

PAF Patient Advocate Foundation

Solving Insurance and Healthcare Access Issues | since 1996



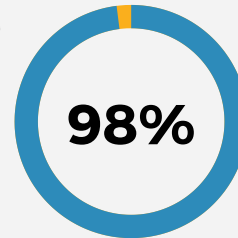
**PAVING A PATHWAY TO ENGAGE
UNDERSERVED POPULATIONS IN RESEARCH**

**Research Experience Survey:
Results Summary**

Executive Summary

Demographic Profile

Our network survey had nearly 3,000 respondents from a diverse mix of communities across every state of the US. Most respondents fall between the ages of 36 and 75 and make less than \$48,000 a year. We were also given insight into our respondents' varied educational and racial/ethnic backgrounds, gender identities, and sexual orientations. Furthermore, we learn that from the different chronic conditions experienced by patients, cancer and HIV/AIDS are the most common amongst this group.



identify as a **patient**, compared to **2%** that identify as a **caregiver** to someone with a chronic illness.

Research Participation

A significant portion (37%) of our network has been contacted in the past to participate in research (as a subject). However, only 12% of respondents have been asked to serve as a part of a research team—with 88% reporting that if approached, they would be willing to consider participation. This highlights the untapped resource of patient expertise.

Our data also shows that patients want to be meaningfully involved. Specifically, less than 10% want to participate as a subject without informing or advising on the research project. Still, most want to contribute their experience and expertise and be informed about the results and findings.

Feelings Towards Research

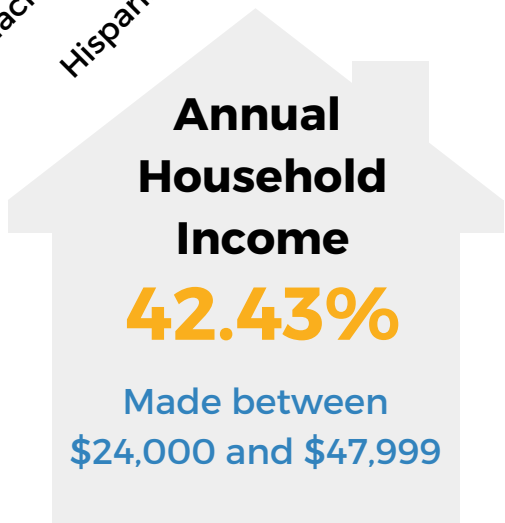
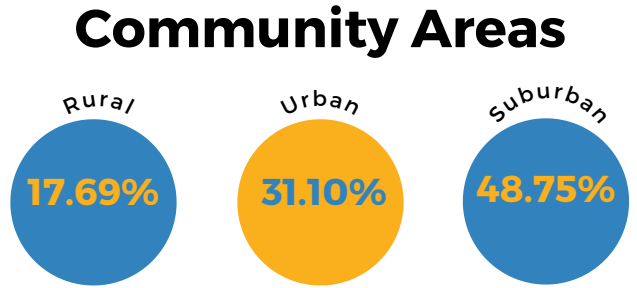
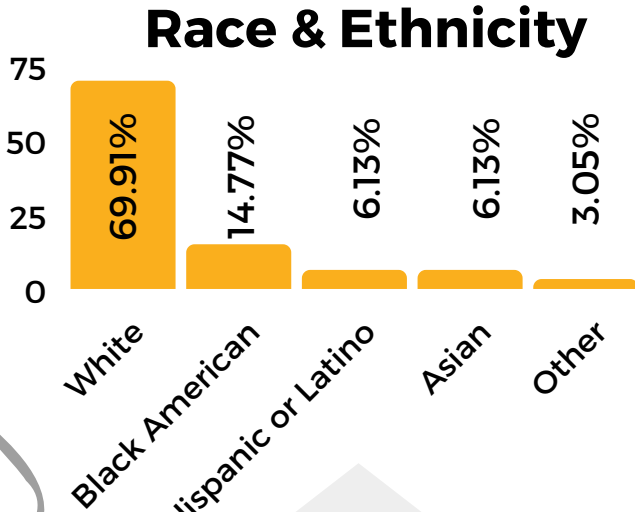
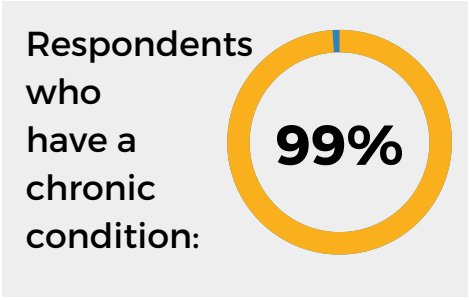
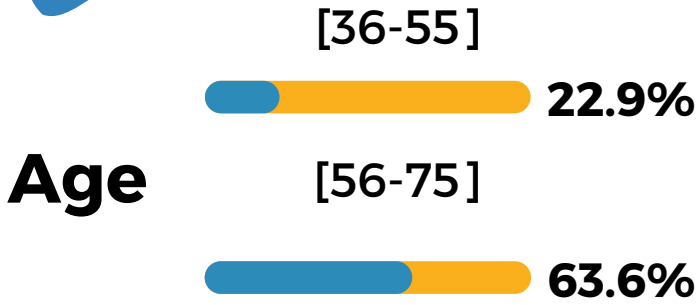
Network respondents primarily have a neutral or positive outlook towards research and overwhelmingly support patient perspectives. Many also feel that they have more valuable experience to share with other patients than with researchers. A common sentiment expressed is that researchers need a better understanding of the challenges low-income, uninsured, and/or minority patients face. Our survey offered the opportunity to increase patients' awareness of the importance of sharing their experience with other patients and research teams.

Research Skills & Knowledge

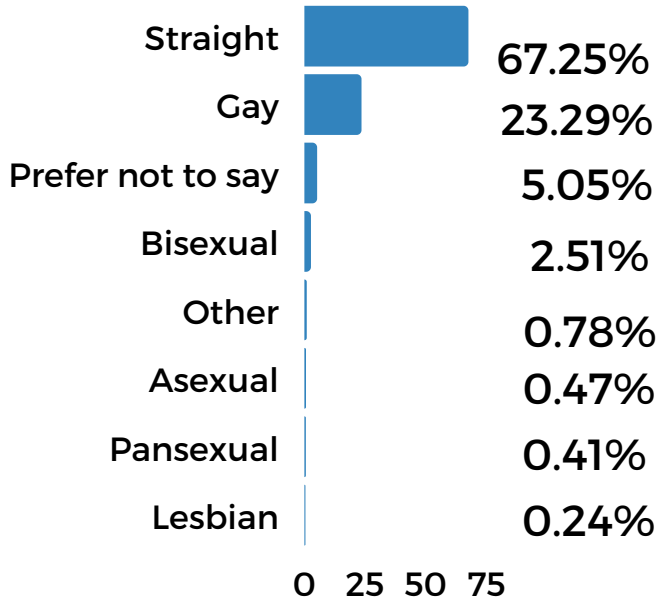
Just over half of network members report feeling comfortable being part of a research team. Surprisingly, technological skills emerge as a larger challenge than access to technology (ex: devices, reliable internet, etc.). Only 52% report having the tech skills required to participate, but many would like to learn these skills and participate if research teams provided training.

Overall, time-related issues were the most frequent barriers reported. Efforts to address/resolve these barriers would increase most patients' willingness to participate and research knowledge. We know that this lack of knowledge likely does not extend to their condition, as network members report spending considerable time researching it.

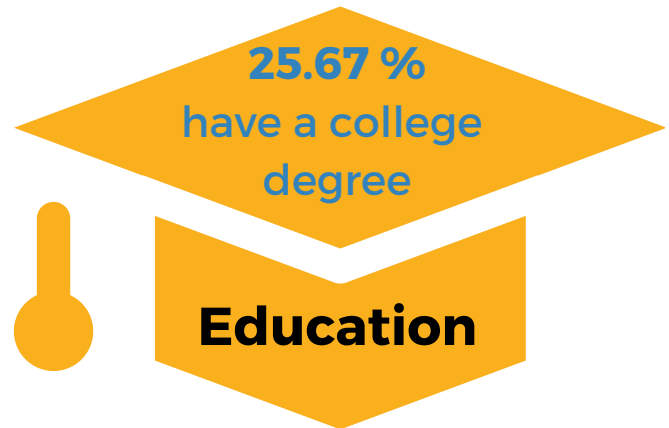
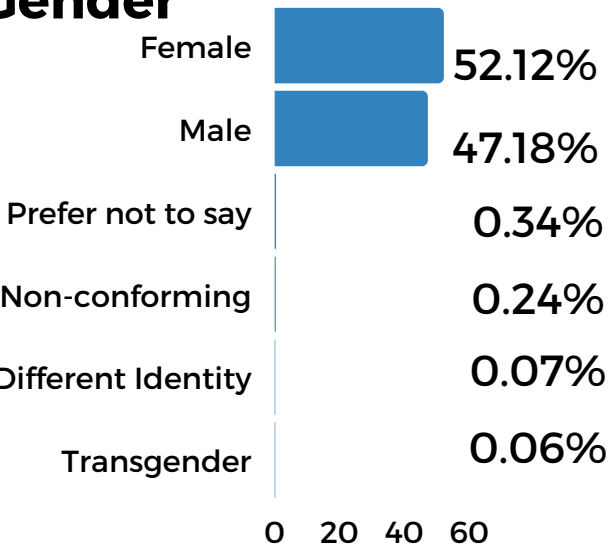
Demographic Profile



Sexual Orientation



Gender



Research Participation



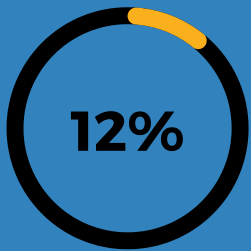
Participants who have **never** been contacted to participate in research:



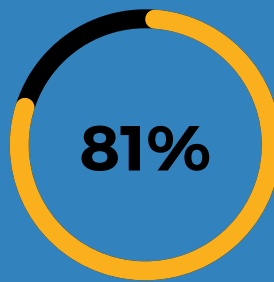
Participants who would consider participating in research (if contacted):



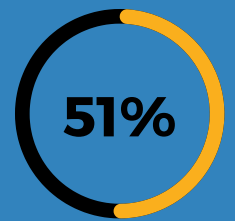
Participants who have been contacted about serving as a patient partner or on a research team:



Respondents who **agreed** to participate:



Participants who would consider participating in a future project (if contacted):

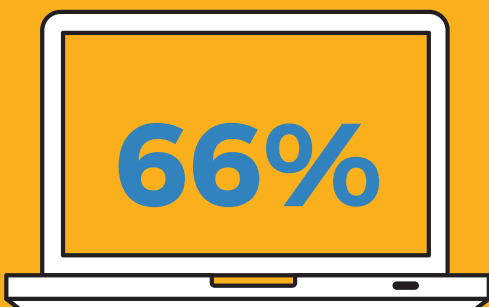


→ **41%** have shared their patient experience with a group.

→ **42%** have participated in a group to better understand their condition and/or care and treatment options.

24.10% of respondents say...

“I want to be kept informed about the project but not actively participate.”



of participants would prefer to inform a project by sharing their experiences and perspectives via survey or email.



feel they have a moderate amount of valuable experience to share with health researchers.

How well do research and researchers understand...

Value of diversity?

13% say extremely well

The needs and challenges uninsured patients face?

19% say not well at all

64%

are **unsure** if their communities have been hurt by research/researchers in the past,

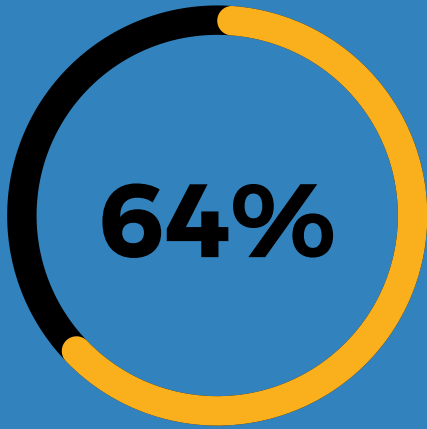
10%

think **"Yes"**, researchers engage with their community as much as they should/could.

97%

believe the patient voice/perspective is important in research.

Research Skills & Knowledge



have **not** been exposed to research via formal training or professional experience.



say they have the tech skills required to participate on a research team.



88.5% would join a research team if tech training were provided.

Top 5 barriers to advising on a research team

1. The total time necessary
2. The time of day that is required to participate
3. A disability or physical limitation
4. Lack of paid compensation
5. Transportation



have spent a **lot** of time researching their own/, loved one's condition, care, and/or treatment options.