

Qualitative Comments About the Survey

Space was provided on the last page of all questionnaires for respondents to volunteer any opinions, concerns, or suggestions related to genetic monitoring and screening in the workplace that they felt the survey did not address. In addition, respondents were encouraged to comment on any survey questions they found confusing or difficult to answer. A total of 78 health officers and 50 personnel officers volunteered comments on the last page of the questionnaire. Most comments volunteered dealt with views on the subject of genetic monitoring or screening. A handful volunteered criticism of the survey or qualified answers to individual questions.

The open-ended comments of survey participants provide additional detail and context on current attitudes and concerns among employers about the use of genetic monitoring and screening in the workplace. Although they may qualify individual responses, the comments are consistent with the quantitative findings of the survey.

Comments on Genetic Monitoring or Screening

Health and personnel officers who volunteered comments offered much more criticism than support for genetic monitoring and screening. However, several indicated that monitoring and screening may be acceptable under certain circumstances. Many of those critical of such testing objected more on practical than philosophical grounds. No health or personnel officer volunteered comments dealing with corporate plans to implement genetic monitoring or screening in the future.

Support for Monitoring or Screening

No health officer volunteered comments giving unqualified support to genetic monitoring and screening. The health officer who gave the most supportive statement regarding genetic monitoring or screening wrote the following:

Genetic testing is an excellent clinical tool. It is very sensitive and very specific, but is not practicable when you try and relate an abnormality to workplace hazards.

Another health officer wrote:

I support any mechanism which would protect the health and safety of our employees. I feel employees should be well informed and the business should have a responsibility for providing a safe working place.

The two personnel officers who volunteered the most supportive comments of genetic monitoring or screening wrote:

I am of the opinion that genetic screening is the answer to protection from occupational disease for the individual and for liability control for the employer. I am an occupational health professional, and a minority, in a Fortune 500 firm that has difficulty condoning preemployment physicals. It will take OSHA [Occupational Safety and Health Administration] to cause it to happen here!

Genetic monitoring or testing can be a valuable tool for both the individual and the company. Neither party is well served by an inappropriate employment situation. There are times, of course, when it may be difficult for certain high-risk individuals to be employed in almost any situation; that issue is a moral and ethical one that does require further study. As indicated in an earlier response, if genetic technology is better perfected, laws are not prohibitively restricted and if society accepts the concept, I would feel that genetic monitoring and testing will occur with more frequency in the future.

Qualified Views on Genetic Monitoring or Screening

However, a number of health officers suggested that guidelines would need to be established for genetic monitoring or screening, with some calling for the development of guidelines as a prerequisite for their companies to consider the use of genetic monitoring or screening. One health officer stated that access to any employee medical information is a very sensitive area for which some guidelines would be helpful. Comments by health officers who volunteered support for genetic monitoring or screening guidelines are given below:

Because of the nature of the subject it is imperative that guidelines, legality, and accuracy of genetic screening and monitoring be well established before our company would consider the use of these tools.

Monitoring should be done only on established guidelines affecting usage. More research is needed in this area before proper implementation can be done.

Collecting data is not problematic. The important and often controversial topic is how that data is used. Genetic information is often not as useful as some may believe, therefore stringent guidelines on how the data may be used should be developed.

Guidelines are needed before testing. Employer and employee must work this testing out together unless it is mandated.

Our industrial exposures are unrelated to illness identifiable with known genetic-related factors. However, unless safeguards are available to protect genetically vulnerable employees it would be appropriate to identify them for proper placement.

Too much work remains to be done at the bimolecular and biochemical level to elucidate the association between genetic testing and specific syndromes, deficiencies or disease states, i.e., elucidate the associations with an acceptable accuracy. Additional R&D should proceed because there are many potential benefits to health promotion and protection, provided a suitable educational program is developed in tandem: one that explains the issues in realistic terms. . . .

Genetic screening and monitoring viewed as primarily a *research* tool at this time.

Key questions or concerns: Testing has to be related to job performance and be documented by objective studies or at least consensus expert opinion. All reasonable (e.g., as OSHA defined) steps to alter jobs should be carried out before applicants are excluded from them. In this state, *any* condition affected by the workplace, even minimally, is fully compensable. That puts extra incentives on business if we are held financially responsible for a minimal aggravation of an at-risk employee's condition.

I favor genetic testing only if such a test would identify an individual at risk of developing a significant illness if exposed to a particular agent in the workplace.

Genetic screening or monitoring would be considered for use if justified to prevent or monitor occupational illness but *only* if it met criteria applied to nongenetic tests. Criteria would include cost, scientific validity, and ethical considerations.

Genetic screening and monitoring is a technique that can now be used to assess and warn an employee of potential harm greater than the general workforce, but should not be used at this time to displace workers or deny employment.

A number of personnel officers volunteered comments on genetic monitoring or screening that can be classified as qualified views on the subject. Like the health officers who supported the development of guidelines, some of these personnel officers indicated the tests may be usable under certain circumstances:

While I believe it to be generally inappropriate to test, I believe that some specific risks dictate wise use of screening.

Definitely can have its value in appropriate (high risk-you define) industries; e.g., chemical. Probably not appropriate- or "cost-effective" -in the great majority of industries. Obvious potential for serious Misuse-perhaps, even abuse.

We believe genetic testing may develop into a very valuable human resource management tool as well as an important guide for personal career and life planning for individuals; we are concerned about the potential social/political (mis)use of the information.

Genetic screening presents a real dilemma in that it can aid in the protection of employees and employers by minimizing exposure to what, for some, are hazardous conditions. If in this context it is used to match people and

jobs there is nothing wrong with it. If on the other hand genetic testing is used to simply exclude people from employment, it doesn't really solve the problem at all. It just swaps one for another.

Only in very select situations can genetic monitoring/counseling/screening be justified as a corporate expense. Even then the individual must be allowed some degree of "free" choice provided that he/she will accept responsibility for the outcome.

I feel to have knowledge of genetic tests incurs amiability on the employer that goes far beyond the employee/ employer relationship. Our role is to focus on job performance. Other issues that don't effect that are none of our business. However, we are also concerned with helping our employees stay healthy so they can be productive.

Provided employment/employability is totally a function of the ability to do the job-then *any* testing that would document that the job assignment is a health risk is appropriate. But *only* to exclude a specific assignment—not to exclude employment.

Genetic screening and monitoring activities should only be used when there is a clear expectation of what will be done with the results, i.e.,-there is a *specific* treatment. If information/purpose has *not* been proven, then telling an employee that he/she has an "abnormal" test (and no one knows what to do with it) only leads to a feeling of hopelessness and suspicion on the part of the employee who holds the employer liable for any possible outcome. Unless the program of screening has been proven, then any data collected should be considered a *research project* and information *not* given to employees unless done in such a way that *no one is* held liable for outcomes. It is not fair to hold employers liable for *unknown outcomes* (*known* outcomes is a different issue). Standard research protocols should be used and rigorously assessed-if not will have the same problem as when the AIDS [acquired immunodeficiency syndrome] test was inappropriately first released.

Criticisms of Genetic Monitoring or Screening

Health officers volunteered several general criticisms of genetic monitoring or screening, including explanations of why such tests were not being conducted. The criticisms of genetic monitoring or screening focused on the perceived lack of practical value and accuracy of the tests; possible problems with actual or perceived discrimination stemming from using genetic monitoring or screening; and even possible abuse of the tests. It should be noted that some of those offering reservations or opposition to genetic monitoring or screening based their objections on primarily practical grounds.

Health officers objecting to genetic monitoring or screening tests as potentially discriminatory or unethical wrote the following:

On a theoretical, altruistic level, I can see the advantages of genetic screening and monitoring; however, on a practical level the potentials for abuse far outweigh the advantages. Furthermore, with a shrinking workforce in

the years to come, such testing would increase the costs of products tremendously.

At present, our corporation has a good risk assessment and reduction program. Any genetic pre- or post-screening is not envisioned. *Any genetic* monitoring during employment would be viewed as potentially discriminatory and against all corporate philosophy.

I have grave reservations as to whether our medical-legal-social-financial structure can deal rationally to genetic screening and/or monitoring. Our track record regarding women and minorities gives me little comfort to believe we could handle a genetic tool in the workplace.

The more testing that is done results in more chances of denying an applicant employment because they can't be placed. This then is often grieved as discrimination. How do you propose to handle this 'Catch 22' situation?

I find the concept of genetic screening as a workplace requirement inappropriate at best and abhorrent at worst. It is a sad commentary on the state of our national ethics.

Genetic screening must never be used to select for those capable of withstanding environmental conditions, as an alternative to making the workplace safe for everyone (or most workers).

Current law requires employers not to discriminate in hiring the handicapped. I assume this includes the use of genetic testing.

Similarly, some health officers noted that genetic monitoring or screening could pose problems related to individual rights:

We must be ever vigilant that individuals are not disadvantaged because of their heredity or environmental circumstances.

In theory business programs involved in using genetic screening and monitoring would appear to be helpful; however, with the present wave of citizens involving themselves with individual rights such programs could present many problems. . . There are few people now who are not aware of their familial health problems and their potential for developing such problems themselves

Genetic screening and monitoring seem to be in direct conflict with the Rehabilitation Act, etc.

Other health officers objected primarily to the perceived lack of practical value of genetic monitoring or screening:

We do not believe the science pertaining to genetic testing is sound enough at this time. Strong consideration of the value of genetic testing is contingent on the reliability of the tests. This testing is not reliable currently.

In the future genetic screening will be sufficiently developed technically to apply as a screening tool. Not yet. Biggest problem is absence of studies correlating findings with health outcomes.

At the present time I have no confidence in state-of-the-art genetic testing and/or interpretation of test results.

You will observe from my responses that I have an objection IN PRINCIPLE with many aspects of genetic screening or monitoring. However, the reason my company has not and does not plan to implement such procedures in the future is that the state-of-the-art, validity of interpretation of many of the tests is still unclear. . . .

Genetic testing does not currently appear to have much practical value in protecting persons or reducing their risk of harm. We have no moral or ethical opposition to testing that is useful in promoting health. If we had full testing of all employees, placement would be about as it is now.

We do have exposures to mutagenic agents. However, consultation with our genetics department reveals the conditions mentioned in question 2 above are not presently met. Such testing has no merit; the goals are achievable by conventional industrial hygiene measures.

Personnel officers also offered a range of criticisms of genetic monitoring or screening. A number were strongly opposed to conducting genetic monitoring or screening:

I believe that genetic testing for any reason is morally wrong and an infringement on privacy rights. I have a fear it will lead to a 'super race' philosophy. Our country was founded on principles of privacy, equal rights. I feel this is a step to destroy those rights. The only exception to this is if it violates safety rules.

From a personal, professional and employee relations point-of-view, I would *oppose any* form of genetic screening and/or testing! !!! A total and complete invasion of privacy!!

I don't believe the efficacy or reliability of genetic testing is sufficiently proven to warrant mandated genetic testing programs. I have concerns about the abuse of testing results which potentially could involve employers in areas beyond their need to know resulting in invasion of privacy, employment discrimination, scaring employees with incomplete or incorrect medical information.

Genetic screening belongs in Star Wars. To our knowledge, no reliable cost-effective screening exists for such screening.

I think that genetic testing is too new a concept for us to properly evaluate. It conjures images of the "dark" side of science. If it is appropriate, much is needed by many of us in the way of understanding the implications.

There would be a reluctance to make employment decisions based on genetic testing because of antidiscrimination laws.

We are unaware of the use/benefit of such testing. I am sure cost considerations and EEO [equal employment opportunity] (handicap) legislation could be problem.

You should consider the impact of screening as another possible cause for discrimination in the workplace, and the cost of such screenings to the employer.

What is the reliability level of this type monitoring/screening? What are the costs? Since I am unfamiliar with the efficacy of such tests my perception is shaped by a “Star Wars” image. You have also not asked questions about privacy and legality and conflict with handicap antidiscrimination laws.

I’m not familiar with genetic testing but would be concerned about legal issues that will inevitably arise.

I have a problem with the morality of such testing—“Big Brother” is too much a part of our lives already. Carry genetic engineering to its logical conclusion, and we’ll be breeding engineers, MD’s, research scientists, etc., like we breed race horses.

I wonder if the collection of this type of data doesn’t ultimately lead to further unnecessary government intrusion into the workplace!

The use of genetic monitoring/screening will become more evident when the results and studies can be directly linked to the prevention or reduction of liability in the workplace. The current use of genetic testing does not appear to be ‘socially’ acceptable and will require education of employers either through insurance companies or legislative initiatives.

I am decidedly against genetic interference. Products should be designed with humans in mind not vice versa.

Comments on the Lack of Information About Genetic Monitoring or Screening

Several health officers stated that they lacked information on genetic monitoring or screening. One attributed the paucity of information to the technology’s newness. This person said that the company should do everything reasonable to protect the employee and, “must change attitude of public that this is an invasion of privacy any more than a H&P [History and Physical]. Others wrote:

Not enough information available to me to know value and costs of genetic evaluations.

A most difficult area.

We have not as yet seriously considered or researched the matter of genetic screening/monitoring.

It’s never been discussed as an option” in our company.

Genetic screening does not apply to this industry.

Considering our type of operation this has little relevance to us.

Similarly, one personnel officer reported working for a very sophisticated employer who lacked experience with the subject. Other personnel officers wrote that:

The entire area of genetic testing in the workplace is a new one and one which has not been widely discussed or

presented in HR [human resources] type publications. I feel a total educational process will be required.

We have not, as a company, explored the ethical and/or philosophical considerations of genetic testing.

Difficult to respond because of a lack of information regarding genetic and biochemical testing.

It’s difficult to answer many of the questions when I have little or no knowledge of biochemical genetic screening, cytogenetic monitoring or DNA-based screening or monitoring techniques.

At this point in time I do not possess enough information or knowledge with respect to genetic screening to make informed judgments or recommendations to corporate management.

Need to know a great deal more about this type of testing.

Many compensation/benefits practitioners will need more information on genetic testing and how it would be administered before they can provide meaningful input on this topic.

At this point we have not made an intensive examination of the issue of mandatory testing of the type(s) outlined in this questionnaire. We will continue to review this issue in future Benefit/Health committee meetings held at the management level of the company.

Some difficulty in truly understanding the specific testing suggested and scope because of the huge controversy re: genetic testing and implications of judgments and decisions which might be made re: results, discrimination, etc.

General Comments on Testing

Two health officers wrote that any practical tests that would identify applicants or employees at greater health risk would be helpful, with one stating “all practical technology” should be employed. One health officer simply stated support for proceeding deliberately to protect employees and companies. One personnel officer volunteered opposition to medical testing that attempts to limit an individual’s employment on the basis of predisposition or susceptibility to a specific medical condition, although that officer noted some use of tests in hazardous job environments. Another personnel officer volunteered opposition to additional Federal legislation to cover any additional testing, national health care and/or the employment of persons with physical limitations.

Comments on the Survey

Several health officers volunteered comments on the last page of the survey that explained or modified their answer to specific questions. One explained cytogenetic monitoring was not conducted because the technology was considered unsatisfactory. Two felt that “exposure” means the potential for exposure, with one volunteering

that chest x-rays are not usually required and that rotating employees to prevent exposures was not necessary in most instances. One health officer wrote this comment to explain how the company performs genetic screening:

The only genetic screening we perform is to diagnose; such as for sickle cell disease/trait, or thalassaemia or G-6-PD [glucose-6-phosphate-dehydrogenase] deficiency to aid us in the diagnosis of an anemia. The only blood test performed on our preemployment form is hemoglobin/hematocrit/white blood cell count.

This was the only comment volunteered by a health officer dealing with actual use of genetic monitoring or screening.

In addition, a number of health officers volunteered criticisms of the questionnaire or found some items difficult to answer, including two with objections that the questionnaire contained questions that were poorly worded, simplistic, loaded, and skirted the law on affirmative action. For example:

Many of the survey questions are difficult to answer yes or no. There are questions of definitions that apply to almost all.

Some questions were left unanswered mainly due to lack of understanding of the terminology involved.

Some questions difficult to understand.

One health officer wrote that broader answers are needed on questions dealing with workplace exposures. One found the attitudinal questions difficult primarily because they did not take “good faith efforts” at accommodation into account. One health officer wrote

that one question (Q.29) is confusing and had some “ambivalence” about some of the general attitude items because genetic monitoring or screening was “not bad *per se*” but there was “a potential for misuse.”

In addition, one health officer commented that positive genetic tests do not translate into poor performance. This person wrote that such tests were not totally accurate, but were discriminatory. Finally, one respondent wrote that “care must be taken in interpreting and conveying the results of the survey responses.”

Several personnel officers also volunteered criticisms of the surveyor offered criticisms to individual questions. Two personnel officers called the survey a waste of money and one thought the questionnaire assumed a higher level of sophistication than corporations have. One personnel officer reported difficulty in answering some questions because of a lack of information on the costs associated with genetic testing. Two objected to the way question 9 was framed, including one who wrote that the answers to question 19 are inappropriate. One stated that questions regarding “risk” were vague and made suggestions for related concepts that should have been included.

Two respondents to the health officer questionnaire noted that their companies have no health officer. One health officer indicated that the company is decentralized, so the answers might not reflect company policy, while one personnel officer simply noted that the organization was highly decentralized. Finally, one health officer indicated that the survey was difficult to fill out because the scope of the “company” was not easily defined.