**OBJECTIVES**

- To outline the procedure to be followed when collecting the sample.
- To ensure the initial sample is collected between 24 and 72 hours of age and as close to 24 hours as possible.
- To ensure every effort is made to collect the initial sample at the birth facility prior to discharge or transfer.
- To ensure collection of the sample is not delayed for sick or preterm infants, regardless of feeding practices, unless there is a Physician refusal for clinical reasons.
- To ensure consistent accommodation of special circumstances related to sample collection.

**APPLICABILITY**

Compliance with this document is required by all Alberta Health Services employees, members of the medical and midwifery staffs, Students, Volunteers, and other persons acting on behalf of Alberta Health Services (including contracted service providers as necessary).

**ELEMENTS**

1. Accommodating Special Circumstances
   
   1.1 If an infant is admitted to a neonatal intensive care unit (NICU) or special care nursery, refer to the Alberta Health Services (AHS) Newborn Blood Spot...
Screening: Neonatal Intensive Care Unit Guideline.

1.2 If any of the following special circumstances occur, refer to Section 11 of this document for additional information:

a) adoption;
b) surrogacy;
c) infant in the care of Children’s Services;
d) unique lifetime identifier (ULI) not available;
e) infant deceased;
f) parent or guardian request for partial screening;
g) parent or guardian request for additional screening;
h) Physician refusal of sample collection;
i) parent or guardian refusal of sample collection;
j) parent or guardian request for return of the sample; or
k) parent or guardian request for removal of personal information from the Newborn Metabolic Screening (NMS) Program’s application.

2. Verifying Infant Identity

2.1 The health care provider collecting the sample shall be responsible for verifying the infant’s identity in accordance with the AHS Patient Identification Policy.

3. Obtaining Informed Consent

3.1 The most responsible health practitioner (MRHP) shall be responsible for obtaining informed consent from the infant’s parent(s) or guardian(s) prior to any sample collection in accordance with the AHS Consent to Treatment/Procedure(s) Policy and the AHS Consent to Treatment/Procedure(s): Minors/Mature Minors Procedure.

3.2 As a part of the informed consent discussion, the MRHP shall give the parent(s) or guardian(s), or ensure the parent(s) or guardian(s) has received information about the NMS Program, including but not limited to (see the NMS Program staff education resource Talking with Parents Essentials):

a) the screened conditions;
b) the nature of sample collection;
c) the risks and benefits of newborn blood spot screening; and
d) the potential consequences of not undertaking newborn blood spot screening.

3.3 The parent or guardian shall be given the opportunity to ask questions and to receive understandable answers.

3.4 Verbal express consent shall be obtained and the informed consent discussion documented by the MRHP in the infant’s health record.

a) Parent or guardian refusals shall be managed in accordance with Section 11.9 below.

4. Protecting the Requisition Card

4.1 The requisition card shall be stored, handled and packaged with care to avoid contamination, physical damage and to protect from direct sunlight, heat and water. The filter paper area shall not come in contact with gloved hands, formulas, antiseptic solution, lotions, petroleum jelly and other materials at any time before, during or after collecting the sample.

4.2 The expiration date on the requisition card shall be verified to ensure the card is not expired. Expired requisition cards shall not be used and shall be destroyed. The use of an expired requisition card will result in the need for a repeat sample collection.

5. Filling out the Requisition Card

5.1 The requisition card shall be filled out fully and accurately (see the NMS Program staff education resource *Filling out the Blood Spot Card Essentials*) prior to collecting the sample. Requisition cards that are incomplete and/or inaccurate may result in the need for a repeat sample collection.

a) Expired requisition cards shall not be used.

b) Cursive writing shall not be used.

c) Addressograph or paper labels shall not be used.

d) Only black ink shall be used.

5.2 Special attention shall be paid to accuracy and legibility when filling out the following fields on the requisition card as they may significantly affect the interpretation of screen results:

a) birth weight;

b) gestational age;
c) feeding type; and
d) blood transfusions.

5.3 All reasonable efforts shall be made to find missing or unavailable information to fill out the requisition card. If information is still unavailable after reasonable efforts have been made to find it, the requisition card shall be submitted to the NMS Laboratory in a timely manner.

6. Collecting the Sample

6.1 Preparing to collect the blood spots:

a) All necessary supplies shall be gathered.
b) Hand hygiene shall be performed in accordance with the AHS Hand Hygiene Policy and powder-free gloves shall be used.
c) The infant’s leg shall be positioned below the heart to increase venous pressure and the infant’s foot gently massaged to increase blood flow.
d) The puncture site shall be located on either the most medial or most lateral portion of the planter surface of the heel (see the NMS Program staff education resource Collecting the Blood Spots Essentials). Puncturing other areas of the foot may cause injury to nerves, tendons, cartilage or bone.
e) The health care provider collecting the sample shall keep the infant warm to increase the rate of blood flow. As deemed necessary, the health care provider may:

(i) remove as few items of clothing as possible to reveal the infant’s foot;
(ii) swaddle the infant in a blanket;
(iii) have the parent or guardian hold the infant which may include skin to skin contact and/or breastfeeding;
(iv) leave only the extremity of the puncture site exposed; and/or
(v) warm the area of puncture for three (3) to five (5) minutes with a commercial infant heel warmer or a soft cloth moistened with warm water that has been held comfortably against the inner aspect of the health care provider’s forearm.
f) The puncture site shall be cleansed using 70% isopropyl alcohol. The puncture site shall be air dried prior to puncture as failure to do so may dilute the sample with isopropyl alcohol and adversely affect the screen results.
g) Infants with rare collection challenges (e.g., bilateral casts, foot deformities) may have a sample collected by venipuncture in consultation with the infant’s Physician or Midwife to ensure the collection occurs at a neonatal/pediatric venipuncture laboratory site.

6.2 Puncturing the heel and collecting the sample:

a) The skin shall be punctured using a sterile, single-use, retractable NMS Program approved lancet (see the NMS Program staff education resource Collecting the Blood Spots Essentials) placed securely against the infant’s heel according to lancet manufacturers’ instructions. The trigger of the lancet shall be firmly and completely depressed and released, and the lancet disposed of promptly in a biohazard/puncture-proof container for sharps.

b) The first drop of blood shall be wiped away with dry sterile gauze or a cotton ball as the first drop may contain tissue fluids which may dilute the sample. Blood shall be allowed to flow freely.

c) The fold-over cover attached to the requisition card shall be pulled back, but not removed, exposing the filter paper and the pre-printed circles.

d) The filter paper area of the requisition card shall be gently touched to the blood drop to fill each pre-printed circle with a single application of blood.

(i) The filter paper area shall not be pressed against the puncture site.

(ii) Blood shall only be applied to the front side of the filter paper area until no areas of white within the pre-printed circle are visible on the front and the blood has seeped through to the back.

e) All five (5) blood spots on the filter paper area shall be fully saturated (see the NMS Program staff education resource Getting Great Blood Spots Essentials).

(i) As deemed necessary by the health care provider collecting the sample, the blood flow shall be increased by applying gentle intermittent pressure to areas surrounding the puncture site. The puncture site shall not be milked or squeezed as this may adversely affect the screen results, which may result in the need for a repeat sample collection.

(ii) If one (1) drop of blood fails to fully saturate the pre-printed circle, a second drop shall be applied only while the first drop of blood is still wet. If the first drop of blood is dry when the second drop of blood is applied, the quality of the sample can be negatively affected, which may result in the need for a repeat sample collection.
(iii) If unable to obtain a sufficient quantity of blood with the first puncture, a second puncture shall be performed on the opposite foot. If using the opposite foot is not an option, a new puncture site shall be located on the opposite side of the original foot. The process for collecting the sample shall be followed as outlined in Section 6.

(iv) If it is not possible to fully saturate five (5) blood spots, a minimum of four (4) blood spots shall be fully saturated. If it is not possible to fully saturate four (4) blood spots after two (2) unsuccessful attempts, another collection shall be arranged with a new requisition card at a later time, following Sections 2 to 10. The time of the new collection shall be determined at the discretion of the MRHP.

6.3 After collecting the sample:

a) The infant’s foot shall be elevated above their body post puncture and pressure applied to the puncture site with clean gauze until the bleeding stops. If bleeding persists, gauze shall be applied to the puncture site with gentle pressure until the bleeding stops.

   (i) Adhesive bandages shall not be used.

b) Hand hygiene shall be performed in accordance with the AHS Hand Hygiene Policy.

c) The parent(s) or guardian(s) shall be encouraged to comfort their infant.

d) The date and time of collection fields on the requisition card shall be filled out.

e) The collector ID and collection location fields on the requisition card shall be filled out.

f) The requisition card shall be double checked to ensure accuracy, legibility and completion. Incorrect, illegible or missing information on the requisition cards may affect the analysis and reporting of results and could lead to the need for a repeat sample collection.

g) The fold-over cover shall not be placed over the blood spots until they are completely dry.

h) The collection of the sample shall be documented in:

   (i) the infant’s health record;

   (ii) the notice of birth within birth facilities; and
(iii) other sources as required in accordance with Zone-specific or facility-specific practices.

i) All samples shall be submitted to the NMS Laboratory, even in the event the health care provider suspects the quality of the sample may be compromised or the sample is incomplete.

7. Drying the Sample

7.1 The sample shall be allowed to air-dry for a minimum of three (3) hours at ambient temperature. A drying rack that separates the requisition cards may be used to facilitate the drying process. During the drying process, care shall be taken to protect requisition cards by:

a) keeping requisition cards in a suspended, horizontal position to avoid contact with any surfaces;
b) keeping the fold-over cover from touching the blood spots;
c) not exposing requisition cards to direct sunlight; and
d) not stacking requisition cards or allowing them to have direct contact with other requisition cards.

7.2 Samples that are not completely dried may be transferred from an infant’s home to a health centre or laboratory in a box that separates the requisition cards, ensuring the fold-over cover is not touching the blood spots. Once the requisition cards have been transferred to the health centre or laboratory, they shall be removed from the box and air-dried as indicated above.

7.3 The fold-over cover shall be closed over the blood spots once the requisition has completely dried.

7.4 For additional information, see the NMS Program staff education resource Drying & Transportation Essentials.

8. Packaging the Sample

8.1 The requisition card shall only be packaged once the sample is completely dry (a minimum of three [3] hours drying time).

8.2 Requisition cards shall be packaged and sealed in a paper envelope pre-addressed to:

University of Alberta Hospital
Department of Laboratory Medicine
Room 4B2.10
Newborn Metabolic Screening
8440 – 112 Street NW Edmonton, AB
T6G 2B7

a) The return address of the health centre or laboratory responsible for packaging and transporting the requisition cards shall be included on the outside of the envelope.

b) Confidential health information shall not be recovered on the outside of the envelope.

c) No further labeling is required.

8.3 Sealed, leak-proof plastic bags, including biohazard bags, shall not be used to package requisition cards. The lack of air exchange may cause heat build-up and moisture accumulation, with the potential to negatively affect the quality of the sample which could result in the need for a repeat sample collection.

8.4 Multiple requisition cards may be packaged together in an envelope, provided they are alternatively stacked by rotating each requisition card so that the blood spots on each requisition card do not touch.

8.5 For additional information, see the NMS Program staff education resource Drying & Transportation Essentials.

9. Transporting the Sample

9.1 The dried, packaged sample shall be transported to the NMS Laboratory as soon as possible after drying of the sample. The sample must be received by the NMS Laboratory within 72 hours after sample collection.

a) Local transportation practices shall be consulted for instructions on how to transport the sample.

b) Samples shall not be mailed through Canada Post.

9.2 For additional information, see the NMS Program staff education resource Drying & Transportation Essentials.

10. Collecting the Sample Prior to Discharge and Transfer

10.1 Every effort shall be made to collect the initial sample at the birth facility prior to discharge or transfer if the infant is 24 hours of age or older.

10.2 When an infant is discharged or transferred from the birth facility, the MRHP shall inform the receiving facility or zone public health nursing services whether or not the initial sample was collected at the birth facility.

a) The MRHP shall ensure that this information is recorded on the notice of birth.
10.3 If the sample has not been collected prior to the infant’s discharge or transfer from the birth facility, the requisition card shall not be given to the parent or guardian and shall be destroyed.

10.4 If the MRHP believes that an infant less than 24 hours of age may be difficult to locate in the community, the sample may be collected prior to discharge or transfer. The birth facility shall inform zone public health nursing services that a repeat sample collection is required between 24 and 72 hours of age.

10.5 If an initial sample was not collected prior to discharge from the birth facility, zone public health nursing services shall follow Sections 2 to 3 and either collect the sample or refer an infant to the nearest laboratory for collection.

10.6 If an initial sample was not collected prior to the infant’s transfer from the birth facility, the receiving facility shall collect the initial sample following Sections 2 to 10.

11. Accommodating Special Circumstances: Additional Information

11.1 Adoption:

a) In cases where an adoption of an infant is pending or finalized at the time of sample collection, the requisition card shall be filled out based on the infant’s identity at the time of sample collection.

b) For an infant using their birth identity at the time of sample collection, the requisition card shall contain:

(i) the infant’s birth name;
(ii) birth demographics;
(iii) birth parent information; and
(iv) birth ULI.

c) For an infant using their adoptive identity at the time of sample collection, the requisition card shall contain:

(i) the infant’s adoptive name;
(ii) adoptive demographics;
(iii) adoptive parent information; and
(iv) adoptive ULI.

d) The sample shall be collected and transported in accordance with Sections 2 to 10 above.
11.2 Surrogate birth:
   a) In cases where an infant is born to a gestational carrier:
      (i) the requisition card shall be filled out using the information currently available in the infant’s health record in accordance with Section 5 above; and
      (ii) the sample shall be collected and transported in accordance with Sections 2 to 10 above.
   b) For additional information, see the NMS Program staff education resource *Special Situations when Collecting Essentials*.

11.3 Infant in the care of Children’s Services:
   a) If an infant is in the care of Children’s Services at the time of sample collection (e.g., apprehended, temporary guardianship order, permanent guardianship order) the requisition card shall be filled out using the infant’s birth name, birth demographics, birth parent information and birth ULI in accordance with Section 5 above.
      (i) “Infant in care of children’s services” shall be written clearly on the requisition card.
   b) The sample shall be collected and transported in accordance with Sections 2 to 10 above with the following consideration:
      (i) the MRHP shall work with Children’s Services to ensure that informed consent is obtained from a person with appropriate legal authority in a timely manner.
   c) For additional information, see the NMS Program staff education resource *Special Situations when Collecting Essentials*.

11.4 ULI not available:
   a) If a ULI is not available for an infant at the time of sample collection (e.g., registration pending or unavailable, adoptive ULI not yet requested or not yet received), the requisition card shall be filled out in accordance with Section 5 above and sample collection shall not be delayed.
      (i) “ULI pending” shall be written clearly in the ULI Field of the requisition card.
   b) The sample shall be collected and transported in accordance with Sections 2 to 10 above.
c) For additional information, see the NMS Program staff education resource *Special Situations when Collecting Essentials.*

**11.5 Infant deceased:**

a) If an infant is deceased at the time of sample collection, the requisition card shall be filled out in accordance with Section 5 above.

   (i) “Neonatal death” shall be written clearly on the requisition card.

b) The requisition card shall be transported to the NMS Laboratory in accordance with local transportation practices.

c) The completion and transportation of the requisition card shall be documented in the infant’s health record.

d) For additional information, see the NMS Program staff education resource *Special Situations when Collecting Essentials.*

**11.6 Parent or guardian request for partial screening:**

a) If a parent or guardian requests partial screening, the parent or guardian shall be informed that it is not possible to screen for select conditions within the NMS Program.

b) Sample collection shall proceed in accordance with Sections 1 to 9 above.

c) For additional information, see the NMS Program staff education resource *Special Situations when Talking with Parent Essentials.*

**11.7 Parent or guardian request for additional screening:**

a) If a parent or guardian requests screening for conditions in addition to the screened conditions, the parent or guardian shall be referred to their infant’s Physician or Midwife to discuss their request.

b) Sample collection shall proceed in accordance with Sections 2 to 10 above.

c) For additional information, see the NMS Program staff education resource *Special Situations when Talking with Parent Essentials.*

**11.8 Physician refusal of sample collection:**

a) If a Physician refuses sample collection for clinical reasons (i.e., the infant is medically unstable), the requisition card shall be filled out in accordance with Section 5 above.

   (i) “Physician refusal” shall be written clearly on the requisition card.
b) The requisition card shall be transported to the NMS Laboratory in accordance with local transportation practices.

c) The clinical circumstances of why sample collection was declined, as well as the completion and transportation of the requisition card shall be documented in the infant’s health record.

d) For additional information, see the NMS Program staff education resource *Special Situations when Collecting Essentials*.

11.9 Parent or guardian refusal of sample collection:

a) If a parent or guardian refuses sample collection, the MRHP shall explain the risks and consequences of the refusal without creating a perception of coercion.

b) If the parent or guardian confirms their refusal for sample collection, the AHS NMS Program *Refusal for Newborn Blood Spot Screen Form* shall be completed in accordance with the form instructions and the parent or guardian shall be asked to sign the form.

   (i) If the parent or guardian confirms their refusal for sample collection over the telephone, the MRHP shall ensure another health care provider witnesses the refusal.

c) The AHS NMS Program *Refusal for Newborn Blood Spot Screen Form* shall be placed in the infant’s health record and a copy shall be sent to the NMS Program coordination team who shall ensure a copy is placed in the infant’s health record at the birth facility.

d) The MRHP shall notify the infant’s Physician or Midwife that the parent or guardian refused sample collection in a timely manner.

e) The requisition card shall be filled out in accordance with Section 4 above

   (i) “Parent refusal” shall be written clearly on the requisition card.

f) The requisition card shall be transported to the NMS Laboratory in accordance with local transportation practices.

g) The MRHP shall document the refusal, as well as the completion and transportation of the requisition card in the infant’s health record.

h) For additional information, see the NMS Program staff education resource *Parent Refusal Essentials*. 
11.10 Parent or guardian request for return of the sample:

a) If a parent or guardian requests to have their infant’s sample returned, the parent or guardian shall be informed that their infant’s sample can be returned after newborn blood spot screening is complete.

b) The parent or guardian request for the return of their infant’s sample shall be managed in accordance with the AHS Laboratory Services Release of Samples Policy.

c) The sample shall be collected and transported in accordance with Sections 2 to 10 above.

d) The parent or guardian request for return of the sample shall be documented in the infant’s health record.

e) For additional information, see the NMS Program staff education resource Special Situations when Talking with Parents Essentials.

11.11 Parent or guardian request for removal of identifiers from the NMS Program’s application:

a) Removal of data refers to masking, which makes personal and health information not automatically visible within the NMS Program’s application.

b) If a parent or guardian requests to have information that identifies them or their infant removed from the NMS Program’s application, the parent or guardian shall be informed that their infant’s personal information can be removed after newborn blood spot screening is complete.

c) The parent or guardian shall be directed to www.albertahealthservices.ca or Health Link to obtain the AHS NMS Program Removal of Personal Information from the Newborn Metabolic Screening Application Form.

d) The sample shall be collected and transported in accordance with Sections 2 to 10 above.

e) The parent or guardian request for removal of personal information from the NMS Program’s application shall be documented in the infant’s health record.

f) For additional information, see the NMS Program staff education resource Special Situations when Talking with Parents Essentials.

DEFINITIONS

Birth facility means the Alberta Health Services hospital or health care setting where an infant is born.
Discharge means the process of exiting the system or services of the organization. It may include continuation of service or care by another agency or provider not a part of Alberta Health Services.

Express Informed Consent means direct, explicit agreement to undergo treatment/procedure(s), given either verbally or in writing (signed).

Guardian means, where applicable:
For a Minor:
a) A guardian as defined by the Family Law Act, a divorced parent with custody of the minor, or a person appointed pursuant to a will, personal directive, court order, agreement or by authorization of legislation (e.g. Child, Youth and Family Enhancement Act).

For an Adult:
a) an individual appointed by the Court in accordance with the Adult Guardianship and Trusteeship Act to make to make decisions on behalf of the adult patient when the adult patient lacks capacity.

Health care provider means any person acting on behalf of Alberta Health Services who is providing a good or a service to a patient, inclusive of health care professionals, staff, students, volunteers and other persons acting on behalf of or in conjunction with Alberta Health Services.

Health information means information that identifies an individual and is stored in any format that relates to:
a) diagnosis, treatment and care; and
b) registration (e.g., demographics, residency, health services eligibility, or billing).

Health record means the Alberta Health Services legal record of the patient’s diagnostic, treatment and care information.

Informed Consent means the patient’s agreement (or alternate decision-maker) to undergo a treatment/procedure after being provided, in a manner the patient can understand, with the relevant information about the nature of the treatment/procedure(s), its benefits, potential risks and alternatives, and the potential consequences of refusal.

Most responsible health practitioner means the health practitioner who has responsibility and accountability for the specific treatment/procedure(s) provided to a patient and who is authorized by Alberta Health Services to perform the duties required to fulfill the delivery of such a treatment/procedure(s) within the scope of their practice.

Newborn Metabolic Screening Laboratory means the Alberta Health Services designated laboratory for newborn blood spot screening located at the University of Alberta Hospital.

Newborn Metabolic Screening Program means an organized population-based newborn blood spot screening program delivered by Alberta Health Services.
Newborn Metabolic Screening Program coordination team means the Alberta Health Services designated team within Population, Public and Indigenous Health that integrates, organizes and manages the Newborn Metabolic Screening Program and its operations.

Notice of birth means the document used to collect personally identifiable information about the mother and her infant or about a stillbirth.

Parent means the guardian of a child with the legal authority to make decisions of behalf of the minor in accordance with the Alberta Family Law Act.

Physician refusal within the Newborn Metabolic Screening Program means the physician does not allow a sample collection on an infant for clinical reasons (i.e., the infant is medically unstable).

Requisition card means the Newborn Metabolic Screening Program requisition consisting of an area for the infant’s blood spots and an area for health information.

Sample means the blood spots and health information collected on the requisition card for the purpose of newborn blood spot screening.

Sample collection means the process of completing the requisition card and poking the infant’s heel to obtain the blood spots for the purpose of newborn blood spot screening.

Screened condition means one or more of the treatable conditions currently screened for within the Newborn Metabolic Screening Program.

Surrogate birth means an arrangement in which a woman carries and delivers a child for another couple or person. This woman, the gestational carrier, may be the child’s genetic mother or she may be biologically unrelated to the child.

Transfer means re-assignment or physical re-location to/from a health care setting, service, health care provider or level of care.

Unique Lifetime Identifier (ULI) means a unique and permanent number assigned to all persons who receive health services in Alberta. Unique Lifetime Identifiers are assigned to all Alberta residents, residents of other provinces/territories or other countries.

Zone public health nursing services means the public health nursing services responsible for providing newborn blood spot screening services at the zone level.

REFERENCES

- Alberta Health Services Governance Documents:
  - Consent to Treatment/Procedure(s) Policy (#PRR-01)
  - Consent to Treatment/Procedure(s): Minors/Mature Minors Procedure (#PRR-01-03)
  - Hand Hygiene Policy (#PS-02)
  - Newborn Blood Spot Screening Neonatal Intensive Care Unit Guideline (#HCS-32-04)
  - Patient Identification Policy (#PS-06)
- Release of Laboratory Samples Procedure (#LTR100844)
- Alberta Health Services Forms:
  - Refusal for Newborn Blood Spot Screen Form (#18826)
  - Removal of Personal Information from the Newborn Metabolic Screening Application Form (#18827)
- Alberta Health Services Resources:
  - Collecting the Blood Spot Essentials
  - Drying & Transportation Essentials
  - Filling out the Blood Spot Card Essentials
  - Getting Great Blood Spots Essentials
  - Parent Refusal Essentials
  - Special Situations when Collecting Essentials
  - Special Situations when Talking with Parents Essentials
  - Talking with Parents Essentials

**VERSION HISTORY**

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