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## Participants' Role Expectations in Genetics Research and Re-consent: Revising the Theory and Methods of Mental Models Research Relating to Roles

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### Abstract

The rise of large cohort-based health research that includes genetic components has increased the communication challenges for researchers. Controversies have been amplified over requirements for re-consent, return of results, and privacy protections, among other issues. This study extended research on the impact that the perceived role of “research participant” might have on communication expectations to illuminate research participants’ preferences for re-consent. The study employed an on-line survey of participants in a long-standing cancer genetics registry. Results confirmed previous exploratory findings that research participants endorse multiple mental models of participant roles in research (doctor-patient, collaborator, donor, legal contract, etc.). Regression analyses indicated that high and low salience of different models of the role of research participant are related to different communication expectations. However, the pattern of relationships among roles is relevant. The results of the regression analysis also indicated that preference for mandatory re-consent and its relationship to mental models of roles are related to

attitudes of trust, benefits, and informational risks. The discussion identifies implications as including the use of explicit approaches to address role relationships in communication with research participants. It also points to implications for methodological approaches in mental model research.

### Keywords

Mental Models; Roles; Re-consent; Research Ethics; Health Communication

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Research involving human participants often involves communication between researchers and participants. Much of that communication has been made more complex by recent developments. Notably, the increasing expense, complexity, and participant burden of “big data” studies have encouraged re-use of data from existing studies or maintaining registries or cohorts from whom additional data can be requested. The National Institutes of Health have, for example, increased their promotion of data sharing ([https://www.nlm.nih.gov/NIHbmic/nih\\_data\\_sharing\\_policies.html](https://www.nlm.nih.gov/NIHbmic/nih_data_sharing_policies.html)). These issues have also been intensified by the Precision Medicine Initiative (<https://www.nih.gov/precision-medicine-initiative-cohort-program>).

Much of the existing research on these issues has focused on genetic research, in part because of the large social investment in genetics. That research stream has indicated divergence of expectations among researchers, participants, and IRBs on key communication obligations including re-consent and return of results (Bledsoe et al., 2013; Ziniel et al., 2014). The use of on-line communication in these studies has likewise intensified concerns about the protection of privacy of communications.

The process of obtaining informed and autonomous consent for participation is the most common communicative experience required in research involving human subjects. Therefore, this study focuses especially on that process. Past research shows that expectations regarding re-consent diverge between IRBs and researchers (Edwards et al., 2012). The expectations of those groups also appear to differ in some dimensions from opinions of participants (Ludman et al., 2010; Edwards et al., 2016; Edwards et al., under review). Similar divergences seem to exist with regard to the related alternative of “broad” or “blanket” consent (i.e., consent documents that do not specify purposes and limits of use for the data collected from participants; Kelly, Spector, Cherkas, Prainsack, & Harris, 2015; Platt, Bollinger, Dvoskin, Kardia, & Kaufman, 2014). Other potential divergences may occur with regard to the role of consent in medical practice research (Cho et al., 2015).

Such divergences in expectations might be accounted for by differences in the way researchers and participants envision the role of research participant. Role theories of communication hold that communicative expectations arise in part from the intuitive beliefs people have about the character of different social roles (e.g., friendship, parent-child, doctor-patient; Dillard, Solomon, & Palmer, 1999; Dillard, Solomon, & Samp, 1996; Fiske, 1992; Koerner, 2006; Solomon, Dillard, & Anderson, 2002). These theories and previous research warrant the present investigation of whether participants might hold models of the relationship between researchers and participants that might lead to different communicative

expectations. Additionally, the research literature in both human subjects ethics and on role relationships in health care warrant specific inclusion of trust and risk-benefit as potential variables affecting the impact of such models.

## Roles and Health Communication Expectations

Studies outlining expectations for the roles of physicians and patients have been on-going for decades (Adams, Parrott, & Segall, 1976; Berkanovic, 1972; Hebdon, Fahnestock, & McComb, 2014; Stone, 1979). As articulated by Larsen and Rootman (1976), role theory holds that “a role consists of a set of behavioral expectations, which contain a normative (ought or should) component, applied to an incumbent of a particular social position” (p. 29). Research assessing the communicative interactions between physicians and health care providers has shown that role expectations have measurable impacts. Larsen & Rootman (1976), for example, showed that patient satisfaction increases when physicians fulfill patient’s role expectations. Of particular interest given the unfamiliarity of the role of “research participant” to many people, the research stream has also indicated that “role ambiguity increases the probability that a person will be dissatisfied with a role” (Adams & Parrott, 1994, p. 39). Additional research has indicated a lack of convergence in role expectations between patients and health care providers (Cichon & Masterson, 1993). To pursue further people’s perceptions of roles in research, we turned to the theoretical and methodological framework of mental models research.

## Mental Models Theory and Roles

Morgan, Fischhoff, Bostrom, and Atman (2002) introduced research on mental models in order to improve success in communicating expert knowledge to lay people. They argued that it was as important to understand what people already believed as it was to outline clearly what experts needed to communicate. This was true because people’s existing “mental models” shaped their predispositions to accept and understand the models offered by experts. Mental models are considered to consist of representations of a context (including key actors, scenic factors, available tools, etc.). Research in specific contexts generally has focused on those aspects of mental representations that account for behavioral choices. Mental models of lay individuals in multiple health contexts have been examined (Anderson et al., 2005; Byram, Fischhoff, Embry, de Bruin & Thorne, 2001; Damman & Timmermans, 2012; Henderson & Maguire, 2000; Kealey & Berkman, 2010). Some of this research has focused on the models shared among teams of health experts (Burtscher, Kolbe, Wacker, & Manser, 2011; Biemann, Ellwart, & Rack, 2014).

Candidates for mental models for this research project were initially derived from prescriptive studies that suggested that the researcher-participant relationship should be analogized to specific familiar roles. Common recommendations among medical researchers have been to suggest that research participants should employ the “donor” model (Clayton & McGuire, 2012; Dressler et al., 2012; Miller, Mello, & Joffe, 2008). Common among IRBs and ethicists has been a preference for the “legal contract” (Bredenoord, Onland-Moret, & Van Delden, 2011; Zawati & Rioux, 2012) or “collaborative” models (Beskow, Burke, Fullerton, & Sharp, 2012; Murphy, Scott, Kaufman, Geller, LeRoy, & Hudson, 2008). There

was also evidence that among research participants, the “doctor-patient” or “altruistic” models might be operative (Hunter, Corcoran, Leeder & Phelps, 2012; Kelley et al., 2015; Michie, Henderson, Garrett, & Corbie-Smith, 2011; Ruiz-Canela, Valle-Mansilla, & Sulmasy, 2011).

In an exploratory interview-based study, Condit and colleagues (2015) found that rather than selecting a single one of these mental models (i.e., “gift,” “doctor-patient,” “legal,” “collaborator”) to form the expectations for the role of research participant, interviewees accepted several different familiar models as applicable. In the face of the availability of several models, it was unclear how and whether mental models would guide communication expectations. It was possible that in the absence of a strong, clear or singular norm, lay participants in research effectively have no governing role expectations for communication. Given the research stream in attitude accessibility, a more likely possibility was that a particularly salient model might shape the communication (Higgins, 1996; Bargh, Lombardi, & Higgins, 1988). Activation of one model might have facilitated and/or resulted in activation of other similar mental models through an associative process (cf. Taylor & Crocker, 1981). Alternatively, there might have been synergistic effects among multiple models. We therefore framed the following hypothesis: where roles endorsed by participants are important and salient, those roles will be associated with specific communicative expectations, even in the face of the participants’ recognition of other models for the role. Because of the importance of informed consent (as described above), and because of its clarity as a communicative expectation, we employed support of mandatory policies for re-consent as our operational measure of a concrete communicative expectation.

## **Trust, and Risk-Benefit in Medical Genetics Practice & Research**

Trust and risk-benefit trade-offs are a significant component of the requirements for informed consent (Erllich et al., 2014; Hill, Turner, Martin, & Donovan, 2013; Picillo, Kou, Barone, & Fasano, 2015). They also play a prominent role in the literature on health related outcomes (Berry et al., 2008; Gabay, 2015; Hillen, de Haes and Smets, 2011; Jauffret-Roustide et al., 2012; Lee & Lin, 2009). Therefore, trust and risk-benefit should be actively considered in any effort to develop a model of role expectations for genetic research. Empirical studies had begun to identify the impact of trust on research participation (Gao et al., 2014; Hatfield & Pearce, 2014), including the existence of a correlation between trust and enrollment in a National Cancer Genetics Registry (Skinner et al. 2008). Some studies had addressed trust at the institutional level (Overby, et al., 2015). However, most research has emphasized trust at the interpersonal level, and hence as an aspect of a social role (as illustrated by the mapping of 596 empirical papers on trust in the health-care setting by Brennan and colleagues, 2013). These studies pointed up the possibility that trust may be important both in the conceptualization or choice of specific models of roles for research participation and in enrollment. However, there had been no empirical research assessing their relationship to specific roles or preferences for re-consent in research. Trust in the researcher and the research institution was therefore included as an exploratory variable in the analysis.

## Risk/Benefit

Because of the essentially probabilistic nature of most genetic information, concerns with the balance of benefits and risks (or harms) have been a long-standing focus of studies about research in genetic medicine. Recent empirical studies have confirmed that participants' perceptions of risks (or harms) and benefits play a substantial role in decisions about research participation (Christensen et al., 2015; Gollust et al., 2011; Hatfield & Pearce, 2014; Jamal et al., 2014; Wood, Kowalczyk, Elwyn, Mitchell, & Gallacher, 2011; Tarrant et al., 2015). Perceived benefit and risks were therefore included as exploratory variables in a research question framed as follows: What are the relationships among role, trust, benefit, risk, and communication expectations? A scale based in perceived information risks was employed to operationalize trust, because information risks are of potentially greatest salience in large research cohorts (Hawkins, 2010; Homer et al., 2008; McGuire, et al., 2011),

## Method

### Participants

Participants were recruited for an on-line survey from a long-standing genetics cancer registry. The Northwest Cancer Genetics Registry (NWCGR) was established in 2010 as the continuation of the Northwest Cancer Genetics Network (NWCGN) established in 1998 as one of the eight original sites of the Cancer Genetics Network, funded by the National Cancer Institute to provide centers specializing in the study of inherited predispositions to cancer. The NWCGR includes as recruited cases persons with cancer ( $n=2027$ ), family members with and without cancer ( $n=451$ ), a population-based comparison sample ( $n=527$ ), and a self-referral group ( $n=340$  with cancer of 904), and their relatives ( $n=464$ ). Participants in the Registry will have had experience at least with the registry core data research questionnaires and subsequent follow-ups, and may have had additional research participation through the NWCGN and outside of it.

Members of the NWCGR ( $n=3352$ ) were recruited for the present study via letters sent by US mail. Up to two follow-up letters were sent at approximately two-week intervals. The study was reviewed and approved by the University of Washington's Human Subjects Division, and by the University of California, Irvine Institutional Review Board. All participants provided informed consent prior to participation.

A total of 450 participants completed the survey (Age:  $M = 63.64$  years,  $SD = 11.81$ ). There were more females (64.9%) than males. Ninety-four percent identified themselves as white, 3.3% as multi-racial, 1.6% as Asian, and 0.9% as African American, and one participant not answering. Regarding education, 61.3% are with bachelor degrees, 23.8% had some college, 8.9% with high school or less, and 6.0% failed to disclose their education level.

### Survey Development

The survey was designed to document the concerns of potential research participants with regard to human genetics in a manner that maximized the possibility for comparison with previously reported data gathered from researchers and IRB professionals (the "GRIPP"

survey; Edwards et al., 2012). The survey was developed through a multi-stage process. First, 31 individuals participated in qualitative interviews (described in Condit et al., 2015). These interviews were used 1) to format or word those questions aligned with the GRIPP survey in language intelligible to research participants, and 2) to identify new topic areas and sub-topics of specific concern to research participants. Changes based on the qualitative survey included, for example, a shift to “donor” from “gift” based on participant explanations and recommendations, and the addition of a distinction in the goals of “collaboration” (whether focused on economically valuable products or health care).

Preliminary versions of the present survey were reviewed by internal and external experts. Changes were made to enhance clarity after these reviews and after cognitive interviews with 37 eligible participants. Final pilot testing on the web platform was used to assess technical difficulties and completion time of the survey.

### Survey Features

The final instrument had 22 questions in six topic areas, including factors affecting decisions to participate in research, elements of relationships between participants and researchers (the focus of the current report), re-consent and blanket consent, return of results, privacy, and family communication relating to health issues.

The survey was delivered through Catalyst, a software developed by the University of Washington. Survey confidentiality was established by employing a unique participation number for each participant and an individual URL to access the survey. Links to individual surveys were retained to enable the use of existing demographic and other participation information and thus reduce the survey length for participants.

### Measures

**Benefit.**—Participants reported how important the following were to them when making decisions to give consent to participation on a 1–4 scale, where 1 = “very important”, 2 = “somewhat important”, 3 = “not very important”, and 4 = “not at all important.” The items were: “the value of incentive from participation”; “the research must be meaningful to me personally”; “the research will improve my health”; “the research will provide information I can use to improve my health”; “the research will provide information about me I didn’t know”; “the research can benefit my family”; and “the research could benefit people I know.” The items were reverse coded and then averaged into a composite score ( $\alpha = .83$ ) such that higher scores indexed more benefits.

**Trust.**—Participants reported how important (1 = “very important”, 2 = “somewhat important”, 3 = “not very important”, and 4 = “not at all important”) each of the following were when asked to provide health information about themselves and a biological sample. The items were: “the reputation of the research institution or researcher”; “the researcher is trustworthy”; “the institution where the research is being conducted is trustworthy”; and “data and sample are stored securely.” The items were reverse coded and then averaged into a composite score ( $\alpha = .60$ ) such that higher scores reflected higher levels of trust.

**Risk.**—Participants estimated the likelihood of certain events occurring in genetic research studies in the next five years (1 = “very likely”, 2= “somewhat likely”, 3= “neither likely nor unlikely”, 4=“somewhat unlikely”, and 5= “very unlikely”): “A research participant would be personally identified in a study involving de-identified data by someone other than the researchers”, “ A research participant would be harmed as a result of identification from de-identified genetic data”, and “a federal agency or other law-enforcement agency might compel researchers to disclose information about genetic research participants.” The items were reverse coded and then averaged into a composite score ( $\alpha = .81$ ) such that higher scores meant more severe risk.

**Roles.**—Roles were measured by single items. Participants reported their opinions about what the relationship between genetic researchers and participants should be like (1 = “strongly agree”, 2 = “somewhat agree”, 3= “somewhat disagree”, and 4 = “strongly disagree”). The relationship statements were: “collaborators working together to make scientific discoveries to improve health”; “a legal contract between two parties”; “a doctor-patient relationship”; “collaborators working together to produce commercial health products”; “participants making a donation to the researcher’s work”, and “a personal relationship.” These variables were also reverse coded such that higher scores reflected more salient roles.

**Mandatory re-consent.**—Participants reported their opinion regarding a national policy that would make it mandatory for researchers to re-contact participants and ask for permission again in each of the following situations (1 = “strongly agree”, 2= “somewhat agree”, 3= “neither agree nor disagree”, and 4= “somewhat disagree” 5= “strongly disagree”): when the researcher wants “to investigate a different, but related health condition”, “to investigate an unrelated health condition or cancer”, “to look at genetic factors in a study that did not originally include those genetic factors”, “to share samples or data with an investigator at another institution”, “the original consent was given by the parents of a child, and the child is not old enough to decide for him or herself”. These items were reverse coded and then averaged into a composite score ( $\alpha = .92$ ) such that higher scores indicated stronger opinion that re-consent should be mandatory.

### Data Analysis Strategy

To test the hypothesis (i.e., that salient and important models of roles predict preferences for re-consent, even in the face of the participants’ recognition of multiple models) and to answer the research question (i.e., What are the relationships among role, trust, benefit, risk, and preferences for re-consent?), a series of hierarchical linear regression analyses were conducted to predict re-consent: age, gender and education were entered in the first block, and the role variables were entered in the second block. The regression model was estimated first with the overall data, and then when each of the roles were salient (strongly agree and somewhat agree), and when non-salient (strongly disagree and somewhat disagree). With these parameters, the sample size of 450 yielded statistical power of about .56 to detect an effect size equivalent to  $r = .10$  when  $\alpha < .05$ . To enhance statistical power, and given the relative exploratory nature of this study, the significance level was adjusted to  $\alpha < .10$ .

## Results

Table 1 presents the descriptive statistics, which indicate that participants endorse multiple roles. Table 2 presents the zero order correlation matrix among the role variables.

### The Impact of Demographics

Table 3 presents the results from the regression analyses. There was impact from demographic variables overall. While there was no impact from education, there was impact from age ( $\beta = -.10, p = .06$ ), which means that older participants were less likely to believe that re-consent should be mandatory. There was no gender effect (female coded as “0” and male coded as “1”) overall, but gender had a positive impact when the following roles were not salient: doctor-patient, donation, legal contract, and personal relationship. The negative coefficients (ranging from  $-.14$  to  $-.22$ ) indicated that females were more likely than males to believe that re-consent should be mandatory than were males.

### The Impact from Benefit, Trust, & Risk

The group of benefit ( $\beta = .16, p = .01$ ), trust ( $\beta = .13, p = .03$ ), risk ( $\beta = .15, p = .003$ ) had robust effects on re-consent preferences. The positive coefficients mean that 1) the more benefits the participants believed there were, 2) the greater the trust they had for the institution and researcher, and 3) the more risk of identification they perceived in genetic research, the more likely they were to agree that re-consent should be mandatory. In other words, the higher the perceived stake, the more likely they were to agree that re-consent should be mandatory. Notably, the influence on participants’ opinion regarding mandatory re-consent was inhibited when the roles were not salient, particularly for scientific collaborator, doctor-patient relationship, donation, and community relationship. This is consistent with the notion that where there is an absence of a strong, clear or singular norm, lay participants in research in effect have no governing role expectations for communication.

### The Impact of Roles

Except for donation and community relationship, the other roles all had impact on the opinion of whether re-consent should be mandatory. Personal relationship had the most robust impact: It had an overall positive effect ( $\beta = .15, p = .02$ ) and such an effect was most salient when other goals were salient, with donation as the only exception: When the donation role was most salient, the role of personal relationship no longer had any impact; on the other hand, when the donation role was not activated, personal relationship enhanced likelihood of believing that re-consent should be mandatory. Legal contract had a positive, overall effect ( $\beta = .09, p = .095$ ). Such effects were manifest mainly when the roles of donation and commercial collaboration were activated and salient. The negative coefficient ( $\beta = -.12, p = .07$ ) suggested that the role of commercial collaboration reduces the opinion that re-consent should be mandatory, especially when the expectations of scientific collaboration and legal contract were dominant. The expectation of doctor-patient relationship did not have an overall effect, but it tended to mitigate the preference for mandatory re-consent, especially when the norms of donation, legal contract, and community relationship were at play.



Combined with the mutual correlations among the roles (Table 2), these results showed that it was probably rare that roles functioned by themselves; rather they formed an associative network: 1) the majority of roles had significant and substantial correlations; 2) the roles that did not correlate (i.e., donation) or had low correlations (i.e., community) with other roles did not have any impact on re-consent preference; and 3) most importantly, the impact from roles on re-consent preference decision making was most pronounced when multiple roles are activated and salient.

## Discussion

This project added survey-based support to previous interview-based findings that research participants do not employ a singular role as an analogy for research participation, but rather endorse multiple analogies. The results further indicated that particularly high or low salience roles nonetheless predicted communication expectations, specifically the expectation for re-consent. Third, the results indicated that trust and assessments of risk and benefit play a role in participants' expectations and are related to some role expectations, but the relationships are not homogeneous across roles.

The generalizability of these results is limited by the profile of these respondents, who are older and less ethnically diverse than the general population. As members of a cancer genetics registry, they bring more research participation experience to bear than would people who are new to research participation.

Although this study has not resolved the issue, it has provided substantial grounds to justify additional research that would move beyond the exploratory stage. In addition to including other types of participants, next stage research will need to develop instruments for measuring role perceptions that are based on scales rather than single questions. That research stage may also profit from integrating the above results with the approaches to roles embodied in relational framing theory and "working models" theories.

Pursuing this line of research would be valuable because these findings have implications for policies related to re-consent in large cohort studies that examine the role of genetics in medical outcomes. The findings that there are multiple role models employed by research participants for the research relationship mean that researchers cannot simply take for granted a singular model for the research participant role and therefore for the researcher-participant relationship. However, our findings also suggested that these role expectations should not be ignored because they have concrete implications for communication expectations. Research by Adams and Parrott (1994) offers a potential resolution of this challenge. Their experimental results showed that formal communication related to roles (in their case articulated as rules) increased the satisfaction of nurses and patients and reduced role ambiguity. This suggests that explicit address of role relationships in consent, recruitment, or other materials framing research participation in large cohort studies such as the Precision Medicine Initiative might be productive. Empirical research to confirm the added value of such explicit address of roles in communication with research participants seems warranted.

These results also extend and support developments in mental models theory that emphasize the creative and emergent character of mental models (Roskos-Ewoldsen, Davies, & Roskos-Ewoldsen, 2004; Zhou & Wang, 2010), especially as related to role theory. The results indicate that, even in the presence of multiple models recognized by participants as relevant, models of particularly high or low salience may inform communication expectations. The finding that the impact was least when roles were least correlated with other roles and that impact was greater with higher activation of multiple roles further suggests the importance of methodological approaches to mental models research that seek to assess the presence of multiple roles and trace their interactions rather than seeking to identify a single dominant mental representation.

The exploratory results have also pointed to the role of salience-guiding variables (in this case, trust and risk/benefit) as involved in the selection of a particular mental model and/or its expectations. Because this exploratory work cannot definitively establish the causal directions of the relationships among these variables, further research is needed to assess these dynamics. However, these results do suggest that in addition to the general variables that influence role expectations across contexts as specified by relational framing theory (dominance/affiliation) or working models of relationship theory (communal sharing, authority ranking, equality matching, and market pricing), adding more role variables specific to particular relational contexts (e.g., risk/benefit, trust) may add additional explanatory power for particular types of roles (such as the health context or research context).

Finally, these results add further stimulation to on-going ethical debates. There is a robust discussion of which consent approaches are most appropriate for biobank research (Brown, Drake, Gehlert, et al., 2016; Ewing, Erby, Bollinger, Tetteyfo, Ricks-Santi, & Kaufman, 2015; Grady, Eckstein, & Berkman, 2015; Tindana & de Vries, 2016). Frameworks include blanket or broad consent, sometimes in the context of opting in or opting out, as well as tiered consent, in which a participant indicates which types of additional research would be acceptable (Garrison, Sathe, Antommara, et al., 2015). Processes for re-consent may be seen by some as one way to fill gaps left by the difficulties involved in projecting the range of future information that may become relevant for evolving biobank usages, especially in the context of increasing roles for the internet in research processes (Kaye, Curren, Anderson, et al., 2012; Trinidad, Fullerton, Bares, Jarvik, Larson, Burke, 2012). The present research results raise the intriguing possibility that understanding more about how both researchers and participants frame the role of “participant” might better inform the presentation of consent and re-consent options to participants. Research to explore how different formats and depths of communicative interactions are affected by and, in a spiral fashion, may affect particular role perceptions, might be both interesting and useful.

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**Table 1:**

## Frequencies of Endorsement of Role Options

	<b>1 Strongly Agree % (N)</b>	<b>2 Somewhat Agree % (N)</b>	<b>3 Somewhat Disagree % (N)</b>	<b>4 Strongly Disagree % (N)</b>
Collaborators working together to make scientific discoveries to improve health	57% (256)	32% (143)	8% (36)	3% (13)
A doctor-patient relationship	42% (185)	35% (154)	17% (73)	7% (29)
Participants making a donation to the researcher's work	32% (142)	42% (185)	16% (72)	10% (44)
A legal contract between two parties	24% (104)	48% (210)	19% (85)	9% (39)
A relationship between an individual and a community	23% (98)	54% (233)	17% (72)	7% (32)
Collaborators working together to produce commercial health products	16% (71)	32% (143)	30% (134)	21% (93)
A personal relationship	9% (40)	27% (121)	31% (138)	33% (145)

Note: Percentages are rounded to nearest whole number. Raw number totals are different because participants were free to skip questions.



**Table 2:**

Zero Order Correlations among the Role Variables (N=450)

	1	2	3	4	5	6	7
1. Scientific collaborator	1.0						
2. legal contract	.23	1.0					
3. Doctor-patient	.36	.34	1.0				
4. Commercial partner	.40	.30	.43	1.0			
5. Donation	.08 <sup>a</sup>	.09 <sup>a</sup>	.09 <sup>a</sup>	.18	1.0		
6. Personal	.39	.33	.49	.49	.17	1.0	
7. Community	.21	.19	.14	.15	.21	.26	1.0

<sup>a</sup>Note: all correlations significant at  $p < .01$  except.

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**Table 3:**

Regression Coefficients Predicting Preference or Mandatory Re-consent

Predictor	Overall	Scientific Collaborator		Doctor-patient		Donation		Legal contract		Community		Commercial collaborator		Personal	
		High	Low	High	Low	High	Low	High	Low	High	Low	High	Low	High	Low
Age	-.10 (.06)	-	-.29 (.09)	-.10 (.08)	-	-	-	-	-	-	-	-.24 (.02)	-	-	-.14 (.03)
Gender	-	-	-	-	-.22 (.049)	-	-.21 (.04)	-	-	-.22 (.04)	-	-	-	-	-.14 (.04)
Benefit	.16 (.01)	.13 (.04)	-	.14 (.04)	-	.17 (.03)	-	.16 (.04)	-	.12 (.08)	-	.15 (.07)	-	.21 (.04)	.15 (.06)
Trust	.13 (.03)	.11 (.08)	-	.12 (.07)	-	-	-	.12 (.08)	-	.14 (.04)	-	-	.21 (.02)	-	.16 (.03)
Risk	.15 (.003)	.14 (.01)	-	.16 (.006)	-	.17 (.006)	-	.14 (.02)	.22 (.03)	.16 (.007)	-	.17 (.02)	.15 (.06)	.17 (.05)	.12 (.06)
Doctor-patient	-	-	-	-	-	-.13 (.07)	-	-.13 (.07)	-	-.19 (.01)	-	-	-	-	-
Legal contract	.09 (.095)	-	-	-	.22 (.057)	-	-	-	-	-	-	.17 (.04)	-	-	-
Commercial collaborator	-.12 (.07)	-.14 (.04)	-	-	-	-	-	-	-.20 (.06)	-	-	-	-	-	-
Personal	.15 (.02)	.16 (.02)	-	.16 (.02)	-	-.27 (.02)	-	.14 (.07)	-	.16 (.04)	-	.22 (.02)	-	.24 (.01)	-

Notes:

<sup>1</sup> Non-significant coefficients suppressed for the sake of clarity.

<sup>2</sup> Education, donation and community did not have any significant effect, hence, dropped from the table.

<sup>3</sup> p-values in parentheses.