A TOOLKIT FOR

COMMUNITY-ENGAGED SUBSTANCE USE RESEARCH

Effective Community Board Partnerships Using Community-Based Participatory Research (CBPR)

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Disclaimer

This toolkit was created by a team at the Lighthouse Institute of Chestnut Health Systems, which partners with various national Community Boards. These Boards are sometimes referred to as panels or community advisory boards (CABs). The national Boards we have collaborated with meet virtually and include members from across all time zones in the continental U.S.

*We have made efforts to ensure relevance in both **virtual** and **in-person** environments, although some guidance in this toolkit may not translate to an in-person setting. Our intent isn't to present ourselves as CBPR experts, but to share what we've learned while striving to uphold CBPR principles in our work.*

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CHESTNUT HEALTH SYSTEMS LIGHTHOUSE INSTITUTE

JEAP Initiative

CHEARR Collaborative Hub for Emerging Adult Recovery Research

NIH HEAL INITIATIVE | CONNECTIONS Partnering to Accelerate Research into Action

PATH (Peer Advanced Training in Harm reduction)

Acknowledgements

We extend heartfelt thanks to the community members who have partnered with us. Your passion, strength, and wisdom inspire us all. None of our work would be possible without you, so we want you to know that we are grateful for the time and energy you have invested with us.

We also express our gratitude to the community organizations, research collaborators, and staff members who have supported our CBPR work. Your collective knowledge and resources helped enhance our efforts in ways far beyond what we had imagined.

Finally, we extend a special thank you to the National Institutes of Health, the National Institute on Drug Abuse, the Justice-involved and Emerging Adult Populations (JEAP) Initiative Community Boards, the HEAL Connections Lived Experience Panel, Addiction Policy Forum, the Collaborative Hub for Emerging Adult Recovery Research (CHEARR) Community Boards, and the Peer Advanced Training in Harm reduction (PATH) Community Board for making a tremendous impact in the broader community.

Throughout this toolkit, we have included quotes from HEAL Connections Panel members, JEAP Community Board members, and PATH Community Board members to provide additional insights. Members have provided permission for their quotes to be used in this toolkit and have selected how they want to be represented (i.e., full name, photo, anonymous).

Community Board members are experts on their experience. When discussing how to improve the life experience of others with similar struggles as the board members, the board members' experience can lead researchers to more effective research strategies by mentally placing themselves in the participant's role. Conversations about us, without our involvement, are inherently incomplete.

Eleanor Byrd

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THE PURPOSE OF THIS TOOLKIT

People with lived experience in substance use, substance use disorder, and the criminal legal system bring a critical perspective to the field. Most members of our team have either direct or indirect lived experience in these areas, and their insights and perspectives have been invaluable to our work. We also have had the opportunity to partner directly with impacted community members through many research studies.

Within community-engaged research, there exists a **spectrum ranging from community consultation to community partnership to community-led**. Community-Based Participatory Research (CBPR) is positioned at the upper end of this spectrum, with researchers and community members partnering and jointly making decisions about research activities and goals. As a research team, which includes impacted community members, we believe this end of the spectrum is optimal for researchers pursuing community-engaged research, particularly substance use research and other areas where stigma is significant. At the same time, we recognize that our team has the advantages of experiential expertise and years of partnering with impacted communities. Other research teams may face constraints that prevent them from fully utilizing CBPR methods. We support researchers striving to achieve community engagement, no matter what level they can achieve on the spectrum.

Therefore, our goal in creating this toolkit is to help others strive for the highest quality of community-engaged research that is feasible for them at this moment.

Researchers interested in pursuing CBPR in substance use must ensure that all partnerships remain mutually beneficial for everyone involved, recognizing that community members contribute their own specialized expertise. Therefore, we recommend checking in with these individuals often and asking for their guidance in determining what processes should be improved, if any.

TIP

As an example, the term **Community Board** may seem more inclusive than the term **Community Advisory Board** (or **CAB)**, as the word "Advisory" could imply a shift from equal partner to advisor or rubber-stamp approval/tokenism—it could make a community member feel demoted, othered, or excluded from the research team. In turn, this may make them less inclined to provide their expertise and honest input, as they might not believe that their suggestions will be taken into consideration. Word choice can be critical for communities facing pervasive stigma. At the same time, **CAB** and **Advisory Panel** are commonly used terms in community-engaged research, so may be preferred by some teams and Boards; the most important thing is for researchers to ensure the Board is not designed as just a rubber stamp/tokenized, but rather as an expert partnership.

This toolkit was created based on questions other research teams have posed to us. Our intent is to assist other researchers in learning from our experiences and mistakes, with a focus on **"when rubber meets the road"** for CBPR in substance use research. There has been a growing interest in engaging people with lived experience in research via Community Boards, as demonstrated by recent contributions to the literature such as Nelson and colleagues (2024).[1]

We believe that our hands-on experience can be helpful to those seeking a more practical, concrete guide to building and maintaining a Community Board partnership.

Additionally, we provide guidance based on our specific areas of expertise to offer:

- Examples based on two priority populations:
    - **Emerging Adult Populations:** A group of individuals experiencing many life transitions at once. These may include moving out of their familial home, starting work, attending college, getting a job, marriage, starting a family, and much more.
    - **Criminal Legal System-Involved Populations:** A group of individuals with current or former experience with the juvenile or adult legal systems.
- Step-by-step guides
- Personal reflections from Community Board members
- Sample materials to help you get started
- And much more!

Chapter reference(s)

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UNDERSTANDING AND APPLYING CBPR PRINCIPLES IN SUBSTANCE USE RESEARCH

This chapter provides information about CBPR principles, rather than the more "how-to" information that can be found in the rest of this toolkit. The purpose is to provide an overview and orientation of the topic. We will also provide specific examples of how CBPR principles work in action.

- You're likely aware that **addressing substance use issues requires considering a host of individual and community characteristics**.
  - Underlying causes and solutions that apply to one person may not apply to another.
  - This is complicated by differences in social and community factors—what works for one group of people in a particular community may not work for others.
- **Traditional research often overlooks real-world barriers and facilitators.**
- Effectively understanding and addressing such a difficult problem requires more. **This work requires community partnerships!**
- We have found that the **rigorous application of CBPR principles in substance use research facilitates such a partnership**.

In this chapter, we will:

- Explain where CBPR falls within the larger community-engaged research context
- Define the underlying principles of CBPR
- Highlight long-term benefits of CBPR, especially in substance use research

I believe involving people with lived experience enhances the study's relevance, credibility, and impact. It has the potential to foster trust and reduce skepticism, leading to more honest and meaningful conversations. People with lived experience provide invaluable insights into the community's cultural norms, challenges, and strengths; ensuring that research methods and questions are respectful, relevant, and not unintentionally harmful. Lived experience brings nuance to data collection and interpretation. They can identify patterns, meanings, or barriers that traditional researchers might overlook, leading to more accurate and actionable findings.

Brandy Morris-Hafner

CBPR in Community-Engaged Research

Community-engaged research methods can vary depending on several factors. Key and colleagues[1] conceptualized this as a continuum with **no community involvement** at one extreme (research on vs. with people), and **community-driven/led research on the other** (initiated by community members with little to no researcher support).

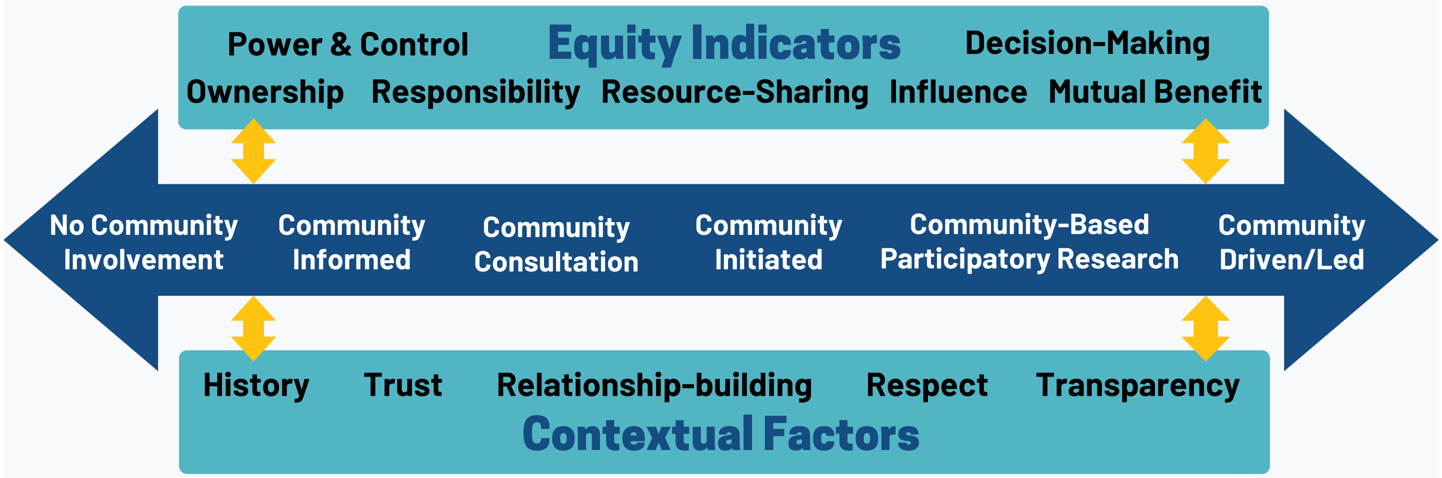

Figure 1. **Continuum of Community Engagement in Research**

From Key et al.[1]

Placement of a specific research project within this model depends on both:

Equity indicators (**Figure 1**, upper box) + **Contextual factors** (**Figure 1**, lower box)

We present this model both to show where CBPR fits into the continuum and as **a tool to determine the most beneficial type of engagement for you to pursue given your resources and goals**.

- A crucial point here is to follow through on the type of engagement you communicate to community partners. For instance, if you start with a decision-making framework that involves community partners, but then make decisions <u>without</u> their input, it will be highly detrimental to both your project and research-community relations in the long-term.
- Our experience has shown the value of applying high-quality CBPR methods, where researchers (who are not necessarily from the impacted community) have a genuine, meaningful partnership with impacted community members.
- Considering this goal and the underlying principles of CBPR, rigorous application of CBPR methods falls toward the right side of Key's continuum, with researchers and community members partnering and jointly making decisions about research activities and goals. We believe this end of the spectrum is optimal for substance use research.

CBPR Principles and the Cultural Exchange Model

In several of our projects researching substance use, we found immense value in **centering the expertise of impacted community members**, which has been largely missing from research conversations. CBPR and striving for good cultural exchange have been key to our work with Community Boards.

Adhering to CBPR principles and using an approach based on the Cultural Exchange Model has been particularly important when engaging with impacted communities where mistrust of healthcare and research exists:

- It enables meaningful engagement, preventing exploitation and ensuring community members benefit directly.
- It recognizes that community "outsiders," like researchers, are more effective when they collaborate with community partners (impacted individuals) who serve as culture brokers (see more on this and the Cultural Exchange Model below).[1-6]
- It leverages end-users' unique knowledge about the research topic and their community to ensure optimal relevance and success of research questions, methods, and communication to impacted communities.[7-10]

The **principles of CBPR** listed here are infused into all of the processes presented in this toolkit.

CBPR Principles:[11-12]

1. **Recognize the community as a unit of identity.**
2. **Build on strengths and resources within that community.**
3. **Facilitate collaborative, equitable involvement of all partners in all phases of the research.**
4. **Promote co-learning and capacity-building among all partners.**
5. **Integrate and achieve a balance between knowledge generation and intervention.**
6. **Focus on local relevance of public health problems and ecological perspectives that recognize and attend to the multiple determinants of health.**

7 **Involve systems development using a cyclical and iterative process.**

8 **Disseminate results to all partners and involve them in the dissemination process.**

9 **Involve a long-term process and commitment to sustainability.**

One other overarching concept in this toolkit is Cultural Exchange. **The Cultural Exchange Model is a transactional method** (that is, a method of two-way communication and interaction between different groups of people where each group influences and is influenced by the other) to:

- Facilitate effective communication and collaboration between research and community members
- Increase the relevance of research
- Address end participants' priorities
- Achieve lasting change[13]

In particular, this model would describe researchers as having one "culture" and impacted community members as having a different "culture," and the researchers and Community Board members are coming together as "culture brokers" for one another.

- Cultural exchange is the process of exchanging knowledge, attitudes, and practices between members of different collaborating groups.
- Through iterative, bidirectional communication that allows these different cultures (i.e., community members and researchers) to express ideas, they ensure the research's relevance to real-world practice in community settings and ultimate success.

This model also provides a valuable approach to examining the quality level of the CBPR methods by assessing how well the cultural exchange is functioning between researchers and community partners, ensuring the effective application of CBPR principles.

- As discussed in the **What strategies and processes to use?** section in the **Evaluating and Adapting the Partnership** chapter, we have measured successful collaboration using the Cultural Exchange Inventory[14] adapted to assess exchange between researchers and community partners, followed by a collaborative process to address any deficits observed.

CBPR Principles in Action

We infused CBPR principles into all processes throughout this toolkit, but here we demonstrate the principles in practice. We have not cross-referenced other chapters in this section, but the T**able of Contents** should help you find related concepts and processes. Presented here are some (but not all) ways to apply CBPR in research:

1 Recognize the community as a unit of identity

a. CBPR work itself does this by centering the voices of impacted community members from project inception through implementation and dissemination

b. Utilize bidirectional communication to communicate how the research team acts on community input

c. Ensure privacy and confidentiality, in order to maintain trust with the community

2 Build on strengths and resources within that community

a. Recognize community members' unique contributions explicitly

b. Involve community members as partners throughout the research process

c. Design meetings and communication to convey that the purpose of the partnership is not necessarily to reach consensus on any one issue, but rather to include diverse voices from across the community

3 Facilitate collaborative, equitable involvement of all partners in all phases of the research

a. Provide fair compensation, useful opportunities, accessible meetings, and other supports

b. Define clear roles and expectations for both researchers and community members

c. Establish decision-making processes and guardrails in partnership with community members

4 Promote co-learning and capacity-building among all partners

a. Practice bidirectional communication

b. Regularly evaluate and adapt the partnership with community member input

c. Train research team members well in CBPR principles and practice, as well as destigmatizing language

5 Integrate and achieve a balance between knowledge generation and intervention

a. Consider this when developing goals for a partnership

b. Incorporate community voices into research planning and study implementation

6 Focus on local relevance of public health problems and ecological perspectives that recognize and attend to the multiple determinants of health

a. Ensure partner criteria and recruitment practices cover a representative range of relevant characteristics

b. Incorporate community members into research planning, interpretation of findings (given their lived experience), and study implementation

7 Involve systems development using a cyclical and iterative process

a. Regularly evaluate and adapt the partnership with community member input

b. Provide an opportunity for the Board to reflect on things without researchers present, as well as anonymous formats for feedback

8 Disseminate results to all partners and involve them in the dissemination process

a. Practice bidirectional communication, co-create dissemination materials with community partners, and ensure their access to all results

b. Include Community Board members as presenters or authors in dissemination efforts

9 Involve a long-term process and commitment to sustainability

a. Establish a sustained partnership, including long-term project goals like dissemination efforts (e.g., published manuscripts that include community members as co-authors) and providing information about other opportunities for community members to engage in research

Long-Term Impacts and Benefits of CBPR

Looking back at **Figure 1** and considering the CBPR principles outlined here, applying these in research may seem like a daunting task.

- For instance, sharing power and decision-making with community members may feel unfamiliar to researchers accustomed to more conventional approaches.
- To be sure, using community-engaged research methods does not provide the most straightforward approach—it requires more work and the quality of intellectual humility (see also **The Role of the Researcher(s)** section in the **Clarifying Roles and Expectations** chapter).
- As discussed earlier, if the goal is impactful substance use research—to save lives—then we must use all of the tools at our disposal. Application of these methods have demonstrated their benefits.

On one hand, our research has advanced because of community input through CBPR. On the other, Community Board members have expressed a sense of empowerment, being heard, and feeling part of a system that can improve based on their input. This is the beauty of CBPR in action!

The staff has fostered a sense of community between me, my fellow Panel members, and the research team by staying engaged with me/us. They have been very friendly and interested in what we had to say, making us feel that, for once, somebody was actually listening to us and making us feel that it was alright to open up, that our experience was valuable. Nobody has done that before. In the past we were pushed aside as if we were not valued at all. But not with this team. They have been a breath of fresh air to many of us.

Kimberly Moore

As discussed in the chapter on **Engaging in Research Planning, Study Implementation, and Results Dissemination with Boards**, community members have provided valuable input throughout the research process, including co-creating dissemination materials and helping distribute them—even acting as "champions" for studies.

Last but certainly not least, proven CBPR benefits include improvements in:

- Research design, recruitment, and impact of research findings[15-17]
- Ethical guidelines in SU research[18]
- Identifying crucial harm reduction strategies[19]
- Community support for research and empowerment
- Policy changes
- Healthy behaviors and health outcomes[20]
- Health equity[21]

I feel that researchers thinking of Community Board members as valued partners is empowering. People with lived experience empowers them and the community as a whole. It shows that their voices matter and that they play a critical role in shaping research that affects their lives. The added value is that I feel research outcomes can be significantly enhanced when the experiences and insights of individuals directly affected by opiate use disorder are considered and shared.

Monifa J.

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DEFINING LIVED AND LIVING EXPERIENCE

This chapter provides considerations and processes when you're defining lived and/or living experience of substance use in relation to Community Board creation. Broadly, in the substance use field and as defined in Hogue et al. (2025),[1] lived experience refers to substance use problems that have occurred in the past and can be:

Direct Lived Experience

as in experienced the life event firsthand

or

Indirect Lived Experience

as in experienced the life event through a close family member or other close contact who has direct lived experience (also sometimes called familial lived experience when it is a close family member)

Of course, people without direct or indirect lived experience may have exposure to people with substance use problems personally or professionally, but this typically would be considered to be **remote experience**, as in no close contacts who have firsthand experience of the life event.

Alternatively, **living experience refers to current substance use**. Whether that means use of particular substances, chaotic substance use, or an active substance use disorder depends on the definitions you choose to apply, as described on the next pages.

In our work, we have typically focused on direct lived experience, but **the choice should be driven by your definition of the impacted community you are working with and the goals of your research**. For example, if your project also looks at caregiver perspectives, you could consider involving Community Board members who have indirect lived experience via caring for a loved one struggling with substance use.

Determining Your Definition for Lived Experience

Importantly, the definition of substance use in relation to lived experience needs careful consideration. Are you seeking individuals who have had substance use issues? Had issues with a specific substance (e.g., opioids)? Had a substance use disorder? Received specific types of substance use services? Are in recovery?

Recognize that **perceptions will differ**, so the words you choose to use in your recruitment materials will elicit varied responses from different individuals.

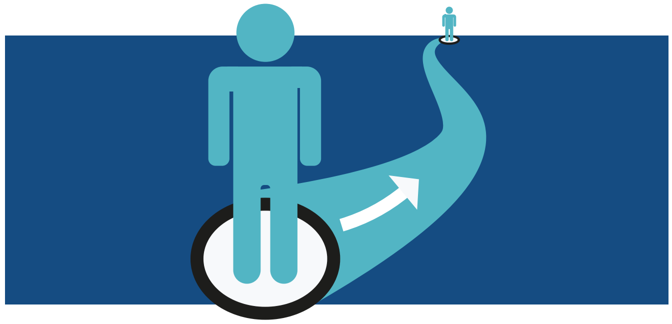
- For example, while some Board members have suggested using "substance use disorder" in our work, the JEAP Initiative's Young Adult Board requested that we instead use "substance use issues." Their reason for this is that some of them said because they hadn't been diagnosed by a medical professional, they don't identify as being in recovery from a "substance use disorder." Given the disparity in treatment access and utilization for emerging adults, issues like this might greatly affect who applies for your Board.

If you use the word "recovery," be aware that there are multiple ways to define it.

- In our work, we allow Board members to **self-identify their lived experience** and have used the definition of recovery provided by the Recovery Research Institute, along with some additional notes. We also have found it useful to be explicit if you want a specific type of recovery pathway (i.e., one of our projects focused on harm reduction, while another focused on medications for opioid use disorder), or else specify that you want a range of recovery pathways. See tips and examples for framing questions about lived experience in the **Appendix**.

Here is a broad example from one of our projects:

> *For applicants to this Community Board, we are using the following definition of recovery:*
>
> *"A process of improved physical, psychological, and social well-being and health after having suffered from a substance-related condition." See more here. We believe that recovery is self-defined, and for individuals coming to a Board with lived experience in recovery, we are open to different recovery pathways, including abstinence-based recovery, harm reduction approaches, medications for opioid use disorder, and other pathways.*



Consider the **timeline for a person's recovery**. For instance, setting an expectation for "time in recovery" may make sense on some projects; for other projects, it may not. This decision can be nuanced, especially for virtual boards, and requires careful thought to promote genuine inclusivity and avoid unintended exclusionary practices.

Recovery is not a linear process with a fixed endpoint; it is highly individualized and encompasses various pathways. At times, setting timeframes for recovery can inadvertently perpetuate stigma and exclude individuals who are actively engaged in managing their substance use but may not fit a traditional, abstinence-based definition of "recovery" or have a specific duration of sobriety. Given disparities in healthcare access and quality, decisions you make may disproportionately affect marginalized communities. This is why a clear definition of recovery is needed.

Alternatively, "time in recovery" may be helpful for Boards where discussions will **focus on long-term recovery challenges, strategies, and services, or policy implications over time**.

Whichever approach is taken, **other factors should be considered along with or without a "time in recovery" component**. These may include:

- Amount of current recovery capital when selecting Board members, such as asking about social supports and coping mechanisms
- Readiness to engage in the work (e.g., can they commit to attending meetings, fulfilling tasks, and contributing consistently?)
- Commitment to the Board's purpose
- Diversity of perspectives related to the proposed work

These aspects can be assessed through initial conversations and by offering clear expectations. See the **Selecting Community Board Members** chapter for more information.

More considerations about "Time in Recovery" can be found on the next page.

Remember: People who have lived or living experience by these definitions may still not identify with those terms. Language is living, and so is our terminology, especially around identities that carry stigma.

Decision-Making Around "Time in Recovery" Requirement

Depending on the project, we have decided whether to include a "time in recovery" requirement or not. For example, because of the large size, diverse perspectives, and potential for triggers for opioid use problems on the HEAL Connections Panel meetings, members were asked to have a minimum of one year in recovery to promote stability in recovery, although this certainly is not a guarantee.

Example wording on webpage:

> *Because the Panel members' well-being and recovery are of primary importance, we ask that members with lived experience in recovery from opioid use disorder have a minimum of one year in recovery and that all Panel members have solid supports in place before joining the Panel.*

Alternatively, the CHEARR investigative team carefully considered whether Board members should have a minimum length of time in recovery before serving on a Community Board. Given the varying definitions of recovery and our emphasis on respecting individuals' autonomy in deciding whether serving on a Community Board is right for them, we opted NOT to set specific guidelines for length of recovery. Instead, during the selection process, we thoroughly described the opportunities provided by serving on the Boards, including the topics expected to be discussed during Board meetings, and encouraged prospective Board members to determine whether their interests and stage of recovery align with the goals of the project. In addition, it was made clear to Board members that they may step away from their position on the Boards for any reason (recovery-related or otherwise) and at any time.

Whichever decision you make, you should be sure to have an internal process in place should a Board member return to chaotic use of substances. See the **example from HEAL Connections** below:

> *A return to substance use after being selected as a Panel member would not result in automatic removal from the Panel, but a collaborative decision with the Panel member would be made about their continued involvement with the Panel, with a primary goal of supporting their recovery journey and physical and mental health. A Panel member's supports for their recovery and/or pain condition (e.g., recovery capital including social supports) would be considered.*

Considerations for Engaging Community Members with Living Experience

Most of the processes detailed throughout this toolkit apply for those both with lived and living experience. However, our experience is that working with community members with living experience requires some distinct considerations.

Having a Board with members both in recovery and members with active substance use disorder **could create concerns for members**, including greater potential for triggers for those in recovery, low support for those with active use, and conflicts between members who have widely divergent views about ongoing substance use.

While there is also potential for risk of people in recovery to return to use, if Board members are people with active substance use disorders, the research team may want to **develop risk protocols and explore supports** that are local to members, similar to what they might do for research participants with active substance use disorders.

Stigma is greater for people with living experience, and the consequences of disclosure of living experience may be greater (e.g., legal issues). Therefore, establishing clear guidelines for confidentiality, particularly regarding personal experiences shared, as well as how information will be used, stored, and disseminated to protect Board members' privacy is essential.

Recognize that individuals with active substance use disorder may **face unpredictable challenges**. Be flexible with meeting schedules, attendance expectations, and the overall structure of the board. Consider if the length of meetings needs to be adjusted. Allow for breaks or a temporary leave of absence if needed.

Consider **keeping activities local** (or virtual) so individuals can have access to their familiar surroundings, providers (especially in the case of MOUD), and supplies for physical needs. When travel is involved, planning ahead for exposure to potential triggers (e.g., alcohol served on flights/in hotel lobbies), discussions of safe places and times to use, and planned support (e.g., support in finding or attending local meetings) is needed.

An extension of this comes up if you are engaging family members and caregivers of someone with substance use disorder. **Consider the differences** between family members/caregivers of people who are actively using substances, recovered from substance use, or have died due to substance use. Combining these groups could mean members easily trigger each other (e.g., unintentionally causing an adverse emotional reaction in a parent whose child died of overdose when another parent discusses their living child's active chaotic use).

Remember: Hiring research staff with lived experience, especially when you are determining definitions and terminology for a project, can be crucial for genuinely incorporating diverse voices and ensuring their insights influence all levels of research involvement and decision-making.

Chapter reference(s)

1. Hogue, A., Satcher, M. F., Drazdowski, T. K., Hagaman, A., Hibbard, P. F., Sheidow, A. J., Coetzer-Liversage, A., Mitchell, S. G., Watson, D. P., Wilson, K. J., Muench, F., Fishman, M., Wenzel, K., de Martell, S. C., & Stein, L. A. R. (2024). Linkage facilitation services for opioid use disorder: Taxonomy of facilitation practitioners, goals, and activities. *Journal of Substance Use and Addiction Treatment*, *157*, Article 209217. https://doi.org/10.1016/j.josat.2023.209217

DECIDING ON OVERARCHING GOALS, OBJECTIVES, AND RESEARCH TEAM TRAINING

What is the goal for establishing this Community Board?

Be clear about what your focus is and what change you aim to achieve within the scope of your work. For the JEAP Initiative, which focused on building research infrastructure, the following goal was the starting point:

In partnership with our Community Boards, the JEAP Initiative aims to advance research on the effectiveness of peer recovery supports and recovery residences for emerging adults and justice-involved adults with substance use disorder through:

- Identifying priority areas of research via engaging individuals in recovery and providers/payors
- Growing the field of skilled early career investigators, particularly those with lived experience, focused on this research
- Providing seed funds and guidance to produce preliminary studies for National Institutes of Health funding
- Conducting dissemination and outreach to the larger field

Later, the JEAP Community Boards and investigators worked together on a vision statement that took a wide variety of voices into account and encapsulated the overarching goal in this way:

Our work starts and ends in meaningful partnership with impacted communities. We envision a world where recovery housing and peer recovery support services are equitable, effective, and accessible for all communities. Our mission is to elevate the voices of people with lived experience to inspire quality research affecting young adults and those with criminal legal system involvement.

It is important to have people with lived experience working with your team because we have knowledge and wisdom that you can never get from a book. We are not numbers in the research. We are the real deal. Actually, you can't even buy our experience. Our experience is more than valuable, it's priceless. We lived it.

Kimberly Moore

What objectives could help you reach that goal(s)?

Decide the level of community engagement you wish to pursue.

- There is a spectrum of community-engaged research, from community consultation all the way to community-led (see **Figure 1**). CBPR is a type of community-engaged research that is a partnership between researchers who are not from the impacted community and community members, including joint decision-making about research activities and goals.
- Our belief is that all community-engaged research is helpful to finding effective solutions faster, but what level of community-engaged research can be achieved may vary.
- Decide what level is achievable for you by reviewing this article (Key et al., 2019).[1]

***Figure 1*. Spectrum of Community Involvement**

> *There is also a general distrust among individuals with lived experience and "experts" or those in positions of authority. Knowing that someone who has also been through what they have been through is working with these researchers, it gives the researchers validity. It "vouches" for them and the work they are doing. Community Board members also have valuable insights into how to get the information to the population they are from and what modes of media are most effective or most often used. They can help make the information presentable and understandable for those members of their community.*

Leonor Gualchi

Ask specific questions about the nature and make-up of the Community Board or other key roles.

- Who needs to be reached in terms of lived experience? Who needs to be reached in terms of specific communities related to the focus of our research?
- If we are focused on an intervention, services, or a particular population, who are the stakeholders of that, and do we need to have more than one kind of stakeholder involved in multiple Community Boards, or is it appropriate to combine into a single Board? While diversity is useful, having fundamental things in common may be important, along with considering potential hierarchy/authority issues (e.g., young people or peer supports with physicians).

Examples of having combined or separate Boards:

JEAP Initiative

In JEAP, there were **three** stakeholder groups identified, to ensure that each had a distinct voice and were able to discuss in depth among themselves, although annually these three Boards come together in a virtual two-hour Retreat:

- **Young Adult Community Board** – This Board is made up of emerging adults (age 18–25) who are in recovery from substance use.
- **Justice-Involved Community Board** – This Board is made up of adults who are in recovery and who have former or current involvement with the juvenile or adult justice system.
- **Provider and Payor Community Board** – This Board is made up of staff from organizations that provide or pay for recovery support services.

CHEARR

In CHEARR, **two** Community Boards were created and meet separately:

- **Young Adults in Recovery Community Board** – This Board is made up of young adults (ages 18–28) who are in recovery and have lived experience receiving treatment involving medications for opioid use disorder.
- **Peer Recovery Support Specialist Community Board** – This Board is made up of certified peer recovery specialists and recovery coaches who have experience working with young adults.

HEAL Connections

In HEAL Connections, a **single** Panel was created and meets, but there are **11 different Subpanels** representing distinct priority populations (African American/Black, family/caregivers, Hispanic/Latino/a/x/é, Indigenous, legal system-involved, LGBTQI+, pregnant or postpartum) and some topics such as Landscaping Mapping for each community was completed during separate Subpanel meetings.

What training might be helpful for research team members who work with the Board(s)?

Gaining foundational knowledge can help a research team foster respectful and effective collaboration with Community Boards. It prepares everyone to engage meaningfully in this valuable partnership. We have found it helpful to tailor training to fit the needs of each staff member, **depending on their prior experience with community-engaged research and their familiarity with the populations involved**.

Additional recommendations are available in the Appendix.

To determine what training is most appropriate for each research team member, consider the following key areas of training and other items.

Community-Based Participatory Research (CBPR): Is anyone on your team new to CBPR, or just curious to learn more? Understanding the principles of CBPR has been incredibly valuable to our team. The following examples feature several modules with varying time commitments, ranging from two hours to several days. Please note that some options may have associated fees*:

- Collaborative Institutional Training Initiative (CITI) CBPR Course*: Explores the benefits, challenges, and value of CBPR from the perspectives of researchers, community members, and local organizations.
- University of Rochester CBPR Training: Covers foundational principles, communication, funding, and sustainability.

De-Stigmatizing Language: Gaining a deeper understanding of the nuances of language, particularly regarding preferred terminology, can benefit everyone involved. While the words and phrases we use often depend on the individual, it's crucial to keep these ideas in mind when collaborating with the Board(s).

People with lived experience recognize all the harmful language that is used to describe us. We need to know that people are learning how to identify with us. This is important because some people with lived experience have not moved away from using stigmatizing language themselves.

Jose Nicolas Flores

TIP

Here are some lessons we have learned in our work:

- Some terms are easier to identify as offensive, while others are more subtle. For example, using "clean" to mean drug-free or abstinent is widely viewed as stigmatizing, while **"Medications for Opioid Use Disorder (MOUD)" vs. "Medication-Assisted Treatment (MAT)"** reflects an ongoing shift in the preferred terminology that some individuals may use.
- Supportive and affirmative language can vary by community. Meet people where they are and ask them which phrases feel most comfortable for them.
  - For example, individuals impacted by the criminal legal system may refer to it as the **criminal justice system, criminal legal system, carceral system, criminalization system, or other terms**.
  - We have found it important to let people from a given community use language to describe themselves, while also being provided de-stigmatizing alternatives for describing others in group settings. For instance, individuals may refer to themselves as an "addict," especially based on what programs were critical to their recovery, but other individuals may find that label and non-person first language to be stigmatizing.
- JEAP Initiative – Language & Imagery Resources is a great starting point for learning how to use non-stigmatizing language across different populations.

Implicit Bias: Implicit bias is a normal cognitive process that affects everyone. It includes the unconscious attitudes or stereotypes that influence our perceptions, decisions, and actions, driven by brain processes that operate outside of our awareness, based on the neuroscience of cognitive associations. An initial training like the one below may lead team members who are curious to delve into more in-depth trainings:

- The University of Michigan offers a free 1-hour webinar on-demand that explores the neuroscience of implicit bias, its impact on health outcomes and organizations, and offers science-based strategies to challenge and change biased behaviors: Implicit Bias: Using Brain Science to Understand, Recognize, and Counter It

Be open to learning more about the community with whom you hope to partner: What prior experience do you have with this particular community? If you have none, that's perfectly fine, so long as you take responsibility for increasing your knowledge and exposure. Some individuals also may be interested in training on cultural humility. Below are some steps you could take.

Ask yourself, or research, the following questions about the community:

1. **What current developments in the local or national sphere are relevant to this community?**
2. **What are some current challenges facing this community?**
3. **What are current topics of conversation within this community?**

Here are a few actionable steps to help you approach these partnerships with greater awareness and understanding of the community with whom you want to partner:

Follow relevant news: Keep an eye on national (or local, if your Board focuses on a particular area) news stories that impact this community. If you're short on time, you might ask Google or AI for a weekly or monthly roundup of top news stories affecting that community.

Join newsletters: Subscribe to newsletters from organizations relevant to that community. This can be a helpful way to hear about current topics affecting that population. For instance, if you're forming a Community Board of individuals impacted by the criminal legal system, consider signing up for newsletters from organizations like From Prison Cells to PhD, Formerly Incarcerated College Graduates Network, and Just Leadership USA.

Listen to podcasts: If you enjoy listening to podcasts, this can be a great way to learn more about a particular community. Not sure where to begin? Try asking Google or using your favorite AI software, "What are the top ten podcasts or podcast episodes I should check out to learn more about the _____ community?" You can also search specifically for episodes related to that community and substance use.

Use social media to expand your knowledge: If you use social media in your personal life, consider following public figures or influencers from that community. Since each community is not a monolith, aim to find individuals from a range of different perspectives. If you're uncertain where to start, you can ask Google or use an AI platform of your choice to generate a list of top public figures or influencers from a particular community, and "follow" some. After this initial 10 minutes of setup, during your regular time on social media, you'll also gain insights into different perspectives from this community.

Engage locally: To gain more experience engaging with this community face-to-face, are there any local events you can attend that are relevant to this community, or local groups you can get involved with?

Attend webinars: Look for webinars or panel discussions related to this community (see the tip above about joining newsletters). These can be helpful ways to expand your knowledge and hear directly from individuals in that community.

Chapter reference(s)

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CLARIFYING ROLES AND EXPECTATIONS

Researcher(s)	• Organizers of the project/program • Individuals who spearhead the project/program
Research Staff	• Staff of the project/program who contribute to the operations of the Community Board
Community Board Members	• Individuals with lived experience or from a specific impacted community • Considered experts on these research areas both personally and very often professionally • Do not need formal training to share their expertise • May appreciate some lay training about research and research methods prior to giving guidance about specific research studies • Are not research participants/subjects • Are partners in this work

The Role of the Researcher(s)

For community-engaged research, depending on where in the spectrum a researcher is able to reach, the role of the researcher can vary: from guiding the conversation and gathering input from the impacted community, to listening and being responsive to the community's priorities, to partnering with the community such that each is bringing unique expertise to the table and sharing in decision-making. And, of course, a researcher also may be from the impacted community.

TIP

A brief note on **researchers being from the impacted community:** a researcher may need to be careful to listen to perspectives that differ from their direct experience, but this is no different in substance use research than for any other area of research. Further, all researchers must check for biases, and strategies (e.g., from anthropology research methods) can be used to help such researchers reduce potential biases.

In high-quality CBPR with Community Boards, the researcher should bring a perspective of **humility, reciprocity, respect, and transparency**. See also the section on **What training might be helpful for research team members who work with the Board(s)?** The researcher plays multiple roles that **balance scientific rigor with community engagement**, including:

Overall Role

- Rather than acting as an external expert, the researcher collaborates with the Community Board as partners, ensuring their voices shape the research process
- Ensures that the work is conducted ethically, addressing power imbalances, protecting confidentiality, and prioritizing the benefit to the community
- Translates research findings into meaningful actions or policies that address the needs and priorities of the Board members' communities
- Supports Board members in developing research-related knowledge and skills, while also learning from the members' lived experience
- Acknowledges that knowledge is co-created, valuing both academic expertise and community expertise
- While integrating community input, the researcher ensures the use of rigorous and valid research methods that are appropriate and tailored to the community

It is the **researcher's responsibility to do their own due diligence and take steps to avoid tokenizing** Community Board members. Concretely, the researcher's role includes the following responsibilities:

Concrete Strategies

- Establishes and maintains trust, including being honest about their limitations in knowledge and expertise
- Uses active listening and transparency
- Selects a study design and methods that are ethical and sound while incorporating Community Board input
- Provides training, support, and linkages to help Community Board members
- Advocates for fair compensation and recognition for Community Board contributions
- Makes research findings accessible and actionable, with plain language and accessible formats
- Supports community-led initiatives that may arise from the research
- Remains engaged beyond a single study
- Does their homework: spends time to understand community priorities, history, and concerns before approaching the community with ideas
- Does member-checking, circling back to ensure that you accurately captured the views of Board members and that research ideas align with their perspectives
- Co-develops materials with the Community Board and acknowledges Board input
- Protects their confidentiality (more on this is provided in the **Ensuring Privacy and Confidentiality** chapter)
- Leads data analysis, but ensures Board members are involved in guiding analyses and interpretation, as well as dissemination of findings

Once the Board is established, **researchers are "guests" who visit a Community Board meeting** to obtain guidance. In fact, we start and end our Community Board meetings without researchers present See below for **The Role of Research Staff** section and also the chapter on **Organizing Meetings and Agendas**.

> *A benefit to research teams considering starting and ending their Community Board meetings without any guest researchers in the room would be clear and honest responses from members. Despite the kind and mindful approach we have seen from researchers on this team, there is still a potential to adjust our answers, even subconsciously, when there are individuals with such high status around us. This is the reason why the prioritization of researchers with lived experience is so important, as it minimizes the likelihood of this outcome.*

Brenda Huerta

The Role of Research Staff

Research staff may include individuals in various roles within the research team who support community-engaged work with the Community Board, such as a Project Coordinator or Research Assistant. Depending on the size of your team and the structure of your project, multiple staff members may support the Board, or it may be handled by a single person. More information on workload planning is offered in the **Types of Staff Support Needed** section in the **Addressing Administrative Considerations Before a Community Board Is Established** chapter.

Some responsibilities included in the role of research staff are:

- Conducts recruitment steps for new Board members
- Collaborates with researchers on selection processes
- Develops Board training materials as needed
- Ensures completion of any required paperwork (e.g., agreements) for Board members
- Builds the network for recruitment, including making recruitment materials
- Organizes orientation for new members
- Corresponds with Board members, using formats Board members prefer (e.g., email, phone call, text message, various social media platforms)
- Schedules Board meetings or other activities

- Coordinates with any guests outside of the immediate research team
- Ensures Board receives materials in time to review ahead of meetings
- Assists with use of non-stigmatizing language and imagery
- Supports the ongoing engagement of Board members such as by identifying opportunities for them
- Processes stipend payments for Board members and tracks budget
- Collaborates with researchers and the Board to develop knowledge translation materials (including website, if applicable)
- Prepares materials for Board meetings (agendas, slides, talking points, materials for Board members to review)
- Prepares the facilitator prior to Board meetings
- Provides logistical support during Board meetings (e.g., sharing slides, monitoring chat, technical problem-solving, note-taking)
- Ensures bidirectionality of communication (e.g., member-checking with the Board)
- Creates surveys for Board members to give feedback on the collaboration
- Protects confidentiality of Board members

Through all of these tasks, staff members frequently serve as the first point of communication that Board members have with the team. Along with the researchers, staff must ensure that CBPR principles are applied throughout all processes involving the Community Board. It is essential for staff to approach this role with the values of humility, reciprocity, respect, and transparency. See also the section on **What training might be helpful for research team members who work with the Board(s)?**

TIP

We encourage you to consider employing people with lived experience with substance use or the criminal legal system for staff positions, as they bring additional expertise to their work with Community Board members. Most of the individuals on our team have either direct or indirect lived experience of the research areas we focus on. These insights and perspectives have significantly contributed to the success of our Community Boards.

> *It is important for researchers to prioritize employing people with lived experience on their team so that Community Board members who often have feelings of shame or guilt can be more open to talking about their true, raw experiences. Knowing that someone has lived experience would enable a Community Board member to share openly with limited fear of the stigmatized responses they are accustomed to.*

Brenda Huerta

The research team emailed us different opportunities, but most importantly in the beginning OF ANYTHING they always said whatever feels comfortable for YOU. They always said this was a safe space and they also allowed us to go by the name we choose or to step away if something triggered us. They were very aware of us and our own personal needs above the reason for meeting.

D'Layna Reitz

The Role of the Community Board Member(s)

This includes individuals with lived experience, those who belong to a specific community, have held a relevant role in the continuum of care, or are otherwise connected to the community we aim to engage. Examples of tasks a Community Board may take on include: determining research priorities, providing guidance to investigators, identifying preferred methods, problem-solving barriers, developing plans, co-producing knowledge translation materials, or driving dissemination plans. Use the sections on **What is the goal for establishing this Community Board?** and **What objectives could help you reach that goal(s)?** to help you determine what the specific role of the Board for your project/program should be.

Broadly, Community Board members:

- Are considered experts on these research areas both personally and very often professionally
- May appreciate some lay training about research and research methods prior to giving guidance about specific research studies
- Are not research participants/subjects—that means they will not be compensated like research participants, but instead be compensated as expert consultants (see the chapter on **Addressing Administrative Considerations Before a Community Board is Established** for more details)
- Do not need formal training to share their expertise, but when they possess formal training, that should also be honored and acknowledged (for example, if Board members are acknowledged on the website, they should have any credentials they'd like listed such as PRSS, MSW, PhD)
- Are partners in this work

Community Board members can benefit from opportunities for leadership, so aim to create leadership roles as makes sense for your Community Board:

- Examples include a facilitator or co-facilitator and a timekeeper.
- Of note, we utilized "Facilitator" for the JEAP Initiative to reduce a sense of hierarchy, but the Board on another project decided they wanted to use the term "Chair" because it is a more helpful title for their resumes.

Community Board members bring the work of the experts to life—where the rubber meets the road. While the results of the experts might look great on paper, the Board members can identify roadblocks or sticking points in the practical application of the research.

Bob Jordan

Additional Role Requirements

Here are some additional aspects about roles of the Board members and research team (both the Researcher and the Research Staff):

Additional Role Requirements	Board Members	Research Team
Meeting Attendance	**Be Consistent:** • Ensures they are receiving all necessary information provided **Be Fully Present:** • Shows value of one another and the facilitator (may be fellow Board members) • Allows for learning about the topic and engagement in the group discussion **Meeting Flexibility:** • Be willing to be flexible with scheduling (including evenings or weekends) and to adapt to a different meeting date and time to accommodate the needs of the group	**Be Consistent:** • Show Community Board members that you care about their time and experiences **Be Fully Present:** • Ensure engagement with Community Board members throughout the meeting • Show Community Board members that you are interested in their contributions to the discussion **Meeting Flexibility:** • Be willing to be flexible with scheduling (including evenings or weekends) and to adapt to a different meeting date and time to accommodate the needs of the group
Honesty	• Honesty about what they are and are not comfortable with for participation or sharing	• Honesty about what you can and cannot do within a meeting or within the confines of your CBPR work

Additional Role Requirements	Board Members	Research Team
Confidentiality	**The Right to Confidentiality:** • Community Board members have the right to keep their information private and have the choice with how much they choose to share about their personal lives **Keep Information Confidential:** • Community Board members should not share what is discussed during meetings to protect the ideas of the researchers and to protect the personal information of other Board members who wish not to reveal their identities publicly	**Explain Confidentiality:** • Ensure Community Board members understand confidentiality and help protect against the sharing of information that could reveal identities or prematurely disclose research ideas or findings **Keep Information Confidential:** • Ensure all forms filled out by Board members are kept organized and private • Ensure all emails sent to Community Board members are sent to the correct individual • Double check for the correct email, name(s), and information being disclosed during your communication • Do not mention anything confidential during meetings that you have learned about a Community Board member that they themselves have not shared with the rest of the Board
Preparation for Discussions	**Come Prepared:** • Watch and/or read all of the pre-materials before attending Board meetings	**Come Prepared:** • Practice using lay language and non-stigmatizing language • Know if any Community Board members have contacted you about not being able to attend any upcoming meetings • Know which information is being covered in the meeting and have any supporting materials • Know what/if any materials will be provided after the meeting

Processes for Establishing Community Board Members as Experts and Contracting

Present the Community Board as expert consultants within the grant application.

- If needed, advocate with your institution's legal and IRB leadership that Community Board members are considered expert consultants rather than research participants.
- When describing a proposed Community Board within a grant submission, make it clear that these individuals will be expert consultants and partners in the project so that reviewers understand they will not be research participants.
- Generally, Community Board members do not need to be listed in the NIH grant proposal Protection of Human Subjects forms if they are compensated and presented as expert consultants.
- However, even though they are not research participants, it is a good practice within the grant to describe how you will protect their information and the process they will undergo to be selected for the Board and agree to serve on the Board.

Confirm with your institution's contracting office what type of contract and other paperwork will be needed from Community Board members.

- Review the standard contract language and, as needed, request modifications:
  - Board members may come from various age groups, professional backgrounds, and education levels, and they might not have previously served as independent contractors or dealt with these types of contracts. Consequently, some standard contracts may appear off-putting because of the extensive 'legalese' they often include.
  - The amount of flexibility may vary by institution, so consider discussing the role and purpose of the Community Board with your institution's contracting office to see if any modifications are possible.
  - Our team worked with our institution's contracting/legal team to create a modified and shortened version of the independent contractor agreement specifically for Community Board members.

A note about language: when communicating with Community Board members, it is helpful to refer to this as an 'agreement' rather than a 'contract.'

- Depending on your organization's requirements for a legal agreement and the extent to which it can be modified, it may also be helpful to have a **separate informal agreement** that outlines the expectations and includes details such as:
  - Expectations about attendance (e.g., attend at least 75% of all meetings)
  - Average meeting lengths
  - Expectations about active participation
  - Stipend amounts or hourly rates
  - Standards of confidentiality

See examples of Board Agreements in the Appendix.

We have found it helpful to **set the standard length of commitment at one year** and state this in the agreement. This allows for revisitation of the agreement at the end of each year to ensure that everyone is on the same page and willing to continue in the mutual collaboration. If a Board member has not been able to attend regularly, this also provides an opportunity to bring someone else onto the Board.

Find out what **signing method** will need to be used for any required paperwork. Our team has found DocuSign to be the most user-friendly and accessible tool for Community Board members, as it enables signing on a computer or phone without the need for printing.

Confirm with your institution if a **W-9 form or any other paperwork** is needed.

Confirm whether a background check is required for independent contractors. If this is typically a requirement, advocate for flexibility, such as exempting Board members or allowing consideration of the nature of any previous charges. When making this case, be sure to explain the Board members' role within your work (e.g., whether they will be remote or not interacting with research participants), highlight the valuable expertise they bring, and acknowledge that some members may have a criminal record.

If a background check is required, include this information in your recruitment materials so prospective Board members are aware upfront. You could also consider adding an FAQ to your Community Board webpage, clarifying whether a criminal record automatically disqualifies someone or if exceptions are possible.

Confirm with your institution's contracting office what types of payments are possible for Community Board members.

- See the **Stipend Payment Options** in the **Community Board Stipends and Budget Considerations** subsection below for more information.
- Ideally, include this information in your grant submission, as well as later in your recruitment materials for the Community Board.

Special Administrative Considerations for Minors and Individuals Currently Incarcerated

For Community Board members **under the age of 18**, take the following into consideration:

- You will need additional forms for parents/guardians to sign (confirm with your institution's contracting office).
- Consider the interactions that could be had between the adults and minors who are on the Board (either virtually or in-person) and any protections required.
- Are there any state laws that apply to minors who engage in Community Boards?

For individuals who are **currently incarcerated,** take the following into consideration:

- Are there any contracting hurdles from your institution?
- Do you have some flexibility in payment methods if someone has constraints about how they can receive payment?
- Would it be acceptable for Community Board virtual meetings to potentially be monitored, which may be the case for someone who is currently incarcerated?

Optimal Number of Board Members

You will want enough members to allow for diverse perspectives while still maintaining a manageable group for discussion and decision-making.

Balance perspectives and participation

A Board that is too small may lack varied viewpoints, while a Board that is too large can make interactive discussions challenging.

Typical Board size

In general, our Boards have ranged from 8–11 members, which has worked well for fostering discussion and maintaining engagement.

Budget for your Board size

Plan your budget based on your target number, but keep in mind that actual attendance will fluctuate.

Decide between a single Board or multiple Boards

If you want to include a wide range of different perspectives and roles within the Board, such as emerging adults, family members/caregivers, and leaders of recovery organizations, consider whether that can work effectively within one Board or if you need to break it into more than one Board.

Consider a slightly larger Board

Since Board members have busy lives, it's unlikely that all members will attend every meeting. This is particularly true for emerging adults, whose schedules may change frequently. To ensure a strong turnout at each meeting, recruit 1–2 more members than your target size.

Community Board Stipends and Budget Considerations

Community Board Member Stipends

Anyone who works on the project **deserves to be fairly compensated** for their time. These individuals include both research staff and Community Board members. Equitable compensation models honor the value of Board members' time and expertise that they contribute to the project.

The compensation rates we currently use for Community Boards were established through the HEAL Connections project, a collaboration of 22 organizations including several patient advocacy groups led by individuals with lived experience.

- The standard stipend rate set by this project was $50 per hour, which should include time spent attending meetings as well as any pre- or post-meeting preparation.
- For example, a 60-minute virtual meeting with one hour of preparation would result in a stipend of $100.
- Similarly, a 90-minute virtual meeting with 1.5 hours of preparation would result in a stipend of $150.
- When you communicate the compensation rate to Board members, it is helpful to be clear that the pre- or post-meeting preparation is a part of what is being compensated so that members feel their time and contributions are fully valued. That is, instead of saying the rate is $100 per meeting, state that the rate is $100 for each one-hour meeting **plus** approximately one hour of preparation and follow-up time—**two hours total** for each meeting including prep work.

A brief resource describing compensation considerations for various types of community-engaged research is provided by the **Patient-Centered Outcomes Research Institute**:

PCORI - Financial Compensation

For Board members serving in a leadership role, an increased stipend might be appropriate.

For example, when our team has had Board members serve as co-facilitators, they have received an additional stipend of $50 per meeting. This amount covers a brief meeting with the research team prior to the Board meeting, the preparation time they invest independently, and serves as compensation for their enhanced role during the Board meeting.

TIP If Community Board members are paid as independent contractors, there is an IRS threshold of when that income becomes taxable. You could also consider this when determining what the total compensation per calendar year will be. See further information at the link below:

Reporting Payments to Independent Contractors

Stipend Payment Options

Each institution has its own policies about what forms of payment will be allowed for Community Board members. Below are the payment methods our team has utilized, along with the pros and cons we've encountered with each.

	Pros	Cons
Electronic Gift Card	• Usually a shorter processing time for Community Board members to receive payment • Simple to distribute and redeem • Many different electronic gift card platforms can be used ◦ Tango ◦ Tremendous • Typically can be used at a wide range of retailers, offering flexibility	• Some gift cards may come with activation or usage fees • Some funders may restrict funds from being used to pay for fees • Restricted to specific retailers, which may not be convenient for all recipients • Some gift cards may have expiration dates or inactivity fees • Some institutions may not allow this as a payment method for Community Board members
Direct Deposit	• Funds are transferred directly to the recipient's bank account, reducing the risk of loss or theft • No need for physical handling or trips to the bank • Typically, there are no fees for the recipient	• Recipients must provide their bank account details, which some may be hesitant to share • Individuals may not have a bank account
Physical Check	• A check is mailed to the Community Board member and can be cashed or deposited • Can be cashed at various locations, including banks and check-cashing services	• Takes time to mail and receive • Checks can be lost or stolen in transit • If lost or stolen, there may be a fee for having to reissue the check • Recipients need to visit a bank or check-cashing service to access the funds • Some check-cashing services may charge fees

Other Stipend Considerations

Our institution requires an invoice for each payment, but we have been allowed to utilize a **Microsoft Form** that the member completes. At your institution, find out what types of invoices are acceptable so that you can make the form and process as straightforward and easy as possible for Board members.
The goal is to make being compensated as seamless as possible, rather than someone feeling like they need to jump through a lot of hoops to be paid.

See example form in the Appendix.

Some groups of individuals are not able to accept stipends or would have potential impacts from accepting a stipend:

- Federal or state government employees: May be barred from accepting stipends.
- People who are using their work time to participate: May be barred from accepting stipends.
- People who are currently incarcerated: See the **Special Considerations for Community Boards with Populations Who Have Criminal Legal System Involvement** section in the **Establishing Criteria for Board Membership** chapter.
- Individuals on public assistance/public benefits/financial need-based funding for school: Mention to Board members that if the compensation exceeds the IRS threshold for contractor income, it will be taxable and it will be part of their total income for that year.
- Individuals who prefer to donate their stipend: It may not be possible for your organization to transfer stipends directly to another organization—especially if the recipient is an advocacy organization and the grant is NIH-funded.
    - See info here: Lobbying Guidance for Recipient Activities
    - Instead, the Board member may choose to accept the stipend themselves and personally donate it to their organization of choice.

IRS Guidelines:

- Reporting Payments to Independent Contractors
- Taxable and Nontaxable Income

Budgeting for Other Meeting-Related and Communications Expenses

If you are holding Board meetings in-person, consider **additional costs** you should budget for:

- Space/location rental
- Audiovisual equipment
- Printing costs for materials
- Transportation or parking costs for Board members
- Childcare costs for Board members
- Refreshments (if allowed)

Think holistically about what barriers individuals may face for participating in meetings (such as transportation and childcare) and get creative with how you can address those challenges.

If there will be other communications needs, consider if there are additional costs you should budget for (note that some tools provide a discount to nonprofits):

- Website design and hosting costs if you are creating a new webpage
- Tools like Mailchimp for sending newsletters/bulletins to Board members about opportunities (can also be done via email)
- Cost for virtual cards (like Kudoboard) to celebrate big events that Board members share (such as recovery anniversaries, promotions, graduations, having a child)
- Tools like Qualtrics or Microsoft Forms for Board application forms and for anonymous feedback forms after Board meetings
- Zoom or a similar easy-to-use platform if holding virtual meetings
- Zoom Phone or a similar tool if planning to use texting from your project as a method of communication with Board members (Google Voice may be a free option)
- Canva Pro or a similar tool for creating recruitment or other materials (a free version is available)
- A DocuSign subscription or a similar tool for Board members to electronically sign agreement forms or other required paperwork

Budgeting for Community Board Travel

If you are able to offer in-person opportunities to Board members, check out the **What We've Learned about Supporting Board Members' Travel** section within the **Sustaining Meaningful Connections and Engagement with Board Members** chapter.

Can Board members co-present at conferences? When preparing your budget, consider including funds to cover travel costs for Board members to co-present at conferences. When offered, these opportunities have been highly valued by our Board members.

Can a virtual Board meet in-person at some point? If your Community Board will be entirely virtual, consider whether you can budget to bring Board members together in person at some point—either at a conference or just for an in-person meeting at your organization. This is something that has been highly requested by our Board members, and in the situations where we've been able to make this happen, it has been very much appreciated.

In addition to compensation, another way that researchers can ensure that Community Board members feel like a valued part of the team: conferences, conferences, conferences!!! Invite us to the places they are sharing their research. Pay for travel and lodging. Let us be included in your conversations about us.

Jose Nicolas Flores

Alternative Forms of Compensation

If you don't have a budget or have a limited budget (e.g., student project), consider providing other forms of compensation or appreciation that would be meaningful to Community Board members:

1 In-Kind Contributions

Professional Services: Offer technical or specialist services that may fall within the expertise of your researchers or research team members.

- Examples include assistance with grant writing, review of grant proposals, evaluation or economic evaluation services, and data analysis.

Training and Development: Provide access to workshops, training sessions, or professional development opportunities that can benefit Board members.

- Are there trainings or opportunities offered by your organization that Board members could join?
- If your team or your collaborators organize workshops or conferences that have a registration cost, could free registration or a discount code be made available to Board members? Some events may welcome opportunities to increase the participation of individuals with lived experience.
- Based on the interests of Board members, is there skill development you can offer specifically to the Board members?
- Is there mentorship you could provide or could members of your team be available for "informational interviews" for Board members to learn about various job options?

If you are providing a stipend to Board members, it's still important to consider other forms of appreciation, as they help ensure Board members feel valued in your collaboration.

2 Co-Authorship

If you are writing publications or creating dissemination products, and some Board members might benefit professionally from co-authorship, you could offer this opportunity.[1] Once the paper or product is published, send them the citation so they can add it to their resume.

3 Resource Sharing

Access to Facilities: Allow Board members to utilize organizational facilities or resources, such as meeting rooms, office equipment, or software tools.

Networking Opportunities: Facilitate connections with other professionals, organizations, or networks that can help Board members in their personal or professional growth.

Being part of a group focused on mutual goals fosters a sense of belonging and camaraderie. It is rewarding to work alongside like-minded individuals who are passionate about making a difference. Participation in the panel has increased my visibility in my professional community. This recognition can lead to further opportunities and involvement in similar initiatives.

Monifa J.

I have greatly appreciated the opportunity to get more involved within the Board by becoming a co-facilitator and by receiving guidance from staff and researchers who are in positions I strive to be in one day. As a first-generation student and college graduate, having the opportunity to ask questions to people in academia and in research is extremely beneficial to my own efforts to be in similar positions one day.

Brenda Huerta

4 Recognition and Appreciation

Awards and Acknowledgments: Recognize Board members' contributions with:

- Certificates
- Awards
- Public acknowledgments: For example, if you are doing a press release about your study, consider asking Board members for a quote you could include.
- Thank-you cards: A member of our team served on a panel of individuals with lived experience and received a handwritten thank you card afterward, acknowledging the specific expertise they brought to the conversation. This was a very touching and meaningful way to be recognized.
- Another example from our previous work is that Board members served as co-authors and co-presenters on a poster presentation, and we printed 11 x 17" copies of the poster for them to keep as mementos. Several expressed their appreciation for this gesture.

Letters of Recommendation: We offer to write letters of recommendation for Board members, which can be valuable for their career advancement. Our team has also written letters of recommendation for Board members seeking to have their records expunged.

> *Yes, compensation is nice, but just knowing my voice matters, that my opinions matter, means more than any amount of money. When we are in addiction, we beat ourselves up or second-guess anything we do because we don't trust in ourselves. So when we sit on a panel of people who are important in our eyes, and they care what we say, it helps us know we do know what we are talking about and our words matter. WE MATTER.*

D'Layna Reitz

5 Student-Based Experiences

Engage students seeking experience or internship opportunities, and complete the paperwork or other steps for them to receive course credit or other school requirements such as capstone projects.

Meeting Frequency, Length, and Schedule

Frequency and Length of Meetings

The needs of your project and the size of your budget will influence how often your Community Board meets—that frequency may shift from year to year. In our team's experience, Board meetings have ranged from monthly to quarterly, depending on the project's goals and stage.

As you develop your project timeline, think about which phases will require the most collaboration from the Community Board. Will they be helping to develop study measures early on, or more involved in creating and guiding dissemination efforts later? These considerations will help you determine how to pace and budget for Board meetings over the course of the project.

It is beneficial to have Board meetings occur more frequently at the beginning of your project, such as monthly meetings. This allows Board members to build rapport and trust with each other and your team, while also gaining familiarity with the project more quickly. Having a gap of several months between meetings early on makes it more challenging to retain information from one meeting to the next.

Based on requests from some of our Boards, we have occasionally hosted informal Zoom calls.

- In some instances, the request was for Board members to spend more time getting to know each other without the research team present.
- In other cases, Boards requested such a session to get to know the research team members more informally.
- We have made attendance to these optional, and no stipend was attached to participating.
- Note that this should not replace the portions of orientation focused on getting to know each other.

We have found that **meeting lengths of 60 or 90 minutes tend to be the most successful**.

- If meetings are less frequent than monthly, consider 90 minutes, as you may need more time to re-acquaint everyone with the key information and topics, or to facilitate more in-depth icebreakers.
- Additionally, because Board members have given us repeated feedback that the pace of the agenda should not feel rushed, we tend to use 90 minutes.

If you have more than one Community Board in your project, consider budgeting to hold an annual retreat or joint meeting that brings all Board members together virtually. It's a chance for members from different Boards to connect, exchange insights, and feel part of a larger effort.

Scheduling Meetings

Board members are often juggling multiple responsibilities and have busy schedules, so scheduling meetings may pose some challenges.

- Depending on a Board member's employment/school schedule and the flexibility available to them in their job, they may be able to attend meetings during regular working hours, or they may only be available to attend meetings outside of their regular work schedule.
- You may have Board members across various time zones.
- Some Boards may need meeting times during the evening or on weekends.

Finding a time that works for all your Board members and your research team can be difficult, so approaching this with as much flexibility as possible is helpful. For example, when identifying time slots that work for your team, could you include days and times when any preexisting meetings your team has could be rescheduled?

Identifying a recurring day and time for Board meetings is helpful so that you are not repeatedly needing to work on scheduling. While scheduling tools like Doodle can assist, it's advisable to first inquire about Board members' general availability, asking questions like, "What days or times are you generally available for a Board meeting, and how much flexibility do you have?" This allows you to determine if, for instance, someone is unavailable for any meetings before 5pm. Adopting a thoughtful approach to scheduling is one more way to show Board members that their time and input are genuinely valued.

Reminder:

Always be clear about time zones when scheduling, especially when working with individuals in different parts of the country.

> *I think that choosing the day and time (or just the time if it is a set date) is most helpful and welcoming. It makes me feel like my schedule matters and that my life and what I have going on also matters. It is less "dictated" and more collaborative. You feel like a partner or a member of a team and it is just respectful.*

Leonor Gualchi

Types of Staff Support Needed

Staff on the research team will be responsible for coordinating the Community Board(s) and integrating CBPR principles throughout all aspects of the project.

Researchers often underestimate the amount of work it takes to maintain high-quality CBPR. Under-resourcing this work can undermine the central role of CBPR and result in less effective collaboration with Boards.

The level of staffing you'll need to plan for will depend on:

1. **The number of Community Boards you are forming**
2. **The number of members on each Board**
3. **The frequency of Board meetings**
4. **Your team's level of experience with CBPR or similar community-engaged work**
5. **The complexity of the tasks on which the Board will be collaborating**

TIP

We also want to take a moment to reiterate that employing people with lived experience brings a tremendous wealth of knowledge to the team. Their expertise has played a key role in the success of our Community Boards and Panels and serves as a powerful example of what effective CBPR can look like in the context of substance use research.

Our staffing structure for supporting Community Boards has evolved over time based on the needs of each project. Sometimes, a single Senior Project Coordinator has taken on most of the responsibilities listed below. In other instances, the Coordinator has been supported by a Project Assistant at a partial FTE (that is, “full time equivalent”). We've also had projects where a larger team supported the Boards, as described in the following example. The breakdown below reflects what we’ve found to be most effective when supporting Community Boards with 8–9 members per Board and approximately monthly meetings. We have listed the workload for one Board versus three Boards so that we could show scaling for when there are multiple Boards.

This is intended as **a starting point for estimating FTE needs for support staff for the Community Board, and it does not include the researcher’s FTE**. We realize that this level of FTE is not always possible, or that you may have a different configuration for your team.

Example Job Title	FTE (in % of time)	Additional Thoughts
Advanced-Level Manager/Director	10% for 3 Boards 5% for 1 Board	This position oversees the grant’s budget, staffing, contract agreements with Board members (whom we consider as expert consultants and independent contractors), and more. If there are only 1–2 Boards, this role could be accomplished by a senior-level Project Coordinator.
Project Coordinator	50% for 3 Boards 30% for 1 Board	This position oversees internal staff meetings, helps with Board member recruitment, plans orientation for Board members, collaborates with the researchers to determine what the Board needs to be involved with during each phase of the project, creates Board meeting agendas, ensures feedback from Board members is incorporated into Board processes, ensures continued engagement with Board members, collaborates with researchers to ensure that Board member feedback is incorporated into the study, and more.

Example Job Title	FTE (in % of time)	Additional Thoughts
Senior Project Assistant (or Project Associate)	30-40% for 3 Boards 10-20% for 1 Board	This position engages directly with the Board and supports meeting preparation (i.e., creating PowerPoint presentations, meeting with co-facilitators), handles the logistics of the Board meetings (i.e., keeping track of time, admitting guests from the Waiting Room, notetaking), assists with creating lay language documents for Board members, seeks out other opportunities for Board members to get involved with, and more. If there are only 1–2 Boards, this role could be accomplished by the Project Coordinator position.
Project Assistant	20% for 3 Boards 10% for 1 Board	This position has more of a behind-the-scenes role as they help with scheduling, creating feedback surveys, handling invoices, editing materials, and more. If there are only 1–2 Boards, this role could be accomplished by one of the positions mentioned above.
Graphics/ Communications Associate	5-20%*	This position creates knowledge translation products (e.g., infographics, briefs, tipsheets, webinars, and videos). *If the project has a website that needs routine updating, a regular e-newsletter that needs to be created, products such as infographics to build, or a listserv to be maintained, then the FTE will be on the higher end. Depending on skillset, this role could be accomplished by one of the positions mentioned above.

> *The research team supported our participation. They recognized and respected that showing up takes energy, time, and often emotional labor, especially when we're asked to share painful or personal things. Providing stipends, meeting reminders, flexible formats, and creating a space of respect and care really made a difference.*

Garland G.

Chapter reference(s)

1. Sheikhan, N. Y., Kuluski, K., Hiebert, M., Munro, C., Cappe, V., van Kesteren, M. R., Kidd, S., & Hawke, L. D. (2025). Co-authoring and reporting on lived experience engagement in mental health and/or substance research: A qualitative study and guidance document. *Health Expectations*, *28*(2), Article e70198. https://doi.org/10.1111/hex.70198

ENSURING PRIVACY AND CONFIDENTIALITY

Importance of Privacy and Confidentiality

Protecting the privacy of everyone on the Board is a vital aspect of CBPR, and particularly when working with people who have had substance use issues or criminal legal system involvement. It is a necessity for building and maintaining a strong level of trust between the research team and the Community Board.

A **breach of privacy** could have varying repercussions on different members of the Community Board depending on their demographics (i.e., age, race, birth-assigned gender, gender identity, sexual orientation, etc.). There could also be repercussions for the research team as well.

Potential consequences for **Board members** might include:

- **Personal harm due to stigma or publicity**
  - Public disclosure of someone's involvement or their recovery status—especially if they had previously kept it private—can lead to social judgment, damaged relationships, or worse.

> *We never know what someone is or has gone through... like me personally, I have been in hiding from my abuser for eight years. My near-death experiences are now a part of my story, but I still don't use my own social media pages. Yes, I'm slowly putting my name back out there, but on my own terms and building up my strength and self-power again with people I've built connections and trust with.*
>
> **Anonymous**

- **Professional setbacks**
  - Public disclosure of recovery status for some people can trigger employment restrictions such as revoked clinical privileges.
- **Additional challenges for those with intersectional identities or legal system involvement**, where overlapping forms of marginalization can intensify the risks and repercussions of public disclosure.

Potential consequences for the **research team** might include:

- **Diminished reputation and credibility**
  - These actions could undermine the integrity of the Board itself and make other researchers apprehensive about collaborating with the team in the future.
- **Lowered rates of participation from Board members**
  - Revealing sensitive information without proper approval may lead some individuals to engage less frequently in these meetings.

TIP

Another benefit of employing people with lived experience: employing people with lived experience with substance use disorders or criminal legal system involvement has many benefits, especially their deep understanding of what's at stake. They can offer valuable perspective that helps the research team make more informed and grounded decisions.

Board Member Autonomy on What is Shared Publicly

Story ownership

- Board members are free to disclose as much or as little information about their personal stories with others (i.e., the research team, their fellow Board members, and all guests attending their meetings) as they choose.
- It is important for Board members to have ownership over their story, and for that story (or even just the fact that they are in recovery or have legal system involvement) not to be shared without their explicit permission.
- Set this expectation from the outset both with your research team and with Board members. See also the chapter on **Establishing Meeting Guardrails and Community Guidelines**.

Transparency

- Explain upfront during the recruitment process what level of anonymity (or not) will be possible for Community Board members so that prospective applicants can decide if that fits with their needs. This can be noted in an FAQs section on the recruitment webpage. See more about FAQ portion of the **Recruitment Materials** section in the **Recruiting Community Board Members** chapter.

Explicit permission

- Ensure you ask before disclosing any information.
  - If someone has an opportunity that might be relevant for a Board member, before linking the Board member and thus sharing their contact info, ask the Board member if it is okay to share their information.
  - If there are public forums as part of your project or if you co-present with a Board member, allow the Board member to share what information they would like to disclose.

- If you would like to feature Board members on a website, provide everyone with the option to choose how they would prefer to be represented online:
    - See also the **Board Member Bios and Photos** section in the **Conducting Onboarding and Orientation** chapter.
    - We've found it useful to share the names, locations, photos, and bios of Community Board members, but we make it clear that they can choose to disclose only the information they wish.

Visit one of our websites to see how we've helped some of our Board members remain anonymous:

About Our Community Boards - JEAP Initiative

Confidentiality of Meetings and Board Member Information

Clearly set the expectation from the outset that information shared by Board members in meetings should be kept private by other Board members and the research team.

Although the information of Board members is not research data, we recommend treating it with the same level of sensitivity.

Hearing personal stories from the Community Board is a privilege that should not be taken for granted. Protect this information to the best of your ability; they are entrusting you to keep these insights safe.

Sharing lived experiences can be deeply personal and sometimes traumatic. Giving individuals control over what, when, and how they share protects their emotional well-being and prevents re-traumatization. People should have full understanding and control over how their stories will be used—whether in meetings, publications, websites, or public presentations. Without autonomy, there's a risk of individuals feeling pressured to disclose more than they're comfortable with. Researchers must ensure that lived experiences are not used in a way that sensationalizes or exploits individuals for the sake of a compelling narrative.

Brandy Morris-Hafner

Store all information in a secure location. If information is stored in a shared environment (e.g., Microsoft Teams), ensure that only a select few can access it.

Documents with personally identifiable information, including application materials, contact information, and Board meeting notes, should be shared within the research team only on a need-to-know basis.

Our team has used **Zoom** for our virtual meetings, and we've had great success with this platform. It is particularly easy for Board members to navigate. We encourage you to take advantage of the key security features available within Zoom or other platforms. While Zoom provides many settings to improve security, these options have proven to be the most useful for our team:

Creating a Waiting Room and admitting people at different times during the meetings. For example, we admit Board members within the first 1–3 minutes of the meeting. We then admit guests (such as researchers) when it is their turn to present.

Updating Zoom on a regular basis. As with any software, we suggest keeping Zoom updated to avoid missing the latest security updates.

Protecting Board members' information. We do not enter email addresses into the Zoom website, but rather set up a calendar invite (in Outlook) with email addresses and the Zoom link. This also makes it easier to update the invites if an email address changes.

- If external guests attend the meeting who should not have access to the Board members' email addresses, we set up a separate calendar invite so members' info is not shared without their permission.

Recording meetings and uploading them to the Cloud. Virtual meetings can be recorded for note-taking purposes, but we make clear to the Board who will have access to this information and what it is going to be used for. **For example,** we often have two members from the research team attend Board meetings to provide support:

- One advances the slide deck and handles technical issues, and the other takes notes (see the chapter on **Organizing Meetings and Agendas** for more details).
- At the end of the meeting, the notetaker prepares a transcript, using the recording as needed to ensure everything was accurately captured, and de-identifies info.
- These notes are then shared with the Community Board and research team members (only for the portion they attended).

ESTABLISHING CRITERIA FOR BOARD MEMBERSHIP

Recruitment Preparation

Questions worth considering	Additional details
Based on the focus of our work, what type of expertise should be included in the **minimum qualifications** for joining the Community Board?	Determine what criteria all Community Board members will need to meet: • Will this be a specific age group (e.g., emerging adults)? • Within SUD, do you need Community Board members with specific types of experience, such as opioid use disorder (OUD), MOUD, harm reduction, etc.? • If your work focuses on the criminal legal system, do you need the Community Board members to have that type of lived experience as well, and what aspect of experience do you need (adult vs juvenile, arrest, probation, incarceration)? • Do you need Community Board members to be from a particular area of the country or type of setting (e.g., rural communities)?
How do I ensure the Community Board is **balanced in terms of backgrounds, perspectives, and experiences?**	**Start by asking yourself the following questions:** • Who needs a seat at the table? • What groups of people don't already have a seat at the table? Additional considerations may include: • **Demographics** (age, race, ethnicity, gender, sexual orientation, education, job/profession, socioeconomic status, disability, etc.) • **Location** (region of the country, rural vs. urban spaces, Medicaid expansion states vs. non-expansion states, etc.) • **SUD and recovery experiences** (length of time in recovery, MOUD, polysubstance use, abstinence-based, harm reduction, mutual aid, experience with recovery support services, etc.) • **Co-occurring physical/mental health conditions** • **Reproductive history** (pregnancy, parenting, etc.) • **Criminal legal system history**

TIP

Try your best to balance between diverse perspectives and retaining some shared commonalities when forming the group. Having varied voices is important, but we also have found that we need to ensure members have something in common to have shared experiences as a starting point. Striking this balance helps foster diverse insights while maintaining a sense of safety and shared understanding among its members. In addition to building a Community Board with some shared experiences, or if you are unable to, plan for ice breakers and introductions to help the Board members identify commonalities among themselves.

Here are a few examples we have seen:

- A Board with peer supports, hospital administrators, and physicians encountered difficulty finding common ground or having members overcome the perceived power imbalances.
- Another project considered having parents with different types of experiences in the same Board—those who had lost children to SUD, those with children in recovery, and those with children actively using substances—but thought better of it. The criteria we used for the group were revised to create a more focused group who would not have such high potential to trigger one another when discussing their unique experiences.

Whether your Community Board is already rooted in shared experiences or not, include ice breakers and introductions to help members discover commonalities among themselves.

Special Considerations for Community Boards with Emerging Adults

Emerging adults experience many life transitions at once. These may include moving out of their familial home, starting work, attending college, getting a job, starting a family, and much more. We are honored to collaborate with emerging adults on our Community Boards. They have shared thoughtful and valuable guidance that has strengthened our work. If you plan to partner with individuals from this population, we encourage you to keep the following considerations in mind:

- These individuals are often **under-researched** in the field of substance use.
- They also are one of the groups at **highest risk for experiencing complications related to SUD**.
- The age range for emerging adults varies across studies, typically starting between ages 16 and 18 and ending between ages 25 and 30.
- Consider the **feasibility of recruiting** individuals for the Board—particularly if they need to meet any specialized criteria—when deciding what age range to include in a Community Board of emerging adults. For example, in one project our team built a Community Board made of emerging adults with MOUD experience, so we set the upper age limit at 28 years old since recruiting for this specialized expertise would be an added challenge.
- If your project's definition of emerging adults includes individuals aged 16 to 17, see more information on the **Special Administrative Considerations for Minors and Individuals Currently Incarcerated** section in the **Addressing Administrative Considerations Before a Community Board is Established** chapter.

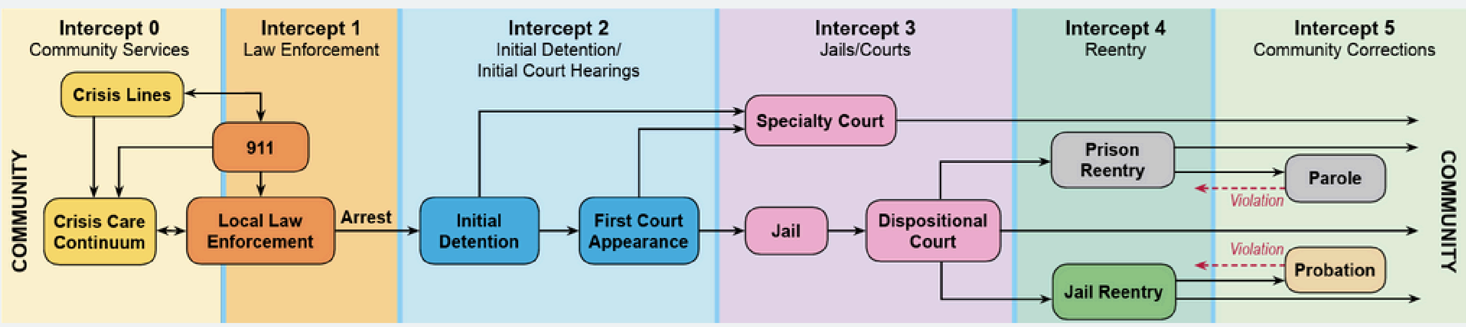
Special Considerations for Community Boards with Populations Who Have Criminal Legal System Involvement

Every individual with criminal legal system involvement has a critical perspective worth sharing. These insights have guided our work since day one, and we are incredibly grateful to all the members of our Community Board.

If you are interested in collaborating with members of this population, we hope you'll keep these considerations in mind throughout your partnership:

- As with emerging adults, this group is sadly **under-researched** throughout the field and is also at **significant risk for enduring issues from SUD**.
- Individuals impacted by the criminal legal system have a broad array of experiences. We encourage you to refer to the **Sequential Intercept Model**.
- Check out this resource from SAMHSA to learn more: The Sequential Intercept Model Brochure

Sequential Intercept Model[1]



- Consider your research focus and decide whether to form a Community Board with a wide range of experiences or more specific criteria (e.g., requiring a history of incarceration).
  - Additionally, we encourage you to be mindful of the sensitivity surrounding these types of conversations. You'll need to decide how much information is directly asked for during the selection process compared to allowing applicants to choose how much they want to disclose in a written application or follow-up call.
  - Remember that there is a high level of stigma attached to legal system involvement, compounded by the stigma related to SUD, and individuals have no reason to trust that you'll be sensitive to this.

- Experiences and perspectives may vary depending on when someone was incarcerated, when their involvement in the criminal legal system began or ended, how long it lasted, and the nature of the involvement. A few examples of this include:
    - Someone who only has experience with the juvenile legal system and not the adult criminal legal system
    - Someone who was arrested but not convicted
    - Someone who was incarcerated more than a decade ago
    - Someone who was either recently released or is still on parole
    - Someone who was never incarcerated but spent time on probation
    - Someone who was able to access SUD-supportive portions of the criminal legal system (e.g., drug court)
    - Someone who is currently incarcerated

Justice involvement is not a one-size-fits-all experience—seek members from diverse backgrounds, including formerly incarcerated individuals (varied lengths of incarceration), people on probation/parole, families of justice-involved individuals, and those impacted by juvenile justice, reentry, or collateral consequences (housing, employment, etc.). Also, justice-involved individuals often face financial hardships due to employment barriers, so offer fair compensation (stipends, hourly pay, or gift cards) for their expertise, and ensure compensation does not interfere with benefits (like SNAP, disability, or reentry assistance). And more importantly, don't just include justice-involved individuals for symbolic representation—ensure their voices shape decision-making at every stage!

Brandy Morris-Hafner

- What about "lived" vs. "living" experience with the criminal legal system?
  - Lived experience may be viewed as someone who is no longer legal system-involved. Living experience refers to individuals who are currently incarcerated or are currently on probation, parole, or otherwise "on paper." While there are challenges, including people with living experience may bring a valuable perspective to the table and can help enhance your efforts.
  - Especially for individuals who are currently incarcerated, you may need to build relationships with facilities where individuals are housed. You will need to be prepared for the additional challenges this subsection of the population may face during the recruitment and engagement process:

1. **How often will they be able to respond to email correspondence from your team?**
2. **Will they be able to receive messages by text as other team members may?**
3. **Would they be able to attend virtual meetings with the rest of the Board on a regular basis?**
4. **Are they able to speak freely, or are their interactions with your team being monitored?**
5. **If one member of the Board is monitored, will this mean everyone else on the Board is monitored, too?**
6. **If travel is involved in your study, would they be able to attend? If so, how much time would they be allowed to travel for?**

  - See also the section on **Special Administrative Considerations for Minors and Individuals Currently Incarcerated**.

1. Substance Abuse and Mental Health Services Administration. (2019). *The Sequential Intercept Model: Advancing community-based solutions for justice-involved people with mental and substance use disorders* [Brochure]. SAMHSA's GAINS Center. https://library.samhsa.gov/product/sequential-intercept-model-trifold-brochure/pep19-sim-brochure

RECRUITING COMMUNITY BOARD MEMBERS

Recruitment Materials

A potential candidate's first impression of your project comes from the recruitment materials for the Community Board. Here are some examples of recruitment materials you may want to create:

1 A logo that is visually appealing and relevant to the project

- Use design elements that make your logo distinctive and aligned with your project's purpose. Reviewing logos from similar studies and organizations can give you direction, prevent overlap or confusion, and ensure that your project stands out.
- Notably, be willing to change your logo once your Community Board is in place so that they have a say in the design and coloring. Share the rationale for your choices, but be open to their guidance.

2 A landing webpage with key information about the project and a direct link to the Community Board application

- Additional details about this critical resource can be found in the section below on making an effective **landing webpage**.

3 A short 'blurb' about the Community Board opportunity that can be used in email outreach

- Include brief information about the project and key details about the Community Board to grab someone's attention.
- Link to your landing page for more information.

4 Posters and flyers

- Physical copies are useful for in-person outreach.
- Electronic copies can be included as attachments for recruitment emails.
- Include a QR code that links to your landing page on all printed outreach materials.

5 Social media posts

- Canva allows you to easily adapt the sizing to each platform.
- Remember to include a link to your landing page.

6 If feasible, create a brief 1–3 minute video describing this opportunity in more detail and why people should join

- This could be from a member of the research team or a current Board member (if applicable).
- See an example here: https://www.jeapinitiative.org/community-boards/

7 If feasible, an infographic could be more approachable

- Here's an example infographic from the Collaborative Hub for Emerging Adult Recovery Research (CHEARR): https://chearr.org/

CHEARR

So You Want to Join a Community Board?: Debunking Common Myths

MYTH	FACT
Community board members are directly involved in leading or doing research.	• Community board members do not collect data or lead the projects themselves, but instead use their lived experience to influence and co-create projects. • Together with researchers, they work towards making a positive difference in their community.
Research experience or higher education is required to be a community board member.	• No prior training or experience with research is needed. • You do not need a degree or even a high school diploma, because your lived expertise is valuable.
Community board members are expected to share their personal story publicly.	• It is not required for members to share their picture or name on our website- it is entirely optional. • Specific information shared through your application and during board meetings will not be made publicly available.
Researchers are "checking a box" by talking to people with lived experience.	• Researchers and agencies that fund research are working to recognize and amplify the knowledge gained from lived experience. • Community board members' expertise is valued in participatory action research; members are paid and given credit for their time and contributions

For previous examples of recruitment materials for our Community Boards, refer to the Appendix.

An effective **landing webpage** shapes the narrative of your study and assists potential candidates in deciding whether they want to get involved. Make the most of this opportunity by including some, or all, of the following items.

Make sure your webpage is mobile-friendly.

- Many applicants are likely to view this information on their mobile devices, so we encourage you to ensure it is easily accessible.
- You might create a page within your institution's website, or you might create a separate webpage with user-friendly software like WordPress, Canva, or Wix.

Use non-stigmatizing language and imagery to emphasize collaboration between the Board and your team.

- We believe all recruitment materials must be approachable, respectful, and sensitive to the unique needs of the populations for which they are intended.
- Resources about using non-stigmatizing language and imagery for substance use research are available on our website.
- See tips and examples for framing questions about lived experience in the **Appendix**.

Include informative and engaging content, such as:

1. **An overview of the project.**
   - Remember to use lay language and write for an audience that may have no previous experience with research.

2. **The role of the Community Board member.**
   - Explain what their involvement will be and emphasize how the relationship will be mutually beneficial (more details below).
   - Share additional project details, including the number of individuals that will serve on the Board, meeting frequency, meeting format (i.e., virtual, hybrid, or in-person), and whether there is compensation.
   - See examples of this section on the following page.

Need inspiration? Check out our recruitment pages:

- JEAP Initiative
- HEAL Connections Lived Experience Panel
- CHEARR Community Board

Example 1: HEAL Connections

As a Lived Experience Panel member, you will:

- Participate in a **virtual orientation** (with Q&A) and **2–4 virtual meetings** per year and review materials in between these meetings—see more details under Frequently Asked Questions below
- Provide **input on studies** related to pain, opioid use disorder, and the intersection of those issues (where relevant to you and/or your community)
- Help to identify ways to share, distribute, and implement research findings and strategies related to the current opioid and/or pain management crises **within your community**
- Provide feedback on how your community prefers to learn about **new research findings**
- Provide input into **priorities and gaps** for your community
- Share **your unique experiences and perspectives** (lived experience) on emerging trends, priorities, and challenges in the coming years
- Offer perspectives to the HEAL Connections team on how best to **engage other people with lived experience** in research
- **Receive compensation** for your service on the Panel—see more information under Frequently Asked Questions below

Example 2: JEAP Initiative

As a Board member, you will:

Help improve recovery support services

This research will serve to improve recovery support services. The Community Boards are integral to ensuring that the research focuses on the most important issues, serves the most critical populations, and that the results are shared with the community.

Shape research on recovery support services

The Community Boards will set the research priorities, give input on the design of research studies (training will be provided), and will decide which research projects on recovery support services receive pilot funding.

Shape the next generation of researchers

The Community Boards will determine which researchers are selected for our Postdoctoral Fellowship, our Training Institute, and our pilot study funding. We will be seeking applicants who have lived experience with substance use or the justice system, or who are from communities that otherwise are not as involved in research careers.

Identify priorities for research

Board members will brainstorm what topics and populations are important for researchers to study within recovery support services.

Share your expertise and lived experience

Community Board members bring the unique perspective and expertise of having lived experience. To the extent that you are comfortable, you will have the opportunity to share within the board your lived experience and how it shapes your perspective on recovery support services.

Gain skills and make connections

You will be working alongside a team of your peers from around the country, and will receive training to enhance your knowledge on research and recovery support services. Meet our current board members here. No previous knowledge of research is required—all training will be provided.

3

Eligibility criteria and other qualifications for joining the Board.

Try to write this section in a way that makes all potential applicants feel welcome and included. Several team members have received feedback from previous applicants (e.g., Community Board members, interns, job candidates) that the language we used made a difference in their decision to apply. Additional details and an example can be found below.

- Outline the specific requirements you are looking for (if applicable)
- Include a list of any ‘soft skills’ that you are seeking
- Express interest in creating a Board with a range of perspectives
- Clearly state that having previous experience with another Community Board is not required

Example: JEAP Initiative

Skills and experience we’re looking for

The qualifications to join a Community Board are:

- For the Young Adult Board: ages 18–25; for the Justice-Involved Board: all ages welcome
- Lived experience with recovery from substance use
- For the Justice-Involved Board only: lived experience with the justice system
- Enthusiasm for participating in the Board and sharing your perspective
- No specific educational or professional background is required; all training will be provided. We aim to have Board members from a range of backgrounds, education levels, and perspectives
- No previous Board or committee experience is required

Because we want to effectively address the needs of a variety of communities affected by substance use disorder, including communities that may be overlooked in research, we are working on creating a Board with members who bring a variety of experiences to the table.

4

A hyperlink to the application and a quick overview of the selection process.

- Use friendly and welcoming language to help make the application process feel more approachable to candidates, rather than intimidating. Throughout the application and selection process, the goal is to foster a collaborative and inclusive approach, minimizing any sense of power imbalance.
- Example language for this section:

Please fill out this brief online application form. From these applications, our team will select people to move to the next round of consideration. We will email to schedule a 30-minute follow-up Zoom call so that we can share more about the project, get to know you, and answer any questions you have. No specific educational or professional background is required; all training will be provided. We aim to have Board members from a range of backgrounds, education levels, and perspectives.

- Clearly state whether you are actively recruiting new Board members or, if you have rolling applications for any spots that become available, that completing the application will put them on the waitlist.
- Highlight important dates (e.g., application deadline, priority deadline).
- See further information in the **Establishing Application and Selection Steps** chapter about creating an application form.

Researchers should ensure the recruitment and selection process feels welcoming for potential applicants because you don't want to run anyone off. That would be like inviting someone to your home for dinner then mean mugging them at the front door. Why would they want to come in, let alone eat your food?

Kimberly Moore

5

A Frequently Asked Questions (FAQs) section or description of key details.

- This may include stipend amount(s), expected time commitment, length and frequency of Board meetings, and whether their participation in the Board will be made public.
- Also refer to the **Ensuring Privacy and Confidentiality** chapter for more details, as this is a common area of concern within SUD CBPR and especially for individuals with legal system involvement.
- For inspiration, see the example FAQ on the next page for a few questions we have used in the past.

Example: HEAL Connections

How do I apply?

Click on this link to fill out our brief online application form. The online application form will allow you to select and rank multiple Subpanels. Our team will review all applications and may email or text you to schedule a 30-minute follow-up Zoom call. During the call, we can share more information about the Lived Experience Panel, answer any questions you have, and get to know you. Information that you share will be private, and you can decide what information you want to share.

Do I need to have previous work/volunteer experience or a specific degree to join the Panel?

No. We are aiming to have Panel members with a wide mix of educational and work backgrounds. No previous experience on a Panel or advisory group is required. We will provide all the training you need.

Is this a paid opportunity?

Yes. Panel members will be compensated at a rate of $50 per hour. So, for example, if there were a one-hour meeting and approximately one hour combined for preparation and follow-up work (such as reviewing materials or responding to questions), compensation would be $100 for the two hours of total time.

Do I need to know about research to join the Panel?

Nope! We will provide training on what you need to know about research so that you are prepared to give input on ways to share, distribute, and implement research findings and strategies related to the opioid crisis and pain management within various communities.

What is the time commitment?

We ask for a minimum commitment of one year, but your participation on the Panel could be longer than that. Between now and the end of August 2023, Panel members will attend 2–3 virtual meetings (approximately 1–2 hours each) and review different materials (approximately 1–3 hours). In the following year (September 2023 to August 2024), Panel members would be asked to participate in 3–5 virtual meetings per year and to review materials between meetings.

When will the meetings be held?

The meetings will take place virtually on Zoom. This is a national Panel that will include members in all US time zones. If you are invited onto the Panel, we will ask you for your availability and do our best to accommodate it. We may have evening or weekend meetings to accommodate everyone's schedules better.

Will my participation on the Board be made public?

You will have the option of publicly sharing your participation on the Panel or keeping your participation on the Panel confidential.

How many people will serve on the Panel?

Each of the Subpanels will have 5 members, and all Subpanel members will be full and equal members in the overall HEAL Connections Lived Experience Panel.

Do I need to live in a particular area to join the Panel?

The Lived Experience Panel is open to individuals living in any part of the U.S. We aim to include Panel members from a variety of geographical locations (e.g., regions of the U.S., urban/rural, Medicaid expansion/non-expansion states).

6

Contact information.

- Questions are inevitable. Make sure potential candidates can easily get in touch with you if they have questions or concerns.
- Consider creating a general email account that you use throughout your project. That way, Board members have a single email address to reach out to, and if there is turnover on your team, the email address does not need to change.

7

Photos and bios of the members of the research team.

- This may help applicants see you as more approachable.
- If members of your team have lived experience, invite them to mention this in their bio if they are comfortable.
- See links to the right for examples of how we have done this.

Check out our About Us pages to see how we have introduced applicants to our research team:

- JEAP Initiative - About Us
- CHEARR - About Us

Outreach and Recruitment Methods

Build a supportive network to help with recruitment once your materials are ready. This could include people you already know, as well as local and national organizations that serve or engage communities you're hoping to include on your Board. You may also want to consider whether you want to focus on **individuals already involved in advocacy efforts or working in substance use services**, or **on those outside the field** (i.e., whose lived experience with substance use is the primary expertise they bring to the table).

Regardless of your decision, we recommend keeping contact information in an outreach list for getting the word out broadly about opportunities. We also suggest periodically checking in with everyone on your outreach list to confirm their information is up to date.

Identify organizations and institutions connected to individuals who may be a good fit for your Board. It might be helpful to ask yourself the following questions:

1. **Are there organizations delivering services that relate to your research?**

2. **Are there organizations working with the populations you hope to collaborate with?**
As an example for JEAP, we identified organizations working with people who have been involved with the criminal legal system.

3. **What organizations do I admire, and have I already subscribed to their newsletter/listserv?**

4. **Are there universities or institutions with relevant programs?**
As an example for JEAP, we identified collegiate recovery programs.

Here are some types of organizations we have reached out to:

- Recovery Community Organizations (RCOs)
- State and local peer support networks
- Recovery residences and sober living networks
- Collegiate recovery programs
- Harm reduction and public health organizations
- Organizations focused on prevention and prevention coalitions
- Research listservs (such as the College on Problems of Drug Dependence and relevant American Psychological Association divisions)
- State-level or county-level departments of behavioral health
- Organizations serving justice-impacted individuals

Consider using AI to brainstorm potential organizations.

- This option might be helpful when looking for region-specific organizations.

It's helpful to save a list of organizations in a spreadsheet so you can add contact details and reuse it if you need to recruit again.

Generate a list of the names of every organization and institution that comes to mind and determine how you'd like to reach out to them.

- Is anyone on your research team already connected?
- Does anyone in your broader network have a connection with someone from that organization? If so, would they be willing to connect you?
- If not, could you fill out the contact form on the organization's website? Could you reach out to the director of the organization via email? Or, is there a different member of their team listed on their website whose focus area most aligns with your work?

Set aside time to prepare talking points before reaching out to someone at an organization or institution.

- Explain your credentials and the organization you work for.
- Describe your research and what you hope to accomplish.
- Share how your interests align with theirs.
- Ask them if they'd be willing to support your efforts by spreading the word about future opportunities, like an opening on your Community Board.

On the next page is an example of an email we have used for recruitment:

Hello [Name],

I hope you're doing well! The Justice-Involved and Emerging Adult Populations (JEAP) Initiative is actively recruiting two new members to join its Young Adult Community Board, and I was wondering if you could help share this opportunity with the [organization's name] newsletter listserv. I've attached a flyer and included a short blurb below for easy sharing.

Thank you so much for your help—it really means a lot! Please feel free to reach out if you have any questions.

Warm regards,
[Name]
The JEAP Initiative Team

Help us spread the word! The JEAP Initiative (Justice-Involved and Emerging Adult Populations Initiative) is currently recruiting members for our Young Adult Community Board. We're looking for young adults aged 18–25 who are in recovery from substance use to help guide our work and influence research. Serving on a Community Board is a great opportunity to use your voice and lived experience to impact research on this topic!

Importance of Community Boards
The work of the JEAP Initiative is guided by three national Community Boards. The purpose of these Community Boards is to shape research on recovery support services, identify priority areas for research, and ultimately help improve recovery support services—an important role with the potential to benefit many populations. Our three Community Boards are made up of individuals from all around the country who bring their diverse expertise to this work. Learn more about our community boards here and click here to apply.

Requirements
- *No previous Board/work experience or education level required*
- *Aged between 18–25*
- *Lived experience with recovery from substance use*
- *Enthusiasm for participating and sharing your perspective*

Details
- *Training will be provided on what you need to know about research*
- *Community Board meetings are held remotely*
- *Meetings are typically 1.5 hours in length and are held about four times a year*
- *You will receive a stipend for each Board meeting you attend*

Because we want to effectively address the needs of a variety of communities affected by substance use disorder, including communities that may be overlooked in research, we are working on creating a Board with members who bring a variety of identities and experiences to the table. Everyone is encouraged to apply, including people in the Black, Indigenous, Latinx, and other communities of color; women; people who are gender non-binary; people with disabilities; and people in the LGBTQIA+ community.

No previous Board experience, work experience, or degree is required!

Please see our website for more information about the Community Boards: https://www.jeapinitiative.org/community-boards/
You are welcome to contact our team with questions before or after you apply: JEAP@chestnut.org

APPLY HERE

Applications reviewed upon receipt.

Considerations for Applicants with Dual Roles

You might consider inviting members of your current Community Board to join additional Boards if you're forming a new one.

- These individuals will already be familiar with your research and trust you as a researcher.
- However, you may want to consider whether or not the new Board should have the same voices as the prior Board.
- If you decide to ask your current Board members, ask if they'd be willing and able to dedicate enough time to both projects and reassure them that it's okay if they can't commit to the new one.

You might receive applications from individuals who are employed at your organization.

- In general, we have not allowed people in the research sector of our institution to be on our Boards, but we have allowed staff in the clinical sector to be considered.
- Some questions we found we needed to explore with prospective Board members before inviting them to the Board included:
  - Does the prospective Board member want to receive a stipend for serving on the Board? If so, you may need to consult with your Human Resources department and/or contracting department to see whether receiving a stipend from the organization in addition to their regular pay is possible.
  - Is the prospective Board member comfortable with their supervisor knowing they are serving on the Board (since being a part of the Board would indicate they have certain types of lived experience such as being in recovery)? If they are not comfortable with that, this would make figuring out payment or shifting work hours more difficult.
  - Would the prospective Board member be attending Board meetings during their regular scheduled work time, or outside of their usual hours? Participating in Board meetings during their regularly scheduled work time may impact their ability to receive a stipend, and it would also require their supervisor's approval. Are they able to work with their supervisor to adjust their work hours if needed to accommodate the Board meetings?
  - Would the prospective Board member be coming to the Board with a greater familiarity with your team or your work that would give them a 'leg up' over other Board members, and if so, how can you best navigate that so that it is an even playing field?

On the flip side, you might have Board members apply for opportunities with your project, such as employment on your project or as an intern.

- In general, we let Board members know that if they are selected for the opportunity, then they will need to rotate off the Board to avoid a conflict of interest or dual role issue.

If you obtained permission to recontact former study participants, you could see if they would like to apply to the Board as they have been exposed to being a participant in research, and they are already familiar with you and your team. If you have multiple studies happening at the same time, you could also consider reaching out to current participants in a different study (i.e., not the study that the Board will be working closely with, as that would be a conflict of interest).

Some individuals may not be able to accept a stipend because of their employment. This does not need to be a barrier to being on the Board (see the **Other Stipend Considerations** section in the **Addressing Administrative Considerations Before a Community Board is Established** chapter).

Special Considerations for Recruiting Emerging Adult Community Board Members

- Understand that emerging adults experience many life transitions at this age and our experience is that they are **harder to reach than other populations** when conducting Board recruitment.
  - See the **Special Considerations for Community Boards with Emerging Adults** section in the **Establishing Criteria for Board Membership** chapter to learn more about this population.
- **Connect with collegiate recovery programs.**
  - Share how your research could impact the individuals in their programs.
  - Offer to send them flyers and ask if they can post them around campus.
  - Alternatively, you could have staff members set up a table around campus to help students learn more about your project.
- **Connect with treatment centers**, especially those that focus on young adults.
  - See the above points about collegiate recovery programs, as they may be applicable.
- **Identify organizations that focus on this population.**
  - Subscribe to their newsletter listserv so you can learn about them before asking them to help spread the word about your recruitment efforts.
  - Printing flyers and tabling at an in-person event would also be a great idea if the Board is based in a specific geographic area.
- Determine if there are any **relevant conferences or national meetings** you could attend to make connections.
- If your Board is limited in location, **put up flyers** in local shops, libraries, and other places where young people may be present.
- **Consider posting content across multiple social media platforms** to engage with emerging adults online.
  - If existing Board members belong to this population, ask them which social media platforms they use, to guide these efforts.
- Ask the **staff at your organization and any existing Board members** to help spread the word.

Don't forget friends and family who may have contact with young people! Ask them to help you spread the word, including by amplifying social media posts about recruitment.

ESTABLISHING APPLICATION AND SELECTION STEPS

Narrowing down a list of highly qualified applicants for a limited number of spots on the Community Board is a challenging but essential part of the selection process. Below, we outline the processes we have used across various projects.

1. **Review all application materials submitted by candidates**
2. **Meet candidates in an informational Zoom call to learn more**
3. **Invite selected candidates to the Board and update others on their application status**
4. **Welcome new Board members with an orientation call to help them get onboarded**

Every person with lived experience has a story and perspective worth sharing. This has often made it difficult to determine which candidates should move forward in the selection process. **Regardless of who receives an invitation to join your Community Board, we recommend sending a follow-up email to everyone who applied shortly after you receive their application to confirm receipt.** Closing the loop is an important part of CBPR and prevents candidates from wondering about their application status.

Application Form

- Decide whether the application will be **online, in print, or a mix of both**.
  - While online applications work well in most situations, consider the population you are recruiting from and whether they have access to reliable internet. If they do not, a paper version of the application may be a better choice.

See example application forms in the Appendix.

- Have a **user-friendly application** that is accessible across mobile devices.
  - Microsoft Forms, Google Forms, and Qualtrics have worked well for us.
  - Consulting your IT department about the **security** of each option is beneficial.
    - Although this may not be research data, these applications will contain sensitive information about individuals and should be protected carefully.
    - Additionally, **limiting access exclusively to team members who require it** is another crucial factor to consider, ensuring you offer added protection to applicants.

- Obtain **contact information and any relevant demographic details** (limit to those that are essential for your selection decisions) at the top of the application.
  - These details help to identify candidates quickly, making it easier to follow up for clarification on specific points later.
  - It also helps create a clear structure when reviewing multiple submissions.

- Then, ask **open-ended questions** (i.e., questions that ask 'why' and 'how' instead of 'what' and 'when') to learn more about a potential candidate's interest in joining the Board and the perspective(s) they offer.
  - For suggestions on how to phrase questions about lived experience, see the **Terminology Considerations** section in the **Defining Lived and Living Experience** chapter.
  - Marking all questions as 'required' ensures the application will be fully completed. You can also **include an option like 'prefer not to answer'** for candidates who choose not to respond to specific questions.
    - Sometimes, a candidate might mention professional or indirect experiences without specifying direct lived experience in their online application. In these cases, we reach out to confirm while allowing them to disclose as much or as little as they choose. Here's an example message:

Dear _____ ,

Thank you for your interest in the ____Community Board! We truly appreciate the time you took to complete the application. I'm reaching out because this opportunity specifically requires direct personal experience with recovery from substance use disorder, and based on your application, it wasn't clear if this applies to you. If you're comfortable sharing this information, could you please reply to confirm whether you meet this requirement? I'm also happy to answer any questions you may have, so please let me know if you have any concerns.

Best regards,

[Your name and role with the project/program]

- Evaluate the pros and cons of **which questions to include and how many to have**.
  - On the one hand, the more information you receive, the easier it will be to create a well-balanced Board.
  - On the other hand, asking for too much personal information upfront can discourage candidates from completing the application or reduce their trust in your team.

Follow-Up Calls with Applicants

- First, **confirm that each applicant meets the eligibility requirements** to join the Board, remembering to limit access to applications (see security information above).

- Then decide if you will do a call with each applicant or if you will **narrow it down to certain candidates**.
  - If there are a large number of applicants, it may be helpful to begin a selection rubric at this stage (see the section below on making **Selection Decisions** for guidance on a selection rubric).

See example script and questions in the Appendix.

- Meet all candidates in a **follow-up call to learn more about their experiences and determine if this might be a good fit** for them and the project.
  - We prefer to call this step an "informal call" or "follow-up call" rather than an "interview" both internally (i.e., within our team) and externally (i.e., when communicating with applicants). We believe this language reflects the collaborative nature of the relationship between researchers and community members and helps minimize any perceived power imbalance.
  - In most cases, this step is beneficial because it allows you to meet candidates and get to know them beyond their application. At the same time, it gives candidates the chance to ask clarifying questions.
  - A written application with brief or less polished responses does not truly reflect the individual behind the materials. We have engaged with many applicants who provided such responses, but after meeting them, we recognized that they would make fantastic Community Board members.
  - Create a "script" that can be used by your team members.

A follow-up Zoom call provides an opportunity to assess the culture, values, and inclusivity of the research team. A relaxed, conversational tone (instead of a formal interview) makes the process feel more like relationship-building than an evaluation. Demonstrating genuine appreciation for lived experience not just as a "box to check" but as essential expertise makes individuals feel valued. The key is to create an atmosphere of mutual respect, trust, and inclusivity.

Brandy Morris-Hafner

Compared to traditional job applications, less weight should be given to the writing, grammar, etc. within the written application since a Community Board seeks to have individuals from a variety of educational and professional backgrounds.

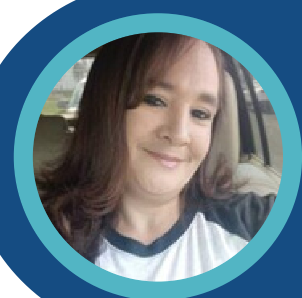
Having two of your staff members attend these calls could be helpful when possible.

- Ideally, at least one of these individuals has lived experience, whether it is direct or indirect.
    - Doing so could help create a safe environment for the candidate to share more of their personal story, if they feel comfortable.
    - At the same time, all members of your research team must have the autonomy to decide when and how to disclose sensitive information, whether to the candidate or in any work situation.
    - Additionally, staff who do not have direct or indirect lived experience may express this to convey that they value lived expertise; this is often framed in relation to their passion for this work: "Although I do not have direct or indirect lived experience, I worked in substance use treatment for many years and am honored to be supporting better engagement of the community."
- Set aside time for a debriefing and encourage self-care after the call ends.
    - Hearing another person share their personal story can be emotionally taxing, especially if a member of your team has similar lived experiences.

Create a friendly, respectful, and interactive environment.

- Remember that this will be the first 'face-to-face' interaction a potential Board member will have with you and your team.
- Focus on building trust and fostering a collaborative spirit in this relationship. Remind candidates that the conversation is informal and that they are encouraged to ask questions along the way.

> *If you don't encounter someone that is understanding or welcoming, you may not ever do it again. There is so much stigma in this world. So, the first two minutes of a conversation can make or break it for someone in recovery and someone on the other side.*



D'Layna Reitz

Selection Decisions

Decide if a **selection rubric** would be useful for scoring applications objectively.

- Here are some points to consider before making this decision:
  - How many Community Boards do you hope to create?
  - How many criteria are being considered?
  - How many applicants do you anticipate applying for this opportunity?
    - For example, we anticipated a great number of applicants for a large national project (HEAL Connections), so we created a detailed selection rubric. This proved to be highly effective in evaluating the nearly 500 applications we received for only 55 spots.
    - If you aim to create a smaller Community Board (i.e., a single Community Board with fewer than 10 members) or pursue smaller-scale recruitment, a formal selection rubric may not be necessary.

See example selection rubric and emails notifying applicants in the Appendix.

Focus on which factors will be considered, how they will be rated, and who will rate them.

- Consider the overarching goals and objectives for this Community Board.
- Consider what voices are important to have represented on the Board.
- Consider whether applicants have ties to their community (of people in recovery who share characteristics with them) and can help represent other perspectives of their community.
- Consider the role of the Community Board members for this particular Board.
- See considerations in the **Establishing Criteria for Board Membership** chapter.

Invite the selected candidates to the Board and update other applicants.

- For applicants who were not selected for the Board:
  - Acknowledge the time they took to apply for this opportunity and to connect with you and your team (if applicable).
  - We also encourage you to find ways to keep them engaged with your efforts (e.g., subscribing to your email newsletter) or share resources about other opportunities they may be interested in.

For applicants who are waitlisted:

- Hold off on sending them an update until you have received confirmation from everyone who was invited to the Board, in case anyone selected is no longer available.
- Expect occasional turnover and decide whether you would like to ask some candidates to remain on a waitlist if there are future openings.

Turnover and New Members

As described in the **Length of Service and Addressing Absences** section in the **Conducting Onboarding and Orientation** chapter, Community Board members may need to rotate off the Board. When this happens, we generally:

- Make a Kudoboard (www.kudoboard.com) for the research team and other Community Board members to sign and send to the exiting Board member.
- Review the characteristics of each current Board member to determine if there is still balance in terms of backgrounds, perspectives, and experiences such as demographics, geographical location, SUD and recovery experiences, personal characteristics (see the **Recruitment Preparation** section in the **Establishing Criteria for Board Membership** chapter).
  - Determine in partnership with the Community Board how they would like to proceed with the new member process, which may include:
    - Your team reviewing the waitlist of potential Community Board members (i.e., people who expressed interest in joining the Community Board) who can be contacted in case of an opening.
    - Asking Board members if they know any individuals who fill the gaps.
    - Gathering input from Community Board members about the selection process.
    - Bringing options for new Board members to the Board for discussion and decision.
    - Planning with the Community Board for the new Board member to be introduced to the Board.
- All new Community Board members should receive a group or personalized orientation session (see the **Conducting Onboarding and Orientation** chapter) and, if joining after the initial year, an overview of the current activities of the Community Board.
- Remember to **update your webpage**, if you have one, to remove the exiting member and add the new member.

CONDUCTING ONBOARDING AND ORIENTATION

All your invitations for the new Community Board have been accepted—congratulations! This is a remarkable milestone for you and your team. After recognizing the hard work and energy that went into building these relationships, thoroughly review the procedures outlined below to learn about the next step in this process.

First, have each Board member complete any required paperwork—see the chapter on **Addressing Administrative Considerations Before a Community Board is Established** for more information.

Board Member Bios and Photos

Celebrate your new Board members and feature them on the project website, if applicable.

- Including **brief bios and photos** of the Community Board members on the project's website is an excellent way to amplify the voices of people with lived experience. Additionally, it emphasizes that you regard Board members as key experts in the field and value your collaboration with them.
  - See example at [About Our Community Boards – JEAP Initiative]
- Encourage everyone to choose how much personal information they want to share online, if any.
  - For example, some individuals prefer that we share only their first name or a pseudonym on our website. We have also received requests from Board members to exclude their photos, so we use an alternative image, such as a photo of a landscape.
    - See **Example Website Form for Bios and Photos** in the **Resources Appendix**.

Sharing my name or email publicly without my consent would be a breach of trust. I would have a hard time being as open as I am in the participation if I did not know that every single time my name or picture are disclosed, I have consented to it. It would feel like a violation.

Leonor Gualchi

You can offer to assist Board members with drafting a brief bio about themselves or provide examples, but it is critical to **respect their choice** to use the language they prefer when describing themselves.

- For example, we found that some individuals who are in a 12-step program may use language like 'addict' when describing their background, which in other contexts might be viewed as stigmatizing.
- Consider including a brief description on the webpage to explain that everyone had full autonomy over their bios (see example below).

Example: JEAP Initiative

Note: *Community Board members had a choice of how much of their personal information to include on this page, including the option of providing an anonymous bio. Members also chose the language and terminology themselves.*

Topics to Include in Orientation Session(s)

The section below focuses on orientation and training for Board members. Since it is important for both parties to come prepared for the collaboration, refer back to the section on **What training might be helpful for research staff who work with the Board(s)?**

We suggest including the following components in Board member orientation meeting agenda(s). Each of these includes details based on our experiences. See example agendas and time to set aside for items in the **Organizing Meetings and Agendas** chapter.

You don't have to cover everything at once—these topics can be spread out over multiple meetings if needed. In fact, we find that **Board members appreciate a slower pace** and generally recommend that introductions and orientation span more than one meeting.

1

Welcome:

- We encourage you to create a welcoming space during this session where Board members feel comfortable seeking clarification and voicing their concerns along the way. Here are a few phrases we've used at the beginning of orientation meetings to set this tone:
    - "This meeting is informal, so please feel free to interrupt us at any point if you'd like us to revisit any topic."
    - "We'll be sharing a lot of information today, and we understand it might feel overwhelming at times. If you have any questions afterward, please don't hesitate to send us an email. We'll be happy to help!"

2

Introductions:

- At the initial meeting, this is a wonderful opportunity for Board members and the research team to begin getting to know each other. Allow ample time for introductions and icebreakers (see the **Selecting Icebreakers** chapter).
- If there are members of your team supporting the Community Board's functioning who won't regularly attend Board meetings, consider having them come to a portion of this first meeting so they can say hello and put a face to the names that Board members might see in emails.
- To help minimize the sense of power imbalance, we encourage research team members to use their first names instead of honorifics like "Dr." when introducing themselves. However, Board members with honorifics are welcome to include them in their introduction as they see fit. If the Board includes individuals where a power imbalance may be problematic, such as peer supports and hospital administrators being on the same Board, you might consider asking the group to stick with first names. See additional cautions related to this in the **Recruitment Preparation** section in the **Establishing Criteria for Board Membership** chapter.

3

Overview of the Project:

- Orientation presents a valuable opportunity to share more about the project and its future goals. You can expand upon any project overview you provided during the selection process. When discussing the project, clarify which aspects the Board members will engage with. Additionally, it is helpful to mention the sources of the study's funding and what will happen with the findings once the study is completed.
- Determine which written materials about your project you could send out to Board members, such as the Project Narrative from the grant application. Some Board members might appreciate receiving excerpts from the grant application, but you can give the caveat that it's optional to read and it is heavy in research jargon. If possible, you could convert jargony material into an infographic and/or a video overview with more details for Board members who are interested.

Verbalizing the team's mission to prioritize, validate, and value Community Board members' experiences is an extremely beneficial addition to the onboarding and orientation process for new Community Board members. If Community Board members feel safe and valued from the very start, this would increase the likelihood of continued participation and passionate participation.

Brenda Huerta

4

Community Board Key Information and Expectations:

- Explain the stipend amount, including when and how it will be distributed, as well as what it covers. Let Board members know if the stipend includes time spent outside of meeting—such as preparing for meetings or reviewing materials—and provide an estimate of how much time that might take. Explain that if their contractor income exceeds the IRS threshold, it will be taxable.
- Mention the meeting frequency and the expected length of service for Board members—see the **Length of Service and Addressing Absences** section below for more information. It is also important to clarify that Board members may withdraw at any time for any reason (e.g., concerns for their health or recovery, as those are of primary importance). This approach helps set the tone that the research team respects Board members' time and cares about their well-being.
- If this hasn't been established yet, you might inquire with Board members about their communication preferences—do they prefer email, text, or apps like GroupMe, etc.?
- Explain what the expectations are for both research team members and Board members about confidentiality—see more in the **Ensuring Privacy and Confidentiality** chapter.

5

Establishing Guardrails/Guidelines within the Group:

- At the beginning of your collaboration, it is helpful to take some time to identify and agree on guidelines within the group—see the chapter **Establishing Meeting Guardrails and Community Guidelines** for more information.

6

Identify Facilitator(s) for the Board:

- If you plan to have any Board members serve as Facilitators, the first meeting is a great time to introduce that idea. Begin by describing what the role involves—such as leading icebreakers, guiding discussions during meetings, and preparing with the research team ahead of time.
- Once everyone understands the role, ask if anyone is interested. In the spirit of supporting shared decision-making and allowing the Board to shape its own norms, you might invite the group to decide how a Facilitator should be selected if multiple people express interest. Alternatively, consider rotating the role regularly, such as every six months or annually. See the chapter on **Organizing Meetings and Agendas** for more information.

7

Training on Research for Community Board Members:

- Providing some basic training on research will help set Board members up for success in the future as valuable partners. See the following section for more detailed information.

TIP

Depending on what types of research you are discussing with the Board, some of the **Research 101 videos** from the Implementation Science and Practice Advances Research Center (iSPARC) at UMass Chan Medical School might be useful for Board members:

- Research 101: Participatory Action Research
- Research 101: Research Designs
- Research 101: Experimental Designs
- Research 101: Quantitative vs. Qualitative
- Research 101: Measurement

Research Overview for Community Board Members

Board members likely have varying levels of understanding regarding the scientific research process, ranging from little to no previous experience to some prior experience.

- Provide them with some basic training to help level the playing field. This fosters a welcoming and safe environment where everyone can thrive. It will also help Board members feel more comfortable expressing their opinions and ideas freely.

Consider asking yourself the following questions in order to determine what areas of training would be most useful:

- **What aspects of research are helpful for the Board members to be familiar with?**
- **What aspects of your project will the Board members be involved in?**

- On the next page is an example list of topics. Training does not have to cover all of these, but consider your specific project and the aspects in which the Board members will be involved to determine which of these is most relevant for their learning.

- This training could be conducted as a combination of live sessions during meetings and Board members reviewing materials or watching videos outside of meeting time (ideally with compensation still included for that time). You might also ask Board members about their preferred formats for receiving this type of training.

- An online search can help you find existing training resources, such as tipsheets or YouTube videos. If you don't find what you need, consider creating materials tailored to your Board's needs.
    - AI tools (e.g., ChatGPT) can be a helpful starting point for drafting materials in plain language.

One aspect that is helpful when the research team is preparing Board members for participating in various activities is reassurance that Board members are subject matter experts on their own experience and not expected to be experts regarding the research component.

Bob Jordan

Here's an example of **research topics** we have covered with Community Board members during orientation sessions. We hope you find them helpful!

Research 101

- What is research? (definition and purpose)
    - Qualitative vs. quantitative research
    - Observational vs. experimental studies
- The importance of including voices with lived experience in research
    - How can the Community Board get involved? (e.g., advising on study design, outreach, dissemination)

TIP

Many people without prior research experience may primarily associate research with randomized controlled trials involving medications. It can be helpful to explain that research also includes other study types, such as observational studies, to provide a broader understanding.

Key Research Terminology

- This section should only cover terminology that would be useful for Board members to learn, as it relates to their work on the project. This may include the following:
    - Hypothesis, variables, and outcomes
    - Sample size and representativeness
    - Bias and validity
    - Data collection methods (e.g., surveys, interviews, biological samples)

Ethical Considerations in Research

- Informed consent and participant rights
- Institutional Review Boards (IRBs) and their role
  - This topic might be helpful for Board members with no previous research experience; it can help them understand that there are standard protections already in place
- Extra protections for vulnerable populations such as individuals with criminal legal system involvement
- Acknowledge historical harms from research, particularly in marginalized communities, that led to the creation of these policies (e.g., Tuskegee experiment)

Although we haven't needed to use this, if community members need human subjects training, which typically is arduous and burdensome for non-researchers, here's a resource that could be useful:

- UIC CIRTification

Funding & Research Process

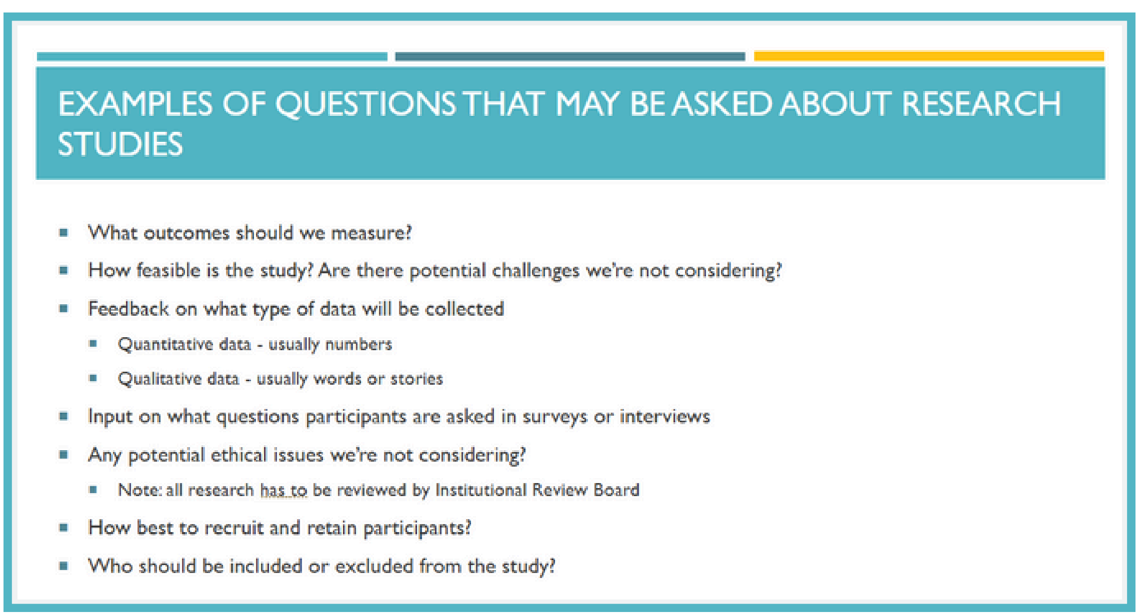
- How is the research funded? (e.g., NIH grants)
- What is the process for designing a study?
- How are research findings shared? (e.g., publications, conferences, other dissemination efforts)
- Policies related to advocacy when conducting federally-funded research

Understanding & Interpreting Research Findings

- Examining a research article (key sections: abstract, methods, results, discussion)
- What does "statistical significance" mean?
- Limitations of research studies

What types of questions will researchers ask your Community Board for feedback on?

- Below is an example slide:

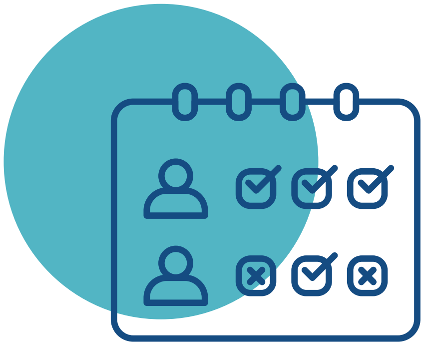


Question & Answer

- Encourage questions throughout, but make sure to leave time for questions at the end

Remember, the goal is not for Board members to become research experts, but rather to provide them with a solid foundation in the key research concepts and terminology relevant to your study. This will help them feel more confident and empowered in their collaboration with the research team.

Length of Service and Addressing Absences



See more information in the chapter on **Sustaining Meaningful Connections and Engagement with Board Members**.

- Members are asked to commit to one-year terms, after which investigators and each Board member can mutually decide if the Board member will continue for another term or if they will rotate off the Community Board.
- During the orientation process for Community Board members, it should be made clear that Community Board members may withdraw at any time for any reason (e.g., concerns for their health or recovery, as those are of primary importance).
- Members may decide over time that the Board commitment does not fit their schedule, or they may have other reasons for withdrawing their commitment.
- If a Board member's attendance stops for an extended period, it is important to approach the situation with care, understanding, and flexibility.
    - Reach out to the individual and first check on their well-being.

"Hi [Name], I noticed we haven't seen you at recent Board meetings, and I just wanted to check in. I hope everything is okay."

-
    - Ask if there is anything you can do to help support them to participate in the Board.

"I understand life gets busy—if there's anything we can do to make it easier for you to stay involved, please let us know. We truly value your contributions."

- Reassure them that you understand Board members must prioritize their needs and that Board members sometimes need to withdraw, given personal or other commitments.
- Reassure them that stepping away is understandable. If their circumstances have changed, remind them that stepping back is okay and that their contributions have been appreciated.

"We completely understand that priorities or needs can shift, and we know that sometimes a Board member needs to step back. If now isn't the best time for you to continue, we respect that and are grateful for your time on the Board."

- Ask if they can continue their contributions and time commitment as a Community Board member or if they would prefer to rotate off the Board to create a spot for someone else.

"Would you like to continue, or do you prefer to step away at this time? No pressure—we just want to support whatever works best for you."

- If they choose to leave:
  - Discuss how they'd like to wrap up their involvement (e.g., do they want to email Board members, or would they prefer you notify the Board? Discuss what they want the messaging to be).
  - Consider creating an electronic card, such as a Kudoboard, for the research team and other Community Board members to sign, or invite Board members to share their well wishes in an email thread.
  - Complete any offboarding processes that your institution has for expert consultant contractors, although there may be none.
  - Remember to update your webpage, if you have one, to remove the exiting member.
- Select a new Board member to fill the vacant position and onboard them with orientation processes (see more info in the **Turnover and New Members** section in the **Establishing Application and Selection Steps** chapter).

ESTABLISHING MEETING GUARDRAILS AND COMMUNITY GUIDELINES

Guardrails are vital to help prevent unintended consequences from Board members' involvement, as serving on a Community Board can carry risks, especially for those with lived experience.

Throughout this toolkit, we discuss a number of different guardrails to implement, including:

Allowing Board members to remain anonymous or choose what information is shared publicly—see the **Board Member Autonomy on What is Shared Publicly** section in the **Ensuring Privacy and Confidentiality** chapter.

Upholding a high level of confidentiality within the research team when working with any Board member information or ideas—see the **Ensuring Privacy and Confidentiality** chapter.

Having a standard length of commitment to the Board but setting the expectation that members' health, recovery, and wellness are of primary importance—see the **Length of Service and Addressing Absences** section in the **Conducting Onboarding and Orientation** chapter.

Encouraging Board members to share as much or as little of their story as they want within Board meetings. Their input will draw from their lived experience even if they don't expand upon the details of their experiences.

Within this chapter, we are discussing the important additional guardrails of providing resources and support during the Board meetings and the Board developing their own community guidelines.

Providing Resources and Support During the Meetings

We encourage you to create and explain to Board members the process on how Board members can discretely share when they are feeling triggered by the discussion during a meeting and may need to temporarily step away. For example, a Board member could send a private message to the facilitator(s).

If an individual steps away from the meeting, we recommend doing a wellness check to make sure they're okay. This will set up the expectation that your team values their contributions to the Board and encourages them to rejoin the group when they are ready.

- See the **Topics to Include in Orientation Session(s)** section in the **Conducting Onboarding and Orientation** chapter for more info.

As part of your orientation materials, provide helpful phone numbers such as the National Suicide Hotline, Lifeline (988), and Chat, Trans Lifeline, Addiction Policy Forum Helpline, and NAMI Helpline to each Board member so that they have numbers they can reach out to for assistance.

Share national search engines and suggestions for how to find quality substance use and mental health treatment, including SAMHSA's behavioral health treatment locator and national helpline.

Find support services in the area of each of the Board members. Refer to both **Outreach and Recruitment Methods** and **Special Considerations for Recruiting Emerging Adult Community Board Members** in the chapter **Recruiting and Selecting Community Board Members** for information on finding support services. Additional details on how to ask Board applicants what supports they use are available in the **Example Zoom Call Script and Processes** in the **Resources Appendix.**

Supporting Conflict Resolution During Meetings

Each Board should determine which methods for conflict resolution works best for them. For example, one option is the **Ouch and Oops method** to navigate unexpected challenges during Board meetings. This technique can help individuals recognize and acknowledge when they (or others) have caused harm through their words or actions. It's a way to pause the conversation, acknowledge feelings, and potentially de-escalate a situation. Here's how the Ouch and Oops method works:

1 **"Ouch"**

When someone says or does something that is hurtful or offensive, anyone in the room can say **"Ouch"** to acknowledge the potential harm. This signals to the speaker that their words or actions may have caused discomfort or pain.

2 **"Oops"**

The speaker who said or did something hurtful can respond with **"Oops"** to acknowledge their mistake and let other individuals know they are sorry for the impact of their words or actions.

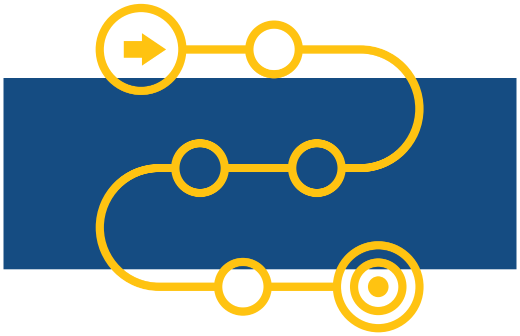
3 **Pause and continue the conversation**

Pause after both parties have acknowledged the "Ouch" and "Oops" remarks. This creates space for more conversation and understanding, allowing the person who felt hurt to share their experience and for the speaker to understand the impact of their words.

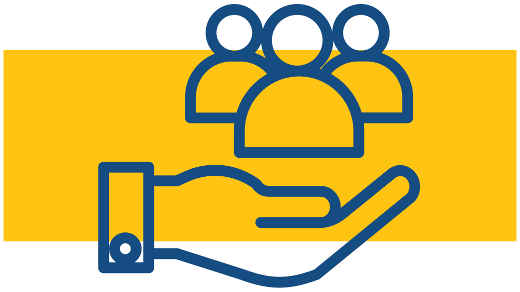
Establishing Community Guidelines

A strong partnership requires **mutual trust and respect** between Board members and the research team, but an often overlooked area is building this trust and respect between Board members. Establishing some guidelines early in the Board's existence can help jumpstart this, providing a critical internal guardrail.

We've found that Board members appreciated set-aside time for an open discussion of group guidelines at the start of the collaboration (see the **Agenda Development** section in the **Organizing Meetings and Agendas** chapter for more info). This helped build transparency, collective ownership, and community on the Board.



It also made it easier to navigate conflict (e.g., how to respond if a Board or research team member uses offensive or stigmatizing language), since the group already agreed on shared expectations (see the **Facilitating Meetings and Navigating Conflicts** chapter for more info).



Remember:

- When working with people with lived experience with SUD, it's important to highlight that there are multiple pathways to recovery. Everyone should respect each other's decisions and perspectives, regardless of the path they choose.
- It is also important to honor the language individuals use to describe themselves, while still encouraging non-stigmatizing language within the group. For example, some individuals who found recovery via 12-step programs may use the term 'addict' when referring to themself.

TIP We encourage all facilitators to keep these nuances in mind and be **mindful of their language when discussing SUD treatment and recovery options**.

For example, when talking about a service that worked for an individual in the group but that has not been found to be effective at the public health level, one might state, "XYZ intervention certainly helps some individuals, but hasn't shown to work on a large scale across the population. We should try to figure out why, or find out if XYZ intervention can have a broader impact."

It might be helpful to ask each Board applicant what they need from the research team to feel safe and supported on the Community Board. We've spoken with many community members on hundreds of calls with Board applicants across 48 states to create an environment where everyone feels comfortable serving on the Board. This means supporting their overall well-being, which includes their recovery, physical, and mental health. We've included the questions below as an example. See the **Example Zoom Call Script and Processes** section in the **Resources Appendix** for more information.

- **Question asked:** We aim to create a welcoming space where people feel empowered to speak on behalf of their communities and express their opinions. Thinking about your own personal experiences, what would make you feel comfortable sharing your experiences or what would make you choose not to share your personal experiences?
- **Follow-up question:** What do you think could be helpful to create a safe, empowering space within this Board and what supports would you like our team to provide?

Some of the suggestions we have heard are related to the logistics of how the Community Board is coordinated and supported, such as sending materials and questions in advance, what type of information to provide to Board members, sharing notes afterwards, etc. Many suggestions have been related to the interactions within the Board and between Board members and researchers.

Here's a list of general guidelines we've developed that could serve as a sample **starting point for group guardrails**, based on the thoughtful feedback shared during these calls:

- **Removing stigma and engaging in mindfulness:** Create a learning space, be open-minded, don't reject what you don't understand, and respect all forms of diversity.
- **Uphold confidentiality:** Confidentiality is something we all value; we don't all have the same comfort levels with how little or how much is shared. Allow people to set their own personal boundaries. Any personal, sensitive, or information not pertaining to research findings discussed should be treated as confidential.
- **Active listening and kindness:** Listen to learn as much as you listen to respond, use thoughtful language, don't weaponize anybody's words or thoughts against them, and be compassionate and encouraging.
- **Build trust:** Allow others to be authentic, leave politics out of the conversation, and provide trigger warnings. Someone may need time to process their thoughts and feelings. Aim to create a safe space for honest discussions and allow individuals to take breaks and speak without fear of judgment.
- **Value one another:** Be welcoming! The goal is not to "one-up" one another's experiences. Recognize that everyone brings a unique lens that is important to solving what's going on in our nation. Don't speak over others.

> *Something I believe the research team did in order to prepare me to help guide the research priorities was never pressuring me to share before I was ready. Members of the team have always taken the time to verbalize this to members who are part of the Board. In turn, this has made me more open to doing so on my own. I have given greater contributions to the team as a result of this trauma-informed approach.*

Brenda Huerta

We often send the above list of sample guidelines to Board members in an email before their first meeting, letting them know that guidelines will be discussed and decided upon during the meeting. Here's an **example of a message** that's accompanied this information:

> *We're so excited that you have agreed to form a part of the HEAL Connections Lived Experience Panel. One of our goals is to assure that everyone who participates, whether they're a panel member, the facilitator, or any other invitees, feels that this is a safe space to be in. This includes feeling safe to share as much or as little as they choose, and that the communication style and dynamics of the group help facilitate respectful and meaningful exchanges.*
>
> *Bearing this in mind, you were asked in your initial Zoom call what you need us to provide so that we can create and maintain this safe space within the Panel. The following are a few reoccurring ideas that were suggested during those Zoom Calls (and what those might look like) which we're sharing here as a starting point to help build some guidelines that the group decides together.* ***Before our first meeting, please review these and consider any areas that may need improvement or are missing. It will be helpful if you are prepared to share your thoughts so we can work together to ensure a positive experience for everyone involved.***

You can then **use these guidelines to jumpstart the conversation**, with support from a research team member who can help facilitate. We also suggest **displaying the full list of guidelines** on a virtual whiteboard so everyone can see and refer to it as needed.

On the next page is a sample script, along with an image of a virtual whiteboard we've used to support this meaningful discussion.

Example: Board facilitator speaker notes for reviewing guidelines

You may recall that when you met with one of the team members, they asked what you think would help create a safe and empowering space within the Board, because in order for this to be a genuine discussion that helps make progress, this needs to be a space where everyone feels a lot of comfort in speaking up and sharing their thoughts.

You were emailed some guideline starting points, which we put into an online comment board that we can all look at together and make comments anonymously. I'm putting a link into the chat—if you are able to click on it, a new window should open where you can see the comment board.

Each post-it note lists one of the guidelines that has been suggested. Feel free to add your own post-it notes with comments or if you see things that have been overlooked.

Now that you have had a chance to review, do you feel as though these guidelines are good for the Board? Why or why not? Are there any that would be good to discuss further?

After Board members agree on guidelines within the group, **consider how you want to formalize this with members**. This could include just emailing a final list to the full group, sharing a revised image or infographic, or asking members to sign a document.

Be sure to **occasionally revisit the guidelines**, especially during Board member turnover.

ORGANIZING MEETINGS AND AGENDAS

We know the first few Board meetings can feel a bit intimidating, but taking time to review this toolkit can help ease those feelings. The truth is, most people aren't sure what a Community Board meeting is supposed to look like, which is why shared knowledge is so vital to this work. The lessons we've learned along the way by partnering with people with lived experience across several Community Boards represent a wealth of knowledge that we're excited to share in the following sections.

Overall Suggestions

People may be anxious about attending their first Board meeting, whether they're a part of the research staff or a part of the Community Board. If possible, recording a mock Board meeting (which doesn't have to be a full-length meeting) can help new individuals understand what to expect.

Face-to-face interactions, even in a virtual setting, can help Board members feel more comfortable sharing personal or sensitive information with the group. To support this, we recommend that the research team try not to rely too much on slides or keep screen share off when it's not needed. **Turning off slides during discussion sections and pausing between agenda items can create space for more open and honest conversations.**

Encourage the facilitator(s) to **actively invite participation and encourage everyone to contribute** to the discussion.

- For example, they could ask their fellow Board members to unmute themselves or leave comments in the chat. They could also reach out to members individually via direct message and invite them to share their thoughts, if they're comfortable doing so.
- Every perspective is valuable, no matter how quiet or vocal someone may be. It's the facilitator's responsibility to make sure each person has an opportunity to contribute meaningfully to the discussion.
- See more guidance in the **Facilitating Meetings and Navigating Conflicts** chapter, as well as the **Facilitator Selection** section below.

Board members often can detect when their perspective is being treated with respect or if it's being sought only to satisfy a checklist. The use of open-ended questions and inviting members to expand on a thought/statement to further understand is helpful.

Bob Jordan

If the Board is larger than about 12 people, consider using **breakout rooms to create smaller groupings for some conversations, increasing the chance for each person to voice their perspective**. For example, in the JEAP Initiative, we hold an annual virtual retreat that brings together all three Community Boards; for this retreat, we build breakout room discussions into the agenda.

- See the **Special Considerations for Board Meeting Retreats** section below to learn more.

Create a **structured agenda and utilize visual aids** to support a variety of learning styles. This also helps Board members understand the meeting's focus and what to expect next.

- See the **Agenda Development** section below to learn more.

Provide Board members with **multiple ways to share feedback on the current process**, such as asking how they feel about group dynamics or whether recent comments made them feel more or less comfortable sharing their thoughts on certain topics.

- See more guidance in the **Evaluating and Adapting the Partnership** chapter.

Pre-/Post-Meeting Materials

Recognizing that Board members have diverse learning and processing styles, we suggest sharing materials at least <u>one week</u> in advance.

This provides people with the opportunity to review each item at their own pace. It also ensures they come to the meeting feeling prepared for an engaging discussion.

It's helpful to send materials to Board members ahead of the meeting so we know what we are fixing to get into. Yes, folks with lived experience can adapt to any environment, but sometimes surprises can be too much. Also, we don't have a lot of time, so to have us prepared serves you as well.

Jose Nicolas Flores

We've shared the following types of materials ahead of time:

- Meeting agendas (see the **Agenda Development** section below for more information)
- Microsoft surveys asking for feedback or clarification on any information that was included in the pre-meeting materials
- 1- to 2-page written summaries of a study or particular topic
- PowerPoint slides (including the main discussion questions)
- Infographics
- Audio and visual recordings

Audio and Visual Recordings: Audio recordings of the items were requested by several Board members and created by a member of our research team using Zoom (that is, reading the materials aloud while on a Zoom meeting that is recording the audio into a file that can be sent to Board members).

- These recordings are intended to **make the written materials more accessible** for people with different learning styles, and to allow Board members to listen to the materials while they are on the go.
- Although creating these recordings takes extra time, we believe it's important to meet people where they are at and **reduce barriers to participation** whenever possible.
- We recognize that some teams may not have the bandwidth or staff support to create additional materials requested by Board members. **If a request isn't feasible, we encourage you to be open with Board members about those constraints.** Clear communication helps manage expectations and fosters mutual trust.

Regardless of what meeting materials are shared with the Board, we recommend the following:

- Use plain language and define any research terms.
- Create bulleted lists, short paragraphs (e.g., three sentences), and images/graphics so that it's easier to understand.
- Let Board members know approximately how much time they should spend reviewing pre- and post-meeting materials. When determining the number of materials to send, we also keep in mind how much pre- or post-meeting time is built into the stipend we are providing. If we need Board members to review longer materials, we offer additional compensation as a sign of respect for their time and effort.
- Think carefully about the flow of information and how it's presented to the Board. The flow of information in grant applications, research journals, or academic presentations may be challenging for non-researchers to digest. For example, Board members requested that we frontload "the ask"—that is, state clearly at the beginning of the document the questions you would appreciate Board members discussing, while also emphasizing that all feedback is welcome.
- Determine which information is necessary, as providing too many materials can feel overwhelming. At the same time, we've also received feedback from our Community Board members that they appreciate it when we include additional reading materials or links that further their understanding of the topic. Importantly, however, clearly indicate that this information is entirely optional and not required.

Regarding optional reading materials provided to Board members in case they want more in-depth information:

I like that you offered the link to the actual RFA. Most research entities that ask for lived experience feedback NEVER do this.

Jose Nicolas Flores

TIP

We've also found it helpful to have a staff member who is not a doctoral-level investigator **review any materials created by investigators and provide feedback** before sending any materials to the Board. This ensures the information is concise and easy to understand, uses de-stigmatizing language, is in the optimal format, and fits within the amount of prep time planned. Although the staff member assists in revising the materials, the investigator must review them to ensure that the meaning is retained. Therefore, we suggest reserving 3–4 business days for material development before the date it needs to be sent to the Board.

There have been times when we emailed Board members a time-sensitive request for feedback (e.g., within 72 hours), which we call "rapid feedback requests." We have made these optional and, to prevent Board members feeling pressured or overwhelmed as well as to fit within our budget, we stated in our email that we would take the first eight who volunteered (or a smaller number if your Board is small). As with all tasks, we compensated Board members for their contribution.

The team prepared me for various activities by first informing me ahead of time what was coming up, asking me if I wanted to participate, letting me know that my time and input was valuable to them, and even assisting me whenever I had a technical issue.

Kimberly Moore

Agenda Development

Creating a well-balanced meeting agenda often requires patience, flexibility, and a bit of reflection. After each meeting, we suggest taking a moment to reflect on how it flowed (e.g., was there enough time to cover everything that was planned? Was the order of items optimal? Was there feedback from Board members that could improve future agenda development?)

Below are a few suggestions to keep in mind as you plan agendas.

1

Determine the topic(s) that may require the Community Boards' attention the most and structure the rest of the agenda around those priorities.

- We've often referred to the project's specific aims or goals to help determine which steps to take first.
- Keep in mind that some topics can be prioritized based on timing (e.g., reviewing applicants for the project's postdoctoral fellowship), while others are prioritized by the importance of the issue (e.g., identifying key areas of research).

We've often found it helpful to include a table of the finalized agenda in the pre-meeting materials email shared ahead of time so that Board members know what to expect.

2

Create a clear outline for each agenda item, including discussion questions, estimated timeframes for each section, and the names of any guests who will be joining and the specific sections they'll be presenting at.

3

Allow adequate time for each agenda item.

- Plan the agenda carefully so that the Board meeting can start and end as scheduled, showing respect for everyone's time and helping build trust.
- Packing too much into one meeting can make things feel rushed, which might affect how some Board members perceive this partnership. We've received feedback from Board members that having only 1–2 main agenda topics per meeting helps prevent the meeting from feeling too rushed.

4

Take into account **buffer periods and time for building connections and fostering group cohesion**.

- For example, one of our Young Adult Community Boards enjoys starting and ending their meetings with a guided meditation or other grounding exercise.
- Allow the Community Board to explore different activities that promote relationship-building and a sense of community, and decide which, if any, resonate with them.
- We suggest also having some buffer time at the beginning of the meeting when Board members are logging in.

5 **Consider beginning and concluding each meeting without researchers present**; based on our experiences, we've found that Board members appreciate having a moment to themselves before diving into the main discussion and for space to debrief and reflect on the meeting.

- The facilitator(s) should be prepared to lead these portions.
- However, we do include one or two staff members for the entirety of the meeting to provide logistical support. These individuals help serve as the link between Board members and researchers. Refer to the **Role of the Research Staff** section in the **Clarifying Roles and Expectations** chapter for more information.
- Limiting the number of non-Board members during these moments can help establish a stronger sense of community, trust, and privacy.
- It is helpful for the facilitator(s) to remind their fellow Board members that they also can share feedback anonymously using the optional post-meeting survey (see the **Evaluating and Adapting the Partnership** chapter).

6 We also keep the Zoom meeting open for an extra 30 minutes after the meeting ends to **allow Board members to connect with their peers** if they'd like. Some individuals have also used this time to provide feedback to our research staff.

Sample meeting agendas are on the next three pages.

Sample Meeting Agendas

To help you get started, here are some examples of agendas from our first few meetings with a Community Board.

Meeting 1 (90 minutes total; see breakdown below)

For the first meeting, research staff involved with the Community Board and the Project Investigators will attend the start of the meeting. After the "Project Overview and Upcoming Next Steps" agenda item, research staff in more behind-the-scenes roles and Project Investigators will leave, while research staff who directly support Board meeting logistics will remain. One of these staff members, or alternatively, a Project Investigator, will need to facilitate the first Board meeting.

Agenda	Notes
Login buffer *(5 min.)*	To fill this time, ask an easy and non-personal icebreaker question that people can respond to aloud or answer in the chat.
Welcome & introductions *(35 min.)* • Welcome *(3 min.)* • Agenda *(2 min.)* • Introductions & icebreaker *(30 min.)*	We encourage all members of the research team who are involved with the Community Board, as well as the Project Investigators, to participate in this, to help establish trust between Board members and the research team, providing a few professional points but also some personal points and doing the icebreaker. • More information can be found in **Selecting Icebreakers**.
Project overview & upcoming next steps *(20 min.)* • Guest(s) from project team: Project Investigators and other research staff	Explain that investigators and the "behind-the-scenes" staff are guests and will leave the meeting after their section ends. Then, a research staff person (preferably one with shared lived experience) will continue to support the rest of the meeting. Also explain that at the next meeting, the Board will decide what process they want to use for selecting a facilitator from among themselves (see the **Facilitator Selection** section below).
Guests leave the meeting	
Establishing group guardrails & guidelines *(25 min.)*	The main takeaways from this discussion will later serve as the foundation for the Community Board member agreement form about guardrails and guidelines the Board decides upon. • See the chapter on **Establishing Meeting Guardrails and Community Guidelines** for more information.
Wrap up & next steps *(7 min.)* • Meeting frequency & next meeting date/time *(2 min.)* • Follow-up email *(2 min.)* • Reminders *(2 min.)* • Upcoming events that may be of interest to the group *(1 min.)*	Let the Board members know that the research team will send a follow-up email that includes important items, such as the stipend invoice form, a scheduling survey (if deciding on when the next meeting should be held), and an optional feedback form. Ideally, this is the time to address any incomplete paperwork or missing information. See the **Processes for Establishing Community Board Members as Experts and Contracting** section in the **Addressing Administrative Considerations Before a Community Board is Established** chapter for more information.
(OPTIONAL) Community-building time	We typically leave the virtual meeting room open for an additional 30 minutes so that Board members can connect with one another if they want.

Meeting 2 (90 minutes total; see breakdown below)

As the Board meetings progress, we recommend starting and ending these meetings with only Board members and the 1–2 research staff supporting Community Board meeting logistics present. If you use the provided agendas, one of these staff members will need to facilitate the second Board meeting (or else one of the investigators will need to do so).

Agenda	Notes
Login buffer *(3 min.)*	
Welcome *(20 min.)* • Agenda *(1 min.)* • Review group guardrails & guidelines *(5 min.)* • Icebreaker *(14 min.)*	Since this is an early meeting, select an icebreaker that allows Board members to share personal information if they would like, such as "What drives your passion for the work this Board is doing?" (or similar discussion topics) to foster connection between Board members.
Overview of Community Board facilitator(s) *(17 min.)* • Share information about the Facilitator role and responsibilities *(5 min.)* • Brainstorm selection criteria together as a group *(5 min.)* • Decide on a clear Facilitator rotation process *(5 min.)* • Outline the next steps moving forward *(2 min.)*	
Introduction to the research priorities process & brainstorming *(60 min.)* • Summary from last meeting *(15 min.)* • Brainstorming part two *(45 min.)* • Guest(s) from project team: Project Investigators	While it can be helpful for multiple investigators to be present for this sort of discussion, we try not to have more than 2–3 investigators present, especially if the Board is small. This helps minimize any sense of power imbalance between Board members and researchers.
Reflections on today's meeting *(5 min.)*	
Wrap up & next steps *(5 min.)* • Next meeting date/time *(1 min.)* • Follow-up email *(2 min.)* • Reminders and upcoming events *(2 min.)*	
(OPTIONAL) Community-building time	

Meeting 3 (90 minutes total; see breakdown below)

If you use the provided agendas, one of the research staff members will need to facilitate the third Board meeting and the start of the subsequent Board meeting (or else one of the investigators will need to do so), but between these meetings, the new Facilitator will be prepared by the research staff to lead the meetings going forward (see below).

Agenda

Login buffer *(3 min.)*

Welcome *(12 min.)*

- Agenda *(1 min.)*
- Member bios and photos for webpage *(2 min.)*
- Icebreaker *(9 min.)*

Community Board facilitator(s) selection *(10 min.)*

Research priorities *(55 min.)*

- Summary from last meeting *(10 min.)*
- Brainstorming part two *(45 min.)*
- Guest(s) from project team: Project Investigators

Reflections on today's meeting *(5 min.)*

Wrap up & next steps *(5 min.)*

- Next meeting date/time *(1 min.)*
- Follow-up email *(2 min.)*
- Reminders and upcoming events *(2 min.)*

(OPTIONAL) Community-building time

Meeting 4 (90 minutes total; see breakdown below)

Agenda

Login buffer *(3 min.)*

Community Board Facilitator Hand-off!
The newly selected facilitator will lead the remainder of the meeting.

Welcome *(10 min.)*

- Agenda *(1 min.)*
- Icebreaker *(9 min.)*

Research priorities *(55 min.)*

- Summary from last two meetings *(15 min.)*
- Brainstorming part three *(30 min.)*
- Next steps of ranking *(10 min.)*
- Guest(s) from project team: Project Investigator(s)

Postdoctoral Fellow *(15 min.)*

- Introduce role of a Postdoc *(3 min.)*
- Postdoc selection processes *(7 min.)*
- Board guidance on job posting wording *(5 min.)*
- Guest(s) from project team: Project Investigator leading Postdoc selection

Reflections on today's meeting *(5 min.)*

Wrap up & next steps *(5 min.)*

- Next meeting date/time *(1 min.)*
- Follow-up email *(2 min.)*
- Reminders & upcoming events *(2 min.)*

(OPTIONAL) Community-building time

Board Meeting Logistics

If you are able, we recommend having between 1–2 members of the research team attend each Board meeting to handle logistics.

The idea is for one person to advance slides and assist with any technical issues, while the other takes detailed notes. That said, we understand that other teams have different capacities, so we simply encourage having at least one member of the research team present during the meeting. You might also ask for permission to record the meeting for internal note-taking purposes only, explaining who will have access to the recording, and then a research staff member could take notes from the recording after the meeting is over.

- We encourage you to review the **Ensuring Privacy and Confidentiality** chapter for more information before recording the Board meeting.
- Additional responsibilities for these staff members are covered in **The Role of Research Staff** section in the **Clarifying Roles and Expectations** chapter.

Identify a few members of the research team who can serve as alternate hosts for Board Zoom meetings in case of an unexpected event (e.g., a family emergency, illness, or unstable Internet connection). It's helpful to designate them in Zoom when creating the meeting link.

We also recommend including them as 'optional attendees' in the calendar invite and keeping them informed by BCC'ing them on emails related to the Board meetings.

Be aware that alternate hosts in Zoom will automatically enter the Zoom room when they log in. So, if they will be guests for only a portion of the meeting, they may need to log in before the meeting starts and be placed into the waiting room by the research staff member assisting with Board meeting logistics.

We're proud to collaborate with people with lived experience on our Community Boards across the continental U.S.

Because of this, we have primarily conducted our Board meetings virtually through Zoom.

TIP

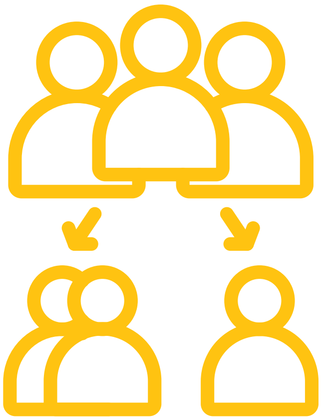
While internet access barriers are considered a low risk—for example, 90% of all households have a broadband internet subscription (87% of rural households; Mejía, 2024) and 91% of adults own a smartphone (88% of adults in rural areas; Pew Research Center, 2024), with services continuing to increase—you may need to address **internet access barriers** for Board members. Here are some suggestions:

- Keeping video off if needed to ease internet connectivity
- Calling into the meeting via smartphone (instead of from the web)
- Texting images of pre-meeting materials (including the PowerPoint)
- Mailing printed copies of materials
- Offering a Wi-Fi-eligible tablet and identifying a local place to access Wi-Fi

Special Considerations for Board Meeting Retreats

- When a project has multiple Community Boards, we've found it useful to hold **an annual retreat that brings all Community Board members together** (virtually).
- This meeting will foster a collaborative learning environment in which the Community Board members across the different Boards and the research team feel like equal partners in the initiative. It can also be an efficient way to gather insights across multiple Boards at once (e.g., for pilot funding awardees).
- Tools like Microsoft Forms and Doodle Polls can make scheduling larger meetings like this one a lot easier, as they can quickly gather everyone's availability and identify the best time to meet.
- If the meeting is more than 90 minutes long, a five-minute break in the agenda can be helpful.
- We've also utilized breakout rooms to ensure everyone's perspective can be shared. If you go this route, we recommend thinking carefully about how many facilitators you might need for each breakout room, and who will take the lead in each one (e.g., prepare Board facilitators or include a combination of the research team members and Board facilitators).

In our first retreat, we had **breakout rooms that were a mixture of members from different Boards,** so many individuals within the breakout room didn't know one another. To facilitate trust and discussion, we had an **initial breakout with an activity** (e.g., find one thing you all have in common and use that to generate a "team name"). Then, we came back together as a large group for each breakout group to share their team name and talk about why they picked it. Afterward, we sent everyone back into their breakout room again for the next discussion.



- The agenda should include **1–2 discussion topics that the Board members are prepared for ahead of time.** We suggest limiting the number of topics that are “reporting” or talking “at” the Board, rather than “with” them. This creates space for more genuine collaboration. It also helps build trust by showing people that their voices and stories are valued, not just their presence or ability to listen. Here are some example topics from previous retreats:

- Reviewing an infographic, sharing where we are in terms of project milestones and what we hope to accomplish in the coming year
- Brainstorming and prioritizing topics for dissemination and knowledge translation products (e.g., infographics, tipsheets, webinars, explainer videos)
- Providing guidance on upcoming grant applications
- Shaping pilot studies (with pilot awardees rotating through the breakout rooms for small group discussions)
- Generating new research ideas
- Refining research measures
- Member-checking and finalizing research priorities

Facilitator Selection

Our hope is that the Community Board will become a safe space where people with lived experience can own their narrative and share their valuable input when they feel ready.

Below are five steps we have used for the facilitator selection process:

1

Present the opportunity:

a. After establishing some rapport in the first meeting or two, provide an overview of the facilitator role to the Board—see the **Facilitating Meetings and Navigating Conflicts** chapter for more details.

b. Present the responsibilities (e.g., additional duties and stipend) and address any questions that arise during this discussion.

c. If your funding will allow the additional stipends, explain that the Board can have one or two facilitators.

d. Have the Board determine the process for facilitator selection and rotation (suggest an option such as what has worked for our projects, but ensure the Board knows they can determine their own processes).

e. Encourage members to think about it and invite them to reach out via text or email if they're interested in the role.

2

Compile a list of people who volunteered:

a. If no one volunteers, it may indicate that Board members don't believe the group is a safe space for them just yet. In this case, it might be helpful to focus on building more trust and fostering a stronger sense of community by incorporating more team building activities in the upcoming meetings. It's also possible that Board members have other commitments and can't take on the extra responsibility. If that's the case, collaborate with your research team to brainstorm potential solutions.

b. If the research team has any concerns about someone who expressed interest in the facilitator role (e.g., someone who typically does not turn their camera on or participate in discussions), develop a plan to address this before the next Board meeting when selection will occur. For example, a one-on-one phone call with the individual could help ensure they understand the facilitator role requirements and are able to fulfill them.

3

Work alongside the Board to shape the selection process and choose a facilitator(s):

a. If multiple Board members express interest in serving in this role, ask the Board what selection criteria they would like to use for selecting a facilitator. Some Boards have also decided to rotate facilitators every six months or annually.

b. Offer the role(s) to the individuals who volunteered to ensure they still want to fulfill the requirements.

c. If there are multiple volunteers, we may discuss the rationale behind the decision with the individuals not selected before announcing the final choice to the rest of the Board.

4

Coordinate a prep meeting:

a. Schedule a prep meeting with the new facilitator(s) before the next Board meeting.

b. Map out specifics of the role (slides could be helpful), and answer any questions that arise.

c. If there are two facilitators:

> **i.** They can rotate meetings, such that one person facilitates the whole meeting, or
>
> **ii.** One can start off the meeting (i.e., welcome, agenda, icebreaker) while the other brings it to an end (i.e., debrief, wrap up/next steps), and main topics and facilitating the discussions can be divided between them.

5

Provide ongoing support:

a. Offer support as needed during the facilitator's first meeting to ensure everyone feels comfortable managing the meeting. This may include helping navigate conflicts as they arise or offering words of encouragement when they feel overwhelmed.

- See the chapter on **Facilitating Meetings and Navigating Conflicts** for more information.

> *I like that the Community Board chose a member to lead the meetings. They involve all members in the entire process. Everyone is thoughtful and open to feedback.*

Venus Staten

Camera-On Culture (when possible)

We have tried to create a "camera-on culture" in our virtual Community Boards to foster the sense that we're all sitting in the same room together. We recommend that all researchers, research staff, guests, and Board members keep their cameras on. We communicate the rationale to everyone, but we don't impose it as a strict requirement.

For the **research team**:

- **Having cameras on can keep each of you accountable and fully present.**
- It may also be helpful to **reduce any nearby distractions** as well, such as a mobile device, a bowl of snacks, a pet, or anything else that may cause you to focus your attention elsewhere.
- We have also been asked whether note-takers should turn off their cameras to minimize distractions for the Board members attending the meeting, but **we encourage everyone to keep their cameras on if they are able**. Doing so gives Board members a clear sense of who is "in the room" with them if they choose to disclose personal or sensitive information during the discussion.
- **Fostering a safe and transparent environment** is crucial for maintaining that level of trust and comfort between the Board members and the research team.

For **Board members**:

- **They may not be in situations where they can have their cameras on.**
  - For instance, they might be in a busy environment with a lot of background movement, they may not want to disclose their location, or they may feel they are not in a place where they are comfortable presenting themselves.
- **There may also be cultural/generational differences.**
  - For instance, many groups within the research field who collaborate remotely tend to have cameras on for virtual meetings, especially in small-group meetings. In other fields, people generally keep their cameras off, even in small-group meetings. Additionally, we have found that many emerging adults prefer to keep their cameras off due to their experiences with online classes, privacy concerns, a desire to multitask, or simply feeling more comfortable without being on display.
  - Keeping all cameras on can help foster connection and safety among Board members, and the sense that they are among their peers. It also makes the meeting feel more interactive for everyone involved.

Engaging with blank screens is challenging, and having cameras on provides speakers with visual feedback, such as recognizing puzzled expressions. However, it's important to meet **Community Board members where they are**. Explain the rationale, but if they feel uncomfortable keeping their camera on for the entire meeting and prefer to turn it on only during certain portions, that is okay.

If a Board member is off-camera and also not participating in other ways, that may be something to address by reaching out to the Board member to ask how you can best support them in sharing their voice and perspective during meetings—see the chapter on **Facilitating Meetings and Navigating Conflicts**.

An exception to allowing Board members to opt for camera-off is the facilitator. Anyone who volunteers to be a facilitator should be asked to remain on-camera. This can help model the behavior for other Board members while ensuring everyone sees at least one friendly face on camera during the meeting. Also, the facilitator may be best positioned to encourage other Board members to turn on their cameras (if they are able), so that this request is coming from a peer within the Board.

SELECTING ICEBREAKERS

A welcoming environment where Board members feel comfortable sharing their opinions starts with a strong foundation of trust, respect, and relationship-building. Icebreakers are a simple yet effective way to help strengthen that foundation and enhance these connections over time.

We've found that **using icebreakers regularly in each Board meeting helps maintain a warm and welcoming environment**. Board members should be told they can share as much or as little as they would like, and the facilitator(s) should guide the discussion.

Ahead of each meeting, **brainstorm creative ideas** with the Community Board facilitator(s) and the research team. Here are a few tried-and-true icebreakers that have received positive feedback from our current Board members to help spark ideas:

- What brought you to this work?
- What's your internal weather report today—sunny, cloudy, scattered showers, full-on thunderstorm, etc.?
- If your energy today was a color, what would it be and what does that say about you?
- Any recent books you've read, recipes you've tried, gardening miracles, or family happenings?
- If you could be one kitchen utensil, what would you be?
- If you were a potato, how would you be prepared?
- If you were a dish at a holiday feast, what would you be and why?
- If you were a dish at a potluck, what would you be and what story would it tell about you?
- What is your favorite home-cooked meal?
- If you could only eat one dish for the rest of your life, what would it be?
- If you could be a vegetable, which one would you be and why?
- If you could pick a fruit to describe what stage of your career you are in, what would it be and why did you choose that?
- What was your favorite song this summer?

A few members of our team also recommend exploring AI tools or subscribing to The Art of Noticing by Rob Walker, a free resource for sparking thoughtful engagement.

- What is the most adventurous thing that you've done?
- What was your favorite cartoon growing up and why?
- Share your best "dad joke."
- What is the last thing you purchased or received that changed your life in a significant way? (could be big or small)
- What's been going on in your life lately? Feel free to share as much or as little as you'd prefer!
- What are three things you feel grateful for?
- What's one thing that brought you joy recently?
- Describe something you're looking forward to.
- What's a small thing in life that always puts a smile on your face?
- What is something you're looking forward to in the next couple months, or what is something you're going to do for yourself in the next couple months?
- If you could set one goal for the upcoming year, what would it be?
- What's the most interesting article/book/movie/TV show you've read/seen lately?
- If you were stranded on an island and you could bring two people with you, who would you bring and why?
- If someone took a candid picture of you, what would they most likely find you doing?
- What's something you're great at, but hate doing?
- What was the first band/artist/poet/show you saw live?
- If you were a postcard, what would it depict?
- If you were a tool in a community garden shed, which one would you be and how would you help?
- If you were a scented candle, what would you smell like? Why?
- If you were a building in your community (like a post office, grocery store, bowling alley, etc.), what would you be and how would it serve the people that live there?
- If you could be in any game show, which one would you choose?
- If you could be any character in a TV show, who would it be and why?
- Describe one thing that people will not believe about you unless you tell them.
- What will your Halloween costume be? If you're not dressing up, what would you have liked to be?
- If you could pick up a new skill in an instant, what would it be?
- If you could be a flower, which one would you be and why?
- If you were a plant, what kind would you be and where would you grow?
- What activity helps you relieve stress?
- If you could do anything in your spare time, what would it be?

FACILITATING MEETINGS AND NAVIGATING CONFLICTS

Engaging conversations are powerful, especially when **every voice is recognized and celebrated for the value they bring**. Effective facilitation of Board meetings is a critical aspect of high-quality CBPR.

You will also need to decide who will facilitate these conversations and determine how many facilitators are needed. A staff member can step in as facilitator, if needed, but we recommend trying to have it be a person who shares lived experience with the Board. When a Board first meets, we generally have a staff member facilitate for the first few meetings, even if a Board member will eventually be selected. See the **Organizing Meetings and Agendas** chapter for example agendas of initial meetings and the process for the Board to select their own facilitator(s).

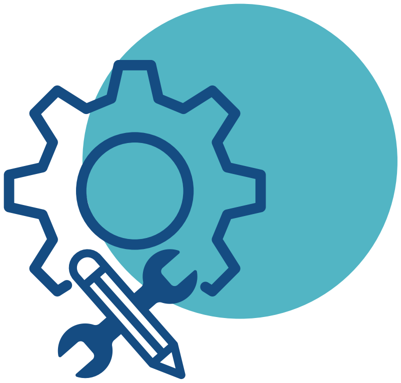
> *The staff sets a welcoming tone where all voices are valued. This includes ensuring non-judgmental discussions and emphasizing mutual respect. I believe they are able to do this by facilitating open dialogue because the staff ensures that everyone's perspectives are heard and taken seriously. They use active listening and responsiveness to concerns which helps build trust. Staff members acknowledge the unique experiences and expertise of the Board members, reinforcing that their contributions are not only welcomed but essential to the research.*

Brandy Morris-Hafner

When possible, we recommend **offering the facilitator role to Board members**. In addition to aligning more closely with CBPR principles, Board members could gain valuable skills from this opportunity that will enhance their resumes and support their professional development. Keep in mind these points described previously:

- Having the Board select a facilitator among themselves, as well as having the Board decide what selection process they wish to use, supports shared decision-making.
- Some of our Boards preferred to rotate the facilitator role (e.g., every six months), and some of our Boards preferred to have two co-facilitators who rotate the role every other meeting.
- We typically use the label "Facilitator" to reduce a sense of hierarchy, but a Board may decide to use a different term (e.g., one of our Boards decided to use "Chair" because they thought it would be a more helpful title for their resumes).
- Facilitators will have extra duties, so should be compensated for this in addition to their regular Board compensation (see the **Community Board Stipends and Budget Considerations** section in the **Addressing Administrative Considerations Before a Community Board is Established** chapter).

Skills for Facilitating Discussions and Navigating Conflicts



The facilitator(s) of the Board is responsible for ensuring that meetings run smoothly. Some important skills for facilitators are to:

- **Emphasize inclusivity and participation**
- **Encourage use of multiple methods of contributing (speaking up, chat functions)**
- **Keep an eye on time and help balance airtime so that all members have space to contribute**
- **Maintain empathic listening and compassion**
- **Set aside one's biases**
- **Show enthusiasm for the process of sharing lived expertise**

Facilitation might involve keeping track of time, encouraging equal participation and engagement, summarizing key takeaways, and helping to de-escalate passionate discussions that may arise. Some examples of potential conflicts include:

- Differences in communication styles, which might include forgetting to use accessible or 'lay' language
- Imbalanced power dynamics between researchers and Board members
- Cultural misunderstandings, microaggressions, or a perceived lack of respect for social identities, backgrounds, and lived experience at the table
- Strong emotional responses to research topics that may be triggering for some Board members
- Disagreements around group decisions, such as identifying research priorities and selecting a candidate(s) for varying opportunities like a post-doctoral fellowship

> *The team made significant efforts to ensure that members felt prepared, supported, and valued, thereby fostering long-term engagement and collaboration within the project. One thing that is evident in every one of our calls was the expression of sincere gratitude and appreciation when opinions were shared by welcoming all voices.*

Monifa J.

Face conflict with confidence by preparing ahead of time. The JEAP Initiative developed a tipsheet on facilitating Community Boards of people with lived experience and explored six practical strategies:

1. **Be neutral in all discussions.**
2. **Expect possible distractions and know how to guide the conversation.**
3. **Appreciate silence.**
4. **Be organized and prepared.**
5. **Know your identity and how it relates and does not relate to the topic.**
6. **Be ready to address challenging topics.**

> *Researchers can ensure everyone is engaged in a large virtual meeting by using ice breakers, making time for everyone to answer a question, sharing how someone's comment assisted the research, understanding that board members process and share in different ways (i.e., sending chats instead of unmuting).*

Eleanor Byrd

Want to learn more? Check out the full tipsheet below and download your copy here for a closer look at the strategies above. There's more info on this topic after the tipsheet!

TIPSHEET:

KEY POINTS FOR FACILITATING COMMUNITY BOARDS

OF PEOPLE WITH LIVED EXPERIENCE

- ***Meeting Facilitators:*** *Staff and/or board members*
- ***Meeting Attendees:*** *Community board/panel members (e.g., community advisory boards, community member panels)*

Being a facilitator in environments where people have lived expertise can be challenging, and it is arguably one of the most important tasks when trying to build relationships and have productive conversations with groups of individuals with varying life experiences and perspectives. How the conversation flows, what decisions are made, and how long the discussions last are up to the facilitator. As the facilitator, it is important that you are prepared to handle the various situations that may arise, keep the conversation going, summarize key points, and show attendees they are being heard. Below is a list of items to keep in mind when preparing to facilitate.

1) Be **neutral** in all discussions.
2) Expect possible distractions and know how to **guide the conversation.**
3) Appreciate silence.
4) Be organized and prepared.
5) **Know your identity** and how it relates and does not relate to the topic.
6) Be ready to address challenging topics.

1 BE NEUTRAL IN ALL DISCUSSIONS

The position of facilitator holds a lot of power - how you choose to use it directly impacts attendee engagement and group dynamics. When you state your opinions on a topic, it is likely to change the minds of the meeting attendees and how they decide to engage with the rest of the group. It is essential to make sure that everyone feels comfortable stating their honest opinions. Here are some tips to help that happen:

- Become aware of any personal opinions you may hold and leave them out of the conversation.
- Continually remind attendees that **all opinions are welcome.**
- Tell attendees that differing opinions or thoughts are valuable and may lead to advances in finding solutions to problems. Diversity is our strength!
- Don't initially explain your point of view or opinion; have attendees state their own.
- Invite everyone in the group to share their opinions.
- Give reminders that **no one is right or wrong**; they are either on-topic or off-topic.
  - An example might be: *"I heard what you are saying and want to write that point down because I think it is relevant to another question we have."*

2

EXPECT POSSIBLE DISTRACTIONS & KNOW HOW TO GUIDE THE CONVERSATION

As a facilitator, you may find that conversations veer off track or that certain attendees will take up more speaking time than others. It is important to have tools to ensure that everyone stays on track and gives space for differing opinions. Don't be afraid to gently remind attendees of the conversation topic. Let them know their thoughts are valuable, but that you need to return to the initial subject to avoid running out of time. Here are some ways to help guide conversations back to the topic:

- Keep an "**idea board**" where you can place off-topic ideas that attendees bring up. Say: *"Hey Kyle, thank you for sharing that. It's a great idea, but it's a little off-topic. I'm going to write this down, and if we have time, I will come back to it."*
- If you know the point is related to a later topic, it is even better to say: *"Thank you for sharing about [xxxx]. That's actually directly related to a later question and topic we have – I'd like to return to that later this meeting, if that's okay?"*
- **Assign tasks** to certain people (those that are having trouble allowing others to speak, those that repeat their opinions, etc.). This could include asking them to take notes during the meeting or asking them to be the timekeeper.
- At the start of the meeting, **set expectations** by stating that you are responsible for keeping track of timing; ask attendees not to take offense if you must move along.
- **Give warnings** when sections of the meeting are coming to an end. **This is a great time to encourage people that have not stated their opinions to do so.**

APPRECIATE SILENCE

3

Discussions do not need to be filled with constant chatter. Many people need time to gather their thoughts before they speak; **give them that opportunity.**

- If you ask a question and no one answers, that is not necessarily a signal for you to rephrase the question or to change topics. **Sit in the silence** for a minute.
  - Although a moment of silence might feel awkward or uncomfortable at first, it gives people time to think about the question and tends to bring out the voices you have yet to hear from.
  - Put questions in the chat. Many people are **visual learners** and need to read questions while they think through their responses.
- Encourage attendees to spend more time thinking about their answers if they would like.
- If everyone answers, feel free to take a few seconds and ask something along the lines of *"What other ideas/opinions/thoughts do you all have?"* and then wait a few more seconds. If there are no more answers, then it is probably a good time to move on.

4

BE ORGANIZED & PREPARED

Facilitating conversations is a lot of work and can be unpredictable. It is extremely important that you anticipate how long discussions are going to take. Here are some tips that can help:

- If there are readings that attendees were supposed to be prepared to discuss, make sure you have a **brief overview** and know how long it will take to describe. It is not uncommon that people won't have time to review materials in depth beforehand. It is **your responsibility** to give an overview so everyone understands the material.
- Before the meeting, practice ways to handle different types of attendees (see below).

For those who do not speak:

- Share a friendly reminder to the entire group on participatory conversations: *"All of you are experts in your own personal lived experiences, and the success of our group depends on your unique perspectives being represented in today's conversation."*
- Try various **facilitation techniques**, such as a round-robin (i.e., attendees share their thoughts and then call on someone else to go after them), icebreaker questions, and small group exercises to help strengthen trust among attendees.
- Have **one-on-one meetings** with individuals to ask for feedback on ways to make them feel more comfortable sharing during group meetings.

For those who are overly talkative:

- Remind the group of any ground rules that were put in place beforehand (i.e., sharing airtime).
- **Acknowledge their viewpoint** and then say a phrase such as: *"We haven't heard from a few other people in our group yet. What's on your minds?"*

- Make sure you get a final decision on necessary topics.
    - Reserve about **5 minutes** for the attendees to get final decisions and action items before going on break or moving on to the next topic.
    - Decide on action items and deadlines:
        - *Who is going to do what? When?*
        - *Who is going to send out notes? When?*
        - *Who is going to reach out to that person?*
- Keep track of time and plan when to end each section of the meeting.

5 KNOW YOUR IDENTITY & HOW IT RELATES & DOES NOT RELATE TO THE TOPIC AT HAND

It is not imperative that you have merging identities or lived experience with the topic that you are facilitating. What is important is that you know where your identity intersects with the topic at hand and where you may be ignorant in certain points of view (attendees explaining their views can be a way for them to relate to each other by helping you understand certain topics).

- Expressing where you may not understand a topic *"is a sacrifice well worth making in the interest of trust-building and facilitator credibility. Far from an admission of weakness, this kind of disclosure suggests the facilitator is comfortable in their own skin – confident in their abilities, not afraid of their limitations, and willing to expose themselves to challenges in the interest of creating the potential for greater group buy-in."* - Berkman and Egol (2020)
- Don't be afraid to say that you lack understanding. This is a perfect time to reassure attendees that the meeting is about their opinions and expertise.

6 BE READY TO ADDRESS CHALLENGING TOPICS

Oftentimes challenging conversations are where the most growth comes from. Don't be afraid of differing opinions! That is diversity, and **diversity is our strength.** It is important to recognize and express that to meeting attendees. In many instances, people will not share their opinion if it differs from the group. It is your job to make attendees feel comfortable sharing those differing opinions. Below is a list of resources and ideas for you to consider in responding to challenging conversations:

- **Move toward the conflict.** Rather than shying away, addressing the issues that arise and the concerns people have is probably the most important thing to do as a facilitator.
  - *"I noticed that there is a difference in opinions here. Let's talk about that."*
  - **Validate everyone's opinions and feelings.** *"Thank you for sharing your perspective. This is great feedback to know that there is not a one-size-fits-all solution. These topics are complicated and we want to hold space for all perspectives."*
  - Anticipate potential conflicts by speaking with other facilitators for more guidance and to help you feel prepared when these moments present themselves.

CONTINUED ON NEXT PAGE

- Be clear about the issue at hand and don't assume you know what the problem is. Ask people if you understand them correctly.
  - When an issue comes up, express how you view the problem, what you think is the main issue to be resolved, and why you think that.
  - This will provide space for people to explain themselves more and potentially reach a solution.
- Remind attendees that we don't need to come to a consensus on any issues/topics; the most important thing is that **everyone is heard.**
- Have scripts in your own words ready and **practice them.**
  - *"This is really great, because we have a difference of opinion, and it's wonderful that everyone feels comfortable enough to share their true opinion! This is how trust is built."*
  - *"I'm so glad we don't have to come to consensus. There are a number of important opinions and I want to make sure we can capture them all here because they are all valid."*
- Continue to **build rapport** (i.e., icebreakers and other fun activities for relationship-building) within the group when appropriate, especially in meetings leading to a potentially lively or heated discussion.

Helpful Resources

- How to Lead Tough Conversations | Adar Cohen | TEDxKeene (YouTube video)
- Facilitator Tips - Challenging Meetings (PDF)
- How to Facilitate Difficult Conversations (Article)

Disclaimer

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References

Berkamn, T., & Egol, D. (2020, October 27). *"Who are you and why do you get to run the meeting?" Reflections on facilitator identity and the management of complex public disputes*. Consensus Building Institute. https://www.cbi.org/article/who-are-you-and-why-do-you-get-to-run-the-meeting/

A few additional questions we have been asked are:

Questions	Responses
This is my first time serving on a Community Board. How do I **facilitate** these types of discussions?	Serving as a co-facilitator on a Community Board might feel exciting and nerve-wracking at times. Try your best to remain calm, respectful, and mindful of the varying perspectives of the other individuals participating on the Board.
How can I **increase engagement** of Board members during our Board meetings?	Start off the Board meeting with a simple icebreaker question before admitting any researcher guests. This helps everyone feel more comfortable sharing their thoughts aloud. In addition, we've found that some Board members are more likely to share when questions are asked by their peers (i.e., the Board facilitator) rather than by the researchers; so, researchers should share any pertinent questions with the facilitator ahead of the meeting.
What should I do if a Board member or research team member uses **offensive** or **stigmatizing language**?	Redirect the conversation in a calm manner. As a facilitator, your fellow Board members will naturally look to you for guidance on how to handle the situation. In addition, you might decide to reach out to the research staff on the project for more guidance. Hopefully, the research team has created a safe environment where you can address things with them directly. However, having anonymous surveys after each Board meeting also gives the facilitator and Board members a chance to give feedback to the team without having to be direct. For more info on this type of survey, see the **Evaluating and Adapting the Partnership** chapter.
Many of my fellow Board members have experiences and perspectives that are different from my own. How do I foster an **inclusive space** and ensure that everyone feels heard during these meetings?	Create a set of group norms (aka ground rules) so that everyone on the Board feels empowered to share their honest feedback at each meeting. Everyone brings their own uniqueness to the table, so keep an open mind and express a willingness to learn from the other individuals around you.

CO-DEVELOPING RESEARCH PRIORITIES WITH COMMUNITY BOARD MEMBERS

One way Community Boards can contribute to advancing an area of research is by conducting a needs assessment, such as co-developing research priorities on a topic. These types of processes seek to answer the question: **What does the community think should be the focus for research?**

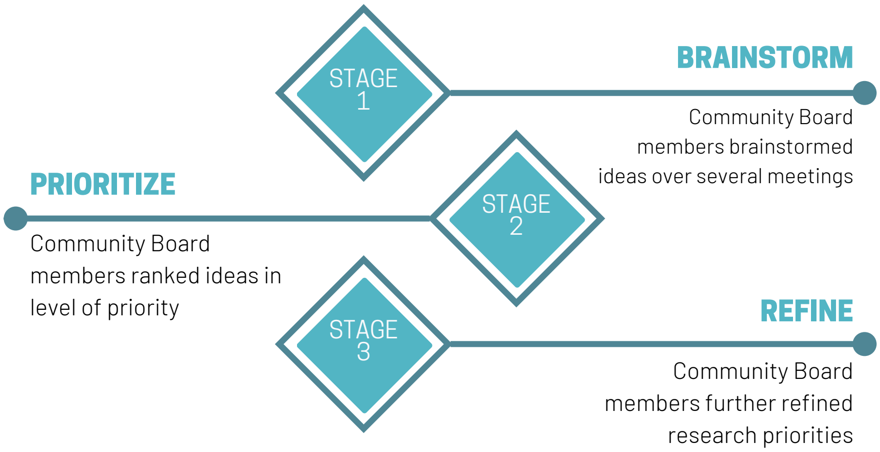
This can be especially beneficial for a research area that is in its infancy or for which there is a significant gap between academic understanding and community needs.

- Co-creating research priorities is an effective strategy to ensure that the research being conducted is **relevant and beneficial** for the communities involved.
- Hundreds of other methods for developing research priorities with key stakeholders have been published across disciplines and locations, as reported in the scoping review by Grill (2021).[1] However, as noted, the vast majority did not actively involve impacted community members in their entire processes, if at all.
- Since setting priorities would be at the "upper end" of the community-engaged continuum (see the chapter on **Understanding and Applying CBPR Principles in Substance Use Research**), it's imperative that any processes used for Boards to co-develop priorities adhere to CBPR methods.

As an example, in the JEAP Initiative, we carried out this process, grounded within CBPR principles, with three different Boards focusing on research topics about recovery housing and peer support services.

The intent was to inspire research studies in the field of recovery support services that **center the priorities of the impacted community**, rather than those of researchers.

Following an iterative three-stage process of brainstorming, prioritizing, and refining, the Board members identified **over 100 research themes** and prioritized and refined them into 73 research questions.



Further details of this process can be found in our toolkit (JEAP Initiative, 2022).[2]

These research priorities have been shared with the larger research community via our resource priorities webpage, a virtual forum, a brief video, an infographic, and national professional conferences. You can view the priorities and many of the dissemination items here: https://www.jeapinitiative.org/research-priorities/

From these priorities, new grant applications have been submitted, pilot studies funded, review papers developed, and dissemination activities and products initiated.

A brief description of this process, as well as the utilization of this process as the basis for a scoping study of recovery housing research, can be found in this paper by Hibbard et al. (2025).[3] This same three-step process is also being used in PATH to focus on developing curriculum for peer recovery supports to learn harm reduction methods.

From the start, the researchers created space for us to share openly about our experiences, what matters most to our communities, and what we see every day on the ground. They didn't try to steer us toward academic priorities; they genuinely wanted to understand what we thought was important. They were willing to change course. When community members raised issues that weren't originally on the researchers' radar, like how policing impacts outreach or how services exclude certain populations, the team didn't push back. They asked questions, learned more, and shifted priorities accordingly.

Garland G.

Chapter reference(s)

1. Grill, C. (2021). Involving stakeholders in research priority setting: A scoping review. *Research Involvement and Engagement*, *7*(1), Article 75. https://doi.org/10.1186/s40900-021-00318-6
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ENGAGING IN RESEARCH PLANNING, STUDY IMPLEMENTATION, AND RESULTS DISSEMINATION WITH BOARDS

The insights of Community Boards can enhance every stage of the research process, in addition to the identification of priorities (see the **Co-Developing Research Priorities with Community Board Members** chapter).

Our experience, along with that of other research teams (e.g.,[1-4]), has shown the **value that community partners bring to the entire life cycle of research projects**, from idea generation and research grant planning, to problem-solving during study implementation, to results interpretation and dissemination.

We have collaborated with Community Boards throughout nearly every stage of the research process. Sometimes a single Board will be involved across various aspects of the project, but depending on the scope or funding, a Board may participate in just one.

Deciding which stages to incorporate community members in and how to do so requires careful consideration.

TIP

An important consideration when working with Community Board members is recognizing the **different but equally valuable perspectives that researchers and community members bring—especially looking for ways that these complement each other**. Researchers often focus on rigor and methodological soundness, such as measurement tools and study design. Community members bring deep insight rooted in lived experience and the realities of their communities, which are critical for ensuring relevance and impact.

To bridge these perspectives and support meaningful collaboration, we recommend:

- Ensuring all research products are clearly translated for lay audiences and accessible to those outside the research community.
- Taking time to explain technical details when they are necessary (e.g., specific types of data required for rigorous analysis). This not only enhances transparency but also supports shared learning and builds Community Board members' capacity to engage with and contribute to the research process.

Community Boards and Research Planning

Planning a research study is a complex undertaking that prompts questions such as:

Exactly what topic should be researched?

The prior chapter on **Co-Developing Research Priorities with Community Board Members** covered a comprehensive process, but more targeted processes could focus on a single project or idea. A good place to start is with questions like this:

- **How do communities view this issue?**
  - Do they consider something solved that the research community has not yet settled on?
  - Do they consider something still in question that the research community has settled in the literature?

What outcomes should be measured?

- In our work, for instance, community members have expressed that outcomes like recidivism and return to use represent a limited perspective —that issues like quality of life provide more expansive understanding of phenomena like substance use recovery.

What is feasible and what barriers can be anticipated and planned for?

- An example comes from projects requiring collaboration with other organizations or people in the community, such as treatment providers or criminal legal system entities. Board members have also helped in our projects to understand how best to engage with the parents of emerging adults.

What research design is best from the community's perspective?

- Community Boards have challenged us to look into designs that are less harmful or off-putting to communities.

How should data be collected and what methodological considerations are there?

- The question of quantitative or qualitative data is more than simply numbers or words; these data represent real people and their lives. We have attained invaluable advice from Community Board members regarding the specific questions to ask in both surveys and interviews. Additionally, conversations with Community Boards have led to stronger research methods (e.g., providing insights into data researchers should collect, that the team may not have been aware of previously).

What sampling method and strategies are best for recruitment and retention (e.g., inclusion and exclusion criteria)?

- While we aim to use the most rigorous sampling methods possible, input from Community Board members is essential in determining which populations should be prioritized for inclusion, ensuring the research is both scientifically sound and community-relevant.
- Community Boards also provide critical insight into outreach and retention strategies, including the feasibility of proposed recruitment goals based on their knowledge of local contexts and lived experience.

What are ethical issues that need to be addressed?

- While researchers must gain competency in research ethics and human subjects concerns, the notion of "ethics" takes on a broader meaning for community members. Community Boards have helped us gain understanding of items like stigmatizing language and power dynamics within groups.

TIP

How to word discussion questions for the Board

The questions listed on the previous page give ideas of topic areas to ask about, but the questions you bring to your Community Board should be specific to your study and adapted to generate genuine, meaningful discussion with the Board. Below are some examples:

- Which groups of service providers would be most appropriate to interview and survey? For example, family physicians? Syringe services programs? Peers? Child welfare caseworkers?
- If you were a young adult who saw this study recruitment flyer, what would you think about participating in this study? Does it make you want to participate, or do you see any concerns?
- Now that you've heard a little about these two options for research designs, which do you think best fits with what we want to accomplish with this study?

The research team was great during the development of topics to prioritize because they allowed us to object and replace topics, we felt might have been redundant as being peers in the field. For example, self-care is often times really over prioritized in many of our community boards opinion, and they pivoted, redeveloped, and helped us to create a new topic that we thought would be more paramount.

Robert Richard-Snipes

I've felt meaningfully involved in shaping the research because the team brought us in early, before decisions were finalized, and treated our lived experience as essential, not optional. They took time to break down complex parts of the research process in ways that felt accessible and respectful, which made it possible for everyone at the table to contribute. We weren't just giving input on broad topics; we were invited to weigh in on real decisions, like which outcomes mattered most to our communities and how certain measures or language might land. When we raised concerns or suggested changes, they listened and made adjustments, and when something couldn't be changed, they explained why. That kind of follow-through, along with creating a space where both recovery and harm reduction voices are centered, has made it clear that our input is not only heard but valued.

Garland G.

Community Boards and Study Implementation

Initiating and implementing a study involves complex challenges that Community Boards are well-positioned to help address:

Recruitment and retention

Community Boards can help ensure a smooth and valid recruitment and retention protocol. For instance, community members in recovery from substance use issues will have insight into how best to reach potential participants who are at a specific point in their substance use or recovery journey and ways to keep current participants from leaving the study.

Collaborating with community organizations

We have encountered issues, such as leadership changes within our partner organizations, which have led to confusion regarding the terms of the partnership (e.g., logistics, benefits to the partner organization). When the partner is a type of organization that Board members are familiar with—such as treatment providers or entities within the criminal legal system—they can offer valuable insights based on their knowledge of how these organizations typically operate, as well as their direct experience with specific organizations or geographic areas.

Ongoing data collection and analysis

Community members can assist with specific issues that may arise during activities such as data collection and analysis. For instance, if a survey is receiving low response rates, Community Boards can help evaluate reasons and come up with solutions.

Ethical concerns

Although planning goes into predicting potential ethical concerns, new issues sometimes arise in the course of a study. Community Boards can help brainstorm and decide on solutions.

Interpretation of findings

Reviewing results of data analysis with Community Boards has proven crucial in our experience, particularly for understanding the meaning of findings and their implications. While researchers bring technical expertise in data analysis, interpreting results often requires insight into lived experience and community context, which Community Board members are uniquely positioned to provide.

Community Boards and Results Dissemination

If we are to close the research-to-practice gap, we must improve how we disseminate research findings into communities who need them. The primary outlets for disseminating research studies, such as peer-reviewed articles, provide narrow pathways for communication, especially when the goal is to reach and benefit communities.

When thinking of a study, **think of the "intended beneficiaries" of the research findings**. These may include providers and policymakers, but also the community who will be impacted by changes made by policymakers and providers. Once you identify the intended beneficiaries, then you can brainstorm the optimal dissemination channels for getting your research to those audiences.

Beyond considering the intended beneficiaries, we urge you to think about effective knowledge translation. Effective knowledge translation tailors dissemination content and platforms to user needs and maximizes parsimony, ensuring accessibility and usability.[5-10] Effective knowledge translation for research usually requires a range of activities that include accessible channels, peer networks, interactive methods, and tailored materials for broad reach to diverse audiences.

We have engaged Community Boards in several different ways for dissemination efforts, including:

Discussing who would benefit from study findings

Community members have helped broaden the traditional definition of a study's 'intended beneficiaries' by identifying individuals and groups who may benefit from or be interested in the findings beyond the usual stakeholders.

Formats used

Our previous efforts have provided useful insights into the communication formats that community members prefer. For instance, in HEAL Connections, members ranked the types of dissemination products that might have the greatest impact in getting research findings to the communities that could benefit from them.

- Top-ranked channels were social media posts, infographics, key summary points, and short summaries (under one page)
- Least valued were white papers, slide decks, and academic publications
- Subpanels also strongly emphasized the need for researchers to co-create materials with people with lived experience, highlighting the value of CBPR

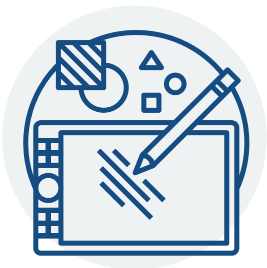
Language used in materials

Board members can help convert study findings into accessible language and tools that cater to a wide range of audiences, including individuals directly impacted by the topic being studied and organizations that provide services.

Board members have also been critical to helping us use language that is welcoming to more individuals and avoids any language that might be unintentionally stigmatizing. Notably, the JEAP Community Boards have assisted with changes to the language used in recruitment and hiring materials for our entire organization.

Images and graphics used

In addition to issues like person-first language, Board members can assist in selecting photographs that both avoid stigmatizing imagery and accurately represent intended audiences. Additionally, they can provide guidance on graphs and other imagery, ensuring they can be understood widely.



Outlets for dissemination

Community Board members have vital insight into both how and where people in their community obtain information. Working with community members to strategize the outlets used can ensure a study's findings reach the intended audience. In HEAL Connections, we asked them to identify moments when information changed outcomes for them and/or members of their community, and where that information came from. The most common were:

- **Word of mouth** from peers or family
- **Community events**, like recovery or church-led events, outreach and mobile social support programs, and "warm hand-offs" within systems
- **Peer-led services**, such as recovery coaches and trained peer doulas
- **Mutual aid and harm reduction services**, like syringe services locations, crisis response, street outreach, 12-step and mutual aid groups, and safe use hotlines
- **Trusted providers**, such as nurses and behavioral health professionals
- **Educators and educational environments**, such as teachers/mentors, continuing education, and jail libraries
- **Online/social media platforms**, such as TikTok, Instagram, YouTube, Reddit, online support groups, brochures/palm cards, and QR codes on posters

This highlights not just where people learn, <u>but who they trust</u>.

Serving as "champions"

In addition to helping with the dissemination activities mentioned above, community members can play a key role of representing research to their communities. Having learned about research through participation in a Community Board and feeling ownership of the study through methods like bidirectional communication, these individuals can not only help get materials out to their communities but also are likely to promote the use of findings in their communities (e.g., improve services).

Logistics and Feasibility Considerations

Incorporating Community Boards into each phase of a research project presents unique considerations.

Early planning and concept development (pre-grant stage)

This stage, when you are developing an idea and preparing to write a grant, rarely includes resources sufficient to engage a Community Board anew. Collaborating with other projects that have a Community Board or seeking pilot funding to support a Community Board is highly recommended.

Grant application process

Grant applications require highly technical content intended for scientific reviewers. When working with Community Board members, it's important to focus their involvement on areas where their expertise and perspective can have the most impact. Being intentional about what you are asking their input on shows respect for their time and ensures their contributions are meaningful.

Project initiation and implementation

As covered in the section on **Bidirectional Communication**, make sure to communicate with Community Boards regarding the activities happening in the project, including how their input has influenced study operations.

Dissemination

For Community Board members to actively support dissemination, especially in the important role of "champion," it is essential they stand behind study's findings. This support is much more likely when key practices from this toolkit are followed, such as bidirectional communication and involving Board members in interpreting results. If Board members do not feel aligned with the findings, they are unlikely to participate in dissemination efforts.

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PRACTICING BIDIRECTIONAL COMMUNICATION

Effective communication with community partners represents a vital element of CBPR. While we mention the practice many times throughout this toolkit, this section is devoted to a thorough understanding of what it means, why it is important, and what it looks like in practice.

Why is bidirectional communication so important?

For research to truly benefit communities, a trusting relationship must exist between research teams and community members.

- Historical extractive research practices (gathering important information and then leaving without providing a direct benefit) have soured research-community relations.
- Building a trusting relationship requires several key practices: active listening; direct and clear communication; ensuring that information is conveyed and understood accurately; and regularly "closing the loop" by showing how shared input has been used.
- Since research teams may not always fully grasp feedback gained from communities earlier in the process, revisiting and confirming that information with community partners can help prevent misunderstandings and improve clarity.

Communicating exactly how researchers put community partner input into action provides several benefits:

- Community Board members know that the research team listened well
- Community Board members understand how the research benefits their community
- Researchers demonstrate how important community members are to the process
- As mentioned in other sections of this toolkit, these practices also lead to improved relationships between researchers and communities more generally

Our insights weren't just feedback or secondary to data; they were considered essential. Researchers made it clear that our knowledge, whether as people in recovery or as harm reduction providers, was critical to shaping the direction of the work. They were transparent and followed through. We weren't just consulted; we were kept in the loop about how our input influenced the research direction. That kind of follow-through built trust and helped us feel like real partners, not token representatives.

Garland G.

How do you put bidirectional communication into action?

Bidirectional communication can be thought of as **loops of different sizes**:

- **Smaller loops represent the short-term**—for example, asking clarifying questions in the moment and providing a summary to Community Board members shortly after a meeting, asking them to ensure the accuracy

> *Researchers can ensure that Community Board members feel like a valued part of the team by seeking to further clarify statements made by Board members to ensure a deeper understanding enhances feeling valued/respected/heard. This could occur during meetings or even in private communication.*

Bob Jordan

- **Mid-size loops relate to mid-term situations**—such as after gathering information from Community Board members and interpreting that information, checking with Board members to ensure their input has been accurately interpreted; another example is showing a draft of something that is being created

- **Large loops represent the long-term**—generally, this is when a research team demonstrates to Community Board members how the information they provided has been put into practice

The first two loops can be described as **"member checking"**[1]—a process in which researchers provide a summary or interpretation of information received from community members, ensuring that these accurately represent what the community members communicated was correctly interpreted—these are also the phases where researchers solicit feedback to improve the final product.

The last one has more to do with letting community members know how their input has been utilized, and less with asking for feedback.

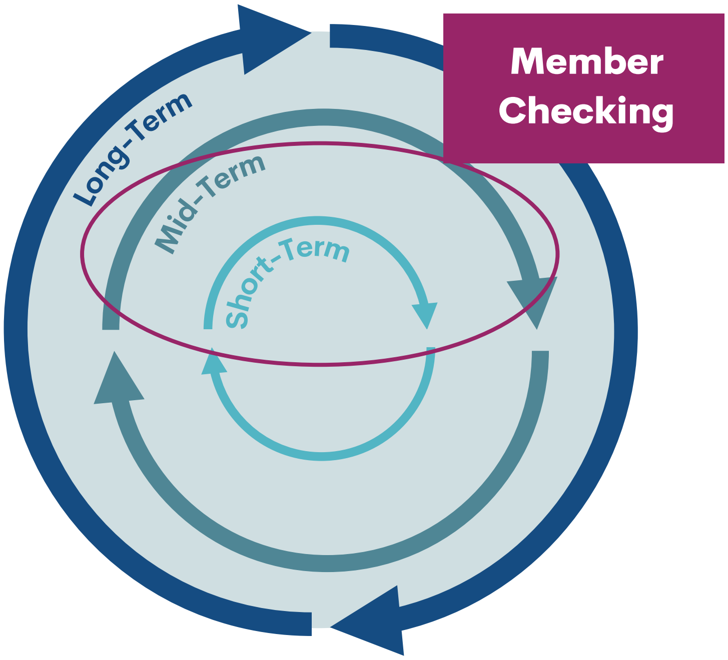

Figure 1. **Bidirectional Communication**

From Birt et al.[1]

TIP

Reminder: Part of bidirectional communication is also about acknowledging and celebrating Community Board members' contributions to research. See the **Alternative Forms of Compensation** section in the chapter on **Addressing Administrative Considerations Before a Community Board is Established** for suggestions on how to do this, such as co-authorship on articles or dissemination products, involvement in press releases, co-presenting at conferences, or other tips.

Important items to incorporate in all stages of bidirectional communication include:

- What you heard from Board members
- How you incorporated that into your plans
- What feedback you weren't able to incorporate and why

How a research team performs bidirectional communication depends on the type of communication underway and the stage of the feedback process:

- **Short-term communication** can include immediate clarifying questions during a meeting, or a summary document/email sent to Board members
- **Mid-term efforts** can be done with a formal presentation to Board members, a summary document, or a video presentation
- **Long-term communication** can be presented directly to Board members, but more often comes in the form of providing specific products (e.g., policy, report, article) that include community input or video presentations

Researchers can demonstrate that Community Board members are integral to the project by listening, and I mean really listening! I want to know that all this information that I have shared is being used for good. Show me in a paper or policy that I was being heard!

Brandy Morris-Hafner

Note that bidirectional communication begins during recruitment and continues throughout a project

Options for "closing the loop" with Board members about how their input was incorporated into the project:

- **Talking through this during a Board meeting**
- **Creating a written summary** (bullet points, narrative form, or possibly making a more polished version using graphic design software like Canva)
- **Creating a simple infographic**
- **Creating a video summary**; options we have used include:
  - Recording a simple video of yourself speaking
  - Recording yourself with slides on a platform like Zoom (see example here)
  - Creating a TikTok-style video, or any other format you're comfortable with

See example emails for "closing the loop" in the Appendix.

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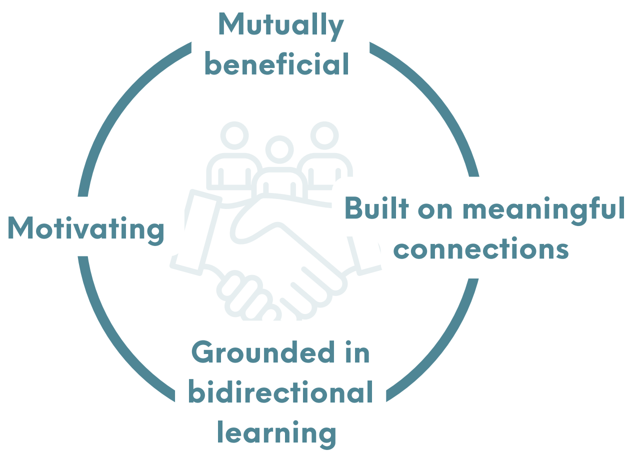
SUSTAINING MEANINGFUL CONNECTIONS AND ENGAGEMENT WITH BOARD MEMBERS

To sustain a strong and meaningful partnership, it's essential to foster an environment that is:



Thoughtful ways of connecting and sharing opportunities with Board members are an important part of achieving this, but they require careful planning by the research team.

This chapter provides insights into early considerations, various types of interactions and opportunities, and lessons learned about Board member travel (since this can be a valuable form of in-person connection if done well). Throughout, we include special considerations for emerging adults and those with criminal legal system involvement.

TIP

We use the term **"engagements"** throughout this chapter to describe instances of sharing opportunities and information or connecting with individual Board members. These engagements help build stronger relationships and create shared value. When communicating with Board members themselves, we instead use language like "exciting news," "something we thought you might be interested in," or "potential opportunities."

Preparing for Effective Engagements

Before exploring types of engagements, it's helpful to consider:

- What information and opportunities Board members might want
- Board members' preferred communication channels
- How often Board members would like to receive information and opportunities

You may want to create a brief survey to gather input directly from Board members. While you can customize the survey, here are some general questions (see next page):

1

"What type of information and opportunities would you like to receive?"

- When asking Board members what they'd like to receive, consider including some examples of what you can offer, so they understand what you're talking about.
- At the same time, make sure to leave room for members to suggest their own ideas for content.
- This two-way approach opens the door for more sharing of ideas and resources, helping everyone learn from each other.

2

"We have several ways to share information, but we want to ensure it reaches you in the way you prefer. Please let us know how you would like us to share information and opportunities that might interest you."

- Email has been the main method we have used, but recent methods have included GroupMe, WhatsApp, Slack, and group texts.
- Communication channels may evolve, so regularly check-in with Board members about their preferred method.

TIP

Early in the JEAP Initiative, Young Adult Board members asked for a private Instagram account to share updates and stay in touch with the research team and other Board members. But as new members joined the Board, the Board decided GroupMe was preferred. At first, it seemed like GroupMe wasn't getting much use. However, after checking in with Board members, we learned that they were regularly using the content shared, even though they weren't posting to it often. This experience taught our team the importance of **staying flexible**, **regularly checking in with Board members** about what is working for them, and **being open to changing communication strategies** to support ongoing connection.

3

"How often would you like to receive information and opportunities?"

- With the constant stream of emails, texts, and notifications nowadays, it's easy to cause overload by sending too many messages. Too much information can cause key details, such as meeting reminders, to be overlooked. Consider how to space out engagements.
- Regular contact with Board members is vital in CBPR, but not all information is equally important. Ask members how often they'd like to receive general information and opportunities that are separate from materials for their work on the Community Board (e.g., monthly, weekly). If the Board decides on monthly, time-sensitive opportunities may need to be communicated outside normal times, so ensure Board members are aware of this potential exception.
- Develop a plan with your research team to find engaging information and opportunities to share with Board members on the Board's preferred schedule.
- Also encourage Board members to share information or opportunities with the research team, so they can share it with the rest of the Board.

TIP For the JEAP Initiative and HEAL Connections, we have sent general engagements monthly via email unless other timely opportunities arose. This helped prevent inbox overcrowding while also providing engaging opportunities and information between meetings.

Conducting a regular follow-up survey (e.g., every 12 months) to ask if there are any changes to these preferences can help you understand what types of opportunities or announcements matter most to Board members.

Types of Engagements

Connections in-between Board meetings should be seen as vital components in making the partnership strong and mutually beneficial. These touchpoints:

- Encourage bidirectional learning through sharing resources, opportunities, events, findings, and more
- Help members feel valued and informed, particularly when meetings are infrequent (e.g., quarterly, biannually)
- Help the research team stay in tune with members' needs and interests
- Demonstrate how valued and appreciated members are, as you seek opportunities that benefit them beyond compensation

We have utilized various types of engagements in our work:

1 Broad engagements

These are sufficiently wide in scope that they might interest all Board members. Seek opportunities and information that can be shared with everyone, as this shows that all members are equal partners, reducing any sense of bias and promoting trust and transparency. It also is helpful to remember that Board members are part of a larger community, and they may know other individuals who would be interested in the opportunity.

Example: A research team member noticed an opportunity for students to attend a conference via a travel award. Although this was specifically for people who were current students, the email to the Board acknowledged that this opportunity was limited, but we wanted all Board members to know about it in case they had contacts who were currently students. In our experience, it's often best to share information with as many Board members as possible—even if an opportunity only applies to a subset—to avoid anyone feeling left out and to foster transparency and inclusion. Further, sharing opportunities with Board members can generate new interests and possibilities a member hadn't previously considered.

Examples of broad engagements:

- Opportunities to attend, speak at, or present at conferences, forums, webinars, and more
- Recently published journal articles or summaries of relevant research
- Podcasts or popular press items
- Federal or state policy announcements and changes
- Conference and travel award information
- Additional opportunities for joining other initiatives or Boards
- Research studies that Board members could participate in
- Co-authorship opportunities

If you are asking Board members to speak or present at an event, it's essential to consider compensation. See the **Community Board Stipends and Budget Considerations** section in the **Considerations Before a Community Board is Established** chapter for more details.

Special considerations for Board members with criminal legal system involvement

When identifying opportunities, we as a research team check whether the opportunity welcomes justice-impacted individuals. We try to assess the inclusiveness of a program, if possible, to help ensure there are no surprises for Board members interested in participating.

We have even encountered instances where, when we contacted the organization providing the opportunity to ask about this, processes were changed to make the opportunity more inclusive! Building trust with Board members involves finding inclusive opportunities—or being upfront when something isn't fully inclusive—so that Board members can decide what's right for them.

2 Networking engagements

These are designed to build connections among Board members, researchers, and other stakeholders. They encourage relationship-building within the Community Board, but also across the broader networks of researchers. By fostering dialogue and collaboration, these kinds of connections help create a supportive community where ideas can flourish, and partnerships can develop.

Examples of networking engagements:

- Planning in-person and/or virtual events, such as meet-ups at shared events or social media pages for connection
- Adding low-pressure activities to build comfort and trust, such as incorporating icebreaker-type questions during Board meetings or spaces for Board and research team members to connect outside of meetings (e.g., informal coffee/tea chats)
- Encouraging Board and research team members to support one another, such as attending if one of them is presenting at a virtual webinar or sharing work from Board members (e.g., if they are publishing a piece of work, creating a blog or website, or creating artwork)

> *By including Community Board members in networks in and outside of JEAP, a sense of equality is fostered between the Board and research team.*

Eleanor Byrd

3 Individualized engagements

Like giving a thoughtful gift, tailoring a specific opportunity to someone's interests can be meaningful and motivating. These individualized engagements stem from understanding members' specific interests and contexts.

Individualized engagements should be used strategically and only when the opportunity or information truly applies to a single individual or small group. The primary goal should be to create engagements that include all Board members. Sometimes, what appears to be an individualized engagement may have a wider scope. When we've been unsure whether to share something broadly or directly, we've found it helpful to talk it through as a team, and have gotten helpful guidance from staff members who have lived experience.

Individualized engagements example		**Broad** engagements example
Two Board members live in Bloomington, Illinois. A research team member finds an opportunity for Bloomington residents. This may be best shared as a one-on-one outreach.	**vs.**	A travel award opportunity for individuals aged 18 to 25 may seem relevant only to young Board members. However, since many Board members represent their communities and could be connected with young adults, it may be valuable to share as a broad engagement to the entire Board.

Examples of individualized engagements:

- Customized information on a specialized topic or field
- Book recommendations tailored to a Board member's interest
- Job openings in specific fields or locations relevant only to select members
- Niche interests, such as music, movies, or hobbies
- Letters of support or recommendation for a specific job and other scenarios (e.g., one of our Board members applied for a grant and we provided a letter of support)
- Special speaking opportunities
  - For example, one of the HEAL Connections Panel members had spoken about her specific combination of experiences and our team was asked if there was anyone we knew who could speak about this specific intersection of experiences. After first checking with the Panel member to see if she was interested, we were able to make a linkage for this national speaking opportunity.

Special considerations for Board members with criminal legal system involvement

Writing a letter of recommendation for a Board member who is in the process of expunging records or something similar can be a meaningful way to support them. This is an individualized engagement, but it also is a type of support that could be offered to anyone for whom this applies.

4 Personal engagements

While we often separate our personal and professional lives, sharing some personal details can help colleagues understand us better, build stronger relationships, and foster a sense of community. Knowing when a coworker is struggling allows for support, and sharing hobbies or interests can enhance collaboration. The same approach is useful when engaging with Community Board members. Research teams can build lasting, meaningful relationships through personal connections. These moments don't need to be big—they simply need to be authentic, timely, and respectful. Although these can be somewhat challenging, here are a few methods through which this type of engagement has been effectively carried out.

Example 1: When a natural disaster has impacted a Board member's area, team members have reached out to check in and offer support—sometimes sharing information about available resources. These moments reflect the kind of care and concern you'd naturally extend to a colleague or collaborator, reinforcing that the relationship is grounded in mutual respect and humanity.

Example 2: As relationships with Board members grow, they may share that they have a big event coming up—like a presentation, medical procedure, or move—and that they're feeling a little nervous or unsure about how it will go. A team member might send a quick "good luck" or "thinking of you" message on the day of the event, using their preferred communication method (e.g., text). These small gestures help reinforce that the relationship extends beyond formal meetings. In some cases, team members have also attended events hosted by Board members—when invited—such as a Zoom celebration of a recovery milestone.

Example 3: Board members also sometimes share major personal milestones such as promotions, certifications, anniversaries, graduations, or births. Sometimes, these come up organically during meetings (e.g., while people are logging on at the start of a meeting, we often invite people to share any milestones or accomplishments or something that has "brought them joy"). In these moments, a thoughtful follow-up—like a card signed by team members (e.g., Kudoboard)—can help acknowledge the whole person and show that their contributions and experiences outside the Board matter, too.

Special considerations for Board members who are emerging adults or those with criminal legal system involvement

Emerging adults and/or those involved with the legal system face unique barriers, challenges, and transitions that can significantly impact their lives. Sometimes, people in these situations face harsher consequences if confidentiality is broken, which can lead to serious repercussions. By respecting confidentiality and asking for permission before sharing sensitive information through any form of engagement, we can foster an environment of trust and bidirectionality, which is crucial for effective collaboration and support within these populations. Always ask before sharing someone's personal information with a larger group.

What We've Learned about Supporting Board Members' Travel

Finally, in-person opportunities can help deepen connections with Board members. If you are able to budget for travel opportunities, such as having Board members co-present at a conference or having a virtual Board get together in-person at some point, here are some tips we've learned to make this go as smoothly as possible.

- **Minimize up-front, out-of-pocket costs:** To reduce financial barriers, consider whether larger travel expenses such as airfare, registration, and lodging can be paid for directly by your organization rather than processed afterward as reimbursements. Additionally, try to cover Board members' meals directly whenever possible, rather than having them pay and wait for reimbursement.

- **Offer preparation support:** Ask Board members if they would like assistance in getting ready for the meeting or conference, which includes preparation for presentations, typical conference/meeting attire, how scheduling works (e.g., selecting sessions to attend, whether they have access to all sessions), detailed ground transportation info, and general things to expect (e.g., the process for asking questions during sessions, reimbursement info). That is, an "orientation" to conferences may be useful if this is a new experience for Board members.

- **Have a designated point of contact:** Members should have a designated person from the research team they can reach out to in case they need logistical support, such as for any conference registration or hotel issues. The research team member could connect them with the appropriate contact as needed.

- **Share contact info:** Share your team members' contact info and consider creating a group text message to connect everyone from your team and the Board members. This also allows you to assist if questions or concerns arise.

- **Support recovery:** Offer to support Board members who will attend mutual aid groups (e.g., AA or NA) while they are traveling. This support could include assisting in finding local groups, providing transportation, or offering to accompany them (if appropriate).

Provide connection if it will be at a large conference:

- Plan get-togethers during the conference. We have found it helpful to schedule a meet-up for coffee/tea the first morning of the conference and then offer to sit together in some sessions; this provides some comfort to Board members who may feel out of place among researchers. We also plan a few meet-ups during the trip to allow Board members to debrief, ask questions, or raise concerns. These seem highly appreciated.
- We provide a document with photos and personal backgrounds of the team members attending so that Board members can find us in the crowd.
- We provide an "Unofficial Conference Guide" that offers tips and lists key dates and times (e.g., group meet-ups, presentations).
- We provide a private, shared online spot where Board members can post photos, questions, and comments (e.g., Google Docs).

Make clear that traveling is optional: While opportunities to engage in person are highly valued by many Board members, travel should be optional unless stated upfront during the recruitment process. Some members may have circumstances that make travel difficult, such as childcare constraints, being on probation or parole, requiring regular access to a clinic for MOUD, lacking flexibility in their work schedule, or concerns about environments that are difficult for their recovery (like the presence of alcohol in airports and conferences).

EVALUATING AND ADAPTING THE PARTNERSHIP

Don't wait until the end of a project to see if your CBPR processes are working! We have found that regularly evaluating the partnership between the Board and researchers, and adapting along the way, can make a big difference.

The core idea is continuous quality improvement—but in CBPR it's especially important to involve community partners **in this process**. While tracking progress towards overall goals is necessary for any project, when you're engaging in CBPR, it's also important to ask, "How well is our partnership working?"

TIP Making thoughtful changes along the way to improve processes helps achieve project goals **and** strengthens trust and relationships between researchers and communities.

Why evaluate?

Community-engaged research functions on the premise of partnership and trust. Therefore, it is also important to track whether these implicit goals are being achieved.

An additional outcome of community-engaged research is the **cultivation of trusting relationships between researchers and impacted communities,** making it important to evaluate the underlying relationships within each research project.

Incorporating community partners in this process furthers the goal of community engagement, ensuring they have a say throughout the entire process and enhancing the relationship while assessing it.

Why adapt?

Every relationship changes over time, evolving and (hopefully) improving based on new information or changes in circumstances. Like the discussion above about evaluation, adapting throughout a research project and ensuring effective operations will better lead to achieving the project's goals. Changing operations in partnership with the community shows that a project, and research in general, is responsive to the needs of the communities they work with, cultivating strong relationships and trust.

> *I feel that researchers thinking of Community Board members as valued partners is empowering. Including people with lived experience empowers them and the community as a whole. It shows that their voices matter and that they play a critical role in shaping research that affects their lives.*

Monifa J.

TIP

Consider these points when cultivating relationships of trust:

- **Using bidirectional communication is essential.** Ensure the involvement of Community Board members throughout the evaluation process, as they can help identify issues and propose solutions the research team might not see. Don't forget to share how their input was used and what actions were taken in response.
- **Have a clear plan for monitoring the quality of engagement between the research team and Community Board members, and adapting processes to facilitate continuous improvement (actually doing something with the information).** This not only benefits those operations but also shows Board members that the research team values their partnership.
- **If possible, communicate these efforts to the broader public.** Your Community Board members might make great "champions" for this. Remember that your work evaluating and adapting also improves the dynamic between research and communities, cultivating trust and a willingness to collaborate beyond the immediate research project.

What strategies and processes to use?

Identify which strategies you will use and determine the best schedule for each strategy. Ensure that everyone on the research team and Board members are aware of the strategies and schedule, as well as what process you will use for making changes in response to feedback. Below, we detail the processes we have used for **(1)** evaluating the partnership on a frequent, ongoing basis, **(2)** evaluating the partnership annually, and **(3)** examining results and determining adaptations.

1 Strategies we have used to evaluate the partnership on a **frequent, ongoing basis** (see below for what we did with the feedback gathered from these strategies):

Reflection questions at the end of each Board meeting

- Without researchers present, the Board discussed:
  - What worked well for you in this discussion with a researcher?
  - What could be done to make these kinds of discussions more successful?
  - Board members were also invited to share additional thoughts after the meeting was over via an optional, anonymous feedback form.
- If there was a staff person the Board preferred to have present for taking notes, that staff person would de-identify feedback and review it with the rest of the research team at the next project meeting. If a staff person wasn't present during the reflection questions, then the facilitator would share de-identified feedback with the research team after the meeting.

See example anonymous feedback form in the Appendix.

Anonymous feedback form after each Board meeting that was optional

- We clarified that this was entirely optional.
- This was emailed as a Microsoft Forms link to all Board members, and responses were anonymous unless a Board member chose to include their name.
- Responses were compiled by a staff member who removed identifying information from any responses before sharing them with the research team at the next project meeting.

Internal debrief form completed by members of our team who attended the meeting

- This was a basic form that asked:
  - What stood out to you about this meeting?
  - Were there any notable difficulties?
  - Note any particular things the research team needs to follow up on.
- These were sent to the research team for review before the next project meeting, and any points were reviewed at that meeting.

Informally asking for feedback during prep meetings with co-facilitators

- The staff member holding these prep meetings brought de-identified feedback to the research team at the next project meeting.

2 Strategies we have used to evaluate the partnership on an **annual basis** (see below for what we did with the feedback gathered from these strategies):

Annually, a survey about "cultural exchange" was completed anonymously by both the Board members and researchers.

- An example of the adapted Cultural Exchange Inventory[1] we used is available here.
- As with other strategies, we assigned one person on the research team to send an anonymous link to the Board and research team, compile this information, and anonymize any open-ended responses that included identifying information.

We relied on the **Cultural Exchange Model** to assist us with the annual measurement of the partnership, finding it not only encompasses key CBPR principles but also provides concrete ways to measure using an adapted version of the Cultural Exchange Inventory.[1]

The Cultural Exchange Model presents a way for people from different backgrounds—people who are "cultural brokers" for their respective communities—to understand each other meaningfully, building mutual understanding and appreciation.[2-4]

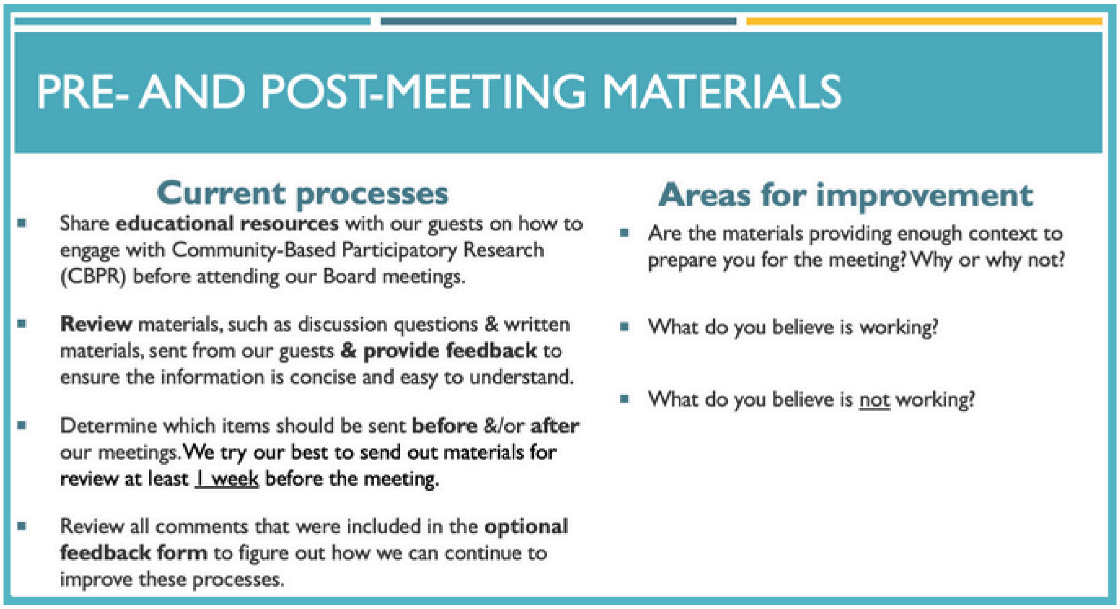
It also provides a method for measuring knowledge exchange, attitudes, and practices between a research team and community partners (e.g., Haralambous et al.).[5] During our projects, every individual involved in the community partnership, both research team and community partners, completed the 15-item instrument.

See more about the Cultural Exchange Model in the **Understanding and Applying CBPR Principles in Substance Use Research** chapter.

3 Processes we used to examine results and determine adaptations to make:

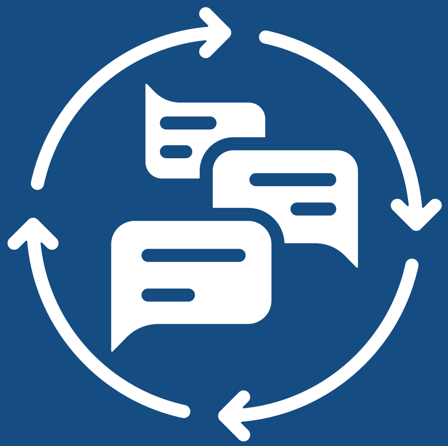
1. A staff person guided relevant research team members through reviewing feedback.
2. The research team identified possible changes to implement, as well as aspects to keep the same.
3. The research team celebrated if they were being successful in building an effective partnership!
4. Minor changes, such as sending materials as both an audio recording and a document, would be made as soon as possible, letting the Board know that we were making the change based on their guidance.
5. For any major feedback, the team would brainstorm potential options, which would then be taken to the Board for a brainstorming session to identify the best options for improvement.

As one example, we received input via the anonymous post-meeting feedback forms indicating that Board members wanted to improve the process for materials they received before and/or after meetings. At the subsequent meeting, we reviewed the existing processes, including the behind-the-scenes steps the team undertook, and then collaborated with the Board to identify ways we could improve. The slide we used for this conversation with the Board is provided here (reminder that researchers are "guests" to the Community Board meetings):



A note about anonymized/de-identified feedback:

Some teams (including research and community partners) may be so small that anonymizing or de-identifying feedback becomes impossible. For example, with only 2–3 researchers and staff, it may become apparent who specific comments are about. Additionally, with a small number of community members participating, it might be obvious which member shared a particular perspective. This underscores the necessity of establishing trusting and open communication throughout the project. When Community Board members feel they can trust the research team—that they will not encounter bias and that their voices are valued—they are much more likely to provide important criticisms.



I think it's important to have multiple, flexible ways for Community Board members to give feedback on how the process is working because we all show up with different communication styles, comfort levels, and life circumstances. Anonymous surveys can be helpful, especially when someone doesn't feel comfortable offering critical feedback in a group setting, but they shouldn't be the only method. Open discussion time during meetings can be really meaningful, especially when trust has been built. Peer-led reflections where board members talk honestly about what is working and what is not, even without researchers present, could also surface helpful insights.

Garland G.

Chapter reference(s)

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FINAL THOUGHTS

Encouragement for Long-Term Commitment

CBPR is not a quick fix—it's a **long-term dedication** to building relationships, sharing power, and co-creating knowledge with the impacted community. As researchers, it can be tempting to focus on quick wins or short funding cycles, but genuine CBPR work takes time. We've learned that meaningful engagement means being flexible, transparent, and willing to shift timelines or expectations when needed. It requires consistency, intellectual humility, and a willingness to show up—even when progress is slow.

Due to the stigma surrounding substance use, fostering meaningful relationships between researchers and people with lived experience through CBPR principles may need even more time, effort, open communication, and shared learning. These ongoing efforts will build trust and deepen collaboration, resulting in more meaningful and lasting change.

As the toolkit shows, **early and sustained investments in trust and connection will continue to yield powerful collaborations over time**. If we want to solve the substance use crisis, we need all hands—and minds—on deck. Your research will be stronger for it, so we encourage you to invest in the long-term relationships necessary for high-quality community-engaged research.

> *I just wanted to make sure I wasn't being used as a token or a 'lab rat,' but that my voice and feedback were genuinely valued. I often find myself at tables where I'm the only person with lived experience, and it can feel like my perspective isn't truly heard or respected. When that happens, it becomes discouraging, and over time, it's easy to lose the motivation to speak up or try to shift people's understanding of addiction and justice-involvement.*

Brandy Morris-Hafner

CBPR and Community Impact

CBPR is a powerful tool for transformative research and for impacted communities.

By creating space for people with lived experience to shape research questions, methods, and outcomes, CBPR applied with Community Boards shifts traditional power dynamics and centers the voices of those most impacted. This is especially critical for substance use research and populations impacted by substance use challenges, including those we've worked most closely with: emerging adults and people with legal system involvement.

The **ripple effect** of this approach extends well beyond any single study. For instance, serving on the Board allows community members to assert influence in research spaces that have not traditionally reflected their lived experiences, helping to foster a sense of agency within systems that have historically excluded them. This partnership will lead to better research and, more importantly, to stronger communities and more just systems.

Individuals with lived experience bring a very relevant perspective to research. They are aware of the struggles that population deals with firsthand. It lends credibility to the research studies and findings to have someone with lived experience involved. It gives the impression that someone with lived experience has more "skin in the game" and they seem more likely to have the interest of the lived experience population in mind, versus just seeing research and findings from a detached, observer perspective. It makes it easier to trust what is being presented and it is less about the "experts" in positions of authority dictating what is best to a population they are not a part of.

Leonor Gualchi

In my opinion, when researchers include people with lived experience, it fosters a sense of authenticity and credibility. I feel that it shows that my voice does matter and that my experience can play a critical role in shaping research that affects the lives of those within my community.

Monifa J.

Reflections on the Research Team’s Journey

Our journey with CBPR and cultural exchange with Community Boards has been one of continuous learning and growth. Collaborating with these Boards—especially those comprised of people with lived experience of substance use and recovery—has inspired us to re-evaluate how we conduct every stage of the research process. What matters most to community members often differs from traditional research priorities. Understanding this distinction and listening closely to the needs of impacted community members leads to better science.

It’s important for researchers to think of Community Board members as valued partners and experts because no one knows the true nature of addiction unless that person has been directly or indirectly been affected by it. Addiction remains one of the least understood diseases in the field. This is why people with lived experience who are willing to voice and recount their experiences add a lot of value to the work researchers do. No matter how much a researcher with no lived experience may read about the topic, there will always be a barrier to understanding its true nature.

Brenda Huerta

Here are a few practical ways these collaborations have directly benefitted our work:

- Uncovering new knowledge and expanding the real-world impact of our research. For example, we’ve received critical insights on how to strengthen our ongoing research processes and Community Board processes from Board members.
- Using respectful language and imagery to make our research more accessible and supportive for impacted individuals.
- Offering insights that go beyond mutual learning and improved research, such as relationship-building skills, leadership skills, and cultural and intellectual humility for individual researchers.

When researchers recognize Community Board members as equal partners and experts, the research becomes more ethical, accurate, and impactful. People with lived experience bridge the gap between academic knowledge and real-world application, ensuring that research is meaningful and transformative rather than detached or extractive. Community Board members bring critical knowledge, lived experience, and community connections that researchers simply cannot replicate through academic expertise alone.

Brandy Morris-Hafner

In sum, our experiences have demonstrated to us that:

- Engagement isn't optional or complementary—it's **essential**. If we're to make a difference and save lives, research must be tailored to real-world contexts and barriers.
- Engagement must be **ongoing, not extractive**, throughout project lifecycles and with a meaningful, mutual-benefit focus.
- Partnership must be **accessible and co-owned**. Evaluate the quality of your Community Board engagement, course-correct as needed, and use co-production to continually improve.
- As researchers, we believe we must commit to **genuine, reciprocal partnerships** that elevate lived experience as **expertise**. For many of us, partnering with Community Boards and doing high-quality CBPR has been a highlight of our careers thus far.
- Most importantly, CBPR with Community Boards has reminded us that **the heart of research is relationships**. We're deeply grateful for the partnerships we've built through this work, and we're committed to continuing to show up, learn, and grow alongside our community partners.

As the saying goes, 'nothing about us without us.' If we are valued for our lived experience, then researchers should come to us and gain an insight that will prepare them when they begin asking questions of communities that we came from.

Jose Nicolas Flores

Thanks to each of you for including me in these vital discussions. It was truly a pleasure participating with you. I felt included, heard, appreciated, and important. Never have I thought that anyone outside of my community would ever want to hear what I have to say without letters behind my name or your approved language. You made it clear that my voice is wanted and needed. My hope is that I can continue to participate in other opportunities that may arise.

Kimberly Moore

Invitation to connect

Thank you for spending time with this resource. We hope it offers practical insights on community-engaged research and amplifies the voices of people with lived experience. While this toolkit reflects what we know now, we're continually learning and striving to do better. **We genuinely welcome your feedback, corrections, or ideas to improve this resource and our work.** Whether it's sharing a story, offering an example, making an edit, or identifying a gap; we appreciate your feedback. These insights ensure that this toolkit is beneficial for substance use researchers engaging in CBPR with Community Boards.

Stay in touch—we'd love to hear from you. The best way to reach us would be to contact us through JEAP (see email address and links below). Let's keep learning together and continue building a stronger research field!

jeap@chestnut.org

https://www.jeapinitiative.org/

Facebook Instagram X Bluesky LinkedIn Threads YouTube

TABLE OF CONTENTS: RESOURCES APPENDIX

If an item has a **link**, click to access it. If it has a **page number**, it is included within the Appendix.

- **NIH Helping to End Addiction Long-term® (HEAL) Initiative | Patient and Community Engagement:** This webpage provides a collection of resources on patient and community engagement broadly. We especially recommend exploring the following tipsheets:
  - **Planning Tipsheet:** This resource outlines key steps and considerations for planning research that engages people with lived experience.
  - **Considerations and Challenges Tipsheet:** This resource offers practical tools for research and shows how partnering with people with lived experience strengthens each part of the process.
  - **Disseminating Research Tipsheet:** This resource explains how to share findings and request feedback when partnering with people with lived experience.
- **HEALing Communities Study (HCS) | Engaging Community Coalitions to Decrease Opioid Overdose Deaths:** This practice guide offers tools, insights, and real-world examples to help build and strengthen community coalitions working to reduce opioid overdose deaths.
- **Reporting on Addiction | Trauma-Informed and Empathy-Based Reporting:** This toolkit advises how to approach impacted community members and includes a field-ready checklist for support on the go.
- **JCOIN Training and Engagement Center (JTEC) | Research Partnerships:** This online course includes training and support for justice-impacted individuals and behavioral health professionals addressing substance use challenges. It is also valuable for those currently partnering with researchers, as well as for those interested in future collaborations.
- **Center for Dissemination and Implementation at Stanford (C-DIAS) and HEAL Data2Action Research Adoption Support Center (RASC) | The Partner Engagement Guide:** This resource shares principles of engagement, case studies, and practical tools for building meaningful research partnerships (broad and not specifically about engaging with Community Boards).
- **Urban Institute | Tools and Resources for Project-Based Community Advisory Boards:** This toolkit provides guidance, reflection questions, and strategies for incorporating a Community Board into a project.

- **Urban Institute | Fostering Partnerships for Community Engagement:** This toolkit covers community engagement broadly (broad and not specifically about engaging with Community Boards).
- **Patient-Centered Outcomes Research Institute (PCORI) | Engagement in Research:** This comprehensive resource explores a range of community-engaged research methods (broad and not specifically about engaging with Community Boards).
- **Community Engagement Alliance Consultative Resource (CEACR) | Community Engagement:** This webpage features five fact sheets covering a range of community-engaged research topics (broad and not specifically about engaging with Community Boards).
- **Nevada Minority Health and Equity Coalition | Community Based Participatory Research:** This comprehensive guide explores health equity through the lens of CBPR methods (broad and not specifically about engaging with Community Boards).
- **Brandeis Opioid Resource Connector | Coalitions and Task Forces:** This in-depth collection highlights community-focused programs, tools, and resources for stakeholders to choose, design, and implement essential interventions (broad and not specifically about engaging with Community Boards).
- **Community-Campus Partnerships for Health (CCPH) | Community Engagement Webinars:** This resource shares insightful videos on community engagement.

Guides on Community-Engaged Research with Special Populations

- **Youth Engagement in Research**
  - **Youth Engagement in Research and Evaluation**
  - **Youth Engagement in Policy, Research, and Practice**
  - **Youth Participatory Action Research (YPAR) Hub**
- **Domestic Violence Communities Engagement in Research**
  - **Power Through Partnerships: A CBPR Toolkit for Domestic Violence Researchers**
- **Tribal Communities Engagement in Research**
  - **A Roadmap for Collaborative and Effective Evaluation in Tribal Communities**

- **Veterans Engagement in Research**
  - [Strengthening Excellence in Research through Veteran Engagement]
- **Pain Community Engagement in Research**
  - [Partnering with People with Lived Experience in Pain Research]

Addressing Administrative Considerations Before a Community Board is Established

Board Agreement Forms and Stipend Invoices – This section shows example agreement forms that give an overview of what to expect when joining the Board. This is in addition to the institution's independent contractor agreement, which we have worked with our contracting office to streamline and reduce the amount of 'legalese.' Also included is an example invoice that shows the type of questions we've included in past invoice forms.

- **Example Board Agreement Form (JEAP Initiative)** 161
- **Example Board Agreement Form (HEAL Connections)** 162
- **Example Board Member Stipend Invoice Template (HEAL Connections)** 163

NIH and IRS Guidelines that Apply to Community Boards – The following webpages provide guidance on how NIH and its recipients may use appropriated funds for advocacy, lobbying, and related activities. They also cover taxable and nontaxable income, which may be useful to share with Board members.

- NIH Lobbying Guidance for Recipient Activities
- Topic No. 421, Scholarships, Fellowship Grants, and Other Grants | Internal Revenue Service
- Publication 525 (2023), Taxable and Nontaxable Income | Internal Revenue Service

Ensuring Privacy and Confidentiality

About our Community Boards | JEAP Initiative: This webpage provides an example of allowing Board members to choose what information to share and whether to remain anonymous.

Recruiting Community Board Members

Landing Page for Recruitment – This section highlights the range of information we've shared on past recruitment pages for our projects.

- Example Landing Page | JEAP Initiative
- Example Landing Page | HEAL Connections
- Example Landing Page | CHEARR

JEAP COMMUNITY BOARD LETTER OF AGREEMENT

As a member of the JEAP Community Board, you will be asked to:

- Draw upon your professional experience to provide input about the areas that researchers should prioritize around recovery support services, in particular peer recovery supports and recovery residences
- Brainstorm and recommend research topics that are important to justice-involved adults and young adults recovering from substance use
- Assist in the selection process for early career scientists who will participate in training and fellowship programs
- Help decide which pilot studies on recovery support services receive funding and provide feedback on the focus of the research
- Offer ideas about how research findings can be shared with service providers, justice-involved adults in recovery, and young adults in recovery

By joining the Provider & Payor Community Board, you agree to the following:

- To serve on the board for one year (renewable for additional years) and attend at least 7 out of the approximately 9 total meetings.
- To participate in regular Zoom meetings – approximately 9 total meetings during the year, that are each one and a half hours long.
- To review materials and prepare for meetings (approximately 1 and a half hours/month), and you have the option to participate in additional activities.
- To protect and maintain the confidentiality of information I receive during Board meetings (from other Board members or the research team) or as part of materials I receive for Board meetings.

Community Board member name: ________________________________

Community Board member signature: ____________________________ Date: ________

NIH HEAL INITIATIVE | CONNECTIONS
Partnering to Accelerate Research into Action

The NIH Helping to End Addiction Long Term (HEAL) Initiative
HEAL Connections Lived Experience Panel Member Agreement

As a member of the HEAL Connections Lived Experience Panel, you will be asked to:

- Help elevate your voice and the voices of those in your community with lived experience in relation to opioid use disorder and/or pain, in a meaningful partnership to increase equitable, effective, and accessible research for all.
- Provide input on studies related to pain and/or opioid use disorder, and the intersection of those issues (where relevant to you and/or your community)
- Help to identify ways to share, distribute, and implement research findings and strategies related to the current opioid and/or pain management crises within your community
- Provide input into priorities and gaps for your community
- Provide feedback on how your community prefers to learn about new research findings
- Share your unique experiences and perspectives (lived experience) on emerging trends, priorities, and challenges in the coming years
- Offer perspectives to the HEAL Connections team on how best to engage other people with lived experience in research

By joining the HEAL Connections Lived Experience Panel, you agree:

- To serve on the Panel for one year
- To serve on at least one of the following strategy teams. Each of these teams has their own action items and compensation rates that come with them:
    - Ambassador/Disseminator Strategy
    - Lending Your Voice Strategy
    - Participation in Stakeholder Feedback Team (SFT) Strategy
    - Scientists Consulting with you on Research Projects Strategy
    - Reviewing Study Materials Strategy
- To participate in periodic Zoom meetings associated with your strategy(s), sharing your expertise on topics and the perspectives of your community. These meetings will contain different amounts of frequency and associated work, usually including document/product reviews and collaboration with NIH HEAL research teams and HEAL Connections Staff. Subsequent work will be determined after that, with stipends following the rate of $50 per hour. The number of hours will vary and will be determined based on project needs and in partnership between you and HEAL Connections staff.
- To participate in infrequent Panel and/or Subpanel meetings, discussing various topics regarding the scope of the HEAL Initiative.
- You are not an employee of Chestnut Health Systems, the HEAL Initiative, or HEAL Connections. You will receive the stipend from Chestnut Health Systems. Chestnut Health Systems will neither pay nor withhold federal, state, or local income tax or payroll tax of any kind on your behalf. You will not be treated as an employee for the services performed according to this agreement for federal, state, or local tax purposes.
- During your time serving as a Panel member, you may receive information about others on the Panel; you agree to protect and maintain the confidentiality of such information.

HEAL Connections Lived Experience Panel member name: ______________________________

HEAL Connections Lived Experience Panel member signature: ___________________________

Date: ___________

NIH HEAL INITIATIVE | CONNECTIONS Partnering to Accelerate Research into Action

Invoice for Full Panel Meeting

Thank you for joining us on Monday (12/4/2023) at the HEAL Connections Lived Experience Panel Meeting. We value your input and appreciate your time greatly. For those who attended, you will receive a stipend of $150 for the 90-minute meeting, including the prep work.

* Required

1.First name: *

Please note that this is the name we will include on the check that gets sent out to you, if you wish to receive a check as your preferred method of payment.

2.Last name: *

Please note that this is the name we will include on the check that gets sent out to you, if you wish to receive a check as your preferred method of payment.

3.Email address: *

4.Street number and street name of mailing address: *

5.City of mailing address: *

6.State of mailing address: *

7.Zip code of mailing address: *

8.Phone number: *

9.Which method of payment would you prefer to receive your stipend as? *

- Paper Check (mailed to the address you provide above)
- Tango Universal Gift Card (see website for more info https://www.tangocard.com - sent to the email address we have on file for you)

10.Did you attend the Panel meeting on 12/4? *

- Yes (stipend amount: $150)
- No

11.What is today's date? *

Dear Community Board Members,

I am reaching out today because we are once again looking to recruit 2 new Young Adult board members. Below is an email blurb you can share with your contacts. I have also attached the social media post you could use to spread the word. However, if you follow any of the JEAP social media pages, you can also share the link if you'd like.

Thank you all for your help in spreading the word and for all you do!

Best,

Help us spread the word! The **JEAP Initiative** (***J****ustice-Involved and* ***E****merging* ***A****dult Populations* ***I****nitiative*) is currently recruiting members for our Young Adult Community Board. We're looking for **young adults aged 18–25** who are **in recovery from substance use** to help guide our work and influence research. Serving on a Community Board is a great opportunity to use your voice and lived experience to impact research on this topic!

Importance of Community Boards

The work of the JEAP Initiative is guided by three national Community Boards. The purpose of these Community Boards is to shape research on recovery support services, identify priority areas for research, and ultimately help improve recovery support services – an important role with the potential to benefit many populations. Our three Community Boards are made up of individuals from all around the country who bring their diverse expertise to this work. Learn more about our community boards here and click here to apply.

Requirements

- No previous board/work experience or education level required
- Aged between 18-25
- Lived experience with recovery from substance use
- Enthusiasm for participating and sharing your perspective

Details

- Training will be provided on what you need to know about research
- Community Board meetings are held remotely
- Meetings are typically 1.5 hours in length and are held about four times per year
- You will receive a stipend for each board meeting you attend

Because we want to effectively address the needs of a variety of communities affected by substance use disorder, including communities that may be overlooked in research, we are working on creating a board with members who bring a variety of identities and experiences to the table. Everyone is encouraged to apply, including people in the Black, Indigenous, Latinx, and other communities of color; women; people who are gender non-binary; people with disabilities; and people in the LGBTQIA+ community.

No previous board experience, work experience, or degree is required!

- Please see our website for more information about the Community Boards: https://www.jeapinitiative.org/community-boards/
- You are welcome to contact our team with questions before or after you apply: JEAP@chestnut.org

APPLY HERE

Applications reviewed upon receipt.

Follow us on social media!

Greetings [Name],

We are contacting you about an opportunity to join the HEAL Connections Lived Experience Panel. The goal of the Panel is to center the voices of people with lived experience in the work of the HEAL Initiative, partnering with people who can effectively speak to the priorities and needs of their communities. The Helping to End Addiction Long-term Initiative, or NIH HEAL Initiative, is a research effort funded by the National Institutes of Health to better understand poorly treated pain, opioid misuse, addiction, and overdose. For an exciting peek into what serving on this Panel potentially means for your community and centering their voices at the heart of research, we invite you to look at a video detailing the purpose and mission of the HEAL Connections Lived Experience Panel at the following link: HEAL Connections Lived Experience Panel

While we initially filled the panel, we recently had an opening on the LGBTQI+ subpanel become available. We would love to invite you to discuss with us your availability to join the Subpanel focused on the LGBTQI+ community.

Some more information on what to expect if you were to join the Panel:

- This is a year-long commitment; however, **your well-being, health, and safety are the utmost priority.** So, you are free to end this collaboration at any time, and we will always support your choices and respect your needs.
- In this same spirit, **you are also free to disclose as much or as little of your personal journey as you choose** with other panel members, panel facilitators, or other HEAL Connections communications. **You are the sole owner of your lived experience and how that is shared is fully up to you!**
- **Please note, if you are employed, wholly or in part, by a National Institutes of Health (NIH) project or other federal funding, you will not be excluded from participating on the panel.** However, we need you to let us know if this applies to you before you accept this role. Please reply to this email and we'll reach out to talk with you about the specifics before you accept.

What are the next steps if you want to participate?

1. Please fill out this Microsoft Form telling us a little bit about yourself: [link].
2. Respond to this email with your availability for a 30-minute Zoom meeting during the week of April 8th at your earliest convenience, including your time zone. We will follow up to schedule a meeting with you to discuss the Panel in more detail.

Please let us know **by April 4th** if you are interested in being considered for the Lived Experience Panel, and if you have any questions or concerns. We look forward to hearing from you soon!

With our highest regards,
The HEAL Connections Lived Experience Panel Team

Hello,

We are contacting you about applying for the **P**eer **A**dvanced **T**raining in **H**arm Reduction (PATH) Community Board. Our goal is to amplify the voices of people with lived experience of substance use by creating meaningful partnerships with individuals who can effectively highlight the needs and priorities of their communities.

The PATH project, funded by the National Institute on Drug Abuse (NIDA), aims to develop and test a program for reducing stress and burnout among peer recovery specialists, with a focus on skills in harm reduction. Our Community Board will be a genuine partner guiding this work. We hope the members of our Community Board can help us develop and test PATH, which will ensure that our research remains equitable, effective, and accessible.

What will the PATH Community Board do?

- Provide input on harm reduction training curriculum for peer recovery specialists.
- Help identify ways to share, distribute, and implement curriculum and research findings.
- Offer unique experiences and perspectives on emerging trends, priorities, and challenges in the coming years.
- Offer perspectives on how to best engage other people with lived experience of substance use.

What are the details of being a Community Board member?

- Participate in virtual meetings lasting approximately 1.5 hours. Meetings will occur monthly for the first five months and then change to every other month.
- Review materials in preparation for or after meetings.
- Receive a $50/hour stipend for participation in community board activities.
- Participate in an optional 1.5-day, in-person meeting in Indianapolis, IN. Travel expenses will be covered, and a stipend for your time will be provided.

Are there requirements?

- Direct experience using or delivering harm reduction services or resources.
- At least 18 years of age.
- Enthusiasm for participating and sharing your perspective.
- Access to phone or internet technology to participate in virtual activities (i.e., Zoom).
- Speak and understand spoken and written English.
- There are no education or writing ability requirements.

While we hope you will remain on the Board for a year-long commitment, please know that your well-being, health, and safety are our utmost priority. So, you are free to end this collaboration at any time. We will always support your choices and respect your needs. We also encourage you to disclose as much or as little of your personal journey as you choose with your fellow Board members. You are the sole owner of your experiences, and the decision to share information is yours. Thank you for your consideration, and we hope to see your application soon. Please feel free to share this opportunity with others in your network as well. Email pathstudy@chestnut.org if the application link does not work. Apply by clicking **HERE**!

I am writing to request your assistance in making your network aware of an opportunity to help guide a peer support specialist (PSS) research project funded by the National Institutes of Health/National Institute on Drug Abuse (NIH/NIDA). This project is a partnership between Chestnut Health Systems in Chicago, Illinois and Mental Health America of Indiana. The study is being led by Dr. Dennis Watson, PhD.

Our team is seeking individuals to participate as members of a Community Board that will help prioritize research questions, finalize the study design, and interpret and disseminate study results.

To be eligible to participate in the Board, candidates must:

- Have direct experience using or delivering harm reduction services or resources.
- Be at least 18 years of age.
- Have enthusiasm for participating and sharing your perspective.
- Have access to phone or internet technology to participate in virtual activities (i.e., Zoom).
- Speak and understand spoken and written English.
- There are no education or writing ability requirements.

All Community Board members will be compensated for their time.

If you are able to help us spread awareness of this opportunity, we would appreciate if you could distribute the email announcement we have prepared below and/or the attached flyer. We have also attached a copy of the email announcement.

If you have any questions, please contact pathstudy@chestnut.org.

JEAP Initiative

The JEAP Initiative

Advancing research on recovery support services for justice-involved and emerging adult populations

YOUNG ADULTS IN RECOVERY:

MAKE A DIFFERENCE IN RECOVERY RESEARCH BY JOINING A VIRTUAL COMMUNITY BOARD!

The **JEAP Initiative**, funded by the National Institute on Drug Abuse, aims to advance research on the effectiveness of peer recovery supports and recovery residences for emerging adults and justice-involved adults with substance use disorder.

Our work is guided by three national **Community Boards** which help determine the research priorities for recovery support services, determine the selection of early career investigators for our Fellowship and Trainee programs, give input on pilot studies and other research projects, and participate in sharing research findings with the broader community.

The JEAP Initiative is currently recruiting more members for our **Young Adult Community Board. Young adults aged 18-25** who are in recovery help guide our work and influence research. Scan the QR code to learn more and apply today!

The JEAP Initiative team can be reached at:

JEAP@chestnut.org

CHESTNUT HEALTH SYSTEMS
LIGHTHOUSE INSTITUTE

path

(Peer Advanced Training in Harm reduction)

CHESTNUT HEALTH SYSTEMS
chestnut.org

Looking for **Community Members** with ***harm reduction experience***

The Opportunity

Are you someone who has personally used or delivered harm reduction services to others?

The PATH (Peer Advanced Training in Harm reduction) project is looking to develop effective harm reduction training for peer support specialists. We are doing this by working with peer service providers, harm reduction and recovery advocates, and researchers.

We also need input from people who have experience using drugs and knowledge of harm reduction resources and strategies.

We are looking for people from all over the U.S. who can provide different perspectives on harm reduction. This role will involve regular virtual meetings and giving feedback on things we show you.

Learn More and Get in Touch!

tinyurl.com/326m2fpt

pathstudy@chestnut.org

221 W. Walton St. Chicago, IL 60610

812-521-2588

Commitment

6–8 meetings/year, each lasting 1.5–2 hours

Paid Opportunity

You will be paid for your time because we value your input!

EXAMPLE RECRUITMENT POST (JEAP INITIATIVE)

JEAP Initiative - Justice and Emerging Adult Populations Initiative's Post

JEAP Initiative - Justice and Emerging Adult Populations Initiative
March 6, 2024 ·

The JEAP Initiative - Justice and Emerging Adult Populations Initiative is looking for young adults (18-25) in recovery to join our Young Adult Community Board! This is a great opportunity to use your lived experience to shape research in this important area.

Learn more about our Community Boards and apply here:
https://www.jeapinitiative.org/community-boards/

9 · 37 shares

Like · Comment


LOOKING FOR
YOUNG ADULTS IN RECOVERY
TO
JOIN OUR COMMUNITY BOARD
NO PRIOR RESEARCH EXPERIENCE NECESSARY
APPLY TODAY:
https://chearr.org/
CHEARR
Collaborative Hub for Emerging Adult Recovery Research
Paid opportunity
Ages 18 - 28
Has received treatment involving medications for opioid use disorder
Join our national community board and influence research on how to best support young people in recovery from opioid use disorder
Meetings are held remotely
Compensation: $150 per meeting
$200 if chosen to be a facilitator by your peers
Use your voice and lived experience to advance research on this topic
We would like to include a diversity of voices, including those who have been traditionally underrepresented in research

HEAL Connections Lived Experience Panel

Outreach Toolkit

Resources

- Newsletter article
- Sample social media posts
- Graphics

Links

- Panel information page, JEAP Initiative
- Application
- APF panel information page
- NIH HEAL
- NIH HEAL Connections

Newsletter Article

Do you have lived experience with opioid use disorder or a pain condition?

The NIH HEAL Initiative and HEAL Connections is inviting individuals in recovery from opioid use disorder and individuals who have experience with a pain condition to join a Lived Experience Panel.

Selected panel participants will:

- Participate in 2-4 virtual meetings per year
- Provide input into priorities and gaps for your community
- Receive $300-$500 compensation for your service on the Panel

Criteria for participation:

- No specific educational or professional background is required; all training will be provided. We want to include Panel members from a range of backgrounds, regions, education levels, and perspectives. No previous Panel or committee experience is required.
- Have lived experience with an opioid use disorder or a pain condition
- Have access to phone or internet technology to participate in virtual activities (i.e., Zoom calls)
- Speak and understand spoken English

[Apply Now]

About the HEAL Initiative

The Helping to End Addiction Long-term® Initiative, or NIH HEAL Initiative®, is a research effort funded by the National Institutes of Health (a government agency) to better understand poorly treated pain, opioid misuse, addiction, and overdose. HEAL-funded research is meant to make a difference in the lives of individuals and communities across America. Learn more here.

About HEAL Connections

Research results need to benefit people living with pain, addiction, and other co-occurring conditions but too often are not shared with people working outside of universities. HEAL Connections believes that lived experience expertise has been missing from research conversations. We want to partner with impacted communities to speed research into action by communicating research findings in ways that everyone can understand. Learn more here.

Sample Social Media Posts

Both Pain and OUD

Do you have firsthand experience living with pain or an opioid use disorder? Join the HEAL Connections Lived Experience Panel to provide your insights on using research to address the #opioidcrisis and improve #painmanagement. #HEALconnections Learn more here: https://bit.ly/3GxKQ06

Do you have experience living with a pain condition or are you in recovery from an opioid use disorder? HEAL Connections would like your insights on a Lived Experience Panel to help make sure pain and addiction research findings lead to meaningful change in your community. #HEALconnections Learn more here: https://bit.ly/3GxKQ06

Are you in #recovery from opioid use disorder or do you have a pain condition? Join the @NIHendaddiction Lived Experience Panel to provide your insights on using research to address the #opioidcrisis and improve #painmanagement. #HEALconnections Learn more here: https://bit.ly/3GxKQ06

Pain

Do you have firsthand experience as a patient with a pain condition? HEAL Connections would like your insights on a Lived Experience Panel to help make sure pain research findings lead to meaningful change in your community. #HEALconnections Learn more here: https://bit.ly/3GxKQ06

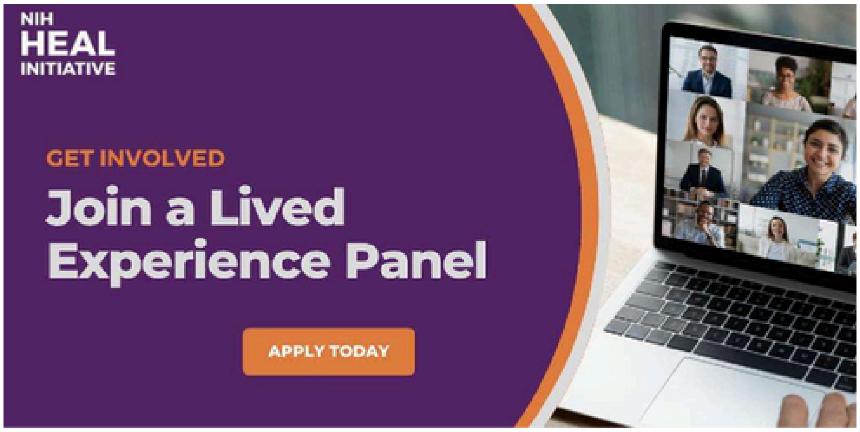
Do you have firsthand experience as a patient with a pain condition? Join a @NIHendaddiction Lived Experience Panel to help research make a positive impact in your community. #HEALconnections Learn more here: https://bit.ly/3GxKQ06

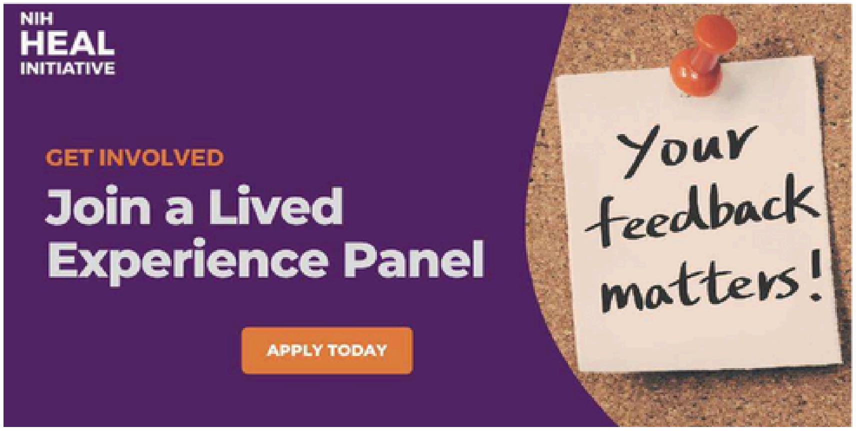
OUD

Are you in #recovery from opioid use disorder? HEAL Connections would like your insights on a Lived Experience Panel to help make sure addiction research findings lead to meaningful change in your community. #HEALconnections Learn more here: https://bit.ly/3GxKQ06

Are you or a loved one in #recovery from opioid use disorder? Join a Lived Experience Panel to help research make a positive impact in your community. #HEALconnections Learn more here: https://bit.ly/3GxKQ06

Graphics





[File]

CHEARR

So You Want to Join a Community Board?: Debunking Common Myths

MYTH	FACT
Community board members are directly involved in leading or doing research. 	• Community board members do not collect data or lead the projects themselves, but instead use their lived experience to influence and co-create projects. • Together with researchers, they work towards making a positive difference in their community.
Research experience or higher education is required to be a community board member. 	• No prior training or experience with research is needed. • You do not need a degree or even a high school diploma, because your lived expertise is valuable.
Community board members are expected to share their personal story publicly. 	• It is not required for members to share their picture or name on our website- it is entirely optional. • Specific information shared through your application and during board meetings will not be made publicly available.
Researchers are "checking a box" by talking to people with lived experience. 	• Researchers and agencies that fund research are working to recognize and amplify the knowledge gained from lived experience. • Community board members' expertise is valued in participatory action research by being paid for and given credit for their time and contributions

EXAMPLE COMMUNITY BOARD APPLICATION (JEAP INITIATIVE)

JEAP Initiative

JEAP Community Board Application

Thank you for expressing an interest in the JEAP Initiative Community Boards. The purpose of these Community Boards is to shape research on recovery support services, identify priority areas for research, and ultimately help improve recovery support services. **Please note there are no current openings on the Community Boards at this time.** However, we encourage you to fill out an application to be put on the waitlist in case future opportunities arise.

All of your responses will be kept confidential, so please read through each question carefully and answer as honestly as possible. We look forward to reviewing your application soon, and we will conduct follow-up phone/Zoom calls with all interested applicants.

* Required

1. How did you learn about this opportunity? *

2. First name: *

3. Last name: *

4. Age: *

5. Pronouns:

   Please note this question is completely optional. (Pronoun examples: she/ her, they/them, he/him)

6. Gender

   Please note this question is completely optional.

7. Email address: *

8. Phone number: *

9. City of residence: *

10. State of residence: *

11. Race/Ethnicity:

12. Preferred contact method: *

- ◯ Phone call
- ◯ Text message
- ◯ Email

13. Which Community Board(s) are you interested in joining? *

Please note that you may select more than one option if applicable.

- ☐ Young Adult Board – for young adults (i.e, 18-25 years old) with lived experience in recovery from substance use
- ☐ Justice-Involved Board – for adults of *any* age (i.e., 18+) with lived experience in recovery from substance use *and* with former justice system involvement
- ☐ Provider & Payor Board – for staff from organizations that either provide or pay for recovery support services

14. Please describe how your lived and/or professional experiences will inform your work as a member of one of our Community Boards.

CHEARR Community Board Application

Please complete the online application below.

You can see a preview of all the questions that will be asked here. You do not need to have any experience in research to apply.

If selected to move forward in the process, our team will contact you to schedule a 30-minute follow-up virtual meeting so that we can share more about what is involved, answer any questions you have, and get to know you.

Information you share will be private, and you can decide what information you want to share.

General Information

Name Full Name

____

Email E-Mail Address

____

Phone Number

____

Preferred Contact Method

- ◯ Phone Call
- ◯ Text
- ◯ E-Mail

City of Residence

____

State of Residence: (Drop Down)

Zip Code

____

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Age

____

Demographics

We ask the following demographic questions to make sure we have representation from a wide range of communities and identities. **If you are not comfortable answering any of these questions, you do not have to. Your answers are private.**

Understanding more about your personal identity is important to us and will be used to make sure our Community Boards have representation from diverse groups. **Choosing to share this information now does not mean that you need to share it with Community Board members or publicly.**

Pronouns

- ○ She/Her
- ○ He/Him
- ○ They/Them
- ○ Ze/Zim
- ○ Zie/Zir
- ○ Other Pronouns Not Listed Here
- ○ Decline to Answer

If your pronouns are not listed, please enter them here

____

Gender Identity

- o Agender
- o Genderqueer or Genderfluid
- o Man
- o Non-Binary
- o Questioning or Unsure
- o Transgender male/man
- o Transgender female/woman
- o Woman
- o Gender Identity Not Listed Here
- o Decline to Answer

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If your gender identity is not listed, please enter it here

____

Sexual Orientation

- ○ Aromantic
- ○ Asexual
- ○ Bisexual
- ○ Fluid
- ○ Gay
- ○ Lesbian
- ○ Pansexual
- ○ Queer
- ○ Questioning or unsure
- ○ Same-Gender-Loving
- ○ Straight (heterosexual)
- ○ Another identity not listed here
- ○ Decline to Answer

If your sexual orientation is not listed, please enter it here

____

Please describe your racial and ethnic identity.

If you do not want to answer, please type in "Decline to Answer"

____

How did you hear about this opportunity?

____

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Community Board Questions

Descriptions of Community Boards (Please read before continuing application)

Our work is guided by two national community boards to identify research priorities related to recovery support services for young adults in recovery from opioid use disorder. We have a particular interest in recovery supports for young adults who take or who have taken medications for opioid use disorder. In addition to identifying research priorities, our Community Boards help us select candidates for research training opportunities, give input on which research studies should receive funding, designing research measures of treatment outcomes that are relevant to young adults, and participate in sharing research findings with the broader community.

· **Young Adults in Recovery Community Board:** this board is made up of young adults (ages 18-28) who are in recovery and have lived experience receiving treatment involving medications for opioid use disorder.

· **Peer Recovery Support Specialist Community Board:** this board is made up of certified peer recovery specialists and recovery coaches who have experience working with young adults.

Which community board are you interested in joining? (Choose one or both).

- [ ] Young Adult Board
- [ ] Peer Recovery Support Specialist Board

Please describe how your work and life experiences will inform your work on this community board.

____

____

____

____

____

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Are you willing to commit to at least one year of service which includes active participation in approximately 6-9 activities per year?

◯ Yes

◯ No

Aside from the main goals of this Community Board, please share any other goals you hope to accomplish by serving on this Community Board.

If you do not have any, please type in "N/A"

____
____
____
____
____

Q32 We are seeking Board members who are either young adults with lived experience taking medications for the treatment of opioid use disorder or peer recovery specialists/recovery coaches who work with young adults in recovery from opioid use disorder and are able to represent the voice of their community (e.g., have contact and deep conversations with others in the community so they can bring as many voices as possible to be heard).

Please describe how you are engaged with or are active in the community represented by the Board(s) you selected.

____
____
____
____
____

NIH HEAL INITIATIVE | CONNECTIONS
Partnering to Accelerate Research into Action

Below is a preview of the questions you will be asked to answer in the online application for the Lived Experience Panel. Information that you share will be private, and you can decide what information you want to share. Please use the online application form to submit these answers.

1. First Name
2. Last Name
3. Pronouns
4. Email Address
5. Phone Number
6. Preferred Contact
7. City of residence
8. State or territory of residence
9. Age
10. Gender identity
11. Sexual orientation
12. Are you of Latino, Latinx, or Hispanic ethnicity?
13. Race
14. The overall Lived Experience Panel will include 55 Panel members, made up of 11 Subpanels representing different Priority Populations, each with 5 members. There are some Subpanels that are open to any individuals with lived experience with pain conditions or recovery from opioid use. There are also Subpanels that are tied to specific identities or populations. You may be interested in one or more of these Subpanels. Please select which Priority Population Subpanel(s) you are interested in joining. You will then be asked to rank the Subpanels you select in your order of preference.
    - Opioid Use
    - Pain
    - Pregnant or Postpartum
    - Co-Occurring Mental Health Conditions
    - Family/Caregiver
    - Hispanic/Latino/a/x/é
    - African American/Black

- LGBTQI+
- Justice-involved
- Youth & Young Adult
- Indigenous

15. How did you hear about this opportunity?
16. The purpose of this Lived Experience Panel is to involve people with lived experience to identify ways to better use and share research findings to address the opioid crisis and improve pain management within their communities. Please describe how your work on this Lived Experience Panel will be guided by your lived experiences (with recovery from opioid use/opioid use disorder and/or a pain condition).
17. We are seeking Subpanel members who identify as part of a priority population and are able to represent the voice of that community (e.g., have deep connections and interactions within that community so they can also bring forth the perspectives of other community members). Please describe how you are engaged with or are active in the priority population(s) you selected.
18. Are you willing to commit to at least one year of service which includes active participation in approximately 3-5 activities per year ranging from 0-4 hours in a given month?
19. Because the Panel members' well-being and recovery are of primary importance, we ask that members with lived experience in recovery from opioid use/ opioid use disorder have a minimum of one year in recovery and that all Panel members have solid supports in place before joining the Panel. If applicable, how long have you been in recovery?
20. Aside from the main goals of the Lived Experience Panel, please share any other goals you hope to accomplish by serving on this Panel and Subpanel(s).

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Automated message to send to applicants (if using Qualtrics or similar software that has this capability)

Subject: Thank you for applying to the HEAL Connections Lived Experience Panel

Dear ____,

We received your application for the HEAL Connections Lived Experience Panel. Thank you for your interest! We are currently reviewing applications and we will be in touch soon. If your application is selected for the next step, we will send you a follow-up email where you can choose the best time and date for a Zoom call.

Best regards,

[Name}

The HEAL Connections LE Panel Team

Invitation to Follow-Up Zoom Call:

Subject: HEAL Connections Lived Experience Panel – Zoom call invitation

Dear ______,

Thank you for your interest in the HEAL Connections Lived Experience Panel! We are scheduling Zoom calls with folks who express interest so that we can share more about this opportunity, get to know you more, and answer any questions you may have.

Please use the link to select which time you are available for a 30-minute Zoom call at this link: https://healconnectionslivedexperiencepanel.youcanbook.me

Please feel free to let me know if you have any questions, and I look forward to speaking with you soon!

Best regards,

[Name}

The HEAL Connections LE Panel Team

Example Zoom Call Script and Processes

Brief Reminders for Staff:

- Follow up with a reminder the day before to confirm the applicant's availability
- Share the applicant's name, full application, and inform each staff member of their role (i.e., Person "A" and Person "B") before the meeting to ensure responsibilities are clear
- Log in a few minutes early to review relevant materials, such as the applicant's name, full application, meeting script, and shared note sheet.
- Open the conversation with a round of introductions – name, role/institution, location, and lived experience (if comfortable sharing).
- Both staff members will alternate asking questions and taking notes.
- Reserve some time (10-15 minutes) right after the Zoom call for staff to debrief whether the applicant is a good fit for the Board and to discuss next steps.

Person A: {Name of Research Team Member}
Person B: {Name of Research Team Member}

Person A: Overview of the Project.

- Share the name of the project and its abbreviation, along with how it's being funded.
- Briefly explain why the project was launched, what it aims to achieve, and the impact it hopes to have in the community.
- You might also note how long it typically takes for research findings to be put into practice, to help frame the importance of the Board's role in the process.
  - For example, you could say "Research usually takes a really long time to be implemented into the 'real world' - usually takes 17 years on average!"

Person B: Overview of Board member responsibilities.

- Explain key requirements for serving on the Board, such as regular meeting attendance, engaging in discussions, collaborating with researchers, participating in various training, and providing feedback on pre- and/or post- meeting materials.
- If a meeting date and time have already been set, be sure to share those details with the applicant.
- Let them know whether the Board meets virtually, in person, or in a hybrid format.
- Mention compensation will be provided (if they are able to accept compensation).

- Briefly describe how the Board will work together to develop a group agreement—such as guidelines around confidentiality or shared expectations.

Person A: Briefly go over any housekeeping items before starting the question portion of the call (see below for examples of what you might say).

- The information you share in our conversation today is private and will only be shared with the team members involved in selecting Board members. You own your own story, and you can decide what information you want to share or not.
- Heads up about timing: Reminder that the meeting invite was for 45 minutes but the call will just be 30 minutes total. We have about ________ minutes left and have ___[Number]___ questions for you.
- We'll be taking notes so we might look down sometimes. I want to emphasize that this is an informal meeting and we really just want to get to know you and hear about your involvement in the communities you work with. We want you to feel as relaxed as possible.

Person B: Ask Question #1

- What led you to be interested in serving on the Community Board?

Person A: Ask Question #2

- We are working to create a Community Board with members who bring a variety of perspectives and experiences to the table, because we want to share new findings and implement new strategies that would normally take years to reach different communities. Could you share what communities you identify with?
- For example, when I share my perspective during Community Board meetings, I'll be bringing my experience as ______ (share your example)____.

Person B: Ask Question #3

- We aim to create a welcoming space where people feel empowered to speak on behalf of their communities and express their opinions. Thinking about your own personal experiences, what would make you feel comfortable sharing your experiences or what would make you choose not to share your personal experiences?

Person A: Ask Question #4

- Can you share a little bit about your lived experiences and how you think they would lend well to this group and our particular topics of focus? (this may need some prompting and support)

Person B: Ask Question #5

- What types of support do you have for your recovery? *(Internal note: This question is included because the discussions Board members will engage in can include triggers for substance use or other symptoms, and having strong supports is one of the best indicators of continued recovery and successful coping. The response to this question also will allow you to better tailor the resources provided to the Board member in the event of a concern about their recovery).*

Person A: Ask Question #6

- The Board meetings will take place (virtually on Zoom, in-person, etc.). This is a national Board that will include members in all US time zones. We'll be factoring in Board members' availability when scheduling meetings, and we may have evening or weekend meetings to accommodate everyone's schedules better. Could you let us know what your general availability is? For example, do you have availability during the day on weekdays, or in the evening, or on weekends?

Person B: Ask Question #7

- What supports would you like our team to provide to help you achieve success on this Board?
- For example, do you prefer to review materials in an audio recording, or do you prefer to read through materials in a Word document instead?

Person A: Ask Question #8

- Do you have any questions for us?

Person B: Explain next steps in the process, when they should expect to hear from you about a selection decision, and how they can contact you if they have additional questions or information they want to share.

Example Scoring Rubric for Community Board Applicants

Selecting from so many excellent candidates can be challenging! To help with the process, we use a scoring rubric that each staff member completes immediately after the Zoom call. The rubric is typically set up in a shared spreadsheet, with the two staff members coming to consensus on ratings and input during the debrief following each Zoom call.

1. Applicant's First Name
2. Applicant's Last Name
3. Overall Score (0-3 point scale, with 0 = Not a fit at this time and 3 = Excellent fit)
4. City (and if it is rural, suburban, or urban)
5. State
6. Age
7. Gender Identity and Sexual Orientation
8. Race and Ethnicity
9. (If you have more than 1 Board) Which Board(s) did they apply to?
10. How will their direct or indirect lived experience guide their work on the Board?
11. (If applicable) What other goals do they hope to get from this partnership?
12. Additional Notes from Staff: Describe the strengths or concerns that informed your rating.

JEAP Initiative

Hi [Name],

We are excited to share that you've been chosen to join the JEAP Initiative's Provider & Payor Community Board. Your unique perspective and expertise will be invaluable to this field, and we eagerly anticipate your contributions and guidance. Please let us know by **Monday**, **January 27th**, if you are still interested in serving as a Community Board member or if you cannot proceed at this time.

If you're still interested in serving on the Community Board, we'd like to outline a few next steps to get started. The first step is scheduling an orientation session. **Could you let us know your availability between Friday**, **January 24th**, **and Friday**, **February 7th?** The orientation call will take approximately 45 minutes.

Our next meeting will include members from all three JEAP Community Boards and is scheduled for Tuesday, February 11th from 12:00 – 2:00 p.m. PT / 1:00 – 3:00 p.m. MT / 2:00 – 4:00 p.m. CT / 3:00 – 5:00 p.m. ET. We would be pleased if you could attend, but we understand that this date is approaching quickly, and you may have prior commitments. If you are unable to attend, please let us know. Your absence will not affect your status as a Board member.

Finally, on behalf of the entire JEAP team, thank you for lending your voice and lived experiences to help change the research world. We would like to congratulate you on making the Board.

Warm regards,

[Name]

The JEAP Initiative Team

EXAMPLE NOTIFICATION EMAIL ON NON-SELECTION FOR BOARD MEMBERSHIP (HEAL CONNECTIONS)

Subject: HEAL Connections Panel– update

Dear [Applicant Name],

I hope this email finds you well. Thank you for your interest in participating as a panelist on the HEAL Connections Lived Experience Panel. We truly appreciate the time and effort you put into your application and we enjoyed getting speaking with you during our Zoom call.

After careful consideration, we regret to inform you that you have not been selected for the current subpanel. I want to emphasize that your application stood out, and you were one of the strongest candidates. Ultimately, the selection is based on ensuring a well-rounded representation that aligns with the specific needs and objectives of the subpanel to fill the current empty seat and it is not a reflection of any lack on your part.

Your passion and dedication to advocacy are invaluable, and we believe there may be other opportunities where your unique perspective and insights would greatly contribute to our initiatives. We'll definitely reach out if anything comes up in the future, and we encourage you to subscribe to the newsletter to stay updated on upcoming events and other ways to get involved.

Thank you once again for your interest in HEAL Connections and for your ongoing commitment to supporting others. We wish you continued success in all your endeavors, and we hope to have the chance to collaborate with you in the future.

Warm regards,

[Name]

HEAL Connections Team

When gathering information about lived experience or recovery (such as in your Community Board application form or follow-up Zoom call), it's important to approach these questions with care. Below are considerations and sample phrasings based on lessons learned through ongoing input from Community Board members.

Considerations

- **Preface the questions**
  In the context of your application process, it's fine to ask about lived experience, but make sure to explain why you're asking and how responses will be used. Clarify that the questions are optional, and reassure people that their answers will remain confidential. This helps reduce stigma and builds trust.
- **Be clear about what you mean**
  Decide whether you're asking about active substance use, experience with recovery, or both. Some people also use the term "living experience" to mean active use, but it and the term "recovery" are not widely understood—especially among young people. Also be clear if you mean recovery from substance use versus mental health disorders.
- **Use accessible, non-clinical language**
  Our Young Adult Board has recommended saying "substance use issues" rather than "substance use disorder," especially for individuals who haven't received a clinical diagnosis and don't identify with the term "disorder."
- **Include a "Decline to Answer" option**
  This is essential. People from different backgrounds face different levels of stigma and potential consequences related to being open about substance use or recovery.
- **Clarify what you mean by indirect experience**
  "Family member or friend" may be too broad. Consider more specific language like "close family member or friend" or "familial lived experience (that is, a close family member or partner has struggled with substance use)."
- **Be specific about recovery**
  If you are asking about **recovery experience**, it can help to include a working definition. One example:
  "The process of improved physical, psychological, and social well-being and health after having suffered from a substance-related condition." -see

https://www.recoveryanswers.org/resource/recovery-definitions/ *for more examples*
Let people know you honor self-defined recovery, including abstinence-based paths, harm reduction, medications for opioid use disorder (MOUD), or other approaches.

Examples of Phrasing

Example 1: Framing the questions in a form or survey

"The next two questions ask about direct (you personally experienced it) or indirect (a family member or close friend experienced it) experience with substance use or addiction. These are optional questions that we ask for [insert reason—e.g., to better understand the perspectives informing this project]. We will not share your responses with anyone else."

Then ask:

- Do you have **direct lived experience** with substance use issues or addiction and/or recovery?
- Do you have **indirect lived experience** (e.g., through a close family member or friend)?

Example 2: Application form phrasing

"Do you identify as having lived experience with recovery from substance use issues and/or with the adult or juvenile legal system?"
Response options: Yes / No / Decline to answer

Example 3: Stating lived experience as a preferred qualification

"Preferred: Lived experience (your own or through people with whom you are close) with one or more of the following: recovery from substance use, former involvement with the adult criminal legal system, or former involvement with the juvenile legal system."

Example 4: Including a definition of recovery

"We define recovery as the process of improved physical, psychological, and social well-being and health after having suffered from a substance-related condition. We recognize and support multiple recovery pathways, including abstinence, harm reduction, MOUD, and other approaches. We believe recovery is self-defined."

Example 5: Multiple-choice format

"Do you identify as having direct (your own) or indirect (through people with whom you are close) lived experience with any of the following? Select all that apply."

☐ Direct lived experience with substance use issues, substance use disorder, or recovery from substance use

☐ Indirect lived experience with substance use issues, substance use disorder, or recovery from substance use

☐ Direct experience with the juvenile or adult legal system

☐ Indirect experience with the juvenile or adult legal system

☐ Direct or indirect experience with other public systems (e.g., child protective/welfare system)

☐ None of the above

☐ Decline to answer

NIH HEAL INITIATIVE | CONNECTIONS
Partnering to Accelerate Research into Action

Example 1

Subject: See how your feedback shaped the final materials for the [project name] study

Email:

Hello everyone,

I hope you're doing well today!

The HEAL materials you provided in-depth written feedback on as part of the Stakeholder Feedback Team (SFT) have now been finalized. Your thoughtful perspective played a key role in shaping these resources, which covered a study on [project info]. The amount and depth of feedback you gave was right on target and helped the research team to strengthen these materials.

As a quick refresher, you shared your feedback on the following items:

- [project name] material #1
- [project name] material #2
- [project name] material #3

I thought you might enjoy seeing how the study team incorporated your input, so I've included a direct link here: [link from our internal server]. I hope it reflects the care and effort you put into this process!

Thank you again for all that you do. Enjoy the rest of your day!

Warm regards,

[Name]

The HEAL Connections Lived Experience Panel Team

Example 2

Subject: Thank You – See How Your Input Helped Shape [PROJECT NAME]'s Work

Email:

Hi Panel Members,

We're reaching out with a sincere thank you to each of you who met with the [PROJECT NAME] team over the last few months. Your insights and lived experience helped shape their research in meaningful ways.

The team has created a short video showing how your input influenced their study design and approach. You can watch the video at the link below: [link from our internal server].

Please don't hesitate to let us know if you have any trouble accessing it. Thank you again for contributing your time and expertise to the project. Your input has had a real impact.

Warm regards,

[Name]

The HEAL Connections Lived Experience Panel Team

Example Community Board Feedback Form

Using this form is optional!

JEAP Initiative

1. Is there anything else you'd like to add about (a) the topics described in the full slide deck from this month's Board meeting or (b) the materials sent to you for review, such as any videos, infographics, documents, audio recordings, etc.?

2. Were there any parts of the topics you reviewed that sounded confusing to you or you would like more clarification on?

3. This box is for any suggestions you have for the JEAP Initiative Team, whether it's feedback on the materials, an idea for a future meeting talking point, or any other feedback. Thank you for sharing!

4. [OPTIONAL] If you'd like us to get in touch about how your feedback was utilized, please leave your full name (i.e., first and last) and email address, otherwise you can leave this box blank.