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“The Evolving Ecology of Genetic Privacy”

For years, the debate about genetic privacy focused on two major issues: 1) that genetic information in the medical record would be used to deny people insurance and employment; and 2) that people would try to identify someone from de-identified DNA. In this talk, I will address the impact of several major changes that both change and broaden the debate. A growing amount of research that can be conducted without any consent, and the pressure for broad data sharing continues to mount, raising questions about control of downstream use. Giant databases are being created. Research is occurring in more diverse settings, which vary in their institutional oversight. Direct to consumer genetic testing has exploded, and a large number of people who post their identified genomic data online, typically to find previously unknown relatives, which may or may not be well received. Forensic genetic genealogy is front page news. The Affordable Care Act may fail. The European Union enacted the General Data Protection Regulation, while the US takes a more piecemeal approach to privacy protection. I will suggest how these and other developments affect genetic privacy.