



Published in final edited form as:

*Sex Transm Dis.* 2016 June ; 43(6): 390–395. doi:10.1097/OLQ.0000000000000456.

## Community-Based Assessment to Inform a Chlamydia Screening Program for Women in a Rural American Indian Community

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### Abstract

**Background**—Rates of chlamydial infection in American Indian/Alaska Native women in the United States are approximately 4-fold those in non-Hispanic white women. We conducted a community-based survey of self-identified American Indian/Alaska Native women 14 to 25 years of age on a reservation in the Northwestern United States to inform a chlamydia screening strategy.

**Methods**—The anonymous survey assessed respondents' knowledge, perceptions, and preferences related to chlamydia screening, results receipt, and partner notification. We recruited women using respondent-driven sampling, school-based sampling, and direct recruitment through social media and fliers. Participants in schools completed the survey as a paper-based, self-administered survey. Other participants could complete the survey in person, by phone as an interviewer-administered survey, or online.

**Results**—We recruited 162 participants, most in schools (n = 83; 51%) or by peer referral (n = 55; 34%). Only 1 woman completed the survey online. Thirty-one respondents (19%) reported a history of an unplanned first pregnancy, and 19 (12%) reported a history of a diagnosed sexually transmitted disease. Most women (n = 98; 63%) recognized the potential impact of *Chlamydia*

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Supplemental digital content is available for this article. Direct URL citations appear in the printed text, and links to the digital files are provided in the HTML text of this article on the journal's Web site (<http://www.stdjournal.com>).

Conflicts of Interest and Sources of Funding: This work was supported by a Community Partners in Health Research grant from the Institute for Translational Health Sciences at the University of Washington (Y07-CRT-DOMBRJ), National Institute of Mental Health Indigenous HIV/AIDS Research Training Program (R25 MH0846), and the National Institute of Minority Health and Health Disparities Indigenous Wellness Research Institute Center of Excellence P60MD006909. J.C.D. has participated in research unrelated to this work funded by grants to the University of Washington from Genentech, Melinta Therapeutics, and the ELITech Group. Other authors had no conflicts of interest.

*trachomatis* on fertility. The preferred site for chlamydia screening was the Indian Health Service Clinic (n = 114; 70%), but 79 women (41%) would accept a *C. trachomatis* test at a nonclinical testing site. Of the 56 women (35%) who would accept home testing, most preferred to get the test kit from a clinic.

**Conclusions**—Our results suggest that Indian Health Service efforts to increase chlamydia screening in the clinic and through outreach may be more successful than promotion of home testing in this population.

American Indian women bear a disproportionate burden of *Chlamydia trachomatis* (CT) infection in the United States.<sup>1-3</sup> Nationwide, rates of reported CT cases among American Indian/Alaska Native (AIAN) women are approximately 4-fold those in non-Hispanic white women.<sup>4</sup> Published CT case rates may underestimate the burden of infection in AIAN populations because sexually transmitted disease (STD) case reports frequently mis-classify the race of AIAN women.<sup>5</sup> Although the reasons for the disparity between chlamydial infection rates in AIAN women and non-Hispanic white women are not clear, they likely include differential access to screening and treatment, sexual network factors, and complex community factors related to historical trauma, poverty, and geographic isolation. Importantly, the disparity is not attributable to differences in sexual behavior<sup>3</sup>; thus, interventions designed to change the sexual behavior of AIAN women are unlikely to have any meaningful impact on disparities in CT infection.

Screening of asymptomatic women, prompt treatment for infected women and their partners, and rescreening are key components of chlamydial control programs.<sup>6</sup> Implementing and optimizing CT screening programs requires consideration of local contextual and health systems factors, particularly in AIAN communities. Publicly funded medical and public health systems on reservations operate under the auspices of sovereign tribal governments or the Indian Health Service (IHS), independent of local and state health departments. Reservations have distinct cultural contexts and geographic factors that require flexible adaptive CT prevention strategies and may limit generalization across communities.

Several effective interventions can increase chlamydia screening and treatment in women. Prior reports have described success with home-based screening among AIAN women,<sup>7</sup> and prompts in the IHS electronic medical record for providers to offer chlamydia screening.<sup>8,9</sup> Although not specific to AIAN communities, investigators have demonstrated the feasibility of chlamydia screening in schools and community settings,<sup>10</sup> the effectiveness of home-based testing with reminder calls for increasing rescreening,<sup>11</sup> and the use of text messaging for results delivery and partner services.<sup>12,13</sup> In Washington State, the use of patient-delivered partner therapy exceeds that in any other US state.<sup>14</sup> Free, prepackaged partner treatments for gonorrhea and chlamydial infection are available through clinics, including the IHS, and pharmacies throughout the state.<sup>15</sup> Any of these interventions, alone or in combination, could potentially be implemented or enhanced in AIAN communities in Washington.

The objectives of our study were to assess the preferences of young (14- to 25-year-old) self-identified AIAN women residing in a rural community in the Northwestern United States regarding chlamydia screening programs and to assess their knowledge and perceptions of

*CT* infection. At the IHS clinic in the community that is the focus of this study, the chlamydia positivity among AIAN persons screened in 2012 was 15.9% (Dawn Conquest, IHS, personal communication), approximately twice that of women aged 15 to 24 years tested for chlamydia statewide in family planning clinics in 2010.<sup>15,16</sup> The community-based survey we conducted was one component of a larger project designed to assess the community's readiness and capacity to develop an adolescent sexual health and trauma-related mental health program. This study was conducted in partnership between the tribal community, the IHS, and the University of Washington.

## METHODS

### Setting and Population

We surveyed 162 self-identified AIAN young women living on or near a large rural tribal reservation from May to November 2014. Using a combined strategy of targeted venue-based and respondent-driven sampling, we recruited participants in community and tribal high schools and via social media and fliers posted at tribal housing projects, community centers, the IHS clinic, the local college, tribal center, and pow-wows. Interested persons contacted study staff who obtained verbal consent and administered the anonymous self-administered surveys. If requested, study staff assisted participants in reading or understanding the questions. Participants recruited in schools completed paper-based surveys. For all other participants, the survey was available as an in-person self-administered paper-based survey, by phone as an interviewer-administered survey, or online. We asked participants who completed the survey by phone if they had completed the survey before in order to prevent duplication. The survey took approximately 10 to 15 minutes to complete. Participants were compensated \$20. The University of Washington institutional review board and the Tribal Council approved this study.

### Measures

All data in our study were self-reported. The full survey is included as an Appendix, <http://links.lww.com/OLQ/A131>.

**Demographic Factors, Health Care Access, and Sexual Health History**—The survey questions included age and tribal enrollment status. We assessed health care access with 2 questions about whether respondents had a primary care provider and had received human papillomavirus (HPV) vaccine. Sexual health history questions included current use of contraception (yes/no and type), pregnancy history (ever/never and first pregnancy planned/not planned), and history of an STD (yes/no and which STD). We categorized contraception use in the following mutually exclusive hierarchical categories: none, condoms only, oral contraceptive pills, hormonal injectable, patch or ring; or long-acting reversible contraceptives (e.g., intrauterine device or hormonal implant). We stratified women by self-reported history of STD or unplanned pregnancy to assess whether women at higher risk for *CT* infection expressed different screening preferences than did lower-risk women.

**Health Priorities**—To assess the relative importance of STD/HIV prevention broadly within the context of other sexual and general health topics, the survey asked respondents to select their top 3 health concerns from the following list: “staying healthy,” “losing weight,” “preventing pregnancy or having a healthy pregnancy,” “mental health treatment,” “reducing or quitting alcohol and/or drugs,” “preventing sexually transmitted diseases and HIV,” “managing a chronic illness like diabetes or high blood pressure,” and “other” as identified by respondent.

**Knowledge and Perceptions Related to Chlamydial Infection and Screening**—

To assess knowledge about key aspects of chlamydial infection, we included 8 declarative statements and asked participants to designate each as “true” or “false.” The statements included factors related to chlamydial infection (familiarity with the term “chlamydia,” infertility as a consequence of untreated *CT* infection, and the asymptomatic nature of most *CT* infections) and chlamydia screening and treatment (highly accurate tests, single-dose treatment, recommendations for screening in women aged <math>\geq 25</math> years). We used the same “true/false” format to assess respondents’ perceptions of the risk of chlamydial infection (community and individual) and barriers to screening. Respondents were asked to indicate why women in the community might not get screening rather than their personal barriers.

**Preferences for Chlamydia Screening**—Survey questions asked about preferences and

perceived barriers to chlamydia screening in both clinical and nonclinical settings. We queried respondents about sites they would go to seek screening, whether it would be acceptable for medical or nonmedical staff to offer routine chlamydia screening, and what type of specimen respondents would prefer to give. We also asked about possible nontraditional testing sites including a mobile public health van, school, community center, pow-wows, or other community event. Survey questions sought opinions related to home-based screening, preferred source for home test kits (online request, pharmacy, clinic), and whether a call from support staff would make it more likely for the respondent to complete home-based testing.

**Preferences for Results Notification and Comfort Level With Partner**

**Notification**—Respondents were asked whether they would prefer to receive test results by phone, text, or in-person. We assessed respondents’ comfort with notifying their sexual partners of a positive chlamydia test result. At the end of the survey, we posed an open-ended question soliciting input about how chlamydia screening could be increased in the community.

## Analysis

We conducted univariate analyses for each survey question. We stratified the responses by whether or not the respondent indicated having a history of STD or an unplanned first pregnancy. Our sample size did not provide sufficient power for statistical comparisons. We used an informal thematic approach to analyze the single open-ended question on the survey, and we report here the general themes of the comments and illustrative quotes in each area.

## RESULTS

We recruited 162 women for the survey: 83 (51%) from schools, 55 (34%) from peer referral, 13 (8%) at community events, and 11 (8%) from focus groups for the larger needs assessment project. Most (n = 156 [96%]) of respondents completed the surveys on paper at the time of recruitment; only 5 women completed the survey over the phone and 1 completed it online. Table 1 summarizes the sociodemographic reproductive health and health care characteristics of the survey respondents. Almost all (93%) were enrolled tribal members, and most (64%) were 14 to 17 years old. Approximately two-thirds (69%) of the women had a primary care provider, but only 28% reported having received the HPV vaccine. Thirty-one percent of women used hormonal or long-acting-reversible contraception; this was more common among women with a history of pregnancy compared with nulliparous women (61% vs. 21%). Among all respondents, 31 (19%) reported a history of an unplanned first pregnancy and 19 (12%) reported a history of an STD.

Overall, participants reported their top health priorities as follows: “staying healthy,” 91%; “losing weight,” 59%; “preventing pregnancy or having a healthy pregnancy,” 42%; and “preventing sexually transmitted diseases & HIV,” 35%. Most respondents were familiar with the term “chlamydia” (83%) and recognized the infection’s potential impact on fertility (63%; Table 2). Despite the majority (88%) agreeing that “all sexually active women under age 26 should get tested for chlamydia,” and chlamydia testing should be “part of a regular health check-up” (72% affirmative for each), relatively few (n = 41; 26%) respondents were aware that chlamydia is usually asymptomatic. More women with a self-reported history of STD or unplanned first pregnancy agreed that *CT* is common in the community (60%) compared with women without such a history (40%). When asked about their perceptions of barriers to chlamydia screening, slightly more participants endorsed personal barriers (e.g., embarrassment [68%]) than organizational barriers, such as not knowing where to get a test (50%) or lack of trust in staff at testing sites (33%). Cost was the least commonly endorsed barrier (15%).

Table 3 summarizes participants’ preferences for obtaining chlamydia screening. Most women indicated that if they were to seek a *CT* screening test, they would go to the IHS Clinic. Respondents were roughly evenly split regarding for the acceptability of medical personnel offering a *CT* test at a medical visit that was not scheduled specifically for the purpose of STD screening. However, acceptance of testing within the context of the health care system was acceptable to many more women than testing at any sites outside of medical clinics. The only site that garnered acceptability among more than 20% of participants was a mobile public health van.

When asked how they would want to receive the results of their chlamydia testing, 96 (59%) preferred face-to-face notification. Relatively few found alternate modalities such as text message (12%), e-mail (10%), or a secure Web site (9%) to be acceptable. Approximately half (51%) of the respondents said they would be somewhat or very uncomfortable notifying a sex partner about positive test results.

Forty-six survey respondents (28%) completed the open-ended questions at the end of the survey asking for input on how to increase chlamydia screening in the community. The most common theme from the participants was to ensure that *CT* screening is offered at clinic appointments and to provide more encouragement and education to women about the importance of being screened as part of maintaining good health. Example quotes are included in Table 4.

## DISCUSSION

In this convenience sample survey of young AIAN women in a rural reservation community, we found that respondents were generally familiar with the potential impact of chlamydial infection on fertility and recognized they might be at risk for it, but did not know about the asymptomatic nature of most *CT* infections. Most women had a primary care provider and preferred clinical to nonclinical screening venues. Responses indicated that inadequate information and personal barriers such as embarrassment were more often perceived as barriers to chlamydia screening than access to health care or cost concerns.

Home testing has shown promise as a mechanism to increase chlamydia screening in other settings,<sup>17, 18</sup> and an Internet-based test ordering system has been implemented in at least one other native community.<sup>7</sup> However, some findings from our survey suggest that a screening program with a significant Internet-based component could be challenging in this community. First, 65% of the women did not think home-based testing would be an acceptable method of screening for them personally, although the greater acceptability among women with a history of STI or unplanned pregnancy indicates that it could perhaps be a successful strategy for rescreening women with recent infection. Of the women who found home testing acceptable, medical clinics and pharmacies were both preferred to online requests as a source for home testing kits. Finally, though by no means a definitive indication of how many women would seek home test kits online, only one participant completed our survey online. If home testing were to be undertaken, it would need to be accompanied by efforts to increase demand for the service and accessibility of kit acquisition.

Our survey results suggest that a clinic-based strategy to improve chlamydia screening, particularly one conducted in partnership with the IHS clinic, would have the broadest base of acceptability in the community at present. Most respondents preferred clinical sites for testing and did not support nonclinical venues for test kit distribution, and the local IHS clinic was the site most respondents said they would go if they were seeking testing. Our survey did not assess the reasons for these preferences, and thus, it is uncertain to what degree these preferences represent familiarity versus truly informed preferences. Nonetheless, to the extent that these surveys represent the views of young women in the community, IHS is an important institutional resource in the community.

Improving clinic-based chlamydia screening in this population will require a better understanding of women's experience with the health care system. Many respondents indicated that they had a primary care provider, but the low percentages of women who reported using hormonal contraceptives, receiving HPV vaccine, and screening for

chlamydia suggest either that women are underusing health services or that the providers they are seeing are not universally promoting sexual health services. Gaining a better understanding of this issue is a key area for future work as efforts to improve clinic-based *CT* screening need to address both patient and provider factors. Many respondents who preferred on-site clinical testing indicated that it would not be acceptable for providers or other medical staff to offer a chlamydia test at a visit not scheduled specifically for an STD evaluation. Given this and the fact that embarrassment was the most common perceived barrier to screening, additional work is needed to understand how clinic staff, including pediatric providers, currently discuss chlamydial screening with women. Additional training for providers and education for patients may be needed to normalize chlamydial screening as a part of routine health care. The Indian Health Service has developed a clinical reminder system for chlamydia screening that is available agency-wide and used in many tribal areas,<sup>9</sup> which could aid this process.

Chlamydia screening programs based in high schools have been effective in case finding and may be particularly useful for reaching adolescents who would not otherwise test.<sup>19–22</sup> Indeed, the IHS has encouraged communities in rural Indian Country to implement school-based chlamydia screening projects.<sup>23</sup> Although acceptance of school-based chlamydia screening in our survey was low, a school-based screening program might still be a viable option. We did not specify in the survey that a school-based strategy could offer voluntary universal screening to students regardless of sexual history, which would normalize testing and protect student confidentiality, nor did we include details about how test results and treatment would be handled confidentially. In addition, the local IHS Clinic staff have experience with school-based screening in other communities and are well positioned to lead the effort if the tribe elects to implement a school-based screening program.

Our study has several strengths. In a relatively short period of time, we completed a community-based survey of a young AIAN population sampled from multiple venues to inform the development of *CT* screening and treatment. Young women, particularly those younger than 18 years, can be hard to reach for such efforts, but we were able to do so in large part due to a tribal government and tribal school facilitating our efforts. Nonetheless, our study has limitations that could impact the generalizability of our findings to the community of interest and, more broadly, to other AIAN communities. Our study population was drawn from convenience sampling and may be dissimilar from young women in the broader community. The nature of our survey approach did not provide an in-depth understanding of respondents' opinions or health seeking behaviors. Survey responses about what participants would do in hypothetical situations may not come to fruition if and when new screening programs are implemented. We did not ask detailed questions about partner notification or treatment, including patient-delivered partner therapy, which could be addressed in future work with the tribe. Lastly, we did not ask about women's sexual behavior or assess risk beyond a history of unintended first pregnancy or STD. However, this facilitated our ability to complete the survey in schools, and the relatively high prevalence of unintended pregnancy and STD history among the respondents to our survey is a marker of risk in the population.

In summary, we found that most AIAN women who completed our survey have access to a primary care provider, recognize the potential impact of *CT* on fertility, and would prefer to test for *CT* in clinical settings. Acceptability of home testing in this population was lower than clinic-based testing, and qualitative comments emphasized the importance of “on the spot” testing, but 35% of women indicated that home testing would be acceptable to them. Because most respondents did not recognize the typically asymptomatic nature of chlamydial symptoms and corresponding need for routine screening, efforts to increase chlamydia screening in the community need to normalize screening and promote it in the framework of health maintenance and wellness.

## Acknowledgments

The authors would like to acknowledge Elsie Howard, public health nurse, for her contribution to conceptualizing the study; the school leaders and community members who facilitated completion of the survey; Ashley Minaei for her assistance with survey administration; and JoceIn Castillo for data entry.

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TABLE 1

Sociodemographic, Health History, and Health Care Access/Utilization Characteristics of Survey Respondents  
(n = 162)

Variable	n (%)
Age, y	
14–17	103 (64)
18–21	31 (19)
21–25	28 (17)
Missing	0
Enrolled tribal member	
Yes	151 (93)
No	11 (7)
Has a primary care provider	
Yes	112 (69)
No	21 (13)
Don't know	29 (18)
Contraception use *	
None	90 (56)
Condoms only	21 (13)
Oral contraceptive pills	10 (6)
Hormonal injection, patch, or ring	16 (10)
Long-acting reversible	24 (15)
Yes, but type information missing	1 (1)
Received HPV vaccine	
Yes	45 (28)
No	76 (47)
Don't know	41 (25)
Ever pregnant	
Yes	41 (25)
No	121 (75)
First pregnancy planned, among pregnant women (n = 41)	
Yes	9 (22)
No	31 (76)
Missing	1 (2)
History of STD	
Yes	19 (12)
No	135 (83)
Don't know/Missing	8 (5)

\* Mutually exclusive and hierarchical in the order listed.

TABLE 2

Knowledge and Perceptions of Chlamydial Infection and Screening Among Survey Respondents (n = 162)

	Complete Responses, n	Affirmative Responses, n (% of Complete Responses)		
		Overall	History of STD or Unplanned Pregnancy (n = 42)	No History of STD or Unplanned Pregnancy (n = 120)
Knowledge *				
Have heard of <i>CT</i>	162	134 (83)	37 (88)	97 (81)
<i>CT</i> can cause infertility	156	98 (63)	23 (56)	75 (65)
<i>CT</i> is usually asymptomatic	160	41 (26)	13 (31)	28 (24)
<i>CT</i> tests are highly accurate	156	111 (71)	32 (76)	79 (69)
<i>CT</i> treatment requires one dose of antibiotic	157	74 (47)	21 (50)	53 (46)
<i>CT</i> screening recommended for all women aged 25 y	160	140 (88)	38 (93)	102 (86)
Perceptions *				
<i>CT</i> is common in the community	156	72 (46)	25 (60)	47 (41)
Someone like me is at risk for <i>CT</i>	159	97 (61)	30 (71)	67 (57)
<i>CT</i> testing should be part of a regular health check-up	162	117 (72)	28 (67)	89 (74)
Barriers to <i>CT</i> screening in the community †				
Embarrassment		110 (68)	33 (79)	77 (64)
Do not perceive need for testing		95 (59)	25 (60)	70 (58)
Lack of knowledge		81 (50)	23 (55)	58 (48)
Lack of trust in staff at testing sites		54 (33)	16 (38)	38 (32)
Don't know where to get a test		41 (25)	12 (29)	29 (24)
Cost		25 (15)	4 (10)	21 (18)

\* Survey questions and answers are paraphrased in the table. Please see Appendix, <http://links.lww.com/OLQ/A131> for full survey instrument.

† For the assessment of barriers, the survey instructed respondents to check all applicable answers; missing responses assumed to indicate negative response.

TABLE 3

## Preferences for Chlamydial Screening

	Complete Responses, n	Affirmative Responses, n (% of Complete Responses)		
		Overall	History of STD or Unplanned Pregnancy (n = 42)	No History of STD or Unplanned Pregnancy (n = 120)
Clinical test collection				
Preferred clinical site for <i>CT</i> test	162			
IHS clinic		114 (70)	30 (71)	84 (70)
Planned parenthood		20 (12)	9 (21)	11 (9)
Other medical clinic		45 (28)	12 (29)	33 (28)
School clinic		1 (1)	0	1 (1)
At a medical visit not specifically for STD	162			
Acceptable for nurse or medical assistant to offer <i>CT</i> test		85 (52)	27 (64)	58 (48)
Acceptable for doctor to offer <i>CT</i> test		81 (50)	26 (62)	55 (46)
Preferred specimen type *	162			
Urine		139 (85)	34 (81)	105 (88)
Clinician-obtained swab		23 (14)	11 (26)	12 (10)
Self-obtained swab		9 (6)	1 (2)	8 (7)
Nonclinical test collection				
Acceptable testing sites outside of medical clinics	162			
None		83 (51)	20 (48)	63 (53)
Mobile public health van		53 (33)	15 (36)	38 (32)
School		29 (18)	10 (24)	19 (16)
Community center		21 (13)	8 (19)	13 (11)
Pow-wow or other community event		17 (10)	4 (10)	13 (11)
Home testing acceptable	162	56 (35)	21 (50)	35 (29)
Preferred source of home testing kits *	56			
Medical clinic		41 (73)	14 (67)	27 (77)
Pharmacy		12 (21)	7 (33)	5 (14)
Online request		10 (18)	6 (29)	4 (11)
School or community center		4 (7)	2 (10)	2 (6)
More likely to test at home if someone called or texted to answer questions	161	57 (35)	18 (43)	39 (33)
Among respondents who said they would test at home	56	33 (59)	11 (52)	22 (63)
Among respondents who did not say they would test at home	105	24 (23)	7 (33)	17 (20)

\* Results sum to more than 100% because many respondents indicated more than one preferred testing site.

TABLE 4

Common Themes Expressed in the Comments Section With Example Quotes From 46 Respondents

Theme	Examples
Offer chlamydia testing routinely	<p>“Just start offering and asking, it will help keep women healthier.”</p> <p>“Talk about it during medical exams.”</p> <p>“I think when you go for a regular check-up at a clinic or for a Dr.’s appointment it should be offered.”</p> <p>“I think most clinics need to offer the test at any given moment. Especially if the woman has reported that she is sexually active. Just like the nurse brings up the menstrual cycle and birth control before an appointment or during a walk in. I usually have to ask for an appointment to get tested.”</p> <p>“It should be offered to young women at school without consent of the parents.”</p>
No wait for testing	<p>“The best way of offering women to test for chlamydia, I would say would be to ask if they’re willing to do it right then and there. To get it done right away.”</p> <p>“If there were an easy way to set up an assembly line for chlamydia testing, that would be pretty awesome...In my case, I just have never gotten around to being tested for these things... My doctor hasn’t really approached me about it and I haven’t asked.”</p> <p>“It would be nice if nurses could go to the school and meet with all the girls and send them in the restroom with their own kit for self-testing. If everyone was doing it girls would feel comfortable.”</p>
Focus on preservation of health as the reason for testing	<p>“To let women know it’s okay to be tested for the benefit of your health.”</p> <p>“Be supportive, women on the reservation can be easily scared by health issues.”</p> <p>“Maybe advertise that ... it is nothing to be scared of.”</p> <p>“Tell the girl that it is for her own health safety and her partners if she has one. It could also affect her future if she wants to have children.”</p>

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