



# CRISP

## Public Health Use Case: CRISP Access for MDH Newborn Screening Follow-up Program

### ***Overview***

Newborn screening (aka Newborn Screens, NBS, metabolic panel) is a panel of blood tests performed for nearly all infants born in the state. These lab tests help identify newborns who may have one of the over 50 conditions that can cause irreversible harm to an infant if left unidentified and untreated.

All tests are processed by the Maryland Department of Health (MDH) State Lab. Abnormal results are communicated through the MDH Newborn Screening Follow Up Program – housed in the Office for Genetics and People with Special Health Care Needs in the Maternal and Child Health Bureau. There, a nurse will reach out to the patient's guardian and/or clinical provider to communicate abnormal results and next steps. There are occasions when, due to incorrect contact information or unanswered calls, the nurse is unable to contact the patient's guardian or clinician. During these situations, access to CRISP may provide updated contact information and reduce administrative burden on the nurses doing outreach.

Per guidance from MDH Assistant Attorney General: Health-General §§ 13-101 through 13-113 give the Secretary of the Maryland Department of Health the authority to create the Newborn Screening Follow Up Program and to take necessary follow-up activities to facilitate rapid identification and treatment of children that are identified through laboratory testing and screening. Additionally, Health-Gen. § 13-111 authorizes the Secretary to create a coordinated system throughout the state to allow the sharing of information with hospitals, health care providers, treatment centers, and laboratory personnel.

### ***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***

A nurse contracted with MDH newborn screening follow up program will be notified of an abnormal laboratory result through their standard operating procedures (outside of CRISP). If a member of the outreach team is unable to identify and reach the patients' guardian and/or clinician – the nurse will login to CRISP's web portal. There the nurse will search for the



# CRISP

newborn and identify additional or updated contact and/or clinician information. The nurse will use that information to reach out to the patient's guardian and/or clinician.

Access to CRISP is limited to the staff performing the outreach. Those accessing CRISP will only review information necessary to perform their task. As is the nature of their job, the NBS follow-up staff will not have a panel of their patients prior to their need to access CRISP. As such, the NBS staff will need to break the glass – and provide a monthly panel of all patients for whom they have a relationship for audit purposes to ensure privacy and security standards are maintained.

## ***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.

## ***Eligible Participants***

Newborn screen follow up staff will only be able to access records for newborn patients with abnormal newborn screens requiring follow up.

## ***Patient Impact Statement***

A newborn's parent or guardian expects to be contacted if that newborn had an abnormal result on that child's newborn screen. It would be within reason that Maryland Department of Health staff identify up to date contact information for the patient or the patient's clinical practitioner. It may be beyond a reasonable expectation that MDH staff have access to other clinical data within the newborn patient's CRISP record.

## ***Approval***

DocuSigned by:

Jonathan Thierman, MD, PhD

602198D0FB35450...

Chairperson

3/22/2022

Dated