

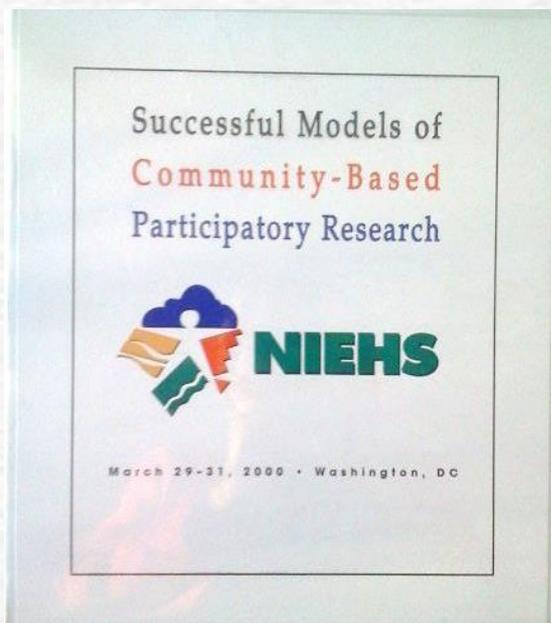


Citizen Science as a Strategy for Involving Communities in Health Research

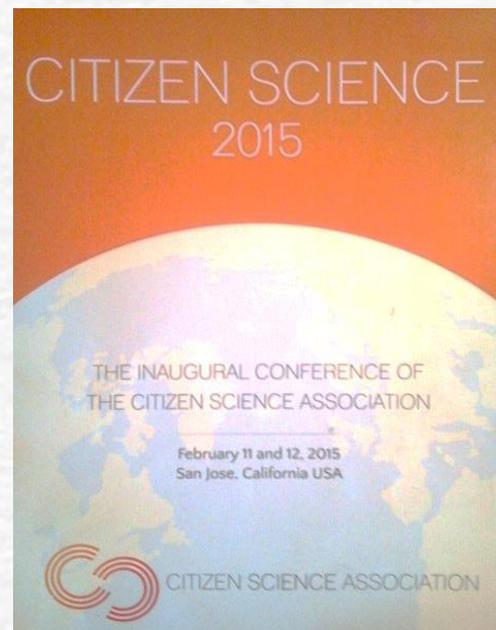
Linda Silka
University of Maine



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

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.



Cambodian Community Health 2010



The CAMBODIAN COMMUNITY HEALTH 2010 project is funded through grant number U54CCU-122151 from the United States Department of Health and Human Services, Centers for Disease Control and Prevention. It is part of a federal initiative entitled, Racial and Ethnic Approaches to Community Health 2010 (REACH 2010). By fostering community mobilization and resources, REACH 2010 encompasses a goal under Healthy People 2010, to eliminate disparities in health status experienced by racial and ethnic populations.

LOWELL COMMUNITY HEALTH CENTER
is the central coordinating agency

Community-Based Participatory Research

Resources

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, Khmer 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@cchealth.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* publication addresses health care needs of the Cambodian community

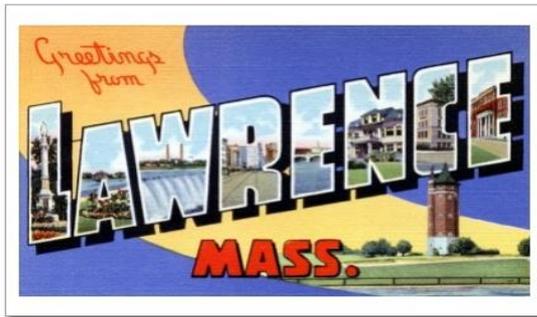
SELECTED HEALTH INDICATORS - LOWELL, MA

- It is estimated that over 25,000 residents of Lowell are of Southeast Asian descent, out of a total population of 105,000 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.
- 78% 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 all MA adults.
- Among adult Cambodians in Lowell, a disproportionate share of adult deaths 45 and older are attributable to stroke, 15.99%, and diabetes, 13.4%, when compared with all MA residents, 6.5% and 2.5% respectively.

*Bureau of Health Statistics, MA DPH & Cambodian BRFSS

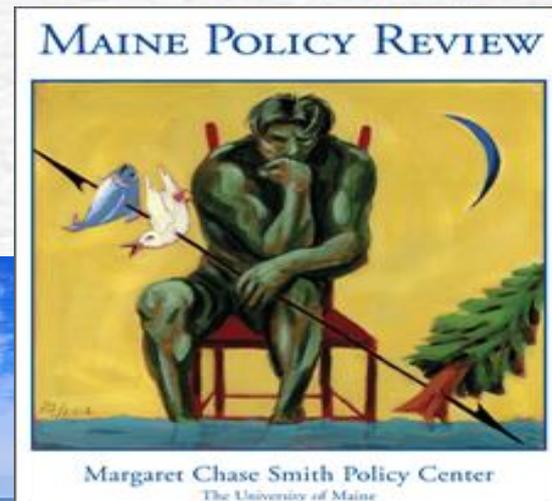
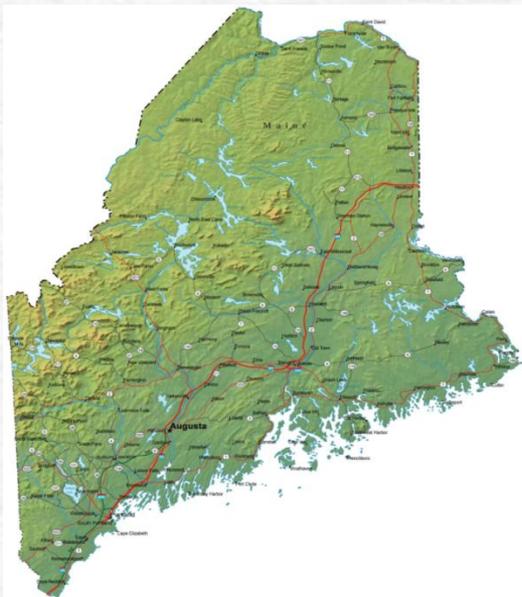
Cambodian Community Health 2010

Lawrence, Massachusetts



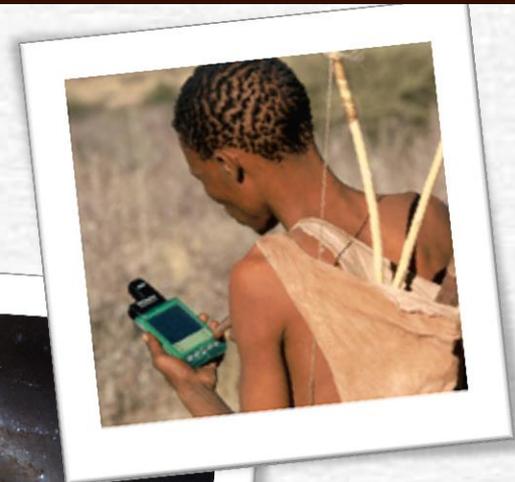
Worker-Scientist Community-Based Participatory Research

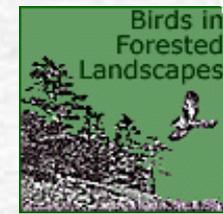
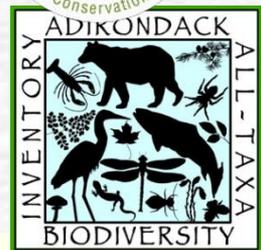
Maine..... Citizen Science!



Partnership Citizen Science

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





TAXILES SKIPPER © PAUL A. OYLER



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

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

Contributory

Collaborative

Co-Created

(Bonney et al. 2009)

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"Silos" in the Democratization of Science

Linda Silka
University of Maine

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

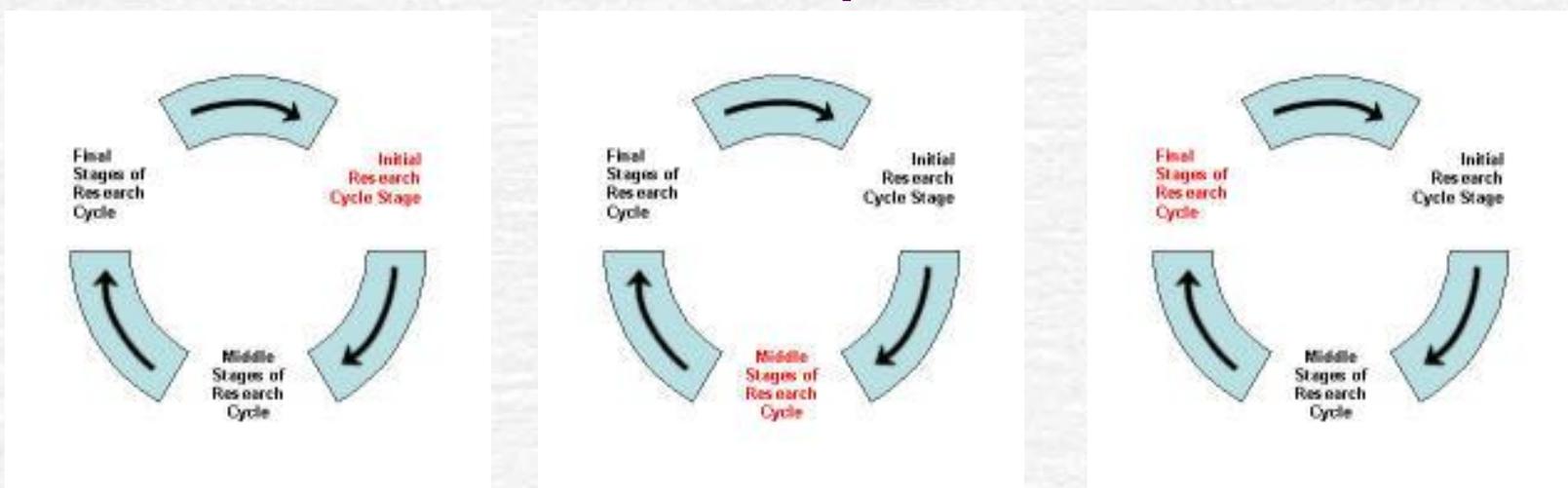


CBPR: Israel's 9 Principles of CBPR and Emphasizing Strategies for Collaborating at Every Stage

- ❖ 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

Type of Partnership	Problem Identification	Research	Proposed Solutions	Implementation
University as Lead Partner	Researchers	Researchers	Researchers	Municipal Officials
University as Consulting Partner	<ul style="list-style-type: none"> ▪ Researchers ▪ Municipal Officials 	Researchers	Researchers	Municipal Officials
University as Facilitating Partner	<ul style="list-style-type: none"> ▪ Researchers ▪ Municipal Officials 	Researchers	<ul style="list-style-type: none"> ▪ Researchers ▪ Municipal Officials 	Municipal Officials
University as Full Partner	<ul style="list-style-type: none"> ▪ Researchers ▪ Municipal Officials 	<ul style="list-style-type: none"> ▪ Researchers ▪ Municipal Officials 	<ul style="list-style-type: none"> ▪ Researchers ▪ Municipal Officials 	<ul style="list-style-type: none"> ▪ Municipal Officials ▪ Researchers



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

Contributory

Collaborative

Co-Created

(Bonney et al. 2009)



Contact Information

Linda Silka

Silka@maine.edu

