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# Data to Care – Efficiently Using Technology to Create a True Out of Care List


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# Agenda



I. Introduction to Data to Care Program
II. Current Data Management System
III. Construction of Out of Care List
IV. REDCap Demonstration
V. Results of Investigations from AZ D2C Program
VI. Questions

# What is Data to Care?



Data to Care is a recent public health strategy that aims to use HIV public health data to identify HIV-diagnosed individuals not in care, link them to care, and support the HIV Care Continuum.

Beyond helping individuals overcome the obstacles that are preventing them from accessing care, this program supports the larger U=U and 90/90/90 public health initiatives.

# Data to Care Goals



1. Increase number of individuals living with HIV who are engaged in HIV care.
2. Increase number of individuals living with HIV who are virally suppressed.
3. Decrease the number of individuals who acquire HIV.
4. Improve accuracy of care cascade and eHARS data.

# Arizona's Data to Care Program



- PAETC was approached by the Arizona Department of Health Services (ADHS) in 2017 to collaborate on Arizona's Data to Care Program.
- Team identified REDCap as an extremely powerful and flexible database for the evolving needs of the program.
- Automated import data cleanup resulted in a large number of dispositions not needing human review.
- Secondary manual research from sources that cannot be automated further narrowed the universe of potentially out of care individuals needing direct contact to determine status.
- Those results are then accessed by a colleague at ADHS who will then contact the medical provider of the client or the client directly.

# Common Data Management Approaches



- Obtain data list
  - How often is this list obtained?
  - Order of clients on list is arbitrary
  - File type - .csv, .accdb, other type?
- Results of investigations
  - Store results in spreadsheets (Excel) and/or other databases (Access, CAREWare)
- This is problematic and inefficient.
  - Who has access to this data?
  - No log available – no idea who has altered what data.
  - Need to be familiar with multiple data files?

# Main Steps in the D2C Not In Care Program



**Steps found in "Data-to-Care Reporting Guidance for PS18-1802 Recipients" documentation**

- Step 1: Identification
- Step 2: Investigation
- Step 3: Linkage to HIV Medical Care
- Step 4: Support Services
- Step 5: HIV Prevention Services
- Step 6: Feedback Loop

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**Steps found in "Data-to-Care Reporting Guidance for PS18-1802 Recipients" documentation**

- **Step 1: Identification**
- **Step 2: Investigation**
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- Step 5: HIV Prevention Services
- **Step 6: Feedback Loop**

# Step 1: Identification



- **Definition:** Use HIV surveillance and other data to identify person with diagnosed HIV infection who may not be **receiving regular HIV medical care**

- Who is considered Out of Care (OOC)?
  - An individual diagnosed with HIV and living in Arizona is considered OOC if they are alive and **a) their most recent lab (viral load, CD4 count, or genotype) is at least 15 months old** or **b) no labs have been recorded into the state's electronic HIV surveillance database**.

# Step 1: Identification

- OOC list acquired monthly from the Enhanced HIV/AIDS Reporting System (eHARS).

- Client profile from eHARS consists of basic demographic information (name, sex, gender, age, race/ethnicity), contact information, and labs.

# Step 2: Investigation

- **Definition:** Use other databases and information sources and conduct outreach to locate, contact, and interview them and verify their care status.

- Databases: CAREWare, LexisNexis, Cerner (EMR), etc.

- We use data from these sources to construct a more complete client profile (name, date of birth, address(es), phone(s), etc.) in addition to updating labs.

# Step 2b: Results of Investigation

- Deceased
- Resides Out of Jurisdiction
- In Care
- Not in Care (confirmed)
- Unable to Determine

# Step 2b: Results of Investigation

- ~~Deceased~~
- ~~Resides Out of Jurisdiction~~
- In Care
- ~~Not in Care (confirmed)~~
- ~~Unable to Determine~~

# Steps 1 and 2: What Do We Do With All this Data?



- We use SAS (Statistical Analysis System), a statistical programming language, to do the following:
  - Assign *active* and *inactive* OOC status to all clients.
    - *Active* = All clients that <u>are</u> on the latest OOC list (all new + some existing).
    - *Inactive* = All clients that <u>are not</u> on the latest OOC list (some existing clients).
  - Routinely (monthly) update demographics, contact information, and labs of *active* OOC clients.
    - Disposition cases as *In Care* if labs from other databases are <u>≤</u> 6 months old.

# Steps 1 and 2: What Do We Do With All this Data?



- This is done monthly without any human research (all programming).
- Once profiles are constructed, data are exported to a single CSV file.
- Now what?

# Data Storage: REDCap



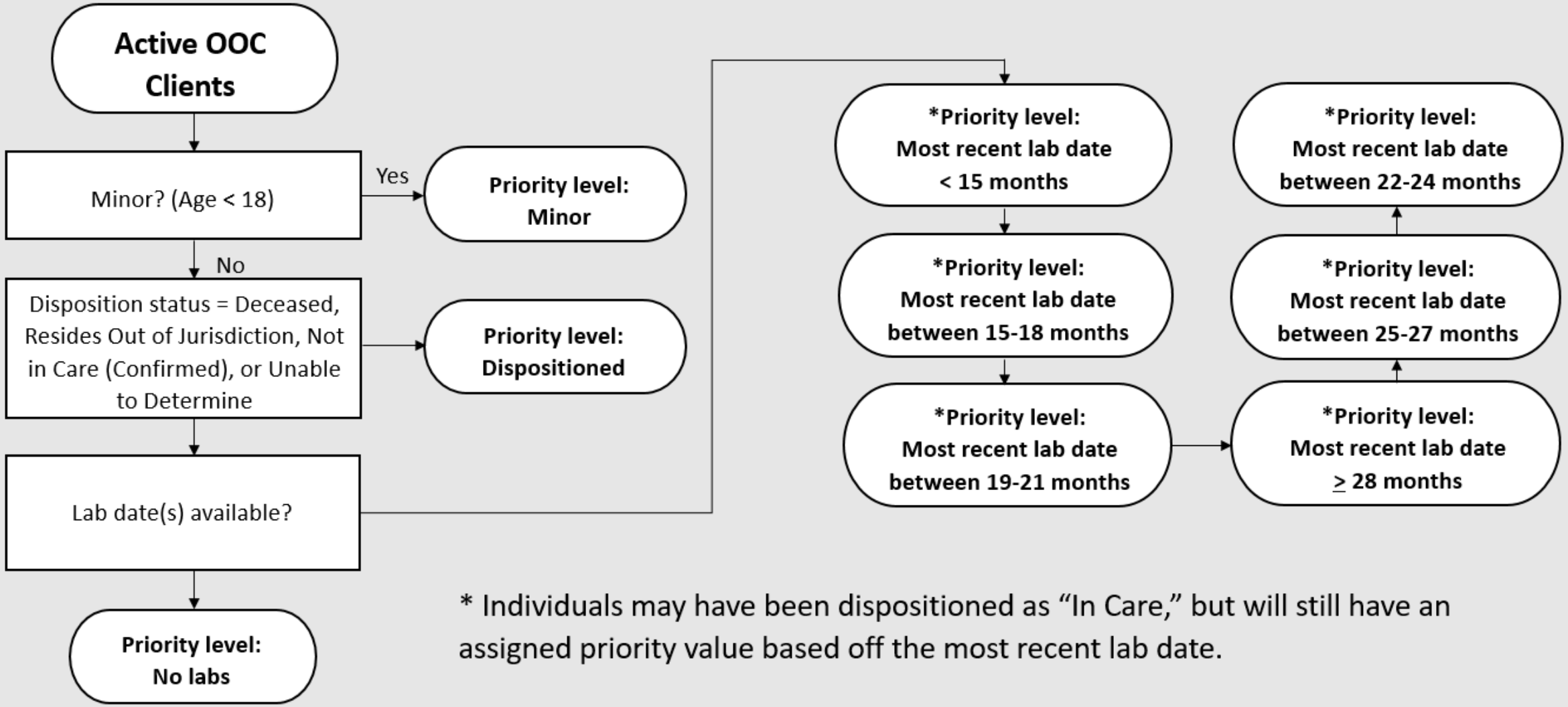
- All client information is stored in a secured online database system called REDCap (Research Electronic Data Capture), which is HIPAA compliant.
  - Our version of REDCap is housed on the UArizona server. Most universities house REDCap on their servers and have a dedicated team for REDCap.
  - Extremely user friendly and has flexible user interface.
  - Data are stored in "real time." Once data has been entered and saved, it is accessible immediately.
  - Custom reports are available for data exportation.
  - Administrator can limit access to users.
  - Can use client information to assign to specific groups and create custom "priority levels."

# Prioritization of Active OOC Clients



- Once profile is uploaded into REDCap, each active OOC client is assigned a “priority level”.
  - This is also done with programming – no human interaction required.
- Arizona D2C team has developed a prioritization system so we can efficiently and effectively utilize the resources at our disposal.
- Priority levels are NOT static.
  - An individual is prioritized based off of **age**, **disposition outcome**, and **date of most recent lab**.

# Priority Levels




* Individuals may have been dispositioned as "In Care," but will still have an assigned priority value based off the most recent lab date.

# Summary of Data Life Cycle (steps 1 and 2)



- Obtain Out of Care list from eHARS monthly.
- Download data from outside sources (CAREWare, LexisNexis, EMRs, etc).
- Use SAS to
  - construct and update profiles for each OOC client using this information
  - Close out any cases with recent labs
- Upload data into REDCap.
- REDCap assigns an individual an interactive “priority level”.
- Active OOC clients are now ready to be investigated by another user.

# REDCap demonstration

# Step 6: Feedback Loop

- **Definition:** Update and improve surveillance data with information obtained through the Data-to-Care process to facilitate future use of surveillance data for program purposes.

- Data obtained from our investigations (automated and user entered) is stored in REDCap and sent to AZDHS (at a minimum) biannually.

- Profiles in eHARS are updated with the results of investigations and subsequently dropped off OOC list if confirmed as Deceased, Resides Out of Jurisdiction, or In Care.
  - We also send over most recent contact information so client profiles are accurate and up to date.

# Results of AZ D2C Investigations



- Program started in March 2019.
- Number of OOC clients as of June 2020: 7,274.
- Total number of cases closed: 870 (12% of total database).
- Over half (473, 54%) were closed because of recent labs found in other data sources.
- **All cases were closed without any contact to clients.**

# Questions?

- REDCap: Main webpage for REDCap
- Contact information
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