

# Generational Value Differences Affecting Public Perceptions of and Willingness to Participate in Clinical Trials

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## Abstract

**Background:** It is widely acknowledged that patient recruitment is a significant challenge and represents one of the primary reasons for drug development delays. Data from the Center for Information and Study on Clinical Research Participation (CISCRP) “Perceptions & Insights” study indicate that the 18- to 34-year-old Generation Y subgroup was the least willing to participate in a clinical trial. **Methods:** The willingness of Generation Y to participate in clinical studies was compared to that of older groups in the CISCRP study. These results were then compared to data from earlier studies. **Results:** Statistically significant differences existed between the willingness of Generation Y to participate in clinical studies when compared to older age groups. Generational perceptions and value differences were explored via corporate and sociological research findings to determine why disparities existed among age groups regarding the willingness for clinical trial participation. **Conclusions:** Preliminary results indicate that members of Generation Y are less willing to participate in clinical studies and that these differences are truly generational and not simply age related.

## Keywords

Generation Y, clinical trial participation

## Introduction

In the quest to develop new drugs, study volunteer recruitment into clinical trials is a significant problem, causing untimely delays, financial setbacks, and the frequent need to reach larger numbers of patients globally through the use of outsourcing.<sup>1</sup> According to EvaluatePharma,<sup>2</sup> the pharmaceutical industry spent approximately US\$137 billion on research and development in 2012. Other authors have noted that approximately 40% of research and development spending is dedicated to conducting clinical trials.<sup>3</sup> The primary reason for clinical trial delays is due to challenges in patient recruitment.<sup>4</sup> One approach to improving patient recruitment effectiveness has been to conduct clinical trials in developing countries with large, treatment-naïve patient populations. In 2013, one-third of all pharmaceutical and biotechnology company-sponsored clinical trials were conducted in developing countries.<sup>5</sup>

Despite patient recruitment challenges, as many as 87% of the general population are willing to participate in a clinical research study.<sup>6</sup> Additionally, national and international polls indicate that a high percentage of the public believes that clinical research is of great societal value.<sup>7</sup> A 2013 survey from the

Center for Information and Study on Clinical Research Participation (CISCRP)<sup>6</sup> revealed that persons between the ages of 18 to 34 years were the least willing to participate in a clinical research study (Figure 1). This subgroup represents the Generation Y population. By viewing this problem in relation to society’s hope to advance global health care initiatives, the future of recruiting potential clinical trial participants is unknown.

The current literature offers many reasons why people choose to participate in clinical trials. According to the recent

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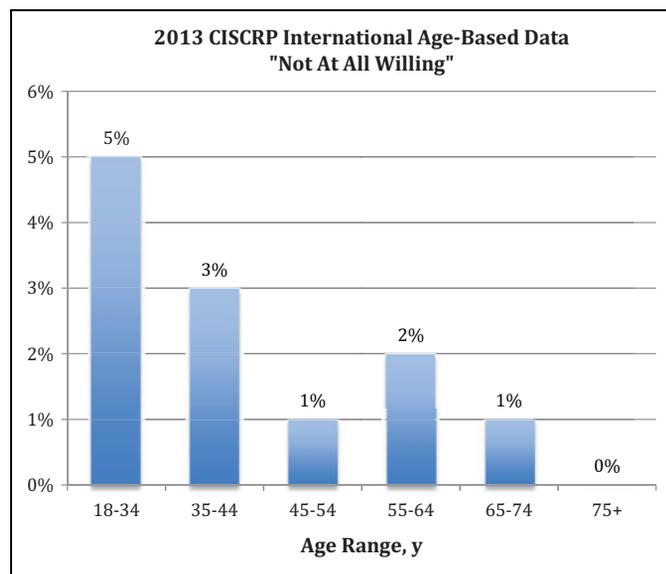
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**Figure 1.** Graphical representation of survey respondent data, stating that respondents are “not at all willing” to participate in a clinical research study. Source: Adapted from CISCRP (2013).<sup>6</sup>

CISCRP study,<sup>6</sup> respondents cited gaining access to quality medical care (85%) and medical professionals (83%), learning about their illness (79%), and feeling part of a community (61%) as top factors influencing their decision to participate in a clinical trial. Motivations for clinical trial participation are also reinforced globally to include wanting therapeutic options, financial compensation, access to ancillary care, curiosity or scientific interest, and demonstrating altruism.<sup>8,9</sup>

Additionally, many studies have been conducted outlining reasons why eligible participants would not want to participate in a clinical trial; examples include not wanting a placebo, concern over side effects and potential risks, worries about loss of privacy and loss of treatment upon trial completion, utilization of current standard treatments, inconvenience, and unanticipated costs.<sup>10,11</sup> There are even studies that explore the decision-making processes that potential study volunteers apply when determining whether or not to participate in a clinical trial.<sup>12,13</sup>

Understanding these data is of utmost importance; yet, there has been no identifiable research evaluating the reasons why differences exist among age groups regarding the perceptions of and willingness for clinical trial participation. The biomedical research industry would benefit from engaging in a directive to increase participation in clinical trials. Healthcare and research communities are placing greater emphasis on individual preferences by initiating patient-centered practices, establishing meaningful patient-physician relationships, and personalizing information—for instance, during the informed consent process.<sup>11,14,15</sup> However, recognizing factors, such as generational values, that influence prospective subjects’

decision-making processes may potentially provide the framework necessary for successful patient recruitment and clinical trial participation.<sup>11</sup>

According to White,<sup>16</sup> generational thinking is important to understand by directing attention to the intent and various elements that influence the context of perceptions and bases for choices. As perceptions shape willingness, this includes viewing generationalism in the milieu of clinical trial participation.

The primary objective of this study was to analyze the 2013 CISCRP survey for age-based data to determine if statistically significant differences exist among the 18- to 34-year-old Generation Y subgroup compared to older age groups regarding the willingness to participate in a clinical trial. Secondary objectives include exploring Generation Y value differences that may impact the perception of clinical trial participation. As such, this information may contribute to the body of knowledge that the biomedical research community has concerning patient recruitment within this age group as future participants of clinical trials. It was hypothesized, based on the media-hyped life experiences, individualistic attitudinal differences, and defining generational characteristics, that Generation Y would represent statistically significant differences in their willingness to participate in a clinical trial compared to older age groups or generations.

A generation is formalized as a distinct cohort of people who share birth years, age, and unique historical, political, economic, and social life experiences at critical developmental life stages. These shared commonalities and viewpoints help define the uniqueness and character of each generation.<sup>17</sup> As a result of these social categorizations, perspectives are formed and shaped that inspire mindsets toward authority, organizations/industries, and work as well as how to respond to and satisfy problems.<sup>16,18</sup> This includes, for instance, Generation Y’s viewpoint on healthcare initiatives and the clinical research enterprise.

Generation Y is a cohort of society born between 1979 and 2000, placing these individuals, at present day, at 14 to 34 years of age. The birth year range varies slightly by author, but overall, this date range classifies Generation Y. A summary of distinctive characteristics for this generation includes information seeking and media/technology savvy; demonstrating a robust work ethic with an emphasis on individualism; accepting change and transition adequately; displaying efforts to create a more cultured, educated, and tolerant society; exhibiting a high self-regard; and a belief of self-entitlement and instant gratification.<sup>19,20</sup>

Prominent historical, political, and economic occurrences experienced by this generation during principal developmental milestones and vulnerable formative times consist of exceptional numbers of media-sensationalized events (Table 1). For example, Generation Y observed and/or experienced the effects

**Table 1.** Historical events experienced by Generation Y during critical developmental years.

| Event  | Year |
|--|------|
| US involvement in Gulf War (Operation Desert Shield)                 | 1990 |
| 51-day Waco, Texas standoff (cult members and federal agents killed) | 1993 |
| Oklahoma City domestic terrorism bombings (168 people killed)        | 1995 |
| Columbine school massacre  | 1999 |
| September 11: Islamic fundamentalist terrorists attacks on US        | 2001 |
| US initiates War on Terrorism against the Taliban and Al-Qaida       | 2001 |
| Enron scandal  | 2001 |
| Southeast Asian tsunami (290,000 people die)                         | 2004 |
| Drug recalls (Cox-2 inhibitors, ie, Vioxx)                           | 2004 |
| Hurricane Katrina  | 2005 |
| Subprime mortgage crisis   | 2007 |
| Barack Obama takes oath as first African American US president       | 2009 |

of the financial and housing catastrophe, fraud and deception from major corporations, terrorism, controversial government practices, natural disasters, schoolyard shootings, and numerous high-profile pharmaceutical and medical device company recalls, just to name a few. Moreover, this social media society has constantly been inundated with advertisements fraught with individuals portrayed as victims of scams: drug- and device-related deaths and recalls, occupational hazard exposures, and corporate class action law suits.

## Methods

The CISCRP, an independent nonprofit organization, conducted an online international survey between January and March 2013, titled “The 2013 CISCRP Perceptions & Insights Study: Report on General Perceptions.” The study objectives were aimed toward gathering a “global assessment of public and patient perceptions, motivations, and experiences with clinical research participation in order to monitor trends and identify opportunities to better inform and engage the public and patients as stakeholders and partners in the clinical research enterprise.”

The total number of survey respondents to the CISCRP survey was 5701. The participants were  $\geq 18$  years of age, of which 75% were North American, while the remaining participants were South American (5%), European (15%), and Asian-Pacific (5%). Additionally, 61% of respondents never participated in a clinical trial, while 39% reported previous participation in a clinical trial.

A quantitative subset analysis of the North American data ( $n = 4276$ ) was conducted from the 2013 CISCRP Perceptions & Insights study,<sup>6</sup> focusing on 1 question of importance: “How willing are you to participate in a clinical research study?” Of

**Table 2.** Number of North American respondents by age group.

| Age Range, y | Respondents, n (%) |
|--------------|--------------------|
| 18-24        | 121 (3)            |
| 25-34        | 348 (8)            |
| 35-44        | 638 (15)           |
| 45-54        | 1032 (24)          |
| 55-64        | 1253 (30)          |
| 65-74        | 645 (15)           |
| 75+          | 191 (5)            |

Source: CISCRP (2013).<sup>6</sup>

the North American participants, 4228 responded to this question and disclosed age and education information. There were 5 survey response options: “I am not sure,” “not at all willing,” “not very willing,” “somewhat willing,” and “very willing.” The response “I am not sure” ( $n = 89$ ; 2% of participants) was omitted from the data analysis, thus revising the sample size to 4139.

The survey responses were grouped by the following ages: 18-24 plus 25-34 years (Generation Y) compared with the responses of participants aged  $\geq 35$  years (Table 2). The total number of survey respondents representing the 18- to 34-year-old Generation Y subgroup ( $n = 469$ ) denoted 11% of the North American study population.

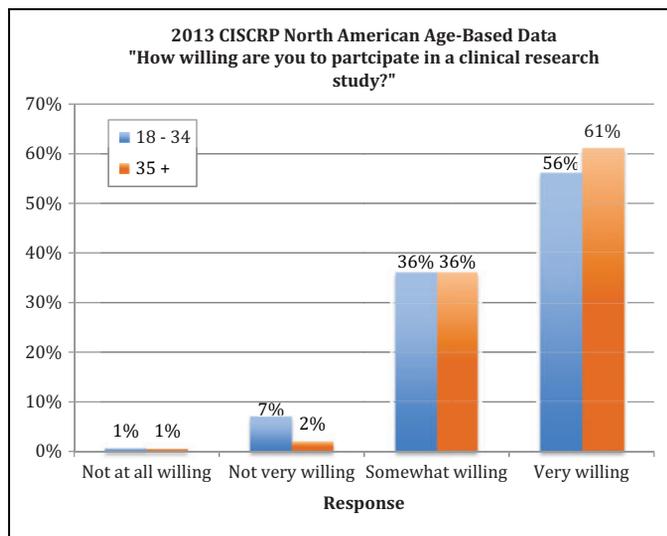
The dependent variable “willingness to participate in a clinical trial” was measured on an ordinal scale consisting of 4 categories: 1 = not at all willing, 2 = not very willing, 3 = somewhat willing, and 4 = very willing. An adjusted *t* test was used to test for generational differences.

## Results

The mean ( $\pm$  standard deviation) response among 18- to 34-year-old subjects was  $3.46 \pm 0.686$ , and the mean response among subjects aged  $\geq 35$  years was  $3.59 \pm 0.554$ . Mean responses were thus lower, meaning less likely to participate, among younger respondents compared to older ones. An independent-samples *t* test adjusted for unequal group variances showed statistical significance ( $t(524.21) = 3.771$ ;  $P < .001$ ). Statistical significance is not always the same as clinical significance, however, so Cohen  $\delta$  was also calculated as an effect size. Values of Cohen  $\delta \leq .2$  indicate a small effect size, values around .5 indicate a medium effect size, and values around .8 indicate a large effect size. The estimate of Cohen  $\delta$  for these data was .222, indicating that the effect size was closer to the small end of the scale than the medium point.

## Discussion

Based on the quantitative subset analysis of the 2013 CISCRP “Perceptions & Insights Study: Public and Patient Perceptions

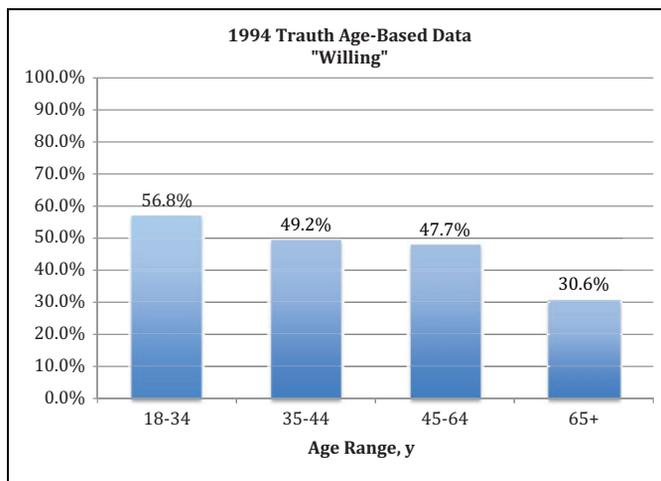


**Figure 2.** Graphical representation of survey respondent data, stating respondents' willingness to participate in a clinical research study. Source: Adapted from CISCRP (2013).<sup>6</sup>

of Clinical Research,”<sup>6</sup> the Generation Y subgroup did harbor a more negative view of clinical trials and was less willing to participate in a medical research study as compared with older age groups (Figure 2). These results are indicative of generational differences. Furthermore, these findings can be reinforced as a review of the literature-revealed ancillary findings of a study conducted by Trauth et al<sup>1</sup> in 1994, which sought to determine the willingness of respondents to participate in a clinical research study (Figure 3). Although the Trauth et al<sup>1</sup> survey results were limited to a sample size of 489 persons living in Pennsylvania, the survey is the best representation of data for this age group in this time period and may still shed light on important generational, rather than maturational, differences.

The 18- to 34-year-old subjects in the 2013 CISCRP study represent Generation Y, whereas the 18- to 34-year-old subjects in the 1994 Trauth et al<sup>1</sup> study represent Generation X due to the date in time. The results displayed in the 2013 CISCRP chart (Figure 1) represent age-based data, stating the percentage of respondents “not at all willing” to participate in a clinical research study. Clearly, the Generation Y subgroup stands out, yielding the highest percentage (5%) of the respondent population as least willing to contribute to the clinical research enterprise. However, in the Trauth et al<sup>1</sup> study, the then 18- to 34-year-old subgroup, classified as Generation X, represented the highest percentage of respondents (56.8%) willing to participate in clinical research.

It is important to note that the overall CISCRP sample included respondents who had not participated in clinical trials in the past (61%) and those who had participated (39%). Responses by these 2 subgroups were compared. No significant differences were observed on any of the perception, attitude,



**Figure 3.** Graphical representation of survey respondent data, stating that respondents are “willing” to participate in a clinical research study. Source: Adapted from Trauth et al (2000).<sup>1</sup>

and experience questions included in the analysis supporting this study.<sup>21</sup>

To acquire a more comprehensive overview of the Generation Y subset with regard to clinical trial participation, initial questions presented in the 2013 CISCRP “Perceptions & Insights” study,<sup>6</sup> such as understanding what is meant by the term “clinical research study” and rating one’s “general knowledge about clinical research,” must be reviewed foundationally to delineate between age-based maturational distinctions and progress toward value differences related to clinical trial participation such as viewing temporal aspects, social media influence, information-seeking characteristics, and generational value factors. For example, the 18- to 34-year-old population typically presents with fewer health conditions and concerns as compared with older persons and generations. Although these younger individuals tend to encompass the value of health and demonstrate concern, their main focus is on preventive measures such as weight control, healthy living habits (exercise and diet), and disease prevention. This age group also is transitioning from pediatric to adult medical care. As such, these younger individuals may lack continuity in the awareness of medical conditions more common to older adults.

Because a clinical trial is defined as a “prospective biomedical or behavioral research study of human subjects that is designed to answer specific questions about biomedical or behavioral interventions,” understanding what is meant by the term “clinical research study” is likely less relevant and significant to this younger population; they are in less demand of this targeted information.<sup>22</sup>

Rating one’s general knowledge of clinical research may also be temporally related. Generation Y was born between the years of 1979 and 2000. However, many of the medical

breakthroughs that affected the population and had significant epidemiological consequences took place prior to their existence. The treatment of diabetes; vaccinations for diphtheria, pertussis, tuberculosis, and tetanus; and the discovery of penicillin took place in the 1920s. Vaccinations for yellow fever and typhus, along with blood banking and the creation of the heart-lung machine, happened in the 1930s. The antibiotic streptomycin, vaccinations for influenza and polio, and the development of the cardiac pacemaker occurred in the 1940s and 1950s. Vaccinations for measles, mumps, rubella, chicken pox, and pneumonia took place in the 1960s and 1970s.<sup>23</sup> Each of these medical advances produced a tangible impact for the older subgroups, while providing monumental strides in health care for future generations.

Many of the aforementioned diseases had been eradicated and have not been seen or experienced by Generation Y, whereas the older age groups were and may continue to be deeply affected by these conditions. Older generations may have experienced the death of a family member due to influenza, male infertility due to mumps, or postpolio syndrome as the result of acquiring the poliovirus as a child. Although medical breakthroughs have continued to occur throughout the known lifetime of the Generation Y subgroup, such as with the advent of vaccinations for hepatitis or the treatment of AIDS, Generation Y may have been too young to realize the epidemiological impact. Therefore, Generation Y's lack of general knowledge about clinical research, as compared with the older age groups, may be temporally related versus differences in generational values.

As temporal factors relate to the understanding of what is meant by the term "clinical research study" and rating one's knowledge about clinical research, aspects of generationalism do impact social media practice and the perception of clinical trial safety. According to the CISCRP,<sup>6</sup> more than 60% of the 18- to 34-year-old population have engaged in social media forums to learn about clinical research, and while patient recruitment for clinical trial participation presents a significant problem to the biomedical industry, social media usage may open many opportunities for Generation Y to uphold the importance of clinical research and continue to strive toward the pursuit of scientific advancement through education and contribution.

To help solve patient recruitment issues, social media usage offers a valuable marketing tool for sponsors to target a wide range of demographics, especially reaching out to the Generation Y subgroup. For example, in 2014, greater than 80% of persons from Generation Y were Internet users, while more interestingly, Generation Y represented the highest percentage of Internet users (>20%) actively seeking specific information about experimental treatments or medicines.<sup>24</sup> Websites such as ClinicalTrials.gov provide information seekers with

comprehensive resources to learn about clinical studies. Additionally, ClinicalTrials.gov offers users the ability to set up Rich Site Summary or Really Simple Syndication (RSS) feeds to receive trial-related information and updates. However, these web-based conveniences are not social media centered and require the user to actively pursue the content.

Generation Y has grown up during a digital revolution; they value the use of and are sophisticated consumers of technology. Generation Y is composed of e-learners; therefore, websites such as ClinicalTrials.gov appear to be yet another resource in reaching this population of society.<sup>25</sup> Furthermore, in a 2013 Research America poll,<sup>26</sup> 53% of survey respondents reported hearing about clinical trials via the Internet, but they cited lack of trust and information as barriers to clinical trial participation.

Equipped with this information, sponsors knowingly have access to this demographic and should use social media to educate this critical and cynical audience about the value of clinical research. To reinforce this, according to a survey of 500 Generation Y individuals, 68% of Generation Y news is obtained via social media sources; however, 66% of this population is not confident that the news they receive is accurate.<sup>27</sup>

Lack of confidence in information presented via social media sources may directly impact the perception of clinical trial safety as well as present a noteworthy barrier to sponsor marketing and education. Yet, it does yield useful evidence regarding the methods of information exchange for and information-seeking behavior of this generation. They want the facts and are willing to pursue other online resources to ensure the integrity and accuracy of the information. In fact, more than 70% of the Generation Y population use the Internet to seek information about health-related issues.<sup>24</sup>

Most importantly, why does Generation Y represent the highest percentage of the CISCRP 2013 survey<sup>6</sup> respondents not at all willing or not very willing to participate in a clinical research study? Temporal factors have been explored and discussed, coupled with the generational importance placed on technology regarding the perception of clinical trials, but what are the generational thinking and value factors influencing the context of and basis for choices in the milieu of Generation Y clinical trial participation? Overarching themes in the literature are abundant with this generation's defining characteristics.

Generation Y has been coined by some as "Generation Me" and has been deemed, by some reviewers, as having a pampered upbringing, serving to signify the individualistic nature of this cohort.<sup>20</sup> In a recent study evaluating generational changes in "community feeling," Generation Y was found to have greater civic and political disengagement, place more emphasis on materialistic principles, and demonstrate less concern toward helping the public at large than were Generation X and Baby Boomers at the same ages.<sup>28</sup> This information is

further strengthened by the 1994 Trauth et al<sup>1</sup> study findings, which show the then 18- to 34-year-old subgroup (Generation X) was the most willing age group to participate in a clinical research study. Furthermore, the 18- to 34-year-old subjects in the Trauth et al<sup>1</sup> study did not even have comparable access to the Internet for information exchange. Considering that clinical research or investigations are designed to contribute to generalizable knowledge, meaning the greater good of society, it is apparent that the suggested individualistic values that Generation Y upholds would hinder their willingness to participate in a clinical trial.

Moreover, Generation Y has been referred to as harboring a sense of self-centeredness, narcissism, and entitlement. They place greater importance on extrinsic values, as compared to intrinsic values, such as concern for others.<sup>28</sup> For example, in the corporate workplace, they have been cited for their impatient nature, combined with their unrealistic expectations for career advancement, despite job performance.<sup>20</sup> In other corporate circumstances, they need continual positive reinforcement, nurturing, and tangible recognition, to the point of companies hiring “praise teams.” Furthermore, this generational group has been in the spotlight for not taking responsibility for their own actions, while expecting others to pay the consequences of their mistakes.<sup>29</sup>

Thus, this same value system is reflective of and can be applied to and correlated with Generation Y’s lack of willingness toward clinical trial participation. In light of their perceived sense of narcissism and self-centered traits and features, Generation Y may take for granted the altruistic nature of those study participants contributing to the medical sciences—those who are bearing the burdens of clinical research—by demonstrating apathy or simply feeling entitled to reap the benefits of the research. They may lack the sense of shared responsibility or public health impact that their contribution could make; yet, they are very driven by creating tolerance for individualism and advocating for social change.

The generational value and perception differences discussed earlier provide insight into targeted communication custom tailored to the Generation Y subgroup. Patient recruitment advertising and promotion have historically targeted a typical and more traditional adult audience whose perceptions have been shaped by vastly different influences. Acknowledgment and recognition of the unique value differences of the Generation Y audience will play a key role in the successful recruitment of this prospective study volunteer community in the future.

## Conclusions

The analysis of the 2013 CISCRP<sup>6</sup> and 1994 Trauth et al<sup>1</sup> data suggests true generational differences. Generational disparities exist among age groups related to the perceptions of and

willingness for clinical trial participation. Although temporal factors must be taken into account when attempting to understand why Generation Y harbors negative views of and is the least inclined cohort to participate in a clinical trial, generational value factors, versus simply age, certainly offer objective support via corporate and sociological study findings. These conclusions are not offered to cast a negative view about Generation Y. Rather, they are intended to point out some of the differences that exist among generations or age groups, to characterize the impact that these differences may have on individual subgroup willingness to participate in clinical trials, and to offer insight into opportunities to better position patient recruitment messages for prospective Generation Y study volunteers.

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