

Public Interest in Medical Research Participation: Differences by Volunteer Status and Study Type

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Abstract

Purpose: We assessed national levels of public interest in medical research participation (MRP) and factors associated with interest as a healthy volunteer; as a diagnosed volunteer; and in seven study types.

Method: Cross-sectional, Web-based survey of the US population in June 2012. Descriptive statistics estimated interest in MRP and multivariable logistic regression determined associations between respondent-level predictors and interest in MRP.

Results: Of 2,668 respondents (response rate = 61%), 41% were interested in MRP as healthy volunteers and 60% as diagnosed volunteers. Respondents with some college (OR = 1.54, 1.09–2.19) or higher education (OR = 1.86, 1.29–2.70) had higher adjusted odds of interest as healthy volunteers. Non-Hispanic black race (OR = 0.56, 0.37–0.86) and education below high school (OR = 0.57, 0.35–0.92) were associated with lower adjusted odds of interest as diagnosed volunteers. Non-Hispanic black race was associated with lower odds of interest in medication trials as diagnosed volunteers (OR = 0.61, 0.40–0.93).

Conclusions: We found high levels of interest in MRP that contrast with low levels of prior research participation. Interest is higher in medical research involving noninvasive designs. Comparatively lower levels of interest in MRP among non-Hispanic blacks and those with less education raise concerns about disparities in future study enrollment. *Clin Trans Sci* 2014; Volume 7: 145–149

Keywords: research participation, non-Hispanic black, Hispanic, drugs, devices, vaccines, clinical trial behavior, mental health, nutrition, volunteer

Background

Medical research advances the knowledge and practice of clinical medicine, but public participation in medical research in the United States is low.¹ Many US trials experience slow or insufficient enrollment and therefore incur greater-than-expected costs and may fail to meet enrollment goals entirely.² The consequences on clinical care are profound: recently the Institute of Medicine reported that “fewer than 15% of major recommendations in clinical practice guidelines in infectious disease and cardiovascular disease are based on solid evidence.”²

Moreover, racial/ethnic minorities are underrepresented in clinical trials. In order to tackle continuing health disparities,³ research and public research participation must include racial/ethnic minority groups who are often disproportionately affected by diseases such as stroke, heart disease, and HIV/AIDS.⁴ Since 1993, the NIH has called for more balanced representation of the nation’s population in clinical trials,⁵ and a large body of subsequent literature has identified attitudes, barriers, facilitators, and methods to increase specific populations’ participation in clinical research.^{6–14} However, existing evidence about public participation in research commonly focuses on disease-specific and/or minority group patterns,^{15–19} rather than taking a national perspective.

In this study, we examine the public’s interest in medical research participation (MRP) in a nationally representative sample, with oversampling of racial/ethnic minorities in order to obtain robust estimates of their perspectives. We also address the challenge of understanding low public research participation rates by examining public interest in MRP by study type. The purpose of this study was to determine the public’s interest in MRP, and factors associated with MRP as a healthy volunteer with low risks or as a person with a specific condition. A second

objective was to characterize in which type of medical research, ranging from survey questions to DNA sampling, the public is most likely to participate.

Methods

Study sample

This was a nationally representative, cross-sectional, Web-based survey of the US population, conducted in June 2012. GfK/Knowledge Networks fielded the survey using a Web-enabled Knowledge Panel that includes cell-phone-only households,²⁰ employing a 50-state sampling approach that has served as the basis for several peer-reviewed publications.^{20–25} GfK/Knowledge Networks uses probability-based sampling of US Postal Service delivery addresses and provides Internet access for those who wish to participate but do not have computer hardware or Internet access at the time of initial contact; this provision ensures that the study includes households from a wide range of age groups, racial/ethnic groups, and income strata who have different *a priori* probabilities of being Web-enabled households. Households using their own computers and Internet access to complete the survey are enrolled in a points program. At the completion of the survey, Knowledge Panelists received incentive points that are redeemable for gift cards, merchandise, or cash.

Survey respondents reported sociodemographic information, including age, gender, education, household income, insurance status, and race/ethnicity. The investigators designed survey items used in other published work,¹ and included questions about interest in MRP as a healthy volunteer exposed to low risks and if diagnosed with the disease being studied (described hereafter as “diagnosed volunteer”). Using

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Age of respondents (years)	
18–29	18%
30–44	27%
45–59	29%
60+	26%
Gender	
Male	48%
Female	52%
Race/ethnicity	
White, non-Hispanic	69%
Black, non-Hispanic	11%
Hispanic	13%
Other, non-Hispanic	7%
Education	
Less than high school	11%
High school	30%
Some college	29%
Bachelors degree or higher	30%
Annual household income	
Up to \$24,999	19%
\$25,000–\$49,999	24%
\$50,000–\$99,999	35%
\$100,000 or more	23%
Health insurance at time of survey completion	
Private	55%
Public	27%
Other	5%
None	14%
Employment status at survey time	
Working	56%
Not working—retired	18%
Not working—disabled	7%
Not working—other	18%

*Proportions within individual variables may not sum to 100% because of rounding.

Table 1. Characteristics of study respondents ($n = 2,668$)*.

separate questions, we inquired about likelihood of participating in seven different study types, selected by the investigators to span a wide variety of project foci: trials of medications, trials of vaccines, trials of medical devices, tests of DNA/genetic material with information stored in a confidential file, questions about nutrition/eating, questions about behavior, and questions about mental health. The survey items presented hypothetical scenarios and asked about respondent levels of interest in MRP based on the scenario.

For purposes of logistic regression analysis described below, we collapsed the 3-category response options (*very likely, somewhat likely, not likely*) or (*yes, no, unsure*) into 2 categories (*likely, not likely*) or (*yes, no*), respectively.

Statistical analyses

We used descriptive statistics to estimate the proportion of respondents who would consider MRP as healthy volunteers exposed to low risks and as diagnosed volunteers. Subsequently, we focused on the types of studies that respondents would participate in as diagnosed volunteers.

We used bivariate and multivariate logistic regression to determine if there were associations for these outcome variables across the following respondent-level predictors: age, gender, race/ethnicity, annual household income, education, health insurance type, and employment status at the time of survey administration.

The survey partner, GfK/Knowledge Networks, provided sampling weights that we incorporated in all analyses to generate nationally representative estimates for all analyses using Stata, version 12 (Stata Corporation, College Station, TX, USA).

Results

Overall, 2,668 adults participated in this study (response rate 61%). The majority of participants (75.1%) reside in households with their own computers and Internet connectivity. The characteristics of the study sample are presented in *Table 1*.

Interest in MRP by volunteer status

About two out of every five respondents (41%) expressed that they would consider MRP if asked to do so as a healthy volunteer if the risks were low. There were no statistically significant differences in likelihood of MRP as a healthy volunteer associated with respondent age, gender, race/ethnicity, annual household income, health insurance type, and employment status. Respondents with higher education levels indicated higher odds of interest in MRP as healthy volunteers (*Table 2*).

In comparison, three of every five respondents (60%) indicated interest in MRP if they were invited to do so as diagnosed volunteers. In multivariate analyses, non-Hispanic black race and less than high school education were associated with lower odds of interest in MRP as a diagnosed volunteer compared with non-Hispanic white race and high school education, respectively (*Table 3*).

Likelihood of MRP by study type

Respondents were asked about the likelihood of MRP in different study types as diagnosed volunteers. Varying proportions of respondents indicated that they were likely to participate in each study type, with most respondents likely to answer questions about nutrition or eating, and the fewest likely to participate in a vaccine trial (*Table 4*).

Multivariate analyses of likelihood of MRP as a diagnosed volunteer across respondent age, gender, race/ethnicity, household income, education, employment status at survey time, and insurance type were conducted. For trials of medication, non-Hispanic black race was associated with lower odds of interest in MRP compared with non-Hispanic white respondents (*Table 5*). Otherwise, there were no differences in likelihood of MRP by race/ethnicity.

For other types of studies, there were differences in likelihood of MRP related to education and insurance status. For studies involving questions about nutrition or eating, respondents with bachelor degrees or higher were significantly more likely than respondents with only high

	Unadjusted odds ratio (95% CI)	Adjusted* odds ratio (95% CI)
Age (years)		
18–29	1.0 (ref)	1.0 (ref)
30–44	1.17 (0.79)	1.04 (0.68)
45–59	1.03 (0.68)	1.01 (0.65)
≥60	0.89 (0.44)	0.89 (0.48)
Gender		
Male	1.0 (ref)	1.0 (ref)
Female	0.94 (0.73–1.22)	0.95 (0.72–1.25)
Race/ethnicity		
White, non-Hispanic	1.0 (ref)	1.0 (ref)
Black, non-Hispanic	0.72 (0.48–1.07)	0.71 (0.47–1.06)
Hispanic	1.03 (0.68–1.56)	1.11 (0.70–1.76)
Other, non-Hispanic	0.87 (0.51–1.50)	0.74 (0.43–1.27)
Education		
Less than high school	0.66 (0.40–1.08)	0.63 (0.38–1.06)
High school	1.0 (ref)	1.0 (ref)
Some college	1.56 (1.11–2.20)	1.54 (1.09–2.19)
Bachelors degree or higher	1.96 (1.40–2.75)	1.86 (1.29–2.70)
Household income		
Up to \$24,999	1.0 (ref)	1.0 (ref)
\$25,000–\$49,999	0.69 (0.46–1.04)	0.60 (0.39–0.93)
\$50,000–\$99,999	0.95 (0.65–2.15)	0.74 (0.47–1.17)
\$100,000 or more	1.40 (0.93–2.10)	0.90 (0.55–1.49)
Health insurance at time of survey completion		
Private	1.0 (ref)	1.0 (ref)
Public	0.69 (0.51–0.94)	1.04 (0.70–1.54)
Other	0.80 (0.37–1.69)	1.00 (0.44–2.28)
None	0.83 (0.56–1.24)	0.97 (0.62–1.51)
Employment status at the time of survey completion		
Working	1.0 (ref)	1.0 (ref)
Not working—retired	0.57 (0.38–0.84)	0.69 (0.40–1.20)
Not working—disabled	0.77 (0.46–1.30)	0.97 (0.54–1.75)
Not working—other	1.00 (0.72–1.39)	1.20 (0.84–1.71)

*Adjusted for all the other variables listed in the table.

Table 2. Odds of interest in medical research participation as a healthy volunteer.

school education to say they were likely to participate. For studies involving questions about nutrition or eating and questions about behavior, respondents with no insurance coverage were significantly less likely than respondents with private insurance to say they were likely to participate. For studies involving questions about behavior or that collect a DNA sample for databank entry, respondents with less than high school education were significantly less likely than those with only high school education to indicate they were likely to participate (data not shown; available from the authors upon request).

Discussion

To our knowledge, this is the first study to examine rates of US public interest in MRP at the national level without regard to disease processes or clinical settings, and to further characterize that interest across a variety of study types. This analysis provides new perspectives to inform national dialogue about the clinical trials enterprise.

Our main finding was that just under one-half of this nationally representative sample is interested in MRP as healthy volunteers if the risks were low—and that higher proportions of adults would consider participation as diagnosed volunteers rather than as healthy volunteers. This is a novel finding that has not been previously reported. By contrast, the rate of prior MRP nationally is markedly lower at 11%.¹ There were no differences in interest in MRP as a health volunteer by age, race/ethnicity, annual household income, and health insurance type. However, respondents with more than high school education expressed greater interest in MRP than their peers. Our findings suggest that there are many willing and interested potential research participants who would consider MRP if they were invited.

To broaden participation in future medical research efforts, reasons for underenrollment in current trials²⁶ must be identified, including issues related to awareness, access, and eligibility. Another key aspect of enrollment highlighted in this study is the type of research involved, and the finding that very common types of research involving medications and medical devices were the study formats least likely to appeal to the public. Importantly, nutrition and behavioral research that can illuminate key etiologies of diseases such as obesity, heart disease, and diabetes mellitus were the study types most likely to appeal to the public. Another way to view these findings is that respondents were more interested in MRP that is less invasive, and potentially poses less individual risk. Cottler et al. found similar results in a seven-site study of community members' perceptions of health

research when polled by community health workers,²⁷ although their inquiry did not examine as many different types of research as we asked respondents to consider in this study.

We found that non-Hispanic blacks expressed significantly less interest than non-Hispanic whites in MRP as diagnosed volunteers. We also found that non-Hispanic blacks endorsed less interest than non-Hispanic whites if MRP involved testing a medication, and similar levels of interest as non-Hispanic whites for genetic studies. Consistent with our findings, Braunstein found that blacks were less willing to participate in cardiovascular drug trials and that blacks carried a greater level of

	Unadjusted odds ratio (95% CI)	Adjusted* odds ratio (95% CI)
Age (years)		
18–29	1.0 (ref)	1.0 (ref)
30–44	0.91 (0.61–1.35)	0.78 (0.52–1.19)
45–59	0.82 (0.54–1.25)	0.78 (0.50–1.24)
≥60	0.59 (0.37–0.93)	0.74 (0.40–1.37)
Gender		
Male	1.0 (ref)	1.0 (ref)
Female	0.79 (0.61–1.03)	0.77(0.58–1.01)
Race/ethnicity		
White, non-Hispanic	1.0 (ref)	1.0 (ref)
Black, non-Hispanic	0.56 (0.37–0.83)	0.57 (0.37–0.86)
Hispanic	0.84 (0.56–1.27)	0.85 (0.56–1.29)
Other, non-Hispanic	0.88 (0.51–1.52)	0.75 (0.43–1.30)
Education		
Less than high school	0.51 (0.32–0.83)	0.57 (0.35–0.92)
High school	1.0 (ref)	1.0 (ref)
Some college	1.36 (0.96–1.91)	1.32 (0.93–1.87)
Bachelors degree or higher	1.65 (1.17–2.33)	1.38 (0.94–2.00)
Household income		
Up to \$24,999	1.0 (ref)	1.0 (ref)
\$25,000–\$49,999	0.86 (0.57–1.30)	0.70 (0.45–1.08)
\$50,000–\$99,999	1.36 (0.92–2.01)	1.01 (0.64–1.60)
\$100,000 or more	1.82 (1.20–2.77)	1.10 (0.66–1.83)
Health insurance at time of survey completion		
Private	1.0 (ref)	1.0 (ref)
Public	0.57 (0.42–0.78)	0.96 (0.64–1.43)
Other	0.97 (0.46–2.05)	1.31 (0.58–2.96)
None	0.69 (0.47–1.02)	0.79 (0.50–1.26)
Employment status at the time of survey completion		
Working	1.0 (ref)	1.0 (ref)
Not working—retired	0.57 (0.39–0.83)	0.66 (0.37–1.17)
Not working—disabled	0.51 (0.30–0.86)	0.70 (0.39–1.27)
Not working—other	1.09 (0.78–1.51)	1.41 (0.99–2.02)

*Adjusted for all the other variables listed in the table.

Table 3. Odds of consideration of medical research participation as a diagnosed volunteer

Study type	
Questions about nutrition or eating	86%
Questions about behavior	82%
Questions about mental health	80%
Medical device	75%
Medication	70%
Sample of DNA	69%
Vaccine	59%

*Respondents were able to choose more than one study type.

Table 4. Proportions of respondents likely to participate in medical research as diagnosed volunteers, by study type*.

distrust compared to whites.²⁸ Such findings, which may reflect subjects' concerns about being in a study but left untreated, echo the Tuskegee Experiments of 1932–1972.²⁹ More broadly, distrust of the medical system and medical research has been reported in black communities for over a decade.^{6,7,30,31} Whether such distrust translates into less willingness to participate in medical research at the national level is suggested by our findings, but cannot be conclusively determined because we did not specifically ask about this concern.

Of note, Cottler et al. found that blacks were more likely to be interested in MRP in general and specifically more willing to participate in studies requiring blood and DNA samples.²⁷ However, Cottler's study did not make the distinction between respondents' participation as healthy or diagnosed volunteers. Furthermore, our study differs with Cottler's with regard to scope (national vs. seven local sites) and survey method (Web-based, self-administered vs. administered by community health workers).

The chief limitation of this study is that it is a cross-sectional survey. Like other surveys, it can indicate associations but not causal relationships. Additionally, survey respondents were asked about their general interest in participating in certain types of medical research. Since these survey items were presented to participants as hypothetical scenarios, responses may be different when actually faced with the circumstances posed. Nonetheless, patterns we report are consistent with disparate patterns of enrollment in clinical trials by race/ethnicity that have been observed objectively elsewhere.

Conclusions

In this nationally representative survey, we found generally high levels of interest in MRP that contrast with low levels of prior research participation among adults in the United

States. Interest is comparatively high for research efforts that involve questions about nutrition, behavior, and mental health, and markedly lower for trials of drugs, devices, and vaccines. Levels of public participation in research may be increased in the future with greater attention to the public's preferences for particular study types, and with efforts to address racial/ethnic disparities in interest in participating as healthy or diagnosed volunteers, especially among non-Hispanic black adults.

Conflict of Interest

Authors report no conflicts of interest.

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	Medication (95% CI)	Vaccine (95% CI)	Medical device (95% CI)	Nutrition survey (95% CI)	Behavioral survey (95% CI)	Mental health survey (95% CI)	DNA study (95% CI)
Race/ethnicity							
White, non-Hispanic	1.0	1.0	1.0	1.0	1.0	1.0	1.0
Black, non-Hispanic	0.61 (0.40–0.93)	0.77 (0.51–1.16)	0.66 (0.43–1.03)	0.97 (0.56–1.68)	0.99 (0.61–1.60)	1.01 (0.63–1.61)	0.76 (0.49–1.16)
Hispanic	0.96 (0.62–1.51)	1.32 (0.87–2.01)	1.07 (0.67–1.70)	0.92 (0.50–1.69)	1.00 (0.56–1.77)	0.96 (0.55–1.68)	1.39 (0.88–2.20)
Other, non-Hispanic	0.70 (0.40–1.24)	1.08 (0.63–1.83)	0.92 (0.52–1.62)	1.11 (0.48–2.58)	1.06 (0.52–2.15)	1.01 (0.53–1.96)	1.00 (0.53–1.91)

*Adjusted for age, gender, education, household income, health insurance type, and employment status.

Table 5. Adjusted odds of likelihood of research participation as diagnosed volunteer, by study type*.

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