

Appendix B:

SOMBRA Website Materials

Study Overview

Thinking About Skin Cancer Genetic Testing

- The SOMBRA website has four sections to help you learn about whether skin cancer genetic testing is right for you.
- You can complete Sections 1, 2, and 3 in any order you want.
- After you complete Sections 1, 2, and 3, you will be able to go to Section 4 to let us know your decision about whether to get skin cancer genetic testing.
- You can always return to the information in Sections 1, 2, and 3 if you want to read them over again.

Below, you will find a brief description of each section. Please click the Go button to start.

Section One

What Genetic Testing Can and Cannot Tell You

80% Complete

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Section Two

Skin Cancer & Genes

75% Complete

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Section Three

Your Rights if You Take Part in Skin Cancer Genetic Research

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Section Four

Your Decision to be Tested or Not

0% Complete

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Section 1 - What Genetic Testing Can and Cannot Tell You

Introduction

What is Genetic Testing?

Genetic Testing looks at genes that affect a person's chance of getting certain diseases. The test you are being offered can show if you have types of a gene that may increase your chances of getting skin cancer.


What's involved in being tested?

- Read and sign a consent form. (You signed a consent form when you agreed to be part of SOMBRA.)
- Provide a saliva (spit) sample using the kit we will send you.
- A DNA sample is gathered from your saliva and sent to a lab at the University of New Mexico.
- You will receive your test results by mail.
- About two weeks after you receive your results, a SOMBRA staff member will contact you to discuss your results.

What should I consider before deciding whether or not to have skin cancer genetic testing?

- Have the testing done only if you are sure you want to know the information. It is important to consider how you might react to the test results. Your decision to be tested should be completely voluntary and made without pressure from relatives, health care providers (doctors, nurses, PAs), or anyone else.

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Glossary

Cancer

A disease that happens when cells are not normal and spread very fast and out of control.

DNA

DNA is the material in living things that carries information about how they look and work. There is DNA in all parts of your body, including in your saliva.

Gene

Genes are short sections of DNA that affect how a living thing looks and works. Some genes affect physical traits like eye color. Others affect the chances of getting diseases like cancer.

Melanoma

The most harmful form of skin cancer.

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Section 1 - What Genetic Testing Can and Cannot Tell You

Introduction

What Gene Are We Testing?

Genetic Risk

Genes and Your Choices

Survey 1

What Gene Are We Testing?


The test you are being offered looks at types of a gene related to skin cancer.

How did we pick the gene type to test for?

Skin cancer is common and affects many Americans, often as adults. Skin cancer can be prevented. The gene type we are testing for has been shown to increase a person's chances of developing melanoma skin cancer.

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What does genetic risk mean?

Genetic risk means you have a higher chance of developing a disease if you have a certain type of a gene. The increased chance of getting the disease may be small, but the risk types of some genes are common in the general population.

This does not mean you are certain to get the disease.

What does having a genetic risk type mean?


Genes come in more than one type. When you have a risk type of a gene, it raises your chance of getting cancer.

This does not mean your children will get the disease or the risk type of the gene that you might be found to have. You pass on half of your genes to your children, so they may also have the same risk type of a gene.

However, just as with your risk, there are many other factors that influence their risk for disease. These factors include how much they are in the sun, their diet, how much they exercise, and whether or not they smoke.

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Section 1 - What Genetic Testing Can and Cannot Tell You

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Genes and Your Choices

How could types of genes increase your chance of getting a disease?




Genes play a role in most diseases. This is because genes affect how your body handles foods, medicines, and infections. Some types of genes make the gene work well, while some types make the gene work poorly or not at all. This is why the type of the gene you have can increase your chance of getting a disease.

It's not that simple though...

- Health habits, such as poor diet, cigarette smoking, and lack of exercise, also affect a person's chance of getting cancer.
- Those who have certain types of genes may be more harmed by these health habits than those with other types.
- Health habits can be changed, while someone's genes cannot.

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Section 2 - Skin Cancer and Genes

Why Skin Cancer?

Skin Cancer (Melanoma)


The *MC1R* Gene

Survey 2


Why Skin Cancer?

This section provides you with information on skin cancer and genes that affect skin cancer risk.

We picked skin cancer because it is common, affects many Americans, occurs in adults, and can be prevented. The *MC1R* gene was chosen because there is evidence that types of this gene increase a person's chance of getting skin cancer. Many people have the types that increase the chances of disease.



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Why Skin Cancer?


Skin Cancer (Melanoma)

Skin cancer is a malignant growth on the skin. Melanoma is the most harmful form of skin cancer. Sunlight contains ultraviolet (UV) rays, which are the cause of sunburns and tanning. These UV rays can damage the genes in the skin cells that produce color in the skin. About 73,870 Americans will be diagnosed with skin cancer this year, and nearly 9,940 of them will die. Skin cancer can almost always be cured in its early stages. This is because skin exams can find cancerous changes in moles early, when they are most curable.

A risk factor is anything that increases your chance of getting a disease.

Factors that increase risk for skin cancer include:

- Light skin, hair, and eye color
- High levels of UV exposure (from being in the sun or from tanning booths/lamps) without protective clothing or sun screen
- Having five or more sunburns in your life




We are testing one of the genes for skin cancer. The gene for skin cancer that we are testing is:

- *MC1R*

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Malignant
Cancer that is more likely to spread from one part of the body to another.

Mole
A small spot on the skin. Most moles are brown and they are sometimes raised.

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Section 2 - Skin Cancer and Genes

Why Skin Cancer?

Skin Cancer (Melanoma)

The *MC1R* Gene

Survey 2


Why Skin Cancer?

What does the *MC1R* gene do?


Scientists have found that compared to individuals who do not have a risk type of the *MC1R* gene, individuals who do have a risk type are more likely to have light skin and hair color. Individuals who have these features are at higher risk for skin cancer. People can have one or more risk types of *MC1R*.

What is the chance of someone getting skin cancer in their lifetime if they have any *MC1R* risk types?


On average, people who do not have a risk type have a 1 in 100 chance of getting skin cancer. On average, people who have one or more risk types of *MC1R* have a 3 in 100 chance of getting skin cancer.



Out of 100 people at average risk for skin cancer, ONE (shown in red) would be expected to develop skin cancer.



Out of 100 people of higher risk for skin cancer, THREE (shown in red) would be expected to develop skin cancer.



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Things You Should Consider

This risk information presented is based on current research. Some of these studies are listed in the references below. The genetic risk information did not come from a study that looked at people's risk over time. Current and future research is adding to what we know and may change this risk information.

How common are the risk types of *MC1R*?

About half of the adults in the U.S. have one or more risk types of *MC1R*.

For more information...

Development of a melanoma risk prediction model incorporating *MC1R* genotype and indoor tanning exposures: Impact of mole phenotype on model performance. L. A. Penn and colleagues, 2014. Published in PLoS One, 9(7): e101507. [Click here read the article.](#)

Interactions between ultraviolet light and *MC1R* and *OCA2* variants are determinants of childhood nevus and freckle phenotypes. A. E. Barón and colleagues, 2014. Published in Cancer Epidemiology Biomarkers & Prevention, 23(12):2829-39. [Click here to read the article.](#)

MC1R variants increased the risk of sporadic cutaneous melanoma in darker-pigmented Caucasians: A pooled-analysis from the M-SKIP project. E. Pasquall and colleagues, 2015. Published in the International Journal of Cancer, 136(3):618-31. [Click here to read the article.](#)

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Section 3 - Your Rights if You Take Part in Skin Cancer Genetic Research

Introduction

Rules for Researchers

Survey 3

What you should know about participating in skin cancer genetic research:

How can I have skin cancer genetic testing?

- You will be given an opportunity to have skin cancer genetic testing by choosing "yes" in Section 4 of this website. The testing is free of charge.
- If you choose "yes," you will be mailed a kit. The kit will have instructions on how you can send a "spit" sample for genetic testing.
- Your skin cancer genetic testing results will be sent to you in the mail, within one month of you providing your "spit" sample.
- We will call you two weeks after your results are mailed to you. We will ask you what you think about your results and answer any questions you may have about your skin cancer genetic testing results.

Can I get another copy of my skin cancer genetic test results after you mail them to me?

Yes. You can call SOMBRA and get your results again, anytime before August 1, 2017. Our phone number is 1-844-SOMBRA-4 (1-844-766-2724). After August 1, 2017, we will not keep information about your results.

Can researchers study my other genes without me knowing about it or giving my permission?

No. The researchers will destroy your DNA sample after it has been tested. No further research will be done on it.

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DNA is the material in living things that carries information about how they look and work. There is DNA in all parts of your body, including in your saliva.

Gene

Genes are short sections of DNA that affect how a living thing looks and works. Some genes affect physical traits like eye color. Others affect the chances of getting diseases like cancer.

Genetic testing

Genetic testing looks at genes that affect a person's chance of getting certain diseases.

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Section 3 - Your Rights if You Take Part in Skin Cancer Genetic Research

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Rules for Researchers

Researchers are required to do the following in genetic research:

- Researchers are required by law to provide you with a detailed consent form for you to read and sign.
- Before collecting samples of your DNA, researchers must tell you the purpose of their study and how long your DNA sample will be stored.
 - In this study, your DNA sample will not be stored.
 - Any remaining DNA sample will be destroyed as soon as the DNA data are collected using procedures approved by the University of New Mexico.

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DNA is the material in living things that carries information about how they look and work. There is DNA in all parts of your body, including in your saliva.

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Section 4 - Your Decision to be Tested or Not

Introduction
Survey 4
Testing Kit Confirmation
Thank You

We hope you will take a few minutes to complete this survey on your decision whether or not to be tested. As you make your decision here, you can go back and look at the information in Sections 1, 2, and 3.

Please keep in mind that skin cancer genetic testing is being offered free to you as part of the SOMBRA study. The researchers will destroy your DNA sample after it has been tested.

All you have to do is answer each question and click "Submit Survey."



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Genetic Testing
Testing a person's DNA to look for genes that cause certain diseases.

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Survey 4

Please tell us about how you came to a decision regarding testing...

How easy or hard is it for you to make a decision about whether or not to get skin cancer genetic testing?

1	2	3	4	5	6	7
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Very Easy			Neither			Very Hard

Would you like to receive a test kit to have skin cancer genetic testing?

☐ Yes ☐ No

Submit Survey

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Section 4 - Your Decision to be Tested or Not

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Testing Kit Confirmation

- You will receive a testing kit and instructions in the mail.
- The testing kit will ask you to provide a sample of saliva (spit). The saliva will be used to get a sample of your DNA.
- This kit will also come with a pre-paid postage envelope so that you can send the used kit back.
- Once you send us the test kit with your saliva sample, we will do the testing. We will send your skin cancer genetic results to you by mail (or by e-mail if you prefer).

☐ If you would prefer to receive your results by email, please check here.



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DNA
The material that carries information about how a living thing will look and how it will work.


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Section 4 - Your Decision to be Tested or Not

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Thank You!

Thank you for completing Section 4! We hope that you found the information helpful and educational.



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