

# National Assessment of HIV/AIDS Surveillance Capacity and Training

Thank you for taking the time to complete the National Assessment of HIV/AIDS Surveillance Capacity and Training. The purpose of this assessment is to identify and share best practices in HIV/AIDS Surveillance by obtaining detailed information concerning:

1. What resources surveillance programs have available to them (both staff and funding) through the core surveillance grant as well as through supplemental surveillance projects, HIV prevention and care funding, and their own agencies.
2. How surveillance programs are situated in their agencies and how well they are integrated and/or collaborate with other health department programs (such as STD, hepatitis, HIV prevention).
3. Nuts and bolts information about surveillance practices, rules and regulations that impact surveillance, security and confidentiality practices, and data dissemination.

A wide variety of interested parties, including CSTE Surveillance Coordinators from states with different levels of HIV morbidity, State Epidemiologists, and CDC staff, participated in the development of this assessment in an effort to minimize the number of assessments that will be distributed to surveillance coordinators this year. This instrument will provide information that will allow surveillance coordinators as a group to articulate in detail the resources needed to meet increasing workloads. The assessment will provide information about the technical assistance needs of surveillance coordinators and will identify opportunities for provision of peer-to-peer technical assistance. Finally, the assessment will also serve as a useful tool to help identify items to include in this year's cooperative agreement applications.

In order to complete some sections of the assessment, you may need to consult with other staff. For instance, there are some detailed questions about funding and staffing (e.g. numbers of FTEs) that you may not be able to answer without talking to other staff or consulting records. There are also some detailed questions about technical processes, such as conducting data linkages that may need to be answered in collaboration with staff that performs these activities.

We are aware that for smaller programs, certain questions will not apply; however, please complete the assessment to the best of your ability.

Please complete the assessment by **[enter date]** to enable CSTE to analyze the data and produce finding so that the needs, concerns, and best practices in HIV/AIDS surveillance are shared nationally with decision makers. It is CSTE's policy that results will only be shared as aggregate data; states and large cities will not be specifically identified.

CSTE appreciates your support in this matter and we look forward to completing the report of assessment results in Fall 2007. We plan to discuss these results at the Surveillance Coordinators meeting in December in Atlanta, GA. If you have any questions or technical difficulties, please contact Tanja Walker ([twalker@cste.org](mailto:twalker@cste.org)) at 770-458-3811.

### I. Level of morbidity

1. What was the reported HIV/AIDS prevalence in your area as of 12/06?  
\_\_\_\_\_

2. How many people were newly diagnosed with HIV (including AIDS) in (Note: if not a full year of HIV data, please indicate)

2004? \_\_\_\_\_

2005? \_\_\_\_\_

2006? \_\_\_\_\_

3. According to [www.census.gov](http://www.census.gov) data, what is the July 2004 population of your area? \_\_\_\_\_

### II. Funding Level

4. What percentage of your HIV Core Surveillance activities are funded from the following sources (total = 100%)?

\_\_\_\_\_ % federal funds HRSA

\_\_\_\_\_ % federal funds CDC Prevention

\_\_\_\_\_ % federal funds CDC Surveillance

\_\_\_\_\_ % state funds

\_\_\_\_\_ % other (specify) \_\_\_\_\_

5. Please provide the total amount your surveillance area received from Program Announcement 04017/Part 1 - Core Surveillance. Do not include incidence, MMP, Epi Capacity, Resistance, Enhanced Perinatal, Behavioral Surveillance or any other surveillance program's funding.

\$ \_\_\_\_\_

6. Does your program rely on assistance from local health department personnel which are not funded by surveillance money to conduct field investigations?

NO

YES

If yes,

A great deal

Very little

### III. Funded Projects

7. For which of the following surveillance activities has your state/city received CDC funding since 2004 (check all that apply):

HIV/AIDS Core Surveillance

HIV Incidence Surveillance

HIV Resistance Surveillance (VARHS)

- Capacity Building for Epidemiologic and Program Evaluation Activities
- Enhanced Surveillance for Perinatal Prevention
- National HIV Behavioral Surveillance (NHBS)
- Medical Monitoring Project (MMP)
- Never in Care Project (NIC)
- Evaluating Integration of HIV/AIDS Surveillance Data with Geographic Information System (GIS)

8. Did your health department or a community-based organization in your state participate in a rapid assessment activity with assistance from CDC's Behavioral and Clinical Surveillance Branch since 2004? (These events would include assessments at Gay Pride, Minority Gay Pride, or other rapid assessment activities).

- NO
- YES

#### IV. Staffing

9. Below is a table with typical job responsibilities within HIV Surveillance programs. Please indicate the number of FTEs conducting surveillance activities in your program. When completing the column "Number of current FTEs", only consider employees funded by CDC Program Announcement 04017—Part 1 - Core Surveillance.

*Example: If you have 3 staff working 50% of their time on field investigations that would be 1.5 FTEs. Record that in column 2. If you need additional field investigators, you should determine the actual number of FTEs you need for field investigation and record that in column 3. The number in column 3 should be what you need in addition to what you already have.*

<i>Function</i>	<i>Number of current FTEs</i>	<i>Number of current FTEs using funding from other surveillance projects (MMP, Incidence, etc.) to assist with Core Surveillance</i>	<i>Number of additional FTEs needed</i>
<i>Field Investigation</i>	<i>1.5 FTE</i>	<i>2.5 FTE</i>	<i>2.5 FTE</i>

Function	Number of current FTEs	Number of current FTEs using funding from other surveillance	Number or additional FTEs needed

		projects (MMP, Incidence, etc.) to assist with Core Surveillance	
Field Investigation			
RIDR/Out of State Record Searches			
Data Entry			
Data Management			
Data Analysis			
Surveillance Coordinator			
Administrative Support			
IT			
Epidemiologists			
Other 1:			
Other 2:			
Other 3:			

10. How many HIV surveillance staff, regardless of funding source, use SAS for the following\_

- Data analysis? \_\_\_
- Data management (including data matching)? \_\_\_
- Other (specify): \_\_\_\_\_? \_\_\_

11. The following table is a list of possible areas of training for surveillance staff. Please check the **top 3** areas you feel are most needed by your staff?

- eHARS/HARS
- Database Management/Manipulation
- SAS
- GIS
- Linking/Database matching
- Statistics
- MS Excel
- MS Access
- Medical Record Abstraction

12. Providing continuing education for surveillance staff is a problem in our organization

No Problem -----Major Problem

1                       2                       3                       4                       5

13. In the past twelve months, have you been able to acquire the resources necessary to enhance essential staff training?

- NO
- YES
  - If yes, name funding source? \_\_\_\_\_

14. Please select the average salary in your program for 1 FTE in each of the major job classes in HIV Surveillance programs.

	\$20,000 to \$29,999	\$30,000 to \$39,999	\$40,000 to \$49,999	\$50,000 to \$59,999	\$60,000 to \$69,999	>\$70,000	N/A
Data Entry	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Field Staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Entry Level Epidemiologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Senior Level Epidemiologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Surveillance Coordinator	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
IT	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
*Other:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
*Other:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
*Other:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
* Please Specify							

15. Recruitment/Retention

The following series of questions will ask about problems that you have in recruiting and retaining key surveillance staff. Please indicate if any of the following factors are problems for your program recruiting and retaining staff using a 5 point scale.

a. To what extent is each of these factors a problem in recruiting and/or retaining epidemiologists.

No Problem -----Major Problem  
 1                      2                      3                      4                      5

- Salary scale                      1  2  3  4  5
- Enough qualified applicants                      1  2  3  4  5
- Personnel policies and procedures                      1  2  3  4  5



Job benefits	1	2	3	4	5
Job security	1	2	3	4	5
Job location	1	2	3	4	5
Opportunity for promotion	1	2	3	4	5
Travel required	1	2	3	4	5
Travel permitted	1	2	3	4	5
Job interests/fulfillment	1	2	3	4	5
Opportunities for training	1	2	3	4	5
Limitations recruiting outside your organization	1	2	3	4	5
Restrictions on choosing the best candidate	1	2	3	4	5
Restrictions on hiring quickly enough	1	2	3	4	5
Restrictions on offering competitive pay	1	2	3	4	5
Hiring freezes	1	2	3	4	5
Loss to private or government sector	1	2	3	4	5
Restrictions on merit raises	1	2	3	4	5
Restrictions on travel outside jurisdiction	1	2	3	4	5

## V. Technical Capacity

### NEDSS and eHARS

16. Does your health department use a NEDSS or NEDSS-like electronic reporting system for reporting of some notifiable diseases?

- NO, skip to question 20
- YES

17. Can providers use it (i.e., providers electronically report cases to the system)?

- NO, skip to question 20

YES

18. Are all conditions reported this way (including HIV)?

- NO, skip to question 20  
 YES

19. Do you use digital certificates or some other method of authentication besides userid and password?

- NO  
 YES  
 Other (Specify): \_\_\_\_\_

20. Are you planning on messaging or communicating information between eHARS and any other system (such as a local NEDSS) in your health department?

- NO, skip to question 21  
 YES

Check one:

- One direction (e.g. export or import eHARS/HARS data to or from other systems)  
    o (Please specify, which way): \_\_\_\_\_  
 Both directions (e.g. import/export between eHARS/HARS and other system)

21. Do you maintain a database separate from HARS/eHARS to collect any surveillance data?

- NO  
 YES

If yes, check all that apply.

- Laboratory test results  
 HIV (not AIDS)  
 Co-infections (i.e., Hepatitis, TB, STDs)  
 Residential street address  
 Perinatal exposure  
 Anonymous cases  
 Other (please specify): \_\_\_\_\_

22. Have you ever cleaned your provider and facility lists?

- NO  
 YES

If yes, do you routinely clean them in order to maintain standardized lists?

- NO  
 YES

### **IT Support**

IT Support is support with hardware, software, and electronic security.

23. Do you have internal IT support within the HIV/AIDS surveillance unit?

- NO
- If no, is the IT supported...
  - Internal to Health Department
  - External to Health Department (Contractor)
- YES

### **Geographic Information Systems (GIS)**

Geographic Information Systems (GIS) is analysis and display of data in a special/map format. ArcGIS and MapInfo are two popular GIS software packages.

24. Does your health department have a multi-departmental GIS system which provides access to geospatial data, common datasets, and services?

- NO
- YES

25. Does your program map its HIV/AIDS surveillance data?

- NO
- YES

26. Do you think GIS should play a larger role in routine HIV surveillance in your State?

- NO
- YES

27. If GIS technology and training were available, would your surveillance program use it?

- NO
- YES

### **Geocoding**

Geocoding is the process of assigning spatial information, such as x and y coordinates, to a common postal address.

28. Does your program geocode HIV/AIDS Surveillance data?

- NO (If No, skip to Q 35)
- YES

29. Is the geocoding performed on a secure computer or network in your HIV/AIDS Surveillance program?

- NO (If No, skip to 31)
- YES

30. What software is used to perform geocoding? (Check all that apply)

- StreetMap (ArcView)
- Centrus
- MapInfo
- MapMarker
- External Vendor (e.g. contractor, Map Quest, Geocode.com)
- Matchmaker
- Geostan
- Other (please specify) (skip to 32)

31. Who is geocoding the data?

- Surveillance Staff (skip to Q33)
- Another program in the health department (i.e., centralized multidepartmental GIS program, cancer registry) (skip to Q33)
- Private vendor/contractor (go to Q32)
- Other (please specify) (go to Q32)

32. How does the other program/contractor ensure the confidentiality of address-level records during geocoding? (Check all that apply)

- Program/contractor signs a data confidentiality agreement
- Program/contractor does not retain a copy of the addresses after geocoding
- Personal identifiers are removed
- Other (please specify)

33. Have you evaluated the accuracy of your geocoded data?

- NO
- YES

34. Describe how your program uses geocoded HIV/AIDS Surveillance data?

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(After describing, go to Q36)

35. Indicate the main reason why your HIV/AIDS surveillance program has not geocoded. (Check all that apply)

- Budget constraints
- Lack of trained staff
- Time constraints
- Not a priority
- Unsure of maintaining confidentiality
- Other (please specify)

36. How confident are you in the quality of street addresses collected through routine HIV/AIDS surveillance?

Not Confident-----Extremely Confident

1                      2                      3                      4                      5

## VI. Program Structure

### Reporting relationships

37. Do you or does anyone above you, in your agency's organizational structure, report directly to the State AIDS Director (NASTAD member)? (NA for cities)

- NO
- YES
  - You, the Surveillance Coordinator
  - Someone Else

38. Do you or does anyone above you, in your agency's organizational structure, report directly to the State Epidemiologist ?

- NO
- YES
  - You, the Surveillance Coordinator
  - Someone Else

### Centralized vs. Decentralized

39. Do you utilize local health departments (i.e. county, city, regional) to complete case report forms?

- NO
- YES

If yes, to what extent do you oversee or determine HIV Surveillance procedures at the local levels?

Do not oversee-----Completely Oversee  
1                       2                       3                       4                       5

**Satellite:** a site that is physically separated from the site where central HIV/AIDS registry is located but can access the registry electronically.

**Remote:** a site that has its own separate registry that is a subset of the central registry.

40. Does your state have satellite HARS installation?

- Do not have HARS
- NO
- YES

If yes, which of the following do you envision for eHARS installation: (Check one)

- Satellite
- Remote
- Central eHARS

## VII. Integration/Collaboration

The following questions are designed to ask about level of structural integration as well as collaboration, which varies regardless of level of integration. For the purposes of this survey please use the definitions below to answer the questions in this section.

**Integration:** Proximity on organizational chart; shared supervisory oversight.

**Collaboration:** Integration notwithstanding, degree to which programs share resources, conduct joint planning or projects, and provide mutual program support.

41. Please describe the relationship between your program and the programs listed in the first column in the next two tables

### a. LEVEL OF INTEGRATION

Not at all Integrated-----Completely Integrated

	1	2	3	4	5	
HIV Prevention*	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	N/A <input type="checkbox"/>
HIV Care (Ryan White)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	N/A <input type="checkbox"/>
STD Program (excludes PCRS)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	N/A <input type="checkbox"/>
Partner Counseling Referral Services	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	N/A <input type="checkbox"/>
STD Surveillance	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	N/A <input type="checkbox"/>
TB	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	N/A <input type="checkbox"/>
Hepatitis	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	N/A <input type="checkbox"/>
<b>Funded HIV-Related Projects</b>						
Medical Monitoring Project (MMP)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	N/A <input type="checkbox"/>
National HIV Behavioral Surveillance	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	N/A <input type="checkbox"/>
Incidence	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	N/A <input type="checkbox"/>
Resistance	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	N/A <input type="checkbox"/>
GIS	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	N/A <input type="checkbox"/>
Epi Capacity Building and Technical Assistance Grant	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	N/A <input type="checkbox"/>
Enhanced Perinatal Surveillance	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	N/A <input type="checkbox"/>

\* includes counseling and testing but excludes PCRS

† N/A = Don't have this program/project in my HD

b. LEVEL OF COLLABORATION

Collaborate Very Poorly-----Collaborate Very Well

	1	2	3	4	5	
HIV Prevention*	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	N/A <input type="checkbox"/>
HIV Care (Ryan White)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	N/A <input type="checkbox"/>
STD Program (excludes PCRS)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	N/A <input type="checkbox"/>
Partner Counseling Referral Services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	N/A <input type="checkbox"/>
STD Surveillance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	N/A <input type="checkbox"/>
TB	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	N/A <input type="checkbox"/>
Hepatitis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	N/A <input type="checkbox"/>
<b>Funded HIV-Related Projects</b>						
Medical Monitoring Project (MMP)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	N/A <input type="checkbox"/>
National HIV Behavioral Surveillance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	N/A <input type="checkbox"/>
Incidence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	N/A <input type="checkbox"/>
Resistance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	N/A <input type="checkbox"/>
GIS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	N/A <input type="checkbox"/>
Epi Capacity Building and Technical Assistance Grant	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	N/A <input type="checkbox"/>
Enhanced Perinatal Surveillance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	N/A <input type="checkbox"/>

\* includes counseling and testing but excludes PCRS

† N/A = Don't have this program/project in my HD

42. Are your HIV/AIDS prevention and care community planning groups integrated?

- NO
- YES

43. Do you have surveillance staff that work directly with community planning groups (CPGs) on an on-going basis?

a. Prevention CPGs

- NO
- YES

b. Care CPGs

- NO

YES

44. To what extent are surveillance data utilized in the prioritization process of community planning groups (CPGs)?

a. Prevention CPGs

Not at all ----- Completely  
1                       2                       3                       4                       5

b. Care CPGs

Not at all ----- Completely  
1                       2                       3                       4                       5

45. Do you use the CDC/HRSA Integrated Guidelines for Developing Epi-Profiles?

Not at all ----- Completely  
1                       2                       3                       4                       5

46. How can CDC provide further guidance or technical assistance to improve the usefulness and production of Epi-Profiles by CPGs? (Check all that apply)

- Funding for a dedicated position
- Usable SAS programs to adjust for reporting delay to produce trends over time
- Examples of best practices in the use of surveillance data in prevention/care planning
- Opportunities for peer-to-peer sharing of effective processes
- Examples and models of CPG/surveillance relationships
- Further guidance for surveillance sections in the Epi-Profile Guidelines
- Expertise for linkages to various datasets
- SAS programs for estimation of unmet needs
- Expanded national surveillance reports
- Respond to specific data requests
- Other, specify: \_\_\_\_\_

### VIII. Surveillance Practices

47. Does your surveillance program receive direct reports of the following:

a. HIV Viral Loads?

- NO
- YES

If yes,

- Mail \_\_\_%
- Electronic Transmission \_\_\_%
- Other (specify) \_\_\_\_\_ %

b. CD4 Counts?

- NO
- YES
- If yes,
  - Mail \_\_\_%
  - Electronic Transmission \_\_\_%
  - Other (specify) \_\_\_\_\_ %

c. Confirmed Positive Antibody Test?

- NO
- YES
- If yes,
  - Mail \_\_\_%
  - Electronic Transmission \_\_\_%
  - Other (specify) \_\_\_\_\_ %

d. Electronic sequence data from HIV genotyping results?

- NO
- YES
- If yes,
  - Mail \_\_\_%
  - Electronic Transmission \_\_\_%
  - Other (specify) \_\_\_\_\_ %

48. Do you use an electronic database separate from HARS/eHARS to store laboratory test results?

- NO
- YES

49. Do you use laboratory records for the following purposes?

- Case ascertainment
- Monitor morbidity
- Monitor proportion in-care
- Update HARS

50. What percent of your HIV cases are initially identified through...

- Direct Provider Reporting? \_\_\_\_\_(%)
- Lab reporting? \_\_\_\_\_(%)
- PCRS? \_\_\_%
- Other (specify) \_\_\_\_\_? \_\_\_%

51. Does your state have laws or regulations requiring reporting of the following:

a. Lab tests:

- i. Viral loads? All Some None Under consideration
- ii. CD4 counts? All Some None  Under consideration
- iii. Antibody tests? All Some None  Under consideration

iv. Electronic sequence data from HIV genotyping results?

- All
- Some
- None
- Under consideration

b. Conditions:

i. Pregnancy in known HIV+ women?

- All
- Some
- None
- Under consideration

ii. Perinatal HIV exposure?

- Explicitly stated in state rules or regulations
- State rules or regulations interpreted to include HIV exposure reporting
- Exposure reporting is not included in state rules or regulations
- State rules or regulations interpreted as not including exposure reporting
- Exposure reporting under consideration

52. Does your surveillance program have a method for systematically identifying and tracking the following?

a. Antiretroviral HIV drug resistance?

- NO
  - YES
- If yes,
- VARHS
  - Other (specify) \_\_\_\_\_

b. Incident cases of HIV Infection?

- NO
- YES

c. Incident opportunistic infections in persons with previously reported cases of HIV infection?

- NO
- YES

d. Multiple CD4 counts over time in persons with previously reported cases of HIV infection?

- NO
- YES

e. Cases of HIV/AIDS diagnosed outside of your jurisdiction but living in/receiving care in yours?

- NO

YES

53. Does your state (city) have a legal requirement to offer anonymous HIV testing?

NO  
 YES

54. Is it permissible in your state (city) for a provider or laboratory to report a new HIV/AIDS case without the name or other personal identifiers (i.e. anonymously)?

NO  
 YES

55. Since 2004, how many times has your surveillance program formally evaluated HARS?

	# Evaluations	Written Protocol?			(If not done) Why Not?			
		No	Yes-CDC	Yes-Local	\$	Time	Skill	Other (explain)
<i>Check all that apply</i>								
a. Completeness of Case Reporting	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Timeliness of Case Reporting	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Intrastate Case Count Accuracy	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Completeness of Risk Factor Ascertainment	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Validity of Data Elements	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Other (_____) Specify	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

56. Are you reporting to CDC a version of Soundex code different from the one automatically generated in HARS or eHARS when the name is entered?

NO  
 YES

a. If yes, what is the other version you are reporting (Sybase Soundex, SAS Soundex)? \_\_\_\_\_

**Reporting of AIDS-defining Opportunistic Illnesses (OIs)**

57. What priority does your health department place on actively looking for AIDS-defining opportunistic illnesses in an HIV-infected patient?

Lowest -----Highest

1                       2                       3                       4                       5

58. For comparison with the above, what priority does your health department place on collecting data on CD4 counts in an HIV-infected patient?

Lowest -----Highest

1                       2                       3                       4                       5

59. How much time does your surveillance staff spend collecting data on AIDS-defining opportunistic illnesses?

- Little or none
- A moderate amount
- A large amount

## IX. Linking

**Manual linking:** Linking achieved by using a hardcopy report from one source and performing a record search in HARS using the person's name and date of birth from the hardcopy.

**Electronic linking:** linking achieved by using electronic reports from two databases and using a software program to determine reports on the same individual.

60. Does your surveillance program link its HIV/AIDS case data with the following auxiliary registries or databases?

**Please complete the following table.**

<b>Linking HARS to Auxiliary Data</b>						
<b>Registry/Database</b>	<b>Do you link to this database? Yes/No</b> (Please check Y or N for each data source.) <b>If no, skip to subsequent columns for each row</b>	<b>Do you link Manually or Electronically? (See definitions above.) Please use Codes 1-3:</b> 1. Manually 2. Electronically (not E-HARS) 3. Electronically (E-HARS)	<b>How frequently do you link?</b> (Please use Codes 1-6 for Frequency of linking:) 1. Monthly 2. Quarterly 3. Semi-Annually 4. Annually 5. Did it once 6. Other (describe)	<b>Do you have an MOU or a data sharing agreement? Yes/No</b> (Please check Y or N for each data source.)	<b>Do you link to this database for the purposes of (please use codes 1-3, list all that apply:)</b> 1. Case ascertainment 2. Co-morbidity 3. Updating HARS	<b>What barriers have you experienced with linking records?</b> (Please use Codes 1-6, list all that apply:) 1. Lack of time 2. Lack of staff with technical skills 3. Lack of software 4. Lack of funds 5. Data sharing Problems 6. Other (describe)
STD	<input type="checkbox"/> No <input type="checkbox"/> Yes			<input type="checkbox"/> No <input type="checkbox"/> Yes		
ADAP	<input type="checkbox"/> No <input type="checkbox"/> Yes			<input type="checkbox"/> No <input type="checkbox"/> Yes		
TB	<input type="checkbox"/> No <input type="checkbox"/> Yes			<input type="checkbox"/> No <input type="checkbox"/> Yes		
Hepatitis B	<input type="checkbox"/> No <input type="checkbox"/> Yes			<input type="checkbox"/> No <input type="checkbox"/> Yes		
Hepatitis C	<input type="checkbox"/> No <input type="checkbox"/> Yes			<input type="checkbox"/> No <input type="checkbox"/> Yes		
State/Local Birth Records	<input type="checkbox"/> No <input type="checkbox"/> Yes			<input type="checkbox"/> No <input type="checkbox"/> Yes		
Birth Defects	<input type="checkbox"/> No <input type="checkbox"/> Yes			<input type="checkbox"/> No <input type="checkbox"/> Yes		
Cancer	<input type="checkbox"/> No <input type="checkbox"/> Yes			<input type="checkbox"/> No <input type="checkbox"/> Yes		
Medicaid	<input type="checkbox"/> No <input type="checkbox"/> Yes			<input type="checkbox"/> No <input type="checkbox"/> Yes		
Hospital Discharge	<input type="checkbox"/> No <input type="checkbox"/> Yes			<input type="checkbox"/> No <input type="checkbox"/> Yes		
Counseling and Testing	<input type="checkbox"/> No <input type="checkbox"/> Yes			<input type="checkbox"/> No <input type="checkbox"/> Yes		
Client Services (Careware, ARIES, etc.)	<input type="checkbox"/> No <input type="checkbox"/> Yes			<input type="checkbox"/> No <input type="checkbox"/> Yes		
EPS (for areas with EPS)	<input type="checkbox"/> No <input type="checkbox"/> Yes			<input type="checkbox"/> No <input type="checkbox"/> Yes		
TIS Testing History Forms	<input type="checkbox"/> No <input type="checkbox"/> Yes			<input type="checkbox"/> No <input type="checkbox"/> Yes		
Electronic Lab Reports	<input type="checkbox"/> No <input type="checkbox"/> Yes			<input type="checkbox"/> No <input type="checkbox"/> Yes		
State/Local Death Certificate Records	<input type="checkbox"/> No <input type="checkbox"/> Yes			<input type="checkbox"/> No <input type="checkbox"/> Yes		

61. What experience does your surveillance program have with types of linking software?

Type of Software/Program	Have you ever used this software?  <b>Yes/No</b> (Please check Y or N for each software/program.) If no, skip to other columns for that row	How would you describe the ease of use of this software? (Please use Codes 1-5:) 1. Not applicable, don't use 2. difficult to use 3. somewhat difficult to use 4. easy to use 5. very easy to use	How would you describe the specificity of linkage for case ascertainment, updating HARS records, or co-morbidity findings? (Please use Codes 1-4:) 1. Not applicable, don't use 2. Low (too many matches are actually different persons or too many non-matches are actually the same persons for this method to be worthwhile) 3. Intermediate, 4. High (almost all matches are true [same persons] and almost all non-matches are truly different persons)	How would you describe the sensitivity linkage for case ascertainment, updating HARS records, or co-morbidity findings? (Please use Codes 1-4:) 1. Not applicable, don't use 2. Low (too many true matches are missed for this method to be worthwhile) 3. Intermediate 4. High (few true matches are missed).	Would you recommend this software to another surveillance program?  <b>Yes/No</b> (Please check Y or N for each software/program.)
<b>Software developed outside the health department:</b>					
Link Plus	<input type="checkbox"/> No <input type="checkbox"/> Yes				<input type="checkbox"/> No <input type="checkbox"/> Yes
Link King	<input type="checkbox"/> No <input type="checkbox"/> Yes				<input type="checkbox"/> No <input type="checkbox"/> Yes
AutoMatch (Matchware)	<input type="checkbox"/> No <input type="checkbox"/> Yes				<input type="checkbox"/> No <input type="checkbox"/> Yes
Integrity (Vality)	<input type="checkbox"/> No <input type="checkbox"/> Yes				<input type="checkbox"/> No <input type="checkbox"/> Yes
Quality Stage (IBM)	<input type="checkbox"/> No <input type="checkbox"/> Yes				<input type="checkbox"/> No <input type="checkbox"/> Yes
<b>Software developed by the health department:</b>					
Custom Program developed by Surveillance or IT staff  Describe:(e.g. SAS,	<input type="checkbox"/> No <input type="checkbox"/> Yes				<input type="checkbox"/> No <input type="checkbox"/> Yes

MS Access, etc)					
Other Describe:	<input type="checkbox"/> No <input type="checkbox"/> Yes				<input type="checkbox"/> No <input type="checkbox"/> Yes

62. What experience does your surveillance program have with state or local level death ascertainment?

	<b>Does your surveillance program receive?</b>  <b>Yes/No</b> (Please check Y or N for each data source.)	<b>What type of death data does your surveillance program receive?</b> (Please use Codes 1-6, choose one:) 1. Records with HIV/AIDS as the underlying cause of death 2. Records with any mention of HIV/AIDS, regardless of whether it was the underlying cause or one of the multiple causes (e.g., a contributing cause) of death 3. Records with ICD codes for opportunistic disease 4. Both of the last two choices (2-3) 5. All death records, regardless of causes of death. 6. Other (describe)	<b>Who provides the death data to your surveillance program?</b> (Please use Codes 1-3, choose one:) 1. City or county registrars 2. State vital statistics office 3. Other (describe)	<b>How frequently do you receive death data?</b> (Please use Codes 1-9 for Frequency, choose one) 1. Monthly 2. Quarterly 3. Semi-Annually 4. Annually 5. Every 2 years 6. Every 3 years 7. Less frequently, but more than once 8. Only once 9. Never	<b>For electronic linkage to state death records, which procedure do you followed?:</b> 1) Linkage to all deaths records, including those with no mention of HIV/AIDS, to find all deaths, 2) Linkage only to death records that mentioned HIV/AIDS to find potential new cases from non-matching death records 3) Both, with two linkages: #1 followed by #2 4) Both, with two linkages: 2 followed by 1 5) Only 1 as a single linkage combining features of both 1 and 2 (after the linkage, but ICD codes for HIV in non-matching death records were then used to identify potential new cases)	<b>How much does your surveillance program pay for the data?</b> (Please use Codes 1-5, choose one) 1. No cost 2. Less than \$1000 3. Greater than \$1000 and less than \$5000 4. Greater than \$5000 5. Not applicable
<b>State/local Level</b> Hardcopy Death Certificates	<input type="checkbox"/> No <input type="checkbox"/> Yes					
<b>State/local Level</b> Electronic Death Records	<input type="checkbox"/> No <input type="checkbox"/> Yes					

63. What experience does your surveillance program have with national level death ascertainment?

	<p><b>Has your surveillance program used any of the national death data sources?</b>                      (Please use Codes 1-5)                      1. Yes                      2. No because we do not collect Social Security Numbers (skip to 65)                      3. No, because although we collect Social Security Numbers, the percentage of missing SSN is greater than 30% (skip to 65)                      4. No, because it hasn't been a high priority (skip to 65)                      5. No, because we don't have the funds (skip to 65)</p>	<p><b>Please indicate the year or range of years you have used each source</b> (e.g. 1999 or 1999-2003).                      If you do not know the earliest year, at least state the most recent year.                       If you did not use the source then code as "Not Applicable"</p>	<p><b>Please indicate the usefulness of the source in identifying deaths among HARS cases:</b>                      (Please use Codes 1-6)                      1. Not useful at all                      2. Somewhat useful                      3. Moderately useful                      4. Very useful                      5. Extremely useful                      6. Not applicable</p>
Social Security Administration's Death Master File (DMF) also referred to as SSDI			
National Death Index (NDI)			
National Death Index Plus (NDI-Plus)			

64. For linkage to the National Death Index (NDI) or to the NDI-Plus, what methods did you use to determine a true match:

a. Probabilistic Score?

- NO
- YES

If Yes, please provide the range of probabilistic scores for a true match: \_\_\_\_\_

b. Class Code?

- NO
- YES

If Yes, please provide the class values for a true match:

\_\_\_\_\_

c. Status Code?

- NO
- YES

If yes, please provide the status code for a true match:

\_\_\_\_\_

d. We assumed it was a true match if it was the only potential match listed for a case?

- NO
- YES

e. Other (describe): \_\_\_\_\_

## X. Security and Confidentiality

65. Does your program have written guidelines for security and confidentiality?

- NO
- YES

a. Are they the CDC Confidentiality and Security Guidelines as exactly written?

- NO
- YES

If no, are they a local adaptation of the CDC Guidelines?

- NO
- YES

b. Do you have local guidelines that do not incorporate the CDC Confidentiality and Security Guidelines?

- NO
- YES

66. How often does staff receive training in security/confidentiality? (Check all that apply)

- Annually
- Less than annually

- More than annually
- When new staff comes on board

67. What is required for non-surveillance staff that has access to potentially identifiable surveillance data? (Check all that apply)

- Security training
- Signed confidentiality agreement
- Background check
- Direct oversight by surveillance unit staff
- Restrictions on physical work location

68. What additional steps do you take when HIV surveillance data are linked to other databases (e.g. hospital discharge data)? (Check all that apply)

- Conduct linkages in our own office
- Encrypt HIV data when in transport to and from offsite location
- Sign Memorandum of understanding with other unit of how HIV data will be protected and used
- Obtain IRB approval
- Other (please specify)

69. Do you have adequate IT support to meet your security and confidentiality requirements? (e.g. transmission of data, laptops, encryption software, etc.)

- NO
- YES

70. In what organizational unit of your health department is your HIV ORP located? Is it over:

- All HIV programs
- HIV surveillance only
- HIV Prevention and Surveillance
- All infectious diseases
- Other (specify): \_\_\_\_\_

a. Is your ORP? (check one)

- State Epidemiologist
- State Health Officer
- State AIDS Director
- HIV Surveillance Manager
- Other (specify): \_\_\_\_\_

b. Does the ORP have the authority to make changes regarding security and confidentiality policies?

- NO
- How are changes made? (specify:)

- YES \_\_\_\_\_

71. What encryption software do you use?

- None
- PGP
- Seal
- Point Sec
- Other (please specify): \_\_\_\_\_

b. Is it 128 byte encryption?

- No (higher than 128 byte)
- No (lower than 128 byte)
- Yes, 128 byte

72. Are personally identifiable information in ancillary datasets (e.g. lab database) encrypted when not in use?

- NO, we do not encrypt databases
- YES, all ancillary databases are encrypted
- YES, some databases are encrypted

73. Is HARS/eHARS accessible on a: (Please check one)

- Stand-alone machine (HARS)
- Server, dedicated/isolated
- Server, part of regular LAN

## XI. Dissemination

### Data sharing and release

74. Do you routinely share individual-level data with other programs, agencies, or local health departments (excluding routine communication with other HIV/AIDS surveillance programs)?

- NO
- YES

b. When individual-level data are shared do you require or usually have the provisions outlined in a specific data sharing agreement (e.g., memoranda of understanding or memoranda of agreement)?

- NO
- YES

c. Is sharing of individual-level data addressed in your program's data release policy?

- NO
- YES

75. Do you share individual-level information with personal identifiers? (Check all that apply.)

<input type="checkbox"/> NEVER	Please indicate for which of the options below are there laws, rules, and/or regulations that address the release of personal identifiers.
<input type="checkbox"/> YES  If yes, with whom? <input type="checkbox"/> Local health department, <input type="checkbox"/> Other health department programs external to the surveillance program <input type="checkbox"/> HIV/AIDS Surveillance program of another state <input type="checkbox"/> Partner notification If yes, for what purpose? <input type="checkbox"/> Court order <input type="checkbox"/> Deduplication of cases <input type="checkbox"/> Research purposes <input type="checkbox"/> Other (please explain)	<input type="checkbox"/> Local health department, <input type="checkbox"/> Other health department programs external to the surveillance program <input type="checkbox"/> HIV/AIDS Surveillance program of another state <input type="checkbox"/> Partner notification <input type="checkbox"/> Court order <input type="checkbox"/> Research purposes <input type="checkbox"/> Deduplication of cases <input type="checkbox"/> Other (please explain)

76. Please indicate which **one** of the following **best** describes how HIV cases are reported to the health department in your jurisdiction:

Cases are reported directly to the HIV surveillance program or unit, but not to the health department program or unit that conducts HIV Partner Counseling and Referral Services (HIV PCRS program). (Skip to Q77)

Cases are reported to a central point in the health department, then forwarded to the HIV surveillance program or unit, but not to the HIV PCRS program. (Skip to Q77)

Cases are reported directly to both the HIV surveillance program or unit and the HIV PCRS program. (Skip to Q81)

Cases are reported to a central point in the health department, then forwarded to both the HIV surveillance program or unit and the HIV PCRS program. (Skip to Q81)

77. Does your HIV surveillance program or unit provide any HIV case information to the health department program or unit that conducts HIV Partner Counseling and Referral Services (HIV PCRS program)?

NO, the HIV surveillance program does not provide any information from HARS to the HIV PCRS Program.

YES

If yes, check all that apply on how HIV case information is provided to the HIV PCRS program.

(a) The HIV surveillance program provides names and locating information to the HIV PCRS program for all reported cases to initiate follow-up for PCRS

(b) The HIV surveillance program provides names and locating information to the HIV PCRS program only for some subset of cases to initiate follow-up for PCRS (e.g., from some specific providers, those who request assistance, from public clinics only)

Please describe: \_\_\_\_\_

(c) The HIV surveillance program provides names and locating information to the HIV PCRS program to initiate follow-up for PCRS only when specifically requested by the provider reporting the case.

(d) The HIV surveillance program notifies the HIV PCRS program of providers that may be requesting assistance with PCRS or have newly diagnosed patients that may need PCRS.

(e) The HIV surveillance program provides aggregate data only to the HIV PCRS program for evaluation purposes or to guide outreach or screening activities (no individual level data shared).

(f) HIV PCRS staff request additional information from the HIV surveillance program on individual cases as needed, and the surveillance program provides this information on a case-by-case basis.

Please describe types of additional information that might be provided: \_\_\_\_\_

(g) HIV PCRS staff are granted access to search in HARS directly as needed.

(h) The HIV Surveillance program obtains information from PCRS program staff regarding certain variables (e.g. risk factor) for select cases (e.g., cases that have been followed up and still have unreported risk factors).

(i) Other ( please specify)

78. How do you handle the requirements for security/confidentiality of data when individual level HIV surveillance data are provided to the HIV PCRS program?

(a) The HIV PCRS program follows HIV/AIDS surveillance security and confidentiality guidelines

- (b) The HIV PCRS program has written security and confidentiality guidelines and/or policies that are equivalent to or more rigorous than those for HIV/AIDS surveillance
- (c) The HIV PCRS program has written security and confidentiality guidelines and/or policies, but they are less rigorous than those for HIV/AIDS surveillance
- (d) Unknown

79. Does your jurisdiction have legislation or regulations in place that prohibit the use of surveillance data for purposes (including PCRS) other than statistical analysis?

- NO
- YES

80. Does your jurisdiction have legislation or regulations in place that mandate/allow the use of surveillance data for PCRS or other public health purposes?

- NO
- YES

81. From the list below select the SINGLE response that best describes your HIV/AIDS data release policy:

- We have a written data release policy specific to HIV/AIDS surveillance data.
- We use a data release policy that covers infectious diseases (STD, TB, etc.).
- We use the general health department data release policy.
- We do not have a written data release policy that applies to HIV/AIDS surveillance data.
- None of the above. Please describe\_\_\_\_\_

a. Are you willing to share your data release policy?

- NO
- YES

82. Is there a specific STATE/TERRITORY law or regulation that defines your data release policy?

- NO
- YES

83. Is there a process for responding to non-routine or external data requests?

- NO
- YES

a. If yes, is this process included in any written policy, or standard operating procedures?

- NO

YES

84. Who decides how to respond to non-routine data requests? (check all that apply)

- Surveillance coordinator
- Data manager
- Assigned staff in surveillance unit
- Ad hoc depending on subject matter
- As specified in security or data release policy
- Senior staff (above surveillance coordinator)
- ORP
- Committee
- Other, specify: \_\_\_\_\_

85. How often are you asked for data (inclusive of maps, tables, reports) but are not able to provide because of uncertainty of confidentiality?

Never ----- Very Frequently

1                       2                       3                       4                       5

86. What is the most detailed level of maps provided in any of your publicly disseminated HIV/AIDS materials? (*Check one.*)

- No maps are provided in surveillance reports
- Public Health Jurisdictions / Regions (e.g. Ryan White Title areas)
- County
- Metropolitan statistical area
- City
- Zip code
- Census Tract (1,000–8,000 people)
- Census Block Group (300–3,000 people)
- Census Block
- Case level
- Other \_\_\_\_\_

87. What is the most detailed level of tabular data provided in any publicly disseminated HIV/AIDS materials? (*Check one.*)

- State
- Public Health Jurisdictions / Regions (e.g. Ryan White Title areas)
- County
- Metropolitan statistical area
- City
- Zip code
- Census Tract (1,000–8,000 people)

- Census Block Group (300–3,000 people)
- Census Block
- Case level
- Other \_\_\_\_\_

**Statistical Disclosure Limitation / Policy**

Statistical disclosure limitation refers to the process of modifying a data table, such as suppressing low case counts, not releasing data below a geographic level, or aggregating categories, so as to protect the confidentiality of individual records.

88. Does your surveillance unit have a statistical disclosure policy?

- NO
- YES

89. Does your program or health department provide training on statistical disclosure limitation for staff that responds to data requests?

- Unknown

Do you have a need for training or additional training on statistical disclosure limitation?

- No
- Yes

If yes, which topics?

- Protecting tabular data (e.g., removing small values)
- Removing personal identifiers
- Construction and release of maps

- NO

Do you have a need for training or additional training on statistical disclosure limitation?

- No
- Yes

If yes, which topics?

- Protecting tabular data (e.g., removing small values)
- Removing personal identifiers
- Construction and release of maps

- YES

How is this training provided?

- Training manual (formal)
- Short course/presentation (formal)

- No manual but staff learns from each other/supervisor (informal)
  - Other mechanism (specify):
- 

Which of the following topics does your training cover?

- Protecting tabular data (e.g., removing small values)
- Removing personal identifiers
- Construction and release of maps

### Publications

90. Which of the following types of aggregated data do you routinely release in standard dissemination products? (Check all that apply)

- HIV (not including AIDS)
- AIDS only
- HIV and AIDS
- Incidence estimates
- Persons living with HIV/AIDS (PLWHA)
- Persons in care
- Co-morbid conditions, please specify:
- Mortality
- Other (please specify:) \_\_\_\_\_

91. How often do you disseminate aggregate HIV/AIDS data through the following formats/products? (For each, use the following codes:)

1. *Monthly*
  2. *Quarterly*
  3. *Twice a year*
  4. *Annually*
  5. *Every other year*
  6. *Every funding cycle*
  7. *Sporadically*
  8. *When requested*
  9. *Never*
- \_\_\_\_ Integrated Epi-Profiles
  - \_\_\_\_ Standard statistical reports
  - \_\_\_\_ Fact sheets
  - \_\_\_\_ Slide sets
  - \_\_\_\_ Presentations
  - \_\_\_\_ On website
  - \_\_\_\_ Peer-reviewed journal articles
  - \_\_\_\_ Tables for data requests
  - \_\_\_\_ Other, specify: \_\_\_\_\_

a. Where do you obtain your staff expertise for developing these dissemination products? (Check all that apply.)

- HIV/AIDS surveillance unit (in-house)
- Other units in the health department
- Contract mechanism
- University partner
- Other, specify \_\_\_\_\_

b. Which groups utilize these dissemination products? (Check all that apply)

- Other HIV/AIDS surveillance staff
- Health department prevention programs
- Health care programs
- Community-based organizations
- HIV/AIDS Prevention CPGs
- HIV/AIDS Care CPGs
- Legislature
- Funding sources
- Anyone who accesses the web
- Other, specify \_\_\_\_\_

92. Do you utilize data sources other than HARS/eHARS during the development of HIV/AIDS dissemination products?

- NO
- YES

If yes, check all data sources utilized:

- STD
- ADAP
- TB
- Hepatitis B
- Hepatitis C
- Cancer
- Medicaid
- Hospital Discharge
- Counseling and Testing
- Client Services (Careware, Aries, CADR, etc.)
- Perinatal surveillance
- Behavioral surveillance
- Special project surveys (specify): \_\_\_\_\_
- Other (specify): \_\_\_\_\_

93. Which of the following CDC-developed SAS programs do you use/have you used? (Check all that apply)

- None
- Canned tables/reports for Integrated Epi-Profiles
- Adjustments for reporting delays
- Redistribution of HIV/AIDS risk factors (NIR)

- In care/Not in care estimations
- Estimates for HRSA/Ryan White Care Act
- Data cleaning for preconversion to eHARS

94. Which dissemination products are developed with these CDC-provided SAS programs?

- None
- Epi-Profiles/Annual reports
- Integrated Epi-Profiles
- Fact Sheets
- Slide sets
- Presentations
- Grant Proposals
- Data Requests
- Evaluation purposes
- Reports to legislature
- Annual trend reports
- Other, specify

95. Which of the following are barriers to developing dissemination products?  
(Check all that apply)

- No barriers/not applicable
- Lack of technical expertise to analyze HARS data
- Lack of technical expertise to program SAS
- Lack of modifiable SAS programs provided by CDC
- Lack of expertise for data management
- Lack of funding
- Insufficient staff
- Lack of time
- Other, specify:

96. Do you use the national annual HIV/AIDS surveillance report information in your data dissemination products?

- NO
- YES

97. If you could have additional information in the national annual HIV/AIDS surveillance report, what would you add?

## XII. Technical Guidance

98. What are your surveillance program's experiences with the Technical Guidance for HIV/AIDS Surveillance Programs?

a. Does each of the staff involved in HARS data collection have access to a copy of the TG?

- NO
- YES

b. Does your surveillance program have a policy and procedures manual?

- NO
- YES, fully completed and operational
- Under development, partially completed

c. How would you rate the usefulness of the table of contents in terms of your ability to readily find specific information?

Don't Use-----Very  
easy to use

- 1       2       3       4       5

d. Are you using the Technical Guidance at this time?

- NO  
If no, what are the barriers that you are experiencing to using it?
- YES  
If yes, how are you using it and what are you using it for?

99. What are your surveillance program’s experiences with each ‘Topic Area’ of the Technical Guidance for HIV/AIDS Surveillance Programs? (referred to as TG in table below)

	<p>a. Has your surveillance program used the TG to train staff?</p> <p>Yes/No (Please check Y or N for each Topic Area)</p>	<p>b. Are you incorporating any of the following procedures into a state or local policy procedure manual?</p> <p>(Please use Codes 1-5)</p> <p>1. We have not incorporated it and are not planning to incorporate it into our manual.                  2. We have incorporated it into our manual (final version)                  3. We are currently working on incorporating it into our local manual (still drafting)                  4. We’re planning to incorporate it into the manual, but we have not started working on it yet.</p>	<p>c. How would you rate the usefulness of the contents in terms of your ability to understand how to implement them within your surveillance program?</p> <p>(Please use Codes 1-5)</p> <p>1. Not applicable, don’t use                  2. difficult to understand how to implement                  3. somewhat difficult to understand how to implement                  4. easy to understand how to implement                  5. very easy to understand how to implement</p>
<b>Topic Area</b>	<b>No</b> <b>Yes</b>		
Policies and Procedures	<input type="checkbox"/> <input type="checkbox"/>		
Access to Source Data and Completeness of Reporting	<input type="checkbox"/> <input type="checkbox"/>		
Risk Factor Ascertainment	<input type="checkbox"/> <input type="checkbox"/>		
Death Ascertainment	<input type="checkbox"/> <input type="checkbox"/>		
Electronic Reporting	<input type="checkbox"/> <input type="checkbox"/>		
Case Residency	<input type="checkbox"/> <input type="checkbox"/>		
Duplicate Review	<input type="checkbox"/> <input type="checkbox"/>		
Data Management	<input type="checkbox"/> <input type="checkbox"/>		
Record Linkage	<input type="checkbox"/> <input type="checkbox"/>		
Data Quality	<input type="checkbox"/> <input type="checkbox"/>		

100. In your opinion, what would need to be changed about the Technical Guidance – in terms of either form or content – that would make it more accessible, easier to use, or otherwise useful?

101. Is there anything else, no matter how distantly related, that you would like to communicate to CDC about the Technical Guidance?

### XIII. CSTE HIV/AIDS Surveillance Coordinators Workgroup

102. The CSTE HIV/AIDS Surveillance Coordinators Workgroup conducts monthly conference calls the second Wednesday of each month from 2-3 pm eastern time. How often do you participate?

- Every month
- Most months
- About half the time
- Less than half the time
- I have never participated

103. If you answered about half the time or less, why?

- the call day doesn't work for me
- The call time doesn't work for me
- I didn't know that there were monthly calls
- Call agendas do not seem relevant to my work
- Just not a priority
- I don't understand the purpose of the calls
- Other (specify): \_\_\_\_\_

## Appendix

### Variety of 5 pt. scales found in Assessment:

Do not oversee-----Completely Oversee

1 2 3 4 5

1. Do not oversee
2. Somewhat oversee
3. Moderately oversee
4. Mostly oversee
5. Completely oversee

Not at all Integrated-----Completely Integrated

1 2 3 4 5

1. Not at all integrated
2. Somewhat integrated
3. Moderately integrated
4. Mostly integrated
5. Completely integrated

Collaborate Very Poorly -----Collaborate Very Well

1 2 3 4 5

1. Collaborate Very Poorly
2. Collaborate Somewhat
3. Moderate Collaboration
4. Collaborate mostly
5. Collaborate Very Well

Not at all -----Completely

1 2 3 4 5

1. Not at all
2. Somewhat
3. Moderately
4. Mostly
5. Completely

No Problem -----Major Problem  
1 2 3 4 5

1. No problem
2. Somewhat Problematic
3. Moderately Problematic
4. Mostly problematic
5. A Major Problem

Lowest -----Highest  
1 2 3 4 5

1. Lowest priority
2. Somewhat of a priority
3. Moderate Priority
4. High Priority
5. Highest priority

Not Confident-----Extremely Confident  
1 2 3 4 5

1. Not at all confident
2. Somewhat confident
3. Moderately confident
4. Confident
5. Extremely Confident

Never-----Very Frequently  
1 2 3 4 5

1. Never
2. Rarely
3. Occasionally
4. Frequently
5. Very Frequently

Don't Use-----Very easy to use  
1 2 3 4 5

1. Don't Use
2. Difficult to use
3. Somewhat difficult to use
4. Easy to use
5. Very Easy to use

