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Sharing is About Caring? Motivating and Discouraging Factors in Sharing Individual Genomic Data

Scott Thiebes  
*University of Kassel*, thiebes@uni-kassel.de

Kalle Lyytinen  
*Case western reserve university*, kjl13@case.edu

Ali Sunyaev  
*University of Kassel*, sunyaev@uni-kassel.de

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Scott Thiebes
University of Kassel
Mönchebergstr. 19,
34109 Kassel, Germany
thiebes@uni-kassel.de

Kalle Lyytinen
Case Western Reserve University
10900 Euclid Avenue
Cleveland, Ohio, United States
kjl13@case.edu

Ali Sunyaev
University of Kassel
Mönchebergstr. 19,
34109 Kassel, Germany
sunyaev@uni-kassel.de

Abstract

Reasons for individuals to (not) share their genomic data with human genomic research remain largely unexplored. We employ privacy calculus as our theoretical lens and conduct a ranking-type Delphi study among genomic data donors, genomics professionals, and health privacy experts to elicit 19 motivating and 17 discouraging factors that influence individuals’ willingness to donate their genomic data to human genomic research. Our results suggest that altruistic reasons form major motivators, whereas privacy concerns, trust issues, and a fear of adverse medical implications are major discouraging factors. We also see noteworthy differences in donors’ and non-donors’ rankings of motivating and discouraging factors. The study adds to ongoing research on health information disclosure and shows that genomic data, despite their unique characteristics, are not that different from other patient’s health information. The study also contributes to privacy calculus literature by highlighting the need to incorporate altruistic motivators into the privacy calculus.

Keywords: Genomics, genome data sharing, health information, information privacy, privacy calculus, Delphi study

Introduction

Fueled by the completion of the Human Genome Project in 2003 and rapid advances in DNA sequencing technologies, the price for sequencing a human genome has dropped from over $95,000,000 to less than $1,500 (Wetterstrand 2016). The long-held dream of precision medicine, which allows for the targeted treatment of individual patients on a variety of diseases such as cancer, is no longer a distant vision, but an emerging reality in contemporary clinical practices (Koboldt et al. 2013). Such precision medicine offers new, effective means to treat patients according to their specific genomic profiles lowering overall morbidity and mortality of those patients (Tsimberidou et al. 2012). While the large-scale sequencing analysis of
human genomic data forms the foundation of precision medicine, it comes with inherent information privacy challenges (Dove et al. 2015). A prominent example of such challenges is Henrietta Lacks' case. She died in 1951, but her genomic information has been made public posthumously without her or her family's consent (Skloot 2013). Shortly after Henrietta Lacks' genome was published online, researchers were able to compile a full personal information report about her and her family not only breaching Henrietta Lacks' privacy but also breaching her family's privacy (Skloot 2013). Access to genomic data is thus accompanied with significant personal, social, professional, financial, and insurance-related risks (Shoenb bill et al. 2014). The information can cause stigmatization and discrimination of data donors and their relatives and might ultimately lead to a loss of insurance or employment (Shoenb ill et al. 2014). The real presence of such risks as well as recent, prominent breaches of sensitive medical information, like the Anthem breach which affected about 80 million US citizens (McNeal 2015), have raised the public’s skepticism towards providing private health, especially genomic data to healthcare organizations and research institutes (Heath et al. 2016). Recent trends in genomics towards cloud computing and related heightened information security and privacy risks are likely to further amplify such skepticism. Potential data donors will increasingly fear to contribute their genomic data to research eventually impeding advances in genomics and precision medicine. Given this precarious situation, we ask the following research question:

**RQ: What motivates or discourages individuals to disclose their genomic data to genomic research?**

In general, past research has investigated individuals’ motivations to participate in medical research and receive genetic testing. Consistent with prior research on individuals’ motivations to contribute to genomic research, we posit that research knowledge on general motivations of individuals to contribute to medical research cannot necessarily be transferred to human genomic research (Heath et al. 2016). In principle, all types of individual health data can be considered sensitive. But genomic data is inherently different from other health data in that it possesses several unique characteristics. Contrary to other types of data, genomic data cannot be readily anonymized (Gymrek et al. 2013) and future possibilities for analyzing genomic data and deducing information seem almost unlimited and can hardly be foreseen at the time of sequencing one’s genome (Nyholt et al. 2009). Research in information systems has a long tradition of investigating individuals' information disclosure behavior (e.g., Anderson and Agarwal 2011; Angst and Agarwal 2009; Culnan and Armstrong 1999; Dinev and Hart 2006; Kordzadeh and Warren 2017). Thus far, there is dearth of research which has investigated the role of motivational factors that drive individuals’ intentions to provide or withhold their genomic data from human genomic research given the apparent privacy related risks in this “high-risk/high-reward scenario” (Heath et al. 2016, p. 289). We can employ general privacy calculus (Culnan and Armstrong 1999; Dinev and Hart 2006) as a theoretical lens to elicit and organize factors that are likely to motivate or discourage individuals to disclose their genomic data. However, privacy calculus does not offer context sensitive information about the specifics of these factors. To address this weakness, we conduct a ranking-type Delphi study to identify and rank related factors. Through this study, we hope to foster a deeper understanding of individuals’ motivations to contribute to genomic research by uncovering specific factors that influence why individuals do or do not share their genomic data. Overall, our results identify 19 motivating and 17 discouraging factors which can serve as a foundation to assist policy makers and research institutes in designing privacy policies and data governance processes that honor data donors’ needs. As a result, data donors will be more willing to share their data which will facilitate medical advances. From a scholarly point of view, we add to the discourse on what motivates individuals to participate in medical research by sharing information. At the same time our study goes beyond scrutinizing general attitudes in participating in medical research by focusing on specific motivational factors to contribute to genomic research. We also apply privacy calculus to a novel and timely phenomenon, thereby demonstrating its applicability to a diverse and unique domain.

The remainder of this paper is structured as follows. In the next section, we provide an overview of the current state of research on genomic privacy as well as an overview of applications of the privacy calculus in health information disclosure. In section three we outline our research methods by detailing the followed three-phased Delphi method. Section four presents the results of our Delphi study in form of a list of 19 motivating and 17 discouraging factors as well as their relative ranking. We discuss these results in section five, and provide implications for practice and research before concluding the paper in the last section.
Motivating and Discouraging Factors in Sharing Genomic Data

Literature Review

Genomic Privacy and Sharing of Genomic Data

Due to the sensitive nature of health data and the rapid diffusion of health information technologies, information privacy (i.e., an individual's interest in controlling or at least significantly influencing the flow of her personal health information (Clarke 1999)) is a growing concern in healthcare. Extant research highlights that individuals are particularly concerned about the (unintended) disclosure of their health data and such information privacy concerns having a negative impact on individuals’ willingness to disclose their health data (Bansal and Gefen 2010). Nevertheless, numerous individuals have decided to provide research with their genomic data as shown by the success of projects like the 1000 Genomes Project (The 1000 Genomes Project Consortium 2012). Individuals’ motivations to disclose their personal health data to research are not understood well and subject to ongoing discussions. As noted, genomic data is inherently different from other health data. First, disclosure of genomic data does not only have information privacy implications for data donors themselves but also for their relatives (Humbert et al. 2013). Second, benefits from using the data may not be restricted to individuals but can expand to groups of individuals or entire societies. In the context of human genomic research individuals have thus heightened interests in controlling the flow of their personal information (i.e., to contribute their genomic data to or withhold their genomic data from human genomic research).

Despite a large body of literature on attitudes to participate in medical research (e.g., Kim et al. 2015; Robling et al. 2004), or general attitudes towards human genomic research (e.g., Lemke et al. 2010), only a limited number of studies so far has explored people’s attitudes towards sharing their genomic data (e.g., Haga and O’Daniel 2011; Oliver et al. 2012; Shabani et al. 2014; Trinidad et al. 2010). Even fewer studies have gone beyond attitudes and investigated specific factors that either motivate or discourage individuals to share their genomic data (see Table 1). While the sharing of genomic data is not the primary reason for receiving direct-to-consumer genomic testing, receiving such tests makes it nonetheless inevitable to disclose one’s genomic data to a third party. Extant research has identified several health related reasons for such disclosure (Goldsmith et al. 2012; Gollust et al. 2012) as well as individual’s urge to learn about one’s ancestral history (Christofides and O’Doherty 2016) as main drivers for receiving direct-to-consumer genomic testing. Related health reasons include the desire to learn more about specific health conditions such as heart diseases (Gollust et al. 2012), the intention to adopt a healthier lifestyle in case of a predisposition for an inheritable disease or to support physicians in monitoring one’s health, or informing children about possible inheritable diseases (Cherkas et al. 2010). Research also indicates that financial reasons (Ries et al. 2010) and privacy concerns (Christofides and O’Doherty 2016) can negatively impact individuals’ willingness to receive direct-to-consumer genetic testing, especially for low-income females (Bloss et al. 2010). Another stream of literature not directly concerned with the sharing of genomic data for research purposes has been concerned with the idea of precision medicine and patients' willingness to provide genomic data as a means to receive targeted treatments. Research in this area has found that patients are willing to share their genomic data in situations where it could help with improving their drug prescriptions and/or lowering the likelihood of trial-and-error treatments (Issa et al. 2009). Moreover, relatives are often willing to share their genomic data as to support treatments for their family (Helm et al. 2015). Similar to direct-to-consumer genetic testing, high costs and privacy concerns have been found to be main reasons against sharing genomic data (Issa et al. 2009).

To the best of our knowledge there currently exist only few studies that have sought to uncover specific factors which motivate or discourage individuals to disclose their genomic data to human genomic research and their relative importance. Heath et al. (2016) investigated the effects of information privacy concerns and the awareness of benefits of human genomic research on one’s intention to disclose genomic data to research. Using a theory of planned behavior (TBP) (Ajzen 1991) lens, they found evidence that privacy concerns have a negative influence on individuals’ intentions to share genomic data as well as that awareness (of privacy incidents) has a positive influence on privacy concerns. Kim et al. (2016) explored the effects of participating in online discussions about the benefits and risks of human genomic research on individuals’ intentions to disclose their genomic data to research. They found that participating in online discussions about human genomic research results in fewer negative beliefs about contributing one’s genetic data. Anderson and Agarwal (2009) researched the effects of altruism as well as monetary and non-monetary incentives in conjunction with trust in the genome data receiver on individuals’ willingness to
share their genome data. They found that altruism influences individuals’ decisions to disclose their genome data to trusted third parties like their doctors. For entities more distant to the potential donor (e.g., pharmaceutical companies), altruism seems to be less relevant. Furthermore, their findings suggest that non-monetary incentives may enhance the effects of altruism on one’s willingness to share genomic data with trusted entities, whereas monetary incentives weaken the effects. For distant entities, non-monetary and monetary incentives may both serve as motivating factors to share genome data. Sanderson et al. (2016) examined motivations, concerns, and preferences of human genomic research participants. According to their results, individuals are especially motivated to learn more about their health, genes, and ancestry, and are eager to help others. At the same time, their results also indicate that individuals have concerns related to privacy and medical results of genome analyses. Lastly, Haeusermann et al. (2017) studied a genome data sharing website’s users motivations to share their genomic data. The results highlight that users’ willingness to share their genomic data is often influenced by non-medical reasons such as curiosity about oneself or altruistic reasons. They also show that users are well aware of the privacy-related, non-medical risks associated with disclosing one’s genome data publicly.

While the previously outlined studies are similar to this research, they also call for further investigating individuals’ motivations to disclose their genomic data (Haeusermann et al. 2017). To this end, Sanderson et al. (2016), for example, focus on motivations and concerns of healthy individuals, whereas Haeusermann et al. (2017) conducted a quantitative study with genomic data donors. In this study, we do not restrict our sample to only healthy individuals or genome data donors. Instead, we seek to also account for those who have decided against disclosing their genomic data and also take a broader view of discouraging factors as opposed to concerns. Moreover, we provide rich insights by conducting a qualitative study and examine the relative importance of elicited factors.

<table>
<thead>
<tr>
<th>Stream of Literature</th>
<th>Identified Reasons For (+) or Against (-) Sharing</th>
<th>Exemplary references</th>
</tr>
</thead>
</table>
| Sharing genomic data for direct-to-consumer genetic testing                           | + Health related: Learn about a certain health condition; adopt a healthier lifestyle; inform relatives about inheritable diseases  
  + Learn more about one’s family history  
  - High costs of receiving a genetic test  
  - Privacy concerns                                                                 | Bloss et al. (2010); Cherkas et al. (2010); Christofides and O’Doherty (2016); Goldsmith et al. (2012); Gollust et al. (2012); Ries et al. (2010) |
| Sharing genomic data for receiving treatment (i.e., precision medicine)                | + Reduce trial-and-error treatments  
  + Support treatments of family members  
  - Absence of clinical experience  
  - High costs of receiving genetic testing/precision medicine  
  - Privacy concerns                                                                 | Helm et al. (2015); Issa et al. (2009)                                                                     |
| Sharing genomic data for research purposes                                            | + Help others  
  + Advance medical research  
  + Learn more about oneself  
  + Curiosity/fun  
  + Monetary incentives  
  - Privacy concerns  
  - Concerns about medical results                                                  | Anderson and Agarwal (2009); Haeusermann et al. (2017); Heath et al. (2016); Kim et al. (2016); Sanderson et al. (2016) |

Table 1. Streams of literature and exemplary findings on sharing genomic data.

**Privacy Calculus in Health Information Disclosure**

Drawing upon expectancy theory, the privacy calculus concept analyzes tradeoffs between benefits and costs that individuals perceive in situations of information disclosure (Culnan and Armstrong 1999). Hence, the privacy calculus aims at rationalizing individuals’ attitudes, beliefs, intentions, and behaviors in cases
where information disclosure is accompanied with a perceived disclosure risk (Keith et al. 2013). In its essence privacy calculus stipulates that individuals are willing to accept certain information privacy risks, in exchange for some perceived benefits (Dinev and Hart 2006). In the context of this study this translates into potential data donors accepting risks of unintended uses of their genomic data or inadvertent results of genomic data analyses (e.g., learning to have a predisposition for a certain disease) in exchange for benefits related to the analysis of this data (e.g., improved treatment). Extant research has explored the privacy calculus concept in diverse areas such as e-commerce (Dinev and Hart 2006), social networking (Krasnova et al. 2012), and location-based services (Keith et al. 2013).

So far, only few studies have applied the privacy calculus in the context of health information disclosure. Kordzadeh et al. (2016) and Kordzadeh and Warren (2017), for instance, explored the privacy calculus in context of virtual health communities. Their research indicates that privacy concerns as well as expected outcomes for users of virtual health communities and the communities themselves affect users’ willingness to reveal personal health information (Kordzadeh and Warren 2017). Furthermore, they identified age, health status, and affective commitment as antecedents to privacy calculus constructs (Kordzadeh et al. 2016). Lee and Kwon (2015) on the other hand utilized privacy calculus for the development of a user-centered feature selection method for mobile health wellness services. Overall, extant research suggests that individuals are willing to disclose personal health information and, thus, accept certain information privacy risks in exchange for perceived benefits like improved healthcare quality, improved health management, or better physician-patient communication (Li et al. 2014). Moreover, Anderson and Agarwal (2011) found that the decision to disclose personal health information for some perceived benefit is dependent on a variety of contextual factors such as type of collected information, purpose of information collection, and who collects the information (e.g., physicians, governments, researchers, etc.). While this highlights the need for context-specific research on the disclosure of personal health information, individuals’ willingness to provide their genomic data to research regarding the tradeoff between perceived information disclosure risks and perceived benefits of disclosing one’s genomic data remains largely unexplored. Employing privacy calculus as our theoretical lens, we elicit what factors motivate or discourage individuals to share their genomic data with research in this study.

Research Approach

Within extant literature there are few, often contradicting claims about what motivates individuals to donate their genomic data. Thus, we need to obtain first contextual knowledge from experts involved in collecting genomic data (e.g., people who have already donated their genomic data) as to answer specifically our research question. To address this type of inquiry goal, the Delphi method is the most flexible and well-established research method available. It aims at collecting and consolidating expert judgments that relate to complex and ambiguous decision-making scenarios (Gnatzy et al. 2011; Hsu and Sandford 2007; Piccinini et al. 2015). Since the decision on whether to make one’s genomic information widely accessible is followed by a diverse set of potential benefits and risks it can be approached as a complex decision-making scenario. the Delphi method is also particularly suited for research tasks that are exploratory in nature and for situations where the researcher has a limited access to knowledgeable experts (Paré et al. 2013; Piccinini et al. 2015; Singh et al. 2009). This is the case with our research question. Hence, we deemed the Delphi method suitable in addressing our research question. We employ specifically a ranking-type Delphi process outlined by Schmidt (1997). While there are numerous variations of the Delphi method, ranking-type Delphi studies are probably the most commonly used variation today. In addition, that this method allows us to elicit motivating and discouraging factors for individuals to disclose their genomic data, ranking-type Delphi also delivers insights concerning the relative ranking of those factors. Ranking-type Delphi studies consist of the three phases (1) Brainstorming, (2) Selection, and (3) Ranking. Figure 1 highlights our research approach adapted from Piccinini et al. (2015).

Panel Selection

Delphi does not rely on a large sample to generate meaningful insights. Instead it seeks input from knowledgeable experts with a good understanding of the problem domain (Okoli and Pawlowski 2004). Since our research objective is to identify motivating and discouraging factors for individuals to disclose their genomic data, our panel should ideally consist of individuals who have donated their genomic data at least once in the past and individuals who have decided not to donate their genomic data.
Motivating and Discouraging Factors in Sharing Genomic Data

Figure 1. Three-phased research approach adapted from Piccinini et al. (2015).

However, due to privacy-related and regulatory reasons it is very difficult to get in contact with people who have donated their genomic data. Even more so, there is an inherent difficulty in getting a hold of individuals who have considered to donate their genomic data but eventually decided against doing it. Consequently, we sought to include other domain experts in our panel. To this end, we decided to include experts in the realm of health information privacy and genomic privacy since they should be aware of risks of sharing one’s health information. We also reached out to professionals involved in the collection and processing of genomic data, presuming they can report of their experiences with both, genome data donors and individuals that have chosen to not donate their genomic data.

We used purposeful sampling (Miles and Huberman 1994) and employed different techniques to recruit genome data donors and professionals. To recruit donors, we set up a website describing our research objectives and a form to sign up for participating in our study. Subsequently, we contacted the operators of openSNP.org, a website that provides a platform for people to publish their genome data that they received from services such as 23andMe, deCODEme, or FamilyTreeDNA. They offered to send out a description of our research and the link to our project website to subscribers of their mailing list and Twitter account. One administrator also offered to participate in our study. We also contacted individuals of several Facebook groups, concerned with genealogy and genomics services such as 23andMe. In total, 30 individuals registered for our study via the project website with 13 of them actually participating in the study (return rate 43.33%). For experts on health information privacy and genomic privacy as well as for professionals involved in the collection and processing of genomic data we used personal contacts from a multidisciplinary cancer genomics project we are involved with (MILES Project Consortium 2017) and snowball sampling (Miles and Huberman 1994). We also reached out to researchers involved in renown genomics projects like The Human Genomic Project and ENCODE (ENCyclopedia Of DNA Elements), as well as DNAdigest, a charitable organization promoting the sharing of genomic data. We specifically reached out to researchers that were organized in research groups concerned with or had published

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1 By the time the emails were sent out by openSNP.org about 5,053 users had registered for their mailing list whereas 802 people followed openSNP.org on Twitter.

2 Since he had a background in bioinformatics and was working with genomic data, we considered this individual to belong to the group of professionals involved in the collection and processing of genomic data.
research articles or blog posts concerned with ethical and privacy-related aspects of genomic data donations. A total of 60 emails were sent out with 15 experts joining our study. Finally, one more individual confronted with the decision to donate his genomic data who eventually decided against doing so was recruited via a personal contact. As a result, the panel for our Delphi study consisted of 30 participants, of which 50% (n = 15) had donated genomic data at least once in the past. While only 13 participants were included in our panel primarily for being genomic data donors, two more experts from the other groups had also donated their genomic data before. Table 2 lists relevant demographic data of our panelists.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Panel profile (n=30)</th>
</tr>
</thead>
</table>
| **Primary reason for panel inclusion** | Genomic data donor: 43.33%  
Potential genomic data donor: 3.33%  
Professional involved in the collection and/or processing of genomic data: 40.00%  
(Genomic/Health) Privacy researcher: 13.33% |
| **Ethnicity** | White: 96.67%  
Asian / Pacific Islander: 3.33% |
| **Sex** | Female: 26.67%  
Male: 70.00%  
Other: 3.33% |
| **Age** | Min: 27 years; Max: 73 years  
< 28 years old: 3.33%  
28-35 years old: 33.33%  
36-44 years old: 23.33%  
> 44 years old: 40.00% |
| **Nationality** | German: 43.33%  
American: 30.00%  
Canadian: 6.67%  
British: 6.67%  
Other (French, South Korean, Surinamer): 10.00%  
Unknown: 3.33% |
| **Level of education** | High school graduate, diploma or equivalent: 6.67%  
Some college credit, no degree: 13.33%  
Bachelor’s degree: 6.67%  
Master’s degree: 40.00%  
Doctorate degree: 33.33% |
| **Blood donors** | Yes: 46.67%  
No: 46.67%  
Prefer not to say: 6.67% |
| **Organ donors** | Yes: 23.33%  
No: 56.67%  
Prefer not to say: 20.00% |
| **Genomic data donors** | Yes: 50.00%  
No: 43.33%  
Prefer not to say: 6.67% |

Table 2. Panel demographics.
Motivating and Discouraging Factors in Sharing Genomic Data

Data Collection and Analysis Methods

A key drawback of ranking-type Delphi studies is their long duration due to the iterative nature of the inquiry process (Bardecki 1984). It often results in high panel attrition and dropout rates (Bardecki 1984). To minimize dropouts and to reduce our own logistical overhead, we conducted our Delphi study entirely over the internet, using a standard online survey software for the questionnaire rounds and email to communicate with our participants.

Starting with the brainstorming phase, panelists were presented a brief overview of the Delphi process in each phase as well as information about the purpose of the current phase. Next, panelists were given a brief introduction to the study context and the overall objective of the study. We also informed panelists that they could participate in a raffle for a $100 Amazon gift card after completing the survey. Following the introduction, we asked the panelists to name and describe (Okoli and Pawlowski 2004) at least three motivating and discouraging factors for donating their genome data to research. Thereby, we chose to ask panelists for three reasons each since our pretests showed that this would provide a good coverage of the problem domain while at the same time reducing the efforts required from participants to complete the brainstorming phase. If necessary, panelists could name and describe up to 10 motivating and 10 discouraging factors. During the brainstorming phase, some participants felt unable to provide more than one discouraging factor. Since we deemed their input relevant for our study we enabled those panelists to complete the survey nonetheless.

In total, 30 panelists completed the brainstorming phase. They provided us with 94 motivating factors and 93 discouraging factors. Each panelist named between one and four motivating factors (avg. 3.13) and between one and four discouraging factors (avg. 3.10). Following the suggestions by Paré et al. (2013) and Schmidt (1997), we consolidated both sets of responses (i.e., motivating and discouraging factors) by aggregating duplicate responses, unifying terminology, and grouping similar factors. An initial consolidation was performed by a single researcher, which was then discussed with two other researchers familiar with this topic. This consolidation process resulted in a list of 19 motivating factors grouped into five categories of similar factors and 17 discouraging factors grouped into five categories of similar factors. Getting the consolidation approved by the panelists is an essential step in any Delphi study because otherwise one cannot be sure that the panelists’ thoughts have been adequately captured and represented (Paré et al. 2013). Thus, we sent a list of all consolidated motivating and discouraging factors to the panelists and asked for feedback or approval. The list contained a mapping of each participant response to an aggregated motivating or discouraging factor. To avoid any potential form of unwanted bias, it did, however, not contain the grouping of these factors. The feedback lead to minor adjustments of our consolidated list in the form of slight rephrases and mapping one response to a different aggregated motivating factor. This did not yield adding new or removing existing factors.

As it becomes increasingly difficult for surveyed experts to manage many items and provide a meaningful ranking (Schmidt et al. 2001), extant literature typically suggests to provide 20 or less items during the ranking phase of a ranking-type Delphi study (Schmidt 1997). Although, considered for themselves, the lists of motivating and discouraging factors had less than 20 items each, we nonetheless followed the approach of Schmidt et al. (2001) and asked participants to select the at least 10 most important motivating and the at least 10 most important discouraging factors during the selection phase. Since we considered keeping experts on the panel for consecutive questionnaires more important than artificially forcing them to select 10 items no matter what, we nonetheless enabled experts to complete the selection phase even in cases where they felt unable to select the at least 10 most important items. We also asked participants to provide a short explanation for their selection of items. This was, however, not mandatory. Overall, 27 out of 30 panelists completed the selection phase. They considered between 10 and 13 motivating factors as most important (avg. 10.59) and between 6 and 13 discouraging factors as most important (avg. 10.15). Following the suggestions by Schmidt et al. (2001), we decided to keep all items for the ranking phase that were selected by most panelists. Again, extant literature does not provide any definite cutoff value but instead uses diverse values ranging from as low as 30% (e.g., Piccinini et al. 2015) up to as high as 70% (e.g., Singh et al. 2009). We experimented with different cutoff values (i.e., 30%, 50%, and 70%), with a 50% cutoff value producing the most promising results. With this criterion neither too many items were dropped nor kept for both sets of factors. By the end of the selection phase, panelists had narrowed down the list of motivating and discouraging factors to 12 items each.

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In the ranking phase, we asked our panelists to rank the remaining motivating and discouraging factors in their order or priority (separately for both sets of factors). We presented the 12 most important motivating and 12 most important discouraging factors to the remaining 27 panelists in random order and also provided information on how many panelists considered an item important as well as the reasons that were given during the second round. Adding to this, we again asked panelists to justify their rankings. Of the 27 remaining panelists, 26 completed the ranking phase. To measure the degree of consensus between the experts in our ranking phase, we employed Kendall’s coefficient of concordance (W), which is frequently used in Delphi (Paré et al. 2013; Schmidt 1997; Singh et al. 2009). Thereby, a value of close to 0 or 0 for Kendall’s W indicates a weak to no consensus, whereas a value close to 1 or 1 expresses strong or perfect consensus. Typically, consensus is considered weak for values of W = 0.3, moderate for W = 0.5, and strong for W = 0.7 (Schmidt 1997). Moreover, we used a Friedman test to calculate the mean rank for each item (Friedman 1937). Twenty-six panelists completed the ranking phase, reaching a consensus of W = 0.23 for the motivating factors and W = 0.19 for the discouraging factors. Although this represents a relatively weak consensus for both sets of factors, we discuss potential reasons in the Discussion section.

**Results**

**Brainstorming Phase: Motivating and Discouraging Factors**

The brainstorming phase yielded 19 factors that motivate (Table 3) and 17 factors that discourage (Table 4) individuals to donate their genomic data to human genomic research.

<table>
<thead>
<tr>
<th>Categories</th>
<th>Motivating Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Altruistic Factors (ALT)</td>
<td>• Contribute to scientific research in general</td>
</tr>
<tr>
<td></td>
<td>• Support medical research for a certain disease</td>
</tr>
<tr>
<td></td>
<td>• Facilitate medical research</td>
</tr>
<tr>
<td></td>
<td>• Satisfaction of helping others</td>
</tr>
<tr>
<td></td>
<td>• Help people to find family members</td>
</tr>
<tr>
<td>Personal Benefits (PB)</td>
<td>• Therapeutic relevance for myself</td>
</tr>
<tr>
<td></td>
<td>• Identify predispositions for certain diseases</td>
</tr>
<tr>
<td></td>
<td>• Learn about myself</td>
</tr>
<tr>
<td></td>
<td>• Curiosity about genealogical history</td>
</tr>
<tr>
<td></td>
<td>• Support my own or a friend's research</td>
</tr>
<tr>
<td></td>
<td>• Establish innocence in a criminal investigation</td>
</tr>
<tr>
<td></td>
<td>• Monetary compensation</td>
</tr>
<tr>
<td>Benefits for Relatives and Friends (BRF)</td>
<td>• Therapeutic relevance for family members or someone I know</td>
</tr>
<tr>
<td></td>
<td>• Test for inheritable disease prior to conception</td>
</tr>
<tr>
<td>Socially Desirable Behavior (SDB)</td>
<td>• Community</td>
</tr>
<tr>
<td></td>
<td>• Challenge public stigmas</td>
</tr>
<tr>
<td></td>
<td>• Set an example for others</td>
</tr>
<tr>
<td>False-Positives (FP)</td>
<td>• Protection of my data</td>
</tr>
<tr>
<td></td>
<td>• Being healthy</td>
</tr>
</tbody>
</table>

*Table 3. Motivating factors that emerged from the brainstorming phase.*

We categorized similar motivating factors into five categories: 1) Altruistic Factors (ALT), 2) Personal Benefits (PB), 3) Benefits for Relatives and Friends (BRF), 4) Socially Desirable Behavior (SDB), and 5) False-Positives (FP). The ALT category consists of factors related to outcomes that are desirable from a broader perspective but do not yield any direct benefits for the data donor, her relatives or friends. Panelists differentiated between a general desire to contribute to research, willingness to donate genomic data to especially facilitate medical research as opposed to all research, and supporting the advancement of existing or the development of new diagnostic means and therapies for a specific disease one is personally involved with, without directly benefiting from this research. Adding to this, the ALT category also includes simply
being satisfied by helping others and providing genomic data to help others find long lost family members as motivating factors.

The PB category includes by far the largest number of motivating factors. Thereby, panelists cited health-related benefits such as donating genomic data to support researchers and medical professionals in developing new or targeted therapies for a disease one suffers from and receiving information about predispositions for certain diseases to promote a healthier lifestyle and protect against increased risks. Panelists were also interested in learning more about themselves and their genetic makeup, and were curious about their genealogical history (e.g., one’s ethnic background, paternal and maternal lineages, and family histories). Other motivating factors related to personal benefits comprise receiving monetary compensation for providing researchers with genomic data, establishing one’s innocence in a criminal investigation, and supporting one’s or a friend’s research by confirming results or redirecting the research through the donation of genomic data.

We classified two motivating factors to belong to the BFR category. First, panelists named helping researchers and medical professionals to develop new or targeted therapies for a disease a family member or friend suffers from as a motivating factor. Second, panelists were interested in supporting genomic research to help with family planning by testing for inheritable disease prior to conception.

The category of SDB consists of such motivating factors that are socially desirable on a personal and societal level. On a personal level, our panel expressed feeling to be part of a community as a motivating factor. On a societal level, participants cited challenging the stigmatization of certain disease within the society and thus motivating others to share their genomic data, and setting an example for others as motivating factors.

Finally, the FP category consists of factors that do not convey a direct motivation, but instead are considered positively expressed discouraging factors. Panelists stated that they wanted their data to be protected, meaning that they want to be informed about the implications of making their genomic data accessible, knowing that appropriate security standards are applied for the collection, storage, and processing of their genomic data, and that data is anonymized and treated confidentially. We interpreted this as an expression of privacy concerns and the fear of inadequate privacy protection, which is also one of the listed discouraging factors. Similarly, being healthy and not expecting any seriously damaging information to be present in one’s genome corresponds to a variety of cited discouraging factors such as discrimination or governmental abuse of genomic data.

<table>
<thead>
<tr>
<th>Categories</th>
<th>Discouraging Factors</th>
</tr>
</thead>
</table>
| Privacy and Security Concerns (PSC) | - Privacy infringement  
- Discrimination or misuse of my genomic data  
- No possibility to withdraw data  
- Insecure data handling |
| Medical Implications (MI)   | - Fear of medical implications for myself  
- Uncertain implications for relatives |
| Secondary Uses (SU)         | - Unethical use of genomic data  
- Governmental abuse  
- Commercial use |
| Research Process (RP)       | - Absence of feedback  
- No well-defined objectives  
- Exploitation of data by researchers  
- Long study durations |
| Beliefs and Personal Situation (BPS) | - High costs  
- Being in a bad condition  
- Absence of a serious disease  
- Religious beliefs |

Table 4. Discouraging factors that emerged from the brainstorming phase.
Like the motivating factors, we also categorized the discouraging factors into five categories: 1) Privacy and Security Concerns (PSC), 2) Medical Implications (MI), 3) Secondary Uses (SU), 4) Research Process (RP), and 5) Beliefs and Personal Situation (BPS). Privacy-related factors in the PSC category include fearing that one’s privacy might be irreparably compromised, for example, by being able to link genomic data to personal profiles (i.e., insufficient anonymization) and the fear of being discriminated against or that one’s genomic data is misused (e.g., identity theft, insurers increasing fees, or employers screening employees). Panelists also expressed their concern about being unable to withdraw data or the permission to use data in cases where personal situations or attitudes have changed. On the security side, panelists feared insecure storage and processing of genomic data, including lack of security standards and inadequate data governance.

Two discouraging factors belong to the MI category. First, participants expressed to be discouraged to donate their genomic data due to fear of learning something about themselves that they are not prepared for (e.g., knowing the possibility of suffering from a certain disease) or the opposite, learning that they are healthy, which could in turn lead to complacency in lifestyle. Second, panelists voiced their concern over the possibility of using their genomic data against their relatives and that it is difficult to get permission of all relatives that might be affected by the disclosure of one’s genomic data.

The SU category of discouraging factors includes the potential of using genomic data for reasons considered unethical, such as creating so-called designer babies, military research or unethical ideologies like “eugenics” in Nazi Germany (David et al. 1988). Panelists were also concerned that their genomic data might be abused by governments to control people (e.g., to establish a police state). Adding to this, panelists stated that the possibility of corporations using their genomic data for commercial purposes, including copyrighting and patenting (with or without profit sharing) would impede their willingness to donate their genomic data.

The RP category comprises discouraging factors that are associated with how research is carried out and communicated. Surveyed experts reported that the absence of any feedback whatsoever about the results of a research project they donated to would discourage them to support future research projects. It was also stated that unclear research objectives or researchers repeatedly exploiting donors’ genomic data for their own benefits (e.g., to publish in prestigious journals) would hamper willingness to provide one’s genomic data to researchers. Finally, participating in human genomic research can be a time-consuming endeavor, which might deter some from participating at all.

We aggregated discouraging factors rooted in one’s beliefs and personal circumstances in the BPS category. Panelists stated that costs of providing genomic data can be prohibitive. This might, for instance, be the case if individuals get their genome sequenced privately and later decide to donate this data to research, thus having to cover the expenses by themselves. Another discouraging factor is the absence of a serious disease, whereby individuals might feel that they are unable to make a meaningful contribution due to no special, worth-investigating condition being present in their genomic data. At the other end of the spectrum, being in a bad condition might also impede individuals’ willingness to participate in research, since they are tired and unable to cope with the inevitable stress. Lastly, religious beliefs can conflict with scientific expectations and keep individuals from participating in human genomic research.

Selection and Ranking Phase: Ranking of Motivating and Discouraging Factors

Our results show that 12 motivating and 12 discouraging factors were deemed important by at least 50% of panelists during the selection phase. With selection rates of 96% Contribute to scientific research in general and Facilitate medical research were the most often selected motivating factors. Monetary compensation (11%) was the least often selected motivating factor. The most often selected discouraging factor was Discrimination or misuse of my genomic data (96%), whereas the least often selected discouraging factor was Religious beliefs (4%). It must be noted that both motivating factors in the FP category were selected by less than 50% of our panelists. Thus, no factor in this category was ranked. Similarly, most discouraging factors in the BPS category were selected by less than 50% of panelists, with only High costs being selected by more than 50%. Except for the FP category, each category had at least one motivating or respectively discouraging factor present in the ranking phase, which highlights the importance of a variety of factors influencing individuals’ decisions to provide research with their genomic data. Moreover, there were only two edge-cases where the selection of a single panelist decided over whether a factor was included in the ranking phase. The motivating factor Testing for inheritable diseases was selected by 48% of panelists and...
therefore not present in the ranking phase. The discouraging factor *High costs* on the other hand was selected by 52% of our panelists and hence just important enough to be retained for the ranking phase. Table 5 and Table 6 provide an overview of the results of the selection and ranking phases for the motivating and discouraging factors, respectively.

<table>
<thead>
<tr>
<th>Category</th>
<th>Motivating Factor</th>
<th>Selection Phase Percentage of Selection</th>
<th>Ranking Phase Mean Rank (Overall Rank)</th>
</tr>
</thead>
<tbody>
<tr>
<td>ALT</td>
<td>Contribute to scientific research in general</td>
<td>96%</td>
<td>Composite: 3.46 (Rank: 1)</td>
</tr>
<tr>
<td>ALT</td>
<td>Facilitate medical research</td>
<td>96%</td>
<td>Composite: 3.69 (Rank: 2)</td>
</tr>
<tr>
<td>ALT</td>
<td>Support medical research for a certain disease</td>
<td>85%</td>
<td>Composite: 5.23 (Rank: 3)</td>
</tr>
<tr>
<td>PB</td>
<td>Identify predispositions for certain diseases</td>
<td>74%</td>
<td>Composite: 5.88 (Rank: 4)</td>
</tr>
<tr>
<td>BRF</td>
<td>Therapeutic relevance for family members or someone I know</td>
<td>67%</td>
<td>Composite: 6.58 (Rank: 5)</td>
</tr>
<tr>
<td>PB</td>
<td>Therapeutic relevance for myself</td>
<td>63%</td>
<td>Composite: 6.73 (Rank: 6)</td>
</tr>
<tr>
<td>PB</td>
<td>Learn more about myself</td>
<td>67%</td>
<td>Composite: 6.81 (Rank: 7)</td>
</tr>
<tr>
<td>SDB</td>
<td>Set an example for others</td>
<td>56%</td>
<td>Composite: 7.73 (Rank: 9)</td>
</tr>
<tr>
<td>PB</td>
<td>Support my own or a friend’s research</td>
<td>56%</td>
<td>Composite: 7.92 (Rank: 11)</td>
</tr>
</tbody>
</table>

**Table 5. Ranking of the 12 most important motivating factors.**

Overall, reasons related to contributing to research are deemed major motivating factors for donating genomic data. For the donors panel, the two most important motivating factors belong to the ALT category, while for the non-donors and composite panel the three most important motivating factors belong to the ALT category. Interestingly, the top three motivating factors for the composite panel are in reverse order compared to the non-donors panel. Next to altruistic factors, donors seem to consider personal benefits associated with learning more about themselves and their genealogical highly important, whereas medical benefits are viewed as less important (see motivating factors ranked 3rd and 5th and motivating factors ranked 9th and 11th). In contrast to this, non-donors seem to consider medical benefits for their relatives and for themselves more important than access to knowledge about their genetic makeup (see motivating factors ranked 4th and 5th and motivating factors ranked 10th and 11th). Both panels considered *Challenge public stigmas* the least important motivating factor.
Based on the results of the ranking phase, the most important discouraging factors belong to PSC and SU categories (see factors ranked 1st to 4th for the donors panel and factors ranked 1st to 7th for the non-donors and composite panels). For the non-donors panel, discouraging factors in the RP category as well as medical implications and high costs of genome data sharing are deemed less important. Compared to non-donors, donors attributed higher importance to the high costs of genome data sharing and discouraging factors in the RP category, while factors in the MI category were seen equally important by both groups. In general, looking at the mean rankings of individual factors and Kendall’s W, the overall profile of discouraging factors is not that clear when compared to the motivating factors ranking, especially for the donors panel. No single category stands out as the most important one with clarity. Interestingly, discouraging factors in the PSC category span the entire spectrum, from most to least important factors in the donors panel’s ranking.

<table>
<thead>
<tr>
<th>Category</th>
<th>Discouraging Factor</th>
<th>Selection Phase</th>
<th>Percentage of Selection</th>
<th>Ranking Phase</th>
<th>Mean Rank (Overall Rank)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Selection Phase</td>
<td></td>
<td>Composite</td>
<td>Donors</td>
</tr>
<tr>
<td>PSC</td>
<td>Discrimination or misuse of my genomic data</td>
<td>96%</td>
<td>4.08 (Rank: 1)</td>
<td>3.62 (Rank: 1)</td>
<td>4.54 (Rank: 4)</td>
</tr>
<tr>
<td>SU</td>
<td>Unethical use of genomic data</td>
<td>85%</td>
<td>4.50 (Rank: 2)</td>
<td>5.38 (Rank: 4)</td>
<td>3.62 (Rank: 1)</td>
</tr>
<tr>
<td>SU</td>
<td>Governmental abuse</td>
<td>89%</td>
<td>5.12 (Rank: 3)</td>
<td>4.38 (Rank: 4)</td>
<td>5.85 (Rank: 7)</td>
</tr>
<tr>
<td>SU</td>
<td>Commercial use</td>
<td>93%</td>
<td>5.23 (Rank: 4)</td>
<td>4.85 (Rank: 2)</td>
<td>5.62 (Rank: 6)</td>
</tr>
<tr>
<td>PSC</td>
<td>Insecure data handling</td>
<td>78%</td>
<td>5.50 (Rank: 5)</td>
<td>6.69 (Rank: 6)</td>
<td>4.31 (Rank: 2)</td>
</tr>
<tr>
<td>PSC</td>
<td>Privacy infringement</td>
<td>78%</td>
<td>6.50 (Rank: 6)</td>
<td>8.54 (Rank: 11)</td>
<td>4.46 (Rank: 3)</td>
</tr>
<tr>
<td>PSC</td>
<td>No possibility to withdraw data</td>
<td>67%</td>
<td>6.92 (Rank: 7)</td>
<td>8.54 (Rank: 11)</td>
<td>5.31 (Rank: 3)</td>
</tr>
<tr>
<td>RP</td>
<td>Absence of feedback</td>
<td>78%</td>
<td>7.35 (Rank: 8)</td>
<td>5.46 (Rank: 5)</td>
<td>9.23 (Rank: 11)</td>
</tr>
<tr>
<td>MI</td>
<td>Uncertain implications for relatives</td>
<td>67%</td>
<td>7.58 (Rank: 9)</td>
<td>7.54 (Rank: 8)</td>
<td>7.62 (Rank: 8)</td>
</tr>
<tr>
<td>RP</td>
<td>Exploitation of data by researchers</td>
<td>56%</td>
<td>8.23 (Rank: 10)</td>
<td>7.69 (Rank: 9)</td>
<td>8.77 (Rank: 10)</td>
</tr>
<tr>
<td>RP</td>
<td>No well-defined objectives</td>
<td>70%</td>
<td>8.31 (Rank: 11)</td>
<td>8.46 (Rank: 10)</td>
<td>8.15 (Rank: 9)</td>
</tr>
<tr>
<td>BPS</td>
<td>High costs</td>
<td>52%</td>
<td>8.69 (Rank: 12)</td>
<td>6.85 (Rank: 7)</td>
<td>10.54 (Rank: 12)</td>
</tr>
</tbody>
</table>

Kendall’s coefficient of concordance (W) **0.19** **0.23** **0.40**

Table 6. Ranking of the 12 most important discouraging factors.

**Discussion**

Motivating and Discouraging Factors

We employed a ranking-type Delphi method and drew on the privacy calculus approach to rigorously elicit and rank 19 motivating and 17 discouraging factors that influence to what extent individuals are likely to
Motivating and Discouraging Factors in Sharing Genomic Data

participate in human genomic research and share their genomic data. Interestingly, the brainstorming phase yielded a nearly identical number of motivating and discouraging factors and the selection phase yielded the exactly same number of salient motivating and discouraging factors. This suggests that from data donors’ perspective neither side dominates and may indicate that individuals are well-aware of and thoroughly weigh the benefits and risks associated with genome data sharing, indeed engaging in some form of calculus when facing the decision whether to donate their data to human genomic research.

Consistent with past findings on individuals’ willingness to disclose personal health information to researchers (e.g., Anderson and Agarwal 2011) and attitudes towards sharing genomic data (Oliver et al. 2012), we found altruistic reasons (e.g., contributing to research) to be the most important motivating factors across the entire panel. Interestingly, panelists assigned different levels of importance to different forms of contributing to research. Thereby, more general contributions (e.g., Contribute to scientific research in general) where considered more important than specialized contributions (e.g., Support medical research for a certain disease). Our ranking of discouraging factors also confirms past findings which point to potential data donors being particularly concerned about their privacy, trust in research institutes and other potential users of genomic data, the commercialization of genomic data, and medical implications of genomic data sharing (e.g., Haga and O’Daniel 2011; Sanderson et al. 2016). Although privacy concerns are often described as a major issue in sequencing the human genome and although privacy-related factors are also highly ranked in this study, some participants seemed to be surprisingly unaffected by such concerns. As one panelist noted during the brainstorming phase: “Nothing that is actually true would discourage me’. However, our results also highlight the importance of aspects related to the research processes (e.g., clear communication of research objectives and sharing back research results to data donors), something that has been largely unaccounted for in extant research.

Although the objective of our research was to specifically elicit motivating and discouraging factors for donating genomic data to human genomic research, a variety of motivating factors such as Curiosity about genealogical history seem to be only indirectly linked to contributing to human genomic research. A potential reason for this could be that data donors first came into contact with genomic research for reasons other than supporting research and that this has changed over time the more they are engaged with genomics. One panelist, for example, commented “I guess it began personal but branched out into altruism”.

Differences Between Donors’ and Non-Donors’ Rankings

Kendall’s W for both sets of factors indicates that the panelists achieved only a low level of consensus. Consensus around motivating factors is slightly higher, though still weak, than consensus around the discouraging factors. Several reasons are likely to account these low levels of consensus. On such reason might be the heterogeneity of the overall panel, which consisted of donors with diverse backgrounds and non-donors, who were mostly genomics and information privacy experts. Consequently, we decided to analyze consensus levels separately among genome data donors and non-donors. Our analysis shows that for genome data donors the level of consensus slightly increases from W = 0.23 to W = 0.31 for motivating factors and from W = 0.19 to W = 0.23 for discouraging factors. For non-donors consensus increases to W = 0.40 for both, the motivating factors and the discouraging factors. Although still relatively weak, these results indicate a noticeable difference in the perceptions of the importance of motivating and discouraging factors between the two groups. This calls for separate rankings and analyses for both groups in future research. Moreover, there seems to be stronger consensus among non-donors, which can be due to higher homogeneity of the group (i.e., non-donors were mostly trained genomics or privacy experts).

Comparing the motivating and discouraging factors rankings for both groups reveals some interesting insights. Looking at the altruistic factors, we see that donors seemed to value more general contributions to research higher than more specialized contributions, whereas non-donors seemed to value more specialized contributions to research higher than more general contributions. Interestingly, donors ranked Support medical research for a certain disease considerably less important (7th rank) than the other altruistic factors. A potential explanation for the differences in the rankings of altruistic factors between donors and non-donors can be found in the perceived distance between giving and receiving entities in genome data sharing situations. Extant research indicates that altruism positively influences individuals’ decisions to disclose their genomic data to close others such as their doctors, while it has no effects on disclosure decisions to distant others such as pharmaceutical companies or government agencies (Anderson and
Agarwal 2009). As such, members of our non-donor panel, who often had a research background, might perceive less distance between themselves and other researchers and thus relate more to the benefits of contributing to medical research for a specific disease. This is further supported by the fact that the donors panel ranked *Governmental abuse* as a major discouraging factor. Another noteworthy difference between the rankings of donors and non-donors can be found in the importance of personal benefits. While donors perceived personal benefits related to knowledge about their genetic makeup more important than medical benefits, non-donors perceived medical benefits more important than knowledge about their genetic makeup. On the one hand, this is in line with past research on motivations for taking direct-to-consumer genetic tests, which shows that individuals taking such tests are well-aware of the limited medical benefits they currently provide (Haeusermann et al. 2017). On the other hand, many non-donor panelists might have been biased towards medical benefits due to their backgrounds in cancer genomics research. Donors also seemed to be less concerned about their privacy than non-donors but more concerned about secondary uses of their genome data. Given the backgrounds of our non-donor panelists, these results may be of little surprise for the non-donors panel. For the donors panel, however, the relatively low ranking of most privacy-related discouraging factors is rather counter-intuitive and in contrast to the prevailing notion of privacy risks being the major issue of sharing one’s genome data.

Overall, our comparison of motivating and discouraging factors between the donor and non-donor panels shows that the composite panel rankings were slightly skewed towards the non-donor panel’s rankings due to its higher level of consensus (e.g., medical benefits were ranked higher by the composite panel than by the donor panel whereas discouraging factors related to the research process were ranked lower by the composite panel than by the donors panel). Thus, our results warrant further research with respect to the differences between donor and non-donor rankings.

**Implications for Practice and Research**

For practice, we provide a rigorously elicited and ranked list of motivating and discouraging factors that can guide researchers and research institutes in designing their data governance policies and processes in line with potential data donors’ needs. Individuals are highly motivated to donate their genome data to genomic research for altruistic reasons, like the desire to support the advances in science. Nonetheless, altruism is not a magic bullet. If researchers seek to establish a sustainable relationship with their data donors they must clearly communicate the objectives of their research, how they collect genome data, and how it is used. Researchers should also proactively inform data donors about the results of their research and provide means for individuals to opt-out later. For profit-oriented organizations in the genomics industry our findings paint a more difficult landscape. While individuals seem to be interested in learning more about their genomic makeup, they are also concerned about the impacts of commercialization of their genomic data - something that is a common business model for companies like 23andMe (Herper 2015).

We add to research focused on the use of genomic data a better understanding of individuals’ motivations to participate in human genomic research. We provide for the first time a comprehensive list of motivating and discouraging factors that go beyond common medical research privacy concerns which have been in the past the dominant reason against genomic data disclosure. We also add to the current understanding of the uses of privacy calculus by highlighting the existence of a diverse set of potential personal and non-personal benefits and risks that influence individuals’ information disclosure decisions. In particular, our results illustrate the strong motivational efficacy of altruistic considerations. This calls for extending the privacy calculus to integrate altruistic explanations for data use contexts that are altruistic in nature (e.g., healthcare and health research). Furthermore, we note that individuals perceive varying forms of altruism and weigh them differently. We also deepen our understanding of the role of patient data in medical research in that the treatment of genome data, despite its unique characteristics, is not that different from participating in conventional medical research.

**Limitations and Further Research**

Our study is not without limitations. Deciding to get one’s genome sequenced and providing this data to human genomic research is a highly personal choice. As such, the ranking of motivating and discouraging factors, although a promising first indicator that conforms to the findings of past research, might be rather subjective and should be interpreted with care. This is also expressed by the relatively weak consensus among our panelists, for both, motivating factors \((W = 0.23)\) and discouraging factors \((W = 0.19)\).
Moreover, we conducted only a single ranking round. In ranking-type Delphi studies it is common to conduct several rounds of ranking to allow participants to revise their rankings based on provided feedback, with the aim to increase consensus (Singh et al. 2009). Due to the very weak initial consensus, additional ranking rounds are likely to yield only minor improvements in terms of panelists' consensus. Adding to this, multiple panelists signalized high attrition and their intention to drop out of the survey at this stage. We therefore decided to stop after one ranking round, with the option to conduct additional ranking rounds at a later point in time. As such, running additional ranking rounds with two different panels (i.e., genomic data donors vs. non-donors) might be more promising and lead to higher consensus. Another limitation of our study concerns the constitution of our panel. For practical reasons, we decided to include a wide range of domain experts in information privacy and genomics in our sample. In doing so, we aimed to substitute for limited access to individuals who were confronted with the decision to donate their genomic data but eventually decided against doing so. As a result, many of our panelists had a research background (33.33% had a doctorate degree), which might have skewed the ranking of motivating factors in favor of altruistic reasons and the ranking of discouraging factors in favor of information privacy-related factors. Adding to this, donors were mostly recruited from pro-sharing websites, which might have resulted in a sampling bias towards more active internet users. Nevertheless, demographics of our donor sample are comparable to donor demographics reported in past research (e.g., Haeusermann et al. 2017). We are confident that our sample of donors serves as a good starting point that includes individuals with diverse backgrounds (see Appendix A). Future research should nevertheless address these sampling issues by specifically investigating motivations of individuals who have actively decided against donating their genomic data to research and recruiting additional donors from non-internet channels.

Surprisingly, Testing for inheritable disease prior to conception was deemed important by less than 50% of our panelists. A potential reason for this counter-intuitive result may lie in the fact that our panel mainly consisted of men (70%). Future research should investigate more gender driven motivations for or against participating in human genomic research in more detail. Adding to this, our panel comprises mostly white individuals from in North America and Western Europe. Investigating the impact of different cultures or ethnicities can result in additional insights and, for example, deliver a different ranking of factors. Two promising avenues for further research include the role of religious beliefs in context of genomic research and individuals’ perceptions of genomic data donations compared to blood donations or organ donations. Religious beliefs as a discouraging factor were deemed important by only 4% of our panelists during the selection phase, which might be due to our panel comprising of mostly scientists who are, in general, considered less religious. Thus, investigating the relationship between individuals' religious beliefs and their willingness to contribute to genomic research – something that to the best of our knowledge is largely unexplored – might be worth investigating. Moreover, we found that several panelists were genomic data donors but not blood donors. Future research should therefore explore the difference in people’s perceptions of donating blood, organs, and genomic data.

**Conclusion**

We wanted to unveil what motivates and discourages individuals to donate their genomic data to human genomic research. Based on data from a ranking-type Delphi survey with individuals who have either donated their genomic data to research at least once in the past, potential genome data donors, experts in health information privacy, and genomics experts, as well as a privacy calculus perspective, we provide a ranked list of 19 motivating and 17 discouraging individual factors to participate in human genomic research. Our findings suggest that altruistic reasons are highly motivating factors, whereas privacy concerns and uncertainty about potential secondary uses of genomic data are significant discouraging factors. The study furthers overall knowledge on what drives individuals to contribute to highly rewarding and at the same time highly risky fields of research such as genomics - an important, yet scarcely investigated stream of research which is likely to grow in influence as more and more personal data becomes accessible to research and private businesses alike.
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Acknowledgements

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References


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Wetterstrand, K. 2016. "DNA Sequencing Costs: Data from the Nhgri Genome Sequencing Program (Gsp)." Retrieved May 4th, 2017, from https://www.genome.gov/sequencingcostsdata/
Appendix A – Donors and Non-donors Panels Demographics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Panel profile (n=30)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Donors (n = 15)</strong></td>
<td><strong>Non-donors (n = 15)</strong></td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td>White: 100%</td>
<td>White: 93.33%</td>
</tr>
<tr>
<td></td>
<td>Asian / Pacific Islander: 0.00%</td>
<td>Asian / Pacific Islander: 6.67%</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td>Female: 20.00%</td>
<td>Female: 33.33%</td>
</tr>
<tr>
<td></td>
<td>Male: 73.33%</td>
<td>Male: 66.67%</td>
</tr>
<tr>
<td></td>
<td>Other: 6.67%</td>
<td>Other: 0.00%</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td>Min: 30 years; Max: 73 years</td>
<td>Min: 27 years; Max: 62 years</td>
</tr>
<tr>
<td></td>
<td>&lt; 28 years old: 0.00%</td>
<td>&lt; 28 years old: 6.67%</td>
</tr>
<tr>
<td></td>
<td>28-35 years old: 26.67%</td>
<td>28-35 years old: 40.00%</td>
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<td></td>
<td>36-44 years old: 6.67%</td>
<td>36-44 years old: 40.00%</td>
</tr>
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<td></td>
<td>&gt; 44 years old: 66.67%</td>
<td>&gt; 44 years old: 13.33%</td>
</tr>
<tr>
<td><strong>Nationality</strong></td>
<td>American: 60.00%</td>
<td>German: 66.67%</td>
</tr>
<tr>
<td></td>
<td>German: 20.00%</td>
<td>British: 13.33%</td>
</tr>
<tr>
<td></td>
<td>Canadian: 6.67%</td>
<td>Canadian: 6.67%</td>
</tr>
<tr>
<td></td>
<td>Surinamer: 6.67%</td>
<td>French: 6.67%</td>
</tr>
<tr>
<td></td>
<td>Unknown: 6.67%</td>
<td>South Korean: 6.67%</td>
</tr>
<tr>
<td><strong>Level of education</strong></td>
<td>High school graduate or equivalent: 6.67%</td>
<td>High school graduate or equivalent: 6.67%</td>
</tr>
<tr>
<td></td>
<td>Some college credit, no degree: 26.67%</td>
<td>Some college credit, no degree: 0.00%</td>
</tr>
<tr>
<td></td>
<td>Bachelor's degree: 13.33%</td>
<td>Bachelor's degree: 0.00%</td>
</tr>
<tr>
<td></td>
<td>Master's degree: 46.67%</td>
<td>Master's degree: 33.33%</td>
</tr>
<tr>
<td></td>
<td>Doctorate degree: 6.67%</td>
<td>Doctorate degree: 60.00%</td>
</tr>
<tr>
<td><strong>Blood donors</strong></td>
<td>Yes: 40.00%</td>
<td>Yes: 53.43%</td>
</tr>
<tr>
<td></td>
<td>No: 46.67%</td>
<td>No: 46.67%</td>
</tr>
<tr>
<td></td>
<td>Prefer not to say: 13.33%</td>
<td>Prefer not to say: 0.00%</td>
</tr>
<tr>
<td><strong>Organ donors</strong></td>
<td>Yes: 26.67%</td>
<td>Yes: 20.00%</td>
</tr>
<tr>
<td></td>
<td>No: 60.00%</td>
<td>No: 53.33%</td>
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<tr>
<td></td>
<td>Prefer not to say: 13.33%</td>
<td>Prefer not to say: 26.67%</td>
</tr>
<tr>
<td><strong>Genomic data donors</strong></td>
<td>Yes: 100.00%</td>
<td>Yes: 0.00%</td>
</tr>
<tr>
<td></td>
<td>No: 0.00%</td>
<td>No: 86.67%</td>
</tr>
<tr>
<td></td>
<td>Prefer not to say: 0.00%</td>
<td>Prefer not to say: 13.33%</td>
</tr>
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