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Strengthening Outreach and Engagement with Underserved Populations through CABs

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Agenda

- About NASTAD
- Objectives
- CAB Overview and Considerations
- Guest Speakers (x2)
- Q&A
- Closing

About NASTAD

- **WHO:** A non-profit association founded in 1992 that represents public health officials who administer HIV and hepatitis programs funded by state and federal governments.
- **WHERE:** All 50 U.S. states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, seven local jurisdictions receiving direct funding from the Centers for Disease Control and Prevention (CDC), and the U.S. Pacific Islands.
- **HOW:** Interpret and influence policies, conduct trainings, offer technical assistance, and provide advocacy mobilization for U.S. health departments.

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OBJECTIVES

- Increase knowledge and enhance strategies to strengthen outreach and engagement with underserved populations through CABs
- Explain 2-3 benefits and opportunities of having a prevention CAB
- Identify 2-3 important considerations and best practices for developing and implementing a successful CAB
- Strategize at least one next step for developing a CAB

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Community Advisory Boards

Community Advisory Boards

> “Community advisory boards (CABs) serve as a voice for the community and local study participants. CABs provide input into study design and local study procedures. CABs work to ensure that research strategies acknowledge and respect the values and cultural/ethnic differences among participants”

https://www.hptn.org/community/community-toolbox/faq/what-a-community-advisory-board

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CAB Benefits

CABs provide opportunities for meaningful community engagement

Helps identify and bring attention to issues and concerns in the community

Maximizes program and service outcomes – community members are the experts

Lead as a collective

Development Considerations

IDENTIFYING EXPECTATIONS & LIMITATIONS

Be clear and explicit about what you understand the expectations and limitations to be, such as time constraints, finances, and resources available.

What issues are not up for discussion, for example, legislative framework, decisions already made, confidential information, or available budgets and resources?

Some of these stated expectations and limitations may be challenged and you should be prepared to explain why they exist.

Think SMARTIE!

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Example Community Agreements

In this space, we agree to:

Manage our technology	Respect different opinions	“Say it Ugly”	Own both intention and impact	Use “I” Statements
ELMO (Enough Let’s Move On)	Be comfortable in silence	Make space, take space	Maintain a “brave” space	Respect different levels of experience and progress
Be accountable to each other and ourselves	Ask questions, even when feeling uncertain	Ask clarifying questions	Practice compassion for each other and ourselves	

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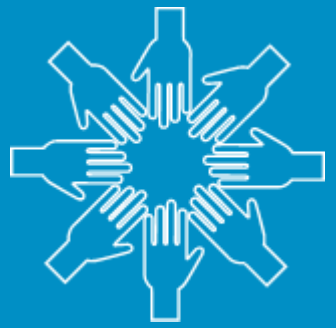

CAB Topics

CAB members can provide valuable insight and feedback on many aspects of an HIV prevention program, these include but are not limited to:

- Marketing materials
- Testing locations
- Event ideas
  - Logistics (location and time)
  - Incentives
  - Knowledge of existing community special events
- Program implementation and development
  - Brainstorm ideas
  - Project promotion

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CAB Participation

Who should be part of a CAB?

- Individuals representative of your program's priority population
- Individual's utilizing your services
- Community leaders
  - Opinion leader community members respect (example: elders, night life leaders, performers, etc.)
- Individuals impacted by HIV/AIDS

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WHY REPRESENTATION MATTERS

The description or portrayal of individuals, populations, and communities, as well as, societal norms.

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https://www.oxfordlearnersdictionaries.com/us/definition/english/representation?q=representation

CAB Facilitators

- Individuals representative of the community
- Ideally having two facilitators to support the CAB
  - Meeting facilitation
  - Logistics support
  - Member recruitment
- Prioritizing the CAB as a part of their role
- Helps define goals and expectations of the group

Maintaining a CAB requires commitment

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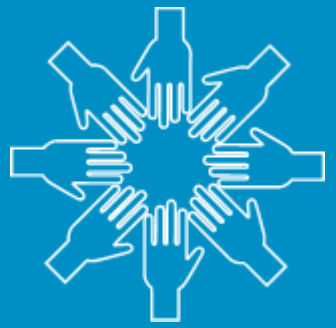

Size

- Quality of input vs the quantity
- Budget– how many people can the budget accommodate to help with transportation needs and meals.

Smaller CABs

- Best for CABs focused on a single issue
- Easier to manage discussions and meeting logistics
- Low attendance may lead to very small or cancelled meetings

Larger CABs

- Best for CABs with a broader scope
- Allows for a CAB with a larger variety of lived experiences and profession fields
- Easier to maintain active CAB meetings even with lower attendance

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https://www.hsph.harvard.edu/isccce/wp-content/uploads/sites/2575/2024/02/Community-Health-Center-Community-Advisory-Board-Toolkit.pdf

Meeting Frequency

- **Try to find a “sweet spot”**
- **Be consistent**

- Organization capacity
- Meeting times may vary

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CAB Marketing and Recruitment

- Work with facilitators and prospective members on a name for the CAB.
- Consider a variety of recruitment strategies, such as word-of-mouth, social media, and recommendations from staff and other clients.
  - QR Codes, outreach events, palm cards/ flyers
- Clearly share expectations and goal of the CAB during recruitment.

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Successful Practices for Effective CABs.

Assessing CAB Members

- Seek information from CAB members on:
- Time(s) and date(s) that works for them
- Topics/ activities that the CAB members can contribute their insights and expertise
- CAB participation barriers / opportunities to strengthen participation
- Transportation
- Gain input on what they want the goal of the CAB to be
- Create CAB community agreements

After receiving information from CAB members--- honor what they said and be transparent on what can be achieved.

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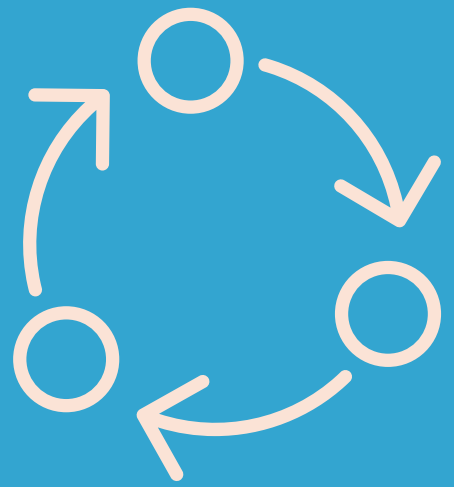
Adjust Accordingly

If something doesn't work, try a different approach.

Make adjustments and be transparent as to why things are changing

Process evaluation can help strengthen the CAB



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Final Reminders and Considerations

Meeting Experience

- Trust and listen to community member’s expertise
- Provide a meal, preferably a warm meal, for CAB meetings
- Pay participants if possible
- They are taking time to provide guidance to your program
- Value participants time and investment– make sure they know they are appreciated.
- Provide opportunities for individuals to GROW
- Leadership development
- Guest facilitation
- Certificates of participation annually to recognize CAB members' contributions and insights

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PERSON-CENTERED LANGUAGE

Linguistic prescription to avoid marginalization and dehumanization regarding a health issue or disability

BEST PRACTICES:

- Don't describe people by their illness/disability/drug use (addict, alcoholic, epileptic, psychotic)
- Recognize the complexity/many identities people have
- Don't use morally-loaded descriptions when describing someone (infected, dirty, clean, junkie, bad blood, hobo, carrier)
- Avoid using group/illness/disability language to describe negative states (gypped, retarded, crazy, spaz)
- Value the preferences of the person, rather than your opinion (addict as self-identification vs. label, or sex worker)
- Language is powerful – it can build bridges or marginalize

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APPROACHING UNDERREPRESENTED COMMUNITIES

Don't Assume

QUESTIONS YOU CAN ASK:

What do they care most about? What are they most concerned about?

Why do they/should they care about your goals?

How have you previously engaged this group ? How engaged are they?

What are you asking of them?

What barriers might they face with engaging with you?

What is best way to approach and engage them?

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https://collectiveimpactforum.org/sites/default/files/Community%20Engagement%20Toolkit.pdf

NEXT STEPS

Now that you know some best practices and considerations for developing a CAB:

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Thank you!

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Family Health Centers at NYU Langone

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FAMILY HEALTH CENTERS AT NYU LANGONE

FAMILY HEALTH CENTERS AT NYU LANGONE

COMMUNITY ADVISORY BOARD

PRESENTER: MITCHELL CAPONI, MPH
NETWORK HIV DIRECTOR

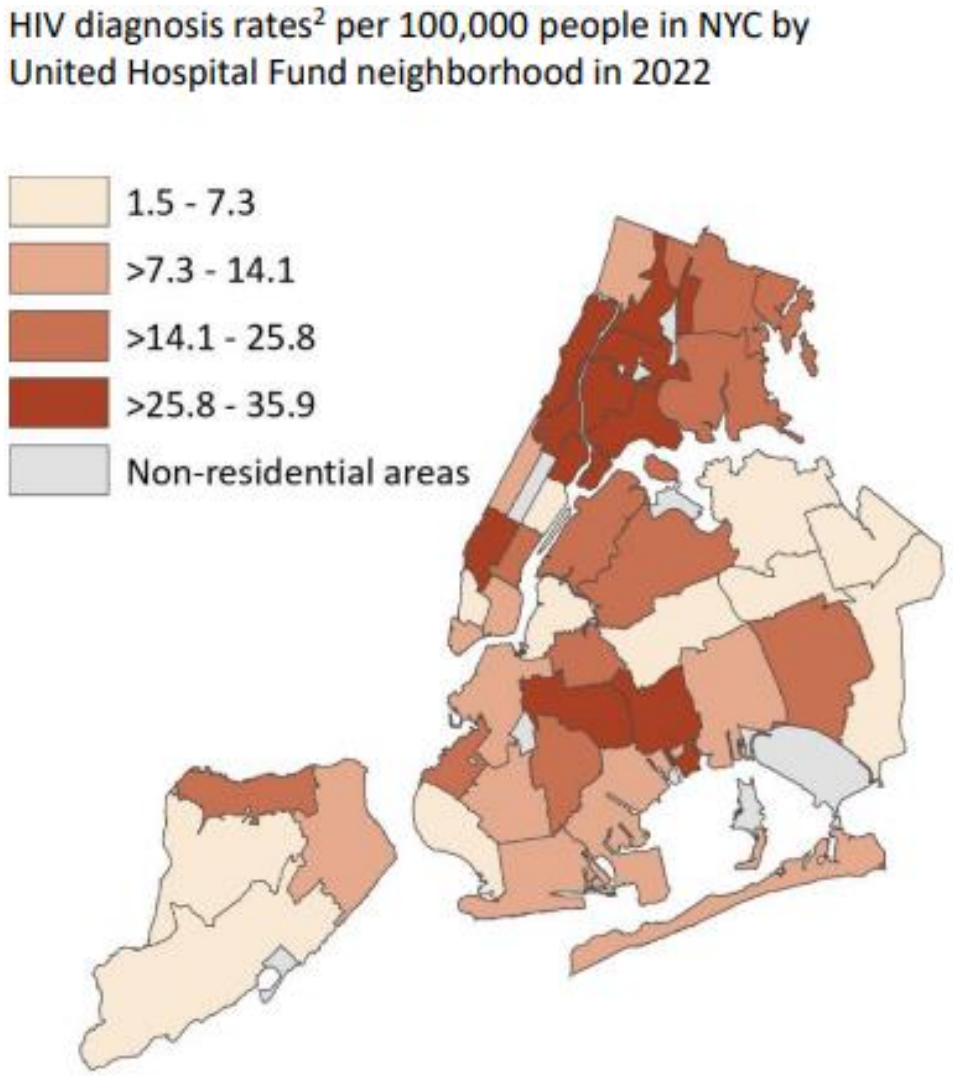
Family Health Centers at NYU Langone (FHC)

FHC is a large federally qualified health center network that serves a largely immigrant, people of color, low income, and English as a second language patient population in Brooklyn, New York. Brooklyn is the largest Borough in NYC.

- Established in 1967 (formerly known as Lutheran Family Health Centers)
- Affiliated with NYU Langone Health hospital system
- Primarily serves Sunset Park, Park Slope, and Flatbush neighborhoods of Brooklyn
- Ryan White program active since 1990
- 600+ patients currently active in HIV care
- The FHC serves over 100,000 patients annually

FAMILY HEALTH CENTERS AT NYU LANGONE

Epidemiologic Overview of the Jurisdiction



- Neighborhoods served by the FHC have an HIV prevalence ranging from 7.3 per 100,000 up to 35.9 per 100,000—much higher than the national average. Prevalence of chronic hepatitis C ranges from 47.9 per 100,000 to 51.5 per 100,000
- In 2022, Sunset Park had the second highest rate of chronic hepatitis B in the city, at 290.03 per 100,000. As such, FHC is well positioned to intervene to provide HIV Prevention methods such as condom distribution, PEP, PrEP, and health education. In addition to being able to diagnose cases of HIV, HCV, and HBV and to link patients to appropriate care

.
https://www.nyc.gov/assets/doh/downloads/pdf/dires/hiv-surveillance-annualreport-2022.pdf

FAMILY HEALTH CENTERS AT NYU LANGONE

HIV/STIs in Brooklyn

- In 2022, 1,624 people were newly diagnosed with HIV in New York City
- According to 2022 data from DOHMH, Brooklyn remains the Borough in NYC with the highest rate of newly diagnosed HIV with over 451 cases as well as 18% concurrent AIDS diagnosis.
- In addition to HIV risk, Brooklyn has the highest death rate among people with HIV in NYC.
- In 2022, Brooklyn had the highest rates of newly diagnosed Gonorrhea and Chlamydia in both New York City and New York State.

FAMILY HEALTH CENTERS AT NYU LANGONE

Who Are We?

- Our CAB is made up of current HIV+ patients
  - Currently our CAB has 10 members
- The CAB currently meets quarterly
  - With more Ad Hoc sessions around planning events
    - World AIDS Day
    - Pride
- Bi-directional information sharing
  - Reporting
- Priority Setting/Projects
  - Sexual Wellness Screening Tool

FAMILY HEALTH CENTERS AT NYU LANGONE

FAMILY HEALTH CENTERS AT NYU LANGONE

THANK YOU!

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Tyler Huynh, MPH

HIV CDR Community Advisory Board for CDPH

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EXPERIENCES WITH THE CALIFORNIA HIV CLUSTER DETECTION AND RESPONSE CAB

Tyler Huynh

California DPH HIV CDR Community Advisory Board

NASTAD/CDC HIV CDR Community Partners Panel

PERSONAL INVOLVEMENT WITH THE CAB

- Applications for first cohort disseminated thru community partners, DPH communications, and social media in August 2022
- Applied while UCLA undergraduate student involved in on-campus and Los Angeles community organizing, especially for sexual and gender health, as well as in substance use counseling
- Through first meetings, learned about basics of CDR, current status of HIV epidemic in California, discussed elements of confidentiality/stigma, met w/ health departments from Los Angeles and San Francisco
- In 2023, became a member of the NASTAD/CDC national CPP
- Attended 2023 and 2024 CDR Summit

CAB ONBOARDING

- Introduction to various aspects of CDR throughout first year of CAB meetings
- Member expectations/goals
- Guided discussion of prioritization of topics
- Quarterly required meetings w/ aditionl ad hoc meetings
- Currently 8 members, inc. people living w/ HIV, medical practitioners, community organization members, university professors, etc.

INTRODUCTION TO CDR TOPICS

- Targeted towards all knowledge levels, informed by member surveys
- CDR Program summaries: LADPH, SFDPH, CADPH
- Introduction to CDR: Molecular HIV Surveillance, Time-Space Surveillance, Partner Services
- Member-level, Cluster-level, Programmatic response

MEMBER-LED TOPICS/INPUT

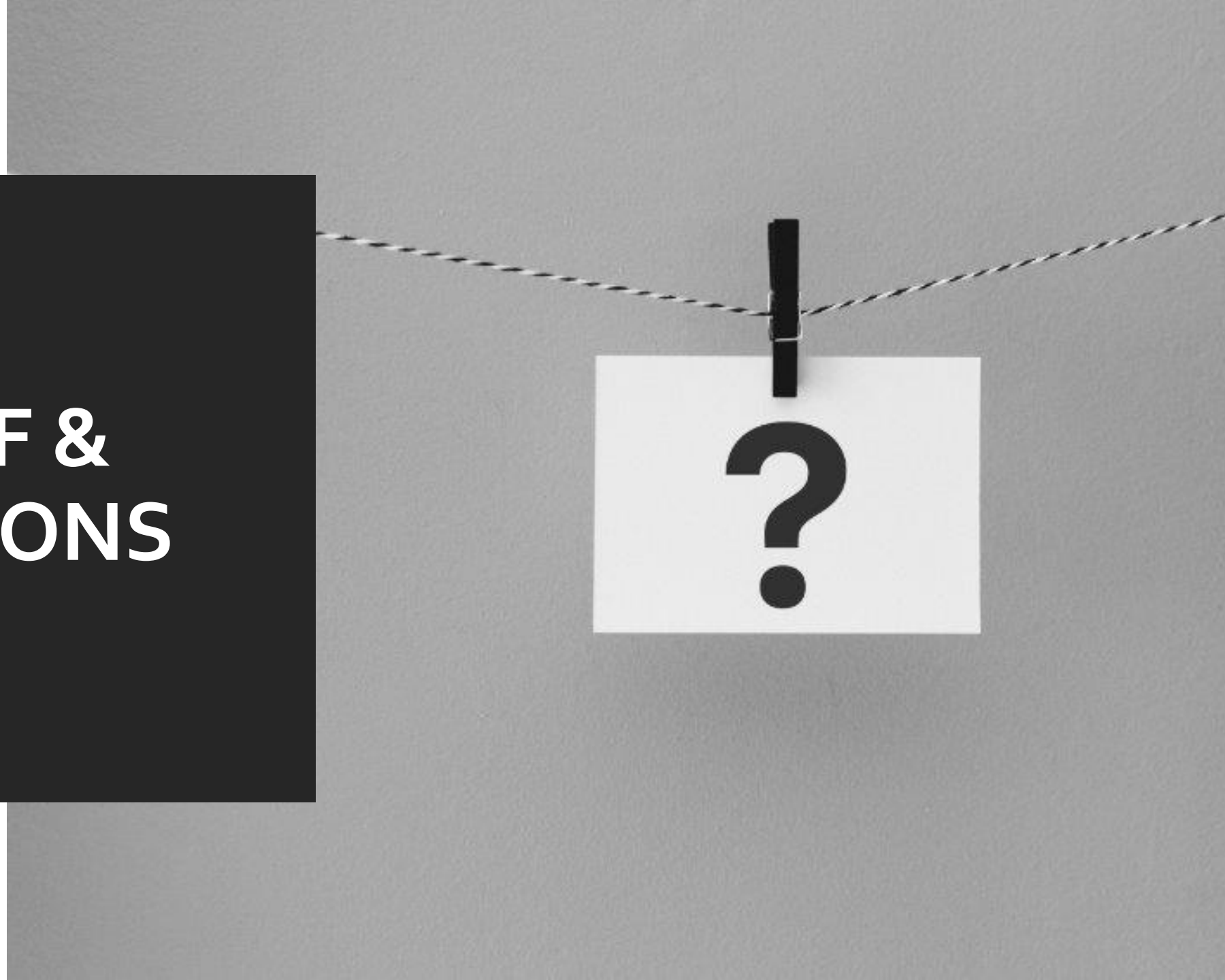
- Data privacy presentation and discussion: What would members like to see in terms of privacy and surveillance? How can respect and transparency be conveyed in communication?
- Stigma and misinformation discussion: How to combat stigma? How can health departments best use language (e.g. "cluster) to avoid perpetuating stigma?
- Town hall meeting with members asked to invite partners from their community/organizations

- How do you feel about language like: “molecular”, “surveillance”?
- What do you think about using words like “cluster” or “outbreak” when the health department is talking to individuals who are part of a cluster? Examples:
  - “The type of HIV in your body is similar to others indicating you may be part of a larger cluster where HIV transmission is occurring…”
  - “We are trying to prevent a large scale HIV outbreak…”
- Is it important for the health department to tell people that they are part of a cluster OR part of a group of people where HIV transmission is occurring?
  - Why or why not?
  - If yes, when should this information be introduced?
  - If yes, how much information should be communicated initially vs. to those who would like to know more? (E.g., “You may be a member of a group of people with diagnoses that may be related. If you would like to know more details about this, I am happy to share that.”)
- What can be done to avoid stigma when discussing clusters with individuals?

RECOMMENDATIONS FOR CAB

- Those who already have positional privilege (i.e. those who need less intervention) are the most likely to join by default
- Compensation/incentive important to reach most underserved populations
- Consider which avenues are most likely to reach target audience e.g. homeless population may use local FQHC as mailing address
- Allow opportunities for CAB members and their associates to attend events, network w/ health departments and associated bodies, and join other advisory panels or groups

DEBRIEF & QUESTIONS



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Resources

- Center for Health Care Strategies- Best Practices for Convening a Consumer Advisory Board
- Tips for Developing a CAB
- What is an Advisory Board and Should We Have One?
- NASTAD CBO Hub
- Community Engagement Toolkit
- Principles of Community Engagement

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Contact Information

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Thank you!