Alberta Health Services
Newborn Metabolic Screening

AHS Provincial Newborn Metabolic Screening Program Report 2017-2018

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Prepared by

Screening Programs

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Table of contents

Executive summary

The purpose of the *AHS Provincial Newborn Metabolic Screening Program Report 2017-2018* is to highlight Newborn Metabolic Screening (NMS) Program performance between April 1, 2017 and March 31, 2018. The report provides an overview of NMS Program service delivery along the newborn blood spot screening pathway and illustrates the NMS Program key performance measures.

Alberta's NMS Program is a population-based screening program delivered by AHS in partnership with Alberta Health, Health Canada - First Nations and Inuit Health Branch (FNIHB) Alberta Region, physicians and midwives, and parents and guardians. The NMS program screens for 17 treatable conditions (14 metabolic, 2 endocrine and cystic fibrosis [CF]) to identify and treat infants with a treatable condition as early as possible. Without timely screening and intervention, infants with treatable conditions could experience significant and potentially irreversible health complications including intellectual development delays, nervous system damage, physical disabilities and death. Early detection and treatment of screened conditions can make the difference between healthy development and lifelong impairment.

By informing parents and guardians, health professionals and the public, the NMS Program can ensure that all infants born in Alberta receive timely access to effective newborn blood spot screening and have an initial screen reported within 10 days of age.

Delivery of screening services within the NMS Program occurs along the following four interconnected steps of the newborn blood spot screening pathway (Figure 2). Time standards for each step were determined by Alberta Health (1).

- **Registration** of the infant in Person Directory (PD) and assignment of a Unique Lifetime Identifier (ULI) occurs within 24 hours of age.
- **Collection** of the infant's blood spot sample in hospital, community laboratory, home or clinic occurs between 24 and 72 hours of age and as close after 24 hours of age as reasonably possible, and **transportation** of the sample to the NMS Laboratory (NMS Lab) at the University of Alberta Hospital (UAH) occurs within 72 hours of collection.
- **Analysis** of the sample at the NMS Lab and the Molecular Diagnostic Laboratory (MD Lab) and **reporting** of the screen results occurs within 96 hours of NMS Lab receipt (21 days for CF analysis).
- **Follow-up** in a timely manner is coordinated to ensure an initial sample is collected from all infants born in Alberta, a repeat sample is collected when required, referrals for clinical assessment and diagnostic testing are completed when required, and diagnostic outcomes are received.

This year's report includes data from previous years as a comparator to visualize the improvement 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.

NMS Program performance measures

Data for the NMS Program performance measures were retrieved from NMS Application reports and NMS Lab statistics. Data were excluded for all samples analyzed and reported by the NMS Lab for infants born outside of Alberta and whose samples were collected outside of Alberta.

Summary of NMS Program key performance measures, 2017-2018

Performance	2017-2018 data	2016-2017 data
Registered infants who received an initial blood spot screen	99.40% (52,898/53,215)	99.46% (54,891/55,190)
Registered infants who did not receive an initial blood spot screen	0.60% (317/53,215) 59.62% of infants not screened were due to neonatal death (189/317)	0.54% (299/55,190) 57.19% of infants not screened were due to neonatal death (171/299)
Registered screened infants who had a screen result reported within 10 days of age	99.15% (52,449/52,898)	99.22% (54,465/54,891)
Screened infants who received normal screen results	99.41% (52,646/52,958)	99.36% (54,608/54,960)
Screened infants who received abnormal screen results requiring clinical follow-up	0.44% (231/52,958) (200 critical results and 31 double borderline results)	0.49% (271/54,960) (250 critical results and 21 double borderline results)
Screened infants who received unknown screen results	0.15% (79/52,958)	0.15% (80/54,960)
Infants with abnormal screen result who received abnormal diagnostic outcomes	30.30% (70/231)	27.31% (74/271)
Infants born in Alberta who were registered in PD within 24 hours of birth	98.71% (52,529/53,215)	98.95% (54,608/55,190)
Registered screened infants who had an initial blood spot sample collected between 24 and 72 hours of age	97.07% (51,349/52,898)	97.30% (53,409/54,891)
Samples received by the NMS Lab within 72 hours of collection	94.90% (53,304/56,168)	94.96% (55,226/58,158)
Samples received by the NMS Lab that were determined to be inadequate	2.03% (1,139/56,168)	1.94% (1,129/58,158)
Samples received that had screen results reported within 96 hours of NMS Lab receipt	95.78% (53,795/56,168)	95.50% (55,538/58,158)
Repeat samples collected within 96 hours of notification of reported inadequate results	82.29% (878/1,067)	81.16% (853/1,051)
Repeat samples collected within 96 hours of notification of reported borderline results	89.33% (561/628)	89.24% (531/595)

Definitions

- **AHS zone not assigned** means infants not assigned within the NMS 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 Health Canada - First Nations and Inuit Health Branch [FNIHB] Alberta Region). 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 of intermediate risk for a screened disorder that requires follow-up through repeat sample collection to classify as normal or abnormal.
- **Double borderline screen result** means a second borderline result is obtained for the same condition and is therefore treated as an abnormal result.
- **Received samples** means newborn blood spot samples received by the NMS Laboratory (NMS Lab) and reported to the NMS 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 Alberta's NMS Program during the reporting period.
- **Screened infants** means all infants that received an initial newborn blood spot screen within Alberta's NMS Program 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.
- **Zone of birth** means the AHS zone mapped within the NMS 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 NMS Application to the infant's PD mailing address postal code.
- **Zone of responsibility** means the AHS zone within the NMS 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's NMS Program

Alberta's Newborn Metabolic Screening (NMS) Program is a population-based screening program delivered by Alberta Health Services (AHS) in partnership with Alberta Health, FNIHB, physicians and midwives, and parents and guardians.

Early screening helps find conditions that can be treated early, when treatment can help infants the most. Without timely screening and intervention, infants with treatable conditions could experience significant and potentially irreversible health complications including intellectual development delays, nervous system damage, physical disabilities and death. Early detection and treatment of screened conditions can make the difference between healthy development and lifelong impairment.

NMS Program approach

The NMS Program uses a health promotion process that combines aspects of the Public Health Agency of Canada Population Health Promotion model (2) with a Community as Partner process cycle (3) to operate. The program integrates this approach with a quality management methodology to achieve continuous improvement in service quality. The NMS Program quality management framework (QMF) includes the processes and structures necessary to manage population-based screening program quality in Alberta.

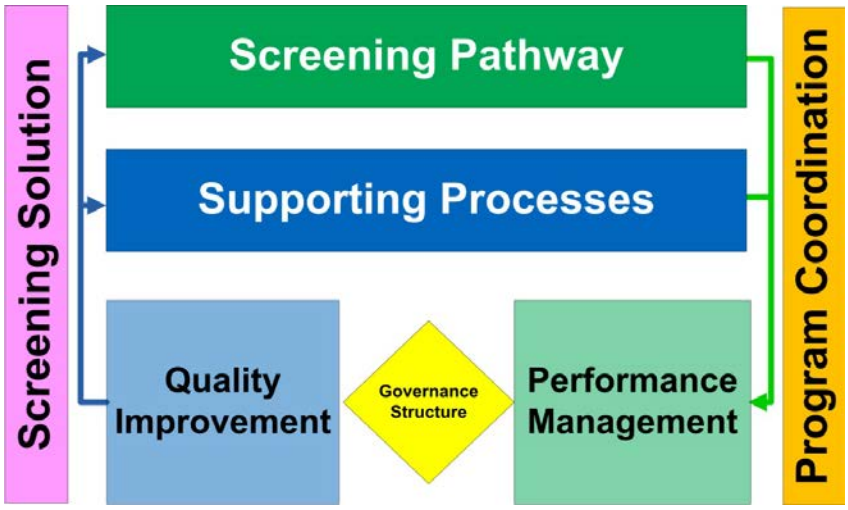


Figure 1. NMS Program quality management framework

NMS Program performance measures

Scope

The performance measures reported here were set by Alberta Health in the *Alberta Newborn Metabolic Screening Program Policy Document, March 2010* (1).

The *AHS Provincial Newborn Metabolic Screening Program Report 2017-2018* highlights NMS Program performance between April 1, 2017 and March 31, 2018 for these measures. Data retrieved from the NMS Application (reports and statistics) and NMS Lab statistics on May 14, 2018 are presented in the remainder of the report. Data were excluded for all samples analyzed and reported by the NMS Lab for infants born outside of Alberta and whose samples were collected outside of Alberta.

The NMS Program 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

Amended screen results and diagnostic outcomes from the 2016-2017 reporting period are available in Appendix A. Amendments for the 2017-2018 reporting period will be available in the 2018-2019 NMS Program annual report.

Newborn metabolic screening in Alberta

Population screening

Alberta's NMS Program: 2017-2018 population screening

Target population = 53,215
(infants born and registered as newborns in Alberta)

Participation rate = 99.40%
(52,898/53,215) of registered infants

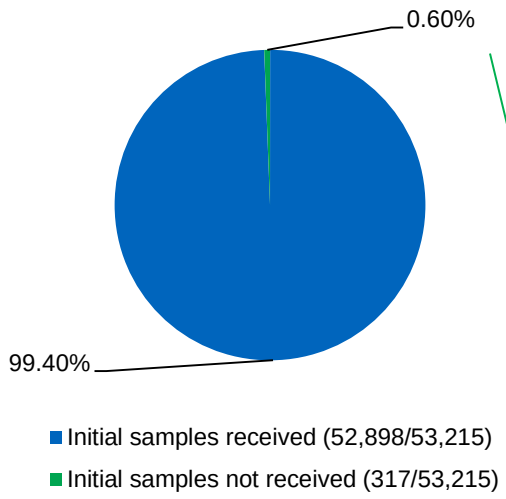
Screen results reported by 10 days of age = 99.15%
(52,449/52,898) of registered screened infants

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

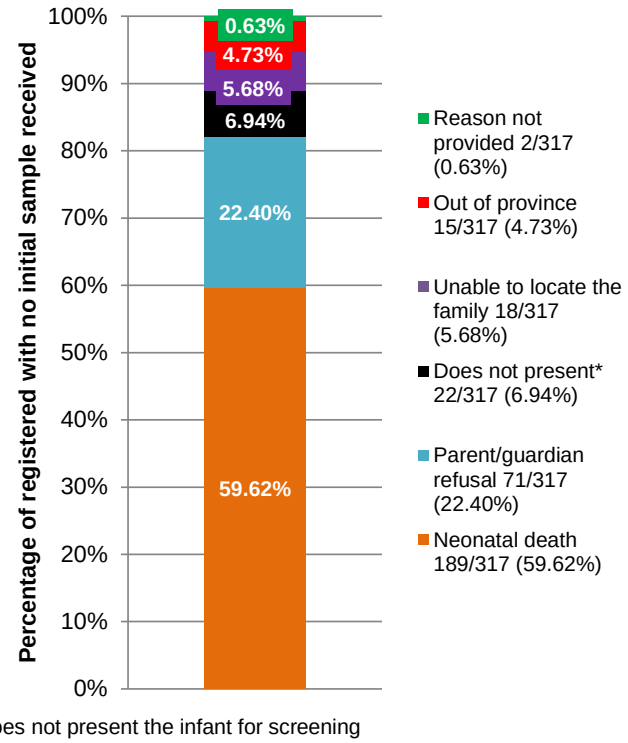
Participation rate and non-participation rationale[a]

In 2017-2018, 99.40% of registered infants received an initial blood spot screen. Rationale for the 0.60% that did not participate is provided in the graph below. NMS Program participation and non-participation rates in 2017-2018 are similar to 2016-2017 (99.46% 54,891/55,190). This measure has remained consistent since reporting began in 2010-2011.

Program participation, provincial total, current year

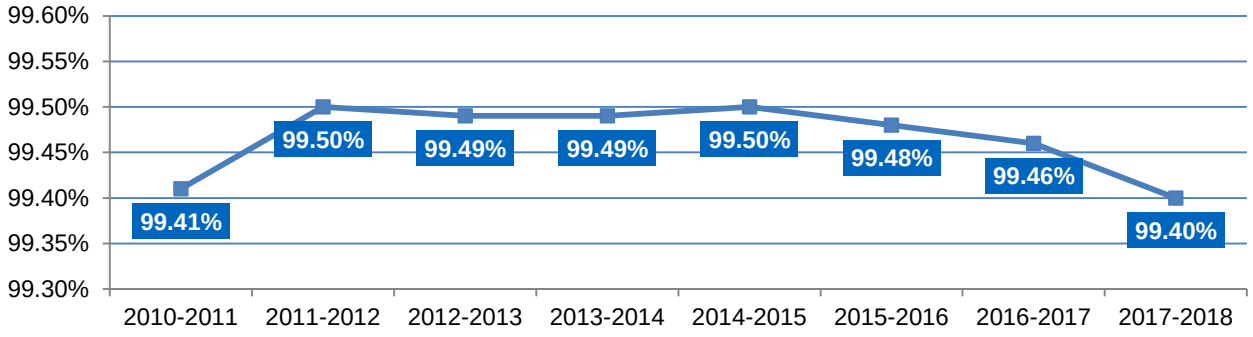


Program non-participation rationale, provincial total, current year



*Does not present means the parent or guardian does not refuse but does not present the infant for screening

Program participation, provincial trend 2010-2018

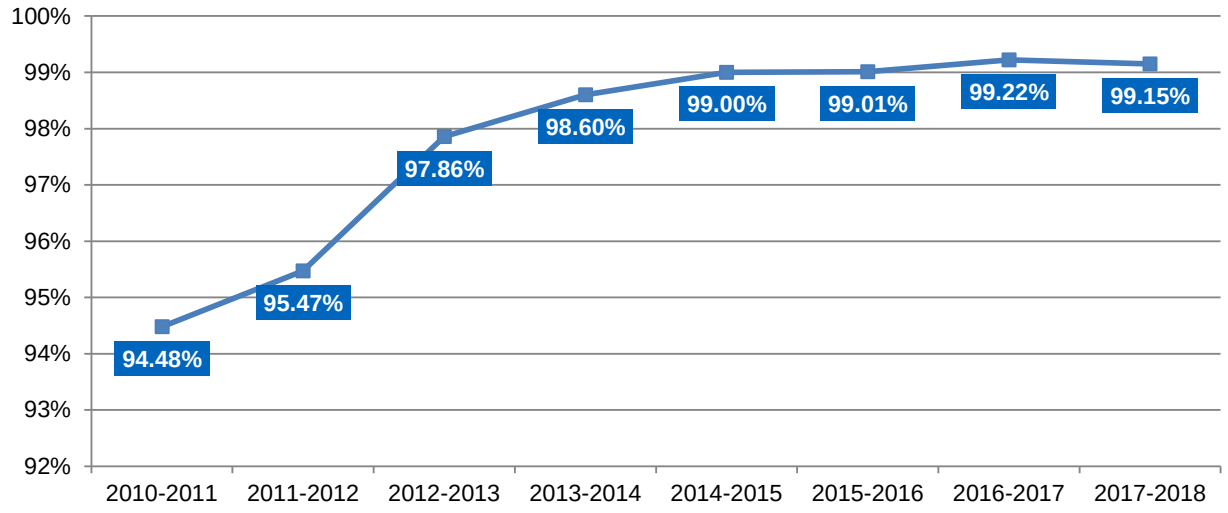


[a] **Data retrieved May 14, 2018 from NMS Application Report 1 and NMS Application statistics. Data are for all registered infants by zone of responsibility.** For comparison, previous years' data and NMS Program annual reports can be requested through nmsprogram@ahs.ca.

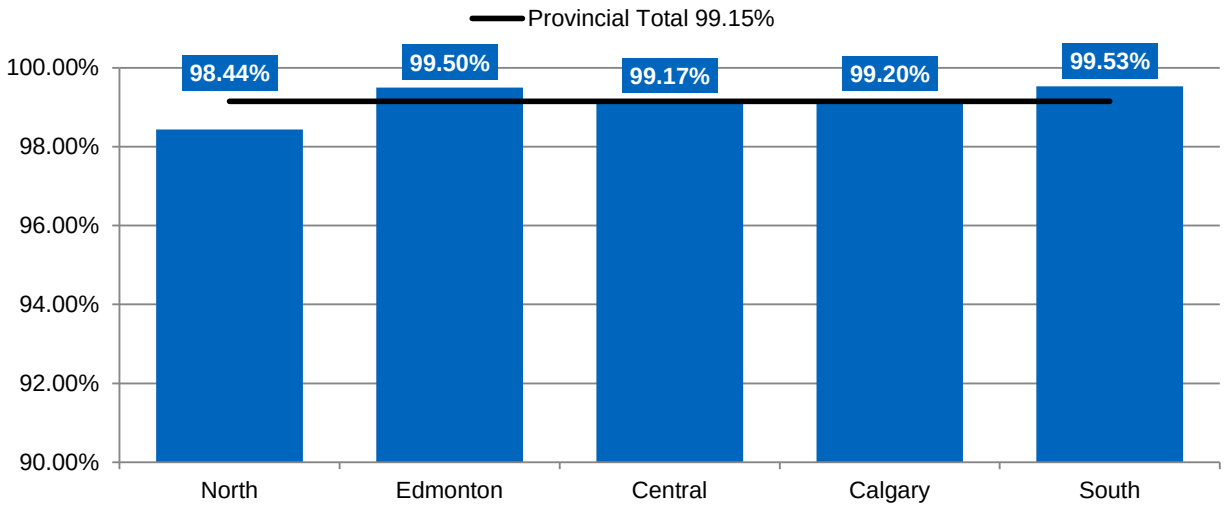
Initial screen results reported[b]

In 2017-2018, 99.15% (52,449/52,898) of registered screened infants had an initial screen result reported by the NMS Lab within 10 days of age (excluding cystic fibrosis), 0.81% (428/52,898) did not meet the standard and 0.04% (21/52,898) were unable to determine. Improvement in this measure is representative of quality improvement work across the newborn blood spot screening pathway that began during the NMS Program Initiative (2010-2014) and that continues as part of regular program operations. The range among the AHS zones for meeting the standard is between 98.44% and 99.53% (AHS Zone not assigned is 90.85%). The data table for initial screen results reported by zone can be found in Appendix B.

Initial screen results reported meeting standard, provincial trend 2010-2018



Initial screen results reported meeting standard, zone totals, current year



[b] **Data retrieved May 14, 2018 from NMS Application Report 8, Section F. Data are for all registered screened infants by zone of responsibility.** For comparison, previous years' data and NMS Program annual reports can be requested through nmsprogram@ahs.ca.

Screen results

Alberta's NMS Program: 2017-2018 screen results

Screened infants in the NMS Program = 52,958

Normal screen results = 99.41%
(52,648/52,958) of screened infants

Abnormal screen results = 0.44%
(231/52,958) of screened infants

Unknown screen results = 0.15%
(79/52,958) of screened infants

Abnormal diagnostic outcomes = 70
(of 52,958 screened infants)

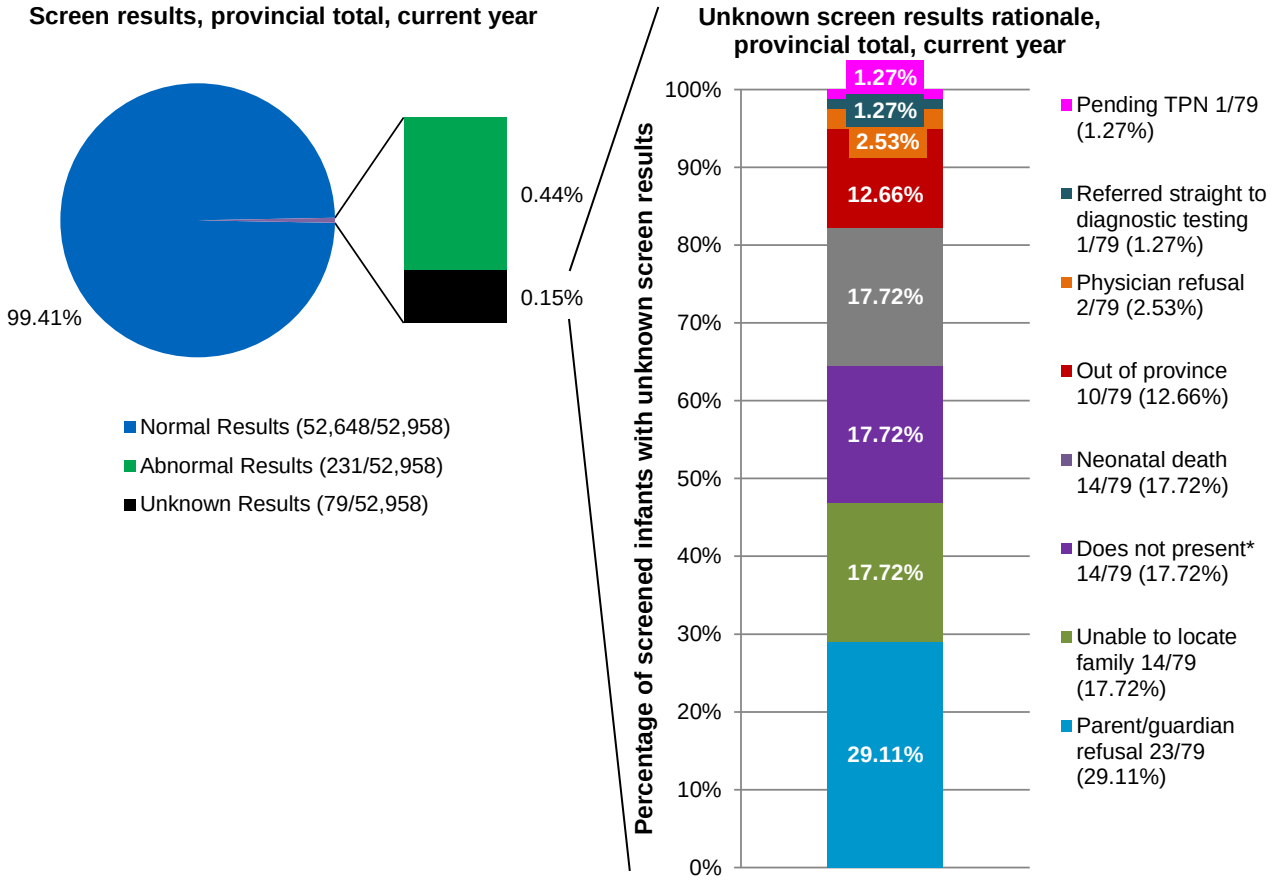
The NMS Program screens for 17 treatable conditions to identify and treat infants with any of the screened conditions as early as possible.

- Metabolic conditions (14)
  - Citrullinemia (CIT)
  - Maple syrup urine disease (MSUD)
  - Phenylketonuria (PKU)
  - Glutaric acidemia type 1 (GA1)
  - 3-Hydroxy-3-methylglutaryl-CoA lyase (HMG) deficiency
  - Isovaleric acidemia (IVA)
  - Methylmalonic acidemia (MMA)
  - Propionic acidemia (PA)
  - Carnitine uptake defect (CUD)
  - Long chain 3-hydroxyacyl-CoA dehydrogenase (LCHAD) deficiency
  - Medium chain acyl-CoA dehydrogenase (MCAD) deficiency
  - Tri-functional protein (TFP) deficiency
  - Very long chain acyl-CoA dehydrogenase (VLCAD) deficiency
  - Biotinidase deficiency (BIOT)
- Endocrine conditions (2)
  - Congenital adrenal hyperplasia (CAH)
  - Congenital hypothyroidism (CH)
- Cystic fibrosis (CF)

Screen results and unknown screen results rationale[c]

In 2017-2018, 99.41% of screened infants received normal screen results; 0.44% received abnormal screen results (200 critical screen results and 31 double borderline results); 0.15% were unknown (meaning an infant reported with inadequate, borderline or TPN results has no confirmed normal or abnormal results on record). Amended details of 2016-2017 screen results can be found in Appendix A and amended screen results for the 2017-2018 reporting period will be available in the 2018-2019 NMS Program annual report.
Of the abnormal screen results:

- 22.08% (51/231) of infants received abnormal results for a metabolic condition
- 29.87% (69/231) of infants received abnormal results for an endocrine condition
- 48.05% (111/231) of infants received abnormal results for cystic fibrosis



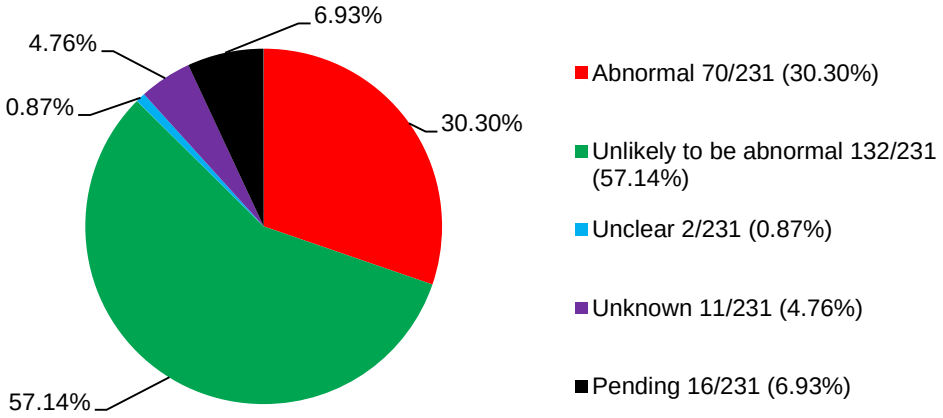
*Does not present means the parent or guardian does not refuse but does not present the infant for screening

[c] **Data retrieved May 14, 2018 from NMS Application Reports 5, 6 and 7, NMS Application statistics and NMS Lab statistics. Data are for all screened infants.** For comparison, previous years' data and NMS Program annual reports can be requested through nmsprogram@ahs.ca.

Diagnostic outcomes[d]

In 2017-2018, 30.30% of infants with abnormal screen results received abnormal diagnostic outcomes after referral for clinical assessment and diagnostic testing; 57.14% received unlikely to be abnormal diagnostic outcomes; 0.87% received unclear diagnostic outcomes (meaning diagnostic tests neither confirmed nor excluded the screened condition); 4.76% received unknown diagnostic outcomes (meaning infant died prior to diagnostic testing, unable to locate infant, or parent or guardian refusal of diagnostic testing); and 6.93% were pending at the time of reporting. Amended details of 2016-2017 diagnostic outcomes can be found in Appendix A and amended diagnostic outcomes for the 2017-2018 reporting period will be available in the 2018-2019 NMS Program annual report.

Diagnostic outcomes of abnormal screen results, provincial total, current year



Diagnostic outcomes by category	Metabolic conditions, n=51	Endocrine conditions, n=69	Cystic fibrosis, n=111
Abnormal	25.49% (13/51)	65.22% (45/69)	10.81% (12/111)
Unlikely to be abnormal	62.75% (32/51)	26.09% (18/69)	73.87% (82/111)
Unclear	0.00% (0/51)	0.00% (0/69)	1.80% (2/111)
Unknown	0.00% (0/51)	2.90% (2/69)	8.11% (9/111)
Pending	11.76% (6/51)	5.80% (4/69)	5.41% (6/111)

[d] **Data retrieved May 14, 2018 from NMS Lab statistics. Data are for all screened infants.** For comparison, previous years' data and NMS Program annual reports can be requested through nmsprogram@ahs.ca.

NMS Program performance along the screening pathway

Delivery of screening services within the NMS Program occurs along four interconnected steps of the newborn blood spot screening pathway: registration, collection and transportation, analysis and reporting, and follow-up (Figure 2).

Time standards for each step were determined by Alberta Health (1) and service delivery is provided by many providers within AHS, Covenant Health. Calgary Laboratory Services (CLS), Dyna**LIFE**$_{DX}$, FNIHB, physicians and midwives.

Important components integrated along each step of the newborn blood spot screening pathway are the care and safety of the infant, and the involvement of the parent or guardian. This is represented by the footprint graphic in Figure 2.

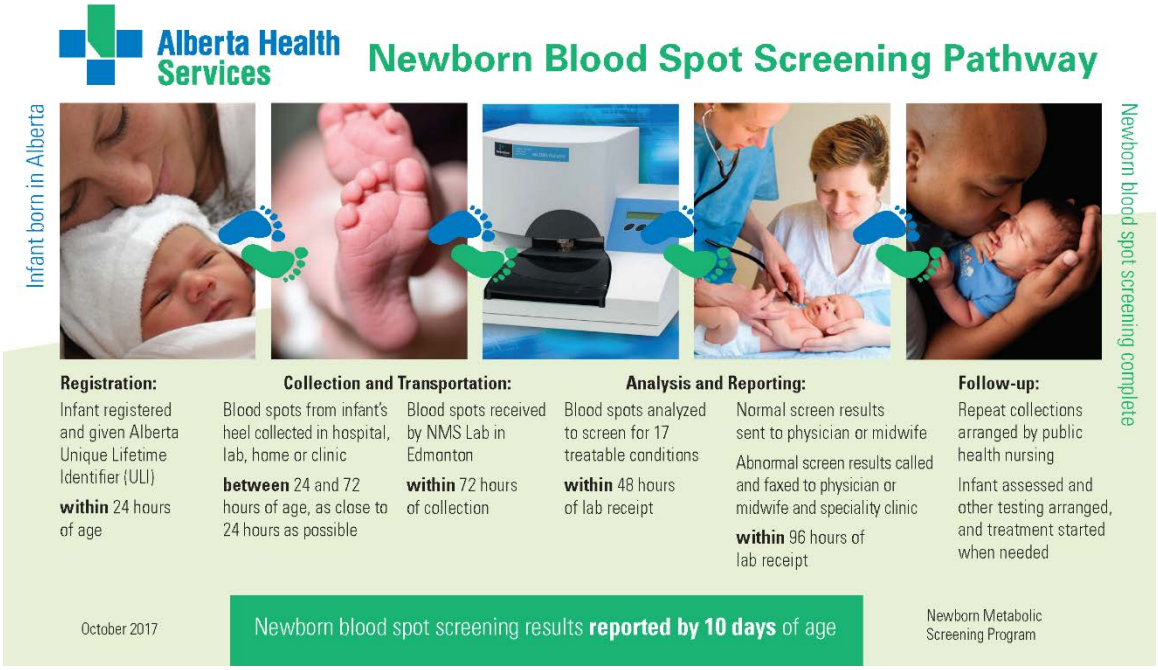


Figure 2. Newborn blood spot screening pathway

Registration

Newborn blood spot screening pathway:

2017-2018 registration

Registration by 24 hours = 98.71%

(52,529/53,215) of infants born in Alberta

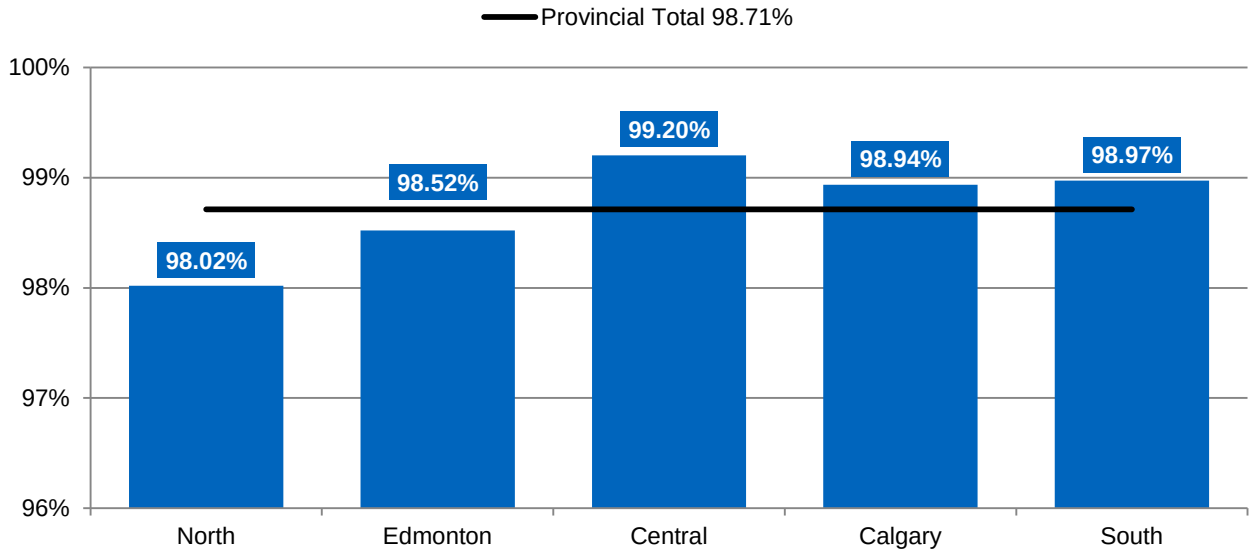
Birth registration consists of registering an infant in PD and assigning a ULI within 24 hours of age.

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

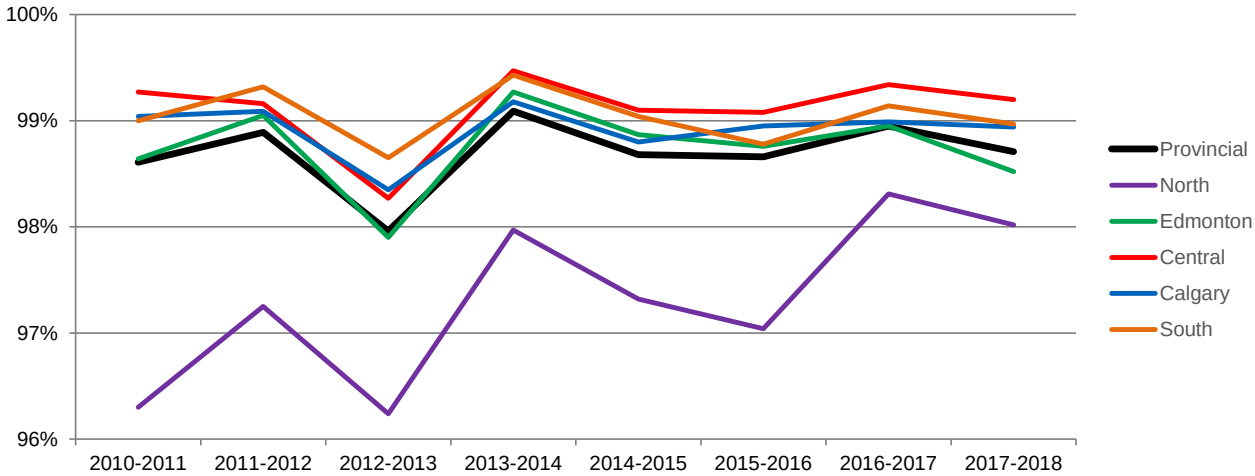
Birth registration[e]

In 2017-2018, 98.71% (52,529/53,215) of infants born in Alberta were registered in PD within 24 hours of birth, 0.08% (45/53,215) did not meet the standard and 1.20% (641/53,215) were unable to determine. This measure has remained consistent with the exception of 2012-2013 when a major service disruption (Shaw Court Fire) caused delays in PD registration. The range among the AHS zones for meeting the standard is between 98.02% and 99.20%. The data table for birth registration by zone can be found in Appendix B.

Birth registration meeting standard, zone totals, current year



Birth registration meeting standard, trend 2010-2018



[e] **Data retrieved May 14, 2018 from NMS Application Report 8, Section A. Data are for all registered infants by zone of birth.** For comparison, previous years' data and NMS Program annual reports can be requested through nmsprogram@ahs.ca.

Collection and transportation

Newborn blood spot screening pathway:

2017-2018 collection & transportation

Initial collection between 24 to 72 hours = 97.07%

(51,349/52,898) of registered screened infants

Samples received within 72 hours of collection = 94.90%

(53,304/56,168) of received samples

Inadequate samples = 2.03%

(1,139/56,168) of received samples

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

Transportation of the sample to the NMS Lab at the University of Alberta Hospital (UAH) occurs within 72 hours of collection.

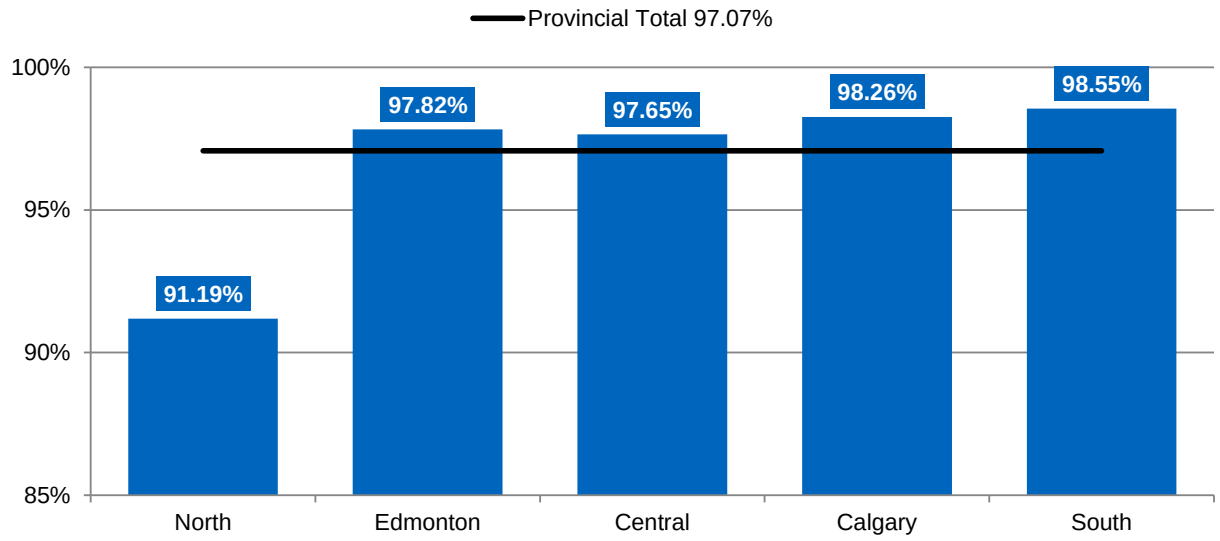
Collection and transportation services are delivered by:

- Postpartum units in each birth facility (including Covenant Health and midwives) who provide NMS Program information to parents and guardians, obtain informed consent, and arrange or perform sample collection
- Neonatal Intensive Care Units (NICU) and Special Care Nurseries (SCN) in each zone (including Covenant Health) who provide NMS Program information to parents and guardians, obtain informed consent, and arrange or perform sample collection
- Inpatient laboratory services in each birth facility and outpatient laboratory services in each zone (including CLS, Covenant Health and Dyna**LIFE**$_{DX}$) who perform sample collection and arrange for sample transportation
- Public health nursing services (PHNS) in each zone (including FNIHB and midwives) who provide NMS Program information to parents and guardians, obtain informed consent, arrange or perform sample collection, and arrange for sample transportation

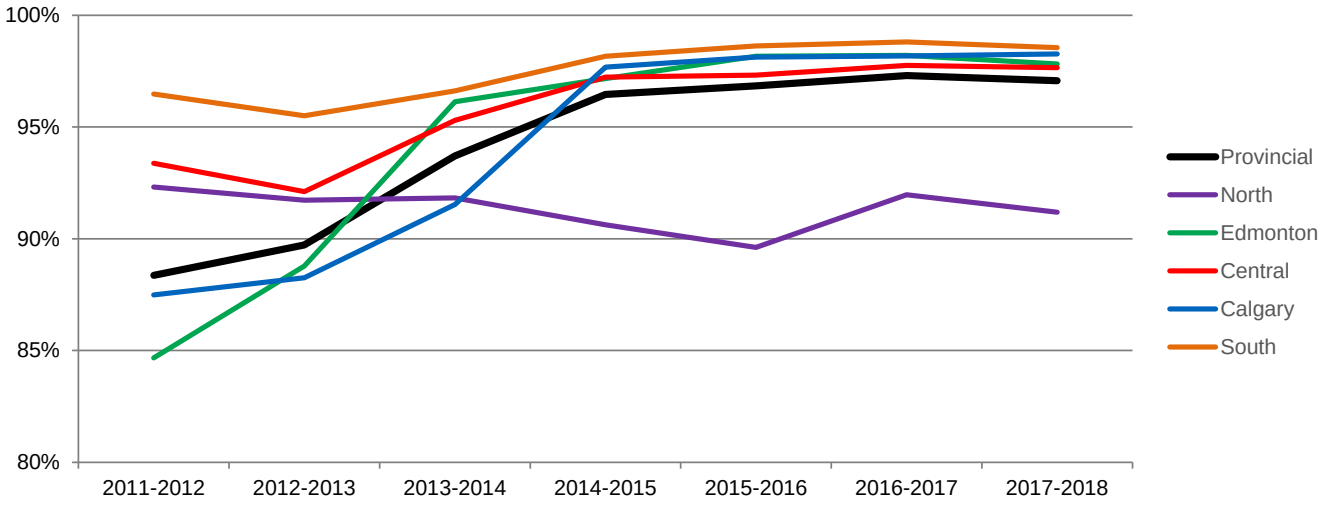
Initial collection[f]

In 2017-2018, 97.07% (51,349/52,898) of registered screened infants had an initial sample collected between 24 and 72 hours of age, 2.73% (1,442/52,898) did not meet standard and 0.20% (107/52,898) were not determined. This measure has steadily increased since the standard was implemented in 2011. Data for comparison is not available for the 2010-2011 year due to a different time standard being acceptable for part of the reporting year. The range among the AHS zones is between 91.19% and 98.55% (AHS Zone not assigned is 87.50%). The data table for initial sample collection by zone can be found in Appendix B.

Initial sample collection meeting standard, zone totals, current year



Initial sample collection meeting standard, trend 2011-2018

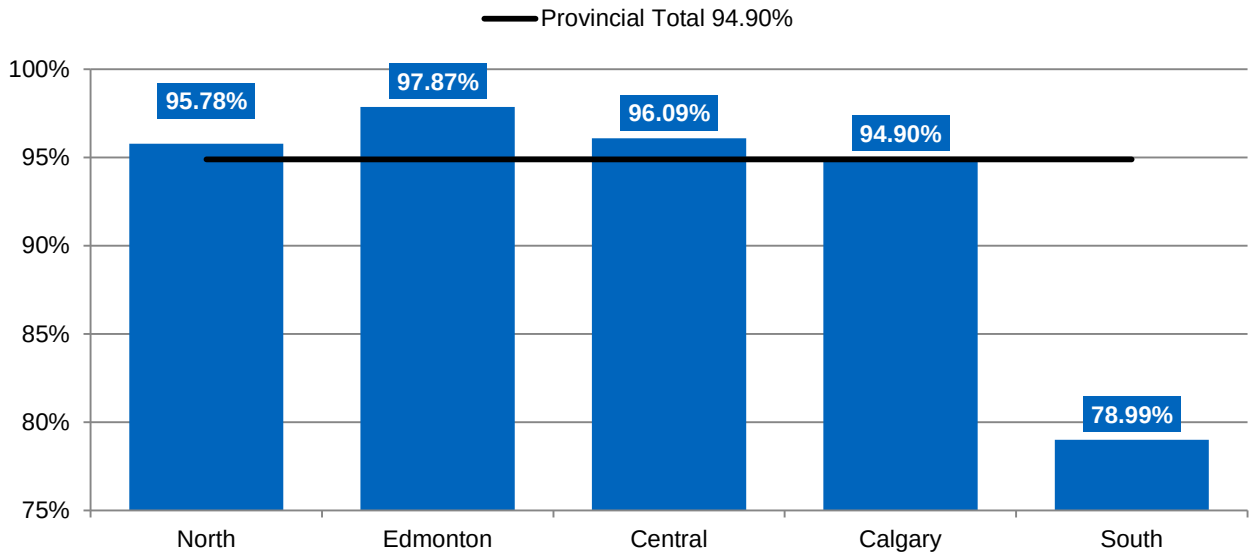


[f] **Data retrieved May 14, 2018 from NMS Application Report 8, Section B. Data are for all registered screened infants by zone of responsibility.** For comparison, previous years' data and NMS Program annual reports can be requested through nmsprogram@ahs.ca.

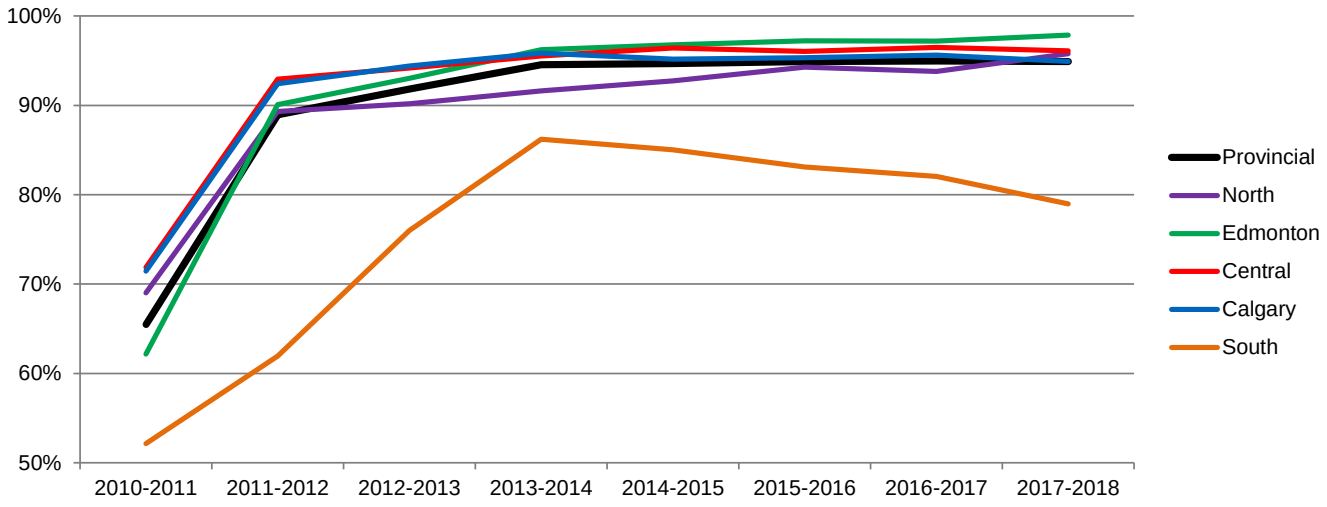
Sample receipt[g]

In 2017-2018, 94.90% (53,304/56,168) of samples were received by the NMS Lab within 72 hours of collection and 5.10% (2,864/56,168) did not meet standard. This measure has remained high since 2011 when this time standard was implemented across the zones. The range among the AHS zones for meeting the standard is between 78.99% and 97.87% (AHS Zone not assigned is 90.60%). The data table for sample receipt by NMS Lab by zone can be found in Appendix B.

Sample receipt by NMS Lab meeting standard, zone totals, current year



Sample receipt by NMS Lab meeting standard, trend 2010-2018



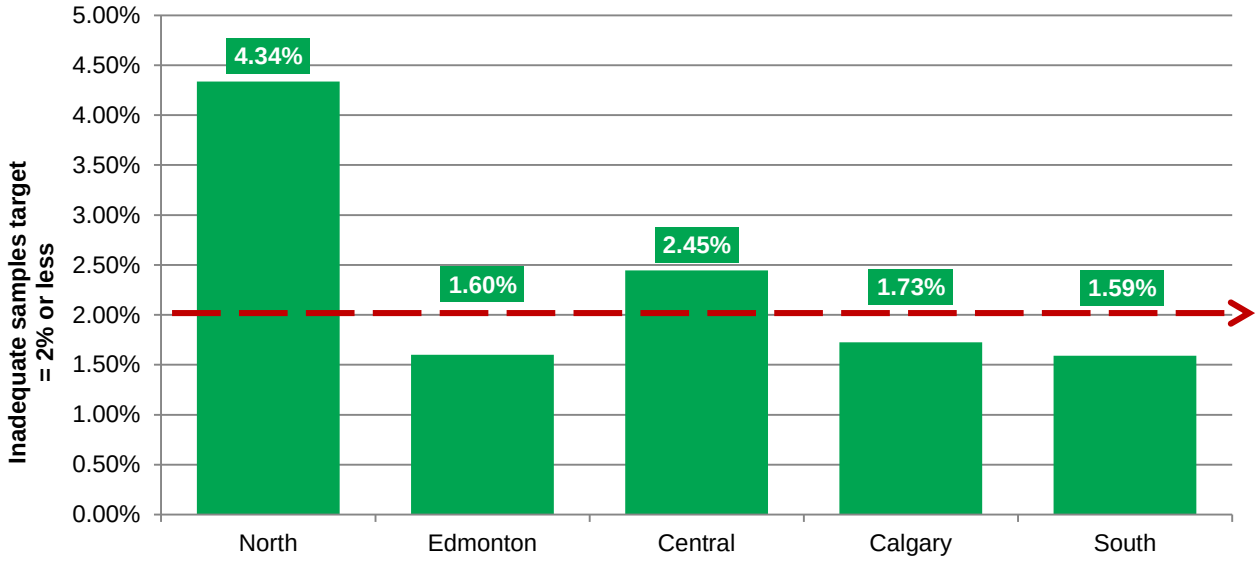
[g] **Data retrieved May 14, 2018 from NMS Application Report 8, Section D. Data are for all received samples by zone of responsibility.** For comparison, previous years' data and NMS Program annual reports can be requested through nmsprogram@ahs.ca.

Inadequate samples[h]

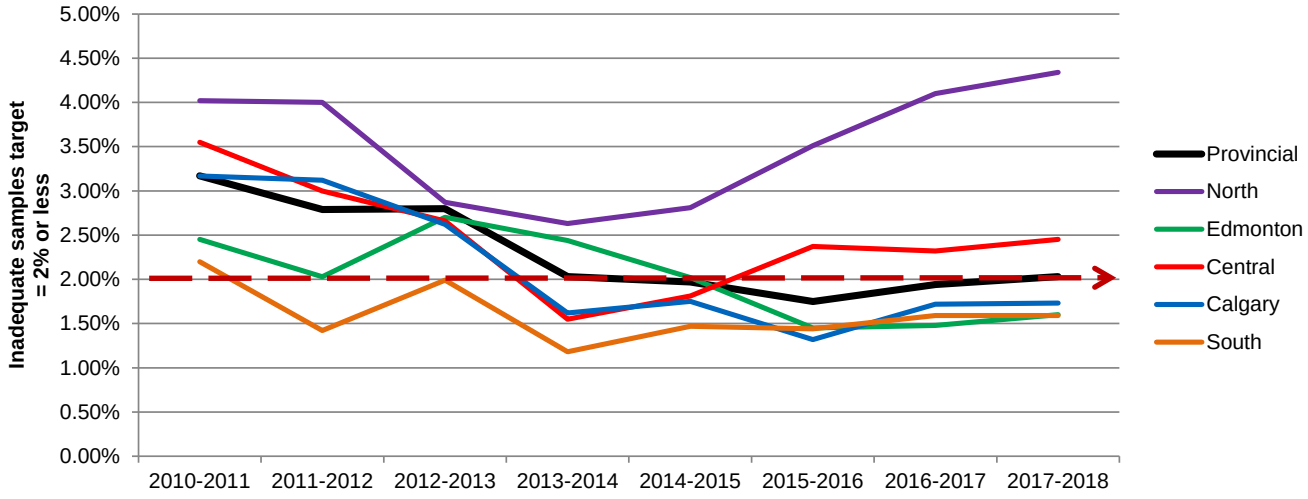
This performance measure is unique among the measures reported in the annual report in that the NMS Program is striving for a reduction in inadequate samples to a target of 2% or less. Each inadequate sample requires a repeat sample which has significant costs and implications to the health care system and the families.

In 2017-2018, 2.03% (1,139/56,168) of samples received by the NMS Lab were determined to be inadequate. The range among the AHS zones for meeting the standard is between 4.34% and 1.59% (AHS Zone not assigned is 5.26%). The data table for inadequate samples received by zone can be found in Appendix B.

Inadequate samples, zone totals, current year



Inadequate samples, zone trend 2010-2018



[h] **Data retrieved May 14, 2018 from NMS Application Report 3. Data are for all received samples by zone of collection.** For comparison, previous years' data and NMS Program annual reports can be requested through nmsprogram@ahs.ca.

Analysis and reporting

Newborn blood spot screening pathway:

2017-2018 analysis & reporting

Analysis and reporting within 96 hours of NMS Lab receipt = 95.78%

(53,795/56,168) of received samples

Analysis of newborn blood spot samples and reporting the screen results occurs within 96 hours of NMS Lab receipt (21 days for CF analysis).

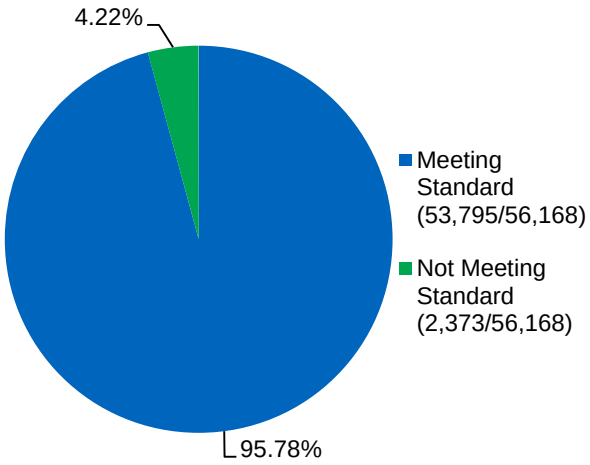
Analysis and reporting services are delivered by:

- NMS Lab within Genetic Laboratory Services at UAH who enter data from samples, perform sample analyses including determining sample quality, and report screen results to the NMS Application, Netcare, ordering physicians and birth facilities
- MD Lab within Genetic Laboratory Services at UAH who perform DNA testing for CF screening and report CF results to the NMS Lab

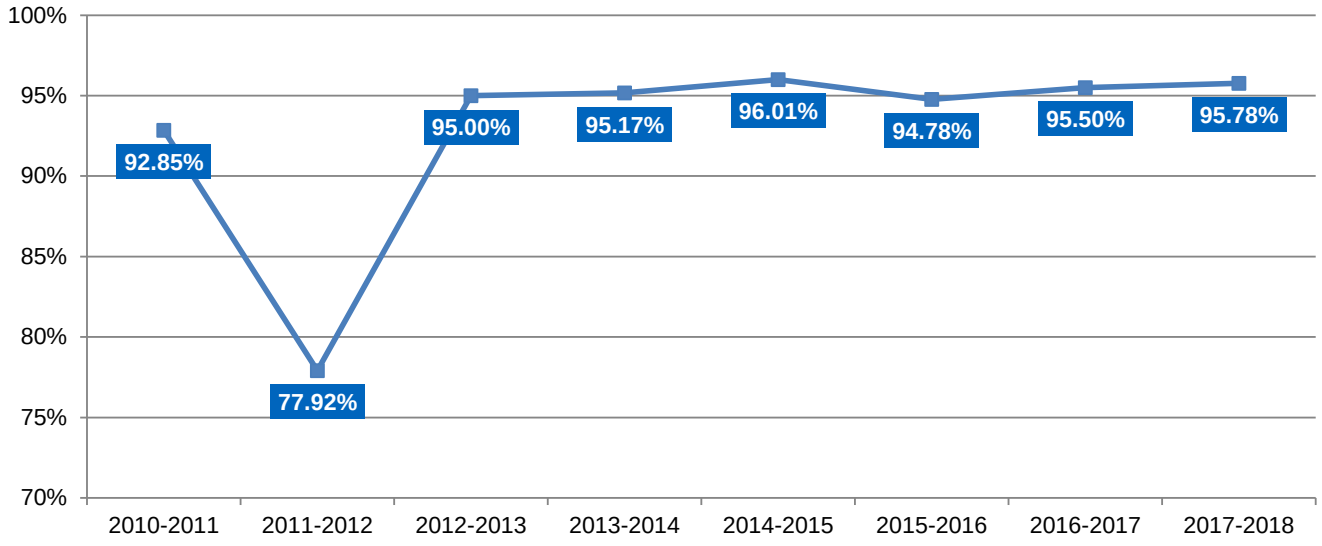
Results reported[i]

In 2017-2018, 95.78% of samples received had screen results reported by the NMS Lab within 96 hours of NMS Lab receipt (excluding CF). This measure has remained above 94.00% since NMS Lab operational practices were modified between 2011 and 2013.

Reported results, provincial total, current year



Reported results meeting standard, provincial trend 2010-2018



[i] **Data retrieved May 14, 2018 from NMS Application Report 8, Section E. Data are for all received samples excluding CF for all zones combined.** For comparison, previous years' data and NMS Program annual reports can be requested through nmsprogram@ahs.ca.

Follow-up

Newborn blood spot screening pathway:

2017-2018 follow-up

Repeat collection within 96 hours of notification of inadequate sample rate = 82.29%

(878/1,067) of repeat samples

Repeat collection with 96 hours of notification of reported borderline results rate = 89.33%

(561/628) of repeat samples

Follow-up in a timely manner is coordinated to ensure an initial sample is collected from all infants born in Alberta, a repeat sample is collected when required, referrals for clinical assessment and diagnostic testing are completed when required, and diagnostic outcomes are received.

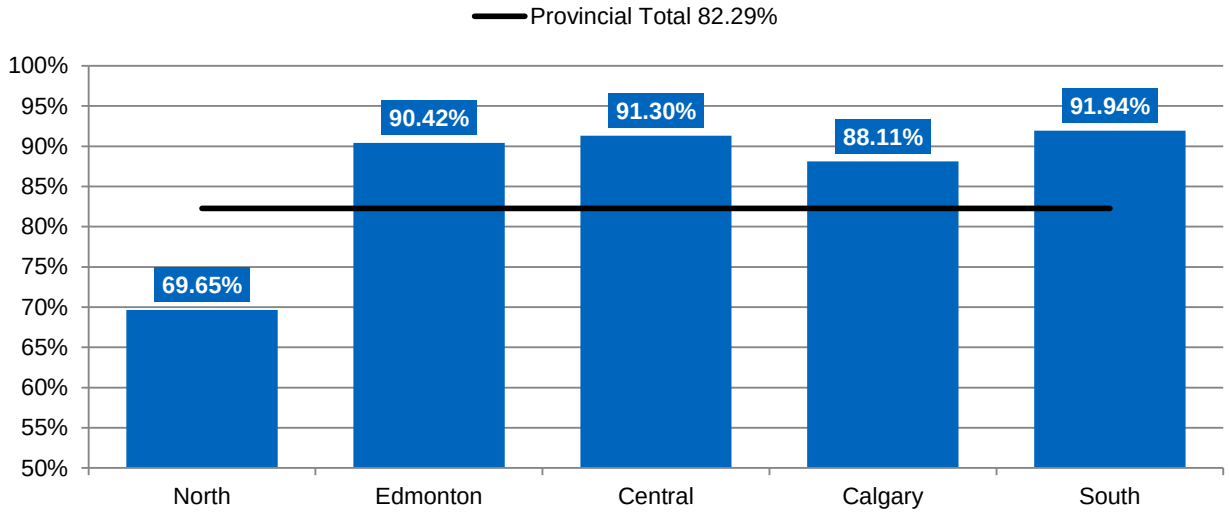
Follow-up services are delivered by:

- NMS Program coordination team within Population, Public & Indigenous Health who distribute NMS Application notifications (i.e., alerts) to zone PHNS and FNIHB, and track and monitor the completion of follow-up for data corrections, repeat and missed initial sample collection
- PHNS in each zone (including FNIHB and midwives) who confirm and correct infant demographics as required, provide NMS Program information to parents and guardians, obtain informed consent, and arrange or perform repeat and missed initial sample collection
- NICU/SCN in each zone (including Covenant Health) who provide NMS Program information to parents and guardians, obtain informed consent, and who arrange or perform repeat or missed initial sample collection upon referral from zone PHNS
- Inpatient laboratory services in each birth facility and outpatient laboratory services in each zone (including CLS, Covenant Health and Dyna**LIFE**$_{DX}$) who perform repeat sample collection upon referral from zone PHNS
- Health Information Management in each zone who confirm and correct infant demographics as required
- NMS Lab within Genetic Laboratory Services at UAH 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 NMS Program information to parents and guardians, obtain informed consent, refer infants to specialty clinics as required, and in consultation with speciality clinics provide clinical assessments of infants with abnormal screen results, arrange for diagnostic testing, initiate treatment, , and notify the NMS Lab of the diagnostic outcomes
- Specialty clinics (metabolic, endocrinology, CF) 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 NMS Lab of the diagnostic outcomes
- Diagnostic laboratories who collaborate with physicians, midwives and speciality clinics to perform diagnostic testing of infants with abnormal screen results, and report test results to physicians, midwives and specialty clinics

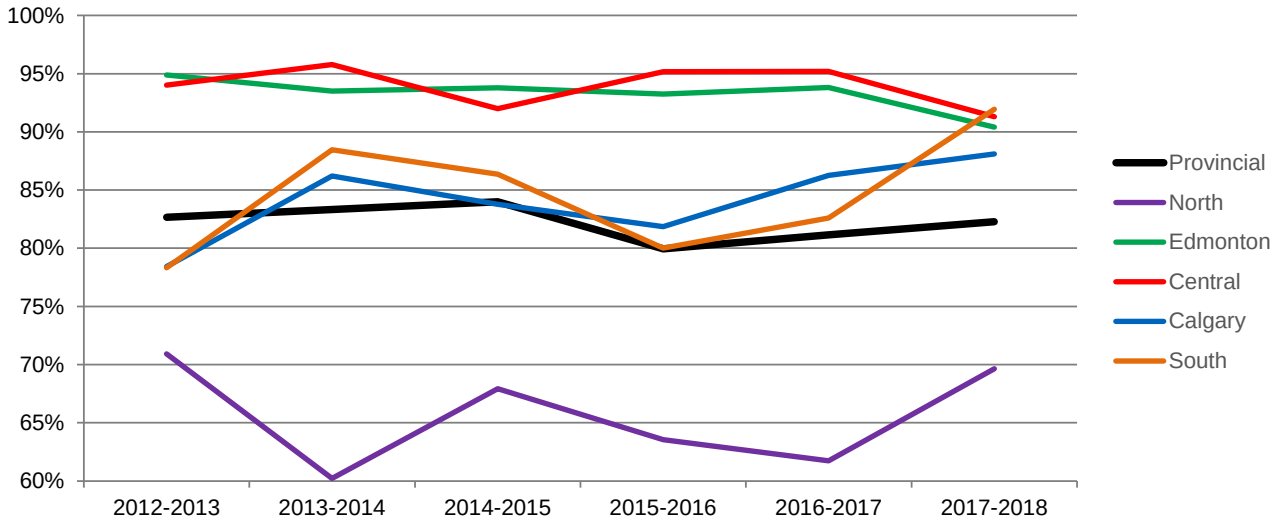
Repeat sample collection for inadequate results[j]

In 2017-2018, 82.29% (878/1,067) of repeat samples were collected within 96 hours of notification of reported inadequate results and 17.71% (189/1,067) did not meet standard. This measure has remained fairly consistent since 2012. Data for comparison is not available for 2010-2011 and 2011-2012 due to different reporting practices being used for those reporting years. The range among the AHS zones for meeting the standard is between 69.65% and 91.94% (AHS Zone not assigned is 27.27%). The data table for repeat sample collection for inadequate results by zone can be found in Appendix B.

Repeat sample collection for inadequate results meeting standard, zone totals, current year



Repeat sample collection for inadequate results meeting standards, trend 2012-2018

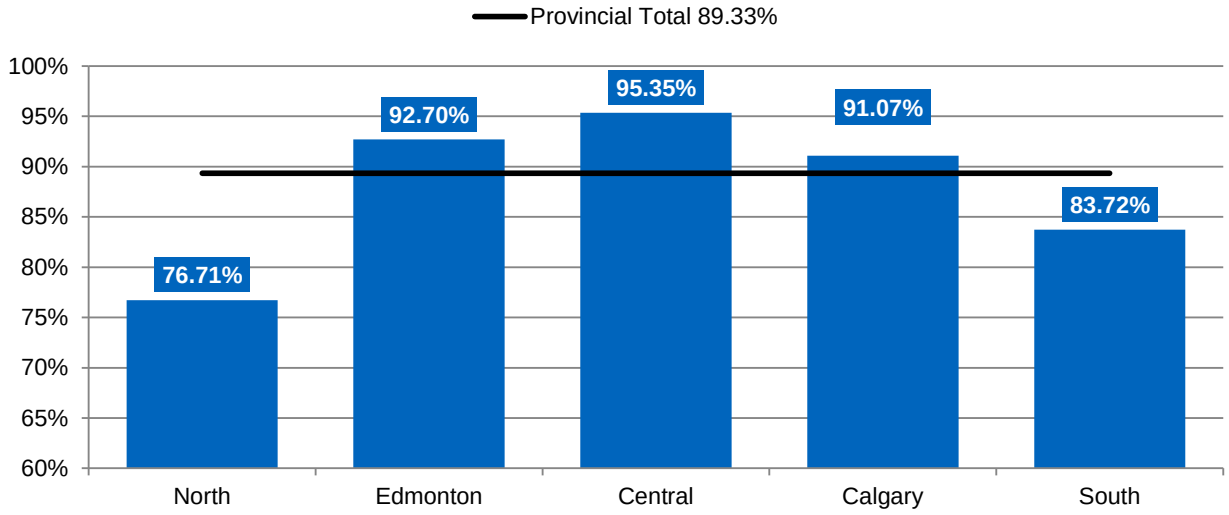


[j] **Data retrieved May 14, 2018 from NMS Application Report 8, Section G. Data are for all repeat samples due to inadequate results by zone of responsibility.** For comparison, previous years' data and NMS Program annual reports can be requested through nmsprogram@ahs.ca.

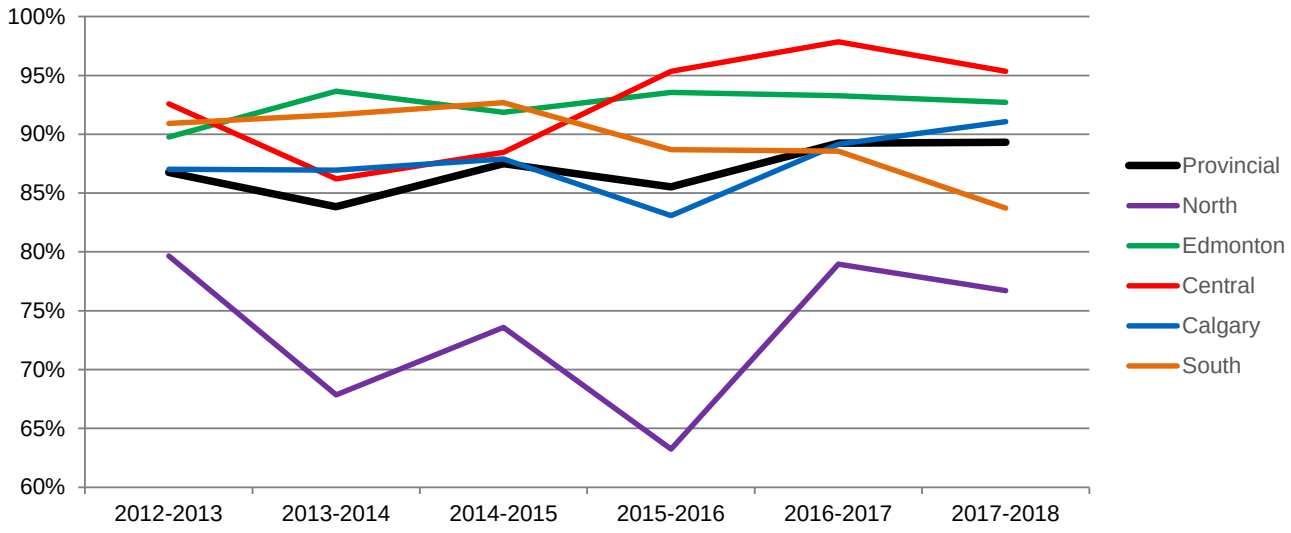
Repeat sample collection for borderline results[k]

In 2017-2018, 89.33% (561/628) of repeat samples were collected within 96 hours of notification of reported borderline results (excluding tyrosine) and 10.67% (67/628) did not meet standard. Data for comparison is not available for 2010-2011 and 2011-2012 due to different reporting practices being used for those reporting years. The range among the AHS zones for meeting the standard is between 76.71% and 95.35% (AHS Zone not assigned is 66.67%). The data table for repeat sample collection for borderline results by zone can be found in Appendix B.

Repeat sample collection for borderline results meeting standard, zone totals, current year



Repeat sample collection for borderline results meeting standards, trend 2012-2018



[k] **Data retrieved May 14, 2018 from NMS Application Report 8, Section H. Data are for all repeat samples due to borderline result excluding tyrosine by zone of responsibility.** For comparison, previous years' data and NMS Program annual reports can be requested through nmsprogram@ahs.ca.

Highlights

Recollection on low birth weight infants

In response to an AHS Quality Assurance Review conducted in 2016-2017, a pilot project between NMS Program and NMS Lab was initiated in the last quarter of 2017-2018 to improve recollection rates for low birth weight (LBW) infants. LBW infants are defined as infants that weigh less than 2000 grams at birth. These infants require a repeat sample to be collected between 21 and 28 days of age in order to support the detection of congenital hypothyroidism (CH) and congenital adrenal hyperplasia (CAH). As there is no alert generated in the NMS Application to trigger these recollections, the NMS Program worked with the NMS Lab to develop a process to receive data for LBW infants and use that data to generate and distribute alerts manually through the already established alert management process. The pilot project timeline ran from January 1, 2018 to March 31, 2018.

The NMS Program received data for LBW infants born starting January 1, 2018 and then began to send out alert action forms (AAFs) for LBW infants at 21 days of age. There were 273 LBW infants identified during the pilot project, for which 260 recollections were completed[l].

Thirteen infants were considered to have incomplete[m] LBW recollections, 10 of those were due to neonatal death. Other reasons are detailed in the table below.

Incomplete LBW Recollection Rationale

Rationale	Number of infants
Infant was deceased at the time of 2nd collection	10
Parental refusal[n]	2
Birth weight was incorrect on blood spot card for the initial collection, therefore the infant did not meet LBW criteria	1

Zone Public Health and NICU staff were extremely supportive in this initiative. 70.95% of infants had their blood spots recollected while still in the NICU. Of the 260 completed LBW recollections, four infants were confirmed to have CH (one additional infant's result was still pending at the time of publication).

This pilot project was considered very successful with 95.23% of requested recollections completed, and the program was able to help the lab identify four cases of CH that may have been otherwise missed.

[l] Completed is considered when a normal or a confirmation of diagnostic outcome is reported.
[m] Incomplete LBW recollection for this report is considered when there is a valid reason (deceased, refusal, correction) for not undertaking a repeat sample collection.
[n] One parent refusal was for the initial recollection. The other parent refusal was for a third collection due to sample quality.

The distribution of manual alerts for LBW recollections will continue as part of program operations through the next fiscal year and until there is an alert generated through the NMS Application.

Reducing inadequate samples

The NMS Program initiated a NICU sample quality monitoring project, which involved collecting and analyzing data for each NICU and distributing quarterly, site specific reports to identified stakeholders within each NICU and zone. The aim of this project was to identity the type of sample collection errors occurring in each NICU and to help health care providers identify quality improvement strategies.

Using targeted data allowed each site to focus on their specific issues instead of looking at overall zone averages which may or may not be relevant to their NICU. After the initial report was sent out in July 2017 a number of NICUs reached out through the zone designates for additional support including asking the NMS Program and zone designates to attend monthly skills days with NICU nurses. By the end of the 2017-2018 fiscal year the NMS Program had given eight skills day presentations and visited six NICUs across the province to help support quality improvement efforts at those sites.

In the 2017-2018 fiscal year the provincial NICU inadequate sample quality rate dropped from 3.54% to 2.49%, an overall decrease of 29.41% when comparing quarter one data to quarter four data.

Provincial NICU Inadequate Sample Quality Rate

	Quarter 1	Quarter 2	Quarter 3	Quarter 4
# Inadequate samples	51	49	38	36
Inadequate sample rate	3.54%	3.25%	2.59%	2.49%

Using targeted, site specific sample quality data to reduce inadequate sample collections with NICUs was successful. In addition to improving sample quality, the NICUs were also able to help reduce work for the health system (collecting and analyzing fewer repeat samples) and by doing so decreased the harms of screening for infants and families (discomfort of another collection; inconvenience and worry for parents). This project also provided the added benefit of increasing awareness and engagement of staff working along the blood spot screening pathway.

Conclusion

The purpose of the *AHS Provincial Newborn Metabolic Screening Program Report 2017-2018* was to highlight NMS Program performance between April 1, 2017 and March 31, 2018. The report summarized AHS performance for the reporting year and the improvement trends that have come through the centralized coordination of the program since 2010.

Multiple program partners and service areas involved in delivering the NMS Program contributed to the continued success of newborn blood spot screening in Alberta. This year's performance within the NMS Program has remained consistent in comparison to 2016-2017 reporting year. Key accomplishments for this reporting year were:

- the significant improvement in the recollection rates for low birth weight infants and
- reducing inadequate sample collection within NICUs by using targeted, site specific sample quality data

As an operational program within AHS Screening Programs, NMS Program systems and processes have continued to support ongoing provincial coordination activities in 2017-2018. The quality management framework continues to guide sustainability and quality improvement along the newborn blood spot screening pathway and supporting processes, and 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. **Alberta Health and Wellness.** Alberta Newborn Metabolic Screening Program Policy Document. [Online] 2010. http://www.health.alberta.ca/documents/Newborn-Metabolic-Screening-Policy-2010.pdf.

2. **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.

3. **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.

Appendix A

Amendments to the 2016-2017 AHS Provincial NMS Program Report[o]

Screen results and unknown screen results rationale

Screen Results	Previously Reported, n=54,960	Amended, n=54,960
Normal results	*99.36% (54,608/54,960)*	**99.36% (54,608/54,960)**
Abnormal results	*0.49% (271/54,960)*	**0.49% (271/54,960)**
Unknown results	*0.15% (80/54,960)*	**0.15% (81/54,960)**
Pending results	*0.002% (1/54,960)*	**0.00% (0/54,960)**
Unknown Screen Results Rationale	**Previously Reported, n=80**	**Amended, n=81**
Does not present	*13.75% (11/80)*	**13.58% (11/81)**
Neonatal Death	*8.75% (7/80)*	**8.64% (7/81)**
Out of province	*7.50% (6/80)*	**7.41% (6/81)**
Parent/guardian refusal	*41.25% (33/80)*	**41.98% (34/81)**
Unable to locate family	*21.25% (17/80)*	**20.99% (17/81)**
Referred straight to diagnostic testing	*1.25% (1/80)*	**1.23% (1/81)**
Physician refusal	*6.25% (5/80)*	**6.17% (5/81)**

Diagnostic outcomes

Diagnostic outcomes by category	Metabolic conditions, n=62		Endocrine conditions, n=59		Cystic fibrosis, n=150		Total, n=271	
	Previously reported	**Amended**	*Previously reported*	**Amended**	*Previously reported*	**Amended**	*Previously reported*	**Amended**
Abnormal	*32.26% (20/62)*	**35.48% (22/62)**	*52.54% (31/59)*	**59.32% (35/59)**	*10.67% (16/150)*	**11.33% (17/150)**	*24.72% (67/271)*	**27.31% (74/271)**
Unlikely to be abnormal	*45.16% (28/62)*	**62.90% (39/62)**	*40.68% (24/59)*	**40.68% (24/59)**	*78.00% (117/150)*	**82.00% (123/150)**	*62.36% (169/271)*	**68.63% (186/271)**
Unclear	*0.00% (0/62)*	**0.00% (0/62)**	*0.00% (0/59)*	**0.00% (0/59)**	*3.33% (5/150)*	**3.33% (5/150)**	*1.85% (5/271)*	**1.85% (5/271)**
Unknown	*0.00% (0/62)*	**1.61% (1/62)**	*0.00% (0/59)*	**0.00% (0/59)**	*3.33% (5/150)*	**3.33% (5/150)**	*1.85% (5/271)*	**2.21% (6/271)**
Pending	*22.58% (14/62)*	**0.00% (0/62)**	*6.78% (4/59)*	**0.00% (0/59)**	*4.67% (7/150)*	**0.00% (0/150)**	*9.23% (25/271)*	**0.00% (0/271)**

[o] **Amended data retrieved May 14, 2018 from NMS Application statistics and NMS Lab statistics. Data are for all screened infants.** For comparison, previous years' data and NMS Program annual reports can be requested through nmsprogram@ahs.ca.

Appendix B

Performance measures data tables[p]

Initial screen results reported by the NMS Lab within 10 days of age by zone

	North	Edmonton	Central	Calgary	South	AHS Zone n/a*	Provincial total
Meeting standard	6746	17163	5112	19182	3839	407	52449
Not meeting standard	103	81	40	146	18	40	428
Unable to determine	4	5	3	8	0	1	21
Grand total	**6853**	**17249**	**5155**	**19336**	**3857**	**448**	**52898**

Birth registration in PD within 24 hours of birth by zone

	North	Edmonton	Central	Calgary	South	AHS Zone n/a*	Provincial total
Meeting standard	5690	19058	4483	19444	3854	0	52529
Not meeting standard	22	11	3	6	3	0	45
Unable to determine	93	275	33	203	37	0	641
Grand total	**5805**	**19344**	**4519**	**19653**	**3894**	**0**	**53215**

Initial sample collected between 24 and 72 hours of age by zone

	North	Edmonton	Central	Calgary	South	AHS Zone n/a*	Provincial total
Meeting standard	6249	16873	5034	19000	3801	392	51349
Not meeting standard	567	360	107	305	49	54	1442
Unable to determine	37	16	14	31	7	2	107
Grand total	**6853**	**17249**	**5155**	**19336**	**3857**	**448**	**52898**

Sample receipt by the NMS Lab within 72 hours of collection by zone

	North	Edmonton	Central	Calgary	South	AHS Zone n/a*	Provincial total
Meeting standard	7042	17859	5229	19423	3211	540	53304
Not meeting standard	310	388	213	1043	854	56	2864
Unable to determine	0	0	0	0	0	0	0
Grand total	**7352**	**18247**	**5442**	**20466**	**4065**	**596**	**56168**

Inadequate samples received by zone

	North	Edmonton	Central	Calgary	South	AHS Zone n/a*	Provincial total
Total inadequate samples	269	325	116	358	64	7	1139
Total adequate samples	5934	19990	4628	20394	3957	126	55029
Pending samples	0	0	0	0	0	0	0
Grand total	**6203**	**20315**	**4744**	**20752**	**4021**	**133**	**56168**

Repeat sample collection for inadequate results within 96 hours of notification by zone

	North	Edmonton	Central	Calgary	South	AHS Zone n/a*	Provincial total
Meeting standard	179	236	105	289	57	12	878
Not meeting standard	78	25	10	39	5	32	189
Grand total	**257**	**261**	**115**	**328**	**62**	**44**	**1067**

Repeat sample collection of reported borderline results within 96 hours of notification by zone

	North	Edmonton	Central	Calgary	South	AHS Zone n/a*	Provincial total
Meeting standard	56	216	41	204	36	8	561
Not meeting standard	17	17	2	20	7	4	67
Grand total	**73**	**233**	**43**	**224**	**43**	**12**	**628**

[p] **Data retrieved May 14, 2018 from NMS Application Report 3 & Report 8.** For comparison, previous years' data and NMS Program annual reports can be requested through nmsprogram@ahs.ca.
AHS Zone n/a* = AHS Zone not assigned

Appendix C

Further screening by the NMS Program in 2017-2018

- 60 infants who were born out of province were screened in Alberta (had a sample collected by the NMS Program)
- 56 of 60 infants who were part of a multiple birth set had a repeat sample collected. Three infants did not have a repeat collection as they were deceased and one had an abnormal screen result and therefore went straight to diagnostic testing.
- 1,228 infants had a low birth weight (less than 2000 grams at birth) that required a repeat sample collection
    - 61.40% (754/1,228) had a repeat sample collected during the recommended time period of 21 to 28 days of age
    - 30.70% (377/1,228) had a repeat sample collected earlier or later than the recommended time period of 21 to 28 days of age
    - 7.90% (97/1,228) did not have a repeat sample collected; of these infants 23.71% (23/97) are reported as deceased