

Newborn Screening Ontario Critical Congenital Heart Disease Screening Pathway

This document provides an overview of the Newborn Screening Ontario (NSO) Critical Congenital Heart Disease (CCHD) Screening pathway. It describes the responsibilities of NSO, submitting hospitals and midwifery practices (submitters), at each stage of the pathway.

It should be read in conjunction with the [NSO Submitter Hub](#), where embedded links can be found.

Critical congenital heart disease screening

CCHD screening using pulse oximetry is the standard of care for all newborns in Ontario. During the screening window of 24-48 hours of age, front line screeners measure two oxygen values, one taken from the right hand (pre-ductal) and another from either foot (post-ductal). These values are then evaluated using an NSO recommended algorithm.

The purpose of CCHD screening is to:

- Identify hypoxemia (or a more than allowable difference between pre- and post-ductal measurements), which can be an early sign of CCHD, prior to clinical deterioration resulting in potential life-threatening consequences

Normal fetal to newborn transition includes the closure of the ductus arteriosus (DA), a blood vessel that is patent in utero and shortly after birth, that connects the pulmonary artery to the aorta allowing the blood flow to bypass the developing lungs. A notable differential between pre- and post-ductal measurements after 24 hours can be an indicator of a patent ductus arteriosus (PDA), which can provide enough blood flow to hide a critical defect. Screening after 24 hours of age allows time for transition to normal newborn circulation, which can include closure of the DA. Newborns who are unable to achieve a passing result are screen positive and are then assessed at the time of the screen by a physician for potential causes of hypoxemia.

Pulse oximetry screening, when used in conjunction with other clinical tools, including prenatal ultrasound and physical assessment, offers a three-layer best practice approach to identifying newborns with CCHD. It should be a rare situation where it is missed.

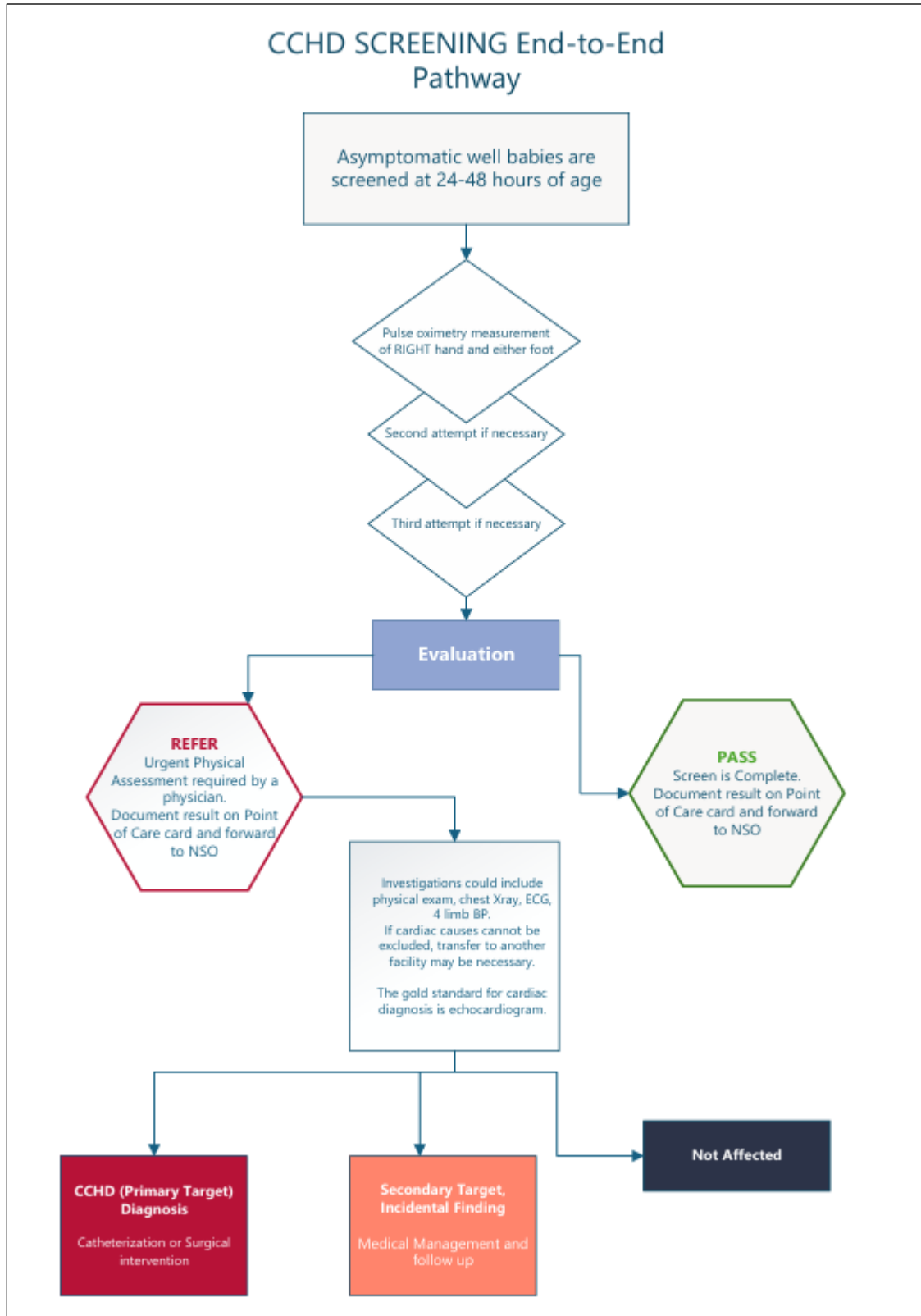
Find out more about [Critical Congenital Heart Disease Screening](#) on our website.

CCHD screening pathway:

The pathway for CCHD screening contains the following elements:



CCHD SCREENING End-to-End Pathway



1. DBS CARD SUPPLY AND USE

CCHD screening information is documented on the Point of Care Screening portion of the newborn screening dried blood spot (DBS) card. These requirements relate to ensuring DBS cards are available to submitters and are completed fully and accurately.

Birth hospital and midwifery care providers will:

- Maintain a robust supply of DBS cards proportional to the number of births they expect each month
- Develop a process for ordering DBS cards from NSO's distributor, VWR
- Notify parents/caregivers about the CCHD screen and answer their questions
- Parents may decline screening, and health care providers should discuss this decision with them to ensure they are informed.
 - Review the decline/deferral form for CCHD with the parents/guardians
 - This should be documented in the infant's medical record, and on the decline/deferral form for CCHD portion of the DBS card
 - The parents/guardians should sign the decline/deferral form indicating they have refused CCHD screening for their infant.
- Complete the demographic information on Point of Care Screening page of the DBS card. A ballpoint pen should be used; soft-tip pens will not copy through to the other sheets of paper. Hospital stickers or stamps may be used if the patient information is not obscured; if used, ensure the sticker/stamp is placed on both copies of the card.
- Provide accurate and complete screening results to NSO for every infant screened, or a valid reason the screen was not performed, by completing the Point of Care Screening page of the newborn screening card and sending it to NSO

2. PERFORMING THE CCHD SCREEN

Ensuring that every eligible infant born in Ontario is offered screening and that every screen positive infant receives appropriate investigation, treatment and follow-up requires the coordinated efforts of parents/guardians and three main groups of health care providers:

Hospitals, birthing centres and midwifery practices will:

- Ensure pulse oximetry equipment is compliant with [NSO recommendations](#), is reliable and in good working order
- Identify eligible and appropriate infants for screening, and screening within the [appropriate timeframe](#)
- Obtain parent/guardian consent and provide education about CCHD screening
- Perform the screen as per NSO's [best practice recommendations](#)
- Evaluate the measurements obtained from pre- and post-ductal sites using the [NSO recommended algorithm](#) or associated approved resource ([evaluation chart](#) or [decision pathway](#)) to make a screening determination (screen positive, screen negative, or repeat)

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- Document completion of the CCHD screen and results in the patient chart/as per institution guidelines, as well as on the Point of Care Screening portion of the DBS card.
- Promptly follow up with the family in the event a baby requires a repeat screen, or a screen is missed

NSO will:

- Provide education about CCHD screening to health care providers and the public through the NSO website resources, webinars, online presentations, professional organization publications, and discussions with NSO team members when required
- Record submitted CCHD screening results in the NSO Laboratory Information System (LIS)
- Evaluate CCHD screening results and ensuring accuracy and quality assurance standards are maintained
- Report unsatisfactory CCHD screening results and potential missed screens to submitters, including communication regarding the need for repeat screening or primary care provider follow up

3. CCHD RESULTS AND FOLLOW-UP

These requirements relate to the action required and follow up that should take place in the event of a screen positive result.

Birth hospital and midwifery care providers will:

- Escalate the care of the newborn for consultation to the most responsible physician (MRP) for assessment
- Provide assessment and follow-up information for screen positive cases through completion of the Diagnostic Evaluation Report Form (DERF) upon request by NSO

NSO will:

- Enter all information provided on the newborn screening requisition into NSO's LIS
- Document clinical details regarding the screen positive case and follow up in the LIS
- Collaborate with the midwife or screening organization's CCHD key contact to ensure completion of the DERF

Consulting/MRP will:

- Provide timely assessment (within 6 hours) and confirmatory testing of CCHD screen positive infants referred to them after a screen positive result, including the management and care of affected infants
- Consult with Criticall for discussion of a plan of care when necessary or a pediatric cardiologist for arranging an echocardiogram if a non-cardiac cause for the screen positive result cannot be determined (prior to discharge if the infant is stable and discharge is considered)

Symptomatic presentation of CCHD

This section outlines required actions when an infant presents clinically with CCHD outside of a positive CCHD screen, including false-negative screens and missed screening cases.

1. Infant Presents with CCHD After a Negative CCHD Screen (False Negative)

A false negative occurs when the CCHD screen is reported as negative, but the infant is subsequently diagnosed with CCHD.

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Hospital, birthing centre, and midwifery care providers will:

- Conduct a clinical and system review for quality assurance and identification of potential system improvements when notified of a confirmed false-negative CCHD case.

NSO will:

- Provide feedback on the confirmed false-negative case to the clinical leadership of the screening organization.

2. Infant Presents with CCHD with No CCHD Screen Completed (Outside the Screening Pathway)

A missed screen occurs when an infant eligible for CCHD screening presents clinically with a CCHD without having undergone screening.

Hospital, birthing centre, and midwifery care providers will:

- Notify NSO by telephone or email when aware of a symptomatic infant with a confirmed CCHD who was eligible for screening but did not present through the CCHD screening pathway.
- Complete a [Symptomatic Diagnostic Report Form \(SDRF\)](#) for quality assurance and tracking purposes and submit it to NSO.
- Conduct a clinical and system review for quality assurance and identification of potential system improvements related to the missed screening.

NSO will:

- Perform an investigation to identify reason for the missed screen.
- If the infant was truly missed (eligible for screening, did not decline, and screen was not performed), document the SDRF case in the NSO Laboratory Information System (LIS).
- NSO will follow up on confirmed missed screen cases who present with a CCHD to the clinical leadership of the screening organization.