Viewpoint: To protect genetic privacy, it's 'crucial' that we develop an international code of conduct

Genomics researchers worldwide are increasingly dealing with vast data sets gathered by consortia spanning many countries. Most are unclear on what to do to protect people's privacy and to comply with international and national data-protection laws, especially given recent and ongoing changes in legislation.

An international code of conduct for genomic data is now crucial. Built by the genomics community, it could be updated as technologies and knowledge evolve more easily than is possible for national and international legislation.

. . .

A code of conduct could provide researchers with guidance on how to deal with government requests for personal data, including what legal protections they can appeal to. In the United States, for example, the National Institutes of Health's Certificates of Confidentiality are designed to shield researchers from such requests.

. . .

If genomics researchers are instead left in the dark about how to properly address data protection and sharing, they could either be excessively cautious and fail to share as consents allow, or fail to provide participants with appropriate <u>protection</u>. In other words, further regulatory uncertainty risks stalling new genomic analyses and undermining people's faith in scientific collaboration for the public good.

Read the original post