

Application for Massachusetts All-Payer Claims Data (Non-Government) [Exhibit A – Data Application]

I. INSTRUCTIONS

This form is required for all Applicants, Agencies, or Organizations, hereinafter referred to as “Organization”, except Government Agencies as defined in [957 CMR 5.02](#), requesting protected health information. All Organizations must also complete the [Data Management Plan](#), and attach it to this Application. The Application and the Data Management Plan must be signed by an authorized signatory. This Application and the Data Management Plan will be used by CHIA to determine whether the request meets the criteria for data release, pursuant to 957 CMR 5.00. Please complete the Application documents fully and accurately. Prior to receiving CHIA Data, the Organization must execute CHIA’s [Data Use Agreement](#). Organizations may wish to review that document prior to submitting this Application.

Before completing this Application, please review the data request information on CHIA’s website:

- [Data Availability](#)
- [Fee Schedule](#)
- [Data Request Process](#)

After reviewing the information on the website and this Application, please contact CHIA at apcd.data@chiamass.gov if you have additional questions about how to complete this form.

The Application and all attachments must be uploaded to IRBNet. All Application documents can be found on the [CHIA website](#).

Information submitted as part of the Application may be subject to verification during the review process or during any audit review conducted at CHIA’s discretion.

Applications will not be reviewed until the Application and all supporting documents are complete and the required application fee is received.

A [Fee Remittance Form](#) with instructions for submitting the application fee is available on the CHIA website. If you are requesting a fee waiver, a copy of the Fee Remittance Form and any supporting documentation must be uploaded to IRBNet. Please be aware that if your research is funded and under that funding you are required to release raw data to the funding source, you may not receive CHIA Data.

II. FEE INFORMATION

1. Consult the most current [Fee Schedule](#) for All-Payer Claims Database data.
2. After reviewing the Fee Schedule, if you have any questions about the application or data fees, contact apcd.data@chiamass.gov.
3. If you believe that you qualify for a fee waiver, complete and submit the [Fee Remittance Form](#) and attach it and all required supporting documentation with your application. Refer to the [Fee Schedule](#) (effective Feb 1, 2017) for fee waiver criteria.
4. Applications will not be reviewed until the application fee is received.
5. Data for approved Applications will not be released until the payment for the Data is received.

III. ORGANIZATION & INVESTIGATOR INFORMATION

Project Title:	Health Outcomes and Expenditures for Children using All Payer Claims Data (APCD)
IRBNet Number:	2249300-1
Organization Requesting Data (Recipient):	Icahn School of Medicine at Mount Sinai
Organization Website:	https://icahn.mssm.edu/research/mindich/research/cchsr
Authorized Signatory for Organization:	Hadijah Vactor
Title:	Director, Grants and Contracts
E-Mail Address:	Hadijah.Vactor@mssm.edu
Telephone Number:	646-605-8676
Address, City/Town, State, Zip Code:	One Gustave L. Levy Place, Box 1075, New York NY 10029
Data Custodian: (individual responsible for organizing, storing, and archiving Data)	Pengfei Jiang, MS
Title:	Senior Data Analyst
E-Mail Address:	Pengfei.jiang@mssm.edu
Telephone Number:	Click here to enter text.
Address, City/Town, State, Zip Code:	One Gustave L. Levy Place, Box 1075, New York NY 10029
Primary Investigator (Applicant): (individual responsible for the research team using the Data)	Brett R. Anderson, MD MS MBA
Title:	Director, Center for Child Health Services Research
E-Mail Address:	Brett.anderson@mssm.edu
Telephone Number:	Click here to enter text.
Address, City/Town, State, Zip Code:	One Gustave L. Levy Place, Box 1075, New York NY 10029
Names of Co-Investigators:	Click here to enter text.
E-Mail Addresses of Co-Investigators:	Click here to enter text.

IV. PROJECT INFORMATION

IMPORTANT NOTE: Organization represents that the statements made below as well as in any study or research protocol or project plan, or other documents submitted to CHIA in support of the Data Application are complete and accurate and represent the total use of the CHIA Data requested. Any and all CHIA Data released to the Organization under an approved application may ONLY be used for the express purposes identified in this section by the Organization, and for no other purposes. Use of CHIA Data for other purposes requires a separate Data Application to CHIA **or** written request to CHIA, with approval being subject to CHIA's regulatory restrictions and approval process. Unauthorized use is a material violation of your Organization's Data Use Agreement with CHIA.

1. What will be the use of the CHIA Data requested? [Check all that apply]

- | | | |
|---|---|---|
| <input checked="" type="checkbox"/> Epidemiological | <input checked="" type="checkbox"/> Health planning/resource allocation | <input checked="" type="checkbox"/> Cost trends |
| <input checked="" type="checkbox"/> Longitudinal Research | <input checked="" type="checkbox"/> Quality of care assessment | <input type="checkbox"/> Rate setting |
| <input type="checkbox"/> Reference tool | <input checked="" type="checkbox"/> Research studies | <input type="checkbox"/> Severity index tool (or other derived input) |
| <input type="checkbox"/> Surveillance | <input type="checkbox"/> Student research | <input checked="" type="checkbox"/> Utilization review of resources |
| <input type="checkbox"/> Inclusion in a product | <input type="checkbox"/> Other (describe in box below) | |

[Click here to enter text.](#)

2. Provide an abstract or brief summary of the specific purpose and objectives of your Project. This description should include the research questions and/or hypotheses the project will attempt to address, or describe the intended product or report that will be derived from the requested data and how this product will be used. Include a brief summary of the pertinent literature with citations, if applicable.

Healthcare disparities persist in outcomes and resource utilization for children and young adults. Neighborhood economics, education, environment, and interpersonal bias have been implicated in these inequities. However, the specific mechanisms underlying these inequities remain unclear. One of our primary aims is to use healthcare resource utilization (claims) data to examine potential drivers of health outcomes for children and to identify and quantify mediators of health inequities. We will focus, in particular, on children and young adults with congenital heart disease (CHD) and other chronic conditions, and contrast their outcomes and utilization with the general pediatric/young adult population.

This study will use all-payer claims data (APCD) for children / young adults and their birthing parents to define longitudinal risk-stratified, multi-dimensional outcomes (mortality and morbidities) and associated healthcare utilization/costs/expenditures for children. The study will incorporate social determinants of health (SDOH) and other neighborhood, policy, payer, healthcare provider characteristics to examine how factors such as socioeconomic status, race/ethnicity, geographic location, policy, payer, and providers influence healthcare disparities. We will also use locally-held clinical registry data and neighborhood level measures of social determinants of health / the built environment to provide more nuanced information on procedures and hospitalizations. Ultimately, the study will provide insights into the modifiable drivers of health inequities and inform targeted interventions to improve outcomes and reduce disparities for kids and young adults.

3. Has an Institutional Review Board (IRB) reviewed your Project?

- ☒ Yes [*If yes, a copy of the approval letter and protocol must be included with the Application package on IRBNet.*]
☐ No, this Project is not human subject research and does not require IRB review.

4. **Research Methodology:** Applications must include either the IRB protocol or a written description of the Project methodology (typically 1-2 pages), which should state the Project objectives and/or identify relevant research questions. This document must be included with the Application package on IRBNet and must provide sufficient detail to allow CHIA to understand how the Data will be used to meet objectives or address research questions.

V. PUBLIC INTEREST

1. Briefly explain why completing this Project is in the public interest. Use quantitative indicators of public health importance where possible, for example, numbers of deaths or incident cases; age-adjusted, age-specific, or crude rates; or years of potential life lost. *Uses that serve the public interest under CHIA regulations include, but are not limited to: health cost and utilization analysis to formulate public policy; studies that promote improvement in population health, health care quality or access; and health planning tied to evaluation or improvement of Massachusetts state government initiatives.*

This work will allow for identification of areas with large variation in practice, outcomes, and payments, in order to prioritize ways in which Massachusetts healthcare providers might improve healthcare delivery, patient outcomes, and health equity. Using healthcare claims allows us to apply rigorous methods of evaluating long-term outcomes and resource requirements for children and young adults. This will allow us to develop more

accurate quality metrics predictive of long-term wellbeing and interventions. This would not only build an important data resource and produce generalizable knowledge but also establish a methodology that could be applied to other populations. This in turn, has the potential to translate into public health changes.

VI. DATASETS REQUESTED

The Massachusetts All-Payer Claims Database is comprised of medical, pharmacy, and dental claims and information from the member eligibility, provider, and product files that are collected from health insurance payers licensed to operate in the Commonwealth of Massachusetts. This information encompasses public and private payers as well as data from fully-insured and self-insured plans. APCD data are refreshed and updated annually and made available to approved data users. For more information about APCD Data, including available years of data and a full list of elements in the database please refer to layouts, data dictionaries and similar documentation included on [CHIA's website](#).

Data requests are typically fulfilled on a one time basis, however; certain Projects may require future years of data that will become available in a subsequent release. Projects that anticipate a need for future years of data may request to be considered for a subscription. Approved subscriptions will receive, upon request, the same data files and data elements included in the initial Release annually or as available. Please note that approved subscription requests are subject to the Data Use Agreement, will require payment of fees for additional Data for Non-Government Entities, and subject to the limitation that the Data can be used only in support of the approved Project.

1. Please indicate below whether this is a one-time request, or if the described Project will require a subscription.
☐ One-Time Request **OR** ☒ Subscription
2. CHIA is currently supporting requests for claims data from 2016 to 2022. Requests made outside of these years may not be supported by CHIA and will be considered on a case-by-case basis. Please specify the years of data that are being requested: 2016-2022 .
3. Specify below the data files requested for this Project, and provide your justification for requesting each file.

<input checked="" type="checkbox"/> Medical Claims
Describe how your research objectives require Medical Claims data: Medical claims data will be used to identify diagnoses and procedures, access to care, healthcare resource utilization patterns, morbidities, and healthcare expenditures and associations between healthcare delivery and outcomes, value, and equity of care.
<input checked="" type="checkbox"/> Pharmacy Claims
Describe how your research objectives require Pharmacy Claims data: Pharmacy claims are needed to assess medication usage and pharmacy expenditures.
<input type="checkbox"/> Dental Claims
Describe how your research objectives require Dental Claims data:

N/A
<input checked="" type="checkbox"/> Member Eligibility
<p>Describe how your research objectives require Member Eligibility data:</p> <p>Individual's monthly enrollment status, eligibility category, insurance plan and type are needed to assess impacts of insurance on outcomes and to link pregnant parents to their children to assess impacts of prenatal care and parental health on health outcomes and health expenditures.</p>
<input checked="" type="checkbox"/> Provider
<p>Describe how your research objectives require Provider data:</p> <p>Provider data are needed to assess impacts of healthcare providers and provider networks on health outcomes and health expenditures; we will join to publicly available information on providers.</p>
<input type="checkbox"/> Product
<p>Describe how your research objectives require Product data:</p> <p>N/A</p>

VII. DATA ENHANCEMENTS REQUESTED

State and federal privacy laws limit the release and use of CHIA Data to the minimum amount of data needed to accomplish a specific Project objective.

All-Payer Claims Database data is released in Limited Data Sets (LDS). All Organizations receive the "Core" LDS, but may also request the data enhancements listed below for inclusion in their analyses. Requests for enhancements will be reviewed by CHIA to determine whether each represents the minimum data necessary to complete the specific Project objective.

For a full list of elements in the release (i.e., the core elements and additional elements), please refer to [release layouts, data dictionaries](#) and similar documentation included on CHIA's website.

1. Specify below which enhancements you are requesting in addition to the "Core" LDS, provide your justification for requesting each enhancement.

a. Geographic Subdivisions

ZIP code and state geographic subdivisions are available for Massachusetts residents and providers only. Small population ZIP codes are combined with larger population ZIP codes. One ZIP Code per person (MEID) per year has been assigned based on the ZIP code/state reported in the member eligibility record's earliest submission year month. If the record does not have an MEID, assignment is based on distinct OrgID/Carrier Specific Unique Member ID.

Non-Massachusetts ZIP codes and state codes except for CT, MA, ME, NH, NY, RI, and VT are suppressed.

Select one of the following options.

<input type="checkbox"/> 3-Digit Zip Codes (standard)	<input checked="" type="checkbox"/> 5-Digit Zip Codes***
<p>***If requested, provide justification for requesting 5-Digit Zip Code. Refer to specifics in your methodology:</p> <p>Addresses and ZIP codes will be used to add publicly available information about neighborhood-level social determinants of health / their built environment in order to assess how neighborhood factors impact health. We will use measures from the U.S. Census Bureau and the Center for Disease Control and Prevention, as well as composite measures / descriptors (such as the Social Vulnerability Index, the Childhood Opportunity Index, etc). As many of these measures are generated at Census Geographic Entity levels such as Census Tract or Census Block Group, we will use validated crosswalks to convert them to 5-digit ZIP codes as necessary.</p>	

b. Date Resolution

Select one option from the following options.

<input type="checkbox"/> Year (YYYY) (Standard)	<input type="checkbox"/> Month (YYYYMM) ***	<input checked="" type="checkbox"/> Day (YYYYMMDD) *** [for selected data elements only]
<p>Exact dates and ages in days are needed to assess associations between the timing of healthcare delivery / healthcare utilization and outcomes / outcome timing. This level of nuance is particularly necessary when examining impacts of pre- and perinatal care / exposures. In some of our previous work, for example, we found that for some neonates requiring cardiac surgery, even after adjusting for clinical risk, “for every day later that surgery was performed beyond day of life 3, the odds of major morbidity increased by 47% (range: 23% to 66%, $p < 0.001$) and costs increased by 8% (range: 5% to 11%, $p < 0.001$).”(1) For children who required a type of second cardiac surgery later in infancy, known as stage-2-palliation (S2P), we further showed that “for low- and intermediate-risk infants, performing S2P after age three months was associated with $89\% \pm 3\%$ and $82\% \pm 3\%$ 2-year survival, respectively.”(2). These studies resulted in immediate changes in practice in cardiac surgical scheduling across the United States. We intend to use the dates to look for similar types of patterns across a broader set of conditions and treatments and to use these data to improve care delivery.</p> <p>References:</p> <p>(1) Anderson BR, Ciarleglio AJ, Hayes DA, Quaegebeur JM, Vincent JA, Bacha EA. Earlier arterial switch operation improves outcomes and reduces costs for neonates with transposition of the great arteries. J Am Coll Cardiol. 2014 Feb 11;63(5):481-7.</p> <p>(2) Meza JM, Hickey E, McCrindle B, Blackstone E, Anderson B, Overman D, Kirklin JK, Karamlou T, Caldarone C, Kim R, DeCamp W, Jacobs M, Guleserian K, Jacobs JP, Jaquiss R; Congenital Heart Surgeons’ Society Timing of S2P Working Group. The Optimal Timing of Stage-2-Palliation After the Norwood Operation. Ann Thorac Surg. 2018 Jan;105(1):193-199. doi: 10.1016/j.athoracsur.2017.05.041. Epub 2017 Aug 25. PMID: 28847537; PMCID: PMC6594160.</p>		

c. National Provider Identifier (NPI)

Select one of the following options.

<input type="checkbox"/> Encrypted National Provider Identifiers (standard)	<input checked="" type="checkbox"/> Decrypted National Provider Identifiers***
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***** If requested, provide justification for requesting decrypted National Provider Identifier(s). Refer to specifics in your methodology:**

Provider IDs are needed to assess impacts of healthcare provider characteristics and provider teams on outcomes. Publicly available data on provider demographics, training, work history, etc., will be assessed.

VIII. MEDICAID (MASSHEALTH) DATA

1. Please indicate whether you are seeking Medicaid Data:

☒ Yes

☐ No

2. Federal law (42 USC 1396a(a)7) restricts the use of individually identifiable data of Medicaid recipients to uses that are **directly connected to the administration of the Medicaid program**. If you are requesting MassHealth Data, please describe, in the space below, why your use of the Data meets this requirement. *Your description should focus on how the results of your project could be used by the Executive Office of Health and Human Services in connection with the administering the MassHealth program.* Requests for identifiable MassHealth Data will be forwarded to MassHealth for a determination as to whether the proposed use of the Data is directly connected to the administration of the MassHealth program. CHIA cannot release MassHealth Data without approval from MassHealth. This may introduce significant delays in the receipt of MassHealth Data.

How does the project relate directly to the administration of the Medicaid program?

- MassHealth is currently estimated to cover ~40% of children and pregnant woman residing in the State of Massachusetts. In 2022, The Commonwealth of Massachusetts Executive Office of Health and Human Services, Office of Medicaid released its “Comprehensive Quality Strategy”, in which MassHealth’s stated objective was articulated to be: “To improve the health outcomes of its members and their families by providing access to integrated health care services that sustainably and equitably promote health, well-being, independence, and quality of life.” Our stated objective is the same. We will use these data to assess outcomes, healthcare utilization, and health expenditures / value of care among children and young adults in the State of Massachusetts. We will examine differences in outcomes geographies, neighborhood-level socioeconomic/built environment, patient race/ethnicity, and Medicaid vs. Commercially insured. We will examine both patient-level clinical factors and systems level factors (policy, payer, and provider factors) as potential drivers of outcomes and mediators of healthcare disparities. To disseminate our findings, we will not only publish our results in peer-reviewed journals, but also will work with clinicians in the state to feed back directly to their peers. Further, to the extent to which MassHealth administration would like to partner with us, we would be thrilled to meet with them quarterly or more to share our findings, to listen to their priorities and perspectives, and to continuously align with questions that might be most relevant to MassHealth—given their on-the-ground work—with advancing the quality and equity of care delivery statewide.

What specific Medicaid program, policy, rule or law will be affected or changed based on the outcome of this project?

- Our hope is that our data would assist MassHealth in its oversight of health plan and provider quality and policy impacts. Understanding providers with superior outcomes, for example, can help to educate others as to best practices (Optimal procedure timing/scheduling, as described above, might be one

example of practice pattern variability we have previously assessed that has led to significant improvements in neonatal and infant outcomes after cardiac surgeries). Understanding the impacts of provider networks and teams on outcomes can assist MassHealth both in its selection/oversight of managed care plans and in its guidance to providers on potentially critical aspects of communication and teamwork.

How will MassHealth's objectives be helped by approving this project?

- As described above, our objective is to identify modifiable drivers of health outcomes, healthcare utilization, and health expenditures / value of care. We will not only share all published work with MassHealth, but would also happily meet with MassHealth at least quarterly if desired to better understand their current priorities and questions and to attempt to leverage our methodologic expertise to advance this mission.

Will the results of this research have the potential for:Reducing the costs of the Medicaid Program:

- Yes. Children with poor outcomes tend to have higher healthcare costs than children who do well. Our goal would be to identify targets for intervention that both reduce healthcare spending and improve outcomes (the highest value targets).

Improving access for Recipients:

- Yes. We will look specifically at healthcare access. We will look at access from the prenatal space through transition of care. Further, following the conception of healthcare access articulated by Donabedian in 1973, we will examine which patients, "after gaining access to care, receives greater or lesser qualities of care." We will work with Massachusetts healthcare providers (and MassHealth, as interested), in an attempt to leverage the insights we obtain through our analyses to raise access and quality to/of all care.

Increasing quality of care for recipients:

- Yes. As articulated above, our goal is to identify modifiable ways to improve access and quality.

Describe the project deliverables:

- Drafts of all scientific abstracts and manuscripts will be submitted to MassHealth prior to submission for presentation / publication. We will not only share all published work with MassHealth, but would also happily meet with MassHealth at least quarterly if desired to better understand their current priorities and questions and to attempt to leverage our methodologic expertise to advance this mission.

Describe how MassHealth care use the project deliverables in administration of the MassHealth program:

- We foresee several areas in which MassHealth might use our deliverables. We will use quantitative methods to illuminate potential, modifiable, mediating features of the healthcare system on which MassHealth has influence—providers, provider teams/patient-sharing networks, policies, and plans. Were, for example, we to identify significant differences in outcomes among clinically similar patient populations across Medicaid managed care plans, we might explore managed care plan characteristics associated with these differences. We were to identify specific plan characteristics, MassHealth could

then use these data in contract negotiations, to both direct Medicaid expenditures but also to guide the plans as to how they could modify to improve patient outcomes.

Researchers must provide the following information for MassHealth to determine how the disclosure of identifiable MassHealth claims data is directly related to the administration of the MassHealth program:

- How does the project relate directly to the administration of the Medicaid program?
- What specific Medicaid program, policy, rule or law will be affected or changed based on the outcome of this project?
- How will MassHealth's objectives be helped or impaired by approving this project?
- Will the results of the research have the potential for:
 - reducing cost of the Medicaid program,
 - improving access for recipients, and/or
 - increasing quality of care to recipients?
- Please describe the project deliverables the researchers will provide to MassHealth

Please describe how MassHealth can use the project deliverables in administration of the MassHealth program.

3. Organizations approved to receive Medicaid Data will be required to execute a [Medicaid Acknowledgment of Conditions](#). MassHealth may impose additional requirements on applicants for Medicaid Data as necessary to ensure compliance with federal laws and regulations regarding Medicaid.

IX. DATA LINKAGE

Data linkage involves combining CHIA Data with other data to create a more extensive database for analysis. Data linkage is typically used to link multiple events or characteristics within one database that refer to a single person within CHIA Data.

1. Do you intend to link or merge CHIA Data to other data?

☒ Yes

☐ No linkage or merger with any other data will occur

2. If yes, please indicate below the types of data to which CHIA Data will be linked. [Check all that apply]

☒ Individual Patient Level Data (e.g. disease registries, death data)

☒ Individual Provider Level Data (e.g., American Medical Association Physician Masterfile)

☒ Individual Facility Level Data (e.g., American Hospital Association data)

☒ Aggregate Data (e.g., Census data)

☐ Other (please describe):

3. If yes, describe the dataset(s) to which the CHIA Data will be linked, indicate which CHIA Data elements will be linked and the purpose for each linkage.

To explore the impact of social determinants of health (SDOH) and other neighborhood, policy, payer, healthcare provider / facility characteristics, the APCD will be merged with data sources, such as:

APCD data will be merged with publicly available U.S. Census Bureau and Centers for Disease Control and Prevention data (such as the American Community Survey), and other publicly available composite measures (such as the Social Vulnerability Index, the Childhood Opportunity Index, etc). These data are available either at the ZIP code level or at Geographic Entity levels such as Census Tract or Census Block Group. We will use validated crosswalks to convert them to 5-digit ZIP codes for linkage.

Publicly available healthcare provider, facility, and payer characteristics will be merged to assess to what extent provider, facility, characteristics and insurance status impact outcomes when considering sociodemographics and underlying disease complexity/risk.

APCD data will also be merged with clinical registry data to assess patient- level clinical characteristics and long-term health outcomes. These data are linked to the Center for Disease Control and Prevention's National Death Index which will allow us to examine differences in mortality.

4. If yes, for each proposed linkage above, please describe your method or selected algorithm (e.g., deterministic or probabilistic) for linking each dataset. If you intend to develop a unique algorithm, please describe how it will link each dataset.

Ranked deterministic matching will be used to merge data on indirect patient identifiers. NPIs and ZIP codes will be used to merge 1:1 with provider, facility, and neighborhood characteristics.

5. If yes, attach or provide below a complete listing of the variables from all sources to be included in the final linked analytic file.

The list of variables from the following sources have been attached:

National Death Index

Society of Thoracic Surgeons Congenital Heart Surgery Database

New York State Pediatric Congenital Cardiac Surgery Registry

Examples of publicly available neighborhood characteristics and healthcare provider, facility, and payer characteristics include:

- <https://data.cdc.gov/browse?category=Environmental+Health+%26+Toxicology>
- <https://data.cms.gov/provider-data/dataset/mj5m-pzi6>

6. If yes, please identify the specific steps you will take to prevent the identification of individual patients in the linked dataset.

There is minimal risk to the privacy of the patients. All data will be stored securely following HIPAA guidelines. Merge of APCD data will be done using a secure, encrypted server to ensure the protection of subjects' privacy. Access to sensitive data, stored on server drives or cloud-based shared folders, is strictly limited to authorized personnel. These

servers and platforms require password authentication or are accessible only through a secure VPN, adding an additional layer of security. Data will not be permitted to be stored on local devices or shared outside of the designated research team. The secure server segregates sensitive information from other data to prevent unauthorized access. Cloud-stored files are backed up automatically upon data modification or at regular intervals established by the system administrator. A detailed log of team members who have access to the server is maintained by the PI and the Information Security Team. System privileges and usages are audited automatically at regular intervals by the information security and internal audit teams to ensure ongoing compliance with established security and HIPAA protocols. Only aggregate data will be reported. We will not report any cells with fewer than 11 individuals. Raw data cannot be downloaded to prevent the possibility of indirect re-identification.

1. Do you anticipate that the results of your analysis will be published or made publically available? If so, how do you intend to disseminate the results of the study (e.g.; publication in professional journal, poster presentation, newsletter, web page, seminar, conference, statistical tabulation)? Any and all publication of CHIA Data must comply with CHIA's cell size suppression policy, as set forth in the Data Use Agreement. Please explain how you will ensure that any publications **will not disclose a cell less than 11**, and percentages or other mathematical formulas that result in the display of a cell less than 11.

We intend to disseminate the results of the study via journal publications, poster presentations, seminars, and conferences. All published findings will comply with CHIA's cell suppression policy, ensuring that all frequencies are above 11. When displaying counts by groups with one or more small cells (i.e. race / ethnicity) we will suppress all groups so that frequencies cannot be calculated for individual groups.

2. Describe your plans to use or otherwise disclose CHIA Data, or any Data derived or extracted from such Data, in any paper, report, website, statistical tabulation, seminar, or other setting that is not disseminated to the public.

N/A

3. What will be the lowest geographical level of analysis of data you expect to present for publication or presentation (e.g., state level, city/town level, zip code level, etc.)? Will maps be presented? If so, what methods will be used to ensure that individuals cannot be identified?

Findings will be reported at the state, regional, city/town, or ZIP code levels as appropriate. We will aggregate geographic areas as needed to ensure that we never report frequencies <11 to minimize the possibility of indirect re-identification. Maps will use aggregated data with suppression methods applied, again aggregating data as necessary to ensure that frequencies are >11 to minimize the possibility of indirect re-identification.

4. Will you be using CHIA Data for consulting purposes?

☐ Yes

☒ No

5. Will you be selling standard report products using CHIA Data?

☐ Yes

☒ No

6. Will you be selling a software product using CHIA Data?

☐ Yes

☒ No

7. Will you be using CHIA Data as in input to develop a product (i.e., severity index tool, risk adjustment tool, reference tool, etc.)

☐ Yes

☒ No

8. Will you be reselling CHIA Data in any format not noted above?

☐ Yes

☒ No

If yes, in what format will you be reselling CHIA Data?

Click here to enter text.

9. If you have answered “yes” to questions 5, 6, 7 or 8, please provide the name and a description of the products, software, services, or tools.

Click here to enter text.

10. If you have answered “yes” to questions 5, 6, 7 or 8, what is the fee you will charge for such products, software, services or tools?

Click here to enter text.

X. APPLICANT QUALIFICATIONS

1. Describe your previous experience using claims data. This question should be answered by the primary investigator and any co-investigators who will be using the Data.

The primary investigator and research team have extensive experience analyzing large healthcare datasets, including Medicaid and other claims data. Current research focuses on merging healthcare claims with neighborhood-level social determinants of health, health plan characteristics, clinical registry data, and provider characteristics, and application of biostatistical / econometric modeling to identify modifiable drivers of outcomes, value, and health inequities for children with cardiac disease. We have linked 14 years’ of clinical registry data to New York State Medicaid data, National Death Index Data, provider / facility characteristics, and geocoded social determinants of health data for the purpose of identifying drivers of outcomes, health expenditures, and health inequities for New York Medicaid children and young adults. We previously have extensive experience with the Pediatric Health Information Systems database and HCUP data. Data use will be overseen by the PI, Dr. Brett Anderson, Director of the Center for Child Health Services Research at the Icahn School of Medicine, and Co-I, Dr. Sarah Crook, Epidemiologist and Director of Analytics for the Center for Child Health Services Research at the Icahn School of Medicine.

2. **Resumes/CVs:** When submitting your Application package on IRBNet, include résumés or curricula vitae of the principal investigator and co-investigators. (These attachments will not be posted on the internet.)

XI. USE OF AGENTS AND/OR CONTRACTORS

By signing this Application, the Organization assumes all responsibility for the use, security and maintenance of the CHIA Data by its agents, including but not limited to contractors. The Organization must have a written agreement with the agent or contractor limiting the use of CHIA Data to the use approved under this Application as well as the privacy and security standards set forth in the Data Use Agreement. CHIA Data may not be shared with any third party without prior written consent from CHIA, or an amendment to this Application. CHIA may audit any entity with access to CHIA Data.

Provide the following information for **all** agents and contractors who will have access to the CHIA Data. [*Add agents or contractors as needed.*]

AGENT/CONTRACTOR #1 INFORMATION	
Company Name:	Click here to enter text.
Company Website	Click here to enter text.
Contact Person:	Click here to enter text.
Title:	Click here to enter text.
E-mail Address:	Click here to enter text.
Address, City/Town, State, Zip Code:	Click here to enter text.
Telephone Number:	Click here to enter text.
Term of Contract:	Click here to enter text.

1. Describe the tasks and products assigned to the agent or contractor for this Project and their qualifications for completing the tasks.

Click here to enter text.

2. Describe the Organization's oversight and monitoring of the activities and actions of the agent or contractor for this Project, including how the Organization will ensure the security of the CHIA Data to which the agent or contractor has access.

Click here to enter text.

3. Will the agent or contractor have access to and store the CHIA Data at a location other than the Organization's location, off-site server and/or database?

☐ Yes

☐ No

4. If yes, a separate Data Management Plan **must** be completed by the agent or contractor.

AGENT/CONTRACTOR #1 INFORMATION	
Company Name:	Click here to enter text.
Company Website	Click here to enter text.
Contact Person:	Click here to enter text.
Title:	Click here to enter text.
E-mail Address:	Click here to enter text.
Address, City/Town, State, Zip Code:	Click here to enter text.
Telephone Number:	Click here to enter text.
Term of Contract:	Click here to enter text.

1. Describe the tasks and products assigned to the agent or contractor for this Project and their qualifications for completing the tasks.

Click here to enter text.

2. Describe the Organization's oversight and monitoring of the activities and actions of the agent or contractor for this Project, including how the Organization will ensure the security of the CHIA Data to which the agent or contractor has access.

Click here to enter text.

3. Will the agent or contractor have access to or store the CHIA Data at a location other than the Organization's location, off-site server and/or database?

☐ Yes

☐ No

4. If yes, a separate Data Management Plan **must** be completed by the agent or contractor.

[INSERT A NEW SECTION FOR ADDITIONAL AGENTS/CONTRACTORS AS NEEDED]

XII. ATTESTATION

By submitting this Application, the Organization attests that it is aware of its data use, privacy and security obligations imposed by state and federal law *and* confirms that it is compliant with such use, privacy and security standards. The Organization further agrees and understands that it is solely responsible for any breaches or unauthorized access, disclosure or use of CHIA Data, including, but not limited to, any breach or unauthorized access, disclosure or use by any third party to which it grants access.

Organizations approved to receive CHIA Data will be provided with Data following the payment of applicable fees and upon the execution of a Data Use Agreement requiring the Organization to adhere to processes and procedures designed to prevent unauthorized access, disclosure or use of data.

By my signature below, I attest: (1) to the accuracy of the information provided herein; (2) this research is not funded by a source requiring the release of raw data to that source; (3) that the requested Data is the minimum necessary to accomplish the purposes described herein; (4) that the Organization will meet the data privacy and security requirements described in this Application and supporting documents, and will ensure that any third party with access to the Data meets the data use, privacy and security requirements; and (5) to my authority to bind the Organization.

Signature: (Authorized Signatory for Organization)	 Drag signature image here or delete and physically sign
Printed Name:	Hadijah Vector
Title:	Director, Grants & Contracts Office
Date:	Click here to enter text. 02/12/2025

Attachments:

A completed Application must have the following documents attached to the Application or uploaded separately to IRBNet:

- ☐ 1. IRB approval letter and protocol (if applicable), or research methodology (if protocol is not attached)
- ☐ 2. Data Management Plan (including one for each agent or contractor that will have access to or store the CHIA Data at a location other than the Organization's location, off-site server and/or database);
- ☐ 3. CVs of Investigators (upload to IRBNet)

APPLICATIONS WILL NOT BE REVIEWED UNTIL THEY ARE COMPLETE, INCLUDING ALL ATTACHMENTS.



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