

## **Supplementary Figure 1. Approach Script and Genetics Survey**

**Approach script for potential survey respondents:** Good (morning/afternoon). I have been informed that you have a relative receiving treatment for kidney disease at a Wake Forest Dialysis Center. Dr. Barry Freedman, a kidney specialist at Wake Forest School of Medicine, is performing a research study to learn how relatives of patients on dialysis feel about genetic testing. The survey takes about 10 minutes. The results will be reported in an anonymous fashion; this means that your name or identifying information will be not released. Whether or not you wish to participate, the care that is provided to your family member will not be affected. May I ask whether you would be willing to participate by answering the survey questions?

### **Survey tool:**

We want to know what you think about getting test results after you have genetic testing done in a research study. Genetic testing in a research study usually means looking to see if you have or do not have a change in a gene that researchers think may give people a high chance of getting a disease. Sometimes when you know you have a certain change in a gene, there are things you can do, or things your doctor can do, to lower your chance of getting the disease. Sometimes no one knows what to do to lower your chance of getting the disease. We want to learn your views about these three possibilities.

This survey should take no more than 10 minutes of your time. Please listen carefully and answer the questions as best you can. Some of the questions may sound the same, but they are all different. If you want to hear a question again, please ask. If you want to stop at any time, please say so and we will stop.

(A) Imagine that you join a research study to see if you have or do not have a particular change in a gene. Having this change means that you have a high chance of getting a disease. I have some questions to ask you about having genetic testing done in the study:

1. Would you want to know your test results if YOU could lower your chance of getting the disease by changing how you eat and exercise? Yes or No?

What are your reasons for saying [YES or NO]? Please listen to a list of reasons people might give and tell me if you agree with any of them. You may choose more than one reason: [READ ONLY THE LIST THAT CORRESPONDS TO THE ANSWER GIVEN]

YES LIST

[PAUSE AFTER EACH; REPEAT LIST OR ITEMS AS NEEDED; UNDERLINE CHOICES]

I just want to know health information about myself

I can use this information to improve my health

I have the right to information about me

I can use this information to plan ahead

Are there any other reasons you said YES? [TAKE PRECISE NOTES]

NO LIST

[PAUSE AFTER EACH; REPEAT LIST OR ITEMS AS NEEDED; UNDERLINE CHOICES]

I don't think this information is important

I don't think I could improve my health with this information

I don't want to try to control everything about my life

I worry that information like this could hurt me

Are there any other reasons you said NO? [TAKE PRECISE NOTES]

2. Now, would you want to know your test results if YOUR DOCTOR could lower your chance of getting the disease by giving you a treatment? Yes or No?

What are your reasons for saying [YES or NO]? Please listen to a list of reasons people might give and tell me if you agree with any of them. You may choose more than one reason: [READ ONLY THE LIST THAT CORRESPONDS TO THE ANSWER GIVEN]

YES LIST

[PAUSE AFTER EACH; REPEAT LIST OR ITEMS AS NEEDED; UNDERLINE CHOICES]

I just want to know health information about myself

I can use this information to improve my health

I have the right to information about me

I can use this information to plan ahead

Are there any other reasons you said YES? [TAKE PRECISE NOTES]

NO LIST

[PAUSE AFTER EACH; REPEAT LIST OR ITEMS AS NEEDED; UNDERLINE CHOICES]

I don't think this information is important

I don't think I could improve my health with this information

I don't want to try to control everything about my life

I worry that information like this could hurt me

Are there any other reasons you said NO? [TAKE PRECISE NOTES]

3. Now, would you want to know your test results if NO ONE KNOWS what to do to lower your chance of getting the disease? Yes or No?

What are your reasons for saying [YES or NO]? Please listen to a list of reasons people might give and tell me if you agree with any of them. You may choose more than one reason: [READ ONLY THE LIST THAT CORRESPONDS TO THE ANSWER GIVEN]

YES LIST

[PAUSE AFTER EACH; REPEAT LIST OR ITEMS AS NEEDED; UNDERLINE CHOICES]

I just want to know health information about myself

I can use this information to improve my health

I have the right to information about me

I can use this information to plan ahead

Are there any other reasons you said YES? [TAKE PRECISE NOTES]

NO LIST

[PAUSE AFTER EACH; REPEAT LIST OR ITEMS AS NEEDED; UNDERLINE CHOICES]

I don't think this information is important

I don't think I could improve my health with this information

I don't want to try to control everything about my life

I worry that information like this could hurt me

Are there any other reasons you said NO? [TAKE PRECISE NOTES]

(B) I have a few more questions to ask you about being in the study.

1. If YOU could lower your chance of getting the disease by changing how you eat and exercise, HOW LIKELY are you to want your test results back? I'm going to read 5 possible answers; please choose

1.

Extremely likely - Pretty likely - As likely as not - Pretty unlikely - Very unlikely

2. If YOUR DOCTOR could lower your chance of getting the disease by giving you a treatment, HOW LIKELY are you to want your test results back? I'm going to read 5 possible answers; please choose 1.

Extremely likely - Pretty likely - As likely as not - Pretty unlikely - Very unlikely

3. If NO ONE KNOWS how to lower your chance of getting the disease, HOW LIKELY are you to want your test results back? I'm going to read 5 possible answers; please choose 1.

Extremely likely - Pretty likely - As likely as not - Pretty unlikely - Very unlikely

(C) Now imagine that you have joined a research study to see if you have or do not have a change in a gene that gives a high chance of getting a disease, and you have your test results back.

1. If you found out that you DO NOT have the change in the gene, HOW LIKELY are you to tell your family your results? I'm going to read 5 possible answers; please choose 1.

Extremely likely - Pretty likely - As likely as not - Pretty unlikely - Very unlikely

2. If you found out that you DO have the change in the gene, HOW LIKELY are you to tell your family your results? I'm going to read 5 possible answers; please choose 1.

Extremely likely - Pretty likely - As likely as not - Pretty unlikely - Very unlikely

(D) Is there anything else you would like to say about your views on getting genetic test results in research studies? [TAKE PRECISE NOTES]

Thank you for helping us understand more about your views on getting genetic test results in research studies. We would like to have a longer conversation about genetic research and genetic test results with some of the people who have answered this survey. If we plan a discussion group or longer interview, would you be willing to let us contact you to invite you to talk more about this? You would still be able to say no when we contact you again; we would just like to know if it would be okay to ask you. IF YES: What are the best two ways to get in touch with you? Thank you very much for your help.

## Supplementary Figure 2. Recontact Script

Good morning/afternoon. My name is \_\_\_\_\_ and I'm calling you because you participated in a survey of people with relatives receiving treatment for kidney disease late last year. The survey was about your views about genetic research. You said that it would be OK to call you to get more information about your views. We have just one question to ask you. Is that still OK with you? Please feel free to say no.

If NO, ask if there is a better time to call, and if not just say thank you.

If YES:

When you participated before, we asked your views about getting genetic test results in a research study. Genetic testing in a research study usually means looking to see if you have or do not have a change in a gene that researchers think may give people a high chance of getting a disease.

We would like to know what you think is meant by "a high chance of getting a disease." What chance is high enough for you to want your genetic test results from a research study?

Take the percentage the respondent names. If the respondent doesn't give a percentage or something equivalent, probe as follows:

Would a 10% chance of getting a disease be enough?

Would a 20% chance of getting a disease be enough?

Keep going until respondent says yes.

That's all we want to know. Thanks very much for your participation; your answer will help us clarify our survey results.