Citizen Science as a Strategy for Involving Communities in Health Research

Linda Silka
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Most of Us Working in Health are Familiar with Community-Based Participatory Research
Less so with Citizen Science
Community-Based Participatory Research and Citizen Science

- Both are forms of public participation in research
- Both involve working collaboratively with community members
- Both have strengths but have different histories, topics, approaches
A Few Examples of...

Citizen Science
- Trout Unlimited River’s Calendar Data Collection
- Bike Tourism in the Mississippi Valley
- Bird Counts
- Folding Genes Online Data Collection

CBPR
- North Carolina African-American Hog Farmers Environmental Health Studies
- Chagas Disease Study
- Peruvian Study
- Arsenic In Private Wells
Why These Approaches? Why Now?

- Recognizing limitations with past research practices
- Increased understanding that some problems better addressed through collaboration
- Increasingly seeing need for many types of expertise
- Increasingly recognizing need for “Knowledge-to-Action” emphasis
Both of These Approaches….

- Are Rapidly Growing and in Problem Solving Stage
- Aim to Strengthen Scientific Outcomes and Advance Knowledge
- Work to Add Rigor to Participatory Data Collection
- Are Trying to Ensure Groups Participate in Ways that Enhance Use of Research Findings
- Are Trying to Make Sure Research Leads to Action
Cambodian Community Health 2010

Mission:

The Cambodian Community Health 2010 project is funded by the U.S. Department of Health and Human Services Centers for Disease Control and Prevention. This project was established in 1999 to address the health care needs of the Cambodian population as well as to help eliminate health care disparities in the areas of Cardiovascular Disease and Diabetes. A coalition of Lowell health agencies are implementing actions to modify risk behaviors and educate health care providers regarding the health disparities in the Cambodian community. These agencies have a commitment to providing educational and outreach activities in preventing and managing Diabetes and Cardiovascular Disease.

Goals of CCH2010 Program:

- To identify and implement effective and sustainable ways to improve the health status of Cambodians in Lowell.
- To increase access to the health care delivery system for Cambodians.
- To increase awareness among health providers about Cambodian health care beliefs, practices, and needs relating to Cardiovascular Disease and Diabetes.
- To decrease risk factors and behaviors and enhance protective factors associated with Cardiovascular Disease and Diabetes.
- To increase the capacity of public health researchers to conduct community based research regarding the Cambodian community. This will increase data available regarding Cardiovascular Disease and Diabetes.

Community-Based Participatory Research

FOR THE CAMBODIAN COMMUNITY:

- Case Management services for Cambodians with Diabetes and/or Cardiovascular Disease
- Newsletters in Khmer
- Tours for community residents of health and human service providers in Lowell (such as the police department, Trinity Ambulance, Lowell General Hospital)
- Peer support groups for Cambodians with Diabetes and/or Cardiovascular Disease
- Tai Chi classes
- Walking Meditation Programs
- Khmer Radio, Kemer TV, Khmer newspaper outreach efforts
- Educational workshops (linguistically and literacy appropriate) Covering: Heart Disease, Hypertension, Diabetes, High Cholesterol, Stroke
- Audio tapes in Khmer about Diabetes, Stroke and Hypertension
- Community screenings for blood pressure and blood sugar throughout the year
- Home visits for special concerns

For more information on services contact:

Cambodian Community Health 2010
Sidney Liang
Lowell Community Health Center
978-746-7829
sidneyli@lchealth.org

For providers & community agencies:

- Staff & provider education
  - Medical interpreter training program
  - User friendly guide to Cambodian Health Care beliefs, practices and culture
  - Presentations about Cambodian health beliefs, practices and culture
  - Khmer Medical Terminology Reference Booklet

Patient Education & Intervention

- Fact sheets in Khmer about Diabetes, medications and foot care
- Fact sheets in Khmer about Heart Disease
- A diabetes screening tool in English and Khmer
- Curriculum guide for community education and health promotion about Diabetes and Cardiovascular Disease for Cambodians
- Audio tapes in Khmer about Diabetes, Stroke and Hypertension
- American Heart Association’s Six Steps to a Healthier Heart in Khmer
- Practical Guide to Outreach in the Cambodian Community

Research

- Results from a behavior risk factor survey studying adult Cambodians in Lowell
- Summary data report summarizing available quantifiable data regarding Diabetes and Cardiovascular Disease among Cambodians
- Community conversations publications addressing health care needs of the Cambodian community

Selected Health Indicators - Lowell, MA

- It is estimated that over 25,000 residents of Lowell are of Southeast Asian descent, out of a total population of 125,000 residents.
- At least 72% of Cambodians were born in circumstances such as refugee camps.
- 60% of the adult Cambodian population have no formal U.S. education.
- Close to 87% of Cambodians identify as Buddhists.
- 75% of adults prefer their native Khmer language to English.
- 75% of adults practice traditional medicine and the use of herbs as treatment for illness.
- 45% of the adult Cambodian male population has never had their cholesterol checked in comparison to only 4% of the adult MA male population who have not had their cholesterol checked.
- Heart disease is the leading cause of death for both Cambodian and MA adults.
- Among adult Cambodians in Lowell, a disproportionate share of adult deaths are attributable to stroke, 15.99%, and diabetes, 13.4%, when compared with all MA residents, 6.5% and 2.5% respectively.

Source: Bureau of Health Statistics, MA DPH & Cambodian BPH 3.
Lawrence, Massachusetts

Worker-Scientist Community-Based Participatory Research
Maine....... Citizen Science!
Partnership Citizen Science

Members of the public engaging in real-world scientific investigations: asking questions, collecting data, and/or interpreting results.
Citizen Science Research Outcomes

Documenting range shifts
(Bonter et al. unpublished data, Batalden et al. 2007)

Identifying vulnerable species
(Crimmins et al 2008, 2009)

Health planning
(Levetin and Van de Water 2008)

Anticipating effects on water sources

Citizen Science Learning Outcomes

Science learning, critical thinking
(Trumbull et al. 2000, Kountoupes and Oberhauser 2008)

Environmental action; social networks
(Overdevest et al. 2004)

Social capital
(Ballard 2008)

Improved policy
(Wing et al. 2008)
## Citizen Science Types of Partnership

<table>
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<tr>
<th>Contributory</th>
<th>Collaborative</th>
<th>Co-Created</th>
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<tbody>
<tr>
<td>Define a question/issue</td>
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<td>Gather information</td>
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<td>Develop explanations</td>
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<td>Design data collection methods</td>
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<td>Collect samples</td>
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<td>Analyze samples</td>
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<tr>
<td>Analyze data</td>
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<tr>
<td>Interpret data/conclude</td>
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<td>Disseminate conclusions</td>
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<td>Discuss results/inquire further</td>
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(Bonney et al. 2009)
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"Silos" in the Democratization of Science

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Abstract
Efforts aimed at democratizing science continue to emerge, but these many efforts remain isolated from each other. This article argues that the full impact of democratization efforts will not be felt until they are integrated with each other. Two strategies for integration are proposed: a typology approach and a generative strategy. Uses of such strategies in other areas have been successful and offer pathways for coordinating science efforts. The article ends with recommendations for how such strategies could be pursued to integrate promising but dispersed democratization of science efforts such as citizen science, community based participatory research, participatory action research, and public participation in scientific research.

Keywords: democratization of science, citizen science, community based participatory research, participatory action research, public participation in scientific research, boundary spanning, wicked problems
CBPR: Israel’s 9 Principles of CBPR and Emphasizing Strategies for Collaborating at Every Stage

- Who *Starts* Research Partnerships and How?
- Who *Builds* the Partnership?
- Who Decides *What* Will Be Studied?
- Who Decides *What* Will Be Done With What Is Learned?
Ex: CBPR Strategy Tools Such As The Research Cycle Model

Preparing for Issues That Emerge at Each CBPR Stage
## Ex: Citizen Science Strategy Tool

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<thead>
<tr>
<th>Type of Partnership</th>
<th>Problem Identification</th>
<th>Research</th>
<th>Proposed Solutions</th>
<th>Implementation</th>
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<tbody>
<tr>
<td>University as <strong>Lead</strong> Partner</td>
<td>Researchers</td>
<td>Researchers</td>
<td>Researchers</td>
<td>Municipal Officials</td>
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<tr>
<td>University as <strong>Consulting</strong> Partner</td>
<td>▪ Researchers ▪ Municipal Officials</td>
<td>Researchers</td>
<td>Researchers</td>
<td>Municipal Officials</td>
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<td>University as <strong>Facilitating</strong> Partner</td>
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<td>Municipal Officials</td>
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<td>University as <strong>Full</strong> Partner</td>
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<td>▪ Municipal Officials ▪ Researchers</td>
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Bringing CBPR and CS Together: University of Maine teacher Darren Ranco joins forces with Maine tribal members and basketmakers to address invasive species: Made from native brown ash trees, Maine Indian baskets are functional art forms that have been passed down through generations of the region’s tribal communities. But the future of the art is being threatened by an invasive beetle species — the emerald ash borer — that already has devastated the ash populations in states such as Michigan and Ohio, and is being found in trees in New York and in Quebec.
Ex: Literatures CS People Are Consulting

- Boundary Spanning Literature
- Social Networking Literature
- Resilience Literature
- Management of “the Commons” Literature
- Natural-Human Coupled Systems Literature
- Communication Literatures
- Scale Up Literatures
Next Steps: Learning From What They Are Talking About Among Themselves

CBPR: The Bus Metaphor Analysis
CS: The Loading Dock Problem
Resources

- Community Campus Partnerships for Health (website: ccph.info)
- Citizen Science Association (website: CitizenScienceAssociation.org)
- Cooperative Extensions websites (e.g. www.uwex.edu)
- Kansas’s Community Toolkit (ctb.ku.edu)
And Don’t Forget This Tool.....

Define a question/issue
Gather information
Develop explanations
Design data collection methods
Collect samples
Analyze samples
Analyze data
Interpret data/conclude
Disseminate conclusions
Discuss results/inquire further

(Bonney et al. 2009)
Contact Information

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