

Development of culturally appropriate educational materials on HPV and Pap tests for American Indian women

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Creating the research partnership

- Previous HPV work: African American and Caucasian women
- Asked to extend work to include American Indian women
- Introduction to CWWC staff via mutual colleague
- Face to face meeting – initial agreement by clinic staff
- Institutional Review Board Approval: CDC, USC, EBCI
- Tribal Council approval
- Provide contract with budget to CWWC
- Hire local interviewer (CWWC nurse)
- Meet with CWWC staff to develop plans and procedures

Steps in the materials development process

- Create a timeline and divide tasks
- Review existing literature on HPV knowledge
- Conduct interviews and summarize key findings
- Decide on appropriate educational channel/format (print)
- Locate and critique existing print materials on STIs and HPV, Pap tests, cervical cancer, breast cancer (n=50+)
 - General users, including CDC's materials
 - American Indian users
 - Materials in use at CWWC

Steps in the materials development process (continued)

- Identify cultural, linguistic, and logistical issues through discussions with CWWC staff
- Review principles of patient education
- Identify key knowledge content areas
- Work with tribal artist and print shop to develop draft examples of brochure and poster
- Critique examples: CWWC staff and pretest (n=9 women)
- Make final revisions to content and format
- Tribal print shop prints materials for clinic use

Criteria for evaluation and critique of existing educational materials by USC, CDC, and CWWC clinic staff

Suitability assessment (from Doak et al., 1996)

Content

Literacy demand

Graphics

Layout and type

Learning stimulation and motivation

Cultural appropriateness

(after our previous work: Brandt et al, 2005)

Examples of pros and cons of existing educational materials

Good points

“Personal” information hidden (inside tri-fold brochure)

Question and answer format

Medical terms defined in plain language

Space to add personalized information

Bad points

Cartoon images

Complex language

Bias toward medical procedures in content

Small font

Methods for pretest/critique of example brochures

Women recruited at initial contact; gave consent to be re-contacted

Gift card for participation

Face to face interview by nurse research assistant

Tape recorded and transcribed

Note-based analysis

Discuss findings with CWWC staff, decide on revisions, and create poster content to match brochure

Sample questions from critique of example brochures (n=9 interviews)

Gave woman the 3 examples to read.

Meaning

Now that you have had a chance to read over the pamphlets I am going to ask you some questions.
“What does this information mean? What is it telling women overall?”

Appearance

Which one is your favorite in appearance?

- Probe: Why is this one your favorite?

Sample questions from critique of example brochures (n=9 interviews)

Content --for each section, ask:

- What is this section saying, in your own words?
- What are the main points that you think women would remember from the brochure?
- Is there anything in the brochure that you think other women would not believe or not trust? What? Why?

General

- Is this something you think women would pick up and read?
Probe: Why or why not?
- Is there anything that would make the brochure more helpful to Cherokee women?

Examples of revisions

- Improved clarity of font and size of artwork
- Change labels and appearance of uterus illustration
- Differing opinions re: illustration and terms
- Minor changes to wording

Final four-fold brochure

Cover (outside front panel)

- Artwork matches other CWWC materials
- Use of Cherokee syllabary for main phrase
- Use of term used in other American Indian materials on cervical cancer (“silent disease”)

Cover (outside)

- Resources to find more information
- Contact information about the CWWC
- Acknowledgement of research support

Final four-fold brochure

Inside headings (based on literature review and interviews):

What is cervical cancer?

What is HPV?

What is a Pap test?

How often should women have Pap tests?

What do Pap test results mean?

What happens next if the Pap test result is abnormal?

What else can women do?

Three things to remember

Reading level: 7-9th grade, SMOG (9), Fry (8), Flesch-Kincaid (7)

Outside of four-fold brochure

American Indian women develop and die from cervical cancer too often.* There is something that you can do - have regular Pap tests and get follow-up care as recommended by your health care provider. You can also learn more about Pap tests, what Pap tests results tell you, and what causes abnormal Pap tests, and use condoms.

To Find Out More:

Centers for Disease Control and Prevention
Web Site: <http://www.cdc.gov/std/hpv>
Hotline: 1-800-458-5231

American Social Health Association
Web Site: <http://www.ashastd.org>
Hotline: 1-800-783-9877

American Cancer Society
Web Site: <http://www.cancer.org>
Hotline: 1-800-ACS-2345

*National Cancer Institute**
Web Site: <http://www.cancer.gov>
Hotline: 1-800-4-CANCER

*Native American Cancer Research Corporation**
Web Site: <http://natamcancer.org>

Cherokee Women's Wellness Center
876 Acquoni Road
Cherokee, North Carolina 28719
Phone: (828) 497-8151

The mission of the Cherokee Women's Wellness Center is to provide quality health, wellness, and disease prevention services to eligible women* with emphasis on breast and cervical cancer screening and early detection.

**Women who are eligible for health care services at the Cherokee Indian Hospital.*



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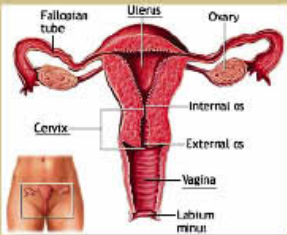
**TCFGT
GWY
DIW
Beloved
Cherokee
Woman:**

**Protect Yourself
from a
"Silent Disease"**

Inside of four-fold brochure

What is cervical cancer?

Cervical cancer is cancer of the cervix, which is at the opening of the uterus or womb. Cervical cancer is not the same as "cancer of the womb." Cervical cancer does not usually make a woman feel ill, so she may not know she has it. This is why cervical cancer is called the "silent disease."



Cervical cancer is caused by a sexually transmitted infection called human papillomavirus (HPV). The infection usually does not last very long because the body is able to fight it. If HPV does not go away, the virus may cause cervical cells to change and become pre-cancer cells. Very few HPV infections lead to cervical cancer. If caught early, cervical cancer is one of the most treatable cancers.

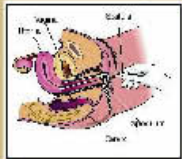
What is HPV?

HPV infects the genital area (vagina, anus, and penis) of both men and women. HPV is passed from one person to another during sexual contact. HPV is a very common sexually transmitted infection. There are 40 types of HPV that can infect the genital area. Some types can cause abnormal cells

on the cervix and cervical cancer and other types can cause genital warts. HPV can be treated but not cured. Most women do not notice any signs of having HPV infection. The only way to know if you have HPV is to have an HPV test (most often done when a woman has an abnormal Pap test). There are currently no HPV tests for men.

What is a Pap test?

The Pap test is done by a health care provider to check for cervical cancer in women. The Pap test does not test for other types of cancer. The Pap test is not the same as a pelvic exam. It is a test done during the pelvic exam. The health care provider takes a sample of cells from a woman's cervix. Then, the cells are sent to a lab to find out if they are normal, abnormal, or cancer. Abnormal cells are most often caused by HPV infection.



How often should women have Pap tests?

By age 21, or within three years of starting to have sex, all women should have their first Pap test. How often also depends on whether the woman has had normal or abnormal results. How often also depends on a woman's age and the type of Pap test that she has. It is important for her to check with a health care provider to find out when a Pap test is needed and to ask any questions she has.

What do Pap test results mean?

Pap test results come back normal or abnormal. If a Pap test is normal, then, a woman does not have to do anything until her next Pap test as recommended by her health care provider. If a Pap test is abnormal, then a woman needs to follow up with her health care provider. Women can ask their health care providers if they have any questions about their Pap test results.

"When I first heard I had HPV, I was scared. I felt better after I talked to my health care provider and found out more information"



What happens next if the Pap test result is abnormal?

An abnormal result does not always mean that a woman has cervical cancer. An abnormal result can mean that some cells could become cancer in the future. If the results are mildly abnormal, your health care provider will recommend one of the following next steps: do another Pap test, or do an HPV test, or do a colposcopy. If the results are more than mildly abnormal, a colposcopy is most

often the next step. A colposcopy is to look more closely at the cervix using a magnifying glass. Sometimes, the health care provider has to take a sample of cervical tissue (called a biopsy). The tissue will be sent to a lab to check for pre-cancer and cancer. The next steps depend on the result of the biopsy. Some women will need treatment and some women may not. A woman can ask her health care provider if she has any questions.

What else can women do?

Having a Pap test is important. Women can also use condoms. Although women may get HPV even with a condom, using a condom greatly lowers the chance of getting HPV and cervical cancer. Women can also limit the number of sex partners. Lastly, women can keep their bodies healthy by not smoking, eating right, exercising, and managing stress. Having a healthy body can help women avoid getting sick.

Three things to remember

- HPV is a *very common* sexually transmitted infection that can cause abnormal cells on the cervix and cervical cancer.
- Cervical cancer is *very rare* among women overall in the United States, but American Indian women are more often affected.
- Women can *prevent* cervical cancer by having regular Pap tests as recommended, following up on abnormal Pap results, and using condoms.

Final poster content

Matches brochure

Three key points

How to find out more

CDC toll-free hotline and website

CWWC address and phone number



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Beloved
Cherokee
Woman:
Protect Yourself
from a
“Silent Disease”



American Indian women develop and die from cervical cancer too often. There is something that you can do.

Know these three things:

- Human papillomavirus (HPV) is a very common sexually transmitted infection that can cause abnormal cells on the cervix and cervical cancer.
- Cervical cancer is very rare among women overall in the United States, but American Indian women are more often affected.
- Women can prevent cervical cancer by having regular Pap tests as recommended, following up on abnormal Pap test results, and using condoms.

To find out more, ask a health care provider or contact the Centers for Disease Control and Prevention (CDC) at 1-800-458-5231 (toll free) or www.cdc.gov/std/hpv.

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References:

Doak CC, Doak LG, Root JH. *Teaching patients with low literacy skills*, 2nd ed. Philadelphia: Lippincott Company; 1996.

Brandt HM, McCree DH, Lindley LL, Sharpe LL, Hutto B (2005). An evaluation of HPV educational materials. *Cancer Control: Cancer, Culture, and Literacy Supplement*, Nov., 103-106.

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