

SOCIAL LEGAL AND ETHICAL ISSUES

Over the past decade, many ethical, legal, and social issues (ELSI) associated with genetic testing and research have been raised. For genetic testing to be.

In contrast to infectious disease, the transmission of genetic diseases does not present an immediate threat to society. Decisional privacy is often very close to personal autonomy. Attention to quality of life for animals used in pharming may increase. Is violating one of the principles the best way to avert the harm? A third approach finds the basis for rights to privacy in respect for personal autonomy. This harm is compounded if they did not choose to learn the information voluntarily. Both the chart and the drawing can be printed and shared with your family members and your doctor. This sort of prevention cannot be viewed in the same way as preventing measles or syphilis, for example. Such a system would be based either on the optical memory card with a microchip capable of storing data or on a card similar to an Automated Teller Card which simply provides access to data stored elsewhere. Certain infectious diseases potentially put society as a whole at immediate risk since the diseases can be transmitted to a large number of people in a short time. In a survey by Dorothy Wertz and John Fletcher, 30 numerous geneticists suggested that there were at least four situations in which they would breach confidentiality and disclose genetic information without the patient's permission, even over the patient's refusal: 1 54 percent said they would disclose to a relative the risk of Huntington disease; 2 53 percent said they would disclose the risk of hemophilia A; 3 24 percent said they would disclose genetic information to a patient's employer; and 4 12 percent said they would disclose such information to the patient's insurer. Patients should be cautious when considering direct-to-consumer genetic testing and are encouraged to discuss this option with their healthcare professional. When people grant health care professionals access to them, they should retain the right to determine who else has access to the information generated in that relationship. For drugs already approved by the regulatory agencies eg, Food and Drug Administration in the US , subsequent discoveries that people with particular genetic profiles may have adverse reactions would require addition of this information to the label and a warning that genetic screening is necessary. Oncology, in particular, is at the leading edge of incorporating genomics, as diagnostics for genetic and genomic markers are increasingly included in cancer screening, and to guide tailored treatment strategies. The overriding ethical issue associated with these developments is equity of access to possibly expensive treatments, especially for those whose genetic responses to common drugs fall outside the usual range. Once sufficient evidence has been generated to demonstrate a benefit to patients, or "clinical utility," professional societies and clinical standards groups will use that evidence to determine whether to incorporate the new test into clinical practice guidelines. These possibilities raise questions about the need to obtain consent for additional and subsequent uses particularly since consent is almost never obtained initially in newborn screening , as well as questions about the duty to warn if disorders are detected in the blood by using the new DNA extraction testing techniques. In addition to fears of discrimination in employment and health insurance, members of some communities often fear that genetic information will be used to stigmatize them. Standards of substantive or material justice establish the identity of the relevant similarities and differences and the appropriate responses to those similarities and differences. In such a situation, the patient's autonomy is compromised even if the sample is used anonymously in the subsequent use. For these conceptions, it is unjust to deny employment to someone who meets the relevant qualifications but also has a genetic disease. One of the reasons for the abolition of the requirements was that they were not the most appropriate way to reach the population at risk. Even if a test is not considered to be medically useful, a patient or the family may still benefit from testing. Some of these companies may play off consumer fears, offer tests with little clinical utility, or not be properly certified or licensed. Most conceptions of justice dictate that employment be based on the ability to perform particular tasks effectively and safely. Employers and insurers may require people to undergo testing for genetic disorders for exclusionary purposes. However, other traditions say that animals and humans are all part of a continuum of life and that all suffering must be taken into account. The translation of new genomic medicine discoveries is already making a difference to patient care. This time lag is due to a combination of factors, including the need to validate research findings, the fact that clinical trials are complex and take time to conduct and then analyze, and because disseminating information and educating healthcare

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workers about a new advance is not an overnight process. In making this argument, Judith Jarvis Thomson holds that privacy rights simply reflect personal and property rights, such as the rights not to be looked at, not to be overheard, and not to be caused distress. DNA from the blood spots collected for newborn screening can now be extracted for further testing. Institutions that store DNA samples³² or store the results of genetic tests also differ in the amount of respect they give to autonomy, confidentiality, and privacy. Most medical testing is done within a physician-patient relationship. HMOs may welcome such tests because they could save the billions lost on adverse reactions or ineffective drugs. North-South inequalities may be exacerbated. Science,