C-Path and RARE-X Establish New Collaboration for Rare Disease Data Sharing

RARE-X and Critical Path Institute align on their mission and commitment for data sharing to improve rare disease research

TUCSON, Ariz. and ALISO VIEJO, Calif., September 13, 2021 — Critical Path Institute (C-Path), who's aim is to catalyze the development of new approaches that advance medical innovation and regulatory science, today announced a collaboration with RARE-X to improve ways researchers can access and analyze patient data. RARE-X is a nonprofit organization dedicated to enabling patient communities to collect, manage and share their de-identified data to advance research.

C-Path, with its Rare Disease Cures Accelerator-Data and Analytics Platform (RDCA-DAP®) initiative, and RARE-X are developing an ecosystem in which rare disease data are collected, shared and used to further research. The two groups have a similar vision to make individual-level data available and used as widely as possible by researchers and drug developers.

"Working jointly with RARE-X, we can develop models and drug development tools informed by the data collected and consented for on the RARE-X platform," said Jeff Barrett, Ph.D., F.C.P., C-Path Senior Vice President and RDCA-DAP Lead. "Such models would be developed with open data science principles in mind and the intention to facilitate the development of new treatments for rare disease patients. For example, an initial collaborative effort with RARE-X may include the co-development of a disease progression model for a specified disease area."

RARE-X supports the collection of structured patient-owned data, and has developed data governance and consents that support patients in sharing their de-identified data broadly and often. In addition to data collection, RARE-X is focused on connecting disparate data, while embarking on comprehensive federated data-sharing initiatives that support data sharing consortia to accelerate research and medicine development.

C-Path's RDCA-DAP provides a centralized and standardized infrastructure to support and accelerate rare disease characterization targeted for clinical development. Additionally, the platform includes a framework that supports the rigorous conduct of natural history studies, with attention to established data quality standards, in order to be most useful to clinical trial design and regulatory review. It includes a robust, integrated database and analytics hub that allows for the aggregation of rare disease data from various sources and the efficient and effective interrogation of that data.

The C-Path and RARE-X collaboration will share learnings around standardization of data elements and data structures, consent language and other elements promoting the inter-operability of data sharing.

"We look forward to bringing forward best practices on structure and standardization of rare disease data, governance, consent and data tracking with C-Path to accelerate research," said RARE-X CEO Charlene Son Rigby. "And by collaborating with C-Path, patients' ability to share their data through the RARE-X platform, enabled with our unique consent and data-sharing agreements, will expand."

A first look at RDCA-DAP's functionality and operability will be unveiled at the 2021 RDCA-DAP Workshop Tuesday, September 14. Those interested in attending can register here.

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About Critical Path Institute
Critical Path Institute (C-Path) is an independent, nonprofit organization established in 2005 as a public and private partnership. C-Path's mission is to catalyze the development of new approaches that advance medical innovation and regulatory science, accelerating the path to a healthier world. An international leader in forming collaborations, C-Path has established numerous global consortia that currently include more than 1,600 scientists from government and regulatory agencies, academia, patient organizations, disease foundations, and dozens of pharmaceutical and biotech companies. C-Path U.S. is headquartered in Tucson, Arizona and C-Path, Ltd. EU is headquartered in Dublin, Ireland, with additional staff in multiple other locations. For more information, visit c-path.org and c-path.eu.

About RARE-X
RARE-X is a 501(c)(3) rare disease technology nonprofit focused on supporting the acceleration and development of life-altering treatments and future cures for patients impacted by a rare disease. Enabled by best-in-class technology, patients, researchers, and other technology vendors, RARE-X will gather structured, fit-for-purpose data to share broadly, benefitting from 21st-century governance, consent, and federated data-sharing technology. RARE-X is building the largest collaborative patient-driven, open-data access project for rare diseases globally. For more information, visit rare-x.org.

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