



MORNING CONSULT®



RARE DISEASE KNOWLEDGE AND PERCEPTIONS

SEPTEMBER 2021



INTRODUCTION

To help better understand the perceptions of registered voters in the US, Morning Consult and Takeda partnered on a large-scale survey in September 2021. The survey was designed to understand voters' knowledge, personal connection, and preferences around the diagnosis, treatment, and investment in rare diseases. Our sample included 2200 nationally-representative registered US voters, balanced across age, gender, income, and regionality.

The results from the present report summarize key findings that should help Takeda both understand and message the perceptions of registered voters with internal stakeholders, policy experts, and government employees.



METHODOLOGY

This survey was conducted from September 15th-19th 2021 among a sample of 2200 nationally-representative US adults. All respondents are currently registered to vote in the US. The interviews were conducted online. Results from the full survey have a margin of error of plus or minus 2 percentage points.

KEY FINDINGS

- 1. Important for all:** While only 10% of voters sampled are personally managing a rare disease (Slide 7), over two-thirds say it is an important topic to them personally (Slide 6). Importance is particularly high among younger adults, parents, and voters who prioritize healthcare as a primary policy issue (Slide 6). Key facts about these conditions, such as '50% of rare diseases impact children' and 'rare diseases affect 1 in 10 Americans' are especially likely to increase perceived importance among voters.
- 2. Big knowledge gap:** While importance of rare diseases is quite high, knowledge of rare diseases is fairly low, with a little over one-third of voters stating they are knowledgeable about rare diseases, genetic counseling, and/or genetic screenings (Slide 8). Among those who are personally managing a rare disease, only ~70% feel knowledgeable about the topic; this number drops to ~50% for those who know someone with a rare disease (Slide 9). Most voters think it should take weeks or months to diagnose these diseases.
- 3. Support for screening:** Over two-thirds of voters are supportive of genetic screenings before birth, and this rises to over three-quarters at later life stages (i.e., as part of annual physicals for children and adults; Slide 12). Over 85% think screenings should be offered more comprehensively in the US healthcare system (Slide 14), and over 80% are open to receiving one (Slide 11). Voters would likely be open to sharing this information with their healthcare provider.
- 4. Open to counsel:** Genetic counseling services are extremely appealing for most voters (80% are interested; Slide 16), and about 85% think these services should be covered by health insurance. Over 90% of rare disease holders would be open to genetic counseling services, implying that (1) they would value consultative support on their current diagnosis, and (2) they would have liked to have had this service available previously.

OVERVIEW

OVERALL RARE DISEASE PERCEPTIONS

GENERAL DIAGNOSIS AND SCREENING

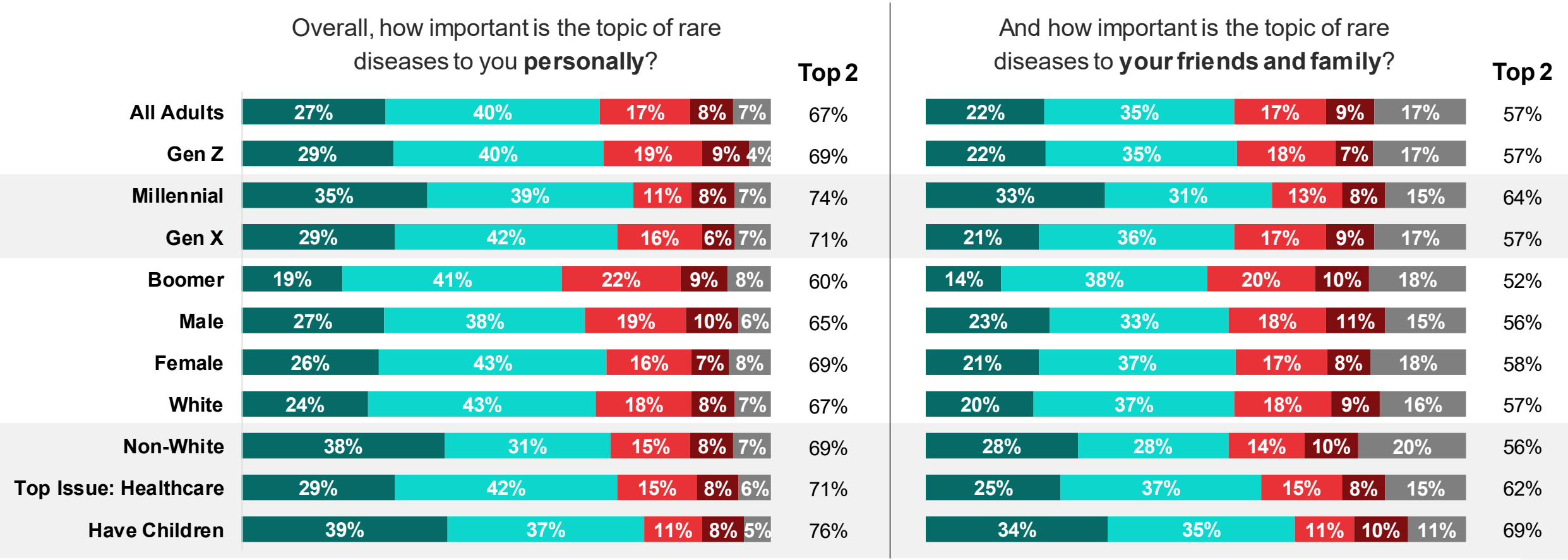
GENETIC SCREENING/COUNSELING DETAIL

SAMPLE DETAIL



OVERALL RARE DISEASE PERCEPTIONS

About two-thirds of voters say that rare diseases are an important topic to them personally. This number is at/above 70% for individuals that are younger, non-white, parents, and whose top voting issue is healthcare.

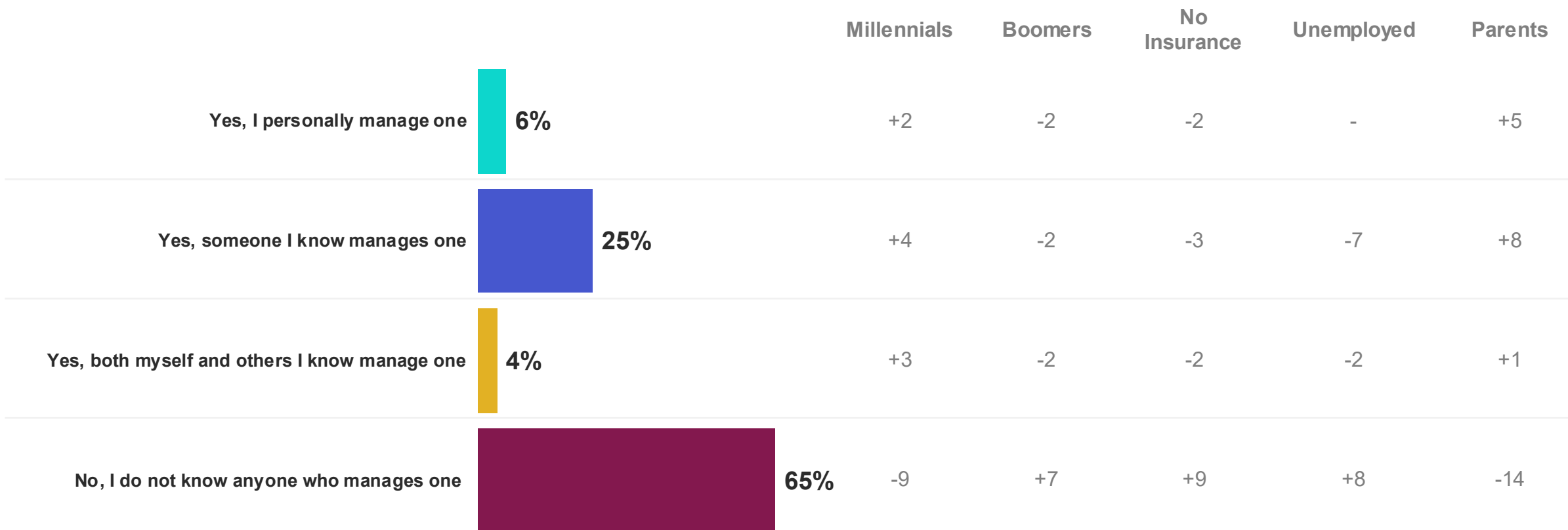


Very important Somewhat important Somewhat unimportant Very unimportant Don't know / No opinion

OVERALL RARE DISEASE PERCEPTIONS

While 1 in 10 voters are personally managing a rare disease, an additional 1 in 4 know someone else who manages one. Personal connections to those with rare diseases is most common among Millennials and parents

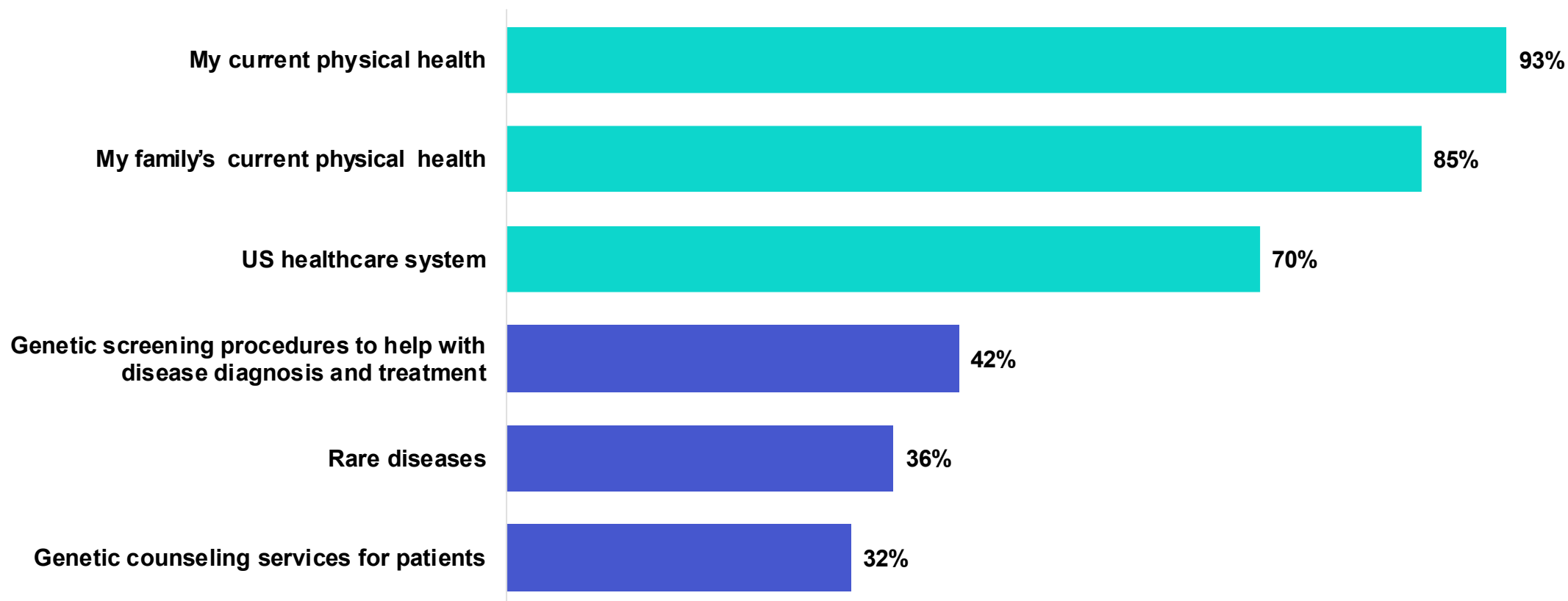
Does yourself or someone you know currently manage a rare disease or genetic condition?



OVERALL RARE DISEASE PERCEPTIONS

Compared to personal health and health of their family, voters feel much less knowledgeable about specific topics like rare diseases and genetic screening procedures. People are least knowledgeable about genetic counseling for patients.

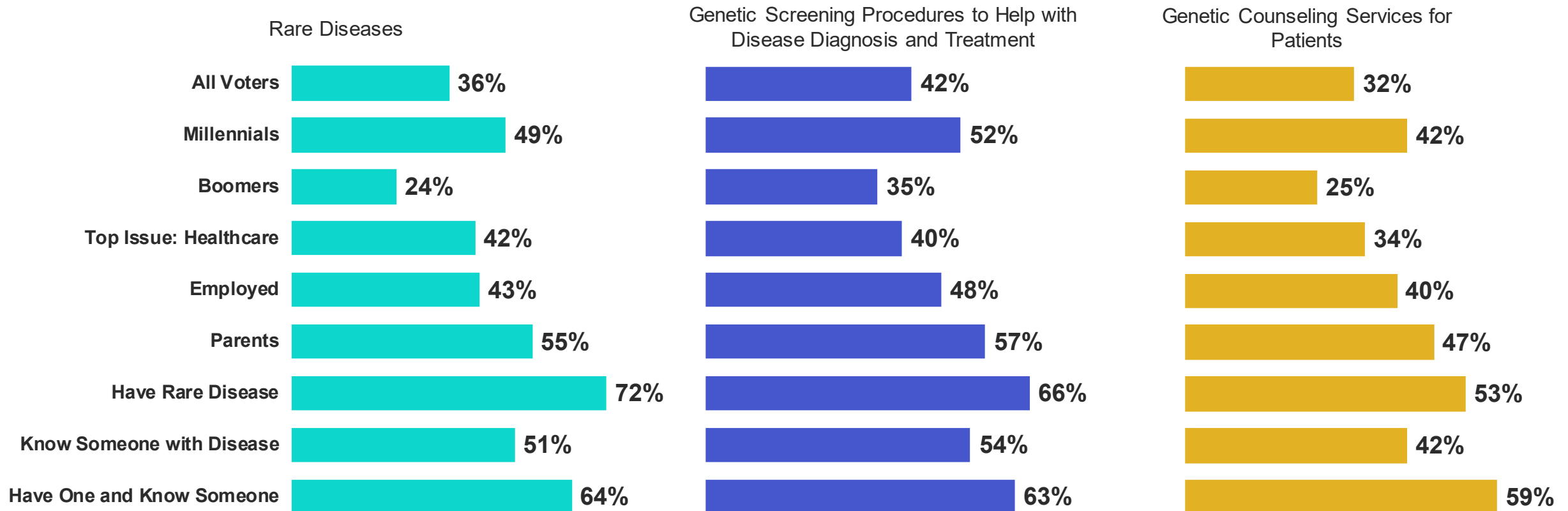
How knowledgeable do you feel about each of the following topics?



OVERALL RARE DISEASE PERCEPTIONS

Topical knowledge in this space is much higher among those who are personally affected or close to someone with a rare disease, along with Millennials and parents. Knowledge is much lower among Boomers and non-disease holders.

How knowledgeable do you feel about each of the following topics?



OVERVIEW

OVERALL RARE DISEASE PERCEPTIONS

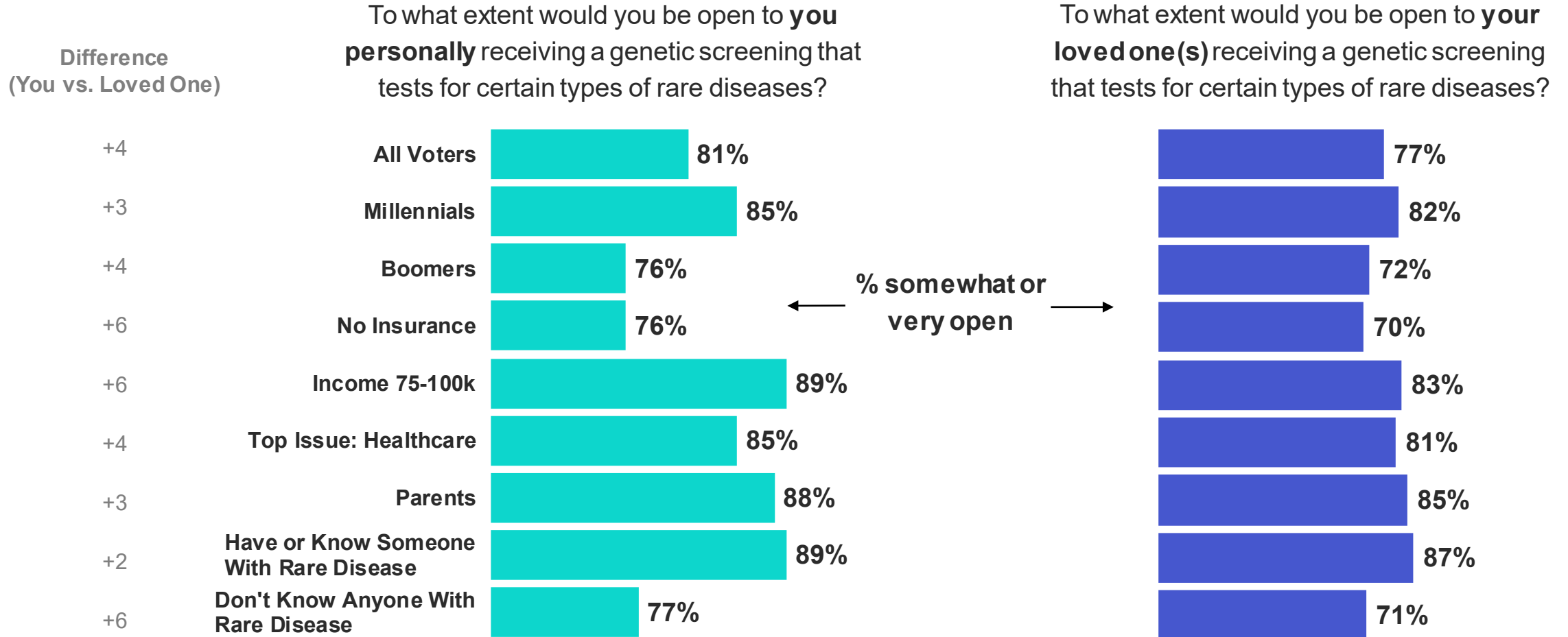
GENERAL DIAGNOSIS AND SCREENING

GENETIC SCREENING/COUNSELING DETAIL

SAMPLE DETAIL



Most voters are highly open to receiving a genetic screening for rare diseases and are just as likely to have their loved ones receive a screening.

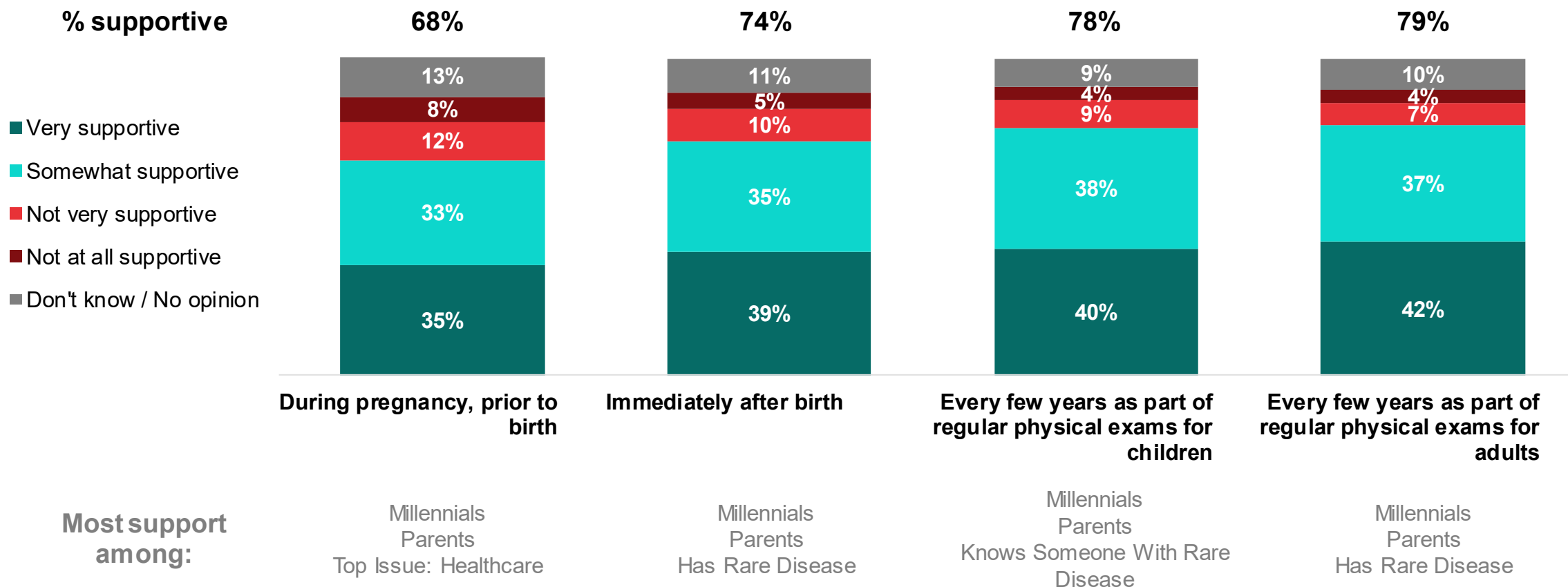


For both questions: "Assume these tests would be administered by your (left) / their (right) general physician, and that they would not require any added costs."

GENERAL DIAGNOSIS AND SCREENING

Support for genetic screening is most notable among Millennials and parents, particularly later in life for children and adults. While weaker overall, support is still very strong for screening during pregnancy and shortly after birth.

How supportive are you of requiring genetic screening at the following life stages?



OVERVIEW

OVERALL RARE DISEASE PERCEPTIONS

GENERAL DIAGNOSIS AND SCREENING

GENETIC SCREENING/COUNSELING DETAIL

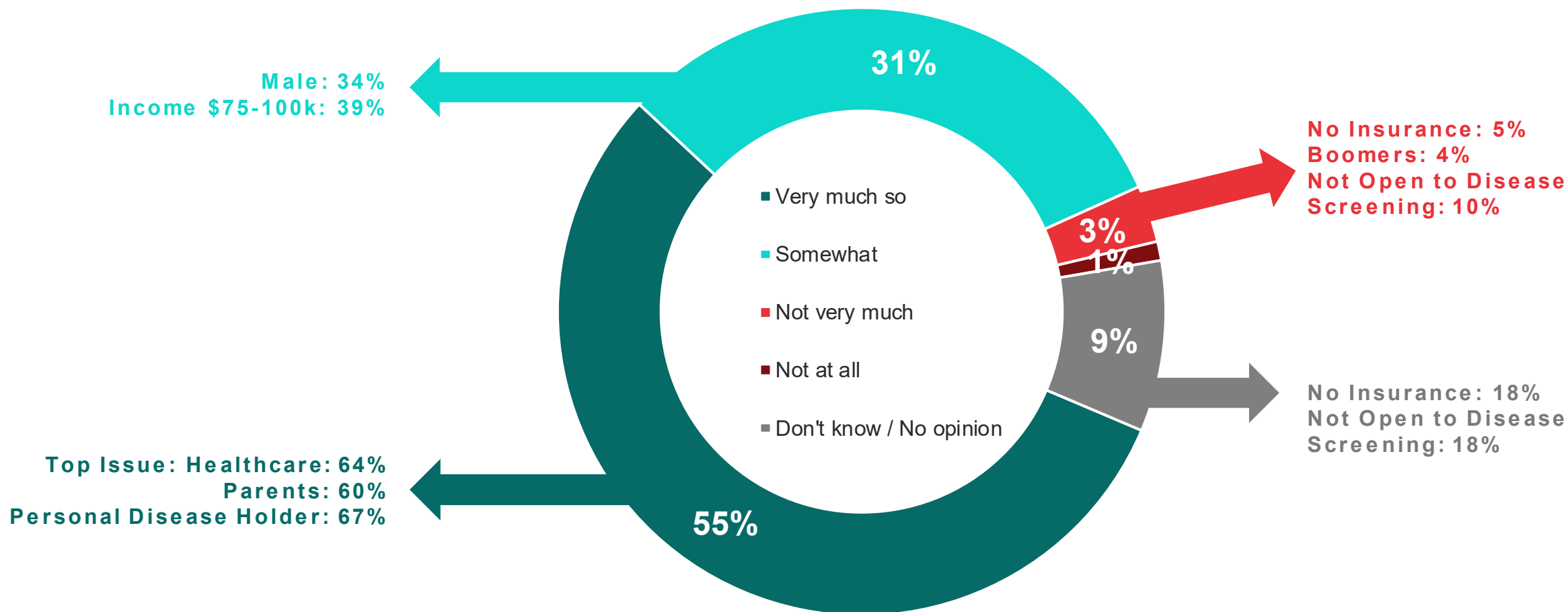
SAMPLE DETAIL



GENETIC SCREENING/COUNSELING DETAIL

Most voters think that genetic testing should be offered more comprehensively in the United States, assuming it can reduce time to diagnose rare diseases.

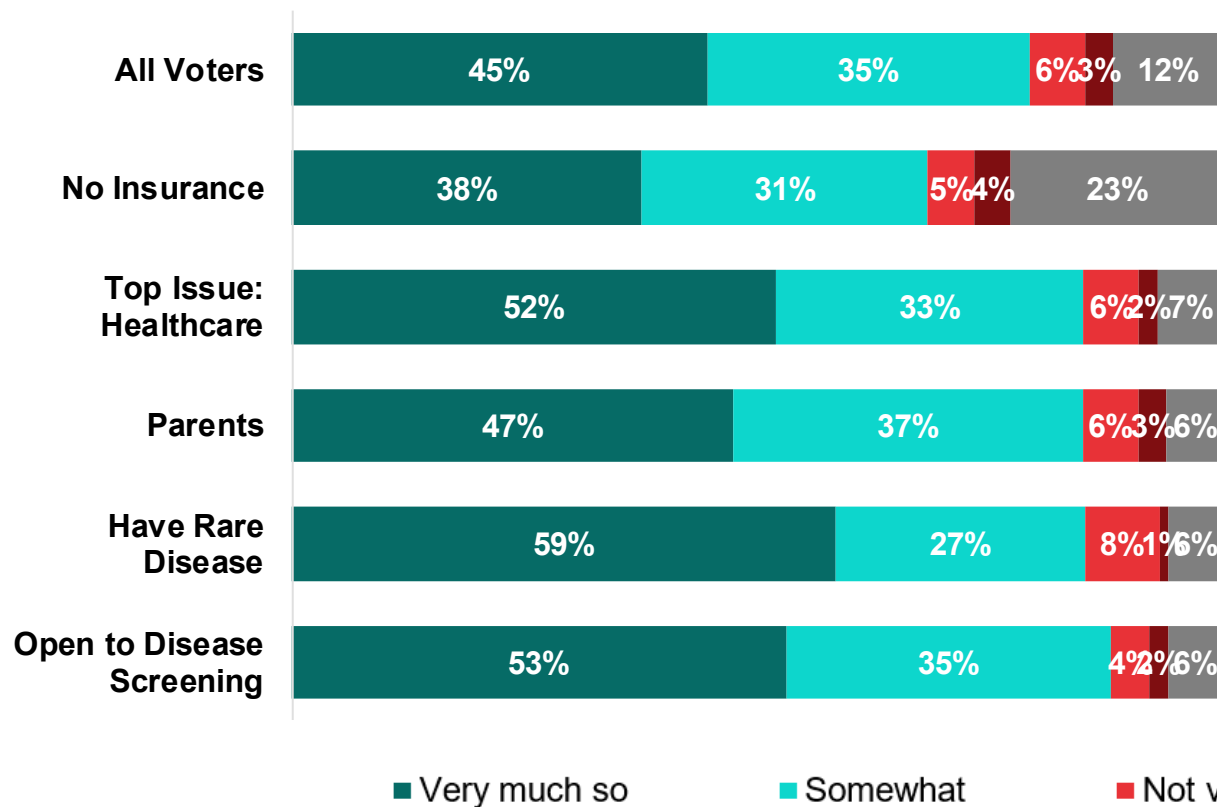
If genetic screening could help reduce time to diagnosis for various rare diseases, do you think it should be offered more comprehensively across the US healthcare system?



GENETIC SCREENING/COUNSELING DETAIL

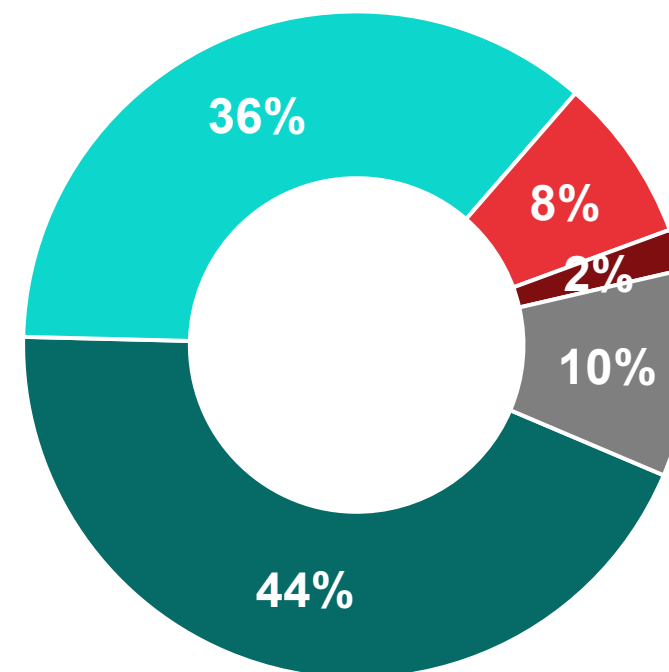
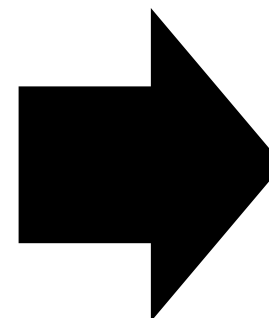
Four in five voters support genetic screening for children, even if it were to identify diseases that there is currently no treatment for.

If genetic screening were available to your children or children you're close to, to what extent would you want them to go through this screening? Assume there is not an added cost for this service.



If genetic screening was capable of identifying conditions in children that there is currently no treatment for, would you still want the child to go through this genetic screening process?

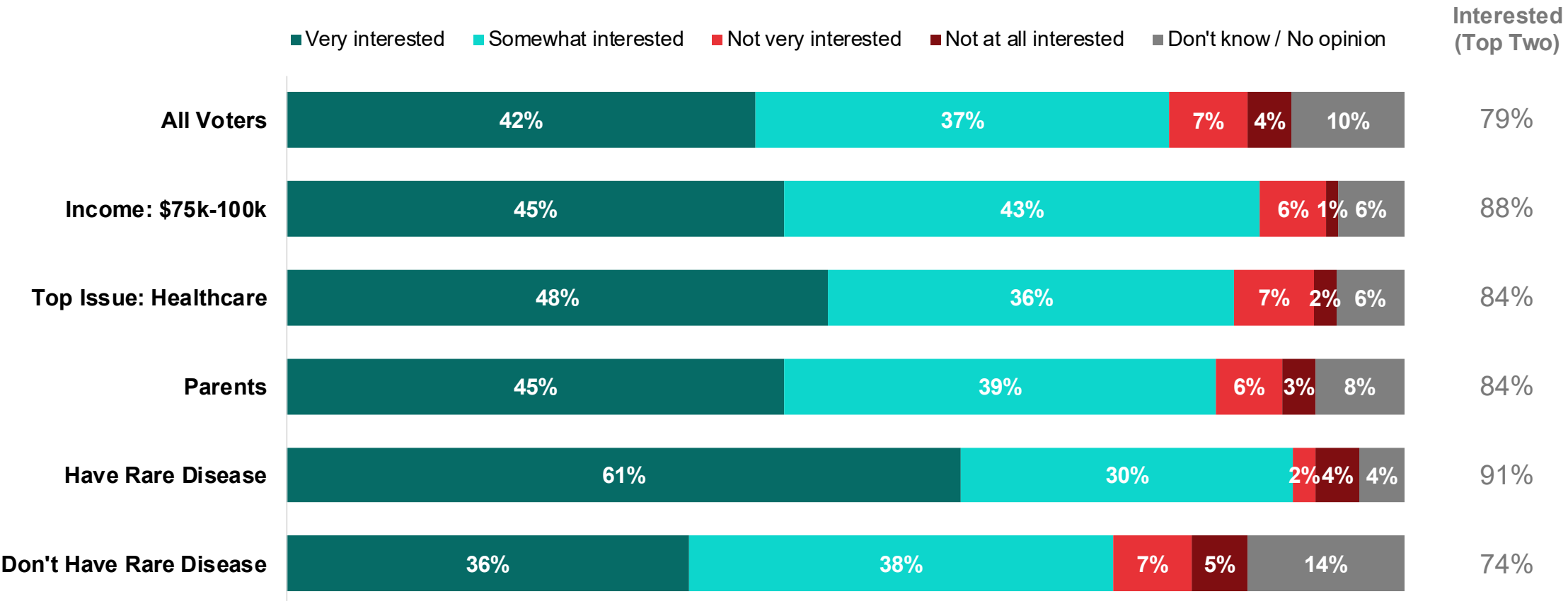
If 'very much so' or 'somewhat' to question on left



GENETIC SCREENING/COUNSELING DETAIL

Genetic counseling services see strong interest overall, with 79% stating they would be interested in talking with a counselor about genetic testing results. Interest is strongest among current rare disease holders and high-income individuals.

If genetic counseling was offered to help interpret your genetic screening results, how interested would you be in talking with a genetic counselor about your results? Assume there is not an added cost for this service.



OVERVIEW

OVERALL RARE DISEASE PERCEPTIONS

GENERAL DIAGNOSIS AND SCREENING

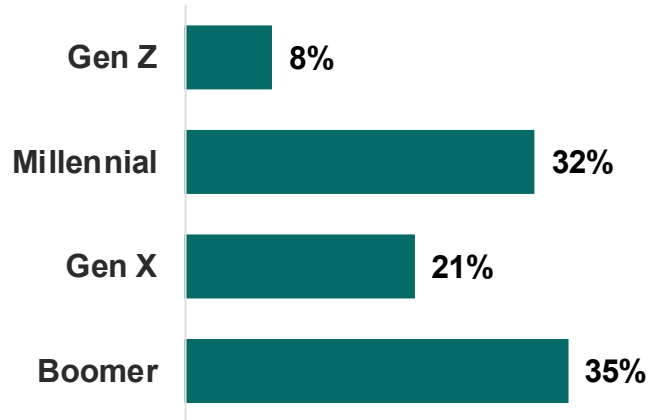
GENETIC SCREENING/COUNSELING DETAIL

SAMPLE DETAIL

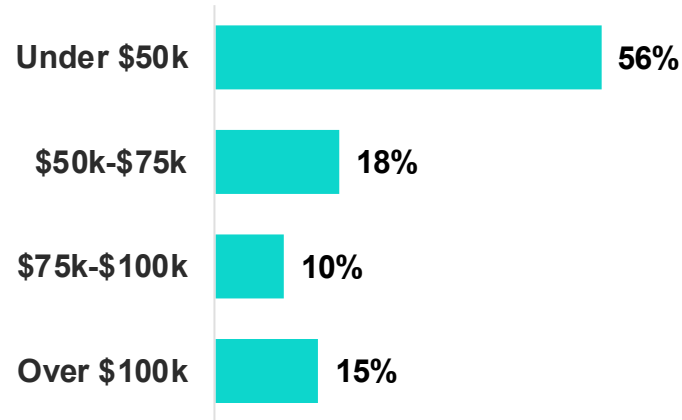


SAMPLE DEMOGRAPHICS

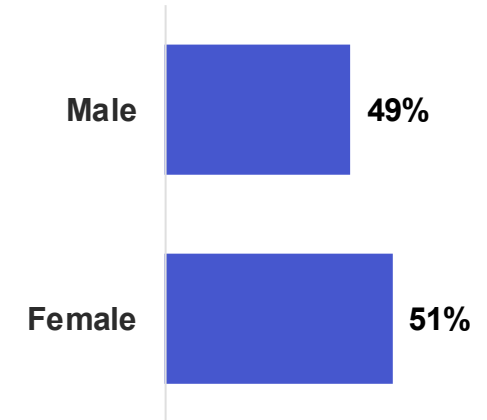
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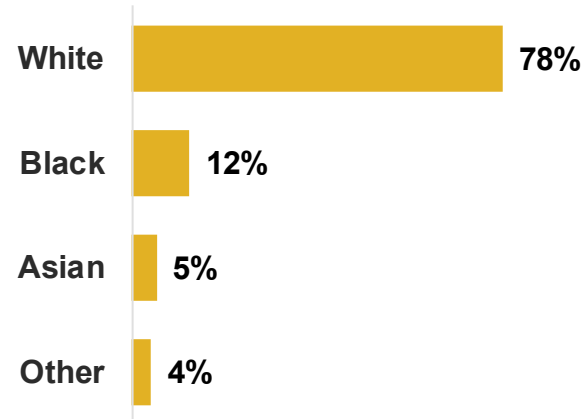
Income:



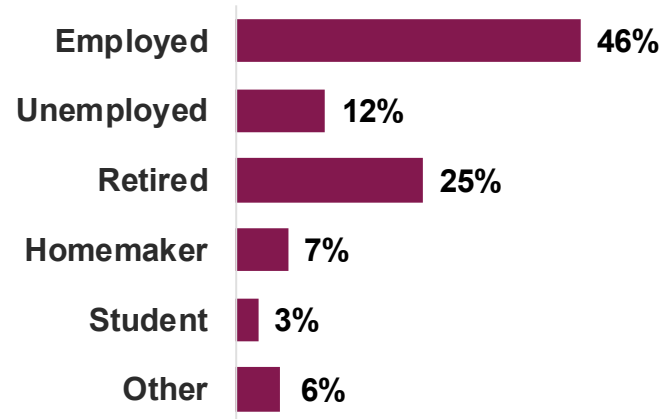
Gender:



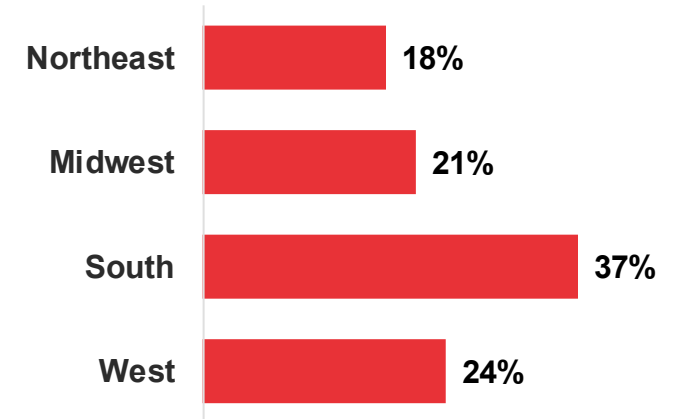
Race / Ethnicity:



Employment:

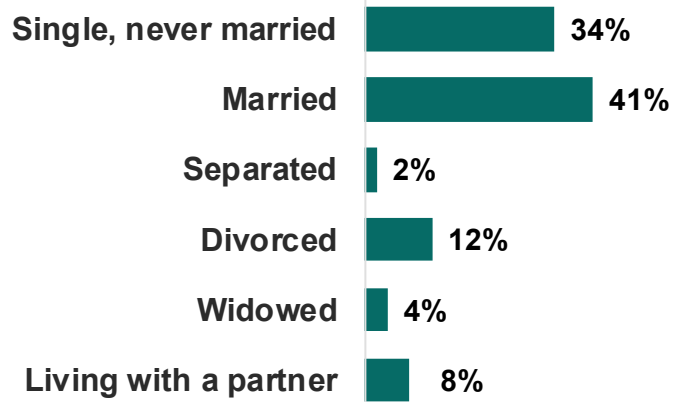


US Region:

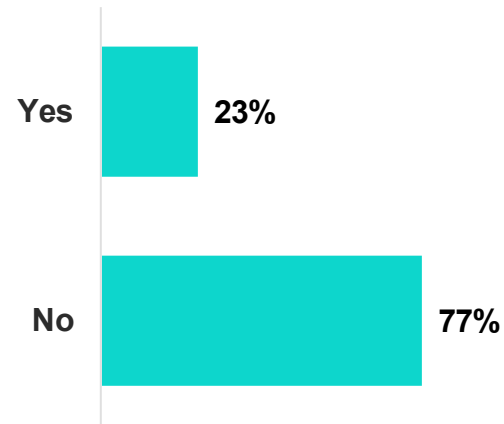


SAMPLE DEMOGRAPHICS

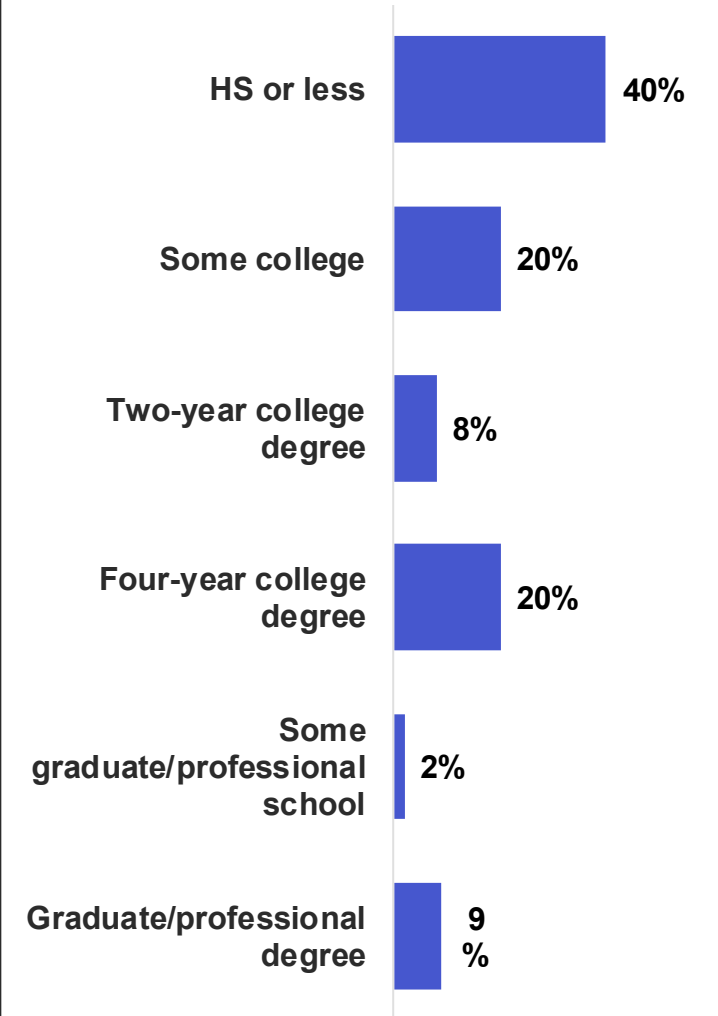
Marital Status:



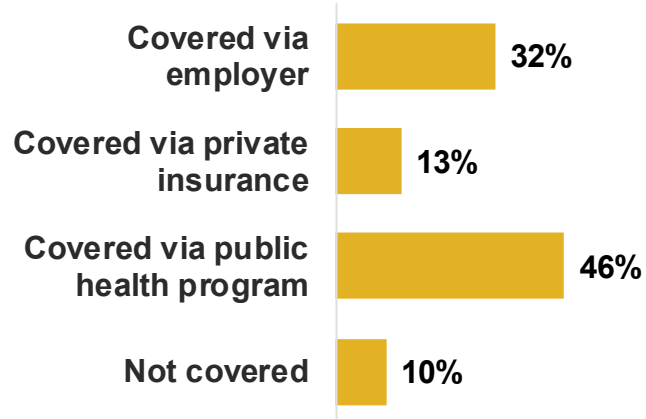
Parent/Guardian of Children:



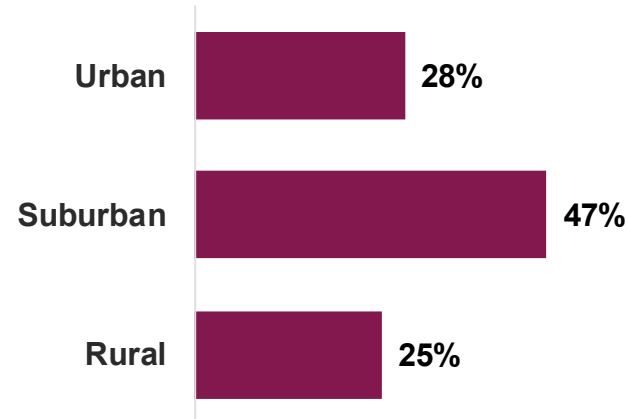
Education:



Health Insurance:



Home Region:





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