2006 CSTE ANNUAL CONFERENCE

INTEGRATING DATA TO MEET NEW CHALLENGES

HIV INCIDENCE AND CASE SURVEILLANCE BRANCH

PRECONFERENCE WORKSHOP

JUNE 4, 2006

HYATT REGENCY ORANGE COUNTY
ANAHEIM, CALIFORNIA

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CSTE Pre-Conference HIV/AIDS Surveillance Workshop
Integrating Data to Meet New Challenges

8:00 a.m. Registration

Morning Session **Moderator: Anthony Merriweather**

8:30-8:45	Welcome (Matthew T. McKenna, CDC)
8:45-9:00	HIV Surveillance Support: The Funding Process (Ronald Sanders, CDC)
9:00 – 10:30	State and Local Implementation of Technical Guidance for HIV/AIDS Surveillance Setting Standards: A CDC/CSTE Collaboration (Martha Miller, CDC) Re-abstraction in Georgia (Luke Shouse, Georgia Department of Public Health) Michigan Quality Assurance Procedures (Nilsa Mack, Michigan Department of Community Health) Risk Factor Ascertainment (Sharon Carter, Virginia Department of Health) Record Linkages and Death Ascertainment in Massachusetts (James Murphy, Massachusetts Department of Public Health) Electronic Lab Reporting in Seattle (Jim Kent, Seattle & King County Public Health)
10:30-10:45	**Break**
10:45 – 11:45	Integration of Core and Incidence Surveillance (Joseph Prejean, CDC) (Susan Scheer, San Francisco Department of Public Health) (Cheryl Jablonski, Texas Department of Health) (Christina Lynch, Washington State Department of Health, Seattle & King County Public Health)
11:45-12:00	**Break – get boxed lunch**

Lunch Session **Moderator: Doug Frye**

12:00-1:15	Roundtable Discussions – Security & Confidentiality Case Studies (Kathleen S. Brousseau, New York State Department of Health) (Maree Kay Parisi, San Francisco Department of Public Health) (Pam Lowell, Florida Department of Health) (Gail Maureen Hansen, Washington D.C. Department of Health)
1:15-1:30	**Break**

Afternoon Session **Moderator: David Fields**

1:30-1:50	Ryan White CARE Act Update (Pat Sweeney, CDC)
1:50-2:30	The Joy of Quality Data (Maria Rangel, CDC) (Becky Grigg, Florida Department of Health) (Jeni Mulqueen, Kansas Department of Health and Environment)
2:30-2:50	Demonstration of eHARS (Sam Costa, CDC)
2:50-3:10	The 411 on Site Visits (Loren Cadena, CDC) (Maree Kay Parisi, San Francisco Department of Public Health)
3:10-3:45	Integration of Surveillance with Other Programs (Marie Courogen, Washington State Department of Health) (Bill Jones, North Carolina Division of Public Health)
3:45-4:15	Presentation from Dr. Kevin Fenton – New NCHHSTP Director
4:15-4:30	Break to convene for Business Meeting
4:30-5:30	CSTE Business Meeting

HIV Surveillance Support: The Funding Process

Ron Sanders, MPA
Program Consultant
HIV Incidence and Case Surveillance Branch

CDC

Topics Covered Today

- 2006 Surveillance Funding Process
- Financial Status Reports
- Carryover requests
- 2007 application timeline
- Answer your questions

CDC

2006 Surveillance Funding Process

- Congress appropriated $8.4 billion in 2006 for CDC – the first overall cut in 25 years
- Congressional rescission of 1.0% ($60 million) compared with 0.8% cut in 2005 – applied across the board at CDC
- HICSB absorbed part of the reduction

CDC

2006 Surveillance Funding Process

- All surveillance grantees were cut 1%
- Initial $300,000 award exempted from further cuts
- Awards above $300,000 were further reduced by 1.0% to 5.36%, to give an overall reduction of 1.98%

CDC

Funding Rescission Example

Total recommended	$450,000
Exempt	- 300,000
Subject to cut	$150,000
Sliding scale cut	$8,040 (**5.36%** X $150,000)
1% rescission	+ 4,500 (1.0% X $450,000)
Total cut	$12,540 (2.78% overall)
Final award	$437,460

CDC

Financial Status Reports

- Due 90 days after the end of the previous funding period
- Documents unobligated funds, not necessarily spent funds
- Must precede or accompany a request for use of carryover funds

CDC

Carryover Funds

- Only unobligated funds from the previous 2 budget periods can be carried over to the new funding year.
- Grants Management determines if a carryover request will be approved.
- Include a purpose, budget summary (SF 424A), budget justification, and FSR if not previously provided to Grants Management.

CDC

Carryover Funds

- Requests must be signed by grantee's business office and the project director.
- Recommendation for approval is required from the program office – copy your Program Consultant
- Response is usually issued within 30 days of receipt

CDC

The Small Print

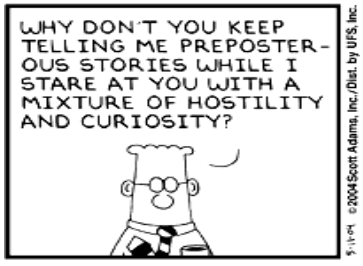
- Proposed activities must be within the scope of the cooperative agreement.
- Carryover funds should be used to support one-time activities.
- Cannot support general education, seroprevalence, or prevention activities.
- Cost of information technology to implement eHARS will be supported through Direct Assistance supplements.

CDC

FY 2007 Funding Timeline

- FY 2007 is the last year for PA 04017
- Funding period: Jan. 1 – Dec. 31, 2007
- Funding Guidance Available: July 1, 2006
- Competitive applications due to CDC: Sept. 1, 2006
- Award notices sent: Nov. 2006

CDC



Questions?

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CDC

State and Local Implementation of Technical Guidance for HIV/AIDS Surveillance

Presented by
Martha Miller, MPH

CSTE Pre-Conference Workshop
June 2006

CDC

Setting Standards

A CDC/CSTE Collaboration

CDC

Uses of HIV/AIDS Surveillance Data

- to monitor the spread of HIV infection at the state and local levels
- to evaluate prevention programs and health care services
- to allocate funding for HIV prevention and care

CDC

Evaluation

Purpose:

- to monitor progress toward achieving program goals (outcome standards)
- to ensure accurate, complete, and timely data
- to find opportunities for continuous quality improvement

CDC

Technical Guidance for HIV/AIDS Surveillance Programs

Volume I: Policies and Procedures

Volume II: Data Collection Resources and Reporting

Volume III: Security and Confidentiality Guidelines

CDC

Standards for Collection of HIV/AIDS Surveillance Data

- **Structural requirements**
- **Process standards**
- **Outcome standards (measurable objectives)**

CDC

The Essence

measuring what matters for data quality

Process Standards

- Intrastate duplicate review: monthly
- Interstate duplicate review: monthly
- Death ascertainment: annually

Outcome Standards (I)

Completeness and Timeliness

- minimum: ≥ 85% of expected cases reported by 12 months after diagnosis year
- target: ≥ 95% of expected cases reported by 12 months after diagnosis year

Outcome Standards (II)

Edits

- minimum: ≥ 97% of case records pass all standard data edits, assessed at 12 months after the diagnosis year
- target: 100% of case records pass all standard edits

Outcome Standards (III)

Risk factor ascertainment

≥ 85% of reported cases (or representative sample) for a diagnosis year with identified HIV risk factor within 12 months of date of initial case report, measured at 12 months after close of diagnosis year

Outcome Standards (IV)

Duplicate reports

- Intrastate
  - < 5% duplicates, assessed at 12 months after diagnosis year
- Interstate
  - < 5% duplicates in national database, assess for each diagnosis year 12 months after diagnosis year

Outcome Standards (V)

Proportion of Death-Certificate-Only (DCO) cases

- < 5% with only a death certificate
- assessed at 24 months after death/diagnosis year

Data reporting and dissemination

annual HIV/AIDS surveillance reports

CDC

Outcome Standards (VI)

CD4 reporting*

≥ 50% initial CD4 counts for newly diagnosed adults (≥ 13 years) reported to national HIV/AIDS surveillance system within 12 months of diagnosis

* developmental standard

CDC

Security and Confidentiality Guidelines (Volume III)

- 5 guiding principles
- 35 requirements
- HHS clearance

CDC

"Knowing is not enough; we must apply. Willing is not enough; we must do."

-- Goethe

CDC

State Implementation of Technical Guidance

- Luke Shouse: Re-abstraction in Georgia
- Nilsa Mack: Michigan Quality Assurance Procedures
- Jim Murphy: Record Linkage and Death Ascertainment Activities in Massachusetts
- Sharon Carter: Risk Factor Ascertainment in Virginia
- Jim Kent: Electronic Lab Reporting in Seattle & King County

CDC

HIV/AIDS Surveillance Program
MI Department of Community Health
Bureau of Epidemiology

Michigan Quality Assurance Procedures

Nilsa Mack, MPH
CSTE Annual Conference-Anaheim, CA
June 5, 2006

Topics

- **Quality Control Activities:**
  - ***Documentation of Procedures- HIV/AIDS Surveillance Procedures Manual and other manuals (HARS)**
  - ***Quarterly data cleaning procedures**
  - ***CRF comparison**
  - ***Re-abstractions**
- **Training of Staff and Report Sources**
- **Feedback**

MI- Background Information

- **Two offices- Detroit and Lansing**
- **Detroit office- handles 2/3 of cases (SE MI), dedicated data entry person, data manager (QA), 4 surveillance staff (1 QA staff), special projects**
- **Lansing office- handles 1/3 of cases (outstate), 3 surveillance staff (1 QA), staff do their own data entry, lab coordinator and lab data entry person. More providers, rural counties, traveling**

MI- Background Information

- **HARS centralized system (both offices connect to same server via a Wide Area Network), ~25,000 HARS records**
- **There were 1,324 cases reported in 2005 and about 240 deaths in 2004**
- **Medium morbidity state**

Documentation of Procedures HIV/AIDS Procedures Manual

- **Data Collection and Data Entry (standardized)**
- **Processing of confidential and anonymous reports**
- **Processing of lab reports, death certificates and other documents**
- **NRRS/NIRs**
- **Linkage of electronic records**
- **Data quality, analysis and dissemination**

Routine Quarterly Data Cleaning

- **Consists of 3 components:**
  1) investigation of possible duplicate cases
  2) investigation of data entry errors
  3) cleaning of site fields (legal list of providers)

Quarterly Data Cleaning Investigation of Duplicate Cases

- HARS duplicate verification utility (intra-)- compares cases by soundex and dob
- CRFs are pulled and compared, duplicates are reconciled (Reconciliation Form)
- Some cases have to be followed up with provider
- Alias field (helpful especially for prisoners and women)
- Findings- 5-10 potential duplicates

Quarterly Data Cleaning Investigation of Data Entry Errors

- Errors checking SAS program- a list of cases with suspect status, errors and missing diagnostic, demographic and death information (E and R records)
- CRFs are pulled, investigated and updated (document on same CRF or do an update, staff initials and date)

Quarterly Data Cleaning Cleaning of Legal List

- SAS program that compares all facilities of diagnoses and sites of care to the legal list of facilities
- Facilities not in the legal list are investigated and corrected (standard codes/format to enter facilities)
- New facilities are added to legal list

Common Data Quality Issues

- HARS- Cases entered as AIDS without AIDS-defining condition(s)
- Residence of HIV or AIDS diagnosis missing
- Demographic information missing
- DOD and/or source of death information missing
- Legal list- typo errors, staff not using standard codes when entering new facilities, etc.

Case Report Form Comparison

- 200 CRFs (100 in Detroit and 100 in Lansing)- ~20% of cases are selected and are compared to what is entered in HARS
- Discrepancies are corrected
- Findings- spelling discrepancies, info recorded on CRF but not entered into HARS, facilities not entered per legal list, typos, etc.
- Once a year

Re-abstraction Studies

- All surveillance staff participate
- Once a year
- Re-abstract: demographic, laboratory, risk factor information
- Discrepancies between "initial" and "reabstraction" CRFs are documented, recommendations are presented to staff
- Findings- middle name discrepancies, race indicated v. blank, address discrepancies, diff facility names, diagnostic tests indicated v. blank, OI's pres v. def, etc.
- Planning to revise current protocol

New Staff Training

- Orientation list
- One-on-one training
- Reference procedures manual
- Site visits with a senior staff for chart abstractions (data collection)
- Visual editing (proofreading of CRF before data entry into HARS) and verify keyed data
- Feedback- provided one-on-one and at surveillance meetings

Existing Staff Training

- SAS and Epi classes at a local university
- CDC workshops and trainings
- Feedback- provided one-on-one and at surveillance meetings. New or updated protocols are presented and discussed. Summary report of data errors (aggregated) is shared with staff

Report Sources Training- LHDs and Private Providers

- Site visits- train one person at the site; consider staff turnover
- Provider packet- includes reportable events, instructions on how to complete CRFs, HIPPA letter, HIV/AIDS reporting law, quarterly stats, etc.
- Mechanisms of reporting- phone, site visits or mail

Report Sources Training- LHDs and Private Providers

- Lab F/U protocol and letter to private providers
- Feedback- quarterly stats newsletter; considering the possibility of using report cards, on line training, timeliness and completeness by report source

Thank You!!!

www.michigan.gov/mdch
Statistics and Reports
Communicable Diseases
HIV/AIDS

Mackn@michigan.gov

Virginia Dept of Health
Division of Disease Prevention

hiv, std, hepatitis, tb, RX

Sharon Carter Hall
Core Surveillance Supervisor

Virginia HIV/AIDS Core Surveillance Staff

- 1 Surveillance Director
- 1 Core "Working" Supervisor + 3 Core Epi Consultants
  based in Central Office
  5 Regions
- 1 HARS Data Manager
- 1 HARS Data Entry Statistician
- 2 Data Entry Staff

Central Registry Unit (CRU) Staff

- 1 Medical Records Technician

  Provides assistance to Disease Intervention Specialists (DIS) & Virginia Emergency Response Team (VERT) for record searches & initiating Field Records (FRs) to Out of Jurisdiction Areas for STD's only
- 1 Office Service Specialists

  Provides assistance to the five regional Disease Intervention Specialists (DIS) and the Epi Consultants for record searches & initiating Field Records to Out of Jurisdiction Areas for HIV & AIDS

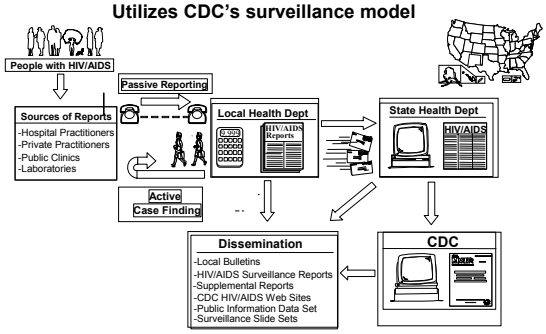
Virginia Surveillance Program

- **Name-based HIV reporting since July 1989**

- **Integrated HIV/STD Program**
  - **Access daily to STD database**
  - **Communicate daily with local health department Disease Intervention Specialists (DIS)**

Virginia HIV/AIDS Surveillance

Utilizes CDC's surveillance model



Division Databases

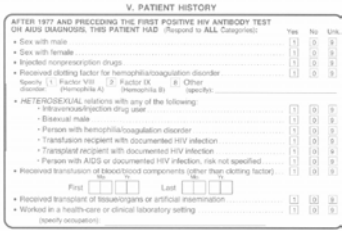
- HARS = HIV/AIDS Reporting System
- STD*MIS = Sexually Transmitted Disease Management Information System
- Code 1 Excel File – Used by Epi Consultant to track patients and potential cases that cannot be entered into HARS or STD*MIS

*Core Surveillance Staff receive and initiate CDC forms, Field Record and/or Interview Record and forwards to Disease Intervention Specialists

*Patient information that is missing pertinent data and cannot be entered into HARS and/or STD*MIS

Focus on Active Surveillance and Risk Factor Ascertainment

What are HIV Risk factors?



V. PATIENT HISTORY

AFTER 1977 AND PRECEDING THE FIRST POSITIVE HIV ANTIBODY TEST OR AIDS DIAGNOSIS, THIS PATIENT HAD (Respond to ALL Categories)

	Yes	No	Unk.
• Sex with male	1	0	9
• Sex with female	1	0	9
• Injected nonprescription drugs	1	0	9
• Received clotting factor for hemophilia/coagulation disorder	1	0	9
Specify (1) Factor VIII (hemophilia A); (2) Factor IX (hemophilia B); (8) Other specify:			
• HETEROSEXUAL relations with any of the following:			
- Intravenous/injection drug user	1	0	9
- Bisexual male	1	0	9
- Person with hemophilia/coagulation disorder	1	0	9
- Transfusion recipient with documented HIV infection	1	0	9
- Transplant recipient with documented HIV infection	1	0	9
- Person with AIDS or documented HIV infection, risk not specified	1	0	9
• Received transfusion of blood/blood components (other than clotting factor):	1	0	9
Mo. / Yr. First ___ ___ / ___ ___ Last ___ ___ / ___ ___			
• Received transplant of tissue/organs or artificial insemination	1	0	9
• Worked in a health-care or clinical laboratory setting (specify occupation):	1	0	9

Why are Risk Factors Important

- Identify new or unusual cases
- Monitor trends in the transmission of HIV
- Allocate resources
- Plan prevention programs
- Target risk reduction interventions
- Evaluate HIV/AIDS programs

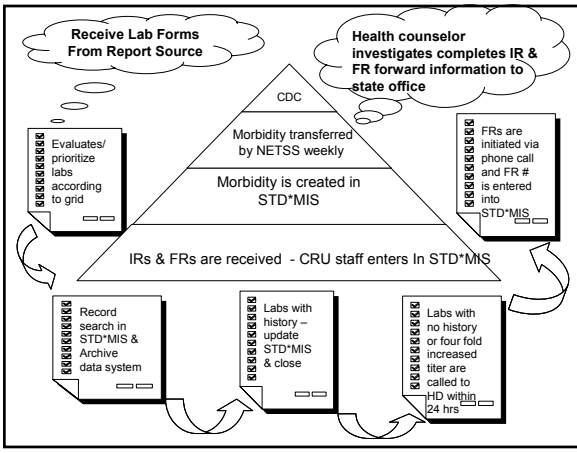
What Data are Collected?

- CDC50 Case Report Form
  - Demographic characteristics
    - Sex, race/ethnicity, age, residence
  - Risk information
    - Potential modes of exposure to HIV
  - Laboratory and clinical information
  - Virologic and immunologic status
  - Opportunistic illnesses diagnosed

HIV/AIDS Surveillance

How Data are Collected

- **Active reporting**
  - Health department surveillance staff find cases by contacting health care practitioners and reviewing medical records in hospitals and clinics
- **Passive reporting**
  - Health care practitioners, hospitals, clinics, and laboratories report cases of HIV/AIDS to state and local health departments
- **Primary case reporting**
  - Providers and facilities
- **Secondary case reporting**
  - Death records, hospital discharge summaries, TB, ADAP, etc.



Risk Factor Ascertainment Procedures

- 4 Epi Consultants work in conjunction with DIS and Central Registry unit
- One Medical Records Technician staff member provides record searches & sends Field Records (FRs) to out of jurisdiction/area (OOJ) for STD patients/cases
- One Office Service Specialist staff member dedicated to provide record searches & sending FR's to OOJ for HIV/AIDS patients/cases
- Epi Consultants & Central Registry Unit (CRU) staff provide Record Searches for 5 regions statewide for STDs and HIV & AIDS cases

Risk Factor Ascertainment Procedures
Continued

- STD*MIS record searches for risk factors on new & existing HARS cases via STD records
- Risk updated in HARS & STD*MIS Databases
- New STD, pregnancy or Contact is a marker for high risk sexual activity in existing cases:
  -Indicator to re-interview patient for Partner Counseling, & Referral Services (PCRS)
  -FR initiated by Epi Consultant
  -Forwarded to local DIS
  -Patient located for re-interview by DIS

Risk Factor Ascertainment Procedures
Continued

- Dedicated Central Registry Units staff members allow Epi Consultants to focus on Active Surveillance
- Reviews: No Reported Risk (NRR), No Identified Risk (NIR), Pediatric Cases and Cases of Public Health Interest (COPHI)
- Educate & Develop with providers
- Actively provide feedback to providers

PROCESS STANDARDS

- Standard Non-Reported Risks (NRR) are changed to Non-Identified Risks (NIR) in 12 months based on Interview Records (IR)
  - Closed – **NO** → further investigation needed
  - Closed –**YES** → no additional investigation needed
- Plan to add eHARS local use fields to specify
  - Outcome of risk investigation
  - If case is still NIR, Epi Consultant and/or Disease Intervention Specialists still needs to review records
  - Review Expanded Risk variables such as:
    - Sex for drugs and/or money
    - Foreign born

PROCESS STANDARDS
Continued

- Sampling
  - Focus on large facilities
  - Regions (areas) with large number of NIR cases
  - Have Core Surveillance Staff work with the Statistical Staff on samples and get their involvement

How to Meet Process Standards

- Utilize non-Core Surveillance staff during down time
- Offer Internships for Grad Students Practicum
- Wage staff

Questions?

Record Linkage and Death Ascertainment Activities in Massachusetts

James Murphy, MPH
Director HIV/AIDS Surveillance
Massachusetts Department of Public Health

HIV/AIDS Surveillance and Incidence Coordinator's Meeting
2006 CSTE Annual Conference
June 4, 2006

Overview

- Record Linkage Activities in Massachusetts
- Death Ascertainment as a Record Linkage Activity in Massachusetts
- Questions

Data Files Used for Record Linkage in Massachusetts

- Death Registries
  - MA Vital Records (annually)
  - NDI (1996 and 2005)
  - Social Security Administration Death Master File (planned 2006)
- TB Registry (annually)
- STD Registry (2001)
- Hepatitis C Registry (planned 2006)
- Laboratory Test Data Files (ongoing)
- HDAP Registry (annually)
- ACT Now Registry (annually)
- National AIDS/Cancer Match Registry or NACMR (1997 and 2004)
- Administrative or Clinical Data Files with ICD-9 Codes
  - Hospital Discharge Data (planned when data available)
  - Medicaid/Medicare Data (data availability under negotiation)
  - Large HMO (data availability under negotiation)

Death Ascertainment Record Linkage in Massachusetts

- State Vital Records Match
  - Annually
- National Death Index
  - 1996 and 2005
- Social Security Administration's Death Master File
  - Planned 2006

Record Linkage to Massachusetts Vital Records Data Collected

- Full Name
- Date of Birth
- Gender
- Social Security number
- Date of Death
- State of Death
- Underlying cause of death
- Death certificate number

Record Linkage to Massachusetts Vital Records Procedure

- Standardize the characteristics of the two datasets:
  - File type (Access 97)
  - Create soundex
  - Variable attributes
    - Name
    - Type (character or numeric)
    - Length
    - Component sequence or format

Record Linkage to Massachusetts Vital Records Procedure - AIDS

- One-to-one match with sex and soundex of last name and:
  1. Date of birth and soundex of first name or
  2. Year of birth, month of birth, and last 4 of ss# or
  3. Year of birth, day of birth, and last 4 or
  4. Year of birth, month of birth, and day of birth

Record Linkage to Massachusetts Vital Records Procedure - HIV

- One-to-one match with sex and first two letters of the first name and:
  1. # of letters in last name, last 4, month of birth, and year of birth or
  2. # of letters in last name, last 4, year of birth, and day of birth or
  3. # of letters in last name, 9999 for last 4 (in either dataset), month of birth, year of birth , and day of birth or
  4. Last 4, month of birth, year of birth, and day of birth

Record Linkage to Massachusetts Vital Records Results

- Visual analysis of output
  - Match
  - Not a match
  - Indeterminate and requires further work
- Update HARS and HIV database

Record Linkage to Massachusetts Vital Records Results 2005

- AIDS – 8,657 records examined
  - 265 new deaths identified
- HIV – 7,007 records examined
  - 61 new deaths identified

Record Linkage with National Death Index

- Part of survival analysis project
- Match to our AIDS and HIV databases
- NDI records 1983-2003 (1999-2003 HIV)

Record Linkage with National Death Index

- Process
  - Application submission
  - NDI approved format
  - Delimited text file
  - Appropriate secure exchange of data
    -PGP encrypted

Record Linkage with National Death Index

- Variables
  - First name
  - Last name
  - Social security number
  - Date of birth
  - Father's surname
  - Sex
  - Race
  - Marital status
  - State of residence
  - State of birth
  - Control (stateno)
  - Optional user data

Record Linkage with National Death Index

- Matching Criteria:
  - ss#, first name
  - ss#, last name
  - month & exact year of birth, first & last name
  - month & exact year of birth, first & middle initials, last name
  - month, & ± one year of birth, first & middle initials, last name
  - month, & ± one year of birth, first, last name
  - month & day of birth, first & last name
  - month & day of birth, first & middle initials, last name

Record Linkage with National Death Index Results

- Records had numerous potential matches
  - One to as many as 50 possible matches per record
- Visual analysis of the results from NDI

Record Linkage with National Death Index Results 2005

- AIDS -7841 records submitted
  - 307 new deaths identified
- HIV - 6404 records submitted
  - 30 new deaths identified

Implementing Technical Guidance for HIV/AIDS Surveillance

Electronic Lab Reporting
Jim Kent,
Seattle & King County

These look complex …

- 86 pages
- Technical terms
- What is HL7?

… but include just 5 elements...

- Electronic *case* reporting versus Electronic *lab* reporting (ELR)
- 1 diagram
- 25 pages of guidance
- 6 page table of desired variables
- Appendices

… and 8 simple steps

- Do your homework
- Set up your database
- Negotiate
- Implement
- Receive data
- Translate data
- Assess and Streamline
- Success!

Do your homework

- What is Public Health already doing?
  - Talk to non-HIV surveillance programs
  - Talk with NEDSS staff
  - Check with Computer / Network support
- What are labs already sending?
- What do the rules already say?
- Have I got all the labs covered?

Set up your database

- Tracking database to store all the incoming records
- Include all the variables you want
- Include stateno for linked records
- Include an outcome indicator

Negotiate

- Talk with each lab
- Talk with network support staff
- Integrate with other programs if you can
- Request HL7
- Request automated delivery
- Request daily / weekly delivery
- Ensure security at every step

Implement

- Labs that already report results
  - create electronic files
  - encrypt them (with PGP)
  - route them electronically
  - automate the reports
- MIS secure file transfer protocol (sftp)
- Automated delivery notification
- Download to secure location

Receive data

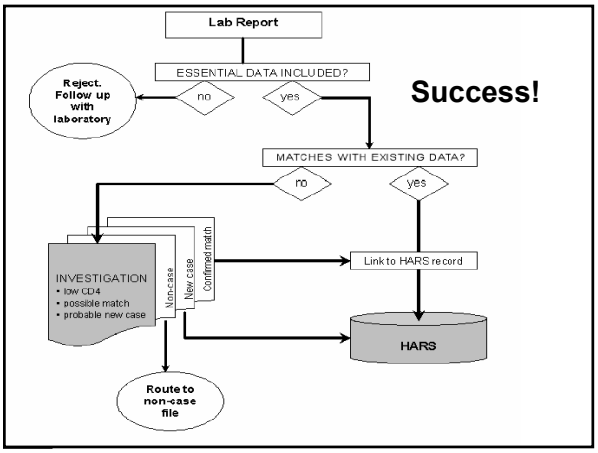
- SKC went live mid-2004
- Public Health lab was not the first in line
- Each lab has accomplished different steps
  - Automated HL7 daily transfers
  - Automated HL7 monthly transfers
  - Electronic monthly transfers
  - Files on floppy disk
  - Paper reports

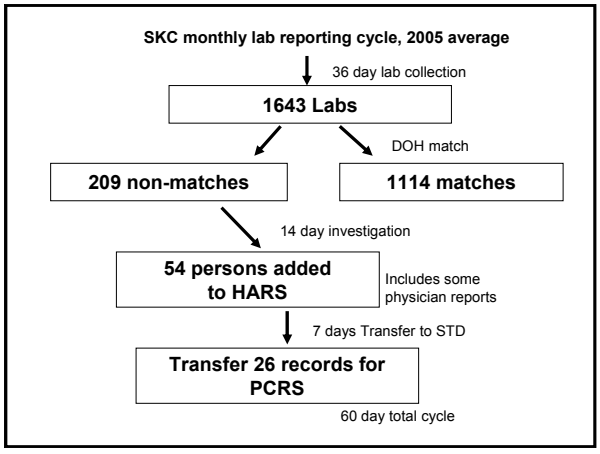
Translate data

- Handle each lab individually
- SAS program to read incoming data and output to your tracking database

Re-assess and Streamline

- Are the contents interpretable?
- Are there missing values?
- Do you know if a lab misses a report?
- Does SAS translator work?
- Are all the results linked to HARS?





Next steps!

- Route data to various projects
  - State and local
  - HIV Incidence Surveillance
  - Antiretroviral Resistance Testing
  - Never-In-Care project
- We are ready to implement expanded laboratory reporting
  - (all CD4s and all viral load results)

Contact Info

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So Happy Together: Integrating HIV Incidence Surveillance with Core Surveillance Systems

Irene Hall, Ph.D.
National Center for HIV, STD, and TB Prevention
HIV Incidence and Case Surveillance Branch
June 4, 2006

The findings and conclusions in this presentation are those of the author and do not necessarily represent the views of the Centers for Disease Control and Prevention.

Using our Assets

- The ability to conduct HIV Incidence Surveillance is dependent on a fully functioning Core Surveillance System
  - People
  - Data
  - Tools

People

- Co-location of staff
- Data Collection
- Quality Assurance
- Reporters
  - Established Relationships
  - New Opportunities

Data

- Targeting/Prioritizing
- Lab Reporting
- Timeliness
- Transition to Name-based Reporting

Tools

- Changing the Case Report Form
- Creating additional reporting Tools
- Databases
- eHARS

Thank You!

Christina Lynch, M.P.H.
Public Health - Seattle & King County
Cheryl Jablonski, M.A.
Texas Department of Health
Susan Scheer, Ph.D., M.P.H.
San Francisco Department of Health

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Integration of Core and Incidence Surveillance: San Francisco's Experience

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Overview of Presentation

- Overview of Core & Incidence Surveillance in San Francisco: structure, activities, status
- How SF has integrated Core & Incidence Surveillance
  - Space
  - Staffing & Staff Responsibilities
  - Other Coordination
- Challenges
- Successes

Overview of Core Surveillance

- Majority of the AIDS cases (79%) are reported actively by Core surveillance field staff
- Can do this because SF is relatively small; have to do this because history of 'spoiling' PMDs
- Laboratory reports processed each month (CD4 and viral load)
- Data from chart review at diagnosis and every 1.5 – 2 years thereafter
- System evaluated every year (>95% complete)

AIDS Cases: Source of Report

- N= 30,105 cumulative AIDS cases
- 79% Active surveillance
  - includes HIV/VL and CD4 lab generated investigations, and validation studies
- 14% Passive surveillance
  - includes Counseling & Testing sites and a few private medical providers (<15)
- 7% Other
  - Includes research studies, other Counties, etc.

Electronic Tracking Database Pending List (PLIST)

- Repository for all electronic labs received (170,800 test reports including AB, CD4, VL)
- Labs are assigned a disposition when it is processed
  - Match HARS
  - Match other jurisdiction's case
  - Possible matches
  - Matches another lab already received
  - Pending (no match to registries/databases)

Overview of Incidence Surveillance

- Implemented Standard protocol in April 2005
- Coordinating Incidence surveillance efforts with the State of CA and Los Angeles
- Testing history questionnaire (THQ) being collected by Core field staff at active surveillance sites
- CTR sites began collecting THQ February 2006 when Prevention branch decided not to implement PEMS
- Passive case report forms changed to include THQ when SF changed from code-based to name-based reporting in April 2006
- The SFDPH laboratory is currently the only lab participating; SF General Hospital has agreed to ship specimens pending letter from Director of Health

Status of HIV Incidence Surveillance

New HIV cases reported since implementation (04/05)	1220	
Total Cases Eligible for Incidence Surveillance	526	43%
Ineligible for Incidence** (**prevalent HIV cases before 4/05)	694	57%
Source of Report	526	100%
Public Facilities	230	44%
Private Facilities	215	41%
CTR Sites	72	14%
Research	8	1%
Other jurisdictions	1	<1%

Labs Reporting New HIV Cases
(Since Implementation 04/2005)

Labs reporting new HIV cases (n=23)	% of specimens
SFGH	19%
DPH Lab	15%
Quest	15%
Kaiser	15%
CPMC	14%
UCSF	5%
UNILAB	4%
Lab Corp	3%
SF VA	2%
Subtotal (n=9)	92%

Overview of Core and Incidence Surveillance Integration

- Physical space is shared
- Staff responsibilities overlap and/or are shared as needed by Core and Incidence surveillance
- Leadership of Surveillance Branch is shared by Co-Directors representing Core and Incidence surveillance
- Coordination & collaboration with other Branches/Departments in the SFDPH such as the Prevention Branch, the SFDPH laboratory, and the Director of Public Health

Physical Space is Shared

- All Surveillance staff is housed on the 5th and 6th floor in the AIDS Office
- Provides easy access to information
- Provides easy access to personnel
- Provides for easy communication and the possibility for 'eavesdropping' on each other
- Provides a sense of common goals and collaboration; equal partners

Staff Responsibilities Overlap and/or are Shared by Core and Incidence Surveillance

- Most Surveillance staff have funding from other surveillance activities: Core, Incidence, MMP
- Dual responsibilities enhance understanding & integration of Core and Incidence surveillance
- If either Core or Incidence has staff shortages or shifting priorities, staff is temporarily shifted to areas of greatest need as needed
- Surveillance staff meetings cover both Core and Incidence activities & are attended by full staff
- Guiding philosophy is that Core surveillance needs to be complete and timely to make Incidence surveillance successful

How Dual Responsibilities Enhance Understanding and Integration of Core & Incidence Surveillance

Project Coordinator:

- Hired before implementation.
- Extensive prior experience as a HIV counselor.
- Worked as Core field staff to understand field activities and case reporting before Incidence implementation.
- Drawing on experience in the field, has been able to train Core field staff to collect THQ and make suggestions on how this is best done without burden to field site. Able to pilot forms and procedures at his assigned field sites.
- Drawing on experience as HIV counselor, was able to train counselors at CTR sites on THQ and was able to design forms in format favorable to counselors.

How Dual Responsibilities Enhance Understanding and Integration of Core & Incidence Surveillance

Data Manager:

- Also works as Core Surveillance lab database manager
- Extensive knowledge of HARS, lab databases and local variables
- This knowledge allows her to modify CDC SAS programs to use local variables that best identify needed Incidence cases, labs or fields
- Has been able to quickly identify Incidence data that is incomplete or missing in HARS and suggest changes; e.g. missing lab accession numbers and laboratory names
- Examples: 1) initiated entering hard copy of lab reports into lab database, encourages labs to report electronically with complete data (accession numbers & collection dates); 2) helped coordinate data management during transition to name-based HIV reporting so that Incidence cases could be easily identified and accessed after the transition 3) set-up programs to rematch Incidence database with lab database to identify other eligible remnant specimens

Leadership of the Surveillance Branch shared by Co-Directors

- Last year the Director of the Surveillance Branch stepped down
- Co-Directors took over; one Co-Director was previously the PI of Incidence Surveillance and the other was the Director of Core Surveillance
- Joint decisions for the Branch ∴ more likely to consider the competing & corresponding needs of both Core & Incidence surveillance
- As Co-Directors, can weigh the needs of Incidence surveillance in Branch level decisions including staffing, budgetary & policy priorities
- Examples: Integrated QA procedures for Incidence data into existed procedures for Core surveillance & during transition to name-based reported, made sure incident HIV cases continued to be a reporting priority

Surveillance Branch Collaboration with other SFDPH Departments

- Incidence draws on past collaborations between Core Surveillance and other SFDPH agencies
- The Surveillance branch has a long relationship of collaboration with the SFDPH Prevention Branch with good communication & working knowledge of each others' work
- Relationship w/Prevention was key to access to CTR sites for implementing the THQ. Incidence staff provided training for CTR counselors
- Relationship with SFDPH Lab is ongoing & positive. SFDPH lab has participated in past Surveillance Branch research studies including STARHS testing
- Director of Public Health supportive and willing to assist with approaching labs & providers

Challenges with Integration

- With the good, comes the bad; there are trade-offs
- Budget is tight, each staff member usually has funding from multiple projects: Core, Incidence, MMP
- Sometimes conflicting goals -- e.g. Incidence staff not working 100% time on Incidence
- As deadlines, priority changes occur, etc., staff is shifted to meet those needs. Examples names-based HIV reporting, implementation of MMP
- Only 14% of AIDS cases reported passively; ∴ no history of PMDs doing the work themselves
- Reliance of Core surveillance on active surveillance has made it difficult for Incidence surveillance to get PMDs to add the THQ to their patient routine

Successes with Integration

- Has been structured as a highly integrated system since the beginning
- Integration has increased over time; examples: 1) as Core staff asked to assist with Incidence they become aware of goals of Incidence and become more pro-active "Incidence thinkers" 2)Co-Directors working together to make joint decisions
- Relatively small geographic area and limited number of providers and labs make integration easier
- Incidence surveillance has been able to exploit relationship that Core surveillance has with providers, labs & other DPH branches
- With name-based HIV reporting, we can perform chart review and follow-up Incidence cases using systems set up for Core surveillance
- Incidence is able to use Core databases to set priorities; e.g. identify high volume labs & providers for inclusion

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Integrating Incidence and Core Surveillance: Texas

June 4, 2006

CSTE Pre-Conference – Anaheim, CA

Cheryl Jablonski, MA
Texas Department of State Health Services
HIV/STD Surveillance Group

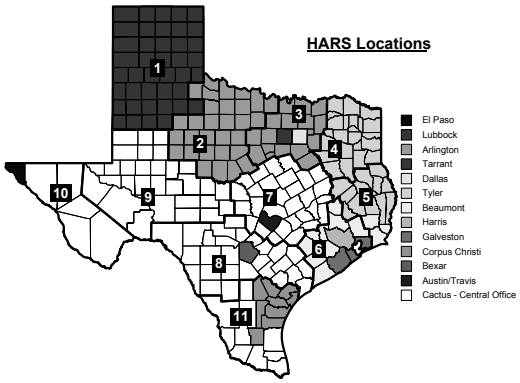
TEXAS Department of State Health Services

First Thoughts

- Core and Incidence are funding streams
- Speak the language of the audience
  - Providers: expanding HIV disease surveillance
  - Surveillance: expanding case surveillance; it's all Surveillance
  - Labs: improving HIV surveillance to use new testing technology
- Build on current structure and processes

Know Your Surveillance Structure and Processes: Texas

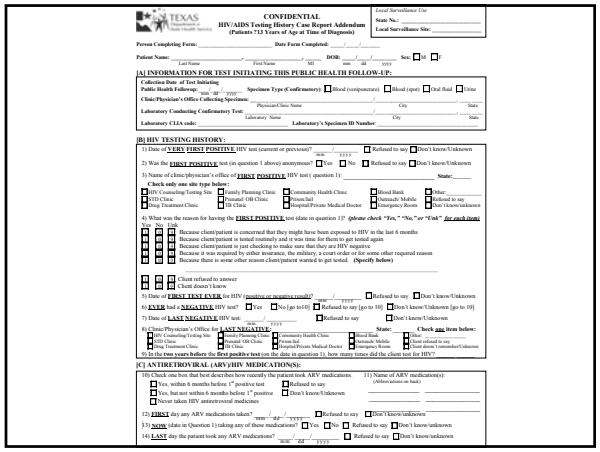
- State separately funded from Houston
- Contracts with 11 local surveillance sites
  - Each has HARS
  - Upload through Texas Health Alert Network (TxHAN)
- UT Southwestern Medical Center (UTSW)-technical assistance provider



Parts of Surveillance System

- Report Sources (public and private)
  - Test providers
  - HIV care provider
  - Laboratories (some electronically)
- Activities of Reporting Authorities
  - Disease intervention specialists (DIS)
  - Data collection: active; case finding activities; alternate records
  - Data management and analysis
  - Dissemination and interpretation of surveillance data
- Consumers of surveillance information
  - Prevention and service planning bodies
  - Prevention and services organizations
  - The public
  - Epidemiologists

Parts of a Surveillance System



CONFIDENTIAL
HIV/AIDS Testing History Case Report Addendum
(Patients 712 Years of Age at Time of Diagnosis)

Local Surveillance Use
State No.:
Local Surveillance Site:

Person Completing Form: _____ Date Form Completed: ____/____/____

Patient Name: _____, _____, _____ DOB: ____/____/____ Sex: ☐ M ☐ F
Last Name First Name MI mm dd yyyy

[A] INFORMATION FOR TEST INITIATING THIS PUBLIC HEALTH FOLLOW-UP:

Collection Date of Test Initiating
Public Health Followup: ____/____/____ Specimen Type (Confirmatory): ☐ Blood (venipuncture) ☐ Blood (spot) ☐ Oral fluid ☐ Urine
mm dd yyyy
Clinic/Physician's Office Collecting Specimen: _____ / _____ / _____
Physician/Clinic Name City State
Laboratory Conducting Confirmatory Test: _____ / _____ / _____
Laboratory Name City State
Laboratory CLIA code: _____ Laboratory's Specimen ID Number: _____

[B] HIV TESTING HISTORY:

1) Date of VERY FIRST POSITIVE HIV test (earnest or previous)? ____/____/____ ☐ Refused to say ☐ Don't know/Unknown
mm dd yyyy

2) Was the FIRST POSITIVE test (in question 1 above) anonymous? ☐ Yes ☐ No ☐ Refused to say ☐ Don't know/Unknown

3) Name of clinic/physician's office of FIRST POSITIVE HIV test (question 1): _____ State: _____

Check only one that describes the clinic or physician's office (check only one):

☐ HIV Counseling/Testing Site	☐ Family Planning Clinic	☐ Community Health Clinic	☐ Blood Bank	☐ Other _____	
☐ STD Clinic	☐ Prenatal/ OB Clinic	☐ Prison/Jail	☐ Outreach/ Mobile	☐ Refused to say	
☐ Drug Treatment Clinic	☐ TB Clinic	☐ Hospital/Private Medical Doctor	☐ Emergency Room	☐ Don't know/unknown	

4) What was the reason for having the FIRST POSITIVE test (date in question 1)? *(please check "Yes," "No," or "Unk" for each item)*

Yes	No	Unk	
☐	☐	☐	Because client/patient is concerned that they might have been exposed to HIV in the last 6 months
☐	☐	☐	Because client/patient is tested routinely and it was time for them to get tested again
☐	☐	☐	Because client/patient is just checking to make sure that they are HIV negative
☐	☐	☐	Because it was required by either insurance, the military, a court order or for some other required reason
☐	☐	☐	Because there is some other reason client/patient wanted to get tested. **(Specify below)**

_____

☐ ☐ ☐ Client refused to answer
☐ ☐ ☐ Client doesn't know

5) Date of FIRST TEST EVER for HIV (positive or negative result)? ____/____/____ ☐ Refused to say ☐ Don't know/Unknown
mm dd yyyy

6) EVER had a NEGATIVE HIV test? ☐ Yes ☐ No [go to10] ☐ Refused to say [go to 10] ☐ Don't know/Unknown [go to 10]

7) Date of LAST NEGATIVE HIV test: ____/____/____ ☐ Refused to say ☐ Don't know/Unknown
mm dd yyyy

8) Clinic/Physician's Office for LAST NEGATIVE: State: _____ Check one item below:

☐ HIV Counseling/Testing Site	☐ Family Planning Clinic	☐ Community Health Clinic	☐ Blood Bank	☐ Other _____
☐ STD Clinic	☐ Prenatal/ OB Clinic	☐ Prison/Jail	☐ Outreach/ Mobile	☐ Client refused to say
☐ Drug Treatment Clinic	☐ TB Clinic	☐ Hospital/Private Medical Doctor	☐ Emergency Room	☐ Don't know/Unknown

9) Is the **two years before** the first **positive test** (on the date in question 1), how many times did the client test for HIV?

[C] ANTIRETROVIRAL (ARV)/HIV MEDICATION(S):

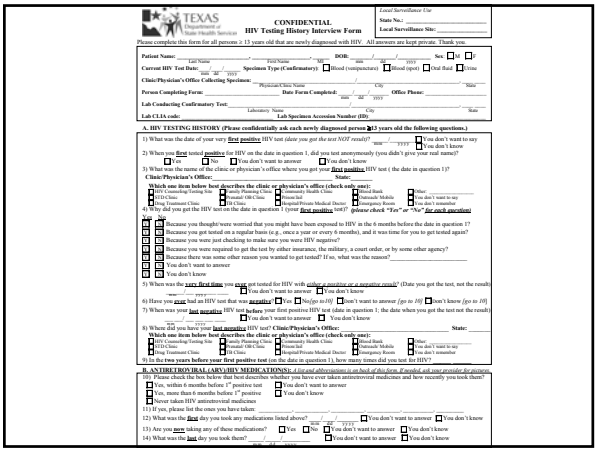
10) Check one box that best describes how recently the patient took ARV medications.
☐ Yes, within 6 months before 1st positive test
☐ Yes, but not within 6 months before 1st positive
☐ Never taken HIV antiretroviral medicines
☐ Refused to say
☐ Don't know/Unknown

11) Name of ARV medication(s): (Million tablets on hand)
_____ _____
_____ _____
_____ _____

12) FIRST day any ARV medications taken? ____/____/____ ☐ Refused to say ☐ Don't know/unknown
mm dd yyyy

13) NOW (date in Question 1) taking any of these medications? ☐ Yes ☐ No ☐ Refused to say ☐ Don't know/unknown

14) LAST day the patient took any ARV medication? ____/____/____ ☐ Refused to say ☐ Don't know/unknown
mm dd yyyy



CONFIDENTIAL
HIV Testing History Interview Form

Local Surveillance Use
State No.:
Local Surveillance Site:

Please complete this form for all persons ≥ 13 years old that are newly diagnosed with HIV. All answers are kept private. Thank you.

Patient Name: _____, _____, _____ DOB: ____/____/____ Sex: ☐ M ☐ F
Last Name First Name MI mm dd yyyy

Current HIV Test Date: ____/____/____ Specimen Type (Confirmatory): ☐ Blood (venipuncture) ☐ Blood (spot) ☐ Oral fluid ☐ Urine
mm dd yyyy

Clinic/Physician's Office Collecting Specimen: _____ / _____ / _____
Physician/Clinic Name City State

Person Completing Form: _____ Date Form Completed: ____/____/____ Office Phone: _____
mm dd yyyy

Lab Conducting Confirmatory Test: _____ / _____ / _____
Laboratory Name City State

Lab CLIA code: _____ Lab Specimen Accession Number (ID): _____

A. HIV TESTING HISTORY (Please confidentially ask each newly diagnosed person ≥13 years old the following questions.)

1) What was the date of your very first positive HIV test *(date you got the test NOT result)*? ____/____/____ ☐ You don't want to say
mm dd yyyy ☐ You don't know

2) When you first tested positive for HIV on the date in question 1, did you test anonymously (you didn't give your real name)?
☐ Yes ☐ No ☐ You don't want to answer ☐ You don't know

3) What was the name of the clinic or physician's office where you got your first positive HIV test (the date in question 1)?
Clinic/Physician's Office: _____ State: _____

Which one item below best describes the clinic or physician's office (check only one):

☐ HIV Counseling/Testing Site	☐ Family Planning Clinic	☐ Community Health Clinic	☐ Blood Bank	☐ Other _____
☐ STD Clinic	☐ Prenatal/ OB Clinic	☐ Prison/Jail	☐ Outreach/ Mobile	☐ You don't want to say
☐ Drug Treatment Clinic	☐ TB Clinic	☐ Hospital/Private Medical Doctor	☐ Emergency Room	☐ You don't remember

4) Why did you get the HIV test on the date in question 1 (your first positive test)? *(please check "Yes" or "No" for each question)*

Yes	No	
☐	☐	Because you thought/were worried that you might have been exposed to HIV in the 6 months before the date in question 1?
☐	☐	Because you got tested on a regular basis (e.g., once a year or every 6 months), and it was time for you to get tested again?
☐	☐	Because you were just checking to make sure you were HIV negative?
☐	☐	Because you were required to get the test by either insurance, the military, a court order, or by some other agency?
☐	☐	Because there was some other reason you wanted to get tested? If so, what was the reason? _____
☐	☐	You don't want to answer
☐	☐	You don't know

5) When was the very first time you ever got tested for HIV with either a positive or a negative result? (Date you got the test, not the result)
____/____/____ ☐ You don't want to answer ☐ You don't know
mm dd yyyy

6) Have you ever had an HIV test that was negative? ☐ Yes ☐ No *[go to 10]* ☐ don't want to answer *[go to 10]* ☐ don't know *[go to 10]*

7) When was your last negative HIV test before your first positive HIV test (date in question 1: the date when you got the test not the result)
____/____/____ ☐ You don't want to answer ☐ You don't know
mm dd yyyy

8) Where did you have your last negative HIV test? **Clinic/Physician's Office:** State: _____

Which one item below best describes the clinic or physician's office (check only one):

☐ HIV Counseling/Testing Site	☐ Family Planning Clinic	☐ Community Health Clinic	☐ Blood Bank	☐ Other _____
☐ STD Clinic	☐ Prenatal/ OB Clinic	☐ Prison/Jail	☐ Outreach/ Mobile	☐ You don't want to say
☐ Drug Treatment Clinic	☐ TB Clinic	☐ Hospital/Private Medical Doctor	☐ Emergency Room	☐ You don't remember

9) Is the **two years before your first positive test** (on the date in question 1), how many times did you test for HIV? _____

B. ANTIRETROVIRAL (ARV)/HIV MEDICATION(S): *(List and abbreviations is on back of this form. If needed, ask your provider for assistance.)*

10) Please check the box below that best describes whether you have ever taken antiretroviral medicines and how recently you took them?
☐ Yes, within 6 months before 1st positive test ☐ You don't want to answer
☐ Yes, more than 6 months before 1st positive ☐ You don't know
☐ Never taken HIV antiretroviral medicines

11) If yes, please list the ones you have taken: _____ / _____ / _____

12) What was the **first** day you took any medications listed above? ____/____/____ ☐ You don't want to answer ☐ You don't know
mm dd yyyy

13) Are you **now** taking any of these medications? ☐ Yes ☐ No ☐ You don't want to answer ☐ You don't know

14) What was the **last** day you took them? ____/____/____ ☐ You don't want to answer ☐ You don't know
mm dd yyyy

Integration at Grantee Level

- Team meetings
- Incorporate into written surveillance procedures
- Accompany surveillance staff on site visits
- Support from someone over all surveillance staff
- Share incidence info from CDC with surveillance partners
- eHARS
- Share resources: funding, people, support
- Combine forms, if appropriate
- Track completion rates to provide feedback

Integration at the System Level

- Develop relationships with providers through their current surveillance contacts
- Provide technical assistance and training
- Seek stakeholder input
- Assess current legislation
- Understand and use current mechanisms of communication
- "Talk up" your surveillance activity
- Carry each other's messages

Surveillance of any reportable condition is a challenge!

Incidence surveillance is another tool in the HIV surveillance tool box.

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Texas Department of State Health Services:
Sharon K. Melville, MD, MPH
HIV/STD Epidemiology & Surveillance Branch Manager

Integration of Core & Incidence Surveillance in King County, Washington

HIV/AIDS Surveillance & Incidence Coordinators Meeting
June 4, 2006

Christina Lynch, MPH
Public Health – Seattle & King County

Public Health
Seattle & King County
HEALTHY PEOPLE. HEALTHY COMMUNITIES.

Overview

- Surveillance in King County
- Core/Incidence points of intersection:
  - Pursuing the THQ
  - Identifying STARHS specimens
  - Other

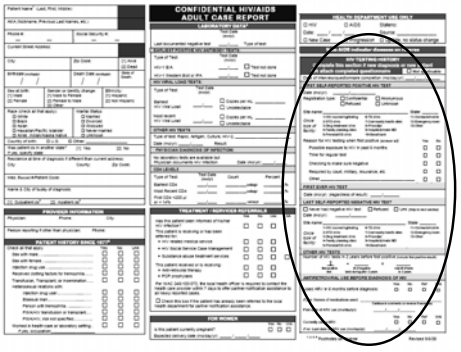
King County HIV Core & Incidence Surveillance Background

- Core and incidence staff housed in separate secure rooms on same floor
- 350-400 new HIV diagnoses annually (~25% w/concurrent AIDS diagnosis)
- Standard BED incidence protocol implemented April 2005
  - As of April 2006, 5/7 of labs that conduct WBs are submitting specimens for STARHS
  - Since Jan 2006, 69% of new cases had sera available and/or THQ collected

THQ: On Case Report Form

- Testing history questions added to adult HIV/AIDS case report form – September 2005
- Announced in our HIV provider newsletter

THQ: On Case Report Form


CONFIDENTIAL HIV/AIDS ADULT CASE REPORT

THQ: On Case Report Form

- Issues
  - >50% of new case reports are completed by PH surveillance staff via medical record chart review
  - THQ section incomplete on forms from providers
- Plan
  - Revision of CRF anticipated this summer due to changes in reporting laws, actively promote new form at that time with focus on THQ section, personalized approaches
  - Evaluate which data elements are being collected
  - Focus provider follow-up on four key data elements

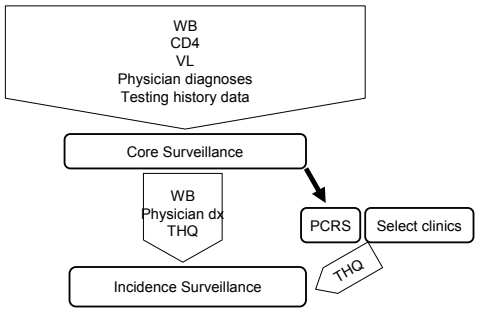
THQ: During PCRS

- Core surveillance prepares list of new cases weekly
- Incidence surveillance reviews list, denotes if THQ is needed
- List of cases submitted to PCRS staff who administer THQ following routine activities (unless inappropriate)
- Approximately 1/3 of THQs currently collected this way

Specimens: Identifying for test/toss lists

- Core surveillance maintains "lab tracking" database with all reported lab results
- SAS dataset with WB results provided to incidence surveillance, weekly or monthly
  - Lab name, accession #, Stateno, first HIV+ date
- Incidence surveillance determines eligibility of each WB for test/toss list, uploads eligibles to local tracking database

Sources of incidence data



Other: Integrate communications to private labs

- When incidence approaches private lab re: submitting specimens for STARHS, good opportunity for core surveillance to address any issues
  - promote electronic reporting
  - promote timely reporting
  - re-establish contact with private labs, put a face on surveillance
- Present unified front, shows incidence as extension of core surveillance

Other: Deidentified data

- Core surveillance de-identified datasets available to incidence staff on secure network drive:
  - HARS
  - Lab reports
- Used by incidence staff for analysis, updating incidence database demographic variables, etc

Lessons learned

- Minimize duplicate data entry
- Automate as much as possible (i.e. with SAS programs)
- Keep things simple

Questions?

Contact Info

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FLORIDA'S HIV/AIDS DATA MONITORING AND QUALITY PROCESS

Becky Grigg, Ph.D.
HIV/AIDS Surveillance Coordinator
Florida Department of Health

HARS Transfers

Transfers from local field offices usually contain six components:

- New cases
- Updates
- Out of Jurisdiction (OJJ) cases
- Labs
- Correction Sheets
- Transfer file

Monitoring Data Quality

Monitoring data quality occurs at three levels in Florida:

- At the local level
- At the case manager level
- At the program reporting manager level

Local Level Procedures to Improve Data Quality

- All new data entry operators (DEOS) receive one-on-one HARS data entry training, as well as a HARS data processing manual
- The data processing manual is a user friendly document developed to provide a reference tailored specifically to the individual responsible for data entry into the HARS software
- This manual provides clear and concise answers to situations and questions that may arise during data entry
- The manual goes into detail on each screen in HARS and each variable on that screen, e.g. what should and should not be entered, correct codes, etc.

Local Level Procedures to Improve Data Quality

- All incoming documents are record searched in the local database to determine status, i.e., new case or previously reported
- If a match is not found in either of these searches, the local DEO calls their case manager at the state health office to do a record search against the statewide database
- Field staff are trained to look for any indication a case may have prior diagnosis/residence in another state and to document this on the completed case report form

Local Level Procedures to Improve Data Quality

- The DEO will search STDMIS and HMS (the health department clinical system) for additional information, if necessary
- Cases are then sorted into new cases and updates
- All new cases are entered prior to entering updates

Case Manager Level Procedures to Improve Data Quality

- Each local field office has a dedicated case manger at the state health office to provide TA and to audit their transfers
- Transfers are audited after the electronic transfer file has been uploaded in HARS
- Every variable on the hard copy case report form is checked against the electronic copy in HARS
- Any data entry errors or fields with incorrect codes are noted on a correction sheet
- The correction sheet contains instructions on the cases that need some form of correction

Case Manager Level Procedures to Improve Data Quality

- The correction sheets are returned to the local DEOs once a month for them to make the necessary updates in HARS
- These audits provide information about each DEOs error rate to better facilitate data entry standards, evaluate data entry practices, and quality control in completing data entry
- They also allow us to monitor the progress of new DEOs or identify the need for "refresher training" for existing staff

Case Manager Level Procedures to Improve Data Quality

- They provide direction for standardization, duplicate resolution, and other data validation procedures
- The correction sheets are returned in the next transfer with an indication of the status of all requested actions
- The case managers periodically audit each other's audits to provide quality assurance on their own work

Program Reporting Manager Level Procedures to Improve Data Quality

- Once the case managers have completed their updates and edits in HARS, the Program Reporting Manager runs the standard HARS validation programs
- These validation programs are run several times a month but specifically prior to freezing the database and prior to sending transfers to CDC
- Any errors found as a result of running the validation programs are returned to the case managers for correction
- The case managers make the necessary corrections and instruct the DEOs at the local level to make the same corrections in their stand-alone HARS

The Future State

- Data entry for all sites will be centralized at the state health office
- Sites will scan all of their case reports and back-up documentation to their secure folders and the case managers will enter the cases in HARS
- Weekly or twice weekly (depending on the sites' morbidity) a backward transfer will be sent to the local offices so they can run reports and respond to data requests

KANSAS DATA QUALITY

Jeni Mulqueen
HIV/STD Surveillance Director
Kansas Department of Health & Environment

How Good Is Our Data?

From the minute I started working at KDHE I was told…..

Garbage In

=

Garbage Out!!!

Source of Data (Garbage In?)

- Doctors
- Ryan White Case Managers (Medical Eligibility)
- Laboratories
- Disease Intervention Specialists
- Counseling and Testing Contractors
- Other States
- Death Certificates
- Chart Reviews

With all those reports, the fun begins……..

- Data Manager Sorts and Reviews Each Report
- Desk Reference Manual (Protocols)

Database Access

Direct Access

- STD MIS
- Ryan White Title II

Indirect Access

- TB Registry
- SRS
- Immunization Registry

Routine Data Quality Control

- In-State Duplicate Check In HARS
- ALL New Cases Are Checked With CDC
- Other Databases Checked As Necessary
- Daily Change Reports From Ryan White
- Weekly List From Care
- Weekly List From Counseling and Testing
- Monthly Patient List From Major Provider
- Review Of Closed Interview Records

Other Data Quality Control

- SAS Program (Quarterly)
- NIR Letter (Annually)
- Database Match With KCMO (At least Annually)
- Hospital Reviews (Annually)
- Chart Reviews (As Needed)
- Ancestry SSDI Check (Annually)

Activities To Come (Hopefully)

- Complete Access to Death Records
- Hospital Discharge Summary Information
- SRS Database Matches

THE END

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Demonstration of eHARS

The findings and conclusions in this presentation are those of the author and do not necessarily represent the views of the Centers for Disease Control and Prevention.

Demonstration of eHARS

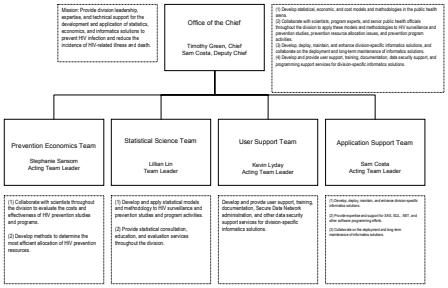
Topics for this session are:

- QSIB Organization
- eHARS Overview
- HARS to eHARS Differences
- HARS to eHARS Conversion
- The Person View document
- eHARS Demonstration
- eHARS Reports

QSIB Organization

(Formerly Statistics and Data Management Branch)

Quantitative Sciences and Informatics Branch (Proposed)
Mission and Functions



eHARS Overview

- eHARS is system designed to replace HARS.
- eHARS can link unlimited documents to a person
- eHARS employs the new surveillance definitions of a case

HARS-to-eHARS Differences

HARS

- One record per case (regardless of source)
- Flat file PRODAS database
- Local installation
- DOS-based
- Limited amount of data fields/local fields
- A lot of field level edits and skip patterns

eHARS

- Document-based
- Relational SQL database
- Server-based
- Browser-based
- Unlimited local fields, IDs, names, addresses, and labs
- Document-based edit checks

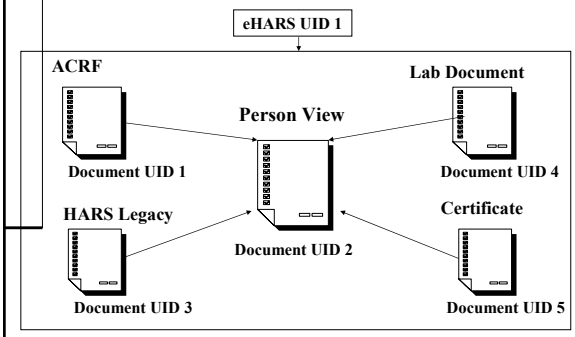
HARS to eHARS Conversion

- Existing HARS records will be converted to eHARS as read only legacy documents
- After conversion, eHARS will generate a synthesized HARS-like document called the Person View for each HARS document converted

Person View Document

- The Person View document is a compilation of all the documents in the eHARS database for a selected person
- The Person View document is created when the first document is entered for a person
- eHARS uses a hierarchy of rules and calculations to determine the primary value displayed in certain fields

Person View Document



Demonstration of eHARS

There will be time for questions after the demonstration

The eHARS demonstration begins now!

Reports

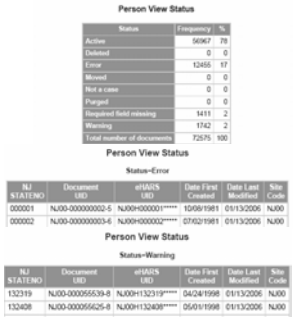
Person View Status Report

This report returns a count of Person View documents by status and lists the documents for statuses selected.

Reports

Person View Status Report

This report can help a site determine which cases are considered eligible for transfer to CDC



Reports

Person View Override Report

This report lists all overrides by field applied to Person View documents

Reports

Person View Override Report

This report is shows the field value selected before and after the override.

Person View Override

S: STATENO C: CITYNO E: eHARS UID	Field Name	Hierarchical / Derived		
		Document Type	Document UID	Value
S: C: E:NJD05000200436-8	Name	Death Document	NJD0-000200439-5	
S: C: E:NJD05000200446-5	Name	Death Document	NJD0-000200449-2	
S: C: E:NJD05000200615-5	Vital Status	Adult Case Report Form	NJD0-000200616-0	2
S: C: E:NJD05000200629-6	Vital Status	Death Document	NJD0-000200633-1	2
S: C: E:NJD05000200676-8	Mother's place of birth	Pediatric Case Report Form	NJD0-000200680-3	ASM

Reports

Auto Match Report

This report provides a list of imported records added to existing cases or used to create new cases. The report also provides a list of records that failed import standardizations

Reports

Auto Match Report

This report can be used for quality assurance, to determine if records have been correctly added to cases or correctly used to create a new case

Auto Match

Filename: Labg_NJ_Test.txt

Records successfully matched

Document UID	eHARS UID	State	STATENO	Entry Date
NJD0003201596-0	NJD0H130614*****	NJ	130614	02FEB2006
NJD0003201626-1	NJD0500021444-2	NJ	NJ14724	02FEB2006
NJD0003201594-8	NJD0500021593-7	NJ	NJ14726	02FEB2006
NJD0003201591-5	NJD0500021590-4	NJ	NJ14727	02FEB2006

Auto Match

Filename: Labg_NJ_Test.txt

Records failed Auto Match

Record ID	STATENO	First Name	Last Name	Failure Reason
247	NJ15768	RAUL	WIMMER	Error in Facility Name. Please contact your Sytem Administrator.
249	NJ15767	MILTON	WOMBLE	Error in Facility Name. Please contact your Sytem Administrator.
251	NJ15766	EDGAR	YAGER	Error in Facility Name. Please contact your Sytem Administrator.
258	NJ15793	CHRISTIAN	BOST	Error in Facility Name. Please contact your Sytem Administrator.

Reports

Indeterminate Match Report

This report supplies information to allow an indeterminate record to be matched to an existing case

Reports

Indeterminate Match Report

The goal of this report is to provide enough demographic information to match an indeterminate record with an existing case or rule out a match

Indeterminate Matches

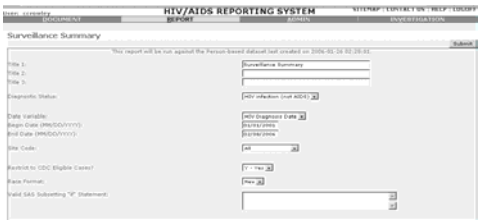
Filename: labg_znl1_020806_NJ.txt

Document UID	STATENO	First Name	Middle Name	Last Name	Sex	Race	Ethnicity	SSN	Date of Birth	Date of Death	Residence City	Residence State	Residence Zip Code
	NJ980545	MISS		PIGGY	U	R4	E2		12/14/1973		TRENTON	NJ	08601
NJD0-000201049-5		MISS		PIGGY									
NJD0-000201049-5		MISS		PIGGY									
POTENTIAL MATCHES: 2													
	NJ980545	MISS		PIGGY	U	R4	E2		12/14/1973		TRENTON	NJ	08601
NJD0-000201049-5		MISS		PIGGY									
NJD0-000201049-5		MISS		PIGGY									
POTENTIAL MATCHES: 2													
	KERMIT			FROG	F	R2	E2		2/21/1960		TRENTON	NJ	08601
NJD0-000201053-3	KERMIT			FROG	F		E2		02/21/1960		TRENTON	NJ	08601
NJD0-000201054-0	KERMIT			FROG	F	R2	E2		02/21/1960				
POTENTIAL MATCHES: 2													

Reports

Surveillance Summary Report

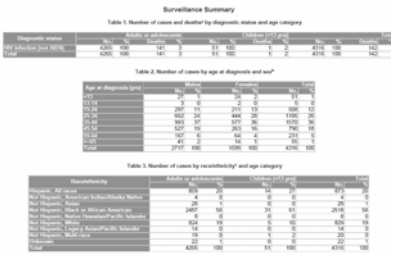
This report lists the numbers of cases and deaths for a chosen diagnostic status. Comparable to HARS Report A



Reports

Surveillance Summary Report

This report can help a site conduct analysis on the cases reported in eHARS



Demonstration of eHARS

Questions?

The 411: on HIV/AIDS Core Surveillance Site Visits

HIV Incidence and Case Surveillance Branch

June 4, 2006

Why CDC conducts site visits?

- Outlined in cooperative agreement
- Provide technical assistance to State/local grantees
- Learn how State/local HIV/AIDS surveillance programs operate
- Understand where national HIV/AIDS surveillance data comes from

Surveillance site visits: Role of all HICSB staff

- Support HICSB funded activities
- Good understanding of case reporting activities
- Principles of data security and confidentiality
- Issues of integrating/prioritizing surveillance activities in the field
- Evaluation issues – minimum performance standards
- TA to states on synthesizing and using data for prevention and treatment program planning

What Determines the Need for a Site Visit

- State/local area identified as a priority for a site visit based on Branch criteria
  - Change in HIV/AIDS infection reporting
  - Identified problems with core surveillance
  - Evaluation activities
  - Have not been visited in a while
  - Morbidity
  - Beginning new HICSB activities
- Grantee requests a site visit

The Process of Site visits

- Pre-site visit preparation
- Conducting the site visit
- Site visit follow-up

Pre-site visit preparation

- Collaboration between Epi(s) and Consultant
  - Determine purpose(s) for visit
  - Agree on visit length and possible dates
  - Agenda guidance – list of discussion topics
  - Materials to review

Collaboration

- Epis and Consultants work together with Grantee to:
  - Goals of visit
  - Proposed agenda
  - Identify problems
  - Consult with other HICSB/SDMB staff as appropriate
- Consultant coordinates visit plans with Grantee and HICSB staff participating in visit
- Select appropriate local reporting sites to visit
- Avoid the “dog and pony show” sessions

Materials to review

- PA 04017 cooperative agreement guidance
- Current year cooperative agreement application
- Previous site visit letters and recommendations
- Local HIV/AIDS Surveillance Report
- Local security and confidentiality guidelines
- Data runs

Materials to review

Cooperative agreement for current year

- Technical review of recent application
- Core surveillance activities proposed
- Staffing and funding issues
- Other funded HICSB activities
- Current progress reports
- Current local HIV/AIDS surveillance report
- Reporting requirements
- Local protocols/procedures for case reporting and follow-up

Materials to review

Previous Site Visit Letters and Recommendations

- Review the major problems identified in letter
  - Were problems resolved?
  - Do they still exist/relevant?
- Review the recommendations made
  - Was action taken?

Materials to review

Local HIV/AIDS surveillance report

- How are they presenting surveillance data?
- Other data dissemination issues/opportunities

Materials to review

Local security and confidentiality guidelines

- Staff training and retraining
- NEDSS/Centralization of activities?
  - Electronic reporting
  - Data storage
- Prior security and confidentiality issues discussed in last site visit

Materials to review

Data runs

- Work with HICSB lead programmer
- Standard data request format
- Site specific data analysis needs
  - Changes/unusual patterns in reporting
  - Primary reporting sources (>2%)
  - Timeliness
  - Risk factor ascertainment
  - HIV reporting
    - **Reporting scheme**
    - **Time since implementation**

Conducting a Site Visit

- The agenda should guide the site visit
- The agenda should balance the needs HICSB and the Site
  - Ample opportunity for the site report to successes and problems
  - Time for HICSB to ask questions and provide positive feedback

Summary of Findings and Recommendations

- Findings should be discussed at the end of the visit
- Recommendations should be made to the site before HICSB departs the visit
- Successed and issues should have been clearly defined. HICSB and grantee should be clear on what the site visit letter will entail before the site visit is completed

Follow up activities

- Follow up on information requested by or promised to grantee during the visit
- Site visit letter – the final letter should be sent to the grantee within one month of visit

Site Visit Letter

- Contents of the letter should have been discussed with the site and reviewed and Ok'ed by the site prior to sending final.
- Serves as record of visit for later planning of next visit

Site Visit Letter cont'd

- Specific problems and recommendations
  - Clearly state deficiencies and recommended correction
  - Each recommendation should include rationale and expected benefits.
  - Identify areas needing improvement, and suggested ways to improve

Site Visit Letter

- Planned Next Steps
  - Note any requests by the site for follow up information or technical assistance
  - Note planned activities and timelines for things listed in the “Problems and Recommendations” section
  - Note any specific need for another site visit

The Importance of the Site Visit Letter to the Grantee

San Francisco Department of Health will present how they use the site visit letter to plan their activities

Receiving and Responding to Site Visit Letter

Maree Kay Parisi
San Francisco Department of Public Health

Influencing letter

- No surprises
  - Overview at site visit of recommendations
    - Dialogue, comments

Receiving Letter

- Draft letter
  - Input
  - Correct, clarify, make requests to add specific needs

Final version from CDC

- Overview
- Specific recommendations

Addressing Letter

- Approach letter as an aide to accomplish tasks
  - Example from SF
- Response to CDC

  Letter on how things are accomplished
  - Issues may have been addressed
  - Prioritize
    - Action plan and timeline
    - Request assistance

Accomplishing Tasks

- Delegate work
  - Revisit letter, stay on track
- Keep CDC in the loop
  - Notify CDC of progress

Receiving and Responding to Site Visit Letter

Influencing letter

- No surprises
  - Overview at site visit of recommendations
    - Dialogue, comments

Receiving Letter

- Draft letter
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Final version from CDC

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Accomplishing Tasks

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Integrate and Conquer

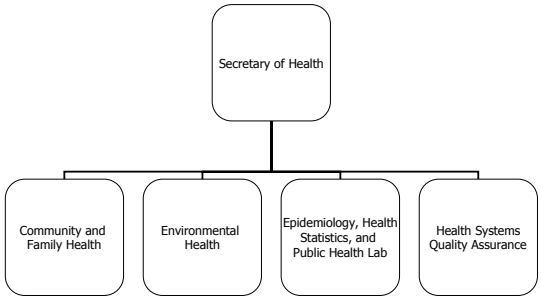
Incorporating HIV surveillance into broader public health assessment activities

Maria Courogen, MPH
WA State Department of Health
CSTE Annual Meeting, June 4, 2005

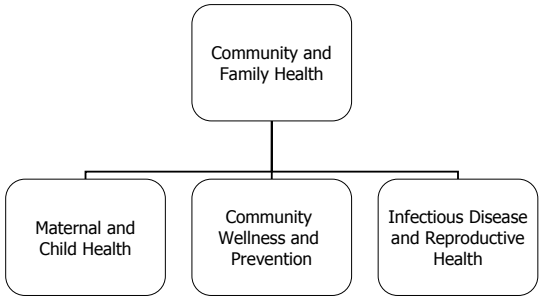
To cover:

- Structure of Washington State Department of Health
- Reasons for reorganization
- Staffing of the Infectious Disease and Reproductive Health Assessment Unit
- Annual work plans
- Benefits and challenges

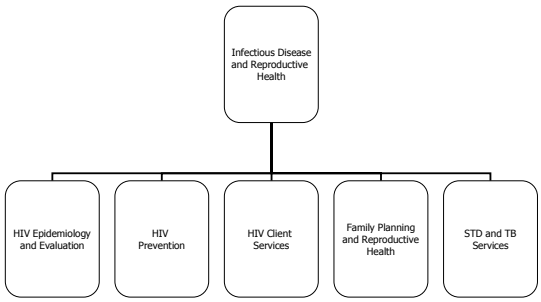
WA DOH Structure



WA DOH Structure



WA DOH Structure – Pre 1996



Reasons for reorganization

- The Future of Public Health - IOM Report
- Core functions of public health – assessment, policy development, assurance
- WA State Public Health Improvement Plan (PHIP) – improve core function capacity
- Consolidate improvement across programs

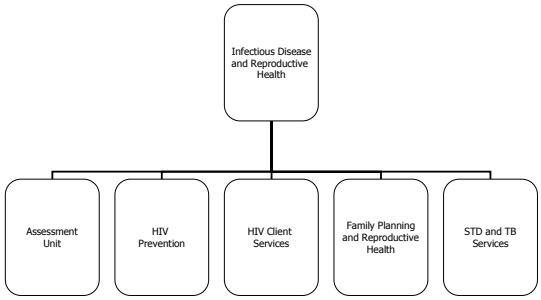
Reasons for reorganization

- HIV Prevention Program – HIV community planning
- HIV Client Services Program – Ryan White Care Act Title II prioritization processes
- *Assessment* identified as the core function that could be consolidated across IDRH programs

Assessment

- Collection, analysis, and dissemination of information on health status, personal health problems, population groups at greatest risk, availability and quality of services, resource availability, and concerns of individuals
- Broader than surveillance

WA DOH Structure – As of 1996



Evolution

- Started with staff working on and funded by HIV surveillance activities (core, SHAS, serosurveys)
- Other IDRH programs contributed resources for additional Assessment Unit staff
- Hired AU staff to meet needs of programs

Assessment Unit staffing

- Four epidemiologists (soon to be five), funded with STD, TB, HIV client services, HIV prevention, HIV surveillance, and HCV dollars
- Research investigator funded with HIV and FPRH dollars
- HIV surveillance coordinator
- Data manager and data compiler funded with HIV surveillance, HIV client services, and TB dollars
- Interviewers and evaluators funded with HIV surveillance, HIV prevention, and HIV client services dollars
- HCV program coordinator funded with HCV and HIV client services dollars
- Fiscal and administrative staff funded across programs

Annual work plans

- Describe agreements with each program about scope of work for the year
- Scope of work to align with %FTE funded
- Document to refer to when scope of work for program changes to avoid overwhelming AU staff
- Reinforcement that AU oversees work methods and staff for project
- Example

Benefits of AU structure

- Multiple funding sources
- Staff become cross-trained across disease areas and types of analyses
- Access to data (STD, TB, HIV client services)
- Analyses are conducted consistently across disease areas
- HIV expertise has been shared
- The bar on security and confidentiality has been raised for non-HIV programs

Examples

- HIV-STD match, HIV-HCV match
- Never In Care
- Participation on planning groups
- Hepatitis program support
- Reascertaining names for HIV reporting
- More data get shared with more stakeholders

Challenges

- As all CDC-funded programs get cut, program managers prioritize funding their own staff
- Need to remain vigilant about work loads
- Continue to deal with different data systems across disease areas
- Programs need to maintain some in-house assessment capacity

Questions?

Maria Courogen, MPH
Washington State Department of Health
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Integration of Surveillance with Other Programs

Bill Jones, MPH
Epidemiologist
NC Division of Public Health

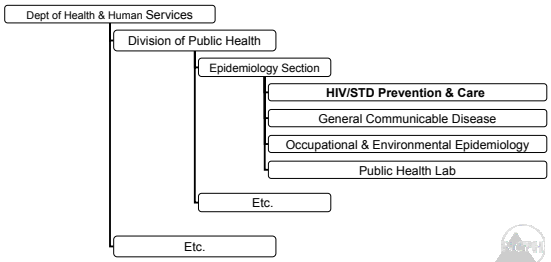
Integration of Surveillance with Other Programs

- NC HIV/AIDS Surveillance
- NC PCRS

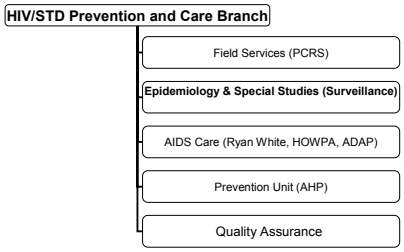
Public Health in North Carolina

- 100 individual counties comprising 87 health departments
- Each county has responsibility for public health in its jurisdiction

Organizational Structure
(state level)



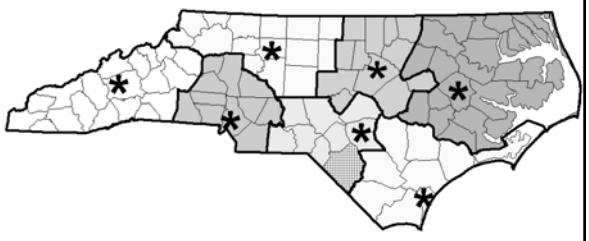
Organizational Structure
(state level)



HIV/STD Prevention & Care Branch

- Units operate under a common mission
  - Branch wide security and confidentiality training (every two years)
    - Common guidelines (unique to the Field Services and Surveillance). Different from TB, LHD , etc.
  - Equivalent unit status (directly reportable to same supervisor/head)
    - Each unit's issues get addressed
- Public Health Law
  - Historical ties within public health
  - Requires case follow up by field services (state) with partner notification

North Carolina HIV/STD Prevention & Care Branch Regional Offices



HIV Case Reporting

Provider report ⇨ Local health dept ⇨ ESSU (surveillance) ⇨ Regional office

- Reviews report
- Director signs morbidity card

June 2006

HIV Case Reporting

Provider report ⇨ Local health dept ⇨ ESSU (surveillance) ⇨ Regional office

- Search case in HARS
  - Update previous cases
  - Assign new state number
- Forward copy of report to Regional Office

June 2006

HIV Case Reporting

Provider report ⇨ Local health dept ⇨ ESSU (surveillance) ⇨ Regional office

- Enter case into local STDMIS
- Assign to DIS
- DIS Provider call-- verification/participation
- Field interview with patient
- Forward copy of interview form to ESSU
- HARS updated (local variables)

June 2006

HIV Lab Reporting

Laboratory reporting (modified reporting flow)

lab report ⇨ ESSU (surveillance) ⇨ Regional office ⇨ Local health dept

- Registrars search labs
- Assign state numbers and enter into HARS

- DIS contact provider to solicit case report
- Begin field follow-up

June 2006

Why it works?

- Each Field Investigation begins with a provider call/visit to address any reporting issues.
- Centralized oversight of field and core surveillance. Reporting doesn't always expected path.
  - Field surveillance coordinator
  - Reporting surveillance coordinator
- Other collaborations – syphilis reporting / follow-up
- Feedback (reports) regional / local level

June 2006

Benefits

- For Field Services
  - ESSU maintains a centralized registry for limited PCRS information (acts as a bridge between the regional STDMIS systems)
  - ESSU conducts interstate contact notifications
  - Notification about new providers. Useful for Field Services to develop relationship with providers

Benefits

- For ESSU
  - Field interview records have much more risk information
    - DIS are trained to collect good risk information
    - Capture four additional risk categories in HARS
      - Used to define "presumed heterosexual" risk
    - Can periodically link to regional STDMIS for additional risk information

Benefits

- For ESSU
  - Expands available resources locally
    - 2000 individual reporters
    - Physical distance to some providers
  - Documentation of case information with provider and patient

Challenges

- Paper based
- Different program focus for surveillance and PCRS
  - Provider interaction/education can be time consuming and challenging for DIS
  - Surveillance must process the reports quickly to determine new cases and assign state numbers. Data entry is often segmented.

Questions?

HIV Incidence Data 2005-2006

María C. Rangel. MD, PhD

HIV Incidence and Case Surveillance Branch
Division of HIV/AIDS Prevention
Centers for Disease Control & Prevention

Presented at the Pre Conference Workshop
Council of State and Territorial Epidemiologists (CSTE)
Anaheim, CA - June 4, 2005

The findings and conclusions in this presentation are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention.

CDC

Outline

- Background
- Status of implementation
- Preliminary findings
- Next steps
- Summary
- Recommendations

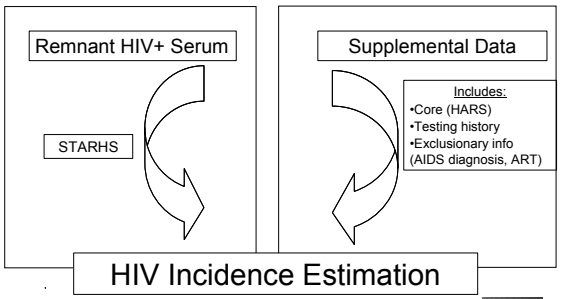
CDC

Incidence Surveillance Goals

- July 2005 – Atlanta, GA
  - To produce estimate of HIV incidence for 2005
  - All sites implementing by end of year
  - Complete coverage of all new diagnoses
- June 2006 – Anaheim, CA
  - To produce estimate of HIV incidence for 2005 & 2006
  - All funded sites fully implemented by June
  - Complete coverage of all new diagnoses

CDC

Requirements for Population-Based HIV Incidence Surveillance



CDC

Data Required for Incidence Estimation

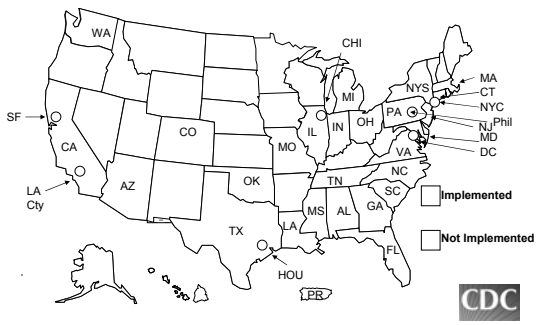
- Demographic information (Core)
  - Location of residency, sex, race, age, risk mode
- Information about the first positive test (Core, THQ)
  - Testing date, testing site, reason for test
- Testing history information (THQ)
  - Previous test, date of last negative test
- Information related to STARHS (Core, THQ, lab data)
  - AIDS at Dx, HAART, sample availability, specimen collection date, BED result

CDC

Status of Implementation

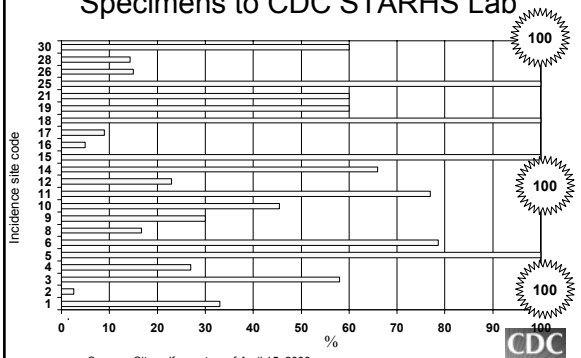
CDC

Current Status of Implementation of HIV Incidence Surveillance under Standard Procedures April 2006



CDC

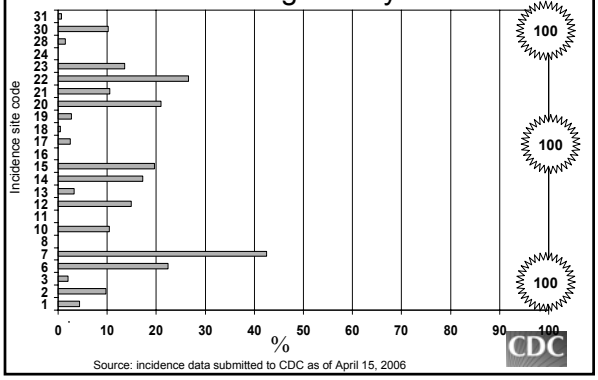
Percentage of Labs Submitting Specimens to CDC STARHS Lab



Source: Site self-report as of April 15, 2006

CDC

Percentage of New HIV Diagnoses with Testing History



Source: incidence data submitted to CDC as of April 15, 2006

CDC

Status of Implementation

- Percentage of cases with information from Testing History Questionnaire:
  - **~12% (range 0—45% between sites)**
- Percentage of labs serving specific area populations submitting specimens to CDC STARHS Lab:
  - **Range 0—100%**

CDC

Preliminary Findings

CDC

Testing History Cumulative Data* 26/34 sites - April, 2006

Testing History ¶	2005		2006	
	N	%	N	%
Yes	3,591	**14.4**	451	**11.8**
No	21,336	85.6	3,359	88.2
Total	24,927		3,810	

*Since implementation

¶ at least one answer to one of 5 questions in THQ

CDC

STARHS Specimen Available cumulative 26/34 sites - April, 2006

Specimen	2005		2006	
	N	%	N	%
Yes	4,694	**18.8**	695	**18.2**
No	20,233	81.2	3,115	81.8
Total	24,927		3,810	

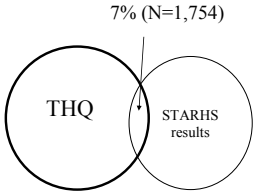
CDC

STARHS Results Available 26/34 sites - April, 2006

STARHS results	2005		2006	
	N	%	N	%
Yes	3,068	**12.3**	126	**3.3**
No	21,859	87.7	3,684	96.7
Total	24,927		3,810	

CDC

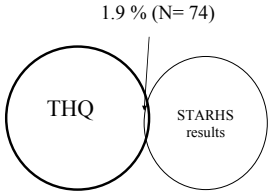
Proportion of New Diagnoses in 2005 with Testing History and STARHS Results*



*Data from 26/34 sites - April, 2006

CDC

Proportion of New Diagnoses in 2006 with Testing History and STARHS Results*



*Data from 26/34 sites - April, 2006

CDC

BED Results among New Diagnosis 22 States, March 2006

- Among cases with BED results (~12% of new reports)
  - BED recent: 24%
  - BED recent among persons with HIV (not AIDS within 12 months) diagnosis: 28%
  - BED recent among persons with concurrent HIV and AIDS diagnosis (within the same month): 10%
  - BED recent among persons on ART: 20%

CDC

NEXT STEPS

CDC

Estimation Procedure

- Stratify cases into risk homogenous or testing homogenous groups
- Calculate incidence weights for cases in each incidence group based on detection probability
- Select cases in a population group of interest
- Incidence = sum of weights from selected cases

Incidence Subgroups

(For 3 main groups determined by status of previous test)

Motivated by recent incident	AIDS dx at HIV dx	On medication or no BED or BED unknown	BED recent	Sub group	Number of cases	Incidence weight
Yes	Yes			G_{ma}	N_{ma}	$W_{ma}=0$
	No			G_{mx}	N_{mx}	$W_{mx}=1$
No	Yes			G_{0a}	N_{0a}	$W_{0a}=0$
	No	Yes		G_{0x}	N_{0x}	W_{0x}
		No	Yes	G_{00}	N_{00}	W_{00}
			No	G_{0b}	N_{0b}	$W_{0b}=0$
Unknown	Yes			G_{xa}	N_{xa}	$W_{xa}=0$
	No	Yes		G_{xx}	N_{xx}	W_{xx}
		No	Yes	G_{x0}	N_{x0}	W_{x0}
			No	G_{xb}	N_{xb}	$W_{xb}=0$

Summary

- All but one incidence site transitioned to standard incidence procedures
- 12% of new diagnoses have THQ
- 18% of new diagnoses have blood
- Low proportion have THQ & lab results
  - 7% in 2005
  - 2% in 2006
- Wide range % lab sending blood to NY

Recommendations

- Keep-up the good work!
- Continue efforts to collect THQ
  - Full implementation in public settings
  - Participation from private
- Get blood for all/most new diagnoses
- Six months to get best data we can

Questions?

Maria C. Rangel

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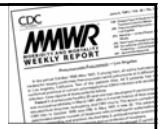
404-639-3958



HIV/AIDS Case Surveillance: Midpoint Workshop for a Third Decade of Excellence

Matthew T. McKenna, MD, MPH

Chief, HIV Incidence and Case Surveillance Branch
Division of HIV/AIDS Prevention
National Center for HIV, Viral Hepatitis, STD, and TB Prevention

CDC

CDC HIV Strategic Plan: Goals

- Overarching: Reduce number of new Infections by 50%
  - Deliver prevention programs to infected persons and those at high-risk of infection
  - Increase percentage who know they are infected from 70% to 95%
  - Increase from 50% to 80% the percentage of HIV infected persons who are linked to prevention, treatment and care services
  - Strengthen the capacity nationwide to monitor the epidemic, develop and implement effective HIV prevention interventions and evaluate prevention programs

CDC

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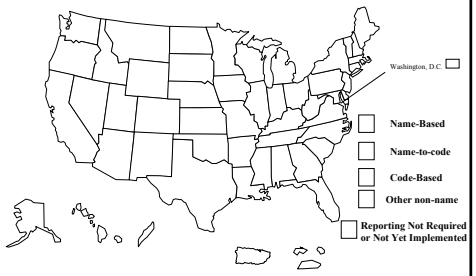
CDC

Strategic Plan: Goal 4 Performance Indicator

Increase the number of states and territories with integrated, name-based, HIV/AIDS reporting systems

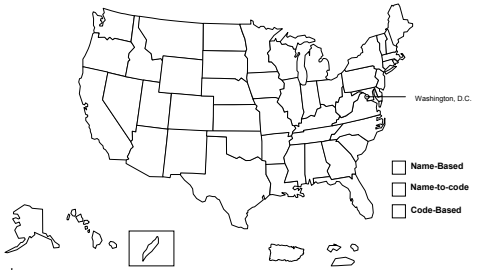
CDC

Status of HIV Infection Reporting
Jan 2001



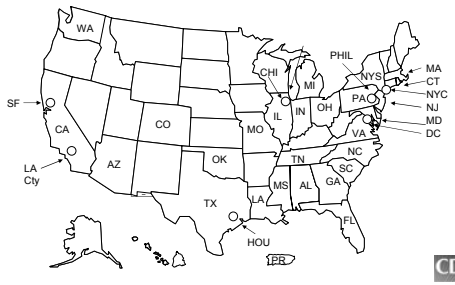
CDC

Current Status of HIV Infection Surveillance
June 2006



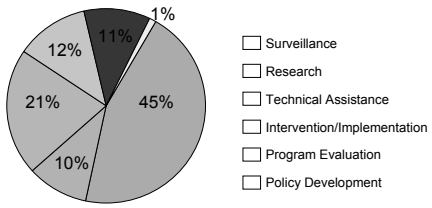
CDC

HIV Incidence Surveillance System, 2006 (n=34)



CDC

Goal 4: Funding by Mission Category



Goal 4
Total: $210.8 Million

CDC

Challenges/ Opportunities (Besides $$$)

- **A national, integrated HIV/AIDS reporting system**
- **Technical Guidance**
- **eHARS**
- **HIV Incidence – First estimates**
- **Ryan White**
- **Program integration**

CDC

Thanks and Appreciation

- CSTE Leadership
  - Pat McConnen
  - Jerry Gibson
- CSTE Workgroup
  - Eve Mokotoff
  - Anthony Merriweather
  - David Fields
  - Nene Diallo
  - Doug Frye
  - Laura Lund
  - Luke Shouse
  - Becky Grigg
  - Wendy Schell
  - Mauda Monger
  - Nanette Benbow
- CDC Workgroup
  - Tonya Ross
  - Kate Glynn
  - Barbara DeCausey
  - Lisa M. Lee
  - Irene Hall
  - Martha Miller

CDC

Implementing the Re-abstraction Guidance: Georgia's experience

R. Luke Shouse, MD, MPH
Georgia Division of Public Health
HIV Epidemiology
June 2006

Re-Abstraction Studies

- Goal: Improve the quality of HIV/AIDS surveillance data
- Assess:
  - The agreement between information recorded in the surveillance system and information recorded in source records (e.g., hospital medical records)
  - The quality and validity of information as it existed in the source file when the record was initially abstracted
  - The quality of data from staff abstracting (active surveillance) and provider reporting (passive surveillance)

Challenges

- Personnel resources
  - Re-abstracting
  - Data entry
  - Analysis
- Provider fatigue
- Buy-in from surveillance staff

Georgia's approach

- Honestly, re-abstraction was not a top priority in implementing new technical guidance in Georgia
- Opportunity for MPH student to conduct abstraction study to fulfill her practicum requirement (400 hours)

Sample

- Only adult/adolescent cases in metro Atlanta originally abstracted by surveillance staff in July – December 2005
- Sample size – 45 cases
- Simple random sampling – used random number table
- 8 sites
- One site could not participate due to conversion from paper medical record system to electronic – 2 cases lost
- 3 other cases lost from 2 other sites

Re-abstraction

- Conducted January & February 2006
- All re-abstraction performed by MPH student, Rosebud Mayanja
- Rosebud trained in completing case report form
- Rosebud did not have access to original report
- Re-abstracted information in chart from original abstraction date
- Variables re-abstracted included demographics, date of dx, facility of dx, risk, lab data, OIs, reporting facility information, etc.

Re-abstraction

- Original and re-abstracted data compared
- Discrepancies were categorized as minor or major

Currently

- Study not complete…
- Rosebud has completed her activities and submitted the findings
- Reviewing her findings
- Need to go back to chart to review/reconcile discrepancies

What Worked & What Didn't

- Worked
  - Sampling – flexible
  - Student provided needed personnel resource
  - Limited scope
    - Smaller geographic area – reduced travel expenses
    - Focused on cooperative providers
- Didn't work
  - Student not familiar enough with reporting
  - Slow process, ran out of time
  - Student required lots of supervision
  - Unclear what the results mean
  - Did not evaluate passive surveillance/provider abstracting

Next steps

- Review findings more closely with surveillance staff
- Review and reconcile discrepancies by returning to source of report
- Evaluate how to implement re-abstracting using surveillance staff
  - Annual re-abstraction distributed throughout the year by quarters
  - Focus effort by limiting variables re-abstracted

Ryan White Comprehensive AIDS Resources Emergency (CARE) Act Update

Patricia Sweeney
Epidemiologist and Policy Officer
HIV Incidence and Case Surveillance Branch

CDC

Overview

- Background on the Ryan White CARE Act (RWCA)
- Reauthorization process
- How surveillance data are used
- Key features of the latest bill
- What if the RWCA is not reauthorized?

CDC

Background
Ryan White CARE Act (RWCA)

- Federal legislation to address unmet health needs of persons living with HIV disease
- First enacted in 1990, reauthorized and amended in 1996 and 2000
- Over $2 billion of funds appropriated in FY 2006

CDC

Background RWCA (cont'd)

- Composed of 4 major titles and several other components
  - Title I -Grants to Eligible Metropolitan Areas (EMAs)
  - Title II-Grants to U.S. states and Territories to improve health care and support services and access to medications through ADAP
  - Title III- provides grants directly to nonprofit entities for primary care, early intervention services and capacity building
  - Title IV – grants for family centered care for infants, children, youth and women with HIV
  - Other components (e.g., AIDS education training centers, special projects)

CDC

RWCA Reauthorization Process

2005
- Release of the President's Principles
- Initial findings from GAO report presented to the Senate
- RWCA expired Sept 30, 2005

2006
- Final GAO report released
- Senate HELP Committee and the House Energy and Commerce (E&C) Committee Drafts reauthorization legislation May 9, 2006
- May 17, 2006 Ryan White HIV/AIDS Treatment Modernization Act of 2006 S2823 voted out of committee 19-1
- Statements submitted by a variety of stakeholders
- E&C subcommittee mark-up and full committee mark-up expected in June
- Bill will then be brought to House and Senate for passage prior to August recess

CDC

How surveillance data are currently used in the RWCA

- Based on reported AIDS cases
- Case counts and weights provided by CDC to HRSA
- HRSA calculates allocation formulas
- Act specifies formula for calculation of "Estimated Living AIDS Cases" (ELCs) used for Title I and II base awards
- Current Act states that cases of HIV disease will be used for FY 07 allocations

CDC

How surveillance data are currently used in the RWCA (cont'd)

- Eligible metropolitan area determination
  - AIDS case counts for MSAs over 500,000 with more than 2000 reported cases over the most recent 5 years
- Title I and II Base grants
  - AIDS cases reported during the most recent 10 years with national survival weights (for ELC calculations) by EMA and state
- Emerging Communities under Title II
  - MSA's over 50,000 with 500 or more AIDS cases reported over the most recent 5 years
- Priority for Women Infants and Children
  - AIDS cases reported during the most recent 10 years for specified groups by state and EMA

CDC

How surveillance data are currently used in the RWCA (cont'd)

- Minority AIDS Initiative for Titles I and II
  - Non-white AIDS cases diagnosed during the past 2 calendar years adjusted for reporting delays
- State Match for Title II
  - AIDS cases counts for the last 2 years
- Intergovernmental Agreement (IGA) requirements
  - Listing of counties with at least 10% of an EMAs reported AIDS cases for the most recent 5 years used to establish administrative mechanism to allocate funds
- Descriptive data for creation of epidemiologic profiles in grant applications (*no longer provided*)
  - AIDS incidence and prevalence and diagnosed HIV prevalence (for areas reporting to CDC) by state/EMA and age sex, race, risk (adjusted for reporting delays and risk)
  - Programs now available locally to redistribute risk

CDC

Key Features of the Proposed Bill S2823 Related to Surveillance Data

- Maintains the use of reported AIDS cases to determine EMAs and new transitional grant areas
  - Repeals emerging communities grants under Title II and establishes transitions grants under Title I based on tiered system from 500-2000 reported AIDS cases in the last 5 yrs the distribution based on the proportion of living HIV/AIDS cases
- Does away with 10yr ELC formula
- Uses the number of reported living HIV/AIDS cases…reported and confirmed by CDC through December 31st of the most recent calendar year

CDC

Key Features of the Proposed Bill S2823 Related to Surveillance Data

- Allows for the potential use of a proxy for HIV cases in areas without established HIV reporting systems for FY07-FY10 if
  - The state did not have an "established" HIV surveillance system but had begun reporting
  - Or by Oct 1, 2006 submitted a transition plan for reporting accurate and reliable data to CDC
  - The amount for the Title I grant would be the lesser of the product of .9 and the number of living AIDS cases or an amount equal to 110% of the previous year
  - Hold harmless provisions remain for 3 years but change: for FY07 not less than 90% of FY06, FY08-85% of FY06, FY09-80% of FY06

CDC

What if the RWCA is not reauthorized?

- Current legislative language remains in effect
- HIV disease data will be used beginning this year for FY07 for most parts
- Reported AIDS cases in most recent 5 yrs still used for EMA eligibility and IGA
- HIV data will be included in formulas for all areas reporting HIV cases to CDC
- For areas not reporting HIV cases to CDC, their AIDS case count will be their HIV disease count

CDC

What if the RWCA is not reauthorized? (cont'd)

- CDC/HRSA workgroup established to look issues related to incorporating HIV data given various scenarios within the existing parameters of the law
- What will remain the same?
  - HIV disease cases reported during the 10, 12 month periods through the end of June prior to the fiscal year will be included
  - A single national set of survival weights for each 12 month period will be used and updated on a biannual

CDC

What if the RWCA is not reauthorized? (cont'd)

- What will change?
  - All persons diagnosed and reported with HIV to CDC will be included in the formulas
  - Date will be by earliest report of HIV disease rather than date of report of AIDS
  - Geographic assignment will be based on residence at earliest HIV diagnosis

The future is …uncertain

Resources

- Information about RWCA and funding on the HRSA HIV/AIDS Bureau website: http://hab.hrsa.gov
- Current Bill at http://hab.hrsa.gov/law.htm
- NASTAD website http://www.nastad.org
  Go to CARE Act Reauthorization Watch newsletter

Stay tuned…

The Impact of Changing HIV Testing Technologies on HIV Surveillance Practices

Alison Freeman, MPH

HIV Incidence and Case Surveillance Branch
Division of HIV/AIDS Prevention
Centers for Disease Control & Prevention

Presented at Council of State and Territorial Epidemiologists (CSTE)
Anaheim, CA, June 4-8, 2005

CDC

Outline

- Background
  - Current HIV Case Definition
  - Advancing HIV Prevention Initiative
- Changes in:
  - Testing technologies
  - Testing application for diagnostics
- Summary

CDC

Adult & Adolescent HIV Case Definition

A reportable case of HIV infection must meet at least one of the following criteria:

Laboratory Criteria

- Positive result on:
  - Screening test for HIV antibody (e.g., repeatedly reactive EIA)
    AND
  - Confirmatory test for HIV antibody (e.g., Western blot (WB) or immunofluorescence antibody test)

  or
- Detectable quantities of any of the following biomarkers on HIV virologic tests:
  - HIV nucleic acid (e.g. of tests: DNA PCR, plasma HIV-1 RNA)*
  - HIV p24 antigen (e.g. of test: neutralization assay)
  - Whole HIV (e.g. of test: viral culture)

OR

Clinical Criteria

- Medical documentation of lab criteria

*Plasma viral RNA nucleic acid tests should **NOT** be used in lieu of licensed HIV screening tests (e.g., repeatedly reactive enzyme immunoassay).

CSTE Position Statement 05-ID-04, June 2005

CDC

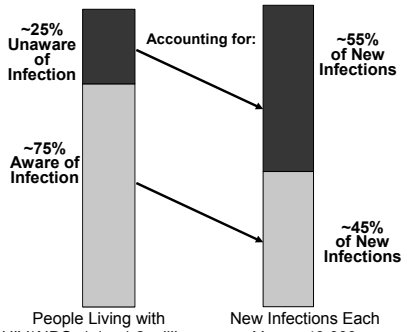
Advancing HIV Prevention Initiative (AHP)

Four priorities:

1. Make voluntary HIV testing a routine part of medical care
2. Implement new models for diagnosing HIV infections outside medical settings
3. Prevent new infections by working with persons diagnosed with HIV and their partners
4. Further decrease perinatal HIV transmission

CDC

Awareness of Serostatus Among People with HIV and Estimates of Transmission



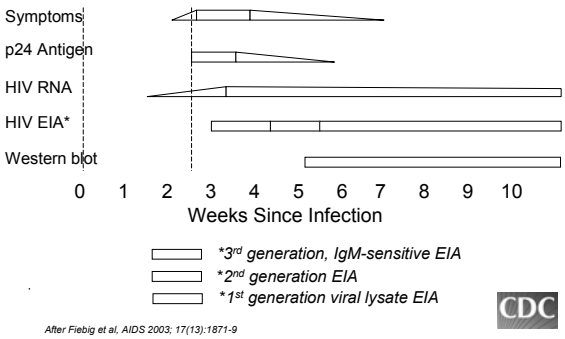
CDC

Changes in HIV Testing Technologies:

2nd/3rd Generation EIAs
Rapid Tests
Nucleic Acid Amplification Tests (NAAT)

CDC

Detection of HIV by Diagnostic Tests



After Fiebig et al, AIDS 2003; 17(13):1871-9

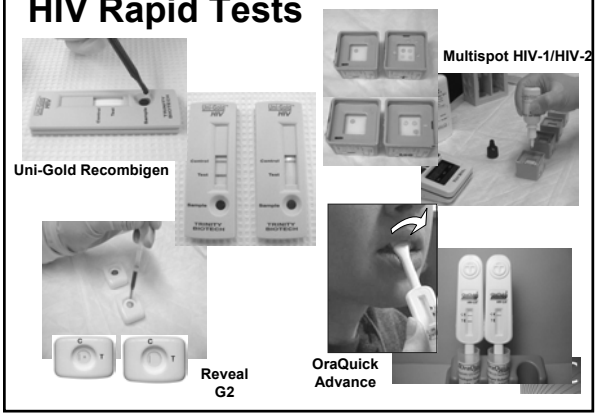
Generations of EIAs

- 1st generation EIA:
  - Viral lysate
- 2nd generation EIA:
  - Recombinant proteins and/or synthetic peptides +/- viral lysates
- 3rd generation EIA:
  - Antigen sandwich EIA → greater sensitivity
  - Detects IgG and IgM → earlier detection
- 4th generation EIA
  - Unavailable in the US

Impact of 2nd/3rd Generation EIAs on HIV Surveillance

- Advantages:
  - Newer EIA technology is able to diagnosis recent infections earlier than 1st gen EIA
  - HIV-1/2 combination screening tests
- Considerations:
  - Potential for increased WB indeterminates
  - Increased cost?

HIV Rapid Tests



Predictive Value of Preliminary Positive Rapid Test Result

Positive Predictive Value (PPV) of a single test depends on specificity & varies with prevalence

	PPV, Single Test			
HIV Prevalence	**OraQuick**	**Reveal**	**Uni-Gold**	**Single EIA**
10%	99%	92%	97%	98%
5%	98%	85%	95%	96%
2%	95%	69%	87%	91%
1%	91%	53%	77%	83%
0.5%	83%	36%	63%	71%
0.3%	75%	25%	50%	60%
0.1%	50%	10%	25%	33%
Test Specificity	**99.9%**	**99.1%**	**99.7%**	**99.8%**

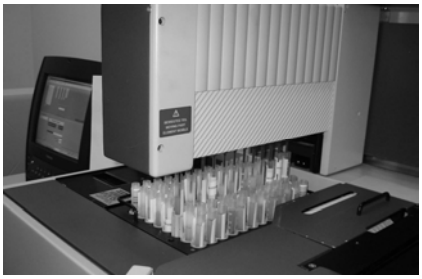
Impact of Point-of-Care / Rapid Testing on HIV Surveillance

- Advantages:
  - Patients more likely to get tested for HIV
  - Decreased loss to follow-up
  - Increased flexibility in testing location
  - Rapid tests may be able to diagnosis recent infections earlier than standard (1st gen) EIA
- Considerations:
  - Increase in number of "unconfirmed" preliminary positives
  - Potential for increased WB indeterminates
  - Decentralized testing → reporting implications

NAAT Testing

NAAT = Nucleic Acid Amplification Testing

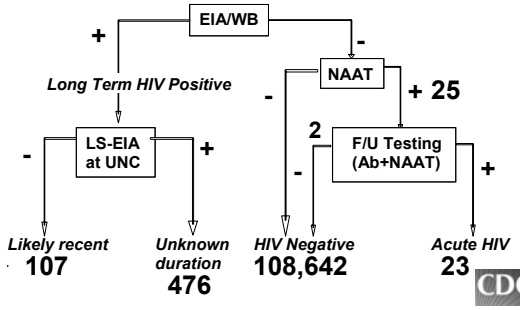
RNA screening for early HIV infection



NC Population Testing Program 2003

n=109,250 at-risk clients (12 months)

(Pilcher et al. NEJM 2005)



Impact of NAAT Testing on HIV Surveillance

- Advantages:
  - Identify antibody-negative acute HIV infections
- Considerations:
  - No changes to case definition – meets requirement for virus detection
  - Implications for reporting
  - Impact on HIV incidence surveillance
  - **Overall impact:** *Lots of lab work for each case, with relatively few new cases identified by NAAT*

Changes in HIV Testing Applications for Diagnostics:

Alternative Testing Strategies

Planning for Potential Changes to the HIV Diagnostic Algorithm

- Alternative algorithms are being systematically evaluated for use in the U.S. Possible alternative testing strategies:
  - EIA / EIA
  - EIA / Rapid
  - Rapid / Rapid
  - 3rd tie-breaker test for discrepant results
- Considerations
  - Two tests must use different antigens and/or assay configurations
  - 2nd test should have higher specificity than 1st test

Impact of Alternative Testing Strategies on HIV Surveillance

- Advantages:
  - Faster turn-around time for confirmed positive results
  - Cost savings
- Considerations:
  - Change in HIV case definition
  - Impact on HIV incidence surveillance
    - Obtaining specimens when only rapid tests are used
  - Will no longer be able to rely on WB report from lab to identify new HIV cases
    - Better clinician reporting
    - More reliance on CD4 and viral load reports

Summary

- HIV testing technology has improved and changed rapidly over the past 25 years
  - Newer EIAs, rapid, and RNA tests can identify infection closer to the time of exposure than traditional testing algorithm
  - Alternative testing strategies may be a reasonable option for HIV diagnostics
- HIV surveillance must remain flexible and be adaptive to these changes
- The advances in testing technology have allowed us to continually better understand and characterize the U.S. HIV epidemic → improved prevention strategies

CDC

Questions?

Alison Freeman, MPH
HIV Incidence and Case Surveillance Branch
Division of HIV/AIDS Prevention
Centers for Disease Control & Prevention

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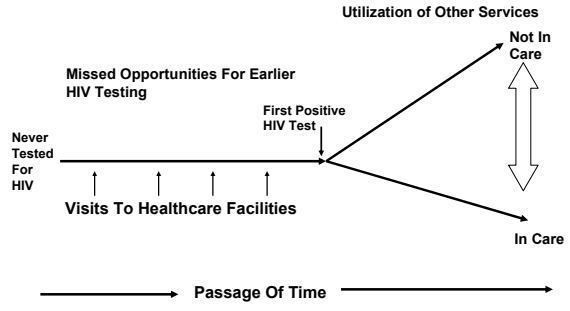
CDC

Analyses of HARS-linked Data Sets

Wayne A. Duffus, MD, PhD

CSTE, June 5th, 2006

Schematic Of Missed Opportunities and Not-In-Care



Agencies Cooperating On Study

- SC Department of Health (DHEC)
- SC Office of Research and Statistics (ORS)

DHEC Security Measures

- File subjected to same security measures as all HIV/AIDS data
- Request that ORS supervisor and staff sign confidentiality statement
- Data physically taken on CD to ORS by the DHEC Surveillance Division Director (SDD)

DHEC Security Measures

- DHEC SDD monitored the deletion of specific variables after linkage completed
  - Unique identifier (UID) assigned to each individual
  - UID not kept with any other information that can possibly identify an individual

DHEC Security Measures

- Agreement on how data will be secured while at ORS (server, initial identified file returned to DHEC)
- No reference to HIV/AIDS in the dataset
- No additional analysis of the dataset than otherwise specified

DHEC File Of Variables To Assist With Linkage

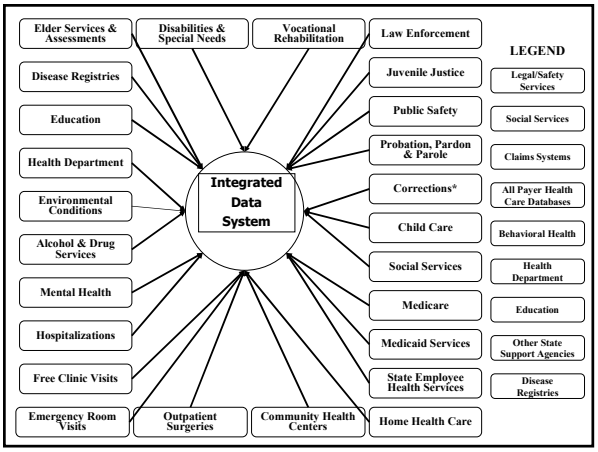
- Patient name
- Birth date
- Gender
- Race/ethnicity
- County of residence
- Social security number
- Date of first positive HIV/AIDS test
- HIV or AIDS status at diagnosis

SC Office of Research and Statistics (ORS)

- A division of SC Budget and Control Board
- Inpatient, emergency department and outpatient services are mandated by law to provide data to ORS
  - 100% reporting since 1980s
- Contractual relationship with other agencies to house data

SC Office of Research and Statistics (ORS)

- Receives data from 5/10 Community Health Centers
- Has 19 Free Medical Clinics participating in the database; about 9 others do not
  - Funding through local support and United Way Donations
  - Duke Endowment Grant helped to start the database project



Missed Opportunities For Earlier HIV Testing In South Carolina

Wayne A. Duffus, MD, PhD

Background

- CDC guidelines: facilities with > 1% seroprevalence should routinely test for HIV
- Disadvantaged patients often use the emergency departments for primary care
- Risk-based testing may miss individuals at risk through partner's practices

Objectives

- To demonstrate that patients access hospital services many times before receiving a positive HIV test result
- To be able to link a positive HIV test result with prior ICD & CPT codes for services received at different facilities
- To determine if a positive HIV test is associated or not with certain diagnostic codes assigned prior to HIV testing

DHEC Actions Taken Prior To Linkage

- De-duplicated list generated from the HIV/AIDS Reporting System (HARS)
- Inclusive years: 1/1/01 – 12/31/05
- Residents of South Carolina

Facilities Data Requested From ORS For Linkage

- Emergency departments
- Hospital inpatient admissions
- Outpatient / ambulatory surgery
- Free medical clinics
- Community health centers
- Time period examined for missed testing opportunities: 1/997 to 12/05

Variables Requested From ORS On HIV-infected Individuals

- Diagnosis codes
- Procedure codes
- DRG
- Admission dates at healthcare facility
- Source of payment
- Admission to special units eg. ICU, CCU
- Physician specialty code
- Urban/rural status of healthcare facility
- Bed size of healthcare facility
- Healthcare facility classification eg. public, private
- Patient zip code
- Unique patient identifier number

Additional Variables Requested To Be Returned With Final Dataset

- Patient name
- Birth date
- Gender
- Race/ethnicity
- County of residence
- Social security number
- Date of first positive HIV/AIDS test
- HIV or AIDS status at diagnosis

ORS Security Measures

- Application to the Data Oversight Council for study approval prior to initiating linkage
  - Signed confidentiality statement
  - Specific variables to be used for linkage and those to be returned in final file
  - Reason(s) for requesting a restricted data variable eg. Date of birth
  - Proposed data uses and expected products from study eg. to promote routine testing
- A unique ID is assigned to each person
- Data returned as SAS file on CD

Characteristics Of Final Data File

- Excludes: names, addresses, social security numbers, facility and physician identifiers
- None of the variables indicate HIV status (eg. CD4, VL, HIV/AIDS)
- Data to be destroyed 5 years from date of receipt
- Access to data restricted to named individuals who have signed confidentiality agreements
- Cannot be linked to other databases at DHEC

Results

Summary Outcome

4,387 people diagnosed with HIV in SC (1/01 – 12/05)

↓

3,176 (72.4%) people visited healthcare facilities prior to HIV testing

↓

20,425 separate visits recorded

↓

1,322 (41.6%) people diagnosed with AIDS within one year of HIV testing

Number Of Visits Prior To HIV Testing

Number of Visits	Number of Patients	% of Total Patients
1 Visit	649	20.4%
2 – 5 Visits	1,362	42.9%
6 – 10 Visits	638	20.1%
> 10 Visits	508	16%

Total visits ranged from 1 to 132 per patient

Time For Receipt Of Diagnosis Of AIDS In Relation To First Positive HIV Test

Diagnosis	Number of People	Percent
HIV only	1,661	52%
AIDS dx within 3 mths	1,192	37.5%
AIDS 3 – 6 mths	65	2%
AIDS 6 mths – 1 yr	65	2%
AIDS 1 – 2 yr	70	2.2%
AIDS 2 –3 yr	56	1.8%
AIDS > 3 yrs	67	2.1%

Timeframe For Visits Prior To The First Positive HIV Testing

Visit Period Before Positive Test	Number of Visits	Percent of Visits
< 6 months	2729	13.5%
6 mth – 1 year	2075	10.2%
1 yr – 2 years	3618	17.9%
2 yr – 3 years	3324	16.4%
> 3 years	8525	42.1%

Limitations

- Cannot tell those who were offered but refused testing
- Lack data on people who tested negative over the study period
- Cannot tell definitively if HIV-infected at the time of visit

Conclusion

- Collaborating with other agencies will provide useful data that can be of benefit to public health
- Documented several missed opportunities for earlier HIV testing (72.4%)
- Many patients if they were offered and accepted testing would have been found to be HIV-infected (41.6%)

Discussion

- No medical test should be mandatory but people should be given the opportunity to "opt out" of testing.
  - Counseling and education about avoiding risky behaviors should continue and should not be linked to testing.
- Potential benefits to sexual and drug-using partners
- Health departments should partner with CPG and healthcare facilities to implement plans for routine HIV screening

Characterizing South Carolina HIV-infected Patients Who Are not In Medical Care

Wayne A. Duffus, MD, PhD

Background

- Starting 1/1/04, all CD4 and Viral loads was reportable by laboratory to DHEC
- All values stored in HARS and a supplemental data base.
- All HIV-infected SC patients who die are reported to DHEC by a variety of sources (other states, Vital Records, Death Match) via file Linkage, ICD Codes, communication with other states.

Background

- DHEC completed the HARS/Social Security Death Registry Linkage
- HRSA definition of in-care: CD4, viral load, or ARV received within one year

Objectives

- To determine what proportion of HIV-infected SC patients are not-in-HIV-care
- To able to describe the other services received by patients not-in-HIV-care
- Characterize individuals who are most at risk to not present for HIV medical care
- Program improvement to evaluate local post-test counseling methods and linkages to care strategies

DHEC Actions Taken Prior To Linkage

- De-duplicated list generated from the HIV/AIDS Reporting System (HARS)
- Residents of South Carolina
- All individuals diagnosed with HIV-infection through 12/31/04
- No reported CD4 or Viral load from 1/1/05 to 12/31/05
- Removed those that have died

DHEC Actions Taken Prior To Linkage

- Excluded CD4/VL if drawn within 4 weeks at the health department

Facilities Requested From ORS For Linkage

- All agencies that provide information to the ORS
- Time period for requested data when not-in-care patients may have received services: 1/1/2001 to 12/31/2005

Variables Requested From ORS On HIV-infected Individuals Not-in-HIV-Care

- Name agencies where services rendered
- Give number (%) of patients served
- Source of payment at last visit
- Top 5 diagnosis/visit reason per year
- Urban vs rural place of residence
- Race/ethnicity
- Gender
- Age group in deciles

ORS Security Measures

- Application to the Data Oversight Council NOT REQUIRED prior to initiating linkage study
- Linkage performed in the ORS building
- Not given data file with variables
- Only summary data to be returned initially
- Preliminary findings will direct future requests where permission may be needed from DOC, IRB, specific agencies

Results

- Total number of individuals on file taken to ORS 2,850
- ORS returned limited data; need to secure additional permission
- ORS reported that ~ 65% were found in the inpatient/ER dataset
- Persons encountered in 2005, 646 (22.8%) of total

Agencies Where Not-in-HIV-Care Patients Were Served in 2005

- Hospital discharge dataset
- Free clinic
- Medicaid
- Department of Mental Health (DMH)
- Temporary Assistance For Needy Families (TANF)
- Food Stamps
- Pardon, Parole and Probation (PPP)
- South Carolina Law Enforcement Division (SLED)

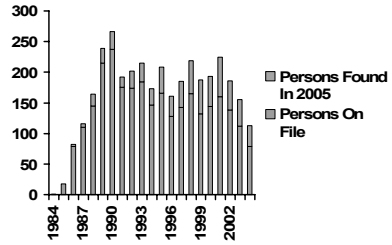
Persons Not-In-Care for HIV Linked to 2005 Data System By Age

Age Cohort	# Persons on File	Persons Found In 2005
	2,850	649 (22.8%)
0 – 19 yrs	15	2 (13.3%)
20 –29 yrs	208	89 (42.8%)
30 – 39 yrs	813	228 (28.0%)
40 – 49 yrs	1,113	229 (20.6%)
> 50	701	101 (14.4%)

Persons Not-In-Care for HIV Linked to 2005 Data System By Race

Race	Persons On File	Persons found In 2005 Data
	2,831	646 (22.8%)
White	717	86 (12.0%)
Black	2,046	555 (27.1%)
Other	68	5 (7.4%)

Persons Not-In-Care for HIV Linked to 2005 Data System By Year Of HIV Diagnosis



Limitations

- Agencies agree to provide information stepwise; time-consuming, labor intensive
- Will ultimately require providing names of matched individuals; IRB, legal basis, fear
- Not able to tell why HIV-infected patients do not enter care

Conclusions/Discussion

- Should provide useful information at HIV testing that will allow better detection of individuals at risk for not presenting for HIV care
- May suggest methods for locating individuals not in HIV care
- Collaborating agencies also may benefit

Acknowledgements

- USC School of Public Health
  - Kristina Weis
- SC Department of Health & Environmental Control
  - Terri Stephens
  - Dana Giurgiutiu
  - Jerry Gibson
- SC Office of Research and Statistics
  - Pete Bailey
  - Mary Tyrell
  - Chris Finney
  - Sandra Kelley

Visit Timing In Relation To HIV Testing And The Diagnosis Received (HIV or AIDS)

Visit Period	HIV Only	AIDS ≤ 1 Year	AIDS > 1 year
≤ 6 months	1,247 (45.7%)	1,298 (47.6%)	184 (6.7%)
6 month – 1 yr	1,109 (53.5%)	827 (39.9%)	139 (6.7%)
1 – 2 yr	2,004 (55.4%)	1,370 (37.9%)	244 (6.74%)
2 – 3 yr	1,717 (51.7%)	1,352 (40.7%)	255 (1.26%)
> 3 yr	4,773 (56%)	3,313 (38.9%)	439 (5.2%)

Top 5 Primary Diagnosis Codes At Missed Opportunity

Diagnosis	Number of Diagnosis	% of Total Diagnoses
UTI	448	2.21%
Acute pharyngitis	438	2.16%
Headache	395	1.95%
Abdominal Pain	347	1.71%
Pneumonia, organism unspecified	291	1.43%

Top 5 Primary Procedure Codes At Missed Opportunity

Procedure	Number of Procedures	% of Total Procedures
Short history and evaluation	433	8.57%
Closure of skin & subcut tissue	345	6.83%
I & D, other	159	3.15%
Application of splint	146	2.89%
Assisted spontaneous delivery	135	2.67%

Method Of Payment (ER, OP, IP)

- Self pay 41.2%
- Medicaid 24.3%
- Commercial insurance 19.9%
- Medicare 6.0%
- HMO 3.2%
- Indigent/Charitable Organization 1.9%
- Worker's Compensation 1.5%

Most Common Physician Specialty (ER, OP, IP)

- 1st Physician
  - Emergency Medicine 66.1%
  - Family Practice 9.2%
  - Internal Medicine 6.1%
- 2nd Physician
  - Emergency Medicine 28.2%
  - Physical Medicine and Rehab 21.3%
  - Family Practice 7.1%
  - Psychiatry 6.5%
  - General Surgery 6.2%
  - Internal Medicine 4.1%

Demographics of Those With Missed Opportunities

- Gender: 1,994 (63%) male
- Race/Ethnicity: 2,518 (79.9%) Black, 565 (17.9%) White, 53 (1.7%) Hispanic
- Age Categories:
  - 13 – 19 yrs, 120 (4%)
  - 20 –29 yrs, 762 (24%)
  - 30 – 39 yrs, 976 (31%)
  - 40 – 49 yrs, 880 (28%)
  - > 49 yrs, 438 (14%)

Number Of Visits Prior To HIV Testing (ER, IP, OP)

Number of Visits	Number of Patients	% of Total Patients
1 Visit		20.5%
2 – 5 Visits		43.2%
6 – 10 Visits		20.2%
> 10 Visits		15.5%

Total visits ranged from 1 to 136 per patient

Setting Where Missed Opportunities Occurred

- ER - 80.7%
- In-patient – 12.6%
- Out-patient – 6.7%

Monitoring the Incidence of HIV Infections in the United States

María C. Rangel MD, PhD

HIV Incidence and Case Surveillance Branch
Division of HIV/AIDS Prevention
Centers for Disease Control & Prevention

Presented at Council of State and Territorial Epidemiologists (CSTE) Annual Conference

Anaheim, CA - June 5, 2005

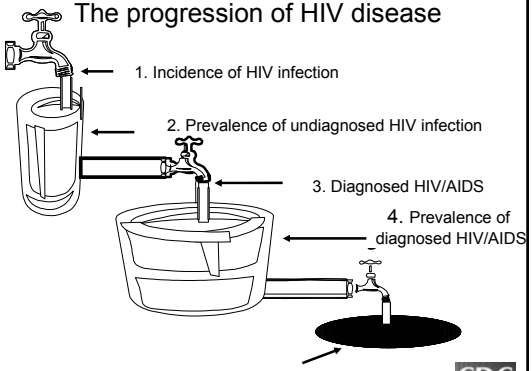
CDC

Outline

- Direct measures of HIV incidence
- Back-calculation from AIDS cases
- "Back of the envelope calculation"
- Snapshot estimator approach
- Population-based HIV incidence

CDC

The progression of HIV disease



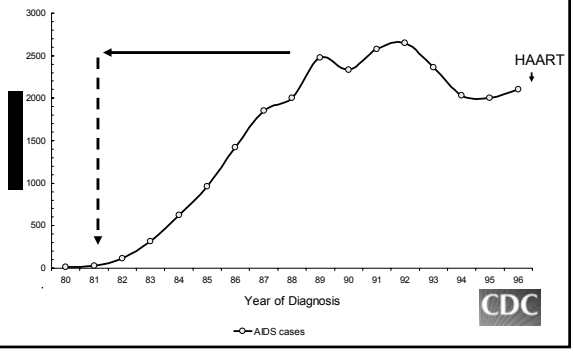
CDC

Direct measures of HIV incidence

- Retrospective cohort studies
- Prospective cohorts studies
- Record-based studies of repeated testers

CDC

Estimating HIV incidence using back calculation from AIDS cases



CDC

"Back of the envelope calculations" to estimate number of HIV infections in the United States - 1997

60.5 million men aged 15-44

2% "active" MSM ⇒ 1.2 million MSM

0.4 million have HIV ⇒ 0.8 million at risk

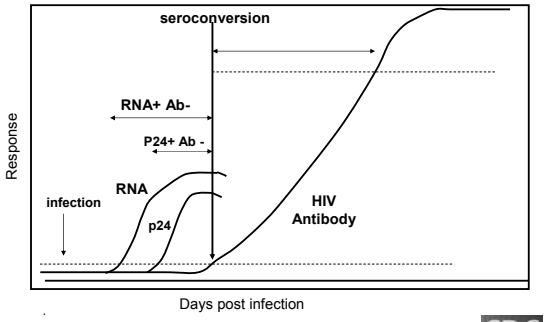
2% incidence MSM/year ⇒ 16,000 infections MSM/year

60% of infections in MSM ⇒ 27,000 inf /year in men

70% of infections in men ⇒ 38,000 infection/year

CDC

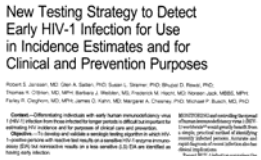
Immunological markers for HIV infection



CDC

STARHS

- **STARHS**
  - **S**erologic
  - **T**esting
  - **A**lgorithm for
  - **R**ecent
  - **H**IV
  - **S**eroconversion


New Testing Strategy to Detect Early HIV-1 Infection for Use in Incidence Estimates and for Clinical and Prevention Purposes

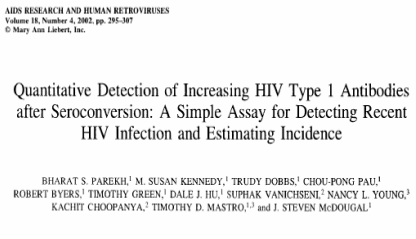
CDC

Applications of STARHS to calculate incidence

- Cross-sectional seroprevalence studies using stored HIV-positive serum specimens
- The proportion of recent infections were use to estimate annualized incidence rates and 95% confidence intervals
- STARHS in population-based incidence surveillance
- Required IRB approval and consent

CDC

Latest assay:BED HIV-1 Capture EIA


AIDS RESEARCH AND HUMAN RETROVIRUSES
Volume 18, Number 4, 2002, pp. 295–307
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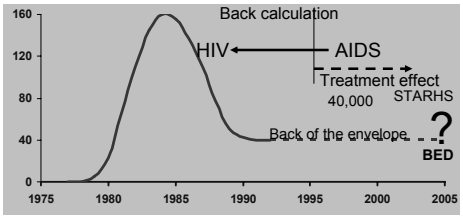
Quantitative Detection of Increasing HIV Type 1 Antibodies after Seroconversion: A Simple Assay for Detecting Recent HIV Infection and Estimating Incidence

BHARAT S. PAREKH,[1] M. SUSAN KENNEDY,[1] TRUDY DOBBS,[1] CHOU-PONG PAU,[1] ROBERT BYERS,[1] TIMOTHY GREEN,[1] DALE J. HU,[1] SUPHAK VANICHSENI,[2] NANCY L. YOUNG,[3] KACHIT CHOOPANYA,[2] TIMOTHY D. MASTRO,[1,3] and J. STEVEN McDOUGAL[1]

CDC

Methods utilized to estimate annual HIV Incidence in the US



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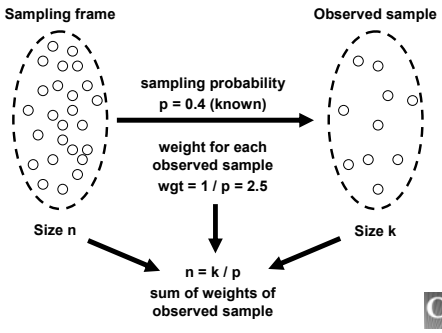
Population-based HIV incidence methods in the US

- Incorporate STARHS using BED into routine national HIV surveillance
- Apply sample survey methods to estimate HIV incidence in the population

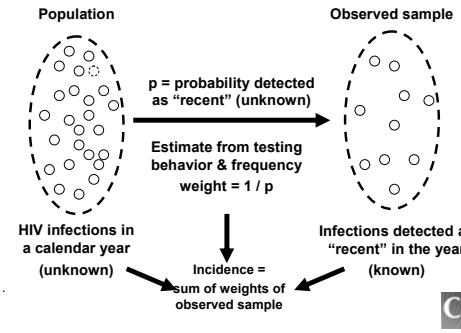
CDC

Sample Survey Method



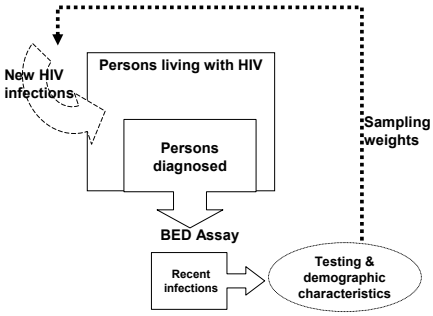
CDC

Application of Sampling Theory to HIV Incidence Estimation



CDC

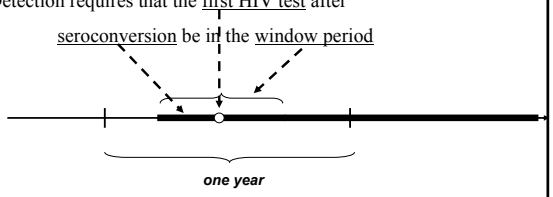
Sampling & HIV Incidence Surveillance in the US



CDC

Estimating the Detection Probability (*p*) for Observed HIV

Detection requires that the first HIV test after seroconversion be in the window period



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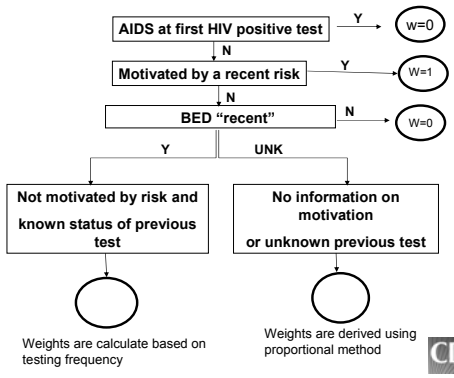
Probability of Being Detected as a "Recent Infection"

- Test motivated by risk behavior/incident
  - Risk driven
  - Target testing
- Repeat testers
  - Tested before the first positive test
  - Active testing
- Not tested before the first positive test
  - First time testers
  - Passive testing

CDC

Weights for Newly Diagnosed HIV Cases



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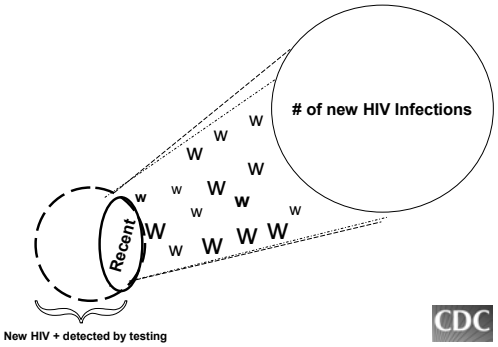
Estimation Procedure

- Stratify cases into risk homogenous or testing homogenous groups
- Calculate incidence weights for cases in each incidence group based on detection probability
- Select cases in a population group of interest
- Incidence = sum of weights from selected cases

CDC

Population-based HIV incidence estimation



CDC

Potential problems

- Violation of assumptions
- Incomplete testing information
- Validity of the estimation
- Local estimates (low morbidity)

CDC

"The essentials"

- Complete, high quality HIV surveillance
- Routine collection of testing history/behavior
- Secure blood for new diagnoses
- National, standardized HIV reporting
- Keep-up the good work….

CDC

Questions?

CDC

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404-639-3958

CDC

Additional slides

CDC

"Back of the envelope calculations" to estimate number of HIV infections in the United States - 1997

60.5 million men aged 15-44

2% "active" MSM " ⇒ **1.2 million MSM**

0.4 million have HIV ⇒ **0.8 million at risk**

2% incidence/year ⇒ **16,000 infections/year**

60% of infections in MSM ⇒ **27,000 inf /year in men**

70% of infections in men ⇒ **38,000 infection/year**

CDC

Incidence Subgroups

(For 3 main groups determined by status of previous test)

Motivated by recent incident	AIDS dx at HIV dx	On medication or no BED or BED unknown	BED recent	Sub group	Number of cases	Incidence weight
Yes	Yes			G_{ma}	N_{ma}	$W_{ma}=0$
	No			G_{mx}	N_{mx}	$W_{mx}=1$
No	Yes			G_{0a}	N_{0a}	$W_{0a}=0$
	No	Yes		G_{0x}	N_{0x}	W_{0x}
		No	Yes	G_{00}	N_{00}	W_{00}
			No	G_{0b}	N_{0b}	$W_{0b}=0$
Unknown	Yes			G_{xa}	N_{xa}	$W_{xa}=0$
	No	Yes		G_{xx}	N_{xx}	W_{xx}
		No	Yes	G_{x0}	N_{x0}	W_{x0}
			No	G_{xb}	N_{xb}	$W_{xb}=0$

CDC

Integrating HIV Incidence and Case Surveillance at the Local Level- *The New York City Experience*

New York City Department of Health and Mental Hygiene
HIV Epidemiology Program

June 5, 2006

Need for incidence data

- HIV surveillance data had been limited to monitoring HIV diagnoses, not infections.
- Data on new infections so important because:
  - Local epidemics can be diverse and constantly evolving
  - In NYC, 28% of all new diagnoses in 2004 were simultaneously diagnosed with AIDS
  - An additional ~10% diagnosed with AIDS within 1 year
  - HIV reporting relatively recent in NY (6/2000); still receiving many previous diagnoses that are only newly reportable

Two main tasks for incidence surveillance:

1. Obtaining HIV testing history information
2. Obtaining specimens for STARHS

Importance of seamless integration

- Large volume of cases (3,724 new dx in 2004) makes specific interview with all new dx's for incidence surveillance unrealistic
- Relatively large proportion of HIV testing done outside of health department
  - Limited ability to adjust C+T protocols
- Integrating incidence needs into existing procedures minimizes required provider training
  - 87 hospitals
  - >500 freestanding clinics
  - >2,200 private MDs
  - Additional CBOs performing rapid testing

Importance of seamless integration

- Integrating HIV incidence surveillance into regular HIV surveillance minimizes staff training needs
- Special arrangements with laboratories for obtaining specimens may be expensive and not financially sustainable
  - Needed to make specimen submission routine
- Want to minimize personnel time spent on additional data entry
  - Data entry also provides additional opportunity for error

I. Obtaining testing history data

- Testing history needed to be collected in a standard way, regardless of test site
- Only realistic solution was using provider case report form
  - Too many laboratories to modify lab submission forms
  - Detailed follow-up by field staff for every reported case not realistic
  - Provider report form required from providers for all new diagnoses of HIV and AIDS
- Provider compliance already a challenge (~65%)

Obtaining testing history, cont'd

- Space on Provider Report Form (PRF) was already limited, so expanded from 1 to 2 pages.
- Streamlined testing history questions as much as possible to avoid compromising reporting compliance
- To maximize acceptability of the revised form, input was solicited from:
  - Analytic staff
  - Field staff
  - Providers
  - Other health department units providing HIV testing

Revised PRF - Provider training

- Revised PRF advertised, rolled out as "modification of HIV case report form" for "enhancement of HIV surveillance"
  - NOT described as a new or separate activity
  - different version of the same old familiar drill
- Term "HIV incidence surveillance" not used in NYC to discourage perception that it was special or less important task independent of surveillance

Provider training, cont'd

- Multi-faceted approach to rollout of new form
  - Letter distributed to providers several weeks prior to form distribution
  - "Introduction to New PRF" information folders distributed by field staff to reporting providers
  - Large provider training session provided by health department.
  - HIV surveillance website included
    - Information on new PRF
    - Information about trainings
    - Addition of provider FAQ, including answers to questions about the revised provider report form

Staff training

- Though procedures remained same, staff trained to facilitate rollout of new PRF
- Field surveillance staff serve as the key resource to providers
  - All staff trained on changes to provider reporting and basic rationale for changes
  - Additional training on how actual testing history questions should be answered
  - Staff trained to be able to answer incidence-related questions on-site that providers have
  - Field staff conduct site-specific trainings as needed

II. Obtaining specimens

- Original plan was to make individual arrangements with commercial laboratories
  - Many smaller local laboratories expressed strong willingness to cooperate however…
  - …larger lab expressed some legal concerns
- Review of options for routine specimen submission led to NYC/NYS proposal to modify state "Laboratory Reporting of Communicable Diseases" directive

NY State Laboratory Directive

- Provides guidance to laboratories and blood banks on state reporting requirements for all communicable diseases
- Indicates whether isolates/specimens must be submitted to state
- The HIV section was revised in late 2004 asking for specimens from all confirmed HIV antibody tests for the purpose of incidence surveillance

NYS laboratory directive – excerpt for HIV

Agent	Disease	What to Report to the Local Health Department	Submit Isolates or Specimens for Confirmation
Histoplasma capsulatum (NYC)	Histoplasmosis (NYC)	Positive culture	No
Human immunodeficiency virus	HIV infection, HIV-related illness, and AIDS	Confirmed positive HIV antibody test, positive HIV nucleic acid (RNA or DNA) detection test, CD4 lymphocyte counts less than 500 cells per microliter or less than 29 percent of total lymphocytes. **(HIV results are reported to the NYSDOH, not the local health department)**	**Yes**, ©
Legionella species	Legionellosis	Positive culture, NAA ①, DFA or urine antigen or acute/convalescent serology showing a rising titer to L. pneumophila	**Yes –submit isolate only**

© Confirmed positive HIV antibody test specimens will be used for HIV incidence surveillance. Please contact the HIV Incidence Coordinator at (518) 474-4284 in the Bureau of HIV/AIDS Epidemiology to arrange for specimen transfer to the Wadsworth Center

Applying the directive for HIS

- July 2005 - Commercial laboratories were sent a letter referring to the directive's change re: diagnostic HIV specimens
- 3-4 days after each mailing, labs were contacted by NYC DOHMH by phone
  - Repeated purpose of specimen submission
  - Instructions for specimen preparation/shipping
  - NYC DOHMH contact information
  - Obtained lab contact information and, if possible, set up a shipping schedule

Specimen handling

- NYC specimens sent regularly to NYC DOHMH Public Health Laboratories
- Specimens logged in a special tracking database and frozen until deemed eligible for STARHS
- Eligible specimens routinely identified and shipped for STARHS testing

Experiences: obtaining testing history

- Providers are busy
  - Repeated efforts needed to alert them to revisions and need for routine collection of testing history data
  - They notice the case report form is a lot longer and the print is smaller
  - PR work needs to be done to convince providers it's not as much work as it seems
  - NYC providers are not receptive to:
    - Pre-test collection of testing history
    - Self-administered testing history questionnaire
- Large number & diversity of testing sites makes uniform approach challenging

Experiences: obtaining specimens

- To date, all labs have complied except one
- Monthly lab-by-lab QA review
- Many labs have required continuous follow-up
  - Issues include:
    - Unmatchable IDs on tubes
    - Incomplete shipments
    - Infrequent shipments
    - Improper packaging
- Some labs have indicated that they would have been unwilling to provide specimens without state requirement

Experiences: data management

- Minimal changes/additions to data systems:
  - Addition of new testing history variables in existing provider report form database
  - Addition of STARHS results file
  - No changes to lab report database – source of other specimen data
- Data entered using previously-existing mechanisms
- Sources merged, re-formatted to generate monthly CDC data file

Approaches to incidence in low-morbidity surveillance areas

- Jurisdictions not funded through CDC can still estimate HIV incidence
  - Locally/state-funded STARHS testing
    - BED testing relatively inexpensive
  - Testing history data can still be collected
    - Might be used not only for statistical weight, but as proxy for estimating if person recently infected.
    - When was case's last negative HIV test?
  - Smaller case loads may permit more detailed follow-up with newly diagnosed persons
    - Detailed interview with new diagnoses
    - Follow-up blood draw specifically for STARHS, if possible

Other approaches to HIV incidence

- SF Dept. of Public Health examined three approaches to HIV incidence in anonymous testers
  - Linking to prior records using a unique testing code
  - Self-reported dates of last negative test
  - STARHS (sans testing history)
- Each method had limitations
- Found some comparability of incidence rates
- Multiple approaches collectively could be useful to monitor HIV transmission.

Reference: Kellogg TA, et al. Comparison of Three Methods to Measure HIV incidence Among Persons Seeking Voluntary, Anonymous Counseling and Testing. *JAIDS*. 2005;39:112-120.

Questions?

Yussef Bennani, MPH
Coordinator, HIV Incidence Surveillance
Email: ybennani@health.nyc.gov
Phone: (212) 442-3518

From Data to Funding

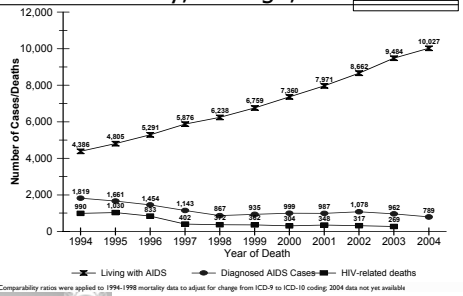
Nanette Benbow, M.A.S.
Demian Christiansen, MPH
David Kern
Office of HIV/AIDS Surveillance (OHAS)

Chicago's HIV/AIDS Burden*

- 22,701 AIDS cases and 10,156 HIV (not AIDS, since 1999) cases have been reported in Chicago
- There are currently 19,769 people living with HIV/AIDS, 10,027 with AIDS and 9,742 with HIV
- 67% of people living with AIDS in Illinois live in Chicago
- Between 2000-2004, an average of 1,200 HIV cases and 963 AIDS cases are diagnosed every year

* As of 3/31/2006.

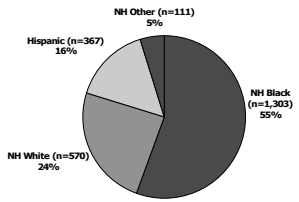
AIDS Incidence, Prevalence and Mortality, Chicago, 1994-2004*



* Comparability ratios were applied to 1994-1998 mortality data to adjust for change from ICD-9 to ICD-10 coding; 2004 data not yet available

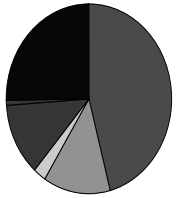
* As of 3/31/2006.

HIV Diagnoses by Race/Ethnicity, Chicago, 2003-2004, (as of Dec 2005)



Source: HIV/AIDS Reporting System, Chicago (as of 12/31/05)

HIV Diagnoses, Mode of Transmission Chicago, 2003-2004



As of 12/31/05

Using Chicago's Data to Inform Funding Priorities

Priority Setting—Why do we do it?

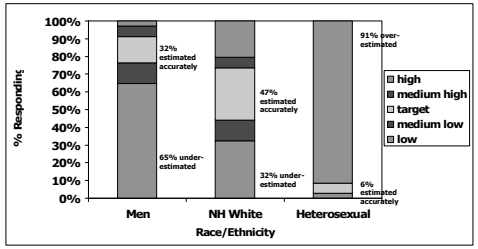
- Maximize limited prevention funds targeted to high-risk populations
- Reduce the number of HIV infections in Chicago
- Respond to changes in the epidemic
- To develop HIV Prevention Comprehensive Plan

Take a deep breath and a step back

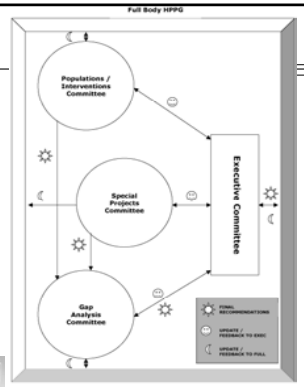
Who do we believe to be affected?

- What is the distribution of new HIV diagnoses?
  - Gender
    - _____% Male
    - _____% Female
  - Race/Ethnicity
    - _____% NH Black
    - _____% NH White
    - _____% Hispanic

Characteristics of Recently Diagnosed HIV Cases: HPPG Members Survey Results



2005 Model



Priority Setting-How did we do it?

- Populations / Interventions (P/I) Committee
  - Driven by epidemiological data
  - Determine specific high-risk populations (based on risk behavior, race / ethnicity, gender, age)
  - Analyze populations in geographic areas
  - Identify high-risk populations within geographic areas

P/I Committee Process

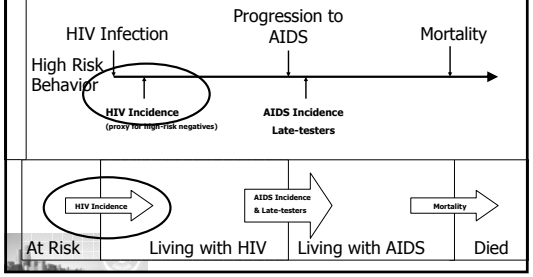
- During a 4 month period:
  - Received an "EPI 101" presentation from the Office of HIV / AIDS Surveillance (OHAS)
  - Considered a model of key points for prevention and care interventions
  - Reviewed current HIV and AIDS incidence and prevalence data and other relevant data
  - Using HIV case data, modeled the epidemic in the City to identify high-risk negative populations, high-risk positive populations and geographic "hot spots"

P/I Committee Guiding Questions

1. Who are those most at risk for acquiring HIV infection?
2. Who are those most at risk for infecting others with HIV?
3. What interventions are most effective at reducing individuals' risk for acquiring / transmitting HIV?
4. Where are cases of new HIV infection occurring in the City?

The Language and Concepts

Key Points of Intervention for Prevention and Care



WHO ARE THOSE MOST AT RISK OF ACQUIRING/TRANSMITTING HIV INFECTION?

⇩

What are their demographic characteristics?

What are their risk-factors?

Where do they live?

Look for similarities and differences…

Data Presentations (1)

- Session I
  - Definition and proper use of epidemiologic measures
    - Proportions
    - Ratios
    - Rates
  - Understand and interpret data for recent HIV infections (2003) in Chicago
- Session II
  - Trends in HIV and AIDS Diagnoses
  - Recent AIDS Diagnoses
  - Prevalence - Living with HIV and AIDS
  - Questions

Data Presentations (2)

- Session III
  - Other data sources:
    - High risk behaviors (STDs)
    - National HIV Behavioral Surveillance
  - Focus on HIV incidence rates
  - Sex, age, race, transmission mode, geography
  - Rankings
  - Data limitations –strengthening data
- Session IV
  - Late-testers
  - Unknown/unspecified modes of transmission (NIRs)
  - Perinatal transmission

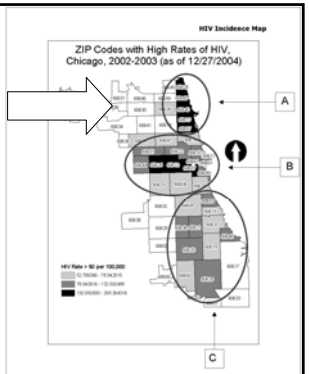
Populations with HIV Incidence Rate Greater Than City Rate

Race/Eth/Gender	Age	Avg. Annual Rate	N
NHB Male	35-44	207.1	145
NHB Male	25-34	181.0	116
NHW Male	35-44	151.6	121
Hisp Male	35-44	91.6	51
NHB Male	45+	90.8	119
NHB Female	35-44	83.6	73
NHB Female	25-34	83.1	69
NHW Male	25-34	77.5	82
Hisp Male	25-34	67.4	55
NHB Male	13-24	66.4	62
NHB Female	13-24	49.0	50
NHO Male	25-34	48.1	9
Hisp Male	45+	46.7	29
Total			978
Percent of City			79.9

Ranked Populations

		13-24			13-24
	Males	25-34		Males	25-34
		35-44			35-44
		45+			45+
NH Black			Hispanic		
		13-24			13-24
	Females	25-34		Females	25-34
		35-44			35-44
		45+			45+
		13-24			13-24
	Males	25-34		Males	25-34
		35-44			35-44
		45+			45+
NH White			NH Other		
		13-24			13-24
	Females	25-34		Females	25-34
		35-44			35-44
		45+			45+

Zip Code Clusters



Comparison of Priority Populations Obtained Using Different Ranking Methods based on HIV Incidence Rates, Chicago, 2002-2003

Characteristic	Distribution of Cases: Ranking Method* Rate	Geography	Total
Gender			
Male	80%	78%	75%
Female	20%	22%	25%
Race/Ethnicity			
NHW	21%	30%	25%
NHB	65%	56%	56%
Hispanic	14%	10%	15%
NHO	0.70%	2%	2%
Age			
< 13	0%	0.3%	0.4%
13-24	11%	11%	13%
25-34	34%	31%	29%
35-44	40%	35%	35%
45+	15%	23%	23%
Mode			
MSM	49%	51%	46%
IDU	15%	15%	16%
MSM/IDU	3%	2%	3%
Hetero	12%	12%	14%
Other	0.5%	0.6%	1%
NIR	20%	19%	20%
Total Cases	976	700	1,224

*Rate represents a selection of populations with an HIV incidence rate greater than the city average. Geography represents a selection of zipcodes with an HIV incidence rate greater than the city average.

Community-based Prevention Funding

- Funding source: CDC, State, City
- Total prevention budget: $5.22 M
- Total subcontracted: $4.83 M (92%)
- Number of funded agencies: 36-38

Data ▪ High-risk populations - $5.12 M (high rates)

Data ▪ Special Projects of Innovative Significance - $.7 M

Data ▪ Research - $.1 M (unanswered by current data)

Data ▪ Community-based PCRS and testing - $.8 M (needed to better understand data)

▪ SPINS Evaluation - $.1 M

Conclusions

- Recognize the bias members arrive with into the planning process
- Be clear about the message and present/repeat accurate measures of risk (e.g. women)
- Make data presentations often
- Create a culture of the importance of data to guide interventions and measure effectiveness……evaluation must follow

Current status of HIV case, incidence, and resistance surveillance, United States, 2006

M. Kathleen Glynn, DVM, MPVM

HIV Incidence and Case Surveillance Branch
Division of HIV/AIDS Prevention
National Center for HIV, STD, and TB Prevention

CDC

Outline

- HIV/AIDS Case Surveillance
  - Status of national HIV case surveillance
  - Status of the HIV epidemic
  - Changes to surveillance case definitions
- HIV Incidence Surveillance
- HIV Resistance Surveillance

CDC

Outline

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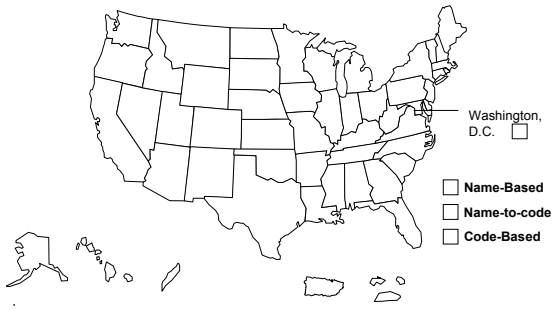
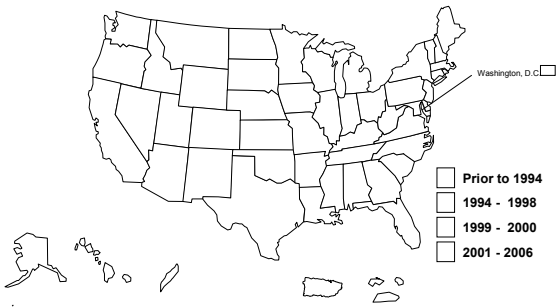
CDC

Current Status of HIV Infection Surveillance, by Reporting Method, As of May 2006



CDC

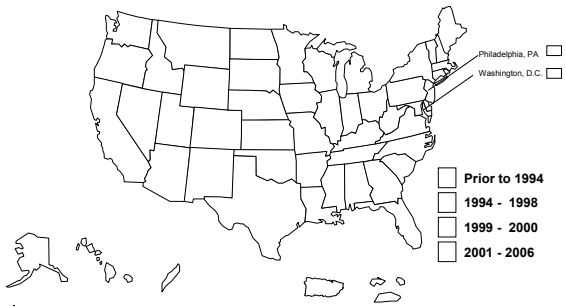
"Staggered" Implementation of HIV Infection Reporting As of May 2006



Areas that have transitioned from one HIV reporting method to another are shown with the date of the most recent reporting implementation

CDC

"Staggered" Implementation of HIV Infection Reporting As of May 2006



Areas that have transitioned from one HIV reporting method to another

CDC

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- HIV Resistance Surveillance

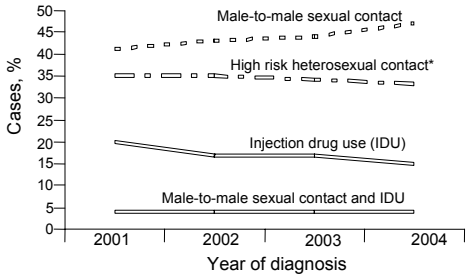
CDC

Status of the HIV Epidemic HIV/AIDS Case Surveillance Data

- Cases of HIV/AIDS
  - Diagnosed 2001- 2004
  - HIV/AIDS = initial diagnosis of HIV infection (including those concurrently diagnosed with AIDS)
- Reported from 35 areas with mature reporting systems
  - Confidential name-based reporting established by 2000
  - Reported to CDC through June 2005
  - Data have been adjusted for reporting delays and cases without risk factor information were proportionally redistributed

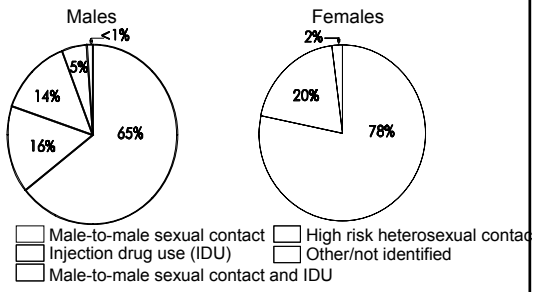
CDC

Proportion of HIV/AIDS Cases among Adults and Adolescents, by Transmission Category 2001–2004—35 Areas



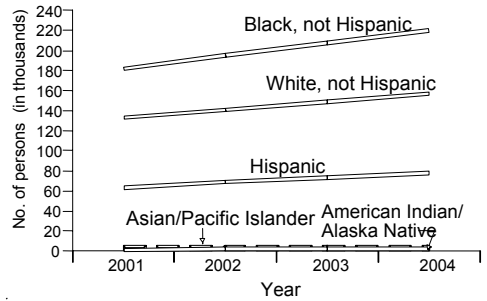
CDC

Proportion of HIV/AIDS Cases among Adults and Adolescents, by Sex and Transmission Category 2004—35 Areas



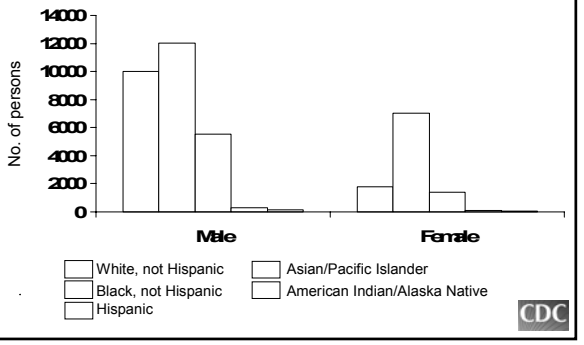
CDC

Estimated Number of Persons Living with HIV/AIDS, by Race/Ethnicity, 2001–2004—35 Areas



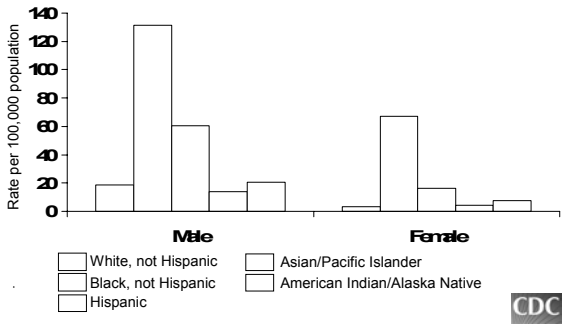
CDC

Estimated Number of HIV/AIDS Cases for Adults and Adolescents, by Sex and Race/Ethnicity, 2004 – 33 States



CDC

Estimated HIV/AIDS Case Rates per 100,000 Population, for Adults and Adolescents, by Sex and Race/Ethnicity, 2004 – 33 States



CDC

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CDC

U.S. HIV/AIDS Surveillance Case Definitions Implemented

Age Category		HIV Case Definition	AIDS Case definition
Pediatric	< 18 months	1999	1994
	≥ 18 months - <13 years	1999	
Adolescent/Adult (≥ 13 years)			1993

CDC

U.S. HIV/AIDS Surveillance Case Definitions Current Activities

Age Category		HIV Case Definition	AIDS Case definition
Pediatric	< 18 months	2006 (p)	1994
	≥ 18 months - <13 years	2006 (p)	2006 (p)
Adolescent/Adult (≥ 13 years)		2005, ongoing	2005, ongoing

CDC

Why Review Existing Definitions?

- Improvements in diagnostics
  - Ability to identify earlier HIV infection
  - Accuracy of screening tests (EIA, Rapid tests)
  - Accuracy in determining non-infection
- Improvements in treatment
  - Delayed progression to AIDS
  - Importance and more consistent availability of CD4 and VL

CDC

Case Definition Changes Proposed or in Development

- 2006 proposed
  - Perinatal HIV non-infected (<18 months)
  - Pediatric HIV (≥18 months - <13 years)
  - Pediatric AIDS (≥18 months - <13 years)
- In Development
  - Unified Adolescent/Adult HIV (including AIDS)
  - Primary HIV infection

CDC

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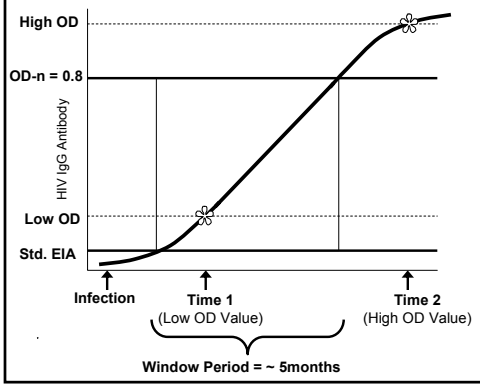
CDC

HIV Incidence Surveillance

- Goal: To provide national and area- specific, population-based estimates of the number of new HIV infections per year

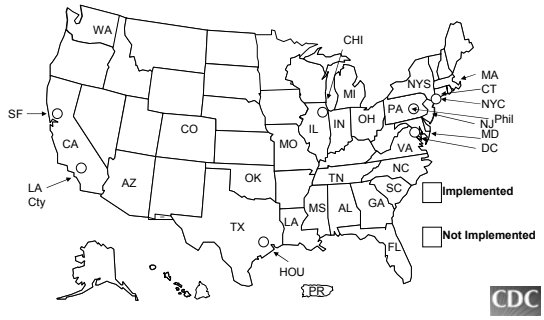
CDC

Identifying Recent Infections



CDC

Current Status of National HIV Incidence Surveillance



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CDC

Purposes of Resistance Surveillance

- Primary Public Health Purpose – Determine extent of transmitted strains with resistance associated mutations (link to incidence)
  - Determine need for routine ARV testing in newly diagnosed
  - Components of empirical "Emergency" regimens:
    - Post-exposure prophylaxis
    - Perinatal treatment
    - Acute infection
- Secondary - "Molecular" surveillance (population level transmission patterns)

CDC

Areas Funded to Participate in HIV Drug Resistance Surveillance Activities

CDC

Findings and Impact of Surveillance Activities

- All patients newly diagnosed and treatment naïve
  - 1082 patients from 10 Cities (35 Clinics)- 1999-2001*
    - 8.3% with mutations associated with drug resistance
  - 539 patients from 5 States (65 Sites) – 2003-2004†
    - 15% with mutations associated with drug resistance
- DHHS Treatment Guidelines (May 4, 2006)
  - *"Drug resistance testing is recommended for…persons with HIV infection prior to initiation of therapy."*

• Weinstock etal. JID 2004, 189:2174-80.
† Bennett etal. CROI 2005; Abst 674.

CDC

Conclusions

- Dynamic HIV case surveillance data availability
  - Increasingly representative of the national HIV epidemic
  - Late implementation of reporting adds complexity to data analysis
- Period of change for case definitions to allow better monitoring of HIV epidemic
- Late 2006, will have first estimate of population-based HIV incidence linked to case surveillance
- Resistance surveillance
  - Best implementation strategy
  - Explore more efficient data collection methods
  - Foundation for molecular surveillance

CDC

- Thank you to the HIV case, incidence, and resistance surveillance staff of the local, state, and territorial health departments

Questions?

CDC

Moderator Information Sheet
CSTE Pre-conference Workshop
June 4, 2006

Moderator	Time	Title of Presentation	Speaker and Location
Anthony Merriweather	8:30-8:45 (15 min)	Welcome	Matthew T. McKenna – CDC National Center for HIV, Hepatitis, STD, and TB Prevention
	8:45-9:00 (15 min)	HIV Surveillance Support: The Funding Process	Ronald Sanders - CDC National Center for HIV, Hepatitis, STD, and TB Prevention
	9:00 – 9:15 (15 min)	Setting Standards: A CDC/CSTE Collaboration	Martha Miller - CDC National Center for HIV, Hepatitis, STD, and TB Prevention
	9:15 – 9:30 (15 min)	Re-abstraction in Georgia	Luke Shouse, Georgia Department of Public Health
	9:30 – 9:45 (15 min)	Michigan Quality Assurance Procedures	Nilsa Mack, Michigan Department of Community Health
	9:45 – 10: 00 (15 min)	Risk Factor Ascertainment	Sharon Carter, Virginia Department of Health
	10:00-10:15 (15 min)	Record Linkages and Death Ascertainment in Massachusetts	James Murphy, Massachusetts Department of Public Health
	10:15-10:30 (15 min)	Electronic Lab Reporting in Seattle	Jim Kent, Seattle & King County Public Health
	10:30-10:45 (15 min)	**Break**	
	10:45 – 11:00 (15 min)	Integrating HIV Incidence Surveillance with Core Surveillance Systems	Irene Hall - CDC National Center for HIV, Hepatitis, STD, and TB Prevention
	11:00 – 11:15 (15 min)	Integration of Core and Incidence Surveillance: San Francisco's Experience	Susan Scheer, San Francisco Department of Public Health
	11:15 – 11:30 (15 min)	Integrating Incidence and Core Surveillance: Texas	Cheryl Jablonski, Texas Department of Health
	11:30-11:45 (15 min)	Integration of Core & Incidence Surveillance in King County, Washington	Christina Lynch, Washington State Department of Health, Seattle & King County Public Health
	11:45-12:00 (15 min)	**Break – get boxed lunch**	
Doug Frye & Pat Sweeney	12:00-12:15 (15 min)	New York State HIV/AIDS Surveillance and HIV Partner Notification Program	Kathleen S. Brousseau, New York State Department of Health
	12:15-12:30 (15 min)	Security and Confidentiality Accountability	Maree Kay Parisi, San Francisco Department of Public Health
	12:30-12:45 (15 min)	Palm Beach County, February 2005	Pam Lowell, Florida Department of Health
	12:45-1:00 (15 min)	How to Survive a HAZMAT Evacuation and Secure Your Data	Gail Maureen Hansen, Washington D.C. Department of Health
	1:00-1:15 (15 min)	Final Q & A and CDC Comments	Pat Sweeney, CDC National Center for HIV, Hepatitis, STD, and TB Prevention
	1:15-1:30 (15 min)	**Break**	

Moderator Information Sheet
CSTE Pre-conference Workshop
June 4, 2006

Moderator	Time	Title of Presentation	Speaker and Location
David Fields	1:30-1:50 (20 min)	Ryan White CARE Act Update	Pat Sweeney, CDC National Center for HIV, Hepatitis, STD, and TB Prevention
	1:50-2:03 (13 min)		Maria Rangel, CDC National Center for HIV, Hepatitis, STD, and TB Prevention
	2:03-2:16 (13 min)	Florida's HIV/AIDS Data Monitoring and Quality Process	Becky Grigg, Florida Department of Health
	2:16-2:30 (14 min)	Kansas Data Quality	Jeni Mulqueen, Kansas Department of Health and Environment
	2:30-2:50 (20 min)	eHars Demonstration	Sam Costa, CDC National Center for HIV, Hepatitis, STD, and TB Prevention
	2:50-3:00 (10 min)	The 411: on HIV/AIDS Core Surveillance Site Visits	Loren Cadena, CDC National Center for HIV, Hepatitis, STD, and TB Prevention
	3:00-3:10 (10 min)	The Importance of the Site Visit Letter to the Grantee	Maree Kay Parisi, San Francisco Department of Public Health
	3:10-3:27 (17 min)	Integrate and Conquer: Incorporating HIV surveillance into broader public health assessment activities	Marie Courogen, Washington State Department of Health
	3:27-3:45 (18 min)	Integration of Surveillance with Other Programs	Bill Jones, North Carolina Division of Public Health
	3:45-4:15 (30 min)	Dr. Kevin Fenton – new NCHHSTP Director	Introduced by Jerry Gibson, South Carolina Department of Health and Environmental Control
	4:15-4:30 (15 min)	Closing remarks and break to convene business meeting	Matt McKenna, CDC National Center for HIV, Hepatitis, STD, and TB Prevention

Notes for David Fields:
At the start of the afternoon session remind attendees that there is no break during the afternoon session so they should feel free to quietly excuse themselves if needed.

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