Government of the District of Columbia
Department of Health
HIV/AIDS, Hepatitis, STD, and TB Administration

2015 Grantee Forum

Data to Care: Using Surveillance Data for Public Health Action

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SESSION OVERVIEW

- Understanding of Data to Care Strategies
- HIV Care Dynamics in the District
- Review of Past/Current Data to Care Efforts
- Expansion of Data to Care Activities
- Discussion:
  - Maximizing the utility of Data to Care efforts
  - Potential barriers/challenges
  - Resource/Support needs

What is Data to Care?

- ***Data to Care*** *refers to the active use of laboratory information routinely reported to health department surveillance programs for the identification and linkage/re-engagement of HIV-diagnosed individuals who are not receiving medical care*.
  - Viral load and CD4 laboratory results serve as markers for the receipt of HIV-related health care
  - Expanded use of HIV surveillance data for individual intervention
  - Expanded monitoring/support for HIV-positive individuals along the HIV care continuum
  - Strategy is promoted by the CDC and has been implemented by multiple jurisdictions

What is Data to Care?

Continuum
Engagement in Care

Not in Care ⟷ **Fully Engaged**

Unaware of HIV status (not tested or never received results)	Aware of HIV status (not referred to care; didn't keep referral)	May be receiving other medical care but not HIV care	Entered HIV primary medical care but dropped out (lost to follow-up)	In and out of HIV care or infrequent user	Fully engaged in HIV primary medical care

What is Data to Care?

- Data to Care Program Models
  - Health Department Model
  - Healthcare Provider Model
  - Health Department/Healthcare Provider Model

- All models share the same basic operational steps

General Data to Care Operational Steps

Use HIV surveillance data to identify NIC individuals

↓

Generate output list from HIV surveillance database with key inclusion data for NIC list

↓

Investigate NIC list to complete missing data and verify care status

↓

Prioritize NIC list for follow-up and outreach

↓

Share key data with field staff and/or providers to locate individuals on NIC list and conduct outreach and linkage/re-engagement activity

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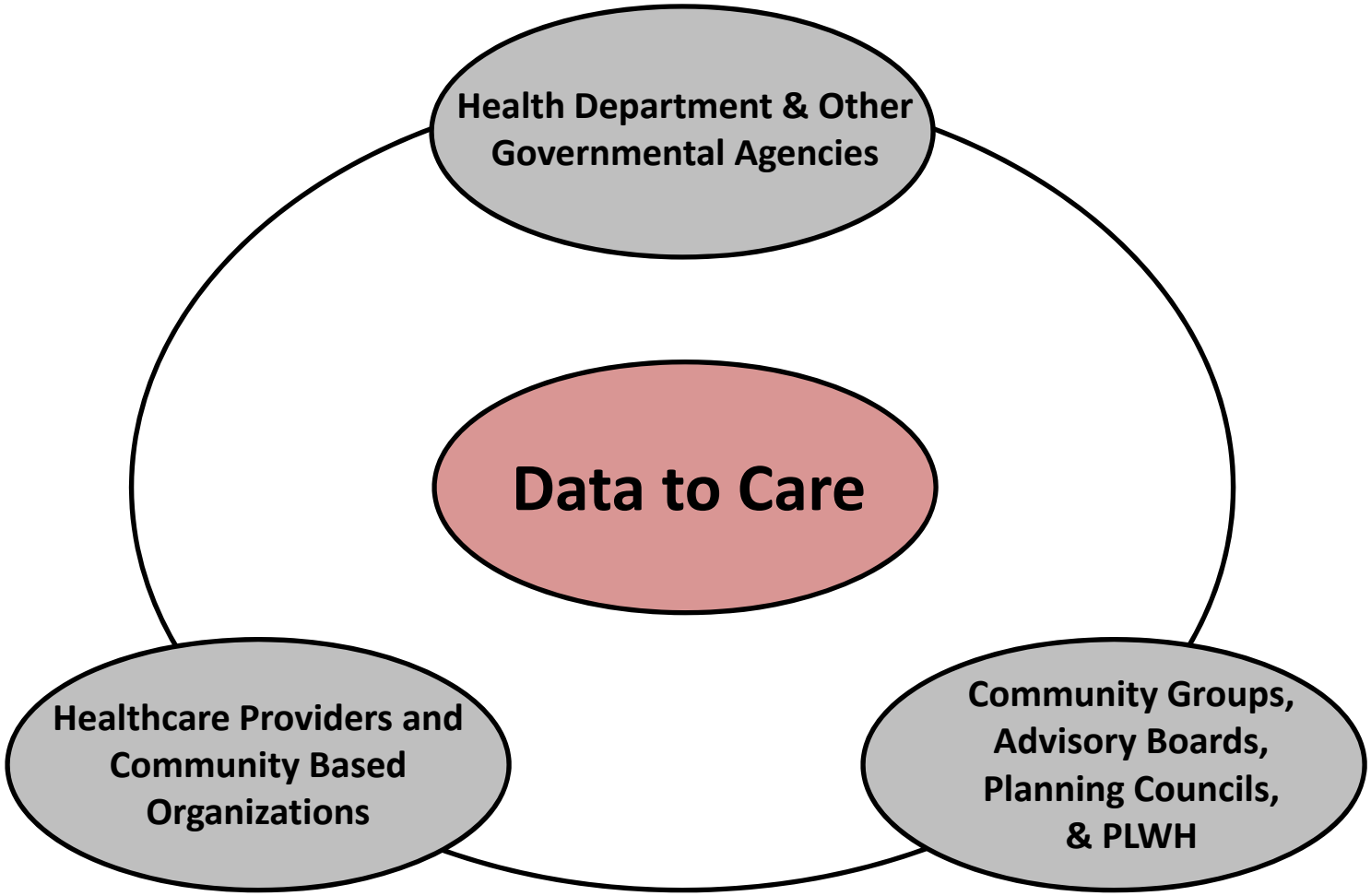
Provide missing data located during investigative and/or programmatic activity to HIV surveillance unit for review and quality assurance

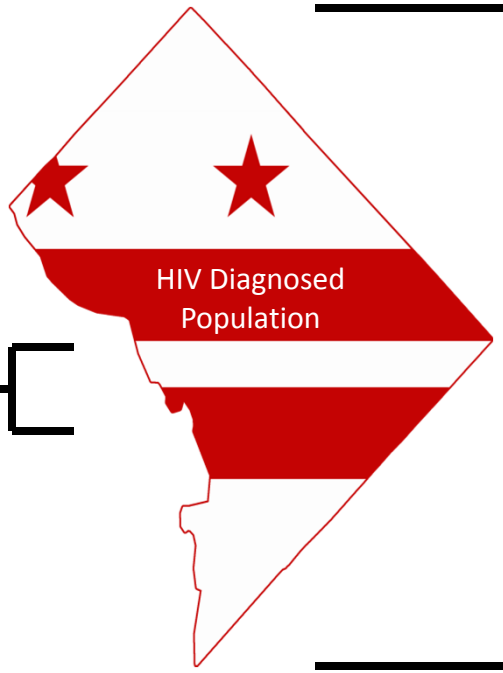
Data to Care: A Collaborative Effort



Benefits of Data to Care Strategies

Facility Based Efforts

- Some providers may lack the data monitoring infrastructure and/or personnel to actively identify and follow-up with patients that have fallen out of care
- Providers work in relative isolation
- Difficult to distinguish individuals with gaps in care vs. those that are receiving services at a different facility



Surveillance Guided Strategy

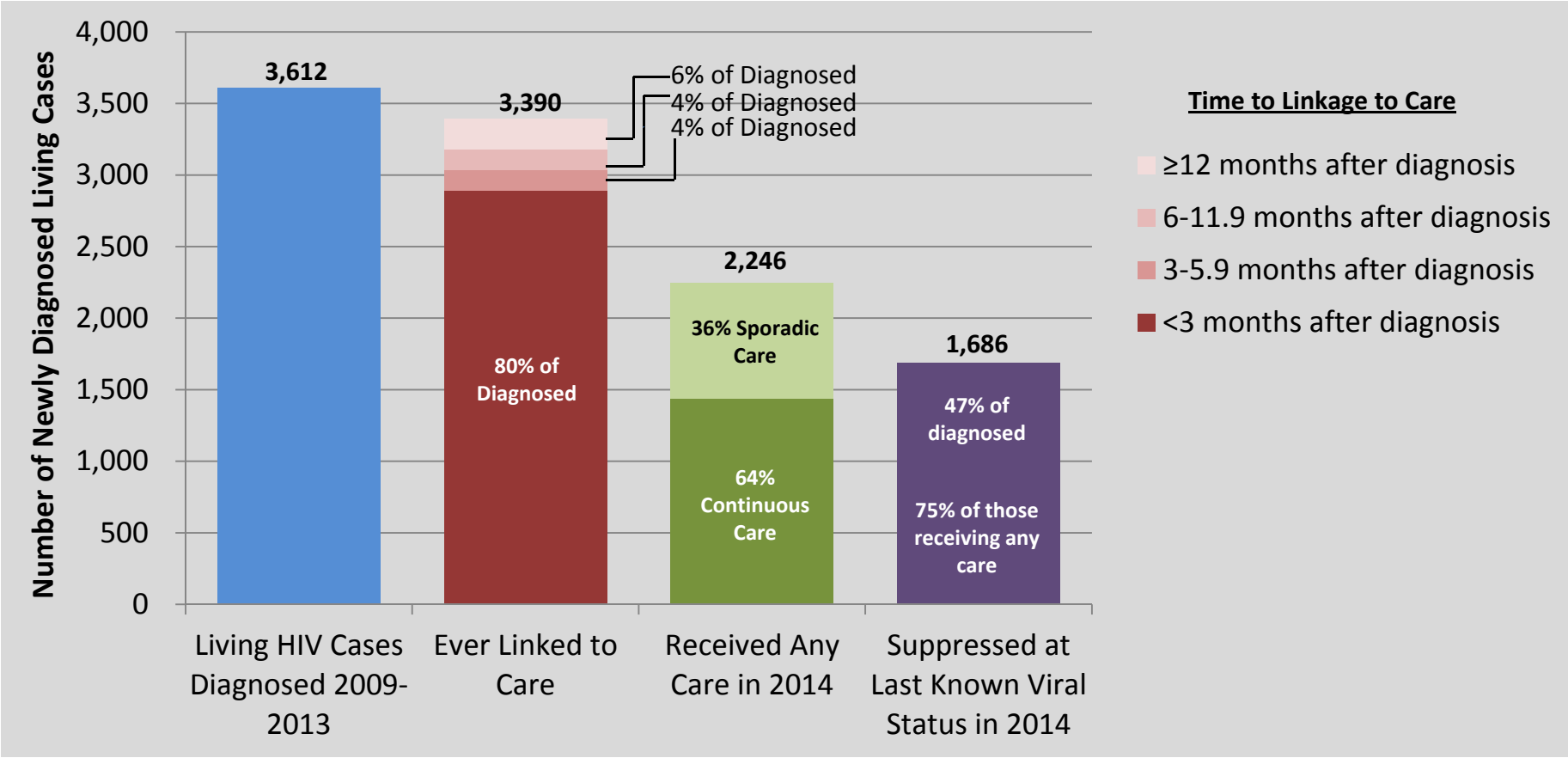
- Population-based
- Integration of information across care sites
- Utilization of multiple data sources facilitates a more accurate identification of those with gaps in care

Surveillance Guided Efforts Aid in Targeting Limited Resources

Goals of Data to Care

- Target Outcomes
  - Reduced number PLWH not engaged with appropriate health care
  - Increased number of PLWH compliant with effective treatment regimens
  - Increased number of PLWH that are virally suppressed
  - Reduced ongoing HIV transmission
- Alignment with National HIV/AIDS Strategy Goals
  - Reduce New Infections
  - Increase Access to Care and Improve Health Outcomes for People Living with HIV
  - Reduce HIV-Related Health Disparities and Health Inequities

Care Dynamics For Newly Diagnosed HIV Cases
District of Columbia, 2009-2013[1,2,3]



[1] Care linkage and retention measures based on individual viral load and/or CD4 laboratory information received by the health department
[2] Continuous care defined as ≥2 viral load and/or CD4 laboratory results >60 days apart
[3] Suppression defined as a viral load ≤200 copies/mL

Current Data-Driven HIV Care Linkage & Retention Efforts in the District

- HAHSTA has previously participated in efforts to improve HIV care dynamics within the District through the utilization of surveillance data in monitoring and/or facilitating individual-level care linkage and re-engagement efforts:
  - SMILE Youth Linkage to Care Program
  - Recapture Blitz

SMILE Linkage to Care Program

- **Strategic Multisite Initiative for the Identification, Linkage, and Engagement in Care of Youth with Undiagnosed HIV Infection (SMILE)**
  - Joint venture through the CDC and the NIH (NICHD)
  - Purpose is to ensure that all youth (ages 12-24) diagnosed with HIV are linked and engaged with HIV clinical care
  - Currently in 13 sites: Detroit, Bronx, Chicago, Miami, Tampa, Denver , Baltimore, Boston , Los Angeles, Memphis, Houston, New Orleans, and the District of Columbia
  - Facilitated locally through a partnership between the D.C. DOH and Children's National Medical Center

SMILE Linkage to Care Program

- Effort under this program is focused on the ***ACTIVE*** monitoring of newly diagnosed youth HIV cases
  - Program coordinator maintains routine contact with participating testing and care facilities to collect target information concerning individual care utilization, treatment compliance, and health outcomes
  - Surveillance data is reviewed to ensure case reporting completeness
  - Access database utilized to track case information
  - Proactive case follow-up by testing and care facilities to prevent gaps in care utilization

SMILE Linkage to Care Program

Identification

- Newly diagnosed
- Never in medical care
- Out of medical care for > 6 months

Linkage (LTC)

1st HIV medical appointment within 42 days (6 weeks) of initial report/referral

Engagement (EIC)

2nd HIV medical appointment within 112 days (16 weeks) of LTC visit

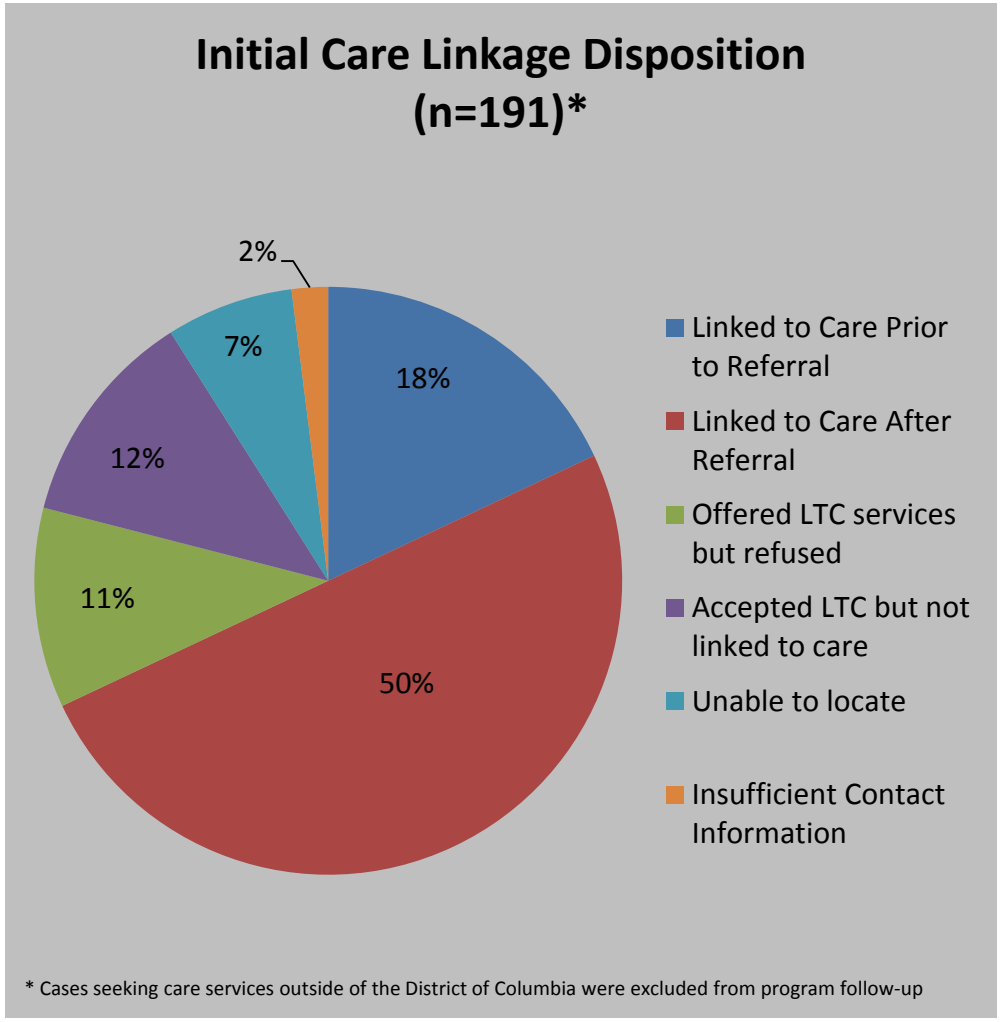
Retention (RIC)

3rd HIV medical appointment within 30 to 365 days (1-12 months) of EIC visit

SMILE II

SMILE Linkage to Care Program

- 31 participating practices and organizations within the District
- 225 HIV positive youth referred to program
- Multi-jurisdictional
  - 67% DC Residential Address
  - 27% MD Residential Address
  - 6% VA Residential Address
- 68% of cases linked to care within 6 weeks of diagnosis



SMILE Linkage to Care Program

- Results of SMILE program
  - Improved timeliness in the identification of newly diagnosed HIV cases by the HIV surveillance program
  - Integration of laboratory data and provider reported information (e.g., ART utilization) in the monitoring of cases
  - Timely follow-up of cases prior to significant gaps in care utilization
  - Increased collaboration and coordination between HIV testing and treatment sites in linking and retaining youth in care

Recapture Blitz

- Collaborative effort between DC DOH and local Ryan White providers
- Effort is targeted on the identification of HIV positive individuals that have been out of care ≥ 6 months based on the following:
  - Provider records
  - HIV surveillance data
  - Ryan White service data
  - ADAP data
- Providers conduct individual outreach and care re-engagement activities

Recapture Blitz

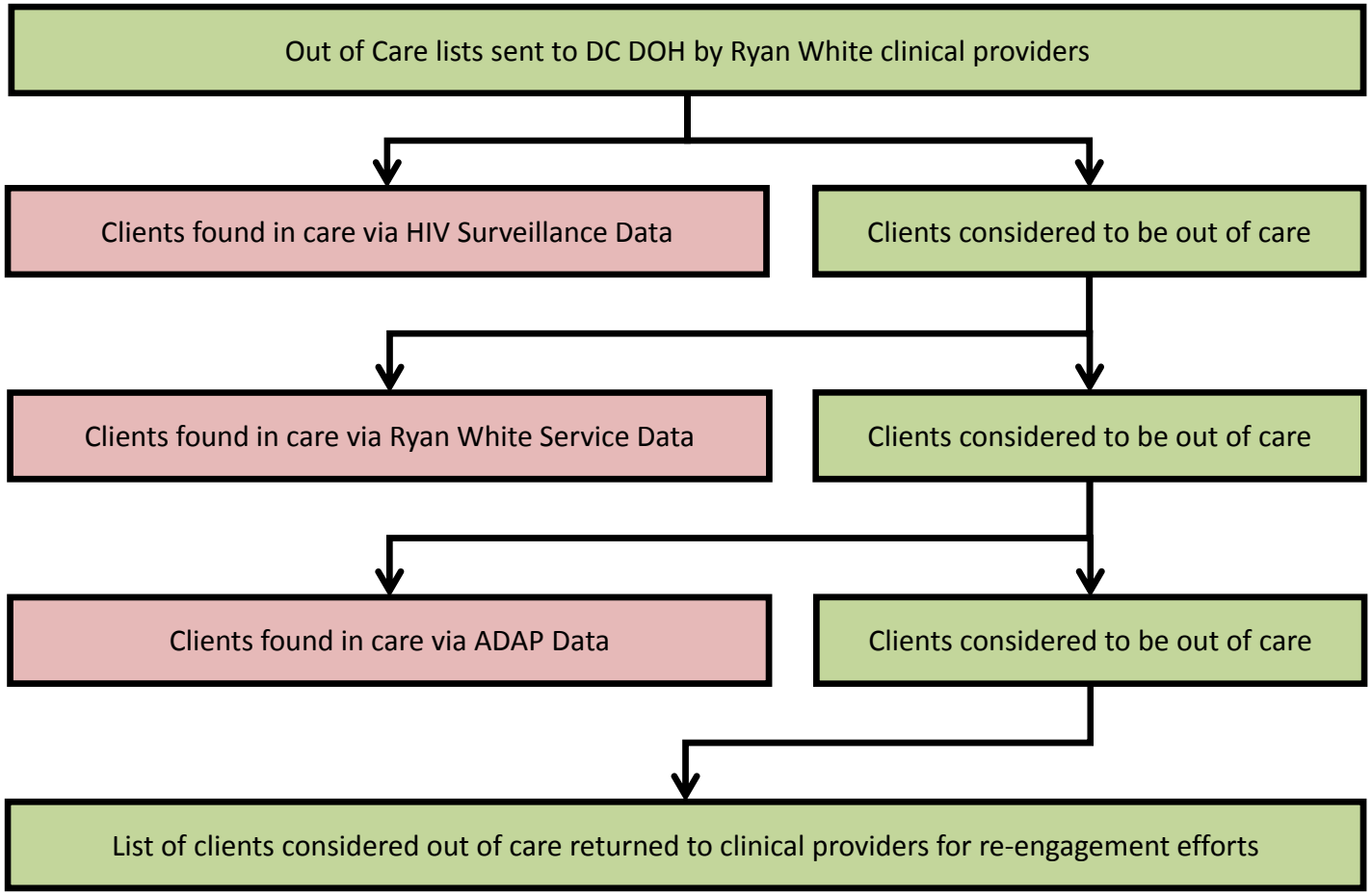


Figure 1. Recapture Blitz Workflow

Recapture Blitz

	2013*
Number of clients on provider generated Out of Care list	**1,015**
Number of clients sent to be contacted	**691**
Number of clients contact attempted	**573 (82.9%)**
• Number of clients reengaged	59 (10.3%)
• Number of clients found to be in care elsewhere	121 (21.1%)
• Number of clients relocated to another jurisdiction	61 (10.7%)
• Number of clients deceased	19 (3.3%)
• Number of clients unable to re-engage	46 (8.0%)
• Number of clients unable to locate	216 (37.7%)
• Number of clients with other disposition	51 (8.9%)
Range of contacts needed to reach a final disposition	**1-10 contacts**

*There are 7 providers reporting activities in this cycle.

Recapture Blitz

- Results of Recapture Blitz
  - Improved accuracy in the identification of out-of-care HIV cases
    - Reduced Out of Care list by 32% based on the review of HIV surveillance, Ryan White service, and ADAP data
  - Enhanced communication and coordination between the health department and care providers
  - Improved care dynamics
    - After direct individual case contact investigation, care providers were successful at reengaging 56% of cases determined to reside within the jurisdiction and to be out of care
    - 75% of reengaged cases had laboratory evidence of being retained in care at 1-year follow-up
    - 57% of cases retained in care at 1-year follow-up were virally suppressed based on their last reported laboratory result

Lessons Learned from Current Data to Care Efforts in the District

- Timeliness of Out of Care Case Identification and Follow-up
  - Tracking care utilization vs. Attempting to locate individuals after substantial gaps in care
- Data Deficiencies
  - Data reporting and processing delays
  - Incomplete and/or Out of Date information
  - Isolated data sources limit the accuracy of out of care case identification
  - Ad Hoc data matching time intensive
  - Need centralized database to track/update case information
- Inter-jurisdictional Needs
  - Consideration for HIV positive individuals receiving services outside of their residential jurisdiction

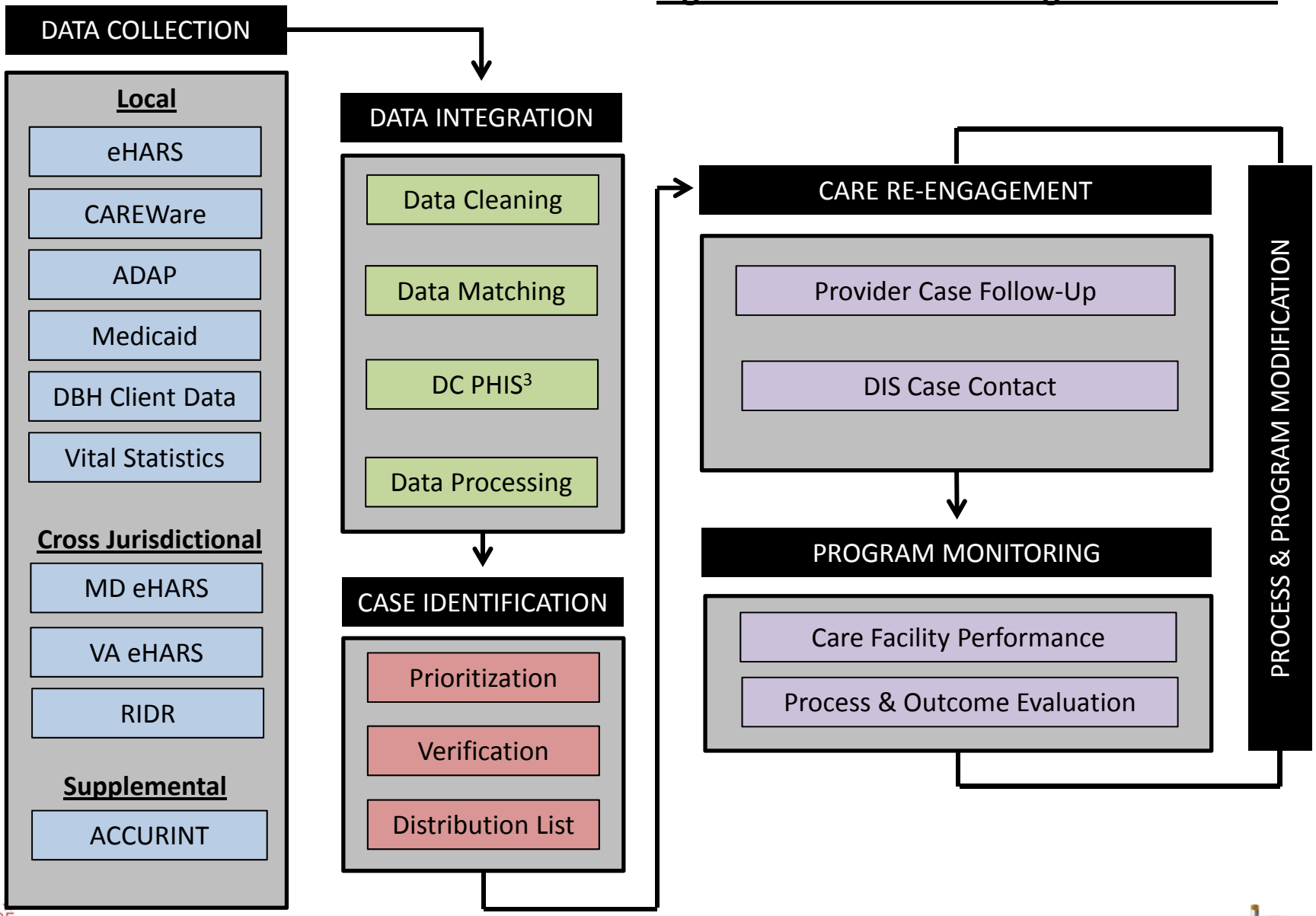
Lessons Learned from Current Data to Care Efforts in the District

- Intensity of Effort
  - Substantial personnel time required for care re-engagement effort
  - Reporting of care linkage/reengagement outcomes can be burdensome on provider facilities
- Case support needs
  - HIV positive individuals requiring care linkage/reengagement efforts may have multiple social, economic, and/or behavioral barriers to treatment compliance
- Utility/Effectiveness
  - DC experience has provided evidence that Data to Care can be an effective strategy

The Future of Data to Care Activities

- Improved Data to Care capacity through:
  - Expanded data acquisition and utilization
  - Improved data integration and management infrastructure
  - Development and implementation of routine processes and protocols
  - Case prioritization
  - Increased communication/coordination between the health department and community providers
  - Expanded role of health department in direct case linkage and retention efforts
  - Performance monitoring & feedback

Figure 1: Data to Care Program Workflow



Data Collection

- Expanded data collection efforts in order to more accurately characterize engagement in HIV care, vital status, and case location
  - Laboratory Results
  - Care Visits
  - Prescription Utilization
  - Ancillary support services
  - Public records

Data Collection

- Department of Health Data
  - HIV Surveillance Data
  - Ryan White CAREWare Database
  - AIDS Drug Assistance Program (ADAP)
  - STD Surveillance Data
- Inter-departmental data sharing
  - Department of Health Care Finance
    - Medicaid Data
  - Department of Behavioral Health
    - Integrated Care Application Management System (iCAMS)

Data Collection

- Cross-jurisdictional HIV Surveillance Data Sharing
  - Maryland Department of Health
  - Virginia Department of Health
- Lexis-Nexis, Accurint Software
  - Commercial, person-locating software package
  - Direct connection to over 37 billion current public records held within 10,000 databases
  - Used to verify identities, obtain current address & telephone information, conduct investigations

Data Integration

- Initial efforts will focus on implementation of more frequent data matching protocols (e.g., quarterly)

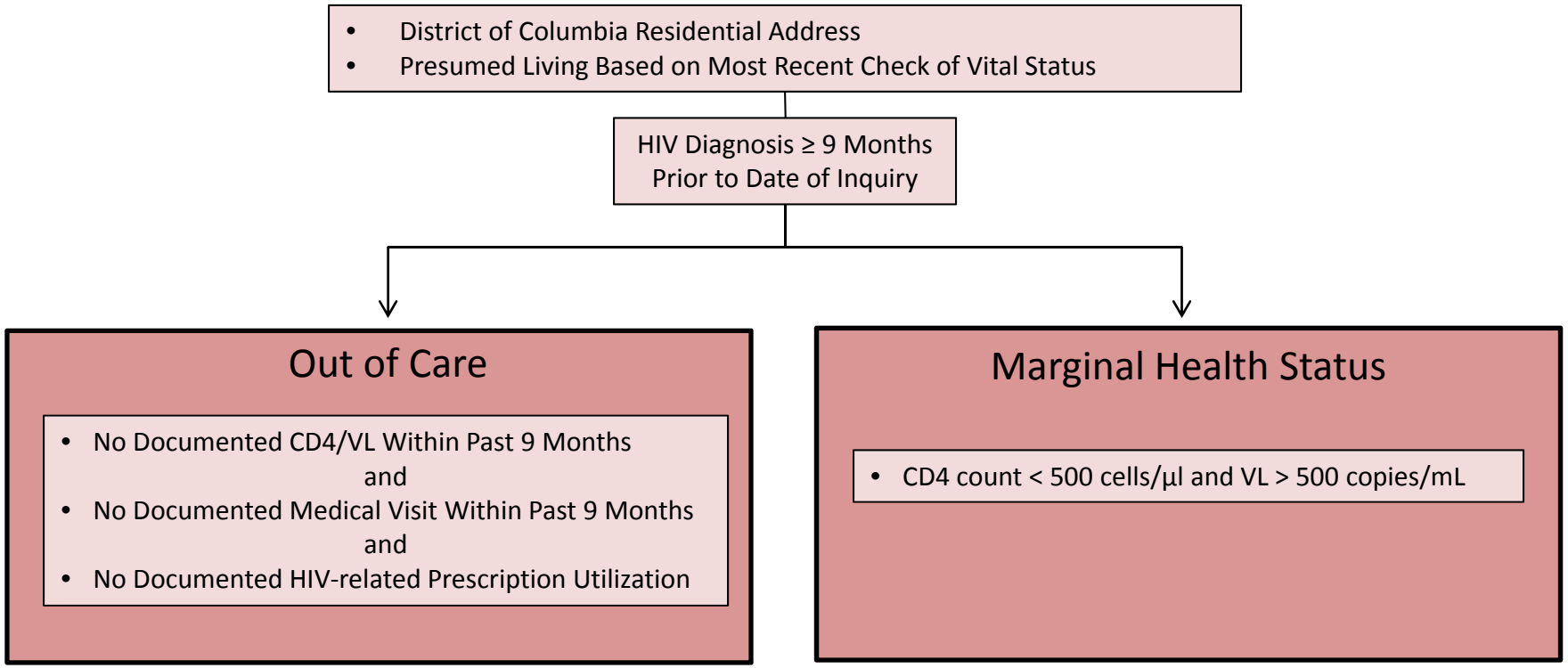
- DC Public Health Information System (DC PHIS) Enhancements

  – ***Expanded Data Collection Capacity*** – Additional data elements will be added to the current HIV-related data modules within DC PHIS to allow the collection of target information from each of the supplementary data sources previously outlined. Data elements will also be added to address required data collection needs for evaluating and monitoring proposed care re-engagement activities and outcomes.

  – ***Automate Data Processing*** – In addition to the modification of current data matching, validation, and reconciliation operations, multiple data processing algorithms related to the specification of target out of care cases (e.g., current residence identification, care engagement and health status assessment) will be incorporated within DC PHIS.

  – ***Expanded Reporting Functions*** – Static reporting functions will be incorporated within DC PHIS to address routine operations such as the creation of target HIV case line listings for outreach activities and the generation of aggregate monitoring and evaluation assessments.

Figure 2: Data-to-Care Case Identification Criteria



Case Prioritization

- Development of Prioritization Schema
- Target populations (e.g., MSM of color, Transgender)
- Case Characteristics
  - Value of last reported viral load and/or CD4 count
  - Time since last medical care visit
  - Time since diagnosis
  - Recency of infection
  - Time since any new case information documented

Care Reengagement

- HIV care providers
  - Assignment of Out of Care cases based on the last reported facility where HIV-related care/treatment services were received
- DOH DIS
  - Expanded role of Disease Intervention Specialist in assisting with the care linkage, navigation, and retention
- Community partners
  - Community Health Worker (CHW) programs
- Capacity building
  - DOH supported TA
  - Model programs
  - Peer-to-Peer Training

Monitoring & Evaluation

- Implementation of expanded Data to Care efforts will be an iterative process
- Integrated monitoring & evaluation processes for assessing:
  - Accuracy of case identification
  - Timeliness of case identification
  - System & Facility care reengagement performance
- Benefits of monitoring & evaluation information
  - Identification of areas for improved efficiency
  - Identification of model practices

Target Process Outcomes

- Improved data timeliness, completeness, and quality related to HIV case demographic, contact, care and treatment, and clinical outcome characteristics based on the routine collection and integration of information from multiple inter-organizational and cross-jurisdictional data sources.

- Enhanced data management infrastructure based on the development of expanded data collection, processing, and reporting functions within the District of Columbia Public Health Information System (DC PHIS).

- Increased accuracy and efficiency in identifying HIV cases for targeted HIV care re-engagement activities based on effective data integration and automated data processing and reporting.

- Increased organizational and system capacity to implement effective HIV care re-engagement activities based on the addition of needed HAHSTA technical and outreach personnel; expanded field and DIS staff roles; and enhanced provider communication, support, monitoring, and feedback through routine protocols and processes.

Target Clinical Outcomes

- Increase in the percentage of the HIV positive that is retained in clinical care and compliant with a prescribed HIV treatment regimen
- Increase in the percentage of the HIV positive population that is virally suppressed
- Reduction in the percentage of the HIV positive population with Stage 3 disease
- Reduction in the number of HIV-related deaths
- Reduction in the number of new HIV infections

Discussion

Discussion Questions

- What are your initial thoughts concerning the utility of past data to care activities, as well as planned effort enhancements?
- In what ways do you feel that your organization has or can benefit from data to care activities?
- What are some of the challenges/barriers that your organization has experienced in relation to past data to care activities (or anticipate given outlined plans)?
- Recommendations for addressing identified challenges/barriers?
- Are there particular resources/trainings/capacity building needs within your organization related to outlined data to care efforts?

INPUTS →	ACTIVITIES →	OUTPUTS →	OUTCOMES		
			SHORT-TERM	INTERMEDIATE	LONG-TERM
Program Coordinator Epidemiologic & Health Informatics Staff Field Outreach Personnel Inter-Governmental and Inter-Jurisdictional Data Sharing Agreements Information Technology Support & Infrastructure HAHSTA, Community Based Organization, & Clinical Provider Partnerships	Modification of Current Data Collection & Processing Procedures Implementation of Routine Data Matching & Cleaning Procedures Implementation of Procedures/Mechanisms for Tracking Re-Engagement Activities and Outcomes Modification of DC PHIS to Incorporate Expanded Data Collection, Management, & Reporting Needs Clinical & Community Partner Engagement Assessment of Provider Capacity for Care Re-Engagement Activities Development of Data to Care Protocols & Standard Operating Procedures DIS & Field Staff Training Concerning Care Re-Engagement Strategies Prioritization of Target HIV Cases for Provider/HAHSTA Follow-Up Provider & HAHSTA Care Re-Engagement Outreach Ongoing Data to Care Program Evaluation & Modification Provider Performance Monitoring & Feedback Automation of Case Identification and Provider Notification Through DC PHIS*	Operational Multi-Jurisdiction and Inter-Governmental data exchange model Standard Data Collection, Processing, Matching, & Cleaning Processes Comprehensive Data Management and Reporting Infrastructure Incorporation of Retention Strategies With DIS & Field Staff Activities Comprehensive Network of Community & Provider Organizations for Care Re-Engaging Activities Policies & Procedures Manual for Care Re-Engagement Activities Target Case Re-Engagement Priority List Provider Facility Report Cards Documenting Care Retention Performance	Improved Data Completeness, Timeliness, & Quality Enhanced Data Collection and Integration Infrastructure Improved Accuracy & Efficiency in the Identification of HIV Positive Individuals Out-of-Care and/or with Suboptimal Clinical Outcomes Improved Workforce Capacity to Implement Care Retention Activities Increased Inter-organizational coordination of Care Retention Activities	Reduced Time to Care Re-Engagement after Gaps in the Receipt of Clinical Services Increased Percentage of HIV Positive MSM & Transgender Population Retained in Clinical Care Increased Percentage of HIV Positive MSM & Transgender Population Compliant with HIV Treatment Regimen	Increased Percentage of HIV Positive MSM & Transgender Population That Is Virally Suppressed Reduced Percentage of HIV Positive MSM & Transgender Population With Stage 3 Disease Reduced Number of HIV-Related Deaths Within HIV Positive MSM & Transgender Population Reduced Number of New HIV Infections Within MSM & Transgender Population

* Project Year 2 & 3 Activity

Government of the District of Columbia
Department of Health
HIV/AIDS, Hepatitis, STD, and TB Administration

2015 Grantee Forum

NEW HIV Diagnostic Testing Algorithm: 4th Generation Immunoassay

Garret Lum, MPH
Acting Chief
Strategic Information Division
HAHSTA

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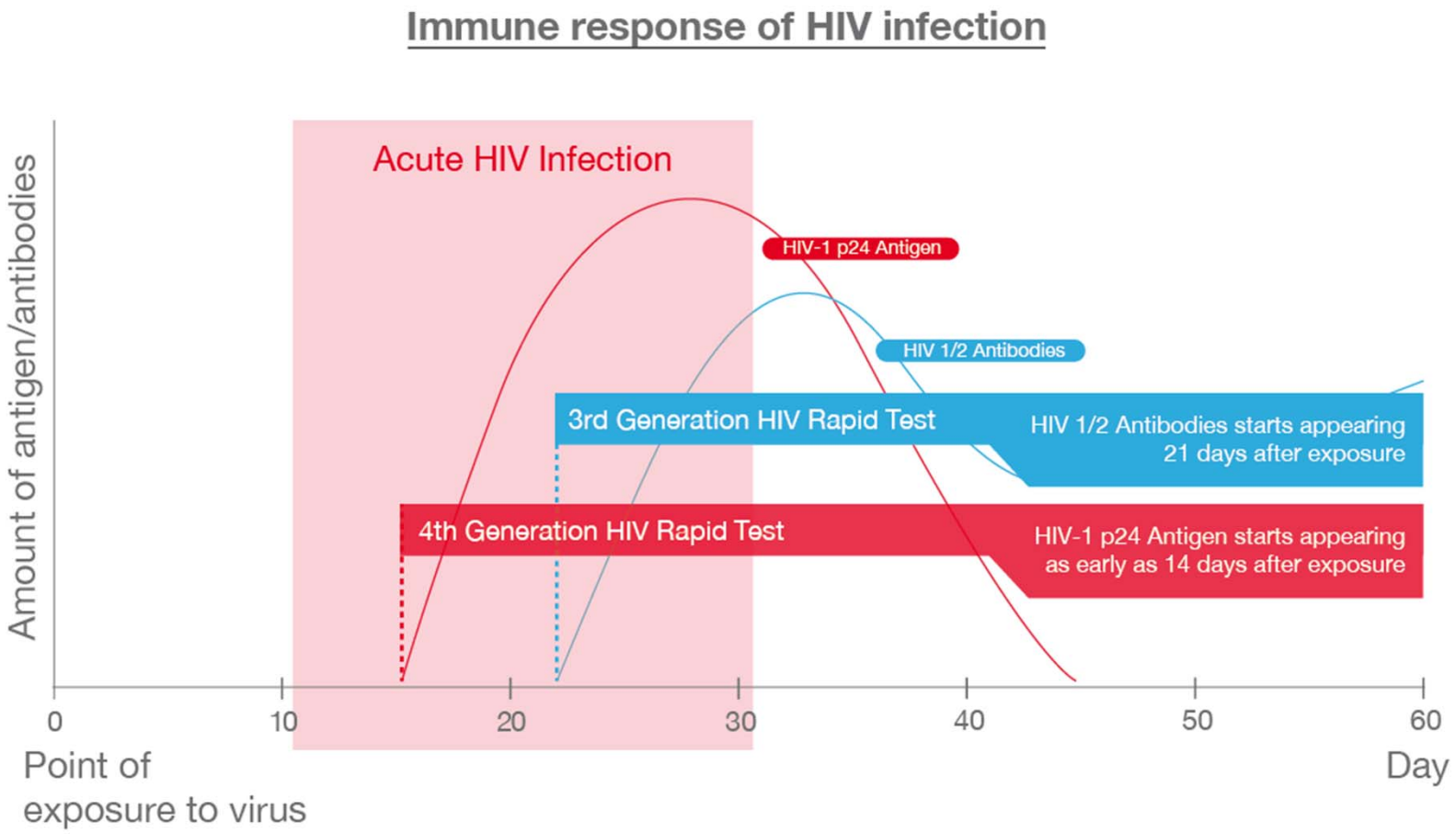
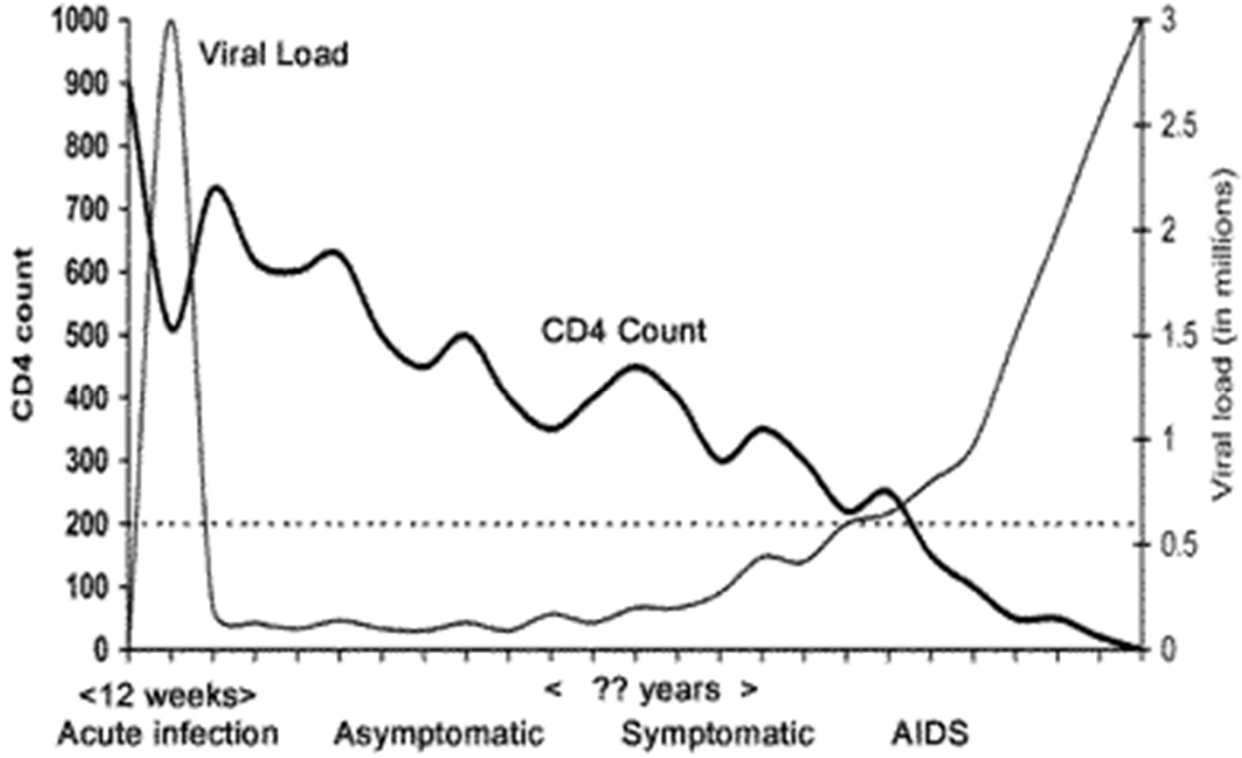
Overview

- HIV testing is a core part of the CDC High-Impact Prevention Approach
  - Gateway to linking HIV positive individuals to appropriate care and treatment services
  - Early HIV detection provides the opportunity for individuals to take action in the prevention of further disease transmission
- 4th Generation HIV-1/2 Immunoassay
  - Detects both the antibody to HIV and the antigen "p24"
  - Reduces the window period for false negatives
  - 1st step in new HIV testing protocol

HIV Infection Detection



The Course of HIV Infection

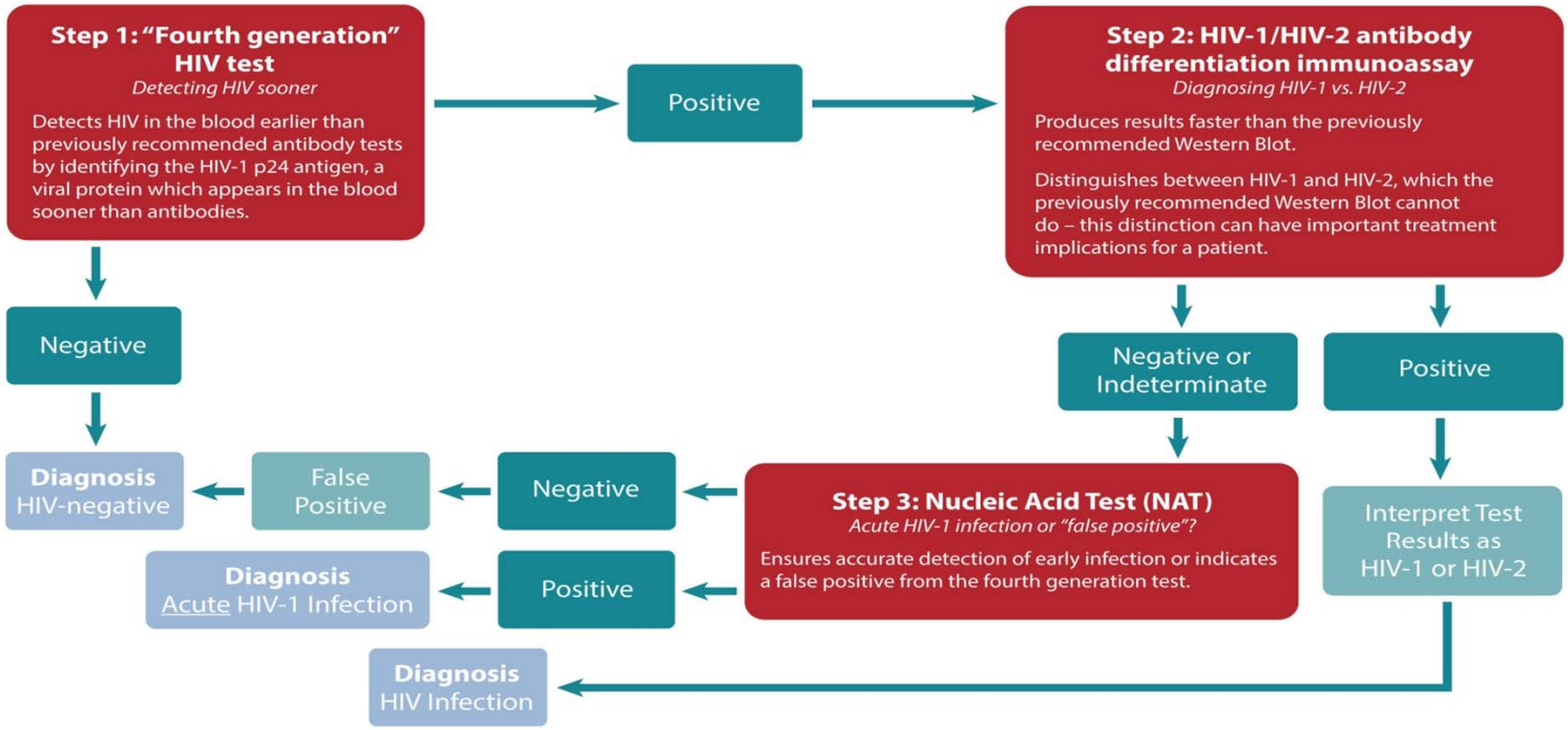


New CDC Recommendations for HIV Testing in Laboratories

A step-by-step account of the approach

CDC's new recommendations for HIV testing in laboratories capitalize on the latest available technologies to help diagnose HIV infections earlier – as much as 3-4 weeks sooner than the previous testing approach. Early diagnosis is critical since many new infections are transmitted by people in the earliest ("acute") stage of infection.

By putting the latest testing technology to work in laboratories across the United States, we can help address a critical gap in the nation's HIV prevention efforts.



This graphic is designed to illustrate key concepts of the new testing approach in laboratories. For more detail, please see the full guidelines here: http://www.cdc.gov/hiv/pdf/HIVtestingAlgorithmRecommendation-Final.pdf.

U.S. Department of Health and Human Services
Centers for Disease Control and Prevention

www.cdc.gov/nchhstp/newsroom

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Discussion/Questions