Community-based Research and Environmental Justice Interventions

CBPR Best Practices and Intercultural designs

Presentation of the Northeast Ethics Education Partnership (NEEP)
Participatory and community-based research approaches are utilized now by researchers with community members in order to ensure a more ethical approach to research/interventions in community settings.
Ethical Benefits

- CBPR will require community consultation about risks/benefits.
- Research designs will be collaborative; promoting the identification of community-based beneficence.
- Exploitation concerns are reduced by offering fair benefits to the community.
CBPR and Respect for the Community

- “Respect for the Community” is new ethical guidance from CIOMS and bioethical researchers.
- In the least, researchers should ensure that community consultation is achieved for risks/benefits of the research.
- Fair benefits are needed to avoid exploitation.
Respect for the Community

- Fair allocation of benefits can be determined by assessing the community infrastructure, resources, personnel needed to do a study.
- Community review committees can determine these benefits with researchers.
- In resource-poor communities, it is critical to create benefits from the research or such research will be unethical to perform.
Improving Informed Consent

- Community liaisons can ensure appropriate recruitment strategies and linguistic communications, improving the disclosure, comprehension and voluntariness of informed consent requirements.
CBPR research processes will be attuned to community needs and culturally-appropriate research methods.

CBPR protocols for data dissemination, publication and ownership will provide protections to community members.

The reporting of findings will be guided by community review, protecting against stigma and miscommunications.
CBPR is a collaborative approach to research that equitably involves all researchers, community members and organizational members in the research process.

Unique strengths and shared responsibilities are contributed to the research effort.
CBPR Rationale

CBPR examines interrelated causes of community problems

- Engages local knowledge and local theory
- Provides equitable benefits for researchers and community members; increasing community capacities and resources.

CBPR Rationale

- Allows community members to have more competent ownership over long-term community-based problems.
- Provides critical outreach to marginalized, racial, ethnic or other groups with high disparities in health, income or other social problems.
CBPR Principles for Partnership/Collaboration

- CBPR recognizes the community as a unit of identity; as a geographic neighborhood, dispersed geographic ethnic group; overlapping communities in a defined area.

- Builds on strengths and resources within the community.
CBPR Principles for Partnership and Collaboration

Facilitates collaborative partnership in all phases of the research:

- problem definition,
- data collection,
- interpretation of results,
- application of results to address community concerns.
Integrates knowledge and action for the mutual benefit of all partners.

Promotes a co-learning and empowering process that attends to social inequalities; a reciprocal transfer of knowledge, skills, capacity and power.
CBPR involves a cyclical and iterative process for:

- Partnership development and maintenance
- Problem definition and community assessment of risks and benefits.
- Adjustment of research methods and tools
- Recruitment of community participants
- Data collection and analysis
- Interpretation of results
- Dissemination of results

Community members can feel exploitation when research studies cannot produce beneficial change for the community conditions that warranted the research but researchers gain benefits.

Community-based assessment tools are needed to ensure a critical evaluation of a health/environmental study’s design and methods for producing beneficial change.
New studies in CBPR have shown creative designs that can result in benefits to communities even if there are scientific analyses that have high uncertainties and lead to inconclusive findings (building community capacities; oversight roles; research funding, etc.)

Community members, as well as public health officials, can set standards for research designs/impacts of results.
The Need for Community Review (Community Advisory Committees)

- Researchers can assist in organizing a community advisory board or community research review committee to serve as liaisons or partners with the researchers to build a community’s solidarity for consenting/approving to research.

Picture: http://www.annarbor.com/assets_c/2010/10/1012_Saline_Crowd-thumb-300x217-57392.jpg
Community review will require us to build understandings of “what/where is the community” and “who represents community”.

Some communities may have existing committees or forms of representation for this function.
Building Community Review for Intervention Studies

- With this community review, the solidarity/autonomy of the community for voluntary approval and consent is improved.

- Improving disclosure, comprehension, assessment of risks/benefits, ensuring beneficial change and research data protections are key elements.
The Need for Community Review (Community Advisory Boards (CABS))

- Strauss et al. reported these benefits from community review:

  (1) better community education for understanding risks and benefits of informed consent
  
  (2) better outreach to the community about the study, its goals, outcomes, improved problem identification, better participant recruitment research monitoring

Intercultural Intervention Designs

- Building more cultural integrity into CBPR and environmental justice approaches requires that we open up to emergent designs that can incorporate cultural beliefs, values, traditions, discourses and histories of the diverse cultural groups in communities.
Cultural Integrity and Research Designs

- How can we incorporate technical, academic or scientific methods with local cultural contexts?
- How do we not dominate the intervention and marginalize community voices, needs and experiences?
Case Studies of CBPR and EJ Best Practices

Excerpts from:

- Charles. J. and Menzie, C. ”Southeast Asians and Contaminated Shellfish, MA”
- Silka, L. (2001) Southeast Asian River Festival, Lowell, MA
- Quandt, S. Latino Pesticide Contamination
CBPR and Fish Contamination
Latinos, African-Americans and Southeast Asians

- The Watchperson Project of Williamsburg and Greenpoint, NY was organized to provide a more accurate risk assessment from the consumption of contaminated fish caught in the East River.
- Fish anglers were mostly non-English speaking and community people would be needed to collect data about fishing practices.
CBPR/Culturally-based Approaches

- First approach – **Toxic Tours**: community-led tours for researchers to meet with and learn about the affected people and the fish-eating practices.
- **Toxic Tours** are rituals of learning for both outsiders and people of the community
The Watchperson Project developed a community-based survey with EPA to identify how many people were eating fish, amounts and frequency of fish consumption and the types of fish.

Sample surveys were provided by EPA but the community survey included a lot of language sensitivity to the local Black and Latino people.
For example, the community researchers tailored the survey with questions about seasonal variable conditions, personal consumptions patterns, family consumptions patterns, species, quantity and preparations of the fish they ate.
Angler Stories

- The interviews brought out angler stories about fishing experiences that the community researchers captured as part of the research process.
- Fishing as a cultural tradition and a way to survive were themes that were common.
- The fishers thought that their fish cleaning practices would protect their families.
Ongoing Collaboration

- EPA researchers met with the community group several times to review data collected and talk about potential risk estimates.
- Watchperson staff oversaw the data collection and provided academic translation of the findings.
- Before findings were available about fish contamination levels, project staff were concerned about ongoing exposures.
Educational Forums

- An educational forum was designed by the Watchperson Project titled “Fish-in Days” to educate fish anglers about the potential exposures of the fish being caught and eaten.

Picture: http://www.thehindu.com/multimedia/dynamic/00165/18_AUG_TNJ_SRI_LANKA_165026f.jpg
Culturally-Sensitive Fish Advisories

- Poverty, cultural tradition, cultural identity and dietary habits were the reasons for fishing and standard EPA fish advisories did not stop fishing.

- These local needs must be addressed as part of a fish advisory program.
Local Knowledge vs. Default Exposure Assumptions

- EPA changed from default assumptions about fish exposures to a local model of exposures for the East River fishers
- without much additional cost.
- Research was much improved from the local contextual knowledge collected.

Shellfishing Exposures to Southeast and Latino Populations, Chelsea, MA

- CBPR methods used in this outreach were part of a community-based pilot project that conducted:
  - (1) observation of fishers
  - (2) developed an ethnographic assessment of community’s cultural interests, linguistic limits, and modes of learning.

(3) designed a community-based education project for local and state agencies.

(4) involving community leaders/members in these educational programs by recognizing their local contributions, inviting community experts to participate in presentations to the community.
Communication tools: videos in native languages, articles in community newsletters, radio announcements, and visiting beaches with informational brochures, and posting multilingual signs for fish advisories.

Monthly meetings with the community and researchers ensured better partnership communication and project management.
Southeast Asian Research Model

- Rituals, Research Ethics and CBPR

The River Festival
Lowell, MA

UMASS-Lowell
Center for Family, Work and Community
Southeast Asian Research Model

- Rituals and celebrations are an intercultural approach for identifying research interests in the community and returning those interests through a community-university partnership.

- Rituals and celebrations are central to our attempts to build initiatives that are sustainable.
Rituals and Research

- These celebrations encourage the discussion of what is important to different people within a culture, what role (if any) outsiders may play.
- Research can become a part of these activities with cultural practices that can be sustained even as a younger Southeast Asian generation rapidly becomes Americanized.
Southeast Asian Research Model

- These activities can expose similarities and differences, conflicts and areas of agreement when planning brings together university researchers and diverse community groups.
University researchers and Southeast Asian groups developed an annual “River Festival” as water was the most important issue to Southeast Asians.

Purity of water was central to so many aspects of their lives in Southeast Asia.

Water is tied to religion, recreation, the economy and jobs. The researchers used the symbol and meanings of water as a gateway to other issues of environmental concern – lead, paint, soil contamination, etc.
Southeast Asian Research Model

- Rituals and celebrations are complex as well so that they represent rich areas for learning, and because these events are taking place in a new culture, these celebrations can be a way to effectively blend the old and the new.”[1]
Workshops and other educational activities are held along the Merrimack River on the days of the festival.

The festival has disseminated important information about contamination events and problems throughout the city affecting diet, nutrition, subsistence activities, health and recreational activities.

Native American Research Model: Webs of Relationships

- Health research models identify webs of relationships impacted and involved in community health protection (English et al. 2000).

- The self and community are part of a natural collective or a web of relations with human, natural and spiritual forces; all requiring balance and harmony (Cajete 2000).
Building Interdependent Relationships in Research

- A Native American model builds relationships with key community/external stakeholders to strengthen community capacities and create beneficial interdependencies among stakeholders for community health.

- These models build trust and mutual learning from diverse stakeholders.

Native American Model: Symbolic Meanings with Technical Research

- Native American approaches will integrate ceremonial, ritual, artistic, and other symbolic activities with community programs for education, outreach and research for health protection.

(English et al 2004).
Native Research Incorporates “Good-Mind Approach (Akwesasne RAC, 1996)” – Virtue Ethics

Virtue principles of “peace” (skennen), “good mind” (kariwiio) and ‘strength” (kasastensera) guide all research processes (Arquette et al 2002).
Expanding Research End-points
Assessing both qualitative and quantitative impacts

This model uses an integrated risk assessment framework that includes assessing impacts to humans, the natural world, cultural, social, subsistence, economic and spiritual practices.
Haudenosaunee Democratic/Communal Model – Cultural Definitions of Health

Expanding Research Questions

- Culturally-based and community-specific definitions of health and risk must be determined in collaboration with community members.
An expanded definition of health will require qualitative data collection on social, physical, and cultural determinants of health and how toxic contamination affects these. Such determinants include: safety of work environments, social supports, equity, language, respect, and relatedness with the natural world.
Partnership Processes of Research

Akwesasne Requires Community Partnership Control with Academic Researchers:

- Community Advisory Committees; hiring Native researchers, consensus decision-making, resource-sharing in research budget, community consent procedures for research data dissemination.
Akwesasne Research Model

- Integration of Ceremonial/Spiritual Practices: Respect, Building Trust, Data Collection, Knowledge-Sharing

- Specialized Strategies for Communication, Participation and Respect for Multidisciplinary Approaches
Native-based Benefits

- Research Data is More Robust than Current Outcomes
  - These Native approaches offer new research practices/methods for acquiring qualitative, community-generated data that highlight socio-cultural and spiritual relations, with empirical impacts, and restoration needs.
Native-based Benefits

- Research Processes Improve Conditions of Social Inequities
  - These approaches improve the social processes of research, overcoming the social inequities in “expert-driven” scientific practices; requiring a respect and value for “community” processes, knowledge and needs.

- Research Results Include Interdependent, Relational and Moral Aspects of Contamination Impacts
Native-Based References:

- Arquette, Mary et al. “Holistic Risk-based Environmental Decision-making: A Native Perspective”, Environmental Health Perspectives, Environmental Justice, 110 (suppl 2) 2002-04-0
- English, KC, Wallerstein, N, Chino, M et al. “Intermediate outcomes of a tribal community public health infrastructure assessment”. Ethnicity and Disease 14, 3 Supplement 1
- Peat, David. 1994. Lighting the Seventh Fire. NJ: Birch Lane Press
Latino Research Model

- Migrant Farmworkers and Pesticide Exposure Studies

_A Community and Academic Partnership to Address Farmworker Pesticide Exposure in North Carolina_

Latino Research Model

- Quandt et al. worked outside of traditional models to build trust with the exposed communities by discussing power and privilege issues, negotiating and articulating scientific and cultural boundaries.
They built methods that would accommodate multiple sectors of the community; drawing on local knowledge to adapt research designs to the specific contextual conditions.
Time and Space Flexibility

- Community partnerships can require new adaptations to time and space.
- Community groups are in much more flux than academic centers.
- Scheduling meetings, appointments and setting up locations are much more varied, needing a flexibility that is much more demanding than that of researchers working with each other in an academic center.
Community Forums

- To gather in community knowledge and community feedback to research designs and methods, the research project sponsored community forums.

Picture: http://www.globalalumina.com/Gallery/full/Community_Forum_With_GAC.jpg
Community Forums

- These forums offered avenues for expressing multiple forms of discourse (skits, role plays, community dinners, social events) for acquiring understandings about pesticide exposures.
“The Face to Face”

- Research sampling methods and data analysis were enhanced with in-person, on-site discourses with Latino community members.
- Written reports, publications and educational materials were worked on in face-to-face interactions with specific community staff that required more time and negotiations of presentation.
African-Americans and Storytelling Projects

- Alaimo et al. write of the use of storytelling in their article "We don’t only grow vegetables, we grow values.." a research project on neighborhood benefits of 14 community gardens in four neighborhoods of Flint.

- Results from the storytelling indicated community conditions regarding social capital, intergenerational relationships, crime and disorder prevention and perception of neighborhood environments.

Alaimo, K., Reischl, T. et al. “We don’t only grow vegetables, we grow values,” Neighborhood Benefits of Community Gardens published in Brugge, D. and Hynes, P. Community Research and Environmental Health, 2005:134
Individualized Narratives

- The data collection integrated both quantitative and qualitative methods including participant observation, personal interviews, photography, a survey of neighborhood residents in three of the four case study neighborhoods and storytelling.
Individualized Narratives

- The storytelling provided rich, detailed individualized narratives, that can inform quantitative results, leaving the study participants’ perspectives in tact.
Researcher Learning

- The community stories and storytelling in the community garden projects facilitated trust and the building of relationships between researchers and the community. They allowed for a learning process by the researcher as well as the community.
Researcher Learning

- The qualitative data of the stories allowed the individual gardeners to own the research findings in a personal way; providing a rich personal and cultural context for researchers to interpret quantitative findings.
CBPR and Inner-City Asthma


El Puente, a community organization in Brooklyn, NY, used Service Delivery Surveys. In this study is a mix of quantitative and qualitative data gathered by existing community organizations.

Community researchers conduct questionnaires, face-to-face interviews, public discussions of survey designs and results, with an emphasis on understanding environmental contextual conditions and personal health issues, for action outcomes.
Community Health Educators

- Local community health educators were recruited and trained at local colleges on the etiology of asthma, epidemiological methods (survey methods) and community meetings facilitation.

- The CHEs were bridge-builders between residents, cultural and folk practices, professional providers of clinical health care and medication regimes.
Collective Self-Help

- Community-based efforts to deal with asthma were not only to generate local knowledge about conditions but to organize collective self-help strategies.

- The CHEs conducted asthma management plans along with survey data collection and findings.
These asthma management plans were individualized for children, adults and families. They assisted in reducing in-home triggers, housing conditions, indoor heating methods, smoking, pesticides, cockroaches, etc....

The CHEs translated health documents, accompanied individuals to physician offices, helped patients understand social services and their health rights.
Other Community Responses

- Mural projects in an urban neighborhoods educated the community on indoor air triggers for asthma, the effects on the body from asthma, and what sufferers can do for treatment.

- Latino home remedies – legitimized the use of herbal or other home healing remedies.
CBPR Youth Project – Airbeat, Roxbury, MA

- The Roxbury community-based organization, Action for Community Alternatives (ACE) organized the Roxbury Educational Empowerment Project (REEP) for high school youth to identify and solve community environmental and health problems.
Youth Outreach

Two youth outreach methods were an in-school curriculum and after-school internship project.

Youth mapped air pollution sources: salons, waste facilities, bus depots.

They focused in on 15 bus depots in Dudley Square and 1,150 diesel buses within 1.5 miles of Dudley Square.
REEP Anti-Idling Day

- 75 grade school and high school students marched on the streets of Roxbury in 1997 and handed out anti-idling tickets to polluting buses and trucks to educate them on the law for a 5 minute limit to idling.
- Significant newspaper and television coverage was achieved for this community-based education effort.
- Youth also developed a flag warning system and environmental justice tours of Roxbury.
- The school curriculum centered on asthma and environmental and public health topics.

![Image: idling makes kids sick](http://energyemp.com/wp-content/uploads/2009/05/no_idling_sticker.jpg)
Research Ethics and Cultural Difference

- Research designs and results need a fairer representation of diverse community-based/cultural groups than solely quantitative research.

- One-sided designs and their results can stigmatize cultural groups and whole communities.
Research Ethics and Cultural Difference

- The health literature on a cultural group may just represent its health problems or traumatic stresses and not incorporate cultural and community strengths and contextual narratives.

- This leads to literature sources that are collectively stigmatizing whole cultural groups with a predominance of reporting on their most adverse conditions. Here again, ethics can assist with this by providing new models for research reporting.