



Data Release Application

Limited and Identifiable Extracts

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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)
11/26/2024	V.01	Initial version drafted with client.	Lucía Sanders, Key Account Manager
12/6/2024	V.02	Added details regarding how financial cost elements will be used in analysis.	Lucía Sanders, Key Account Manager
12/9/2024	V.03	Expanded on justification for PHI data elements.	Lucía Sanders, Key Account Manager
12/18/2024	V.04	Updated linkage section.	Lucía Sanders, Key Account Manager
	V.05		
	V.06		
	V.07		
	V.08		
	V.09		
	V.10		

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Data Requestor Details

General Project Details

Project Title:	Healthcare Resource Utilization in Patients with Stiff Person Spectrum Disorder
Application Start Date:	11/16/2024
Requested Project Delivery Date:	2/1/2025
Client Organization (legal name):	University of Colorado School of Medicine
Client Organization Address:	12631 East 17 th Ave. Mail Stop B185 Aurora, CO 80045
CIVHC can publicly share the Client Organization's name in its Change Agent Index .	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No
To be completed by CIVHC staff	
CIVHC Contact (full name, complete title):	Lucía Sanders
Project Number:	25.13
Condensed Project Title:	Stiff Person Syndrome

Project Contacts

Project Contact Name:	Amanda Piquet
Title:	MD
Email:	amanda.piquet@cuanschutz.edu
Phone Number:	610-223-7132
Analytic Contact Name:	Eric Gutierrez
Title:	MPH
Email:	eric.gutierrez@cuanschutz.edu
Phone Number:	520-401-6881

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Invoice Contact Name:	Neurology Billing
Title:	
Email:	neurologybilling@ucdenver.edu
Phone Number:	303-724-0350
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

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Project Schedule and Purpose

Proposed Project Start Date ¹ :	2/1/2025
Anticipated Project End Date:	4/5/2027
Proposed Publication or Release Date:	4/5/2025

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.

The purpose of this project is to describe healthcare resource utilization in patients diagnosed with Stiff Person Syndrome Disorder (SPSD), focusing on hospital admissions, emergency room (ER) visits, outpatient consultations, and medication use. We will retrospectively analyze utilization and associated costs in 59 patients diagnosed with СПSD at a large academic center to identify areas for interventions.

Individual research questions:

- i. What is the pattern of resource utilization in patients with СПSD?
- ii. What is the annual cost of healthcare services of patients with СПSD?
- iii. Are there unnecessary or redundant services being utilized in patients with СПSD?
- iv. How often are patients with СПSD hospitalized or presenting to the emergency room?
- v. Are there clinical and demographic factors and/or gender disparities associated with healthcare resource utilization among patients with СПSD?
- vi. Does misdiagnosis of СПSD play a role in unnecessary or redundant services being utilized in patients with СПSD?
- vii. Does urban vs rural areas impact the pattern of resource utilization in patients with СПSD?
- viii. What is the out of pocket cost burden for patients in their diagnostic odyssey to СПSD?

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.

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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.

We will use the data obtained to quantify hospitalizations, emergency room visits, outpatient visits, laboratory and radiology services, and pharmacy related services to evaluate all-cause and SPSP related healthcare resource utilization and costs. In addition, patient out of pocket costs incurred while obtaining the SPSP diagnosis will also be estimated.

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

Understanding the healthcare resource utilization of patients with rare disease and the out of pocket cost burden during their diagnostic odyssey can help identify areas for intervention to decrease unnecessary use, lower patient and healthcare system costs and increase efficiency. This can in turn benefits residents of Colorado by making healthcare more accessible and less costly. We recently completed an epidemiology study (Crane P, Sillau S, Dreher R, Fix R, Winters P, Van Coevering R, Engebretson E, Valdez B, Matthews E, Nair KV, Carlson AM, **Piquet AL**. A Population-Based Study of the Epidemiology of Stiff Person Syndrome in a Large Colorado-Based Health System. Neurology. Accepted, in press), demonstrating a prevalence of 1-2 per 100,000 person years in the UCHHealth system. Given this number, there is a large impact on this disease in the state of Colorado. Understanding health care resources in this patient population can lead to future improvements in diagnosis and the treatment of this disease and potential cost reduction with improved efficiency in the use of healthcare resources.

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

Understanding the patterns of healthcare resource utilization will aid in allocating appropriate system resources and defining standards of care for a rare disease. As mentioned above, while considered a rare disease, there is substantial impact to Colorado residents based on our prevalence rates of 1 to 2 per 100,000. We can improve our health outcomes in SPSP once we understand the health care utilization of patients and identify areas for intervention. In addition, the identification of patient out of pocket costs incurred by patients along their diagnostic odyssey to SPSP will provide critical information on how to reduce this burden.

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.

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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.

Data collected can be used to identify disparities in care among differing patient demographics within the SPSP patient population. We know that SPSP is more prevalent in women, we can look at gender disparities among SPSP patients. Often times women with SPSP have common misdiagnosis of multiple sclerosis, fibromyalgia, and functional neurologic disease before SPSP is confirmed. This misdiagnosis may lead to unnecessary use of healthcare resources. We will explore this hypothesis.

Additionally we are requesting data for the 5-digit zip code. We will explore the question of does urban vs rural areas impact the pattern of resources utilization in patients with SPSP? There may be disparities, particularly with the use of medication and access to either home infusion services or infusion centers based on urban vs rural locations.

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.

Data may be presented at the annual American Academy of Neurology conference. Data may also be published in medical journals. There will be no protected health information made publicly available.

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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 CIVHC 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.

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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?
Health Data Compass
Who will perform the data linkage?
Eric Engebretson (Analyst, CU Research Team)
What identifying data elements will be used to perform the data linkage?
CO APCD Member Composite ID and Health Data Compass MRN (via crosswalk provided by CIVHC)
What non-CO APCD data elements will appear in the new linked file?
Clinical data for SPSD diagnosis: Neurology encounters, diagnostic testing, treatments

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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 checked="" type="checkbox"/> Member County	<input checked="" type="checkbox"/> Member City
<input checked="" type="checkbox"/> Member Dates of Service	<input checked="" type="checkbox"/> Member Eligibility Dates	<input checked="" type="checkbox"/> Claim Paid 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	
Provide detailed justification for the inclusion of all PHI data selected above, and explain how its inclusion meets the Minimum Necessary Requirement . ³		
<p>Zip codes, counties and cities are being requested to understand if living in urban, rural or frontier impacts the resource patterns and utilization of patients with SPSP. This may aid in identifying disparities of care with regards to proximity to treatment and other resources.</p> <p>Dates of service and eligibility dates are being requested to explore the timeline of patients' access to care along their diagnostic journey of SPSP. This, in addition to claim dates, can help understand the costs incurred before and after a patient's diagnosis.</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.

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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 |
| <input type="checkbox"/> 2024 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 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 type="checkbox"/> Plan Pre-Paid Amount | <input checked="" type="checkbox"/> Member Copay | <input checked="" type="checkbox"/> Member Deductible |
| <input checked="" 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 incomplete and not fully adjudicated. Consult with your CIVHC Contact to find out what data is available at the time of your request.

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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):

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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:		
All patients in finder file.		
<input type="checkbox"/> At the time of service	<input type="checkbox"/> At year end	<input type="checkbox"/> By another anchor date: <i>Specify here</i>
With these ICD Diagnosis Code(s):		
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

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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.

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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

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 5/5/2027 based on the [Anticipated Project End Date](#).

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

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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
Amanda Piquet	Principle Investigator	University of Colorado
Mallory Lowe	Co-Investigator	University of Colorado
Aaron Carlson	Co-Investigator	University of Colorado
Kavita Nair	Co-Investigator	University of Colorado
Eric Engebretson	Project Manager	University of Colorado
Stefan Silau	Statistician	University of Colorado
Eric Gutierrez	Analyst	University of Colorado

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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:	Amanda Piquet
Title:	Key Account Manager	Title:	Principal Investigator
Date:		Date:	

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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.02	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:	Amanda Piquet
Title:	Key Account Manager	Title:	Principal Investigator
Date:		Date:	