

CBPR IN ACTION

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AGENDA

Our Context and Motivation

Rationale for Partnership Approach

CBPR: What is it?

Principles

CBPR: How to start?

Putting Principles into Practice

Organizational Structure

Group Process

Why It's Worth It



CONTEXT

Our Place: Detroit

Our Health Concern:

- Health Inequities
- Community distrust of researchers

Our Stories



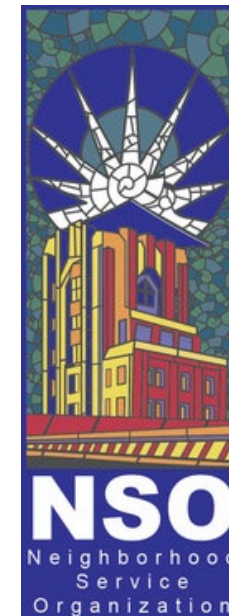
ACKNOWLEDGEMENT

The Detroit URC: fostering health equity through community-based participatory research (CBPR) for over 25 years



Detroit URC: 27 Years of CBPR Partnership

M | SOCIAL WORK



DETROIT
HISPANIC
DEVELOPMENT
CORPORATION



HENRY
FORD
HEALTH



FRIENDS OF
PARKSIDE



M | NURSING



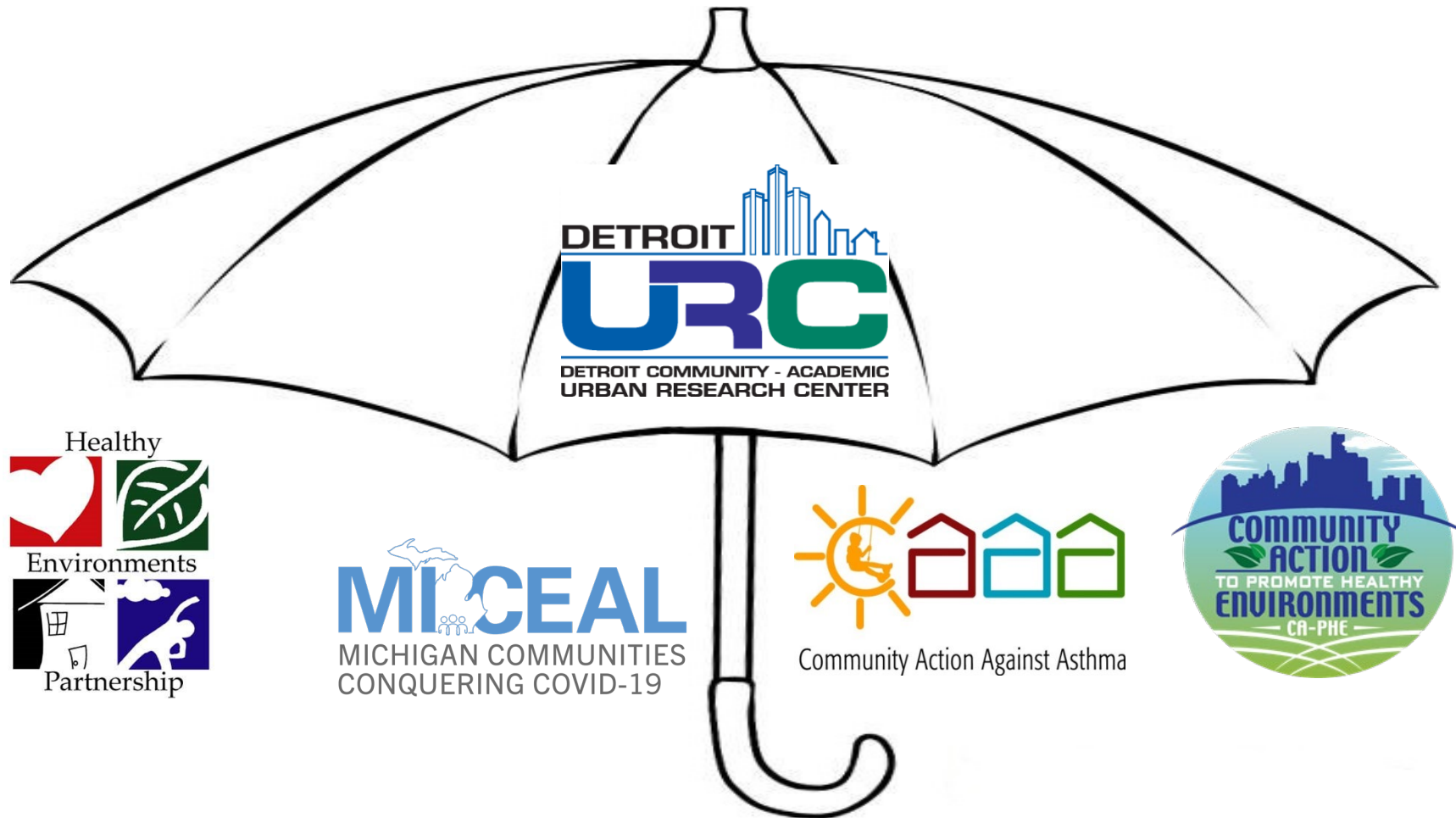
EASTSIDE
COMMUNITY
NETWORK

M | PUBLIC HEALTH



CHASS
Community Health And Social Services Center

DETROIT URC AND SELECTED AFFILIATED CBPR PARTNERSHIPS



WHO DRIVES THE RESEARCH? WHO RECEIVES THE BENEFITS?

Investigator-Controlled



Continuum of Engaged Research

Levels of partners' decision-making authority for study design and implementation



EXAMPLE

Focus Groups,
Town Halls, Crowdsourcing



EXAMPLE

Advisory
Committee



EXAMPLE

Patient Co-I or Multi-
Disciplinary Executive Team



EXAMPLE

Patient Co-PI,
Patient-led tasks

PHOTO CREDITS: A. ELEARNINGINDUSTRY.COM;
B. PCORI WEBINAR "SCIENCE OF ENGAGEMENT"

ADDITIONAL CREDIT: COMMUNITY-BASED RESEARCH
CONTINUUM | HUMAN SUBJECTS OFFICE (UIOWA.EDU)

Adapted from: Hanley et al. (2004). Involving the public in NHS, public health and social care research. *Carman et al. (2013). Patient and family engagement: A framework for understanding the elements and developing interventions and policies. Health Affairs, 32(2), 223-231. Arnstein, S. R. (1969). A ladder of citizen participation. Journal of the American Planning Association, 35, 216-24*

RATIONALE FOR COMMUNITY BASED PARTICIPATORY RESEARCH (CBPR)

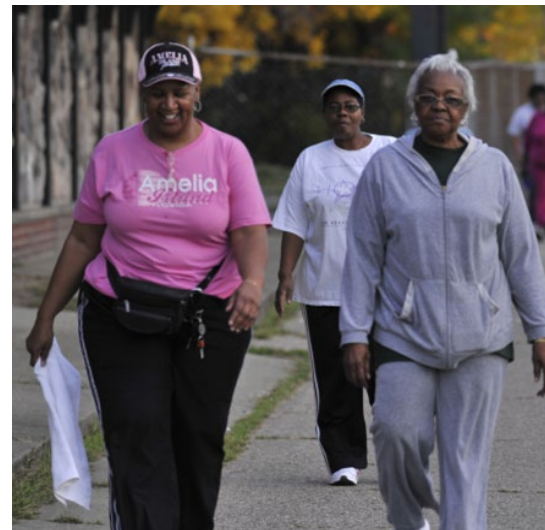


RATIONALE FOR CBPR

- Burden of disease is concentrated in certain communities – this can be related to geography, income, racial/ethnic background, or family genetics
- Stressors related to social, physical, and health system environments are associated with poor health outcomes
- Extensive set of skills, strengths and resources exist among community members



Detroit URC;



Detroit URC



CDC

RATIONALE (CONTINUED)

- Historically, research has not often directly benefited and sometimes actually harmed the communities involved
- Communities most impacted by health inequities least likely to be involved in the research process
- Resulted in understandable distrust of, and reluctance to participate in, research



PHOTO: LILLIAN TYSON HEAD

[HTTPS://ABCNEWS.GO.COM/HEALTH/FAMILY-TUSKEGEE-SYPHILIS-STUDY-PARTICIPANT-THEYLL-COVID-19/STORY?ID=74787123](https://abcnews.go.com/health/family-tuskegee-syphilis-study-participant-theyll-covid-19/story?id=74787123)

RATIONALE (CONTINUED)



- Health interventions have often not been as effective as could be because:
 - Not tailored to the concerns & cultures of participants;
 - Seldom include participants' lived experiences; and
 - Focused on individual behavior change or treatments with less attention to broader social & structural determinants of health.

RESEARCH IS EVOLVING

- Increasing recognition of need for more comprehensive & participatory approaches

Examples:

- NIH Community Engagement Alliance (CEAL): <https://ceal.nih.gov/>
- FDA Announcement (Dec 2023): Advancing the Development of Therapeutics Through Rare Disease Patient Community Engagement; 88 FR 80728
- Community-based participatory research is one such partnership approach



COMMUNITY BASED PARTICIPATORY RESEARCH (CBPR): WHAT IS IT AND HOW DOES IT ADDRESS NEEDS?

DEFINITION OF COMMUNITY-BASED PARTICIPATORY RESEARCH (CBPR)

- Community-based participatory research is a partnership approach to research that:
 - equitably involves all partners in all aspects of the research process;
 - enables all partners to contribute their expertise, with shared responsibility and ownership;
 - enhances understanding of a given phenomenon; and
 - integrates the knowledge gained with interventions.

APPLICATION OF CBPR APPROACH

CBPR is an approach to or process by which research is conducted

- CBPR is not a specific scientific method or research design
- CBPR can involve qualitative and quantitative methods and multiple research designs



SELECT PRINCIPLES OF CBPR

1. Recognizes community as a unit of identity.
2. Builds on community strengths and resources.
3. Promotes collaborative and equitable partnerships.
4. Facilitates co-learning and capacity building.



The Detroit URC: Southwest Detroit Community Garden

SELECT PRINCIPLES OF CBPR (CONTINUED)

5. Balances research and action for mutual benefit of all partners.
6. Addresses issues of race, ethnicity, racism, and social class and embraces cultural humility.
7. Disseminates findings to all partners and involves them in the dissemination process.
8. Promotes long-term process and commitment.

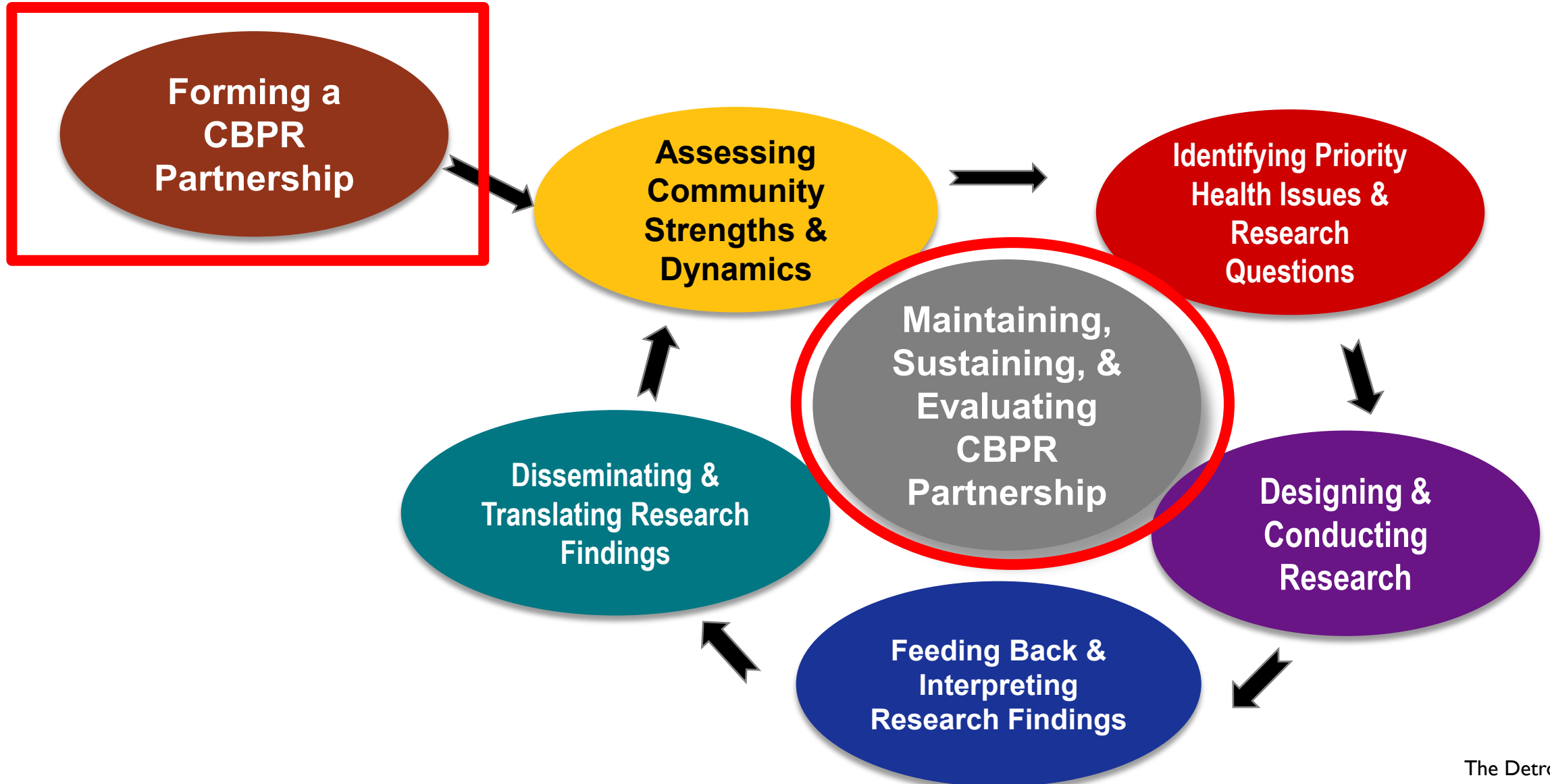


The Detroit URC

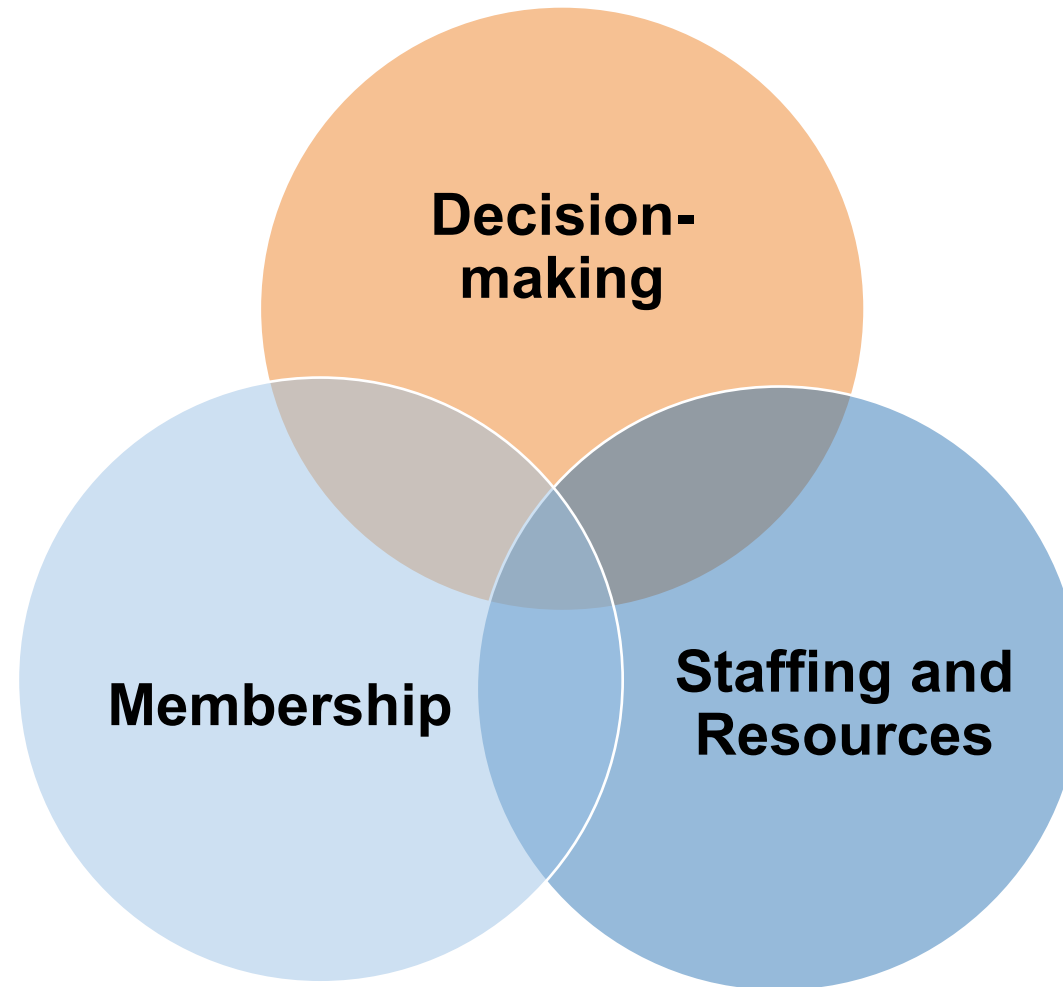


PUTTING PRINCIPLES IN ACTION

CORE PHASES OF USING A CBPR APPROACH



FORMING THE PARTNERSHIP: ORGANIZATIONAL STRUCTURE



FORMING THE PARTNERSHIP: ORGANIZATIONAL STRUCTURE



Decision-
making

- Who will guide, oversee and carry out the work of the partnership
- Issues to consider:
 - Size - number of organizations and/or individuals
 - Who is the lead organization
 - How often to meet
 - Roles and responsibilities of members
 - How work is carried out
 - What decisions are made by whom

FORMING THE PARTNERSHIP: ORGANIZATIONAL STRUCTURE



Membership

- What does it mean to be a member?
- Organizations and/or individuals?
- What roles and responsibilities are involved?
 - Memorandum of Agreement, or
 - Less formal structure
- What level and types of compensation are provided to members?

FORMING THE PARTNERSHIP: ORGANIZATIONAL STRUCTURE



- Facilitate and support participation of partners
- Ensure that partners' time is used to maximize input and influence
- Resource allocation: Who gets the money?
- Carry out tasks related to the CBPR project (e.g., data collection and analysis, intervention implementation, and dissemination)

MAINTAINING EFFECTIVE PARTNERSHIPS: PAY ATTENTION TO PROCESS IT'S SLOW, BUT IT MATTERS!



Detroit URC: Measurement Approaches to Partnership Success (MAPS)

MAINTAINING THE PARTNERSHIP: EFFECTIVE GROUP PROCESS

1. Developing and maintaining mutual trust
2. Ensuring equitable participation and sharing of power and resources
3. Sharing leadership
4. Making decisions
5. Addressing conflict



1. STRATEGIES FOR DEVELOPING AND MAINTAINING MUTUAL TRUST

- Show respect, listen, consider opinions of other partners
- Strive to achieve cultural humility
- Follow through on commitments
- Act as allies and participate in each other's activities
- Stay curious and open-minded to feedback that may challenge you
- Help support the partner's trust and credibility with their own community
- Acknowledge, credit, and celebrate everyone's contributions



2. EQUITABLE PARTICIPATION AND SHARING OF RESOURCES AND POWER



- Ensure that all members' knowledge and skills are used fully to accomplish partnership goals
- Establish multiple networks of communication and avenues for participation
- Be transparent with budget and resource allocation
- Ensure inclusion in agenda setting, budget and staffing decisions, subcommittees guiding work

3. SHARED LEADERSHIP

- Intentionally build co-leadership into partnership structure
- Utilize the range of skills and experiences of partners
- Build capacity of group and individuals to assume and share roles
- Group facilitation requires skills and attention to CBPR principles

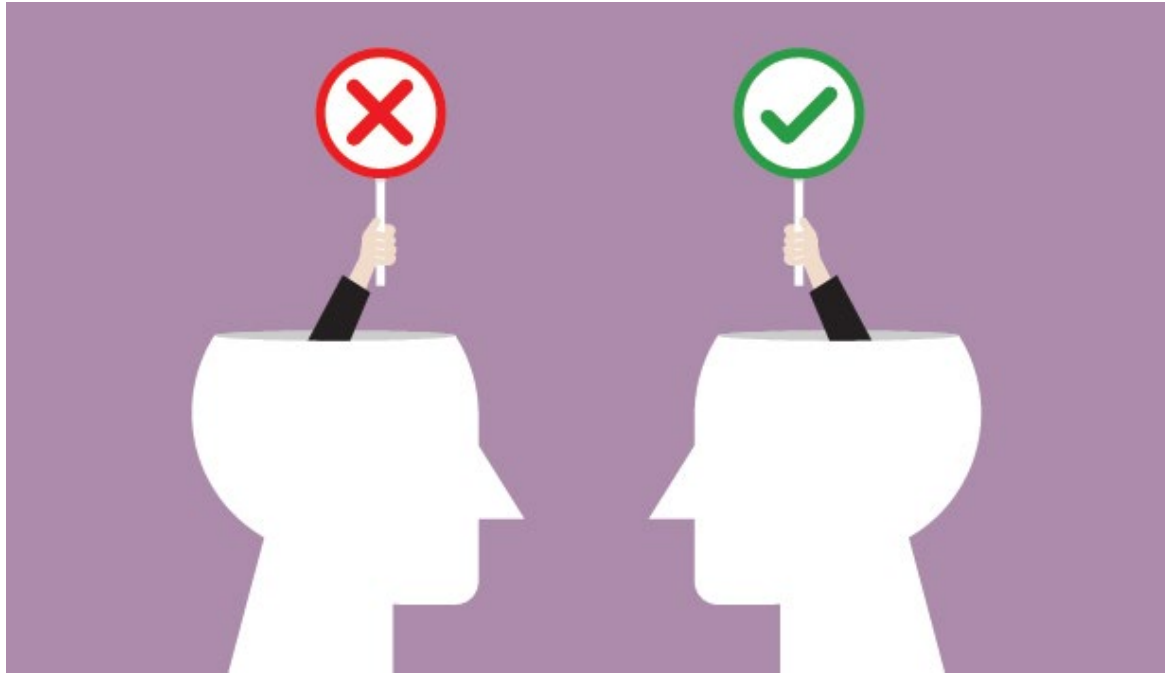


4. SHARED DECISION MAKING

- Develop decision making guidelines; that is, “decide how to decide”
- Different types of decisions need different decision-making methods
- Use consensus decision making for major and complex decisions
- Consensus decision making using the 70% rule
- Passive consent



5. ADDRESSING CONFLICT



- Conflict is challenging, inherent in diverse groups, and necessary
- Establish norms for addressing conflict, including acceptance, management, resolution
- Nature and source of conflict determine appropriate means for addressing it.
- Apply CBPR principles to guide partnership's ability to address conflict

OUR PERSPECTIVES ON BENEFITS OF CBPR: WHY ITS WORTH IT



Study gives hope to asthmatic kids

Machine helps U-M researchers measure quality of air both indoors and outside in urban areas

By WENDY WENDLAND-BOWYER
FREE PRESS STAFF WRITER

Everywhere 9-year-old Danielle Smith goes this week she wears a backpack slung on her shoulder that sucks in the air with a steady purr.

And when she's relaxing at home, a larger but similar machine is at work, swooping up the household air for careful analysis.

Danielle is participating in an innovative, \$7-million study by University of Michigan researchers who are trying to discover what in the air may be making kids in urban areas sick with asthma at alarming rates.

"The thing that is really unique about this project is it is looking at both indoor and outdoor air quali-

ty. No other project I am aware of is looking at both," project manager Katherine Edgren said.

Asthma rates are rising for children and adults throughout the country, with the highest rates in big cities. In Detroit, studies have shown 20 percent of children have asthma. Nationally, the rate is about 7 percent. The number of people with asthma nationwide has grown from 6.7 million in 1980 to 17.3 million in 1998.

Though no one knows the reason for the dramatic rise, a combination of factors including socioeconomics, genetics and pollution are expected to play a role.

What U-M researchers hope to discover is not only what in the air may be causing problems, but what types of home intervention



HUGH GRANNUM/Detroit Free Press

Danielle Smith, 9, of Detroit breathes into a machine to measure her air intake.

can help the kids live healthier lives. The project involves 300 asthmatic children from east and southwest Detroit.

"Before you can make a substantial improvement in the lives

Please see ASTHMA, Page 5A

>KNIGHT RIDDER<

TAKE AWAY POINTS

- Recognize there are multiple avenues and opportunities for community engagement to add value to research
- Prepare to be flexible; bring a willingness to listen to another perspective
- Expect to give time and commitment to process
- Embrace the necessity for joint problem-solving
- Dedicate ongoing effort to the balance multiple priorities
- Enhance longevity of partnership by demonstrating that contributions are valued
- Accomplish more together than you could ever do alone

SELECTED RESOURCES

Detroit URC



- [Home | Detroit Urban Research Center \(detroiturc.org\)](#)
- [Detroit URC CBPR Tools | Detroit Urban Research Center](#)

PCORI



- [Engagement Resources | PCORI](#)
- [Engagement Award: Stakeholder Convening Support -- April 2024 Cycle | PCORI](#)

Community-Campus Partnerships for Health



- [Community-Campus Partnerships for Health | Promoting health Equity and Social Justice \(ccphealth.org\)](#)

THANK YOU

Question and Answer



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COMMUNITY INVOLVEMENT IN ACTION

Power & control
Responsibility & ownership
Participation
Influence

Low

High

Practitioner-Driven
Action

Community Placed/
Based Action

Community-
Engaged
Action

Community-Based
Participatory
Action

Community-
Driven
Action

Adapted by the Detroit URC from Hacker, K (2012) and from Cornelia Ramsay, Virginia Commonwealth University, 2008, in Hacker (2012).

TIPS FOR ACADEMICS STARTING IN CBPR

- DO meet partners in person; get to know people
- DO talk about your interests and how this might connect with group goals
- DO listen to partner perspectives and be open-minded to feedback that may challenge you
- DO discuss plans in detail – What kind of contact with participants? What kind of help will be needed?
- DO address particular concerns about participant privacy, burden, and benefit
- DO give participant incentives, if at all possible
- DO discuss data and results sharing – what existing data are you interested in? How will you share your results? How will you include partners in dissemination?
- DO keep partners apprised of progress along the way

TIPS FOR ACADEMICS STARTING IN CBPR

- DON'T get stuck on the “way it’s always been done” or “the way I think is best”
- DON'T talk so much that there’s no chance for others to voice their questions or opinions
- DON'T do things you haven’t run past the partners
- DON'T promise what you can’t deliver
- DON'T say one thing and do another
- DON'T blow the partner’s trust and credibility with their own community
 - DON'T talk down to participants
 - DON'T be too pushy
 - BE respectful that participation is voluntary
- DON'T publish or present results without getting partner feedback

TIPS FOR COMMUNITY PARTNERS STARTING IN CBPR

- DO speak up when you have a question, interest, or concern
- DO learn about the research process
- DO volunteer for sub-committees and presentations so your voice can be heard
- DO communicate regularly with your organization or constituency to keep them informed of research progress and bring their experience to the research
- DO feel empowered to ask for resources for your community/organization
- DON'T expect research to happen fast

TIPS ON RESOLVING DIFFERENCES OF APPROACH OR OPINION

- Step back and try to understand and address the root concern being expressed by partners
- Can you bring more information to help explain or support your point of view?
- Focus on areas of mutual interest and agreement
- See if there is a path that can provide satisfaction to both sides
- Look for alternative approaches that accomplish the goal a different way
- Stay flexible, keep dialogue open and respectful.

COMMUNITY MEMBERS AS STAFF INTERVIEWERS

In CAAA, Steering Committee members:

- Championed community capacity building: community members to be hired as interviewers, willingness to hire staff with “intrinsic” skills and provide research skills training
- Participated in identifying potential job candidates
- Served in interview committees and gave input into hiring decisions
- Participated in training and evaluation of new hires
- Provided mentorship for community hires

