Published in final edited form as:

Alzheimers Dement. 2019 February ; 15(2): 267–272. doi:10.1016/j.jalz.2018.09.005.

Community Perceptions Related to Brain Donation: Evidence for Intervention

Catherine W Striley, Sadaf A Milani, Evan Kwiatkowski, Steven T DeKosky, Linda B Cottler
University of Florida, Gainesville, FL 32610 USA

Abstract

INTRODUCTION: Research progress on neurocognitive disorders requires donation of both healthy and diseased brains. Here we describe attitudes towards brain donation among a large community sample in Florida.

METHODS: HealthStreet, a community engagement program at the University of Florida, used Community Health Workers to assess community attitudes towards research participation, including brain donation.

RESULTS: Over 60% of people, primarily Caucasian and employed, indicated that they would be likely or somewhat likely to donate their brain for research. Those who would be willing to donate were also more likely to be willing to participate in other research studies and to have participated in research.

DISCUSSION: Brain donation will add to the science of disorders of aging, including accurate diagnoses and validation of in vivo biomarkers. Increasing willingness to donate is a first step toward donation. Community populations are willing; CHWs can educate others about the need for this initiative in communities.

Keywords

Alzheimer's; Dementia; Brain Donation; Community Health Worker; Public Health; Epidemiology; Research Perceptions

Introduction

Brain research is needed for progress in preventing and treating neuropathologic disorders, including Alzheimer's Disease (AD). Banked brain tissue has been the basis for many important scientific findings, including the confirmation of diagnoses during life [1] and validation of peripheral or imaging biomarkers [2], and will continue to be important in understanding neurodegenerative diseases on a biological and molecular level.

Corresponding Author: Catherine Woodstock Striley, Department of Epidemiology, College of Public Health and Health Professions, College of Medicine, 2004 Mowry Road, PO Box 100231, Gainesville, FL 32610, 352-273-5359, 352-273-5365 Fax, cstriley@ufl.edu.

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

The importance of brain donation among both healthy and impaired adults will increase as the population ages, and it is expected that the global prevalence of neurocognitive disorders, particularly dementia and AD, will increase [3]. In the US alone, 10,000 people reach the age of 65 each day [4]; by 2035, adults 65 years and older will outnumber children [5]. Pursuing the science needed to treat these disorders successfully requires the donation of brains from people of all ethnic groups and levels of impairment to understand how the brain ages. However, a shortage of such varied brain tissue samples exists [6].

Many factors can affect an individual's likelihood to donate their organs, especially something like the brain, perceived to comprise the essence of humanity. In a qualitative study among spouses of dementia patients in the US, Austrom and colleagues [7] found that most were willing to participate, but willingness was related to who asked for the donation, the time at which the issue was raised, and the quality of communication between the clinicians and caregivers. Other issues affecting decisions to donate included the subject's not wanting to undergo autopsy; philosophical or religious objection to donation; actual or perceived objections from other family members; and the patient's actual or, if deceased, perceived wishes[8]. Focus groups among participants with dementia and their caregivers revealed additional factors discouraging participation, including worry about potential side effects of experimental drugs and a perception that research results were not or would not be communicated to participants [9]. In another study [10], focus group participants believed the donation procedure was too intrusive, and that it would demand too much of the patient. Participants with such responses and questions expressed some distrust of research and researchers; some participants believed the research would not benefit Black communities [10]. In a focus group study among subjects followed in four Alzheimer's Disease Centers, research participants' and family members' concerns and attitudes varied by ethnic group (African American, Chinese, Caucasian, and Latino), religious beliefs, and particular fears about research. For instance, participants of Chinese ancestry expressed a desire for body wholeness; something also expressed by Roman Catholics [11]. Similarly, observant Jews believe that all the body parts must be buried with the person. In their quantitative survey of African American, Caucasian, Asian, and Latino research participants, Boise [11] found that African American ethnicity, concern over respect for the body, concern for the specific process of brain removal, and apprehension about the role of family members decreased willingness to donate.

Reasons to consent were not simply the opposite of reasons to decline. Individuals stated they were interested in advancing scientific knowledge [8,12-15], had a desire to help others [8, 10, 14-15] and wanted information to also help themselves due to having a personal or family history of [8, 10, 15]. Even though people in these studies expressed some concerns with how their bodies would be treated, they still maintained that their desires to help others would be motivating. The opportunity to participate in research and thus to potentially improve health outcomes was appreciated by many, especially in the African Americans queried [11]. Those who worked in medical settings expressed greater comfort and trust in medical research and were more willing to donate than those who did not work in medical settings[10]. More educated and younger people were also more likely to express their likelihood to donate than their counterparts [12-14]. Studies in Australia by Garrick [12] and Glaw [13] found that those who expressed a greater likelihood to participate in brain

donation were also sicker and more likely to have signed up for other organ and tissue donation programs. In one study among neurologically normal African-American minority members aged 65 and older (n=46), participants were asked reasons why they would participate in dementia-related research. 30.8% were motivated “to help others” and 7.7% “to increase scientific knowledge.” A minority (5.1%) were motivated by “participation incentives” such as money or free medical services [16]. About one-third (31.7%) agreed to yearly neurological testing with eventual brain donation [16]. In the previously mentioned Boise Study, having a supportive confidant and understanding what would be done with the brain were related to increased likelihood to donate [11].

Studies that include healthy people are important because Alzheimer’s and dementia research requires “normal” controls with which to compare the brains of those with a clinically diagnosed disorder. Brains from those without manifest clinical symptoms are also important in understanding brain changes that occur because of aging rather than disease. The aim of this paper was to report on the rate of positive attitudes towards brain donation among a community recruited sample of the general adult population in North Central Florida.

Methods

Population:

Data come from HealthStreet, a community engagement initiative at the University of Florida, gathered by Community Health Workers (CHWs). These trained members of the communities in which they live assess community members’ health needs. Training takes about two weeks and each CHW is personally certified by a supervising faculty member before they enter the field, after which they engage community members where they live, work, and recreate. CHWs know how to ensure adequacy of consent, including assessing comprehension of the information presented during the consent process.

After individuals are consented, a bilingual CHW (if needed) interviews people using the HealthStreet Intake Form. The interview takes approximately 20 minutes and elicits information on sociodemographics, health conditions, health concerns, substance use, and willingness to participate in different types of health research studies. Additionally, CHWs asked all participants how willing they would be to donate their brain for research. The brain donation question was added to the intake in 2015; thus, the sample size was reduced to 3,279 out of a total 10,000. Most participants (n=1,942) came from Alachua County (north central Florida); 848 were assessed in Duval County (northeastern Florida) and about 450 assessed in other counties in Florida, including the Miami area.

Measures:

The first question asked of participants was “Florida has the 2nd highest Alzheimer’s disease death rate in the United States and researchers are trying to find out more about this. How likely would you be to donate your brain for research?” with “likely”, “somewhat likely”, and “not all at likely” the options for response. Participants could refuse to answer the question as well. For this analysis, we categorized participants into three groups: those who

were not at all likely to donate their brain for research, those who were somewhat likely, or “likely” to donate their brain for research.

Covariates included in these analyses were sex, age, race, marital status, body mass index (BMI), education, employment, veteran status, household size, and food insecurity (defined below). Sex was coded as male or female. We recorded age, BMI, and household size as continuous variables. Race was recorded as non-Hispanic African American, non-Hispanic White, non-Hispanic Other, and Other. We collapsed marital status into three categories: never married, married, and divorced/separated/widowed. Information on education was elicited by last grade completed; we collapsed this information into less than 12 years versus 12 years or more (equivalent to high school degree or GED and beyond). Information on employment, elicited through the question “are you employed full or part time” and veteran status, were both coded yes or no. The Intake Form contained the question “Have there been times in the last 12 months when you did not have enough money to buy food that you or your family needed?” We categorized answers to this question as food insecure, yes/no.

Statistical Analysis:

SAS 9.4 was used for this analysis. Chi-square tests of independence were used to test group differences by willingness to participate in brain donation. P-values less than 0.05 were considered to be statistically significant.

Results

Of the 3,279 participants who were asked how willing they would be to donate their brain for research, 38.0% (n=1,247) said they would be likely to donate their brain for research, 22.7% (n=745) said they would be somewhat likely to donate their brain for research, and 39.2% (1,287) said they would be not at all likely to donate their brain for research.

Among the three groups (likely, somewhat likely, or not at all likely willing to donate their brain), some demographic differences were noted. First, likelihood to donate was not associated with sex, age of women, BMI or food insecurity (the last possibly a proxy for SES). More of those not likely to donate were younger males and non-Hispanic African American (68.1%). More of those who were likely to donate were veterans compared to the somewhat likely and not likely groups (13.5% vs. 8.9 and 9.0, respectively, $p<0.001$). Those who were somewhat likely to donate reported higher levels of employment compared to those who were likely and not likely (38.0% vs. 34.7% and 32.2%, respectively, $p=0.03$).

Nearly everyone included in these analyses reported being very likely to participate in research, regardless of donation willingness (Table 2). Those likely or somewhat likely to donate were significantly more likely to report past research participation (22.1% and 24.0% vs. 16.3%) and to report more interest in participation in future research (97.7% and 97.5% vs. 91.6%) than those who were not likely to donate. In addition, those who were likely or somewhat likely to donate their brain vs. those who were not at all likely were more willing to participate in studies that only asked questions about their health (97.2% and 96.5% vs 93.3%) or to participate if researchers wanted to see their medical records (94.0% and 92.0% vs 81.6%). Those who were likely or somewhat likely were also more likely, than those who

were not at all likely to donate, to be willing to participate in research if they had to give a blood sample (93.2% and 91.6 vs. 79.4%) or genetic sample (95.9% and 93.0% vs. 80.8%), if they had to take medicine (68.0% and 65.5% vs. 53.3%), if they had to stay overnight in a hospital or clinic (82.5% and 77.3% vs. 62.5%), or if they had to use medical equipment (93.4% and 92.6% vs. 79.4%). This group was also significantly more likely to participate in a study even if they didn't get paid (87.4% and 86.7% vs 70.6%) compared with those who were not at all likely to donate.

Discussion

Within this Southeastern US community sample, more than 6 out of 10 people indicated that they would be likely or somewhat likely to donate their brain for research. Demographically, those who said they would be unlikely to donate their brain were more often Caucasian and less often African American. These differences are consistent with previous findings [10,11]. However, prior literature focused on those already enrolled in Alzheimer's research and/or their caregivers. The current community-based sample allowed comparison of likelihood by employment status; our finding that employed individuals were more likely to be willing to donate their brain than those unemployed is novel. However, we did not find a statistically significant difference in likelihood to donate as a function of food insecurity status and we used food insecurity as a proxy for lower socioeconomic status.

Our finding that veterans were more likely to be willing to donate is consistent with other literature finding high support for research participation among that population [17]. For a number of reasons, it would be highly informative to recruit a large enough sample of Veterans who have been exposed to war trauma and other stressors. It is also a great tribute that they are willing to continue their service to their country through donation. We did not find a statistically significant difference in willingness to donate when grouped by sex and then by age.

As might be expected, those who expressed a higher likelihood of donating their brains also indicated a greater willingness to participate in research under a variety of different research conditions, and were more likely to have already participated in a research study. Those who were somewhat likely or likely to donate their brain were statistically significantly more likely to say they would participate in every research condition we queried. This was true despite all three groups having high rates of likelihood to participate in different types of research. Of note, our community-recruited sample had a higher interest in participation in studies than is commonly assumed. Our previous work has found that lack of interest is not the barrier to participation; rather, most people are never asked to participate [18].

Implicit bias may prevent researchers from asking people to donate their brains because of underlying assumptions. It is highly likely that many people are not aware of the urgent need for brain donations to advance our knowledge of brain health. Yet when people understand how donating their brain might impact the lives of others, they are much more likely to report willingness to donate [8, 10, 14-15]. One has to know that the possibility exists to act on it.

Much of the research on brain donation has been conducted using qualitative methods among older adults who are either already ill or caring for someone with a neurodegenerative disease. A great deal of prior research has also been restricted to attitudes and preferences for when and how to broach the subject [e.g. 7]. Our findings indicate greater openness among the general population to begin such a discussion about research participation, perhaps earlier in the course of a person's life. Organ donation, which has been normalized to the point that one can often donate one's organ, if it becomes appropriate, merely through checking a box and signing one's driver's license or through checking a box on a driver's license application, provides one possible model for promoting the discussion of possible brain donation.

Our findings suggest that younger African American men may be likely to agree to donate their brain if given the opportunity to do so. Given the underrepresentation of minority brains in brain banks, it is very likely that African American males are rarely asked to donate their brain to a brain bank. An intervention study of new outreach efforts among community-dwelling African American males seems warranted. Such an intervention could send paraprofessionals, most preferably from the same communities as the proposed sample, into the community to talk about brain donation, providing information and materials on practical matters and the community benefits that could accrue. As a recent article in the Atlantic articulates "Why my grandmother carried a plastic brain in her purse" [19], such an intervention could help "enhance public awareness and engagement" and more effectively "prevent and treat AD by 2025," two of the 5 goals of the National Alzheimer's Project Act (NAPA) [20, 21].

Conclusions

Brain donation will continue to be vital as the prevalence of neurodegenerative disorders increases in the aging population as well as to take advantage of the remarkable advances in neuroscience and neurotechnology. In this community-based sample of over 2000 individuals, more than half said that they were somewhat likely or likely to be willing to donate their brain for research. Some of the factors affecting an individual's decision to donate their brain appear modifiable and should be addressed; by properly informing individuals about the possibility of brain donation, the process, and the benefits, we can increase the number of both healthy and diseased brain tissue available for research.

Acknowledgements:

This work was supported in part through the National Institutes of Health's Clinical and Translational Science Awards program, which is led by the National Center for Advancing Translational Sciences [UL1TR001427], by the 1Florida Alzheimer's Disease Research Center [NIH P50 AG047266], sponsored by the National Institute on Aging which governs Alzheimer's Disease Research Centers through the National Alzheimer's Coordinating Center, by the Florida Department of Health – Ed and Ethel Moore Alzheimer's Disease Research Program [6AZ05], and by the Department of Epidemiology with funding from the College of Medicine and College of Public Health and Health Professions. Sadaf Milani is funded by the Graduate School Fellowship at the University of Florida. The content is solely the responsibility of the authors and does not necessarily represent the official view of the National Institutes of Health.

References

- [1]. McKhann GM, Knopman DS, Chertkow H, Hyman BT, Jack CR Jr, Kawas CH, Klunk WE, Koroshetz WJ, Manly JJ, Mayeux R, Mohs RC, Morris JC, Rossor MN, Scheltens P, Carrillo MC, Thies B, Weintraub S, Phelps CH. The diagnosis of dementia due to Alzheimer's disease: recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimers Dement*. 2011 5;7(3):263–9. doi: 10.1016/j.jalz.2011.03.005. Epub 2011 Apr 21. [PubMed: 21514250]
- [2]. Ikonomic MD, Klunk WE, Abrahamson EE, Mathis CA, Price JC, Tsopelas ND, Lopresti BJ, Ziolkowski S, Bi W WR, Paljug, Debnath ML, Hope CE, Isanski BA, Hamilton RL, DeKosky ST. Post-mortem correlates of in vivo PiB-PET amyloid imaging in a typical case of Alzheimer's disease. *Brain*. 2008 6;131(Pt 6):1630–45. doi: 10.1093/brain/awn016. Epub 2008 Mar 12. [PubMed: 18339640]
- [3]. Prince M, Bryce R, Albanese E, Wimo A, Ribeiro W, Ferri CP. The global prevalence of dementia: A systematic review and metaanalysis. *Alzheimers Dement*. 2013;9:63–75.e2. [PubMed: 23305823]
- [4]. Alzheimer's Association. FY19-FY21 Strategic Plan. Accessed: May 14, 2018 https://www.alz.org/documents_custom/FY19-21StrategicPlan.pdf
- [5]. The United States Census. An Aging Nation: Projected Number of Children and Older Adults. 3 13, 2018 <https://www.census.gov/library/visualizations/2018/comm/historic-first.html>
- [6]. Samarasekera N, Al-Shahi Salman R, Huitinga I, Klioueva N, McLean CA, Kretschmar H, Smith C, Ironside JW. Brain banking for neurological disorders. *Lancet Neurol*. 2013;12:1096–1105. [PubMed: 24074724]
- [7]. Austrom MG, Dickinson SL-J, Denny SS, Matthews BR, Gao S, Lu Y. Frontotemporal Dementia Caregivers and Researchers: Partnering for Brain Donation. *Am J Alzheimers Dis Other Dement*. 2011; 26(6): 477–483. [PubMed: 22021861]
- [8]. Fonseca MK, Rodrigues-Neto E, Costa ASR, Rockembach MABC, Padilha RS, Fernandez LL, Oliveira FH, Garcia LP, Hilbig A. Assessing families' and patients' attitudes toward brain donation for research purposes in a Brazilian population sample. *Cell Tissue Bank*. 2015; 16:287–294. [PubMed: 25098349]
- [9]. Law E. What motivates patients and carers to participate in dementia studies? *Nurs Older People*. 2013; 25(9): 31–37 Garrick T, Howell S, Terwee P, Redenbach J, Blake H, Harper C. Brain donation for research: Who donates and why? *J Clin Neurosci*. 2006; 13: 524–528 [PubMed: 16678423]
- [10]. Lambe S, Cantwell N, Islam F, Horvath K, Jefferson AL. Perceptions, knowledge, incentives, and barriers of brain donation among African American elders enrolled in an Alzheimer's research program. *Gerontologist*. 2011; 51(1): 28–38. [PubMed: 20679141]
- [11]. Boise L, Hinton L, Rosen HJ, Ruhl M. Will my soul go to Heaven if they take my brain? Beliefs and worries about brain donation among four ethnic groups. *The Gerontologist*. 2017; 57(4): 719–734. [PubMed: 26935242]
- [12]. Garrick T, Sundqvist N, Dobbins T, Azizi L, Harper C. Factors that influence decisions by families to donate brain tissue for medical research. *Cell Tissue Bank*. 2009; 10: 309–315. [PubMed: 19517269]
- [13]. Glaw XM, Garrick TM, Terwee PJ, Patching JR, Blake H, Harper C. Brain donation: who and why? *Cell Tissue Bank*. 2009; 10: 241–246. [PubMed: 19184533]
- [14]. Kuhta T, Zadikoff C, Simuni T, Martel A, Williams K, Videnovic A. Brain donation - What do patients with movement disorders know and how do they feel about it? *Parkinsonism Relat Disord*. 2011; 17: 204–207. [PubMed: 21220205]
- [15]. Schnieders T, Danner D, McGuire C, Reynolds F, Adner E. Incentives and barriers to research participation and brain donation among African Americans. *Am J Alzheimers Dis Other Dement*. 2013; 28(5): 485–490. [PubMed: 23728297]
- [16]. Danner DD, Darnell KR, McGuire C. African American participation in Alzheimer's Disease research that includes brain donation. *American Journal of Alzheimer's Disease and Other Dementias*. 2011;26(6):469–476. doi:10.1177/1533317511423020

- [17]. Kaufman D, Murphy J, Erby L, Hudson K, Scott J. Veterans' attitudes regarding a database for genomic research. *Genet Med*. 2009; 11:329–337. [PubMed: 19346960]
- [18]. Cottler LB, McCloskey DJ, Aguilar-Gaxiola S, Bennett NM, Strelnick H, Dwyer-White M, Collyar DE, Ajinkya S, Seifer SD, O'Leary CC, Striley CW, Evanoffl B. Community needs, concerns, and perceptions about health research: findings from the Clinical and Translational Science Award Sentinel Network. *Am J Public Health*. 2013; 103:1685–92. [PubMed: 23409875]
- [19]. Bramson D. Why My Grandmother Carried a Plastic Brain in Her Purse. *The Atlantic*. 4 11, 2018 <https://www.theatlantic.com/science/archive/2018/04/grandmother-brain-donation/557510/>
- [20]. National Institute of Aging. NIA and the National Plan to Address Alzheimer's Disease. Accessed: May 14, 2018 Available from: <https://www.nia.nih.gov/about/nia-and-national-plan-address-alzheimers-disease>
- [21]. U.S. Department of Health & Human Services. National Alzheimer's Project Act. 6 13th 2018 Available from: <https://aspe.hhs.gov/national-alzheimers-project-act>

Highlights

- Brain donation of healthy and diseased brains is essential to advance research
- Community members were mostly likely or somewhat likely to donate their brain
- Community health workers can increase awareness of the need for brain donation

Research in Context

Systematic review: We explored previous peer-reviewed publications for factors relating to attitudes towards brain donation. While previous work has suggested individuals are willing to participate in brain donation, barriers to donation exist.

Interpretation: Over half of community members assessed by Community Health Workers as a part of a community-engaged research program were likely or somewhat likely to be willing to donate their brain for research. Those who indicated that they were willing to donate were also more likely to be interested and willing to participate in multiple types of research studies.

Future directions: As the population ages, the prevalence of neurocognitive disorders will increase. Healthy and disease brains are vital to advance research on these disorders. Some barriers to brain donation are modifiable. Community health workers who foster relationships with community members can educate the public on the importance of brain donation and address barriers.

Table 1:

Demographics of Likely vs Somewhat Likely vs Not At All Likely (n=3279).

	Overall (n=3279/or as noted)	Likely (n=1247; 38.0%)	Somewhat Likely (n=745; 22.7%)	Not At All Likely (n=1287; 39.3%)	P- value
Gender (n=3264)					
Female	2139 (66.5%)	787 (63.6%)	501 (67.3%)	851 (66.4%)	0.17
Male	1125 (34.5%)	451 (36.4%)	243 (32.7%)	431 (33.6%)	
Average Age (n=3278) (±SD)					
Female	47.6 ± 17.3	48.2 ± 17.2	47.8 ± 17.1	46.9 ± 17.4	0.28
Male	48.4 ± 17.0	49.9 ± 16.6	49.3 ± 15.5	46.4 ± 18.1	0.01
Race (n=3268)					
non-Hispanic African-American	1664 (50.9%)	438 (35.2%)	354 (47.6%)	872 (68.1%)	<.0001
non-Hispanic Caucasian	1191 (36.4%)	618 (49.7%)	290 (39.0%)	283 (22.1%)	
non-Hispanic Other	129 (4.0%)	56 (4.5%)	30 (4.0%)	43 (3.4%)	
Hispanic	284 (8.7%)	131 (10.5%)	70 (9.4%)	83 (6.5%)	
Marital Status (n=3264)					
Never Married	1349 (41.3%)	475 (38.2%)	316 (42.5%)	558 (43.7%)	0.02
Married	760 (23.3%)	302 (24.3%)	184 (24.8%)	274 (21.5%)	
Divorced/Separated/Widowed	1155 (35.4%)	468 (38.1%)	243 (32.7%)	444 (34.8%)	
Body Mass Index (±SD)					
Female (n=3236)	30.2 ± 8.3	29.8 ± 8.4	30.1 ± 8.3	30.5 ± 8.2	0.30
Male (n=3269)	28.0± 6.6	27.9 ± 6.2	28.7 ± 7.1	27.7 ± 6.8	0.12
Other Sociodemographic Characteristics					
12+ Years of Education	2655(81.0%)	1038 (83.2%)	628 (84.3%)	989 (76.9%)	<0.001
Currently Employed (n=3269)	1126 (34.4%)	431 (34.7%)	283 (38.0%)	412 (32.2%)	0.03
Veteran Status (n=3268)	348 (10.7%)	167 (13.5%)	66 (8.9%)	115 (9.0%)	<0.001
Mean household size (including participant)(±SD) (n=3273)	1.8 ± 2.3	1.8 ± 2.7	1.6 ± 2.1	1.9 ± 2.1	<0.001
Food Insecure (not enough \$ to buy food) (n=3263)	1504 (46.1%)	602 (48.4%)	307 (41.5%)	595 (46.5%)	0.09

Table 2:

Research Perceptions of Likely vs Somewhat Likely vs Not At All Likely (n=3279 when complete).

	Overall (n=3279)	Likely (n=1247; 38.0%)	Somewhat Likely (n=745; 22.7%)	Not At All Likely (n=1287; 39.3%)	P-value
Ever been in a health research study (n=3261)	660 (20.2%)	274 (22.1%)	178 (24.0%)	208 (16.3%)	<0.001
Interested in participating in research (n=3276)	3120 (95.2%)	1215 (97.7%)	726 (97.5%)	1179 (91.6%)	<0.001
Would you volunteer for a health research study...					
that only asked questions about your health? (n=3274)	3127 (95.5%)	1209 (97.2%)	719 (96.5%)	1199 (93.3%)	<0.001
if researchers wanted to see your medical records? (n=3258)	2889 (88.7%)	1168 (94.0%)	679 (92.0%)	1042 (81.6%)	<0.001
if you had to give a blood sample? (n=3271)	2860 (87.4%)	1160 (93.2%)	681 (91.6%)	1019 (79.4%)	<0.001
if you were asked to give a sample for genetic studies? (n=3269)	2920 (89.3%)	1191 (95.9%)	692 (93.0%)	1037 (80.8%)	<0.001
if you might have to take medicine? (n=3257)	2008 (61.7%)	842 (68.0%)	482 (65.5%)	683 (53.3%)	<0.001
if you were asked to stay overnight in a hospital or clinic? (n=3272)	2404 (73.5%)	1028 (82.5%)	573 (77.3%)	803 (62.5%)	<0.001
if you might have to use medical equipment? (n=3271)	2869 (87.7%)	1163 (93.4%)	687 (92.6%)	1019 (79.4%)	<0.001
Would you participate in a study if you didn't get paid? (n=3264)	2633 (80.7%)	1088 (87.4%)	644 (86.7%)	901 (70.6%)	<0.001

* Note that these are column percentages, which are descriptive statistics of the research perceptions between the three groups "Not At All Likely" vs "Likely" vs "Somewhat Likely."