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Primary care providers' preferences for the communication and management of actionable genomic findings from a research biobank

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Abstract

Purpose: Little is known about non-genetics health care specialists' attitudes toward the return and utilization of actionable genomic results from a research biobank. We surveyed primary care providers (PCPs) to explore their perspectives on these results and their preferences for return.

Methods: We administered a paper and web-based 27-question survey to PCPs residing locally and caring for adult patients. Recruitment was conducted in person and by email, focusing on PCPs likely to interact with results generated by our institution's biobank.

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Ethics Declaration

This work was reviewed by the Colorado Multiple Institutional Review Board (COMIRB #20–2965) and was determined not to be human subject research. Informed consent was not obtained because study participants were informed that survey completion implied consent to participate.

Additional Information

The online version of this article (https://doi.org/10.1016/j.gimo.2023.100830) contains supplemental material, which is available to authorized users.

Results: Of the ~482 PCPs contacted, 77 (16%) returned surveys. Although most respondents (90%) prefer that a genetics specialist be involved in communicating biobank-generated genomic results to patients, about 40% of respondents reported that a PCP shares the responsibility to discuss these results along with other specialists. A majority of respondents (74%) felt uncomfortable communicating these results to patients. However, respondents reported significantly greater comfort with this process when offered targeted educational resources (62% with vs 10% without resources; $P < 10^{-5}$).

Conclusion: PCPs recognize the need to engage with their patients' biobank-generated genomic results but feel uncomfortable in doing so. Relevant resources are needed to improve PCPs' confidence in the use of these types of results to affect patient care.

Keywords

Biobank; Genetics; Pharmacogenetics; Primary care provider; Research

Introduction

As participation in research biobanks expands, there is a growing expectation to return clinically actionable genomic results to research participants. Clinicians, researchers, and the public largely support the return of secondary findings.[1–4] However, the process of returning results is complicated by ambiguity around what results to return, how to deliver this information, and who should be involved in the clinical workflow.[5–8] Although biobanks have begun to describe their return processes, these protocols differ by institution, and there is varied involvement of genetic counselors (GCs), medical geneticists, and non-genetics clinicians, particularly primary care providers (PCPs).[9–11]

Many PCPs prefer that a medical geneticist and/or GC be involved in the return of secondary findings[2,12–14] and that a pharmacist be involved in the return of pharmacogenetic (PGx) results.[15,16] However, the shortage of genetics professionals does not meet the demand for genetic services already utilized in the clinical setting.[17,18] As efforts to return genomic results generated by research studies will add to this unmet need, PCPs and other non-genetics professionals will have to contend with these results in clinical care.[18]

PCPs consistently cite a lack of knowledge of and low confidence in using genomic results to inform clinical decisions,[12,13,19,20] which may result in missed opportunities to utilize genetics in disease prevention and screening.[13] Integrated educational resources are needed to ensure appropriate utilization of genomic results in clinical care.[12,13,19–21] This need is magnified when considering the complexity of results generated by a research biobank, in which the PCP did not order genetic testing and may be unaware of a patient's research study enrollment and/or consent to receive results.[7,11]

The preferences of biobank participants for the return of actionable genomic results have been detailed.[22] To date, we are unaware of any studies evaluating the preferences of PCPs for the return of these findings. Herein, we describe results from a survey of local PCPs conducted to explore their perspectives on the return of clinical-grade genomic results

generated by a research biobank. The findings have informed the return process for results generated by our institution's biobank.

Materials and Methods

Overview

As of January 2023, the Biobank at the Colorado Center for Personalized Medicine (CCPM Biobank) has 217,695 enrolled participants, among which 34,435 have undergone genotyping on a customized version of the Infinium Expanded Multi-Ethnic Genotyping Array (Illumina, Inc., San Diego, CA).[23] Two types of actionable genomic results are available for return to participants: (1) PGx results and (2) secondary findings as defined by the American College of Medical Genetics and Genomics (ACMG).[24] These are clinical genomic results generated in our institution's biobank laboratory, which is Clinical Laboratory Improvement Amendments (CLIA) certified and College of American Pathologists (CAP) accredited.

Before developing a protocol for the return of these results, we obtained input from various stakeholders, including PCPs. The Return of Results Roadmap Committee (RRR) was established to develop our process for the return of genomic results from our biobank. We invited several PCPs representing the different geographic regions of our institution to review our proposed return process and provide feedback at RRR meetings. Based on this input, the return processes for PGx results and secondary findings were separated, with significant differences in how clinicians would be contacted regarding these results. At the recommendation of RRR members, the study described herein was undertaken to garner further input from local PCPs. Before survey administration, a limited number of PGx results had been returned to test the clinical workflow. The initial PGx return of results was restricted to Cardiology providers, limiting potential contamination of the PCPs surveyed for this study.

Study population

In this cross-sectional study, we administered a 27-question survey to PCPs residing locally and caring for adult patients. We focused our recruitment efforts on adult PCPs affiliated with or employed by the University of Colorado because enrollment in our institution's biobank is restricted to patients of the university's affiliate hospital, UCHealth. Thus, genomic results generated by participation in the biobank would primarily affect this group of providers. We recruited PCPs for study inclusion in person and by email. All internal medicine and family medicine physicians employed by University of Colorado and its affiliate institutions were invited to complete the study questionnaire by email once. We also recruited PCPs in attendance at our institution's annual family medicine and internal medicine conferences.

There were approximately 430 adult PCPs affiliated with our institution at the time of study recruitment; all of these clinicians received an invitation to participate in our study. Out of 133 and 126 clinicians in attendance at our institution's annual family medicine and internal medicine conferences, respectively, we identified an additional 52clinicians who were

eligible for our study and not reached through our email recruitment. In total, an estimated 482 unique clinicians were contacted through these methods and invited to complete our survey. To bolster recruitment, we used quarterly town hall meetings (in-person meetings for affiliated faculty) to remind providers of our study and encourage participation.

Survey instrument and data collection

We developed the survey instrument to assess provider awareness of our institution's biobank and preferences for the return of actionable genomic results available to patients through biobank participation. Questions were written based on a thorough review of published literature on provider knowledge of genomic results.[4,12,19,25–27] All study team members (E.L.K., J.T.L., Y.M.L., and S.R.) were involved in developing the initial survey instrument, which under-went a series of revisions.

We began the survey with a brief introduction describing our biobank research program, including its purpose, number of participants, and possible results returned. The potential processes for the return of these results were not specified because the survey was meant to explore PCP views without a particular return process being considered by respondents. The final survey instrument consisted of 27 questions covering the following domains: familiarity with our institution's biobank (3 questions), clinician preferences for communication of genetic test results (6 questions), preferred resources for interpretation and discussion of findings (2 questions), comfort with communication of results with and without specified resources (5 questions), concerns around the return of genomic results from a research biobank (3 questions), future educational preferences (3 questions), and demographic information (5 questions). See Supplemental Materials for the survey instrument.

To promote study recruitment, we made the survey available in paper and online. We administered a web-based version of the survey via REDCap[28] electronic data capture tools hosted at our institution from June to August 2018, using a link emailed to the study population. Paper surveys were available for completion at institution events that specifically targeted the study population and were held during the summer of 2018. After these in-person meetings, completed paper surveys were added to REDCap to simplify data analysis. The preamble of the survey contained information describing the purpose of the study and that survey completion implied consent to participate; written informed consent was not obtained. An incentive was not offered for participation. The study was initially undertaken as part of a quality improvement project aimed at improving the return of results process for genomic findings generated by our institution's biobank. The study was reviewed by the Colorado Multiple Institutional Review Board (COMIRB #20–2965) and was determined not to be human subjects research. Survey responses were anonymous, and participant names were not collected.

Data analysis

Surveys with at least 65% of the primary survey questions completed, excluding demographic questions, were included for data analysis. A minimum survey completion of 65% was chosen because there was a natural cutoff between the number of respondents (*n*

= 77; 94%) who completed 65% or more questions vs respondents (n = 5; 6%) who returned surveys with fewer completed questions. Histograms were used to visualize responses' heterogeneity and assess each question's performance and response trends. Categorical response frequencies were analyzed to generate descriptive statistics. To simplify the data analysis, responses were collapsed into fewer categories for 1 question: years in practice less than 6 years, 6 to 20 years, and greater than 20 years. Incomplete responses were not included in response frequency calculations. Pearson chi-square tests were used to evaluate relationships between preferred resources and educational opportunities, with demographic variables, including sex, specialty, type of training, and years in practice. Paired t tests and one-way ANOVA were used to evaluate relationships between respondent comfort and offered resources, with demographic factors. A P value < .05 was considered significant.

Results

Survey performance

Of the approximately 482 PCPs contacted, 77 (16%) returned surveys that met criteria for study inclusion. Individual question response rates ranged from 94% to 100%, excluding the demographic portion of the survey, in which 31 (40%) respondents did not complete all the questions.

Respondent characteristics

The characteristics of the respondents are shown in Table 1. Approximately half (52%) of the respondents were female. Most respondents (86%) were physicians, whereas 14% were nurse practitioners or physician assistants. About two-thirds (58%) of the sample practiced family medicine, whereas 38% practiced internal medicine. Other primary care specialties represented included geriatrics and combined internal medicine-pediatrics. Half (54%) of the respondents had 20 or more years of clinical experience.

Modalities used to return results

Respondents' preferences for how genomic results generated by a research biobank should be returned to clinicians and their patients are summarized in Figure 1. Most respondents (87%) wanted to be notified about all available genetic test results, including PGx results and secondary findings. Close to two-thirds (64%) of respondents preferred to be informed of both normal and abnormal results; one-third (34%) only wanted to be notified of abnormal results. Respondents preferred to have results delivered to them via an electronic health record (EHR) alert (62%) or letter (58%). Few respondents (8%) preferred having results provided by phone. Respondents had differing opinions on how these results should be communicated to patients. The most preferred methods of communication were in person (73%) or by letter (35%).

Perceived responsibility for communication of results

Figure 2 presents respondents' thoughts on the responsibility for the communication of actionable genomic results generated by a research biobank. Respondents were given the following options for responsible parties: GC or medical geneticist, PCP, or appropriate non-genetics specialist, ie, a cardiologist for a genomic finding associated with cardiomyopathy.

Most respondents (90%) felt that a GC or geneticist should be involved in communicating these results (Figure 2). A little over one-third (38%) of respondents thought that a GC or geneticist should have sole responsibility for returning these results. Although 39 percent of respondents felt that a PCP has responsibility for the communication of these results along with other specialists, only a few respondents (5%) thought that a PCP has sole responsibility for this disclosure. Two respondents (3%) reported that responsibility for discussing these results depended on the significance of the findings.

Preferred resources and resource delivery

We asked respondents to indicate what resources they would prefer to have to improve their comfort with communicating genomic results to their patients (Figure 3). The 2 most preferred resources were written guidelines (68%) and a phone number to reach a genetics specialist for real-time assistance (60%). About one-third (38%) of respondents felt that the resources listed were insufficient and that a GC or geneticist should deliver these types of results. Respondents in practice for 6 to 20 years were significantly less likely to prefer written guidelines than those in practice for shorter or longer periods ($P = .007$; results not shown). Sex, specialty, and type of training were not significantly associated with preferred resources. When asked how the offered resources should be provided, the majority (74%) of respondents preferred that they be attached to the result report. Half (48%) of respondents desired for resources to be embedded in the EHR, whereas only 20% preferred for them to be available through webpage links.

Comfort with discussion of results based on resource availability

Respondents' comfort level with the discussion of biobank-generated genomic results based on their current expertise alone compared with their knowledge with the aid of specific resources is shown in Figure 3. With no additional resources available, a majority (74%) of respondents reported feeling somewhat or very uncomfortable communicating genomic results to their patients. When compared with no additional help, the number of providers stating that they felt somewhat or very comfortable with the discussion of these results significantly increased with the resources offered: written guidelines (51% with vs 10% without resource; $P < 10^{-5}$), phone number to a genetics specialist (55% with vs 10% without resource; $P < 10^{-5}$), list of genetics websites (40% with vs 10% without resource; $P < 10^{-5}$), and a combination of all resources (62% with vs 10% without resource; $P < 10^{-5}$). Respondents rated their comfort level the highest when a combination of all resources was offered. Although written guidelines were the most preferred resource offered, only half (51%) of respondents reported feeling somewhat or very comfortable communicating genomic results with the utilization of this resource. When comparing comfort with the resources offered with no additional help, there was no significant difference in the number of respondents that were unsure about their comfort levels. Sex, specialty, type of training, and years in practice were not significantly associated with respondents' comfort levels.

Concerns about return of results

Figure 4 summarizes respondents' concerns about biobank-generated genomic testing and the return of these results. These concerns were separated into 2 areas of emphasis: (1) considerations related to the provider, including clinical knowledge, time, reimbursement,

scope of practice, and liability and (2) considerations related to the patient, including insurance implications, family's response, access to care, and the costs of care needed. Respondents' greatest concern about their medical practice was an inability to answer patient questions (68%) related to a lack of training (65%). Respondents' most significant concerns relating to their patients were the implications of results on insurance coverage (78%) and results being present in a patient's health record (74%). Respondents were allowed to write in other concerns not listed in the survey; the most frequently cited additional concerns were patient anxiety (5%) and implications on life insurance (3%).

Educational opportunities

We asked respondents about their preferred educational venues to learn about future biobank endeavors and the process developed for returning biobank-generated genomic results. The majority (79%) preferred in-person meetings, such as Grand Rounds or conferences. Less than half preferred other educational venues, including webinars or podcasts (39%), email (23%), or provider-targeted marketing campaigns (12%). Two respondents wrote that they preferred online education through a website or modules. Sex, specialty, and years in practice were not significantly associated with preferred educational venues.

Discussion

In this report, we examined PCPs' preferences for the return of actionable genomic results from a research biobank. It is crucial to engage with PCPs when developing a return of results process and to provide supportive resources, as genomics is progressively being integrated into the clinical setting, with PCPs likely being called upon to coordinate genomics-informed care. We found that PCPs want to be notified of all genomic results identified through participation in a biobank, including secondary findings and PGx results. However, most PCPs prefer the involvement of a genetics specialist in communicating these results and are uncomfortable discussing these findings without additional support. PCPs' perceived comfort with reviewing this information significantly increased when targeted resources were offered. The findings from our study demonstrate that PCPs recognize the need to engage with their patients' biobank-generated genomic results, but specific supports are needed to ensure that PCPs have the confidence to do so.

Biobanks seeking to return genomic results will have to consider who will communicate these findings. Whether a genetics professional is involved in discussing this information, patients may prefer to seek further consultation with their PCP. Because PCPs may be the first point of contact for a patient when a result is received, this group of clinicians must be ready to handle these findings.[12,13,18–20] In addition, PCPs are responsible for ongoing longitudinal care coordination for some genetic conditions, such as surveillance for neoplasia associated with Lynch syndrome (*MLH1*, *MSH2*, *MSH6*, *PMS2*, and *EPCAM*) or hereditary breast and ovarian cancer syndromes (for example, *BRCA1* and *BRCA2*).[12,13,20] Previous studies have highlighted that PCPs feel underprepared to utilize genomic results in clinical decision making because of a lack of knowledge and low confidence levels.[12,13,18,19] Similarly, we found that PCPs' most significant concerns related to their medical practice and the return of biobank-generated genomic results stemmed from

their perceptions that they would be unable to answer patients' questions because of a lack of training.

Given these concerns, it is not surprising that most PCPs in our study preferred that a geneticist and/or GC communicate results from a research biobank. This is consistent with previously reported preferences for genomic findings generated through clinical testing.[13,14,20] Furthermore, about 40% of our respondents felt that a PCP shares the responsibility for discussing these results along with other specialists. This supports previously published literature that PCPs recognize their evolving role in utilizing genomic results in clinical care.[13]

Our study explored the resources PCPs would need to feel comfortable discussing genomic results with their patients. Studies have consistently emphasized the need for education and resources to improve provider comfort with genomic results.[12,13,18–20] In 2022, Hajek et al showed that provider preparedness to utilize genomics in clinical care increased with institution-specific educational modules.[18] However, no studies have evaluated preferences for specific educational resources and how these may increase confidence in utilizing genomic results in the clinical setting, particularly results generated by a research biobank. In our study, we found that PCPs' most preferred resources were written guidelines and a phone number to a GC or genetics specialist for real-time assistance. Half of our respondents wanted resources embedded in the EHR. Compared with no additional help, survey respondents reported significantly increased comfort in discussing biobank-generated genomic results when resources were offered. Thus, a multi-faceted approach with embedded educational materials is one strategy to increase provider comfort in utilizing biobank-generated genomic results and, potentially, all genomic results.

Similar to findings from other studies,[12–14,20] our survey respondents shared concerns of being unable to answer patient questions about their genomic results and wanted GCs or geneticists to be involved. One primary difference to consider is the ownership of the genomic results generated as part of a research biobank versus clinical care.[7] In the clinical setting, a provider usually orders a test he or she is familiar with and hence "owns" the results, implying that the provider will communicate these results and enact a clinically appropriate subsequent management plan.[7,11] On the other hand, results generated in a biobank context may be unfamiliar to a PCP and he or she may be unaware that these results are available to inform clinical decisions.[7,11] Consequently, the provider may defer to a geneticist or GC to return the results to the patient. This may explain our study finding that 38% of respondents thought a geneticist or GC had the sole responsibility of returning these types of results. This issue of long-term data ownership and responsibility was highlighted by providers in the Pharmacogenomic Resource for Enhanced Decisions in Care and Treatment program, in which ordering clinicians were concerned about handing off PGx results to PCPs who did not order the test and had limited PGx training.[29] This underscores the importance of providing resources to PCPs to support the long-term clinical utilization of results generated by a biobank.

Additional education will likely be necessary as biobanks prepare to return genomic results. The preferred modality for delivering this education to PCPs is unclear. Although a

preference for online genomics education has been reported,[30] other studies have highlighted a desire for face-to-face learning.[13,20,31] In our study, PCPs preferred in-person education. This may reflect the fact that half of our study population had been in practice for more than 20 years; an older cohort of physicians may be less comfortable with online education. Alternatively, a preference for in-person education may suggest that our respondents live in urban areas because Harding et al noted that urban PCPs prefer this educational modality.[13]

One limitation of our study is the use of a convenience sample. Our results describe the views of PCPs affiliated with one large university-based health care system and may not be representative of all PCPs nationally. PCPs responded to questions regarding the return of biobank-generated genomic results in the hypothetical without having received results for their patients. Our survey respondents' attitudes and preferences toward these results may differ from PCPs who have experienced receiving results in the clinical setting. Future work will clarify these perspectives, as well as assess the resource needs of PCPs once they have utilized these results in patient care.

Any study that uses a survey is limited by response bias. PCPs more interested in genomic medicine may have been more likely to complete our survey. This could have resulted in overestimating PCPs' interest in genomic results return and comfort with utilizing these findings in clinical care. Conversely, our study may have underestimated PCPs' comfort with biobank-generated genomic results because we combined all results, secondary findings, and PGx data, that could be returned from our biobank. It is common to merge these types of findings and generically refer to "genomic results" when assessing PCPs' attitudes toward this domain of medicine.[13,20] Thus, it is unclear if there is a significant difference in PCPs' knowledge of and comfort with secondary or incidental findings versus PGx data. Previous studies focused solely on PGx have highlighted PCPs' limited understanding of this area of genomic medicine.[16,31] In our study, PCPs may have reported lower comfort levels for all genomic results due to little knowledge of PGx testing. Future studies would benefit from separating these types of results to assess if knowledge, comfort levels, and resource needs vary based on genomics result type.

Our study shows that PCPs feel uncomfortable utilizing biobank-generated genomic results in clinical care and prefer the involvement of a genetics specialist. PCPs want to engage with these results, but their concerns must be addressed when developing a process to return genomic results generated by a research biobank. Targeted education and associated resources will be essential to ensure PCPs use these results in the clinical setting. Further studies will be needed to assess the effectiveness of developed protocols and associated education to ensure that PCPs have sufficient support to promote the use of genomic results in clinical decision making. Actionable genomic results, regardless of whether a biobank or clinical testing generates them, can significantly influence disease morbidity and treatment choices.[24,32] However, this potential may not be realized if genomic results utilization is limited to genetic specialists, and other clinicians are left behind without the necessary resources and education to use these results.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Conflict of Interest

Dr Raghavan's work is supported by the US Department of Veterans Affairs Career Development Award IK2-CX001907 and by the Webb Waring Biomedical Research Award of the Boettcher Foundation. Drs Kudron, Lee, and Lowery declare no potential conflicts of interest.

Data Availability

This work does not include any clinical data. The data are available for review upon request; inquiries can be directed to the corresponding author.

References

1. Kaufman DJ, Baker R, Milner LC, Devaney S, Hudson KL. A survey of U.S Adults' Opinions about Conduct of a Nationwide Precision Medicine Initiative® Cohort Study of Genes and Environment. PLoS ONE. 2016;11(8):e0160461. 10.1371/journal.pone.0160461 [PubMed: 27532667]
2. Mackley MP, Fletcher B, Parker M, Watkins H, Ormondroyd E. Stakeholder views on secondary findings in whole-genome and whole-exome sequencing: a systematic review of quantitative and qualitative studies. Genet Med. 2017;19(3):283–293. 10.1038/gim.2016.109 [PubMed: 27584911]
3. Middleton A, Morley KI, Bragin E, et al. Attitudes of nearly 7000 health professionals, genomic researchers and publics toward the return of incidental results from sequencing research. Eur J Hum Genet. 2016;24(1):21–29. 10.1038/ejhg.2015.58 [PubMed: 25920556]
4. Strong KA, Zusevics KL, Bick D, Veith R. Views of primary care providers regarding the return of genome sequencing incidental findings. Clin Genet. 2014;86(5):461–468. 10.1111/cge.12390 [PubMed: 24673592]
5. Jarvik GP, Amendola LM, Berg JS, et al. Return of genomic results to research participants: the floor, the ceiling, and the choices in between. Am J Hum Genet. 2014;94(6):818–826. 10.1016/j.ajhg.2014.04.009 [PubMed: 24814192]
6. McGuire AL, Knoppers BM, Zawati MH, Clayton EW. Can I be sued for that? Liability risk and the disclosure of clinically significant genetic research findings. Genome Res. 2014;24(5):719–723. 10.1101/gr.170514.113 [PubMed: 24676095]
7. Prince AE, Conley JM, Davis AM, Lázaro-Muñoz G, Cadigan RJ. Automatic placement of genomic research results in medical records: do researchers have a duty? Should participants have a choice? J Law Med Ethics. 2015;43(4):827–842. 10.1111/jlme.12323 [PubMed: 26711421]
8. Wolf SM, Amendola LM, Berg JS, et al. Navigating the research-clinical interface in genomic medicine: analysis from the CSER Consortium. Genet Med. 2018;20(5):545–553. 10.1038/gim.2017.137 [PubMed: 28858330]
9. Blout Zawatsky CL, Shah N, Machini K, et al. Returning actionable genomic results in a research biobank: analytic validity, clinical implementation, and resource utilization. Am J Hum Genet. 2021;108(12):2224–2237. 10.1016/j.ajhg.2021.10.005 [PubMed: 34752750]

10. Papaz T, Liston E, Zahavich L, et al. Return of genetic and genomic research findings: experience of a pediatric biorepository. BMC Med Genomics. 2019;12(1):173. 10.1186/s12920-019-0618-0 [PubMed: 31775751]
11. Schwartz MLB, McCormick CZ, Lazzeri AL, et al. A model for genome-first care: returning secondary genomic findings to participants and their healthcare providers in a large research cohort. Am J Hum Genet. 2018;103(3):328–337. 10.1016/j.ajhg.2018.07.009 [PubMed: 30100086]
12. Carroll JC, Makuwaza T, Manca DP, et al. Primary care providers' experiences with and perceptions of personalized genomic medicine. Can Fam Physician. 2016;62(10):e626–e635. [PubMed: 27737998]
13. Harding B, Webber C, Ruhland L, et al. Primary care providers' lived experiences of genetics in practice. J Community Genet. 2019;10(1):85–93. 10.1007/s12687-018-0364-6 [PubMed: 29700759]
14. Klitzman R, Chung W, Marder K, et al. Attitudes and practices among internists concerning genetic testing. J Genet Couns. 2013;22(1):90–100. 10.1007/s10897-012-9504-z [PubMed: 22585186]
15. Frigon MP, Blackburn MÈ, Dubois-Bouchard C, Gagnon AL, Tardif S, Tremblay K. Pharmacogenetic testing in primary care practice: opinions of physicians, pharmacists and patients. Pharmacogenomics. 2019;20(8):589–598. 10.2217/pgs-2019-0004 [PubMed: 31190623]
16. Haga SB, Burke W, Ginsburg GS, Mills R, Agans R. Primary care physicians' knowledge of and experience with pharmacogenetic testing. Clin Genet. 2012;82(4):388–394. 10.1111/j.1399-0004.2012.01908.x [PubMed: 22698141]
17. Dragojlovic N, Borle K, Kopac N, et al. Correction: the composition and capacity of the clinical genetics workforce in high-income countries: a scoping review. Genet Med. 2020;22(9):1570. 10.1038/s41436-020-0903-5 [PubMed: 32651549]
18. Hajek C, Hutchinson AM, Galbraith LN, et al. Improved provider preparedness through an 8-part genetics and genomic education program. Genet Med. 2022;24(1):214–224. 10.1016/j.gim.2021.08.008 [PubMed: 34906462]
19. Mikat-Stevens NA, Larson IA, Tarini BA. Primary-care providers' perceived barriers to integration of genetics services: a systematic review of the literature. Genet Med. 2015;17(3):169–176. 10.1038/gim.2014.101 [PubMed: 25210938]
20. Nisselle A, King EA, McClaren B, et al. Measuring physician practice, preparedness and preferences for genomic medicine: a national survey. BMJ Open. 2021;11(7):e044408. 10.1136/bmjopen-2020-044408
21. Wilkes MS, Day FC, Fancher TL, et al. Increasing confidence and changing behaviors in primary care providers engaged in genetic counselling. BMC Med Educ. 2017;17(1):163. 10.1186/s12909-017-0982-4 [PubMed: 28903733]
22. Henrikson NB, Scrol A, Leppig KA, Ralston JD, Larson EB, Jarvik GP. Preferences of biobank participants for receiving actionable genomic test results: results of a recontacting study. Genet Med. 2021;23(6):1163–1166. 10.1038/s41436-021-01111-2 [PubMed: 33603197]
23. Bien SA, Wojcik GL, Zubair N, et al. Strategies for enriching variant coverage in candidate disease loci on a multiethnic genotyping array. PLoS ONE. 2016;11(12):e0167758. 10.1371/journal.pone.0167758 [PubMed: 27973554]
24. Miller DT, Lee K, Chung WK, et al. ACMG SF v3.0 list for reporting of secondary findings in clinical exome and genome sequencing: a policy statement of the American College of Medical Genetics and Genomics (ACMG). Genet Med. 2021;23(8):1381–1390. 10.1038/s41436-021-01172-3 [PubMed: 34012068]
25. Bonter K, Desjardins C, Currier N, Pun J, Ashbury FD. Personalised medicine in Canada: a survey of adoption and practice in oncology, cardiology and family medicine. BMJ Open. 2011;1(1):e000110. 10.1136/bmjopen-2011-000110
26. Hamilton JG, Abdiwahab E, Edwards HM, Fang ML, Jdayani A, Breslau ES. Primary care providers' cancer genetic testing-related knowledge, attitudes, and communication behaviors: a systematic review and research agenda. J Gen Intern Med. 2017;32(3):315–324. 10.1007/s11606-016-3943-4 [PubMed: 27995427]

27. Shields AE, Burke W, Levy DE. Differential use of available genetic tests among primary care physicians in the United States: results of a national survey. Genet Med. 2008;10(6):404–414. 10.1097/GIM.0b013e3181770184 [PubMed: 18496223]

28. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research Electronic Data Capture (REDCap)—a metadata-driven methodology and workflow process for providing translational research informatics support. J Biomed Inform. 2009;42(2):377–381. 10.1016/j.jbi.2008.08.010 [PubMed: 18929686]

29. Unertl KM, Jaffa H, Field JR, Price L, Peterson JF. Clinician perspectives on using pharmacogenomics in clinical practice. Pers Med. 2015;12(4):339–347. 10.2217/pme.15.10

30. Simpson S, Seller A, Bishop M. Using the findings of a national survey to inform the work of England's genomics education programme. Front Genet. 2019;10:1265. 10.3389/fgene.2019.01265 [PubMed: 31921303]

31. Jia T, Wu C, Hu X, et al. Physicians' knowledge, attitude, and experience of pharmacogenomic testing in China. J Pers Med. 2022;12(12). 10.3390/jpm12122021

32. Jukarainen S, Kiiskinen T, Kuitunen S, et al. Genetic risk factors have a substantial impact on healthy life years. Nat Med. 2022;28(9):1893–1901. 10.1038/s41591-022-01957-2 [PubMed: 36097220]

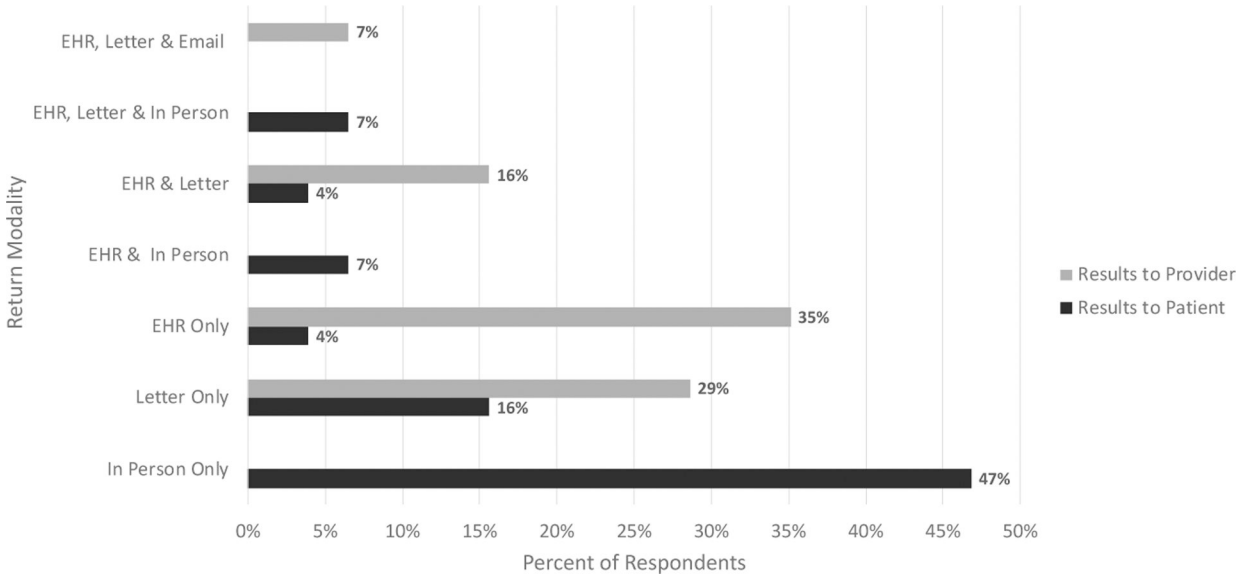

Figure 1. Primary care providers' preferred modalities of return of biobank-generated genomic results to patients and providers (*n* = 77).

Primary care providers' opinions of the delivery of genomic results to patients and their providers are shown above. Patients did not participate in this study. EHR, electronic health record.

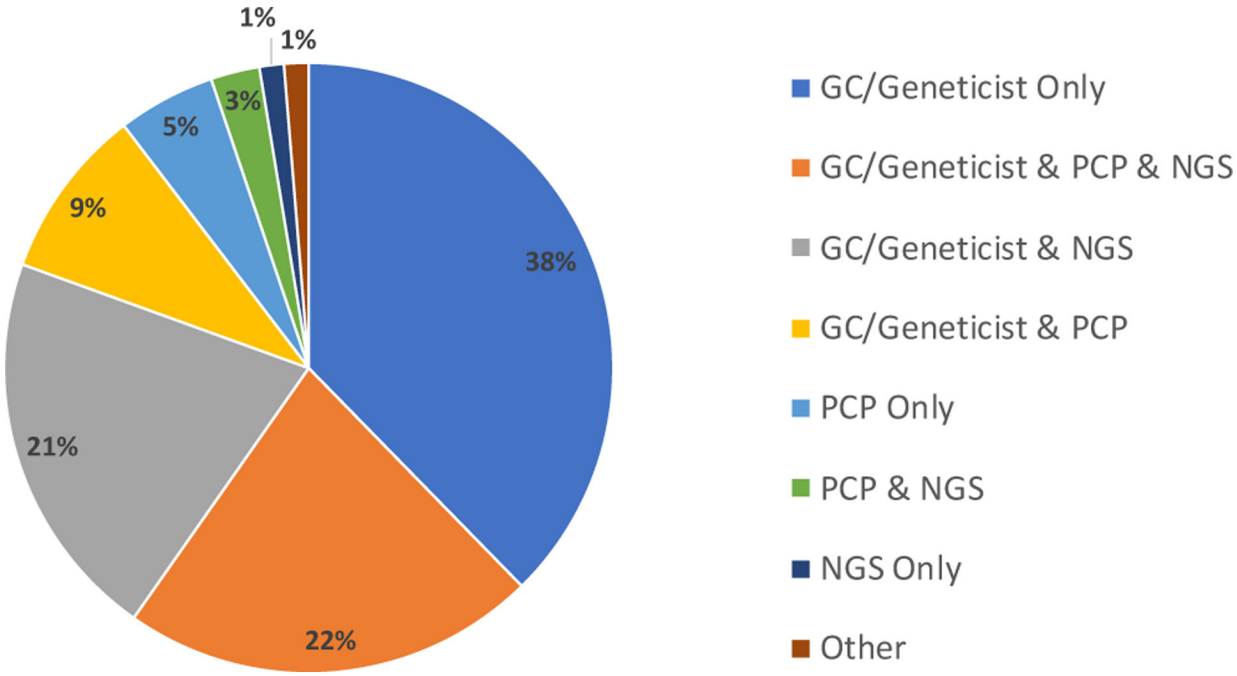

Figure 2. Primary care providers' perceived responsibility for communication of actionable genomic results to patients (*n* = 77).

GC, genetic counselor; PCP, primary care provider; NGS, non-genetics specialist.

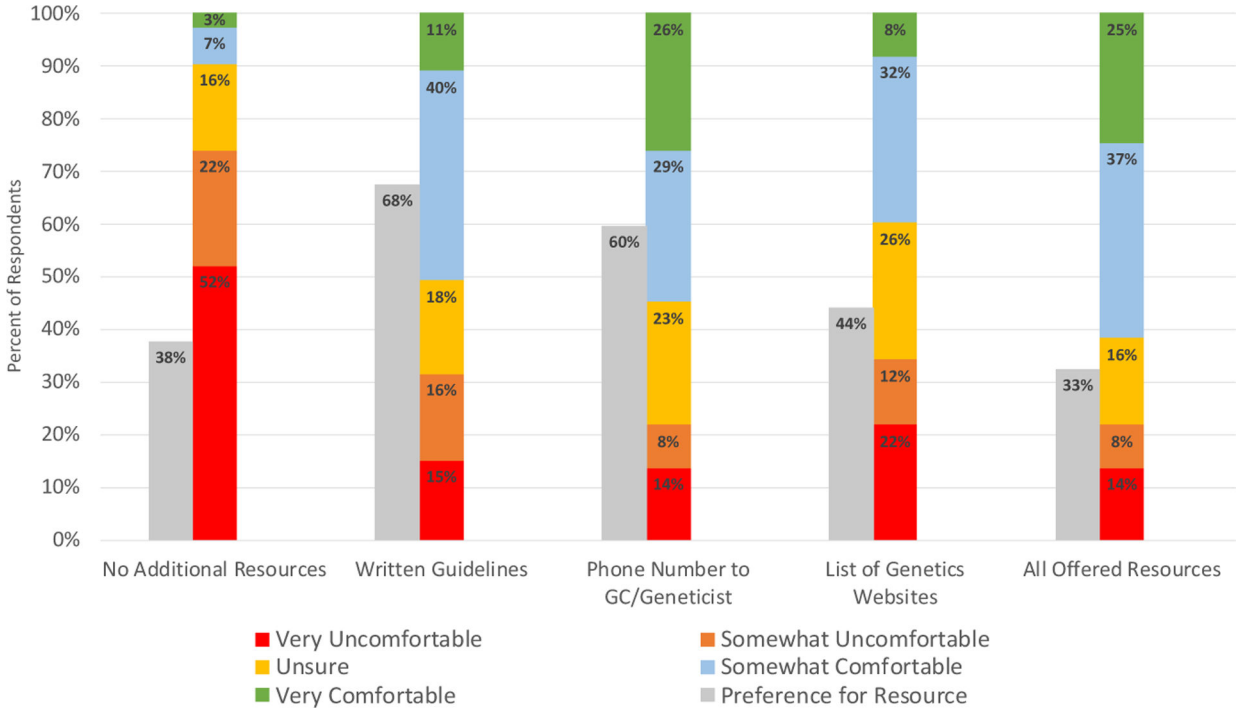

Figure 3. Primary care providers' comfort with discussing genomic results based on resource availability (*n* = 73).

GC, genetic counselor.

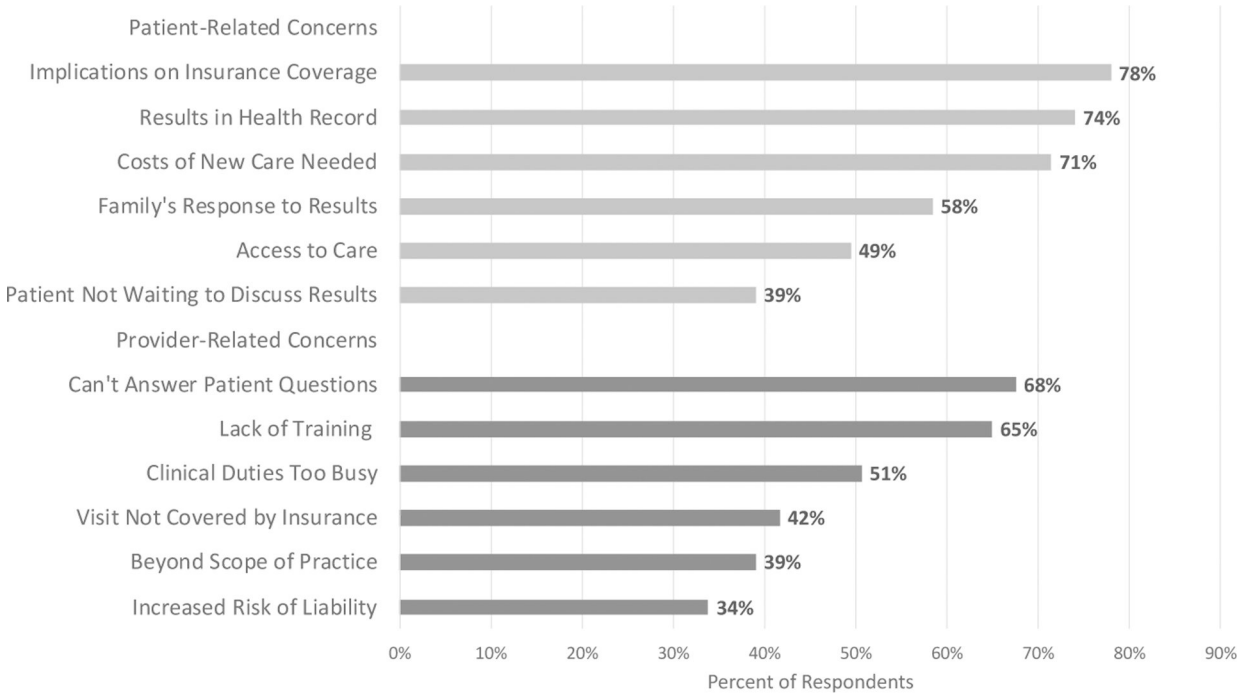

Figure 4. Primary care providers' concerns around the return of biobank-generated genomic results (*n* = 77).

Primary care providers (PCPs) were asked to consider concerns relating to the clinician's ability to provide care and those that they perceived the patient may have. PCPs' concerns are shown above; patients did not participate in this study.

Table 1

Characteristics of respondent population

Characteristic *(n)*	**Survey Response (*N* (%))**
Sex (*n* = 46)	
Female	24 (52%)
Male	22 (48%)
Specialty (*n* = 71)	
Internal Medicine	27 (38%)
Family Medicine	41 (58%)
Other	3 (4%)
Training (*n* = 57)	
MD or DO	49 (86%)
PA or NP	8 (14%)
Years in Practice (*n* = 71)	
<6 years	17 (24%)
6–20 years	16 (23%)
>20 years	38 (54%)

MD, medical doctor; *DO*, doctor of osteopathic medicine; *PA*, physician assistant; *NP*, nurse practitioner.