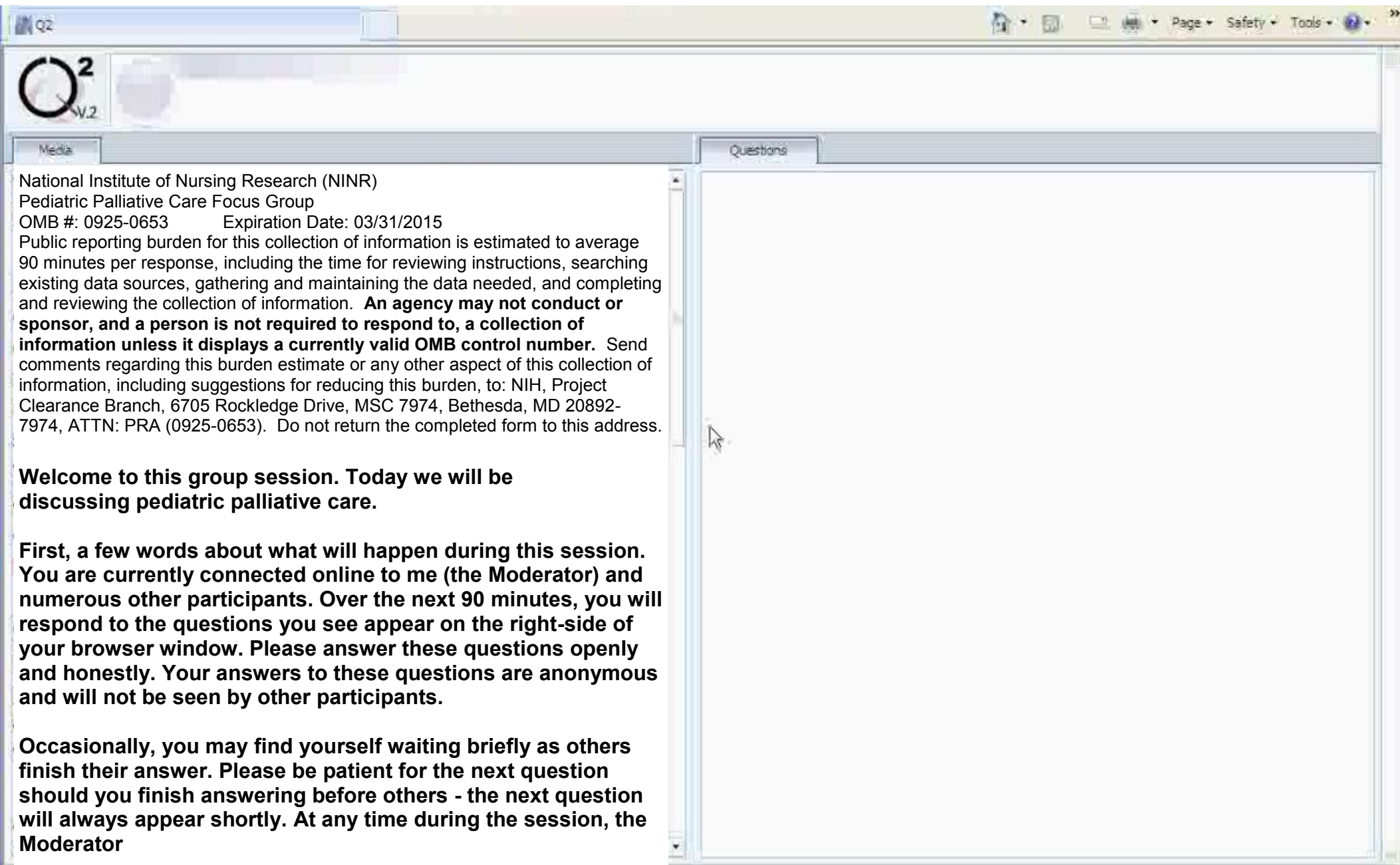


Appendix D: Screenshots - Focus group

* Probe questions are shown for clarity only. As with any focus group, probe questions will only be asked if more information is needed.



Q2

Media

Questions

National Institute of Nursing Research (NINR)
Pediatric Palliative Care Focus Group
OMB #: 0925-0653 Expiration Date: 03/31/2015
Public reporting burden for this collection of information is estimated to average 90 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 (0925-0653). Do not return the completed form to this address.

Welcome to this group session. Today we will be discussing pediatric palliative care.

First, a few words about what will happen during this session. You are currently connected online to me (the Moderator) and numerous other participants. Over the next 90 minutes, you will respond to the questions you see appear on the right-side of your browser window. Please answer these questions openly and honestly. Your answers to these questions are anonymous and will not be seen by other participants.

Occasionally, you may find yourself waiting briefly as others finish their answer. Please be patient for the next question should you finish answering before others - the next question will always appear shortly. At any time during the session, the Moderator

Q2

2
v.2

Media

Questions

may begin an instant messaging chat discussion. You should respond to the Moderator's questions as the discussion proceeds. Note that for these chats, you will also be able to see other participants' comments and respond to them. Please be courteous and polite.

All information disclosed during the focus group meeting will be kept private under the Privacy Act and none of the information discussed during the open chats will be shared with any other individual or organization outside of the purpose of this focus group.

We greatly appreciate your participation and you will receive a \$40 honorarium for taking the time to contribute your opinions tonight. However, you must answer all of the questions throughout the session until the Moderator finishes the session, or you will not receive your honorarium.



We greatly appreciate your participation and you will receive a \$40 honorarium for taking the time to contribute your opinions tonight. However, you must answer all of the questions throughout the session until the Moderator finishes the session, or you will not receive your honorarium.

As I mentioned, today we will be discussing pediatric palliative care. Palliative care is comprehensive treatment of the discomfort, symptoms and stress of serious illness with the goal to prevent and ease suffering and improve the patient's quality of life. It is available to patients of any age and at any stage of an illness, and in the pediatric setting, it is tailored to meet the needs of this unique patient population being treated for a serious illness or life-limiting condition.

If you encounter any technical difficulties while participating in this focus group, please send an email to support@stratalys.com.

Questions

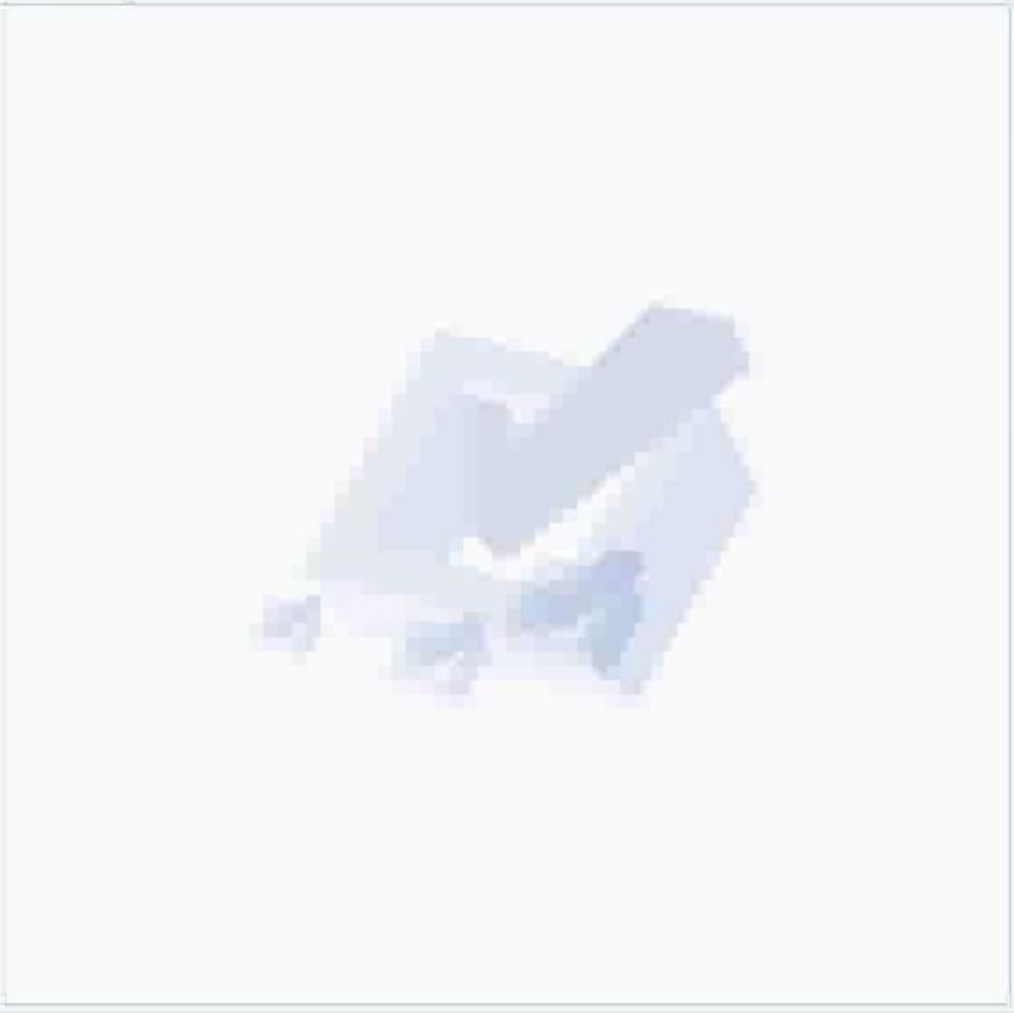
If you are ready to get started, please select 'Yes' below and then click the Submit button.

- Yes, let's get started.

Submit



Media



Questions

If you are ready to get started, please select 'Yes' below and then click the Submit button.

- Yes, let's get started.

What does the term "palliative care" mean to you?

I am not familiar with the term.

Submit



Media

Questions



If you are ready to get started, please select 'Yes' below and then click the Submit button.

- Yes, let's get started.

What does the term "palliative care" mean to you?

I am not familiar with the term.

How comfortable are you initiating conversations about palliative care with pediatric patients and their families?

- Very comfortable
- Somewhat comfortable
- Not very comfortable
- Not at all comfortable

Submit

Q2

Please respond to the Moderator's questions in the Discussion Room chat

Media Questions Discussion Room

Ok, I'm going to open a chat discussion so that we can talk as a group and respond to each other's comments. The chat discussion window will appear on the right side of your screen.

You should pay careful attention to the Moderator's questions that will appear in red text. You will enter your own comments in the box at the bottom of the screen and add them to the discussion by clicking the Send button.

Moderator: What is most concerning to you when it comes to discussing palliative care with pediatric patients and their families?
Scott: Not having the information.
Moderator: What barriers specifically prevent you from discussing palliative care with your pediatric patients and their families?
Scott: Time constraints, lack of knowledge.
Moderator: What additional resources would be helpful to have when discussing palliative care with pediatric patients and their families?
Scott: Training on the topic/subject

I

send



Media

Questions

I'd like to have you read the following description about a potential pilot program. After you read the description, please answer the questions that follow.

I



Media

Questions

A pilot program is being launched to directly address barriers that might prevent health care professionals from recommending palliative care for pediatric patient populations. The pilot program aims to assist health care professionals in initiating and facilitating ongoing conversations about palliative care with parents and families of pediatric patients living with a serious illness or life-limiting condition. The pilot program may offer various resources/tools that could assist health care professionals. An overview of the importance of palliative care, instruction on how to use the materials, and enhance communications skills will be provided during the pilot program.

How beneficial do you believe the pilot program would be for people like you?

- Very beneficial
- Somewhat beneficial
- Not very beneficial
- Not at all beneficial

Submit

I



Please respond to the Moderator's questions in the Discussion Room chat

Media Questions Discussion Room

A pilot program is being launched to directly address barriers that might prevent health care professionals from recommending palliative care for pediatric patient populations. The pilot program aims to assist health care professionals in initiating and facilitating ongoing conversations about palliative care with parents and families of pediatric patients living with a serious illness or life-limiting condition. The pilot program may offer various resources/tools that could assist health care professionals. An overview of the importance of palliative care, instruction on how to use the materials, and enhance communications skills will be provided during the pilot program.

Moderator: What are your first impressions of this pilot program? What about it stands out to you?
Scott: Seems like it would give me the knowledge I lack.
Moderator: How do you believe you would use this information from this pilot program to care for your seriously ill pediatric patients?
Scott: I would use it daily for explaining to parents.

I [send]



Media

Questions

I am now going to show you a few materials that are in development for the pilot program. The first is a description of a video that is under development. Please review and then answer the questions that follow.

Please indicate how much you agree or disagree with each of the following statements about the message

	Strongly agree	Somewhat agree	Somewhat disagree	Strongly disagree
I learned something new after seeing the teaching modules	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I would be likely to try the examples provided in the teaching modules	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I would share the information presented in the teaching modules with my colleagues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How beneficial do you believe this video would be for people like you?

- Very beneficial
- Somewhat beneficial
- Not very beneficial
- Not at all beneficial

Submit

Please respond to the Moderator's questions in the Discussion Room chat

I am now going to show you a few materials that are in development for the pilot program. The first is a description of a video that is under development. Please review and then answer the questions that follow.

Moderator: How would you sum up in just a few words your first impression of this tool? Do you like it? Not like it? Why?
Scott: I liked it. Seems to be comprehensive.
Moderator: How do you feel about the tone of the video?
Scott: Seemed fine to me.
Moderator: How do you feel about the format of this information?
Scott: I like the video format
Moderator: Let's discuss this a bit more. How realistic were the examples in the teaching modules?
Scott: They seem to be realistic but I don't have experience to say for sure.
Moderator: What makes it difficult to carry out the recommendations outlined in the teaching modules?
Scott: Time constraints.
Moderator: Do you see yourself using this or something like it in the future? Why? Why not?
Scott: Sure, if it is easily available.
Moderator: Which actions, if any, are you likely to implement? Why? Why not?
Scott: I'd be open to all of them.
Moderator: What could be changed to make it more effective?
Scott: Not sure.
Moderator: Thinking back to the information the pilot program is trying to convey, is there anything else you would add?
Scott: Not to this. no



Media

Please review the following document description and then answer the questions that follow.

Questions

Please indicate how much you agree or disagree with each of the following statements about the message

	Strongly agree	Somewhat agree	Somewhat disagree	Strongly disagree
I learned something new after reading it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I would be likely to try the exercises outlined	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I would share the information in the document with my colleagues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How beneficial do you believe this document would be for people like you?

- Very beneficial
- Somewhat beneficial
- Not very beneficial
- Not at all beneficial



Please respond to the Moderator's questions in the Discussions Room chat.

Please review the following document description and then answer the questions that follow.

Moderator: How would you sum up in just a few words your first impression of this tool? Do you like it? Not like it? What makes you say that?
Scott: I like it but not as much as the video
Moderator: How do you feel about the tone of the document?
Scott: The tone was fine
Moderator: How do you feel about the language used in the document?
Scott: Language was easy to follow.
Moderator: How do you feel about the format in which the information was presented?
Scott: Fine for this although I like the video more
Moderator: Let's discuss this a bit more. Do you disagree with any of the recommendations provided in the worksheet? If so, which ones and why?
Scott: I don't disagree with them.
Moderator: Do you see yourself using this or something like it in the future? Why? Why not?
Scott: I could but a worksheet can be cumbersome
Moderator: Which actions, if any, are you likely to implement? Why? Why not?
Scott: All of them are possible.
Moderator: What could be changed to make it more effective?
Scott: Nothing, seems fine.
Moderator: What makes it difficult to carry out the recommendations outlined in the worksheet?
Scott: Time constraints. Having worksheet handy.
Moderator: Thinking back to the information the pilot program is trying to convey, do you feel like anything is missing? What additional topics would you want covered in the worksheet?
Scott: None that I can think of.

I

send



Media

Questions

Now, I am going to show you a couple of potential names that are being considered for the pilot program and a subsequent communications campaign that may follow. Please review and then answer the questions that follow.

Blank area for questions and answers.



Media

Palliative Care: Conversations Matter

Questions

I



Media

Palliative Care: Choices for Children

Questions

I



Media

NAME A
Palliative Care: Conversations Matter

NAME B
Palliative Care: Choices for Children

Questions

Now that you've seen the potential campaign names, which name...?

	Name A	Name B
Most catches your attention	<input type="radio"/>	<input type="radio"/>
Is most compelling to you	<input type="radio"/>	<input type="radio"/>
Best fits the pilot program description you read earlier	<input type="radio"/>	<input type="radio"/>

Submit



Media

Questions

Now, I am going to show you a couple of potential tag lines that are being considered for the pilot program and a subsequent communications campaign that may follow. Please review and then answer the questions that follow.

Blank area for questions and answers.



Media

Easing symptoms and enhancing lives.

Questions

I



Media

Discussing options and enhancing lives.

Questions

I



Media

TAG A
Easing symptoms and enhancing lives.

TAG B
Discussing options and enhancing lives.

Questions

Which tag...?

	Tag A	Tag B
Most catches your attention	<input type="radio"/>	<input type="radio"/>
Is most compelling to you	<input type="radio"/>	<input type="radio"/>
Best fits the pilot program description you read earlier	<input type="radio"/>	<input type="radio"/>

Submit



Please respond to the Moderator's questions in the Discussion Room chat

Media

Questions

Discussion Room

NAME A
Palliative Care: Conversations Matter
Easing symptoms and enhancing lives.

NAME B
Palliative Care: Choices for Children
Discussing options and enhancing lives.

Moderator: Let's discuss these names as a group. We'll start by discussing the Name and Tag A. What about this particular combination is most engaging? If you did NOT find this engaging, what specifically was less engaging about it?

Scott: It was more attention grabbing.

Moderator: What about the Name and Tag B. What about this particular combination is most engaging? If you did NOT find this engaging, what specifically was less engaging about it?

Scott: I liked it but just not as much as A.

I

send



Media Questions

Now, I am going to show you a couple of potential logos for the pilot program and potential communications campaign. Please review and then answer the questions that follow.

Now that you've seen the potential logos, which one catches your attention the most?

- Logo A
- Logo B
- Logo C
- Logo D

I

 Please respond to the Moderator's questions in the Discussion Room chat

Media Questions Discussion Room

Now, I am going to show you a couple of potential logos for the pilot program and potential communications campaign. Please review and then answer the questions that follow.

Moderator: Let's discuss Logo A. What about it is especially attention-getting or appealing?
Scott: I liked the graphics and colors.
Moderator: What do you like or dislike about the graphics of this logo?
Scott: Graphics are great for this one.
Moderator: Now, let's discuss Logo B. What about it is especially attention-getting or appealing?
Scott: A bit more dull than A. Not as attention grabbing.
Moderator: What do you like or dislike about the graphics of this logo?
Scott: Graphics aren't bad but color choices don't fit.
Moderator: Thinking back to the information the pilot program is trying to convey, what additional information or tools would you need to help you talk about palliative care to pediatric patients and their families?
Scott: None that I can think of.
Moderator: Is there anything else you would add that you think could enhance the pilot program?
Scott: No, I don't think so.



Media

Questions

Thank you so much for your participation. This has been extremely helpful to us. You may close your browser now.