

Should privacy be abolished in genetics?

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The concept of privacy has expanded as innovations in technology have made it possible to render public what was previously out of the public view. Initially it was photographs and newspapers that "invaded the sacred precincts of private and domestic life" (Warren and Brandeis, 1890). In recent decades, other developments have complicated and enriched the concept of privacy. The right to privacy as a right to self-determination in choices regarding individual life and medical treatments (use of contraceptives, abortion and end-of-life decisions) has grown up from the extraordinary development of biological sciences and medicine. The idea of informational privacy stems from information technology, which makes it possible to collect, store and access of huge quantities of data (including medical and health data) on individuals. Questions of informational privacy include whether people have any ownership rights to information held about them and whether they have a right to view, verify, and challenge that information.

We see that the individual's legal dowry is widening gaining new ground, as new aspects of a person's sensitivity, personality, ideas and interests are perceived to come under threat and require legal protection.

This individualistic approach works well in areas where the individual can be considered an isolated entity, independent of society. However this approach leads to paradoxical consequences when applied to genetics, which is the domain of familiarity of heritable characteristics.

The idea that individuals have the right to decide about and control their biological information is not under discussion. But what about when information is genetic information about characteristics shared by a biological group? Should each member of the group be entitled to interfere with the lives of other members of the group? And how should the extent of the biological group be determined? Should it date back to a common ancestor? If not, where do we draw the boundary line, and using what criteria? Drawing such a line is essential today for we want avoid, on one hand, abuse of personal information and, on the other, paralysis of scientific research.