# EHDI Program

2022-2023 Annual Report

April 1, 2022 to March 31, 2023

JANUARY 2024

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This report has been prepared by Screening Programs. For more information about the EHDI Program, visit <u>Early Hearing Detection & Intervention Program | Alberta Health Services.</u>

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## **Executive Summary**

The Early Hearing Detection & Intervention (EHDI) Program is a provincial, population-based screening program that identifies permanent congenital hearing loss (PCHL) early on in an infant's life. This ensures that follow-up and support can be provided sooner to infants and their families.

The EHDI Program became a provincial Alberta Health Services (AHS) program in October 2018. Program activities are coordinated by a dedicated team within AHS Screening Programs.

The measures described in this report reflect the EHDI Program's performance during the 2022-2023 reporting year (April 1, 2022 to March 31, 2023):

- Hearing screening was completed for 80.4% of infants born in Alberta
- 94.8% of those screened infants had their screening completed by one month of age
- 80.9% of infants who did not pass their hearing screening received a final diagnostic result
- 87.1% of infants who did not pass their hearing screening completed a diagnostic assessment by three months of age
- 74 infants born during the reporting year were confirmed to have PCHL

Program performance for this reporting period remained fairly consistent with performance during the 2021-2022 reporting year. Hearing screening participation rate was almost identical to the previous reporting year (0.1% decrease). Overall, there was an increased adherence in meeting program standards. There was a more significant increase in meeting the 3-month standard for diagnostic assessments (14.3% increase) compared to the 1-month screening standard (0.4% increase). Additionally, compared to the previous reporting period, there was a 3.1% increase in the number of infants who did not pass their hearing screening and received a final diagnostic result.

## Summary of EHDI Program provincial performance

Performance	2022-2023 data	2021-2022 data
Screening participation rate	80.4% (42,158/52,441)	80.5% (43,894/54,553)
Percentage of screened infants who completed hearing screening by one month of age (target >95%)	94.8% (39,968/42,158)	94.4% (41,422/43,894)
Distribution of screening	NICU: 9.8% Postpartum: 69.4% Community: 20.0%	NICU: 9.0% Postpartum: 67.5% Community: 22.8%
Percentage of screened infants who completed hearing screening and received a PASS result	95.0% (40,064/42,158)	94.9% (41,646/43,894)
Percentage of screened infants who completed hearing screening and received a PASS WITH RISK FACTORS result	1.9% (807/42,158)	2.1% (922/43,894)
Percentage of screened infants who completed hearing screening and received a REFER result (target <4%)	3.1% (1,287/42,158)	3.0% (1,326/43,894)
Number of diagnostic assessments performed	2,841	2,599
Percentage of infants who were referred for diagnostic audiological assessment and received a final diagnostic result	80.9% (1,041/1,287)	77.8% (1,032/1,326)
Percentage of infants who completed diagnostic assessment by three months of age (target >90%)	87.1% (1,036/1,190)	72.8% (869/1,193)
Average number of calendar days between screening date and diagnostic ABR assessment	44 days	62 days
Number of infants born during the reporting year confirmed with PCHL by the EHDI Program	74	64
PCHL detection rate	0.18% (74/42,158) (1.76/1,000)	0.15% (64/43,894) (1.46/1,000)

#### EHDI Program performance measures

Alberta's EHDI Program adheres to the international standard of 1-3-6: screen hearing by one month of age; diagnose permanent hearing loss by three months of age; and, ensure access to intervention by six months of age.

The performance measures reported here are in alignment with this international standard and reflect, in part, the standards set by Alberta Health and, in part, the targets and key performance indicators set by the EHDI Program.

Certain performance measures and indicators cannot be reported at this time as the EHDI Program does not have access to certain sets of data, in particular, data related to intervention services and lost to follow-up. Transition from current manual data collection to a provincial, electronic clinical information system (Connect Care) is expected in 2024, at which time, data availability and quality will improve and will allow the EHDI Program to expand the scope of performance reporting to include all elements of the program pathway.

## **About this report**

This report covers the period April 1, 2022 to March 31, 2023.

The purpose is to report on performance measures identified by Alberta Health in the EHDI Policy Document (2016) and key performance indicators identified by the EHDI Program.

Data was retrieved from the EHDI Database on October 4, 2023.

A **glossary of terms** is included in Appendix 1.

NOTE: In cases where an AHS Zone cannot be identified due to poor data collection or geographical ambiguity, the data is reported as "unknown".

#### Limitations of reporting

The EHDI Program's current data collection is a mix of manual and electronic processes as AHS implements an electronic clinical information system (Connect Care) across the province. Limitations of manual processes where Screening Reports and Diagnostic Summary Reports are submitted to the program and manually entered into the EHDI Database include accuracy, completeness and legibility of information provided on forms, and timeliness of their receipt and entry. As such, the EHDI Program can report only on certain performance measures. Site level data or the ability to identify infants who are lost to follow-up is not possible with the current paper-based reporting system, and therefore cannot be reported on at this time.

Provincial implementation of Connect Care will help alleviate the current issues with data collection and accuracy and will improve the effectiveness of program reporting. The EHDI Program team is working with planners and architects to ensure our ability to identify and track infants who are lost to follow-up for screening or diagnostic assessment; to ensure the program's ability to report on key performance indicators; and to identify and address potential gaps in data.

## **Alberta's EHDI Program**

Alberta's Early Hearing Detection and Intervention (EHDI) Program is a provincial, population-based screening program provided by Alberta Health Services (AHS). The program identifies permanent congenital hearing loss (PCHL) as early as possible in an infant's life, ensuring families receive timely access to follow-up and support.

Without screening, there are no obvious signs early on to tell if an infant has hearing loss. In these cases, the average age of diagnosis is between 2½ and 3 years, and mild to moderate losses will often go undiagnosed until school age. When found early, infants and their families can access follow-up and support sooner, to prevent developmental delays and enable children to thrive.

The EHDI Program was fully implemented in October 2018. Through a collaborative partnership across all five AHS Zones, newborn hearing screening is available, free of charge to families, at many hospitals and community-based screening sites throughout Alberta. Diagnostic services to confirm or rule out PCHL, and intervention services to support infants and families identified with PCHL, are also accessible provincewide.

Organized population screening activities are coordinated along a pathway that identifies the critical steps from recruitment and screening, through to diagnosis and treatment. The EHDI Program pathway is shown below.



## **Newborn Hearing Screening**

The screening test is a key component of an effective screening program. All infants born in Alberta, or to parents who are Alberta residents, are eligible for hearing screening up to 90 days of age. The aim of Alberta's EHDI Program is to screen infants by one month of age.

Screening is offered in all 14 neonatal intensive care units (NICUs) and in 18 postpartum units in Alberta. Additionally, there are 37 community-based hearing screening sites available to facilitate screening of infants who are missed in hospital, or born in hospitals where screening is not offered, or born outside of hospitals. Referrals to community-based hearing screening sites are coordinated by AHS Zones across the province based on operational capacity and family preference.

During the reporting period, 82.9% (n=43,481) of eligible infants in Alberta were offered hearing screening. The screening test was completed and a result provided for 96.7% (n=42,055) of the offers.

- Most screens (69.4%) occurred in postpartum units, 9.8% of screens occurred in NICUs prior to infant discharge, and 20.0% of infants were screened at community sites. The proportion of infants completing screening in postpartum units, NICUs, and community sites showed minimal changes (1.9% increase, 2.8% decrease, and 0.8% decrease, respectively) between the previous and current reporting year.
- There was a slight increase in the percentage of infants who completed hearing screening by one month of age, from 94.4% to 94.8%.
- Refer rate continues to meet its target, remaining under 4%.

The following four measures describe screening participation, performance in meeting the 1-month standard, and the breakdown of screening results including analysis of refer rate as a key performance indicator.

The EHDI Program collects screening data to track trends in participation to identify areas where work to improve screening rates needs to occur. As part of ongoing operations, the EHDI Program provides this data to, and works closely with, AHS Zones to help identify ways to improve screening rates.

#### Provincial screening participation rate

The screening participation rate is defined as the percentage of the eligible infants who have completed hearing screening. This measure provides an indication of overall screening coverage and effectiveness of recruitment.

Figure 1 shows that of the 52,441 infants born in Alberta between April 1, 2022, and March 31, 2023, 80.4% completed hearing screening and received a result. Infants who did not receive a hearing screening result are considered to have not participated in the program. The reasons and breakdown are provided below and in Figure 2:

- No offer infants for whom no screening report was received (n=5,972)
- Unable to locate infants whose families relocated out of the province prior to completion of hearing screening or who are not eligible for health care coverage in Alberta (n=2,442)
- No result infants for whom no screening result was obtained; includes results not obtained (RNO) and MISSED (n=1,626)
- Refused infants whose parents did not consent to hearing screening for their baby (n=162)
- Neonatal death infants who died prior to completion of hearing screening (n=64)
- Ineligible for screening infants with bilateral aural atresia or meningitis (n=17)

**Figure 2.** Breakdown of Non-Participants Figure 1. Screening Participation 100% 90% 80% ■ Ineligible (0.2%) 70% ■Neonatal death (0.6%) 60% ■ Refused (1.6%) 50% 19.6% ■No result (15.8%) 80.4% 40% Unable to locate (23.7%) 30% ■ No offer (58.1%) 20% 10% Participated (42, 158) 0% Did not participate (10,283)

#### Zone screening participation rate

The screening completion rate by zone over the last four reporting years is shown in Figure 3. This is the ratio of completed screens per live births in each zone.

Screening participation varies between zones primarily based on the proportion of screening done in hospital versus in the community. In line with the previous reporting period, most screenings in the South, Calgary, and Edmonton zones took place in post-partum sites in contrast with the Central and North Zones who rely more on community-based screening, where uptake is typically lower than in hospital. The EHDI Program provides data and training to support screening participation improvement in AHS Zones.

The zone where screening was performed could not be identified for 0.5% of infants screened. Refer to Table 1 (Appendix 2) for the current reporting year's data related to this measure.

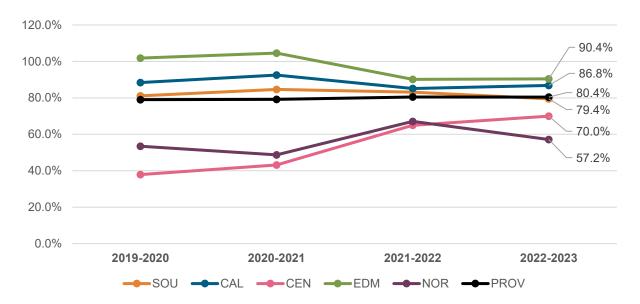


Figure 3. Zone Participation Rates by Reporting Year\*

\*Completed screens are identified by screening site and live births are identified by the infant's home address. This is how, in 2019-2020 and 2020-2021, Edmonton Zone screened more infants than were born in the zone. Information on where the additional infants were from, or reasons for not participating at the zone level, cannot be determined with accuracy due to unknown zone numbers and outliers from demographic data feeds.

Central Zone's focused efforts to improve screening uptake is reflected in its third consecutive year of improvement in this measure. Conversely, North Zone saw a decline this reporting year due to persistent operational challenges with Hearing Screener staffing, which is particularly problematic with North Zone's staffing levels and distribution.

#### Completed screens meeting 1-month standard

This measure is a subset of the screening participation rate that provides an indication of how well the EHDI Program is meeting the standard of screening infants within one month<sup>1</sup>. That is, the number of screens completed within one month of birth out of the total number of screens completed for eligible infants (participants). Figure 4 shows the rates for meeting the 1-month standard across the AHS Zones and in comparison to the provincial rate over the last four reporting years. The target for this key performance indicator is > 95% and is indicated by the red line in Figure 4.

The range for AHS Zones meeting the 1-month screening standard during this reporting period was 90.0% to 96.2%. The provincial rate for meeting this standard was 94.8%; although this is slightly below the 95% target, it is the best performance seen in this measure since the program was implemented in 2018. Table 2 (Appendix 2) outlines the breakdown of screens meeting and not meeting standard, for the current reporting year.

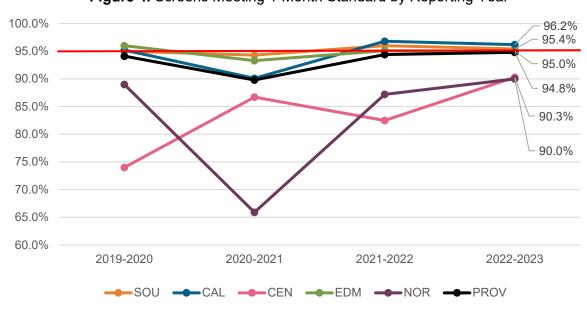


Figure 4. Screens Meeting 1-Month Standard by Reporting Year

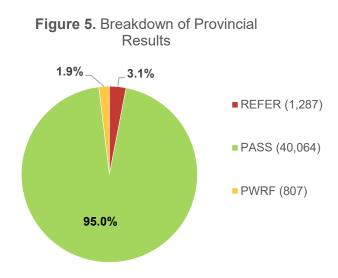
<sup>&</sup>lt;sup>1</sup> For data extraction and calculation purposes, one month is defined as 30 days after date of birth.

#### Breakdown of submitted screening reports and results

43,953 screening reports were received by the EHDI Program for infants born between April 1, 2022 and March 31, 2023. Of these, 42,158 (95.9%) had a final result. The breakdown of the provincial screening results is shown in Figure 5.

95.0% (40,064) of infants with a final screening result passed their screening test and required no further follow-up (PASS), while 1.9% (807) passed their screening test, but had risk factors that required follow-up to monitor for late onset hearing loss (PWRF).

3.1% of infants received a REFER result. This means that 1,287 infants that had a final result did not pass their hearing screening test and were referred for diagnostic assessment.



4.1% of the total reports received did not have a final result or final recommendation and were therefore deemed incomplete.

A detailed breakdown of the current reporting year's screening reports by AHS Zone, with a comparison to the provincial rates, is shown in Table 3 (Appendix 2). The zone where screening was done could not be identified in 0.5% of the submitted screening reports. These are indicated in Table 3 (Appendix 2) as "unknown".

#### Refer rate

The refer rate shows the percentage of screened infants who were screened and then referred for a diagnostic audiological assessment. It provides an indication of the overall impact on follow-up services. It may also help inform the performance of screeners and screening equipment. The target for this measure is < 4%.

Figure 6 shows the refer rates across the AHS Zones compared to the provincial rate over the last four reporting years. Unlike other performance measures, the EHDI Program strives <u>not to exceed</u> the target of 4%, which is indicated by the green line.

The provincial refer rate during the reporting period was 3.1%, which meets the target. Refer rates across the province by AHS Zone varied from 2.2% to 3.2%.

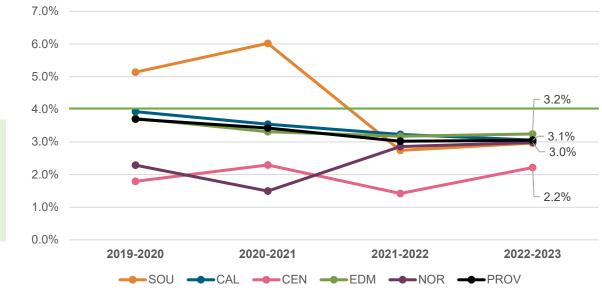


Figure 6. Provincial and Zone Refer Rates by Reporting Year

## **Diagnostic Assessment**

Infants who do not pass their hearing screening require diagnostic assessment to confirm or rule out PCHL. The main test used for diagnostic assessment is the Auditory Brainstem Response (ABR).

There are nine sites in Alberta that perform pediatric ABRs for infants who have been referred from hearing screening. The average time from screening date to first diagnostic assessment date is 44 days. This is 18 days shorter compared to last reporting period and reflects a return to pre-pandemic interval levels.

During the reporting period, 2,841 diagnostic assessments were performed: 46.6% were performed in Edmonton Zone; 41.4% in Calgary Zone; 7.4% in North Zone; 4.3% in South Zone; and 0.2% in Central Zone.

Of the 1,287 infants who were <u>screened</u> during the reporting year and did not pass their hearing screening (i.e., had a REFER result), 64 were confirmed to have PCHL. This leads to the positive predictive value (PPV) of the screening test to be 5.0%.

A total of 74 infants who were <u>born</u> during the reporting year were confirmed to have PCHL, and the detection rate was 0.18% or 1.76 per 1000 infants screened.

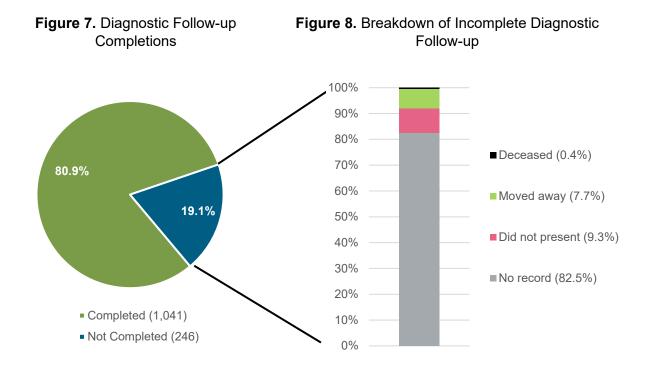
The following three measures describe diagnostic follow-up completion rate, performance with respect to meeting the 3-month standard, and detection of PCHL.

#### Diagnostic follow-up completion rate

The diagnostic follow-up completion rate is defined as the percentage of infants who did not pass hearing screening (i.e., had a REFER result) and have received a final diagnostic result. This measure provides an indication of the effectiveness of the EHDI Program at providing diagnostic assessment after screening.

Figure 7 shows that of the 1,287 infants who received a REFER result from screening during the reporting period, 80.9% attended a diagnostic assessment and received a final diagnostic result. For the 246 infants (19.1%) who did not receive a final diagnostic result the rationale is provided below and shown in Figure 8.

- No record infants for whom no Diagnostic Summary Report was received (n=203)
- Did not present infants who did not attend their diagnostic appointment (n=23)
- Moved away infants whose families relocated out of province before diagnostic assessment was completed (n=19)
- Deceased infants who died prior to completion of diagnostic assessment (n=1)



#### Diagnostic assessments meeting 3-month standard

The EHDI Program strives to ensure that infants who 'REFER' on hearing screening attend a diagnostic assessment by three months of age<sup>2</sup>. The target for this measure, as a key performance indicator, is to have > 90% of referred infants receive a diagnostic assessment by three months (90 days) of age.

During the reporting period, 1,190 diagnostic assessments were completed across nine diagnostic sites in Alberta. Provincially, 1,036 (87.1%) of them were completed within three months of age.

Figure 9 shows the rates for completed diagnostic assessments meeting the 3-month standard for each AHS Zone compared to the provincial rate over the last four reporting years. The red line indicates the target of 90% for this measure. Though provincial performance did not meet this standard, the 14.3% improvement over the previous year reflects a return to pre-pandemic service capacity. Changes in the service delivery model used in Central Zone have impacted their performance in this area and the very small number of diagnostic assessments performed make the fluctuations more pronounced. The EHDI Program continues to work closely with AHS Zones to monitor performance and support their process improvement efforts.

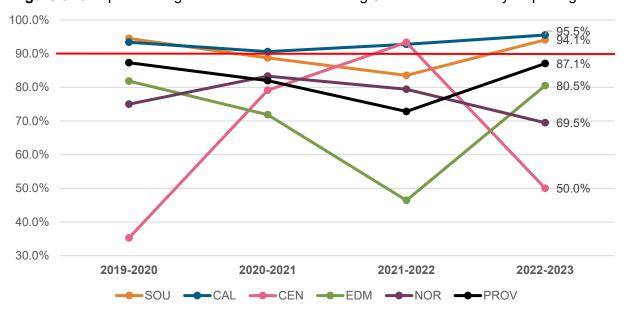


Figure 9. Completed Diagnostic Assessments Meeting 3-Month Standard by Reporting Year

<sup>&</sup>lt;sup>2</sup> For data extraction and calculation purposes, three months is defined as 90 days after date of birth.

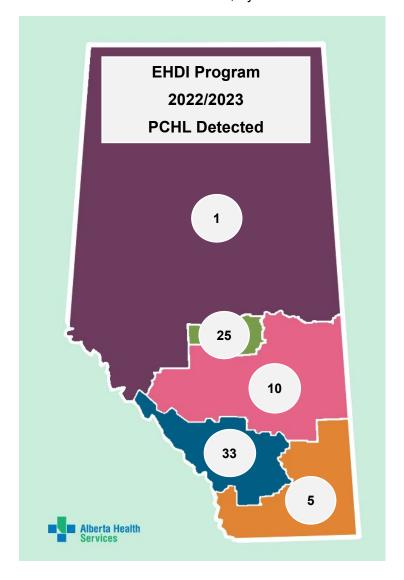
The total number of diagnostic assessments performed in each AHS Zone and their breakdown (i.e., meeting or not meeting the 3-month standard) for the current reporting year are detailed in Table 4 (Appendix 2). The data was calculated from the Diagnostic Summary Reports received by the program and entered into the EHDI Database.

#### PCHL detection

Of the 52,441 infants born during the reporting period, 74 infants were reported to the EHDI Program as confirmed to have PCHL.

Based on reported numbers, the PCHL detection rate is 0.18% or 1.76 per 1,000 infants screened in Alberta during the reporting year.

Figure 10. Distribution of infants identified with PCHL, by zone of residence



#### Intervention

The ability to provide access to intervention services to infants who are identified with PCHL is a critical part of the EHDI Program pathway. The screening and diagnostic steps identify the target population for intervention. The delivery of intervention services in an evidence-informed and standardized manner ensures optimal outcomes for children with permanent hearing loss in Alberta.

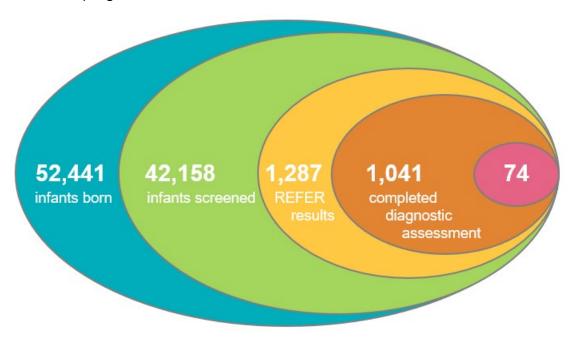
With the establishment of standardized screening and diagnostic services in Alberta, the EHDI Program continues to work on standardized processes to enhance access to intervention programs and services for infants newly diagnosed with PCHL and their families. This is a complex, large-scale initiative involving the collaboration of many partners and stakeholders within and external to AHS.

The EHDI Program's ability to track uptake of intervention services and intervention outcomes is not possible in the current data system. The EHDI Program is working to determine how intervention reporting measures can be drawn from Connect Care, expected by the end of 2024.

#### Conclusion

Alberta's EHDI Program is a provincial population-based screening program that aims to identify PCHL as early as possible to help improve outcomes for children with this target condition.

During the 2022-2023 reporting year, 42,158 (80.4%) infants born in Alberta were reported to the program as having completed hearing screening. Of those, 1,287 (3.1%) infants did not pass screening and were referred for diagnostic assessment. 1,041 (80.9%) infants completed their diagnostic assessment and of those, 74 infants were reported to the program as confirmed to have PCHL.



The EHDI Program is looking to leverage the functionality of Connect Care to address its data limitations and reporting needs, including the data and reporting gaps identified in this report. As operations continue and more data is collected, reporting will improve and opportunities for quality improvement will be identified. This will enable targeted mitigation for improved overall program quality and success over time.

## **Appendix 1: Glossary of terms**

Deceased - infants who died prior to completion of diagnostic assessment

**Detection** – the number of cases identified through screening in a given time period

**Did not present –** infants who did not attend their diagnostic appointment

**Incidence –** the number of new cases identified in a population at risk in a given time period

**Incomplete –** for the purpose of this report, indicates that a screening report was received, but a final result was not obtained due to RNO, MISSED or the final recommendation was not indicated

Ineligible - infants with bilateral aural atresia or meningitis

Missed – infants for whom screening was not offered or attempted

**Moved away –** infants whose families relocated out of province before diagnostic assessment was completed

**Neonatal death –** infants who died prior to completion of hearing screening

**No offer –** for the purpose of this report, indicates that a screening report was not received for that infant

**No record –** infants for whom no Diagnostic Summary Report was received

**No result –** for the purpose of this report, indicates that a screening report was received, but either MISSED or RNO was indicated on the form, so a final result was not obtained

**PASS** – a screening result indicating that the infant was hearing well on the day of the screening test and likely does not have PCHL

Pass with risk factors (PWRF) – a screening result indicating that the infant was hearing well on the day of the screening test and does not have PCHL, however the infant does have factors that put it at risk for developing late onset hearing loss and therefore should be assessed by an audiologist at a later date

**Permanent Congenital Hearing Loss (PCHL) –** hearing loss in one or both ears that is confirmed to be permanent (not temporary or transient) and congenital (present at birth); this is the target condition for the EHDI Program

**Positive Predictive Value (PPV)** – the probability that individuals with a positive screening test truly have the condition; demonstrated as the percentage of infants who do not pass the screening test (i.e., have a REFER result) who are then confirmed to have PCHL

**Prevalence** – the measure of the proportion of persons with a condition in a population at a given point in time

**REFER** – a screening result indicating that the infant did not pass the screening test and must be referred for audiological assessment to confirm or rule out permanent hearing loss

Refused – infants whose parents did not consent to hearing screening for their baby

**Results not obtained (RNO) –** infants for whom screening is attempted and conclusive results are not obtained

**Unable to locate** – infants whose families relocated out of the province prior to completion of hearing screening or who are not eligible for health care coverage in Alberta

**Unknown zone** – the AHS Zone that the data pertains to is not indicated or on the screening report or could not be determined from the information provided, often due to missing or illegible documentation

## **Appendix 2: Performance Measures Data Tables**

Table 1. 2022-2023 screening participation rates, by zone and provincially.

	SOUTH	CALGARY	CENTRAL	EDMONTON	NORTH	UNKNOWN	PROVINCIAL
Completed screens (n)	2,833	16,857	3,340	16,426	2,681	21	42,158
Live births (n)	3,566	19,417	4,774	18,169	4,690	1,825	52,441
Infants screened (%)	79.4%	86.8%	70.0%	90.4%	57.2%	1.2%	80.4%
Infants not screened (%)	20.6%	13.2%	30.0%	9.6%	42.8%	98.8%	19.6%

Table 2. 2022-2023 breakdown of screens meeting and not meeting standard, by zone and provincially.

	SOUTH	CALGARY	CENTRAL	EDMONTON	NORTH	UNKNOWN	PROVINCIAL
Meeting 1-month standard (n)	2,702	16,209	3,016	15,610	2,413	18	39,968
Not meeting 1-month standard (n)	131	648	324	816	268	3	2,190
Total infants screened	2,833	16,857	3,340	16,426	2,681	21	42,158

Table 3. 2022-2023 breakdown of submitted screening reports, by zone and provincially.

	RE	FER	PASS		PWRF		INCOMPLETE		TOTAL
PROVINCIAL	2.9%	1,287	91.2%	40,064	1.8%	807	4.1%	1,795	43,953
SOUTH	2.8%	84	91.4%	2,695	1.8%	54	3.9%	115	2,948
CALGARY	3.0%	515	93.5%	16,072	1.6%	270	1.9%	329	17,186
CENTRAL	2.0%	74	85.2%	3,204	1.6%	62	11.2%	422	3,762
EDMONTON	3.2%	533	92.5%	15,514	2.3%	379	2.1%	354	16,780
NORTH	2.6%	80	83.2%	2,559	1.4%	42	12.8%	393	3,074
UNKNOWN	0	1	0	20	0	0	0	182	203

Table 4. 2022-2023 breakdown of diagnostic assessments meeting and not meeting standard, by zone and provincially.

	нтиоѕ	CALGARY	CENTRAL	EDMONTON	NORTH	PROVINCIAL
Meeting 3-month standard (%)	94.1%	95.5%	50.0%	80.5%	69.5%	87.1%
Meeting 3-month standard (n)	32	515	2	446	41	1,036
Not meeting 3-month standard (n)	2	24	2	108	18	154
Total diagnostic assessments	34	539	4	554	59	1,190



Early Hearing Detection & Intervention Program