

Alberta Newborn Screening Program Quarterly Performance Report 2024-2025





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ANSP QPR Q1 April – June

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Alberta Newborn Screening Program: 2024-2025 Q1 Quarterly Performance Report April 1, 2024 – June 30, 2024

October 15, 2024



This report has been prepared by the Alberta Newborn Screening Program.

Contact

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Email: newbornscreening@albertahealthservices.ca



Quality management

Alberta Newborn Screening Program (ANSP) quality is managed through a quality management framework (QMF), see Figure A. The QMF is actively used to support newborn blood spot screening service delivery, manage program performance, and improve screening services and supports. The QMF encompasses program coordination and a screening solution to fully manage quality within the ANSP as a population-based screening program.

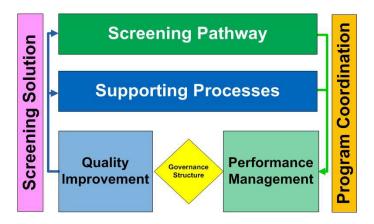


Figure A. Alberta Newborn Screening Program quality management framework

ANSP performance is measured, reported and managed to prevent or reduce negative impacts on patient safety and to facilitate continuous improvement to ensure the screening of every infant, every time.

Quarterly performance report scope

Data presented is compiled for reporting based on Alberta Newborn Screening Program (ANSP) Application reports. Data for each quarter is retrieved on the last day of the following quarter, for example data for quarter 2, July 1- September 30, is retrieved on December 31. 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. Percentage rates to the second decimal point are presented to illustrate incremental changes especially above the 90th percentile. For more information, including previous years' quarterly performance reports and annual reports, contact newbornscreening@ahs.ca.



Quarterly performance report 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.
- Low birth weight means an infant weighs less than 2000 grams at birth.
- Received samples means newborn blood spot samples received by the Alberta Newborn Screening Lab as 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 that 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.
- 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.
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Quarterly performance comparisons

ANSP quarterly performance data for comparison are presented in Table 1 for the current quarter (April 1 to June 30) and previous four quarters. Improvements in performance over the previous quarter are shown in **bold**.

Note: For comparison, contact newbornscreening@ahs.ca to see previous years' quarterly performance reports and annual reports



Table 1: ANSP performance measures for the reporting period and previous four quarters

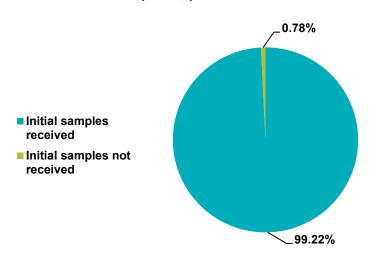
QPR figure & ANSP performance measure*	Q1 2023- 2024	Q2 2023- 2024	Q3 2023- 2024	Q4 2023- 2024	Q1 2024- 2025
Figure 1: Program participation rate and non-participation rationale Percentage of infants born and registered as newborns in Alberta that received an initial newborn blood spot screen. Reported by zone of responsibility	99.07%	99.09%	99.06%	99.15%	99.22%
Figure 2: Inadequate samples and inadequate samples rationale Percentage of samples received by Alberta Newborn Screening Laboratory deemed to be inadequate as determined by the lab. Reported by zone of collection	1.50%	1.41%	1.80%	1.65%	1.81%
Figure 3: Birth registration within 24 hours of age Percentage of infants born and registered as newborns in Alberta within 24 hours of age. Reported by zone of birth	98.64%	98.68%	98.53%	98.58%	98.84%
Figure 4: Initial sample collection between 24 and 72 hours of age Percentage of infants registered as newborns in Alberta with an initial sample collected between 24 and 72 hours of age. Reported by zone of responsibility	98.03%	98.34%	97.79%	98.17%	98.04%
Figure 5: Sample receipt by Alberta Newborn Screening Laboratory within 72 hours of sample collection Percentage of samples received by the Alberta Newborn Screening Laboratory within 72 hours of collection. Reported by zone of responsibility	95.89%	96.37%	96.18%	97.22%	97.52%
Figure 6: Results reported by Alberta Newborn Screening Laboratory within 96 hours of lab receipt (excluding cystic fibrosis) Percentage of received samples with screen results reported by the Alberta Newborn Screening Laboratory within 96 hours of lab receipt (note: does not include cystic fibrosis result reporting). All screen results reported by Alberta Newborn Screening Laboratory	75.55%	73.66%	71.15%	77.99%	76.88%
Figure 7: Initial screen results reported by Alberta Newborn Screening Laboratory within 10 days of age (excluding cystic fibrosis) Percentage of infants born and registered as newborns in Alberta that received an initial newborn blood spot screen and results reported by the Alberta Newborn Screening Laboratory within 10 days of age (note: does not include cystic fibrosis result reporting). Reported by zone of responsibility	98.19%	97.74%	98.58%	98.40%	98.64%
Figure 8: Repeat sample collection within 96 hours of notification of reported inadequate results Percentage of repeat samples collected within 96 hours of notification of reported inadequate results. Reported by zone of responsibility	80.56%	82.39%	83.17%	82.13%	77.78%
Figure 9: Repeat sample collection within 96 hours of notification of reported borderline results (excluding tyrosine) Percentage of repeat samples collected within 96 hours of notification of reported borderline results (note: does not include increased tyrosine result). Reported by zone of responsibility	81.90%	91.92%	90.32%	86.84%	85.56%
Figure 10: Samples collected between 21 days and 28 days of age for infants with low birth weight Percentage of samples collected for low birth weight infants within 504 hours and 672 hours of birth	96.82%	95.08%	96.64%	96.24%	96.17%
Source: ANSP Application reports Date: Date retrieved from ANSP Application	September 29, 2023	December 29, 2023	April 1, 2024	July 2, 2024	October1, 2024

^{*}excludes all samples analyzed & reported by the Alberta Newborn Screening Laboratory for infants whose samples were collected outside of Alberta



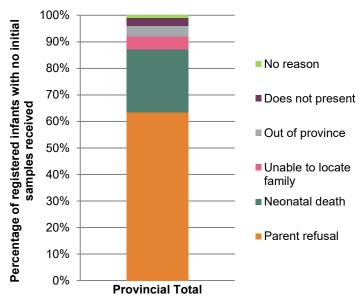
Figure 1: Program participation rate and non-participation rationale¹

Participation, provincial total



Initial Samples	Provincial Total	Provincial Total %
Initial samples received	12931	99.22%
Initial samples not received	101	0.78%
Grand Total	13032	100.00%

Non-participation rationale, provincial total



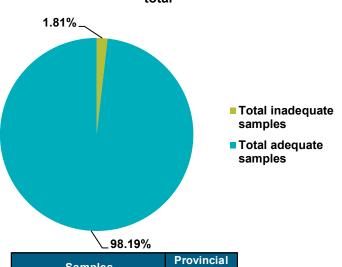
Non-participation rationale	Provincial Total	Provincial Total %
Parent refusal	64	63.37%
Neonatal death	24	23.76%
Unable to locate family	5	4.95%
Out of province	4	3.96%
Does not present	3	2.97%
No reason	1	0.99%
Grand Total	101	100.00%



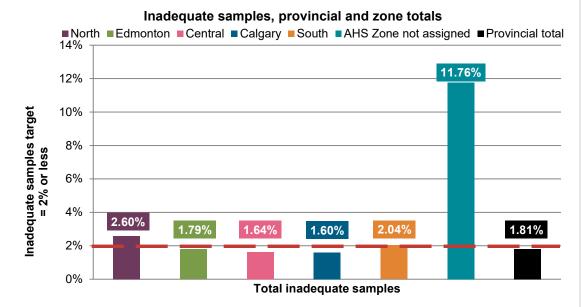
¹ Data retrieved October 1, 2024 from ANSP Application Report 1 & ANSP Application statistics. Data are for all registered infants by zone of responsibility.

Figure 2: Inadequate samples and inadequate samples rationale²

Inadequate and adequate samples, provincial total



∑98.19%								
Samples	Provincial total							
Total inadequate samples	246							
Total adequate samples	13357							
Grand Total	13603							



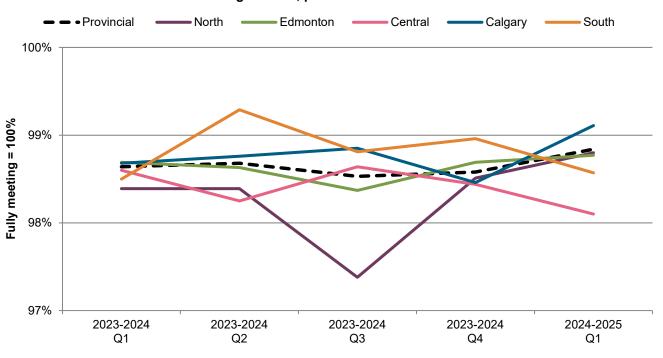
Inadequate samples rationale		Edmonton	Central	Calgary	South	AHS Zone not assigned	Provincial Total
<24 hours	5	17	5	23	8	0	58
Assay failed	0	1	0	0	0	0	1
Blood clotted and layered	6	16	1	26	2	0	51
Date or time of birth illegible or not indicated	1	0	1	0	0	0	2
Date or time of collection illegible or not indicated	8	11	3	9	3	1	35
Query patient identification	0	4	0	1	0	0	5
Sample contaminated	0	2	0	4	0	0	6
Sample insufficient (NSQ)	6	3	10	3	3	0	25
Sample stability exceeded	0	0	3	0	0	0	3
Specimen abraded	16	5	25	10	3	1	60
Grand Total	42	59	48	76	19	2	246

² Data retrieved October 1, 2024 from ANSP Application Report 3. Data are for all received samples by zone of collection. Details on AHS zone not assigned available upon request.



Figure 3: Birth registration within 24 hours of age³

Birth registration, provincial and zone trend



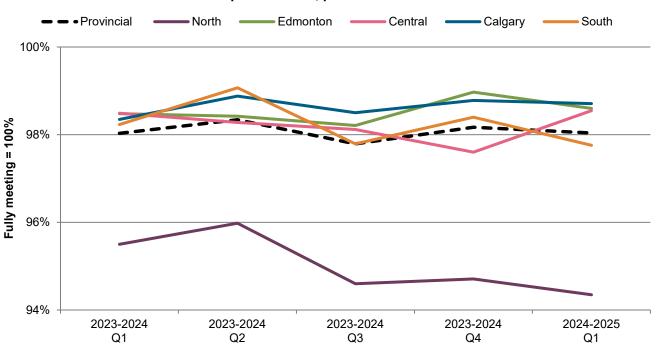
Q1 2024-2025	North	Edmonton	Central	Calgary	South	Provincial total
Meeting standard (%)	98.80%	98.77%	98.10%	99.11%	98.57%	98.84%
Meeting standard (n)	1151	4747	981	5106	895	12880
Not meeting standard (n)	1	0	0	3	0	4
Unable to determine (n)	13	59	19	43	13	147
Grand Total	1165	4806	1000	5152	908	13031



³ Data retrieved October 1, 2024 from ANSP Application Report 8, Section A. Data are for all registered infants by zone of birth.

Figure 4: Initial sample collection between 24 and 72 hours of age⁴

Initial sample collection, provincial and zone trend



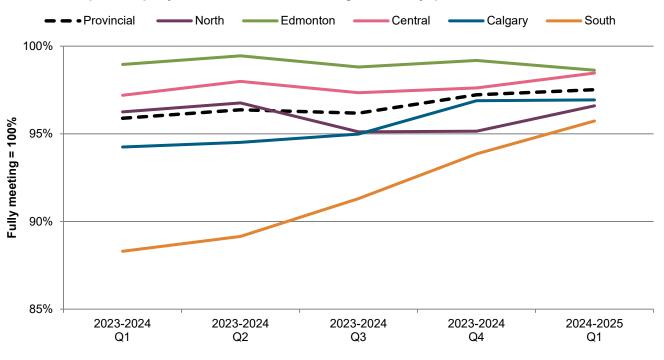
Q1 2024-2025	North	Edmonton	Central	Calgary	South	AHS Zone not assigned	Provincial total
Meeting standard (%)	94.35%	98.60%	98.55%	98.71%	97.76%	86.96%	98.04%
Meeting standard (n)	1320	4295	1157	4910	915	80	12677
Not meeting standard (n)	72	58	14	57	20	10	231
Unable to determine (n)	7	3	3	7	1	2	23
Grand Total	1399	4356	1174	4974	936	92	12931

⁴ Data retrieved October 1, 2024 from ANSP Application Report 8, Section B. Data are for all registered screened infants by zone of responsibility. Details on AHS zone not assigned available upon request.



Figure 5: Sample receipt by Alberta Newborn Screening Laboratory within 72 hours of sample collection⁵





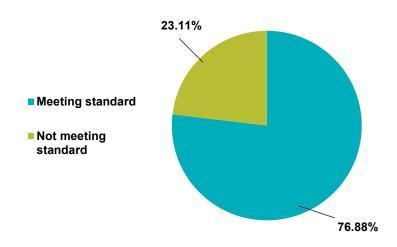
Q1 2024-2025	North	Edmonton	Central	Calgary	South	AHS Zone not assigned	Provincial total
Meeting standard (%)	96.60%	98.63%	98.46%	96.93%	95.73%	96.58%	97.52%
Meeting standard (n)	1419	4525	1213	5054	942	113	13266
Not meeting standard (n)	50	63	19	160	42	4	338
Unable to determine (n)	0	0	0	0	0	0	0
Grand Total	1469	4588	1232	5214	984	117	13604

⁵ Data retrieved October 1, 2024 from ANSP Application Report 8, Section D. Data are for all received samples by zone of responsibility. Details on AHS zone not assigned available upon request.



Figure 6: Results reported by Alberta Newborn Screening Laboratory within 96 hours of lab receipt (excluding cystic fibrosis)⁶

Results reported, provincial total



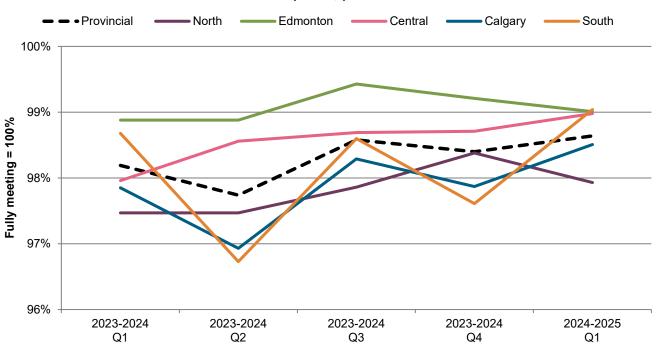
Q1 2024-2025	Provincial total
Meeting standard	10459
Not meeting standard	3144
Unable to determine	1
Grand Total	13604



⁶ Data retrieved October 1, 2024 from ANSP Application Report 8, Section E, Data are for all received samples excluding CF for all zones combined.

Figure 7: Initial screen results reported by Alberta Newborn Screening Laboratory within 10 days of age (excluding cystic fibrosis)⁷

Initial screen results reported, provincial and zone trend

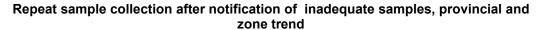


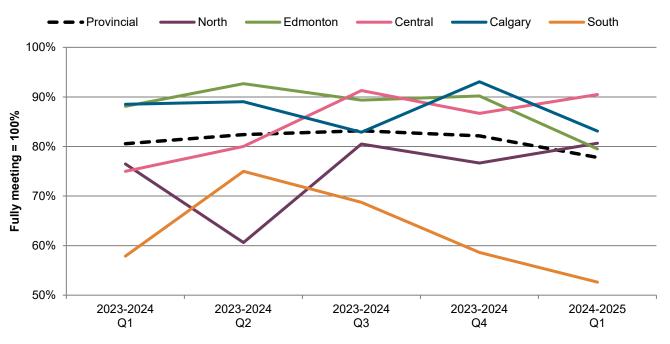
Q1 2024-2025	North	Edmonton	Central	Calgary	South	AHS Zone not assigned	Provincial total
Meeting standard (%)	97.93%	99.01%	98.98%	98.51%	99.04%	90.22%	98.64%
Meeting standard (n)	1370	4313	1162	4900	927	83	12755
Not meeting standard (n)	29	43	12	71	9	8	172
Unable to determine (n)	0	0	0	3	0	1	4
Grand Total	1399	4356	1174	4974	936	92	12931

⁷ Data retrieved October 1, 2024 from ANSP Application Report 8, Section F. Data are for all registered screened infants by zone of responsibility. Details on AHS zone not assigned available upon request.



Figure 8: Repeat sample collection within 96 hours of notification of reported inadequate samples8





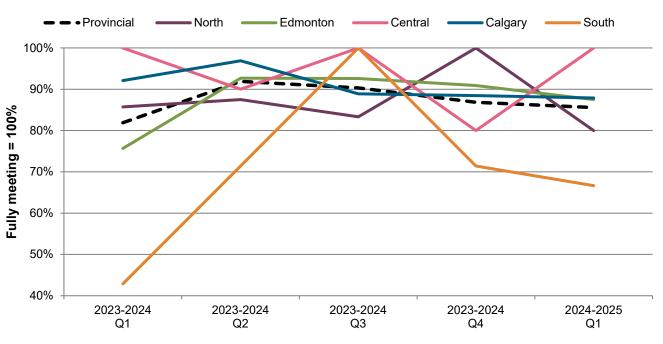
Q1 2024-2025	North	Edmonton	Central	Calgary	South	AHS Zone not assigned	Provincial total
Meeting standard (%)	80.65%	79.49%	90.48%	83.12%	52.63%	25.00%	77.78%
Meeting standard (n)	25	62	19	64	10	2	182
Not meeting standard (n)	6	16	2	13	9	6	52
Grand Total	31	78	21	77	19	8	234

⁸ Data retrieved October 1, 2024 from ANSP Application Report 8, Section G. Data are for all notifications of reported inadequate results by zone of responsibility. Details on AHS zone not assigned available upon request.



Figure 9: Repeat sample collection within 96 hours of notification of reported borderline results (excluding tyrosine)⁹

Repeat sample collection after notification of borderline results, provincial and zone trend

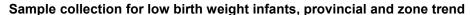


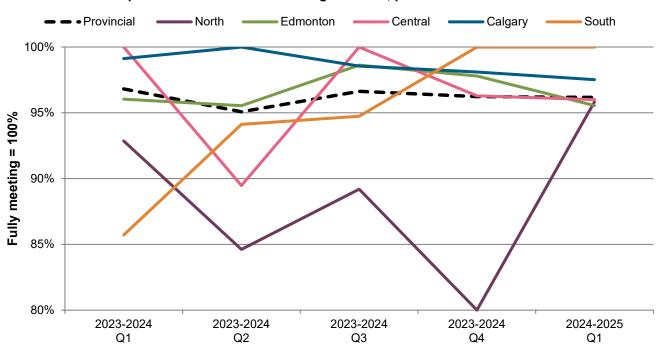
Q1 2024-2025	North	Edmonton	Central	Calgary	South	AHS Zone not assigned	Provincial total
Meeting standard (%)	80.00%	87.50%	100.00%	87.88%	66.67%	0.00%	85.56%
Meeting standard (n)	8	28	8	29	4	0	77
Not meeting standard (n)	2	4	0	4	2	1	13
Grand Total	10	32	8	33	6	1	90

⁹ Data retrieved October 1, 2024 from ANSP Application Report 8, Section H. Data for all notifications of reported borderline results by zone of responsibility. Details on AHS zone not assigned available upon request.



Figure 10: Sample collection between 21 days and 28 days of age for low birth weight infants 10





Q1 2024-2025	North	Edmonton	Central	Calgary	South	AHS Zone not assigned	Provincial total
Meeting standard (%)	95.83%	95.56%	96.00%	97.52%	100.00%	71.43%	96.17%
Meeting standard (n)	23	86	24	118	20	5	276
Not meeting standard (n)	1	4	1	3	0	2	11
Grand Total	24	90	25	121	20	7	287

¹⁰ Data retrieved October 1, 2024 from ANSP Application Report 10 & 11. Data for all low birth weight infants by zone of responsibility. Details on AHS zone not assigned available upon request.



Alberta Newborn Screening Program: 2024-2025 Q2 Quarterly Performance Report July 1, 2024 – September 30, 2024

January 15, 2025



This report has been prepared by the Alberta Newborn Screening Program.

Contact

For more information, please contact:

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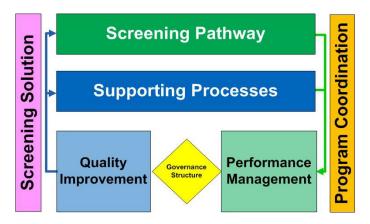


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Table 1: ANSP performance measures for the reporting period and previous four quarters

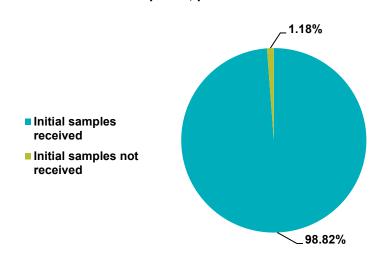
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Source: ANSP Application reports Date: Date retrieved from ANSP Application	December 29, 2023	April 1, 2024	July 2, 2024	October1, 2024	January 2, 2025

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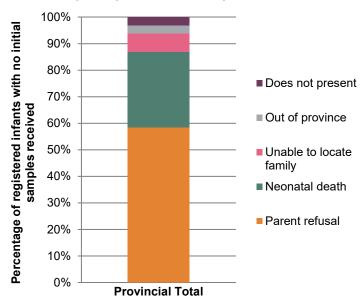
Figure 1: Program participation rate and non-participation rationale¹

Participation, provincial total



Initial Samples	Provincial Total	Provincial Total %
Initial samples received	13474	98.82%
Initial samples not received	161	1.18%
Grand Total	13635	100.00%

Non-participation rationale, provincial total



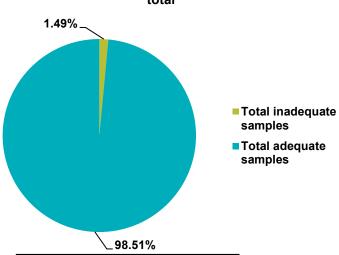
Non-participation rationale	Provincial Total	Provincial Total %		
Parent refusal	94	58.39%		
Neonatal death	46	28.57%		
Unable to locate family	11	6.83%		
Out of province	5	3.11%		
Does not present	5	3.11%		
Grand Total	161	100.00%		



¹ Data retrieved January 2, 2025 from ANSP Application Report 1 & ANSP Application statistics. Data are for all registered infants by zone of responsibility.

Figure 2: Inadequate samples and inadequate samples rationale²

Inadequate and adequate samples, provincial total



Samples	Provincial total
Total inadequate samples	210
Total adequate samples	13894
Grand Total	14104

Inadequate samples, provincial and zone totals ■North ■Edmonton ■Central ■Calgary ■South ■AHS Zone not assigned ■Provincial total 10.81% 10% Inadequate samples target = 2% or less 8% 6% 4% 2.29% 1.47% 1.31% 1.94% 1.49% 2% 0.83% 0% Total inadequate samples

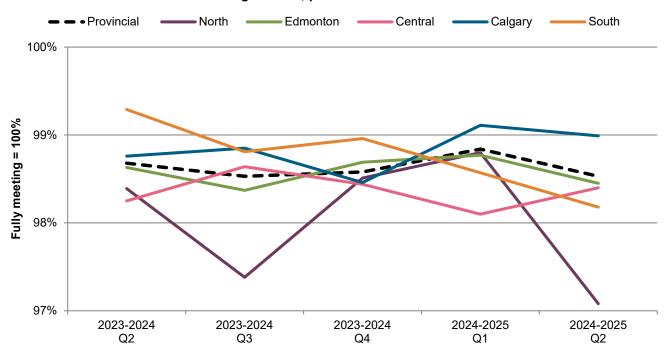
Inadequate samples rationale	North	Edmonton	Central	Calgary	South	AHS Zone not assigned	Provincial Total
<24 hours	7	25	1	19	7	0	59
Assay failed	0	1	0	1	0	0	2
Blood clotted and layered	1	4	1	18	0	0	24
Date or time of birth illegible or not indicated	0	1	0	1	0	0	2
Date or time of collection illegible or not indicated	2	6	0	4	2	1	15
Query patient identification	3	1	0	3	0	0	7
Sample contaminated	0	2	0	10	1	0	13
Sample insufficient (NSQ)	4	11	3	3	4	0	25
Sample stability exceeded	3	0	0	2	0	1	6
Specimen abraded	8	27	3	13	4	2	57
Grand Total	28	78	8	74	18	4	210

² Data retrieved January 2, 2025 from ANSP Application Report 3. Data are for all received samples by zone of collection. Details on AHS zone not assigned available upon request.



Figure 3: Birth registration within 24 hours of age³

Birth registration, provincial and zone trend



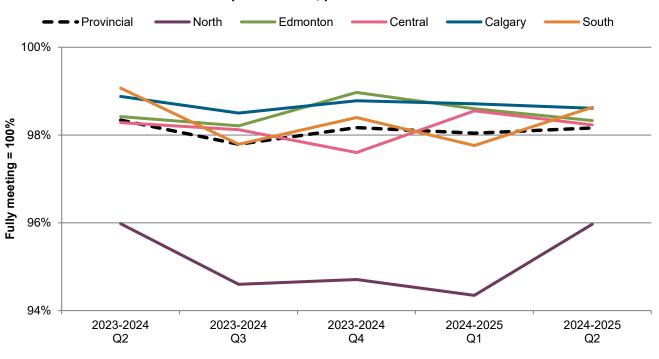
Q2 2024-2025	North	Edmonton	Central	Calgary	South	Provincial total
Meeting standard (%)	97.08%	98.45%	98.40%	98.99%	98.18%	98.53%
Meeting standard (n)	1165	5088	922	5397	862	13434
Not meeting standard (n)	5	5	0	2	0	12
Unable to determine (n)	30	75	15	53	16	189
Grand Total	1200	5168	937	5452	878	13635



³ Data retrieved January 2, 2025 from ANSP Application Report 8, Section A. Data are for all registered infants by zone of birth.

Figure 4: Initial sample collection between 24 and 72 hours of age⁴

Initial sample collection, provincial and zone trend



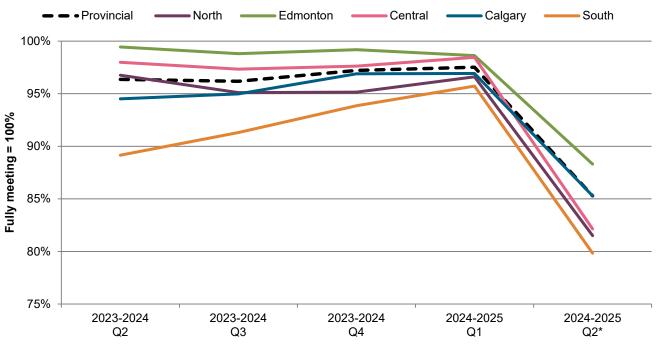
Q2 2024-2025	North	Edmonton	Central	Calgary	South	AHS Zone not assigned	Provincial total
Meeting standard (%)	95.97%	98.33%	98.23%	98.61%	98.63%	94.12%	98.16%
Meeting standard (n)	1380	4582	1111	5174	867	112	13226
Not meeting standard (n)	57	76	19	69	9	7	237
Unable to determine (n)	1	2	1	4	3	0	11
Grand Total	1438	4660	1131	5247	879	119	13474

⁴ Data retrieved January 2, 2025 from ANSP Application Report 8, Section B. Data are for all registered screened infants by zone of responsibility. Details on AHS zone not assigned available upon request.



Figure 5: Sample receipt by Alberta Newborn Screening Laboratory within 72 hours of sample collection⁵





^{*}Implementation of Connect Care resulted in change to the receiving process and a new waypoint.

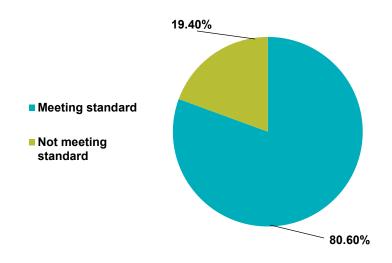
Q2 2024-2025	North	Edmonton	Central	Calgary	South	AHS Zone not assigned	Provincial total
Meeting standard (%)	81.51%	88.30%	82.15%	85.29%	79.83%	82.64%	85.28%
Meeting standard (n)	1221	4293	971	4691	736	119	12031
Not meeting standard (n)	277	567	211	809	186	25	2075
Unable to determine (n)	0	2	0	0	0	0	2
Grand Total	1498	4862	1182	5500	922	144	14108

⁵ Data retrieved January 2, 2025 from ANSP Application Report 8, Section D. Data are for all received samples by zone of responsibility. Details on AHS zone not assigned available upon request.



Figure 6: Results reported by Alberta Newborn Screening Laboratory within 96 hours of lab receipt (excluding cystic fibrosis)⁶

Results reported, provincial total



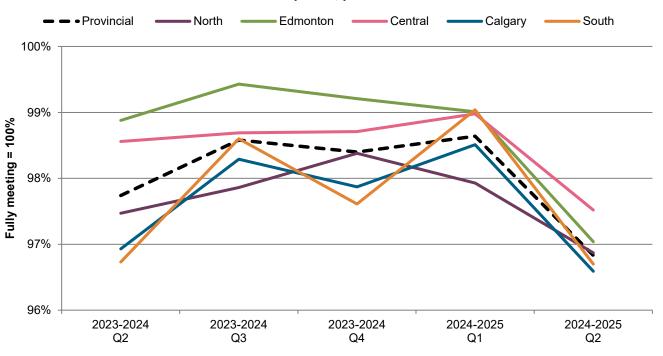
Q2 2024-2025	Provincial total
Meeting standard	11371
Not meeting standard	2737
Unable to determine	0
Grand Total	14108



⁶ Data retrieved January 2, 2025 from ANSP Application Report 8, Section E, Data are for all received samples excluding CF for all zones combined.

Figure 7: Initial screen results reported by Alberta Newborn Screening Laboratory within 10 days of age (excluding cystic fibrosis)⁷

Initial screen results reported, provincial and zone trend

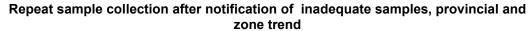


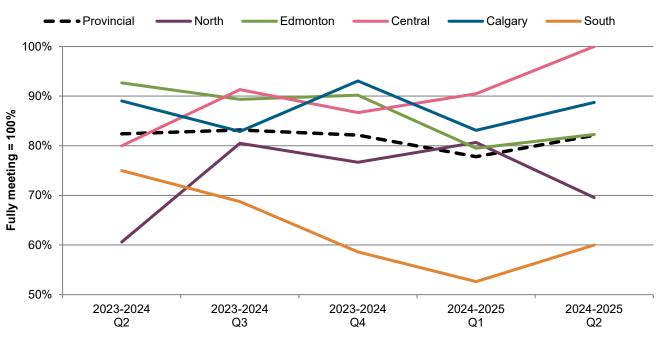
Q2 2024-2025	North	Edmonto n	Central	Calgary	South	AHS Zone not assigned	Provincial total
Meeting standard (%)	96.87%	97.04%	97.52%	96.59%	96.70%	93.28%	96.83%
Meeting standard (n)	1393	4522	1103	5068	850	111	13047
Not meeting standard (n)	45	138	28	179	29	8	427
Unable to determine (n)	0	0	0	0	0	0	0
Grand Total	1438	4660	1131	5247	879	119	13474

⁷ Data retrieved January 2, 2025 from ANSP Application Report 8, Section F. Data are for all registered screened infants by zone of responsibility. Details on AHS zone not assigned available upon request.



Figure 8: Repeat sample collection within 96 hours of notification of reported inadequate samples8





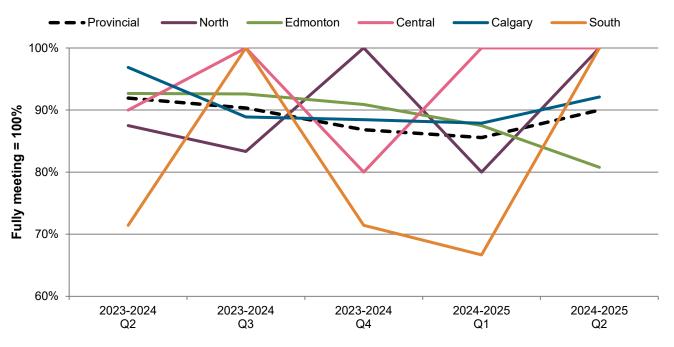
Q2 2024-2025	North	Edmonton	Central	Calgary	South	AHS Zone not assigned	Provincial total
Meeting standard (%)	69.57%	82.26%	100.00%	88.73%	60.00%	60.00%	82.11%
Meeting standard (n)	16	51	14	63	9	3	156
Not meeting standard (n)	7	11	0	8	6	2	34
Grand Total	23	62	14	71	15	5	190

⁸ Data retrieved January 2, 2025 from ANSP Application Report 8, Section G. Data are for all notifications of reported inadequate results by zone of responsibility. Details on AHS zone not assigned available upon request.



Figure 9: Repeat sample collection within 96 hours of notification of reported borderline results (excluding tyrosine)⁹

Repeat sample collection after notification of borderline results, provincial and zone trend



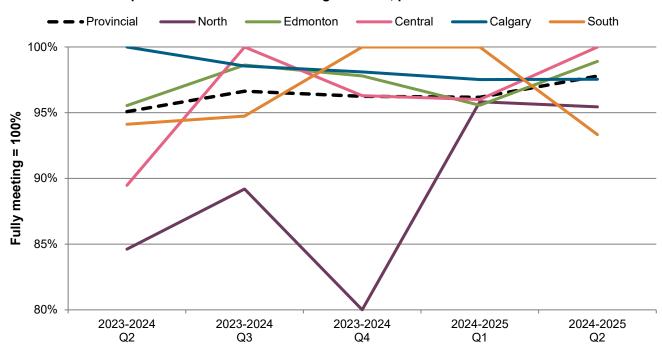
Q2 2024-2025	North	Edmonton	Central	Calgary	South	AHS Zone not assigned	Provincial total
Meeting standard (%)	100.00%	80.77%	100.00%	92.11%	100.00%	50.00%	90.00%
Meeting standard (n)	8	21	9	35	7	1	81
Not meeting standard (n)	0	5	0	3	0	1	9
Grand Total	8	26	9	38	7	2	90

⁹ Data retrieved January 2, 2025 from ANSP Application Report 8, Section H. Data for all notifications of reported borderline results by zone of responsibility. Details on AHS zone not assigned available upon request.



Figure 10: Sample collection between 21 days and 28 days of age for low birth weight infants 10

Sample collection for low birth weight infants, provincial and zone trend



Q2 2024-2025	North	Edmonton	Central	Calgary	South	AHS Zone not assigned	Provincial total
Meeting standard (%)	95.45%	98.91%	100.00%	97.54%	93.33%	100.00%	97.79%
Meeting standard (n)	21	91	19	119	14	1	265
Not meeting standard (n)	1	1	0	3	1	0	6
Grand Total	22	92	19	122	15	1	271

¹⁰ Data retrieved January 2, 2025 from ANSP Application Report 10 & 11. Data for all low birth weight infants by zone of responsibility. Details on AHS zone not assigned available upon request.

