Clinical Trial Recruitment: Understanding Participation and Strategies for Boosting Enrollment

Civis Healthcare and Life Sciences

March 2019

Introduction

Clinical trials are vital to medical research as they're often the best and only way to test new interventions, such as treatments or drugs. However, recruiting subjects - especially from demographic or socioeconomic groups that are typically underrepresented in research - is often a major challenge for study coordinators. We examined some of the barriers to clinical trial participation and suggest some outreach strategies that may improve enrollment.

Survey

In November 2018, Civis Analytics conducted an online survey of 4,922 US adults that asked whether people had ever participated in a clinical trial and assessed their attitudes toward medical research. Specifically, respondents were asked if they trust institutions that conduct clinical trials to have their best interest at heart, if they believe that the benefits of participating outweigh the risks, and the importance of being compensated for their participation.

Findings

Very few people have participated in clinical trials in the past.

Only 7% of respondents have participated in one or more clinical trials, and they differ demographically from non-participants for the following reasons: participants are more likely to be under 50 years old, have high incomes, are more likely to be Caucasian, are more likely to be male, and self-report to be in excellent health, as shown in Figure 1. Our study confirms the well-documented lack of participation in clinical trials overall,[1,2] as well as lack of participation, especially among certain demographic and socioeconomic groups.

[1] Participation in Clinical Trials: Race, Age, and Sex based disparities
[2] Race, Medical Researcher Distrust, Perceived Harm, and Willingness to Participate in Cardiovascular Prevention Trials

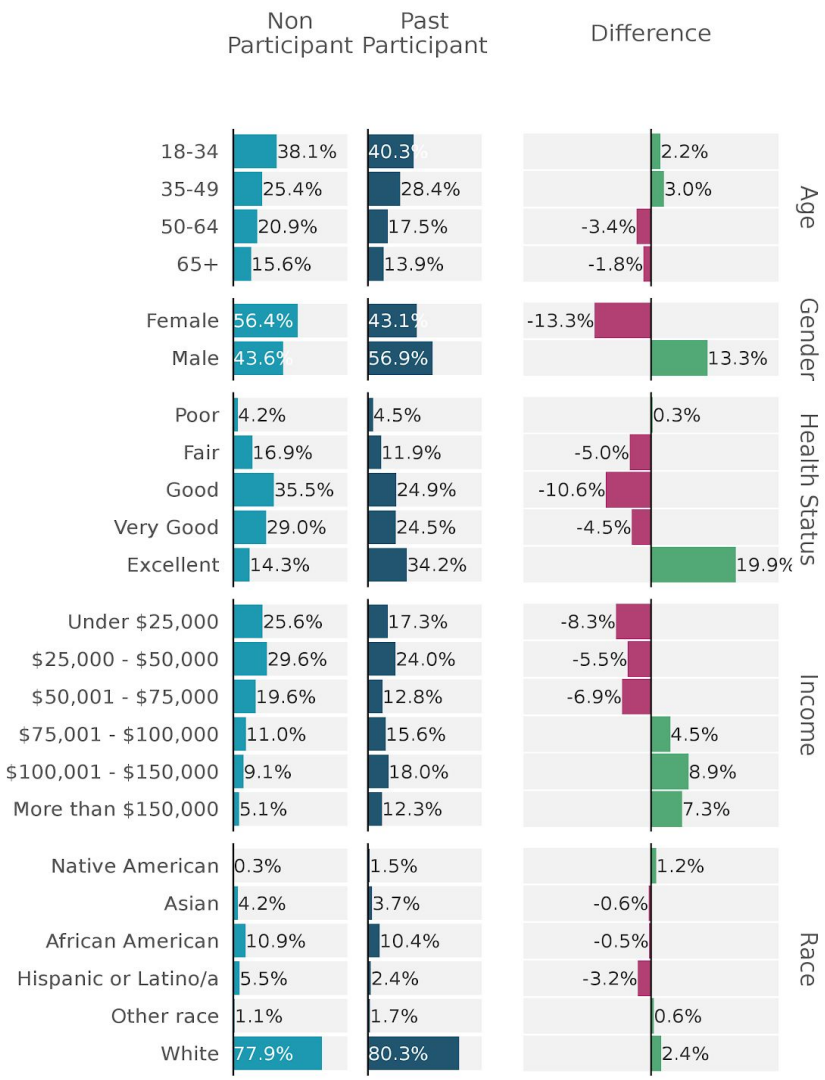

Figure 1: A comparison of people who have participated in clinical trials with those who have not

Most people who have never participated are open to discussing whether they qualify for a trial.

Although only 7% of people have participated in a trial before, 73% of non-participants said that they would be open to discussing it (the remainder of people explicitly answered that they would not want to discuss it), suggesting that there is a sizeable pool of people that can be reached. The composition of these potential participants was as follows:

- 56% are females
- 21% are non-white
- 53% make less than $50,000
- 36% are 50 or older and;
- 86% self-report to be in less than excellent health

Very few patients overall are having conversations with their healthcare providers about eligibility for a clinical trial. Those who have had conversations are much more likely to have participated than those who have not.

Overall, only 8% of all respondents had talked with their doctors about participating in clinical trials. However, this varies greatly between participants and non-participants: 54% of participants had talked to their doctors about joining a clinical trial, compared to only 3% for non-participants.

These differences also exist between men and women, although they are not as wide: 11% of men have discussed this topic with their doctors, compared to only 5% of women. Additionally, only 3% of Hispanics have talked with their doctors, compared to 8%, 9%, and 10% for Caucasian, African Americans, and Asians respectively.

Participants are more trusting of institutions and more likely to believe that the benefits of joining a trial outweigh the risks, while non-participants take a more neutral stance.

Respondents were asked if they agreed, disagreed, or had a neutral stance on statements about clinical trial participation, see Figure 2. Non-participants are 4x less likely to think that the benefits of participating in a clinical trial outweigh the risks, and 3x less likely to trust the institutions that conduct them. However, it's critical to note that rates of outright distrust are not any higher for non-participants than participants: they tend to take a neutral stance on the possible benefits of participating in a trial and on trusting medical institutions. This suggests that non-participants could be persuaded, perhaps, if given an effective message delivered through a trusted source that addresses these concerns.

The most effective message will depend on the target audience. For example, our survey responses show that Asians highly value being compensated for their participation and the importance of finding new treatments. Therefore, emphasizing these benefits may be effective for recruiting people from this particular demographic group. On the other hand, Hispanics similarly value compensation but are most likely to trust medical institutions, so messages that solely emphasize compensation may be helpful to recruiters.

Statement	Answer[3]	Participants	Non Participants				
		All	Asian	Black	Hispanic	Male	Female
It is important to be compensated for participation.	Yes	88%	88%	80%	87%	85%	85%
	Neutral	2%	8%	12%	8%	8%	9%
	No	10%	3%	8%	5%	8%	6%
Clinical trials are important for finding new treatments.	Yes	96%	90%	83%	81%	86%	87%
	Neutral	2%	9%	12%	13%	9%	9%
	No	2%	1%	5%	5%	5%	4%
The benefits from participating in a clinical trial outweigh the risks.	Yes	46%	10%	13%	17%	13%	9%
	Neutral	52%	87%	79%	76%	82%	86%
	No	2%	3%	8%	7%	5%	5%
Medical researchers have the best intentions for participants.	Yes	49%	17%	19%	22%	21%	18%
	Neutral	49%	81%	76%	75%	76%	78%
	No	2%	2%	5%	4%	3%	4%
Pharmaceutical companies have the best intentions for participants.	Yes	35%	12%	13%	17%	13%	11%
	Neutral	59%	84%	78%	74%	76%	78%
	No	6%	4%	8%	9%	11%	11%

Figure 2. A comparison of participants vs. non-participants and their general attitudes towards clinical trial research.

Among all demographic groups, direct mail was the preferred contact method. The second and third most preferred contact methods varied by group.

Overall, most respondents were open to invitations by letter (44%), followed by in-person conversations with their healthcare provider (33%). Another third stated that they'd prefer to go a website (33%) for this information. These preferences differed by age: older respondents

[3] For ease of interpretation, a 5-point scale (1 = Completely Agree, 2 = Somewhat Agree = 3 = Neutral, 4 = Somewhat Disagree, 5 = Completely Disagree) was collapsed into 3 points for this Figure. Respondents answering 1-2 is collapsed into "Yes", 3 into "Neutral", and 4-5 into "No".

preferred being notified through their healthcare provider and by letter, while younger respondents said they'd prefer going to a website.

Demographic	Best Method		2nd Best Method		3rd Best Method	
50+	Letter	53%	HC Provider	36%	Website	26%
African American	Letter	45%	Text message	35%	Website	29%
Hispanic	Letter	38%	Website	32%	Text message	30%
Asian	Letter	37%	HC Provider	32%	Website	31%
Female	Letter	46%	HC Provider	35%	Website	35%

Figure 3. The best, second best and third best preferred contact methods for outreach to non-participants from groups that are typically underrepresented in clinical trials

Conclusion

There are major consequences to under-enrollment in clinical trials. An immediate one is cost: one source estimates that from 2006-2010, $2 billion was wasted on starting up clinical trials that weren't conducted due to lack of participants.[4] Beyond cost, under-enrollment, especially for certain demographic and socioeconomic groups, leads to questions of how generalizable the conclusions from clinical trial results can be to groups who were not included as research subjects.

Though the barriers that impede recruitments are complex,[5] our findings suggest that given the opportunity, many people would be open to discussing eligibility to participate in clinical trials, even people from groups that are traditionally underrepresented in research. There are several data-driven strategies, many of which are borrowed heavily from targeted digital marketing, that can be adopted to address these issues, as long as they meet IRB and legal requirements. For example, instead of using the same blanket strategy of deploying an identical message to all potential recruits, recruitment coordinators could attempt to use more personalized messaging that is tailored to specific groups of desired enrollees. As suggested by our survey, some recruits

[4] Addressing Ever Rising Cost In Conducting Clinical Trials
[5] Barriers to Clinical Trial Enrollment in Racial and Ethnic Minority Patients With Cancer

may be more persuaded by text and visuals that emphasize trust in medical institutions, while others need to be affirmed that their participation will help researchers find new treatments for certain conditions.

In addition to the content of the messages themselves, personalizing the channels through which those messages are delivered can also improve outreach. Our data show that there are noticeable differences in how people prefer to be contacted about clinical trials by group, and this should be taken into consideration when designing enrollment efforts. Another strategy is to use tools like geocoding and population data to identify optimal bus stops or train lines where placing recruitment ads would reach the most people from desired enrollment groups.

Greater personalization of content and channels requires more up-front investment in smart design, coordination, and even small-scale message testing prior to officially launching recruitment efforts. This can be a challenge considering that study budgets are often already limited. However, the downstream consequences of failing to meet recruitment goals can be far more costly - enough to justify the expense of smart campaign design.

If you want more information on the process we used in this research, please feel free to get in touch at hello@civisanalytics.com.

Authors

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About Civis Analytics

Civis Analytics helps leading public and private sector organizations use data to gain a competitive advantage in how they identify, attract, and engage people. With a blend of proprietary data, technology and advisory services, and an interdisciplinary team of data scientists, developers, and survey science experts, Civis helps organizations stop guessing and start using statistical proof to guide decisions. Learn more about Civis at www.civisanalytics.com.