



Connecticut's Health Insurance Marketplace

APCD Privacy, Security, and Confidentiality (PSC) Committee

April 1, 2014

Meeting Agenda

- I. Call to Order and Introductions
- II. Public Comment
- III. Approval of Minutes for the January 23, 2014 Meeting
- IV. Revised Committee Charge Language
- V. Legal Issues Concerning Data Privacy and Security
- VI. Initial DUA Research Findings and Best Practices
- VII. Next Steps
- VIII. Future Meetings
- IX. Adjournment

IV: Revised Committee Charge Language - Proposed Privacy, Security, and Confidentiality Committee Objectives (Draft)

The overall objective of the Database Privacy, Confidentiality, and Data Security Workgroup is to create effective and transparent policy to ensure ~~PH~~ **individually identifiable information** is properly protected, while maintaining health information needed to improve healthcare quality and efficiency in Connecticut. To this point, the workgroup will focus on the following initiatives:

- Formulation of a review/approval framework for data release to the research and public health community
- Creation of a data accessibility charter to determine use cases and clearance levels for varying levels of data access
- Preparation of a functional data use agreement between Access Health Analytics and future data requesters
- Ongoing development and evaluation of data protection policies to functionally mitigate data breach and re-identification risks
- Identification of legal limits/boundaries of data reporting, e.g., FTC DOJ requirements for price transparency, HIPAA restrictions on cell size requirement for reporting

V: Legal Issues Concerning Data Privacy and Security

- A large volume of questions have surfaced regarding:
 - APCD Entity Status Under HIPAA
 - APCD Compliance with HIPAA
 - Privacy and Security Mandates
 - Data Disclosure and Accessibility Clarifications
- A Privacy and Security Frequently Asked Questions (FAQ) document was circulated to the committee to answer questions received.
- Development of this document iterative and will serve as an informational tool for sub-committee members.
- Our Attorneys have determined that the current APCD legislation limits us to releasing only deidentified data

VI: CMS's Definitions of Deidentified Data and Limited Data Set

There are 18 pieces of information that are not allowed to be included in the Deidentified data.

Similarly, in Limited Data Sets, there are 16 pieces of information on members that are not allowed to be included. The two rows highlighted in yellow means in Limited Data Sets, members' town, zip, city are allowed; secondly, actual date of birth or medical / pharmacy services are allowed.

Other than those two, deidentified and limited data sets are exactly similar!

#	Deidentified Data	Limited Data Set
1	Names	Names
2	State only, allowed 3-digit Zip if >20,000 eligibles	Zip Codes
3	No dates, just Year	Actual dates of events
4	Telephone #	Telephone #
5	Fax #	Fax #
6	Electronic Mail Address	Electronic Mail Address
7	Social Security Number	Social Security Number
8	Medical Record #	Medical Record #
9	Health Plan Beneficiary #	Health Plan Beneficiary #
10	Account #	Account #
11	Certificate/License #	Certificate/License #
12	Vehicle Identifiers, serial number, inc. license plate	Vehicle Identifiers, serial number, inc. license plate
13	Device identifiers and serial #	Device identifiers and serial #
14	Web Universal Resource Locators (URLs)	Web Universal Resource Locators (URLs)
15	Internet Protocol (IP) address #	Internet Protocol (IP) address #
16	Biometric identifiers, inc. finger or voice prints	Biometric identifiers, inc. finger or voice prints
17	Full face photographic images and any comparable images	Full face photographic images and any comparable images
18	Any other unique identifying number, characteristic, or code	Any other unique identifying number, characteristic, or code

VI: Data Governance - Data Security Level

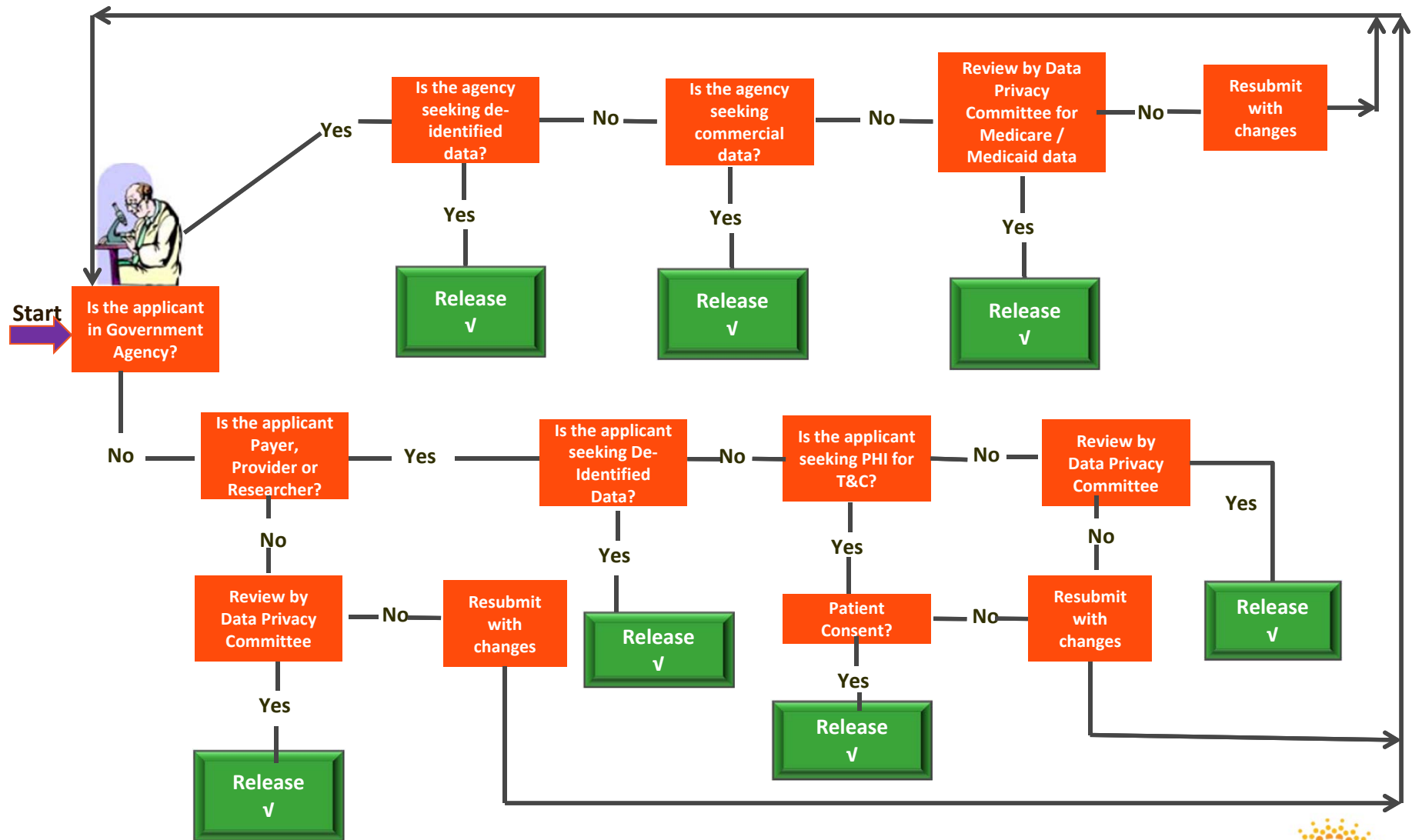
- Level 1 – data with full identifiable information on members
- Level 2 – data with good quality but limited personal information, masked on limited set of identifiable characteristics like name, SS#, address, email, telephone, etc., also called limited data sets
- Level 3 – data with lower level of identifiable than Level 2; include broader zip 3, target other identifiable variables like dates for admission, etc.
- Level 4 – de-identified with personal information and also other HIPAA sensitive data; can be shared with public
- Level 5 – aggregate data with very no personal information



VI: DUA Research Findings from Other State APCDs

- Data Use Agreements (DUAs) are required in most of the APCDs for the following data sets:
 - Deidentified
 - Limited Data Set
 - PHI data
- Reasons for implementing DUAs are the following:
 - Define terms and conditions for data disclosure and data use
 - Define terms and conditions of data use between APCD and receiving entity
 - Protects disclosure of direct patient identifiers or reidentification of members
 - Establishes definitional clarity around eligible data recipients / entities
 - Identifies custodian of data receiving entity and its accountability
 - Defines terms of conditions of data misuse
 - Defines data disposal and/or return policies and procedures

VI: Massachusetts APCD Data Use Policy



VI: DUA Research Findings/ DRC Overview

Data Review Committee (DRC)

An Aggregate Summary of DRC Practices in MA and CO

- Administrator works with Data Review Committee (DRC) to review data release requests and discuss terms of Data Use Agreements (DUAs).
- DRC is usually created by APCD Administrator by drawing membership from the public, representing a wide group of stakeholders.
- Data requests are evaluated by the DRC and Administrator on whether release of the data is consistent with the statutory purpose of the APCD.
- Data release recommendations are made by DRC to Administrator, but are not binding.
- DUAs are implemented by the APCD Administrator.
- Data release requests are typically made publicly available for commentary.

**Information obtained from the CIVHC's APCD website: <http://civhc.org/All-Payer-Claims-Database/Data-Release-Review-Committee.aspx/> and the CHIA's APCD website: <http://www.mass.gov/chia/researcher/>*

VI: Data Release/DUA Case Study: CIVHC (Colorado's APCD)*

- **Case Study: Center for Improving Value in Health Care (CIVHC):**
 - Established in 2008, by the Department of Health Care Policy and Financing, as a public-private entity designed to represent a variety of healthcare stakeholders and perspectives.
 - Dedicated to containing health care costs, improving quality, enhancing consumers' experiences and improving the overall health of the state
 - Transitioned to a stand alone non-profit Colorado corporation in May, 2011.
 - Appointed APCD administrator in August 2010, and received first APCD data on March 31, 2012

**Information obtained from the CIVHC's APCD website: <http://civhc.org/All-Payer-Claims-Database/Data-Release-Review-Committee.aspx/>*

VI: Data Release/DUA Case Study: CIVHC (Colorado's APCD)*

- **CCR 2505-5 Allows Release of APCD Data Provided:**
 1. HIPAA privacy and security requirements are strictly enforced
 2. The purpose of the data request meets the goals of the Triple Aim for Colorado: better health, better care and lower costs.
 3. A multi-stakeholder Data Release Review Committee (DRRC) review requests and advise the APCD administrator whether the request satisfies release criteria

**Information obtained from the CIVHC's APCD website: <http://civhc.org/All-Payer-Claims-Database/Data-Release-Review-Committee.aspx/>*

VI: Data Release/DUA Case Study: CIVHC (Colorado's APCD)*

Data Release Process:

- Data requesters are advised to:
 1. Review the CIVHC Data Release Policies and Resources to understand available data components and processes.
 2. Complete and return to CIVHC:
 - a) Pre-Application Form – indicating high level project detail and data needs
 - b) Data Element Request Sheet – Indicates data element, PHI level, and request status
 3. Requester is contacted by CIVHC team with details on:
 - a) Cost estimates
 - b) Estimated time to complete
 - c) Directions for additional application requirements
 - d) Further clarification of request questions
 4. Applications are evaluated by the Data Release Review Committee (DRRC) monthly. Approval or decline of application is decided by DRRC.

**Information obtained from the CIVHC's APCD website: <http://civhc.org/All-Payer-Claims-Database/Data-Release-Review-Committee.aspx/>*

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Data Release and Data Use Agreement Materials:

1. Data Release Applications and DUA:

- a) **Pre-Application** – Data request triage document intended to facilitate communication between administrator and requester, and determine level of data requested.
- b) **Custom Report or De-Identified Data Set Application** – Application containing questions regarding project description, requested data elements, filters, applicant need for counts, aggregate totals and data linkages, and data management and governance plans.
- c) **Limited Data Set or Identifiable Information Application** – Application containing questions regarding funding sources, request for privacy board approval, and rigorous data management audits, in addition to the topics highlight 1.b.
- d) **Data Use Agreement** – “addresses the conditions under which the APCD Administrator will disclose and the Receiving Organization may obtain, use, reuse, and disclose the APCD data file(s) or reports specified in this Agreement and/or any derivative file(s) (collectively, the “Data” or “APCD Data”)”

**Information obtained from the CIVHC's APCD website: <http://civhc.org/All-Payer-Claims-Database/Data-Release-Review-Committee.aspx/>*

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Data Release and Data Use Agreement Materials:

2. Data Release Resources and Policies:

- a) **Data Release Review Committee Policies and Procedures** – A framework for response to requests for APCD data and reports.
- b) **Data Release Review Committee Criteria for Release of Data** – DRRC operates under a criteria based methodology, this document outlines the criteria through which the committee evaluates requests.
- c) **Data Release Overview of Legal and Regulatory Issues** - Provides an overview of Colorado APCD data release policies from a legal and regulatory perspective
- d) **Data Release Review Committee Members** – Publicly available list of DRRC members, their organization affiliation and title, and industry affiliation.

**Information obtained from the CIVHC's APCD website: <http://civhc.org/All-Payer-Claims-Database/Data-Release-Review-Committee.aspx/>*

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Data Release and Data Use Agreement Materials:

3. Data Release FAQs and Information Guides:

- a) **APCD Privacy, Security and Data Release Fact Guide – FAQ**
regarding data release, privacy, and security.

- b) **Payer/Provider Guide to CO APCD Data Release and Licensing Model** – A guide intended for the payer/provider community outlining CIVHC’s data release policy.

**Information obtained from the CIVHC’s APCD website: <http://civhc.org/All-Payer-Claims-Database/Data-Release-Review-Committee.aspx/>*