Shared Stewardship in Collaborative Curation of Rare Disease Datasets

Patient data is a key asset in understanding the progression of rare diseases and may be provided in a variety of forms from a multitude of sources. The Rare Disease Cures Accelerator-Data and Analytics Platform serves as a catalyst for gathering and organizing this information. This requires coordination and diligence to ensure data integrity, security, and privacy are not compromised in any part of the process. In this talk, we will discuss some of the best practices and collaborative approaches utilized by NORD and C-Path. From collection through curation, we will demonstrate the importance of data stewardship and its consistency throughout.