

Conference Report on a “Dialogues for Improving Research Ethics in Environmental and Public Health”, (held May 30 – June 1, 2003 at Brown University, Providence, RI).

Conference Background and Sponsorship

The “Collaborative Initiative for Research Ethics in Environmental Health” sponsored the national conference “*Dialogues for Improving Research Ethics in Environmental and Public Health*” as a part of its project activities under a National Institute of Health grant program for Short Courses in Research Ethics. The Collaborative Initiative is administered through Syracuse University and involves an interdisciplinary team of public health, social science, biomedical and behavioral researchers, including several ethicists in public health from five collaborating universities. The project focuses on research ethics with culturally-diverse populations (i.e. Native Americans, Southeast Asians, African-Americans, Chinese and Hispanic populations) and community health studies. The investigators not only develop courses with an emphasis on the problems and challenges of culturally-diverse populations, but each investigator produces important case studies and articles in this field (see website: www.researchethics.org). The conference was organized in the project’s third year of activity with this purpose and objectives.

Conference Purpose and Objectives

This conference sought to bring together community representatives, academic scientists, government researchers 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 sought to generate new recommendations, tools and resources for dealing with the difficult challenges of key research ethics issues that were identified by the interdisciplinary team and community health organizers through the project’s outreach and training activities.

After two years of the project team’s outreach of short courses to researchers and community populations in other regions of the United States, important feedback was gained about research harms to communities, skills and training needed by researchers in the field and ethics policy recommendations that need to be promoted. These six panel topic areas had emerged as priorities for conference panels from our short course presentations (1) Research Protections and Institutional Needs for Community Research (2) Promoting Community Rights in Research (3) Reshaping Science for Environmental and Public Health (4) Perspectives on the Status of Funding for Community-Researcher Partnerships (5) Institutional Review Boards and Institutional Protections and (6) Research Ethics and Community Partnerships. The highlights of these panel presentations are discussed below.

Conference Panel Presentations – Issues and Needs

Thirty-three panel speakers were recruited for the conference panel topics from around the country. This included racially diverse researchers (Native American, Asian, African-American, and Hispanic) as well as a mix of government, academic and community-based researchers in the field. (see speaker list at www.researchethics.org). We prepared a booklet of abstracts for the speaker presentations which can be found on our website, as well.

Research Protections and Institutional Needs

This panel presentation included community-based innovations to dealing with community research harms, such as the conduct of scientific research that offers no benefits to communities;

the exploitation of community members in research activities and the failure to inform communities of risks and benefits of research. Panel presentations provided models of community control (i.e. a community research councils) and successful strategies in community collaborative participation by two community-based research programs. A tribal group discussed how their community research councils can function to allow and disallow research through a set of community criteria. Additionally, they can exercise control over data ownership and dissemination. Also discussed was the model of a regional center in the Southeast that can provide infrastructure support and participatory strategies to communities engaging in health research with academic researchers to assist communities with research protections. Another speaker highlighted the important role that community members can play on IRBs with federal agencies and universities to ensure ethical research. This however introduces complexities in building a community around human subjects, such as defining affiliated and unaffiliated members; victims, subjects, activists, geography and participants.

Promoting Community (Group) Rights in Research

This panel held two sections; the first section provided an overview of the complexities in establishing community rights for research that are extensions of individual rights. The second section stressed community field experiences in seeking rights in research.

In the first section, the Syracuse University project team members debated the need for community rights as the project's p.i. set out ethical principles that exist for individual rights that should be applied to communities. A list of ethical innovations developed from a compilation of community health studies in Native communities demonstrated how beneficence, justice and autonomy can be protected by (1) training community members on risks and benefits of standard health research methodologies; (2) developing partnerships with community members through research design, training, data collection, shared control and infrastructure support; and (3) the integration of the local knowledge of the community with the more quantitative research data. The project ethicist argued that there are no established principles on group rights in research, in trying to establish them, a number of moral complexities face us, i.e. when does a group become worthy of separate ethical consideration? How should informed consent guidelines be modified to take into account particular group characteristics? How does the researcher deal with competing group representatives from one community; the problem of community stigmatization from research results; the questions of ownership of data and results? How are individual rights protected when the community owns the data? The third speaker, an anthropologist, had written of the need for emergent ethics in situational contexts with different power differentials and cultural and racial differences in community partnerships. Codes of ethics can become problematic when applied to many of these differing research contexts.

A second section brought forth field stories from community-based organizations engaging in collaborative research with academic and government scientists and how community rights can be protected and/or violated. Struggles for shared control over research were highlighted as often a research department may use a community project for its benefit and override community consultation and control mechanisms. Additionally, communities (particularly culturally-diverse communities) can become like guinea pigs for multiple research teams that provide no benefits to the community and frequently do not even report findings back to the community. Mechanisms for control such as creating a research center out of a community controlled organization and inviting scientists and policy-makers to be part of the governing board were described. Some important ethical challenges were raised here for community rights and included problems of community stigmatization from environmental contamination results, issues of access to state controlled cancer and/or community-generated data. and the responsible reporting of data back to study participants.

Reshaping Science for Environmental and Public Health

Two sections of this panel were conducted and included presentations on Native science methods as a model for more integrated, holistic research approaches. Additionally, several presentations highlighted issues in western science that address limitations of “objectivity”: as defined by mainstream science and the courts. The Akwesasne multi-tier definition of health incorporates a research design that incorporates cultural and traditional practices as a part of the research effort. A risk assessment study that is culturally-based may produce findings that go beyond measuring levels of PCB in fish but highlight losses of language, cultural practices, and relatedness with the earth. Research methods may stress conversing with elders, radio shows and mentoring relationships. Similarly, a research model for studies of fish contamination from the Yakima Indian Nation is titled the “medical ecological model” (or medicine wheel) includes four interrelated components: ecology, epidemiology, cultural study and clinical medicine, producing a rich data source in the understanding and data collection from the interaction of these components together. Another speaker described basic principles of Native science as written by Gregory Cajete and how objectivity is gained through subjective processes. She highlighted the need for community members to become local knowledge-producers in order to inform this type of objectivity. Another speaker described a new method in the practice of western environmental health science, that of “weight of evidence” whereby no single study determines causality but a number of studies including qualitative data become a subjective weighting system; focused on a social level and not by court law suits. Another speaker then described the Daubert challenges as the way courts will decide causality among uncertainties; usually relying on reductionistic methods and excluding testimony from innovative scientific methods that incorporate the community reporting of health harms.

The Status of Funding for Community-based Participatory Research (CBPR)

For most community groups seeking ethical research around the country, the biggest challenge to this is the lack of funding support for CBPR. Two speakers from federal agencies that support environmental health research (NIEHS and EPA) discussed the commitment of their agencies to CBPR and spoke of successes such as community empowerment and capacity-building as well as the policy impacts, be they reduction of contamination or institutional changes to scientific practices and funding priorities. Some challenges in funding decisions were discussed such as the performance of evaluations and types of assistance for partnerships to ensure their success. A community speaker highlighted the important need for communities to have control over research funding to ensure its ethical outcomes. An academic speaker reflected on the benefits and challenges to academics involved in CBPR research projects. Academics involved in CBPR usually lose peer support in their department but nonetheless, the speaker recommended the need to create institutional change in universities to legitimize CBPR and bring more university support to the problems of communities.

Institutional Review Boards (IRBs)

Four presenters highlighted the importance of community participation on IRBs and the need to establish protections for communities in IRB guidelines. A speaker from Indian Health Service (IHS) presented the work of IHS IRBs in maintaining an important principle, that of “Respect for Communities” and this involves a set of guidelines that require evidence of community (tribal) approval, cultural sensitivity, community partnerships in each stage of research all the way to publication, and a listing of benefits to the communities for the research performed. Another speaker highlighted concerns about lay involvement in academic IRBs; including how lay involvement is defined, how can community members participate equitably with academic representatives, what training is provided, etc. Other models of IRBs may be more appropriate that would ensure the community’s independence from academic control and provide more

accessibility. Concerns were also raised about informed consent for population studies. Who are the providers of consent, particularly in very culturally-diverse communities. How is training conducted on the true benefits and risks of health studies, as well as the burdens and benefits of informed consent? Two other speakers echoed concerns about a clash of interests and values when community people participate on academic IRBs. There is a disconnect about important values of CBPR, there is a need to train academics on CBPR and to train communities on IRBs and their processes. Also there is a need for relationship-building between two groups. Power differentials can be hidden by so-called “objectivities”. There are conflicts of interests if universities are dependent on certain funding sources. Lay person is too broad a term when there are multiple kinds of research (environmental, public health, genetic) and multiple needs for representation (those with certain diseases, those from certain neighborhoods). It is too problematic to develop a one size fits all for prescriptions to community involvement on IRBs. These challenges require investments of training funds to IRBs, funding for community involvement in IRBs, a process to address inequities and power differentials on IRBs. and guidelines to overcome conflicts of interests between community needs and university funding needs. Many recommended the need for community review boards to ensure ethical research.

Research Ethics and Community Partnerships

Key ethical challenges have emerged from community-academic partnerships. Such issues as how partners seek to balance power, how to gain community input and integrate community knowledge, how to build capacity and promote institutional change define the work of partnering. This panel held three sessions with six speakers who addressed many of these and other issues with their personal experiences in the field. Community-based speakers highlighted the importance of including scientific research activities in their campaigns for social change that centered on improving the quality of life for their communities. Urban speakers spoke of common contamination issues of air pollution from waste facilities, diesel exhaust, and other industrial activities that expose multi-ethnic city neighborhoods. Technical studies of air monitoring, environmental sampling and mapping of disease incidences often engage these communities in partnerships with universities. They outlined important considerations with research partners, including up-front agreements about community control in the process, skills-building for community members (youth projects), inclusion of qualitative data of the community’s experience of contamination, the identification of concrete action benefits to the community from the research, and translation of research results to the community.

Both academic and community presenters focused on the difficult challenges to partnerships from unequal power differentials, specifically white privilege issues and powerful academic institutional values that can dominate the research interactions. Mutual trust and understanding must be exercised through listening and a sharing of each other’s contexts and values. Partners need to be aware of each other’s daily constraints in meeting common goals and have a shared accountability to each other. One speaker stressed a need for structures and norms to guide processes of working together and offered two case examples of this. Several spoke of celebrating our differences in coming together and allowing conflicts to emerge as part of a dance of sharing power together. Most supported the need for resources and time in developing partnership relationships before research begins. This would allow culturally-diverse communities to ask research questions that derive from their own experience and not from scientific frameworks. One speaker urged an opening of “hidden transcripts” of community members who lack the trust in researchers to reveal their true opinions and needs in the partnership.

One academic speaker stressed the importance of attending to partnership research planning in a cyclical approach that addresses more of the “when” in the research process than the “what”. Another spoke extensively about the importance of using qualitative methods (i.e. community

narratives and data collection) to enrich the scientific goals of research; including “member validation” processes that allow community members to review and critique initial research data analyses. Several speakers emphasized the benefits to universities and scientists of community research studies and that institutional reform is needed in universities to encourage more CBPR activities.

Conference Participants and Follow-Up

One hundred and seven participants attended the conference. This included 50% community researchers representing over 40 community health organizations across the country; 40% academic researchers from departments of public health, medicine, environmental health, epidemiology, sociology, religion, psychology and environmental studies; and 10% government researchers and state/tribal health departments. The conference recruitment was racially diverse with 26% African-American, 16% Native American, 14% Hispanic, 6% Asian, 3% other and 42% white. From written and oral feedback, the conference was considered highly successful...” the cultural diversity, the strong presentations and creative ideas were very impressive.” Participants highlighted the opportunity to just focus on ethical issues, the strong field experiences and expertise of the diverse representatives, the sharing of cultural values, contexts and humanistic issues with scientific issues. Participants stressed the need to improve language issues with one another and the need for more conferences on ethical issues. Being a working conference, six panel working groups produced numerous recommendations for follow-up work and ongoing training needs from the conference. All the evaluation comments, conference proceedings and recommendations will be compiled into a conference report by the end of 2003. This will be available on the project’s website – www.researchethics.org.

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