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# Healthcare access, satisfaction, and health-related quality of life among children and adults with rare diseases

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Survey of 1,128 U.S. residents with rare diseases and caregivers

- Collaboration with the Minnesota Rare Disease Advisory Council
- 344 different RDs

**1/3 of respondents waited 4+ years for a diagnosis**

**~1/2 reported traveling more than 60 miles for healthcare**

**1/4 paid \$3,000+ out-of-pocket for healthcare expenses**

**~20% experienced insurance denials or delays**

The majority reported **insufficient medical, mental health, and dental care**

Compared to the general U.S. population and people with common chronic conditions, people with RDs **had poorer health-related quality of life**

# Rare Disease Advisory Council Impact



## Policies implemented in response to survey findings

Require insurers to cover out-of-network and out-of-state care when needed for people with rare diseases

Launched Project ECHO to connect general care physicians around the state with RD specialists



## Conduct additional research to examine impact and emerging challenges