

**FOCUS GROUPS WITH OLDER WOMEN
TO TEST MOTIVATIONAL MESSAGES ON
CERVICAL CANCER AND THE PAP TEST**

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1. EXECUTIVE SUMMARY

1.1 INTRODUCTION AND METHODOLOGY

The National Cervical Cancer Awareness Program (NCCAP) was established by the National Cancer Institute's (NCI) Office of Communications (OC) to increase women's awareness of cervical cancer. To achieve program objectives, NCI strives to develop messages that convey the importance of regular Pap test screening. An important part of this effort is designing messages that appeal to women ages 65 and older - an age group that accounts for approximately 41% of all cervical cancer deaths in the United States.¹

During October 1999, OC conducted a series of focus groups with women ages 65 to 75. The specific objectives of these groups were:

- **To learn what older women know about cervical cancer and Pap tests;**
- **To better understand their attitudes, perceptions, and practices with regard to Pap tests and cervical cancer;**
- **To assess their reactions to messages encouraging women to get Pap tests; and**
- **To obtain their feedback on a physician's pad tear-sheet containing consumer information on Pap tests.**

Four focus discussions were conducted in two locations - Richmond, VA (two groups) and Chicago, IL (two groups). Each group included a mix of African American and Caucasian women drawn from diverse socio-economic backgrounds. Women were excluded from participating if they had had a hysterectomy, a Pap test in the past four years, or if they had ever had a cancer diagnosis. Each group was composed of nine to ten women.

During each two-hour discussion, participants were asked first about the health conditions or illnesses that concern them most, followed by their perceived risk for cervical cancer. Subsequent questions concerned their knowledge, perceptions, and personal experiences with the Pap test. The remaining time was spent in message testing: first, asking participants to react to and discuss the strengths and weaknesses of

¹ OC is collaborating with the Health Care Financing Administration (HCFA) to increase awareness of Medicare coverage for cervical cancer screening among women ages 65 and older. In 1998, Medicare expanded its coverage for cervical cancer screening, paying for Pap tests once every three years for women ages 65 and older who are at average risk and once a year for women in this age group who are at higher risk.

11 messages designed to motivate women to get regular Pap tests; and second, having them provide feedback on an informational tear-sheet titled “Why Get Pap Tests?” The 11 motivational messages were as follows:

1. *Get a Pap test – it’s a quick, easy way to protect yourself against cervical cancer.*
2. *Even after menopause, you continue to be at risk for cervical cancer and need regular Pap tests.*
3. *You can develop cervical cancer at any age, so make regular Pap tests a habit for life.*
4. *Cervical cancer can develop without symptoms. Getting regular Pap tests can find the disease before you do.*
5. *If you think you are no longer at risk for cervical cancer because you’re over 65, think again.*
6. *Did you know that advanced cervical cancer is most likely to be diagnosed in women over 50? Talk to your doctor about a Pap test.*
7. *You see your doctor for many reasons. Getting screened for cervical cancer should be one of them.*
8. *Don’t forget to talk to your doctor about how often you need Pap tests.*
9. *Regular Pap tests can catch cervical changes before they have a chance to become cancerous.*
10. *Cervical cancer is most treatable when detected early – get regular Pap tests.*
11. *Cervical cancer is almost entirely preventable if you get regular Pap tests.*

Transcripts were prepared from audiotapes and then content analyzed as a basis for the findings in this report.

1.2 CONSUMERS’ CONTEXT FOR UNDERSTANDING PAP TEST MESSAGES

Knowledge and Attitudes

Focus group participants showed a striking lack of knowledge or concern about cervical cancer. In general, they did not think about cervical cancer very much, being far more worried about other potential medical problems. A host of personal beliefs and misconceptions contributed to this general indifference to cervical cancer and Pap tests. Participants were unsure of the anatomical location of the cervix. They also seemed to confuse cervical cancer with ovarian or uterine cancer, feeding a misperception that cervical cancer is especially perilous. A similar confusion surrounded Pap tests: participants were not certain how they worked, when they were needed, or what they could detect.

On a personal level, women in these focus groups felt they were at virtually no risk for the disease. To them, cervical cancer posed a danger only to women with detectable symptoms, an unhealthy lifestyle, a history of the disease in their family, or an active sex life more characteristic of younger women.

Participants also indicated that cervical cancer receives little attention from their doctors or the media. They said their doctors are mainly concerned about the more publicized, high-profile medical tests such as those for colon or breast cancer.

Behaviors

Most of the focus group members saw little reason to visit their doctor unless they were very ill. As a result, they stated that they do not typically get medical screening tests. When they *do* see their doctors, they said they might bring up some tests, but Pap tests are not among them. The family practice doctors and internists whom they visit do not usually recommend Pap tests, perhaps because the cervix is considered to be the domain of the gynecologist. Some have not been to a doctor in 15 years or more.

Motivations and Barriers

Focus group participants acknowledged that having Pap tests could bring them peace of mind and the benefit of early detection, but felt that their lack of symptoms or risk factors for the disease (in particular family history) outweighed any need for having the test. They felt it unnecessary to endure the discomfort, inconvenience, cost, and potential inaccuracy of the Pap test.

1.3 RESPONSES TO MOTIVATIONAL MESSAGES

When participants were exposed to 11 messages encouraging women, especially older women, to have Pap tests, their attitudes began to change. They found the following two messages most convincing:

- *Cervical cancer can develop without symptoms. Getting regular Pap tests can find the disease before you do.*
- *You can develop cervical cancer at any age, so make regular Pap tests a habit for life.*

These messages resonated well because they explained that women can get cervical cancer without symptoms, at any age, and that the disease can be detected early. Participants were generally unenthusiastic about messages that told them to talk to their doctors, a practice they said was becoming increasingly more difficult under the prevailing system of managed care. They also disliked messages that mentioned advancing age as a consideration for Pap test screening, as this made them feel old.

Women offered some of their own suggestions for message concepts they thought could be effective. One suggestion was to explain that all women are at risk for cervical cancer even if they are not currently sexually active (a reference to the human papillomavirus). Another suggestion was to explain that women need Pap tests at specified intervals to help them live long, healthy lives.

1.4 RESPONSES TO INFORMATIONAL TEAR-SHEET

When participants reviewed an information sheet (“Why Get Pap Tests?”) designed as take-home information for doctors to give their patients regarding cervical cancer, participants found it informative and convincing -- enough to change their minds about their personal risk for cervical cancer. They particularly liked the explanations for what the human papillomavirus (HPV) is, why there is risk for the disease at older ages, and how Pap tests detect abnormal cells. Women indicated, however, that this fact sheet would be more effective if it had less text, a definition of what “regular” testing means (so that they did not have to discuss frequency of Pap tests with their doctors), and less emphasis on the test’s limitations. Nonetheless, this sheet was enough to convince most participants that they should get a Pap test.

1.5 CONCLUSIONS

Older women lack basic knowledge of cervical cancer and the Pap test, and most do not consider themselves at risk for the disease. However, older women are receptive to learning more about cervical cancer and Pap tests and said they would be willing to change their behavior accordingly; all who had rated themselves at zero risk for cervical cancer changed their minds after reading the physician's pad information tear-sheet and discussing the 11 tested messages.

1.6 RECOMMENDATIONS

Based on the findings from these focus groups, messages for older women regarding cervical cancer and Pap tests should:

- Explain what a Pap test is for;
- Tell older women what and where the cervix is, and what causes cervical cancer;
- Tell older women exactly how often they should have Pap tests;
- Tell older women they can get cervical cancer without symptoms or being sexually active, at any age, and even if they have been monogamous;

- Be sensitive to older women's dislike for references to advancing age and assumptions regarding the easy accessibility of doctors; and
- Provide a call to action.

Concurrent messages should also be designed for doctors, reminding them to give older women regular Pap tests.

2. INTRODUCTION AND METHODOLOGY

2.1 BACKGROUND

The National Cervical Cancer Awareness Program (NCCAP) was established by the National Cancer Institute's (NCI) Office of Communications (OC) to increase women's awareness of cervical cancer and the importance of Pap tests. To fulfill program objectives, NCI strives to develop messages that convey the importance of regular Pap test screening. An important part of this effort is designing messages that appeal to women ages 65 and older - an age group that accounts for approximately 41% of all cervical cancer deaths in the United States.²

During October 1999, OC conducted a series of focus groups with women ages 65 to 75. The specific objectives of these groups were:

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- **To assess their reactions to messages encouraging women to get Pap tests; and**
- **To obtain their feedback on a physician's pad tear-sheet containing consumer information on Pap tests.**

2.2 METHODOLOGY

2.2.1 Group Composition

Four focus groups were conducted in two locations - Richmond, VA (two groups) and Chicago, IL (two groups). Each group was composed of nine to ten African American and Caucasian women, ages 65 to 75, drawn from diverse socio-economic backgrounds. They were led in discussion by a trained moderator in her early 50s. Conversations lasted approximately two hours. To participate in the focus groups, women had to meet the following eligibility criteria (see Appendix A for screener):

- No Pap test in the past four years;

² OC is collaborating with the Health Care Financing Administration (HCFA) to increase awareness of Medicare coverage for cervical cancer screening among women ages 65 and older. In 1998, Medicare expanded its coverage for cervical cancer screening, paying for Pap tests once every three years for women ages 65 and older who are at average risk, and once a year for women in this age group who are at higher risk.

- Never been diagnosed with cancer;
- Never had a hysterectomy;
- Age 65 to 75;
- Fluent in English; and
- High school education or some college.

2.2.2 Content of Discussion

The moderator's guide (see Appendix B) was developed to test older women's reactions to 11 motivational messages and a physician's pad informational tear-sheet on Pap tests, as well as to:

- gauge women's level of concern about cervical cancer relative to other health conditions or illnesses;
- determine women's knowledge, attitudes, and behaviors regarding cervical cancer and Pap tests;
- assess women's perceptions of their personal risk for cervical cancer;
- understand the potential benefits and motivators for women to have Pap tests;
- examine women's perceived barriers to seeking Pap tests and explore ways to overcome them.

Each discussion group began with introductions and a warm-up question about participants' hobbies. The moderator then asked participants about the health conditions or illnesses foremost in their minds. Discussion then moved to a conversation about cervical cancer in general and participants' perceptions of their personal risk for cervical cancer. Questions about the Pap test in general and personal experiences with the Pap test followed.

During the second half of the discussions, participants were shown 11 motivational messages that summarized reasons why women should get regular Pap tests. Each message was unveiled individually on a large poster board displayed in the room. Participants were given stacks of index cards with a single message on each card and asked to sort through them, choosing the two messages they liked best and the two they liked least. Participants were told that all messages were factual statements that were being considered as drafts of message concepts to be used in a campaign to encourage women (especially women their age) to have regular Pap tests. The 11 messages are listed below:

1. *Get a Pap test – it's a quick, easy way to protect yourself against cervical cancer.*
2. *Even after menopause, you continue to be at risk for cervical cancer and need regular Pap tests.*
3. *You can develop cervical cancer at any age, so make regular Pap tests a habit for life.*

4. *Cervical cancer can develop without symptoms. Getting regular Pap tests can find the disease before you do.*
5. *If you think you are no longer at risk for cervical cancer because you're over 65, think again.*
6. *Did you know that advanced cervical cancer is most likely to be diagnosed in women over 50? Talk to your doctor about a Pap test.*
7. *You see your doctor for many reasons. Getting screened for cervical cancer should be one of them.*
8. *Don't forget to talk to your doctor about how often you need Pap tests.*
9. *Regular Pap tests can catch cervical changes before they have a chance to become cancerous.*
10. *Cervical cancer is most treatable when detected early – get regular Pap tests.*
11. *Cervical cancer is almost entirely preventable if you get regular Pap tests.*

After the moderator tallied participants' votes for most and least persuasive message, each message was discussed individually to identify its strengths and weaknesses.

Finally, participants were asked to react to an informational tear-sheet titled "Why Get Pap Tests?" The 8 ½" x 11" tear-sheet was designed as a physician's pad, similar to a prescription pad, providing the doctor with take-home information sheets on cervical cancer and the Pap test to give his/her patients. (See Appendix C)

2.2.3 Analysis

Transcripts were prepared from the audiotapes and then content analyzed as a basis for reporting the findings and formulating the conclusions found in this report.

The focus group methodology was chosen because its exploratory nature provides an appropriate vehicle for learning about an audience's attitudes, beliefs, and perceptions, and it is an effective forum for pre-testing messages and materials. It should be noted, however, that because participants are not independent random samples and the data take the form of group conversations rather than answers to identically administered questionnaires, the results are not statistically generalizable to any population. Nonetheless, qualitative research of this sort is highly instructive for developing communication messages and strategy because it provides rich, in-depth information that is useful in understanding what and how people think, feel, and behave.

3. DETAILED FINDINGS

3.1 CONSUMER CONTEXT FOR UNDERSTANDING PAP TEST MESSAGES

Older women's reactions to the tested messages were shaped by the following factors:

- their knowledge -- resulting from their formal education, experience, exposure to media, and the advice of their doctors;
- their attitudes -- predisposing them toward certain views;
- their behaviors -- reflecting and reinforcing their knowledge and attitudes;
- their motivations -- providing meaning and direction to their perceptions and practices; and
- their perceived barriers -- setting limits to what they can do, expect, and perceive concerning Pap test screening.

3.1.1 Knowledge

Most participants were confused and misinformed about cervical cancer, partly due to a lack of knowledge of their own anatomy. Most participants were confused about what cancer of the cervix is, partly because of a surprising lack of knowledge of their own anatomy. The majority of women tended to lump all organs in the pelvic region together and did not know what or where the cervix is. They also confused cancer of the cervix (cervical cancer) with other types of cancer, including ovarian, uterine, and even colon cancer. The following quotes illustrate participants' level of confusion about their bodies:

"I don't know enough about cervical cancer. What's the difference between cervical cancer and ovarian cancer? It sort of blends together. It is a little confusing."

Participant 1: "Is cervical cancer and colon cancer the same thing?"

Participant 2: "No, one's in the front, one's in the back."

Participant 1: "Oh, thank you. Which is which?"

Most participants misperceived cervical cancer as especially perilous. When asked what came to mind when they heard the words "cervical cancer," the following terms were participants' first associations: "real serious," "terror," "probably fatal" and "a very painful death." Participants believed that if they were to get cervical cancer, they

would have little chance of surviving. Many women confused cervical cancer with ovarian or uterine cancer.

"I feel like after a certain age, why put yourself through a lot of agony with the treatments if it's not going to cure it? Like she said, when you find out you have it [cervical cancer], it's too late."

"I think if you've got it, you're not going to cure it anyway."

Many participants were unsure about what the Pap test is designed to detect. Some participants knew that Pap tests detect cervical cancer, but only one person in all of the groups knew about the possibility of finding suspicious cells before they become cancerous. Many thought the Pap test can also detect ovarian cancer, uterine cancer, sexually transmitted diseases (STDs), and other infections.

"They [Pap tests] can find whether or not you have other types of diseases down there like venereal diseases. They can find that out when they give you the Pap test."

Many participants had erroneous ideas about who needs Pap tests. Participants believed cervical cancer is mostly a danger for women who show symptoms, lead an unhealthy lifestyle, are young, and/or have a history of cancer in their family.

One of the strongest assumptions made by participants in all the groups was that a woman would know if she had cervical cancer since she would experience unmistakable symptoms such as pain in the abdomen, excessive bleeding (hemorrhaging), discharge, or discoloration of discharge. Participants believed that, as with any serious disease, their body would show signs if something were wrong.

"If I have no blood and no discharge or pain, I figure I'm okay. Once something starts showing, then I'd worry and run to the doctor."

"Well, I think our body tells us. Something gives us some kind of hint – a twinge of pain or something."

"I think you would have some kind of symptom. I don't care what they say, there will be something in the body that lets you know something is wrong."

Participants believed an unhealthy lifestyle increases a woman's risk for cervical cancer (including factors such as smoking, poor diet, stress, and sexual activity). Almost all participants believed that having multiple sex partners and being sexually active were risk factors. Interestingly, participants did not consider past sexual activity a risk factor. (See section 3.1.2 on risk perception.)

"Well, I don't have a husband so I don't need a Pap test because I'm not sexually active. If you had a whole slew of boyfriends, you'd need it."

Women in the focus groups speculated that those most likely to get the disease were "promiscuous" women and "prostitutes," while those less likely to get cervical cancer were men, nuns, and older women like themselves. Some participants, moreover, perceived a link between cervical cancer and the number of children a woman had birthed, although the meaning of this connection differed among participants. Several said that women who never had children would be more susceptible to cervical cancer, while others thought that women who had given birth to "too many babies" would be more vulnerable to the disease.

Participants also believed only younger and middle-aged women who are sexually active need to get Pap tests every year. Many of the participants indicated that older women, like themselves, are safe from cervical cancer unless they have a family history of it. Most participants thought women are supposed to have Pap tests once a year until the age of 45 or 50. None of these women reported having Pap tests as often as they used to when they were younger. (See section 3.2.1 on risk perception.)

"In childbearing years it's different, but you don't need it when you're older."

"When I was younger, I used to get Pap smears yearly, but now I don't."

Some participants were aware that Medicare pays for a Pap test every three years. A few participants in each group knew that Medicare pays for Pap tests every three years. But there was a great deal of confusion over what it means to have "regular" Pap tests, and participants expressed a desire for unambiguous guidelines that clearly communicate how often they should get the test.

3.1.2 Attitudes

Cervical cancer is not among the diseases or medical conditions that participants spontaneously think about. When the moderator asked participants what diseases or health conditions they worry about, none mentioned cervical cancer. Instead, they cited stroke, cancer (especially breast and colon cancer), heart attacks, Alzheimer's disease, and diabetes as their top-of-mind health concerns. According to the women in the focus groups, these other diseases get far more attention from the medical profession and the media.

"I'm inclined to think in terms of cancer in general – not just cervical."

"There's so much talk about breast cancer and there's very little talk about cervical cancer."

Participants believed that screening tests recommended by the medical profession go in and out of fashion. According to the participants, medical tests other than the Pap smear currently appear to be more important for their age group. Many participants believe that the medical tests recommended by their doctors change according to what

is currently receiving high visibility on television or in the newspapers. During some years, they are told that certain medical tests are extremely important, only to find out a few years later that other tests have usurped the spotlight. This leaves them wondering about the necessity of having any medical tests or procedures. The following exchange from one of the focus groups illustrates this point:

Participant 1: "Years ago they used to give chest x-rays and they even had mobile units giving them. Now they've stopped that completely – too much x-raying is damaging. And they used to x-ray your feet when you bought shoes and now they don't do that anymore either."

Participant 2: "And they'd take your tonsils out at the drop of a hat – they don't do that anymore."

Participant 3: "And for a while they were doing a lot of hysterectomies and C-sections."

Participant 1: "So, I'm not going to take everybody's word for every little thing they can come up with. I think you have to use your own common sense."

Due to the perceived decline in attention to Pap tests by television news, newspapers, and the medical profession, Pap tests have basically dropped out of participants' awareness.

"About 20 or 25 years ago it seemed like they used to talk about cervical cancer. But today it's mainly breast cancer that they seem to be concerned about. I don't think about cervical cancer because it's not brought up that often."

"Today they talk a lot about colon cancer, and that everybody's supposed to have a test every year."

"You don't hear about Pap tests these days. Years ago you did, but today it's the colon test they want to do."

The few participants who stated they still visit their doctors (for other than specific problems) said it is more common for them to receive the following medical screening tests: mammograms; cholesterol checks; blood pressure checks; colonoscopies; routine blood tests; bone density tests; and visual field tests for glaucoma.

Focus group participants considered themselves at very low risk for cervical cancer because they had no family history of the disease, were monogamous or no longer sexually active, or were post-menopausal. Probably because cervical cancer does not figure prominently in their minds, participants described their risk of getting cervical cancer as very low or non-existent. When asked to estimate their risk of cervical cancer on a scale of zero to ten (zero being "not at all likely" and ten being "extremely likely"), a majority said they had "zero chance" of getting the disease.

"I never think of getting cervical cancer. I worry about stroke or heart disease more."

"I never got a Pap test because I never thought of it."

"I don't really think about it too much because I try to take care of myself by eating well, exercising, and not smoking."

"I feel like I'm not gonna get it. But I also say there's always the chance. You can't always be sure that you're not going to get it, but I feel my chances are very slim."

Participants tended to assess their risk as extremely low primarily because they have no family history of cervical cancer (or cancer in general), and they hold an underlying belief that they will die in ways similar to their parents. In addition, participants believe that their healthy lifestyles place them at a lower risk for cervical cancer.

"I put my risk at zero because there's no cancer in my family and I have periodic exams [physicals], try to eat properly, and I don't drink or smoke or eat foods with a lot of fat."

"Cervical cancer is an inherited condition and I do not know of anyone in the family that had it."

"If you haven't ever had any cancer in your family, unless the doctor feels like you need it, I don't think you should be bothered getting a Pap test."

"I worry more about the heart because most everybody in my family went with a bad heart."

"I think if it's in your family and you've got concerns, then I guess you should get Pap tests and not stop at any age. In my case, my family history says that no one I know of in my family or my mother's or father's [family] had cancer, so that doesn't occur to me as a concern."

*"My mother died in a car crash when she was 78, so I guess I'll go in a car crash at 78 too!"
(tongue in cheek)*

Most participants also believed that women their age are not as susceptible to cervical cancer as younger women because they are monogamous or no longer sexually active.

"I never think about my risk for cervical cancer. We all die ultimately and I figure something's gonna get me in the end. But as far as my bottom goes, that thing has been out of commission for awhile. I've been a monk for the past 25 years! As someone said, 'If it ain't broke, don't fix it,' so I don't mess around with mine! There are other parts of my body I worry about more – like my lungs and my heart – I use them every day!"

"I'm not sexually active and haven't been for 25 years, so I don't live a lifestyle that I believe might contribute in any way to cervical cancer."

Finally, participants did not perceive themselves to be at risk for cervical cancer because they are post-menopausal, beyond their childbearing years, and therefore "too old" to get cervical cancer.

"I don't think I'll get it because I'm 68. If I don't have it by this age, I don't believe I'll get cervical cancer."

"In childbearing years, it's different. But you don't need it when you're older."

"Those of us who have had children have been monitored through our last child. My last child was born when I was 40 and, frankly, since then it has never occurred to me to have anyone peaking and prodding at my innards!"

"I think after a certain age you don't need it...I don't really see the sense in it for older people."

Many participants prefer to "think healthy" than to think about disease. Some participants indicated that they do not want to think about cervical cancer because they are superstitious and fear that thinking negative thoughts could actually bring on a disease. Instead, they subscribe to the belief that positive thoughts will guard their health.

"I put down zero for my chances of getting cervical cancer. I'm thinking positive. I'm not going to put down any number that indicates that it is a possibility. I'm not going to think cancer. I believe I'm a very strong person and I try to keep mind over matter and think positive."

"I think positive – I don't dwell on, 'Gee, I wonder if I've got this or that.' I just like to live my life."

Many women in the focus groups expressed concern about the reported inaccuracies of Pap test results. Participants had heard stories and seen media accounts of laboratories that made serious mistakes and oversights in reading Pap test results, sometimes costing women their lives. As a result, they did not express a great deal of confidence in the accuracy of the Pap test. Only a few women indicated that this situation underlined the importance of having regular Pap tests, since what is missed one year could hopefully be picked up the next.

"Some labs aren't very accurate. They said a person didn't have cancer when they did and they said they did when they didn't. It's frightening because I think it is more common than most of us are aware."

"You often don't trust the [Pap] test results when you get the answers back because the journals now give you so many examples of places where they are not using qualified people and the tests are not accurate."

"I've read that many of the companies that do tests aren't careful and the results aren't accurate. That's very disconcerting."

“I’ve heard some bad reports about those Pap tests. Sometimes, depending on what lab takes care of it, certain things that should be found are bypassed by that particular laboratory. The report goes to the doctor and the doctor gives the person a clean bill of health. Then, down the line something occurs. I’ve heard of that quite often.”

3.1.3 Behaviors

Most focus group participants said they do not visit doctors unless they have a specific problem or are very ill; typically, therefore, they do not get medical screening tests. Some participants said they had not visited a doctor in 15 years or more, attributing their behavior to the philosophy: “Don’t go looking for trouble” or “If it ain’t broke, don’t fix it.” They tend to judge people who frequently go to doctors as hypochondriacs, stating that they have better things to do with their lives than worry about all the diseases they can get. As a result, these particular women rarely have routine medical screening tests.

“I don’t go to the doctor much because I don’t want to hear nothing. The body is like an old sink pipe – once you start monkeying with it, it is one thing after another. I’m ticking all right so I figure I must be doing something right.”

“I was brought up that you don’t go to the doctor unless you are dying!”

“Some people are just paranoid about their bodies and run to the doctor any time they sneeze. What I say is that if you get too involved in your body, you haven’t got enough to keep you busy.”

Others in the focus groups were almost complacent, reasoning that since they have reached their current age with relatively few health problems, there is no reason they should not continue to stay healthy.

“When I was younger I would go to the doctor for a physical every two years. But somehow when I passed 50, I realized that I’m a pretty healthy specimen – it’s probably just the genes that came down the line. I realized that I was spending an awful lot of time out of my life sitting in a [doctor’s] office somewhere, and I just felt that it wasn’t necessary. So, the last real physical I had was probably eighteen years ago. I’m fortunate and I hope I stay fortunate.”

3.1.4 Motivations

During the groups, the moderator asked women to consider what possible benefits there would be to getting a regular Pap test.

Focus group participants cited the following as benefits women could reap from regular Pap tests: finding cancer early enough for it to be treated; peace of mind; and extending one’s life. Along these same lines, participants suggested crafting messages to include such statements as, “You’ve got a lot of living to do, so you want to be here!

Get a Pap test..." or "I've got a lot of living to do and I want to be here! That's why I get a Pap test...."

Women in the focus groups said they would be more likely to get Pap tests under the following conditions: their doctors recommended it; they had a family history of cancer; they were currently sexually active; they were experiencing symptoms; the test was less painful and embarrassing; and/or it were free of charge.

When the moderator asked participants to finish the sentence "I would get regular Pap tests if..." most participants indicated that they would get the test if they felt at some risk for the disease. The following were typical responses:

I would get regular Pap tests if...

- "... my doctor recommended it."
- "... I had a family history of cervical cancer."
- "... cancer ran in my family."
- "... I had pain, bleeding, or discharge."
- "... I were sexually active."
- "... I had multiple sex partners."
- "... it were less invasive, uncomfortable, or embarrassing."
- "... the cost were covered by insurance."

3.1.5 Barriers

When asked about barriers to getting Pap tests, participants said the tests are awkward, embarrassing, uncomfortable, and painful. "Pain," "stirrups," "embarrassing" and "fear of a bad report" were some of participants' immediate associations with Pap tests. Moreover, participants insisted that getting on a table and placing their feet in stirrups is not as easy as it was when they were younger and more physically agile.

"It's a cotton swab pushed into a place by a doctor and analyzed."

"You lay on the table with your legs spread and you have to put your feet into stirrups and have somebody messing around there...I resent somebody getting that personal."

Lack of awareness, perceived lack of risk, and lack of symptoms also emerged as primary reasons participants do not get Pap tests. According to participants, cervical cancer and Pap tests are overlooked by both their doctors and the media. Because of this, they are unaware that they should have a Pap test or that they may be at risk for the disease. Most participants never even think about cervical cancer, and are much more aware of other diseases and conditions that figure prominently in the media, such as breast cancer, colon cancer, heart disease, stroke, and diabetes. Many participants hold the strong belief that if they had cervical cancer they would experience

unmistakable symptoms like bleeding or pain. In the absence of such symptoms, they feel safe.

Focus group participants said that their family practice doctors and internists do not talk to them about cervical cancer or recommend Pap tests, possibly because the cervix is considered to be the domain of the gynecologist. Most participants said they no longer go to a gynecologist, having stopped after their childbearing years; those who still go to a gynecologist tended to be generally better informed about the Pap test and cervical cancer. Overall, participants said that if they were at risk for cervical cancer, their doctors would have told them so.

“I go to an internist and he doesn’t think it’s necessary for me to have a Pap test. If your doctor is not interested in it, then it makes you think it’s not really that necessary.”

“My general practitioner doesn’t give me a Pap test unless I insist.”

“I was told by one of the doctors if you don’t mess around much [sexually] you don’t have any worries. I’m a widow for 19 years and I haven’t had sex since then. So I never think about cervical cancer.”

“My doctor says I don’t need a Pap test. If it were recommended by my doctor, I would have one, because I have a lot of confidence in my doctor.”

Some participants suggested that since they no longer go to gynecologists, they are not reminded to get Pap tests or told about their continuing risk for cervical cancer. They speculated that the cervix and the Pap test are “claimed” by the gynecologist and that family practice physicians and internists do not want to give Pap tests to women.

“The Pap test is something that usually you talk to a gynecologist about. I haven’t been to a gynecologist in quite a few years, so no one has brought that up. But then a doctor wouldn’t bring up having your fillings checked either because that’s something your dentist does.”

“My family doctor hates to give Pap tests.”

Lack of confidence in the accuracy of Pap test results led women to think that getting these tests may be a pointless activity. This belief only added one more item to participants' list of reasons not to get Pap tests. It was also apparent that participant lack of confidence was based on accounts of this problem dating back five or more years.

3.2 RESPONSES TO 11 MOTIVATIONAL MESSAGES

The moderator presented participants with 11 motivational messages, unveiling them one at a time on a large poster board displayed in the room. Participants were then

given a stack of index cards with one message on each card and asked to sort through them, choosing the two messages they liked best and the two they liked least. (A total of 76 votes were cast for most and least liked.) Most of the subsequent focus group discussion was devoted to evaluating the strengths and weaknesses of each of the 11 messages. The messages are reviewed below in order of decreasing preference.

3.2.1 Most liked message: "Cervical cancer can develop without symptoms. Getting regular Pap tests can find the disease before you do."

This message received the highest number of votes for most liked (20 votes) and only a few votes for least liked (only four). No other message came even close to this one in popularity.

In all focus groups, this message was chosen as one of participants' top two favorites. The phrase "without symptoms" was the key to why women preferred this message; they said this new information would help convince them to get Pap tests, since otherwise they would have assumed that the absence of symptoms meant no disease. "That would make me get a Pap test," or, "That changes my mind!" were common reactions to this message. Participants also liked the phrase, "Pap tests can find the disease before you do" because it implied that early detection meant a greater chance to save their lives. As one woman said, "This message says it all!"

Those who selected this message as one of their least favorites said they did not believe, or did not want to believe, that one could have the disease without symptoms. Intuitively, this did not make sense to them.

3.2.2 Second most-liked message: "You can develop cervical cancer at any age, so make regular Pap tests a habit for life."

This message received 14 of 76 votes for best liked and only four votes for least liked.

Women in all groups had generally positive reactions to this message. They liked its straightforward approach and the phrase "at any age," which they found preferable to giving an actual number or singling out a group (e.g., "women over 65"). The fact that older women are at continued risk for cervical cancer was new information to them and would be helpful in convincing them that they need a Pap test.

Those who did not like this message did not believe that older women are truly at risk for cervical cancer.

3.2.3 Mildly popular message: "Cervical cancer is most treatable when detected early - get regular Pap tests."

Although this message received only four of 76 possible votes for most liked, it received 0 votes for least liked.

Participants generally liked this simple message for its credibility (e.g., "It's true"). The use of "regular," however, was confusing and frustrating to many participants because the message does not specify what "regular" means.

3.2.4 Neutral message: "Regular Pap tests can catch cervical changes before they have a chance to become cancerous."

This message received an equal number of votes for most and least liked - five votes in each category.

According to some participants, the information was "good to know." Those who liked the message responded positively to the phrase "can catch cervical changes before they have a chance to become cancerous." This was a hopeful statement to them.

Those participants who did not like the message said it was confusing because they did not understand how having regular Pap tests could catch the disease before it becomes cancerous. This was probably tied into the belief that cervical cancer is accompanied by detectable symptoms.

3.2.5 Mildly unpopular message: "Even after menopause, you continue to be at risk for cervical cancer and need regular Pap tests."

As with the previous message, this message received an equal number of votes, albeit fewer - three votes for most liked and three for least liked.

Participants readily acknowledged the truth of the statement ("it's true"), but also rationalized that if they hadn't gotten cervical cancer by now, they were probably safe.

3.2.6 Ambivalent message: "Cervical cancer is almost entirely preventable if you get regular Pap tests."

This message received an equal number of votes for most and least liked - nine each.

Some participants liked the idea that cervical cancer is almost entirely preventable. "Preventable" was a word that elicited their attention and seemed hopeful. It also told them to get regular Pap tests.

The qualifying word "almost," however, was somewhat unsettling to participants since it implied that there is no guarantee that cervical cancer can be prevented. This message raised many doubts among participants regarding whether regular Pap tests can actually help prevent cervical cancer. Most found the notion of Pap tests as a preventive measure extremely perplexing and contradictory, probably because they did not understand the difference between prevention and detection.

3.2.7 Disliked/unpopular message: "If you think you are no longer at risk for cervical cancer because you're over 65, think again."

This message received eight votes for least liked and six votes for most liked.

Some participants liked the content of this message because it reminded them that older women like themselves can get this disease.

However, many participants did not like the reference to a specific age ("65"), preferring statements such as "older women" or "at any age." Giving a specific number for age ("65") made participants feel they are part of an "over-the-hill" group. Some, moreover, did not like the message's lecturing tone (i.e., "think again").

3.2.8 Disliked/unpopular message: "Don't forget to talk to your doctor about how often you need Pap tests."

This message received eight votes for least liked and only two votes for most liked.

Participants who liked this message said it would be a good reminder for women to get Pap tests.

Those who did not like this message thought the directive "Don't forget..." has a condescending tone, one that an adult would use speaking to a child. Some participants added that under the current system of managed care, "there is no time to talk to the doctor about anything." Furthermore, they said they would be suspicious of an individual doctor's opinion, given that the medical profession is in constant disagreement.

3.2.9 Disliked/unpopular message: "Get a Pap test - it's a quick, easy way to protect yourself against cervical cancer."

This message received ten votes for least liked and six votes for most liked.

Those who liked this message said they liked the phrase "protect yourself against cervical cancer." They also liked the simplicity of the directive, "Get a Pap test."

Participants who did not like this message said that getting a Pap test is neither quick nor easy. In reality, they said women usually spend a long time in the waiting room of a doctor's office. In addition, lying on a table with their feet in stirrups is not as easy as it was when they were younger and more physically agile. Many participants also found this message confusing since they did not understand how getting this test would "protect" them from getting cervical cancer.

3.2.10 Disliked/unpopular message: "You see your doctor for many reasons. Getting screened for cervical cancer should be one of them."

This message received 11 votes for least liked and only three votes for most liked.

Participants liked the fact that this message tells women to get cervical cancer screening. But it did not resonate with them because they do not see their doctors regularly for a variety of reasons (some have not been to a doctor in 15 years or more). Participants claimed they only go to the doctor when they become very ill or have a specific problem. Medical emergencies, therefore, rather than preventive checkups and screening, are the main reason for their encounters with the medical system. On the rare occasions that they visit the doctor, their appointments focus on the problem at hand; doctors do not take the time to talk to them about preventive tests.

3.2.11 Least liked message: "Did you know that advanced cervical cancer is most likely to be diagnosed in women over 50? Talk to your doctor about a Pap test."

This message received the most votes in the least liked category (14) and only four votes for most liked.

Although participants acknowledged that this message gives helpful information, they questioned the meaning of "advanced." Many did not like this word since it sounded like the disease was no longer curable.

They also did not like the reference to a specific age ("women over 50"). "I have a thing about mentioning age – it turns me off!" was a comment that echoed the thoughts of many participants. Women in the focus groups recommended a more tactful approach such as, "Women of all ages should have Pap tests" or "You need a Pap test at any age."

As mentioned in 3.2.10, participants reiterated that there is not much time to "talk to your doctor." They again stated that a typical doctor's visit focuses on immediate health problems, not on preventive medicine.

3.3 RESPONSES TO PHYSICIAN'S PAD INFORMATIONAL TEAR-SHEET

After discussion of the 11 motivational messages, participants were asked to read and react to a physician's pad tear-off sheet on cervical cancer and Pap tests. The tear-off sheet (titled "Why Get Pap Tests?") was designed so physicians can tailor hand-written information to each patient's Pap test needs and then give the sheet to the patient as a take-home reminder and educational piece (see Appendix C). Information on the tear-off sheet is divided into several sections that do the following:

- provide general information on the Pap test (purpose, etc.);
- ask the reader to review certain factors to assess if she is at risk for cervical cancer;

- inform the reader about the benefits and limitations of Pap tests;
- list various calls to action; and
- instruct the reader on methods for preparing for the Pap test.

“Informative” was the word focus group participants used most commonly to describe this fact sheet. On the whole, participants liked the piece because they were able to obtain a great deal of important and new information from it. Participants found the following facts on the tear-sheet to be most persuasive [information that was new to them is underlined]:

- *Introduction Section.* “The Pap test can detect abnormal changes in the tissues of the cervix before cervical cancer develops. During the Pap test, cervical cells are collected and examined under a microscope. If abnormal cells are caught early, cervical cancer can almost always be prevented.”
- *“Are You at Risk for Cervical Cancer?” Section.* “Keep in mind that even if you are not currently sexually active, you may have been infected years ago. HPV can live in the body for many years, without any symptoms.”
- *“What Can You Do?” Section.* “Women who have completed menopause continue to be at risk for cervical cancer and should continue to have regular Pap tests.”

However, some criticism of the tear-sheet was also expressed. First, participants commented that there should be less text and more white space. Secondly, they thought the tear-sheet would be more effective without the “*Limitations*” section, since this disclaimer might give women an excuse for not getting a Pap test. Participants also strongly believed that when a screening recommendation includes the word “regular,” it should define what “regular” means; the vagueness of this word was frustrating. Finally, participants thought the statement, “Talk with your doctor or nurse about planning your personal schedule for getting Pap tests” (in the *What Can You Do?* section) was overkill and should be omitted. They felt it was enough just to be told to have the test done.

Many participants indicated that the information from the tear-sheet, as well as from the messages tested during the focus group discussions, would be enough to convince them to go to their doctors and insist on having a Pap test. All those who had previously rated themselves as having zero risk of getting cervical cancer changed their minds after reading and discussing the physician's pad information tear-sheet.

4. CONCLUSIONS AND RECOMMENDATIONS

4.1 CONCLUSIONS

4.1.1 Older women lack basic knowledge of cervical cancer and the Pap test

Findings from these focus groups indicate that older women's misconceptions of cervical cancer and the Pap test are due to a number of factors, including lack of knowledge of basic female anatomy, confusion, and distrust. Participants were confused about the severity of cervical cancer, the purpose of a Pap test, who needs a Pap test, and the frequency with which a Pap test should be given. Women in the focus groups also felt that medical tests are like any other fleeting fad - one test may be popular today, another test may be popular tomorrow. Participants also emphasized that doctors do not have the time to devote to discussing or performing preventive medical tests.

4.1.2 Older women do not consider themselves at risk for cervical cancer

Many women in the focus groups had not visited a doctor in years -- for *any* reason, let alone to have a Pap test. Participants felt little concern about developing cervical cancer because they manifest no symptoms, lead a healthy lifestyle, are "too old," and/or do not have a history of cancer in their family. In particular, they do not consider a woman at risk if she is not currently sexually active.

4.1.3 Older women are receptive to learning more about cervical cancer and Pap tests and are willing to change their behavior accordingly. All who had rated themselves at zero risk for cervical cancer changed their minds after discussing the 11 tested messages and reviewing the information on the physician's pad information tear-sheet.

Focus group participants said that a doctor's recommendation to get a Pap test would motivate them to get one. In addition, many commented that the new information they learned from the fact sheet, as well as from the messages tested, would be enough to convince them to go to their doctors and insist on getting a Pap test.

4.2 RECOMMENDATIONS

Based on the findings from these focus groups, the following recommendations should be considered when developing messages to promote Pap tests for older women.

4.2.1 Explain what a Pap test is for and why it is performed

Women need to learn that Pap tests can catch pre-cancerous cells and detect abnormal changes before they become cancerous. Given the Pap test's early detection benefit,

older women suggested adding to messages the notion of acquiring peace of mind from a Pap test -- e.g., "Pap tests will help give women peace of mind."

4.2.2 Tell older women what and where the cervix is, and what causes cervical cancer

Women need to learn where the cervix is located and that cervical cancer (or cancer of the cervix) is caused by the human papillomavirus (HPV), a sexually transmitted virus carried by males and females. It is also important to educate women that not every HPV infection is destined to become cervical cancer.

4.2.3 Inform older women exactly how often they should have Pap tests

Participants were unclear about what "regular" meant when it appeared in the tested messages (e.g., "Get regular Pap tests"). They also wondered whether "regular" meant once every three years, given the frequency with which Medicare currently covers Pap tests. Moreover, older women wondered if they should receive the test more frequently (e.g., every six months), given that Pap tests can miss abnormal cells. What was clearly conveyed in the groups was that older women want a specific time interval to guide their Pap test behavior.

4.2.4 Tell older women they can get cervical cancer without symptoms or being sexually active, at any age, and even if they have been monogamous

Participants wanted to know how they could get the human papillomavirus. They also asked whether a couple could get HPV if they had met when they were young and had sex only with each other. Participants liked the metaphor of a "sleeping giant" to describe how HPV can live in a human being for a long time without exhibiting any signs, then "awake" without warning.

4.2.5 Provide a call to action

In addition to information on recommended intervals for having the Pap test, participants wanted to know what to do if they learned they or their husbands had the human papillomavirus. They also wondered if and how men could be tested for HPV. Listing additional toll-free numbers and/or web site address on the tear-sheet would provide women with a convenient mechanism for having their questions answered and taking appropriate action.

4.2.6 Be sensitive to language and tone when referring to doctors and specific ages

Messages that include statements such as "Ask your doctor" or "Talk to your doctor about Pap tests" were perceived by many older women as condescending and too directive. Such messages also assumed an easy accessibility to doctors which many older women said they did not have or utilize. In addition, messages that mentioned a specific age (e.g., "65") reminded respondents of their age, making them feel old.

4.2.7 Target doctors and remind them to give older women regular Pap tests

Participants had an almost cynical view of the health care system, believing that doctors do not have time to spend on preventive screening tests, much less discuss patients' individual preventative needs. Doctors may represent the most effective target audience for a campaign to encourage older women to get Pap tests: If doctors believe in the importance of Pap tests, regardless of a woman's age, and act on this belief, they will transmit and reinforce the value of Pap tests to all their female patients, including those who need it the most -- older women.

APPENDICES

A – Participant Recruitment Screener

B – Discussion Guide for Focus Group Moderator

C – Physician’s Pad Information Tear-Sheet: “Why Get Pap Tests?”