Return of genomic results does not motivate intent to participate in research for all: Perspectives across 22 countries

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ABSTRACT

Purpose: The aim of this study was to determine how attitudes toward the return of genomic research results vary internationally.

Methods: We analyzed the "Your DNA, Your Say" online survey of public perspectives on genomic data sharing including responses from 36,268 individuals across 22 low-, middle-, and high-income countries, and these were gathered in 15 languages. We analyzed how participants responded when asked whether return of results (RoR) would motivate their decision to donate DNA or health data. We examined variation across the study countries and compared the responses of participants from other countries with those from the United States, which has been the subject of the majority of research on return of genomic results to date.

Results: There was substantial variation in the extent to which respondents reported being influenced by RoR. However, only respondents from Russia were more influenced than those from the United States, and respondents from 20 countries had lower odds of being partially or wholly influenced than those from the United States.

Conclusion: There is substantial international variation in the extent to which the RoR may motivate people's intent to donate DNA or health data. The United States may not be a clear indicator of global attitudes. Participants' preferences for return of genomic results globally should be considered.

Introduction

Significant ethical, legal, and clinical attention has concentrated on whether the results from genomic research should be returned.[1-4] Divergent and evolving positions on this question are reflected in the diversity of policy and normative approaches—varying from compulsion to return to total prohibition.[5,6] Such debates are further complicated by the range of forms such results might take, from interpreted, actionable findings to access to raw data.[7] In practice, in Europe and North America, some form of return of results (RoR) occurs in a growing number of studies, most prominently the All of Us precision medicine initiative, which plans to return health-related information by early 2022.[8]

Influential voices in this debate have been those of members of the public, patients, and research participants, which have featured prominently alongside that of bioethicists and researchers—both directly and through a series of studies that suggest that RoR is valued and even expected by participants and particularly by patients.[9-16] The 2018 National Academies report on RoR, eg, draws on this work to argue that participants want and expect personal feedback on research results.[1]

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Furthermore, it has been suggested that not only do potential research participants value or expect findings, but also the possibility of receiving feedback may motivate participation in genomics research and biobanks.[9,10,17] Feedback of results to motivate participation has also been raised as a means of addressing the lack of diversity in data sets and reach populations who are currently under-represented.[16,18] However, this discourse has mostly involved researchers, policy makers, and public audiences from the United States, and thus, it cannot be assumed that it will naturally translate to global contexts outside the United States.[19]

The differences in policy and normative positions on RoR around the world reflects differing cultural views about participant needs, different national health care systems, and the constraints of research sector resources in different contexts.[5] To date, however, there is little evidence on how public perceptions of the desirability of RoR—and their ability to motivate participation—vary across such contexts and internationally. The study by Middleton et al[20] of the views of 7000 people across 75 countries suggests some widespread support for the return not only of findings but also of raw genomic data among potential research participants. However, although this work was international in scope, it was not sampled to enable comparative conclusions. Such a detailed ability to compare across contexts is essential if we hope to ensure that dialogue and debate include diverse global perspectives in the development of inclusive genomic medicine.

In this article, we provide such a comparative view, presenting patterns of consistency and variability in public attitudes toward the RoR across 22 countries, on the basis of data from the "Your DNA, Your Say" survey of public attitudes toward the donation and sharing of genomic data.

Materials and Methods

A convenience mix of countries were involved in the "Your DNA, Your Say" study via the international network of researchers within the Global Alliance for Genomics and Health, with collaborators either supporting recruitment into the project or translating the survey. Data were collected using a cross-sectional online survey. Background information about the landscape of genomic research and data sharing was provided via 9 films that sit within the survey; no prior knowledge about genomics was required for participation.

The development of the study methodology, design, and limitations are discussed in more detail elsewhere.[21,22] In most countries, participants were recruited to the online survey via market research company Dynata (formerly ResearchNow). As the study expanded to a wider range of countries, the recruitment strategy and process of data collection were adapted. In Japan, participants were recruited through a survey research company (Cross Marketing) using the same approach. In Pakistan and India, recruitment was conducted by market research companies (Foresight and Maction, respectively), and methods were varied to account for lower internet and computer access. In Pakistan, participants completed the questionnaire on tablets at a central testing location. In India, participants completed the questionnaire on tablets provided by field researchers.

Completed surveys were gathered from Argentina, Australia, Belgium, Brazil, Canada, China, Egypt, France, Germany, India, Italy, Japan, Mexico, Pakistan, Poland, Portugal, Russia, Spain, Sweden, Switzerland, United Kingdom, and the United States. We aimed to recruit a sample that was as representative as possible of each country's population with respect to gender, age, and education level. To this end, participant characteristics were monitored during recruitment to proactively ascertain individuals from under-represented population subgroups. Sociodemographic characteristics of participants from each country are shown in Supplemental Table 1. Participants were paid a small financial reward (<£1) for participating, and owing to the nature of recruitment there are no details on nonresponse rate. Because of the approach to data collection, missing data were very limited (<5% for all questions) and complete case analyses were conducted.

Measures

The questionnaire consisted of 29 questions; in this paper, we concentrate on the analysis of a question in which participants were asked to consider whether their decision to donate their DNA for research would be influenced by whether they would receive feedback or research results in return (full question and choice of answers in Table 1). In the pilot work for the survey design we discovered that pilot participants wanted more information about what RoR might look like. To answer this, we drew on the contemporaneous state of the literature that considered the practice and feasibility of returning genome sequences in a research setting.[7] This revealed that the return of clinically actionable results required clinical pathways for which researchers may not have access or funding and that participants may have unrealistic expectations of what they could do with the raw sequence data.[2,5]

We selected and piloted the words "DNA readout" as a proxy for some form of results from the research. We used this deliberately broad term to include any level of results from raw DNA sequence to results related to disease risk. In the pilot work, with public participants who spoke English, French, Polish, and Swedish, the term "DNA readout" was deemed a translatable concept into different languages, basically meaning any form of result from the genomic research. A glossary explanation of "DNA readout" was given to all participants in the "Your DNA Your Say" survey and was provided if they hovered their mouse over the words. The wording of this question and glossary definition are shown in Table 1.

Education level was categorized as "Tertiary," "Secondary," "Primary," or "Other" on the basis of structured and free text descriptions of educational qualifications and collapsed to a binary indicator of tertiary education for multivariable analyses. Religiosity was determined by the response to the

Table 1 "Your DNA, Your Say" survey questions and multiple-choice options relating to the influence of a DNA readout on an individual's decision to donate their DNA for research

Survey Question	Options Provided
Let's assume you were asked to consider donating your DNA information for research. Would being offered a DNA readout influence your decision to donate?	My decision to donate is wholly influenced by being able to get my DNA readout in return. My decision to donate is partly influenced by being able to get my DNA readout in return, but it is also influenced by other factors. My decision to donate is not influenced by being able to get my DNA readout in return, I would donate for other reasons. I wouldn't donate my DNA information. I'm not sure.

A "DNA readout" was defined as "DNA readout: type of DNA information. The computer transforms DNA into a sequence of letters that can be read. Raw sequence data, pretty meaningless on its own but can be translated into disease risks by putting it into other software."

question "Independent of whether you attend religious services or not, would you say you are…?" with options "A religious person" or "Not a religious person." Familiarity with genetics was derived from 2 questions. The first was "Are you familiar with DNA, genetics, or genomics?" Participants who responded "No" were categorized as unfamiliar. Respondents who answered in the affirmative could then specify. Participants who stated they were familiar through having a genetic condition in their family or through work (eg, genetic health professional) were categorized as having "Personal" experience of genetics, whereas participants without this experience were categorized as "Familiar." Respondents' perception of DNA information (genetic exceptionalism) was collected via the question, "Is DNA information different to medical information—what do you think?" Response options were "Different, "The same, and "I'm not sure." The latter 2 categories were collapsed for analysis.

Statistical analysis

Survey responses were summarized as counts and percentages by country of residence. We used multinomial logistic regression to investigate the association between RoR influencing stated intention to donate and country of residence, adjusting for sociodemographic factors (age, gender, education, religiosity, having children), familiarity with genetics (categorized as "unfamiliar," "familiar," or "personal"), and the extent to which DNA information was same as other forms of health information (genetic exceptionalism). Multinomial logistic regression was used to enable the analysis of an outcome variable with > 2 categories; the "partly influenced" response was used as the reference category to enable us to investigate the more "extreme" responses ("wholly influenced" vs "not influenced"). Using this model, the association between being influenced by RoR to donate data and each predictor in the model is represented by an odds ratio (OR) estimate with an associated 95% CI. Country of residence was used as the primary predictor, with the United States as the reference category because the majority of research in this area has been conducted using samples from the United States. This analysis allowed us to determine how similar other countries are to the United States regarding the importance of RoR on DNA donation. The outcomes of the multinomial logistic regression are presented as lollipop plots that depict the ORs for the main outcomes. All analyses were performed with the R statistical software (R Foundation).

Results

Sample and participant characteristics

The sample consisted of 36,263 participants from 22 different countries. Participant characteristics stratified by perspective on RoR are shown in Table 2. Overall, 25.2% of the participants said they would not donate their DNA and medical information (regardless of RoR); 24.4% of the participants said their decision to donate would be partially influenced and 18.4% of the participants said their decision would be wholly influenced by RoR. A little more than 17% of the participants reported that they were unsure, whereas 14.7% of the participants reported that their decision to donate would not be influenced by RoR at all.

Variation in influence of RoR on willingness to donate

The results in Figure 1 and corresponding Table 3 show that being wholly influenced by RoR was most commonly reported by participants from Russia (32.7%), the United States (30.5%), India (28%), and Pakistan (26.9%). It was least commonly reported by participants from Japan (9.7%), Spain (11.6%), Sweden (12.7%), and the United Kingdom (13.9%). Being partially influenced by RoR was most commonly reported by participants from China (39.4%), Poland (27.8%), and Russia (27.6%; although Russian participants were more likely to report being wholly influenced). Participants from Brazil, Portugal, and Italy were most likely to report that RoR had no influence on their willingness to donate their data (24.1%, 23.7%, and 22.2%, respectively).

Influence of RoR on willingness to donate: Inferential analysis

Multinomial logistic regression was performed to assess the relationship between country of residence and the influence

Table 2 Characteristics of the overall sample, stratified by view on return of results

Characteristic	Total	Wholly Influenced	Partly Influenced	Not Influenced	Unsure	Would Not Donate
Age (y)						
<30	8718	1874 (21.5)	2681 (30.8)	1379 (15.8)	1229 (14.1)	1555 (17.8)
31-40	8027	1822 (22.7)	2133 (26.6)	1147 (14.3)	1256 (15.6)	1669 (20.8)
41-50	7043	1189 (16.9)	1662 (23.6)	1021 (14.5)	1380 (19.6)	1791 (25.4)
51-60	6190	980 (15.8)	1244 (20.1)	875 (14.1)	1227 (19.8)	1864 (30.1)
>60	6285	795 (12.6)	1118 (17.8)	922 (14.7)	1191 (18.9)	2259 (35.9)
Gender						
Female	18,521	3155 (17)	4528 (24.4)	2573 (13.9)	3533 (19.1)	4732 (25.5)
Male	17,742	3505 (19.8)	4310 (24.3)	2771 (15.6)	2750 (15.5)	4406 (24.8)
Children						
No	13,901	2386 (17.2)	3752 (27)	2036 (14.6)	2389 (17.2)	3338 (24)
Yes	21,846	4203 (19.2)	4999 (22.9)	3263 (14.9)	3769 (17.3)	5612 (25.7)
Tertiary education						
No	14,764	2375 (16.1)	2961 (20.1)	2099 (14.2)	3148 (21.3)	4181 (28.3)
Yes	21,484	4281 (19.9)	5871 (27.3)	3243 (15.1)	3133 (14.6)	4956 (23.1)
Religiosity						
Not a religious person	19,580	3116 (15.9)	5032 (25.7)	2920 (14.9)	3465 (17.7)	5047 (25.8)
A religious person	16,677	3543 (21.2)	3804 (22.8)	2423 (14.5)	2818 (16.9)	4089 (24.5)
Relationship status						
Divorced/single/widowed	13,138	2247 (17.1)	3247 (24.7)	2007 (15.3)	2437 (18.5)	3200 (24.4)
Married/civil partnership/living together	23,121	4412 (19.1)	5589 (24.2)	3337 (14.4)	3846 (16.6)	5937 (25.7)
Familiarity with genetics						
Unfamiliar	23,272	3272 (14.1)	4951 (21.3)	3234 (13.9)	4983 (21.4)	6832 (29.4)
Familiar	9182	2306 (25.1)	2598 (28.3)	1431 (15.6)	1033 (11.3)	1814 (19.8)
Personal	3802	1082 (28.5)	1288 (33.9)	677 (17.8)	264 (6.9)	491 (12.9)
Perspective on DNA status						
Same/unsure	17,044	2227 (13.1)	3425 (20.1)	2489 (14.6)	4063 (23.8)	4840 (28.4)
Different	19,217	4433 (23.1)	5413 (28.2)	2854 (14.9)	2219 (11.5)	4298 (22.4)

Data are reported as counts with percentages in brackets. Tertiary education refers to those who reported the highest level of education equivalent to study at a university, college, or other tertiary education institution. Familiarity with genetics reports responses to the question, "Are you familiar with DNA, genetics, or genomics?"; those who answered in the affirmative were asked to specify how. Perspective on DNA status refers to the extent to which respondents saw DNA information as different to medical information.

of RoR on willingness to donate. The model was adjusted for age, gender, children, education, religion, relationship status, familiarity with genetics, and whether respondents felt DNA was the same or different from other forms of information (genetic exceptionalism). The reference categories for the outcome and primary predictor were "partially influenced" and the United States, respectively. Results for the association between country of residence and influence of RoR, adjusted for the factors listed earlier, are shown in Figure 2 and Supplemental Table 2.

Overall, there were no countries for which the odds of being wholly influenced were significantly greater than those for the United States. Respondents from most countries had significantly lower odds than those of respondents from the United States of being "wholly influenced" rather than "partly influenced" to donate their data by receiving a readout of their DNA. This association was strongest for respondents from Spain (OR = 0.5; 95% CI = 0.4-0.7), China (OR = 0.3; 95% CI = 0.2-0.3), and Japan (OR = 0.6; 95% CI = 0.5-0.7). Exceptions to this trend were Russia, Pakistan, India, Germany, and Brazil, for which the odds of being wholly influenced were similar to those of being partially influenced.

Respondents from most countries had higher odds than those of respondents from the United States of reporting that they were "not influenced" by receiving a DNA readout. This difference was statistically significant in several cases, notably among respondents from Brazil (OR = 3.8; 95% CI = 3.0-4.9), Sweden (OR = 3.0; 95% CI = 2.3-4.0), and Portugal (OR = 3.0; 95% CI = 2.4-3.8). The direction of the association was the same, albeit of smaller magnitude, for a number of other countries, from Italy (OR = 2.9; 95% CI = 2.3-3.8) and Argentina (OR = 2.9; 95% CI = 2.2-3.9) through the United Kingdom, Spain, Mexico, and Egypt to Germany (OR = 1.7; 95% CI = 1.3-2.3) and Australia (OR = 1.55; 95% CI = 1.2-2.01). Russia (OR = 0.6; 95% CI = 0.4-0.8) was the only country with significantly lower odds than those of the United States of not being influenced rather than being partly influenced.

There was a mix of higher and lower odds among countries within the "Unsure" category. Argentina, Brazil, Egypt, Pakistan, Sweden, and the United Kingdom had significantly higher odds of being unsure rather than partly influenced than the United States. On the contrary, Belgium, China, France, Germany, India, Japan, Mexico, Poland,

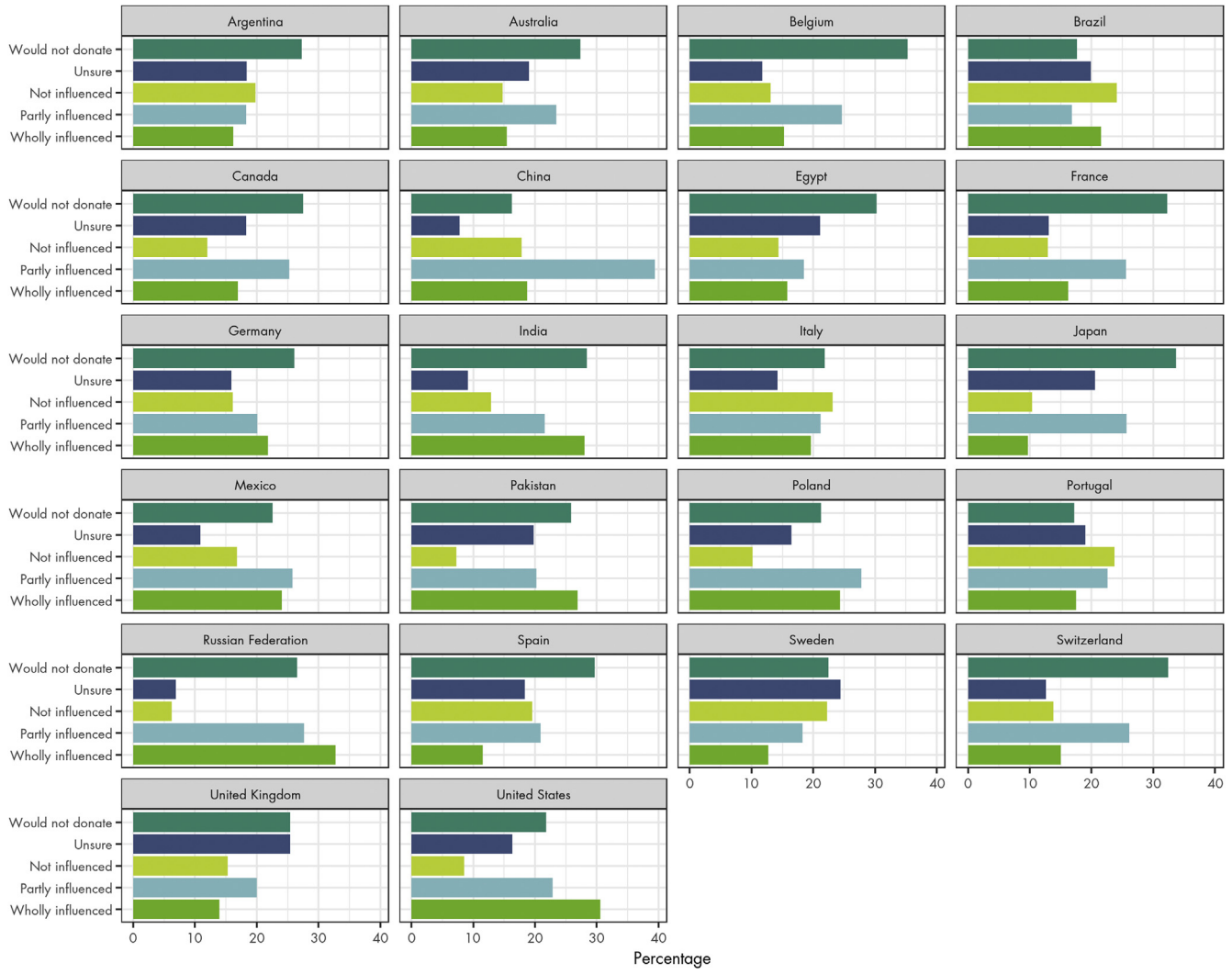

Figure 1 **Influence of return of results on the willingness to donate data by country of residence**.

Russia, and Switzerland had significantly lower odds of being unsure.

Discussion

Our analysis of the "Your DNA, Your Say" data highlights substantial international variation in the extent to which the return of genomic results motivates people to donate DNA or health data. Studies in the United States, notably All of Us, have been at the forefront of making results available to participants, reflecting a commendable responsiveness of the research community to the expressed patient and public wishes to drive a shift in approach to RoR over the last 2 decades. However, our central finding is that the United States, the subject of the substantial majority of research on RoR, may not be a clear indicator of global attitudes.

For some members of the public, the decision to participate in research is partly or even wholly contingent on the RoR. Most notably, more than half of the respondents in the United States sample in our study said that they would be partly or wholly motivated to donate data by receiving DNA information in return, with the proportion who said they would be wholly motivated being second only to Russia. This corresponds with the substantial quantitative and qualitative evidence from the United States around the desirability of RoR to the general public and its potential to motivate participation in large scale genomics research.[9-12] This work also suggests that the RoR in some form may motivate participation among traditionally underrepresented populations.[16,18]

Our study situates these findings in a comparative global context. We found that in 16 of the 21 countries studied, respondents were substantially less likely to be motivated to donate DNA or health data than those in the United States by the RoR and more likely to be not influenced at all. Previous work has suggested that conclusions related to RoR from the United States may be transferrable—eg, to South Korea.[23] Work with the general public—and particularly with patients—in other locations, including Australia,

Table 3 Influence of return of results on the willingness to donate data by country of residence

Country	Total	Wholly Influenced	Partly Influenced	Not Influenced	Unsure	Would Not Donate
Argentina	919	149 (16.2)	168 (18.3)	182 (19.8)	169 (18.4)	251 (27.3)
Australia	1212	187 (15.4)	284 (23.4)	179 (14.8)	231 (19.1)	331 (27.3)
Belgium	544	83 (15.3)	134 (24.6)	71 (13.1)	64 (11.8)	192 (35.3)
Brazil	1348	290 (21.5)	227 (16.8)	325 (24.1)	268 (19.9)	238 (17.7)
Canada	2966	502 (16.9)	749 (25.3)	356 (12.0)	543 (18.3)	816 (27.5)
China	3007	563 (18.7)	1185 (39.4)	536 (17.8)	234 (7.8)	489 (16.3)
Egypt	1426	225 (15.8)	264 (18.5)	205 (14.4)	301 (21.1)	431 (30.2)
France	790	128 (16.2)	202 (25.6)	102 (12.9)	103 (13.0)	255 (32.3)
Germany	1193	260 (21.8)	240 (20.1)	192 (16.1)	190 (15.9)	311 (26.1)
India	482	135 (28.0)	104 (21.6)	62 (12.9)	44 (9.1)	137 (28.4)
Italy	1229	241 (19.6)	260 (21.2)	284 (23.1)	175 (14.2)	269 (21.9)
Japan	4747	462 (9.7)	1219 (25.7)	491 (10.3)	975 (20.5)	1600 (33.7)
Mexico	1347	324 (24.1)	347 (25.8)	226 (16.8)	146 (10.8)	304 (22.6)
Pakistan	925	249 (26.9)	187 (20.2)	67 (7.2)	183 (19.8)	239 (25.8)
Poland	2904	707 (24.3)	807 (27.8)	296 (10.2)	477 (16.4)	617 (21.2)
Portugal	2224	389 (17.5)	502 (22.6)	528 (23.7)	423 (19.0)	382 (17.2)
Russia	1075	352 (32.7)	297 (27.6)	67 (6.2)	74 (6.9)	285 (26.5)
Spain	1272	147 (11.6)	266 (20.9)	249 (19.6)	233 (18.3)	377 (29.6)
Sweden	820	104 (12.7)	150 (18.3)	182 (22.2)	200 (24.4)	184 (22.4)
Switzerland	333	50 (15.0)	87 (26.1)	46 (13.8)	42 (12.6)	108 (32.4)
United Kingdom	3407	474 (13.9)	681 (20.0)	520 (15.3)	867 (25.4)	865 (25.4)
United States	2093	639 (30.5)	478 (22.8)	178 (8.5)	341 (16.3)	457 (21.8)

Botswana, Switzerland, Denmark, and the United Kingdom has reached similar conclusions to those of the United States studies regarding the desirability of feedback.[13,14,24-27] This work, however, is sparse compared with the volume of studies generated within United States and limited in its extension of the geographical and cultural reach of research.[19] Our findings suggest that these limitations have implications for genomics policy, both in the formal development of international standards and guidance, and in the extent to which pioneer initiatives function as informal exemplars of best practice.

The comparative findings from "Your DNA, Your Say" presented in this article suggest 2 important considerations in relation to public attitudes that merit further reflection. The first relates to the nuance of public attitudes, as well as the heterogeneity within them. Specifically, our findings suggest the need to distinguish between people's general interest in information about themselves and the expectation that this will be provided as a quid pro quo for data donation. Previous research suggests significant public interest in receiving research results, but interest in the possibility of receiving results does not equate to an expectation that they will be returned. The work of Middleton et al[28] on the return of incidental findings, eg, emphasizes on an important nuance between public interest in receiving findings, which is high, and public expectations related to researchers' responsibilities to look for such findings, which are low. Similarly, recent work around public perceptions of the RoR in population research in Germany suggests that although participants may value the RoR, they do not necessarily require it.[29]

The second relates to the need to reflect and better understand the diversity of global perspectives because they relate to genomics and the balance between the ethical norms that guide discussion of RoR. Specifically, we highlight the need to distinguish between arguments that are based on autonomy and an individual's right to know information about them and those based on reciprocity.[30] Reciprocity is an expectation that those who help or are likely to help should be helped in turn and plays a crucial role in shaping public attitudes toward contributing to medical research.[31,32] In case of genetics, arguments related to reciprocity have been used to consider the duty of studies to compensate or recompense participants, eg, through health care benefits or even payment.[32] Discussions of RoR have even equated it with such payment as a potential incentive or motivator.[11]

Our findings, however, suggest that caution is needed in extrapolating from the attitudes of potential US participants about the extent to which research participation involves a form of a contract or transaction that is based around individualized exchange of participation for direct feedback. The limited extent to which the RoR serves to motivate the intent to donate among our international respondents suggests that those developing genomics initiative should not overly emphasize the potential for individual returns at the expense of communal and generalized value. Doing so risks limiting reciprocity to a quid pro quo for participation that neglects the wider return of value associated with the gift of biosamples and data—not only to participants but also to the families and communities and not only in the present but also in the future.[33,34] Such future returns can continue to

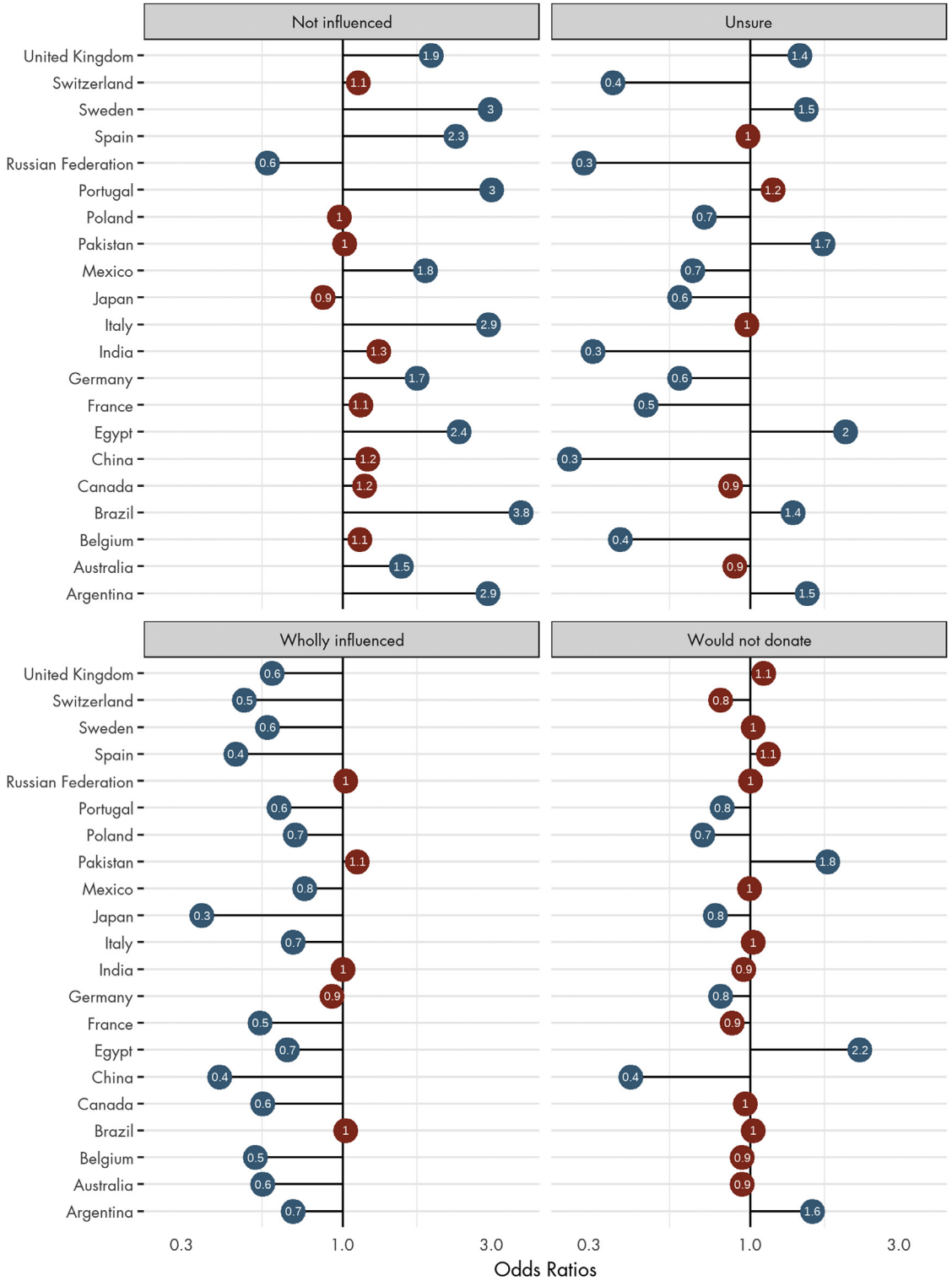

Figure 2 Lollipop plots displaying the odds ratios of being influenced by return of results to donate data across the different countries assessed in this study (United States of America and "partly influenced" categories correspond to the reference groups). The odd ratios are represented by the numbers within the dots with the distance from the baseline (value 1.0) determined by the respective 95% CI. In blue: statistically significant differences, in red: non–statistically significant differences.

underpin the evolution of a robust social contract for genomic medicine.[35]

Limitations

The overall limitations of the study design have been published separately.[21] There remain limitations related to the current discussion that are important to highlight. First, differences in approaches to data collection may have introduced variation in the responses—particularly the use of central location testing and tablets provided by field researchers in India and Pakistan. Such mixed modes of data collection can, however, help to contact harder to reach populations.[36] In this case, the limitations of this approach are outweighed by the value of obtaining responses from lower resource settings that might otherwise be excluded from the study. Although recruitment aimed to achieve a sample that was as representative as possible with regard to gender, age, and education level, we suggest that our results are tentative and do not necessarily indicate views of all people from each of the countries studied. As an exploratory cross-sectional online survey, the study is also limited in that it captures intended behavior at a single time point. Finally, although the survey terms were piloted and the text was translated and back-translated, nuances of language and culture may affect how participants interpret the options presented. Further studies might usefully consider how responses may vary in terms of the more granular categories of RoR encompassed within the broad definition of DNA readout used in this study and within country variation in views, particularly in terms of underrepresented populations.

Conclusion

There are firm ethical reasons to support the feedback of findings or data from genomics research to participants, alongside concerns about the consequences and practicalities of doing so. The views and expectations of patients, research participants, and the public are an important and powerful voice in contemplating these debates as they translate into practice. To date, however, much of the debate and research related to such public perspectives has concentrated on the United States. Our findings from the "Your DNA, Your Say" study suggest that we should be cautious about extending these findings internationally, particularly in considering the potential of RoR to motivate participation. The findings suggest the need for a nuanced appreciation of expectations and an approach to the return of value from research that does not necessarily emphasize a transactional relationship with participants around findings and data.

Data Availability

The full data set is registered and available at 10.17605/OSF.IO/ZPFGM. It is available, without restriction, for anyone to access, download, and analyze.

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Ethics Declaration

The online survey is fully anonymous. Participants are informed that their consent is given when they choose to click off the landing page and start answering the questions. On the landing page, the purpose of the project and what participation involves are explained, and participants have a choice at any stage within the survey to stop answering the questions and withdraw. The online project is physically based at the Wellcome Genome Campus with all data collected and stored in encrypted files at the Wellcome Sanger Institute in Cambridge. As part of the conditions of research delivery at this research institution the project passed ethical review by the Human Materials and Data Management Committee of the Wellcome Sanger Institute (Registration number: 16/029) as well as legal review to ensure that it was compliant with ethical and legal standards for participant involvement and data collection and storage. This ethics approval was sufficient to cover recruitment into the online survey for most of the collaborators attached to the project, with the exception of Australia, whereby the University of Tasmania required an additional local Institutional Review Board process to be completed in addition to their own separate consent form adding onto the landing page of the survey for Australian participants only. The study was approved by the Tasmanian Social Sciences Human Research Ethics Committee on the July 5, 2017 (reference number H0016682). This research conformed to the Declaration of Helsinki.

Conflict of Interest

The authors declare no conflicts of interest.

Additional Information

The online version of this article (https://doi.org/10.1016/j.gim.2022.01.002) contains supplementary material, whichis available to authorized users.

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