Voices That Matter:

Transforming Healthcare Through Patient Research

Pam Cusick, Senior Vice President, Rare Patient Voice

About
Rare Patient Voice

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

Founded in 2013, the RPV community now includes 180k+ patients and family caregivers across 1,500+ diseases and conditions in 9 countries.

Overview

Patients Communication Preferences in Clinical Trials

N=1147 patients and family caregivers in United States

The Voice of the Patient: Preferences in Healthcare Research Participation

N= 369 patients and family caregivers in United Kingdom

Why Participate in Clinical Trials?

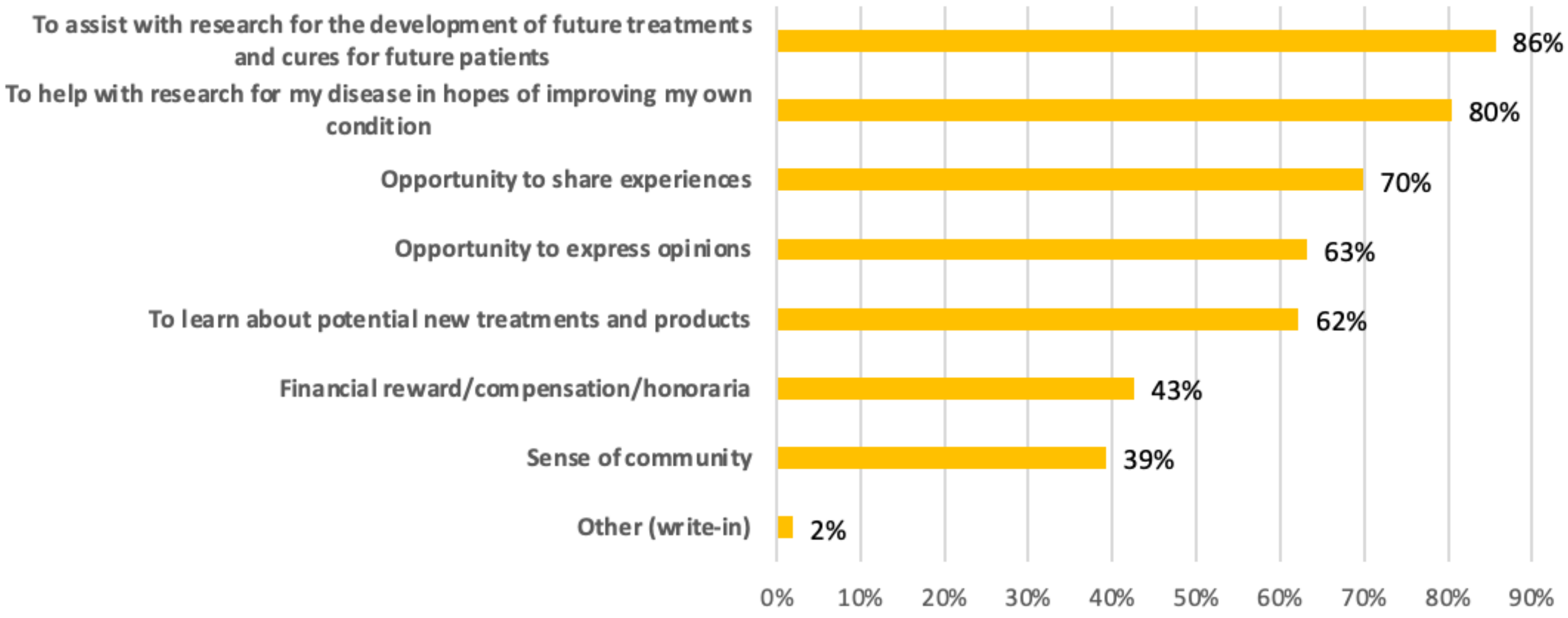
Helping Others

Advancing Research

Compensation

Why Participate in Market Research?

Q5. What factors led to your decision to participate in a research study? Please select all that apply.



N=209

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Factors That Encourage Participation in Clinical Trials

Clear and detailed information about trial and its goals	20%
Reimbursement for expenses (travel, meals, etc.)	18%
Financial compensation for time	18%
Receiving results once trial is complete	15%
Assurance of safety and confidentiality	15%
Support from healthcare providers	14%

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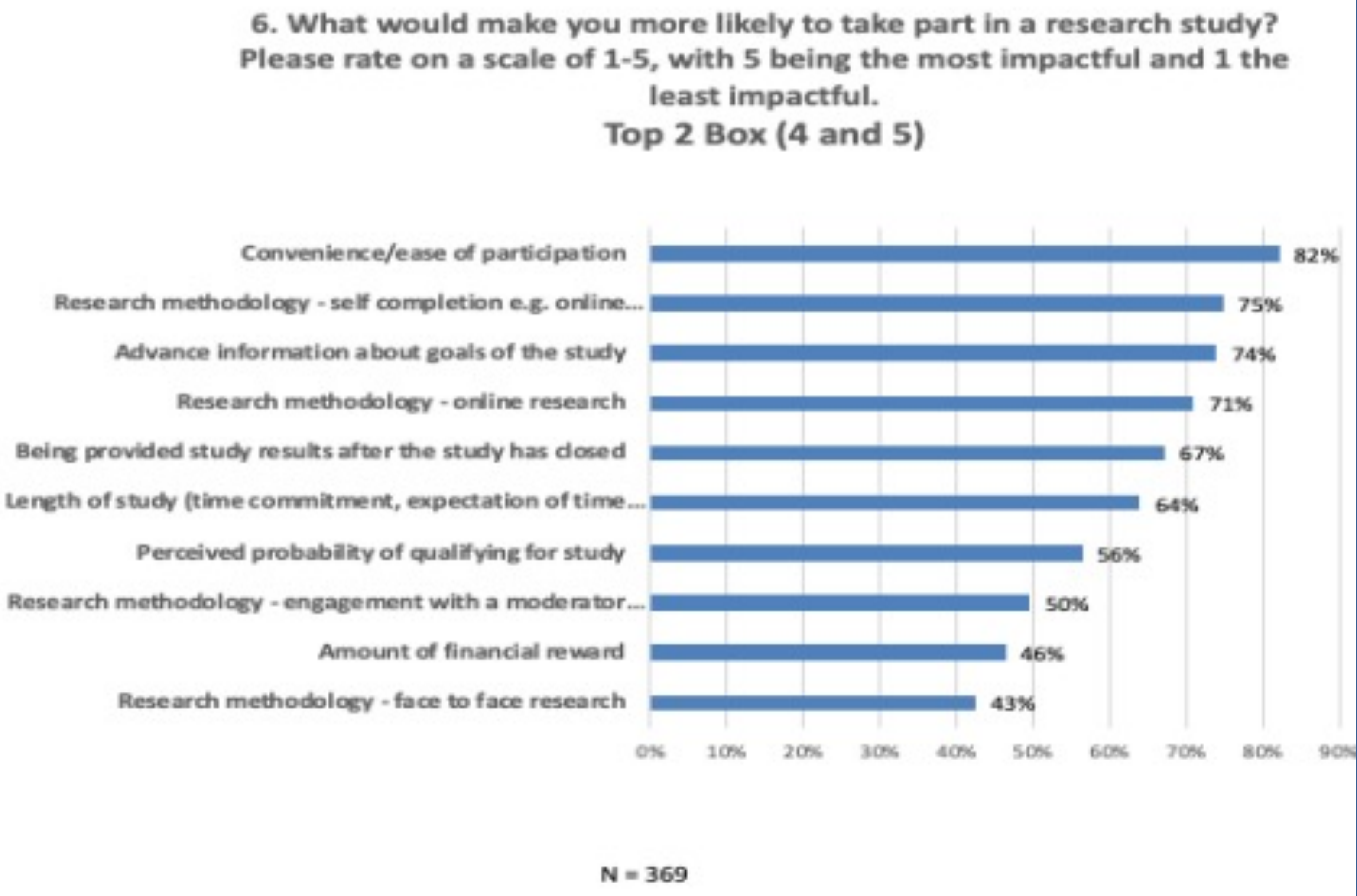
Factors That Encourage Participation in Market Research Studies



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

Main Concerns About Participating in Clinical Trials

Safety & side effects	30%
Travel logistics	20%
Costs & insurance	18%
Understanding Trial Process	12%
Time commitment	15%
Privacy & confidentiality	6%

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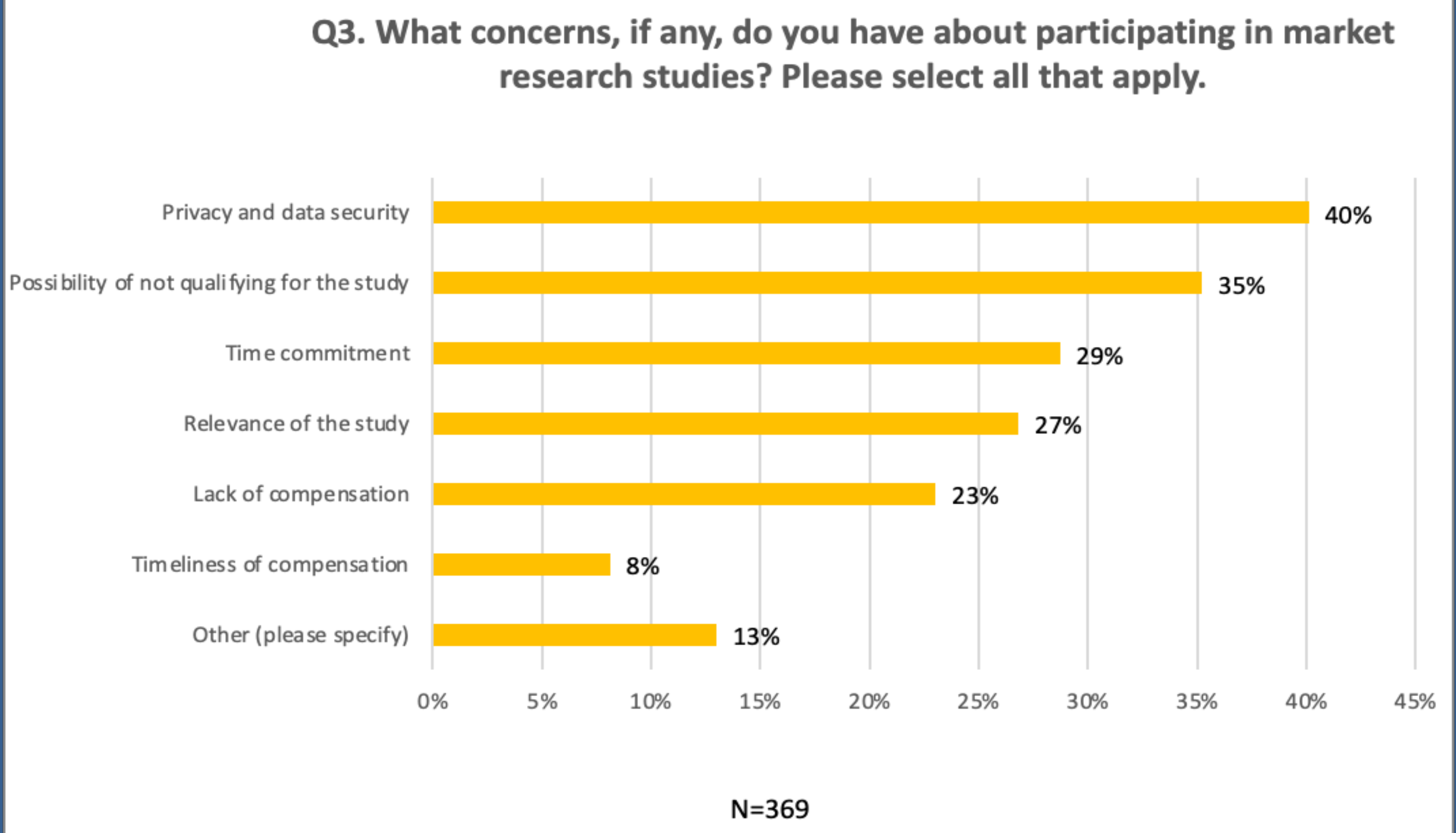
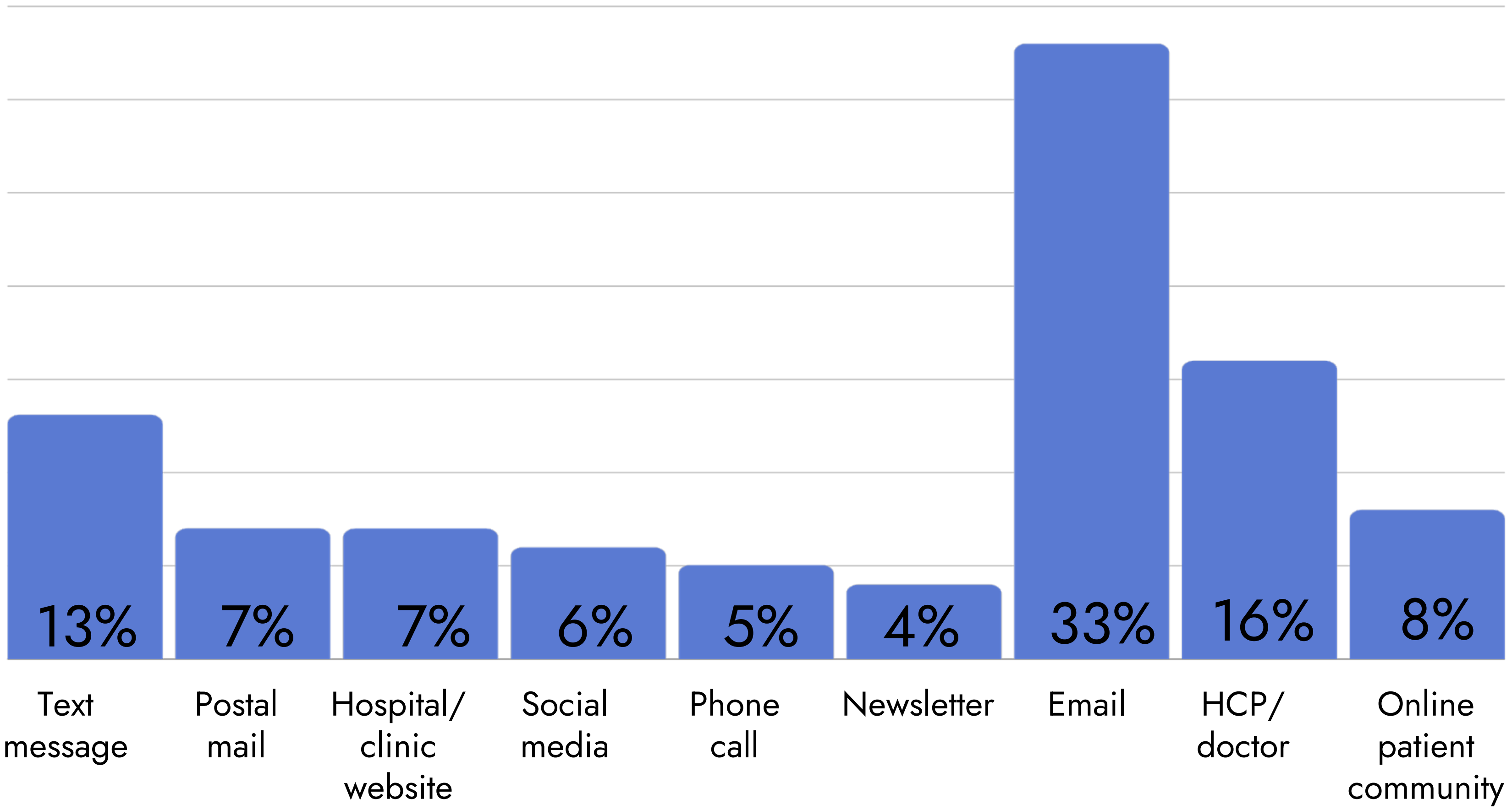
Main Concerns About Participating in Market Research



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

N=369

How Would You Prefer to Receive Information About Clinical Trials?



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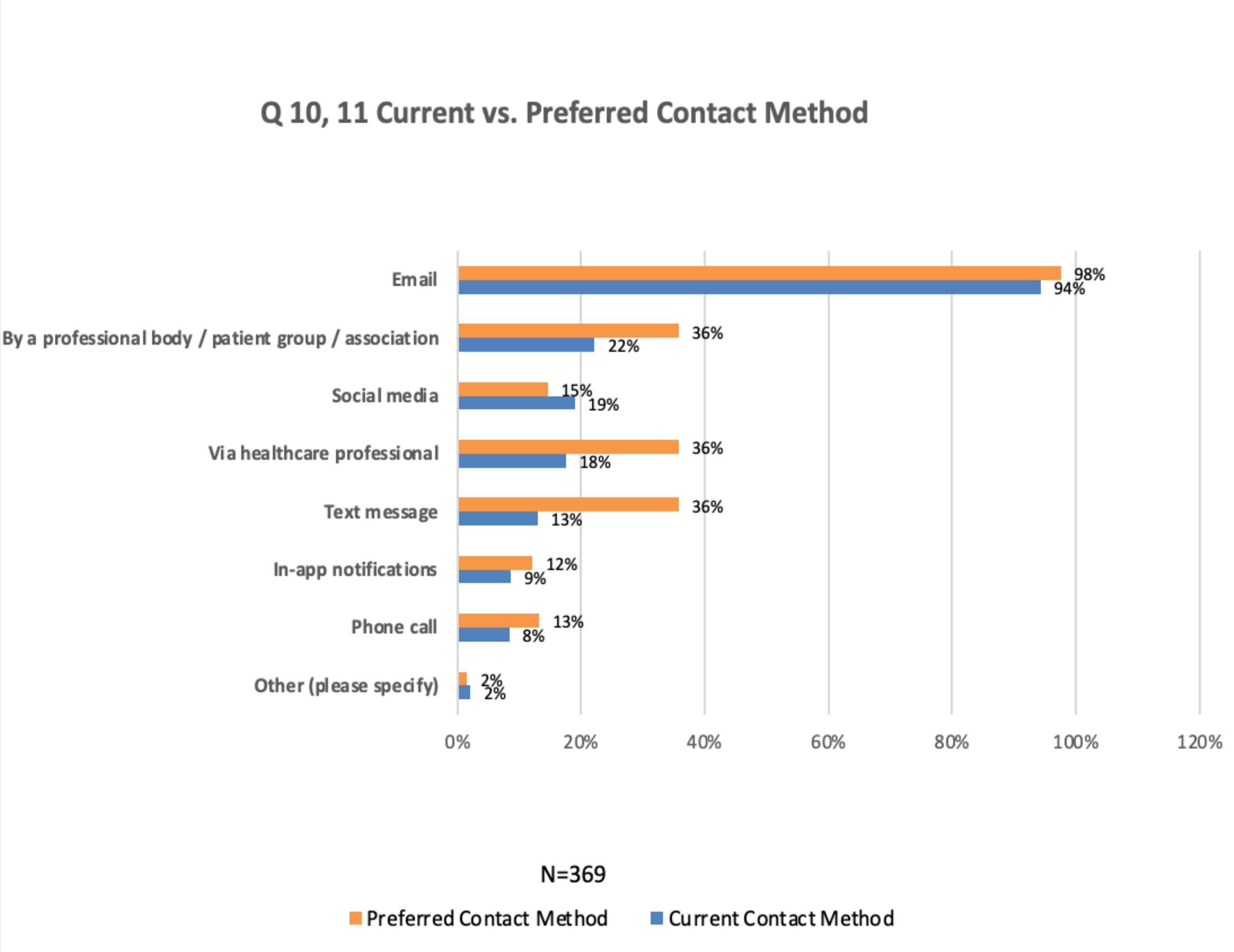
Preferred Method of Contact


Q 10, 11 Current vs. Preferred Contact Method

N=369

Key Takeaways

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. Provide information on study goals upfront.

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

3. Offer appropriate compensation that values participants' time and insights. Consider their needs related to health limitations. Be respectful of time commitments and out- of-pocket costs.

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

Key Takeaways

4. **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."*

5. Researchers should be empathetic and have knowledge of the condition being studied.

> "Compassion and understanding from researchers."

6. 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."

What Can Researchers Do?

- 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 and informed.
- Use email to contact respondents.

Questions?

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

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