

Paradigm shift: Empowering caregivers, self-advocates, and community members to participate in the research process

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Learning objectives

- Understand community engaged research and why it is important for science.
- Identify applications of community engaged research.
- Identify next steps to become involved as a community scientist.

Learning together

Tenemos un momento para participar...es algo nuevo para mí, pero creo que es una buena idea porque ya habíamos comentado antes que este tipo de curso nos ayuda a los que no, no es nuestra lengua nativa a aprender junto con los niños. [2022.01.18]

We have a moment to participate...it is something new for me, but I think it is a good idea because we had already commented before that this type of course helps those of us for which English is not our native language, to learn together with our children.

Ensuring linguistic proficiency in children

A mí me gustaron los libros en español, porque en sí, hasta ahorita los uso con la otra nena, que ahorita tiene tres años, le gusta mucho que le leamos los libros. [2021.12.12]

I liked the books in Spanish, because even today I use them with my other daughter, who is now three years old, she likes it that we read these books to her. [2021.12.12]

What is Community Based Participatory Research?

- Paradigm shift in conducting research
 - Brings out from the periphery community members or community organizations
 - Involvement shifts from participant as “subject” to assisting in developing questions for the study, guidance throughout study process, and even collecting and analyzing the data (Israel, 2012).
 - Differing levels of involvement can be had depending on design and structure of study
 - By engaging families/community we are engaging the most important contributor in finding solutions to the varying challenges we face today (Israel, 2012).
- Aim is to have equal partners in research

...continued

- Research partners include
 - Researchers
 - Self advocates and family members
 - Community members and leaders
 - Clinicians
- Partners make contributions and all benefit
- One benefit for partners is the sharing of results and using the data to help the community more broadly

Why is it important?

- Self advocates, caregivers, families, community members, community organizations may either be directly involved in research or assist in sharing and advocating for policy change (Israel, 2012).
- Elevate the voices of historically under-represented communities in science due to:
 - Language barriers
 - Cultural barriers
 - Power dynamics
- Break down barriers of power in research to engage and empower communities that in the past have been othered or marginalized (Shaikh, et. al, 2023)
- Quality and meaningful scientific data engages and sheds light on community-based solutions

...Continued

- Perspective moves from top down to horizontal/equal to respect the knowledge of those involved in research
 - Leaving behind a feeling of extracting information from community to learning together as a team (Shaikh, et. al, 2023).
- Mutual understanding

What is your story? Getting to know each other.

- From your perspective what health condition should be a high priority for researchers?
- How has this health condition impacted you, your family, and/or your community?

Examples from the field

- Assuring Patient Centered Literacy for Underserved Children (APLUS) Randomized Control Trial
- NJ Healthcare Essential Worker Outreach and Education Study – Testing Overlooked Occupations (NJHEROES TOO)
- Ready and Healthy for Kindergarten Study
- Early Relational Health Study

APLUS: 2016-2019

- Partnership with long-serving community leader helped shape questions for qualitative study on early literacy among Spanish speaking Latina parents, the overall research question, and an intervention to help families engage in shared reading
- Led a daycare center in urban city for decades. Lived and worked in city
- Added perspective and uncovered potential blind spots in our process

Table with examples

Table 1. Influence of Ethnographic Interviews With a Community Leader on in-Depth Interviews With Parents.

Research Activity	Pre-Ethnographic Interviews	Postethnographic Interviews
Research Question	“What are the barriers to shared reading?”	“How is shared reading nested in daily parenting?”
Interview guide development	Focus on shared reading after literature review	Inclusion of questions regarding how parents connect with their children and their views on different parenting styles
Sampling for in-depth interviews	Spanish-speaking mothers of children aged 3 years and below	Further refined to seek parents who engage in “invitational parenting behaviors”
Analysis	Review of analytic categories from literature review and cultural categories from research team’s self-reflections	Review of cultural categories also includes those identified during ethnographic interviews

Jimenez ME, Hudson SV, Lima D, Crabtree BF. Engaging a Community Leader to Enhance Preparation for In-Depth Interviews With Community Members. Qual Health Res. 2019 Jan;29(2):270-278. doi: 10.1177/1049732318792848. Epub 2018 Aug 12. PMID: 30101661.

NJ Healthcare Essential Worker Outreach and Education Study – Testing Overlooked Occupations (NJHEROES TOO): 2020-2021

- Study engaged community-based organizations and healthcare organizations across 4 counties in central and northern New Jersey
 - 1st: qualitative interviews with members of the community helped shape the understanding of barriers/challenges community faced with regards to COVID-19 testing
 - 2nd : community leaders from more than 20 community-based organizations and healthcare partners led the efforts to promote study and engage community to broaden access to saliva based COVID-19 testing
- Partnered decision-making; monthly team meetings with all partners involved
- Research team held continuous check-ins with community leaders and assisted them throughout study process

Ready and Healthy for Kindergarten: 2019-present

- Partners in study
 - Parents
 - Teachers
 - Pediatricians

Ready and Healthy for Kindergarten: 2019-present

- Parents
 - Parent Advisory Committee comprised of alumni parents that participated in program
 - Provided guidance and insight to the refinement of the program
 - Session materials to be used were piloted with them
 - Surveys
 - Logistics of program (time/dates)
 - Duration of program
 - Assisted in spreading awareness of study during subsequent enrollment periods

Ready and Healthy for Kindergarten: 2019-present

- Teachers
 - Continuous communication with research team
 - Expertise in bilingual education
 - Addressed ways to strengthen program
 - Materials
 - Methods to engage children
 - Recruitment of families during enrollment period
- Pediatricians
 - Shaped health messages in program
 - Referred families to participate in study

Early Relational Health: 2021-2022

- Parent Advisory Committee
 - Comprised of family members from various racial/ethnic backgrounds
 - Guided research questions
 - Reviewed findings from the study's focus groups
 - Facilitated the distribution of findings
- Community partner co-investigator

Learning from these experiences

- Making research process easier for community partners to understand and engage in
 - IRB
- Communication is key
- Patience; as it can be more time intensive; however, it is more rewarding experience and results are much more robust

Wrapping up

- Examples presented are some of the ways that CBPR can happen
- Differing levels of engagement
- Navigating shared decision making and understanding goals of CBPR
 - What level of engagement with partners is to be had?
 - No “tokenism”
- Mutual respect and mutual learning involved from all parties
 - Traditional researchers may not understand the layers of CBRP
 - Learning and understanding from partners about research process/methods

Interested in learning more?

- NJ ACTS Community Scientist Program
 - njactscommunity@rwjms.rutgers.edu



COMMUNITY SCIENTIST PROGRAM

Are you a community member interested in getting involved and learning how human subject research can be conducted effectively and safely in your communities?

It's as easy as these simple steps:



Questions?

Works Cited

- Israel BA. Methods for Community-Based Participatory Research for Health. 2nd ed. Jossey-Bass; 2012.
- Jimenez ME, Hudson SV, Lima D, Crabtree BF. Engaging a Community Leader to Enhance Preparation for In-Depth Interviews With Community Members. Qual Health Res. 2019 Jan;29(2):270-278. doi: 10.1177/1049732318792848. Epub 2018 Aug 12. PMID: 30101661.
- Shaikh, Y., Jeelani, M., Gibbons, M. C., Livingston, D., Williams, D. R., Wijesinghe, S., Patterson, J., Russell, S.. Centering and collaborating with community knowledge systems: piloting a novel participatory modeling approach. Int J Equity Health. 2023. 22(1): 45. DOI:10.1186/s12939-023-01839-0.PMID:36915080
- "Family Youth Researcher Education (FYREworks) by Bevans et al. is licensed under CC BY 2.0."