



Data Privacy and Security Subcommittee Meeting




January 8, 2015

Presentation Overview

- Approval of April 1 and June 26, 2014, Meeting Minutes
- Chairperson's Update
- Broad Outline of Data Governance Process
- Develop Data Disclosure Policy & Procedure
- Straw-man Model for Data Disclosure
 - Data Release Application (DRA)
 - Data Review and Release Committee (DRRC)
 - Develop Data Use Agreement (DUA)
 - Determine data distribution fees schedule
- Next Steps

Outline of Data Governance

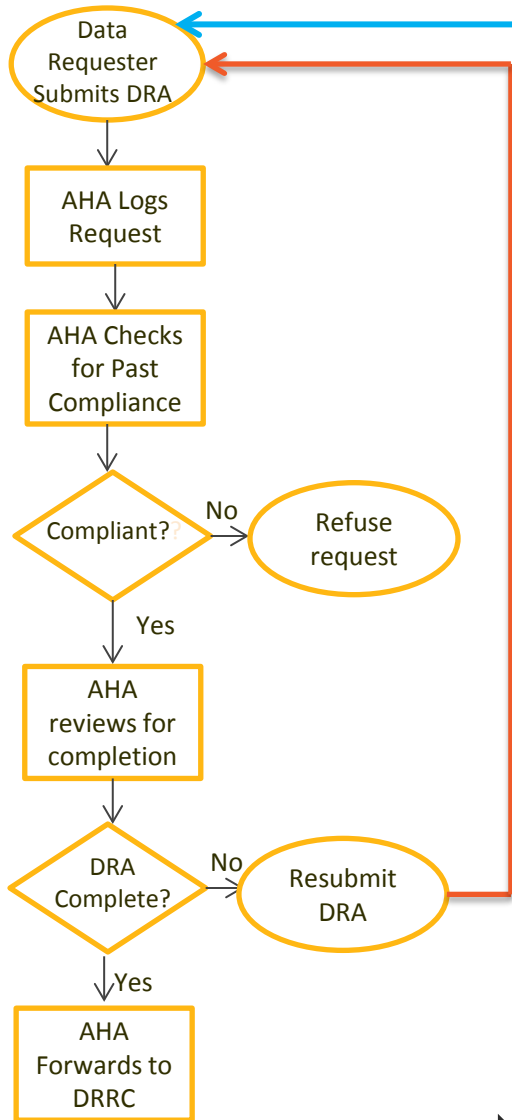
Policy and Procedures document cite a number of data governance issues, referenced below.

- Data Collection - legislation mandates data collection from commercial payers 
- Data Management & Security - legislation enables Access Health Analytics (AHA) to manage All-Payer Claims Database (APCD); AHA ensures best practices in security and privacy are implemented and maintained 
- Data Reporting - legislation objective is to use APCD's data to report on healthcare market trends, costs and utilization which may "...improve efficiency, enhance outcomes and improve understanding of healthcare expenditures in public and private sector." AHA ensures data is reported to public in an appropriate manner 
- Data Disclosure - legislation allows only deidentified data to be released

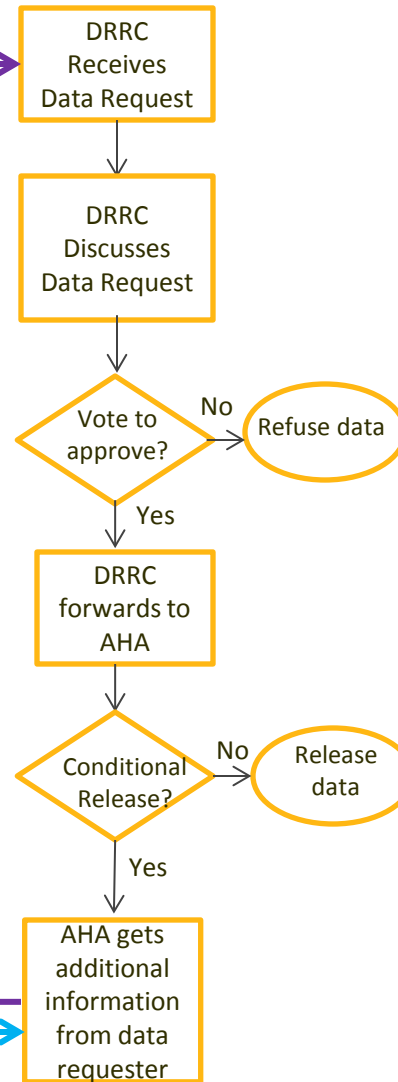
Data Disclosure Highlight

- Data Requesters - academic, private and public (e.g., state agencies) entities
- Data Release Entity - a committee, Data Review & Release Committee (DRRC), will be created which receives, evaluates and approves data requests
- AHA will enter into data use agreement (DUA) with approved data requestors
- AHA will charge a cost for developing data extracts and/or performing research on requestors behalf
- Releasable Data -
 - Only deidentified data, i.e., 18 safe-harbor identifiers suppressed
 - Claims from facilities (inpatient & outpatient), professionals, pharmacy, provider
 - Includes diagnoses, procedures, drug codes, financials, types and places of services

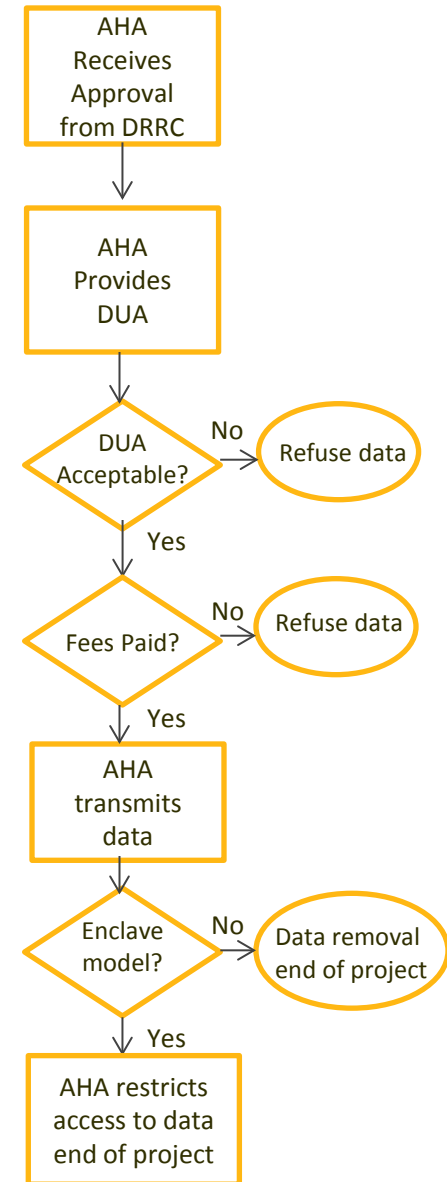
Data Request Application (DRA) Process



Data Review & Release Committee (DRRC) Approval Process



Data Use Agreement (DUA) & Data Release Process



Data Disclosure - Data Request Application (DRA) process

Data Release Criteria -

- Identifying varying levels of data - aggregated vs. detailed claims data
- “Minimum necessary” standard under HIPAA
- Requestors will not be allowed to link with other data sets to minimize reidentification risk
- Requestors will need to provide evidence of infrastructural adequacy
- Requesters will also have to demonstrate -
 - Purpose of the data request
 - Methodology and data elements needed to support research
 - Qualifications of the researcher and/or the institution (s)he belongs to
 - Privacy and security measures to protect the data
 - State how the research will support CT’s objective
 - Requirement that the committee will be given the preview prior to publication
- DRA is the first and foremost process in data release (and disclosure)

Data Disclosure - Data Review and Release Committee (DRRC)

Composition of Data Review and Release Committee (DRRC)

- AHA Administrator will coordinate in identifying & nominating committee members to APCD Advisory Group. The following representations is proposed -
 - Physician organization
 - Hospital organization
 - Academic institution
 - Research & non-profit organization
 - State agency
 - Consumer advocate
 - Employer purchaser
 - Health insurance payer
 - Access Health Analytics

Data Disclosure - Data Review and Release Committee Tasks

- Review data applications received via data request application (DRA)
- Scrutinize applications for consistency in meeting broad strategic objectives -
 - Adherence to meeting the statutory purpose of APCD
 - Addressing research issues for the betterment of health care in Connecticut
- DRRC will review whether the DRA meets the following criteria -
 - Data requirements – types of data, span of time, fields requested
 - Risk of Reidentification – scrutinize possibility that researcher can reidentify members from a deidentified data set
 - Security – applicant’s ability to secure data in compliance with NIST and HIPAA standards
 - Commercial use – allowing data to be used to construct product for commercial use (need to formulate types of data uses)
 - Methodology conforms to acceptable standard and practices in the analytics/research domain

Data Disclosure - Data Review and Release Committee (DRRC) Tasks

- DRRC will treat each Data Request Application (DRA) as confidential and proprietary information
- DRRC members must receive DRA and supporting materials at least 15 days in advance of a DRRC meeting
- If DRRC members require additional clarifications, it needs to be communicated to the Administrator at least 5 days prior to the meeting
- If DRRC requires additional information to make a determination for a DRA, it can advise the Administrator on the following:
 - In case of minor deficiency, the DRRC may issue conditional recommendation for approval pending submission of supplemental information, or
 - In case of major deficiency, the DRRC will require supplemental information to be considered at the next regular meeting
- DRRC members must be present in person or via teleconference
- Majority of votes will determine approval of a DRA

Data Disclosure - Data Review and Release Committee Tasks

- DRRC members cannot delegate authority to designees
- DRRC member will recuse from any discussion of a DRA if he/she has a self-disclosed or discovered financial or other conflict of interest with the applicant(s) immediately upon receiving the DRA
- A DRA will be -
 - Recommended for approval,
 - Recommended with a conditional approval, or
 - Recommended for approval and returned to Administrator with reasons and/or list of deficiencies that must be corrected before reconsidering it as a new request
- DRRC will approve or disapprove based on majority votes of the members present in the meeting; no quorum rule will be applied
- DRRC will meet according to a pre-published schedule posted on the APCD website
- DRRC meetings are not open to the public
- A DRRC meeting will be cancelled if no new application is available for review or complete

Data Disclosure - Data Review and Release Committee (DRRC) Supporting Tasks by Access Health Analytics (AHA)

- Receive requests for data or report via Data Request Application (DRA)
- Maintain a system to enter data or report requests for each DRA
- Administrator will deny applicant's access to data if the latter failed to comply with data use agreement in the past
- Administrator will determine if data or report request is incomplete; upon completion of those deficiencies Administrator will forward DRA and other supporting materials to DRRC
- Administrator will publish name and affiliations of each member in the DRRC in public APCD website
- Administrator shall create a meeting schedule at the beginning of the data review cycle, typically a calendar year, and under special circumstances, convene a meeting with at least 15 days advance notice

Data Disclosure - Data Review and Release Committee (DRRC) Supporting Tasks by Access Health Analytics (AHA)

- Administrator must receive DRA 30 calendar days before the DRRC meeting to be considered for its review
- Administrator will provide data application and other related materials to DRRC at least 15 days prior to the meeting for review consideration of a DRA
- Administrator will receive questions, clarifications and other related concerns from DRRC at least 5 days prior to the meeting for review consideration of a DRA
- Administrator shall coordinate identification and nomination of representative(s) with APCD Advisory Group for approval
- AHA will be represented by the Administrator and a subject matter expert as voting members of the DRRC
- Conduct meeting and associated administrative tasks - preparing agenda, materials supporting DRRC's decision making process, provide web-based secured location for on-going decision process, preparing meeting minutes and documenting process for DRRC's decision
- Collection of fees

Data Disclosure - Data Review and Release Committee (DRRC) Supporting Tasks by Access Health Analytics (AHA)

- Communicate with applicant(s) with determinations of their data or report request(s)
- AHA will tally votes to determine approval of a DRA
- Administrator can propose and establish additional requirements as a precondition for data release, to ensure data security and data privacy
- Administrator will publish summary of each approved application on an APCD website within 30 days of approval. Summary will include abstract of the DRA, type of data requested, duration of the study, purpose of the study, benefit of the study in alignment of the APCD statute, primary and secondary researchers' names, organization(s) sponsoring research, and funding source of the research
- Administrator will provide technical assistance regarding data, system, transmission and security
- In the event requester plans to make public research/analysis findings, Administrator will provide review of the completed work prior to publication to ensure compliance with HIPAA reporting requirements

Data Disclosure Process - Data Use Agreement (DUA)

DUA must include the following -

- Ensure that data will be used only for the purpose of the proposed research
- Data recipient must safeguard data by having appropriate administrative, technical and physical capabilities
- Recipient of data agrees to grant access to AHA for site inspecting to ensure compliance
- Recipient of data agrees to the cell suppression policy by HIPAA on any document - manuscript, table, chart, study, report, etc.
- Recipient of data must not reidentify individuals from APCD data
- Recipient of data agrees to provide APCD administrator advanced copy of results derived from APCD data
- Recipient of data must ensure that the data is not used by other(s) not stated in the research proposal and/or used for any other projects, unless approved by DRRC
- Data recipient must assign a person who is accountable for compliance on data security standards and procedures

Data Disclosure Process - Data Use Agreement (DUA)

DUA must include the following -

- Data recipient must provide, on demand by AHA, logs of all data users
- Data recipient must report any unauthorized uses or disclosures of data
- Data recipient will indemnify, defend, and hold AHA harmless from any and all claims, losses, liabilities, damages, judgments, fees, expenses, awards, penalties and costs, etc.
- Data recipient will not use APCD data for anticompetitive or other unlawful purposes
- Data recipient will ensure that their employees, contractors and clients adhere to the requirements of the DUA including signing it
- Data recipient agrees to notify AHA within 30 days of the project completion date, if such date comes before the original last day of data retention period, and agrees to destroy all APCD data

Data Disclosure Process - Data Use Agreement (DUA)

DUA must include the following -

- Data recipient may request an extension by submitting written request to the APCD Administrator if the purpose for the data is same as the original request
- Data recipient or AHA may terminate this agreement at any time upon 30 days written notice; however, even with termination data recipient must submit certificate of data destruction
- Recipient agrees to defray costs of producing the data in advance of data delivery
- Breaches of DUA may constitute enough grounds to
 - Immediate cancellation and return of data to AHA
 - Will result in future denial of any data from APCD
 - May lead to civil action by the AHA, at State and/or Federal level

Next Steps
