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Views of Cohort Study Participants about Returning Research Results in the context of Precision Medicine

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Abstract

Background—The practice of biorepository based genetics research raises questions related to what ethical obligations researchers have to their participants. It is important to explore and include the thoughts of current biorepository participants as we move forward with this type of research.

Methods—30 participants (17 cancer patients, 7 cancer-free controls, and 6 relatives) were drawn from the Northwest Cancer Genetics Registry and participated in qualitative interviews lasting between 45–90 minutes. Topics explored in this study include what types of genetic test results participants of large biorepositories expect and would like to receive from research analyzing their samples, and thoughts on best practice for conducting this type of research.

Results—Cancer cases, controls, and first degree relatives have differing views on what results they would like to receive from biorepository based research. Participants across all groups attempted to balance the costs and benefits of returning individual research results.

Discussion—In the wake of Precision Medicine, it is important to describe the range of ways participants in large biorepositories both think about and talk about the utilization of their specimens for genetic research.

Keywords

Biorepository; Genetics; Qualitative; Precision Medicine; Biobank; Cancer; Return of Results; Ethics

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INTRODUCTION

Collecting and storing tissue and genetic data in large repositories represents a powerful tool for researchers by allowing continued and repeated access to reliable sources of data [1]. Utilizing large data-bases of stored genetic information saves both time and resources, allowing for more rapid advancement of genetic research [2]. However, one issue that has not been resolved is what information to provide to participants regularly from these databases. Important and unaddressed considerations that researchers have for returning results to participants in research projects include: what results to return, when to return them, and best practice for how to return results [2]. Returning results is a key area of debate in genetics research. Some groups believe that research funds should not be allocated to returning results to participants [3,4,5], while others consider it a duty to return some or all results to participants if certain criteria are met, especially if these results could be used to inform medical care [6,7,8]. This problem is especially difficult to address because of the privacy issues related to participation in biorepositories, de-identification of samples, and informed consent [9], which are issues important to Institutional Review Boards (IRBs) [10].

Participants in studies also have ideas about return of results, and these must be considered when creating policy for returning results. Previous research has explored the opinions of members of the general public about return of results in several different contexts, including studies focusing on predominately African American members of the general public participating in focus groups [11], members of the general public participating in focus groups [12], an online survey of the general population [13], prospective biorepository candidates [14], and diverse members of the public in focus groups [15]. These studies of the opinions of people who had not previously participated in genetic research have tended to show similar results, including a strong interest in return of results, both because of a belief that such results could help participants improve their health and due to a sense of control that is provided. In contrast to the general public, study participants (those currently involved in research studies) may have different concerns, interests, and motivations, deriving either from their greater personal experience with research, increased personal investment in a particular health issue, or simply because people who volunteer to be part of research hold different opinions than the general public. However, there are fewer studies of research participants' views on return of results, especially those directly applicable to a large biorepository which includes genetics and other health measures and outcomes. The potentially informative nature of focusing on research participants is indicated, for example, by the study of parents whose children are enrolled in a genetic biorepository (focus groups) by Harris and colleagues [16]. This study revealed a strong motivation by parents for their children to be part of a biorepository precisely in an effort to gain information about their child's condition, so in this case, return of results was a particularly critical reason for enrolling. Similarly, among participants in a multicenter genetic epidemiologic study of adults, motivations for wanting to receive results related to melanoma risk focused on gaining information about their own and their children's risks of developing the disease [17]. These distinctive qualities of experienced research participants indicate the importance of further explorations and inclusion of the thoughts of current biorepository participants to

inform decisions about the use of their genetic information and the results that they receive from participation in future genetics research.

This qualitative study explores the ideas of participants in a large-scale cancer biorepository about use of their data for future genetics studies, what genetic test results they would like to receive, and how they want to receive them. Because previous studies of research participants had highlighted the possible variation in motivations, we compared the views of participants who had a previous diagnosis of cancer (cases), first degree relatives of cases, and cancer-free controls in order to explore any potential differences in preference for return of results. Research questions explored include: 1) What preferences do current biorepository participants have for return of genetic test results and how do these preferences differ between participants who are cancer “cases”, cancer-free “controls”, and first degree relatives of “cases”? 2) What views on the ethical obligations for researchers do current biorepository participants believe exist for biorepository based genetics research studies? These findings will be important in the context of Precision Medicine [18], where a large cohort of participants will be gathered, sampled, sequenced, and eventually have some results returned to them.

SETTING & METHODS

The source of participants for this study and methods for data collection were described previously [19]. Briefly, 30 participants were drawn from the Northwest Cancer Genetics Registry (NWCGR), which includes individuals with cancer (n=1796; about 51% of the registry), their relatives and controls. The majority of participants in the NWCGR with cancer had melanoma and skin cancer (43%), followed by thyroid (20%), prostate (9%), breast (8%) and pancreatic (1%) cancer, as well as a number of other less frequent cancer types. The majority of NWCGR participants self-reported as non-Hispanic white (89%), followed by, Asian (3%), Hispanic white (2%), and Black (1%), with the remaining 3% self-reported as American Indian, Pacific Islander or other.

Letters, including consent language and participation instructions, were mailed to eligible participants in 2011 and 2012 to invite them to participate in interviews assessing their opinions regarding consent issues for cancer genetics research. Participants were asked to call a toll-free line or email if they were interested in participating. A maximum of two follow-up letters were mailed at two-week intervals. Due to the predominance of non-Hispanic whites in the sample, minority participants were oversampled. 17 cases (skin, breast, prostate and colorectal cancer patients), 6 first-degree relatives and 7 cancer free controls participated in interviews for the study (Table 1). First-degree relatives and controls were included in the sample because their expectations and motivations for participating in research may differ from the cancer cases.

For this study we focused on the subset of interview questions that asked participants to consider: (1) whether research participants should receive results and in what ways; (2) what information would be of most interest; (3) whether results were desirable in three scenarios (a genetic risk factor had been discovered; an increased risk factor had been discovered; a genetic or risk factor had been discovered for something for which there was no treatment—

e.g., Alzheimer's); (4) whether the original researcher or all researchers were ethically obligated to return research results; (5) the costs of returning results to all participants; and (6) whether it was more important to maintain or sever the links between participants and their information in a data repository with a view to returning results or acquiring re-consent. Both interviewers were trained in standard interview techniques, and each interview lasted between 45 and 90 minutes. Study identification numbers were assigned to participants to protect confidentiality. Interviews were recorded, transcribed, and de-identified. Transcriptions were checked for accuracy by a non-interviewer before coding commenced.

Data was coded by MF and JG and analyzed using a content analytic approach as described in [19]. Minimal acceptable kappa was set at the moderate level of .80 because many of the answers have high levels of ambiguity; respondents offered very brief answers or tended to "think out" their answers, including perspectives on both sides. Individual kappa coefficients are reported in relationship to each coding category in Tables 2 and 3. Where inter-coder agreement was below .80, the disagreements were discussed, the code-book was reformulated, and coders recoded the entire set of answers independently.

RESULTS

An overall summary of results for the questions about return of results, including kappa scores (mean=.85) can be found in Table 2. In general, the majority of cases (n=13; 76.5%) and relatives (n=4; 66%) tended to affirm that researchers should provide research participants with a report about the progress of the research results, while more than half of controls were most likely to indicate that researchers had no obligation to return reports about the research (n=4; 57%). The majority of participants said that they would prefer it be an aggregate or lay-summary of the research results at the conclusion of the study rather than progress reports throughout. In general, cases were not in favor of having researchers provide reports on personal data, whereas both controls and relatives were evenly split on this topic.

> Participant 34284 (Female Case, Breast Cancer): Well, yeah, I think they should have the ability to have access to any published papers. You know, maybe they would go to a website or a journal or something. But I don't think the researchers would necessarily have to provide each person with results.

In contrast, some participants felt as though resources should be used to return results that may be useful to inform healthcare decisions or as a courtesy for having their sample utilized.

> Participant 4271 (Male Case, Prostate Cancer): I think it would be nice, is, not only having a study that is coming up with certain results, but if you could actually help people – you know, people who are willing to participate [or] volunteer.

When probed specifically about types of results, several participants contradicted themselves from earlier statements regarding beliefs about researchers providing personal reports, noting that they would like to receive certain types of results. This held especially true of results which were framed as hypothetically increasing the risk of developing a condition,

but where the results were not diagnostic, and also for results related specifically to an increased risk of cancer.

> Participant 79722 (Female Relative) on a result related to increased risk of cancer: Yes. *[laughs]* Which just directly contradicts what I said last time. But I guess where I'm coming from is to share it seems al most like reporting really important information. So yeah, I'm going to have to backup on that one, and say yes, I think you should share it.

Participants with a history of cancer were also more likely to indicate that they would like to receive results related to a predisposition for additional cancers or at least be given a choice as to whether they would like this type of result to be returned. Cancer-free controls did not feel as strongly that researchers had an obligation to return this type of result. The most noted reasons for wanting results related to a cancer predisposition were so that the participant could be aware of potential symptoms and ensure that they took necessary screening measures. Across all groups the most common reason for not wanting to receive results related to an increased risk of cancer is the possibility of undue worry or stress related of knowing such a result.

Most participants did not believe that researchers should return results for conditions that they could not do anything about or they felt as though receiving these results should be left up to the individual. Alzheimer's disease was used in these interviews as an example of this type of result. Various reasons were cited for not wanting to receive this type of result, most commonly, the emotional burden, concern, or worry of knowing that there is nothing you could do about it. Some participants mentioned the financial burden on the research project of returning this type of result, indicating that it would be wasted resources since there would be no medical benefit to returning these results. In contrast, participants who did want to know about these results felt that knowing could help themselves or their family for long term planning purposes such as insurance, estate, and major end-of-life decisions.

A summary of participants' views related to the mechanics of biorepository based genetics research including kappa scores (mean=.89), can be found in Table 3. The majority of participants felt as though the ethical obligations for return of results should apply not only to the original researchers but to everybody who uses their data from the repository and that these should be decided upon when consenting to the original sample collection.

When prompted that research funds were often limited and returning results to participants involved a significant cost, the majority of participants in all 3 groups--cases (53%), controls (57%), and relatives (83%)--felt that the priority should be in conducting the research rather than returning the results to participants.

> Participant 54361 (Male Control): You're doing it for the research. Anything that you can do that is-- other than that, you know, hurray for that, but that's not the purpose.

Most participants felt as though the link between their personally identifiable information and the data contained in a biorepository should be maintained. The main reasons noted for this were to potentially return critical health information and also in case researchers had to

collect important information to advance the project. Conversely, participants who did indicate that they would prefer severing the link between their personally identifiable information and the biorepository cited privacy concerns.

> Participant 13537 (Female Case, Skin Cancer): I think maintaining the link to get re-consent [and] to being able to direct the results if it would benefit the person I guess from the get-go you should let the person know that's the way it would be. And if they choose privacy, they would also know that then they would no longer be able to get results.

Discussion

Several differences were observed between preferences in return of results between the three groups of participants. Controls were more likely to indicate that research results did not need to be provided to participants of biorepository based research studies, when compared to first-degree relatives and cases. This could be because of differences in the motivation for participating in this type of research. However, in all three groups, participants mentioned that they would value receiving a report of the progress of the research at the end of the study in the form of a summary that they could understand and identify with. There are several advantages to providing aggregate reports or lay-summaries of research including building trust with participants, the possibility to educate them about the research process and potentially include them in future studies, and affirming the participants' own personal contribution to the research [20]. This must be considered in the context of the resources available for the study, but potential benefits to both participant and researcher exist and are recommended as good research practice [20].

There is an inconsistency within some participants framing of the return of individual results. While some participants generally expressed that funding priorities should lie in conducting the research rather than returning the results, they also expressed desire to receive certain types of results. All three groups tended to agree that the priorities of the project should be in the conducting of the research rather than return of results. This being the case, participants in all three groups desired some types of results, should the resources be available to return them. This indicates that they value receiving these results but do not consider it the highest priority of researchers. As has been previously observed, merely returning results to participants without providing the resources and support necessary to understand and utilize this information can be a potential harm to the participants [21]. Previous studies have shown that negative affective impact of receiving even high impact genetic test results are rare in participants who choose to participate in genetics research projects if counseling about the health implications of results is provided through the research project [22]. Returning results should be considered when developing a research project, as providing adequate funding for staff time and other resources for this activity can be costly [23].

Another difference between groups was that after probing for specific types of results, cases seemed to be more likely than controls to indicate that they would be amenable to receiving results related to increased risk of developing an unspecified condition and also results

related to an increased risk of cancer. This was not, however, true for results related to conditions where there were no treatment options available. This indicates that individuals with a previous cancer diagnosis seem more aware of the potential benefits of knowing genetic test results so that they could remain aware about warning signs and symptoms, and could be vigilant about any screening opportunities. Several interviewees mention that they value personal choice in receiving results, indicating that they understood that not all participants in biorepositories have the same views about receiving information from genetics research studies and that some free choice in the return of results is valued.

As a whole, participants tended to come to the conclusion that the link between researchers and the personally identifiable information (PII) of participants should be maintained. Several participants had difficulty answering this question while some were unable to come to a conclusion at all. This may indicate that participants' concerns for anonymity may not be as great as is often assumed in the context of biorepository based research. Again, participants seemed to balance the desire to be able to have access to the results from the study with the fiscal and mechanistic limitations of the project to begin with. This being the case, studies have highlighted the importance of maintaining privacy and protection of PII to potential participants of biorepository based research [24,25]. Again, as a whole, participants believed that ethical obligations for return of results should apply to all researchers, even outside of the original research group for future studies using their samples. The desire for return of results obligations that apply to all researchers, rather than just the original, calls for consent forms that are comprehensive and address potential future contact. This is a complex issue as the more comprehensive a consent form is, the longer and more burdensome the consent process will be which can be confusing and frustrating for participants [26]. Some work has been completed [10] on how to shorten consent forms while maintaining a comprehensive amount of information to ensure both ease and also protection for potential biorepository participants.

There are several limitations of this project. A small sample size and the qualitative nature of the interviews limit our ability to evaluate statistical significance in any of the observed differences between groups. The goal of this project was to describe the range of opinions on these issues which we will later be able to test quantitatively. The methods utilized in this analysis also allowed participants to freely express their ideas on topics including weighing pros and cons to statements. While this allowed for an enriched array of ideas to come forth throughout the interviews, it also presented challenges in making general statements about these topics without collapsing some response categories for analysis. Finally, we chose to classify participants based on their cancer status at enrollment to the registry as this may have influenced their initial decision to enroll. However, in the interim, some "controls" in this biorepository may have developed cancer, and some cases and relatives developed additional cancers. Although this may modify responses to the questions it would be likely to make the groups more similar in their thinking. Despite this, there still appears to be differences between the groups.

The results of this study highlight a variety of opinions participants have about return of results and indicate that in general they are open to receiving feedback from researchers about how their data is being used. The range of ideas across this sample about return of

results in this population are intriguing and point to potential differences in motivation for participating in this type of research. It appears that participants' desire to receive results can serve as an indicator both that this research is valued, and that they may consider themselves meaningful and ongoing stakeholders in the process. These results will direct future studies with this population using both mixed methods and quantitative survey data, which will allow for statistical testing to be conducted. Hypotheses pertaining to differences between groups of individuals in motivation for participating in biorepository based genetics research, what results participants want returned, and how to best share this information with different groups of people will be explored.

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Table 1

Demographic Summary of Interview Participants

	Gender		Age (mean)	Breast	Prostate	Colorectal	Skin
	M	F					
Cases n=17 *	**5**	**12**	**71.5**	**6**	**3**	**6**	**6**
Controls n=7	**4**	**3**	**69.7**	**0**	**0**	**0**	**0**
Relatives n=6	**3**	**3**	**58.5**	**0**	**0**	**0**	**1**
Total n=30	**12**	**18**	**68.5**	**6**	**3**	**6**	**7**

* Some cases had more than one type of cancer

Table 2

Questions related to preference for return of results

Question	Response Categories	Cases n=17	Controls n=7	Relatives n=6	Total n=30	Kappa
Should participants receive reports of findings from research data?	Yes	13 (76.5%)	2 (28.5%)	4 (66%)	19 (63.3%)	.82
	If they want	2 (11.7%)	1 (14%)	1 (16.6%)	4 (13.3%)	
	Undecided	2 (11.7%)	0	0	2 (6.6%)	
	No	0	4 (57%)	1 (16.6%)	5 (16.6%)	
Should participants receive information on personal findings from data?	Generally good idea	5 (29.4%)	3 (42.8%)	2 (33%)	10 (33.3%)	.83
	Generally bad idea	10 (58.5%)	3 (42.8%)	2 (33%)	15 (50%)	
Should participants receive a personal report on cancer predisposition	Yes (unqualified and qualified)	7 (41%)	2 (28.5%)	2 (33.3%)	11 (36.6%)	.91
	Given to doc. To decide	1 (5.8%)	1 (14.2%)	0	2 (6.6%)	
	Patients Choice	5 (29.4%)	1 (14.2%)	3 (50%)	9 (30%)	
	Not mandatory but okay	0	1 (14.2%)	0	1 (3.3%)	
	No	1 (5.8%)	2 (28.5%)	1 (16.6%)	4 (13.3%)	
Should Participants receive personal information about increased risk?	Yes if useful for healthcare	13 (76.5%)	4 (57%)	3 (50%)	20 (66.6%)	.83
	Preferences assessed before study	1 (5.8%)	0	1 (16.6%)	2 (6.6%)	
	No	1 (5.8%)	3 (42.8%)	1 (16.6%)	5 (16.6%)	
What if findings were something you couldn't do anything about? Ex Alzheimer's disease	Yes	4 (23.5%)	1 (14.2%)	2 (33.3%)	7 (23.3%)	.87
	Participants choice	2 (11.7%)	1 (14.2%)	2 (33.3%)	5 (16.6%)	
	No	8 (47%)	3 (42.8%)	1 (16.6%)	12 (40%)	
	Notify doctor not participant	2 (11.7%)	0	0	2 (6.6%)	

Table 3

Questions related to mechanism of biorepository research

Question	Response Categories	Cases n=17	Controls n=7	Relatives n=6	Total n=30	Kappa
Priorities: conducting the research or return of results?	Research is priority (unqualified and qualified)	9 (52.9%)	4 (57%)	5 (83.3%)	18 (60%)	.86
	RoR is important enough to justify cost	4 (23.5%)	2 (28.5%)	1 (16.6%)	7 (23.3%)	
	Depends on the case and situation	4 (23.5%)	1 (14.2%)	0	5 (16.6%)	
Maintain or sever link to personally identifiable information?	Link should be Severed	1 (5.8%)	1 (14.2%)	2 (33.3%)	4 (13.3%)	.87
	Link should be maintained	10 (58.5%)	5 (71.4%)	2 (33.3%)	17 (56.6%)	
	Participant decides	1 (5.8%)	1 (14.2%)	2 (33.3%)	4 (13.3%)	
	Unsure	4 (23.5%)	0	0	4 (13.3%)	
Do ethical (ROR) obligations only apply to original researcher or all others using biobank?	Only to original	2 (11.7%)	1 (14.2%)	3 (50%)	6 (20%)	.94
	Original except in life threatening situations	1 (5.8%)	0	0	1 (3.3%)	
	To all researchers	12 (70.5%)	4 (57%)	3 (50%)	19 (63.3%)	