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Communicating unexpected pharmacogenomic results to biobank contributors: A focus group study

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ABSTRACT

Objectives: The goals of this study were to explore 1) the impact of returning unexpected pharmacogenomic (PGx) results to biobank contributors, and 2) participant views about improving communication.
Methods: We conducted a qualitative focus group study with biobank participants (N = 54) who were notified by mail of an individual research result indicating increased risk for adverse events associated with the common cancer drug 5-fluorouracil (5-FU). We employed a framework approach for analysis.
Results: Our results revealed three themes illustrating participants' questions and uncertainty, especially regarding how to share results with health providers and family members, and remember them over time. Participants valued results for themselves and others, and for the future of medicine. Risk perception was framed by health identity. "Toxicity narratives," or familiarity with another's adverse reaction to chemotherapy, increased the sense of importance participants reported.
Conclusion: These focus group results highlight research participant remaining questions and high valuation of PGx results, even when unexpected.
Practice implications: We identify PGx research participants' needs for clear clinical translation messaging that attends to health identity, pragmatics of sharing information with family members, and patient perceptions of barriers to transferring research results to a clinical context.

1. Introduction

There is debate in bioethics about researchers' obligations to return genetic results [1,2]. Some biobanks have return of results policies to disclose individual research results carrying implications for contributors' health [3]. As drug-gene interactions are increasingly clinically actionable, this discourse bears greater relevance for pharmacogenomic (PGx) research results [4–6]. Guidance for PGx research disclosure is still being developed [7–9].

Disclosure of PGx biobank results is complex due to three interrelated communications challenges. First, disclosure of PGx results involves risk communication mediated by contributors' risk perceptions. Second, the return of individual research results can be surprising for biobank contributors, especially when a long period of time has elapsed since broad consent. Third, PGx findings are distinct in that many are contingently medically actionable, depending upon a relevant diagnosis, prescription, and dosage.

Although strategies for improving risk communication for genetic disease susceptibility variants have been studied for decades within the context of genetic counseling [10–13] and genetic research [14,15], much less is known about risk perception for PGx results or how biobank participants may view receiving unexpected PGx results. Prior studies of PGx communication in a research context include investigation of aggregate disclosure [16], predictors of comprehension [17] and improvement of PGx laboratory reports for patient and clinician audiences [18].

An example of PGx results that can be returned in a research setting due to clinical actionability are PGx variants that confer

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increased risk of dihydropyrimidine dehydrogenase (DPD) deficiency. 5-fluorouracil (5-FU) and its prodrug capecitabine are widely prescribed chemotherapeutic agents used in the treatment of several cancers [19]. Fluoropyrimidine-associated toxicity leads to side-effects that reduce quality of life and include life-threatening adverse reaction [20,] [21]. However, challenges in how to best screen for a DPD deficiency phenotype have delayed implementation of DPD PGx testing as standard clinical practice [22,23].

In this study, PGx results reflecting an increased risk of DPD deficiency were disclosed to biobank contributors. Goals of focus group discussions included assessing the impact of returning DPD deficiency PGx risk variants and exploring participants' views on improving biobank communication. The findings we report can inform communication messages for disclosing PGx results, especially in research contexts.

2. Patient involvement

The Mayo Clinic Biobank has had a community advisory board (CAB) network involved in biobank governance for over a decade [24]. In November 2017, CAB members in Jacksonville, FL and Rochester, MN reviewed an initial draft of DPD deficiency PGx variant disclosure letters. Their feedback informed revisions. The disclosure letter included three main recommendations: (1) share the result with doctors, (2) store the result in case of a cancer diagnosis, and (3) share it with family members. CAB feedback also prompted development of additional materials, including a frequently asked questions (FAQ) document and a list of 5-FU and related medications (See Supplementary Materials).

3. Methods

3.1. Data collection

236 contributors to the Mayo Clinic Biobank were mailed disclosure materials. Disclosed individual research results included one of three variants (*2A, D949 V, I560S, and rs75017182). These variants were selected for disclosure due to their association with increased risk of adverse event (grade 3 or higher) when exposed to 5-FU or related chemotherapies [19,22]. Research staff confirmed receipt and conducted a brief survey. Focus group participants were recruited from among survey respondents. At the time of biospecimen collection, biobank contributors resided near Rochester, Minnesota or Jacksonville, Florida. In contrast, current residence within driving distance of Rochester was an inclusion criterion for focus group participation. Focus groups were conducted in February, March and April of 2019 within three to five weeks of mailing disclosure materials. The moderator guide was refined throughout data collection to maximize its effectiveness until data saturation was achieved [25].

Focus group participants were asked to complete a six-item questionnaire in addition to focus group discussions. Questions included: 1) In general would you say your health is good? 2) Before you received the laboratory results letter, had you ever had genetic testing? 3) Before you received the laboratory results letter, had you ever had pharmacogenetic testing? 4) Have you ever had cancer? 5) Have you ever worked directly with cancer patients? And 6) How confident are you filling out medical forms by yourself? This last questionnaire item is a question used to assess health literacy [26].

Participants' questions and uncertainty during early focus groups revealed their need for additional information. To meet this need without biasing focus group discussions, the study team worked with DPD deficiency PGx experts to support a "debriefing" discussion after subsequent focus groups concluded, providing additional information and addressing common questions (See Supplementary materials).

3.2. Data analysis

Focus group discussions were audio recorded and transcribed verbatim. A framework analysis approach was employed for analysis, selected for its fit with multidisciplinary health research and strength in combining deductive and inductive code derivation [27]. Framework analysis consists of five stages: (1) Familiarization with the data (2) Creating a thematic framework (3) Indexing (4) Charting, and (5) Mapping and interpretation [28,29]. Deductive codes included those derived from research aims and prior approaches tracking focus group dynamics [30,31]. The initial study team (KM, SC, AB, AC) familiarized themselves with data through collective analytic memo writing [32]. Three team members coded transcripts (KM, SC, SB); all authors developed a thematic framework through team-based iterative codebook development, charting, and mapping stages [28,33].

3.3. Ethics

Approval of the study was obtained from the Mayo Clinic Institutional Review Board (#18−000897).

4. Results

4.1. Participant characteristics

Of 196 biobank contributors who completed the phone survey, 35 were ineligible because they did not reside in proximity to focus group discussion locations. 61 did not clarify their reasons for refusal. Nine who did provide reasons reported scheduling conflicts, illness or impairment, and transportation barriers. 29 contributors initially indicated interest in participation, but were either unable to be scheduled or did not attend. A total of 54 survey respondents participated in focus groups. Ten focus group interviews were conducted, ranging in size from 2 – 8 participants.

52 of 54 focus group participants completed the brief questionnaire in addition to focus group discussions (See Table 1). Most (93 %) self-reported a positive health status. A majority reported no prior experience with genetic (85 %) or PGx (80 %) testing. A small number of participants (7%) reported personal experience with cancer, a third (33 %) indicated work with cancer patients, and over half (54 %) reported a family member had received chemotherapy. Most (92 %) indicated high confidence filling out medical forms by themselves. Biobank records indicated that for focus group participants an average of 8.2 years (range of 5.4–10.0 years) had passed from time of biobank consent to receipt of the disclosure materials.

4.2. Questions and uncertainties

Participants appreciated disclosure materials for their simple messaging, including the list of actions to take (FG1, FG3, FG5, FG8, FG10, FG11). Some also highlighted the clarification provided by FAQ and list of medicines (FG2, FG3, FG4). In contrast, other participants continued to find genetic information in the letter highly technical (FG5, FG7, FG9). Several focus group participants mentioned receiving other PGx results through participation in a different biobank study [34] and their responses sometimes reflected confusion between the two. All focus groups discussed potential improvements, including the mode of communication. Several participants wanted an electronic version of the materials (FG2, FG4, FG5, FG7, FG11), while others preferred communication

Table 1
Focus Group Characteristics.

N = 54		
	Average	Range
Age	60	35–85
Time from consent (years)	8.2	5.4–10.0
	N (%)	
Gender		
Female	36 (67 %)	
Male	18 (33 %)	
Race		
White	54 (100 %)	
Marital Status		
Married	43 (80 %)	
Divorced	4 (7%)	
Widowed	3 (6%)	
Single (never married)	3 (6%)	
Cohabiting	1 (2%)	
Education		
High School	3 (6%)	
Vocational or some college	18 (33 %)	
College	18 (33 %)	
Graduate	16 (30 %)	
Self Reported Health		
Excellent	4 (8%)	
Very good	29 (60 %)	
Good	12 (25 %)	
Fair	3 (6%)	
Previously had Gx testing		
Yes	6 (12 %)	
No	44 (85 %)	
Not sure	2 (4%)	
Previously had PGx testing		
Yes	6 (12 %)	
No	41 (80 %)	
Not sure	4 (8%)	
Ever had cancer?		
Yes	7 (13 %)	
No	45 (87 %)	
Have family member who had chemo?		
Yes	28 (54 %)	
No	18 (35 %)	
Not sure	6 (12 %)	
Heard of 5-FU before?		
Yes	11 (21 %)	
No	40 (77 %)	
Not sure	1 (2%)	
Worked directly with cancer patients?		
Yes	17 (33 %)	
No	35 (67 %)	
Confidence with medical forms		
Extremely	35 (67 %)	
Quite a bit	13 (25 %)	
Somewhat	3 (6%)	

via health portal (FG2, FG5, FG8, FG11), or mailed letters (FG1, FG2, FG5, FG10, FG7).

Participant uncertainty concerned what would happen to the body if exposed to these chemotherapy drugs (FG1, FG2, FG3, FG6, FG8), and availability of alternatives (FG1, FG2, FG3 FG4, FG6, FG7, FG8, FG9). Participants' main questions centered on perceived obstacles to acting on the disclosure materials' three main recommendations.

4.2.1. Sharing PGx results with physicians and health systems

Most focus groups discussed whether the PGx results would be successfully incorporated into their electronic health records (FG1, FG3, FG5, FG6, FG7, FG8, FG9). In the following exchange, focus group participants traded tips for how they navigated communicating results to their clinicians:

FG3-P2: I wasn't sure how to do it. Should I take a picture? Should I bring it to her in person? Should I call the office? Then it's always such a hassle to get a hold of my doctor, so what is the best way? Do I email her? Do I blah, blah, blah.

Moderator: That was a barrier, not clear-cut?

FG3-P2: Yeah, no clear-cut way that I could think through.

FG3-P4:Yeah. I do everything through the portal if I can help it. It's easier than going in.

FG3-P1:Or waiting in line.

FG3-P2: Exactly.

FG3-P1: Mm-hm.

FG3-P6: (Sarcastic) Five secretaries later.

Several participants reported on clinical encounters sharing the PGx results with primary care providers (FG1, FG2, FG3, FG5, FG6, FG7, FG8, FG9). Their descriptions of these meetings included discordance between participants and clinicians and shared confusion (FG1, FG3, FG4, FG5, FG8). Participants' accounts often specified difficulties ascertaining the correct electronic health record (EHR) section to document a PGx research result. For example, this participant reflects on one experience:

FG1-P6: When I did share it with my doctor, she said, "Well, we can put this on file, but we won't have any way to reference this." She didn't seem concerned at all. She didn't seem alarmed. And to me, that killed the momentum of, "Okay, I need to share this," or anything along that nature.

All focus groups mentioned improving communication between the biobank and providers (FG1–10), at times suggesting an "opt-in" alternative for results to be directly communicated to providers.

4.2.2. Remembering findings Over time

The second theme around questions and uncertainty arose around the letter's third recommendation to store the disclosure letter in a safe place in case of cancer diagnosis. Participants implied that the burden of memory fell primarily to participants:

FG6-P2: My doctor did not take the-the copy that I put down there for him. He did not take it. But he did look at it. You know, he read it and everything—and the nurse did, too. But, uh— I don't think he put it in my history, so it's gonna be up to me to, to mention it.

FG7-P1: Right. Yeah, there's this thing with things I can't pronounce. I'm not gonna remember it. When it comes up, I'm gonna think, oh, yeah, there was a thing with words on it that I don't know how to pronounce, and it was important. It's just a matter of making sure that paper and that record is in the right place in my future.

Concern about memory was often linked to concerns about the unreliability of the health system tracking the information (FG1, FG2, FG3, FG5, FG6, FG7, FG8, FG9). One participant mentioned telling others and keeping personal records as a fail-safe:

FG2-P7: and if something happens to you where you cannot tell a physician what's going on, and all of a sudden, they give you this drug, then that's pretty bad too. I shared it with my family right away. We keep it in a safe spot.

4.2.3. Sharing findings with family

Questions regarding sharing PGx results with family often revolved around appropriate scope of disclosure within a family circle. Many participants wanted to understand the inheritance pattern of 5FU toxicity. This was often expressed as a question about the chance that a given family member might have the variant of interest (FG1, FG2, FG3, FG5, FG8, FG9). Sometimes interest in heritability related to the practicality of sharing with family, as expressed by this participant:

FG5-P1: If I start going out, cousins, do I go to my grandfather, both sides, how high up, but then how wide do I go? I mean, I could easily get to hundreds of cousins. Why bother, right, without knowing more information?

Most focus groups identified family members who should not receive results, especially minors for whom the results seemed

irrelevant (FG1, FG4, FG5, FG6) or elderly or currently ill relatives for whom the information might be distressing (FG1, FG2, FG3, FG6, FG7, FG8). Participants also questioned availability and financial costs of clinical testing both locally and in different health systems (FG 1, FG2, FG4, FG5, FG9). Some expressed uncertainty about what to say to relatives (FG1, FG 11, FG 6), while others noted that the initial disclosure letter was easy to copy and share (FG5, FG8, FG9).

Participants' concerns about health system tracking of results cascaded to family members. A few participants sought to know whether their children would require additional clinical testing or if their own results letter would suffice for incorporation into children's records (FG1, FG8, FG9).

4.3. Participant valuation of PGx results

Emergent themes identified three distinct forms of value that can inform PGx disclosure, including value to self, family, and the future. Positive valuation was the dominant reaction, even when participants found results to be unexpected or surprising.

4.3.1. Value to self

The first form of value participants often expressed was personal, especially how immediate action could be taken by following the recommendations. One of the few participants who had direct experience with a cancer diagnosis immediately discussed it with his oncologist (FG2). Those who had personal experience with a death they attributed to reaction to chemotherapy often shared these experiences in narrative form. These "toxicity stories" were spontaneously shared by at least one participant in 7 of the 10 focus groups, and served as cautionary tales:

FG5-P5: I was thankful, because I know two people who actually did not survive their chemotherapy. One was a friend of mine, her brother, who I did not know personally. On his second treatment he had a severe reaction and passed away from it. The other one was a gentleman I have known basically my whole life who was in his 80s and was diagnosed with lung cancer, and debated whether he even wanted to do chemotherapy because of his age. It was a surprise to him that he had. Then he decided that well yes, he would, he'd have one treatment and see how he felt. He had one treatment and he died.

As the following exchange reflects, some participants found the directive to discuss results with a primary care provider to be empowering and indicative of actionability:

FG1-P2: And having the direction in the letter to speak with your primary care physician gives you the courage to bring it up . . . That forces the conversation. It also gives you the time to say, okay, I'll see my physician in three months or six months or whatever. I'm fine until then. I think it was reassuring to be told to discuss it with my physician.

FG1-P8: I also think that makes it seem more important. You would not tell us to talk to our physician about it if we weren't supposed to take it seriously.

Some participants also directly addressed their comprehension of the contingent nature of PGx results:

FG5-P6: First of all, I would have to get some kind of nasty cancer. Then a doctor would have to prescribe one of the purple sheet listed meds, and then—as you point out, sir, maybe it has to be at a certain dose level, and maybe not, who knows. Then at that point I might or might not have a reaction. I'm not sure I wanna gamble, which is why I'm glad that you guys were able to let us know this, that you were able to spot this and tell us.

While focus group participants reported research disclosure by mail wording helped them understand or communicate results (FG1, FG3, FG5, FG8, FG10, FG11), many reported that focus group recruitment phone calls implied the results had greater importance (FG1, FG 3, FG7, FG 8, FG9, FG 11).

4.3.2. Familial relevance

Participants also reported valuing the information based on its familial relevance. This form of valuing included both the potential of results to help guide future treatment of family members, and the ability to interpret the result in light of family history. A sense of familial value was often tied to a family history of cancer, including personal cancer diagnosis:

FG1-P7: I still am pumped. I'm really pumped about it and I want to get the word out to my family. I'm just so glad that I did donate to the biobank, that I know this because now I'm the first one in the known family to have cancer. It's there. It can happen to anybody. I want my children, grandchildren, I want this in their files. Really, I'm very grateful.

FG4-P9: I know that cancer is rampant in my family, so I was extremely happy to get this kind of information in advance.

Several participants considered reinterpreting the death of a family member given these results, for example:

FG5-P9: My father died of cancer, and he couldn't tolerate the chemotherapy at all. He said, 'If I have to be this sick, I might as well die.' And he did. You suppose that was maybe a connection?

FG2-P3: I think from my standpoint—my dad has been through four different types of cancers. He's still kicking. [Knocking] on wood. When he went through this, he had no knowledge of—nobody's ever said, 'Hey, you should not take this.' For me to have that information going into it, especially with my family history, that just makes me a little bit more informed, and I don't think that's ever a bad thing. It was really helpful to find that out.

A lesser sense of importance often accompanied the absence of such family history. For example, when asked if any discussants experienced hesitancy to share with family members, one participant countered:

FG1-P1: I don't think I told them [my family] 'cause I'm not freaked out at all. I don't feel any urgency.

*[laughter from multiple people]*4.3.3.

A third form of value expressed by participants was a sense of appreciation for biobank contribution or the future of medicine. This value persisted even when results were unexpected. While several participants expressed feeling "shocked" or "surprised" upon reading the disclosure materials, subsequent probes often revealed a positive tenor to the experience of surprise (FG1, FG2, FG4, FG6, FG7, FG10). For example, in the following exchange, participants reflected on having forgotten about their biobank participation entirely:

FG1-P8: I heard nothing for nine years. I completely forgot I was even part of it.

FG1-P5: I did too.

FG1-P8: Then in a two-month period, I got both of these things [referencing DPD deficiency risk results and those froma different PGx study]. Honestly, I think they're worth their weight in gold, so it was fine to wait so long.

FG1-P8: Yeah. I completely forgot I was even part of it. That's why I asked [the focus group recruiters] when they started [this study] because I'd completely forgotten when I'd done it.

FG1-P6: I think I've gotten requests to participate in other studies that were related to [the biobank]—I don't think I've ever gotten any results.

Participants more commonly framed this form of value in terms of advances in genetics or the future of medicine. For example:

FG7-P8: It's like the whole intention behind individualized medicine is to identify these things to say, 'These are effective and this isn't effective.' Think about the cost savings, if we could just eliminate all the ineffective treatment, and Identify—

FG7-P6: Adverse reactions.

FG7-P8: Right. Think about all the costs that creates and just go for the one that's gonna actually do something for you.

FG2-P2: It's really impressive that they can find these genetic markers.

5. Discussion and conclusion

5.1. Discussion

Our aims in this study were to explore the impact of returning DPD deficiency PGx risk variants and ascertain biobank participants' views on improving PGx communication. PGx disclosure can require new forms of logistical coordination on the part of biobanks as it is often unclear who bears primary responsibility and ability for disclosure. Relevant expertise is dispersed between pharmacists, clinical geneticists, health communication specialists, and genetic counselors [35]. Identifying strategies to effectively communicate PGx results will support a variety of professionals who could be responsible for disclosure.

These results join the literature laying the evidentiary foundation for PGx communication. Previous research found that public consumers, patients, and physicians generally appreciate or are interested in PGx testing [36–42]. For example, Haga and colleagues (2016) report that patients perceived testing to be useful when results were clearly delivered by providers [17]. Our findings provide additional evidence of high valuation of research PGx disclosure, including by mail. These findings also resonate with other reports of patient preferences for clear language and written presentation of PGx information [43,44]. In addition, these findings are also in keeping with reported high valuation of genetic results more broadly, including lay valuations that do not coincide with a biomedical view of clinical utility [45,46] and participant reports of difficulty understanding the meaning of the results [47]. For the Mayo Clinic Biobank, study findings provide initial evidence supporting responsible disclosure of PGx results from future biobank utilization. However, the wide range of participant reactions also reflect the possibility of distinct reactions shaped by health status and disease familiarity. These findings reinforce the current biobank governance model that reviews study return of results plans on a case-by-case basis consistent with contributors' broad consent to participation [48].

One complexity of communicating PGx results is the role of risk perception. Our findings confirm the role of health identity in shaping reactions to PGx results, similar to studies of heritable disease risk [49–51] and test results [52,53]. Awareness of narrative constructs could help anticipate different responses to disclosure, varying with personal and familial cancer diagnoses and bereavement [54]. However, in contrast to previous findings about risk perception shaped by familial disease, the emergence of toxicity narratives during focus group discussion demonstrates the power of story-telling that extends well beyond the family circle. Any familiarity with another's bad reaction to chemotherapy can alter how participants interpret DPD deficiency risk variants. Participants' remaining questions and uncertainty, especially about inheritance, might reflect challenges with genetic literacy [55,56], which merits further study. Common questions regarding inheritance patterns and who to share with is in accordance with other studies reporting need for additional support in sharing genetic results with family members [57].

A second complexity of this PGx communication is its unexpected nature. Biobank contributors are often unaware of the studies using their samples, and often do not recall their donation or aspects of the consent process [58,59]. In keeping with prior biobank return of results studies, focus group participants reported positive appreciation of disclosure despite the passage of time since biobank broad consent [60,61], even reframing shock and surprise as positive experiences. These findings also concord with disease susceptibility studies which elicited approval from the vast majority of recipients when using letters to disclose unexpected genetic results, [62,63].

Finally, some study results reflect appreciation of the actionability of PGx results, which is contingent upon a relevant diagnosis and intervention, among other factors. Two prior reviews have captured the literature on patient understanding of PGx results and preferred communication format [64,65]. Participants' responses reflect some grasp of contingencies, but also some struggles with the concept of adverse reaction. Their uncertainty might also reflect the biobank setting's lack of pre-test conversations with health care professionals, which otherwise might have set expectations and framed comprehension of results [41].

In contrast to decades of research on communicating disease susceptibility through genetic counseling—including their psychosocial impact—there is currently less evidence to support best practices for disclosing PGx results. This study demonstrates one approach to disclosure by mail. As these results were generated in the context of a research study, they might not be viewed as sufficient for guiding clinical decision making [66,67]. Here, participants' accounts affirm clinicians' perceptions of inconsistent placement of PGx research results in the EHR, including documentation that effectively triggers clinical decision supports [68]. These results elevate the importance of communicating how PGx results can be best tracked over time, which might help alleviate participants' sense of solely shouldering a burden of memory. To a lesser degree in these participants, proposals to deposit PGx results in the EHR has elsewhere elicited greater concerns about discrimination, stigmatization, and physician overreliance on results for clinical care [36,43,69,70].

5.2. Limitations

This study has several limitations. Biobank contributor demographics have less ethnic diversity and a higher educational attainment level than the population in the surrounding upper Midwest and Florida communities [24]. Participation in the Mayo Clinic biobank might have given focus group participants greater familiarity with genetic research, affecting valuations. Eligibility for focus groups was limited by proximity to Rochester, MN. Focus group discussions likely influenced perceptions, as participants reviewed disclosure materials prior to attending and reported the recruiting phone call increased their perception of the result's importance. Participants' self-report of unfamiliarity with prior genetic test might be inaccurate. Participants might have experienced genetic testing in clinical, direct-to-consumer, and other research contexts. As their conflation of this disclosure with another biobank study exemplifies, these additional exposures to genetic testing might also have been accompanied by educational materials that increased these participants' familiarity with genetics.

5.3. Conclusion

To our knowledge, this is the first study to qualitatively examine the reactions of biobank contributors to unexpected PGx results and their views on improving communication. Findings suggest possible strategies for grappling with the communication complexity presented by PGx results, especially in research settings. In sum: Narrative illness identity framed participant risk perception of PGx results. Biobank contributors highly valued PGx information even when unexpected. The contingent actionability of PGx results influences assessments of urgency, and can be attended by a sense of burden or responsibility for remembering the result over time.

Future research should be directed at studying disclosure alternatives including different recipients, result types, disclosure modes, and the expertise of disclosers. Additional research should engage cohorts with greater racial, ethnic, educational, and socioeconomic diversity [71]. The emergence of "toxicity narratives" suggests additional research in populations with a current diagnosis or regarding other conditions will help clarify if and when PGx results are most valued or upsetting. Much-needed comparisons to receipt of disease susceptibility variants could advance knowledge of whether PGx disclosure is distinctive from the recipients' point of view, or equally laborious to other forms of return or results. PGx disclosure in biobanks should also determine if our participants' generally appreciative attitude toward surprising results persists across contexts. Memory is also more generally worthy of further study, including participants' recall of biobank participation, and their attitudes toward tracking research results that are contingently clinically actionable. Longer established biobanks might also be a place to compare and contrast participant experiences across genetic disclosure.

5.4. Practice implications

As evidence of PGx clinical utility grows, the case for a research duty to disclose is also strengthened. This study unpacks several underlying reasons for why research participants value PGx results. We identify PGx research participants' needs for clear clinical translation messaging that attends to health identity, pragmatics of sharing information with family members, and how research results can be reliably transferred to a clinical context.

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CRediT authorship contribution statement

Karen M. Meagher: Project administration, Conceptualization, Methodology, Formal analysis, Writing - original draft, Writing - review & editing. **Susan H. Curtis:** Conceptualization, Methodology, Investigation, Formal analysis, Writing - original draft, Writing - review & editing. **Sarah Borucki:** Writing - review & editing. **Annika Beck:** Writing - review & editing. **Tarika Srinivasan:** Writing - review & editing. **Amal Cheema:** Writing - review & editing. **Richard R. Sharp:** Supervision, Conceptualization, Methodology, Data curation, Writing - review & editing.

Declaration of Competing Interest

The views expressed here are those of the authors and not of Mayo Clinic. The authors have no conflicts of interest to declare.

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Appendix A. Supplementary data

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