### EXECUTIVE SUMMARY

#### Introduction

Sexually transmitted diseases (STDs) remain a significant public health concern in the United States. There are more than 25 diseases that are transmitted through sexual activity and the trends vary considerably for each. Other than HIV, the most common STDs in the United States are chlamydia, gonorrhea, syphilis, genital herpes, human papillomavirus, hepatitis B, trichomoniasis, and bacterial vaginosis. Each affects different audience segments and requires different communication approaches to prevent and control disease.

Given the dearth of information available about the general public, their knowledge of STDs, and their communication preferences, the Division of Sexually Transmitted Disease Prevention (DSTD) at the Centers for Disease Control and Prevention (CDC) contracted with ORC Macro to conduct a series of focus groups to address these particular gaps in health communication literature. In the study reported here, the intent was to collect data regarding the knowledge, attitudes, and beliefs of the general public relevant to STDs and their ideas for increasing knowledge of how to prevent these diseases.

The focus groups were designed to address the following five research questions:

- 1. What do members of the general public ages 25 45 know about STDs?
- 2. What do members of the general public ages 25 45 know about HPV?
- 3. What are the most effective channels and sources of information to reach this audience with STD prevention messages?
- 4. What are the most effective message tone and qualities for STD prevention messages?
- 5. When should prevention campaigns focus on only one STD and when should STDs be bundled together to provide a general prevention message?

# Methodology

Thirty-five focus groups were conducted with members of the general public from July – September 2003. Groups were segmented by sex (male, female), race/ethnicity (African American, Caucasian, Hispanic), and geography (urban, rural). These groups were held in six geographically dispersed U.S. sites, selected because of high county-specific rates of cervical cancer mortality or prevalence of syphilis, as well as available census data indicating proportion of the population identifying as African American, Caucasian, or Hispanic. Groups were held in Kelseyville, California; Miami, Florida; Atlanta, Georgia; Kansas City, Missouri; Lumberton, North Carolina; and McAllen, Texas.

Professional focus group companies recruited participants. Potential participants were only considered if they were within targeted zip codes, between the ages of 25 and 45, and of the designated race/ethnicity. Potential participants were not selected for

participation if they were: employed by federal, state, or local health department; employed in a health care setting; employed by an organization promoting awareness of health issues including STDs; employed in marketing or advertising; pregnant; or a participant in a focus group within the previous six months.

Each group was conducted by a professional moderator and assisted by a notetaker. Audiotapes of the discussions were transcribed and a thematic analysis was conducted using the notes and the transcripts.

#### Highlights of Findings

Key findings are presented by research question below. Unless otherwise noted, no differences emerged among the segments.

### Research Question 1: What Members of the General Public Know about STDs

Overall, the most striking finding from this section of the focus group study was the fact that most participants were aware of sexually transmitted diseases, but not very knowledgeable about them. For many participants the focus group discussions pointed out how much they did not know about STDs. Many parents expressed concern that they needed to learn more about the diseases so they could educate their children. Other participants indicated that they needed to learn more to protect themselves, and to be able to help someone they care about if they become infected.

- When asked to identify health conditions and diseases they were most concerned about, participants responded in very similar ways. Across all of the groups, participants generally developed a long list of health conditions that could be placed in the following categories:
  - Chronic diseases/conditions (e.g., diabetes, high/low blood pressure, arthritis, asthma)
  - Life threatening/fatal diseases (e.g., cancer, heart disease/attack, stroke, AIDS, SARS, West Nile Virus)
  - Health conditions associated with aging
  - Health conditions they have control over, such as weight
  - STDs other than AIDS, most often hepatitis
- In almost all of the groups, AIDS was included in the list of concerns. Participants attributed this to the fact that they have heard so much about AIDS over a period of years and they associate it with death. In a few groups, someone added STDs to the list of general health concerns, stating that it was because of a concern for their children, or that it would be a concern if they were not married.
- For most participants, STDs were not a major health concern. They said this was because other health conditions were more of a concern for them and because they just do not think of STDs except for AIDS.

- Focus group participants were asked to identify thoughts, concerns, or feelings that came to mind when they heard the term "sexually transmitted disease." Responses included a list of diseases; behaviors such as unprotected sex, condom use, promiscuity, infidelity, drug/alcohol use, and having multiple sex partners; and emotional responses such as depression, worry, sadness, shame/embarrassment, guilt, and discomfort. Heard across all of the groups was the association of severe consequences associated with STDs, including death, infertility, pain, treatment/drugs, doctor visits, medical bills, and divorce.
- In general, participants' knowledge of sexually transmitted diseases was very limited. Most often, participants indicated that they had heard of the diseases but did not know a lot of specific information about them. Aside from HIV, the diseases that participants knew the most about were syphilis, gonorrhea, and herpes.
- Women had more knowledge about chlamydia, trichomoniasis, and pelvic inflammatory disease than men. Men were somewhat more knowledgeable about gonorrhea and syphilis than women and typically identified symptoms and treatment accurately.
- In one site (Robeson County, North Carolina) in the study, the public health department had begun a campaign to educate people about syphilis, in response to a very high incidence of the disease. This campaign was mentioned in all of the focus groups conducted at this site, with participants stating that there was a high incidence of the disease and that the health department was trying to educate people about the symptoms and when to come in for treatment. Surprisingly, these participants did not know any more than other groups about the consequences of not getting treatment.

### Research Question 2: What Members of the General Public Know about HPV

HPV awareness was low among participants across the segments, although awareness of this disease was more common among females than among males regardless of race or ethnicity. In general, participants were concerned that most of them had never heard of the disease.

- Due to participants' lack of awareness of and knowledge about HPV, the moderators explained to participants that prior research has shown that a link exists between some forms of HPV and cervical cancer. In response, many participants expressed concern that they had not been previously informed of the disease and did not have the important information they needed to address their concerns.
- Participants across the groups were interested in receiving information to better understand what HPV is, its transmission route, its symptoms, and ways to protect themselves. Often participants wanted to receive information from health care providers; women mentioned gynecologists as the specific health care provider they preferred. Participants also mentioned pamphlets in clinics, reputable Internet sites, schools, magazines, local television news, and television advertisements as appropriate vehicles.

- Participants were asked about the acceptability of a vaccination for HPV. Many
  participants were uncomfortable with the idea of accepting a vaccine because of their
  limited knowledge and awareness of HPV. Responses centered around three main
  themes: additional information about HPV, additional information about the vaccine,
  and assessment of one's own susceptibility.
- In addition, participants expressed needing to know their own risk for and susceptibility to HPV before being able to offer an opinion about the vaccine. Those who were married did not view themselves as susceptible and thus did not see a need for vaccination. Participants expressed that the vaccination should be personal choice based on one's lifestyle.
- When asked what would discourage people from getting vaccinated, participants noted lack of knowledge about HPV, the cost of the vaccine, and lack of susceptibility as main reasons. Participants' desire to protect their individual health was noted as a factor that would encourage them to accept vaccination.

### Research Question 3: Effective Channels and Sources of Information

Participants stated that they go through similar channels to obtain information about general health and information about STDs. They spoke of interpersonal channels, the Internet, and print, television and radio as the resources they most often utilize to obtain information about general health and information about STDs.

- Most participants stated that the stigma associated with STDs might prevent them from seeking more information if they or a loved one thought they had a problem.
- Participants stated that any information or materials developed should be made available in a variety of languages. Preferred formats of information included:
- Billboards
- Brochures/flyers
- Hotline/800-number
- Magazine articles
- Newsletters
- Newspaper articles
- Posters
- Radio ads
- Radio programs
- School programs
- Television ads
- Television programs
- Websites

- The American Red Cross, CDC, and Planned Parenthood were frequently mentioned as specific organizations that would be trusted. Other trusted organizations include community-based organizations, doctors' offices, health departments/clinics, and insurance companies. Participants further stated that they would not trust information developed by pharmaceutical companies.
- Participants had mixed reactions to the notion of a specific spokesperson for an STD campaign. Some participants believed that individuals who have, or are affected by, a particular STD would be most appropriate. They also believed that other reputable celebrities with knowledge of health issues, such as the U.S. Surgeon General, would be appropriate representatives to speak about STDs. Other participants stated that the most believable spokesperson would be an "average person" who has been affected by an STD. These participants believed that this person would be able to provide a credible testimonial about his/her experience with STDs. African American participants believed that the most effective spokesperson to deliver STD messages to their community would be an African American person.
- Most participants viewed CDC as a credible and trustworthy organization. They believed that CDC would be an appropriate organization to develop an STD prevention campaign. Some participants in the African-American focus groups stated their distrust of CDC and other government agencies. They referenced the Tuskegee Study as the impetus for their distrust and made other references to government conspiracy with regard to HIV and genocide of the African-American population.

#### Research Question 4: Effective Message Tone and Qualities

Participants said the most important things they would like to know about STDs would be the symptoms of STDs and treatment options. Participants were also interested in the consequences of the disease. In particular, participants were interested in whether or not the STDs were curable, merely treatable, or life threatening.

- With the exception of the urban Caucasian females, participants in the other segments were interested in knowing how to prevent STDs. Participants also expressed interest in understanding how STDs are transmitted from person-to-person. Of note, African American males in urban areas and Hispanic females in rural areas were interested in knowing if the STD could be transmitted to a child during pregnancy or childbirth.
- Across all segments participants stated that the main point of materials should be factual information about the diseases, their symptoms, and means to prevent them. Participants expressed that prevention information should focus on abstinence, safer sex, and condom usage. In addition, participants noted the importance of including resource information about whom to contact with questions or when experiencing symptoms.

- Participants across the groups recognized the need to educate all people about STDs while creating messages that are appropriate for different audience segments.
   Participants believed that STD prevention information should be provided to young children, although there was no consensus as to what age information about sexual health should begin to be shared. Participants did agree, however, that age-appropriate language was necessary.
- Across the groups, participants recognized the need to be "realistic" about people engaging in sexual activity. This recognition led participants to suggest that a combination of abstinence and condom usage messages would be appropriate. Most people agreed that messages should focus on abstinence as an effective method to prevent STDs, but that providing information on using condoms correctly to reduce the likelihood of contracting STDs was imperative.
- Discussions in the groups demonstrated that the need to craft different types of messages for adults. First, some participants saw the need for STD prevention information so that they could protect themselves from STDs. Second, some participants expressed the need as parents for information so they could provide information to their children.
- Discussion within the groups also highlighted the need for personal responsibility and parental responsibility. A few participants expressed the importance for individuals to take responsibility for protecting their own sexual health, including understanding the different methods for preventing STDs and the behaviors that increase one's risk. Through this understanding, individuals would be able to make informed decisions and choices. A few participants also expressed the need for parents to establish and foster open relationships with their children so that the parents and not the government, schools or churches would be guiding the choices their children make.
- Participants expressed the need for factual information to be delivered using serious tones in clear, simple language. Participants suggested that humor not be used because STDs are serious and humor would detract from that message. Scare tactics were also mentioned as an effective way to convey STD messages, although some participants believed that STDs are "scary enough on their own" that a scare tactic can instill unnecessary panic. In addition, participants wanted materials to provide real-life examples to which they could relate.

### Research Question 5: Individual STD Focus Versus Bundling of STD Messages

Participant reactions to this question were mixed. Some participants stated that the use of smaller specific campaigns would help differentiate the diseases from one another; others believed that a general campaign that provided information common to all diseases would be more effective.

 Participants who preferred a series of smaller campaigns focusing on specific diseases stated that this approach would allow for a more narrow focus on the details of each disease including symptoms, transmission, treatment, cure, and other statistics. They believed that this would be the best approach for filling in gaps in knowledge among the general public about certain STDs.

 Participants who preferred a more general campaign focusing broadly on all STDs noted that this would be the most efficient means of disseminating the most important pieces of information about all STDs. They believed that it would be best to provide information common to all diseases, such as prevention.

#### Limitations

This study has several limitations:

- First, focus groups rely on convenience samples. As such, the generalizability of these findings is limited.
- Second, all of the participants were willing to participate in the focus groups. It is not known how, if at all, these participants differ from those who did not participate.
- Third, the topic of discussion may have made individuals uncomfortable and unwilling to express their ideas and opinions.
- Fourth, in this study, groups were segmented by sex, race/ethnicity and geography. This precludes being able to examine differences among people based on marital status or based on having a child.
- Fifth, defining geography (urban/rural) by location introduces a confounding variable. It is possible that the differences in urban and rural locations are due to the city in which the groups were held rather than a true difference.
- Sixth, as a result of participating in a 1½ hour discussion about this topic, participants are likely very different than those who did not participate. They may have become more open and willing to discuss sex, STDs, and prevention methods.

## **Summary**

This focus group study offers an initial exploration of the knowledge, attitudes, beliefs, and communication preferences of the general public related to STDs and STD prevention. The results suggest that campaigns need to focus on increasing knowledge of STDs. To do this, materials should use straightforward language, personal testimonials. Trusted sources for the information should include local organizations such as churches, community-based organizations, health care providers, and businesses such as beauty parlors and barber shops. Separate materials should be developed for people who want to learn information to protect themselves and for people who want to educate others. This speaks to the need to develop materials targeted to specific audiences. The data from this study suggest that interpersonal and mediated communication (Internet, television, radio)

are channels through which individuals seek out and receive health-related information, including information on STDs.