Each individual has a unique genome. Even in identical twin the mix of the genomes of the two parents will never be repeated. The accumulation of individual genomes with clearly documented phenotypes that are available for research significantly facilitates discoveries. From the multi alignment and phylogenetic concepts we have discussed in the previous lectures, although the benefits of a personal genome for the owner are evident, profiling a large number of genomes is mutually beneficial, because of a strong network effect.

If we consider that any two of us have common ancestry back to a certain point, people nearly always share a significant fraction of genetic variation sites. Therefore, the personal genetic information of one individual provides clues to better understand other's genomes and their medical implications. Therefore, a personal genome is not only for one, but also for all humanity.

For medical purposes, genomic data often needs to be correlated with clinical and physiological data. For example, clinical analysis may require correlating electronic health records reported during hospital stays and genomic information. In precision medicine, genome sequencing data is the basis for making genome-guided treatment decisions in patients with cancer or other diseases. However, it can also uncover secondary or incidental (also termed unsolicited) findings in genomes that could have a substantial impact on the quality of lives of patients and their relatives, i.e. finding that are discovered unintentionally, as a by-product of a research. Some of these finding may concern sexual or intellectual information that could affect other relatives. Several studies (see references at the bottom) showed that the most of cancer patients would like to receive all incidental findings of genome analysis; a substantial minority had a strong opposite opinion. Leakage of personal genomic data can lead to exposure and then to a wide variety of unforeseen attacks. Whether accidentally or intentionally electronically transmitted, the genetic information cannot be revoked. Consequently, it is very important to use a high level of privacy concern for personal genomic data. It is very important to note our genomic data, remains sensitive data forever. Even worse, the methods to interpret genomic data improve over time, which means that it is unclear at the moment how much sensitive information a genome encodes and which consequences a genomic data breach has. Furthermore, it is likely that genomic data will not only be used personally to support medical treatments (insurance companies and other possible cases).

References:

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