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Chapter 21

The Genetic Revolution: Ethical Implications for the 21st Century

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The following chapter defines the practice of DNA analysis and identifies the ethical considerations of human genetic testing in the workplace and technological issues. The topics presented include: the history of DNA testing, future genetic test development inclusive of, large scale, three-dimensional computational technology for analyzing, storing and presenting complex relationships between gene products and clinical outcomes, and currently enacted legislation pertaining to genetic information. Also examined are the ethical concerns pursuant to human genetic testing and information technology security.

A survey was conducted to determine the view and level of knowledge among business professionals in the workplace on the ethical considerations of genetic testing. Questions included business ethics, confidentiality issues and the enactment of state and federal legislation for genetic testing. The results of the survey indicate concern within the business community for ethical issues concerning confidentiality of genetic test results and a strong desire for passage of state and federal legislation to avoid the misuse of genetic information.

Finally, conclusions are determined based upon the data and the direction for future study is defined.

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INTRODUCTION

According to the Director of the National Human Genome Research Institute, National Institutes of Health, the multi-million dollar effort focused on mapping and sequencing the entire three billion base pairs of the human genome, will be completed in less than a decade (Mansoura et al., 1998). The primary purpose of this massive task undertaken by the Human Genome Project (HGP), is to provide the biomedical research community with the tools necessary to identify the molecular basis of virtually all diseases. Since genetic predisposition plays a role in almost every disease, HGP holds the promise of significant medical benefit for humanity. This hope also raises serious ethical concerns for potential misuses of genetic information. Information technology security is a primary concern because of the threat to confidentiality of genetic test results. According to Ken Sharurette, information security staff adviser for American Family Insurance, "The longer you go without a security breach, the closer you are to your next incident" (Larson, 1999). A number of states have enacted legislation regarding genetic information, but as yet, no fully comprehensive federal laws are in place.

DNA Testing

Genes, the chemical messages of heredity, are working subunits of DNA. Deoxyribonucleic acid or DNA, is a vast chemical information database that carries the complete set of instructions for making all the proteins a cell will need. DNA exists as two long, paired strands spiraled into a double helix. Each strand contains millions of chemical building blocks called bases. There are only four different chemical bases in DNA (adenine, thymine, cytosine, and guanine), but the order in which the bases occur determines the information available, similar to the way specific letters of the alphabet combine to form words and sentences (Klausner et al, 1995). Within the nucleus of every human somatic cell, in two versions distributed over 23 chromosomes (some maternally derived, and the other paternally derived), lies a genetic instruction tape embodied in DNA. Each cell uses this information to create proteins which do the work necessary to carry out the functions of that particular cell type. The sequence is 99.9% identical from one individual to another. This makes it reasonable to speak of a human genome, at least for the purposes of determining a complete representative sequence (Collins, 1997).

Gene testing involves examining a person's DNA, taken from cells in a sample of blood or, occasionally, from other body fluids or tissues, for some anomaly that flags a disease or disorder. Genetic testing in a broader sense includes biochemical tests for the presence or absence of key proteins that signal aberrant genes.

In recent years, many genes involved in hereditary diseases have been identified. The ability to isolate and copy these genes allows biologists to study what goes wrong in cells to cause the diseases. Research on the sequence of all of the