

A TOOLKIT FOR GENERATING RESEARCH PRIORITIES THROUGH COMMUNITY-BASED PARTICIPATORY RESEARCH



JEAP INITIATIVE

SEPTEMBER 2022

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TABLE OF CONTENTS

01

Overview of the
JEAP Initiative

02

About this Toolkit

02

Advancing Science
via CBPR

04

Overview of the JEAP
Initiative Community
Boards

05

Staged Process for
Generating Research
Priorities

06

Stage 1:
Brainstorm

10

Stage 2: Prioritize

15

Stage 3: Refine

20

How to Use These
Research
Priorities

21

Impact of These
Research Priorities on
the JEAP Initiative

OVERVIEW OF THE JEAP INITIATIVE

We aim to advance research on recovery support services for individuals struggling with substance use disorder, including opioid use disorder.

The JEAP Initiative is a five-year project funded by the National Institute on Drug Abuse. It is a collaboration between the Oregon Social Learning Center, Sponsors Inc., and the Transitions to Adulthood Center for Research at the University of Massachusetts Chan Medical School.

The JEAP Initiative aims to advance research on the efficacy/effectiveness of **peer recovery supports** and **recovery residences** for **emerging adults** and **justice-involved adults** with substance use disorder through the following four goals:



Identify priority areas of research via engaging individuals in recovery and providers/payors of recovery support services



Provide funding and guidance to produce preliminary studies on recovery support services



Grow the field of skilled early career investigators focused on this research



Serve as a national resource for dissemination and outreach to the larger field

ABOUT THIS TOOLKIT

This toolkit is designed for individuals who want to use Community-Based Participatory Research (CBPR) methods to engage members of affected communities in determining priority areas for research.

This toolkit is applicable to researchers focused on issues of recovery, substance use disorder, and the justice system as well as researchers focused on other related topics. Throughout the toolkit, we describe the processes and tools that the JEAP Community Boards used to develop research priorities and also suggest ways that this process could be adapted based on the structure of the reader's collaboration with community members.

Look for
Options for Adaptation
within each stage

ADVANCING SCIENCE VIA CBPR

A primary goal of the JEAP Initiative is to generate research on recovery support services. When the JEAP Initiative began in 2020, the science on recovery support services was in its infancy. Thus, an important first step for the JEAP Initiative was to specify the research gaps and to highlight priority areas for investigation.

Typically, when determining priority areas for research, investigators and/or the agencies that fund research (e.g., the National Institutes of Health) peruse the literature on a particular topic to identify the current gaps. Unfortunately, in the context of recovery support services, the scientific literature as of 2020 was quite limited.

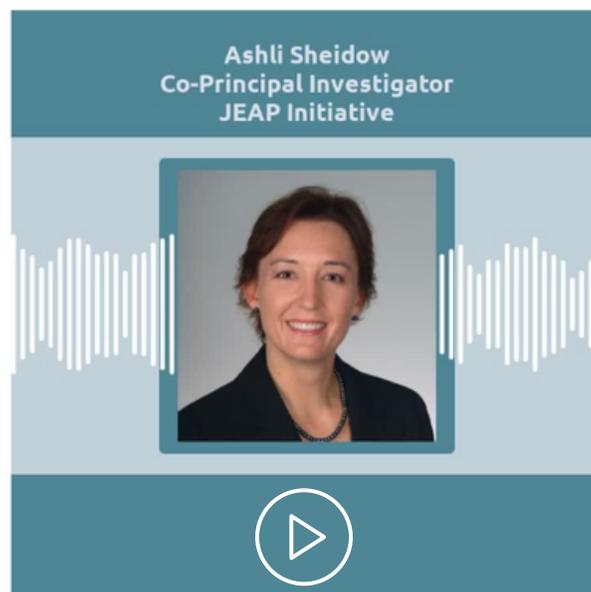
Thus, the JEAP Initiative took a different approach. Specifically, CBPR methods were leveraged to determine the research priorities. **At its core, CBPR recognizes that scientific advances are best made when research incorporates the perspective of affected community members.**

Indeed, CBPR promotes collaboration between researchers and the end-users of knowledge and leverages their combined expertise to increase the relevance of research questions, the success of research methods, and the likelihood that research findings will benefit the people who are most affected.

CBPR also provides a forum for marginalized groups to express concerns and ideas in a way that is appropriate to their specific communities, and it is a preferred method to address health disparities. It is through the blending of lived experience and research expertise that services-relevant phenomena are better understood and services have more relevance. Given the marginalization of people with substance use disorder, CBPR is valuable for enhancing substance use research. CBPR has produced improved ethical guidelines in substance use research, identified harm reduction strategies for people who inject drugs, and used with young adults to evaluate smoking cessation programs. These are powerful examples of how CPBR can enhance science.

Most commonly, CBPR is conducted by engaging members from the affected communities in Community Boards. Within this document, we describe the Community Boards established for the JEAP Initiative and outline the approach the Community Boards used to develop research priorities. These research priorities come directly from Community Board members' ideas and reflect their collective expertise, which comes from their lived and professional experience.

[Click below to hear a brief overview of CBPR](#)



OVERVIEW OF JEAP INITIATIVE COMMUNITY BOARDS

All aspects of the JEAP Initiative are guided by three national Community Boards. Our Community Boards 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. Our three Community Boards are made up of individuals from all around the country who bring their diverse expertise to this work.



Justice-Involved Community Board

This board is made up of adults who are in recovery from substance use 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.



Young Adult Community Board

This board is made up of emerging adults (aged 16-25) who are in recovery from substance use.

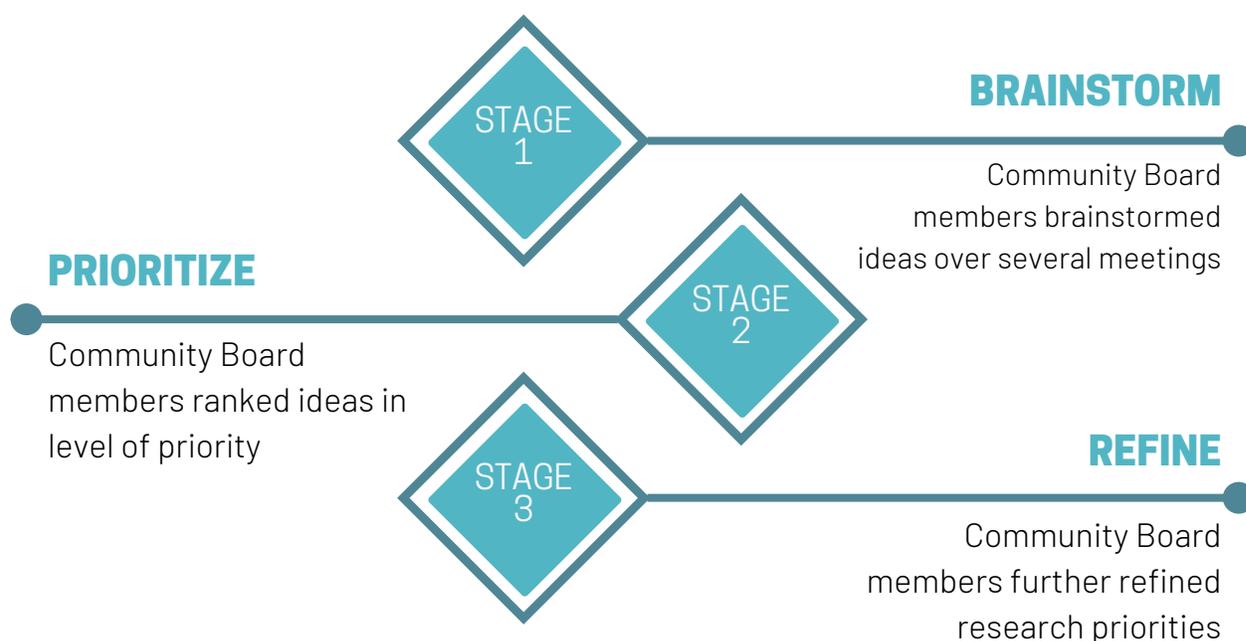
Within each Community Board, two Community Board members serve as co-facilitators. The project coordinator for the JEAP Initiative provides logistical support for the Community Boards. Each Community Board has 7-9 members. These Community Boards are national boards with members from all around the country; thus, it was planned from the outset that this process would take place virtually (i.e., via Zoom). Due to Covid-19 restrictions, the JEAP team was also working remotely throughout this process.

STAGED PROCESS FOR GENERATING RESEARCH PRIORITIES

Community Board members were recruited for their expertise on recovery support services from lived experience and/or professional experience. Community Board members did not, however, need to have prior research experience. While some Community Board members had previous research experience, the JEAP team was intentional about making this opportunity accessible to those who were new to research.

The process for generating research priorities included three stages: Brainstorm, Prioritize, Refine.

This was a back-and-forth/iterative process, with Community Board members taking the lead and the JEAP Investigators providing support along the way. In the sections below, we provide a detailed summary of each stage.



STAGE 1: BRAINSTORM

Community Board Members Brainstormed Ideas Based on Their Experiences

The Justice-Involved, Provider and Payor, and Young Adult Community Boards separately brainstormed research ideas. Each Board devoted 45 minutes in three monthly Zoom meetings (i.e., 2.25 hours total per Board) to this task. Prior to the brainstorming, a JEAP Investigator reminded Board members about the following focus areas of the JEAP Initiative:



Next, the JEAP Investigator presented a series of open-ended brainstorming questions. The questions, provided below, were tailored, since all members of the Justice-Involved and Young Adult Boards had lived experience, but that was not a requirement for the Provider and Payor Board.

Brainstorming Questions for the Justice-Involved and Young Adult Boards:

Within your experience with the focus areas of the JEAP Initiative:

What helped/worked? What didn't help/work?

What were the barriers or challenges?

What helped you overcome a barrier or a challenge?

What do policymakers/funders/legislators need to know in order to make the right decisions?



Brainstorming Questions for the Provider and Payor Board:



Within your experience with the focus areas of the JEAP Initiative:

What are the most compelling issues that you and other decision makers face?

What kinds of knowledge are needed to better address these issues?

For those of you who are aware of the research, what are the gaps in this area?

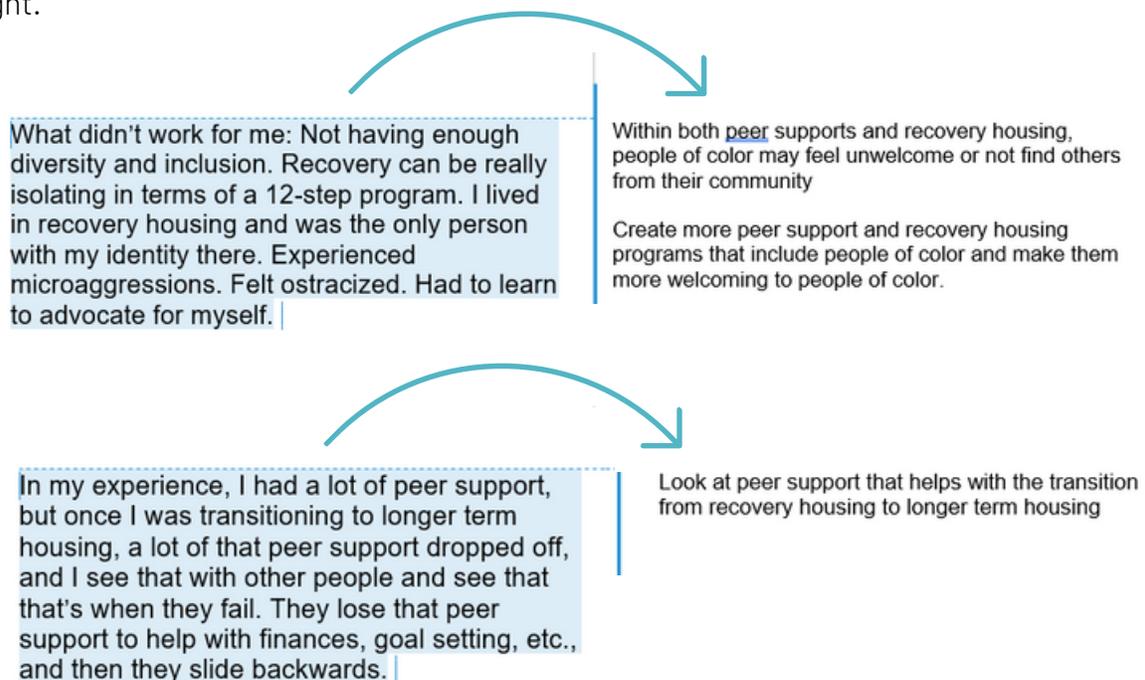
In most cases, a JEAP Investigator was present during the brainstorming, but the discussions were facilitated by the co-facilitators for each Community Board. The co-facilitators helped the Community Boards be as efficient as possible with time and encouraged all Community Board members to participate in the discussion either verbally or through the chat feature within Zoom.

Click below to hear from a Community Board member about the brainstorming stage



JEAP Team Synthesized Community Board Members' Brainstorming into Concise Statements

The project coordinator who provides logistical support to the Community Boards took notes throughout each brainstorming meeting. Several members of the JEAP team then went through the notes, which were de-identified but often included a full transcription of the Community Board members' comments, and synthesized each comment into a shorter statement. The intent was to encapsulate as closely as possible the key idea or theme shared during the meeting. Below is an example of this process, with the notes from the Community Board meeting on the left, and the synthesized statements on the right.



Community Board Members Reviewed and Edited Concise Statements

After synthesizing the Board Members' comments from the brainstorming meetings into shorter statements, the JEAP team sent each Community Board a list of their statements and posed the question below. Community Board members then had an opportunity to add to the list or clarify statements if anything was misunderstood.

In reviewing the list of research topics/themes pulled from the discussions so far, is there anything you would like to add or modify?

Options for Adaptation of Stage 1

Single Meeting vs. Multiple Meetings: The brainstorming stage consisted of each Community Board member sharing their ideas verbally, and occasionally using the chat feature within Zoom. Sharing one at a time allowed for the Community Board members to build off of each other's comments and to get to know each other better since this process started soon after the Community Boards were formed. However, this form of brainstorming is time consuming, and we recognize that researchers may need to condense this process. Other methods of brainstorming could be considered, such as having community members generate electronic sticky notes during a meeting and then have a brief discussion of the sticky notes. See Stage 2 below for an example of using this type of tool. Community members could also be sent the questions ahead of time and asked to come to a meeting with some ideas already in mind.

Virtual vs. In-Person: If this engagement was in person, community members could write on actual sticky notes and place them on a whiteboard. If the brainstorming was condensed into a single meeting, it could also allow for a greater number of community members to be involved, either by having a larger single meeting or by conducting meetings with several different groups. While having nationally dispersed Community Boards makes gathering in-person difficult, Community Board members expressed that an in-person meeting would allow everyone to fully focus without the distractions that can happen when meeting virtually.

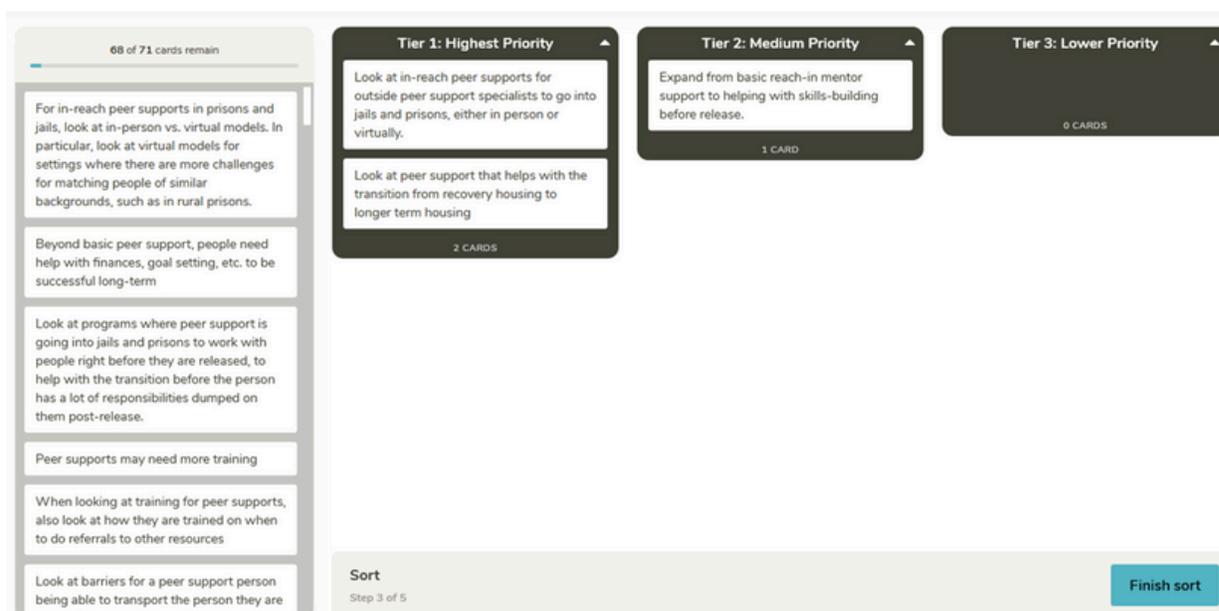
Larger vs. Small Group: If you are engaging with a larger group of community members, breakout groups could also be used during brainstorming to give everyone more time to share ideas. This could either be done in-person or with breakout rooms in a virtual meeting. We used virtual breakout groups when bringing all Community Boards together in Stage 3 (described below).

Brainstorming as Separate Groups vs. Mixing Groups: This process of developing research priorities was conducted shortly after our Community Boards were formed, and thus each Community Board brainstormed separately, so that Community Board members could develop a sense of community within their specific Community Board. If you collaborate with several different groups of community members and these groups are already well established, consider bringing together members of different groups for the brainstorming stage.

STAGE 2: PRIORITIZE

Community Board Members Ranked Ideas by Level of Priority

After several months of brainstorming, each Community Board member was given the full list of ideas generated by their Community Board. Each Community Board member ranked these ideas into “High,” “Medium,” or “Low” priority categories. The Provider and Payor Board used Microsoft Excel for this process. Based on input from the co-facilitators of the Justice-Involved Community Board, an electronic ‘card sorting’ tool was used to make this process more user friendly for the Justice-Involved and Young Adult Community Boards. This tool, called UXtweak, allows a set of cards, each with an idea from the Community Board, to be electronically sorted into ‘piles’ of High, Medium, or Low priority. Community Board members used this tool to prioritize between 40-75 different ideas, depending on the Community Board. Below is a screenshot of this process.

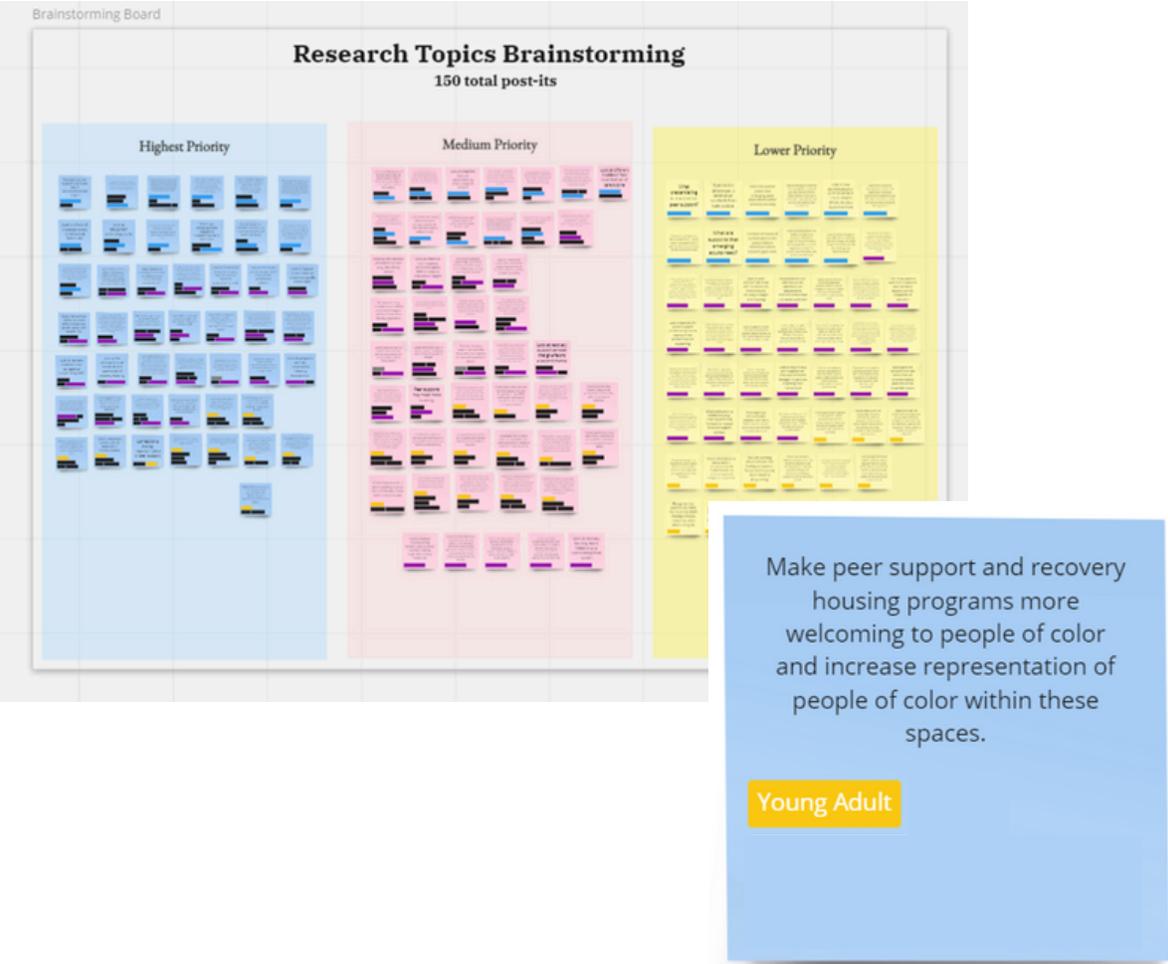


Lesson Learned: It is expected that similar themes will come up several times across multiple brainstorming meetings. Within this process, similar themes were kept as separate ideas in the list. This meant that for the Justice-Involved Community Board, members ranked 71 ideas, which was a difficult task. It would have been helpful to first condense ideas with similar themes to narrow the list. A Community Board member shared “it was user friendly but difficult because we are passionate about so many things, it’s hard to rank.”

JEAP Team Compiled the Rankings

After Community Board members individually ranked the ideas from their particular Community Board into High, Medium, or Low priority categories, the rankings were assigned a score. A ranking of 'High Priority' was assigned a score of '1,' a ranking of 'Medium Priority' was assigned a '2,' and a ranking of 'Low Priority' was assigned a '3.' For each idea on the list, the score from all Community Board members were averaged. The list was then sorted from lowest number (highest priority) to highest number (lowest priority). The ranked list was then separated into thirds of High, Medium, and Low Priority.

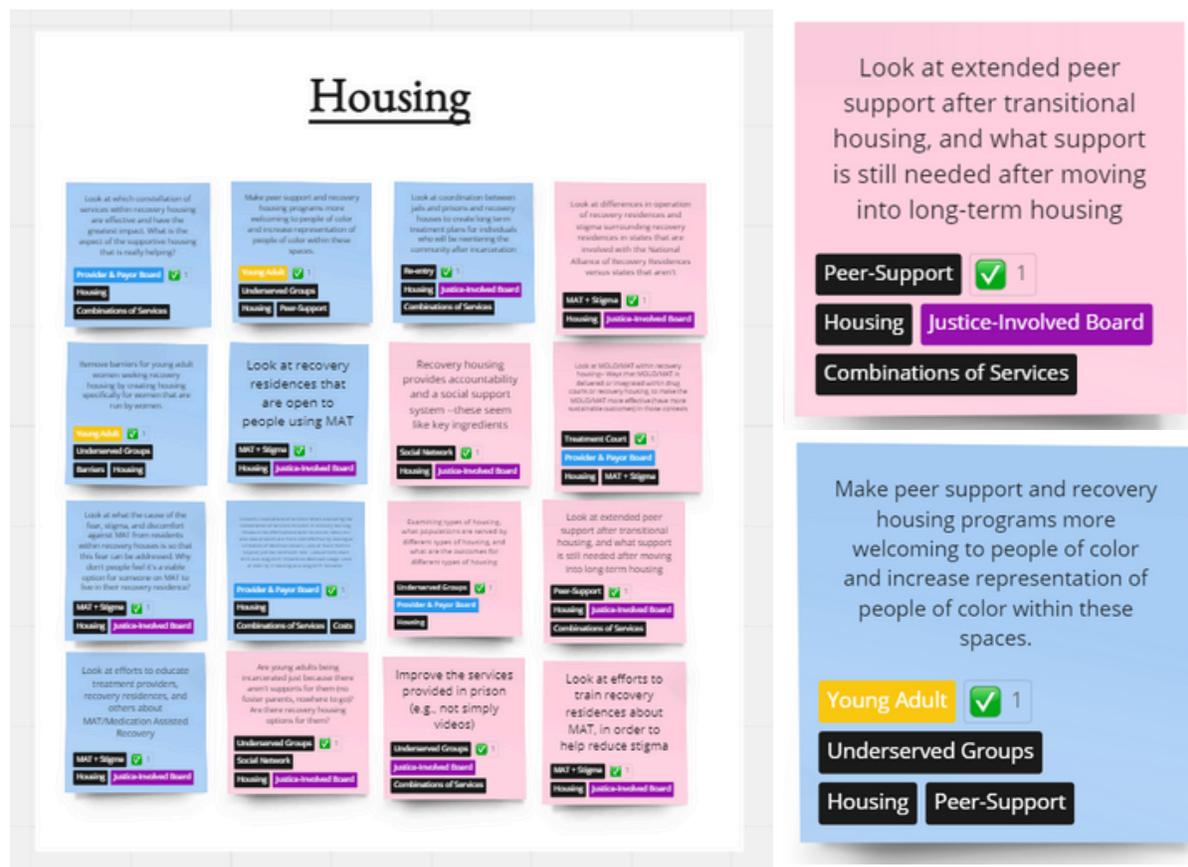
The JEAP team then used an online tool called Miro to turn each idea into an electronic sticky note. Each idea was color coded for the level of priority and 'tagged' with the Community Board that generated the idea. There was a total of 150 separate sticky notes, with all the ideas generated by the three Community Boards. Below is an example of one of those sticky notes, as well as an image showing all sticky notes.



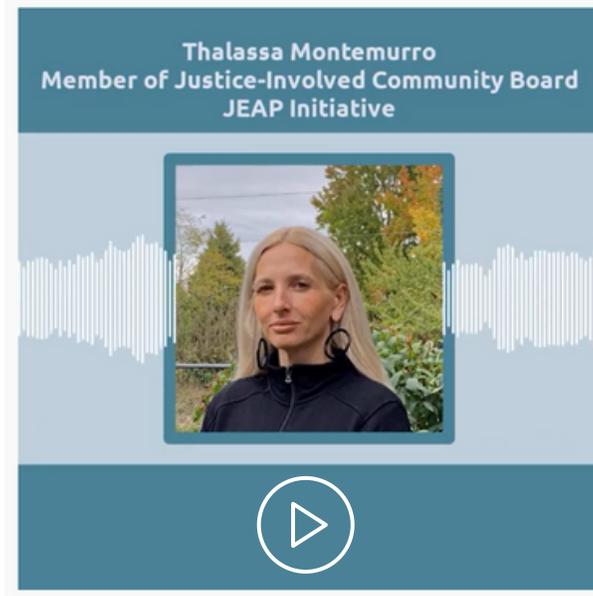
JEAP Team Categorized Ideas Based on Theme

Four members of the JEAP team then went through each of the High and Medium priority ideas and came to a consensus on a core theme 'tag' for each idea. The Low priority ideas were excluded from this point forward in an effort to hone the focus on ideas collectively viewed by the Community Boards as having elevated importance/urgency.

The High and Medium priority ideas were grouped by theme. Due to the large number of ideas at the outset of this process, this step took place over several 2-hour virtual meetings. Below is an example of a sticky note with the core theme 'tag' added, as well as an image showing all the ideas within the theme of 'Housing' after categorization.



Click below to hear from a Community Board member about the prioritization stage



Options for Adaptation of Stage 2

Individually vs. As a Group: In our process, each Community Board member individually ranked the ideas that were generated by their Community Board. However, the ranking could be done as a group exercise. Community Board members could discuss each idea and come to a consensus on whether it should be ranked as High, Medium, or Low priority. The number of ideas would need to be narrowed to a smaller list to make this feasible, since the ranking will take longer if a group is discussing each item and coming to a consensus. If this is occurring virtually, one person could have the card sorting tool pulled up and be in charge of moving ideas to the appropriate 'pile' once consensus is achieved.

One Community Board member shared "it would be cool to do the prioritizing and ranking as a group activity because I was thinking about what's most important here in my community but it would be interesting to hear about the priorities in different parts of the country and urban/rural."

Virtual vs. In-Person: If you are able to have everyone in person, each Community Board member could be provided with a set of physical index cards with each idea written on a separate card, and then each person can sort the cards into piles of High, Medium, or Low priority. Alternatively, it could be done as a group exercise, with larger cards that are put up on a wall or whiteboard. Conducting this in person with physical cards may be a better option if community members are less tech-savvy.

Prioritizing as Separate Groups vs. All Together: Within our process, Community Board members ranked ideas that were generated by their particular Community Board, and it was later in the process that ideas were combined across all three Community Boards. If you are working with multiple different groups of community members, another option would be to combine all ideas after brainstorming, and then have community members prioritize the ideas that were generated by their group and other groups.

Community Board members expressed that they enjoyed getting to collaborate with members of other Community Boards in Stage 3 and would have welcomed opportunities to interact and collaborate earlier on.

Card sorting vs. Other Methods: As noted above, if community members are comfortable with Microsoft Excel, it could be used for ranking, with each idea on a separate row and a cell for community members to indicate a rank for each idea. However, this approach is less visual than the card sorting method. While we used a tool called UXTweak, there are other electronic tools that allow for card sorting and also have a free version, including UX Metrics, Kardsort, and OptimalSort. Many of these tools are used within user experience (UX) design.

Assigning Theme Before vs. After Ranking: Another variation would be to include the theme labels on each idea prior to community members prioritizing the ideas so that they can also more easily see which general themes are getting ranked more highly than others.

STAGE 3: REFINE

JEAP Team Turned Community Board Members' Ideas into Proposed Research Questions

Now that the Community Board members' ideas were sorted into thematic categories, the JEAP team transformed each idea into a proposed research question. Ideas that were similar or overlapping were combined into a single research question. During this process, the JEAP team was very intentional about having the questions reflect as directly as possible the Community Board members' ideas rather than making edits or additions based on the JEAP team's ideas.

Each question was tagged with an icon showing which Community Board generated the question. Some ideas were discussed by a single Community Board whereas others were discussed by multiple Community Boards. The JEAP team also drafted a global 'problem statement' to encompass the questions within each category. Below is an example of research questions within the thematic category of Recovery Housing.



Make peer support and recovery housing programs more welcoming to people of color and increase representation of people of color within these spaces.

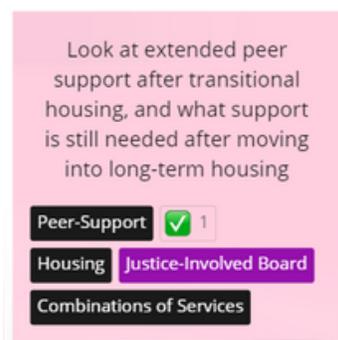
Young Adult ✓ 1

Underserved Groups

Housing Peer-Support



What strategies can increase representation of people of color within recovery housing? How can recovery housing be more welcoming for people of color?



Look at extended peer support after transitional housing, and what support is still needed after moving into long-term housing

Peer-Support ✓ 1

Housing Justice-Involved Board

Combinations of Services



How can peer support specialists effectively assist individuals with the shift from transitional housing to long-term housing?

Community Board Members Refined Problem Statements and Proposed Research Questions

All three Community Boards and the JEAP team met virtually for the first time in a collaborative 2-hour retreat. The purpose of this retreat was for Community Board members to finalize the research priorities. It would not have been feasible for all Community Board members and JEAP team members to discuss all of the problem statements and research questions as a large group. Thus, prior to the retreat, Community Board members received the full list of problem statements and proposed research questions, and each Community Board member was asked to indicate the three categories that they preferred to discuss during the retreat.

Then, at the retreat, Community Board members and JEAP team members were separated into breakout groups, with a mix of different Community Boards represented within each group. Based on their preferences stated ahead of time, each breakout group was assigned 1-3 categories to review and refine. Below are the questions posed to each breakout group:

Do the questions capture the key issues that need to be examined?

Are the questions understandable?

Do any of the questions not belong in the thematic category?

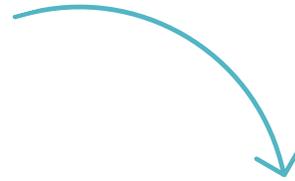
Do the themes capture the focus of the questions?

Do the problem statements need to be edited?

The intention of this activity is to encourage researchers to conduct studies on the areas you deem most important. Thinking back to the conversations your Community Board had about these research priorities, do you see your conversations reflected here?

See below for an example of a proposed research question that was modified during the retreat. Within the breakout group focused on the recovery housing category, a Community Board member recommended that the context of the broader housing crisis be added to the question about peer supports helping individuals transition to long-term housing.

How can peer support specialists effectively assist individuals with the shift from transitional housing to long-term housing?



How can peer support specialists effectively assist individuals with the shift from transitional housing to long-term housing, especially given the housing crisis that is felt more broadly?

In discussions after the retreat, Community Board members shared that it was very helpful to have a joint activity that allowed them to work alongside and get to know members of the other Community Boards.

A member of the Justice-Involved Community Board shared what they appreciated about their experience of being in a breakout group with a member of the Provider and Payor Community Board who is a director of probation:

“

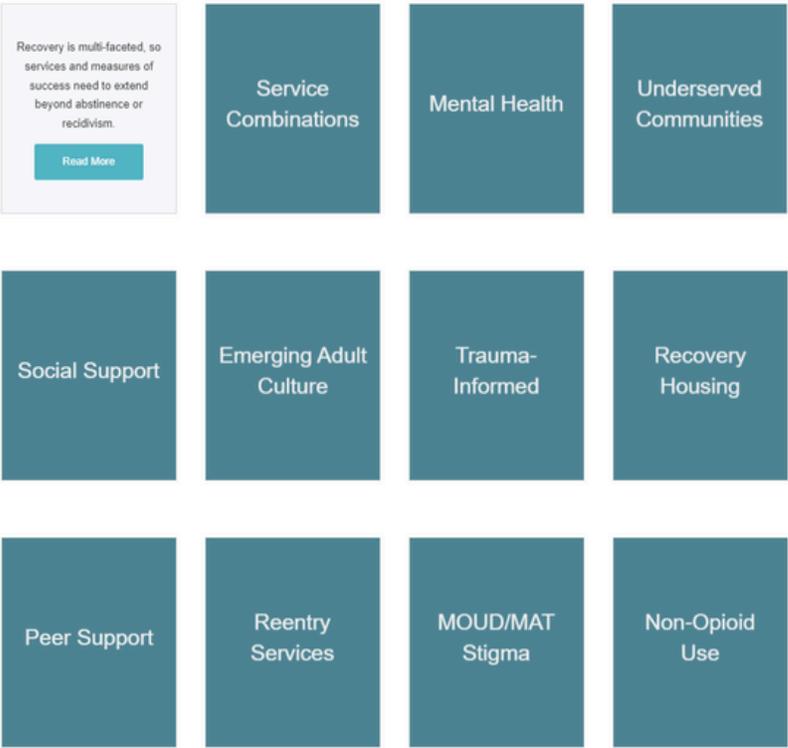
Both of us have perspectives from different sides of the spectrum, so to speak, and so us being able to bounce things off each other let us glean each other's perspective and then spark ideas that neither one of us might have considered on our own had we not had that conversation to begin with, and so I think there is something to be said about the benefits that could come from conversations that don't typically take place [with] people with lived experience versus providers in you know, especially in the justice system.

”

JEAP Team Added Finalized Problem Statements and Research Questions to the JEAP Initiative Website

The final list of prioritized research questions and problem statements were then added to the [JEAP Initiative website](#).

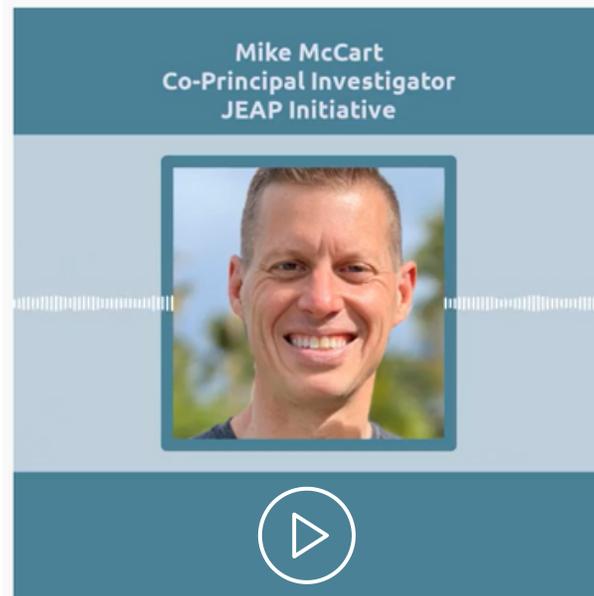
The landing page (screenshot at right) shows each of the thematic categories, which flip around to show the problem statement for that theme. Each subpage (screenshot below) then includes the Community Boards’ research questions within that theme. Icons indicate which Community Board(s) generated each research question.



- Beyond recidivism and abstinence from substance use, what other elements can be considered as benchmarks to evaluate success along the recovery journey? J P
- How can MOUD/MAT¹ and harm reduction be incorporated into measures of success? J P
- What fosters resilience along the recovery journey and what role do recovery support services play? And especially how does this apply to emerging adults? P Y
- Are there any holistic approaches for recovery support services – that address not just physical addiction (i.e., detox) but physical, emotional, social, and spiritual wellbeing – that show promise? J P
- What helps emerging adults² come back from a recurrence of use, especially if they have limited resources? Y
- What factors increase substance use or criminogenic risk, and what recovery support services might help address these factors? P

In the future, we will build these webpages out further by linking to studies and resources related to each of the research questions.

Click below to hear about the stage of refining research priorities



Options for Adaptation of Stage 3

Virtual vs. In-Person: If community members are not geographically disbursed, or if there is funding to allow for travel, this stage could take place in person. If taking place in person, this stage could potentially be extended beyond 2 hours and include more steps of the stage within that one meeting.

Single vs. Multiple Meetings: As mentioned above, the format of bringing members of several different groups together could also be used earlier in the process, such as during brainstorming.

HOW TO USE THESE RESEARCH PRIORITIES

These research priorities provide a foundation for investigators to develop new research projects or expand ongoing research projects. The JEAP Initiative hopes to stimulate new research in these areas, improving understanding of recovery support services and, ultimately, policies and practices related to recovery support services.



We plan to build upon the [research priorities webpages](#) on our website by linking to relevant resources, organizations, and research. We encourage you to check back to dive deeper into the research questions.



As new research is conducted, we hope to include links to this research. Toward this end, if readers build on these research priorities, please let us know of your efforts so that we can feature your research in relevant categories. In addition, please let us know if we could be of assistance.



If readers use any of the research priorities to inform a future grant application, please cite these research priorities that were generated through CBPR methods by the NIDA-funded JEAP Initiative to further strengthen your application. A suggested citation for this document is provided after the title page.

Questions? Reach out to the JEAP Initiative team!

You are welcome to reach out to our team via the [contact form on our website](#).

IMPACT OF THESE RESEARCH PRIORITIES ON THE JEAP INITIATIVE

Within the JEAP Initiative, these research priorities shape all aspects of our work:



New grant applications from JEAP Investigators are based on these priorities.

Pilot studies funded by the JEAP Initiative must address one or more of the priorities.



The development of our dissemination activities, including virtual forums, tipsheets, videos, and toolkits, are driven by these priorities.

Applicants for our offsite Training Institute and onsite Postdoctoral Fellowship must specify which of these priorities they plan to address during their time with the JEAP Initiative.



As stated above, our intention is that other researchers who are focused on recovery support services, substance use disorder, the criminal justice system, or related fields will also use this resource to guide their work.

