



CRISP

Public Health Use Case: Data sharing with the Maryland Early Hearing Detection and Intervention Program

Overview

1 to 3 out of every 1,000 babies born in the U.S. have hearing levels outside the typical range.¹ As such, the Joint Committee on Infant Hearing recommends “all infants should undergo hearing screening prior to discharge from the birth hospital and no later than one month of age”.² Each year, approximately 80 to 100 infants are reported to Maryland Health Hearing Detection and Intervention Program (EHDI) as having a permanent hearing status that could affect language acquisition.

Per Maryland Department of Health (MDH):

On July 1, 2000, Universal Newborn Hearing Screening legislation was passed in Maryland requiring all birthing hospitals to conduct a newborn hearing screen prior to discharge. Insurance coverage for the hearing screening was also mandated under this law. The legislation required hospitals to report results and any risk factors for late onset/progressive hearing status that could affect language acquisition to the Maryland Department of Health.

The Maryland Early Hearing Detection and Intervention (MD EHDI) Program was established within MDH to promote the best communication outcomes for children with a hearing status that could affect language acquisition, by creating and maintaining systems of care that identify the infant's hearing status and ensure referral to appropriate intervention services at the earliest possible age. The MD EHDI Program is housed in the Office for Genetics and People with Special Health Care Needs, part of the Department's Prevention and Health Promotion Administration³

EHDI staff provide follow-up services by contacting families and staff at hospitals, birthing centers, primary care physician offices and other healthcare facilities to ensure that Maryland babies receive the newborn hearing screen and necessary follow up. Program staff ensure referral to early intervention services for infants who are reported to MD EHDI as having a

¹ <https://www.healthychildren.org/English/ages-stages/baby/Pages/Purpose-of-Newborn-Hearing-Screening.aspx>

² (2019). Year 2019 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs. *Journal of Early Hearing Detection and Intervention*, 4(2), 1-44. DOI: <https://doi.org/10.15142/fptk-b748>

³ (2020). Maryland Early Hearing Detection and Intervention Program: Best Practices Guidelines for Hospitals and Birthing Center Staff, Midwives, Physicians and Staff, Audiologists and Early Intervention Providers



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permanent hearing status that could affect language acquisition. Newborn hearing screen and follow up data are entered and maintained in a secure web-based data system, accessible to providers for babies in their care (Oz systems). MD EHDI Program staff also assist families with navigating the EHDI process throughout all steps.

COMAR regulations 10.11.02.07⁴ requires that “for each infant delivered at the facility or site, birthing hospital staff and, in the cases of alternative birthing sites, the licensed professional attending the birth shall: within 48 hours of delivery, enter demographic and birth event data into the Department database.”

Permitted Purpose Category

For a Public Purpose, as permitted or required by Applicable Law and consistent with the mission of the HIE to advance the health and wellness of patients in the CRISP service area (Permitted Purpose #2).

Use Case Description

To ease administrative burden and user errors in entering demographic data into the Department of Health database (Oz systems), MDH requested that birthing hospitals begin sending their Admission, Discharge, Transfer (ADT) feeds for newborns to the Maryland Early Hearing Detection and Intervention Program IT system as early as 2013. At the time, CRISP received individual approval from most birthing hospitals to route their newborn ADTs to the MDH database (some facilities chose to send ADTs for newborns directly to Oz systems and not through CRISP). For the newborn data flowing through CRISP, ADTs from participating birthing hospitals are flagged to be sent to the database when their DOB falls within an allowable range (see “eligible participants” below). This data automatically creates the newborn’s chart in the MD EHDI system, allowing system users (staff at the birthing facilities) to access the newborn’s automatically created chart to then enter hearing screen results into the system. The demographic data and hearing results are available to MDH EHDI follow-up staff. This use case will enable CRISP to send ADTs for all newborns at a CRISP participating hospital to MD EHDI system.

Opt-Out Applicability

Opt out applies in this use case from a technical standpoint, though practically – very few (if any) newborn infants would be opted out by their parent in the first few hours of life. Parents opting out newborn participation later would restrict updated ADT information from flowing to the MD EHDI program.

⁴ COMAR 10.11.02.07:

health.maryland.gov/phpa/genetics/docs/EHDI/_10.11.02_Revise%20and%20Effective%2006.22.2015.pdf



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Eligible Participants

Individuals born at a participating birthing hospital in Maryland will have their data sent to the MDH EHDI IT system. Data are sent to database when an Admission message (ADT A01) is received within 72 hours of the date of birth, which creates a record in OZ Systems. Subsequent patient events (including transfers/A02, discharges/A03, demographic updates/A08, or cancel discharges/A13 message types) are sent within 274 days of date of birth to account for infants in Neonatal Intensive Care and will update already existing records. ADT data outside of these ranges will not be transferred.

Patient Impact Statement

A newborn in the state of Maryland will have their hearing tested within the first 30 days of life, and typically before discharge from the birthing hospital. The results of this hearing test for all newborns are communicated through the EHDI system database as required by legislation. Newborns with abnormal results will be reached out to by EHDI staff to ensure proper follow up. This use case helps ensure demographic data is captured accurately, and thoroughly, and user error does not result in challenges with ability to contact the patient's parent/guardian. No additional data is sent to EHDI; the CRISP connection merely allows providers to more expeditiously enter data mandated by the state. Therefore, no substantive privacy concerns result from this use case.

Approval

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Chairperson

Dated