Academic-Community Partnerships: Networks Near and Far

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Brown University

Partnerships for Environmental Public Health
March 7, 2012
NIH Natcher Center

Our PEPH team at Brown University

Children's Environmental Health Center
(Evaluation of the Formative Impacts of Fetal Development)

Superfund Research Program
(Reuse in Rhode Island: A State-Based Approach to Complex Exposures)

Brown/Silent Spring Institute/Communities for a Better Environment/University of California-Berkeley

Contested Illnesses Research Group

Early Origins – Contested Illnesses Research Group Responds to Requests for Assistance

Alliance for a Health Tomorrow

- Needed pesticide survey

Silent Spring Institute

- Needed data on history of public involvement in science

Toxics Action Center

- Needed interviews and analysis of local leaders' activism trajectories

Early Origins: Environmental Health Research Ethics Training

- NIH Environmental Health Research Ethics grants with Dianne Quigley for training and education
  - Enabled us to bring her on as adjunct faculty in Environmental Studies to teach Research Ethics
  - Workshops in Boston and Providence on research ethics, environmental justice, CBPR

Working with friends at Alternative for Community and Environment (ACE)

Research Ethics Workshop

PREPARING FOR RESEARCH IN THE COMMUNITY

Monday September 23, 2002

1-4 PM

Harvard School of Public Health

1. Brief Introduction - Phil Brown, Brown University
2. Group introductions

Case Studies: Learning from the Field

3. Dianne Quigley, Syracuse University
4. Penn Loh, Alternatives for Community and Environment (ACE)
5. Neal-Dra Osgood, Committee for Boston Public Housing
6. Attieno Davis, Committee for Boston Public Housing

ACE and Toxics Action Center help us lay groundwork for formation of Environmental Justice League of Rhode Island

Activists' Workshop

Providence Environmental Justice Educational Forum

November 19, 2004

First Session

Quita Sullivan (Alternatives for Community and Environment), and Matt Wilson (Toxics Action Center)
"Environmental Health and Justice Networks: How it works in Michigan and Massachusetts, How it could work in Rhode Island"

Second Session

Gail Corvello (Environmental Neighborhood Awareness Committee of Tiverton)
"Victories and Setbacks: ENACT's Ongoing Effort to Clean Up Hazardous Waste Under our Homes"

Third Session

Sandra Neugen (Alton Community Action)*"ACA's Campaign for Clean Air and Clean Water"*
Gina D'Ambra (Bradford Citizens Against Pollution)*"BCAP's Campaign to Clean Up the Bradford Textile Dyeing Company"*
Eric Garcia (Rhode Island Minority Asthma Collaborative of American Lung Association) *"Tracking Asthma in Rhode Island"*

Fourth Session

Discussion: How can we build an Environmental Justice Collaborative in Rhode Island?

May 2003 National Conference at Brown: Dialogues for Improving Research Ethics in Environmental and Public Health

THE COLLABORATIVE INITIATIVE FOR RESEARCH ETHICS IN ENVIRONMENTAL HEALTH

Announces

A NATIONAL CONFERENCE on

"DIALOGUES FOR IMPROVING RESEARCH ETHICS in ENVIRONMENTAL and PUBLIC HEALTH"

Friday, May 30, 2003
Sunday, June 1, 2003

At Brown University, Providence, Rhode Island

For More Information: contact
Dianne Quigley - diquigle@syr.edu
Tel (315)443-3861, Syracuse University,
please see our website www.researchethics.org

Conference Purpose:

This conference is organized to bring together community representatives, academic scientists, and government and private research agencies and funders in the field of environmental and public health to facilitate a dialogue on important research ethics issues. Through case study presentations and panel discussions, the conference organizers seek to generate new recommendations, tools and resources for dealing with the difficult challenges of the research ethics issues identified below.

Conference Panels - May 30 – June 1, 2002

Panel One

Research Protections and Institutional Needs

This panel will identify research protections needed for communities lacking experience with community-based research (CBR). Finding funding for CBR and recruiting appropriate research partners are major challenges. This panel will review models of community experiences with research protections and research partners. It will also explore the possibilities of establishing regional community research centers or new university programs for community-based research.

Panel Two

Promoting Community (Group) Rights in Research

This panel will consider the problems of community/groups rights in research. Few guidelines and regulations exist to protect group or community rights in research. The complexities of establishing community rights, such as defining community, building community authority, mediating community differences, will be discussed. How these can be promoted with funders and IRBs and effect national research policy changes will be explored.

Panel Three

Reshaping Science for Environmental and Public Health

Communities are demanding new changes to science that would overcome the narrow limitations of solely quantitative research outcomes. This panel will offer presentations on holistic models of science, including Native science where social, spiritual and other qualitative impacts are assessed as part of the research activity. Democratic knowledge production and the historical problems of ethics in western science will be highlighted.

Panel Four

Perspectives on the Status of Funding Community-Researcher Partnerships

This panel will address two major challenges to community research ethics. These include (1) how to help communities have more access to research funding and to have grants go directly to their organizations and (2) how do we make more funding available for preparing communities for research - building infrastructure, learning benefits/risks of research, and research ethics. Various presentations will be offered to address resolutions to these long-standing problems.

Panel Five

Institutional Review Boards (IRBs) and Institutional Protections

IRBs all over the country are grappling with the problems of community rights. Presentations and discussion will be offered on how IRBs can be more prepared for evaluating community rights in research and the major challenges still to be addressed.

Panel Six

Research Ethics and Community Partnerships

Community partnerships are critical to improving research ethics and dealing with environmental and public health problems. This panel will review progress in the field for making these partnerships successful. This includes new work on (1) research life cycle approaches to partnerships (2) current successful partnerships in participatory action research and CBR (3) strategies and considerations in finding the right research partners and (4) understanding the contexts, values and knowledge traditions of our partners for consensual decision-making.

Caucuses/Affinity Groups

Participants may organize caucus or affinity group discussions on issues of their specific interests. These will be organized on Friday evening.

This conference is sponsored by The Collaborative Initiative for Research Ethics and Environmental Health and is funded by a grant from the National Institute of Health, National Institute of Allergies and Infectious Disease Grant Program for Research Ethics - T15 A149650-01

At the conference…

- Shobha Srinivasan highlighted the EJ grant program
- Brown University and Silent Spring Institute immediately pursued this opportunity

Linking Breast Cancer Advocacy and Environmental Justice

- Conduct community-based exposure assessment in Cape Cod and Richmond, CA
- Community-based outreach and education
- Develop guidelines for reporting back study results to communities and individual study participants
- Connect breast cancer movement with EJ movement

Linking Breast Cancer Advocacy and Environmental Justice Publications

"Improving Disclosure and Consent: 'Is It Safe?' New Ethics for Reporting Personal Exposures to Environmental Chemicals" (J. Brody, R. Morello-Frosch, P. Brown, R. Rudel, R. Altman, M. Frye, C. Osimo, C. Perez, and L. Seryak). *American Journal of Public Health*, 2007 97: 1547-1554

"Elevated house dust and serum concentrations of PBDEs in California: Unintended consequences of furniture flammability standards?" (A. Zota, R. Rudel, R. Morello-Frosch, and J. Brody). *Environmental Science and Technology* 2008 42:8158–8164

"Pollution Comes Home and Gets Personal: Women's Experience of Household Chemical Exposure." (R. Altman, R. Morello-Frosch, J. Brody, Ruthann Rudel, P. Brown, and M. Averick) *Journal of Health and Social Behavior* 2008 49:417-435

"PCB-containing wood floor finish is a likely source of elevated PCBs in residents' blood, household air and dust: a case study of exposure." (R.Rudel, L. Seryak and J. Brody. 2008. *Environmental Health*, 7:2

"'Toxic Ignorance' and the Right-to-Know: Assessing Strategies for Biomonitoring Results Communication in a Survey of Scientists and Study Participants" (R. Morello-Frosch, J. Brody, P. Brown, R. Altman, R. Rudel, C. Pérez. *Environmental Health*. 2009 8:6

"Linking Exposure Assessment Science with Policy Objectives for Environmental Justice and Breast Cancer Advocacy: The Northern California Household Exposure Study" (J. Brody, R. Morello-Frosch, A. Zota, P. Brown, C. Pérez, and R. Rudel) *American Journal of Public Health* 2009 99:S600-S609

"Institutional Review Board Challenges Related to Community-Based Participatory Research on Human Exposure to Environmental Toxins: A Case Study" (P. Brown, R. Morello-Frosch, J. Brody. R. Altman, R. Rudel, L. Senier, C. Pérez and R. Simpson) *Environmental Health* 2010 9:39.

"Semivolatile endocrine disrupting compounds in paired indoor and outdoor air in two northern California communities." (R. Rudel, R.Dodson, L. Perovich, R. Morello-Frosch, D. Camann, M. Zuniga, A.Yau, A.Just, and J.Brody). *Environmental Science & Technology*, 201044 (17), pp 6583–6590

"Disentangling the Exposure Experience: The Roles of Community Context and Report-back of Environmental Exposure Data" (C. Adams, P. Brown, R. Morello-Frosch, J. Brody, R. Rudel, A. Zota, S. Dunagan, J. Tovar, and S. Patton*). Journal of Health and Social Behavior* 2011 52 (2):180-196

See our article on CBPR aspects of this project in March 2012 EHP

Measuring the Success of Community Science: The Northern California Household Exposure Study

Phil Brown, Julia Green Brody, Rachel Morello-Frosch, Jessica Tovar, Ami R. Zota, Ruthann A. Rudel

Research trajectory from that first EJ grant

- Linking Breast Cancer Advocacy & Environmental Justice (NIEHS) *and* Research Right -to-Know: Ethics and Values in Communicating Research Data to Individuals and Communities (NSF)
  - *partners:* Silent Spring Institute, Communities for a Better Environment, UC-Berkeley (NIEHS) and (NSF)

Led to:

- "Ethical and Legal Challenges in Communicating Individual Biomonitoring and Personal Exposure Results to Study Participants: Guidance for Researchers and Institutional Review Boards" (NIEHS)
  - *adds partners: Harvard Law School and Harvard School of Public Health*
- "Toxic Ignorance and the New Right-to-Know: The Implications of Biomonitoring for Regulatory Science." (NSF)
- "Flame Retardant Chemicals: Their Social Discovery as a Case Study for Emerging Contaminants" (NSF)
- Addition (ViCTER) to "Ethical and Legal Challenges in Communicating Individual Biomonitoring and Personal Exposure Results to Study Participants: Guidance for Researchers and Institutional Review Boards." (NIEHS)
  - *adds partners: Harvard Law School, Harvard School of Public Health, Harvard Dept. of Computer Science*

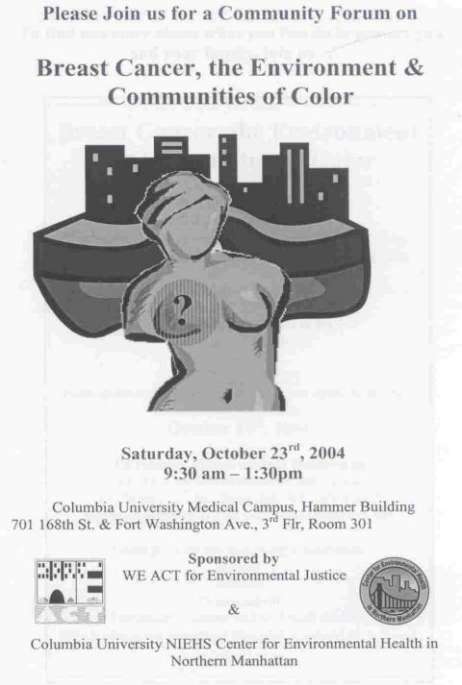
Also, pending grant:

- "Data Sharing and Privacy Protection in Digital-Age Environmental Health Studies" NIEHS)
  adds partner: Harvard Department of Computer Science (additional computer scientist)

Creating Connections at Annual Grantees Meeting

- Overall, amazing venue to meet people around the US doing this work

- Specific connections on breast cancer and EJ
  - WEACT and Concerned Citizens of Tillery – led us to help with WEACT conference on Breast Cancer, the Environment, and Women of Color”


Please Join us for a Community Forum on

Breast Cancer, the Environment & Communities of Color

Saturday, October 23rd, 2004
9:30 am – 1:30pm

Columbia University Medical Campus, Hammer Building
701 168th St. & Fort Washington Ave., 3rd Flr, Room 301

Sponsored by
WE ACT for Environmental Justice

&

Columbia University NIEHS Center for Environmental Health in Northern Manhattan

NIEHS Environmental Justice Grantees Conference, 2007 – Our Team Hosts

NIEHS Environmental Justice Grantees Conference

Continuing Networks and Connections

ACAT
Alaska Community Action on Toxics

- My past graduate student Becki Altman (now with Science and Environmental Health Network) interned at ACAT and prepared Bulletin on toxics and reproductive health

- My current student, Alissa Cordner interned there and revised the Bulletin

- We helped them think about how to deal with IRB problems in their PCB research

- Our NIEHS grant on bioethical issues in reporting back data includes the “Is it in Us?” study that is co-led by ACAT’s director Pam Miller

- Liz Hoover, faculty member in CIRG research group is collaborating with ACAT on project on environmental health in Native American and Alaska Native communities

Continuing Networks and Connections

Commonweal

- Commonweal joined our “Linking Breast Cancer Activism and Environmental Justice” project when we added Bolinas to Richmond as a sampling location

- Our NIEHS grant on bioethical issues in reporting back data includes the “Is it in Us?” study that is co-led by Commonweal’s Sharyle Patton

- Commonweal started Health Care Without Harm, with whom our Superfund and Children’s Center collaborate in Hospitals for a Health Environment in RI

New Networks and Connections

- **Erin Haynes** (University of Cincinnati), PI of a PEPH grant "Communities Actively Researching Exposure Study (CARES)" wanted help with formats for reporting back data to participants - We shared our models from our EJ grant.

- **David Taylor** (Roger Williams University – Bristol RI) wanted help in extending his fish mercury research to human exposures in anglers– We collaborated on a new proposal with RWU, Brown, and Silent Spring Institute, since Laurel Schaider has a PEPH Research-to-Action grant on mercury in Tar Creek, OK anglers

Enduring Networks and Connections

- **We have made friends and colleagues in these processes that we treasure, and make us feel deeply connected to a large environmental health and justice community**

Talkeetna

Need Multi-pronged Approach on campus

- Work with community organizations and make that widely recognized
- Teach students about EJ and CBPR in regular and service-learning courses
- Develop more courses
- Get other faculty interested in this work, to develop campus-wide group
- Educate faculty in your own department
- Solicit administration support financially and organizationally
- Educate IRB about special needs of CBPR projects
- Collaborate with other environmental health researchers who may not yet be doing this kind of work
- Link up with like-minded academics and community groups across the US

Impact of a Research Group

- Contested Illnesses Research Group (CIRG)
  - Integrates all of our environmental health and justice work
  - Started 2000
  - “Social science lab” – analog to science lab
  - Currently two faculty, 3 postdocs, 6 doctoral students
  - Weekly meeting for discussion of articles in progress, grant writing, guest scholars, discussion of outreach and engagement activities
  - Training and socialization in all components of interdisciplinary work, much of it with biomedical scientists – this includes joint appointments, as with current Mellon postdoc in Environmental Studies and Pathology, teaching a course in each
  - New NSF training grant on Environmental Health Research Ethics Involving Emerging Contaminants and Technologies

Superfund Research Program Community Engagement Core

Tiverton ENACT

Work with Environmental Neighborhood Action Group (ENACT) to obtain adequate clean up of the soil contamination that has been discovered in Tiverton from manufactured gas plant waste

Local demonstration

Gas plant waste found in soil

Disrupted lives

Woonasquatucket River Watershed Council

- Helped to plan educational events concerning the development of site clean-up plans for the Centredale Manor NPL site
- Convinced EPA to sample dioxin contaminated sediment deposited from floods in highly used public parks
- Proposing a plan for procedure for future catastrophes

Cleanup

Flooding dislodged toxic sediment

Recreation

Environmental Justice League of Rhode Island

- Gorham cleanup – major industrial legacy site where high school was built
- Energy Efficient Barn Raisings
- Science Café
- GreenStage – high school theater group, with public performances
- Brownfields Environmental Equity Stakeholder Workgroup (Dept. of Environmental Management)
- Community Environmental College
- Providence Healthy Corner Store Initiative

Energy Efficient Barn Raising

Healthy recipes for the community

Community Environmental College

Creating a shared knowledge base about environmental justice issues in the community

- **Three summer courses for Providence youth: *Environmental Justice; Food Justice; Leadership, Media and the Arts* – 47 students in third year 2011**
- **Field trips to local farms, the landfill, a wind turbine and a "toxic tour" of Providence**
- **Expanding into a year-round environmental justice leadership program**

Guest speakers

"Toxic tour" of Providence

Rosasharm Farm

Providence Healthy Corner Store Initiative

For equal access to healthy foods in urban areas:

- Student and community leadership teams
- 3 corner store makeovers in 2010, 12 in 2011
- Statewide policy initiative

Working with store owners

Engaging the media

Shifting to healthy foods

Key element of our work – sustainability for community partners

Environmental Justice League of RI has become our most involved partner

We have played major role in writing proposals, with successes like EPA CARE grant and many other state and private grants.

Children's Environmental Health Center Community Outreach and Translation Core

Environmental health training for early intervention and developmental disability home visitors

Meeting Street School arranged for us to present to RI Inter-Agency Coordinating Council for early intervention programs, January 20, 2011

Hospitals for a Healthy Environment in RI

- Coalition of hospitals, hospital associations, professional associations, nursing schools, unions, academic institutions, government agencies, local food groups, and environmental organizations

- Promotes cost effective, efficient, healthy and sustainable green care practice in health care institutions

Hospitals for a Healthy Environment in RI

•80 participants attended first conference March 2011

• As result of the event Miriam Hospital has appointed a sustainability coordinator, and we are doing consultations with other hospitals

• Close to 40 people are in the Hospitals for a Health Environment coalition

• We are now a member of Practice Greenhealth

•Second conference will be April 2012

In the Classroom

Our Environmental Justice seminar sends many students into the field, working with community groups with whom we have *prior* involvement.

Some of their work involves research as well as service:

- 50-state survey of state guidelines on school siting on contaminated land – published as EPA document and in another form by Center for Health, Environment, and Justice

Some of their service work gets published in major journals:

- One class project worked with a community toxics groups (Environmental Awareness Committee of Tiverton) to pass state law establishing ECHO (Environmentally Compromised Home Ownership Loan Program). Article on this published in *Environmental Science & Technology*

f*orms of community engagement*

Community Engaged Activity
Like CBPR, the needs of communities are central.
Service and education, rather than research -- topics are identified by and useful to community partners.

Community-Based Participatory Research (CBPR)
Collaborative, equitable involvement of all partners in all phases of the research, from design to dissemination.

Furthermore, CEA and CBPR can interact…

The two are part of a whole

Working with students on Community Engaged Service prepares them for CBPR in terms of their sensibilities, ethics, and experience

Students may go back and forth between the two, just as many of us do

Environmental Justice class poster session

Brown Engagement Core

A ‘one-stop shop’ for Brown student engagement in youth-related community environmental justice initiatives

- **20 dedicated students from various departments who help coordinate and implement CEC community projects**

Supporting Brown environmental leaders to get off “the hill” and into the community

Brown Engagement Core

- **Brings together students working on Superfund Research Program's Community Engagement Core, Children's Environmental Health Center's Community Outreach and Translation Core, and other related projects**

- **Creates community of students, community group partners, and faculty**

- **Generates further campus-wide activity**

- **Provides leadership training**

- **Example of current "additional" projects**
  - **Working with high school students from Eco-Youth on a community teach-in on proposed incinerator**

  - **Organizing celebration of 50th anniversary of publication of Rachel Carson's *Silent Spring***

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MI KIM CHI
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Healthy Choice!
Watermelon
Healthy Corner store
Healthy Choice!
med tom
Healthy Corner store
Healthy Choice!
Raw Peanut
$2.00/Bag
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SAU
KOSO
PRODU

What students learn – in classroom, CIRG research group, Brown Engagement Core:

- Work with community organizations
- Practice community research ethics
- Write proposals for CBPR
- Experience with national networks of activists, academics, government officials
- Reflexivity – understand their role in the field
- Become better citizens by promoting democracy
- Respond to requests from groups for assistance

How to build departmental interest:

discussions of public sociology in Sociology Department following 2004 talk by ASA President Michael Burawoy on "public sociology"

2004-2005

Forum on "Public Sociology Meets Community-Based Participatory Research"

6 workshops over the rest of the year, featuring presentations by graduate students and faculty from Sociology and other departments

Publication Potential

Show faculty and grad students that CBPR and community-engaged work has been published in top journals:

- *Journal of Health and Social Behavior*
- *American Journal of Public Health*
- *Environmental Health Perspectives*
- *Environmental Health*
- *Environmental Science & Technology*
- *Social Science and Medicine*
- *Sociology of Health and Illness*
- *Science, Technology, and Human Values*
- *Health Affairs*
- *Sociological Forum*

How to build faculty interest across campus

Work with Swearer Center for Public Service to design

Engaged Scholars Initiative

- Support individual faculty doing community-engaged work

- Build community of these scholars on campus

- Open up dialog across the campus on how faculty can do such work
Be part of national network of community-engaged scholars -- specifically working with Tulane and Pennsylvania on faculty visits for training, summer exchanges for students in community placements

- Funding for students and faculty doing engaged scholarship

Activities of the Engaged Scholars Group

- **Monthly lunches to discuss projects**
- **Annual campus-wide presentation of our work, with posters and talks**
- **Presentation to Graduate School forum**
- **Occasional special visitors with unique community approaches**
- **Collaborations between projects**

How to build faculty, grad student, and postdoc interest across campus

NSF Ethics Training Grant: "Northeast Ethics Education Partnership for Research Ethics/Cultural Competence Training"

- Ethics training session for trainees of T32 Pathobiology Training Program and Superfund Research Program
  - Brings in faculty, as well as postdocs and students

- Research ethics presentations to individual departments, followed by certificate training programs for graduate students
- Preparing ethics training program for School of Engineering

If it's that easy for academics…???

Junior faculty to need to be aware of issues

- *Potentially longer time in data gathering*
- *More complexity in developing projects and writing proposals*
- *Potentially longer time in writing articles*
- *Need to ensure that chairperson and senior faculty understand*
- *Need mentorship from senior faculty in the larger community of engaged scholars*

If it's that easy for community groups…???

Tensions in Collaborative Research

- CBOs & research: time consuming → mission drift?
- Enough time for evaluating collaborative processes and outcomes?
- What will happen if we have negative findings?
- Geographic distance between groups

Tensions in Collaborative Research

- Fundamental inequalities:

  - Salary differentials
  - Funds for infrastructure support
  - Indirect costs at universities eat up much budget
  - Legacy of “helicopter” research
  - Institutional racism—predominance of white academics and scientists working in communities of color.

- Who represents the community?
- IRB: will university IRBs cover CBOs?
- Sampling design—aligning scientific standards for sampling with community groups’ needs

Key Lessons Learned and Challenges Encountered

- There are many great opportunities to spread CBPR work across the campus
- There are many wonderful connections to make with community groups and to help sustain them
- There are great grant opportunities and publication outlets for CBPR

but

- Many scientists don't grasp EJ and CBPR, as evidenced at review panels
  - Those of us who do understand must take part in those reviews
  - We need to educate scientists more broadly about this

- Many IRBs don't grasp EJ and CBPR
  - We need to work strenuously with them and also get agency assistance
  - We need to write articles about IRB issues, especially with reporting data to participants

Advice to activists and scholars new to PEPH

- **Don't be shy – contact other groups and people**
  - **Ask for assistance**
  - **Offer your contributions**
  - **Initiate collaborations**

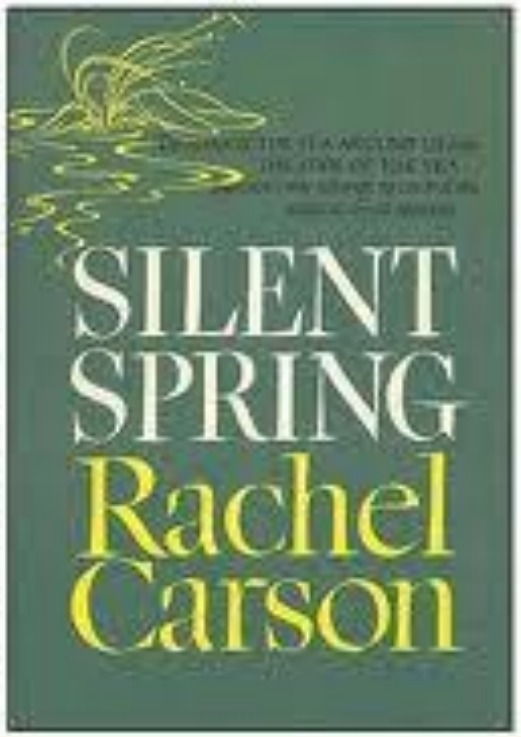
- **Post your materials to the PEPH Resource Center – people will use them**

- **Resources for you to use**
  - **PEPH Resource Center**
  - **CBPR listserv**
  - **Campus-Community Partnerships for Health**

Suggestions for NIEHS to Expand and Improve PEPH

- **Develop a traveling externship, similar to Superfund Research Program's K.C. Donnelly Externship, where young scholars and community organization members can travel to a diverse set of locations to meet and work with others**
- **Develop postdoctoral training program based at non-profit organizations so that academics can really learn CBPR first-hand**
- **Provide mentoring program for junior faculty**
- **Provide consultation for IRBs on appropriate action for community partnerships**

Other parting words: Don't forget to organize events for 50th anniversary of publication of *Silent Spring*



Women's Community Cancer Project–Precautionary Principle Mural (Cambridge)