

Health Insurance Literacy & Burden of Access in Niemann-Pick Disease

Diaz GA, Crowe J, Hopkin J. Health insurance literacy and health services access barriers in Niemann-Pick disease: the patient and caregiver voice. Orphanet J Rare Dis. 2022 Sep 2;17(1):332. doi: 10.1186/s13023-022-02490-8



BURDEN OF ACCESS

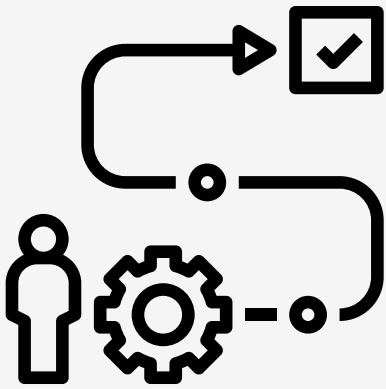
Background

- In anticipation of having commercial therapies available, the National Niemann-Pick Disease Foundation (NNPDF) desired an understanding of:
 - The health insurance literacy among their community
 - The burdens currently faced by families as they attempted to access desired care, services, medications, medical equipment, and assistive devices



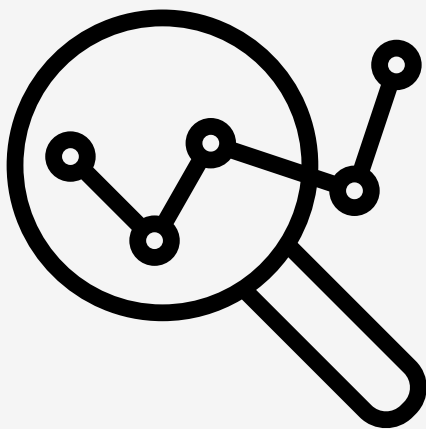
Patient Experience

Patient experience data serves multiple purposes throughout the drug development timeline and is also critical to activities related to uncovering opportunities to finding new medical need and planning patient support services.



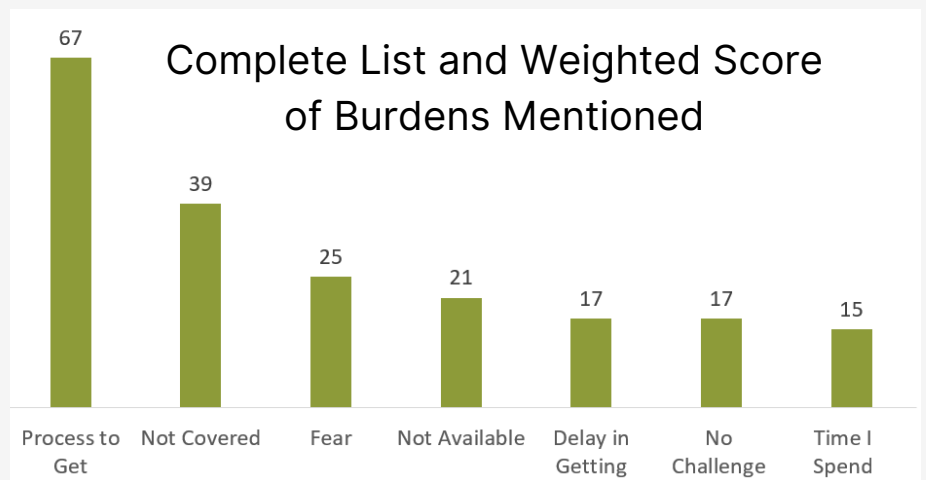
Research Methods

Of the 450 NNPDF members, there were 79 caregivers who completed the survey. Of those, 67 caregivers participated in a one hour telephone interviews, which collected burdens associated with NPD in the voice of the patient. Burdens were weighted, with those mentioned first receiving a higher score than those mentioned subsequently.



Results

- Caregivers of patients with Niemann-Pick Disease scored higher on health insurance literacy than a control group of patients without a rare disease
- The *process to obtain access* to needed medications, services and assistive devices was the most burdensome aspect for caregivers, followed by those items *not being covered*



Real-World Implications

Through this study, the NNPDF was able to obtain an understanding of health insurance literacy and access burdens of their audience, thereby informing design of support programs.