



# Data Release Application

## Limited and Identifiable Extracts

### Navigation

Client Application Revision History .....	1
Data Requestor Details.....	3
Project Schedule and Purpose .....	5
Data Matching and Linkage.....	10
Data Inclusion Criteria.....	12
Additional Documentation.....	16
Client Acknowledgements and Signatures .....	17

# Data Release Application

## Limited and Identifiable Extracts



### Client Application Revision History

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

To be completed by CIVHC staff			
Date	New Version Number	Description of Change(s)	CIVHC Change Author (full name, complete title)
10/18/2024	V.01	Initial version drafted with client.	Lucía Sanders, Key Account Manager
11/27/2024	V.02	Added details regarding past project 21.81, which includes mother data.	Lucía Sanders, Key Account Manager
12/9/2024	V.03	Clarified dates of original 21.81 data request.	Lucía Sanders, Key Account Manager
12/10/2024	V.04	Updated date range for member match and added pharmacy claims.	Lucía Sanders, Key Account Manager
2/3/2025	V.05	Updated for inclusion of father's claims data and changed to repull mother's data (no longer reusing 21.81 extract).	Lucía Sanders, Key Account Manager
2/14/2025	V.06	Updated data flow diagram. Expanded on justification for amount of data requested. Added new data flow diagram for final linked data set.	Lucía Sanders, Key Account Manager
2/19/2025	V.07	Expanded on impact to health equity. Added additional background to project purpose.	Lucía Sanders, Key Account Manager
	V.08		
	V.09		
	V.10		

# Data Release Application

## Limited and Identifiable Extracts



# Data Release Application

## Limited and Identifiable Extracts



## Data Requestor Details

### General Project Details

Project Title:	Understanding Disparities in Preventive Care Utilization, Hospitalization and Emergency Department visits Among Children of Deaf and Hard of Hearing Parents
Application Start Date:	10/15/2024
Requested Project Delivery Date:	2/1/2025
Client Organization (legal name):	The Lundquist Institute for Biomedical Innovation
Client Organization Address:	1124 W. Carson St, Torrance, 90502 CA
CIVHC can publicly share the Client Organization's name in its <a href="#">Change Agent Index</a> .	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No
To be completed by CIVHC staff	
CIVHC Contact (full name, complete title):	Lucía Sanders, Key Account Manager
Project Number:	24.49
Condensed Project Title:	Disparities Children DHHP

### Project Contacts

<b>Project Contact Name:</b>	<b>Frank Wu</b>
Title:	Research Associate
Email:	Frank.wu@lundquist.org
Phone Number:	310-222-3699
<b>Analytic Contact Name:</b>	<b>Dennys Estevez</b>
Title:	Biostatistician
Email:	Dennys.estevez@lundquist.org
Phone Number:	310-222-3699

# Data Release Application

## Limited and Identifiable Extracts



<b>Invoice Contact Name:</b>	<b>Rie Sakai-Bizmark</b>
Title:	Associate professor
Email:	rsakaibizmark@lundquist.org
Phone Number:	310-222-3699
<b>Data Release Fee Signatory:</b>	<b>Rie Sakai-Bizmark</b>
Title:	Associate professor
Email:	rsakaibizmark@lundquist.org
Phone Number:	310-222-3699
<b>Data Use Agreement Signatory:</b>	<b>Rie Sakai-Bizmark</b>
Title:	Associate professor
Email:	rsakaibizmark@lundquist.org
Phone Number:	310-222-3699

# Data Release Application

## Limited and Identifiable Extracts



### Project Schedule and Purpose

Proposed Project Start Date <sup>1</sup> :	6/1/2025
Anticipated Project End Date:	6/30/2028
Proposed Publication or Release Date:	10/1/2028

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.

#### Background:

Infants born to Deaf and Hard of Hearing (D/HH) women are at a higher risk of adverse birth outcomes, such as preterm birth, compared to those born to hearing women. This vulnerability may stem from the unique barriers that D/HH individuals encounter. A common misconception is that communication challenges can be fully resolved by providing sign language interpreters or using written communication to replace spoken language. However, prelingual hearing loss often causes language deprivation, impacting psychosocial and language development, which frequently leads to differences in general conceptual understanding. These differences in language development hinder the ability to accurately respond to healthcare-related questions, even with interpreters or written materials. Additionally, D/HH individuals, including those who are post-lingually deaf, are at risk for literacy challenges, which further impacts their ability to comprehend and complete written questionnaires designed for the general population, reducing the reliability and accuracy of these assessments. Collectively, these challenges hinder their ability to navigate complex healthcare systems effectively. Given that parents typically serve as the primary healthcare navigators for their children, these barriers likely affect the health outcomes of children of D/HH parents.

Our preliminary analysis using CO APCD mother's claims data identified 595.8 births from D/HH mothers per year. We also linked Pregnancy Risk Assessment Monitoring System (PRAMS) data with the APCD data found that less than 0.6% the D/HH women identified in the APCD records identified as non-D/HH in the PRAMS data, validating our method of using claims record to identify hearing status.

#### *Individual research questions:*

---

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

# Data Release Application

## Limited and Identifiable Extracts

- i. Are there differences in healthcare utilization between children of deaf and hard of hearing parents (CD/HHPs) and children of hearing parents?
- ii. Are there differences in healthcare utilization between children of deaf and hard of hearing parents (CD/HHPs) served by healthcare systems who see a large volume of CD/HHPs compared to those served by healthcare systems with a low volume of CD/HHPs?
- iii. Are there differences in healthcare utilization between CD/HHPs and non-CD/HHPs served by the same healthcare system?

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.

CIVHC will send a member match file of individuals aged 0-2 years (babies) and 10-60 years (potential parents) to Vital Statistics at CDPHE.

Using the member match file, CDPHE will identify infants born between September 2016 and December 2021, and send birth records for these infants to Lundquist. CDPHE will also provide us (Lundquist) with mother-father-baby trios, as it is not feasible to identify families via claims data in the CO APCD.

Additionally, CDPHE is not authorized to send PII to CIVHC. Finally, CIVHC is unable to restrict CO APCD members aged 10-60 years from the member match file sent to CDPHE because CIVHC is unable to accurately identify which individuals were a parent to a birth from September 2016-December 2023. As such, this is the only data transfer method available to create the required control and study groups to answer our research aims.

Using linked data, we will examine infant CO APCD records within one year after birth, as well as their mothers' CO APCD records nine months before delivery and up to two year after, aiming to focus on pregnancy and one year postpartum. Thus, this longitudinal study will cover January 2016 (i.e., nine months before September 2016 birth) through December 2023.

# Data Release Application

## Limited and Identifiable Extracts

Using the linked CDPHE & CO APCD extract of members aged 10-60 years, we will identify Deaf and hard of hearing (D/HH) parents using ICD-10-CM codes (H90, H91, and Q16), which have been used in existing studies, including NIH funded projects.

To improve the accuracy of D/HH mother identification via ICD-10-CM, we will examine mothers' CO APCD records nine months pre-delivery and up to one year postpartum.

Parents with H90, H91 or Q16 codes in their CO APCD records anytime during this period will be classified as D/HH.

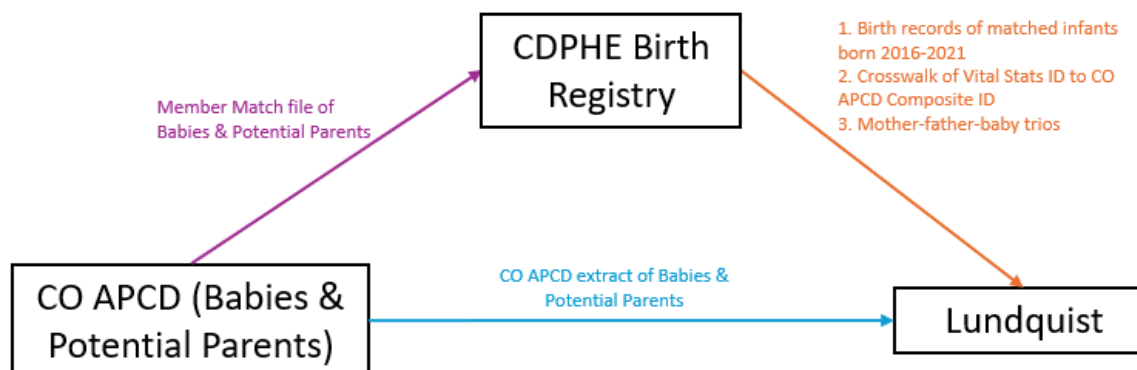
Father's claims data will also be linked with infant/mother pair through the CDPHE & CO APCD linked data extract. D/HH status of father will be determined using the same method above and will serve as an adjustment variable.

The healthcare systems responsible for patient care will be defined as the systems that billed the largest number of claims identified in APCD data for a given CD/HHM patient. In cases where a patient had two or more systems submitting an equal number of claims, we will choose the system that submitted the first claim. The facility ID or tax identified number or health system names on the patients claims records will be used to identify healthcare systems.

We will rank healthcare systems by the number of CD/HHPs they serve. Systems will be classified as "high-volume D/HH [HVD] health systems" or "low-volume D/HH [LVD] health systems" to achieve an equal number of patients in both groups.

Outcomes of interest are infants' well-baby visit and vaccination schedule adherence within the first year of life. We will also examine hospitalizations, ED visits, and outpatient care as other forms of healthcare utilization.

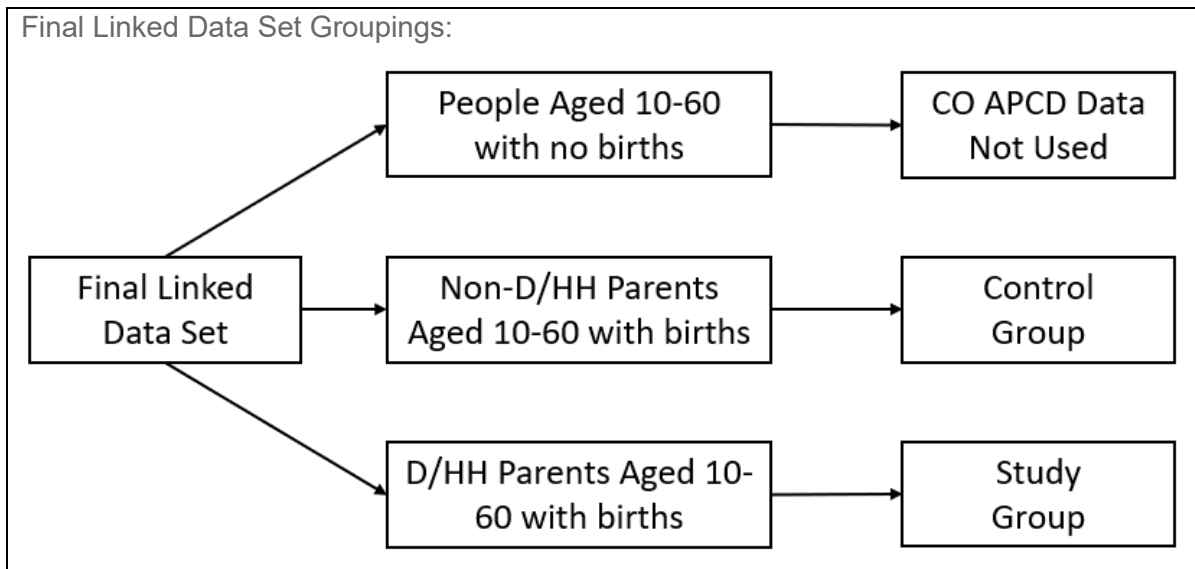
Data Flow Diagram:





# Data Release Application

## Limited and Identifiable Extracts



3. Explain how this project will benefit Colorado and its residents.<sup>2</sup>

Findings from this proposed project will reveal if there are any associations with being CD/HHP and adverse infant health outcomes and healthcare utilization. This will provide valuable information for the development of potential interventions to reduce communication barriers between healthcare settings and DHH parents in Colorado.

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

If our proposed study finds an association between a healthcare system's volume of CD/HHP patients and health outcomes, regionalizing CD/HHP patient care to experienced healthcare systems may yield improved health outcomes.

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

# Data Release Application

## Limited and Identifiable Extracts



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.

D/HH women face a higher risk of pregnancy complications and adverse birth outcomes, such as preterm birth, compared to their hearing counterparts. Communication and cultural barriers, along with mistrust in the healthcare community, are key factors contributing to adverse health outcomes among D/HH individuals. A spouse's hearing status can affect a D/HH mother's access to care and communication support, influencing how she navigates the healthcare system. The spouse's influences has primarily relied on anecdotal assumptions and remains unexamined. Despite reported disparities in healthcare utilization and health outcomes among D/HH individuals, disparities among CD/HHPs remain uninvestigated. This project will aim to assess the factors associating with CD/HHPs' healthcare utilization.

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.

Findings will also be disseminated through multiple other channels. First, we aim to publish the research findings in top-ranked, peer-reviewed journals including JAMA and the American Journal of Epidemiology and present the findings at medical conferences. Second, additional dissemination methods will include individual consultations, group training sessions, conference workshops, newsletters, magazines and newspapers, and the project's website.

# Data Release Application

## Limited and Identifiable Extracts



## Data Matching and Linkage

### Finder File

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

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

- ☒ No  
☐ Yes

### Member Match File

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

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

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

Answer the following:

Who will receive the Member Match File?
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.

# Data Release Application

## Limited and Identifiable Extracts

### Linkage

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

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

- ☐ No
- ☒ Yes. Answer the following:

What is/are the other data source/s?
CDPHE birth records
Who will perform the data linkage?
CDPHE, Lundquist
What identifying data elements will be used to perform the data linkage?
Mother's and Father's data (first and last name, SSN, and date of birth)
What non-CO APCD data elements will appear in the new linked file?
Birth records data: (DOB, race/ethnicity, prenatal care, c-section, gestation, birth weight, etc) Mother-Father-Baby trios

# Data Release Application

## Limited and Identifiable Extracts



### Data Inclusion Criteria

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

#### Protected Health Information (PHI)

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

Available for Limited and Identifiable extracts:		
<input checked="" type="checkbox"/> Member 5-Digit Zip Code	<input type="checkbox"/> Member County	<input type="checkbox"/> Member City
<input checked="" type="checkbox"/> Member Dates of Service	<input type="checkbox"/> Member Eligibility Dates	<input type="checkbox"/> Claim Paid Dates
<input type="checkbox"/> Employer Name	<input type="checkbox"/> Member <a href="#">Census Tract</a>	<input type="checkbox"/> Member <a href="#">Census Block</a>
<input type="checkbox"/> Member <a href="#">Census Block Group</a>		
Available for Identifiable extracts only (see also <a href="#">Identifiable Data Use Approval</a> ):		
<input type="checkbox"/> Member Name	<input checked="" 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 <a href="#">Minimum Necessary Requirement</a> . <sup>3</sup>		
Zip code will be used to determine income quartile as an adjustment variable. Dates of service will be used to assess if infant followed well-baby/vaccination schedule adherences. Date of birth will be used to identify starting date of analysis for infants.		

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

# Data Release Application

## Limited and Identifiable Extracts



### Line(s) of Business

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

### Year(s) of Data

- |  |  |  |  |  |  |
|--|--|--|--|--|--|
| <input type="checkbox"/> 2012              | <input type="checkbox"/> 2013            | <input type="checkbox"/> 2014            | <input 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 <sup>6</sup> |  |  |  |  |  |

### 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 checked="" type="checkbox"/> Charged Amount | <input checked="" 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    |  |

---

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

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

<sup>6</sup> 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.

# Data Release Application

## Limited and Identifiable Extracts



### Filter Criteria – Services, Providers, Facilities

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

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

# Data Release Application

## Limited and Identifiable Extracts



Other claim specification:

### Filter Criteria – Members/Patients

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

Ages:		
<= 2 years old (infants born 2016-2021); 10-60 years old (potential parents to infants born 2016-2021)		
<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):		
Who have had the following procedure(s) (list CPT, HCPCS, DRG, ICD, and/or CDT codes):		
Within these geographical areas (list county, zip code, <a href="#">Census Tract</a> , etc.):		

### Value-Add Data Elements

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

*Specify here*



# Data Release Application

## Limited and Identifiable Extracts



## Additional Documentation

### Data Element Selection Form (DESF)

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

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

### Identifiable Data Use Approval

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

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

### Approval Type

- ☒ IRB Approval
- ☐ Privacy Board Approval

### Approval Type

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

### Approval Documentation

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

# Data Release Application

## Limited and Identifiable Extracts



### Data Management Plan

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

Date Submitted to CIVHC:	11/8/2024
Date Approved by CIVHC:	11/11/2024

## 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](#)<sup>7</sup> must be completed and returned to [DataCompliance@CIVHC.org](mailto:DataCompliance@CIVHC.org) by 7/30/2028 based on the [Anticipated Project End Date](#).

---

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

# Data Release Application

## Limited and Identifiable Extracts



### Data 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
Rie Sakai-Bizmark	Principal Investigator	The Lundquist Institute for Biomedical Innovation
Frank Wu	Research Associate	The Lundquist Institute for Biomedical Innovation
Dennys Estevez	Biostatistician	The Lundquist Institute for Biomedical Innovation
Emily Marr	Assistant Researcher	The Lundquist Institute for Biomedical Innovation

# Data Release Application

## Limited and Identifiable Extracts

### Data Release Application Version Approvals

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

Version	Checkpoint
V.05	Presented at CIVHC Application Review
V.07	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:	Frank Wu
Title:	Key Account Manager	Title:	Research Associate
Date:		Date:	

# Data Release Application

## Limited and Identifiable Extracts

### Data Element Selection Form Version Approvals

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

Version	Checkpoint
V.05	Presented at CIVHC Application Review
V.06	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:	Frank Wu
Title:	Key Account Manager	Title:	Research Associate
Date:		Date:	