



# **Community-Based Participatory Research for Public Health:**

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Challenges, Opportunities, Approaches

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# Agenda

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- Brief Overview of Community-Based Participatory Research
- Challenges: engaging participants in entire research process
- Opportunities: Engaging participants as protagonists
- Approaches: Arts-Based Approaches
- Questions?

# CBPR



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## An Approach more than a Method

- **Community-based = from start to finish**
  - Research design, objectives/aims, data collection, data analysis, dissemination of findings
- **Participatory = participants are protagonists**
  - Deeply collaborative process
- **Action (CBPAR) = often action-oriented, seeks change**
  - Not value-free science
- **Methods may be qualitative or quantitative**
  - Or – arts-based!

# Wallerstein and Duran 2010

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“Community-based participatory research (CBPR) has emerged in the last decades as a transformative research paradigm that bridges the gap between science and practice through community engagement and social action to increase health equity.”



# Building Trust



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Community members retain control over various aspects of the research process

- Especially important in populations with histories of abuses and/or mistrust
- Not an “extractive” process – ongoing involvement through analysis and dissemination
- Democratizes the production of knowledge – engages community members in that process

# Populations of interest





# Hard-to-Reach

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- Inhabitants of Informal Settlements in Asuncion, Paraguay
- DACA Youth in Atlanta
- First Generation Latinx Students at Emory
- Unsheltered people in encampments in Providence



# Challenges

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- Relationships: entire process relies on the relationship between researchers and participants
- Capacity-building: engaging participants in data collection and analysis can be cumbersome (worth it!)
- Timeline: often requires 2x time to complete
  - Academe – slows down publication cycle (with implications for tenure and promotion)



# Community members as protagonists

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Community members are at the center of the process

- Disrupt power differentials/hierarchies
- Reduce distance between academic and lay perspectives
- Privilege unheard or unamplified voices
- Enhance participant control over research outcomes
- Develop skills among community members

# Meet Folks Where They Are

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- Requires flexibility and adaptability
- Attention to specific contexts
  - Hot food
  - Meeting place – dropping by
  - Informal conversation – not all business





# Opportunities

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Transforming Narratives

Creating Innovative Solutions

# New Narratives

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- Create space for new narratives – starting from where *they* are rather than from where we are, or science is
- Generative activities - capable of capturing and privileging new stories and themes
- Especially Arts-based methods

“Freedom University, wow, it was life changing. When I first got involved, I didn't know anyone, but I made a family there because I guess a lot of undocumented students don't open up in their school. I didn't. I never felt safe enough to disclose my status to my counselor or a teacher or anyone. So, after I graduated, at Freedom University you meet everyone and no one cares, or no one calls you an "illegal" or an "alien." They see us as a human being.”

# Creating Innovative Solutions



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## Activism among DACA Youth

- Empowerment across multiple areas
- Addressing GA ban on top state universities

I: Sounds like Freedom University has really opened your eyes but also opened doors to opportunities..

R: Yeah, it is really empowering especially in school since you are so used to hiding in the shadows and not wanting to let people know who you really are. It is really empowering and it is great seeing so many undocumented students and seeing like the power in their voice and the look in their eyes when they are chanting and like fighting for their rights.





# Approaches

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Focusing on the Arts



# Arts-Based Approaches

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“The arts can uniquely educate, inspire, illuminate, resist, heal, and persuade. [...] They can [also] connect us with those who are similar and dissimilar, open up new ways of seeing and experiencing, and illuminate that which otherwise remains in darkness.”

–Patricia Leavy. 2020. *Method Meets Art: Arts-Based Research Practice* (p ix)

# Arts-Based Approaches

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- Digital Stories
- Body Mapping
- Photovoice
- Participatory Theater
- Story Circles
- Participatory Murals/Collage
- Spoken Word/Poetry Slam
- Many more!

# Digital Stories

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- Combination of autobiographical storytelling with photography/images (and background music)
- Takes advantages of the “new” media which has dramatically shifted who is in control of information and media
- Interactive process of development, usually in small group environments with common themes

<https://journals.sagepub.com/doi/10.1177/16094069221111118?icid=int.sj-full-text.citing-articles.4>  
systematic review

# The Story Center

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Remaking El Rancho - by Dulce Alonso



<https://www.youtube.com/watch?v=5lrKOS5jJao&t=35s>



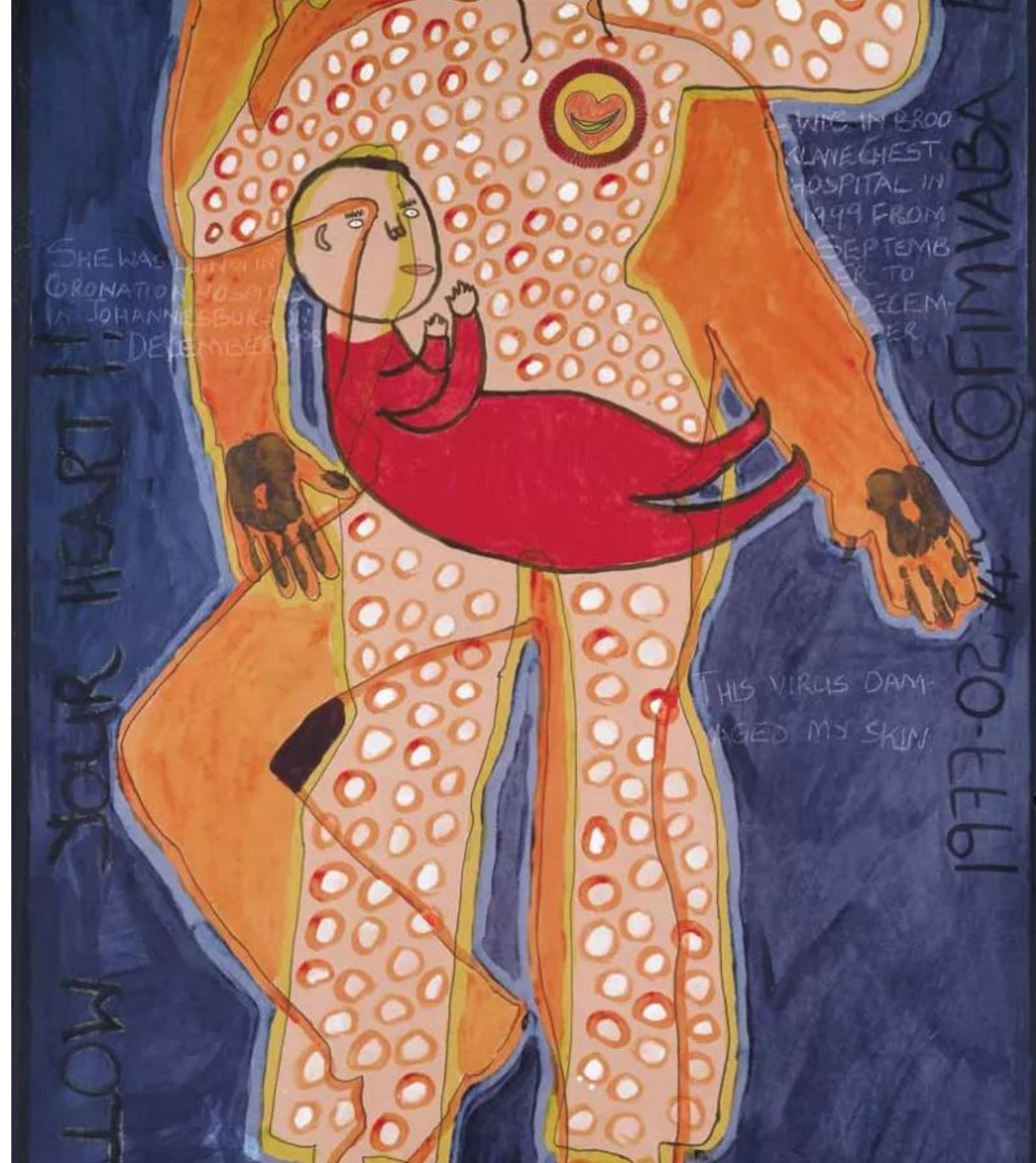
# Body Mapping

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People Living with HIV in South Africa, Jane Solomon, *Long Life — Positive HIV Stories*

“She died on April 1999. It was only at Coronation Hospital in Johannesburg where they tested her and she was found positive. And me too.”

<https://www.msfaccess.org/body-maps-art-and-memory>







# Photovoice

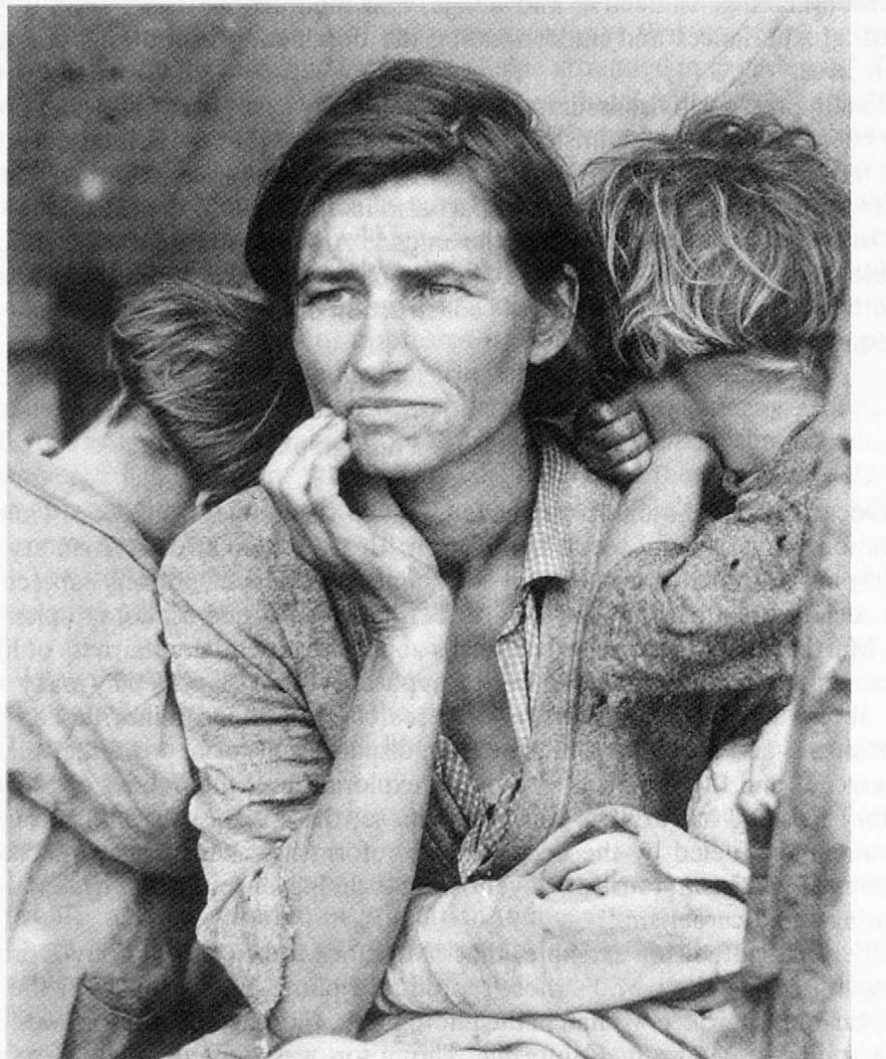
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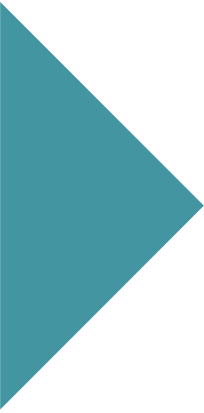
Combines photography and group discussion

Taking photos around a theme or experience

Action-oriented: develop an exhibition that engages a broader audience

Wang and Burris 1994







# Thank you

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