

# SI-CBPAP: Towards structural indicators of community-based participatory action research

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## Abstract

**Introduction:** Structural aspects of community-engaged research are not well measured yet have critical implications for community research empowerment. This is particularly so with people who use drugs. We introduce the Structural Indicators of Community-Based Participatory Action Research (SI-CBPAP) to measure structural indicators of community-research entity relationships.

**Methods:** A three-phased process of iterative development, feasibility and applicability assessment was used to examine the instrument with community-engaged studies as a first stage of instrument development. The development team included people with university, non-government organisation and lived/ing drug use experience. Four studies on the health of people who use drugs were reviewed for indicator evidence followed by iterative discussion about construct and item discrepancies. Indicators were measured for the degree to which they were observed using a three-point scale.

**Results:** All but two constructs were confirmed for meaning. Constructs of ‘community’ and ‘coalition’ required revision and explanation. The need for further exploration of power differentials between community and community-based organisations was identified. Indicator evidence was found for all six categories across studies. The instrument was deemed applicable and easy to use. It was observed that categories could apply to studies with various degrees of community engagement and to other research focal areas.

**Discussion and Conclusions:** SI-CBPAP applicability testing and initial category confirmation indicate its potential utility for community research collaboratives. The next phase of development involves cognitive interviewing with researchers from across community engaged research orientations, and with communities engaged in research beyond drug user health.

## KEYWORDS

community-institutional relations, harm reduction, people who use drugs, instrument development, engagement measurement

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**Key points**

- The Structural Indicators of Community-Based Participatory Action Research (SI-CBPAR) is the first instrument to measure structural indicators of community-engaged research.
- The SI-CBPAR was found to be applicable and feasible for examining structural aspects of the community-research entity relationship.
- The SI-CBPAR may be applicable to research along the continuum of community-research engagement.
- The SI-CBPAR has the potential to redirect study implementation towards greater and more community-valued research engagement.

**1 | INTRODUCTION**

Statements about community engagement in research have become so ubiquitous to have lost all meaning, and in some cases are merely performative. Research behaviours can resemble extraction-based research even while being called ‘community engaged’ or ‘community-based’ [1, 2]. Terminology confusion remains, with definitions not widely shared across disciplines or even known in communities. Community-based participatory action research (CBPAR), community based participatory research, participatory action research, community-engaged research and community-advised research all express research partnerships whereby communities have some level of ownership in the research [3, 4] and all involve power distribution even when not transparent to all participants engaged [5–7].

We introduce the term ‘research entity’ to specify what is often murky in the community-research relationship. The term refers to the array of actors controlling research processes. Research entities are not exclusively universities. Government agencies, foundations, donor organisations and even community-based organisations (CBO) operated by, or with histories being operated by, the communities they serve can be research entities. Including entities beyond academia allows a more transparent understanding of power in the research act. Such power may be funding, political or social standing, or structural assets used to control the research act. Whoever initiates the research process is in a position of power, reinforced by these assets, and can control meaning-making or access to it in the research process. All forms of research are included here: from standard program evaluation (needs assessments, process and outcomes evaluations, etc.) to randomised controlled clinical trials.

Over the last two decades, there have been many attempts to identify or develop tools measuring aspects of community engagement in research. Boivin’s systematic review identified 14 tools published between 1980 and 2016, but most were not based in the literature and did not include validation evidence [8]. And as observed by

Aurora et al., the public was generally not involved in instrument development [3]. Bowen’s systematic review of 68 studies for quantitative engagement measures found that most tracked attendance, engagement satisfaction or community perceptions of the research relevance [9]. Higher education studies establishing indicators of community engagement yielded classifications, but did not focus on structural indicators [10, 11]. Recent studies of structural engagement focus on community context (place-based) [12, 13] or historic power differentials between universities and communities [14], though these frameworks do not include measures [15]. Three instruments remain closest to measuring community research engagement, though they do not directly address structural elements in a manner that allows the interrogation of power distribution across the project. The Participant Assessment in Community-based Research instrument measures partnership across five dimensions, including communication, collaboration, partnership values, benefits and evaluation [3]. The Community Engagement in Research Index measures degree of engagement across 12 research activities, including grant proposal writing, conducting background research, choosing research methods, developing sampling procedures, recruiting study participants, implementing the intervention, designing instrument items, collecting primary data, analysing collected data, interpreting study findings, writing reports and journal articles, giving presentations based on findings [16]. The Research Engagement Survey Tool (REST) measures community perspectives about the quality of activities (how well) and their frequency using a five-point Likert scale across eight principles: focus on community perspectives and determinants of health, partnership is vital, partnership sustainability to meet goals and objectives, foster co-learning, capacity building and co-benefit for all partners, build on strengths and resources within the community, facilitate collaborative, equitable partnerships, involve all partners in the dissemination process, build and maintain trust in the partnership [17]. REST is, to our knowledge, the only validated measure of community engagement in research.

We introduce an instrument to measure the existence of structural indicators in the community-research entity relationship because community power sharing in research is essential to co-create the evidence scaffolding for social change; yet remains elusive to measure. This preliminary instrument provides clarity about what constitutes the structures of CBPAR, and can help advance its application through a collaborative, iterative review of the degree to which elements are and should be expressed in a particular research effort. The objective is to establish an easily applied instrument across research-community engagement orientations (CBPAR, participatory action research, community-engaged research, etc.) and across issue-focus areas. We developed this instrument in context and with a community of people who use drugs (PWUD). This is precisely because research relationships with PWUD have been called superficial, objectifying, tokenising and without appropriate community attribution [18, 19]. The stigmatisation of drugs and people who use them facilitates the reduction of PWUD in the community-research entity relationship to a master status of 'drug user' [20]; effacing professional and personal areas of expertise advancing the research [21]. This totalising status also haunts researchers with lived or living drug use experience, as they are often repeatedly compelled to hide it from academic and societal gaze to be considered credible [22, 23].

The US National Survivors Union (a union of PWUD) recently called for a 'collaborative ecosystem' of research efforts led by PWUD [19]. A central critique was lack of university practices reflecting community-based research. This is likely because CBPAR is not often part of university research training beyond an elective course (if available). Therefore researchers working with PWUD tend not to use this research orientation. CBPAR, as grounded in the work of Paulo Freire [24], calls for leadership by the people about whom the transformation is focused; however, US expressions of it have been infused by academic capitalism and grounded in power structures with the university at the zenith [25]. Thus, well-meaning researchers with or without CBPAR training are formed in this system with research productivity expectations of peer-reviewed publications and extramurally funded research [26]. Community outcomes and a sense of productivity (action on community goals) are not institutional values. Thus, an instrument focused on structural aspects of community-research entity engagement is appropriately developed within and with communities of PWUD.

This paper introduces the Structural Indicators of CBPAR (SI-CBPAR) and examines its applicability against selected studies as a first step in the instrument development process. The intention is to begin conversations with

research entities and communities engaged in research to continue the development of the SI-CBPAR for ease of application, and to inform community-research entity relationship negotiations throughout the research act.

## 2 | METHODS

Similar to Arora et al., [3] the SI-CBPAR emerged from many converging experiences and inputs: (i) years of community-research entity collaboration among authors; (ii) CBPAR university research instruction and mentoring; (iii) discussion and survey feedback from a state-wide Drug Policy Research and Advocacy Board (DPRAB); (iv) the influence of CBPAR theorists [19, 27, 28]; and (v) thorough review of current literature associated with structural indicators of community engagement in research. The SI-CBPAR development team itself had a range of experience, including combinations of research, lived/ing drug use experience, harm reduction organisation leadership and membership on the DPRAB overseeing several studies conducted by the University of Arizona Harm Reduction Research Lab.

We report here the outcomes of initial instrument development: (i) identification of structural engagement indicators; (ii) construct definition and clarification; and (iii) assessment of feasibility and applicability. A subsequent phase (not reported here) will involve (iv) cognitive interviewing to assess dimension and subcategory meaning using respondent interpretation [29].

Phase 1 involved construct development with the community based on a literature review for extant instruments measuring structural elements of community-research entity relationships and approaches to measurement, and iterative discussion informed by survey feedback from the DPRAB focused on engagement safety and empowerment. This phase occurred over a 3-month period in 2022. Phase 2 was a discursive process with the development team to clarify, sort and prioritise key dimensions and their subcategories. Phase 3 involved an assessment of instrument feasibility and applicability to confirm concept alignment. This step involved the examination of four published studies for SI-CBPAR indicators. These studies, published since 2019, were focused on PWUD health in Arizona, USA: (i) syringe access in community pharmacies [30]; (ii) abuse of PWUD by healthcare providers [31]; (iii) hepatitis C screening and treatment experiences by people on methadone or buprenorphine during COVID [32]; and (iv) patient experiences of federal accommodations during COVID to expand access to methadone and buprenorphine [33]. Study background information was needed for comparison. Therefore, two authors (Beth E. Meyerson and Danielle M. Russell) constructed the

**TABLE 1** Histories of studies selected to assess SI-CBPAP applicability and feasibility, 2022.

| Study focus  | Study history  |
|--|--|
| Syringe access in Arizona pharmacies [30]  | <p>The need for this study emerged from a coalition effort to change Arizona law to decriminalise syringe access (2016–2019). In 2018, it became apparent that there was a need for Arizona-specific data about pharmacy syringe access. No grant funded the study. Instead, the university researcher (BEM) used their own research account funds to hire, train and support people with lived experience (PWLE) to conduct interviews for a recall study among PWLE. One of the interviewers was able to use this experience to move from a service-oriented job to a harm reduction organisation job</p> <p>Interviewer recruitment was facilitated by payment to a statewide syringe service program (SSP). Due to institutional requirements at the time (Indiana University), community interviewers were paid to become certified for human subjects research using the CITI<sup>a</sup> online training system. This meant completing an online, self-paced 3 h training in human subjects protection for socio-behavioural research. Interviewers became equal partners on the research team and co-authored the publication. Following data gathering and initial analyses, the research team met to review and interpret data and prioritise findings for reporting</p> <p>Both interviewers and participants were paid for their efforts. The university researcher was not paid for this project, and funded the open access publishing cost to facilitate community information and translation for policy use</p>   |
| Abuse of people who use drugs by healthcare providers in Maricopa County, Arizona [31] | <p>The need for this study emerged from the executive director of a statewide SSP who received a Robert Wood Johnson Culture of Health Leadership award to conduct a community project. Using these funds, a committee was formed of PWLE and was called the Community Health Advisory Committee (CHAC). This committee was convened to conduct a survey among PWUD and collaborate with the national drug user union</p> <p>The CHAC was asked to develop and conduct a survey of drug user experiences with various community services in the Phoenix area. While the survey instrument was being discussed with the CHAC, the SSP executive director asked a university research partner (BEM) for assistance with survey development. BEM met with the CHAC to sketch out the survey, provided community human subjects research training, hosted the study through the university institutional review board (IRB), and analysed the data with a doctoral student who convened the CHAC as a PWLE (DMR)</p> <p>Field surveyors were paid for recruitment and completed surveys, and participants were paid for time completing a survey. Payment was in cash</p> <p>DMR shared the findings with the CHAC for data interpretation. A report was prepared for the SSP (by BEM) detailing all findings. A manuscript focused on healthcare experience was published because it was determined by DMR and BEM that the focus on healthcare access would help advance the community's agenda to improve healthcare. All surveyors were invited to co-author the paper with BEM and DMR along with the SSP leadership</p> <p>DMR and BEM were not paid for the work on this project. The university researcher funded the open access publishing cost for use by the community and for policy and practice translation</p> |

TABLE 1 (Continued)

| Study focus   | Study history   |
|---|---|
| Patient experiences of federal accommodations during COVID to expand access to methadone and buprenorphine [32] | <p>Harm reduction community leaders from Indiana and Arizona reached out to a research partner (BEM) to devise a study to examine the impact of policy changes on buprenorphine and methadone treatment access during COVID. This was because the US federal government relaxed regulations governing methadone and buprenorphine dispensing and treatment to protect people from COVID exposure during the course of treatment access. Together these leaders, BEM and a doctoral student with lived experience (DMR), planned the study</p> <p>The university researcher developed the funding applications for the agreed-upon grant targets. The funded project included grant resources for the university, partner organisations and a statewide coalition that directed the study: The Drug Policy Research and Advocacy Board (DPRAB) which included people on methadone and buprenorphine, PWLE who were not in treatment, harm reduction organisational partners, providers of methadone and buprenorphine and university researchers</p> <p>The DPRAB advised the study, directed instrument evolution, interpreted the findings and co-authored papers. Interviewers with lived experience were hired, trained, supported and paid for their work. They joined the DPRAB to interpret the data and co-authored papers resulting from their work. Institutional IRB required community-based IRB training which was deemed low barrier</p> <p>DPRAB members, interviewers, participants and university researchers were paid for their work on the project. The grant funded the open access publishing cost</p> |
| Hepatitis C screening and treatment experiences by people on methadone or buprenorphine during COVID [33]       | <p>The Arizona's Hepatitis C Free planning committee, a statewide coalition to eliminate hepatitis C in Arizona, is chaired by a harm reduction leader who is also a PWLE. When they learned of the study among people on methadone and buprenorphine (above), they asked if they could add a few questions to the interview guide to learn about hepatitis C testing and treatment experiences as they planned for practice and policy change in Arizona</p> <p>The DPRAB and the Interviewers considered the request and agreed to add the questions to the interview study</p> <p>Data from the study were not interpreted by the DPRAB or the interviewers, but were discussed at length with members of the Hepatitis C Free planning committee</p> <p>Participants, interviewers, and university researchers were paid for their work on the project by the same grant funding the methadone and buprenorphine project previously described (above). The grant funded the open access publishing cost</p>   |

<sup>a</sup>CITI Program for training in research ethics and compliance. See <https://about.citiprogram.org>

study histories, verifying them with those directly involved. The constructed histories became part of the data for consideration (see Table 1). Three authors (Beth E. Meyerson, Danielle M. Russell, and Arlene Mahoney) independently reviewed all papers and their histories, and coded them using the initial categories and subcategories emerging from phase 1. A coding conference informed the results reported here.

## 3 | RESULTS

### 3.1 | Preliminary concept clarity

Disagreement emerged about the meaning of 'community' and 'coalition'. 'Community' was conflated with CBO by the university research partner in the case of the healthcare abuse study, whereas the other coders considered the CBO

**TABLE 2** SI-CBPAR instrument development process, outcomes and instrument iterations.

| Activity   | Initial outcome   | Iterations of instrument elements   |
|--|---|---|
| Phase 1: Initial identification of structural engagement elements  |   |   |
| Community and researcher ad hoc discussions during 2022 and DPRAB membership engagement survey outcomes  | Array of issues related to community-research engagement initially identified for literature review   | <ul style="list-style-type: none"> <li>• Power dynamics</li> <li>• Trust and safety</li> <li>• Pay equity without burden</li> <li>• Power sharing throughout process</li> <li>• Attribution</li> <li>• Capacity development</li> <li>• Level setting</li> <li>• Communication</li> <li>• Access to research products</li> </ul> |
| Literature review to identify instruments measuring these issues   | Identification of structural issues that were not address by extant instruments or tools  | No new elements added and none removed  |
| Phase 2: Dimension and indicator characterisation  |   |   |
| Development team engaged in a discursive process to clarify, sort and prioritise key dimensions and their subcategories  | <p>Dimensions and subcategories identified. Preference to reflect research development stages (study development through attribution).</p> <p>Revised to reflect emerging conceptualisation of 'research entity'.</p>   | <ul style="list-style-type: none"> <li>• Study initiation and funding</li> <li>• Coalition engagement</li> <li>• Research implementation</li> <li>• Community capacity development</li> <li>• Dissemination and attribution</li> <li>• Power sharing</li> </ul>   |
| Phase 3: Feasibility and applicability assessment  |   |   |
| Assessment of instrument feasibility and applicability to confirm concept alignment using four studies with additional histories confirmed by the co-authors   | <p>Instrument feasibility confirmed.</p> <p>Applicability confirmed but need for further testing of the conception of 'community' and 'coalition' during validation process. Exploration of CBO power vs. community</p> | <ul style="list-style-type: none"> <li>• Study initiation and funding</li> <li>• Coalition engagement</li> <li>• Research implementation</li> <li>• Community capacity development</li> <li>• Dissemination and attribution</li> <li>• Power sharing</li> </ul>   |
| Phase 4: Cognitive interviewing to assess dimension and subcategory meaning with respondent interpretation   |   |   |
| Cognitive interviewing with researchers ( $n = 5$ ) and community members ( $n = 5$ ) focused on drug user health to explore alignment of dimensions and subcategories and intended meaning                          | Documentation of sources of confusion   | Revised dimensions and subcategories for next round   |
| Cognitive interviewing with researchers ( $n = 5$ ) and community members ( $n = 5$ ) working on other issues, such as disability, incarceration, housing and gender justice to assess applicability to other issues | Documentation of sources of confusion   | Revised dimensions and subcategories for next round   |
| Cognitive interviews with researchers ( $n = 10$ ) along the spectrum of community engagement  | Documentation of sources of confusion   | Finalisation of dimensions and subcategories, wider introduction and testing across research entity-community collaboratives  |

to be the research entity with university-provided assistance [31]. The power differential between communities and CBOs that serve them was identified as a crucial element for future examination during next phases of instrument development. Another coder conflated coalition with the community investigator team for the pharmacy syringe

access study [30], yet in that study, there was no coalition to guide that study; though field investigators, who were all people with lived/living drug use experience, were full research team members with input into methods and data interpretation. Additional sorting and clarification of instrument elements followed (see Table 2).

## 3.2 | SI-CBPAP applicability

Independent reviewers found indicator evidence from almost all SI-CBPAP categories across studies, and the instrument was found to allow nuanced review, such as examination of several aspects of study initiation and financing. For example, study initiation and funding were generally shared by research entities and community coalitions across studies, for the exception of the syringe study where funding was provided from the researcher's university account and there was no coalition [30]; and for the healthcare abuse study where the CBO research entity did not consult with the community or coalition about study initiation, and funding for participant incentives was determined and provided by the CBO research entity [31].

Granular indicators of study participant payment were identified. For example, in cases where barriers were present, the issue involved using visa gift cards for participant payment instead of cash. For the MOUD COVID [32] and HCV MOUD/COVID [33] studies, gift cards were used due to university auditing barriers and because payment programs, such as Venmo, Paypal or Zelle required participant bank accounts.

Dissemination and attribution indicators were generally observed across studies, and the SI-CBPAP allowed examination of dissemination responsibility. The research entity took responsibility for dissemination through published studies and translated findings for practice and policy audiences through developed materials and their delivery. In these cases, it was a matter of institutional capacity and connection to audiences desiring information. Presentation delivery was often shared with a member or members of the research team who had lived/living drug use experience as a matter of capacity building and community leadership. With all studies, community members who were field investigators and coalition members were offered the opportunity to serve as co-authors on published manuscripts.

Instrument application allowed specificity of focus on the extent to which projects advanced community goals, however information about this was not present in the manuscripts or the constructed histories. Instead, co-authors recalled this information during coding comparison and discussion. For example, syringe access study findings [30] informed Arizona's legislative process resulting in syringe possession decriminalisation. Healthcare abuse findings [34] are continually used with state regulators and healthcare professional associations to demonstrate why PWUD do not access healthcare in AZ; and both HCV studies [32, 33] informed the state policy process to lift two barriers to curative HCV treatment. These efforts were research-entity driven and not community-initiated, despite community value.

Finally, the SI-CBPAP permitted reviewers to examine power sharing. Veto power over study direction and methods was shared by the community in all cases for the exception of the healthcare abuse study [31]. This was also the case with the syringe access study because, while there was no coalition, community field investigators had equal power to determine the focus, methods and data sensemaking [30]. But as with community goals, this information was not available in the papers or the histories, but emerged in the study team coding discussions.

The outcome from the reported three-phased process (Table 2) involved the preliminary confirmation and clarification of six categories representing important structural aspects of community-research entity collaboratives. They include: (i) study initiation and funding; (ii) coalition engagement; (iii) research implementation; (iv) community capacity development; (v) dissemination and attribution; and (vi) power-sharing. The SI-CBPAP categories, subcategories and measurement indicators are shown in Table 3 and explained below.

## 3.3 | SI-CBPAP categories

### 3.3.1 | Study initiation and funding

While often the realm of university-based research, research funding can be obtained by any type of entity and with it comes the power to determine several project aspects and participation in them. Each subcategory allows exploration of choices normally made at this research stage: grant/funding targets, budget development and grant development participation. This category also connects with the Power Sharing category.

### 3.3.2 | Coalition engagement

Coalition membership, recruitment, financing and leadership are four of many possible structural indicators of coalition engagement. The choice of community partner can also structure what happens during community-research entity engagement. The question of 'who is the community to be engaged and how should they be engaged?' is central to this category. Other, more operational aspects include engagement funding and the distribution of burdens based on choices made. Community-borne costs of research engagement can include coalition meetings occurring during the workday, requiring in-person attendance and location of coalition meetings. The outcomes of choices made can result in unreimbursed costs of missed work, childcare, parking and transportation.

**TABLE 3** Structural Indicators of Community Based Participatory Action Research (SI-CBAR), 2022.

| Category                             | Explanation   | Measurement |
|--------------------------------------|---|-------------|
| Study initiation and funding         |   |             |
| Study initiation                     | Community and research entity share the study goal  | Y N U NA    |
| Determination of grant targets       | Grant funding targets are co-determined with the community  | Y N U NA    |
| Budget development                   | Community partner(s) are engaged in determining their portions of funded project  | Y N U NA    |
| Grant development participation      | Community participates in the grant development if funding is sought  | Y N U NA    |
| Coalition engagement                 |   |             |
| Coalition membership                 | Research conducted with the involvement of a community coalition comprised of people with living experience   | Y N U NA    |
| Coalition recruitment                | Responsibility for recruitment and selection of coalition is shared between community and research entity   | Y N U NA    |
| Engagement funding                   | Community is paid for coalition participation at market rate  | Y N U NA    |
| Coalition leadership                 | Community facilitates or co-facilitates coalition   | Y N U NA    |
| Coalition payment barrier            | Community members of the coalition are paid in a low-barrier manner (e.g., not with gift cards)   | Y N U NA    |
| Research implementation              |   |             |
| Methods determination                | Community and research entity share decision(s) about methods   | Y N U NA    |
| Paid research implementation         | Community is paid for data gathering and interpretation   | Y N U NA    |
| Paid research participation          | Community research participants are paid at market rate for participation in low-barrier manner   | Y N U NA    |
| Participant anonymity                | Research participants have the option for anonymous participation without documentation burden (IRB)  | Y N U NA    |
| Data interpretation                  | Coalition interprets data together (e.g., decides what data mean and what is important)   | Y N U NA    |
| Community capacity development       |   |             |
| Community capacity development goals | Community members of coalition identify capacity development goals as part of the project   | Y N U NA    |
| Research training                    | Community research training process is accessible   | Y N U NA    |
| Community network development        | Coalition process includes opportunity for community members to develop social and professional networks to advance community goals                         | Y N U NA    |
| Dissemination and attribution        |   |             |
| Dissemination decision               | Community shares decisions about dissemination of study findings  | Y N U NA    |
| Dissemination responsibility         | Responsibility for dissemination of study findings is shared by community and research entity   | Y N U NA    |
| Co-publishes                         | Community members co-publish or have option to co-publish peer-reviewed articles  | Y N U NA    |
| Community acknowledgement            | Published documents (peer reviewed or otherwise) acknowledge the community participants or coalition  | Y N U NA    |
| Translation (action with data)       | Study findings are translated for policy or program change as appropriate   | Y N U NA    |
| Power sharing                        |   |             |
| Veto                                 | Community has veto power over key aspects of the research: goals, methods, findings, engagement process   | Y N U NA    |
| Use of institutional access          | Research entity uses institutional privilege and access to advance community goals  | Y N U NA    |
| Data request approval                | Requests for generated and de-identified data following the study are reviewed by selected members of the coalition and not only the principal investigator | Y N U NA    |



TABLE 3 (Continued)

| Category                                | Explanation   | Measurement |
|---|---|-------------|
| Equitable distribution of grant funding | Grant funding is equitably distributed among all implementation partners based on their role in the project | Y N U NA    |
| Community benefit                       | Benefits to the community (individual or social-level) result from participation in the project             | Y N U NA    |

Note: Measures of the degree to which a project or study expressed a particular indicator included four possible outcomes: Yes (evidence was present); No (evidence was not present); Unclear (it was not apparent whether or not evidence was present); or NA (not applicable).

### 3.3.3 | Research implementation

This category addresses community as research implementors (those who study) and as research participants (those who are studied). Burdens for community members who gather data reflect the above-discussed engagement burdens and may involve other issues unique to a specific project. Other research implementation indicators also include collaborative determination of study focus and methods and coalition role in data interpretation. For community members allowing themselves or their experiences to be studied, there are similar burdens of requirements and travel costs, as well as issues of anonymity or safety, and assurances that findings will be shared with them in some manner.

Related to participant safety are structural barriers introduced by the research entity itself. For example, university institutional barriers include the US Internal Revenue Service tax reporting and auditing requirements when reaching participant payment thresholds [35]. The US National Institutes of Health offers certificates of confidentiality protecting participant anonymity for university audit [36], but not Internal Revenue Service reporting. Participant anonymity throughout research processes is crucial for maintaining trust in community-based research among PWUD and other communities criminalised and targeted for incarceration, and should be openly discussed at the study planning stage. Further, some research entities impose participant payment constraints due to institutional fiscal policy or state moral policy. This includes not paying PWUD in ways that facilitate agency over the money they earn, such as requiring payment only in gift cards, specific store-based gift cards or requiring participants to sign statements indicating they will not use the gift cards to purchase specific items, such as drugs, tobacco, firearms or alcohol.

### 3.3.4 | Community capacity development

Community capacity building is a central part of CBPAR [4, 14, 27] because it facilitates full research participation

and ongoing community benefit beyond the research project itself and can assure community research sustainability. When planning, communities need opportunity to identify capacity development goals. Community benefits resulting from participation emerge from capacity-building goal setting (above) or organically from the collaborative research and can be objectively measured. For example, skills developed, or jobs obtained due to research experience are micro-level indicators. Strengthened or developed professional and/or social networks among collaborators are mezzo-level indicators. Efforts to change practice or public policy and their outcomes are macro-level indicators. This category also connects with Power Sharing in its focus on community benefit.

### 3.3.5 | Dissemination and attribution

Authorship inclusion remains an important form of research credit attribution. Closely related is public coalition acknowledgment, which may be important for participants needing anonymity. Dissemination is usually conceived of as sharing the research outcomes with target audiences to effect change. It should also involve ongoing access to work products by the people who did the work as well as the communities engaged or in focus. Peer-reviewed journal publications are often unavailable to participants due to a lack of communication by research entities or (more frequently) because journal publishing paywalls were not removed by those controlling authorship. While open access publishing is punishingly expensive [34], efforts must be made to assure continuous access by those who made results possible.

Findings dissemination for research-to-policy or -program translation can be wide-ranging and involve the development of practice or policy recommendations, information briefs, published articles, white papers, social media posts or online product (video panels, podcasts, etc.). The development of these allows shared skill development across the collaboration. There is also a connection with the category Community Capacity Development.

### 3.3.6 | Power sharing

Power sharing is a stream flowing beneath the collaborative relationship. Power can involve structural assets held only by the research entity (such as institutional review board or contractual infrastructure), built-in decision-making processes and the extent to which the partners share in it. Coalitions could design veto structures over aspects of the research planning and implementation. Power sharing can also include research entity use of institutional privilege to benefit the coalition effort, such as research ethics training for community partners [37] in lieu of typical online, institutionally owned human subjects certification. Grant and budget development are found in another category, but the funding aspect in this category involves sharing power to assure the equitable distribution of resources across the project effort.

### 3.3.7 | SI-CBPAR coding

SI-CBPAR was designed so that each indicator within every category can be qualitatively assessed and quantitated for the degree to which it is evident in a study or project. Measures included four possible outcomes: yes (evidence is present), no (evidence is not present), unclear (it is not apparent) or not applicable. It is recommended that multiple people simultaneously assess a study or project to assure diverse assessment viewpoints. The SI-CBPAR could be used throughout the research relationship as a means of (re)negotiation and troubleshooting. The scale's simplicity facilitates partner participation irrespective of skill level and can be used as a 'red light', 'yellow light', 'green light' system for discussion and negotiation.

## 4 | DISCUSSION

This paper introduced the SI-CBPAR and reported outcomes from the instrument development phase. Applicability and feasibility were confirmed, and the next phase will involve the process of construct and item validation using cognitive interviewing [29] with researchers from across the continuum of community-engaged research, and with communities engaged in research beyond drug user health.

During the applicability assessment, we observed the value of SI-CBPAR's application throughout the research collaboration process, because elements allowed measurement of nuanced indicators, such as payment burden (for participant, collaborators and community investigators), aspects of study initiation and funding distribution,

and concepts of power. The Community Engagement in Research Index instrument measures research methods indicators [16], but does not measure the distribution of benefits and burdens across them. Like the REST tool, which measures dissemination involvement, capacity building and co-benefit [17], SI-CBPAR measures similar aspects with an additional analysis of power.

Engaging a development team of people to examine the SI-CBPAR from various research experiences, including the community being studied, was valuable because it allowed the emergence of discrepant conceptualisations about 'community' and 'coalition' based on reviewer positionality. Examining the possible construals of 'community' or 'coalition' will be important for instrument validation and should be an active conversation with context-specific community-research entity projects. Continuous interrogation of important constructs of 'community' as well as external definition by powerful entities in the course of research is important because we have witnessed misconstruals of community. For example, 'men who have sex with men' is a concept defined not by gay or bisexual men, but by epidemiologists in the public health realm for the purpose of quantification [38]. The difference between community self-conceptualisation and external labelling travels alongside the research-community endeavour and can feel 'baked in' to the history of relations between research entities and communities.

We also observed the conflation of CBOs with people in the community and know this is a historic practice based on institutional efficiency, researcher inexperience with communities themselves, or uninformed opinion that these organisations always 'represent' the community. We submit that it is easy to recognise power differentials between institutional controllers of research and communities, but more difficult to distinguish power differentials among actors and institutions from which communities emerge [39]. Lack of knowledge about power differentials can disrupt cooperation across differences by making claims around who belongs or does not belong in a community or in a coalition. Examining these understandings at the outset will be an important step in the community-research entity relationship, and we hope the SI-CBPAR outcomes can inform discussion about them in the community-research entity collaboration.

Several issues emerge for further reflection with our coalitions and the DPRAB based on the initial phases of SI-CBPAR development. First, any research entity can miss opportunities to share power, even a CBO, as with the healthcare abuse study [34]. Second, even as research resources may be available beyond grants, as in the case of university research account funding [36], there are opportunities to consider resource sharing. Third, data

request approvals may not be possible with research institution policy, or even (in some cases) journal publishing policy. A solution to data sharing may involve establishing a 'first stop' practice, whereby the data use request first comes before the research coalition. With coalition approval, the applicant can move through the research entity's data sharing request procedure. This issue closely relates to the question of data ownership raised by the National Survivors Union [19]. Study authors fully discussed the question of data ownership and could not avoid superior institutional capacity for data protection.

The question of participant payment barrier will be an important topic of conversation with our research partners going forward. As members of two different research entity types (community-based organisation and academic), we will explore the possibilities of creating auditable, yet low-barrier payment methods for participants. However, institutional audit practices and federal tax policy require that payment above a certain amount (currently \$600) requires the gathering of personal information and tax document filing, especially when the university is providing the funding (or is the grantee). Limiting participant payment to lower thresholds functions to limit community earning potential and this has been criticised as systemic maldistribution of research resource [19].

There are skill sets that community coalitions and their members may not have, such as grant development or data analysis. These skills, however, can become a focus for community capacity building to continuously democratise the research act. The issue of community dissemination capacity remains because funding entities often do not permit budget line items for dissemination beyond materials production. Underwriting the development and presentation time for community partners engaged in dissemination would be a huge step forward. Otherwise, communities and coalition members will likely be limited to giving input into what the dissemination products and targets might be, presenting materials that they did not directly develop, or giving unpaid labour to a dissemination effort.

A possible and additional use of the SI-CBPAR is with reporting structural aspects of the community-research entity engagement in peer-reviewed publications for transparency. This is akin to the STROBE checklist for the reporting of epidemiologic studies [40]. We recommend this based on our observation that such details (if author-provided) are often removed during the journal editorial process. Community engagement as a research *orientation* should be emulated and critiqued for improvement as a matter of praxis for studies in any journal.

## 4.1 | Limitations

A study limitation was the inclusion of papers for the assessment which might appear to bias their examination or worse, be self-serving. This is understandable; however, the selection rationale was based on the fact that published studies often exclude important elements describing most of the research entity-community engagement behaviours examined by the SI-CBPAR. This study's authors could construct the history with the help of other co-authors of the examined studies. Yet even as we attempted to develop the study histories, these 'snapshots in time' were dimensionally insufficient. As a team we found ourselves telling additional stories about the research collaborations, such as with veto power processes or with how the project met community goals. These experiences highlight the value of a living application of this instrument to collaboratives throughout the process in real-time.

## 5 | CONCLUSION AND NEXT STEPS

Community-research entity collaborations need to interrogate the structures of research collaborations to centre equity. The simplicity and accessibility of the SI-CBPAR can help coalitions and their research entity partners plan for equity in the process by focusing on structural aspects of the project. The next steps of instrument development will confirm construct and item validation, instrument applicability, and feasibility across researcher orientations and communities beyond those engaged with the health of PWUD.

### AUTHOR CONTRIBUTIONS

Beth E. Meyerson and Danielle M. Russell conceived of this study. Beth E. Meyerson, Danielle M. Russell and Arlene Mahoney refined and finalised the instrument. Beth E. Meyerson, Danielle M. Russell and Arlene Mahoney conducted analyses. Beth E. Meyerson, Danielle M. Russell, Arlene Mahoney, Irene Garnett and Savannah Samorano interpreted the findings, reviewed and edited the manuscript. Beth E. Meyerson led the writing of the manuscript and all revisions. Each author certifies that their contribution to this work meets the standards of the International Committee of Medical Journal Editors.

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### CONFLICT OF INTEREST STATEMENT

All authors have no competing interests to declare. In terms of service relationships, Danielle Russell was most recently on the Board of Directors of Sonoran Prevention Works, a state-wide harm reduction program. Arlene Mahoney is the Executive Director of Southwest Recovery Alliance, a harm reduction program located in Phoenix, Arizona. Beth Meyerson is on the board of directors of Southern Arizona AIDS Foundation and the American STD Association.

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