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ETHICAL AND SOCIAL ASPECTS OF GENOME STUDIES

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Genome sequencing and genome studies have raised fears of ethical, legal, social and medical concerns with no satisfactory solutions in sight. Foremost among these are the risks of discrimination, public exposure of private records with the consequent fears of possible blackmail, loss of income and employment, loss of insurance protection and medical coverage, exposure of confidential information which could result in divorce and disruption of family life, social stigma, embarrassment, and possible legal actions and other complications. When an individual undergoes whole genome sequencing, they reveal information about not only their own DNA sequences, but also about probable DNA sequences of their close genetic relatives. This information can further reveal useful predictive information about relatives' present and future health risks. Hence, there are important questions about what obligations, if any, are owed to the family members of the individuals who are undergoing genetic testing. A major ethical dilemma can develop when the patients refuse to share information on a diagnosis that is made for serious genetic disorder that is highly preventable and where there is a high risk to relatives carrying the same disease mutation. Privacy concerns can also arise when whole genome sequencing is used in scientific research studies.

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