

# Newborn Bloodspot Screening Program Procedure

# 1. Purpose

The *Newborn Bloodspot Screening Program Procedure* outlines the minimum process requirements for implementation of MP 0163/21 *Newborn Bloodspot Screening Policy*.

The aim of the WA Newborn Bloodspot Screening Program is to improve the health of babies by identifying those at risk of developing a serious condition early, generally before symptoms present. The Program screens for around 25 conditions.

# 2. Procedural Requirements

### 2.1 PathWest Laboratory Medicine WA

PathWest Laboratory Medicine WA is responsible for providing administrative, management, pathology services and quality assurance for the WA Newborn Bloodspot Screening Program. They are responsible for relevant operational policies and procedures to support a safe and quality Newborn Bloodspot Screening Program in line with the Mandatory Policy.

#### 2.1.1 Administrative and Management Services

PathWest Laboratory Medicine WA must provide administrative support to the WA Newborn Bloodspot Screening Program for both Health Service Providers and consumers. They must have procedures in place to:

- develop and maintain information for consumers on the WA Newborn Bloodspot Screening Program
- develop and maintain information for Health Service Providers on the WA Newborn Bloodspot Screening Program
- inform the training and ongoing education for Health Service Providers on how to conduct Newborn Bloodspot Screening
- provide and distribute bloodspot cards and return postal envelopes to maternity and/ or neonatal services.

PathWest Laboratory Medicine WA must nominate a contact position to manage the WA Newborn Bloodspot Screening Program. This contact position is responsible for liaising with Health Service Providers to:

- arrange for repeat testing in a timely manner for babies whose samples were unsuitable or had equivocal results
- arrange for referral in a timely manner for babies with abnormal results
- ensure that results are reported to the original maternity and/ or neonatal service that arranged for the collection of the bloodspot sample
- provide feedback, if required, to Health Service Providers regarding timeliness and suitability of the bloodspot samples
- follow up and record diagnostic outcomes for all abnormal results

- monitor cases lost to follow-up
- follow up and investigate reported potential false negative cases.

### 2.1.2 Pathology Services

PathWest Laboratory Medicine WA undertakes pathology services in addition to their administrative and management functions for the WA Newborn Bloodspot Screening Program. PathWest Laboratory Medicine WA must:

- ensure that bloodspot cards are analysed within appropriate timeframes
- provide further diagnostic testing if required
- manage the storage, secondary use, release and destruction of bloodspot cards
- consider the inclusion of screening tests for newly approved conditions.

#### 2.1.3 Quality Assurance

PathWest Laboratory Medicine WA must undertake quality assurance activities related to the WA Newborn Bloodspot Screening Program. Quality assurance activities include:

- monitor test performance for conditions currently in the WA Newborn Bloodspot Screening Program
- develop and validate assays for the testing of new conditions
- collation of data for annual reporting.

## 2.2 Health Service Providers that provide maternity and/ or neonatal services

Health Service Providers must have operational policies and procedures for the WA Newborn Bloodspot Screening Program that:

- outline the responsibilities of the contact position at each site for the WA Newborn Bloodspot Screening Program
- ensure the necessary resources are available for sample collection staff
- ensure that sample collection staff samples are appropriately trained
- ensure that sample collection staff have access to relevant educational resources education
- ensure all parent/ guardian are offered screening for their baby
- provide information about the WA Newborn Bloodspot Screening Program to the parent/ guardian
- obtain consent from the parent/ guardian; or document their "declined consent" to testing on the bloodspot card
- ensure the bloodspot sample is collected in a timely manner
- ensure timely postage or courier collection of bloodspot cards to go to PathWest Laboratory Medicine WA
- ensure timely follow-up of those babies requiring repeat testing
- ensure all neonates have a screening result or "declined consent" to testing documented
- refer and manage the follow up of babies at higher risk of missing the newborn bloodspot screening test, these include:
  - o early discharge patients, especially those who discharge against medical advice
  - low birth weight babies
  - o premature babies
  - home births
  - $\circ$   $\,$  babies who require admission/ intensive care
  - o babies who require an inter hospital transfer

- o babies who have received transfusions of blood or other blood products
- babies of Aboriginal mothers
- o babies of culturally and linguistically diverse mothers
- babies of young mothers
- o babies of mothers affected by drugs or alcohol
- o babies of mothers who had no antenatal care
- babies who may die soon after birth
- o babies who present after the recommended time frame.
- have mechanisms to record a complaint or report an incident regarding newborn bloodspot screening.
- 2.2.1 Health Service Providers that provide clinical specialist services

Health Service Providers must have internal procedures or guidelines that include the following:

- a diagnostic pathway for all babies with abnormal screening results referred to their service from the WA Newborn Bloodspot Screening Program
- a management plan for babies referred to their service, who become unwell prior to the outcome of diagnostic testing.

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