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Lisa Chan

Justin Cottrell

Pamela Denny-Griffith

Debra Roth

Nora Stephany

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Attitudes Toward a Presumed Consent Organ Donation System

Lisa Chan, BS; Justin Cottrell, BS; Pamela Denny-Griffith, BS, MD; Debra Roth, BA; Nora Stephany, BS;
Noha Daher, DrPH; Kenrick C. Bourne, DrPH, PA-C

Purpose: Obtaining consent for post-mortem organ donation is a complicated process, and the current system for obtaining consent has not been very effective in procuring sufficient transplantable organs for the current demand. A streamlined method of organ procurement, such as presumed consent, is needed to simplify this process and increase the number of available organs for donation. The purpose of this descriptive study was to evaluate the public's attitudes toward a presumed consent system of organ donation. **Methods:** A convenience sample of 275 adults, aged 18 years or older, was recruited from public establishments in California. Subjects were required to understand, speak, read, and write English fluently. Data was obtained using a survey that consisted of statements regarding various aspects of presumed consent, in particular, and organ donation, in general, using a 5-point Likert scale, with 1=Strongly Agree and 5=Strongly Disagree. The survey also included questions about the subject's age, income level, gender, educational background, race/ethnicity, and religious and political affiliation. **Results:** We found significant differences regarding the opinions toward presumed consent and organ donation based on race, gender, religious affiliation, and political affiliation ($p < .05$). Blacks/African Americans were most likely to be against presumed consent ($\chi^2=17.4$, $p=.002$) and organ donation ($\chi^2=47.4$, $p < .001$) after death as compared to other races. Income level was also a contributing factor, though its effect on opinion was not statistically significant. **Conclusion:** These findings can help increase public awareness of the issues of presumed consent and organ donation, and indicate the need for public education on the subject of organ donation.

INTRODUCTION

The Organ Shortage Crisis

The shortage of organs for donation continues to be problematic within the medical establishment, especially in developed countries,

Lisa Chan, Justin Cottrell, Pamela Denny-Griffith, Debra Roth, and Nora Stephany are students in the Physician Assistant Program, School of Allied Health Professions, Loma Linda University.

Noha Daher is an Associate Professor of Research and Statistics; and Kenrick C. Bourne is an Assistant Professor and Chairman of the Department of Physician Assistant Sciences, School of Allied Health Professions, Loma Linda University.

such as the United States. This problem is primarily attributed to an insufficient number of consenting donors available to provide viable organs to patients. The number of people waiting for organs is increasing at three times the rate of available donor organs.¹ The resulting shortage has more than 83,000 people waiting for solid organs (e.g. heart, lung, liver, kidney, or intestine).² The median waiting time for patients 35 – 49 years of age is 205 days for a heart, 882 days for a lung, and 911 days for a liver.² In 2002, 6,187 people on the United States organ transplant waiting list died, while on the waiting list.³ If the American public is willing to accept a change in the process for obtaining organs, many lives could be saved.⁴ The process of presumed consent might

allow for an organized and practical method of organ procurement. The present system of “opting-in” (also known as “express donation”) allows a patient to voluntarily consent to organ donation prior to death, or alternatively allows next-of-kin to consent on behalf of the decedent at death. Ultimately, the final decision is almost always relegated to the family, even if the decedent signed a donor card or opted for organ donation by legal endorsement.⁵ Only about half of the families who are approached regarding organ donation from their recently deceased relative will agree to have organs removed from the body.⁵

Ethics and Presumed Consent
Presumed consent must be based on a reasonable and convincing

assumption that the patient was properly informed about the process and consequences of organ donation. Only if the patient did not object to doing so prior to death would it be justified to assume that the patient would want to donate his/her organs. According to the ethical principle of justice, consent can only be "presumed" when 1) individuals are truthfully informed, and 2) they are given an opportunity to "opt-out" of donating organs.⁶ Presumed consent (also known as "opting-out") assumes that all individuals consent to be organ donors unless they specifically refuse to donate prior to death. A recently deceased person is presumed to have consented to organ/tissue recovery if he/she had not pre-registered a refusal to do so. Next-of-kin would not be able to override this presumption under any circumstance.⁷

Other Studies on the American Public's Attitudes toward Presumed Consent

Members of the International Society for Heart and Lung Transplantation were polled about how to improve organ donation. Of the 739 respondents, 75% supported presumed consent, and 39% identified it as the best way to increase donation.⁸ While this study supported presumed consent, it must be noted that the sample consisted of transplant professionals from the United States and other countries, and these professionals are more likely to favor any system that increases transplantation rates.⁸ In addition, other countries do not have the same principles of autonomy as the United States.⁸

Spital⁹ conducted a study to determine whether young, educated people would support presumed consent as a solution to the organ shortage. Over 60% of the participants favored presumed consent. In this study, researchers

also reported that it was difficult to discern whether a participant's age or educational level had a greater impact.⁹ Klenow and Youngs¹⁰ reported that respondents 25 years of age or younger were the most supportive of presumed consent and those aged 25 to 44 years were the least supportive. A study by Conesa et al¹¹ also indicated that age and educational level were important factors in determining support for or against presumed consent. Only 24% of their sample supported the process of presumed consent. Subjects 40 years of age or older with a low educational level had a negative attitude toward the system of presumed consent.

Few studies have addressed the general public's opinion toward presumed consent.⁸⁻¹¹ A study that can be generalized to the public is necessary. Profiles of non-supporters can then be developed, and this population can be targeted for public education campaigns. The purpose of this study was to assess the public's opinion toward a presumed consent system of organ donation.

METHODS

Subjects

A convenience sample of 275 adults, aged 18 years and older, was recruited from public establishments in Redlands and Huntington Beach, California. Participants were required to understand, speak, read, and write English fluently.

Instruments

The instrument used for this study was a survey (see Appendix). In the survey, subjects were asked whether or not they would be in favor of presumed consent. Items in the survey consisted of statements regarding various aspects of presumed consent, in particular, and organ donation, in general. Answers were recorded on a 5-point Likert Scale, which ranged

from 1-5 (1=Strongly Agree, 5=Strongly Disagree). An open-ended statement was provided so subjects could write any reasons why they would or would not support presumed consent. The second part of the survey was comprised of questions regarding demographic characteristics (age, income level, gender, educational level, race/ethnicity, religious affiliation, and political affiliation).

Procedures

An information letter stating the purpose and benefits of the study was attached to the survey. Return of the completed survey from a subject signified his/her consent to participate. An identification number was assigned to each survey to ensure the anonymity of the subjects.

Data Analysis

The results were analyzed using the Statistical Package for the Social Sciences (SPSS) version 12.0.¹² We summarized data using frequencies and relative frequencies. To determine whether opinions regarding presumed consent were associated with age, income level, gender, educational level, race/ethnicity, religious affiliation, or political affiliation, a Chi-square test for independence was conducted. The level of significance was set at .05

RESULTS

Two hundred seventy-five respondents completed the survey. The demographic characteristics of the sample are shown in Table 1. There was an equal representation of males and females, 55% of the respondents were 18-35 years of age and almost 91% had an educational level of some college or higher. Almost 40% of respondents were in the \$60,000+ annual income range, 55% were Caucasian, 83% had no religious affiliation, and Republicans,

Table 1. Characteristics of the Sample (n=275)

Demographic Variable	Frequency (%)
Gender	
Male	140 (50.9)
Female	135 (49.1)
Age (Years)	
18-35	151 (54.9)
36-50	67 (24.4)
51-65	52 (18.9)
66+	5 (1.8)
Educational Level	
Less than High School	3 (1.1)
High School Graduate	23 (8.4)
Some College/Associate Degree	86 (31.3)
Bachelor's Degree	96 (34.9)
Master's or Doctoral Degree	67 (24.4)
Annual Income Range	
\$0-20,000	52 (18.9)
\$21,000-39,000	54 (19.6)
\$40,000-59,000	60 (21.8)
\$60,000+	109 (39.6)
Race/Ethnicity	
White/Caucasian	151 (54.9)
Hispanic/Latino	31 (11.3)
Black/African American	29 (10.5)
East Asian/Pacific Islander/South or Asian Indian	47 (17.1)
Other Races*	17 (6.2)
Religious Affiliation	
Protestant†	73 (26.5)
Catholic	63 (22.9)
Non-Denominational Christian	23 (8.4)
Seventh-day Adventist	12 (4.4)
No Affiliation	83 (30.2)
Other Believers‡	21 (7.6)
Political Affiliation	
Republican	87 (31.6)
Democrat	81 (29.5)
No Affiliation	98 (35.6)
Independent	5 (1.8)
Other Affiliation§	4 (1.5)

*Includes Middle Easterners and individuals of mixed ancestry.

†Includes members of the following Protestant denominations: Baptist, Methodist, Lutheran, Pentecostal, Anglican, and Episcopalian.

‡Includes the following: Jewish, Muslim, Buddhist, Jehovah's Witness, Baha'i, Mormon, and Atheist.

§Includes members of the Libertarian Party in Canada, UK, and Australia

Table 2. Religious Affiliation vs. Opinion Regarding Whether Presumed Consent Will Effectively Increase the Number of Available Organs for Transplantation* (n=275)

Religious Affiliation	Strongly Agree/Agree		Neutral		Strongly Disagree/Disagree	
	Frequency	(%)	Frequency	(%)	Frequency	(%)
Protestant/Catholic/Seventh-day Adventist	124	(83.8)	17	(11.5)	7	(4.7)
No Affiliation	73	(88.0)	5	(6.0)	5	(6.0)
Non-Denominational/Other Believers	30	(68.2)	8	(18.2)	6	(13.6)

* $\chi^2=9.58$, $p=.048$.

Democrats, and those with no political affiliation were almost equally represented. Overall, 46.9% (n=129) of respondents were in favor of presumed consent.

Differences in Opinion Based on Gender, Age, Education, and Income

A greater proportion of males than females agreed with the statement, “*Presumed Consent* will increase the chance that organs will be taken from people who did not originally want to donate” (74.3% vs. 54.8%; $\chi^2=11.5$, $p=.003$). There were no significant differences in the opinions of subjects regarding presumed consent or organ donation due to age or educational level ($p>.05$).

There were no statistically significant differences in responses from the different income level groups for any of the questionnaire items ($p>.05$). A larger proportion of respondents in the \$0-20K income level group, however, were opposed to presumed consent compared to the other income level groups (69.2% in the \$0-20K group vs. 46.3%, 48.3%, and 51.4%, respectively, in the \$21K-39K, \$40K-59K, \$60K+ groups; $\chi^2=7.1$, $p=.07$).

Differences in Opinion Based on Race, Religion, and Political Affiliation

A majority of Black/African American respondents were against presumed consent (86.2%) followed by individuals in the

“Other races” group (64.7%). This group consisted primarily of Middle Easterners and individuals of mixed ancestry. Most of those who were in favor of presumed consent were White/Caucasians (54.3%; $\chi^2=17.4$, $p=.002$).

Most of the Hispanics (93.5%) agreed with the statement, “I believe prior explicit consent should always be required from a person before taking organs from his/her body”. They were significantly different when compared to other races ($\chi^2=22.3$, $p=.004$). White/Caucasians (78.1%) were more likely to agree with the statement, “I would agree to donate my organs prior to my death”, while most of those who disagreed were Black/African American (41.4%; $\chi^2=47.4$, $p<.001$).

A higher proportion of subjects in the “Other races” group and Hispanic/Latinos agreed with the item, “*Presumed Consent* will restrict individuals’ freedom to choose whether or not to donate organs” (64.7% and 61.3%, respectively) as compared to White/Caucasians and East Asian/Pacific Islander/East Indians ($\chi^2=16.8$, $p=.03$). The largest proportions of respondents who agreed with the statement, “*Presumed Consent* will violate many individuals’ personal, cultural, and/or religious beliefs” were Middle Easterners, individuals of mixed ancestry, and Black/African Americans (82.3% and 72.4%, respectively) compared to the other racial groups

($\chi^2=18.4$, $p=.02$).

There was a significant difference in opinion among the various religious groups for the statement, “*Presumed Consent* will effectively increase the number of available organs for transplantation” (Table 2). Protestants/Catholics/Seventh-day Adventists and subjects with no religious affiliation were more likely to agree with this statement (83.8% and 88%, respectively) compared to the “Other believers” group, (which included Jewish, Muslim, Buddhist, Jehovah’s Witness, Baha’i, Mormon, and Atheist members) ($\chi^2=9.6$, $p=.048$).

A higher proportion of subjects who had no political affiliation or were affiliated with the Libertarian Party (of Canada, UK, and Australia) were in favor of the statement, “I believe that prior explicit consent should always be required from a person before taking organs from his/her body after death” (83.7% and 77.8%, respectively) compared to the other political affiliations ($\chi^2=15.2$, $p=.02$).

Subjective Opinions in Favor of Presumed Consent

Respondents in this study were also given the opportunity to express their personal opinions regarding presumed consent. Encouraging personal accountability, altruism toward those who need organs the most, and the salvaging of otherwise “wasted” organs were the

primary reasons behind support for presumed consent. One strong supporter reported that presumed consent should be a national standard, and proposed a design for an internet-based organ registry system that could accommodate such a policy. Many of those who were in favor of presumed consent, however, thought that it should be modified to account for individuals whose religious beliefs forbade organ donation after death, and that the wishes of family or next-of-kin should still be considered. A common theme was the opinion that keeping organs intact in the body after death was selfish, especially if they could be used to save another's life. Other reasons for supporting presumed consent were the following: presumed consent would place the primary responsibility to register a refusal on those who are against donation, rather than those who are willing, allowing for freedom of choice; persons in favor of donation could readily donate if they meant to, but had never taken the time to fill out the required paperwork; the burden of making a choice on behalf of the deceased would be lifted from the family's shoulders; presumed consent would force everyone to be more proactive in stating their wishes regarding organ donation; saving lives is of utmost humanitarian importance when it comes to salvaging organs from the deceased; and presumed consent would be an ideal system for a rational society.

Subjective Opinions against Presumed Consent

Written comments against presumed consent included concerns about invasion of privacy; lack of autonomy or freedom to make an informed choice; religious or cultural beliefs; and sovereignty over one's own body, even after death. Many believed that a policy like presumed consent would not

be well received by society, would be poorly understood or implemented by an uninformed public, and therefore, would not be a plausible option to alleviate the current shortage of organs. Other reasons for opposition to presumed consent were the following: an increased possibility for exploitation and illicit financial gain by unscrupulous people involved in the trafficking of organs, and increased chance of performing unnecessary surgery; family involvement in decision-making should always be maintained and protected; presumed consent fails to account for people with special circumstances who might be incapable of legally making their own decisions (e.g. those with mental disorders or deficits, children, immigrants); there is a high potential for "loopholes" in such a policy which could invite excessive litigation; organ transplants don't always improve patients' quality of life; it is too impractical for people to "opt-out" of organ donation as required by presumed consent; recording and keeping track of individual preferences is complicated; ethical presumptions are inappropriate and unreasonable; it would be too expensive and impractical to educate the entire public about presumed consent; there is a lack of pro-active initiative within most of the public to express their wishes regarding organ donation; genetic engineering might be a superior method of procuring organs for transplant; it would not be right to receive organs donated from someone who originally did not want to donate; and the issue of presumed consent is simply fraught with excessive moral and legal implications.

DISCUSSION

Over half (53.1%) of the respondents in this study were

opposed to presumed consent. This may be explained by the high value that Americans place on freedom of choice and individual autonomy.⁷ Income was a contributing factor in whether one was for or against presumed consent. Those in the lowest income bracket (\$0-20K) were more often against this policy than those in other income groups. This may be explained by the fact that income level is often related to education, and those with a lower educational level might be less likely to approve of presumed consent.¹¹ Another possible explanation for subjects' opposition to presumed consent could be their unwillingness to let this policy determine the fate of their organs without being given the autonomy to proactively decide for themselves.⁷

Gender played a role only in whether one believed that presumed consent would increase the chance that organs would be taken from people who did not originally want to donate. Males were much more likely to agree with this statement than females. This may be due to gender differences in altruism. In line with these results, a prior study showed that women are more altruistic than men, and therefore may be more likely than men to feel that others would actually want to donate organs.¹³

Race was the biggest determinant in influencing one's opinions regarding presumed consent and organ donation. Blacks/African Americans and individuals in the "Other races" category were most likely to be against presumed consent and organ donation after death. The opposition to presumed consent and organ donation among Blacks/African Americans may be explained by a carry-over of feelings of discrimination, distrust, and oppression this group may have harbored toward the medical establishment during past decades

of racism and exploitation in America. Examples of exploitation by the medical establishment include the Tuskegee Syphilis Study of the 1940s, the ante-bellum use of slaves in medical experiments, and the reported non-consensual use of Blacks' remains for dissection.¹⁴ Presumed consent and the harvesting of organs after death may have been regarded as another example of the dominant "White American" establishment threatening to take away the hard-won freedoms and rightfully owned "property" of the African American people, presumably for the benefit of white people and not other blacks. In addition, Siminoff et al¹⁵ show that blacks are more likely to believe that rich people receive organs more often than others, and that doctors would not try as hard to save a black person's life if they know he/she is an organ donor. Educational efforts focused on African Americans should emphasize that they are most affected by the shortage of donor organs. Siminoff and Arnold¹⁶ indicate that Blacks are more likely to suffer end-stage renal disease and have a longer waiting time on kidney transplant lists, which results in higher morbidity and mortality as compared to other races.

Hispanics/Latinos and individuals in the "Other races" group felt that presumed consent would restrict personal freedom to choose whether to donate organs. This may be due to cultural differences and religious beliefs. Middle Easterners, who were also Muslim, may have adhered to the Islamic belief that the body is not human property and should be returned to the Creator intact upon death.¹⁷ Religious affiliation appeared to have an influence on the opinion that presumed consent will increase the number of available organs for transplantation. "Other believers" were less likely to favor presumed consent

compared to the other groups. This may be due to the fact that this group included Jewish and Muslim individuals who do not favor organ donation. Possible reasons for these beliefs include the dictates of Islam which require the body to be buried intact and the perception of some Jews that organ donation is against Jewish law.^{17,18} In addition, one of the respondents in this group was a Jehovah's Witness, and this religion prohibits transfusion of blood or transplantation of tissues or organs containing blood.¹⁹

Respondents with no political affiliation were more likely than any other group to agree that prior consent should be required before taking organs from the deceased. Possible explanations for this finding are the following: individuals with no political affiliation may harbor an innate distrust toward the government, and feel that individuals' voluntary decisions to donate should not be impeded by the government; individuals with no political affiliation may be characterized as "independent thinkers" who are more apt to make decisions based on their own personal moral/ethical codes, rather than those of any specific political group, and feel it is only right that others also get the chance to base their decisions on their own principles and ideals; and Democrats, who were least in favor of prior consent, could have ascribed to a more "socialistic" approach to organ donation, in that presumed consent would provide "the greatest good for the greatest number", and they may have felt that the need for prior consent before taking organs would unduly reduce the number of organs available to those who needed them the most. A study by Grubestic²⁰ showed that political affiliation can affect one's potential to donate organs, though it did not specifically address the issue of presumed consent.

We found no significant differences in opinion based on either age or educational level. Our results differed from prior studies, which show that age and educational level were the most important factors in determining attitudes toward presumed consent and organ donation.⁹⁻¹¹ This is probably due to the differences among the populations studied.

Strengths of the Study

We obtained 275 completed surveys, and only 8% of the surveys had to be discarded because of incomplete responses. In general, the questions in the survey were clear and concise, and the majority of participants had no difficulty understanding or completing them in a timely manner. In addition, we had a heterogeneous sample, containing diverse individuals from various racial, religious, age, educational, and income groups. The subjective written comments and feedback which participants provided regarding presumed consent and organ donation were informative and enriching.

Limitations of the Study

This study had several limitations. Our sample came from only two major southern California geographical regions: Redlands in San Bernardino County and Huntington Beach in Orange County. Participants recruited from these areas were from a high socioeconomic class (i.e. highly educated, more affluent), and most of them were White/Caucasian; hence, there was not an equal representation of respondents among the various racial/ethnic groups. Due to the survey design, many participants overlooked the first question, "Would you be in favor of presumed consent?" since it was separate from the other questions, and some participants reported that they were unsure

whether this referred to donating organs *before* or *after* death.

Contribution to the Overall Body of Research on Presumed Consent and Organ Donation

This study contained survey questions which expanded on various aspects of organ donation, addressing both the personal and global consequences of presumed consent. For example, subjects were asked whether they would personally be willing to donate organs after death, as well as whether they thought presumed consent would globally increase the number of available organs for transplantation. Also unique to this study, we found significant differences in attitudes toward particular aspects of organ donation based on gender and political affiliation. These findings may shed some further light on how demographic characteristics can contribute to attitudes regarding presumed consent and organ donation.

Implications of the Study

These findings can help increase public awareness of the issues of presumed consent and organ donation. Educational campaigns to encourage support for organ donation, in general, and presumed consent, in particular, can be precisely targeted toward specific populations (e.g. African Americans). This might create more incentive for these groups to support policies that increase organ donation efforts. On a smaller scale, this study may have raised participants' awareness of post-mortem issues that are rarely considered until it is too late. Furthermore, this study elucidates the need for public education on the subject of organ donation.

Suggestions for Further Research

Further research regarding attitudes toward presumed consent and organ donation could elaborate on

the effect of race on opinions toward these issues by studying a larger population of ethnically diverse individuals. In addition, factors such as age and educational level could be studied more closely to observe whether their effect on attitudes toward presumed consent is truly significant or just coincidental/artifactual.

CONCLUSIONS

Race was the strongest factor in determining one's attitudes toward presumed consent and organ donation, with Blacks/African Americans being least favorable to either. Gender and political affiliation also had a significant effect on attitudes toward particular aspects of organ donation. Income level influenced attitudes toward presumed consent, though this effect was not statistically significant.

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Appendix

ATTITUDES TOWARD A PRESUMED CONSENT ORGAN DONATION SYSTEM

Please carefully read the statement below and answer the question that follows by checking the correct box:

“*Presumed Consent* assumes that all individuals consent to be organ donors prior to death unless they specifically refuse to donate (this refusal must be documented in writing). Next-of-kin or family members would not be able to override this presumption after a patient’s death.”

1.) Would you be in favor of *Presumed Consent*? Yes No

For each of the following statements, please circle the answer that most closely fits your opinion on the subject. Use the key below to assist you in the selection of your answers.

1=Strongly Agree	2=Agree	3=Neutral	4=Disagree	5=Strongly Disagree	
2.) I believe that prior <i>explicit</i> consent (i.e. record of written or spoken agreement) should always be required from a person before taking organs from his/her body after death.	1	2	3	4	5
3.) I would agree to donate my organs prior to my death.	1	2	3	4	5
4.) I would consent to have a family member make the decision to donate my organs after my death if I did not already make the decision myself.	1	2	3	4	5
5.) <i>Presumed Consent</i> will increase the chance that organs will be taken from people who did not originally want to donate.	1	2	3	4	5
6.) <i>Presumed Consent</i> will effectively increase the number of available organs for transplantation.	1	2	3	4	5
7.) <i>Presumed Consent</i> will restrict individuals’ freedom to choose whether or not to donate organs.	1	2	3	4	5
8.) <i>Presumed Consent</i> will violate many individuals’ personal, cultural, and/or religious beliefs.	1	2	3	4	5

Please provide us with any additional reasons why you would or would not support *Presumed Consent*:

(This survey is continued on the reverse side of this page)

Please answer the following questions about yourself (check only one box).

Age Range	Income Level	Gender	Educational Level
<input type="checkbox"/> 18-35 Years	<input type="checkbox"/> \$0 - \$20,000	<input type="checkbox"/> Male	<input type="checkbox"/> Less than High School
<input type="checkbox"/> 36-50 Years	<input type="checkbox"/> \$21,000 - \$39,000	<input type="checkbox"/> Female	<input type="checkbox"/> High School Graduate
<input type="checkbox"/> 51-65 Years	<input type="checkbox"/> \$40,000 - \$59,000		<input type="checkbox"/> Some College
<input type="checkbox"/> 66+ Years	<input type="checkbox"/> \$60,000+		<input type="checkbox"/> Bachelor's Degree
			<input type="checkbox"/> Master's or Doctoral Degree (i.e. PhD, MD/DO, DDS, JD, etc.)

Race/Ethnicity	Religious Affiliation
<input type="checkbox"/> White/Caucasian	<input type="checkbox"/> Protestant
<input type="checkbox"/> Hispanic/Latino	<input type="checkbox"/> Catholic
<input type="checkbox"/> Black/African American	<input type="checkbox"/> Jewish
<input type="checkbox"/> East Asian or Pacific Islander	<input type="checkbox"/> Muslim
<input type="checkbox"/> Middle Eastern	<input type="checkbox"/> Buddhist
<input type="checkbox"/> Native American/Alaskan Native	<input type="checkbox"/> Hindu
<input type="checkbox"/> South Asian/Asian Indian	<input type="checkbox"/> Eastern Orthodox
<input type="checkbox"/> Other (Please List: _____)	<input type="checkbox"/> No Affiliation
	<input type="checkbox"/> Other (Please List: _____)

Political Affiliation
<input type="checkbox"/> Republican
<input type="checkbox"/> Democrat
<input type="checkbox"/> No Affiliation
<input type="checkbox"/> Other (Please List: _____)

We thank you very much for taking the time to contribute to this study. If you have any questions or concerns regarding this research project, please do not hesitate to request more information from us.