

“...work really is being done and it’s very worthwhile...”: Reflections from Community Advisory Board members

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Submitted 19 March 2024, revised 25 July 2024, accepted 6 September 2024.

Funding *This research was supported by the National Institutes of Health and the Substance Abuse and Mental Health Services Administration through the NIH HEAL (Helping to End Addiction Long-term®) 1UM1DA049412-01 Massachusetts HEALing Communities Study. This study protocol (Pro00038088) was approved by Advarra Inc., the HEALing Communities Study single Institutional Review Board. We wish to acknowledge the participation of the HEALing Communities Study communities, community coalitions, community partner organizations and agencies, and Community Advisory Boards and state government officials who partnered with us on this study.*

Acknowledgements to Melanie Rocco for graphics, to Madison Kitchen for citations, and to all of the CAB members for their passion and commitment to saving lives: CAB members include Dick Alcombright, Andrew Laudate, Kim Powers, Magda Colón, Marline Amedee, Jerry Lund, Michael Kelly, Mike Berggren, Chris Bonsall, Jesus Lazu, Deb Kelsey, Richard Johnson, Pedro Alvarez, Teri Tirado, Tania Keating, Gail Gramarossa, Andrea Macone, Jennifer Kimball, Derek Reynolds, Jess Tilley and former CAB member Damon Chaplin. This paper reflects the views of the authors and the content is solely the responsibility of the authors and does not necessarily represent the official view of the National Institutes of Health (NIH) or its NIH HEAL Initiative®.

ABSTRACT

Background: The federally-funded four-state HEALing Communities Study (HCS) aims to reduce fatal opioid overdoses. Each state was required to establish a Community Advisory Board (CAB). CABs have the potential to shape research priorities, ensuring relevance to affected communities.

Objectives: Describe personal and professional benefits of Massachusetts HCS CAB participation. Discuss strategies that promote HCS-MA CAB member benefits.

Methods: Nineteen of 20 HCS-MA CAB members responded to prompts: *How has your involvement in the CAB impacted you as an individual, in your work in the community, and on the study? Consider the personal and professional benefits.* Responses were analyzed using Thematic Analysis.

Lessons Learned: Benefits of serving on the HCS-MA CAB included mutual learning in an “honest and open space,” forming new relationships, and pride and gratitude in working together on a shared goal.

Conclusions: The results of this case study suggest how valuable community engagement and sharing multiple ways of knowing can be for CAB members.

KEYWORDS: Community-Based Participatory Research, Community health partnerships, Community health research, Health outcomes , Health promotion, Power sharing, Process issues, Substance-Related Disorders, Opioids, New England, Health Resources

Background

Fatal opioid overdoses are an ongoing public health threat. Although there are effective evidence-based strategies for reducing fatal opioid overdose,¹ access to, acceptability and implementation of these strategies continues to pose a challenge in many communities.^{2,3}

Community engagement (CE) has been identified as a critical component for translating research into practice, i.e., increasing uptake of evidence-based strategies. Community Advisory Boards (CABs) present an important opportunity to maximize community engagement on a research study.⁴⁻⁶ In Community Engaged Research (CEnR) the CAB is intended to inform the research focus and create a structured mechanism for community members to shape research activities and priorities, ensuring that they are meaningful and relevant to communities.⁶⁻¹¹

The creation of a CAB is often a recognition of and a response to power dynamics between community members and researchers, re-aligning academic health care research with the needs and vision of a community.¹¹⁻¹⁴ As such, community advisory boards have the potential to address both racial equity and stigma in substance use research.¹⁵⁻¹⁶ Halladay et al. (2017) suggest that successful research collaborations with CABs require shared power, while Wallerstein et al. (2019) focus on strategies that address equity in partnerships.^{12,17} For community advisory boards, which may be advising but not power-sharing entities, one aspect of power may be the opportunities for “making historic and current oppressions visible.”¹⁷ Through making visible their perspectives, CAB members have the potential to shift power dynamics.

The HEALing Communities Study (HCS), a community-level, cluster randomized trial with a waitlist control group was implemented in 67 communities across four states, (Kentucky, Massachusetts, New York and Ohio) with the overall aim to reduce fatal opioid overdoses using the Communities That Heal (CTH) intervention, a community-engaged, coalition and data-driven

planning process.^{1,18} Each state was required to establish a Community Advisory Board which acts in an advisory capacity to the study.¹⁹ CAB members brought expertise and varied perspectives to advise on the stated goal of reducing overdoses fatalities. This case study examines reflections of Massachusetts HCS CAB members.

Objectives

Few studies address CAB member perceptions of their personal and professional experiences serving on a CAB^{5,20}, leaving community partner perspectives and experiences unheard in the literature. This paper highlights CAB member experiences, shifting the power imbalance by centering CAB members as both producers and subjects of knowledge.⁵ We describe the creation of the HCS Massachusetts CAB, followed by study results, and lessons learned.

Methods

As the study started, Massachusetts study leadership selected 7 at-large CAB members to bring state-wide perspectives to the CAB. The at-large members, with assistance from staff, recruited, interviewed, and selected community representatives from the 16 study communities, 8 representing intervention communities and 8 representing the waitlist control group¹⁸. Waitlist communities received the CTH intervention after the first group of 8 communities completed the intervention activities. At large members were intentional in their recruiting and selection efforts, using consensus decision-making to create a CAB inclusive of people who use or have used drugs, their family members, people working in a variety of sectors, and people with a diversity of identities. The current Massachusetts CAB has 20 members; 16 represent the Massachusetts HCS study communities and four are at-large members. The CAB includes ten people who identify as having past and/or current experience using drugs, and three more have or had family members with drug use experience. CAB members represent multiple sectors (e.g., public

health, harm reduction, recovery support) and identities (e.g., Latino, Black, African American, White, queer, immigrant, and living with HIV).

The development of the CAB was rooted in Shea's Principles of Community Engagement (be clear, be knowledgeable, establish trust, the community empowers itself, partnering is necessary, respect the community, utilize community assets, release control, be committed).²¹ The HCS-MA CAB model incorporated other recommendations from the literature including development of a Charter, use of group facilitation techniques, and frequent communication.¹³ The literature also emphasizes the importance of compensating CAB members, demonstrating the value of member expertise, knowledge, and time.⁹ HCS-MA offered a \$200 monthly honorarium for attendance at monthly meetings and other CAB related activities.

The first full CAB meeting took place in person in February 2020 before the dislocations and challenges of the COVID-19 pandemic began. The CAB moved to monthly two-hour zoom meetings in March 2020 continuing through April 2022, when we added twice-a-year all-day in-person meetings. To engage CAB members, CAB meetings included relationship building activities (e.g., check-ins; breakout room activities); invited guest speakers who offered trainings and insights into key study issues (e.g., harm reduction; drug policy; the role of law enforcement); and frequent discussion and recommendations about the needs of study communities, for example, local transportation and housing issues.^{5,13} Meeting agendas were drafted by facilitator(s) after talking with members and staff to address the interests and needs of both groups. In addition to monthly CAB meetings, the HCS CAB facilitator (DC) checked in by phone with each member every 1-2 months to facilitate relationship building.¹³

CAB members were well-integrated into study activities with opportunities to participate in HCS-MA Core meetings, co-author papers, and take on other leadership roles in the study,

regionally and nationally. (See **Figure 1.**) Each of these activities and structures demonstrated staff commitment to community-engaged efforts to lift up CAB member perspectives, sharing power to inform study activities and foster growth.

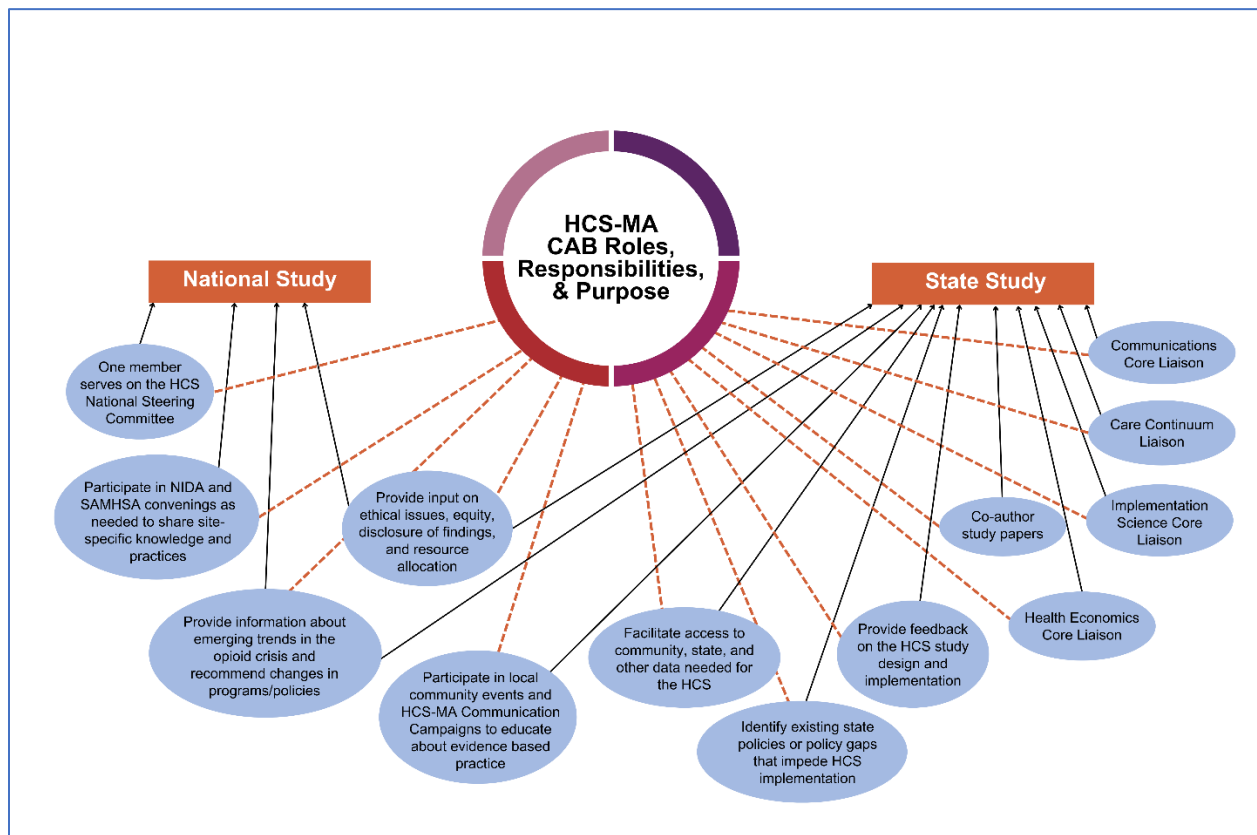


Figure 1: HCS-MA CAB Member Roles, Responsibilities, and Purpose

We explore CAB member perceptions of their involvement with the CAB, gathering responses at the July 2022 Zoom meeting during an interactive group activity using Jamboard.²⁵ Jamboard is a shared media platform that everyone at the meeting can see through “screen sharing” or access by linking to the online site.

The sixteen CAB members present at the meeting were divided into two groups of eight and invited to reflect and respond to the prompts: *How has your involvement in the CAB impacted you as an individual, in your work in the community, and on the study? Consider the personal and professional benefits.* Participants could state their answers to the questions aloud and/or write their thoughts on electronic sticky notes.^a If CAB members did not want to use the technology, HCS staff were available to write down as close to verbatim as possible what individuals said aloud. All quotations were written down without attribution. After the meeting, the four CAB members who were unable to attend the meeting were invited to reflect on the prompts using the same shared Jamboard platform; three of those four members contributed responses resulting in 19 of the 20 CAB members' participation.

Following this activity the CAB discussed their responses, observing that the structure of the CAB meetings had contributed to their experiences. After the meeting, HCS staff discussed this observation and its potential contribution of the CAB member reflections to the literature. CAB members agreed to the suggestion to write a paper about the activity. All CAB members were invited to participate in writing the paper and four members became co-authors.

Data management and analysis. All quotations from the Jamboard were saved in a Microsoft Excel file and reviewed by three HCS staff members (DC, CM, MD). Duplicative text was removed.

Thematic analysis, a flexible approach used to identify themes or patterns in a body of work, was employed to explore CAB member reflections.²² We followed Braun and Clarke's (2006) six step thematic analysis process, which includes: 1) familiarizing yourself with the data, 2) generating

^a For the purposes of this paper, we refer to these sticky notes as quotations.

initial codes^b, 3) searching for themes, 4) reviewing themes, 5) defining and naming themes^c, and 6) producing the report.²² Three HCS staff members each separately coded the initial 39 quotations. Over multiple meetings we aligned our codes using reflexive practice, examining how our subjective experiences influenced how we understood the data (the reflections).

Next, the three HCS staff members developed a final codebook and each independently used the codebook to code the quotations. As the next step, we met to reconcile our coding using a consensus-driven collaborative approach to resolve any identified discrepancies and to assure inter-rater reliability. We took notes during these sessions to track the resolution of differences we found in our coding. We then developed coding summaries to synthesize coded quotations and to identify the larger story within the data. Throughout this process we met to discuss emergent themes and narratives and used consensus-driven collaboration to assign quotations to themes.

Once we had identified themes, they were presented to HCS staff and the four CAB member co-authors who reviewed the themes and felt they reflected the quotations written by CAB members on the original Jamboard.

We provide a short description of each theme and illustrative quotes from the Jamboard activity.

Four themes were identified. **See Figure 2.**

^b Coding is a process wherein the researchers identify content that seems interesting or stands out in some way. For example, a respondent's remarks about leadership could be coded as leadership, or perhaps as success, or capacity building, and so on. (Braun & Clarke, 2006)

^c Themes, here, are a mechanism for interpreting the codes. (Braun & Clarke, 2006)

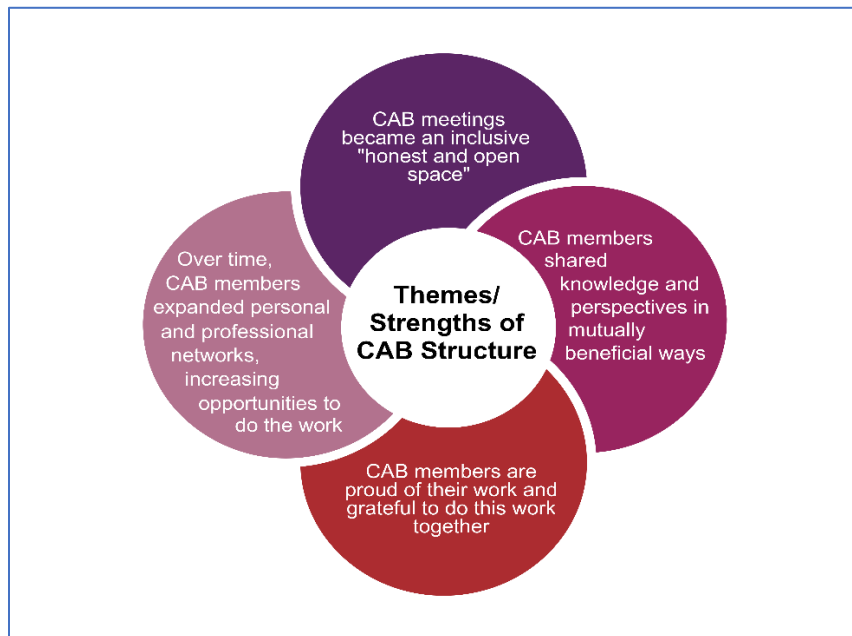


Figure 2. Themes/Strengths of CAB Structures

CAB meetings became an inclusive “honest and open space”

This theme illustrates CAB members’ feelings about the monthly CAB meetings. Attending monthly meetings became a way for CAB members to feel grounded, knowing they would see each other and HCS staff the 4th Wednesday of the month.

[the] CAB creates a space with other people who are grounded and doing the work.

After more than 2 years of Zoom meetings CAB members described feeling inspired by and connected to each other and found:

...these relationships are so beneficial to us.

Having a group of people, a monthly place to ground yourself and support, message them after, get specific answers, one of the biggest, [was] connection of other people.

Meetings provided an “*honest and open space*” for CAB members to develop relationships with one another and “*find kindred spirits in this group.*”

Thank you for being yourselves, being honest, [it has] rounded out my view of things.

During CAB meetings individuals could deepen existing relationships and find new friendships and working partners through activities and discussions about their work in communities. CAB members found support in the group, benefitted from their shared connections, and felt supported in their work.

...the work on the CAB is important for people.

I have also many so many wonderful connections and friendships.

A lot of great work has been done and great relationships have been built.

CAB members shared knowledge and perspectives in mutually beneficial ways

CAB meetings developed into a space where members could learn new things *and* educate others. Because it became a space where one could be honest, diverse perspectives could be spoken aloud and responded to. CAB members could ask each other questions and expect to hear answers representing a variety of viewpoints.

...as things began to evolve, I found myself much more committed to the voices and experiences of my fellow CAB members, which eventually lead to a much deeper conversations about intervention, treatment and of course, root cause analysis.

Members spoke of learning from each other, sharing their experiences with each other, and helping to “expose” members to new ideas.

Experience is the best teaching and [I] feel grateful to be exposing people to things they wouldn't have heard.

I knew so much and I have learned so much....I was skeptical at first. This group is about education.

The experience of being in the group helped CAB members to understand and develop new perspectives.

...help me to grow about harm reduction, how we talk about it here.

They expressed appreciation for the CAB meeting as a place to find connection with each other through learning.

Get gratification from giving feedback and it's heard.

CAB members are proud of their work and grateful to do this work together.

The goal of the study is to reduce fatal opioid overdoses, what CAB members refer to as “the work.” This shared goal is felt deeply and personally among CAB members and grounds the CAB’s work. CAB members described feeling proud and grateful to be able to do this work and to do it together. They spoke of having an impact and feeling proud of the work CAB members do, saying CAB members bring “*strength, compassion and fortitude.*”

This group is really inspirational. I'm not a spiritual person but how many times between meetings and I come across something....real honor to hear what people are doing all over the state, knowing how hard everyone is working. I often think of you all in between meetings day after day.

I think professionally my participation has allowed me to share with peers the realities that work really is being done and it's very worthwhile.

[the CAB] Impacts me daily and feel proud. Want to be able to make an impact and this helps me do that.

CAB members described that being on the CAB provided opportunities to give back to communities.

Happy to be giving back to my community who I work with.

...the ability to influence local outcomes...

I can help – so I feel good about that.

Over time CAB members expanded personal and professional networks, increasing opportunities to do the work.

CAB members offered each other acceptance and valued each other's different approaches to the work. CAB members described that by being on the CAB they could expand their social connections and networks. Expanding networks increased personal and group capacity for leadership work in communities and community coalitions, engaging in activities within the HEALing Communities Study at the local, state and national level, including involvement in dissemination activities. The CAB was a springboard for a variety of new connections and learning.

CAB brings together people from different silos. Everyone is working towards the same goal and within the CAB we can develop and strengthen our effectiveness towards creating the future we are striving towards.

We're all doing the work on our own, but the CAB provides a space where we can come together and learn about what's working in other areas. MA is a small state but certain areas are affected. Coming together allows us to brainstorm and learn from one another and see what's working in other communities.

Lessons Learned

This case study tells the story of community members who were brought together to become the HEALing Communities Study Massachusetts CAB. As the themes describe, CAB members felt they could speak honestly with each other. They shared their own perspectives, appreciated others' perspectives, and were grateful to learn from each other. They were proud of their work, the learning that had taken place, and the contributions they were making. Personal and professional networks were created and strengthened which created more opportunities to continue the work. These 'outcomes' are previously under-explored in the community engagement literature.

The personal and professional benefits of CAB participation described by CAB members support the use of community engagement principles²¹ and other strategies detailed in the literature for developing effective CABs: frequent communication (including phone) and regular CAB meetings; taking time to build relationships; using consensus decision-making; setting clear expectations about how the study uses CAB advice; roles and responsibilities of CAB members and study staff, and; establishing trust.⁹⁻¹³ Salsberg et al. (2015) identify successful strategies for community research partnerships including capacity building, “using group facilitation techniques” and frequent communication (p. 10 -11).¹³ Halladay et al., (2017) specifically mention “Allowing time for relationship building and culture change” as a challenge for CAB development (p.375).¹²

We use CAB member reflections to improve understanding of how community engagement and the strategies and structures described in the literature may have fostered and supported the development of a close-knit CAB which felt proud of their work together. CAB meetings were intentionally designed to shift the culture and provide time and space for everyone in the meeting to be together in relationship and for trust to develop. For example, staff were flexible,

developing agendas and meeting structures that were responsive to the members, meeting them “where they were at.” A draft agenda was sent one week ahead of meetings so members (and staff) would have an opportunity to revise or add to it, and, it was not unusual receive suggestions. Given the constraints of both time and space (Zoom-only meetings), the CAB facilitator (DC) stayed engaged with the CAB members individually and as a group with phone calls, emails, texts, and, for one year, extra drop-in meetings for group social support. When new members joined the CAB they were mentored by experienced members. When we lost a CAB member to an overdose we mourned together. Each of these efforts seemed to create a web that held together the CAB community across two plus years of Zoom meetings. Further, the HCS Principal Investigator and Project Director actively participated in CAB meetings, conveying an important and appreciated message of interest, commitment, and respect to CAB members. The challenges of the difficult work the CAB members were doing demanded a specific kind of support. In addition to community engagement, harm reduction²³ was used as a working model for building relationships and designing CAB meetings that supported CAB members and HCS staff with the goal of creating a space that could hold everyone. Harm reduction also provided a framework for understanding root causes of the opioid epidemic, which opened opportunities for policy and systems level analysis that centered equity, naming and addressing the racially disproportionate harms of fatal overdoses.²⁴ CAB meetings became a place where members could talk about failures (e.g., continued and increasing fatal overdoses) as well as successes (e.g., innovative ways to distribute naloxone), where pain was heard and acknowledged. One CAB member said in frustration, “We do the same things over and over again, expecting a different outcome.” CAB members brought multiple perspectives to how they understood drug use, harm reduction, recovery, and the needs of people who use drugs, their families and friends.

They endorsed “nothing about us without us” as a key element of their vision. They acknowledged that they need to be more aggressive to address the continuing disproportionate rise in fatal overdoses in communities of color. They appreciated how much they were learning from the study and they critiqued some study design elements. For example, some CAB members repeatedly raised and expressed frustration about the study’s waitlist control group design given the urgency of fatal overdoses.

This case study has limitations. By suggesting personal and professional benefits as the prompt in the study Jamboard activity, answers skewed in a positive direction. Future studies should intentionally ask for both positive benefits and the challenges CAB members experience.

Further, data were collected in a group setting which may have led to social desirability bias and reflect one point in time, at the mid-point in the timeframe of the CAB and may not encompass the entirety of the CAB experience. In addition, this paper does not address the impact of power-sharing on staff, an important area for future research.

Conclusions

This study is consistent with the literature on the strategies and structures that can support the development of an effective CAB. Intentional use of community engagement principles and the harm reduction approach in the creation and development of the HCS-MA CAB may have contributed to the growth of a “honest and open space” where “work is really being done.” In that space, CAB members demonstrated multiple ways of creating, expressing, and sharing knowledge with each other and HCS staff, and were grateful to be able to do so. The implications of new knowledge gained and shared are critical for future evaluation of the role and capacity of CAB members. Future research should continue to probe community-engaged meeting structures and facilitation methods that facilitate the CAB’s work and the growth of trust and

efficacy in the group. Research studies and academic spaces don't always recognize non-academic ways of expressing, sharing, and creating knowledge.²⁶ The results of this case study suggest how valuable community engagement and harm reduction can be for sharing multiple ways of knowing among CAB members.

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