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LETTERS

Sound policy


L. CARROLL

Several of this week's letters discuss professional and policy concerns of the working scientist. "One in four whistleblowers reported severe consequences" to their jobs, according to a survey study. Comparing the quality of research done at national laboratories to that at universities (to determine allocation of funding) is not a simple exercise, two writers say. Another gives an example of a successful fellowship program that "strengthens ties" between universities, industry, and government. A question about equity for people who "live far away from the information highway" is raised. The ethics of using previously collected tissue samples for genetic research is discussed. And the achievement of the amateur scientist is trumpeted.

Whistleblowing Consequences

As the project officer for the study of the consequences of whistleblowing, I was pleased to see the Random Samples item about the study (5 Jan., p. 35). Readers should also be made aware of the following important findings of the study.

Although 69% of whistleblowers in scientific misconduct cases experienced one or more negative consequences as a result of their whistleblowing, 62% perceived the consequences of whistleblowing to have had a neutral impact on their careers, professional activities, and personal lives; 28% perceived a negative impact; and 10% perceived a mixed (positive and negative) impact.

Whistleblowers attributed the negative consequences they experienced to institutional officials, the accused, colleagues, and professional societies. The most serious negative consequences were most frequently attributed to institutional officials and secondarily to the accused. One in four whistleblowers reported severe consequences, including loss of position or denial of tenure, promotion, or salary increases.

Negative consequences for whistleblowing were most likely to begin while the institution was responding to the allegation and continue after the inquiry and investigation were completed. Negative consequences were experienced whether or not the allegation was substantiated.

Negative consequences reduced the willingness of whistleblowers to blow the whistle again but did not extinguish it. More than half of the whistleblowers who experienced severe negative consequences reported that they would blow the whistle again.

Although positive consequences of whistleblowing were seldom cited, one in four whistleblowers reported a positive impact on their self-esteem.

Readers may access the whistleblower study report on the Office of Research Integrity (ORI) Home Page at <http://phs.os.dhhs.gov/phs/ori/ori_home.html> or obtain it in hard copy or diskette from the ORI.

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Academia vs. National Labs

The observation in ScienceScope of 2 February (p. 585) that "a recent National Academy of Sciences panel recommended [that] federal agencies should 'favor' universities over national labs and other research institutions because the quality of the science is generally higher on campus" does not reflect what the panel's report said. In fact, the report states that the "committee does not presume that academic research is always of higher quality than that conducted in industry, federal laboratories, or other nonacademic institutions" (*1*). The committee did urge that federal funding for science and technology should generally favor universities because of the greater flexibility of their programs, inherent quality control, and linkage of research to education. It also recommended that excellent, well-evaluated federal laboratories supporting the missions of their sponsoring agencies should not be diminished.

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1. *Allocating Federal Funds for Science and Technology* (National Academy Press, Washington, DC, 1995), p. 20.

The Institute of Scientific Information's (ISI's) analysis of citations to Department of Energy (DOE) labs and academia is an interesting starting point for comparing research quality, but it misses a critical point of institutional culture. In academia, all faculty members, even those without extramural funding, are under pressure to publish all results, even minor ones. In DOE labs, less important and less citable results are likely to be placed in technical reports that are not captured in ISI's database. A more appropriate comparison would be between publications from DOE labs and publications reporting results of university research funded by DOE.

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Genetics and Informed Consent

Eliot Marshall's News & Comment article, "Policy on DNA research troubles tissue bankers" (26 Jan., p. 440) describes an ongoing debate about researchers' use of previously collected tissue samples for research about which patients were not advised or asked for consent (*1*, *2*). In one such case, a pathologist tested a woman's surgical sample for the breast cancer gene, then called her, and told her she had the gene. The woman thus received psychologically troubling and financially risky information she did not want. She and her children will likely be denied health-care insurance (or at least coverage for breast, coronary, and prostate cancer) on the basis of this information (K. L. Hudson *et al.*, Policy Forums, 20 Oct., p. 391).

The article makes it appear that new, burdensome regulations are being proposed that would require the patient's consent before research is done on his or her sample. In fact, federal regulations already in force generally require consent when the patient will be identifiable. These existing regulations are being ignored, sometimes to the detriment of patients.

Marshall's article also makes it appear that research on a set of samples collected by the Centers for Disease Control and Prevention (CDC) has been delayed because of frivolous concerns by ethicists. Not mentioned is the profound dilemma that the CDC has found itself in. The initial collection of samples by the CDC was not, as Marshall says, "to create a repository for research on genetic diseases." Rather it was to monitor the state of national health and nutrition by testing people on a limited number of health indicators such as blood pressure, cholesterol level, and so forth. In its original consent form, CDC promised all the research participants that they would be recontacted with abnormal results. What happens now, though, if researchers use the CDC samples to study the prevalence of the Huntington's gene or a gene linked to male sexual preference and they reveal this information to the person? This may not be information the person wants to have, given that, for example, fewer than 15% of at-risk individuals seek screening for Huntington's disease (*3*). And what about those people who are given unasked for genetic information that is erroneous because the research tests have not been perfected—and take drastic action on the basis of the results?

Research in this country is based on the idea of voluntary, informed consent; it is