

Understanding health insurance literacy and challenges in accessing health services in Niemann-Pick Disease through the eyes of patients and families.

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Background

Niemann-Pick Disease is a group of ultra-rare genetic disorders characterized by intracellular lipid accumulation. There are multiple active clinical trials in both ASMD and NPC that offer hope to a community with no FDA approved therapies. As our community looks to a post-approval era, the National Niemann-Pick Disease Foundation aims to support our families by gaining a thorough understanding of the community's current health insurance status as well as the health consumer literacy.

Method

In partnership with Engage Health, NNPDF conducted an IRB-approved PRO research study of the U.S. Niemann-Pick Community via online survey and follow up structured interviews. A total of 79 surveys were completed and 67 follow up interviews were conducted. Participants consisted of persons with NPD 18 years or older, or parent/legal guardians of adult patients and minors with NPD. Parents whose child had passed on in the last two years were also eligible to participate. The online survey was carried out to measure health insurance literacy and interviews were conducted to collect the experience of patients and families impacted by Niemann-Pick Disease (NPD) related to accessing desired care, services and treatments/medications.

Health insurance literacy was modeled on the work of Paez et al. 2014¹ and assessed knowledge, information seeking, document literacy and cognitive skills.

Primary Outcome Measures

1. Health insurance Literacy as scored on a brief quiz of key health insurance terms (Norton and Hammel, 2014²) as well as self assessment of the ability to navigate and understand insurance (Paez et al. 2014³).
2. Health Insurance Coverage as scored on multiple choice and open-ended questions capturing insurance type, description of co-pay and other features such as services covered.

Significant Findings

NPD patients and families scored higher than the population studied by Norton and Hammel, which was representative of the general US population⁴. Insurance literacy gaps included insufficient knowledge of terminology and difficulty calculating expenses based on insurance coverage. Also evident was a gap in the awareness and use of Medicaid waivers, knowledge of insurance plan deductibles, and out-of-pocket maximums. Childhood onset NPC patients were more likely to be enrolled in Medicare/Medicaid and were more likely to have a Medicaid Waiver. ASMD patients were more likely to have only private insurance without an

additional public plan. ASMD respondents reported higher rates of fear for coverage of services, equipment, and medications as compared to NPC patients and families. The process to get care and services was ranked the greatest access challenge overall. Fear was most often related to the coverage of medications.

The most common life impacts from access challenges were mental health and physical symptoms. Caregivers' most frequent burdens were caregiver burnout and concerns about advocating in the right way. Community members fear delays in access or being unable to access medications, services and providers. These fears impacted both patients and caregivers.

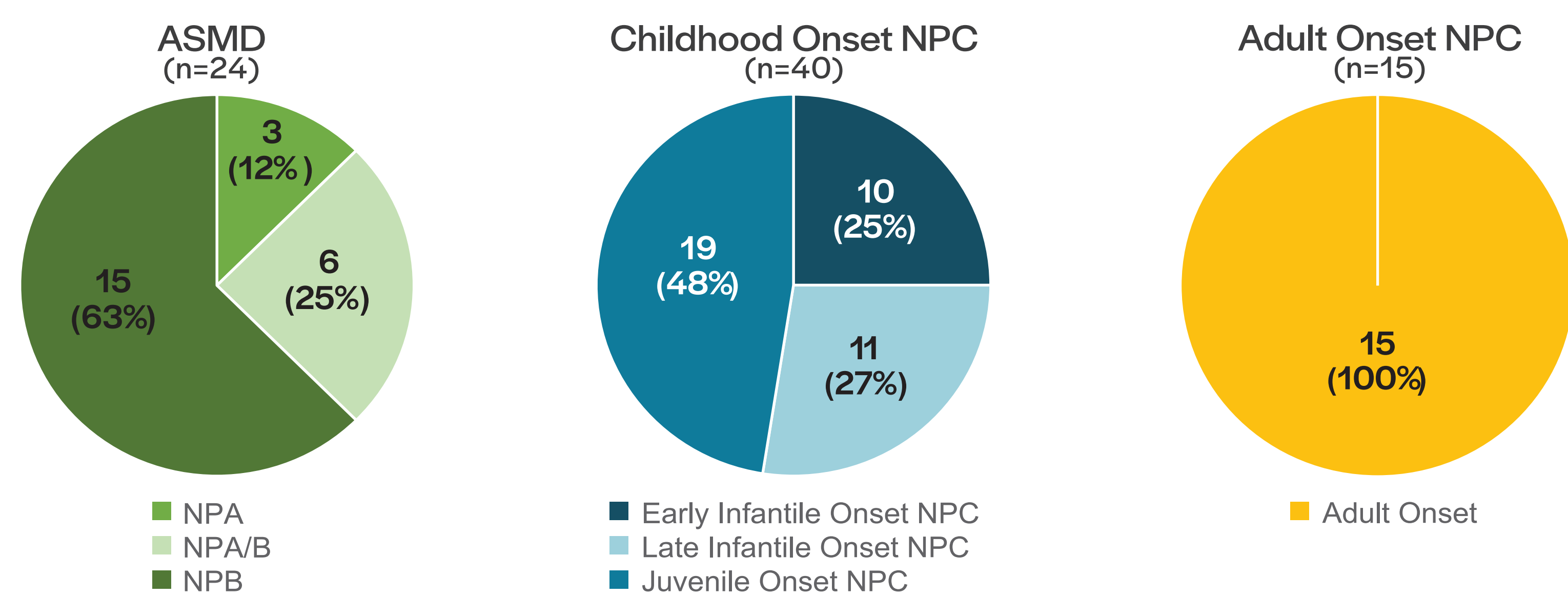
Conclusion

While members of the Niemann-Pick community having higher insurance literacy than the general public, targeted educational efforts are needed. The results of this research will be used to inform ongoing advocacy efforts by the National Niemann-Pick Disease Foundation to improve patient outcomes in a post-approval landscape.

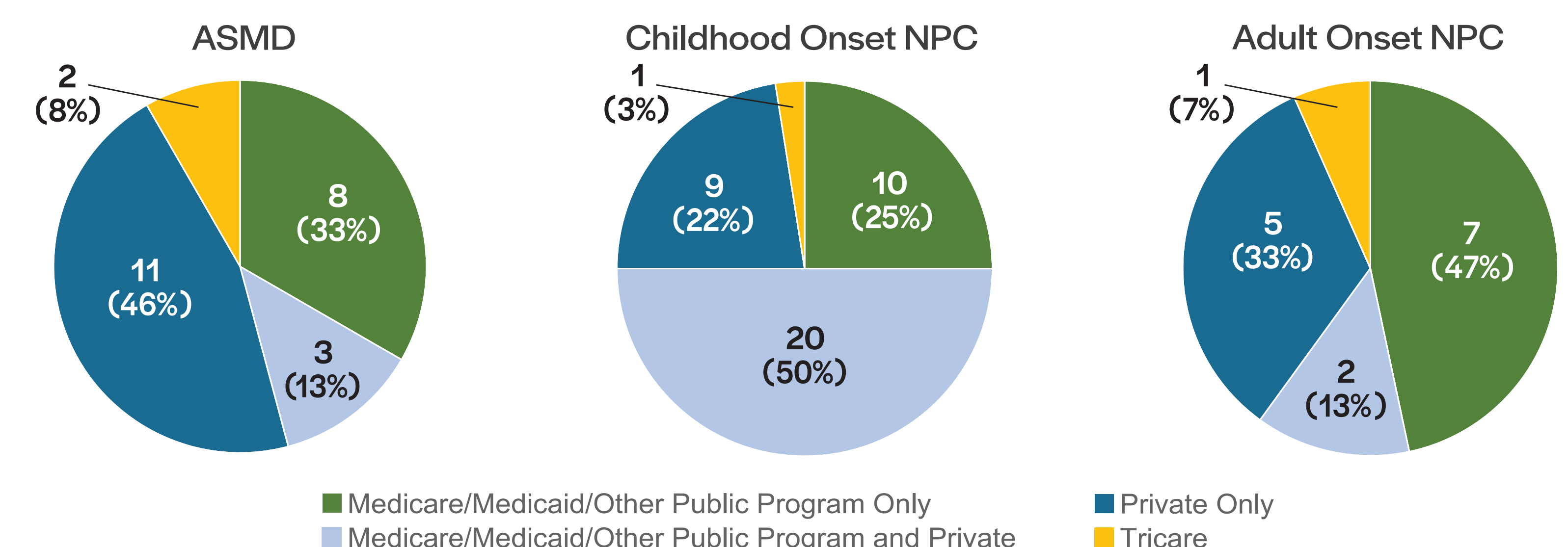
¹Paez et al, Journal of Health Communication, 19:225-239, 2014

²Mira Norton, Liz Hamel, Nov 2014. "Assessing Americans' Familiarity With Health Insurance Terms and Concepts." KFF, 12 Nov 2014, www.kff.org

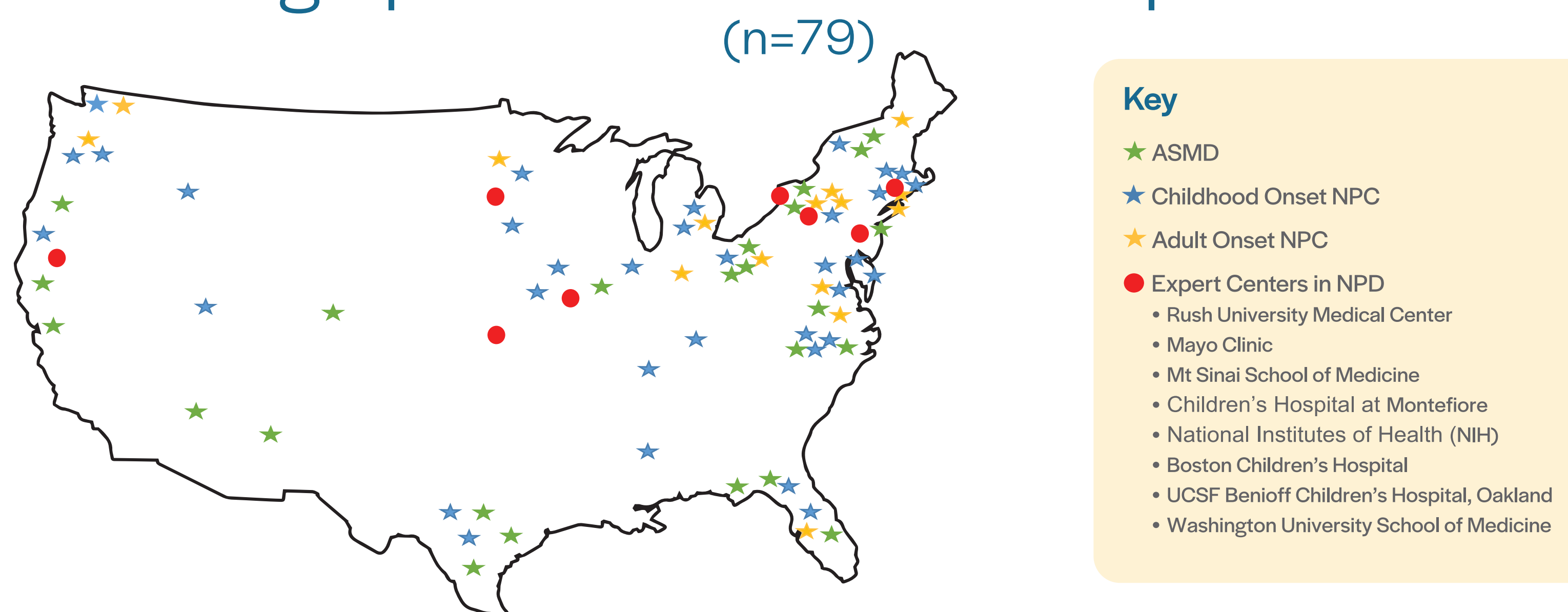
Insurance Breakdown by Subtype (n=79)



Insurance Types by Disease Group (n=79)

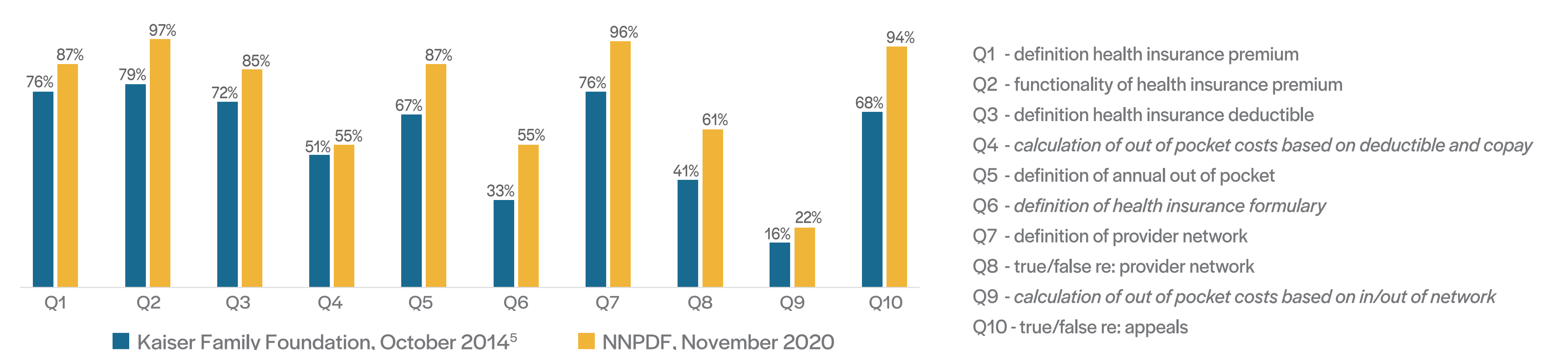


Geographic Distribution of Respondents (n=79)



Health Insurance Terminology Quiz

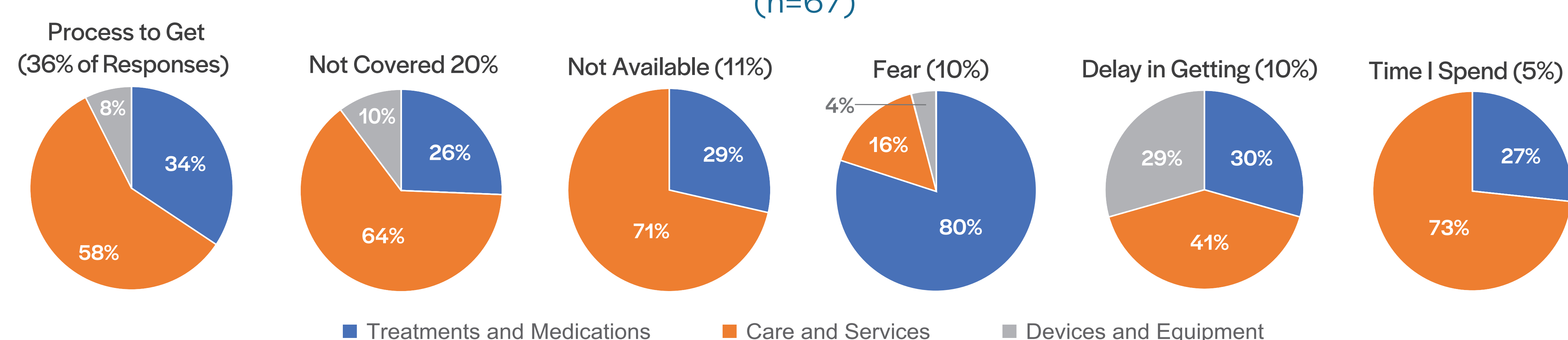
- Same 10 questions used by Kaiser Family Foundation, *Assessing Americans' Familiarity with Health Insurance Terms and Concepts* October 2014
- Using the population from the KFF study with health insurance and similar education, compared the number and percent correct



The greatest challenge is it [accessing care] turns into a second full time job; You have to be in the mindset of "we accomplished this, what is next, what else can I do, what do I need to do more, what phone calls to make?" Instead of a mother-child relationship, it is a job trying to manage the office side of things.

- Parent of NPC Child

Most Important Challenges - Open Ended (n=67)



"The biggest challenge was learning what kind of stuff was out there to help- resources. We were new to this when he got diagnosed, [we] didn't realize you could have secondary [coverage], what Medicaid waivers were, things that have helped us so much. It was up to me on my own to do the research, finding all of that out."

- Parent of ASMD Child