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## Self-administered sample collection for screening of sexually transmitted infection among reservation-based American Indian youth

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### Abstract

**Background**—American Indians suffer a disproportionate burden of sexually transmitted infection, particularly adolescents. Screening access barriers in rural and reservation-based communities necessitate alternatives to clinic-based options.

**Methods**—Self-administered screening for three sexually transmitted infections was piloted among 32 American Indian adolescents aged 18 to 19. Participants self-collected in a private location; specimens were processed by trained, American Indian paraprofessionals and analysis was conducted by an outside laboratory. Participants testing positive were treated by a Public Health Nurse from the Indian Health Service.

**Results**—Results suggest high overall acceptability: 69% preferred a self-administered method over clinic-based screening, 75% would encourage their friends to use this method and 100% would use it again.

**Conclusions**—A self-administered screening method has the ability to reach this and other high-risk populations that might not otherwise access screening, with added potential within the Indian Health Services system for uptake and dissemination in rural, reservation communities facing significant screening barriers.

### Keywords

Chlamydia; gonorrhea; North America; screening; trichomoniasis; American Indians

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### Conflict of interest

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## Introduction

American Indians and Alaskan Natives (AI/AN) suffer a disproportionate burden of sexually transmitted infection (STI) morbidity compared with other racial/ethnic groups.<sup>1</sup> In 2011, AI/AN chlamydia and gonorrhea rates were the second highest among all races/ethnicities and were four and five times the rate among Whites, respectively.<sup>1</sup> Among AI/ANs, the majority of STIs occur among adolescents and young adults.<sup>2,3</sup> In 2011, 67% of all AI/AN chlamydia cases and 57% of all AI/AN gonorrhea cases were among those aged 15–24.<sup>1</sup> AI/AN female adolescents are disproportionately affected; in 2011, chlamydia and gonorrhea rates among AI/AN female adolescents were 3.9 and 2.2 times that of AI/AN male adolescents.<sup>1</sup> Although screening of all sexually active women under age 25 for chlamydia and gonorrhea is recommended annually by the Centers for Disease Control and Prevention (CDC),<sup>4,5</sup> data suggest chlamydia screening coverage rates among sexually active female adolescents is less than 60% in many states,<sup>6</sup> and in spite of national screening guidelines and disproportionate STI morbidity,<sup>7</sup> even lower among AI/AN female adolescents.

Among American Indians living in Arizona in 2011, the state-wide ratio of chlamydia infection between women and men was 4.7:1.<sup>8</sup> However, recent studies indicate young male partners who have not been diagnosed or treated for chlamydia may contribute to high re-infection rates among young women previously diagnosed and treated.<sup>9,10</sup> This research suggests that in addition to young women, there is a significant STI screening gap especially with regard to chlamydia, and possibly other STIs among young AI men.<sup>9,10</sup>

There are numerous barriers to clinic-based screening. Confidentiality and stigma-related concerns arise in rural, reservation communities with few or one health care facility where individuals are likely to encounter a friend or relative.<sup>11,12</sup> Screening practices in reservation-based clinics may also be suboptimal; a recent review of medical records at one Indian Health Service facility indicated considerable missed STI screening opportunities, even among pregnant women.<sup>13</sup> Geographic isolation, long travel distances and limited transportation are additional screening obstacles on reservations.<sup>14,15</sup>

Alternatives to clinic-based STI screening are necessary to increase screening uptake and reduce disease burden among high-risk, reservation-based AI/AN adolescents. Self-administered sample collection for STI screening has been demonstrated efficacious in reaching other high-risk groups to detect STIs, and an acceptable screening method among men and women.<sup>16,17</sup>

In this study, we evaluated the feasibility and acceptability of self-administered sample collection for screening among sexually active American Indian adolescents in a rural Southwest reservation community. Implications for clinical and public health practice are discussed.

## Methods

A community-engaged participatory research process was utilised by a team of Native and non-Native researchers to develop the study design. Garnering community input builds trust

and increases the likelihood that programs are conceived sensitively and appropriately.<sup>18–21</sup> Our community-informed research process included ongoing collaboration with a Community Advisory Board (CAB) comprising key stakeholders and leadership from the Indian Health Service, as well as 14 focus groups conducted with youth (n = 9) and parents (n = 5) from the participating community. Community input guided selection of a screening method for piloting, processes and key targets for necessary adaptations to the screening method implementation and evaluation procedures, as well as protocols for follow-up and treatment of participants screening positive. This process identified the self-administered screening-method “I Want the Kit” (iwantthekit.org [IWTK]; described in detail elsewhere) for adaptation and feasibility piloting.<sup>17,22</sup>

IWTK is a website where self-administered STI screening kits can be ordered free of charge and mailed to an individual’s home. Individuals self-collect specimens (urine or vaginal/penile swabs) and mail to a laboratory for processing; results and treatment referral (if necessary) are provided by phone. CAB and focus group feedback elicited several issues with IWTK implementation procedures including (1) inconsistent internet access on the reservation which would preclude access to ordering screening materials; (2) privacy concerns with having screening materials mailed to homes, especially in multi-generational households where parents and/or other family members may be residing; and (3) preference for in-person results disclosure (as opposed to over the phone). Community input also identified youth ages 18 to 19 to be the most important and appropriate sub-group in the community to pilot the screening method.

To address these identified issues, a key adaptation to the original IWTK protocol included in-person delivery of screening materials, sample collection, as well as results disclosure and treatment (if indicated). CAB members preferred AI paraprofessionals with public health experience and fluency in English and the Native language to act in this role, understanding that STI screening is sensitive and paraprofessionals must be trusted members of their community, and comfortable interacting with youth. Study partners agreed these screening method adaptations were essential to replication and sustainability in other AI communities. Individuals were eligible if they were men or women, a resident of the participating AI reservation, and were between the ages of 18 and 19 at the time of consent. Convenience sampling was used to recruit participants during a summer basketball camp hosted by the local study team in July 2011 and June 2012. Camp participants (n = 267) were men and women aged 13 to 19 and residents of the participating AI reservation. CAB members believed it would not be culturally appropriate for study staff to ask if potential participants had ever had sexual intercourse; therefore ever having engaged in past sexual intercourse was not a study exclusion criterion. Eligible participants were approached by study staff that explained the study, delivered informed consent and scheduled a separate time and location for specimen collection.

Native paraprofessional study staff met participants at a private location of their choosing with a bathroom (typically their home or local study office), gave hardcopy instructions describing the self-administered screening process, and verified understanding. Study staff was present to address questions about instructions or problems with collection. Participants independently self-collected their urine sample and transferred it to a secure transport tube.

Participants handed the transport tube to the study team member who deposited it into a biohazard bag and mailing envelope. Study staff compiled mailing envelopes with collected specimens in a temperature-controlled container and shipped to an off-reservation CLIA-certified laboratory that processed IWTK samples in Baltimore, Maryland. Urine samples were tested by transcription-mediated amplification assays (APTIMA Combo 2) for chlamydia and gonorrhea,<sup>23</sup> and the APTIMA *Trichomonas vaginalis* (ATV) assay for trichomoniasis (Gen Probe, San Diego CA).<sup>24,25</sup>

The laboratory furnished results to the study team within two business days. STI positivity was determined as a positive test by urine for any one of chlamydia, gonorrhea, or trichomoniasis. Participants with negative test results by urine for all three STIs were considered negative. For negative results, trained Native paraprofessional study staff met privately with the participant for disclosure. For positive results, study partners collaborated with Public Health Nurses (PHN) at the local Indian Health Service (IHS) Hospital; whereby a referral was made to a PHN who met with the participant (in their home or another private location) for disclosure and treatment initiation. The PHN also fulfilled state and federal surveillance reporting, provided counseling and education, and followed-up again with each participant to complete a test of cure.

Data on demographics, STI outcomes, and participant comfort, acceptance, and likelihood of future use of the self-administered screening method were collected immediately post-screening and again after results disclosure through a self-report questionnaire created by the study team. Participants were given a \$15 Walmart gift card if they completed the second assessment administered post-results disclosure. Likert response categories were dichotomised and data were analysed using Stata 11.0 (StataCorp LP, 2005). The study was approved by relevant tribal, IHS, and University research review boards. This manuscript was approved by the authorised tribal review board and Tribal Council.

## Results

We approached 68 youth for potential participation and 30 declined (n = 17 men, 57%). Reasons for declining included they were uncomfortable with screening for STIs (n = 15), gave no specific reason (n = 12), were scared of finding out result (n = 1), were scared of parent finding out result (n = 1), or said they had already been tested and treated (n = 1). We consented 38 participants. At the first data collection time-point post-sample collection, six participants indicated they had never engaged in sexual intercourse. We present results for participants who reported ever having engaged in sexual intercourse (n = 32/38, 84%). The median age was 19 and 69% (n = 22) were men; 81% (n = 26) reported sexual intercourse in the past six months, with an average of 1.6 partners (range 1–3, SD 0.7). Of those screened, 44% (n = 14) tested positive for at least one STI (50%, n = 7 men); 10 were positive for chlamydia (70%, n = 7 men), one for gonorrhea (woman), two for trichomoniasis (both women), and one was co-infected with chlamydia and gonorrhea (woman). Of those who tested positive (n = 14), 64% (n = 9) had never been screened in the past. All participants who tested positive were treated.

Table 1 summarises participants' experience with self-administered STI screening. The majority (88%) reported test procedures were not difficult; a few had trouble urinating into the cup (n = 3), using the dropper to suction urine (n = 1), transferring urine into the collection tube (n = 3), and adding urine to the correct level in the tube (n = 2). 100% of participants were comfortable with the person who disclosed their results and nearly all (96%; n = 24) felt their questions were sufficiently answered.

Table 2 summarises participants' preferred method of future STI screening. The majority 69% (n = 22) preferred a self-administered method over clinic-based screening and 100% would use the self-administered screening method again. Those that preferred IHS clinic-based screening indicated wanting direct access to a physician as the reason for this preference. Of those who had experienced clinic-based screening in the past (n = 18), 78% (n = 14) preferred self-administered over clinic-based screening. The majority (94%) reported they would access the internet to order the self-administered test.

## Discussion

A self-administered STI screening method was found highly acceptable among rural, reservation-based American Indian adolescents. Participants felt comfortable with this method's privacy, non-clinic-based option, in-person assistance from a Native paraprofessional, and in-person results disclosure and treatment from a local PHN. Participants understood testing instructions and were confident in their ability to complete the test independently. Importantly, the majority (69%) preferred this method over visiting the IHS clinic, 94% said they would order it online, and 75% (n = 24) said they would encourage their peers to use this method. These results suggest high overall acceptability.

Self-administered STI screening, especially if provided free of charge, has potential to reach this high-risk population for testing and treatment referral, overcome barriers of stigma and confidentiality, and reach those that might not otherwise access STI testing. Despite national screening recommendations focused on women of reproductive age, our majority sample of men with a high rate of positivity (all for chlamydia), and limited access to testing, argue for targeted screening promotion among young AI men. Self-administered STI screening could be replicated and scaled-up in other AI communities through incorporation into the IHS standard of care, which has access to a ready infrastructure of two viable outreach work forces: Community Health Representatives (CHRs) and PHNs. CHRs could be trained to offer self-administered screening as an alternative to clinic-based testing and connect individuals to high-quality follow-up, treatment, and risk-reduction counseling already provided through the IHS-PHN system. Finally, since only 30% of our study sample were woman, future directions should include additional piloting of self-administered STI screening methods with young AI women.

This study was exploratory, and results should be understood within the context of study limitations. First, limited resources including study staff availability and convenience sampling from a camp (as opposed to throughout the reservation) precluded recruitment of a large sample size; so the sample cannot be considered representative but appropriate nonetheless for a feasibility study. Second, the CDC recommends self- or clinician-collected

vaginal swab as the preferred sample type and screening method for women.<sup>26</sup> During our community-engaged research process, however, community partners agreed this method would not be culturally acceptable and a first-catch urine specimen was chosen instead. While considered acceptable by the CDC, first catch urine may detect up to 10% fewer infections when compared with vaginal swabs and may reduce user ease with specimen collection (due to necessary pipette of urine).<sup>26</sup> The proportion of those who tested positive cannot be extrapolated to population rates, and in general, would likely underestimate as the most at-risk segment of this population is highly mobile and hard-to-reach. Finally, this study was based on one IHS-catchment in a rural reservation area, and caution should be exercised in generalising findings.

Limitations aside, to our knowledge this is the first study to explore a self-administered method of STI screening among AI adolescents in the United States and yielded important indications for other communities experiencing similar barriers. While our sample was not large enough to determine prevalence, the proportion of participants who tested positive (44%) sounds an urgent call to action.

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**Table 1**

Comfort with self-administered sexually transmitted infection screening procedures.

	<b>Women (n = 10)</b>		<b>Men (n = 22)</b>	
	<b>Not at all/not very comfortable N (%)</b>	<b>Somewhat/very comfortable N (%)</b>	<b>Not at all/not very comfortable N (%)</b>	<b>Somewhat/very comfortable N (%)</b>
Privacy of testing location	0 (0)	10 (100)	3 (14)	19 (86)
Feelings about taking the test	2 (20)	8 (80)	2 (9)	20 (91)
Understood test directions	10 (100)	0 (0)	19 (90)	2 (10)
Complete the test itself	9 (90)	1 (10)	19 (86)	3 (14)
Post-results disclosure				
	No N (%)	Yes N (%)	No N (%)	Yes N (%)
Understood test results	0 (0)	10 (100)	1 (5)	21 (95)
Comfortable with person giving results	0 (0)	10 (100)	0 (0)	22 (100)
Questions were answered (n = 24)	0 (0)	8 (100)	1 (6)	15 (94)
Diagnosis concerns addressed (n = 22)	2 (29)	5 (71)	9 (60)	6 (40)

**Table 2**

Future utilisation of self-administered sexually transmitted infection screening (post-results disclosure).

If you were at risk of contracting a STI in the future, would you:	Women (n = 10) N (%)	Men (n = 22) N (%)
Take a self-administered test again	10 (100)	22 (100)
Prefer to (mutually exclusive):		
Take a self-administered test	8 (80)	14 (64)
Go to the IHS clinic for testing	2 (20)	7 (32)
Neither	0 (0)	1 (4)
If test were free, available online and could be mailed, would you:		
Order this test	9 (90)	21 (95)
No (specify why)	1 (10)	1 (5)
No internet access	1 (100)	0 (0)
Don't trust internet	0 (0)	1 (100)

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