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Perspectives of Decisional Surrogates and Patients Regarding Critical Illness Genetic Research

Bradley D. Freeman, MD FACS¹, Dragana Bolcic-Jankovic, MA², Carie R. Kennedy, RN¹, Jessica LeBlanc, BA², Alexander Eastman, MD MPH³, Jennifer Barillas, BS³, Catherine M. Wittgen, MD⁴, Kathryn Lindsey, RN⁴, Rumel S. Mahmood, MA², and Brian R. Clarridge, PhD²

¹ Washington University School of Medicine in St. Louis

² Center for Survey Research

³ University of Southwestern Medical Center

⁴ St. Louis University School of Medicine

Abstract

Background—Critical illness research is challenging due to disease severity and because patients are frequently incapacitated. Surrogates called upon to provide consent might not accurately represent patient preferences. Though commonplace, genetic data collection adds complexity in this context. We undertook this investigation to understand whether surrogate decision makers would be receptive to permitting participation in a critical illness genetics study and whether their decision making was consistent with that of the patient represented.

Methods—We invited individuals identified as surrogates for critically ill adults, if required, as well as patients once recovered to participate in a survey designed to understand attitudes about genetic research. Associations between dependent (receptivity to participation, concordance of responses) and independent variables were tested using bivariate and multivariate logistic regression analyses.

Results—Most of the entire surrogate sample (n=439) reported familiarity with research, including genetic research; tended to view research as useful; and were receptive to allowing their family member participate (with 39.6% and 38.1% stating that this would be “very” and “somewhat likely,” respectively) even absent direct benefit. Willingness to participate was similar comparing genetic and non-genetic studies (χ^2 [1,n=439]=0.00127, $p=0.972$), though respondents expressed worry regarding lack of confidentiality of genetic data. Responses were concordant in 70.8% of the 192 surrogate-patient pairs analyzed. In multivariate analysis, African American race

Address Correspondence to: Bradley D. Freeman, MD, FACS, Professor, Department of Surgery, Washington University School of Medicine, 660 South Euclid Ave, Box 8109, St. Louis, MO 63110, freeman@wustl.edu.

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was associated with less receptivity to genetic data collection ($p < 0.05$). No factors associated with concordance of surrogate-patient response were identified.

Conclusions—Surrogates' receptivity to critical illness research was not influenced by whether the study entailed collection of genetic data. While more than two-thirds of surrogate-patient responses for participation in genetics research were concordant, concerns expressed regarding genetic data often related to breach of confidentiality. Emphasizing safeguards in place to minimize such breeches might prove an effective strategy for enhancing recruitment.

Keywords

Critical Illness; Biomedical Research; Genetics; Ethics Committees (Research)

INTRODUCTION

Critical illness constitutes a substantial, costly, and increasing disease burden (Coopersmith et al. 2012). While essential to developing and evaluating new approaches to treatment, clinical trials enrolling critically ill patients are characterized by logistical and ethical challenges not encountered in studies of chronic disease (Ad Hoc Statement Committee of the American Thoracic Society 2004; Burns et al. 2013; Coopersmith et al., 2012). Conditions prompting ICU admission are often precipitous and life-threatening and the care provided highly technological (Ad Hoc Statement Committee of the American Thoracic Society, 2004; Freeman et al. 2001).

In addition to immersion in a foreign environment, patients and family members often have little opportunity for education regarding the nature of the disease process, expected outcome, treatment alternatives, or research opportunities. Further, given the rapid tempo of many illnesses (such as for myocardial infarction, stroke, or sepsis), treatment must be instituted in a timely manner (Freeman et al. 2001). Finally, it is often the case that ICU patients are incapacitated and unable to provide informed consent permitting research participation (Ad Hoc Statement Committee of the American Thoracic Society 2004; Burns et al. 2013; Davis et al. 2003; Luce 2003a; Luce 2003b; Silverman, Luce, and Schwartz, 2004). In order to enroll critically ill patients in clinical studies, permission must often be obtained expediently from surrogates (e.g., a family member or domestic partner), many of who are being confronted with these serious issues for the first time.

Paralleling trends in most fields of medicine, collection of genetic biospecimens as a component of critical illness investigations is increasingly commonplace (Collins 1999; Freeman et al. 2010; Smart et al. 2013). Genetic data collection nonetheless potentially introduces an additional layer of complexity in this context. For example, individuals providing substitute consent may not possess sufficient insight as to the nature of genetic data to permit informed decision making regarding study participation (Iverson et al. 2013a; Iverson et al. 2013b). Similarly, the emotional distress surrogates experience may overwhelm concerns that genetic data possess characteristics rendering it distinct from other commonly collected information (Barrett and Scales 2012; Green and Botkin 2003; Iverson et al. 2013a; Iverson et al. 2013b; Pochard et al. 2001). Finally, surrogates may not

accurately reflect the preferences of the patients represented (Ciroidi et al., 2007; Coppolino and Ackerson, 2001; Newman et al. 2012).

These considerations may partly underlie ambiguity on the part of institutional review boards (IRBs) as to how participant protections should be applied in this context. For example, when presented with a hypothetical study involving incapacitated patients in which genetic specimens would be collected, IRB members at several institutions were conflicted as to the risk such a study would pose with 40% reporting that they would not permit such a study in the absence of direct patient benefit (Gong et al. 2010).

Similarly, in a multicenter genetic epidemiology acute stroke trial, Chen et al. (2008) reported that investigators preferentially enrolled less severely affected, cognitively intact participants because IRBs at 40% of participating institutions would not permit use of decisional surrogates to provide consent in such a study. Inconsistent application of participant protections is problematic insofar as it introduces sampling and recruitment bias (McWilliams et al. 2003; Silverman, Chandros, and Sugarman 2001). Further, such restrictions may not align with the concerns of surrogates and patients potentially approached for enrollment (Trinidad et al. 2010; Trinidad et al. 2011).

While attitudes concerning genetic research have been examined in many settings, the manner in which the exigencies of acute illness may impact these attitudes is poorly characterized (Achter, Parrott, and Silk, 2005; Halbert et al. 2006; McGuire et al. 2008). We undertook this observational, cross-sectional investigation to explore this question.

Our objectives were twofold. We first sought to understand whether surrogate decision makers would be receptive to permitting participation in a critical illness study that entailed collection of genetic data, using a non-genetic study for comparison. We hypothesized that those providing substitute consent for critically ill adults would perceive genetic data as distinct and would be less receptive to permitting participation in a genetic study compared to studies not capturing this information. Second, we sought to determine the extent to which decision making on the part of the surrogate reflected patient preference. Because receptivity to clinical trial participation may be influenced by demographic factors, familiarity with research and trust in healthcare providers, we incorporated this information into our analysis (Hull et al. 2008).

Our goal was to achieve greater insight into specific concerns expressed by those invited to participate in critical illness genetics studies, thus enabling investigators and oversight bodies to develop safeguards directly responsive to the interests and preferences of enrollees (Trinidad et al. 2011).

METHODS

Description of Survey Instrument and Variables Collected

The survey instrument used in this study has been previously described (Freeman et al. 2012). Briefly, our questionnaire, modified from Hull et al. (2008) examines domains related to providing substitute consent, clinical research, and genetic data collection as it

pertains to the critical care environment (Freeman et al. 2012). Information collected included familiarity with research (non-genetic, genetic), perceptions as to usefulness of research, likelihood of allowing a patient to participate in research (non-genetic, genetic), importance of direct benefit of research, concerns about disclosure of genetic information, and demographic variables.

Prior to fielding the final survey instrument, cognitive interviews were performed with six individuals recruited from the study sites in an effort to assess readability and clarity of the questions, uniformity in comprehension, and respondent comfort with content. As a result of these interviews, only very minor changes were made in the survey instrument, which did not affect its overall structure or content (Freeman et al. 2012).

Surrogate and Patient Recruitment, Data Collection

English-speaking participants were recruited from the surgical and medical ICU's of three tertiary care institutions (Barnes Jewish Hospital, St. Louis, MO; St. Louis University Hospital, St. Louis, MO; and Parkland Hospital, University of Texas-Southwestern Medical Center, Dallas, TX) over a 34-month period (March 2010-December 2012). These study sites were chosen because of the demographic and ethnic diversity afforded.

Our selection criteria have previously been reported (Freeman et al. 2006; Iverson et al. 2012). Briefly, we sought to interview individuals identified to serve as surrogate decision makers for critically ill adults, if required, as well as the patients themselves once they had sufficiently recovered from acute illness. At the time of study initiation, admissions to participating ICUs were screened to identify patients who were 18 years of age, intubated and mechanically ventilated for 48 hours, and expected to require ventilatory support for 24 additional hours. We excluded patients who were freedom-impaired, pregnant, had sustained severe head injury, or who possessed pre-existing cognitive dysfunction (which would preclude interview participation).

As the study evolved, two minor modifications were made to the inclusion criteria in an effort to increase enrollment. The requirement for mechanical ventilation was first decreased to 24 hours and then subsequently eliminated. Surrogates (i.e., family members, guardians, domestic partners, legally-appointed individuals) for patients meeting inclusion criteria were approached by research staff and invited to participate. Those agreeing provided informed consent and completed an in-person, on-site, computer-assisted interview conducted by dedicated field staff.

Corresponding patients who had recovered within six weeks of the surrogate interview were approached for participation. We did not use a standardized assessment to determine if patients were sufficiently recovered to participate in our interview. Rather, a qualitative assessment was performed by the research team who followed patients longitudinally. Reasons that patients were deemed insufficiently recovered for participation most commonly included receiving substantial doses of medications that affected cognition (e.g., narcotics or benzodiazepines) or general deconditioning which likewise limited their ability to fully participate in the interview process. Those agreeing completed an interview in a manner identical to that described for surrogates.

Patient interviews, whether occurring during hospitalization or afterward, were conducted in-person. Participant responses were recorded electronically and submitted in a de-identified fashion to a central repository (located at the Center for Survey Research, University of Massachusetts, Boston, MA) for coding and analysis.

Analysis

Objective 1—Comparison of surrogates' receptivity to permitting participation in non-genetic compared with genetic studies.

We compared receptivity to non-genetic and genetic study enrollment by asking surrogates about their likelihood of permitting patient participation in these two settings. Specifically, surrogates were asked:

Suppose one of [the patient's] ICU doctors came to you today asking to enter him/her in a medical research study. Assuming participation would cause him/her no harm and would not affect his/her care in any way, how likely would you be to allow his/her participation?

The responses "very likely" and "somewhat likely" were categorized as *receptive*; the responses "not very likely" and "not at all likely" were categorized as *non-receptive*. Similarly, surrogates were also asked:

If one of [the patient's] ICU doctors came to you today asking to enter [the patient] in a medical research study requiring the use of some of his/her genetic material, how likely would you be to allow his/her participation?

Responses were coded in an identical fashion.

Because receptivity to research may be influenced by demographic characteristics and baseline attitudes, we sought to determine the influences of these attributes in our analysis (Hull et al. 2008). We examined the distribution of variables presented in Table 1 in addition to the survey items "How often do you hear something new about research?" and "How much of research is useful?" (Table 2) comparing subjects receptive and non-receptive to **non-genetic research** (χ^2 test). Variables statistically significant in bivariate analysis ($p < 0.05$) were tested using multivariate logistic regression analysis. We similarly examined the distribution of variables presented in Table 1 in addition to the survey items "How often do you hear something new about research?," "How much of research is useful?," and "Have you heard about genetic research?" (Table 2) comparing subjects receptive and non-receptive to **genetic research** (χ^2 test). Variables found statistically significant in bivariate analysis ($p < 0.05$) were tested using multivariate logistic regression analysis. Lastly, we explored differences in attitudes regarding genetic research according to race (χ^2 test).

Objective 2—Determination of the extent to which decision making on the part of the surrogate reflected patient preference.

A subset of the surrogates participating in this study had a matching patient cohort allowing us to determine the extent to which surrogate responses represented patient preferences. Concordant pairs (i.e., receptive surrogate/receptive patient; non-receptive surrogate/non-

receptive patient) and discordant pairs (receptive surrogate/non-receptive patient; non-receptive surrogate/receptive patient) were created. Bivariate analysis and multivariate logistic regression analysis were used to examine the relationship between characteristics collected by our quantitative instrument and concordance in a manner analogous to that described under Objective 1.

SigmaPlot 12.5 (Systat Software Inc., San Jose, CA) was used in all analyses.

Human Subjects Protections

This study was approved by the Human Studies Committees of Washington University School of Medicine (HRPO 06-0637) in addition to all sites participating in this effort.

RESULTS

Surrogate Characteristics

Of 568 surrogates who consented for this study, 63 were excluded due to withdrawal of consent or inability to meet with the field interviewer, and 60 were excluded because their corresponding patient had expired or was discharged before the interview could be completed. Six of the 445 remaining participants did not provide responses for the outcome elements of interest, leaving 439 surrogates for analysis (Table 1).

The participants (most commonly spouses/domestic partners [45.1%] and parents [25.7%]) were predominately middle-aged, female (75.2%) and Caucasian (72.9%). While the majority (85.5%) enjoyed “good,” “very good,” or “excellent” health, many (43.5%) had been diagnosed with chronic illness. More than one-half described themselves as “very religious.” A minority (34.5%) had completed a college education, and 72.4% endorsed complete trust in the doctors and nurses providing care for the critically ill patient for whom they were providing substitute consent.

Surrogate Attitudes and Perceptions of Research

Most surrogates reported familiarity with research, including genetic research; tended to view research as useful; and were receptive to allowing their family member to participate (with 39.6% stating that this would be “very likely,” and 38.1% stating that this would be “somewhat likely”) even in the absence of direct benefit (Table 2). Willingness to participate was similar comparing genetic and non-genetic studies (χ^2 [1,n=439]=0.00127, $p=0.972$) (Figure 1(A)).

Our survey probed possible concerns about research conduct. Over one-half of respondents expressed worry regarding lack of confidentiality of genetic data. Disclosure of this information to insurance companies appeared particularly problematic with 60% stating that this was a “big” or “moderate” worry. Similarly, the possibility that genetic data might lead to some form of discrimination constituted a “big” or “moderate” worry for 45% of respondents.

Surrogate Factors Associated with Receptivity to Non-Genetic and Genetic Research Participation

We explored the relationship between surrogate characteristics, attitudes about research, and willingness to permit participation in **non-genetic research**. Hispanic ethnicity and African American race were associated with decreased likelihood of participation, while familiarity with research and level of trust in physicians and nurses providing care were associated with increased likelihood of participation in bivariate and multivariate logistic regression analysis (Table 3).

We next explored the relationship between surrogate characteristics, attitudes about research, and willingness to permit participation in **genetic research**. African American race and lack of familiarity with research (both non-genetic and genetic) were associated with less receptivity to participation in genetic research in bivariate analysis (Table 3). In multivariate analysis, African American race and lack of familiarity with research remained significantly associated with less receptivity to participation in genetic research (Table 4).

Given the association between African American race and decreased receptivity to research participation relative to Caucasian surrogates (Figure 1B), we examined differences in research attitudes comparing these racial groups (Table 5). While Caucasian and African American surrogates reported comparable familiarity with research in general (χ^2 [3,n=399]=5.518, $p=0.138$) and viewed it with equivalent utility (χ^2 [3,n=397]=3.420, $p=0.331$), African Americans were less likely to participate in research in the absence of direct benefit (χ^2 [1,n=373]=40.885, $p<0.001$). Further, African Americans reported less familiarity with genetic research (χ^2 [1,n=406]=24.906, $p<0.001$), and appeared more concerned regarding the potential for breach of confidentiality (χ^2 [3,n=398]=23.406, $p<0.001$) and discrimination (χ^2 [3,n=398]=18.758, $p<0.001$).

Concordance Analysis

Two hundred eighty-five patients associated with the surrogate participants were recruited. Of these, 36 individuals failed to recover sufficiently to participate, 16 declined to participate, 19 could not be interviewed within six weeks of the surrogate interview, and 22 did not provide responses for the outcome variable of interest, leaving 192 surrogate-patient pairs for analysis. No significant differences existed comparing the entire surrogate cohort with the subsample of surrogates with a matching patient for any of the variables presented in Table 1 (data not shown).

We examined concordance in responses with respect to genetic study participation among the 192 surrogate-patient pairs. Approximately two-thirds of these individuals (70.8%) provided answers that were concordant with respect to genetic research participation, with the majority (93.4%) of concordant surrogate-patient pairs being receptive to participation. Among discordant surrogate-patient pairs, 32.1% of surrogates stated that they would be receptive to study participation while their corresponding patient reported that they would be either “somewhat” or “very” unlikely to participate; the converse relationship was observed in the remaining 67.8%. Thus concordant and discordant surrogates differed with respect to their receptivity to study participation (χ^2 [1,n=192]=77.190, $p<0.001$) (Figure 1(C)). We

were unable to identify any demographic variable associated with concordance in multivariate analysis.

DISCUSSION

Genetic data are described as “exceptional,” potentially providing insight (disease predisposition) and entailing risks (uniquely identifiable, potential for racial stereotyping) that render them distinct from other types of commonly collected clinical information (Green and Botkin 2003). These features may serve as a disincentive to participation in genetic research.

Our primary objective in this investigation was to understand whether surrogate decision makers would be receptive to permitting participation in a critical illness study that entailed collection of genetic data, using a non-genetic study as a basis of comparison. Surrogates were familiar with research and viewed it positively, but expressed concerns regarding genetic data, including the potential for breach of confidentiality, economic harm, and stigmatization. Nonetheless, surrogates expressed equal willingness to permit participation in both types of studies, even absent direct benefit. One interpretation of these findings is that surrogates did not perceive the risks associated with genetic and non-genetic data differently.

Our secondary objective was to understand the extent to which a decision to permit or deny study participation on the part of the surrogate aligned with the preferences of the patients represented. A number of authors have examined this question using a variety of experimental constructs (Ciroidi et al. 2007; Coppolino and Ackerson 2001; Newman et al. 2012;). Newman et al. (2012) found that the likelihood of providing discordant responses was proportional to the perceived risk of the study being presented, but could not identify demographic factors associated with these discrepancies. Ciroidi et al. (2007) reported similar findings.

We found that 71% of surrogates participating in our study provided responses consistent with those of the patient. Concordant respondents were much more likely to be receptive to study participation relative to individuals providing discordant responses. Similarly, 90% of surrogates permitting study participation provided concordant responses. Like other investigators, we were unable to identify surrogate characteristics associated with providing concordant responses. The effects of demographic factors such as race or ethnicity on alignment of responses are likely subtle and our study may have been underpowered to detect them. Alternatively, our survey instrument may not have collected information regarding important factors significantly influencing this outcome.

Our findings mirror those reported by Smart et al. (2013) who found that most surrogates granting permission for participation in clinical trials coordinated through the *Acute Respiratory Distress Syndrome Network* likewise permitted genetic specimen collection and that patients largely affirmed participation when given the opportunity for re-consent. Collectively, these findings might provide reassurance to the investigative and research oversight communities that grapple with the uncertainty inherent in relying on a surrogate to

provide judgment for an incapacitated patient. That is, if the surrogate permits study inclusion, it appears that the patient will also agree when provided the opportunity for re-consent.

As has been well described in non-acute settings, we found that African American surrogates were much less receptive to enrollment in non-genetic and genetic studies than their Caucasian counterparts (Corbie-Smith, Thomas, Williams, and Moody-Ayers 1999; Shavers, Lynch, and Burmeister 2002). While Caucasian and African American respondents were comparable with respect to research familiarity, Caucasians appeared more knowledgeable about genetic research and more likely to permit participation in the absence of direct benefit. Conversely, African Americans were more concerned about the potential for lapses of confidentiality as well as the potential for genetic data to have stigmatizing or discriminatory consequences. Coupled with other factors common in under-represented populations, such as the inability to locate a surrogate from whom to request participation, racially-associated reluctance to enroll in research presents a significant hurdle to minimizing disparities in critical care (Glassberg, Luce, and Matthay 2008; Glickman et al. 2008; Soto, Martin, and Gong 2013).

Limitations

While there is precedence for employing quantitative techniques to understand attitudes about research, there are inherent limitations to this approach (Brothers, Morrison, and Clayton, 2012; Hull et al. 2008). We questioned participants as to the likelihood that they would permit participation (or participate themselves) in a research study. The fact that these individuals had agreed to complete a survey may confound this analysis; their views might not be representative of those declining to be interviewed (Johnson and Wislar 2012).

In addition, because we were sampling the opinions of surrogates immersed in the ICU environment (and confronting the emotional stress of caring for an acutely ill family member), we designed our survey instrument to test concepts as unambiguously as possible. Our intent in presenting a hypothetical study as entailing no risk was to convey to participants that the proposed trial did not involve an intervention with some possibility of morbidity and mortality. Further, we felt this scenario was analogous to a minimal risk study, which IRBs are often called upon to consider.

We cannot exclude the possibility that this approach may have resulted in our inability to detect a difference in receptivity to research comparing non-genetic and genetic studies. Finally, the attitudes about participation in a hypothetical trial presented in the context of a survey – irrespective of the risk described – may not accurately reflect a surrogate's or patient's decision making if approached about an actual clinical study.

Our study had additional shortcomings. The emotional and physical burdens of the surrogate role may evolve over the course of a patient's ICU stay. This evolution may have implication both for how effectively a surrogate functions as well as how receptive such an individual might be to research participation. We did not account for time-dependence in our analysis.

In addition, we made adjustments to our protocol during recruitment in an effort to enhance enrollment. While we did not detect a difference in receptivity to study participation comparing participants enrolled prior to and after these changes were made (data not presented), we cannot exclude the possibility that changes in acuity of illness might have translated into important differences in survey responses as the study progressed.

Finally, we recruited participants from academic medical centers. While a large proportion of critical care research occurs in this environment, the demographic makeup, types of illnesses treated, and care delivery models employed may differ substantially from non-academic settings. Collectively, these factors may limit the generalizability of our findings.

CONCLUSION

Surrogates' receptivity to critical illness research was not influenced by whether the study entailed collection of genetic data. More than two-thirds of those who might be called upon to grant substitute consent for genetic research participation provided responses consistent with the patients represented. While IRBs have shown variability in application of protections governing genetic research involving incapacitated subjects, one interpretation of these findings is that such protections should not be overly restrictive and should mirror those in place for comparable non-genetic studies. Importantly, many of the concerns surrogates expressed regarding genetic research were related to breach of confidentiality. Emphasis as to safeguards in place to minimize such breeches might prove an effective strategy to allaying these concerns and to enhancing recruitment for all types of critical illness research.

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Figure 1.
Receptivity to Study Enrollment

Table 1Surrogate Characteristics¹

Demographic Factors	Surrogates (n=439)
Gender	
Female	330 (75.2)
Male	109 (24.8)
Age	
20	3 (0.6)
21-40	90 (20.6)
41-60	243 (55.6)
61-80	100 (22.9)
>80	1 (0.2)
Current Health Status	
Excellent	75 (17.2)
Very Good	174 (39.8)
Good	124 (28.4)
Fair	58 (13.3)
Poor	6 (1.4)
Serious or chronic medical illness?	
Yes	190 (43.5)
No	246 (56.5)
Hispanic or Latino Ethnicity?	
Yes	22 (5.0)
No	413 (95.0)
Race	
Black/African American	85 (19.6)
White/Caucasian	316 (72.9)
Other ²	32 (7.4)
Religiosity	
Not religious	22 (5.1)
Somewhat religious	181 (42.1)
Very religious	227 (52.8)
Education	
Did not complete high school	28 (6.4)
High school graduate or equivalent	127 (29.0)
Some College	130 (29.7)
College Graduate	82 (18.7)
Some Graduate School	17 (3.9)
Graduate Degree	54 (12.3)
Trust doctors and nurses	
Completely	315 (72.4)

Demographic Factors	Surrogates (n=439)
Somewhat	110 (25.3)
A little/Not at all	10 (2.3)
Annual Income	
< \$20,000	64 (15.9)
\$20,001 - \$40,000	85 (21.1)
\$40,001 - \$60,000	94 (23.4)
\$60,001 - \$80,000	61 (15.2)
\$80,001 - \$100,000	38 (9.4)
>\$100,000	60 (14.9)

¹ Data are presented as n (%).

² Includes Asian, American Indian, and other.

Table 2Surrogate Attitudes Regarding Research¹

Survey Item	Surrogates (n=439)
How often do you hear something new about research?	
Every Day	43 (9.8)
Most Days	148 (33.7)
Once in a while	223 (50.7)
Almost Never	25 (5.7)
How much of medical research is useful?	
Almost all of it	69 (15.6)
Most of it	153 (34.5)
Some of it	187 (42.2)
Almost of none of it	34 (7.7)
How likely to allow patient to participate in research?	
Very likely	174 (39.6)
Somewhat likely	169 (38.1)
Not very likely	59 (13.3)
Not likely at all	37 (8.3)
Willing to participate in the absence of direct benefit?	
Yes	340 (83.1)
No	69 (16.9)
<hr/>	
Heard about genetic research?	
Yes	314 (71.8)
No	123 (28.1)
How likely to allow patient to participate in genetic research?	
Very likely	162 (37.1)
Somewhat likely	180 (40.6)
Not very likely	52 (11.7)
Not at all likely	43 (9.7)
Worry about researchers giving genetic material by mistake?	
Big worry	89 (20.4)
Moderate worry	117 (26.9)
Small worry	116 (26.7)
No worry at all	113 (26.0)
Worry genetic material given to insurance companies?	
Big worry	171 (39.2)
Moderate worry	91 (20.9)
Small worry	107 (24.5)

Survey Item	Surrogates (n=439)
No worry at all	67 (15.4)
Worry genetic material used to discriminate?	
Big worry	95 (21.8)
Moderate worry	101 (23.2)
Small worry	107 (24.5)
No worry at all	133 (30.5)

¹ Data is presented as n (%).

Table 3

Factors associated with receptivity to non-genetic and genetic research among surrogates in bivariate analysis (n=439)¹

Survey Items	Non-genetic Research			Genetic Research		
	Receptive	Not receptive	p-value	Receptive	Not receptive	p-value
Hispanic or Latino Ethnicity?						
Yes	12 (3.5)	10 (10.5)	0.013	na	na	na
No	328 (96.5)	5 (89.5)		na	na	
Race						
Black/African American	47 (13.8)	38 (41.3)	<0.001	50 (14.6)	34 (35.8)	<0.001
Other ²	21 (6.1)	11 (11.9)		266 (77.8)	49 (51.6)	
White/Caucasian	273 (80.0)	43 (46.7)		26 (7.6)	12 (12.6)	
Trust doctors and nurses						
Completely	255 (74.8)	60 (63.8)	0.004	na	na	na
Somewhat	82 (24.0)	28 (29.8)		na	na	
A little/Not at all	4 (1.2)	6 (6.4)		na	na	
How often hear something new about research?						
Every Day	29 (8.4)	14 (14.6)	0.005	29 (8.5)	14 (14.7)	0.02
Most Days	127 (37.0)	21 (21.9)		121 (35.4)	25 (26.3)	
Once in a while	172 (50.1)	51 (53.1)		177 (51.7)	46 (48.4)	
Almost Never	15 (4.4)	10 (10.4)		15 (4.4)	10 (10.5)	
Heard about genetic research?						
Yes	na	na	na	259 (75.7)	55 (57.9)	<0.001
No	na	na		83 (24.3)	40 (42.1)	

¹ Data is presented as n (%).

² Includes Asian, American Indian, and other.

Table 4

Factors associated with receptivity to non-genetic and genetic research among surrogates in multiple logistic regression analysis (n=439)

Survey Items		Non-genetic Research	Genetic Research
		Odds Ratio 95% (Confidence Interval)	Odds Ratio 95% (Confidence Interval)
Constant		0.47 (0.11-2.02)	1.44 (0.60-3.45)
Hispanic or Latino Ethnicity?			
	Yes	0.33 (0.12-0.93)	na
	No (reference)	1.000	na
Race			
	Black/African American	0.21 (0.12-0.38)	0.30 (0.17-0.53)
	Other ^I	0.59 (0.23-1.51)	0.54 (0.23-1.25)
	White/Caucasian (reference)	1.000	1.000
Trust doctors and nurses			
	Completely	4.50 (1.35-14.97)	na
	Somewhat	4.07 (1.15-14.35)	na
	A little/Not at all (reference)	1.000	na
How often hear something new about research?			
	Every Day	2.02 (0.68-6.02)	1.75 (0.60-5.13)
	Most Days	5.10 (1.90-13.66)	3.32 (1.28-8.62)
	Once in a while	2.95 (1.18-7.39)	2.79 (1.13-6.88)
	Almost Never (reference)	1.000	1.000
Heard about genetic research?			
	Yes	na	1.57 (0.94-2.63)
	No (reference)	na	1.000

^I Includes Asian, American Indian, and other.

Table 5Comparison of Caucasian and African American Surrogate Attitudes Regarding Genetic Research¹

Survey Item	Caucasians (n=316)	African Americans (n=85)	<i>p-value</i>
Heard about genetic research?			<0.001
Yes	255 (79.7)	45 (52.3)	
No	65 (20.3)	41 (47.7)	
How likely to allow patient to participate in genetic research?			<0.001
Very likely	136 (43.2)	17 (20.2)	
Somewhat likely	130 (41.2)	33 (39.3)	
Not very likely	35 (11.1)	13 (15.5)	
Not at all likely	14 (4.4)	21 (25.0)	
Worry about researchers giving genetic material by mistake?			<0.001
Big worry	49 (15.6)	26 (31.3)	
Moderate worry	75 (23.8)	29 (34.9)	
Small worry	102 (32.4)	9 (10.8)	
No worry at all	89 (28.2)	19 (22.9)	
Worry genetic material given to insurance companies?			0.010
Big worry	108 (34.4)	44 (52.4)	
Moderate worry	74 (23.6)	12 (14.3)	
Small worry	85 (27.1)	14 (16.7)	
No worry at all	47 (15.0)	14 (16.7)	
Worry genetic material used to discriminate?			<0.001
Big worry	55 (17.5)	30 (36.1)	
Moderate worry	68 (21.6)	22 (26.5)	
Small worry	86 (27.3)	17 (20.5)	
No worry at all	106 (33.6)	14 (16.9)	

¹ Data is presented as n (%).