

January 1999


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Repository Citation

Lillian Trettin, Catherine Musham & Richard Jablonski, *Genetic Monitoring in the Workplace: A Tool Not a Solution*, 10 RISK 31 (1999).

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Genetic Monitoring in the Workplace: A Tool Not a Solution*

Lillian Trettin, Catherine Musham & Richard Jablonski**

Introduction

Health risks endured by workers as a result of exposure to toxic substances is a recurring theme in the story of American industry. Occupational medicine, the discipline arising from the need to protect the health and safety of workers, seeks to identify potential risks in workplace environments and implement appropriate interventions. Genetic testing may be used to predict health and has considerable promise for industrial risk assessment. However, due to public opposition to the sweeping use of predictive health tests, its pros and cons continue to be debated. For instance, a recent article in *Newsweek* warns: "Flunk the Gene Test and Lose Your Insurance."¹ Much of this attention stems from public interest in the Human Genome Project, one of the first international biological initiatives of the 1990's to result in radically new medical technology.

Increasingly, conferences have been convened to discuss the Genome Project and the multitude of ethical, social, and legal issues surrounding the use of genetic testing. As organizers of one such conference asked in 1995, "[w]hat is the appropriate balance between encouraging biotechnological innovation while protecting the public from risks that accompany any new technology?"²

* We thank the reviewers for their careful, critical observations.

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¹ Greg Cowley, Flunk the Gene Test and Lose Your Insurance, *Newsweek*, December 23, 1996.

² Gianna Julian-Arnold & Suzanne Sprunger, Promoting and Managing Genome Innovation, 7 *Risk* 197 (1996).

This article will examine the potential risks and benefits of a new type of predictive testing: genetic monitoring based on advances in biomarker research. The future development of this technology is particularly applicable to hazardous workplaces, where the incentive to test employees for exposure to toxicants has been substantial. As these tests improve, it will become feasible to determine whether a worker was exposed to toxicants and whether the exposure results in increased risk for particular diseases, including some forms of cancer.

The key issue is whether genetic monitoring can offer significant benefits to occupational medicine (and society in general) without the discrimination and confidentiality violations that have plagued genetic screening. Theoretical support for examining a new medical technology in terms of its social implications and consequences is provided by "social constructionism." This perspective emphasizes the importance of considering medical or technological issues in the full social context of scientific and lay knowledge and practices. Rather than question the effectiveness of technological advances, it aims to understand and interpret their potential impact through cultural and social analysis.³

Following an explanation of the differences in screening and monitoring and a brief history of each procedure, this paper discusses potentially greater benefits of monitoring along with the problems that could result from its use. Next, the paper points out that that investigation of the ethical, social and legal aspects of genetic monitoring is urgently needed to ensure that it will be used constructively is occupational medicine and not as an instrument of discrimination. Several specific issues that require further study are identified. Finally, we conclude that genetic monitoring has a significant role to play in occupational medicine, but it does not offer an easy solution to the many social problems that have accompanied use of genetic screening.

Genetic Screening and Monitoring Defined

Although not obvious in popular semantic usage, the definitions of screening and monitoring are precise and distinctive according to

³ See Deborah Lupton, *Medicine as Culture: Illness, Disease and the Body in Western Societies* (1994).

biomedical and occupational medicine literature. Much of the writing in this area discusses the relative advantages of genetic screening and monitoring using these definitions as a basis for comparison.⁴

Genetic screening focuses on the individual. It is defined as a one-time-only test that determines if an individual possesses inherited traits that increase his or her risk of a specific disease. Typically, this approach is used to measure the likelihood that an individual will develop a particular disease, prior to the appearance of symptoms. Although screening criteria is based on populations at risk, the application of this procedure is focused on the individual rather than the population. Validity and reliability are of key importance in screening procedures.

Genetic monitoring, on the other hand, focuses on the environment. It uses a form of medical surveillance to identify hazards in the environment before they cause disease. John Last writes that the purpose of monitoring is: "to detect changes in the trend to distribution in order to initiate investigative or control measures."⁵ Thus, the emphasis is on the population, not the individual, and the ultimate purpose is to reduce risk by changing the environment. Accuracy of individual test results is less important than in the case of screening.

Historical Perspectives

Based on government and corporate reports, news accounts, and interviews with corporate and government officials, scientists, and labor experts, many scholars conclude that applications of genetic screening in the workplace show a history of discrimination.⁶ For instance, susceptibility to toxic chemicals has been falsely linked to genetic conditions associated with particular ethnic groups, making it appear that there are "scientific reasons" for discrimination against them.⁷ Discrimination against African Americans at risk of developing sickle-cell anemia, a genetically inherited condition which has nothing to do with exposure to toxic chemicals, is a glaring example. Gender has also

⁴ See Nicholas A. Ashford et al., *Monitoring the Worker for Exposure and Disease: Scientific, Legal, and Ethical Considerations in the Use of Biomarkers* (1990); *Americans With Disabilities Act* 42 U.S.C. §§ 12101-12213 (1990).

⁵ John M. Last, *Dictionary of Epidemiology* (1993).

⁶ See Dorothy Nelkin & Laurence Tancredi, *Dangerous Diagnostics: The Social Power of Biological Information* (1989); Elaine Draper, *High Risk Workers or High Risk Work*, 6 *Int'l. J. Sociology & Soc. Pol'y* 12 (1986).

⁷ *Id.*

been a basis for discrimination, as exemplified by the corporate trend in "fetal exclusion policies" of the 1970's and 1980's. Non-sterile women of childbearing age were regularly restricted from holding certain hazardous (but lucrative) jobs to avoid the possibility of lawsuits from genetic damage to fetuses through exposure should they be "irresponsible" enough to become pregnant.⁸

Recently, the genetic makeup of individual workers or groups of workers has become a focus of occupational disease in much the same way "worker carelessness" was a focus of industrial safety programs at the turn of the century. Prior to the recent advent of regulatory controls, genetic screening gave the appearance of providing a "scientific basis" on which to exclude workers presumed to have health risks from employment. In addition to genetic screening, many industries routinely monitor for emissions. Both are less costly alternatives than high-priced engineering solutions.

Because of these and other cases, workplace screening to ensure employee health and safety is out of favor with legislators, regulators and many business leaders. Public concern over confidentiality of test data and potential discrimination by employers and insurers culminated in congressional hearings and a ruling in 1995 that people with genetic abnormalities are covered under the Americans with Disabilities Act (ADA).⁹ In the interest of better assuring confidentiality, federal officials proposed a more comprehensive law in 1997 to "protect the privacy of medical records, to let consumers inspect their own files and to punish any unauthorized disclosures of personal data by hospitals, insurers, health plans or drug companies."¹⁰

Genetic monitoring is regarded enthusiastically by many as a revolutionary new way to protect workers from exposure-linked disease. They predict immense benefits. Potential application in the work place is the driving force behind much of the research in genetic monitoring.

The use of biological markers in occupational medicine is not new. What is new is the increased sensitivity of the current generation of

⁸ *Id.*

⁹ See Elaine Draper, *Social Issues of Genome Innovation and Intellectual Property*, 7 Risk 201 (1996); Americans With Disabilities Act 42 U.S.C. §§ 12101-12213 (1990).

¹⁰ Richard Pear, *Clinton to Back a Law on Patient Privacy*, N. Y. Times, Aug. 10, 1997 at A4.

biomarkers. Scientists' ability to work with biomarkers at the molecular level has increased dramatically since the 1960's and 1970's, when corporations like Dow Chemical initiated monitoring programs. In 1982, pioneering molecular epidemiologist Frederica Perera and her colleagues noted that a well-known class of carcinogens, resulting from exposure to tobacco smoke, polluted household air, or barbecue-grilled foods as well as workplace pollutants, left a unique "fingerprint" in human lung and blood cells — an adduct (a complex that results when a chemical attaches to a biological molecule, usually to DNA or a protein in a cell). Subsequent studies showed that people with higher levels of these adducts had heightened likelihood of developing various cancers.¹¹ Increasingly, biologists claim, these biomarkers will make it possible to flag critical precancerous events within the body long before clinical evidence is available.

Recent advances in biomarkers make it possible to identify an exact continuum of events in the progressive development of a disease like cancer. Biomarkers are generally classified into three groups: biomarkers of exposure, effect, or susceptibility. An exposure marker indicates increased levels of a specific toxicant in the body. An effect marker exhibits temporary or permanent response to that exposure, such as cell mutation. A susceptibility marker measures an individual's innate (genetic) or acquired capacity for responding to an exposure.¹² There is some debate over what kind of markers are the most useful. Markers of susceptibility offer the greatest possible benefit of early detection, but their reliability is questionable and subject to conflicting interpretations. Genetic monitoring generally focuses on markers of exposure and effect.

Currently, biomarker technology is not sophisticated enough for precise and uniformly dependable test results. Given these limitations, reliable early detection of disease is not always possible.¹³ However, it is likely that with further development, biomarker technology can be used to monitor any population at risk for exposure to harmful

¹¹ See Frederica P. Perera, *Uncovering New Clues to Cancer Risks*, *Scientific American*, May 1996 at 54.

¹² See Rogene E. Henderson & Jonathan B. Ward, *Identification of Needs in Biomarker Research*, 104 *Env'tl. Health Perspectives* 895 (1996).

¹³ See Perera, *supra* note 11 and Ashford et al., *supra* note 4.

environmental toxicants, to determine whether they have been exposed to a particular toxicant, and, if so, whether they have sustained reversible or irreversible damage. Scientists predict that it will soon be feasible to identify a set of markers in an individual and assess the likelihood that the person will acquire, or will be at heightened risk of acquiring cancer. At this time the number of dependable monitoring programs (for example, monitoring for the work-related chronic beryllium disease), is limited.¹⁴

The enthusiasm about biological monitoring should be balanced with understanding of the potential social effects, including possible abuses of this technology. Workplace monitoring programs will have to deal with the existing context of policy decisions brought about by industry's experience with genetic screening. The potential for enhanced preventive interventions in the hazardous workplace using monitoring procedures is striking. However, many of the ethical, social, legal and economic issues raised by screening apply to monitoring as well. Genetic monitoring is likely to create some social problems.

For example, in 1977 after monitoring employees for over ten years, Dow Chemical's company scientists found evidence that workers exposed to benzene and epichlorohydrin showed high rates of chromosome breakage. Proponents hailed the research for identifying the industry's hazardous risks. However, opponents criticized the research as unreliable and charged that publicizing it would induce unwarranted stress in workers before real impacts could be determined.¹⁵ Debates of this kind over the results of monitoring are likely to occur in the future and may affect its prospects.

Discussion

Proponents claim that biological monitoring will result in overall health improvements and will support a mandate to change the hazardous workplace rather than change the worker.¹⁶ This claim

¹⁴ See Perera, *supra* note 11; see F. Joseph Furman et al., *Rocky Flats Beryllium Health Surveillance*, 104 *Env'l Health Perspectives* 981 (1996).

¹⁵ See Elaine Draper, *Risky Business: Genetic Testing and Exclusionary Practices in the Hazardous Workplace* (1991).

¹⁶ See Paul A. Schulte, *Introduction: The Role of Biomarkers in the Prevention of Occupational Disease*, in *Biomarkers and Occupational Health: Progress and Perspectives* 1 (Mortimer Mendelsohn et al. eds., 1995).

requires close examination. Unfortunately, historical evidence shows that workers exposed to health hazards ranging from unsafe settings to toxic substances have been blamed for careless behavior, failure to use correct procedures or good judgment, and — more recently — perceived health risk on the job. It is still the case that corporate findings more often target problematic individuals or groups than more expensive engineering problems involved in changing workplace environments. It is possible that eventually genetic monitoring will be used in this capacity rather than its intended purpose.

Some scholars ask: why not reduce the potential for health threat to the lowest possible denominator based on the findings of monitoring and thereby avoid unforeseen dangers to all workers rather than gather evidence that certain workers are likely to develop health problems and assume that, if those workers are eliminated, the workplace is “safe”?¹⁷ In simplest terms, these scholars raise a basic social-constructionist dilemma, shaped by partisan interests: workers would like to make the workplace as hazard-free as possible. Employers want to protect their workforce, but prefer means that minimize legal and financial liability — most often, a policy of removing problem workers. Resolving this dilemma is not simple.

Pragmatists question whether it is realistic to resolve the dilemma by insisting on zero-risk conditions in the workplace, given current market conditions. From that perspective, there may be little practical alternative to removing high-risk employees from the most hazardous workplaces if our society continues to support demands for products that require the use of hazardous substances for which we identify no replacements. A potential solution to the problem of displaced high-risk workers would be for companies to offer them a “worker removal policy” that guarantees them salaries and benefits comparable to those they previously earned. Under the Occupational Safety & Health Administration (OSHA), lead and benzene are now regulated in this way. Some economists like W.K. Viscusi believe that these expensive financial reimbursement practices will eventually force employers to provide safer workplaces.¹⁸ However, the obvious limitation is that

¹⁷ See Draper, *supra* note 15.

¹⁸ See Ashford et al., *supra* note 4 and W. Kip Viscusi, *Risky Business*, 12 J. Policy Anal. & Mgmt. 399 (1993).

worker removal or rotation programs only divert attention from the primary prevention measure of cleaning up a dangerous workplace.

Meanwhile, even harsh critics of workplace testing indicate that, as it becomes more precise, biomarker-based monitoring has the potential to better serve workers' interests than genetic screening because of the potential for arresting or avoiding disease in the most vulnerable.¹⁹ Whether employers will adopt monitoring programs based on this without mandates remains to be seen. Monitoring programs could prove costly and legally threatening for companies. Employers, corporate physicians and third-party payers have all demonstrated their preference for one-time-only procedures like screening. One time only procedures facilitate sorting workers into high-risk and low-risk groups, cost less than repeated monitoring, and provide "scientifically objective" data.²⁰ However, if monitoring acquires the weight of regulatory mandate or otherwise gains widespread support it will be truly beneficial only if workers can avoid being segregated into "high risk" and "low risk" groups and can maintain a sense of control over the data collected.²¹ This will remain difficult to achieve. Those most likely to face the prospects of biomarker-based monitoring in the future readily identify and express vital interest in these concerns.

The Need For Research on Related Ethical and Social Issues

Ethical questions are of pressing concern, as are questions of economic cost and benefit.²² Concerns persist about the reliability and cost effectiveness of monitoring programs and about the use of information derived from such programs. Specific issues that should be studied include: the increased impact of new systems of information management on employees' privacy and autonomy, tacit cultural assumptions about the role of monitoring and data management in occupational medicine, and the input of people who are likely to be affected by the use of genetic information in the workplace.

¹⁹ See Draper, *supra* note 15.

²⁰ See Nelkin & Tancredi, *supra* note 6; Draper, *supra* note 15; Draper, *supra* note 9, and Neil A. Holtzman, *Medical and Ethical Issues in Genetic Screening: An Academic View*, 104 *Env'tl Health Perspectives* 987 (1996).

²¹ See Draper *supra* note 15; Draper, *supra* note 9.

²² See Holtzman, *supra* note 20.

Innovations in managing research data have been fueled by the Human Genome Project. Charles Cantor writes that tremendous changes in data management are needed. He predicts that specialized data banks concerned with only a part of the genome and requiring sophisticated information linkages will be developed.²³ Resulting improvements in “informatics” — computerized information management systems — have aided rapid access to genome data and promoted development of large-scale programs of biological research in academia and industry.²⁴ This should affect monitoring programs.

Privacy and discrimination are crucial issues for all medical, especially genetic, data. Greeley concludes that statistical data management may ultimately more affect health management than the most dramatic medical innovations from human genome research. Unlike medical prediction geared toward the individual, statistical prediction sorts groups (like employees or job applicants) into positions of high and low potential medical costs.²⁵ The danger increases that discrimination will be based on assessment of an individual's record, or on that individual's statistical association with an undesirable group. The potential for statistical evaluation of “trends” in health risk is particularly strong for monitoring. Research must determine what safeguards can be designed to protect monitored data from misuse.

Further research is also needed on tacit cultural assumptions about biomedical research in contemporary Western societies. Scholars have made numerous claims about underlying beliefs. The growth of medical technology and associated research dollars is said to artificially elevate the role of diagnostic testing in health care. The result is that some people adopt or are labeled with a “potential sick” role based on the prevalence of testing.²⁶

A proposed metaphor comparing the body to a computer implies that modern societies think of disease as an “information malfunction”

²³ See Charles Cantor, *The Challenges to Technology and Informatics*, in *The Code of Codes: Scientific and Social Issues in the Human Genome Project* 98 (Daniel J. Kevles & Leroy Hood eds., 1992).

²⁴ See 7 *Human Genome News* 3, at 4 (1995).

²⁵ See Horace T. Greeley, *Health Insurance, Employment Discrimination, and the Genetics Revolution*, in *The Code of Codes: Scientific and Social Issues in the Human Genome Project* 264 (Daniel J. Kevles & Leroy Hood eds., 1992).

²⁶ See Lupton, *supra* note 3.

that more data can correct. This metaphor is in contrast to growing recognition that some chronic illnesses are not “curable” as were earlier major diseases like smallpox, cholera and polio.²⁷ Applying biological assumptions in non-clinical settings may lead to blaming the individual for his or her own poor health (or perceived risk of it) due to “bad genes” or a weak immune system. This makes it easier to redefine socially derived problems as individuals’ problems, thereby reducing public accountability and protecting routine institutional practices.²⁸ These concerns are as relevant to monitoring as to screening — perhaps more so, if the illusion that advanced technology and more data necessarily promote better health grows stronger.

Such underlying beliefs have readily discernible political and social dimensions. As anthropologist Emily Martin wrote, a healthy immune body, resistant to disease, becomes a new form of “cultural capital” in Western society. Issues of preventive intervention quickly become partisan: If a politically strong majority requires preventive intervention, the costs seem legitimate and reasonable. If a weak minority requires intervention (e.g., those with AIDS) then the working, healthy immune system predominates and costs for the immunity-impaired might well be considered wasteful.²⁹ The result can be a “caste” of the potentially weak or seemingly disease-prone. Workers in one plant, during the early days of implementing OSHA standards, identified such a group as a “leper colony”.³⁰

A strategy for conducting research on tacit cultural assumptions as they apply to monitoring programs could combine close analysis of descriptions of the workplace from a variety of sources (e.g., news media, popular literature, corporate correspondence, worker interviews) with reader responses to hypothetical texts in a study with controlled experimental design.³¹

²⁷ See Lupton, *supra* note 3; Edward S. Golub, *The Limits of Medicine: How Science Is Reshaping Our Search for the Cure* (1994).

²⁸ See Nelkin, *supra* note 6.

²⁹ See Emily Martin, *Flexible Bodies: Tracking Immunity in American Culture* (1994).

³⁰ Sheldon W. Samuels, *A Moral History of the Evolution of a Caste of Workers*, 104 *Env'tl Health Perspectives* 918 (1996).

³¹ See Martin, *supra* note 29; Peter M. Sandman et al., *Agency Communication, Community Outrage, and Perception of Risk: Three Simulation Experiments*, 13 *Risk Anal.* 585 (1993).

Research should also examine expressed opinions of non-specialists, such as front-line workers, who will eventually face the prospect of workplace monitoring. In 1997, as part of a pilot project, five focus groups were conducted in two midsize industrial cities in the Southeast with a range of potential stakeholders. Using a fictional but plausible scenario to generate discussion, researchers interviewed human resource managers, company physicians and nurses, third-party payers, attorneys, and front-line workers (both unionized and non-unionized) to learn how their perspectives on monitoring varied.³² Initial results of this study indicate that at least some members of all these groups share concerns over the reliability of monitoring and question how practical it would be to use it in today's workplace.

Participants in this study agreed that biological monitoring has potentially constructive uses but that it is likely to result in employee discrimination, given the United States' current social structure and values. All groups saw inevitable conflict between industry's interests and employees' well-being. Managers doubted that companies would adopt monitoring due to increased liabilities and cost. Workers (particularly non-unionized workers) were highly concerned about who would control monitored data and whether increased preventive benefits would offset the risk of job discrimination or loss of health insurance coverage. They questioned whether the need for baseline data as a basis for comparing monitored data would reopen the door to screening. All participants in this study agreed on the importance of measures to ensure employees of protection from discriminatory uses of biological monitoring. Despite its limited scale, the results of this research are instructive and indicate the need for additional qualitative research and surveys of the potential social consequences of monitoring, particularly in light of what is already known about screening in the workplace. This research would extend the argument for a socially constructed policy by further examining the ordinary workplace context in which groups of relevant stakeholders form opinions about biological monitoring.

³² See Catherine Musham et al., *Biomarker-based Health Monitoring in the Workplace: Perspectives of Diverse Stakeholder Groups. A Focus Group Study*, unpublished manuscript, Environmental Hazards Assessment Program, Medical University SC (1997).

Research of this kind, aimed at clarifying the social dimensions of medical policy, maintains that ethical decisions about medical technology will have practical application only if they are embedded in an understanding of real-world situations.³³ Preliminary research with stakeholder groups strengthens the recognition that stakeholders need forums in which to air their concerns and resolve their differences before innovative monitoring programs can have a chance of succeeding.³⁴ To date, experts and scholars have written extensively about possible applications of biological testing in industry and related social, legal, and ethical issues. However, there has been little investigation of the perspectives of "non-experts" who are likely to be involved in and affected by biomarker-based decision-making.³⁵

For instance, Draper's important treatment of genetic testing as a "social construct" considers only the insights of top authorities and policy makers. It does not consider input from the wide range of business executives, attorneys, third-party payers, and health care professionals who will likely be involved with and affected by biological monitoring in the future.³⁶ Nor does Draper interview any of America's front-line workers, the group most likely to be affected personally by this testing and most frequently identified in the literature as potential victims of its misuse. Studies are needed that record insights of people like these based on their day-to-day workplace experience.

Efforts to draw public attention to innovations in biological monitoring may ignite controversy. Although not as dramatic as "cloning," biomarker research is more likely to impress people with its immediate uses and consequences. Industrial leaders, front-line workers, occupational health professionals, environmental attorneys and third-party payers are likely to be affected by potential uses of biological monitoring. It will be important to bring these diverse stakeholder groups together to obtain their practical insights into

³³ See Barry Hoffmaster, *Morality and the Social Sciences*, *Social. Science*, in *Perspectives on Medical Ethics* 241 (George Weisz, ed., 1990).

³⁴ Rogene E. Henderson & Jonathan B. Ward, *Identification of Needs in Biomarker Research*, 104 *Envtl. Health Perspectives* 895 (1996).

³⁵ William Freudenburg, *Risky Business*, 99 *Am. J. Soc.* 835 (1993) (book review).

³⁶ See Draper *supra*, note 15.

biological monitoring while awareness of biomarker research is still limited. The process of identifying similarities and differences in stakeholder perspectives may avert eventual conflict by suggesting areas of agreement and areas requiring negotiation. Research on health promotion innovations emphasizes the importance of taking this step.³⁷ Otherwise, biomarker-based monitoring will have no more success than screening in occupational medicine.

Conclusion

Although monitoring has advantages compared with screening, a great deal of research needs to be done to ensure that it will be used in a socially constructive manner. Nothing will stop the rapid advance of genetic research. Given the inevitability of tremendous gains in knowledge about the human genome, the need for understanding of the social impact of its potential applications is critical. Monitoring uses of genetic information in the workplace raises a host of ethical, social and legal issues that should be studied and fully understood before this technology becomes widely available. Issues of confidentiality, ownership and storage of genetic information collected through monitoring procedures are as pressing and complex as those pertaining to that obtained through screening procedures. It is generally agreed that decisions regarding the use and regulation of genetic monitoring are needed to safeguard its benefits for occupational medicine and minimize the possibility it will be used for discriminatory purposes.

A social constructionist approach suggests that the extent to which policies are based upon a balanced decision-making process, one that acknowledges and equitably reflects views of varied and competing interest groups will largely determine whether genetic monitoring can be as socially beneficial as proponents claim. Genetic monitoring has great promise in occupational medicine with obvious advantages over genetic screening. However, given the range of social and ethical issues related to its potential uses, it is not a simple solution.



³⁷ See Mario A. Orlandi, *The Diffusion and Adoption of Worksite Health Promotion Innovations: An Analysis of Barriers*, 15 *Preventive Med.* 522 (1996).

