

Healthcare access in rare disease: a public health priority!

There are over 7,000 rare diseases in existence with over 25 million patients affected. Yet, healthcare access and quality of life are elusive to many rare disease patients, and only 5% of rare disease patients have an approved treatment option. Even when compared to adults with common chronic diseases, adults in Minnesota with rare diseases had significantly worse stigma, physical function, fatigue, and depression, and marginally worse anxiety.

The 2020 Rare Diseases Health Care Access Study set out to learn more about rare disease patients' barriers to care. Find the study at www.cbacraredisease.org



56% of rare disease patients waited over **one year and up to ten years** to receive a diagnosis.

LOCAL CARE? ONLY FOR SOME.

Participants living in outstate Minnesota were more likely to report traveling **over 60 miles** for rare disease care.



PERCEPTIONS OF PROVIDER KNOWLEDGE

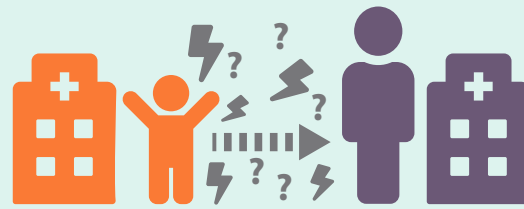


40%

rated the initial provider as "poor" on their knowledge of rare diseases.



37% saw **4-10 PROVIDERS** prior to receiving a diagnosis



44% of participants reported **problems with transition from pediatric to adult care.**

INVESTIGATIONAL DRUG ACCESS

72% MN adult respondents
79% MN pediatric respondents



reported delays or denials for use of an investigational treatment.

CARE COORDINATORS: EQUALLY RARE



12% of rare disease patients surveyed have a care coordinator.

TELEHEALTH'S USEFULNESS



58% of all participants reported using telehealth visits for specialist care appointments.



INSUFFICIENT PATIENT EDUCATION FROM PROVIDERS

General practioners **21%** Specialists **15%**

did **not** provide sufficient information.

IN



OUT



OUT OF NETWORK ACCESS

27% pediatric **19%** adult

Respondents reported being **initially denied** seeing a specialist due to that specialist being out of network.