

Alberta Newborn Screening Program Quarterly Performance Report 2023-2024





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ANSP QPR Q1 April – June

ANSP QPR Q2 July - September



Alberta Newborn Screening Program: 2023-2024 Q1 Quarterly Performance Report April 1, 2023 – June 30, 2023

October 15, 2023



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

Contact

For more information, please contact:

Grace Johner Manager, Newborn Screening Programs Provincial Population & Public Health Alberta Health Services

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.

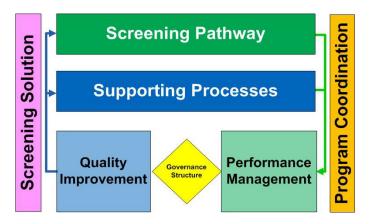


Figure A. Alberta Newborn Screening Program quality management framework

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.
- **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 for 2012-2013 to better reflect population health reporting practices based on the location of official residence.



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

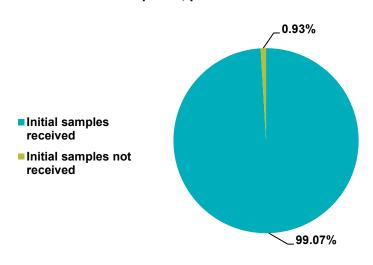
QPR figure & ANSP performance measure*	Q1 2022- 2023	Q2 2022- 2023	Q3 2022- 2023	Q4 2022- 2023	Q 1 2023- 2024
Figure 1: Program participation rate and non-participation rationale Percentage of infants born and registered as newborns in Alberta that received an initial newborn blood spot screen. Reported by zone of responsibility	99.22%	99.29%	99.25%	99.02%	99.07%
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	1.79%	1.62%	1.44%	1.58%	1.50%
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	98.79%	98.84%	98.61%	98.39%	98.64%
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	97.59%	97.97%	97.89%	98.38%	98.03%
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	96.91%	97.13%	95.54%	96.31%	95.89%
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	82.04%	71.53%	82.69%	80.57%	75.55%
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	99.00%	98.43%	99.15%	99.28%	98.19%
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	82.09%	83.33%	76.88%	88.10%	80.56%
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	93.98%	85.56%	92.11%	94.23%	81.90%
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	97.72%	98.23%	96.01%	95.73%	96.82%
Source: ANSP Application reports Date: Date retrieved from ANSP Application	October 3, 2022	December 30, 2022	March 31, 2023	June 30, 2023	September 29, 2023

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



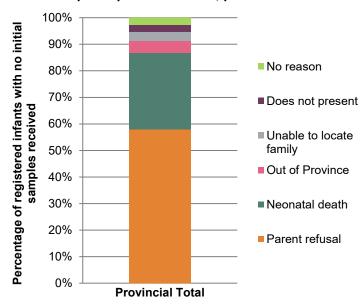
Figure 1: Program participation rate and non-participation rationale¹

Participation, provincial total



Initial Samples	Provincial Total	Provincial Total %
Initial samples received	12172	99.07%
Initial samples not received	114	0.93%
Grand Total	12286	100.00%

Non-participation rationale, provincial total



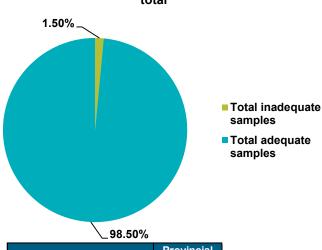
Non-participation rationale	Provincial	Provincial
Non-participation rationale	Total	Total %
Parent refusal	66	57.89%
Neonatal death	33	28.95%
Out of province	5	4.39%
Unable to locate family	4	3.51%
Does not present	3	2.63%
No reason	3	2.63%
Grand Total	114	100.00%



¹ Data retrieved September 29, 2023 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	192
Total adequate samples	12616
Grand Total	12808

Inadequate samples, provincial and zone totals ■North ■Edmonton ■Central ■Calgary ■South ■AHS Zone not assigned ■Provincial total 12.90% 12% Inadequate samples target = 2% or less 10% 8% 6% 4% 2.66% 2.42% 1.32% 1.50% 1.09% 1.72% 2% 0% Total inadequate samples

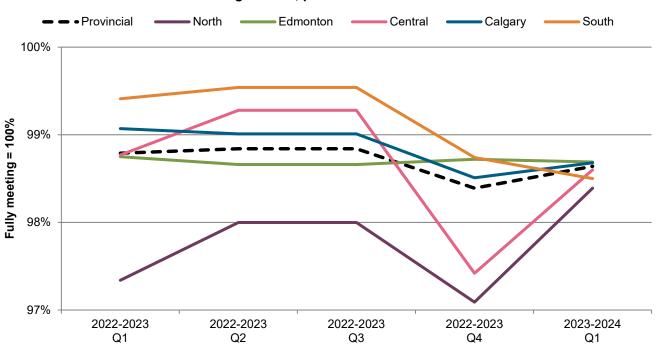
Inadequate samples rationale	North	Edmonton	Central	Calgary	South	AHS Zone not assigned	Provincial Total
<24 hours	8	15	4	20	4	0	51
Blood clotted and layered	1	7	0	12	1	0	21
Date or time of birth illegible or not indicated	0	0	0	0	1	0	1
Date or time of collection illegible or not indicated	5	6	2	5	4	3	25
Poor elution	0	0	0	0	1	0	1
Query patient identification	3	2	0	3	0	0	8
Requisition expired	0	2	1	2	1	0	6
Sample contaminated	1	1	0	2	0	0	4
Sample insufficient (NSQ)	5	10	3	10	3	0	31
Sample stability exceeded	0	2	0	0	1	0	3
Specimen abraded	9	6	7	12	6	1	41
Grand Total	32	51	17	66	22	4	192

² Data retrieved September 29, 2023 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



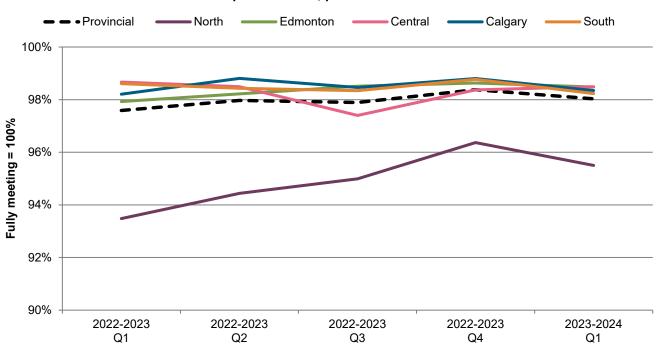
Q1 2023-2024	North	Edmonton	Central	Calgary	South	Provincial total
Meeting standard (%)	98.39%	98.69%	98.60%	98.68%	98.50%	98.64%
Meeting standard (n)	1098	4375	918	4875	853	12119
Not meeting standard (n)	4	0	5	7	0	16
Unable to determine (n)	14	58	8	58	13	151
Grand Total	1116	4433	931	4940	866	12286



³ Data retrieved September 29, 2023 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



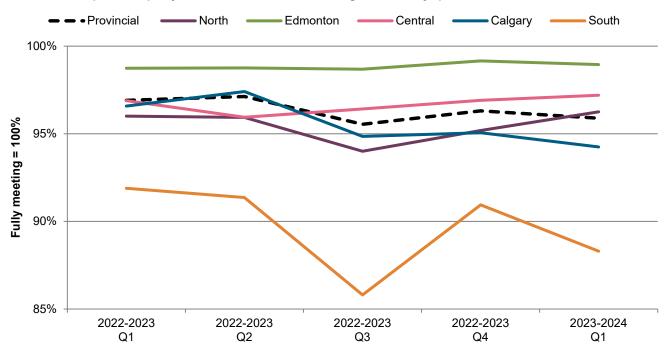
Q1 2023-2024	North	Edmonton	Central	Calgary	South	AHS Zone not assigned	Provincial total
Meeting standard (%)	95.50%	98.48%	98.49%	98.35%	98.23%	94.78%	98.03%
Meeting standard (n)	1357	3940	1108	4528	890	109	11932
Not meeting standard (n)	60	58	14	70	12	6	220
Unable to determine (n)	4	3	3	6	4	0	20
Grand Total	1421	4001	1125	4604	906	115	12172

⁴ Data retrieved September 29, 2023 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





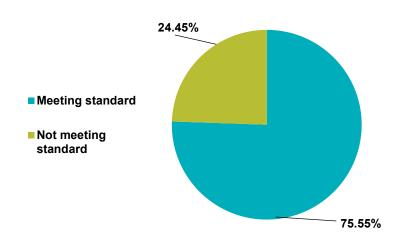
Q1 2023-2024	North	Edmonton	Central	Calgary	South	AHS Zone not assigned	Provincial total
Meeting standard (%)	96.25%	98.95%	97.20%	94.25%	88.30%	97.26%	95.89%
Meeting standard (n)	1436	4160	1145	4553	845	142	12281
Not meeting standard (n)	56	44	33	278	112	4	527
Unable to determine (n)	0	0	0	0	0	0	0
Grand Total	1492	4204	1178	4831	957	146	12808

⁵ Data retrieved September 29, 2023 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



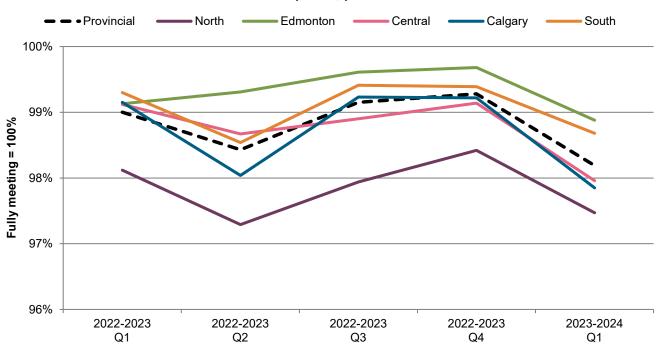
Q1 2023-2024	Provincial total
Meeting standard	9676
Not meeting standard	3132
Unable to determine	0
Grand Total	12808



⁶ Data retrieved September 29, 2023 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

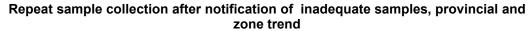


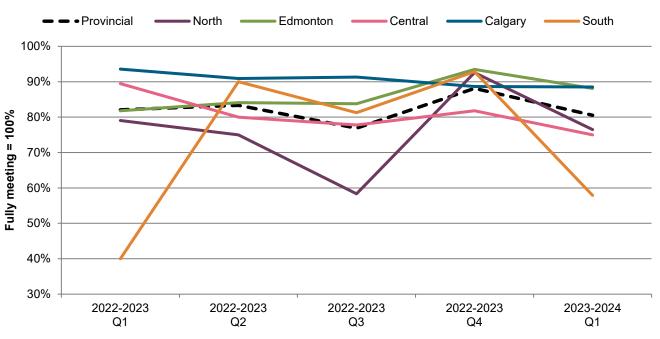
Q1 2023-2024	North	Edmonton	Central	Calgary	South	AHS Zone not assigned	Provincial total
Meeting standard (%)	97.47%	98.88%	97.96%	97.85%	98.68%	95.65%	98.19%
Meeting standard (n)	1385	3956	1102	4505	894	110	11952
Not meeting standard (n)	36	45	23	99	12	5	220
Unable to determine (n)	0	0	0	0	0	0	0
Grand Total	1421	4001	1125	4604	906	115	12172

⁷ Data retrieved September 29, 2023 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





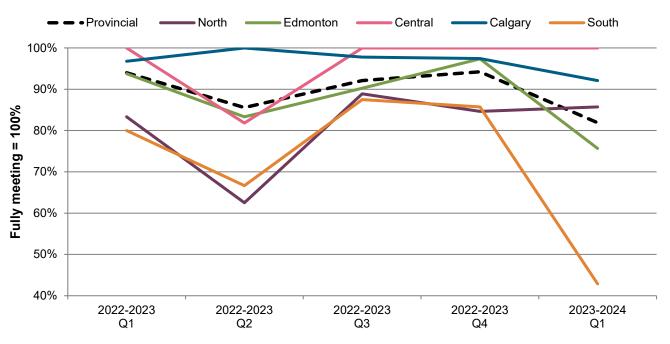
Q1 2023-2024	North	Edmonton	Central	Calgary	South	AHS Zone not assigned	Provincial total
Meeting standard (%)	76.47%	88.10%	75.00%	88.52%	57.89%	50.00%	80.56%
Meeting standard (n)	26	37	15	54	11	2	145
Not meeting standard (n)	8	5	5	7	8	2	35
Grand Total	34	42	20	61	19	4	180

⁸ Data retrieved September 29, 2023 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



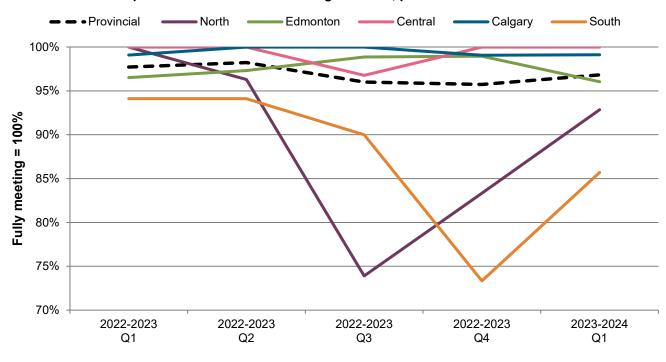
Q1 2023-2024	North	Edmonton	Central	Calgary	South	AHS Zone not assigned	Provincial total
Meeting standard (%)	85.71%	75.68%	100.00%	92.11%	42.86%	66.67%	81.90%
Meeting standard (n)	12	28	6	35	3	2	86
Not meeting standard (n)	2	9	0	3	4	1	19
Grand Total	14	37	6	38	7	3	105

⁹ Data retrieved September 29, 2023 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



Q1 2023-2024	North	Edmonton	Central	Calgary	South	AHS Zone not assigned	Provincial total
Meeting standard (%)	92.86%	96.04%	100.00%	99.13%	85.71%	100.00%	96.82%
Meeting standard (n)	13	97	22	114	18	10	274
Not meeting standard (n)	1	4	0	1	3	0	9
Grand Total	14	101	22	115	21	10	283

¹⁰ Data retrieved September 29, 2023 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: 2023-2024 Q2 Quarterly Performance Report July 1, 2023 – September 30, 2023

January 15, 2024



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

Contact

For more information, please contact:

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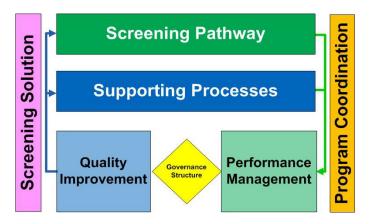


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Table 1: ANSP performance measures for the reporting period and previous four quarters

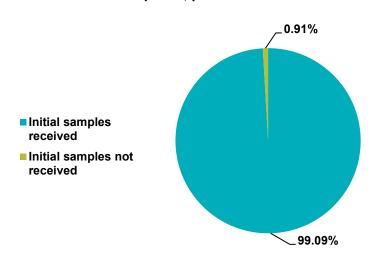
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Source: ANSP Application reports Date: Date retrieved from ANSP Application	December 30, 2022	March 31, 2023	June 30, 2023	September 29, 2023	December 29, 2023

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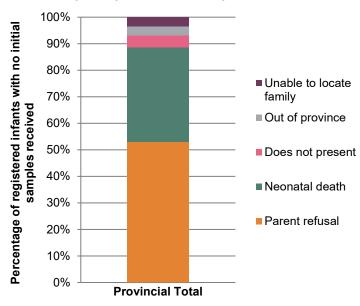
Figure 1: Program participation rate and non-participation rationale¹

Participation, provincial total



Initial Samples	Provincial Total	Provincial Total %
Initial samples received	12546	99.09%
Initial samples not received	115	0.91%
Grand Total	12661	100.00%

Non-participation rationale, provincial total



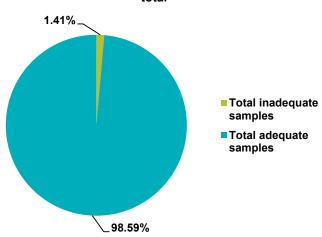
Non-participation rationale	Provincial Total	Provincial Total %
Parent refusal	61	53.04%
Neonatal death	41	35.65%
Does not present	5	4.35%
Out of province	4	3.48%
Unable to locate family	4	3.48%
Grand Total	115	100.00%



¹ Data retrieved December 29, 2023 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



13024

13210

_98.59%					
Samples	Provincial total				
Total inadequate samples	186				

Total adequate samples

Grand Total

Inadequate samples, provincial and zone totals ■North ■Edmonton ■Central ■Calgary ■South ■AHS Zone not assigned ■Provincial total 14.29% 14% 12% Inadequate samples target = 2% or less 10% 8% 6% 4% 2.68% 1.00% 1.45% 1.44% 1.48% 1.41% 2% 0%

Total inadequate samples

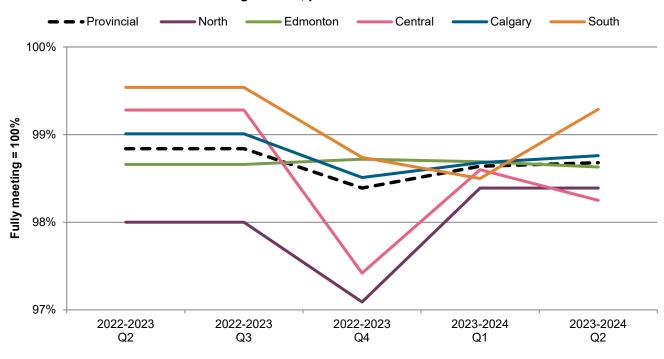
Inadequate samples rationale	North	Edmonton	Central	Calgary	South	AHS Zone not assigned	Provincial Total
<24 hours	5	8	7	14	1	0	35
Assay failed	0	1	0	1	0	0	2
Blood clotted and layered	2	4	0	22	1	0	29
Date or time of birth illegible or not indicated	0	1	0	0	0	0	1
Date or time of collection illegible or not indicated	2	12	0	6	5	0	25
Poor elution	0	0	0	1	0	0	1
Query patient identification	0	3	0	0	0	0	3
Requisition expired	0	0	0	1	0	0	1
Sample contaminated	1	0	0	5	0	0	6
Sample insufficient (NSQ)	5	9	2	12	2	0	30
Sample stability exceeded	0	0	1	0	0	0	1
Specimen abraded	16	11	5	13	4	3	52
Grand Total	31	49	15	75	13	3	186

² Data retrieved December 29, 2023 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



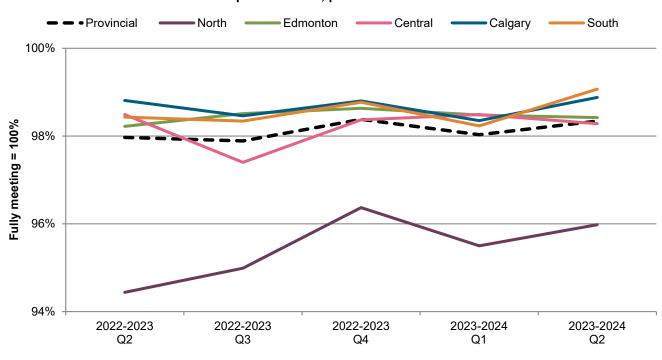
Q2 2023-2024	North	Edmonton	Central	Calgary	South	Provincial total
Meeting standard (%)	98.39%	98.63%	98.25%	98.76%	99.29%	98.68%
Meeting standard (n)	1038	4605	899	5112	840	12494
Not meeting standard (n)	2	1	5	3	0	11
Unable to determine (n)	15	63	11	61	6	156
Grand Total	1055	4669	915	5176	846	12661



³ Data retrieved December 29, 2023 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



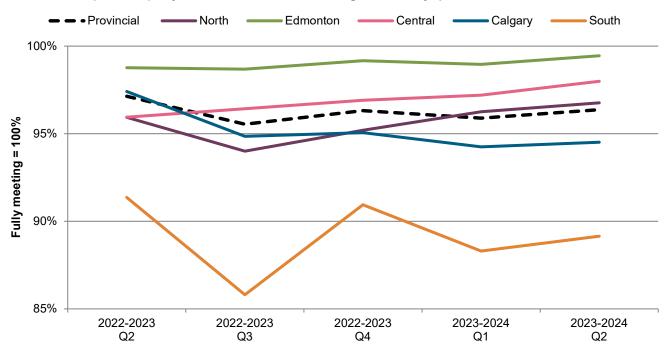
Q2 2023-2024	North	Edmonton	Central	Calgary	South	AHS Zone not assigned	Provincial total
Meeting standard (%)	95.98%	98.42%	98.28%	98.88%	99.07%	96.46%	98.34%
Meeting standard (n)	1289	4112	1027	4870	849	191	12338
Not meeting standard (n)	54	58	18	50	6	7	193
Unable to determine (n)	0	8	0	5	2	0	15
Grand Total	1343	4178	1045	4925	857	198	12546

⁴ Data retrieved December 29, 2023 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





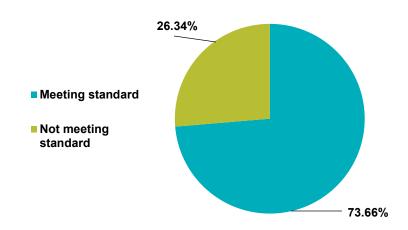
Q2 2023-2024	North	Edmonton	Central	Calgary	South	AHS Zone not assigned	Provincial total
Meeting standard (%)	96.76%	99.45%	97.99%	94.51%	89.15%	96.93%	96.37%
Meeting standard (n)	1375	4373	1072	4892	797	221	12730
Not meeting standard (n)	46	24	22	284	97	7	480
Unable to determine (n)	0	0	0	0	0	0	0
Grand Total	1421	4397	1094	5176	894	228	13210

⁵ Data retrieved December 29, 2023 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



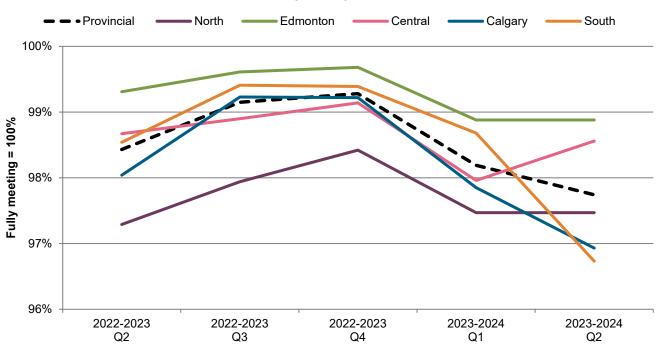
Q2 2023-2024	Provincial total
Meeting standard	9731
Not meeting standard	3479
Unable to determine	0
Grand Total	13210



⁶ Data retrieved December 29, 2023 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

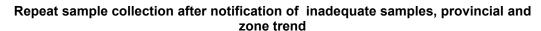


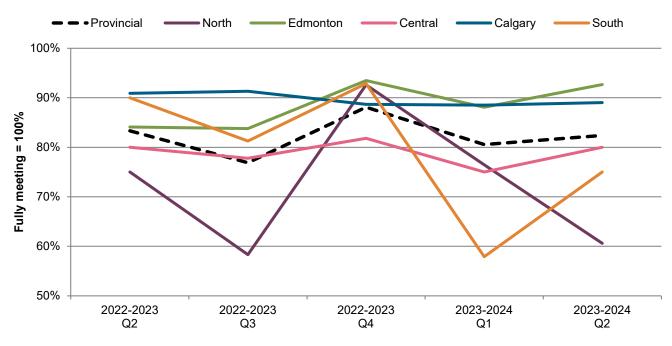
Q2 2023-2024	North	Edmonton	Central	Calgary	South	AHS Zone not assigned	Provincial total
Meeting standard (%)	97.47%	98.88%	98.56%	96.93%	96.73%	95.96%	97.74%
Meeting standard (n)	1309	4131	1030	4774	829	190	12263
Not meeting standard (n)	34	47	15	151	28	8	283
Unable to determine (n)	0	0	0	0	0	0	0
Grand Total	1343	4178	1045	4925	857	198	12546

⁷ Data retrieved December 29, 2023 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





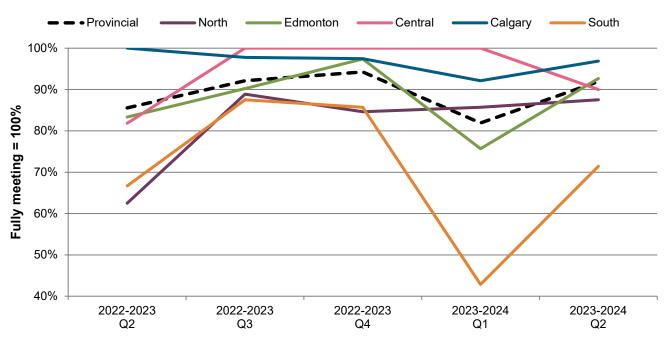
Q2 2023-2024	North	Edmonton	Central	Calgary	South	AHS Zone not assigned	Provincial total
Meeting standard (%)	60.61%	92.68%	80.00%	89.04%	75.00%	66.67%	82.39%
Meeting standard (n)	20	38	12	65	6	4	145
Not meeting standard (n)	13	3	3	8	2	2	31
Grand Total	33	41	15	73	8	6	176

⁸ Data retrieved December 29, 2023 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



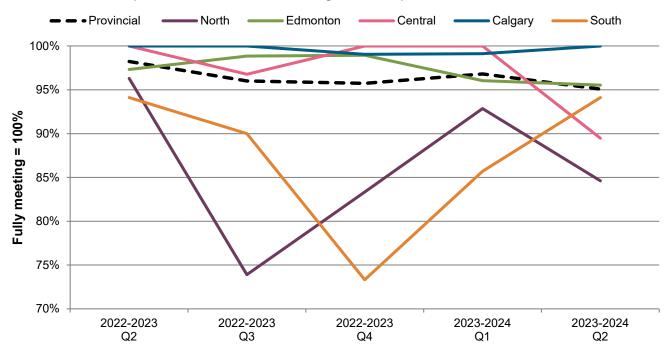
Q2 2023-2024	North	Edmonton	Central	Calgary	South	AHS Zone not assigned	Provincial total
Meeting standard (%)	87.50%	92.68%	90.00%	96.88%	71.43%	100.00%	91.92%
Meeting standard (n)	7	38	9	31	5	1	91
Not meeting standard (n)	1	3	1	1	2	0	8
Grand Total	8	41	10	32	7	1	99

⁹ Data retrieved December 29, 2023 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 2023-2024	North	Edmonton	Central	Calgary	South	AHS Zone not assigned	Provincial total
Meeting standard (%)	84.62%	95.54%	89.47%	100.00%	94.12%	57.14%	95.08%
Meeting standard (n)	22	107	17	124	16	4	290
Not meeting standard (n)	4	5	2	0	1	3	15
Grand Total	26	112	19	124	17	7	305

¹⁰ Data retrieved December 29, 2023 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.

