stops the masculinization process. Affected females may require surgical correction of masculinized genitalia.

Congenital hypothyroidism (CH): insufficient production of the thyroid hormone thyroxine due to malformation or malfunction of the thyroid gland. If untreated, CH can result in severe neurological and developmental damage. Treatment consists of hormone replacement with synthetic thyroxine. Affected infants develop normally with proper treatment.

Cystic fibrosis (CF): defect in the cystic fibrosis transmembrane conductance regulator (CFTR) gene which regulates the body's salt and water secretions. This results in the build-up of thick, sticky mucus in the lungs and digestive system. Treatment consists of pancreatic enzymes, vitamin supplements, chest physiotherapy, and antibiotics. Early treatment improves physical growth, cognitive function, and lung function.

Fatty acid oxidation (FAO) disorders: disorders of metabolism characterized by the inability to efficiently use fat to make energy. During times of extra energy need such as prolonged fasting or acute illness, affected infants can suffer dangerously low blood sugar and metabolic crises resulting in serious damage affecting the brain, liver, heart, eyes, and muscle, and possibly death. Early detection and treatment can prevent most or all of these consequences. Disorders are:

- Carnitine uptake deficiency
- Long-chain L-3-OH acyl-CoA dehydrogenase (LCHAD) deficiency
- Medium chain acyl-CoA dehydrogenase (MCAD) deficiency
- Trifunctional protein (TFP) deficiency
- Very long-chain acyl-CoA dehydrogenase (VLCAD) deficiency

Galactosemia (GALT): deficiency in one of three enzymes that help convert galactose into glucose. Screening targets the most common, classic form of the disorder. If untreated, an affected baby may develop jaundice, vomiting, lethargy, hepatosplenomegaly, cataracts, and failure to thrive. Also, the condition can lead to liver failure, sepsis, and death. A galactose-free diet with strict avoidance of lactose (milk sugar) and lactose containing foods prevents death and assists growth and development.

Hemoglobinopathies:

Sickle cell disease (SCD): a condition marked by a tendency for the blood cells to take on a sickle shape due to an abnormal structure of the hemoglobin molecule. The altered shape shortens the life span of the blood cells, impedes circulation, especially in capillaries, and results in anemia. Children with sickle cell disease are highly susceptible to bacterial infections and rapid pooling of blood in their spleens. Either can rapidly lead to death. Treatment consists of prophylactic penicillin to prevent infection and training parents to recognize splenic crisis. Preventive treatment dramatically reduces infections and death.

Other significant hemoglobinopathies (Hb): other hemoglobin abnormalities that have significant clinical consequences (for example, transfusion-dependent thalassemia). These conditions generally don't require immediate treatment, but early identification allows families to adjust to the diagnosis, anticipate the medical needs, and begin early treatment plans as necessary.

Organic acid disorders (OA): disorders of metabolism characterized by the accumulation of non-amino organic acids and toxic intermediates. This may lead to metabolic crisis with elevation of acid and ammonia in the blood, and dangerously low blood sugar resulting in severe neurologic and physical damage and possibly death. Early detection and treatment can prevent most or all of these consequences. Disorders are:

- 3-hydroxy-3-methylglutaric aciduria (HMG)
- Beta-ketothiolase deficiency (BKT)
- Isovaleric acidemia (IVA)
- Methylmalonic acidemia (cobalamin A, B deficiency)(Cbl A, B)
- Methylmalonic acidemia (mutase deficiency) (MUT)
- Multiple carboxylase deficiency (MCD)
- Propionic acidemia (PROP)

Severe combined immunodeficiency (SCID): a group of disorders of immune system development characterized by absent or low T-cell counts. Babies with SCID are at risk for developing life-threatening infections within the first year of life. Early detection and treatment allow for curative bone-marrow transplant in the first months of life.

The following tables show the breakdown of the conditions during 2017.

Table 10:	Infants Detected with Newborn Screening Disorders by County of Residence
Table 11:	Infants Detected with Newborn Screening Disorders by Infant's Reported Race
Appendix H:	Infants detected with Newborn Screening Disorders 2010-2016
Appendix I:	Newborn Hemoglobin Screening Infants Detected by Phenotype and Reported Race/Ethnicity

Table 10: Infants Detected with Newborn Screening Disorders by County of Residence (births by county of occurrence)

Births January 1, 2017 - December 31, 2017

County	Births	Amino acid disorders	Biotinidase deficiency	Congenital adrenal hyperplasia	Congenital hypothyroidism	Cystic fibrosis	Fatty acid oxidation disorders	Galactosemia	Hemoglobinopathies	Organic acid disorders	Severe combined immunodeficiency	All Infants Detected
Adams	481	-	-	-	-	-	-	-	-	-	-	0
Benton	5,239	1	-	-	2	1	-	-	-	-	1	5
Chelan	1,498	-	-	-	1	-	-	-	-	-	-	1
Clallam	587	-	1	-	2	-	-	-	-	-	-	3
Clark	5,614	-	-	-	4	3	-	-	1	-	-	8
Cowlitz	835	-	-	-	-	-	-	-	-	-	-	0
Douglas	164	-	-	-	-	-	-	-	-	-	-	0
Ferry	1	-	-	-	-	-	-	-	-	-	-	0
Grant	1,044	-	-	-	2	-	1	-	-	-	-	3
Grays Harbor	450	-	-	-	1	-	-	-	-	-	-	1
Island	458	-	-	-	-	-	-	-	-	-	-	0
Jefferson	132	-	-	-	-	-	-	-	-	-	-	0
King	30,065	5	-	3[b]	37[c]	4[e]	5[f]	2	13	10	7	86
Kitsap	2,589	-	-	-	-	-	-	-	-	-	-	0
Kittitas	336	-	-	-	1	-	-	-	-	-	-	1
Klickitat	37	-	-	-	-	-	-	-	-	-	-	0
Lewis	748	-	-	-	2	-	-	-	-	1	-	3
Lincoln	1	-	-	-	-	-	-	-	-	-	-	0
Mason	257	-	-	-	-	-	-	-	-	-	-	0
Okanogan	339	-	-	-	1	-	-	-	-	-	-	1
Pacific	2	-	-	-	-	-	-	-	-	-	-	0
Pend Oreille	92	-	-	-	-	-	-	-	-	-	-	0
Pierce	11,809	-	-	3	5	2	2	-	8	1	4	25
San Juan	481	-	-	-	-	-	-	-	-	-	-	0
Skagit	1,118	-	-	-	1	1	1	-	-	-	-	3
Skamania	4	-	-	-	-	-	-	-	-	-	-	0
Snohomish	6,603	1	-	-	13	-	-	-	-	1	2	17
Spokane	6,776	-	-	1	8[d]	2	-	-	1	-	1	13
Stevens	244	-	-	-	-	-	-	-	1	-	-	1
Thurston	2,921	-	-	-	7	-	-	-	1	1	1	10
Walla Walla	687	-	-	-	-	-	1	1	-	-	-	2
Whatcom	2,181	-	-	-	3	-	1	1	-	-	-	5
Whitman	466	-	-	-	2	-	-	-	-	-	-	2
Yakima	2,975	-	-	-	10	2	-	-	-	-	1	13
All WA Births[a]	**87,234**	**7**	**1**	**7**	**102**	**15**	**11**	**4**	**25**	**14**	**17**	**203**

[a]There were zero birth occurrences in the following counties; Asotin, Columbia, Franklin, Garfield and Wahkiakum. Excludes 437 infants born out-of-state who received one or more newborn screens in Washington.

[b]Excludes one infant from King County with CAH who was not detected through newborn screening.

[c]Excludes three infants from King County with CH; one was born out-of-state and two were not detected through newborn screening.

[d]Includes one infant born in Spokane County with CH who resides out-of-state. Excludes one infant from Spokane County with CH who was born out-of-state.

[e]Excludes one infant born in King County with CF that was not detected through newborn screening.

[f]Includes one infant born in King County with an FAO disorder who resides in Alaska.

Table 11: Infants Detected with Newborn Screening Disorders by Infant's Reported Race

Births January 1, 2017 - December 31, 2017

Infants Race	Births	Amino Acids disorders	Biotinidase deficiency	Congenital adrenal hyperplasia	Congenital hypothyroidism	Cystic fibrosis	Fatty Acid Oxidation disorders	Galactosemia	Hemoglobinopathies	Organic Acid disorders	Severe combined immunodeficiency	All Infants Detected
White	49,226	5	1	3[a]	44[b]	10	7	4	-	3	7	84
Black	3,520	-	-	-	4[c]	-	1	-	13	2	4	24
Asian	5,400	1	-	1	17	1	1	-	3	5	-	29
Native American	934	-	-	-	4	-	2[f]	-	1	-	-	7
Other[g]	16,040	1	-	1	21[d]	1[e]	-	-	8	3	2	37
Unknown[h]	12,114	-	-	2	12	3	-	-	-	1	4	22
All WA Births[i]	**87,234**	**7**	**1**	**7**	**102**	**15**	**11**	**4**	**25**	**14**	**17**	**203**
Hispanic[j]	17,606	-	-	2	18	4	-	-	-	1	3	28

[a]Excludes one white infant with CAH who was not detected through newborn screening.

[b]Includes one white infant with CH who resides out-of-state. Excludes one white infant with CH who was born out-of-state and one white infant with CH who was not detected by newborn screening.

[c]Excludes one black infant with CH who was not detected through newborn screening.

[d]Excludes one infant of other race with CH who was born out-of-state.

[e]Excludes one infant of other race with CF who was not detected by newborn screening.

[f]Includes one Native American infant with a FAO disorder who resides in Alaska.

[g]Reflects other races not listed above (including Pacific Islander) and multiracial (more than one race designation on the screening form).

[h]Race was not reported on the screening form.

[i]Excludes 437 infants born out-of-state who received one or more newborn screens in Washington.

[j]Hispanics can be of any race and are included in the figures above.

Newborn Screening Follow-up

All specimens determined to be presumptive positive through the Newborn Screening Program are followed up immediately through direct telephone contact with the child's primary care provider. This is to ensure that diagnostic testing and treatment, if indicated, begins as quickly as possible. Specialty care clinics throughout the state are supported by a clinic subsidy fee. Funds from this fee are passed to the clinics to subsidize the consultation and care for babies diagnosed with newborn screening conditions. Following a definitive diagnosis, a long-term, disease-specific medical management program is implemented as follows:

Phenylketonuria (PKU): Children are seen monthly in Seattle and every other month in Spokane by the department-supported University of Washington Phenylketonuria Clinic. An interdisciplinary team consisting of a pediatric metabolic physician, nutritionists, social worker, and genetic counselor work closely with each family to optimize the child's dietary compliance through intensive education and support services. Periodic neuropsychological assessments are also provided for all patients to monitor cognitive and emotional development. For adults with PKU, consultative, support, and nutritionist management services are provided at the University of Washington Division of Metabolism and Nutrition. Critical reproductive counseling and maternity services for women at risk of fetal damage due to Maternal PKU are also available. Other program components include a summer camp and Science Night through the private, nonprofit PKU Action Group.

Galactosemia, Biotinidase deficiency, Amino acid, Organic acid, & Fatty acid oxidation disorders: All children with these disorders are seen periodically as needed by the department-supported University of Washington, Seattle Children's Biochemical Genetics Clinics or Mary Bridge Children's Hospital in Tacoma. There are twice-yearly satellite clinics held in Spokane. Like PKU, an interdisciplinary team consisting of a pediatric metabolic physician, nurses, nutritionists, and genetic counselor work closely with each family to optimize the child's compliance with the specific treatment plan through intensive education and support services.

Congenital hypothyroidism (CH): Thyroid hormone therapy is monitored by the child's primary health care provider and/or pediatric endocrinologist. The department-supported Congenital Hypothyroidism Developmental Evaluation Clinic located within the Center on Human Development and Disability (CHDD) at the University of Washington provides developmental, neuropsychological and occupational therapy assessments for affected children.

Congenital adrenal hyperplasia (CAH): All children are seen for a diagnostic work-up by a pediatric endocrinologist to establish appropriate steroid hormone therapy. Long-term management is monitored by the child's primary health care provider and/or pediatric endocrinologist. Affected females with genital abnormalities related to the disorder are referred for surgical consultation.

Cystic fibrosis (CF): All children with cystic fibrosis are seen periodically, as needed, by one of the four regional CF Foundation accredited clinics – Seattle Children's Hospital (Seattle), Mary Bridge Children's Hospital (Tacoma), Sacred Heart Medical Center (Spokane), or Oregon Health Sciences University (Portland). As with PKU, an interdisciplinary team consisting of a pediatric pulmonologist, nutritionist, social worker, and nurse work closely with each family to optimize the child's growth and minimize medical complications of the condition, particularly lung disease.

Sickle cell diseases and other clinically significant Hemoglobinopathies (Hb): Affected children receive prophylactic penicillin and folic acid when indicated. Long-term management is provided by a pediatric hematologist or an interdisciplinary team consisting of a pediatric hematologist, nurse, social worker, and genetic counselor at a department-supported Comprehensive Sickle Cell Clinic – Seattle Children's Odessa Brown Children's Clinic or Mary Bridge Children's Hospital. The clinic staff works closely with each family to optimize the child's health and well-being through intensive education and support services. Periodic assessments are also provided for all patients to monitor cognitive and emotional development. Other sickle cell disease program components include a summer camp and other educational and support activities through the department-supported Northwest Sickle Cell Collaborative.

Severe combined immunodeficiency (SCID): Affected children receive immediate clinical care by immunologists at Seattle Children's Hospital. Caregivers take preventive measures to avoid exposing the baby to infectious agents while a bone marrow donor is identified (best if there is a sibling match). Transplants are typically performed at two to three months of age at the Fred Hutchinson Cancer Research Center in Seattle. The babies are closely followed for one to two years by immunologists following transplant to ensure that the transplant was successful in establishing a functional immune system.

Table 12: Follow-up Status of Infants Detected with Severe Forms of Newborn Screening Disorders

Table 13: Age at which Treatment Began for Infants Detected with Severe Forms of Newborn Screening Disorders

Table 12: Follow-Up Status of Infants Detected with Severe Forms of Newborn Screening Disorders

Births January 1, 2017 - December 31,2017

Usually babies identified with a newborn screening disorder are referred to a medical subspecialist for clinical evaluation and medical management. In rare instances, a primary care provider will assume medical care with consultation from a subspecialist. This table documents where babies with severe forms of newborn screening disorders were referred for medical care.

Follow-Up	*Amino acid disorders*	*Biotinidase deficiency*	*Congenital adrenal hyperplasia*	*Congenital hypothyroidism*	*Cystic fibrosis*	*Fatty acid oxidation disorders*	*Galactosemia*	*Hemoglobinopathies*	*Organic acid disorders*	*Severe combined immunodeficiency*	**All Infants**
Referred to medical specialist – (i.e., pediatric endocrinologist, hematologist, or comprehensive clinic)	5	1	7[a]	48[b]	15[c]	8	4	14	6	4	112
Followed by primary care provider, with some consultation from specialist	-	-	-	-	-	-	-	-	-	-	0
Infant died or Lost to Follow-up	-	-	-	-	-	1[d]	-	-	-	-	1
Total	**5**	**1**	**7**	**48**	**16**	**9**	**4**	**14[e]**	**6**	**4**	**113**

[a]Excludes one infant with congenital adrenal hyperplasia not detected through newborn screening due to an unsatisfactory specimen.

[b]Excludes two infants born out-of-state with congenital hypothyroidism and referred to an endocrinologist.

[c]Excludes one infant with cystic fibrosis not detected through newborn screening.

[d]Infant with Tri-functional protein (TFP) deficiency expired on day of life eight from multi-organ failure.

[e]See Key 3: Newborn Hemoglobin Screening Explanations and Definitions of Phenotypes.

Table 13: Age at which Treatment Began for Infants Detected with Severe Forms of Newborn Screening Disorders

Births January 1, 2017 - December 31, 2017

This table documents the age at treatment for the babies diagnosed with severe newborn screening conditions. Please note that a subset of these babies were referred for diagnostic testing after the second newborn screen (following a normal first test or a pattern of abnormal results), prompting the additional testing and diagnosis.

Disorder	Number of Infants	Age Treatment Began (days)	
		Median	Range
Amino acid disorders	5	6	2 - 20
Biotinidase deficiency	1	20	n/a
Congenital adrenal hyperplasia	6[a]	15	5 - 30
Congenital hypothyroidism	47[b]	9	3 - 99
Cystic fibrosis	14[c]	19	4 - 52
Fatty acid oxidation disorders	7[d]	6	1 - 50
Galactosemia	4	4	3 - 6
Hemoglobinopathies[e]	14	17	5 - 45
Organic acid disorders	6	13	3 - 156
Severe combined immunodeficiency	3[f]	13	12 - 16
Total	**107**	**12**	**1- 156**

[a]Excludes two infants: one where treatment began on day of life one due to clinical symptoms and one who was not detected by newborn screening due to an unsuitable specimen, infant received treatment at day of life nine.

[b]Excludes three infants: two infants born out-of-state and one infant with a prenatal diagnosis where treatment began on day of life one.

[c]Excludes two infants: one with a prenatal diagnosis where treatment began on day of life six and one infant who was not detected through newborn screening.

[d]Excludes two infants: one with Tri-functional protein (TFP) deficiency where treatment began on the first day of life due to clinical symptoms and one infant with Medium-chain acyl-CoA dehydrogenase (MCAD) deficiency where treatment and follow-up were delayed due to a positive family history.

[e]See Key 3: Newborn Hemoglobin Screening Explanations and Definitions of Phenotypes.

[f]Excludes one infant where treatment began on the first day of life due to a positive family history.

Newborn Screening Future Activities

Newborn Screening Conditions

In January of 2016, the Washington State Board of Health accepted the Newborn Screening Advisory Committee's recommendation to add X-linked adrenoleukodystrophy (X-ALD) to the Washington mandatory screening panel. X-ALD is a disorder affecting the body's nervous and endocrine systems that can cause death or permanent disability if not detected and treated early. The Department of Health and Board of Health began routine screening for X-ALD March 1, 2018.

The Newborn Screening Program (NBS) received a $70,000 grant from the Association of Public Health Laboratories to assist in implementing testing for new conditions. Program efforts focused on validating laboratory methods, evaluating and improving educational materials, improving long-term follow-up efforts, and providing in-person outreach and training opportunities at hospitals, birth centers, and clinics.

Newborn Screening Operations

To better serve our customers, NBS implemented in summer of 2018 an online web portal for accessing newborn screening results. Secure Remote Viewer (SRV) is a module of the current newborn screening database Neometrics. SRV allows customers (hospitals, clinics, midwives, and laboratories) to view and download newborn screening results from a secure web portal. It is anticipated that SRV will provide timely access to screening results and greatly reduce the high volume of result requests. Any partner interested in gaining access to SRV can sign up by visiting the Newborn Screening SRV website www.doh.wa.gov/nbs/srv.

Education and Compliance Outreach

The Newborn Screening Program is developing online training modules to expand outreach and provide on-demand training for health care professionals. The first module will focus on how to complete the newborn screening cards accurately and completely. Future modules will focus on general newborn screening guidelines, specimen collection techniques, and specimen handling and shipping.

In addition to general training regarding specimen collection and reporting, NBS will continue to provide outreach and education to Washington State hospitals and other providers regarding their responsibility for specimen collection, specimen transit, and parent notification. The program routinely monitors the performance of hospitals and health care providers in meeting these responsibilities and will work with them to ensure timely testing and specimen submission, and appropriate diagnostic actions in order to protect and improve the health of Washington's youngest citizens.

Appendices

Appendix A:	Recommended Uniform Screening Panel (RUSP)
Appendix B:	Washington's Newborn Screening Panel - History of Conditions Added
Appendix C:	Specimen Collection and Transit Report by Hospital Birth Volume
Appendix D:	Specimen Collection and Transit Report by Hospital Geographic Location
Appendix E:	Specimen Age at Collection and Specimen Transit Time
Appendix F:	Unsatisfactory Specimens
Appendix G:	Demographic Errors on Specimen Cards
Appendix H:	Infants Detected with Newborn Screening Disorders – Births 2010-2016
Appendix I:	Newborn Hemoglobin Screening Infants Detected by Phenotype and Reported Race/Ethnicity

Keys

Key 1:	Unsatisfactory Specimen Descriptions
Key 2:	Hospital Volume Categorizations
Key 3:	Newborn Hemoglobin Screening - Explanations and Definitions of Phenotypes

Appendix A: Recommended Uniform Screening Panel (RUSP)

Each state has autonomy to decide how to operate newborn screening, including the number of conditions on their screening panel. The Advisory Committee on Heritable Disorders in Newborns and Children is an advisory committee that makes recommendations for national newborn screening standards. The Secretary of Health and Human Services uses work from this advisory committee to make changes to the Recommended Uniform Screening Panel (RUSP). The conditions on the RUSP at the end of 2017 are in the following table.

Code	Core Condition	Required in WA?	Notes
PROP	Propionic acidemia	Yes	
MUT	Methylmalonic acidemia (mutase deficiency)	Yes	
Cbl A,B	Methylmalonic acidemia (cobalamin A, B deficiency)	Yes	
IVA	Isovaleric acidemia	Yes	
3-MCC	3-methylcrotonyl-CoA carboxylase deficiency	No	Often detected as a differential diagnosis for HMG or MCD[a]
HMG	3-hydroxy-3-methyglutaric aciduria	Yes	
MCD	Holocarboxylase synthase deficiency	Yes	
ßKT	ß-ketothiolase deficiency	Yes	
GA1	Glutaric acidemia, type I	Yes	
CUD	Carnitine uptake defect/carnitine transport defect	Yes	
MCAD	Medium-chain acyl-CoA dehydrogenase deficiency	Yes	
VLCAD	Very long-chain acyl-CoA dehydrogenase deficiency	Yes	
LCHAD	Long-chain L-3 hydroxy acyl-CoA dehydrogenase deficiency	Yes	
TFP	Trifunctional protein deficiency	Yes	
ASA	Argininosuccinic acidemia	Yes	
CIT	Citrullinemia, type I	Yes	
MSUD	Maple syrup urine disease	Yes	
HCY	Homocystinuria	Yes	
PKU	Classic phenylketonuria	Yes	
TYR I	Tyrosinemia, type I	Yes	
CH	Primary congenital hypothyroidism	Yes	
CAH	Congenital adrenal hyperplasia	Yes	
Hb SS	S,S disease (Sickle cell anemia)	Yes	
Hb S/ßTh	S, βeta-thalassemia	Yes	
Hb S/C	S,C disease	Yes	
BIO	Biotinidase deficiency	Yes	
CCHD	Critical congenital heart disease	Yes	Point of Care Test
CF	Cystic fibrosis	Yes	
GALT	Classic galactosemia	Yes	
GSD II	Glycogen storage disease, type II (Pompe)	No[b]	Approved by SBOH 2017
HEAR	Hearing loss	No	Point of Care Test: universally offered, but not required by law
SCID	Severe combined immunodeficiencies	Yes	
MPS I	Mucopolysaccharidosis type I	No[b]	Approved by SBOH 2017
X-ALD	X-linked adrenoleukodystrophy	Yes[c]	Added to WAC 246-650 in 2017

[a]The NBS Technical Advisory Committee considered adding 3-MCC in 2008. It did not meet the Prevention Potential and Medical Rationale and Public Health Rationale criteria because the expert biochemical geneticists believe it is largely a benign condition.

[b]The Department of Health and State Board of Health are preparing to add Pompe and MPS-I and anticipate starting screening for these two conditions in fall 2019 pending funding from legislature.

[c]The Department of Health began screening for X-ALD in March 2018.

Appendix B: Washington's Newborn Screening Panel History of Conditions Added

In 1963 phenylketonuria (PKU) screening was offered through the state's Public Health Laboratories as a voluntary service. The legislature subsequently adopted revisions to the statute in 1976 to require screening of all infants born in a hospital in Washington State unless the parents refused on religious grounds. The legislation also gave authority to the State Board of Health (SBOH) to determine which other disorders should be included in the screening and to adopt rules to achieve the intent of the law. The table below is a timeline of disorders added to the panel:

Year	Disorders Added
1963	Phenylketonuria (PKU) - test available, voluntary
1978	Congenital hypothyroidism (CH)
1984	Congenital adrenal hyperplasia (CAH)
1991	Hemoglobinopathies (Hb)
2004	Biotinidase deficiency (BIO)
	Galactosemia (GALT)
	Homocystinuria (HCY)
	Maple syrup urine disease (MSUD)
	Medium-chain acyl-CoA dehydrogenase (MCAD) deficiency
2006	Cystic fibrosis (CF)
2008	Amino acid (AA) disorders:
	· Arginosuccinic acidemia (ASA)
	· Citrullinemia (CIT)
	· Tyrosinemia type 1 (TYR-1)
	Fatty acid oxidation (FAO) disorders:
	· Carnitine uptake deficiency (CUD)
	· Long-chain L-3-hydroxy acyl-CoA dehydrogenase (LCHAD) deficiency
	· Trifunctional protein (TFP) deficiency
	· Very long-chain acyl-CoA dehydrogenase (VLCAD) deficiency
	Organic acid disorders (OA)
	· 3-hydroxy-3-methylglutaric aciduria (Hydroxymethylglutaric aciduria - HMG)
	· Beta-ketothiolase (BKT) deficiency
	· Glutaric acidemia type 1 (GA-1)
	· Isovaleric acidemia (IVA)
	· Methylmalonic acidemia - mutase (MUT) deficiency
	· Methylmalonic acidemia – cobalamin A, B (Cbl A,B) deficiency
	· Multiple carboxylase deficiency (MCD)
	· Propionic acidemia (PROP)
2014	Severe combined immunodeficiency (SCID)

In 2015, a Newborn Screening Advisory Committee convened by the SBOH considered X-linked adrenoleukodystrophy (X-ALD) as a candidate for screening. The SBOH accepted the Advisory Committee's recommendation and the Department of Health (DOH) began screening in March 2018.

In 2017, a Newborn Screening Advisory Committee convened by the SBOH considered Pompe disease and mucopolysaccharidosis type-1 (MPS-I) as candidates for screening. The SBOH recommended adding both of these conditions to the mandatory panel. The DOH is seeking authority to increase the newborn screening fee from the legislature before adding these conditions. The Department of Health and SBOH are preparing for this expansion and anticipate starting screening in fall 2019.

Appendix C: Specimen Collection and Transit Performance Report by Hospital Birth Volume

Births January 1, 2017 - December 31, 2017

Each hospital or health care provider attending a birth outside of a hospital is required to collect and transport specimens to the State Public Health Laboratories (PHL) within specified timeframes (70.83.020 RCW). These requirements ensure timely testing and diagnostic treatment for the protection of newborns. The timeframes for specimen collection and transport are:

1) Initial specimen collected no later than 48 hours following birth

2) Initial specimen received by State PHL within 72 hours of collection (excluding Sundays and Thanksgiving)

Hospital of Birth	City	Eligible Infants	1) Collection Compliance	2) Transit Compliance
High Volume Hospitals (> 500 births per quarter)		**51,731**	**99.2%**	**91.3%**
EvergreenHealth Kirkland	Kirkland	4,596	99.5%	99.7%
Good Samaritan Hospital - MultiCare	Puyallup	2,280	99.6%	96.5%
Kadlec Regional Medical Center	Richland	2,798	99.6%	60.1%
Legacy Salmon Creek Medical Center	Vancouver	3,422	99.4%	96.7%
Overlake Medical Center	Bellevue	3,687	99.5%	98.7%
PeaceHealth Southwest Medical Center	Vancouver	2,062	97.9%	95.0%
Providence Everett Regional Medical Center	Everett	4,706	99.0%	95.3%
Providence St Peter Hospital	Olympia	2,090	99.6%	41.1%
Sacred Heart Medical Center - Providence	Spokane	3,104	99.1%	96.0%
St Joseph Hospital PeaceHealth - Bellingham	Bellingham	2,004	99.3%	86.7%
St Joseph Medical Center - Tacoma	Tacoma	4,235	99.1%	97.5%
Swedish - First Hill	Seattle	7,532	99.0%	99.4%
Tacoma General Hospital - MultiCare	Tacoma	2,916	98.4%	96.0%
Valley Medical Center - UW Medicine	Renton	3,736	99.0%	90.5%
Virginia Mason Memorial	Yakima	2,563	99.6%	77.5%
Medium Volume Hospitals (100-500 births per quarter)		**29,261**	**98.7%**	**91.5%**
Auburn Medical Center - MultiCare	Auburn	1,214	99.4%	97.4%
Capital Medical Center	Olympia	662	98.2%	90.8%
Central Washington Hospital/Confluence Health	Wenatchee	1,339	98.4%	95.9%
Deaconess Hospital - MultiCare	Spokane	1,427	99.2%	96.8%
Grays Harbor Community Hospital	Aberdeen	442	98.2%	33.5%
Harrison Medical Center	Bremerton	1,953	99.2%	98.5%
Highline Medical Center	Burien	982	99.3%	97.4%
Holy Family Hospital - Providence	Spokane	1,225	99.6%	90.9%
Island Hospital	Anacortes	481	98.3%	98.1%
Madigan Army Medical Center	Joint Base Lewis-McChord	1,939	99.9%	91.0%
Naval Hospital - Bremerton	Bremerton	527	99.1%	96.2%
Northwest Hospital - UW Medicine	Seattle	1,080	99.5%	99.7%
Olympic Medical Center	Port Angeles	501	95.8%	72.3%
Othello Community Hospital	Othello	480	98.1%	44.0%
Providence Centralia Hospital	Centralia	683	99.3%	47.1%
Pullman Regional Hospital	Pullman	422	99.3%	88.6%
Samaritan Healthcare	Moses Lake	1,026	93.6%	92.2%

Appendix C: Specimen Collection and Transit Performance Report (cont.)

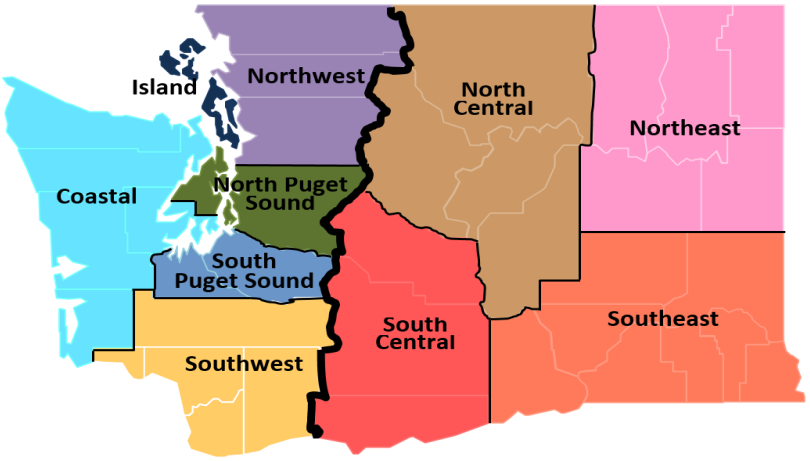
Hospital of Birth	City	Eligible Infants	1) Collection Compliance	2) Transit Compliance
Medium Volume Hospitals (100-500 births per quarter) cont.		**29,261**	**98.7%**	**91.5%**
Skagit Valley Hospital	Mount Vernon	989	99.2%	85.6%
St Francis Hospital	Federal Way	1,275	98.5%	96.1%
St John Medical Center - PeaceHealth	Longview	812	98.8%	96.3%
St Mary Medical Center - Providence	Walla Walla	687	95.5%	94.0%
Sunnyside Community Hospital	Sunnyside	522	99.8%	85.1%
Swedish - Ballard	Seattle	1,122	99.5%	98.9%
Swedish - Edmonds	Edmonds	1,370	99.5%	98.2%
Swedish - Issaquah	Issaquah	1,623	99.8%	99.0%
Toppenish Community Hospital	Toppenish	404	99.0%	94.8%
Trios Health Hospital	Kennewick	1,439	99.2%	85.0%
University of Washington Medical Center	Seattle	1,927	97.2%	98.2%
Valley Hospital	Spokane	708	99.0%	92.8%
Low Volume Hospitals (< 100 births per quarter)		**2,932**	**97.4%**	**70.8%**
Cascade Valley Hospital	Arlington	155	96.1%	55.5%
Coulee Medical Center	Grand Coulee	69	97.1%	36.2%
EvergreenHealth - Monroe	Monroe	2	100%	100%
Forks Community Hospital	Forks	46	97.8%	97.8%
Jefferson Healthcare	Port Townsend	113	92.0%	45.1%
Kittitas Valley Healthcare	Ellensburg	324	97.8%	84.9%
Klickitat Valley Hospital	Goldendale	2	100%	50.0%
Lake Chelan Community Hospital	Chelan	95	93.7%	66.3%
Lincoln Hospital	Davenport	1	100%	100%
Mason General Hospital	Shelton	256	97.3%	57.8%
Mid-Valley Hospital	Omak	229	95.2%	72.5%
Mount Carmel Hospital - Providence	Colville	217	95.9%	92.2%
Naval Hospital - Oak Harbor	Oak Harbor	183	98.4%	86.3%
Newport Hospital	Newport	92	100%	95.7%
North Valley Hospital	Tonasket	83	100%	86.7%
Prosser Memorial Hospital	Prosser	381	100%	25.2%
St Clare Hospital	Lakewood	4	100%	100%
St Elizabeth Hospital	Enumclaw	335	98.2%	96.1%
Summit Pacific Medical Center	Elma	4	100%	50.0%
Three Rivers Hospital	Brewster	93	96.8%	58.1%
WhidbeyHealth Medical Center	Coupeville	214	97.2%	86.4%
Whitman Hospital and Medical Center	Colfax	32	100%	93.8%
Willapa Harbor Hospital	South Bend	1	100%	100%
Yakima Regional Medical Center	Yakima	1	100%	100%
All Hospital Births		**83,924**	**98.9%**	**90.2%**

Appendix D: Specimen Collection and Transit Performance Report by Hospital Geographic Location

Births January 1, 2017 - December 31, 2017

Each hospital or health care provider attending a birth outside of a hospital is required to collect and transport specimens to the State Public Health Laboratories (PHL) within specified timeframes (70.83.020 RCW). These requirements ensure timely testing and diagnostic treatment for the protection of newborns. The timeframes for specimen collection and transport are:

1) Initial specimen collected no later than 48 hours following birth
2) Initial specimen received by State PHL within 72 hours of collection (excluding Sundays and Thanksgiving)



Hospital of Birth	City	Eligible Infants	1) Collection Compliance	2) Transit Compliance
Northwest Hospitals		**9,226**	**99.1%**	**92.2%**
Cascade Valley Hospital	Arlington	155	96.1%	55.5%
EvergreenHealth - Monroe	Monroe	2	100%	100%
Providence Everett Regional Medical Center	Everett	4,706	99.0%	95.3%
Skagit Valley Hospital	Mount Vernon	989	99.2%	85.6%
St Joseph Hospital PeaceHealth - Bellingham	Bellingham	2,004	99.3%	86.7%
Swedish - Edmonds	Edmonds	1,370	99.5%	98.2%
North Puget Sound Hospitals		**31,589**	**99.1%**	**97.8%**
Auburn Medical Center - MultiCare	Auburn	1,214	99.4%	97.4%
EvergreenHealth Kirkland	Kirkland	4,596	99.5%	99.7%
Harrison Medical Center	Bremerton	1,953	99.2%	98.5%
Highline Medical Center	Burien	982	99.3%	97.4%
Naval Hospital - Bremerton	Bremerton	527	99.1%	96.2%
Northwest Hospital - UW Medicine	Seattle	1,080	99.5%	99.7%
Overlake Medical Center	Bellevue	3,687	99.5%	98.7%
St Elizabeth Hospital	Enumclaw	335	98.2%	96.1%
St Francis Hospital	Federal Way	1,275	98.5%	96.1%
Swedish - Ballard	Seattle	1,122	99.5%	98.9%
Swedish - First Hill	Seattle	7,532	99.0%	99.4%
Swedish - Issaquah	Issaquah	1,623	99.8%	99.0%
University of Washington Medical Center	Seattle	1,927	97.2%	98.2%
Valley Medical Center - UW Medicine	Renton	3,736	99.0%	90.5%

Appendix D: Specimen Collection and Transit Performance Report (cont.)

Hospital of Birth	City	Eligible Infants	1) Collection Compliance	2) Transit Compliance
South Puget Sound Hospitals		**14,126**	**99.2%**	**87.5%**
Capital Medical Center	Olympia	662	98.2%	90.8%
Good Samaritan Hospital - MultiCare	Puyallup	2,280	99.6%	96.5%
Madigan Army Medical Center	Joint Base Lewis-McChord	1,939	99.9%	91.0%
Providence St Peter Hospital	Olympia	2,090	99.6%	41.1%
St Clare Hospital	Lakewood	4	100%	100%
St Joseph Medical Center - Tacoma	Tacoma	4,235	99.1%	97.5%
Tacoma General Hospital - MultiCare	Tacoma	2,916	98.4%	96.0%
Southwest Hospitals		**6,979**	**98.9%**	**91.3%**
Legacy Salmon Creek Medical Center	Vancouver	3,422	99.4%	96.7%
PeaceHealth Southwest Medical Center	Vancouver	2,062	97.9%	95.0%
Providence Centralia Hospital	Centralia	683	99.3%	47.1%
St John Medical Center - PeaceHealth	Longview	812	98.8%	96.3%
Coastal Region Hospitals		**1,363**	**96.6%**	**55.5%**
Forks Community Hospital	Forks	46	97.8%	97.8%
Grays Harbor Community Hospital	Aberdeen	442	98.2%	33.5%
Jefferson Healthcare	Port Townsend	113	92.0%	45.1%
Mason General Hospital	Shelton	256	97.3%	57.8%
Olympic Medical Center	Port Angeles	501	95.8%	72.3%
Summit Pacific Medical Center	Elma	4	100%	50.0%
Willapa Harbor Hospital	South Bend	1	100%	100%
Island Region Hospitals		**878**	**98.1%**	**92.8%**
Island Hospital	Anacortes	481	98.3%	98.1%
Naval Hospital - Oak Harbor	Oak Harbor	183	98.4%	86.3%
WhidbeyHealth Medical Center	Coupeville	214	97.2%	86.4%
North Central Hospitals		**2,934**	**96.3%**	**89.0%**
Central Washington Hospital	Wenatchee	1,339	98.4%	95.9%
Coulee Medical Center	Grand Coulee	69	97.1%	36.2%
Lake Chelan Community Hospital	Chelan	95	93.7%	66.3%
Mid-Valley Hospital	Omak	229	95.2%	72.5%
North Valley Hospital	Tonasket	83	100%	86.7%
Samaritan Healthcare	Moses Lake	1,026	93.6%	92.2%
Three Rivers Hospital	Brewster	93	96.8%	58.1%

Appendix D: Specimen Collection and Transit Performance Report (cont.)

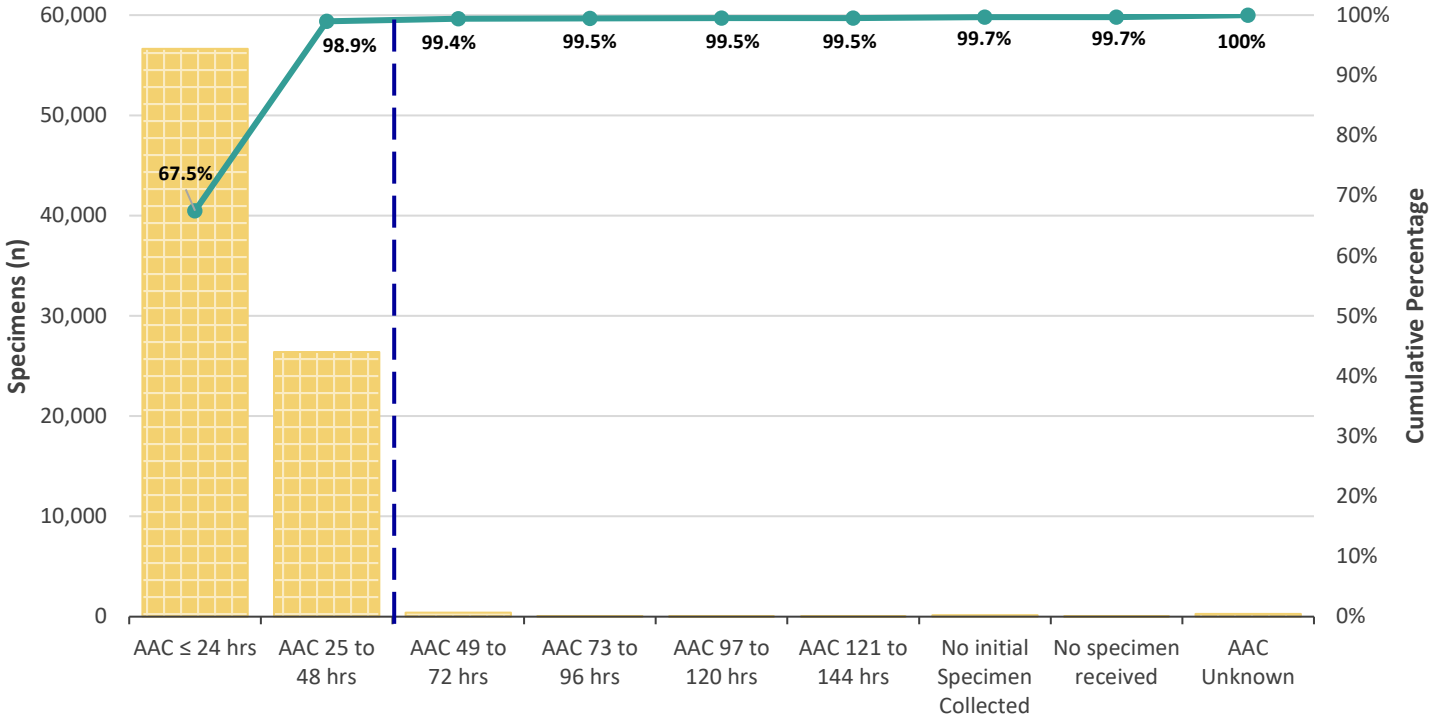
Hospital of Birth	City	Eligible Infants	1) Collection Compliance	2) Transit Compliance
South Central Hospitals		**3,294**	**99.3%**	**80.3%**
Kittitas Valley Healthcare	Ellensburg	324	97.8%	84.9%
Klickitat Valley Hospital	Goldendale	2	100%	50.0%
Toppenish Community Hospital	Toppenish	404	99.0%	94.8%
Virginia Mason Memorial	Yakima	2,563	99.6%	77.5%
Yakima Regional Medical Center	Yakima	1	100%	100%
Southeast Hospitals		**6,761**	**99.0%**	**69.6%**
Kadlec Regional Medical Center	Richland	2,798	99.6%	60.1%
Othello Community Hospital	Othello	480	98.1%	44.0%
Prosser Memorial Hospital	Prosser	381	99.7%	25.2%
Pullman Regional Hospital	Pullman	422	99.3%	88.6%
St Mary Medical Center - Providence	Walla Walla	687	95.5%	94.0%
Sunnyside Community Hospital	Sunnyside	522	99.8%	85.1%
Trios Health Hospital	Kennewick	1,439	99.2%	85.0%
Whitman Hospital and Medical Center	Colfax	32	100%	93.8%
Northeast Hospitals		**6,774**	**99.1%**	**94.8%**
Deaconess Hospital - MultiCare	Spokane	1,427	99.2%	96.8%
Holy Family Hospital - Providence	Spokane	1,225	99.6%	90.9%
Lincoln Hospital	Davenport	1	100%	100%
Mount Carmel Hospital - Providence	Colville	217	95.9%	92.2%
Newport Hospital	Newport	92	100%	95.7%
Sacred Heart Medical Center - Providence	Spokane	3,104	99.1%	96.0%
Valley Hospital	Spokane	708	99.0%	92.8%
Western Washington Out-of-Hospital Births		**2,592**	**81.9%**	**70.1%**
Eastern Washington Out-of-Hospital Births		**559**	**75.0%**	**44.9%**
All Hospital Births	**Statewide**	**83,924**	**98.9%**	**90.7%**
All Out-of-Hospital Births	**Statewide**	**3,151**	**80.6%**	**65.7%**
All Washington State Births	**Statewide**	**87,234**	**98.3%**	**89.7%**

Appendix E: Infant's Age at Collection

Born January 1, 2017 - December 31, 2017

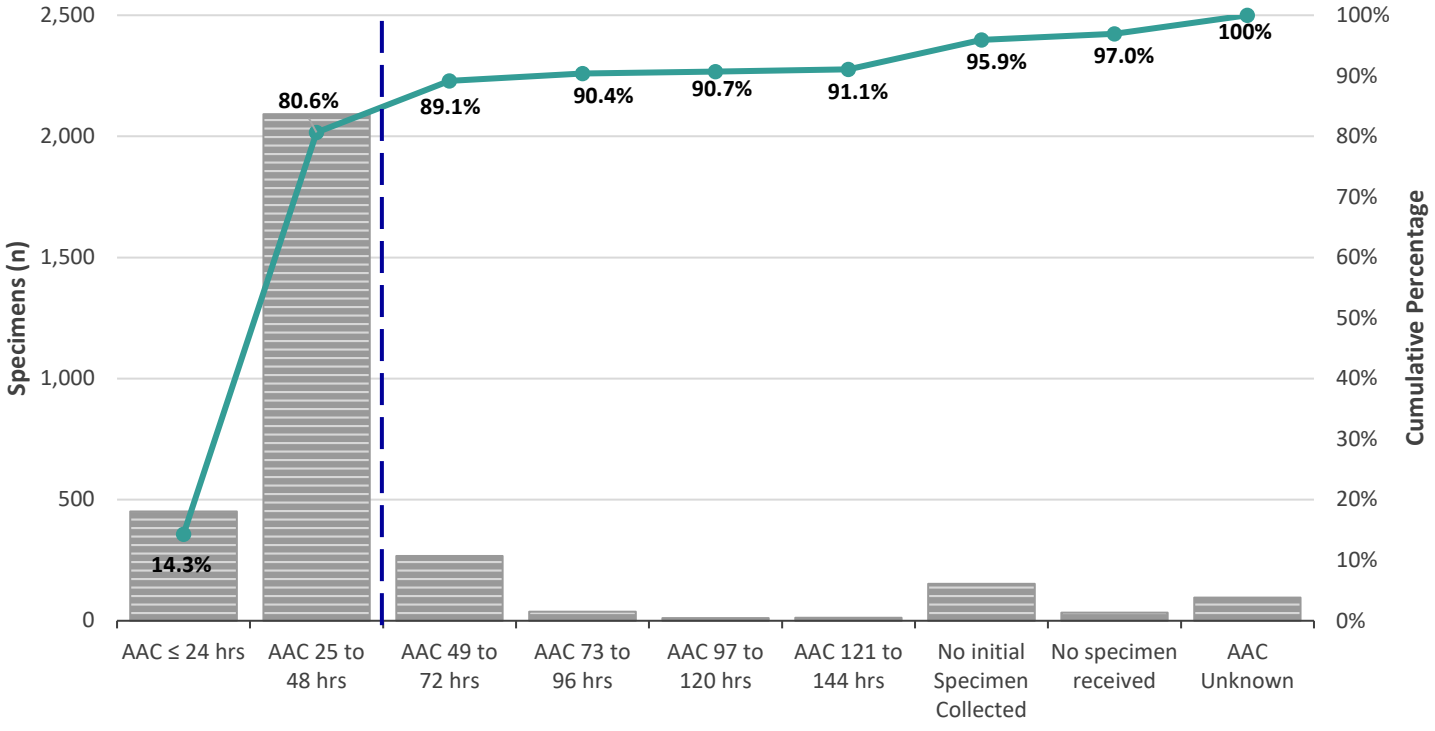
Age at Collection (AAC) Compliance - Hospital Births

884 specimens were not collected within 48 hours of birth (1.1% of hospital births)



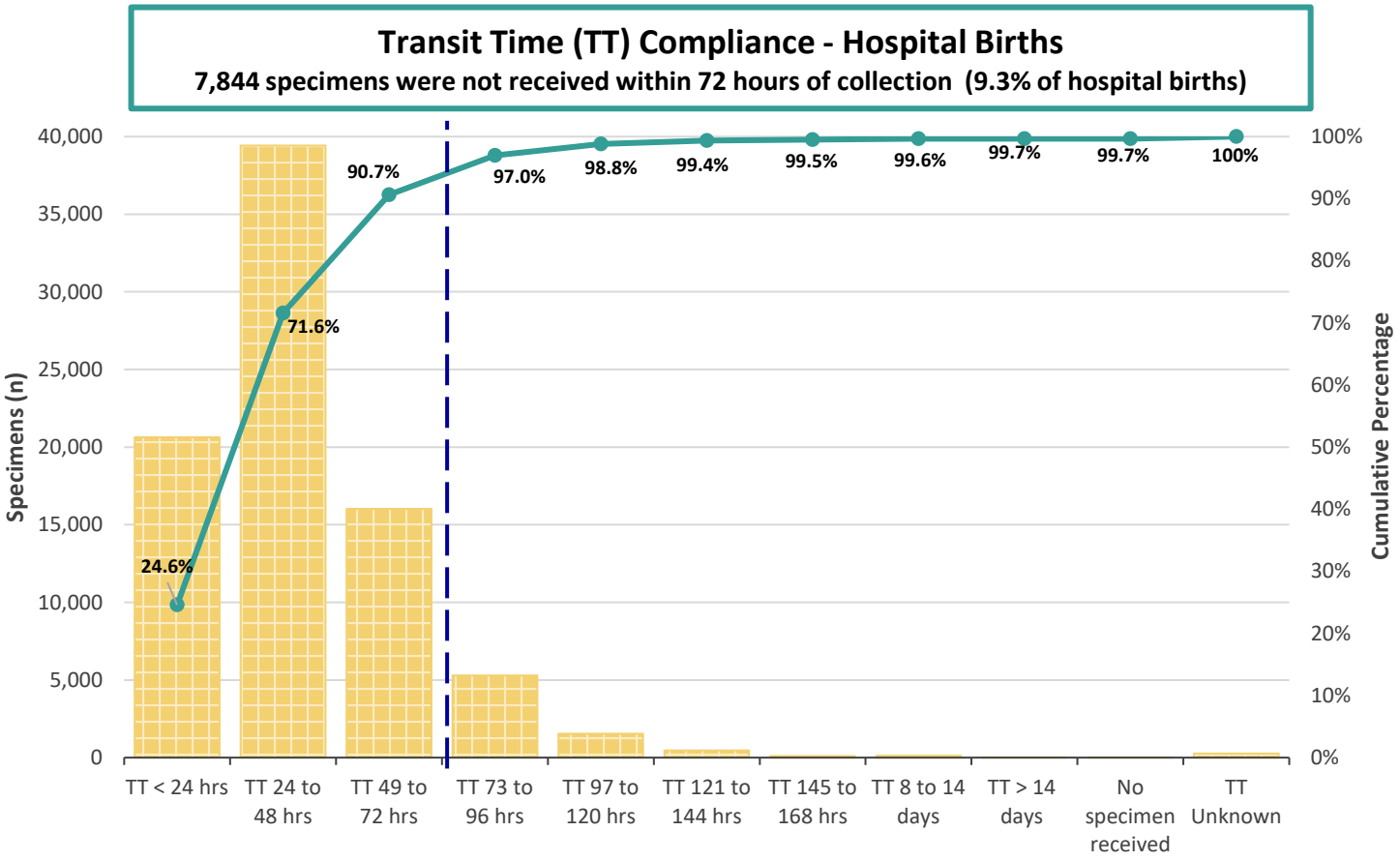
Age at Collection (AAC) Compliance - Out of Hospital Births

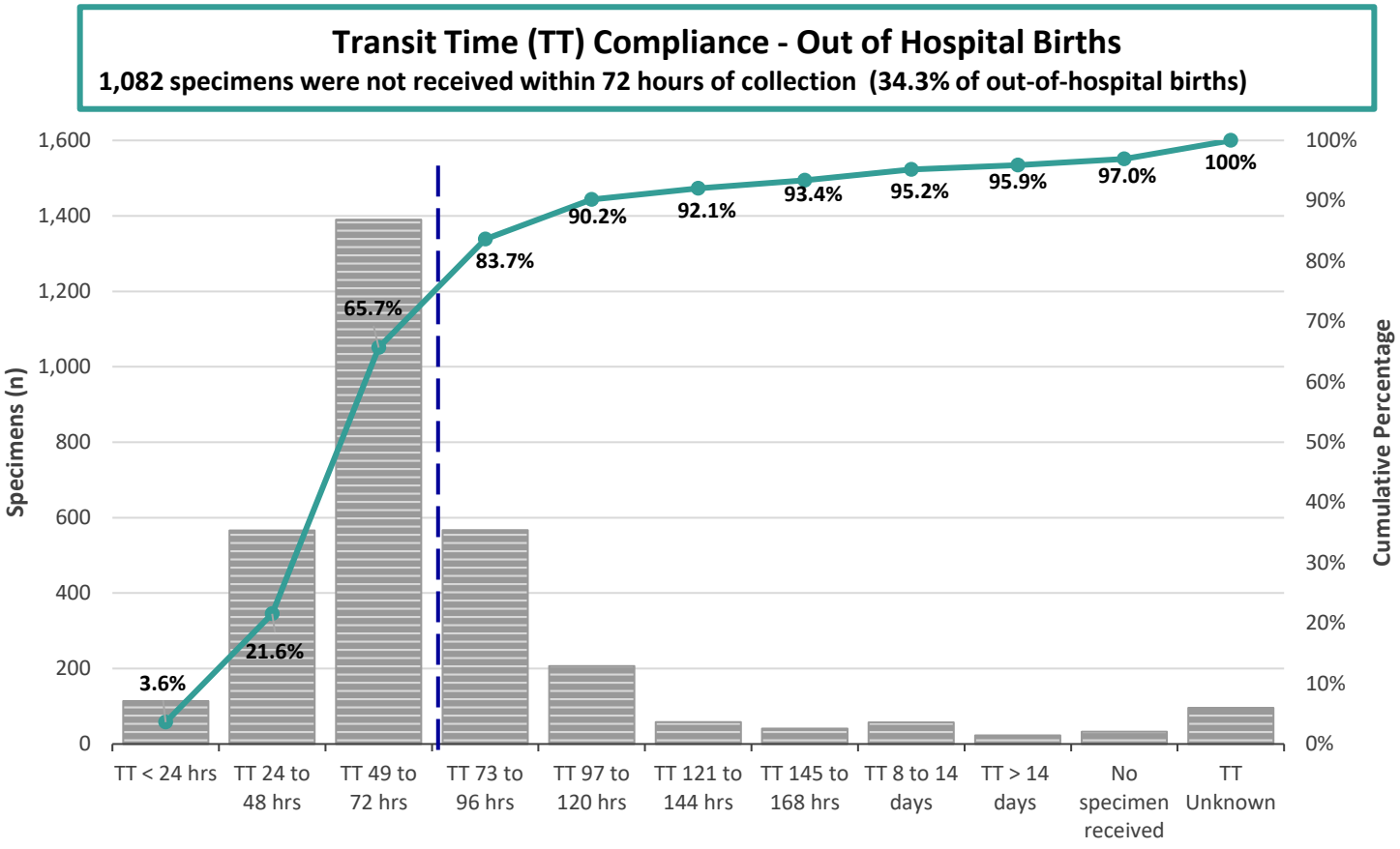
610 specimens were not collected within 48 hours of birth (19.4% of out of hospital births)



Appendix E: Specimen Transit Time

Born January 1, 2017 - December 31, 2017



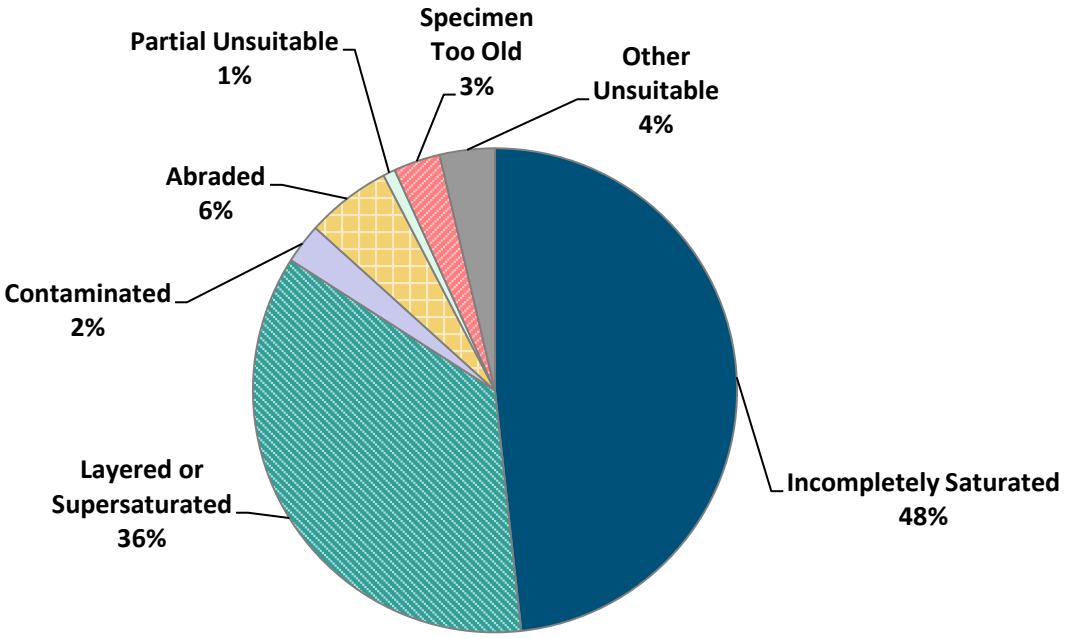


Appendix F: Unsatisfactory Specimens

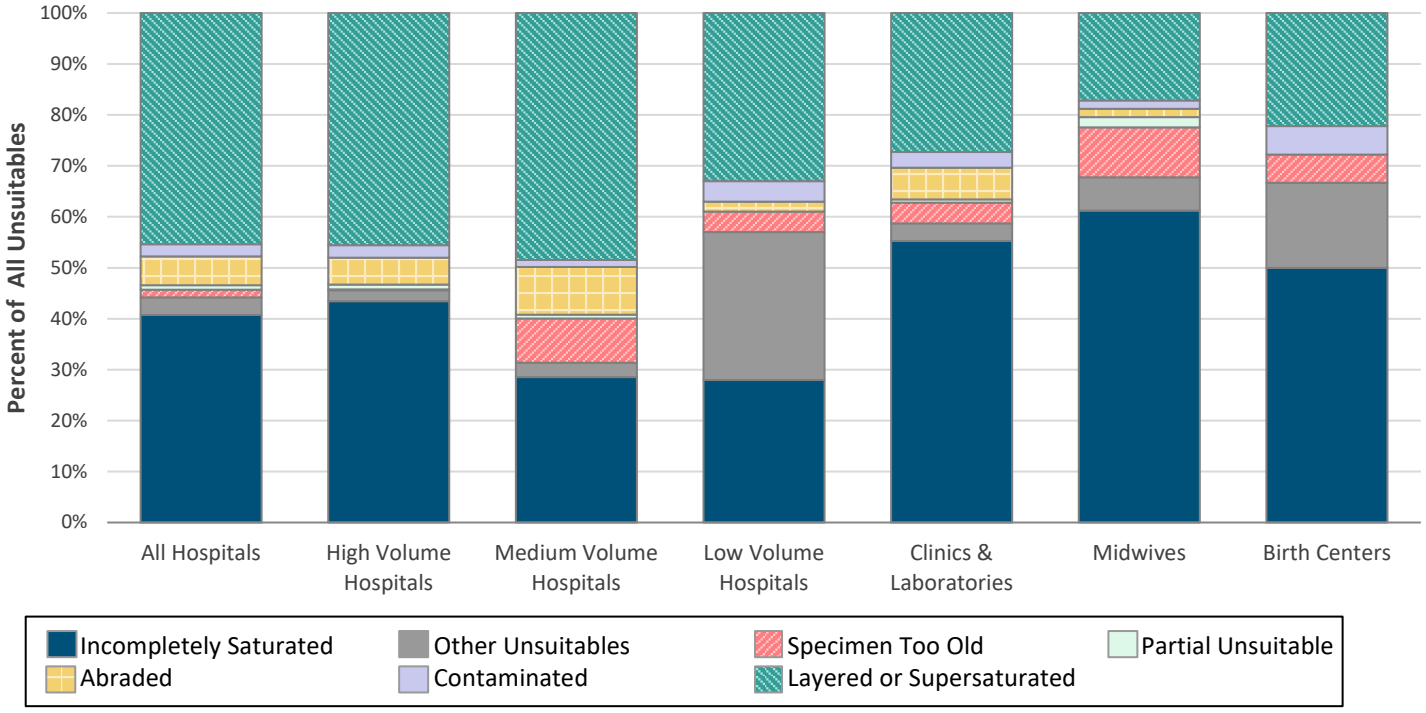
Received January 1, 2017 - December 31, 2017

Unsatisfactory Specimen Error Types[1]

Statewide: 4,324 specimens were unsatisfactory (2.5% of all specimens)



Unsatisfactory Specimen Error Type by Submitter Group[2]

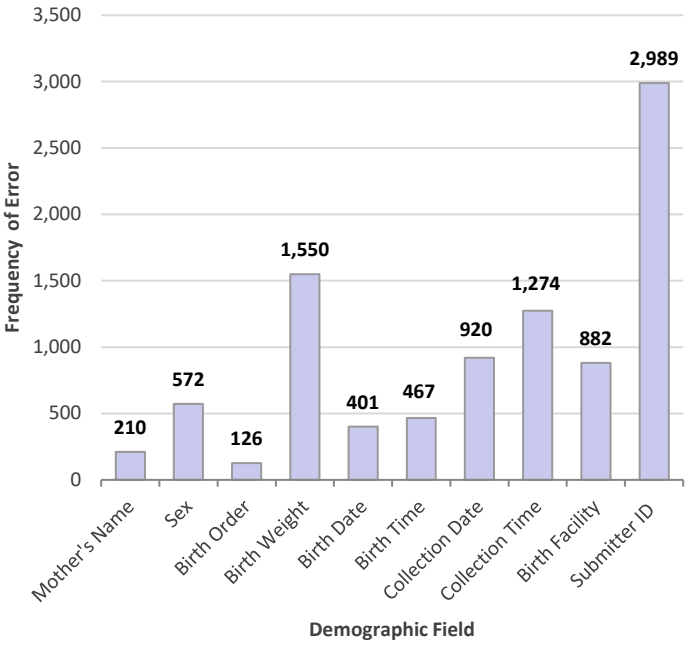


[1] See Key 1: Unsatisfactory Specimen descriptions for descriptions and causes of unsatisfactory specimens.

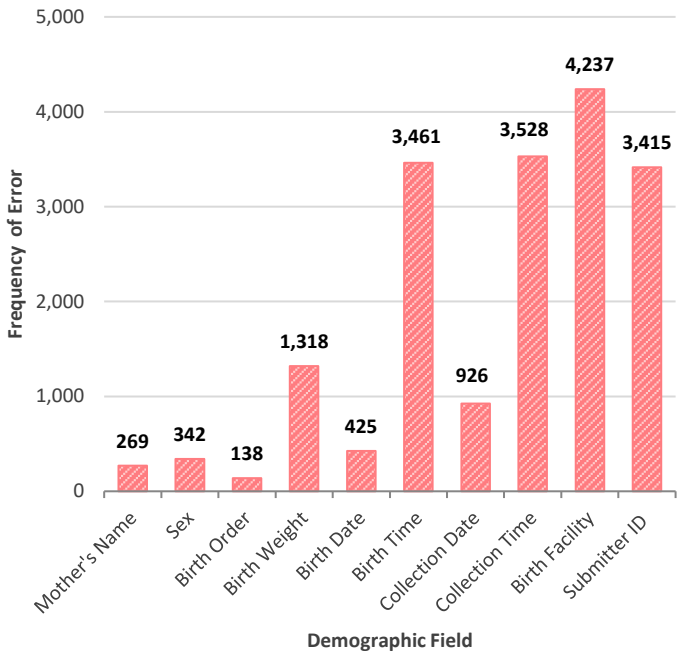
[2] See Key 2: Hospital Volume for hospital volume categorizations.

Appendix G: Demographic Errors on Specimen Cards
Received January 1, 2017 - December 31, 2017

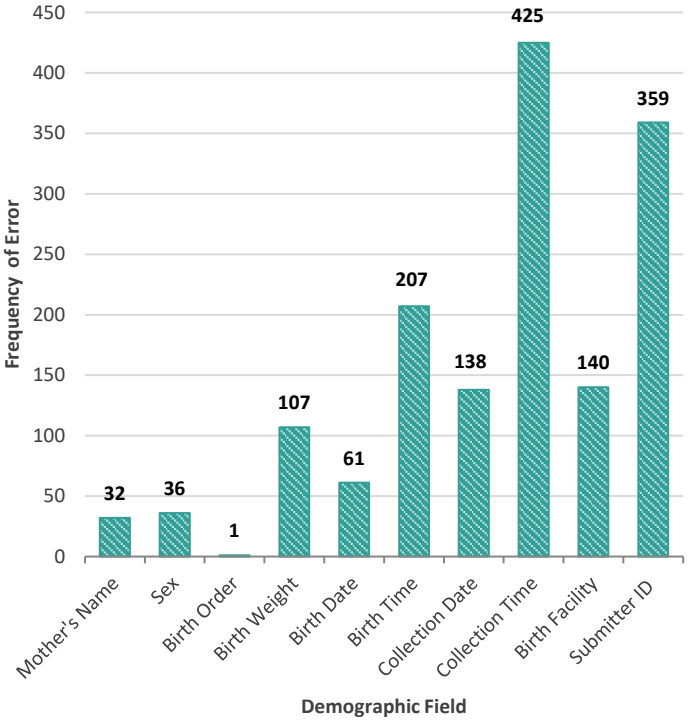
Hospital Errors



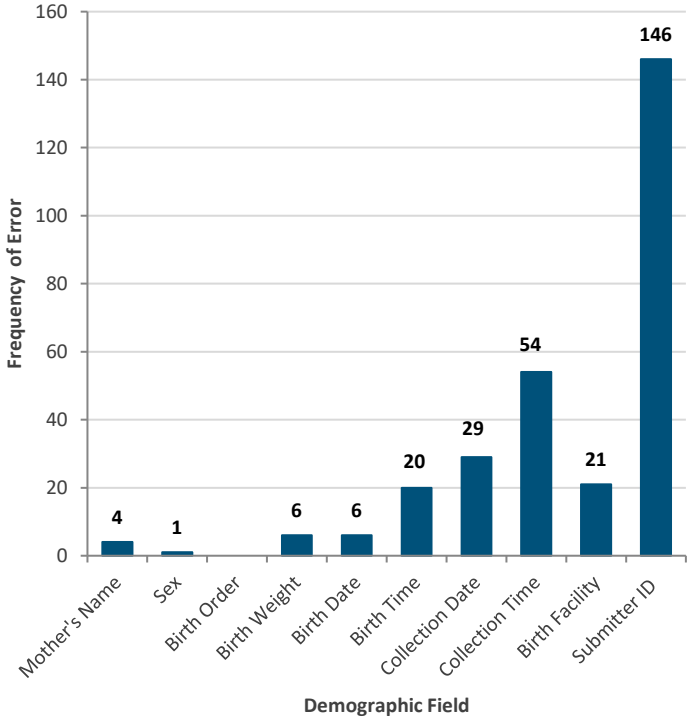
Clinic and Laboratory Errors



Midwife Errors



Birth Center Errors

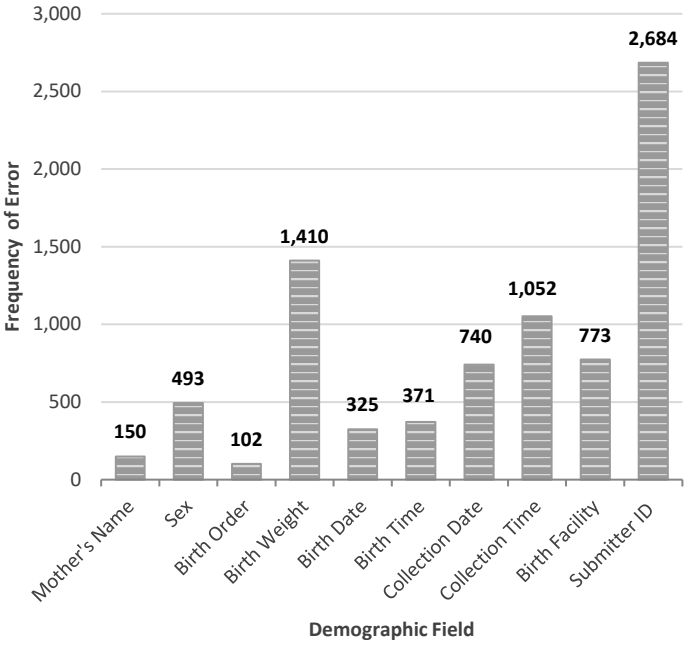


Appendix G: Demographic Errors on Specimen Cards (cont.)

Received January 1, 2017 - December 31, 2017

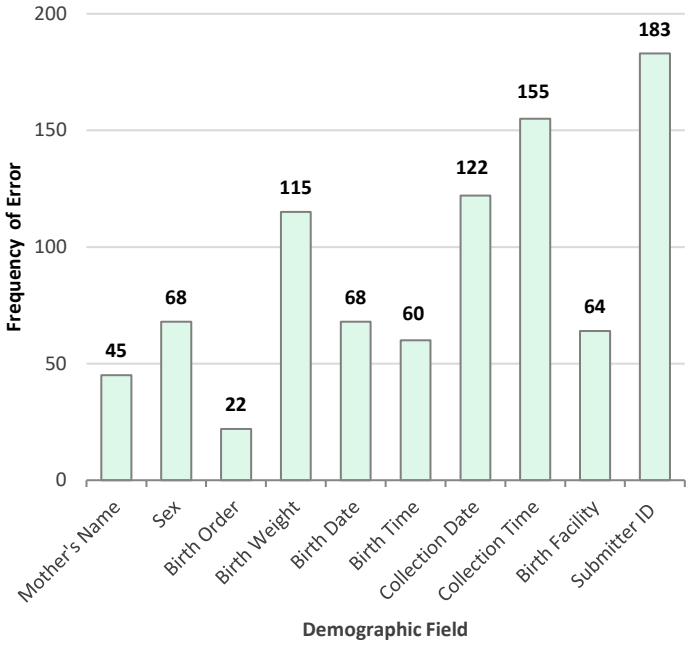
High Volume Hospital Errors[1]

> 3 specimens/day



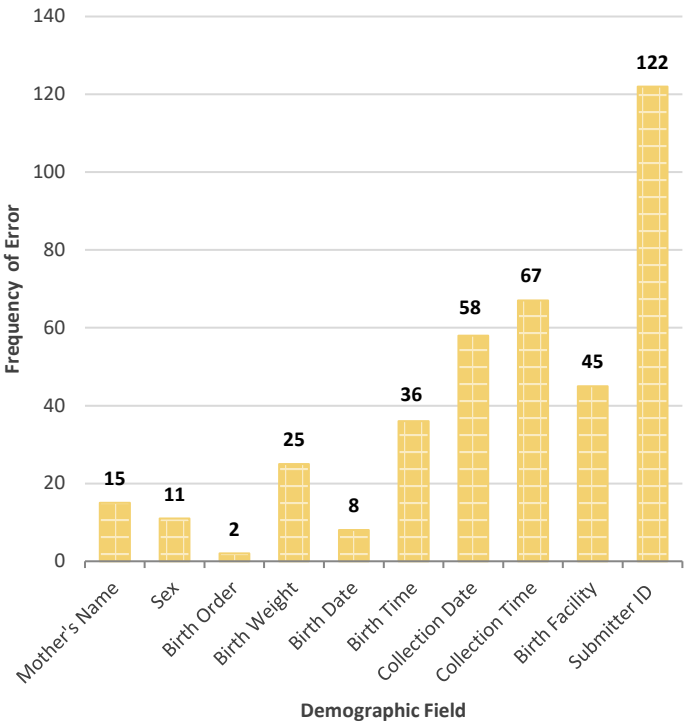
Medium Volume Hospital Errors[1]

1 to 3 specimens/day

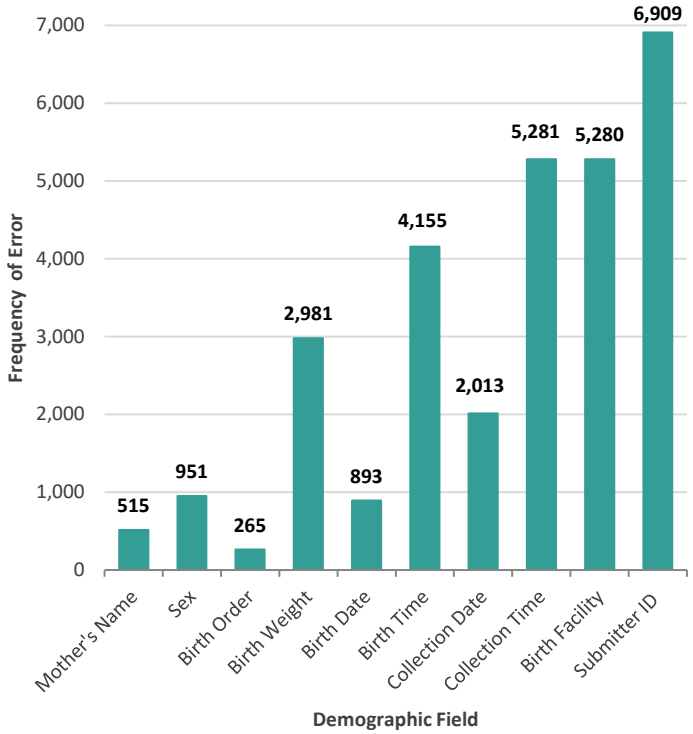


Low Volume Hospital Errors[1]

< 1 specimen/day



Statewide Errors

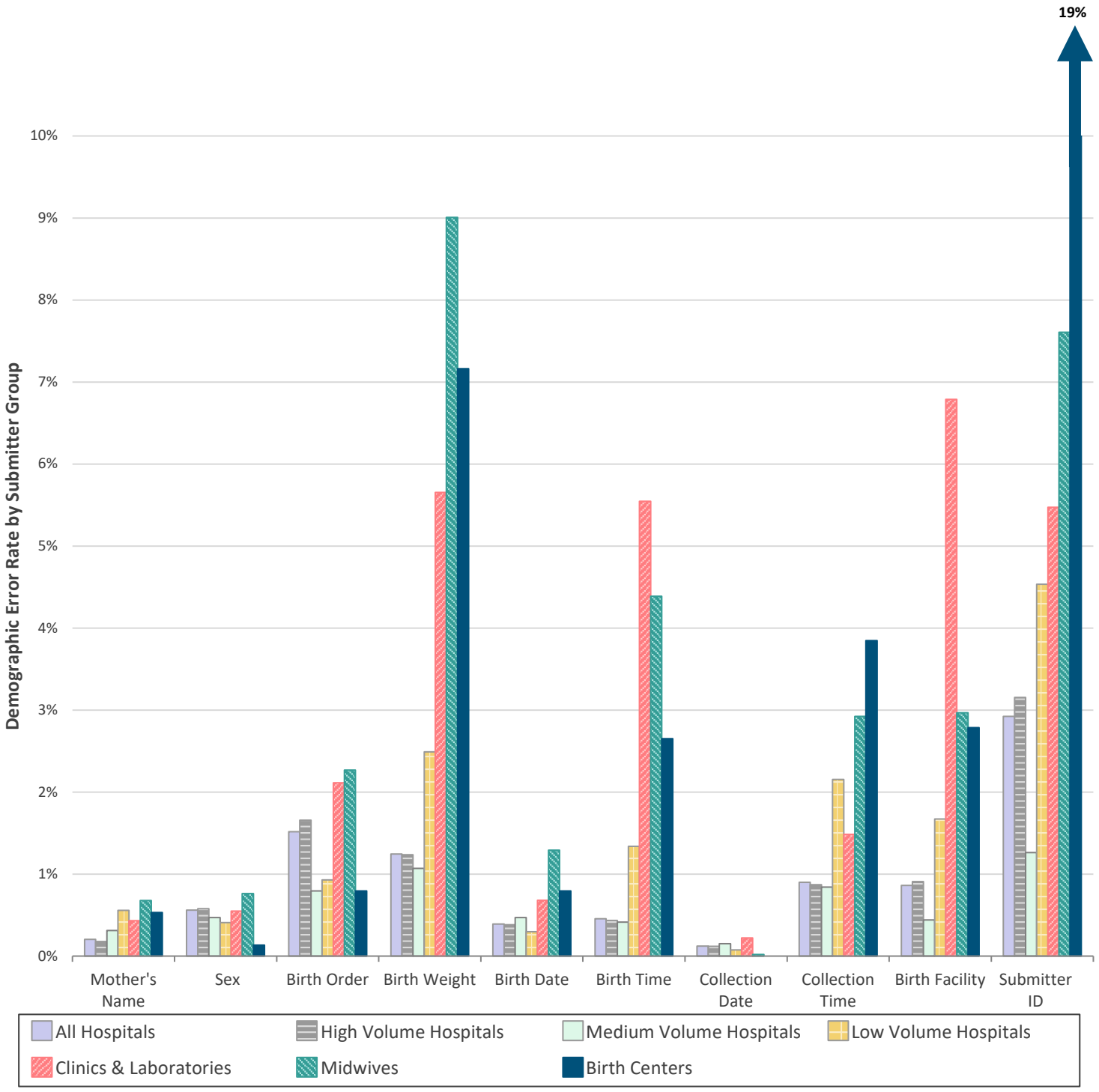


[1] See Key 2: Hospital Volume for hospital volume categorizations

Appendix G: Demographic Errors on Specimen Cards (cont.)

Received January 1, 2017 - December 31, 2017

Demographic Field Error Rates for All Specimens by Submitter Group[2]



[2] See Key 2: Hospital Volume for hospital volume categorizations.

For example: 6% of specimens submitted by Clinics & Laboratories have an incorrect or missing time of birth

Appendix H: Infants Detected with Newborn Screening Disorders Births 2010-2016

Disorder	2010	2011	2012	2013	2014	2015	2016
Amino acid disorders	**7**	**10**	**10**	**9**	**6**	**11**	**7**
Argininosuccinic acidemia (ASA)	0	0	0	0	1	0	0
Citrullinemia (CIT)	0	1	0	0	0	0	2
Homocystinuria (HCY)	0	1	1	0	0	0	0
Maple syrup urine disease (MSUD)	0	1	0	3	1	1	0
Phenylketonuria (PKU)	7	6	9	5	4	10	5
Tyrosinemia type 1 (TYR-1)	0	1	0	1	0	0	0
Biotinidase deficiency (BIO)	**0**	**2**	**3**	**1**	**1**	**1**	**1**
Congenital adrenal hyperplasia (CAH)	**3**	**11**	**10**	**6**	**5**	**6**	**5**
Congenital hypothyroidism (CH)	**77**	**104**	**117**	**98**	**116**	**87**	**106**
Cystic fibrosis (CF)	**23**	**17**	**16**	**20**	**14**	**13**	**10**
Fatty acid oxidation disorders	**11**	**6**	**7**	**3**	**10**	**13**	**7**
Carnitine uptake deficiency (CUD)	1	0	0	0	0	0	0
Medium-chain acyl-CoA dehydrogenase (MCAD) deficiency	7	5	4	2	4	9	4
Long-chain L-3-hydroxy acyl-CoA dehydrogenase (LCHAD) deficiency	0	0	0	0	2	1	1
Very long-chain acyl-CoA dehydrogenase (VLCAD) deficiency	3	1	3	1	4	3	2
Galactosemia (GALT)	**3**	**11**	**17**	**6**	**10**	**17**	**5**
Hemoglobinopathies (Hb)	**17**	**15**	**24**	**17**	**26**	**26**	**24**
Sickle cell diseases	9	7	12	8	15	9	12
Hemoglobin E-beta thalassemia	1	3	2	2	0	1	1
Hemoglobin H disease	6	4	7	6	6	7	8
Other moderate to severe hemoglobinopathies	1	1	3	1	5	1	3
Mild hemoglobin conditions and traits	1,199	1,130	1,244	1,330	1,339	1,370	1,384
Organic acid disorders	**2**	**4**	**3**	**2**	**3**	**5**	**1**
Beta-ketothiolase (BKT) deficiency	1	0	0	0	0	0	0
Glutaric acidemia type 1 (GA-1)	0	0	0	0	0	0	1
Isovaleric acidemia (IVA)	0	0	0	1	1	4	0
Methylmalonic acidemias (MMA)	1	2	2	1	2	1	0
Propionic acidemia (PROP)	0	2	1	0	0	0	0
Severe combined immunodeficiency (SCID)	**-**	**-**	**-**	**-**	**1**	**1**	**0**
Non-panel Disorders	**2**	**8**	**2**	**4**	**13**	**11**	**5**
2-methylbutyryl-CoA dehydrogenase (2-MBD) deficiency	0	3	0	0	0	0	0
3-methylcrotonyl-CoA carboxylase (3-MCC) deficiency	0	1	1	3	3	5	2
3-methylglutaconic aciduria (3-MGA)	0	1	0	0	0	0	0
Carnitine palmitoyltransferas II (CPT-II) deficiency	0	0	0	0	1	0	0
Citrin deficiency	0	0	0	0	0	0	1
Glutaric acidemia type II (GA-II)	1	0	0	0	0	0	0
Methionine adenosyltransferase (MAT-II) deficiency	0	0	1	0	0	3	0
Methylmalonic acidemia Cbl C	1	3	0	1	0	0	1
Other T-cell lymphopenias	-	-	-	-	9	3	1
Total Infants Detected*	145	188	209	166	205	183	171
Total Infants Screened*	83,086	84,918	86,180	85,427	87,415	87,769	89,873
Overall Frequency*	1 in 573	1 in 452	1 in 412	1 in 515	1 in 426	1 in 480	1 in 526

*Excludes mild hemoglobin conditions and traits.

Appendix I: Newborn Hemoglobin Screening Infants Detected by Phenotype and Reported Race/Ethnicity

Births January 1, 2017 - December 31, 2017

Phenotype[a]	Total	White	Black	Asian	Native American	Other[b]	Unknown[c]	Hispanic[d]
Severe Disease	**14**	**-**	**10**	**-**	**-**	**4**	**-**	**-**
FSS	10	-	6	-	-	4	-	-
FS-	1	-	1	-	-	-	-	-
FSC	3	-	3	-	-	-	-	-
Moderate Disease	**11**	**-**	**3**	**3**	**-**	**5**	**-**	**1**
FAA + High Bart's	7	-	-	3	-	4	-	1
FSV	1	-	1	-	-	-	-	-
FC-	1	-	1	-	-	-	-	-
FCC	1	-	1	-	-	-	-	-
FSE	1	-	-	-	-	1	-	-
Mild Disease	**3**	**-**	**-**	**2**	**-**	**1**	**-**	**-**
FEE	3	-	-	2	-	1	-	-
Trait	**1,382**	**212**	**287**	**241**	**16**	**495**	**131**	**238**
FAA + CS + Bart's	15	-	-	10	-	5	-	1
FAE + CS + Bart's	2	-	-	1	-	1	-	-
FAS + Bart's	11	-	6	-	-	5	-	-
FAE + Bart's	4	-	-	4	-	-	-	-
FAA + Bart's	267	23	40	97	2	94	11	22
FAS	490	45	179	4	5	193	64	104
FAE	233	9	6	108	3	98	9	21
FAE + Var	2	-	-	-	-	2	-	-
FAC	124	15	45	1	1	54	8	29
FAD	40	17	-	6	2	10	5	10
FA + Var	194	103	11	10	3	33	34	51
Total	**1,410**	**212**	**300**	**246**	**16**	**505**	**131**	**239**

[a]See Key 3: Newborn Hemoglobin Screening Explanations and Definitions of Phenotypes.
[b]Includes other races not listed above and multi-racial (more than one race designation on the screening form).
[c]Unknown race (no designation made).
[d]Hispanics can be of any race, they are included in the figures to the left.

Key 1: Unsatisfactory Specimen Descriptions

January 1, 2017 - December 31, 2017

Some specimens are considered unsatisfactory due to the quality of specimen collection or handling. These specimens are tested for extreme values but another specimen must be obtained to complete screening. The need to obtain a repeat specimen could delay diagnosis and treatment of an affected infant.

Unsatisfactory Specimen Errors		
Error		**Description**
Layered or Supersaturated		Blood was layered, clotted or supersaturated. Caused by: • Repeated application of blood to the same filter paper circle • Blood applied to both sides of the filter paper • Blood clotting in a capillary tube • Application of too much blood
Incompletely Saturated		Blood did not completely soak through the filter paper or not enough blood on the filter paper. Caused by: • Filter paper circles not fully saturated or not completely filled • Application of small blood spots • Blood applied to both sides of the filter paper
Contaminated		Blood was diluted, discolored, contaminated or exhibited serum rings. Caused by: • Alcohol not completely drying before skin puncture • Puncture site squeezed or 'milked' to expel blood • Improper drying of specimen • Exposure to high temperatures • Filter paper contact with gloved or ungloved hands, or by substances such as alcohol, feeding or antiseptic solutions, hand lotion or powder
Specimen Too Old		Specimen was delayed in transit and is too old for testing due to deterioration of the dried blood spots. • Specimens received more than 14 days after collection are too old for hemoglobin and galactosemia testing • Specimens received more than 30 days after collection are too old for all tests
Abraded		Specimen surface was scratched, dented, or abraded. Caused by: • Improper application of blood with capillary tube or other device
Partial Unsuitable		Validation of the preliminary screening results was not possible due to the unsuitability of the residual blood. Caused by: • Partial abrasion, contamination, damage, or oversaturation of residual blood • Insufficient quantity of blood
Other Unsuitables	Ambiguous Degradation	Hemoglobin screening results indicate degradation or chemical modification of hemoglobins present causing assay interference.
	Damaged Specimen	Specimen was damaged during transport and blood sample may be torn or contaminated by rain and/or other substances.
	Old Collection Card	Specimen was submitted on a collection card past its expiration date. Cards expire three years after their manufacture date.
	Received in Plastic	Specimen was received in a sealed plastic bag and may be damaged by heat exposure and moisture accumulation.
	No Blood	Specimen card received with no blood on filter paper nor valid refusal signature.

Key 2: Hospital Volume Categorizations

January 1, 2017 - December 31, 2017

Hospital Birth Volume

Average number of hospital births quarterly
- **High Volume:** > 500 births/qtr
- **Medium Volume:** 100 to 500 births/qtr
- **Low Volume:** < 100 births/qtr

Hospital Specimen Volume

Average NBS specimens submitted daily
- **High Volume:** > 3 specimens/day
- **Medium Volume:** 1 to 3 specimens/day
- **Low Volume:** < 1 specimen/day

Hospital	City	Births per qtr	Birth Volume	Specimens per day	Specimen Volume
Auburn Medical Center - MultiCare	Auburn	304	Medium	3.4	High
Capital Medical Center	Olympia	166	Medium	1.8	Medium
Cascade Valley Hospital	Arlington	39	Low	0.6	Low
Central Washington Hospital/Confluence Hea	Wenatchee	335	Medium	3.7	High
Columbia Basin Hospital	Ephrata	-	-	< 0.1	Low
Coulee Medical Center	Grand Coulee	17	Low	0.4	Low
Deaconess Hospital - MultiCare	Spokane	357	Medium	5.1	High
East Adams Rural Hospital	Ritzville	-	-	< 0.1	Low
EvergreenHealth - Monroe	Monroe	< 1	Low	0.1	Low
EvergreenHealth Kirkland	Kirkland	1,149	High	13.6	High
Fairchild Air Force Base	Fairchild AFB	-	-	< 0.1	Low
Ferry County Memorial Hospital	Republic	-	-	< 0.1	Low
Forks Community Hospital	Forks	12	Low	0.3	Low
Good Samaritan Hospital - MultiCare	Puyallup	570	High	6.5	High
Grays Harbor Community Hospital	Aberdeen	111	Medium	1.2	Medium
Harborview Medical Center - UW Medicine	Seattle	-	-	0.3	Low
Harrison Medical Center	Bremerton	488	Medium	5.8	High
Highline Medical Center	Burien	246	Medium	2.8	Medium
Holy Family Hospital - Providence	Spokane	306	Medium	3.9	High
Island Hospital	Anacortes	120	Medium	1.9	Medium
Jefferson Healthcare	Port Townsend	28	Low	0.5	Low
Kadlec Regional Medical Center	Richland	700	High	9.0	High
Kaiser Permanente WA - Capitol Hill	Seattle	-	-	< 0.1	Low
Kittitas Valley Healthcare	Ellensburg	81	Low	0.9	Low
Klickitat Valley Hospital	Goldendale	< 1	Low	-	-
Lake Chelan Community Hospital	Chelan	24	Low	0.4	Low
Legacy Salmon Creek Medical Center	Vancouver	856	High	10.0	High
Lewis County Hospital	Morton	-	-	< 0.1	Low
Lincoln Hospital	Davenport	< 1	Low	0.1	Low
Lourdes Medical Center	Pasco	-	-	< 0.1	Low
Madigan Army Medical Center	Joint Base Lewis-McChord	485	Medium	10.9	High
Mary Bridge Children's Hospital - MultiCare	Tacoma	-	-	0.1	Low
Mason General Hospital	Shelton	64	Low	0.7	Low
Mid-Valley Hospital	Omak	57	Low	0.6	Low
Mount Carmel Hospital - Providence	Colville	54	Low	0.7	Low
Naval Hospital - Bremerton	Bremerton	132	Medium	3.1	High

Key 2: Hospital Volume Categorizations (cont.)

Hospital	City	Births per qtr	Birth Volume	Specimens per day	Specimen Volume
Naval Hospital - Oak Harbor	Oak Harbor	46	Low	1.2	Medium
Newport Hospital	Newport	23	Low	0.4	Low
North Valley Hospital	Tonasket	21	Low	0.3	Low
Northwest Hospital - UW Medicine	Seattle	270	Medium	4.3	High
Olympic Medical Center	Port Angeles	125	Medium	2.6	Medium
Othello Community Hospital	Othello	120	Medium	2.2	Medium
Overlake Medical Center	Bellevue	922	High	10.6	High
PeaceHealth Southwest Medical Center	Vancouver	516	High	6.3	High
Prosser Memorial Hospital	Prosser	95	Low	1.4	Medium
Providence Centralia Hospital	Centralia	171	Medium	1.9	Medium
Providence Everett Regional Medical Center	Everett	1,177	High	14.2	High
Providence St Peter Hospital	Olympia	523	High	6.4	High
Pullman Regional Hospital	Pullman	106	Medium	1.2	Medium
Sacred Heart Medical Center - Providence	Spokane	776	High	12.7	High
Samaritan Healthcare	Moses Lake	257	Medium	2.9	Medium
Seattle Children's Hospital	Seattle	-	-	2.2	Medium
Skagit Valley Hospital	Mount Vernon	247	Medium	2.8	Medium
St Clare Hospital	Lakewood	1	Low	-	-
St Elizabeth Hospital	Enumclaw	84	Low	1.2	Medium
St Francis Hospital	Federal Way	319	Medium	4.1	High
St John Medical Center - PeaceHealth	Longview	203	Medium	2.4	Medium
St Joseph Hospital PeaceHealth - Bellingham	Bellingham	501	High	5.7	High
St Joseph Hospital Providence - Chewelah	Chewelah	-	-	< 0.1	Low
St Joseph Medical Center - Tacoma	Tacoma	1,059	High	13.7	High
St Mary Medical Center - Providence	Walla Walla	172	Medium	1.9	Medium
Summit Pacific Medical Center	Elma	1	Low	0.1	Low
Sunnyside Community Hospital	Sunnyside	131	Medium	2.4	Medium
Swedish - Ballard	Seattle	281	Medium	3.4	High
Swedish - Cherry Hill	Seattle	-	-	< 0.1	Low
Swedish - Edmonds	Edmonds	343	Medium	5.4	High
Swedish - First Hill	Seattle	1,883	High	23.4	High
Swedish - Issaquah	Issaquah	406	Medium	4.6	High
Tacoma General Hospital - MultiCare	Tacoma	729	High	10.2	High
Three Rivers Hospital	Brewster	23	Low	0.4	Low
Toppenish Community Hospital	Toppenish	101	Medium	1.9	Medium
Trios Health Hospital	Kennewick	360	Medium	4.1	High
University of Washington Medical Center	Seattle	482	Medium	6.2	High
Valley Hospital	Spokane	177	Medium	2.7	Medium
Valley Medical Center - UW Medicine	Renton	934	High	11.0	High
Virginia Mason Hospital	Seattle	-	-	0.1	Low
Virginia Mason Memorial	Yakima	641	High	11.8	High
Walla Walla General Hospital	Walla Walla	-	-	< 0.1	Low
WhidbeyHealth Medical Center	Coupeville	54	Low	1.1	Medium
Whitman Hospital and Medical Center	Colfax	8	Low	0.2	Low
Willapa Harbor Hospital	South Bend	< 1	Low	< 0.1	Low
Yakima Regional Medical Center	Yakima	< 1	Low	< 0.1	Low

Key 3: Newborn Hemoglobin Screening
Explanations and Definitions of Phenotypes
January 1, 2017 - December 31, 2017

Hemoglobins are perhaps the most complex of the conditions detected by newborn screening. More than a dozen genes are involved in hemoglobin production and over 700 abnormalities have been described by researchers and clinicians. Also, a variety of combinations are possible for any individual. Many of the abnormalities are rare and most have no clinical implications. A primary objective of our program is to identify those infants with sickle cell disease because these infants will suffer far less illness and death if they are promptly entered into a comprehensive health care program that includes prophylactic treatment with penicillin.

Phenotype	Most Likely Genotype/Clinical Implications
Severe Hemoglobin Disease	
FSS	Homozygous for hemoglobin S. Results in sickle cell anemia, a severe form of sickle cell disease.
FSS + Bart's	Homozygous for hemoglobin S in combination with α-thalassemia[b]. Results in sickle cell anemia, a severe form of sickle cell disease.
FS–	Hemoglobin S in combination with b-thalassemia[a] major. A severe form of sickle cell disease.
FSC	Hemoglobin S in combination with hemoglobin C. Results in sickle C disease, a moderate to severe form of sickle cell disease.
F-Only	β-thalassemia[a] major. A severe hemolytic anemia requiring regular blood transfusions.
FE–	Hemoglobin E in combination with β-thalassemia[a] major. A moderate to severe hemolytic anemia.
FAA + CS + High Bart's	High level of hemoglobin Bart's indicative of multiple α-thalassemia[b] genes. Likelihood of Hemoglobin H/Constant spring disease, a moderate to severe hemolytic anemia.
FAE + CS + High Bart's	Hemoglobin E trait with combination with two hemoglobins (Constant Spring and Bart's) indicative of multiple α-thalassemia[b] genes. Likelihood of Hemoglobin H/Constant Spring disease, a moderate to severe hemolytic anemia (might be somewhat ameliorated by presence of hemoglobin E).
Moderate Hemoglobin Disease	
FSA	Hemoglobin S in combination with β-thalassemia[a] intermedia. A moderate to severe hemolytic anemia.
F-beta+	β-thalassemia[a] intermedia. Ranges from mild to moderate hemolytic anemia and may require blood transfusions.
FSE	Hemoglobin S in combination with hemoglobin E. Results in sickle E disease, a moderate form of sickle cell disease.
FSD	Hemoglobin S in combination with hemoglobin D. Results in sickle D disease, a moderate form of sickle cell disease.
FSV	Hemoglobin S in combination with unknown variant hemoglobin. Depending on the unknown variant may result in a mild to moderate sickle cell disease.
FEA	Hemoglobin E in combination with β-thalassemia[a] intermedia. A mild to moderate hemolytic anemia.
FAA + High Bart's	High level of hemoglobin Bart's indicative of multiple α-thalassemia[b] genes. Likelihood of Hemoglobin H disease, a moderate to severe hemolytic anemia.
FAE + High Bart's	Hemoglobin E in combination with high level of hemoglobin Bart's indicative of multiple α-thalassemia[b] genes. Likelihood of Hemoglobin H disease, a moderate to severe hemolytic anemia (might be somewhat ameliorated by presence of hemoglobin E).
FC-	Hemoglobin C in combination with β-thalassemia[a] major. A moderate to severe hemolytic anemia.
FCA	Hemoglobin C in combination with β-thalassemia[a] minor. A mild to moderate hemolytic anemia.

[a] Decreased production of β globin chains; benign to severe anemia. Significant interaction with other β chain variants such as hemoglobin S, E, and D.

[b] Decreased production of α globin chains; benign to severe anemia depending on how many of the four α globin genes are affected.

Key 3: Newborn Hemoglobin Screening (cont.)

Phenotype	Most Likely Genotype/Clinical Implications
Moderate Hemoglobin Disease Cont.	
FDA	Hemoglobin D in combination with β-thalassemia[a] minor. A mild to moderate hemolytic anemia.
FCC	Homozygous for hemoglobin C. A mild to moderate hemolytic anemia.
FDD	Homozygous for hemoglobin D. A mild to moderate hemolytic anemia.
Mild Hemoglobin Disease	
FEE	Homozygous for hemoglobin E. Mild anemia.
FEE + Bart's	Homozygous hemoglobin E in combination with α-thalassemia[b]. Mild anemia.
Hemoglobin Traits	
FA + CS + Bart's	Two hemoglobins (Constant Spring and Bart's) indicative of α-thalassemia[b] genes. Mild anemia.
FAE + CS + Bart's	Hemoglobin E trait in combination with two hemoglobins (Constant Spring and Bart's) indicative of α-thalassemia[b] genes. Mild anemia. Family may be at risk for hemoglobin E/β-thalassemiaa, a significant hemoglobin disease.
FAS + Bart's	Hemoglobin S trait in combination with α-thalassemia[b]. No clinical implications for S trait (see FAS, below). Benign to mild anemia. Family may be at risk for sickle cell disease.
FAC + Bart's	Hemoglobin C trait in combination with α-thalassemia[b]. No clinical implications for C trait (see FAC, below). Benign to mild anemia. Family may be at risk for hemoglobin C diseases.
FAE + Bart's	Hemoglobin E trait in combination with α-thalassemia[b]. No clinical implications for E trait (see FAE, below). Benign to mild anemia. Family may be at risk for hemoglobin E/β-thalassemiaa, a significant hemoglobin disease.
FAA + Bart's	α-thalassemia[b]. Benign to mild anemia.
FA + Var + Bart's	An unidentified hemoglobin variant trait and α-thalassemia[b]. Benign to mild anemia.
FAS + Var	Hemoglobin S and unidentified variant trait. No clinical implications for S trait; clinical effects from variant trait unlikely. Family may be at risk for sickle cell disease.
FAC + Var	Hemoglobin C and unidentified variant trait. No clinical implications for C trait; clinical effects from variant trait unlikely. Family may be at risk for hemoglobin C diseases.
FAE + Var	Hemoglobin E and unidentified variant trait. No clinical implications for E trait; clinical effects from variant trait unlikely. Family may be at risk for hemoglobin E/β-thalassemia[a], a significant hemoglobin disease.
FAS	Hemoglobin S trait. No clinical implications for child. Family may be at risk for sickle cell disease.
FAE	Hemoglobin E trait. No clinical implications for child. Family may be at risk for hemoglobin E/β-thalassemia[a], a significant hemoglobin disease.
FAC	Hemoglobin C trait. No clinical implications for child. Family may be at risk for homozygous C, a mild to moderate hemolytic anemia or hemoglobin SC, a moderate to severe form of sickle cell disease.
FAD	Hemoglobin D trait. No clinical implications for child. Family may be at risk for hemoglobin SD, a moderate to severe form of sickle cell disease.
FA + Var	Unidentified variant trait. Clinical effects unlikely.

[a] Decreased production of β globin chains; benign to severe anemia. Significant interaction with other β chain variants such as hemoglobin S, E, and D.

[b] Decreased production of α globin chains; benign to severe anemia depending on how many of the four α globin genes are affected.


Washington State Department of
Health