Abstract:

While a strong case for not sharing information to preserve individual privacy can be made, an equally compelling case for sharing genome information for the public good (i.e., to support new discoveries that promote health or alleviate the burden of disease) should also be made. In fact, these cases do not need to be mutually exclusive: genome data sharing on a cloud does not necessarily have to compromise individual privacy, although current practices need significant improvement. So far, protection of subject data from re-identification and misuse has been relying primarily on regulations such as HIPAA, the Common Rule, and GINA. However, protection of biometrics such as a genome requires specialized infrastructure and tools. I will describe how we are approaching this issue in our center for biomedical computing based at UCSD in terms of hardware, software, and policy.