Data driven messaging to increase participation in HIV cluster detection and response

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Study Team and Partners

Community Partner: **Public Health Seattle and King County (PHSKC)**

Study team:
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- Richard Lechtenberg
- Julia Dombrowski
- Joshua Herbeck
- Matthew Golden
Background

• The focus of molecular HIV surveillance has shifted from drug resistance to cluster detection and response (CDR)
• No RCTs to support the use of CDR in reducing HIV transmission
• People living with HIV (PLWH) and advocacy groups have voiced concerns and calls to halt MHS/CDR
  • Ethical concerns: Privacy, criminalization
• CDR is part of Pillar 4 (Respond) of the Ending the HIV Epidemic Initiative
• No structured community engagement process around CDR
Aims

1. To better understand local community awareness of and concerns about CDR
2. To develop a video to increase engagement CDR in King County, WA
3. To evaluate the video’s impact on acceptability of CDR and willingness to engage in CDR
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Implementation Science Methodologies

• **EBI:** HIV Cluster detection and response
• **Implementation strategies**
  • Capture and use local knowledge
  • Obtain and use consumer feedback
  • Develop educational materials
  • Use of mass media
• **Implementation outcomes measured**
  • Acceptability of CDR
  • Appropriateness of CDR

Formative work: Key informant interviews and focus group discussions
Educational video
Online survey

*Ending the HIV Epidemic*
Methods: Formative work

- Key informant interviews (KII) and focus group discussions (FGD)
  - Data collection by zoom
    - MSM and transgender women
    - Oversampled Latinx individuals and those in 25-45 age group
  - Recorded interviews and FGD: transcription and notes
- Rapid coding and analysis to identify salient themes
Formative Work: Methods

Adapted interview guide from 2019 EHE supplement project

- Awareness of MHS and CDR
- How to message to the community

Added social marketing questions:

- Is there a better/simpler/easier way of saying molecular HIV surveillance?
- Is there a better/simpler/easier way of saying HIV cluster detection?
Methods: Video Evaluation

• Brief pre-/post-video online survey (RedCAP)
• Participants
  • MSM and transgender women
  • People with HIV and without (most taking PrEP)
  • English and Spanish versions
• Recruitment
  • Madison Clinic (UW HIV Clinic)
  • PHSKC Sexual Health Clinic PrEP program
  • Entre Hermanos
  • PHSKC DIS
• $30 digital gift card incentive
Formative work: Results

<table>
<thead>
<tr>
<th></th>
<th>KII: N=10</th>
<th>FGD: N=18</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>MSM</td>
<td>Transgender women</td>
</tr>
<tr>
<td>Latinx</td>
<td>11</td>
<td>2</td>
</tr>
<tr>
<td>Black/African American</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Asian</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>White</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>24</strong></td>
<td><strong>4</strong></td>
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</table>
Is there a better/simpler/easier way of saying molecular HIV surveillance that would make it more understandable and acceptable?
Is there a better/simpler/easier way of saying molecular HIV surveillance that would make it more understandable and acceptable?

HIV tracing
Key topic areas: HIV Tracing Video

**Explain**
- HIV tracing
- The steps of HIV tracing
- The different ways clusters are identified
- How HIV tracing fits with EHE
- The goal of HIV tracing (prevent new HIV transmissions)

**Address concerns**
- Assure confidentiality/safety/privacy
- Address immigration concerns
- Discuss the services, resources, and information provided during the CDR
- Address fear and stigma related to HIV tracing
- Acknowledge community perspectives
The plan to end the HIV epidemic
Results– Video Evaluation

N = 87 participants

Participant Characteristics

<table>
<thead>
<tr>
<th>Category</th>
<th>Total</th>
<th>English</th>
<th>Spanish</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living with HIV</td>
<td>51</td>
<td>65</td>
<td>13</td>
</tr>
<tr>
<td>Taking PrEP</td>
<td>33</td>
<td>25</td>
<td>54</td>
</tr>
<tr>
<td>Other</td>
<td>15</td>
<td>10</td>
<td>33</td>
</tr>
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</table>

N = 87 63 24
PRE-VIDEO RESPONSES
Pre-Video Responses Re: HIV Tracing

Do you think that Public Health - Seattle and King County should contact people who are a part of HIV outbreaks, or clusters?

- Should PHSKC contact cluster members? YES
- Contacting cluster members very important
- How likely is it that you would respond?

- Living with HIV
- PrEP
- Other
- English
- Spanish
Pre-Video Responses Re: HIV Tracing

One a scale of 1-5, where 1 is not important at all, and 5 is very important, how important do you think it is that the health department contacts people who are part of HIV outbreaks or clusters? [\% responding “very important”]

<table>
<thead>
<tr>
<th>Should PHSKC contact cluster members? YES</th>
<th>Contacting cluster members very important</th>
<th>How likely is it that you would respond?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living with HIV</td>
<td>PrEP/Other</td>
<td>Other</td>
</tr>
<tr>
<td>78</td>
<td>83</td>
<td>73</td>
</tr>
</tbody>
</table>
Pre-Video Responses Re: HIV Tracing

On a scale of 1-5 (where 1 is not at all likely, and 5 is very likely), how likely would you be to respond to public health if they contacted you and informed you that you were part of an HIV cluster? [% responding “very likely”]

- Should PHSKC contact cluster members? YES: Living with HIV - 78, PrEP/Other - 83
- Contacting cluster members very important: Living with HIV - 73, PrEP/Other - 79, English - 64, Spanish - 67
- How likely is it that you would respond? Very likely: Living with HIV - 57, PrEP/Other - 66, Other - 36, English - 59, Spanish - 50
POST-VIDEO RESPONSES
Should Public Health Contact People Who Are in Clusters?

Percent

<table>
<thead>
<tr>
<th>Percent</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>91</td>
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</tbody>
</table>

Pre-video
Post-video
Should Public Health Contact People Who Are in Clusters?

<table>
<thead>
<tr>
<th>Percent</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-video</td>
<td>91</td>
</tr>
<tr>
<td>Post-video</td>
<td>97</td>
</tr>
</tbody>
</table>

- Pre-video: 91%
- Post-video: 97%
Post-Video: Responding to PH

After watching the video on HIV cluster response, are you more or less likely to respond to public health if they contacted you and informed you that you were part of HIV cluster? (Less likely, the same, more likely)
Acceptability of HIV Tracing

On a scale of 1-5 (where 1 is not at all acceptable, and 5 is very acceptable), how acceptable are the activities described in the video, for example, identifying HIV clusters and contacting people in the clusters to make sure they're in HIV care, or to connect them to services? [% Very acceptable]
After watching this video, on a scale of 1-5 (where 1 is not at all concerned, and 5 is very concerned), how concerned are you that the information that the health department might collect about you is not confidential or private? [% Very concerned]
Results summary

• >90% participants supported PHSKC contacting people who were part of clusters
• A smaller proportion (36-66%) said they were very likely to respond to PHSKC contact about a cluster investigation
• Most changes in responses after watching the video were in a positive direction
• 85% of respondents said that HIV Tracing activities were very acceptable after watching the video
Limitations

- Formative data may not be representative of populations in other areas of the country or other communities.
- Interviews and FGD conducted in English only.
- A large proportion of the KII were with people who had been living with HIV for many years.
- Limits on material that can be covered in 3-5 minute video.
- Small numbers of people who were not living with HIV or taking PrEP completed the evaluation survey.
Conclusions

• Tension between community wanting more information and public health concern over providing too much information
  • What is the right amount of transparency?
• Need for conversations across the divide (community and PH)
• How has the pandemic affected the public’s understanding of public health surveillance and contact tracing?
  • Can we capitalize on this?
Acknowledgements

- FGD, KII, survey participants
- Mike Barry
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- Alex Topper
- Cheryl Malinski
- Emmanuel Rodriguez
- Entre Hermanos
- UW-Fred Hutch CFAR
- C+C
WATCH THE VIDEOS

English Video: https://www.youtube.com/watch?v=330Md1lVrLI&t

Spanish video: https://www.youtube.com/watch?v=MSb5n2_mDvs&t
Thank you

rkerani@uw.edu
Cluster detection and response

EHE funding improved our ability to identify clusters of people living with HIV and offer them HIV testing and PrEP or HIV care services.

Watch a video to learn more.
Video format

Trusted messenger(s)

1. Epidemiologist – What is HIV tracing?
2. DIS – Why do HIV tracing?
3. Person living with HIV – What is the HIV tracing experience?
Support for CDR

• “I feel very comfortable with it. I strongly agree with it if it'll help to slow down the spread or even stop the spread of HIV. I think that it's a good thing.”  
  *African American transgender woman*

• “You got me at the get go, saying that we're almost there [with ending the HIV epidemic]. We got to get rid of this. That's enough for me.”  
  *African American MSM.*

• “That's going to be a preventive measure that's going to allow them to reach their goal. And, you know, getting those percentages down in the time frame that they want. I think it's a good thing.”  
  *White MSM*
Concerns about CDR

• “Retribution is the term, I'm thinking. That you're going to be targeted. That you are going to be persecuted.” *White MSM*

• “Well, I'm from [another state]. And they're not really known for being forward in their thinking about things like this. ....I am scared of - I would be scared as a gay man to be in a situation there. I'm not as trusting of the government there as I am here. If you could find a way to make sure that the [privacy] rules were followed more closely in those places, I think it would be less of a concern to me.” *White MSM*
Post-Video Responses: Concern about Confidentiality

After watching this video, on a scale of 1-5 (where 1 is not at all concerned, and 5 is very concerned), how concerned are you that the information that the health department might collect about you is not confidential or private? [% Very/slightly concerned]