

Caregiving in hereditary cancer: Caregivers’ resource and support needs



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Introduction

5-10% of all cancers are hereditary; caused by damage to DNA in cells

Unique context of caregiving: Navigating caring for a family member with cancer as well as personal cancer diagnosis/risk. Extends to future generations (e.g., family planning)

Limited inherited cancer-specific resources; FORCE is working to fill the gaps informed by experiences and opinions from past/current caregivers

Goals

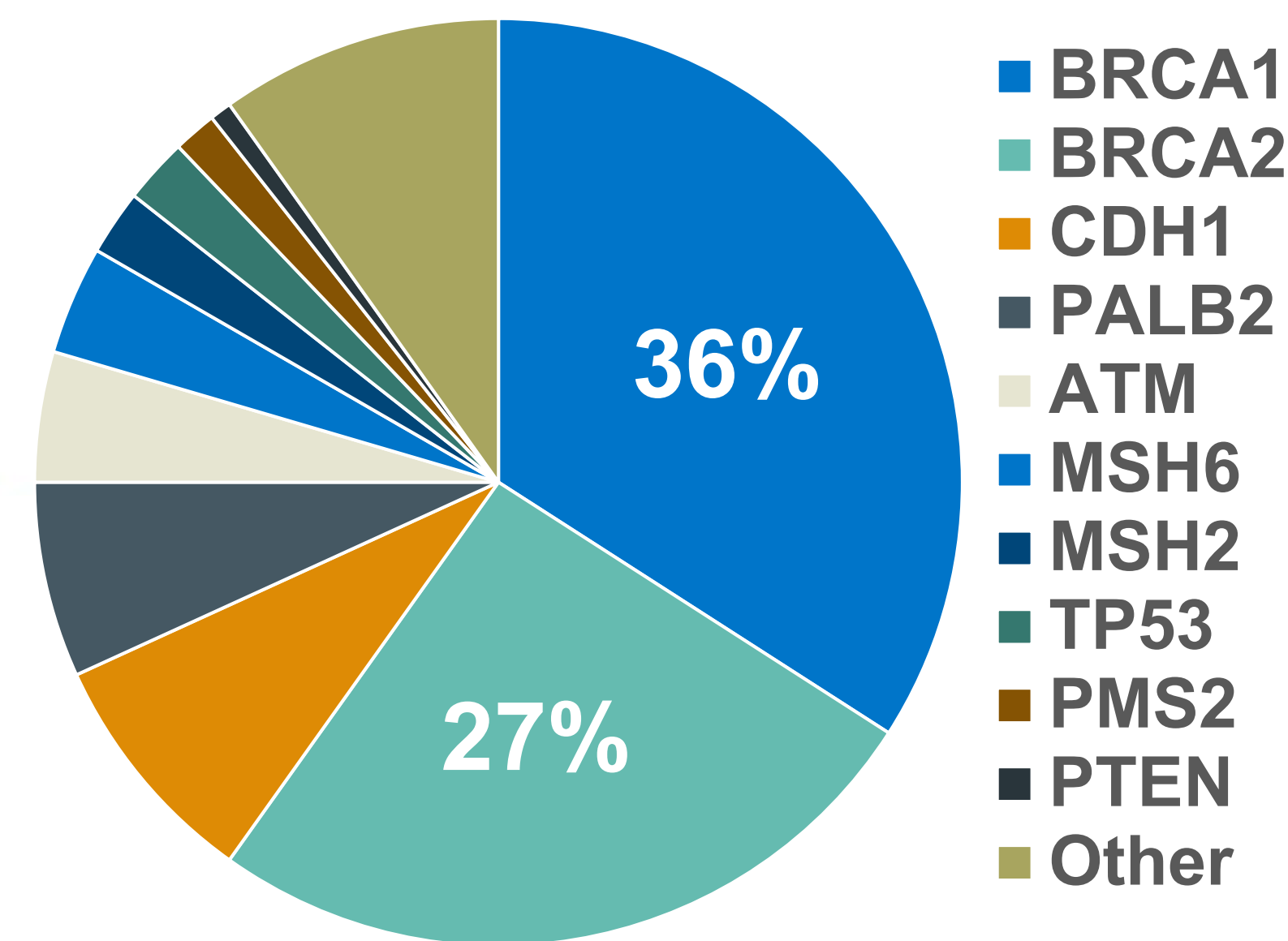
1. Identify resources needs for caregivers in the context of hereditary cancers
2. Consider modes of disseminating resources (e.g., genetic counselors)

Methods

An anonymous survey assessed caregiver (n = 124; 77% female, 72% white, 72% from U.S.) needs and attitudes regarding their experience. Recruitment via an inherited cancer specific advocacy group

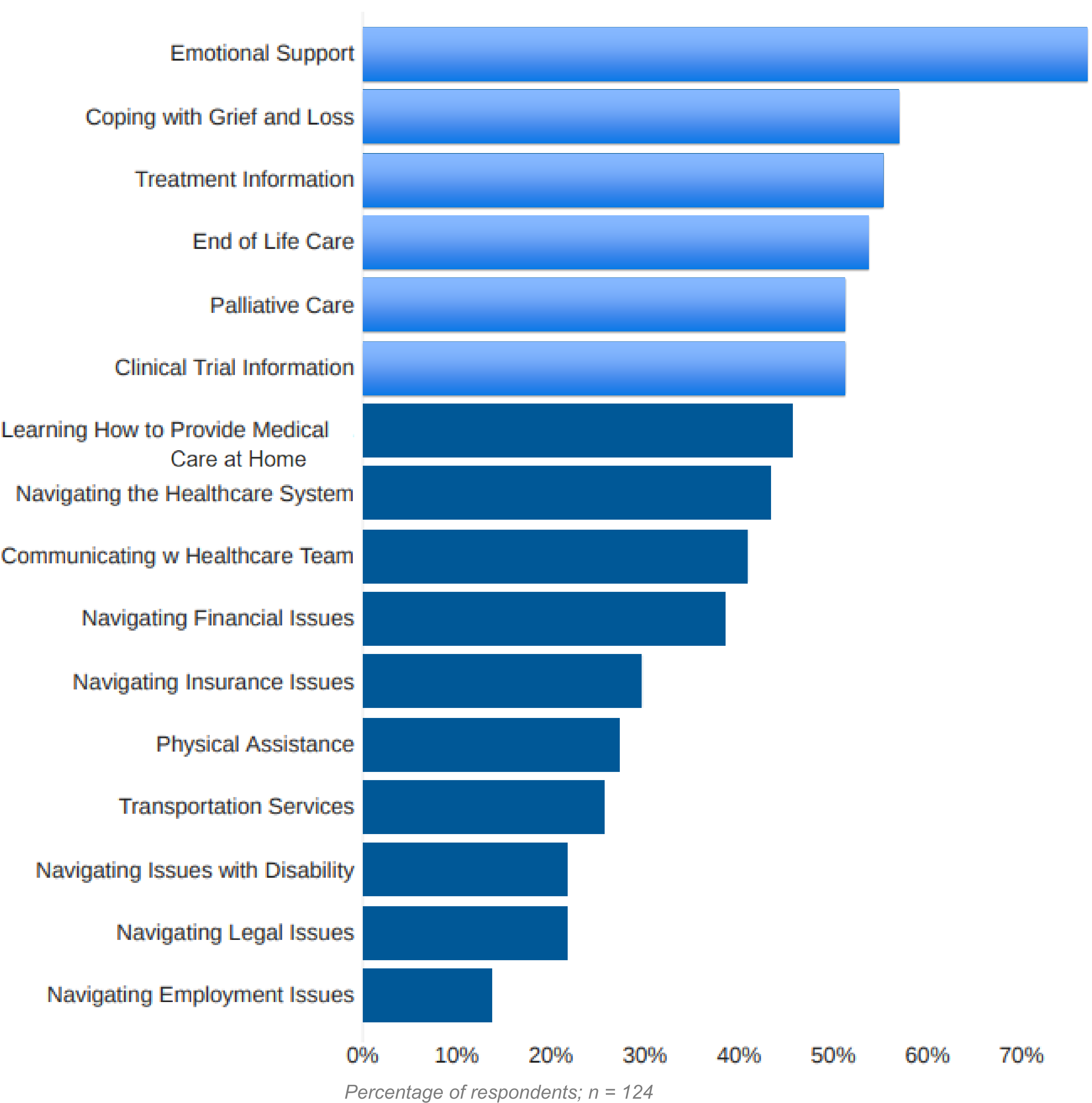
Demographics

96.8% of caregivers reported family history of a positive pathogenic mutation



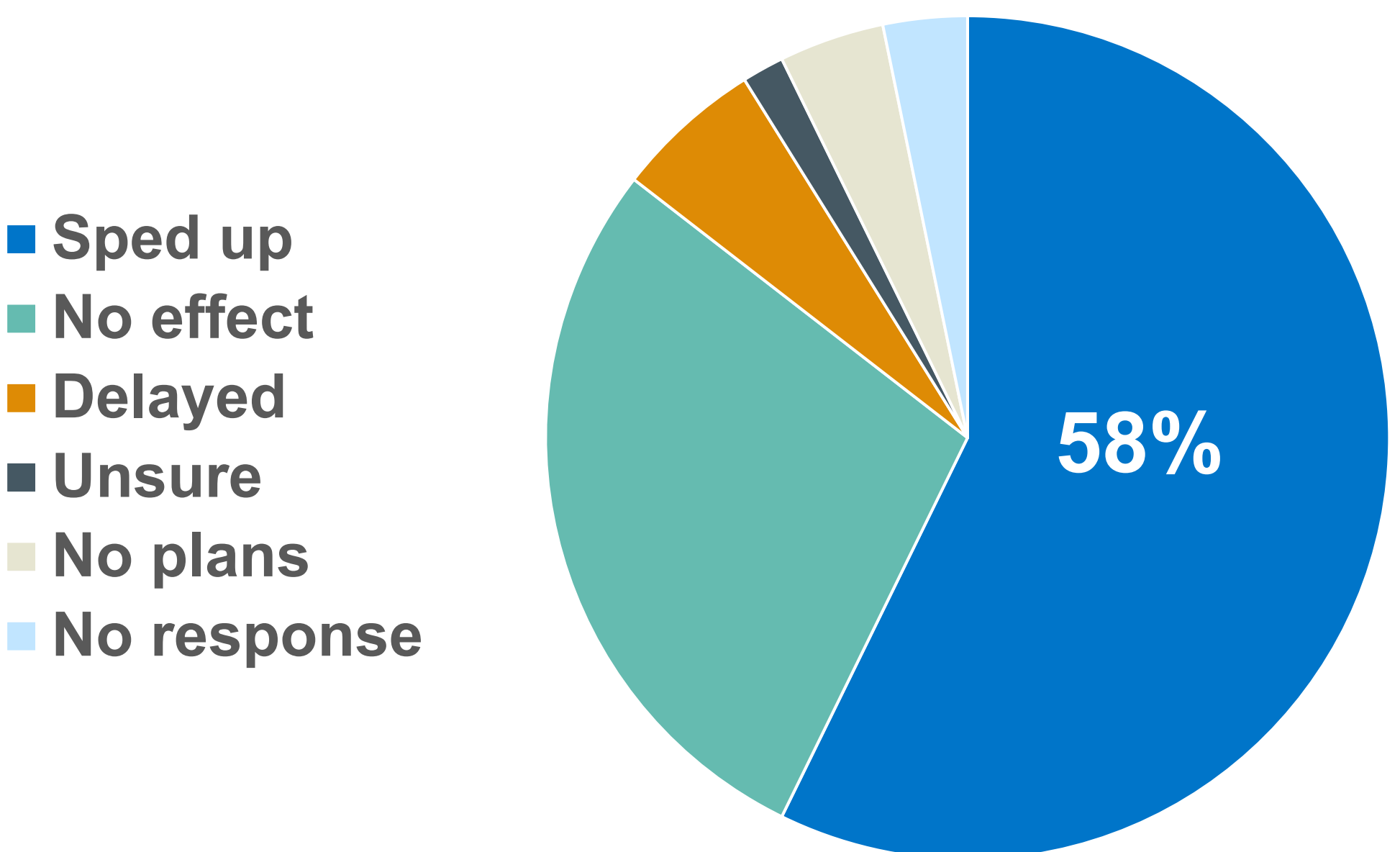
Results

What would be helpful? A **resource guide** covering topics such as:



Role of Genetic Counselors

In what way has caregiving affected your plans to **receive genetic counseling**?



Genetic counselors play a pivotal role in helping families navigate their cancer risk

Potential to incorporate resources into cascade testing; starting point in the genetic counseling process and may reach a large subset of caregivers

Discussion

- Identified caregiver needs and informed the development of new resources
- Reaffirmed the unique stressors related to caregiving for someone while also having a cancer diagnosis/cancer risk:

“It is very scary and unnerving caring for a sibling who is dying of cancer when you’ve already been through surgeries and chemo for cancer. We both carry the same mutation. I don’t think anyone can understand how that feels unless you’ve been in that situation.”