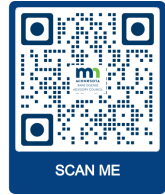


# Healthcare access in rare disease: A PUBLIC HEALTH PRIORITY!

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. The full survey results can be found at <https://pubmed.ncbi.nlm.nih.gov/35549731/> For more information on the council, please scan the QR code or visit [www.mnrareisease.org](http://www.mnrareisease.org)

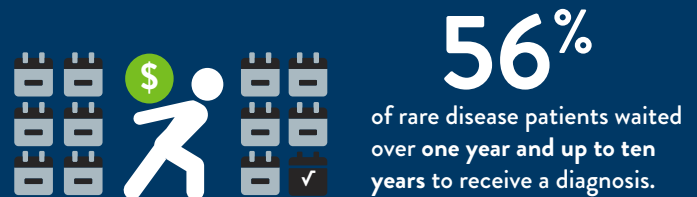


## LOCAL CARE? ONLY FOR SOME.

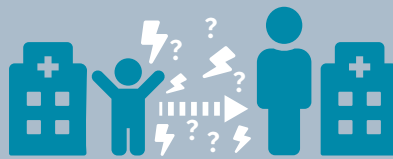
Participants living in outstate Minnesota were more likely to report traveling **over 60 miles** for rare disease care.



## DELAYED TIME TO DIAGNOSIS



37% of patients 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.

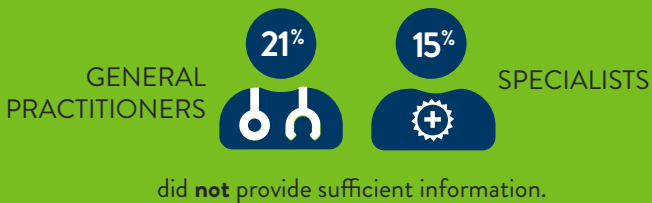
## PERCEPTIONS OF PROVIDER KNOWLEDGE



**40%** rated the initial provider as "poor" on their knowledge of rare diseases.



## INSUFFICIENT PATIENT EDUCATION FROM PROVIDERS



## OUT OF NETWORK ACCESS

