

Alberta's NMS Program

Key Learnings from a Literature Review

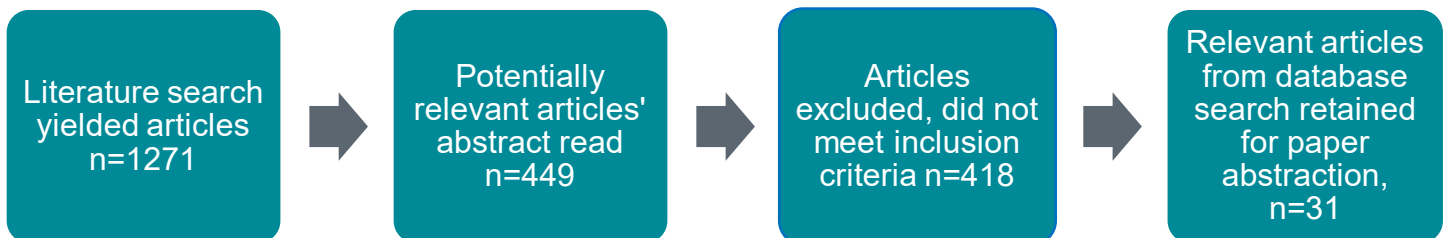
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The Newborn Metabolic Screening (NMS) Program is a population-based screening program that provides newborn blood spot screening to all infants born in Alberta. It works toward minimizing morbidity and mortality of Alberta infants through early diagnosis and treatment of screened conditions. To facilitate evaluation and strategic development of the program, a literature review was conducted to determine what defines a successful newborn screening program and if and how comparison of newborn screening elements or systems can be made between jurisdictions.

Method

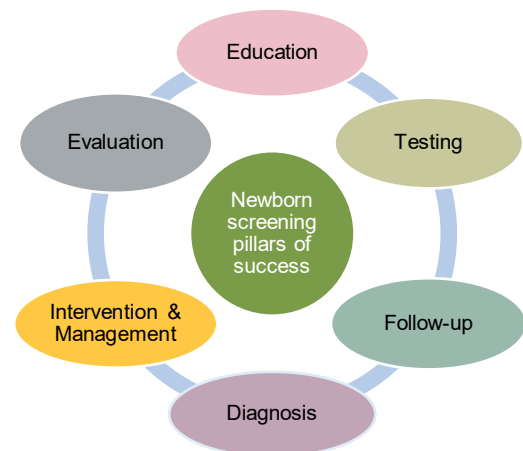
A comprehensive literature review of newborn screening programs' elements related to success, measuring success, demonstrating success, and comparison between jurisdictions was conducted by the NMS Program from October 2021 to February 2022. This method was intended to answer the following research questions: What comprises a successful newborn screening program? How is success in newborn screening programs measured and demonstrated? Can newborn screening programs from different jurisdictions be fairly and appropriately compared?

The literature was searched in a systematic way using Medline, Embase, Pubmed, Cinhal and Web of Science databases from 2010 to 2021. AHS Insite, Oaister, Google and Google scholar were searched for grey literature. Abstracts were read for articles meeting the inclusion criteria for relevance. Relevant articles were fully read and information was analyzed according to the criteria developed to understand newborn screening program success and what comparisons have been drawn so far between different jurisdictions' newborn screening programs.



Results from the literature review:

- Newborn screening is one of the most successful public health achievements of the modern world. However, this success story is limited to the screening part of the pathway.
- Newborn screening should be considered as a process not an event, a system including sampling, delivery, testing, analysis, reporting results, communicating results to family, primary provider and specialist, follow up diagnostic testing and initiating therapy, and long term follow up.
- A program's success should be based on six pillars: education, testing, follow-up, diagnosis, intervention & management, and evaluation.



Adapted from McCandless SE, Wright EJ. (2020). Mandatory newborn screening in the United States: History, current status, and existential challenges. *Birth Defects Research*, 112(4),350–366. <https://doi.org/10.1002/bdr2.1653>



- Prenatal education can facilitate prompt follow-up and reduce psychosocial harms, as well as promote trust in screening programs. It is important to find balance between providing complete information on newborn screening to parents, but at the same time, not to overload them.
- The informed consent process consists of two parts: first, the health practitioner informs parents about newborn blood spot screening and answer any questions they have; and second, the screening is 'offered' and the parents decide if their baby will be screened or not. For most births, newborn screening is considered routine and the baby gets screened automatically. This means the second part, where consent is given, is missed in most births except in the case of midwives and their patients, where the consent process is also explained and consent is attained in a true sense.
- A systematic public health approach needs to be applied to long term follow-up elements to ensure high level of quality assurance for lifetime care. It is important to have access to cleaned and unbiased outcome data for evidence-based quality improvements.
- Partnerships and coalitions are very important for overcoming current and future challenges as well as making the system efficient and effective. These partnerships are needed for an increase in formal research, clinical studies and systematic reviews based on public health principles. The resulting evidence will inform decision making, parent education and engagement, short and long-term outcomes, and adding and deleting conditions to a newborn screening panel.
- Evaluation and decision-making varies among the world because of how the Wilson and Jungner principles are interpreted by different countries. With technological advancements the variations that currently exist will increase due to the number and type of conditions that can be screened. Some of these conditions are untreatable thereby shifting the beneficiary of newborn screening from the child to the family which may result in changing the fundamental basis of newborn screening. To overcome these challenges, it is crucial to follow a proactive approach, including horizon scanning and building a thoroughly structured and well-informed policy decision-making process so that only conditions that meet the intent of the newborn screening can be added to the panel.

Key Learning

Organized newborn screening programs are a public health success, but the success is limited to the screening part of the pathway.

Key Learning

Newborn screening is a process, not an event. Therefore, to be successful, a program should perform well in all six identified pillars.

Key Learning

Comparisons can not be made between jurisdictions due to lack of standardized case definitions, performance measures and outcome data.