

Barriers to Engagement with HIV/STI Partner Services among Men who have Sex with Men (MSM)

Feedback from MSM with a Syphilis Diagnosis, 2019

6-28-21

Acknowledgments

This report was prepared on behalf of Oregon's HIV/STD Prevention & Surveillance Program by Program Design & Evaluation Services (PDES), an interagency research and evaluation unit affiliated with Oregon Health Authority (OHA) and Multnomah County Health Department. Doc Ramblings and Julian Adanaque-Bugarin collected the data. Brie Kennedy conducted the literature search. Linda Drach drafted the Background section of this report. Lindsay Hixson analyzed the data and wrote this report. Linda Drach, Doc Ramblings, Kristen Rohde gave editorial feedback on this report.

Thanks to the 32 individuals who shared their experiences and opinions in key informant interviews.

Contents

Acknowledgments..... 2

Background 4

Specific Aims & Methods 4

Results..... 6

 Sample..... 6

 Response Rate..... 6

 Participant Characteristics 6

Key Themes..... 7

 Syphilis Testing & Diagnosis Experience 7

 Understanding what Partner Services Means 10

 Using Various HIV/STI Partner Services 11

 Evaluating Specific Services Offered through STI Partner Services 13

 Motivating Others to Use Partner Notification..... 15

 Improving Health Department Services..... 17

Summary 19

Discussion..... 20

Conclusions 21

Recommendations to Improve Health Department Services..... 22

References 23

Appendix 1: HIV/STI Partner Services Evaluation Questionnaire & Interview Script 25

Background

Partner services for HIV and other sexually transmitted infections (STI) include a broad array of services, including partner elicitation and notification that should be offered to people newly diagnosed with HIV/STI and their sexual and/or needle sharing partners. The CDC defines the following characteristics as foundational for partner services: client-centered; confidential; voluntary; free; evidence-based; culturally, linguistically, and developmentally appropriate; accessible and available to all; and comprehensive. In Oregon, partner services are often delivered through disease intervention specialists (DIS) and other staff at local public health authorities (LPHA).

Data from Oregon's Early Intervention Services & Outreach (EISO) Program (2019) show that testing partners of individuals newly diagnosed with HIV, syphilis, and/or rectal gonorrhea yielded the highest proportion of new HIV diagnoses (7%) compared to other testing strategies, including providing HIV testing to people with syphilis and rectal gonorrhea (3%), and community-based outreach testing (.01%).

The higher yield of new positives found among Oregon EISO HIV/STI partner contacts is consistent with the scientific literature. Partner services as a targeted HIV screening activity has been found to be highly effective¹⁻² and has been recommended as a key strategy for high-income countries to achieve the 90/90/90 HIV testing target.³ A 20-country study found that testing contacts of HIV index cases yielded twice as many new HIV positive cases as all other testing strategies.⁴ San Francisco saw an extremely high yield using this strategy: 23% of people tested through HIV partner services were newly diagnosed with HIV.⁵

However, acceptance of partner services among those who could benefit from it is lower than optimal for interrupting disease transmission. Many clients decline partner services or are unable or unwilling to identify partners for follow up. Clients may face social or structural factors that make participating in partner services not a priority and/or may have met partners online or in other anonymous settings. Delivery of partner services is inherently challenging for LPHA staff who may not have the tools needed to follow up on online partnerships (e.g., digital partner services).

Specific Aims & Methods

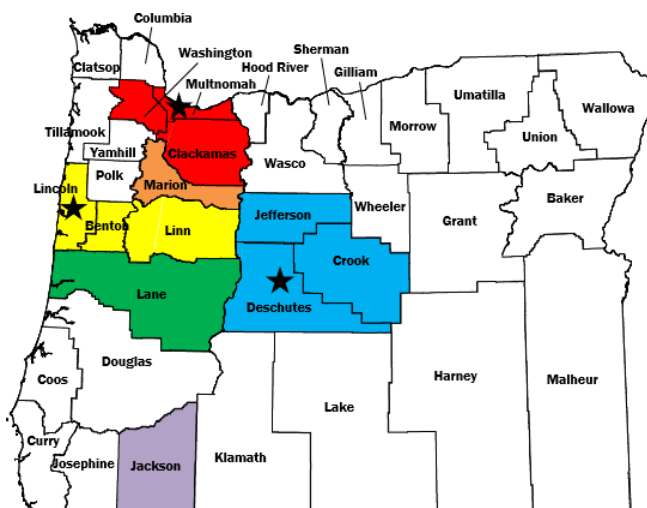
The specific aims of this project were to:

- Gather descriptive information to improve HIV/STI partner services in Oregon.
- Develop recommendations for outreach efforts that may help counter barriers and improve participation in HIV/STI partner services in Oregon.

This project used qualitative methods to explore the perspectives of men who have sex with men (MSM) who were diagnosed with early syphilis in 2019 about their syphilis testing and diagnosis experience and their thoughts about HIV/STI partner services.

Potential participants were selected for key informant interviews using purposive sampling. First, a list of potential participants was generated by the HIV/STD Prevention & Surveillance Program; the list included: (1) early syphilis cases (defined as primary or secondary syphilis), in 2019 among men who have ever reported having sex with men, based on surveillance data, and (2) cases identified within EISO counties (see Figure 1). Next, we narrowed the sample based on the distribution of 2019 syphilis cases among MSM by EISO county. Last, we finalized our sample using stratified sampling for maximum variation within defined strata, including demographics (age and race/ethnicity).

Figure 1. EISO Grantee Counties



Participants were recruited using the same protocols that have been successfully used for the HIV Medical Monitoring Project. Specifically, participants received a letter on OHA letterhead that informed them that they may be eligible for a telephone interview on a health-related topic. The letter had a toll-free call-back number, connected to a confidential project line. The letter did not mention syphilis or STIs. Trained interviewers from PDES followed up by phone within one week. All participants received a mailed letter and at least two phone calls inviting them to participate.

All interviews were conducted by phone, in February through April 2021, using a semi-structured interview guide of nine open-ended items, with additional prompts (Appendix 1). The guide was developed with input from the HIV/STD Prevention & Surveillance Program and three external subject matter experts in HIV/STI from local public health authorities. The project was approved by the OHA Science & Epidemiology Council, which classified it as evaluation of a public health issue, not research.

Participants provided verbal consent to be interviewed. Each participant who completed an interview received a \$50 Visa gift card as a token of appreciation.

Interviews were recorded, with participant permission, and transcribed verbatim. Transcripts were analyzed using a general inductive approach to identify and code major and minor themes.⁶

Results

Sample

The final sample included 96 individuals, selected using the sampling criteria previously described. Recruitment started with an initial sample of 75 people, and then an additional 21 individuals were added to ensure adequate representation from each of the EISO regions.

According to Oregon’s integrated electronic disease surveillance system, Orpheus, the 96 individuals in the sample were all male and had reported ever having sex with men (MSM). Sixty-five percent (n=62) were listed in Orpheus as White, non-Latino, 14% as Latino, 8% as Black/African American, 6% as multiracial, 4% as Asian, 4% as Other, 2% as American Indian/Alaska Native (AI/AN), 2% as Pacific Islander, and 2% as refused/unknown. Seventy-three percent were from the Portland tri-county area, and the mean age was 38 years (range: 16 – 79).

Response Rate

Of the 96 people contacted, 32 completed interviews, six declined, three agreed to participate but did not complete an interview, and 55 did not respond to invitations to participate.

All interviews were conducted by telephone in English. Interviews averaged 15 minutes in length (range: 7 – 28 minutes), minus the introductions, consent, and arrangement of payment.

Participant Characteristics

There were no significant differences between respondents and non-respondents regarding demographic characteristics or geographic region. The average age was 41 (range 26 – 60) years old and 72% were from the Portland tri-county area.

The distribution of participants closely matched the distribution of 2019 syphilis cases among MSM by EISO county. For example, Multnomah County represented 57% of syphilis cases and 53% of participants in this study lived in Multnomah County. See Table 1 for a breakdown of EISO county representation among participants.

Table 1. Early Syphilis Cases among MSM and Respondents by County

County	Syphilis Cases among MSM n (%)	Respondents n (%)
Benton, Deschutes, Jackson	20 (5.3)	3 (9.4)
Clackamas	22 (5.9)	2 (6.3)
Marion	25 (6.7)	2 (6.3)
Lane	39(10.4)	4 (12.5)
Washington	43 (11.5)	4 (12.5)
Multnomah	212 (56.5)	17 (53.1)
Other EISO counties & missing	14 (3.7)	0 (0.0)
Total	375 (100%)	32 (100.0)

We asked the 32 participants three demographic questions: gender identity, sexual orientation, and race/ethnicity. All three questions offered open-ended response options.

All participants self-identified as male, which matched the Orpheus data on sex. Most participants identified as gay (n=27, 84%), three identified as bisexual, two as pansexual, one as gender queer/gender fluid, and 1 refused. About one-in-ten (n=3) identified with more than one sexual orientation category.

We used an open-ended response option for self-reported race/ethnicity. Nearly two-thirds identified as White (n=20) and about 1 in 10 (n=3) identified as Latino or Asian (n=3). Two respondents identified as American Indian or Alaska Native (AI/AN), 1 person identified as Black/African American and 1 as Native Hawaiian. Nearly half of participants reported different racial and ethnic information than how they were categorized in Orpheus (n=15). Seven individuals categorized as White in Orpheus self-reported different racial identities, including each of the other major Office of Management & Budget race categories, except for Native Hawaiian/Pacific Islander. Conversely, four individuals self-reported White, while they were categorized as either AI/AN or multiracial in Orpheus. No one chose more than one racial or ethnic identity compared to three people who were listed as “multiracial” in Orpheus. Despite these differences, the race/ethnic distribution of participants generally matched the distribution of 2019 syphilis cases among MSM by EISO race/ethnicity.

Key Themes

Participants shared testing and diagnosis experiences as well as recommendations for improving health department services. The summarized results are reported by theme, with sample quotes to support the themes presented in italics.

Syphilis Testing & Diagnosis Experience

We started each interview asking participants about their syphilis testing and diagnosis experience. Participants generally described efficient and positive interactions. Most participants were tested and diagnosed at their County Health Department (i.e., Multnomah, Lane, and Marion, 44%, n=14) or with their primary care physician (25%, n=8). Smaller proportions were tested at other clinics such as Planned Parenthood or Prism Health (16%, n=5), urgent care (3%, n=1) or unknown/couldn't recall (13%, n=4).

Table 2. Syphilis Testing by Clinic Type

Clinic type	n (%)
Multnomah County Health Department	12 (38%)
Primary care physician	8 (25%)
Other Clinic	5 (16%)
Don't know/can't recall	4 (13%)
Other County Health Department (Lane, Marion)	2 (6%)
Urgent Care	1 (3%)
Total	32 (100%)

Participants chose their testing location based on accessibility, routine, and health insurance coverage. Most people said they would test at the same location again (n=25, 78%). Three participants said they would go somewhere else for testing because they previously used urgent care (n=1), preferred a closer proximity to home (n=1), or the private testing service was too expensive (n=1). A few respondents noted that the interaction with staff at the Multnomah County Health Department cemented their decision to return to that testing site.

They're super friendly and there's nobody looking at you funny. #224

She was awesome. She was really cool. I explained my whole life to her, and she was good. She didn't judge me, and that's why I felt comfortable having that conversation. #205

Most participants (n=27, 84%) indicated they received their diagnosis immediately or via a phone call. Eight people said they saw it on their online health record, My Chart (25%), with half indicating they also received a call and half utilizing their My Chart exclusively. All of those who used My Chart received care from their primary care doctor or a private clinic. Among those who received their diagnosis by phone, a majority (n=19, 83%) could not remember if they received it from a doctor, nurse, or other type of provider.

More than half of respondents (n=19, 59%) said they were informed that the health department would be contacting them for follow-up, while 22% (n=7) were not told, and another 19% could not recall (n=6). Nearly everyone who reported “no” to the question about whether they were informed that the health department would follow-up were tested at their county clinic (n=6, 86%) and the remaining person was treated at a private testing service.

Waiting for test results was a frustrating experience for three respondents (9%), and two of them were not notified of their positive syphilis test result.

They told me they were going to call me and tell me. Unfortunately, a week later I had to go in and my result was just sitting there waiting for me. #204

They preemptively gave me antibiotics to treat it, but I never got anything stating that it was positive. I took the antibiotics because they prescribed them for me, but I assumed that it was negative because I never heard anything back. #228

A quick turnaround encourages people to engage more. Waiting a couple of weeks and not really understanding the process of how you're going to be notified is a sensitive time. The faster that people can be recontacted with further instructions or some reassuring information, I think the more likely they are to engage. #232

A few participants experienced inconsistency with their syphilis diagnosis and treatment. Two people said they were treated presumptively, while another wished he could have been treated

before the official diagnosis was received. In two other scenarios, the health department wanted to do a second test, even after the first test came back as positive.

It's hard because if you have a known exposure some will treat you right away and some won't. My doctor told me when you're positive, a false negative could come up in the future. Another doctor said "No, that's not true. If you're not experiencing these symptoms, you have to test positive first to get treatment." #224

Once the test comes back positive, you should allow people to take antibiotics, instead of having to wait for the second confirmation test. #226

I had a chancre back in 2010 that I recognized as syphilitic. The gram stain was positive, so they treated me presumptively. The (second test) FTA came back negative, so they stopped after one treatment. Two years later, I ended up in the hospital for several weeks with neurosyphilis. When people have compromised immune systems, they should continue to treat to make sure people are adequately covered, and they don't progress to a much more serious illness like I did. #216

One respondent described the frustrating process of getting diagnosed with syphilis because the provider did not know what the symptoms looked like.

I went in because I had a skin rash, and I had to see three different doctors and eventually a dermatologist before they actually told me I had syphilis...I was surprised that this was such a shock to them, especially after seeing three doctors and none of them knowing that a skin rash is a symptom... #213

Follow-up post-treatment and education was sometimes overlooked despite its importance to the participant. Some respondents said they didn't know what to expect next or were confused about how it worked after they received a syphilis diagnosis, wondering "do I still have syphilis or not?" They were not told about the kinds of support services that are available. This could be due to providers being confused about or unaware of the services provided from the health department. Regardless, if they understood the range of services provided, the communication several respondents received from their providers was not clear enough to answer all their questions about next steps.

I wasn't positive about how long I would be carrying it, not in a transmissible way, but just in the sense of health. You folks know more by looking at blood counts that people are free and clear, but patients are less aware of that and need a little more comforting. #222

I would've liked more information about syphilis and the health ramifications. It's still not clear to me what I really need to do afterwards. #206

It was just the aftermath of education and the confirmation of the results of the testing that did not actually come through. #228

The likelihood of having a negative testing or diagnosis experience was not contingent on clinic type. Problems with receiving the syphilis diagnosis occurred for some who received care at Multnomah county, another County clinic, and their primary care physician. Inconsistency with treatment (i.e., some being treated presumptively while others waited for treatment after diagnosis) was experienced by some receiving care at Multnomah county and a private clinic. Lacking appropriate follow-up post-treatment was experienced by some who were treated at Multnomah county and another County clinic.

Understanding what Partner Services Means

Most respondents (n=28, 88%) had never heard of partner services before. Only one of those who had heard of it remembered where they learned about partner services from: “a *medical non-profit group in town.*”

To understand what may contribute to barriers in participating in HIV/STI partner services, we asked respondents what they thought of when they hear the term “partner services.” Overwhelmingly, respondents did not have a clear understanding of what partner services entails. Nearly two-thirds of respondents (63%) had difficulty with the term; forty-four percent thought the term was vague/ambiguous/not specific enough (n=14) and 19% didn’t know what it meant and could not offer an idea about what it was (n=6). One-quarter (n=8) thought it meant partnering with other organizations or entities to “*best take care of [their] health care.*” Only one-quarter (n=8) of respondents offered a definition, example, or close approximation of what partner services entails.

I guess personally it's not very memorable and/or specific to the reason for the visit. I wouldn't immediately associate it with the reason why I would go there. #225

It takes some steps to put it together. It doesn't really speak for itself. #218

I would not have known that it was directly related to STI infections. It does not make me think of that if that's what the question is. #213

I don't know that have strong feelings one way or the other. #221

Even when someone had an accurate definition of partner services, there was still hesitancy about whether the interviewer was referring to the same thing.

Partner services, meaning like wraparound services for other things besides getting treated? Or are you talking about the network of providers that you would go to get treatment? Referring to services about communicating with your sex partners? #216

One respondent was asked the follow-up question, “*What kind of services do you think would be included under that umbrella?*” The response was:

Good question. That's a hard question. #220

Using Various HIV/STI Partner Services

We asked respondents whether they received any additional services when they were diagnosed with syphilis, offering them a list of possible services they may have received. The most common service was receiving testing for other STIs such as gonorrhea or chlamydia (n=30, 94%), followed by HIV testing (n=22/25, 88%). High proportions also reported receiving information about PrEP (n=12/15, 80%) and education about safer sex (n=25, 78%). Receiving free condoms was the least common (n=19, 59%).

Table 3. Counts of receiving HIV/STI partner services, by service type

STI partner service	n (%)
Testing for other STIs	30 (94%)
HIV testing, among HIV negative (n=25)	22 (88%)
Help contacting sex partners	26 (81%)
Information about PrEP, among those not on PrEP or HIV+ (n=15)	12 (80%)
Education about safer sex & how to prevent future infection	25 (78%)
Resources to inform partners about syphilis infection	20 (63%)
Free condoms	19 (59%)

About one-fifth of respondents disclosed that they were HIV+ (n=7, 22%) and nearly half of the remainder reported being on PrEP (n=12/25, 48%). One respondent credited the interaction at Kaiser during his syphilis diagnosis as the impetus for starting PrEP.

I am on PrEP because of that doctor's office. There's somebody there that I see frequently. I had a lot of questions, but don't like medicine and she talked me through it over multiple visits. I think it took about two years of me going there before it happened. #212

There was no pattern in the likelihood of receiving specific services by facility type, except for receiving free condoms. Three-quarters of respondents who were not offered condoms received care at their primary care doctor rather than a county health department or other health care clinic (n=8/12).

To be honest with you, the ones that you guys provide are just really cheap and don't fit. #205

I go for the lube because I'm gay. I go for the condoms. I go for all the swag. #230

Contacting Sex Partners

Twenty-six respondents (81%) said they were offered help contacting sex partners (known as partner notification or contact tracing) to let them know they were infected; about 1 in 5 (n=6, 19%) reported they were not offered help and didn't know the service was available.

One-fifth of respondents (22%, n=7) utilized partner services to help contact their sex partners. While a relatively small group, their experiences with this service were positive. One person remarked, "It was easy. It was smooth sailing."

They contacted people that I had sex with that I knew and wasn't like just hooking-up on Grindr. They told me that they would be anonymous about it and they wouldn't drop my name, but they'd let them know that, "Hey, you better go get tested." #230

There were some people that I contacted myself and then there were other partners that I wasn't able to reach, but I gave them the contact information that I did have so that they could track them down. #216

I especially like that they can handle contact tracing online or hookup apps because that's often hard for a person to do. I know some people have a lot of problems telling a sex partner face-to-face or over the phone, "Hey, by the way, you might want to get tested." If you're not comfortable approaching a partner, it is nice to have a third-party intervention if you need it. #211

Despite the positive feedback about using partner services, there was some confusion about how partner services staff would help contact sex partners.

I was like, "I'll do it," because I don't honestly have all of the info for every person, but for the people that I do have, I just contacted them instead, because isn't it like giving information about them, or how does that work? #218

I didn't realize that there was a deeper system. I probably would have done that if they were like, "Yeah, we can figure out people that you might not even be able to contact." I would have some questions about that, like how that all works? #209

Then for the folks whose numbers you didn't have, there was no way to contact them, is that right? #230

About half (46%) of those offered help contacting partners said they turned it down because they would contact the partners on their own (n=12). An additional 15% reported they didn't know how to contact their partners (n=4). No one answered affirmatively that they were not interested in contacting partners or were afraid of their partners' reactions. One sentiment was "you play, you pay." Only one participant answered that they didn't like the staff, and one other respondent thought help with contacting partners could be viewed as a privacy violation.

On the phone call they offered them, but I just communicated that I didn't feel the need to rely on their communication about it. I just reached out to [my partners] and let them know. #221

I had already told my partners about the infection by the time the Health Department reached out to me, but I gave them the information they asked for anyway. I was probably offered help with those things. I probably said, "No." My general response to that is, "I'm a big boy, and I can talk to my partners about these things." #232

They offered to do it for me and so I guess at the time I preferred to do it myself. #222

With my partners at the time I was meeting them through Grindr, so there's not really a way for the Health Department to message them, I think. #226

Table 4. Reasons for denying help contacting sex partners, among respondents who did not utilize partner services (n=25)

Reason	n (%)
Not interested – I wanted to tell my sex partners myself	12 (48%)
Didn't know help was available	6 (24%)
Don't know who my sex partners are or how to contact them	4 (16%)
Not interested – none of your business/privacy violation	1 (4%)
Partner notified me/was already getting treated	1 (4%)
Didn't like/trust the staff	1 (4%)
Afraid of partners' reaction	0 (0%)
Not interested in contacting my partners	0 (0%)
Total	25 (100%)

One-quarter (n=6) of those not using partner services said they didn't know help was available and don't recall being offered help contacting sex partners. It is possible that because most respondents did not know what partner services meant, they did not realize that there were anonymous contacting services available.

I did not know. If I knew, yeah, I would use it. #220

I did not know that there was assistance. I don't know exactly how this assistance works, but I may have used it, but probably would have just initially taken the time to reach out to the people on my own. #213

I don't really know what the services is all about. It was just them telling me to contact the people that I have been with since that time or anyone else. That was already told to me by my doctor. So, that would just be the same information unless they have something else or other resources that I don't know about. #215

There was no pattern in the lack of awareness about the service to help contact partners and clinic type; three people received care at the Multnomah County clinic, one person at their primary care physician, one person at Planned Parenthood, and one person at urgent care.

Evaluating Specific Services Offered through STI Partner Services

Health Department Staff

Given the potential sensitivity of talking with staff about a syphilis diagnosis and contacting sex partners, we asked how respondents felt interacting with the health department staff. Nearly everyone who interacted with the staff had a positive response. Over half (53%) of respondents indicated a positive interaction with the staff (n=17), while 44% (n=14) did not provide any feedback on their interactions with staff. Only one person reported a negative interaction that

was “awkward and uncomfortable” where they perceived one staff person to be “judgey.” The most common feedback was that staff made them feel comfortable or more relaxed.

I felt very comfortable. I was embarrassed and they talked me through it. Just provided a great resource. It wasn't just a, "Hey, you're in line. Here's your shot." It was a full-service. I felt very cared for. #212

The person I spoke with was engaging and friendly and informative, even though I didn't have a ton of questions, but I did not find it to be too invasive or anything. #219

Participants also said that there was a nice balance between making them feel comfortable, while also discussing the seriousness of the diagnosis.

The staff was great. I really liked them. My doctor was really nice. We had funny conversations, although it was a very serious matter. He made it kind of lighthearted, but still made it clear that it was a serious issue. #204

It didn't seem like overly clinical and I felt like, they were being as kind as possible. I felt good about it as much as you can for those kinds of services. #222

In addition, one participant who received care at Prism (a local organization) said he was educated about syphilis.

They did educate me a lot. They told me, "You have these titers that we look for and after a while the infection will clear, but you'll still have these, so that's how we know. If you don't get tested here, you have to tell them that you've had it before and that there'll be titers, so they won't freak out." They told me that's how they monitor it. #218

Other Health Department Services

Generally, respondents did not have much feedback about other services offered by the health department (i.e., HIV testing, PrEP, education, etc.). They viewed the health department as a place to get tested and treated, rather than a place to receive additional services. Some respondents may not have realized the full array of STI partner services available, while others simply thought they did not need the additional services offered.

I wasn't really in need of any services that I wasn't already receiving. #231

I thought that was the standard stuff [they] do. I didn't really think anything of it. #217

Most of that was deferred back to my primary care physician because that's who I was comfortable with. And when I said that to them, they were okay with that, but they were ready to give me that information. I had no issues with the information they were offering. I went a different route to receive that information. #229

The most useful service was getting tested and treated right on the spot. “Having them available as a testing resource when I need it” was a sentiment expressed by three respondents. In

addition, two respondents mentioned free condoms and one mentioned lube as being useful.

It's nice to get treated perceptibly or because there's signs and symptoms of something on the spot. That's one of the greatest things and being able to get in quickly with an appointment, whereas you might not be able to with a primary care doctor. In the [health care] system, sometimes you have to wait weeks to get in because they're booked. With the county you can call get in within a day or two, especially if you have symptoms. #216

While most respondents didn't have much to say about specific STI partner services, over three-quarters (n=25) felt satisfied with the services offered. Of the seven people who felt there were services missing, three people recommended educational resources and making information “*a little more digestible.*” Two people said they had trouble getting their results, and two people wanted help making follow-up appointments.

Very few respondents (n=2, 6%) had heard of the website tellyourpartner.org. Six people asked a follow-up question about it during the interview and one other person said he would look into it. Thus, 22% of respondents showed interest in learning more about the website. Of the two people who had heard about the website, one had never used it and the other one said he used it as a prank.

Motivating Others to Use Partner Notification

When asked what might motivate more people to participate in partner notification or to let their sex partners know they have been exposed to an infection, four themes were identified by participants who offered recommendations: education about STIs, personal responsibility, anonymity, and normalizing and de-stigmatizing STI diagnoses.

The most common theme was education (n=8, 25%): specifically, providing accessible, consistent education about STIs and communicating the potential health consequences of “*continuing to have unprotected sex and being unaware of it and the medical problems that can occur.*”

Education and showing the actual visual, negative things would really make an impact, because just reading through it really doesn't resonate. #220

They need to know how one STD can piggyback on something else and how you could get more things because it lowers your immune system. #201

Reminding the community that this is a huge thing and just because you're on PrEP, doesn't mean that there aren't other risk factors. #219

Another theme to motivate others to participate in partner notification was personal responsibility because “*it's the right thing to do*” (n=7, 22%). Participants expressed that it shouldn't be an issue to contact partners “*if you're responsible and take care of yourself and you respect the people around you.*” Communication with partners “*prior to hooking up is going to be a benefit.*”

It's like do you want me to tell you or not? And I feel like most people are going to say, "Yeah, I appreciate it." In fact, lots of times if I'm like, "Oh, I tested positive for this," people will say, "Okay, thanks." And it's worked the other way, too. It's kind of like a reciprocal thing. I think it is this kind of community. People understand there has been a lot of education around testing. #218

Seven individuals (22%) recommended making the process easier through anonymity. Participants discussed having “something set up where you don’t have to do it yourself” or “an alert that doesn’t have to tell you who it was.”

For some people, particularly married men who have sex with men, being able to have anonymity when they're contacting or when partners are contacted. #207

Four people (13%) described normalizing and de-stigmatizing STI diagnoses because “some people are just uncomfortable with the conversation, so just talking about it more openly” could help motivate others to use partner notification.

Education and openness in talking about it within the community. I've seen it come a long way and the stigma has changed for a lot of the STIs. I've been impressed at how ex-partners or partners have reached out to me, with at least confidence, or they've been nervous or whatever, but they've at least reached out. I've seen that a lot more recently and I think that's because the culture around STIs isn't so shrouded in mystery. #219

The more people can understand that people would rather be informed about possible risks than the shock of receiving that news in the first place, then maybe more people might be willing to follow up with all the right people. #223

I believe that people talking more about those types of sexual experiences would fix more of the stigmas and the things that are happening that create more STDs to beat. #201

Three respondents (9%) mentioned media campaigns or mobile testing at venues where men typically seek out other men for sex.

When I lived in Eugene, they had a bus campaign with syphilis (SyphAware) and it was funny, but it also started the conversation. #212

In the past, if there was a certain breakout in gonorrhea or something, I would see a poster at a bar that had some facts that gonorrhea is increasing and make sure you're getting testing. I think it is good, if there is some rise in syphilis in the Portland or Oregon area to spread that word that syphilis is rising and make sure you're talking to your doctor to do a very specific test. Syphilis, in general, was a big shock to me. #213

While most people provided a response to what would motivate others to participate in partner notification, four people (13%) did not have an answer.

I don't have an answer for that because I know some people internalize contracting STIs very differently. #208

To spark input about ways to encourage participation in partner notification, some respondents were offered prompts, such as at home testing, incentives, or community-based services. While not everyone received each prompt, respondents generally were receptive to the ideas put forward. One exception was about using monetary incentives to get tested; opinions were split about its utility.

I don't understand why people need an incentive to do what they should do. I'm tested because it's my responsibility to test and I don't understand why other people don't do the same. #202

I think that'd be really cool. People might take advantage of that and just go get tested because they really wanted a gift card to Target or something, but I don't think that's a bad idea. You're still getting tested and then you'll know your status. #204

Some people will be enticed by money. Others will be enticed by making it simple. Others will have concerns about confidentiality. You have to give them extra reassurance that no one is going to find out and all that stuff. It depends. People have different issues. #216

Home testing as an option to motivate people to participate in contact tracing had a lot of traction from the respondents who were given this prompt as an example (n=20/22, 91%).

If there was a way to mail a kit, people would be more open to getting tested at home rather than going to the clinic, because stigma is real. They probably don't even want to be seen going to a clinic. If they could get it in the privacy of their home and mail in their test results to a lab, then people would be more open to getting tested regularly. #230

Improving Health Department Services

Participants shared a variety of ideas about improving health department services for people with an STI like syphilis. Improvements are listed by the following four themes: outreach, STI testing accessibility, communication, and procedural refinements.

Outreach was the most common recommendation for improving health department services (n=13, 41%). One form of outreach was making data available to the gay community and “*emphasizing the significance of why you need to protect yourself.*” One respondent said, “*just because you're on PrEP, doesn't mean that there aren't other risk factors.*” A specific recommendation was to spread the word about the epidemic through advertisements on apps or including an alert when you log in to the app.

I wasn't aware that syphilis was pretty high in the area until after I tested positive. #228

It seems like the department is very good at educating once someone has contracted an STI, but in terms of public outreach, a lot more could be done. #207

Another form of outreach identified by participants was increasing awareness about the services that are already available, including anonymous messaging, contact tracing and free testing options (n=4, 13%). One respondent recommended *“more visibility and the kind of services you offer, and more knowledge about how you can engage in those services.”*

People may know that you could send an anonymous message, but I don't think a lot of people have heard there's a specific tool will send this message anonymously. #218

More free events, free test centers, or at least, better advertising of the ones that we already have. #231

Participants said offering more accessible, affordable testing opportunities would improve health department services (n=7, 22%). Specifically, they mentioned pop-up testing locations (i.e., community events, street fairs). One respondent recommended offering STI testing at every medical appointment, *“even if I'm not even there for an STI appointment.”* In addition, ease of access and cost of testing could be barriers for some people, so participants encouraged more free testing opportunities.

The third theme about improving health department services was communication and knowledge sharing (N=7, 22%). Educating providers about their interactions with gay clients was perceived as an area for improvement among respondents. Participants wanted more information from their providers, specifically about what to expect next and the services the health department will be offering such as contact tracing and anonymous notification.

Doctors trying to educate about gay health need more education so that they're more knowledgeable about things like PrEP. #205

I know syphilis is sometimes hard to diagnose, but if I had had more education about the symptoms of syphilis. I've been STI tested many times, and then when I had the initial painful sore, I also had no idea it was syphilis. #206

I had to ask a lot of questions about it because I didn't understand. And if there was a way to demystify or explain it a little better. There's a lot of mistruths out there about it. #212

If you could find a way to have providers give people a head's up, like if people are expecting a call (from the health department), then they'll be like, "Oh, my doctor told me about this, and I went there already for treatment." #218

Another component of the communication theme was capitalizing on the timing of the diagnosis for harm reduction to be *“a little more open and willing to talk and get things done and together.”* One respondent recommended providing an opportunity to talk with a case worker for follow-up questions and *“for assurance that this is normal, and this happens.”*

Because when they're there already, people are there, they have a little bit of shame, so they're more approachable, where they wouldn't be normally. They're out of their space. #217

Some counseling around harm reduction is a really good time to address that, where people are feeling a little more vulnerable and exposed and could maybe absorb something more than just, "Hey, you should use condoms." #232

Three procedural recommendations were improving follow-up treatment (n=5, 16%), making the services more accessible to people with disabilities (n=1, 3%), and sensitivity training for staff (n=1, 3%).

I think that the follow-up scheduling visits could have been done better...I did leave the office sort of unsure about whether my treatment was successful. #222

I just wish they would have reached out to me and let me know that my results were ready and to come talk. I had to reach out on my own. #204

It was a bit frustrated with the amount of service that they were able to provide based on my disability. Better accessibility and sensitivity training as well, as to how to handle different abled people and people with disabilities. #220

Summary

Thirty-two individuals with a syphilis diagnosis in 2019 shared information about their testing/diagnosis experience and their thoughts about HIV/STI partner services. All participants were men who had sex with men and represented the geographic and race/ethnic makeup of the 2019 distribution of syphilis cases in counties funded to provide EISO services. Most participants were tested and diagnosed at the local health department (44%) or with their primary medical provider (25%). They generally described efficient and positive interactions, with one-quarter of participants expressing frustration with the delay in receiving test results, treatment, or the lack of follow-up and post-treatment – experiences that crossed the spectrum of clinic types. Some respondents were confused about how it worked after they received a syphilis diagnosis. Participants wanted more information from their providers, specifically about what to expect after diagnosis and/or treatment and what additional services the health department will be offering.

Overwhelmingly, respondents did not have a clear understanding of what “partner services” refers to, with only one-quarter offering a definition, example, or close approximation of what partner services entails. Given the ambiguity around the term “partner services,” developing language that more descriptively describes the services (i.e., Testing & Connecting) that the health department offers may highlight opportunities for patients to engage more with partner services.

High proportions of respondents received various partner services (i.e., STI and HIV testing, information about PrEP). Most (81%) said they were offered help contacting sex partners, yet only 22% reported using partner services to help contact their sex partners. Nearly half (46%) of

those offered help said they turned it down because they would contact the partners on their own. An additional 15% reported they didn't know how to contact their partners.

Nearly everyone who interacted with health department staff had a positive response, and some noted a nice balance between staff making them feel comfortable, while also discussing the seriousness of the diagnosis. The most useful health department service was getting tested and treated right on the spot.

Respondents said education (specifically providing accessible, consistent education about STIs, anonymity, and de-stigmatizing STI diagnoses) would motivate more people to participate in partner notification. They also discussed personal responsibility as "*the right thing to do.*" Home testing was overwhelmingly supported as an incentive to participate in contact tracing, while financial incentives had some support.

Participants shared a variety of ideas about improving health department services, including outreach (i.e., making data available, ads on apps, showcasing available services), STI testing accessibility (i.e., pop-up testing locations), communication (i.e., educating providers and harm reduction), and procedural refinements (i.e., follow-up treatment and accessibility for people with disabilities).

This evaluation has limitations. The overall number of participants was small, and we don't know how the experiences of non-participants compares to the individuals we interviewed. While there were no significant differences between respondents and non-respondents related to demographic characteristics or geographic region, their experiences with partner services may have differed. We talked with participants who had a syphilis diagnosis in 2019 and some had difficulty recalling the details of their testing and diagnosis interactions, which may have hindered their perceptions about being offered specific partner services or using them.

Discussion

From national literature, we know that designing consumer-driven partner services will increase participation.⁷ Embedding gay-friendly partner services staff in STD clinics and supporting efforts linking MSM to providers sensitive to their needs may help alleviate some of the discontent participants felt about understanding next steps for life after a syphilis diagnosis.

Providing multiple options for partner notification, including tailoring by partner type, and offering app-based anonymous notification may encourage individuals to notify partners. Even if participants do not have contact information for partners met through apps, results from one qualitative study suggests that partners are generally easy to find again on the apps unless partners block them, delete their profiles, or change usernames.⁸ In addition, most were comfortable with health departments having app profiles to provide sexual health services.⁸

Potential strategies that have shown some success in increasing the number of named partners include (1) emphasizing the benefits of partner services at preventing disease within the patient's own community or sexual network,⁹ (2) educating providers about the partner services process

and level of confidentiality to help prepare patients for their encounters with the DIS,¹⁰ and (3) utilizing experienced DIS who are successful at eliciting named partners from a high proportion of patients as training and mentoring resources.

Eliciting social contacts, in addition to sexual contacts, may reveal additional STI cases because the social contacts are from similarly vulnerable populations with similar behavior, sexual networks, and STI risk, or because contacts are actually sexual contacts that the respondent chooses not to reveal. In a recent study,¹¹ males almost never referred to other males as sexual contacts, but males were likely to refer males as social contacts. These male-male connections may be friendships, or they may be sexual contacts between males who conceal their male-male sexual involvements.¹¹

New technology protocols that are anonymous, decentralized, encrypted, and automated, such as the Exposure Notification protocol developed by an Apple/Google collaboration¹² could be adapted for STI partner notification if they are successful in maintaining maintain public trust.¹¹ Finally, one study found there was no difference in the proportion of locatable partners between app users and no-app users.¹³

While many respondents did not recall who gave them their syphilis diagnosis, the importance of disease intervention specialists (DIS) is widely recognized given their array of duties. A national effort to develop a certification to standardize the skill set of DIS is expected to increase recognition of the crucial public health¹⁴ contributions made by DIS.¹⁵

Conclusions

Based on findings from this qualitative study, use of most HIV/STI partner services among MSM with a syphilis diagnosis was common, specifically HIV/STI testing and receiving information about PrEP. Health department staff were appreciated, and respondents felt satisfied with the services offered. Partner notification, however, was not utilized as often, either because respondents wanted to contact partners on their own or did not think partner services could help with identifying partners they met online. Further work on contacting partners met online continues to be an important challenge, yet the literature offers some promising ideas.

Recommendations for improving health department services centered on outreach and education – two areas where OHA’s HIV/STD program could play a significant role. Developing a media campaign to inform the public about the syphilis epidemic (similar to SyphAware, OHA’s syphilis awareness campaign in 2015-2016)¹⁶ and providing support for increased access to affordable STI testing would support this effort.

Participants also wanted better follow-up, post-treatment care from their providers. Additional efforts to increase provider knowledge about how to engage with their patients following a syphilis diagnosis is another intervention that HIV/STD program could further explore.

Recommendations to Improve Health Department Services

From key informants:

Standardize follow-up scheduling of appointments after patient has received syphilis treatment. The follow-up appointment should review processes for patient follow-up and education after syphilis diagnosis and treatment. This should include education about what having a syphilis diagnosis means for future STI testing situations and any potential testing/health consequences of a diagnosis. Whenever possible, the process for scheduling follow-up appointments and labs should be standardized.

1. Given the ambiguity around the term “partner services” among participants, use more descriptive terms to showcase HIV/STI services provided by the health department (i.e., partner notification, Testing & Connecting).
2. Set up an 800 number that people could call to directly reach out to people who provide partner services (i.e., DIS), rather than it being initiated through the health department.
3. Develop an outreach and education campaign to inform the public about the syphilis epidemic and to highlight the variety of services available through the health department.

From the literature:

1. Partner with app companies to integrate partner services and increase access to public health programs, which has potential to improve MSM sexual health.
2. Explore patients’ broader social contexts by identifying unnamed sexual partners in their friendship networks to identify additional STI cases.
3. Routinize partner notification services into DIS investigations to benefit syphilis partner notification outcomes for MSM.
4. Embed gay-friendly staff in STD clinics and support efforts linking MSM to providers sensitive to their needs.

References

1. Katz, D. A., Dombrowski, J. C., Kerani, R. P., Aubin, M. R., Kern, D. A., Heal, D. D., Bell, T. R., & Golden, M. R. (2016). Integrating HIV Testing as an Outcome of STD Partner Services for Men Who Have Sex with Men. *AIDS Patient Care and STDs*, 30(5), 208–214.
2. Bergman, J., Gratrix, J., Pillay, T., Houston, S., Cooper, R., Charlton, C. L., Lemire, S., Paradis, K., Birse, T., & Singh, A. E. (2015). Intensive HIV Partner Notification Is Effective in Identifying New and Previously Diagnosed HIV Infections in Edmonton, Canada. *AIDS Patient Care and STDs*, 29(8), 419–422.
3. Karatzas, N., Peter, T., Dave, S., Fogarty, C., Belinsky, N., & Pant Pai, N. (2019). Are policy initiatives aligned to meet UNAIDS 90-90-90 targets impacting HIV testing and linkages to care? Evidence from a systematic review. *PloS One*, 14(6), e0216936.
4. Lasry A, Medley A, Behel S, et al. (2019). Scaling up testing for Human Immunodeficiency Virus infection among contacts of index patients—20 countries, 2016-2018. *MMWR Morb Mortal Wkly Rep*;68:474-477.
5. Bernstein, K. T., Stephens, S. C., Moss, N., Scheer, S., Parisi, M. K., & Philip, S. S. (2014). Partner services as targeted HIV screening—changing the paradigm. *Public Health Reports (Washington, D.C.: 1974)*, 129 Suppl 1, 50–55.
6. Thomas, D. (2006). A general inductive approach for analyzing qualitative evaluation data. *American Journal of Evaluation*, 27 (2): 237-246.
7. Bertrand, T. Improving Partner Services for Syphilis among Gay and Bisexual Men I. 2018 STD Prevention Conference. Retrieved from <https://cdc.confex.com/cdc/std2018/webprogram/Session15212.html>.
8. Contesse, M. G., Fredericksen, R. J., Wohlfeiler, D., Hecht, J., Kachur, R., Strona, F. V., Katz, D. A., & Contesse, M. G. (2020). Acceptability of Using Geosocial Networking Applications for HIV/Sexually Transmitted Disease Partner Notification and Sexual Health Services. *Sexually Transmitted Diseases*, 47(1), 41–47.
9. Hogben M. Partner notification for sexually transmitted diseases. *Clin Infect Dis* 2007; 44(Supplement_3):S160–S174.
10. Mimiaga MJ, Reisner SL, Tetu AM, et al. Partner notification after STD and HIV exposures and infections: Knowledge, attitudes, and experiences of Massachusetts men who have sex with men. *Public Health Rep* 2009; 124:111–119.
11. Rosenbaum, J. E., Jennings, J., Ellen, J. M., Borkovic, L. M., Scott, J.-A., Wylie, C., & Rompalo, A. (2020). Giving syphilis and gonorrhea to friends: using in-person friendship networks to find additional cases of gonorrhea and syphilis. *BMC Public Health*, 20(1), 1526.
12. Apple and Google Corporations. Exposure notification: frequently asked questions, version 1.1; 2020. Retrieved from <https://www.apple.com/covid19/contacttracing>.
13. Mobley, V., Cope, A., Dzialowy, N., Maxwell, J., Foust, E., & Samoff, E. (2018). A Comparison of Syphilis Partner Notification Outcomes by Reported Use of Internet-based Apps to Meet Sex Partners in North Carolina, 2013-2016. *Sexually Transmitted Diseases*, 45(12), 823–828.

14. Public Health Accreditation Board. DIS certification project update.
http://www.phaboard.org/wp-content/uploads/DIS-Certification-Project-Update_4-Page_2.17.2017.pdf. Published 2016. Accessed March 15, 2021.
15. Cope, A. B., Mobley, V. L., Samoff, E., O, C. K., & Peterman, T. A. (2019). The Changing Role of Disease Intervention Specialists in Modern Public Health Programs. *Public Health Reports, 134*(1), 11–16.
16. Ferrer, J. (2018). “Increasing awareness of syphilis using public transportation.” In Newton, David (Ed.), *Sexually Transmitted Infections* (138-142). Santa Barbara, CA

Appendix 1: HIV/STI Partner Services Evaluation Questionnaire & Interview Script

I. Interview Script/Protocol

Hello. May I speak with <name of participant>?

Hi, my name is <interviewer> and I work for the Oregon Public Health Division. I'm calling to see if you might be interested in participating in a paid interview about a health-related topic. We sent you an official letter about this project <last week>.

Before I tell you more about the project, I want to make sure I'm talking to the right person, so I can protect your privacy. Can I confirm your full name and date of birth?

___/___/___ (Confirm you are talking with the correct person; If not, thank & discontinue. If yes, initial date of birth and proceed.)

Thank you. We are talking with people who had a syphilis infection in 2019. Oregon is experiencing a syphilis epidemic and we are trying to improve our services at the health department. I'm hoping you would be willing to talk with me for about 20 minutes on the phone—either now or at a time that's convenient for you. If you decide you want to do the interview, we will send you a \$50 Mastercard gift card afterwards as a small way to say thank you for your time.

If you agree to talk with me, everything you tell me will be confidential. We will use an ID number, not your name, to record any information you give me in the interview. Talking with me is completely voluntary and you don't have to answer any of the questions I ask if you don't want. You can also end the interview at any time. Also, please know that whether you do this interview or not, it won't affect any services you might get from the State of Oregon like insurance or food stamps—this is not connected with any of those things.

If you have any questions or concerns about the interview, I can give you the number of Josh Ferrer, who is the manager in charge of this project. (971-673-0149)

Would you be interested in talking with me? YES NO (*thank you*)

Would now be a good time or should we schedule another time?

Interviewer initial here to indicate informed consent given: _____

SCHEDULED FOR: _____

II. Partner Services Study Questionnaire

Introduction—

Thank you so much for agreeing to talk with me about your experiences with the health department. We want to improve our services and hear from people about what kinds of support they may need.

<Review elements of consent if interview script read a different day... “Just to remind you...”>

Permission to Audio Tape—

I’d like to audiotape this call, with your permission, to make sure I understand everything you say. If you decide that’s OK, we will transcribe what you say from the tape—making sure anything that might identify you or another person is taken out—and then erase the tape. The written summary would not include your name or anything that could identify you. Is it OK with you if I tape this call?

YES *(begin recording. tell participant that you have started recording. Remind them that you will strike any identifying information that they mention, like names, from the transcript, but encourage them to avoid identifying themselves or others, whenever possible.)*

NO *(say OK, and tell the participant you will continue the interview without recording)*

TESTING & DIAGNOSIS EXPERIENCE

1. Where did you get tested? (PROMPT AS NEEDED):

- Why did you choose that place?
- Would you go there again for testing? Why or why not?

2. How did you find out about your syphilis results? (PROMPT AS NEEDED):

- Was the person who told you a nurse, a doctor, or a health department worker (like a Disease Intervention Specialist or DIS)?
- Where did you receive your diagnosis (like at a doctor’s office or health clinic – or over the phone)? Is that the same place you got tested?

3. What happened next?

- (If someone other than the health department gave the diagnosis): Did you know that the health department would be following up with you about your syphilis diagnosis?

EXPERIENCE WITH PARTNER SERVICES

“Partner services” is the name the health department uses to refer to a group of services we provide to people with a new sexually transmitted infection like syphilis.

- 4. Have you heard the term “partner services?” (PROMPT AS NEEDED):**
- **Where did you hear about it?**
 - **What do you think of when you hear the term “partner services?”**
- 5. When you were diagnosed with syphilis, did you receive any of the following STI partner services? (YES/NO)**
- education about safer sex/ how to prevent future infection**
 - free condoms**
 - HIV testing**
 - testing for other STIs, like gonorrhea or chlamydia**
 - information about PrEP (pre-exposure prophylaxis or the pill to prevent HIV)**
 - resources for you to tell your sex partners about your syphilis infection**
 - help contacting your sex partners to let them know they were infected (contact tracing)**

(if no, ask 5a) (if yes, ask 5b)

5a. It sounds like you didn’t receive help contacting your sex partners (contact tracing). I’d like to know if any of the following reasons contributed to the reason you didn’t use that service: (YES/NO)

- didn’t know help was available**
- partner notified me/was already getting treated**
- not interested – I wanted to tell my sex partners myself/didn’t need help**
- not interested – none of your business/privacy violation**
- not interested in contacting my partners**
- don’t know who my sex partners are or how to contact them**
- afraid of partners’ reaction**
- didn’t like/trust the staff**

5b. Conversations about contacting sex partners about STIs can be difficult. How was your experience with the health department staff? (PROMPT AS NEEDED):

- **Did they make you feel comfortable?**
- **Did you share information with them about your sex partners?**
- **What could have made that interaction better for you?**

5c. What did you think about any of the other services you were offered from the health department? (i.e.: PrEP, HIV testing, education)

- **Did you use any services? If yes, which one(s) were most useful?**
- **Was there anything that could have made these services better/more relevant?**
- **Was there something missing that would have helped you?**

6. Have you heard about the website tellyourpartner.org? (PROMPT AS NEEDED):

- **Have you ever used it?**

7. When people know they have been exposed to an STI, they get tested and treated. What might motivate more people to participate in contact tracing or let their sex partners know they have been exposed to an infection? (PROMPT AS NEEDED):

- offering different services
- offering services in a different way
- incentives for testing at home testing
- more online services
- peers/community-based services

8. What other ideas do you have for improving health department services for people with an STI like syphilis?

9. Would you be willing to answer 3 quick demographic questions?

a. What is your gender identity? (choose all that apply)

- Male
- Female
- Transgender
- Non-binary or nonconforming or genderqueer
- Something else: _____
- Don't know/refused

b. What is your sexual orientation?

- Gay
- Lesbian
- Bisexual
- Straight or heterosexual
- Queer
- Something else: _____
- Questioning/don't know/refused

c. **How do you identify your race, ethnicity, tribal affiliation, or ancestry? (choose all that apply)**

American Indian/Alaska Native

Asian

Black or African American

Hispanic/Latino/Latinx

Middle Eastern/North African

Native Hawaiian or Pacific Islander

White

Something else: _____

Don't know/refused

That's my last question. Is there anything else you want to talk about or do you have any questions for me? ARRANGE FOR PAYMENT OF INCENTIVE. PROVIDE ANY REFERRALS NEEDED.