

Initiatives to Improve Data Accuracy, Completeness and Timeliness Across the HIV Care Continuum

Introduction to the Session

Acknowledgement/Disclosure

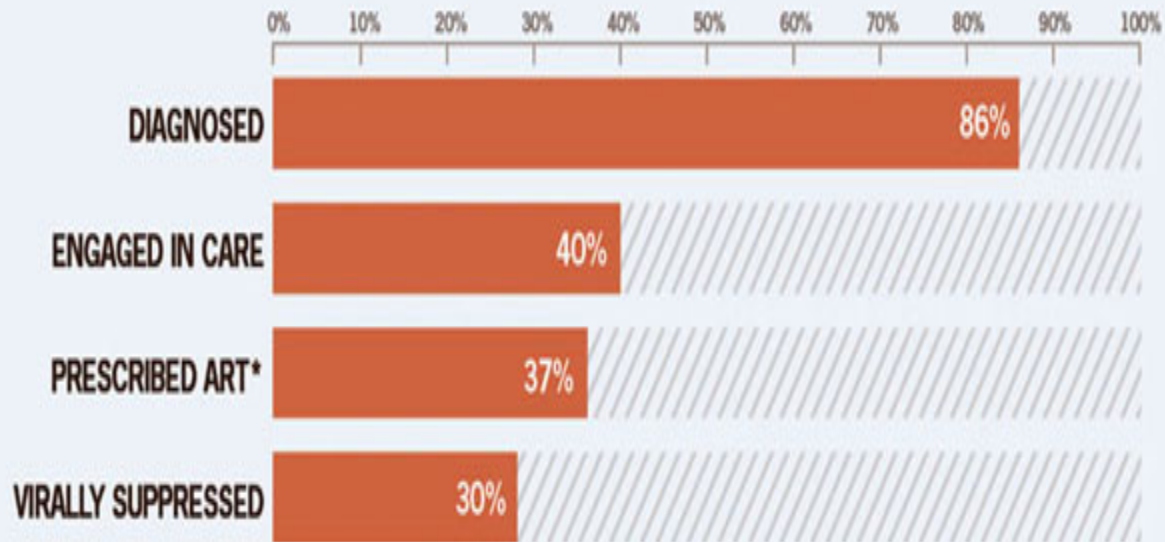
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National HIV Care Continuum

HIV Care Continuum Shows Where Improvements are Needed

DATA and PROGRAM

In the US, 1.2 million people are living with HIV. Of those:



SOURCES: CDC National HIV Surveillance System and Medical Monitoring Project, 2011.

*Antiretroviral therapy

Data Quality: What, Why, How?

- Surveillance, Ryan White, and other HIV data are not just utilized for funding formulas and static reports
- Real-time tracking of diagnosis, linkage, care engagement, medication adherence and viral suppression are needed
- Current data systems – set up artificially with barriers based on funding streams, jurisdictions, disease status, etc.

Accuracy

How do people get included in/excluded from Continuum of Care analyses?

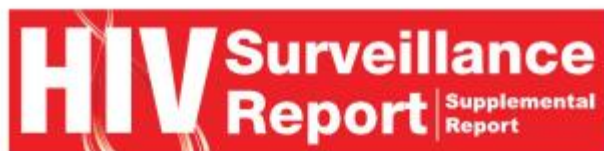
- Death
- Proof of out of jurisdiction address
- No care in xx period of time?
- Modeling methods?
- Only care in xx period of time?

24% of current living cases in VA eHARS – no lab in last 5 years (n=6,005)

Completeness

- Markers for care cannot all be tracked in eHARS
- Systems outside of health department purview often have data on care status for PLWH
- Electronic medical records/health information exchanges/all payer claims databases often available in jurisdictions

Timeliness



Volume 21, Number 4

**Monitoring Selected National
HIV Prevention and Care Objectives
by Using HIV Surveillance Data
United States and 6 Dependent Areas, 2014**



- NHAS – 4th Goal calls to “strengthen the timely availability and use of data”
- Viral suppression rates for 2013 for persons living with HIV as of 12/31/2012 released by CDC in July 2016

This session...

- Features presentations from
 - Virginia: Health Information technology initiatives to improve HIV Surveillance data
 - Louisiana: Electronic HIV Data to Care System
 - North Carolina: System for Data to Care using CAREWare data
 - HRSA: Building Bridges in Electronic Medical Record Systems

Virginia's Health Information Technology Initiatives: Improvements in Care Continuum Measurement

Anne Giuranna Rhodes, PhD

*Virginia Department of Health
Division of Disease Prevention
Grant H97HA27534*

Background

Division of Disease Prevention

- Integrated division comprised of several programs focused on HIV prevention, identification, care, and data management.
- HIV Surveillance, HIV Prevention, HIV Care Services, STD Surveillance, Data Operations and Administration (SODA), TB program and services for recent immigrants.

Mission Statement:

- *“To maximize public health and safety through the elimination, prevention, and control of disease, disability, and death caused by HIV/AIDS, viral hepatitis, other sexually transmitted infections and tuberculosis.”*

What data systems have information about PLWH

How do we utilize data

Where do PLWH get care

Measure Care Continuum Outcomes

Who is living with HIV in VA

How do we get data

2014: SPNS Health Information Technology Grant (HRSA)

- **Objective 1:** Expand the Care Markers Database to more systematically integrate data from all DDP HIV databases to enhance tracking clients along the care continuum.
- **Objective 2:** Develop a new system to collect and report on HIV care data for Ryan White clients in Virginia.
- **Objective 3:** Develop a process for sending out of care (OOC) lists to providers/agencies for the purposes of identification and re-engagement of PLWH in HIV medical care.
 - Develop a web-based application to send and receive information on OOC list data to and from provider sites.

Defining Virginia's HIV Continuum of Care

What's considered a care marker?

CD4 test

Viral load test

HIV medical care visit

ART prescription

Linkage



Evidence of a care marker within 30 days of initial HIV diagnosis

Retention



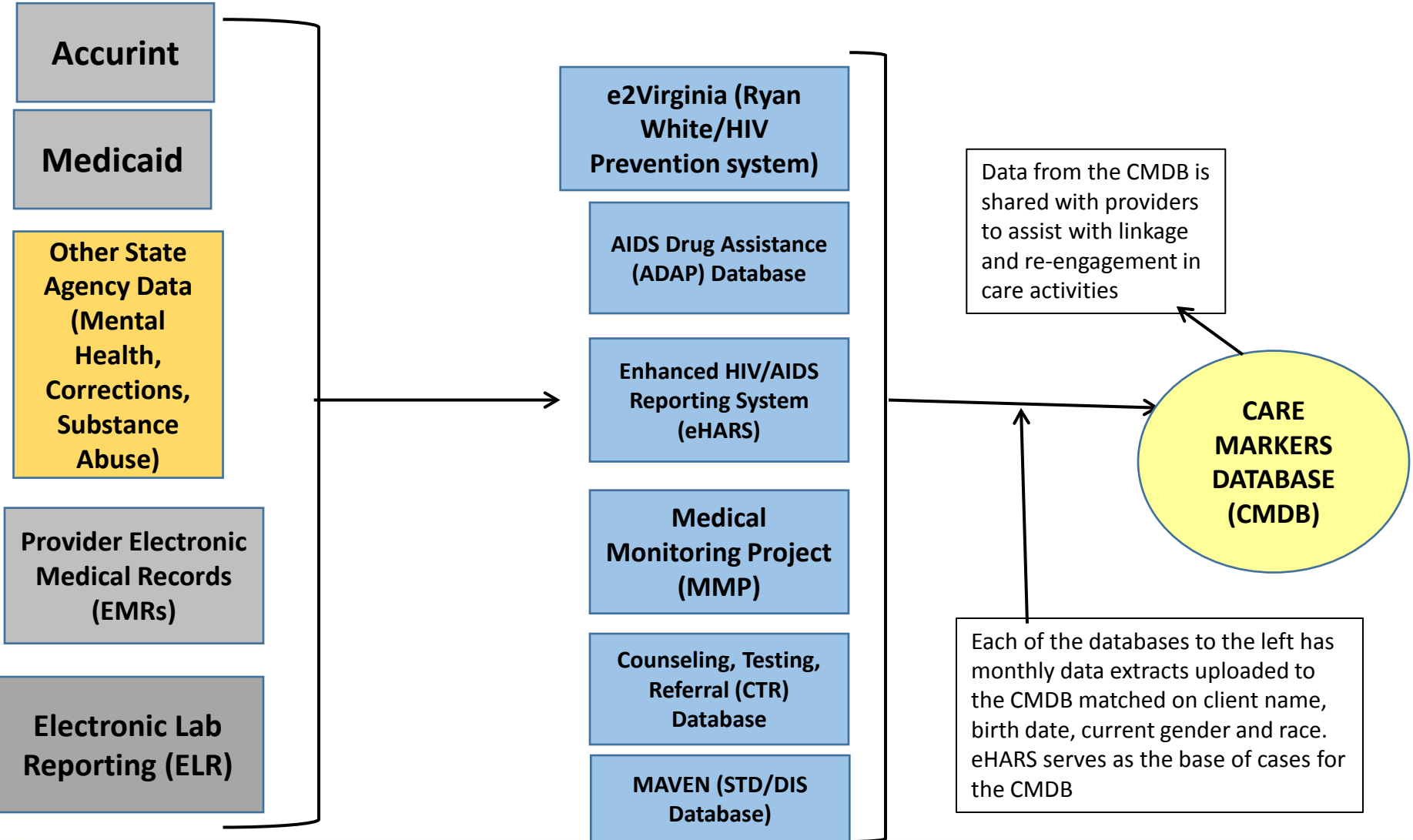
2 or more care markers in 12 months at least 3 months apart

Viral Suppression



Last viral load <200 copies/mL in the time period being measured

Care Markers Database Flow



Care Markers: Considerations

- Have found new cases to investigate
- Fuzzy matches to be researched/ongoing quality assurance
- Working on utilizing for feedback loop from Data to Care forms

New Data System: Integrated HIV Care and HIV Prevention Data

e2Virginia
Powered by COMPAS

VDH VIRGINIA DEPARTMENT OF HEALTH
Protecting the well and their development

Login

Username

Password

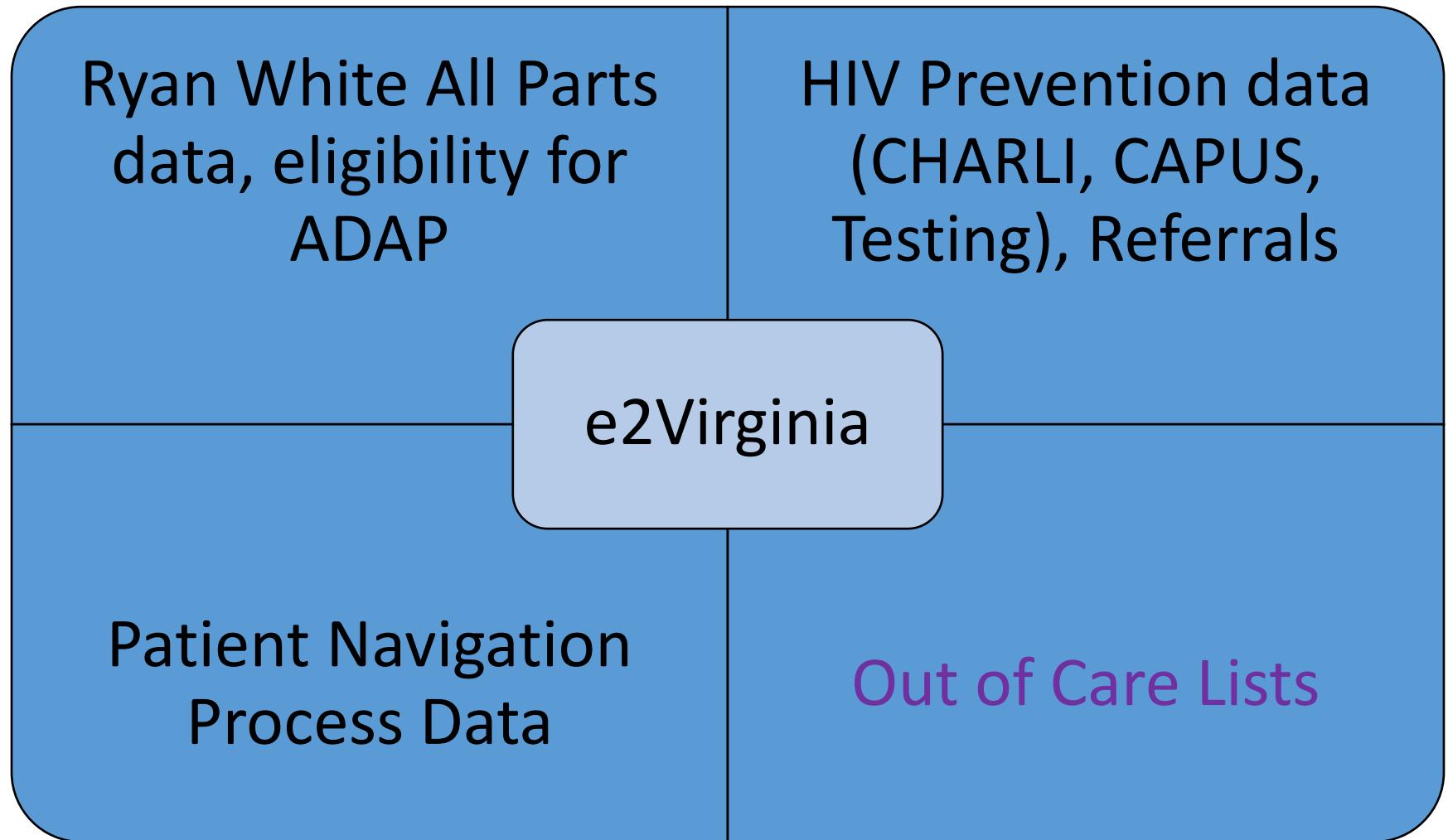
[Forgot your password?](#)

Log in

This is a secured web connection. All data is protected by the highest level of Internet encryption (SSL).

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e2Virginia: Content



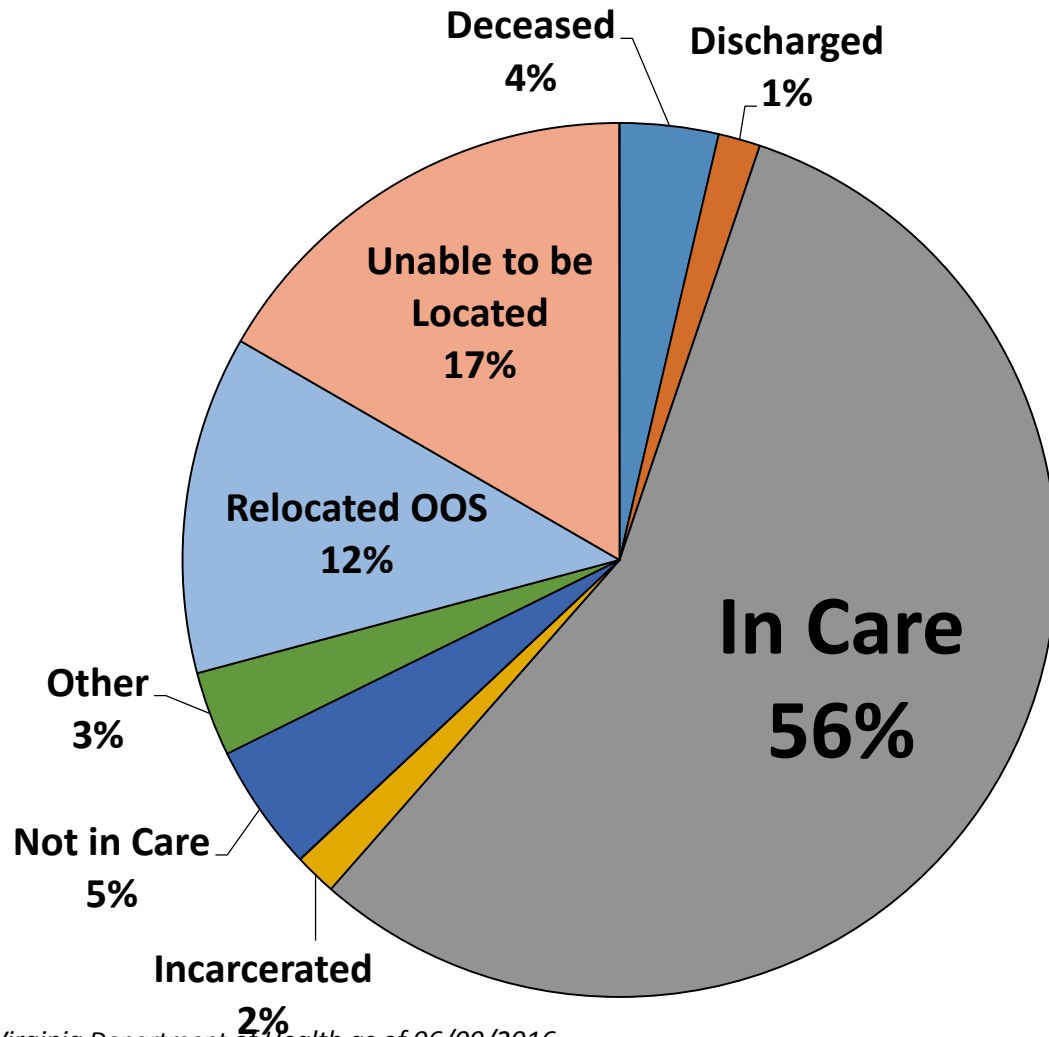
Launch of e2Virginia

- Launched statewide in February 2016
- Imported 3 years of data from legacy system.
- Used by 64 providers
- RSR-Compliant
- Holds over 15,846 client records
- Has client-sharing module for medical and service data
- Has reports that unduplicate at contractor, regional and state levels

Eligibility for Data to Care

- 18 years of age or older
 - HIV-positive and reported to the HIV Surveillance database (eHARS)
 - Have a last known address in Virginia
 - Meet the OOC definition:
 - Have evidence of care via a reported care marker in the reference year but no evidence in the following calendar year
- *The 4 Care Markers:*
 - HIV Medical Care Visit
 - CD4 Lab Test
 - ART Prescription
 - Viral Load Lab Test

Overall DtC Outcomes



N=192

Data reported to the Virginia Department of Health as of 06/09/2016



Virginia Results: So Far

Improved Accuracy of Case Numbers

- After address and vital status updates, number of PLWH living in Virginia as of 12/31/2015 was reduced by 760 persons

Increased Number of Care Markers for Continuum

- Increased retention rates by 8% and viral suppression rates by 9% in 2015 with additional data sources/quality assurance

For More Information...

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LA Links: a Data to Care Intervention Using an Automated Real-time Surveillance Data System

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Disclosures

Presenter(Debbie Wendell) has no financial interest to disclose.

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Learning Objectives

At the conclusion of this activity, the participant will be able to:

1. Describe how real-time surveillance data can be used for “Data to Care” interventions
2. Demonstrate the benefit of automatically updating electronic out of care line lists
3. Describe ways to improve line lists and HIV surveillance data



Obtaining CME/CE Credit

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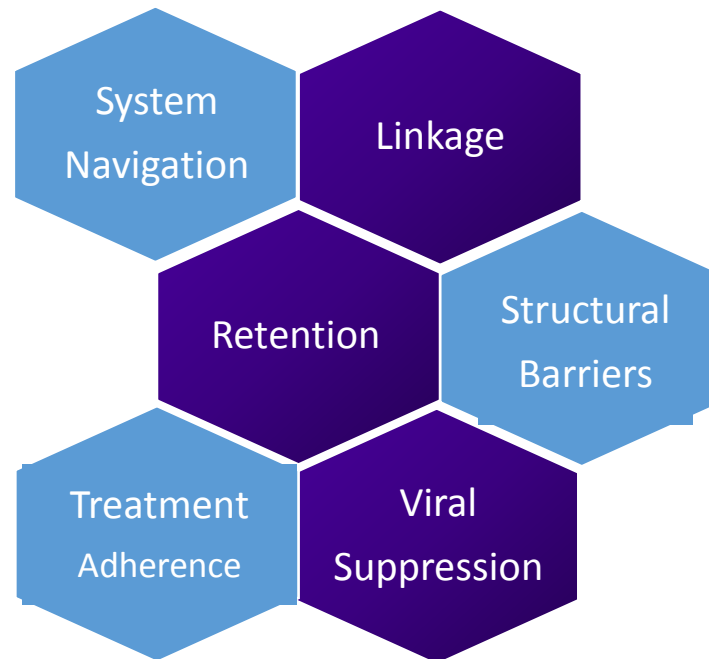
<http://ryanwhite.cds.pesgce.com>

Louisiana Links

- CAPUS-funded, “Data to Care” intervention
- October 2013-September 2015 – demonstration project in 3 metro areas with highest prevalence
 - Expanded statewide in 2016
- Utilizes surveillance data to identify PLWH who are:
 - Newly diagnosed and not linked to care
 - Previously diagnosed who need re-engagement
 - Persons not virally suppressed
- Automated electronic line lists with weekly automated update process

Louisiana Links

- 10 Linkage to Care Coordinators (LCCs) – provide extensive services above and beyond the scope of traditional linkage services



Surveillance Databases

- eHARS

- HIV diagnoses
- Contact information
- Demographics and risk
- Case notes
- Pregnancy data

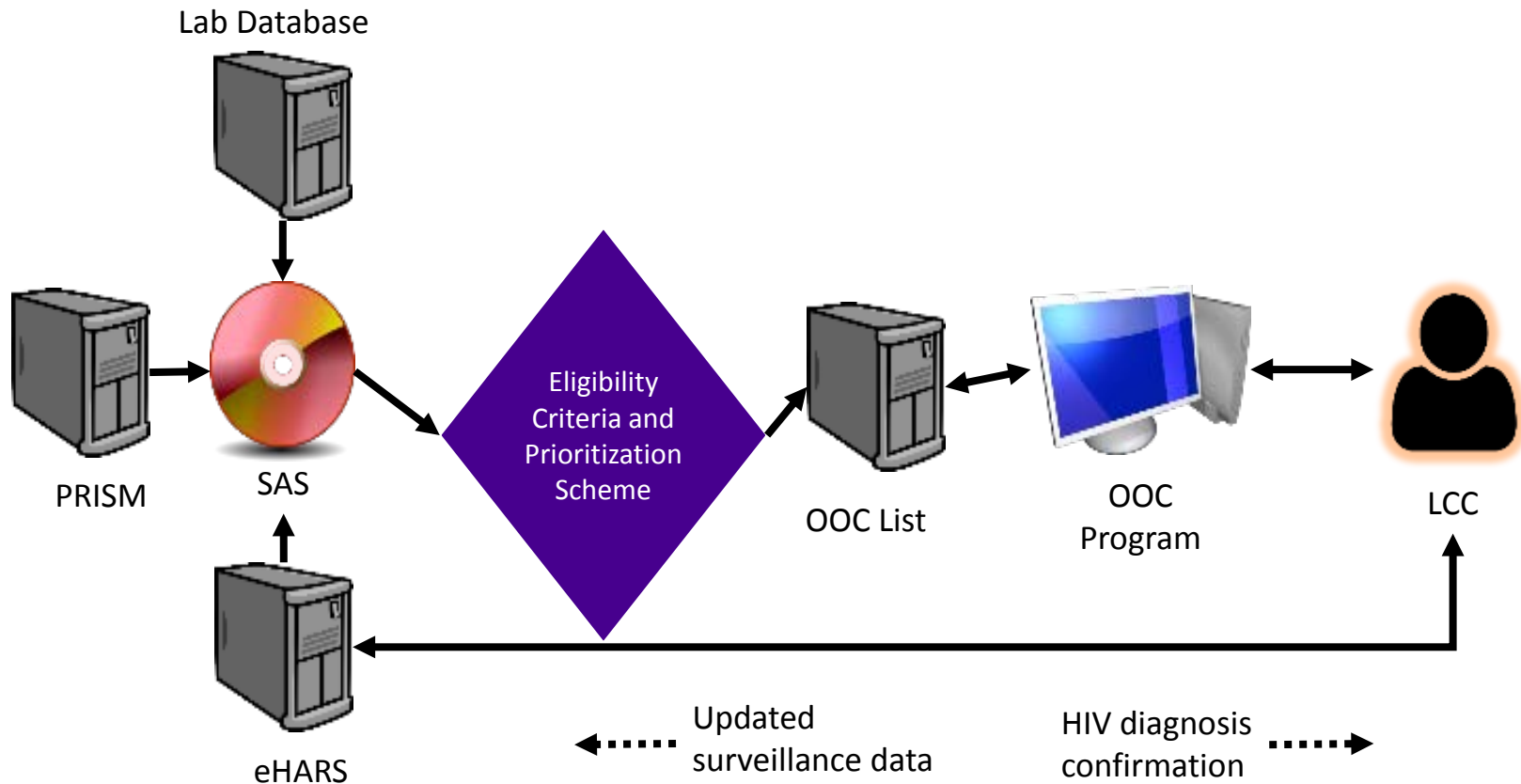
- Laboratory Database

- HIV-related labs reportable
- Electronic lab reports uploaded in real time
- Contact information
- Facility and provider

- PRISM

- New STD/HIV cases
- Demographic and risk data
- Case notes
- Contact information
- Partner services

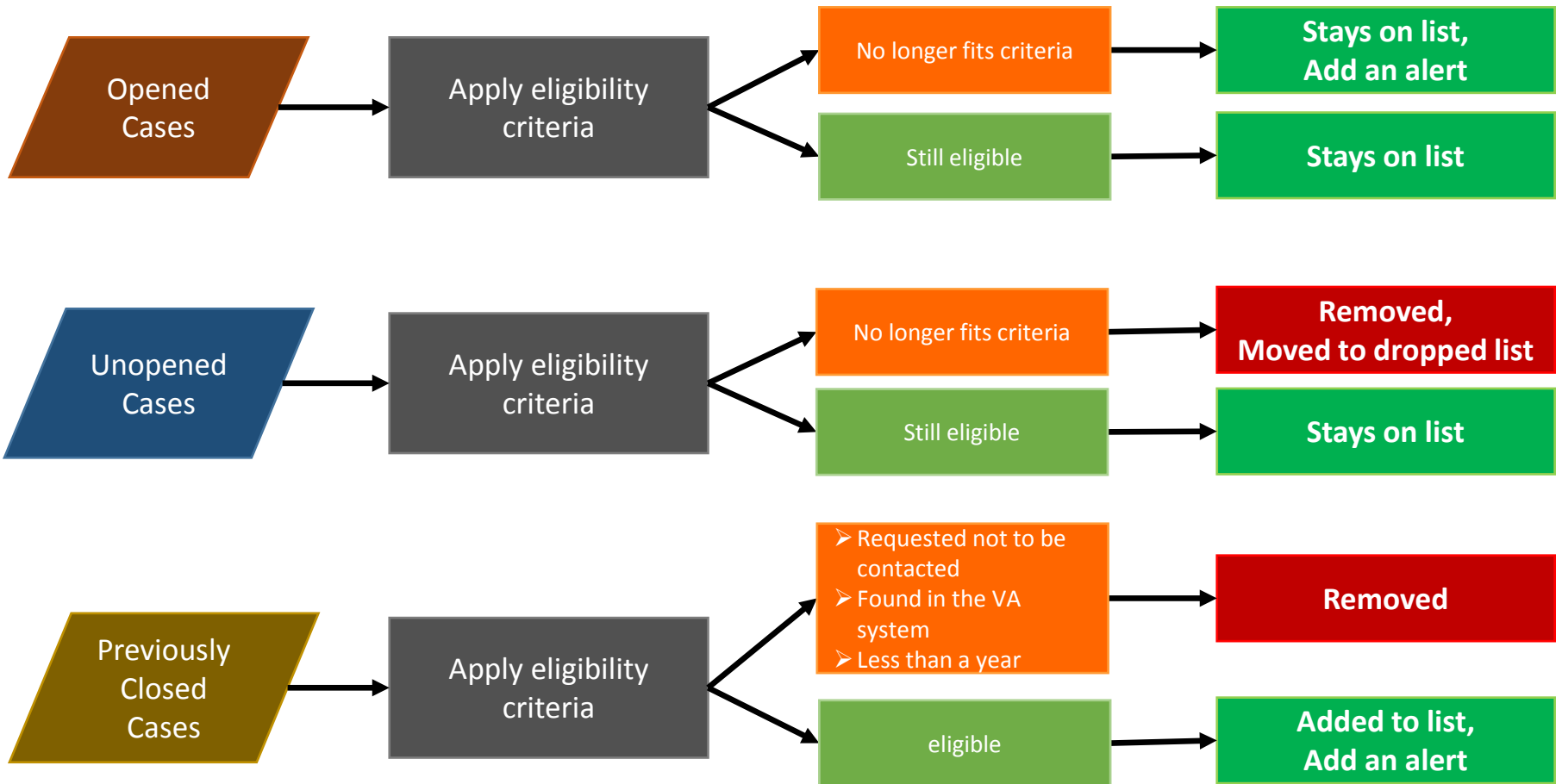
Generating the OOC List



Updating the OOC List

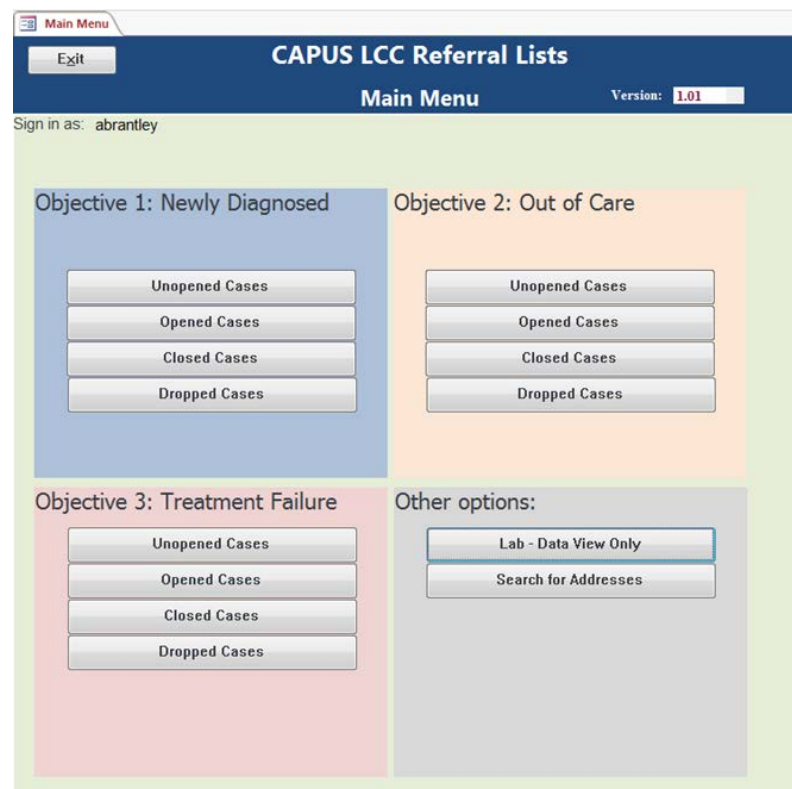
- Lists are updated weekly using a SAS program
- Finds newly eligible people and adds them automatically to the list
 - An alert is generated for the LCC
- Identify changes in eligibility status for existing referrals
 - Reasons for change in eligibility: accessed care independently, no longer experiencing virologic failure, moved out of state, deceased, eligibility time limit passed
 - Uninitiated cases: if no longer eligible, case is automatically closed
 - Active cases: if no longer eligible, generate an alert in Referral List Program and keep on the list until LCC closes cases

Updating Process



OOC Program

- Displays ordered list of referrals
- Multiple pieces of contact and identification data from eHARS, lab database, and PRISM for each referral
- Data inputs such as date case initiated, date case closed, and contact outcome
- Update alerts
- Contact attempt log
- Quick access to all lab data



OOC Program

Obj 2: Opened Cases

State no: First or Last Name: SSN: DOB:

Alerts

Status: **PREVIOUSLY ENROLLED**

Important Open Case Issues: **RECENT LAB WORK**

Last LCC Assigned to Case:

Contact Change (eHARS?): **YES**

Date Case Added to List: 6/30/2016

State no: X9999

Date case opened: 7/1/2016

Date case closed:

Contact Disposition Date:

Contact Disposition 1:

Contact Disposition 2:

Last Name (eHARS): SOME

First Name (eHARS): JOE

Middle Name (eHARS):

Suffix (eHARS):

Date of Birth: 1/1/1960

Birth Sex: M

Current Gender:

Race:

Current Street 1 (eHARS): 99 SOUTH DR

Current Street 2 (eHARS):

Current City (eHARS): NEW ORLEANS

Current County Name (eHARS): ORLEANS

Current State (eHARS): LA

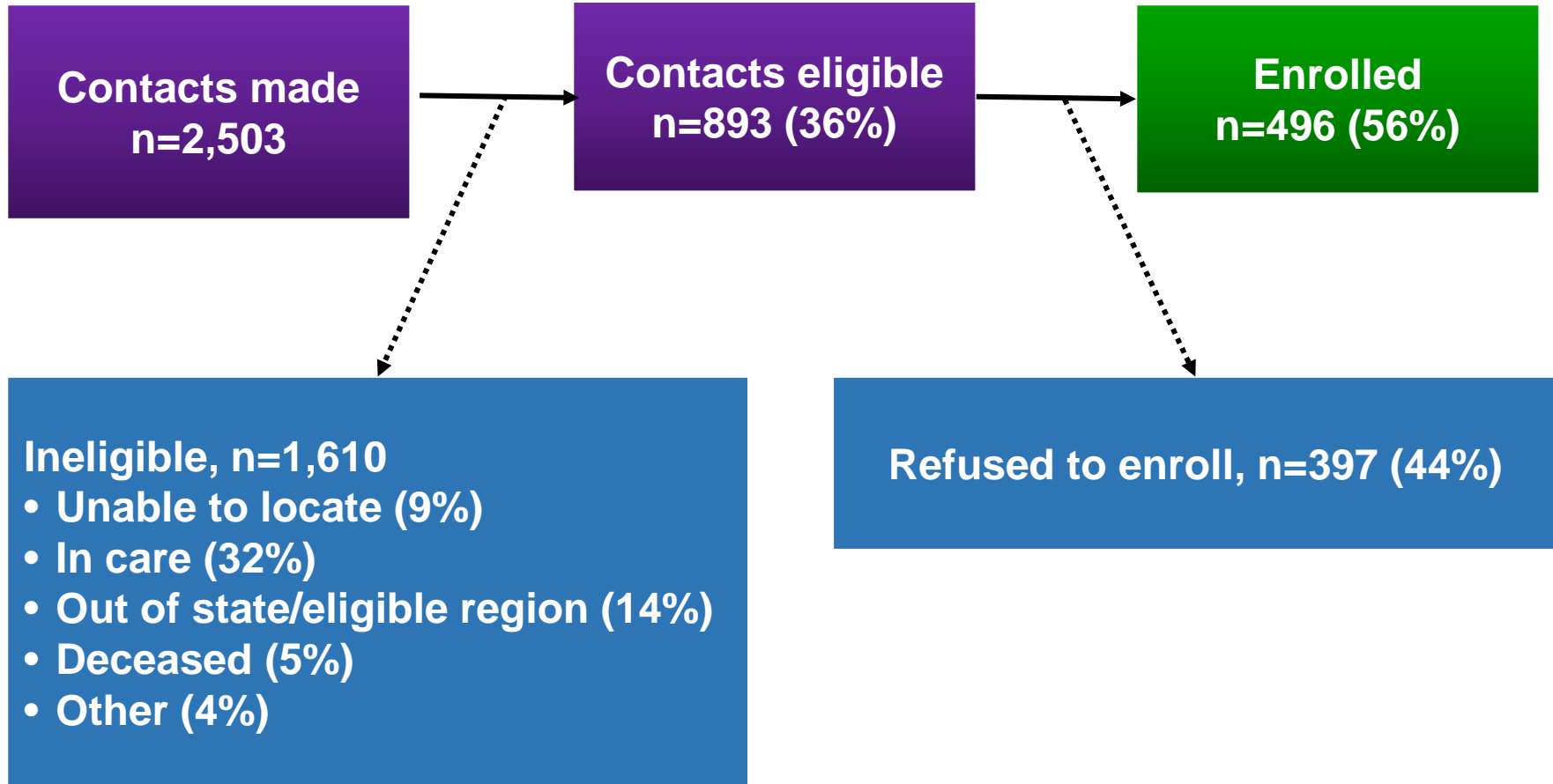
Current Zip Code (eHARS): 70112

Current Phone Number (eHARS): 5049999999

State no	Important O	Status	Last LCC Assi	Date case op	Date case cl	Contact Disp	Contact Disp	Last Name (r	First Name (Middle Nam	Suffix (eHAF	Date of Birth	Birth Sex
X9999	RECENT LAB W	PREVIOUSLY E		7/1/2016				SOME	JOE			1/1/1960	M

LA Links Results

October 2013 – September 2015



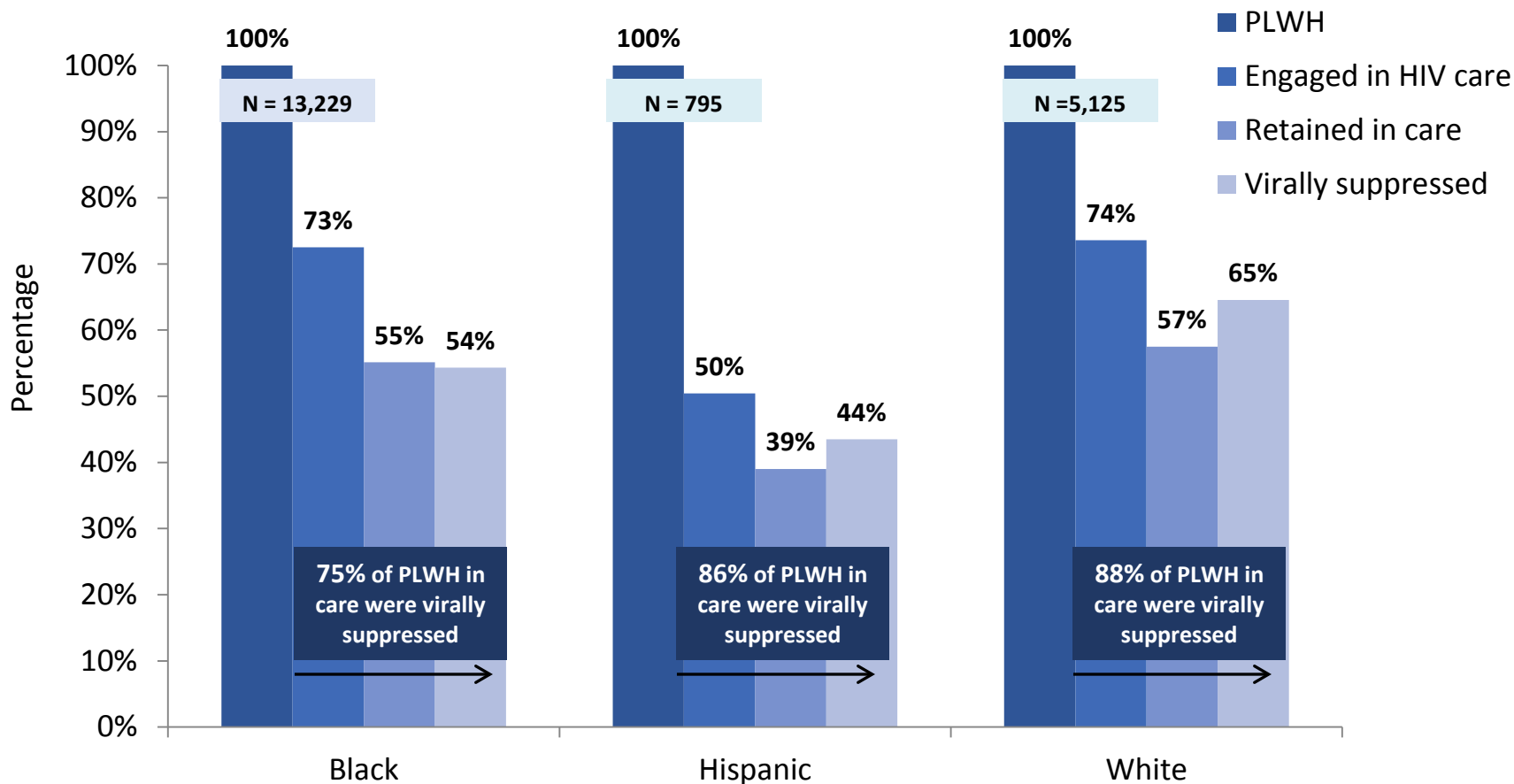
Improving Surveillance Data

- LCCs fill out case report forms to update Louisiana surveillance database (eHARS)
 - New addresses, risk information, deaths, earlier diagnoses
 - Identify labs that may not be reporting completely
- Other ways to improve surveillance:
 - Persons newly enrolled in Ryan White services are looked up immediately in eHARS and unreported cases are investigated
 - Newly reported HIV cases are automatically transferred to the Partner Services database daily and info obtained during DIS interviews provided back to eHARS
 - Routinely link eHARS data to Vital Records, Medicaid data, CAREWare, National Death Index, and SSDMF

Lessons Learned

- Automatic update process saved time and resources
 - 30% of referrals were closed automatically during update process before LCC had to do an work on them
 - Alerts helped LCCs close 942 ineligible cases
- Linkages to external data systems and data to care interventions have improved HIV continuum data
 - Still have PLWH in the first bar who are likely not living in Louisiana, so the percentages in the subsequent bars are underestimated
 - Louisiana focuses on viral suppression on persons in care; best able to show inequities

HIV Continuum by Race/Ethnicity Louisiana, 2015



Questions?

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NC-ECHO

A North Carolina model data
warehouse for
Engagement in Care and HIV
Outreach

Evelyn Byrd Quinlivan, MD
Jenna Donovan, MPH



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No authors have no financial interest to disclose.

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NC-LINK NC-ECHO Planning and Development

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Affiliations are based on where the work was performed.



Learning Objectives

The audience will be able to:

Describe the development process for creation of a data warehouse for HIV outreach.

Describe the key functions and the purpose of each function within the model data warehouse.

Describe the staffing needs for data warehouse construction and use.



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Setting: HIV in North Carolina

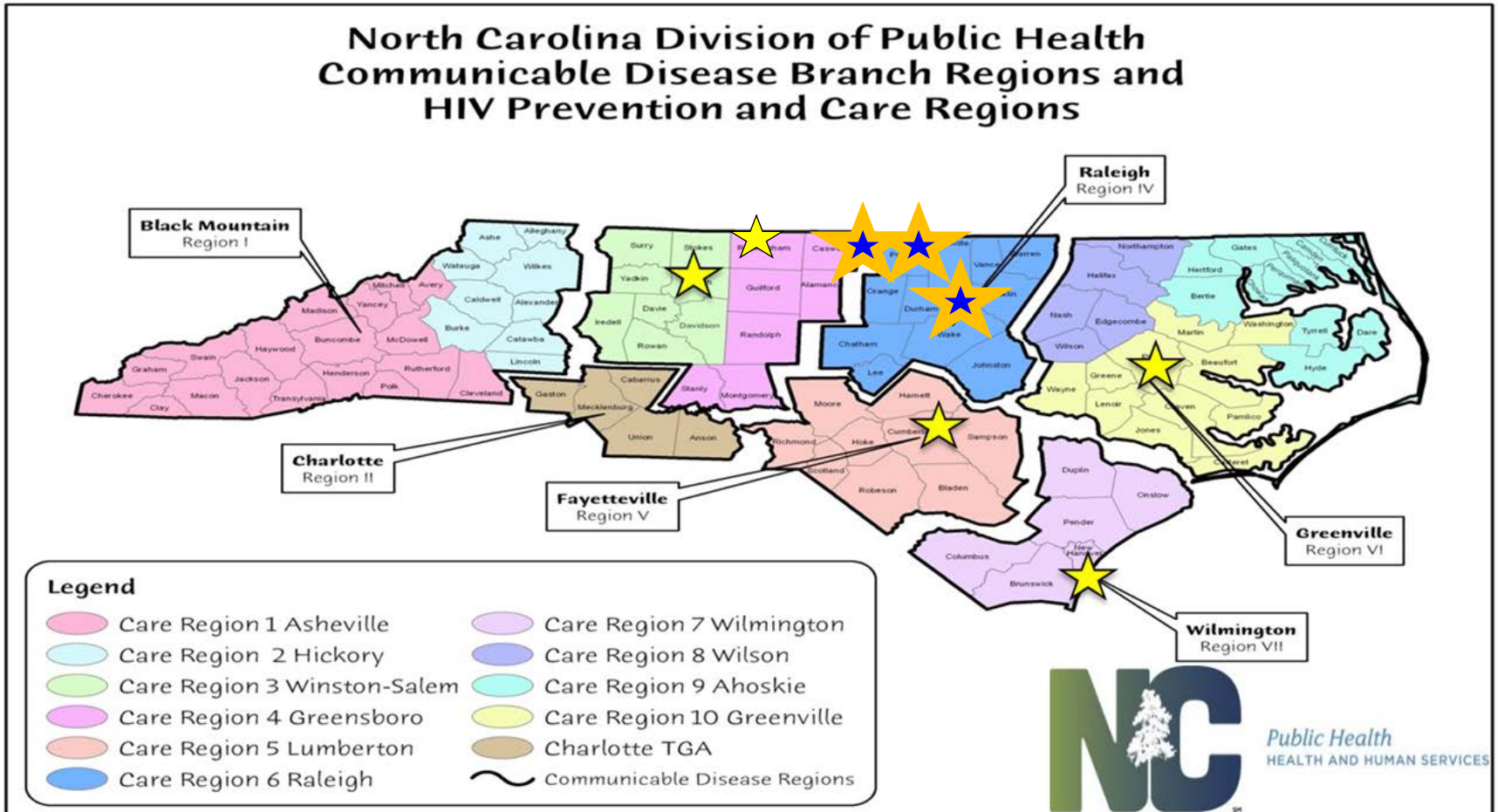
North Carolina HIV/AIDS Epidemiology

- **28,101**: estimated total number of persons living with HIV at the end of 2013
- **1,347**: reported new diagnoses of HIV infection in 2012
- **15.0 per 100,000**: three-year average HIV diagnosis rate (2011-2013)
- **31.0 per 100,000**: three-year average HIV diagnosis rate in Mecklenburg County (Charlotte)- county with the highest rate in the state
- African Americans accounted for **64%** of all new HIV cases in 2013

Ryan White Supported Care

- Part A TGA area, funded through the Mecklenburg County Health Department for Charlotte MSA
 - 5 NC counties and
 - 2 SC counties
- Part B funds through the NC Department of Health and Human Services, Division of Public Health
 - 10 HIV Ryan White HIV care regions
 - 95 of NC's 100 counties
- Part C funds through 13 medical clinics
- Part D funds through 8 sites

NC-LINK Sites



Challenges for Linkage and Re-engagement

- NC HIV Prevention (6) and Care Regions (10) within the state were not aligned
- Large geographic distances with limited fieldwork capacity for linkage and retention staff within regions/clinics
- Efforts to re-engage clients being conducted at state level were challenging when conducted by DIS (punitive role)
 - Need for a more supportive role for working with clients and more training
- Lack of streamlined processes for clinics/regional networks of care to collaborate with others across the state to locate clients or document efforts (i.e. could lead to duplicative work)

Linkage and Re-engagement Information

- NC EDSS Surveillance of HIV RNA & CD4
 - New database designed to have individual as base record that than specific events.
 - Addresses, staff contacts and other notes are updated with each event.
- eHARS – Surveillance of HIV RNA & CD4
 - Official CDC surveillance reporting tool with built-in hierarchy for race, exposure, matching.

Linkage and Re-engagement Information

- NC AIDS Care Unit CAREWare
 - Database with all Part B service data
 - Includes Part C, D to large extent
 - Many sites include all patients for quality monitoring (even insured)
 - HIV RNA, CD4 data prior to complete reporting
- NC ADAP
 - Data for medication use by ADAP enrollees
- MEDICAID
 - Visit, ART and labs claims data

NC LINK Overview

NC-LINK

- Systems Linkage for Access to Care
 - Four-year HRSA Special Projects of National Significance (SPNS) demonstration project
 - NC one of six states to receive funding
- Follows the goals of the National HIV/AIDS Strategy
 - Purpose: Increase the number of people living with HIV/AIDS engaged in consistent care by creating a system of linkages along the HIV Continuum of Care in NC
- Communicable Disease Branch at the North Carolina Division of Public Health, *grantee*
 - Partnership between Duke University, University of North Carolina-Chapel Hill and intervention sites around the state
- Key strategies: alternative HIV testing and retention and reengagement efforts for quality and consistent HIV care

Overview of Final NC-LINK Interventions

- Clinic-based HIV Testing
 - Offers an individual who accompanies an HIV-positive patient to a clinic appointment the opportunity to receive free and confidential rapid HIV testing at the clinic and immediate linkage to care
- Retention Protocol
 - Implemented at the clinic and regional levels to re-engage patients who have not had an HIV care appointment in a designated time period (usually 6-9 months)
- State Bridge Counseling – Linkage & Re-engagement
 - Program at NCDHHS, Communicable Diseases Branch to ensure rapid linkage to care for people who have been newly-diagnosed with HIV and to re-engage PLWH who have been out of care ≥ 12 months

NC-LINK Support Activities

- ONE CALL
 - Nurse –run warm line to immediately connect PLWH to care
- CAREWare Data Sharing
 - CAREWare Data Sharing to allow all NC RW Part B providers to access records for any location in state
 - Policy and Security Procedures for shared use of NC CAREWare
- NC ECHO
 - Data warehouse for matching records of PLWH from surveillance and clinical care systems for the purposes of linkage and re-engagement of PLWH to care and to perform routine reports of progress towards statewide public health goals.

NC ECHO



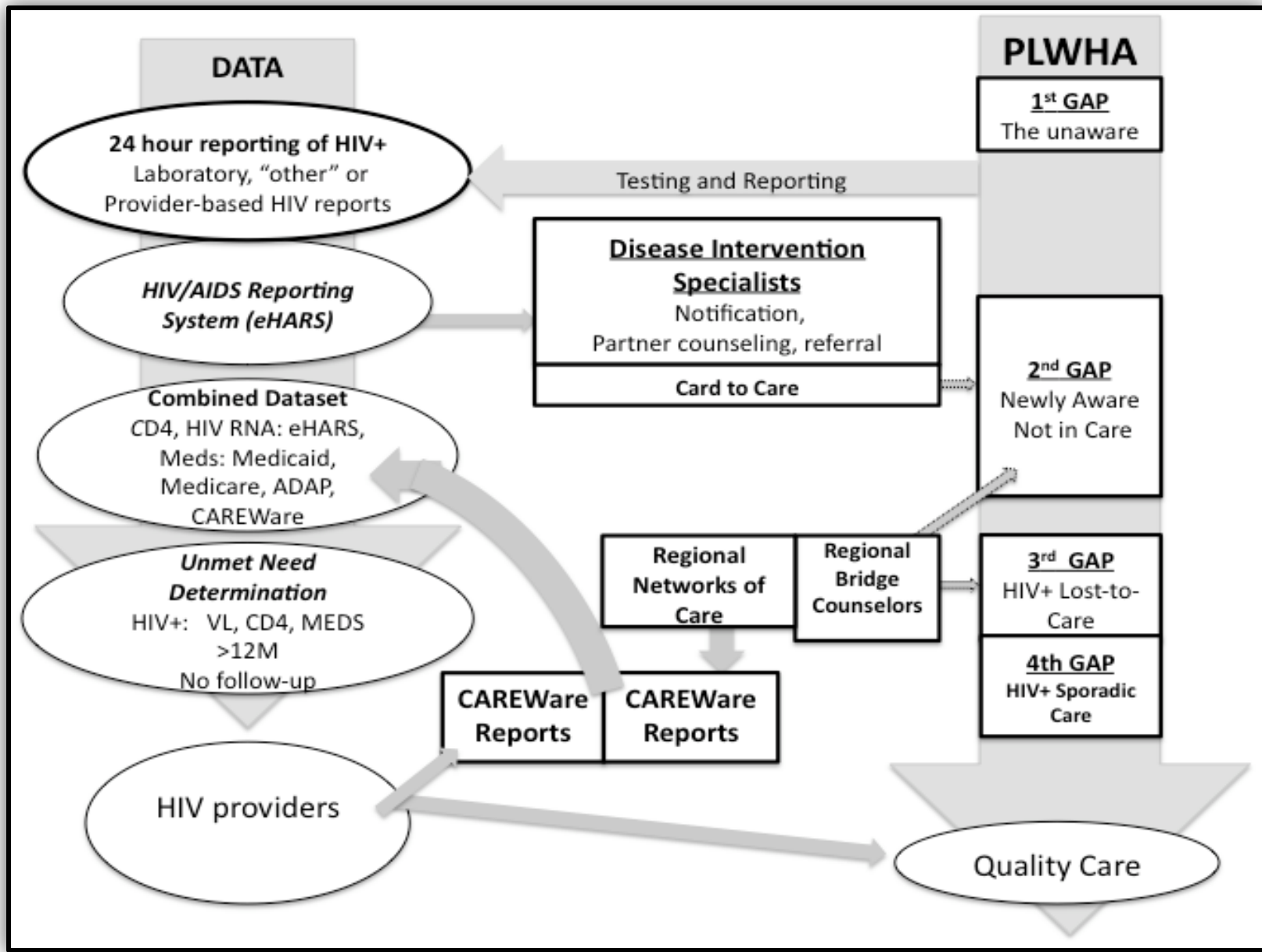
Development process for creation of a data warehouse for HIV outreach.



Data Warehouse Need, 2011

- Public health data reside in multiple locations
 - Surveillance data
 - Clinical data
- Surveillance data can be used as a proxy for care
- Combining datasets provides meaningful assessments of health and needs of PLWH
- Manual efforts to combine data are labor intensive and done infrequently
- Combined data provided “big picture” direction
- Combined data had limited direct impact in the care of individuals

2011



Phase I: Conceptualization

- Data existed: Use of data in multiple locations:
 - Surveillance data in NC EDESS & eHARS
 - Clinical care data in CAREWare, ADAP records and Medicaid
- Feasible: intermittent combining of the data for determination of unmet need
- NC LINK team: research team with assigned task to develop system
- HIV Software developer provided experience for framing the architecture
- Source representatives: knowledge about both data, compatibility of data vs. other systems
- Stakeholders in the Communicable Disease Branch, high level commitment
- Expertise:
 - Clinical care needs
 - Epidemiology
 - IT and databases
 - Data system representatives
- Timeline: 2 years to get to complete concept and institutional buy-in

Proposed Data Sources

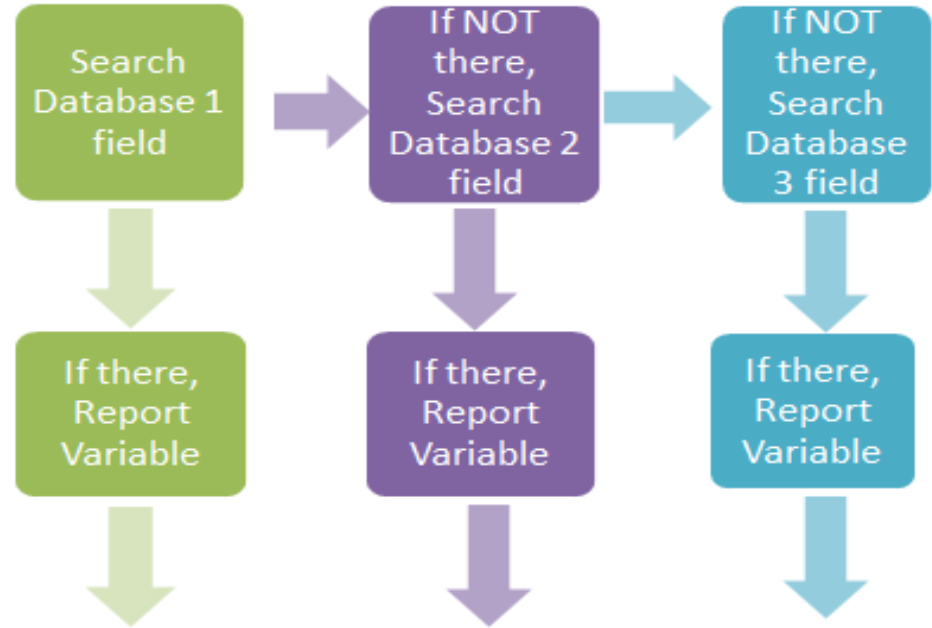
- ADAP
- CAREWare
- Medicaid
- NCEDSS
- eHARS
- CTR

Data Import



Data Warehouse

Mapping



Proposed NC-LINK Data Warehouse Data Flow

Reports pulled from Data Warehouse

Phase II: Planning Phase - Staffing

- Selection of staff & contracts
- Planning team:
 - Project management
 - Web resource development and IT leadership; prior experience with public health data
 - Warehouse development and record matching
 - HIV epidemiologist , liaison with DPH
 - HIV clinician, representing concept, experience with retention in care interventions
- Onboarding – 2months

Phase II: Planning Phase

- Weekly meetings - ~ 3 hours x 8 weeks
 - Review of concept details for builders
 - Translation of concept into specific steps.
- Presentation to 2 user groups: Bridge counselors & epidemiologists
 - Maintain interest
 - Frame discussion realistically (system limits)
 - Allow processes to be developed to support use of DWH
 - Reality check



Key functions and the aim of each function within the model data warehouse.



Readiness Checklist

	WHO	NAME	TASK / PRODUCT
1. Needs assessment	Who will do it?		What is the final product?
2. Leadership buy-in	Who will get?		What commitment do you need?
3. IT Depart. buy-in	Who will get?		What commitment do you need? -- long term support
4. Software expertise	Who will provide? Internal vs. external?		
5. Staff to manage efforts			

Readiness Checklist

	WHO	HOW	WHAT
5. Data Source 1 _____	Leadership? Contact?	How will work be done with this person?	What is the final product?
5. Data Source 2 _____	Leadership? Contact?	How will work be done with this person?	What is the final product?
5. Data Source 3 _____	Leadership? Contact?	How will work be done with this person?	What is the final product?
5. Data Source 4 _____	Leadership? Contact?	How will work be done with this person?	What is the final product?

Readiness Checklist

	WHO	HOW	WHAT
Web builder			
DWH Architecture Builder			
Report Builder			
End users			
Team manager			

Readiness Checklist

	WHO	HOW	WHAT
Web Interface			
Data warehouse			
Reports			
Security			
Out of care identification			

Timeline

Need (6m)

Stakeholders = 4 months

Statement of Need = 1 m

Hires/ Contracts, 6m

Concept (18m)

Source data assessments = 6 m
Reports = 6

Concept Report = 6 m

Hires/ Contacts /Reviews 9m

Planning with Build Team (4 m)

Bring Build Team on Board 2 m

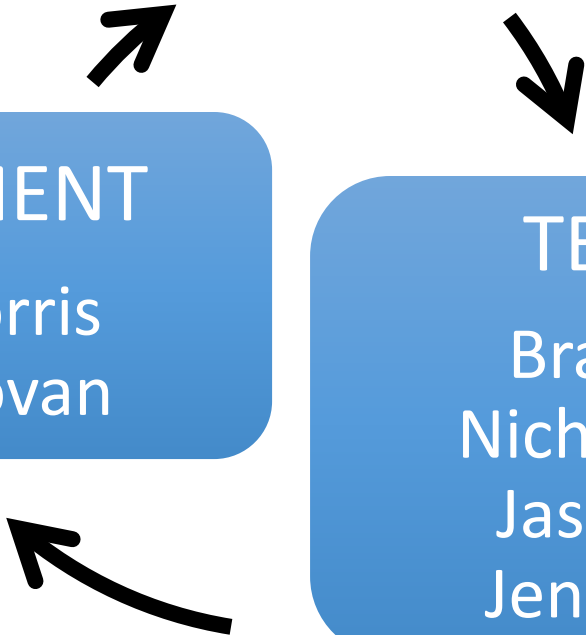
Planning Series = 2 m

BUILD PHASE

BUILD TEAM
Bruce Chao
Ian Sun

MANAGEMENT
Pamela Morris
Jenna Donovan

TEST TEAM
Brad Wheeler
Nichole Dzialowy
Jason Maxwell
Jenna Donovan



NC ECHO: Key Functions

- 1) 2-factor user authentication for high level of security;
- 2) Matching algorithm to merge client records from multiple data sources;
- 3) Standard monthly state-level out-of-care (OOC) list reports;
- 4) Assignment of OOC clients to HD staff for re-engagement services;
- 5) Standardized reports for monitoring HIV public health;
- 6) Data extraction tools for creation of customizable data sets.

NC- ECHO Display

Lessons Learned

- Large and diverse team, with variety of expertise. Important to carefully identify these as resources.
- Best to think of this project in phases and each phase may require different people.
- Measure twice, cut once. Stakeholder involvement, concept development & planning took much longer than the build.
- Gap in progress between each phase due to need to involve others, obtain government agency permissions and the state government contract and hire processes.
- Dedicated staff to keep momentum moving forward.

Questions?