

## C-Path Receives Largest Data Transfer to Date from UK's National Neonatal Research Database

The EPR data transfer is the first from the United Kingdom and includes data from nearly 200 hospitals



TUCSON, Ariz., June 1, 2022 — <u>Critical Path Institute (C-Path)</u> has received fully anonymized electronic patient record (EPR) data from the National Neonatal Research Database (NNRD). This is part of efforts to better understand and find treatments for a chronic lung disease which frequently affects premature infants. This initiative, funded by a grant from the U.S. Food and Drug Administration (FDA), is being executed through a neonatal pilot project within C-Path's International Neonatal Consortium (INC). It is the first time C-Path has received EPR data from the United Kingdom and includes data from a network of nearly 200 hospitals in England.

The NNRD data transfer received ethics approval from the UK Health Research Authority, and none of the data can be traced back to individual patients.

"We have been working with the NNRD team for more than five years and are very excited that extensive discussions have brought us to this significant milestone in data sharing," said Mark Turner, Ph.D., Professor of Neonatology and Research Delivery, University of Liverpool, UK and INC Co-director. "This EPR data, coupled with previous clinical trial data transfers from other international centers, will shed new light on the causes and treatments of a major cause of death and disability among babies born very prematurely."

The data transfer is the largest ever for C-Path to date, with nearly 200,000 fully anonymized patient-level data points to be used to understand how the lung condition bronchopulmonary dysplasia (BPD) develops in premature infants. The aim is also to identify stages when doctors can intervene to reduce the risk of BPD, to help find treatments, and to help understand the long-term effects of BPD.

The generation of these real-world evidence solutions will be led in partnership between INC and C-Path's Quantitative Medicine Program with support from its Data Collaboration Center. C-Path's INC Executive Director Kanwaljit Singh, M.D., MPH, added, "C-Path has extensive experience in real-world data project collaborations and we're ecstatic to welcome the NNRD's data into this initiative. We can't thank Professor Neena Modi enough for recognizing the unmet need in neonatal drug development and accelerating this important collaboration."

The EPR data shared by the NNRD will be integrated with other patient-level real world data national registries and networks, as well as clinical trial datasets contributed by INC industry members.

Neena Modi, FMedSci, who established the NNRD and is a Professor of Neonatal Medicine at Imperial College London, said, "The NNRD is a one-stop source of clinical data to improve newborn care, developed

with wide stakeholder and parent involvement. We are exceptionally grateful to the families who agree to share data, and to the healthcare staff who carefully record this. By combining the NNRD data with data from other international registries and clinical trials, C-Path has created a novel resource for researchers to study BPD in detail and hopefully reduce the risk of a preterm baby developing the condition. I hope that in time this will improve treatments and the outlook for infants with BPD."

C-Path's INC will continue to partner with collaborators and new data contributors to integrate additional patient-level datasets.

Learn more about Imperial College of London's Neonatal Data Analysis Unit, which supports the management and development of the NNRD, here:

https://web.www.healthdatagateway.org/search?search=NNRD&tab=Datasets.

For more information on collaborating with INC, and how to contribute data, please email Christine Barry at cbarry@c-path.org.

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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 hundreds of pharmaceutical and biotech companies. C-Path U.S. is headquartered in Tucson, Arizona, is headquartered in Amsterdam, Netherlands and C-Path Ltd. operates from Dublin, Ireland with additional staff in multiple other locations. For more information, visit c-path.org.

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