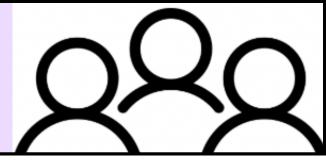
Seeking Research Participants



Uncommon Illness, Unequal Burden: Rare Disease at the Intersections of Identity

Purpose

To learn more about how individuals with rare diseases view their patient journey at the intersection of their personal identity.

Research Procedures

Eligibility: Diagnosed with a Rare Disease or a family member of an individual with a rare disease

You will be asked to:

- (1) Answer a 10-minute questionnaire regarding identity
- (2) If eligible and willing, individuals can be interviewed on zoom for 1 hour to elaborate on their answers in the questionnaire on how they view their rare disease in the context of identity.

Compensation (\$25) is provided for study completion.

Email Us If Interested

Emory University Departments of Data Science and Anthropology

Study Coordinator: Anita Osuri

Email: aosuri2@emory.edu

IRB Protocol #: 2025P011832