



Clinical Myth-teries: A Video Game about Clinical Studies Funded by the National Heart, Lung, Blood Institute

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SCREENING FORM Qualitative Focus Group

1.0 Potential Participants' Families

Good morning/afternoon/evening, Mr/Mrs._____. My name is _____ and I am an employee at New England Research Institutes (NERI). NERI is conducting a research study to evaluate a video game. This study is being conducted by NERI on behalf of the National Institute of Heart, Lung, and Blood (NHLBI), National Institutes of Health (NIH).

This video game is built on the successful program, 'Children and Clinical Studies' available at <http://www.nhlbi.nih.gov/childrenandclinicalstudies/>.

We have posted signs at the [Cumberland Lincoln Boys and Girls Club] explaining the study and your child expressed interest in participating in our focus group. Is your child still interested in participating in the Focus Group?

[If calling back] I am calling you because your child expressed interest in participating in our focus group about video games. Is your child still interested in participating?

PRIVACY STATEMENT - READ TO ALL RESPONDENTS

Before we begin, let me remind you that all the information we discuss is strictly private and will be kept secure to the extent permitted by law. Neither your name nor your child's name will be used in any reports. For quality assurance, my supervisor may monitor this call. Please answer each question as accurately as you can. Both this brief telephone call to screen your child for eligibility and, if eligible, attending the focus group are completely voluntary. Your decision whether to permit your child to participate in this group will not affect his or her standing at the (*location we choose to recruit from*). You may decide to stop the questions at any time. If you have any questions or concerns about this call, you may call the Principal Investigator Lisa Marceau, at 1-800-775-6374 x511. If you have any questions about your rights as a research subject, you may call Nancy Gee of NERI's Institutional Review Board at the same toll-free number at extension 249. There will be no charge for these calls.

If no:
Ok, well thank you for your time.

If yes:

First, let me thank you for you and your child's interest in this qualitative focus group. This group is being held to help us understand how interesting the video game we are developing is to adolescents. We need to make sure that the game is interesting to play before we can determine if it helps adolescents learn about clinical studies. This videogame is an adventure where a young boy escapes into a book so he does not have to take his medicine. The reader (the player) follows him into the book to help understand his fears and give him the right information about clinical studies. It is rated E for everyone.

In this group, we are *not* asking your child to tell us about their experiences with clinical studies or their personal health. We will explain to them what a clinical study is, and then spend most of the group talking about the video game we are developing. We will show sections of the game to the group and ask them to share their ideas about what they like and don't like about different parts of the game, like the characters, the setting, the tools they have, and the awards they can earn. This is known as a serious game which has a primary goal of education through entertainment.

Your child does not have to know anything about clinical studies to participate in this group.

This group has a limited number of spaces so I need to ask you a few questions to determine if your child is eligible to participate. It should take no more than ten minutes. Is that ok?

If no:
Ok, is there a time that would be better when I could call you back?

If yes:
Ok, great. I will call you back then. (Record date and time here):

Date _____; Time _____

If no:
Ok, well thank you for your time.

If yes:
Ok, great. Do you have any questions before I continue? (Read through the form)

If the child can be assigned to the group:

Your child is **eligible** for the group. Please read and sign the consent and review and have your child sign the assent forms that your child brought home recently. If you have any questions you can contact me (Michael Maura) at 1-800-775-6374 x675.

Alternative Text: If your child did not bring home a consent and assent form, I can mail them or email them to you. Would you prefer:

mail

email

Please provide your:

Mailing address _____

Email address _____

When you receive the forms, please read and sign the consent and review and have your child sign the assent forms.

You can send them back by fax (617-673-9535), or email to Mmaurao@neriscience.com, or send them by mail in the enclosed Self Addressed Stamped Envelope. You can bring them in the day of the group, but your child can only participate if we have both forms signed.

We will contact you prior to the group to confirm participation and remind you of the date and time.

If group is full for child's age or gender category:

Thank you for taking the time to answer these questions. Currently the available spaces in the group are full, but one may open before the date of the group. May we keep your information and contact you again should a spot become available?

If yes:

Ok, thank you again for your time. If a spot opens up we will contact you.

If no:

Ok, thank you again for your time today.

If child is not eligible (outside age range or cannot attend date):

Thank you for your interest. Unfortunately, your child is [*outside of the age range / cannot attend the scheduled date*] for this qualitative focus group. We appreciate your interest.

Note to Reviewer: This is a qualitative discussion guide. Not all questions may be asked, as they are probes to encourage discussion. In the small group discussion (page 6) main questions are numbered and probes to elicit discussion are bulleted.



Clinical Myth-teries Qualitative Video Game Focus Group Discussion

I. INTRODUCTION AND GUIDELINES – 15 minutes

Hi everyone and welcome. Thank you for coming and talking with us today. **My name** is Lisa and I am going to be leading our group today. I have with me **Mick** and **Patti** who will be helping out. We work with a company in Watertown called **New England Research Institutes**. We do lots of different research projects about health.

We are working on a project to develop a **video game that kids can play** to learn about Clinical Studies. We've been working hard and are developing a game that kids your age can play. We tried to use many **ideas from kids we interviewed when we developed the game**, and we would like to know what you think about what we have created. That is why you are here today. This is just the first part of the game, and we would like to know:

- what you like about the game so far,
- what you don't like about it, and
- how you think we can make the game better.

Before we begin, let me first tell you **what we will be doing**.

1. First, we will review the group **guidelines** that we would like everyone to follow for the rest of our discussion.
2. Then, you will each have a chance to play the game on a laptop.
3. We have a **handout** that we will pass out to you that asks you to think about
 - what you like about different parts of the game,
 - what you don't like about certain parts of the game,
 - and how we can make it better as we complete the game.

We'll ask you to **write down** some of your thoughts after playing the game.

4. Then, we'll break up into **small groups**. In the small groups, we'd like you to **talk with each other** about what you liked and didn't like about the game.
 - a. A **group leader** will be with you and may ask you about specific features in the game that may not be coming up as you talk with each other.
5. Finally, we will come back together into our one **big group** and have one person from each group be a **reporter** and tell the rest of us what those in the group thought of the game.
 - a. Don't worry- if you don't want to talk in front of the whole group, you don't have to. Someone else in your group can be the reporter, or the group leader can do that part.
6. We will have **2 breaks** during the session so you will have a chance to stretch your legs and get a snack.

We are really **interested in what you think** about the game and if you think this is a fun game to play. We hope you'll share any thoughts or ideas you have about what you like and do not like about the game.

- We're creating a video game for kids your age, and we want it to be **fun**. You know a lot more than we do about what you think is fun!
- So, we're here to **learn from you**.

You will notice that everyone has a **name card** in front of them.

1. We will use **first names only** during our session.
2. We won't use any of your names after this session; so, basically, for any type of report we do based on our session, **your name won't be used in the report**.

Also, we will be **recording** this session so that we can remember everything that you say about the game,

1. but as I said we won't use any names in our reports and no one other than the people creating the game will listen to the recording.
2. So, you can **feel free to share your thoughts** and ideas.

GUIDELINES

Before we get started, I would like to just go over a few guidelines that everyone needs to keep in mind and follow during this session.

[MODERATOR NOTE: PRIOR TO THE BEGINNING OF THE GROUP, LIST THE HIGHLIGHTED SECTION OF EACH GUIDELINE ON THE BOARD/EASEL]

1. It is important for only **one person to talk at a time**. You have a piece of **scratch paper** in front of you to jot down any ideas you have so you will remember (if someone is already talking when you think of it).
2. When it's your turn to talk, **please speak up** so you can be heard by everybody.
3. Please **don't talk with your neighbors** because this could distract the rest of us.
4. We would like to have **everyone participate**, so please share what you think about the video game with us.
 - a. But it's also important to remember that you **don't have to answer** any question that you don't want to answer.
5. Since we're really interested in what you think, everyone should **turn off any electronics** that you have with you, like cell phone, iPod, or anything else with an on/off switch.
6. Everyone's ideas are important, and in this group we will **listen to everyone's ideas**. So, please be respectful of others.
 - a. Even if you don't agree with someone's idea, it is still important to listen to it and think about it. Another person's idea just might **spark an idea of your own!** For example, if someone says something but I have a different way of thinking about the same topic, I might say "That's a good idea; I have another idea to add to that" or "That's an interesting idea; I have another way of looking at that."
7. We want everyone to feel comfortable sharing their ideas, so everything we say in this room needs to be **private**. This means that once we leave this room you should not talk about anyone who is here or what that person says. You can talk about what we're doing in general, but don't talk about who was here or what they have said. That's a really important part of participating in a group like this. Does anyone have any questions about this?

These guidelines are listed on this board [SHOW EASEL WITH LIST] which I will keep displayed over here to help us remember.

Are there any **questions** before we begin?

INTRODUCTIONS

Ok, so to start off – I would like to **go around** to everyone in the room.

1. Please tell us your **first name** and
2. Something that you are looking forward to doing once **spring** comes.

[HEAR FROM EVERYONE] Thank you all – it's great to meet you and thank you for coming to help us out.

II. Play Game – 15 minutes

We're going to get started by playing the video game. As you play the game, think about three questions:

- 1) What features do you like about the game?
- 2) What features do you not like about it?
- 3) How do you think we can make the game better?

We really want to know what you **honestly think** about the game, but remember there are some things we can't change, like how many worlds there are, and the basic game structure. We do want to know about characters, costumes, activities in the worlds, how hard or easy it is, and other features like rewards.

[PASS OUT HANDOUT]

To help you remember these questions, we're passing out a handout with the questions on it. You'll have a chance after you play the game to think about these questions and write down what you think.

[Play Game]

III. INDIVIDUAL REFLECTION - 10 minutes

We would like each of you to take a few minutes to think about the questions on your handout:

- 1) What features do you like about the game?
- 2) What features do you not like about it?
- 3) How do you think we can make the game better?

If you have any questions, please raise your hand and one of us will come over.

[MODERATOR NOTE: ALLOW ABOUT 10 MINUTES FOR PARTICIPANTS TO WRITE DOWN THEIR ANSWERS].

We're going to take a 5 minute break now. Please feel free to come get a snack and a drink, get up and stretch your legs, and we will start back again in 5 minutes.

BREAK – 5 minutes

We're now going to divide into three and one of us will come to your group to lead this part.

[DIVIDE PARTICIPANTS INTO 3 SUBGROUPS OF 3 PEOPLE: 8-10 YEARS OLD, 10-12 YEARS OLD, 12-14 YEARS OLD]

[TURN ON TAPE RECORDERS FOR EACH SUBGROUP]

IV. SMALL GROUP DISCUSSION - 30 minutes

GROUP FACILITATOR NOTE:

- *START WITH THE FIRST QUESTION ON THE HANDOUT TO ELICIT PARTICIPANTS VIEWS WITHOUT DIRECTING THEM TO A SPECIFIC FEATURE OF THE GAME. FOLLOW THE LEAD OF THE PARTICIPANTS IN TERMS OF THE ORDER IN WHICH FEATURES ARE DISCUSSED.*
- *AS A PARTICIPANT REFERS TO A FEATURE OF INTEREST, USE THE PROBES FOR THAT FEATURE OF INTEREST (SEE BELOW).*
- *AS PARTICIPANTS REFER TO PARTICULAR FEATURES OF THE GAME, USE THE PICTURES OF THE SCENE AS A VISUAL AID FOR WHAT PART OF THE SCENE IS BEING REFERRED TO.*
- *AS THE DISCUSSION PROGRESSES TO SPECIFIC FEATURES, PROBE ABOUT WHAT THE PARTICIPANTS LIKE AND DON'T LIKE ABOUT THAT PART OF THE GAME.*

[RECORDERS SHOULD BE ON FOR EACH SUBGROUP]

GENERIC PROBES:

- What do you like about that part of the game?
- What do you not like about that part of the game?
 - o Do you have any ideas about how we could make it better?
- What did you learn from that part of the game?
- Could you tell us more about why you thought that?
- Did anyone else have a different view?

1. Ok, let's start by talking about **what you liked** about the game.

PROBES FROM HANDOUT:

- What do you think about the story?
- What do you think about the characters you play as?
- What do you think about the way the characters talk to one another and to you?
- What do you think about the graphics?
- What do you think about the way you get around in the game?
- What do you think about the goals and missions of the game?
- What do you think about the information that you learned by playing the game?

- What do you think about the characters you meet and interact with in the game?
- What do you think about the monsters in the game?
- What do you think about the ways you battle the monsters in the game?
- What do you think about the help and controls menu?
- What do you think about the quest menu that lets you know about your progress in the game?
- What do you think about the health meter?

FEATURES OF INTEREST

FACILITATOR NOTE:

- *USE THESE PROBES AS A PARTICIPANT RAISES A FEATURE OF INTEREST.*
- *IF, AFTER DISCUSSING THE TOPICS THE PARTICIPANTS RAISE, ONE OR MORE OF THE FEATURES OF INTEREST WAS NOT DISCUSSED, THEN RAISE THE FEATURE(S) AND ASK FOR THE GROUP'S OPINION.*

CHARACTERS

2. What did you think of your character, "Hero", in the game?
 - What did you think of the choices for what you will look like in the game? Were there enough options?
 - Did you like the way your character talked?
 - Did you like the way your character moved?

3. What did you think of Dr. Chroma?
 - Would the doctor be someone you would want to help out in the game?
 - Can you tell us more about why you would/would not want to help out the doctor?

4. What did you think of Tint?
 - Did you like the way Tint told you about each patient?
 - Did you like that Tint gave you quests to complete?
 - Did you like recovering the lost paper folding designs from Tint's paper-folding book?

5. What did you think of your brother?
 - What do you think about your brother in the game being sick and you needing to help him?
 - Did you like that you were on a mission to rescue your brother from Shade?

6. What did you think of Shade?
 - Did you like the way Shade looked?
 - Did you think Shade was too scary?
 - Did you like that you had to battle all of the other monsters before you could take on Shade?

7. What did you think of the other characters in the game?
 - Did you like the way the characters talked?
 - Did you like the way the other characters looked?
 - Did you like the idea of helping characters in this game to not be afraid of clinical studies?
 - Did you like the characters that you helped to complete quests?
 - Did you like the way you restore color to the characters by taking power from Shade?

8. What did you think of the other monsters in the game?
 - Did you like how the monsters talked?
 - Did you like how the monsters looked?
 - Did you think the monsters are too scary?

SETTING

9. What did you think of the way the game starts out?
- Did you like the story about the Paper Kingdom?
 - Did the story about the Paper Kingdom make sense?
 - Did the explanation of what a clinical study is make sense?
 - What questions do you still have about clinical studies?
10. What did you think of the village?
- Did you like the way the village looked?
11. What did you think of the jungle level?
- What did you learn from playing the jungle level?
 - o Did you learn that clinical studies aren't just for sick people?
 - o Did you learn that studies sometimes don't involve shots or medication, sometimes they're just surveys or observations?
 - o Did you learn that not all studies last the same amount of time, and that you will find out ahead of time what is expected from you?
 - Did you like the monsters in this level?
 - o What did you think of the Gorilla?
 - o What did you think of the Wasp?
 - o What did you think of the Dragons?
 - What did you like/dislike about the jungle level?
12. What did you think of the ice level?
- What did you learn from playing the ice level?
 - o Did you learn that you shouldn't participate in a study because of money, and that it's okay to say no if you aren't comfortable?
 - o Did you learn that being in a clinical study should not be something that's embarrassing, and that maybe even other people you know are also participating, or your participation could even help others?
 - o Did you learn that sometimes it's better to participate than to worry about what other people might think of you?
 - Did you like the monsters in this level?
 - o What did you think of the Yeti?
 - o What did you think of the Ice Worm?
 - o What did you think of the Dragons?
 - What did you like/dislike about the ice level?

ACTIVITIES

13. The doctor gives you a map that lets you decide where to go in the paper world. Do you like deciding where to go?
 - Or would you rather follow the game wherever it takes you?
 - Do you like to be able to go back and replay parts that you missed or that you liked?
 - Did you like the way the map looked?
 - Did you like that each part of the map had its own theme (ice, jungle)?
14. What did you think of the ways you battle against the monsters in the game?
 - What did you think of the Sword of Truth?
 - What did you think of the armor?
 - Did you like the different kinds of special powers that different swords and armor give you?
 - What did you think of the way you move and attack in the game?
 - In the game, would you like to do combat between characters more or would you rather explore the paper world more?
15. What did you think of the way you create new items by collecting orbs and paper?
 - Did you like the way the armor and swords could change when you “unlocked” new options?
 - Did you like the way you collect stars to buy new armor and sword colors?
 - Did you like the way you could see your progress in the game?
16. Do you like the idea of healing the creatures of the paper world with paint?
17. Did you think the game was easy to use?
18. Did you think the game was fun to play?
19. Why would you/wouldn't you like to play this game at home?
20. Did you think this game was similar to other entertainment games you've played?
21. Did you like the way the graphics in the game looked?
22. Did you like the way the menus looked?
23. Did you have any trouble using any of the menus in the game?
24. Did you have any trouble moving around in the game?
25. Did you have any trouble solving any of the quests in the game?
26. Was there anything in the game that didn't work the way you expected it/wanted it to?
27. What features and functionalities would you add to the game?

28. Did you like the sounds and music in the game?
29. How would you make the game better overall?
30. Did you learn anything new from The Paper Kingdom?

*[AT **25 MINUTES** INTO THE SMALL GROUP DISCUSSION, THE MODERATOR SIGNALS NEED TO SUMMARIZE SMALL GROUP DISCUSSIONS]*

Can I have everyone's attention please? You have about ten more minutes to finish your small group discussions. Finish up the point you're talking about and then your group leader will tell you how to summarize your group's discussion. Remember to choose one person to report back to the rest of us what your group thought.

FAVORITE AND LEAST FAVORITE FEATURES

31. Okay, now we need to summarize what we thought about the game idea. I've taken some notes, but I want to be sure I have it right. What are the three things that our group **liked most** about the game?
32. What are three things that our group **did not like** about the game?
33. What are three ways that our group thinks the game can be **better**?

[MODERATOR CONCLUDES SMALL GROUP DISCUSSIONS]

We're going to take another **5 minute break** now. Again, please feel free to come get a snack and a drink, get up and stretch your legs, and we will start back again in 5 minutes. When you come back we will meet back with the entire group and one person from each group will report on what their group talked about – basically a summary of the different ideas and thoughts that were discussed.

BREAK – 5 minutes

[TURN OFF RECORDER DURING BREAK]

[TURN ON TAPE RECORDERS FOR LARGE GROUP]

V. SUMMARY OF GROUP DISCUSSIONS - 30 minutes

Ok, we're going to start up again; everyone please be seated. I would like to ask one member of each group to please stand up and **report** back to the group about what was discussed in your small group. Please let us know what the kids in your group liked and did not like about the video game and if you have other ideas or suggestions that your group thinks would make it better.

[MODERATOR NOTE: AFTER THE REPORTER SPEAKS, ASK QUESTIONS AS APPROPRIATE TO THE REPORTER AND HIS/HER GROUP TO EXPAND ON WHAT S/HE REPORTS.]

[MODERATOR NOTE: FOLLOWING THE SMALL GROUP REPORTS, PROVIDE A BRIEF SUMMARY OF LIKES AND DISLIKES AFTER HEARING ALL GROUPS. ASK THE GROUP IF THE SUMMARY IS ACCURATE AND IF THEY HAVE OTHER COMMENTS TO ADD]

[WISDOM TOOLS MAY WANT TO ADD IDEAS IN THIS SECTION]

Ok, thank you all so much for coming today and sharing your thoughts with us once again. Your feedback will help us very much as we move ahead with creating this video game.