# Attachment L

Pre-Post Study Questionnaire

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Public reporting burden for this collection of information is estimated to average 240 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-XXXX). Do not return the completed form to this address.

#### **PRE-TEST**

#### **Section 1**

Instructions: Please select the best answer underneath each question.

#### 1. What is a clinical trial?

- O A type of research study
- O A place you can go to the doctor for free
- O When a new clinic opens in the neighborhood

#### 2. Who is involved in a clinical trial?

- O You
- O Doctor
- O Research Team
- O All of the above

#### 3. What is an example of a **COST** of participating in a clinical trial?

- O Helping other people in the future
- O Time away from school or home
- O Close monitoring of health
- O Access to medical care

#### 4. What is assent?

- O When parents give their "ok" for their child to be a part of a research study
- O When a child agrees to participate in research
- O When the doctor signs a child up for a study
- O When the research team invites you to participate in a study

#### 5. Once you agree to participate, can you stop before the study is over?

- 0 Yes
- O No
- O It depends if you are being paid to participate

# 6. If your parents give their permission for you to participate in a clinical trial, is it ok for you to say NO?

- 0 Yes
- O No
- O It depends on what the doctor says.

#### 7. Do all clinical trials have to take the same amount of time?

0 Yes

O No

- 8. Do you think that clinical trials can help find new medicines and treatments for kids who have an illness or disease?
  - 0 Yes
  - O No

Section 2
Instructions: Please select the best answer next to each question.

	Very Good	Good	Not Good
How do you feel about kids participating in clinical trials?	0	0	0
How do you feel about being part of a clinical trial some day?	0	0	0
How would you feel if your friend or your family member was in a clinical trial?	0	0	0
How do you feel about helping kids' health in the future by participating in a clinical trial?	0	0	0

	Very Important	Important	Not Important
How important is it to participate in a clinical trial to test a new ways for you or other kids to feel better?	0	0	0

	Yes	No	Maybe
If you were offered a chance to be in a clinical trial, would you want to participate?	0	0	0

Section 3
Instructions: How sure are you that you can do the following things? Please select the best answer next to each question.

Finding/Getting Information	1 I cannot do it at all.	2	3 I maybe can do it.	4	5 I know I can do it.
Use this website to help me learn more information	0	0	0	0	0
Ask doctor(s) questions for more information about clinical trials	0	0	0	0	0
Ask my parents questions for more information about clinical trials	0	0	0	0	0
Ask research team members questions for more information about clinical trials	0	0	0	0	0
Ask my doctor for help when I am confused about any part of the clinical trial	0	0	0	0	0
Ask the research team members for help when I am confused about any part of the clinical trial.	0	0	0	0	0

Communication with Others	1 I cannot do it at all.	2	3 I maybe can do it.	4	5 I know I can do it.
Tell my parents that I don't want to participate in the clinical trial, even if they really want me to do it	0	0	0	0	O
Express my opinions about clinical research even when people disagree with me	0	0	0	0	0
Stand up for myself when I feel like I am being treated wrongly	0	0	0	0	0
Stand up for myself when someone is asking me to do something I am not comfortable with	0	0	0	0	0
Talk to my parents if I am not feeling well during the clinical trial	0	0	0	0	0
Tell my doctor if I am feeling sick or have problems during the clinical trial	0	0	0	0	0
Tell my doctor if I want to stop the clinical trial	0	0	0	0	0
Tell my parents if I want to stop the clinical trial	0	0	0	0	0
Tell the research team if I want to stop the clinical trial	0	0	0	0	0

## **Background Information**

**Instructions:** These questions are going to ask about yourself. Please read each statement carefully and select your answer.

1. Are yo	ou male or femal	e?			
Male O		Female O			
2. Are yo	ou of Hispanic, La	atino or Spani	sh origin?		
No		Yes			
0		0			
3. What i	is your race?				
Black or African American	American Indian/Alaska Native	White or Caucasian	Native Hawaiian/Pacific Islander	Asian	
O	0	0	0	0	
4. What i	is your age?				
5. What	grade are you in	?			

Please stop here and let the researcher know you are ready to look at the website.

#### **POST-TEST**

#### Section 1

Instructions: Please select the best answer underneath each question.

#### 1. What is a clinical trial?

- O A type of research study
- O A place you can go to the doctor for free
- O When a new clinic opens in the neighborhood

#### 2. Who is involved in a clinical trial?

- O You
- O Doctor
- O Research Team
- O All of the above

#### 3. What is an example of a **COST** of participating in a clinical trial?

- O Helping other people in the future
- O Time away from school or home
- O Close monitoring of health
- O Access to medical care

#### 4. What is assent?

- O When parents give their "ok" for their child to be a part of a research study
- O When a child agrees to participate in research
- O When the doctor signs a child up for a study
- O When the research team invites you to participate in a study

#### 5. Once you agree to participate, can you stop before the study is over?

- 0 Yes
- O No
- O It depends if you are being paid to participate

# 6. If your parents give their permission for you to participate in a clinical trial, is it ok for you to say NO?

- 0 Yes
- O No
- O It depends on what the doctor says.

#### 7. Do all clinical trials have to take the same amount of time?

- 0 Yes
- O No
- 8. Do you think that clinical trials can help find new medicines and treatments for kids who have an illness or disease?
  - 0 Yes
  - O No

Section 2 Instructions: Please select the best answer next to each question.

	Very Good	Good	Not Good
How do you feel about kids participating in clinical trials?	0	0	0
How do you feel about being part of a clinical trial some day?	0	0	0
How would you feel if your friend or your family member was in a clinical trial?	0	0	0
How do you feel about helping kids' health in the future by participating in a clinical trial?	0	0	0

	Very Important	Important	Not Important
How important is it to participate in a clinical trial to test a new ways for you or other kids to feel better?	0	0	0

	Yes	No	Maybe
If you were offered a chance to be in a clinical trial, would you want to participate?	0	0	O

Section 3
Instructions: How sure are you that you can do the following things? Please select the best answer next to each question.

Finding/Getting Information	1 I cannot do it at all.	2	3 I maybe can do it.	4	5 I know I can do it.
Use this website to help me learn more information	0	0	0	0	0
Ask doctor(s) questions for more information about clinical trials	0	0	0	0	0
Ask my parents questions for more information about clinical trials	0	0	0	0	0
Ask research team members questions for more information about clinical trials	O	0	0	0	0
Ask my doctor for help when I am confused about any part of the clinical trial	0	0	0	0	0
Ask the research team members for help when I am confused about any part of the clinical trial.	0	0	0	0	0

Communication with Others	1 I cannot do it at all.	2	3 I maybe can do it.	4	5 I know I can do it.
Tell my parents that I don't want to participate in the clinical trial, even if they really want me to do it	0	0	0	0	O
Express my opinions about clinical research even when people disagree with me	0	0	0	0	O
Stand up for myself when I feel like I am being treated wrongly	0	0	0	0	0
Stand up for myself when someone is asking me to do something I am not comfortable with	0	0	0	0	0
Talk to my parents if I am not feeling well during the clinical trial	0	0	0	0	O
Tell my doctor if I am feeling sick or have problems during the clinical trial	0	0	0	0	0
Tell my doctor if I want to stop the clinical trial	0	0	0	0	O
Tell my parents if I want to stop the clinical trial	0	0	0	0	O
Tell the research team if I want to stop the clinical trial	0	0	0	0	0

## What I think

**Instructions:** These questions are going to ask about your thoughts on the website you just saw. Please read each statement carefully and select the answer that best expresses your own feelings. There are no right or wrong answers.

## **Feature Stories**

Content	Strongly Agree	Agree	Undecided	Disagre e	Strongly Disagree
The things I learned in the feature stories were easy to understand.	0	0	0	0	Ο
The things I learned in the feature stories were interesting to me.	0	0	0	0	O
The things I learned in the feature stories were helpful.	0	0	0	0	0
I had fun learning with the feature stories	0	0	0	0	0
The things I learned in the feature stories are important to me.	0	0	0	0	O
I learned something in the feature stories that I did not know before.	0	0	Ο	0	Ο

Content	Too young	Just right	Too grown-
	for me	for me	up for me
I thought that the feature stories were	0	0	0

Format	Strongly Agree	Agree	Undecide d	Disagree	Strongly Disagree
I liked the voices I heard in the feature stories.	0	0	0	0	O
I liked the videos I saw in the feature stories.	0	0	0	0	O
I liked that there were games and activities I could play in the feature stories.	0	0	0	0	0
I liked hearing from kids my age.	0	0	0	0	0
I liked that I could listen to different guides.	0	0	0	0	O

Format	Too short	Just right	Too long
I thought the length of feature stories was	О	0	O

Usability	Strongly Agree	Agree	Undecide d	Disagree	Strongly Disagree
The words in the feature stories were easy for me to understand.	0	0	0	0	0
The directions in the feature stories were easy to follow.	0	0	0	0	O
I found it easy to move through the feature stories.	0	0	0	0	O
It took a long time for pages to load in the feature stories.	0	0	0	0	0

### Please tell us a bit more about the feature stories.

(1) What did you like best about th	e feature stories?
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(2) What did you like least about the feature stories?

(3) What would make the feature stories better?

# Family spotlights

Content	Strongly Agree	Agree	Undecide d	Disagree	Strongly Disagree
The things that the families talked about were easy to understand.	0	0	0	0	0
The things that the families talked about were interesting to me.	0	0	0	0	0
The things that the families talked about were helpful.	0	0	0	0	0
I had fun learning from the families.	0	0	0	0	0
The things that the families talked about are important to me.	0	0	0	0	0
I learned something from the families that I didn't know before.	0	0	0	0	0

Content	Too young for me	Just right for me	Too grown- up for me
I thought that things the families talked about were	0	0	0

Strongly	Agree	Undecide	Disagree	Strongly
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Format	Agree		d		Disagree
I like watching videos like these.	0	0	0	0	0
I liked that I could watch videos to learn more about the guides.	0	0	0	0	0

Format	Too short	Just right	Too long
I thought the length of the family spotlights was	0	0	0

Usability	Strongly Agree	Agree	Undecide d	Disagree	Strongly Disagree
I could understand what the families were saying. The language used in the family spotlights was easy for me to understand.	Ο	Ο	О	О	0
I could figure out how to play the videos.	0	0	0	0	0
I could figure out how to choose a different video to play.	0	0	0	0	0
It took a long time for videos to play.	0	0	0	0	0

Please tell us a bit more about the family spotlights.

(1) What did you like best about the family spotlights?
(2) What did you like least about the family spotlights?
(3) What would make the family spotlights better?

# **Comic Book**

Content	Strongly Agree	Agree	Undecide d	Disagree	Strongly Disagree
The things I learned in the comic book were easy to understand.	0	0	0	0	0
The things I learned in the comic book were interesting to me.	0	0	0	0	0
The things I learned in the comic book were helpful.	0	0	0	0	0
The things I learned in the comic book are important to me.	0	0	0	0	0
I learned something from the comic book that I did not know before.	0	0	0	0	0

Content	Too young	Just right	Too grown-
	for me	for me	up for me
I thought that the comic book was	О	0	0

	Strongly	Agree	Undecide	Disagree	Strongly
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Format	Agree		d		Disagree
I liked the story in the comic book.	0	0	0	0	0
I like the character(s) in the comic book.	0	0	0	0	0
I liked what I could do with the comic book.	0	0	0	0	O

Format	Too short	Just right	Too long
I thought the length of the comic book was	0	0	0

Usability	Strongly Agree	Agree	Undecide d	Disagree	Strongly Disagree
The words used in the comic book were easy for me to understand.	0	0	0	0	0
I could figure out how to make the comic book work.	0	0	0	0	0
I found it easy to move through the comic book.	0	0	0	0	0
It took a long time for comic book to work.	0	0	0	0	0

Please tell us a bit more about the comic book.

(1) What did you like best about the comic book?
(2) What did you like least about the comic book?
(3) What would make the comic book better?
<u>Instructions:</u> These questions are going to ask about your thoughts on the <u>overall quality</u> of the website you just saw. Please read each statement carefully and select which answer best expresses your own feelings. There are no right or wrong answers.

Overall Quality	Strongly Agree	Agree	Undecide d	Disagree	Strongly Disagree
I learned things from using this website.	0	0	0	0	0
I can use the things I learned from this website to help me make decisions in the future.	0	0	0	0	0
I enjoyed using this website.	0	0	0	0	0
I would tell a friend who wanted to know about clinical trials about this website.	0	0	0	0	0

# When you have finished, please let the researcher know that you are done.