

Alberta's NMS Program 2019 Panel Expansion Evaluation Summary

June 2020

Introduction

Alberta's Newborn Metabolic Screening (NMS) Program is a population-based screening program delivered by Alberta Health Services (AHS) which screens for certain conditions to identify and treat infants with one of those conditions as early as possible. The panel expansion in 2019 added four treatable conditions to the screening panel (classic galactosemia [GALT], tyrosinemia type 1 [TYR1], severe combined immunodeficiency [SCID] and sickle cell disease [SCD]) and initiated universal notification of sickle cell trait (SCT).

Approach

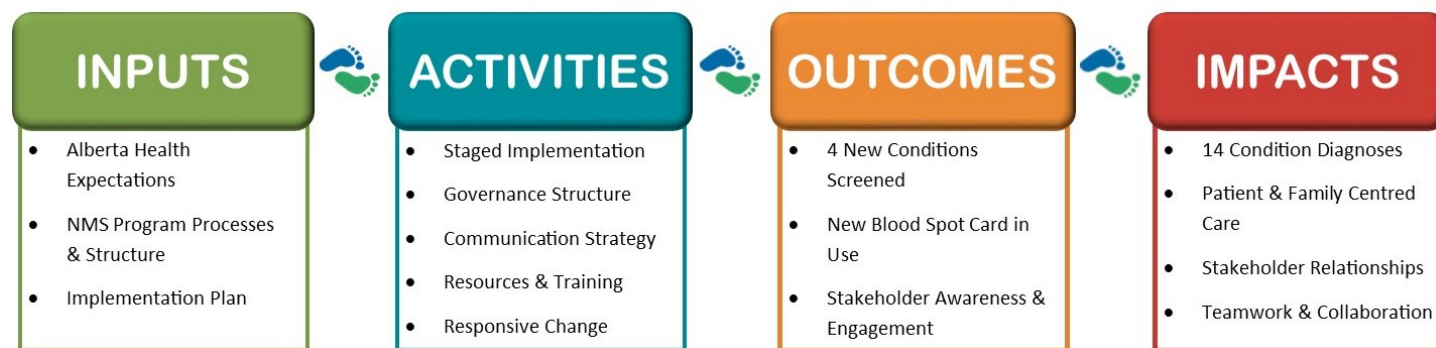
A staged approach was used to achieve implementation. Focusing on a governance structure and a communication strategy prepared newborn blood spot screening pathway service areas and stakeholders for panel expansion. The governance structure provided organizational oversight, operational integration and support for resource requirements for all aspects of the expansion. The communication plan utilized NMS Program's existing communications methods, tools and templates to inform and engage identified stakeholders. Communication themes were used to guide messaging provided to stakeholders in both the development and implementation stages of panel expansion.

Activities

Key deliverables were coordinated within the approach to manage change, maximize resources and increase impact of the change. The key deliverables aimed to inform stakeholders about: panel expansion, revised or new resources, updates to the clinical policy suite, operational impacts and completion of the panel expansion. Resulting in:

- **45,000+** healthcare providers reached through six practice specific newsletters
- **100+** stakeholder education sessions held
- **74** parent, provider and staff education resources updated
- **21** mass communications distributed to stakeholders
- **5** provider information resources developed

The NMS Program also used responsive change, adapting its strategy and resulting activities as needed to meet unanticipated needs or emerging issues as they became known. For example, responsive change work was used to address inadequate samples caused by the introduction of new blood spot cards. This quickly resulted in a greater than 70% decrease in abraded samples and improved the knowledge and understanding of stakeholders. Responsive change activities enhanced ongoing collaborative support with front line staff and improved patient and family centred care.



Survey Findings

Enablers:

- A. **Trusted Processes:** Using established processes and structures, helped stakeholders apply practice changes to their work with less interruption.
- B. **Communication:** Interactive communication ensured the teamwork necessary to meet timelines and the methods used to distribute information were effective, such as email.
- C. **Governance:** The structure, made up of a steering committee and working groups, was an appropriate forum to support and facilitate panel expansion.

Obstacles:

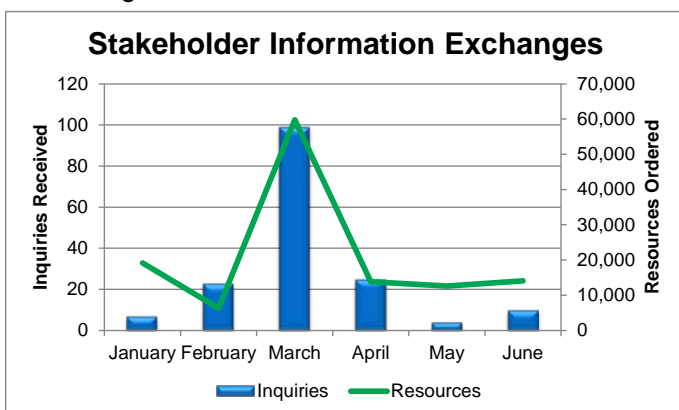
- A. **Timelines:** Timeline conflicts, delays and changes in practice increased risks to patients and workload for staff.
- B. **Communication:** Fewer emails and more targeted content was needed by stakeholders. While more flexibility around key roles in the governance structure was needed to ensure appropriate membership was maintained across working groups to increase alignment and clarity.

Project Outcomes

All key objectives from the 2019 NMS Program Panel Expansion Implementation Plan were achieved.

1. Implementation of the expanded panel was complete and all infants born in Alberta were screened for 21 conditions as of June 3, 2019.
2. Stakeholders were aware of the expanded panel, updated clinical policy and supporting resources.
3. Resources and training opportunities were available to all stakeholders.

Stakeholder engagement was also achieved, resulting in exchanges between the targeted audience and the NMS Program.



Program Impacts

Beyond key objectives, staff involved in newborn blood spot screening achieved intangible benefits through teamwork and collaboration on levels previously not experienced.

However, the most significant impact of expanding the panel was changing the lives of infants who had one of the four conditions and of their families due to better health outcomes and access to more equitable newborn screening across Canada.

- **39,000** infants screened between April 1 December 31, 2019
- **10** diagnosed with SCD
- **4** diagnosed with SCID
- **246** infants identified with SCT

Recommendations

The evaluation indicates that the 2019 NMS Program panel expansion was successful. Building on the foundation of communication and relying on staff expertise allowed the newborn blood spot screening pathway to reach success together. Three main recommendations stand out.

1. Continue to use trusted processes, structures, tools and relationships in times of change that have proved effective in the past.
2. Improve communication clarity by distributing more targeted content by stakeholder area and role, and supplementing individual communications with a consolidated communications summary document when applicable.
3. Ensure appropriate leadership and committee members are involved in the governance structure to mitigate potential issues and timeline challenges.

The 2019 NMS Program panel expansion has shown that dedication, adaptability and collaboration of committed stakeholders, through already established processes and structures were able to overcome insufficient time and resources to implement a system wide change to the provincial program.