

This article was downloaded by: [University of Arizona]
On: 06 October 2011, At: 16:24
Publisher: Taylor & Francis
Informa Ltd Registered in England and Wales Registered Number: 1072954
Registered office: Mortimer House, 37-41 Mortimer Street, London W1T 3JH,
UK



Accountability in Research

Publication details, including instructions for authors and subscription information:

<http://www.tandfonline.com/loi/gacr20>

The Ethical Issues in Uranium Mining Research in the Navajo Nation

BINDU PANIKKAR^a & DOUG BRUGGE^b

^a Department of Civil and Environmental Engineering, Tufts University, Massachusetts, USA

^b Department of Public Health and Family Medicine, Tufts University, Massachusetts, USA

Available online: 10 Apr 2007

To cite this article: BINDU PANIKKAR & DOUG BRUGGE (2007): The Ethical Issues in Uranium Mining Research in the Navajo Nation , *Accountability in Research*, 14:2, 121-153

To link to this article: <http://dx.doi.org/10.1080/08989620701290473>

PLEASE SCROLL DOWN FOR ARTICLE

Full terms and conditions of use: <http://www.tandfonline.com/page/terms-and-conditions>

This article may be used for research, teaching, and private study purposes. Any substantial or systematic reproduction, redistribution, reselling, loan, sub-licensing, systematic supply, or distribution in any form to anyone is expressly forbidden.

The publisher does not give any warranty express or implied or make any representation that the contents will be complete or accurate or up to date. The accuracy of any instructions, formulae, and drug doses should be independently verified with primary sources. The publisher shall not be liable for any loss, actions, claims, proceedings, demand, or costs or damages

whatsoever or howsoever caused arising directly or indirectly in connection with or arising out of the use of this material.

THE ETHICAL ISSUES IN URANIUM MINING RESEARCH IN THE NAVAJO NATION

BINDU PANIKKAR

Department of Civil and Environmental Engineering, Tufts University,
Massachusetts, USA

DOUG BRUGGE

Department of Public Health and Family Medicine, Tufts University,
Massachusetts, USA

We explore the experience of Navajo communities living under the shadow of nuclear age fallout who were subjects of five decades of research. In this historical analysis of public health (epidemiological) research conducted in the Navajo lands since the inception of uranium mining from the 1950s until the end of the 20th century, we analyze the successes and failures in the research initiatives conducted on Navajo lands, the ethical breaches, and the harms and benefits that this research has brought about to the community. We discuss how scientific and moral uncertainty, lack of full stakeholder participation and community wide outreach and education can impact ethical decisions made in research.

Keywords: *community-based participatory research, uranium mining, research ethics, Navajo, Native American*

Introduction

Uranium gained prominence in use in the 1940s with the growing sophistication of atomic research and the proliferating atomic nuclear interest at that time specifically catering to the urgent need of developing atomic weaponry for national security reasons. In the U.S., the Navajo lands became one of the prime targets for mining, contributing thirteen million tons of uranium ore to military use from 1945 to 1988. Mining throughout the U.S. employed over 10,000 miners, of which approximately 3,000

This article not subject to United States copyright law.

Address correspondence to Doug Brugge, Department of Public Health and Family Medicine, 136 Harrison Ave, Boston, MA 02111, USA. E-mail: dbrugge@aol.com

were Navajos (Eichstaedt, 1994; Brugge and Goble 2003; Markstrom and Charley, 2003; Dawson and Madsen, 1995).

Today, there are at least 1,000 abandoned and partially unreclaimed uranium mines within the Navajo Nation (Dawson and Madsen, 1995; Brugge and Goble 2003). During most of the peak years of mining, from 1948–1969, no federal occupational standards kept uranium miners safe. Under the federal Metal and Non-metallic Mine Safety Act of 1966 and the 1969 Coal Act the coal mining conditions improved with new equipment and modified mining practices, with a compensation program extended to those suffering from black lung disease, but the enforcement focused mostly on coal mines. A broader regulatory program in mining was set only in 1978 under the federal Mine Safety and Health Administration (MSHA, 2003). Apart from unrecorded accidents, health impairments and ailments, an estimated 500–600 uranium miners died of lung cancer over a period of 40 years; a similar number is expected to die from this cancer after 1990 (Brugge and Goble 2003; Markstrom and Charley, 2003; Dawson and Madsen, 1995). Still the extent of health threats to the community, those exposed to the unreclaimed sites and who drink contaminated uranium water, is unknown (South West Research and Information Center or SRIC, 2004; Lewis, Personal communication, 2006). Roughly eighteen years since mining ended, the Navajo community is still struggling daily with high radiation and uranium exposures and many unknown environmental threats (SRIC, 2004).

This article conducts an historical analysis of environmental and public health (epidemiological) research conducted in the Navajo Nation and questions its ethical breaches.

The Navajo Uranium Mining History

The Navajo Nation extends across 16 million acres of Arizona, Utah, and New Mexico. There are over 250,000 enrolled members of the tribe, over 160,000 of whom reside on tribal land. Sovereignty of the Navajo Nation has been recognized under Article I, Section 8 of the U.S. Constitution. Today the Navajo Nation has jurisdiction over most, but not all legal issues within their reservation land. Tribal sovereignty tends to predominate over traditional civil rights when dealing with Native Americans, but most federal law applies to the Navajo Nation. Uranium mining in the Navajo region started in

1948, when the U.S. Atomic Energy Commission introduced a massive procurement program and announced that it would purchase all the uranium that was mined in the United States. Radium and Vanadium were already mined at that time in the high plateaus of the Navajo lands (Brugge and Goble, 2002). Expanding the operations to mining uranium was relatively simple. Abundance was discovered primarily on the reservation in Shiprock, NM; Monument Valley, UT; Churchrock, NM, and Kayneta, AZ.

Mining boomed in 1955–56 and became a flourishing occupation for many Navajo men, partially transforming the reservation from traditional grazing communities to a modern industrial wage economy (Brugge and Goble, 2002). The Navajo people, at the time, largely removed from the economic and social systems of mainstream U.S. culture and possessing different environmental and political consciousness, were unaware of the health effects associated with mining and had no understanding of the ionizing radiation properties of the ores being mined. While federal worker health requirements were established for companies that handled beryllium in the 1940s, such requirements were not established for uranium and few precautionary measures were undertaken in these mines (Advisory Committee on Human Radiation Experiments or ACHRE, 1995; Brugge and Goble, 2002).

U.S. Public Health Service (PHS) research on occupational health effects of uranium mining began two years after the mining started, but ventilation requirements in mines were enforced only by the early 1960s. The first federally enforceable standard (.3 working-levels for radon and its daughters) in mines that supplied the federal government with uranium was announced in 1967 by Secretary of Labor, Willard Wirtz (ACHRE, 1995). By then, the Federal contracts for uranium mining nearly ended in the Navajo Nation, but private companies continued mining until 1988.

Community organizing around uranium mining started in the early 1960s. Harry Tome of Red Valley, a member of the Navajo Tribal Council, was one of the early advocates on the issue for a compensation system similar to the black lung benefits to disabled Appalachian coal miners in 1968 (Smith, 1987; Brugge and Goble, 2002). Tome's efforts lead to the first legislative bill, filed in 1973, with the U.S. Congress to extend the black lung benefits to uranium miners, but the bill never passed (Brugge and Goble, 2002).

It took two decades of organizing for the Radiation Exposure Compensation Act (RECA) to be passed in 1990 after the first legislative remedy was filed. RECA acknowledged that the U.S. Government historically mistreated the uranium miners and made provision for compassionate payment of up to \$100,000 to underground uranium miners. It took another 10 years for the original law to be amended by the U.S. Congress to address the shortcoming in the original law (Board on Radiation Effects Research or BRER, 2005; see Brugge and Goble, 2003). As of October 2006, of those who had applied, 63.1% of uranium miners, 81.1% millers, 76.4% ore transporters, 77.7% downwinders, and 43% onsite participants had been compensated a total of \$407 million (U.S. Department of Justice or USDOJ, 2005).

Community activism and scientific research collectively played roles in the passage of 1990 RECA. Scientific research was the basis for determining safer mining conditions, legalizing appropriate levels of exposure, and providing evidence for better policies and regulations. While rigorous scientific investigations eventually helped uranium miners, it came with a cost: the costs associated with ignoring early warnings from the research, and the cost of delaying occupational safety measures until causality was unequivocally determined, with recognized harms to people, cultures, communities and the environment.

Methods

In this article, we conduct an historical analysis of public health (epidemiological) research conducted in the Navajo lands since the inception of uranium mining. We track about 50 years of public health research from the 1950s until the end of the century. Our literature review include all the epidemiological studies on uranium mining conducted on the Navajo Nation in Medline and the extensive Southwest Research and Information Center bibliography of literature on Navajo uranium mining. Personal communication and correspondences were another means of procuring information, especially on current research initiatives in the Navajo Nation. Our analysis is divided into: 1) The “early” public health studies or series of studies which led to controlling radon exposures in mines in the 1960s; 2) The studies conducted between 1970 and 1990, before the passing of 1990 RECA; and 3)

The studies conducted since 1990. We conclude our analysis with a discussion of the ethical breaches in research.

Research in the Uranium Mining Communities from the 1940s to the 1970s

When the U.S. government decided to start mining in 1948 it was developing a nuclear arsenal and was considering extending the technology to develop nuclear power. Though the Atomic Energy Act of 1946 did not allow for private commercial application of atomic energy, it did acknowledge in passing the potential “peaceful benefits” of atomic power. Entering “the nuclear power race” was considered by many government officials vital to maintaining dominance in the international scientific community and in maintaining international prestige (U.S. Nuclear Regulatory Commission, 2003). By 1954, a broad political consensus was achieved and new legislation was passed permitting commercial use of atomic energy for power generation (ACHRE, 1995). At the same time, the act also instructed preparation of regulations that would protect public health and safety from commercial radiation hazards (Federal Radiation Council or FRC No.8., 1967; ACHRE, 1995).

At the time the mining started the health effects of radiation and uranium mining in particular were known from earlier studies conducted in Europe. In response to a lung disease called “Bergkrankheit” first reported in detail in studies of miners in Schneeberg and Joachimsthal in 1879, a ventilation project had been established in 1930 even though the causal agent was unknown at the time (Lorenz, 1944; Peller, 1939; Brugge and Goble, 2002; Donaldson, 1969; Stellman, 2003). In 1942, Wilhelm Hueper, the founding director of the environmental cancer section of the National Cancer Institute (NCI), a branch of the National Institutes of Health, reported that excess occupational risk of lung cancer in miners was due to exposure to radon gas (Hueper, 1942). Despite this scientific awareness, there was little thought given to public health and safety measures in the workplace when uranium mining started.

The first wave of research studies on uranium mining in the U.S. started two years after mining began in 1948 led by the U.S. PHS in conjunction with other state and federal agencies

(Archer, 1962; Lundin et al., 1971). The PHS study of Colorado Plateau miners was started on the assumption that uranium mining causes lung cancer.

The PHS study involved an environmental study and an epidemiological study. The environmental study included air samples, and occupational histories that were gathered to calculate individual exposure expressed in “working-level-months” (WLM).¹ Under the auspices of the Colorado, Utah, New Mexico, and Arizona Health Departments, Duncan Holaday was recruited to direct the environmental study measuring radon levels in the mines. In a memo presented to the PHS Salt Lake City office in 1950, Holaday reported that levels of radon in the Navajo region exceeded expectations and concluded that results presented a rather serious picture. He recommended that a control program be instituted as soon as possible (ACHRE, 1995). In 1951, two researchers, William Bale and John Harley, showed that radon daughter isotopes attaching to dust can remain in the lungs and contribute to lung cancer (Bale, 1980; Harley, 1980). Following an internal meeting in 1951, both the PHS and Atomic Energy Council (AEC) acknowledged that the levels of radon in these uranium mines were high enough to cause cancer and that ventilation was the way to abate the hazard (ACHRE, 1995).

However, this information was not shared with those at risk, nor was there willingness on the part of AEC to introduce relatively safe tolerance levels for radon in the mines. In 1952, a PHS interim report distributed on a restricted basis reported no evidence of health damage from radioactivity. Other health officials, such as Dr. Heuper, were asked to limit their speech on risks involved (ACHRE, 1995). Victor Archer, head of the PHS medical team, justified, “We did not want to rock the boat... We had to take the position that we were neutral scientists trying to find out what the facts were, that we were not going to make any public announcements until the results of the study were published” (Ball, 1993, p. 46).

The PHS investigators did not provide informed consent, which was justified “out of fear that many miners would quit”

¹One WLM is equal to spending 170 hrs, or a month exposed to one “working level” (WL), a concentration of radon decay products that will release 1.3 million electron volts per liter of air.

(ACHRE, 1995). In fact, the research was conducted with an oral understanding with the mine owners that the miners will not be warned by the PHS researchers of the levels of hazards. At the time of the start of the PHS study, the Nuremberg standards required informed consent in *experimental* studies, that the “subjects volunteer for the experiment after being informed of its nature and hazards... The subjects were given as much autonomy as the physician researcher” (Shuster, 1998, p. 974). But the uranium studies were *observational*, something we will come back to.

The environmental study ended in 1956 (ACHRE, 1995). A 1957 research report by Holaday and colleagues (Holaday, 1969) on controlling radon in mines proposed a threshold exposure value of 1 WL. By 1960, the states² slowly started responding to the issue and adopted a guideline for radon exposure of one working-level (WL).³ And a federal standard of .3 WL for radon and its daughters was set in 1969 (ACHRE, 1995; Brugge and Goble, 2002).

The epidemiological study was a prospective study and the miners were enrolled if they volunteered for at least one physical examination and provided social and occupational data in sufficient detail to allow follow-up. Not many miners were examined in 1950, 1951, and 1953. From 1954 onward the study grew and became a systematic epidemiological study. As many men that could be located and would cooperate were examined (Archer 1962; FRC No.8., 1967). This renewed interest and enthusiasm in the study may not be entirely coincidental considering that the second Atomic Energy Act was also passed in the same year (1954) with its expressed commitment to the protection of health.

It is estimated that between 1957 and 1960, close to 90% of the men working in the industry were examined for their occupational history and level of exposure (FRC N0.8., 1967; Archer, 1962). Estimates of exposure were used when direct measurements were not possible. The total study group consisted of over 5,000 underground miners, uranium mill workers and other above-ground workers, including both white and nonwhite men. Despite

²New Mexico began its enforcement in 1958. Colorado and Utah did not begin serious enforcement until the 1960s, and Arizona, according to Duncan Holaday, did “nothing outside of take air samples.” (ACHRE, 1995, Holaday, 1969).

³WL is the measure of the energy released by radon daughters. At equilibrium (expected with poor ventilation) one WL corresponds to 100 pCi/L in air.

the fact that the Navajo people represented about 30% of the uranium miners in the Colorado plateau, white miners (40%) were chosen for the primary research outcomes (FRC No. 8., 1967).

The analysis made for the FRC focused on a subgroup of 1,981 white male underground workers who started mining before 1955. The analysis showed a clear association between exposure to radon daughters in mine air and a higher than expected likelihood of lung cancer death when the cumulative exposures were more than 1,000 WLM (FRC No. 8., 1967; Archer, 1962). Subsequently, Wagoner (1965) reported a 10-fold excess in lung cancer in underground miners exposed over a longer period controlling for age, smoking, nativity, hereditary, urbanization, self-selection, diagnostic accuracy, prior mining exposure or exposure to silica. A mortality study that followed miners from the same data pool looked at 3,414 white underground miners in the region between 1950–1963. It substantiated these results with higher than expected observed violent deaths and deaths from malignant neoplasms of the respiratory system. Cancer deaths markedly progressed with increasing exposure beginning in the range of 840–1,799 WLM. Smoking miners experienced cancer deaths 10 times greater than nonsmoking miners (Lundin et al., 1969). While these studies showed associations between Uranium mining and lung cancer, lung cancer associations with smoking miners clouded the analysis leading to suggestions such as “uranium miners should not smoke” (Lundin et al., 1969, p. 571).

An important feature of these studies was the estimation of the relationship between dose and disease outcomes. This method, highly sophisticated for the time, was used to define the dose-response relationship. Stellman (2003) considered the occupational health study on uranium workers in his article on the history of epidemiology as on par with the other occupational health studies on chemical dye workers, bituminous coal workers, smelting workers. He stated that these studies have been important sources of innovation in methodology and in the development of logical reasoning leading to acceptance of causal relationships of occupational exposures that lead to respiratory diseases and cancer.

The fact that the research focused on establishing the dose-response curve rather than on establishing a causal association per se, shows that this was a search for an acceptable level of risk.

Possible preventive measures under these circumstances focused on finding a safe level of risk, because withdrawing from mining was not an option considered by the government. Safe levels of risk that would not hamper production or profits or criteria for standard setting were determined at the expense of many uranium miners who were not warned of the health risks and became sick in the process. At the time, no system was introduced to see that those who became ill were provided the needed care and assistance.

The issue of compensation for uranium miners reached the courts only in the late 1970s, but the courts did not find it violating the ethical norms of the time since the Nuremberg Code addressed only experimental studies. The PHS study was considered *observational* as opposed to *experimental*. In the *Begay* decision (cf. *Begay vs. U.S.*, Updated), the court found: “the epidemiological study and the conduct of the researchers were consistent with the medical, ethical and legal standards of the 1940s and 1950s.” The researchers “were not *experimenting* on human beings. They were gathering data to be used for the establishment of enforceable maximum standards of radiation. ... Thus, the court concluded, it was neither necessary nor proper for those physicians to advise the miners voluntarily appearing for examinations of potential hazards in uranium mines... The government did not seek volunteers to work in the mines so that they could become part of the study group ...” (ACHRE, 1997, Chapter 12, p. 11).

As noted above the Nuremberg Codes did not apply to workplace exposures not introduced by research and similar decisions are commonly made by researchers today based on the principle that subjects or workers should be informed about risks due to participation in research but not necessarily about risks they encounter in the course of work activities of daily living.

While the PHS study did not violate the Nuremberg Code with respect to informed consent, it can be argued that it ran against the established norms of the time, as informed consent was broadly practiced, even if it was not codified in law. But the 1995 Presidents Advisory Committee on Human Radiation Experiments (ACHRE) report did not take this view and saw no ethical violations (See Egilman et al., 2001). Though ACHRE claimed to recognize the Nuremberg Code, it made weak ethical arguments that “informed consent was not an accepted standard for

physicians till 1957, and that Government bodies did not enforce or promote them". Contrary to ACHRE argument, Egilman and his colleagues in their article *Ethical aerobics: ACHRE's flight from responsibility*, points out that scientific and ethical discussion on informed consent had emerged by 1890 and that "legal standard for informed consent had emerged in court cases by 1905" (Egilman et al., 2001, p. 5).

PHS (the agency that undertook the study), who is responsible for this ethical violation and the only federal officials in direct contact with the miners (ACHRE, 1995) was also not instrumental in enforcing or recommending environmental or occupational regulations. While PHS had the legal and moral standing to do so, it upheld the confidentiality agreement with the mine owners and made no effort to address the troubling information they were gathering.

Many institutions capable of setting the standards existed at the time. With respect to mining, a Federal Mining Bureau was established as early as 1865, but it did little to protect miner safety or to inspect mines. Under the 1936 Walsh–Healy Act, the Labor Department had the authority to ensure safe working conditions in mines and installed a requirement for ventilation as in the case of beryllium, but it was not until 1967 that the Department of Labor applied that act (ACHRE, 1995). A broader regulatory program to reduce injuries, fatalities, and illness in mining was set only in 1969, under the federal Mine Safety and Health Administration (MSHA, 2003).

Uncertainty or doubts of smoking being the modifier of risk also perhaps slowed interventions. However, issues of uncertainty and ideologies such as precautionary approaches were not uncommon at the time. A. W. Donaldson in his 1969 article on *The epidemiology of lung cancer among uranium miners* ends with testimony by Dr. Abel Wolman, the major architect of Baltimore's water system, that "the responsible health officer cannot wait upon perfect knowledge before interposing barriers between man and industrial poisons. He moves with best in hand... with the objectives of reducing diseases and fatality and not with the preconceived notion as to how many people we have a right to kill" (Donaldson, 1969 p. 568–569). The British biostatistician, Austin Bradford Hill famous for setting criteria for identifying true causal relationships in observational studies stated that, "All

scientific work is incomplete... All scientific work is liable to be upset or modified by advancing knowledge. That does not confer upon us the freedom to ignore the knowledge we already have, or to postpone the action that it appears to demand at the given time" (Gradjean, 2005, p. 657).

So, by the 1980s, there were federal regulations of radon in mines, although we might argue that they were still inadequate. Within the research community, the perception was that additional research was needed to tease out the effects of smoking from those of radon.

Research in the Navajo Uranium Mining Community, 1980s–1990

The early 1980s saw the second wave of research activities about the health effects of uranium mining. While the struggle for setting worker safety conditions and standards in the mines for uranium workers was slow, but ultimately victorious, the workers still did not have a compensation system. In the 1960s, a compensation system was established for coal miners following a pitched struggle, but black lung benefits did not extend to uranium miners (Smith, 1987). Scientifically, it was established by then that uranium mining caused lung cancer. But studies on smoking itself as the cause of lung cancer and as a modifier of risk in uranium studies created doubts and uncertainties in associating a true causal relationship between uranium mining and lung cancer. The uranium mining research objectives in the 1980s were focused on establishing that uranium mining caused lung cancer independent of the smoking status of the workers. Navajo people with their low smoking rate and low lung cancer rates fit the perfect picture for research to clarify the relationship of cigarettes and radon daughters.

The epidemiological studies from 1980 to 1990 focused on: 1) Establishing that uranium mining caused lung cancer regardless of smoking status; 2) Other ethnic groups with lower smoking rates, such as the Navajo uranium miners (Samet et al., 1984; Gotlieb and Husen, 1982; Gilliland et al., 2000; Mulloy et al., 2001; Roscoe et al., 1995); 3) Causes of mortality among uranium miners in addition to lung cancer (Roscoe, 1997; Waxweiler et al., 1981; Lundin et al., 1969); and 4) Meta-analyses of lung cancer among uranium miners

across studies (Biological Effects of Ionizing Radiation or BEIR IV, 1988; BEIR VI, 1999). This section will focus only on studies conducted in the Navajo Nation on Navajo men.

Most of these studies were secondary analyses of data obtained from disease registries (Samet et al., 1984; Gilliland et al., 2000; Roscoe et al., 1995; Roscoe, 1997). Development of hospital-based cancer registries is as recent as 1956, initiated by the American College of Surgeons. Early hospital registries were, for the most part, inaccessible and used card files for data recording. More valuable information came with the development of large central registry systems such as the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program in 1973 (SEER, 2005). Also the advent of microcomputer registry systems in the 1980s opened a new window of opportunity for research.

Some of the studies in the Colorado Plateau benefited from the existence of these registries. Gilliland and Samet used the New Mexico Tumor registry, a member of SEER, to collect data, and they also drew from death certificates, abstracts of medical records, National Institute for Occupational Safety and Health (NIOSH) records, and several uranium mining databases. Roscoe's mortality study (1997, 1995) used the PHS medical surveys conducted between 1950 and the 1960s, as well as records maintained by the Social Security Administration, the Internal Revenue Service, the National Death Index, and the Health Care Financing Administration.

These studies looked into periods between 1960 and 1993, and were published after 1982.⁴ Many of the mines had been closed by then. Community level organizing gained strength as well during the time. Phil Harrison, an advocate and educator on radiation and health since 1975, was elected as the president of Uranium Radiation Victims Committee in 1982 and the establishment of the Red Mesa/Mexican Water Four Corners Committee was established in 1985. Community organizing also had a part in assigning a pulmonary specialist, Leon S. Gottlieb, at Indian Health Service (IHS) for the first time. He was the first physician to associate and document lung cancer and uranium mining among the Navajo people. (Dawson et al., 1997).

⁴Roscoe et al. (1995), Roscoe (1997), and Gilliland et al., (2000) are put under this section between 1980s–1990 because they observe data between 1960 and 1963.

Gotlieb and Husen (1982) used health center records in the four corners area of New Mexico, Arizona, Utah, and Colorado to identify Navajo men who were admitted to the hospital between 1965 and 1979. They found that of 17 patients with lung cancer, 16 had been uranium miners. The lowest WLM for disease induction was 58.8 WLM, and the lowest latency period for disease induction was 5 years, while the longest was 30 years. Five cases out of 16 cases developed lung cancer under the dose of 1,000 WLM, which had been considered the threshold for disease induction at that time.

Samet followed Gottlieb's findings with a case-control study but with a larger population of lung cancer cases from the years 1969 to 1982. Of 32 cases and 64 controls, the relative risk for lung cancer was estimated to be 14 times that of controls. Samet attributed the occupation of Navajo uranium miners as their primary risk factor for lung cancer (Samet, 1984). A follow-up study conducted by Gilliland of lung cancer incidence in Navajo Uranium miners over a period of 24 years from 1969 to 1993 concluded that 67% of lung cancer occurred in former uranium miners, suggesting that a majority of the lung cancers in the Navajo population were solely attributable to their occupation (Gilliland et al., 2000).

The BEIR reports produced by the National Academy of Sciences had been summarizing scientific evidence for radiation risks with a particular focus on dose-response relationships. The history of the BEIR reports and their administrative links with the Atomic Energy Council (AEC) and the Department of Energy (DOE) has long been seen by some as troubling. The BIER III report was particularly controversial for substantially lowering the estimated risk of low-dose radiation (NIRS, Undated). However, the BEIR IV (1988) and later BEIR VI (1999) were, in our opinion, largely impartial meta-analyses of 4 and then 11 studies of uranium miners that assessed the dose-response relationship for radon exposure and lung cancer.

The BEIR studies arrived at several important conclusions, that 1) there were substantial uncertainties in the actual doses received by miners in different mines; 2) the risk rises linearly with level of exposure; 3) the risk per WLM varies strongly by age, latency, mining cohort, and especially by dose rate or duration; 4) on average more than half of the lung cancers among white miners and the Navajo people in the Colorado Plateau were

caused by radon exposures; and 5) smoking and radon interacted in a greater than additive, but less than multiplicative manner.

Apart from lung cancer incidence studies, mortality studies in Navajo men were also conducted. Roscoe's mortality study in Navajo men from 1960 to 1990, found elevated risks for lung cancer, tuberculosis, and pneumoconiosis and other respiratory diseases and lowered ratios for heart disease, circulatory disease, and liver cirrhosis. In conclusion, Roscoe stated that light-smoking Navajo miners face excess mortality risks from lung cancer and pneumoconiosis and other respiratory diseases (Roscoe et al., 1995).

The early uranium studies have been widely criticized as unethical for various reasons mostly due to lack of informed consent, but the later studies met basic individual rights of study subjects and have not been, to our knowledge, subject to criticism. For these studies, largely based on secondary sources, informed consent was not an issue as in earlier observational studies as long as confidentiality was maintained (See Soskolne et al., 1995 for Ethics guidelines for environmental epidemiologists). Also post the Tuskegee Syphilis experiment (Center for Disease Control or CDC, 2005), there was a growing movement among epidemiologists to construct clear ethical guidelines, distinguishing reasonable and unreasonable ethical actions (Winkler, 1996⁵) in epidemiological studies (Soskolne et al., 1995; Office of Human Subjects Research or OHSR, 2004). The National Research Act was instituted in 1974. The Belmont Report of 1979 (OHSR, 2004) enforced the protection of human subjects in biomedical and behavioral research. And the federal Health Research Extension Act of 1985, required institutions requesting and receiving funds from a federal department or agency for research involving human subjects be reviewed and approved by the institution's Institutional Review Board (IRB) (OHSR, 2004). Hence, the ethical concerns with regard to individual rights for these studies were met through IRB regulation of the studies.

Conceptually in terms of furthering the knowledge and protecting public health, these studies provided credible scientific evidence on the causal relationship between occupational uranium exposure and lung cancer which informed policy making but it failed to address communal responsibilities.

⁵Winkler saw that "the proper terms of evaluating moral standards or judgments are not 'true' and 'false' but rather reasonable and unreasonable".

Developments in Uranium Mining in the Navajo Area Since 1990

By 1990, 10% of the participants in the Colorado Plateau study group died of lung cancer; as opposed to expected 1.8% lung cancer deaths in a group of miners such as this. In the same year, RECA was passed providing compensation for miners with lung cancer or nonmalignant respiratory disease (ACHRE, 1995).

Socially, the 1990s were the era of environmental justice movements. Poor communities were identified to be disproportionately suffering from the existing/growing environmental calamities, usually as the result of industrial pollution. Consequently, federal dollars flowed to affected communities, and participatory research was encouraged to solve local environmental health problems. The paradigm of community based participatory research (CBPR) was not new and has had a long and successful history in the social sciences and international and rural development (AHRQ, 2001). Moving beyond categorical approaches and emphasis on individual level risk factors, Barbara Israel says CBPR has a positive model of health that recognizes the individual as “embedded within social, political, and economic systems that shape behaviors and access to resources necessary to maintain health” (Israel, 2001, p. 16).

These social influences were well reflected in the uranium mining studies conducted since the 1990s. Quite contrary to the epidemiological studies in the 1980s these studies explored different facets of uranium mining-related diseases and exposures. Many studies since the 1990s looked into 1) disease etiology besides lung cancer, such as birth outcomes and renal disease; 2) outcomes on affected families as opposed to only miners; 3) environmental exposures as opposed to occupational exposures.

Some of these studies were conducted with community input and participation and experimented with new styles of investigations including qualitative investigations such as oral histories (Brugge et al., 1997; Brugge et al., 2006; Brugge and Missaghian, 2006) Brugge and Benally, 2006) and in-depth case studies of lung cancer in a single miner (Mulloy et al., 2001) and; survey-based community outreach, and educational projects (SRIC, 2004) and epidemiologic studies on birth outcomes and chronic kidney disease (Shields et al., 1992; Lewis Personal communication, 2006).

A series of qualitative studies was conducted to explore the lives of uranium miners and consequences of uranium mining in individual workers as well as the community. A case study of a 72-year-old Navajo male detailing his 17 years as an underground miner and the inception of lung cancer 22 years after leaving the industry was recorded by Mulloy et al. (2001). Brugge et al. (1997) compiled a collection of oral histories of Navajo uranium miners containing 25 interviews with former uranium miners or family members, 5 video recordings, and photographs of sceneries from the mines and the areas where the miners lived. Markstrom and Charley (2003) studied the psychological impacts on Navajo uranium miners and observed psychological impacts from human losses and bereavement, environmental losses and contamination, feelings of betrayal by the U.S. government and the companies, fears about current and future effects and in offspring, and anxiety and depression. Other studies focused on advocacy and social work in health settings (Dawson et al., 1997). These reports contain a wealth of information related to the social context of the Navajo miners and their families.

Lora M. Shields, a visiting professor at the Shiprock campus of Navajo Community College, initiated a 12-year March of Dimes Birth Defects study looking into the birth outcomes from environmental radiation in Navajo people born at the Public Health Service/Indian Health Service Hospital in the Shiprock, NM, uranium mining area (1964–1981). A weak association between proximity to mining areas and birth defects was found (Shields et al., 1992).

Also shaping the research in the Navajo Nation in the 1990s and protecting the interests of the Navajo people and their community was the establishment of Navajo Nation Health Research Review Board in 1996. Though the Navajo Nation IRB is not substantially different from the Navajo Area IHS IRB and follows the traditional western framework, it does require pre-publication review of research and does not allow for exemptions. It also reviews secondary scholarship that reports on the Navajo people that does not engage human participants directly. In 1999, the Navajo Nation also adopted a Navajo Nation Privacy and Access to Information Act to preserve the privacy interests of individuals. The Navajo government views their regulations as a means to prevent harmful research that might stigmatize the Navajo people. The main requirement for community input is approval by

affected local governmental units within the Navajo Nation called chapters (Brugge and Missaghian, 2006).

Ongoing Projects

A set of new studies has been initiated in the community and by the community to examine health threats apart from respiratory diseases. Setting examples of community based participatory research; three new community projects have been initiated in the Eastern Navajo Nation—the Church Rock Uranium Monitoring Project (CRUMP), Diné Network for Environmental Health (DiNEH), and Navajo Uranium Assessment and Kidney Health Project (NUAKHP) (SRIC, 2004; Lewis, 2006).

These studies focused on environmental monitoring and on the extent of environmental contamination (i.e., a hazard assessment), the levels of exposures in these communities, and the prevalence of renal disease from contaminated drinking water (i.e., a health evaluation). By the late 1950s, views had evolved on the toxicity of uranium that it may damage the kidney, but it had not been the focus of research in the Navajo Nation (Thun et al., 1985; Legget, 1989). Though much research on Navajo lands until 1990 focused on respiratory diseases, a series of studies was conducted on uranium ingestion through drinking water and changes in renal biomarkers in Canada between 1982 and 1999 (e.g., Zamora et al., 1998).

CRUMP is an environmental monitoring project initiated by Churchrock Chapter of Navajo Nation to address the impact of abandoned mines on the community. Since 2003, the project has monitored environmental contaminants in water, land, and air in residential areas located near abandoned uranium mining and milling operations in an area located about 12 miles northeast of Gallup, NM. CRUMP tested 14 unregulated water wells for gross alpha radiation, radium, uranium, heavy metals, and general chemistry and found that only two wells satisfied all federal primary and secondary drinking water standards. One well had radium levels exceeding the federal standard, and the well was subsequently abandoned. Another well had uranium levels more than two times the federal drinking water standard, and residents have been advised not to use the well for drinking water. Gamma radiation was measured along highways and roads and next to residences located close to abandoned mines. Gamma rates were

found to be significantly higher along highways and roads and on Navajo grazing lands next to abandoned mines, in some cases exceeding local background by up to 16 times. Gamma radiation levels were 10 times greater than the background next to homes located within 500 feet of an unremediated uranium mine that has not operated since 1982. These results led in part to a recent Navajo Nation backed United States Environmental Protection Agency (USEPA) Superfund enforcement order. Thirty-four of 139 homes tested for radon exceeded the USEPA action level of 4.0 pci/l; the source of sources of these high indoor levels were believed to be natural uranium outdoors, and in limited cases, proximity to abandoned mines. Air particulate matter (PM-2.5 and PM-10) data are being gathered at two stationary monitors in the area (SRIC, 2004; Lewis, 2006; Shuey, 2006).

Following this DiNEH, an educational and technical assistance project started in 2004 funded by the National Institute of Environmental Health Sciences (NIEHS). The purpose of the project is to research the capacity of 20 Navajo chapters in the Eastern Navajo Agency. The project will administer a water-use survey for four years, from 2004 to 2008. They will survey unregulated water wells, windmills, and springs. At the end of their project the effort will be transitioned to the NUAKHP for testing associations between drinking water and observed kidney disease.

NUAKHP epidemiological study, started in 2006, will explore the toxicity of uranium as opposed to that of radon exposure. It is a surveillance study funded by NIEHS to assess kidney health through both standard clinical screening techniques and detailed biochemical analyses of markers of early kidney damage. NUAKHP will also continue the survey and water analysis begun by the DiNEH project. These findings of kidney health status will be combined with detailed exposure assessment and other physical and socio-economic risk factors to develop a model of use for kidney disease in these communities. NUAKHP will draw heavily on data from the earlier CRUMP and DiNEH projects.

In conducting these three studies, the Navajo community hopes to reduce uranium exposure through drinking water and estimate relative risks for chronic kidney diseases from ingestion of uranium from drinking water in the Eastern Navajo area and address community concerns. The Navajo community is an equal participant in these community-based participatory research

projects. The CRUMP, DiNEH, and NUKHP are collaborative projects that include community groups, health agencies, academic institutions, and governmental agencies. They are led by the University of New Mexico Community Environmental Health program, partnering with the Eastern Navajo Health Board, the Crownpoint Services Unit, the Southwest Research and Information Center, Navajo Area Indian Health Service (NAIHS), Navajo Nation Water Resources Department, USEPA Region 6 and U.S. Army Corps of Engineers (USACE) and Navajo Tribal Utility Authority.

Recent Developments in Uranium Mining in the Navajo Area

Despite the long battle to bring justice to the issue of uranium mining and allot compensation to uranium miners, the issue of uranium mining is far from settled. Since 2001, there have been efforts to revive the nuclear power industry. With energy prices soaring in the U.S., a new energy bill was passed in August 2005 providing subsidies for the development of nuclear power plants. There is a shortage of uranium worldwide; about twice as much of what is produced now is needed. Accordingly, the price of uranium in the world market has increased. The price of uranium was approximately \$10.75 per pound in early 2003. By mid 2006, the price had risen to approximately \$45.00 per pound (Depleted Uranium F6 Guide, 2006).

The western plains are targeted again for renewed mining, including mining proposals for Navajo lands that would use in situ leachate (ISL) methods that extract uranium by dissolving ore and drawing it to the surface (Dawsen and Madsen, 2005). With ISL mining, oxygen and sodium bicarbonate are pumped into the rocks to leach uranium into the ground water yielding uranium concentrations 100,000 times higher than is normally found in the groundwater. Some hydrologists predict that such mining is going to contaminate drinking water wells in a matter of seven years, destroying the only source of drinking water to about 15,000 people (Eastern Navajo Dine Against Uranium Mining or ENDAUM, 2005).

Mining resumed in parts of Colorado in 2004 and some of the neighboring states are following the lead. About 8,500 new mining claim permits have been issued in both Colorado and Utah. About four mines in the Navajo area have been targeted to

resume uranium mining. Hydro Resources Incorporated (HRI), a Texas based company, has proposed starting mining at Crownpoint and Churchrock, NM using the ISL mining process (ENDAUM, 2005). Policymakers have not addressed the reduction in working-level-months proposed by NIOSH in 1987 that would be one-fourth of the 1970 standard, thus leaving new workers who enter the profession at substantial risk.

Counter to this trend, the Navajo Nation Council has recently passed legislation to prohibit mining on Navajo lands based on past experiences and community insistence respecting the importance of environment in the Navajo culture. In the current economically challenging and competitive climate this is a bold and firm precautionary stance that the Navajo Nation has made to uphold their values.

This historical analysis shows how public/environmental health research has evolved over the years, shaped by the people and the dominant ideologies of the time. It has broadened into a more encompassing, socially engaging, responsive, and ethical science, and has shaped itself to be a vehicle for direct social change, more powerful and more equipped to deal with the challenges and demands being made on Navajo lands.

Ethical Concerns Specific to the Uranium Mining Research in the Navajo Community

Occupational and environmental epidemiology is conducted in circumstances where hazards exist but when unsure if such exposures pose risks to human health. Understanding the pathways of health risks in environmental epidemiology includes evaluating the environment and community, and questioning the technological and economic factors driving the pollution in addition to individual factors. Soskolne et al. (1996) point out that in many respects, this is a controversial and political field, for groups or populations are often harmed while another group has benefited from such pollution. The presence of stakeholders with opposing interests also makes it an ethically complex context for research.

Ethically, environmental/occupational epidemiologic concerns go far beyond just the protection of individual rights. It is also about understanding the technological and

economic developmental needs in par with protecting community rights, and understanding their environmental values, the man to nature relationship, and societal norms. It includes a broader realm of positions with regard to socially aggregated decision-making. At times, technology, environment, and society are stakeholders in this project. And all decisions have ethical aspects. In the case of the PHS uranium mining project, AEC was an active stakeholder in the project which not only oversaw the production of uranium but participated in the decisions made and implemented throughout the PHS project. The power of AEC or even the private industries in terms of influencing the research studies and steering them in directions of interest to them cannot be ruled out. Understanding and addressing these webs of relations and influences is important to maintaining an equitable and fair ethical research practice.

Today most environmental and epidemiological studies are conducted after hazardous exposures have occurred and when health risks can be measured. Interventional epidemiological studies though not as common are gaining popularity. An insight into this trajectory of research in the Navajo Nation is that the timing of the research is important. If a study is conducted early on, when the exposures of concern are happening, there are greater chances of introducing positive interventions to better the health of the public. If the study is conducted after the exposure has occurred, it mostly informs the science, the regulatory practices that limit exposures to the public for future references.

Scientific research has been shown to be an important player 1) as a tool for informing the policy process, but as one that can delay action as well as a function of the threshold set for the level of uncertainty acceptable to the policy-makers; 2) that informs our course of actions regarding the making of informed decisions about our health; and 3) in responding to health risks, and developing safer alternatives. Collectively, science should help guide and serve the public interest to promote a healthy and safe workplace and environment.

The discussion of ethical issues in this study is based on observations of five decades of studies on uranium mining. Based on the ethical analysis of the studies conducted on uranium

mining we discuss seven complex ethical issues that are most important today.

Loopholes in Informed Consent: Does Informed Consent Protect Workers?

Informed consent requires that the research subject only be informed of any hazards introduced by the research. Researchers are not required to make full disclosure of other risks. While the subjects or workers should be informed about risks due to participation in research with an *intervention* or with research tests, such as a blood draw, or confidentiality issues with observational research, an IRB would say that it is not necessary for the investigators to share the risks the research subjects or workers encounter in the course of work activities and of daily living under current rules. The researcher is not obligated to warn the research subjects of the effects of exposure from work, but is obligated to warn of the risks from participation in a study. This was essentially the issue of informed consent that was contested in the case of uranium mining, namely, that the health risks from uranium mining exposures were not disclosed. Lack of disclosure resulted in the deaths of hundreds of uranium miners.

These days, company occupational health and safety training programs implement protective measures to reduce acute injuries and hazards based on the set threshold levels but do not address chronic exposure issues and chronic health risks adequately from such work. Essentially, the same argument about exposing workers to unsafe conditions may exist today as in the 1960s. The matter gets more complex when we are uncertain of the toxicity of many chemicals and are still identifying their health risks and even more complex as chemicals used in commerce become ubiquitous and in our daily activities.

*Beyond Individual Value: Individual Value vs. Communal
and Bio-Systemic Value*

Winkler in his article on “Reflections on the relevance of the Georgetown paradigm for the ethics of environmental epidemiology” argues that the single comprehensive theory of biomedical ethics derived from the deductivist Euclidean ideal of moral reasoning and extended to fields such as epidemiology is unable to

explain the ethical concerns in environmental epidemiology (Winkler, 1996). While biomedical ethics satisfies the individual interests, environmental epidemiology often deals with public interests and public assets as opposed to individual interests, and of communal and bio-systemic value as opposed to individual value, creating a dissonance between the principles of autonomy and beneficence (Winkler, 1996).

Environmental and occupational epidemiology often studies a community that is affected by a specific exposure from a specific source. Communities such as Navajo Nation not only have a collective identity of their own but share common values and cultural practices that uniquely define them that cannot be easily generalized to other groups. Their cultural and spiritual values are very much linked to environmental values, which is possibly relevant to environmental conservation, management, and sustainable use of resources (Freeman and Carbyn, 1988).

The Pros and Cons of Community-Based Participatory Research in Environmental Epidemiology

Conventional epidemiological studies are not participatory. However, the 1996 ethics guidelines for environmental epidemiologists require community involvement and participation in environmental epidemiological research (Soskolne and Light, 1996). CBPR seeks to address problems as defined by the community, where the community partners and academic partners are equal participants in conducting and disseminating the study, as in the case of NUAKHP kidney health study. In particular, actively involving the community may assist with better aligning research questions with public policy needs. Further, recommendations have been made to use CBPR to reduce racial and ethnic disparities. CBPR may increase community capacity and affect social change by making research responsive to the community rather than seeing research simply as a process for increasing knowledge (Chen et al., 2006).

One of the most challenging aspects of CBPR in the field of environmental epidemiology is that as a community defines the problems of importance and interest to them, the environmental problems can be deemed secondary compared to other existing socioeconomic and infrastructural problems. Often,

addressing environmental health issues also requires addressing these socioeconomic aspects and in such cases long term vision and ensuring the sustainability of the project is important to see that the needs of both the community and the environment are met. For example if CBPR had been done in the 1950s when uranium mining research had started, the community might have defined poverty or economic development and other sociological problems to have been of greater importance than respiratory problems or lung cancer. Our developmental options could come with unforeseen effects and a price tag that costs lives. So, while participatory research presents a systemic view of the community, it need not be focused on the environment or even health. In that respect, there is merit in conventional research investigations in environmental and occupational health problems in a community as it may reveal substantial health problems not apparent to the affected community.

Do Researchers Have a Responsibility Beyond Conducting Technically Valid Studies?

Richard Rhodes, an historian on developing atomic weaponry, noted that many physicists allowed themselves to become assets of national security in exchange for the resources to pursue their dreams of unlocking nature's secrets (Overbye, 2005). There is something similar at work in the way that public health researchers were willing to conduct the early uranium mining studies without pressing very hard for alleviating the exposures of the miners. Public health agency and government department officials have substantial power over decision-making and regulations and they are directly or indirectly responsible for many occupational work standards, especially in cases such as uranium mining. The judgment of a scientist or the controlling officials has consequences and repercussions that could cost or save lives.

At what point is it ethically incumbent upon researchers to "go public" or even commit civil disobedience by disobeying orders to protect the lives of affected workers? Whistle blower laws, however imperfect, provide a modern pathway through which imminent serious dangers can be reported. Researchers conducting studies of human health have an ethical obligation to publicly raise findings that appear to show risk. The manner in

which such findings are made public could vary, but at a minimum, researchers must seek venues beyond academic journals to publicize their results and should prioritize reporting their findings to the affected populations through various means. Further, we feel that researchers should refuse to participate in studies that do not fully disclose health risks to study participants or that are conducted where known risks are allowed to persist unabated.

*Science in the Private Interest⁶: Corporate Interest and
Public Interest Are Not the Same*

It took nearly 30 years since the first PHS study came out for the compensation package to be extended to uranium miners. Scientific doubt is often used as a tool to prolong regulations. Manufacturing doubt, as David Michaels explains, is a strategy that industries often use to hold up regulation by creating controversy (Michaels and Monforton, 2005).

Companies seeking to extract resources (hazardous or otherwise) have become a concern for affected communities. When a corporate industry walks into the neighborhood with their best researcher/technical expert and presents their view of research, such as ISL mining, as safe or risk free, and that it will, in the long term, benefit their communities, there is a potential that the analysis is skewed to justify the company's interest. These companies often use the practice of "royalties" (small payments to show good faith), jobs, and other incentives to smooth the path to expropriation of these resources regardless of the disruption, disharmony, and imbalance of indigenous life in the process.

As Krinsky (2003) argues in his book, *Science in Private Interest*, this web of the political and industrial influence restricts the beneficial application of science for public interest by withholding information. If the scientific motives, validity, and uncertainties in such research are not questioned, it could be identified only at the expense of people who may become sick from ingesting uranium contaminated water, repeating essentially what happened with uranium mining. Mounting death and disease tolls are the perverse results of public interest science with *distorted research priorities* that do not want to incur the displeasure

⁶The title is based on a book by S. Krinsky (cf. Krinsky, 2003).

of the industry or influential committees (Krimsky, 2003). Occupational and environmental health risks are a major externality of capitalism, that is, costs that the company does not pay. This is an inherent and systemic problem.

Moral Uncertainty: Questioning the Environmental Ethics of the Current Generation

The ACHRE report on nuclear experiments recommended that the Government neither apologize nor compensate the victims. Just as scientific doubts are manufactured on the basis of scientific uncertainty, we see that moral uncertainty can be manufactured by emphasizing weak moral arguments such as informed consent not being the norm at the time, or justifying the ethical breaches of the PHS officials as largely a problem of inefficiency.

The fact that this report came out in 1995 and was composed by scholars, namely, ethicists, doctors, and lawyers, is not reassuring that ethical standards have advanced enough. Instead, it is a reminder that justice will be served mostly when there is good representation of all the stakeholders concerned. Perhaps, if some of the victims, were part of the ACHRE committee, the verdict would have been different.

While most aspects of research ethics for individual participants and some community needs are being addressed, the environmental ethical issues are inadequately addressed as they conflict with the current consumeristic interests of our economy and technological interests. We have easily compromised our ethical values for the returns of progress, for national security, to quickly boost the economy, for change, in turn harming the environment, polluting the land, air, and water, and jeopardizing our health. Winkler states that the current forces in the social and economic domain contributes to moral uncertainty, and that we need to question these social domains to further understand the ethical issues in the field of environmental epidemiology (Winkler, 1996).

The Declaration of Helsinki and Belmont Report suggest using risk benefit analysis as a decision-making tool to make ethical decisions on the research conducted. The use of risk assessments and cost benefit analysis to make environmental decisions may be inadequate for making a case that upholds the values of environmental ethics.

Is Precaution an Ideology or a Target that Can Be Attained to Prevent Conditions that Are Harmful?

Public/environmental health science has well-prescribed models to investigate disease etiologies, calculate and interpret disease incidence, and understand disease patterns in communities/populations. Often they prove only what we already know. In these circumstances research becomes just a tool in winning a compensation battle, a regulation that buys an extra breath of ventilation, or a tool that has bought remediation for polluting lands and rivers.

In the case of early uranium mining, preventive measures were not implemented and even when standards were enacted they allowed considerable risk to miners. Philippe Grandjean in his views on science for precaution thinks that these tools for public policy have often worked against precaution under the premise that lack of scientific data or lack of a statistically significant association. "the absence of universally accepted evidence is often assumed to mean evidence of safety or absence of hazard" (Grandjean et al., 2004, p. 383). The precautionary principle calls for shifting the burden of proof to safety and developing more democratic and thorough decision-making criteria and methods (Tickner et al., 1999).

Currently, the Navajo Nation has decided to prevent further mining. This precautionary stance was made despite the scientific uncertainties in ISL mining. While we rely on scientific certainty to define risks; past experiences, upholding one's environmental ethics can be the basis of decision making as well.

Conclusion

The relationship between the environment and development is complex. There is growing awareness that social determinants, public policy, and socio-economic structure are related to health (Raphael, 2006). Most often careless socio-economic growth is accepted even at the expense of environmental exploitation. The issue of ethics in environmental research cannot be resolved without questioning the values and the forces in the social, economic, and technological domain that steer ethical decisions regarding the environment. Because of this, it is important to consider the ethical impact of reductionism of environmental concerns (Svedin, 1998).

Particularly striking is the shift toward CBPR in recent years. While community participatory studies are more accountable and egalitarian than traditional nonparticipatory studies, they may not go deep enough with respect to questioning the basis of our individual, communal, and institutional decision making and the biases hidden there. It is important to maintain accountability in research as well as making ethical stances that are protective and environmentally reasonable and sustainable.

Uno Svedin in the article “Implicit and explicit ethical norms in the environmental policy arena” addresses issues of scientific uncertainty and the inefficiencies of our current decision-making tools and asks useful questions in ethical analysis: “What are the effects of uneven distribution of knowledge about potential exposures? Who are the victims of it? To what extent is incompleteness of knowledge on certain issues problematic to different actors? How is relative lack of knowledge today to be considered in relation to the need to choose an environmentally relevant position today? ...Who is to be favoured, and who is to carry burdens of such scheme of changes—and on which normative grounds?” (Svedin, 1998, p. 302).

A good choice of analytical variables may shift the entire discussion about distribution of future responsibilities. Adopting a burden of proof that ensures safety offers a good approach to risk analysis, a better scale to assess the quality of environment that places more value to public good as well as environmental good. Considering the inadequacies in assessing risk, the European Commission has initiated discussions on how qualitative aspects such as ethical values, animal welfare, quality of life issues, socioeconomic considerations, and sustainability can be incorporated (European Commission, 2003; Grandjean, 2005). Winkler (1996) suggests that our ethical evaluation be domain specific, historically situated, and socially contextualized moral reasoning, and that it include our basic social patterns of resource use and consumption, and our fundamental moral attitudes towards future generations, other animals, and the natural world as a whole, and that we have a clear, ordered, and widely shared conception of the primary social good.

This historical analysis shows a broad sweep of slow but positive change in addressing ethical issues in research about the

Navajo uranium miners and their communities. Given the direction of change over time, perhaps, there is hope for further evolution of ethics in environmental research toward a view that is kinder to humans as well as nature.

Acknowledgment

This article was supported in part by the Collaborative Initiative for Research Ethics and Environmental Health (CIREEH) at www.researchethics.org, from its project on “Ethical Reviews of Populations Exposed to Cold War Nuclear Experiments.” funded by the National Institutes of Health, National Heart, Lung and Blood Institute’s grant program for Short Courses for Research Ethics, T15HL069792.

References

- Advisory Committee on Human Radiation Experiments (ACHRE). (1995). *Final Report: Advisory Committee on Human Radiation Experiments*, Washington, DC: U.S. Government Printing Office.
- Agency for Health Care Research and Quality (AHRQ). (2001). *Community-based participatory research: Conference Summary Report*, November 27 – 28, 2001. Rockville, MD: U.S Department of Health and Human Services.
- Archer, V. E., Magnuson, H. J, Holaday, D. A., and Lwariance, P. A. (1962). Hazards to the health in uranium mining and milling. *Journal of Occupational Medicine* 4: 55–60.
- Bale, W. F. (1980). Memorandum to the files, March 14, 1951; Hazards associated with radon and thoron. *Health Physics* 38:1062–1066.
- Begay vs. United States, 591 F. Supp, 991, 1007. (Undated).
- Ball, H. (1993) *Cancer Factories: America’s Tragic Quest for Uranium Self-Sufficiency*. Westport, CT and London: Greenwood Press.
- Board on Radiation Effects Research (BRER). (2005). *Assessment of Scientific Information for Radiation Exposure Science and Education Program*. National Academy of Sciences. Washington, D.C.: National Academies Press.
- Brugge, D., Benally, T., Yazzie-Lewis, E., eds. (2006). *The Navajo People and Uranium Mining*. Albuquerque, N.M.: University of New Mexico Press.
- Brugge, D. and Missaghian, M. (2006). Protecting the Navajo people through tribal regulation of research. *Science and Engineering Ethics* 12(3): 491–507.
- Brugge, D. and Benally, T. The Navajo uranium miner oral history and photography project. In: Brugge, D., Benally, T., Yazzie-Lewis, E., eds. (2006) *The Navajo People and Uranium*. Albuquerque, N.M: University of New Mexico Press.
- Brugge, D., Benally, T., Harrison, P., Austin-Garrison, M., Fasthorse-Begay, L. (1997). *Memories come to us in the rain and the wind: Oral histories and photographs of Navajo uranium miners and their families*. (reprinted in 1999 and 2000). Boston, MA: Tufts University School of Medicine.

- Brugge, D. and Goble, R. (2002) The history of uranium mining and the Navajo people. *American Journal of Public Health*. 92: 1410–1419.
- Brugge, D. and Goble, R. (2003) The Radiation Exposure Compensation Act: What is fair? *New Solutions: A Journal of Environmental and Occupational Health Policy*. 13:385–397.
- Center for Disease Control and Prevention CDC (2005) *The Tuskegee Syphilis Study*. Department of Health and Human Services. URL: <http://www.cdc.gov/nchstp/od/tuskegee/time.htm> Accessed October 2006.
- Chen, D. T., Jones, L. and Gelberg, L. (2006) Ethics of clinical research within a community-academic partnered participatory framework. *Ethnicity & Disease* 16:118–135.
- Committee on the Biological Effects of Ionizing Radiation. (1999) *Health effects of exposure to Radon (BEIR VI)*, Washington DC: National Academy Press.
- Committee on the Biological Effects of Ionizing Radiation. (1988) *Health risks of radon and other internally deposited alpha-emitters (BEIR IV)*, Washington DC: National Academy Press.
- Dawson, S. E. and Madsen, G. E. (2005) Safety concerns with resumption of uranium mining. Utah: *Salt Lake Tribune*, October 23, 2005.
- Dawson, S. E., Charley, P. H., and Harrison P. Jr. (1997) *Advocacy and Social Action among Navajo Uranium Workers and their Families in Social Work in Health Settings: Practice In Context, (2nd Ed)*. New York and London: Haworth Press. pp 391–407.
- Depleted Uranium F6 Guide, (accessed October, 2006) Uranium Quick Facts, U.S. Department of Energy (DOE) URL: <http://web.ead.anl.gov/uranium/guide/facts/>
- Donaldson, A. W. (1969) The epidemiology of lung cancer among uranium miners. *Health Physics* 16: 563–569.
- Egilman, D., Wallace, W., Stubbs, C., and Mora-Corrasco, F. (1998). Ethical aerobics: ACHRE's flight from responsibility. *Accountability in Research* 6: 15–61.
- Eichstaedt, P. (1994) *If You Poison Us: Uranium and Native Americans*. Santa Fe, NM: Red Crane Books.
- Eastern Navajo Dine Against Uranium Mining ENDAUM. (2005) Interview with Rita and Mitchell Capitan. Homeland: Four portraits of Native Action (film).
- European Commission (2003). Final Report on Setting the Scientific Frame for the Inclusion of New Quality of Life Concerns in the Risk Assessment Process. Available at http://europa.eu.int/comm/food/fs/sc/ssc/out362_en.pdf.
- Federal Radiation Council (FRC). (1967). Report No.8 Revised. Guidelines for the control of radiation hazards in uranium mining. U.S. Government Printing Office, Washington DC.
- Freeman, M. M. R. and L. N. Carbyn (editors) 1988. *Traditional Knowledge and Renewable Resources Management in Northern Regions*. Occasional Paper No. 20, Boreal Institute for Northern Studies, Edmonton.
- Gilliland, F. D., Hunt, W. C., Pardilla, M., and Charles, R. (2000) Uranium mining and lung cancer among Navajo men in new Mexico and Arizona, 1969 to 1993. *Journal of Occupational and Environmental Medicine*. 42(3): 278–283.
- Gottlieb, L. S. and Husen, L. A. (1982) Lung cancer among Navajo uranium miners. *Chest*. 81: 4.

- Grandjean, P. (2005) Non-precautionary aspects of toxicology. *Toxicology and Applied Pharmacology* 207: 652–657.
- Harley, J. H. (1980) Sampling and measurement of airborne daughter product of radon. (Reprinted) *Health Physics*; 38: 1067.
- Holaday, D. A. (1969) History of the exposure of miners to radon. *Health Physics*; 16:547–552.
- Hueper, W. C. (1942) *Occupational Tumors and Allied Diseases*. Charles C. Thomas, Springfield, IL.
- Israel, B. A. (2001) Community-based participatory research: Principles, rationale and policy recommendations. (keynote address) in Successful models of community based participatory research, National Institute of Environmental Health Sciences (NIEHS) March 29–31, 2001. Washington DC.
- Krimsky, S. (2003) *Science in private interest: Has the lure of profits corrupted biomedical research?* Lanham, MD, USA. Rowman & Littlefield Publishers, Inc.
- Leggett, R. W. (1989) The behavior and chemical toxicity of U in the kidney: A reassessment. *Health Physics* 57: 365–383.
- Lorenz, F. E. (1944) Radioactivity and lung cancer: A critical review of lung cancer in the miners of Schneeberg and Joachimsthal. *Journal of the National Cancer Institute*; 5: 1–15.
- Lundin, F. E., Lloyd, W., Smith, E. M., Archer, V. E., and Holaday, D. A. (1969) Mortality of uranium miners in relation to radiation exposure, hard-rock mining and cigarette smoking -1950 through September 1967. *Health Physics*. 16: 571–578.
- Lundin, F. E., Wagoner, J. K., and Archer, V. E., (1971) Radon daughter exposure and respiratory cancer quantitative and temporal aspects. NIOSH-NIEHS Joint Monograph No.1. U.S. Department of Health Education and Welfare.
- Markstrom, C. A. and Charley, P. H. (2003) Psychological effects of human caused environmental disasters: Examination of the Navajo and uranium. American Indian and Alaska Native Mental Health Research: *The Journal of the National Center* 11: 19–45.
- Michaels, D. and Monforton, C. (2005). Manufacturing uncertainty: Contested science and the protection of the public's health and environment. *American Journal of Public Health* 95: 539–548.
- Mulloy, K. B., James, D. S., Mohs, K., and Kornfeld, M. (2001) Lung cancer in a nonsmoking underground uranium miner. *Environmental Health Perspectives*. 109 (3).
- Nuclear Information and Resource Service NIRS. (2005) Controversial history of radiation epidemiology and risk estimation. Available at <http://www.nirs.org/mononline/appendixhisbeirletter1.htm> Accessed October, 2005.
- Office of Human Subjects Research (OHSR). (2004) *Guidelines for the conduct of research involving human subjects*. National Institute of Health. Available at: <http://ohsr.od.nih.gov/guidelines/GrayBooklet82404.pdf>.
- Overbye, D. (2005) Dr. Atomic: unthinkable yet immortal. *New York Times*, Oct 18.
- Peller, S. (1939) Lung cancer among mine workers in Joachimsthal. *Human Biology* 11:130–143.
- Radiation Exposure Compensation Act. (1982) Hearings of 1981 – Part 2, April 8.

- Raphael, D. (2006) Social detriments of health: Present status, unanswered questions, and future directions. *International Journal of Health Services*, 36 (4): 651–677.
- Roscoe, R. J., Deddens, J. A., Salvan, A., and Schnorr, T. M. (1995) Mortality among Navajo uranium miners. *AJPH* 85:535–540.
- Roscoe, R. J. (1997) An update of mortality from all causes among white miners from the Colorado plateau study group. *American Journal of Industrial Medicine*. 31: 211–222.
- Samet, J. M., Kutvirt, B. A., Waxweiler, R. J., and Key, C. R. (1984) Uranium mining and lung cancer in Navajo men. *The New England Journal of Medicine*. 310 (23).
- Surveillance Epidemiology and End Result (SEER). (2005) A brief history of cancer registration. National Cancer Institute. Accessed 2005. URL: . Available at http://training.seer.cancer.gov/module_cancer_registration/unit1_history.html
- Shields, L. M., Wiese, W. H., Skipper, B. J., Charley, B., and Benally, L. (1992) Navajo birth outcomes in the Shiprock uranium mining area. *Health Physics*, 63: 542–51.
- Shuey, C. (2006) The 20 year wait – Church Rock chapter emerges as leader in community based research in uranium mining impacts. *Voices from the Earth*. 7:1, 3–5.
- Smith, B. E. (1987) *Digging our own graves: Coal miners and the struggle over black lung disease*. Philadelphia, PA: Temple University Press.
- Soskolne, C. L. and Light, A. (1996). Towards ethics guidelines for environmental epidemiologist. *The Science of the Total Environment* 184: 137–147.
- South West Research and Information Center (SRIC). (2004) Mitchell Capitan and eastern Navajo Dine against uranium mining: Take their message to the international stage. *Voices from the Earth*. 5(3).
- Stellman, S. D. (2003) Issues of causality in the history of occupational epidemiology. Series: History of Epidemiology. *Soz – Präventivmed*. 48: 151–160.
- Svedin, U. (1998) Implicit and explicit ethical norms in the environmental policy arena. *Ecological Economics*. 24: 299–309.
- Tickner, J., Raffensperger, C., and Myers, N. (1999). *The precautionary principle in action – A handbook*. Windsor, North Dakota: Science and Environmental Health Network.
- Thun, M. J., Baker, D. B., Steenland, K., Smith, A. B., Halperin, W., Berl, T., (1985) Renal toxicity in uranium mill workers *Scand J. Work Environ. Health*. 11: 83–90.
- U.S. Department of Justice (USDOJ). (2005) Radiation Exposure Compensation System: Claims received by 10/25/2006. URL: http://www.usdoj.gov/civil/omp/omi/Tre_SysClaimsToDateSum.pdf
- U.S. Nuclear Regulatory Commission. (2003) A short history of nuclear regulation 1946 – 1999. (NUREG/BR-0175, Rev. 1) June 23, 2003. URL: <http://www.nrc.gov/who-we-are/short-history.html>
- U.S. Mine Safety and Health Administration. MSHA (2003) 25 years of safety and health values, United States Department of Labor. 2003. URL: <http://www.msha.gov/MSHAInfo/25Years/MSHA%2025%20Years.pdf>

- Wagoner, J. K., Archer, V. E., Lundin, F. E., Holaday, D. A., and Lloyd, J. W. (1965) Radiation as the cause of lung cancer among uranium miners. *New England Journal of Medicine* 273:181–188.
- Waxweiler, R. J., Roscoe, R. J., Archer, V. E., Thun, M. J., Wagober, J. K., Lundin, F. E. Jr., (1981) Mortality follow-up through 1977 of the white underground uranium miners cohort examined by the United States Public Health Service. In Gomez M (ed): *Radiation Hazards in Mining. Society of Mining Engineers*, AIME. Kingsport, Tennessee: Kingport Press. pp823–830.
- Winkler, E. R. (1996) Reflections on the relevance of the Georgetown paradigm for the ethics of environmental epidemiology. *The Science of the Total Environment* 184: 113–120
- Zamora, L. M., Tracy, B. L., Zielinski, J. M., Meyerhof, D. P., and Moss, M. A. (1998) Chronic ingestion of uranium in drinking water: A study of kidney bioeffects in humans. *Toxicological Sciences* 43(1): 68–77.