

The Collaborative Initiative in Environmental Health has funded the development of these courses. The syllabi are attached. Additionally, we have sponsored workshops around the country and often for community members. A listing of these is included below.

(1) Courses Developed and Conducted at Collaborating Universities

- **EPID- 278 - Community-Driven Epidemiology and Environmental Justice; Steven Wing, UNC, Spring 2002.** This semester-long graduate course presented topics on research ethics in the field of public health and epidemiology; particularly for research ethics with African-American and other environmental justice affected communities. Students from public health and ecology attended this seminar-type course which included a requirement for student projects in the field. . The course syllabus with a list of materials used is in Appendix One .
- **Community-Based Environmental Health Methods for Research Intervention and Evaluation; Doug Brugge, Tufts University, Spring 2002.** This new intensive five-week course focused on community-based research, the formation of partnerships and the ethical considerations that arise in this field. The course was extremely popular and well-attended by students in Masters of Public Health and medical (MD) students. The course will be now offered on a regular basis. The course syllabus/materials is in the Appendix One.
- **Research Ethics with Underserved Groups, Linda Silka, UMASS, Lowell, MA, Spring 2002.** This new semester-long graduate course was organized around the concept of the research cycle and the ethical considerations that are important in each phase of a community research project. The course attracted graduate students from community development, social psychology and community health, who are also community leaders from Cambodian, Indonesian, French, Chilean, Puerto Rican and American backgrounds. The course was a great success and was approved for formal course offering every year. The course syllabus/materials are in Appendix One.

(2) National/International Short Course and Seminar Presentations (Past and Upcoming for Year 2)

a. Past

- (1) American Psychological Association, Panel Presentations, Aug. 25, 2001, Linda Silka, Dianne Quigley, Case Study Presentations on Research Ethics developed from grant project work.
- (2) "Research Ethics and the Woburn, MA Health Studies", Gretchen Latowsky, Community Researcher Consultant,
- (3) Presentation to the Epidemiological Methods Journal Club, CA Dept. of Health Services, Oakland, CA, Aug, 26, 2001
- (4) "Research Ethics and Environmental Health", Short Course Project Presentation to the NIEHS Grantees of the Environmental Justice Grant Programs, Steve Wing, Dianne Quigley, Linda Silka, Conference Site - UMASS, Lowell, MA, October 29, 2001
- (5) "Ethics and Technologies", Ninth European Conference of Science and Theology, Netherlands, March 19-24, 2002, Dianne Quigley, Syracuse University.
- (6) Presentation to Institutional Review Board of UMASS, Lowell on Research Ethics, Linda Silka, December 12, 2001
- (7) "Protecting People from Radiation: How Standards Get Set, and Plutonium Health Effects" at CO University, sponsored by Rocky Mountain Peace Center, Boulder, CO., Steve Wing, UNC, January 25-26, 2002
- (8) "Research Ethics Workshop 1" for Lowell Area Researchers, 3-hour short course, April 2002, Linda Silka, UMASS, Lowell
- (9) "Research Ethics Workshop 2" for Lowell Area Community Leaders, 3-hour short course, April 2002, Linda Silka, UMASS, Lowell

- (10) "Research Ethics and Research Partnership Workshop" 3-hour short course to qualitative researchers, April, 2002. Linda Silka, UMASS-Lowell.
- (11) "Health disparities, research ethics and epidemiology. Epidemiology Branch, National Institute of Environmental Health Sciences, Steve Wing, UNC, May 13, 2002
- (12) "Environmental Justice in North Carolina: the case of pork production", Peace Lunch Forum, Presbyterian Campus Ministry, NC State University, Raleigh, NC, January 31, 2002

b. Grant Project Sponsored Short Courses(Summer and Fall 2002)

- (1) "Research Ethics and Community Health Research", day-long short course for southeastern U.S community activists and health researchers; at Morehouse College, Atlanta, GA, Dianne Quigley, Syracuse University, Steve Wing, UNC,, July 27, 2002.
- (2) "Research Ethics in Environmental Health", second year short course presentation to Epidemiology Journal Club, CA Dept. of Health Services, Oakland, CA, Dianne Quigley, Syracuse University, August 13, 2002
- (3) "Ethical Issues in Community-Scientific Research Collaborations"; community short course presentation, , Western States Legal Foundation, San Francisco, CA, Dianne Quigley, Syracuse University, Aug. 13 (evening), 2002
- (4) "Preparing for Research in the Community", community activist day-long short course, Alternatives for Community and Environment, Boston-Roxbury, MA, Dianne Quigley, Syracuse University, Phil Brown, Brown University, Sept.23, 2002

Doug Brugge, PhD, MS

Catalog Description

There is growing interest in community-based research and in particular in forming partnerships with the communities affected by public health studies. More and more, these studies also engage the community in a participatory fashion in the actual research. This course will explore the various methods that are used in such studies, the benefits and challenges to such an approach and the possibility that new ethical considerations arise in such circumstances. Particular emphasis will be placed on the relationship of service, education and research, the use of focus groups, interviews and surveys and the relationship to conventional research methods. The course will include case examples and guest speakers from communities engaged in collaborative studies.

Rationale/need for the course

There is a growing interest in communities to participate in various ways in research that is intended to address their concerns as well as a growing respect among researchers for community-based methods of research. In response researchers are being drawn into collaborations with community partners, often called community-university collaborations or community-based research. Unfortunately there are many mistakes that researchers have made repeatedly from lack of training in the lessons that others have learned before them. This course would train future researchers at the graduate stage in order to help prepare them to engage more effectively with communities in their later career. The course director also hopes to use the course to write/edit a book that compiles case studies and that can be used in courses like this one.

Learning Objectives

- To be able to list and explain the basic principles that constitute community-based research.
- To understand why community-based research is important, how it fits into the scientific process and literature, and how it is different from yet incorporates classic methods of research.
- To be able to identify several ethical issues that differ in form or content between community-based and traditional research.
- To be able to discuss several community-based project case studies critically and identify strengths and weaknesses of each, both in methods and ethics.
- To understand that there is not a single model for community based work that applies to all communities or all types of projects and to be able to explain why a particular model might be chosen in a specific situation.
- To be able to form a cooperative relationship with a community partner.
- To be able to synthesize the knowledge they have gained into a concrete, written grant proposal.

Course Structure

The course will run in the month of April.
It will run 8 sessions, on Tuesday and Thursday mornings from 9 AM to noon
from March 26 - April 18.
Classes will be held in the DFM&CH conference room.

Student Evaluation

Students will be expected to work in a team over the course period to design a community-based study and write a research proposal (in response to an r.f.a.). Possible topics could include a child injury prevention program for public housing, a study of asthma at a local elementary school, or an evaluation of a health and housing survey and intervention program. The proposal would need to include research, intervention and evaluation components. Students would work with actual community preceptors and will be evaluated in part on their ability to construct relevant solutions to the concerns of the community preceptors. Grades would be based primarily on the written research proposal (40%) and final presentation (20%) by the students. Class attendance (20%) and participation (20%) will also be graded.

Course Outline

Session One, March 26, 2002

- (1) An introduction to the course.
- (2) Research and community based research.
- (3) Basics of research ethics.

READING:

Peavy JV. Surveys and sampling. in Gregg MB ed., *Field Epidemiology*. Oxford University Press, 1996:152-163.

Baker EA, Homan S, Schonhoff R, Kreuter M. Principles of Practice for Academic/Practice/Community Research Partnerships. *American Journal of Preventive Medicine*. 1999 April;16(3 Suppl):86-93.

Israel BA, Schulz AJ, Parker EA. Review of Community-Based Research: Assessing Partnership Approaches to Improve Public Health. *Annual Review of Public Health*. 1998;19:173-202.

Schensul JJ. Organizing Community Research Partnerships in the struggle Against AIDS. *Health Education and Behavior*. 1999;26(2):266-283.

Weijer C, Emanuel EJ. Protecting communities in biomedical research. *Science*. 2000;

289:1142-1144.

Take NIH test @ <http://cme.nci.nih.gov/>

Scocca T. Hopkins arm sued over lead-paint study. *Baltimore City Paper*. August 8-14, 2001.

Session Two, March 28, 2002

Case study: Public Health in Public Housing. The history and development of this collaboration and early data will be described. The focus will be on the challenge of forming a collaboration that includes city agencies, university faculty, technical consultants, community activists and residents of public housing.

(1) Slide show presentation reviewing the project and recent data

(2) Guests: A panel of members of the Healthy Public Housing Initiative

(3) Ethics discussion

READING:

Hynes P, D Brugge, J Watts, J Lally. Public health and the physical environment in Boston public housing. *J. Planning, Practice, and Research* 2000;15:31-49.

Brugge D, Vallarino J, Ascolillo L, Osgood N, Steinbach S, Spengler J. Comparison of multiple environmental factors for asthmatic children in public housing. (in press, *Indoor Air*).

Kole A, Brugge D. Exploring community-based research ethics. Case study: Healthy Public Housing Initiative (Draft manuscript).

Session Three, April 2, 2002

Teams must report the community partner that they have chosen.

Case Study: Community-based Evaluation

2) Guest: Bart Laws of the Latino Health Institute

READING:

Allston-Brighton Healthy Boston Coalition. *The Neighborhood in Transition, A Time for Mobilization: The Allston-Brighton Community Assessment Report*, March 1993.

Minkler M. Using participatory action research to build healthy communities. *Public Health Reports* 2000; 115:191-197.

Sharp PA, Greaney ML, Lee PR, Royce SW. Assets-oriented community assessment. *Public Health Reports* 2000; 115:205-211.

Case Study: Urban gardening.

1) Guest: H. Patricia Hynes, Professor, Boston University School of Medicine.

READING:

Blair D, Giesecke C, Sherman S, A dietary, social and economic evaluation of the Philadelphia Urban Gardening Project. *Journal of Nutrition Education* 1991; 23:161-167.

Hynes HP, Maxfield R., Carroll P., Hillger R. Dorchester Lead-Safe Yard Project: A Pilot Program to Demonstrate On-site Techniques to Reduce Exposure to Lead-Contaminated Soil. *Journal of Urban Health: Bulletin of the New York Academy of Medicine*, January 2001.

Session Four, April 4, 2002

Case Study: Boston Chinatown. Presentation of the development of community based research methods for Boston Chinatown and approaches to being responsive to and involving the community in research addressing the impact of development on this community (air pollution and safety problems from traffic, lack of open space and other concerns).

1) Guest: Andrew Leong, Associate Professor, University of Massachusetts Boston

2) Presentation of data and discussion of its use

3) Walking tour of Chinatown

READING:

Lai Z, Leong A, Wu CC. (2000) The Lessons of the Parcel C Struggle: Reflections on Community Lawyering. *UCLA Asian Pacific American Law Journal*, 6:1-43.

Brugge D, Lai Z, Hill C, Rand W. The effect of traffic on injuries in Boston Chinatown: Lessons from three years of data. *Journal of Urban Health*. 2002; 79:87-103.

Brugge D, A Leong, A Averbach, F Cheung. An environmental health survey of residents of Boston Chinatown. *Journal of Immigrant Health*. 2000; 2:97-111.

Session Five, April 9, 2002

Grant writing tutorial

READING:

Cummings SR, Washington AE, Ireland C, Hulley SB. Writing and funding a research proposal. In Hulley SB and Cummings SR eds. *Designing clinical research*. Williams & Wilkins Baltimore, MD, 1988.

Healthy Public Housing Initiative proposal.

Chinatown environmental education proposal.

Session Six. April 11, 2002

Ethics Case Studies:

1) Discussion

2) Activity

READING:

Wing S. Social responsibility and research ethics in community driven studies of industrialized hog production (Draft manuscript).

Silka L. Rituals and research ethics: Using one community's experience to reconsider the ways that communities and researchers build sustainable partnerships (Draft manuscript).

Session Seven. April 16, 2002

Case Study: Radiation and Native Americans

1) Slide show of history and impact of uranium mining on Navajos

2) Presentation of Sequoyah Fuels Corporation hazardous waste site

3) Ethics discussion

READING:

Brugge D and Goble R. The history of uranium mining and the Navajo Indians. (in press *American Journal of Public Health*).

Brugge D, Benally T, Harrison P, Austin-Garrison M, Stilwell C, Elsner M, Bomboy K, Johnson H, Fasthorse-Begay L. Using oral histories and photographs to document the experience of the Navajo People with uranium mining. (submitted).

Quigley D, Handy D, Goble R, Sanchez V, George P. Participatory research strategies in nuclear risk management for native communities. *Journal of Health Communication*. 2000; 5:305-31.

Frohberg E. Goble R. Sanchez V. Quigley D. The assessment of radiation exposures in Native American communities from nuclear weapons testing in Nevada. *Risk Analysis*. 2000; 20:101-11.

Brugge D and Missaghian M. Protecting the Navajo People through tribal regulation of research (Draft Manuscript).

Session Eight, April 18, 2002

Students will present their final projects.

Spring, 2002
Research Ethics in Research with Underserved Groups

Wednesdays 6-8:40

Dr. Linda Silka, Professor, Regional Economic and Social Development

Office Hours: Mondays 2 to 4 pm 500 O'Leary Library, Wednesdays 4-5 500 O'Leary

My Schedule: M, W, F: O'Leary Library 978-934-4247; T, Th, Center for Family, Work,
and Community 978-934-4675

Email: Linda_Silka@uml.edu

Welcome to the new course "Research Ethics in Research with Underserved Groups." In this course we will explore together the recent work that is changing the way we build partnerships between universities and communities. Research has become an important part of our world: we learn about research, we participate in research, and we carry out research. It used to be the case that researchers selected a research problem and then asked people to be subjects in their research. The researcher was the person in authority and the one who made the decisions about how the research should be done and how the results should be interpreted.

This approach is now undergoing dramatic changes in which communities and universities are struggling to find more effective ways to ask and answer questions that address society's problems. People are struggling with issues such as:

- Who decides what questions should be asked?
- Who has the power in the relationship?
- How can communities and universities work together in carrying out research?
- How do we make certain that people new to the research partnerships have opportunities to make decisions about the research?
- How can research findings be used to address the problems individuals and groups confront?

This course has eight objectives.

1. Students will gain in depth knowledge of community-university research partnerships and the dilemmas they raise for ethical research.
2. Students will learn how these issues become especially pronounced when large power differences exist between communities and universities.
3. Students will learn about the life cycle of research and some of the implications of this life cycle for ethical dilemmas.
4. Students will be provided with examples of innovations in addressing ethical dilemmas that have emerged from work with communities.
5. Students will learn how to link research goals to more effective strategies for involving communities in research.
6. Students will be encouraged and assisted in collaborating with multidisciplinary teams in addressing ethical issues in research partnerships.
7. Students will be assisted in identifying resources available to carry out effective community research using community decision making boards.
8. Students will be encouraged to develop strategies for increasing the quality and quantity of research that is being carried out in collaboration with communities.

Course Attendance: Students who must miss class need to notify me that they will not be in class. Participation is important to the quality of the learning experience. Students will be expected to participate fully in the class.

Grading Allocation

Attendance and Participation	20%
Checked Assignments	20%
Training Session for Community	15%
Training Session for Researchers	15%
Tip Sheets (2)	15%
Resource Manual	15%

Welcome to the Class!

Tentative Schedule

Date	Topic
January 23	Topic: Overview of Issues and Goals for the Course: • Why are research partnerships between communities and universities becoming more common and what issues do they raise? • How can we strengthen research by building partnerships? • How can we increase the value of research through partnerships? • Why are ethics at the heart of effective partnerships?
January 30	Topic: The Process of Developing Community-University Partnerships that Include Research: Why are ethical issues central? Identifying these ethical issues and concerns. Reading to complete before class: Centers for Disease Control and Prevention, <i>Building Community Partnership in Research: Recommendations and Strategies</i> ; Israel, <i>Community-Based Participatory Research: Principles, Rationale, and Policy Recommendations</i> ; <i>APA Symposium Abstract: Science That Matters: Building Effective Community-University Research Partnerships</i> Checked Assignment to bring to class: Bring a short (one page or less) letter you have composed (either in the role of a researcher or a community person) describing a topic you believe needs to be studied (ex: childhood asthma, affordable housing, elder diabetes) and asking the other potential partner (researcher or community person) to work with you to study the problem.
February 6	Topic: Who begins the Research Partnership? Opportunities and Dilemmas in Starting to Work Together. Reading for Class: Silka, <i>Using One Community's Experience to Reconsider the Ways that Communities and Researchers Build Sustainable Partnerships, The Paradoxes of Partnership</i> ; Wolf, <i>Healthy Communities Massachusetts</i> ; NIEHS RFP on Ethics Checked Assignment for Class: Bring a short (one page or less) memo to class in which you describe how you would organize and run a meeting between the community and researchers in a way that would start the partnership along a path that responsive to ethical issues.
February 13	Topic: Identifying and Addressing the Ethical Dilemmas that Arise During the Data Gathering Phase. Reading for Class: American Journal of Public Health, <i>Can Public Health Researchers and Agencies Reconcile the Push from Funding Bodies and the Pull from Communities, What is Community? An Evidence-Based Definition of Participatory Public Health, The Role of Community Advisory Boards: Involving Communities in the Informed Consent Process</i> Checked Assignment for Class: Bring a short (one page or less) memo in which you summarize in bullet items the issues that need to be decided by a partnership to make sure that the research and the partnership are carried out in an

	ethical manner.
February 20	Topic: Collecting and Analyzing Data: Opportunities for Ethical Relations Reading for Class: Case study materials from University of North Carolina, Syracuse University, and Tufts University; Shepard, <i>Achieving Environmental Justice Objectives and Reducing Health Disparities Through Community-Based Participatory Research and Interventions</i> ; Jones, <i>Healthy African American Families</i> Checked Assignment for Class: No written assignment
February 27	Topic: The Findings: Who Owns Them? How Do They Get Used? Reading for Class: Case study materials from Boston Partnership, Seattle Partnership, and the Lawrence Partnership; Quigley, <i>Summary of Issues on Environmental Health Research Ethics with Native Communities from Various Case Studies and Selected Articles</i> Checked Assignment for Class: Using one of the case studies in the readings write a short (one page or less) “guide” for either a researcher or a community person about the ethical lessons that can be learned from the case.
March 6	Topic: Overcoming the Ethical Challenges at Every Stage Reading for Class: Silka, <i>Evaluation as a Strategy for Documenting the Strengths of Community-Based Participatory Research</i> ; Brakefield-Caldwell & Parker, <i>Successful Models Combining Intervention and Basic Research in the Context of Community-Based Participatory Research</i> Assignment for Class: No written assignment
March 13	Topic: Changing IRB Rules and Requirements Reading for Class: Do NIH Online Research Ethics Module and read over UML IRB Requirements Checked Assignment for Class: Draft a short (one page or less) memo to either the Institutional Review Board, a Community Health Center Board or a City Health Department that describes how community oversight of research could be included in a research process.
March 20	No Class (Spring Break)
March 27	Topic: How to Ensure that Partnerships Continue; Confronting Common Conflicts Reading for Class: Case Study Materials from the Akwinase Partnership; materials from LOKA community research network Checked Assignment for Class: Write a short (one page or less) memo in which you explain how your partnership would concretely address an ethical dilemma that has emerged.
April 3	Topic: Preparing a workshop for the Community on Ethical Issues in Research Partnerships Reading for Class: Materials from LOKA; materials on social disparities Assignment for Class: Draft of training materials for community
April 10	Topic: Preparing a workshop for Researchers on Ethical Issues in Research Partnerships Reading for Class: Ethics Case Study Materials Assignment for Class: Draft of training materials for researchers
April 17	No Class (Monday Class Schedule)
April 24	Topic: Class will host training for researchers Reading for Class: No readings Graded Assignment for Class: Final training materials due
May 1	Topic: Class will host training for community Reading for Class: No readings Graded Assignment for Class: Final training materials due
May 8	Topic: Putting it All Together, Applying the Lessons We have Learned Reading for Class: Israel, <i>Review of Community-Based Research: Assessing Partnership Approaches to Improve Public Health</i> Graded Assignment for Class: Two Tip Sheets Due (one for Community, one for Researchers)
May 15 Final Week	Graded Assignment for Class: Resource Manual Due

