

Massachusetts Division of Health Care Finance and Policy Application for All-Payer Claims Database (APCD) Data

Applications for APCD data must meet the requirements set forth in regulation **114.5 CMR 22.00: Health Care Claims Data Release** and any Administrative Bulletins promulgated under this regulation. The regulation and bulletins are available online at <http://www.mass.gov/eohhs/gov/departments/hcf/regulations.html>. Information provided on pages 1-4 of this application will be posted on the internet for public comment.

A. APPLICANT INFORMATION	
Applicant Name:	Marlene Anderka, ScD, MPH
Title:	Director, Massachusetts Center for Birth Defects Research and Prevention (MCBDRP)
Organization:	Massachusetts Department of Public Health (MDPH)
Project Title:	Surveillance of Congenital Heart Defects (CHDs)
Date of Application:	9/1/2012
Brief Description of Project (240 character limit)	<p>This data request will be used to conduct a preliminary study to assess and explore the potential use of the APCD data for an upcoming grant.</p> <p>The Massachusetts Center for Birth Defects Research and Prevention (MCBDRP) is slated to receive grant funding from CDC to pilot a surveillance system determining the prevalence of individuals with Congenital Heart Defects (CHDs) that grow into adolescent and adulthood, including pregnant women with CHDs, in the state. The grant will allow us to further examine the prevalence, morbidity, mortality, service utilization, and costs associated with CHDs.</p>

B. DATA REQUESTED

1. PUBLIC USE			
File	SINGLE USE* '08 – '09 – '10	REPEATED USE* '08 – '09 – '10	MULTIPLE USE* '08 – '09 – '10
Medical Claims	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Pharmacy Claims	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Dental Claims	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Membership Eligibility	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Provider	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Product	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

2. RESTRICTED USE			
File	SINGLE USE* '08 – '09 – '10	REPEATED USE* '08 – '09 – '10	MULTIPLE USE* '08 – '09 – '10
Medical Claims	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

Pharmacy Claims	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dental Claims	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Membership Eligibility	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Provider	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Product	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

* The Division reserves the right to change proposed “use level” after review of this application.

<p>Definitions:</p> <ul style="list-style-type: none"> • Single Use: Use of the data for a project or study. • Repeated Use: Use of the data as an input to develop a report or product for sale to multiple clients or customers provided that it will NOT disclose APCD data. Examples include: development of a severity index tool, development of a reference tool used to inform multiple consulting engagements where no APCD data is disclosed. • Multiple Use: Use of the data to develop a product or service that will be sold in the marketplace and will disclose APCD data. Examples include: a benchmark report produced by analyzing APCD data, a query tool to ease access to APDC data.
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3. **Filters:** If you are requesting data elements from the Restricted Use dataset, describe any filters you are requesting to use in order to limit your request to the minimum set of records necessary to complete your project. (For example, you may only need individuals whose age is less than 21, claims for hospital services only, or only claims from small group products.)
4. **Restricted data elements:** If you are requesting Data Elements from the Restricted Use dataset, list each restricted data element you are requesting on the attached Data Element List and explain why you need access to EACH Restricted Use data element for your project. Limit your request to the minimum data elements necessary to complete the project and be specific as to how each element relates to your proposed model/analytic plan. Add rows to this table as needed.

Restricted Data Element Name	Restricted Data Element Description	Data File (Medical, Pharmacy, Dental, Eligibility, Provider, Product)	Justification (reason this data element is necessary for your project)
MC018	Admission date	Medical	Needed for analysis to understand service utilization patterns and intensity of services for those with CHDs
MC059	Date of service – From	Medical	Needed for analysis to understand service utilization patterns and intensity of services for those with CHDs
MC060	Date of service – To	Medical	Needed for analysis to understand service utilization patterns and intensity of services for those with CHDs
MC069	Discharge date	Medical	Needed for analysis to understand service utilization patterns and intensity of services for those with CHDs
ME014	Month of Birth	Eligibility	Needed to identify age of CHD cases for

			appropriate calculation of prevalence estimates
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Listing of Public Use fields that will be included the projects proposed analysis:

Public Use Data Element Name	Public Use Data Element Description	Data File	Masked?
ME003	Insurance Type Code/Product	Eligibility	
ME007	Coverage Level Code	Eligibility	
ME013	Member Gender	Eligibility	
ME014	Member Birth Year	Eligibility	
ME016	Member State or Province	Eligibility	
ME021	Race 1	Eligibility	
ME022	Race 2	Eligibility	
ME023	Other Race	Eligibility	
ME024	Hispanic Indicator	Eligibility	
ME025	Ethnicity 1	Eligibility	
ME026	Ethnicity 2	Eligibility	
ME027	Other Ethnicity	Eligibility	
ME028	Primary Insurance Indicator	Eligibility	
ME029	Coverage Type	Eligibility	
ME033	Member language preference	Eligibility	
ME034	Member language preference -Other	Eligibility	
ME001/ME107	Payer / CarrierSpecificUniqueMemberID	Eligibility	X
ME001/ME117	Payer / CarrierSpecificUniqueSubscriberID	Eligibility	X
MC012	Member Gender	Medical	
MC013	Member Birth Year	Medical	
MC015	Member State or Province	Medical	
MC020	Admission Type	Medical	
MC021	Admission Source	Medical	
MC023	Discharge Status	Medical	
MC026	National Service Provider ID	Medical	X
MC032	Service Provider Specialty	Medical	
MC039	Admitting Diagnosis	Medical	
MC041	Principal Diagnosis	Medical	
MC042	Other Diagnosis – 1	Medical	
MC043	Other Diagnosis – 2	Medical	
MC044	Other Diagnosis – 3	Medical	
MC045	Other Diagnosis – 4	Medical	
MC046	Other Diagnosis – 5	Medical	
MC047	Other Diagnosis – 6	Medical	
MC048	Other Diagnosis – 7	Medical	
MC049	Other Diagnosis – 8	Medical	
MC050	Other Diagnosis – 9	Medical	
MC051	Other Diagnosis – 10	Medical	
MC052	Other Diagnosis – 11	Medical	
MC053	Other Diagnosis – 12	Medical	
MC055	Procedure Code	Medical	

Public Use Data Element Name	Public Use Data Element Description	Data File	Masked?
MC056	Procedure Modifier - 1	Medical	
MC057	Procedure Modifier - 2	Medical	
MC058	ICD9-CM Procedure Code	Medical	
MC083	Other ICD-9-CM Procedure Code – 1	Medical	
MC084	Other ICD-9-CM Procedure Code – 2	Medical	
MC085	Other ICD-9-CM Procedure Code – 3	Medical	
MC086	Other ICD-9-CM Procedure Code – 4	Medical	
MC087	Other ICD-9-CM Procedure Code – 5	Medical	
MC088	Other ICD-9-CM Procedure Code – 6	Medical	
MC108	Procedure Modifier - 3	Medical	
MC109	Procedure Modifier - 4	Medical	
MC136	Discharge Diagnosis	Medical	
MC001/MC024	Payer / Service Provider Number	Medical	X
MC001/MC032	Payer / Service Provider Specialty	Medical	X
MC001/MC112	Payer / Referring Provider ID	Medical	X
MC001/MC125	Payer / Attending Provider	Medical	X
PC044	Prescribing Physician First Name	Pharmacy	
PC045	Prescribing Physician Middle Name	Pharmacy	
PC046	Prescribing Physician Last Name	Pharmacy	
PV008	Last Name	Provider	
PV009	First Name	Provider	
PV010	Middle Initial	Provider	
PV018	City Name	Provider	
PV019	State Code	Provider	
PV021	Zip Code	Provider	
PV029	Provider Type Code	Provider	
PV030	Primary Specialty Code	Provider	
PV042	Secondary Specialty2 Code	Provider	
PV043	Secondary Specialty3 Code	Provider	
PV044	Secondary Specialty4 Code	Provider	
PV055	PCP Flag	Provider	

C. PURPOSE AND INTENDED USE

1. Please describe the purpose of your project and how you will use the APCD.

This request is intended to pilot an analysis of the APCD data in preparation for larger projects in the future. Our intention is to identify adults and adolescents with CHDs to better understand the prevalence, related co-morbidities, the scope and any potential disparities in healthcare utilization for the treatment of this disease. Requested variables will serve the purposes of identifying cases in the three groups specified in the attached methodology, understanding disparities in service utilization (demographics drawn from *Eligibility* and *Claims* data), understanding utilization and co-morbidities associated with these cases (*Medical*, *Pharmacy*, and *Provider* data), and de-duplicating claims data to allow for an accurate count of unique cases (masked member ID and payer ID variables).

In the future, we intend to use this pilot to contribute to a CDC-funded collaborative project with two large adult CHD clinical programs and a hospital-based malformation surveillance program to

more fully understand how healthcare resources are used and develop and implement a pilot surveillance system for CHDs among adolescents and adults in MA.

2. Please explain why completing your project is in the public interest.

CHDs are the most common type of structural birth defects and the most common birth defect type in the United States (US)—affecting approximately 81 per 1,000 live born children—yet we know little about the prevalence, health service needs, and morbidity/mortality beyond childhood. Advances in pediatric cardiology and cardiac surgery have led to improved survival, with 85% or more of patients surviving through adulthood. Additionally, while there are no CHDs registries, about 1/2 to 1/3 of surviving adults are expected to have moderately or highly complex disease. This project allows the first steps in developing prevalence estimates of adolescent and adult populations that have a previously fatal medical condition. There are broad public health concerns regarding building a successful healthcare system for this emerging population including accessing specialized care, tracking and improving outcomes, providing resources, and addressing disparities in this growing and medically complex group.

It is estimated that there are now more adults with CHDs than exist in the pediatric CHD population. This population presents unique challenges such as long-term effects of pediatric interventions and the interaction of CHDs with adult co-morbidities such as diabetes, pregnancy, and hypertension.

A better understanding of these populations is crucial to the development and evolution of effective systems of care for individuals with CHDs.

3. **Attach** a brief (1-2 pages) description of your research methodology. (This description will not be posted on the internet.)
4. Has your project received approval from your organization's Institutional Review Board (IRB)?
- Yes, and a copy of the approval letter is attached to this application
 - No, the IRB will review the project on _____ Date TBD _____
 - No, this project is not subject to IRB review
 - No, my organization does not have an IRB

D. APPLICANT QUALIFICATIONS

1. Describe your qualifications to perform the research described or accomplish the intended use.

Trained specialists in birth defects surveillance, clinical classification of CHDs, and epidemiology are available from the MA Birth Defects Monitoring Program to work on the project to minimize start-up time. Project personnel will include Dr. Marlene Anderka, the Principal Investigator, who chairs the National Birth Defects Prevention Network (NBDPN) Surveillance Guidelines and Standards

Committee which is in the process of developing national standards for birth defects. The project team will also include Dr. Angela Lin, a clinical geneticist trained in pediatric cardiology. Though Dr. Lin will not have direct access to the data, she has been instrumental in defining CHD classifications for the CDC's National Birth Defects Prevention Study (in which the MCBDRP participates) which have been used in the Brigham and Women's Active Malformation Surveillance Program since 1997. Dr. Lin also serves as the clinical geneticist consultant to the MA Birth Defects Monitoring Program which provides consistency and continuity in the clinical review of CHDs.

As a Center for Birth Defects Research and Prevention since 1997, MA has participated as a research partner to the CDC in the multi-center National Birth Defects Prevention Study.

- Describe the software you plan to use to analyze the data and the experience that the applicant's team members have in using that software.

The primary means for data analysis will be Microsoft Access and SAS 9.2. The MA BDMP employs a number of epidemiologists, with many years of experience in epidemiologic and biostatistics research. All have extensive SAS programming expertise and prior experience in the area of birth defects.

- Attach résumés or curriculum vitae of the applicant/principal investigator, key contributors, and of all individuals who will have access to the data. (These attachments will not be posted on the internet.)

- Marlene Anderka (applicant, PI)
- Rebecca Liberman, Kelly Getz, Chris Borger (analysts)

E. DATA LINKAGE AND FURTHER DATA ABSTRACTION

- Does your project require linking the APCD to another dataset?
 YES NO
- If yes, will the APCD be linked to other patient level data or with aggregate data (e.g. Census data)?
 Patient Level Data Aggregate Data
- If yes, please identify all linkages proposed and explain the reasons(s) that the linkage is necessary to accomplish the purpose of the project.
- If yes, specify the specific steps you will take to prevent the identification of individual patients in the linked dataset.

F. RE-RELEASE OF DATA

Applicants must obtain prior approval from the Division to publish reports that use APCD files. Applicants must provide the Division with a copy of any report at least 30 days prior to release to outside parties, including peer review and prepublication analysis by anyone other than the individuals named in this Application. The Division will review the report to ensure that the publication will not permit identification of an individual patient or permit identification of a specific payment by individual payer. The Division may prohibit release of reports that may permit identification of individual patients or specific payment by individual payer.

1. Describe your plans to publish or otherwise disclose any APCD data elements, or any data derived or extracted from such data, in any paper, report, website, statistical tabulation, or similar document.

The primary purpose of this project is to arrive at prevalence estimates for adolescents and adults with CHDs in MA and the associated utilization of health care services. Any release of results will be limited to aggregated prevalence and utilization figures. Being a pilot analysis of the APCD data, there is a slight possibility of the publication of aggregated results in medical and/or epidemiologic journals. These aggregated results may also be shared with collaborators in the subsequent CDC grant, when funded. We will adhere to all APCD suppression rules.

2. Will the results of your analysis be publicly available to any interested party? Will you charge a fee for the reports or analysis? Please describe how an interested party will obtain your analysis and, if applicable, the amount of the fee.

Aggregate results may be included in manuscript submission to medical and/or epidemiologic journals. No fees will be involved. We will adhere to all APCD suppression rules.

3. Will you use the data for consulting purposes?

YES NO

4. Will you be selling standard report products using the data?

YES NO

5. Will you be selling a software product using the data?

YES NO

6. If you have answered "yes" to questions 3, 4 or 5, please (i) describe the types of products, services or studies; (ii) estimate the number and types of clients for which the data will be used and (iii) describe any rerelease of data by your clients.

G. USE OF AGENTS OR CONTRACTORS

Third-Party Vendors. Provide the following information for all agents and contractors who will work with the APCD data.

Company Name:	
Contact Person:	
Title:	
Address:	
Telephone Number:	
Fax Number:	
E-mail Address:	
Organization Website:	

1. Will the agent/contractor have access to the data at a location other than your location or in an off-site server and/or database?

YES NO

2. Describe the tasks and products assigned to this agent or contractor for this project.

n/a

3. Describe the qualifications of this agent or contractor to perform such tasks or deliver such products.

n/a

4. Describe your oversight and monitoring of the activity and actions of this agent or subcontractor.

n/a