



Public Health Use Case: MDH access to Demographic and Diagnosis Data for Required Newborn Screening Programs

Overview

The Maryland Department of Health (MDH) requires health providers to report data for multiple programs that ensure the health and wellbeing of newborn infants across the state. Some programs require the reporting of certain conditions to measure change in incidence and prevalence over time to identify patterns of public health significance.¹ Routine screenings are performed on nearly all newborns in Maryland to evaluate for conditions that were not discovered prenatally and may cause permanent and irreparable harm to the infant if not identified and addressed timely. Information from these screenings is reported to MDH, and some follow-up may be initiated depending on the findings of the specific screening.

The process to submit newborn demographic and diagnosis data to MDH is largely manual. This often creates administrative burden for both providers at birthing hospitals who are required to submit these data and care for these newborns, and MDH staff who must ensure appropriate care for these infants and epidemiologic evaluation for the population. The manual process can be labor intensive, inefficient, and prone to human error which can lead to delays in reporting and treatment, inaccurate data capture, and missing data submission.

The Maryland Department of Health would like to reduce these burdens through automated data sharing from CRISP-connected birthing facilities to support the newborn-specific programs as required by law. This use case allows MDH to request specific information for newborns as allowed by law and supported by a legal justification. To date, MDH has submitted legal justification for birth defects, metabolic conditions, and cardiac conditions. As new conditions or screening requirements are identified for newborns, MDH may submit additional data

¹ Birth Defect Information- MD Code Ann., Health General ("Health Gen.") § 18-206(b). This information must be released by hospitals to MDH for its public health mandates and in order to provide information or services to the child's family. Health Gen. § 18-206(d) - (e)(2).

Metabolic Screening- The Department has the authority to conduct both the newborn screening program, and a coordinated statewide system which communicates the results of that screening to providers and families. Health Gen. § 13-111(d)(3). The Department has enacted regulations for the detection and management of congenital and hereditary disorders as authorized by Health Gen. §13-109. COMAR 10.10.13 details the procedures for conducting the newborn screening program, including the authority to collect the dried blood spot and the associated patient demographics for both newborn and subsequent testing.

Critical congenital heart disease-. The Newborn Screening program follows all federal screening recommendations for critical congenital heart disease. Health Gen. § 13-111(e)(2). Birthing facilities and midwives are required to conduct a screening on newborn babies in their care and report the results pursuant to COMAR 10.52.15.05. The Newborn Screening Follow Up unit then receives this information and provides information and resources to families. COMAR 10.52.15.07.



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requests that would be permissible under this use case. There is no net-new data access required as MDH is already receiving data through providers. Additionally, by enabling automated data sharing of newborn screening data, this use case further reduces provider burden while increasing overall efficiency and data quality. MDH has a duty under HIPAA, the Maryland Medical Records Confidentiality Act, and Health Gen. § 18-206(e) to keep all such records confidential.

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).

Each data request for new screenings must be accompanied by a legal opinion from the Maryland Attorney General's Office and will undergo legal review by CRISP General Counsel. Information will only be shared as permitted by law.

Use Case Description

CRISP will share demographic data on all newborns born in Maryland hospitals for legally allowable data requests. Diagnosis data will be shared for specific conditions defined by MDH and governing regulations. This data will be shared upon and after birth as required by law and/or regulations for a period not to exceed 12 months from date of birth.

Data shared may include but is not limited to:

1. Name
2. Date of Birth
3. Address
4. Phone Number
5. Social Security Number (if available)
6. Birth Facility
7. Birth Facility Medical Record Number
8. Birth Weight
9. Parental Demographics (Name, DOB, Phone number)
10. Diagnosis Codes (as legally allowed)

Data will be shared with MDH in the manner and frequency they prefer including file transfer, HL7 feed or CCD.

Opt-Out Applicability

Any newborn whose parent or guardian opts them out of CRISP will not have their data included in CRISP for this use case.



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Eligible Participants

Newborns born in participating Maryland hospitals or birthing facilities.

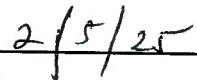
Patient Impact Statement

It is within reasonable expectation that the Maryland Department of Health receives information about newborns so that support and follow-up care can be provided to infants with serious medical conditions requiring prompt attention, and their families, as such reporting is required by law.

Approval



Chairperson



Dated