# Building a Provincial Approach: Key Learnings from a Literature Review and a National Environmental Scan

## Toward an Understanding of Newborn Metabolic Screening Programs

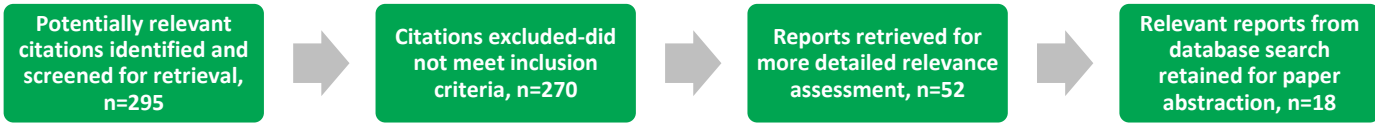
In 2010, Alberta Health and Wellness (AHW) directed Alberta Health Services (AHS) to offer the Newborn Metabolic Screening (NMS) Program in accordance with the Alberta Newborn Metabolic Screening Program Policy Document March 2010. Population and Public Health (PPH) was identified to lead the overall coordination of the NMS Program in collaboration with key stakeholders within AHS including program improvements. To facilitate the development of an integrated provincial NMS Program, a literature review of public health best practices related to newborn metabolic screening programs and an environmental scan of existing Canadian newborn metabolic screening programs were undertaken by PPH. A summary of the findings are presented in this report.

## Method

A comprehensive literature review on public health best practices including planning, implementation and evaluation within newborn metabolic screening programs, and a national environmental scan of Canadian newborn metabolic screening programs were conducted by Health Promotion Disease and Injury Prevention (HPDIP) within PPH from July to November 2010. Together these methods were intended to answer the main research question: *How are public health newborn metabolic screening programs typically structured, implemented and evaluated?*

### Literature Review

The literature was searched in a systematic fashion using both Embase and Medline searches of articles published from 2000 to 2010. Hand searching of the grey literature was also utilized. The Google search engine was used to identify newborn screening programs' websites from Canada, the United States, the United Kingdom, New Zealand and Australia which were searched for relevant reports. Population Intervention Method and Outcome (PIMO) inclusion/exclusion criteria were established. Articles that met the inclusion criteria were read and examined for relevant information. Evidence was analyzed according to gaps, similarities, differences and common newborn metabolic screening programming recommendations.




### Environmental Scan Survey

A survey was conducted to identify and understand the programming processes and performance standards of newborn metabolic screening programs across Canada. A 31-item survey was drafted and sent to all provincial and territorial newborn metabolic screening programs. A combination of qualitative and quantitative methods was used to analyze and interpret findings. Descriptive statistics were used to describe basic features of the data. Quantitative data were further analyzed to identify similarities and differences in programming, highlight programming "best-practices" and determine whether identified best practices were suitable, adaptable and or transferable to Alberta.


**Newborn Metabolic Screening Program**
For more information, please contact: NMSProgram@albertahealthservices.ca

Alberta Health Services

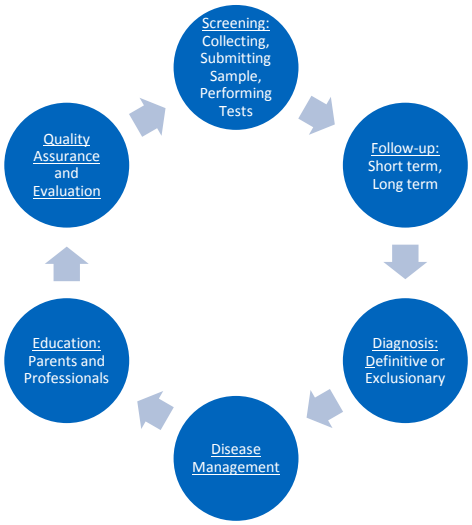
Newborn Metabolic Screening Program

# Newborn Metabolic Screening Program Initiative

**September 2011**

## Results from the Literature Review

- Newborn metabolic screening programming decisions were primarily informed through expert opinion and experience
- There were large gaps in the literature regarding program effectiveness, program outcomes and disease outcomes due to the small number of children affected by these disorders and because of the lack of surveillance data collection
- Two main organized screening frameworks were used to inform newborn metabolic screening programs:
  - *Principles and Practice of Screening for Disease*, World Organization of Health in 1968
  - *Population Based Screening Framework*, Australian Population Health Development Principle Committee, 2008
- Newborn metabolic screening programs were viewed in the literature to be more than the collection of blood from newborns; rather they were part of an organized screening system that involved the coordination of care across multiple settings and service providers, and access to rapid follow-up
- The literature recommended that effective newborn metabolic screening programs include the smooth integration of the following components:




Adapted from: Therrell, B., Johnson, A., & Williams, D. (2006). Status of newborn screening programs in the United States. *Pediatrics, 117,* S212- S252. doi:10.542/peds.2005-2633C

## Results from the Environmental Scan

- Canadian newborn metabolic screening programs' practices and policies were varied most likely because the responsibility for newborn metabolic screening lies within the jurisdiction of each provincial government
- Each province, with the exception of the territories, had a centralized 'provincial newborn metabolic screening program'. The number of genetic and metabolic disorders included in provincial newborn metabolic screening programs ranged from 5 to 32 disorders
- Saskatchewan was the only province that had a mandated newborn metabolic screening policy. Other provinces had voluntary newborn metabolic screening programs. Alberta was the first province to undertake the development of provincial newborn metabolic screening policy
- There were no consistent newborn metabolic screening sample collection practices or tracking processes. Some provinces lacked the infrastructure to track infants. Many factors such as location, climate, weather conditions, and mode of sample transportation contributed to delays in sample submission
- There were no national requirements for providing parents with education on newborn metabolic screening including information on storage retention and secondary use of samples. Printed parent brochures were commonly available in the hospital and on the Internet
- There were no national requirements for professional education on newborn metabolic screening. Printed blood spot collection resources were cited as the most commonly used source of professional education
- The three most common quality assurance activities were tracking and monitoring: positive test results, false positive test results and confirmatory diagnoses

**KEY LEARNING** *A newborn metabolic screening program is more than a simple blood test; it is a large interconnected system*

**KEY LEARNING** *A newborn metabolic screening program is an organized population based screening system*

**KEY LEARNING** *A newborn metabolic screening program's effectiveness and efficiency are impacted by each component of the system*

**Newborn Metabolic Screening Program**

For more information, please contact: NMSProgram@albertahealthservices.ca