

INTRODUCTION

Hi, my name is _____. I am working with the Endometriosis Foundation of America, which is an organization that raises awareness about endometriosis and runs programs with youth in NYC. We are conducting a research study together along with a professor from George Mason University in Virginia.

(Go to consent form – read through with participants, have them sign – skip next two paragraphs)

First, we want to thank you for taking the time to participate in our focus group today. Essentially we will be discussing different topics together as a group. These topics will be related to several issues that people your age may face – specifically those that pertain to reproductive health. We are here because we want to learn more about your perceptions of these issues.

There are a few things I want to discuss before beginning the focus group. The information you give us is completely confidential. All of your answers will be kept secret by our study team. Also, you should also keep the conversations here private and refrain from sharing any of our discussion with people outside of the group.

Just a few more things before we begin. We ask that you respect one another and do not interrupt when someone else is talking to ensure that everyone's thoughts are heard. We value and want to hear all of your opinions. Also, there is no right or wrong answer. It's completely fine to agree or disagree with one another but please be respectful of all points of view. Also, feel free to share your opinion even if the facilitator has not called on you.

Our session today will end in about 90 minutes. This session will be audio recorded. The audio recordings and transcriptions will be stored securely in password-protected files. We will be also taking notes; however, we will not use your names in any of the reports. No one will be able to identify who made specific comments.

Lastly, if at any point you are uncomfortable with the subject matter, you do not have to contribute. Or if you are feeling upset and decide you no longer want to participate, please talk to the facilitator.

Does anyone have any questions before we begin?

GENERAL QUESTIONS

Let's start with introductions. You all have a name tag and marker. For the introductions, instead of using your real name, please use a name that you would like to

be called for today. It can be a name you like that is after a celebrity you admire, or a good friend, for instance. The key is, we want to help make sure that your names stay private, so we don't want you to use your real name. Now, let's go around the room and everyone tell us the name that you'd like to be called today, and something that you are looking forward to in the new year.

First, we would like to learn about health issues that people your age may face:

What are some of the biggest health issues facing people your age?

Probes for descriptions:

- Please tell me more about that"
- "Could you explain what you mean"
- "Can you tell me something else about that"

What are some of the biggest health issues facing girls your age specifically?

[If they name reproductive health issues]: **I notice you mentioned these reproductive health issues, what are some others that girls your age have to deal with?**

[If they don't name reproductive health issues]: **Are there reproductive health issues girls your age have to deal with? If so, what are they?**

Have you ever heard of a health condition called Endometriosis? (It's ok if you haven't heard of it – most adults haven't either)

[If some answer yes]: **What do you know about this condition?
What are some of the symptoms?
Do you know anyone with this condition?**

VIGNETTES

Now, we are going to read some short stories – very short! – that describe different scenarios of a girl experiencing a health problem. Listen carefully to the story and then we will ask some follow up questions.

This is a story about Amanda, who is an athlete, but has been suffering from severe menstruation symptoms.

Vignette 1:

Amanda is the captain of the varsity volleyball team. She loves to stay active and work out with her teammates. But whenever Amanda gets her period she bleeds very heavy causing her to pass out. She says she feels like someone is stabbing, especially feeling like being stabbed with a

knife, the inside of her stomach, legs, and lower back. The first time she passed out at a volleyball game, everyone assumed it was due to exhaustion or dehydration, but even after drinking enough water, this kept happening. Amanda noticed that these episodes kept happening almost every period, and so she had to miss practice and a few games. She told her teammate, Kelly, who then told Amanda to “quit being such a girl” and toughen up.

Where did Amanda say she had pain?

Why do you think Amanda’s teammate (Kelly) told her to “quit being such a girl” and to “toughen up”?

How do you think this made Amanda feel?

How do you think Kelly’s reaction might impact Amanda’s willingness to share her health concerns with other teammates?

How do you think Kelly’s reaction might impact Amanda’s ability to get help for her health issues?

Do you think Kelly would react differently if Amanda’s health issues didn’t have anything to do with her period? Why or why not? (give some examples, for instance – if Amanda had asthma)

This is a story about Dominique is having a difficult time in school because of some health issues.

Vignette 2:

It’s November and Dominique has already missed 10 days of school and her grades are suffering. Previously a straight-A student, it is really tough for her to struggle this much. Around her period, Dominique has severe pain in her belly making it hard for her to walk, stand, and even sit at times, so she has to stay home from school, or leave school early. The school nurse sent a note to her parents saying that she is concerned that Dominique is exaggerating her symptoms since almost all teenage girls get cramps, and that she doesn’t look ill.

If you were Dominique’s friend and you did not know about her health problems, what would you think about her missing so much school?

Why do you think the school nurse thought that Dominique was exaggerating?

Do you think the school nurse would have believed Dominique if:

- a) Dominique had a different health issue such as depression? diabetes? Why or why not?
- b) She was the same race as the school nurse? Why or why not?

Put yourself in Dominique's shoes, how would it feel to suddenly have your grades and attendance drop because of these symptoms?

What do you think being "ill" looks like? How is that the same or different from what you think Dominique is experiencing?

Who do you think Dominique can get help from inside or outside of school for her health issues? What would be some barriers in getting this support?

The next one is a story about Sam, who is experiencing very painful sex.

Vignette 3:

Clayton really likes his girlfriend, Sam. They have been dating for almost a year and have had sex a few times. Sometimes when they have sex, Sam cries afterwards. Clayton wonders if it's something he's doing wrong. Sam eventually told him that sex hurts her stomach and it doesn't feel good to her. She also told him that she feels sharp pains in her lower stomach for a few days after they have sex, and she vomits as well.

What do you think is happening with Sam? Why does she have so much pain?

Why do you think Sam may have felt uncomfortable telling Clayton that she was in pain and instead 'sucked it up'?

If you were Sam, do you think it would be easier or harder to talk to Clayton about other issues related to sex, such as using a condom? Why or Why not?

Now that Clayton is aware of how Sam is feeling, what do you think he should and should not do to support her?

What do you think other people in Sam's life (such as her friends or family members) should do to support her? What should they not do? Why?

Do you think it would be easier or harder for Sam to ask her friends for support if her main issue was that she was pregnant? Why? What if she thought she had HIV?

Do you think it would be easier or harder for Sam to ask her family for support if her main issue was that she was pregnant? Why? What if she thought she had HIV?

Aside from family/friends, are there places in your school or neighborhood that you think could help Sam could go to for help? What are these places? What would make them helpful? What would make them unhelpful?

Do you think it would be easier or harder for Sam to get help from these places if her issue was that she was pregnant? Why? What if she thought she had HIV?

If you were Sam, are there other people you would not trust to talk to about this situation? Why would you not trust them?

The last story about Bianca, who is worried about a big party she has coming up. This story might seem a little funny to you, but it's still very important that you share your thoughts with us because we can learn a lot from you.

Vignette 4:

Bianca has her quinceanera coming up, and she is very excited about that. She has a gorgeous dress picked out and her family is planning a big party for her. However, Bianca has also been having a lot of pain. She is confused because the pain feels like someone is stabbing her when she poops. This pain with pooping is worse when she is on her period, and she has even passed out while pooping. As her quinceanera approaches, Bianca figures out that she will be on her period during that time and worries that she won't be able to enjoy her big day because of the pain and pooping. She feels too embarrassed to share these worries with her family, so she just keeps it to herself.

How would you feel if you were Bianca?

Why do you think Bianca decided to keep her worries to herself, even though she knows she will be in a lot of pain during her quinceanera?

How do you think Bianca's family members would react if she shared her problems and worries with them?

How do you think Bianca's friends would react if she shared her problems and worries with them?

Compared to other health problems that girls in your school might experience [that you mentioned today—such as diabetes, drug/alcohol], do you think it would be easier or harder for Bianca to seek help for her problems? Why or why not?

Each of the characters in these stories represent people who have a symptoms of endometriosis.

We have talked a lot about endometriosis.

Endometriosis is a disease that affects the female reproductive system. It occurs when tissue similar to that of the uterus is found in other parts of the body. Girls that have endometriosis often experience extremely painful cramps that don't get better

with Advil, heavy periods that last over a week, painful bowel movements and urination, and discomfort during sex.

If you have questions about endometriosis, we will provide you with more information at the end of the session and we will be happy to answer questions then as well.

Provide info on Endometriosis/ Show a video

In addition to what we've discussed, is there anything else that would be hard about having this condition?

How do you think challenges that girls with endometriosis face are the same or different from other health issues that you named today?

Do you have any questions about Endometriosis or anything else we discussed today?

Hand out demographic survey.

FOR FORMER ENPOWR PARTICIPANTS

Now we want to discuss your experience in the ENPOWR program.

Before ENPOWR, what did you know about normal periods and abnormal periods? And afterwards?

Since you heard the ENPOWR presentation, have you met anyone or seen anyone who may be suffering from endometriosis? If so, what was your reaction to them (e.g. provided support, felt unsure how to help, told them to think positively, told them to get help, etc.)? Before the ENPOWR presentation, what do you think your reaction would have been?

What information from the ENPOWR program did you share with friends?

If you did not share ENPOWR information with friends/family, why not?

What do you think about the currently available tools/resources/supports to help teens who might be facing endometriosis?

What more would do you think can be done to help teens with endometriosis?