SPECIAL ARTICLE | Genetics inMedicine

Public preferences regarding the return of individual genetic research results: findings from a qualitative focus group study

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Purpose: People are interested in receiving their individual research results in exchange for participating in genetic research. However, it is unclear whether the public understands the nature and limitations of these results and whether they would want information with unknown clinical utility.

Methods: We conducted 10 focus groups in three US cities to examine the types of results people would want and the perceived value of different types of individual research results.

Results: Nearly all focus group participants said they would want at least some individual research results returned. Priority was placed on results that are well understood. Less important to participants were the magnitude of the risk conferred and actionability of the result. In addition to helping treat or prevent disease, participants identified several other potential health-related and personal reasons for wanting individual research results. Many believed that researchers have an obligation to return individual research results. Although most people would prefer to receive as much information as possible, many would accept the return of a limited set of results.

Conclusion: Participants understood the nuances and limitations of individual research results. Researchers deciding the value of returning a given result should consider using a broader definition of clinical utility as well as the possible personal utility of the information.

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Key Words: genetic; individual; IRR; research; results

INTRODUCTION

Whether, and to what extent, individual research results (IRRs) should be returned to study participants in genetic research is under debate in the scientific and bioethics communities.[1–7] The proliferation of biobanks and the imminence of affordable whole-genome sequencing add urgency and complexity to the discussion.[8] Some proponents argue that researchers have ethical obligations to return genetic research results to participants, citing standards of beneficence and respect for persons.[3,4] Returning results may also encourage participation in research.[9,10] Those not in favor argue that the intent of research is to gather generalizable scientific knowledge to benefit society, not individual study participants.[11] Some argue that returning IRRs would consume valuable research resources.[10,12] Many question the benefit of returning results that may harm research participants, who may attribute more meaning to these results than scientific evidence would warrant.[2,5]

There is mounting evidence in the literature that potential participants in genetic research studies are interested in receiving their IRRs and may increasingly expect the return of at least some IRRs as a condition of enrollment.[13–19] A 2008 survey of US adults found that 91% of individuals wanted their IRRs even if nothing could be currently done with the information, and 75% would be less likely to participate in research if IRRs were not returned. Receiving IRRs had a greater influence on hypothetical willingness to participate than increasing compensation or reducing study burdens.[20]

Most genetic epidemiology studies have not returned individual genetic research results.[21–23] However, policies and guidelines supporting the return of results in limited circumstances have recently been issued.[6,24,25] These guidelines specify criteria to help researchers decide which information to return. Considerable discretion is left to researchers, however, to select results and determine how and when to deliver them. These decisions may be informed by the preferences of potential study participants. To this end, we conducted focus groups with US adults to gather information about the preferences of the people with respect to IRRs, their understanding of the limited clinical utility of many IRRs, and their desire for results given these limitations. Discussion centered around which IRRs hold the most interest and why, assumptions made about IRRs, interest in results with limited clinical validity and utility, and the extent of trade-offs a study should make in order to return IRRs. The opinions of the general public may be relevant for population-based studies and biobanks recruiting healthy volunteers.

MATERIALS AND METHODS

A total of 89 individuals participated in 10 focus groups between October 2009 and January 2010. Eight groups were conducted in person—in Washington, DC; Philadelphia, PA; and Denver, CO—and two online. Participants were selected from a broad

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range of demographics including race, gender, age, ethnicity, socioeconomic status, and social-networking behavior (Table 1). One group that comprised Hispanics from predominantly Spanish-speaking households was conducted in Spanish. The sample was set up to efficiently collect a broad range of opinions from people in a number of major US geographic and sociodemographic groups. However, we did not specifically recruit groups of Asian Americans, American Indians, Alaska Natives, or people living in rural areas.

At the beginning of each focus group, a 3-min video describing the goals and design of a proposed cohort study was shown.[26] A remastered version with a Spanish voice-over was used in the Spanish-speaking focus group. The audiotape of this group was transcribed directly into English. A bilingual project consultant reviewed the translated script, video, tape, and transcript to ensure that the integrity of the content was retained.

Following the video, moderators conducted a three-part discussion of IRRs. First, participants discussed their general preferences for the return of IRRs. Next, the moderator presented specific examples of results that might be generated during a large-cohort study (Table 2 lists the categories of results discussed), and participants discussed how the attributes of different results influenced their interest in the information. Finally, moderators explained why IRRs are often not returned to participants—reasons including regulatory requirements and resource burdens—and explored trade-offs that study designers and participants might make to pay for the return of IRRs.

Table 1 Focus group locations and characteristics

	Location	Group characteristics
Group 1	Washington, DC	White, non-Hispanic, mid-high SES
Group 2	Washington, DC	White, non-Hispanic, low SES
Group 3	Washington, DC	Mixed, non–social networkers
Group 4	Philadelphia, PA	African American, mid-high SES
Group 5	Philadelphia, PA	African American, low SES
Group 6	Philadelphia, PA	Mixed, social networkers
Group 7	Denver	Hispanic, English-speaking household (conducted in English)
Group 8	Denver	Hispanic, Spanish-speaking household (conducted in Spanish)
Group 9	Online	Mixed, social networkers
Group 10	Online	Mixed, social networkers

Lower SES, household income <$45,000; mid-high SES, household income >$45,000; non–social networkers, individuals who did not have a personal website or blog, did not have (or used "rarely" or "not at all") an account with the following social-networking sites: Facebook, MySpace, Bebot, Orkut, Classmates, Match.com, eHarmony, or Twitter; social networkers, individuals who had an account with the social-networking website Facebook and had posted to that account in the past week.

SES, socioeconomic status.

Local focus group companies in the three study cities recruited 12–14 participants per group to ensure 8–10 participants would attend. E-mail and telephone reminders were sent the day before the focus group. Focus group members signed a consent form and provided demographic information. Participants were compensated $100 for their time. Focus groups lasted 2 h. Each group was audio-recorded and transcribed.

Detailed explanation of the online focus group methodology is included in the **Supplementary Methods and Procedures** online. Briefly, participants were recruited through an online advertisement on Craigslist for the Philadelphia metropolitan area. Eligible respondents were invited to participate in an online focus group hosted by the website Chatzy (http://www.chatzy.com). Two focus groups of 3–4 people were conducted in real time. Participation in the online focus group implied consent.

Focus group transcripts were entered into NVivo 8.0.[27] Primary codes corresponding to the topic headings from the interview guide were assigned. Four project investigators independently generated initial secondary codes based on two transcripts. Two investigators applied the secondary codes to two additional transcripts, and the team compared the coded transcripts, discussed discrepancies, finalized secondary codes, and developed rules to make coding consistent. Transcripts were then coded with secondary codes. Text pertaining to returning IRRs was organized and analyzed for common themes. This research was approved by the Johns Hopkins University institutional review board.

RESULTS

In total, 89 individuals participated in 10 focus groups. The quotes presented in the following were selected to be representative of all groups. Group numbers following each quote correspond to the numbers found in Table 1.

The majority of participants in each focus group supported the proposed study and expressed a strong general desire to receive IRRs. Table 3 shows several common reasons given for wanting individual results. Of primary importance was that the results could directly help people treat or avoid disease. In addition to clinical utility—as defined in the traditional sense—participants identified more ways in which the results might improve their health or confer personal utility. Individuals

Table 2 Attributes of the hypothetical results discussed by focus group participants

Availability of treatment: Results might be associated with conditions for which treatment is or is not available.
Level of risk: Results might be associated with low or high disease risk.
Certainty of the information: Risk estimates might be well validated or might change over time with further research.
Unknown significance: The clinical relevance of a finding may be unknown.
Nonmedical traits: Variants may be associated with traits unrelated to health.

Table 3 Reasons focus group participants would want individual research results

Reason related to the narrow definition of clinical utility
The information may help participants to treat or avoid disease
Reasons related to a broader definition of clinical utility
The information may motivate participants to change their behavior
Participants could learn more about the condition or gene
Participants could monitor research and progress
Participants could participate in other related research
The information could be useful to participants in the future
Reasons related to personal utility
The knowledge could empower participants
The information could give participants a feeling of control
The information could benefit the participant's family
The information could make participants feel respected by the researchers
The information could make participants feel more involved in the study
The information could help participants plan or live more fully
Other reasons
Results belong to the participant
Participants want to know what the researchers learn about them
Results are compensation for participating

could learn about relevant conditions or genes and participate in and monitor the progress of other research. IRRs could also motivate participants to take action pertaining to their health. The information might be useful in the future as research leads to better understanding of the data.

Participants also listed several personal reasons for why they would want IRRs. For many, the desire for IRRs appeared to be related to a sense of ownership, i.e., that information about their genes belongs to them.

> I would want to know because it is pertaining to me, myself. (Group 3)
> Why would the information be more important to you all than for us, our individual information? The specifics would be more important to us than to the study, I think. (Group 4)

Some saw the information as empowering; others said that returning IRRs would increase participants' commitment to the study and show them respect. Many said that receiving IRRs would be a form of compensation for participation, given that the study was asking for a significant commitment from volunteers.

Not all focus group members believed that returning IRRs would be a condition of research participation. A small number said that the purpose of the research was to examine health in the population and not to benefit individual participants. Others would accept IRRs if they were offered, but would not require them to participate.

> If there is the option for me to get results, I'm going to say yes. But if you tell me I'm not going to get them, I'm not really going to care. (Group 2)

Availability of treatment

Participants were asked whether the availability of treatment would influence their desire to receive a given IRR. Colon cancer served as the example of a treatable condition and Alzheimer disease as an example of a currently untreatable condition.

In all 10 groups, almost everyone wanted to receive IRRs indicating an increased risk of a treatable or preventable condition. Some said researchers would be obligated to return such findings.

> You found out that I had a high risk of colon cancer. I develop it five years later. You didn't tell me nothing. I'm going to want to sue you. (Group 7)

Most focus group participants also wanted IRRs for conditions that could not currently be treated. Participants in nearly every group said that there is always something one could do to make use of these data. The information could empower people, giving them a sense of control over their situation and allowing them to make some kind of change, even if the change might not be effective. Those at risk could learn more about the condition, stay abreast of research, and monitor for developments in clinical interventions (**Table 3**).

> Even if there's nothing you can necessarily do about it, at least you kind of know. So, you can change your diet, or, you know, exercise more, or whatever … at least feel like you have some kind of control over what's going to end up happening even though you really don't. (Group 7)

In three focus groups some people preferred not to receive results about untreatable conditions because of the sense of inevitability the information would confer, the lack of control over development of the disease, and the psychological burden the knowledge would cause.

> If there is no cure and there is no treatment, I would think that the quality of life for that person would be much better if they did not know. (Group 8)

Level of risk

Focus group participants were asked whether the magnitude of the risk identified would influence their desire to receive IRRs. Participants first considered two hypothetical research results.

In one, their lifetime risk for developing colon cancer increased from the population average of 5% to 80%. In the other, the risk was elevated from 5% to 6%. After discussing the two hypothetical results, a similar discussion was held about Alzheimer disease.

For the majority of participants in all the groups, the magnitude of the risk had little influence on desire to obtain IRRs. Most participants wanted to learn about very high and slightly elevated risks for both colon cancer and Alzheimer disease. Some focus groups felt that even if their risk was the same as the general population, that information would be useful.

> Whether it's high risk, low risk, or no risk, I want to know. (Group 5)

Four groups included people who were less interested in small increases in risk; some believed this information would not be informative.

> I don't think it would help me that much unless there was a real big difference … not 1 or 2 percent. I don't think it would make a difference. (Group 2)

Finally, when asked whether they would still want IRRs even if most results from the study revealed small changes in risks, a few participants changed their initial opinion that they would want all results returned.

Information that could change over time

Focus group participants were told that many study findings would be new and would not have been confirmed by other researchers, that it could take several years to confirm a result, and that the interpretation of IRRs would be likely to change over time as more research was done. Many focus group participants said that they understood the iterative nature of medical research and would expect the information to change. For most, the unsettled nature of the information did not diminish their interest. Many felt that the validity or reliability of the information was less important than researchers' transparency about their level of certainty about each result.

> I think you have to make that clear to people … . I don't mind if it changes, as long as it is not presented to me as something being definitive. (Group 3)

Some people expressed contradicting views about their need for certainty, saying that they understood research results would be subject to change while simultaneously expecting the results to be accurate and confirmed.

> I'd want to know every finding. I don't expect science to be perfect, so I don't expect one set of results to be final … . Again, I know scientific findings can never be 100% accurate, but I would expect the researchers and their institutions to be very sure of what they are reporting. (Group 9)

There were a few participants who did not want to receive information that might change over time.

> Then you put me in a frenzy for nothing and this could have been avoided by you just waiting? (Group 6)
> I don't want to know if you're not 100 percent. If you're not sure, don't tell me. If you've got to do further research, five years down the line, OK. Then keep it to yourself. Five years, call me and let me know what's up. (Group 5)

Results with unknown meaning

Participants were also asked whether they would want genetic information of unknown significance. We presented a scenario in which a variant in a gene known to be associated with colon cancer is detected, but the clinical relevance of the variant is unknown.

Some people who wanted other types of research results did not want results for which researchers could offer little or no interpretation. Some said findings of unknown significance would not be useful and might cause anxiety. They preferred to learn about these variants only after further research clarified the associated risk.

> I think there should be a threshold of certainty that should be put in place. (Group 3)

Still, a cadre of focus group participants remained steadfast in their desire to learn every available piece of information about themselves, including variants of unknown significance. These individuals believed that the information could become meaningful later on; they could find additional information about it on their own; they could follow the research in this area; or they might pass the information on to family.

> I would want it in my report … . Even if I don't know the consequences of it, at least I know it is there, and if the information comes later, then maybe I can pinpoint it, but I want to know it. (Group 4)

Interest in results for nonmedical traits or conditions

Participants were asked about variants associated with traits unrelated to health, such as premature graying of hair or sticky ear wax. In all but one group, at least some people wanted this kind of information. Some noted that results that seem medically insignificant now could become meaningful later.

> If the study is [about] the connection between ear wax and migraines, then let me know. But if the study shows that I have a 2 percent [chance] of having more ear wax, then, no, I'm cool. (Group 5)

Others were interested in IRRs for nonmedical conditions because the data would tell them something about themselves and their family. However, most people thought such results

were "frivolous" or "vain," and some said that such research studies should not even be done.

Trade-offs to obtain IRRs

After reviewing various types of research results, the moderator explained why IRRs were not usually returned to study participants, including the regulatory requirement of confirming test results in a Clinical Laboratory Improvement Amendments–certified laboratory and the financial and personnel burdens to the study. Specific costs of testing were not described.

When asked about their willingness to pay to confirm research results in a Clinical Laboratory Improvement Amendments–certified laboratory, a large majority of focus group participants said study funders should cover all expenses associated with returning IRRs and that these costs should be considered essential elements of the study budget. Many participants said that study funders had some form of obligation to cover the cost of returning IRRs.

> They are the ones doing the study, so they should be the one paying. (Group 8)

Many participants viewed the return of IRRs as an incentive to participate in the study and believed that requiring study participants to pay for their IRRs could impede recruitment. Not everyone agreed. A few individuals strongly believed that the intent of the study was to conduct research for the population and not to satisfy individual participants' curiosity.

> The study is not geared towards the individual, but research on what develops out of it … the goal of the study is not to treat or actually diagnose. (Group 6)

However, several people expressed concern about the cost of the testing and raised issues of fairness and justice for those who could not afford to pay for their results.

> A lot of people don't have funds, period. So what would happen with them? Would they just not know, you know … would they just be out, X-ed out? I mean, come on. (Group 5)

In all but one focus group, some said they would pay to receive their IRRs. The types of results they would pay for varied by individual interest and opinions about the overall responsibility of the National Institutes of Health to return research results. Focus group members were most willing to pay for results that indicated they were at high risk for a condition.

Participants were asked about trade-offs they felt the study and participants should make in order to return IRRs. We presented the possibility of reducing the proposed study from 500,000 to 250,000 participants to free up funds for returning results, explaining that in a smaller study, rare factors that increase disease risk might not be discovered or might take twice as long to find. In all but one focus group, there were individuals who said study size should not be reduced as it would threaten the integrity of the research. However, many individuals said that reducing the sample size was a reasonable trade-off for the return of IRRs. Several people said they would prefer a smaller study if it meant results would be returned. It is unclear, however, whether all participants understood the significance of the difference in the two samples sizes; both seemed abstract and large.

> Whether it's a quarter of a million or half a million is fairly arbitrary unless you're a statistical research design expert, right? (Group 1)

The possibility that the study would return only a select number of IRRs in order to reduce costs was presented. A few held steadfast to their belief that all results should be returned, citing issues of fairness and ownership of such personal information. Some questioned how researchers could determine which results were important, and thus advocated that all results should be returned.

> But how do you know which level is a high risk and which level is a low risk? That's why I think it's better to just see all the results, you know? (Group 6)

Many participants said that if the return of IRRs was limited, they would want to learn about "high-risk" results. People used the term "high-risk" to describe both the severity of the condition and the level of risk involved. A few others suggested that the study's priority should be the return of the IRRs that affect the greatest number of study participants.

DISCUSSION

When considering participating in a large, prospective study, the majority of focus group participants expressed a strong desire to receive their IRRs. This widespread interest, found among all 10 focus groups, supports other reports of a public desire for IRRs.[13–15,17–20,28,29] Although some individuals would be willing to participate without receiving any results, for many, receiving IRRs was both a major incentive to participate in the proposed study and a form of compensation for their time and effort. Furthermore, the opinions expressed in the focus groups did not appear to vary substantially by race, gender, socioeconomic status, geographic location, focus group format, or self-reported social-networking habits.

Three main reasons why people want IRRs consistently emerged in each group. The first was the potential utility of IRRs to improve health. Participants identified several possible positive health-related outcomes of returning IRRs that represented a broader definition of clinical utility than the one used by the biomedical community. In addition to helping treat or prevent disease, IRRs might encourage people to learn more about their health, change health-related behaviors, share the information with family members, and participate in other research studies. This broader set of utilitarian health outcomes

may be worth considering when deciding whether the return of IRRs is justified.

Second, participants noted that learning about IRRs could produce several benefits unrelated to health outcomes. These benefits may help to define the concept of the personal utility of IRRs. Receiving IRRs may give participants a sense of personal power or control, make them feel respected by and engaged in the study, and help them to plan for the future. Although our research is not intended to encourage more people to participate in longitudinal studies, our findings may have implications for researchers who are planning genetic research projects and are interested in recruiting and maintaining research populations.

Last, some participants believed that the study had an obligation to return genetic results as it was "the right thing to do." Some participants expressed that it would be unfair or wrong for researchers to know a person's IRRs without sharing them.

Participants were able to understand and discuss many of the nuances of IRRs. At the beginning of the focus group, most participants stated that they would like to receive all of their results. However, as participants discussed the different types of results, some reconsidered their earlier position on wanting IRRs. A few individuals did not change their opinion throughout the discussion and wanted all of their IRRs back, regardless of the limitations. Another small group remained adamantly opposed to the return of any IRRs, citing that returning IRRs was not the intent of the study and that the cost to do so could negatively affect the research. Participants were most likely to change the position that they wanted all of their results when asked to consider situations in which the certainty of the result was called into question. People were less interested in variants of unknown clinical significance, results that had not been confirmed in other studies, and results whose interpretation may change over time.

Some participants appear to expect uncertainty from research results, viewing it as part of the scientific process. Nevertheless, there may be an underlying expectation that any IRR returned would and should be well understood. The implication of these findings is that transparency on the part of researchers about what is and is not yet known about the IRRs is essential if they plan to return research results. The availability of treatment and the magnitude of risk seemed to have little effect on participants' interest in their IRRs. Most focus group members wanted to receive results regardless of whether a treatment was available or the result revealed a very small change in risk. Participants considered these results relevant to their health, highlighting the broader definition of clinical utility used by the public.

Some participants recognized the burden incurred by studies that return IRRs and believed it might be fair for the study to return a limited number of results or to ask research subjects to pay for some IRRs themselves. Many, however, viewed the return of IRRs as an essential element of the study design and said the study should sacrifice other design elements, such as study size, in order to return IRRs. With respect to how researchers should prioritize what to return, results that were viewed as "high-risk" were the most important, although there was no consensus on what conditions met those criteria. "High-risk" was used to describe both the level of the risk as well as the severity of the disorder. The willingness of some to accept a limited number of results and the recognition that some results would be less important than others may be useful to those planning large-cohort studies; our findings suggest that providing interested research participants with a limited number of IRRs may satisfy some participants' expectations and increase participation in research. Despite the broad interest in all types of information, the public (and those willing to take part in research) may accept emerging research guidelines emphasizing the return of a limited number of IRRs.[6,24,25] Researchers must be transparent about whether studies will return results, what will be returned, and how these decisions will be made.

Limitations

A major limitation of this research is that it is based on a large, National Institutes of Health–funded hypothetical scenario. Responses about what people would want in a hypothetical study should not be construed as definitive and may not correspond to actual future behaviors. For example, when predictive testing for Huntington disease was being developed, many at risk expressed interest in testing. When predictive Huntington disease testing became available, however, uptake was significantly lower than expected.[30] It is our hope that we have captured the range of opinions regarding potential research participants' interest in receiving individual genetic research results.

Another limitation of the study, and of focus group research in general, is that the opinions gathered cannot be quantified meaningfully or ranked in terms of importance. Additional quantitative research is warranted to measure the relative importance of opinions and preferences observed in this study.

Collecting opinions about participating in research from individuals who have agreed to take part in a research study may produce skewed results. In addition, because we provided a financial incentive, our participants may be biased toward incentive-based studies.

SUPPLEMENTARY MATERIAL

Supplementary material is linked to the online version of the paper at http://www.nature.com/gim

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DISCLOSURE

The authors declare no conflict of interest.

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