

**Ethics of Research on Health Impacts of  
Nuclear Weapons Activities in the  
United States**

**Report Conducted by the Collaborative Initiative for  
Research Ethics and Environmental Health (CIREEH) at  
Syracuse University**

**Compiled and Edited by: Dianne Quigley, Amy Lowman,  
and Steve Wing**

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## **INTRODUCTION: “THE ETHICS OF RESEARCH ON HEALTH IMPACTS OF NUCLEAR ACTIVITIES IN THE UNITED STATES”**

The Collaborative Initiative for Research Ethics and Environmental Health (CIREEH) received funding in 2003 from the National Institute of Health (NIH) Program on “Short Courses for Research Ethics” to assemble a collection of reviews of ethical issues in environmental and occupational health studies of populations exposed to Cold War nuclear experiments; in particular, communities near nuclear weapons labs and nuclear workers at those labs. CIREEH focused on health assessments conducted since 1990 when responsibility for etiologic epidemiology (but not surveillance) was transferred from the Department of Energy (DOE) to the Department of Health and Human Services (DHHS). These funds primarily were administered through the National Center for Environmental Health (NCEH) of the Centers for Disease Control (CDC) and the Agency for Toxic Substances and Disease Registry (ATSDR). In this time, DOE also funded several state health departments (i.e. California and Colorado) to conduct health assessments of community and worker populations. The CIREEH focused on studies that have been conducted in the past decade and are most relevant to policy issues and plans for future research. These selected studies permit a focus on research relationships that involve community and worker participation. This collection also includes an ethical review of Navajo mining studies in order to evaluate the environmental justice and cultural implications of nuclear activities, including Cold War nuclear experiments.

In this review, CIREEH collaborators were concerned with ethical issues related to (1) methodological approaches that are criticized in the field for their incomplete assessments of exposures, (2) research findings and study designs that have created distrust of scientific research, particularly among exposed populations, (3) research approaches that create unethical practices by failing to recognize community approval/consent, and (4) research and public health barriers that limit the potential for research to contribute to public health policy. The quality of radiation risk research can be adversely affected by failure to establish respectful and democratic scientific partnerships involving radiation researchers and exposed populations. For example, a lack of attention by researchers to American Indian nutritional use of wild plants and game (including fish) has hampered efforts to estimate radiation doses from certain radionuclides released during production and testing of nuclear weapons.<sup>1</sup> The lack of detailed knowledge about the life styles

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<sup>1</sup> Frohberg, E; Goble, R; Sanchez, V; Quigley, DP; “The Assessment of Radiation Exposures to Native Communities from Nuclear Weapons Testing in Nevada”, Society for Risk Analysis, March 2000

of populations downwind of many DOE facilities, as well as lack of consideration of work practices at the weapons production facilities that are not part of the official record, have led not only to poor science but to distrust on the part of residents and workers whose knowledge has not been represented in official studies. Poor science and low trust limit policy contributions.

The Hanford Thyroid Disease Study involved an extensive attempt to reconstruct doses of people born in areas potentially exposed to large releases of radioiodine from the Hanford plutonium production facility in the 1940s and 1950s, who were offered screening for thyroid problems.<sup>2</sup> The accuracy of exposure classification, upon which the validity of estimates of risk depended, was a function of a large number of assumptions including the magnitude and timing of releases, modeling of weather conditions, dispersion of fallout through the food chain, and individual behaviors. The HTDS provides an example of ethical issues involved in obtaining participation from the exposed population and communicating findings with the public.

In all, eleven ethical reviews have been written and compiled in this collection. CIREEH collaborators contacted community health leaders around the DOE weapons sites where major research studies were conducted. These community health leaders were directly involved in public participation efforts with those studies and bring a collective ethical assessment from their community to this monograph. They were also involved at national levels, having appointments with CDC-ATSDR for national research agenda oversight. Four community narratives from Hanford, WA (Trisha Pritikin), Rocky Flats, CO (LeRoy Moore), Livermore Labs, CA (Patricia Sutton, Marylia Kelley, Tracy Barreau, Jackie Cabasso) and the Fernald Feed Materials Production Center, OH (Edwa Yocum) were developed and compiled here. Three narratives were written from nongovernmental researchers who have published in the radiation research field and have expressed concerns about the ethical adequacy of certain research methods and public involvement in health studies. These narratives include ethical reflections on the National Cancer Institute (NCI) nationwide fallout study by Seth Tuler, who assisted in coordinating public participation in that study. Researchers from Tufts University, Bindu Pannikar, Doug Brugge, and Esther Yazzie, a Navajo community health leader, provide a narrative about ethical issues pertaining to Navajo uranium miner health studies. Bob Alvarez, a policy analyst, provides a narrative on research conducted on nuclear workers and the compensation awarded to them

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<sup>2</sup> Sciences NAo. An Assessment of Centers for Disease Control and Prevention Radiation Studies: Review of Hanford Thyroid Disease Study Final Results and Report. Washington, DC, National Academy Press 2000

several years ago. Don Austin, an epidemiologist who conducted a state health department health assessment of workers, provides an ethical analysis of his research experience. The last section of this collection includes three ethical analyses of the eight narratives that precede them. Ethical analyses are provided by Sheldon Krinsky from Tufts University and Dianne Quigley and Ernest Wallwork of Syracuse University. These ethical analyses provide moral reflections on the conduct of these studies that can assist improving future research or public health interventions.

The overall purpose of this monograph is to identify practices that can improve health research and public health programs among populations affected by nuclear weapons activities by considering research ethics. Usually the design and conduct of exposure assessments, epidemiologic studies, and risk assessments, are developed only from the narrow technical perspectives of each discipline. The collections of narratives and ethical analyses here assist us in realizing that these fields provide an incomplete framework for understanding the potential for research to benefit or harm human populations and their natural environments. Many researchers have little training in public health ethics and do not approach their narrowly defined research with broader considerations for how to maximize benefit and protect affected communities and workers. This problem, evident in the reflections of community and nongovernmental researchers assessing these health studies, is brought out strongly in the ethical analyses. The field of research ethics can support researched communities by increasing the integrity of studies conducted by government and academic scientists. Ethics as a field will prioritize protection of individuals/groups, the provision of community agreements/approvals, the guarding and mitigating against potential research harms and a vigilance against forms of scientific contrivance, denial and suppression of findings. Trained ethicists can bring expertise and experience to complex research issues, particularly those that can affect the multiple interests of diverse stakeholders. Ethical reviews can also contribute to democratic processes and help guard against control of research by institutions that have responsibility for exposing people to hazardous substances.

The chapters of this monograph suggest that public participation efforts, as defined by researchers in government and academic institutions, have often failed to address the needs of exposed communities. Future research could be substantially improved by taking account of past mistakes through use of democratic and inclusive approaches to the planning and conduct of environmental health research.

While these studies were underway, the Advisory Committee for Human Radiation Experiments (ACHRE) was compiling recommendations for the federal government concerning research harms and abuses that had occurred to human radiation victims; including atomic veterans, downwinders, Marshall Islanders and Navajo uranium miners. Many of their recommendations focused on the harms to individual research subjects with only several recommendations focused on group harms. Two major areas of their recommendations are priority issues in these ethical reflections. The ACRHE was not supportive of expensive dose assessments studies in the absence of adequate measurements and recommended that funds be allocated for direct aid to survivors and their families, particularly atomic veterans.<sup>3</sup> This similar issue runs through the narratives which focus on the consequences of dose assessment studies conducted around the named facilities that often had poor exposure measurements. The cost of these studies was, at least, 100 million dollars that was paid mostly to researchers and their institutions. A second major recommendation of ACHRE was to increase research ethics training among researchers. There was a grave concern regarding the lack of basic research ethics training and the cultural ignorance of researchers.

This monograph is an initial effort to expand understandings of ethical issues involved with the collective risks from human radiation experiments; those to nuclear workers, downwind populations, Native Americans, and other affected cultural groups. There were a number of other research health assessments conducted at the DOE sites that are not included here. Savannah River, Oak Ridge, the Nevada Test Site, Los Alamos, Mound Laboratories, Piketon, OH, Paducah, Kentucky are areas where there has been considerable community health organizing to understand health impacts from nuclear weapons testing and production. Some of these sites had major health assessments during the past decade. The CIREEH could not include more narratives at this time but would like to expand these ethical assessments.

The CIREEH seeks to promote more assistance to these affected groups and communities with the support of research ethics. In this compilation, we promote the collection of narratives for the purpose of understanding ethical issues and problems. We believe that the experiences of community members, health organizers and researchers captured in the narratives here broaden an understanding of beneficence and nonmaleficence in research related to nuclear weapons activities. The narratives point to considerable work to be done in increasing our moral progress with these research ethics issues.

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<sup>3</sup> ACHRE., 1995. Chapter 18, Rec. V. Wash. DC, US Gov. Printing Office

## Contributor Biographies

**Bob Alvarez** is a Senior Scholar at the Institute for Policy Studies in Washington, D.C., where he is currently focused on nuclear disarmament, environmental and energy policies.

**Don Austin, PhD** teaches epidemiology as Emeritus Professor at Oregon Health Sciences University (OHSU) and participates in research at the VA Medical Center in Portland. His career spans both research and public health in state and federal health agencies, and academia. He has developed cancer surveillance systems, conducted and interpreted epidemiologic research, and applied his experience to the curriculum for medical students, residents and MPH students.

**Tracy Barreau**, is an Environmental Scientist with the California Department of Health Services, Environmental Health Investigations Branch. She has worked for the past eleven years evaluating health impacts to communities living near hazardous waste sites. In collaboration with citizen groups, community members, the City of Livermore and Alameda County she conducted an investigation into the historic distribution of plutonium-contaminated sewage in Livermore.

**Douglas M. Brugge, PhD, MS** has a PhD from Harvard University and a MS in from the Harvard School of Public Health. He is currently an Associate Professor in the Department of Public Health and Family Medicine at Tufts University School of Medicine. He is director of the Navajo Uranium Miner Project and the Tufts Community Research Center. He has published over 100 papers and is co-editor (with Pat Hynes) of a book from Ashgate Publishing Group (UK) on community research in environmental health and co-editor (with Esther Yazzie-Lewis and Timothy Benally) of *The Navajo People and Uranium Mining* (University of New Mexico Press, 2006).

**Jacqueline Cabasso** has served as Executive Director of the nonprofit Western States Legal Foundation (WSLF) in Oakland, California since 1984. Founded in 1982, with a local focus on the Livermore Nuclear Weapons Laboratory, WSLF seeks to abolish nuclear weapons as an essential step in making possible a more secure, just, and environmentally sustainable world. Cabasso has extensive experience with community education and outreach and speaks frequently in local, national and international settings. She is also a published author. [www.wslfweb.org](http://www.wslfweb.org)

**Marylia Kelley** is Executive Director of the Livermore, California-based Tri-Valley CAREs. Marylia brings to Tri-Valley CAREs' program 23 years of in-depth research, writing and facilitating public participation in decisions regarding Livermore Lab and nuclear weapons, waste and cleanup. Marylia serves on the "Community Work Group" (since 1989) to advise the federal Environmental Protection Agency, state agencies and the community on the Superfund cleanup of Livermore Lab. She has provided input to the National Academy of Sciences, including on the nuclear proliferation risks of the National Ignition Facility and on toxic and radioactive pollution at the Livermore Lab's main site and site 300. She can often be found speaking at diverse venues, from local City Council meetings to international conferences in Russia and Japan. Marylia has written for numerous publications, including Bulletin of the Atomic Scientists. Marylia also serves as editor for Citizen's Watch, Tri-Valley CAREs' monthly newsletter. Marylia's work with Tri-Valley CAREs has garnered numerous awards over the years, and, in 2002, she was named to the Alameda County Women's Hall of Fame. Marylia has a background in journalism and humanities, and graduated summa cum laude from John F. Kennedy University in 1984. She has lived in Livermore since 1976. [marylia@trivalleycares.org](mailto:marylia@trivalleycares.org)

**Sheldon Krinsky, PhD** is professor of Urban & Environmental Policy & Planning in the School of Arts & Sciences and Adjunct Professor in Public Health and Family Medicine in the School of Medicine at Tufts University. He received his bachelors and masters degrees in physics from Brooklyn College, CUNY and Purdue University respectively, and a masters and doctorate in philosophy from Boston University. Professor Krinsky has been elected Fellow of the American Association for the Advancement of Science for "seminal scholarship exploring the normative dimensions and moral implications of science in its social context."

**Esther Yazzie** is a board member and board president of the Southwest Research and Information Center, Albuquerque, NM working on nuclear risk issues in New Mexico. She worked with Total Benefits Communication, Atlanta, Georgia in presenting the Navajo Nation 401(k) to the Navajo Nation employees with the assistance of the Navajo Nation Retirement Office, Window Rock, Arizona. Ms. Yazzie was a faculty member to the Native American Alliances Foundation - Native Americans on "The Healing and Wellness Courts" across the country. She is a member on the Diversity Advisory Committee with the Federal Judicial Center, Washington, D.C. She is a member of the Justice and Women of Color Committee, National Consortium of Task Forces and Commissions on Racial and Ethnic Bias in the Courts with the National Center of State Courts. Ms Yazzie serves as a peer review consultant to the National Institute of Justice through the Technical Assistance and Support Program in Washington, D.C. She was an advisory committee member to the "All My Relations" project for First Nations and Health Source, Albuquerque, New Mexico.

**LeRoy Moore, PhD**, a founder of the Rocky Mountain Peace and Justice Center of Boulder, has worked on issues related to Rocky Flats since 1979. He served on several bodies set up to advise DOE and the regulators on cleanup of the Rocky Flats site. Author of the Citizen's Guide to Rocky Flats (1992), "Rocky Flats: Bait and Switch Cleanup," Bulletin of the Atomic Scientists (Jan/Feb 2005) and numerous other writings, he served on the board of the Alliance for Nuclear Accountability and was the token outsider on two committees of the National Council on Radiation Protection and Measurement.

**Bindu Pannikar** is a doctoral student in Environmental Health at Tufts University. Her current areas of focus are occupational health issues, immigrant health, environmental history, environmental hormones, ethics in research and community based participatory research. She is one of the board members at Tufts Community Research Center. She is also a recipient of the National Institute of Occupational Safety and Health Student Research Award for her doctoral work on "Assessing and Controlling Occupational Risks Among Immigrants in Somerville, MA". She has an MA in Urban and Environmental Policy and Planning and MS in Environmental Health from Tufts University.

**Trisha Thompson Pritikin** was born in Richland, Washington, adjacent to the Hanford nuclear weapons facility in southeastern Washington State, during years of offsite radioactive emissions from the plant. Over many years, she has volunteered her time as a member of the Hanford Health Information Network (HHIN) advisory board, and served for consecutive terms as a citizen representative on the Hanford Health Effects Subcommittee. As a result of her work, she was appointed to the Subcommittee for Community Affairs to the federal Advisory Committee on Energy Related Epidemiologic Research, and served as co-chair of that committee. Trisha's mother and father died from aggressive cancers, which she believes were more likely than not caused by exposure to fallout from the Hanford facility. Trisha herself has health problems that she attributes to in-utero and childhood exposures to Hanford's radiation. It is her goal to secure medical and other help for people who, like herself and her family, have suffered harm due to US nuclear weapons production and testing programs.

**Dianne Quigley, ABD** is a researcher and PhD candidate, concentrating in ethics in the Religious Studies department at Syracuse University. Ms. Quigley is the principal investigator of a grant from the National Institute on Health titled "Collaborative Initiative for Research Ethics in Environmental Health" (Year 2000-2007). She was also a principal investigator on several major NIH grants for "Nuclear Risk Management to Native Communities" (1994-2000) and Executive Director of the Childhood Cancer Research Institute (1987-2000). Ms. Quigley is currently an adjunct instructor at Brown University's Environmental Studies Department, teaching community research ethics. She holds a Master's Degree from Clark University, Worcester, MA in the Environment, Science and Policy Program.

**Patrice Sutton, MPH** is a Research Scientist with 20 years of experience in occupational and environmental health research, public health practice and policy development, and professional and community-based public health advocacy. Ms. Sutton has published over two-dozen peer-reviewed scientific articles and government technical reports, and has also co-authored chapters on Nuclear Weapons in War and Public Health (Oxford University Press, in press, 2007) and Radiologic and Nuclear Weapons in Terrorism and Public Health (Oxford University Press, 2002). Ms. Sutton was a member of the Board of Western States Legal Foundation between 1992-2002, and has been an active member of the American Public Health Association since 1986.

**Seth Tuler, PhD** has extensive research experience on hazard management, public involvement in environmental and risk assessment and decision-making, and program evaluation. Over the last decade he has been involved with a variety of projects to facilitate environmental health education, training, and public participation with community residents affected by contamination from US nuclear weapons production and related facilities.

**Ernest Wallwork, PhD** is Professor of Ethics at Syracuse University and a psychoanalyst in private practice. His books include Durkheim: Morality and Milieu and Psychoanalysis and Ethics. Dr. Wallwork has been the D.R. Sharpe Lecturer on Social Ethics at the University of Chicago, a Fellow at the Kennedy Institute of Ethics, Georgetown, Bioethicist at N.I.H., and a Fellow at the Woodrow Wilson International Center.

**Edwa Yocum** is a Community Leader for Fernald Residents for Environmental Health and Safety (FRESH), Inc. and Fernald-Community Health Effects Committee, Inc. From 1984 to the present time, she has been the officer and health chairperson for FRESH. Ms. Yocum created the FRESH Cancer Incidence Map. From 2001 to the present, Ms. Yocum became a research assistant for the Fernald Community Health Effects Committee (F-CHEC) working with University of Cincinnati on a CBPR research project related to the Fernald contamination. Ms. Yocum lives one and half mile south of the former Fernald Nuclear Weapons Plant located eighteen miles northwest of Cincinnati, Ohio

**Amy Lowman, MPH** is a Project Manager & Research Associate. Ms. Lowman has five years of experience participating in epidemiological studies and three years serving in the capacity of project manager for a CBPR study of the health effects of industrial swine production. She is also the project manager for a proposal to develop a protocol for the surveillance and investigation of citizen complaints related to the land application of sewage sludges. She has coauthored an article published in the American Journal of Public Health.

**Steve Wing, PhD** teaches epidemiology at the University of North Carolina School of Public Health and conducts research on occupational and environmental health. Recent work has focused on health impacts of ionizing radiation, industrial animal production, and environmental injustice. He is a founding member of the North Carolina Environmental Justice Network.