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Short communication

Public attitudes toward genetic risk scoring in medicine and beyond

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ABSTRACT

Advances in genomics research have led to the development of polygenic risk scores, which numerically summarize genetic predispositions for a wide array of human outcomes. Initially developed to characterize disease risk, polygenic risk scores can now be calculated for many non-disease traits and social outcomes, with the potential to be used not only in health care but also other institutional domains. In this study, we draw on a nationally-representative survey of U.S. adults to examine three sets of lay attitudes toward the deployment of genetic risk scores in a variety of medical and non-medical domains: 1. abstract belief about whether people should be judged on the basis of genetic predispositions; 2. concrete attitudes about whether various institutions should be permitted to use genetic information; and 3. personal willingness to provide genetic information to various institutions. Results demonstrate two striking differences across these three sets of attitudes. First, despite almost universal agreement that people should not be judged based on genetics, there is support, albeit varied, for institutions being permitted to use genetic information, with support highest for disease outcomes and in reproductive decision-making. We further find significant variation in personal willingness to provide such information, with a majority of respondents expressing willingness to provide information to health care providers and relative finder services, but less than a quarter expressing willingness to do so for an array of other institutions and services. Second, while there are no demographic differences in respondents' abstract beliefs about judging based on genetics, demographic differences emerge in permissibility ratings and personal willingness. Our results should inform debates about the deployment of polygenic scores in domains within and beyond medicine.

1. Introduction

Recent advances in genomics have produced new tools that expand the range of potential applications of genetic data. Among such tools are polygenic risk scores (PGS), which reflect the latest scientific understanding that many complex traits are influenced by many genes, rather than single genes (Boyle et al., 2017). Whereas early genetic testing typically examined relationships between single candidate genes and diseases, polygenic risk scoring offers a framework for summarizing propensities toward a wider set of disease and non-disease outcomes, such as the years of formal education a person attains or their risk aversion (Conley and Fletcher, 2017; Bliss 2018).

In turn, this broad set of outcomes to which polygenic scores can be applied engenders possibilities for non-healthcare entities to deploy polygenic risk scores. While the Genetic Information Nondiscrimination Act (GINA) barred the use of genetic information in the domains of employment and health insurance, there are few legal or regulatory protections barring the use of genetic information in other areas of life.

To date, scholars have documented how genetic risk testing *within* medicine, such as newborn screening for metabolic disorders, blurs boundaries between health and disease (Shostak et al., 2008; Timmermans and Buchbinder 2010). By contrast, in this study, we examine genetic risk scoring's potential use *beyond* medicine, for instance by schools or financial institutions. We ask: how does the public perceive

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the use of genetic risk testing within and beyond applications in health and medicine?

We draw on the first nationally-representative survey of U.S. attitudes toward polygenic risk scoring. We first examine the public's abstract beliefs about whether it is acceptable to judge others based on their genetic predispositions. Next, we study attitudes toward the permissibility of concrete institutional uses of polygenic risk prediction. Finally, we explore the respondents' personal willingness to submit genetic information to various institutions and services. These three analyses present distinct vantage points on views toward institutional uses of polygenic risk prediction: the first captures normative ideals; the second captures prescriptive attitudes toward specific applications; and the third captures personal preferences about different institutions accessing one's own genetic information.

1.1. Relation to existing research on public attitudes toward genetic testing and data

Existing scholarship on attitudes toward genetic information emerges primarily from two strands of research. The first investigates views on genetic testing, primarily in the context of clinical care and reproductive services (Dodson et al., 2015; Dye et al., 2016; Hathaway et al., 2009; Jallinoja et al., 1998; Marshall et al., 2016; Vermeulen et al., 2014; Winkelman et al., 2015). While most studies focus on tests for diseases (Cain et al., 2016; Marshall et al., 2016; Vermeulen et al., 2014) or genetic testing in general (Dodson et al., 2015; Dye et al., 2016; Haga et al., 2013; Saylor et al., 2019), select studies that contrast attitudes towards testing for medical and non-medical outcomes suggest that support tends to be lower for outcomes considered essential to one's identity – those viewed as fixed, stable, and/or natural, such as one's height or inherent talents – and greater for outcomes considered incidental to identity, which is typically mediated by whether they are considered a disease state (Condit 2010; Hathaway et al., 2009; Winkelman et al., 2015).

The second strand examines how consent structures, incentives, and privacy concerns shape willingness to provide genetic information for research purposes (Briscoe et al., 2020; Clayton et al., 2018; Dye et al., 2016; Kaufman et al., 2009; Sanderson et al., 2017). These studies show that respondents fear that employers and insurers might use genetic information to discriminate and indicate concerns about commercial entities and government, especially law enforcement, accessing genetic information (Bollinger et al., 2013; Clayton et al., 2018; Kaufman et al., 2009).

In the present study, we examine attitudes toward polygenic risk scoring in a manner that builds on both literatures. First, nearly all research frames the main user of genetic information as medical actors, whether healthcare providers, medical researchers, or health-focused direct-to-consumer genomics companies. When these studies measure attitudes towards other institutional actors accessing genetic information, they are framed as unintended or downstream users. Our study, by contrast, presents health care and non-health care users of genetic information on an even playing field. This approach aligns with the practical reality that non-medical actors can now collect and analyze genetic information and, further, allows us to compare attitudes toward health-related and non-health-related applications.

Second, we extend past research on inconsistencies in attitudes toward genetic technologies (Condit 2010; Jallinoja et al., 1998), which has suggested that views can hinge on the generality of questions posed, what dimensions of technologies are highlighted, and whether questions are about what should be permitted or personal interest in participating. Building on this work, we explicitly distinguish between and contrast three types of attitudes toward polygenic risk scoring: abstract beliefs about the acceptability of the kind of action polygenic risk scores could enable; concrete attitudes about the permissibility of specific instantiations of such uses; and personal willingness to contribute genetic information for such uses. Third, past research has shown some persistent demographic differences in attitudes towards health-focused genetic testing and research. Notably research shows that younger people and non-Hispanic whites generally, though not consistently, express more favorable attitudes (Vermeulen et al., 2014; Clayton et al., 2018; American Society of Human Genetics, 2020), while those with greater genetics knowledge express less favorable views (American Society of Human Genetics, 2020). We investigate whether these patterns extend to applications outside of health. Combined, these advances provide a multidimensional view of how different types of attitudes toward genetic technologies are interrelated.

1.2. Questions

1) Abstract belief: To what extent does the public believe that it is acceptable to judge based of genetic predispositions?

2) Permissibility of concrete applications:

a. How does acceptance of PGS compare across institutional settings?

b. How does acceptance of PGS compare across outcomes predicted?

3) Willingness to provide genetic information: To which institutions and services is the public willing to provide genetic information?

4) Demographic variation: How do abstract beliefs, attitudes toward concrete applications, and willingness to provide genetic information vary by respondent demographics?

1.3. Data and methods

We draw on an original survey of public attitudes toward the use of genetic information (n = 1457) fielded online in April 2019. Respondents were sourced from NORC's AmeriSpeak Panel, a probability-based panel designed to be nationally representative of U.S. adults with respect to age, race, Hispanic ethnicity, education, and gender.

Figure S1 in the Online Supplement shows the survey flow. At the outset, we presented an explanation of both PGS and GINA. Respondents were then asked whether they thought PGS should be permitted in five settings described in vignettes, with some settings varying the trait predicted: sperm/egg donor selection (IQ; skin tone; height; schizophrenia; diabetes); embryo selection (same five traits); school admissions (IQ); life, car, and long-term care insurance (IQ); and a dating app, which we exclude due to lack of direct comparability (see Online Supplement for vignette text). The traits reflect ones that are medicalized (schizophrenia; diabetes) and ones that are not viewed as diseases (skin tone; height; IQ). Relative to a traditional survey design, a randomized vignette enabled us to better isolate and compare the effects of traits on permissibility attitudes.

In our analyses, we dichotomized ratings of the permissibility of polygenic risk scoring in the vignettes. Responses indicating belief that the institution should be forbidden from conducting testing were coded as "not permitting," while responses indicating that the institution should be allowed to require or make testing an option were coded as "permitting."

We then asked respondents if they would be personally willing to provide their genetic information to five institutions or services randomly drawn from a list of ten (see Online Supplement for selection procedure details). Since the public is sensitive to how questions about genetics are worded (Condit 2010), we randomized whether the question asked about willingness to provide "a sample of saliva for DNA analysis" or "genetic information." We also randomized how much respondents would hypothetically be compensated. In the results we present, we average over these randomizations to analyze how willingness compares across institutions beyond question wording and compensation structure.

Respondents were then asked to indicate whether they agreed with the statement, "No one should be judged on the basis of their genetic predispositions" or that "It's normal and acceptable to judge individuals on the basis of their genetic predispositions." Responses to the first

version of the statement were reverse-coded.

2. Results

Abstract belief: Fig. 1 displays the extent to which respondents agreed that it is acceptable to judge people based on their genetic predispositions. The vast majority of respondents reported a strong aversion to judging others on the basis of genetic predispositions. Only nine percent thought it was acceptable to do so.

Permissibility of concrete applications: Fig. 2 presents respondents' ratings of the permissibility of using polygenic risk scores across settings (Panel A) and traits (Panel B). Overall, results show a marked contrast between abstract belief and attitudes toward concrete applications. While only nine percent of respondents considered it acceptable to judge based on genetic predispositions in the abstract, large proportions of respondents rated individual concrete applications as permissible (ranging from 38% to 83% across applications). Fig. 2, Panel A indicates that respondents rated polygenic prediction as most permissible in sperm/egg donor selection, followed by embryo selection. It was rated as substantially less permissible in school admissions and least permissible in insurance pricing.

Fig. 2, Panel B reveals that views depend on what traits PGS would be applied to predict, though we note that the range in responses across traits (15 percentage points) was smaller than across settings (45 percentage points). Support was greatest for diseases and lowest for non-disease physical traits. We find no statistically significant difference between skin tone and height and between diabetes and schizophrenia. We do, however, find a statistically significant difference between these two sets of outcomes. Ratings for IQ sat in the middle: polygenic scoring for IQ was rated as significantly less permissible than for diabetes and schizophrenia, but more permissible than for skin tone.

Willingness to provide genetic information: Fig. 3 displays the proportion of respondents who were willing to provide their genetic information to each institution or service listed. Willingness was highest for health care providers and relative finder services, with more than half of respondents indicating willingness. Police forensic databases followed with 41% of respondents indicating willingness. The remaining services and institutions saw a steep drop-off. Between 20 and 23% of respondents were willing to provide genetic information to Departments of Motor Vehicles, public schools, employers, and life insurance providers. Willingness was lowest for online music and video services, lenders, and social networks.

Demographic variation: Table 1 summarizes demographic variation in our three sets of questions. We find no evidence of demographic differences in abstract beliefs about acceptability. We do, however, find significant differences in ratings of the permissibility of concrete applications and in willingness to provide genetic information by respondent gender, race/ethnicity, age, education, and religious affiliation. Pairwise Wilcoxon tests with Benjamin-Hochberg p-value adjustments (full results in Online Supplement) indicate that patterns were broadly consistent across the two outcomes: men, Hispanics, younger respondents, respondents with a high school education or less, and respondents without religious affiliations were permissive toward more applications and willing to provide genetic information to more institutions than were women, white non-Hispanics, older respondents, respondents with greater educational attainment, and Protestants, respectively. The Online Supplement discusses additional smaller differences between permissibility ratings and personal willingness.

3. Discussion

In this study, we examined three sets of attitudes toward polygenic risk scoring. We found a contrast between respondents' strong rejection of judging people based on genetic predispositions in the abstract and their more permissive attitudes on the whole toward specific institutions using genetic data. We further observed a contrast in demographic differences across the three outcomes: whereas no differences emerged in respondents' abstract beliefs, demographic differences emerged across respondents' ratings of the permissibility of concrete applications and in their stated willingness to provide genetic information, with demographic differences consistent with those found in past studies focused on healthcare applications (American Society of Human Genetics, 2020). These results suggest that the use of genetic risk information to discriminate violates widely shared normative ideals, but that the public holds more ambivalent views about limiting the technology in concrete settings and contributing their own genetic information. These results are consistent with past research that has found contrasts between responses to abstract rather than concrete scenarios involving genetic information (Jallinoja et al., 1998), and suggest that when respondents react to specific applications of genetic technology, their responses tend to be both more differentiated and patterned along demographic groupings. Future research should investigate which mechanism drives the discrepancy: (1) wording differences like respondents objecting to "judging" based on genetics (wording of abstract belief question) but supporting genetics as an input to decision-making (wording of concrete application questions) or (2) substantive differences like more support for institutions incorporating genetics into existing institutional processes than for individuals using or contributing

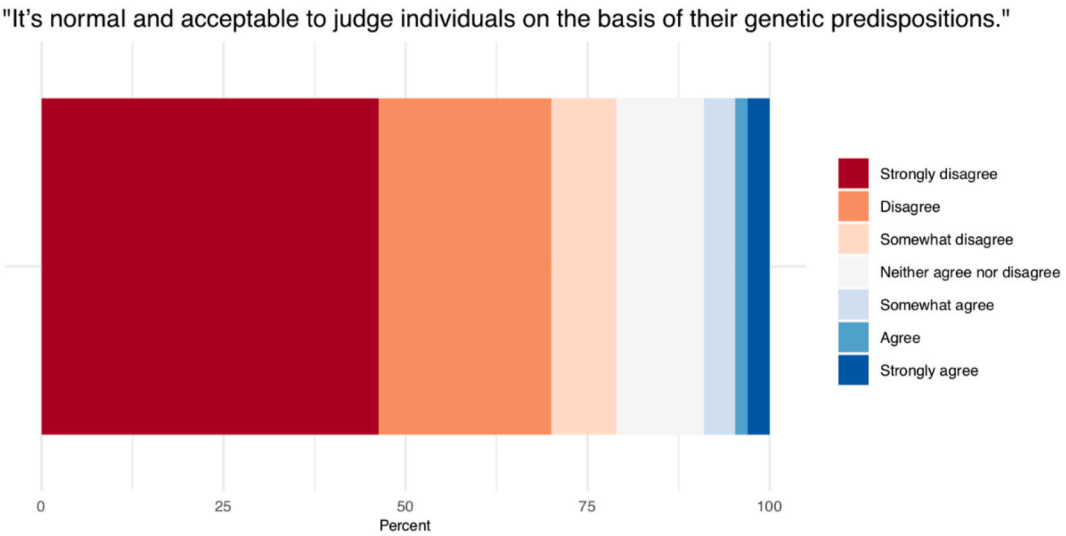

Fig. 1. Agreement with judging based on genetic predispositions. Color indicates degree of agreement.

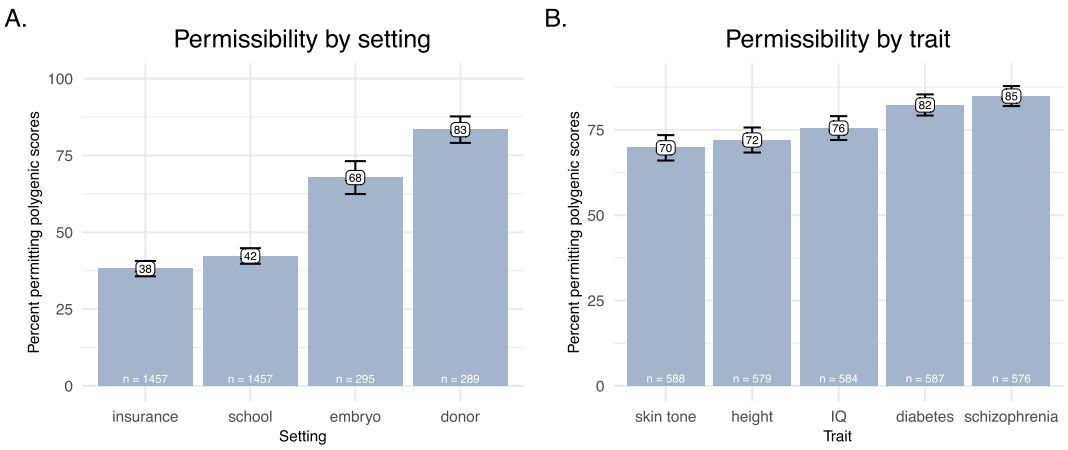

Fig. 2. Percent of respondents who believed polygenic scores should be permitted in different settings (Panel A) and for different traits (Panel B). Panel A uses only observations in which PGS was said to predict IQ. Panel B is limited to responses to the embryo selection and sperm/donor vignettes. Error bars represent 95% confidence intervals.

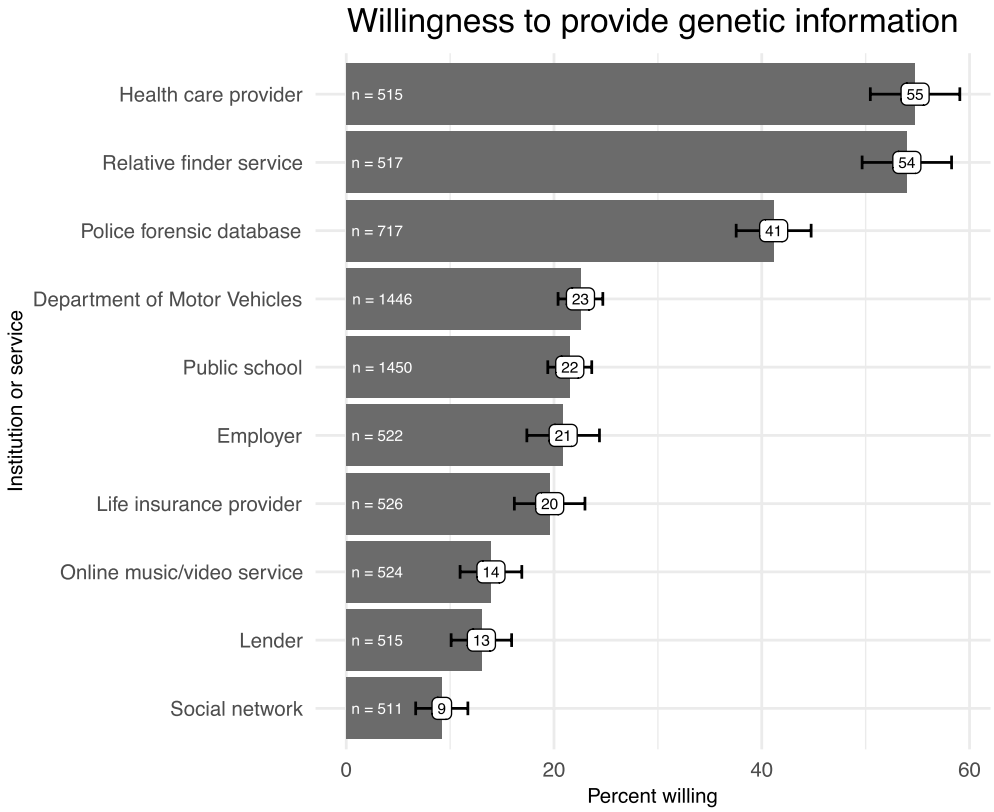

Fig. 3. Willingness to provide genetic information to different institutions and services. Error bars represent 95% confidence intervals.

genetic information.

Comparing across application settings, we observed that respondents were most permissive toward polygenic risk scoring in egg/sperm donation, followed by embryo selection. The difference between these two applications may reflect popular and bioethical notions that embryos have moral worth, thus making genetic selection less morally permissible (Hudson 2006). School admissions and insurance pricing were rated as significantly less permissible. These findings suggest that respondents may be differentiating between applications based on who is empowered by genetic information: individuals making decisions for themselves – as in embryo selection and egg/sperm donation – or institutional actors making decisions that affect other people's opportunities – as in school admissions and insurance pricing. They are also consistent with respondents drawing distinctions between applications related and unrelated to health care. Additional research is needed to disentangle these possibilities.

Comparing across traits predicted by polygenic scoring, we found that respondents saw the use of polygenic scores for diseases – schizophrenia and diabetes – more favorably than for non-disease outcomes – height and skin tone. Ratings for IQ sat in the middle. This pattern partially supports scholarship suggesting that the use of genetic information is more accepted when it reflects outcomes seen as diseases and incidental to a person's essential identity (Condit 2010; Shostak et al., 2008). However, it is noteworthy that permissibility ratings across traits varied little in comparison to studies on other forms of genetic testing, where attitudes varied by larger margins (Condit 2010; Winkelman

Table 1
Responses by respondent demographics. p-values presented are based on Kruskal-Wallis tests for differences between subgroups.

	N	Proportion rated acceptable to judge based on genetic predispositions	# of applications rated as permissible (out of 4)	Proportion of institutions to which respondent is willing to provide genetic info
Gender				
Male	701	0.10	2.4	0.30
Female	756	0.081	2.3	0.23
P-value		*0.20*	*0.0073*	*0.00062*
Race/Ethnicity				
White, non-Hispanic	960	0.088	2.3	0.25
Black, non-Hispanic	141	0.11	2.3	0.23
Other	127	0.055	2.4	0.29
Hispanic	229	0.11	2.6	0.31
P-value		*0.32*	*0.0016*	*0.028*
Age				
18–29	222	0.10	2.6	0.38
30–39	313	0.070	2.6	0.28
40–49	206	0.087	2.4	0.23
50–59	256	0.078	2.1	0.23
60+	460	0.11	2.2	0.22
P-value		*0.45*	*0.00000012*	*0.000000010*
Education				
High school or less	303	0.089	2.5	0.33
Some college	464	0.086	2.3	0.26
Associates	224	0.080	2.3	0.24
Bachelors	279	0.11	2.4	0.23
Advanced	185	0.086	2.0	0.22
P-value		*0.84*	*0.0023*	*0.0035*
Religious Affiliation				
Protestant	369	0.081	2.2	0.21
Catholic	297	0.13	2.4	0.27
Other	373	0.075	2.3	0.28
None	408	0.083	2.5	0.28
P-value		*0.075*	*0.00070*	*0.012*
Party Identification				
Republican	360	0.089	2.4	0.27
Democrat	557	0.086	2.3	0.27
Independent	366	0.11	2.4	0.25
Other/No Preference	171	0.070	2.4	0.23
P-value		*0.54*	*0.80*	*0.24*

et al., 2015). It is further worth highlighting that polygenic scoring for IQ was seen as permissible by a large majority of respondents, despite intelligence being viewed as an essential characteristic and despite challenges to the genetics of intelligence (Plomin and von Stumm, 2018). A limitation, however, is that we only randomized the trait in vignettes on embryo selection and egg/sperm donor selection, with a need for future research that compares these traits in other spheres.

Health care providers and relative finder services, followed by police forensic databases, were the entities to which the public was most willing to provide genetic information. Reported willingness was substantially lower for employers, financial services, entertainment-related services, and other government agencies. These results suggest that healthcare providers remain the most trusted beneficiaries of genetic information, but that select other entities may be gaining ground. They further indicate that past studies, which prime respondents to think about health-related applications, may understate variation in attitudes across and within public and commercial applications (Cain et al., 2016; Dodson et al., 2015; Dye et al., 2016; Haga et al., 2013; Marshall et al., 2016; Sanderson et al., 2017; Saylor et al., 2019; Vermeulen et al., 2014). Notably, departing from some past studies (Bollinger et al., 2013; Kaufman et al., 2009) but consistent with a more recent investigation (Guerrini et al., 2018), we observed a surprisingly high degree of willingness to provide genetic information to law enforcement, trailing that for health care providers and relative finders but exceeding that for other institutions by 18 percentage points or more. Future research can investigate whether these differences are due to different framings of law enforcement's role — as unintended recipients of medical information (Bollinger et al., 2013) or as direct beneficiaries as in the present study — or shifting views caused by events like the use of ancestry databases to solve criminal cases (Guerrini et al., 2018).

We acknowledge several additional limitations. To start, our survey provides a minimal introduction to polygenic scoring and GINA. Thus, our respondents likely lack a deep understanding of polygenic scoring and how it compares to other forms of testing. Future research should examine whether varying educational interventions shapes responses. A related limitation is that we cannot directly evaluate whether responses would differ if participants read about single gene testing rather than polygenic scores. Because our study is among the first to examine attitudes toward polygenic risk scoring, our survey consisted primarily of de novo measures. While we have noted where our results depart from studies focused on other technologies, it would be valuable for future studies to adopt designs that would facilitate comparisons across single gene testing and polygenic scoring.

Finally, our study design suggests potential considerations that may guide attitudes, but does not enable direct tests. For instance, responses may be shaped by perceptions of the legality of different applications of polygenic scoring or by variation in the extent to which a trait is medicalized. Past research further suggests that, beyond legality or medicalization, attitudes may further be influenced by the perceived strength of the protections that existing laws provide (Clayton et al., 2018). Scholars interested in testing these mechanisms may wish to directly measure legality perceptions to examine whether they moderate attitudes.

In an era where commercial entities control several major biobanks,

the cost of collecting and analyzing genetic data is falling, and personal data are combined and shared across institutions, it is increasingly important to analyze public attitudes and understandings of genetic technologies as they migrate from medicine and health to other domains.

Author credit statement

DC, SZ and RJ conceptualized the project designed the study. DC, SZ, EF, JN, and RJ designed the survey experiment and pre-analysis plan. SZ and RJ conducted the analyses and constructed figures and tables. DC, SZ, and RJ drafted the paper. DC, SZ, EF, JN, and RJ contributed revisions to the paper.

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Appendix A. Supplementary data

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