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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)
11/21/2024	V.01	Initial version drafted with client.	Lucía Sanders, Key Account Manager
12/4/2024	V.02	Modifications after feasibility review.	Lucía Sanders, Key Account Manager
12/6/2024	V.03	Removed request for Member City, Census Tract/Block/Group.	Lucía Sanders, Key Account Manager
	V.04		
	V.05		
	V.06		
	V.07		
	V.08		
	V.09		
	V.10		

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Data Requestor Details

General Project Details

Project Title:	Colorado Sickle Cell Data Collection Program
Application Start Date:	11/4/2024
Requested Project Delivery Date:	4/1/2025
Client Organization (legal name):	Center for Public Health Innovation
Client Organization Address:	891 Evergreen Pkwy, Evergreen, CO 80439
CIVHC can publicly share the Client Organization's name in its Change Agent Index.	☒ Yes ☐ No
To be completed by CIVHC staff	
CIVHC Contact (full name, complete title):	Lucía Sanders, Key Account Manager
Project Number:	25.91
Condensed Project Title:	Sickle Cell Surveillance

Project Contacts

Project Contact Name:	**Joshua Miller**
Title:	Senior Public Health Analyst
Email:	Joshua.Miller@CPHInnovation.org
Phone Number:	720-412-1174
Analytic Contact Name:	**Rhonda West**
Title:	Associate Public Health Analyst
Email:	Rhonda.West@CPHInnovation.org
Phone Number:	434-227-1072

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Invoice Contact Name:	**Joshua Miller**
Title:	Senior Public Health Analyst
Email:	Joshua.Miller@CPHInnovation.org
Phone Number:	720-412-1174
Data Release Fee Signatory:	**Marci Sontag**
Title:	Executive Director
Email:	Marci.Sontag@CPHInnovation.org
Phone Number:	303-549-5613
Data Use Agreement Signatory:	**Marci Sontag**
Title:	Executive Director
Email:	Marci.Sontag@CPHInnovation.org
Phone Number:	303-549-5613

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Project Schedule and Purpose

Proposed Project Start Date[1]:	2/15/2025
Anticipated Project End Date:	9/29/2028
Proposed Publication or Release Date:	4/1/2025

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 Colorado Sickle Cell Data Collection (SCDC) Program uses data to study long-term trends in diagnosis, treatment, and healthcare utilization to improve the lives of people with sickle cell disease (SCD) through community driven educational and policy initiatives supported by public health surveillance data.   The Colorado SCDC program is funded by the CDC and is a partnership between the Center for Public Health Innovation (CPHI), the Colorado Sickle Cell Treatment and Research Center, and the Colorado Sickle Cell Association. Colorado SCDC combines data from vital statistics, newborn screening, electronic medical records, and all-payer claims data to better understand the prevalence of SCD and to identify long-term trends in diagnosis, treatment, and healthcare utilization for people with SCD in Colorado.
>
> Just as important as collecting data on SCD in Colorado is sharing that data with stakeholders to improve access to necessary resources and improve the quality of life for the SCD community. Colorado and the other state SCDC programs, working together as a national collaborative, are continuously working on educational materials, journal articles, policy briefs and other dissemination materials to share with those living with sickle cell disease, family members and caregivers, health care providers, and policy makers.
>
> As such, we seek to enter into a subscription with CIVHC for CO APCD data on patients with an SCD diagnosis, including creation of a member match file for the purposes of linking with Vital Statistics and Newborn Screening at the Colorado Department of Public Health and Environment (CDPHE). We request an initial delivery of data for the period 1/1/2012-12/31/2023 in February 2025. Then, beginning in 2026 and continuing through 2028, we request an annual delivery of data for the prior calendar year. Below is the proposed data delivery schedule:

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[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.

Dates of Service Date Range	Requested Delivery Date
01/01/2012-12/31/2023	2/15/2025
01/01/2024-12/31/2024	2/15/2026
01/01/2025-12/31/2025	2/15/2027
01/01/2026-12/31/2026	2/15/2028

Individual research questions:

i.   How many individuals with sickle cell disease live in Colorado?

ii. What is the geographic distribution and prevalence of sickle cell disease in CO?

iii. What are the acute care utilization patterns of individuals with sickle cell disease?

iv. How many acute care visits result in a repeat acute care visit within 30 days?

v.   Which insurance plans account for most sickle cell related claims, and what is the associated cost for hospitals, individuals, and Medicaid/Medicare?

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.

> After data is received and linked, we will apply national SCDC case definitions to determine which individuals represent a case of possible, probable, or definite. Possible cases are identified as any individual with three or more healthcare encounters across participating hospitals, emergency departments, or outpatient clinics with a SCD ICD-9-CM or ICD-10-CM code over any 5-year period between January 1, 2012, and December 31, 2023. Possible cases are upgraded to probable if the individual has a hospital discharge in the reporting year, emergency department visit in the reporting year, or both before and after the reporting year. A case is confirmed as definite if they have a confirmed diagnosis of SCD after a presumptive positive newborn screen or are confirmed to have SCD via chart review by a clinical hematologist at the Colorado Sickle Cell Treatment and Research Center. Only probable and definite cases will be reported to the CDC. Cases reported to the CDC are de-identified and aggregated.

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

> Public health surveillance for sickle cell disease (SCD) could bring numerous benefits to Colorado and its residents by improving health outcomes, informing policy, and addressing health disparities. Tracking the prevalence, complications, and outcomes associated with SCD can guide resource allocation to appropriate geographic areas. Surveillance data also supports evidence-based policy making to enhance access to specialized care and treatments, and can help empower advocacy groups to push for policies that improve access to care, insurance coverage, and support services. Additionally, SCD primarily afftecs individuals of African American ancestry and surveillance can help address disparities by identifying gaps in care and targeting underserved populations. Surveillance findings can also inform public health campaigns to increase awareness about SCD and empower the community to advocate for themselves.

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[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.

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

> This project will improve health outcomes by tracking the prevalence, complications, and outcomes associated with SCD that can guide resource allocation and the development of care protocols. Additionally, insights from surveillance can help healthcare providers tailor care for specific populations, reducing acute complications and hospitalizations.

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.

> Sickle cell disease patients are a historically underserved population with limited access to transportation, health resources, and subject to worse health outcomes due to a racist and biased infrastructure. This project addresses health equity by reporting the geographic prevalence of sickle cell disease in CO and addressing the need for the appropriate allocation of resources to areas where individuals with sickle cell disease reside.

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.

> We plan on publishing on the prevalence of sickle cell disease in CO, the geographic distribution of the disease, the acute care utilization of these individuals, the cost of health care for patients, hospitals, Medicaid and Medicare, and the burden of the disease on job retention. All publications will be publically available in Pubmed.

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?
Kirk Bol at the Vital Statistics Program at CDPHE

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?
1. Individuals with a confirmed diagnoses of sickle cell disease after a positive newborn screen. These individuals are entered into a REDCap database annually.   2. Birth records from the vital statistics program.   3. Death records from the vital statistics program.

Who will perform the data linkage?
Kirk Bol at the vital statistics program (CDPHE) currently links the birth records with the newborn screening records. Those fields that are acquired from the linkage are then uploaded into the newborn screening redcap database. CPHI will perform the linkage between the already linked newborn screening records (newborn screening + birth records) to the APCD data, and the death records to the APCD data.

What identifying data elements will be used to perform the data linkage?
First name   Last Name   Date of birth   Date of death (Vital Statistics program)   Sex   SSN (Vital Statistics program + Newborn Screening)

What non-CO APCD data elements will appear in the new linked file?
Race reported at birth
Ethnicity reported at birth
County of residence at birth
Date of death
Reason of death

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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:		
☒ Member 5-Digit Zip Code	☒ Member County	☐ Member City
☒ Member Dates of Service	☒ Member Eligibility Dates	☒ Claim Paid Dates
☒ Employer Name	☐ Member Census Tract	☐ Member Census Block
☐ Member Census Block Group		
Available for Identifiable extracts only (see also Identifiable Data Use Approval):		
☒ Member Name	☒ Member Date of Birth (if requesting more than year only)	
☒ Member Street Address	☒ 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]		
Member name and date of birth are necessary variables for linking the data to newborn screening data, birth records, and death records. Additionally, our case definition flow requires manual case validation by an adult and pediatric hematologist on the project. In order for them to perform a chart review via medical record, they must have the name and DOB of the individual.		

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[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.

Street address and latitude and longitude are necessary for mapping distances from residence to sickle cell specialty care centers, especially as it relates to this historically underserved population with limited access to transportation and necessary health resources. Census tract will not suffice in this instance as there are some large census tracts in rural areas of Colorado that may skew distance calculations for those in areas with the least access to healthcare resources for SCD.

Member county is necessary for annual reporting requirements to the CDC.

5-digit zip codes are necessary for identifying groups of sickle cell individuals living in socially vulberable areas based on the Social Vulnerability Index (SVI) which defines areas by zip code.

Dates of service are necessary for determining acute care utilization statistics for annual reporting years, and are a required reporting metrics for the annual data report to the CDC.

Member eligibility dates are necessary for determining whether an individuals was eligible for Medicaid during a given reporting year. Medicaid eligibility determination is a requirement for applying the national sickle cell surveillance case defiitions.

Claim paid dates are necessary for determining healthcare costs for given annual repoting years.

Employer name will be used to determine employment status and better understand the need for vocational rehabilitation services for this underserved population.

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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

☒ 2012   ☒ 2013   ☒ 2014   ☒ 2015   ☒ 2016   ☒ 2017

☒ 2018   ☒ 2019   ☒ 2020   ☒ 2021   ☒ 2022   ☒ 2023

☐ 2024[6]

Claim Type(s)

☒ Inpatient Facility   ☒ Outpatient Facility   ☒ Professional

☒ Pharmacy   ☐ Dental

Financial Detail by Line Item

☐ Charged Amount   ☒ Allowed Amount   ☒ Plan Paid Amount

☐ Plan Pre-Paid Amount   ☐ Member Copay   ☐ Member Deductible

☐ Member Coinsurance   ☒ Total Member Liability

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[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):

CENTER FOR IMPROVING
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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:		
☐ At the time of service	☐ At year end	☐ By another anchor date: *Specify here*
With these ICD Diagnosis Code(s):		
ICD-9 Codes: 282.4, 282.41, 282.42, 282.49, 282.6, 282.60, 282.61, 282.62, 282.63, 282.64, 282.68, 282.69 ICD-10 Codes: D56, D56.0, D56.1, D56.2, D56.8, D56.9, D57, D57.0, D57.00, D57.01, D57.02, D57.03, D57.04, D57.09, D57.1, D57.2, D57.20, D57.21, D57.211, D57.212, D57.213, D57.214, D57.218, D57.219, D57.4, D57.40, D57.41, D57.411, D57.412, D57.413, D57.414, D57.418, D57.419, D57.42, D57.43, D57.431, D57.432, D57.433, D57.434, D57.438, D57.439, D57.44, D57.45, D57.451, D57.452, D57.453, D57.454, D57.458, D57.459, D57.8, D57.80, D57.81, D57.811, D57.812, D57.813, D57.814, D57.818, D57.819 No sickle trait (D57.3 and 282.5). If individual has one claim with ICD code then we need all claims.		
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

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: 12/1/2024

- ☐ 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:	12/16/2024
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 10/29/2028 based on the Anticipated Project End Date.

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

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
Joshua Miller	Project Director	Center for Public Health Innovation
Rhonda West	Project Analyst	Center for Public Health Innovation

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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.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:	Joshua Miller
Title:	Key Account Manager	Title:	Senior Public Health Analyst
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.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:	Joshua Miller
Title:	Key Account Manager	Title:	Senior Public Health Analyst
Date:		Date:	