

CENTERS FOR DISEASE CONTROL AND PREVENTION

***Inside Knowledge: Get the Facts About Gynecologic Cancer
2009 Focus Groups with Women, ages 40-60***

Moderator Discussion Guide

I. BACKGROUND (@4 minutes)

Thank you for joining me today. My name is ____; I am very happy to have this chance to talk with you about some important women's health issues. The people who are sponsoring our discussion are looking forward to your feedback -- to help them make sure that information they plan to create will be as useful as possible.

Before I ask you to introduce yourselves, I'll tell you a few things that I hope will put you at ease and also help us make the most of our time together.

Moderator will quickly address:

- **Importance and value of hearing everyone's candid opinions: I am so interested in what each of you thinks about the things I'm going to ask. This is truly about your opinions and ideas – nobody else's. Please be true to yourself – you do not have to agree with anyone else here. This is a time to be selfish...we truly want to know what you think – not what you think someone else would say or want to know. It's also very important to let me know when you hear or read something that is new to you or hard to understand. The more our sponsor understands what is new or confusing to you, the better their information will be.**
- **CDC sponsorship: We are sponsored today by the Centers for Disease Control and Prevention. This is part of the government's public health service and is located in Atlanta. I'll refer to it as "C-D-C" while we talk.**
- **Moderator not being involved in preparation of materials and not being subject expert: It's very important that you tell me about anything you see today that you don't like or think is confusing – it won't hurt my feelings. I did not help prepare anything I'll show you today, and I am not an expert on what we'll discuss. I'll give you some take-home materials later in case you have questions.**

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CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road, MS D-74, Atlanta, GA 30333, ATTN: PRA (0920-0800)

II. INTRODUCTIONS (@10 minutes)

Let's introduce ourselves. Please share with everyone...

- Your *first* name only.
- **One** thing about you that will help us know you better...for example, a favorite movie or TV show, a hobby you enjoy, the #1 thing you'd like to have more time for...any one thing you'd like to share.

III. DISCUSSION TOPICS

A. CONTEXT FOR DISCUSSION ABOUT SYMPTOMS (@1 minute)

Let me tell you more about why we're here. The CDC has a new health education program called *Inside Knowledge*. It's about how familiar we are with our bodies and what is normal for us...and what things we would see a doctor about.

B. SYMPTOMS AND CARE-SEEKING (25 minutes)

Let's look at a list of some of the things I'm talking about. Please don't worry if some of the words aren't familiar to you; that's OK.

- Pain or pressure in the pelvic area (the area below your stomach and between your hip bones).
- Back or abdominal pain.
- Being tired all the time.
- Bloating, which is when the area below your stomach swells or feels full.
- A change in your bathroom habits, such as having to pass urine very badly or very often.
- An upset stomach or heartburn that doesn't go away or comes and goes a lot over a couple of weeks.
- Bleeding or discharge from your vagina that is not normal for you.
- Itching or burning in the genital area that does not go away.
- Changes in the color of the skin or a rash, sores, or warts in the genital area.

1. **Would you be concerned about any of these if I had not said anything about noticing changes in our bodies?**

Which ones?

Are there some that you would be more concerned about than others?

Why would you be concerned about those?

Listening for/will probe:

Whether any concerns are because of unfamiliar words or not knowing what's normal. [If there are "yes" responses, moderator will assure participants that she will provide more information later and thank women for letting her know that this is unfamiliar.]

Would having any of these make you concerned at all about particular diseases? What diseases? [Probe about cancer only...]

Does anyone associate cancer with anything on the list?

Any particular type or types of cancer?

Which symptoms made you think of that type of cancer?

2. **If anything on the list happened now for you, how do you think you would react?**

Probe:

For example, do you think you would talk to someone?

Look something up online? Can you give me an example of what you would do – for example, the search words you would use, or the Web site you'd go to?

Call your doctor? In general for any of these things, or for particular ones?

If you think you'd call the doctor, how long would you have the symptom before you called or made an appointment to see the doctor?

What kind of doctor would you see (primary care doctor, OB? GYN? Other?)?

Would it depend on which symptom you have? If so, which one(s)?

If you don't think you would call or see a doctor, why not?

3. *[If time...since it seems likely that women will have referred already to experience with some of these]* **If you've had any of these symptoms, can you share with us how you reacted?**

C. CANCER AWARENESS AND RISK PERCEPTION (25 minutes)

[Depending on time and how discussion unfolds in first group, may find that some of the probes in this section can be shortened.]

As I said earlier, things on the list could have many explanations. Sometimes, these things could be warning signs of some types of cancer. Here is a list of them.

These are all gynecologic cancers: cervical, ovarian, uterine, vaginal, vulvar

1. **As a group, these are referred to as "gynecologic" cancers.**

Have you heard that term before – gynecologic cancers?

What else, if anything, do these words make you think of?

2. **Have you heard of any of these cancers? Which ones? Where/how did you hear about them?**

3. **Have you ever looked for information about any of these cancers?**

What prompted you to look?

Where did you look and what did you want to know?

4. Let's talk about what you have heard about some of these, if anything. Please don't feel like this is a test – finding out what is unfamiliar to women will help CDC figure out what they need to cover in this program.

a. Are there some gynecologic cancers that you think are more serious than others?

Will probe some of the following for the three main cancers only – uterine, cervical, ovarian.

b. Have you heard anything about who gets (insert specific cancer)? (e.g., what age, what gender, what race, any particular ethnic groups?)

c. Have you heard anything about what causes any of these cancers?

d. Have you heard about whether there are ways to be tested for (insert specific cancer)? Or who should be tested for (insert specific cancer)?

e. Are you familiar with the Pap test -- also referred to as a Pap Smear? What have you heard about what it's used to screen for? Where did you learn this?

f. Have you heard about any ways to prevent (insert specific cancer)?

5. How concerned are you that you may develop any of these?

D. RESPONSE TO INSIDE KNOWLEDGE CAMPAIGN MESSAGES (20 minutes)

1. CDC's health education program will be called, *Inside Knowledge: Get the Facts About Gynecologic Cancer*. Here are the program's main messages

a. Pay attention to your body and know what is normal for you. Gynecologic cancers have warning signs.

Do you believe that?

Would this catch your attention? Why or why not?

Is this new information? How does this information make you feel?

Is any part of this message confusing?

What does this mean to you – “pay attention” and “know what's normal”?

Can you give me an example of something you think you personally would need to do to follow this advice?

b. When gynecologic cancers are found early, treatment is most effective.

Probe:

Whether the message:

...is believable

...is attention-catching

...has new information

...has anything confusing

- c. If you notice any unexplained signs or symptoms that persist for more than two weeks, see a doctor right away.

**Do you think you would do this? Why or why not?
What type of doctor would you see? Primary care or a gynecologist?**

Probe:

What does “unexplained” mean to you? Is it clear that the symptoms are important if they don’t pass/subside?

What does ‘right away’ mean to you? Does it seem urgent?

- d. Get a Pap test regularly to screen for cervical cancer.

Probe:

Whether the message:

...is believable

...is attention-catching

...has new information.

...has anything confusing

What does “regularly” mean?

- 2. Which of these would you pay attention to the most? Which one would you pay attention to the least?**
- 3. Is there another message you think is missing?**
- 4. What do you think of the campaign name *Inside Knowledge: Get the Facts About Gynecologic Cancer*?**

E. CELEBRITY ADS (@5 minutes)

- 1. What types of people do you think should be featured in educational materials, advertisements, or public service advertisements that talk about gynecologic cancers? For example, would you recommend that they feature celebrities? Real women? Both? Why?**

Probe why celeb vs. real women:

Do celebrities make you more or less likely to pay attention?

Are they believable? What makes them believable?

Should the celebrity/real woman be personally affected by the disease?

How important is that? What if they aren’t personally affected?

- 2. Suppose a celebrity appeared in a TV public service ad promoting awareness about gynecologic cancers. Can you think of anyone who might be likely to catch your attention?**

Why do you like (insert name)?

What makes (insert name) appealing or credible for this topic?

Thanks participants for time and ideas.
Provides departure instructions.

TOTAL TIME: 90 minutes