



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)
7/26/2024	V.01	Initial version drafted with client.	Lucía Sanders, Key Account Manager
9/10/2024	V.02	Incorporation of client updates.	Lucía Sanders, Key Account Manager
9/19/2024	V.03	Following feasibility meeting discussion, removed request to filter members by NDC. Updated member age filter to less than 46 years. Added detail to methodology.	Lucía Sanders, Key Account Manager
9/25/2024	V.04	Removed ICD-9 codes. Updated aims end dates from 2024 to 2023. Added details to Linkage and PHI/PII Data Elements sections.	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:	SEARCH for Diabetes in Children and Young Adults 0-45 years (SEARCH-DiCAYA) Diabetes Surveillance Study
Application Start Date:	8/27/2024
Requested Project Delivery Date:	2/15/2025
Client Organization (legal name):	University of Colorado LEAD Center
Client Organization Address:	1890 N Revere Ct. Ste. 1002, MS F426, AHSB, Aurora, CO 80045
To be completed by CIVHC staff	
CIVHC Contact (full name, complete title):	Lucía Sanders, Key Account Manager
Project Number:	25.85
Condensed Project Title:	LEAD Center DiCAYA

Project Contacts

Project Contact Name:	Anna Bellatorre/Tessa Crume
Title:	Research Associate/Associate Professor
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Phone Number:	303-724-7704
Analytic Contact Name:	Shawna Burgett/Chloe Friedman
Title:	Research Instructor/Research Associate
Email:	SHAWNA.BURGETT@UCDENVER.EDU; CHLOE.FRIEDMAN@CUANSCHUTZ.EDU
Phone Number:	720-771-5365

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Invoice Contact Name:	Anna Bellatorre
Title:	Research Associate
Email:	Anna.Bellatorre@cuanschutz.edu
Phone Number:	303-724-7704
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 :	9/30/2020
Anticipated Project End Date:	9/29/2026
Proposed Publication or Release Date:	12/31/2025

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.

This is a continuation of past project 21.85r, which included claims for years 2012-2021. This project is seeking the addition of claims for the period 2021-2023.

Aim 1: PREVALENCE – Starting with year 2017 and continuing through year 2023, to ascertain prevalent diabetes cases among youth <18 years of age and adults 18-45 years of age on a yearly basis from an integrated surveillance system using algorithms that distinguish diabetes type.

Research question 1.1: What are the yearly state-level age-, sex- and race/ethnicity-specific prevalence estimates of T1D and T2D among youth and young adults?

Research question 1.2: Using prevalence data from SEARCH-Colorado, what are the long-term temporal trends in the prevalence of T1D and T2D and do they vary by race/ethnicity, age, and sex?

Aim 2: INCIDENCE – Starting with year 2017 and continuing through year 2023, to ascertain newly diagnosed diabetes among youth <18 years of age and young adults 18-45 years of age on a yearly basis from an integrated surveillance system using algorithms that estimate date of onset and distinguish diabetes type.

Research question 2.1: What are the yearly state-level age-, sex- and race/ethnicity-specific incidence estimates of T1D and T2D among youth and young adults?

Research question 2.2: Using incidence data from SEARCH-Colorado, what are the long-term temporal trends in the incidence of T1D and T2D and do they vary by race/ethnicity, age and sex?

Research question 2.3: What is the prevalence of diabetic ketoacidosis (DKA) at the time of diagnosis in youth and young adults with T1D and T2D? Using data from SEARCH-Colorado, what are the long-term temporal trends in prevalence of DKA at diagnosis with T1D and T2D?

Aim 3: EVALUATE PUBLIC HEALTH SURVEILLANCE METHOD – To evaluate the strengths and challenges of our integrated surveillance approach to determine the burden of diabetes among

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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youth <18 years of age and young adults 18-45 years of age by ascertaining validity, completeness and representativeness of case ascertainment methods.

Research question 3.1: What is the sensitivity, specificity and positive predictive value of the surveillance approach, overall and by diabetes type in a random sample of T1 and T2 cases?

Research question 3.2: What are the capture-recapture adjusted prevalence and incidence estimates of T1 and T2 diabetes while accounting for the potential bias introduced by less than complete case ascertainment?

Individual research questions:

- i.
- ii.
- iii.
- 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.

We will use incremental record linkage to match participants from the APCD data to data received from other hospital and care networks around Colorado to deduplicate cases and generate numerators for cases of new (incident) and existing (prevalent) cases of diabetes for the purposes of diabetes surveillance in youth and young adults aged 0-45 who live in and receive their care in Colorado.

In summary, we only use CO APCD data to adjust estimates of data collected through our core network by way of capture-recapture analyses performed locally.

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

Increasing trends in the incidence and prevalence of diabetes among youth and young adults, particularly among various racial and ethnic subpopulations, necessitate an efficient, timely, accurate surveillance system that produce consistent estimates over time that will inform the U.S. health care and public health system, specifically in Colorado, to effectively plan and care for youth with diabetes.

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

Access to accurate and timely diabetes surveillance data is vital for public health planning needed to assess the size of the burden of diabetes by age and subpopulations. This information will be informative for public health stakeholders and medical professionals to better allocate resources and identify groups at risk for diabetes.

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.

By incorporating data from the APCD we move towards our shared goal of health equity by better counting and accounting for varied access and healthcare use across the state of Colorado particularly by those who receive public assistance for their health insurance.

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.

Since this study is NIH funded, all manuscripts are required to obtain PMIDs and be made publicly available. We intend to publish several manuscripts related to surveillance of diabetes trends in incidence and prevalence.

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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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.

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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?
Our other data sources include Health Data COMPASS at the University of Colorado, Denver Health and Hospital Authority (DHHA), Children's Hospital Colorado (CHCO), SCL Health, Centura Health, Valley Wide Health System, and St. Mary's Grand Junction.
Who will perform the data linkage?
Member matching will only be needed/used within our group where we will internally de-duplicate records. Shawna Burgett and Toan Ong will perform our deduplication across sites.
What identifying data elements will be used to perform the data linkage?
First name, last name, date of birth, gender, and address data elements (census tract, census block, census block group, county, 5-digit zip code, city, street address).
What non-CO APCD data elements will appear in the new linked file?
Demographics, encounter, diagnosis, procedures, vitals, lab results, prescribing, and death information from our other data sources. Our other data sources include Health Data COMPASS at the University of Colorado, Denver Health and Hospital Authority (DHHA), Children's Hospital Colorado (CHCO), SCL Health, Centura Health, Valley Wide Health System, and St. Mary's Grand Junction.

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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 type="checkbox"/> Employer Name
<input checked="" type="checkbox"/> Member Census Tract	<input checked="" type="checkbox"/> Member Census Block	<input checked="" type="checkbox"/> Member Census Block Group
Available for Identifiable extracts only (see also Identifiable Data Use Approval):		
<input checked="" type="checkbox"/> Member Name	<input checked="" type="checkbox"/> Member Date of Birth (if requesting more than year only)	
<input checked="" 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>These identifiable and select limited data elements are needed solely for de-duplication of cases. All elements will be stripped from any dataset before inclusion in our data surveillance repository or any data used in a manuscript. These are the minimum necessary elements to uniquely identify and deduplicate cases.</p> <p>Additionally, all elements requested here were previously approved and included in the 21.85r data extract.</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 type="checkbox"/> 2012 | <input type="checkbox"/> 2013 | <input type="checkbox"/> 2014 | <input type="checkbox"/> 2015 | <input type="checkbox"/> 2016 | <input type="checkbox"/> 2017 |
| <input type="checkbox"/> 2018 | <input type="checkbox"/> 2019 | <input 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 type="checkbox"/> Dental | |

Financial Detail by Line Item

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

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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:		
0-45 years (inclusive)		
<input checked="" 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):		
See tab "ICD-10 Dx" on DESF.		
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):

<i>Specify here</i>

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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:	9/5/2024
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 10/29/2026 based on the [Anticipated Project End Date](#).

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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
Anna Bellatorre	Research Associate	University of Colorado
Tessa Crume	Associate Professor	University of Colorado
Shawna Burgett	Research Instructor	University of Colorado
Chloe Friedman	Research Associate	University of Colorado
Toan Ong	Associate Professor	University of Colorado

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 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:	Anna Bellatorre
Title:	Key Account Manager	Title:	Research Associate
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:	Anna Bellatorre
Title:	Key Account Manager	Title:	Research Associate
Date:		Date:	