

# Gateways: International Journal of Community Research and Engagement

Vol. 16, No. 1 June 2023



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Citation: Spencer, R., Hwang, J., Sinclair, R., Alramadhan, F., Montgomery, S. 2023.

'I Want to Be Screened
Just Like the Pirates!': The
Power of Community-Based
Participatory Research
(CBPR) Theatre to Aid
Research Participation.
Gateways: International Journal
of Community Research and
Engagement, 16:1, 1–10.
https://doi.org/10.5130/ijcre.
v16i1.8397

ISSN 1836-3393 | Published by UTS ePRESS | http://ijcre.epress.lib.uts.edu.au

PRACTICE-BASED ARTICLE

# 'I Want to Be Screened Just Like the Pirates!': The Power of Community-Based Participatory Research (CBPR) Theatre to Aid Research Participation

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**DOI:** https://doi.org/10.5130/ijcre.v16i1.8397

**Article History:** Received 05/10/2022; Revised 22/02/2023; Accepted 15/03/2023;

Published 06/2023

### Abstract

Research participation is an important component of advancing whole health and eliminating health disparities, especially in communities facing environmental justice (EJ) issues. Though federally mandated, recruitment of racial and ethnic minorities can be a daunting task and recruitment of children an even greater challenge. A range of typical recruitment strategies (printed materials, word of mouth, broadcast etc.) for those of ethnically and culturally diverse backgrounds have exhibited only limited to modest success, depending on the community being served and the type of engagement. To date, there has been only limited assessment of the use of community-based participatory research (CBPR) theatre as a culturally relevant recruitment strategy.

The ENRRICH Railyard Study used CBPR theatre to engage an underserved EJ community, and to assess the health impact of residential proximity to a major freight railyard. The railyard community is comprised of primarily low-income Hispanic families. To promote participation, a CBPR theatre play – a partnership between a community-based organisation (CBO) and a university institution – was produced, from design to production, at two elementary schools. Following the play, parental consents and surveys

**DECLARATION OF CONFLICTING INTEREST** The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article. **FUNDING** This article was made possible in part from research grant G20-CAGP-34 California Air Resources Board (CARB) Community Air Grant.



were sent home. The response was immediate and one of the largest to date – 74 percent of children participated in the study.

The CBPR theatre, university and CBO partnership provided an opportunity to engage underserved minority children and their parents, thus encouraging participation and facilitating education on respiratory health and the environment. This article includes experiences and lessons learned from using CBPR theatre to encourage study participation, critical for promoting sustainable change in an EJ community.

# **Keywords**

Community Partnerships; Minority Population; Theatre; Research Participation; Youth

# Introduction

Researchers working with disadvantaged populations publish extensively on the difficulty in encouraging community participation, an important component of driving change especially for communities facing environmental justice (EJ) issues (Cyril et al. 2015). Disadvantaged groups residing in EJ communities are often racial and ethnic minorities who experience the added burden of adverse environmental exposures, which coincide with limited access to health care, thus synergistically promoting disease and significantly reducing their life expectancy. EJ communities are often plagued by poor air quality, which is now one of the leading causes of disease and premature death throughout the world (Landrigan et al. 2018). Adding fuel to fire was the onset of the COVID-19 pandemic which made even more glaringly apparent the health disparities facing racial and ethnic minority communities, especially those living in EJ communities. Participation in scientific research studies is an important component of driving advancements in health and reducing health disparities. Furthermore, a solid body of research has found that community engagement can lead to positive outcomes and improved health across a variety of health conditions (O'Mara-Eves et al. 2015).

Despite the federal initiatives led by the National Institutes of Health (NIH), the Federal Drug Administration, and the Centers for Medicare and Medicaid Services to encourage the inclusion of racial and ethnic minorities in health research, they remain under-represented in research studies (George et al. 2014). One might wonder why nothing has significantly changed. Barriers to participation in studies are long-standing, deeply rooted, highly prevalent and diverse, and include factors such as language, time, trust, political perspectives, health status, cultural values and beliefs, and literacy levels. Unfortunately, low enrolment of racial and ethnic minorities in studies specifically aimed at eliminating health disparities and improving minority health severely hinders and reduces the likelihood of success of such studies and development of future interventions to reduce the impact of conditions that disproportionately impact minorities (George et al. 2014).

In working to address the difficulties and challenges of engagement, a wide range of strategies have been developed. These include partnering with community-based organisations (CBOs), hiring bilingual staff, and establishing face-to-face long-term relationships with participants (Khubchandani et al. 2016). Some research has indicated the use of proactive (face-to-face) strategies; reactive recruitment approaches (including collaboration with key leaders, word of mouth, print material and broadcast media); or providing compensation, being flexible, building rapport and trust, and employing ethnically and culturally diverse research staff as effective in recruiting participants. A systematic review of the effectiveness of typical recruitment strategies (printed materials, word of mouth, broadcast media etc.) for those of ethnically and culturally diverse backgrounds showed only limited to modest success (33–60%), depending on the community's make-up and the type of engagement (Ibrahim & Sidani 2014).



As the majority of community-engaged research focuses on adults, recruitment and participation of children and their families in research could be a challenge (Svensson et al. 2012). Inclusion of minors in research comes with a greater level of complexity, both in enrolment and retention, than in adult populations, as parents' and children's beliefs and characteristics would influence the decision process around participation, thus calling for innovative strategies in recruiting both children and their families (Lewis 2009). Understanding the potential adverse impact on children – one of the most vulnerable populations – of living in an EJ community would primarily come from research participation of children and their families from these regions. With the increased threat of infectious disease, impacted by climate change and worsening pollution, children residing in EJ communities may be at even greater risk of poorer health and reduced educational attainment outcomes, and ultimately lifespan. Thus, there is a critical need for innovative and effective research engagement strategies for diverse racial and ethnic communities, especially within EJ communities.

# **Methods**

### LOMA LINDA UNIVERSITY (LLU) APPROACH

Researchers at Loma Linda University (LLU) in Southern California, while working on an environmental justice research study, identified aspects within CBPR that may prove fruitful in increasing community involvement in research studies. Community-based participatory research (CBPR) has emerged as a promising tool for engaging hard-to-reach communities, especially in the fight against health disparities. CBPR is a research approach characterised by a continuous and equal collaborative partnership between researchers and the community affected by the issue that is the focus of this study; that is, seeking to provide solutions to enhance the community's health and wellbeing within its contextual (social, political, cultural and economic) environment (Kamanda et al. 2013). CBPR is founded on a solid environment of meaningful and trust-based relationships between researchers and the community, resulting in high interest and participation from community members in the research process. Furthermore, CBPR is an important tool as a driver for change in environmental justice communities and those facing tremendous environmentally related hazards.

Researchers with the LLU ENRRICH (Environmental Railyard Research Impacting Community Health) study strategically built their foundation on CBPR methods to study the health effects on community members living in close proximity to a major freight railyard. With operations running 24/7, the San Bernardino Railyard (SBR) is one of the major freight railyards in California and a crucial shipping hub for the nation (BNSF; CARB 2008). Air pollution emission sources at the SBR facility include diesel locomotives, on-road and off-road loading equipment, and associated machinery and typical roadway vehicles. Based on a risk assessment conducted by the California Air Resources Board (CARB), the SBR ranks among the top five most polluting railyards in California, and first in terms of community health risk due to the large population living in the immediate vicinity (Castaneda et al. 2008). The SBR community is located in the inland region of Southern California and primarily comprises low-income Hispanic families. Here children are at greater risk of various adverse health outcomes due to recurrent elevated exposure concentrations of pollutants from local sources, including the freight railyards, freeways and communities in the vicinity (Spencer-Hwang et al. 2015; 2016). This routine exposure to poor air quality puts an additional strain on the already pre-existing poverty, inadequate care and other social inequalities experienced by children, jeopardising their future health and development.



### **COMMUNITY PARTNERSHIPS**

In taking a CBPR approach, LLU researchers partnered with a local CBO and their community health workers (*promotoras*), along with two school districts and their school principals, one school near the SBR and a second comparison school eleven kilometres away. Aware of the health effects from living in close proximity to a major pollution source, the school administrators understood the importance of screening for respiratory health among their students and facilitated access to a school-wide participation in the study. As researchers considered various approaches to recruiting children for the study, school administrators became engaged. The school principal near the SBR suggested a school-wide assembly with an interactive skit as the recruitment vehicle. In delivering on the promise made to the school principal, the CBO and the LLU team worked together and developed a theatrical play script about pirates with asthma, titled 'Captain Jack Snuffles and the Coughing Crew', complete with a musical number.

As the idea for the theatre play came after the grant was funded, there weren't any funds to cover the cost. The university and the CBO thus got in touch with contacts they knew to secure donations of items needed to produce the play. The majority of the materials and props were generously donated by local churches, hardware stores, and families and friends. In building the set, which included a gigantic pirate ship and a wide variety of colourful props, the university and the CBO spent many evenings side by side building it. The principal's school assembly idea resulted in a community informed interactive/musical theatre production about pirates with asthma, co-created and performed by university researchers and CBO members (Figure 1). Together we produced an age and humour appropriate 30-minute educational production, which introduced students to health knowledge of asthma symptoms, respiratory screening procedures, air pollution and environmental literacy.



Figure 1. Theatre production 'Captain Jack Snuffles and the Coughing Crew' Included in the CBPR theatre production are members from the partnering community agency and the university, including faculty, staff, students and their families.



# Results

#### IMPACT AND BENEFITS OF THE CBPR THEATRE PRODUCTION

The play was met with unanticipated excitement from the students. Following the production, numerous children lined up with paper and pencil in hand, determined to get an autograph from the performing characters. Afterwards, they were sent home with a parental consent form, which included information about participating in a study of non-invasive biological testing for airway inflammation to measure exhaled fractional nitric oxide with a NIOX device, lung function via Peak Expiratory Flow (PEF), and height and weight. Additionally, data on self-reported clinical symptoms and adverse health outcomes were collected via send-home parental questionnaires on demographic information, residential history, parental smoking and physician diagnosis history. Once the parental consents were collected and approved, the children were screened. We realised an overwhelming response of 74% (n = 1,066 across two schools) of all children who had participated in the respiratory screening (Spencer-Hwang et al. 2015). With a total of 1,066 children screened (531/680 Railyard School and 535/760 Comparison School), the Railyard School alone exhibited a 78% participation rate.

Initially, the study aimed to assess a sample of the student body; however, students were greatly motivated by the pirates' story and a census-type of participation resulted from the CBPR theatrical play. Through the entire production, the children's interest and enthusiasm were evident in their strong engagement, both visually and verbally. The interactive play included opportunities for the children to supply performance suggestions, which resulted in an enormous response. The children's enthusiasm was matched by the parents' interest in participation, with an equally high response on the self-reported symptoms survey. The overall participation rate of 74 percent across both elementary schools was one of the largest participation rates reported, when compared with findings from a systematic review of community-engagement studies (30–60% rates) (Ibrahim & Sidani 2014). CBPR theatre may instil in children the desire to take part in a study, and children's interest may inspire parents and school staff to participate in the screening activities, potentially making CBPR theatre a highly successful tool for recruitment and retention. The overwhelmingly positive response of the children had a wonderful impact on all who took part in the theatrical production.

Another unexpected success of the CBPR theatre was the increased interest in CBPR research methods among the LLU study team, comprised of epidemiologists, pediatricians and environmental scientists with limited previous exposure to and participation in CBPR studies. After witnessing the children's, parents' and school staff successful participation, there was a transformation among the team, which translated into greater interest in CBPR theatre to engage underserved young populations in health research. CBPR theatre became a bridge between health researchers/clinicians, the local CBO and children/school administrators who now had the ability to initiate and create long-term relationships founded on trust and open dialogue during the implementation of the study and in future collaborations. Furthermore, the theatre experience of the LLU team led to additional larger grant funding both for them and for the CBO. There were many major benefits (both anticipated and unanticipated), as well as lessons learned along the way (Table 1).

# Major benefits of incorporating theatre in a CBPR study

• *Increases CBPR study participation.* Theatre may prove to be a powerful tool in engaging underserved and minority populations and encouraging participation in health studies. We recommend more research assessing CBPR theatre in community engagement.



- *Promotes camaraderie*. Theatre may promote camaraderie and empower those involved in producing theatrical productions. Theatre also has a positive impact on those performing in the play. We found that it helped with team-building and encouraging enthusiasm especially useful tools for breaking down barriers and building partnerships between the CBO and university team members.
- Theatre may increase visibility and open doors for additional community services or research projects.
   Through our theatrical performance, the ENRRICH team expanded their scope of work and were awarded a five-year contract with the First 5 Commission to produce theatrical productions with a health message throughout the county. The CBO received additional funding as well. CBPR Theatre has also been used in other research studies, such as CARB.
- Theatre may encourage other researchers, faculty, and even health professionals not previously drawn to CBPR to engage in CBPR studies. Such engagement may increase awareness, education and participation, and encourage other health professionals (e.g. paediatricians) to take part in a CBPR team.
- *Increasing knowledge*. Theatre may not only be a useful tool for engaging, entertaining and educating children, but also adults, as it is able to reach a wide audience. Even though a production may target children, it is useful to include tips for adults who may be watching as well. Teach concepts about air quality and promoting environmental health to children, but also include key concepts/tips for adults viewing the production.

### Table 1. Top ten lessons learned in designing and producing a theatrical production

Limited or no budget for producing a show – no problem. If the original CBPR grant application does not include a line item for funds dedicated to producing a theatrical event within your study, one can still be performed. For the ENRRICH study, which had only a few hundred dollars, donated by the principal investigator, we were able to develop and produce two theatrical productions for each participating elementary school.

Take a team approach to designing the script and include key ingredients: laughter and music. In designing the script, and even the performance, work with a group, including people from both the CBO and the university. Our ENRRICH team included students, faculty and community members, who worked together to develop a list of objectives for the design and development of the script. Even though no-one on the team had professional theatre training, some were able to draw on their experience in raising their own children or taking part in church theatre productions. If possible, include live music and a jingle theme song. Help all the kids to remember key thoughts.

Seek out materials and props from local stores, churches, and even the university. Develop a list of necessary materials and check if a local hardware store could donate items. Contact them well in advance as they will need time to get approval from upper management. Seek out major stores, such as Walmart and Target, to see if they are willing to donate costumes, especially for the day after Halloween. Churches may also be able to provide props from previous musicals or activities. Also check out second-hand stores for slightly used items that could be made into props and even costumes. Students, staff, faculty and members of a CBO partner may also have items that they may be willing to donate.

Request help from family and friends. Family and friends of both the university and the CBO partner are good resources. They may be able to lend a hand and also provide advice on numerous aspects, such as script design, set development, how to transport and set up equipment, and organise music. They may also be able to provide props or assist with building them, or help out by providing live music (e.g. playing a keyboard) during the production. They are also a great source of encouragement.



#### Table 1. continued

No-one with professional theatrical training – no problem! Children are an easy audience to perform for. When lines are forgotten, don't worry, just improvise. Make sure that performers agreeing to take on a leading role can attend all events, as it is difficult to have stand-ins for leading roles. Most likely, volunteers will come with various skill levels. Some will be naturals and some will need support. Patience and practice will help them to gain the needed skills.

Build the theatrical set in such a way that it can be easily transported, set up or stored. Building, storing, transporting and setting up were difficult for our team, given the large size of our major prop, a pirate ship. Additionally, we had no formal moving van and needed to transport all items in our own vehicles (cars, SUVs, trucks, minivans, etc.).

Plan site visits and dress rehearsals for future performances well in advance. Stages in elementary schools are different sizes, so visit sites early to take measurements of the stage to ensure the students and materials will fit. As elementary schools typically don't have a large enough cafeteria or conference hall to house all the students at the same time, in warm regions you may need to stage the performance outside.

Provide refreshments for the theatrical crew and volunteers. Many long hours are spent by CBO and University team members working on building the set and performing rehearsals, so it is a good idea to provide light refreshments to help sustain them.

Be engaging and dynamic when interacting with the kids. Have the children interact with the audience, descending from the stage down to their level during the show. After the show, the children may want an autograph or even high fives with the crew before they head back to class. Take time with them and remain in character as long as possible. We had a play mascot arrive at times during the actual health-screening event, which was a big hit with the children. The mascot also showed up to greet the kids at a party hosted at each school for classrooms with a 100 percent participation rate.

Record the theatrical production and all the preparations, from building the set to dress rehearsals, using cameras and video devices. It is great to have a photojournalistic view of the development and production of the event. If possible, make a video of the characters in a live performance, and include the photos in posters and articles, and on websites and in other formats to share with the audience. Make sure you seek consent from the audience if planning to include them in the pictures, otherwise take photos from the back of the building.

### Discussion

### RATIONALE FOR CBPR THEATRE

The success of CBPR theatre rests partly on a solid framework of strategic, interdisciplinary and crossagency partnerships between researchers and community members. Researchers provide best evidence for the science and analysis of health issues, and the CBO and school districts have excellent connections with the community and greater understanding of the problems in the context of the targeted audience. Altogether, they make an effective team for promoting positive change. Given the budget limitations on research studies and recruitment efforts, collaborative work that builds on existing partnerships and knowledge among researchers is critical to implementation of CBPR theatre. The ENRRICH study drew on a university and a CBO's pre-existing relationship and expertise to develop a fictional narrative script, a pirate theatre set and scenography, as well as technical sound and music assistance for the play's production. Additional support was provided by neighbouring faith-based organisations and hardware stores that



donated or lent play props, costumes, scenography materials and pirate ship-building materials, while graduate student volunteers and CBO members created and performed play jingles.

### FURTHER ACKNOWLEDGEMENT OF THE SUCCESS OF CBPR THEATRE

The success of CBPR theatre in engaging young minority populations came from substantial evidence pointing to fictional narrative stories as a communication method that produces lasting impressions on beliefs and behaviours (Green & Clark 2013; Murphy et al. 2015). The narrative transportation theory suggest that individuals highly immersed in narrative stories are more likely to be persuaded, change aptitude towards a behavior, and imitate the behavior portrait in the story (Green & Clark, 2013). When narrative stories are delivered through theatre, young populations have been found particularly influenced or highly immersed, with greater levels of cognitive and affective engagement. These attitudinal and behavioural effects in children suggest that CBPR theatre may instill motivation in study participation. During the fictional narrative story, pirates portrayed asthma-like symptoms and limited knowledge about the condition, and were asked to execute an 'asthma screening test' similar to the NIOX and Peak Expiratory Flow non-invasive screening tests in the study. Following the play, children expressed their desire to be screened 'like the pirates in the play'. The result was a young diverse audience highly motivated to participate in respiratory screening.

### PRINCIPLES FOR SUCCESSFUL CBPR THEATRE IN HEALTH RESEARCH RECRUITMENT

The fundamental principles of CBPR theatre for collaboration, research engagement and recruitment are:

- Create and maintain cross-agency collaborations and partnerships, founded on CBPR principles, between researchers and community members for contributions to knowledge and expertise in the development and implementation of CBPR theatre.
- Build on existing partnerships within the research team and CBO (e.g. local organisations that service
  target populations and can provide in-kind donations), or recruit volunteers to maximise resources for
  development of the CBPR theatre.
- Include beliefs and practices of the targeted audience on the health issue being investigated in the theatrical narrative. The CBPR theatre should portray the targeted health issue in the context of the community's understanding of events that could happen in their real world to focus their attention on the research study.
- Include interactive elements of theatrical productions. Interventions aimed at influencing beliefs have shown to be more effective when role-play, musical and audience responses/exchanges are included in the production, especially those targeting children.
- Ensure participation in the theatrical production by all agencies involved in the research, including the lead university researchers and a willing spirit to be a character and to potentially act and dress silly in front of the children.

### Conclusion

At the time we created the theatrical assembly, we did not realise what a critical component it was to become in encouraging children to participate in the research study. Indeed, we now strongly believe that we tapped into an unexpected way to effectively reach a hard to engage audience using a multiple intelligence approach that was not only fun, but also resulted in our unusually high participation rate. Furthermore, what transpired from this experience was awareness of the power of CBPR theatre, a community informed and co-produced educational theatre method to encourage research study participation in efforts to promote sustainable community change. CBPR theatre promotes principles of CBPR by encouraging participation in the theatre,



cooperative co-learning and capacity building. Research has shown that real power sharing with community has found to be effective in disadvantaged community engagement, and CBPR theatre may be an effective tool to promote equal distribution of power (<u>Cyril et al. 2015</u>).

The ENRRICH study produced evidence that CBPR theatre – in collaboration with CBO and other key community stakeholders (such as school districts) – provides a feasible innovative approach to engage children and their families from underserved and racial minority backgrounds in health research. Public health practitioners, health researchers and clinicians might find CBPR theatre a useful cost-effective, partnership-driven tool for recruitment in health research programs. Future research should investigate CBPR theatre's effectiveness in other underserved young minority racial populations, and tailor it to reach additional communities, e.g. adults from diverse backgrounds, especially those with limited literacy. Additional exploration of CBPR theatre as a recruitment tool for other forms of health research, e.g. clinical trials and screening procedures, within different racial and ethnic communities could also be useful. The continuing search for innovative CBPR approaches to engaging children and their families in research, especially racial and ethnic minorities and those living in EJ communities, is an important priority for investigators, which could lead to positive and sustainable change and to building more health equitable communities.

Please note that our database is available for sharing data.

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