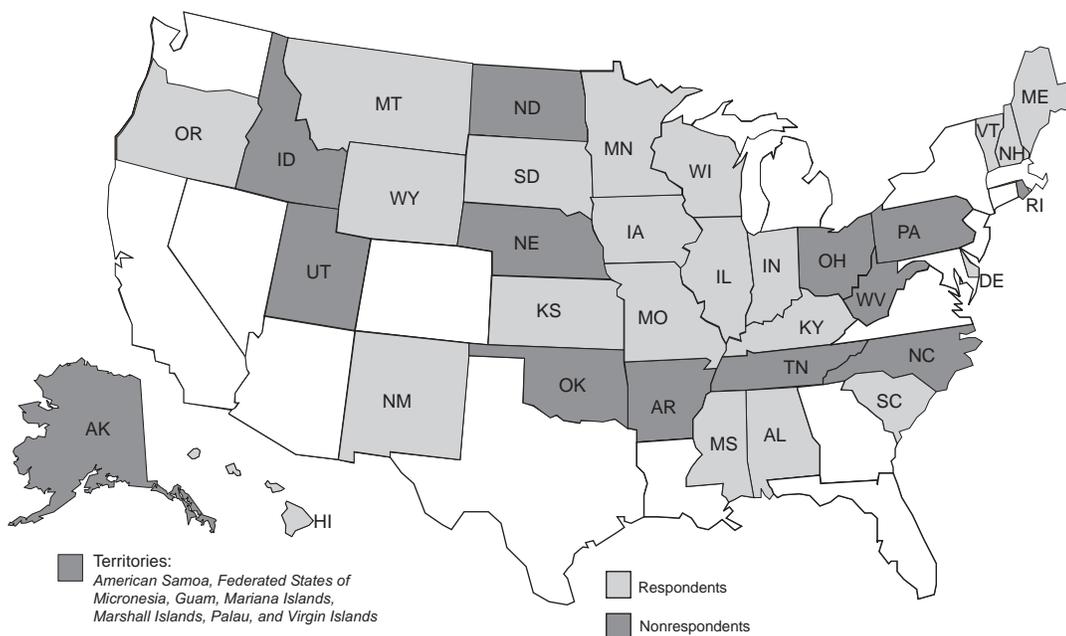


# HIV/AIDS

## Special Surveillance Report

Number 3

### Supplemental Surveillance Needs of States with Low-to-Moderate HIV/AIDS Prevalence 2004



DEPARTMENT OF HEALTH AND HUMAN SERVICES  
Public Health Service  
Centers for Disease Control and Prevention  
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# Summary

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In December 2003, the Division of HIV/AIDS Prevention at CDC launched a Web-based survey on the needs for supplemental HIV/AIDS surveillance data in areas with low-to-moderate HIV/AIDS prevalence. The survey, developed in response to discussions at the National HIV Surveillance Coordinators Conference in June 2003, was designed to assess priorities for the collection of supplemental data. The AIDS surveillance coordinators in 34 states and 7 territories with low-to-moderate HIV/AIDS prevalence were invited to participate. Two reminders were sent before the termination of data collection on January 13, 2004.

The survey questionnaire, developed by the Division of HIV/AIDS Prevention, with input from, and review by, representatives of the National Alliance of State and Territorial AIDS Directors and the Council of State and Territorial Epidemiologists, was available to participants on a password-protected CDC Web site. The questions covered the following topics:

- Estimates of geographic distribution of persons living with HIV/AIDS in the state or territory (urban, rural, and suburban settings)
- Estimates of HIV/AIDS prevalence among specific groups (men who have sex with men, injection drug users, heterosexual adults with no identifiable risk) in the state or territory
- Estimates of HIV/AIDS prevalence among specific demographic groups (sex, age, race/ethnicity) in the state or territory
- Populations of emerging concern or for whom the state or territory has little or no data (racial/ethnic minority groups, immigrants, youth, college students, transgendered persons, heterosexual adults who do not inject drugs)
- Priorities for the collection of supplemental data (clinical outcomes, incidence estimation, targeted specimen collection, behavioral surveillance)
- Priorities for approaches to data collection (episodic, regional, rapid assessments)
- Priorities for short-term technical assistance (staff training, meeting support, tool kits for rapid assessments, listserv)
- Option of providing additional comments at the end of survey (Qualitative data are not included in this summary report.)

Responses were received from 21 (62%) of the 34 states and 0 of 7 territories (see Appendix A for a list of the invited states and territories and those who responded). The states that did respond identified key gaps in the content and process of surveillance data collection in areas with low-to-moderate HIV/AIDS prevalence.

Interest in three main content areas were identified: behavioral surveillance, incidence estimation, and clinical outcomes. Interest in targeted specimen collection (for example, serological surveys for prevalence estimation) was limited to 5 states. Respondents who expressed a preference for behavioral surveillance identified 2 top priorities: information on HIV risk behavior and use of HIV prevention services among HIV-infected and noninfected populations. Other key priorities in behavioral surveillance were issues concerning access to care for HIV-infected persons and the HIV testing history of noninfected populations. For incidence estimation, the main reported needs were technical support in statistical modeling and methods of estimating incidence. The top 3 priorities for clinical outcomes data were health care utilization, laboratory data, and information on how to address the reporting requirements of the Health Resources and Services Administration.

Respondents' preferences for approaches to data collection differed according to the type of data. Rapid assessments were preferred by those whose priorities were the collection of behavioral surveillance and clinical outcomes data. Regional approaches to data collection were preferred by respondents who assigned priority to incidence estimation and targeted specimen collection. Episodic data collection seems to be a feasible approach for all content areas.

The question about emerging concerns or groups for whom the respondents had little or no HIV/AIDS data elicited unanticipated results. A particularly striking finding was the large proportion of respondents who listed immigrants as an emerging concern. A less surprising, yet notable, finding was that most of the respondents specified racial/ethnic minority groups as an emerging concern. Immigrants and racial/ethnic minority groups also emerged as the top 2 groups for whom respondents said they had little or no data.

The findings presented in this summary report underscore the need to consider the next steps in assessing

approaches that will meet the needs concerning the collection of supplemental data in areas with low-to-moderate HIV/AIDS prevalence. These steps are to determine (1) which data collection methods are suitable in specific geographic locations (for example, rural vs. urban) and among specific populations (for example, men who have sex with men, injection drug users), (2) which approaches will work best in populations deemed of emerging concern or for whom areas with low-to-moderate prevalence have little or no data, and (3) how CDC and states or territories with low-to-moderate HIV/AIDS prevalence can best work together on these issues.

## Emerging Concerns and Little or No Data

In addition to the population groups for which you provided information, are there other groups of special interest or emerging concern in your area, such as those with a relatively low, yet growing, prevalence or groups for which you do not have enough data to adequately assess their needs?

After providing percentage estimates of people living with HIV/AIDS, by geographic and demographic distribution, respondents were asked to indicate groups of emerging concern in their state or groups for whom they had little or no HIV/AIDS data. Of the 21 states that responded to the survey, 16 (76%) listed racial and ethnic minority groups as an emerging concern, and 11 (52%) listed immigrants. A summary of the responses to this question are presented in Table 1.

**Table 1. Population groups of emerging concern (N = 21 States)**

Population groups	States	
	No.	%
<b>Racial and ethnic minority groups</b> <i>An option to identify specific racial/ethnic minority groups or issues elicited the following:</i> African Americans ("Black females" also specified) Hispanics ("Hispanic males and females" also specified) Native Americans Pacific Islanders other than Hawaiian Natives High proportion with no identified risk Behavioral risk factors, access to prevention	16	76
<b>Immigrants</b> <i>An option to identify specific immigrant groups or immigrant-related issues elicited the following:</i> Africans ("East African" and "Sudanese and Ethiopian" also specified) Hispanics ("Care and treatment of undocumented Hispanics" also specified) Hmong Migrant workers	11	52
<b>Youth (13–24 years)</b>	10	48
<b>Heterosexual adults who do not inject drugs</b>	10	48
<b>College students</b>	3	14
<b>Other</b> <i>An option to specify "other" elicited the following:</i> Comorbidity of mental health problems and substance abuse Homeless	3	14

Respondents also noted groups for whom they had little or no data. Immigrants and racial/ethnic minority groups were the top 2 groups in this category (see Table 2). Of the 21 states, 13 (62%) said they had little or no HIV/AIDS data for immigrants; 11 states (52%) said they had little or no data for racial/ethnic minority groups.

**Table 2. Population groups for whom states have little or no data (N = 21 States)**

Population groups	States	
	No.	%
<b>Immigrants</b> <i>An option to identify specific immigrant groups or immigrant-related issues elicited the following:</i> Africans ("Ethiopian and Sudanese" and "Somalis" also specified) Hispanics ("Care and treatment of undocumented Hispanics" also specified) Hmong Migrant workers	13	62
<b>Racial and ethnic minorities</b> <i>An option to identify specific racial/ethnic minority groups or issues elicited the following:</i> Hispanics ("Hispanic men" also specified) Pacific Islanders other than Hawaiian Natives Behavioral risk factors, access to prevention	11	52
<b>Youth (13–24 years)</b>	7	33
<b>Heterosexual adults who do not inject drugs</b>	5	24
<b>Other</b> <i>An option to specify "other" elicited the following:</i> Comorbidity of mental health problems and substance abuse Homeless Migrant workers CDC definitions that force obvious heterosexual transmission into NIR category Young men who have sex with men	5	24
<b>College students</b>	4	19

Note. NIR, no identified risk.

## Priorities for Supplemental Data Collection

We would like your insight into the most pressing needs for supplemental data collection in your state. We are specifically interested in 4 key surveillance areas: clinical outcomes, incidence estimation, targeted specimen collection, and behavioral surveillance. Please rank these 4 areas in order of preference, using '1' for your highest priority and '4' your lowest.

States were asked to prioritize their data collection needs among 4 surveillance content areas: clinical outcomes, incidence estimation, targeted specimen collection, and behavioral surveillance. Descriptions of these four content areas appear in Box 1 below.

### Box 1. Description of 4 Key Content Areas

#### *Clinical outcomes*

Data elements for clinical outcomes are those collected through the Adult/Adolescent Spectrum of HIV Disease Project. This project collects information about persons living with HIV who are receiving medical care. The information includes data on HIV morbidity, CD4 counts, viral loads, health care utilization, drug resistance, and proportion of persons in care who are receiving highly active antiretroviral therapy.

#### *Incidence estimation*

The goal of incidence estimation is to provide population-based data that will accurately characterize current HIV transmission. Specimens from newly reported HIV cases are tested by using STARHS (the serologic algorithm for recent HIV seroconversion) to detect recent infections.

#### *Targeted specimen collection*

The goal of targeted specimen collection is to collect biologic specimens in order to estimate HIV prevalence or the occurrence of new infections in specific subpopulations or settings.

#### *Behavioral surveillance*

Behavioral surveillance involves monitoring HIV risk and prevention behaviors among men who have sex with men, injection drug users, and heterosexual adults. Comparable to the behavioral questions asked in the Supplement to HIV/AIDS Surveillance and the HIV Testing Survey studies, behavioral surveillance may be conducted among persons living with HIV/AIDS or among persons at risk for HIV infection.

Of the 21 states, 8 (38%) listed behavioral surveillance as their 1st priority for supplemental data collection; 10 (48%) listed it as their 2nd priority. Incidence estimation was the 2nd most-selected content area: 10 states listed incidence estimation as their 1st or 2nd priority. States' 1st and 2nd priorities for supplemental data collection, by content area, are presented in Table 3.

**Table 3. 1st and 2nd priorities for supplemental data collection (N = 21 States)**

Content area	1st Priority		2nd Priority		1st or 2nd Priority	
	States		States		States	
	No.	%	No.	%	No.	%
Behavioral surveillance	8	38	10	48	18	86
Incidence estimation	5	24	5	24	10	48
Clinical outcomes	5	24	4	19	9	43
Targeted specimen collection	3	14	2	10	5	24

## Behavioral Surveillance among HIV-Infected and Noninfected Populations

The eighteen respondents who listed behavioral surveillance as a 1st or 2nd priority were asked to identify their top 3 priorities for the content of behavioral information. As shown in Table 4, most listed information on risk behaviors (89%), use of prevention services (61%), and access-to-care issues (56%) as 1 of their top 3 priorities for HIV-infected populations. Similar proportions listed data on risk behaviors (89%) and use of prevention services (61%) among noninfected populations. In addition, 11 (61%) respondents indicated a need for information on the HIV testing history of noninfected populations.

**Table 4. Top 3 priorities for content of behavioral information (N = 18 States)**

Behavioral information	No.	%
<b>Among HIV-infected persons</b>		
Risk behaviors (sexual, drug-related)	16	89
Use of prevention services	11	61
Access-to-care issues (medical care, sources of payment)	10	56
Types of partners	5	28
HIV testing history	4	22
Identification of venues frequented	3	17
Adherence to medications	2	11
<b>Among noninfected populations</b>		
Risk behaviors (sexual, drug-related)	16	89
Use of prevention services	11	61
HIV testing history	11	61
Types of partners	7	39
Identification of venues frequented	5	28
Other		
Education to prevent HIV infection	1	6

*Note.* Responses from states that chose behavioral surveillance as their 1st or 2nd priority surveillance needs.

## Incidence Estimation

The ten respondents who indicated that incidence estimation was a 1st or 2nd surveillance priority were asked to rank their preference among 5 areas of technical assistance related to incidence estimation. As shown in Table 5, developing statistical models for estimation, an introduction to STARHS, and methods for estimating incidence emerged as the top 3 choices. Technical assistance for the processing of specimens was the lowest priority.

**Table 5. Top 3 priorities for technical assistance in estimating incidence (N = 10 States)**

Type of technical assistance	1st Priority		2nd Priority		3rd Priority		Total	
	No.	%	No.	%	No.	%	No.	%
Statistical models for estimation	4	40	0	0	5	50	9	90
Methods for estimating incidence	2	20	4	40	3	30	9	90
Introduction to/uses of STARHS	3	30	3	30	0	0	6	60
Management of incidence data	1	10	2	20	2	20	5	50
Processing of specimens	0	0	1	10	0	0	1	10

*Note.* STARHS, serologic testing algorithm for recent HIV seroconversion.

## Clinical Outcomes

The collection of clinical outcomes data emerged as the 3rd highest priority for supplemental HIV/AIDS surveillance data. Among the 9 respondents that listed clinical outcomes as a 1st or 2nd priority, data on health care utilization (78%), laboratory data (67%), and addressing the reporting requirements of the Health Resources and Services Administration (44%) constituted the top 3 priorities. See Table 6.

**Table 6. Top 3 priorities for clinical outcomes data (N = 9 States)**

Type of data	No.	%
Health care utilization (frequency, continuity of care)	7	78
Laboratory data (CD4 counts, viral load)	6	67
Addressing HRSA reporting requirements	4	44
Prevalence of antiretroviral resistance	3	33
Immunization and prophylactic services	2	22
Opportunistic infections	2	22
Prescription of antiretroviral medications	2	22
Compliance with IAS/DHHS guidelines	1	11
Cancers and infections other than HIV	0	0

*Note.* HRSA, Health Resources and Services Administration; IAS, International AIDS Society; DHHS, Department of Health and Human Services.

### Targeted Specimen Collection

Of the 21 states, 5 listed targeted specimen collection as a 1st or 2nd priority for supplemental data collection. All 5 indicated a preference for assistance with blood collection and testing history and with the management of incidence data (Table 7). Of the 5 states, 4 indicated a need for information on STARHS.

**Table 7. Top 3 priorities for targeted specimen collection (N = 5 States)**

Priorities	No.	%
Blood collection, testing history, etc.	5	100
Management of incidence data	5	100
Introduction to, and the uses of, STARHS	4	80
Processing of specimens	1	20

*Note.* STARHS, serologic testing algorithm for recent HIV seroconversion.

## Approaches to Data Collection

Because of the limited available funding for supplemental surveillance in low-prevalence areas, we need to consider multiple strategies to support the collection of supplemental surveillance data. Some of the ideas discussed during the Surveillance Coordinators meeting were episodic data collection, regional approaches, rapid behavioral assessments among high-risk groups or rapid assessments of clinical surveillance. Please indicate your 1st and 2nd priorities for the method of collecting supplemental data.

After listing their priorities for supplemental surveillance data collection, respondents were asked to indicate their preferences for approaches to data collection. A list of 3 approaches was provided: (1) episodic data collection, (2) regional approaches, and (3) rapid assessments. These approaches are defined in Box 2 below.

### **Box 2. Types of Approaches to Data Collection**

#### ***Episodic data collection***

In this approach, supplemental data would not be collected every year. For example, behavioral surveillance data might be collected only every 3rd year among men who have sex with men; or specimens for annual incidence estimation and data might be collected once every 3rd year.

#### ***Regional approaches***

In this approach, neighboring states with similar data needs could share a funded position to coordinate data collection in those states.

#### ***Rapid behavioral assessments among high-risk groups or rapid assessments of clinical surveillance***

In this approach, CDC could provide tools and technical assistance to conduct time-limited surveys to interview high-risk people at a well-attended gathering (for example, at Gay Pride events) or to conduct medical-record reviews to determine compliance with recommended standards of care.

Preferences for approaches to data collection differed according to the state's surveillance priority. Most of the respondents who listed behavioral surveillance as a 1st or 2nd priority preferred rapid assessments and episodic data collection. The respondents who listed incidence estimation as a 1st or 2nd priority preferred regional and episodic approaches to data collection. Preferences for approaches to data collection are summarized in Table 8.

**Table 8. Preferences for approaches to data collection for states' top 2 priority surveillance areas**

Surveillance area	Episodic data collection		Regional approaches		Rapid assessments	
	No.	%	No.	%	No.	%
Behavioral surveillance ( <i>N</i> = 18)	10	56	5	28	11	61
Incidence estimation ( <i>N</i> = 10)	5	50	5	5	2	20
Clinical outcomes ( <i>N</i> = 9)	5	56	3	33	4	44
Targeted specimen collection ( <i>N</i> = 5)	3	60	3	60	2	40

*Note.* States could endorse more than one approach for each surveillance area.

### Priorities for Short-Term Technical Assistance

Given that resources are limited, we may not be able to provide direct financial assistance, such as funding particular projects for some areas. However, we are exploring the possibility of providing short-term technical assistance that would enhance your state's ability to collect supplemental data. Please indicate your preference for short-term technical assistance from CDC, using '1' for your highest priority.

Respondents were also asked to prioritize their short-term needs for technical assistance among 4 possibilities: staff training, rapid assessment tool kits, meeting support, and the creation of a listserve. Of these, staff training, rapid assessment tool kits, and meeting support emerged as the top 3 priorities (see Table 9).

**Table 9. Summary of states' top 3 priorities for short-term technical assistance (N = 20 States)**

Type of short-term technical assistance	1st Priority		2nd Priority		3rd Priority		Total	
	No.	%	No.	%	No.	%	No.	%
Staff training	8	40	8	40	3	15	19	95
Rapid assessment tool kits	8	40	7	35	3	15	18	90
Meeting support	2	10	5	25	10	50	17	85
Listserve	2	10	0	0	4	20	6	30
<i>Suggestions submitted:</i>								
Share protocols, tools, evaluations								
Discuss issues common to low-prevalence areas								
Discuss updates, methods, new ideas								
Discuss successful approaches to reticent reporting sources								
Provide periodic HIV-related updates								
Involve surveillance, prevention, care, evaluation programs								

# Appendixes

## Appendix A. Survey respondents and nonrespondents

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<b>Respondents</b>	<b>Nonrespondents</b>
<b>States</b>	<b>States</b>
Alabama	Alaska
Delaware	Arkansas
Hawaii	Idaho
Illinois	Nebraska
Indiana	North Carolina
Iowa	North Dakota
Kansas	Ohio
Kentucky	Oklahoma
Maine	Pennsylvania
Minnesota	Rhode Island
Mississippi	Tennessee
Missouri	Utah
Montana	West Virginia
New Hampshire	
New Mexico	<b>Territories</b>
Oregon	American Samoa
South Carolina	Federated States of Micronesia
South Dakota	Guam
Vermont	Mariana Islands
Wisconsin	Marshall Islands
Wyoming	Palau
	Virgin Islands

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**Appendix B. Surveillance needs: distribution of priorities 1 and 2 by state (N = 21 States)**

Needs	States	
	Priority 1	Priority 2
<b>Behavioral surveillance</b>	Delaware Maine Minnesota Mississippi Missouri Montana South Dakota Vermont	Alabama Hawaii Iowa Kansas Kentucky New Mexico Oregon South Carolina Wisconsin Wyoming
<b>Incidence estimation</b>	Alabama Hawaii Illinois Kentucky South Carolina	Indiana Maine Missouri South Dakota Vermont
<b>Clinical outcomes</b>	Indiana Kansas New Hampshire Wisconsin Wyoming	Delaware Minnesota Mississippi Montana
<b>Targeted specimen collection</b>	Iowa New Mexico Oregon	Illinois New Hampshire

## **Appendix C. States that identified racial/ethnic minority groups as an emerging concern (N = 16 States)**

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### ***Ancestry as specified by respondents***

#### **Hispanics**

Indiana, Mississippi, Kentucky, South Carolina, Wisconsin

Kansas (men and women)

Minnesota (men)

#### **African Americans**

Illinois, Wisconsin

Missouri (women)

South Dakota (Sudanese and Ethiopian)

#### **Native Americans**

New Mexico

#### **Other Asians/Pacific Islanders**

Hawaii

#### **Issues related to racial/ethnic minority groups**

Iowa (high proportion with no indicated risk)

Oregon (behavioral risk factors, access to prevention)

#### **Emerging concern, but racial/ethnic minority group not specified**

Delaware, Montana

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## Appendix D. Racial/ethnic minority groups for whom states have little or no data (N = 11 States)

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### *Ancestry as specified by respondents*

#### **Hispanics**

Kentucky, Minnesota, Mississippi, South Carolina, Wisconsin

#### **Other Asians/Pacific Islanders**

Hawaii

#### **Related issues**

Oregon (behavioral risk factors, access to prevention)

#### **Racial/ethnic minority group not specified**

Delaware, Montana, New Hampshire, Wyoming

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## Appendix E. States that identified immigrants as an emerging concern (N = 11 States)

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### *Ancestry as specified by respondents*

#### **Africans**

Minnesota, Wisconsin

Indiana (East African)

South Dakota (Sudanese and Ethiopian)

#### **Hispanics**

Mississippi, Missouri

Kentucky (Migrant workers)

#### **Hmong**

Minnesota

#### **Immigrant-related issues**

Oregon (care and treatment of undocumented workers)

Iowa (250% increase in diagnoses since 1999)

Illinois (Chicago suburbs)

#### **Ancestry or immigrant-related issue not specified**

Alabama

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## Appendix F. Immigrant groups for whom states have little or no data (N = 13 States)

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### *Ancestry as specified by respondents*

#### **Africans**

Minnesota

Maine (Somali and other Africans brought to Maine through refugee resettlement)

South Dakota (Sudanese and Ethiopian)

#### **Hispanics**

Kentucky, Mississippi, Missouri

#### **Hmong**

Minnesota

#### **Immigrant-related issues**

Iowa (250% increase in diagnoses since 1999)

Oregon (care and treatment of undocumented workers)

#### **Ancestry or immigrant-related issue not specified**

Alabama, Kansas, New Hampshire, Wyoming

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