Supplemental File 2

Study 1: Community Member Focus Group Moderator's Guide

Introduction/Background [10-15 minutes]

[Show Welcome Slide] Introduction
My name is [state name] and I am a [state title] working at Northwestern University. Today, I'll be guiding the discussion with you, and it will last about 90 minutes. I am also accompanied by my research colleagues, Dr. Elisa Gordon and Jessica Gacki-Smith.

[Show About the Study Slide] Focus of Discussion:
Before we get started, I'm going to share some important information for our discussion today. As you know, living kidney donation is a generous act. New studies show that living kidney donors have a higher chance of getting kidney failure than healthy people who did not donate. And, African American living donors have an even higher chance of getting kidney failure than White living donors. Some scientists think there is a genetic basis to this finding.

That's because there is a genetic basis to getting some kidney diseases. All people have a gene called APOL1. People are more likely to get kidney disease if they have 2 changes to the APOL1 gene, called 'gene variants'. African Americans are much more likely to have 2 APOL1 gene variants than are Whites. That's why African Americans are 4 times more likely to have kidney disease than are Whites.

Preliminary studies show that living donors with 2 APOL1 gene variants are more likely to get kidney failure after donating. This means that living donors with 2 APOL1 gene variants may have a higher risk of getting kidney failure.

Any questions?

Just because people have the 2 APOL1 gene variants does not mean that they will get kidney disease. So, scientists believe that the act of removing a kidney could be an environmental trigger that sets off kidney disease.

Transplant doctors are now being extra cautious and offering a genetic test to African American living donor candidates to find out if they have 2 APOL1 gene variants. Doctors want to be sure that African American donors make an informed decision about donating, by having more personalized information about their risks and benefits of donating.

Any questions?

[Go through the next sections quickly] Purpose of the Focus Group:
Now, that brings me to our study. Our study goal is to give APOL1 testing to all African American living donor candidates to help them make informed decisions about donating. Any time you get a genetic test, then someone needs to give you information about it and counsel you about the results.

We developed a [first draft/second draft/beta draft] of 2 new educational materials that give information and counsel living donor candidates about APOL1 to help donors make informed decisions about donating.
Today, we would like your input on improving these materials:

1) First, is a chatbot. It is a form of artificial intelligence that uses text-based recognition software to simulate human conversation. A chatbot is delivered using a smartphone app. We are using a chatbot called “Gia” in this study to give information to live donor candidates about APOL1 genetic testing.

2) Second, we prepared information that a transplant doctor can use to counsel a live donor candidate about their APOL1 genetic test results.
Before we get started, let’s go over some ground rules:
I ask of you that:
- First, we are interested in your opinions.
- Next, we are here to learn from you. You are the expert on these topics.
- Only one person speak at a time
- When you start to talk, please state your name
- Everyone participate with no one dominating
- Give details and examples.
- Say why you agree or disagree with another person’s responses
- If you do not understand any question, please let me know and I will rephrase it.
- We are audio-recording the discussion so that we can remember what you said. Only the research staff will listen to the recordings.
- After the discussion ends, I’ll ask you to fill out a brief survey about your views of the discussion. This will be an online survey that you can access with the link I will send to you via email. When you’re done with that, we will compensate you for your time.

Participant Introductions:
Let’s now go around the room and introduce ourselves. Please tell us your name and share something about yourself. [Call each person by name and ask them to introduce themselves]

[Show Link to Gia Slide]
[Show Link to Gia Slide]
[ paste Gia chat link in Zoom Chat]

Now let’s start
We’re going to start by sharing the link to the Gia chat so that everyone can try it out right now.
The link to the chat is pasted in the Zoom chat. Please click the link and take about 5 or so minutes to run through it now.
After everyone is done, we’ll have a discussion about it.

What do you see on the screen when you click the link?

[Wait 7 minutes while everyone reviews Gia chat]

Okay, we’re going to start up our discussion now. I want to find out from everyone, how far did you get in the Gia chat? What is the last thing you saw?

[Show First Impressions Slide]
- What did you think?
- What worked well/what didn’t work well?
- What do you think of the way Gia looks? How can we improve the way it looks?
  - color, images, text font, what “Gia” looks like
- What did you like/what did you not like about your experience with the chat?

[Show Onboarding Messages Slide] [3 minutes]
- What did you think of the onboarding instructions at the beginning?
- Was it obvious where the menu was located?
  - Should it say “Menu”, or should we specify in the chat that it is at the top left corner?
- How can we make these instructions clearer?
Now, we want to get your feedback on specific language and sections of the chat. I am going to share my screen and we will go through the Gia chat together. As we go through the chat, reflect on the time when you were being evaluated as a living donor. Keep in mind, we will be showing this chat to potential living donors before they visit the Nephrologist.

GO THROUGH CHATBOT ON SCREEN [30 minutes]

Questions to Ask During the Chat Review:

13 out of every 100 (13%) people who identify as Black or African American have 2 APOL1 risk variants.

Donor candidates with African ancestry are asked to do the APOL1 genetic test because of their increased chances of having APOL1 risk variants and getting kidney disease.

Do people who do not identify as Black or African American have these APOL1 risk variants?

What do you think of having 3 response options here?

Our transplant team asks donor candidates what their ancestry is to personalize the evaluation process and the care that the team provides to each donor candidate.

For example, when evaluating kidney donor candidates, the transplant team sometimes runs tests based on the donor’s family history of kidney disease.

To find out about a donor’s family history, the team has traditionally asked the donor. But now, the team can get additional, personalized information by doing genetic testing.

The transplant team can find out if donors have APOL1 risk variants through the...

Should we keep this section?
What do you think of the way this is phrased?

Donors who identify as Black or African American have higher chances of getting kidney disease after donating than donors who identify as White.

Sure!

Nearly 75 out of 10,000 Black/African American living donors are estimated to get kidney disease 15 years after donating.

By comparison, 23 out of 10,000 White living donors are estimated to get kidney disease 15 years after donating.

Black/African American living donors have a 3 times greater chance of getting kidney disease after donating than White living donors.

However, it’s important to remember that the chance of getting kidney disease is still quite small.

Even 75 out of 10,000 is 0.75% (less than 1%).

What do you think of this clarification of who the research personnel refers to: One solution is to do a tool tip over ‘research personnel’ that states something like: “This is the person who asked for your informed consent for this study, the Principal investigator of the study, and other staff working to collect and analyze study data.”

The section above mentions “authorized research personnel”.

- Who comes to mind when you hear that?
- How does that statement make you feel?

To clarify who ‘research personnel’ refers to, a box pops up when you hover over the phrase with the following description:

- “This is the person who asked for your informed consent for this study, as well as the Principal investigator of the study, and other staff working to collect and analyze study data.”
- What do you think of this language? Does it help to allay any concerns/answer questions?
- How do you feel about the sharing of your test results with these people?
Would this phrasing encourage donors to complete the APOL1 testing NOW, as opposed to LATER?

- Is knowing who pays for this genetic test necessary?
- Should we add that the test is free and does not go through the donor’s insurance?
- Is this the correct location for this information?

What do you think of this sentence about HIPAA?

- Is the hover-over definition adequate?
- Alternatively, we can replace it with, “the law says we cannot share personal information” – would this be better?
  - Should we put this phrase in place of the term HIPAA?

How do you feel about Gia making this comparison between Black/AA and Latinx or White?
• Should we include statistics for Asian people here also? Is that needed?

Thank you very much for considering donating the gift of life.
The transplant team’s goal is to make sure that living kidney donation is safe for each donor.

Is the first sentence in the right place of the chat?

All people have 2 copies of the APOL1 gene. One is passed down from each biological parent.

People can have different versions of the APOL1 gene. We call these variants.

Variants can result in things like different eye colors.
Variants are part of what makes each person unique.
Sometimes a variant of a gene can be associated with health issues, but many variants have no impact on health.

People with two of these risk variants have a higher chance of getting kidney disease than people without these risk variants.

Is this definition of ‘variant’ clear?

APOL1 risk variants are most commonly found in people with African ancestry, like Blacks/African Americans, Caribbeans, and Central/South Americans.

Is Afro-Caribbean the correct term to use here?

Sure!

Nearly 75 out of 10,000 Black/African American living donors are estimated to get kidney disease 15 years after donating.

By comparison, 23 out of 10,000 White living donors are estimated to get kidney disease 15 years after donating.

It’s important to remember that there is still a chance of getting kidney disease.
Is the last sentence worth keeping? Should we convey that the risk is low?

The APOL1 genetic test is easy to complete.

APOL1 genetic test is done by taking a saliva sample. This means spitting into a tube that gets sent to a laboratory.

If you choose to get the APOL1 test, the saliva sample will be collected after your kidney doctor visit. A research staff member will assist you.

Is this the correct location for this information?

One of these tests looks at a gene called Apolipoprotein L1 or ‘APOL1’, which is known to be related to kidney health.

APOL1 genetic testing is a new way for the transplant team to evaluate a donor’s future chances of getting kidney disease.

You will be having a lot of discussions during your donor evaluation about the risks related to donating.

In this chat, we’re mostly focused on APOL1.

That makes sense  Can you remind me how genes work?

• How do you feel about the word “risks” compared to pros and cons?

Why do APOL1 risk variants occur mostly in people with African ancestry?

The APOL1 risk variants evolved about four thousand years ago in Sub-Saharan Africa to protect against sleeping sickness.

Thanks, I got it

• Does the response “The APOL1 risk variants evolved and so on...” answer the question about why APOL1 risk variants occur mostly in people with African ancestry?

• Does the hover-over description about sleeping sickness help answer the question?
  o Hover-over: “Sleeping sickness is an infectious disease typically found in Sub-Saharan Africa that is transmitted by the tsetse fly. Infected individuals experience fever, headaches, extreme fatigue, neurological symptoms, and other problems.”
- Does this hover-over sentence provide enough information?
  - Is this a feature you noticed as you went through the chat on your own?
  - How can we make this hover-over feature more noticeable?
- What else can we do to do a better job answering this question?

Sure!

- Do you like the first word, “Sure!”?
- How do you feel about the use of the exclamation mark in this context?
- What suggestions do you have for other responses that could be used in place of “Sure!”?
- Do you prefer the phrase “Sure, I'm happy to” more?

I know we went through a lot of information together.

If you would like a copy of this conversation, just enter your email address below.

name@domain.com

Submit Skip

[Do round robin] Would you want to email yourself the chat script?
- Do you think we should include a message at the beginning of the chat to let people know that this email function is available?
- Should we add this sentence: “Would you like me to include some resources in the email along with the transcript?”
The chance that someone in the general population with 2 APOL1 risk variants will get kidney disease in their lifetime is up to 20% (or up to 20 people out of 100 people).

However, most people who have 2 APOL1 risk variants DO NOT develop kidney disease.

- For this statistic, would it help to provide a comparison like: “By comparison, people have a 1 out of xxx chance of dying from xyz”

Sometimes a certain version of a gene can be associated with health issues.

For example, if a person has a version of a gene that is associated with kidney health, then their chance of having kidney disease may increase.

This brings us back to our discussion of APOL1.

- Some previous focus group participants were concerned that the current response option may not fit the tone of Gia, given the serious nature of the information presented. Looking at the text in this section, what do you think of this response option?
  - Does the response option fit the tone of the information Gia presents?
  - Should we change it to “Alright, let’s move on” or “Alright, let’s continue”?

People with two of these risk variants have a higher chance of getting kidney disease than people without these risk variants.

Can you explain a bit more?

- How does this statement make you feel?
You should also know that this is a secure chat and meets HIPAA requirements.

If you want to change your response, click on the response or go to the menu (≡) to find other options.

You may see some words or phrases in our chat that are underlined. You can tap on these underlined words to get a little more information.

• What do you think of the highlighted sentence?
• Do you like this instruction? Is it helpful?
• Did you notice this as you began the chat?
• Should we keep this?

How can we make the questions and answers clearer?
• What other questions should we add to this list?
• Are there any we should cut?
• Would you prefer being able to select one question at a time, or would you prefer to select multiple questions at once and seeing all of the answers together?
• Here is another question: “If I have 2 APOL1 risk variants, what is the likelihood that my child will also have 2 risk variants?” Do you think we should add this?
• Another question is, “Who is responsible for my post-transplant care?” Should we add this question?
• Should we add this question, “Will my results disqualify me from donating?”
• Should we add a brief statement saying that users can go through all the questions and not just one?
• “Does APOL1 testing happen before the other evaluation testing?” Is this something you would want to know?
Based on feedback from earlier focus groups, we added website links so that users could get access to additional information. What other topics would you want us to provide links to? That is, what topics from the chat would you like to know more about?

- What additional resources would you like to see here?
- Would you want a link to see video testimonies of other living donors?
  - Would you prefer to see testimonies of African American living donors?
QUESTION GUIDE: CHATBOT [30 minutes]

Appearance [3 minutes]
First, let’s talk about the way Gia looks.

- What do you think of the way Gia looks?
  - color, images, text font, what “Gia” looks like
- How can we improve the way it looks?

[Show GIA Avatars – Slide]
- We are working to make Gia look more like the people who will be using the chat. We have four different options in the way that the face of Gia can look. Which one do each of you prefer?
  - What improvements would you make?

Design & Functionality [5 minutes]
Now, let’s talk about Gia’s design and how it functions.

- What do you think of the way you interact with Gia?
  - How can we improve the way you interact with it to make it easier?
  - What was confusing in the way the chat works?
- What do you think about the phrases or words used on the buttons at the bottom of the screen during the chat?
  - Are the responses ‘Okay’ and ‘Got it’ fine?
  - Are there other words that would work better?
  - Would words like ‘Next’ or ‘Continue’ be better?
- What do you think of the default font size?
- As you can tell, the information is presented kind of like a branching tree. There’s the main pathway and sometimes 2 response options are provided: one to continue on the main pathway, and one if you want more information on a subject. After you finish reading about the additional information, you’re put back on the main pathway. What do you think about that design?
- Should we use “kidney doctor (nephrologist)” throughout? Or just one of those terms? Which term?
- [Show Slide] Looking back at this section describing GINA, should we add information about the penalties for violating GINA?
  - For example, we could add a sentence like, “If someone violates GINA, they could be forced to pay a fine ranging from $2500 to $500,000 per incident.”
  - In this sentence, is “protects” the right word to underline for the tooltip, or is there another word that would be better?
    - There is a law called GINA (Genetic Information Nondiscrimination Act) that protects patients against discrimination by health insurance providers and employers based on genetic information. Fines for violating GINA range from $2,500–$500,000.
- [Show Slide] Here are 3 statistics:
  1. “In 2021, 465 Black/African American people donated a kidney, representing
7.8% of all living kidney donors nationally."

2. "In 2021, 777 Black/African American patients received a living donor kidney transplant, representing 2.8% of all Black/African American patients on the waiting list.

3. "28,251 Black/African Americans are waiting for a kidney transplant, as of January 16, 2022."

- Which of these statistics are important to know? Which is the most important? Which is the least important?
- Where do they belong in Gia? Either:
  - In the Q&A section at the bottom of the chat?
  - Or in the resources section, e.g., “Statistics about AA kidney patients and living donors”
  - Or, as a hover over in the body of the chat?
- In the question/answer section at the end of the chat, we are planning to develop additional questions and include these statistics as the answers.
  - Should we keep these statistics in the question/answer section of Gia?
  - Do you find this information helpful to know?

- Should we put the Gia avatar in the body of the chat? If so, where? (the icon would remain on the top of the chat as well)
  - How many times would you like to see the avatar in the chat?

[Show Slide] Do you think potential donors should be given this information? Would this information scare them from donating?
- Will I get chronic kidney disease if I donate with 2 APOL1 gene variants?
  - You can have 2 APOL1 gene variants, but still not get chronic kidney disease.
  - Environmental factors, along with having the 2 gene variants, may trigger chronic kidney disease.
  - Living kidney donors have a higher chance of getting chronic kidney disease than healthy non-donors.
  - Black/African American living donors have an even higher chance of getting chronic kidney disease than White living donors. APOL1 gene variants may contribute to Black/African Americans’ higher chance.
  - Early research on APOL1 gene variants in living donors suggests that having 2 APOL1 gene variants increases living donors’ chances of getting chronic kidney disease after donating.
  - Black/African American living donors with 2 APOL1 gene variants had worse kidney function than those with 1 or 0 gene variant on average 12 years after donating.

[Show Slide] We have two options in the way that we can set up Gia. The first is having a set of questions that most people are likely to ask along with their answers. This is how the chat is currently set up. The second option is to allow people to type in their own questions. There are pros and cons to each option:
- With the pre-selected questions, that makes it easier for users to know what to
ask but your own question might not be there,
  o With the option of typing in your question, you get to ask your own question, but Gia might not recognize your question, and that might make the user frustrated.
  o Which option would you prefer?

**Educational Materials: Content [5 minutes]**

OK, now, let’s talk about the information included in Gia.

- Would it help if the chat included links to the article references, evidence-based resources, and other trusted sources at the end of the chat?
  o This way, the user can know where the information in the chat came from and also know where to get more info if they want it?
- Did the information come across as scary or worrisome?
- For future focus groups, do you think people should use a smartphone to test Gia during the focus group? Or was it fine going through the chat together on the screen?
- Do you think the order of information presented in the chat is correct? What suggestions do you have to make the flow more logical?
- What information could we cut from Gia to make it shorter?

**Cultural Competency [10 minutes]**

*Now, let’s talk about how to make Gia more culturally competent by addressing African American’s values, beliefs.*

- How could we make Gia more culturally sensitive to African American perspectives?
- We are trying to move away from the concept of “race”, which is a social construct. Instead, we want to emphasize the genetic basis of the presence of APOL1 variants in the population.
  o Does the Gia content emphasize “race, when it should focus on genetics?
- How can Gia talk about APOL1 in a way that does not stigmatize the African American community?
- Many African Americans have reported concerns about undergoing genetic testing, such as a breach of confidentiality, and the information will be used to discriminate against them. What can we do to change Gia to allay such concerns?
- Many African Americans distrust doctors and the healthcare system because of a history of injustices in the way that they are treated in the health care arena. What can we change about Gia to increase African Americans’ trust in the healthcare system?
- What do you think of the green color of Gia’s responses? How can we make the color scheme more culturally sensitive?
- Would it be helpful to include statistics on the number of African American living kidney donors?
- How can we revise Gia to help African Americans’ feel more comfortable about
participating in medical research?

- Does Gia currently make stereotypes about African Americans? If yes, which stereotypes?
- Should Gia talk about any myths or stereotypes about African Americans and genetic testing? If yes, which myths or stereotypes should be addressed?
- Are there any symbols or phrases that should be added to Gia to make Gia more meaningful to African Americans?

**Using Gia**

*Let’s talk a bit about using a chatbot.*

- What do you think about living donors using Gia to get some basic information before talking to their transplant doctor?
- What barriers are there to using Gia in a healthcare setting?
- How would African Americans feel about using a chatbot like this?
  - The use of chatbots have been studied in other populations, but have not been tested among the African American community.
- After going through the entire chat, how did Gia make you feel about getting or not getting an APOL1 genetic test?
Gia-Specific questions [5 minutes]

1. [Show Slide #] [For Living Donor FGs]: Are the opening and closing phrases worded strongly enough to convey the appreciation to the potential donor?

   **Opening:** Thank you very much for considering donating the gift of life.
   **Closing:** And, thank you again for considering the heroic act of donating the gift of life.

If time permits:

2. [Show Slide] Which phrase do you like better:
   - **Gia:** Keep in mind: like all tests, APOL1 genetic testing is voluntary
   - **Gia:** Keep in mind: like all tests, APOL1 genetic testing is completely up to you.

3. Some people have suggested that we include a statement about the chance of getting kidney disease by having 1 APOL1 risk variant (in general, not after donating). The problem is that very little research on APOL1 has examined the risks of kidney disease by having 1 APOL1 risk variant. There isn't enough research to make any conclusion about it.
   - So, what should we do – leave out of the Gia chat this topic altogether? Or, should we include a brief discussion about how little is known about the risks of getting kidney disease by having 1 variant?
QUESTION GUIDE: TRANSPLANT DOCTOR COUNSELING CONTENT [10 minutes]
As a reminder, Gia will be given to potential donors before they meet with the Nephrologist. Part of our study involves training doctors on how to counsel donors in a culturally sensitive manner. Now, we would like your feedback on some of this Training Program content and how to make it better.

- Now that you’ve been through Gia, what do you think the conversation with the doctor might be like? Can you think of any questions you might have when meeting with the doctor?
  - Would it be helpful if Gia included a list of questions in the chat that you could ask your doctor?
- What phrases could a transplant doctor say to address the mistrust in the healthcare system that potential donors may have?
- Some African American living donors reported concerns that APOL1 genetic testing would be used to discriminate against or rule out African American donors – what phrases could a doctor use to address these concerns?
- [Show Phrases Slide] We have developed some potential phrases for kidney doctors to use when counseling donors. Take a moment to read these.
  - Which phrases do you think are the best?
  - What are your favorites (for each slide)?
  - Which do you like/dislike?

What questions might people have about this study? – ask LDs this at the next FG

**Conclusion [5 minutes]**
We’ve got to wrap up our discussion in the next 5 minutes. [Do Round Robin for this section, calling on everyone]

I’d like to use this time to ask each of you two general questions:

1. Can you give me a final statement summarizing your thoughts and recommendations for the educational materials?

2. What do you think are the key takeaways for us to know from the discussion today?

This has been a great conversation. Thank you all so much for participating. [Staff] will now discuss the next steps with you.

[Staff]

As a reminder, please fill out the post-focus group survey online and then we will send you your e-gift card via email.

Before we hang up, we sent you the URL link to the post-focus group survey. Please confirm that you have received it before logging off. If you received it our discussion is complete. Have a great day!

If you have not yet received the URL link, please stay on the line while we help you to get it. Thank you!