





Research and Applications

Integrating public preferences to overcome racial disparities in research: findings from a US survey on enhancing trust in research data-sharing practices

Stephanie Niño de Rivera, BA¹, Yihong Zhao, PhD, MPhil¹, Shalom Omollo, BA¹, Sarah Eslami, BS¹, Natalie Benda, PhD¹, Yashika Sharma , PhD, RN¹, Meghan Reading Turchioe , PhD, MPH, RN¹, Marianne Sharko , MD², Lydia S. Dugdale, MD³, Ruth Masterson Creber , PhD, MSc, RN^{*,1}

¹Columbia University School of Nursing, Columbia University Irving Medical Center, New York, NY 10032, United States, ²Weill Cornell Medicine, NewYork-Presbyterian Hospital, New York, NY 10065, United States, ³Center for Clinical Medical Ethics, Columbia University Vagelos College of Physicians & Surgeons, New York, NY 10032, United States

*Corresponding author: Ruth Masterson Creber, PhD, MSc, RN, Columbia University School of Nursing, Columbia University Irving Medical Center, 560 West 168th Street, New York, NY 10032, United States (rm3284@cumc.columbia.edu)

Abstract

Objectives: Data-sharing policies are rapidly evolving toward increased data sharing. However, participants' perspectives are not well understood and could have an adverse impact on participation in research. We evaluated participants' preferences for sharing specific types of data with specific groups, and strategies to enhance trust in data-sharing practices.

Materials and Methods: In March 2023, we conducted a nationally representative online survey with 610 US adults and used logistic regression models to assess sociodemographic differences in their willingness to share different types of data.

Results: Our findings highlight notable racial disparities in willingness to share research data with external entities, especially health policy and public health organizations. Black participants were significantly less likely to share most health data with public health organizations, including mental health (odds ratio [OR]: 0.543, 95% CI, 0.323-0.895) and sexual health/fertility information (OR: 0.404, 95% CI, 0.228-0.691), compared to White participants. Moreover, 63% of participants expressed that their trust in researchers would improve if given control over the data recipients.

Discussion: Participants exhibit reluctance to share specific types of personal research data, emphasizing strong preferences regarding external data access. This highlights the need for a critical reassessment of current data-sharing policies to align with participant concerns.

Conclusion: It is imperative for data-sharing policies to integrate diverse patient viewpoints to mitigate risk of distrust and a potential unintended consequence of lower participation among racial and ethnic minority participants in research.

Lay Summary

As data sharing for research becomes more common, much remains unknown about how people feel about it. This uncertainty can influence whether they choose to participate in research studies. Our study explored the types of personal data people are willing to share, whom they are comfortable sharing it with, and how trust in researchers can be strengthened. We surveyed 610 US adults in March 2023 and found that racial differences influence the willingness to share sensitive data. Black participants were significantly less likely to share health data, notably mental and sexual health information, with public health organizations compared to White participants. Most respondents (63%) said they would trust researchers more if they had control over who accessed their data. These findings suggest that data-sharing policies need to better consider diverse perspectives to prevent reduced participation in research, especially from racial and ethnic minoritized communities.

Key words: data sharing; transparency; patient participation; trust; personal autonomy.

Background and significance

Data-sharing policies are evolving in the current research environment, presenting an opportunity for researchers to establish data-sharing policies that prioritize transparency and foster trust in research. Recent shifts, including increased data-sharing requirements from funding agencies like the National Institutes of Health (NIH) and mandates from

leading journals, now require that datasets be made available in public repositories, with varying levels of accessibility.¹ Individuals who decide to participate in research often grant broad consent for secondary uses and frequently do not have a clear understanding of how their data might be used and by whom in the future. This lack of clarity has the potential to erode trust between researchers and participants who

Received: August 16, 2024; Revised: October 28, 2024; Editorial Decision: April 9, 2025; Accepted: April 10, 2025

© The Author(s) 2025. Published by Oxford University Press on behalf of the American Medical Informatics Association. This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial License (<https://creativecommons.org/licenses/by-nc/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited. For commercial re-use, please contact reprints@oup.com for reprints and translation rights for reprints. All other permissions can be obtained through our RightsLink service via the Permissions link on the article page on our site—for further information please contact journals.permissions@oup.com.

perceive limited transparency and control over how their research data is shared, especially when it involves more sensitive data such as sexual health, mental health, and genomic data.^{2,3} While there is a substantial body of literature exploring public attitudes toward data sharing in research, particularly regarding specific types of data (eg, genetic, biospecimen⁴⁻⁶) and the varying entities involved (eg, health-technology companies, medical professionals, governmental organizations, commercial entities),⁷⁻¹⁰ there is a notable gap in examining perspectives on data-sharing practices in the current landscape, especially among racial and ethnic underrepresented communities.

Researchers' data-sharing practices influence participants' trust in researchers.^{3,11} Trust research is crucial to promote diverse participation in research, and it is important that current data-sharing practices do not contribute to participants' hesitancy to participate in research. Previous studies support that trust in researchers can increase among participants when there are transparent efforts to inform participants about the future intended use of their data.^{3,12-14} Data sharing is important to promote transparency and reproducibility in science, but it must be done in an inclusive manner that incorporates the preferences of the diverse communities with whom researchers work. Racial and ethnic minorities have historically been and continue to be underrepresented in research due to concerns surrounding exploitation, fears of discrimination, and cultural and language barriers.¹⁵⁻²⁰ These experiences have contributed to a perception among them that researchers are not transparent about potential conflicts of interest with external industries.^{21,22} This distrust can contribute to lower representation of racial and ethnic minorities in health-related research,²³ which limits the generalizability of research findings to these populations, creating cycles of inequity.

To ensure an inclusive research environment is established and does not perpetuate the exclusion of underrepresented communities or cause intervention-generated inequities,²⁴ it is necessary to explore research on the views of a diverse representation of participants. Addressing concerns about sharing sensitive data is essential to protecting participants' autonomy and ensuring their priorities are reflected in data-sharing policies, especially with the shift toward public repositories. This study aims to fill this gap by examining how these changes in data-sharing policies affect participants' trust, using a representative sample from the United States to ensure that research practices are inclusive of diverse populations.

Objective

In this study, we evaluated public data-sharing preferences regarding the intersection of: (1) the type of research data shared (eg, sexual health and fertility data, mental health data, imaging data, etc.) and (2) with whom the data would be shared with (eg, health policy institutions, public health organizations, health-technology companies). Given the importance of inclusiveness in data-sharing policies, our analysis focused on assessing sociodemographic differences in data-sharing preferences. We also evaluated the impacts on willingness to participate and trust in research if participants could decide on the potential external recipients of their research data.

Materials and methods

Ethics statement

The Institutional Review Board at Columbia University approved this study. Participants were administered an information sheet about the study and provided informed consent by checking a box on the online survey. Participants were able to stop the survey at any time and withdraw participation.

Study design

A cross-sectional survey was administered in March 2023 using Prolific,²⁵ an online survey sampling tool, to recruit a sample balanced on age, gender, and race to match the US census. Participants were verified Prolific users of the age 18 or older with English proficiency. The survey was first piloted with 10 participants, and then administered to an additional 600. In total, 610 participants completed the survey with no missing data.

Survey items

Survey questions were developed by team members with experience in prior work evaluating the impact of trust on data sharing,³ a pediatrician, and medical ethicist. The survey had 4 primary areas of focus: (1) types of research data participants are willing to share with external recipients, (2) types of research data participants want to be returned to them, (3) the impact of returning data on willingness to participate in research, and (4) changes in trust toward researchers when they can choose who their data is shared with.

First, participants selected the types of data they would want to access after participating in a research study. The 7 different types of data presented for the questions included: (1) biological, (2) genetic, (3) clinical, (4) mental health, (5) sexual health and fertility, (6) imaging, and (7) consumer-generated data. Each type of data presented was based on the NIH guideline for types of data researchers should share in data repositories.²⁶ Examples for each type of data were provided for clarity. Additional information regarding the descriptions for the types of data presented in the survey can be found in the [Supplementary Material](#). Next, participants were asked to select whether their willingness to participate in research would change if they could access the data researchers collected about them.

Using lay terms, participants were then informed about the possibility of research studies sharing their anonymous data with outside groups for secondary uses. An example of secondary uses was also provided: "An example of an outside group includes health-technology companies who make applications for health monitoring." Then, participants had the option to select the types of research data they would share with different external recipients. The 5 types of external recipients included: (1) doctors and nurses, (2) health policy institutions, (3) public health foundations, (4) health-technology companies, and (5) private foundations. Next, participants were asked whether they wanted to have the option to review, remove, or do nothing with their data before sharing it with external recipients. Participants were also asked whether trust or willingness to participate in research would change if they could select which outside groups had access to their data. Finally, participants answered sociodemographic questions including age, gender, race, ethnicity, socioeconomic information, and health literacy.²⁷

Data collection

We created the survey using Qualtrics, a Health Insurance Portability and Accountability Act (HIPAA) compliant survey development tool provisioned by Columbia University. Prolific recruited eligible individuals to participate, and upon consenting to participate in the study, participants were directed to a link with the Qualtrics survey. Participants were able to review their answer choices before submitting the survey and compensated \$15 per hour.

Statistical analysis

Descriptive statistics on sociodemographic variables and closed-ended survey responses were generated for the overall sample. Bivariate associations between survey responses and self-reported race were assessed with Pearson's Chi-squared test or Fisher's exact test. Native American or Alaska Native, Native Hawaiian or Pacific Islander, Multirace, or participants who identify as a race not listed were combined into "Another race" category due to the small number of participants in these race categories. Logistic regression models were used to assess whether there were racial differences in participants' willingness to share different types of data with health policy institutions and public health institutions. Age, gender, education level, and health literacy status were included in the models as control variables. All tests were 2-sided with a statistical significance level set at 0.05.

Qualitative analysis

A thematic analysis was conducted for the open-ended survey responses on perspectives about what makes a researcher trustworthy. Two members of the research team identified relevant codes and themes for analysis. The interrater reliability (IRR) was calculated using 10% of the double-coded qualitative responses to calculate Cohen's kappa score. After establishing the IRR, the remaining responses were independently coded and any discrepancies between coders were resolved by reaching a consensus through discussion.

Results

Sample characteristics

Participant characteristics are summarized in [Table 1](#). The analytic sample included 610 participants with a mean of 46 years (± 16 ; range 19-93). Among the sample, 50% were female, 79% identified as White, and 7% identified as Hispanic/Latinx. Over half of participants completed a college degree or higher, and 31% of participants reported financial instability/not having enough resources to make ends meet. The majority of participants (95%) had adequate health literacy and 5% of participants had limited or marginal health literacy. The average time of completion for the survey was 13 minutes and 55 seconds.

Participant preferences for sharing data

Participants' willingness to share research data differed based on the type of data and which group it was shared with. Regardless of research data type (eg, biological, genetic, clinical, mental health, sexual health and fertility, imaging, and consumer-generated data), participants were most willing to share with their doctors and nurses ([Table S1](#)). For example, 77% of participants would share their mental health data with doctors and nurses, compared to 40% with health-technology companies and 28% with private foundations. Similarly, 88%

of participants would share their imaging data with their health-care team, compared to 54% with health policy institutions and 49% with health-technology companies. There were also significant differences by race, when choosing to share with doctors and nurses. Fewer Black/African American participants wanted to share with doctors and nurses their biological (70%, $P < .001$), genetic (70%, $P = .019$), clinical symptom (81%, $P = .014$), imaging (73%, $P < .001$), and mental health data (59%, $P < .001$) compared to other racial groups.

[Figure 1](#) presents data-sharing preferences with external entities across different racial categories. Racial differences were most prominent among data shared with health policy institutions and public health organizations, compared to health-technology companies and private foundations. For example, a lower proportion of Black/African American participants (33%), Asian participants (42%), and participants who identified with another race (48%) were willing to share their imaging data with health policy institutions compared to White participants (58%) ($P < .001$). Similarly, fewer Black participants (59%), Asian participants (58%), and participants who identified with another race (62%) were inclined to share their clinical symptom data with health policy institutions compared to White participants (72%) ($P = .035$). Similar trends were observed for willingness to share with public health organizations. A smaller percentage of Asian (11%) participants expressed willingness to share sexual health data with health-technology companies compared to Black participants (29%), White participants (34%), and participants who identified with another race (38%) ($P = .020$).

[Figure 2](#) shows the adjusted odds ratio (ORs) and 95% CI for willingness to share different data types with public health institutions and health-technology companies by self-reported race. When deciding to share research data with public health organizations, Black participants were significantly less likely to share most of the data types presented (biological—OR: 0.562 [95% CI, 0.342-0.920]; clinical symptom—OR: 0.455 [95% CI, 0.275-0.756]; mental health—OR: 0.543 [95% CI, 0.323-0.895]; sexual health and fertility data—OR: 0.404 [95% CI, 0.228-0.691]; and imaging data—OR: 0.488 [95% CI, 0.258-0.714]; consumer-generated data—OR: 0.432 [95% CI, 0.258-0.714]) compared to White participants. Similarly, participants who identified as another racial group were significantly less likely to share their sexual health or fertility data (OR: 0.534 [95% CI, 0.284-0.971]), imaging data (OR: 0.466 [95% CI, 0.255-0.832]), and consumer-generated data (OR: 0.493 [95% CI, 0.271-0.885]) with public health organizations compared to White participants. Furthermore, Black/African American participants were significantly less likely to share consumer-generated data (OR: 0.539 [95% CI, 0.324-0.885]) and imaging data (OR: 0.480 [95% CI, 0.285-0.794]) with health-technology companies than their White counterparts. Similar trends were noted for willingness to share with health policy institutions, with all racial minority participants exhibiting lower likelihood of sharing different types of data than White participants ([Figure S1](#)).

Participant preferences for types of data they want returned to them

Participants indicated the types of research data they would want returned to them after participating in a research study ([Figure 3](#)). The majority of participants (93%)

wanted researchers to return at least one of the indicated data types, with the highest proportion of participants selecting clinical symptom data (75%). Racial differences were not found among the types of data participants preferred to receive.

Table 1. Self-identified demographic characteristics of the survey sample.

Demographic characteristic	Overall (N = 610)
Age (mean, SD)	46 (16)
Gender (n, %)	
Female	303 (50%)
Male	293 (48%)
Nonbinary or gender diverse	14 (2%)
Race (n, %)	
American Indian or Alaska Native	3 (0.5%)
Asian	36 (5.9%)
Black/African American	78 (12.8%)
Native Hawaiian or Pacific Islander	1 (0.2%)
White	475 (77.9%)
Multirace	11 (1.8%)
Identifies as a race not listed	6 (1.0%)
Ethnicity	
Hispanic or Latino origin	43 (7%)
Non-Hispanic or non-Latino origin	567 (93%)
Education (n, %)	
High school graduate or less	86 (14%)
Some college or Bachelor's	422 (69%)
Graduate degree	102 (17%)
Financial resources (n, %)	
Not enough	192 (31%)
Enough	347 (57%)
More than enough	71 (12%)
Health literacy ^a (n, %)	
Adequate	582 (95%)
Limited/marginal	28 (5%)

^a Health literacy was measured using a standardized instrument.²⁰

Data sharing and impacts on participation and trust

Participants' willingness to engage in research, and trust in researchers is influenced by being able to choose who gets access to their data (Figure 4). When asked if they could select which external groups could access their data, 52% of participants would increase their willingness to participate in research, 44% of participants would have no change, and 4% would decrease their willingness. Moreover, when asked about changes in trust if they could select which external recipients, 63% of participants would increase their trust, 35% would not change their trust, and 2% would decrease their trust toward researchers. Sixty percent of participants reported increasing their willingness to participate in research if their data were returned to them. Racial differences were not found for changes in willingness to participate and changes in trust.

Finally, 34% of participants wanted to review their data before sharing, 37% wanted to be able to remove some of their data, and 30% did not feel it was necessary to review or remove their data before sharing with external groups. A significantly greater proportion of Black/African American (47%) and Asian (50%) participants were more likely to want to remove their data from data repositories compared to White (35%) and participants who identified with another race (24%).

Qualitative results

Cohen's kappa score was high ($\kappa = 1.0$), indicating strong agreement between coders. Participants were asked to describe what they believe makes a researcher trustworthy. Table 2 shows the four core themes found from the responses: (1) transparency (59.0%), (2) practices surrounding data management, sharing, and privacy (23.7%), (3) institutional reputation (45.8%), (4) ethical oversight

Table 2. Open-ended responses regarding themes for the question: *What do you believe makes a researcher trustworthy?*

Emergent theme or category (# of responses)	Description	Exemplary quote
Transparency (n=361)	Participants wanted transparency around the purpose of the research study, any risks, and clear information on potential conflict of interests	<p>"Full disclosure of conflicts of interest, up front about risks for participants"</p> <p>"They are honest and tell you exactly what the data will be used for. They don't make promises they can't keep, and they respect your identity as a person. They don't treat you like a means to an end."</p>
Data management, sharing, and privacy (n=145)	Participants want clear, easy-to-read information about how their research data will be used in the study, and who may have access to the data (and for what purpose) after the study conclusion. Some participants wanted the ability to remove all identifying data if they chose	<p>"Someone who will not take your data and use it for advertisement purposes and are honest and upfront on how they will use your data."</p> <p>"[...] Clearly outlined research guidelines including protections for the researcher/the patient/the data, clearly stated guidelines for who can access the data and why, clear instructions on how and what control I retain over my data over time (i.e, can I withdraw it from the research pool in the future?)."</p>
Institutional reputation (n=280)	Participants stated that they trusted academic research institutions	<p>"I think what makes a researcher trustworthy is who they are doing it for and [the] institutions behind it. If [the] government was involved I would be less likely to trust it as opposed to an academic researcher."</p>
Ethical oversight (n=49)	Participants wanted assurance of IRB approval of research studies, in addition to concerns around data security	<p>"Having some type system to make sure they do not take advantage of participants (IRB) and strong security around data."</p>

Abbreviation: IRB, Institutional Review Board.

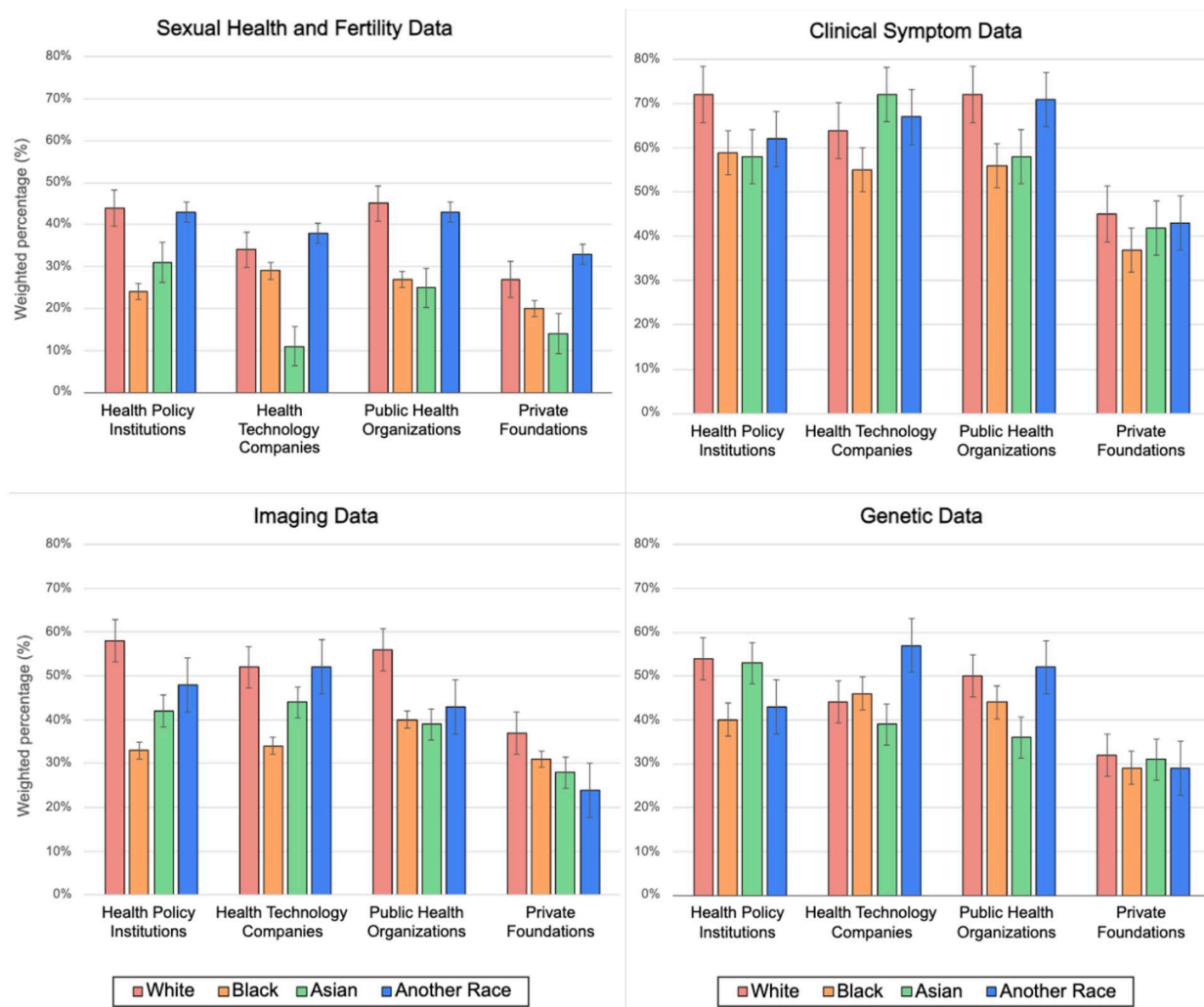


Figure 1. Bar charts showing Sharing preferences for sharing specific types of data (sexual health and fertility, clinical symptom, imaging, and genetic data) with external recipients by different racial groups.

(8.0%). There were a few missing responses or those that could not be categorized (6.9%).

Discussion

Inclusion of research participants' perspectives regarding their preferences on external data sharing presents an opportunity for researchers to cultivate trust in data-sharing practices. Despite the evolution of data-sharing policies geared toward increased data sharing,¹ there is limited data on participants' viewpoints regarding updated data-sharing policies. Our findings demonstrate that the perceived sensitivity of the type of data and the identity of the recipient significantly contribute to participants' willingness to share data. Across diverse data categories, our results are consistent with hesitancy among racial minority communities to share data with external recipients, such as health policy institutions and public health institutions. To enhance trust in research practices, it is important to implement data-sharing approaches that address participants' concerns and promote initiatives that provide participants with more control over the sharing of their data. These efforts can be particularly beneficial in

establishing trust within underrepresented communities in research.

Participants generally felt most comfortable sharing their research data with health-care providers. However, we found that Black participants showed less willingness to share certain data types, such as genetic and mental health data, with their health-care providers. This reluctance may stem from historical discrimination and abuse by health professionals against the Black community.^{28–31} In addition, ongoing discrimination in health-care settings can contribute to fears that researchers may exploit their genetic data^{32–35} alongside the stigmatization of mental health conditions.³⁶ Previous research has highlighted hesitancy in sharing genetic data among Black communities due to fear of exploitation and mistrust.^{37–40}

Across all racial groups, participants are less willing to share genetic data with external entities including health policy institutions, health-technology companies, and private foundations, which is possibly due to the heightened concerns regarding the uniqueness and traceability of genetic data, impact on progeny, and the ambiguity of future uses.^{41–44} These apprehensions are justified, as even with efforts to ensure de-identification, genetic data can still be linked to

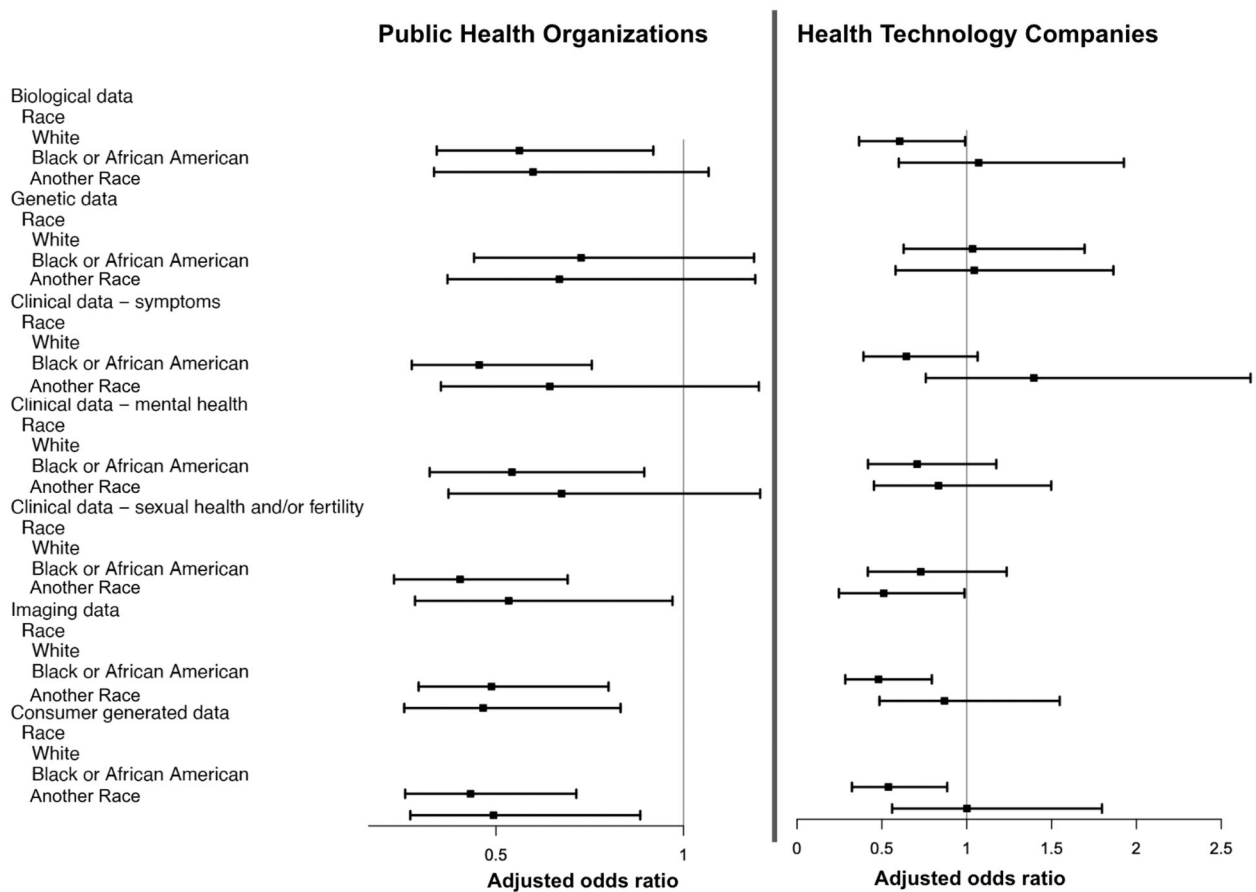


Figure 2. Odds ratios (95% confidence intervals) of participants' willingness to share different types of research data with health-technology companies and public health organizations. The "Another Race" category comprises individuals identifying as Asian, Multirace, Native American or Alaska Native, Native Hawaiian or Pacific Islander, or a race not listed.

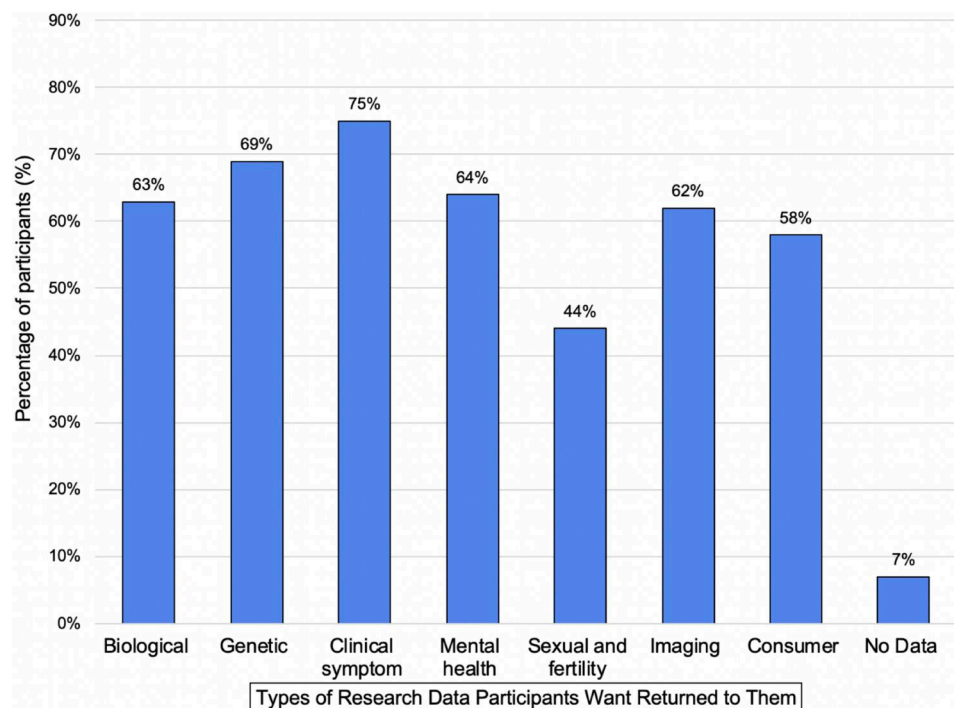


Figure 3. Types of research data participants want returned to them after participating in a research study.

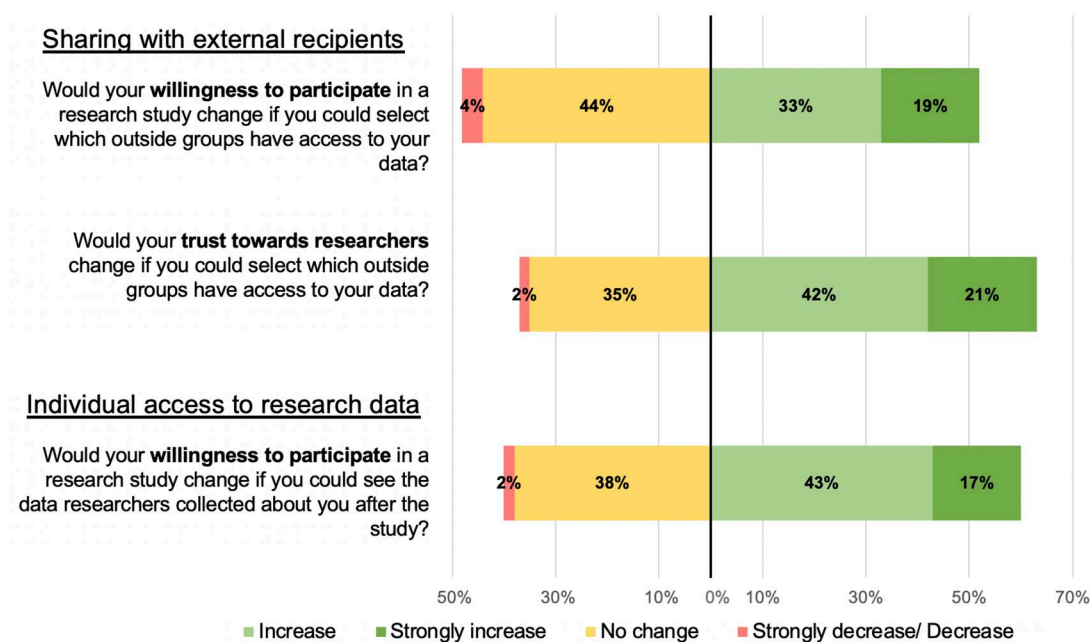


Figure 4. Changes in willingness to participate in research and trust toward researchers.

individuals due to its unique nature.⁴⁵ Furthermore, advancements in technologies such as facial recognition have sparked additional fears around the potential for reidentification through facial images.⁴⁶

In addition, participants across all racial groups expressed greater hesitancy in sharing sexual health and fertility data compared to other data types. In particular, Black and Asian participants reported the least comfort in sharing sexual health and fertility data with nonhealth-care providers. This finding aligns with current public perspectives given that health-technology companies acquiring and collecting sexual health and fertility data have been scrutinized for their privacy practices and commercialization of data.^{47–49} However, we did not expect participants to share this hesitancy with groups that are often perceived as serving the public good (such as public health institutions and health policy institutions). Increasing fears following the overturn of *Roe v. Wade* could contribute to this broader reluctance, as information about fertility or menstruation could expose individuals to penalties and legal consequences.^{50–52}

Black and Asian participants were also less comfortable sharing imaging data with health policy institutions and public health organizations compared to White participants. We hypothesize that along with distrust, participants may perceive imaging data to be more sensitive given that medical images may capture inherently identifiable features. For instance, with advances in artificial intelligence and facial recognition, it is more feasible to match images generated from MRI scans to photographs of an individual.⁵³

To further investigate increased hesitancy to share with organizations established for the public good, when controlling for age, gender, educational attainment, and health literacy, we continued to find that Black/African Americans and other racial minority participants were less likely to share various types of data with public health organizations and health policy institutions compared to health-technology companies. Heightened distrust in governmental institutions post-COVID could have contributed to a reluctance to share

with entities that are associated with the medical system and the government.^{54,55} In particular, racial and ethnic minorities were significantly impacted by COVID-19 pandemic due to disparities in medical treatment and systemic racism.^{56–58}

With increasing distrust in health policy institutions, it is crucial to develop data-sharing practices that do not further exacerbate distrust in research. Previous research has demonstrated that returning participant data can serve as a method to increase trust in researchers.⁵⁹ Our findings align in that most participants want access to their research data.⁶⁰ This adds to the importance of discovering methods of returning data to participants in a manner that is comprehensible and inclusive of health literacy and numeracy, allowing patients to participate in research.

Previous research underscores the impact of data sharing on research participation, highlighting a decrease in trust when participants perceive a lack of transparency in the use of their data when shared with others.³ Therefore, we assessed whether having the choice to select external recipients of their data would influence research participants' trust in researchers. We found that granting greater autonomy to select external data recipients can influence trust in research and participation. Black and Asian participants expressed a desire for greater autonomy over their data, with a higher proportion indicating a preference for the option to review or remove some of their research data before sharing it with external recipients. This discovery aligns with literature emphasizing participants' desire for more customization when consenting to participate in a research study.^{61–64} Furthermore, our findings of racial differences in the desire for greater autonomy in data-sharing practices highlight an opportunity for researchers to build trust through data sharing with racial and ethnic minorities.¹⁷ However, current research practices, particularly those funded by the NIH, promote broad consent for secondary uses of data.^{56–59,65} Many participants in studies lack a clear understanding of how their data might be used in the future.^{66–68}

Our qualitative results highlighted that participants believe transparency regarding future uses of their research data is a critical attribute of a trusted researcher. Supporting our findings, the Pew Research Center conducted a survey in 2022 on trust in medical research, revealing that racial minorities were more likely to believe that, despite existing strict de-identification practices, researchers could escape consequences for data breaches resulting in public disclosure of identifiable data.⁶⁹ Such findings make it imperative for researchers to consider strategies to improve participants' understanding of data-sharing practices, with an emphasis on confidentiality and the de-identification process of personal health data.⁷⁰ This will also help promote a trustful, transparent research community, and not further perpetuate the exclusion of racial and ethnic minorities from research studies. Therefore, data-sharing practices must consider the priorities and concerns of racial and ethnic minority communities to ensure current practices are guided by diverse perspectives.

Our findings demonstrate the importance of researchers moving toward a participant-centered approach that is inclusive of participants' concerns and priorities regarding how they want their data to be shared with external entities.^{70,71} The patient perspective on evolving data-sharing practices requires further exploration, with an emphasis on obtaining a better understanding of the concerns shared among racial minorities and participants from diverse backgrounds (eg, participants with low health literacy, low socioeconomic status, etc.). Including these perspectives will help the research community develop best practices for data-sharing policies that are both patient-informed and trust-building, especially with underrepresented communities.

Our work emphasizes the need to move beyond broad consent by offering customizable options that allow individuals to specify which data can be shared and with whom. However, achieving this level of customization requires a robust informatics infrastructure to support individualized consent mechanisms that warrant further exploration. By enhancing transparency and control, such systems could help alleviate fears of data misuse. Additionally, the informed consent process must communicate data-sharing practices clearly and accessibly to ensure participants are empowered and fully informed about the benefits and risks of sharing their data. This approach may bridge the trust gap through transparency, inclusivity, and participant autonomy.

Limitations

Limitations of this study include the use of the online survey platform, Prolific in English. To use Prolific, respondents must have a high degree of English proficiency, access to the Internet, and familiarity with technology. These individuals tend to have higher levels of health, graph, and subjective numerical literacy. Additionally, they likely have a higher trust in researchers, seeing as they are participating in research. The Prolific survey is representative of the US population based on census data. However, it is only representative of age, race, and sex and it is not representative of ethnicity (Hispanic or Latinx). We also acknowledge the limitations in the way we measured and presented results by race. The NIH sets 5 categories for race (Asian, Black/African American, Alaska Native, Native Hawaiian or Other Pacific Islander, and White). Respondents to this survey were provided only with a summary of the current NIH Data

Management and Sharing policy and were not fully informed about specific data privacy and security measures for deidentified or anonymized data. As a result, participants answered the questions based on their own knowledge or assumptions. In our data analysis, due to limitations with our sample size, we collapsed them into 4 race categories (Asian, Black or African American, Another race, and White). Due to the limitations of using Prolific, further research efforts focusing on sample populations with lower health and technology literacy and different language skills should be carried out.

Author contributions

Stephanie Nino de Rivera (Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Visualization, Writing—original draft), Yihong Zhao (Data curation, Formal analysis, Methodology, Software, Visualization, Writing—original draft, Writing—review & editing), Shalom Omollo (Formal analysis, Visualization, Writing—review & editing), Sarah Eslami (Visualization, Writing—review & editing), Yashika Sharma (Writing—review & editing), Natalie C. Benda (Visualization, Writing—review & editing), Meghan Reading Turchioe (Writing—review & editing), Marianne Sharko (Writing—review & editing), Lydia Dugdale (Conceptualization, Writing—review & editing), and Ruth Masterson Creber (Conceptualization, Funding acquisition, Investigation, Methodology, Project administration, Supervision, Validation, Visualization, Writing—original draft, Writing—review & editing)

Supplementary material

[Supplementary material](#) is available at *JAMIA Open* online.

Funding

This work was supported by the National Institute of Neurological Disorders and Stroke, R01NS123639-03S2, 5R01NS123639-03, R01NS123639 and National Heart, Lung, and Blood Institute Division of Intramural Research, R01HL161458, R01HL152021. The funders had no role in the study design, data collection, analysis, decision to publish, or preparation of the manuscript.

Conflicts of interest

Our team has the following competing interests to disclose: MRT Boston Scientific (consulting), Iris OB Health (equity). The remaining authors have no conflicts of interest to disclose. This does not alter our adherence to JAMIA policies on sharing data and materials.

Data availability

The dataset underlying this study cannot be publicly shared in a repository due to current restrictions imposed by the Columbia University Institutional Review Board (IRB) and the participants did not consent to the public sharing of their data. However, the data are available upon request from the Columbia University IRB for researchers who meet the criteria for accessing confidential information. Please contact the corresponding author to request the dataset.

References

- NOT-OD-21-013: final NIH policy for data management and sharing. Accessed January 17, 2024. <https://grants.nih.gov/grants/guide/notice-files/NOT-OD-21-013.html>
- Steinsbekk KS, Kåre Myskja B, Solberg B. Broad consent versus dynamic consent in biobank research: is passive participation an ethical problem? *Eur J Hum Genet*. 2013;21:897-902.
- Mangal S, Park L, Reading Turchioe M, et al. Building trust in research through information and intent transparency with health information: representative cross-sectional survey of 502 US adults. *J Am Med Inform Assoc*. 2022;29:1535-1545.
- Lemke AA, Wolf WA, Hebert-Beirne J, et al. Public and biobank participant attitudes toward genetic research participation and data sharing. *Public Health Genomics*. 2010;13:368-377. <https://doi.org/10.1159/000276767>
- Haga SB, O'Daniel J. Public perspectives regarding data-sharing practices in genomics research. *Public Health Genomics*. 2011;14:319-324. <https://doi.org/10.1159/000324705>
- Kim J, Kim H, Bell E, et al. Patient perspectives about decisions to share medical data and biospecimens for research. *JAMA Netw Open*. 2019;2:e199550. <https://doi.org/10.1001/jamanetworkopen.2019.9550>
- Niño de Rivera S, Masterson Creber R, Zhao Y, et al. Public perspectives on increased data sharing in health research in the context of the 2023 National Institutes of Health Data Sharing Policy. *PLoS One*. 2024;19:e0309161. <https://doi.org/10.1371/journal.pone.0309161>
- Ghafur S, Van Dael J, Leis M, et al. Public perceptions on data sharing: key insights from the UK and the USA. *Lancet Digital Health*. 2020;2:e444-e446. [https://doi.org/10.1016/s2589-7500\(20\)30161-8](https://doi.org/10.1016/s2589-7500(20)30161-8)
- Garett R, Young SD. Ethical views on sharing digital data for public health surveillance: analysis of survey data among patients. *Front Big Data*. 2022;5:871236. <https://doi.org/10.3389/fdata.2022.871236>
- Middleton A, Milne R, Almarri MA, et al. Global public perceptions of genomic data sharing: what shapes the willingness to donate DNA and health data? *Am J Hum Genet*. 2020;107:743-752. <https://doi.org/10.1016/j.ajhg.2020.08.023>
- Kalkman S, van Delden J, Banerjee A, et al. Patients' and public views and attitudes towards the sharing of health data for research: a narrative review of the empirical evidence. *J Med Ethics*. 2022;48:3-13.
- Lee Y, Li J-YQ. The role of communication transparency and organizational trust in publics' perceptions, attitudes and social distancing behaviour: a case study of the COVID-19 outbreak. *J Contingencies Crisis Manag*. 2021;29:368-384.
- Frank RD, Chen Z, Crawford E, et al. Trust in qualitative data repositories. *Proc Assoc Inf Sci Technol*. 2017;54:102-111.
- Diprose WK, Buist N, Hua N, et al. Physician understanding, explainability, and trust in a hypothetical machine learning risk calculator. *J Am Med Inform Assoc*. 2020;27:592-600.
- Hemphill R, Forsythe LP, Heckert AL, et al. What motivates patients and caregivers to engage in health research and how engagement affects their lives: qualitative survey findings. *Health Expect*. 2020;23:328-336.
- Etti M, Fofie H, Razai M, et al. Ethnic minority and migrant underrepresentation in Covid-19 research: causes and solutions. *EClinicalMedicine*. 2021;36:100903.
- Turner BE, Steinberg JR, Weeks BT, Rodriguez F, Cullen MR. Race/ethnicity reporting and representation in US clinical trials: a cohort study. *Lancet Reg Health Am*. 2022;11:100252. <https://doi.org/10.1016/j.lana.2022.100252>
- Mohan SV, Freedman J. A review of the evolving landscape of inclusive research and improved clinical trial access. *Clin Pharmacol Ther*. 2023;113:518-527.
- Premji S, Kosny A, Yanar B, et al. Tool for the meaningful consideration of language barriers in qualitative health research. *Qual Health Res*. 2020;30:167-181.
- Carson C, Hinton L, Kurinczuk J, et al. 'I haven't met them, I don't have any trust in them. It just feels like a big unknown': a qualitative study exploring the determinants of consent to use Human Fertilisation and Embryology Authority registry data in research. *BMJ Open*. 2019;9:e026469.
- Griffith DM, Jaeger EC, Bergner EM, et al. Determinants of trustworthiness to conduct medical research: findings from focus groups conducted with racially and ethnically diverse adults. *J Gen Intern Med*. 2020;35:2969-2975.
- Ahmed A, Vandrevale T, Hendy J, et al. An examination of how to engage migrants in the research process: building trust through an 'insider' perspective. *Ethn Health*. 2022;27:463-482.
- Shea L, Pesa J, Geonnotti G, et al. Improving diversity in study participation: patient perspectives on barriers, racial differences and the role of communities. *Health Expect*. 2022;25:1979-1987.
- Veinot TC, Mitchell H, Ancker JS. Good intentions are not enough: how informatics interventions can worsen inequality. *J Am Med Inform Assoc*. 2018;25:1080-1088.
- Palan S, Schitter C. Prolific.ac—a subject pool for online experiments. *J Behav Exp Finance*. 2018;17:22-27.
- 2023 NIH Data Management and Sharing policy. Accessed March 1, 2024. <https://oir.nih.gov/sourcebook/intramural-program-over-sight/intramural-data-sharing/2023-nih-data-management-sharing-policy>
- Chew LD, Bradley KA, Boyko EJ. Brief questions to identify patients with inadequate health literacy. *Fam Med*. 2004;36:588-594.
- Bailey ZD, Feldman JM, Bassett MT. How structural racism works—racist policies as a root cause of U.S. racial health inequities. *N Engl J Med*. 2021;384:768-773.
- Girolamo T, Parker TC, Eigsti I-M. Incorporating dis/ability studies and critical race theory to combat systematic exclusion of Black, Indigenous, and people of color in clinical neuroscience. *Front Neurosci*. 2022;16:988092.
- Adkins-Jackson PB, Chantarat T, Bailey ZD, et al. Measuring structural racism: a guide for epidemiologists and other health researchers. *Am J Epidemiol*. 2022;191:539-547.
- Scharff DP, Mathews KJ, Jackson P, et al. More than Tuskegee: understanding mistrust about research participation. *J Health Care Poor Underserved*. 2010;21:879-897.
- Skloot R. *The Immortal Life of Henrietta Lacks*. Broadway Books; 2017.
- Lounsbury O, Roberts L, Goodman JR, et al. Opening a 'can of worms' to explore the public's hopes and fears about health care data sharing: qualitative study. *J Med Internet Res*. 2021;23:e22744.
- Hutchings E, Loomes M, Butow P, et al. A systematic literature review of attitudes towards secondary use and sharing of health administrative and clinical trial data: a focus on consent. *Syst Rev*. 2021;10:132.
- Jaiswal J, Halkitis PN. Towards a more inclusive and dynamic understanding of medical mistrust informed by science. *Behav Med*. 2019;45:79-85.
- Eylem O, de Wit L, van Straten A, et al. Stigma for common mental disorders in racial minorities and majorities: a systematic review and meta-analysis. *BMC Public Health*. 2020;20:879.
- Scherr CL, Ramesh S, Marshall-Fricker C, et al. A review of African Americans' beliefs and attitudes about genomic studies: opportunities for message design. *Front Genet*. 2019;10:548.
- Dash C, Wallington SF, Muthra S, et al. Disparities in knowledge and willingness to donate research biospecimens: a mixed-methods study in an underserved urban community. *J Community Genet*. 2014;5:329-336.
- Hagiwara N, Berry-Bobovski L, Francis C, et al. Unexpected findings in the exploration of African American underrepresentation

- in biospecimen collection and biobanks. *J Cancer Educ.* 2014; 29:580-587.
40. Skinner HG, Calancie L, Vu MB, et al. Using community-based participatory research principles to develop more understandable recruitment and informed consent documents in genomic research. *PLoS One.* 2015;10:e0125466.
 41. Bonomi L, Huang Y, Ohno-Machado L. Privacy challenges and research opportunities for genomic data sharing. *Nat Genet.* 2020;52:646-654.
 42. Mohammed Yakubu A, Chen Y-PP. Ensuring privacy and security of genomic data and functionalities. *Brief Bioinform.* 2020;21: 511-526.
 43. Wan Z, Hazel JW, Clayton EW, et al. Sociotechnical safeguards for genomic data privacy. *Nat Rev Genet.* 2022;23:429-445.
 44. Wang S, Jiang X, Singh S, et al. Genome privacy: challenges, technical approaches to mitigate risk, and ethical considerations in the United States. *Ann N Y Acad Sci.* 2017;1387:73-83.
 45. Kasperbauer TJ, Schwartz PH. Genetic data aren't so special: causes and implications of reidentification. *Hastings Cent Rep.* 2020;50:30-39. <https://doi.org/10.1002/hast.1183>
 46. Lotan E, Tschider C, Sodickson DK, et al. Medical imaging and privacy in the era of artificial intelligence: myth, fallacy, and the future. *J Am Coll Radiol.* 2020;17:1159-1162. <https://doi.org/10.1016/j.jacr.2020.04.007>
 47. Alfawzan N, Christen M, Spitale G, et al. Privacy, data sharing, and data security policies of women's mHealth apps: scoping review and content analysis. *JMIR Mhealth Uhealth.* 2022;10: e33735.
 48. Hutton L, Price BA, Kelly R, et al. Assessing the privacy of mHealth apps for self-tracking: heuristic evaluation approach. *JMIR Mhealth Uhealth.* 2018;6:e185.
 49. Grundy Q, Held FP, Bero LA. Tracing the potential flow of consumer data: a network analysis of prominent health and fitness apps. *J Med Internet Res.* 2017;19:e233.
 50. Londoño Tobón A, McNicholas E, Clare CA, et al. The end of Roe v. Wade: implications for women's mental health and care. *Front Psychiatry.* 2023;14:1087045.
 51. Coen-Sanchez K, Ebenso B, El-Mowafi IM, et al. Repercussions of overturning Roe v. Wade for women across systems and beyond borders. *Reprod Health.* 2022;19:184.
 52. Robinson GE, Brown KM, Grigoriadis S, et al.; Group for Advancement of Psychiatry Committee on Gender and Mental Health. The mental and physical health impacts of overturning Roe v Wade. *J Nerv Ment Dis.* 2022;210:891-893.
 53. Lotan E, Tschider C, Sodickson DK, et al. Medical imaging and privacy in the era of artificial intelligence: myth, fallacy, and the future. *J Am Coll Radiol.* 2020;17:1159-1162.
 54. Nadeem R. Americans' views of government: decades of distrust, enduring support for its role. Pew Research Center—U.S. Politics & Policy. Updated 2022. Accessed March 11, 2024. <https://www.pewresearch.org/politics/2022/06/06/americans-views-of-government-decades-of-distrust-enduring-support-for-its-role/>
 55. Best AL, Fletcher FE, Kadono M, et al. Institutional distrust among African Americans and building trustworthiness in the COVID-19 response: implications for ethical public health practice. *J Health Care Poor Underserved.* 2021;32:90-98.
 56. Ezell JM, Salari S, Rooker C, et al. Intersectional trauma: COVID-19, the psychosocial contract, and America's racialized public health lineage. *Traumatology.* 2021;27:78-85.
 57. Tai DBG, Sia IG, Doubeni CA, et al. Disproportionate impact of COVID-19 on racial and ethnic minority groups in the United States: a 2021 update. *J Racial Ethn Health Disparities.* 2022;9:2334-2339.
 58. Truong TB, Calac AJ, Nasir SL, et al. Challenges and opportunities: structural racism and its impact on COVID-19. In: Syed U, Hou C, eds. *COVID-19 Viral Sepsis.* Academic Press; 2023: 165-182.
 59. Sgro GM, Maurer M, Nguyen B, et al. Return of aggregate results to study participants: facilitators, barriers, and recommendations. *Contemp Clin Trials Commun.* 2023;33:101136.
 60. Mangal S, Niño de Rivera S, Choi J, et al. Returning study results to research participants: data access, format, and sharing preferences. *Int J Med Inform.* 2023;170:104955.
 61. De Sutter I, Borry P, Geerts D, et al. Personalized and long-term electronic informed consent in clinical research: stakeholder views. *BMC Med Ethics.* 2021;22:108.
 62. Kassam I, Ilkina D, Kemp J, et al. Patient perspectives and preferences for consent in the digital health context: state-of-the-art literature review. *J Med Internet Res.* 2023;25:e42507.
 63. Feinsinger A, Pouratian N, Ebadi H, et al.; NIH Research Opportunities in Humans Consortium. Ethical commitments, principles, and practices guiding intracranial neuroscientific research in humans. *Neuron.* 2022;110:188-194.
 64. Harle CA, Golembiewski EH, Rahmanian KP, et al. Patient preferences toward an interactive e-consent application for research using electronic health records. *J Am Med Inform Assoc.* 2018;25:360-368.
 65. Maloy JW, Bass PF. 3rd., Understanding broad consent. *Ochsner J.* 2020;20:81-86.
 66. Lynch HF, Wolf LE, Barnes M. Implementing regulatory broad consent under the revised common rule: clarifying key points and the need for evidence. *J Law Med Ethics.* 2019;47:213-231.
 67. Clayton EW, Halverson CM, Sathe NA, et al. A systematic literature review of individuals' perspectives on privacy and genetic information in the United States. *PLoS One.* 2018;13:e0204417.
 68. Mello MM, Lieou V, Goodman SN. Clinical trial participants' views of the risks and benefits of data sharing. *N Engl J Med.* 2018;378:2202-2211.
 69. Funk C, Lopez MH. 3. Hispanic Americans' trust in medical scientists and views about the potential for researcher misconduct. Pew Research Center. Updated 2022. Accessed July 13, 2024. <https://www.pewresearch.org/science/2022/06/14/hispanic-americans-trust-in-medical-scientists-and-views-about-the-potential-for-researcher-misconduct/>
 70. O'Doherty KC, Shabani M, Dove ES, et al. Toward better governance of human genomic data. *Nat Genet.* 2021;53:2-8.
 71. Gefenas E, Lekstutiene J, Lukaseviciene V, et al. Controversies between regulations of research ethics and protection of personal data: informed consent at a cross-road. *Med Health Care Philos.* 2022;25:23-30.