

Reviewing the ACHDNC Evidence-review Process: Evaluating Conditions on the RUSP

Presented to the Advisory Committee on Heritable Disorders in Newborns and Children

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Approach and Timeline through May 2021

Date	Review of the Committee Process Discussions
Feb 2019	Expert Advisory Panel Meeting to review the process
April 2019	Systematic Evidence Review and Population-level Health
July 2019	Public Health Impact Assessment
<i>Oct 2019 – April 2020</i>	<i>Legislative Hiatus</i>
May 2020	Recap of progress
	Considerations regarding values assessment and using this in the recommendation process
August 2020	Assessing values – recommendations, decision-making criteria/matrix/recommendations
December 2020	Decision-making and decision matrix
February 2021	Evaluating conditions on the RUSP
	Nomination Process/Form
May 2021	Overview of process review Summary of recommendations for the future

The Review Process: Four Focus Areas

1. Nomination

2. Review Process

- *Add on: Assessing Values in the decision-making process*

3. Decision Matrix

4. Review of Conditions on the RUSP

Review of Conditions on the RUSP

Rationale

- Updates in evidence on screening and treatment for core and secondary conditions on the RUSP
 - Focus on
 - New treatments, new clinical recommendations
 - Better of understanding of the conditions during infancy
 - Longer-term follow-up
 - Impact on public health, clinical services, individuals and families
 - Any other unresolved issue during a previous review

Review of Conditions on the RUSP - Con't

Defining the Process

- Frequency
 - Periodic reviews for regular learning opportunities
 - e.g., 3-, 5-, or 10-year updates
 - Ad hoc based informed by changes related to screening or treatment – but would need a process to nominate for review
- Principles and review criteria should remain consistent for added RUSP conditions
 - Key questions for evidence reviews can be used, with minor modifications
 - Increased emphasis on implementation

Review of Conditions on the RUSP (con't)

- **Define purpose and potential recommendations**
 - Clarify recommendation (e.g., target of screening)
 - Inform issues related to newborn screening and care delivery
 - Removal – not the goal

Questions for the Advisory Committee

- What information would be most important for you to learn about from a review?
- In what ways could a review help guide improvements in the process of newborn screening and follow-up?
- How should conditions be selected for review (e.g., routine process vs. ad hoc)?