

**Patient
Communication
Preferences in
Clinical Trials**



Joining you today



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ABOUT RARE PATIENT VOICE

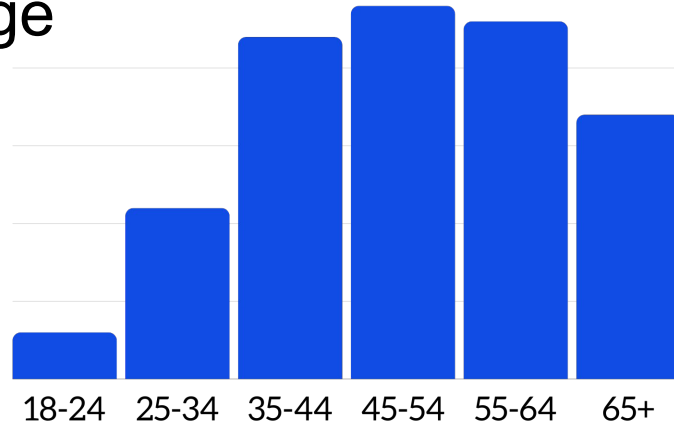
Rare Patient Voice (RPV) connects patients and family caregivers with research opportunities.

Founded in 2013, the RPV community now includes 145k+ patients and family caregivers across 1,500+ diseases and conditions in 9 countries.

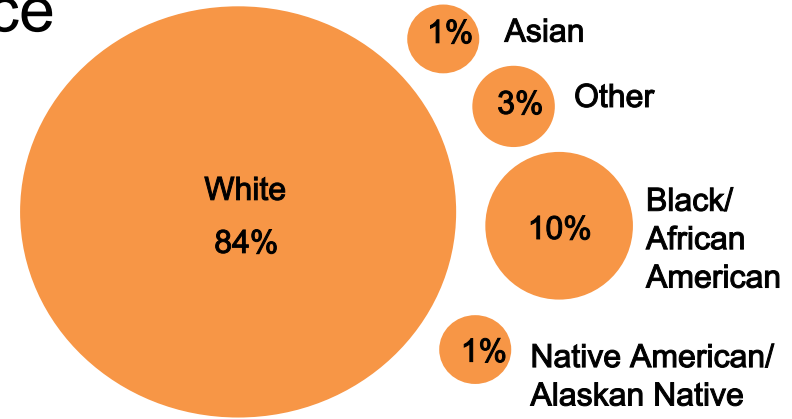


2024 RARE PATIENT VOICE SURVEY

Age



Race



- 58% suburban
- 23% rural
- 19% urban

Community 

- 888 women
- 240 men
- 18 nonbinary/third gender
- 1 prefer not to answer

Gender 

- 7% Hispanic
- 93% nonHispanic

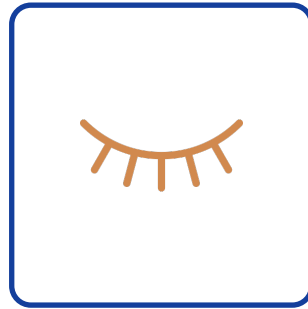
Ethnicity 

1147 patients in the United States were asked about communication preferences regarding clinical trials.

HOW AWARE ARE YOU OF CLINICAL TRIALS?



Very aware = 36%



Somewhat aware = 57%



Not aware at all = 7%

Most respondents were aware of clinical trials.

HAVE YOU EVER PARTICIPATED IN A CLINICAL TRIAL?



Yes=32%



No= 68%

Nearly a third of respondents had participated in a clinical trial.



WHAT ARE THE MAIN REASONS YOU DECIDED TO PARTICIPATE IN A CLINICAL TRIAL?



Helping Others



Advancing Research



Compensation



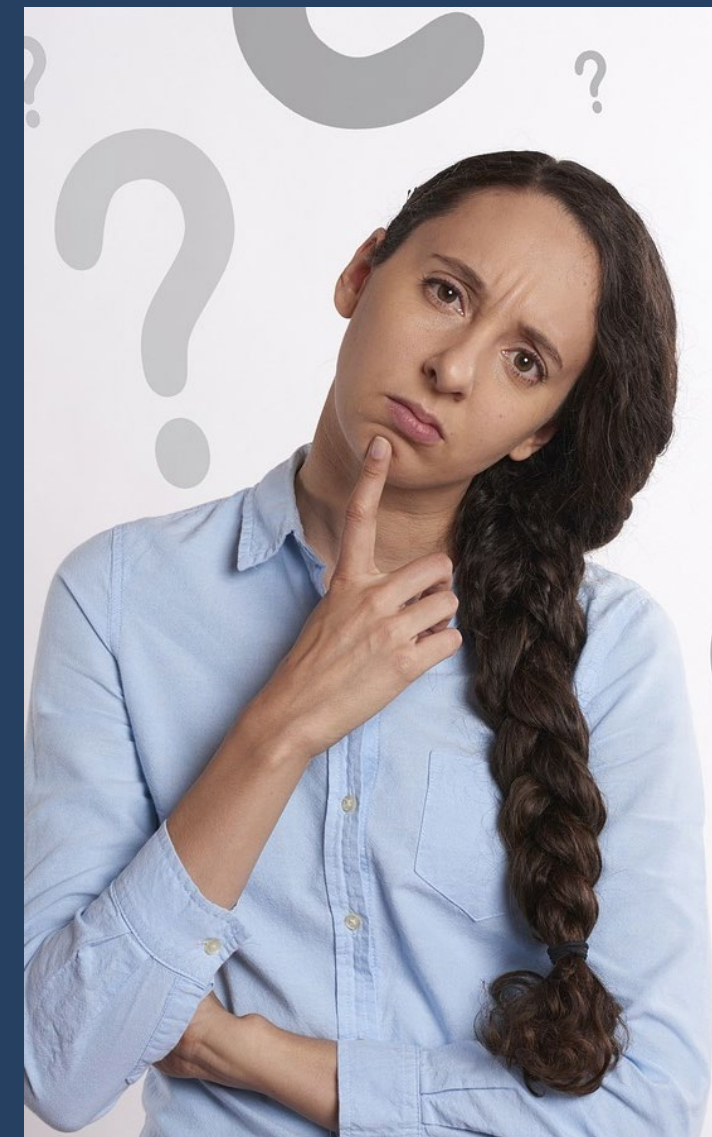
WHAT ARE THE MAIN REASONS YOU **HAVE** **NOT** PARTICIPATED IN A CLINICAL TRIAL?

"I'VE NEVER BEEN
INVITED"

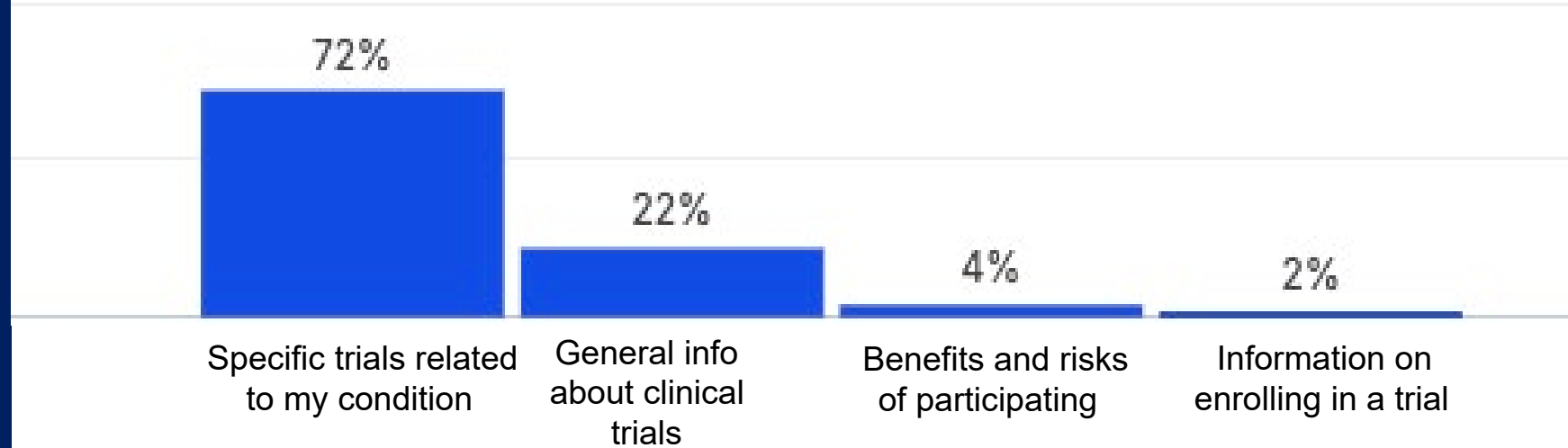
"NONE ARE CLOSE
ENOUGH TO MY
TOWN OR STATE"

"I NEVER QUALIFY!!!
MY MEDICAL HISTORY
IS TOO COMPLEX!"

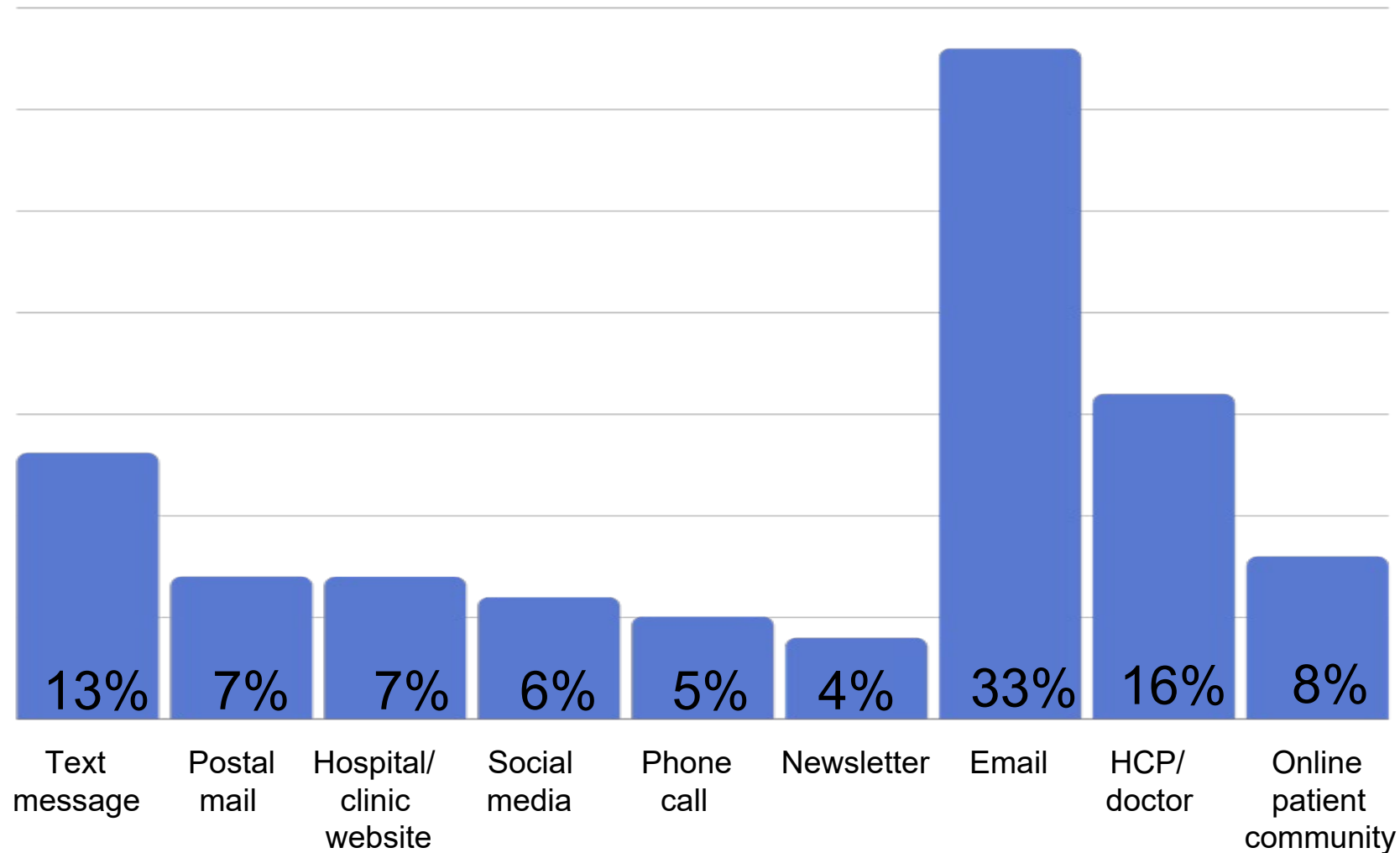
"NOT AWARE OF
ANY"



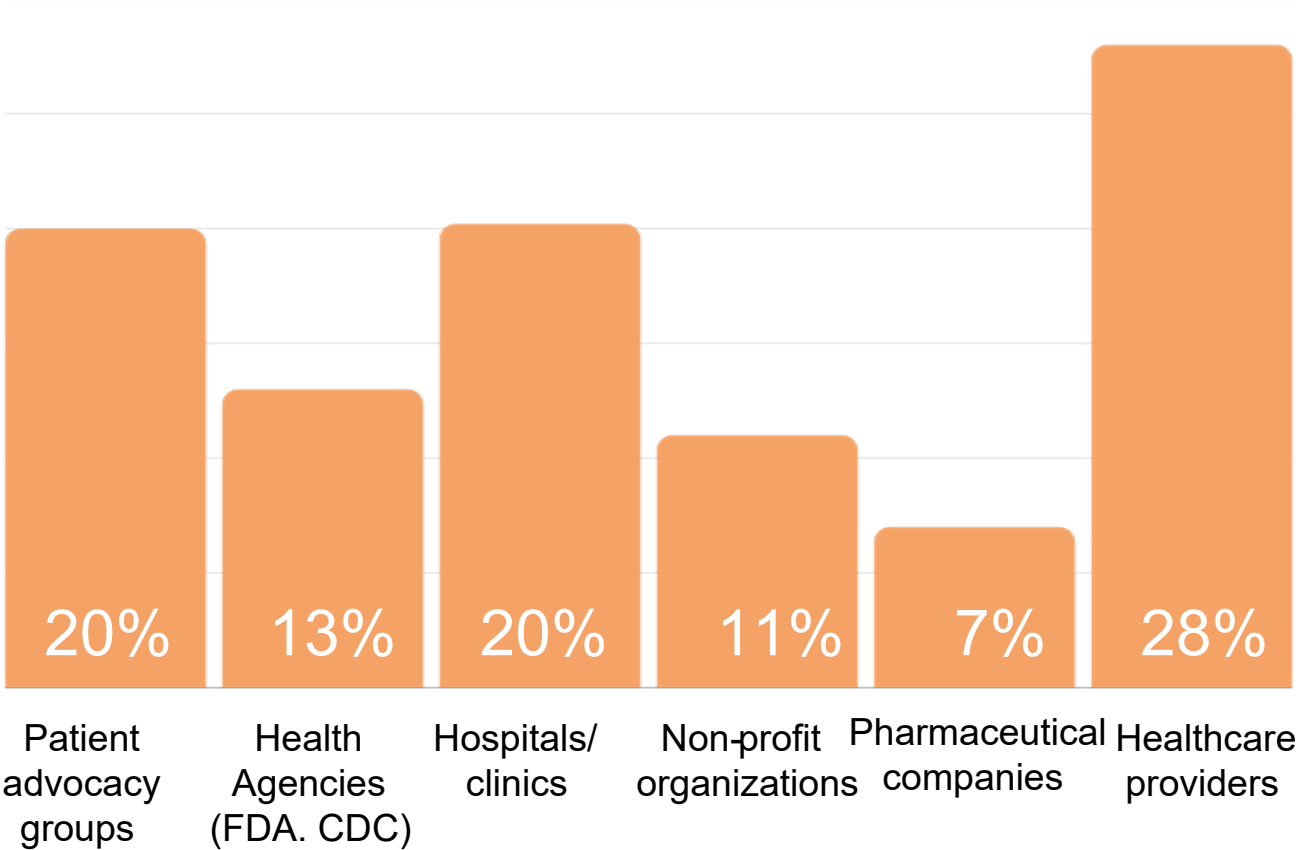
MOST HELPFUL INFORMATION ABOUT TRIALS



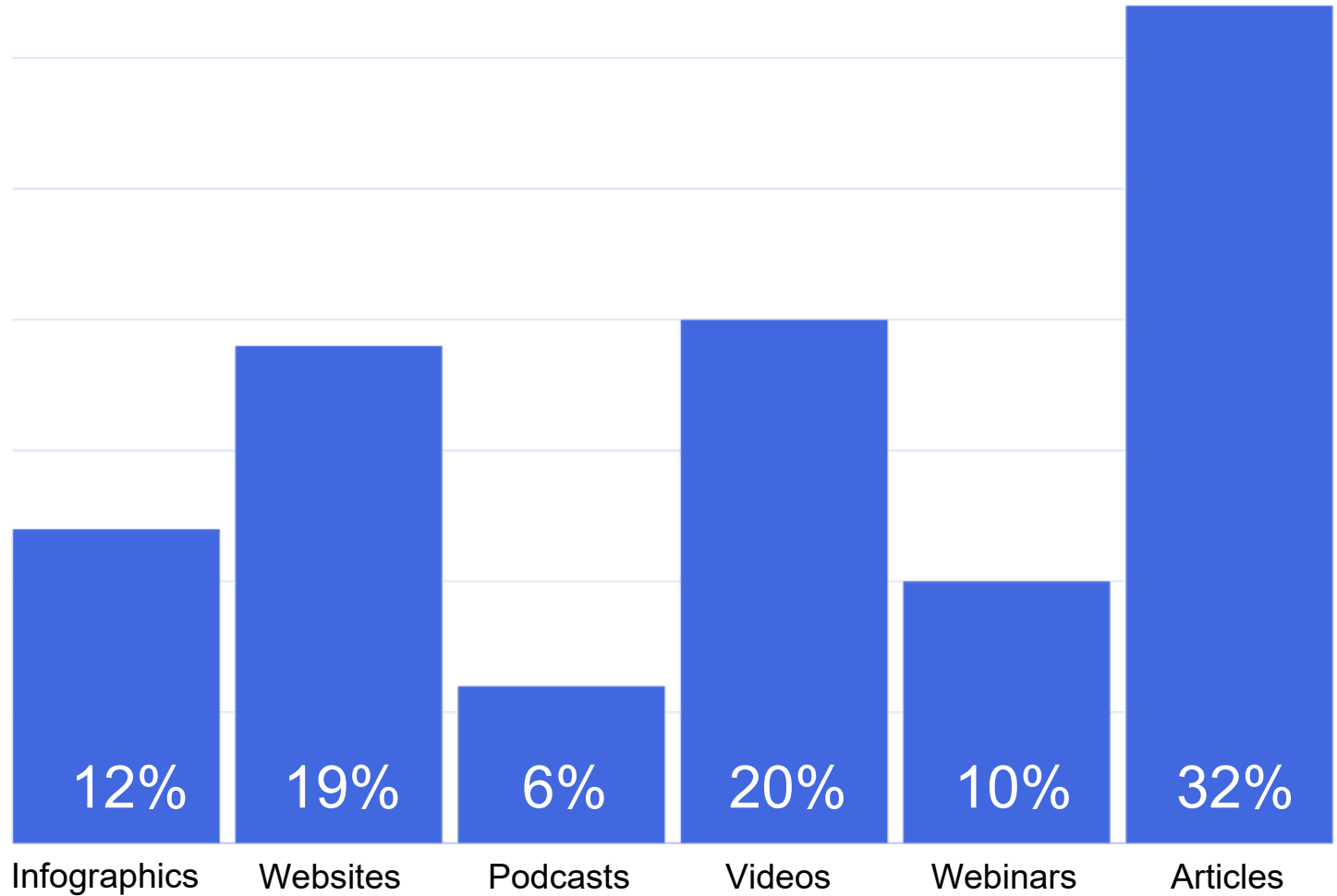
HOW WOULD YOU PREFER TO RECEIVE INFORMATION ABOUT CLINICAL TRIALS?



MOST TRUSTED RESOURCES FOR CLINICAL TRIALS



PREFERRED FORMATS FOR RECEIVING INFORMATION ABOUT CLINICAL TRIALS



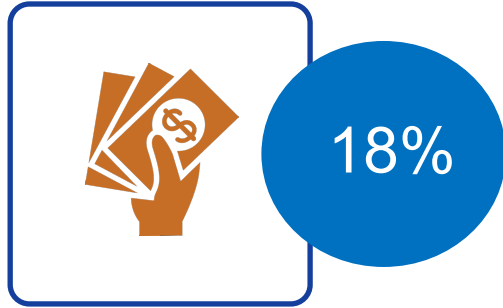
MAIN CONCERNS ABOUT PARTICIPATING IN CLINICAL TRIALS



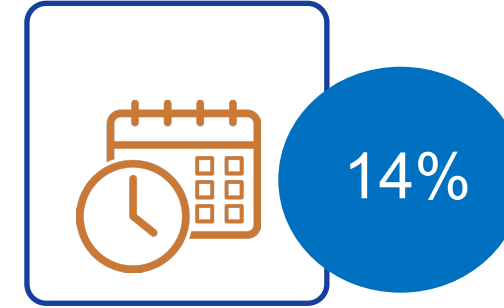
Safety & side effects



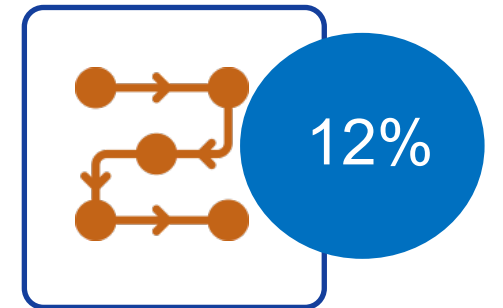
Travel logistics



Costs & insurance



Time commitment



Understanding the trial process



Privacy & confidentiality

WHAT MIGHT ENCOURAGE STUDY PARTICIPATION

Clear and detailed information about trial and its goals

18%

Reimbursement for expenses (travel, meals, etc.)

17%

Financial compensation for time

16%

Receiving results once trial is complete

14%

Assurance of safety and confidentiality

14%

Support from healthcare providers

13%

ADDRESSING PATIENT COMMUNICATION PREFERENCES

- ✓ Provide clear and concise information
- ✓ Use multiple communication channels
- ✓ Frequent updates
- ✓ Involvement of healthcare providers
- ✓ Accessibility and inclusivity

- ✓ Transparency about trial process
- ✓ Targeted information to ensure relevance
- ✓ Patient support and advocacy contacts
- ✓ Awareness and outreach
- ✓ Feedback mechanisms

Resources



www.eactproject.org



mrctcenter.org/glossary



nationalhealthcouncil.org



PFMD.org

Questions?



For more information, to request the survey data,
or to schedule a call, please reach out to:

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