

## **Course Syllabus: Community and Environmental Health Research Ethics**

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### **Course Description**

New ethical research practices with community populations stress partnership and participatory models with community members. Working in partnership and sharing control over the research process can lead to significant new challenges in the scientific practice of community and environmental health research. Such challenges include community rights and “community informed consent”. This course will explore how bio-medical research protections for individuals can be extended to groups and communities by reviewing case studies in participatory research and ethical theories of virtue ethics, communitarian, liberalism and post-modern ethics. Moral complexities such as deciding who has community authority to consent to research and how you adapt and modify research methods to respond community needs in research will be analyzed? How do you deal with sharing the process of data collection; the control of data; the interpretation of research findings, the dissemination of results and intellectual property rights? These difficult issues are made even more challenging when dealing with culturally-diverse groups. We will discuss how western scientific methods can capture the local lifestyle contexts and ecologies of Native Americans, Southeast Asians, African-Americans, and Hispanic populations. Through case studies, we will review unique considerations about each of these diverse groups and their values as a community before research is conducted with them. Current research partnerships with these diverse groups are seeking to integrate cultural values and knowledge traditions to improve research results. How can a research design reflect multiple knowledge systems? In this course, students will actively participate in adding new insights and reflections to the complex issues of community research protections.

### **Rationale/need for the course**

There is a growing need to educate researchers and scientists on new ethical practices in the field of community and environmental health research to avoid both harmful and culturally-inappropriate research methods, specifically to Native American, African-American, Southeast Asian and Hispanic populations. Research harms have often occurred with environmental and public health research activities conducted in community settings; particularly culturally-diverse communities. These include the conduct of research that offers no benefits to the community but strains community resources; research that stigmatizes communities; researchers who do not consult or involve community members in the research process and produce inaccurate exposure scenarios. Many researchers fail to inform communities of their findings. These and other harms have burdened and exploited community populations who already suffer many socio-economic stresses. Students can benefit from ethical reviews of case studies in the field of community research and discussions of contemporary research ethics issues to ensure successful research experiences in their careers.

**Learning Objectives**

- To have an understanding of principle ethics in biomedical research as well as perspectives in virtue ethics, communitarian, liberalism and post-modern ethics.
- To become familiar with ethical issues that arise from the use of complex research methodologies in epidemiology, exposure assessments, health risk assessments and dose reconstruction.
- To learn about community-based participatory research principles used in community health and environmental research and for environmental justice needs; to discuss and debate the value of these new approaches
- To gain an understanding on the need for community or group rights in research and offer critiques for guidelines on “community informed consent”.
- To become aware of culturally-appropriate research methods for specific ethnically-diverse populations from literature sources and case examples.
- To review and understand how different cultural knowledge traditions, values and contexts can be accommodated, mediated and integrated in research partnerships with culturally-diverse communities.

**Course Structure and Methods**

This course is proposed to run for twelve sessions for a 2.5-hour time period each session. The course will use a seminar type approach with readings in research ethics and with the use of numerous case studies in the field. Several guest presenters will be invited. Students will be required to actively participate as discussion leaders, in panel debates and break-out groups.

**Student Evaluation**

Students will be graded on class participation and student papers. Students will be required to complete either two short papers on the major topics of the course or one 25 – page paper on a specific challenging issue in community research ethics that would offer new insights into this field..

## **Course Outline**

### **PART ONE: RESEARCH ETHICS IN THE FIELD**

#### **Class One**

- Standard biomedical ethical principles for individual human research participants (Nuremberg Codes, Belmont Report, International Research Ethics, Institutional Review Board (IRB) principles)

#### *Readings:*

- (1) Beauchamp, T. and Childress, J. 2001, *Principles of Biomedical Ethics*, Oxford University Press, Part 1, Chapter 1; Part II, Chapters 3,4,5,6, and Part III, Chapters 8 and 9.
- (2) Council for International Organizations of Medical Sciences. (1993). International ethical guidelines for biomedical research involving human subjects. Geneva
- (3) The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (1979). The Belmont Report. Ethical Principles and Guidelines for the Protection of Human Subjects of Research
- (4) The National Institute of Health (1995). Guidelines for the conduct of research involving human subjects at the National Institutes of Health, Washington, DC
- (5) Handout on IRBs, Southeast Community Research Center, Atlanta, GA

#### **Class Two**

- Environmental justice and research ethics; community-based participatory research (CBPR) arrangements and models of community informed consent for establishing research protections for communities engaged in research;

#### *Readings:*

- (1) Minkler, M. and Nina Wallerstein, *Community-Based Participatory Research for Health*, Josey-Bass, San Francisco, CA 2003: Part One – Introduction to CBPR
- (2) Quigley, Dianne 2003, “A Review of Ethical Innovations to Environmental and Public Health Research: Case Examples from Native Communities”, manuscript submitted to Journal of Health Education, MI in *Course Reader for Collaborative Initiative for Research Ethics in Environmental Health*
- (3) Brugge, Doug and M. Missaghian 2003 “Protecting the Navajo People Through Tribal Regulation of Research” Tufts University, in *Course Reader for Collaborative Initiative for Research Ethics in Environmental Health*
- (4) “Focusing on Community-Based Research,” *Protecting Human Subjects*, Number 9, Fall 2003, Protecting Human Subjects Web site—[www.science.doe.gov/ober/humsubj/](http://www.science.doe.gov/ober/humsubj/)
- (5) “Dialogues for Improving Research Ethics in Environmental and Public Health – Conference Report 2004”- instructor handout.

#### **Class Three**

- A focus on ethical theories relevant to community research protections: principle and virtue ethics, communitarianism, liberalism and post-modern ethics.

- (1) Wallwork, Ernest 2003 “ Ethical Analysis of Group and Community Rights” *Course Reader for Collaborative Initiative for Research Ethics in Environmental Health*
- (2) Grodzins-Gold, Ann 2001, “Research Ethics from the Cultural Anthropologist’s Point of View” in *Course Reader for Collaborative Initiative for Research Ethics in Environmental*

*Health*

- (3) Selected Readings from Etzioni, A, 1996, *The New Golden Rule*, Basicbooks, NY
- (4) Selected Reading from MacIntyre, Alasdair, *After Virtue*, Duckworth, London, 1981
- (5) Meara, Naomi, Lyle Schmidt, Jeanne Day, 1996. "Principles and Virtues: Foundation for Ethical Decisions, Policies and Character", *The Counseling Psychologist*, Vol. 24, No.1, pp: 4-77. January

**Class Four**

- Ethical challenges in environmental and public health methodologies (epidemiology, disease surveillance, risk assessments, exposure assessments); ethical aspects of exposure uncertainty and requirements of statistical significance

*Readings:*Community Voices

- (1) Connor, T., 1997. *Burdens of Proof: Science and Public Accountability in the Field of Environmental Epidemiology with a Focus on Low Dose Radiation and Community Health Studies*. Columbia, SC: Energy Research Foundation.
- (2) Russell, D., S. Lewis, and B. Keating. 1992. *Inconclusive by Design: Waste, Fraud and Abuse in Federal Environmental Health Research*. Boston, MA: The National Toxics Campaign Fund and Chesapeake, VA. Environmental Health Network.

Academic Reflections

- (3)Wing, S., 1998. "Whose Epidemiology, Whose Health?" *International Journal of Human Services*, 28 (2):241-252.
- (4)Wynne, Brian 1992. "Risk and Social Learning: Reification to Engagement" chapter in *Social Theories of Risk*, edited by Krimsky S. and Golding D., Praeger, Westport, CT
- (5) Greene, Gayle 1999, *The Women Who Knew Too Much, Alice Stewart and the Secrets of Radiation*, University of Michigan Press, Chapter 14.
- (6) Sexton, K. 2000. "Socioeconomic and Racial Disparities in Environmental Health: Is Risk Assessment Part of the Problem or Part of the Solution, *Human and Ecological Risk Assessment*; 6:561-574
- (7) Course Reader on "*Survey of Environmental Health Studies*"

**Class Five – Phil Brown, Guest Lecturer**

- New theoretical approaches to social responsibility in research (popular epidemiology, critical epidemiology, advocacy science)

**PART TWO: RESEARCH ETHICS WITH CULTURALLY-DIVERSE GROUPS****Class Six**

- Overview of the need to prepare for research with culturally-diverse groups, learning specific contexts and traditions in community relationships.
- Cultural considerations with research in Native American and Southeast Asian communities: histories of genocide and oppression, case studies in research ethics (Native risk assessments/dose reconstruction, rituals and research ethics, data control)

*Readings:* (Students will select among these readings)Native American:

- (1) LaDuke, Winona, 1999 *All Our Relations, Native Struggle for Land and Life*, South End

Press, Cambridge, MA

(2) Norton, I. and Manson, S., “Research in American Indian and Alaskan Native Communities: Navigating the Cultural Universe of Values and Process”, *Journal of Consulting and Clinical Psychology*, v.64, No.5, 1996

(3) Akwesasne Research Advisory Committee,, “Akwesasne Good Mind Research Protocol.”, *Akwesasne Notes*, v. 2, No. 1, Winter 1996

(4) Davis, Sally; Reid, R. “Practicing Participatory Research in American Indian Communities”, *American Journal of Clinical Nutrition*, v.69, i4, p.755s (1), April 1999

(5) Quigley, D “Ethical Considerations in Research Methodologies for Exposure Assessment for Toxic and Radioactive Contaminants in Native Communities” in *Course Reader for Collaborative Initiative for Research Ethics in Environmental Health Southeast Asian*

(1) Minkler, et al, see pp. 316-332, *CBPR with Cambodian Girls in Long Beach, CA*

(2) Becker, G. and B. Yewoubdar 1999, “Narratives of Age and Uprootedness among Older Cambodian Refugees,” *Journal of Aging Studies*, 13 (3): 295-314

(3) Kulig, J. 1994, “Those with Unheard Voices; the plight of the Cambodian Refugee Woman” *Journal of Community Health and Nursing* 11 (2): 99-107

(4) Uehera, E. 2001. “Understanding the Dynamics of Illness and Help-seeking. Events structure analysis and a Cambodian-American narrative of spirit invasion, *Social Science and Medicine* 52 (4):519-536

(5) Silka, Linda 2001, “Rituals and Research Ethics”, Lowell, MA: University of Massachusetts, in *Course Reader for Collaborative Initiative for Research Ethics in Environmental Health*

### **Class Seven**

- Cultural considerations with African-American and Hispanic Communities– the environmental justice movement, urban and rural case study examples in research ethics (hog wastes in the rural south, urban asthma efforts by environmental justice organizations, research and policy action).

(1) Wing, Steve 2002. “Environmental health research ethics: Lessons from community driven studies of industrialized hog production in North Carolina”, University of North Carolina, *Environmental Health Perspectives*, 110:437-444

(2) Kinney PL, Aggarwal M, Northridge ME, Janssen NA, Shepard P. Airborne concentrations of PM(2.5) and diesel exhaust particles on Harlem sidewalks: a community-based pilot study. *Environmental Health Perspectives* 2000;108:213-8.

(3) Arcury, TA, Quand SA, MaCauley L., “Farmworkers and Pesticides: Community Based Research”, *Environmental Health Perspectives* 2000; 108:787-792

(4) Selected presentations from “Dialogues for Improving Research Ethics – Conference Report”.

(5) Brandt, AM. “Racism and Research: the case of the Tuskegee Syphilis Study, Hasting Center Report 1978, 8: 21-9.

- Several other readings to be assigned.

## **PART THREE: MEDIATING KNOWLEDGE TRADITIONS AND VALUES FOR IMPROVED ETHICAL RESEARCH PRACTICES**

### **Class Eight**

- The western scientific method: objectivity and reductionism and its ethical consequences; the need for qualitative and subjective data sources through community narratives, Native science methods, and integration of multiple knowledge systems with western methods.

(1) Brugge D, Benally T, Harrison P, Austin-Garrison M, Stilwell C, Elsner M, Bomboy K, Johnson H, Fasthorse-Begay L. The Navajo Uranium Miner Oral History and Photography Project. In *Dine baa hane bi naaltsoos: Collected papers from the seventh through the tenth Navajo Studies Conferences*. J Piper, ed. Navajo Nation Historic Preservation Department, Window Rock, AZ. 1999:85-96.

(2) Cajete, Gregory 1999. *Native Science, Natural Laws of Interdependence*, Clear Light Publishers, Santa Fe, NM. Chapters 1, 2, 3, 6, 8

(3) Brown, Phil, 2003. 2003 "Ethical Issues Regarding Qualitative Methods in Environmental Health Research", *Environmental Health Perspectives* 2003 111:1789-1798

(4) Corsiglia, John, Snively, Gloria, "Discovering Indigenous Science: Implications for Science Education", *Science Education* v.85, no. 1 January 2001

(5) Verran-Watson, Helen and David Turnbull "Science and Other Indigenous Knowledge Systems" in Jasonoff, S., GE Markle, JC Peterson, and T. Pinch 1995. *Handbook of Science and Technology Studies*, Newbury Park, CA, Sage Press

(6)Wing, Steve, "Science, Objectivity and Environmental Health", *Environmental Health Perspectives.*, October 2003

### **Class Nine**

- Race and class power differentials and equity needs in CBPR partnerships; problems of language, communication, cultural sensitivity and privilege in research ethics. Community presenter to be invited.

#### *Readings:*

(1) Minkler, M. and Nina Wallerstein, *Community-Based Participatory Research for Health*, Josey-Bass, San Francisco, CA 2003:, Part Two, Power, Trust and Dialogue

(2) Selected Reading from Habermas, Jurgen (1984). *The Theory of Communicative Action*, Boston, Beacon Press

(3) Kesler, John "Healthy Communities and Civil Discourse: A Leadership Opportunity for Public Health Professionals", *Public Health Reports* 2000; 115 238-242

### **Class Ten – Phil Brown, Guest Lecturer**

- The Precautionary Principle as a growing paradigm for community-based environmental research

## **PART FOUR: STUDENT PRESENTATIONS AND COURSE EVALUATION**

### **Class Eleven**

- Student paper presentations

### **Class Twelve**

- Student paper presentations (continued) and course evaluation