

# Health Insurance Literacy in Acid Sphingomyelinase Deficiency (ASMD)

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## Background

- With the recent FDA approval of olipudase alfa for acid sphingomyelinase deficiency (ASMD) in adult in pediatric patients, there is an urgent need for the community to understand their health insurance benefits for optimal utilization
- Through this research, the National Niemann-Pick Disease Foundation (NNPDF) sought to understand the health insurance literacy among the community and the burdens faced by families as they attempted to access desired care, services, medications, medical equipment, and assistive devices
- While the outcomes of this research were used by NNPDF to design programs and inform various other workstreams intended to assist ASMD families, only the results regarding health insurance literacy are addressed here

## Objectives

- To better understand health insurance literacy and healthcare coverage situations for patients and families
- To better understand patient experience in Niemann-Pick disease as it pertains to access various healthcare services
- To create a baseline dataset to benchmark future progress, academic publications, and family programming

## Methods

1. Twenty-three (23) participants who were diagnosed with ASMD or their caregiver participated in the study, with broad representation across the United States (**Figure 1**)
2. Participants were provided ten questions previously utilized by the Kaiser Family Foundation (KFF) to capture the understanding of health-insurance related questions and calculations by consumers in the United States <sup>1</sup> (**Figure 2**)
3. Results of the total percentage of participants who provided the correct answer were compared to the results of the general population, provided by KFF<sup>1</sup>
4. After the quiz, participants were also asked to self-rate their knowledge in terms of health insurance and general components of health insurance literacy, including information seeking, document literacy, and cognitive skills (**Figure 3**)

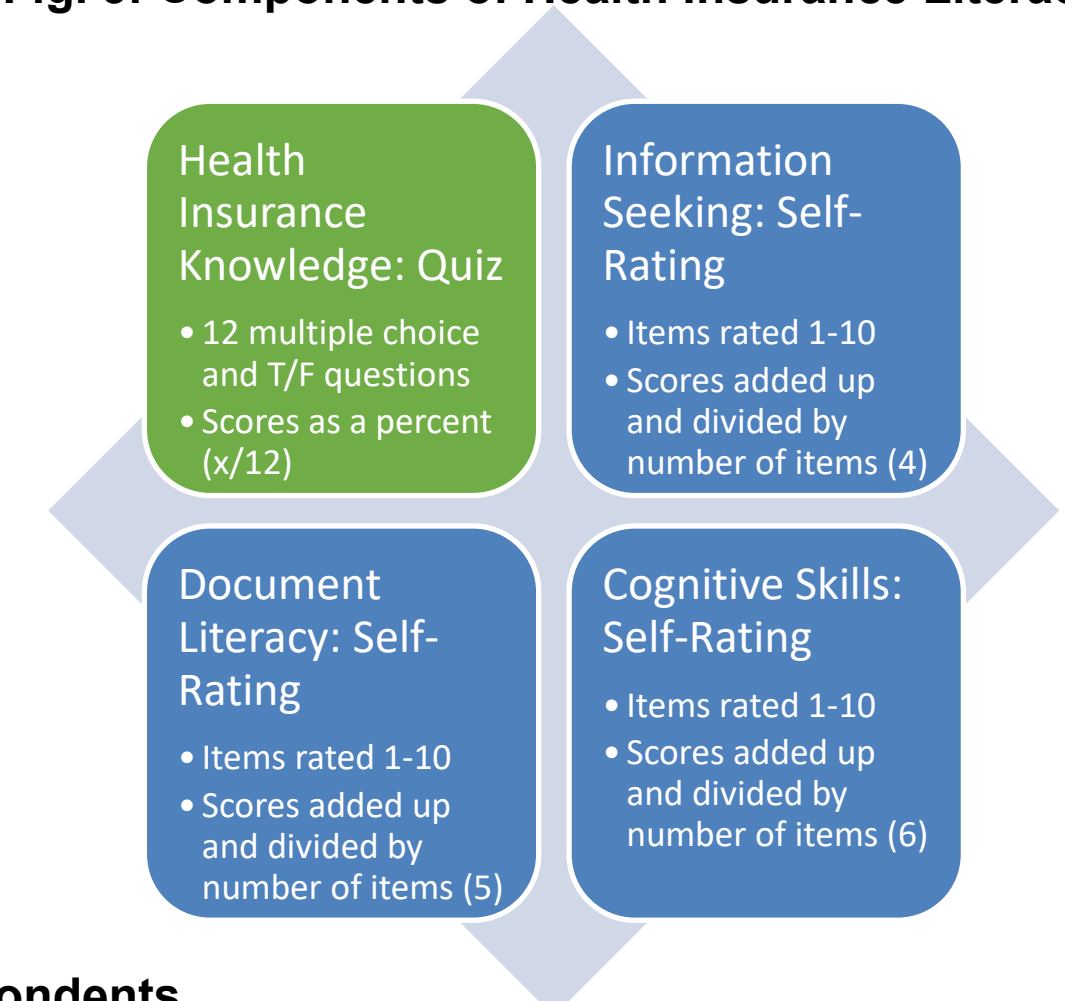
## Results

- On average, participants scored higher (average of 63%) than the general population sampled by KFF (average of 58%) (**Figure 4**)
- The most significant difference between KFF and our participants was on Q9, a calculation of out-of-pocket costs in- versus out-of-network, potentially reflecting the community's frequent involvement procuring coverage for out-of-network care
- The NNPDF participants most frequently missed questions 4, 6, and 8, which related to;
  - Out of pocket costs based on deductible and co-pay
  - The definition of a health insurance formulary
  - Whether inpatient care at a hospital in a certain network would mean all doctors in the hospital are considered in-network
- After the quiz, participants rated themselves highest in information seeking (72/100) compared to document literacy (70/100) and cognitive skills (67/100)

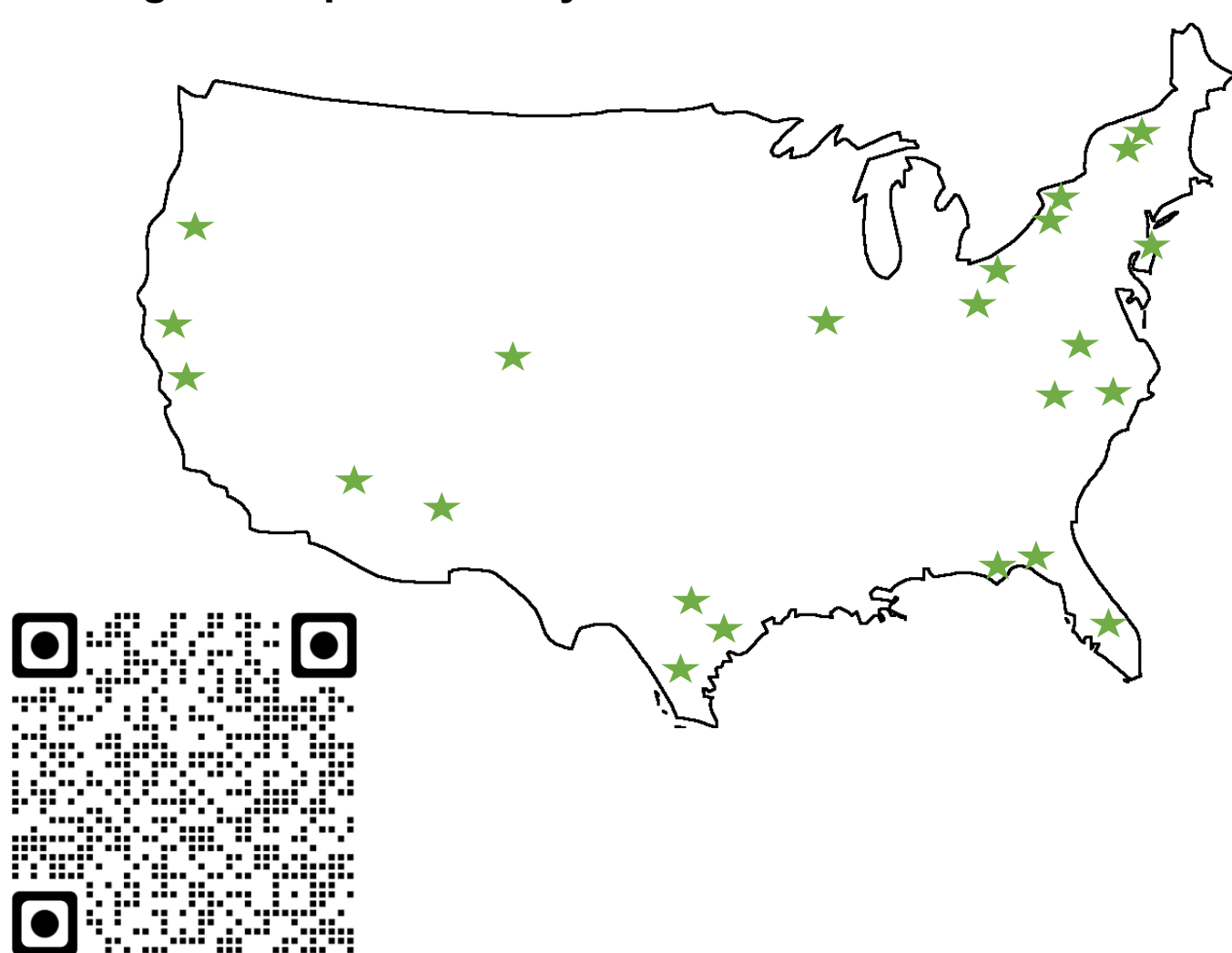
**Fig. 2: Questions Summary from KFF**

Q1- definition health insurance premium  
 Q2- definition health insurance premium  
 Q3- definition health insurance deductible  
 Q4- calculation of out of pocket costs based on deductible and copay  
 Q5- definition of annual out of pocket  
 Q6- definition of health insurance formulary  
 Q7- definition of provider network  
 Q8- true/false re: provider network  
 Q9- calculation of out of pocket costs based on in / out of network  
 Q10- true/false re: appeals

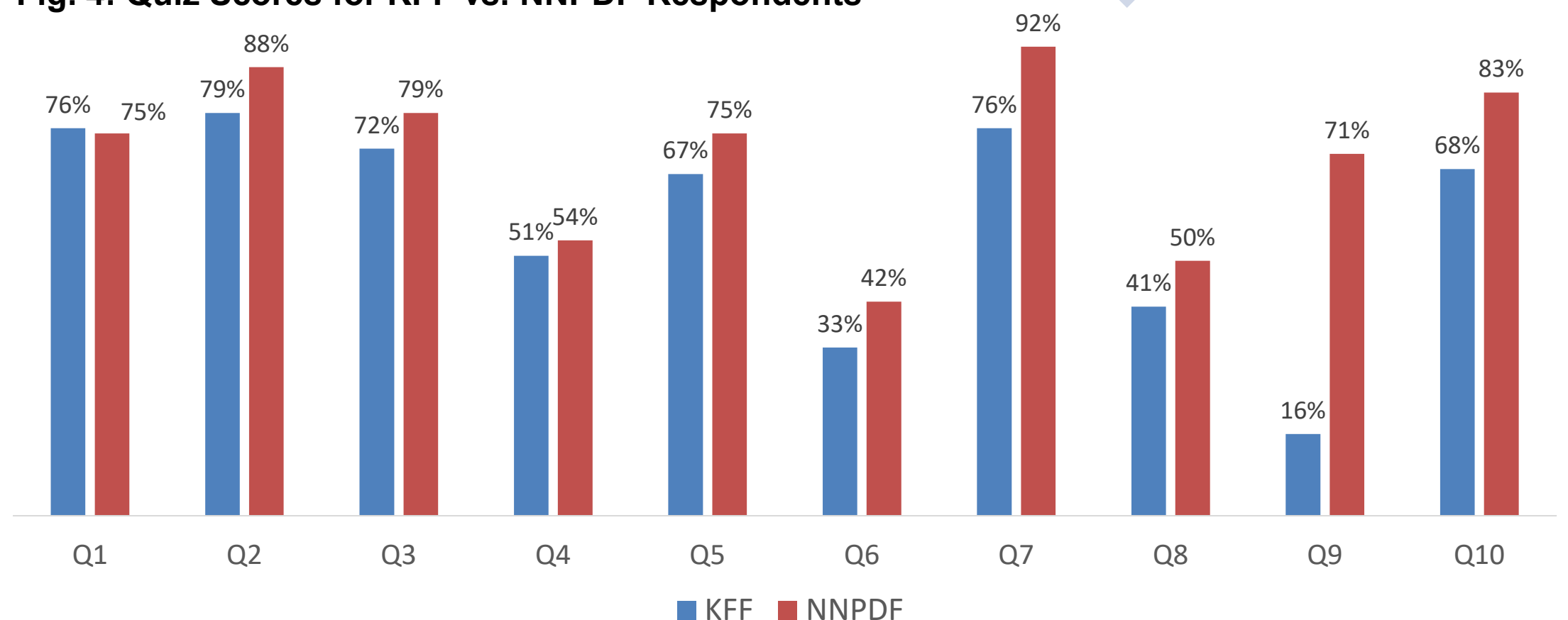
**Fig. 3: Components of Health Insurance Literacy**



**Fig. 1: Respondents by Location**



**Fig. 4: Quiz Scores for KFF vs. NNPDF Respondents**



**Summary:** Results from this study highlighted unique opportunities for patient support organizations such as the NNPDF to prepare their communities for specific issues to support healthcare access and understanding the out-of-pocket cost associated with new treatment options, in order to optimize access to new therapies. The results were utilized as a benchmark for future family programming initiatives



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