P20.05A / A - Raw Genomic Data: Storage, Access and Sharing

June 17, 2018, 10:15 AM - 11:15 AM | Poster Area

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Disclosures

M. Shabani: None. **D. Vears:** None. **P. Borry:** None.

Abstract

Whole Genome Sequencing (WGS) and Whole Exome sequencing (WES) for diagnostic and research purposes generate a large volume of raw data. Previous ethical and legal discussions concerning genomic data management have mainly focused on concerns related to interpretation of the results and the return of both primary and secondary findings from these tests. Yet to date, issues related to the storage and return of primary sequencing data (such as bam (Binary Alignment) or fastq files (unaligned reads)) that allow both the regeneration of primary results and the reanalysis of data have received far less attention, particularly in the clinical setting. This is despite the huge potential for long-term data storage to lead to future data re-analysis and reinterpretation in light of new evidence. In this paper, we critically appraise three main issues, namely, data storage policies and practices of clinical laboratories, patients' access to raw data, and sharing of raw data by individuals. We argue that there is a need for well-established and transparent raw genomic data retention and returning policies in order to enable patients to practice their rights to access raw genomic data. In addition, professional communities could guide laboratories in adopting best practices for the storage and return of raw data, and introduce uniformity to these practices. As WES and WGS become more embedded in diagnostics, it is timely to consider how current data storage policies align with patients' rights and interests to access raw data, and how these rights can be managed in the clinical setting.