2016

Washington State Department of Health

Newborn Screening Program

October 2017

Newborn Screening Program Annual Report

Saving lives with a simple blood spot

PUBLIC HEALTH
ALWAYS WORKING FOR A SAFER AND HEALTHIER COMMUNITY

Washington State Department of Health

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acknowledgments

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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 Board of Health and the general public. This report summarizes data for the period January 1, 2016 through December 31, 2016.

The Department of Health's Newborn Screening Program tests all infants born in Washington for 28 treatable but potentially deadly or disabling disorders that the Washington State Board of Health has specified in Chapter 246-650 Washington Administrative Code (WAC).

During 2016 there were 89,873 infants born in Washington. An additional 227 were born at two military facilities[1] in our state that did not participate in the Washington screening program from January 1, 2016 to April 30, 2016. Both naval hospitals (Bremerton and Oak Harbor) joined our screening program on May 1, 2016.

Infants Identified with a Disorder

The Newborn Screening Program identified 171[2] infants born in 2016 with one of the 28 disorders on the screening panel. Among these infants, 93[2] 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 78 infants were identified with a condition that required treatment or close monitoring[3].

An additional 1,384 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' healthcare 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 is necessary because early detection and clinical intervention is 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 2016—including hospitals, birth centers, and home births—98.2 percent of initial specimens were collected within this timeframe, a slight improvement of 0.2 percentage points over the previous reporting period (January 1, 2015 – December 31, 2015).

State law also requires initial newborn specimens to be received at the State Public Health Laboratories within 72 hours of collection. During 2016, 89.2 percent of specimens were received within the required timeframe. This was an increase of 4.3 percentage points from the previous reporting period (January 1, 2015 – December 31, 2015).

State law requires healthcare providers to notify the Newborn Screening Program of the date they communicated the need for diagnostic testing to the parent or guardian. During 2016, 50.7 percent of the required notifications were received by the program. This was a decrease of 8.5 percentage points from the previous reporting period (January 1, 2015 – December 31, 2015).

This report also includes data regarding specimen quality measures. Detailed specimen quality statistics by hospital are included in subsequent sections of this report. All midwife, birth center, clinic and laboratory performance data are reported in aggregate.

[1] These federal facilities had a contract with a private laboratory for the screening of infants born in their hospitals.
[2] Excludes one infant with cystic fibrosis not detected by newborn screening. Excludes two infants with congenital hypothyroidism that were born out-of-state.
[3] 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[4].
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.

[4] 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 Washington State Newborn Screening Program, healthcare facilities (hospitals, clinics, laboratories, and birth centers), healthcare 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 246-650-020).
- 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 healthcare providers for newborns with abnormal screening test results to facilitate prompt diagnostic and treatment services.
- Consult with healthcare 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 healthcare.
- 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, healthcare professionals, families of affected children, and the general public.

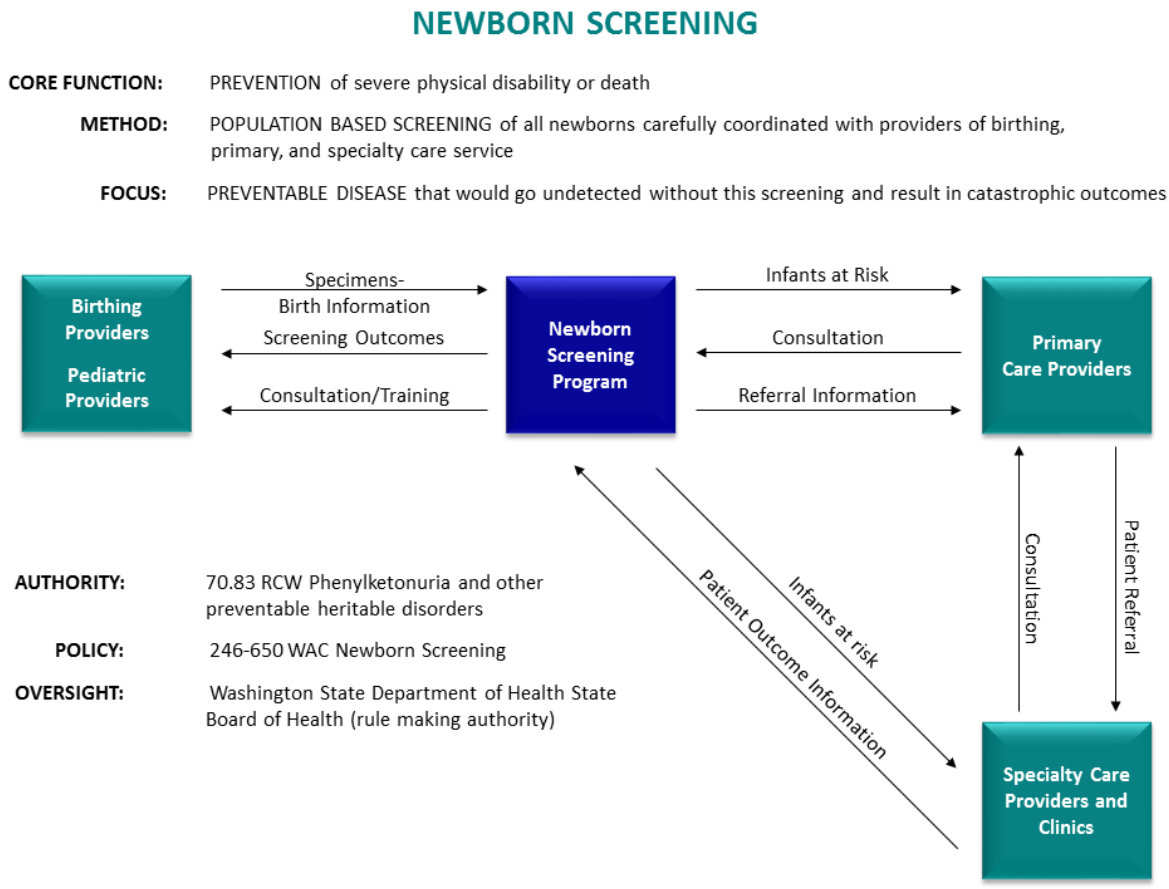
Responsibilities of the healthcare facilities and providers:

- 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.
- 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 the Newborn Screening Program the date the parent/guardian was notified of the need for further diagnostic testing.

Responsibilities of the families:

- Receive education from their healthcare provider about the newborn screening tests that will be performed on their infant and ask questions if they have any.
- Report to their healthcare provider the presence of a family history of any screened or unscreened disorder.
- Respond quickly to requests from the healthcare provider or Department of Health (department) for repeat screening.
- Cooperate with healthcare 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. From January 1 – August 31, 2016, this charge was $69 for each child. This charge increased on September 1st to $76.10 to cover increasing operational costs. This fee is typically covered by insurance and other third-party payers. In return, the state's healthcare 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:

To augment general training for specimen collection and reporting, the Newborn Screening 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 healthcare 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.

In January 2016 the Newborn Screening Program expanded their quarterly reporting activities to include clinics and outpatient laboratories. These quality reports, previously sent only to hospitals, 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:

In May 2016 the Newborn Screening Laboratory expanded operations on Saturdays. This increased capacity improved turnaround time for time-sensitive tests. A lead worker also reviews results on Sunday morning, which allows for follow-up of urgent conditions on Sundays.

The Washington Newborn Screening Laboratory began testing samples from babies born at two naval hospitals in Washington State on May 1, 2016. The naval hospitals in Oak Harbor and Bremerton previously sent specimens out of state for testing at a private laboratory. With the addition of these hospitals, the Washington Newborn Screening Laboratory provides testing and follow-up services to *all* of Washington's newborns.

Newborn Screening New 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 are preparing for this expansion and anticipate implementing routine screening for X-ALD during or before the first quarter of 2018.

2016 Performance Data

Collection and Transport Performance:

During the 2014 Legislative Session, a revision was made to Chapter 70.83 RCW to specify both collection times 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 had provided guidelines only to providers. The new requirements apply to all hospitals and birthing providers throughout the state.

Under the rule revision, each hospital or healthcare provider attending a birth outside a hospital is required to collect and transport specimens to the Newborn Screening Laboratory 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 2016—including hospitals, birth centers, and home births—98.2 percent of initial specimens were collected within this timeframe.
>
> **Transit Performance**: Initial specimens must be received by the State Laboratory within 72 hours of collection (excluding days that the laboratory is closed – Sundays and Thanksgiving). For all Washington births in 2016—including hospitals, birth centers, and home births—89.2 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 2016, hospitals improved their aggregate transit time compliance by 4.4 percentage points to reach 90.2 percent compliance. This improvement can be anecdotally attributed to the increase usage of courier services and hospitals improving their internal specimen handling procedures. The NBS program plans to collect data on specimen transport methods during 2018. In 2016 only 64.4 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 as they do not have access to courier services. This is further exacerbated by geography with only 39.9 percent of out-of-hospital specimens from Eastern Washington meeting the transit time requirements (see Appendix D). This highlights a need for this community to have access to alternative methods of specimen transport. 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, 2016 - December 31, 2016

Each hospital or healthcare provider attending a birth outside of a hospital is required to collect and transport specimens to the Newborn Screening Laboratory 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 Lab within 72 hours of collection (excluding Sundays and Thanksgiving)

Facility of Birth	City	Eligible Infants	1) Collection Compliance
Forks Community Hospital	Forks	71	100%
Harborview Medical Center - UW Medicine	Seattle	3	100%
Lewis County Hospital	Morton	2	100%
Lourdes Medical Center	Pasco	1	100%
Newport Hospital	Newport	65	100%
Ocean Beach Hospital	Ilwaco	1	100%
St Clare Hospital	Lakewood	1	100%
Summit Pacific Medical Center	Elma	1	100%
Willapa Harbor Hospital	South Bend	1	100%
Madigan Army Medical Center	Joint Base Lewis-McChord	2,013	99.8%
Swedish Issaquah	Issaquah	1,594	99.7%
Prosser Memorial Hospital	Prosser	343	99.7%
Providence St Peter Hospital	Olympia	2,255	99.7%
Swedish Edmonds	Edmonds	1,247	99.6%
Northwest Hospital - UW Medicine	Seattle	1,211	99.6%
Othello Community Hospital	Othello	478	99.6%
Sacred Heart Medical Center - Providence	Spokane	3,326	99.5%
Overlake Medical Center	Bellevue	3,921	99.5%
Deaconess Hospital	Spokane	1,445	99.4%
Swedish First Hill	Seattle	7,852	99.4%
Swedish Ballard	Seattle	1,166	99.4%
Legacy Salmon Creek Medical Center	Vancouver	3,491	99.4%
Auburn Medical Center - MultiCare	Auburn	1,202	99.3%
Kadlec Regional Medical Center	Richland	2,815	99.3%
EvergreenHealth	Kirkland	4,765	99.3%
Trios Health Hospital	Kennewick	1,627	99.3%
Harrison Medical Center	Silverdale	2,007	99.3%
Mid-Valley Hospital	Omak	226	99.1%
Yakima Valley Memorial Hospital	Yakima	2,748	99.1%
Valley Hospital	Spokane	735	99.0%
Central Washington Hospital	Wenatchee	1,344	99.0%
Holy Family Hospital - Providence	Spokane	1,306	99.0%
Tacoma General Hospital - MultiCare	Tacoma	3,042	99.0%

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

Facility of Birth	City	Eligible Infants	1) Collection Compliance
St Joseph Medical Center	Tacoma	4,234	98.9%
Skagit Valley Hospital	Mount Vernon	1,109	98.9%
Coulee Medical Center	Grand Coulee	92	98.9%
Providence Everett Medical Center	Everett	4,814	98.9%
Island Hospital	Anacortes	433	98.8%
St Joseph Hospital - PeaceHealth	Bellingham	2,038	98.7%
St Francis Hospital	Federal Way	1,349	98.7%
Good Samaritan Hospital - MultiCare	Puyallup	2,386	98.7%
Pullman Regional Hospital	Pullman	426	98.6%
Valley Medical Center - UW Medicine	Renton	3,771	98.5%
St John Medical Center - PeaceHealth	Longview	839	98.3%
Highline Medical Center	Burien	862	98.1%
Toppenish Community Hospital	Toppenish	431	98.1%
Sunnyside Community Hospital	Sunnyside	533	98.1%
Grays Harbor Community Hospital	Aberdeen	472	98.1%
Naval Hospital - Oak Harbor	Oak Harbor	198	98.0%
University of Washington Medical Center	Seattle	1,900	97.9%
WhidbeyHealth Medical Center	Coupeville	180	97.8%
Kittitas Valley Healthcare	Ellensburg	311	97.7%
Mason General Hospital	Shelton	301	97.7%
Cascade Valley Hospital	Arlington	164	97.6%
Naval Hospital - Bremerton	Bremerton	478	97.5%
PeaceHealth Southwest Medical Center	Vancouver	2,125	97.4%
Mount Carmel Hospital - Providence	Colville	231	97.4%
Providence Centralia Hospital	Centralia	727	97.1%
Samaritan Healthcare	Moses Lake	1,004	97.0%
Three Rivers Hospital	Brewster	108	96.3%
St Elizabeth Hospital	Enumclaw	333	96.1%
Olympic Medical Center	Port Angeles	464	95.9%
Capital Medical Center	Olympia	700	95.7%
St Mary Medical Center - Providence	Walla Walla	661	95.5%
Walla Walla General Hospital	Walla Walla	113	94.7%
North Valley Hospital	Tonasket	84	92.9%
Whitman Hospital and Medical Center	Colfax	39	92.3%
Lake Chelan Community Hospital	Chelan	113	91.2%
Jefferson Healthcare	Port Townsend	101	86.1%
All Hospital Births	**Statewide**	**86,429**	**98.9%**
All Out-of-Hospital Births	**Statewide**	**3,372**	**80.3%**
All Washington State Births	**Statewide**	**89,873**	**98.2%**

Table 2: Specimen Transit Compliance by Birth Facility

Births January 1, 2016 - December 31, 2016

Each hospital or healthcare provider attending a birth outside of a hospital is required to collect and transport specimens to the Newborn Screening Laboratory 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 Lab within 72 hours of collection (excluding Sundays and Thanksgiving)

Facility of Birth	City	Eligible Infants	2) Transit Compliance
Harborview Medical Center - UW Medicine	Seattle	3	100%
Lourdes Medical Center	Pasco	1	100%
Ocean Beach Hospital	Ilwaco	1	100%
St Clare Hospital	Lakewood	1	100%
Summit Pacific Medical Center	Elma	1	100%
Willapa Harbor Hospital	South Bend	1	100%
EvergreenHealth	Kirkland	4,765	99.8%
Northwest Hospital - UW Medicine	Seattle	1,211	99.7%
Swedish Issaquah	Issaquah	1,594	99.6%
Swedish First Hill	Seattle	7,852	99.4%
Island Hospital	Anacortes	433	99.1%
University of Washington Medical Center	Seattle	1,900	98.8%
Harrison Medical Center	Silverdale	2,007	98.8%
Overlake Medical Center	Bellevue	3,921	98.2%
Providence Everett Medical Center	Everett	4,814	98.2%
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Deaconess Hospital	Spokane	1,445	95.6%
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Whitman Hospital and Medical Center	Colfax	39	94.9%
St Francis Hospital	Federal Way	1,349	94.1%
Valley Hospital	Spokane	735	93.3%
St Mary Medical Center - Providence	Walla Walla	661	93.0%
Newport Hospital	Newport	65	92.3%
PeaceHealth Southwest Medical Center	Vancouver	2,125	92.1%
Good Samaritan Hospital - MultiCare	Puyallup	2,386	92.0%
St Elizabeth Hospital	Enumclaw	333	91.9%
Naval Hospital - Bremerton	Bremerton	478	91.8%

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

Facility of Birth	City	Eligible Infants	2) Transit Compliance
Mount Carmel Hospital - Providence	Colville	231	91.8%
Tacoma General Hospital - MultiCare	Tacoma	3,042	90.7%
Forks Community Hospital	Forks	71	90.1%
Trios Health Hospital	Kennewick	1,627	90.0%
Valley Medical Center - UW Medicine	Renton	3,771	88.9%
Holy Family Hospital - Providence	Spokane	1,306	88.7%
Madigan Army Medical Center	Joint Base Lewis-McChord	2,013	88.3%
Kittitas Valley Healthcare	Ellensburg	311	87.5%
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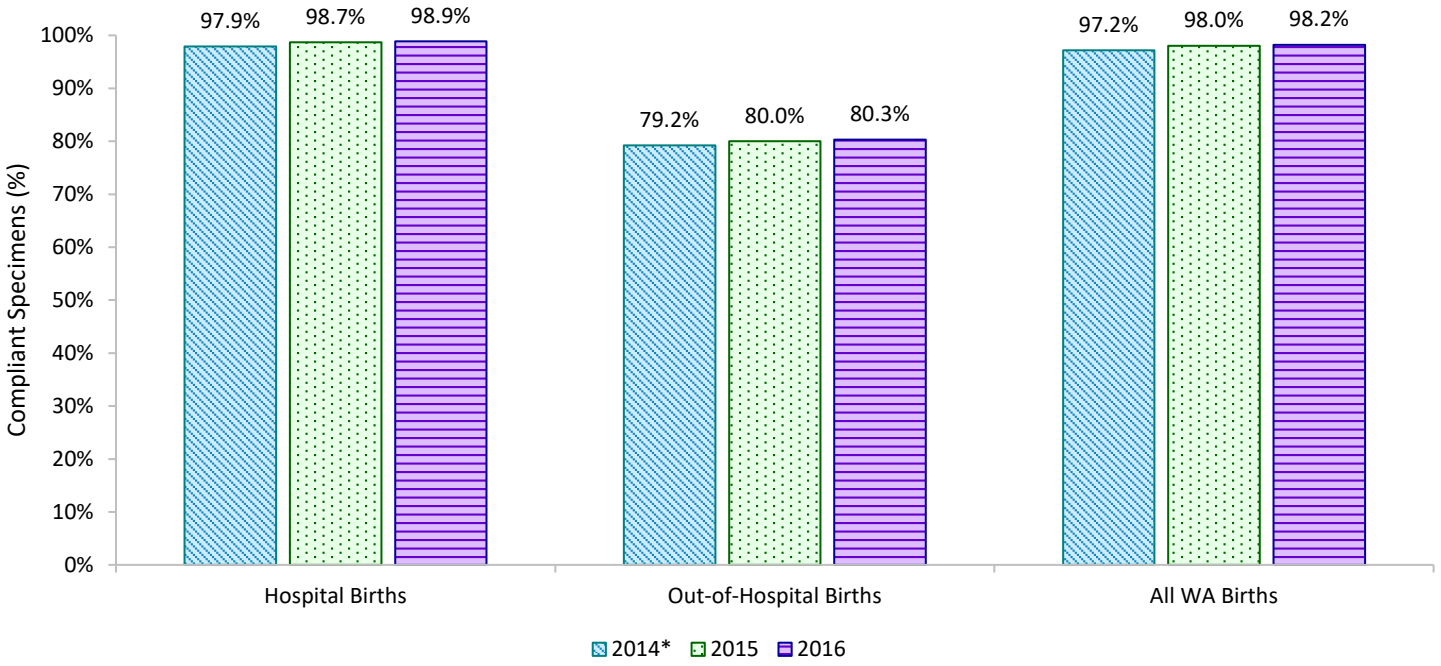
Samaritan Healthcare	Moses Lake	1,004	86.4%
Mason General Hospital	Shelton	301	85.7%
Sunnyside Community Hospital	Sunnyside	533	84.4%
Naval Hospital - Oak Harbor	Oak Harbor	198	84.3%
WhidbeyHealth Medical Center	Coupeville	180	82.2%
Central Washington Hospital	Wenatchee	1,344	81.5%
St Joseph Hospital - PeaceHealth	Bellingham	2,038	80.6%
Capital Medical Center	Olympia	700	79.0%
North Valley Hospital	Tonasket	84	77.4%
Mid-Valley Hospital	Omak	226	77.0%
Skagit Valley Hospital	Mount Vernon	1,109	75.8%
Olympic Medical Center	Port Angeles	464	75.0%
Providence St Peter Hospital	Olympia	2,255	74.6%
Yakima Valley Memorial Hospital	Yakima	2,748	68.3%
Kadlec Regional Medical Center	Richland	2,815	62.7%
Cascade Valley Hospital	Arlington	164	62.2%
Walla Walla General Hospital	Walla Walla	113	61.9%
Three Rivers Hospital	Brewster	108	58.3%
Lake Chelan Community Hospital	Chelan	113	53.1%
Othello Community Hospital	Othello	478	52.1%
Lewis County Hospital	Morton	2	50.0%
Providence Centralia Hospital	Centralia	727	46.8%
Jefferson Healthcare	Port Townsend	101	41.6%
Prosser Memorial Hospital	Prosser	343	39.7%
Grays Harbor Community Hospital	Aberdeen	472	34.1%
Coulee Medical Center	Grand Coulee	92	32.6%
All Hospital Births	**Statewide**	**86,429**	**90.2%**
All Out-of-Hospital Births	**Statewide**	**3,372**	**64.4%**
All Washington State Births	**Statewide**	**89,873**	**89.2%**

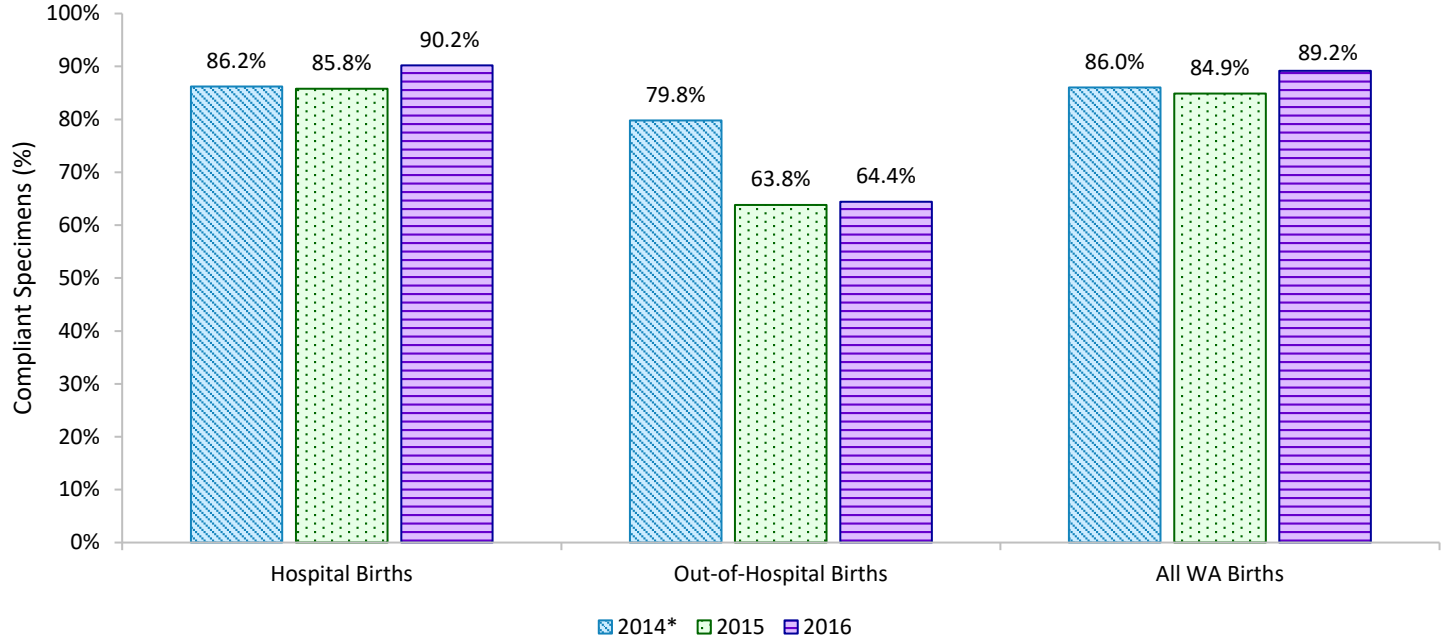
Table 3: Annual Compliance Measures

Born July 1, 2014 - December 31, 2016

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 hospitals to ensure the best possible testing results. The program contacts submitters and provides guidance when errors occur, and offers onsite training for hospital staff as needed and upon request. The program is available to visit and provide hands-on training and answer questions specific to a given hospital.

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, 2.1 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, 14.7 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, 2016.

Table 7 depicts the annual quality measures. There has been a slight increase in the percentage of unsatisfactory specimens submitted by midwives, this highlights an area for targeted education and outreach. The large improvement in the demographic error rate for clinics and laboratories from 2015 to 2016 can be attributed to increased education of demographic errors through the expansion of the quarterly reports. In particular explanations are the fields of Birth Weight, Birth Time, Collection Time and Birth Facility. More detailed information regarding quality measures can be found in the appendices.

Table 4: Unsatisfactory Specimens & Demographic Errors Report

Received January 1, 2016 - December 31, 2016

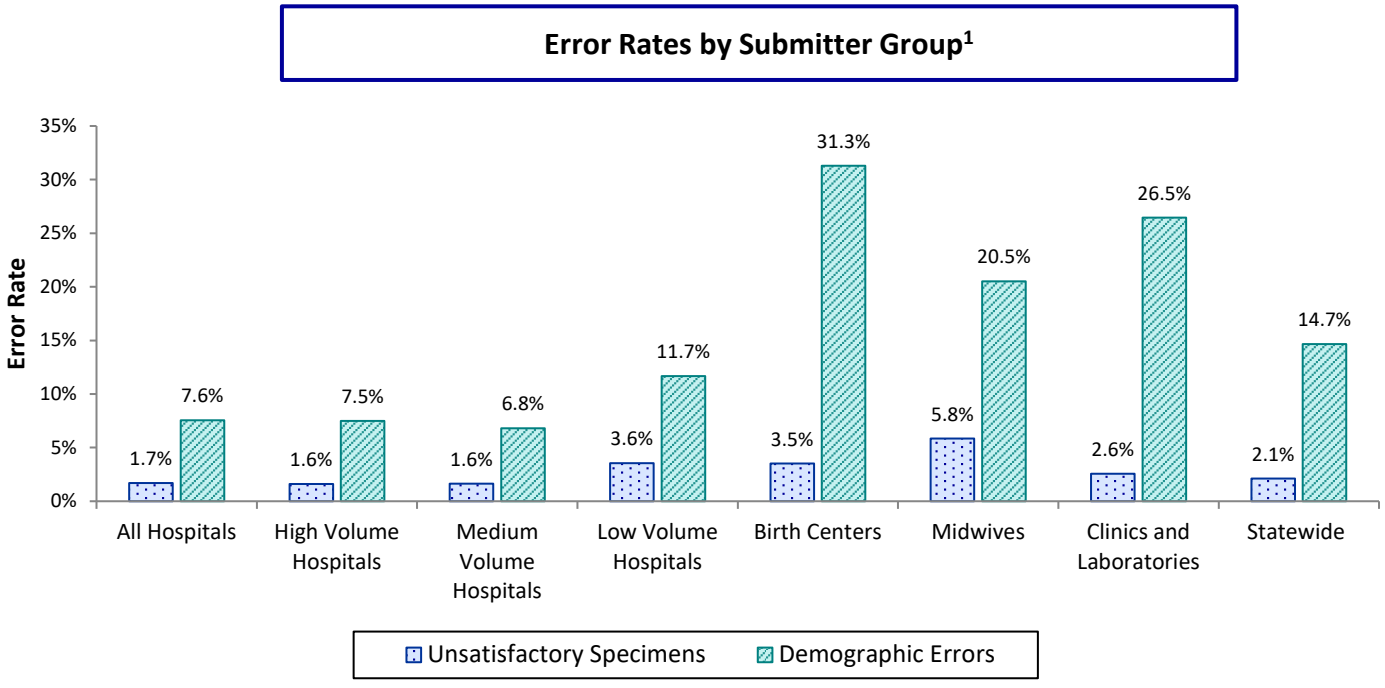
Unsatisfactory Specimens

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	**107,251**	**1,801**	**1.7%**	**8,102**	**7.6%**
High Volume Hospitals	89,752	1,449	1.6%	6,729	7.5%
Medium Volume Hospitals	13,782	223	1.6%	939	6.8%
Low Volume Hospitals	3,717	129	3.6%	434	11.7%
All Birth Center Specimens	**655**	**23**	**3.5%**	**205**	**31.3%**
All Midwife Specimens	**4,912**	**284**	**5.8%**	**1,008**	**20.5%**
All Clinic and Laboratory Specimens	**61,457**	**1,554**	**2.6%**	**16,254**	**26.5%**
Statewide	**174,275**	**3,662**	**2.1%**	**25,569**	**14.7%**



[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, 2016 - December 31, 2016

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
Columbia Basin Hospital	Ephrata	2	0%
Ferry County Memorial Hospital	Republic	5	0%
Group Health Cooperative	Seattle	1	0%
Lewis County Hospital	Morton	5	0%
Lourdes Medical Center	Pasco	5	0%
Mary Bridge Children's Hospital - MultiCare	Tacoma	53	0%
Odessa Memorial Healthcare Center	Odessa	1	0%
Prosser Memorial Hospital	Prosser	521	0%
Snoqualmie Valley Hospital	Snoqualmie	1	0%
St Clare Hospital	Tacoma	3	0%
St Joseph Hospital - Providence	Chewelah	28	0%
Swedish Cherry Hill	Seattle	4	0%
Three Rivers Hospital	Brewster	162	0%
Willapa Harbor Hospital	South Bend	6	0%
Yakima Regional Medical Center	Yakima	1	0%
Naval Hospital - Bremerton	Bremerton	976	0.3%
Harrison Medical Center	Silverdale	2,096	0.5%
Samaritan Healthcare	Moses Lake	1,007	0.5%
PeaceHealth Southwest Medical Center	Vancouver	2,331	0.5%
Madigan Army Medical Center	Joint Base Lewis-McChord	4,139	0.6%
Overlake Medical Center	Bellevue	4,117	0.6%
St Mary Medical Center - Providence	Walla Walla	667	0.7%
Good Samaritan Hospital - MultiCare	Puyallup	2,475	0.8%
Capital Medical Center	Olympia	685	0.9%
Providence Everett Medical Center	Everett	5,392	0.9%
Sacred Heart Medical Center - Providence	Spokane	4,995	0.9%
Valley Hospital	Spokane	1,060	0.9%
Deaconess Hospital	Spokane	1,970	1.0%
Auburn Medical Center - MultiCare	Auburn	1,220	1.0%
Yakima Valley Memorial Hospital	Yakima	5,069	1.0%
St Francis Hospital	Federal Way	1,883	1.1%
Holy Family Hospital - Providence	Spokane	1,566	1.1%

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

Submitting Facility	City	Total Specimens	Unsat Specimen[1] Error Rate
Central Washington Hospital	Wenatchee	1,375	1.1%
Legacy Salmon Creek Medical Center	Vancouver	3,725	1.1%
Jefferson Healthcare	Port Townsend	171	1.2%
EvergreenHealth	Kirkland	5,073	1.2%
Island Hospital	Anacortes	650	1.2%
Naval Hospital - Oak Harbor	Oak Harbor	402	1.2%
Grays Harbor Community Hospital	Aberdeen	478	1.3%
Olympic Medical Center	Port Angeles	926	1.3%
Othello Community Hospital	Othello	767	1.3%
St Joseph Hospital - PeaceHealth	Bellingham	2,126	1.4%
Kadlec Regional Medical Center	Richland	3,287	1.4%
St Joseph Medical Center	Tacoma	6,209	1.5%
Skagit Valley Hospital	Mount Vernon	1,127	1.5%
Northwest Hospital - UW Medicine	Seattle	1,712	1.5%
St Elizabeth Hospital	Enumclaw	446	1.6%
Newport Hospital	Newport	126	1.6%
Toppenish Community Hospital	Toppenish	739	1.6%
Forks Community Hospital	Forks	123	1.6%
Seattle Children's Hospital	Seattle	664	1.7%
Swedish Edmonds	Edmonds	1,792	1.7%
Valley Medical Center - UW Medicine	Renton	4,013	1.8%
EvergreenHealth - Monroe	Monroe	54	1.9%
Coulee Medical Center	Grand Coulee	161	1.9%
Summit Pacific Medical Center	Elma	48	2.1%
Mid-Valley Hospital	Omak	232	2.2%
Swedish Issaquah	Issaquah	1,643	2.2%
Virginia Mason Hospital	Seattle	319	2.2%
WhidbeyHealth Medical Center	Coupeville	340	2.4%
Mason General Hospital	Shelton	320	2.5%
St John Medical Center - PeaceHealth	Longview	837	2.5%
Swedish Ballard	Seattle	1,314	2.8%
Sunnyside Community Hospital	Sunnyside	920	2.8%
Swedish First Hill	Seattle	8,843	3.0%
Harborview Medical Center - UW Medicine	Seattle	99	3.0%
Pullman Regional Hospital	Pullman	436	3.2%
Trios Health Hospital	Kennewick	1,766	3.2%
Kittitas Valley Healthcare	Ellensburg	330	3.3%
Tacoma General Hospital - MultiCare	Tacoma	3,866	3.4%

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

Submitting Facility	City	Total Specimens	Unsat Specimen[1] Error Rate
University of Washington Medical Center	Seattle	2,205	3.7%
Highline Medical Center	Burien	896	3.9%
North Valley Hospital	Tonasket	101	4.0%
Providence Centralia Hospital	Centralia	705	4.1%
Lincoln Hospital	Davenport	23	4.3%
Providence St Peter Hospital	Olympia	2,423	4.7%
Walla Walla General Hospital	Walla Walla	184	4.9%
Whitman Hospital and Medical Center	Colfax	82	6.1%
Mount Carmel Hospital - Providence	Colville	252	6.7%
Cascade Valley Hospital	Arlington	263	8.4%
Lake Chelan Community Hospital	Chelan	212	9.9%
All Hospital Specimens	**Statewide**	**107,251**	**1.7%**
Non-Hospital Specimens	**Statewide**	**67,024**	**2.8%**
All Birth Center Specimens	Statewide	655	3.5%
All Midwife Specimens	Statewide	4,912	5.8%
All Clinic and Laboratory Specimens	Statewide	61,457	2.6%
All Washington State Births	**Statewide**	**174,275**	**2.1%**

[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, 2016 - December 31, 2016

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]
Columbia Basin Hospital	Ephrata	2	0%
Group Health Cooperative	Seattle	1	0%
Snoqualmie Valley Hospital	Snoqualmie	1	0%
Swedish Cherry Hill	Seattle	4	0%
Yakima Regional Medical Center	Yakima	1	0%
Holy Family Hospital - Providence	Spokane	1,566	2.4%
EvergreenHealth	Kirkland	5,073	2.6%
Swedish Edmonds	Edmonds	1,792	2.7%
Olympic Medical Center	Port Angeles	926	2.9%
Naval Hospital - Bremerton	Bremerton	976	3.0%
Madigan Army Medical Center	Joint Base Lewis-McChord	4,139	3.0%
Overlake Medical Center	Bellevue	4,117	3.0%
Northwest Hospital - UW Medicine	Seattle	1,712	3.3%
Yakima Valley Memorial Hospital	Yakima	5,069	3.5%
Samaritan Healthcare	Moses Lake	1,007	3.5%
Othello Community Hospital	Othello	767	3.7%
Forks Community Hospital	Forks	123	4.1%
Swedish Issaquah	Issaquah	1,643	4.5%
Skagit Valley Hospital	Mount Vernon	1,127	4.5%
Kadlec Regional Medical Center	Richland	3,287	4.7%
University of Washington Medical Center	Seattle	2,205	5.0%
St Mary Medical Center - Providence	Walla Walla	667	5.1%
Providence St Peter Hospital	Olympia	2,423	5.2%
WhidbeyHealth Medical Center	Coupeville	340	5.3%
St Francis Hospital	Federal Way	1,883	5.4%
Swedish Ballard	Seattle	1,314	5.6%
Deaconess Hospital	Spokane	1,970	5.7%
Island Hospital	Anacortes	650	5.7%
Harrison Medical Center	Silverdale	2,096	5.9%
North Valley Hospital	Tonasket	101	5.9%
Mid-Valley Hospital	Omak	232	6.0%
Whitman Hospital and Medical Center	Colfax	82	6.1%

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

Submitting Facility	City	Total Specimens	Demographic Error Rate[1]
Sacred Heart Medical Center - Providence	Spokane	4,995	6.1%
Central Washington Hospital	Wenatchee	1,375	6.4%
Mason General Hospital	Shelton	320	6.6%
Tacoma General Hospital - MultiCare	Tacoma	3,866	6.6%
Pullman Regional Hospital	Pullman	436	6.7%
St Joseph Hospital - PeaceHealth	Bellingham	2,126	6.7%
Three Rivers Hospital	Brewster	162	6.8%
Coulee Medical Center	Grand Coulee	161	6.8%
Grays Harbor Community Hospital	Aberdeen	478	6.9%
Prosser Memorial Hospital	Prosser	521	6.9%
St John Medical Center - PeaceHealth	Longview	837	6.9%
Trios Health Hospital	Kennewick	1,766	7.1%
Legacy Salmon Creek Medical Center	Vancouver	3,725	7.3%
Valley Medical Center - UW Medicine	Renton	4,013	7.5%
Jefferson Healthcare	Port Townsend	171	7.6%
St Elizabeth Hospital	Enumclaw	446	7.6%
Seattle Children's Hospital	Seattle	664	7.7%
St Joseph Medical Center	Tacoma	6,209	8.0%
Virginia Mason Hospital	Seattle	319	8.2%
Highline Medical Center	Burien	896	8.5%
Valley Hospital	Spokane	1,060	8.6%
Toppenish Community Hospital	Toppenish	739	8.7%
Sunnyside Community Hospital	Sunnyside	920	8.8%
Capital Medical Center	Olympia	685	9.1%
Kittitas Valley Healthcare	Ellensburg	330	9.1%
Providence Centralia Hospital	Centralia	705	10.4%
Good Samaritan Hospital - MultiCare	Puyallup	2,475	10.5%
St Joseph Hospital - Providence	Chewelah	28	10.7%
Cascade Valley Hospital	Arlington	263	12.5%
Auburn Medical Center - MultiCare	Auburn	1,220	13.2%
Providence Everett Medical Center	Everett	5,392	13.3%
PeaceHealth Southwest Medical Center	Vancouver	2,331	14.5%
Naval Hospital - Oak Harbor	Oak Harbor	402	15.2%
Walla Walla General Hospital	Walla Walla	184	15.2%
Newport Hospital	Newport	126	18.3%
Lake Chelan Community Hospital	Chelan	212	18.4%
EvergreenHealth - Monroe	Monroe	54	18.5%
Swedish First Hill	Seattle	8,843	18.5%

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

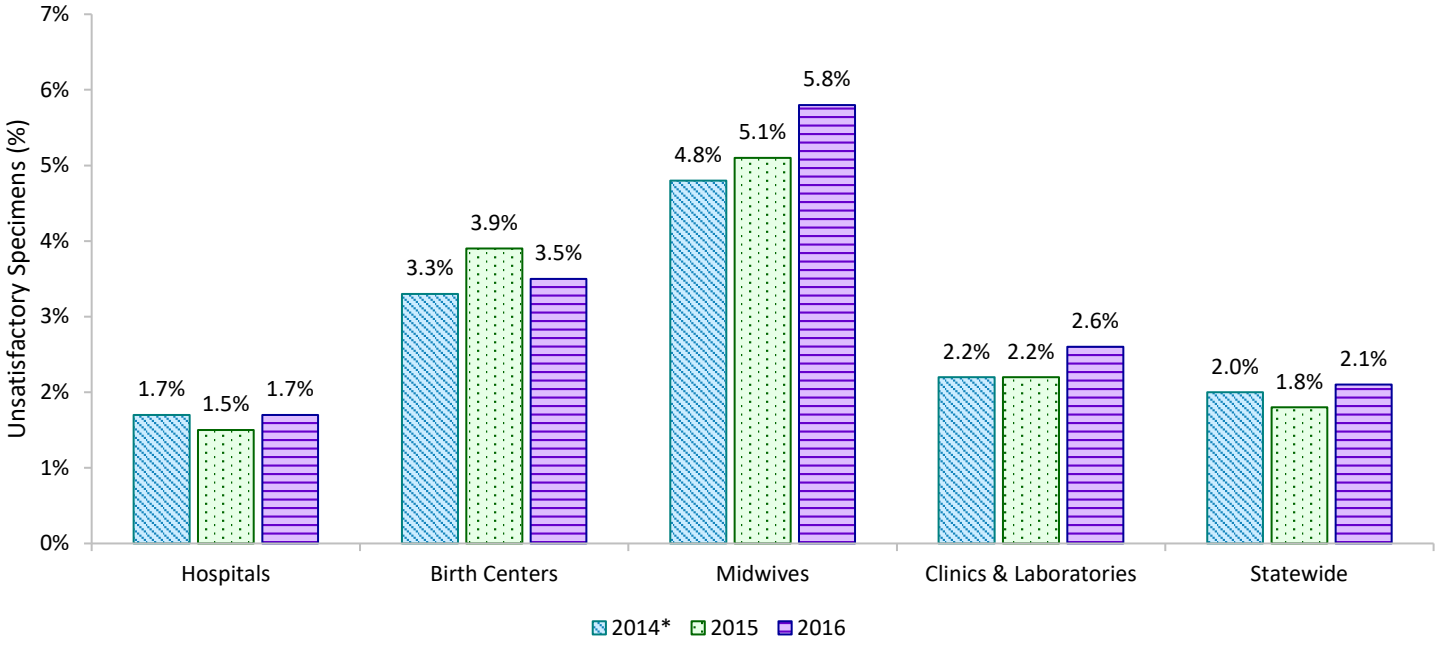
Submitting Facility	City	Total Specimens	Demographic Error Rate[1]
Ferry County Memorial Hospital	Republic	5	20.0%
Lourdes Medical Center	Pasco	5	20.0%
Mount Carmel Hospital - Providence	Colville	252	20.6%
Lincoln Hospital	Davenport	23	21.7%
Summit Pacific Medical Center	Elma	48	22.9%
Mary Bridge Children's Hospital - MultiCare	Tacoma	53	37.7%
Harborview Medical Center - UW Medicine	Seattle	99	39.4%
Lewis County Hospital	Morton	5	40.0%
St Clare Hospital	Tacoma	3	66.7%
Willapa Harbor Hospital	South Bend	6	66.7%
Odessa Memorial Healthcare Center	Odessa	1	100%
All Hospital Specimens	**Statewide**	**107,251**	**7.6%**
Non-Hospital Specimens	**Statewide**	**67,024**	**26.1%**
All Birth Center Specimens	Statewide	655	31.3%
All Midwife Specimens	Statewide	4,912	20.5%
All Clinic and Laboratory Specimens	Statewide	61,457	26.4%
All Washington State Births	**Statewide**	**174,275**	**14.7%**

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

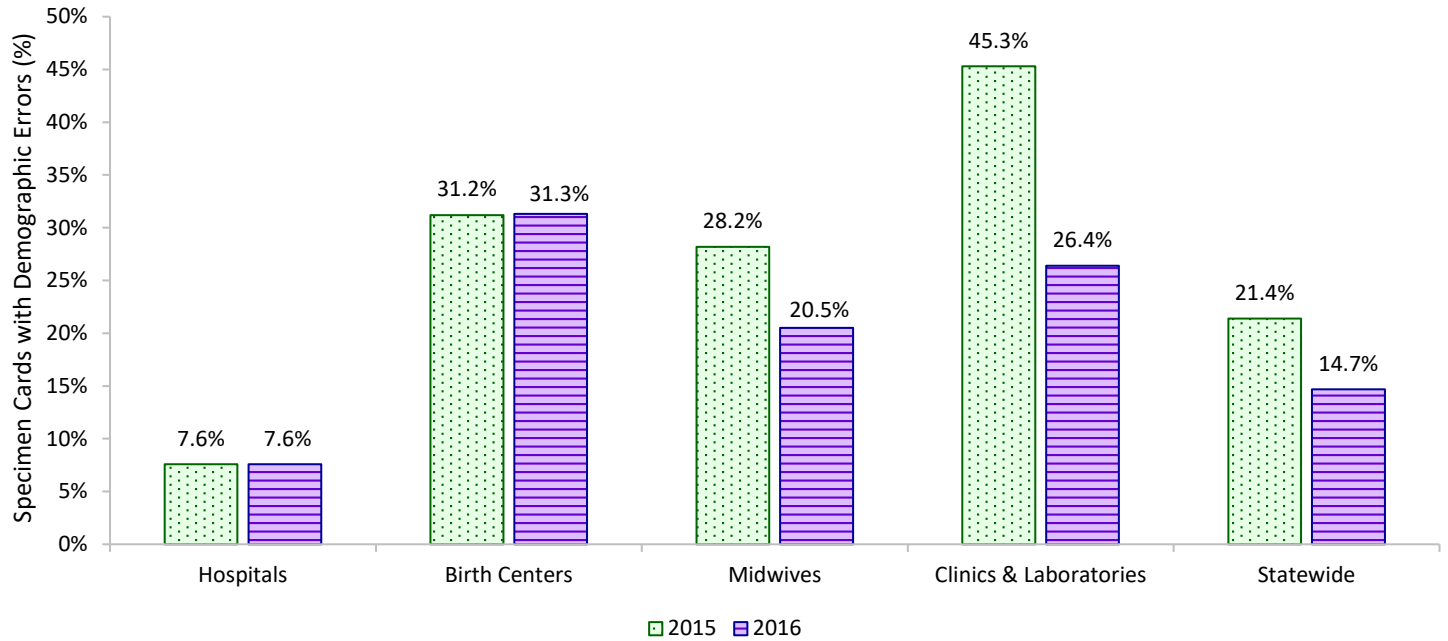
Table 7: Annual Quality Measures

Received July 1, 2014 - December 31, 2016

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 healthcare 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, 47.8 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, 52.2 percent of the required notifications were reported to the department. Of the reported notifications, 81.2 percent reported that parents were notified within three days of the referral.

The following Table 8 details the timeliness of parent notification by their healthcare provider in 2016.

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. Since the implementation of the reporting requirement there has been a decrease in the percent of notifications returned and the percent of on-time parent notifications. In 2016 only 50.7 percent of the required notifications were reported to the department. Of the reported notifications, 77.2 percent of parents were notified of the need for diagnostic testing and evaluation in the recommended timeframe. This highlights the need for better education of healthcare providers regarding their responsibility to notify parents timely 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 healthcare provider if the referral notification form is not returned.

Table 8: Timeliness of Parent Notification by Healthcare Providers

Births January 1, 2016 - December 31, 2016

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

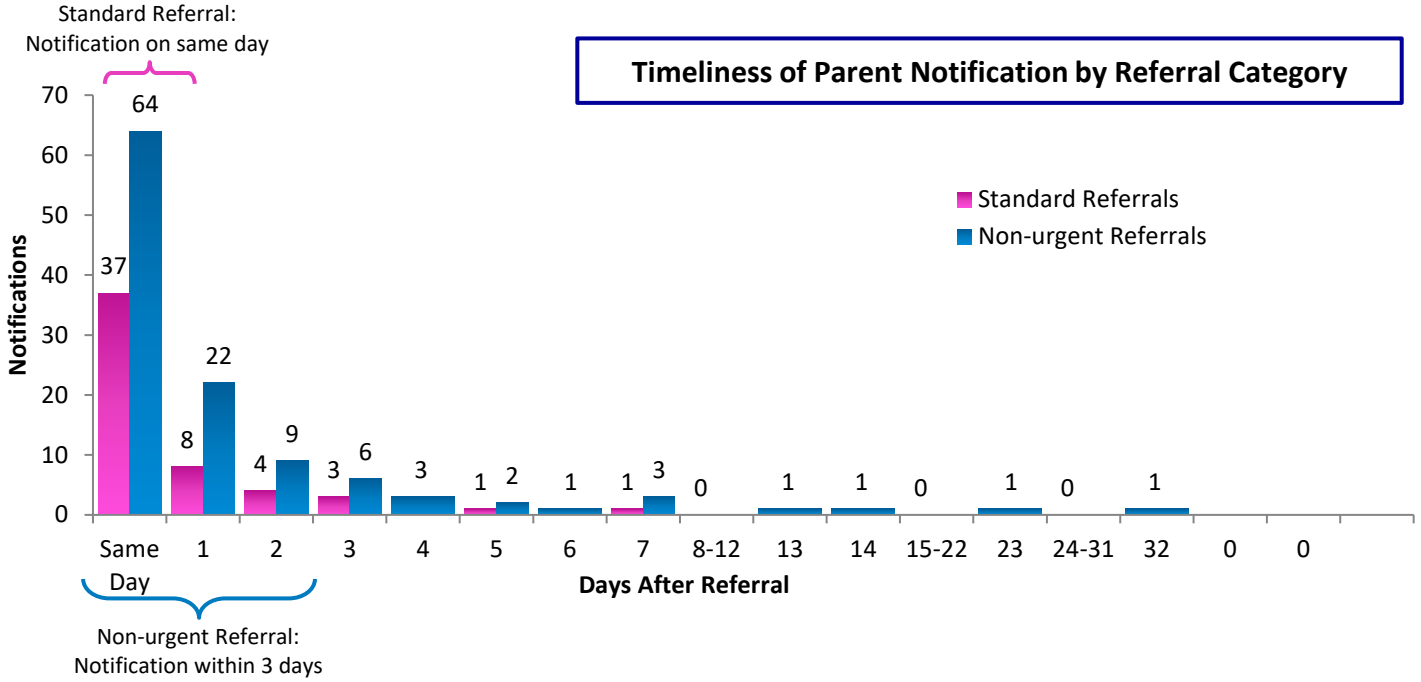
Due to the potential severity of the condition clinical evaluation and diagnostic testing should be done immediately. Parents should be notified the same day as the referral.

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		Healthcare Provider Reported Date of Parent Notification		On-time Parent Notification	
	Total	Percent	Total	Percent	Total	Percent
Standard Referral	113	33.5%	54	47.8%	37	68.5%
Non-urgent Referral	224	66.5%	117	52.2%	95	81.2%
All Referrals	**337***	**100%**	**171**	**50.7%**	**132**	**77.2%**

*Excludes 12 instances where the healthcare provider began diagnostic testing prior to screening results based on family history, prenatal diagnosis, or clinical symptoms.



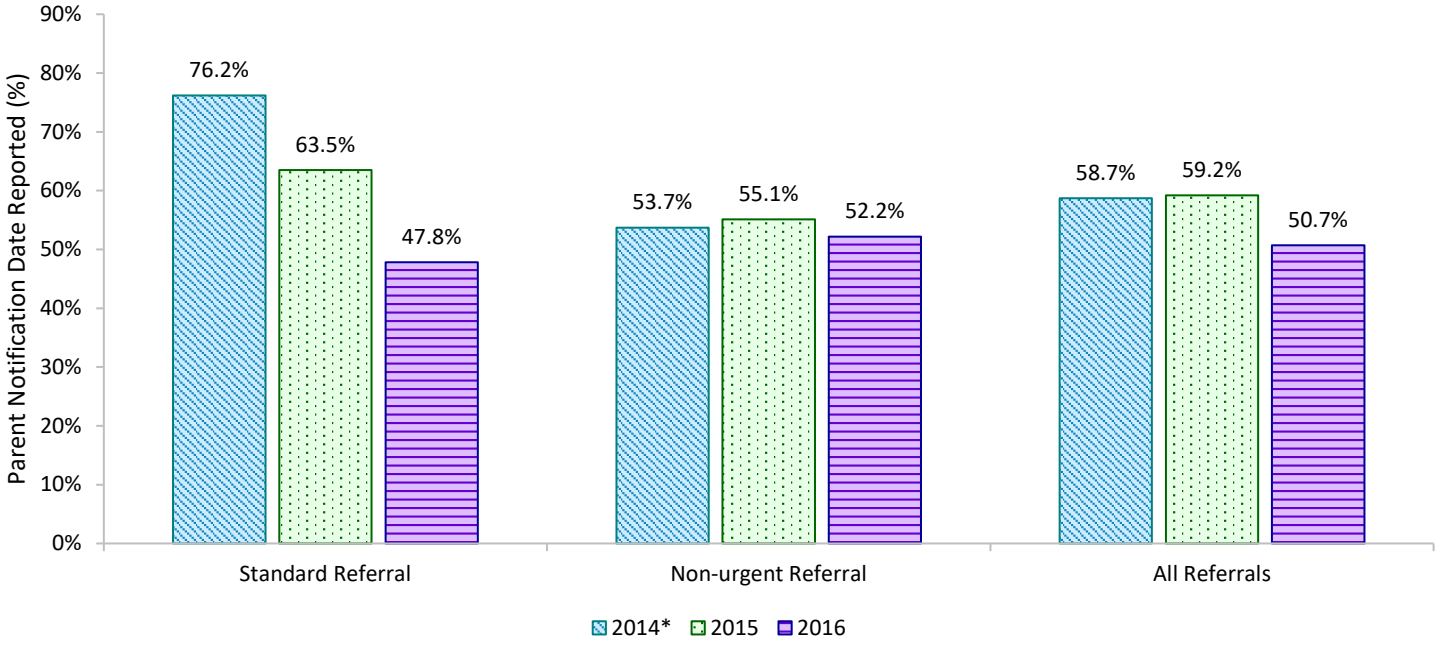
Disorders included in Standard Referrals: Argininosuccinic acidemia (ASA), Citrullinemia (CIT), Congenital adrenal hyperplasia (CAH), Congenital hypothyroidism (CH), Galactosemia (GALT), Isovaleric acidemia (IVA), Long-chain L-3-hydroxy acyl-CoA dehydrogenase (LCHAD) deficiency, Maple syrup urine disease (MSUD), Medium chain acyl-CoA dehydrogenase (MCAD) deficiency, Methylmalonic acidemias (MMA)/Propionic acidemia, Phenylketonuria (PKU), Very long-chain acyl-CoA dehydrogenase (VLCAD) deficiency

Disorders included in Non-urgent Referrals: Biotinidase deficiency (BIO), Cystic fibrosis (CF), Mild congenital hypothyroidism (CH), Carnitine uptake defect (CUD), Partial Galactosemia (GALT), Homocystinuria (HCY), Hemoglobinopathies (HB), 3-hydroxy-3-methyglutaric aciduria (HMG)/ Multiple carboxylase deficiency (MCD), Severe combined immunodeficiency (SCID)

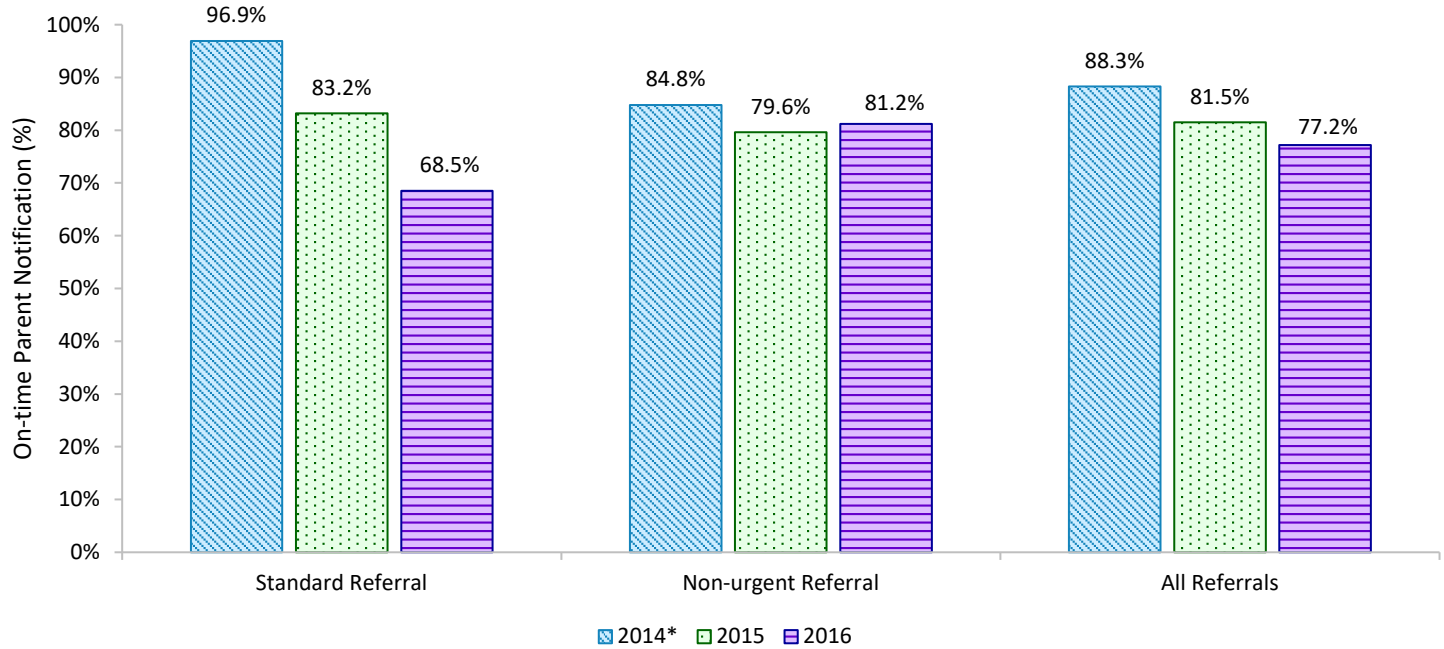
Table 9: Annual Parent Notification Measures

Received July 1, 2014 - December 31, 2016

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 notifed 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: 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 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: 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 2016.

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

Births January 1, 2016 - December 31, 2016

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	480	-	-	-	-	-	-	-	-	-	-	0
Asotin	1	-	-	-	-	-	-	-	-	-	-	0
Benton	5,427	-	-	-	3[b]	-	-	-	-	-	-	3
Chelan	1,505	-	-	-	-	-	-	-	-	-	-	0
Clallam	587	-	-	-	-	-	-	-	-	-	-	0
Clark	5,750	1	-	-	1	-[c]	1	-	-	-	-	3
Columbia	0	-	-	-	-	-	-	-	-	-	-	0
Cowlitz	862	-	1	-	-	-	-	-	-	-	-	1
Douglas	204	-	-	-	-	-	-	-	-	-	-	0
Ferry	3	-	-	-	-	-	-	-	-	-	-	0
Franklin	3	-	-	-	1	-	-	-	-	-	-	1
Garfield	0	-	-	-	-	-	-	-	-	-	-	0
Grant	1,028	-	-	-	2	-	1	-	-	-	-	3
Grays Harbor	480	-	-	-	-	-	-	-	-	-	-	0
Island[a]	444	-	-	-	1	-	-	-	-	-	-	1
Jefferson	125	-	-	-	-	-	-	-	-	-	-	0
King	30,930	4	-	1	48	4	2	3	13	1[d]	-	76
Kitsap[a]	2,605	-	-	-	1	2	-	-	-	-	-	3
Kittitas	318	-	-	-	-	-	-	-	-	-	-	0
Klickitat	28	-	-	-	-	-	-	-	-	-	-	0
Lewis	808	-	-	-	-	-	-	-	-	-	-	0
Lincoln	0	-	-	-	-	-	-	-	-	-	-	0
Mason	301	-	-	-	-	-	-	-	-	-	-	0
Okanogan	321	-	-	-	-	-	-	-	-	-	-	0
Pacific	3	-	-	-	-	-	-	-	-	-	-	0
Pend Oreille	65	-	-	-	-	-	-	-	-	-	-	0
Pierce	12,137	-	-	1	11	1	1	-	5	-	-	19
San Juan	433	-	-	-	-	-	-	-	-	-	-	0
Skagit	1,228	-	-	-	3	-	1	-	-	-	-	4
Skamania	0	-	-	-	-	-	-	-	-	-	-	0
Snohomish	6,624	1	-	1	15	-	-	1	3	-	-	21
Spokane	7,085	-	-	-	7[e]	1	1	1	-	1	1	12
Stevens	267	-	-	-	-	-	-	-	-	-	-	0
Thurston	3,138	-	-	1	1	-	-	-	3	1	-	6
Wahkiakum	0	-	-	-	-	-	-	-	-	-	-	0
Walla Walla	775	-	-	-	-	-	-	-	-	-	-	0
Whatcom	2,242	1	-	1	3	2	-	-	-	-	-	7
Whitman	483	-	-	-	2	-	-	-	-	-	-	2
Yakima	3,183	1	-	-	7	-	-	-	-	1	-	9
All WA Births[a]	**89,873**	**8**	**1**	**5**	**106**	**10**	**7**	**5**	**24**	**4**	**1**	**171**

[a]Excludes 227 infants born in two naval hospitals (41-Oak Harbor, 186-Bremerton) before May 1, 2016 that did not participate in the WA NBS Program. Also excludes 441 infants born out-of-state who received one or more newborn screens in Washington.

[b]Excludes one infant from Benton county with CH that was born out-of-state.

[c]Excludes one infant from Clark county with CF that was not detected through newborn screening.

[d]Includes one infant born in King county with an OA disorder who resides in Alaska.

[e]Excludes one infant from Spokane county with CH that was born out-of-state.

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

Births January 1, 2016 - December 31, 2016

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	51,115	6	1	1	48[a]	9[c]	5	4	1	1	1	77
Black	3,376	-	-	-	4	-	-	-	9	-	-	13
Asian	5,251	-	-	2	18	-	-	-	8	-	-	28
Native American	912	-	-	1	-	-	-	-	-	-	-	1
Other[d]	16,158	2	-	1	24[b]	-	2	1	4	2	-	36
Unknown[e]	13,061	-	-	-	12	1	-	-	2	1	-	16
All WA Births[f]	**89,873**	**8**	**1**	**5**	**106**	**10**	**7**	**5**	**24**	**4**	**1**	**171**
Hispanic[g]	18,202	-	-	-	15	2	-	1	-	2	-	17

[a]Excludes one white infant with CH born out-of-state.

[b]Excludes one other race infant with CH born out-of-state.

[c]Excludes two white infants (one born out-of-state) with CF that were not detected through newborn screening.

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

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

[f]Excludes 227 infants born in two naval hospitals (41-Oak Harbor, 186-Bremerton) before May 1, 2016 that did not participate in the WA NBS Program. Also excludes 441 infants born out-of-state who received one or more newborn screens in Washington.

[g]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 or 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 healthcare 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 healthcare 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

Births January 1, 2016 - December 31,2016

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)	4	1	4	51[a]	10[b]	4	1	17	1	0	93
Followed by primary care provider, with some consultation from specialist	-	-	-	-	-	-	-	-	-	-	0
Infant died or Lost to Follow-up	-	-	-	-	-	-	-	-	-	-	0
Total	**4**	**1**	**4**	**51**	**10**	**4**	**1**	**17[c]**	**1**	**0**	**93**

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

[b]Excludes two white infants (one born out-of-state) with CF that were not detected through newborn screening.

[c]See Key 3: Newborn Hemoglobin Screening Explantions and Definitions of Phenotypes

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

Births January 1, 2016 - December 31, 2016

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	4	10	7 - 12
Biotinidase deficiency	1	15	n/a
Congenital adrenal hyperplasia	3[a]	5	3 - 39
Congenital hypothyroidism	50[b]	8	3 - 51
Cystic fibrosis	10[c]	26	15 - 45
Fatty acid oxidation disorders	4	9	6 - 11
Galactosemia	1	7	n/a
Hemoglobinopathies[d]	13[e]	28	10 - 161
Organic acid disorders	1	4	n/a
Severe combined immunodeficiency	0	-	-
Total	**87**	**12**	**3 - 161**

[a]Excludes one infant where treatment began on day of life 2 due to clinical symptoms.

[b]Excludes two infants born out-of-state with congenital hypothyroidism and one infant where treatment began on day of life 1 due to clinical symptoms.

[c]Excludes one infant not detected by WA newborn screening.

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

[e]Excludes four infants with hemoglobin diseases that do not require immediate treatment.

Newborn Screening Future Activities

Newborn Screening 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[5] and mucopolysaccharidosis type-I[6] (MPS-I). Both conditions are on the national Recommended Uniform Screening Panel (RUSP). The advisory committee reviewed the first four screening criteria and determined that both Pompe and MPS-I met the criteria. 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 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. Testing for the new conditions is expected to start in the fall of 2018.

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 January 2018.

To better serve our customers, the Newborn Screening Program will implement in spring 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 will allow 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.

Education and Compliance Outreach

The Newborn Screening Program is developing online training modules to expand outreach and provide on-demand training for healthcare 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, the Newborn Screening Program 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 healthcare 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.

[5] 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.
[6] 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.

Supplemental Documents

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 2009-2015

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 2016 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)	Yes[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	Yes[b]	Approved by SBOH 2017
X-ALD	X-linked adrenoleukodystrophy	Yes[b]	Approved by SBOH 2016

[a]The NBS Techincal 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 (SBOH) are preparing for this expansion and anticipate starting screening for X-ALD during the first quarter of 2018, with Pompe and MPS-I anticipated for late 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 Laboratory 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 Board of Health 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 statute revisions and additional 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 November 2015, a Newborn Screening Advisory Committee convened by the Board of Health considered X-linked adrenoleukodystrophy (X-ALD) as a candidate for screening. The Board of Health accepted the Advisory Committee's recommendation to add X-ALD to the mandatory screening panel. The Department of Health and Board of Health are preparing for this expansion and anticipate starting screening for X-ALD during or before the first quarter of 2018.

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

Births January 1, 2016 - December 31, 2016

Each hospital or healthcare provider attending a birth outside of a hospital is required to collect and transport specimens to the Newborn Screening Laboratory 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 Lab 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)		**57,603**	**99.1%**	**91.7%**
EvergreenHealth	Kirkland	4,765	99.3%	99.8%
Good Samaritan Hospital - MultiCare	Puyallup	2,386	98.7%	92.0%
Harrison Medical Center	Silverdale	2,007	99.3%	98.8%
Kadlec Regional Medical Center	Richland	2,815	99.3%	62.7%
Legacy Salmon Creek Medical Center	Vancouver	3,491	99.4%	96.5%
Madigan Army Medical Center	Joint Base Lewis-McChord	2,013	99.8%	88.3%
Overlake Medical Center	Bellevue	3,921	99.5%	98.2%
PeaceHealth Southwest Medical Center	Vancouver	2,125	97.4%	92.1%
Providence Everett Medical Center	Everett	4,814	98.9%	98.2%
Providence St Peter Hospital	Olympia	2,255	99.7%	74.6%
Sacred Heart Medical Center - Providence	Spokane	3,326	99.5%	96.3%
St Joseph Hospital - PeaceHealth	Bellingham	2,038	98.7%	80.6%
St Joseph Medical Center	Tacoma	4,234	98.9%	97.3%
Swedish First Hill	Seattle	7,852	99.4%	99.4%
Tacoma General Hospital - MultiCare	Tacoma	3,042	99.0%	90.7%
Valley Medical Center - UW Medicine	Renton	3,771	98.5%	88.9%
Yakima Valley Memorial Hospital	Yakima	2,748	99.1%	68.3%
Medium Volume Hospitals (100-500 births per quarter)		**25,743**	**98.6%**	**88.8%**
Auburn Medical Center - MultiCare	Auburn	1,202	99.3%	95.8%
Capital Medical Center	Olympia	700	95.7%	79.0%
Central Washington Hospital	Wenatchee	1,344	99.0%	81.5%
Deaconess Hospital	Spokane	1,445	99.4%	95.6%
Grays Harbor Community Hospital	Aberdeen	472	98.1%	34.1%
Highline Medical Center	Burien	862	98.1%	95.9%
Holy Family Hospital - Providence	Spokane	1,306	99.0%	88.7%
Island Hospital	Anacortes	433	98.8%	99.1%
Naval Hospital - Bremerton	Bremerton	478	97.5%	91.8%
Northwest Hospital - UW Medicine	Seattle	1,211	99.6%	99.7%
Olympic Medical Center	Port Angeles	464	95.9%	75.0%
Othello Community Hospital	Othello	478	99.6%	52.1%
Providence Centralia Hospital	Centralia	727	97.1%	46.8%
Pullman Regional Hospital	Pullman	426	98.6%	86.4%
Samaritan Healthcare	Moses Lake	1,004	97.0%	86.4%

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

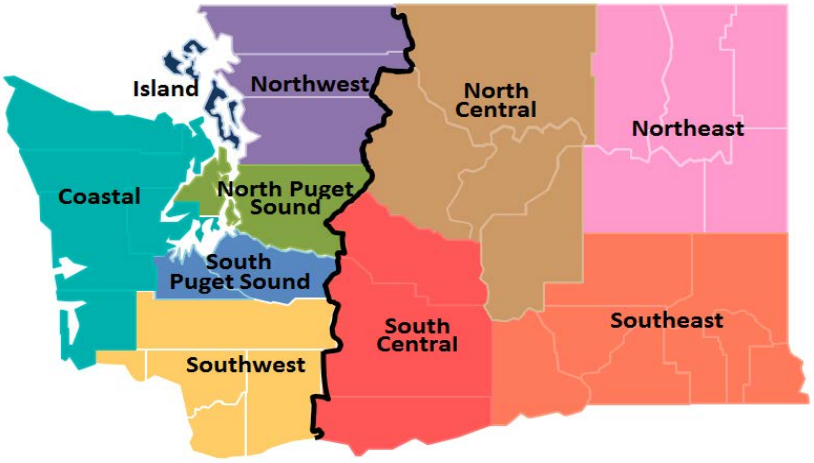
Hospital of Birth	City	Eligible Infants	1) Collection Compliance	2) Transit Compliance
Medium Volume Hospitals (100-500 births per quarter) cont.		**25,743**	**98.6%**	**88.8%**
Skagit Valley Hospital	Mount Vernon	1,109	98.9%	75.8%
St Francis Hospital	Federal Way	1,349	98.7%	94.1%
St John Medical Center - PeaceHealth	Longview	839	98.3%	86.4%
St Mary Medical Center - Providence	Walla Walla	661	95.5%	93.0%
Sunnyside Community Hospital	Sunnyside	533	98.1%	84.4%
Swedish Ballard	Seattle	1,166	99.4%	97.9%
Swedish Edmonds	Edmonds	1,247	99.6%	97.8%
Swedish Issaquah	Issaquah	1,594	99.7%	99.6%
Toppenish Community Hospital	Toppenish	431	98.1%	95.1%
Trios Health Hospital	Kennewick	1,627	99.3%	90.0%
University of Washington Medical Center	Seattle	1,900	97.9%	98.8%
Valley Hospital	Spokane	735	99.0%	93.3%
Low Volume Hospitals (< 100 births per quarter)		**3,083**	**97.0%**	**73.8%**
Cascade Valley Hospital	Arlington	164	97.6%	62.2%
Coulee Medical Center	Grand Coulee	92	98.9%	32.6%
Forks Community Hospital	Forks	71	100%	90.1%
Harborview Medical Center - UW Medicine	Seattle	3	100%	100%
Jefferson Healthcare	Port Townsend	101	86.1%	41.6%
Kittitas Valley Healthcare	Ellensburg	311	97.7%	87.5%
Lake Chelan Community Hospital	Chelan	113	91.2%	53.1%
Lewis County Hospital	Morton	2	100%	50.0%
Lourdes Medical Center	Pasco	1	100%	100%
Mason General Hospital	Shelton	301	97.7%	85.7%
Mid-Valley Hospital	Omak	226	99.1%	77.0%
Mount Carmel Hospital - Providence	Colville	231	97.4%	91.8%
Naval Hospital - Oak Harbor	Oak Harbor	198	98.0%	84.3%
Newport Hospital	Newport	65	100%	92.3%
North Valley Hospital	Tonasket	84	92.9%	77.4%
Ocean Beach Hospital	Ilwaco	1	100%	100%
Prosser Memorial Hospital	Prosser	343	99.7%	39.7%
St Clare Hospital	Lakewood	1	100%	100%
St Elizabeth Hospital	Enumclaw	333	96.1%	91.9%
Summit Pacific Medical Center	Elma	1	100%	100%
Three Rivers Hospital	Brewster	108	96.3%	58.3%
Walla Walla General Hospital	Walla Walla	113	94.7%	61.9%
WhidbeyHealth Medical Center	Coupeville	180	97.8%	82.2%
Whitman Hospital and Medical Center	Colfax	39	92.3%	94.9%
Willapa Harbor Hospital	South Bend	1	100%	100%
All Hospital Births		**86,429**	**98.9%**	**90.2%**

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

Births January 1, 2016 - December 31, 2016

Each hospital or health care provider attending a birth outside of a hospital is required to collect and transport specimens to the Newborn Screening Laboratory 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 Lab within 72 hours of collection (excluding Sundays and Thanksgiving)



Hospital of Birth	City	Eligible Infants	1) Collection Compliance	2) Transit Compliance
Northwest Hospitals		**9,372**	**98.9%**	**91.0%**
Cascade Valley Hospital	Arlington	164	97.6%	62.2%
Providence Everett Medical Center	Everett	4,814	98.9%	98.2%
Skagit Valley Hospital	Mount Vernon	1,109	98.9%	75.8%
St Joseph Hospital - PeaceHealth	Bellingham	2,038	98.7%	80.6%
Swedish Hospital - Edmonds	Edmonds	1,247	99.6%	97.8%
North Puget Sound Hospitals		**32,415**	**99.1%**	**97.3%**
Auburn Medical Center - MultiCare	Auburn	1,202	99.3%	95.8%
EvergreenHealth	Kirkland	4,765	99.3%	99.8%
Harborview Medical Center - UW Medicine	Seattle	3	100%	100%
Harrison Medical Center	Silverdale	2,007	99.3%	98.8%
Highline Medical Center	Burien	862	98.1%	95.9%
Naval Hospital - Bremerton	Bremerton	478	97.5%	91.8%
Northwest Hospital	Seattle	1,211	99.6%	99.7%
Overlake Medical Center	Bellevue	3,921	99.5%	98.2%
St Elizabeth Hospital	Enumclaw	333	96.1%	91.9%
St Francis Hospital	Federal Way	1,349	98.7%	94.1%
Swedish Ballard	Seattle	1,166	99.4%	97.9%
Swedish First Hill	Seattle	7,852	99.4%	99.4%
Swedish Issaquah	Issaquah	1,594	99.7%	99.6%
University of Washington Medical Center	Seattle	1,900	97.9%	98.8%
Valley Medical Center - UW Medicine	Renton	3,771	98.5%	88.9%

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

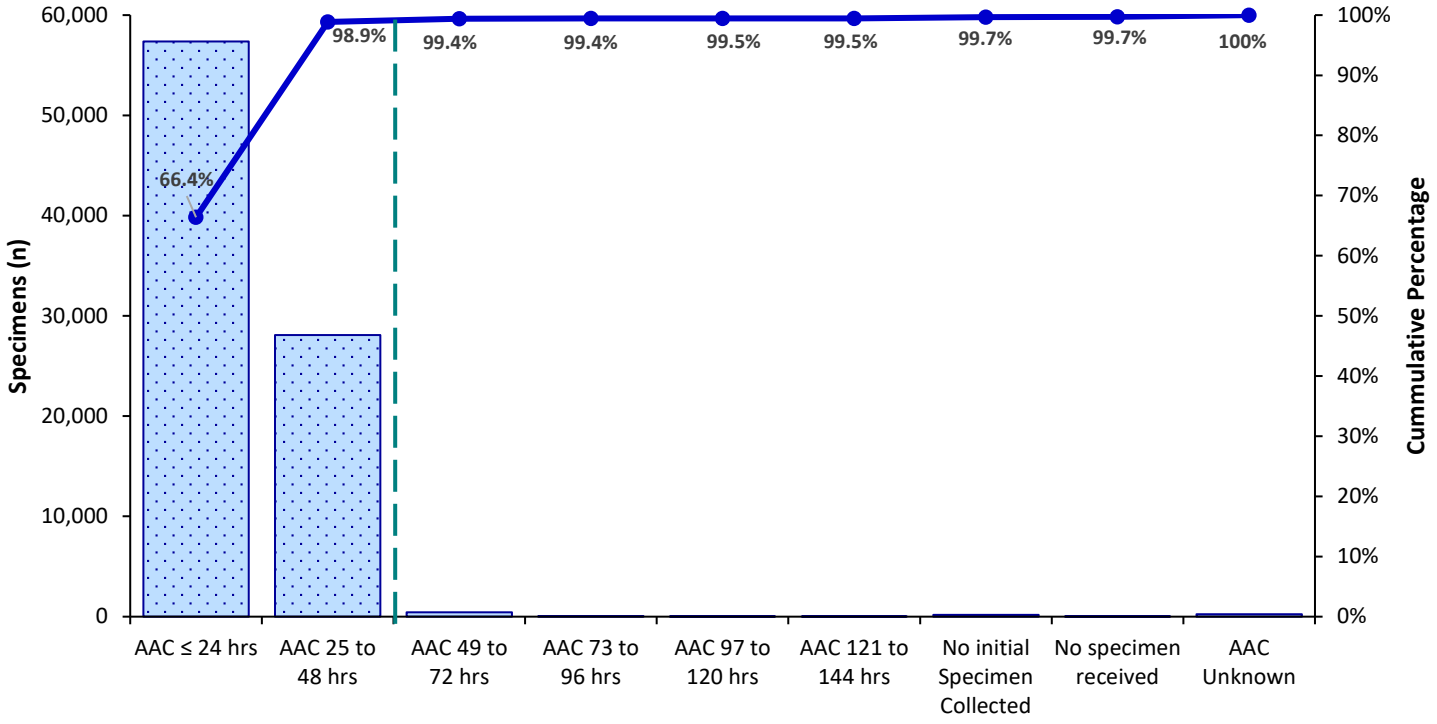
Hospital of Birth	City	Eligible Infants	1) Collection Compliance	2) Transit Compliance
South Puget Sound Hospitals		**14,631**	**99.0%**	**89.4%**
Capital Medical Center	Olympia	700	95.7%	79.0%
Good Samaritan Hospital - MultiCare	Puyallup	2,386	98.7%	92.0%
Madigan Army Medical Center	Joint Base Lewis-McChord	2,013	99.8%	88.3%
Providence St Peter Hospital	Olympia	2,255	99.7%	74.6%
St Clare Hospital	Lakewood	1	100%	100%
St Joseph Medical Center	Tacoma	4,234	98.9%	97.3%
Tacoma General Hospital - MultiCare	Tacoma	3,042	99.0%	90.7%
Southwest Hospitals		**7,184**	**98.5%**	**89.0%**
Legacy Salmon Creek Medical Center	Vancouver	3,491	99.4%	96.5%
Lewis County Hospital	Morton	2	100%	50.0%
PeaceHealth Southwest Medical Center	Vancouver	2,125	97.4%	92.1%
Providence Centralia Hospital	Centralia	727	97.1%	46.8%
St John Medical Center - PeaceHealth	Longview	839	98.3%	86.4%
Coastal Region Hospitals		**1,412**	**96.5%**	**62.0%**
Forks Community Hospital	Forks	71	100%	90.1%
Grays Harbor Community Hospital	Aberdeen	472	98.1%	34.1%
Jefferson Healthcare	Port Townsend	101	86.1%	41.6%
Mason General Hospital	Shelton	301	97.7%	85.7%
Ocean Beach Hospital	Ilwaco	1	100%	100%
Olympic Medical Center	Port Angeles	464	95.9%	75.0%
Summit Pacific Medical Center	Elma	1	100%	100%
Willapa Harbor Hospital	South Bend	1	100%	100%
Island Region Hospitals		**810**	**98.5%**	**91.9%**
Island Hospital	Anacortes	433	98.8%	99.1%
Naval Hospital - Oak Harbor	Oak Harbor	198	98.0%	84.3%
WhidbeyHealth Medical Center	Coupeville	180	97.8%	82.2%
North Central Hospitals		**2,971**	**97.8%**	**79.2%**
Central Washington Hospital	Wenatchee	1,344	99.0%	81.5%
Coulee Medical Center	Grand Coulee	92	98.9%	32.6%
Lake Chelan Community Hospital	Chelan	113	91.2%	53.1%
Mid-Valley Hospital	Omak	226	99.1%	77.0%
North Valley Hospital	Tonasket	84	92.9%	77.4%
Samaritan Healthcare	Moses Lake	1,004	97.0%	86.4%
Three Rivers Hospital	Brewster	108	96.3%	58.3%

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

Hospital of Birth	City	Eligible Infants	1) Collection Compliance	2) Transit Compliance
South Central Hospitals		**3,490**	**98.9%**	**73.4%**
Kittitas Valley Healthcare	Ellensburg	311	97.7%	87.5%
Toppenish Community Hospital	Toppenish	431	98.1%	95.1%
Yakima Valley Memorial Hospital	Yakima	2,748	99.1%	68.3%
Southeast Hospitals		**7,036**	**98.7%**	**73.3%**
Kadlec Regional Medical Center	Richland	2,815	99.3%	62.7%
Lourdes Medical Center	Pasco	1	100%	100%
Othello Community Hospital	Othello	478	99.6%	52.1%
Prosser Memorial Hospital	Prosser	343	99.7%	39.7%
Pullman Regional Hospital	Pullman	426	98.6%	86.4%
St Mary Medical Center - Providence	Walla Walla	661	95.5%	93.0%
Sunnyside Community Hospital	Sunnyside	533	98.1%	84.4%
Trios Health Hospital	Kennewick	1,627	99.3%	90.0%
Walla Walla General Hospital	Walla Walla	113	94.7%	61.9%
Whitman Hospital and Medical Center	Colfax	39	92.3%	94.9%
Northeast Hospitals		**7,108**	**99.3%**	**94.3%**
Deaconess Hospital	Spokane	1,445	99.4%	95.6%
Holy Family Hospital - Providence	Spokane	1,306	99.0%	88.7%
Mount Carmel Hospital - Providence	Colville	231	97.4%	91.8%
Newport Hospital	Newport	65	100%	92.3%
Sacred Heart Medical Center - Providence	Spokane	3,326	99.5%	96.3%
Valley Hospital	Spokane	735	99.0%	93.3%
Western Washington Out-of-Hospital Births		**2,813**	**81.8%**	**69.3%**
Eastern Washington Out-of-Hospital Births		**559**	**72.6%**	**39.9%**
All Hospital Births	**Statewide**	**86,429**	**98.9%**	**90.2%**
All Out-of-Hospital Births	**Statewide**	**3,372**	**80.3%**	**64.4%**
All Washington State Births	**Statewide**	**89,873**	**98.2%**	**89.2%**

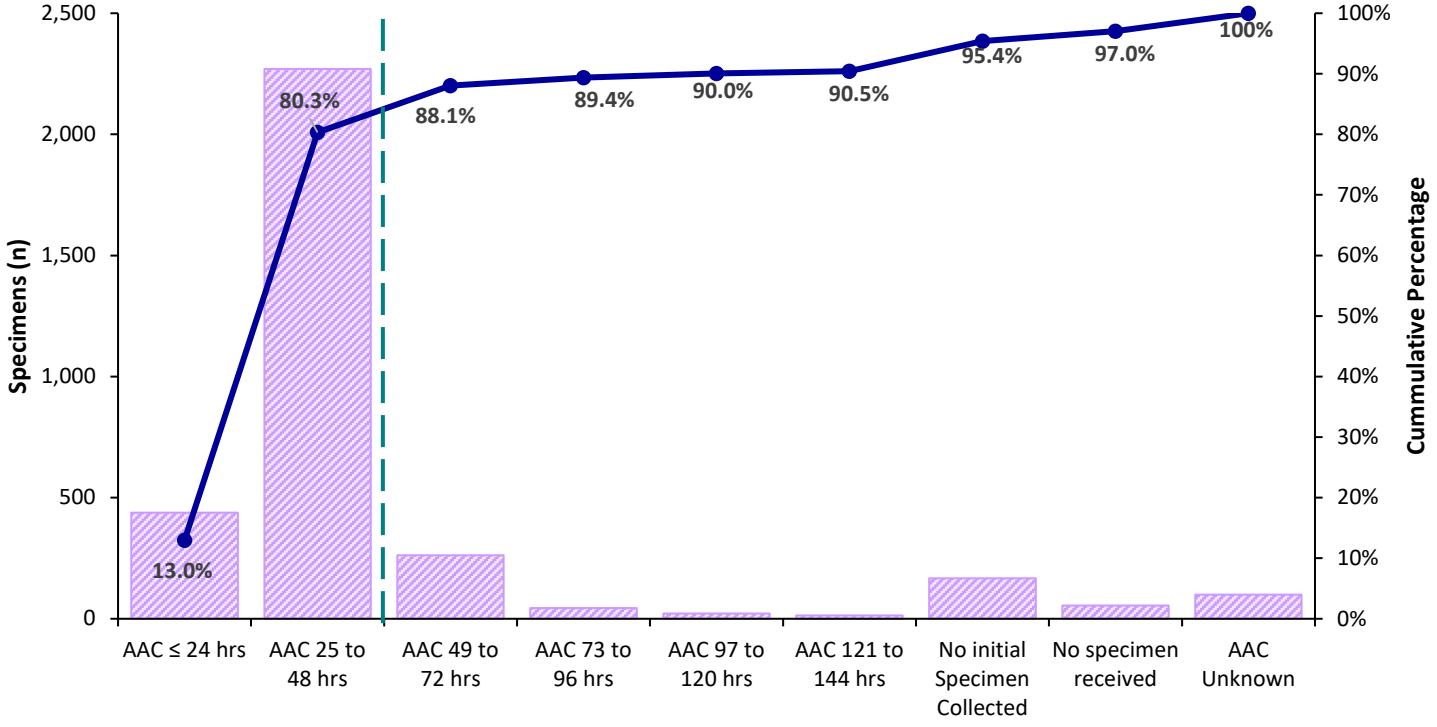
Age at Collection (AAC) Compliance - Hospital Births

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



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

664 specimens were not collected within 48 hours of birth (19.7% of out of hospital births)

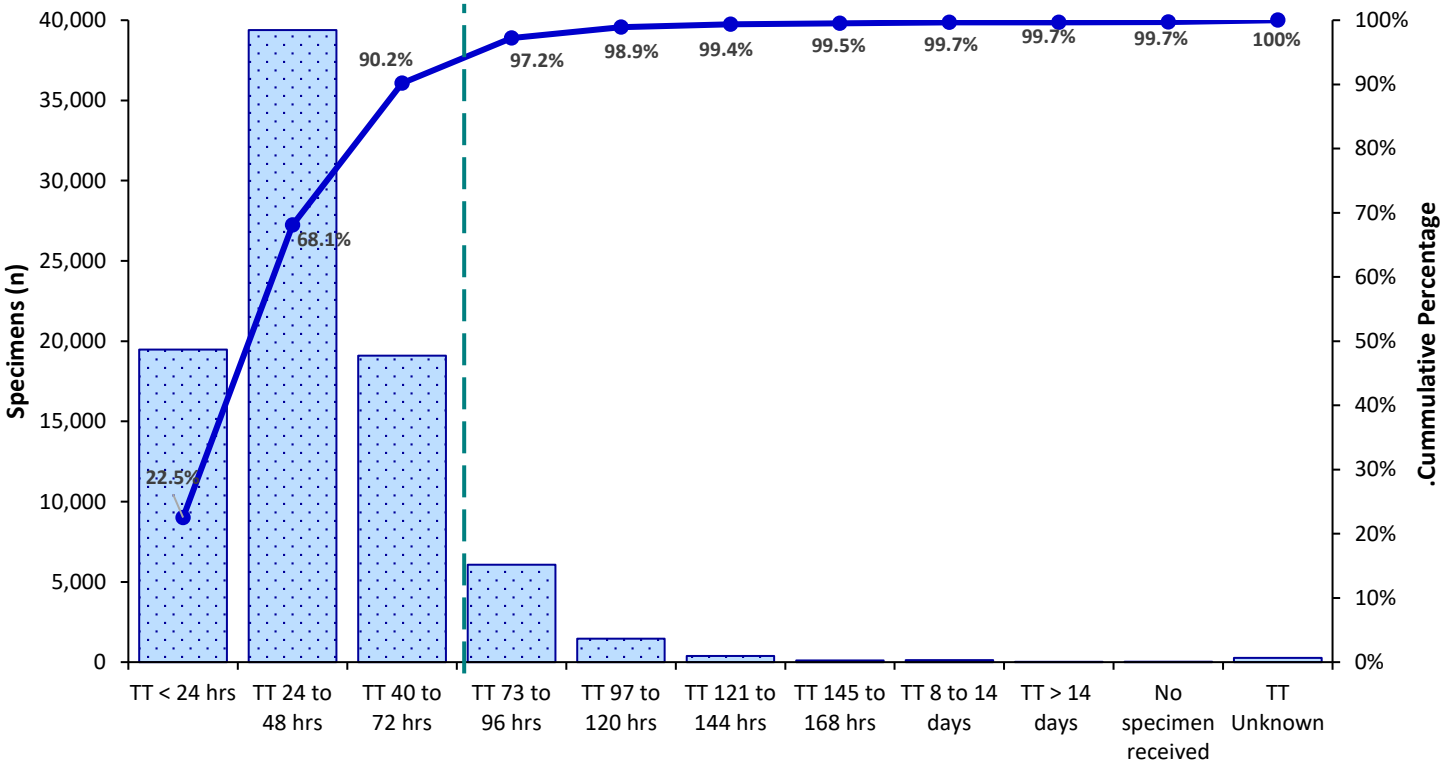


Appendix E: Specimen Transit Time

Born January 1, 2016 - December 31, 2016

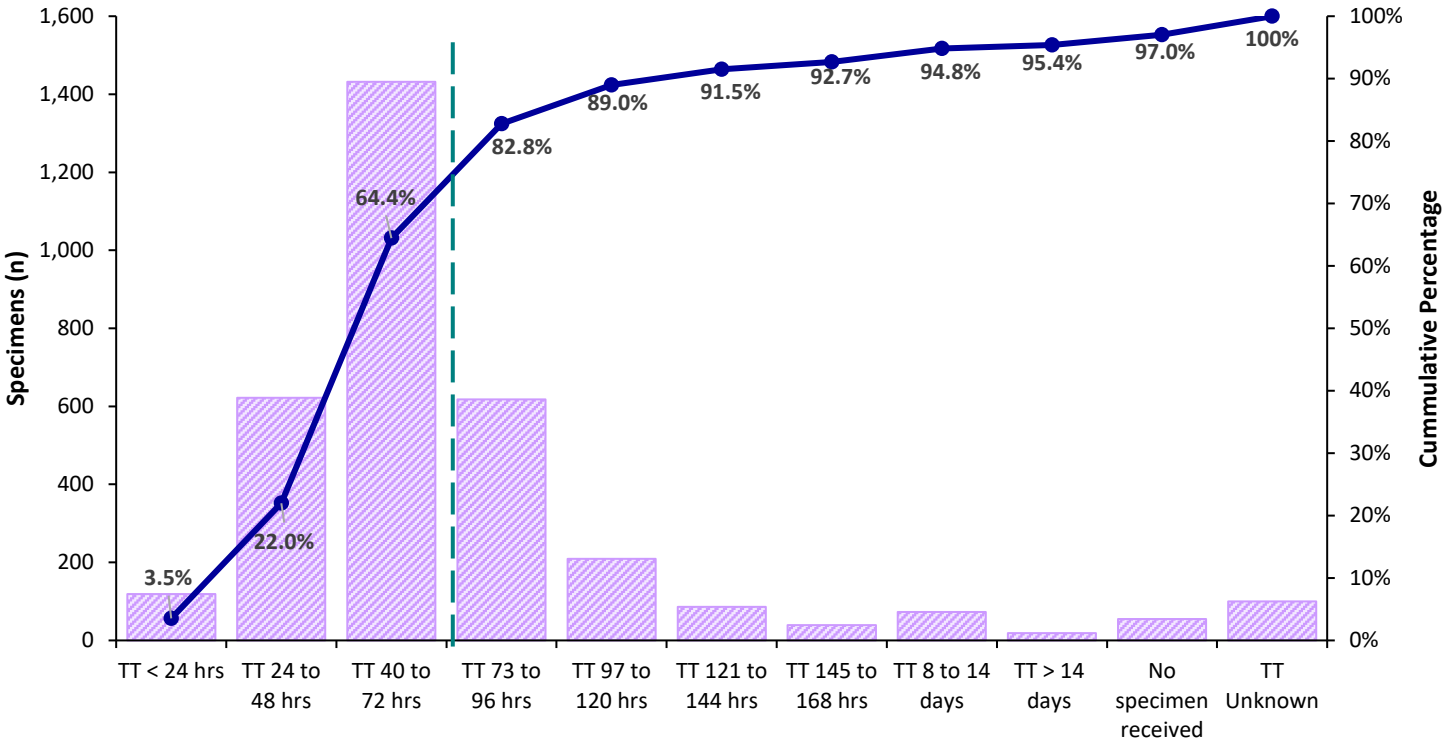
Transit Time (TT) Compliance - Hospital Births

8,468 specimens were not collected within 48 hours of birth (9.8% of hospital births)



Transit Time (TT) Compliance - Out of Hospital Births

1,199 specimens were not collected within 48 hours of birth (35.6% of out of hospital births)

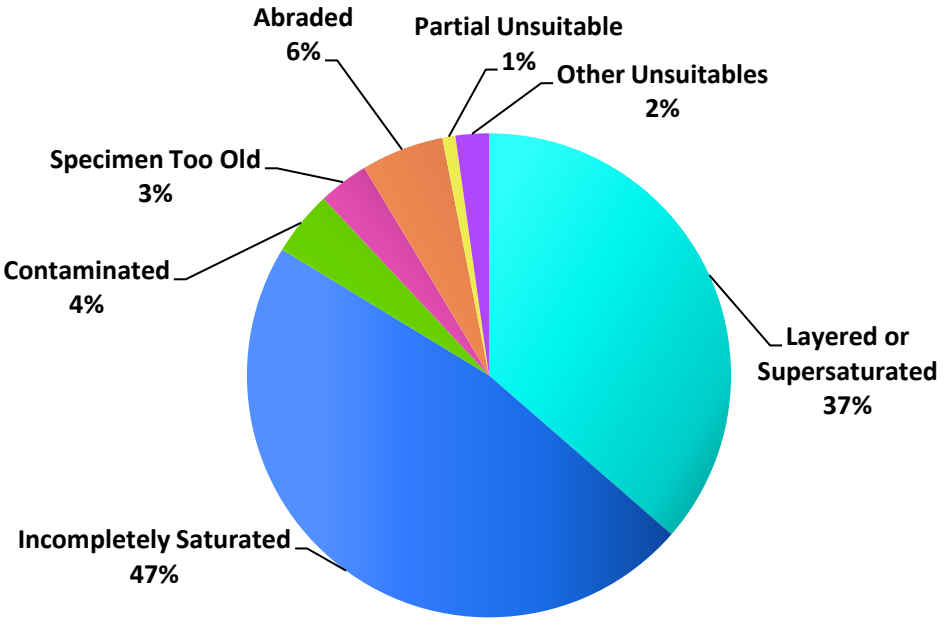


Appendix F: Unsatisfactory Specimens

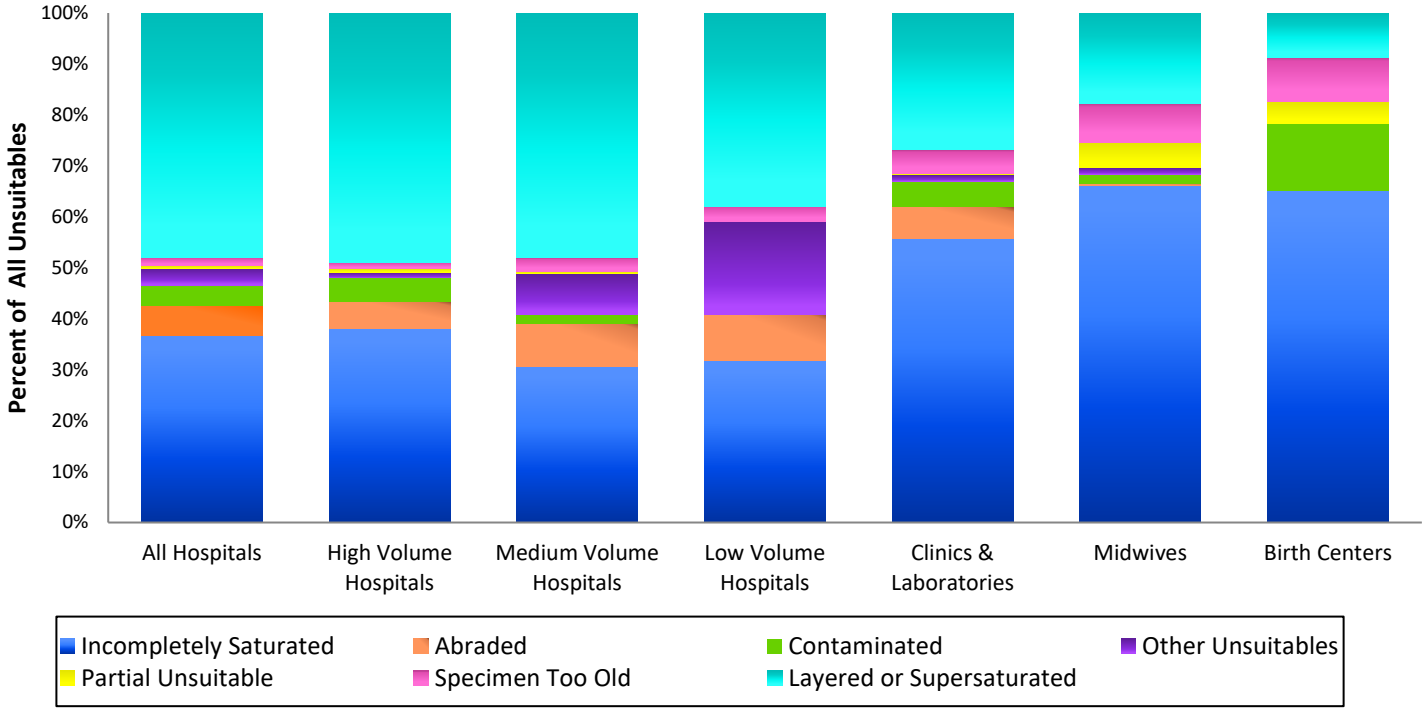
Received January 1, 2016 - December 31, 2016

Unsatisfactory Specimen Error Types[1]

Statewide: 3,662 specimens were unsatisfactory (2.1% of all specimens)



Unsatisfactory Specimen Error Type by Submitter Group[2]



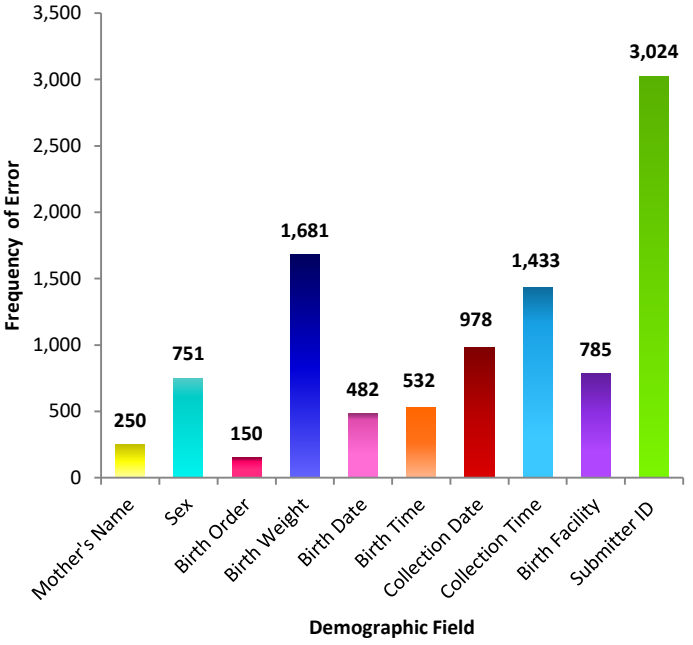
[1] See Key 1: Unsatisfactory Specimen descriptions for descriptions and causes of unsatisfactory specimens

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

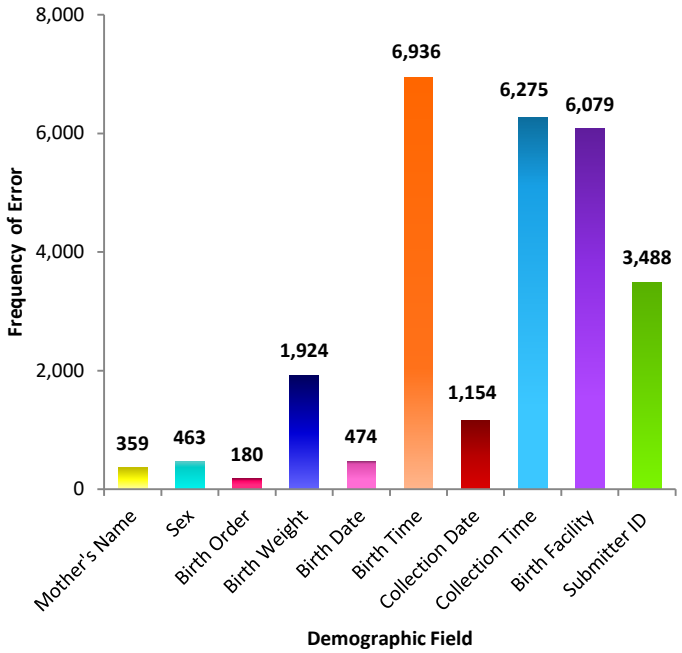
Appendix G: Demographic Errors on Specimen Cards

Received January 1, 2016 - December 31, 2016

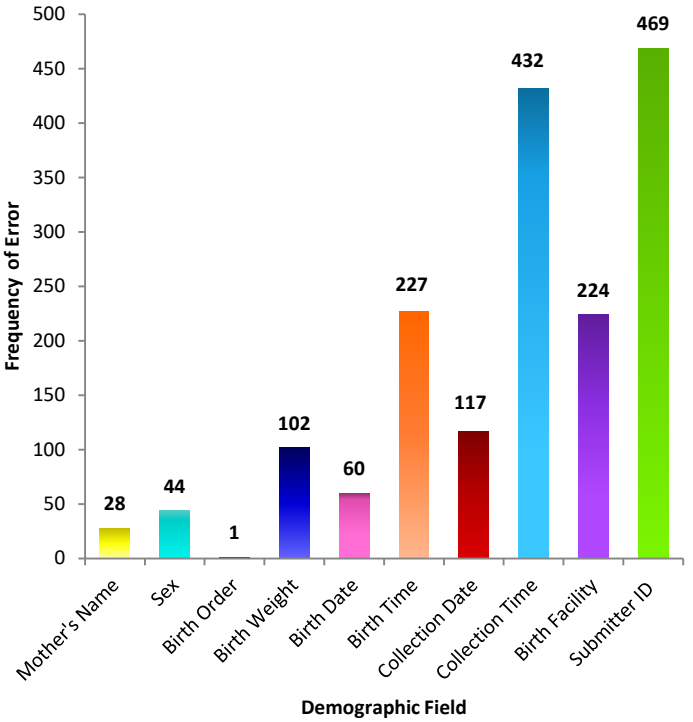
All Hospital Errors



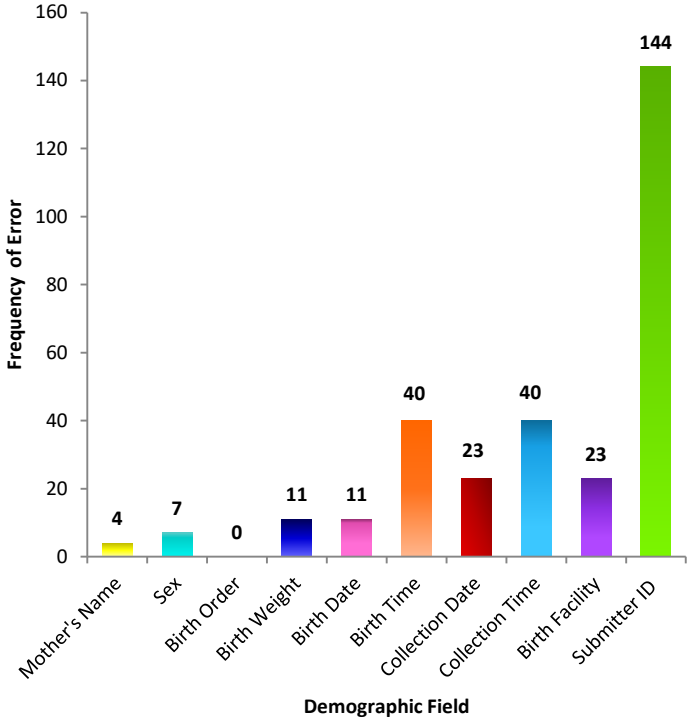
Clinic and Laboratory Errors



Midwife Errors

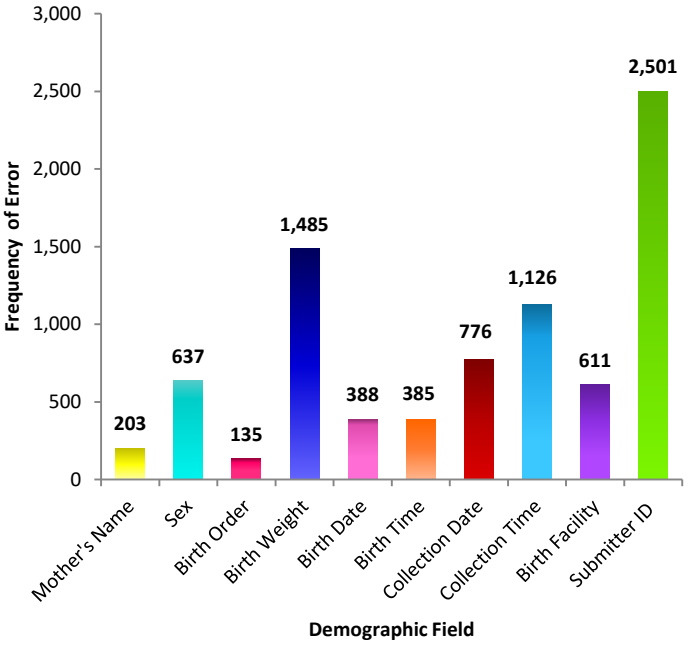


Birth Center Errors



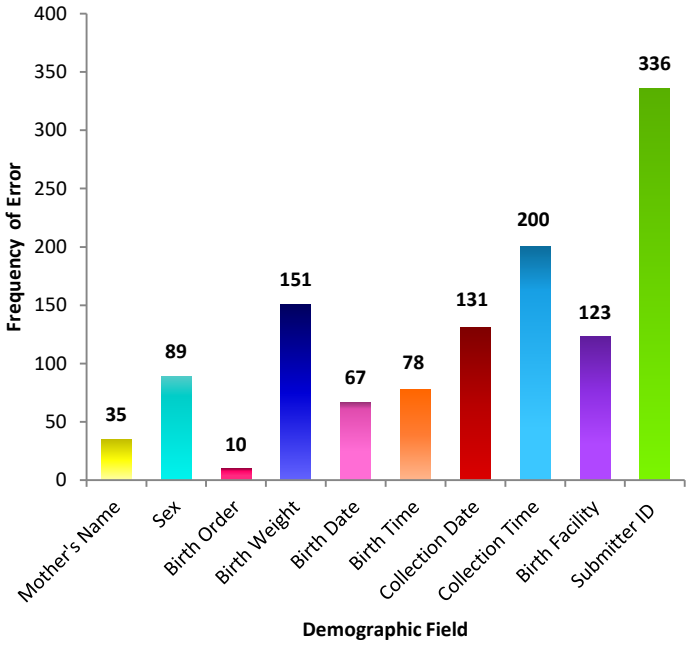
High Volume Hospital Errors[1]

> 3 specimens/day



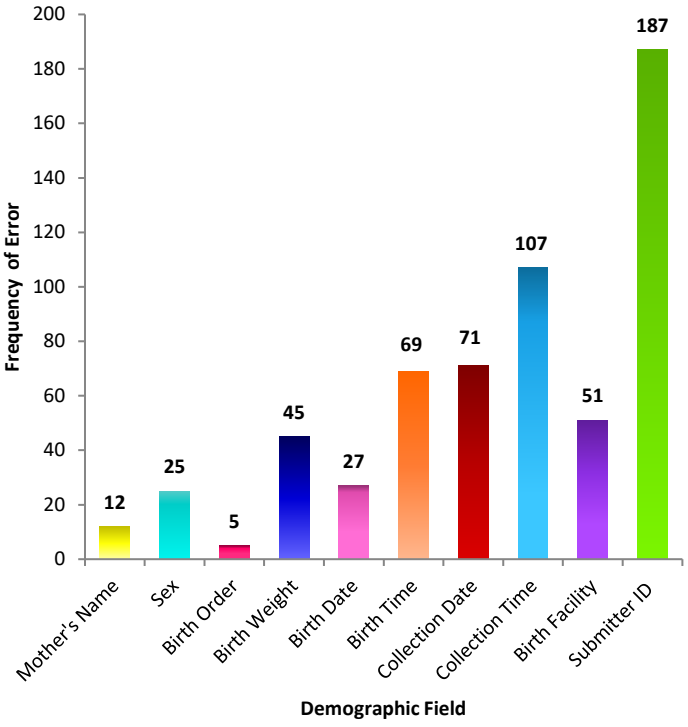
Medium Volume Hospital Errors[1]

1 to 3 specimens/day

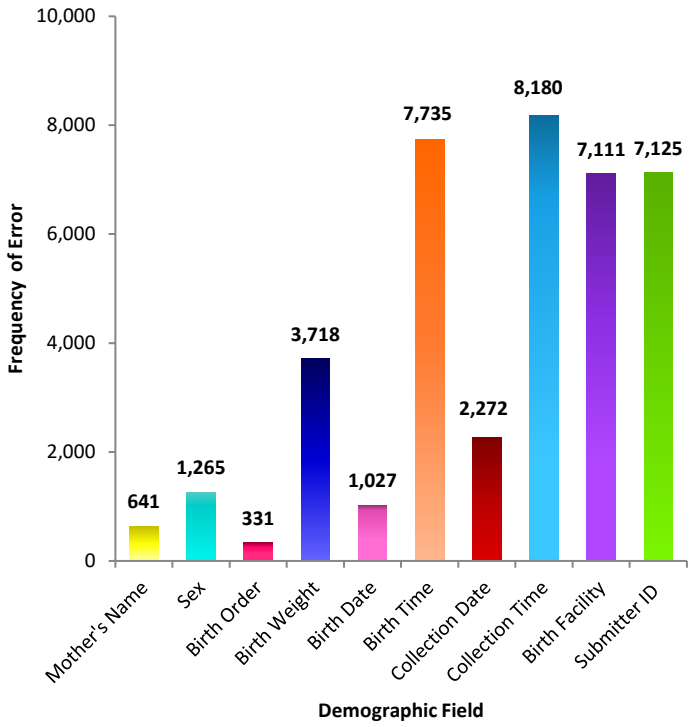


Low Volume Hospital Errors[1]

< 1 specimen/day

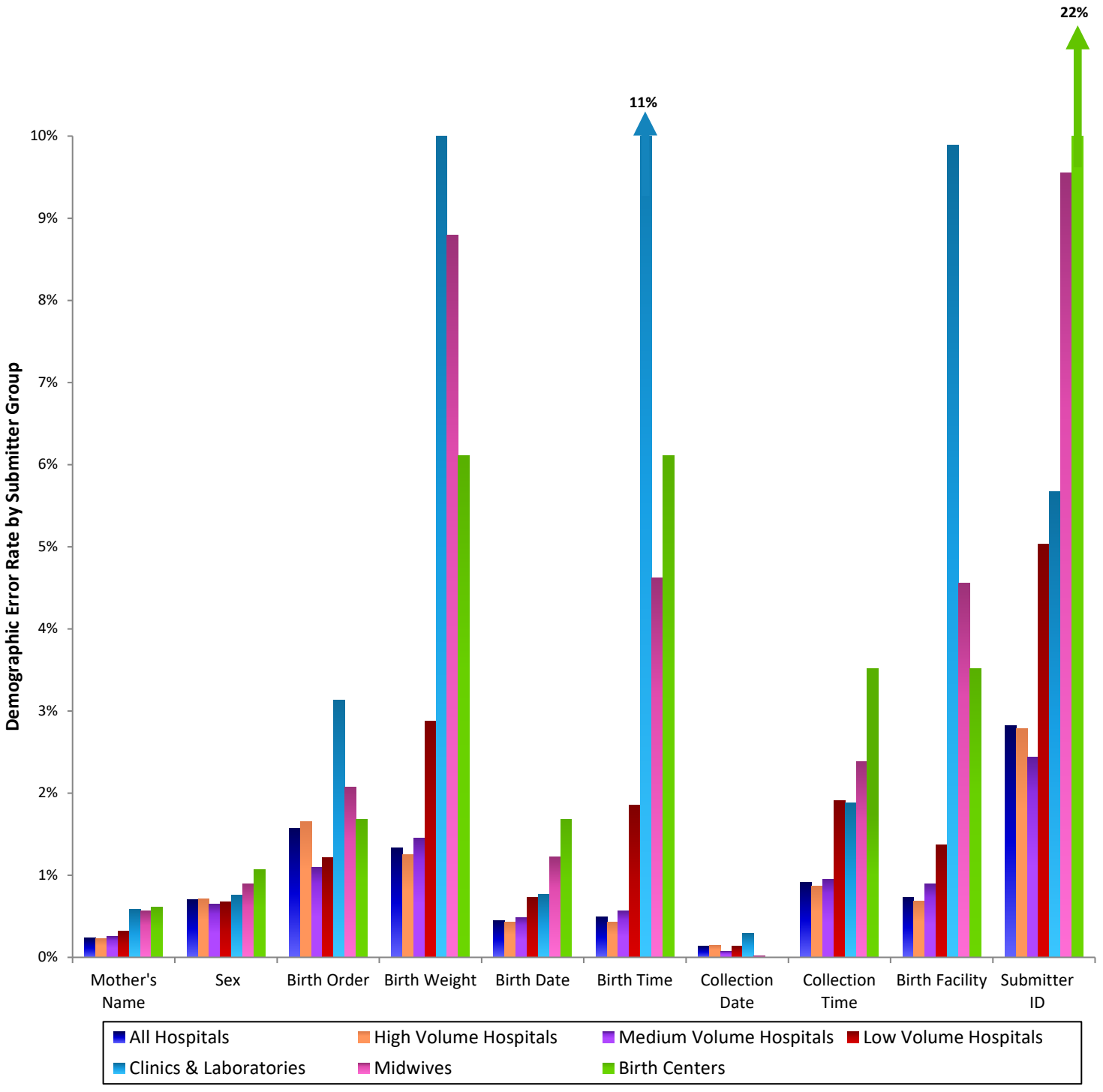


Statewide Errors



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

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



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

For example: 11% of specimens submitted by Clinics & Laboratories have an incorrect or missing time of birth

Appendix H: Infants Detected with Newborn Screening Disorders Births 2009-2015

Disorder	2009	2010	2011	2012	2013	2014	2015
Amino acid disorders	**6**	**7**	**10**	**10**	**9**	**6**	**11**
Arginosuccinic acidemia (ASA)	0	0	0	0	0	1	0
Citrullinemia (CIT)	0	0	1	0	0	0	0
Homocystinuria (HCY)	0	0	1	1	0	0	0
Maple syrup urine disease (MSUD)	0	0	1	0	3	1	1
Phenylketonuria (PKU)	6	7	6	9	5	4	10
Tyrosinemia type 1 (TYR-1)	0	0	1	0	1	0	0
Biotinidase deficiency (BIO)	**0**	**0**	**2**	**3**	**1**	**1**	**1**
Congenital adrenal hyperplasia (CAH)	**4**	**3**	**11**	**10**	**6**	**5**	**6**
Congenital hypothyroidism (CH)	**73**	**77**	**104**	**117**	**98**	**116**	**87**
Cystic fibrosis (CF)	**14**	**23**	**17**	**16**	**20**	**14**	**13**
Fatty acid oxidation disorders	**6**	**11**	**6**	**7**	**3**	**10**	**13**
Carnitine uptake deficiency (CUD)	0	1	0	0	0	0	0
Medium-chain acyl-CoA dehydrogenase (MCAD) deficiency	4	7	5	4	2	4	9
Long-chain L-3-hydroxy acyl-CoA dehydrogenase (LCHAD) deficiency	0	0	0	0	0	2	1
Very long-chain acyl-CoA dehydrogenase (VLCAD) deficiency	2	3	1	3	1	4	3
Galactosemia (GALT)	**1**	**3**	**11**	**17**	**6**	**10**	**17**
Hemoglobinopathies (Hb)	**17**	**17**	**15**	**24**	**17**	**26**	**18**
Sickle cell diseases	7	9	7	12	8	15	9
Hemoglobin E-beta thalassemia	1	1	3	2	2	0	1
Hemoglobin H disease	5	6	4	7	6	6	7
Other moderate to severe hemoglobinopathies	4	1	1	3	1	5	1
Mild hemoglobin conditions & traits*	1,158	1,199	1,130	1,244	1,330	1,339	1,370
Organic acid disorders	**4**	**2**	**4**	**3**	**2**	**3**	**5**
Beta-ketothiolase (BKT) deficiency	1	1	0	0	0	0	0
Glutaric acidemia type 1 (GA-1)	3	0	0	0	0	0	0
Isovaleric acidemia (IVA)	0	0	0	0	1	1	4
Methylmalonic acidemias (MMA)	0	1	2	2	1	2	1
Propionic acidemia (PROP)	0	0	2	1	0	0	0
Severe combined immunodeficiency (SCID)	**-**	**-**	**-**	**-**	**-**	**1**	**1**
Non-panel Disorders	**1**	**2**	**5**	**2**	**4**	**13**	**11**
2-methylbutyryl-CoA dehydrogenase (2-MBD) deficiency	0	0	3	0	0	0	0
3-methylcrotonyl-CoA carboxylase (3-MCC) deficiency	1	0	1	1	3	3	5
3-methylglutaconic aciduria (3-MGA)	0	0	1	0	0	0	0
Carnitine palmitoyltransferas II (CPT-II) deficiency	0	0	0	0	0	1	0
Glutaric acidemia type II (GA-II)	0	1	0	0	0	0	0
Methionine adenosyltransferase (MAT-II) deficiency	0	0	0	1	0	0	3
Methylmalonic acidemia Cbl C	0	1	3	0	1	0	0
Other T-cell lymphopenias	0	0	0	0	0	9	3
Total Infants Detected*	126	145	188	209	166	205	183
Total Infants Screened*	84,871	83,086	84,918	86,180	85,427	87,415	87,769
Overall Frequency*	1 in 674	1 in 573	1 in 452	1 in 412	1 in 515	1 in 426	1 in 480

*Excludes mild hemoglobin conditions & traits

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

Births January 1, 2016 - December 31, 2016

Phenotype[a]	Total	White	Black	Asian	Native American	Other[b]	Unknown[c]	Hispanic[d]
Severe Disease	**17**	**-**	**9**	**4**	**0**	**2**	**2**	**-**
FSS	6	-	5	-	-	1	-	-
FSS + Bart's	3	-	2	-	-	1	-	-
F-Only	1	-	-	-	-	-	1	-
F-Only + Bart's	1	-	-	1	-	-	-	-
FSC	3	-	2	-	-	-	1	-
FE-	1	-	-	1	-	-	-	-
FAE + CS + High Bart's	2	-	-	2	-	-	-	-
Moderate Disease	**7**	**1**	**-**	**4**	**-**	**2**	**-**	**-**
FAA + High Bart's	5	-	-	3	-	2	-	-
FAE + High Bart's	1	-	-	1	-	-	-	-
FDA	1	1	-	-	-	-	-	-
Mild Disease	**4**	**-**	**-**	**2**	**-**	**1**	**1**	**1**
FEE	4	-	-	2	-	1	1	1
Trait	**1,356**	**169**	**281**	**246**	**10**	**495**	**155**	**240**
FAA + CS + Bart's	11	-	-	7	-	4	-	1
FAE + CS + Bart's	4	-	-	2	-	2	-	2
FAS + Bart's	5	-	3	-	-	1	1	-
FAE + Bart's	7	-	-	6	-	1	-	1
FAA + Bart's	289	15	54	103	-	98	19	24
FAS	472	35	167	4	3	180	83	117
FAE	226	11	3	104	3	98	7	17
FAC	117	7	45	-	1	58	6	14
FAC + Var	1	-	1	-	-	-	-	-
FAD	45	17	1	9	1	11	6	14
FA + Var	179	84	7	11	2	42	33	50
Total	**1,384**	**170**	**290**	**256**	**10**	**500**	**158**	**241**

[a]See Key 3: Newborn Hemoglobin Screening Explantions 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

Unsatisfactory Specimen Descriptions

January 1, 2016 - December 31, 2016

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, 2016 - December 31, 2016

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	301	Medium	3.3	High
Capital Medical Center	Olympia	175	Medium	1.9	Medium
Cascade Valley Hospital	Arlington	41	Low	0.7	Low
Central Washington Hospital	Wenatchee	337	Medium	3.8	High
Columbia Basin Hospital	Ephrata	-	-	< 0.1	Low
Coulee Medical Center	Grand Coulee	23	Low	0.4	Low
Deaconess Hospital	Spokane	362	Medium	5.4	High
EvergreenHealth	Kirkland	1,193	High	13.9	High
EvergreenHealth - Monroe	Monroe	-	-	0.1	Low
Ferry County Memorial Hospital	Republic	-	-	< 0.1	Low
Forks Community Hospital	Forks	18	Low	0.3	Low
Good Samaritan Hospital - MultiCare	Puyallup	597	High	6.8	High
Grays Harbor Community Hospital	Aberdeen	118	Medium	1.3	Medium
Group Health Cooperative	Seattle	-	-	< 0.1	Low
Harborview Medical Center - UW Medicine	Seattle	< 1	Low	0.3	Low
Harrison Medical Center	Silverdale	502	High	5.7	High
Highline Medical Center	Burien	216	Medium	2.5	Medium
Holy Family Hospital - Providence	Spokane	327	Medium	4.3	High
Island Hospital	Anacortes	108	Medium	1.8	Medium
Jefferson Healthcare	Port Townsend	25	Low	0.5	Low
Kadlec Regional Medical Center	Richland	705	High	9.0	High
Kittitas Valley Healthcare	Ellensburg	78	Low	0.9	Low
Lake Chelan Community Hospital	Chelan	29	Low	0.6	Low
Legacy Salmon Creek Medical Center	Vancouver	874	High	10.2	High
Lewis County Hospital	Morton	< 1	Low	< 0.1	Low
Lincoln Hospital	Davenport	-	-	0.1	Low
Lourdes Medical Center	Pasco	< 1	Low	< 0.1	Low
Madigan Army Medical Center	Joint Base Lewis-McChord	503	High	11.3	High
Mary Bridge Children's Hospital - MultiCare	Tacoma	-	-	0.1	Low
Mason General Hospital	Shelton	76	Low	0.9	Low
Mid-Valley Hospital	Omak	57	Low	0.6	Low
Mount Carmel Hospital - Providence	Colville	58	Low	0.7	Low
Naval Hospital - Bremerton	Bremerton	120	Medium	2.7	Medium
Naval Hospital - Oak Harbor	Oak Harbor	50	Low	1.1	Medium
Newport Hospital	Newport	17	Low	0.3	Low
North Valley Hospital	Tonasket	21	Low	0.3	Low

Key 2: Hospital Volume Categorizations (cont.)

Hospital	City	Births per qtr	Birth Volume	Specimens per day	Specimen Volume
Northwest Hospital - UW Medicine	Seattle	303	Medium	4.7	High
Ocean Beach Hospital	Ilwaco	< 1	Low	-	-
Odessa Memorial Healthcare Center	Odessa	-	-	< 0.1	Low
Olympic Medical Center	Port Angeles	116	Medium	2.5	Medium
Othello Community Hospital	Othello	120	Medium	2.1	Medium
Overlake Medical Center	Bellevue	981	High	11.3	High
PeaceHealth Southwest Medical Center	Vancouver	532	High	6.4	High
Prosser Memorial Hospital	Prosser	86	Low	1.4	Medium
Providence Centralia Hospital	Centralia	182	Medium	1.9	Medium
Providence Everett Medical Center	Everett	1,206	High	14.8	High
Providence St Peter Hospital	Olympia	565	High	6.6	High
Pullman Regional Hospital	Pullman	107	Medium	1.2	Medium
Sacred Heart Medical Center - Providence	Spokane	833	High	13.7	High
Samaritan Healthcare	Moses Lake	252	Medium	2.8	Medium
Seattle Children's Hospital	Seattle	-	-	1.8	Medium
Skagit Valley Hospital	Mount Vernon	278	Medium	3.1	High
Snoqualmie Valley Hospital	Snoqualmie	-	-	< 0.1	Low
St Clare Hospital	Tacoma	< 1	Low	< 0.1	Low
St Elizabeth Hospital	Enumclaw	84	Low	1.2	Medium
St Francis Hospital	Federal Way	338	Medium	5.2	High
St John Medical Center - PeaceHealth	Longview	210	Medium	2.3	Medium
St Joseph Hospital - PeaceHealth	Bellingham	510	High	5.8	High
St Joseph Hospital - Providence	Chewelah	-	-	0.1	Low
St Joseph Medical Center	Tacoma	1,060	High	17.0	High
St Mary Medical Center - Providence	Walla Walla	166	Medium	1.8	Medium
Summit Pacific Medical Center	Elma	< 1	Low	0.1	Low
Sunnyside Community Hospital	Sunnyside	133	Medium	2.5	Medium
Swedish Ballard	Seattle	292	Medium	3.6	High
Swedish Cherry Hill	Seattle	-	-	< 0.1	Low
Swedish Edmonds	Edmonds	312	Medium	4.9	High
Swedish First Hill	Seattle	1,967	High	24.2	High
Swedish Issaquah	Issaquah	399	Medium	4.5	High
Tacoma General Hospital - MultiCare	Tacoma	763	High	10.6	High
Three Rivers Hospital	Brewster	27	Low	0.4	Low
Toppenish Community Hospital	Toppenish	108	Medium	2.0	Medium
Trios Health Hospital	Kennewick	407	Medium	4.8	High
University of Washington Medical Center	Seattle	483	Medium	6.0	High
Valley Hospital	Spokane	184	Medium	2.9	Medium
Valley Medical Center - UW Medicine	Renton	946	High	11.0	High
Virginia Mason Hospital	Seattle	-	-	0.9	Low
Walla Walla General Hospital	Walla Walla	28	Low	0.5	Low
WhidbeyHealth Medical Center	Coupeville	45	Low	0.9	Low
Whitman Hospital and Medical Center	Colfax	10	Low	0.2	Low
Willapa Harbor Hospital	South Bend	< 1	Low	< 0.1	Low
Yakima Regional Medical Center	Yakima	-	-	< 0.1	Low
Yakima Valley Memorial Hospital	Yakima	688	High	13.9	High

Key 3:

Newborn Hemoglobin Screening
Explanations and Definitions of Phenotypes
January 1, 2016 - December 31, 2016

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 healthcare 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-thalassemiaa 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).
FCA	Hemoglobin C in combination with β-thalassemia[a] minor. A mild to moderate hemolytic anemia.
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.

[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.

Newborn Hemoglobin Screening (cont.)

Phenotype	Most Likely Genotype/Clinical Implications
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.
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.
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.
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.
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.
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.