



CPP Integrated Parkinson's Database

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OVERVIEW

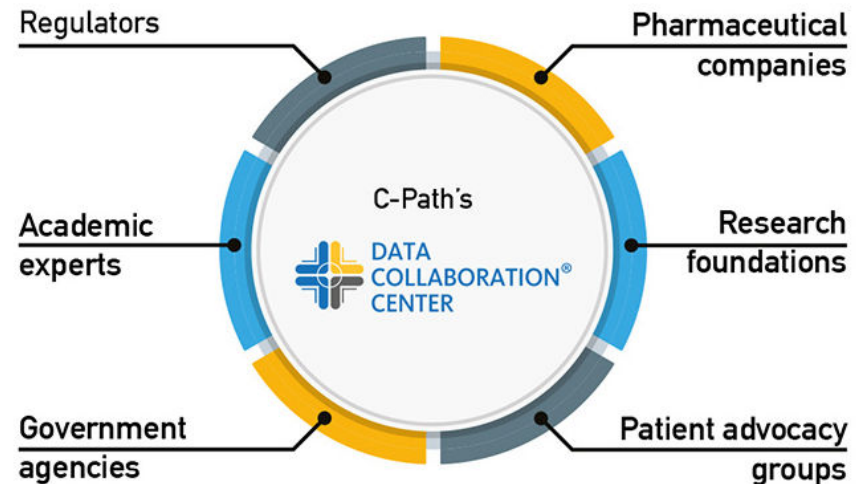
Critical Path for Parkinson's (CPP)'s Integrated Parkinson's Database ("CPP Database") is a database housed in C-Path's data sharing platform (CODR) that contains both observational and clinical trial cohorts, which are compliant with CDISC standards. This database contains patient-level data that has been integrated from Parkinson's clinical studies conducted over the past 30 years.

CPP's database is one of many that Critical Path Institute oversees with generous funding from the U.S. FDA. All databases are managed by C-Path's [Data Collaboration Center](#) which has nearly two decades of experience standardizing and integrating diverse data sources for dozens of projects, including nonclinical and clinical data.

With the large amounts of data from clinical trials, observational studies, and patient registries being shared by members of its consortia, C-Path has developed the infrastructure and expertise in areas such as standards development, patient-level data privacy, security, and controlled access methods. This work entails curating, standardizing, aggregating, and securely housing large amounts of data from controlled clinical trials, observational studies, and registries.

In most cases, data is made available to external qualified researchers with the goal of generating new discoveries and expanding impact. Data that has been shared with external qualified researchers has been used to discover new insights as to the onset and progression of chronic diseases and inform new innovative approaches for optimizing the design of clinical trials.

The CPP Integrated Parkinson's Database offers qualified researchers the opportunity to access this rich and large integrated dataset for analyses. This document includes the entire Data Access Request process for new users to gain access to all data available to qualified external researchers (users).



DATA ACCESS REQUEST WORKFLOW

Before you apply: Verification of approved access to **Parkinson's Progression Markers Initiative (PPMI) database is required** and can be requested at [PPMI's data access request website](#).



1. Data Access Request Application submission

- 1.1. Requester visits the [CODR Database Page](#) and selects “CPP Integrated Parkinson’s Database”.
- 1.2. Requester agrees to the [Terms & Conditions](#) and follow the steps to complete and submit the application. [View additional details in the FAQ](#).

2. Data Access Request review

- 2.1. C-Path staff reviews submitted application to confirm all fields of the form have been completed and contain a reasonable amount of information to allow the Data Use Committee to make an informed decision regarding the request and that the requester is affiliated with a professional organization. C-Path may reach out to the requester to provide additional information, if needed.
- 2.2. Data Use Committee reviews the application to confirm qualifications are sufficient and requirements are met. The committee may request the user provides additional details, supporting documentation, or clarification on the research request.

3. Data Access Request decision

- 3.1. Data Use Committee votes to approve the requester’s application and notifies the requester of the result within 4-6 weeks. [View additional details on the voting process in the FAQ](#).
 - Should the committee’s decision not result in an approved request, the user will be notified at that time. Additional information can be provided to resubmit for approval.
 - If the Data Use Committee votes to approve the request, the applicant will be granted access to the database.

4. Database access for approved applications

- 4.1. After the requester has been notified of an approved application, C-Path will update the user’s CODR application and users can access the data through CODR.

Optional access to Oxford Parkinson’s Disease Centre (OPDC) cohort

A separate approval must come from the OPDC team by completing the OPDC data request form provided by [Prof. Richard Wade-Martins](#) and [Prof. Michele Hu](#). Note: this separate approval can come at any time and will not delay application approval.

FREQUENTLY ASKED QUESTIONS

Q	<i>What potential applications or use cases can be derived from the collected data?</i>
A	The CPP database is available for use by qualified researchers, external to the CPP consortium for their own research purposes to advance Parkinson's drug development.
Q	<i>How are the datasets standardized and formatted?</i>
A	The data collected from patients is converted into a standardized format known as the Clinical Data Interchange Standards Consortium (CDISC), Standard Data Tabulation Model (SDTM), and PD-specific Therapeutic Area User Guide (v1). This makes the data more useful for both regulatory submissions and research purposes. Additionally, all patient data is anonymized to protect their privacy. The SDTM format is a requirement for new drug application submissions to the US FDA, and it is also preferred by regulatory agencies worldwide as a standardized format.
Q	<i>What is the protocol for granting access to the data, and what measures are in place to ensure the security and prevent unauthorized use of the data?</i>
A	To access the CPP clinical data, users must agree to the Terms & Conditions, and have an approved application that includes contact details, academic qualifications, organizational affiliation, and a short project description. Users must also maintain valid login credentials. View the application process here.
Q	<i>What are some examples of analysis that have been performed using the CPP integrated database?</i>
A	Here are several recent examples of how the CPP database has been leveraged to advance drug development: <ul style="list-style-type: none">• Development of A Disease Progression Model to Quantify the Nonmotor Symptoms of Parkinson's Disease in Participants With Leucine-Rich Repeat Kinase 2 Mutation and for Motor Symptoms in Leucine-Rich Repeat Kinase 2 in Parkinson's Disease to Inform Clinical Trial Designs• The Qualification of an Enrichment Biomarker for Clinical Trials Targeting Early Stages of Parkinson's Disease• Creation of a DAT Neuroimaging-Informed Early PD Clinical Trial Simulator• Creation of a model to be used for a Clinical Trial Simulation Platform to Optimize Design of Efficacy Evaluation Studies in Parkinson's Disease
Q	<i>Could you elaborate on the process and procedures of the Data Use Committee?</i>
A	CPP's Data Use Committee is composed of data contributors and uses majority voting to approve requests. Non-responses after the review period are considered non-votes, and the CPP Executive Director casts tie-breaking votes. The review process aligns with C-Path's policies for other databases.

Q	<i>Could you please provide more information about the specific terms and conditions to which I am agreeing when I agree to the Terms & Conditions?</i>
A	<p>Requesters must agree to share draft manuscripts with CPP prior to publication and not distribute data to others. To encourage innovative approaches, especially by young investigators, requests are not peer-reviewed. CPP aims to support expanded research and allow access without detailed proposals. A Data Use Committee reviews requests to protect data and ensure accountability while facilitating new discoveries.</p> <p>Considerations when accepting the Terms and Conditions</p> <ul style="list-style-type: none"> • Users cannot share, sell, or patent data, and they can't identify individual participants. • Users cannot extract individual studies and conduct analysis on individual studies. • Users must cite CPP as the data source in all publications and undergo a two-week review period by CPP Coordinating Committee. <p>Please review full Terms and Conditions here.</p>

Q	<i>I am ready to publish a paper that used CPP data. How do I gain Coordinating Committee approval?</i>
A	To initiate the review process, kindly contact your primary CPP contact for assistance. This process typically takes two weeks and serves to verify the appropriate acknowledgments, citations, and adherence to the data usage Terms & Conditions.

Q	<i>Can I contribute data to the CPP database?</i>
A	<p>Yes. One of C-Path's more impactful initiatives is data sharing to accelerate drug development and has deep expertise in data management and security. C-Path is fully compliant with all requests and agrees to conform to all stipulations and conditions set forth by each individual data contributor. For more information on CPP or how your organization can contribute data, please visit our website: https://c-path.org/programs/cpp/.</p>

Q	<i>Once I have access to the data, what are the requirements to effectively use this data?</i>
A	<p>We recommend following hardware, software, and background to effectively use this data:</p> <ul style="list-style-type: none"> • Experience with STDM terminology and data structure. <ul style="list-style-type: none"> ○ Full file downloads are necessary to work with the data. Search functions and data interrogation are limited on the CODR website. • Software with the ability to process large data files containing 1 million rows or greater. <ul style="list-style-type: none"> ○ MS Excel is not a preferred software for these applications. ○ Recommended Software: SAS, R, Python, or other data analytics software platforms. • Computer hardware with 16 GB of RAM and 250 GB hard drive or greater is recommended. <ul style="list-style-type: none"> ○ Downloading of the CPP integrated database will take time due to file size.