

DISCLOSURE OF GENETIC INFORMATION TO AT-RISK RELATIVES - A SWEDISH PERSPECTIVE

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Genetic information has special features in several respects. For example, it is predictive and it may reveal significant insights into the individual's medical future. Another characteristic feature of genetic information is that it is unique and distinguishes one individual from other individuals. At the same time it may also reveal information about and have implications for that individual's biological family and future family members. When genetic testing for an inherited disease is performed, there is always more than one person involved as a test result reveals genetic information about both the individual and the individual's genetic relatives.

An individual who has consented to a genetic test, the index-patient, may have an interest in knowing the test result and keeping it secret or private. Genetic relatives, present and future, can have an interest both in knowing and not knowing the test results from an index-patient. Disclosure of genetic information has the potential to prevent harm to genetic relatives but may also breach an individual's right not to know about the presence of a serious genetic disorder in the family. In Sweden, there is no legal duty for tested persons to disclose genetic information to their relatives; health-care professionals can only recommend the index-patient to share the result with genetic relatives. According to Swedish law, health-care professionals owe a duty of confidentiality to their patient and disclosure of genetic information to at-risk relatives normally requires the index-patient's consent.

The purpose of this paper is to examine the Swedish law relating to the question of disclosure of genetic information to at-risk relatives against an index-patient's wishes. The focus is placed on the conflict between the index-patient's interest in confidentiality and the genetic relatives interest in knowing. The paper also identifies arguments that could be used to support a change in the Swedish legislation.