

# Considerations Regarding Assessing Values and Preferences

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# Goal

- Consider options related to assessing values and preferences as part of the evidence review process
  - Validity
  - Feasibility
  - Impact on the Advisory Committee's decision-making process

# Consider...

- General NBS or specific condition reviews?
- Which stakeholders should and can we target?
- What values and preferences are needed to facilitate the decision-making process? What are the key points that need this assessment?
- How can the relevant values and preferences be elicited?
- When in the review process should values and preferences be elicited?

# Challenges

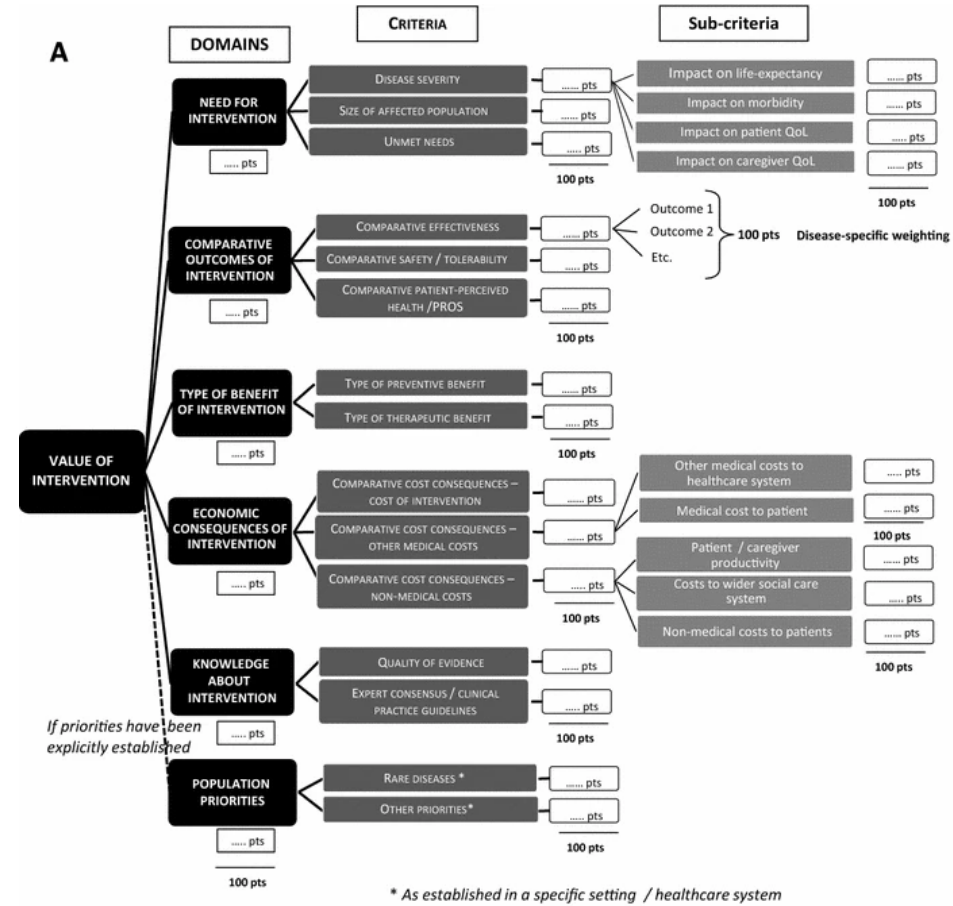
- Uncertainty regarding benefits and harms
- Nature of the recommendation for newborn screening
- Representativeness
- Time, budget, and OMB restraints

# Multicriteria Decision Analysis

- An approach to weigh values and preferences related to evidence, competing priorities, system capacity, and societal context
- Example: EVIDEM MCDA Value Matrix, which could be modified to address
  - Disease Impact (Severity, population size)
  - Screening (Alignment with current newborn screening, feasibility, benefits and harms)
  - Identification Through Newborn Screening versus Usual Clinical Care (Benefits and harms of early treatment)
  - Health Services Considerations (Impact on newborn screening programs, availability of short- and long-term follow up)

# EVIDEM Scoring

How should the weights be set?  
How are the results used?



**B**

<b>CONTEXTUAL NORMATIVE CRITERIA</b>	ALIGNMENT WITH THE MANDATE AND SCOPE OF HEALTHCARE SYSTEM
	ALIGNMENT WITH THE COMMON GOAL RATHER THAN SPECIAL INTERESTS
	ENVIRONMENTAL SUSTAINABILITY
<b>CONTEXTUAL FEASIBILITY CRITERIA</b>	AFFORDABILITY AND OPPORTUNITY COSTS
	SYSTEM CAPACITY AND APPROPRIATE USE
	POLITICAL, HISTORICAL AND CULTURAL CONTEXT

# Stakeholders

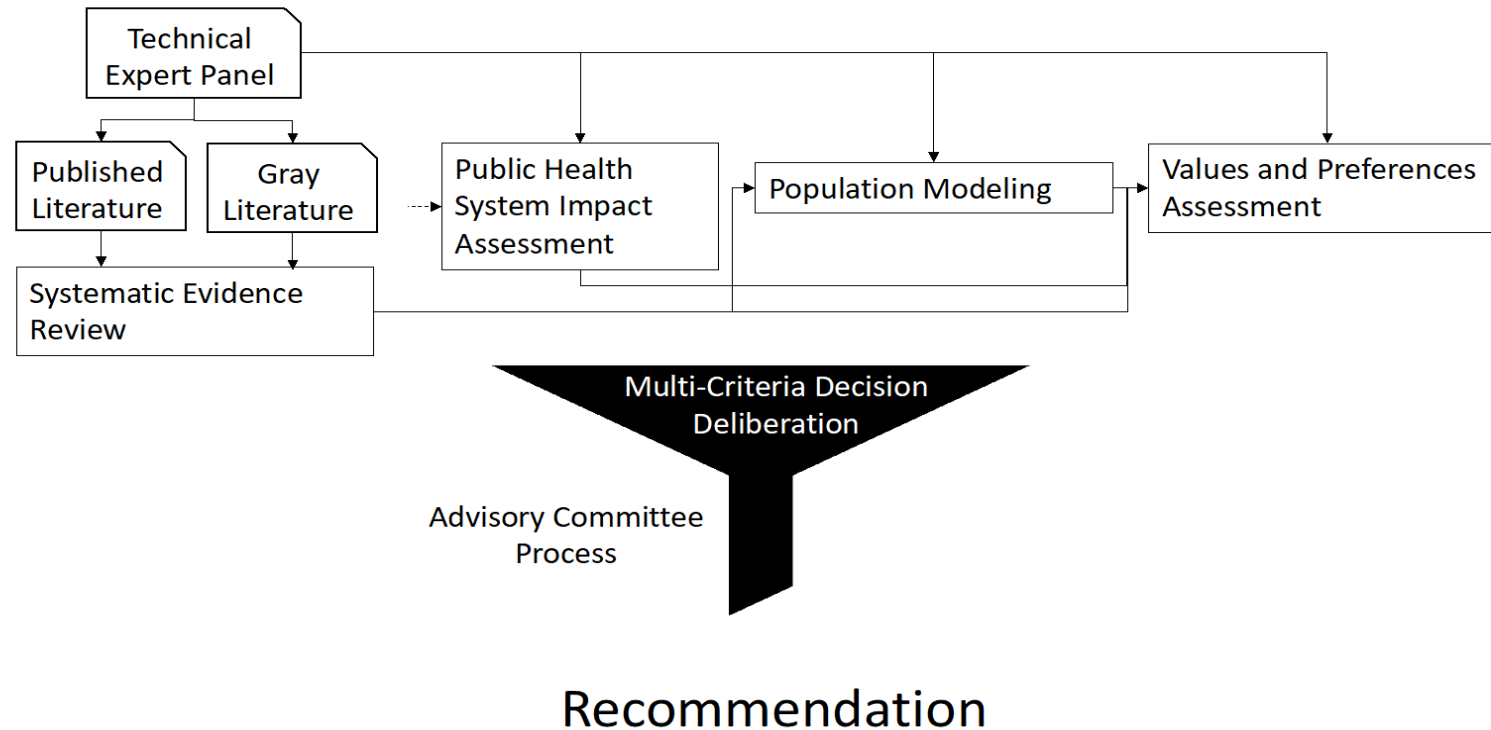
- Individuals with the condition and their families
- Individuals/families exposed to harm related to screening
- Pregnant women and their partners
- Wide variety of others now more likely to be included in the evidence review process
  - Clinicians, researchers, newborn screening program managers, public health officials, payers, etc.

# Methods to Assess Values and Preferences

- Citizen's Jury
  - Feasibility concerns
- Quantitative Approaches
  - Validity concerns
- Qualitative approaches
  - Unclear feasibility (need to be representative (purposive sampling), thematic saturation)
  - Not generalizable, but can describe key issues
  - Formal thematic analysis can be time consuming
- Mixed methods
  - Research is needed to validate the quantitative component
- Novel approaches: Simulation and games



# Incorporating Values and Preferences into the Review Process



# Key questions

- WHAT values and preferences should we and can we assess about newborn screening?
- WHOSE values and preferences should we and can we assess?
- HOW will an assessment of values and preferences be used?
- WHAT is the approach to embed the assessment of values and preferences into the current evidence review process?