

Summary of Recommendations

Toward a Future Pan-Canadian Coordinated Approach for Newborn Screening

As a part of the Government of Canada's National Strategy for Drugs for Rare Diseases, Canada's Drug Agency is supporting the development of pan-Canadian guidance for newborn screening as 1 of the key activities under the strategy. The overall goal of the guidance is to help foster greater consistency in the conditions screened for in newborns across Canada.



The Role of Newborn Screening

Newborn screening, specifically bloodspot screening, is when a small sample of blood is used to check for serious conditions and rare diseases. Screening helps identify certain conditions as early as possible so early treatment can be offered, with the aim of improving health outcomes in newborns and children.

Newborn Screening in Canada

All provinces and territories in Canada conduct newborn screening, but the conditions screened for in each jurisdiction may differ. Because of the variation in approaches to newborn screening across the provinces and territories, there is an opportunity to provide support to decision-makers by convening experts to share the best available advice across Canada.

Overview of the Newborn Screening Advisory Panel's Work

The advisory panel consisted of 2 co-chairs and 11 members from across Canada, each with diverse expertise and perspectives. They developed guidance, with input from interested parties, on 7 key areas related to newborn screening.

The advisory panel developed non-binding, short-term (1 to 2 years) and medium- to long-term (3+ years) recommendations across the 7 areas. The recommendations have been shortened for the purposes of this summary.

A full description of the process for developing the guidance, including the details of the recommendations, can be found in the final report.

Formulating the Guiding Principles

A Future Coordinated Approach for Newborn Screening in Canada

Enhancing Newborn Screening Processes

Criteria for Adding and Reassessing Conditions

Recommended Pan-Canadian Newborn Screening List

Anticipating Emerging Conditions for Newborn Screening

Full Report



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The Advisory Panel's Recommendations

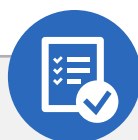
Formulating the Guiding Principles

The advisory panel recommended 6 guiding principles, which are a set of values to guide future work on policies, processes, and procedures related to newborn screening in Canada. They are:

-  **Health rights of the newborn**
-  **Equity**
-  **Effectiveness, safety, and quality**
-  **Transparency**
-  **Collaboration**
-  **Sustainability**



Six guiding principles were recommended to guide future newborn screening work.



Recommendation

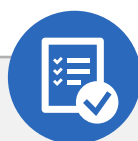
Short-term

- Adopt the guiding principles to support a pan-Canadian approach to newborn screening in Canada. This recommendation was identified as a priority for future work to guide the development of policies, processes, and procedures related to newborn screening.

A Future Coordinated Approach for Newborn Screening in Canada

The administration and delivery of health care is a provincial and territorial responsibility, with each province and territory having its own policies, processes, and procedures for newborn screening. While some provinces and territories rely on the knowledge and infrastructure of other jurisdictions, there is currently no centralized governance structure for newborn screening in Canada. The advisory panel proposed an advisory coordinating body with 3 committees as a governance structure to support a pan-Canadian approach for decision-makers for newborn screening.

Recommendation



Short-Term

- Develop and implement a pan-Canadian governance model for guidance for newborn screening by working with and building from existing organizations. This model could be explored by piloting a secretariat support function for guidance for newborn screening programs across Canada as an initial step to evaluate and learn.
- Explore and establish opportunities to engage with and educate the public about newborn screening, in collaboration with other organizations.
- Assess the need for and feasibility of a pan-Canadian data repository and a centralized resource and laboratory reference centre to provide Canadian-specific data and information to support newborn screening programs and laboratories.

Medium- to Long-Term

- Further develop the proposed pan-Canadian newborn screening governance model to enhance coordination for newborn screening in Canada by establishing and convening expert committees.
- Establish the groundwork for a pan-Canadian data repository by convening interested parties and decision-makers to work toward purpose; participation; and data governance, protection, and sharing.



Every jurisdiction has their own newborn screening policies, processes, and procedures.

Enhancing Newborn Screening Processes

There is an identified need for standardized processes to add a condition to, or reassess a condition for, newborn screening. The advisory panel outlined what a high-level, 4-step series of processes could look like.

The steps include:

- nomination
- evidence review
- deliberation and recommendation
- engagement and communication.

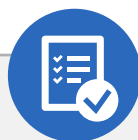
Recommendation

Short-Term

- Pilot the proposed processes for adding a condition by conducting an evidence review on a candidate condition and developing recommendations.

Medium- to Long-Term

- Establish and apply a nomination process for adding or reassessing conditions for the Recommended Pan-Canadian Newborn Screening List.



There is an identified need for standardized processes to add a condition to, or reassess a condition for, newborn screening.

Criteria for Adding and Reassessing Conditions

Recommendations to add or reassess a condition for newborn screening are typically made with criteria that help support deliberations and make them transparent. The advisory panel developed criteria to add a condition by modifying the Wilson and Jungner screening criteria to be relevant to newborn screening in Canada. For reassessing a condition that could lead to changes in implementation, including the potential for removal, the advisory panel modified the questions used by Australia's Newborn Bloodspot Screening National Policy Framework.

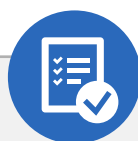
Recommendation

Short-Term

- Adopt the proposed criteria and processes for adding and reassessing a condition for the Recommended Pan-Canadian Newborn Screening List.

Medium- to Long-Term

- Develop a process for reassessing conditions in the Recommended Pan-Canadian Newborn Screening List and prioritize conditions for reassessment.
- Evaluate and refine the criteria for adding and reassessing conditions in the pan-Canadian newborn screening list.



Recommendations to add or reassess a condition for newborn screening are typically made with criteria.

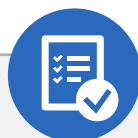
Recommended Pan-Canadian Newborn Screening List

A total of 25 conditions were recommended for inclusion in the pan-Canadian newborn screening list; it was built from the recommended list of conditions from a 2016 Intergovernmental Working Group. Nine conditions were recommended for further evidence review to determine if they could be added to the Recommended Pan-Canadian Newborn Screening List.

Recommendation

Short-Term

- Adopt the Recommended Pan-Canadian Newborn Screening List as a starting foundation to foster discussion and decision-making, leading to more consistent newborn screening across Canada.
- Work with experts to develop pan-Canadian case definitions for primary newborn screening conditions to facilitate a common language and understanding across newborn screening programs.

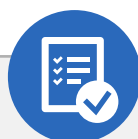


Twenty-five conditions were recommended for inclusion on the pan-Canadian newborn screening list.

Anticipating Emerging Conditions for Newborn Screening

A total of 29 conditions were identified as emerging conditions, meaning the conditions should be monitored because they may be considered in the future for addition to the pan-Canadian newborn screening list.

Recommendation



Short-Term

- Leverage existing processes within pan-Canadian health organizational capacity to develop a process for horizon scanning to anticipate candidate conditions for newborn screening in Canada.

Medium- to Long-Term

- Continue to build on the horizon scanning service to anticipate and expand the list of emerging conditions and technology trends in newborn screening such as genomic sequencing.



Twenty-nine conditions were identified as emerging conditions.

Other Considerations

There were several topics that were out of scope for the advisory panel's work that the advisory panel acknowledges are important for future work on newborn screening:

- other types of newborn screening testing
- genomic sequencing
- laboratory infrastructure
- data sharing, privacy, and quality metrics
- educational materials.

Final Note

This guidance was developed by the [Newborn Screening Advisory Panel](#) to support the National Strategy for Drugs for Rare Diseases and builds on prior newborn screening work in Canada.

Full Report



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