# The Community is the Cure: How African-American Washington, DC Residents Informed Opioid Treatment Engagement

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#### ABSTRACT

**Background**: Recent data indicate rising opioid overdose deaths among African-American residents of Washington, DC.

**Objectives**: We highlight a community-informed approach to assessing attitudes toward opioid use disorder (OUD) treatment among DC residents (February 2019 – March 2020).

**Methods**: A listening tour with trusted community leaders led to the formation of a Community Advisory Board (CAB). When the COVID-19 pandemic commenced in March 2020, community dialogues became exclusively virtual. The CAB partnered with academic leaders to co-create project mission and values and center the community's concerns related to opioid use and its causes, treatment structure, and facilitators of effective engagement.

**Results**: Interview guides were created for the engagement of community members, utilizing values highlighted by the CAB. The CAB underscored that in addition to opioid problems, effective engagement must address community experience, collective strengths/resilience, and the role of indigenous leadership. **Conclusions**: Engaging community prior to project implementation and maintaining alignment with community values facilitated OUD assessments. Community-informed assessments may be critical to building community trust.

**KEYWORDS:** Community-Based Participatory Research, Community health partnerships, Power sharing, Substance-Related Disorders, Social Change

#### BACKGROUND

The opioid overdose epidemic is increasingly affecting urban, predominantly minority populations in the U.S., including Washington, D.C., as indicated by rapidly increasing overdoses clustered in medically underserved, economically disadvantaged, largely African-American areas of the District of Columbia and many of the nation's largest cities (1-3). A major contributor to opioid fatalities nationally is the limited reach or low utilization of medications for opioid use disorder (MOUD), with less than 25% of persons with opioid use disorder (OUD) having received treatment for OUD in the past year (4). The problem is particularly severe for African Americans, who, despite a generally comparable prevalence of OUD, are 47-77% less likely than White Americans to receive OUD treatment (5-9).

Highlighting concerns about low OUD treatment utilization in U.S. cities, Washington, D.C. has experienced one of the fastest increases in opioid-related mortality in the U.S., with rates at least doubling every two years since 2014 (10). African-American residents bear a disproportionate burden of opioid overdose mortality with 73.9 deaths per 100,000 compared to 8.7 per 100,000 among Hispanic residents and 9.1 per 100,000 among White residents (11). The city is divided into eight geopolitical wards. Most recent census data indicate that, combined, DC Wards 7 and 8 make up about 20% of the city's total population age 18 year or older (12). However, these two wards accounted for 46% of the District's opioid overdose deaths in 2020 (13). These wards have predominantly African-American populations (>91%) (12). More than 20% of residents in these wards live below the poverty line (12). Proximity to health care options further compromises these communities (14). Stigma, fears associated with harsh drug laws, institutional mistrust, lack of knowledge and negative attitudes about medication treatments, and lack of recovery resources limit the reach and effectiveness of treatment and compound OUD health care disparities (15, 16). These factors are evidence of the ways in which health inequities are socio-politically determined.

Despite these challenges, these communities also bring significant strengths that can be brought to bear on the problems. Fully leveraging community resources will be essential to stemming the tide of

OUD disparities and the associated morbidity and mortality. These issues and outcomes are embedded in a rich environment of resources and opportunities for enhancing engagement of communities at greatest risk for opioid-related deaths. Potential community-informed solutions may include community-engaged health promotion activities, which have been effective in addressing health disparities among African Americans (17-22) or potentially expanding OUD treatment models to include interventions in nontraditional community settings.

#### **OBJECTIVES**

To address the gaps in OUD treatment engagement for African-American residents of Washington, D.C., faculty at Howard University proposed a community-based participatory research (CBPR) process – the Reach, Engage, Retain Project - to engage community stakeholders and assess feasibility and acceptability of integrating evidence-based interventions, such as low-threshold medication treatment, in non-medical community settings (e.g., churches or religious organizations, social services organizations, or neighborhood barber shops or nail/hair salons). Led by a faculty champion, who embraced her role as Director of Community Engagement and New Program Development, Howard faculty and community members envisioned a community-centered process for each phase of the project: *formative phase, community needs assessment, design and implementation, evaluation, and returning results and resources to the community*.

Here, Howard University faculty and Community Advisory Board (CAB) members report on key activities within the formative and needs assessment phases of our work. This includes conducting a listening tour that culminated in the seating of CAB members and co-creation of the project's mission and values. Mutually agreed upon engagement principles helped shape approaches to building community trust through design of interview templates for use with community members, to gain knowledge about barriers and facilitators of engagement in OUD treatment and recovery services. Creating an interview

approach for discussing opioid problems through community-academic partnership yielded lessons that may be applicable in other contexts.

All study procedures, including project introduction, CAB formation, and interview guide development, were approved by the local Institutional Review Board. CAB members were compensated for their expertise and time.

### **METHODS**

#### Conducting community listening tour, seating CAB, and co-creating project mission and values

Our community engagement process was designed to clarify the experiences of African-American residents of Wards 7 and 8 and identify community-informed approaches for successfully engaging and retaining persons with opioid use disorder in treatment and recovery services. Initial community conversations were launched by a faculty champion who met with a DC-area faith leader who had pastored for over 40 years and functioned as a community guide and connector. This leader assisted the research team in meeting and conducting individual interviews or small group meetings with other faith leaders, mental health clinicians, and community service providers to gather recommendations on ideal strategies for building trust and communicating project milestones. Six small-group dialogues were held. Engaging community before the project started led to the co-creation of project vision and mission statements and ensured the research process operated from an ecologically valid concept of the project and potential solutions.

As a result of the community listening tour (February 2019 – June 2019), six individuals who were active participants during the introductory community discussions and endorsed by trusted community leaders were invited to the CAB (Table 1). Initially, the CAB was chaired by the Howard University faculty champion who had conducted the community listening tour. However, as the project matured, CAB members were invited to participate as community co-chairs, sharing power with faculty

from Howard University. Later, it was jointly decided that the community co-chair position would be on a rotating basis to provide a leadership opportunity for anyone interested. CAB members possessed a range of lived experiences with opioid use and knowledge of community resources, including a person with OUD and taking buprenorphine; the pastor of one of the largest churches in DC Ward 7 with co-located mental health services; the director of a large DC-based non-profit; an economic developer and community organizer; a person in long-term recovery from substance use and the additional lens of motherhood; and a person in recovery from substance use and criminal justice involvement. All CAB members were either residents of Washington, DC or employed within the District. The original charter of the CAB has been included in the Appendix.

#### Co-creating community interview guides

During monthly in-person meetings and intermittent virtual conference calls, the CAB provided detailed commentary and revisions to the interview questions suggested by the research team (July 2019 – March 2020). The COVID-19 pandemic and public health emergency resulted in exclusive use of virtual meetings in Spring 2020 and a delay in beginning the community interview process. Meetings were facilitated by a faculty co-chair and community co-chair; included CAB members, a note-taker, and other academic leaders; and were audiotaped. Quotations included in the Results are based on meeting notes or recordings.

Faculty members suggested a four-part interview structure based on their understanding of community players, including 1) community members in treatment, 2) community members not engaged in treatment, 3) community leaders, and 4) friends/neighbors. The CAB completed a thorough, question-by-question review of all guides over 7 in-person or virtual meetings and utilized an online shared document to communicate suggestions to the research team. Table 2 describes the CAB Interview Assessment Process. Guides for individuals in-treatment vs. not-in-treatment were consolidated into a single template, *interview for individuals with lived experience*, following recognition of the common

experiences of individuals with OUD that did not appear to hinge upon their status with a formal treatment program.

#### RESULTS

**Project mission and values.** The CAB-derived mission and vision statements placed greater emphasis on structural issues and root causes, than on medication treatment, expanding the research team's initial lens for the project scope. Members noted the importance of recognizing the role of social determinants of addiction (23). One member aptly summarized, "...because it all played a part in my addiction." The vision and mission statements reflected these experiences and values: The vision of the Washington, DC "Reach, Engage, Retain" project is for Wards 7&8 to be a healthy, thriving community where residents experience freedom from problems with substance use and addiction. Our mission is to increase access to effective recovery and treatment services; reduce stigma; and deal with the root causes of unhealthy drug use.

*Values-aligned community assessment.* Three interview guides were finalized: *lived experience*, *community leader*, and *family member/neighbor*. Table 3 provides an overview of the CAB's edits and their rationale, for the *lived experience* guide. These changes were reflected across the distinct types of interview guides, along with unique questions for community leaders (summarized in Table 4). The interview questions for family members were largely the same as those in the "lived experience" guide, excepting the removal of questions about drug use and treatment history. Key community values were identified by the CAB and included relationship-focused engagement; community education and empowerment; a strengths-based stance for understanding the community; and project sustainability. Health, social, and economic policy figured prominently into CAB members' conceptualization of the problem of opioid dependence and other addictions. There was consensus that policy solutions needed to be "holistic" representing the multi-faceted nature of addiction. Yet, caution regarding over-reliance on

external players, including policy makers, to solve community problems was expressed. One CAB member remarked,

One of the problems is that the issues that we face are long term. Government can't develop long term strategies. That's not...that's not their agenda. So, we're sitting around here waiting for them to come up with solutions, and they're looking at trying to get re- elected in four years. We've got to develop 20- year strategies.

CAB members clearly and consistently advised that opioid treatment should be considered in the broader context of the community's experience with other social determinants of health. They concluded that the depth, breadth, and history of the problems necessitated structural and social change as part of a path toward long term solutions.

If they don't know, from where they sit, what the real problem is, and they only have a perceived notion of the problem, then the solution oftentimes does not include really the voice of those who are suffering with the problem, or suffering with a challenge, or suffering with whatever the issue or challenge may be.

#### LESSONS LEARNED

*Building trust by communicating participatory values.* The CAB acknowledged a community grappling with a history of oppression and exploitation would have justified concerns about authenticity and motives of the research team. CAB members indicated that a level of trust could begin to be established if respondents knew that the interview was created by members of the community, rather than by researchers, "So the way we build the trust, you know, is simple. People want to know if, you know; you've experienced this before; or how you can relate." Importantly, the introduction to the community interviews stated that CAB members had lived experience with OUD.

*Framing opioid problems within larger community context and concerns.* The CAB also recommended that all interviews begin with a frame of *community first*, and they added probes to clarify how individual experiences are shaped in the context of community. This perspective widely differed from the research team's initial suggestion that interviews begin with a respondent's experience with drug use and treatment. Recognizing the varied ways in which people identify themselves and define their community and that addiction, in part, was an indicator of the health of the community, CAB members recommended beginning the interview with a definition of "community" from the respondent's perspective. As the research team reflected upon the significance of this change, a CAB member commented, "*We have to start with community… because I am a product of my community.*"

*Naming root causes of addiction.* The CAB viewed addiction issues as derived from structural causes, and not solely the fruit of personal choices or problems. As reflected in their reasons for participating in the CAB, members indicated that solutions would be derived not just from community knowledge, but community control of the resources to apply that knowledge. Members conveyed the importance of control of resources.

A lot more can happen when we control resources, because we know as a community, what the problems are. We have the knowledge, we know what the problem is, we just have not been able to have access and control over the resources to come up with and pay for the solutions that we know . . . work. So, I think that's the new frontier for us.

As a result, questions were added about necessary changes to structures and policies to adequately address the root causes of addiction. The CAB recommended that the term "rules," instead of policies, would be more familiar for the participant interview.

Acknowledging therapeutic role of community structure. CAB members challenged the research team to think about holistic solutions to addiction problems, and to avoid leading with concerns about "treatment," especially medication-based therapies. The research team, in turn, had to grapple with its

own sense of powerlessness to fully address structural determinants of substance use. This tension was acknowledged and addressed through frank discussions between community members and academic leaders. Community members gave a resounding answer when asked about their concept of treatment: *The community is the therapy*. The university research team realized that the community's experiences with oppressive structures and an ingrained medical bias that placed the highest value on medication-based interventions would require that the project focus on relational concepts of treatment; according to the CAB, the community itself was the cure.

Adopting a strengths-based view of community. The CAB also recommended that the community be discussed from an asset-based stance. The research team was counseled to emphasize community strengths and to assume that existing community resources and indigenous leadership would be helpful in addressing opioid problems. Several members agreed that,

We've been defined for a long time to be a community of deficits, you know, our whole existence was measured... based on poverty... That's how money came into the community... That's how we saw ourselves... just a community of deficit. And that has all kind of psychological issues that we see play out. To define yourself really means to, you know, create your own reality.

In line with operating from a strengths-based stance, the CAB was also quite interested in understanding the scope of current community interventions. They introduced a new interview question for community leaders that specifically addressed how organizations were measuring their community impact.

Integrating education with community assessment. From the CAB's perspective, the interview was also part of the intervention. They noted that many community members did not associate their heroin addiction with the opioid epidemic. They explained that the word "opioid" was often associated with prescription pain pills and thus classified as *the white people's problem*. Some community members did not know that heroin was also an opioid. The research team was asked to create supplemental materials for use during interviews, explaining the different types of opioids, including heroin and

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fentanyl, and clarifying the current toll on minority communities and especially those living in cities like Washington, DC (10, 24, 25). Additional materials explaining the use, mechanism of action, and availability of medications for treating opioid addiction were integrated into the interview process.

*Creating an empowering context.* The CAB anticipated that each interview would create opportunities for building relationships, sharing knowledge, and thus strengthening the community.

...the interview gives them a chance to be able to speak about things that they probably wouldn't have spoken about to no one else, you know, or it gives them an opportunity to dig deeper to the root causes of some of the problems that they had.... just being conscious of when you create an environment, that you can create an environment that's an empowering environment. You can be conscious of empowering people

#### CONCLUSIONS

Building upon examples of community-informed SUD treatment engagement (17, 18, 26), we have described a CBPR approach for developing a substance use intervention within a population that has, historically, not been well-served by health care systems and experienced social and economic marginalization. Our work adds to a growing body of work focused on the development of collaborative or co-located service models (27). There is increasing recognition of the value of strategically including the community's voice – as in the current study – to build SUD treatment capacity from grassroots to systemic levels.

Changes made to the interview guides ensured that participatory values resonate throughout the data collection process, as each respondent contributes to interview feedback and revisions (28). There are envisioned opportunities to expand upon our engagement framework to build community-based substance use interventions in urban contexts. The interview guides, one of the main products of our CAB, provided a starting place for adapting conversations about addiction to other communities, specifically those

dealing with socioeconomic inequality. The present work emphasizes the criticality of language: what questions we ask and *how* we ask questions informs our approach to identifying root causes and framing solutions. Future CBPR projects on SUD engagement may also find aspects of our approach highly replicable, including the use of a CAB to conceive a project vision, to articulate community values and principles, and to advise on qualitative data generation and interpretation.

Limitations of our engagement approach include reliance on a CAB whose members had largely overcome active-phase SUD and had been in treatment or recovery for a substantial amount of time or had no history of an opioid use disorder. Individuals actively using opioids were not invited to the CAB; a person early in recovery was invited, but ultimately declined out of concern for maintaining abstinence. Community activists and leaders were strongly represented on the CAB and were usually the source of conversations that shifted the intervention frame from one of medication treatment to holistic solutions, such as community development. It is unclear if an advisory board with greater representation of activephase SUD would have similar areas of focus. Certainly, the selection of CAB members must also consider the likelihood of meaningful participation and the presence of psychosocial stability, factors that will be affected by the individual's health and substance use history.

Community members gave a resounding answer when asked about their roles in this process: "*I* think what you all did well was allowed space or gave space to the creation of this whole process. It really was community directed, community driven.... I feel like you all really allowed a safe space for the community members to really give voice and to direct the process." CAB member feedback indicates that community members felt heard and respected as co-creators in a design process. Since March 2020, 74 interviews have been conducted utilizing the CAB-guided assessment approach. Not only were products created to be more attuned to the views and experiences of potential respondents, but the interview guide development process also established a standard for how the collaboration would operate overall.

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### References

1. Substance Abuse and Mental Health Services Administration: The Opioid Crisis and the Black/African American Population: An Urgent Issue. Publication. Publication No. PEP20-05-02-001. Office of Behavioral Health Equity. Substance Abuse and Mental Health Services Administration; 2020.

2. Lippold KM, Jones CM, Olsen EO, Giroir BP. Racial/Ethnic and Age Group Differences in Opioid and Synthetic Opioid–Involved Overdose Deaths Among Adults Aged ≥18 Years in Metropolitan Areas — United States, 2015–2017. Morb Mortal Wkly Rep. 2019;68:967–973(967–973).

3. Leak CR, Medlock M, Beebe-Aryee J, Harper-Nichols T, Hardin C. Opioid Fatality Review Board 2019 Annual Report. Washington, DC.

4. DHHS. Key substance use and mental health indicators in the United States: Results from the 2019 National Survey on Drug Use and Health. Rockville, MD: HHS Publication No. PEP20-07-01-001, NSDUH Series H-55; 2021.

5. Lagisetty PA, Ross R, Bohnert A, Clay M, Maust DT. Buprenorphine Treatment Divide by Race/Ethnicity and Payment. JAMA psychiatry (Chicago, Ill.). 2019 Sep 1,;76(9):979-81.

6. Kilaru AS, Xiong A, Lowenstein M, Meisel ZF, Perrone J, Khatri U, et al. Incidence of Treatment for Opioid Use Disorder Following Nonfatal Overdose in Commercially Insured Patients. JAMA Network Open. 2020 May 1;3(5):e205852.

7. Goedel WC, Shapiro A, Cerdá M, Tsai JW, Hadland SE, Marshall BDL. Association of Racial/Ethnic Segregation With Treatment Capacity for Opioid Use Disorder in Counties in the United States. JAMA network open. 2020 Apr 1;3(4):e203711.

8. Roberts AW, Saloner B, Dusetzina SB. Buprenorphine Use and Spending for Opioid Use Disorder Treatment: Trends From 2003 to 2015. Psychiatric services (Washington, D.C.). 2018 Jul 1;69(7):832-5.

9. Park-Lee, E, Lipari, RN, Hedden, SL, Kroutil, LA, Porter, JD. Receipt of Services for Substance Use and Mental Health Issues among Adults: Results from the 2016 National Survey on Drug Use and Health. NSDUH Data Review. 2017 September.

10. Kiang MV, Basu S, Chen J, Alexander MJ. Assessment of Changes in the Geographical Distribution of Opioid-Related Mortality Across the United States by Opioid Type, 1999-2016. JAMA Network Open. 2019 Feb 1;2(2):e190040.

11. Age-Adjusted Drug and Opioid-Involved Overdose Death Rate (2017-2019) [Internet].; 2021 [cited 7/9/2021]. Available from: <u>https://www.dchealthmatters.org/.</u>

12. 2021 Demographics [Internet].; 2021 [cited July 14, 2021]. Available from: <u>https://www.dchealthmatters.org/.</u>

13. Office of the Chief Medical Examiner. Opioid-related Fatal Overdoses: January 1, 2016 to January 31, 2021. Washington DC: 2021 April 20.

14. COVID-19 era health care workforce capacity in Washington, DC [Internet].: DC Health Policy Center [cited July 16, 2021]. Available from: <u>https://www.dcpolicycenter.org/publications/health-careworkforce-capacity/</u>.

15. Bourgois P. Disciplining Addictions: The Bio-politics of Methadone and Heroin in the United States. Cult Med Psychiatry. 2000 Jun;24(2):165-95.

16. Madras BK, Ahmad NJ, Wen J, Sharfstein J. Improving Access to Evidence-Based Medical Treatment for Opioid Use Disorder: Strategies to Address Key Barriers Within the Treatment System. NAM Perspectives. 2020 Apr 27.

17. Hankerson SH, Weissman MM. Church-Based Health Programs for Mental Disorders Among African Americans: A Review. Psychiatric services (Washington, D.C.). 2012 Mar;63(3):243-9.

18. Bellamy CD, Costa M, Wyatt J, Mathis M, Sloan A, Budge M, et al. A collaborative culturallycentered and community-driven faith-based opioid recovery initiative: the Imani Breakthrough project. Social work in mental health. 2021 June 2,;ahead-of-print(ahead-of-print):1-10.

19. Murphy AB, Moore NJ, Wright M, Gipson J, Keeter M, Cornelious T, et al. Alternative Locales for the Health Promotion of African American Men: A Survey of African American Men in Chicago Barbershops. J Community Health. 2017 Feb;42(1):139-46.

20. Hankerson, Sidney H., MD, MBA, Fenton MC, MPH, Geier TJ, BA, Keyes, Katherine M., PhD, MPH, Weissman MM, PhD, Hasin DS, PhD. Racial Differences in Symptoms, Comorbidity, and Treatment for Major Depressive Disorder Among Black and White Adults. Journal of the National Medical Association. 2011;103(7):576-84.

21. Hays LM, Hoen HM, Slaven JE, Finch EA, Marrero DG, Saha C, et al. Effects of a Community-based Lifestyle Intervention on Change in Physical Activity Among Economically Disadvantaged Adults With Prediabetes. American journal of health education. 2016 Sep 2,;47(5):266-78.

22. Victor RG, Ravenell JE, Freeman A, Leonard D, Bhat DG, Shafiq M, et al. Effectiveness of a Barber-Based Intervention for Improving Hypertension Control in Black Men: The BARBER-1 Study: A Cluster Randomized Trial. Archives of internal medicine (1960). 2011 Feb 28;171(4):342-50.

23. Grinspoon P. Poverty, homelessness, and social stigma make addiction more deadly. Harvard Health Publishing: Health Disparities. 2021 Sept 28. <u>https://www.health.harvard.edu/blog/poverty-homelessness-and-social-stigma-make-addiction-more-deadly-202109282602</u>.

24. Substance Abuse and Mental Health Services Administration. The opioid crisis and the Black/African American population: An urgent issue. 2020.

25. Washington D.C.: Opioid-Involved Deaths and Related Harms [Internet]; 2020 [updated Apr 3; cited 6/23/2021]. Available from: NIDA. 2020, April 3. Washington D.C.: Opioid-Involved Deaths and Related Harms<u>https://www.drugabuse.gov/drug-topics/opioids/opioid-summaries-by-state/washington-dc-opioid-involved-deaths-related-harms.</u>

26. Windsor L, Pinto RM, Benoit E, Jessell L, Jemal A. Community Wise: The Development of an Anti-Oppression Model to Promote Individual and Community Health. Journal of social work practice in the addictions. 2014 Oct 2;14(4):402-20.

27. Jordan A, Babuscio T, Nich C, Carroll KM. A feasibility study providing substance use treatment in the Black church. Journal of substance abuse treatment. 2021 May;124:108218.

28. Schulz AJ, Zenk SN, Kannan S, Israel, Barbara A, Koch, Mary A, Stokes CA. CBPR approach to survey design and implementation: The Healthy Environments Partnership Survey. In: Israel, Barbara A, Eng, Eugenia, Schultz, Amy J, Parker, Edith A., editor. Methods in community-based participatory research for health. 1st ed. ed. Hoboken: Wiley; 2005.

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### Table 1. Howard University CTN CAB and Author Team Roster\*

\*The CAB included representation from three persons in recovery, two community-based organizations, and one faith-based organization.

Table 2.	CAB	Interview	Assessment	Process
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CAB Feedback	Value / Principle	Refinement of Interview Guide
Emphasize participatory action	Co-creation; doing with rather	Interview guide language was
during the interview process.	than doing to	adjusted to emphasize
		community members as
		possessors of expertise and
		partners in project design and
		assessment.
Utilize a framework that begins	Community first; acknowledging	Questions about drug use were
with an understanding of	social determinants of health	moved to later in the interview
community values and structure		guide, while questions about
before delving into what may be		community values and structure
perceived as a community		were moved to the beginning of
problem.		the interview guide.
Relinquish deficit-based models	Approaching community	Questions regarding community
of the community.	members from a strengths-based	input to solutions development
	approach with an appreciation for indigenous wisdom	were added/strengthened.
	for margenous wisdom	Questions that suggested
		community deficiency, a lack of
		resources, or an assumption
		about rampant drug problems,
		were removed from the
		interview guides.
Utilizing community assessment	Reframing academic partnership	Educational tools on fentanyl
as an additional opportunity to	with community as therapeutic	and other deadly substances
educate and empower	not detrimental to community	were added to the assessment
community members.		process, including a path for
		helping interviewees access
		treatment, if desired.

Interview Section	Theme	Initial Language	Revised Language	Rationale
Preamble	Participatory values should be communicated to research participants. i.e., "Doing With"	Hello, my name is and I am a part of a research team doing research to understand opioid use in Wards 7 and 8 of Washington, DC	Initial language with this addition: <i>The interview</i> will include 13-17 questions. <i>The interview</i> questions were developed by a community advisory board made up of DC residents, including those with lived experience and leadership in this area.	Communicate the role of community members in formulating questions. Respond to concerns about data misuse and emphasize authenticity of project.
PART A. Demographic Questions	Measure social determinants of health. Build Trust. Respect Autonomy. Commit to a community benefit.	Race Ethnicity Gender Religious Preference Neighborhood of residence Ward of residence	Initial language with these additional categories: Age category Income source Highest degree or level of school completed	New categories were added: Age, Income, Education. Emphasize that demographic responses were voluntary. Data were collected for the ultimate benefit of the community.
PART B. Views on Drug Addiction Problems	Have a "community first" stance – (i.e., begin with understanding of community structure before asking about drug problems).	The initial version asked a series of questions about personal history using opioids.	<ul> <li>When you hear the word "community" what does it mean to you?</li> <li>In this community what are the top substance issues (i.e., drugs or prescription drugs, alcohol use problems) you see?</li> </ul>	Acknowledge thatindividuals are aproduct of theircommunity.Drug use does notoccur in a vacuum.Questions aboutpersonal historyusing opioids weredeferred until laterin the interview,after larger issueswithin thecommunity werediscussed.

### Table 3. Interview Guide – Community Members with Opioid Problems

		community.	community? In your experience, how do people talk about or describe people who use opioids? Could you tell us about	community has a drug problem.
			how <u>you</u> talk/describe those who use opioids?	
Experiences with pa Opioids and sh Seeking Treatment an Us co nc sti lan ex in ou	Research articipation hould educate nd empower. Use culturally ompetent, on- tigmatizing anguage (lived xperience vs n treatment, ut of reatment).	Experiences withopioidsHow old were youthe first time youused X?How long ago didyou start using Xhabitually/on aregular basis? months / yearsTell me about thefirst time(s) youused?Since Y time agowhen you startedusing X, describefor me how ithas affected yourlife andrelationships?Experiences seekinghelpWhat led you to starttreatment whenyou did?What helped you tostart treatment?Describe anyproblems youenter treatment.Describe what youthink would havebeen helpful in	Open-ended questionsadded, focusing onindividual experience,rather than factual data orpoints in time:Have you had anyexperience withopioids? And if so, doyou mind sharingabout it? By opioids,I'm referring to"fent"(fentanyl),"carfent"(carfentanil), heroin,"smack," etc[Opioid Glossaryadded]Have you had anyexperience seekinghelp for opioid use?And if so, do youmind sharing about it?Have you ever been able tostop using opioids?How long were youable to stay off drugs?What led you to starttreatment when youdid?What types of treatmenthave you received?Was treatment beneficial?If so, how?If there were interruptionsin treatment, whatcaused you to stoptreatment in the past?	Questions arranged to facilitate bi- directional learning. Community knowledge about opioids and opioid treatment is supported. The research team learns about how the community talks about opioid use and barriers or facilitators for engaging and continuing care.

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		you/getting you	What is your	
		in substance use	understanding of	
		treatment earlier.	medications for opioid	
			problems? After	
		Experiences at	response, the	
		current clinic (if in	interviewer provided	
		treatment)	prompts for specific	
		Describe your	medications What is	
		experience in	your understanding of	
		your current	buprenorphine, of	
		treatment	methadone, of	
		program.	Vivitrol? [Opioid	
		Tell me about what	Treatment Glossary	
		helped you	added, and each	
		start/maintain	medication explained	
		treatment/ keep	to conclude interview]	
		you on track.	Where are you currently	
		What do you like	receiving treatment	
		about treatment	for opioid use?	
		at your current	What has your experience	
		treatment	been like at?	
		program?		
		What would you		
		change about the		
		care you receive		
		there?		
PART E.	Adopt a	What do you feel is	In this section, I'd like to	Multiple questions
Recommendations	strengths-based	missing, if anything,	hear more about your	about what is
	approach and	in your community's	ideas for engaging	missing from
	avoid deficit	response to opioid	individuals with	current opioid
	models.	use?	opioid problems in	response were
			treatment and/or	eliminated, thereby
			recovery support.	minimizing
				inference of
			What rules would you	deficiency within
			change about starting	the community.
			and staying in	-
			treatment?	
Summary	"Doing with" –	Is there anything else	Thank you for your time.	The summary
	each	you would like to	The information you	includes the
	respondent is	share with me that we	provided today helps us	anticipated impact
	invited to join	haven't already	understand your	of this process on
	a process of	discussed?	experience and the	the wider
	bringing		community's experience	community and
	change to the		so that we can work	reminds of
	community.		together to bring positive	everyone's role in
	-		change to the residents of	creating change.
	Research		Wards 7 & 8.	
	participation			Education remains a
	· ·			focus to conclude
		1	1	10 sub to contendate

should educate	Be	efore we end, would it be	interview;
and empower.	oka	kay if I take a moment to	researcher shares
	sha	nare a few additional facts	facts about the
	abo	pout the opioid crisis and	opioid epidemic in
	ho	ow it is impacting DC	Washington, DC
	res	esidents?	and where to find
			help, if needed.

Theme	Sample Questions	Rationale
Strengths-based approach Community development should be an integral part of health and health care. Communities should have access to and derive benefit from research derived.	Does your organization address opioid use in the community? If so, how? How do you measure your impact? <i>Recommendations Section</i> : What about any policy changes that might be helpful?	These questions were added out of CAB interest in outcomes/impacts that communities have already attained. This opened a new avenue of understanding outcomes that are of value to the community (which may differ from clinical outcomes).
	Strengths-based approach Community development should be an integral part of health and health care. Communities should have access to and derive benefit	Strengths-based approachDoes your organization address opioid use in the community? If so, how?Community development should be an integral part of health and health care.How do you measure your impact?Communities should have access to and derive benefitRecommendations Section: What about any policy changes that

### **Appendix: CAB Scope of Work**

### Howard University Reach, Engage, Retain Project

### **<u>1. Community Advisory Board</u>**

The DC CTN is designed to be guided by the "lived experiences" of people affected by opioid and other drug addictions. We seek input from people affected on a personal level and on a community level. To make sure that these real-world experiences are included in planning and carrying out CTN research, a Community Advisory Board (CAB) has been formed. The CAB has 6 members. Members represent community-based groups, faith communities, peer recovery groups, businesses, and neighborhood organizations. The CAB will be involved in each phase of the DC CTN start-up projects.

### 2. Community Advisory Board Scope of Work

During the start-up project, the CAB will:

1. Work with DC CTN investigators to find the best ways to talk about these issues with community members

2. Link the research team to people and groups who can give useful input on how to achieve the project's goals

3. Help to plan and implement ways to share new information from the research with the community

4. Advise about ways that the research can contribute to the "big picture" of dealing with the root causes and harmful outcomes of opioid overuse in DC communities

The work will proceed in phases. However, the program has a great level of flexibility to adjust approaches, as needed, to achieve the best results. The expected process is outlined below.

### 2-1. Formative Phase

The CAB and research team will work together to develop the CAB. Outcomes of the planning phase will include:

- A clear shared vision for the CAB's role in the project
- Operating guidelines for CAB activities
- Documentation of expected roles and responsibilities
- Shared understanding of research methods to be used
- Strong working relationship with the research team
- A timetable of planned activities
- A vision for long-term sustainability of the program and CAB beyond the current grant funding

### 2-2. Needs Assessment

Based on the planning phase, CAB members and research staff will begin to implement tasks to support the project's needs assessment. Expected tasks may include:

- Advise on development of language for discussing opioid and other drug addictions
- Advise and give feedback on questions to be asked during focus groups and interviews
- Assist with arranging focus group sessions
- Provide introductions to key persons for one-on-one interviews
- Recommend activities to help the research team learn about the issue from community members
- Provide ongoing needs assessment as demographic changes occur in the community

### 2-3. Design and Implementation

- Give input on ways to improve access to medical treatment for opioid overuse or addiction
- Recommend activities to raise awareness of the project in the community
- Identify people and groups who can join in achieving the project goals
- Recommend ways to assess outcomes of the project activities
- Suggest ways to sustain gains from the project

### 2-4. Evaluation

- Provide feedback on the quality of engagement with communities
- Evaluate the impact of the research on major outcomes including:
  - o Increased use of treatment in primary care settings
  - Increased access to treatment in new types of settings
  - o Decreased opioid overdose rates in Wards 7 and 8
- Identify strengths, weaknesses, barriers and facilitators for research and service integration in the community
- Recommend other ways to assess outcomes of the project activities

### 2.5. Returning Results and Resources to the Community

- Review and approve reports tailored for community audiences
- Help develop resources that will build community capacity
- Assist with planning and promoting meetings or forums to discuss the project with residents and plan future work

### 3. Budget and Justification

The CAB will meet monthly from June to November 2019, and monthly from January to May 2020. Meetings may be conducted in-person or via phone conferences. CAB members will be compensated for each meeting they attend, at a rate of \$250/meeting. This compensation rate includes activities between meetings, such as emails, and individual or small group meetings.

<b>Invoice Period</b>	Justification	# Meetings	Compensation/	Compensation/period
		anticipated	meeting	

06/01/2019 -	Community	6	\$250	\$1,500
12/31/2019	Advisory Board			
	consultancy			
	services			
01/01/2020 -	Community	5	\$250	\$1,250
05/31/2020	Advisory Board			
	consultancy			
	services			
			Total	\$2,750
			compensation	

### **<u>4. Signature</u>**

Name: \_\_\_\_\_\_\_
PRINT

Date:

Signature: