Utah’s APCD & Negative Data Warehouse

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Objectives

• Discuss two unique databases used in Utah
  – APCD and Negative Data Warehouse
• Discuss the process that made them available
  – Utah code, Administrative rules
• Discuss use and impact of each
• Questions
Utah’s All Payer Claims Database (APCD)
Utah’s APCD

- Utah’s All Payer Claims Database includes commercial insurance carriers with 2,500 or more subscribers
  - In Utah, this encompasses 90-95% of insurance plans
- Data that is reported to the APCD:
  - Medical claims
  - Pharmacy claims
  - Lab claims
  - Dental claims
Utah’s APCD

- **Utah Code**
  - Utah Health Code (Title 26), Utah Health Data Authority Act (Chapter 33a)
  - Grants permission to Utah Health Data Committee
    - Housed within the Department of Health as Office of Health Care Statistics (OHCS)

- **Utah Administrative Rule**
  - R428. Health, Center for Health Data, Health Care Statistics
    - Rule R428-15, Health Data Authority Health Insurance Claims Reporting
Utah Administrative Rule

- **R428-15-1. Legal Authority.**
  This rule is promulgated under authority granted in Utah Code Title 26, Chapter 33a and in accordance with the Utah Health Data Plan as adopted in Rule R428-1.

- **R428-15-2. Purpose.**
  This rule establishes requirements for certain entities that pay for health care to submit data to the Utah Department of Health.

  1. Each carrier shall submit health care claims data described in the Data Submission Guide for Claims Data for each covered person where Utah is the covered person's primary residence, regardless of where the services are provided.
  2. Each carrier shall submit data for all fields contained in the Data Submission Guide for Claims Data if the data are available to the carrier. Each carrier shall notify the Office or its designee of any data elements that are required to be reported under this rule, but that are not available to the carrier.
  3. **Each carrier shall submit the health care claims data on a monthly basis.**
  4. Each monthly submission is due no later than the last day of the month following the month in which the carrier adjudicated the claim.
• HIV Surveillance initially used APCD to identify reporting gaps
  • Individuals diagnosed, receiving HIV medical care that have not been reported to surveillance program
  • Individuals incorrectly identified as out of care by HIV surveillance who are actually in care
• Complete an Internal Data Use Agreement to request a dataset from the APCD
• Highly secure, not all requests will be granted
Requesting data from APCD

Utah Department of Health

Utah Health Data Committee

INTERNAL DATA USE AGREEMENT

This agreement permits data collected under the authority of the Utah Health Data Committee (HDC) and maintained by the Utah Department of Health (Department), Office of Health Care Statistics (OHCs) to be used by employees of the State of Utah or contractors performing work on behalf of the State of Utah as permitted by state statute and must be completed before access to such data is granted.

Part A – Required Information for All Data Requests

- Program, Bureau, or Division Requesting Access
- Employee Responsible for the Project
- A List of Persons Who Will Have Access to the Data
- Title of Project
- Purpose for Access/Use
- Total Duration of the Access (An annual review of this agreement is required for projects lasting longer than one year)
- How the Data Will Be Used
- Type and Source of Data Requested
- Location or system where the data will be stored and used

If identified data is needed, please describe the identified data that you need, including a complete list of identified variables and a specific justification for each one. Your description should clearly explain why you cannot use a readily available Public Use Data Set or other data available to the general public.
Part B - Data Use Stipulations

1. The requesting program agrees that the data may only be used for the purposes and by the persons listed in this agreement.
2. The requesting program agrees that they will follow all Utah Department of Health policies regarding the protection of confidential data.
3. The requesting program agrees that employees using the data will complete Department-approved training on HIPAA privacy and security awareness before accessing the data.
4. The requesting program agrees that when the data are no longer needed, the requesting program will properly destroy the data and notify OHCS that this has happened.
5. Each person accessing the data will have a current Confidentiality Pledge on file with OHCS.

Part C. Signatures

Requesting Bureau or Division Director Approval

Signed: ___________________________ Date: ___________________________
Name & Title: _______________________________________________________

Office of Health Care Statistics

Privacy Officer: ___________________________ Date: ___________________________

Director: ___________________________ Date: ___________________________

For Administrative Use

Date Processed: ___________________________
Expiration or Required Review Date: ___________________________

(Requests must be reviewed not longer than one year after the form is signed by the requester.)
Utah’s APCD

• Limitations
  – Cannot use data from APCD for any patient/provider contact
  – No Medicare claims
    • Part A or B
  – Identified data vs de-identified data
    • APCD prefers to give de-identified if possible
    • Surveillance often requires identifiable data
      – Link King requires first name, last name, DoB or SSN
Utah APCD Assessment

- Obtained data set from APCD using:
  - **ICD-9** Codes - HIV Care Visits
  - **CPT** Codes - HIV Viral Load & Genotype lab tests
  - **NDC** Codes for Antiretroviral medications used in HIV Treatment
- APCD data set matched with surveillance data (eHARS)
- 1,692 matches:
  - 1,601 with Link King
  - 91 manually matched
- APCD completeness assessment
  - Total PLWH in Utah: 60% (1,692/2,796)
Preliminary PrEP Assessment

- Of those that didn’t match with eHARS (n=994)
  - 23 perinatal events
  - 74 OOS Residents
  - 546 w/single ARV claims
  - 54 w/ two ARV claims
  - 297 w/multiple ARV claims (3 or more claims)

- Truvada claims
  - 36 Truvada claims among single ARV claims w/no viral load
  - 14 Truvada claims among two ARV claims w/no viral load
  - 73 Truvada claims among multiple ARV claims w/no viral load
  - 123 total Truvada claims indicative of PrEP

- Limitation
  - Assumption that single Truvada prescription without viral load indicates PrEP usage
Special thanks to:

Kristina Larson, MPH
(Former) Utah Department of Health
(Current) Louisiana Department of Health
Utah’s Negative Data Warehouse
Utah’s Negative Data Warehouse

• Why collect negative data?
  – Identify when seroconversion occurs
  – Identify acute cases
  – Determine the denominator of testing to interpret trend data (A true trend or just an increase of testing)
  – Verify cases with positive screening tests, but negative confirmatory tests
  – Reduce investigator time
  – Establish case definition
  – Determine end of infectivity (Tuberculosis)
Utah’s Negative data warehouse

• How did we do this?
  – 2015 Communicable Disease Rule change
  – Worked with state administrative and legal teams
    • Main concern was security
    • Negative data would not be accessible to state/local epidemiologists
    • Identifiable data will be purged at 18 months
  – Worked with infection prevention specialists at hospitals
    • Will not collect negative HIV screening test results
  – Worked with local health officers and nurses
    • Negative cases will not create new cases or add workload
  – Created rules engine
    • Negative data first matched and entered into existing cases OR sent to secured data warehouse
Reporting Negative Results

- **R386-702-4. Electronic reporting of negative results:**
  - (i) **Electronic reporting** shall include negative as well as positive results for the following conditions:
    - (1) Chlamydia
    - (2) Cytomegalovirus (CMV), congenital (see Utah Administrative Rule R398-4-5 and R386-702-4 (2)(b)(i))
    - (3) Gonorrhea
    - (4) Hepatitis A
    - (5) Hepatitis B
    - (6) Hepatitis C, including viral loads
    - (7) **Human Immunodeficiency Virus (HIV), including viral loads and confirmatory tests**
    - (8) Lyme disease
    - (9) Syphilis
    - (10) Tuberculosis
  - (ii) Negative test results reported for these conditions will be used for the following purposes as authorized in Utah Health Code Section 26-1-30(2)(c),(d), and (f):
    - (1) To determine when a previously reported case becomes non-infectious;
    - (2) To identify newly acquired infections through identification of a seroconversion window; or
    - (3) To provide information critical for assignment of a case definition.
  - (iii) Information associated with a negative test result will be retained by the Utah Department of Health for a period of 18 months.
    - (1) At the end of the 18 month period, if the result has not been appended to an existing case, personal identifiers will be stripped and expunged from the result.
(2) The de-identified result will be added to a de-identified, aggregate dataset which will be retained for use by public health to analyze trends associated with testing patterns and case distribution, enabling identification and establishment of prevention and intervention efforts for at-risk populations, and assessment of trends over time in those populations, as authorized by Utah Health Code 26-1-30(2)(f).

(c) Entities reporting electronically shall include all laboratory results (positive, negative, equivocal, indeterminate) associated with the following tests or conditions:

(i) CD4+ T-Lymphocyte tests, regardless of known HIV status;
(ii) Chlamydia; (iii) Clostridium difficile; (iv) Cytomegalovirus (CMV), congenital (infants less than or equal to 12 months of age); (v) Gonorrhea; (vi) Hepatitis A; (vii) Hepatitis B; (viii) Hepatitis C, including viral loads; (ix) HIV, including viral loads and confirmatory tests; (x) Liver function tests, including ALT, AST, and bilirubin associated with a viral hepatitis case; (xi) Lyme disease; (xii) Syphilis; (xiii) Tuberculosis; and (xiv) Zika virus. (d) Non-positive laboratory results reported for the events identified in Subsection R386-702-3(6)(c) will be used for the following purposes as authorized in Utah Health Code Subsections 26-1-30(2)(c), 26-1-30(2)(d), and 26-1-30(2)(f): (i) To determine when a previously reported case becomes non-infectious; (ii) To identify newly acquired infections through identification of a seroconversion window; or UTAH STATE BULLETIN, December 15, 2016, Vol. 2016, No. 24 17 NOTICES OF PROPOSED RULES DAR File No. 41038

(iii) To provide information critical for assignment of a case definition. (e) Information associated with a non-positive laboratory result will be kept by the Department for a period of 18 months. (i) At the end of the 18 month period, if the result has not been appended to an existing case, personal identifiers will be stripped and expunged from the result. (ii) The de-identified result will be added to a de-identified, aggregate dataset. (iii) The dataset will be kept for use by public health to analyze trends associated with testing patterns and case distribution, and identify and establish prevention and intervention efforts for at risk populations.
Impact on HIV Surveillance

• Identify cases unknown to surveillance
  – Identified 50 negative viral loads with CD4s, reported within 30 days. 50% of these labs were part of drug trials, and 50% were cases known by treatment and care but had never been entered into our surveillance system.

• Recent infections are being detected by utilizing negative laboratory reporting
Questions?

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Thank you!