

Alberta Newborn Screening Program Report 2022-2023

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This report has been prepared by the Alberta Newborn Screening Program (formerly known as the Newborn Metabolic Screening Program)

Contact

For more information, please contact:

Grace Johner
Manager, Newborn Screening Programs
Provincial Population and Public Health
Alberta Health Services
Email: newbornscreening@albertahealthservices.ca



Table of contents

Executive summary.....	5
ANSP performance measures.....	5
Summary of ANSP key performance measures, 2022-2023	6
Definitions	7
Alberta Newborn Screening Program.....	8
ANSP approach	8
ANSP performance measures.....	9
Scope	9
Amended performance measures	9
Newborn screening in Alberta	10
Population screening.....	10
Participation rate and non-participation rationale	11
Initial screen results reported	12
Infant results and outcomes	13
Screen results and unknown screen results rationale	14
Diagnostic outcomes	15
ANSP performance along the screening pathway	16
Registration.....	17
Birth registration	18
Collection and transportation.....	19
Initial collection	20
Sample receipt	21
Inadequate samples	22



Alberta Newborn Screening Program

Analysis and reporting.....	23
Results reported	24
Follow-up	25
Repeat sample collection for inadequate samples	26
Repeat sample collection for borderline results	27
Repeat sample collection for low birth weight infants	28
Conclusion	29
References	30
Appendix A	31
Amendments to the 2021-2022 AHS Provincial NMS Program Report	31
Screen results and unknown screen results rationale	31
Diagnostic outcomes.....	31
Amendments to repeat sample collection for low birth weight infants	32
Meeting standard and not meeting standard	32
Appendix B	33
2022-2023 performance measures data tables by zone	33
Appendix C	34
Further screening by the ANSP in 2022-2023	34
Additional findings in 2022-2023	34



Executive summary

The purpose of the *Alberta Newborn Screening Program Report 2022-2023* is to highlight Alberta Newborn Screening Program (ANSP) performance between April 1, 2022 and March 31, 2023. The report provides an overview of ANSP service delivery along the screening pathway and illustrates key ANSP performance measures.

The ANSP is a population-based screening program that screens for 22 treatable conditions (16 metabolic, 2 endocrine, cystic fibrosis [CF], severe combined immunodeficiency [SCID], sickle cell disease [SCD] and spinal muscular atrophy [SMA]) to identify and treat infants with a treatable condition as early as possible. Early detection and treatment of the screened conditions can make the difference between healthy development and lifelong impairment.

The ANSP works collaboratively with partners and service areas across the screening pathway to ensure better health outcomes for Alberta infants. The impact of the ANSP is demonstrated through:

- 47,147 infants screened in Alberta during the reporting year
- 282 infants who received abnormal screen results and were referred for diagnostic testing
- 79 infants diagnosed with one of the screened conditions and referred for treatment

ANSP performance measures

Data for the ANSP performance measures were retrieved from ANSP Application reports and Alberta Newborn Screening Laboratory statistics. Data were excluded for all samples analyzed and reported by the Alberta Newborn Screening Laboratory for infants born outside of Alberta and whose samples were collected outside of Alberta.

The report includes data from previous years as a comparator to visualize the trends that have come through the centralized coordination of the program working with the partners and providers who support newborn blood spot screening in Alberta.

The ANSP actively monitors trends in performance in order to identify areas for quality improvement and engages with AHS Zones and service areas to address issues and achieve improvement. The performance measures described in this report demonstrate the success of the ANSP in 2022-2023.



Summary of ANSP key performance measures, 2022-2023

Performance	2022-2023 data	2021-2022 data
Registered infants who received an initial blood spot screen	99.20% (47,091/47,472)	99.27% (48,818/49,179)
Registered infants who did not receive an initial blood spot screen	0.80% (381/47,472)	0.73% (361/49,179)
Registered screened infants who had a screen result reported within 10 days of age	98.95% (46,597/47,091)	98.57% (48,120/48,818)
Screened infants who received normal screen results	99.17% (46,757/47,147)	99.27% (48,506/48,865)
Screened infants who received abnormal screen results	0.60% (282/47,147)	0.49% (238/48,865)
Screened infants who received unknown screen results	0.23% (108/47,147)	0.25% (121/48,865)*
Infants with abnormal screen results who received abnormal diagnostic outcomes for one of the screened conditions	28.01% (79/282)	26.89% (64/238)*
Infants born in Alberta who were registered in Person Directory (PD) within 24 hours of birth	98.67% (46,839/47,472)	98.81% (48,592/49,179)
Registered screened infants who had an initial blood spot sample collected between 24 and 72 hours of age	97.96% (46,128/47,091)	97.75% (47,722/48,818)
Samples received by the Alberta Newborn Screening Laboratory within 72 hours of collection	96.49% (47,898/49,642)	97.28% (50,069/51,468)
Samples received by the Alberta Newborn Screening Laboratory that were determined to be inadequate	1.61% (798/49,642)	1.95% (1,002/51,468)
Samples received that had screen results reported within 96 hours of Alberta Newborn Screening Laboratory receipt	79.06% (39,249/49,642)	86.62% (44,584/51,468)
Repeat samples collected within 96 hours of notification of reported inadequate screen results	82.66% (596/721)	83.23% (769/924)
Repeat samples collected within 96 hours of notification of reported borderline screen results	91.56% (358/391)	90.91% (260/286)
Repeat samples collected between 21 days and 28 days of age for infants with low birth weight	97.01% (1,069/1,102)	97.13% (1,083/1,115)*

* Amended data for 2021-2022, see Appendix A.



Definitions

- **AHS zone not assigned** means infants not assigned within the ANSP Application to a zone of birth (e.g., infants born outside Alberta but screened within Alberta), zone of collection (e.g., infants whose zone of collection is missing on the blood spot card) or AHS zone of responsibility (e.g., infants under the responsibility of First Nations [FN] communities). Details on why an AHS zone was not assigned to an infant vary with specific performance measures and are available upon request.
- **Borderline screen result** means an inconclusive screen result for a screened condition that requires follow-up through repeat sample collection to classify as normal or abnormal.
- **Double borderline screen result** means a second borderline screen result is obtained for the same condition and is therefore treated as an abnormal screen result.
- **Low birth weight** means an infant who weighs less than 2000 grams at birth.
- **Received samples** means newborn blood spot samples received by the Alberta Newborn Screening Laboratory and reported to the ANSP Application.
- **Registered infants** means infants born in Alberta during the reporting period and registered through the assignment of an Alberta Unique Lifetime Identifier (ULI) using the 'add newborn' function in Person Directory (PD).
- **Registered screened infants** means registered infants who had an initial screen within the ANSP during the reporting period.
- **Screened infants** means all infants who received an initial newborn blood spot screen within the ANSP including registered screened infants and infants born outside of Alberta who were screened in Alberta.
- **Unable to determine** means the time of birth information required to measure whether a specific performance measure has been met or not met is not available from the blood spot card.
- **Unknown screen results** means an infant had no confirmed normal or abnormal screen result on record.
- **Zone of birth** means the AHS zone mapped within the ANSP Application to the birth facility.
- **Zone of collection** means the AHS zone of collection recorded on the blood spot card.
- **Zone of residence** means the AHS zone mapped within the ANSP Application to the infant's PD mailing address postal code.
- **Zone of responsibility** means the AHS zone within the ANSP Application that equals the zone of residence unless there is a manual transfer to an alternate zone of responsibility (e.g., follow-up actions determined an infant had moved). In prior years, the assignment of zone of responsibility was equal to zone of birth but this was changed in 2012-2013 to better reflect population health reporting practices based on the location of official residence.



Alberta Newborn Screening Program

The Alberta Newborn Screening Program (ANSP) is a population-based screening program delivered by Alberta Health Services (AHS) in partnership with Alberta Precision Laboratories (APL) (which includes the Alberta Newborn Screening Laboratory and the Molecular Genetics Laboratory), DynaLIFE, Alberta Health, First Nations (FN) communities, physicians and midwives, and parents.

Early screening helps identify infants with conditions that can be treated early, when treatment can benefit the most. Without timely screening and intervention, infants with treatable conditions may suffer irreversible health problems and possibly death soon after birth. Early detection and treatment of screened conditions can make the difference between healthy development and lifelong impairment.

ANSP approach

The ANSP uses a health promotion process that combines aspects of the Public Health Agency of Canada's Population Health Approach (1) with a Community as Partner process cycle (2). The program integrates this approach with a quality management methodology to achieve continuous improvement in service quality. The ANSP quality management framework includes the processes and structures necessary to manage population-based screening program quality in Alberta.

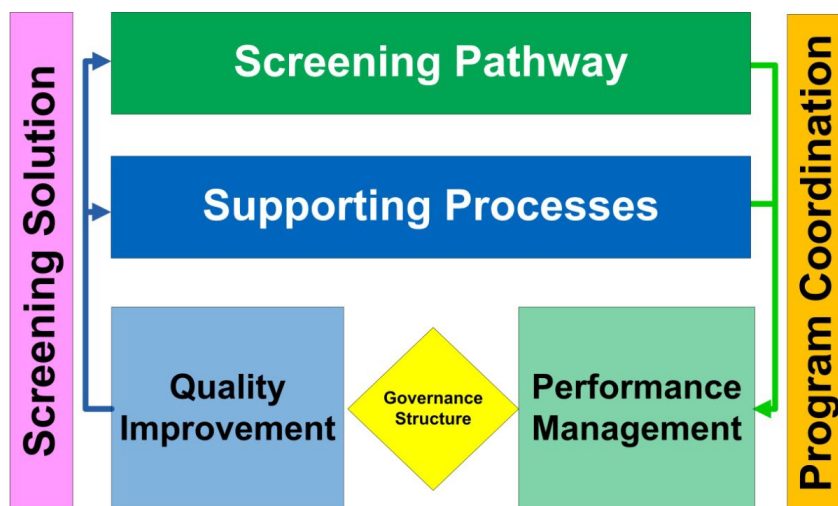


Figure 1. ANSP quality management framework



ANSP performance measures

Scope

The performance measures reported here were set by Alberta Health in the *Alberta Newborn Metabolic Screening Program Policy Document, March 2010* (3).

The *Alberta Newborn Screening Program Report 2022-2023* highlights ANSP performance between April 1, 2022 and March 31, 2023 for these measures. Data retrieved from the ANSP Application (reports and statistics) and Alberta Newborn Screening Laboratory statistics on May 12, 2023 are presented in the remainder of the report. Data were excluded for all samples analyzed and reported by the Alberta Newborn Screening Laboratory for infants born outside of Alberta and whose samples were collected outside of Alberta.

The ANSP utilizes a performance management approach to collect data and monitor the effectiveness of the program. Changes from year to year are incremental within a quality management approach and statistical significance was not calculated.

Amended performance measures

ANSP data is amended when the receipt of an infant's screen result or diagnostic outcome falls outside the reporting period (for example, pending results). Amended screen results and diagnostic outcomes from the 2021-2022 reporting period are available in Appendix A. Amendments for the 2022-2023 reporting period will be available in the 2023-2024 ANSP annual report.



Newborn screening in Alberta

Population screening

**Alberta Newborn
Screening Program:
2022-2023 population
screening**

Target population = 47,472
(infants born and registered as
newborns in Alberta)

Participation rate = 99.20%
(47,091/47,472) of registered
infants

**Screen results reported by
10 days of age = 98.95%**
(46,597/47,091) of registered
screened infants

The ANSP is able to achieve its goal of minimizing morbidity and mortality of Alberta infants through early detection and treatment of screened conditions. By informing parents, health professionals and the public, the ANSP can ensure that infants born in Alberta receive timely access to effective screening and have an initial screen reported within 10 days of age.



Alberta Newborn Screening Program

Participation rate and non-participation rationale ^a

In 2022-2023, 99.20% of registered infants received an initial blood spot screen (Figure 2a). Rationale for the 0.80% who did not participate is provided in the graph below (Figure 2b). ANSP participation has remained consistent over the last five years (Figure 2c).

Figure 2a. Program participation, provincial total, 2022-2023

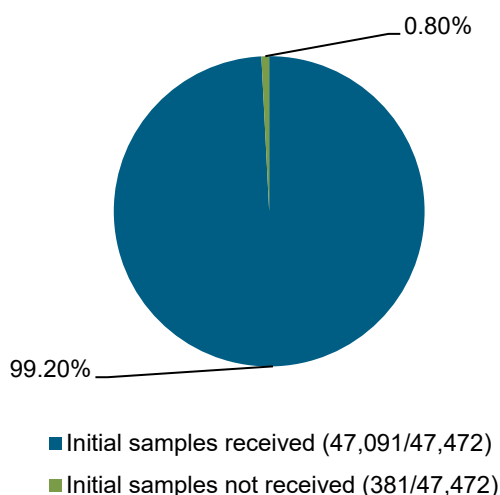
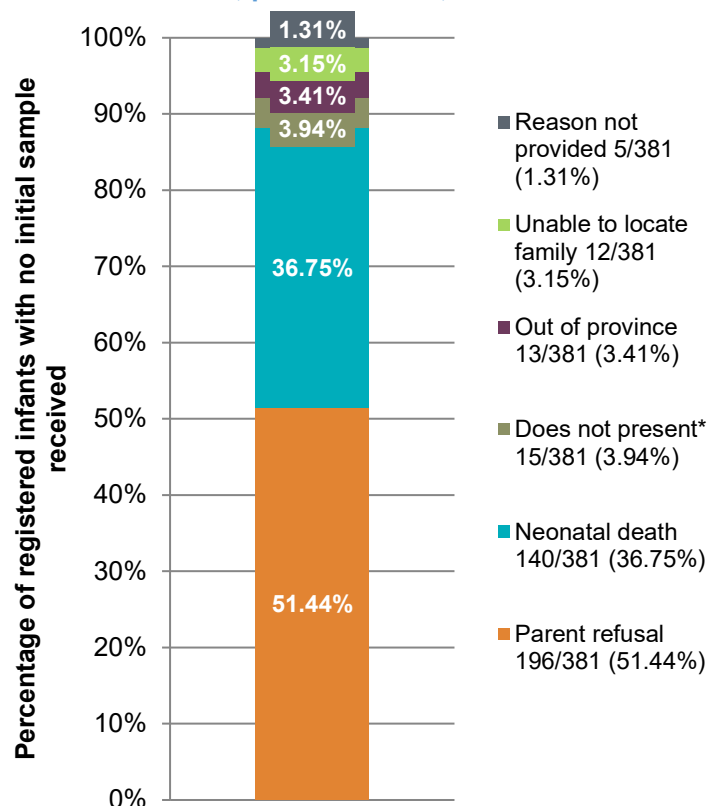
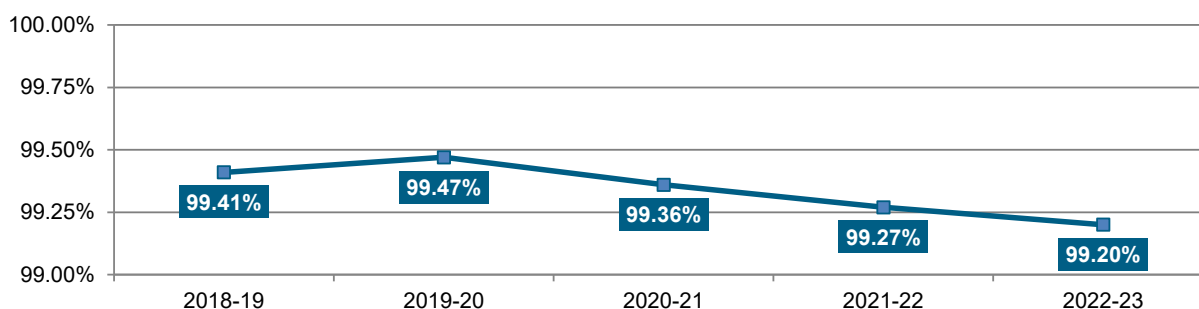


Figure 2b. Program non-participation rationale, provincial total, 2022-2023



*Does not present means the parent does not refuse, but rather does not present the infant for screening.

Figure 2c. Program participation, 5-year provincial trend



^a Data retrieved May 12, 2023 from ANSP Application Report 1 and ANSP Application statistics. Data are for all registered infants by zone of responsibility. For comparison, previous years' data and ANSP annual reports can be requested through newbornscreening@ahs.ca.



Alberta Newborn Screening Program

Initial screen results reported ^b

In 2022-2023, 98.95% (46,597/47,091) of registered screened infants had an initial screen result reported by the Alberta Newborn Screening Laboratory within 10 days of age (excluding cystic fibrosis), 1.03% (485/47,091) did not meet the standard and 0.02% (9/47,091) were unable to determine. The range among the AHS Zones for meeting the standard is between 97.93% and 99.43% (Figure 3a) (AHS Zone not assigned is 95.31% for meeting the standard). The data table for initial screen results reported by zone can be found in Appendix B. The performance in this measure has remained consistent since the 2019 NMS Program Panel Expansion (Figure 3b).

Figure 3a. Initial screen results reported meeting standard, zone totals, 2022-2023

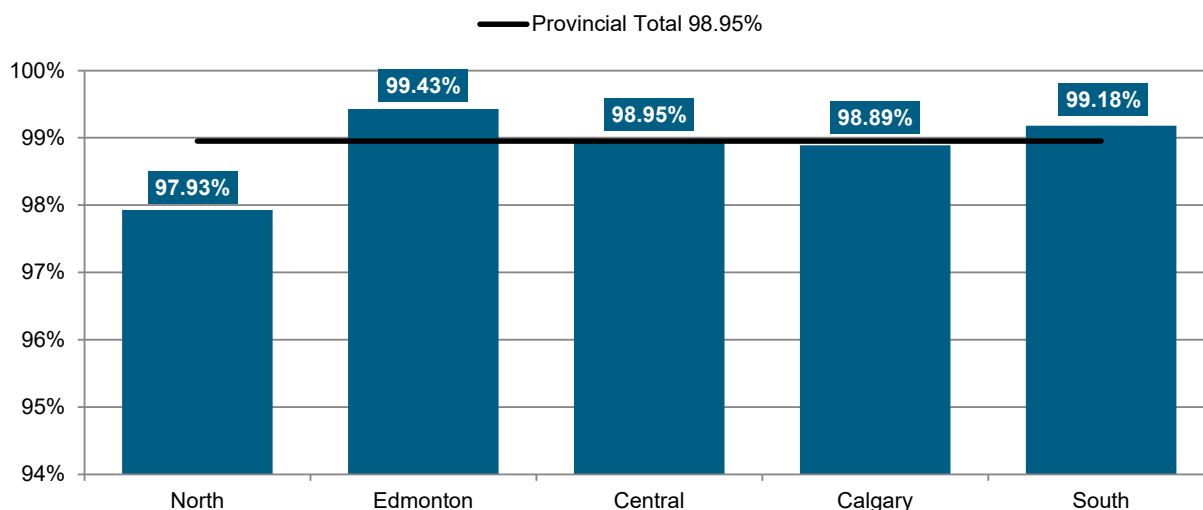
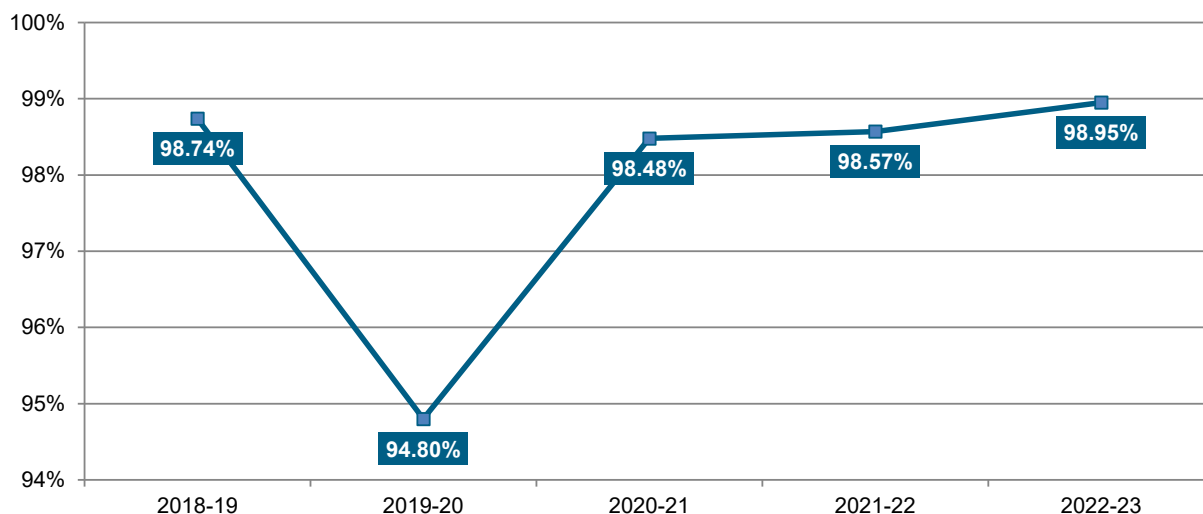


Figure 3b. Initial screen results reported meeting standard, 5-year provincial trend



^b Data retrieved May 12, 2023 from ANSP Application Report 8, Section F. Data are for all registered screened infants by zone of responsibility. For comparison, previous years' data and ANSP annual reports can be requested through newbornscreening@ahs.ca.



Infant results and outcomes

Alberta Newborn Screening Program: 2022-2023 screen results and outcomes

Screened infants in the ANSP = **47,147**

Infants with normal screen results = **99.17%**

(46,757/47,147) of screened infants

Infants with abnormal screen results = **0.60%**

(282/47,147) of screened infants

Infants with unknown screen results = **0.23%**

(108/47,147) of screened infants

Infants with abnormal diagnostic outcomes = **79**

(of 47,147 screened infants)

The ANSP screens for 22 treatable conditions to identify and treat infants with any of the screened conditions as early as possible.

- Metabolic conditions (16)
 - Biotinidase (BIOT) deficiency
 - Carnitine uptake defect (CUD)
 - Citrullinemia (CIT)
 - Galactosemia, classic (GALT)
 - Glutaric acidemia type 1 (GA1)
 - 3-hydroxy-3-methylglutaryl-CoA lyase (HMG) deficiency
 - Isovaleric acidemia (IVA)
 - Long chain 3-hydroxyacyl-CoA dehydrogenase (LCHAD) deficiency
 - Maple syrup urine disease (MSUD)
 - Medium chain acyl-CoA dehydrogenase (MCAD) deficiency
 - Methylmalonic acidemia (MMA)
 - Phenylketonuria (PKU)
 - Propionic acidemia (PA)
 - Tri-functional protein (TFP) deficiency
 - Tyrosinemia type 1 (TYR1)
 - Very long chain acyl-CoA dehydrogenase (VLCAD) deficiency
- Endocrine conditions (2)
 - Congenital adrenal hyperplasia (CAH)
 - Congenital hypothyroidism (CH)
- Other conditions (4)
 - Cystic fibrosis (CF)
 - Severe combined immunodeficiency (SCID)
 - Sickle cell disease (SCD)
 - Spinal muscular atrophy (SMA)



Alberta Newborn Screening Program

Screen results and unknown screen results rationale ^c

In 2022-2023, 99.17% of screened infants received normal screen results; 0.60% received abnormal screen results (268 infants had an abnormal screen result for one condition, 1 infant had an abnormal screen result for more than one condition and 13 infants had a double borderline screen result); 0.23% were unknown (meaning an infant had no confirmed normal or abnormal screen result on record, see Figure 4b for rationale).

This year 400 infants were identified as being potential carriers of sickle cell trait.

Figure 4a. Infant screen results, provincial total, 2022-2023

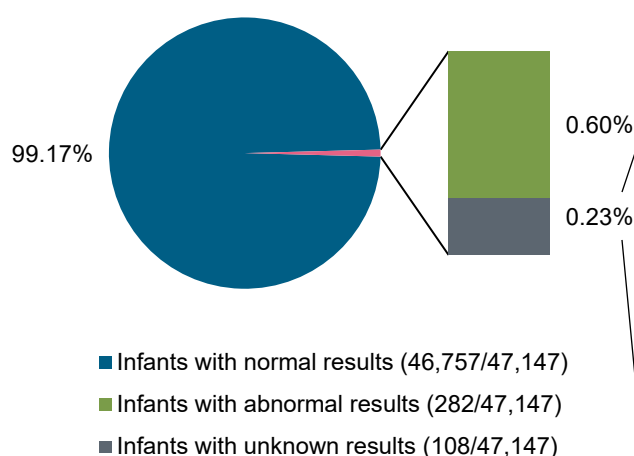
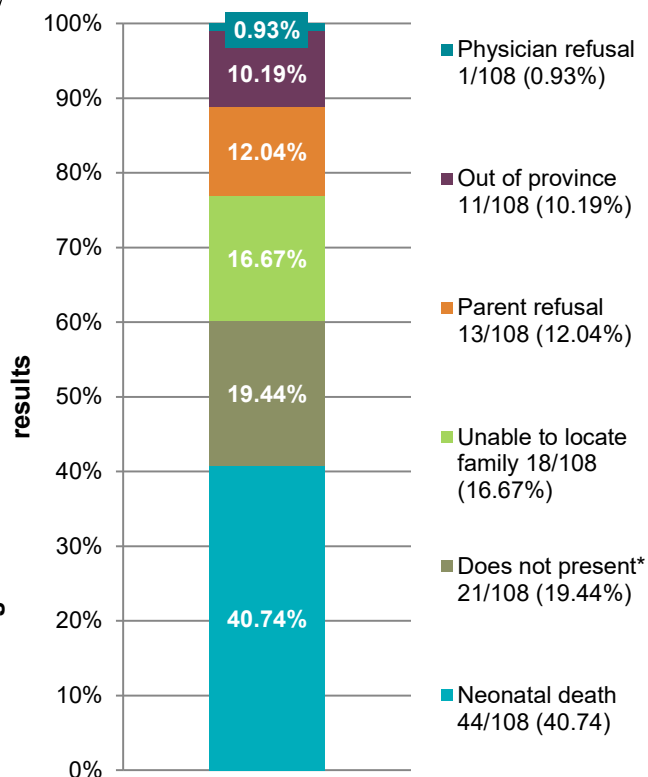


Figure 4b. Unknown screen results rationale, provincial total, 2022-2023



*Does not present means the parent does not refuse, but rather does not present the infant for screening.

Of the 282 abnormal screen results reported:

- 13.43% (38/283) were for a metabolic condition
- 17.67% (50/283) were for an endocrine condition
- 49.47% (140/283) were for cystic fibrosis
- 6.71% (19/283) were for severe combined immunodeficiency
- 10.60% (30/283) were for sickle cell disease
- 2.12% (6/283) were spinal muscular atrophy

^c Data retrieved May 12, 2023 from ANSP Application Reports 5, 6, 7 and 11, ANSP Application statistics and Alberta Newborn Screening Laboratory statistics. Data are for all screened infants. For comparison, previous years' data and ANSP annual reports can be requested through newbornscreening@ahs.ca.

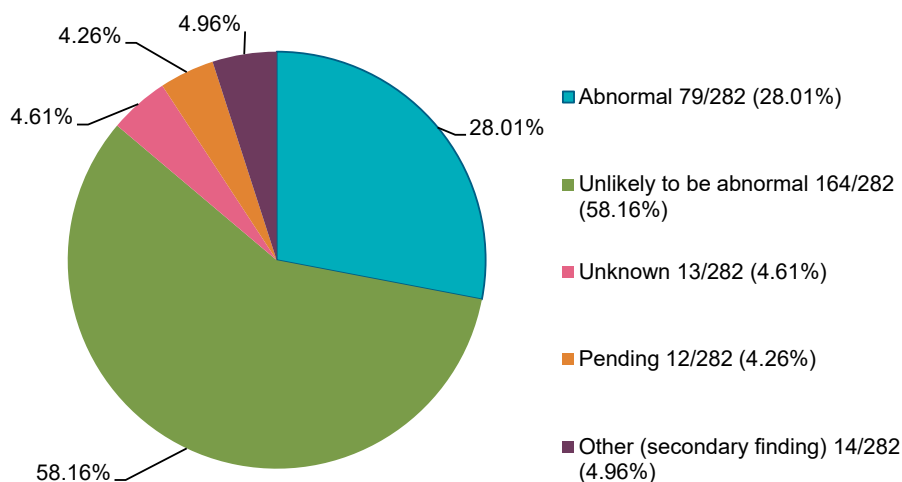


Diagnostic outcomes ^d

In 2022-2023, 28.01% of infants with abnormal screen results received abnormal diagnostic outcomes (after referral for clinical assessment and diagnostic testing) for one of the screened conditions; 58.16% received unlikely to be abnormal diagnostic outcomes; 4.61% received unknown diagnostic outcomes (meaning infant died prior to diagnostic testing, unable to locate infant, or parent refusal of diagnostic testing); and 4.26% were pending at the time of reporting. There were no unclear diagnostic outcomes (meaning diagnostic tests neither confirmed nor excluded the screened condition) reported this year.

Of the 282 infants with abnormal screen results referred for diagnostic testing, 14 (4.96%) received a diagnostic outcome for a condition other than 22 conditions screened for by the ANSP and are included in the “Other (secondary finding)” category.

Figure 5. Infant diagnostic outcomes, provincial total, 2022-2023



There were 283 abnormal *screen results* reported, of which 1 *infant* was referred for diagnostic testing for more than one condition and received more than one diagnostic outcome (Table 1).

Table 1. Diagnostic outcomes of abnormal screen results

	Metabolic conditions, n=38	Endocrine conditions, n=50	CF, n=140	SCID, n=19	SCD, n=30	SMA, n=6	Total, n=283
Abnormal	34.21% (13/38)	64.00% (32/50)	10.71% (15/140)	10.53% (2/19)	40.00% (12/30)	83.33% (5/6)	27.92% (79/283)
Unlikely to be abnormal	55.26% (21/38)	32.00% (16/50)	78.57% (110/140)	68.42% (13/19)	10.00% (3/30)	16.67% (1/6)	57.95% (164/283)
Unclear	0.00% (0/38)	0.00% (0/50)	0.00% (0/140)	0.00% (0/19)	0.00% (0/30)	0.00% (0/6)	0.00% (0/283)
Unknown	2.63% (1/38)	4.00% (2/50)	5.71% (8/140)	10.53% (2/19)	3.33% (1/30)	0.00% (0/6)	4.95% (14/283)
Pending	5.26% (2/38)	0.00% (0/50)	2.86% (4/140)	5.26% (1/19)	16.67% (5/30)	0.00% (0/6)	4.24% (12/283)
Other (secondary finding)	2.63% (1/38)	0.00% (0/50)	2.14% (3/140)	5.26% (1/19)	30.00% (9/30)	0.00% (0/6)	4.95% (14/283)

^d Data retrieved May 12, 2023 from Alberta Newborn Screening Laboratory statistics. Data are for all screened infants. For comparison, previous years’ data and ANSP annual reports can be requested through newbornscreening@ahs.ca.



ANSP performance along the screening pathway

Delivery of screening services within the ANSP occurs along four interconnected steps of the newborn blood spot screening pathway: registration, collection and transportation, analysis and reporting, and follow-up (Figure 6).

Time standards for each step were determined by Alberta Health (3) and service delivery is provided by many providers within AHS, APL, DynaLIFE, FN communities, physicians and midwives.

Important components integrated along each step of the pathway are the care and safety of the infant, and the involvement of the parent. This is represented by the footprint graphic in Figure 6.

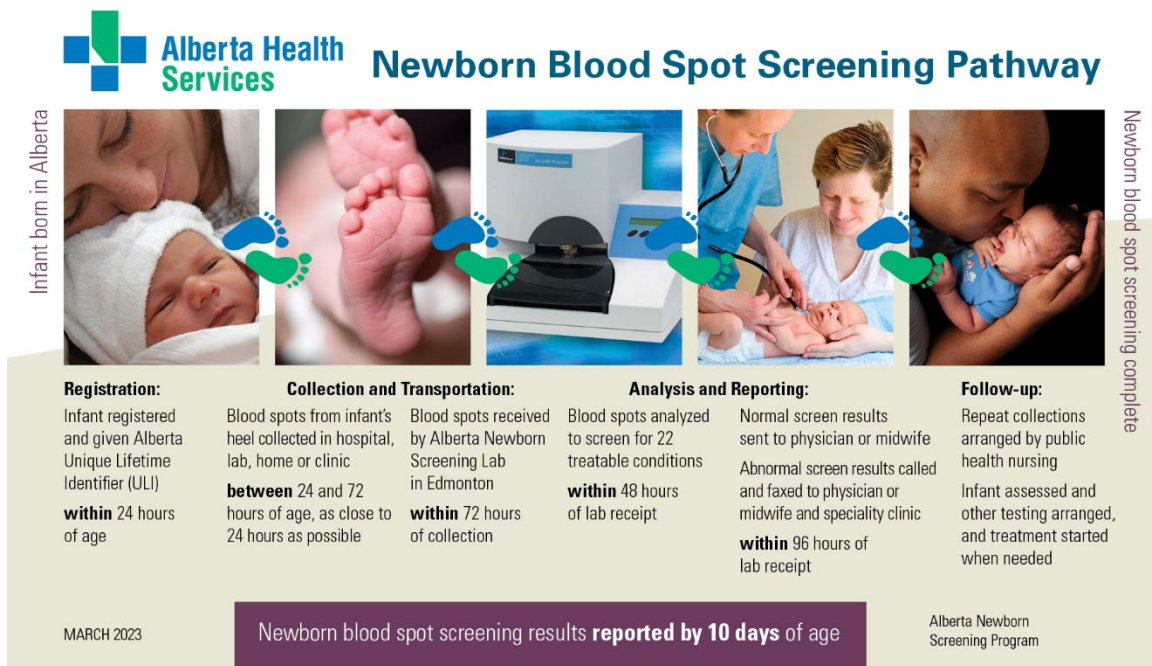


Figure 6. Newborn blood spot screening pathway



Registration

**Newborn blood spot
screening pathway:
2022-2023 registration**

**Registration by 24 hours =
98.67%**

(46,839/47,472) of infants born in
Alberta

Birth registration consists of registering an infant in Person Directory (PD) and assigning a ULI. The standard is met when the ULI is assigned within 24 hours of age.

Registration services are delivered by Health Information Management in each zone who register infants in PD and assign newborn ULIs using the “add newborn” function in order to identify the ANSP’s target population of infants born in Alberta.



Alberta Newborn Screening Program

Birth registration ^e

In 2022-2023, 98.67% (46,839/47,472) of infants born in Alberta were registered in PD within 24 hours of birth, 0.13% (64/47,472) did not meet the standard and 1.20% (569/47,472) were unable to determine. The range among the AHS Zones for meeting the standard is between 97.38% and 99.33% (Figure 7a). The data table for birth registration by zone can be found in Appendix B. This measure has remained consistent for the past five years (Figure 7b).

Figure 7a. Birth registration meeting standard, zone totals, 2022-2023

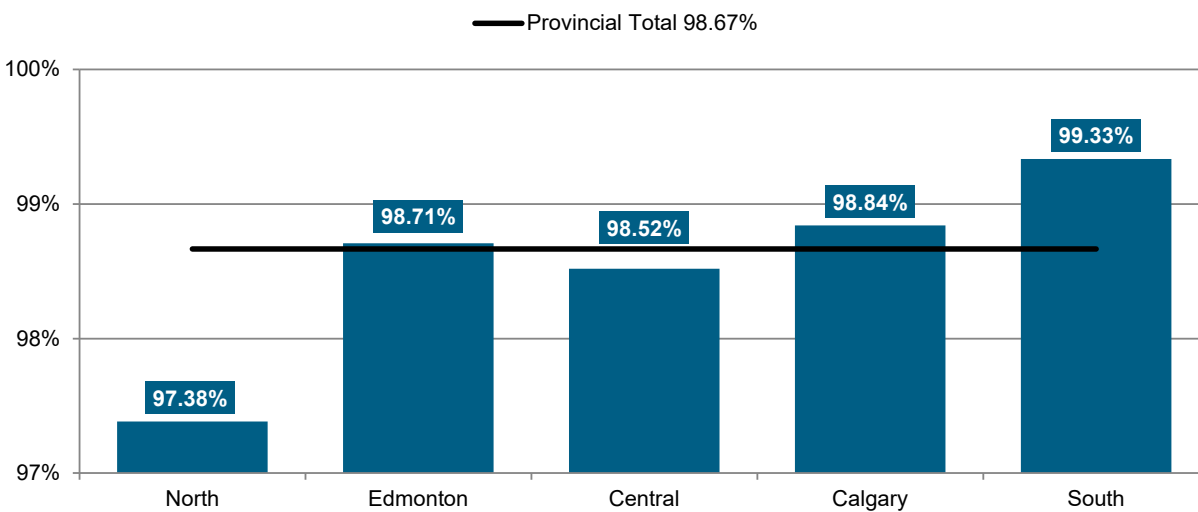
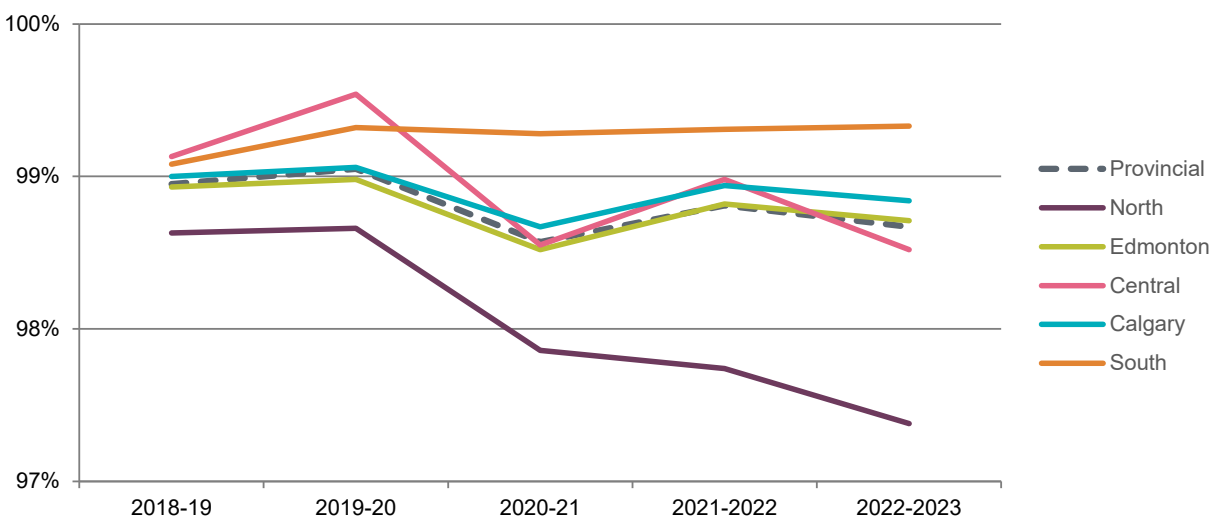


Figure 7b. Birth registration meeting standard, 5-year provincial trend



^e Data retrieved May 12, 2023 from ANSP Application Report 8, Section A. Data are for all registered infants by zone of birth. For comparison, previous years' data and ANSP annual reports can be requested through newbornscreening@ahs.ca.



Collection and transportation

Newborn blood spot screening pathway: 2022-2023 collection & transportation

Initial collection between 24 and 72 hours = **97.96%**

(46,128/47,091) of registered screened infants

Samples received within 72 hours of collection = **96.49%**

(47,898/49,642) of received samples

Inadequate samples = **1.61%**

(798/49,642) of received samples

Collection of the infant's blood spot sample can occur in hospital, community laboratory, home or clinic. The standard is met when the sample is collected between 24 and 72 hours of age and should occur as close after 24 hours of age as reasonably possible.

Transportation to and receipt of the sample by the Alberta Newborn Screening Laboratory at the University of Alberta Hospital is expected to occur within 72 hours of collection.

Collection and transportation services are delivered by:

- Postpartum units in each birth facility and midwives who provide ANSP information to parents, obtain informed consent, and arrange or perform sample collection
- Neonatal Intensive Care Units (NICU) in each zone who provide ANSP information to parents, obtain informed consent, and arrange or perform sample collection
- Inpatient laboratory services in each birth facility and outpatient laboratory services in each zone who perform sample collection and arrange for sample transportation
- Public health nursing services (PHNS) in each zone, FN communities and midwives who provide ANSP information to parents, obtain informed consent, arrange or perform sample collection, and arrange for sample transportation



Alberta Newborn Screening Program

Initial collection ^f

In 2022-2023, 97.96% (46,128/47,091) of registered screened infants had an initial sample collected between 24 and 72 hours of age, 1.90% (896/47,091) did not meet the standard and 0.14% (67/47,091) were unable to determine. The range among the AHS Zones for meeting the standard is between 94.77% and 98.57% (Figure 8a) (AHS Zone not assigned is 92.19% for meeting the standard). The data table for initial sample collection by zone can be found in Appendix B. This measure has remained consistent provincially for the past five years (Figure 8b).

Figure 8a. Initial sample collection meeting standard, zone totals, 2022-2023

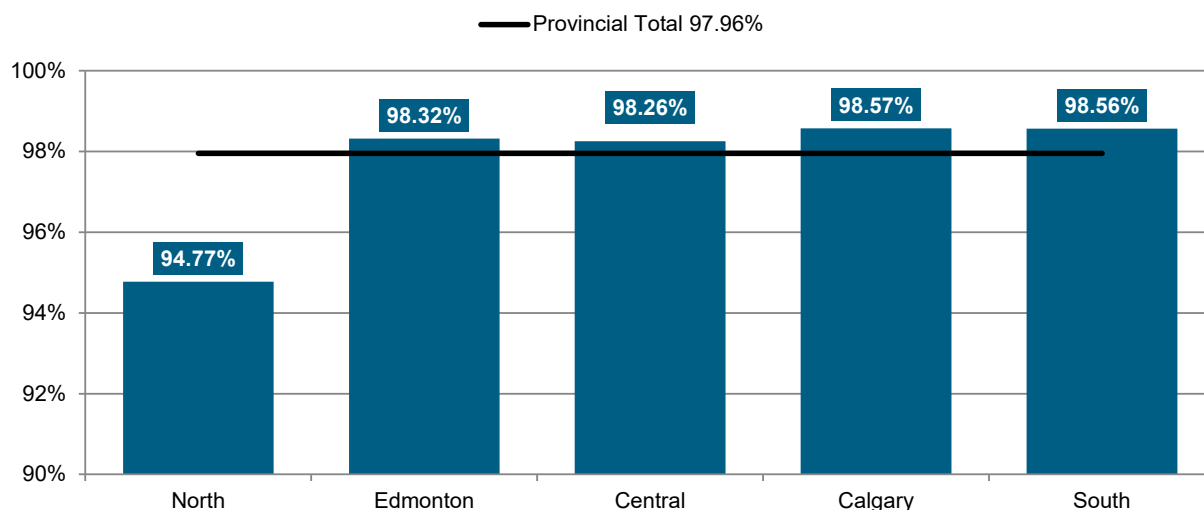
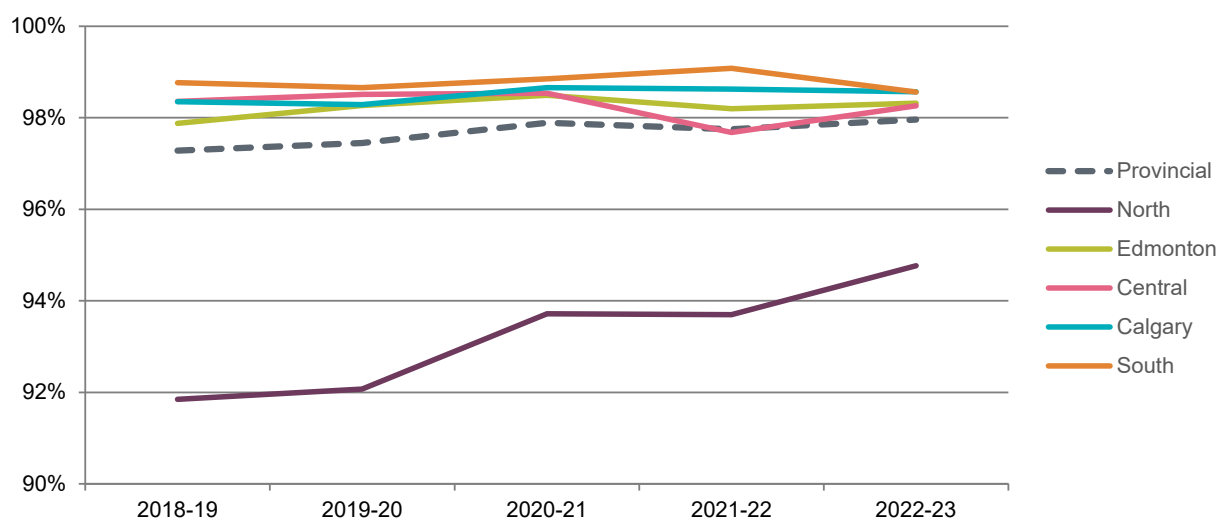


Figure 8b. Initial sample collection meeting standard, 5-year zone trends



^f Data retrieved May 12, 2023 from ANSP Application Report 8, Section B. Data are for all registered screened infants by zone of responsibility. For comparison, previous years' data and ANSP annual reports can be requested through newbornscreening@ahs.ca.



Alberta Newborn Screening Program

Sample receipt ⁹

In 2022-2023, 96.49% (47,898/49,642) of samples were received by the Alberta Newborn Screening Laboratory within 72 hours of collection and 3.51% (1,744/49,642) did not meet the standard. The range among the AHS Zones for meeting the standard is between 90.00% and 98.83% (Figure 9a) (AHS Zone not assigned is 96.42% for meeting the standard). The data table for sample receipt by the Alberta Newborn Screening Laboratory by zone can be found in Appendix B. This measure has remained consistent provincially for the past five years. The ANSP team is investigating the drop in meeting this standard for South Zone and is working collaboratively with partners to support sustained improvement in this area (Figure 9b).

Figure 9a. Sample receipt by Alberta Newborn Screening Laboratory meeting standard, zone totals, 2022-2023

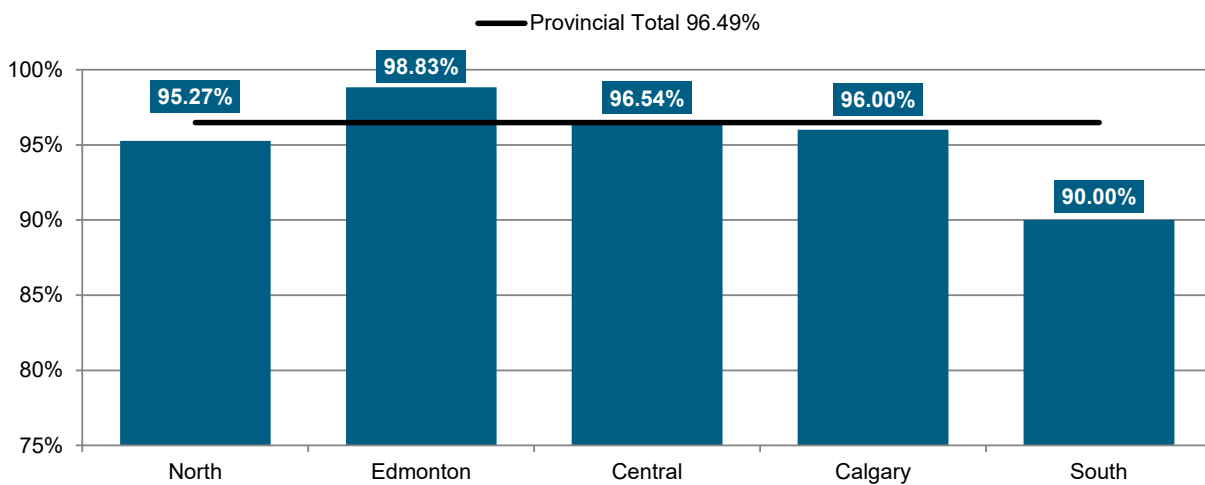
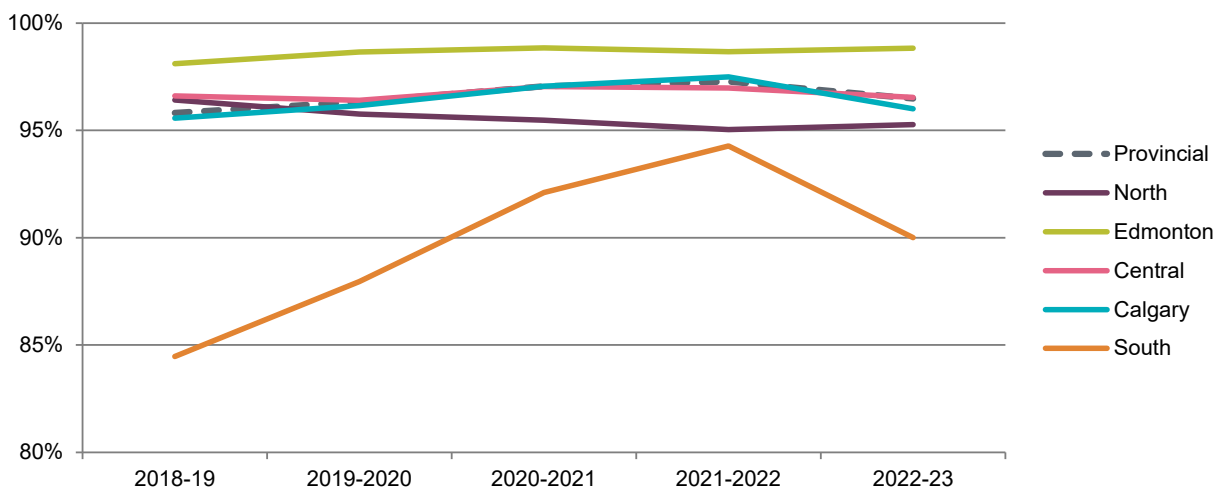


Figure 9b. Sample receipt by Alberta Newborn Screening Laboratory meeting standard, 5-year zone trends



⁹ Data retrieved May 12, 2023 from ANSP Application Report 8, Section D. Data are for all received samples by zone of responsibility. For comparison, previous years' data and ANSP annual reports can be requested through newbornscreening@ahs.ca.



Alberta Newborn Screening Program

Inadequate samples ^h

The ANSP aims to reduce inadequate samples to a target of 2% or less because each one requires a repeat sample, adding significant costs and implications to the health care system and families.

In 2022-2023, 1.61% (798/49,642) of samples received by the Alberta Newborn Screening Laboratory were determined to be inadequate. The range among the AHS Zones for meeting the standard is between 3.31% and 1.14% (Figure 10a) (AHS Zone not assigned is 24.62% for meeting the standard). The data table for inadequate samples received by zone can be found in Appendix B. 1.61% is the lowest provincial inadequate sample rate ever achieved and speaks to the program's focus on quality improvement in this area (Figure 10b).

Figure 10a. Inadequate samples, zone totals, 2022-2023

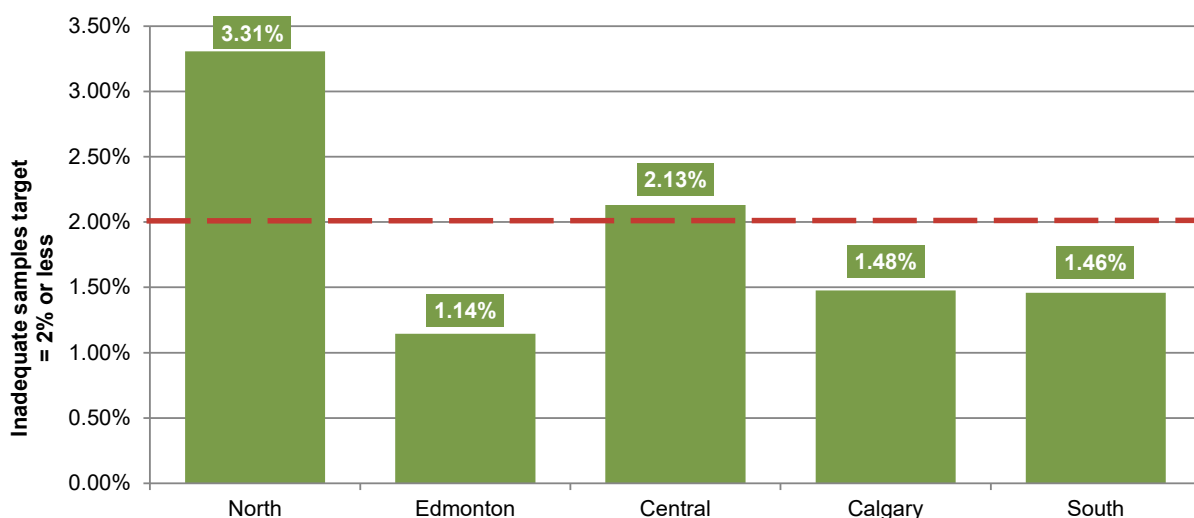
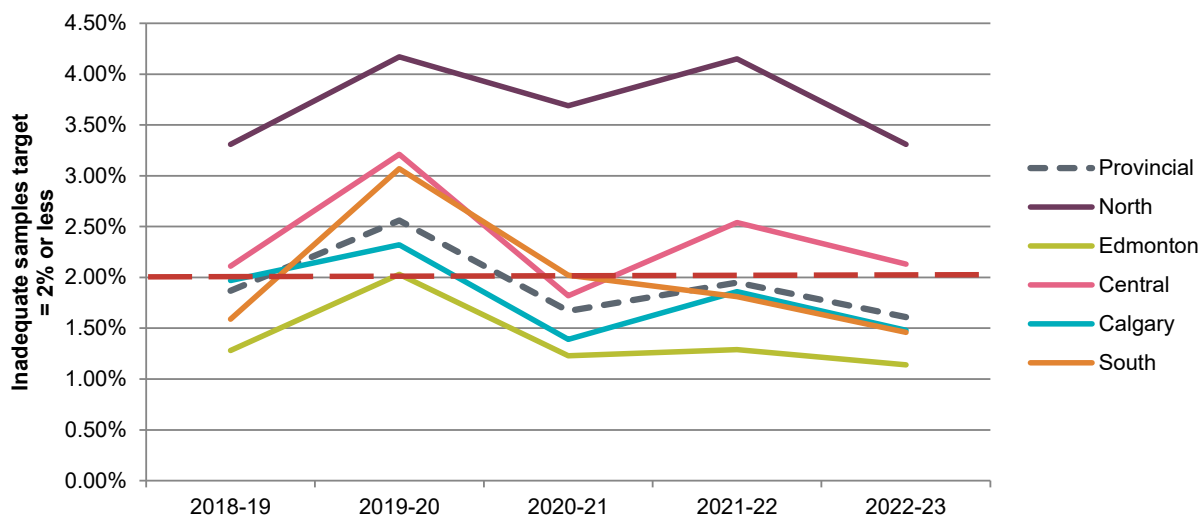


Figure 10b. Inadequate samples, 5-year zone trends



^h Data retrieved May 12, 2023 from ANSP Application Report 3. Data are for all received samples by zone of collection. For comparison, previous years' data and ANSP annual reports can be requested through newbornscreening@ahs.ca.



Analysis and reporting

**Newborn blood spot screening pathway:
2022-2023 analysis & reporting**

Analysis and reporting within 96 hours of Lab receipt = 79.06%

(39,249/49,642) of received samples

Analysis and reporting includes analysis of newborn blood spot samples and reporting the screen results. The standard is met when analysis and reporting occur within 96 hours of Alberta Newborn Screening Laboratory receipt (21 days for CF analysis).

Analysis and reporting services are delivered by:

- Alberta Newborn Screening Laboratory within APL who enter data from samples, perform sample analyses including determining sample quality, and report screen results to the ANSP Application, Netcare, ordering physicians, providers and birth facilities
- Molecular Genetics Laboratory within APL who perform screening for CF, SCID and SMA and report screen results to the Alberta Newborn Screening Laboratory



Alberta Newborn Screening Program

Results reportedⁱ

In 2022-2023, 79.06% of samples received had screen results reported by the Alberta Newborn Screening Laboratory within 96 hours of lab receipt (excluding CF) (Figure 11a). The performance for this measure declined due to repeated instrument failures. Frequent and rotating failures have resulted in repeat assay testing with associated delays to reporting (Figure 11b). This has been identified as a significant quality issue. The Lab is working on securing funding for replacement of aged instruments.

Figure 11a. Screen results reported, provincial total, 2022-2023

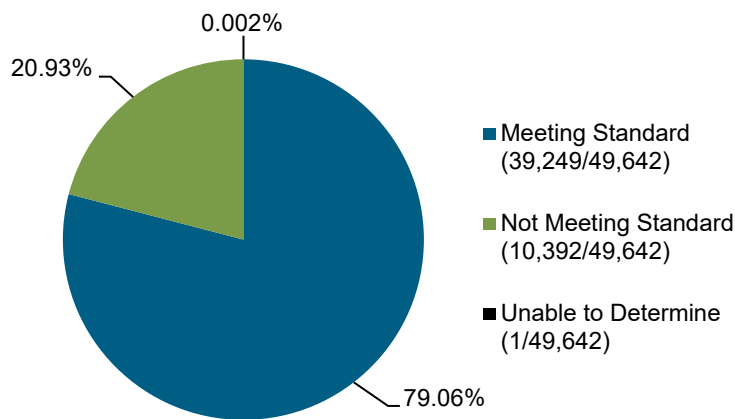
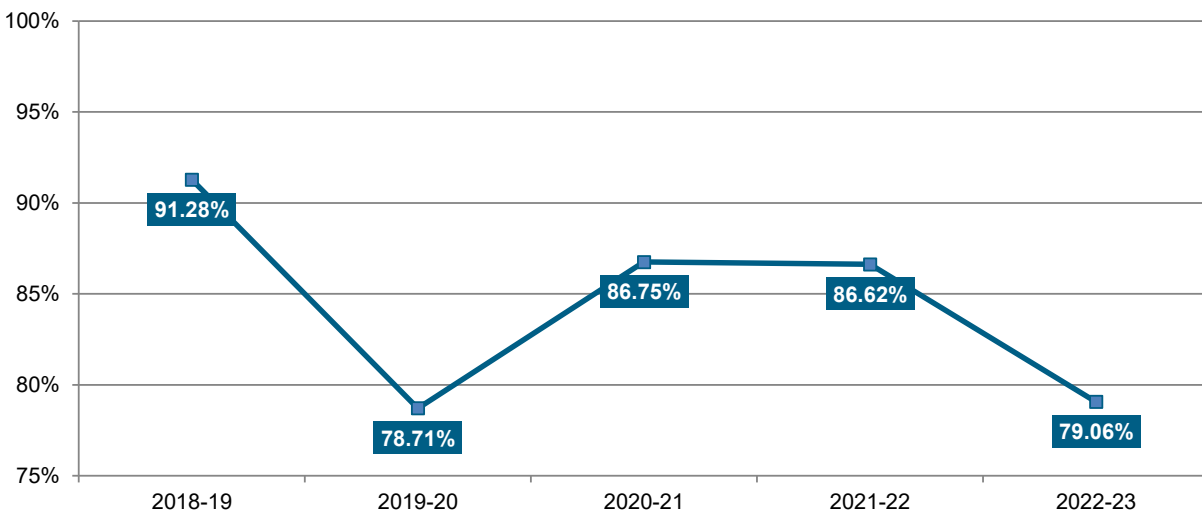


Figure 11b. Screen results reported, meeting standard, 5-year provincial trend



ⁱ Data retrieved May 12, 2023 from ANSP Application Report 8, Section E. Data are for all received samples (excluding CF) for all zones combined. For comparison, previous years' data and ANSP annual reports can be requested through newbornscreening@ahs.ca.



Follow-up

Newborn blood spot screening pathway: 2022-2023 follow-up

Repeat collection within 96 hours of notification of inadequate samples = **82.66%**

(596/721) of repeat samples

Repeat collection within 96 hours of notification of reported borderline results = **91.56%**

(358/391) of repeat samples

Repeat collection for low birth weight infants between 21 and 28 days = **97.01%**

(1,069/1,102) of low birth weight samples

Timely follow-up is coordinated to ensure that initial samples are collected from all infants born in Alberta, repeat samples are collected when required, referrals for clinical assessment and diagnostic tests are initiated when required, and diagnostic testing is completed when required.

Follow-up services are delivered by:

- ANSP coordination team within Provincial Population and Public Health who distribute ANSP Application notifications (i.e., alerts) to zone PHNS and FN communities, and track and monitor the completion of follow-up for data corrections and sample collection
- PHNS in each zone, FN communities and midwives who confirm and correct infant demographics as required, provide ANSP information to parents, obtain informed consent, and arrange or perform sample collection
- NICU in each zone who provide ANSP information to parents, obtain informed consent, and arrange or perform sample collection upon referral from zone PHNS
- Inpatient laboratory services in each birth facility and outpatient laboratory services in each zone who perform sample collection upon referral from zone PHNS
- Health Information Management in each zone who confirm and correct infant demographics as required
- Alberta Newborn Screening Laboratory within APL who confirm and correct infant demographics as required, notify physicians, midwives and specialty clinics of abnormal screen results, provide consultations, track and monitor the completion of follow-up for abnormal screen results and flagged registrations, and monitor the incidence of confirmed diagnoses for screened conditions
- Physicians and midwives who provide ANSP information to parents, obtain informed consent, refer infants to specialty clinics as required, and in consultation with specialty clinics provide clinical assessments of infants with abnormal screen results, arrange for diagnostic testing, initiate treatment, and notify the Alberta Newborn Screening Laboratory of the diagnostic outcomes
- Specialty clinics (metabolic, endocrinology, CF, hematology, immunology and neurology) within the Alberta and Stollery Children's Hospitals who collaborate with physicians to provide clinical assessments of infants with abnormal screen results, arrange for diagnostic testing, initiate treatment, and notify the Alberta Newborn Screening Laboratory of the diagnostic outcomes
- Diagnostic laboratories who collaborate with physicians, midwives and specialty clinics to perform diagnostic testing of infants with abnormal screen results, and report test results to physicians, midwives and specialty clinics



Repeat sample collection for inadequate samples ^j

Infants with an inadequate sample require a repeat sample collection within 96 hours of notification of the reported inadequate sample. In 2022-2023, 82.66% (596/721) of repeat samples were collected within the required time frame and 17.34% (125/721) did not meet the standard. The range among the AHS Zones for meeting the standard is between 75.36% and 91.34% (Figure 12a) (AHS Zone not assigned is 20.83% for meeting the standard). The data table for repeat sample collection for inadequate samples by zone can be found in Appendix B. The five-year zone trend is shown in Figure 12b.

Figure 12a. Repeat sample collection for inadequate samples meeting standard, zone totals, 2022-2023

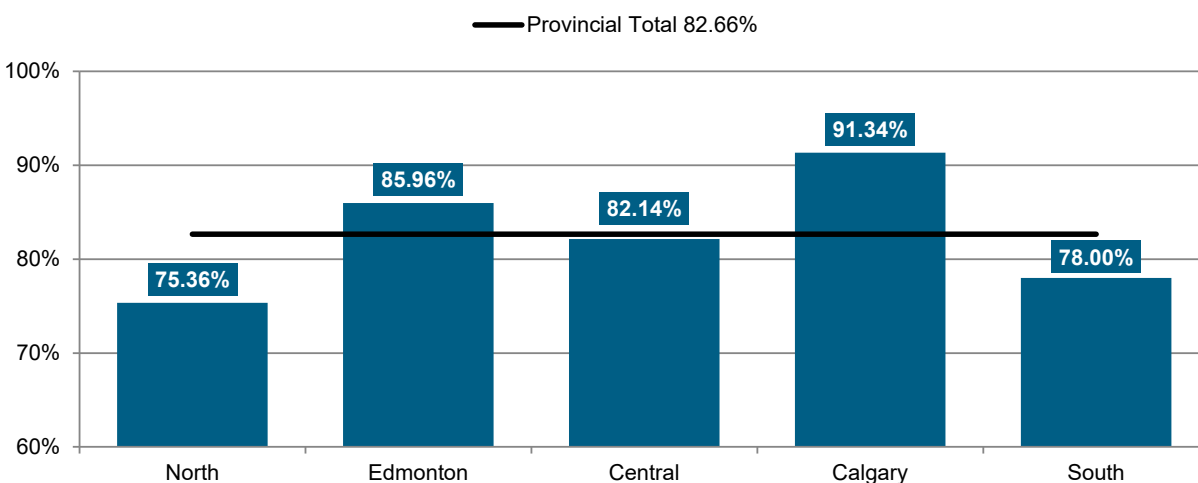
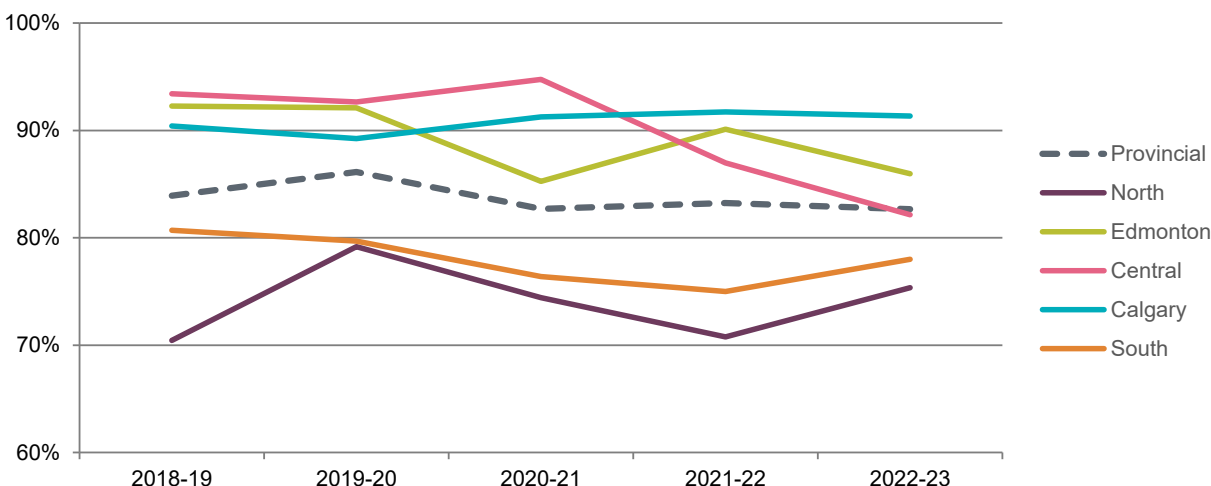


Figure 12b. Repeat sample collection for inadequate samples meeting standard, 5-year zone trends



^j Data retrieved May 12, 2023 from ANSP Application Report 8, Section G. Data are for all repeat samples due to inadequate samples by zone of responsibility. For comparison, previous years' data and ANSP annual reports can be requested through newbornscreening@ahs.ca.



Repeat sample collection for borderline results ^k

Infants with a borderline screen result require a repeat sample collection within 96 hours of notification of the reported borderline screen result (excluding tyrosine). In 2022-2023, 91.56% (358/391) of repeat samples were collected within the required time frame and 8.44% (33/391) did not meet the standard. The range among the AHS Zones for meeting the standard is between 80.56% and 97.87% (Figure 13a) (AHS Zone not assigned is 72.73% for meeting the standard). The data table for repeat sample collection for borderline screen results by zone can be found in Appendix B. The five-year zone trend is shown in Figure 13b.

Figure 13a. Repeat sample collection for borderline screen results meeting standard, zone totals, 2022-2023

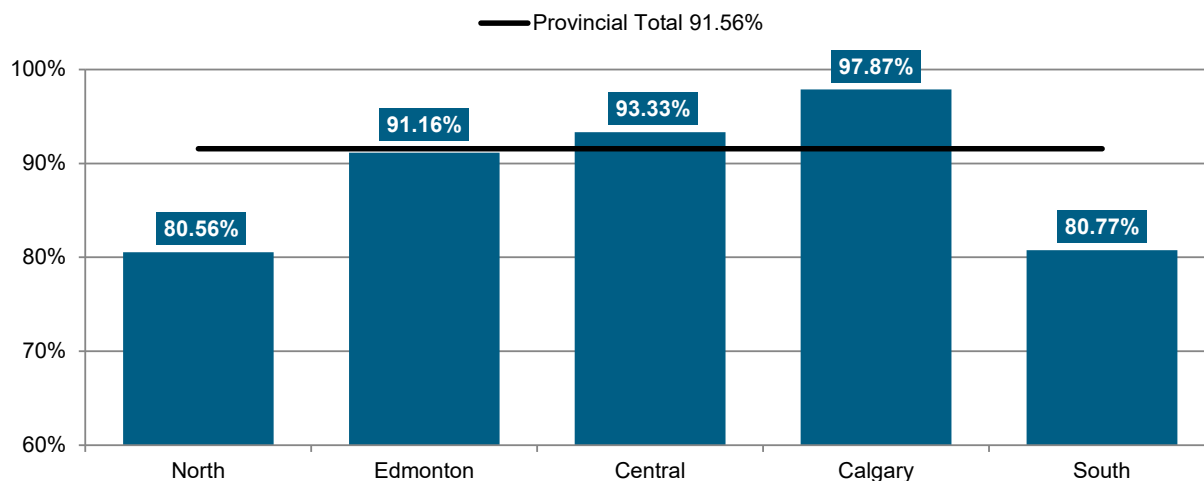
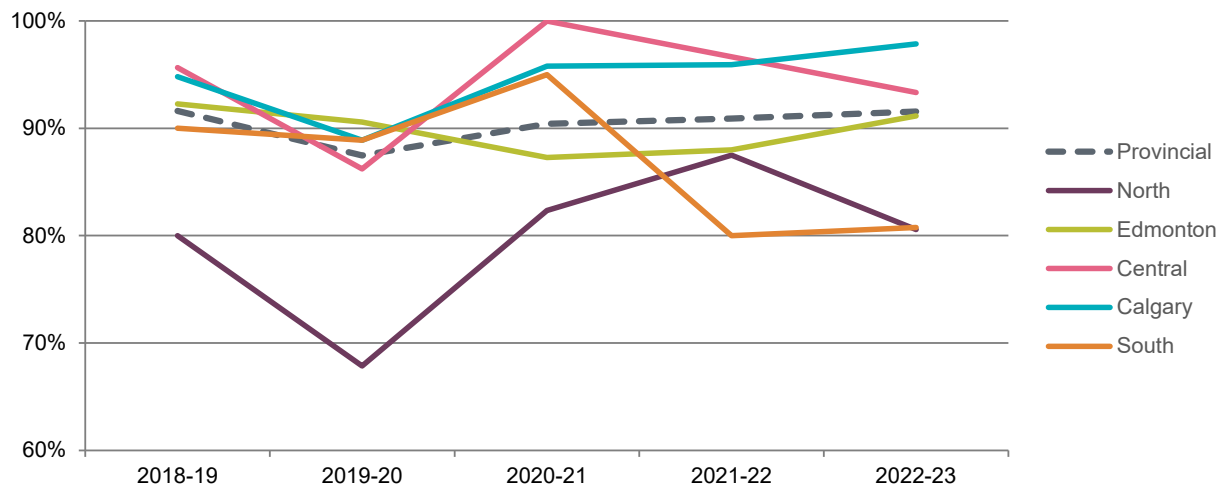


Figure 13b. Repeat sample collection for borderline screen results meeting standard, 5-year zone trends



^k Data retrieved May 12, 2023 from ANSP Application Report 8, Section H. Data are for all repeat samples due to borderline screen result (excluding tyrosine) by zone of responsibility. For comparison, previous years' data and ANSP annual reports can be requested through newbornscreening@ahs.ca.



Repeat sample collection for low birth weight infants ¹

In 2022-2023, 1,142 infants had a low birth weight (less than 2000 grams at birth) that required a repeat sample collection between 21 days (504 hours) and 28 days (672 hours) of age. 3.50% (40/1,142) of infants were lost to follow-up (neonatal death, moved out of province, unable to locate infant, does not present, physician refusal, and parent refusal) and no repeat sample was collected. Of the 1,102 low birth weight infants who had a repeat sample collected, 97.01% (1,069/1,102) were collected during the required time frame and 2.99% (33/1,102) did not meet the standard. The range among the AHS Zones for meeting the standard is between 87.63% and 99.54% (Figure 14a) (AHS Zone not assigned is 88.89% for meeting the standard). The data table for sample collection for low birth weight by zone can be found in Appendix B. The five-year provincial trend is shown in Figure 14b. See Appendix A for amendments to prior years' data.

Figure 14a. Repeat sample collection for low birth weight infants meeting standard, zone totals, 2022-2023

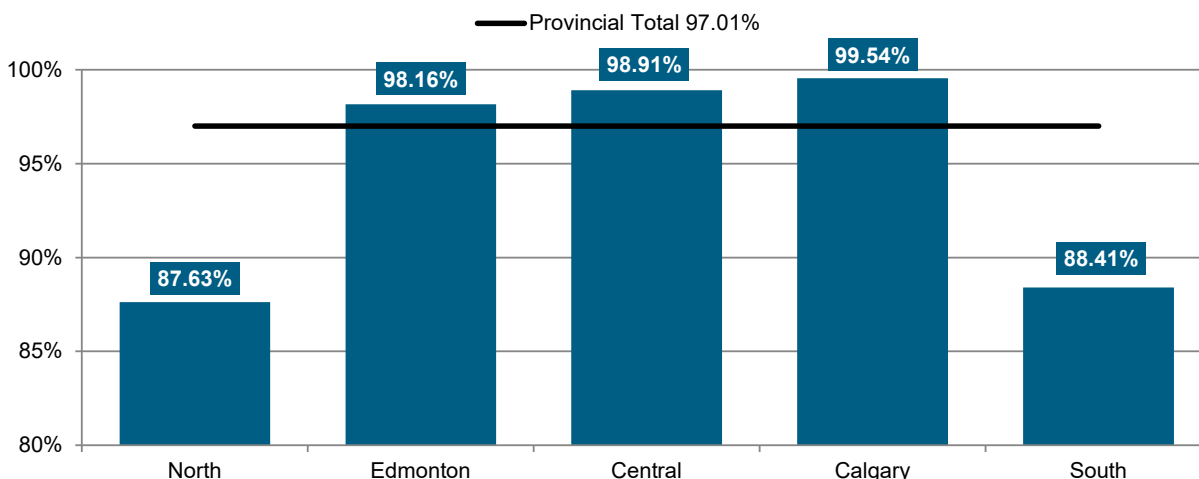
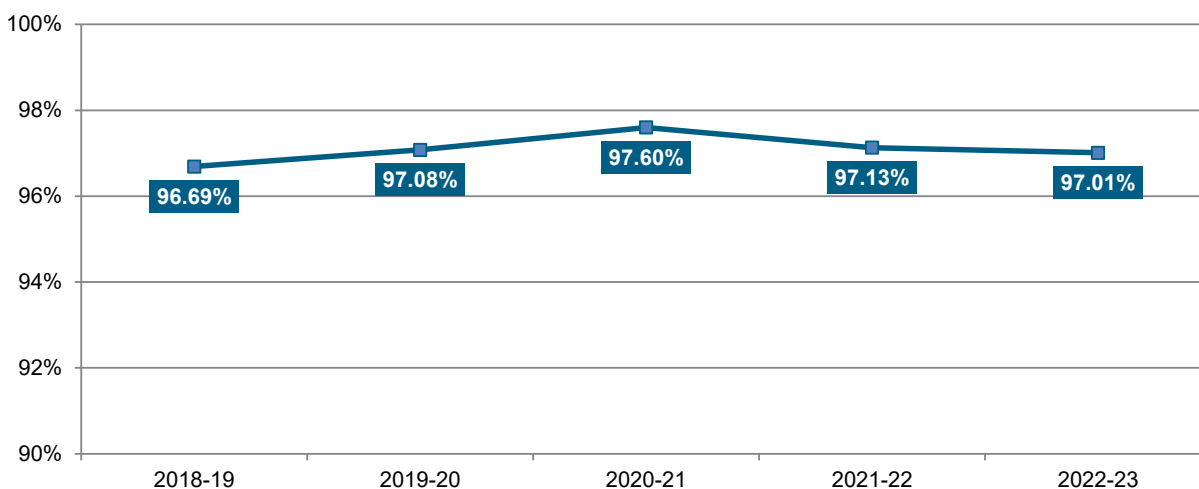


Figure 14b. Repeat sample collection for low birth weight infants meeting standard, 5-year provincial trend



¹ Data retrieved May 12, 2023 from ANSP Application Report 10 and 11. Data are for all repeat sample collection for low birth weight infants by zone of responsibility. For comparison, previous years' data and ANSP annual reports can be requested through newbornscreening@ahs.ca.



Conclusion

The purpose of the *Alberta Newborn Screening Program Report 2022-2023* was to highlight ANSP performance between April 1, 2022 and March 31, 2023. The report summarized ANSP performance for the reporting year and the performance trends that have come through the centralized coordination of the program.

Performance measures have remained consistent, and the program continues to evaluate data and collaborate with partners to support improving performance.

The ANSP systems and processes have continued to support ongoing provincial coordination activities in 2022-2023 while the quality management framework continues to guide sustainability and quality improvement along the screening pathway and supporting processes.

The coordination of program processes and quality improvement activities with our partners and service areas along the screening pathway helps to ensure all infants born in Alberta receive timely access to safe and effective newborn blood spot screening; every infant, every time.



References

1. **Public Health Agency of Canada.** What is the Population Health Approach? [Online] 2004. http://www.phac-aspc.gc.ca/ph-sp/approach-approche/appr-eng.php#key_elements.
2. **Vollman A.R., Anderson E.T., & McFarlane J.** *Canadian Community as Partner: Theory and Multidisciplinary Practice*. Philadelphia, PA : Wolters Kluwer Health | Lippincott Williams & Wilkins, 2012.
3. **Alberta Health and Wellness.** Alberta Newborn Metabolic Screening Program Policy Document. [Online] 2010. <https://open.alberta.ca/publications/9780778582892#summary>.



Appendix A

Amendments to the 2021-2022 AHS Provincial NMS Program Report ^m

Screen results and unknown screen results rationale

Screen Results	Previously Reported, n=48,865	Amended, n=48,865
Normal results	99.27% (48,506/48,865)	99.27% (48,506/48,865)
Abnormal results	0.49% (238/48,865)	0.49% (238/48,865)
Unknown results	0.24% (119/48,865)	0.25% (121/48,865)
Pending results	0.004% (2/48,865)	0.00% (0/48,865)
Unknown Screen Results Rationale	Previously Reported, n=119	Amended, n=121
Unable to locate family	35.29% (42/119)	35.54% (43/121)
Neonatal Death	27.73% (33/119)	28.10% (34/121)
Does not present	16.81% (20/119)	16.53% (20/121)
Out of province	10.92% (13/119)	10.74% (13/121)
Parent refusal	8.40% (10/119)	8.26% (10/121)
Physician refusal	0.84% (1/119)	0.83% (1/121)

Diagnostic outcomes

There were 240 abnormal screen results reported, of which 2 infants were referred for diagnostic testing for more than one condition and received more than one diagnostic outcome.

Diagnostic outcomes by category		Metabolic conditions, n=49	Endocrine conditions, n=49	Cystic fibrosis, n=102	Severe combined immunodeficiency, n=15	Sickle cell disease, n=25	Total, n=240
Abnormal	Previously reported	14.29% (7/49)	65.31% (32/49)	3.92% (4/102)	6.67% (1/15)	64.00% (16/25)	25.00% (60/240)
	Amended	16.33% (8/49)	67.35% (33/49)	3.92% (4/102)	6.67% (1/15)	72.00% (18/25)	26.67% (64/240)
Unlikely to be abnormal	Previously reported	77.55% (38/49)	26.53% (13/49)	71.57% (73/102)	40.00% (6/15)	8.00% (2/25)	55.00% (132/240)
	Amended	79.59% (39/49)	30.61% (15/49)	77.45% (79/102)	60.00% (8/15)	12.00% (3/25)	60.00% (144/240)
Unclear	Previously reported	0.00 (0/49)	0.00% (0/49)	0.00% (0/102)	0.00% (0/15)	0.00% (0/25)	0.00% (0/240)
	Amended	0.00 (0/49)	0.00% (0/49)	0.00% (0/102)	0.00% (0/15)	0.00% (0/25)	0.00% (0/240)
Unknown	Previously reported	0.00% (0/49)	2.04% (1/49)	9.80% (10/102)	0.00% (0/15)	8.00% (2/25)	5.42% (13/240)
	Amended	0.00 (0/49)	2.04% (1/49)	12.75% (13/102)	6.67% (1/15)	8.00% (2/25)	7.08% (17/240)
Pending	Previously reported	6.12% (3/49)	6.12% (3/49)	8.82% (9/102)	20.00% (3/15)	12.00% (3/25)	8.75% (21/240)
	Amended	0.00 (0/49)	0.00% (0/49)	0.00% (0/102)	0.00% (0/15)	0.00% (0/25)	0.00% (0/240)
Other (secondary finding)	Previously reported	2.04% (1/49)	0.00% (0/49)	5.88% (6/102)	33.33% (5/15)	8.00% (2/25)	5.83% (14/240)
	Amended	4.08% (2/49)	0.00% (0/49)	5.88% (6/102)	3.33% (5/15)	8.00% (2/25)	6.25% (15/240)

^m Amended data retrieved May 12, 2023 from ANSP Application statistics and Alberta Newborn Screening Laboratory statistics. Data are for all screened infants. For comparison, previous years' data and ANSP annual reports can be requested through newbornscreening@ahs.ca.



Amendments to repeat sample collection for low birth weight infants

Meeting standard and not meeting standard

In prior years, *not meeting standard* included low birth weight infants who had a repeat sample collected outside of the required time frame plus those who did not have a repeat sample collected (these were infants who were lost to follow-up due to neonatal death, moved out of province, unable to locate infant, does not present, physician refusal, and parent refusal). To better reflect performance for this measure, and to align with how repeat collections for inadequate and borderline samples are reported, the calculation was adjusted to exclude the infants who were not collected from those not meeting standard and from the total denominator. This change is reflected in the table below and is how the data is reported in Figure 14b.

Year	Repeat Sample Collection	Previously Reported	Amended
2018-19	Meeting standard	93.38% (1,227/1,314)	96.69% (1,227/1,269)
	Not meeting standard	3.20% (42/1,314)	3.31% (42/1,269)
	Repeat sample not collected	3.42% (45/1,314)	45
2019-20	Meeting standard	93.76% (1,096/1,169)	97.08% (1,097/1,130)
	Not meeting standard	6.24% (73/1,169)	2.92% (33/1,130)
	Repeat sample not collected	--	39
2020-21	Meeting standard	93.52% (1,056/1,129)	97.60% (1,056/1,082)
	Not meeting standard	6.47% (73/1,129)	2.40% (26/1,082)
	Repeat sample not collected	--	47
2021-22	Meeting standard	94.09% (1,083/1,151)	97.13% (1,083/1,115)
	Not meeting standard	5.91% (68/1,151)	2.87% (32/1,115)
	Repeat sample not collected	--	36



Appendix B

2022-2023 performance measures data tables by zone ⁿ

Initial screen results reported by the Alberta Newborn Screening Laboratory within 10 days of age

	North	Edmonton	Central	Calgary	South	AHS Zone n/a*	Provincial total
Meeting standard	5338	15769	4258	17423	3382	427	46597
Not meeting standard	112	88	44	193	28	20	485
Unable to determine	1	3	1	3	0	1	9
Grand total	5451	15860	4303	17619	3410	448	47091

Birth registration in PD within 24 hours of birth

	North	Edmonton	Central	Calgary	South	AHS Zone n/a*	Provincial total
Meeting standard	4282	17500	3595	18177	3285	0	46839
Not meeting standard	40	5	8	10	1	0	64
Unable to determine	75	224	46	203	21	0	569
Grand total	4397	17729	3649	18390	3307	0	47472

Initial sample collected between 24 and 72 hours of age

	North	Edmonton	Central	Calgary	South	AHS Zone n/a*	Provincial total
Meeting standard	5166	15593	4228	17367	3361	413	46128
Not meeting standard	274	240	68	239	44	31	896
Unable to determine	11	27	7	13	5	4	67
Grand total	5451	15860	4303	17619	3410	448	47091

Sample receipt by the Alberta Newborn Screening Laboratory within 72 hours of collection

	North	Edmonton	Central	Calgary	South	AHS Zone n/a*	Provincial total
Meeting standard	5496	16480	4377	17783	3223	539	47898
Not meeting standard	273	195	157	741	358	20	1744
Unable to determine	0	0	0	0	0	0	0
Grand total	5769	16675	4534	18524	3581	559	49642

Inadequate samples

	North	Edmonton	Central	Calgary	South	AHS Zone n/a*	Provincial total
Total inadequate samples	157	212	82	280	51	16	798
Total adequate samples	4591	18305	3767	18685	3447	48	48843
Total pending samples	0	0	0	0	0	1	1
Grand total	4748	18517	3849	18965	3498	65	49642

Repeat sample collection for inadequate samples within 96 hours of notification

	North	Edmonton	Central	Calgary	South	AHS Zone n/a*	Provincial total
Meeting standard	104	147	69	232	39	5	596
Not meeting standard	34	24	15	22	11	19	125
Grand total	138	171	84	254	50	24	721

Repeat sample collection for reported borderline screen results within 96 hours of notification

	North	Edmonton	Central	Calgary	South	AHS Zone n/a*	Provincial total
Meeting standard	29	134	28	138	21	8	358
Not meeting standard	7	13	2	3	5	3	33
Grand total	36	147	30	141	26	11	391

Repeat sample collection for low birth weight infants between 504 hours and 672 hours of age

	North	Edmonton	Central	Calgary	South	AHS Zone n/a*	Provincial total
Meeting standard	85	373	91	435	61	24	1069
Not meeting standard	12	7	1	2	8	3	33
Repeat sample not collected	9	12	2	12	5	0	40
Grand total	106	392	94	449	74	27	1142

ⁿ Data retrieved May 12, 2023 from ANSP Application Report 3, 8 and 10. For comparison, previous years' data and ANSP annual reports can be requested through newbornscreening@ahs.ca.

*AHS Zone n/a = AHS Zone not assigned



Appendix C

Further screening by the ANSP in 2022-2023

- 56 infants who were born out of province were screened in Alberta (had a sample collected by the ANSP).
- 19 preterm infants (born less than 37 weeks gestational age) required repeat sample collection to support the detection of SCID and SCD.
- 20 of 21 infants who were part of a multiple birth set had a repeat sample collected. The 1 infant who did not have a repeat sample collected had a physician refusal.

Additional findings in 2022-2023

- 32 infants had screen results suggestive of glucose-6-phosphate dehydrogenase (G6PD) deficiency.
 - 14 infants received an abnormal diagnostic outcome for G6PD
 - 4 infants received an unlikely to be abnormal diagnostic outcome and do not have G6PD
 - 3 infants were lost to follow-up
 - 11 infants had a pending diagnostic outcome at the time of reporting

