

PRINCIPLES PROCEDURES FOR POLICY IDENTIFICATION

Minnesota Rare Disease Advisory Council (RDAC) uses the following principles and procedures when selecting areas of focus for its work and recommending policies. This document supplements RDAC's operating procedures and policy recommendations.

Principles

Scope of policy recommendations

- RDAC will consider recommending policies that improve early diagnosis and detection for rare diseases, ensure timely access to currently available rare disease treatments and services, enhance coordination of care for individuals with rare diseases, and accelerate and advance rare disease research.
- Policy options include (but are not limited to) newborn screening, genetic testing, prior authorization practices, value-based care, and medical research.
- RDAC will avoid redundant policy development efforts by engaging with Department of Health Services (DHS), Minnesota Department of Health (MDH), and other relevant state agencies.

Reduced time to Diagnosis

- RDAC will deliberate on topics related to the use of diagnostic tools (genetic testing, newborn screening, etc.) to facilitate early diagnosis.
- RDAC will deliberate on topics related to expedited access to knowledgeable clinicians.

Coordination of Care

- RDAC will seek to identify and deliberate on topics that address fragmentation of care in rare disease management.
- Improvements in widely received health care services that may have a greater positive effect to incrementally reduce barriers to rare disease patients and communities will be considered (ie telehealth).
- RDAC will seek to identify topics that have significant potential for reducing disparities in access or health status among segments of rare disease populations.

Acceleration and Advancement of research

- RDAC will deliberate on topics that increase the ability of the scientific and/or rare disease patient community to address the unique challenges to research for rare diseases.

PRINCIPLES PROCEDURES FOR POLICY IDENTIFICATION, *continued*

Processes

Key considerations

RDAC staff and members will at least annually consider lists of potential topics and rank and recommend a subset of these for inclusion in the RDAC legislative agenda. RDAC will use the following criteria when selecting and prioritizing topics for its work. Order of criteria does not imply priority:

- Exclusivity to the needs of rare disease communities
- Capability of providing benefit to a broad number of rare disease communities
- Alignment with RDAC strategic priorities
- Ability to impact Minnesota rare disease communities
- Opportunity to capitalize on our unique role as an executive branch state agency
- Whether other groups, both in state and out of state, have addressed the topic or are in the process of doing so and whether RDAC's contributions would add value or redundancy.

Sources of Input

RDAC will consider input from the following sources when evaluating potential topics for discussion. Order of sources does not imply priority:

- RDAC will seek systematic input about potential policy topics from individuals and patient advocacy organizations who represent individuals with rare diseases. Further, knowing that a significant number of rare disease patient communities do not have a disease-specific patient advocacy organization, RDAC will engage organizations that provide broad representation for the rare disease community.
- RDAC membership will retain a diverse and broad representation of expertise and will seek full council input when leading any identified policy topics.
- RDAC will accept input on policy topic selection from all stakeholders, including providers, researchers, patient advocacy groups, industry, payers and the general public.
- RDAC will actively monitor the legislative environment in and out of state concerning topics related to rare disease patient populations to evaluate and deliberate on the RDAC's best form of engagement.
- RDAC will actively engage with legislative members on the council and at large as input to understanding how potential policies and legislative agendas will most effectively be realized.
- RDAC will use collected data to determine areas of focus from two expansive needs surveys that we conducted with [providers](#) and [patients/families](#). The patient survey was peer-reviewed and published in 2020.

The Full Council will have final discretion for approving the legislative agenda each year.