

All-Payer Claims Database (APCD) Advisory Group - Special Meeting

NOTICE OF MEETING AND AGENDA

Date: **Thursday, June 4, 2015**

Time: **9:00 a.m. to 11:00 a.m.**

Webinar Link: Click here to join online meeting:
<http://www.mymeetings.com/nc/join.php?sigKey=mymeetings&i=279332022&p=&t=c>

Conference Line: Phone Number: (866) 732-1486
Participant Code: 777801458

Location* Legislative Office Building, Room 1C
300 Capitol Avenue, Hartford, CT 06106

Directions: <http://www.cga.ct.gov/capitolours/directions.htm>

- I. Call to Order and Introductions
- II. Public Comment
- III. Approval of March 4, 2015 Meeting Minutes
- IV. Introduce New APCD Advisory Group Member
- V. CEO / ED Updates
- VI. Overview of APCD Formative Research
- VII. Review of Proposed APCD Website Wireframes
- VIII. Demo of Preliminary Consumer Decision Support Application Wireframes
- IX. Presentation of Proposed Data Security and Privacy Policies and Procedures for Amendments
- X. Next Steps
- XI. Future Meetings
- XII. Adjournment

Webinar Participation Details

I. Conferencing into the meeting:

Phone: (866) 732-1486

Code: 777801458#

II. Joining the Online Webinar:

1. Click the following link to join the webinar now:

<http://www.mymeetings.com/nc/join.php?sigKey=mymeetings&i=279332022&p=&t=c>

2. Enter any required fields.

3. Indicate that you have read the Privacy Policy.

4. Click on Proceed. You will be placed into the webinar at that time.

Webinar Meeting Number: 279332022

****Note regarding Webinar Availability:***

The meeting will be available via webinar, pending WiFi accessibility at the L.O.B.

Public comment of the agenda is limited to two minutes per person and is not to exceed the first 15 minutes of each meeting. A sign-in sheet will be provided.

Access Health CT is pleased to make reasonable accommodations for members of the public who are disabled and wish to attend the meeting. If special arrangements for the meeting are necessary, please notify Christen Orticari at (860) 241-8444. For further information concerning this meeting, please contact Christen Orticari at (860) 241-8444 or Christen.Orticari@ct.gov.

Meeting materials will become available at: www.ct.gov/hix following each meeting.



All Payer Claims Database Advisory Group Special Meeting
Draft Meeting Minutes

Date: Wednesday, March 4, 2015
Time: 9:00 a.m. – 10:30 a.m. EST
Location: Hilton Hartford Hotel, Connecticut Ballroom, Salon C

Members Present

Dr. Tamim Ahmed, Dr. Robert Aseltine, Mary Ellen Breault for Thomas Leonardi, Demian Fontanella for Victoria Veltri (phone), David Guttchen for Ben Barnes (phone), Matthew Katz (phone), James Iacobellis (phone), Kimberly Martone for Jewel Mullen (phone), Michael Michaud for DMHAS, Dean Myshrral for Mark Raymond, Jean Rexford (phone), Dr. Robert Scalettar (phone), Robert Tessier (phone), Dr. Victor Villagra (phone),

Members Absent

James Wadleigh (Acting Chair), Dr. Mary Alice Lee, Joshua Wojcik for Kevin Lembo

Other Participants

Diane Aye (in attendance to represent the Department of Public Health with designee, Kimberly Martone), Phyllis Hyman (in attendance to represent Commissioner Bremby, Department of Social Services), Tyler Kleykamp (in attendance to represent the Office of Policy and Management, with designee David Guttchen), Access Health CT: Robert Blundo, Frank Hoefling, Christen Orticari

I. Call to Order and Introductions

Dr. Tamim Ahmed called the meeting to order at 9:00 a.m. Members introduced themselves.

II. Public Comment

There was no public comment.

III. Approval of February 18, 2015 Meeting Minutes

Dr. Ahmed asked for a motion to approve the February 18 meeting minutes. **Mary Ellen Breault moved to accept the minutes. Matthew Katz seconded. Motion passed.**

IV. CEO/ ED Updates

Dr. Ahmed stated that special meeting was convened, per member request at the February 18 APCD Advisory Group special meeting. The meeting purpose was to amend and approve the proposed APCD Web Reporting Mission Statement, come to an agreement on the member and to review and respond to the reporting inventory and the timeline and approach for development. In addition, he encouraged members to share their thoughts on the report catalogue format, level of detail, and member feedback process.

V. Development of Mission Statement

Dr. Ahmed summarized key points from the enabling legislation and explained how the 11 proposed reports were defined to incorporate strategic direction from the legislative mandate for reporting. He explained how the first 10 reports were designed to satisfy the goals referenced in the legislation. For instance, APCD data was needed for population health and price and quality transparency reporting. Then Dr. Ahmed reviewed the revised version of the amended mission statement for the web report development process. It was modified to reflect feedback received at the February 18 meeting. Members deliberated ways to further clarify the purpose of the mission, as it was to serve as the guiding principles for the report development process in reference to the strategic direction from the legislative mandate. Dr. Robert Aseltine, Robert Tessier, and Matthew Katz proposed changes to amend the mission. **Dr. Robert Scalettar motioned to adopt the Mission Statement for Connecticut APCD Web Reporting as amended. Matthew Katz seconded. Motion passed unanimously without abstention.**

Mission Statement for Connecticut APCD Web Reporting:

The following version was accepted by the APCD Advisory Group as amended. Please note that amendments were marked in the bold text, below.

*The APCD Advisory Group will provide strategic guidance to the Connecticut APCD in identifying web reports that enhances understanding of population health, **provides** price and quality transparency, **provides information on access and utilization of health care**, addresses disparity of care and health care determinants for consumers, state agencies, insurers, employers, health care providers and researchers from academic and research organizations.*

VI. Proposed Report Inventory, Timeline

Dr. Ahmed presented a proposed Report Inventory, which was organized by report purpose, audience, measurement and projected level of effort. Reports were sequenced based on the expertise, time, resources and complexity needed for development. The proposed reporting timeline outlined when each report could be completed given the level of effort required for development. He noted that the reports in yellow boxes fell under the price transparency category while those in peach boxes were more focused on public health matters. Price transparency reports required more time to develop than others as they required significant technical expertise and availability. Members asked for more detail on report specifications. Staff offered to circulate a document explaining the technical terms and definitions behind reports. Robert Blundo added that details about data elements used in reports were available online in the published Data Submission Guide (DSG).

VII. Report Development Process

a. Inputs from Members

Dr. Ahmed thanked members for their feedback and summarized key points from the responses staff received by email. Members discussed reporting purpose statements. Members deliberated reporting priorities, confirmed the first 10 reports for publication and agreed that the fourth report needed for future discussions regarding inclusion/exclusion in the suite. In addition, members deliberated the reassignment of reports to ensure they were appropriately categorized as consumer-focused reports or population health reports. Members commented that five of the reports in the Reporting Suite, not three, merited the nomenclature 'Price/Quality Transparency' reports. Staff made the appropriate report name and re-categorization changes to the Reporting Suite and circulated the revisions after the meeting.

b. Report Inventory Request Form Structure

Dr. Ahmed invited members to submit recommendations and use cases to support the development of the next 10 reports. The **criteria**, outlined below, were suggested as guidelines that may be used when drafting new report recommendations.

- Report Purpose, Goal
- Intended Audience
- Measurement Strategy
- Estimated Level of Effort

- Examples, Citations of existing work

VIII. Next Steps

Dr. Ahmed reiterated the following next steps, based on meeting discussion, decisions and takeaways.

- Dr. Scalettar asked members to review the APCD Manual recently published by the APCD Council. Staff agreed to distribute a copy of the document and post a link to the manual on the APCD Advisory Group Membership [page](#).
- Staff planned to circulate the following materials: (1) the approved Mission Statement for Connecticut APCD Web Reporting, (2) a technical document of report terms, definitions and specifications, and (3) an updated version of the Reporting Suite.
- With reports 11 through 20 not yet defined, Dr. Ahmed encouraged members to send ideas and use cases for additional reports.
- Members expressed interest around the Web Design process. Dr. Ahmed suggested that this topic be addressed at the next meeting.

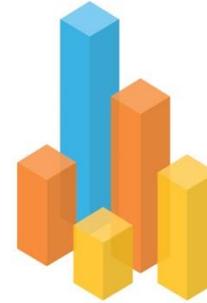
IX. Future Meetings

The next regular meeting of the APCD Advisory Group was scheduled for May 14th from 9:00 to 11:00 a.m.

X. Adjournment

Dr. Ahmed asked for a motion to adjourn the meeting. Mr. Katz motioned. Jean Rexford seconded. Motion passed unanimously. Meeting adjourned at 10:30 a.m.

access health CT
analytics



APCD Advisory Group Meeting

June 4, 2015

Presentation Overview

- Approval of March 4, 2015 Minutes
- Introduce New APCD Advisory Group Member
- CEO/ED Updates
- Communicate Health Presentation:
 - Overview of APCD Formative Research Findings and Preliminary Site Wireframes
- Amtex Presentation:
 - Overview of Consumer Decision Support tool Preliminary Wireframes
- Presentation of Proposed Policies and Procedures for Data Disclosure
- Next Steps
- Future Meetings
- Adjournment

Bernadette M Inskeep, RN BSN

Bernie Inskeep is the National Program Director for the All-Payer Claims Database operations at UnitedHealthcare. She is responsible for coordinating the approach to APCD submissions in all states and ensuring compliance. She is also active in partnering with states as they consider, implement, and create their APCDs.

Bernie actively participates on many APCD technical advisory committees, and is a recognized expert in the APCD space. Previously at UnitedHealthcare, she worked 7 years in compliance and has had many years in operations. Prior to her tenure at UnitedHealthcare, Bernie worked for 10 years as a clinician in several clinical settings including case management, which led to her interest in the business of healthcare. Bernie holds a Bachelors degree in Nursing from Oakland University. When not working, she enjoys traveling, gardening, knitting, and volunteering in her church.

CEO / ED Updates

- On March 4th meeting we discussed the inventory of reports for web-based presentation on the newly designed APCD website (in design phase). We have been working with Onpoint on various aspects of technical and clinical specifications; we have completed approximately 40% of the reports' specifications
- Data disclosure policies and procedures (P&P) are being developed. We held two (2) Data Privacy and Security subcommittee meetings. We are going to propose a set of additional P&P for data disclosure to be included in our current P&P.
- In light of frequent data breaches over the last few months, we have expanded the scope of security audit on our data vendor. We'll need additional 3-month period to complete this task. This will delay the implementation of APCD.
- Our vendor will demonstrate some design concepts (wire frames) for the proposed APCD website. The focus of the design has been to put consumers ahead of other stakeholders based on navigational clarity and easiness
- AHA is developing a Consumer Decision Support (CDS) tool to enable enrollees to select the appropriate metal and plan. More will be discussed at its demo later.

Communicate Health's Presentation

- Overview of APCD Formative Research Findings and Preliminary Site Wireframes

Formative Research and Website Design Update

APCD Advisory Group
June 4, 2015

Submitted by:
CommunicateHealth, Inc.
26 Market Street
Northampton, MA 01060
413.582.0425



Formative Research



Research Activities

- 2 focus groups with Connecticut health care consumers
- **Environmental scan of existing APCD** public websites and other relevant health care or e-commerce comparison tools
- Scan of relevant research on presenting health care cost and quality data to consumers
- Reviewed data from a previous AHA focus group



High Level Findings

- The concept of high-value health care (high quality and low cost) is hard for consumers to understand; many assume that high cost = high quality.
- Consumers are easily overwhelmed when presented with too many options for health care; they are more successful when guided through fewer choices and when information is presented in smaller, accessible chunks.



“The creators who make these things, they have so much information and know all the terminology.

But it has to be simple, easy to read and maneuver, or else [it's] just confusing.”



Recommendations

- Educate consumers on why an APCD is important and what it can do.
 - Explain why it's important to shop for a low cost, high quality facility or procedure.
 - Set expectations from the beginning – make clear that the site is not for finding insurance or user-generated reviews of doctors.



Recommendations

- Create content that consumers care about and can understand
 - Frame health data in a way that is relevant to and useful for consumers using plain language
 - Make sure data are appropriate for consumers – not confusing or worrying (for example, avoiding data related to deaths following a hospital visit)



Recommendations

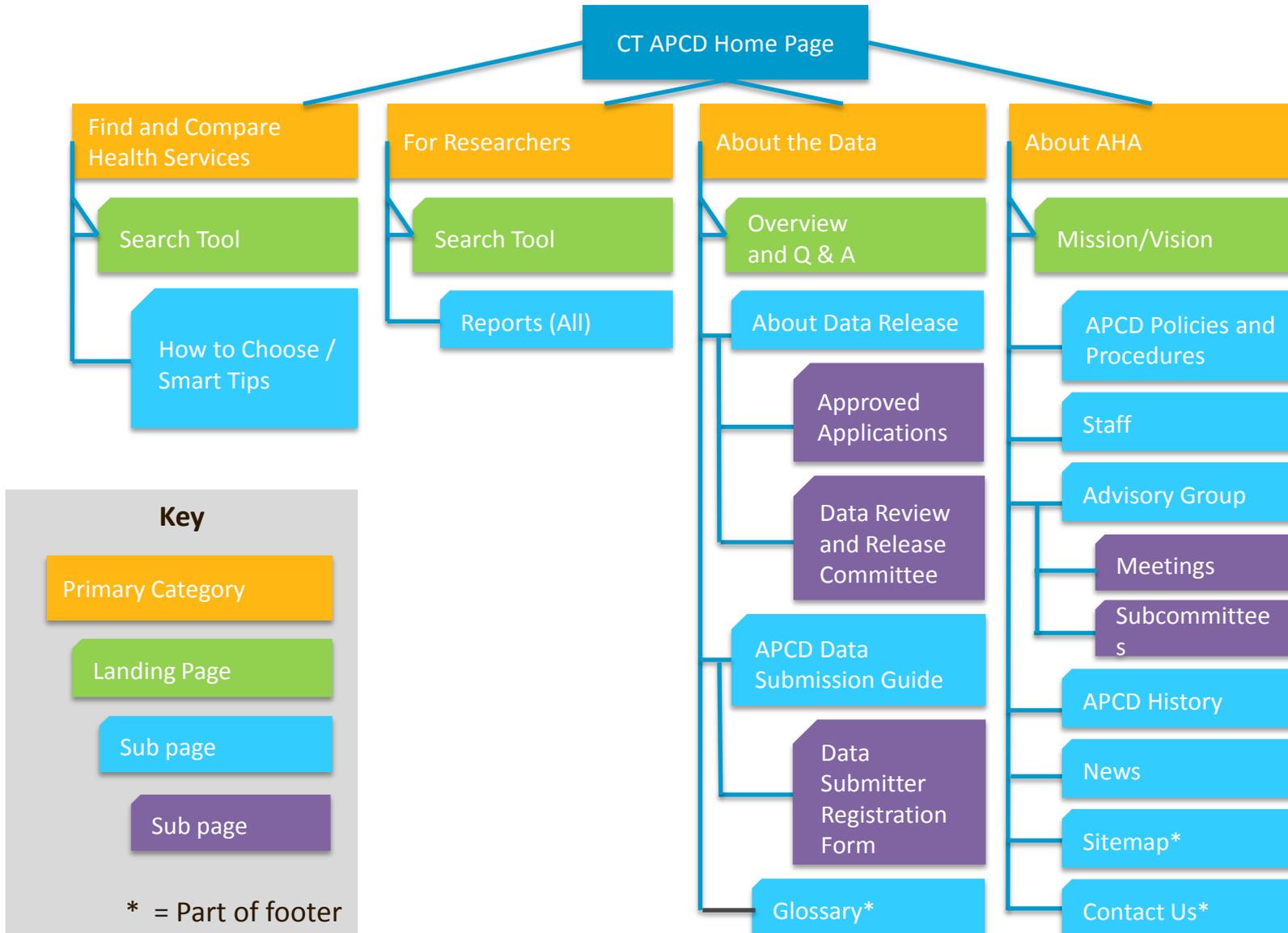
- Keep navigation simple
- Provide additional information at key points for users who want to dig deeper into the data
- Walk users through how the site works – and support them as they make decisions (for example, include a progress indicator that illustrates the process step-by-step)
- Provide a compare feature (so users can compare facilities) and a facility profile feature (so users can learn more about a specific facility) to help people eliminate options and make a decision



Proposed Sitemap



APCD Website Sitemap



Wireframes



Overview

- Wireframes serve as an initial blueprint for the User Interface (UI) by depicting the layout, navigational elements, and interactive components of key screens.
- Wireframes do **not** incorporate look and feel or graphic design elements.
- Wireframes do **not** incorporate final content components.

Site Goals

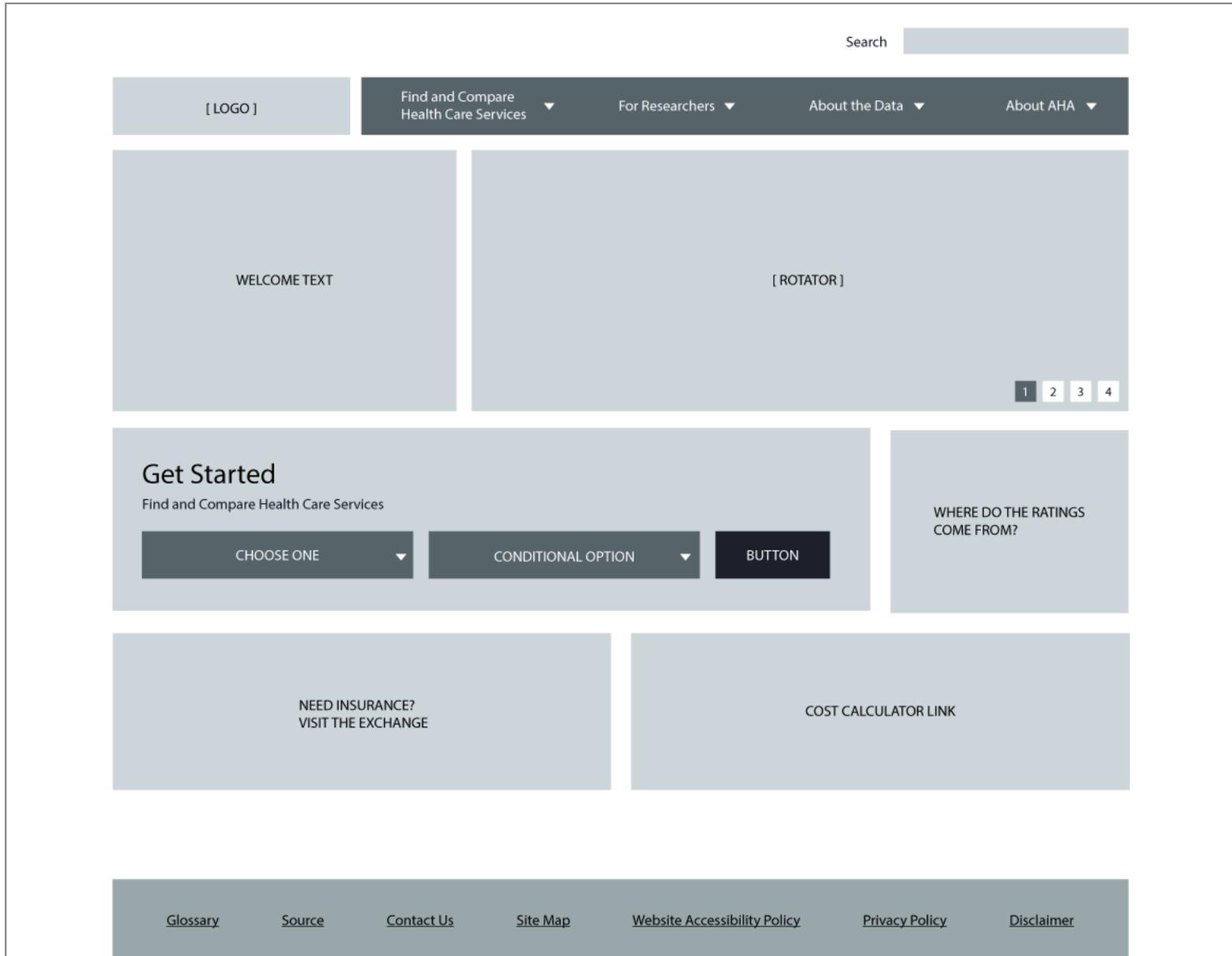
Project goal:

To help people make better decisions about their health care services

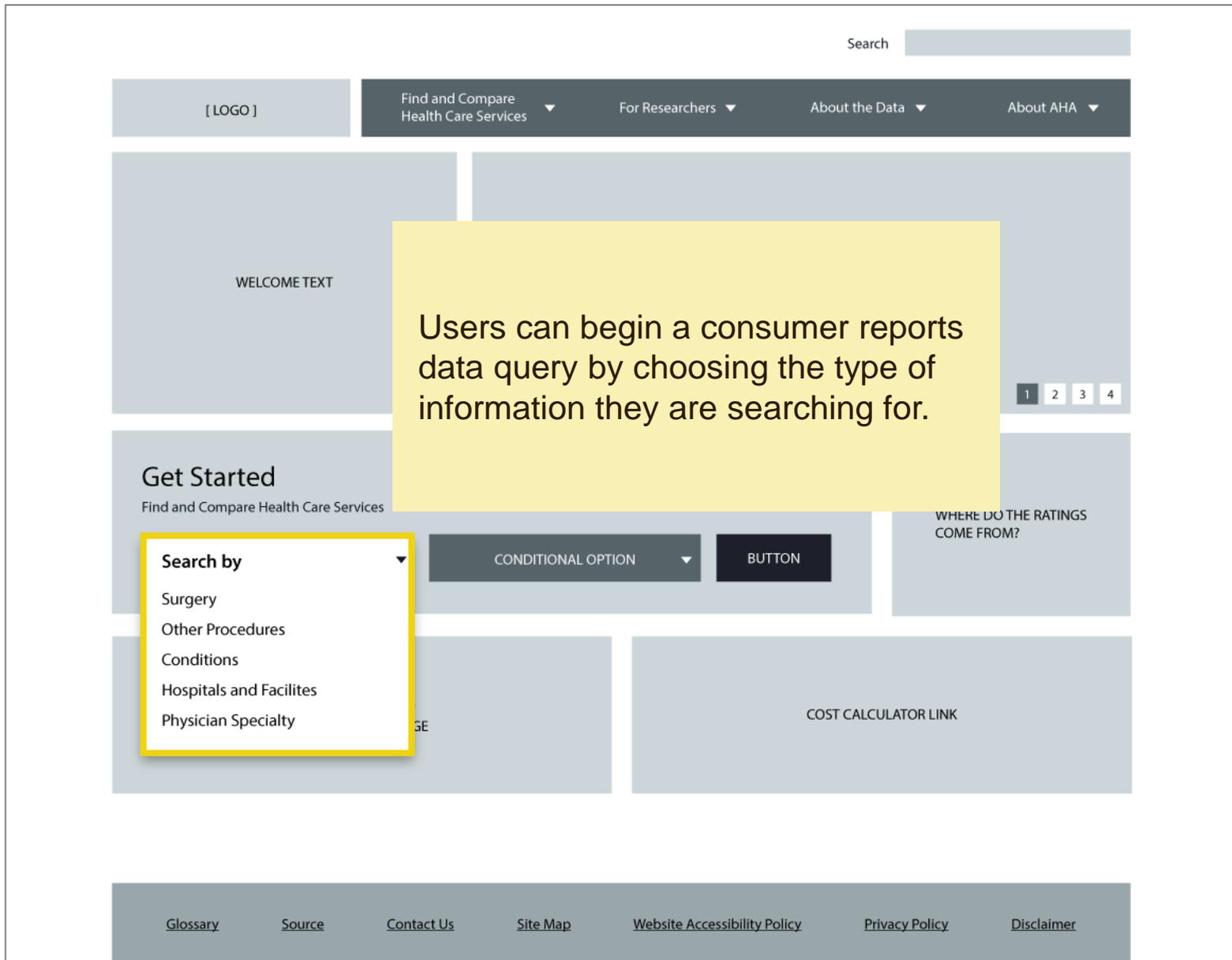
Website goals:

- ① Primary: To enable users, especially consumers, to find and compare low cost, high quality health care facilities and services
- ② Secondary: To give professionals and other users easy access to actionable, accurate CT health care data

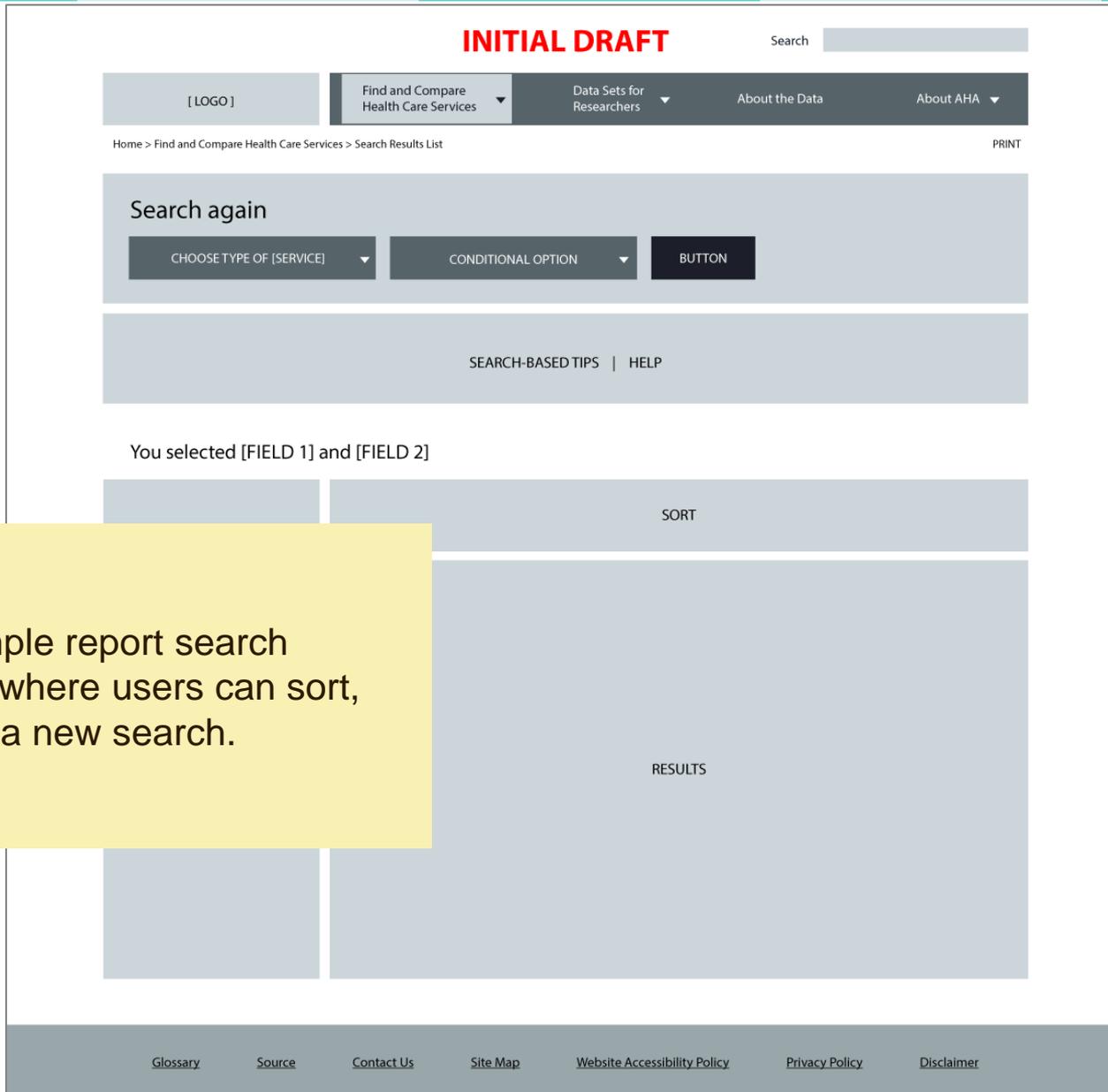
Home Page Option A



Home Page Option A2

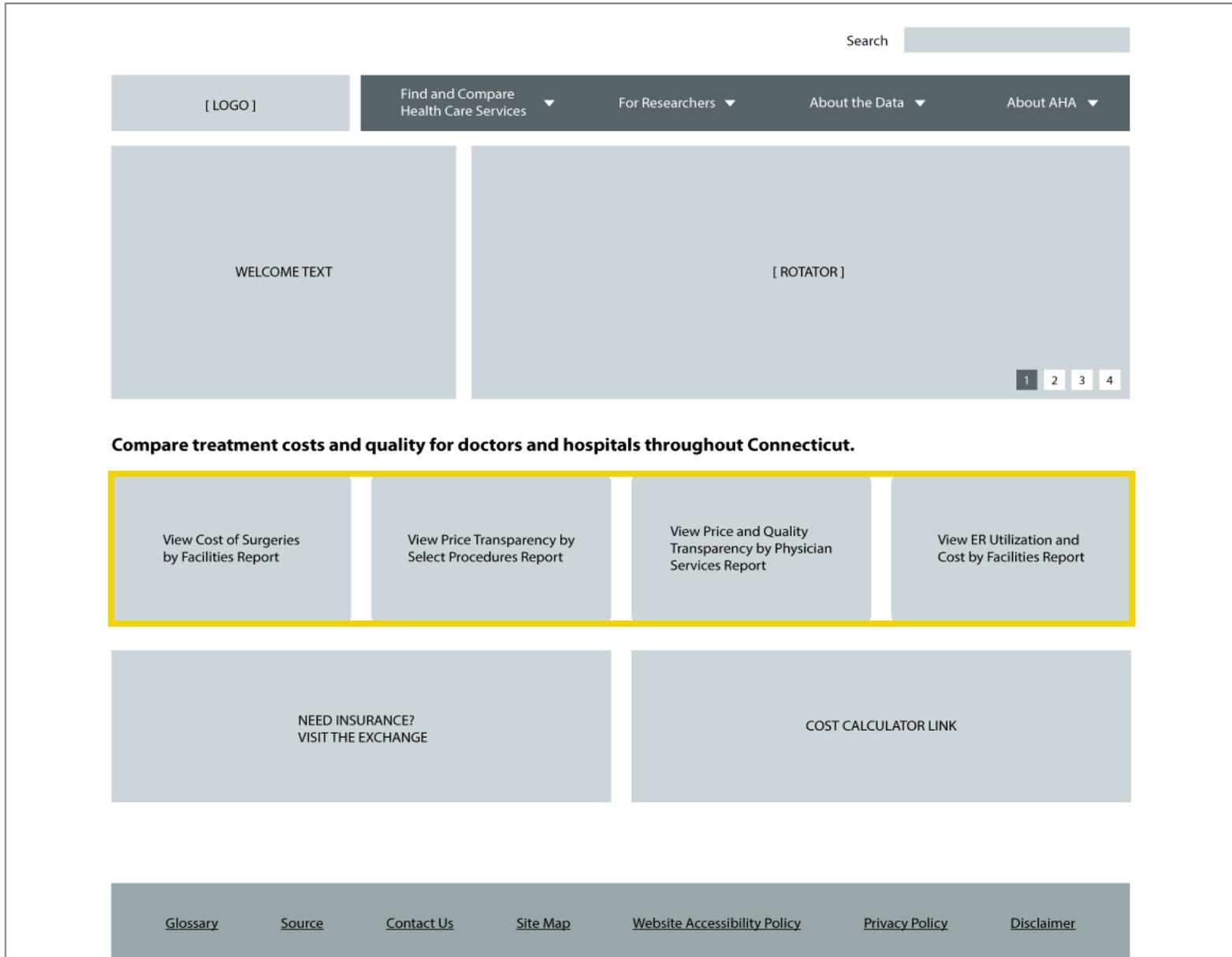


Report Search Results Page



This is a sample report search results page where users can sort, filter, or start a new search.

Home Page Option B



Full Report Page

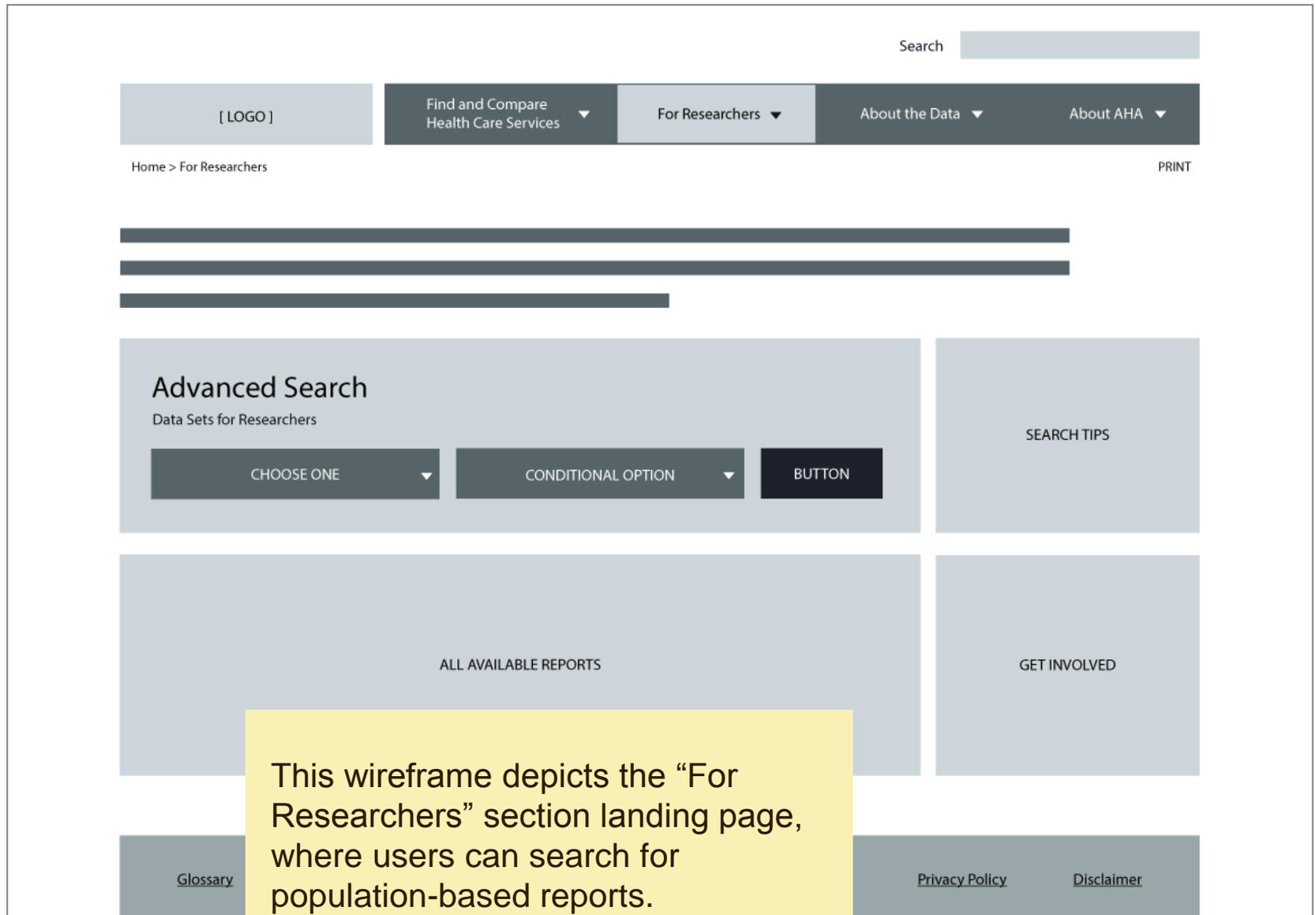
The screenshot shows a web interface for a report. At the top, there is a red banner with the text "INITIAL DRAFT". To the right of this banner is a search bar. Below the banner is a navigation bar with a logo placeholder "[LOGO]", a dropdown menu for "Find and Compare Health Care Services", and links for "For Researchers", "About the Data", and "About AHA". A breadcrumb trail reads "Home > Find and Compare Health Care Services > Cost of Surgeries by Facilities", and a "PRINT" link is on the right. The main heading is "Cost of Surgeries by Facilities", followed by three horizontal bars representing data. Below this is a section for "FILTERING / SORTING TIPS", a "SORT" button, and a large area for "REPORT DATA". The footer contains links for "Glossary", "Source", "Contact Us", "Site Map", "Website Accessibility Policy", "Privacy Policy", and "Disclaimer".

This is a sample full-data set reports page, where users would be directed from Option B of the home page.

For Researchers



For Researchers 1



For Researchers 2

The screenshot shows a website interface for researchers. At the top right is a search bar. Below it is a navigation bar with links: "[LOGO]", "Find and Compare Health Care Services", "For Researchers", "About the Data", and "About AHA". Below the navigation bar is a breadcrumb trail "Home > For Researchers" and a "PRINT" link. The main content area features an "Advanced Search" section with the subtitle "Data Sets for Researchers". A dropdown menu titled "Search by" is open, showing options: "Disease Prevalence", "Insurance Coverage", "Utilization Rates", and "Physician Density". To the right of the dropdown are buttons for "CONDITIONAL OPTION" and "BUTTON". Below these are sections for "ALL AVAILABLE REPORTS" and "GET INVOLVED". At the bottom is a footer with links: "Glossary", "Source", "Contact Us", "Site Map", "Website Accessibility Policy", "Privacy Policy", and "Disclaimer".

Search

[LOGO] Find and Compare Health Care Services For Researchers About the Data About AHA

Home > For Researchers PRINT

Users can begin a population-based reports data query by choosing the type of information they are searching for.

Advanced Search
Data Sets for Researchers

SEARCH TIPS

SEARCH by

- Disease Prevalence
- Insurance Coverage
- Utilization Rates
- Physician Density

CONDITIONAL OPTION BUTTON

ALL AVAILABLE REPORTS GET INVOLVED

Glossary Source Contact Us Site Map Website Accessibility Policy Privacy Policy Disclaimer

Questions?



Amtex's Presentation

- Overview of Consumer Decision Support tool Preliminary Wireframes

Access Health CT

June, 2015

Consumer Decision Support (CDS) Tool

CDS Tool Overview

User Interface Prototype Review

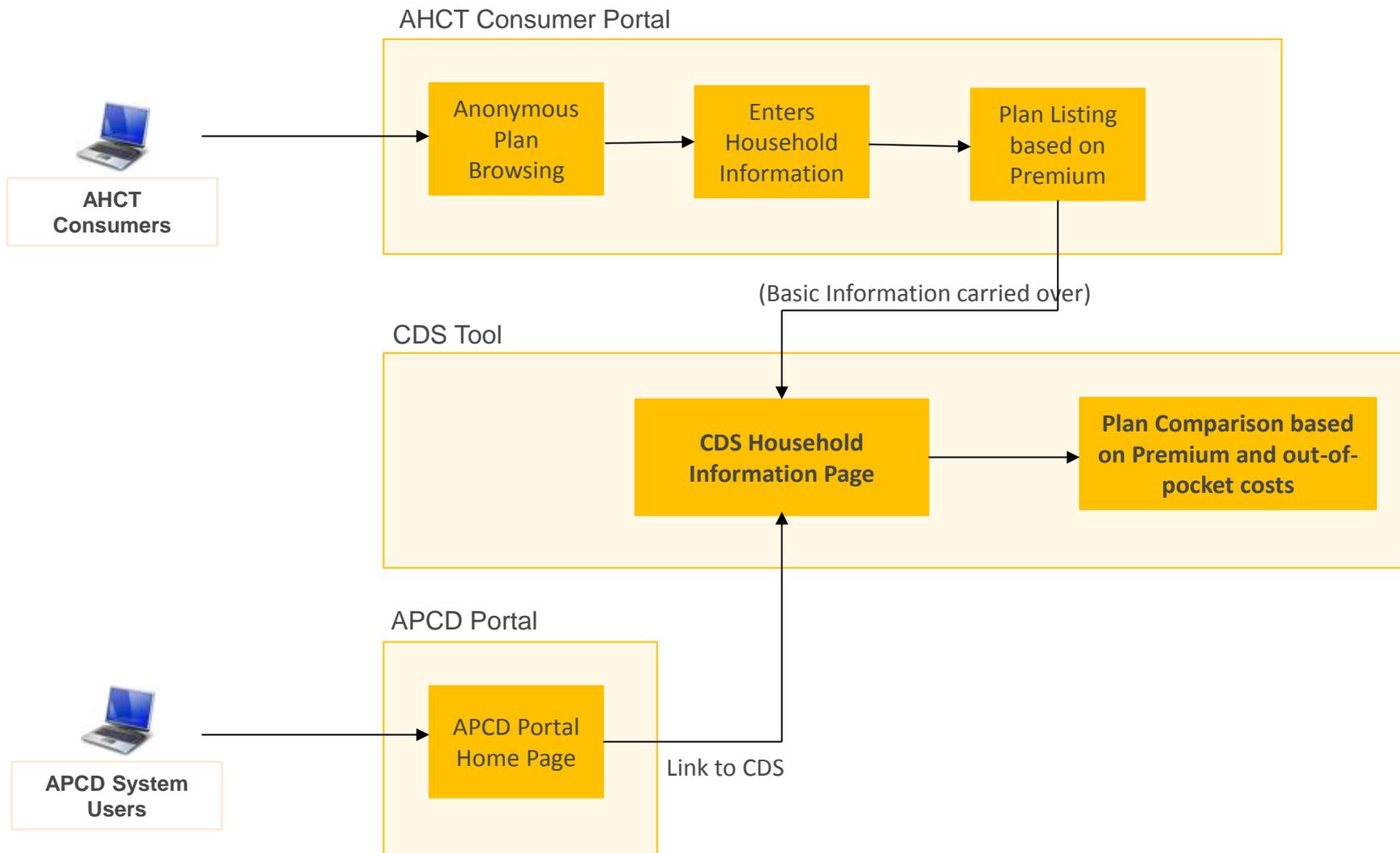
The CDS Tool fills a critical gap in the plan selection process by providing information on total healthcare costs for making more informed choices

- **Enables the Access Health CT consumers to make informed decision to select health plans based on estimated total cost of healthcare**
- **User provides existing health conditions for QHP eligible household members in addition to basic household composition and income**
- **CDS Tool estimates out-of-pocket costs for the health conditions along with premium costs**
 - **Applies QHP / APTC eligibility rules for calculating premium costs**
 - **Uses utilization and unit costs derived from historical claims data**
- **CDS Tool provides tabular and graphical representation of the estimated total costs for the household for various health plans available via Access Health CT**

Access Health CT had previously provided a demo to CID; the following were their feedbacks

- **Medical costs** – enrollees must have clear understanding of medical costs and out-of-pocket costs, and that both are likely to be estimates
- **Strong disclaimer** – provides legal protection
- **Annualize Costs / Premium** – we want to have both options – display it monthly or annually
- **Medicaid/CHIPS suppression** – this application is for QHP population only, but will be able to support projections for split families
- **Carrier-specific information** – will not be used to develop benchmark data
- **Identify other users** who can benefit using this tool to steer enrollees
- **Display Information** – will include both expected medical costs and expected out-of-pocket costs; will not display the lowest cost plan at each metal level explicitly
- **Rounding up numbers** – for expected medical costs and out-of-pocket costs, we'll round up the numbers to the next 5 dollar level, e.g., out-of-pocket costs of \$236.45/month becomes \$240/month
- **Wireframes** – provide wireframe viewing

The CDS Tool will be available from both the APCD Portal and AHCT Consumer Portal



The User Interface (UI) Prototype helps visualize the functionality of the CDS Tool by providing interactive screens with active elements

- **The UI prototype provides interactive wireframes for the system that demonstrate the usage and features of the screens**
- **The screens show visual elements only and do not implement any business logic or the business rules for the system**
- **The main purpose of the UI prototype is to visualize the screen functionality and interaction**
- **Once finalized, we will complete the graphic/artistic design for the system and connect it with business logic to provide the functionality of the CDS Tool**

DRAFT Policies and Procedures for Data Disclosure

- Discussion of the proposed policies and procedures for data disclosure process from APCD

Next Steps

-

Future Meetings

Access Health Analytics

All Payer Claims Database - 2015 Meetings Schedule

All meetings are held on the second Thursday of each month from 9:00 - 11:00 a.m. EST.
(unless otherwise indicated)

*Session - indicates that the meeting will not be held at the LOB due to Legislative Session.

Date	Venue	Venue
February 5, 2015	9:00 - 11:00 AM	Htfd. Hilton
February 18, 2015 [^]	9:00 - 11:00 AM	Htfd. Hilton
March 4, 2015 [^]	9:00 - 11:00 AM	Htfd. Hilton
June 4, 2015 ^{^^}	9:00 - 11:00 AM	LOB
August 13, 2015	9:00 - 11:00 AM	LOB
November 12, 2015	9:00 - 11:00 AM	LOB

[^] Special Meeting

^{^^} May 14 Meeting Moved

Access Health CT

All-Payer Claims Database (APCD) Privacy Policy and Procedure

1. Purpose of Policy.

- a. APCD Legislative Mandate and History. Public Act 13-247 enabled the Exchange's creation of the Connecticut All-Payer Claims Database ("APCD"). Pursuant to Public Act 13-247, various Data Submitters are required to report health care information to the Exchange for inclusion in the APCD. The Act allows the Exchange: (i) to utilize Data collected from Data Submitters to provide health care consumers in Connecticut with information concerning the cost and quality of health care services that allows such consumers to make more informed health care decisions; and (ii) to disclose health information data collected by the APCD to state agencies, insurers, employers, health care providers, consumers, researchers and others for purposes of reviewing such data as it relates to health care utilization, costs or quality of health care services.
- b. Purpose of the Policy. The purpose of this Policy is to ensure the integrity, security and appropriate use of Data collected by the APCD. More specifically, to set forth the process and procedure by which the Exchange will accept, review and evaluate applications from third parties requesting access to the Data collected by the Exchange in a manner consistent with the Act.

2. Definitions.

- a. "*Act*" means Connecticut General Statutes Sections 38a-1090 and 38a-1091, as amended from time to time.
- b. "*Advisory Group*" shall mean the All-Payer Claims Database Advisory Group established pursuant to the Act.
- c. "*APCD*" means the Connecticut All-Payer Claims Database established by the Act and created and maintained by the Exchange.
- d. "*APCD Personnel*" means those Exchange employees, agents and contractors whom the Executive Director permits, in writing, to access Data through the Managed Environment.
- e. "*Applicant*" means an individual or organization that requests access to Data by submitting a Data Release Application to the Executive Director.
- f. "*Applicant Related Party*" means any individual or entity under common ownership or control of an Applicant.

- g. “*Board*” means the Board of Directors of the Exchange constituted pursuant to Public Act No. 11-53 and the Bylaws of the Exchange.
- h. “*Chairperson*” means the member of the Board selected by the Governor of the State to serve as chairperson of the Board in accordance with C.G.S. § 38a-1081.
- i. “*Chief Executive Officer*” means the individual selected by the Board to serve as chief executive officer of the Exchange in accordance with C.G.S. § 38a-1081.
- j. “*Data*” means claim information, including health information, provided to the APCD by Data Submitters.
- k. “*Data Release Application*” means the written application and supporting documentation or other materials an Applicant submits to the Executive Director or the Data Release Working Group in connection with a request to access Data.
- l. “*Data Release Working Group*” means a working group of the Exchange responsible for reviewing and making recommendations to the Executive Director regarding the acceptance or denial of Data Release Applications.
- m. “*Data Submitters*” means: (i) those entities and/or organizations required to report Data to the APCD pursuant to the Act; and (ii) Connecticut state agencies, hospitals, the United States Census Bureau, governmental payers, such as Medicare and Medicaid, and any other third parties who submit Data to the APCD.
- n. “*Data Use Agreement*” means the written agreement entered into by and between an Applicant and the Exchange upon acceptance of the Applicant’s Data Release Application by the Data Release Working Group, which sets forth the obligations and responsibilities of the Applicant with respect to the use of the Data disclosed to it by the Exchange.
- o. “*De-Identified*” means Data from which all eighteen (18) identifiers enumerated at 45 C.F.R. § 164.514(b)(2) have been removed.
- p. “*Executive Director*” means the individual appointed by the Exchange to serve as executive director of the APCD.
- q. “*Exchange*” means The Connecticut Health Insurance Exchange d/b/a “Access Health CT”.

- r. “*HIPAA*” means the Health Insurance Portability and Accountability Act of 1996 and its implementing regulations, each as amended from time to time.
- s. “*Limited Data Set*” means Data from which all sixteen (16) identifiers enumerated 45 C.F.R. § 164.514(e)(2) have been removed.
- t. “*Managed Environment*” means the computer interface by which the Exchange accesses Data.
- u. “*Privacy Officer*” means the individual appointed by the Exchange to have responsibility for the privacy and confidentiality of information maintained by the Exchange.
- v. “*Project*” means the purpose or program for which Data is disclosed to a Recipient.
- w. “*Recipient*” means an Applicant whose Data Release Application has been approved by the Data Release Working Group and which has received Data from the APCD.
- x. “*Recipient Third Party*” means an employee, agent or contractor of a Recipient or any entity or organization to which the Recipient has re-disclosed or made available Data.
- y. “*State*” means the state of Connecticut.
- z. “*Work Product*” means every invention, modification, discovery, design, development, customization, configuration, improvement, process, work of authorship, documentation, formulae, datum, code, technique, reporting logic, know how, secret, or intellectual property right whatsoever or any interest therein (whether patentable or not patentable or registerable under copyright or similar statutes or subject to analogous protection) that is made, conceived, discovered, or reduced to practice by a Recipient or Recipient Third Party.

3. Executive Director.

- a. The Executive Director shall have general oversight responsibility for the privacy, security and access to Data by potential Recipients. In all instances, the Executive Director may delegate functions or responsibilities to other properly qualified Exchange employees, agents or contractors acting in accordance with this Policy.
- b. The Executive Director shall maintain a list of each member of the Data Release Working Group and his or her professional affiliation and shall make such list available to the public on the Exchange’s public-facing

website. The Executive Director shall revise and update such list as necessary.

- c. The Executive Director shall establish a meeting schedule for the Data Release Working Group and communicate that schedule, and any changes thereto, to each member of the Data Release Working Group in a timely manner.

4. Data Release Working Group.

- a. Purpose and Mission. The purpose of the Data Release Working Group shall be to: (i) review, approve and deny Data Release Applications (in accordance with established guidelines) submitted by Applicants for the release of Data; and (ii) provide support to the Executive Director during the receipt and review of Data Release Applications.
- b. Governance.
 - i. Committee Members. The Data Release Working Group shall consist of not less than seven (7) members and shall be composed of at least the following: (i) one (1) member of the Board who is an *ex officio* member of the Board and a representative of a State agency; (ii) an individual with a professional or academic research background involving public health matters; (iii) a representative from the health insurance industry; (iv) an attorney with experience in health care, data privacy or research matters; (v) a health care professional, such as a physician, nurse, social worker or psychologist; (vi) an individual with experience in hospital administration, analytics or research; and (vii) a consumer representative (each a “Member” and collectively the “Members”).
 - ii. Appointment and Removal. Members shall be appointed by and serve at the pleasure of the Chief Executive Officer and Chairperson. When appointing a Member, the Chief Executive Officer and Chairperson shall consider nominations from the Executive Director. The Chief Executive Officer and Chairperson may remove and replace Members at any time in their discretion.
 - iii. Voting Rights. Each Member shall have one vote.
 - iv. Terms. There shall be no term limits with respect to Members.
 - v. Chairperson. The Chief Executive Officer and Chairperson shall designate a Member of the Data Release Working Group to act as chairperson of the Data Release Working Group (“Working Group Chair”), and may designate one or more vice chairs to act only in the

absence of the Working Group Chair. The Working Group Chair (or Vice Chair, in the Working Group Chair's absence) shall preside at meetings of the Working Group.

c. Meetings.

- i. The Data Release Working Group normally shall meet at least quarterly, or more frequently as circumstances dictate, in accordance with a schedule set by the Executive Director. Meetings not scheduled on a regular basis in advance may be called by the Executive Director upon reasonable notice provided such notice is not less than five (5) business days. Members may attend a meeting in person or via teleconference; provided that the Member takes reasonable precautions during such teleconference to ensure the confidentiality of the meeting in accordance with this Policy. The Executive Director reserves the right to cancel any scheduled meeting in the event no Data Release Application is available for review and consideration.
- ii. In order to enhance its ability to fulfill its responsibilities, the Data Release Working Group may invite to its meetings, or communicate with, any member of the Board, any member of the Advisory Group, any employee of the Exchange or such other persons as it deems appropriate for the purpose of securing additional guidance and information.
- iii. All meetings of the Data Release Working Group shall be open to the public. Deliberation of confidential information shall be conducted in executive session in accordance with applicable law.
- iv. In support of the Data Release Working Group's meeting schedule, the Executive Director shall arrange for the preparation of meeting agendas, support materials relevant to the Members' review of Data Release Applications and preparing meeting minutes and circulating such minutes to the Members.

d. Voting.

- i. Voting/Quorum. Four (4) voting Members shall constitute a quorum for the transaction of business, and the vote of a majority of Members present shall be required for the Data Release Working Group to take formal action.
- ii. Recusals/Conflicts of Interest. Each Member shall be free from any relationships or conflicts of interest with respect to an Applicant that may impair, or appear to impair, the Member's ability to make

independent judgments. In the event of any such relationship or conflict of interest, the Member shall disclose such conflict and if necessary, recuse him/herself from any review, discussion or deliberation involving or relating to the Applicant's Data Release Application.

- e. Delegation. The Members shall have no right to delegate any functions or responsibilities hereunder to any third party individual or entity.

5. Use of Data by the Exchange.

a. Access to Data by APCD Personnel.

- i. The APCD Personnel shall be the only individuals permitted to access Data through the Managed Environment.
- ii. All APCD Personnel shall be credentialed in accordance with applicable Exchange policies and procedures prior to being granted access to the Data through the Managed Environment. Access to the Data through the Managed Environment shall be subject to the applicable access authentication and audit report requirements of the Exchange's security program and policies, including but not limited to the use of dual-factor authentication.
- iii. The Executive Director shall review the list of APCD Personnel permitted access to Data through the Managed Environment at least every three (3) months and shall revise as necessary.
- iv. APCD Personnel shall be required to change their password for accessing the Managed Environment every ninety (90) days. APCD Personnel shall be strictly prohibited from disclosing their access credentials, including password, for the Managed Environment to any other individual or entity.

b. Use of the Managed Environment and Data

- i. APCD Personnel may access Data through the Managed Environment only (i) to review and analyze such Data for purposes of fulfilling the Exchange's mandate under the Act, including but not limited to the preparation of consumer and public-facing reports and analyses, or (ii) for Exchange internal business administration or operations.
- ii. APCD Personnel may not access Data through the Managed Environment, or otherwise use or disclose such Data, for (i) any private or illegal purpose, or (ii) any purpose inconsistent with the Act or this Policy.

- iii. When accessing and using the Managed Environment, APCD Personnel shall: (i) never install any software, application or code in the Managed Environment, unless specific written approval has been provided by the Executive Director; (ii) never link external data with De-identified Data from Managed Environment without prior written approval from the Executive Director; and (iii) not re-identify, or attempt to re-identify, De-identified Data.
 - iv. Except as otherwise set forth herein, all Data accessed through the Managed Environment by APCD Personnel shall be De-Identified. Notwithstanding, the Executive Director may, in his or her discretion, permit designated APCD Personnel to access a Limited Data Set from the Managed Environment. APCD Personnel granted access to a Limited Data Set by the Executive Director shall keep such Limited Data Set strictly confidential and shall not disclose, or provide access to, the Limited Data Set to any other individual, either internal or external to the Exchange, without the prior written consent of the Executive Director.
 - v. The Exchange shall maintain: (i) copies of the Managed Environment output and make such information available for the purpose of conducting security audits; and (ii) Managed Environment access logs.
- c. Disclosure of Data by APCD Personnel.
- i. APCD Personnel may not disclose any Data accessed through the Managed Environment except: (i) as explicitly permitted by this Policy, including but not limited to disclosure after approval of a Data Release Application by the Data Release Working Group; (ii) with the written consent of the Executive Director and after the execution of a written confidentiality agreement between the Exchange and the approved recipient, when such disclosure is reasonably necessary for the Exchange's operations or fulfillment of the purpose of the Act; or (iii) as required by state or federal law, regulation or process and after the execution of a written confidentiality agreement between the Exchange and the recipient.
 - ii. Any third-party vendor engaged by the Exchange to maintain, use or disclose the Data shall comply with all applicable Exchange policies and procedures and shall implement and maintain technical, physical and administrative standards sufficient to protect and ensure the privacy and security of the Data, including but not limited to: (i) the specifications and requirements set forth in applicable State and federal law; (ii) industry standards and best practices regarding the maintenance and security of health care data, including but not

limited to applicable guidance from the National Institutes of Standards and Technology (“NIST”), including but not limited to NIST Special Publication 800-53 Rev 4; (iii) the third-party vendor’s privacy and security policies, procedures and protocols; and (iv) the Exchange’s privacy and security policies, procedures and protocols.

d. Safeguarding Data in the Exchange’s Possession.

- i. All Data in the possession or custody of APCD Personnel shall be maintained on the Exchange’s network and servers. APCD Personnel shall not maintain or store Data on any personal electronic device or on any personal or unapproved remote or cloud storage platform or application.
- ii. All Data shall be maintained in accordance with applicable Exchange security policies, protocols and procedures.

e. Disposal of Data in the Exchange’s Possession.

- i. All Data maintained on electronic media shall be sanitized in accordance with NIST Special Publication 800-88 (“Guidelines for Media Sanitation”), as may be amended or superseded from time to time, and in accordance with Exchange policy and procedure. Such sanitation shall be performed and/or certified by the Exchange’s information technology department.
- ii. All Data maintained in paper format shall be shredded, pulverized or otherwise destroyed in a manner that prevents re-identification or re-assembly of the Data.

6. Data Release Application Process.

- a. Data Release Application. The Exchange shall develop and maintain a Data Release Application. The Executive Director shall retain the right, in his or her sole discretion, to modify the Data Release Application for particular Applicants or Projects; provided such modification is consistent with this Policy and applicable law.
- b. Submission. An Applicant must submit a complete Data Release Application to the Exchange and be willing to be interviewed by the Data Release Working Group.
- c. Data Release Application Processing Fees. The Executive Director shall collect a processing fee for each Data Release Application received and such Data Release Application Processing Fee shall approximate the costs

associated with the process of reviewing the Data Release Application. The Executive Director shall create and publish a fee schedule for such processing fees.

- d. Confidentiality. The Executive Director and the Data Release Working Group shall take reasonable steps and implement reasonable measures to safeguard the confidentiality of the Applicant and the Data Release Application, subject to applicable law.
- e. Data Release Application Review Process.
 - i. Role of Executive Director.
 1. Tasks. Within fifteen (15) calendar days of receipt of a Data Release Application, the Executive Director shall perform the following tasks with respect to his or her review of the Data Release Application:
 - a. Receive Data Release Applications from Applicants.
 - b. Maintain a record of each Data Release Application received.
 - c. Determine if the Data Release Application is complete and the Applicant has provided all information required by the Data Release Application.
 2. Right to reject Data Release Application. The Executive Director may reject a Data Release Application in the event the Executive Director, in his or her sole discretion, determines that the Data Release Application is incomplete.
 3. Right to request additional information. The Executive Director may request additional information or clarification from the Applicant, including but not limited to requesting a meeting with the Applicant.
 4. Submission to Data Release Working Group. Within ten (10) business days of the Executive Director's determination that the Data Release Application is complete, the Executive Director shall submit such Data Release Application to the Data Release Working Group. Any complete Data Release Applications received from the Executive Director fifteen (15) or more days prior to the Data Release Working Group's next scheduled meeting, shall be reviewed and

considered at such next scheduled meeting. Any complete Data Release Applications received from the Executive Director less than fifteen (15) business days prior to the Data Release Working Group's next scheduled meeting shall be reviewed and considered at the meeting following the next scheduled meeting. Such review shall include, but not be limited to, the following:

- a. Determine whether the Data Release Application is consistent with the objectives of the APCD as set forth in the Act;
 - b. Review whether the Applicant would reasonably be able to re-identify the Data provided;
 - c. Determine the adequacy of the Applicant's privacy and security infrastructure and safeguards;
 - d. Any other factor or consideration deemed by the Executive Director or Data Release Working Group to be relevant to the Data Release Application or Project; and
 - e. If the Data Release Application is from a researcher or is otherwise for research purposes, determine whether the research methodology is consistent with established norms and the Data Release Application sets forth a sound research design.
5. Right to request additional information. The Data Release Working Group shall have the right to direct the Executive Director to request additional information, seek clarification from the Applicant or request a meeting with the Applicant. Any such requests shall be communicated to the Executive Director at least five (5) business days prior to the meeting at which the Data Release Application will be considered.
6. Support by Executive Director and Exchange. The Data Release Working Group may seek assistance, guidance and technical advice from the Executive Director or the staff of the Exchange at any time during its review and consideration of a Data Release Application. The Data Release Working Group may also obtain assistance, guidance and technical advice from third parties including but not limited to dataset design professionals, clinicians, health insurance experts,

privacy experts, attorneys and regulatory authorities; provided it does not delegate its responsibilities hereunder.

7. Decisions. Upon completion of its review and consideration of a Data Release Application, the Data Release Working Group may issue one of the following three decisions:

- a. Approval. Approval is to be granted when the Data Release Working Group determines, in its sole discretion, that the Data Release Application satisfies each of the requirements and criteria outlined in this Policy and the Data Release Application.
 - b. Conditional Approval. Conditional approval is to be granted when the Data Release Working Group requires additional information from, or actions by, the Applicant in order to address outstanding issues, and the Data Release Working Group determines, in its sole discretion, that such additional information or actions will (i) adequately address and satisfy any concerns of the Data Release Working Group; and (ii) permit the Data Release Working Group to determine, in its sole discretion, that the Data Release Application satisfies each of the requirements and criteria outlined in this Policy and the Data Release Application.
 - c. Denial. Denial is to be issued when the Data Release Working Group determines, in its sole discretion, that the Data Release Application fails to satisfy one or more requirements or criteria outlined in this Policy or the Data Release Application.
- ii. Veto Authority. The Chief Executive Officer reserves the right to veto any decision of the Data Release Working Group.
 - iii. No Right of Appeal. An Applicant shall have no right to appeal a decision of the Executive Director or the Data Release Working Group.
 - iv. Opportunity for Resubmission of Data Release Application. An Applicant which has submitted a Data Release Application that is subsequently denied may re-submit the Data Release Application for re-consideration; provided that in the event an Applicant or an Applicant Related Party has, in the sole discretion of the Executive Director or Data Release Working Group, previously violated any

term or condition of a Data Use Agreement entered into between the Exchange and such Applicant or Applicant Related Party, the Executive Director may deny such Applicant or Applicant Related Party the opportunity to re-submit an existing, or submit a new, Data Release Application. The Executive Director also has the discretion to deny consideration of a new Data Release Application if upon preliminary review by the Executive Director, the Data Release Application has not materially changed.

7. Release of Data Pursuant to Approved Data Release Applications.

a. Data Use Agreement.

- i. The Executive Director, in consultation with the Exchange and Data Release Working Group, shall develop a template Data Use Agreement. The Data Use Agreement shall, at a minimum, require the Recipient to: (i) ensure that Data will be used and re-disclosed only for purposes of the Project; (ii) adequately safeguard the privacy and security of the Data; (iii) grant the Exchange and its designated agents access to the Recipient's premises for purposes of determining compliance with the Data Use Agreement; (iv) agree to all policies and procedures of the Exchange applicable to the APCD, including those addressing cell suppression and this Policy, as applicable; (v) not re-identify, or seek to re-identify, any Data; (vi) if applicable, provide the Executive Director an advance copy of any research or analysis results, publications or manuscripts to determine whether or not the privacy or security of the Data has been compromised in any way; (vii) assign a person to be responsible for the privacy and security of the Data while in Recipient's possession or control; (viii) maintain logs of all individuals and entities who access, use or receive Data, and make such logs available to the Executive Director upon request; (ix) immediately report any unauthorized use or disclosure of Data; (x) not use Data for any unlawful purpose; (xi) require Recipient Related Parties to agree, in writing, to the requirements, terms and conditions of the Data Use Agreement; (xii) notify the Exchange within thirty (30) calendar days of completion of the Project and either return or destroy all Data in accordance with this Policy; (xiii) during all times during which the Data is in the possession or control of the Recipient or a Recipient Related Party, maintain internal written logs recording (a) the date of each use or disclosure of the Data, (b) the identity of each user or recipient of the Data, and (c) the purpose of such use or disclosure; and (xiv) to the extent permitted by law and principles of sovereign immunity, indemnify, defend and hold the Exchange and the State harmless from any and all claims, losses, liabilities, damages, judgments, fee, expenses, awards, penalties and costs

relating to or arising from the use or disclosure of the Data, or the violation of the Data Use Agreement or any applicable law, by the Recipient or Recipient Related Party. In the event that the Recipient is a State agency, and such indemnification is impermissible under State law, such agency shall be required to assume responsibility for any remediation necessary to protect individuals subject to a Data breach that results in re-identification of the subject of the Data.

- ii. Upon approval or conditional approval of a Data Release Application in accordance with Section 6(e)(7) of this Policy, the Executive Director shall provide a Data Use Agreement to the Applicant for review and execution. The Data Use Agreement provided to the Applicant shall be non-negotiable.
 - iii. In the event the Executive Director determines that the Recipient has violated any term or condition of the Data Use Agreement, the Exchange may do any of the following in its sole discretion: (i) immediately cancel the Data Use Agreement; (ii) require the immediate return or destruction of the Data; (iii) if access to the Data is provided via the Enclave Model, immediately terminate the Recipient's access to the Data; (iv) deny the Recipient access to any further Data from the Exchange; and/or (v) institute legal proceedings against the Recipient.
- b. Form/Manner of Access. The Exchange shall make Data available to a Recipient through one of two models. The Recipient, in consultation with the Exchange, shall select the model most appropriate for the Recipient and its approved Project and shall ensure in either case that the access is secure.
- i. Transmission. The Exchange shall offer a "Transmission Model" of Data access, pursuant to which the Exchange shall collect, format and transmit the Data approved for release by the Data Release Working Group to the Recipient.
 - ii. Enclave Model. The Exchange may offer an "Enclave Model" of Data access, pursuant to which the APCD shall permit Recipients remote access to the Data approved for release by the Data Release Working Group. Pursuant to this model, all Data will reside exclusively on Exchange servers.
- c. De-Identification. All Data released to a Recipient shall be De-Identified prior to release and no key, protocol or other information that may reasonably be used to re-identify the Data shall be provided to the Recipient.

- d. Minimum Necessary. The Exchange shall release only the Data the Executive Director and/or Data Release Working Group, in consultation with the Applicant, determines to be the minimum necessary for the Applicant to conduct the Project.
 - e. Access Fees. The Exchange, in its discretion, may charge fees to Recipients for access to Data through the Transmission or Enclave Models. In the event such fees are charged, the Executive Director shall create and publish a schedule of such access fees and such fees shall approximate the Exchange's associated costs related to such access.
 - f. Posting of Approved Data Release Applications on APCD website. All Data Release Applications approved by the Data Release Working Group shall be identified on a website maintained by the Exchange. The Exchange shall include at least the following information on the website for each approved Data Release Application: (i) Applicant name and contact information; and (ii) description and purpose of Project.
8. Return or Destruction of Data.
- a. Return or Destruction of Data. In the event the Recipient, or any Recipient Related Party, violates any term or condition of the Data Use Agreement entered into by and between the Exchange and the Recipient, or at the end of any Project, the Executive Director may require the Recipient, or any Recipient Related Party, to return to the Exchange or destroy any or all Data in the Recipient's or the Recipient Related Party's possession or control. The Executive Director reserves the right, in his or her sole discretion, to require a particular method and/or schedule of return or destruction.
 - b. Standard of Destruction. All Data maintained on electronic media shall be sanitized in accordance with National Institute of Standards and Technology (NIST) Special Publication 800-88 ("Guidelines for Media Sanitation"), as may be amended or superseded from time to time. All Data maintained in paper format shall be shredded, pulverized or otherwise destroyed in a manner that prevents re-identification or re-assembly of the Data.
 - c. Certification of Return or Destruction. The Executive Director may require, in his or her sole discretion, the Recipient to certify, in writing, that all Data in the Recipient's possession or control, or in the possession or control of any Recipient Related Party, has been returned to the Exchange or destroyed in accordance with this Policy.

9. Ownership of Data and Work Product.

- a. Ownership of Data. Neither a Recipient nor a Recipient Related Party shall have any ownership or property rights or interests in the Data received from the Exchange.
- b. Ownership of Work Product. The Exchange shall not obtain any ownership rights to any Work Product developed or prepared by a Recipient or a Recipient Related Party.
- c. Publications. Recipient may publish, otherwise publicly disclose (collectively, "Publish"; such a Publishing is a "Publication"), or submit for Publication an article, manuscript, abstract, report, poster, presentation, or other material that includes the results of the use of the Data, as would be reasonably required for purposes of Publication in a peer-reviewed scientific journal (such article, manuscript, abstract, report, poster, presentation, or other material, a "Manuscript").
 - i. Not less than thirty (30) days prior to the earlier of Publication or submission for Publication of any Manuscript, Recipient shall provide the Exchange with a copy of the Manuscript. Recipient shall delete any Data or other information or content that the Exchange requests in writing be deleted because of concerns with the privacy or confidentiality of the subjects of the Data.
 - ii. Any Manuscript must comply with HIPAA's cell suppression policy and include only De-Identified Data.
 - iii. Recipient shall publicly acknowledge in any Manuscript the Exchange's contribution of the Data, and Recipient may use the Exchange's name for that purpose.
 - iv. Recipient hereby grants a worldwide, perpetual, royalty-free, and transferrable license in the Manuscript to the Exchange for the limited purpose of allowing the Exchange to post the Manuscript on its public-facing website or otherwise make the Manuscript publically available. In the event Recipient does not have the legal right to grant such license to the Exchange, the Recipient shall reasonably assist the Exchange in obtaining such license, or an equivalent license, from the appropriate individual or entity.

10. Annual Reporting.

- a. The Data Release Working Group shall perform a review and evaluation, at least annually, of the performance of the Data Release Working Group, including reviewing the compliance of the Data Release Working Group

with this Policy. In addition, the Data Release Working Group shall review and reassess, at least annually, the adequacy of this Policy and recommend to the Chief Executive Officer any improvements to this Policy that the Data Release Working Group considers necessary or valuable.

- b. The Data Release Working Group shall submit a report to the Chief Executive Officer, at least annually, outlining the Data Release Working Group's activities, statistics relating to the volume and type of Data Release Applications received, the review and acceptance or rejection of Data Release Applications and the percentage of Applications that did and did not result in Publication.

11. Conflicts.

- a. In the event of any actual or perceived conflict between an Exchange policy or procedure and this Policy, this Policy shall control, except as may be necessary to comply with any applicable law or regulation.
- b. In the event that any law or regulation is enacted or promulgated that is in any way inconsistent with the terms of this Policy or that interferes with the Exchange's obligations hereunder, this Policy shall be deemed to be automatically amended to comply with such law or regulation.

12. Confidentiality.

Notwithstanding anything herein to the contrary, the Exchange and the Data Release Working Group shall comply with all applicable laws and regulations regarding confidentiality, including but not limited to the Connecticut Freedom of Information Act set forth at Connecticut General Statutes Sec. 1-200, *et. seq.*, as may be amended from time to time.