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GENETIC INFORMATION ALTRUISTS: HOW FAR AND TO WHOM DOES THEIR GENEROSITY EXTEND?

Completed Research Paper

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Abstract

It is becoming widely accepted that the digitization of healthcare, constructed around a core foundation of electronic health records, is inevitable (American Reinvestment and Recovery Act, 2009). The capture of digital personal health data is expected to drive efficiency, quality of care, and enhanced clinical discovery; culminating in a vision of the future where medical care is tailored to individuals rather than broad populations. Accompanying these developments is an increasingly strident public debate on the privacy and security of digitized health information. To the extent that discovering new drugs, developing new therapies, and understanding the effects of existing treatment regimens requires highly granular genomic data, the promise of personalized medicine cannot be realized unless individuals voluntarily share their personal genetic information. Using theories of altruism, relationship orientation, and commitment as the core conceptual foundations, we investigate the complex trade-off that individuals make between altruism and self-interest in their decision to disclose identified personal genetic information for research purposes to different stakeholders in the healthcare value chain (e.g. hospitals, pharmaceutical companies, government/public health agencies). Depending on the requesting stakeholder and how close the individual feels to the target entity based on levels of interaction and resultant trust and commitment, the influence of altruism and monetary and non-monetary incentives on willingness to disclose is likely to differ. We test our theory with data from 1,089 respondents from a nationally representative sample using a quasi-experimental, survey methodology. Findings suggest the effects of altruism are situational dependent. While incentives were shown to be positive motivators for consumers in their willingness to provide access, consistent with the “motivational crowding” argument, we find that monetary incentives detract from the positive influence of altruism when hospitals make requests to consumers while non-monetary incentives have the opposite effect. The theoretical and policy implications are discussed.

Keywords: Privacy, altruism, incentives, healthcare, personal health information, genetic research

GENETIC INFORMATION ALTRUISTS: HOW FAR AND TO WHOM DOES THEIR GENEROSITY EXTEND?

Introduction

It is becoming widely accepted that the digitization of healthcare in the United States, constructed around a core foundation of electronic health records, is inevitable (ARRA 2009). Accompanying these developments in the digitization of health information is an increasingly strident public debate on health information privacy and security. Digital storage of health information provides a considerably faster, cheaper method of access than traditional paper records (Nakashima 2008), compounding privacy risks (Nakashima 2008; Willison et al. 2007). Studies indicate that the level of general concern related to health information privacy exhibits significant variation across the population (Kohane and Altman 2005). As researchers seek to understand the drivers and motivations underlying individuals' willingness to opt into the electronic storage of their health information, a body of academic research is slowly beginning to emerge (Angst and Agarwal 2009; Agarwal and Anderson 2008; Cox and Thornewill 2008; Raisinghani and Young 2008). Implicit in many of these studies is the assumption that the target use of the information will be for the treatment and care of the individual whose personal health information is being digitized. However, the value of digitized health information extends beyond the individual with the potential to create social value in regard to clinical research and discovery.

In contrast to the current clinical approach of applying treatments for general disease classes and across broad subpopulations, medical care and treatment in the future is envisioned as being "personalized" to the specific genotype and phenotype of the individual (Glaser et al. 2008). Such personalization, it is argued, can make healthcare more "precise, efficacious, and safe" (Kohane and Altman 2005, p. 2074). To the extent that discovering new drugs, developing new therapies, and understanding the effects of existing treatment regimens requires highly granular genomic data, the promise of personalized medicine cannot be realized unless individuals voluntarily share their personal genetic information for research purposes.

The puzzle of pro-social behaviors of contributing to a public good, has been addressed by economists, psychologists, and other scholars and there is agreement that the motivations underlying such behaviors are complex (Reeson and Tisdell 2008). In general, pro-social behavior has been attributed to altruism, the intrinsic desire to benefit others, and self-interest, manifest in incentives or extrinsic rewards. Altruism has been shown to play a role in both health-related behaviors including blood and organ donation (Wildman and Hollingsworth 2009; Miller and Morgan 2002) in which there is a strong expectation that the health of others may benefit (Agarwal et al. 2007) and non-health related charitable giving (e.g. Andreoni 1989). Likewise, incentives have proven efficacious in increasing participation in both marketing and health-related research contexts (James and Bolstein 1990; Ryu et al. 2006; Singer et al. 2000; Slomka et al. 2007; Tishler and Bartholomae 2002). Further, privacy research in online contexts indicates people are willing to share information in return for benefits in the form of personalized service (Awad and Krishnan 2006). Thus, individuals' willingness to disclose digitized genetic health information is likely to be influenced by incentives.

In this paper we investigate the complex trade-off that individuals make between altruism and self-interest in their decision to disclose identified personal genetic information to be stored in a digital database for the purpose of research. Experimental studies show that incentives degrade altruistic tendencies (Ariely et al. 2009, Fehr and Rockenbach 2003; Rodrigue et al. 2006). The logic for the degradation is based on the assertion in theories of motivation that extrinsic rewards tend to undermine the intrinsic motivation typically associated with altruistic tendencies (Deci and Ryan 1984).

Our research extends prior work by examining the influence of situational contingencies: specifically, the target or recipient of the behavior, on the altruism-self-interest tradeoff. We ask the question: under what circumstances does altruism determine willingness to disclose PHI so that it may be digitized and when is self-interest, reflected in incentives, more salient? The request to disclose personal genetic health information (PGHI) to be digitized and used for research purposes may come from a number of different stakeholders in the healthcare value chain (e.g. hospitals, pharmaceutical companies, government/public health agencies), where each benefactor of the research is situated at varied degrees of proximity or remoteness to the individual. Furthermore, individuals have differing levels of interaction with stakeholders, yielding variation in levels of trust and commitment toward them. Altruistic

behavior has been shown to be associated with trust and commitment (Jones et al. 2008; NEJM 2004), and is therefore likely to be differentially exhibited across target entities.

Using theories of altruism, relationship orientation, and commitment as the core conceptual foundations, we explore the relative effects of altruism and self-interest on individuals' willingness to disclose PGHI to different stakeholders. We test our theory with data from 1,089 respondents from a nationally representative sample using a quasi-experimental, survey methodology. Findings from the study yield important implications for policy: the issue of genetic data banking is highly controversial and the subject of vociferous public discourse (Lin et al. 2004; Malin 2005). Policy makers are seeking a deeper understanding of the public's concerns and motivations to participate in voluntary disclosure of PGHI.

The remainder of this paper is organized as follows. We begin with the theoretical foundations, briefly reviewing prior work on altruism and incentives. Next, we discuss the research model and hypotheses. This is followed by the results of empirical tests of the model and a discussion of the theoretical and practical implications of our findings.

Theoretical Background

To understand how altruism and incentives may interact to influence willingness to disclose personal genetic health information, we draw upon theory from psychology and economics that has been applied in diverse domains, including marketing and healthcare. We begin by first examining altruism and how it might vary based on the stakeholder requesting access to PGHI. The literature on altruism and its role in prosocial behavior is extensive and a review is beyond the scope of this paper. As our specific interest is in potential variation in the role of altruism on an individual's willingness to disclose PGHI for research purposes depending on the requesting stakeholder (i.e. the target of commitment), we draw on relationship orientation theory and customer commitment from the marketing domain to inform this potential interaction. We then shift our focus to examining how extrinsic rewards or self-interest in the form of incentives may motivate individuals to share PGHI. Research from economics and healthcare provide insight into how incentives and altruism may interact in the context of digitized PGHI.

Altruism and the Target of Commitment

The notion of altruism has been described and conceptualized in multiple disciplines ranging from evolutionary biology, to philosophy, to social psychology and economics (e.g. Millet and Dewitte 2007; Klapwijk, and Van Lange 2009; Andreoni and Miller 2002). Common across these disciplines is the view that altruism is manifest in behaviors that benefit unrelated "others" without any apparent benefit to the self. Widely discussed examples of altruistic behavior include giving to charity, donating blood, and other-helping behaviors (Andreoni 1989; Andreoni 1995; Tang et al. 2008; Wildman and Hollingsworth 2009). The existence of altruistic behavior in a society appears to be inimical to, at least on the surface, the classic view of rational man and utility-maximizing, self-interested individual behavior that forms the basis for economic theories. However, economists increasingly acknowledge the presence of altruism in human behavior and note that altruism is critical for social welfare as it leads to the production of public goods (Eckel et al. 2005).

Individuals have demonstrated variation in altruistic tendencies based on the nature of the perceived relationship with intended recipients of their behavior. Relationship orientation theory (Clark and Isen 1982) distinguishes between relationships which are exchange-based (acquaintances and colleagues) and those which are communal (e.g. friendships). Exchange-based relationships tend to be more utilitarian in nature and elicit feelings that are more distant. Conversely, communal relationships exist among friends and family members who feel close. The varied degrees of social distance inherent in these two types of relationships can result in different responses during interactions. Prior research shows that the closer, communal relationships yield more helpful behavior (Jones et al. 2008; Loewenstein and Small 2007; Small and Simonsohn 2008). This theory has been applied to explain interactions between both individuals (Small and Simonsohn 2008) and organizations (Jones et al. 2008). For example, in the context of charitable giving, the reduced social distance experienced in communal relationships led to increased levels of sympathy for victims and increased generosity (Small and Simonsohn 2008). Similarly, higher levels of personal commitment in a service provider-consumer relationship led to increased levels of altruism in the form of cooperative behavior (Jones et al. 2008).

Customer commitment is defined as an enduring attitude for a particular organization (Lacey 2007). Committed customers feel an attachment to the target organization and are motivated to maintain the relationship based on this

psychological bond (Jones et al. 2008; Lacey 2007). Such commitment is recognized as valuable by organizations as it can yield numerous positive outcomes including repurchase intentions, positive consumer attitude, willingness to pay, advocacy in the form of recommendations, and altruism (e.g. Gruen et al. 2000; Jones et al. 2008). Trust in an organization is a key driver of customer commitment for consumers (Lacey 2007). Interactions with organizations often involve a level of vulnerability for consumers and trust reduces this uncertainty. In addition, Lacey (2007) found social drivers including shared values and customer recognition were more important in the formation of commitment than economic drivers, including switching costs. Organizations that are more effective at demonstrating shared values by acting on behalf of their customers, recognizing customers and building trust will experience higher levels of customer commitment (Lacey 2007).

In summary, altruistic behaviors are intended to benefit those other than the self. Relationship factors such as social distance and trust between individuals and target organizations influence individuals' altruistic tendencies and levels of commitment toward the organization. Research in the healthcare context is conducted by a number of organizations including hospitals, pharmaceutical companies and government/public health agencies (i.e. stakeholders). This prior research suggests that the factors influencing an individual's willingness to disclose information for research purposes may vary depending on the requesting stakeholder based on the levels of trust and commitment the individual feels for the stakeholder organization.

Incentives in the Presence and Absence of Altruism

Another potential motivating factor which has been explored both in the context of encouraging individuals to engage in research (e.g. marketing research, health research) and in settings where the goal is to encourage people to share personal information, is the role of different forms of incentives. Our context involves both research and personal information, and is further complicated by the fact that research outcomes may benefit other people and, therefore, providing access to the information may appeal to an individual's altruistic nature. We begin by examining literature from a more self-interested view (absence of altruism) and then move to summarize relevant literature on the interaction between incentives and altruism.

Providing access to PGHI to stakeholders for research purposes is not likely to have an immediate benefit to an individual. This is often the case for other types of research conducted by organizations. Consequently, organizations offer incentives in exchange for information they cannot otherwise obtain. In this way, both parties receive something in the transaction. Incentives have a long history of use in marketing research to improve response rates to requests for information made in a variety of formats including by mail, telephone and face-to-face (James and Bolstein 1990; Ryu et al. 2006; Singer et al. 2000). Higher monetary incentives resulted in higher response rates and a greater degree of effort expended in completing questionnaires (James and Bolstein 1990). Prepaid incentives also resulted in greater participation rates in telephone surveys (Singer et al. 2000). Non-monetary incentives such as postage stamps, tickets, or coupons also increase response though not as robustly (Ryu et al. 2006). While incentives in these settings seem highly successful, the risk to the consumer is likewise low. Often, this type of research is anonymous and/or the information is arguably not as sensitive as personal health information or as research conducted on the individual herself with possible physical ramifications.

Offering incentives to recruit volunteers to participate in health-related research is controversial due to potential ethical and legal concerns (Slomka et al. 2007; Tishler and Bartholomae 2002). Nonetheless, it is still frequently used as a method of enticement with Institutional Review Boards relied upon to ensure that researchers do not offer incentives that constitute "undue inducement" (Emanuel 2005; Slomka et al. 2007). Studies show that financial rewards are significant motivators among both healthy and non-healthy volunteers who choose to participate in clinical trials (Slomka et al. 2007; Tishler and Bartholomae 2002).

With the increasing use of the Internet and the opportunity to capture large volumes of information about customers, studies have been conducted to determine the extent to which consumer willingness is influenced by benefits such as personalized service or monetary incentives (Awad and Krishnan 2006; Dinev and Hart 2006; Ward et al. 2005). Results have been mixed. Some studies indicate that offers of personalized service and monetary incentives do not decrease privacy concerns to yield higher subsequent willingness to share personal information (Hoffman et al. 1999; Ward et al. 2005) while others indicate that privacy concerns can be outweighed by personal interest (Dinev and Hart 2006) and a desire for personal service (Awad and Krishnan 2006). In the direct mail context, consumers are willing to provide information in exchange for time savings (Phelps et al. 2000). These contradictory results suggest a need for continued research on the influence of incentives in digitized privacy contexts.

The studies described thus far assume a self-interested consumer receiving either monetary or non-monetary benefits for information provided or for research participation. The majority of research on the effects of incentives in the presence of altruism suggests that monetary incentives reduce prosocial activity (Ariely et al. 2009, Fehr and Rockenbach 2003; Rodrigue et al. 2006). This is particularly true if the incentives or sanctions are perceived as self-interested in which case they can serve to “crowd out” altruism altogether (Benabou and Tirole 2006; Eckel et al. 2005; Fehr and Rockenbach 2003; Seabright 2002). Altruists are not motivated by thoughts of reciprocity (Simpson and Willer 2008) but rather by thoughts of benefiting others (Agarwal et al. 2007). However, if incentives are perceived as fair and moralistic, they do not detract from altruistic behavior (Fehr and Rockenbach 2003).

A specific example in which altruism and the potential effects of incentives have been examined is in the context of organ donation. Altruism is a strong motivating factor associated with organ donation (Morgan and Miller 2002). However, organ donation rates are low compared to the high demand for organs. Financial incentives and other forms of compensation such as charitable contributions made in a loved one’s name have been considered as methods for increasing donation rates. Ninety-one percent of next-of-kin surveyed indicated that incentives would not have made a difference (Rodrigue et al. 2006). Studies have shown that rewards can degrade an intrinsic desire to “do good”. Altruistic individuals have an image of themselves as people who have an intrinsic desire to “do good” and they prefer to do things that are consistent with this view. They are demotivated by incentives which signal to others that their actions may be anything other than purely philanthropic (Ariely et al. 2009) and are turned off by actions taken by others that they perceive to be self-interested (Fehr and Rockenbach 2003).

The research summarized in this section suggest that incentives are customary, almost expected in many settings in which organizations seek information or require participation from individuals. Individuals are often willing to give up their personal information or participate in research with some element of risk to themselves in return for personal gain. However, when their motivations for participation are intended to benefit someone other than themselves, the notion of receiving a personal benefit is noxious and has detrimental effects on their motivation. These findings may influence the role incentives may play on consumer willingness to provide access to personal genetic health information depending on whether the individual’s motivations are partially altruistic or not.

Conceptual Model and Hypotheses

Figure 1 depicts our conceptual model of the drivers of willingness to disclose PGHI for research purposes. We focus on the critical role played by altruism and self-interest and the interaction of these two key motivating factors. The outcome we study is willingness to share identified personal genetic health information for storage in electronic format for research purposes to a particular stakeholder. Healthcare stakeholders are represented by hospitals, pharmacies or governmental/public health agencies each of whom have their own research agendas.

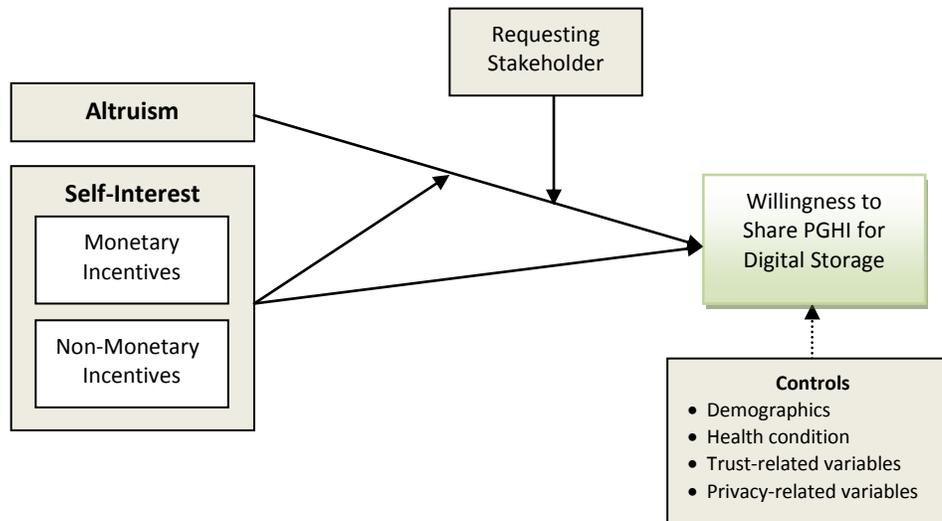


Figure 1. Conceptual Model

As suggested by past research (Agarwal et al. 2007; Miller and Morgan 2002), we expect altruism to play a role in willingness to disclose PGHI for research purposes. However, we anticipate that this relationship will be

complicated by the stakeholder requesting the information due to the variation in the levels of interaction consumers have with each stakeholder. Specifically, we argue that the differences in the types of relationships consumers have with hospitals, pharmaceutical companies and government/public health agencies leads to different perceptions of their roles with regard to healthcare research and different levels of trust and commitment to these organizations. Consumers likely have more interactions with hospitals. For example, physicians send patients to hospitals for tests, individuals visit friends and relatives at hospitals, and individuals may have spent time in a hospital as a patient themselves (either inpatient or outpatient). Many physicians' offices are adjacent to hospitals. In each of these cases, people meet and interact with hospital employees and may form a personal bond with a nurse, doctor or staff member who represents the hospital. These relationships can serve to increase an individual's level of attachment and commitment to the organization (Jones et al. 2008).

Contrast the opportunities individuals have to form impressions of hospitals with the number of opportunities the majority of individuals have to interact with pharmaceutical companies (e.g. Pfizer and Johnson and Johnson) or government/public health agencies. Physicians are visited by sales representatives from pharmaceutical companies. But, unless you are a physician or actually work for a pharmaceutical company, your direct interaction with them is likely limited. Your exposure likely consists of seeing an occasional commercial or print ad for one of their drug therapies. Finally, while people may occasionally visit a local public health agency to obtain free vaccines or other services, the average person rarely interacts with the larger, centralized agencies such as the Centers for Disease Control and Prevention.

This variation in interaction between stakeholders leads to different levels of trust and commitment. We would expect trust to be highest for hospitals given that consumers should be more familiar with hospitals and familiarity has been associated with trust (McKnight et al. 2002). A number of study findings suggest that individuals' privacy beliefs change based on the organization involved in the exchange (Stone et al. 1983). Consumers indicate they are less concerned about sharing medical information with grocery and drug stores than they are about sharing the same information with an insurance company or their employer (Rohm and Milne 2002). Additionally, in a survey conducted by the state of West Virginia, consumers indicated they trust doctors and hospitals the most to own electronically stored health information and trust for-profit companies (e.g. insurance companies) the least (Global Strategy Group 2007). Similarly, consumer commitment is higher when trust exists (Jones et al. 2008; Lacey 2007). Finally, Canadian citizens also trust hospitals and disease foundations the most, followed by drug companies. Distrust for the government was highest (Willison et al. 2007). Trust may also lead consumers to believe that the recipient of the information will actually do something useful with it. For example, they may believe that hospitals will use the data for research while pharmaceutical companies might seek to profit from it, and governments to discriminate against citizens.

Commitment and relationships that feel "closer" have been associated with altruistic behavior across a variety of settings and contexts (Jones et al. 2008; Sargeant, A, and Woodliffe, L. 2007; Small and Simonsohn 2008). The altruistic individuals who volunteer for research in clinical trials must first have a high level of trust in the researchers and their respective institutions that the knowledge gained by their participation will be disseminated to others and contribute to improved health for others (NEJM 2004). People tend to give more when an individual is identified as a target beneficiary (Loewenstein and Small 2007) or when giving to a group with which they identify (e.g. Levine et al. 2002). In general, the existence of a personal link to the organization or cause significantly increase an individual's altruistic tendencies (Sargeant, A, and Woodliffe, L. 2007.). Thus, we expect altruism to be a significant factor influencing willingness to provide access to PGHI to hospitals due to the levels of trust and commitment consumers have for this stakeholder. We do not anticipate altruism will be a factor in willingness to disclose to pharmaceutical companies or government/public health agencies due to the more utilitarian and instrumental nature of the relationships consumers have with these stakeholders. Thus, we hypothesize:

Hypothesis 1: The requesting stakeholder moderates the association between altruism and willingness to provide access to PGHI such that the relationship is significant for socially close stakeholders (i.e. hospitals) and not significant for socially distant stakeholders (i.e. pharmaceutical companies and government/public health agencies).

Although some of the studies conducted in the context of pure marketing (i.e. when the organization is interested in gathering the individual's information and the intentions are not necessarily clear as to what use the information may be put) suggest that individuals may be wary of incentives when they are offered, it is customary in the context of other research settings for people to be compensated for their time and effort in completing surveys or interviews (James and Bolstein 1990; Ryu et al. 2006; Singer et al. 2000) and participating in health-related research (Emanuel

2005; Slomka et al. 2007; Tishler and Bartholomae 2002). When hospitals, pharmaceutical companies and government/public health agencies make requests to consumers for access to their personal genetic health information for the purposes of research, it is more similar to the situation in which consumers are asked to participate in other forms of research in which incentives are frequently offered. In these circumstances, incentives increase participation (Hui et al. 2007; Ryu et al. 2006; Singer et al. 2000; Slomka et al. 2007; Tishler and Bartholomae 2002). Collectively, this research suggests people are receptive to compensation for providing access to their personal information for research purposes. Therefore, we posit:

Hypothesis 2: Incentives are positively associated with willingness to provide access to PGHI.

Hypothesis 2a: Monetary incentives are positively associated with willingness to provide access to PGHI

In the context of digitized information, highly customized and relevant information could be offered to an individual in exchange for disclosure of information. For example, if one were offered the opportunity to be kept informed of new drug therapies relevant to one's own genetic history, might that serve to make an individual more likely to disclose information? Therefore, we examine the influence of not only monetary incentives but also non-monetary incentives including customized emails and newsletters. Forms of appreciation and methods of interaction may serve to establish a social exchange contract between the consumer and the stakeholder because the benefits received by the consumer are feelings of stakeholder gratitude and obligation (Ward et al. 2005; Hoffman et al 1999). Thus, we expect non-monetary incentives to increase consumer willingness to provide access to PGHI:

Hypothesis 2b: Non-monetary incentives (e.g. emails, newsletters) are positively associated with willingness to provide access to PGHI.

The healthcare institution relies heavily on the altruism of individuals when making appeals to the public for help. Altruism is a factor in why people choose to donate blood (Wildman and Hollingsworth 2009), donate organs (Miller and Morgan 2002), participate in research (Kohane and Altman 2005; NEJM 2004), and give to charity (Sargeant and Woodliffe 2007). When altruism is a motivating factor, extrinsic drivers such as incentives tend to serve as demotivating factors (Ariely et al. 2009, Fehr and Rockenbach 2003; Rodrigue et al. 2006). The majority of the research examining the effects of incentives on altruistic behavior has involved monetary incentives or publicly visible incentives such as tickets to events and the like. Therefore, we anticipate that the offering of monetary incentives in the context of our study will dampen the positive influence of altruism.

Hypothesis 3: The offering of incentives moderates the association between altruism and willingness to provide access to PGHI.

Hypothesis 3a: Monetary incentives negatively moderate the association between altruism and willingness to provide access to PGHI.

Fewer studies have examined the influence of non-monetary incentives on altruism and motivation. Many charities offer small tokens of appreciation (e.g. customized return address labels, coffee mugs, stickers) in exchange for donations (Ariely et al. 2009). Routine informational mailings are not uncommon for committed donors to charitable organizations (Sargeant and Woodliffe 2007). In addition to intrinsic motivation to act in an altruistic manner, individuals may be motivated to gain social approval which is a form of image motivation (Ariely et al. 2009). Altruistic individuals like to think of themselves as "good" (Ariely et al. 2009). As described above, the availability of digitized information on the consumer would enable the customization of emails and newsletters including highly relevant information on the status of research to which the consumer's information has contributed. Incentives such as newsletters may enhance the effect of altruism as the consumer is made aware of the benefits of his/her contribution and, as a result, may come to feel even more invested in the research outcomes. Small tokens of appreciation such as coffee mugs or return address stickers can signal to others that the individual is altruistic (Ariely et al. 2009).

Hypothesis 3b: Non-monetary incentives positively moderate the relationship between altruism and willingness to provide access to PGHI.

Methods

Sample and Data Collection

We used a scenario-based repeated measures quasi-experimental strategy to test the research hypotheses. Data were collected using an electronic survey administered by a third party organization. Subjects read hypothetical scenarios and then completed items to indicate how they would respond (Rosenthal and Rosnow 1984). This approach is commonly used in marketing studies (e.g. Rick et al. 2008). The sample for the study is drawn from the target population which is the general adult public and constructed to be representative of the general US population.

The survey first provided contextual information on what the digital health exchange of information could look like to ensure consistency of background understanding of the core issue for each respondent. Each respondent indicated his/her willingness to disclose PGHI to each stakeholder (hospital, pharmaceutical company and government/public health agency). To eliminate ambiguity, the survey provided definitions and examples for genetic health information and for each stakeholder. To infuse realism, we adapted scenarios from those developed for the Health Information Security and Privacy Collaboration (HISPC). Acknowledging the degree of variability in stakeholders and their relationships with consumers of healthcare, in 2005, the federal government's department of Health and Human Services (HHS) created HISPC, a partnership consisting of a multi-disciplinary team of experts (HHS 2005). To address privacy and security policy questions, HISPC created scenarios designed to cover a wide range of types of information as well as the intended use of the information by a variety of stakeholders to ensure coverage of all procedures/policies since different policies/procedures apply based on these factors (Dimitropoulos 2007).

Operationalization of Variables

We adapted measures from prior studies and used multi-item scales to improve reliability and validity. Willingness to disclose PHGI is measured using three items on a 7-point semantic scale anchored by not probable/probable, unwilling/willing and unlikely/likely. To assess willingness to disclose, the respondents replied to items following this general format: A [stakeholder] may be interested in recruiting patients for participating in clinical trials being conducted to test new drug treatments or therapies for certain genetic conditions. Specify the extent to which you would be willing to grant a [stakeholder] access to your personal genetic health information for such purposes.

An individual's altruistic tendencies in terms of helpfulness and giving is measured using 4 items found to be associated with organ donation (Kopfman and Smith 1996; Morgan and Miller 2002). We used single-item measures to assess the extent to which monetary or non-monetary incentives would make the individual more or less likely to share information with each stakeholder. As acknowledged by other researchers, a single item measure is appropriate where there is no ambiguity about the type of response that is being sought (Wanous and Hudy 2001).

The survey also captures demographic variables including age, gender, race/ethnicity, income and education level. We control for the potential influence of a number of other variables that are not central to this study but that are likely to influence willingness to disclose PGHI based on prior privacy research. These include trust-related variables (trust in the medium (Dinev and Hart 2006) and trust propensity (McKnight et al. 2002)); privacy-related variables (media coverage of privacy (Malhotra et al. 2004), prior experience with privacy violations (Malhotra et al. 2004), and electronic privacy concern (Dinev and Hart 2006)); and health condition variables. This final category of controls includes respondents' personal medical history and experience with a close loved one's genetic illness, as well as health status emotion (Agarwal and Anderson 2008). We use the number of doctor appointments and respondent's own indication of genetic illness as proxies for current state of health (Appendix A.) We conducted a pilot study with 28 respondents after which we made minor adjustments to instructions and item wording.

Results

The final sample consists of 1,089 respondents. The third party service organization assures an average 20% response rate. In our efforts to achieve national representativeness in our sample, we acquired numerous samples which enabled us to conduct sub-sample comparisons. In addition, we were also aware of the timing of email reminder notifications which enabled us to compare early and late responder data. These comparisons are consistent with those recommended Rogelberg and Stanton (2007) to assess potential non-response bias. No significant

differences were found between the summated scales for the sub-samples or early versus late responders, alleviating the threat of non-response bias (Armstrong and Overton 1977; Rogelberg and Stanton 2007).

Descriptive statistics for study constructs are shown in Table 1¹. Cronbach's alpha for the study scales are .80 or better suggesting the measures are acceptably reliable. Results of a confirmatory factor analysis support convergent and discriminant validity of the scales². We created indices for the remaining analysis.

We use a repeated measures ANCOVA analysis to test the influence of requesting stakeholder on altruism on an individual's willingness to provide access to identified PGHI. This test is particularly appropriate for assessing differences in an individual's judgment in a variety of circumstances (Potter and Balthazard 2004; Thatcher and De La Cour 2003). A repeated measures analysis provides greater power to detect effects by reducing the unsystematic variability by controlling for individual differences (Grabe and Westley 2003; Rencher 2002). Thus, we compare individuals' within subject willingness to provide access to PGHI to hospitals, pharmaceutical companies and government/public health agencies. We include altruism and a variety of covariates including demographic characteristics, trust- and privacy-related variables and health condition variables. We test for violations of sphericity with Mauchly's test of sphericity and utilize the Greenhouse and Geisser (1959) estimates to obtain a correction factor that assesses the observed F-ratio. Results are reported in Table 2.

The data supports two way interactions between stakeholder and altruism ($F=5.239; p<.05$). Contrasts indicate that the differences in mean levels of willingness between the pharmaceutical company and government/public health agencies do not significantly differ with levels of altruism ($F=.332; p=.565$). However, the mean levels for willingness to disclose to hospitals is significantly different as altruism levels change from both the pharmaceutical company ($F=6.137; p<.05$) and the government/public health agency ($F=8.114; p<.05$). This finding suggests support for hypothesis 1 by indicating that when requests for access to PGHI are made by hospitals, altruism plays a role, but it does not for requests made by pharmaceutical companies or public health agencies. To further explore this relationship and to test the remaining hypotheses, we conducted three separate regressions utilizing willingness to disclose to each of the three stakeholders individually as our dependent variable in each model.

We estimated each model in three stages by first introducing control variables, followed by main effects, and then by interaction terms. The results of the analysis are summarized in Table 3. As the results of the main effects model for hospitals indicate, altruism is positive and significant ($B=.037; p<.05$). As an individual's altruistic tendencies increase, her willingness to disclose to hospitals also increases. Altruism is not significant in either the model for pharmaceutical companies ($B=-.009; p=.579$) or government/public health agencies ($B=-.006; p=.684$). These findings provide support for hypothesis 1.

Across the models for each of the stakeholders, the main effects model results indicate that both monetary and non-monetary incentives are positive and significant factors influencing willingness to disclose. In the case of pharmaceutical companies and government/public health agencies, monetary incentives appear to play a more significant role as the standardized beta coefficients are higher for the monetary incentive as compared to the non-monetary incentive. The reverse is true for willingness to disclose to hospitals (i.e. non-monetary incentives have a higher coefficient). These findings provide strong support for hypotheses 2a and 2b.

Finally, the last set of hypotheses relate to the interaction of altruism with incentives. To test the interaction, we focus on the results of the full model for willingness to disclose to hospitals only since the results to hypothesis 1 indicate that altruism is only a factor in disclosure decisions involving this stakeholder. The interaction between altruism and monetary incentives is negative and significant indicating that monetary incentives tend to reduce the positive influence of altruism on willingness to disclose ($B=-.113; p<.001$). The interaction between altruism and non-monetary incentives is positive and significant indicating that non-monetary incentives enhance the positive influence of altruism on willingness to disclose ($B=.092; p<.05$). Hypotheses 3a and 3b are supported.

As indicated in the change in r-squared values, the addition of the main effects of altruism and incentives to the base model (i.e. model with just controls) results in an increase of 48-49% across the three stakeholder models in total variance explained. This finding supports the importance of these constructs in explaining consumer willingness to provide access to PGHI for research purposes over and above trust- and privacy related variables, individual and loved one's health condition, and demographic characteristics.

¹ Descriptive statistics incorporating control variables are available from the authors.

² Principal Component Analysis results are available from the authors.

In summary, our data provides support for all three hypotheses. Altruism is only a significant predictor in willingness to provide access to PGHI for research purposes for the more trusted hospital stakeholder. Monetary and non-monetary incentives act as significantly positive motivators for consumers in their willingness to provide access to PGHI for research purposes. However, our data does provide evidence that monetary incentives detract from the positive influence of altruism when hospitals make requests to consumers. Intriguingly, non-monetary incentives in the form of informational emails and newsletters can enhance the positive role of altruism on consumer willingness to provide access to hospitals.

Limitations

The implications of the study findings should be considered in light of its limitations. First, the survey was conducted online and, thus, represents the perceptions of consumers who have access to computers and may be more receptive to the digitization of health information than consumers who do not have similar access. Future research should include telephone interviews or face-to-face, hardcopy surveys designed to reach consumers without easy access to the Internet. Second, as is often a concern with self-report survey data, there is the threat of common method bias (Podsakoff et al. 2003). We combat this potential problem procedurally by assuring respondent anonymity, varying the item scale endpoints and formats between the predictor and criterion measures, and providing contextual information in conjunction with definitions to reduce ambiguity (Podsakoff et al. 2003). In addition, an exploratory factor analysis as suggested by Podsakoff et al. (2003) indicates that no single factor explains the majority of covariance among the measures suggesting that common method biases do not present a significant problem with the data.

Second, to gain responses for each stakeholder, each respondent completed three sets of questions for the dependent measure as part of our repeated measures design. Thus, the results are subject to potential order effects as is the case with any such design. Counterbalancing the ordering of questions is one technique to avoid and test for systematic order effects; however, it is labor intensive and does not always work and should be utilized only when there is reason to believe the effects are significant enough to subsume or inflate the treatment effects (Cohen 1995; Reese 1997). We do not have reason to believe that any group of interest in our study is any more sensitive than any other to carryover effects (e.g. practice, fatigue, contrast or assimilation) which suggests our approach of administering the scenarios consistently to all respondents is reasonable (Cohen 1995).

Third, our research *specifically focused* on individual willingness to disclose *genetic* health information. Genetic information is somewhat unique because it is enduring (i.e. not subject to change in the same manner as say, mental health information or general health information). In addition, it can have ramifications not just for the individual but also for family members due to the hereditary nature of some genetic diseases. The extent to which our research model holds for other forms of PHI (e.g. mental health) is an empirical question for further research.

Finally, since participation in the survey was voluntary, it is possible that our sample is comprised of highly altruistic individuals, and that the findings may not generalize to less altruistic individuals. However, the sample was obtained from a third-party organization which provides promotional points as an incentive for qualifying individuals to participate in online surveys. The promotional points can then be used to purchase merchandise or contribute to charitable causes. Therefore, there is the possibility that a portion of respondents are acting in a more self-interested manner.

Discussion and Conclusions

The digitization of personal health information is a deeply sensitive and contentious issue in public debates. On the one hand it raises the specter of privacy violations, discrimination, lack of access to healthcare, and other negative consequences. On the other, it offers value for individuals through benefits related to efficiency and better quality of care at the personal health level, and for society, by enabling clinical research and scientific discovery that could benefit all citizens in the future. Genetic bio-banks that store large volumes of genomic information in electronic form are expected to become increasingly common (Greely 2007); an illustrative example of such a bio-bank is the Personal Genome Project at Harvard University where “volunteers from the general public are working together with researchers to advance personal genomics” (<http://www.personalgenomes.org/>). It is only natural that citizens and governments alike are deliberating the legal and ethical dilemmas these databases create.

Our study was predicated on the inevitability of the importance of population level genomic data. We sought to understand what would motivate individuals to contribute to this “common cause,” and how these motivations might vary depending on who the recipient of the information was. We find that altruism plays a role in influencing disclosure decisions to “trusted” entities but not so for recipients perceived as being distant to the giver. Financial incentives diminish the effects of altruism towards the trusted entity, while non-monetary incentives serve to enhance it. Incentives of both varieties can be efficacious in increasing motivation to share PGHI with pharmaceutical companies and the government.

Several implications for theory and practice follow. For theory, although prior research has examined the altruism-incentives trade-off, no research that we are aware of offers theoretical insight into the situational nature of this relationship. We used theoretical logic drawn from relationship orientation and commitment to argue for differential effects of altruism across targets. This raises the interesting question of whether altruism is a generalized propensity/disposition (as it is frequently conceptualized in the literature that refers generally to “altruists”), or a more specific trait that explains variation in behavior differentially across settings. Future research could explore the nature of the altruism construct in greater depth. Second, this study examined willingness to disclose identified PGHI where, arguably, the risks to the individual are greater than would be the case for de-identified information. In the latter context, it may be the case that altruism does indeed have a positive influence on disclosure decisions even to non-trusted entities. This expectation could be examined in future empirical work. Third, recent work on prosocial behaviors has identified “image” motivations as important behavioral drivers in decisions to give to charity (Ariely et al., 2009). Would visible acknowledgement of genomic database contributors enhance contributions by enhancing the public image of the givers? This issue merits further investigation. Finally, we used operational measures of incentives that are at a fairly coarse level of granularity. Research examining a range of financial and non-financial incentives and their interaction with altruism would be a useful extension to this work.

The key public policy issue that this research has implications for is the source of requests for voluntary contributions of information for social causes in situations where information disclosure can potentially create vulnerabilities for individuals. Appeals coming from hospitals may instigate contribution behaviors without incentives while the government and pharmaceutical companies will need to explicitly motivate the desired behavior through incentives. Even for hospitals, our findings suggest they should consider the use of non-monetary incentives to increase participation in genetic research. Alternatively, given the causal mechanism proposed here, that it is trust and distance from the recipient that de-motivates even the altruists, pharmaceutical companies and governmental agencies could seek to get “closer” to the public and gradually build greater confidence about their trustworthiness. Future research could further explore the factors driving the differences we found across stakeholders. We focused on generic stakeholders to gain a foundational understanding of any differences in motivational factors across types of stakeholders. Additional research could explore the differences between more specific entities (e.g. the Veterans Administration, the Mayo Clinic, Pfizer, the National Institute of Health). A second practical implication of our findings is the need for the development of assurances, both regulatory and legislative, that protect the security and confidentiality of PGHI. A low willingness to disclose to pharma and government may, in part, be a result of a lack of robust policy mechanisms. The absence of such structural assurances may lead consumers to think they have little recourse or redress if their PGHI were to fall into the wrong hands.

In conclusion, it is an aphorism that the health of a nation is an issue of significant social concern. Advances in biomedical science coupled with the increasing capabilities of information technology simultaneously offer societal promise and individual peril. This research explores one facet of the changing nature of medical science and focuses on understanding the challenges associated with building the foundational infrastructure for clinical discovery: large scale electronic genomic data bases. It can serve as the basis for much fruitful future research.

Table 1. Descriptive Statistics													
Variable		Reliability (No. of Items)	Min	Max	Mean	St. Dev	1	2	3	4	5	6	7
1	Willingness	.95 (3)	1.00	7.00	4.22	2.07	1						
2	Altruism	.89 (4)	1.00	7.00	5.67	1.05	.15	1					
3	Mon. incv. (Hos)	n/a	1.00	7.00	4.72	2.01	.69	.15	1				
4	Mon. incv. (Pha)	n/a	1.00	7.00	4.19	2.13	.73	.13	.80	1			
5	Mon. incv. (Govt.)	n/a	1.00	7.00	4.07	2.13	.72	.11	.75	.84	1		
6	Non-Mon. incv. (Hos.)	n/a	1.00	7.00	4.64	1.94	.69	.19	.81	.67	.63	1	
7	Non-Mon. incv. (Pha)	n/a	1.00	7.00	4.13	2.05	.73	.16	.68	.85	.72	.79	1
8	Non-Mon. incv. (Govt.)	n/a	1.00	7.00	4.01	2.02	.72	.12	.64	.72	.86	.74	.83

*Correlation is significant at the .05 level (2-tailed); † Correlation not significant; All other correlations significant at the .01 level (2-tailed)

Table 2. Repeated-Measures ANCOVA Table for Willingness to Provide Access to PGHI				
Source of Variance	Degrees of Freedom *	Mean Square	F-Statistic *	P-Value
Within-Subjects Factors				
Stakeholder	1.95	2.861	2.482	.085
Stakeholder X Altruism	1.95	6.037	5.239	.006
Covariates				
Male	1	.982	.467	.495
Age	1	4.759	2.262	.133
Hispanic	1	.172	.082	.775
Race	1	.103	.049	.825
Income	1	4.004	1.903	.168
Education	1	2.208	1.050	.306
Negative Emotion	1	69.029	32.807	.000
Positive Emotion	1	8.281	3.936	.048
Altruism	1	29.751	14.140	.000
Trust Propensity	1	152.312	72.388	.000
Trust in Medium	1	703.528	334.359	.000
Electronic Privacy Concern	1	36.388	17.294	.000
Medical History	1	11.129	5.289	.022
Prior Privacy Violations	1	.031	.015	.903
Media Exposure	1	12.631	6.003	.014
Genetic Disease	1	1.637	.778	.378
Loved One's Genetic Disease	1	.559	.266	.606
Error	1010	.2104		
Total N		1089		
Number of observations per subject		3		

* The F-statistic violated the sphericity assumption ($p < .001$) for the stakeholder within-subject factor. The Greenhouse and Geisser (1959) estimates were applied to make conservative corrections to the F-ratio which is reported here.

Table 3. Regression Results for Willingness to Disclose PGHI for Research Purposes by Stakeholder

Variables	Hospital			Pharmaceutical Company			Government / Public Health Agency		
	Model 1: Control variables	Model 2: Main effects	Model 3: Full model	Model 1: Control variables	Model 2: Main effects	Model 3: Full model	Model 1: Control variables	Model 2: Main effects	Model 3: Full model
Constant	3.906***	.417*	.416*	4.173***	.383*	.381*	3.618	.078	.078
Male	-.069*	-.045*	-.045*	-.036	-.029	-.029	.007	.008	.008
Age	.120***	.072***	.068**	.041	.024	.025	.038	.038	.038*
Hispanic	-.014	.017	.019	-.009	.001	.001	-.001	.001	.001
Race	-.020	-.013	-.011	-.016	-.012	-.012	.024	.010	.010
Income	-.005	.003	.001	-.028	-.004	-.004	-.032	.004	.004
Education	.062*	.001	.005	-.018	-.014	-.014	.031	-.003	-.003
Negative Emotion	.095**	-.020	-.017	.182***	.014	.013	.176***	.038	.018
Positive Emotion	-.019	-.032	-.035*	.081**	.028	.029	.083**	.028	.038
Trust Propensity	.142***	.006	.009	.220***	.050**	.049**	.214***	.041**	.042**
Trust in Medium	.427***	.063**	.064**	.420***	.048**	.048**	.439***	.047**	.047**
Electronic Privacy Concern	-.054	-.016	-.019	-.092**	-.028	-.027	-.168***	-.074	-.073***
Medical History	.061*	.017	.020	.064*	.023	.022	.066*	.033	.032*
Prior Privacy Violations	-.021	.001	.000	.011	-.004	-.003	.027	.000	.000
Media Exposure	-.012	.025	.023	-.070*	.005	.005	-.084**	-.003	-.002
Genetic Disease	.031	.020	.019	.029	.007	.008	.018	.016	.017
Loved One's Genetic Disease	.015	.019	.023	.014	.004	.002	.015	-.025	-.026
Altruism		.037*	.037*		-.009	-.009		-.006	-.005
Monet. Incentives		.347***	.374***		.499***	.493***		.503***	.501***
Non-Monet. Incentives		.497***	.470***		.375***	.381***		.379***	.380***
Altruism x Monet. Incentives			-.113***			.041			-.002
Altruism x Non-Monet. Incentvs			.092**			-.030			.015
Total N	1089	1089	1089	1089	1089	1089	1089	1089	1089
R-squared	.243	.720	.724	.293	.781	.781	.318	.809	.809
Adjusted R-squared	.231	.715	.718	.282	.777	.777	.307	.805	.805
R-square Change	.243	.477	.004	.293	.488	.000	.318	.491	.000

*: p<.05; **:p<.01; ***:p<.001

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APPENDIX A – Measurement Items

Construct	Measure
WILLING1	Unlikely/Likely
WILLING2	Not Probable/Probably
WILLING3	Unwilling/Willing
TRUST1	The electronic/digital storage format of health information is a safe environment in which to exchange health information with others
TRUST2	The digital storage format is a reliable environment in which to conduct health related transactions
TRUST3	Organizations handle personal health information submitted by patients in an electronic format in a competent fashion
CONCERN1	Compared with other subjects on my mind, the privacy of my electronic personal health information is very important
CONCERN2	I am concerned about threats to the privacy of my electronically stored personal health information today
CONCERN3	All things considered, I believe the privacy of my electronic personal health information is seriously threatened
NEGEMOT1	Right now I feel sad about something that has happened to my health
NEGEMOT2	I feel disgust for my current state of health
NEGEMOT3	I have an intense loathing for my present state of health
NEGEMOT4	I feel furious at my present state of health
NEGEMOT5	I feel very deep sorrow because of my health
NEGEMOT6	Right now other things in my life will have to wait
NEGEMOT7	My current health state is a real inconvenience
NEGEMOT8	I am extremely displeased with my present health state
NEGEMOT9	Health problems are tiresome to me
NEGEMOT10	My present health problems fill me with dread
NEGEMOT11	Recent experience has warned me to be more cautious about my health
NEGEMOT12	I feel everything needs to be approached with caution right now
JOY1	My spirits are high today
JOY2	I feel ecstatic about life right now
JOY3	I am happy about my health right now
ALT1	Helping others is one of the most important aspects of life.
ALT2	I enjoy working for the welfare of others
ALT3	My family tends to do what we can to help those less fortunate than ourselves.
ALT4	I agree with the old saying, “It is better to give than to receive.”
TP1	I usually trust people until they give me a reason not to trust them
TP2	I usually give people the benefit of the doubt
TP3	My general approach is to trust new acquaintances until they prove I should not trust them

Incentive Questions

If you were offered a financial incentive to provide access to your genetic health information for the purposes described in the previous 3 questions (i.e. clinical trial research), would you be more likely to share your information with a [hospital/ pharmaceutical company/government/public health agency]?

If you were offered the opportunity to be kept informed of the progress of research related to health areas of personal interest (e.g. via email, newsletters) in exchange for providing access to your *genetic health* information for the purposes described in the previous 3 questions (i.e. clinical trial research), would you be more likely to share your information with a [hospital/ pharmaceutical company/government/public health agency]?