

ACHDNC Decision Matrix Tool

November 2023

Purpose of the matrix tool

- The tool is meant to support decision making
- It is not meant to make the decision

Summary of suggested changes

- Separate out elements of public health readiness and feasibility from the evidence review and decision regarding magnitude of net benefit and certainty of net benefit
- Change the “grade” classification in the matrix to “designation”

NBS program assessment of feasibility and readiness

- The current assessment approach has not impacted recommendation decisions
- There needs to be an improved approach to assessing barriers to implementation and public health impact
- This assessment should be evaluated separately from the evidence-based decision to add (or not add) a condition
- The inclusion of an assessment of public health impact (including costs) is a required element of the matrix by statute and is critically important in considering addition to the RUSP

Summary of suggested changes

- Create a single A designation of high certainty of substantial net benefit
- Create a B designation that includes:
 - moderate certainty of substantial net benefit OR
 - high certainty of a moderate net benefit
- Create a C designation that includes moderate to high certainty of a zero or small net benefit, or net harm
- Create an I designation, corresponding to low certainty, which indicates that the evidence is (currently) insufficient to assign another designation

Decisions for new designations

- Conditions with an “A” designation will be forwarded to the Secretary with a recommendation to add to the RUSP
- Conditions with a “B” designation MAY be forwarded to the Secretary with a recommendation to add to the RUSP after discussion and a separate vote
- Conditions with a “C” designation will not be forwarded to the Secretary
- Conditions with an “I” designation will be not be forwarded to the Secretary, but evidence gaps will be identified and shared with nominators

Process for B designation and action

- Based on assessment of the magnitude of net benefit, and the certainty of net benefit, the committee votes to assign a B designation
- Based on additional discussion of the evidence and an assessment of the anticipated impact of adding the condition in terms of individual, family and public health benefit, the committee votes on whether to recommend adding the condition to the RUSP
- This separates agreement on the evidence from agreement that the condition should be added to the RUSP

Summary of suggested revised matrix

| Designation | Description | Action |
|--------------------|--|--|
| A | High certainty of substantial net benefit | Recommend addition to the RUSP |
| B | At least moderate certainty of at least moderate net benefit | Discuss and vote on recommending addition to the RUSP |
| C | At least moderate certainty of zero, small or negative net benefit | Do not recommend addition to the RUSP |
| I | Low certainty of net benefit | Do not recommended addition to the RUSP; Identify evidence gaps |

Implementation issues

- The matrix requires judgements in two areas: certainty of net benefit and magnitude of net benefit
 - Certainty of net benefit: there are well-established approaches for this decision; would suggest we adopt or revise the criteria used by the USPSTF
 - Magnitude of net benefit: this is more complex, especially in the setting of creating new levels of net benefit, “substantial” and “moderate”; the Committee will need to outline at least rough criteria we can use to make this judgement consistently over topics and time
 - The listening sessions are intended to support the net benefit assessment with input from differing perspectives about benefits and harms

Public health impact assessment

- Recommendations for addition to the RUSP must include an assessment of public health feasibility and assessment
- The ad hoc topic group did not reach a conclusion on how best to do this: we should consider creating a separate group
- Examples of questions that could be assessed:
 - Is testing for the condition feasible through all state health departments in the next three years?
 - Will all state health departments be ready to implement testing for the condition in the next three years?
 - What is the best current estimate of the total cost of testing, follow-up testing and arrangement for treatment per newborn screened? (point estimate and range)

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| I | Low certainty of net benefit | Do not recommended addition to the RUSP; Identify evidence gaps |
| Is testing for the condition feasible through all state health departments in the next three years? | | Y/N |
| Will all state health departments and associated clinical care systems be ready to implement testing and follow up for the condition in the next three years? | | Y/N |
| What is the best current estimate of the total cost of testing, follow-up testing and arrangement for treatment per newborn screened? | | \$ |

Determination of public health feasibility/readiness

- The Committee should discuss what we want to achieve with this process
 - Identify real barriers to implementation within 3 years
 - Identify support for implementation the ACHDNC could provide
 - Assess the level of support and prioritization from decision makers in the individual states (Newborn Screening Advisory Committees, State Public Health Laboratory Directors, State Public Health Department Executive Directors, Governor's offices, key legislators)
 - Create a set of actions that the assessment results would prompt

Proposal for discussion

- Discuss changes to matrix
- Create an ad-hoc topic group to address a process to assess public health impact
 - In partnership with state newborns screening programs, develop a more robust method of collecting feasibility, readiness and public health impact

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