

## *Getting More Young Women Screened for Chlamydia: Findings from Qualitative Research*

### BACKGROUND

#### Overview

Routine chlamydia screening is recommended for all sexually active females 24 years of age and younger<sup>1</sup>, yet only about half (49.9%) were screened during 2008-09 according to data collected in over 1000 health plans<sup>2</sup>. Why is this the case? For many young women, the negatives associated with getting screened for chlamydia outnumber the positives; they have limited knowledge of chlamydia, and may lack the skills or confidence to ask for the test<sup>3-7</sup>. Other obstacles include systems-level barriers such as limited provider knowledge about chlamydia screening, lack of access to services, and lack of confidentiality<sup>6,8</sup>.

Several qualitative studies provide valuable insights into why women do or do not seek chlamydia screening. These studies help us understand the key factors influencing a woman's decision to get tested, including attitudes, knowledge, beliefs, perceived social norms, and skills. Qualitative research also provides valuable insights into the appeal and effectiveness of various motivators and messages, as well as the structure of STD screening services. By identifying the key factors shaping behavior, effective behavior change communications can be developed and appealing chlamydia screening services can be designed.

Drawing on existing qualitative studies and literature reviews, this research brief summarizes *overall findings and conclusions*. While these studies were conducted with a variety of populations in a range of settings, young women share many similar views about chlamydia screening. However, the research does reveal some important and subtle differences in attitudes based on age, education and race/ethnicity.

It is clear from this review that a limited number of qualitative studies on chlamydia screening have been conducted and that gaps exist in this research. We know more about the barriers to screening than about the perceived benefits or messages that are likely to motivate women to seek screening. To advance the field, additional studies, particularly of women who have never been screened, would be valuable.

#### Sources Reviewed

The primary sources for this National Chlamydia Coalition (NCC) research brief include articles in peer-reviewed journals, program reports and presentations, and literature reviews.

The five published studies include:

- Individual interviews with 192 African American, Hispanic and Caucasian young women 16 to 23 years of age at a community-based reproductive health clinic in Texas (Chacko, 2008).<sup>3</sup>
- A focus group study of young people 14 to 24 years of age from the general community and juvenile detention centers in North Carolina (Tilsen, 2004).<sup>4</sup>
- A focus group study of high-risk youth from Job Corps and Department of Youth Services sites, 15 to 24 years of age, in Massachusetts (Blake, 2003).<sup>7</sup>

- Individual interviews with 125 women 15 to 25 years of age in ten metropolitan areas (Friedman and Bloodgood, 2010).<sup>9</sup>
- A focus group study of women 14 to 49 years of age to explore the development of an internet-based screening program in Baltimore, Maryland (Gaydos, 2006).<sup>10</sup>

A review of two program reports was also conducted. These studies explored knowledge and beliefs about chlamydia, and assessed message concepts and public education materials:

- An individual interview study of 125 women 15 to 25 years of age to assess knowledge, attitudes, and behaviors related to screening (CDC, 2008).<sup>11</sup>
- A focus group study of females 15 to 25 years of age, consisting of 18 groups, to assess message concepts relating to the CDC Infertility Prevention Marketing Project (CDC, 2010).<sup>12</sup>

The two literature reviews consulted for this research brief were:

- A “Summary of a Review of the Literature: Programs to Promote Chlamydia Screening,” (CDC, 2007).<sup>6</sup>
- “Implementing Chlamydia Screening: What do Women Think?” (Pavlin, 2006).<sup>5</sup>

Please see the chart on page 15-16 for a detailed description of the studies.

All of these studies used focus groups or in-depth individual interviews, which allowed researchers to capture insights that often cannot be gleaned from quantitative techniques. Representative quotes from study participants are featured throughout the brief. However, like any qualitative research, findings from these studies cannot be generalized to all sexually active young women.

### **A Framework for Understanding Behavior**

Health behavior is usually shaped by many factors at the individual, organizational, and community levels. Most successful behavior change programs are based on a “clear understanding of the targeted health behaviors and the environmental context in which they occur.”<sup>13</sup>

Numerous health behavior theories have been developed to help program planners uncover the reasons why people do or do not adopt specific health behaviors. They provide a conceptual framework for analyzing problems and creating effective interventions. Some theories focus on changing individual-level behavior, while others focus on changing community and institutional behavior.<sup>13</sup>

One behavior change theory, the *ecological perspective*, emphasizes the interaction between factors within and across all levels of a health problem. The multiple levels of influence include the intrapersonal (individual characteristics, such as knowledge, attitudes, skills), interpersonal (relationships and social identity), and the community (institutional, community norms, and public policy).<sup>13</sup>

“No single theory dominates health education and promotion, nor should it.”<sup>13</sup> Based on a situation analysis of the health problem to be addressed, program planners should review and select theories that are most relevant. A concise summary of behavior change theories can be found in “Theories at a Glance: A Guide For Health Promotion Practice,” by the National Cancer Institute<sup>13</sup>. For step-by-step guidance on designing health communication campaigns, “Making Health Communications Work: A Planner’s Guide” is a helpful tool<sup>14</sup>.

Qualitative research, which is often designed to explore intrapersonal and interpersonal factors, should be guided by one or more theories of behavior change. The theories articulate the key factors that influence an individual’s decision to perform a behavior and frame the research questions to be asked.

An integrated model of behavior change, which was an outgrowth of a National Institutes of Health meeting that brought together leading behavior change theorists, provides a good framework for designing and analyzing qualitative research. This model suggests that individual behavior is influenced by three key variables: the individual makes a commitment to perform the behavior; the individual has the skills to perform the behavior; and the individual has a supportive environment in which to act (including access to affordable, appealing and convenient services and positive social norms).<sup>15</sup>

Taking this a step further, making a commitment to perform the behavior can be influenced by several factors, such as knowledge/awareness; perceived social norms that support the behavior; perception of personal risk; belief that the benefits of the behavior outweigh the disadvantages; positive emotions about the behavior; and the belief that one can perform the behavior.<sup>15</sup>

Throughout the brief, this model will serve as a general framework for synthesizing and presenting the results of existing research. It will also help identify gaps in research relating to the key factors affecting behavior.

## FINDINGS FROM THE RESEARCH

### A Reality Check: What Do Young Women Value?

Uncovering the everyday values, priorities, and aspirations of the target audience is a key component of qualitative research. The research should explore: What does the target audience value most? What do they aspire to? What are their everyday concerns? Gaining these insights enables us to link a desired health behavior to something that the audience truly values. Often, this benefit is not health-related. In line with the behavior change model, this information can be used to help create positive emotions about performing the behavior and to promote its benefits.

When asked what they think about most on a daily basis, a majority of young women in one study described personal relationships – with friends, boyfriends, and family members<sup>6,11</sup>. This was followed by issues relating to their future, such as schools, careers, and money<sup>6,11</sup>. In another focus group study, women voiced similar priorities, and also mentioned goals beyond their relationships with men<sup>16</sup>. It is noteworthy that **health and STDs were not mentioned as top of mind concerns for teens and young women across most of the studies<sup>11,16</sup>. Most reported being healthy and feeling good<sup>6,11</sup>.**

However, when asked about sex-related concerns, unplanned pregnancy was a much bigger worry than STDs for young women<sup>11,16,17</sup>.

*“For one, it’s about (girls) not ready to give up their fun. With an STD you can take a pill or whatever and get rid of it, but if you [have a baby] you’re stuck with it, and maybe have to raise it by yourself. It will change your life.”<sup>11</sup>*

*“I can’t really say when people decide to have sex [they are thinking], ‘I hope I don’t get an STD. I think the big thing they are worried about is ‘I hope I don’t get pregnant.’”<sup>11</sup>*

According to many study participants, STDs were curable and could be easily treated. Many reported that they were not concerned about most STDs<sup>4,7,11</sup>, with the exception of HIV/AIDS, which was considered a serious medical problem<sup>7</sup>. Some women were also concerned that other people would gossip about their sexual activity or worried about having conversations about sex in general<sup>11</sup>.

**Implications:** Most STDs, including chlamydia, were not a major concern among adolescent and young adult women. This audience needs compelling reasons to care about chlamydia. Getting screened should be positioned to help them achieve their everyday goals and aspirations. However, it is important to acknowledge that even with improved communications, getting screened for chlamydia may never become a top priority for some women. Health care providers can play a valuable role in reaching these women by promoting chlamydia screening to their patients and making the test available.

### **Knowledge about Chlamydia is Extremely Limited**

Across all of the reviewed studies, it was clear that young women have limited knowledge about chlamydia, including its consequences, symptoms, prevalence, screening recommendations, testing procedures, and treatment. However, it's important to note that in some studies the knowledge levels were higher among African American women than women in other racial/ethnic groups.<sup>4,6,7</sup>

Based on numerous focus groups held with teens and young adults, it was concluded that most participants had heard of chlamydia, but they had little to no knowledge. In many studies, participants could list STDs by name, but could not describe anything else about them.<sup>4,6,16</sup>

In terms of **symptoms**, many women were shocked and alarmed that in most women chlamydia has no symptoms<sup>11,16</sup>. Many questioned whether it was really possible to have an STD without any symptoms. And, if symptoms did not exist, focus group members did not believe that the STD could be very serious<sup>7</sup>.

*“What would the problem be with having something that doesn’t even show itself?”<sup>4</sup>*

In fact, one study found that only 22% said they would seek screening for chlamydia or gonorrhea in the absence of any symptoms<sup>18</sup>.

Most respondents were unaware of the **potential consequences** of being infected with chlamydia. They were surprised and concerned that chlamydia could lead to infertility, especially when they understood they might not ever realize that they were infected<sup>11,16</sup>.

*“Infertility would concern me the most because that’s really important to me. I am excited to have kids... I think it would totally destroy me if I became infected and I didn’t even know I was infected.”<sup>11</sup>*

Most women were not familiar with the U.S. Preventive Services Task Force **recommendation for chlamydia screening** for all sexually active females 24 years of age and younger<sup>1</sup>, pregnant females, or females and males at higher risk<sup>11,12,19</sup>. Most participants expressed general confusion about what type of screenings they should get for STDs, who should be screened, and how often<sup>11</sup>. Some wondered if they should be tested monthly, annually, or after changing partners?<sup>11</sup>. At the same time, many mistakenly assumed that their providers automatically ordered all of the STD tests that they needed and/or that a single test exists for all STDs<sup>11,12,19</sup>.

Significant confusion exists about **how testing is administered**. Many thought chlamydia screening was included in a Pap test<sup>11,16</sup>.

*“Pap tests for women to prevent or catch things like cervical cancer. It’s like a pre-cancer type test to make sure there’s nothing there. Also they check for STDs – to check for chlamydia, gonorrhea, herpes, and HPV.”<sup>11</sup>*

Across studies, many expressed confusion about how the test is conducted, often asking is it a blood test, pelvic exam, urine test, or a Pap test? They frequently assumed that the screening required a vaginal exam, which was unappealing to many women.<sup>6,11,16</sup>

Among study participants, there were varying levels of awareness about how chlamydia is **treated**, and the ease of treatment<sup>7,11</sup>. Some said that it could be treated with medications, while others were unsure how it could be treated. In one focus group discussion, some expressed fear that treatment could be painful<sup>7</sup>.

Across most of the qualitative research, many women were surprised to learn that chlamydia is a very **common infection**. In one study, participants expressed shock when they learned that one million cases were reported in a single year, and commented that it seemed like a big number. However, when the prevalence was reported as 4/100 women, chlamydia was not perceived as a widespread infection.<sup>11,19</sup>

**Implications:** Overall knowledge of chlamydia is exceedingly low. Increasing the level of awareness and knowledge is one of the important precursors to taking action, as evidenced by successful behavior change campaigns relating to getting tested or screened for high blood pressure, cholesterol level, and for quitting smoking.

Based on the knowledge level and needs of specific audiences, messages could be developed to create awareness of the asymptomatic nature of chlamydia, the potential consequences of infection, including infertility; the ease of getting screened and treated; the recommendation that all sexually active women 24 years of age and younger be screened annually; the prevalence of the condition; and locations for testing.

### **Perception of Individual Risk**

Across all of the qualitative research that was reviewed, many young women underestimated their risk of contracting chlamydia and other STDs, even if they engaged in high-risk behaviors<sup>6,9,19</sup>. In one study, only about half said that everyone who is either sexually active and/or has multiple partners should be tested<sup>11</sup>. Many others believed that they could tell if someone, including their partners, had an STD. However, some did say they might be at risk if they have multiple partners, non-steady partners, or a new partner<sup>9,11,16,20</sup>.

*“People who do it a lot. Or with a lot of different people, and they don’t use protection.”<sup>11</sup>*

**Implications:** Communications should be designed to increase the perception of individual risk. These messages should be combined with the awareness-raising messages described above. Creating awareness and the perception of individual risk are two key steps in the behavior change process. Messages should communicate that screening is recommended for all sexually active women 24 years of age and younger. Related messages include that you can’t tell if someone has an STD just by looking at them or by knowing them.

### **Social Norms**

The perceived social norms relating to screening for chlamydia and other STDs have been explored in a limited number of studies<sup>9,11</sup>. However, it is clear from these studies that many women report being afraid or embarrassed to seek chlamydia screening. When asked about communicating about STDs with family, friends, or partners, most described STDs as “something we’d rather not talk about, unless we’re having problems.”<sup>9</sup> Some thought their peers might disapprove if they disclosed that they were tested for STDs or if they tested positive for an STD.<sup>6,9,11,16</sup>

In one study, however, most participants said they would support a friend if she sought out testing for STDs. Some young women, particularly those 15 to 17 years of age, did say they would be concerned or surprised if a friend sought STD screening. If the friend tested positive, most stated that they would be supportive; however, some did make statements that reflected negative judgments about the friend’s character or behavior.<sup>11</sup>

Getting screened routinely for chlamydia does not appear to be a normative behavior for most women, or perceived as a part of routine healthcare<sup>11</sup>. As a result, stigma is often associated with a provider recommending

a chlamydia test or with a patient requesting a test. One study revealed that the suggestion of a test by a provider threatens the “good girl” identity of a patient<sup>20</sup>. Young women suggested that it would be a lot easier and would reduce their embarrassment if the provider routinely offered the test to everyone who is sexually active.<sup>21</sup>

*“I am wondering why they don’t automatically test for [chlamydia] when you go to the doctor?”<sup>6</sup>*

**Implications:** Most women do not perceive positive social norms around getting screened for chlamydia and other STDs. To increase the acceptability of testing, messages should be designed to promote chlamydia screening as a normal and routine behavior for all sexually active young women. Communications could also role model friends supporting each other, when they seek STD testing and receive their results. However, additional qualitative research is needed to gain a deeper understanding of the perceived social norms relating to getting screened for chlamydia, asking for the test, testing positive, and talking to partners.

### **Negative Perceptions of the Behavior (Barriers)**

Numerous studies have explored the barriers to chlamydia screening from the young woman’s perspective. The most significant barriers included fear; embarrassment and shame; and concerns about confidentiality.<sup>3,4,5,6,7,11</sup>

**Fear:** Among study participants, fear was one of the most commonly expressed barriers to getting screened. There were many dimensions to their fear – fear of getting a positive test result, fear of getting an HIV/AIDS diagnosis, and fear of having an STD with no cure.<sup>3,6,7,11</sup>

*“I have been offered to go [get screened], but it’s just I’m scared.”<sup>7</sup>*

Others were scared of the testing procedure, and wondered if it involved giving blood or having a vaginal exam<sup>3,6,7</sup>. For youth in juvenile justice and Job Corps programs, some were worried that urine-based testing for STDs would also be used for drug testing<sup>7</sup>.

**Embarrassment and Shame:** Feelings of shame and embarrassment about getting an STD test were commonly reported<sup>6</sup>. Seeking an STD test was often associated with significant stigma. However, this was less of a concern for women in their twenties, and for African American women than for women of other racial/ethnic groups<sup>11</sup>. Some women said that getting tested for STDs was linked to being promiscuous, and many worried that friends would talk about them, judge them, and treat them differently<sup>6,16</sup>.

*“Just people don’t want it to be known that they’re being tested for STDs because they don’t want to be considered whores or sluts or something.”<sup>11</sup>*

Many women, particularly teens, did not want to be seen by their peers when going for a test. As a result, some sought screening services outside of their regular community.<sup>4,6,7</sup>

*“You (have) to go to a special side of the building, like Clinic A, or something, and everybody knows you’re going in there because you got an STD.”<sup>4</sup>*

Many participants believed that health care providers, particularly their regular doctors, would judge them negatively if they requested an STD test. They reported being embarrassed to talk to their providers about STDs, sex, or getting screened.<sup>7</sup>

*“(Teens) don’t want to talk to their doctor who’s been their doctor since they were like five years old.”<sup>7</sup>*

*“Most of the time that does keep people away. ‘Cause they don’t want to have a doctor know all about their sex life.”<sup>7</sup>*

*“That’s just embarrassing coming down here and be like: I need a chlamydia check or I need to get a test for an STD.”<sup>7</sup>*

**Confidentiality of Testing and Results:** Concerns about maintaining the confidentiality of the test and the results was another barrier for many women, particularly adolescents<sup>4,6,7</sup>. Many wanted assurance that the test itself and the results would be kept private. They didn’t want their parents to be notified since they were afraid their parents would find out that they were sexually active and might have an STD<sup>6</sup>. Some suggested that anonymous testing would be best so that they could avoid talking to a provider or giving their name<sup>11</sup>.

*“I know that if I went in there, I know it’d get to my mom.”<sup>7</sup>*

**Implications:** Fear, embarrassment and concerns about confidentiality are some of the most significant barriers to chlamydia screening. Yet, many chlamydia campaigns have focused on increasing knowledge and awareness, rather than addressing these significant and challenging barriers. Additional testing of existing messages relating to fear and confidentiality, along with the development of new messages, should be considered. Some of these fears, such as concerns about the testing procedure, can be easily tackled through awareness-raising messages. Others, such as embarrassment and fear of social disapproval, will require more sophisticated message development. Based on local and institutional policies relating to confidentiality, young women should be informed if and how their privacy will be protected when they get screened. Program planners should also assess if structural interventions are needed to address the complex issues related to maintaining confidentiality.

### **Positive Perceptions of the Behavior (Benefits)**

While the majority of studies focus on the barriers to screening, a few studies have explored the perceived advantages of seeking chlamydia screening<sup>3,4,7,11</sup>.

In the Chacko study, participants were directly asked to describe the benefits of getting screened for chlamydia, which they said included:

- *Being aware of what is going on with my body*, either the comfort of knowing that I am healthy and/or finding out early if I have an STD. Knowing my positive or negative status was also equated with my peace of mind.<sup>3</sup>
- *Staying healthy*, both physically and mentally. This was also linked to feeling responsible for myself.<sup>3</sup>
- *Getting treatment*, if the test shows that I am positive. I can get treated before it gets worse, and prevent serious problems from developing.<sup>3</sup>
- *Protecting others*, including partners and unborn children. Several mentioned the desire to not harm anyone else, including an unborn child.<sup>3</sup>

Similar findings about the advantages of getting screened also emerged from several other studies<sup>6,11,16</sup>. *“Staying on track for your future”* was one of the most compelling reasons for young women to get screened. This was usually linked to the desire to protect their fertility so that they could have children at some point in the future; it was also linked to staying in school and being able to work to earn money.<sup>11,12,16,19</sup>

**Implications:** Through additional studies, it would be useful to assess which specific benefits are most likely to motivate women to seek chlamydia screening. Promoting relevant and appealing benefits is essential to motivating women to seek screening. To take action, women must believe the behavior will benefit them in a meaningful way.

It’s already clear from the initial research that women can identify many benefits to screening, including being aware of what is going on with their bodies, taking action to stay healthy, getting treatment, and protecting

others from the infection. Messages should be designed to inform women that getting tested for chlamydia and staying healthy will also help them “stay on track for their future” and achieve their goals.

### **Skills and Confidence to Perform the Behavior**

Assessing whether young women have the skills to ask for a test and talk to their partners is another important component of target audience research. Qualitative and quantitative research has assessed whether women initiate these conversations, along with their comfort level in doing so. However, limited qualitative research has been conducted to explore their skills in this area – both their existing skills and their desire for new skills.

**Skills to ask for the test:** Getting screened for chlamydia often involves having a conversation with a healthcare provider. However, in a survey of teens 15 to 17 years of age, 59% said they had never talked to their providers about STDs while 66% had never discussed condoms or birth control<sup>22</sup>. Similarly, in a national study of 6,728 youth in grades 5 to 12, only 24% of males and 28% of females reported that they discussed STDs with their providers<sup>23</sup>. In another study of 1,689 adolescents through the State Children’s Health Insurance Program only 34% of them reported doing so<sup>24</sup>. However, older adolescents and young women are more likely to discuss STDs with a provider<sup>11</sup>. Yet, Latina women and Caucasian women were less likely to report talking with a provider, compared to African American women<sup>11</sup>.

Research does suggest that many young women want to discuss these issues, but they are unlikely to start the conversation because they are embarrassed or uncomfortable<sup>6</sup>. Instead, many would like providers to initiate the conversation. Young women, particularly teens, don’t know what to say and how to approach the topic with providers. Bringing up the topic is even more difficult if parents are present in the exam room. Yet according to one study, only 28% of adolescents 12 to 18 years of age reported that they had private time with a provider<sup>25</sup>.

**Skills to Communicate with Sexual Partners:** Some limited research about partner communication relating to chlamydia has been conducted. This is a critical area since women are likely to be re-infected if their partners aren’t informed, tested, and, if found positive, treated for chlamydia. Results from one study indicate that some women believe that discussing STDs helps put trust in the relationship, especially if the result is negative<sup>3</sup>. Others, however, were afraid to tell their partners they tested positive for chlamydia, worrying their relationship could be adversely affected<sup>3</sup>.

Another study revealed that almost half of the women said they would be comfortable telling a partner that they planned to get tested for chlamydia. These women believed that their partners would react positively. However, others said that they worried about negative partner reactions, such as suspicion, accusation of cheating, or insults. Women were more likely to tell their partners about testing if they were in a long-term relationship.<sup>9</sup>

Across several studies, many study participants requested advice about how to notify their partners about test results and how to talk with them about STDs<sup>5</sup>.

**Implications:** Qualitative and quantitative research provides significant evidence that the majority of young women, particularly adolescents, don’t discuss STDs with their providers. Many feel uncomfortable having these conversations, and say they are unlikely to start them. Similarly, many women report being afraid to discuss STDs and screening with their partners. Messages should be designed to build the confidence and skills of young women to talk with their providers and partners. Specific examples of how to start the conversation, what to say, and how to handle various responses from providers or partners would be helpful.

## THE TESTING ENVIRONMENT

### Current Barriers to Screening

Numerous barriers related to the delivery of STD services emerged from several studies. The most commonly mentioned barriers included perceived or actual cost of testing, inconvenient hours of operation, ensuring privacy and confidentiality, lengthy waits at the clinic, limited transportation to the clinic, and, for some, a lack of available interpreters.<sup>3,4,7</sup>

**Cost:** For a young person, the first thing they are likely to ask is how much is the test going to cost? Most females, particularly teens, want free or low-cost services. In addition, if the screening test is billed to parents' health insurance, many young people fear information about the medical visit and/or diagnosis will be disclosed to their parents.<sup>4</sup>

**Screening Method:** Most focus group participants expressed fear and dislike of invasive testing methods. Based on preference studies, a pelvic exam was the least desirable screening method, and many women said they would like to avoid it. The most preferred method was a urine test.<sup>10</sup> Many women were relieved to learn that you can get a non-invasive urine test that is simple and painless<sup>7</sup>.

**Privacy for Teens:** In the qualitative studies, many teens report a lack of privacy during their visits with providers because parents are often present in the room<sup>5</sup>. Without privacy, teens are less likely to participate in conversations with providers about sexual issues, STDs, or screening tests<sup>5,6</sup>.

**Waiting for the Test and Results:** Some women complained that when they went to the clinic they often had to wait a long time to get tested for STDs. Others wished that they could receive the results right away so that they didn't have to return to the clinic or call for the results. Many requested quick turnaround of the test results and treatment, ideally receiving them in a single visit which is not feasible with current chlamydia testing technology.<sup>6,10,11,26</sup>

**Access:** Many young people who are in school and/or working, complained that clinics were not open during times that were convenient for them. Some women requested extended evening and weekend hours at clinics. They also wanted assurance that there will not be a lengthy wait for the test or for a language interpreter. Some also requested Spanish-language print materials.<sup>4</sup>

### Screening Services: The Ideal Scenarios

When asked to describe the ideal testing environment, study participants wanted a range of options for how and where they could be tested, allowing them to choose the setting in which they feel most comfortable<sup>16</sup>. These testing locations included their regular provider's office, family planning/reproductive health clinics, STD clinics, at home, or at a non-clinical setting, such as a school<sup>6,11,26</sup>.

**Ideal Setting and Services:** When asked to describe the ideal setting, women wanted a welcoming environment in which staff were friendly, non-judgmental, and respected their confidentiality. The physical environment should be clean, comfortable, and offer privacy. In terms of the testing services, there would be free or low cost testing, short waiting times, and quick results. Many women also requested counseling support, especially if they receive a positive test result. The ideal clinic would be located in a safe neighborhood, be close to where they live, and offer evening and weekend hours.<sup>4,7,11</sup>

**Positioning and Advertising of Services:** Tilsen explored clinic preferences in focus groups with young women concluding "participants reported that the ideal clinic should offer and advertise a broad package of health services, including STDs, to decrease the embarrassment associated with being witnessed accessing services."

However, some of these focus group participants liked going to an STD clinic since they did not have to explain the reason for their visit.<sup>4</sup>

**Screening at Non-Clinical Sites:** Reactions to screening at non-clinical sites was mixed<sup>4,26</sup>. Some liked the convenience of using sites, such as malls, stores, and schools, while many others thought they were too public and were afraid of being seen. In one study, the idea of mobile testing sites was not well received<sup>16</sup>. If non-clinical sites are used, a balance needs to be struck between making them convenient, but not too public to help protect the patient's identity when visiting the site<sup>4</sup>.

**Home-Testing:** The option of home-based testing was appealing to many women. In one study, about half of the women said they liked the option<sup>16</sup>. And, in Blake's focus group study, she concluded there was "overwhelming enthusiasm for using a home test kit...much like a home pregnancy test."<sup>7</sup> Women cited advantages such as anonymity, privacy, and convenience. By testing at home, these women said they could avoid a visit to the clinic and interactions with their doctors and/or parents<sup>10</sup>.

In recent years, several studies have looked specifically at the option of home-based testing, which involved the collection of urogenital samples and mailing them to a test site<sup>27,28</sup>. Currently, some programs, which are not research studies, offer free at home test kits (requiring the collection of urogenital samples, such as vaginal swabs) that can be mailed to a laboratory for testing with subsequent referral to a clinic for treatment (iwantthekit.org program, and LA county's *I Know* campaign).

According to women queried in various studies, the disadvantages associated with home testing could include the woman's uncertainty about whether she could perform the test correctly, and whether the sample could be safely returned in the mail<sup>8,9</sup>. Some suggested that the test kit be packaged discreetly, and be small in size so that it can fit within a purse<sup>10,17</sup>.

At this time, home test kits are mostly under study and are not widely available. For additional information about this topic, please see NCC Research Brief, "Developments in STD Screening: Chlamydia Testing," 2010 Series, No.1 available at [www.prevent.org/NCC](http://www.prevent.org/NCC).<sup>29</sup>

**Getting Test Results:** When asked how they would like to receive their test results, the majority of women said they would like to get them directly from a healthcare provider during an in-person visit. Most also reacted positively to receiving their results from a provider over the phone. Respondents liked the option of being notified that their results were ready via cell phone message or e-mail, and then being able to call for the results at their own convenience. Due to privacy concerns, most women did not want to receive their results via text or voice messaging, or through e-mail or a website.<sup>26</sup>

## MESSAGES AND MOTIVATORS

### Overview

A few qualitative studies have assessed the appeal and effectiveness of messages designed to motivate women to seek screening. However, the scope of work in this area has been limited. Concept testing has primarily focused on messages relating to only three factors that influence behavior—increasing knowledge and awareness, increasing perception of personal risk, and promoting the general benefits of getting screened.

More limited work has been done to develop and assess messages relating to other important factors that affect screening behavior, such as reducing stigma and fear; building skills to talk with partners and providers; creating social norms that support routine chlamydia screening; and addressing issues relating to confidentiality and privacy.

## Increasing Knowledge and Awareness

Across many focus group studies, the authors concluded that women are more likely to get screened if they understand that chlamydia is a serious, common condition that can have long term effects, including infertility; that it is usually asymptomatic; and that a simple test and treatment are available<sup>5,6,7,11,12,16</sup>.

Studies conducted by CDC and by the Los Angeles County, CA Department of Public Health for the *I Know* campaign, also provide some initial insights into specific messages—particularly relating to knowledge and awareness—that could be motivators<sup>11,12,16</sup>.

When tested with focus group participants, the specific messages that had the greatest impact on women included:

- ***Chlamydia is an STD that can have serious consequences.*** It can affect your fertility, prevent you from having children, and hurt your unborn child.
- ***Chlamydia is very common.*** Over one million women are diagnosed each year.
- ***Chlamydia usually has no symptoms.*** You can have it, and not even know it.
- ***Chlamydia testing is not automatic.*** You need to ask for it, and have a test every year
- ***The test is simple, quick and painless.*** It is often inexpensive or free, and can be done with a urine test.
- ***You should test because chlamydia can be cured.*** A simple antibiotic pill is used for treatment.

## Increasing Perception of Individual Risk

Many women did not believe that they were at risk for chlamydia. This misperception is tied to their lack of awareness about the prevalence of chlamydia and their belief that people like them do not contract STDs. However, when presented with the following messages, many women paid attention:

- ***Over one million women are diagnosed nationally each year.*** Or, in the case of LA County, 30,000 women will contract chlamydia this year.<sup>12,16</sup>
- ***Every woman who is sexually active is at risk of chlamydia.*** For the *I Know* campaign the message “some friends with benefits can be friends with drawbacks” was perceived as timely and relevant. The line “getting busy now can mean trouble later” was also well received.<sup>16</sup>
- ***You can have chlamydia, and not even know it*** since chlamydia usually has no symptoms.<sup>12,16</sup>
- ***Getting tested for chlamydia should be a routine test that you get every year.*** If you are a female age 24 and younger who is sexually active, you should be screened.

## Promoting the Benefits of Getting Screened

The direct benefits of getting screened, usually expressed in the form of a tagline at the end of materials, have been explored in a small number of studies<sup>11,12,16,19</sup>. The most persuasive motivators are linked to a young woman achieving her personal goals and aspirations and to reinforcing her positive self-image. This self-image included confidence, assuredness, and pride<sup>16</sup>.

The messages include:

- ***Stay on track for the future and realize your goals.*** This was an appealing message concept, according to the *I Know* campaign. Similarly, the tagline, “be the woman that you want to be,” was well received in the focus groups conducted by CDC. In both studies, women were motivated by the message that chlamydia can have serious consequences, and affect your ability to have children in the future. Women also agreed with the message that women should not allow STDs to interfere with other goals, such as going to school and earning money.<sup>11,12,16</sup>

- **Take Charge of Yourself and Your Health.** A message of empowerment and personal responsibility appealed to women in both studies. The desire to be informed about their STD status is captured in the tagline “Don’t think. Know,” which was created by LA County and is currently featured in their campaign materials. “One word to describe the ‘I Know’ girl is informed,” according to this campaign.<sup>11,12,16</sup>

According to the CDC study, younger women, 15 to 17 years of age, were more highly motivated by two primary messages: that chlamydia is asymptomatic and that testing is simple and painless. For women ages 18-25, messages relating to infertility were more persuasive.<sup>11,12,19</sup>

### **Additional Research and Message Development**

Based on the study results, additional messages should be developed and tested to address some of the key factors influencing screening behavior. Of particular importance are messages designed to address two of the most significant barriers to screening—fear and embarrassment. Specifically, research should be conducted to explore additional message options for:

- Reducing fear (of the test; of asking for the test; of talking to partners; of talking to parents; or of parents finding out a teen is sexually active)
- Reducing embarrassment and stigma (associated with getting tested for STDs)
- Creating the belief and confidence that you can ask for the test and/or talk to your partner
- Building skills to ask for the test
- Building skills to talk to your partner
- Normalizing annual chlamydia screening for sexually active young women.

## **RECOMMENDATIONS**

Additional studies should be conducted to address the gaps in qualitative research around chlamydia screening. To increase the percentage of women screened, we must understand and motivate non-users and inconsistent users of screening services. Of particular importance is using qualitative research to test and refine a variety of concepts and messages relating to fear, stigma, self-confidence, skills to talk to providers and partners, and social norms. This research will help determine which messages are most likely to motivate young women to seek screening.

While not addressed in this brief due to space limitations, several studies have identified channels of communication and messengers that are most appealing to young women. Program planners should consult these studies to help ensure that they use the best channels to reach their intended audiences. (At the end of this brief, see references 6, 11, and 26).

## **CONCLUSION**

In nearly every study, women asked for more information about chlamydia—many wanted to be informed about the symptoms, consequences, screening, treatment, and their risk of being infected. Many women want to be able to act on the information to protect their future and their health. Many also want to know where to get the test, how to ask for it, and how to talk to their partners about getting tested, if appropriate. In addition, they want convenient, appealing, confidential, and affordable screening services.

A woman’s decision to seek screening for chlamydia is influenced by a wide variety of factors. Increasing knowledge and awareness is only one strategy, and is not usually sufficient to produce behavior change, especially when fear, embarrassment, and concerns about confidentiality are some of the most significant patient-level barriers to screening.

We must understand and pinpoint the key factors affecting behavior. For some, it might be a lack of knowledge about chlamydia, a lack of skills to ask for the test from a provider, a lack of awareness about the personal risk of contracting chlamydia, or the fear of being seen at a clinic when getting the test. Or, it could be all of the above. The factors influencing behavior may also vary for different population groups, and could be influenced by factors such as age, race/ethnicity, education/income, and geographic location.

Creating a supportive environment in which to perform the behavior is one of the key conditions for behavior change. Lack of access to appealing screening services could be a major barrier for many women. Research and communications efforts should be coordinated with service delivery organizations to ensure that appropriate chlamydia screening services are designed and available within the community. In addition, healthcare providers should be educated about screening recommendations, including who should be screened, effective testing technology and how to integrate screening into medical practice so that it becomes routine<sup>8</sup>. Substantive structural changes might be needed within the clinical setting, along with provider training to increase their comfort level and skills to discuss and recommend chlamydia screening.

To create an effective communications campaign, program planners should review existing studies, identify gaps in the research, and, when necessary, conduct additional studies to gain a solid understanding of their audiences and to test messages that are likely to motivate young women to get screened. At the same time, the availability and appeal of chlamydia screening services should be assessed. Then, they can “hit the mark” with effective, motivational communications and well-designed services.

*Special thanks to Susan Gilbert, MPA, Consultant, Partnership for Prevention, for writing this brief.*

## Studies Reviewed

Study Name/Director	Participants (Gender and Age)	Sample Size and Racial/Ethnic Demographics	Methodology	Location
<b>Blake et al. (2003):</b> “Improving Participation in Chlamydia Screening Programs: Perspectives of High Risk Youth”	Females and Males, ages 15-24  Recruited from Job Corps and Department of Youth Services sites  Have high prevalence of CT and low use of health services	55 participants  Racial composition of male groups: 34% Hispanic; 34% white; 16% multiracial; 9% African American  For female groups, 39% African American; 22% white; 17% Hispanic; and 22% other race	Focus group discussions	Massachusetts  Job Corps and Department of Youth Services Sites
<b>CDC (January 2010):</b> “Perceptions of Draft and Existing Chlamydia Educational Materials: Final Report from Focus Groups with Females, Ages 15-25”	Females, ages 15-25  Three segments: ages 15-17; ages 18-25 who attend school; and 18-25 who work	122 females  33% African American; 36% Latina; 31% Caucasian	18 focus groups were held	Atlanta, GA Alexandria, VA Chicago, IL Dallas, TX
<b>CDC (November 2008):</b> “Knowledge, Attitudes and Behaviors About STDs, Chlamydia, and Chlamydia Screening”	Females, ages 15-25  Four segments: 15-17 in school; 15-17 not in school; 18-25 working; 18-25 in school	125 females  43 African American; 40 Caucasian; 42 Hispanic	Individual phone interviews; in-person interviews	Atlanta, GA Corpus Christi, TX Portland, OR Detroit, MI Massapequa, NY Akron, OH Houston, TX Orlando, FL Philadelphia, PA San Francisco, CA Dallas, TX Chicago, IL
<b>Chacko et al. (2008):</b> “Young Women’s Perspective of the Pros and Cons to Seeking Screening for Chlamydia and Gonorrhea: An Exploratory Study”	Females, ages 16-21  Attend a community-based reproductive health clinic	192 females  68% African American; 16% Hispanic; and 12% non-Hispanic white; other 4%	Individual interviews	Community-based reproductive health clinic in Texas

### Studies Reviewed (continued)

Study Name/Director	Participants (Gender and Age)	Sample Size and Racial/Ethnic Demographics	Methodology	Location
<b>Gaydos et al. (2006):</b> “The use of focus groups to design an internet-based program for chlamydia screening with self-administered vaginal swabs: what women want”	Females, ages 14-49  Of the group, 36 were 18-28; four were 14-17; and two were 38 or older	42 participants  57% African American; 43% Caucasian; and 2% Latina	Focus group discussions	Baltimore, MD
<b>Tilson et al. (2004):</b> “Barriers to asymptomatic screening and other STD services for adolescents and young adults: focus group discussion”	Females and males, ages 14-24  Males recruited from juvenile detention center; Females from the community.	53 participants  Mix of African American, Hispanic, and Caucasian	Focus group discussions	Wake County, North Carolina

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