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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)
12/11/2023	V.01	Initial version drafted with client.	Lucía Sanders, Key Account Manager
5/16/2024	V.02	Incorporated updates from client.	Lucía Sanders, Key Account Manager
5/30/2024	V.03	Transposed to latest application template.	Lucía Sanders, Key Account Manager
6/4/2024	V.04	Updated DUA/DRF signatories, earliest publication/release date, description of publication, and justification for PHI data elements.	Lucía Sanders, Key Account Manager
6/6/2024	V.05	Added background that this is building on a previous project (21.135) and removed request for dental claims.	Lucía Sanders, Key Account Manager
6/27/2024	V.06	Elaborated on continuation of previous project, and expansion of previous project.	Lucía Sanders, Key Account Manager
7/3/2024	V.07	Included linkage of members to vital records for identification of births where parent has IDD diagnosis.	Lucía Sanders, Key Account Manager
7/8/2024	V.08	Updated patient/member filter criteria to include all patients under age 1 year regardless of ICD diagnosis codes.	Lucía Sanders, Key Account Manager
	V.09		

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	V.10		

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Data Requestor Details

General Project Details

Project Title:	Health Care Transitions and the Health of Adolescents and Young Adults with IDD
Application Start Date:	12/11/2023
Requested Project Delivery Date:	8/23/2024
Client Organization (legal name):	Boston Children's Hospital
Client Organization Address:	300 Longwood Ave, Mailstop: 3450, Boston, MA 02215
To be completed by CIVHC staff	
CIVHC Contact (full name, complete title):	Lucía Sanders
Project Number:	24.135
Condensed Project Title:	Health Care Transitions

Project Contacts

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Data Release Fee Signatory:	August P. Cervini
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Title:	Vice President of Research Administration
Email:	August.Cervini@childrens.harvard.edu
Phone Number:	617-919-2272

Project Schedule and Purpose

Proposed Project Start Date[1]:	8/23/2024
Anticipated Project End Date:	8/23/2029
Proposed Publication or Release Date:	8/1/2026

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 both a continuation and expansion of past project 21.135.
>
> It is a continuation in that the main goal of the project continues to be improve our understanding of how health care is delivered to people with intellectual or developmental disabilities (IDD) and the roles that health insurance and health care providers may play in the experience of gaps or in care quality.
>
> In our first application, we had aimed to understand how many Coloradoan adolescents and young adults had intellectual or developmental disabilities and discovered that this figure was 4.7% among the commercially insured and 11.3% among the Medicaid-insured.
>
> We had also sought to understand how frequently this population was experiencing insurance gaps and found that these experiences spike right at age 19 for Medicaid recipients and age 26 for the commercially insured. The jump up lasts at least 2 years for the commercially insured and 9 years for Medicaid recipients, but with our current age range we can only see up to age 30 and we suspect that this problem endures for even longer, perhaps through age 45.
>
> It is an expansion of past project 21.135 in that we would, in addition to adding more years, like to broaden the age span with which we are working to be 0-45 years (previously it was 10-30 years). This is for two reasons:
>
> -lowering the lower age bound allows us to examine how newborn care relates to reproductive health quality
>
> -raising the upper age bound allows us to how long our study population experiences insurance gaps.
>
> These two reasons why we are also asking to expand the lower bound of the age range to 0 and the upper one to 45 years.

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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.

Individual research questions:

   i. What characterizes health care transitions for adolescents and young adults with intellectual or developmental disabilities (e.g., which types of physicians are involved; at which ages do health care transfers appear to occur)?

   ii. What is the quality of the care being delivered during the time that adolescents and young adults with intellectual or developmental disabilities are making health care transitions?

   iii. Are there gaps in insurance coverage among those turning 19 years of age and how do the gaps associated with Medicaid insurance differ from those who are commercially insured?

   iv. What relationship exists between insurance gaps following Medicaid's eligibility redetermination at age 19 and service utilization indicating lower quality care?

   v. Examine how newborn care relates to reproductive health quality.

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.

Protocol snippet provided by Boston Children's Hospital for research purposes:

3.6 Clinical care quality during HCTs. We will use National Academies of Medicine (formerly the Institute of Medicine) paradigms and both established and exploratory to assess clinical care quality for people with IDD, including detection rates for potentially concerning issues, and avoidance of undesired clinical events such as avoidable emergency or inpatient care (**Table 2**).

Currently, **Table 2** is restricted to diagnoses, measures and algorithms that can be reliably ascertained in claims data, or occur at frequencies in which change can be measured. However, we will also explore the feasibility of including co-morbidities for which claims have historically been less reliable (e.g., obesity) or for which frequencies may be low (e.g., rates of detecting injury, abuse, or neglect). Where possible, we will draw on established methods endorsed by the Agency for Healthcare Research and Quality (AHRQ), the National Committee for Quality Assurance (aka NCQA), and Healthcare Effectiveness Data and Information Set (aka HEDIS). […]

Table 2. Clinical care quality measure examples	
Recommended clinical care	
General health maintenance	Well-visit rates (adolescents, adults)
	Annual influenza immunization
	At least 1 dental exam annually

Rates of screening for at-risk conditions	Hyperlipidemia testing
	Hemoglobin A1c testing
	Pap smears when >21 years
	Pregnancy screening
	Sexually transmitted infection testing
Chronic disease management (if condition is present)	Asthma (e.g., controller medications if persistent)
	Follow-up visits when new psychotropic medications are prescribed (e.g,. ADHD, depression)
	Diabetes (e.g., hemoglobin A1c testing twice annually)
	Epilepsy (e.g., annual visit)
Potentially concerning issues	
Rates well above or below average	Abuse, neglect, domestic violence
	Contraception prescription rates
	Polypharmacy rates, number of sedative, hypnotic, anti-depressant and anti-psychotic medication classes being filled
	Sedation for routine dental care, imaging tests or diagnostic procedures
Undesired clinical events	
Emergency and inpatient services	Avoidable emergency department visits
	Avoidable hospitalizations
	Hospital 30-day readmission rate

> *In the post-October 2015 dates, we may be able to examine body mass index via International Classification of Disease-Version 10.

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

> This project will benefit Coloradoans in three main ways:
>
> 1. It will identify how many insured people with childhood-onset intellectual or developmental disabilities are living in Colorado. Childhood-onset intellectual or developmental disabilities is a life-long condition. People with intellectual or developmental disabilities are an understudied group of "high cost high need" patients—their spending levels can be highest among all sub-populations of children (Chien 2017), the quality of the care being delivered to this population can be sub-optimal (Chien 2015, Chien 2017), and this population likely relies on additional disabilities-related state services. Knowing the size of this population will help state policymakers plan necessary resources and services for people with childhood-onset intellectual or developmental disabilities.
> 2. It will help state officials, health plans, health care providers, and patient stakeholder groups understand what health care transitions look like for Coloradoan teenagers with intellectual or developmental disabilities, how such transitions may vary in terms of timing or provider.
> 3. It will provide Coloradoans with better understanding of how frequently insurance gaps occur at age 19 (in conjunction with changes in Medicaid eligibility) and potentially affect health care access, quality, or spending.

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

> 1. Examines the degree to which those with intellectual or developmental disabilities may be generating higher than average levels of spending because of inconsistent health plan coverage versus or inefficient health care transitions;
> 2. Assesses the relationship between health insurance, health care transitions and the quality of the health care being delivered to this high cost high need population; and in doing so

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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.

> 3. May provide insights into how care quality may be improved or into the patient experience (e.g., when the timing of health care transitions may more optimally occur).

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.

> This project addresses health equity because people with disabilities have been designated as population with health disparities by the National Institutes of Health

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.

> The publications resulting from this project will describe:
>
> 1. How people with intellectual or developmental disabilities may be generating higher than average levels of spending because of inconsistent health plan coverage versus or inefficient health care transitions; and
>
> 2. How health insurance or health care transitions may affect the quality of the health care being delivered to this high cost high need population.

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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?
Colorado Vital Statistics Program at Colorado Department of Public Health and Environment (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 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.

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 Systems and Providers Database (HSPD) at the National Bureau of Economic Research (NBER); Colorado Vital Statistics Program
Who will perform the data linkage?
Boston Children's Hospital research team
What identifying data elements will be used to perform the data linkage?
Provider Taxonomy Code, NPI, birth data (including parent-child relationship)
What non-CO APCD data elements will appear in the new linked file?
None

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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	☐ 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	
☐ 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]		
The requested PHI are the minimum necessary required to conduct this study. We need: 1. Member 5-Digit Zip Code to characterize the sociodemographic area where the patient lives; 2. Member Dates of Service to characterize the timing of health care utilization relative to age and the intervention of interest; 3. Member Eligibility Dates to assess when the enrollees do or do not have insurance; and, 4. Member Date of Birth to know the exact months when the enrollee may not be insured.		

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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.

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> We will conduct this study in full concordance with the Health Insurance Portability and Accountability Act (HIPAA). All of the basic processing of the raw data and all data linkages required for individual research projects are conducted centrally through Boston Children's Hospital's full-time data management personnel, subject to our highest data security standards.
>
> Zip code level linkage: We will link patient zip codes to U.S. Census data to obtain aggregated socio-economic characteristics of individuals living in the zip code and to classify regions as urban/surburban/rural.

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[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 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 of age		
☒ At the time of service	☐ At year end	☐ By another anchor date: *Specify here*
With these ICD Diagnosis Code(s):		
For patients aged 1-45 years, see ICD-10 code list added to DESF. No ICD code filtering will be used on patients less than 1 year of age.		
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:	5/16/2024
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 9/22/2029 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
Yubo Zhang	Clinical Research Specialist I	Boston Children's Hospital
Alyna T. Chien	Research Director	Boston Children's Hospital
Meredith Rosenthal	Professor	Harvard School of Public Health
Ellen Meara	Professor	Harvard School of Public Health
Mary Beth Landrum	Professor	Harvard Medical School
Kathryn P. Gray	Senior Statistician	Boston Children's Hospital
Gabrielle D'Ambrosi	Biostatistician I	Boston Children's Hospital
Carolyn San Soucie	PhD Student	Harvard School of Public Health
Katarina Swanson	PhD Student	Harvard School of Public Health

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[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.06	Presented at CIVHC Application Review
V.08	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:		Name:	
Title:		Title:	
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:		Name:	
Title:		Title:	
Date:		Date:	