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**Research Article**

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# Public attitudes toward cascade genetic screening in the United States

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## Abstract

***Introduction*** **After a patient receives genetic test results that indicate an actionable health condition, cascade genetic screening (CGS) is the process of evaluating the patient's relatives for a potentially elevated genetic risk of disease. The United States primarily relies on patients to communicate with their relatives, resulting in suboptimal rates of risk communication, familial genetic testing uptake, and risk-reducing interventions. There is ongoing debate about whether and how best to inform relatives of a potentially increased genetic risk.**

***Methods*** **We conducted a nationally representative survey of US adults to assess attitudes toward informing at-risk relatives, acceptability of system-mediated communication, and preferences for the patient's role in risk communication.**

***Results*** **Respondents ($n = 2056$) overwhelmingly supported informing relatives about their genetic risk across condition types, with minimal disagreement (<10%) about a relative's right to know this information. Most agreed (>45% agreed; >30% strongly agreed) they would want to decide for themselves whether their results are shared, though many favorably viewed doctor-supported communication. Direct clinician contact was acceptable (37.4%) or totally acceptable (11.5%) with patient permission but rarely acceptable without consent.**

***Conclusion*** **Findings indicate strong public support for sharing genetic risk information within families, alongside clear expectations for patient consent, to guide CGS implementation in the United States.**

**Keywords:** Cascade screening, Genetics, Public opinion

## Introduction

Genetic testing is becoming an increasingly routine part of primary and specialty care.[1-3] When test results indicate that a patient is at elevated risk for a preventable or treatable condition, the implications often extend beyond the tested patient, referred to as the proband, to their biologically related family members who may share the same risk. Cascade genetic screening (CGS) is the process used to identify, contact, and offer genetic testing to these at-risk relatives. Its primary population health benefit lies in enabling early detection among individuals who are unaware of their inherited risk, thereby creating opportunities for timely preventive care, such as enhanced surveillance or risk-reducing interventions.[4]

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Internationally, there is growing recognition that individuals want to be informed of their genetic risk.[5] Two primary approaches are used to communicate genetic risk in CGS programs. In system-mediated (or "direct-contact") models, healthcare professionals or centralized public health programs notify the proband's relatives or relatives' clinicians directly about potential risk, typically with the proband's consent. This model has been associated with higher uptake of genetic testing and has been successfully implemented in countries such as the Netherlands.[4,6,7] Survey data from multiple countries, including Australia,[8] Denmark,[9] Italy,[10] Portugal,[11] and Sweden,[12] show strong public support for system-mediated contact when proband consent is obtained. By contrast, the proband-mediated model relies on the patient who underwent testing to inform their relatives. Healthcare providers may support this process by supplying educational materials, such as letters or pamphlets, but they do not contact relatives directly. The United States primarily relies on proband-mediated approaches, although limited system-mediated programs have been introduced in specific clinical contexts and integrated health systems.[13-15] This approach places greater emphasis on individual autonomy and privacy and may be perceived as less emotionally disruptive for families.[16]

Despite the clinical promise of CGS, uptake in the United States remains low.[4] Studies using linked family data from genetic testing laboratories suggest that approximately 10%–30% of eligible relatives receive testing, although rates vary by condition.[17,18] This gap limits the population health impact of genetic testing and reflects barriers operating at multiple levels.[19] At the individual level, patients may lack knowledge or feel uncertain about how to communicate complex risk information. Family dynamics can further complicate communication, while structural factors, including cost, access to testing, and insurance coverage, may serve as barriers to testing uptake among relatives.[20-22] Clinicians may be uncertain about whether and when it is legally permissible to contact patients' relatives directly, even though federal privacy regulations do not categorically prohibit system-mediated approaches.[23]

Despite the potential for legal system-mediated CGS in the United States,[23] concerns about privacy, autonomy, and personal control may limit public acceptability. Debates about CGS policy and practice often center on opposing ethical considerations: whether at-risk relatives have a *right not to know* about their potentially elevated risk or whether they have a *right to know* this information that triggers a healthcare provider's duty to warn them.[24] These debates assume that a proband's privacy interests are in tension with the interest relatives have in being notified about their potentially elevated risk. Criteria for ethical direct contact of relatives have been developed as a way to balance the interests of probands and their relatives.[24]

Prior studies in the United States have examined the perspectives of patients and research participants on CGS in both clinical and research settings,[14,20-22,25] as well as ethical and legal considerations surrounding CGS.[4,23,24,26] However, less is known about broader public views on how genetic risk information should be shared. Individuals already engaged in care may differ from the general public in their experiences, preferences, and tolerance for various communication approaches. Public attitudes are particularly relevant for policy development because large-scale CGS initiatives will ultimately depend on societal acceptance, not only on the preferences of patients already receiving genetic services.[27] In this study, we assessed US adults' attitudes toward different approaches to genetic risk communication. By examining public perspectives on the roles of patients and health systems in CGS, this work aims to inform policies and health system strategies that improve risk communication and testing uptake, ultimately enhancing the population health benefit of genetic testing.

# Methods

## Survey development

We developed a survey to assess public attitudes toward genomic sequencing and cascade genetic testing (Supplementary Material). Survey content was informed by prior qualitative research and refined through cognitive interviews with 12 adults to ensure clarity and usability.[28,29] Respondents first viewed an educational video explaining genomic sequencing and its relevance for family members,[30] followed by six knowledge-check questions adapted from the UNC Genomic Knowledge Scale.[31] All materials were available in English and Spanish.

The survey assessed attitudes toward CGS across three domains: relative's right to know, acceptability of a doctor's role in genetic result communication, and preferences for the patient's role in sharing their results with relatives. Responses were recorded on a five-point Likert scale (strongly disagree=1 to strongly agree=5 or totally unacceptable=1 to totally acceptable=5). In the relative's right to know domain, we assessed agreement that a patient's genetic relatives should be informed of their own genetic risk across six condition characteristics: severity (with a severe condition defined as one that reduces length of life or quality of life), if they can do something such as start a treatment or get health screenings (actionability), age of onset (childhood and adulthood), and the likelihood that the condition would develop (penetrance, high or low). In the doctor's role domain, we assessed acceptability of seven potential communication approaches to convey risk information to relatives.

In the patient role domain, we aimed to understand whether the respondent's preferred role in genetic risk communication differed according to the nature of the health condition involved. Respondents were randomized to one of two clinical vignettes which asked them to imagine that they had just received a genetic test result that showed they had a genetic condition. The conditions described in the vignettes differed in terms of severity of health risk and complexity of risk-reducing interventions. In comparison with the condition described in Vignette 1 (familial hypercholesterolemia), the condition described in Vignette 2 (hypertrophic cardiomyopathy) was relatively more severe with higher risk of sudden death. Vignette 1 read: "Imagine that you received a genetic test result that showed you have a genetic condition that causes levels of bad cholesterol to be very high and increases your risk of having a heart attack. A common medication (statin) can help reduce this risk. Some of your genetic relatives are at risk of having the same condition." Vignette 2 read: "Imagine that you received a genetic test result that showed you have a genetic condition that increases your risk of having an irregular heartbeat and dying suddenly. Medications and surgeries to implant a device (defibrillator) that monitors heartbeat and

gives the heart small electrical shocks if needed can help lower these risks. Some of your genetic relatives are at risk of having the same condition." Respondents were then asked whether they would want to decide for themselves whether to tell their relatives about their genetic test results and how they would want to communicate the results.

The survey included several measures of respondent attitudes toward related constructs, including trust in doctors,[32] family dynamics,[33] privacy attitudes,[34] health literacy,[35] and access to healthcare.[36] Bespoke items were used to assess personal experience with genetic testing. See Supplementary Material for additional detail. Self-reported demographic data were available for all respondents, including age, race and ethnicity, gender, household income, education, metropolitan area status, and political party identification.

## Survey administration

We administered the survey to a nationally representative sample of US adults 18 years of age and older using NORC's AmeriSpeak probability-based panel.[37] AmeriSpeak provides 97% coverage of the US household population through area–probability sampling and recruitment methods designed to reach hard-to-survey groups.[38] The Harvard Pilgrim Health Care Institutional Review Board approved this study.

## Analysis

To further ensure that respondents were representative of the US general adult population, we applied post-stratification weights. We report weighted descriptive statistics, including proportions, means (with standard deviations, SD), and medians (with interquartile ranges) for skewed distributions. Survey design-based t-tests, Rao–Scott chi-square tests, and Kruskal–Wallis tests were used to compare respondent characteristics by vignette assignment. We descriptively compared responses regarding relative's right to know and the doctor's role. Likert-scale responses were dichotomized (agree vs not agree; acceptable vs not acceptable) for descriptive comparisons. Design-based Kruskal–Wallis tests were used to compare agreement with the patient's role across vignettes.

We ran exploratory multivariable logistic regression models to examine associations between respondent characteristics and agreement or acceptability for each primary survey item on relative's right to know and doctor's role in genetic result communication, reporting the corresponding *P*-value for the F-statistic for the overall significance of each respondent characteristic, as well as odds ratios (OR) and 95% confidence intervals (CI). Attitudinal scale scores, income, education, and confidence completing medical forms were modeled as continuous variables. Respondents with a missing response to an item in the three primary domains were excluded from that analysis; otherwise, the mean was imputed for missing values for respondent characteristics (<1% missing). Analyses were conducted using SAS, version 9.4 (SAS Institute, Cary, NC), and R, version 4.4.2 (R Foundation for Statistical Computing). Statistical significance was set at $P < 0.05$. English-language and Spanish-language responses were analyzed together.

# Results

A total of 2056 complete responses (Table 1) were collected between June 7 and July 2, 2024. The median genomics knowledge score was 5.1 (IQR: 4.3-5.6), with 56.0% of respondents answering all six questions correctly. Eleven percent of respondents reported having had a genetic test ordered to identify a cause of a health condition. Respondent characteristics did not differ based on vignette assignment.

## Relatives' right to know

The majority of respondents agreed or strongly agreed that a patient's genetic relatives should be told about their own risk of developing a genetic condition, across nearly all types of genetic conditions presented (Figure 1). For a severe condition, 47.0% agreed and 28.8% strongly agreed that a relative should be told about their own risk, while 45.8% agreed and 38.0% strongly agreed for an actionable condition. Overall, there was high concordance among respondents agreeing that relatives should be told about their own risk of developing a genetic condition both when it is severe and when it is actionable (72.4% agreed for both) and both when children are affected and when adults are affected (73.7% agreed for both; Supplementary Material). However, slightly more respondents strongly agreed that relatives should be told when the condition affects children than adults (36.9% vs 29.2%, respectively). Similar amounts of agreement were also observed for a condition with high penetrance. Across all types of conditions, disagreement was low, with less than 5% of respondents disagreeing and less than 4% strongly disagreeing that relatives should be told. While agreement was high for informing relatives of their own risk of developing a condition with high penetrance (43.7% agreed and 38.2% strongly agreed), agreement was lowest for conditions with low penetrance (34.7% agreed and 17.1% strongly agreed), and there was slightly more disagreement (13.8% disagreed and 4.4% strongly disagreed). Only 49.8% of respondents agreed that relatives should be informed of their own risk for both low and high penetrance conditions, while 32.3% responded discordantly, agreeing that relatives should be informed when penetrance is high but not when penetrance is low.

## Doctor's role in genetic risk communication

When provided with various roles that their doctor may have in genetic result communication to their relatives, imagining they have a genetic condition, there was high acceptability among respondents for their doctor giving a letter or pamphlet about their genetic test results to share with relatives, with most respondents finding the approach acceptable (47.9%) or totally acceptable (26.0%) (Figure 2). The next most acceptable approach was for their doctor to give them a form that they could share with relatives, who could themselves give permission for the doctor to contact them; more than half of respondents found this approach acceptable (44.8%) or totally acceptable (16.5%). While 53.8% of respondents found both indirect contact approaches acceptable, 20.2% found giving a letter or pamphlet about

**Table 1.** Survey respondent characteristics (weighted[a]).

| Characteristic | Full sample *n* = 2056 | Randomized to Vignette 1 *n* = 1062 | Randomized to Vignette 2 *n* = 994 | *P-value* |
|---|---|---|---|---|
| Age in years, mean (sd) | 47.9 (18.0) | 47.2 (18.0) | 48.7 (18.0) | 0.15 |
| Gender, % | | | | 0.61 |
| Female | 51.3 | 52.0 | 50.5 | |
| Male | 48.7 | 48.0 | 49.5 | |
| Race and ethnicity, % | | | | 0.20 |
| Asian/Pacific Islander, non-Hispanic | 5.8 | 5.7 | 5.9 | |
| Black, non-Hispanic | 12.0 | 10.0 | 14.1 | |
| White, non-Hispanic | 60.8 | 61.5 | 60.1 | |
| Other, non-Hispanic | 0.5 | 0.4 | 0.7 | |
| Two or more, non-Hispanic | 2.9 | 2.6 | 3.2 | |
| Hispanic | 17.9 | 19.7 | 15.9 | |
| Income, % | | | | 0.73 |
| <$30 000 | 21.3 | 22.3 | 20.3 | |
| $30 000 to <$60 000 | 22.9 | 23.4 | 22.3 | |
| $60 000 to <$100 000 | 26.8 | 25.9 | 27.7 | |
| ≥$100 000 | 29.1 | 28.5 | 29.7 | |
| Education, % | | | | 0.32 |
| Less than high school diploma | 8.9 | 10.3 | 7.5 | |
| High school graduate or equivalent | 28.8 | 26.9 | 30.7 | |
| Some college or associate's degree | 26.5 | 27.6 | 25.3 | |
| Bachelor's degree | 20.7 | 20.1 | 21.3 | |
| Post graduate study or professional degree | 15.2 | 15.2 | 15.2 | |
| Metropolitan area status, % | | | | 0.19 |
| Metro area | 86.8 | 87.9 | 85.6 | |
| Non-metro area | 13.2 | 12.1 | 14.4 | |
| Political party identification, % | | | | 0.42 |
| Democrat | 43.6 | 44.0 | 43.2 | |
| Republican | 21.0 | 21.7 | 20.3 | |
| Independent | 35.2 | 34.0 | 36.4 | |
| Missing | 0.2 | 0.3 | 0.0 | |
| Trust in physicians score, mean (sd) | 15.3 (2.8) | 15.4 (2.7) | 15.3 (2.8) | 0.29 |
| Genomics knowledge score, median (IQR) | 5.1 (4.3-5.6) | 5.1 (4.3-5.6) | 5.1 (4.3-5.6) | 0.71 |
| Family dynamics score, mean (sd) | 9.5 (2.8) | 9.4 (2.8) | 9.6 (2.8) | 0.24 |
| Privacy attitudes score, mean (sd) | 10.6 (3.4) | 10.7 (3.3) | 10.5 (3.5) | 0.25 |
| Confidence in completing medical forms, % | | | | 0.11 |
| Extremely confident | 45.6 | 48.3 | 42.8 | |
| Quite a bit confident | 29.5 | 29.3 | 29.8 | |
| Somewhat confident | 18.3 | 16.0 | 20.7 | |
| A little bit confident | 4.9 | 5.1 | 4.6 | |
| Not at all confident | 1.6 | 1.1 | 2.1 | |
| Missing | 0.1 | 0.2 | 0.1 | |
| Ever had a genetic test ordered by a doctor to identify a cause of a health condition, % | | | | 0.47 |
| Yes | 11.0 | 12.2 | 9.8 | |
| No | 83.2 | 82.3 | 84.0 | |
| Not sure | 5.6 | 5.3 | 6.0 | |
| Missing | 0.2 | 0.3 | 0.1 | |
| In the last 6 months, how often were you able to get the healthcare you needed, % | | | | 0.28 |
| Never | 3.5 | 3.4 | 3.7 | |
| Sometimes | 10.3 | 8.4 | 12.2 | |
| Usually | 19.0 | 20.0 | 17.9 | |

(*continued*)

**Table 1.** Continued

| Characteristic | Full sample *n* = 2056 | Randomized to Vignette 1 *n* = 1062 | Randomized to Vignette 2 *n* = 994 | *P-value* |
|---|---|---|---|---|
| Always | 53.6 | 55.5 | 51.7 | |
| Did not need any | 12.8 | 11.7 | 13.9 | |
| Missing | 0.8 | 1.0 | 0.6 | |

Source: Author's analysis of survey data collected for this study.
[a]Weighted proportions, means, and medians are presented to adjust the data to the US general adult population.

results acceptable but a form seeking permission for their doctor to contact relatives to not be acceptable (Supplementary Material). Their doctor directly contacting relatives with their permission was acceptable or totally acceptable to 37.4% and 11.5% of respondents, respectively (Figure 2). Conversely, their doctor directly contacting relatives without their permission was acceptable or totally acceptable to only 4.2% and 1.7% of respondents, respectively, while 29.5% found it unacceptable and 54.1% of respondents found it totally unacceptable.

When comparing acceptability of their doctor directly contacting their relatives with their permission and without their permission, only 3.6% found both approaches acceptable while 48.8% found both approaches to be not acceptable, and 45.2% responded that the approach was acceptable with permission but not acceptable without permission (Supplementary Material). Very similar distributions of acceptability and unacceptability were observed when asked instead about their doctor contacting their relative's doctor (rather than their relative) with and without their permission. There was minimal support for their doctor contacting the local public health department to share their genetic test results with their relative, as it was acceptable or totally acceptable to 8.3% and 1.8% of respondents, respectively, while most found it unacceptable (25.0%) or totally unacceptable (46.3%).

## Patient's role in genetic risk communication

When imagining they have a genetic condition, most respondents agreed (>45%) or strongly agreed (>30%) that they would want to decide for themselves whether to tell relatives about their genetic test results, though agreement was statistically significantly higher for respondents randomized to Vignette 1 than Vignette 2 ($P = 0.021$; Figure 3). There were also statistically significant differences by vignette for whether respondents agreed to want to tell relatives themselves with and without their doctor's help. Fewer agreed (32.9%) or strongly agreed (10.4%) for Vignette 1 than agreed (39.3%) or strongly agreed (12.0%) for Vignette 2 ($P = 0.00068$) that they would want to tell relatives themselves with their doctor's help. The difference in agreement by complexity was reversed for respondents wanting to tell relatives themselves without their doctor's help, as more respondents agreed (36.3%) or strongly agreed (23.5%) for Vignette 1 than agreed (35.5%) or strongly agreed (16.8%) for Vignette 2 ($P = 0.0011$). Agreement was low across vignettes, and there were no statistically significant differences in agreement by complexity of the condition for sending information about genetic results to relatives through a secure mobile app or website or putting results into a registry for healthcare professionals to share results with relatives.

## Characteristics associated with attitudes toward risk sharing and communication approaches

In multivariable logistic regression analyses, increased trust in doctors was most often statistically significantly associated with agreement with sharing results with relatives across condition characteristics and acceptability of risk communication approaches (Supplementary Material). For each unit increase in the physician trust scale (range: 5-25), there was a 12% higher odds (OR = 1.12, 95% CI: 1.06, 1.18; $P = 0.0002$) of agreeing relatives should be told about their own risk of developing a high penetrance condition and a 6% higher odds (OR = 1.06, 95% CI: 1.01, 1.11; $P = 0.0109$) of agreement for a low penetrance condition (Supplementary Material). For each unit increase in the physician trust scale, there was a 12% higher odds (OR = 1.12, 95% CI: 1.08, 1.18; $P < 0.0001$) of acceptability of their doctor contacting their relatives with their permission and a 16% higher odds (OR = 1.16, 95% CI: 1.06, 1.26; $P = 0.0012$) of acceptability without their permission (Supplementary Material).

After trust, genomics knowledge, age, and confidence completing medical forms were the next characteristics most often statistically significantly associated with agreement and acceptability. Higher genomics knowledge was associated with agreement with sharing genetic testing information with relatives for each of the condition types, with the strongest association with actionable conditions (for a unit increase on the knowledge scale: OR = 1.46, 95% CI: 1.25, 1.71; $P < 0.0001$; Supplementary Material) and conditions affecting children (for a unit increase on the knowledge scale: OR = 1.46, 95% CI: 1.26, 1.70; $P < 0.0001$). Increased genomics knowledge was also associated with acceptability of communicating results by sharing a letter or pamphlet ($P < 0.0001$), a form seeking permission for their doctor to contact relatives ($P = 0.0043$), and their doctor contacting relatives with permission ($P = 0.0285$). However, increased knowledge was associated with lower acceptability of their doctor contacting relatives without permission ($P = 0.0032$) or contacting relatives via the public health department ($P = 0.0005$; Supplementary Material).

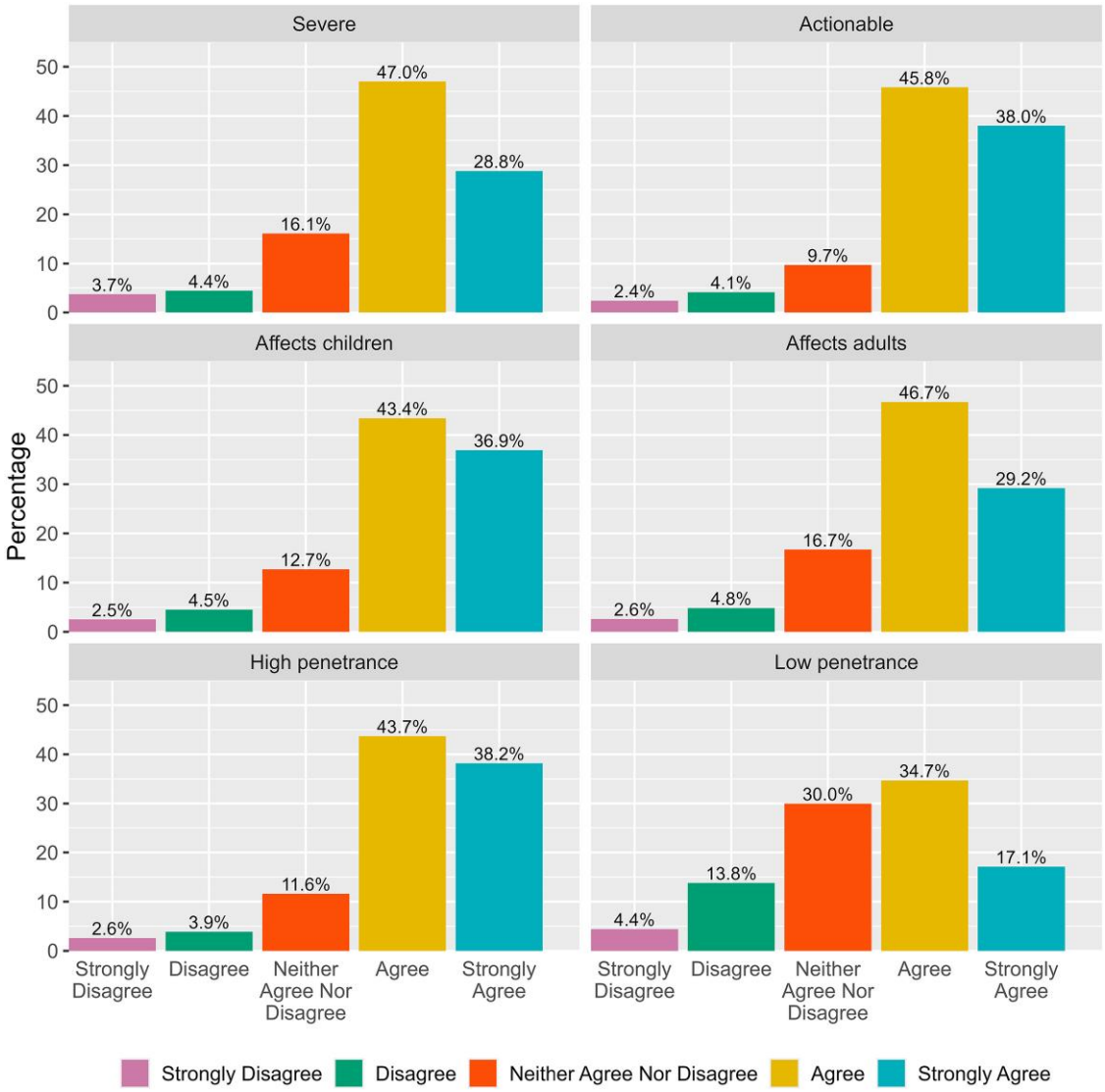


**Figure 1.** Agreement with whether genetic relatives of a patient who receives genetic testing should be told about their own risk of developing a genetic condition according to six condition characteristics. Source: Author's analysis of survey data collected for this study.

Less confidence with completing medical forms was statistically significantly associated with lower agreement to decide for themselves to tell relatives ($P = 0.0062$) or to tell relatives without a doctor's help ($P = 0.0002$), but with higher agreement to tell relatives with their doctor's help ($P = 0.0114$; Supplementary Material). Additionally, lower interpersonal openness about health information (lower score on privacy scale) was statistically significantly associated with less acceptability of each form of communication for sharing results (Supplementary Material). Race and ethnicity, income, and education were not significant predictors of agreement or acceptability for almost all of the survey items on sharing and communicating results.

## Discussion

In this nationally representative survey of US adults, we found strong public support for informing at-risk relatives about their potential genetic risk, regardless of condition severity, actionability, age of onset, or penetrance. These findings do not suggest broad concern about a relative's right not to know and instead reflect substantial endorsement of sharing medically relevant information within families. Respondents expressed a clear preference for retaining control over whether and how their results are shared, underscoring the importance of proband autonomy in CGS implementation.

Trust in doctors emerged as a consistent predictor of support for information sharing and acceptability of doctor-facilitated communication. Notably, race, ethnicity, income, and education were not significant predictors of agreement or acceptability regarding methods for communicating results to relatives in our study. While some evidence suggests that CGS uptake is lower in racial and ethnic minority populations,[18,39] there are substantial data limitations that inhibit understanding real-world CGS uptake,[40] and many studies on this topic use qualitative methodology that does not allow for assessment of the impact of personal characteristics on uptake.

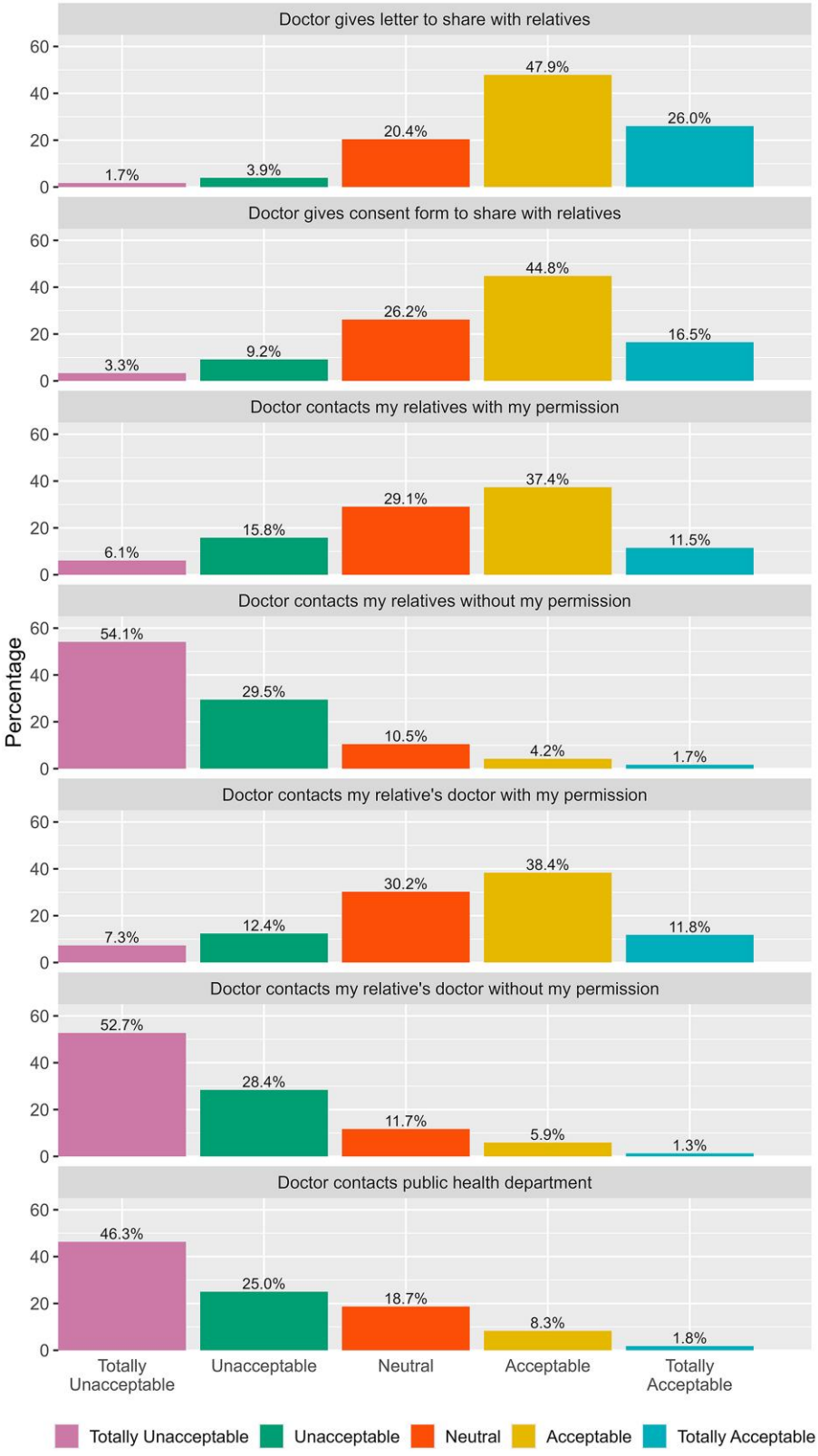


**Figure 2.** Acceptability of seven forms of communication from a patient's doctor about the parts of their genetic test results that could give information about their genetic relatives' risk of developing a genetic condition. Source: Author's analysis of survey data collected for this study.

Our findings are consistent with a growing body of international survey research demonstrating high public support for informing relatives of their genetic risk[5,8-12] while also suggesting a comparatively stronger preference among US respondents for maintaining personal control over disclosure decisions. Among respondents in our study, there was substantial support for system-mediated contact when proband consent is obtained. Approximately half of respondents found it acceptable for a

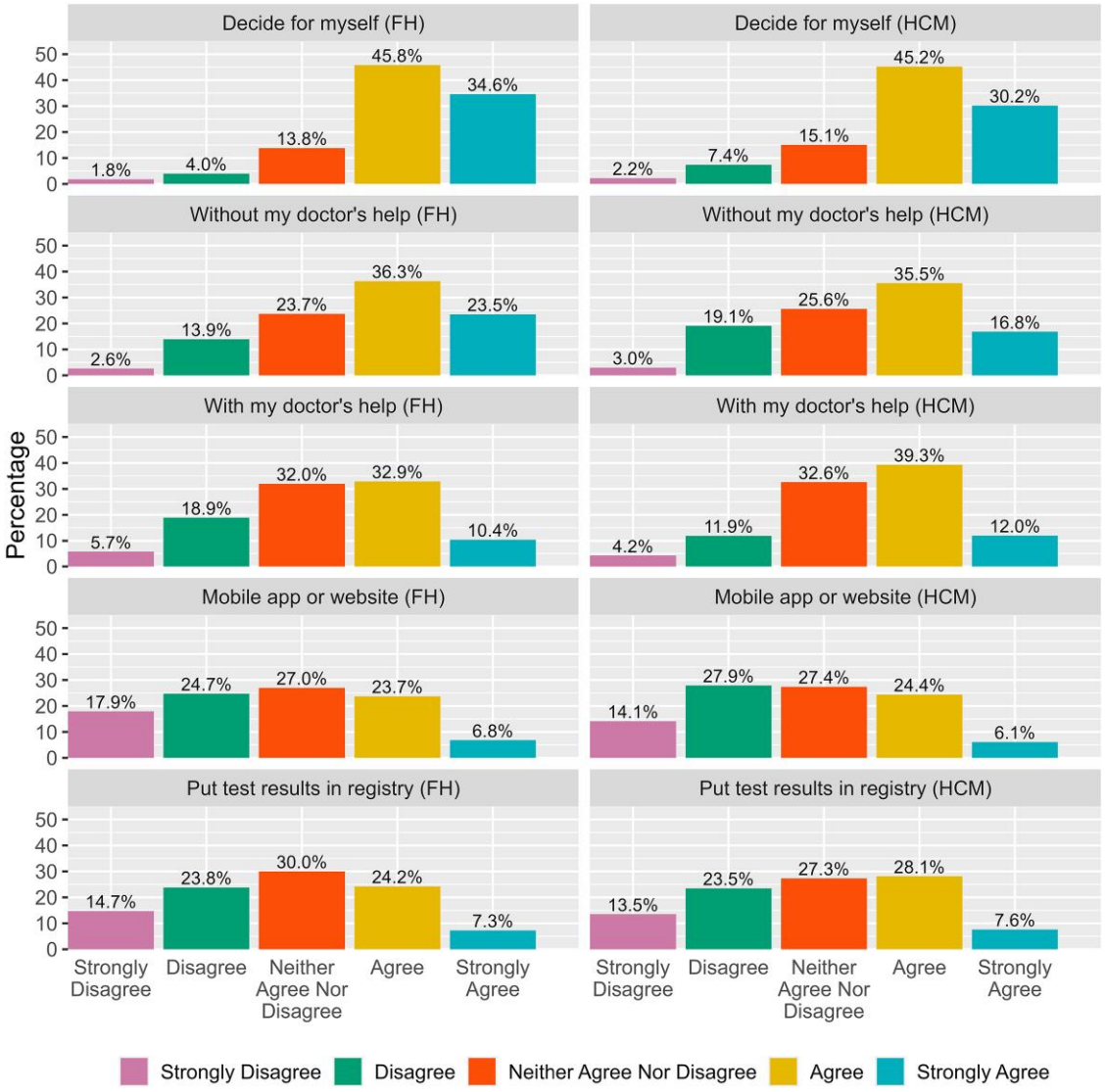


**Figure 3.** Agreement with different approaches for telling a patient's genetic relatives about their results themselves and about sharing their results with relatives using a mobile app or website or a registry by vignette exposure. Source: Author's analysis of survey data collected for this study. Note: FH, familial hypercholesterolemia. HCM, hypertrophic cardiomyopathy.

proband's clinician to directly contact their relatives, or their relatives' doctor, when the proband provided permission, indicating greater openness to direct contact than often assumed in the US context.[41] This level of acceptability is consistent with results from a small US pilot study of direct contact.[15] Our findings also align with those from qualitative research with individuals affected by hereditary cancer syndromes, in which direct contact is viewed as complementary to proband-mediated contact, with key conditions for direct contact including the proband's explicit consent and the relatives' ability to decide what information, if any, they wish to receive.[25] While both patients and members of the general public may support system-mediated approaches under certain conditions,[8,25] patients may be more attuned to practical, emotional, and relational burdens associated with relying on proband-mediated communication alone.[42]

The provision of written materials such as letters or pamphlets to facilitate family communication was viewed by respondents as highly acceptable. However, prior work has identified limitations of letter-based communication in practice.[43] For example, a trial in Sweden found no difference in genetic counseling uptake between standard family-mediated disclosure and an enhanced approach that additionally offered the option of sending direct letters to at-risk relatives.[44] Complementary qualitative research suggests that while relatives who receive such letters often perceive system-mediated disclosure as a useful adjunct to family communication, individuals receiving information without prior awareness of familial risk may experience the disclosure as emotionally challenging, evoking negative feelings and a need for more counseling.[45] Similarly, a Danish study of relatives who received an unsolicited, direct letter disclosing heredity for Lynch syndrome found the information emotionally complex but important, despite high support for letter-based communication and a majority reporting that they preferred information be sent from the hospital rather than from family members.[9] Together, these findings suggest that letters are an acceptable way to ensure equitable information provision to relatives and that they should be part of bundled interventions to improve CGS uptake effectiveness.

We found that methods of information sharing with a lower provider-level implementation burden were not broadly acceptable to the US general population. A common concern among healthcare providers is the practical challenge of implementing direct contact approaches,[21,46] and while public health-driven family outreach has shown success internationally,[47] a substantial majority of respondents viewed this as unacceptable. Additionally, while digital tools are a promising route for returning genetic results and scaling up family communication of genetic risk,[48-53] few respondents said they would want to send information about their genetic test results to relatives through a secure mobile app or website. This finding aligns with survey results from Belgium.[5] However, a recent family cluster randomized trial in Switzerland showed that a web-based platform that allowed patients to send email or text messages to relatives was effective at increasing the number of eligible relatives who received testing and who were identified with genetic risk.[53] Additionally, a recent pilot study of a digital chatbot to improve communication of hereditary cancer risk among at-risk relatives demonstrated high acceptability among probands and uptake of testing among eligible relatives.[54] Scalable digital tools are important to expand outreach given genomics workforce constraints,[55] and our findings suggest that broader implementation efforts would benefit from addressing potential concerns about privacy, trust, and usability.

A key strength of this study is its focus on the general US adult population, extending beyond individuals with personal experience in genetic testing or research. Responses offer insight into societal attitudes relevant to large-scale CGS initiatives. The educational video presented at the beginning of the survey explained concepts relevant to genomic sequencing and its relevance for families and was designed to ensure that respondents were adequately prepared to respond to the survey items. The high genomic knowledge scale scores observed in our sample likely reflect exposure to this video rather than high baseline genetic literacy among respondents. This study has several limitations. Respondents were reflecting on hypothetical scenarios, and responses may not translate into real-world behaviors. We did not assess respondents' personal experience with genetic conditions or prior family-based risk communication, which may shape preferences. In particular, individuals who have received a diagnosis of a hereditary condition, especially in the context of serious illness such as cancer, may hold different views about contacting relatives than members of the general public. For simplicity, survey items referred to a "doctor" in system-mediated communication, although in practice genetic counselors and other allied health professionals would have a critical role. The survey focused only on preferences regarding risk communication but did not assess intentions to pursue genetic testing, so this study addresses only the first step in CGS. Further research should examine whether individuals would want to be contacted about their own genetic risk after a family member was tested and compare perspectives of the general public with those of patients who have experience with a genetic condition.

Overall, there was high public support for informing at-risk relatives across diverse condition characteristics, paired with a strong preference for proband consent and autonomy. Respondents favored clinician-supported communication but expressed less support for non-consented, public health-based, or digital modalities for genetic risk communication. These findings can inform the design of legally permissible, acceptable, and scalable strategies for CGS in the United States.

## Supplementary material

Supplementary material is available at *Health Affairs Scholar* online.

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## Conflicts of interest

Please see ICMJE form(s) for author conflicts of interest. These have been provided as supplementary materials.

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## Data availability

Data are available from the corresponding author upon request.

## Notes

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