*supplementary material*

# Experimental Manipulation

## Content in Two Versions of the NC NEXUS Decision Aid

*screen*

1

*experimental condition*

- EDUCATION-ONLY
- EDUCATION + VALUES CLARIFICATION

*screenshot*


*voice-over script*

[Not applicable. No voice over on this screen.]

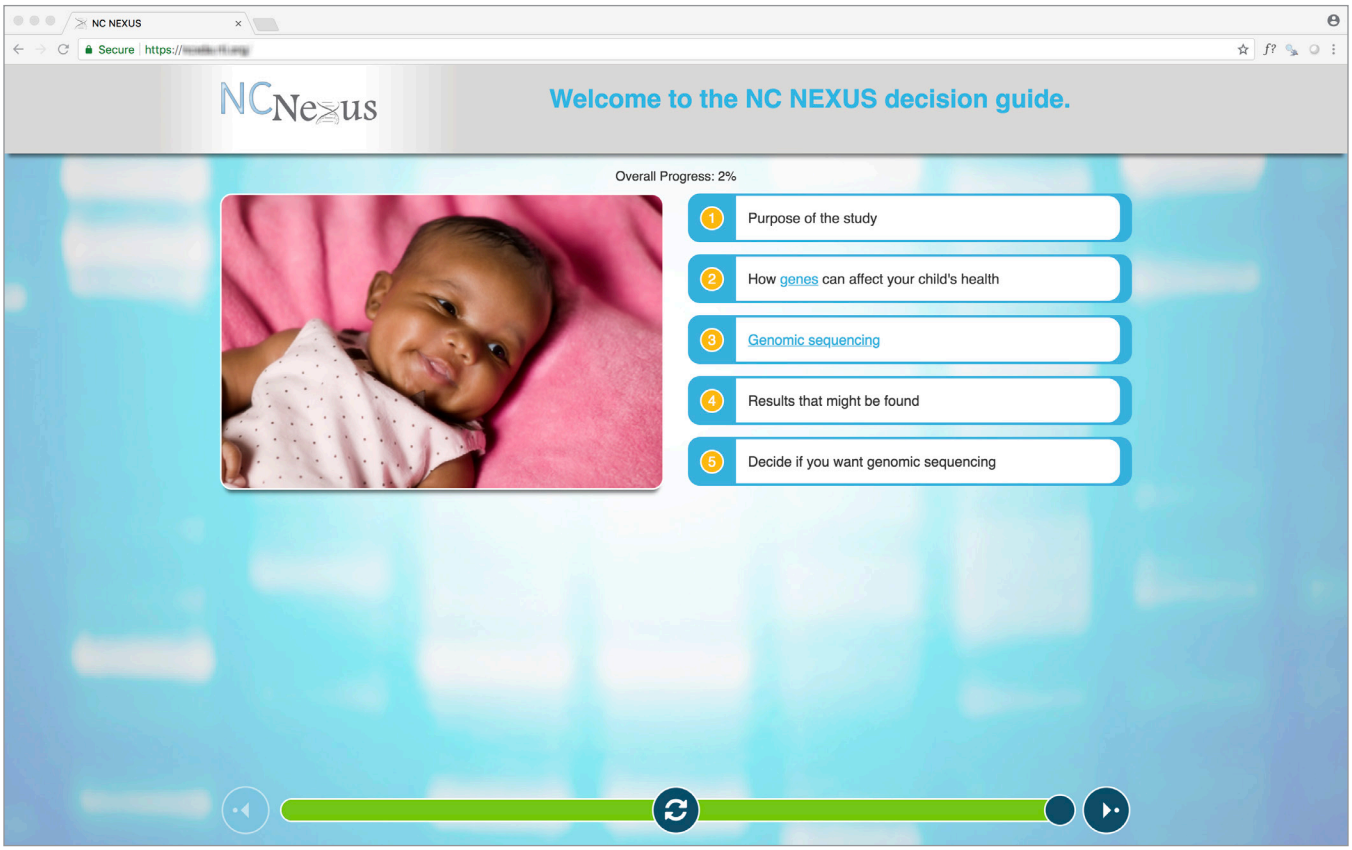
*screen*

2

*experimental condition*

- EDUCATION-ONLY
- EDUCATION + VALUES CLARIFICATION

*screenshot*




*voice-over script*

Welcome to the NC NEXUS decision guide.

This decision guide will help you learn more about the NC NEXUS Study, including:

- The purpose of the study
- How genes can affect your child's health.
- Genomic sequencing, and
- The types of results that might be found.

The guide will also help you decide if you want to have genomic sequencing for your child.

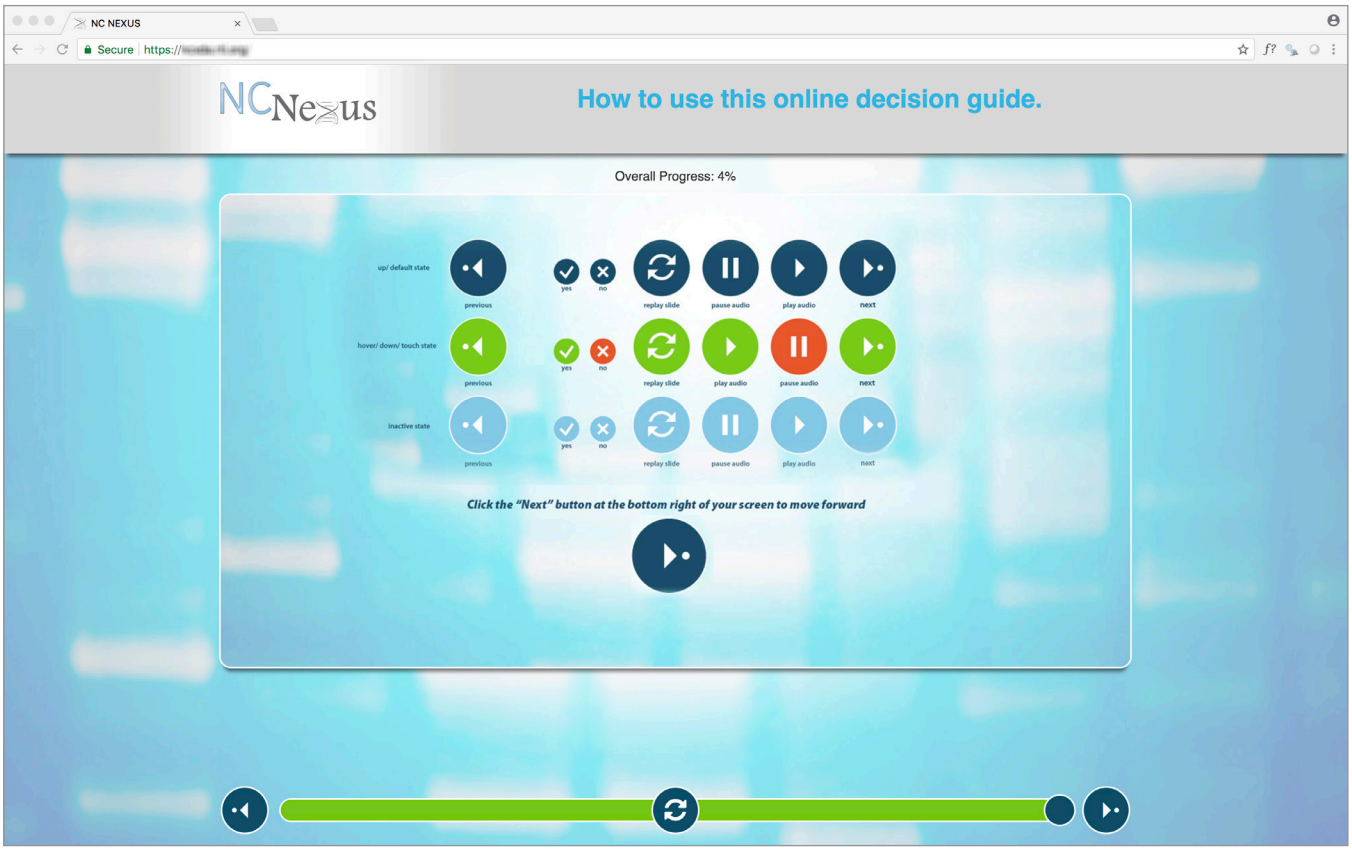
*screen*

3

*experimental condition*

- EDUCATION-ONLY
- EDUCATION + VALUES CLARIFICATION

*screenshot*




*voice-over script*

Before getting started, let's look at the navigation controls you can use to move through the decision guide.
Here is the next button to move forward.

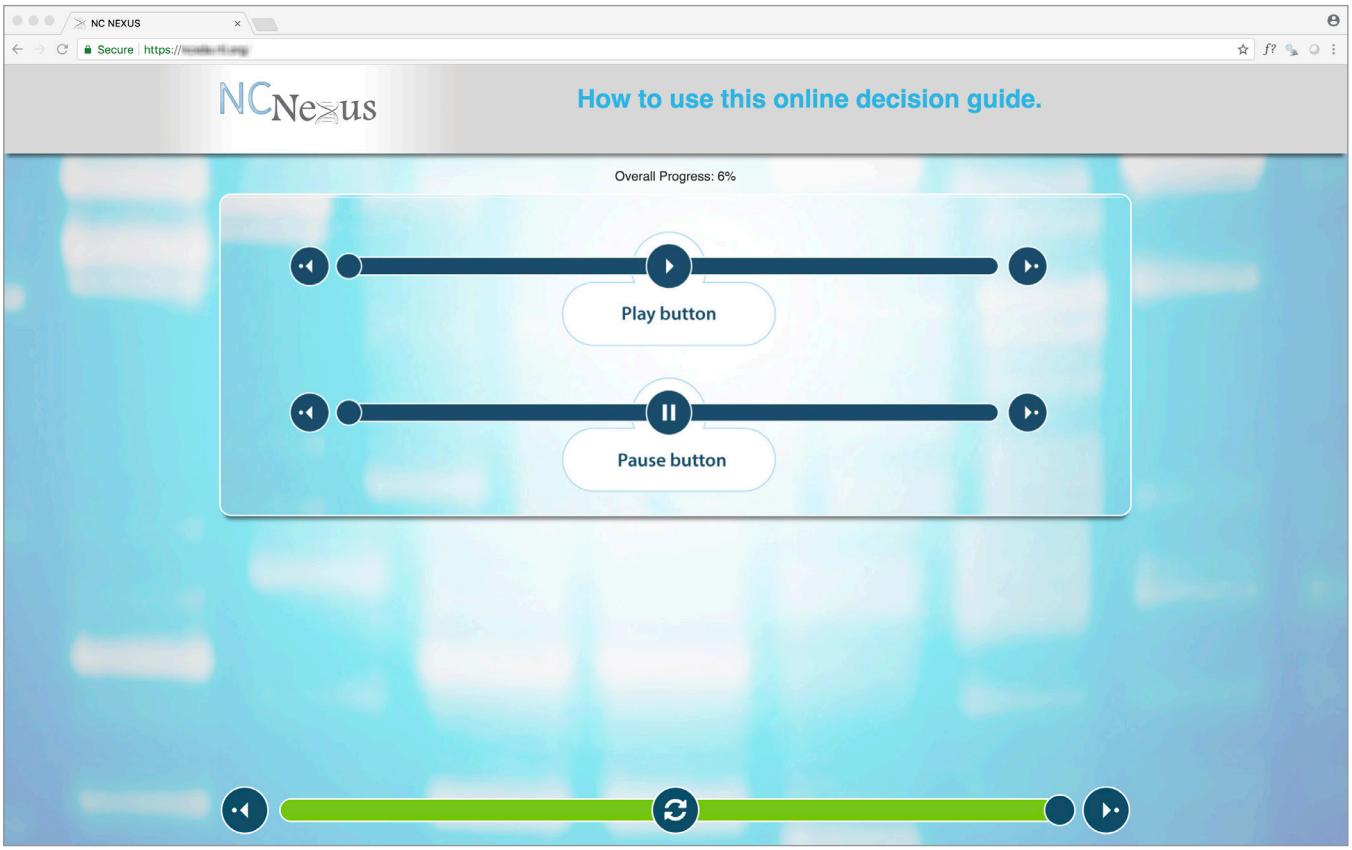
*screen*

4

*experimental condition*

- EDUCATION-ONLY
- EDUCATION + VALUES CLARIFICATION

*screenshot*




*voice-over script*

If you need to pause for a moment and come back, click the play/pause button.

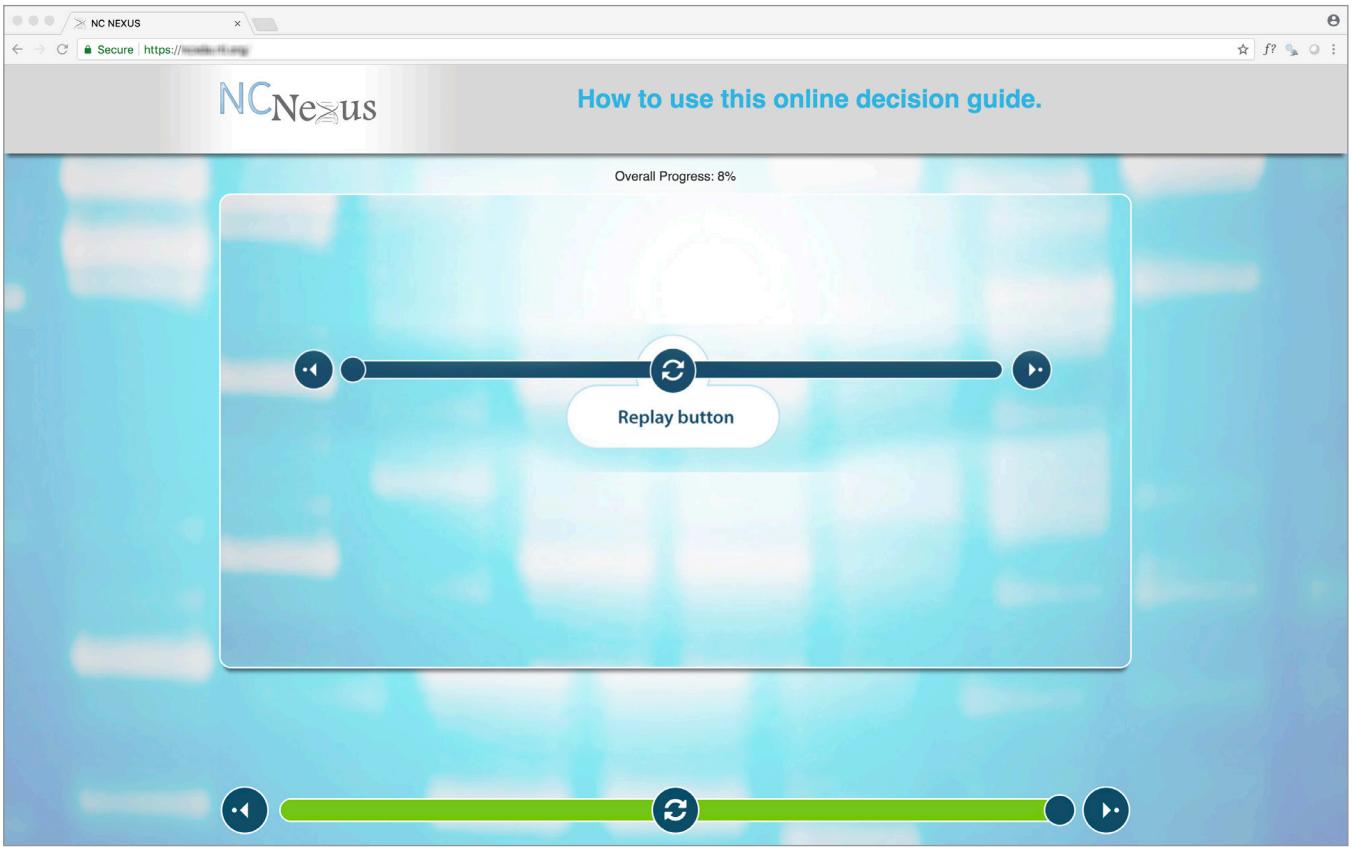
*screen*

5

*experimental condition*

- EDUCATION-ONLY
- EDUCATION + VALUES CLARIFICATION

*screenshot*




*voice-over script*

If you want to listen to information on the screen again, click the replay button.

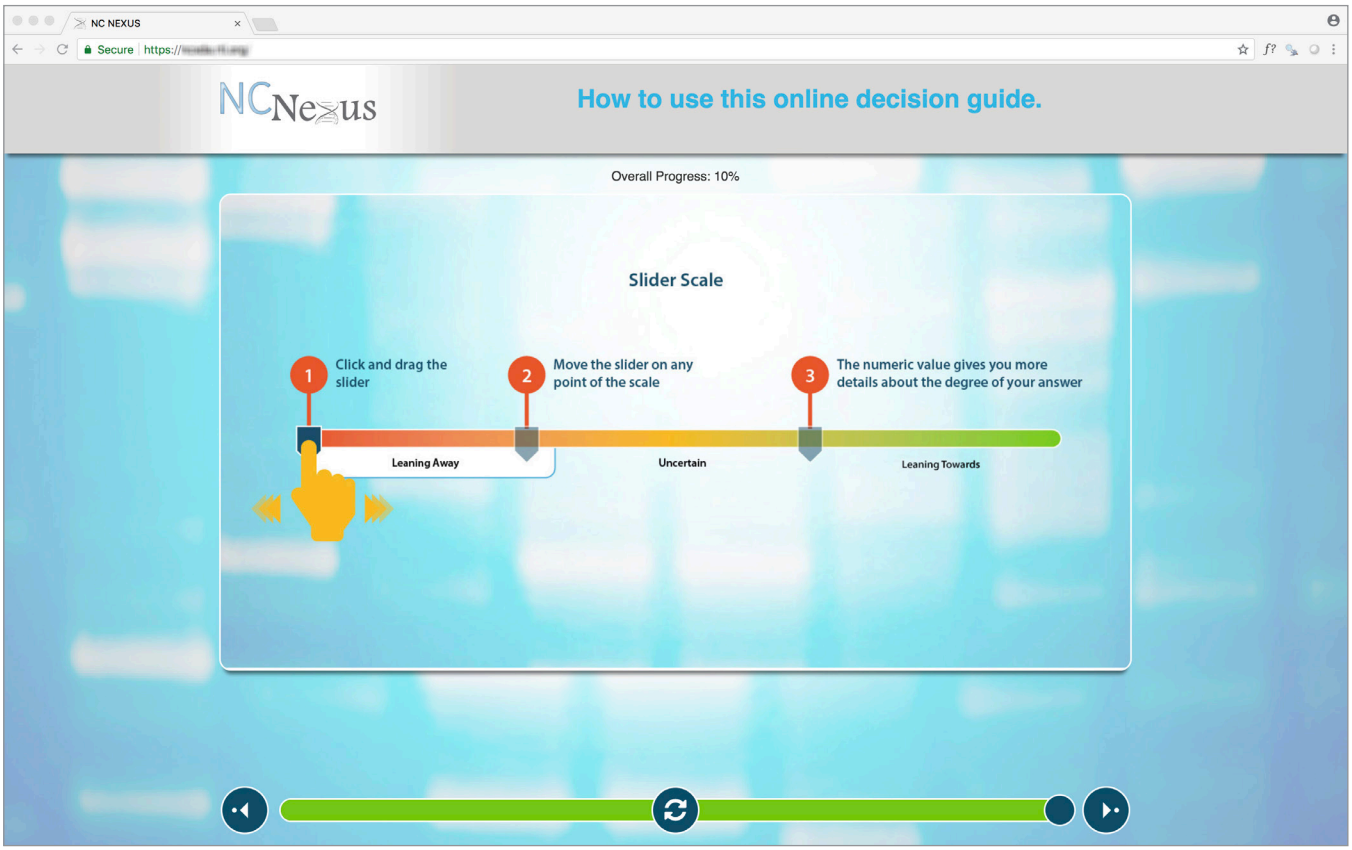
*screen*

6

*experimental condition*

- EDUCATION-ONLY
- EDUCATION + VALUES CLARIFICATION

*screenshot*




*voice-over script*

On some screens you will be asked questions. One way to answer is with a sliding scale. Click and drag the slider, moving it to the point on the scale that best fits your answer. You can choose any point on the scale. Then click the next button to continue.

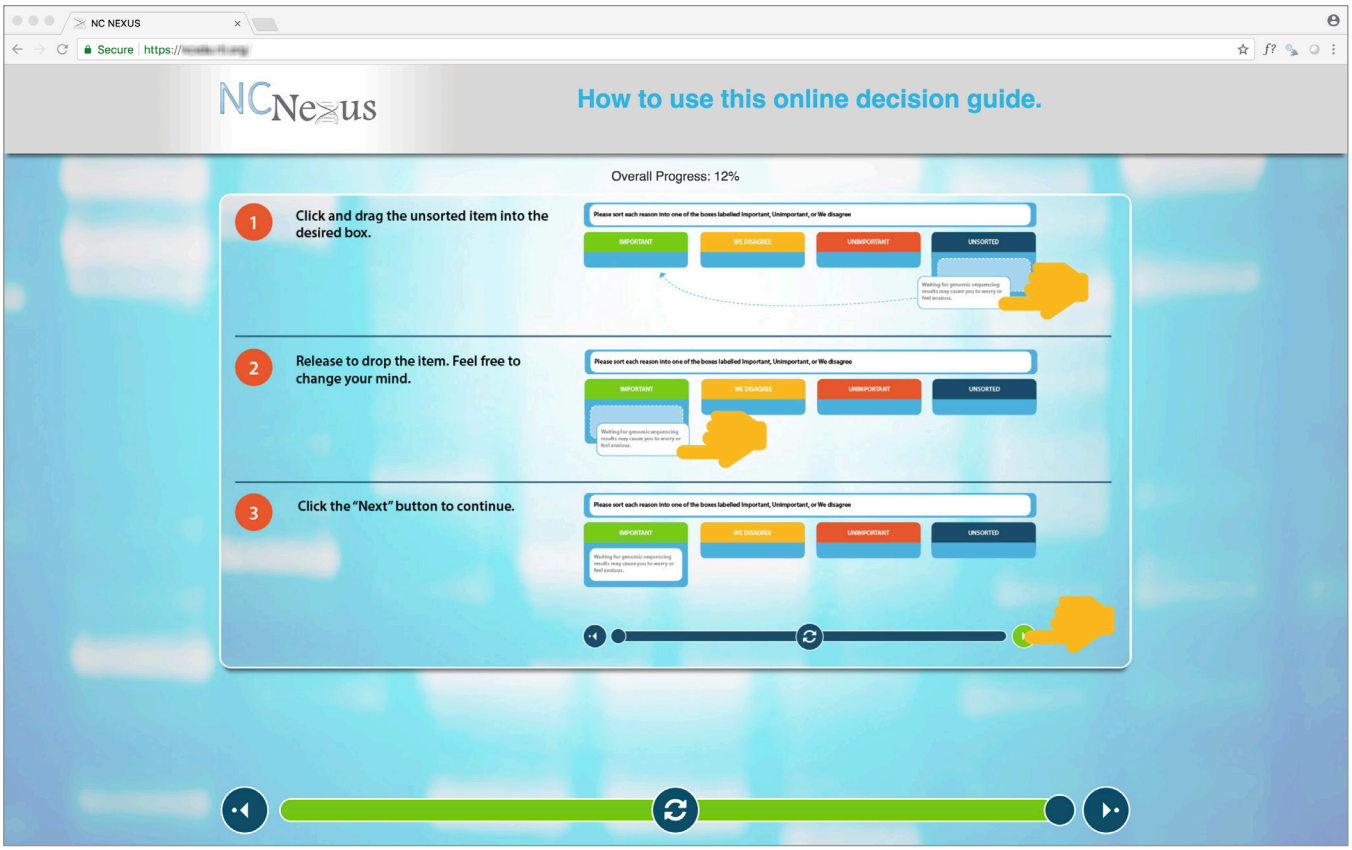
*screen*

7

*experimental condition*

- EDUCATION-ONLY
- EDUCATION + VALUES CLARIFICATION

*screenshot*




*voice-over script*

Other questions will ask you to sort items. Click and drag each item into the desired box. When you are done sorting the items, click the next button to continue.

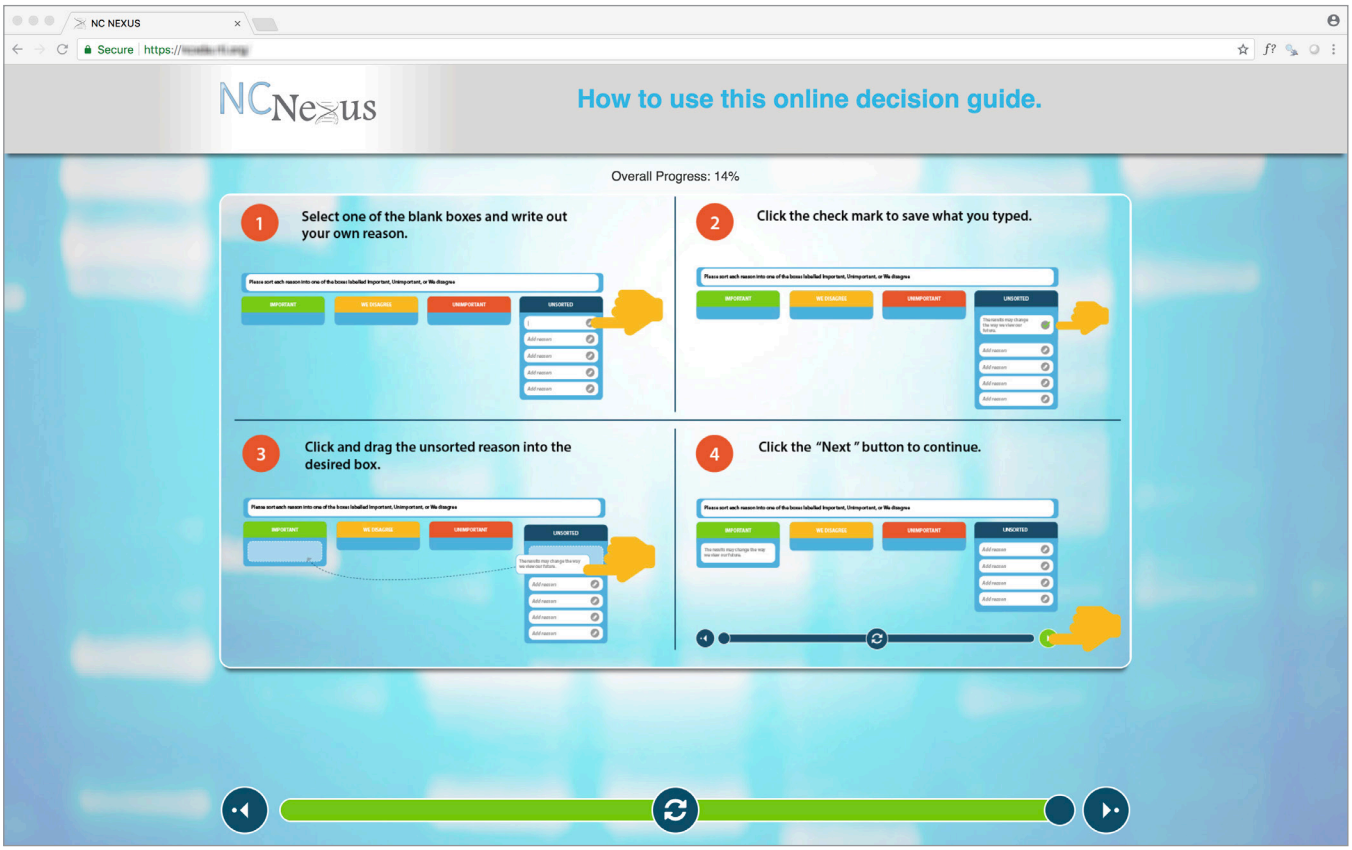
*screen*

8

*experimental condition*

- EDUCATION-ONLY
- EDUCATION + VALUES CLARIFICATION

*screenshot*




*voice-over script*

Some questions will ask you to type in your own thoughts or opinions. Click inside the text box, and then type your answer. When you are done typing, click the check mark to save what you typed.

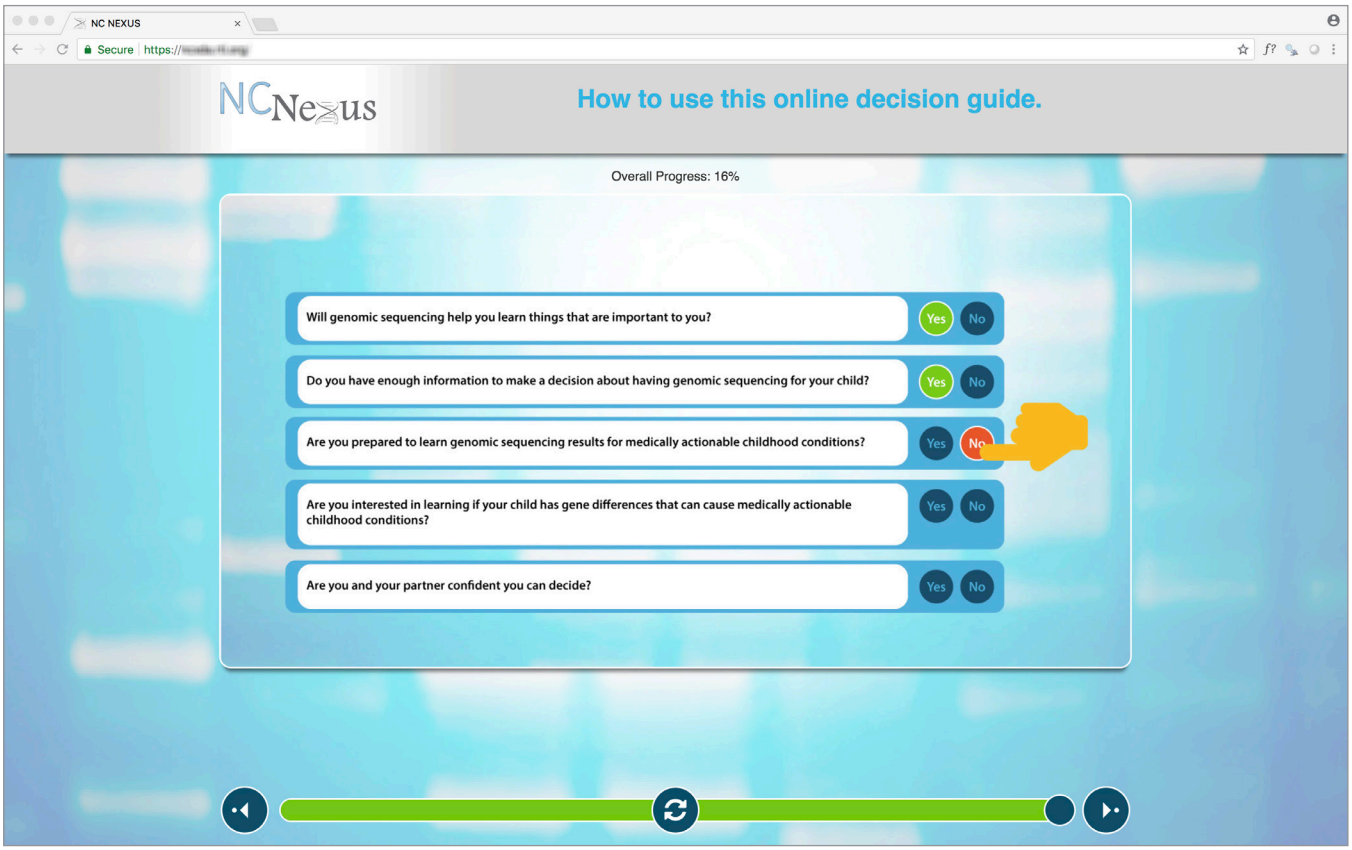
*screen*

9

*experimental condition*

- EDUCATION-ONLY
- EDUCATION + VALUES CLARIFICATION

*screenshot*




*voice-over script*

Lastly, some questions will ask you to select "yes" or "no." You can answer by clicking the button that matches your selection.

Now, if you're ready to begin, please click the next button

*screen*

10

*experimental condition*

- EDUCATION-ONLY
- EDUCATION + VALUES CLARIFICATION

*screenshot*


*voice-over script*

What is NC NEXUS?

NC NEXUS is a research study that offers you the option to have genomic sequencing for your child.

One goal of NC NEXUS is to find out how well genomic sequencing finds over 30 conditions that all babies in North Carolina are tested for at birth. This test is called newborn screening.

Another goal is to find out if genomic sequencing finds hundreds of other important conditions that are not part of newborn screening, but are otherwise similar to them.

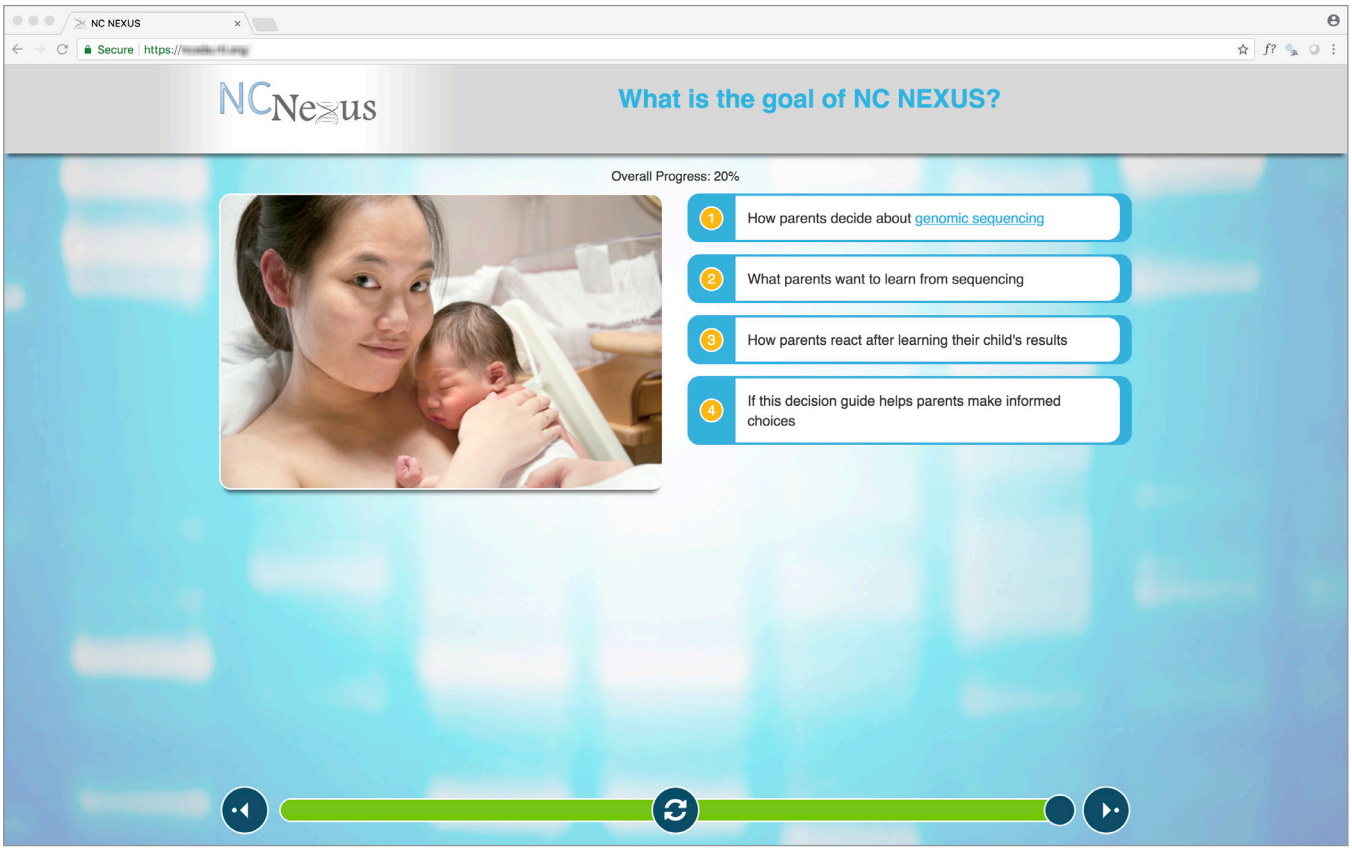
*screen*

11

*experimental condition*

- EDUCATION-ONLY
- EDUCATION + VALUES CLARIFICATION

*screenshot*




*voice-over script*

The NC NEXUS study team hopes to learn

- How parents like you decide if they want to have genomic sequencing for their child
- The types of information parents want to learn from genomic sequencing
- How parents react after learning their child's genomic sequencing results, and
- Whether this decision guide helps parents make informed choices about genomic sequencing

*screen*

12

*experimental condition*

- EDUCATION-ONLY
- EDUCATION + VALUES CLARIFICATION

*screenshot*


*voice-over script*

What is newborn screening?

Newborn screening is testing done when a baby is born to find serious conditions before a child becomes sick. The conditions found by newborn screening can cause disability or even death if they are not treated early.

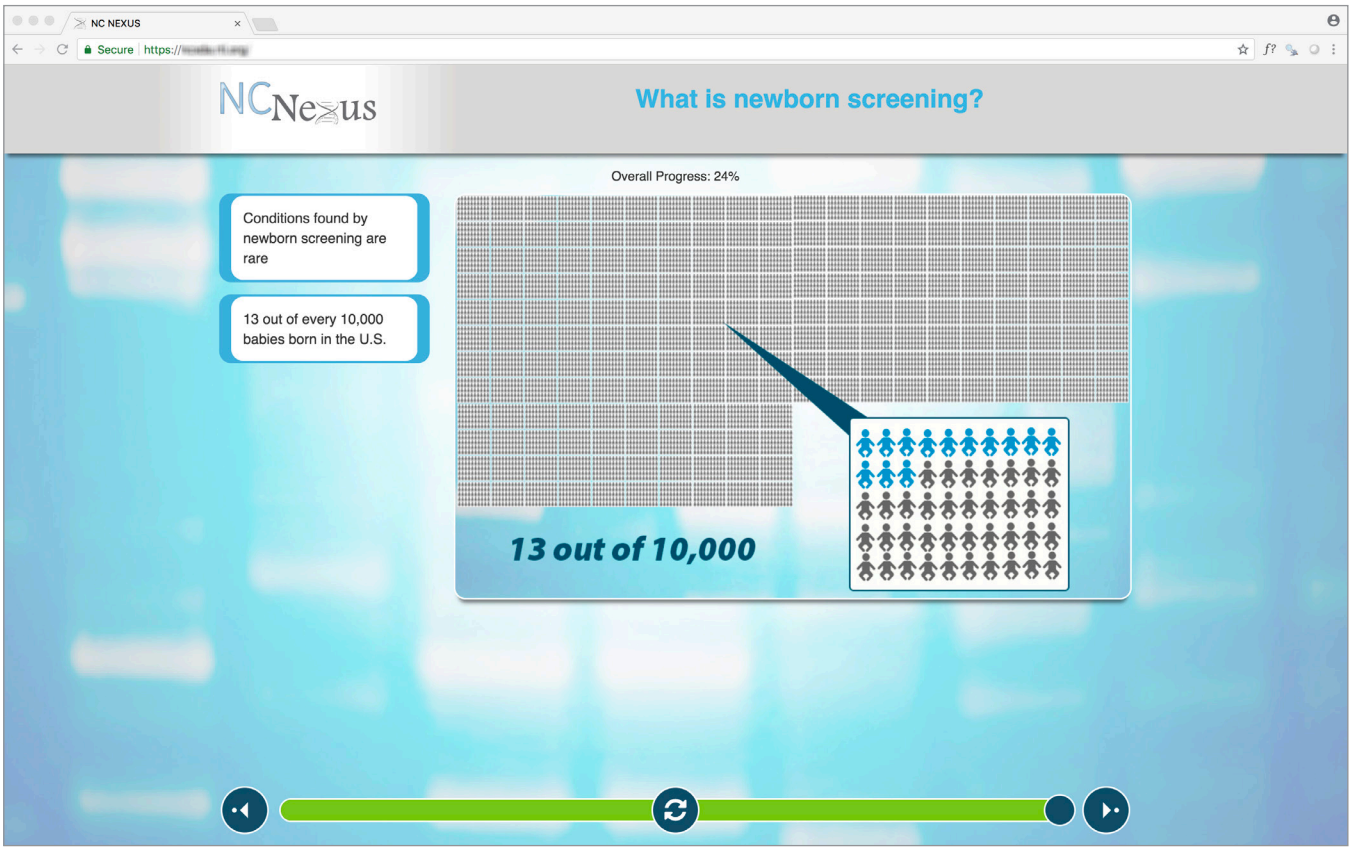
*screen*

13

*experimental condition*

- EDUCATION-ONLY
- EDUCATION + VALUES CLARIFICATION

*screenshot*




*voice-over script*

Most of the conditions are rare. Only about 13 out of every 10,000 babies born in the United States have a condition that can be found by newborn screening.

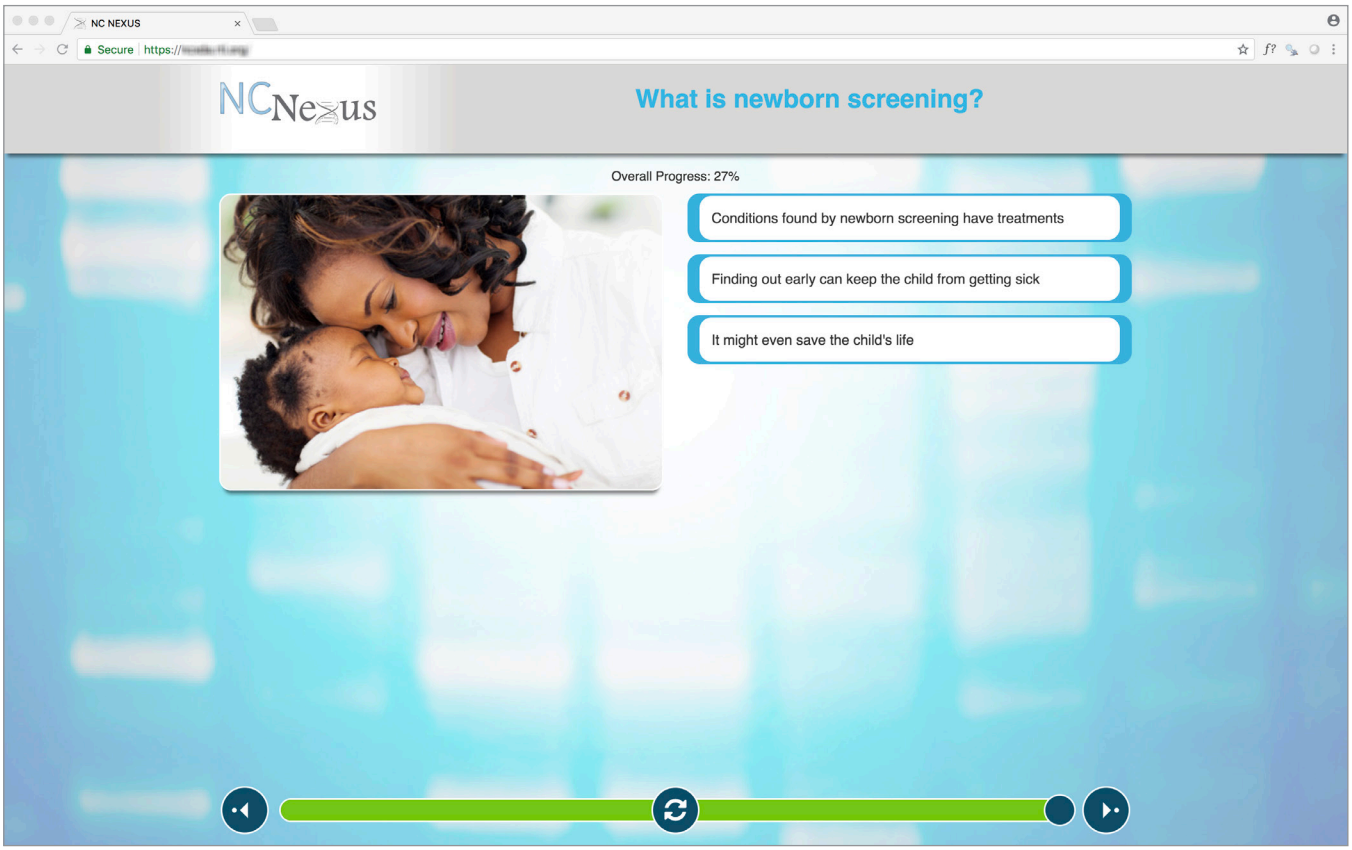
*screen*

14

*experimental condition*

- EDUCATION-ONLY
- EDUCATION + VALUES CLARIFICATION

*screenshot*




*voice-over script*

The conditions found by newborn screening have treatments. If a child has one of these conditions, finding out early can help keep him or her from getting sick. It might even save the child's life. If you decide to have genomic sequencing as part of the NC NEXUS study you would still have regular newborn screening when your baby is born.

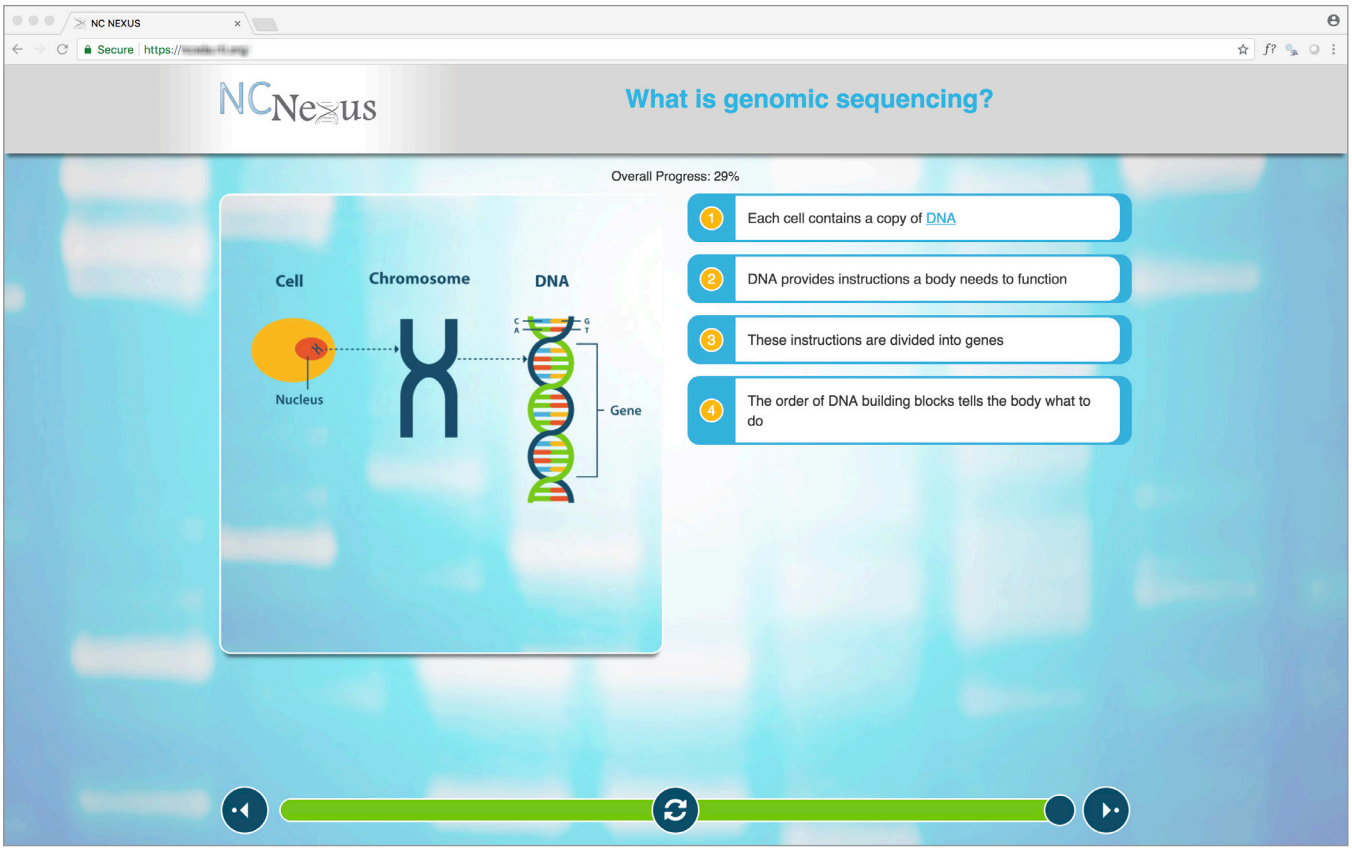
*screen*

15

*experimental condition*

- EDUCATION-ONLY
- EDUCATION + VALUES CLARIFICATION

*screenshot*




*voice-over script*

What is genomic sequencing?

Each cell in a person's body contains a copy of his or her DNA. DNA provides the instructions a person's body needs to grow and function. These instructions are divided into genes. Just like how the order of words in a sentence is important for understanding what you read, the order of DNA building blocks is important for telling the body's cells what to do.

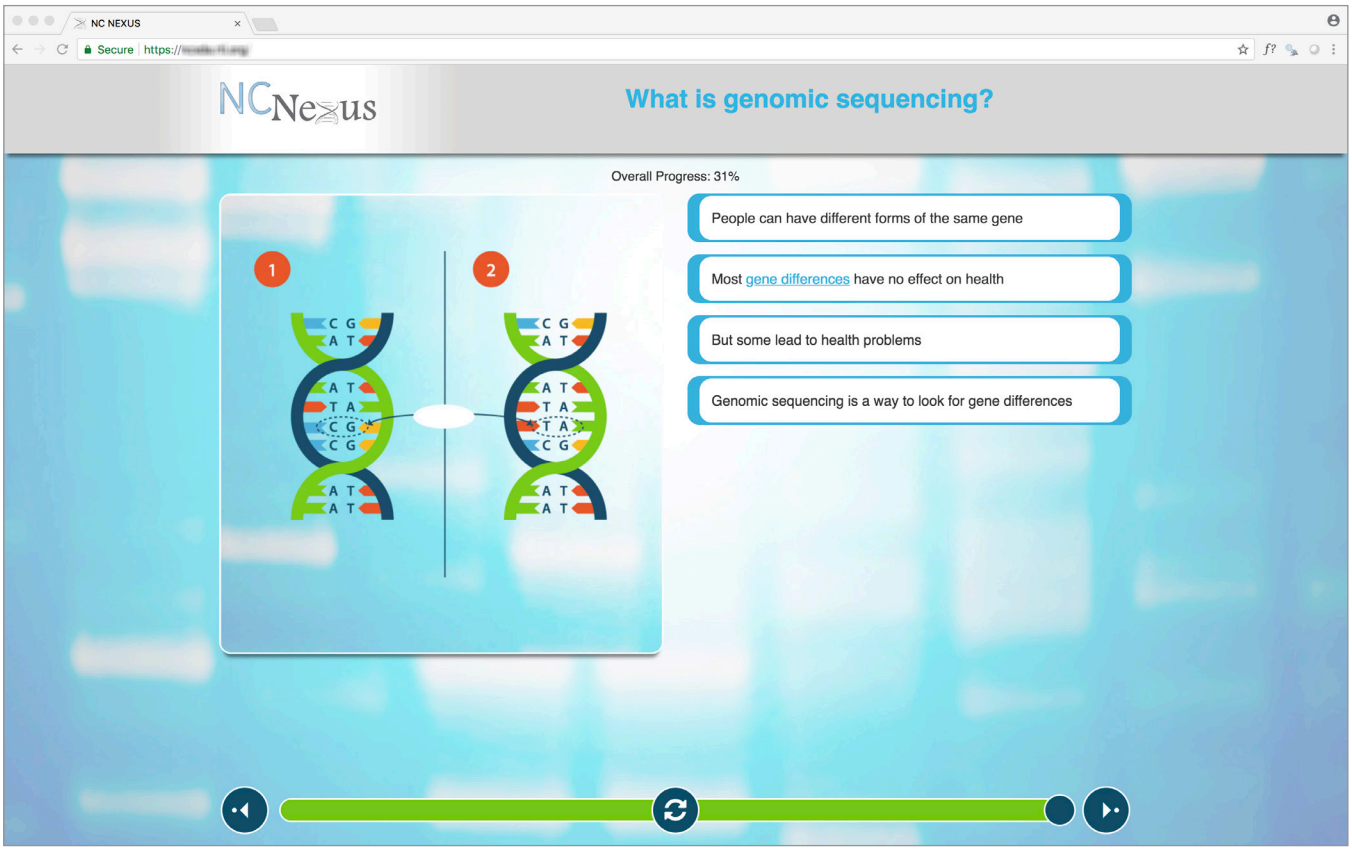
*screen*

16

*experimental condition*

- EDUCATION-ONLY
- EDUCATION + VALUES CLARIFICATION

*screenshot*




*voice-over script*

Differences in a person's DNA can cause people to have different forms of the same gene. Most often these gene differences, or variants, will have no effect on health, but some gene differences can lead to health problems.

Genomic sequencing is a way to look for differences in your child's DNA that could cause rare but serious health problems.

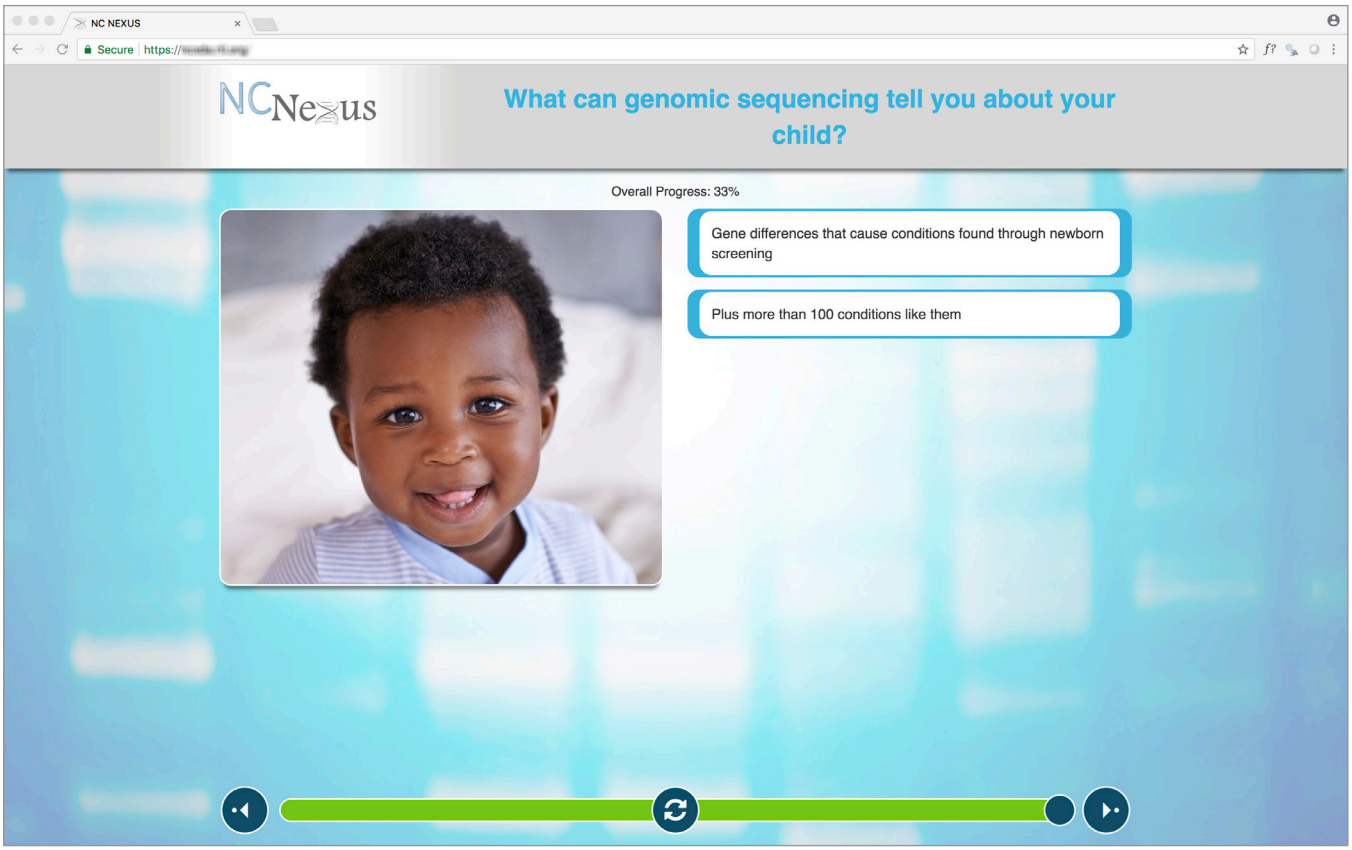
*screen*

17

*experimental condition*

- EDUCATION-ONLY
- EDUCATION + VALUES CLARIFICATION

*screenshot*




*voice-over script*

What Can Genomic Sequencing Tell You About Your Child?

In the NC NEXUS study, genomic sequencing will look for gene differences that cause the same conditions that are found through newborn screening, plus more than a hundred other conditions like them.

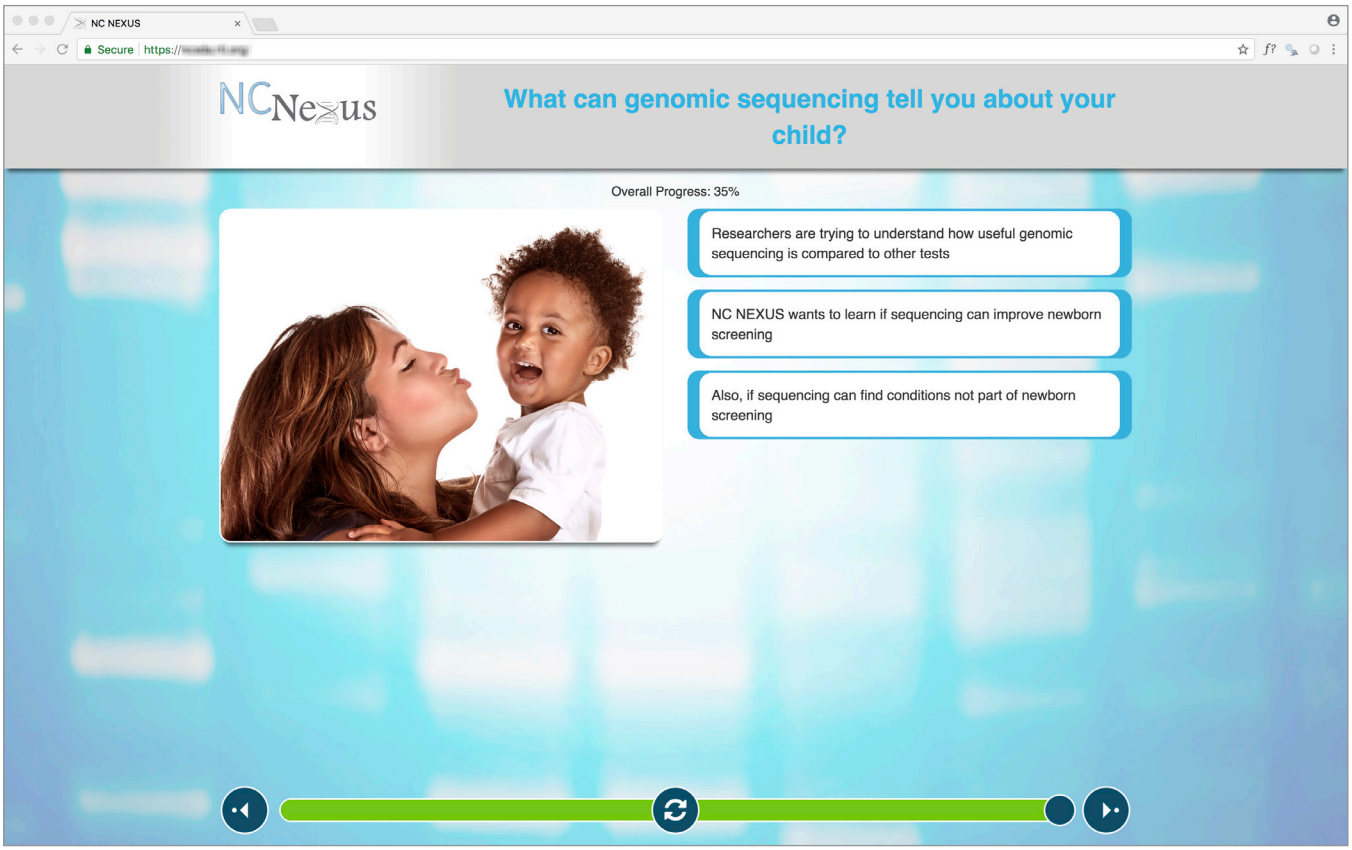
*screen*

18

*experimental condition*

- EDUCATION-ONLY
- EDUCATION + VALUES CLARIFICATION

*screenshot*




*voice-over script*

Researchers are still trying to understand how useful genomic sequencing is compared to other tests that tell people about their health. The NC NEXUS study team wants to learn if genomic sequencing can improve current newborn screening.

They also want to see if genomic sequencing can be used to find conditions that are not part of the current newborn screening, but could be in the future. These are rare conditions that affect children early in life and can be improved with early treatment.

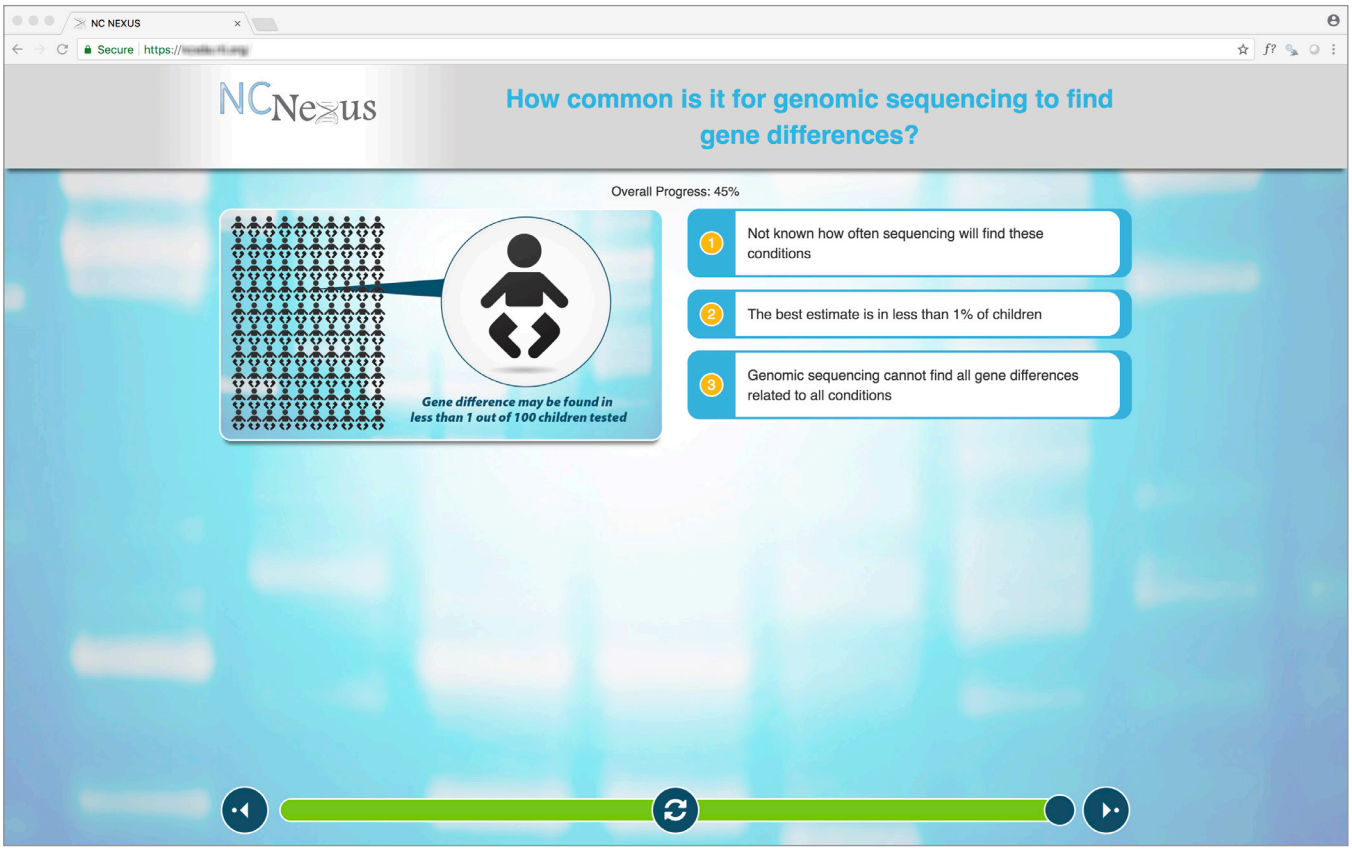
screen

19

experimental condition

- EDUCATION-ONLY
- EDUCATION + VALUES CLARIFICATION

screenshot




voice-over script

How common is it for genomic sequencing to find gene differences that cause medically actionable childhood conditions?

It is not known for sure how often genomic sequencing will find gene differences that cause these conditions. This is one of the things the NC NEXUS study will try to find out. The best estimate is that sequencing will find gene differences that cause these conditions in less than 1% of children. Genomic sequencing done by the NC NEXUS study cannot find all gene differences related to all medically actionable childhood conditions.

*screen*

20

*experimental condition*

- EDUCATION-ONLY
- EDUCATION + VALUES CLARIFICATION

*screenshot*


*voice-over script*

What is a medically actionable childhood condition?

These are rare but serious genetic conditions that…

- Usually begin during childhood and are medically actionable; that is, they
- Can be improved with early treatment, and
- The benefits of treatment typically outweigh the risks.

In addition to over 30 conditions that are part of current newborn screening, the NC NEXUS study will look for more than a hundred other conditions like them.

The signs and symptoms of medically actionable childhood conditions differ greatly from one to the next.

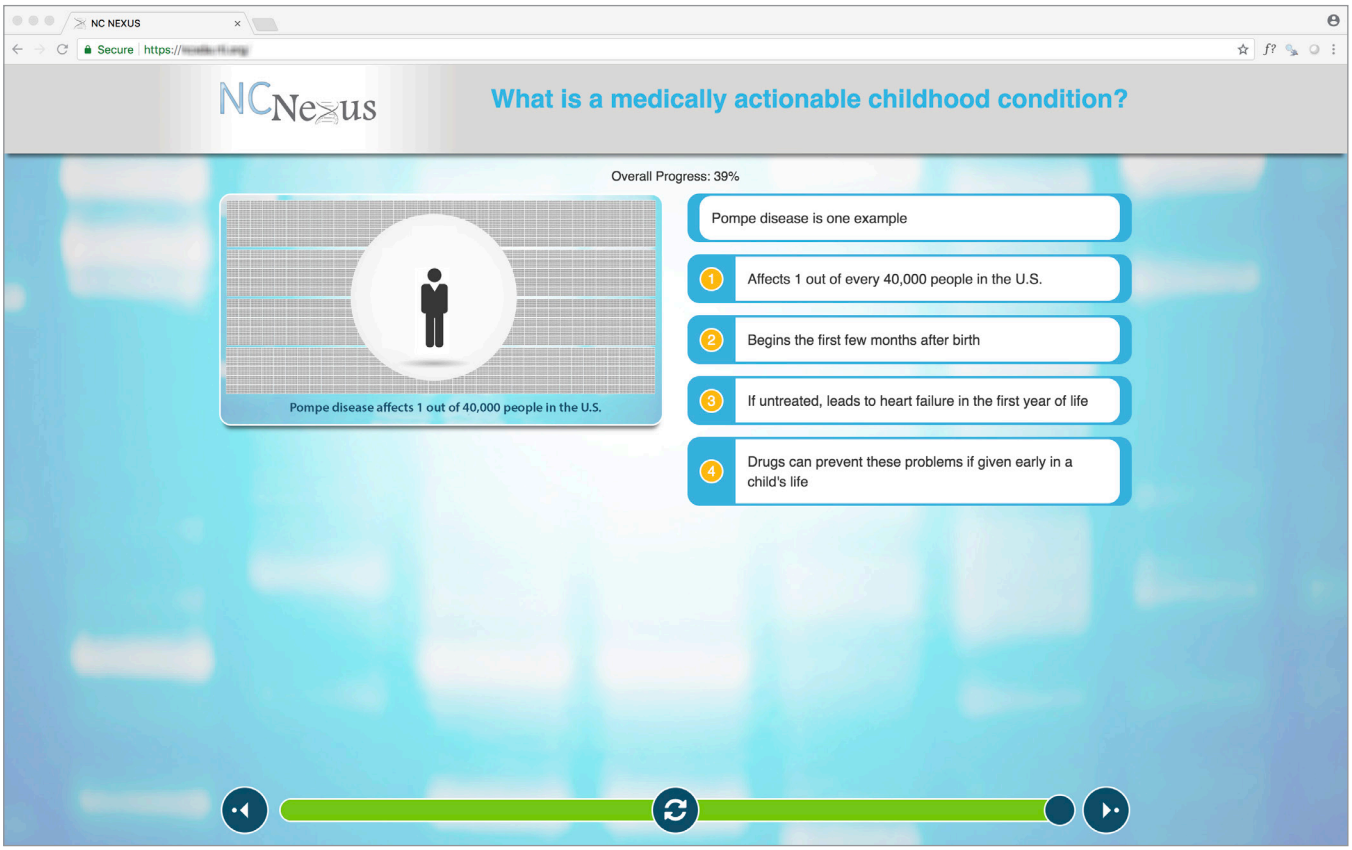
*screen*

21

*experimental condition*

- EDUCATION-ONLY
- EDUCATION + VALUES CLARIFICATION

*screenshot*




*voice-over script*

Pompe disease is one example of a medically actionable childhood condition. Pompe disease affects about 1 out of every 40,000 people in the United States and usually begins in the first few months after birth. Children who have Pompe disease have weak muscles so they are not able to do things like hold their heads up or crawl at the same age as other babies. Other signs of Pompe disease include an enlarged liver and heart problems. If untreated, Pompe disease often leads to heart failure and death in the first year of life. There are drugs that can prevent some of these problems if given early in a child's life.

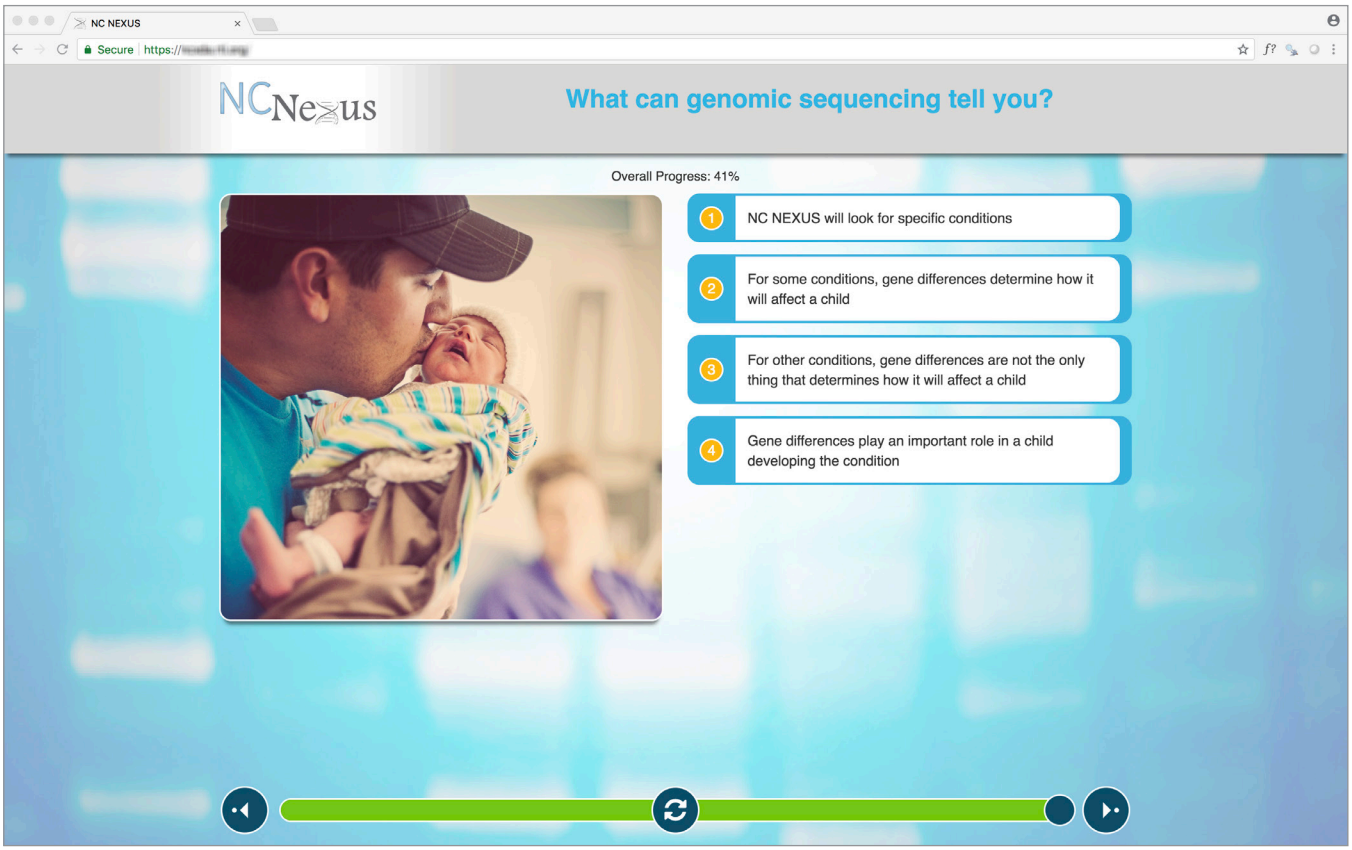
*screen*

22

*experimental condition*

- EDUCATION-ONLY
- EDUCATION + VALUES CLARIFICATION

*screenshot*




*voice-over script*

What can genomic sequencing tell you about medically actionable childhood conditions?

The NC NEXUS team will look for gene differences that are known to cause specific conditions. For some medically actionable childhood conditions, these gene differences determine how the condition will affect a child. For other conditions, these gene differences are not the only thing that determines how the condition will affect a child, but they are known to play an important role in a child developing the condition.

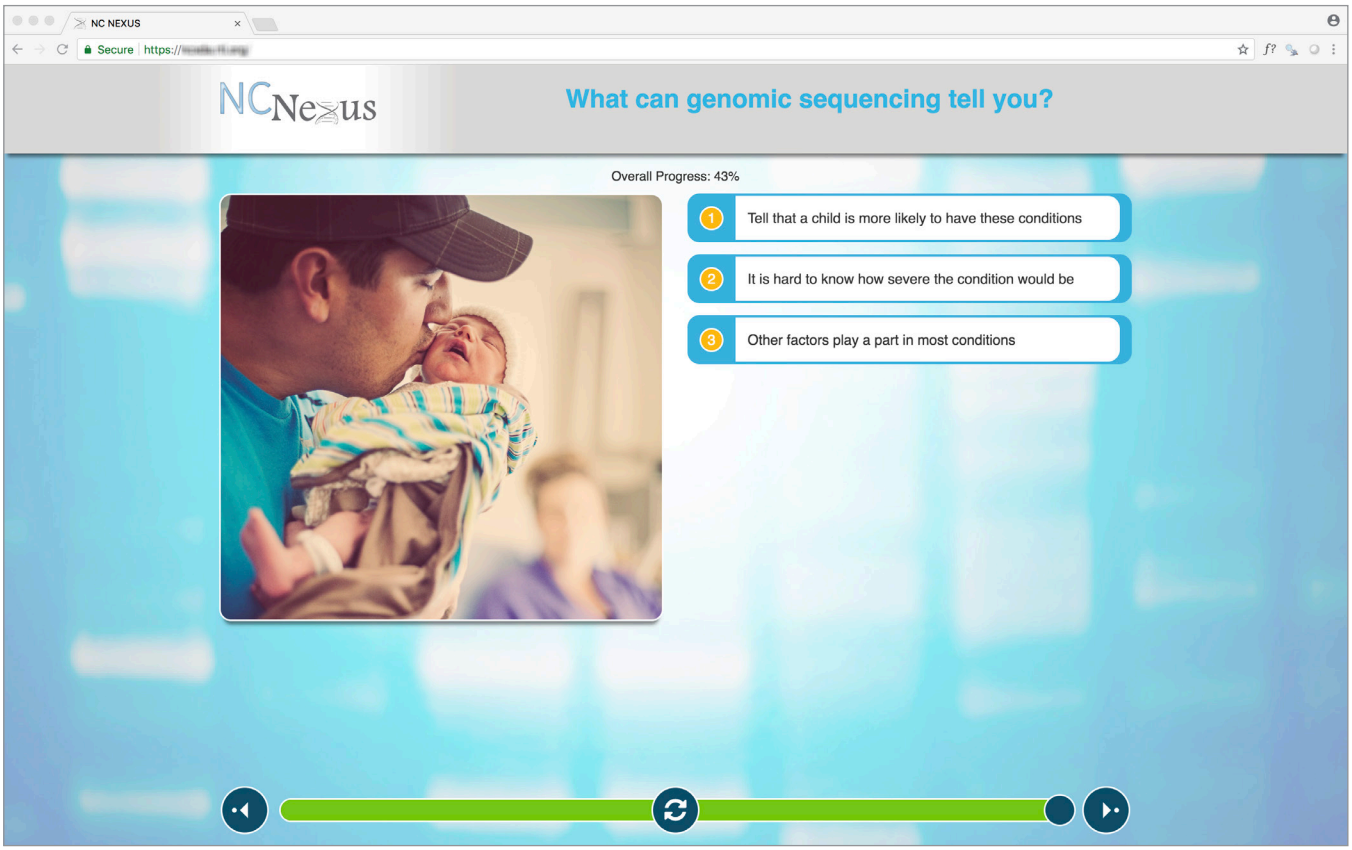
*screen*

23

*experimental condition*

- EDUCATION-ONLY
- EDUCATION + VALUES CLARIFICATION

*screenshot*




*voice-over script*

Finding these gene differences in your child's DNA can tell that he or she is more likely to have one of these conditions during childhood. Still, it is hard to know for sure how severe the condition would be because other factors also play a part in most conditions.

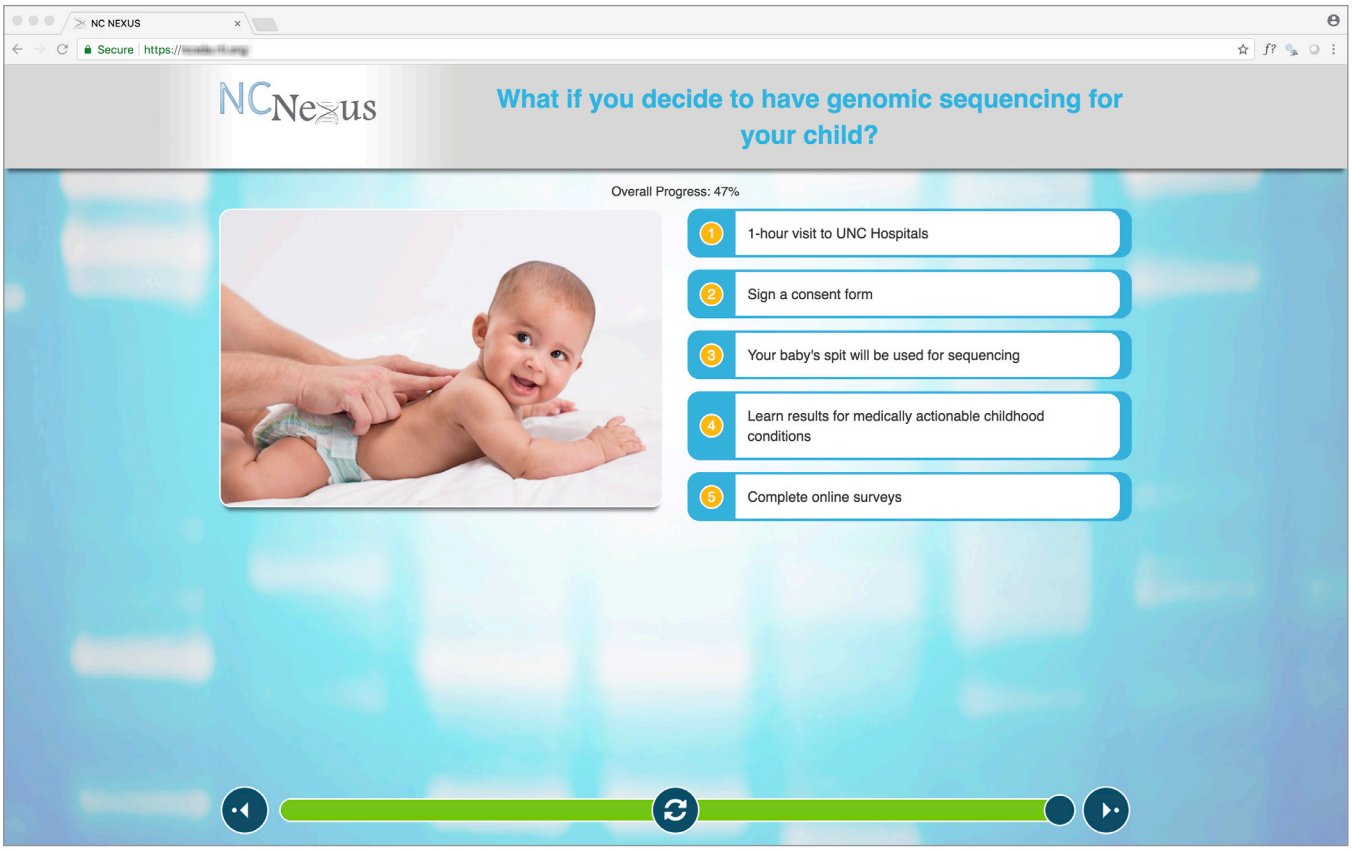
*screen*

**24**

*experimental condition*

- EDUCATION-ONLY
- EDUCATION + VALUES CLARIFICATION

*screenshot*




*voice-over script*

What will happen if you decide to have genomic sequencing for your child?

- If you decide you want your child to have genomic sequencing in NC NEXUS, you will come to UNC Hospitals. The visit will take about one hour.
- If you consent to sequencing, we will ask you to sign a consent form.
- After your baby is born, you will come back to UNC Hospitals. A small sponge will be lightly rubbed inside your baby's mouth to get saliva, or spit, that will be used for sequencing.
- After the sequencing is done, you will learn results for medically actionable childhood conditions found by new born screening, and many other conditions like them.
- All parents in the study will complete several online surveys.

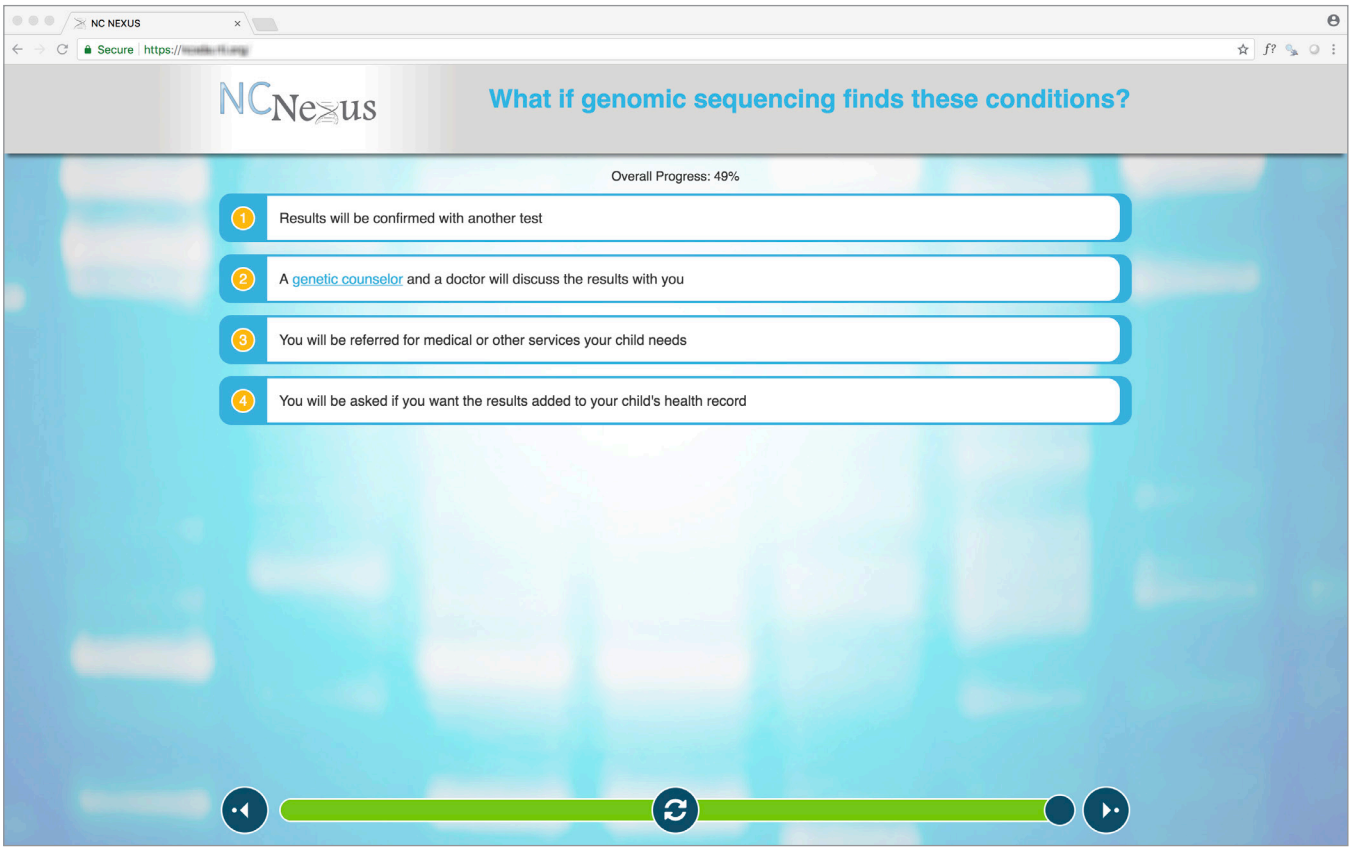
*screen*

25

*experimental condition*

- EDUCATION-ONLY
- EDUCATION + VALUES CLARIFICATION

*screenshot*




*voice-over script*

What if genomic sequencing finds that your child has gene differences that cause these conditions?

- The results will be confirmed with another test.
- A genetic counselor and a doctor will meet with you to discuss the results.
- You will be referred for medical or other services your child needs for those conditions.
- You will be asked if you want the results added to your child's health record at UNC Hospitals.

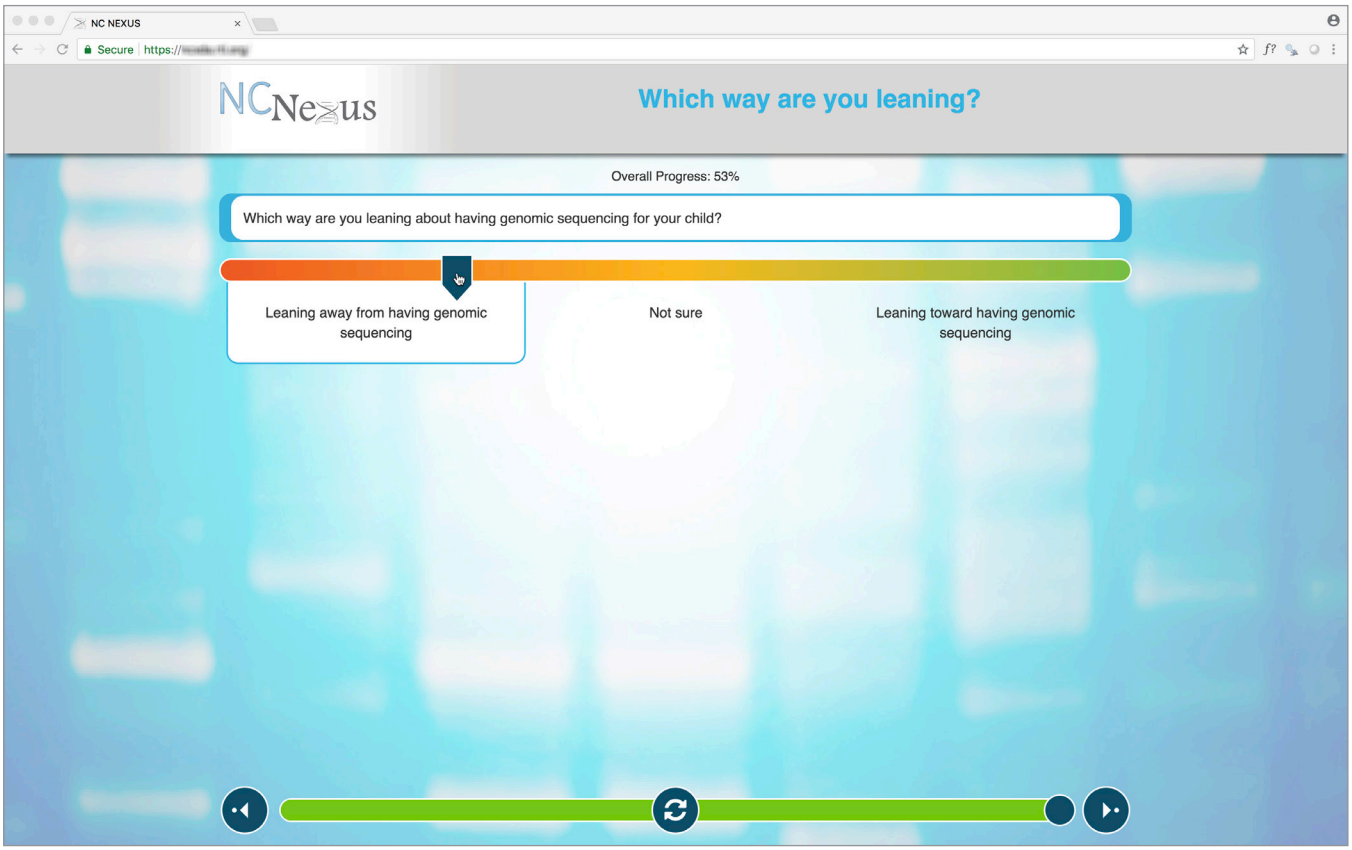
*screen*

26

*experimental condition*

- ○ EDUCATION-ONLY
- ● EDUCATION + VALUES CLARIFICATION

*screenshot*




*voice-over script*

Which way are you leaning?

If you had to decide right now, which way are you leaning about having genomic sequencing for your child in NC NEXUS?

Click and drag the slider, moving it to the point on the scale that fits your answer.

- Leaning away from having genomic sequencing
- 
- Not sure
- 
- Leaning toward having genomic sequencing

When you are done, click the next button to continue.

*screen*

27

*experimental condition*

- ○ EDUCATION-ONLY
- ● EDUCATION + VALUES CLARIFICATION

*screenshot*


*voice-over script*

The following screens will show you some reasons for and some reasons against having genomic sequencing for your child. Thinking about which reasons matter most to you can help you make a decision.

*screen*

28

*experimental condition*

- ○ EDUCATION-ONLY
- ● EDUCATION + VALUES CLARIFICATION

*screenshot*


*voice-over script*

First, tell us if the following reasons for your child to have genomic sequencing in NC NEXUS are important or unimportant to you. Please sort these "reasons for" into the boxes labelled important or not important. You can sort as many or as few reasons into each box as you want. To sort, click the reason and drag it into a box. .

- Knowing your child has a genetic condition may help him or her get early treatment and support services.

When you are done sorting, click the next button to move on to the next reason.

*screen*

29

*experimental condition*

- ○ EDUCATION-ONLY
- ● EDUCATION + VALUES CLARIFICATION

*screenshot*


*voice-over script*

- Knowing your child has a genetic condition may help you and your family be prepared if he or she develops the condition.

*screen*

30

*experimental condition*

- ○ EDUCATION-ONLY
- ● EDUCATION + VALUES CLARIFICATION

*screenshot*


*voice-over script*

- Genomic sequencing may help doctors understand genetic conditions better.

*screen*

31

*experimental condition*

- ○ EDUCATION-ONLY
- ● EDUCATION + VALUES CLARIFICATION

*screenshot*


*voice-over script*

- Genomic sequencing may help scientists make better tools for finding serious conditions before people get sick.

*screen*

32

*experimental condition*

- ○ EDUCATION-ONLY
- ● EDUCATION + VALUES CLARIFICATION

*screenshot*


*voice-over script*

- You would rather not wait to see if any problems occur to find out if your child may have a genetic condition.

*screen*

33

*experimental condition*

- ○ EDUCATION-ONLY
- ● EDUCATION + VALUES CLARIFICATION

*screenshot*


*voice-over script*

Are there any other reasons you can think of? Please type them in the text boxes labelled “Add reason”

When you are done sorting, click the next button to continue.

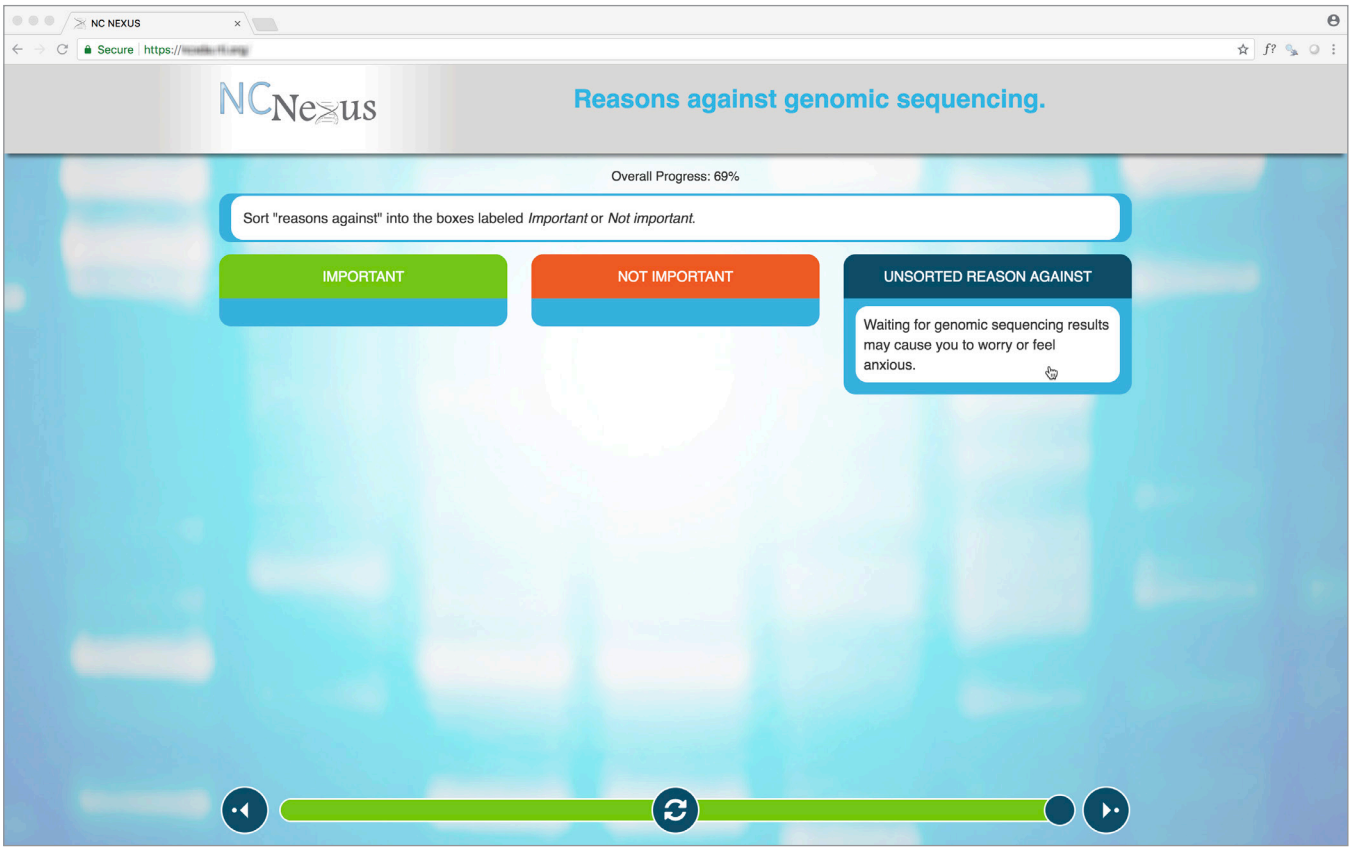
*screen*

34

*experimental condition*

- ○ EDUCATION-ONLY
- ● EDUCATION + VALUES CLARIFICATION

*screenshot*




*voice-over script*

Now we would like you to tell us if the following reasons against your child having genomic sequencing are important or unimportant to you. Please sort these "reasons against" into the boxes labeled important or not important.

- Waiting for genomic sequencing results may cause you to worry or feel anxious.

When you are done sorting, click the next button to move on to the next reason.

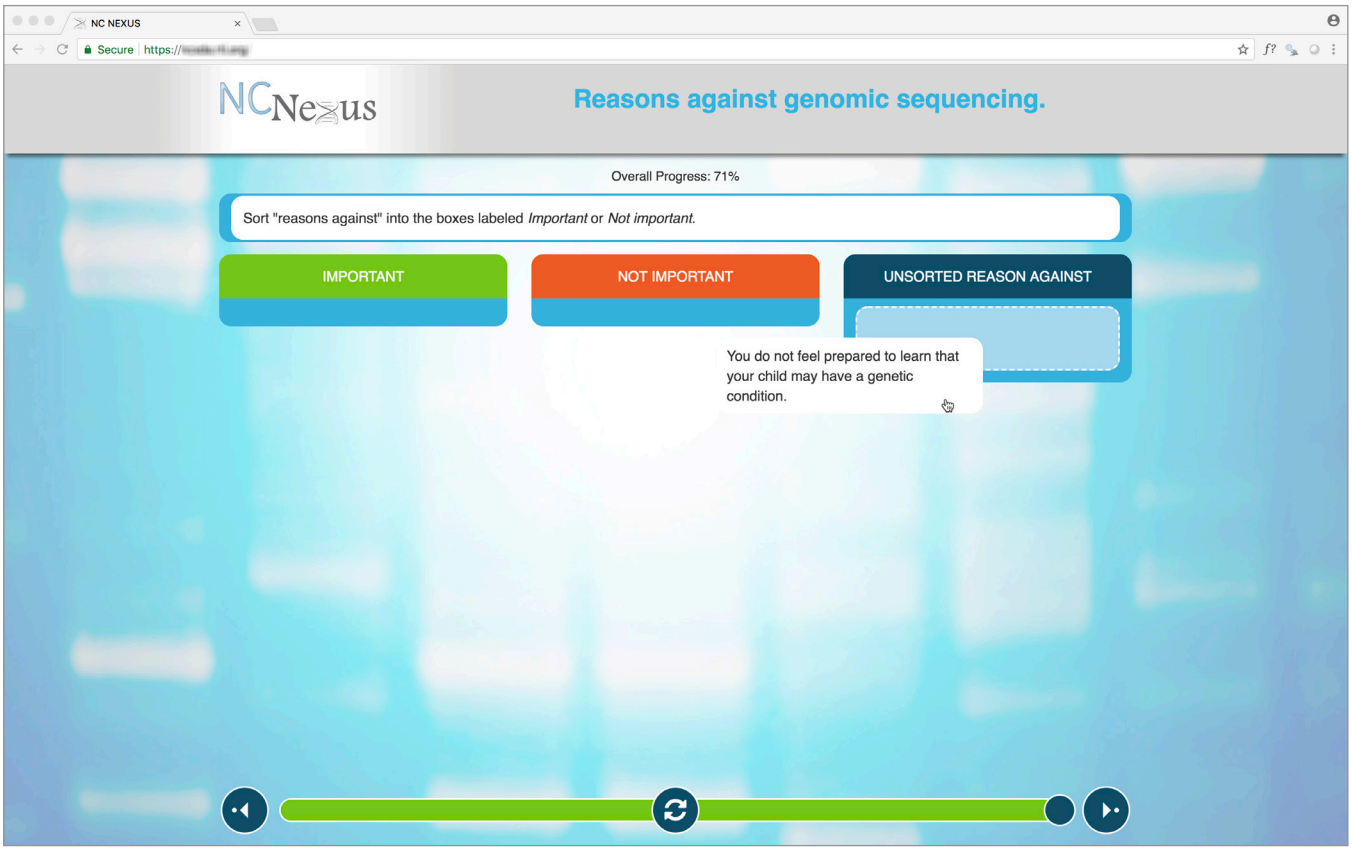
*screen*

35

*experimental condition*

- ○ EDUCATION-ONLY
- ● EDUCATION + VALUES CLARIFICATION

*screenshot*




*voice-over script*

- You do not feel prepared to learn that your child may have a genetic condition.

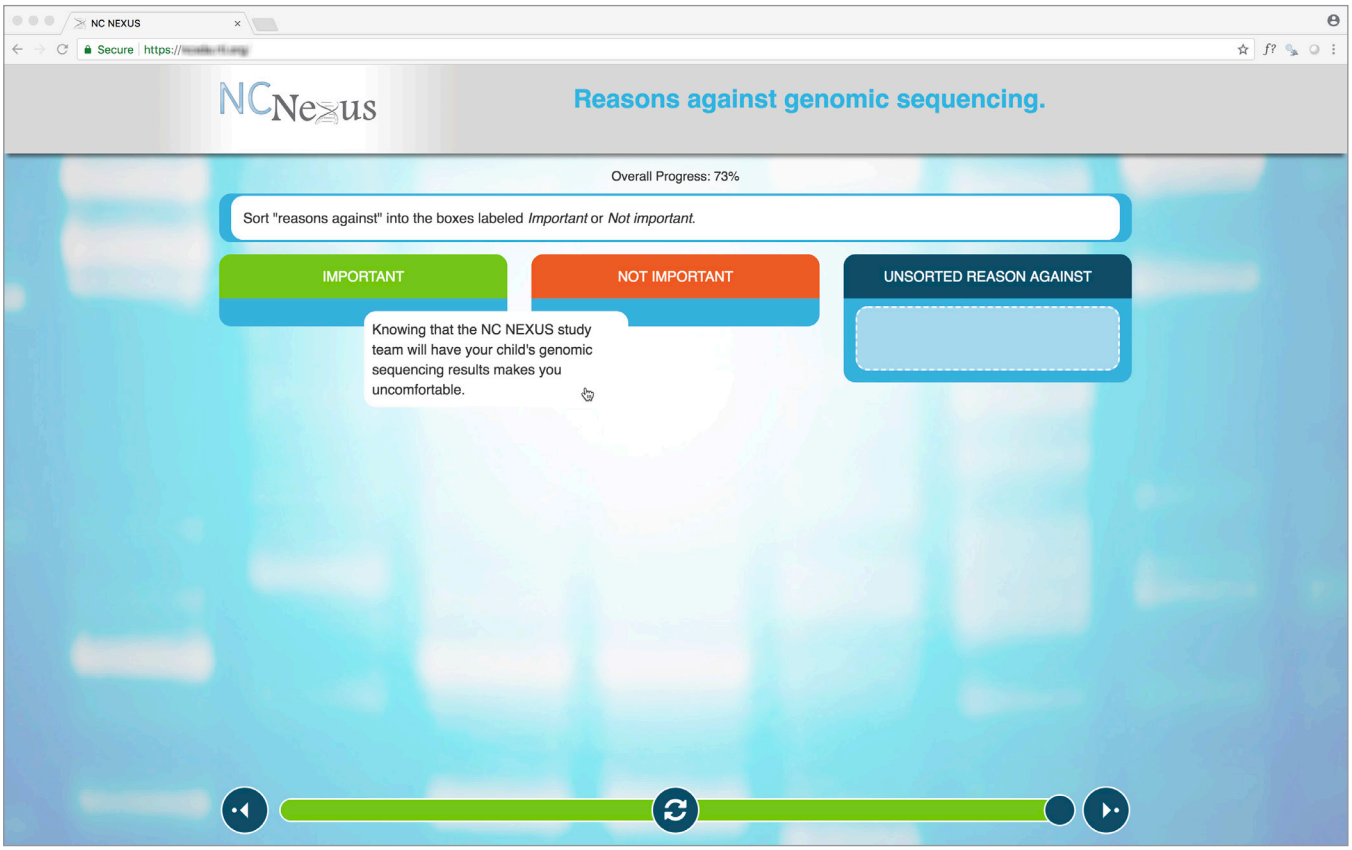
*screen*

36

*experimental condition*

- ○ EDUCATION-ONLY
- ● EDUCATION + VALUES CLARIFICATION

*screenshot*




*voice-over script*

- Knowing that the NC NEXUS study team will have your child's genomic sequencing results makes you uncomfortable.

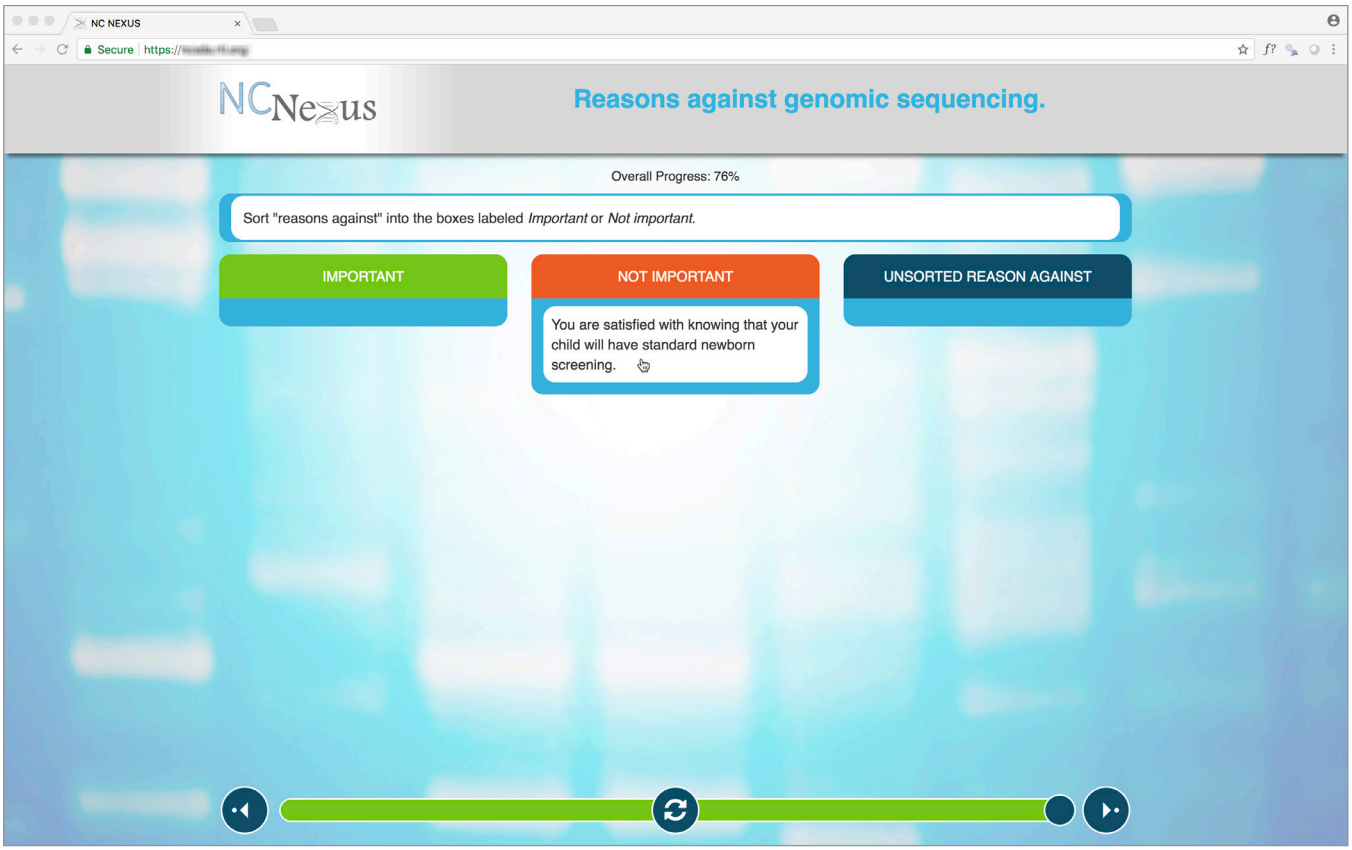
*screen*

37

*experimental condition*

- ○ EDUCATION-ONLY
- ● EDUCATION + VALUES CLARIFICATION

*screenshot*




*voice-over script*

- You are satisfied with knowing that your child will have standard newborn screening.

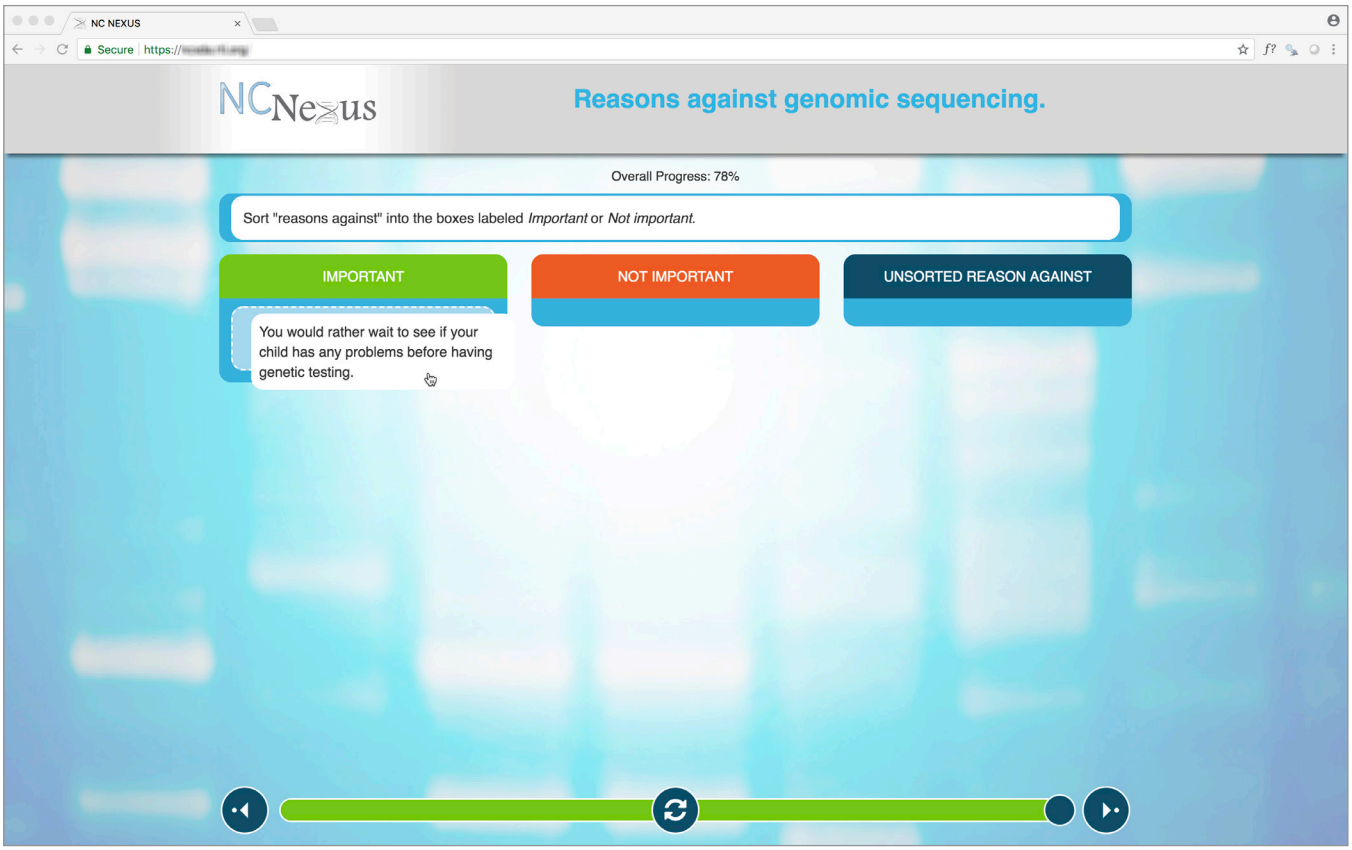
*screen*

38

*experimental condition*

- ○ EDUCATION-ONLY
- ● EDUCATION + VALUES CLARIFICATION

*screenshot*




*voice-over script*

- You would rather wait to see if your child has any problems before having genetic testing.

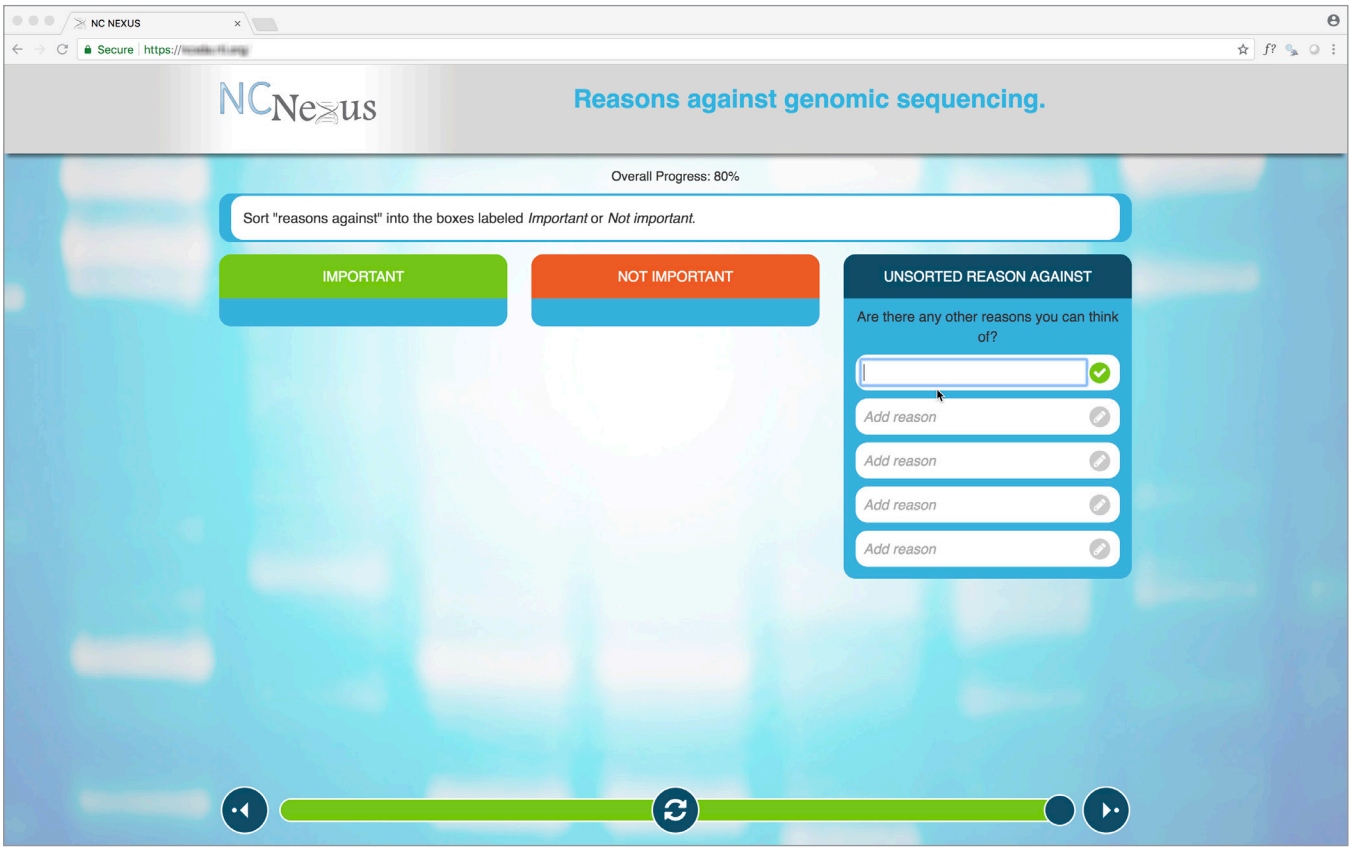
*screen*

39

*experimental condition*

- ○ EDUCATION-ONLY
- ● EDUCATION + VALUES CLARIFICATION

*screenshot*




*voice-over script*

Are there any other reasons against having genomic sequencing that you can think of? Please type them in the text boxes labelled "Add reason"

When you are done sorting, click the next button to continue.

screen

40

experimental condition

- ○ EDUCATION-ONLY
- ● EDUCATION + VALUES CLARIFICATION

screenshot


voice-over script

Here are the reasons for and against genomic sequencing for your child that are important to you. This is a summary of what you just sorted. When you are done reviewing these reasons, click the next button to continue.

*screen*

41

*experimental condition*

- ○ EDUCATION-ONLY
- ● EDUCATION + VALUES CLARIFICATION

*screenshot*


*voice-over script*

Here are some questions that can help you decide if you want your child to have genomic sequencing in NC NEXUS.

Please answer "yes" or "no" to the following questions. You can pick your answers by clicking the button that matches your selection.

- Will having genomic sequencing for your child help you learn things that are important to you?
- Do you have enough information to make a decision about having genomic sequencing for your child?
- Are you prepared to learn genomic sequencing results for medically actionable childhood conditions?
- Are you interested in learning if your child has gene differences that can cause medically actionable childhood conditions?
- Are you confident you can make the decision that is right for you and your family?

When you are done, click the next button to continue.

*screen*

42

*experimental condition*

- ○ EDUCATION-ONLY
- ● EDUCATION + VALUES CLARIFICATION

*screenshot*


*voice-over script*

If you answered Yes to more of these questions, maybe you are ready for your child to have genomic sequencing. If you answered No to more, maybe this is not the right decision for your family at this time. Or you might still need more time or information to decide.

You should make the decision that is best for you and your family. There are no right or wrong choices.

*screen*

43

*experimental condition*

- EDUCATION-ONLY
- EDUCATION + VALUES CLARIFICATION

*screenshot*


*voice-over script*

You have a decision to make at this time.

Do you want your child to have genomic sequencing for conditions like those found in newborn screening?

Click and drag the slider, moving it to the point on the scale that best fits your answer.

- No, I do not want my child to have genomic sequencing at this time for conditions like those found in newborn screening. I do not want to schedule a study visit.
- I'm not sure if I want my child to have genomic sequencing or not, but I want to schedule a study visit with a genetic counselor at UNC Hospitals to discuss the decision.
- Yes, I want my child to have genomic sequencing for conditions like those found in newborn screening. I want to schedule a study visit with a genetic counselor at UNC Hospitals.

If you select "Yes" or "I'm not sure," a member of the NC NEXUS study team will contact you to schedule a study visit at UNC Hospitals. Remember, even if you decide to schedule a study visit, you can change your mind and stop participation in this study at any point in time.

When you are done making your decision, click the next button to continue.

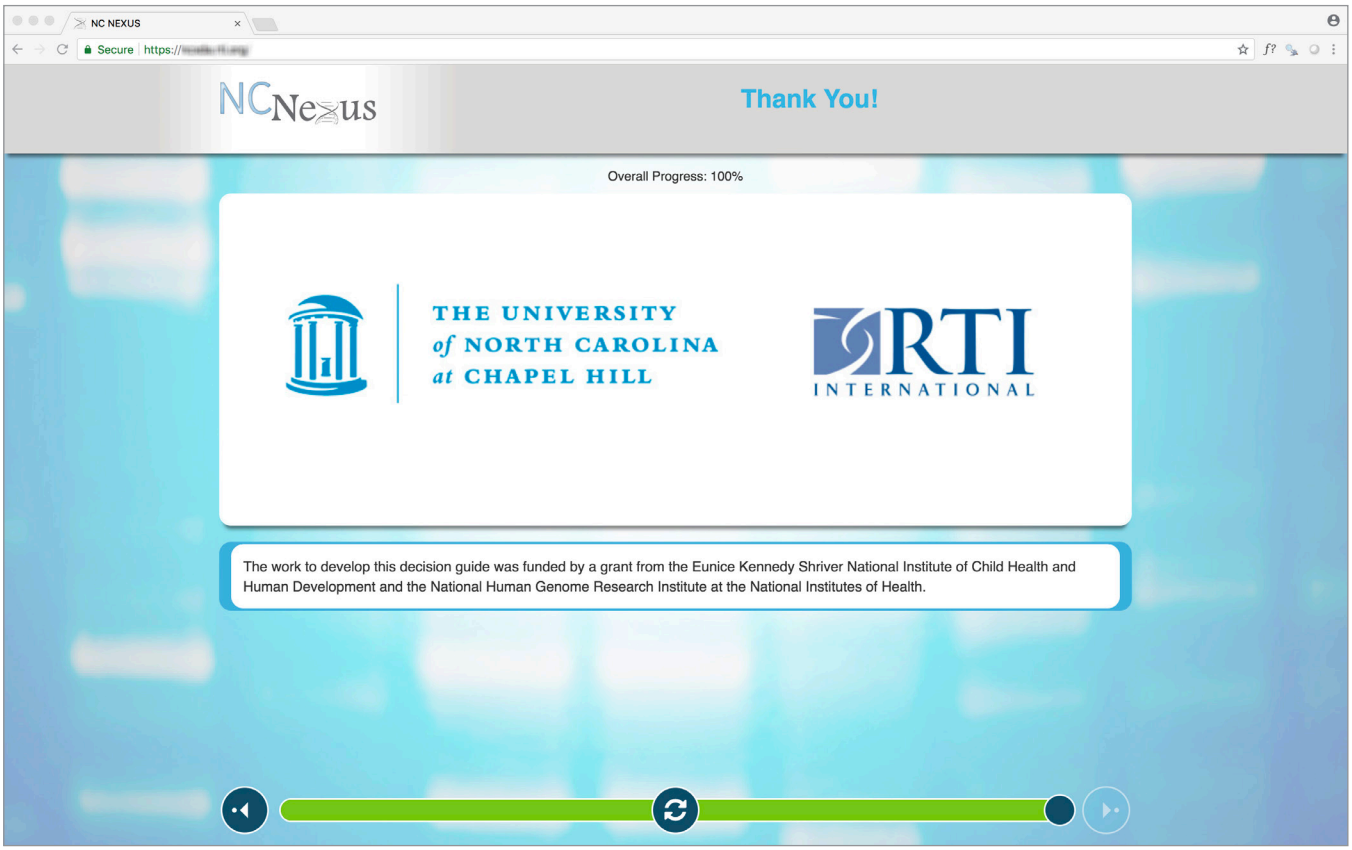
*screen*

**44**

*experimental condition*

- EDUCATION-ONLY
- EDUCATION + VALUES CLARIFICATION

*screenshot*




*voice-over script*

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