

## Colorado All Payer Claims Database Data Release Application

Thank you for your interest in obtaining data from the CO APCD. As you fill out this application, please let us know if you have any questions or concerns by reaching out to [ColoradoAPCD@civhc.org](mailto:ColoradoAPCD@civhc.org). We are here to help!

**Also, please be aware that if you are requesting Protected Health Information (PHI), your request requires a recommendation for approval by the Data Release Review Committee (DRRC). Data elements that are considered PHI under HIPAA are indicated below. If PHI is requested, a CIVHC Account Executive will help you successfully complete an application and navigate the DRRC process.**

Please use this application to submit information regarding your request for data from the Colorado All Payer Claims Database (CO APCD). This information will help the Center for Improving Value in Health Care (CIVHC), the Administrator of the CO APCD, answer any questions you have regarding your data request and assist us in helping you complete the data application form.

**Note: Please reference the CO APCD Data Elements Request Form found at <http://www.civhc.org/get-data/data-release/> when completing this form.**

Introduction: Section 10 CCR 2505-5-1.200.5 describes how the CO APCD Administrator addresses Requests for Data and Reports:

1.200.5.A. A state agency or private entity engaged in efforts to improve health care or public health outcomes for Colorado residents may request a specialized report from the CO APCD by submitting to the administrator a written request detailing the purpose of the project, the methodology, the qualifications of the research entity, and by executing a Data Use Agreement (DUA), to comply with the requirements of HIPAA.

1.200.5. B. A data release review committee shall review the request and advise the administrator on whether release of the data is consistent with the statutory purpose of the CO APCD, will contribute to efforts to improve health care for Colorado residents, and complies with the requirements of HIPAA. The administrator shall include a representative of a physician organization, hospital organization, non-physician provider organization and a payer organization on the data release review committee.

This Data Release Application serves as the written request for information noted in section 1.200.5.A.

## PART ONE

Project Information	
Project Title:	22.18 CU Applying Palliative Care to Parkinson's Disease
Date:	2/28/ 2022
Organization Requesting Data:	University of Colorado, Anschutz Medical Campus
Contact Person:	Robert (Brett) McQueen, PhD
Title:	Assistant Professor
E-mail:	Robert.McQueen@cuanschutz.edu
Phone Number:	303-724-0251
Person Responsible for the Project (if different than above):	Benzi Kluger, MD
Title:	Principal Investigator
E-mail:	Benzi_Kluger@URMC.rochester.edu
Phone Number:	720-320-0734

### **Project Purpose:**

Project questions to be discussed with client representative:

- Please describe your project and project goals/objectives.
- What specific research question(s) are you trying to answer or problem(s) are you trying to solve with this data request? (Please list and number the individual questions.)
- How will this project benefit Colorado or Colorado residents? (this is a statutory requirement for all non-public releases of CO APCD data)

Parkinson's disease (PD) is the second most common neurodegenerative illness affecting approximately 1.5 million Americans and is the 14th leading cause of death in the United States. PD is traditionally described as a movement disorder with characteristic motor symptoms (e.g. tremor). However, more recent research demonstrates the impact of nonmotor symptoms such as pain, depression, and dementia on mortality, quality of life (QOL), nursing home placement and caregiver distress.

Our CO APCD request is a planned aim from an NIH-funded pragmatic comparative effectiveness study examining the impact of a novel community-based model of palliative care in Parkinson's disease and related disorders (PDRD) on patient, caregiver, and clinician outcomes. The Specific Aims of this project are to: 1) Determine the impact of community-based palliative care on patient quality of life and caregiver burden; 2) *Determine the impact of this intervention on healthcare utilization and cost*; and 3) Utilize mixed methods to identify opportunities to optimize this intervention. For our second Aim, we sought to use two complementary methods to examine cost and healthcare utilization, namely patient/caregiver self-report and CO APCD data.

This aspect of the study will evaluate patient use of healthcare services (i.e., ER services, hospitalizations, hospice and palliative care services, respite care and other stays in long-term care

facilities, home health services, and caregivers' use of psychological health services) as well as outpatient visits to physicians to determine impact of palliative care intervention on health care utilization and cost. APCD utilization data evaluations will include hospitalizations, ICU stays, ER visits and use of home health services. CO APCD data will be used to address both methodological questions (1. How well do APCD data and patient self-report agree?) and scientific questions (2. Does community-based palliative care impact the overall cost of care for PDRD? 3. How does community based-palliative care shift the costs of PDRD care (e.g. more home health, less ER).

Analysis of the CO APCD data will provide evidence as to whether Colorado could potentially experience lower healthcare costs for Medicaid patients who have Parkinson's disease. Colorado residents could experience better quality of life and cost savings from reduced copays and insurance payments resulting from hospital stays, ER visits, home health, and other medical services.

- Please answer all applicable questions below (Note that your project must meet one or more of the Triple Aim criteria below to generate a benefit for Colorado):

#### **Benefit for Colorado**

One of the goals of this project is to develop models of care implementable and accessible to persons not getting their care from tertiary academic hospitals. This is particularly important in a state like Colorado which has large rural areas, underserved urban areas, and dispersed geography. Our model of care would allow Coloradans with Parkinson's and related conditions, as well as family caregivers, to receive more comprehensive care and get their palliative care needs met. Our care model also makes advance care planning and caregiver support a more systematic aspect of care. Currently, palliative care is not a routine part of care for people living with Parkinson's. Our model addresses to major gaps in current models of care: 1. Palliative care training for community neurologists – currently, palliative care skills are not addressed in neurology residencies or fellowships. We provide training and coaching around important topics including advance care planning, caregiver support, and care for persons with advanced/terminal illness; 2. Palliative care is ideally provided by teams. We utilize telehealth to provide virtual housecalls for services that are not available in many communities such as social work and chaplains.

- If applicable, how will your project support lowering health care costs?
  - Fewer hospitalizations, ICU stays, ER visits, pharmacy costs, and use of home health services. Symptom burden and associated costs are expected to decrease.
- If applicable, how will you project help improve the health of Coloradans?
  - This community-based model was designed to reach persons in rural and other under-served areas. It could be applied not only to Coloradans living with PDRD but also other serious chronic illnesses. There are potential health benefits for both patients (e.g. improved symptom control) and caregivers (e.g. reduced anxiety and depression).
- If applicable, how will your project improve the quality of care or patient experience?
  - Patients will experience care from a more wholistic viewpoint, rather than solely medical care needs. Our care model also makes advance care planning and caregiver support a more systematic aspect of care. One of the primary goals of this project is to develop models of palliative care that can be

implemented in community settings (e.g. outside of tertiary academic medical centers). Our model of care combines education of community neurologists with access to a palliative care team via telemedicine to provide palliative services to people across the state of Colorado including in rural communities and to other underserved populations. If we can demonstrate this model is feasible, clinically effective and cost-effective we hope to partner with other stakeholders to make this care more widely available.

- Do you need a claims data set or would you like a custom report generated by CIVHC that addresses the specific questions/problems your project seeks to address?
  - **A claims data set is needed, but with specific focus on our patient population and applicable questions.**
- Do you need Protected Health Information (PHI)?
  - Do you need patient-specific dates (e.g., dates of service or DOB) or 5 digit zip code. If so, this is a request for a **Limited Data Set**.  
**Yes – we are seeking data only for certain dates for our pool of patients that will be sent to CIVHC in a Finder File Format. As part of our study, we collected self-reported data on hospitalizations, ED visits and other healthcare utilization. One of the methodology goals of the study was to see how well self-reported data agrees with claims data. When we do our analyses, we will compare how estimates of healthcare utilization derived from self-report compare to those from claims both to see where there is agreement and where each method may have complementary strengths or weaknesses.**
  - Do you need direct patient identifiers such as name, address, or city? If so, this is a request for an **Identifiable Data Set** (requires IRB approval). **Response: Yes we need to link the claims data to CU EMR trial data to address the objectives of the grant.**
  - If you do not require any PHI, please only complete PART ONE of the application.

Please note: your CIVHC representative will work with you to complete **Addendum I – Analyst Supplement** to address data warehouse specific questions.

If you are requesting a Custom Report with analytics to be provided by CIVHC; please stop here and submit the information above to your CIVHC representative.

## PART TWO

### I. Type of CO APCD Analytic Data Set Requested

Please select the type of data set that you are requesting by checking one of the boxes below (**select only ONE option**). Details on each type of CO APCD data set can be found in *The CO APCD Companion Instruction Guide* (available from your CIVHC representative):

#### **Types of Analytic Data Sets (Please select ONE below)**

*For users interested in a wide range of data to analyze on their own.*

☐ De-Identified Data Set

- ☒ Limited Data Set\*
- ☐ Identified Data Set \*

\*These types of data requests include Protected Health Information (PHI). Under HIPAA, PHI may only be released in limited circumstances for public health, health care operations, and research purposes under the terms of a HIPAA compliant data use agreement (DUA).

## 2. **Requested Data Elements – Limited and Fully Identifiable Data Sets**

The CO APCD is committed to protecting the privacy and security of Colorado’s health care claims data. The CO APCD will limit the use of the data to purposes permitted under applicable laws, including APCD Statute/Rule and HIPAA/HITECH, to information reasonably necessary to accomplish the project purpose as described in this Application.

### **Data Element Selection and Justification**

If you have not already done so, please use the Data Element Dictionary (DED) to identify the specific data elements that are required for this project. In keeping with the minimum necessary standard established under HIPAA, CO APCD policy is to release only those data elements that are required to complete your project.

Type of Data	Justification for Elements on the DED
Names	We need to link the trial data to the APCD claims data and without a unique identifier that is consistent across both data sources, we will need patient-specific information
Street Address	We need to link the trial data to the APCD claims data and without a unique identifier that is consistent across both data sources, we will need patient-specific information
City	We need to link the trial data to the APCD claims data and without a unique identifier that is consistent across both data sources, we will need patient-specific information
Zip Code	We need to link the trial data to the APCD claims data and without a unique identifier that is consistent across both data sources, we will need patient-specific information
Health Plan Beneficiary Numbers	
Dates (including Day and Month detail.) Specify which date fields are needed and why.	We need to link the trial data to the APCD claims data and without a unique identifier that is consistent across both data sources, we will need patient-specific information
Provider Identifying Information	Variation in care provided by providers may inform our adjusted analyses

### **A. Counts, Totals and other Summary Statistics**

The CO APCD seeks to provide aggregated summary data whenever possible. Applicants are encouraged to request counts, totals, rates and other summary values whenever such information can reasonably accomplish the purpose of the project (add rows to the table below if necessary). The CO APCD supports the federal CMS minimum cell size suppression policy that requires any cell in any report or data table, printed or electronic, with less than eleven records or observations to be replaced by “Less than eleven” or similar text. You must also apply complementary cell suppression techniques to ensure that cells with fewer than eleven records cannot be identified by manipulating data in adjacent rows and columns.

**Response: N/A we need the patient-level data to address the objectives in the grant**

Field Number and Name	Requested Count or Sum
N/A	N/A
	<i>[add rows as needed]</i>

### **B. Linkages to Other Data Sets**

The CO APCD seeks to ensure that data cannot be re-identified if it is linked to or combined with information obtained from other sources. If this project requires claims line level detail or includes linkages to other databases, or if CO APCD data will be combined with other information, provide a justification for each proposed linkage. Be sure to describe how this will contribute to achieving the project purpose, including whether the project can be completed without this linkage, and the steps you will take to prevent the identification of individual patients: **Data linkage to claims will allow us to identify resource utilization outside of a trial environment. This is crucial to achieving the objectives of the grant and helping to identify whether this model of care can reduce resource utilization in clinical practice environments.**

**Will you link the CO APCD data to another data source?**

☐ No.

☒ Yes. If yes, please answer the following questions.

- Which CO APCD identifying data elements will be used to perform the linkage?  
**Response: the elements listed earlier in part two will be sufficient to perform the linkage**
- Once the linkage is made, what non-CO APCD data elements will appear in the new linked file? **Response: trial data such as clinical biomarkers, demographics, and other patient-level data elements. This data is in one data set.**
- Have all necessary approvals been obtained to receive and link with the other data files (e.g., IRB or Privacy Board approval)?  
☒ Yes, if so please provide copy (provided)  
☐ In progress, anticipated approval date: \_\_\_\_\_  
☐ No or N/A, reason: \_\_\_\_\_

### **C. Distribution of the Report or Product:** **Prior Review by the CO APCD Administrator**

If you are producing a report for publication in any medium (print, electronic, lecture, slides, etc.) the CO APCD Administrator must review the report prior to public release. The CO APCD Administrator will review the report for compliance with CMS cell suppression rules; risk of inferential identification; and consistency with the purpose and methodology described in this Application.

- Please describe your audience and how to you will make your project publicly available?
  - **Finding from our APCD analyses will be disseminated through articles in professional journals, such as JAMA Neurology, Journal of Palliative Care Medicine, the American Academy of Neurology Journal, etc. We will work with CIVHC Marketing.**
- If the report is not to be made publicly available, then briefly describe how the information derived from this data will be used and by whom: **N/A**

**Other Organizations:** Do you intend to engage third parties who will have access to the data requested as part of this project? If so, list the organizations below, describe their role(s); and explain why they will be granted access to the requested data. **No, no other third parties will have access to the data.**

Organization/Company Name:	
Contact Person:	
Title:	
Address:	
Telephone Number:	
E-mail Address:	
Role or responsibility in this project	<i>[add rows as needed]</i>

### **Project Schedule:**

Proposed Project Start Date:	May 2022
Project End Date:	March 2023
Proposed Publication or Release Date:	June 2023
End of Date Retention Period:	3 years after last financial report submitted to NIH

#### **D. Frequency**

Data in the CO APCD Warehouse is refreshed every other month and data products can be provided on a one time basis or under a subscription model (e.g., quarterly, bi-annually or annually). Please select frequency below.

☒ One Time

**OR**

Subscription (Please select subscription model below)

- ☐ Quarterly  
☐ Bi-annually  
☐ Annually

#### **E. Project Reporting**

CIVHC highlights projects and data analysis on the public website: [www.civhc.org/change-agents](http://www.civhc.org/change-agents). This display of CO APCD projects provides future data requesters with ideas of how they can structure their analysis, and allows CIVHC's stakeholders to see how CO APCD data recipients are working to accomplish the Triple Aim for Colorado. Data recipients have the option of choosing whether to be identified or to not be identified.

- ☒ Yes, it is okay for CIVHC to identify my organization  
☐ No, I do NOT wish for CIVHC to identify my organization

## **PART THREE**

### **DATA MANAGEMENT PLAN (Not applicable for Custom Report Requests)**

#### **I. Organizational Capacity**

As an Attachment, please provide copies of the Data Privacy and Security Policies and Procedures for the Requesting Organization as well as those of any third parties that will have access to the requested CO APCD data.

- Has the Requesting Organization or any member of the project team ever been involved with a project that experienced a data security incident? If so, describe the incident, the response procedures that were followed and any subsequent changes in procedures, processes or protocols to mitigate the risk of further events. **No member of our project team has ever been involved in such an incident.**

To the extent that the Data Privacy and Security Policies and Procedures, provided as an Attachment, do not already do so, please answer or attach answers for the following:

- **Physical Possession and Storage of CO APCD Data Files:**
  - Describe how you will maintain an inventory of CO APCD data files and manage physical access to them for the duration of the project: **Response: the trial data are stored in Redcap and then will be downloaded to an encrypted computer**



where we will merge with the APCD files. For now, given this will be a smaller data set, we envision only including the data on a local drive that is encrypted. However, we have multiple protected servers through central OIT available for use if needed.

- Describe your personnel/staffing safeguards, including:
  - Confidentiality agreements in place with individuals identified as being assigned to this study. Include, for example, agreements between the Principal Investigator or Data Custodian and others, including research team members, and information technology and administrative staff:  
**Our study has a data sharing plan approved by the NIH. All investigators are aware of this Aim and participants consented specifically to use of APCD data.**
  - Staff training programs you have in place to ensure data protections and stewardship responsibilities are communicated to the research team:  
**CU has multiple OIT courses and resources available.**
  - Procedures to track the active status and roles of each member of the research team throughout the project and a process for notifying the CO APCD of any changes to the team: **This is tracked through COMIRB.**
- Describe your technical and physical safeguards. Examples include:
  - Actions taken to physically secure data files, such as site and office access controls, secured file cabinets and locked offices. **Encrypted computers are standard at the University.**
  - Safeguards to limit access to CO APCD data and analytical extracts among the research team (Note: if the distribution of analytical data extracts among the researcher team is part of your data management plan, the extracts remain subject to the terms of your Data Use Agreement). **We will have one identified analyst to do the bulk of the work and keep the data on their local machine.**
- Provide a brief description of your policies and procedures for ensuring that CO APCD data are protected when stored on a server. **Please see the OIT procedures at CU Anschutz for more information.**
  - Describe how your organization prevents the copying or transfer of data to local workstations and other hard media devices (CDs, DVDs, hard drives, etc.). Note that Applicants are required to encrypt CO APCD data both in motion and at rest: **Yes data in motion and at rest is encrypted. As mentioned previously, we plan to avoid the use of a server given the data set will be fairly small relative to larger claims data sets.**
- Data Reporting and Publication
  - Your organization must ensure that all analytic extracts, analyses, findings, presentations, reports, and publications based on CO APCD data files adhere to specific requirements of the Data Use Agreement (DUA: refer to sections 6, 7 and 8 in the Data Use Agreement). **Briefly describe your plan for demonstrating that data reporting and publication processes will be consistent with the DUA, including adhering to CO APCD cell suppression policies:**

## 2. **Completion of Research Tasks and Data Destruction**

Your organization must ensure that it has policies and procedures in place to destroy the CO APCD data files upon completion of the project and that you have safeguards to ensure the data are protected when researchers terminate their participation in the research project. Describe your plan for demonstrating that your organization has policies and procedures in place to reliably destroy the data files upon completion of the research: **We will follow NIH guidelines for data destruction 3 years after our last financial report is submitted to NIH. The Department of Neurology uses Iron Mountain as a secure data storage facility.**

## 3. **Request for Privacy Board Approval** *(Only Applicable to Identifiable Data Requests)*

Projects that request Identifiable information for a research purpose may require approval from the DRRC acting as a Privacy Board if an IRB is not available.

- The DRRC, acting as a Privacy Board, may approve a waiver of the individual authorization normally required to release PHI under CFR § 164.508 if:
- It would be impracticable for researchers to obtain written authorization from patients that are the subject of the research; and
- The research could not practicably be conducted without access to and use of the PHI.
- The DRRC, acting as a Privacy Board, is required to evaluate certain criteria in considering whether to approve an authorization waiver. If you are requesting Identifiable Information for a research purpose, explain why your proposed use of PHI involves no more than a minimal risk to the privacy of patients that are the subject of the research. Evidence of minimal risk to the privacy of patients that should be addressed in your explanation includes:
  - An adequate plan to protect PHI identifiers from improper use and disclosure;
  - An adequate plan to destroy PHI identifiers at the earliest opportunity; and
  - Adequate written assurances that PHI will not be reused or disclosed.

## Appendix I

### Certification of Project Completion and Destruction or Retention of Data

(Please Save)

Name:	
Title:	
Organization:	
Address:	
Tel Number:	
Fax Number:	
E-mail Address;	
Project Title:	
Data Sets:	
Years:	
<input type="checkbox"/> Certification of Data Destruction	Date the Data was Destroyed:
<input type="checkbox"/> Request to Retain Data	Date Until Data Will Be Retained:

Instructions: Data must be destroyed so that it cannot be recovered from electronic storage media in accordance with the methods established by the “Guidance to Render Unsecured Protected Health Information Unusable, Unreadable, or Indecipherable to Unauthorized Individuals,” as established by the U.S. Department of Health and Human Services (HHS).

I hereby certify that the project described in the Application is complete as of this date \_\_\_\_\_, \_\_\_, 20\_\_.

Complete the appropriate section, below:

☐ I/we certify that we have destroyed all Data received from the CO APCD Administrator in connection with this project, in all media that were used during the research project. This includes, but is not limited to data maintained on hard drive(s), diskettes, CDs, etc.

☐ I/we certify that we are retaining the data received in connection with the aforementioned project, pursuant to the following health or research justification (provide detail, use as much additional space as necessary and state how long the data will be retained).

☐ I/we hereby certify that we are retaining the Data received from the APCD Administrator in connection with the aforementioned project, as required by the following law. [Reference the appropriate law and indicate the timeframe].

By signing this Agreement, the Receiving Organization agrees to abide by all provisions set out in this Agreement.

**SIGNATURES:**

<b>For the CO APCD:</b>	<b>For Receiving Organization:</b>
<b>Signature:</b>	<b>Signature:</b>
<b>Name: Pete Sheehan</b>	<b>Name:</b>
<b>Title: VP of Client Solutions &amp; State Initiatives</b>	<b>Title:</b>