



Data Release Application

Limited and Identifiable Extracts

Navigation

Client Application Revision History	1
Data Requestor Details.....	2
Project Schedule and Purpose	4
Data Matching and Linkage.....	8
Data Inclusion Criteria.....	10
Additional Documentation.....	14
Client Acknowledgements and Signatures	15

Data Release Application

Limited and Identifiable Extracts



Client Application Revision History

The following reflects the history of changes made to this document during the application process prior to project production. Once in production, any further changes to the application may result in additional cost and production delays.

To be completed by CIVHC staff			
Date	New Version Number	Description of Change(s)	CIVHC Change Author (full name, complete title)
9/26/2024	V.01	Initial version drafted with client.	Lucía Sanders, Key Account Manager
10/2/2024	V.02	Updated diagnosis codes and IRB status.	Lucía Sanders, Key Account Manager
10/8/2024	V.03	Updated financial details requested.	Lucía Sanders, Key Account Manager
10/28/2024	V.04	Updated methodology, PHI justification, ICD9 and ICD10 codes, and Data Users.	Lucía Sanders, Key Account Manager
	V.05		
	V.06		
	V.07		
	V.08		
	V.09		
	V.10		

Data Release Application

Limited and Identifiable Extracts



Data Requestor Details

General Project Details

Project Title:	An Ounce of Prevention: Primary and Preventive Care Gaps, Barriers, and Potential Solutions for Adults with Cerebral Palsy
Application Start Date:	9/13/2024
Requested Project Delivery Date:	12/15/2024
Client Organization (legal name):	University of Colorado Anschutz
Client Organization Address:	13123 East 16th Avenue, Box 285, Aurora, CO 80045
To be completed by CIVHC staff	
CIVHC Contact (full name, complete title):	Lucía Sanders
Project Number:	24.36
Condensed Project Title:	CP Preventive Care

Project Contacts

Project Contact Name:	Cristina Sarmiento
Title:	Assistant Professor
Email:	Cristina.Sarmiento@cuanschutz.edu
Phone Number:	440-668-8344
Analytic Contact Name:	Cristina Sarmiento
Title:	Assistant Professor
Email:	Cristina.Sarmiento@cuanschutz.edu
Phone Number:	440-668-8344

Data Release Application

Limited and Identifiable Extracts



Invoice Contact Name:	Tyonek Ogemareshig
Title:	Grant Manager
Email:	tyonek.ogemareshig@cuanschutz.edu
Phone Number:	303.724.0589
Data Release Fee Signatory:	Chrissy Alexander
Title:	Senior Purchasing Agent
Email:	chrissy.alexander@cu.edu
Phone Number:	303-764-3472
Data Use Agreement Signatory:	Chrissy Alexander
Title:	Senior Purchasing Agent
Email:	chrissy.alexander@cu.edu
Phone Number:	303-764-3472

Data Release Application

Limited and Identifiable Extracts

Project Schedule and Purpose

Proposed Project Start Date ¹ :	9/1/2024
Anticipated Project End Date:	8/31/2029
Proposed Publication or Release Date:	9/15/2025

1. Detail the specific research question(s) you are trying to answer or problem(s) you are trying to solve with this data request. Please list and number the individual questions.

Cerebral palsy (CP) is one of the most common causes of childhood-onset physical and developmental disability, and life expectancy of people with CP is increasing. As such, CP is increasingly viewed as a lifespan, rather than strictly childhood condition. Adults with CP have unique healthcare needs and risks with a higher prevalence of many chronic diseases at earlier ages compared to the general population. Comprehensive primary care and preventive screenings may facilitate earlier detection and treatment of chronic diseases. Preventive services include screening/diagnostic tests (e.g., mammography), counseling services (e.g., smoking cessation counseling), and disease prevention interventions (e.g., influenza vaccination), and are typically provided by primary care providers (PCPs). Preventive care reduces morbidity and mortality, and established recommendations are in place for the general population. However, individuals with disabilities in general receive lower rates of many preventive care screenings. Few studies have evaluated preventive screening in adults with childhood-onset disabilities, and demonstrate lower rates of annual wellness visits in adults with CP and spina bifida (examined together), particularly in those who are Hispanic or Black. To close this gap between high risk of chronic disease and low rates of preventive screening, there is a critical need to understand the extent of this disparity in preventive care to improve early identification and management of chronic conditions for adults with CP.

The goal of this proposed project is to describe adherence to preventive services in adults with cerebral palsy (CP) and compare adherence in adults with CP and adults with autism spectrum disorder (ASD).

Individual research questions:

- i. What is the adherence to preventive services for adults with CP?
- ii. How does the adherence to preventive services in adults with CP compare to adults with ASD?

¹ After all required documents have been signed, typical production time is 30-60 days for a Limited or Identifiable Extract. Anticipate a longer production period for projects including a Finder File or creation of a Member Match File.

Data Release Application

Limited and Identifiable Extracts

- iii. What are the variations in member liability among adults with CP and adults with ASD, and how does this relate to preventive service usage?
- iv.
- v.

2. Describe your methodology or how you will be using data from the Colorado All Payer Claims Database (CO APCD) to answer your research questions.

This is a cross-sectional analysis of healthcare claims data for adults with CP, describing adherence to preventive services in adults with CP compared to both the general population and another population with a developmental disability.

We will include beneficiaries in CO APCD ages 18 years and older with a diagnosis of CP. Persons with CP will be identified with a documented ICD-9/10 code for cerebral palsy on any claim during the study period. We will also examine CO APCD beneficiaries ages 18 years and older with ICD-9/10 codes for autism spectrum disorder, as a comparison group. We are requesting data from all years (2012-2023) for two primary reasons. First, the prevalence of CP is approximately 3 per 1,000. Requesting data from all years will maximize the number of adults with CP that we can include in our study, thereby giving us the most accurate assessment of preventive service use given the relatively low prevalence of CP overall. Additionally, some preventive services are only recommended once every several years, such as colonoscopies which are only recommended every 10 years. As such, 12 years of data would help us capture more of these types of services.

We will calculate descriptive demographic characteristics for all beneficiaries ages 18 years and older with CP, using mean (standard deviation) for continuous variables and percentage (95% confidence interval) for categorical variables. For those preventive services recommended annually (e.g., wellness visits), we will calculate the proportion of those eligible for the service who receive the service in each year (repeated cross-sectional analysis). For those preventive services not recommended annually (e.g., colorectal cancer screening), we will calculate the proportion of those eligible for the service at any point during the study period who receive the service at any point during the study period (cross-sectional analysis). Although this is a conservative definition of adherence, it will identify important disparities in preventive services, which may inform additional analyses to explore stricter adherence to recommended timeframes.

We will use Chi-squared tests to evaluate differences between individuals with CP (without a co-occurring diagnosis of ASD) and individuals with ASD (without a co-occurring diagnosis of CP) for each preventive service. Comparison to individuals with ASD will allow us to determine if screening rates differ between populations with different developmental disabilities. Although CP and ASD can co-occur, a prior registry study found that 4.3% of persons with CP also had a diagnosis of ASD, and thus this overlap is relatively minor compared to other developmental disabilities (e.g., intellectual disability, which co-occurs in up to 30-50% of persons with CP). While all persons with CP have a physical disability by definition, approximately 24% of persons with ASD have a physical disability. ASD therefore provides an interesting comparison as a developmental

Data Release Application

Limited and Identifiable Extracts

disability with predominant social, communication, and behavioral impairments (as opposed to physical impairments).

Among adults with CP, we will also conduct sub-group analyses to compare use of preventive services based on age; sex (among preventive services recommended for both males and females); rural vs. non-rural zip codes; and primary payer type. We will also explore the relationship between preventive service usage and variations in member liability, as this may impact adherence to preventive services. We will use SAS version 9.4 (SAS Institute Inc., Cary, NC, USA); $p \leq 0.05$ will be used to determine statistical significance.

3. Explain how this project will benefit Colorado and its residents.²

This project will benefit Colorado and its residents by helping us understand the extent of disparities in preventive care for adults with CP. Enhanced understanding of this issue will then allow us to identify targets for intervention in order to improve early identification and management of conditions for adults with CP. CP is the most common physical disability that begins in childhood and is also an extremely heterogeneous diagnosis. Individuals with CP can have a host of comorbidities, and the heterogeneity of the severity and types of functional impairment enhances generalizability to other childhood-onset disabilities. Therefore, adults with CP are an excellent model to better understand the complexities of aging with a childhood-onset disability.

4. Describe how your project will improve health care quality, increase health care value, or improve health outcomes for Colorado residents.²

Adults with CP have a high risk of many chronic conditions, and early detection and management through comprehensive preventive care will likely improve outcomes related to health and function. This is a federally funded project that leverages the powerful multi-payer data of CO APCD in a novel application to answer this important question. Though Colorado-specific, this project stands to contribute to existing knowledge about the health and healthcare disparities facing people with disabilities.

5. Health equity is defined as the state in which everyone has a fair and just opportunity to attain their highest level of health. Explain how your project addresses health equity.

CP is the most common motor disability beginning in childhood, and the most people living with CP are adults. And yet, the vast majority of clinical services, programs, research, and funding

² It is a statutory requirement for all non-public releases of CO APCD data to benefit Colorado or its residents. Contributions to generalizable knowledge alone are not sufficient to satisfy this requirement.

Data Release Application

Limited and Identifiable Extracts



focuses on children with CP. This project begins to address this inequity by enhancing our understanding of the healthcare services and utilization of adults with CP. Additionally, people with disabilities have recently been designated as a population with health disparities by the National Institutes of Health, and research focused on people with disabilities can help inform practice and policy changes to help mitigate these disparities.

6. Describe any publication you plan to develop based on your use of CO APCD data, its intended audience, and whether it will be made publicly available.

Results from this project will be presented at national meetings and published in peer-reviewed journals, and will help launch next steps to improve health, function, and quality of life for individuals with CP and other childhood-onset disabilities across the lifespan. We will seek to publish in journals with broad, multidisciplinary audiences including clinicians, researchers, and policy makers.

Data Release Application

Limited and Identifiable Extracts



Data Matching and Linkage

Finder File

A Finder File is a file you submit to CIVHC with information about a pre-selected cohort for matching to CO APCD data. Ask your CIVHC Contact for more information about this process and requirements for Finder File submission.

Will you provide CIVHC with a Finder File as part of this project?

- ☒ No
☐ Yes

Member Match File

A Member Match File is a file that CIVHC creates on your behalf to send to a registry or other outside entity to create a crosswalk connecting data from the CO APCD to the other entity's data.

Does this project require the creation of a Member Match File?

- ☒ No
☐ Yes. Consult with your CIVHC Contact about completing a separate Data Element Selection Form specifying the data elements that should be used to create the Member Match File.

Answer the following:

Who will receive the Member Match File?

Control Group

A Control Group is a group of individuals who can be used to compare against the cohort identified in the Finder File.

Will you need to create a Control Group as part of this project?

- ☒ No
☐ Yes. Consult with your CIVHC Contact about completing a separate Control Group Data Element Selection Form specifying the data elements that should be used to define the Control Group.

Data Release Application

Limited and Identifiable Extracts

Linkage

Data Linkage is a method of joining data from different sources together to create a new data set.

Will the CO APCD data be linked to another data source?

- ☒ No
☐ Yes. Answer the following:

What is/are the other data source/s?
Who will perform the data linkage?
What identifying data elements will be used to perform the data linkage?
What non-CO APCD data elements will appear in the new linked file?

Data Release Application

Limited and Identifiable Extracts



Data Inclusion Criteria

Make selections in the following sections based on what data you want to have included in this extract. If you will be creating a Control Group, complete this section for your study population and not the Control Group.

Protected Health Information (PHI)

Indicate which [Protected Health Information](#) data elements you require for your project purpose:

Available for Limited and Identifiable extracts:		
<input checked="" type="checkbox"/> Member 5-Digit Zip Code	<input type="checkbox"/> Member County	<input type="checkbox"/> Member City
<input checked="" type="checkbox"/> Member Dates of Service	<input checked="" type="checkbox"/> Member Eligibility Dates	<input type="checkbox"/> Employer Name
<input type="checkbox"/> Member Census Tract	<input type="checkbox"/> Member Census Block	<input type="checkbox"/> Member Census Block Group
Available for Identifiable extracts only (see also Identifiable Data Use Approval):		
<input type="checkbox"/> Member Name	<input type="checkbox"/> Member Date of Birth (if requesting more than year only)	
<input type="checkbox"/> Member Street Address	<input type="checkbox"/> Member Latitude and Longitude	
<input type="checkbox"/> Employer Tax ID		
Provide detailed justification for the inclusion of all PHI data selected above, and explain how its inclusion meets the Minimum Necessary Requirement . ³		
<p>We are interested in exploring geographic disparities related to preventive service use, which can be measured at multiple levels and for which different geographic data for merging exist. We are requesting zip code so we can explore these disparities. We are requesting member eligibility date so we can estimate variations based on changes in insurance coverage. Member dates of service are needed to assess timing of preventive care services. Service dates will be important particularly for recommended preventive services that have a time dimension to them. For example, dental cleanings are usually recommended every 6 months. In addition, service dates are very useful for internally validating the sequencing of services.</p>		

³ Limited and Identifiable extracts must adhere to the [Minimum Necessary Requirement](#) under the [HIPAA Privacy Rule](#); only that data required to answer the project purpose can be included in the request.

Data Release Application

Limited and Identifiable Extracts



We are also requesting member age as well as member age at year's end to ensure we are including all individuals who turned 18 in a year. Our focus on preventive care patterns requires us to measure preventative care in the year the person turned 18 to account for services they received in that year. For example, if an individual turns 18 in November, they may have received their seasonal flu vaccine (a preventive service) in October at age 17. The following year, they may receive their vaccine in December at age 19. If we did not examine their preventive service usage in the entire year they turned 18, it would appear as if they did not receive their recommended flu vaccine.

Line(s) of Business

- ☒ Commercial Payers
- ☒ Health First Colorado (Colorado's Medicaid and CHP+ programs)⁴
- ☒ Medicare Advantage
- ☒ Medicare Fee for Service (FFS)⁵

Year(s) of Data

- | | | | | | |
|--|--|--|--|--|---|
| <input checked="" type="checkbox"/> 2012 | <input checked="" type="checkbox"/> 2013 | <input checked="" type="checkbox"/> 2014 | <input checked="" type="checkbox"/> 2015 | <input checked="" type="checkbox"/> 2016 | <input checked="" type="checkbox"/> 2017 |
| <input checked="" type="checkbox"/> 2018 | <input checked="" type="checkbox"/> 2019 | <input checked="" type="checkbox"/> 2020 | <input checked="" type="checkbox"/> 2021 | <input checked="" type="checkbox"/> 2022 | <input checked="" type="checkbox"/> 2023 ⁶ |

Claim Type(s)

- | | | |
|--|---|--|
| <input checked="" type="checkbox"/> Inpatient Facility | <input checked="" type="checkbox"/> Outpatient Facility | <input checked="" type="checkbox"/> Professional |
| <input checked="" type="checkbox"/> Pharmacy | <input checked="" type="checkbox"/> Dental | |

Financial Detail by Line Item

- | | | |
|--|--|--|
| <input type="checkbox"/> Charged Amount | <input checked="" type="checkbox"/> Allowed Amount | <input checked="" type="checkbox"/> Plan Paid Amount |
| <input checked="" type="checkbox"/> Plan Pre-Paid Amount | <input type="checkbox"/> Member Copay | <input type="checkbox"/> Member Deductible |
| <input type="checkbox"/> Member Coinsurance | <input checked="" type="checkbox"/> Total Member Liability | |

⁴ Medicaid-only data requests must be approved by the Colorado Department of Health Care Policy and Financing.

⁵ Medicare FFS data are not available for all requests and must go through a separate approval process.

⁶ This year's data is not fully adjudicated.

Data Release Application

Limited and Identifiable Extracts



Filter Criteria – Services, Providers, Facilities

If you need data for specific services, providers and/or facilities, specify that filter criteria below (ask your CIVHC Contact about including an additional file with this application for large code lists):

ICD Diagnosis Code(s):
Procedure(s) (list CPT, HCPCS, DRG, ICD, and/or CDT codes):
Drug(s) (list pharmacy NDC and/or HCPCS codes):
Facility Type(s):
Facilities (list NPIs and/or Pharmacy IDs):
Facilities within these geographical areas (list county, zip code, Census Tract , etc.):
Provider Type(s):
Provider(s) (list NPIs):
Providers within these geographical areas (list county, zip code, Census Tract , etc.):
Specific payers (minimum of five):

Data Release Application

Limited and Identifiable Extracts



Other claim specification:

Filter Criteria – Members/Patients

If you need data for specific member/patient groups, specify that filter criteria below (ask your CIVHC Contact about including an additional file with this application for large code lists):

Ages:		
18 years and older		
<input type="checkbox"/> At the time of service	<input checked="" type="checkbox"/> At year end	<input type="checkbox"/> By another anchor date: <i>Specify here</i>
With these ICD Diagnosis Code(s):		
cerebral palsy (ICD 9: 343, 343.*; ICD 10: G80, G80.*) on any claim OR autism spectrum disorder (ICD 9: 299.0, 299.0*, 299.8; ICD 10: F84.0, F84.5) on any claim		
Who have had the following procedure(s) (list CPT, HCPCS, DRG, ICD, and/or CDT codes):		
Within these geographical areas (list county, zip code, Census Tract , etc.):		

Value-Add Data Elements

- ☐ [Medicare Severity Diagnosis Related Group](#) Codes (MS-DRGs)
- ☐ [3M All Patient Refined Diagnosis Related Group](#) Codes (3M APR DRGs)
- ☐ [Medicare Repricer](#) (available at the claim line level)
- ☐ Fields from the [American Community Survey](#) (available at the Census Tract level):

Specify here

Data Release Application

Limited and Identifiable Extracts



Additional Documentation

Data Element Selection Form (DESF)

The Data Release Application must be accompanied by a completed Data Element Selection Form. Ask your CIVHC Contact for more information about completing this form.

- ☒ By checking this box, the Client Organization confirms that the Data Element Selection Form has been completed.
- ☐ If applicable, by checking this box the Client Organization confirms that a separate Member Match File Data Element Selection Form has been completed.
- ☐ If applicable, by checking this box the Client Organization confirms that a separate Control Group Data Element Selection Form has been completed.

Identifiable Data Use Approval

If you are requesting [Identifiable](#) information, approval from an [Institutional Review Board \(IRB\)](#) or a [Privacy Board](#) is required before such data can be released.

- ☐ Not applicable; the Client Organization is requesting a Limited Extract.

Approval Type

- ☒ IRB Approval
- ☐ Privacy Board Approval

Approval Type

- ☐ Approval request not yet submitted.
Anticipated submission date:
- ☐ Approval request submitted and under review.
Anticipated project approval date:
- ☒ Approval already received.

Approval Documentation

- ☐ By checking this box, the Client Organization confirms that the IRB or Privacy Board **application and approval documents** have been provided to CIVHC.

Data Release Application

Limited and Identifiable Extracts



Data Management Plan

An organization requesting CO APCD data must submit an organizational Data Management Plan to CIVHC outlining the organization's data security and data management policies and procedures to safeguard the data. This Data Management Plan must be approved by CIVHC prior to any data release.

Date Submitted to CIVHC:	
Date Approved by CIVHC:	

Client Acknowledgements and Signatures

Change Agent Index

CIVHC can publicly share the Client Organization's name in its [Change Agent Index](#)?

- ☒ Yes
☐ No

Report or Product Distribution

If your project results in the production of a report for public distribution in any format (print, electronic, lecture, slides, etc.), including peer-reviewed publication, it must be submitted to CIVHC for review prior to public release. CIVHC will assess compliance with [CMS Cell Size Suppression Policy](#), risk of inferential identification, CIVHC and CO APCD citations, and consistency with the purpose and methodology described in this Data Release Application. CIVHC will not assess the accuracy of the study results or attempt to recreate results.

This requirement is further defined in the Data Use Agreement. Failure to pursue and obtain CIVHC approval prior to publication will be a violation of the Data Use Agreement and may put the organization's future access to data from the CO APCD at risk.

- ☒ By checking this box, the Client Organization acknowledges this requirement.

Data Destruction Period

All data must be destroyed within 30 days of the project end date. If your project end date changes from this application, please reach out to your CIVHC Contact for a project extension request form.

- ☒ By checking this box, the Client Organization acknowledges that CIVHC's [Data Destruction Certificate](#)⁷ must be completed and returned to DataCompliance@CIVHC.org by 9/30/2029 based on the [Anticipated Project End Date](#).

Data Release Application

Limited and Identifiable Extracts

Data Users

List any individuals that will be working with the data. The Data Use Agreement must be updated through your CIVHC Contact every time individuals are granted access to the data during the course of the project.

Full Name	Title/Role	Organization
Liza Creel, PhD, MPH	Co-Investigator	University of Colorado Anschutz
Megan Morris, PhD, MPH, CCC-SLP	Co-Investigator	University of Colorado Anschutz
Mark Gritz, PhD	Co-Investigator	University of Colorado Anschutz
Anna Furniss	Data analyst	University of Colorado Anschutz
Cristina Sarmiento, MD	PI	University of Colorado Anschutz

⁷ Available on the [Data Release Application and Documents](#) page of CIVHC's website under *Privacy, Security, and Regulatory Information*.

Data Release Application

Limited and Identifiable Extracts

Data Release Application Version Approvals

The Client Organization has reviewed and confirms that the final version number of the Data Release Application reflected below correctly represents the project objectives.

Version	Checkpoint
V.03	Presented at CIVHC Application Review
V.04	Presented to the Data Release Review Committee (DRRC)
V.00	Final version approved for production

CIVHC Sign-Off		Receiving Organization Sign-Off	
Signature:		Signature:	
Name:	Lucía Sanders	Name:	Cristina Sarmiento
Title:	Key Account Manager	Title:	Assistant Professor
Date:		Date:	

Data Release Application

Limited and Identifiable Extracts

Data Element Selection Form Version Approvals

The Client Organization has reviewed and confirms that the final version number of the Data Element Selection Form reflected below correctly represents the data specifications needed to meet the project objectives.

Version	Checkpoint
V.02	Presented at CIVHC Application Review
V.03	Presented to the Data Release Review Committee (DRRC)
V.00	Final version approved for production

CIVHC Sign-Off		Receiving Organization Sign-Off	
Signature:		Signature:	
Name:	Lucía Sanders	Name:	Cristina Sarmiento
Title:	Key Account Manager	Title:	Assistant Professor
Date:		Date:	