# COMMUNITY-BASED PARTICIPATORY RESEARCH & HEALTH EQUITY

Rebekka Lee, ScD Lizzie Barnett, MS

#### Acknowledgments

These slides have been adapted from Harvard School of Public Health Prevention Research Center's Leaders in Health Program, including a presentation given by Jocelyn Chu, ScD Institute for Community Health









#### Learning Objectives

- Define CBPR in your own words.
- Define health equity in your own words.
- Give examples of what are and what are not CBPR projects.
- Describe the benefits of doing CBPR in your community (as either a researcher or participant), including how CBPR can be used to address health inequities
- Tomorrow: understand the basics of how and why to conduct mixed methods research and focus groups

#### Ground rules

- □ Safe space
- □ Step up, step back
- Different starting places
- Avoid generalizations
- Ask questions
- Challenge yourself

## Agenda

Introductions	9:00-9:30	
<ul><li>What is CBPR?</li><li>Defining terms &amp; key concepts</li><li>Grid/continuum of CBPR</li></ul>	9:30-10:30	
<ul><li>Why use CBPR?</li><li>Health equity</li><li>Implementation &amp; Dissemination</li></ul>	10:30-11:30	
AM Break 11:30-11:45		
Examples of CBPR projects	11:45-12:45	
Lunch 12:45-1:45		
Social identity exercise	1:45-2:00	
<b>How</b> do I incorporate CBPR?	2:00-3:00	
CBPR application: Change tool	3:00-3:45	
Wrap up: Lessons learned	3:45-4:00	

## Learning Objectives

> Define CBPR in your own words.

# Defining Community-Based Participatory Research (CBPR)

- Community-Based:
  - works in response to the needs of a community
- Participatory:
  - the community is part of the process
- Research:
  - systematic investigation that develops or contributes to generalizable knowledge

#### What is CBPR?

"CBPR is a 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 Scholars Program (2001)

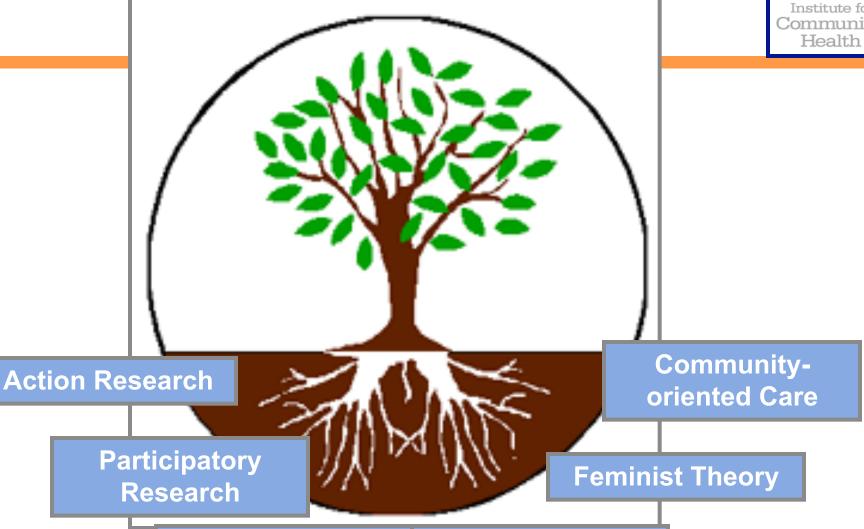
"...a <u>collaborative approach</u> to research that combines methods of inquiry with <u>community</u> <u>capacity-building</u> strategies to bridge the gap between knowledge produced through <u>research</u> and what is <u>practiced in communities</u> to <u>improve health</u>."

#### Other names

- Participatory research
- Participatory action research
- Action research
- Emancipatory research
- Collaborative action research
- Street Science
- Rapid Assessment (some types)

#### Historical Roots of CBPR





**Community Organizing** 

Environmental Justice

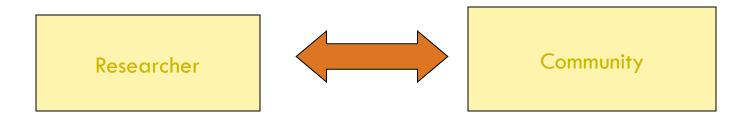
### Key Concepts of CBPR

- Interplay of research, education, and action
  - Balance between knowledge generation and intervention
- Partnership/Mutual Benefit
  - Involvement of community in all steps of the research process
- Cooperative: sharing of expertise, decision-making and ownership
  - Co-learning
- Community as unit of identity
- Building on strengths and resources within community

### Key Concepts of CBPR

- Focus on local relevance of public health problems
  - Honoring local knowledge
- Choice of methods based on research question and feasibility within community
  - Quantitative and qualitative methods
- Dissemination of results to ALL partners
  - Understandable, respectful, useful
- Time and long-term commitment
  - Sustainability

#### CBPR is an Approach



#### CBPR requires:

- Cooperation and negotiation
- Partnership development
- Collaboration between community partners/academic researchers
- Commitment to addressing local health issues

NOT a methodology! Instead, a paradigm shift in the way researchers relate to communities

# Traditional vs. CBPR Research Approaches

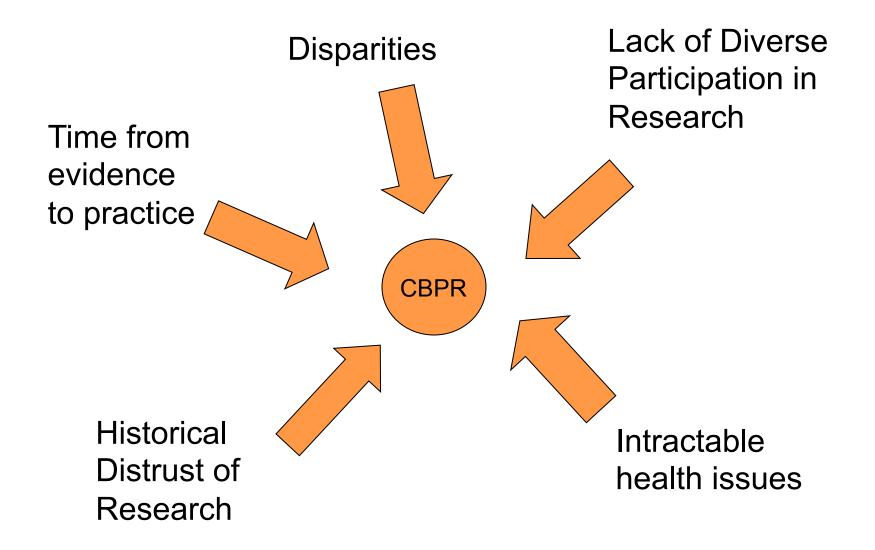
Traditional Research	Community-engaged Research	
Approach	Research with the comm	unity CBPR
Researcher defines	Research IN the	Community identifies
problem	community, or WITH the	problem or works with
	community	researcher to identify
		problem
Research In or ON the	Research WITH community	Research WITH community
community	as partner	as full partner
People as subjects	People as participants	People as participants and
		collaborators
Community organizations	Community organizations	Community organizations
may assist	may help recruit participants	are equal partners with
	& serve on Advisory Board	researchers
Researchers gain skills &	Researchers gain skills &	Researchers and
knowledge	knowledge, some	community work together to
	awareness of helping	help build community
	community develop skills	capacity
Researchers control	Researchers control	Researcher & community
process, resources & data	research, community	share control equally
interpretation	representatives may help	
	make minor decisions	
Researchers own data,	Researchers own data &	Data is shared, researchers
control use and	decide how will be used and	& community decide its use
dissemination	disseminated together	and dissemination

#### Discussion

- Where does your experience with research fit on the grid of the traditional/CBPR continuum?
  - Do you usually follow a traditional or communityengaged approach?
  - In what areas do you take a more community-engaged approach?
  - Are there areas where you typically do research "with the community" that you could shift to a more progressive CBPR approach?

# CBPR? Why

### Forces Driving Towards CBPR



## Why CBPR?

- Complex health and social problems ill-suited to "outside expert" research
- Increasing community and funder demands for community-driven research
- Disappointing results in intervention research
- Increasing understanding of importance of local and cultural context
- Increasing interest in use of research to implement and disseminate best practices

Source: hsc.unm.edu/som/fcm/cpr/docs/CBPR\_Intro.ppt

### Learning Objectives

- ☑ Define CBPR in your own words.
- > Define health equity in your own words.

#### Social Determinants of Health

- BPHC- Center for Health Equity and Social Justice <a href="http://www.bphc.org/chesi">http://www.bphc.org/chesi</a>
  - Where we live, learn, work, and play have a tremendous impact on our health
  - Social factors such as housing, education, income and employment greatly influence health and quality of life because they determine whether or not individuals have:
    - Playgrounds to exercise
    - Supermarkets to buy fresh and affordable fruits and vegetables
    - Job opportunities to support their families
    - Other resources that allow them to be healthy
  - □ While it is definitely important for us to encourage people to make healthy choices, we must remember that people can only make healthy choices if they have healthy options.

#### Social Determinants of Health

WHO (<a href="http://www.who.int/social\_determinants">http://www.who.int/social\_determinants</a>)

- Political Choices
- Distribution of money, power, and resources at global, national, and local levels
- Conditions in which people are born, grow, live, work, and age
- Health Outcomes

## Health Equity

- "absence of *systematic* disparities in health (or its social determinants) between groups with different social advantage/disadvantage (e.g., wealth, power, prestige)"
  - Braverman & Gruskin, 2003
- Health inequities put disadvantaged groups at further disadvantage with respect to health, diminishing opportunities to be healthy

### Health Equity

- WHO Commission on Social Determinants of Health
  - The social determinants of health are mostly responsible for health inequities - the <u>unfair and avoidable differences</u> in health status seen within and between countries.
  - Putting these inequities right is a matter of social justice
  - Social, political, and economic <u>action is needed</u> to address inequities

### Health Equity

- Boston Public Health Commission Center for Health Equity and Social Justice:
  - Health equity means that everyone has a <u>fair opportunity</u> to live a long, healthy life.
  - It implies that health should not be compromised or disadvantaged because of an individual or population group's race, ethnicity, gender, income, sexual orientation, neighborhood or other social condition.
  - Achieving health equity requires creating fair opportunities for health and eliminating gaps in health outcomes between different social groups.
  - It also requires that <u>public health professionals look for solutions outside of</u> the health care system, such as in the transportation or housing sectors, to improve the opportunities for health in communities.
  - A health inequity is unfair, avoidable, and rooted in social justice.

### Inequity ≠ Inequality

#### Health inequality

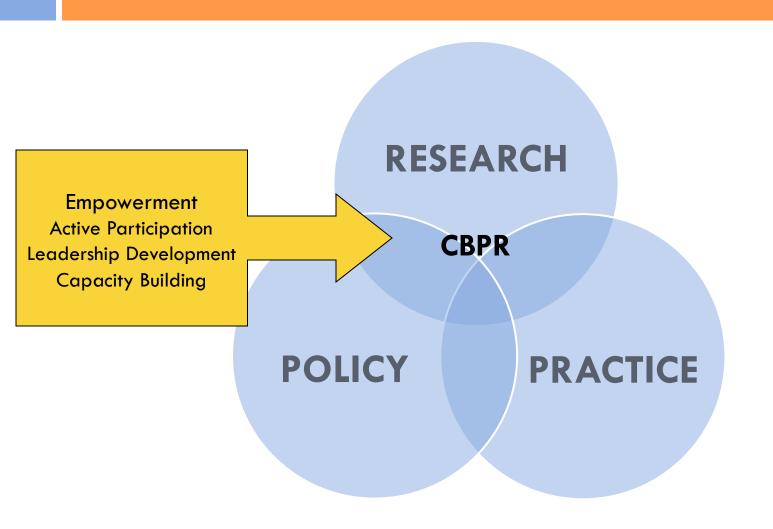
- Difference in health outcome across individuals in a population
- E.g., On average, female newborns have lower birth weights than male newborns

#### Health inequity

- Difference in health outcome is influenced by the unequal distribution of resources to one group over another
- E.g., Racial/ethnic differences in low birth weight rates

# How does CBPR address health inequities?

## **CBPR & Health Inequity**



#### Dissemination & Implementation

- An emerging field within public health
- Dissemination: the intentional process whereby people manipulate the spread of an intervention
- Implementation: the way & degree to which an intervention is taken up & put into practice within an organization
- Looks beyond traditional focus of efficacy research
- Concerned with effectiveness of interventions in real world settings
  - □ What are the factors that influence intervention success?
  - □ How can interventions be designed to become embedded in organizations for sustained impact?

#### DI Theories & Frameworks

- □ Diffusion of Innovations (Rogers 1962)
  - Describes how ideas perceived as new are communicated through channels in a social system over time
  - Stages of development & factors that influence success (e.g. characteristics of the innovation, setting, adopter)
- Framework for Effective Implementation (2008)
  - Developed by Durlak & DuPre
  - Multilevel, ecological
  - Interventions embedded in organization (e.g. schools, hospitals, worksites)
  - Describes types of predictors that influence successful implementation: characteristics of the intervention, provider, organizational capacity, or community context

#### Discussion

- What are some of the environmental, structural, social, or political factors that lead to health inequities in your community?
  - Do you address any of these inequities in your work?
  - How might a CBPR approach be helpful in addressing these inequities?
- What are the best practices that you would like to translate into real world change here in Maine?
  - Do you know how to most effectively implement these strategies?
  - □ How might a CBPR approach be helpful in addressing these implementation and dissemination challenges?

# BREAK

#### Learning Objectives

- ☑ Define CBPR in your own words.
- Define health equity in your own words.
- Give examples of what are and what are not CBPR projects.

#### Example: New Castle, IN

Minkler, M., V. Breckwich Vásquez, J. Warner, H. Steussey, and S. Facente (2006). Sowing the seeds for sustainable change: A community-university research and action partnership in Indiana and its aftermath. Health Promotion International 21(4):293–300.

#### BACKGROUND

- New Castle, IN
  - $\square$  rural community; population  $\sim 18,000$
  - known as center of auto parts manufacturing, but experienced economic hardships with declines in auto industry
  - "has a history of helping itself and using the resources available"
- Funded through initial grant from the WK Kellogg
   Foundation (2003-2005) as part of a study to document impacts of CBPR on healthy public policy in the US

#### Example: New Castle, IN

#### **OVERALL AIM**

- Broad health promotion goal
  - "Make the healthy choice the easy choice"
  - Get city decision-makers and general public to think about potential health impacts of any policies/programs being considered

#### Example: New Castle, IN

#### **PARTNERSHIP**

- Indiana University School of Nursing
  - Academics provided training in basics of research methods
- Healthy Cities Committee (HCC) of New Castle
  - representatives from health and social services, government, business, the arts, environmental concerns, the media, and transportation
  - HCC helped create questionnaires, set agenda, and gain publicity from local media
- Other key stakeholders: City Council, newspaper editor, fire chief, local business owners

#### **METHODS**

- Initial site visit to New Castle in 2004
  - Interviews with academics and community partners
  - Focus group with community members
  - Participant observation
  - Phone interviews with policy-makers
- Door-to-door survey distributed to 1000 households asking various questions about health behaviors

#### **FINDINGS**

- High rates of smoking, low reports of regular exercise, problematic dietary choices, etc.
- Compared results with Healthy People 2000 (national health promotion and disease prevention objectives)
  - City's smoking rate was twice that of HP 2000
  - Proportion of those who exercised less than once a week was 12% higher than stated in HP 2000
  - No group (controlling for income) reached HP 2000 goals for diet, exercise, tobacco, or alcohol consumption
- Results disseminated at town hall meetings

#### **ACTION**

- Based on their discussion of the data, the HCC developed a list of five health problems that it thought merited special attention
  - smoking, exercise, alcohol use and abuse, mental health, and dietary choices
- Undertook policy efforts in the following years
  - Passed a measure creating non-smoking areas in all City buildings
  - Built a large playground with community help (1200 volunteers/week)
  - Continue to tackled longer-term projects (e.g., trail system)

#### ACTION, cont'd

- Community organization established: Healthy
   Communities of Henry County (HCHC) <a href="www.hchcin.org">www.hchcin.org</a>
  - Has operating budget, won several large grants, raises money through fundraisers
  - Puts issues in community context to appeal to broad range of stakeholders
- Results disseminated in community and academic settings (academics and community partners are coauthors)

Traditional Research Approach	Community-engaged Research  Research with the community CBPR			
Researcher defines problem	Research IN the community, or WITH the community	Community identifies problem or works with researcher to identify problem		
Research In or ON the community	Research WITH community as partner	Research WITH community as full partner		
People as subjects	People as participants	People as participants and collaborators		
Community organizations may assist	Community organizations may help recruit participants & serve on Advisory Board	Community organizations are equal partners with researchers		
Researchers gain skills & knowledge	Researchers gain skills & knowledge, some awareness of helping community develop skills	Researchers and community work together to help build community capacity		
Researchers control process, resources & data interpretation	Researchers control research, community representatives may help make minor decisions	Researcher & community share control equally		
Researchers own data, control use and dissemination	Researchers own data & decide how will be used and disseminated together	Data is shared, researchers & community decide its use and dissemination		

# Example: The Out of School Nutrition & Physical Activity Initiative (OSNAP)

- 5-year environmental & policy change initiative
- Group randomized control trial in 20 Boston afterschools
- Learning collaboratives delivered 2010-11 school year
- Partnership with the YMCA, Boys and Girls Club, Boston Centers for Youth & Families, BPS Food and Nutrition Services Dept.
- Data collected in fall 2010 and spring 2011:
  - Snacks served & consumed
  - Child physical activity via observation & accelerometers
  - Screen time offerings, staff behaviors & physical spaces
  - Staff questionnaires & interviews
  - Self-assessments

# Example: The Out of School Nutrition & Physical Activity Initiative (OSNAP)

- Nutrition program aims:
  - Ban sugar-sweetened drinks brought in from outside the snack program & from snacks served
  - Offer water as a drink at snack every day
  - Offer a fruit or vegetable option every day at snack
  - Ban foods with trans fats from snacks served



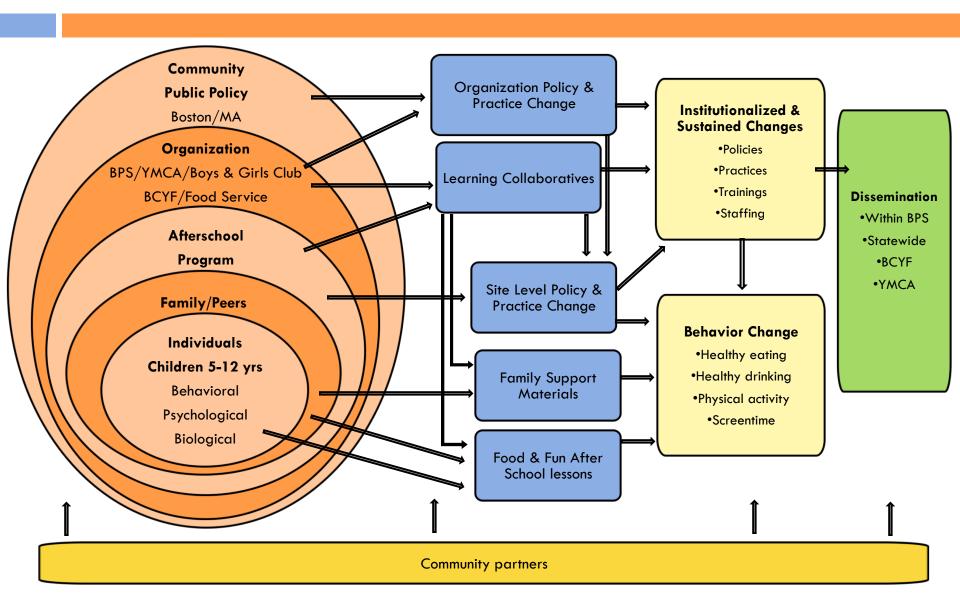
- Physical activity & screen time program aims:
  - Offer 30 or more minutes of physical activity for every child every day
  - □ Include vigorous activity at least 20 minutes 3x/week
  - □ Limit computer time to <1 hour for each child every day
  - Ban all commercial broadcast TV & movies from programs



# Example: Out-of-School Nutrition and Physical Activity Initiative (OSNAP)

- □ OSNAP Research Partners → organizational support, feasibility, capacity building; they include:
  - Boston Public Schools Food and Nutrition Services
  - BPS Department of Extended Learning Time, Afterschool, and Services (DELTAS)
  - Boston Centers for Youth and Families
  - YMCA of Greater Boston
  - Boys and Girls Clubs of Boston
  - Others interested in nutrition and PA, particularly in out of school time programs

## OSNAP Social Ecological Intervention Model



# Example: Out-of-School Nutrition and Physical Activity Initiative (OSNAP)

Traditional Research Approach	Community-engaged Research Research with the community CBPR			
Researcher defines problem	Research IN the community, or WITH the community	Community identifies problem or works with researcher to identify problem		
Research In or ON the community People as subjects	Research WITH community as partner People as participants	Research WITH community as full partner People as participants and collaborators		
Community organizations may assist	Community organizations may help recruit participants & serve on Advisory Board	Community organizations are equal partners with researchers		
Researchers gain skills & knowledge	Researchers gain skills & knowledge, some awareness of helping community develop skills	Researchers and community work together to help build community capacity		
Researchers control process, resources & data interpretation	Researchers control research, community representatives may help make minor decisions	Researcher & community share control equally		
Researchers own data, control use and dissemination	Researchers own data & decide how will be used and disseminated together	Data is shared, researchers & community decide its use and dissemination		

# LUNCH BREAK

# Social identity exercise

# Learning Objectives

- ☑ Define CBPR in your own words.
- Define health equity in your own words.
- Give examples of what are and what are not CBPR projects.
- Understand the benefits of doing CBPR in your community (as either a researcher or participant), including how CBPR can be used to address health inequities.

# Benefits and Challenges of CBPR

#### **Benefits**

- New views
- Resources
- Results more easily translatable into practice
- Data for health improvement
- Visibility and voice for community
- Increased capacity for both researcher and community partners

#### **Challenges**

- Trust
- Time
- Awareness of potential positive and negative consequences of this approach
- Scientific rigor
- Clashing perspectives and responsibilities
- Access to and ownership of data
- Dissemination

### Ethical considerations

- Defining the community
  - Who represents the community?
  - Who gives community consent?
- Community values and ethics
  - Research protocols and standards
- Insider/Outsider tensions
  - Jeopardizing community partner's standing in the community by being an "outsider"

# **Evaluating Potential Collaborations**

- How will research processes and outcomes serve my community?
  - Training, hiring, building on assets, continuity
- How will my community be involved in defining the objectives of the research?
- Are researchers committed to doing necessary follow-up?
- How will my community be involved in the analysis and dissemination of the data?

## Qualities of Participating Collaborators

- Commitment to meet the people where they are
- Ability to respond to situations and interactions, rather than to instigate or control them
- Willingness to learn from and with people
- Sensitivity
- Capacity for critical reflection
  - On the research process
  - On one's own role
- Patience
- Empathy
- Flexibility/adaptability

# Case Study

# Identifying Potential Partners for "Promoting Healthy Living" Project

Your local health department, working with public health faculty persons from a nearby university, is developing a proposal in response to a federal Request for Applications (RFA). The RFA is seeking proposals that will develop effective interventions to increase physical activity in order to reduce disparities in asthma, diabetes, exposure to environmental tobacco smoke, and obesity. Potential strategies will look at school and worksite-based interventions, the built environment, and policy-related barriers to increasing physical activity. A community-based participatory research model must be used, involving key partners from sectors relevant to the topic.

### Task

Brainstorm which community and institutional partners from your setting should be invited to participate in this partnership and why. In addition, list some of the pros and cons associated with these choices. After the brainstorming session, report on which community institutional organizations and/or individuals you selected and why, and the pros/cons of each.

Use the following questions for discussion during the brainstorming:

- What kind of agencies should be invited? What kinds of academic departments should be invited?
- How is "community" defined and who "represents" the community?
- Who decides who belongs?
- Is membership comprised of individuals from organizations or organizations represented by individuals?
- When partnership members are organizations, who decides which organizations are involved, and how they are selected for membership? In the case of community-based organizations, who decides the extent to which they are able to represent the community in which they operate?
- □ When partnership members are individuals, who is able to represent whom?
- How many members do you want on your partnership? How many is too many? How many is enough?
- How will members be invited?
- Why would individuals and organizations want to get involved with this partnership?

# CBPR Application

## Applying the CBPR approach

- How might you apply one or more CBPR concept(s) to your work?
  - If conducting research yourself, in which area(s) on the grid we used earlier could you apply a CBPR approach?
  - If partnering with researchers, do you feel more prepared? What would you look for in a research partner? What would be the added value of CBPR to your organization?

# Strategies for Change

- Essential element of leadership is the ability to get things done, successfully and on time
- The Change Tool facilitates accomplishment through:
  - Identification & utilization of effective strategies +
  - An accountability mechanism to ensure process stays on track
- Writing down goals helps to clarify & commit
- Change Tool is based on Kotter & Schlesinger's
   Strategies for Change & the concept of SMART goals

# Strategies for Change

- Designed to overcome the all too common problem of resistance to organizational change
- Take time before the change to think about who might resist & for what reasons
  - Self interest
  - Misunderstanding & lack of trust
  - Differing assessments
  - Fear of new skills & behavior necessary

# Strategies for Change

- Education & Communication
  - □ Tell people change is coming, use when there is inaccurate or very little information available
- Participation & Involvement
  - Include people in design and implementation of change
- □ Facilitation & Support
  - Listen to concerns, provide trainings for new skills
- Negotiation & Agreement
  - Offer incentives, use if someone may lose out on something
- Command & Enlist
- Explicit & Implicit Coercion

### SMART Goals

- Specific
- Measureable
- Attainable
- Realistic
- □ Timely

http://www.topachievement.com/smart.html

# Change tool example: CTG Corner Store Initiative

				Current Status	
<u>Initiative</u>	Key Strategies	Steps/Actions	<u>Deadlines</u>	<u>Status</u>	<u>Date</u>
1- Collect data on shopping behaviors at Massachusetts stores the aim to adopt healthy corner store	-Education & communication -Participation & Involvement -Negotiation &	Step 1: Coordinate with MDPH	5/10/2013	Bekka met with Tom, Bonnie, & Andrea to determine number of stores that have been recruited & scope of work for baseline	5/3
initiative as part of the community transformation grants	agreement			Bonnie reached out to all community coordinators as a follow-up	5/7
		Step 2: Calls with community coordinators -Describe protocols -Languages for data collectors	5/17/2013	Jenna drafted a template of data report we will feedback to store owners and coordinators	5/10
		-Incentives -Introduction on first day -Best week/days in June		All calls complete → 5 of 6 communities are interested Coordinators all volunteered to visit stores in person next week to describe data collection	5/23
		Step 3: Finalize baseline plan & protocols for MDPH -Update text on methods, tools, consent forms, budget, codebook	5/24/2013	Bekka emailed after review from Steve and Angie	5/29

# Activity: Start your Change Tool

- Start on the left of side of the grid by enumerating the 1-3 change initiatives you'd like to pursue given today's training on community-based participatory research
- Fill in the key strategies that will most likely help you succeed from an overarching perspective
- 3. Think about your situation & determine the optimal speed for the change you have in mind
- 4. Break initiatives down into more manageable action steps that you have control over
- 5. Set deadlines for accomplishing each specific action step and keep track of your progress weekly

# Wrap up

- Lessons learned
  - Health inequities to address in Maine communities
  - CBPR concepts that are most applicable to the needs and interests of today's participants

# Learning Objectives

- ☑ Define CBPR in your own words.
- Define health equity in your own words.
- Give examples of what are and what are not CBPR projects.
- Describe the benefits of doing CBPR in your community (as either a researcher or participant), including how CBPR can be used to address health inequities.

"If we want to realize the promise of community participation we need to be less content with giving historically excluded groups influence at the margins and work to create processes that give them influence that counts"

--Lasker & Guidry, 2009

### **CBPR** Resources

http://www.ccph.info/

http://www.cbprcurriculum.info/

http://catalyst.harvard.edu/services/cbpr.html