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RARE PATIENT Voice LLC ®

Also Non-Rare!

BHBIA

The Voice of the Patient: Preference in Healthcare Research Participation
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About Rare Patient Voice and Wes Michael

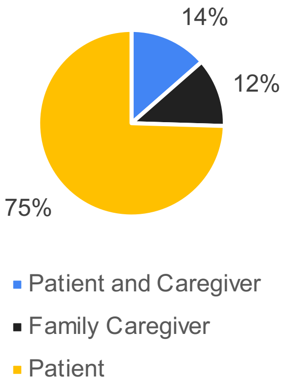
- **Wes Michael** founded Rare Patient Voice in 2013 to empower patients and family caregivers to share their voices through participation in research studies. The RPV community has since grown to 145,000+ across 1,500+ diseases.

- The company has rewarded patients and family caregivers over $13 million for taking part in research. Many have been recruited at in-person patient events and through a referral program with patient advocacy and support groups.

- RPV now covers non-rare as well as rare diseases in the U.S., Canada, U.K., France, Germany, Italy, Spain, Australia, and New Zealand.

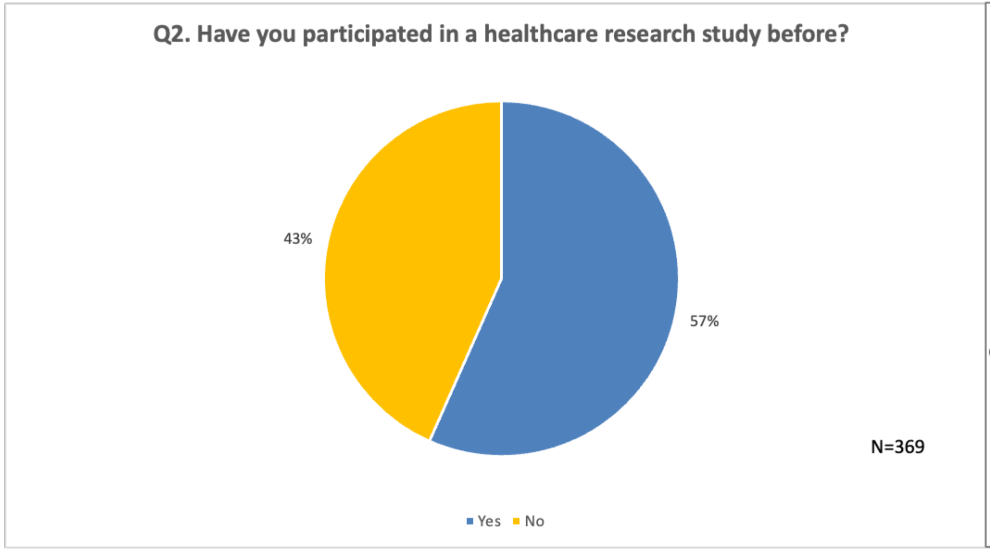
Rare Patient Voice survey

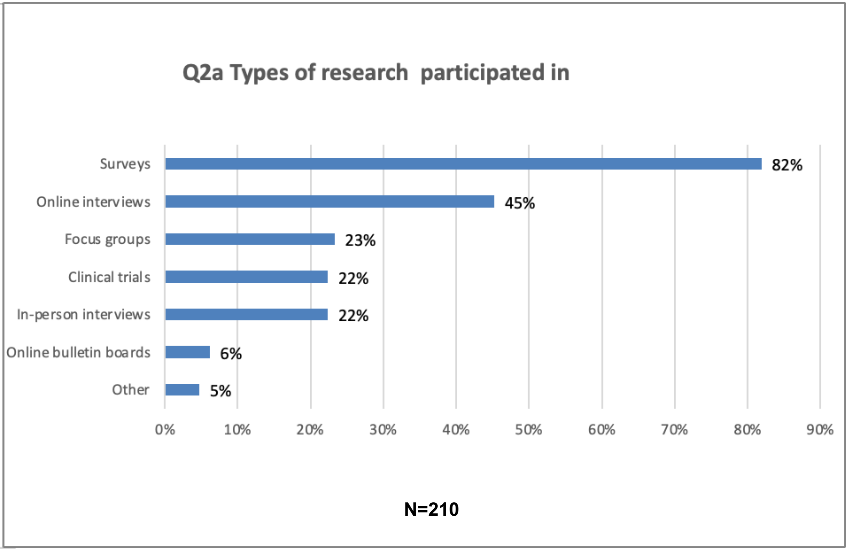
- In March 2024, Rare Patient Voice conducted a survey of 369 patients and family caregivers in the United Kingdom.
- Questions pertained to respondent experiences taking part in market research and the factors that enhance or detract from that experience.



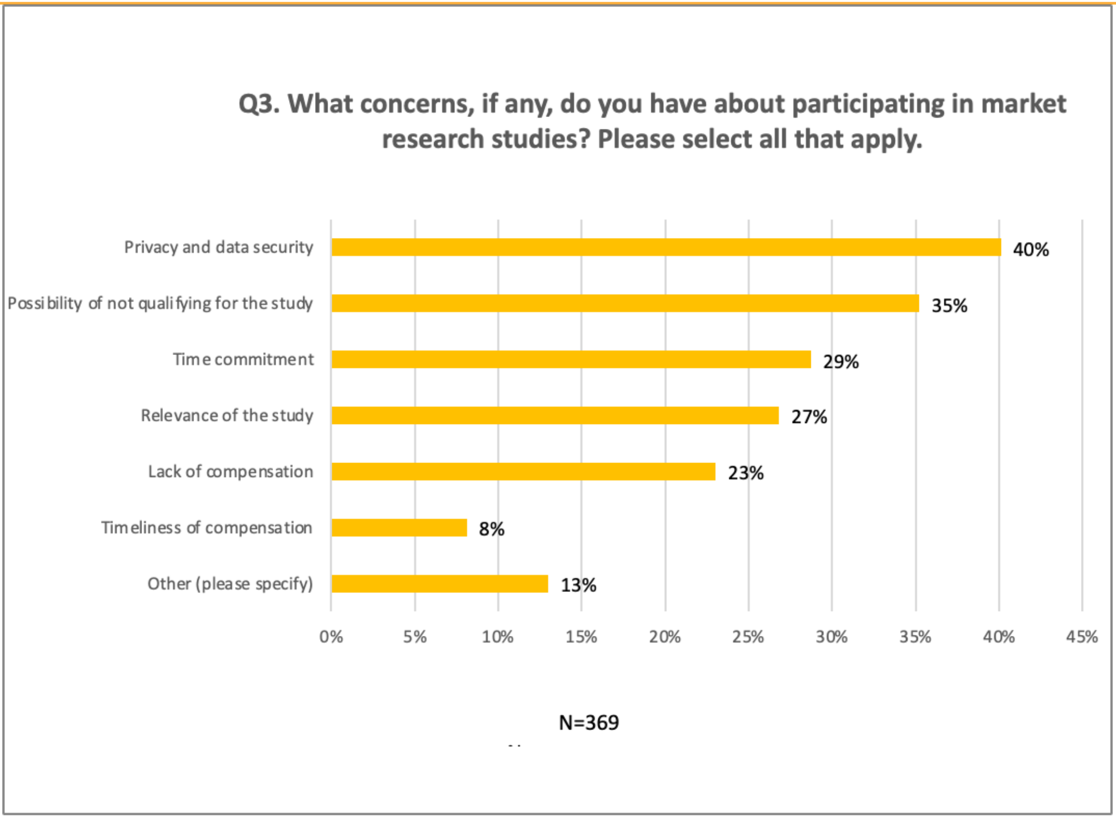
A majority have taken part in a healthcare research study

- Online surveys are the most common methodology reported.



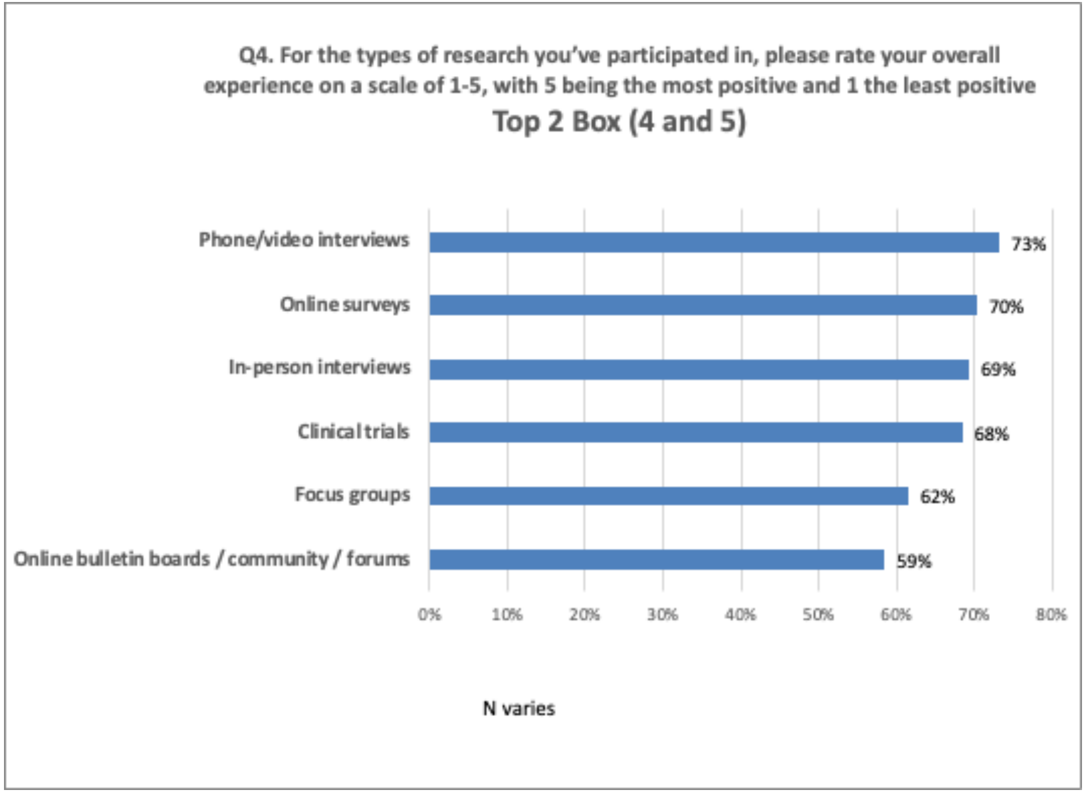


Data security is the leading concern about participation


Q3. What concerns, if any, do you have about participating in market research studies? Please select all that apply.

N=369

A majority have had a positive experience across methodologies

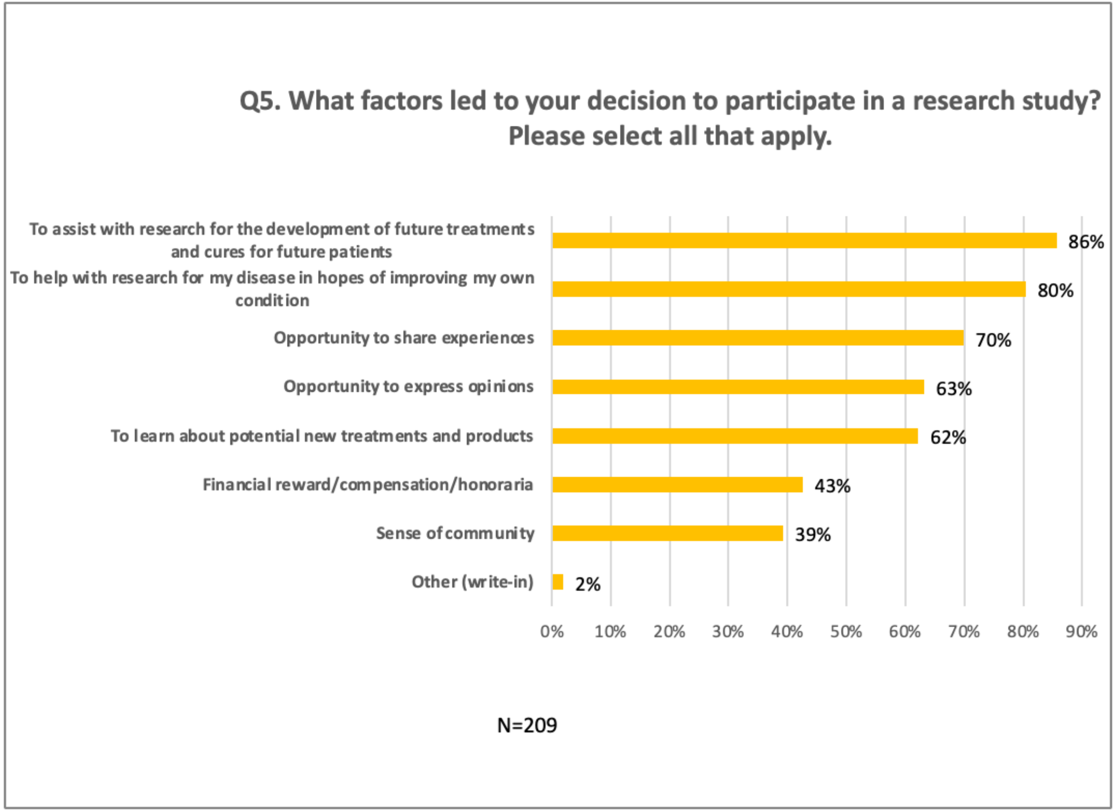


Q4. For the types of research you've participated in, please rate your overall experience on a scale of 1-5, with 5 being the most positive and 1 the least positive

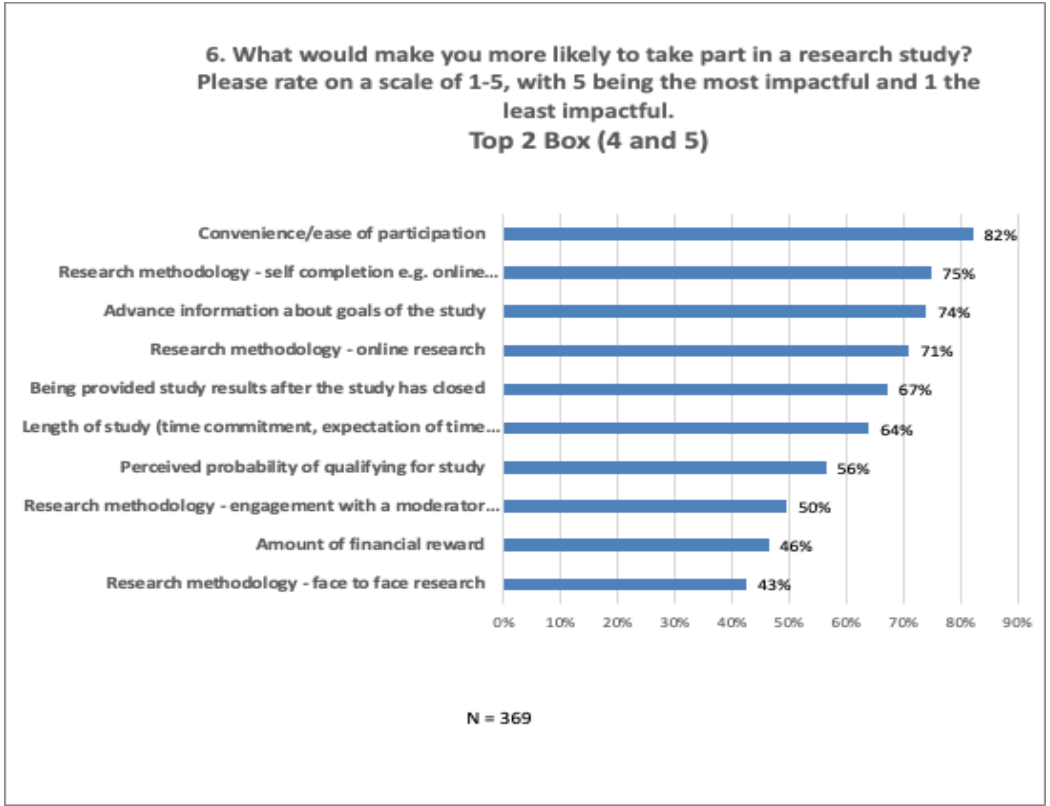
Top 2 Box (4 and 5)

N varies

Most respondents participate to help develop treatments and improve their condition.



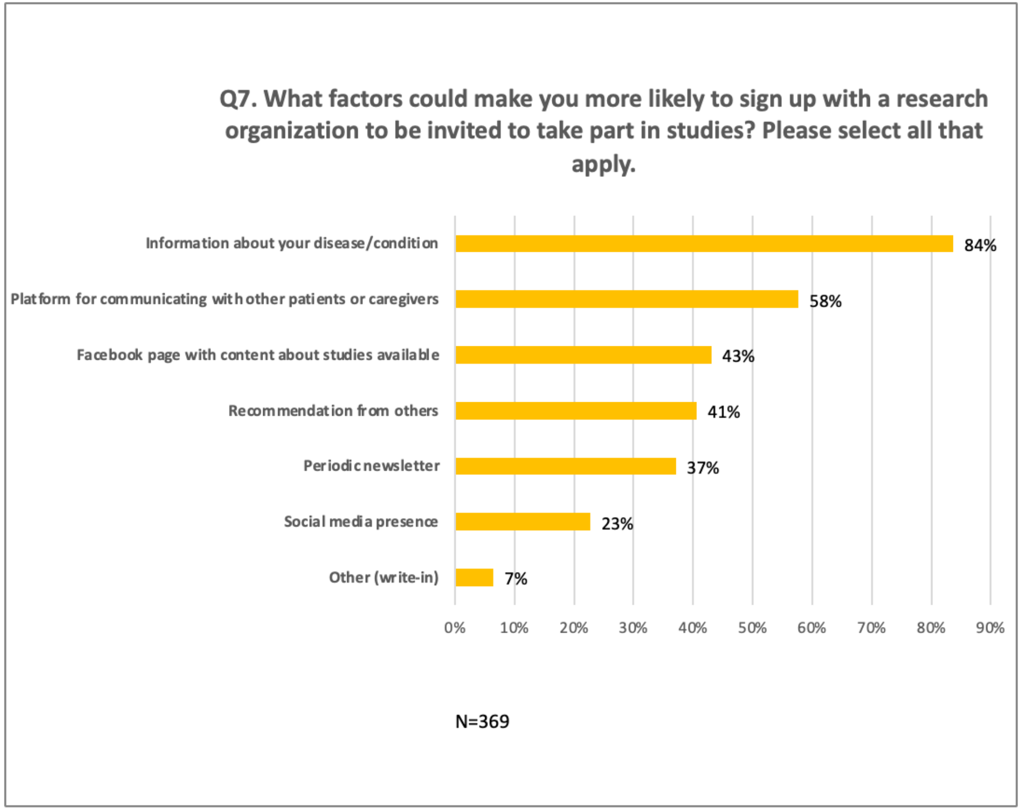
Convenience was rated as the top factor encouraging participation.



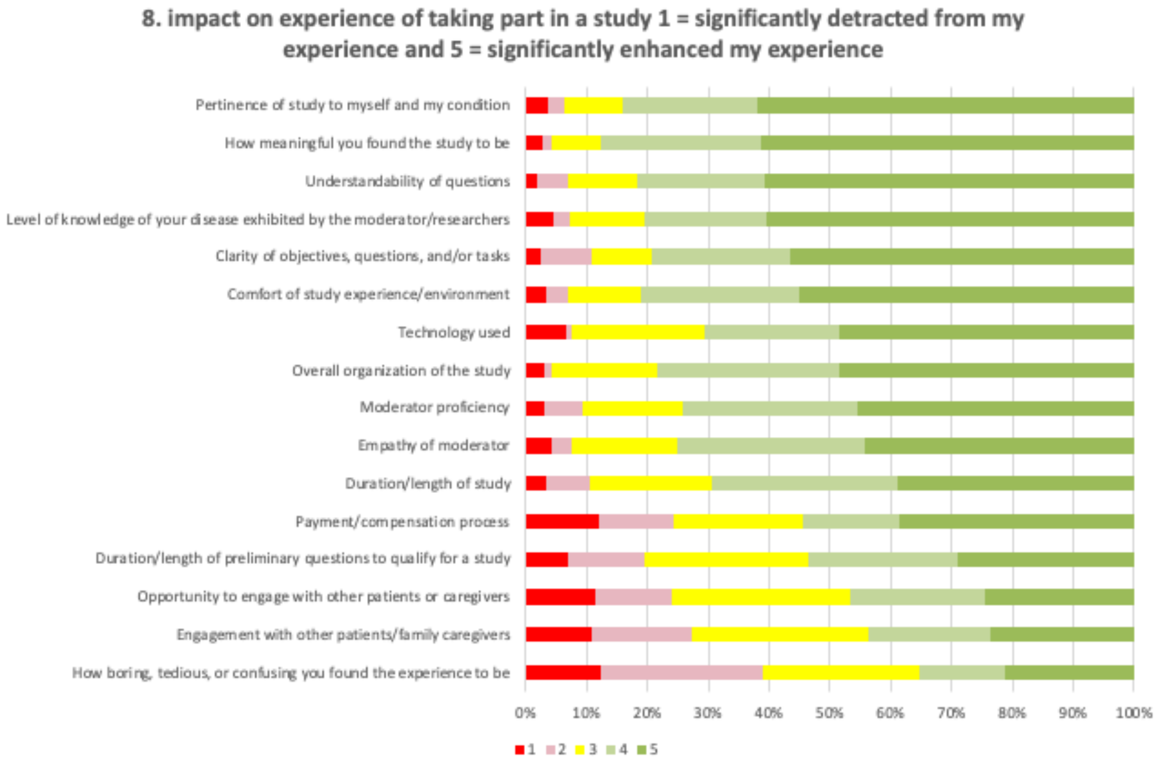
6. What would make you more likely to take part in a research study? Please rate on a scale of 1-5, with 5 being the most impactful and 1 the least impactful.
Top 2 Box (4 and 5)

N = 369

Providing information about the disease would make patients/caregivers more likely to sign up with a research organization.

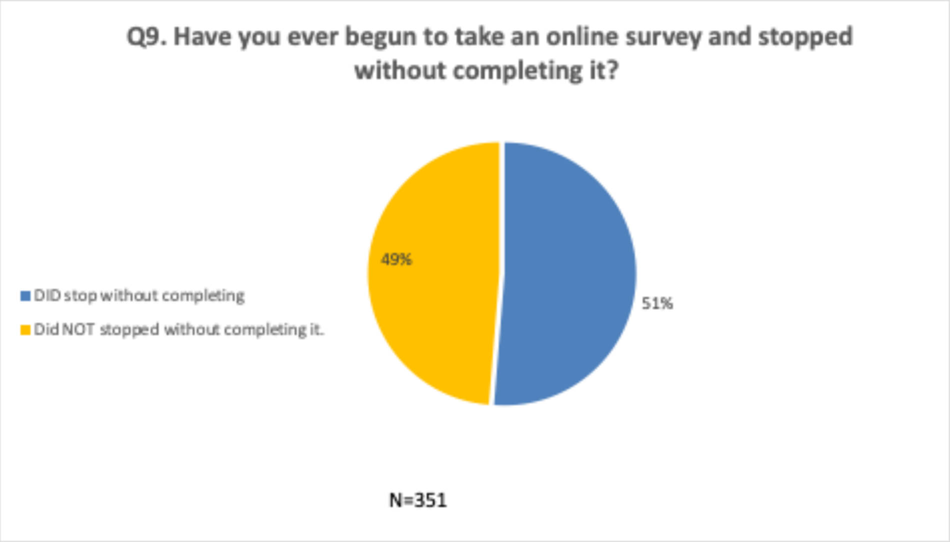


Pertinence and meaning to the respondent had the most positive impact on the research experience.

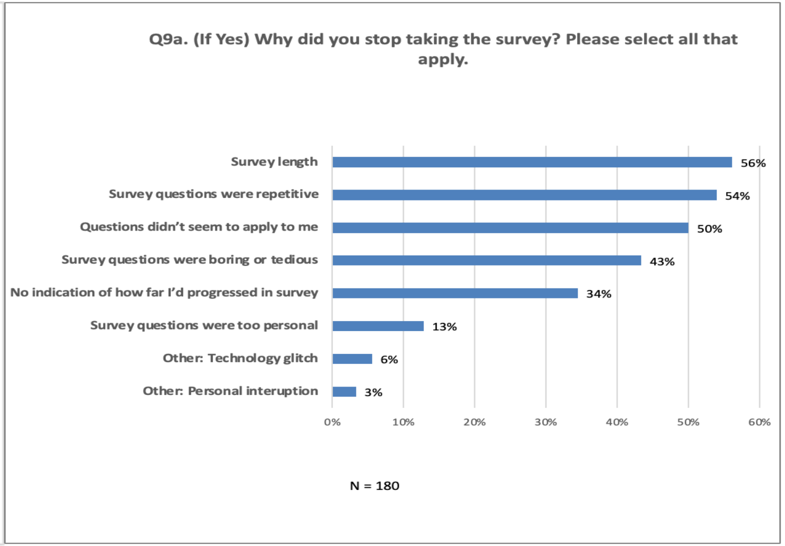


A majority have stopped an online survey without completing it

- **Long surveys, repetitive questions were most often mentioned as reasons for stopping.**

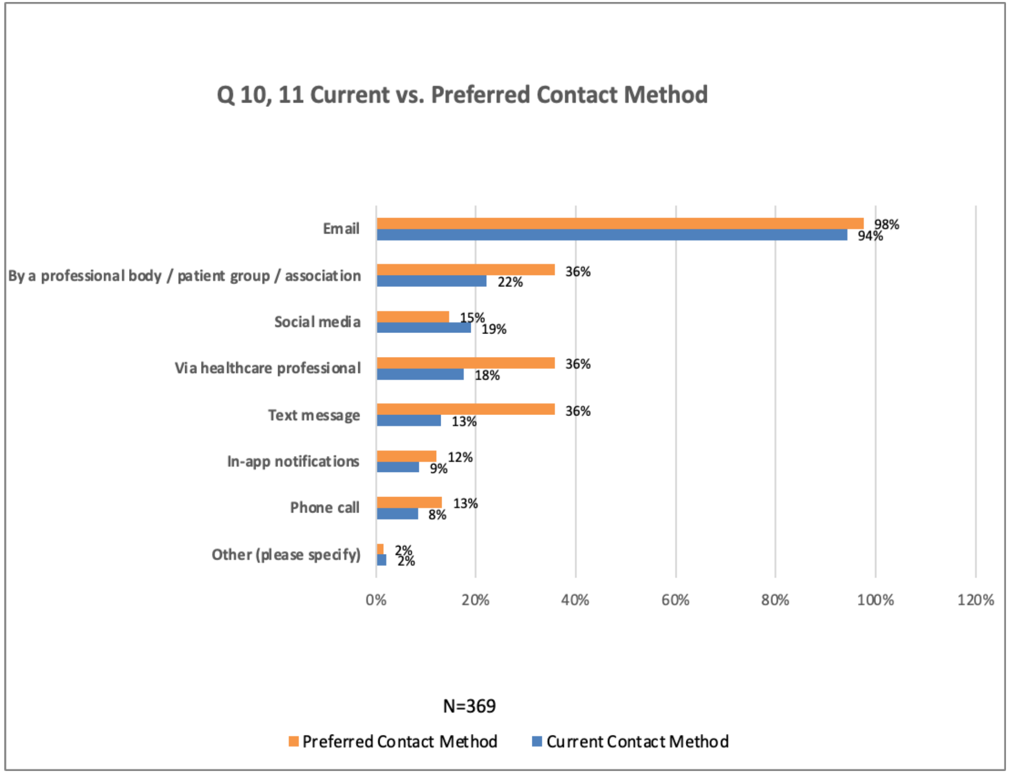

Q9. Have you ever begun to take an online survey and stopped without completing it?

N=351


Q9a. (If Yes) Why did you stop taking the survey? Please select all that apply.

N = 180

Email is the most used and preferred method of contacting respondents



How to make the research experience more engaging, meaningful, and valuable

1. Provide clear communication about the study's purpose, methodology, timeline, and expected outcomes. Participants want to understand the goals and potential impact of the research.

"*Simplicity and clarity around aims, methodology, timeline*"

2. Make surveys concise, relevant, and easy to understand. Avoid repetitive or overly complex questions. Provide an estimated completion time and progress indicator.

"*Keep surveys short and questions relevant and non-repetitive*"

3. Ensure the research is relevant and targeted to participants' specific conditions and experiences. Avoid wasting time on studies they don't qualify for.

"*Has to [be] relevant to my condition or to my support group network patients. Diversity of all participating to get a true understanding. Dissemination to the right people/organisations.*"

How to make the research experience more engaging, meaningful, and valuable (cont'd)

4. Demonstrate empathy, compassion and understanding from researchers. They should have knowledge of the condition being studied.

"*Compassion and understanding from researchers, easy-to-read information for those that require it*."

5. Provide timely feedback and follow-up on study results. Participants want to know how their contributions made a difference.

"*Understanding the goals of the study and being informed of future progress.*"

6. Offer appropriate compensation that values participants' time and insights. Consider their needs related to health limitations.

"*Key factors have to be time and money*"

7. Make the research process as accessible and convenient as possible. Accommodate different abilities and preferences for participation format.

"*Be clear in what you need, I have MS so a survey which takes an hour can fatigue me, being able to complete in sections and coming back to it would be helpful.*"

How to make the research experience more engaging, meaningful, and valuable (cont'd)

8. Foster a sense of community and allow opportunities for participants to interact and share experiences with each other.

"*I would take part in research like this to both contribute my experiences and requirements during a study but also because I would like to meet and talk with other people going through the same things as me.*"

9. Use the research to provide educational opportunities for participants to learn more about their condition and potential treatments.

"*I'm more inclined to participate if I'm going to learn something new about my condition or potential treatments for it. I'm scientifically literate, so I appreciate seeing that the people conducting the study not only understand the condition and/or treatment, but don't treat everyone like a 10-year-old in terms of what they could understand.*"

10. Be transparent about how participant data and insights will be used. Maintain communication and involvement throughout the research process.

"*Transparency. Real Consultation as opposed to already desired outcomes proving study for outcomes*"

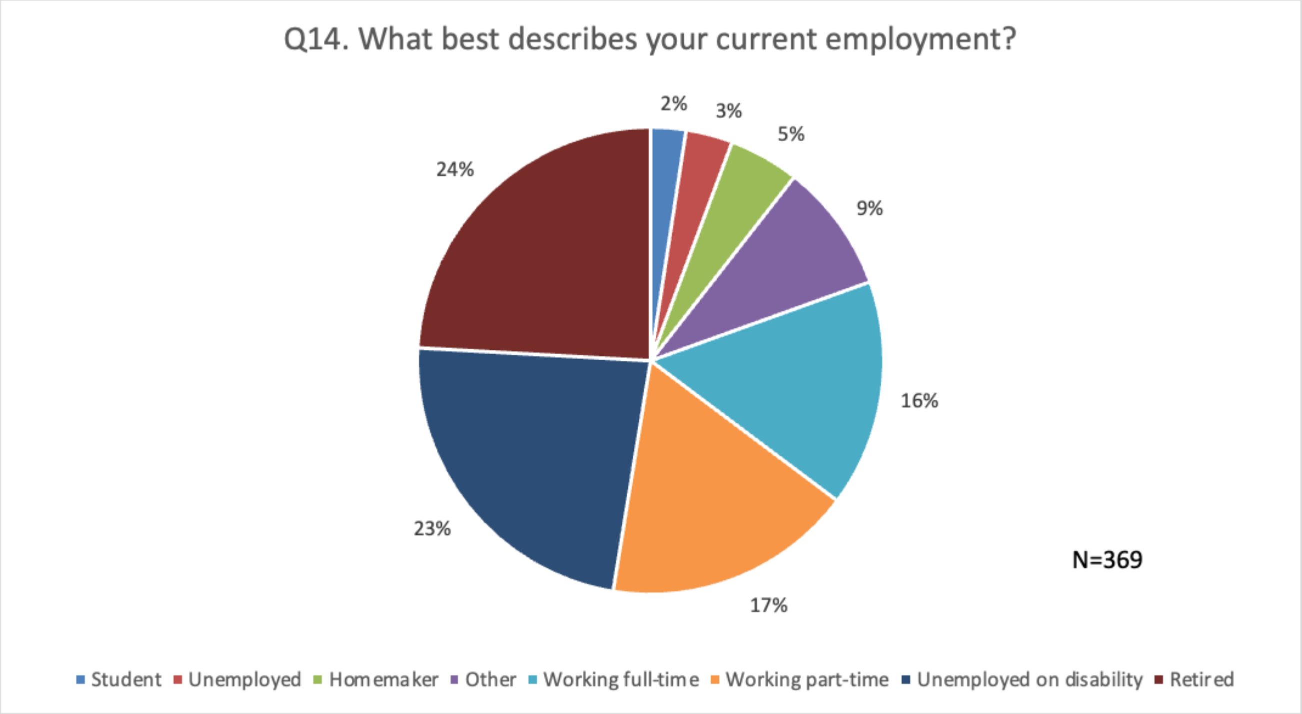
Actions

- Make the experience meaningful by emphasizing how the research will help the respondent and others with the same condition.
- Make the experience convenient.
- Guarantee that data will be kept secure.
- Keep respondents engaged by keeping online surveys short and the questions relevant.
- Email is most use and most preferred method of contacting respondents.
- Respondents are eager to take part if the disease topic is relevant. Honoraria is less of a consideration.

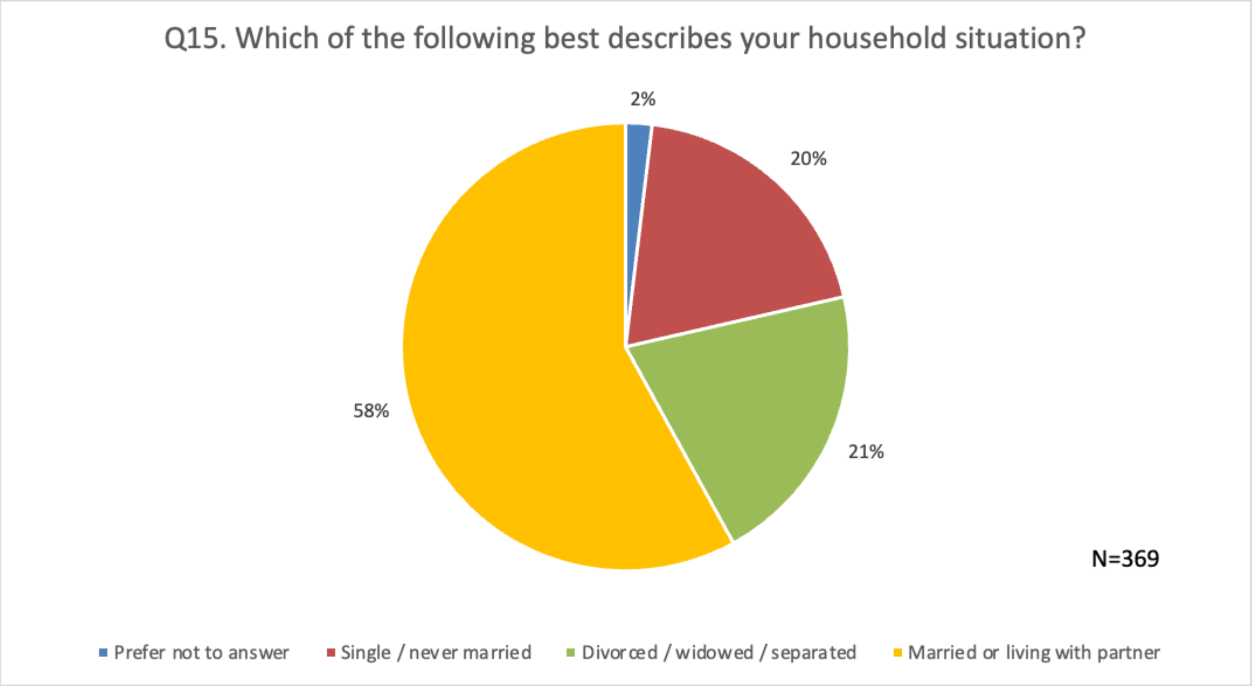
Demographics

- Employment
- Marital Status
- Household Income
- Ethnicity

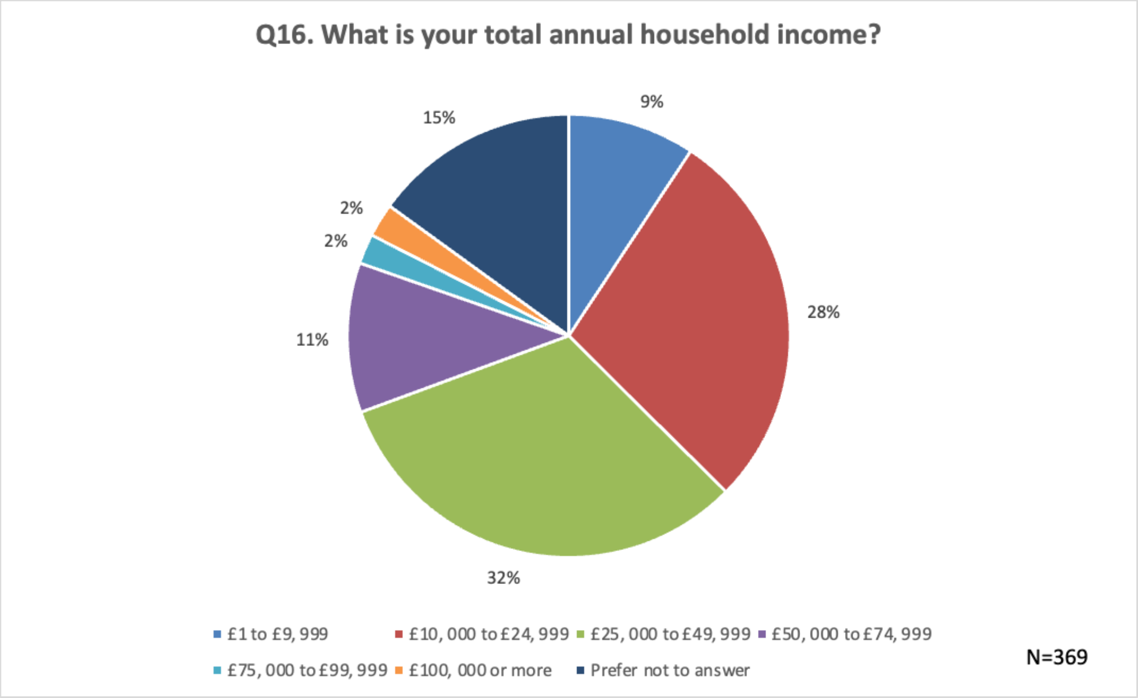
Current Employment



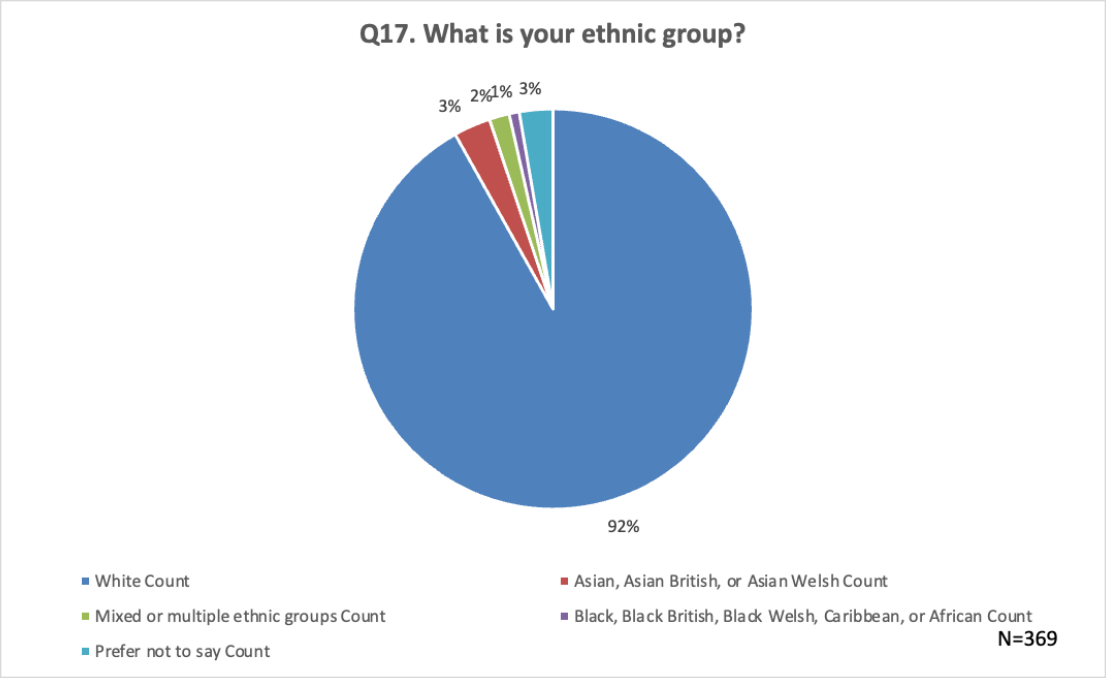
Household Situation



Household Income



Ethnicity


Q17. What is your ethnic group?

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For more information or to request the study data:

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Helping Patients and Caregivers Share Their Voices