

Supplemental Table 1. “About the Study” webpage: text shown on screen before clicking to expand*

GeneScreen is a research study. The goal of GeneScreen is to learn the best ways to offer and do genetic testing for 11 rare, but preventable or treatable, genetic health conditions.
Joining GeneScreen is voluntary, it is your choice. Deciding not to join will not affect your health care at UNC. **
What does GeneScreen test for? It examines a person’s DNA in 17 genes for mutations that can cause one of <u>11 genetic health conditions</u> . ***
The 11 GeneScreen health conditions can be prevented or treated. Each condition has specific medical advice people can follow with their doctors to prevent or treat a serious health problem.
All tests, including the GeneScreen test, have limitations. The test does not examine all 20,000 human genes or all genetic health conditions.
Participating in GeneScreen has several steps. You will be asked to give your consent to join GeneScreen, send us a saliva sample for genetic testing, take two online surveys, learn your results, and possibly be invited for a telephone interview.
Can pregnant women join the study? Yes, GeneScreen is open to all eligible adults. It is important to understand that GeneScreen is not a prenatal genetic test.
Most people will get "negative" GeneScreen results. A negative result means the GeneScreen test did not find a mutation that is predicted to cause one of the GeneScreen conditions.
How do I find out my negative results? We will email you a link to our confidential website where you can view and print a report. We will not put negative results in your medical record. **
What happens if the GeneScreen test finds a mutation (a “positive” result)? We will ask you to send us a second saliva sample to be tested in the UNC Hospitals clinical laboratory to confirm this result.
What happens if the second test <i>confirms</i> the positive result? A genetic counselor will call to set up an in-person appointment to discuss what it means and recommend follow-up care. We will also contact your UNC doctor about the result and enter the laboratory report into your UNC medical record.
What are the possible benefits of joining GeneScreen? If you join, you will help us learn how to offer and do genetic testing in healthy adults. A few people might learn information important to their health and family.

What are the possible risks of joining GeneScreen? If you get a confirmed positive result, you may worry about your future, including if you will need medical care, how much it will cost, and who will pay for your care.

What will happen to your personal information during the study and after it ends? GeneScreen has procedures to protect your privacy and confidentiality.

If you join GeneScreen, you can decide whether to make your genetic information available to other researchers. If you say it's all right, we will put some of your genetic information into a national research database for other researchers to use. We will not include any information that directly identifies you, like your name or age.

What happens if I join GeneScreen now but change my mind later? You can stop participating in the study by contacting us with an email (genescreen@unc.edu) or by calling 919.843.2861.

* Text is specific to the UNC GeneScreen recruitment website. The text for the KPNW recruitment website was very similar. KPNW IRB required two additional statements. These two statements were not included in our analyses of the number of consent items clicked and are not listed in the table above.

** No additional information offered for expansion.

*** "11 genetic health conditions" was a hyperlink to the page listing the names of the health conditions, each of which could be expanded to display detailed information.