

RDCA-DAP and NORD's IAMRARE Platform to Platform Federation: Lessons Learned

RARE/ORPHAN AND PEDIATRIC DISEASE PROGRAMS 2025 WEBINAR SERIES



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Patient data is a key asset in understanding the progression of rare diseases and may it 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. NORD and C-Path have been working together for over 5 years to help patient organizations collect and share rare disease data. In this talk, we will discuss some of the lessons learned that have helped to inform builds, processes, and programs designed to meet patient groups at whatever stage of development they are at. From survey design to secure sharing, we will demonstrate the benefits of implementing these practices and efficiencies.

