Alberta Newborn Screening Program Report 2023-2024

June 30, 2024

Alberta Health Services
Alberta Newborn Screening

This report has been prepared by the Alberta Newborn Screening Program

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Table of contents

Executive summary

The purpose of the *Alberta Newborn Screening Program Report 2023-2024* is to highlight Alberta Newborn Screening Program (ANSP) performance between April 1, 2023 and March 31, 2024. 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:

- 48,962 infants screened in Alberta during the reporting year
- 226 infants who received abnormal screen results and were referred for diagnostic testing
- 72 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 efforts and impact of the ANSP in 2023-2024.

Summary of ANSP key performance measures, 2023-2024

Performance	2023-2024 data	2022-2023 data
Registered infants who received an initial blood spot screen	99.09% (48,923/49,370)	99.20% (47,091/47,472)
Registered infants who did not receive an initial blood spot screen	0.91% (447/49,370)	0.80% (381/47,472)
Registered screened infants who had a screen result reported within 10 days of age	98.23% (48,055/48,923)	98.95% (46,597/47,091)
Screened infants who received normal screen results	99.38% (48,657/48,962)	99.17% (46,757/47,147)
Screened infants who received abnormal screen results	0.46% (226/48,962)	0.60% (282/47,147)
Screened infants who received unknown screen results	0.16% (78/48,962)	0.23% (108/47,147)
Infants with abnormal screen results who received abnormal diagnostic outcomes for one of the screened conditions	31.86% (72/226)	29.08% (82/282)*
Infants born in Alberta who were registered in Person Directory (PD) within 24 hours of birth	98.61% (48,683/49,370)	98.67% (46,839/47,472)
Registered screened infants who had an initial blood spot sample collected between 24 and 72 hours of age	98.08% (47,986/48,923)	97.96% (46,128/47,091)
Samples received by the Alberta Newborn Screening Laboratory within 72 hours of collection	96.42% (49,660/51,506)	96.49% (47,898/49,642)
Samples received by the Alberta Newborn Screening Laboratory that were determined to be inadequate	1.60% (822/51,506)	1.61% (798/49,642)
Samples received that had screen results reported within 96 hours of Alberta Newborn Screening Laboratory receipt	74.58% (38,414/51,506)	79.06% (39,249/49,642)
Repeat samples collected within 96 hours of notification of reported inadequate screen results	81.83% (635/776)	82.66% (596/721)
Repeat samples collected within 96 hours of notification of reported borderline screen results	87.67% (327/373)	91.56% (358/391)
Repeat samples collected between 21 days and 28 days of age for infants with low birth weight	96.18% (1107/1151)	97.01% (1,069/1,102)

* Amended data for 2022-2023, 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.
- **Inadequate sample** means a sample with suboptimal quantity and/or quality of blood or the information on the blood spot card is not adequate for accurate analysis and requires a repeat sample collection.
- **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), 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.

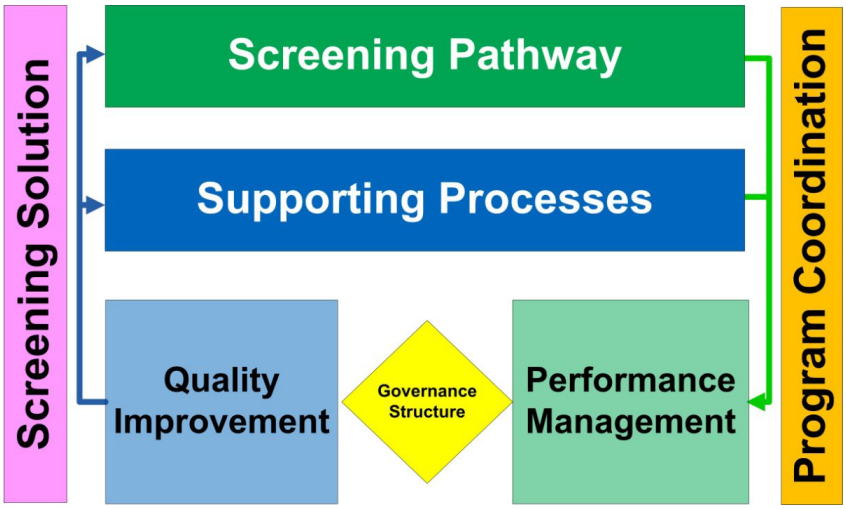


Figure 1. ANSP quality management framework

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 2023-2024* highlights ANSP performance between April 1, 2023 and March 31, 2024 for these measures. Data retrieved from the ANSP Application (reports and statistics) and Alberta Newborn Screening Laboratory statistics on May 13, 2024 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 2022-2023 reporting period are available in Appendix A. Amendments for the 2023-2024 reporting period will be available in the *Alberta Newborn Screening Program Report 2024-2025*.

Newborn screening in Alberta

Population screening

Alberta Newborn Screening Program:

2023-2024 population screening

Target population = 49,370
(infants born and registered as newborns in Alberta)

Participation rate = 99.09%
(48,923/49,370) of registered infants

Screen results reported by 10 days of age = 98.23%
(48,055/48,923) 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. Informing parents, health professionals and the public about the ANSP ensures that infants born in Alberta receive timely access to effective screening and have an initial screen reported within 10 days of age.

Participation rate and non-participation rationale [a]

In 2023-2024, 99.09% of registered infants received an initial blood spot screen (Figure 2a). Rationale for the 0.91% 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, 2023-2024

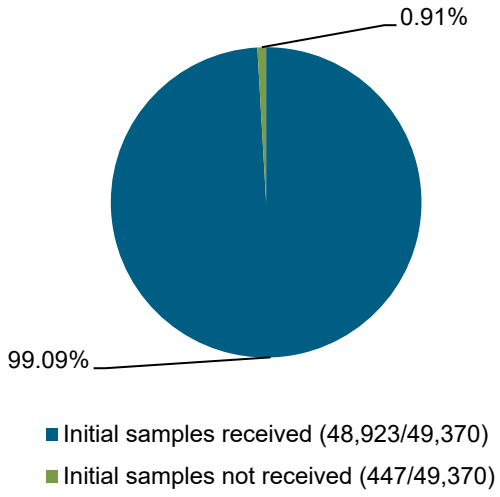
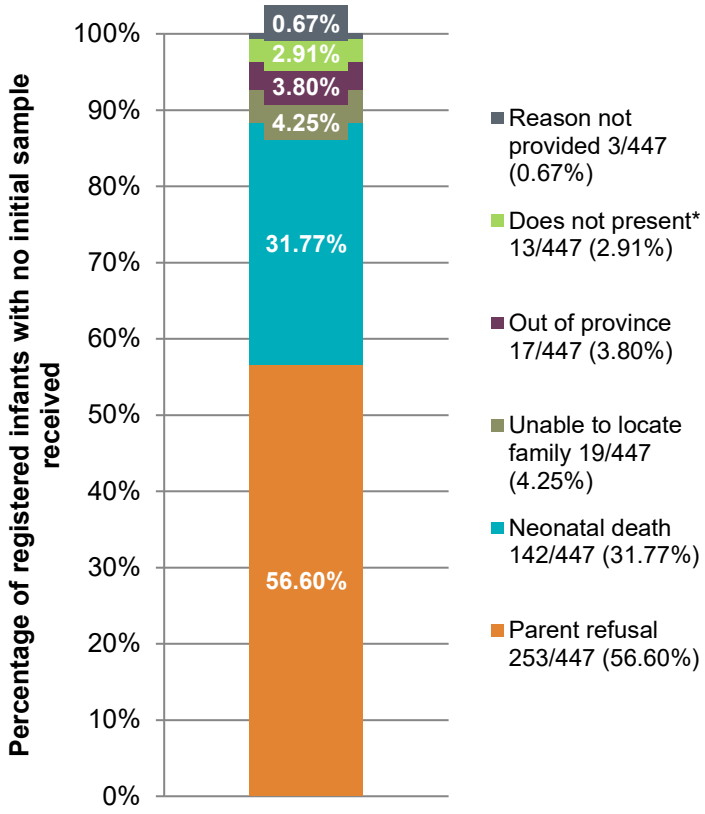
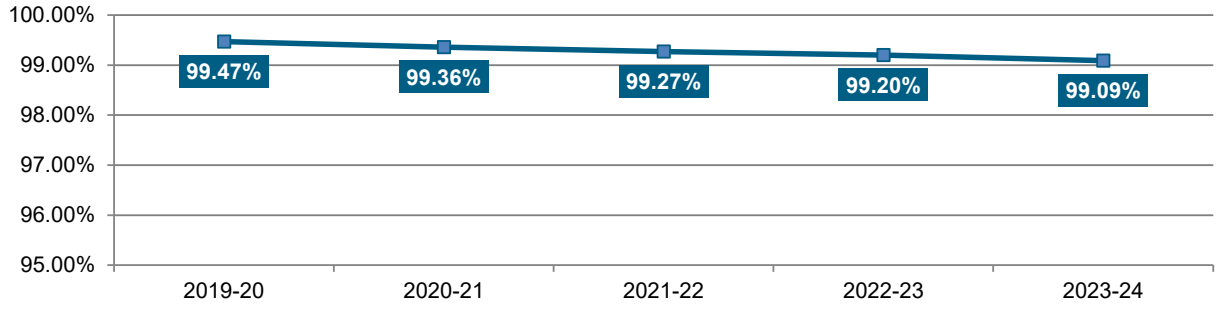


Figure 2b. Program non-participation rationale, provincial total, 2023-2024



*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 13, 2024 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.

Initial screen results reported [b]

In 2023-2024, 98.23% (48,055/48,923) of registered screened infants had an initial screen result reported by the Alberta Newborn Screening Laboratory within 10 days of age (excluding cystic fibrosis), 1.76% (863/48,923) did not meet the standard and 0.01% (5/48,923) were unable to determine. The range among the AHS Zones for meeting the standard is between 97.72% and 99.10% (Figure 3a) (AHS Zone not assigned is 93.92% 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, 2023-2024

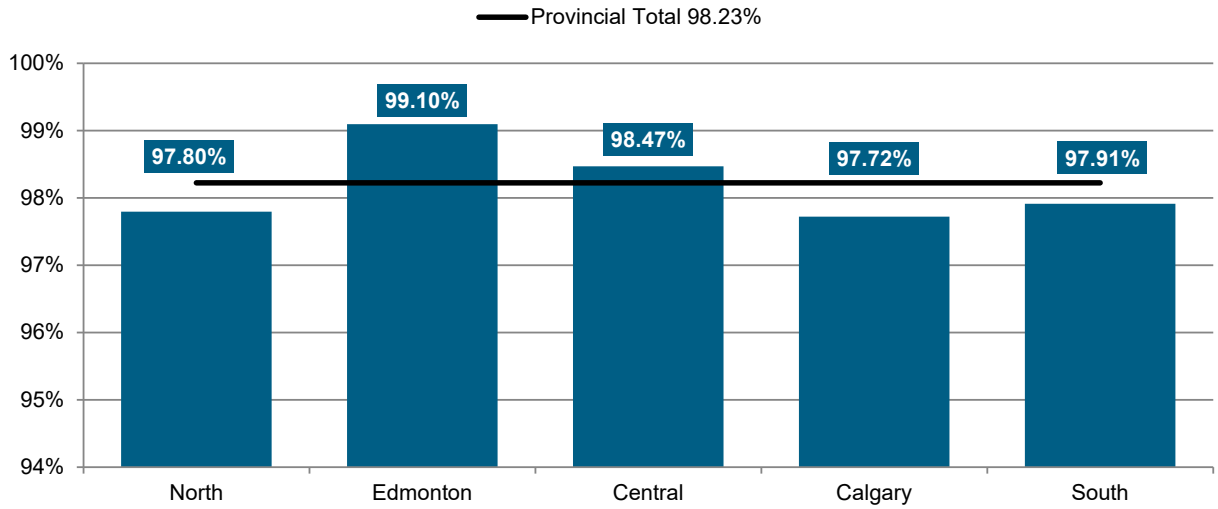
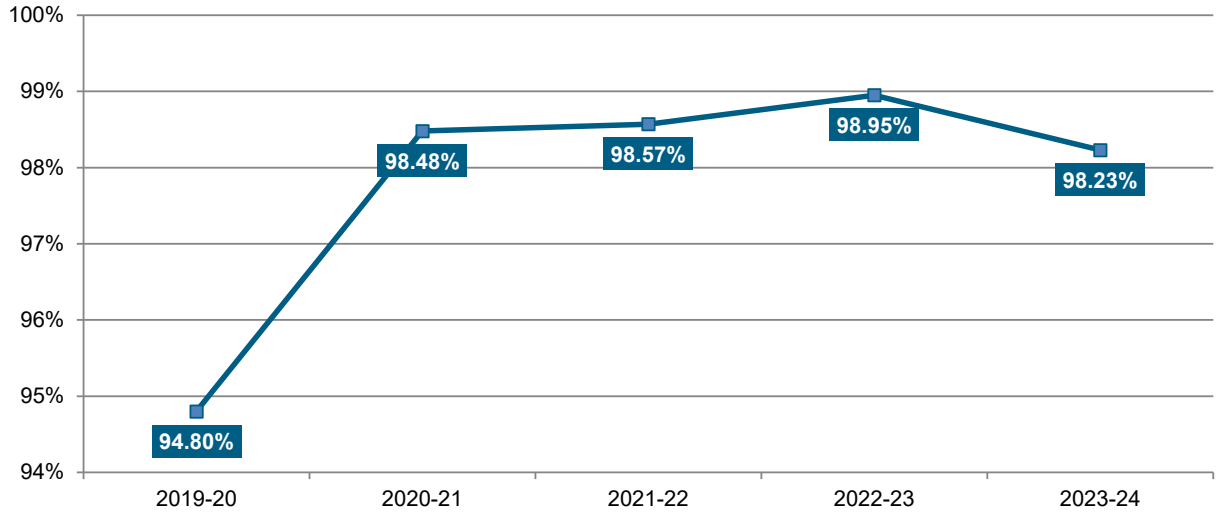


Figure 3b. Initial screen results reported meeting standard, 5-year provincial trend



[b] **Data retrieved May 13, 2024 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:

2023-2024 screen results and outcomes

Screened infants in the ANSP = 48,962

Infants with normal screen results = 99.38%

(48,657/48,962) of screened infants

Infants with abnormal screen results = 0.46%

(226/48,962) of screened infants

Infants with unknown screen results = 0.16%

(78/48,962) of screened infants

Infants with abnormal diagnostic outcomes = 72

(of 48,962 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)

Screen results and unknown screen results rationale [c]

In 2023-2024, 99.38% of screened infants received normal screen results; 0.46% received abnormal screen results (213 infants had an abnormal screen result for one condition, 1 infant had an abnormal screen result for more than one condition and 12 infants had a double borderline screen result); 0.16% were unknown (meaning an infant had no confirmed normal or abnormal screen result on record, see Figure 4b for rationale).

This year 477 infants were identified as being potential carriers of sickle cell trait.

Figure 4a. Infant screen results, provincial total, 2023-2024

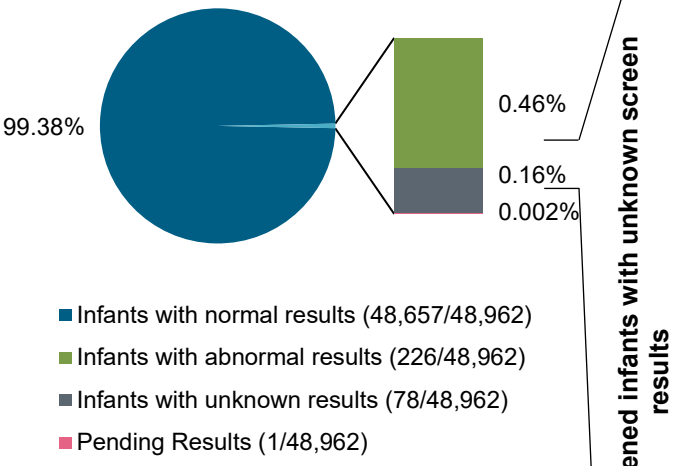
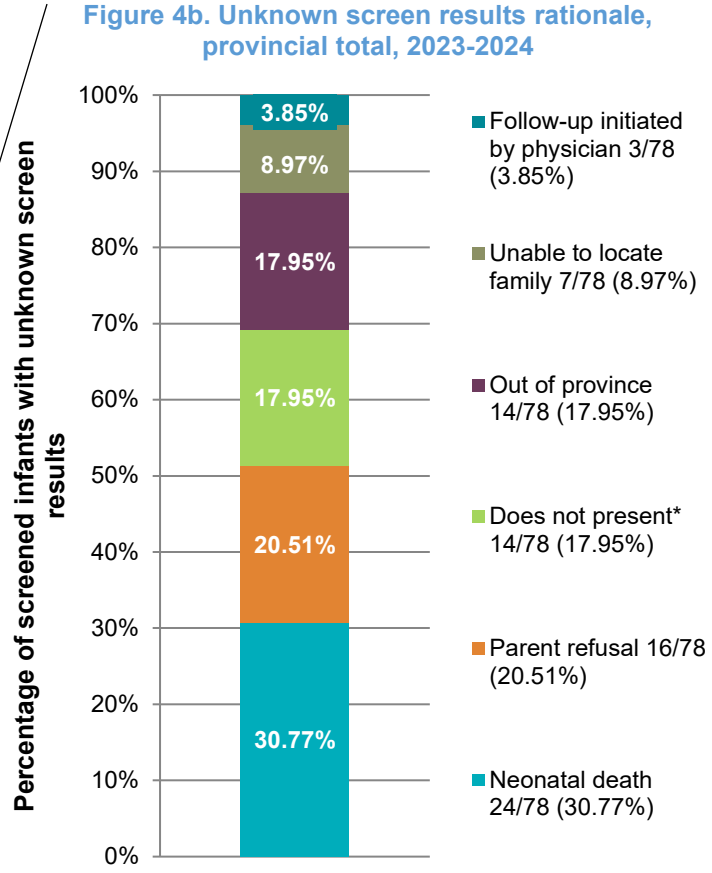


Figure 4b. Unknown screen results rationale, provincial total, 2023-2024



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

Of the 227 abnormal screen results reported:

- 14.10% (32/227) were for a metabolic condition
- 24.67% (56/227) were for an endocrine condition
- 40.53% (92/227) were for cystic fibrosis
- 4.85% (11/227) were for severe combined immunodeficiency
- 14.10% (32/227) were for sickle cell disease
- 1.76% (4/227) were for spinal muscular atrophy

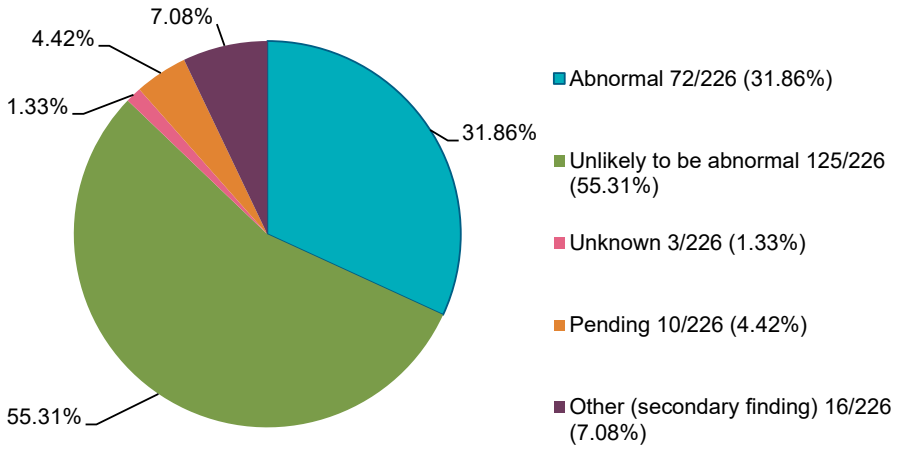
[c] **Data retrieved May 13, 2024 from ANSP Application Reports 5, 6, 7 and 11, ANSP Application statistics and Alberta Newborn Screening Laboratory statistics. Data are for all screened infants.** For comparison, previous years' data and ANSP annual reports can be requested through newbornscreening@ahs.ca.

Diagnostic outcomes [d]

In 2023-2024, 31.86% of infants with abnormal screen results received abnormal diagnostic outcomes (after referral for clinical assessment and diagnostic testing) for one of the screened conditions; 55.31% received unlikely to be abnormal diagnostic outcomes; 1.33% received unknown diagnostic outcomes (meaning infant died prior to diagnostic testing, unable to locate infant, or parent refusal of diagnostic testing); and 4.42% 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 226 infants with abnormal screen results referred for diagnostic testing, 16 (7.08%) 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, 2023-2024



There were 227 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=32	Endocrine conditions, n=56	CF, n=92	SCID, n=11	SCD, n=32	SMA, n=4	Total, n=227
Abnormal	31.25% (10/32)	51.79% (29/56)	9.78% (9/92)	18.18% (2/11)	59.38% (19/32)	75.00% (3/4)	31.72% (72/227)
Unlikely to be abnormal	56.25% (18/32)	44.64% (25/56)	79.35% (73/92)	54.55% (6/11)	12.50% (4/32)	0.00% (0/4)	55.51% (126/227)
Unclear	0.00% (0/32)	0.00% (0/56)	0.00% (0/92)	0.00% (0/11)	0.00% (0/32)	0.00% (0/4)	0.00% (0/227)
Unknown	0.00% (0/32)	0.00% (0/56)	3.26% (3/92)	0.00% (0/11)	0.00% (0/32)	0.00% (0/4)	1.32% (3/227)
Pending	3.13% (1/32)	0.00% (0/56)	7.61% (7/92)	9.09% (1/11)	3.13% (1/32)	0.00% (0/6)	4.41% (10/227)
Other (secondary finding)	9.38% (3/32)	3.57% (2/56)	0.00% (0/92)	18.18% (2/11)	25.00% (8/32)	25.00% (1/4)	7.05% (16/227)

[d] **Data retrieved May 13, 2024 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, 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.

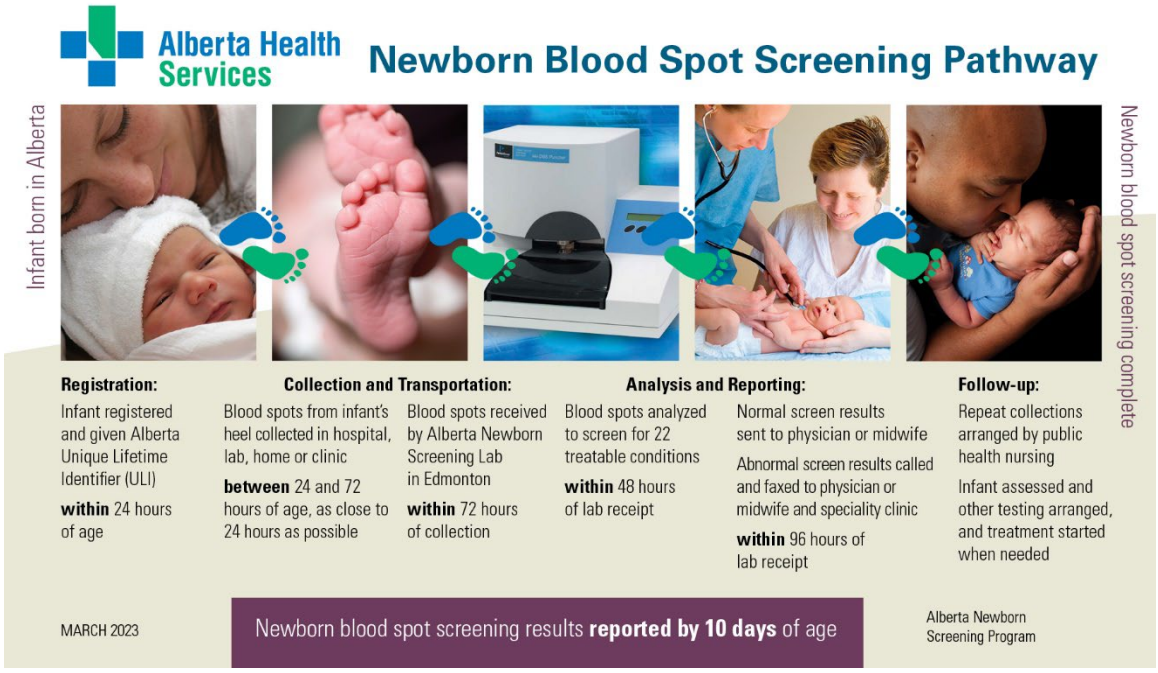


Figure 6. Newborn blood spot screening pathway

Registration

Newborn blood spot screening pathway:

2023-2024 registration

Registration by 24 hours = 98.61%

(48,683/49,370) 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.

Birth registration [e]

In 2023-2024, 98.61% (48,683/49,370) of infants born in Alberta were registered in PD within 24 hours of birth, 0.10% (49/49,370) did not meet the standard and 1.29% (638/49,370) were unable to determine. The range among the AHS Zones for meeting the standard is between 98.17% and 98.89% (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, 2023-2024

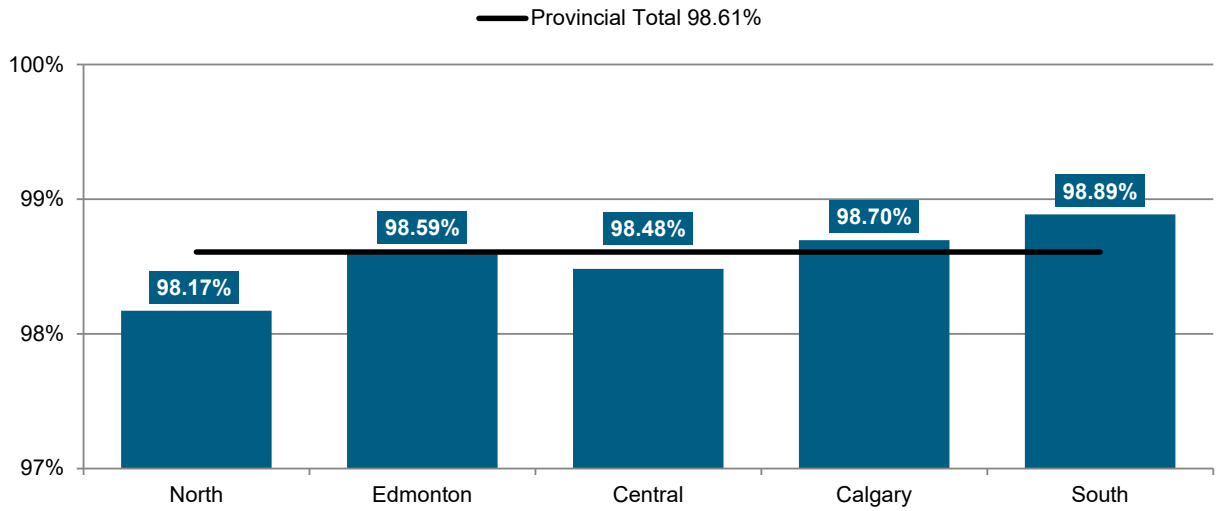
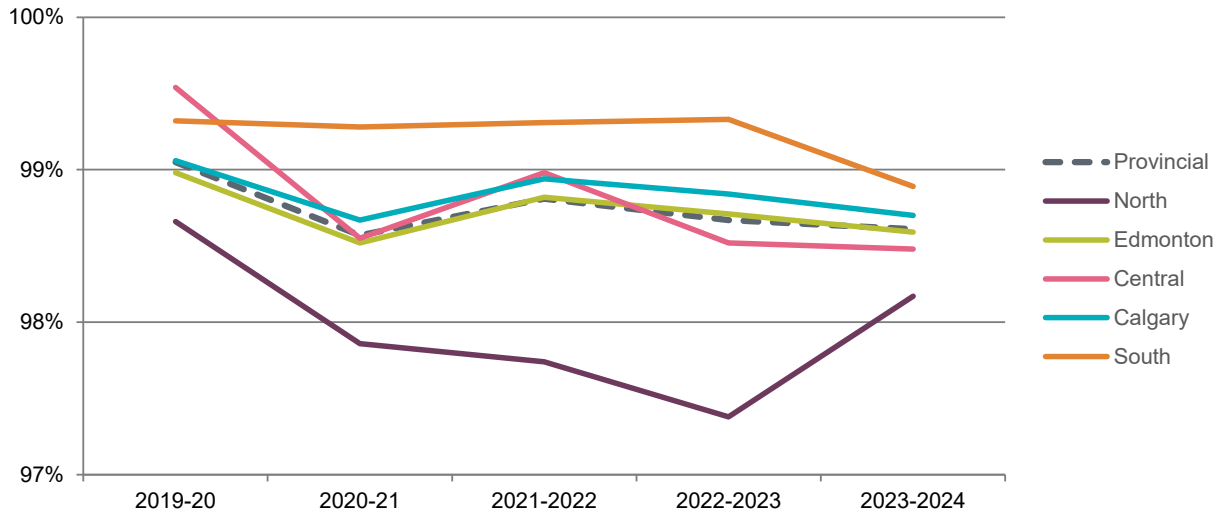


Figure 7b. Birth registration meeting standard, 5-year provincial trend



[e] **Data retrieved May 13, 2024 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:

2023-2024 collection & transportation

Initial collection between 24 and 72 hours = 98.08%

(47,986/48,923) of registered screened infants

Samples received within 72 hours of collection = 96.42%

(49,660/51,506) of received samples

Inadequate samples = 1.60%

(822/51,506) 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

Initial collection [f]

In 2023-2024, 98.08% (47,986/48,923) of registered screened infants had an initial sample collected between 24 and 72 hours of age, 1.74% (853/48,923) did not meet the standard and 0.17% (84/48,923) were unable to determine. The range among the AHS Zones for meeting the standard is between 95.19% and 98.63% (Figure 8a) (AHS Zone not assigned is 93.55% 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, with North Zone showing consistent improvement due to targeted staff education and quality improvement tools provided by the ANSP (Figure 8b).

Figure 8a. Initial sample collection meeting standard, zone totals, 2023-2024

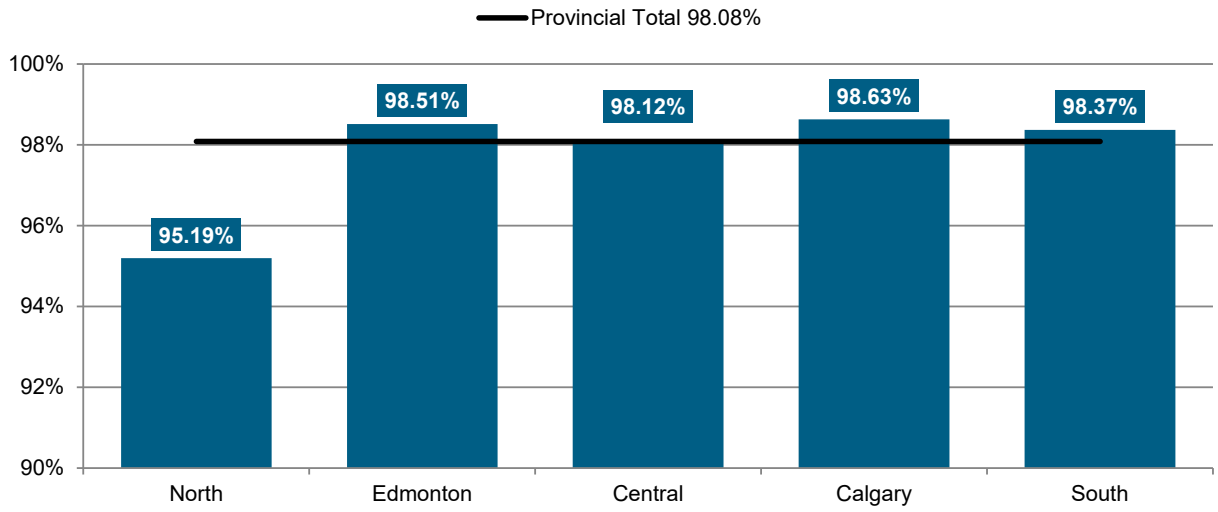
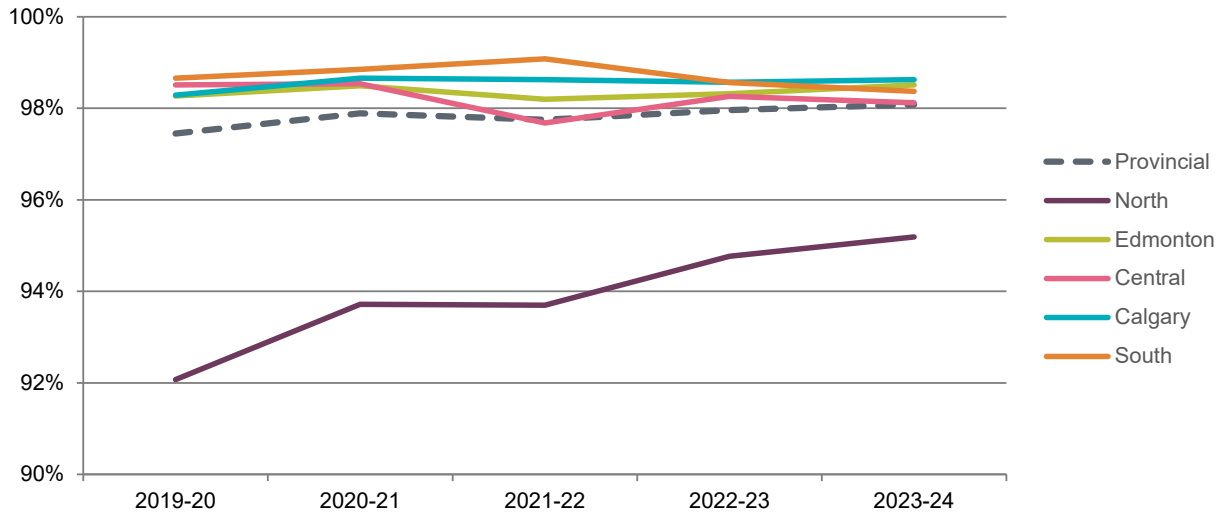


Figure 8b. Initial sample collection meeting standard, 5-year zone trends



[f] **Data retrieved May 13, 2024 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.

Sample receipt [g]

In 2023-2024, 96.42% (49,660/51,506) of samples were received by the Alberta Newborn Screening Laboratory within 72 hours of collection and 3.58% (1,846/51,506) did not meet the standard. The range among the AHS Zones for meeting the standard is between 90.64% and 99.10% (Figure 9a) (AHS Zone not assigned is 94.57% 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 continuing to work collaboratively with South Zone partners to support sustained improvement in this measure (Figure 9b).

Figure 9a. Sample receipt by Alberta Newborn Screening Laboratory meeting standard, zone totals, 2023-2024

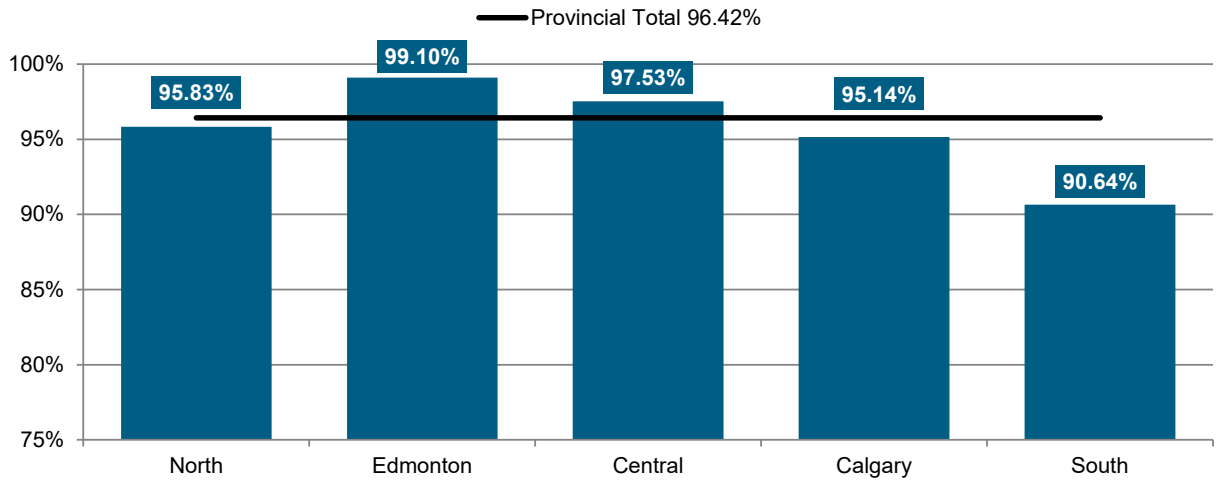
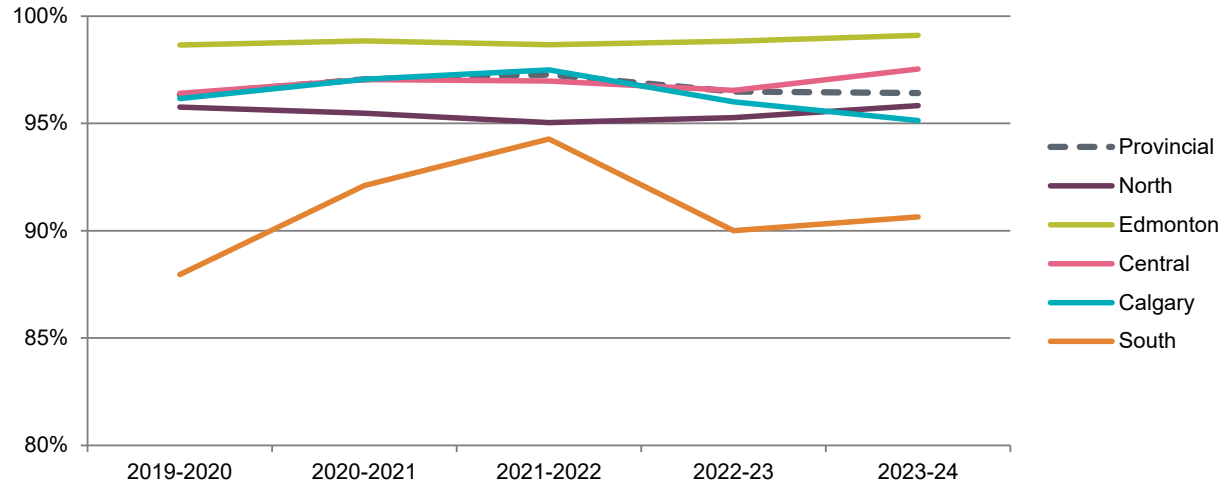


Figure 9b. Sample receipt by Alberta Newborn Screening Laboratory meeting standard, 5-year zone trends



[g] **Data retrieved May 13, 2024 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.

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 2023-2024, 1.60% (822/51,506) 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 2.95% and 1.15% (Figure 10a) (AHS Zone not assigned is 15.85% for meeting the standard). The data table for inadequate samples received by zone can be found in Appendix B. 1.60% 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, 2023-2024

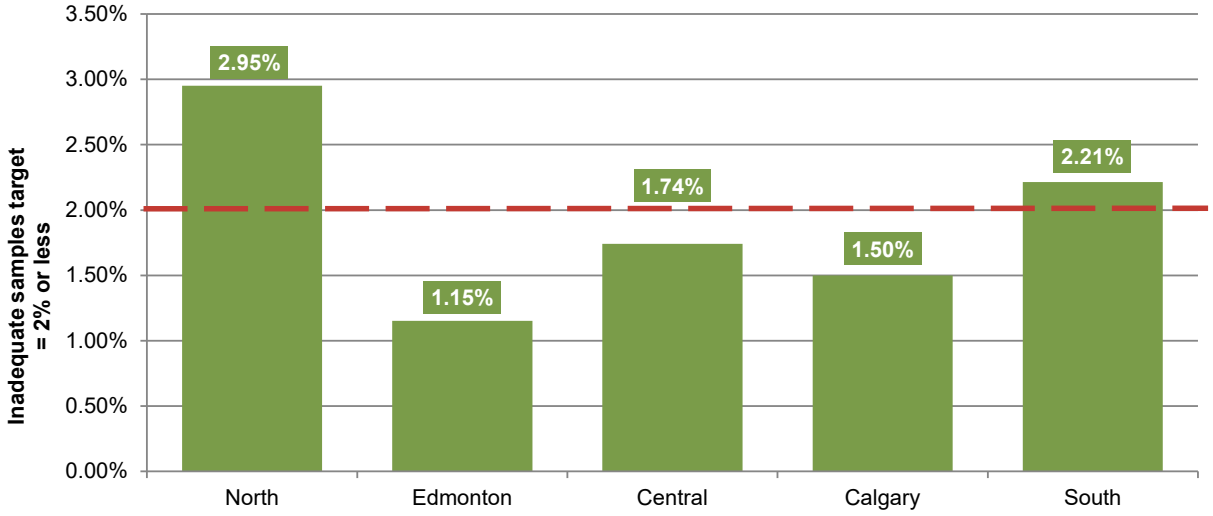
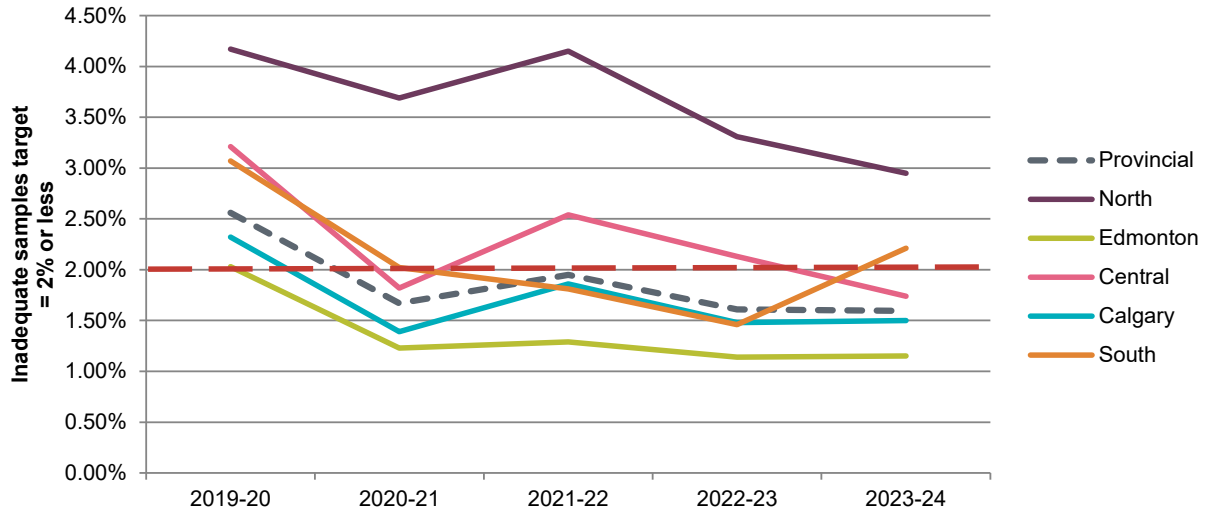


Figure 10b. Inadequate samples, 5-year zone trends



[h] **Data retrieved May 13, 2024 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:

2023-2024 analysis & reporting

Analysis and reporting within 96 hours of Lab receipt = 74.58%

(38,414/51,506) 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 enters data from samples, performs sample analyses including determining sample quality, and reports screen results to the ANSP Application, Netcare, ordering physicians, providers and birth facilities
- Molecular Genetics Laboratory within APL who performs screening for CF, SCID and SMA and reports screen results to the Alberta Newborn Screening Laboratory

Results reported [i]

In 2023-2024, 74.58% 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 procurement of new instruments.

Figure 11a. Screen results reported, provincial total, 2023-2024

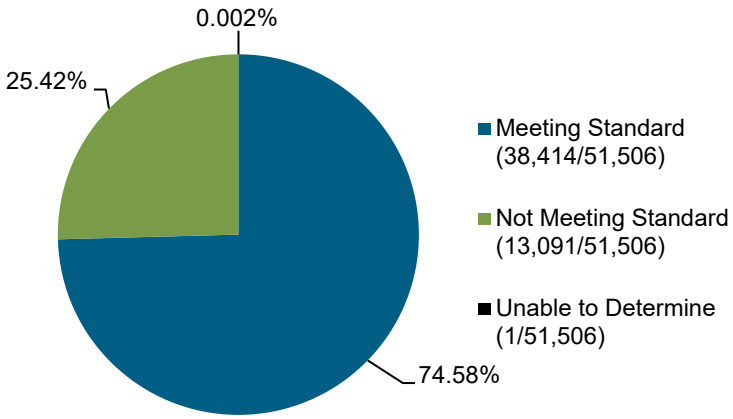
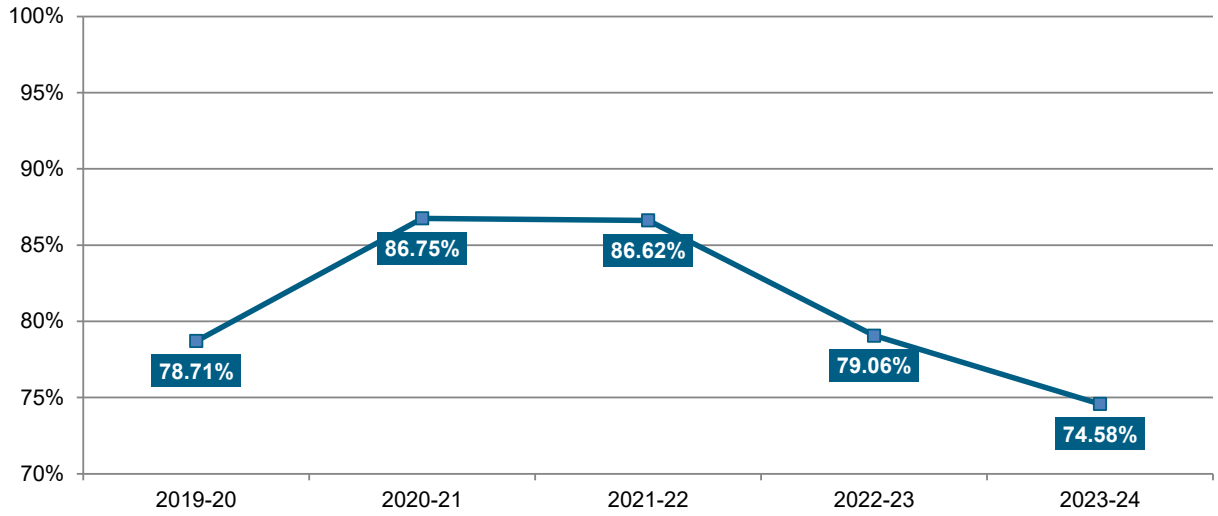


Figure 11b. Screen results reported, meeting standard, 5-year provincial trend



[i] **Data retrieved May 13, 2024 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:

2023-2024 follow-up

Repeat collection within 96 hours of notification of inadequate samples = 81.83%

(635/776) of repeat samples

Repeat collection within 96 hours of notification of reported borderline results = 87.67%

(327/373) of repeat samples

Repeat collection for low birth weight infants between 21 and 28 days = 96.18%

(1,107/1,186) 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 confirms and corrects infant demographics as required, notifies physicians, midwives and specialty clinics of abnormal screen results, provides consultations, tracks and monitors the completion of follow-up for abnormal screen results and flagged registrations, and monitors 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 2023-2024, 81.83% (635/776) of repeat samples were collected within the required time frame and 18.17% (141/776) did not meet the standard. The range among the AHS Zones for meeting the standard is between 62.50% and 88.71% (Figure 12a) (AHS Zone not assigned is 52.00% 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. Zone performance in this measure is highly impacted by the number and timing of follow-up notifications, as seen with the data presented for the South Zone, and is not reflective of program or partner performance.

Figure 12a. Repeat sample collection for inadequate samples meeting standard, zone totals, 2023-2024

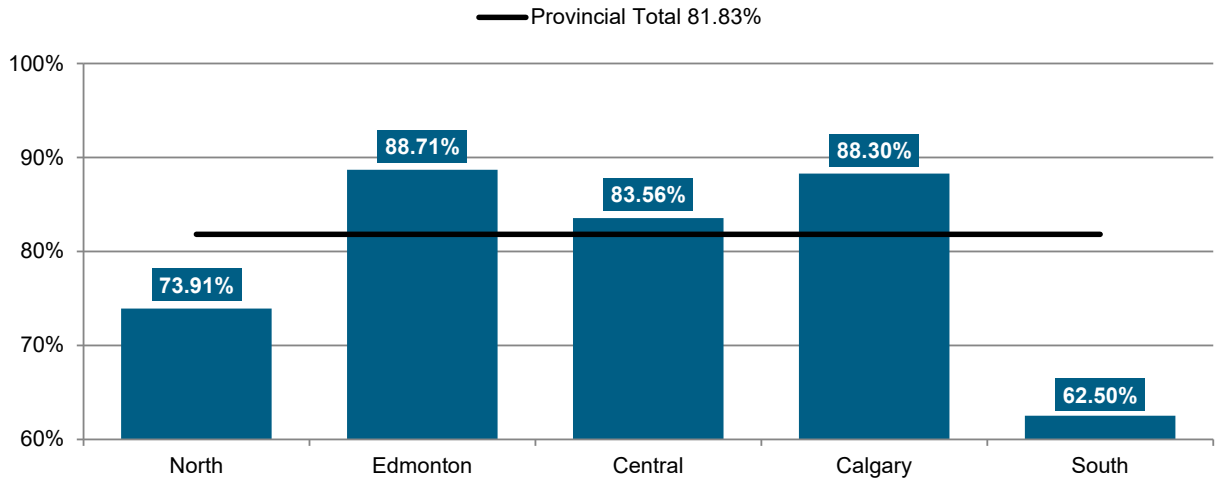
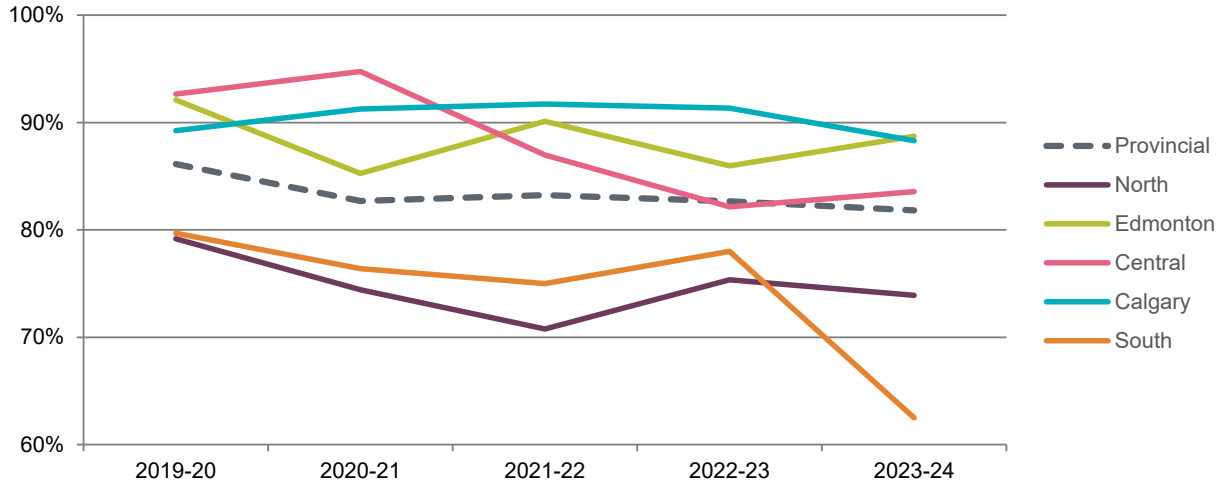


Figure 12b. Repeat sample collection for inadequate samples meeting standard, 5-year zone trends



[j] **Data retrieved May 13, 2024 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 2023-2024, 87.67% (327/373) of repeat samples were collected within the required time frame and 12.33% (46/373) did not meet the standard. The range among the AHS Zones for meeting the standard is between 65.22% and 92.86% (Figure 13a) (AHS Zone not assigned is 60.00% 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. Zone performance in this measure is highly impacted by the number and timing of follow-up notifications, as seen with the data presented for the South Zone, and is not reflective of program or partner performance.

Figure 13a. Repeat sample collection for borderline screen results meeting standard, zone totals, 2023-2024

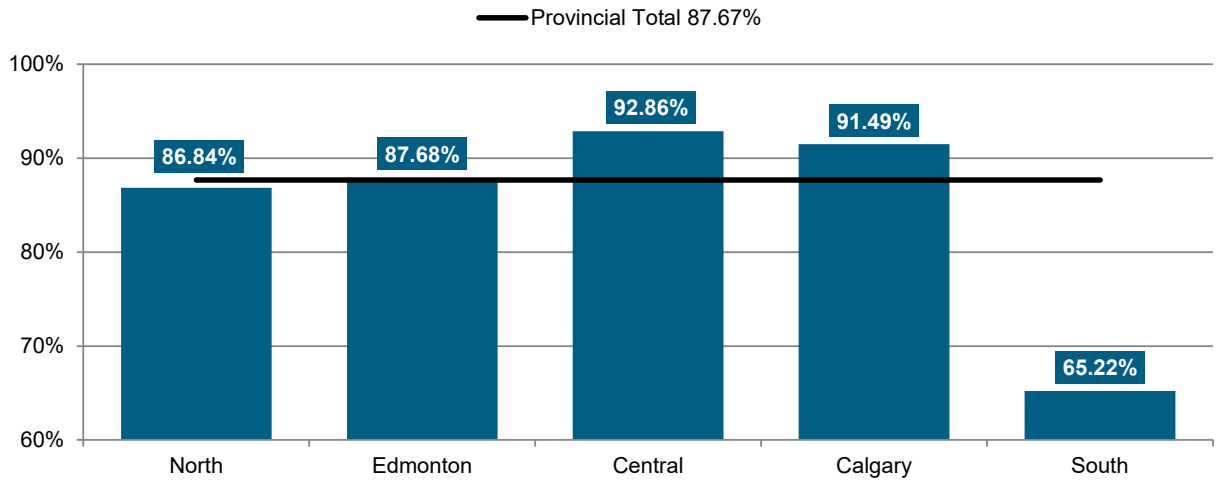
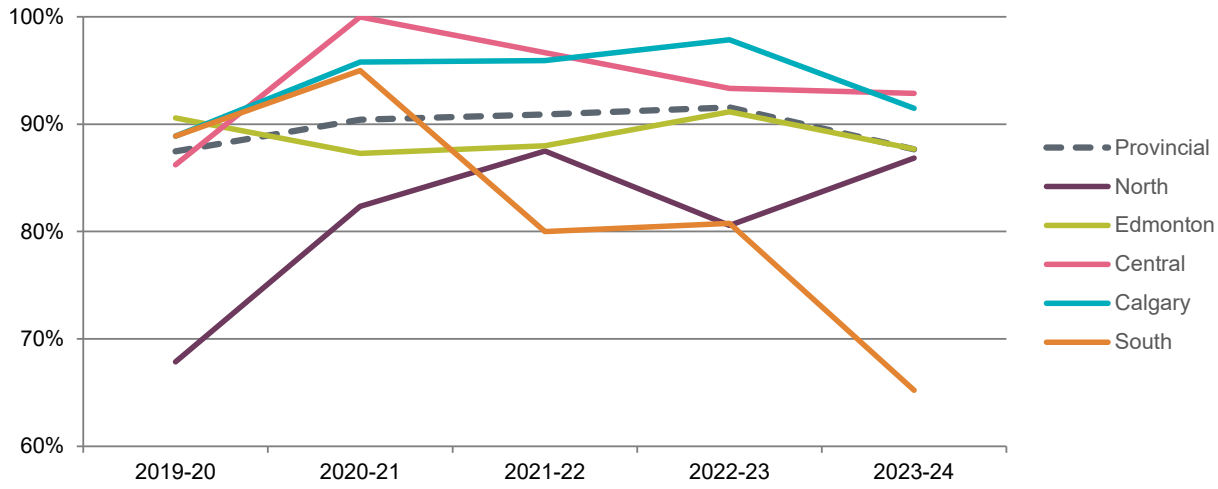


Figure 13b. Repeat sample collection for borderline screen results meeting standard, 5-year zone trends



[k] **Data retrieved May 13, 2024 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 [I]

In 2023-2024, 1,186 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. 2.95% (35/1,186) 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 1,151 low birth weight infants who had a repeat sample collected, 96.18% (1,107/1,151) were collected during the required time frame and 3.82% (44/1,151) did not meet the standard. The range among the AHS Zones for meeting the standard is between 87.13% and 98.96% (Figure 14a) (AHS Zone not assigned is 82.14% 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.

Figure 14a. Repeat sample collection for low birth weight infants meeting standard, zone totals, 2023-2024

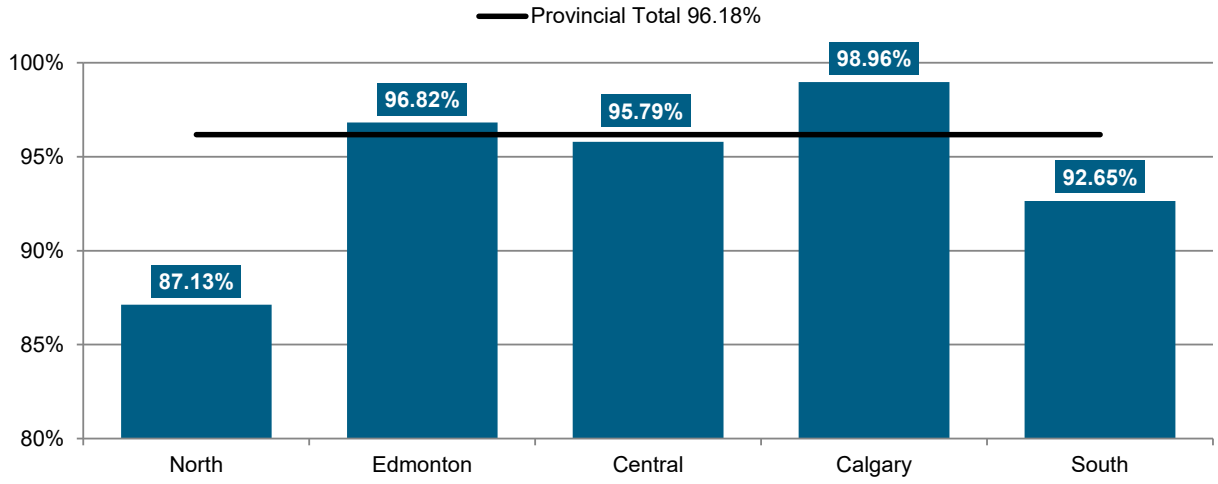
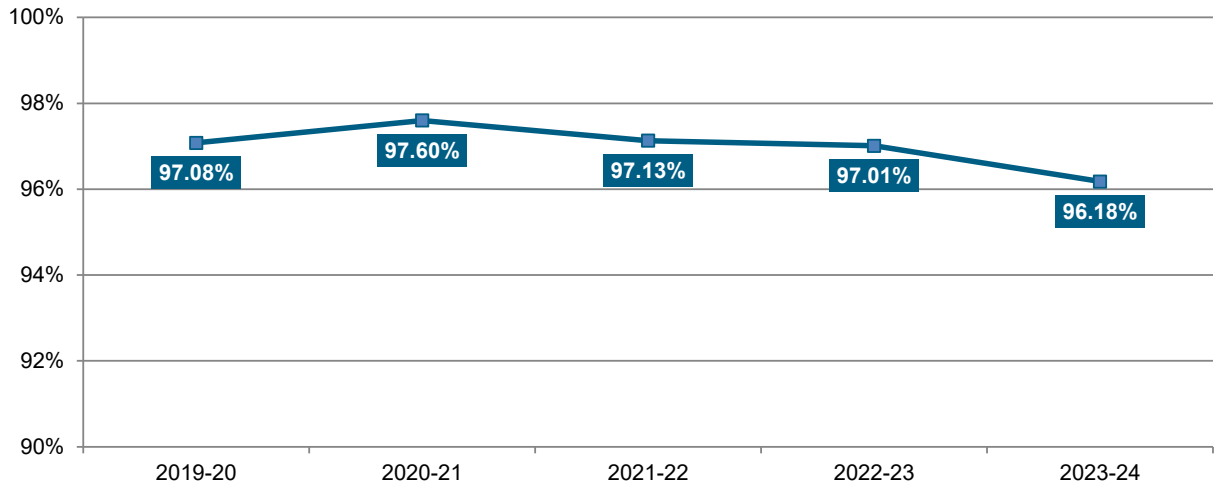


Figure 14b. Repeat sample collection for low birth weight infants meeting standard, 5-year provincial trend



[I] **Data retrieved May 13, 2024 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 2023-2024* was to highlight ANSP performance between April 1, 2023 and March 31, 2024. 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 will continue to monitor and evaluate data and collaborate with partners to support improving performance.

The North Zone is showing consistent improvements in initial sample collection due to collaborative efforts between the program and the zone.

The ANSP systems and processes have continued to support ongoing provincial coordination activities in 2023-2024 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., Amderson E.T., & McFarlene 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 2022-2023 AHS Provincial NMS Program Report [m]

Screen results and unknown screen results rationale

There is no amendment for 2022-2023 screen results and unknown screen results rationale as there were no pending screen results reported.

Diagnostic outcomes

There were 283 abnormal screen results reported, of which1 infant was referred for diagnostic testing for more than one condition and received more than one diagnostic outcome.

Diagnostic outcomes by category		Metabolic conditions, n=38	Endocrine conditions, n=50	Cystic fibrosis, n=140	Severe combined immunodeficiency, n=19	Sickle cell disease, n=30	Spinal muscular atrophy, n=6	Total, n=283
Abnormal	*Prevoiously reported*	*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)*
	Amended	**34.21% (13/38)**	**64.00% (32/50)**	**10.71% (15/140)**	**10.53% (2/19)**	**50.00% (15/30)**	**83.33% (5/6)**	**28.98% (82/283)**
Unlikely to be abnormal	*Prevoiously reported*	*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)*
	Amended	**60.53% (23/38)**	**32.00% (16/50)**	**80.71% (113/140)**	**73.68% (14/19)**	**16.67% (5/30)**	**16.67% (1/6)**	**60.78% (172/283)**
Unclear	*Prevoiously reported*	*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)*
	Amended	**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	*Prevoiously reported*	*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)*
	Amended	**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	*Prevoiously reported*	*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)*
	Amended	**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)**
Other (secondary finding)	*Prevoiously reported*	*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)*
	Amended	**2.63% (1/38)**	**0.00% (0/50)**	**2.86% (4/140)**	**5.26% (1/19)**	**30.00% (9/30)**	**0.00% (0/6)**	**5.30% (15/283)**

[m] **Amended data retrieved May 13, 2024 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.

Appendix B

2023-2024 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	5413	16134	4253	18318	3427	510	48055
Not meeting standard	121	147	66	426	73	30	863
Unable to determine	1	0	0	1	0	3	5
Grand total	**5535**	**16281**	**4319**	**18745**	**3500**	**543**	**48923**

Birth registration in PD within 24 hours of birth

	North	Edmonton	Central	Calgary	South	AHS Zone n/a*	Provincial total
Meeting standard	4297	17909	3570	19529	3378	0	48683
Not meeting standard	14	3	14	16	2	0	49
Unable to determine	66	253	41	242	36	0	638
Grand total	**4377**	**18165**	**3625**	**19787**	**3416**	**0**	**49370**

Initial sample collected between 24 and 72 hours of age

	North	Edmonton	Central	Calgary	South	AHS Zone n/a*	Provincial total
Meeting standard	5269	16039	4238	18489	3443	508	47986
Not meeting standard	250	224	71	230	49	29	853
Unable to determine	16	18	10	26	8	6	84
Grand total	**5535**	**16281**	**4319**	**18745**	**3500**	**543**	**48923**

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	5608	16916	4421	18773	3332	610	49660
Not meeting standard	244	153	112	958	344	35	1846
Unable to determine	0	0	0	0	0	0	0
Grand total	**5852**	**17069**	**4533**	**19731**	**3676**	**645**	**51506**

Inadequate samples

	North	Edmonton	Central	Calgary	South	AHS Zone n/a*	Provincial total
Total inadequate samples	140	219	67	304	79	13	822
Total adequate samples	4604	18780	3782	19958	3491	68	50683
Total pending samples	0	0	0	0	0	1	1
Grand total	**4744**	**18999**	**3849**	**20262**	**3570**	**82**	**51506**

Repeat sample collection for inadequate samples within 96 hours of notification

	North	Edmonton	Central	Calgary	South	AHS Zone n/a*	Provincial total
Meeting standard	102	165	61	249	45	13	635
Not meeting standard	36	21	12	33	27	12	141
Grand total	**138**	**186**	**73**	**282**	**72**	**25**	**776**

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	33	121	26	129	15	3	327
Not meeting standard	5	17	2	12	8	2	46
Grand total	**38**	**138**	**28**	**141**	**23**	**5**	**373**

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	88	365	91	477	63	23	1107
Not meeting standard	13	12	4	5	5	5	44
Repeat sample not collected	2	12	4	15	1	1	35
Grand total	**103**	**389**	**99**	**497**	**69**	**29**	**1186**

[n] **Data retrieved May 13, 2024 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 2023-2024

- 39 infants who were born out of province were screened in Alberta (had a sample collected by the ANSP).
- 16 preterm infants (born less than 37 weeks gestational age) required repeat sample collection to support the detection of SCID and SCD.
- 31 infants who were part of a multiple birth set had a repeat sample collected.

Additional findings in 2023-2024

- 39 infants had screen results suggestive of glucose-6-phosphate dehydrogenase (G6PD) deficiency.
    - 34 infants received an abnormal diagnostic outcome for G6PD
    - 2 infants received an unlikely to be abnormal diagnostic outcome and do not have G6PD
    - 1 infant was lost to follow-up
    - 2 infants had a pending diagnostic outcome at the time of reporting