Collection: LOGIN
Contains: CUSTOMID

Question: CUSTOMID
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The Researcher's Perspective on Disclosing Individual Genetic Results to Research Participants

Web Survey

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INFORMATION SHEET

The Researcher's Perspective on Disclosing Individual Genetic Results to Research Participants

What is this study about?

We are conducting an online survey about the practices and views of genomic investigators regarding the return of individual genetic results to research participants. There has been considerable discussion of this topic among policymakers and ethicists. We feel that it is essential that investigators conducting this type of research also have a voice in this discussion.

Who are the collaborators?

We are a group of investigators at Harvard Medical School (Dr. Rachel Ramoni), the Dana-Farber Cancer Institute (Dr. Steven Joffe), and Baylor College of Medicine (Dr. Amy McGuire).

How was I selected?

You were selected because of your role as a corresponding author on a recent GWAS study. Regardless of whether or not research results were returned in the context of your study, we are interested in your opinions. Due to the current lack of research on investigators' views, we are interested in exploring the wide range of opinions that different investigators conducting genomic research may have on the issue of returning genetic results to participants.

What do I have to do?

We are asking you to complete an online survey, which should take about 10 minutes to complete.

Your participation is voluntary; completing the survey will serve as your consent to participate. You may refuse to participate at any time without penalty or loss of benefits to which you are otherwise entitled. You may skip any questions that you do not want to answer.

As a token of our appreciation for your participation, upon completion of the survey you will be entered into a drawing for a new Apple iPad!

What else do I have to do?

As part of the online survey, we will ask if you are willing to send us a copy of the consent document for your study. We still hope you will complete the survey even if you are unable or prefer not to provide the consent document.

We would like to compare how different studies discuss the return of results in their consent documents. All identifiers (including investigator names and institutions) will be removed from the consent document prior to analysis and replaced with a unique subject ID number. The list of ID numbers, investigator names, and institutions will be secured and confidentiality will be maintained. An email address link, as well as other ways to submit the consent document, will be provided at the end of the survey.

What about confidentiality?

Your responses will remain completely confidential. Your privacy is important to us; although your information is linked to the survey via the

published study indicated above, we will use a secure system to ensure that the link is used for tracking purposes only. Additionally, your answers will be combined with answers from all other respondents, so that no specific information about you or the listed study will ever be reported.

What are the risk and benefits of participating in this study?

There are no known risks to participating in this study and there are no direct benefits. We hope, however, that the results will help guide future policies for the return of genetic research results to individual research participants.

Whom do I contact if I have questions about this survey?

If you have any questions about the administration of the survey, please contact Dr. Rachel Ramoni, Instructor, Harvard Medical School at *rachel_ramoni@hsdm.harvard.edu* . If you have any questions about your rights as a research participant, or to report problems, concerns, or complaints, please contact the Dana-Farber Cancer Institute Office for Human Research Studies at 617-632-3029.

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Dana-Farber Cancer Institute
Center for Population Sciences
Questions or comments? E-mail us at ps_survey@dfci.harvard.edu

Whether and under what circumstances researchers should return individual genetic results to research participants is an area of active discussion in the research and bioethics communities. The scope of the issue is particularly broad in the context of genome-wide association studies (GWAS). We believe that the practices and views of GWAS researchers concerning the return of individual genetic results to participants must be documented and taken into account.

We are inviting you to participate in this survey because of your role as a corresponding author on a recent GWAS study: et al, . . **We are interested in your opinion regardless of whether you think returning results is a good idea or a bad idea.** Your responses will be kept confidential.

As a thank you for completing the survey, you will be entered into a drawing for a new Apple iPad.

Please proceed through the survey using the Next Screen button.

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Before we get to questions about the return of genetic results, we would first like to ask some general questions about you.

Question: A1

How old are you?

_____ years

Question: A2

Scale Summary		
Code	Label	Show-If
1	Female	
2	Male	

What is your gender?

- ○ Female
- ○ Male

Question: A3

What category best describes your race? *You may select more than one.*

- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Native Hawaiian or other Pacific Islander
- ☐ Black or African American
- ☐ White
- ☐ Other (specify): _____

Question: A4

Scale Summary		
Code	Label	Show-If
1	Yes, Hispanic or Latino/a	
0	No, not Hispanic or Latino/a	

Are you Hispanic or Latino/a?

- ○ Yes, Hispanic or Latino/a
- ○ No, not Hispanic or Latino/a

Question: A5

Scale Summary		
Code	Label	Show-If

1	Yes	
0	No	

Have you ever served on an institutional review board or equivalent?

- Yes
- No

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Question: A6

Scale Summary		
Code	Label	Show-If
1	Yes	
0	No	

Have you ever been involved in a study in which you interacted **directly** with the research participants?

- Yes
- No

Question: A7

Scale Summary		
Code	Label	Show-If
1	University or academic medical center	
2	Pharmaceutical or biotechnology	
3	Government	
4	Other (specify):	

Which of the following best describes the setting in which you work?

- University or academic medical center
- Pharmaceutical or biotechnology
- Government
- Other (specify):

Page Break

Question: A8
Show if: (A7 = 1:[University or academic medical center])

Scale Summary		
Code	Label	Show-If
1	Full Professor or equivalent	
2	Associate Professor or equivalent	
3	Assistant Professor or equivalent	
4	Other (specify):	

What is your academic rank?

- ○ Full Professor or equivalent
- ○ Associate Professor or equivalent
- ○ Assistant Professor or equivalent
- ○ Other (specify): _____

Question: A9

What degrees do you hold? *Please select all that apply.*

- ☐ M.D. or equivalent
- ☐ Ph.D. or equivalent
- ☐ M.P.H. or equivalent
- ☐ R.N. or equivalent
- ☐ Other (specify): _____

Question: A10

Scale Summary		
Code	Label	Show-If
1	United States	
2	Canada	
3	Europe	
4	Asia	
5	Other (specify):	

Where do you work?

- ○ United States
- ○ Canada
- ○ Europe
- ○ Asia
- ○ Other (specify): _____

Page Break

In the following questions, we will ask about the role you served on the study:

et al, . .

Question: A11

Considering only the study cited above, which of the following best describes **your** role on the project? *Please select all that apply.*

- ☐ Overall study design
- ☐ Participant recruitment or consent
- ☐ Laboratory analysis
- ☐ Collection of phenotypic information
- ☐ Bioinformatics/statistical analysis
- ☐ Other (specify): _____

Question: A12

Scale Summary

Code	Label	Show-If
1	My team was responsible for primary specimen or data collection, such as recruiting participants, performing the informed consent procedure, collecting specimens, etc.	
2	My team performed secondary analyses using specimens or data collected by another group.	

Considering only the study cited above, which of the following best describes the role you and your team played? *Although your team's role may have been different in other studies, please restrict your response to the role your team played in the study cited above.*

- ○ My team was responsible for primary specimen or data collection, such as recruiting participants, performing the informed consent procedure, collecting specimens, etc.
- ○ My team performed secondary analyses using specimens or data collected by another group.

Page Break

Jump-To: JMP1
Description:
Jump-To-Item: SECTION_C
Jump-If: (A12 = 1:[My team was responsible for primary specimen or data collection, such as recruiting participants, performing the informed consent procedure, collecting specimens, etc.])

Page Break

et al, . .

In the following set of questions, we will ask you about the practices that you followed in the study cited above. Although you may have been involved in other studies, please base your responses on this study only.

Throughout this section we refer to "individual genetic results" and "aggregate genetic results." By "individual genetic results," we mean genetic test results that pertain to a specific research participant. By "aggregate genetic results," we mean the overall results of the study which relate to participants in the study as a group rather than to individual participants.

Question: B1

Scale Summary

Code	Label	Show-If
1	My team obtained the data or specimens directly from the team responsible for primary data collection.	
2	My team obtained the data or specimens from a publicly accessible repository (such as dbGAP). *Please enter name of repository on next screen.*	
3	Other (please describe):	

How did your team obtain the data or specimens for the study cited above?

- ○ My team obtained the data or specimens directly from the team responsible for primary data collection.
- ○ My team obtained the data or specimens from a publicly accessible repository (such as dbGAP). *Please enter name of repository on next screen.*
- ○ Other (please describe): _____

Page Break

Question: B1A
Show if: (B1 = 2:[My team obtained the data or specimens from a publicly accessible repository (such as dbGAP). Please enter name of repository on next screen.])

Please specify from which repository you obtained the data or specimens.

Page Break

Question: B2

Scale Summary		
Code	Label	Show-If
1	Yes	
0	No	
2	Unsure	

et al, . .

You reported that you performed secondary analyses. Did a representative of your research team sign a data use agreement with the original collectors or data/specimen repository for the study cited above?

- Yes
- No
- Unsure

Page Break

Question: B3
Show if: (B2 = 1:[Yes])

Scale Summary		
Code	Label	Show-If
1	Yes	
0	No	
2	Unsure	

Did the data use agreement that you signed forbid your team from attempting to re-identify study participants?

- Yes
- No
- Unsure

Page Break

Jump-To: JMP2
Description:
Jump-To-Item: D1
Jump-If: (B3 = 1:[Yes])

Question: B4

Scale Summary

Code	Label	Show-If
1	The data or specimens were directly labeled with individual identifiers, such as name, date of birth, etc.	
2	The data or specimens were linked to identifiers using a code. The key linking the codes to the individual participants' identities was kept separate from the data.	
3	There was no identifier or code that allowed data or specimens to be linked back to an individual participant's identity.	
4	Other (please describe):	
5	Unsure	

et al, . .

In the study cited above, what method, if any, was used to link the data or specimens you analyzed back to individual identifiers?

- ○ The data or specimens were directly labeled with individual identifiers, such as name, date of birth, etc.
- ○ The data or specimens were linked to identifiers using a code. The key linking the codes to the individual participants' identities was kept separate from the data.
- ○ There was no identifier or code that allowed data or specimens to be linked back to an individual participant's identity.
- ○ Other (please describe): _____
- ○ Unsure

Page Break

Jump-To: JMP3
Description:
Jump-To-Item: D1
Jump-If: (B4 = 3:[There was no identifier or code that allowed data or specimens to be linked back to an individual participant's identity.])

Question: B5
Show if: (B4 is-any-of 1:[The data or specimens were directly labeled with individual identifiers, such as name, date of birth, etc.] or 2:[The data or specimens were linked to identifiers using a code. The key linking the codes to the individual participants' identities was kept separate from the data.] or 4:[Other (please describe):] or 5:[Unsure])

Scale Summary		
Code	Label	Show-If
1	Yes	
0	No	
2	Unsure	

et al, . .

In the study cited above, has your team returned any individual genetic test results to one or more research participants or their proxies?

- Yes
- No
- Unsure

Page Break

Question: B6
Show if: (B5 = 2:[Unsure]) or (B5 = 0:[No])

Scale Summary

Code	Label	Show-If
1	Yes, my team has plans to offer to return individual genetic results to research participants. (*Please select this response even if you plan to return results through the primary sample collectors.)*	
0	No, my team does not have plans to offer to return individual genetic results to research participants.	
2	Unsure	

et al, . .

Considering only the study cited above, does your team have plans to offer to return individual genetic results to any research participants or their proxies?

- ○ Yes, my team has plans to offer to return individual genetic results to research participants. (*Please select this response even if you plan to return results through the primary sample collectors.)*
- ○ No, my team does not have plans to offer to return individual genetic results to research participants.
- ○ Unsure

Question: B7
Show if: (B5 = 1:[Yes])

et al, . .

How were individual genetic results returned to research participants or their proxies in the study cited above? *Please select all that apply.*

- ☐ Through the investigator who collected the sample
- ☐ Through a research ethics board or data access committee
- ☐ Directly to the research participants or proxies
- ☐ Through the participant's physician
- ☐ Other (specify): _____
- ☐ Unsure

Page Break

Question: B8
Show if: (B7 is-any-of [Directly to the research participants or proxies])

et al, . .

How were these results communicated to the research participant or their proxy in the study cited above? *Please select all that apply.*

- ☐ Over the telephone
- ☐ In person, via a genetic counselor
- ☐ In person, by study investigators or staff
- ☐ Other (specify):
- ☐ Unsure

Question: B9
Show if: (B6 = 1:[Yes, my team has plans to offer to return individual genetic results to research participants. (Please select this response even if you plan to return results through the primary sample collectors.)])

et al, . .

How does your team plan to return individual genetic results in the study cited above? *Please select all that apply.*

- ☐ Through the investigator who collected the sample
- ☐ Through a research ethics board or a data access committee
- ☐ Directly to the research participant(s) or proxies
- ☐ Through the research participant's physician
- ☐ Other (specify):
- ☐ Unsure

Page Break

Question: B10
Show if: (B9 is-any-of [Directly to the research participant(s) or proxies])

et al, . .

How does your team plan to communicate those results to the research participant or their proxy from the study cited above? *Please select all that apply.*

- [ ] Over the telephone
- [ ] In person, via a genetic counselor
- [ ] In person, by study investigators or staff
- [ ] Other (specify):
- [ ] Unsure

Page Break

Collection: SECTION_C
Contains: C1, C2, C3, C4, C5, C6, C7
Show if: (A12 = 1:[My team was responsible for primary specimen or data collection, such as recruiting participants, performing the informed consent procedure, collecting specimens, etc.])

et al, . .

In the following set of questions, we will ask you about the practices that you followed in the study cited above. Although you may have been involved in other studies, please base your responses on this study only.

Throughout this section we refer to "individual genetic results" and "aggregate genetic results." By "individual genetic results," we mean genetic test results that pertain to a specific research participant. By "aggregate genetic results," we mean the overall results of the study which relate to participants in the study as a group rather than to individual participants.

Question: C1

Scale Summary

Code	Label	Show-If
1	The data or specimens were directly labeled with individual identifiers, such as, name date of birth, etc.	
2	The data or specimens were linked to identifiers using a code. The key linking the codes to the individual participants' identities was kept separate from the data.	
3	There was no identifier or code that allowed data or specimens to be linked back to an individual participant's identity.	
4	Other (please describe):	
5	Unsure	

What method, if any, was used to link the data or specimens you analyzed back to individual identifiers?

- ○ The data or specimens were directly labeled with individual identifiers, such as, name date of birth, etc.
- ○ The data or specimens were linked to identifiers using a code. The key linking the codes to the individual participants' identities was kept separate from the data.
- ○ There was no identifier or code that allowed data or specimens to be linked back to an individual participant's identity.
- ○ Other (please describe): _____
- ○ Unsure

Page Break

Question: C2
Show if: (C1 is-any-of 1:[The data or specimens were directly labeled with individual identifiers, such as, name date of birth, etc.] or 2:[The data or specimens were linked to identifiers using a code. The key linking the codes to the individual participants' identities was kept separate from the data.] or 4:[Other (please describe):] or 5:[Unsure])

Scale Summary		
Code	Label	Show-If
1	Yes	
0	No	
2	Unsure	

et al, . .

In the study cited above, has your team returned any individual genetic test results to one or more research participants or their proxies?

- Yes
- No
- Unsure

Page Break

Question: C3
Show if: (C2 = 0:[No]) or (C2 = 2:[Unsure])

Scale Summary		
Code	Label	Show-If
1	Yes, my team has plans to offer to return individual genetic results to research participants.	
0	No, my team does not have plans to offer to return individual genetic results to research participants.	
2	Unsure	

 et al, . .

Considering only the study cited above, does your team have plans to offer to return individual genetic results to research participants or their proxies?

- ○ Yes, my team has plans to offer to return individual genetic results to research participants.
- ○ No, my team does not have plans to offer to return individual genetic results to research participants.
- ○ Unsure

Question: C4
Show if: (C2 = 1:[Yes])

 et al, . .

How were individual genetic results returned to research participants or their proxies in the study cited above? *Please select all that apply.*

- ☐ Through a research ethics board or data access committee
- ☐ Directly to the research participant(s) or proxies
- ☐ Through the participant's physician
- ☐ Other (please specify): _____
- ☐ Unsure

Page Break

Question: C5
Show if: (C4 is-any-of [Directly to the research participant(s) or proxies])

et al, . .

How were these results communicated to the research participant or their proxy in the study cited above? *Please select all that apply.*

- [ ] Over the telephone
- [ ] In person, via a genetic counselor
- [ ] In person, by study investigators or staff
- [ ] Other
- [ ] Unsure

Question: C6
Show if: (C3 = 1:[Yes, my team has plans to offer to return individual genetic results to research participants.])

et al, . .

How does your team plan to return individual genetic results in the study cited above? *Please select all that apply.*

- [ ] Through a research ethics board or a data access committee
- [ ] Directly to the research participant(s) or proxies
- [ ] Through the research participant's physician
- [ ] Other (please specify):
- [ ] Unsure

Page Break

Question: C7
Show if: (C6 is-any-of [Directly to the research participant(s) or proxies])

et al, . .

How does your team plan to communicate these results to the research participant or their proxy in the study cited above? *Please select all that apply.*

- [ ] Over the telephone
- [ ] In person, via a genetic counselor
- [ ] In person, by study investigators or staff
- [ ] Other
- [ ] Unsure

Page Break

Question: D1

Scale Summary		
Code	Label	Show-If
1	Yes	
0	No	
2	Unsure	

et al, . .

Is there a process for clinical certification or accreditation of laboratories (such as CLIA certification) in the country in which the genotyping for the study cited above was performed?

- Yes
- No
- Unsure

Page Break

Question: D2
Show if: (D1 = 1:[Yes])

Scale Summary		
Code	Label	Show-If
1	Yes	
0	No	
2	Unsure	

et al, . .

Was all of the genotyping for the study cited above performed at a clinically certified or accredited laboratory?

- Yes
- No
- Unsure

Question: D3

Scale Summary		
Code	Label	Show-If
1	Yes, aggregate genetic results have been returned to research participants.	
2	No, aggregate genetic results have not been returned to research participants.	
3	Unsure	

et al, . .

Have **aggregate** genetic results been returned to research participants or their proxies in the study cited above? As a reminder, by "aggregate genetic results," we mean the *overall* results of the study which relate to participants in the study as a group, rather then to individual participants.

- Yes, aggregate genetic results have been returned to research participants.
- No, aggregate genetic results have not been returned to research participants.
- Unsure

Page Break

Question: D4
Show if: (D3 = 2:[No, aggregate genetic results have not been returned to research participants.]) or (D3 = 3:[Unsure])

Scale Summary

Code	Label	Show-If
1	Yes, my team has plans to offer to return aggregate genetic results to research participants.	
2	No, my team does not have plans to offer to return aggregate genetic results to research participants.	
3	Unsure	

et al, . .

Does your team have plans to offer to return **aggregate** genetic results to research participants or their proxies in the study cited above?

- ○ Yes, my team has plans to offer to return aggregate genetic results to research participants.
- ○ No, my team does not have plans to offer to return aggregate genetic results to research participants.
- ○ Unsure

Question: D5
Show if: (D3 = 1:[Yes, aggregate genetic results have been returned to research participants.])

et al, . .

How did you communicate these **aggregate** results to the research participants or their proxies in the study cited above? *Please select all that apply.*

- ☐ Through a study newsletter
- ☐ Online study updates
- ☐ Individual letter or email
- ☐ Other (specify): _____

Page Break

Question: D6
Show if: (D4 = 1:[Yes, my team has plans to offer to return aggregate genetic results to research participants.])

et al, . .

How do you plan to communicate these aggregate results to the research participants or their proxies in the study cited above? *Please select all that apply.*

- [ ] Through a study newsletter
- [ ] Online study updates
- [ ] Individual letter or email
- [ ] Other (specify): _____

Page Break

In these next questions, we want to learn what you think about the return of individual genetic results to research participants. We are asking you about your general opinions, rather than about your views regarding a particular study. There are no right or wrong answers to these questions.

Question: D7

Scale Summary

Code	Label	Show-If
1	Individual genetic results should generally **not** be offered to research participants.	
2	Individual genetic results should be offered to research participants in **some circumstances**.	
3	Individual genetic results should be offered to research participants in **most circumstances**.	
4	Individual genetic results should be offered to research participants in **all circumstances**.	
5	Other (specify):	

Please indicate which of the following statements, if any, most closely represents your view on the return of individual genetic results to research participants.

- ○ Individual genetic results should generally **not** be offered to research participants.
- ○ Individual genetic results should be offered to research participants in **some circumstances**.
- ○ Individual genetic results should be offered to research participants in **most circumstances**.
- ○ Individual genetic results should be offered to research participants in **all circumstances**.
- ○ Other (specify): _____

Page Break

Question: D8
Show if: (D7 > 1:[Individual genetic results should generally not be offered to research participants.])

Scale Summary

Code	Label	Show-If
1	Individual genetic results should generally be returned directly to participants or their proxies.	
2	Individual genetic results should generally be returned to participants through their physicians.	
3	Individual genetic results should sometimes be returned to participants or their proxies and sometimes should be returned to participants through their physicians.	
4	Other (specify):	

How should the individual genetic results be returned to research participants?

- ○ Individual genetic results should generally be returned directly to participants or their proxies.
- ○ Individual genetic results should generally be returned to participants through their physicians.
- ○ Individual genetic results should sometimes be returned to participants or their proxies and sometimes should be returned to participants through their physicians.
- ○ Other (specify): _____

Page Break

In this last set of questions, we will ask you about what factors would make you more or less likely to disclose individual genetic results to research participants. We are asking you about your general opinions, rather than your views regarding a particular study.

Question Block: E1
Contains: E1A, E1B, E1C, E1D, E1E, E1F, E1G, E1H, E1I, E1J, E1K, E1L, E1M, E1N, E1O, E1P

Scale Summary		
Code	Label	Show-If
1	Not a barrier at all	
2	A minor barrier	
3	A major barrier	

In general, how much of a **barrier** is each of the following to the return of individual genetic results?
In this question, we are asking you about your general opinions, rather than your views regarding a particular study.

	Not a barrier at all	A minor barrier	A major barrier
a. The financial cost of returning results.	○	○	○
b. The time commitment required to return results.	○	○	○
c. The need to keep participants', proxies', or physicians' contact information current.	○	○	○
d. The need to use a lab that is clinically certified (such as CLIA certified).	○	○	○
e. The need to keep up to date with relevant genetic associations.	○	○	○
f. The need to ensure access to a genetic counselor or other appropriately trained clinician.	○	○	○
g. The potential for loss of a participant's confidentiality.	○	○	○
h. The possibility that the participant will experience discrimination in areas such as employment or health insurance.	○	○	○

i. The possibility that the genotyping may not be accurate.			
j. The possibility that the genotype-phenotype association may not be valid.			
k. The uncertain clinical utility of genetic research results.			
l. The possibility that participants will misunderstand the information that they are given.			
m. The potential for causing emotional harm to participants.			
n. The potential to blur the boundary between research and clinical care.			
o. Concern over legal liability for adverse outcomes that might occur as a result of return of results.			
p. Concern about the adequacy of clinical follow-up.			

Question: E2

Are there any other important barriers to returning individual results to participants that we have not listed above? *Please write in here:*

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Question Block: E3
Contains: E3A, E3B, E3C, E3D, E3E

Scale Summary		
Code	Label	Show-If
1	Not a motivation at all	
2	A minor motivation	
3	A major motivation	

In general, how much of a **motivation** is each of the following for returning individual genetic results to research participants?
In this question, we are asking you about your general opinions, rather than your views regarding a particular study.

	Not a motivation at all	A minor motivation	A major motivation
a. Desire to benefit participants' health.	○	○	○
b. Respect for participants' desires to have information about themselves.	○	○	○
c. A belief that participants have a right to their data.	○	○	○
d. Concern over legal liability if individual results are **not** disclosed.	○	○	○
e. Gratitude to participants for taking part in the study.	○	○	○

Question: E4

Are there any other important motivations for returning individual results to participants that we have not listed above? *Please write in here:*

Page Break

Question Block: E5
Contains: E5A, E5B, E5C, E5D, E5E, E5F, E5G, E5H

Scale Summary		
Code	Label	Show-If
1	Greatly decrease willingness	
2	Somewhat decrease willingness	
3	No effect on willingness	
4	Somewhat increase willingness	
5	Greatly increase willingness	

What effect, if any, would each of the following characteristics of a genetic test have on your willingness to return individual research results to research participants?

	Greatly decrease willingness	Somewhat decrease willingness	No effect on willingness	Somewhat increase willingness	Greatly increase willingness
a. The test has established analytic validity (i.e., the test accurately measures whether the genetic variant is present or absent).	○	○	○	○	○
b. The relative risk of the phenotype associated with the genetic test result is high (i.e., >2).	○	○	○	○	○
c. The phenotype associated with the genetic test result has important health implications, such as premature death or substantial morbidity.	○	○	○	○	○
d. Proven preventive or therapeutic interventions are available that can improve the health of research participants who carry the	○	○	○	○	○

genetic variant.					
e. The results have reproductive implications for the participant.	○	○	○	○	○
f. The results relate to a phenotype that the participant is already known to have.	○	○	○	○	○
g. The genetic test was **not** performed in a clinically certified (e.g., CLIA) laboratory.	○	○	○	○	○
h. The participant specifically asks for his or her genetic test results.	○	○	○	○	○

Page Break

Question: E6

Scale Summary		
Code	Label	Show-If
1	Yes, you may contact me at:	
0	No, please do not contact me	

May we contact you to participate in a short follow-up telephone interview? The interview will help us better understand your practices and opinions on the return of individual genetic research results.

We are interested in interviewing you regardless of whether or not you have returned or plan to return individual genetic results and regardless of whether or not you think individual genetic results should be returned.

The interview will last approximately 30-45 minutes. To thank you for your time and effort you will receive a $50 Amazon.com gift certificate.

- ○ Yes, you may contact me at: _____
- ○ No, please do not contact me

Page Break

Question: E7

Scale Summary		
Code	Label	Show-If
1	Yes, I have access to the study consent document. Click NEXT SCREEN for email link to Jill Oliver.	
2	Yes, I have access to the study consent document and will either fax it to Jill Oliver at 713-798-5678 or mail to Jill Oliver, M.A., Research Coordinator, Center for Medical Ethics and Health Policy, Baylor College of Medicine, One Baylor Plaza, Suite 310D, Houston, TX 77030	
3	No, I do not have access to the study consent document. Click NEXT SCREEN to give more information.	
4	No, I have access to the study consent document but do not wish to share it.	

Would you be willing to send us a copy of the consent document for the study: et al, . .

We would like to compare how different studies discuss the return of genetic results in their consent documents.

If so, please email the consent document to Jill Oliver, M.A., Center for Medical Ethics and Health Policy, Baylor College of Medicine, at jmoliver@bcm.edu. You may also fax or mail the document to Jill Oliver (information provided below). All identifiers (including investigator names and institutions) will be removed prior to analysis and replaced with a unique subject number. The list of ID numbers, investigator names, and institutions will be secured and confidentiality will be maintained.

- ○ Yes, I have access to the study consent document. Click NEXT SCREEN for email link to Jill Oliver.
- ○ Yes, I have access to the study consent document and will either fax it to Jill Oliver at 713-798-5678 or mail to Jill Oliver, M.A., Research Coordinator, Center for Medical Ethics and Health Policy, Baylor College of Medicine, One Baylor Plaza, Suite 310D, Houston, TX 77030
- ○ No, I do not have access to the study consent document. Click NEXT SCREEN to give more information.
- ○ No, I have access to the study consent document but do not wish to share it.

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To email consent document to Jill Oliver, click here.

Question: E7A
Show if: (E7 = 3:[No, I do not have access to the study consent document. Click NEXT SCREEN to give more information.])

Please tell us who might have access to the consent document. If possible, please give their name, email address, and telephone number. Thank you.

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Dana-Farber Cancer Institute
Center for Population Sciences
Questions or comments? E-mail us at ps_survey@dfci.harvard.edu

Thank you for participating in this survey!

Your responses will help us understand the practices and views of GWAS researchers concerning the return of individual and aggregate genetic results to research participants. To thank you for your time, we have entered you into a drawing for a new Apple iPad. We will contact the winner by e-mail. If you have any questions concerning this survey, please contact Dr. Rachel Ramoni at *rachel_ramoni@hsdm.harvard.edu* or 617-432-1245.

Please click the SUBMIT RESULTS button to complete your participation.