

# Factors Associated with the Likelihood of Providing Cerebrospinal Fluid for a Medical Research Study in an Ethnically Diverse Sample of Adults

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## INTRODUCTION

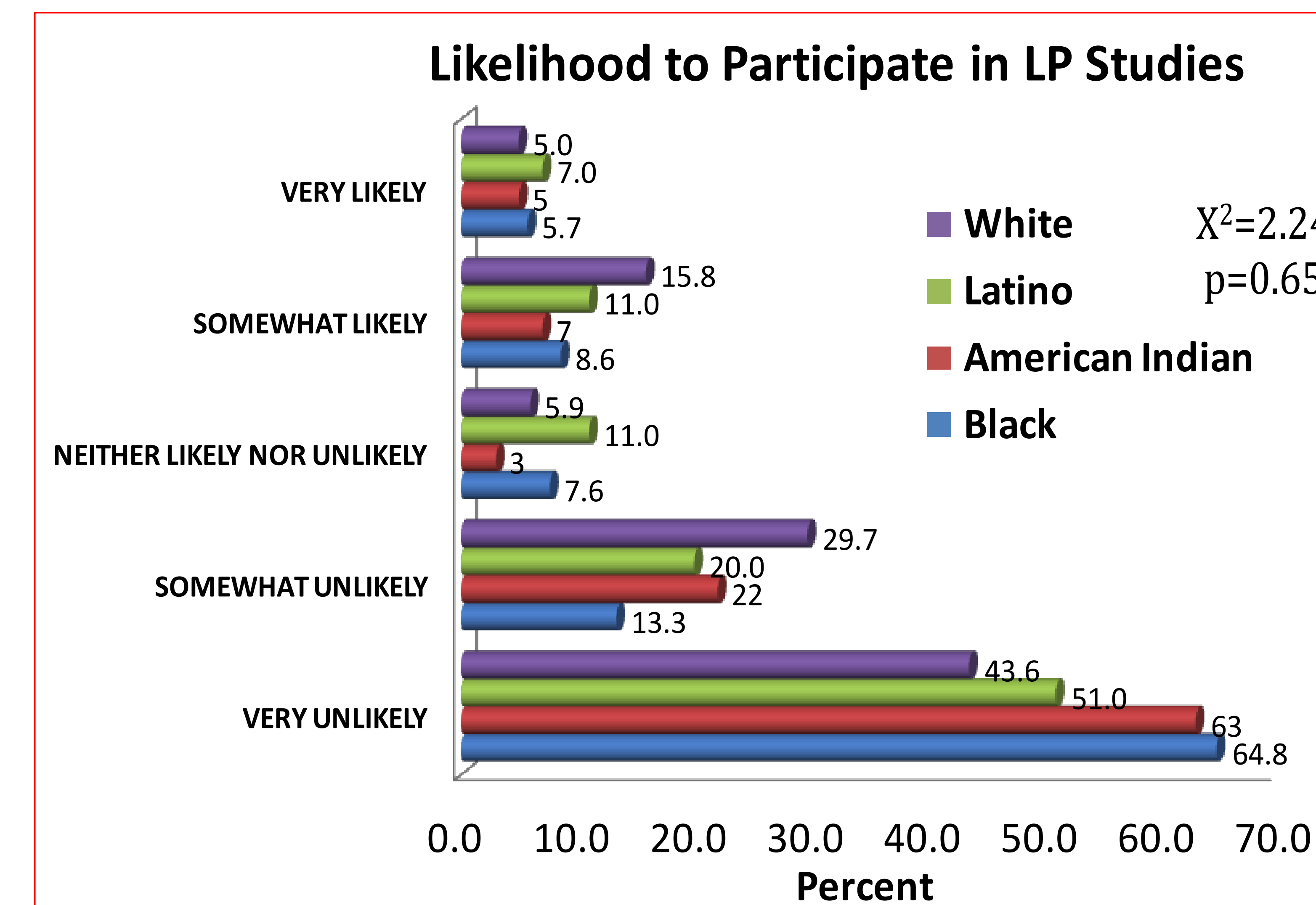
- The use of biomarkers sensitive to neuropathological changes in the brain has been promoted as a path to presymptomatic diagnosis as well as greatly enhanced ability to evaluate response to treatment.
- Autopsy, PET amyloid imaging and cerebrospinal (CSF) fluid studies have shown that approximately one third of clinically normal older individuals harbor evidence of amyloid plaque accumulation.
- In light of the expanding empirical support for the use of CSF biomarkers, a growing number of studies request CSF collection from cognitively normal individuals, persons with mild cognitive impairment and individuals with AD.
- Despite the clinical significance of CSF analysis in the diagnosis and prediction of AD, a major drawback in most studies is the willingness of participants to undergo a lumbar puncture (LP).
- Data on factors affecting the decision to participate in studies requiring a LP are limited. We examined the effect of socio-demographic factors and concerns related to trust in medical research on willingness to participate in research requiring CSF.

## PARTICIPANTS and METHODS

- Sample:** Item responses to a comprehensive survey questionnaire from an ethnically diverse sample of 410 adults (Mean Age: 44.7 (16.7) years ) were used in the analysis. The sample included 25.6 % African Americans , 24.4 % Latinos, 24.4 % American Indians , 24.6% Whites. All participants were Wisconsin residents interviewed by telephone between February 1 and April 30, 2014.
- Survey:** The 96 item survey included items assessing self rated health, health conditions and concerns, likelihood of participation in survey studies, biomarker studies (saliva, blood, CSF, tissue) and clinical trials, factors affecting participation including research related concerns, religious beliefs, trust, prior research participation, and prior blood donation and consent for organ donation.
- Survey Development:** Some survey items were drawn from prior published surveys, items were also developed based on 80 key informant interviews conducted, samples were stratified by gender, age and education: approximately 20 interviews were completed with each of the four racial/ethnic groups. Sixty-four cognitive interviews were conducted to further refine the survey items and response options.
- Analysis:** A confirmatory factor analysis (CFA) 1 was used to create a latent predictor measuring trust in medical research. Other observed predictors included: concerns about infection and physical pain, Family member with AD, ethnic/racial background, income, education, age, and gender. A logistic ordinal model was applied to study the effect of both latent and observed predictors on the “propensity” to participate in CSF studies. The model also examined the effect of race/ethnicity on both trust and propensity of participation outcomes (see Figure 1).

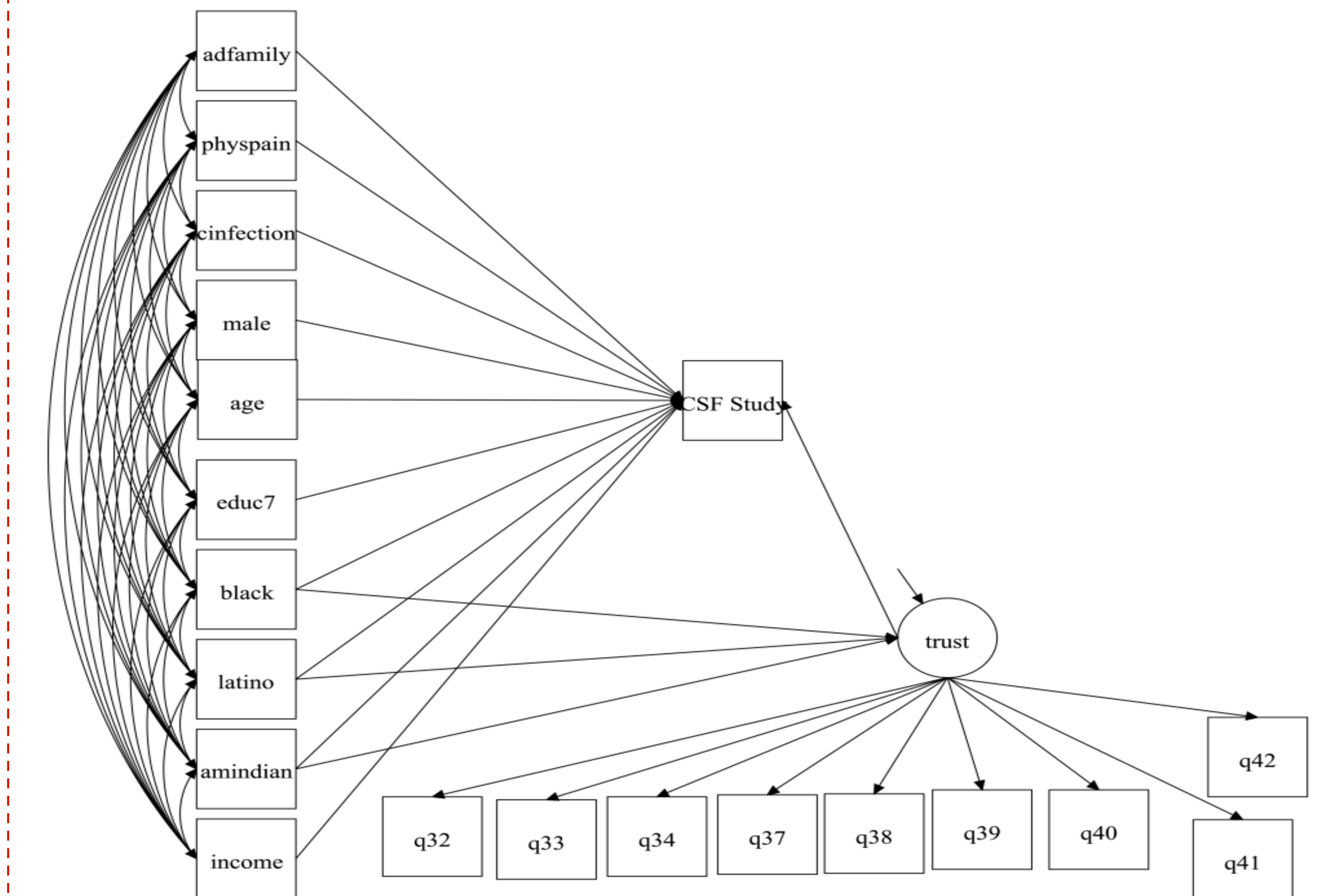
## SAMPLE CHARACTERISTICS

Racial group (N=410)		
Black	105	25.6
Latino	100	24.4
American Indian	100	24.4
White	101	24.6
Other	4	1.0
Educational status (N=410)	N	%
Grades 1 through 8 (Elementary)	5	1.2
Grades 9 through 11 (Some high school)	30	7.3
Grade 12 or GED (High school graduate)	92	22.4
College 1 year to 3 years (Some college or technical school)	135	32.9
4-year college graduate	61	14.9
Graduate work	25	6.1
Gender (N=410)		
Female	268	65.4
Male	142	34.6
Family Income (N=389)		
\$20,000 or less	148	38.0
\$20,000 - \$40,000	94	24.2
\$40,000 - \$60,000	57	14.7
\$60,000 - \$70,000	22	5.7
\$70,000 - \$90,000	35	9.0
\$90,000 or more	33	8.5
Age (N=407)	Mean	SD
	44.7	16.7



- Concern about pain and the latent trust score were the best predictors ( $p < 0.001$ ) of the propensity to participate in CSF studies.
- Younger subjects were less willing to participate than older subjects ( $p=0.030$ ) and Latinos demonstrated more interest than Whites in CSF studies ( $p=0.017$ ).
- Subjects with a higher level of education were less likely to provide a CSF sample than subjects with lower education ( $p=0.016$ ).
- Having a family member with AD did not influence the likelihood to participate.
- The direct effects of race/ethnicity on trust in medical research were highly significant ( $p < 0.001$ ).
- Trust significantly mediates the relationship between race/ethnicity and likelihood of participation.

Figure 1. Pictorial representation of the model.



The indicators for the construct trust were: Q32-Trust in medical researchers; Q33-Trust in the best interests of participants from own racial or ethnic group; Q34-Researchers work to make participants safe; Q37- Information is not hidden; Q38-Participants are treated like guinea pigs; Q39-Participants are told everything about risks; Q40-Participants are treated the same as others; Q41-Researchers work to keep information private/secure; Q42- Information is used to confirm stereotypes.

## CONCLUSIONS

- Although overall willingness to participate in studies involving CSF donation was low, we found interesting and unexpected variations among the four racial/ethnic groups surveyed.
- Results of this study identified both common and group specific barriers to LP studies.
- The analysis also identified issues that can be used to inform tailored recruitment strategies designed to increase the propensity to participate in studies requesting CSF.

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