

Report on Key
Informant Interviews
for the ASTHO Syphilis
Communication
Campaign Project

November 2023



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## **Executive Summary**

## **Background and Purpose**

The Centers for Disease Control and Prevention (CDC) Division of STD Prevention and the Association of State and Territorial Health Officials (ASTHO) are supporting states engaged in syphilis prevention through a strategic communication planning and technical assistance project led by Trillium. To assist states in planning syphilis communication campaigns, which may eventually become the basis for a national campaign, Trillium conducted 22 key informant interviews. Through the key informant interviews, we aimed to better understand (1) best practices and learnings from past and current communication efforts to prevent syphilis or other sexually transmitted infections (STIs); (2) characteristics of potential priority audiences for a syphilis campaign; and (3) "hot buttons," or issues to avoid or treat sensitively, in a syphilis communication campaign.

## Methodology

We conducted one-hour online individual interviews with three categories of interviewees, including seven people with expertise in syphilis or STI communication, or with certain priority audiences (e.g., pregnant people, people experiencing homelessness, people experiencing substance use disorder); eight leaders of current or recent syphilis prevention campaigns; and seven people with professional experience that could inform a syphilis prevention communication campaign in one of the states involved in this project (Arizona, Idaho, Michigan, New York). Two trained moderators conducted the interviews to allow participants more flexibility in scheduling and to complete the interviews in less time than could be accomplished with one interviewer. One moderator conducted each interview while another member of the team listened and took notes in a prepared template. Interviews were recorded and transcribed.

## **Key Findings**

## **Prior and Existing Syphilis Communication Campaigns**

Interviewees with direct experience in prior and current communication campaigns provided details about their campaigns' development, strategies, tactics, audiences, and partnerships, as well as factors that helped or detracted from the success of the campaign.

1. Campaign strategies were developed using epidemiological syphilis data, campaign leaders' experience with similar efforts, and literature reviews.



- 2. Audience selection was based on analysis of syphilis prevalence rates and emerging trends, along with an assessment of perceived risk and awareness among the different populations.
- 3. Formative testing and developing a deep understanding of the priority audience by involving members of the community were critical for developing appropriate messages and tactics.
- 4. Key strategies focused on raising awareness and knowledge about syphilis (testing, treatment, long-term consequences) and presenting the information within a sexpositive framework.
- 5. Key tactics were varied and depended on an understanding of each audience, including where they would most likely be found and be open to receiving information about syphilis.
- 6. Current campaigns do not have the budget to include a comprehensive evaluation.
- 7. Campaign success was attributed to the use of data, formative research, an in-depth knowledge of priority audiences, strong partnerships, and broad support in the community or state.
- 8. Barriers to success included inadequate formative research; lack of state, county, or local government support; concern about reactions to openly discussing syphilis or sexual health; miscommunication among the campaign developers; and a lack of adequate funding.
- 9. The lessons learned that campaign leaders offered for future campaigns focused on carefully tailoring campaign messages and tactics to the intended audiences, including messages of sex positivity, and developing collaborative partnerships in the community.

#### **Audience Profiles**

Audience experts provided in-depth details about audience characteristics that would enhance the development of focused campaigns. Although many groups are at increased risk for syphilis, the interviewees focused on people who work directly with women and pregnant people, people who use drugs and other marginalized groups, and Hispanic and American Indian people.

 Although each audience has different priorities and concerns regarding sexual health, some commonalities include a fear of being judged and concerns about privacy and confidentiality. More specifically regarding syphilis, there are common concerns about being reported for drug use, child neglect, or illegal immigration status when getting tested, along with a sense of stigma and a lack of knowledge and awareness.



Successful campaigns are those that reach audiences in their communities, with
messages and materials that resonate well with them and are not stigmatizing.
 Campaign tactics that help people address other basic needs (e.g., food, transportation,
pet care, housing) while they get tested.

## **Considerations and Advice for Syphilis Campaign Development**

All interviewees were asked about factors that should be considered when syphilis campaigns are being developed, with a focus on barriers and opportunities for syphilis prevention, key audiences, partners, and resources needed.

- 1. Barriers to successful syphilis prevention campaigns include an inadequate campaign development process, limited funding, and ineffective messaging, as well as community and political attitudes.
- 2. Barriers to syphilis prevention in general include audience-specific characteristics (e.g., reaching people experiencing homelessness, communicating the seriousness of the issue to men who have sex with men), lack of awareness of syphilis, and fear of being stigmatized.
- 3. Opportunities for preventing syphilis include centering campaign tactics on the audience and strengthening local and state partnerships.
- 4. A national campaign is seen as an opportunity for state and local campaign planners to have access to materials and messages that could be tailored for local use.
- 5. Advice for future campaigns reflects many lessons learned from prior campaigns along with suggestions to raise awareness of syphilis among local business owners, thereby reducing the community's stigma of those with syphilis.

## **Recommendations**

The following recommendations are based on consistent themes we heard from interviewees about prior and current campaign elements, audiences, and lessons learned:

- Campaigns will benefit from using epidemiological data and formative testing with priority audiences to inform campaign messages, materials, strategies, and tactics.
   Campaign evaluation will help with refining campaign tactics and developing ongoing or new campaigns.
- Campaigns should be based on an understanding of the priority audience's culture, beliefs, and practices. This understanding is best achieved by including members of the priority audience in the development process. Culturally appropriate messages and tactics should be responsive to audience priorities and concerns regarding sexual health.



- More specifically, when it comes to syphilis, many groups share concerns about being reported for drug use, child neglect, or illegal immigration status when getting tested, along with a sense of stigma and a lack of knowledge and awareness.
- 3. Audience selection should be based on epidemiological data, but also on an assessment of each potential audience's current awareness and knowledge of syphilis, how easily they could be tested and treated, and their likelihood of doing so. Audiences can include those at risk of having syphilis as well as those best able to encourage or provide testing and treatment. These audiences may include healthcare providers and other service providers in a community.
- 4. Campaign strategies and tactics should focus on engaging priority audiences where and when they are open to learning about syphilis to increase the likelihood that they will get tested and treated. These places include venues such as:
  - Healthcare provider offices, rehabilitation facilities, and social service organizations where people receive any type of assistance
  - Judicial, immigration, and incarceration institutions or facilities
  - Businesses and places where audiences go for everyday needs (e.g., grocery stores, hair salons, pharmacies)
  - Social and entertainment venues
  - Social media and online hookup platforms where people connect with potential sexual partners

When healthcare and social service providers are priority audiences, tactics should include direct information dissemination, as well as education opportunities with continuing education credits (e.g., professional association meetings, local or state trainings on standards of care).

- 1. Strong and broad partnerships developed at the beginning phases of a campaign will help ensure that all parts of the campaign reach the priority audience community in ways that reflect their beliefs, culture, practices, and characteristics. Syphilis campaign partnerships can build on existing coalitions or partnerships in the state or community or can be developed as a new entity that embraces the mission of reducing syphilis in the community. They can include state and local government leadership, along with businesses, healthcare providers, social service organizations, and members of the primary audience community.
- 2. Biases held by the community at large, along with stigma, fears, and concerns about confidentiality felt by the priority audience, can be addressed directly through messages,



- images, and tactics that raise awareness of these biases with healthcare providers, businesses, and the public.
- 3. A national campaign could support local or state campaigns by developing materials such as videos of syphilis survivors telling their stories or billboards with messages that do not have to be approved by local politicians. All national campaign materials can allow for local tailoring of messages to address their priority audience and feature local resources for testing and treatment.



## **Background and Purpose**

The CDC Division of STD Prevention and ASTHO are supporting states engaged in syphilis prevention through a strategic communication planning and technical assistance project led by Trillium. To assist states in planning syphilis communication campaigns, which may eventually become the basis for a national campaign, Trillium conducted 22 key informant interviews.

The key informant interviews were intended to extend the information learned through a comprehensive environmental scan undertaken by the Trillium team. This scan described the environment in which new syphilis campaigns would launch and included online research, a literature review, a media scan, and discussions with four state teams involved in this project (Arizona, Idaho, Michigan, New York). Together, the environmental scan and key informant interviews represent important formative research upon which state campaigns, and a possible national campaign, will be built.

Through the key informant interviews, we aimed to better understand:

- Best practices and learnings from communication efforts, past and current, to prevent syphilis or other sexually transmitted infections (STIs).
- Characteristics of potential priority audiences for a syphilis campaign.
- "Hot buttons," or issues to avoid or treat sensitively, in a syphilis communication campaign.

This report presents findings from these interviews and recommendations for state and national syphilis prevention campaigns.

## Methodology

We conducted one-hour individual interviews with three categories of interviewees:

- **Experts:** People with expertise in syphilis or STI communication, or with certain priority audiences (e.g., pregnant people, people experiencing homelessness, people experiencing substance use disorder).
- Campaign leaders: Leaders of current or recent syphilis prevention campaigns.
- State interested/informed parties: People with professional experience that could inform a syphilis prevention communication campaign in one of the states involved in this project (Arizona, Idaho, Michigan, New York).



The interviews took place via an online platform: Microsoft Teams or Zoom, depending on interviewee preference.

Two trained moderators conducted the interviews to allow participants more flexibility in scheduling and to complete the interviews in less time than could be accomplished with one interviewer. One moderator conducted each interview while another member of the team listened and took notes in a prepared template. Interviews were recorded and transcribed.

A token of appreciation of \$100, in the form of an online gift card, was emailed to participants upon completion of the interviews. A handful of participants declined the token of appreciation.

## **Selection of Participants**

To identify possible interviewees who fit the categories important for this project, we relied on names yielded by an environmental scan (see description in Introduction), as well as recommendations from CDC, ASTHO, and the states involved in this project.

The table describes the interviewees who participated in this project.

Types of Interviewees	# of Participants
STI/Syphilis Communication and Priority Audience Experts	7
<ul> <li>Communication experts and evaluators of key syphilis prevention campaigns focused on men who have sex with men (MSM) that took place between 2002 – 2009</li> <li>Experts with in-depth knowledge of women and pregnant people, people with substance use disorders, people who are incarcerated, Hispanic people, and American Indian people</li> </ul>	
Leaders of Current or Recent Syphilis Communication Campaigns  These interviewees were currently leading, or recently led, one of the robust syphilis	8
prevention campaigns identified in the environmental scan. Campaigns addressed one	
or more of the following audiences:	
American Indian people	
Hispanic people	
Pregnant people	
Black women	
<ul> <li>People with substance use disorders</li> </ul>	
<ul> <li>People experiencing homelessness</li> </ul>	
<ul> <li>People involved with transactional sex</li> </ul>	
• MSM	



Healthcare providers	
State Interested/Informed Parties  These interviewees had professional experience that could inform a syphilis campaign intended for one of the four involved states and included people working within state, tribal, or local health departments, healthcare organizations, and other community-based organizations.	7
	22

Written consent was obtained for all interviews. See consent form in Appendix A.

## **Discussion Topics**

We developed and used three different moderator guides (see Appendix B), each tailored for an interviewee category. Participants received a list of discussion topics before their interviews so they would feel comfortable and could prepare if they liked.

The topics covered in the moderator guides varied by type of audience but included the following:

- Prior and current campaigns:
  - O Audiences, strategies, tactics
  - Partnerships and spokespeople
  - Factors influencing success
- Ongoing or future campaigns:
  - o Barriers
  - Strengths and opportunities
  - Advice for campaign planners
- Priority audiences:
  - o Characteristics
  - Opportunities to reach



## **Prior and Existing Syphilis Communication Campaigns**

To learn from prior and current syphilis communication campaigns, we gathered information from all interviewees except for those who were selected as audience experts. Those interviewees with direct experience in prior and current campaigns provided details about their campaigns' development, strategies, tactics, audiences, and partnerships, as well as factors that helped or detracted from the success of the campaign.

## **Key Findings**

Campaign strategies were developed using epidemiological syphilis data, campaign leaders' experience with similar efforts, and literature reviews.

- Epidemiological data, often available at the zip code level, was used to identify the problem (i.e., a rise in syphilis rates), the key audiences affected, and the county or neighborhoods most impacted.
- Experience with past syphilis, HIV, or other STI campaigns, as well as with the priority audiences and the communities of focus, was used to develop key strategies.
- Literature reviews helped campaign leaders
   broaden their knowledge about past campaign
   successes and barriers as they selected campaign strategies, moving some from a
   focus on condom use to testing and treatment.

Audience selection was based on analysis of syphilis prevalence rates and emerging trends, along with an assessment of perceived risk and awareness among the different populations.

Prior campaigns focused on MSM and although data still showed MSM to have the highest rates of syphilis, current campaign leaders broadened their audiences to reflect rising rates and lack of awareness among other audiences. Some campaign leaders deliberately chose broader audiences to attempt to decrease the stigma for MSM. These audiences included:

- Women of childbearing age and particularly those unlikely to seek prenatal care.
- Marginalized groups, including people who use drugs, are experiencing homelessness, are involved with transactional sex, or are incarcerated.

## Lesson Learned: Layers of data can strengthen a campaign

We used epidemiological data to identify the problem, but added a geographic data layer that allowed us to identify the zip codes where the most cases were identified, along with community data that indicated the various venues in the area and the public transportation routes in and out of the area. This helped us develop



- People of specific racial or ethnic groups, including African American, Hispanic, and American Indian.
- MSM who do not openly identify as gay or bisexual.
- General audiences.

Some campaigns focused on healthcare providers as a primary audience because they can directly influence, test, and treat patients. Healthcare providers also were included to increase their awareness of syphilis, the available tests, and the importance of testing.

Formative testing and developing a deep understanding of the priority audience by involving members of the community was critical for developing appropriate messages and tactics.

# Lesson Learned: Reach people at higher risk and health care providers to accelerate change

Along with developing messages that raised awareness about the existence of syphilis in the community and educated the public about the signs and symptoms of syphilis, we followed up with education materials to providers so that they would be ready to respond to their patients questions and requests for testing.

- Formative testing—or testing messages, images, concepts, and tactics—was uniformly mentioned as being important, although budgetary constraints limited some campaigns' use of such research.
- Developing a deep understanding of the priority audience's knowledge, culture, beliefs, and habits helped to make messages and tactics relevant for all audiences but was stressed by those focusing on specific cultural and ethnic groups, as well as segments of audiences (i.e., women and men with multiple partners vs. all people living in rural areas vs. all people in a state or county).

Campaign strategies focused on raising awareness and knowledge about syphilis (testing, treatment, long-term consequences) and presenting the information within a sex-positive framework.

Some of the common campaign strategies included:

- Raising awareness of syphilis and the need for testing and treatment.
- Raising awareness of syphilis and its ability to affect anyone who is sexually active.
- Educating people who already know about syphilis about its long-term consequences.
- Educating healthcare providers about syphilis so that they recognize the symptoms, test all appropriate patients, and provide treatment or referrals for treatment.



- Educating the healthcare community about the positive impact of increasing accessibility to testing and treatment.
- Creating a sex-positive climate that will result in increased and more comfortable conversations about sexual health between partners and between patients and providers.

Campaign tactics were varied and based on an understanding of each audience, including where they would most likely be found and be open to receiving information about syphilis.

Some of the common campaign tactics included:

- Provider education materials, in-person outreach, and education modules on syphilis and sex positivity for continuing education credits.
- Public advertisements including billboards, transit ads, and indoor display posters.
- Brochures and branded giveaway items for distribution to priority audiences.
- Social media and content on sites and apps frequented by priority audiences.
- Websites with information about syphilis and links to resources in the community.
- Press releases and media interviews.

Places and opportunities for outreach included:

- Social venues such as bars, adult entertainment establishments, bath houses, and LGBTQ pride events.
- Social services and other community services, including shelters, homeless outreach centers, jails, immigration service centers, and drug courts.
- Healthcare provider offices, association meetings, and continuing education courses.

Strong, broad community partnerships were vital for launching and conducting campaigns. Some partnerships were already in place within communities, and others had to be built intentionally. Early partnership development helped with creating a collaborative community

## Lesson Learned: Understand the depth of the problem

Ethnographic interviews with community members, physicians, public health workers, and community stakeholders and gatekeepers produced a comprehensive report about syphilis in the community showing an overall lack of awareness that syphilis was a current issue with serious health consequences.



where all felt part of the campaign. The history of collaboration and trust among members of a strong, preexisting community partnership helped all members, including those hesitant to support open advertisement of syphilis awareness in the community, to support the campaign.

Highlighted partnerships included:

- Community organizations that serve audiences' other needs (e.g., housing, harm reduction, immigrant support, post-incarceration)
- HIV/AIDS organizations and planning groups
- Existing community planning boards
- Boards of health, including tribal
- Bars and other social venues
- Sex venues and bath houses
- Social media hookup platforms
- Providers and healthcare organizations
- Informal community leaders

# Lesson Learned: Early partnership development yields great benefits

We started planning the partnership even before planning the campaign details. Being transparent about our goals and objectives and getting people's opinions and feedback early in the campaign development process really created a lot of buy in. People took ownership of the campaign, which helped as we moved through the different stages of the campaign development and implementation.

None of the campaigns used celebrity spokespeople as part of their efforts, though some used local leaders for outreach at local events.

#### Current campaigns do not have the budget to conduct comprehensive evaluations.

Most of the earlier campaigns included evaluations that looked at information dissemination, website metrics, requests for information or resources, awareness of campaign, and number of people tested and treated. A few used data on syphilis rates to assess the success of their campaigns more formally over a longer period. However, due to lack of funding, none of the current campaigns were able to conduct a comprehensive evaluation, despite seeing the value in doing so. Whenever possible, these campaigns conducted assessments of material dissemination and website use metrics.

Campaign success was attributed to the use of data, formative research, an in-depth knowledge of priority audiences, strong partnerships, and broad support in the community or state.

Internal factors that contributed to the campaign's success included:



- Employing formative research and data analysis instead of relying on instincts.
- Having strong partnerships with the community.
- Including members of the priority audience community in campaign and material planning and development.
- Simplicity of the message and campaign tactics.
- Focusing on sex positivity and being nonjudgmental.
- Using ads that created some controversy, which helped to grab people's attention.
- Ensuring accurate representation of the audience in images and messages.
- Using branded items that both relay a message and are useful so that they are not thrown away.

External factors that led to campaign success included:

- Support from state and local public health leadership.
- Large budget.
- Existing programs to build upon (e.g., adding testing to existing prenatal standards of care or adding education modules to existing continuing education courses).
- Timing (e.g., started before COVID pandemic, started before a strong conservative movement regarding sexual health).

Several campaigns mentioned the community's reaction as a factor influencing their success. For some, this was a positive reaction and ensuing conversations helped to spread the message. For others, it was a negative reaction that led to more social media posts, which also helped to spread the message. Having a strong community partnership was helpful in using these reactions to benefit the campaign by supporting media releases and defending the campaign messages and tactics if necessary.

Barriers to success included inadequate formative research; lack of state, county, or local government support; concern about reactions to openly discussing syphilis or sexual health; miscommunication among the campaign developers; and a lack of adequate funding.

Internal barriers included:

Inadequately testing concepts, messages, and materials.



- When targeting congenital syphilis, using images of women instead of families emphasized the health of a woman instead of how syphilis can affect an infant and the entire family.
- O Limiting images to those only relevant to men diminished the effectiveness of the message for women.
- Too narrow of a focus meant campaign messaging was not relevant to all affected populations.
- Language in messaging was too technical and wordy.
- O Too many concepts were included (HIV, sexual health, and syphilis), resulting in people ignoring the key message about syphilis.
- Leaving out QR codes on posters due to fear of increasing stigma around syphilis resulted in fewer resources being available to audiences.
- Concern about reactions to openly discussing syphilis or sexual health.
  - Stigma around the word "syphilis" impacted the name of the campaign and its language.
  - Fear of further stigmatizing the priority audience limited campaign messages.
- Tension between the media firm and campaign planners.
  - The media firm was not used to or comfortable with the planner's involvement in decisions.
  - Graphic artists used "typical" symbols, not those true to the culture of the audience, and these had to be changed.

#### External barriers included:

- Lack of leadership support and slow bureaucratic process.
  - Lack of support from the Board of Supervisors.
  - Resistance from leadership, which showed a preference to "fly under the radar."
  - Tension between local and state health departments.
  - Being a government agency that needed to follow a bureaucratic process and timeline.



- Conservative atmosphere that impacted edginess of campaigns and what could be said openly.
- Inadequate funding.
  - o Grant cycle and review timeline made it difficult to attain adequate funds.
  - O Poorly funded campaigns were limited in what and how much they could include in their tactics.



Campaign leaders offered important lessons learned for future campaigns, including carefully tailoring campaign messages and tactics to the intended audiences—including messages of sex positivity—and developing collaborative partnerships in the community.

More specifically, campaign leaders suggested that future campaigns:

- Use epidemiological data and formative research tools to continuously inform the campaign and ensure that all elements are pertinent to the priority audience.
- Go to the places where the priority audiences go to help them connect to the campaign. This can include physical locations as well as virtual places such as websites and hookup apps.
- Bring testing and treatment opportunities to the audience to increase their participation.
- To support campaign development and implementation, develop strong and inclusive community partnerships that include government leaders, communitybased organizations, businesses, health organizations, leaders from the community, and representatives of the priority audience.
- Consider the importance of sex positivity in the development of campaign messages and tactics to help reduce the stigma of talking about sexual health and syphilis.

# Lesson Learned: Health and other community officials can alleviate community concerns

After identifying the problem of having men driving around neighborhoods looking for people that they could pay for sex, we decided to use billboards in residential neighborhoods to reach both the men and women engaging in transactional sex.

Recognizing the potential controversy such a program would create, the idea and initial supporting data was presented to a city official who agreed to its need and proceeded to get buy in from the health commission and board of health. It was agreed that the billboard campaign would be launched in targeted locations.

The billboards were developed with input from the Human Trafficking Coalition and syringe services program to ensure that the billboards would not increase the stigma for the women. A police lieutenant suggested additional neighborhoods and provided additional insight. Having local officials supporting the campaign helped to confirm the seriousness of the issue and alleviate some of the concern in the community about having such a public campaign about sexual health.

## **Audience Profiles**

While all interviewees were asked about campaign audiences, audience experts were asked to provide their insights and expertise about audience characteristics that would enhance the



development of focused campaigns. Although many groups are at increased risk for syphilis, the experts that we interviewed focused their work on women and pregnant people, people with substance use disorders and other marginalized groups, and Hispanic and American Indian people.

Although each audience has different priorities and concerns regarding sexual health, some commonalities that emerged included a fear of being judged and concerns about privacy and confidentiality, specifically about being reported for drug use, child neglect, or immigration status

Lesson Learned: Ensure the audience sees themselves in the campaign

We try to adapt best practices and make it fit our population the best way. So that might be changing some of the language and images to ensure that people in our community see and hear themselves in the ads.

when getting tested, along with a sense of stigma and a lack of knowledge and awareness.

Interviewees with expertise in engaging **women** provided the following insights:

- Younger women are more open to discussions about sexual health and sexuality.
   They seem to advocate for themselves more, are more accepting of sexual fluidity, and are more open to having sex with MSM. However, they are sensitive to real or perceived negative reactions from older healthcare providers, male or female.
- Some women avoid prenatal care because they fear judgment or having children taken from them, particularly women with substance use disorders, so they miss syphilis testing.
- Most women assume that syphilis testing is part of regular gynecology visits.
- Women are generally unaware of syphilis, its symptoms, and its consequences for them and for their babies. They do not understand that miscarriage is a potential consequence and thus it is not a driver for them to test for syphilis.

Interviewees with expertise in engaging **people who use drugs and other marginalized people** provided the following insights:

- Sexual health is not seen as a priority, and because syphilis can be treated, it is not a big concern.
- Sex workers, who may or may not use drugs, understand the risks of not using a condom, but if they are paid more to not use one, they will have unprotected sex.



- Syphilis testing is avoided because of fear of stigma, judgment, and being tested for drugs and reported to the authorities.
- Incarcerated people may have access to testing, but unless in a federal prison where Medicaid covers their health expenses, they would have to pay for testing and treatment.
- People in immigration detention centers are most motivated to be tested and treated if needed so that they can be cleared for legal entry into the United States.

Interviewees with expertise in engaging **Hispanic and American Indian people** provided the following insights:

- Sexual health, syphilis, and prevention are not high priorities.
- There is little knowledge about syphilis, its symptoms and consequences, and the ease of treating it successfully.
- The fear of stigma and being judged keeps people from visiting clinics or openly discussing sexual health with providers.
- There is a lack of openness about sexuality and a fear about confidentiality when talking to providers or sharing a partner's name.

Campaigns that reach audiences in their communities with messages and materials that resonate with them and are not stigmatizing are the most successful. Effective campaign tactics help people address other basic needs (i.e., food, transportation, pet care, housing) while they get tested.

Interviewees with expertise in engaging **women** provided the following insights:

- Women would be open to a campaign if it were obvious that women influenced its
  design, it featured images of women between ages 20 40, and it did not have a
  message that felt shameful.
- Women react well to social media advertisements and public health podcasts.
- Messages and tactics should normalize testing, and the images should give the impression that all women who have sex are at increased risk, not only young or minority women.
- Women with a strong empowerment focus are the best spokespeople.



Interviewees with expertise in engaging **people who use drugs and other marginalized people** provided the following insights:

- Addressing broader needs (transportation, food, child care, diapers, housing, and other necessities) will motivate people to seek testing and treatment.
- A campaign that provides direct information about resources for free and confidential testing and treatment would be best received.
- Materials that can be taken with them are more important than posters or billboards that will be forgotten.
- One-on-one outreach will have the most impact, with peers being the favored conveyor of information.
- Images should not stigmatize but should show empowering and positive body images and convey the message of gaining control of one's health.

Interviewees with expertise in engaging **Hispanic and American Indian people** provided the following insights:

- Campaigns that focus on information about resources for testing and treatment or that bring testing and treatment to their communities are most welcomed.
- Messages about protecting the health of a partner are motivating.
- Campaigns that aim to reach people who primarily speak Spanish should use materials in Spanish.
- Images should be true to the culture.
- Addressing broader needs (transportation, food, child care, diapers, housing, and other necessities) will motivate people to seek testing and treatment.
- Local health leaders from their communities are the best messengers to speak about syphilis.

## **Considerations for Syphilis Campaign Development**

All interviewees were asked about factors that should be considered when developing new syphilis campaigns. This section summarizes their responses, including barriers and opportunities for syphilis prevention, key audiences, partners, and resources needed.



A limited campaign development process, funding, and messaging will hinder the success of syphilis prevention campaigns, as can conservative community and political attitudes.

- Lack of adequate funding hampers ideal campaign development.
- Lack of formative testing and community involvement or buy-in hampers the development of effective materials and placement because:
  - Messages and images are not always culturally relevant or sensitive to health literacy issues.
  - Messages are not sex-positive.
  - Lack of coordination and communication with potential partners slows campaign development and messaging.
- Conservative community beliefs hamper sexual health messaging, materials, and tactics.

Barriers to syphilis prevention include audience-specific characteristics (e.g., reaching people experiencing homelessness, communicating the seriousness of the issue to MSM), awareness of syphilis, and anticipation of stigma.

- Nonprovider audiences' lack of knowledge and awareness and their beliefs about syphilis, its symptoms, and long-term consequences are challenges for message development.
- Provider audiences do not always see syphilis as an issue of concern for their patients and may not pay attention to campaign materials or education opportunities.
- Available services are not used even when people are aware of the issue due to perceived stigma about syphilis and those who are likely to be infected.
- Mistrust of the medical system and government results in fear that their identity will
  not be protected, and the potential consequences of that keep people from testing
  and treatment.

Opportunities for preventing syphilis include centering campaign and program tactics on the audience and strengthening local and state partnerships.

Interviewees recommended that a campaign:

• Test the messages and materials in the community—for example, bring them to liquor stores, hair salons, and other places where people regularly go for everyday needs.



- Bring the campaign to local events such as LGBTQ pride events, county or state fairs, and other local public celebrations.
- Develop a mobile application that reminds people to get tested or treated on specific dates throughout the year.
- Provide transportation for people to access testing facilities. For those fearing stigma
  in their own communities, helping them get to nearby facilities where they may not
  be recognized could increase their willingness for testing.
- Create messages and tactics that directly address the fears people have about confidentiality and being reported for child neglect, substance use, or immigration status.
- To reduce campaign costs, use tested materials from similar local or out-of-state campaigns and tailor them to the local community.
- Educate the provider community to normalize testing.
- Create a grassroots effort for material and message dissemination by organizing community volunteers.
- Develop strong state and local partnerships to expand the reach of campaign messages.
- Expand testing capacity to new communities and new locations within communities, including mobile testing and treatment units.

A national campaign is seen as an opportunity for state and local campaign planners to access materials and messages that could be tailored for local use.

Interviewees recommended that the campaign:

- Create video messages from a diverse set of people who have experienced syphilis at various stages, allowing them to be tailored to promote local resources.
- Create advertisements that can be used on social media and hookup apps that can be tailored for local use to educate and promote local resources.
- Create a national campaign that does not have to abide by local regulations on how to present sexual health information.



Advice for future campaigns reflects many lessons learned from prior campaigns along with suggestions to raise awareness of syphilis among local business owners, thereby reducing the community's stigma of those with syphilis.

Interviewees recommended that the campaign:

- Include leaders and members of the priority audience in the campaign development process.
- Reflect the cultures, beliefs, and practices of the different priority audiences in campaign messages, materials, and tactics.
- Include sex positivity in its messages and images.
- Develop strong partnerships with an array of community and state organizations, venues, and brands.
- Be sensitive throughout the campaign to local stigma and fears.
- Always use data and formative testing in campaign development and relay it to partners and the community to get their buy-in.

In order to counter stigma and bias, interviewees also recommended that the campaign:

- Engage private-sector business owners and workers that may hold biases about syphilis and priority audiences. These biases may inadvertently reduce the effectiveness of campaigns (e.g., materials may be placed in obstructed areas, not disseminated, or provided with an attitude that brings shame to the recipient).
- Educate providers to reduce their biases or preconceived notions about testing and treatment by learning to approach each patient individually, not making assumptions based on their demographic characteristics or assumed personal characteristics.

## **Recommendations**

Based on the findings included in the previous section, the Trillium team offers the following recommendations:

 Campaigns should use epidemiological data and formative testing with priority audiences to inform campaign messages, materials, strategies, and tactics. Ongoing monitoring and evaluation will help with refining campaign tactics and developing ongoing or new campaigns.



- 2. Audience selection should be based not only on epidemiological data but also on an assessment of an audience's current awareness and knowledge about syphilis, how easily they could be tested and treated, and their likelihood of doing so. Audiences can include those at risk of having syphilis along with those best able to encourage or provide testing and treatment—for example, healthcare and other service providers in a community.
- 3. Campaigns should reflect the priority audience's culture, beliefs, and practices. This outcome is best achieved by including members of the priority audience in the development process. Culturally appropriate messages and tactics include those that recognize audience priorities and concerns regarding sexual health. More specifically, regarding syphilis there are common concerns about being reported for drug use, child neglect, or illegal immigration status when getting tested, along with a sense of stigma and a lack of knowledge and awareness.
- 4. Campaign strategies and tactics should focus on engaging priority audiences where and when they are open to learning about syphilis to increase the likelihood that they will get tested and treated. These places include venues such as:
  - Healthcare provider offices, rehabilitation facilities, and social service organizations where people receive any type of assistance.
  - Judicial, immigration, and incarceration institutions or facilities.
  - Businesses and places where audiences go for everyday needs (e.g., grocery stores, hair salons, pharmacies).
  - Social and entertainment venues.
  - Social media and online hookup platforms where people connect with potential sexual partners.

When healthcare and social service providers are priority audiences, tactics should include direct information dissemination and education opportunities that include continuing education credits (e.g., professional association meetings, local or state trainings on standards of care).

5. Strong and broad partnerships developed at the beginning phases of a campaign will help ensure that all parts of the campaign reach the priority audience community in ways that reflect their beliefs, culture, practices, and characteristics. Syphilis campaign partnerships can build upon existing coalitions or partnerships in the state or community, or can be developed as a new entity that embraces the mission of reducing



- syphilis in the community. They can include state and local government leadership along with businesses, healthcare providers, social service organizations, and members of the primary audience community.
- 6. Biases held by the community at large—along with stigma, fears, and concerns about confidentiality felt by the priority audience—can be addressed directly through messages, images, and tactics that raise awareness of these biases with healthcare providers, businesses, and the public.
- 7. A national campaign could help support local or state campaigns by developing materials such as videos of syphilis survivors telling their stories or billboards with messages that do not have to be approved by local politicians. All national campaign materials can allow for local tailoring of messages to address their priority audience and feature local resources for testing and treatment.



## **Appendix A: Consent Forms**

# Interviews with STI/Syphilis Communication Experts and Professionals Who Serve Groups at Increased Risk for Sexually Transmitted Infections

### **Informed Consent**

You are invited to participate in a study to inform syphilis prevention communication campaigns. The goal of this study is to gather information that can be used to help inform a state or national syphilis communication effort. This study is being conducted by Trillium on behalf of the Association of State and Territorial Health Officials or ASTHO and the Centers for Disease Control and Prevention or CDC.

You have been selected as a participant because it has been determined that you are a syphilis or sexually transmitted infection communication expert or evaluator, or a social service provider who has done extensive work with one of the priority audiences: pregnant people, people experiencing homelessness, or people experiencing substance use disorder.

## **Study qualification**

The only qualifications to participate in this study are that you are an expert as described above and can be interviewed using Microsoft Teams or Zoom.

## **Study participation**

Participation in this study is voluntary. If you agree to participate in this study, you will be interviewed for about one hour.

#### Information Collected

The interview includes questions about your professional experience with syphilis communication campaigns or one of the priority audiences; lessons from these campaigns or work with priority audiences regarding messaging, audience selection, strategies, and tactics; guidance for partnerships and spokesperson selection; external factors that may influence a campaign (positively and negatively); and/or advice for state or national syphilis prevention campaign development.

## **Benefit of participation**

Participating in this study may not benefit you directly, but it will help us learn about the best strategies to use in developing state or national syphilis prevention campaigns. You may skip any questions you don't want to answer, and you may end the interview at any time.

If you participate in the study, you will receive a \$100 gift card to thank you for your participation.



## Confidentiality

The information you will share with us if you participate in this study will be kept completely confidential to the full extent of the law. Any information collected during the interview will stay private and will be kept in secure files. Although we will record the discussion, the recording will be transcribed and then erased. All information presented in a final report will be aggregated and no specific comments will be attributed to any one person. The results of this study may be presented at meetings or in published articles. However, your name will never be included.

If you have any questions about this study, please contact Barbara Cohen at barbara.cohen@trilliuminfo.com. If you have any questions or complaints, you may contact a person not on the research team at the Biomedical Research Alliance of New York Institutional Review Board at (516) 318-6877 or at www.branyirb.com/concerns-about-research.

By returning this consent form to barbara.cohen@trilliuminfo.com, you are consenting to participate in this study.

Signature:	
Print Name (participant)	Date

<sup>\*</sup>Please print or save a copy of this form for your records. \*



## **Key Informant Interviews: Syphilis Campaign Leaders**

#### **Informed Consent**

You are invited to participate in a study to inform syphilis prevention communication campaigns. The goal of this study is to gather information that can be used to help inform a state or national syphilis communication effort. This study is being conducted by Trillium on behalf of the Association of State and Territorial Health Officials or ASTHO and the Centers for Disease Control and Prevention or CDC.

You have been selected as a participant because it has been determined that you are a leader of a current syphilis campaign.

## Study qualification

Along with being a syphilis campaign leader, the only qualification to participate in this study is that you can be interviewed using Microsoft Teams or Zoom.

## Study participation

Participation in this study is voluntary. If you agree to participate in this study, you will be interviewed for about one hour.

#### Information Collected

The interview includes questions about your professional experience with syphilis communication campaigns; lessons from these campaigns regarding messaging, audience selection, strategies, and tactics; guidance for partnerships and spokesperson selection; external factors that may influence a campaign (positively and negatively); and/or advice for state or national syphilis prevention campaign development.

## **Benefit of participation**

Participating in this study may not benefit you directly, but it will help us learn about the best strategies to use in developing state or national syphilis prevention campaigns. You may skip any questions you don't want to answer, and you may end the interview at any time.

If you participate in the study, you will receive a \$100 gift card to thank you for your participation.

## Confidentiality

The information you will share with us if you participate in this study will be kept completely confidential to the full extent of the law. Any information collected during the interview will stay private and will be kept in secure files. Although we will record the discussion, the recording will be transcribed and then erased. All information presented in a final report will be aggregated



and no specific comments will be attributed to any one person. The results of this study may be presented at meetings or in published articles. However, your name will never be included.

If you have any questions about this study, please contact Barbara Cohen at barbara.cohen@trilliuminfo.com. If you have any questions or complaints, you may contact a person not on the research team at the Biomedical Research Alliance of New York Institutional Review Board at (516) 318-6877 or at www.branyirb.com/concerns-about-research.

By returning this consent form to barbara.cohen@trilliuminfo.com, you are consenting to participate in this study.

Signature:	
Print Name (participant)	Date

<sup>\*</sup>Please print or save a copy of this form for your records.\*



# Interviews with Interested/Informed Parties for State Health Communication Campaigns

#### **Informed Consent**

You are invited to participate in a study to inform syphilis prevention communication campaigns. The goal of this study is to gather information that can be used to help inform a state or national syphilis communication effort. This study is being conducted by Trillium on behalf of the Association of State and Territorial Health Officials or ASTHO and the Centers for Disease Control and Prevention or CDC.

You have been selected as a participant because you have been identified as an individual who is interested in or informed about syphilis prevention in one of the states selected to be part of this effort.

## Study qualification

The only qualifications to participate in this study are that you are interested or informed about syphilis prevention in your state and can be interviewed using Microsoft Teams or Zoom.

## **Study participation**

Participation in this study is voluntary. If you agree to participate in this study, you will be interviewed for about one hour.

#### Information Collected

The interview includes questions about your professional experience; lessons from your experience regarding the strengths, weaknesses, opportunities and threats at the state level for syphilis communication campaign development; external factors that may influence a campaign (positively and negatively); and/or advice for state or national syphilis prevention campaign development.

## **Benefit of participation**

Participating in this study may not benefit you directly, but it will help us learn about the best strategies to use in developing state or national syphilis prevention campaigns. You may skip any questions you don't want to answer, and you may end the interview at any time.

If you participate in the study, you will receive a \$100 gift card to thank you for your participation.

## Confidentiality

The information you will share with us if you participate in this study will be kept completely confidential to the full extent of the law. Any information collected during the interview will stay private and will be kept in secure files. Although we will record the discussion, the recording will



be transcribed and then erased. All information presented in a final report will be aggregated and no specific comments will be attributed to any one person. The results of this study may be presented at meetings or in published articles. However, your name will never be included.

If you have any questions about this study, please contact Barbara Cohen at barbara.cohen@trilliuminfo.com. If you have any questions or complaints, you may contact a person not on the research team at the Biomedical Research Alliance of New York Institutional Review Board at (516) 318-6877 or at www.branyirb.com/concerns-about-research.

By returning this consent form to barbara.cohen@trilliuminfo.com, you are consenting to participate in this study.

Signature:	
Print Name (participant)	Date

<sup>\*</sup>Please print or save a copy of this form for your records.\*



## **Appendix B: Interview Guides**

Guide for Interviews with STI/Syphilis Communication Experts and Professionals Who Serve Groups at Increased Risk for Sexually Transmitted Infections

## I. Introduction (8 minutes)

Hello, my name is \_\_\_\_\_\_, and I will be conducting this interview today. Thank you for taking time out of your schedule to talk with me. This interview is sponsored by the Centers for Disease Control and Prevention or CDC to help them learn more about the work you have done with syphilis campaigns or priority audiences [gay, bisexual, or men who have sex with men, pregnant people, people experiencing homelessness, people experiencing a substance use disorder] that could inform a state or national syphilis communication effort. I am not with the CDC. I am a consultant who talks with people about all sorts of things—not just health, but many different topics for a variety of organizations.

This interview will take no more than an hour and everything that you say will be confidential. This conversation will be audio recorded, although you should know that your remarks will never be associated with your name or identifying information. I also have a colleague on the line with me who will be taking notes to ensure we're capturing everything. We will not share our notes, the recording, or any identifying information with the CDC. What we gather from this interview will be added to the learnings from our other interviews and summarized in a report.

As a reminder, your participation in this interview is voluntary and you can leave at any time.

Do you have any questions before we begin?

#### II. Warm Up (10 minutes)

1. To begin, could you please tell me about your current work with groups that are at increased risk for sexually transmitted infections?

#### Probes:

Sexual health or health communications campaigns



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### III. In-depth Expertise (20 minutes)

THIS SECTION INCLUDES SEPARATE QUESTIONS FOR SYPHILIS COMMUNICATIONS EXPERTS AND EXPERTS WORKING WITH PRIORITY AUDIENCES.

FOR SYPHILIS COMMUNICATIONS EXPERTS ONLY ASK QUESTIONS 2 – 6. SKIP TO QUESTION 7 FOR PRIORITY AUDIENCE EXPERTS.

2. We have read the publications describing the [name] campaign and would be interested to hear more about it from your perspective. Could you tell me about how it was developed?

Probes, reasons behind the chosen:

- Priority audience (focus on MSM if that was key priority audience)
- Strategies
- Components or tactics
- Partnerships
- Spokespeople
- Evaluation
- 3. What worked well with this campaign?
- 4. What didn't work so well with this campaign?
- 5. What external factors affected the campaign positively? Negatively?

Probes:



- Funding
- Community support
- Other
- 6. What lessons can state health departments take from this campaign? The CDC?

#### Probes:

- Working with MSM (unless the focus was on another priority audience)
- Messages
- Tone
- Strategies
- Activities
- Other

#### SECTION III QUESTIONS FOR EXPERTS WORKING WITH PRIORITY AUDIENCES START HERE:

As you know, we are gathering information about [specify their priority audience of expertise] because they have a high rate of syphilis nationally, and therefore they may be a priority audience for a communication campaign to encourage people to get tested and treated for syphilis.

- 7. Could you please describe for me the most common mindset of [priority audience] when it comes to sexual health?
- 8. What do you think [priority audience] generally feel about syphilis?
- 9. What do you think most [priority audience] currently know about syphilis?



10. What don't [priority audience] know about syphilis? What questions might they have about syphilis?
11. What would they be open to hearing about syphilis through a communication campaign sponsored by the state department of health?
IV. Outreach Strategies (20 minutes)
12. In general, what are some of the best ways you know to reach [specify priority audience] and get them to take action?
Probe:  • Working with family or friends
13. What barriers are there to syphilis prevention today?
<ul> <li>Probes:</li> <li>Barriers for priority groups</li> <li>Barriers related to social marketing or communication campaigns</li> <li>Testing</li> <li>Treatment</li> </ul>
14. What opportunities are there for syphilis prevention today?



#### Probes:

- Opportunities for priority groups
- Opportunities related to social marketing or communication campaigns
- Testing
- Treatment
- 15. What characteristics of [priority audience] might be relevant to the development of a syphilis prevention campaign?

## V. Messengers (10 minutes)

- 16. Thinking of potential messengers or even specific spokespeople, what type of person could resonate with [priority audience]? Put another way, what sort of messenger or spokesperson do you think could deliver a message to [priority audience] in an impactful way?
- 17. Thinking specifically about partnerships, what guidance do you have for state campaign planners as they try to reach the public about syphilis?

#### Probe:

- What organizations would be good partners for a syphilis communication campaign reaching out to [priority audience]?
- When creating partnerships to support a campaign, is there an approach you might recommend (e.g., hosting a meeting with all community organizations to discuss a campaign vs. meeting one-on-one)?



### VI. Wrap Up (2 minutes)

18. What other advice do you have for state campaign planners as they try to reach the public about syphilis? For the CDC?

Thank you for your participation and opinions today. Your thoughts are going to help shape this syphilis communication project at the state and national level. We will be sending you a \$100 Amazon gift card by email. If you don't receive it within a week, please check your junk mail and then contact us so we can make sure you get it. Thanks again.

## **Key Informant Interviews Guide: Syphilis Campaign Leaders**

### I. Introduction (8 minutes)

Hello, my name is \_\_\_\_\_\_, and I will be conducting this interview today. Thank you for taking time out of your schedule to talk with me. This interview is sponsored by the Centers for Disease Control and Prevention or CDC to help them learn more about the work you are doing that could inform syphilis communication efforts in other areas of the country. I am not with the CDC. I am a consultant who talks with people about all sorts of things—not just health, but many different topics for a variety of organizations.

This interview will take no more than an hour and everything that you say will be confidential. This conversation will be audio recorded, although you should know that your remarks will never be associated with your name or identifying information. I also have a colleague on the line with me who will be taking notes to ensure we're capturing everything. We will not share our notes, the recording, or any identifying information with the CDC. What we gather from this interview will be added to the learnings from our other interviews and summarized in a report.

As a reminder, your participation in this interview is voluntary and you can leave at any time.

Do you have any questions before we begin?



### II. Warm Up (10 minutes)

1. To begin, it would be great if you could tell me a little about the work you do.

### III. Current Syphilis Campaign (20 minutes)

Now I'd like to ask you to tell me about the [name of syphilis campaign] that [you are working on, worked on].

- 2. How did you arrive at the priority audience that you are focusing on?
- 3. How did you arrive at your main strategies?
- 4. How did you arrive at the tactics you are using?
- 5. Have you formed any partnerships? How do they work?

#### Probe:

- Is there an approach you might recommend for partnerships?
- 6. Do you use any spokespeople? How does that work?

#### Probe:

 Are there national spokespeople that you would suggest using for a syphilis campaign?



7. What type of evaluation are you able to do, if any?

### IV. Guidance for Campaign Planners (20 minutes)

- 8. What barriers did you face in developing this campaign?
- 9. What opportunities presented themselves as you developed this campaign?
- 10. What do you think this campaign has gotten right so far?
- 11. What do you think this campaign did not get right initially?
- 12. What external factors have affected the campaign positively? Negatively?
- 13. Thinking about the campaign messages, strategies, and activities, what lessons can state health departments take from this campaign? The CDC?

## V. Wrap Up (2 minutes)

14. What other advice do you have for state campaign planners as they try to reach the public about syphilis? For the CDC?

Thank you for your participation and opinions today. Your thoughts are going to help shape this syphilis communication project at the state and national level. We will be sending you a \$100 Amazon gift card by email. If you don't receive it within a week, please check your junk mail and then contact us so we can make sure you get it. Thanks again.



# Interviews with Interested/Informed Parties for State Health Communication Campaigns

#### Guide

Hello, my name is \_\_\_\_\_\_, and I will be conducting this interview today. Thank you for taking time out of your schedule to talk with me. This interview is sponsored by the Association of State and Territorial Health Officials or ASTHO and the Centers for Disease Control and Prevention or CDC. These organizations are working together with the [state] department of health from participating sites to support the development of a campaign to help reduce the sexually transmitted infection syphilis. I am not with ASTHO or CDC. I am a consultant who talks with people about all sorts of things—not just health, but many different topics for a variety of organizations.

This interview will take no more than an hour and everything that you say will be confidential. This conversation will be audio recorded, although you should know that your remarks will never be associated with your name or identifying information. I also have a colleague on the line with me who will be taking notes to ensure we're capturing everything. We will not share our notes, the recording, or any identifying information with the CDC or ASTHO. What we gather from this interview will be added to the learnings from our other interviews and summarized in a report.

As a reminder, your participation in this interview is voluntary and you can leave at any time.

Do you have any questions before we begin?

## II. Warm Up (10 minutes)

1. To begin, could you please tell me about your work?



2.	Have you ever been involved with any effort to promote health in [state]?
	Are you aware of any current or previous efforts to address syphilis within [state or region]? Can you describe it briefly?
	Probes:  • Approach  • Outcomes  • External factors
III. Strength	ns, Weaknesses, Opportunities, Threats (15 minutes)
	What internal strengths does [state] have for supporting a syphilis prevention communication campaign?
	Probe:  • What opportunities are there for a syphilis prevention communication campaign in [state]?
	What external factors, or issues outside the health department that is planning the campaign, might affect the campaign positively?
6.	What internal weaknesses does [state] have that could affect a syphilis prevention communication campaign?



#### Probe:

- What barriers are there to conducting a successful syphilis prevention communication campaign in [state]?
- 7. What external threats, or issues outside the health department that is planning the campaign, that might affect the campaign negatively?

## IV. Audience (15 minutes)

- 8. What group in [state] would you say is the most urgent group to address with a syphilis prevention campaign? Why?
- 9. What characteristics of [chosen priority audience] might be relevant to the development of a campaign with the message to get tested and treated for syphilis?
- 10. Thinking specifically about partnerships, what guidance do you have for the campaign planners at the [state] department of health as they try to reach the public about syphilis?
- 11. Are there any state or local messengers or spokespeople who could effectively reach [chosen audience]? Who?
- 12. Thinking of organizations or brands that could effectively reach [chosen audience], which might be a good partner for a communication campaign about STIs?

### V. Wrap Up (2 minutes)



13. What other advice do you have for [state] campaign planners as they try to reach people in [state] about syphilis?

Thank you for your participation and opinions today. Your thoughts are going to help shape this syphilis communication project at the state and national level. We will be sending you a \$100 Amazon gift card by email. If you don't receive it within a week, please check your junk mail and then contact us so we can make sure you get it. Thanks again.