

# COMMUNITY-BASED PARTICIPATORY RESEARCH (CBPR)

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# OBJECTIVES

- Overview of the Community-Based Participatory Research (CBPR) Approach
- Ethical principles of using the CBPR approach
- Benefits and Barriers to CBPR
- The Good, the Bad, and the Ugly (my own real life experiences)
- Challenges and strategies for implementing CBPR and partnerships



# WHAT IS COMMUNITY ENGAGEMENT?

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The 1997 Edition of the Principles of Community Engagement defines CE as:

...the process of **working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people.** It is a powerful vehicle for bringing about environmental and behavioral changes that will improve the health of the community and its members. It often involves **partnerships and coalitions that help mobilize resources and influence systems, change relationships among partners, and serve as catalysts for changing policies, programs, and practices** (CDC, 1997, p. 9).

# THE SPECTRUM OF ENGAGEMENT

Increasing Level of Community Involvement, Impact, Trust, and Communication Flow 

<i>Outreach</i>	<i>Consult</i>	<i>Involve</i>	<i>Collaborate</i>	<i>Shared Leadership</i>
<p><i>Some Community Involvement</i></p> <p><i>Communication flows from one to the other, to inform</i></p> <p>Provides community with information</p> <p>Entities coexist</p> <p>Outcomes: Optimally, establishes communication channels and channels for outreach</p>	<p><i>More Community Involvement</i></p> <p><i>Communication flows to the community and then back, answer seeking</i></p> <p>Gets information or feed- back from the community</p> <p>Entities share information</p> <p>Outcomes: Develops connections</p>	<p><i>Better Community Involvement</i></p> <p><i>Communication flows both ways, participatory form of communication</i></p> <p>Involves more participation with community on issues</p> <p>Entities cooperate with each other</p> <p>Outcomes: Visibility of partnership established with increased cooperation</p>	<p><i>Community Involvement</i></p> <p><i>Communication flow is bidirectional</i></p> <p>Forms partnerships with community on each aspect of project from development to solution.</p> <p>Entities form bidirectional communication channels</p> <p>Outcomes: Partnership building, trust building</p>	<p><i>Strong Bidirectional Relationship</i></p> <p>Final decision-making is at community level.</p> <p>Entities have formed strong partnership structures</p> <p>Outcomes: Broader health outcomes affecting broader community. Strong bidirectional trust built</p>

Reference: Modified by the authors from the International Association for Public Participation

# PRINCIPLES OF COMMUNITY ENGAGEMENT

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1. Be clear about the purposes or goals of the engagement effort and the populations and/or communities you want to engage.
2. Become knowledgeable about the community's culture, economic conditions, social networks, political and power structures, norms and values, demographic trends, history, and experience with efforts by outside groups to engage it in various programs. Learn about the community's perceptions of those initiating engagement activities.
3. Go to the community, establish relationships, build trust, work with the formal and informal leadership, and seek commitment from community organizations and leaders to create processes for mobilizing the community.
4. Remember and accept that collective self-determination is the responsibility and right of all people in a community. No external entity should assume it can bestow on a community the power to act in its own self-interest.
5. Partnering with the community is necessary to create change and improve health.

# PRINCIPLES OF COMMUNITY ENGAGEMENT

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6. All aspects of community engagement must recognize and respect the diversity of the community. Awareness of the various cultures of a community and other factors affecting diversity must be paramount in planning, designing, and implementing approaches to engaging a community.
7. Community engagement can only be sustained by identifying and mobilizing community assets and strengths and by developing the community's capacity and resources to make decisions and take action.
8. Organizations that wish to engage a community as well as individuals seeking to effect change must be prepared to release control of actions or interventions to the community and be flexible enough to meet its changing needs.
9. Community collaboration requires long-term commitment by the engaging organization and its partners.

# COMMUNITY-ENGAGED RESEARCH VS CBPR

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- Who chose the problem to be studied?
- Is there an intervention or service component?
- Who designed the intervention?
- Who made the research policy decisions? (e.g., is there a control group?)
- Who writes papers/makes presentations? Who owns the data?
- Where and how are the results disseminated?

" Collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities."

W.K. Kellogg Community Scholar's Program (2001)

# Definition of CBPR



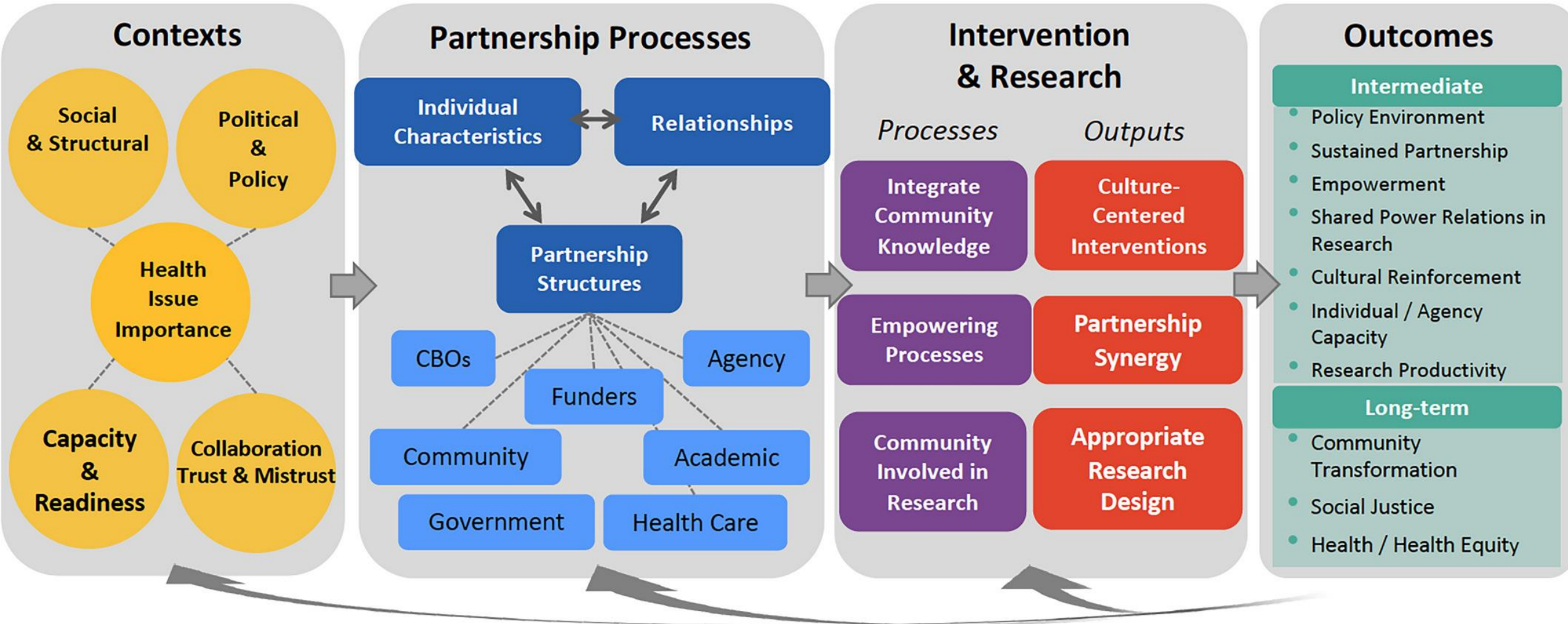
# BENEFITS AND BARRIERS

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- + Enhances relevance of research to communities, reliability and validity of measurement instruments
- + Improves response, recruitment, and retention rates
- Engaged "communities" often have disparate or conflicting goals and agendas
- Distrust, fear, misunderstandings (fallout from "helicopter" research)
- Collaborations vulnerable to loss of funding
- Community and research objectives often misaligned
- Little infrastructure for communication among science, outreach/education, and advocacy

# CBPR Conceptual Model

Adapted from Wallerstein et al, 2008 & Wallerstein et al, 2018



# CBPR PRINCIPLES

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- Facilitates partnership in all research phases
- Recognizes community as self-determining unit
- Builds on strengths and resources
- Promotes co-learning and capacity building
- Focuses on problems of relevance/importance to the local community using an ecological approach
- Seeks balance between research and action
- Disseminates findings and knowledge to all
- Involves long-term process and commitment

Israel, Schulz, Parker, Becker, Allen, Guzman, "Critical Issues in developing and following CBPR principles," Community-Based Participatory Research in Health, Minkler and Wallerstein, Jossey Bass, 2000.

# FACILITATES PARTNERSHIP IN ALL RESEARCH PHASES

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- Partnerships in the true sense of the word/work:
  - Mutual respect
  - Recognition of the knowledge, expertise, and resource capacities of all participants
  - Transparency and open communication
- Community is full partner in:
  - Identifying the problem to be investigated
  - Defining the research question(s) and designing the study
  - Conducting the study
  - Analyzing and interpreting data and disseminating results

# RECOGNIZES COMMUNITY AS SELF-DETERMINING UNIT

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- Communities of identity may be:
  - Defined geographic area (e.g., neighborhood)
  - Geographically dispersed group with a common sense of identity (e.g., ethnic group, age group, sexual orientation)
- Not all geographically defined areas are communities. A real community typically involves:
  - Sense of emotional connection and identification with others
  - Shared norms and values
  - Common language and customs
  - Similar goals and interests
  - Desire to meet shared needs

# BUILDS ON STRENGTHS AND RESOURCES

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- Central to CBPR: all participants bring singular and sometimes critical expertise to the table:
  - Skills and assets of individuals and families
  - Networks of social relationships
  - Mediating structures such as faith-based organizations and community-based organizations that enable community members to work together toward common goals

# PROMOTES CO-LEARNING AND CAPACITY BUILDING

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- Reciprocal transfer of knowledge, skills, and capacity
  - Researchers may learn from community members' local knowledge about their community's history, culture and broader social context, as well as from their administrative and management skills
  - Community members may learn further skills in areas such as how to conduct research and grant proposal preparation

# FOCUSES ON PROBLEMS OF IMPORTANCE TO THE COMMUNITY USING AN ECOLOGICAL APPROACH

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- Research must be not only relevant but important to the community!
- Ecological approach involves:
  - Individuals
  - Immediate context in which they live (e.g., family, social network)
  - Broader context in which they are embedded (e.g., community, society)
- The ecological approach considers
  - Multiple determinants of disease and well-being:
    - Biomedical, social, economic, cultural and physical environmental factors



# SEEKS BALANCE BETWEEN RESEARCH AND ACTION

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- CBPR seeks to contribute to knowledge about health and well-being but balance applying the knowledge generated with community and social change efforts
- Research efforts must not always involve an intervention component BUT there is always commitment to translation of research findings to intervention and policy change strategies that will address the concerns of the community

# DISSEMINATES FINDINGS AND KNOWLEDGE TO ALL

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- CBPR studies produce, interpret and disseminate findings to community members:
  - In clear language respectful of and culturally appropriate for the community
  - In ways which will be useful for developing action plans that will benefit the community
  - On an ongoing basis, using multiple strategies, such that results can be used to guide the development of interventions and policy change
- Dissemination of findings extends beyond the partnership itself and involves all partners as reviewers and co-authors of publications, and co-presenters at conferences and workshops.

# INVOLVES LONG-TERM PROCESS AND COMMITMENT

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- CBPR is the antithesis of helicopter research!!!
  - Emphasizes establishing relationships and commitments that exceed the scope of a single research project or funding period
  - Approach that seeks to strengthen on-going collaboration among community-based organizations, public health agencies, health care organizations, and educational institutions
  - Emphasizes relationships rather than transactions
  - Based upon trust, understanding, and clear, ongoing communications

# EXAMPLES FROM MY OWN RESEARCH

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The good, the bad, and the ugly. . .

THE GOOD...

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GC-SURF & Project COAL

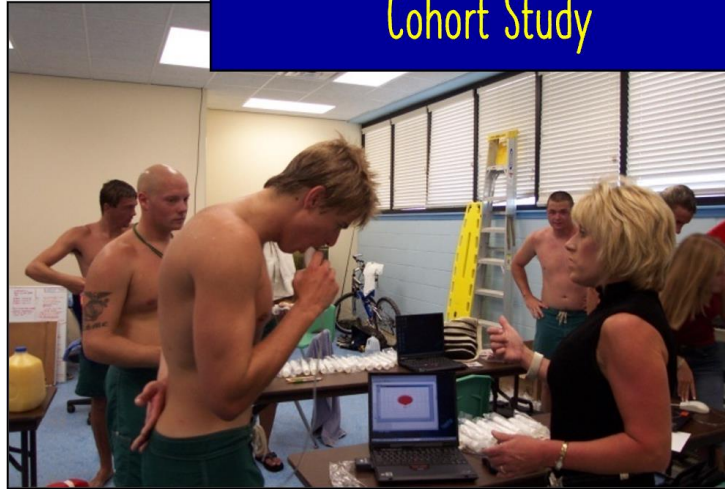
# GULF COAST STUDY OF URBAN AIR POLLUTION AND RESPIRATORY FUNCTION (GC-SURF)

Heavy pollution ( $O_3$ )

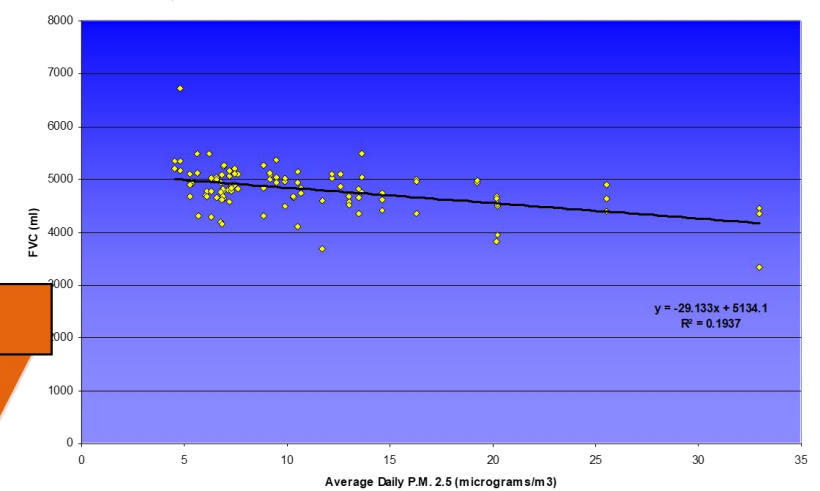
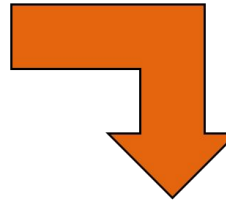


IT'S ALL IN THE TRANSLATION...

Cohort Study



Decrease in FVC associated with particulates



Community Outreach/Intervention

Biomarkers of Inflammation

Genetic Susceptibility

**Average PM<sub>2.5</sub> vs. FVC**

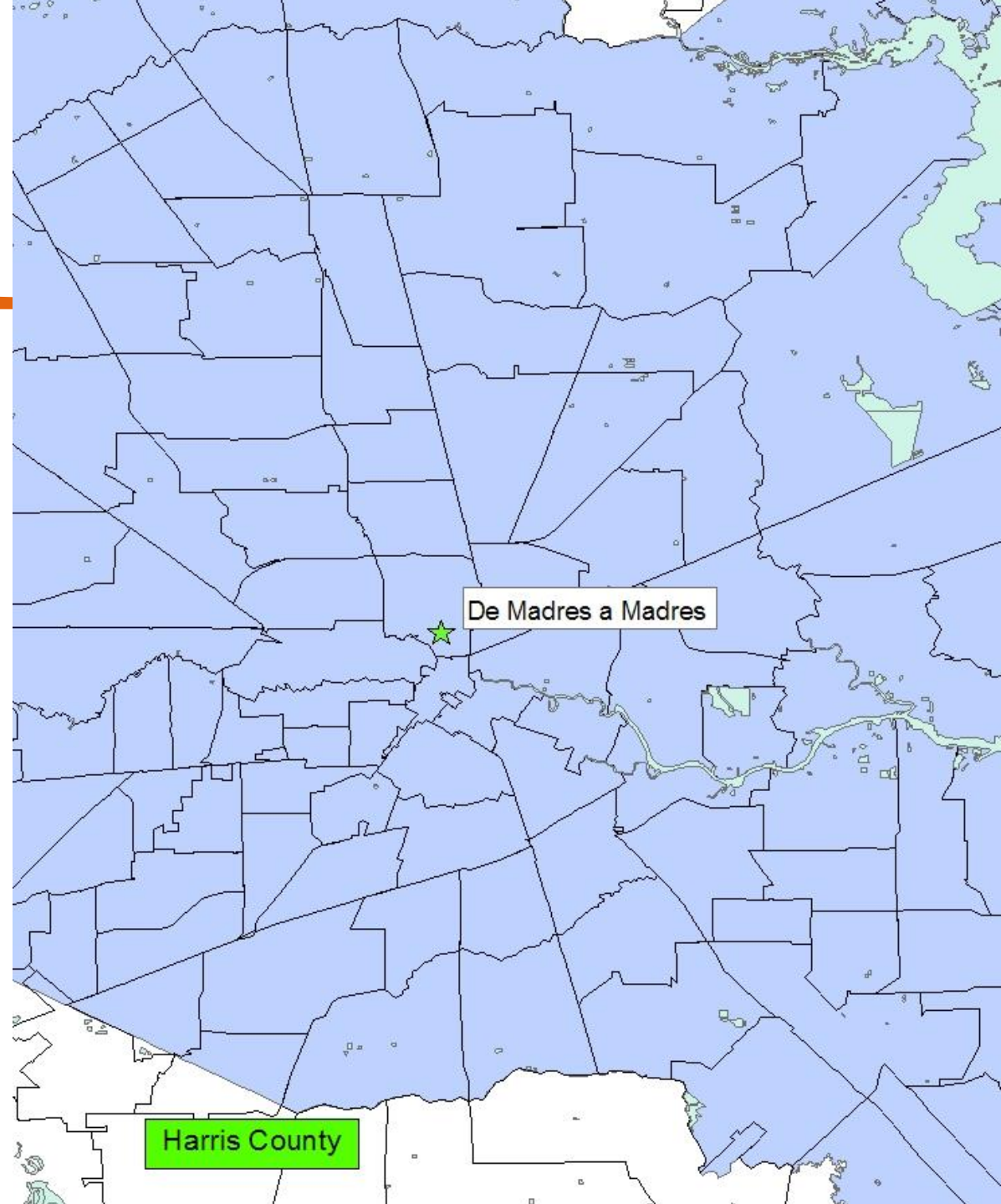
# PROJECT COAL

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- NIEHS Environmental Justice/ Partnerships for Communication Program:
  - Primary objective: to establish methods for linking members of a community directly affected by adverse environmental conditions with researchers and health care providers
  - Project Partners:
    - *de Madres a Madres* (north Houston social services provider)
    - The University of Texas Medical Branch

# TARGET AREA

- Near north side Houston neighborhood
- Predominately Latino (83%)
- Relatively low SES
- Median Family Income by Ethnicity
  - White: \$43,333
  - Black: \$28,235
  - Latino: \$26,026
  - Other: \$27,188





# BARRIERS TO COMMUNITY ACCESS

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- Cultural
- Ivory Tower Syndrome
  - Distrust of academic researchers
    - Previous exploitation of community
    - Little incentive to participate
- Agreement - NOT! - upon community needs

# BUILDING A PARTNERSHIP

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- Community networking
- Coalition building
  - Identifying existing community organizations
  - Integrating CEC members into existing groups
  - Community forums to gather qualitative data

# PROJECT COAL FOCUS AREAS

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- Health Priorities:

- Asthma
- Respiratory disease
- Lead-related cognitive and behavioral deficits

- Physical/Chemical Exposures:

- Asthma triggers
- Lead from paint, food, folk medicines, pottery, diet

- Social Factors:

- Poverty
- Immigrant status
- English as a second language
- Access to health care
- Level of education
- Quality of housing
- Built environment factors
- Diet

# CRITICAL ROLE OF COMMUNITY PARTNER

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- Language - predominantly Spanish
- Knowledge of community - 15 years
- Trust in community - providing multiple services
- Collaborations - *Casa de Amigos* and City programs
- Knowledge of culture
- Awareness of related issues - impact of urban redevelopment and mass transit

# PROJECT COAL ACCOMPLISHMENTS

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- Developed meaningful collaborative partnerships among institutions
- Trained and equipped *de Madres a Madres* to conduct home assessments to identify lead exposure pathways and asthma-inducing agents and triggers
- Educated parents about environmental health hazards
- Collected population-based data on prevalence and location of asthma and lead exposure cases
- Established interactive communications with residents:
  - Forum Theater
  - Traditional methods of information exchange

THE BAD AND  
THE UGLY...

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Houston Exposure to Air Toxics Study  
(HEATS)

# STUDY APPROACH

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## Ideal Study

- Monitor each residence and adult in the Ship Channel and Aldine areas
- Statistically compare the measurements for the two populations

## HEATS

- Monitor a subset of each population statistically selected to be representative of the whole population
- Recruit a probability-based representative sample of 100 nonsmoking adults 21 and older in each area (monitor one child in half the households)
- Extrapolate the results to the whole population in each area (estimates)
- Statistically compare the estimates for the two populations

# HEATS STUDY COMPONENTS

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- Collect the following data on **two separate occasions of four household visits** each:
  - Neighborhood and residence characteristics (including indoor emissions sources)
  - Participant characteristics (socio-demographic)
  - Parallel 24-hour average concentrations of indoor, outdoor, personal and fixed site air toxics
  - Residential air exchange rates
  - Participants' indoor-outdoor activities while monitored
  - Health symptoms and risk perception



# HEATS RECRUITMENT

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- Households randomly selected from postal address lists
- Geographically dispersed sample developed for each area
- Recruiters (employees deployed from a professional research agency from Atlanta):
  - Receive the lists of up to 40 addresses at a time and **visit each address up to six times**
  - Explain the general study and inquire about interest in participating
  - Screen for eligibility (nonsmoking with a resident adult)
  - If eligible, address, participant name and contact information is communicated to the UTSPH via secure email/phone

# HEATS RECRUITMENT

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- UTSPH staff:
  - Contacts the participant
  - Verifies screening information
  - Describes the four visits
  - Consults participant for availability
  - Arranges date/time for the first of four visits

# HEATS FIELD PROTOCOL

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1. UTSPH obtains information on residence location/characteristics via Google/HCAD
2. Visit 1 is arranged at the convenience of the participant
3. Visit 2 is scheduled no less than 48 hours after Visit 1
4. Visit 3 is scheduled 24 hours after Visit 2
5. Visit 4 is scheduled approximately 48 hours after Visit 3

# HEATS FIELD PROTOCOL - VISIT 1 (2 HOURS)

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- Study is explained
- Informed consent form signed after verbal consent
- Baseline Adult Questionnaire
- Technician Walkthrough Survey
  - house measurements/pictures
- Indoor temperature sensors and sources for ventilation measurements
- Date and time set for Visit 2

# HEATS FIELD PROTOCOL - VISIT 2 (1 HOUR)

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- Samplers for air toxics and ventilation source tracer placed indoors
- Sampler for air toxics and temperature sensor placed outdoors
- Sampler for air toxics attached to participant
- Time–location activity log explained to participant
- Sampler for air toxics placed at fixed site

# HEATS FIELD PROTOCOL - VISIT 3 (1 HOUR)

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- All measurement devices collected
- Time-location activity log reviewed
- Household Activity Questionnaire
- Sampler for air toxics removed from fixed site
- UTSPH submits address, participant name and contact information to UTMB by secure e-mail
- Incentive payment (gift card) given

# HEATS FIELD PROTOCOL - VISIT 4 (2 HOURS)

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- UTMB personnel
  - Health Symptom Questionnaire
  - Risk Perception Questionnaire

# HEATS - CRITICAL ISSUE

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- The success of this study depends on our ability to recruit a sufficient number of randomly selected participants.
- The main goal of the study cannot be met without this.
- All components must be completed.



# WHAT DO YOU THINK WENT WRONG?

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What was the single most important thing that we did not do?

# DID NOT CONSIDER CULTURAL BARRIERS

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- Recruiters unfamiliar with the neighborhoods or the people
  - Recruiters deployed were very unlike residents
  - Hounded people
  - Undocumented residents
- Excessive burden upon study participants
  - Time
  - Money & the timing of money!
  - Including communities as partners would have avoided every single problem we encountered!

# TAKE HOME MESSAGE

The best design can fail if you cannot recruit participants.

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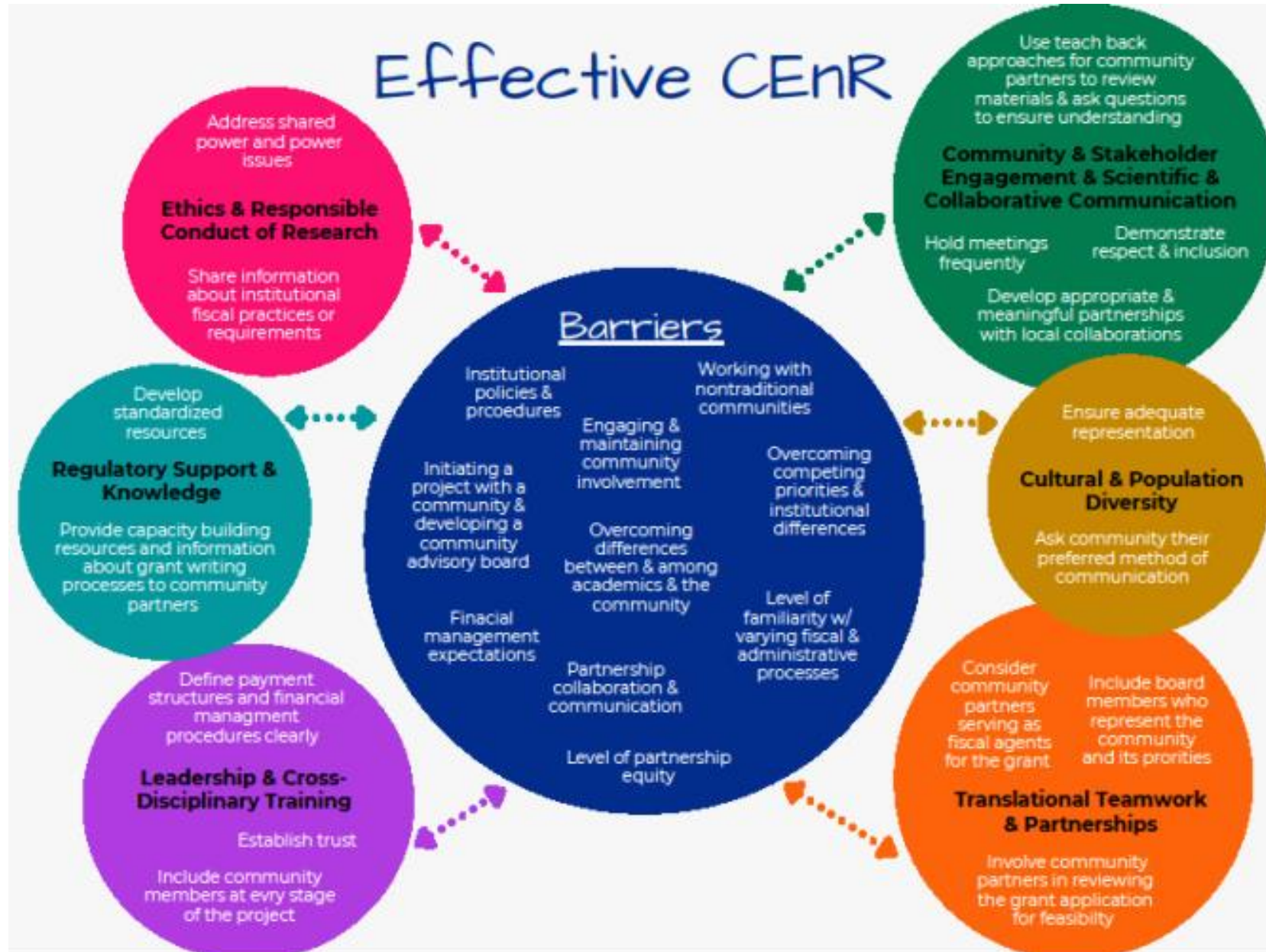
What would you do differently?

# CHALLENGES WITH DEVELOPING PARTNERSHIPS

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- Historical lack of trust and respect
- Helicopter Research
- Inequitable distribution of power and control (institution as the 800-pound gorilla)
- Conflicts associated with differences in perspective, priorities, assumptions, and language
- Conflicts or confusion (not always disagreements) over funding
- Promotion and tenure for academics vs. action-oriented research for communities

# MITIGATING CHALLENGES



# NOTHING FOR OR ABOUT US WITHOUT US

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Thank you!

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