

Form Approved

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## HIV Surveillance Data System Needs and IT Capabilities Instrument

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Dear HIV Surveillance Coordinator:

The Division of HIV/AIDS Prevention (DHAP) within the National Center of HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP) at CDC is planning for the development of the next HIV surveillance data system to replace the current Enhanced HIV/AIDS Surveillance System (eHARS). The decade-old technology used to build eHARS creates many challenges and must give way to modern technologies and dynamic capabilities to simplify, standardize, and streamline HIV surveillance programs' operations. DHAP is committed to fulfill the goals of CDC's Public Health Data Modernization Initiative (<https://www.cdc.gov/surveillance/surveillance-data-strategies/data-IT-transformation.html>); and to ensure that the new system will provide, at all levels, high-quality and timely HIV surveillance data for public health decision making and for monitoring and evaluating the four key strategies of the *Ending the HIV Epidemic* plan (<https://www.hiv.gov/federal-response/ending-the-hiv-epidemic/overview>). The HIV Incidence and Case Surveillance Branch (HICSB) within DHAP is partnering with MITRE, a not-for-profit organization that operates Federally Funded Research and Development Centers (FFRDCs), to conduct the planning activities.

You are invited to participate in this questionnaire survey developed by HICSB and MITRE. The survey is designed to help DHAP and MITRE to gain insight into the challenges and unmet data system needs that state, territorial and local HIV surveillance programs are experiencing; as well as a more comprehensive understanding of the availabilities and constraints of your health department's IT capability.

Responding to this survey is voluntary, however, we strongly encourage your participation and sincerely appreciate the time and effort that you will spend on completing the survey. Your answers to the questions will not be made public and will only be used to inform DHAP and MITRE as we begin to gather, prioritize, and develop system requirements; identify and evaluate existing commercial and government off-the-shelf software systems (COTS or GOTS); and determine if DHAP should buy and customize a COTS or GOTS system or build the next HIV surveillance system.

The questionnaire survey will take approximately two hours to complete. For a few questions, you will need to consult with the technical or legal experts within your health department's IT office or legal services office, respectively.

If you have questions regarding the purpose of the survey or need clarifications on any of the questions, please email your questions to [HIVSurveillance@cdc.gov](mailto:HIVSurveillance@cdc.gov).

Health Department:

**Q1: Does your health department (HD) have a data system for integrated disease surveillance?**

(Integrated disease surveillance data system means one system that is used to collect, store, manage, and report clinical, epidemiological, and laboratory data for multiple reportable diseases and conditions)

- Yes (Answer **Q2** through **Q7**)
- No (Skip **Q2** and **Q3**, but answer **Q4** through **Q7**)

**Q2: What is the data system that your HD uses for integrated disease surveillance?**

**Check One Only:**

- Atlas
- Epic
- EpiTrax
- MAVEN
- NEDSS
- PRISM ASD
- PRISM-Based (A PRISM ASD that has been customized by the state, reside at the state, and is maintained by the state)
- TriSano
- Home grown data collection system [i.e., not a commercial off-the-shelf (COTS) or a government off-the-shelf (GOTS) system]
- Other, **please specify:** \_\_\_\_\_

**Q3: Please answer the following questions about the data system that you checked in Q2:**  
**(If you do not know the answer to Q3a through Q3d, please consult with your HD's subject matter experts on the data system)**

**Q3a: Is the data system document-based?**

(A document-based data system is capable of maintaining the relationships between various data elements, permitting multiple values for a given data element, retaining any conflicts between documents, and providing traceability to the reporting source. For example, eHARS is a document-based data system.)

- Yes
- No

**Q3b: Is the system's database physically stored on a server or servers that are in an environment owned and managed by a cloud service provider [e.g., Amazon Web Services (AWS), Microsoft Azure]?**

- Yes:

- Please specify the name of the cloud service provider:

- Is the cloud service provider certified by the Federal Risk and Authorization Management Program (FedRAMP, <https://www.fedramp.gov/>)?

- 
- Yes     No

- No

**Q3c: Is the data system designed to utilize RESTful web-services?**

[RESTful web-services are services that are built on Representational State Transfer (REST) architecture; they provide interoperability between computer systems on the internet. For example, the calculation of the HIV case definition category (*hiv\_categ*) can be a RESTful web-service that CDC provides to integrated disease surveillance data systems in state, territorial and local HDs]

- Yes
- No

**Q3d: Is the data system capable of automatically sending real-time updates to a centralized cloud-based disease surveillance data system at CDC using web-services?**

- Yes
- No

Check this box if you have consulted with your HD's subject matter experts on the data system when answering Q3a through Q3d.

**Q3e: Does your program use your HD's integrated disease surveillance data system for HIV surveillance?**

- Yes (Answer Q3f, Q4 through Q7)
- No (Answer Q3g, Q4 through Q7)

**Q3f. If the data system you checked in Q2 is a COTS or GOTS system, please use the space provided below to highlight the type of customizations and describe the level of effort that your HD had to make to meet your HIV surveillance program's needs. If your HD did not make any customization, please type "None".**

**(If you do not know the answer to Q3f, please consult with your HD's subject matter experts on the COTS or GOTS system)**

Check this box if you have consulted with the subject matter experts on the COTS or GOTS system when answering Q3f.

**Q3g: Does your program have plans to incorporate HIV surveillance into your HD's integrated disease surveillance data system in the next 5 years?**

- Yes
- No. Please use the space provided below to explain a) why your program does not plan to use your HD's integrated disease surveillance data system for HIV and b) what data system does your program plan to use for HIV?

**Q4:** One of CDC’s Public Health Data Modernization Initiative goals is to store and analyze public health data in the cloud. For the U.S. Department of Health and Human Services (HHS), “cloud storage” means the application and the database are physically stored on a server or servers that are in an environment owned and managed by a cloud service provider that have been certified by the Federal Risk and Authorization Management Program (FedRAMP, <https://www.fedramp.gov/>). Is your program’s eHARS database stored in the cloud?

Yes (After answering the questions in the following two bullets, you may skip **Q4a**, but answer **Q5** through **Q7**):

▪ Please specify the name of the cloud service provider:

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▪ Is the cloud service provider certified by FedRAMP?  Yes  No

No (Answer **Q4a** through **Q7**)

**Q4a:** Does your jurisdiction have a law, regulation, written policy or rule which prohibits your program from storing and analyzing HIV surveillance data in the cloud?

**(Please consult with your HD’s legal counsel when answering this question)**

Yes (Please provide a copy of the law, regulation, written policy or rule to your assigned HICSB epidemiologist)

No

Check this box to confirm that you have consulted with your HD’s legal counsel when answering **Q4a**.

**Q5:** Please describe major “pain points” that your program are experiencing when conducting the following HIV surveillance activities.

“Pain points” could be multifaceted and may include, but are not limited to:

- Lack of automated services or tools (e.g., the process or task is arduous and is by and large manual)
- Lack of common identifier
- Data from external systems or sources must be “massaged” (manipulated, altered, recalculated, reformatted) before they can be used by eHARS or vice versa
- Multiple systems or tools are needed to accomplish a task
- Lack of control due to reliance on staff outside your surveillance program to perform the entire task or part(s) of the task
- Duplication of efforts (e.g., the same data need to be entered multiple times into separate systems)

	<b>List and describe major pain points that your program are experiencing (If there are no pain points, please answer “None”)</b>
<b>A. Identifying cases (HIV cases &amp; perinatal HIV exposure cases) and ascertaining reports from the following sources:</b>	

	<p align="center"><b>List and describe major pain points that your program are experiencing (If there are no pain points, please answer "None")</b></p>
<p><b>1. Laboratories (public health, private commercial, or hospital):</b></p>	
<p><b>2. Health care providers:</b></p>	
<p><b>3. Other public health databases (please specify the public health databases used):</b></p>	
<p><b>4. Other sources not listed above (please specify the source):</b></p>	
<p><b>B. Data collection, data entry, and data management [when describing the pain points, please include descriptions of the data standards used; external systems that are used to temporarily or permanently store and manage the data; and processing tools that are used to triage and massage the data before they can be entered into eHARS]:</b></p>	
<p><b>1. Personally identifiable information:</b></p>	

	List and describe major pain points that your program are experiencing (If there are no pain points, please answer "None")
2. Demographic characteristics:	
3. Geographic locations, including census data for the location:	
4. Risk factors for HIV acquisition:	
5. Health care facility and provider (diagnosing as well as where person receives HIV medical care):	
6. HIV laboratory test results, including prior negative HIV test results:	
7. HIV medical care other than laboratory test results:	



	<b>List and describe major pain points that your program are experiencing (If there are no pain points, please answer "None")</b>
<b>8. Clinical events:</b>	
<b>9. HIV testing history:</b>	
<b>10. Antiretroviral or prophylaxis-use history:</b>	
<b>11. Birth history:</b>	
<b>12. Death and causes of death:</b>	
<b>13. Identification and resolution of potential intra- and inter-state duplicate reports:</b>	

	<b>List and describe major pain points that your program are experiencing (If there are no pain points, please answer "None")</b>
<b>14. Case investigations (e.g., COPHI, transmission cluster, partner services, HIV medical care status):</b>	
<b>15. Other data not listed above (please specify the type of data being collected, entered, or managed):</b>	
<b>C. Data quality control, monitoring, and evaluation (when describing the pain points, please include descriptions of the processes and tools used):</b>	
<b>1. Laboratory data:</b>	
<b>2. Adult Case Report Form data:</b>	
<b>3. Pediatric Case Report Form data:</b>	
<b>4. Birth data:</b>	

	<b>List and describe major pain points that your program are experiencing (If there are no pain points, please answer "None")</b>
<b>5. Death data:</b>	
<b>6. Other data not listed above (please specify the type of data):</b>	
<b>D. Reporting and sharing of data [when describing the pain points related to data sharing, please include descriptions of the standards (e.g., text file, excel file, SAS, HL7) and the mechanisms used to share data]:</b>	
<b>1. Data reporting to CDC:</b>	
<b>2. Data sharing with other programs within your health department [please specify which program(s)]:</b>	
<b>3. Data sharing with HIV surveillance programs in other jurisdictions:</b>	
<b>4. Data sharing with other agencies or entities not listed above (please specify the agency or entity):</b>	

	List and describe major pain points that your program are experiencing (If there are no pain points, please answer "None")
<b>E. Data analyses, visualization, and dissemination (when describing the pain points, please include descriptions of the tools used to analyze, visualize and understand the data):</b>	
<b>1. Routine analyses (please specify the type of analysis, e.g., descriptive analyses to produce fact sheets, annual surveillance report):</b>	
<b>2. Epidemiologic Profile:</b>	
<b>3. Time-space analyses:</b>	
<b>4. Transmission cluster data analyses:</b>	
<b>5. Drug resistance data analyses:</b>	

	List and describe major pain points that your program are experiencing (If there are no pain points, please answer "None")
6. Statistical modeling (e.g., multiple imputations, estimations):	
<b>F. Data security, privacy, integrity, confidentiality, and availability:</b>	
1. Data access control (e.g., authorization, authentication, remote access):	
2. Data storage and backup:	
3. Small cell suppression:	
4. Data encryption:	
5. Data retention and records management:	

	List and describe major pain points that your program are experiencing (If there are no pain points, please answer "None")
G. Data system maintenance [when describing the pain points, please indicate whether your surveillance team has staff members who are capable of maintaining the data system (e.g., performing system upgrades) and your team's level of dependency on your HD's IT office for system maintenance]:	

**Q6:** One of CDC's Public Health Data Modernization Initiative goals is that public health data collection systems are interoperable. "Interoperable" means two or more separate data collection systems can communicate and exchange data with one another. Please indicate how important it is to your program that the next HIV surveillance system provided by CDC is interoperable with the data systems listed below:

	Check One Only		
	Not at all Important	Moderately Important	Extremely Important
1. AIDS Drug Assistance Program (ADAP) Data Reporting (ADR) System (HRSA)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Birth registries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Cancer registries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. CAREWare (HRSA) or a local data collection system for Ryan White Care Act recipients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Death registries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Hepatitis data system	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Medical Monitoring Program (MMP) data systems (respond only if your jurisdiction conducts MMP)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Medicare/Medicaid data systems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. National Fatality Review - Case Reporting System (NFR-CRS) or a local data collection system for Fetal and Infant Mortality Review (FIMR)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. National HIV Prevention Monitoring and Evaluation (NHM&E)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Perinatal Hepatitis B Surveillance System	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Prescription data systems [e.g., IQVIA Longitudinal Prescription Data (LRx)]	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Check One Only		
	Not at all Important	Moderately Important	Extremely Important
13. Sexually Transmitted Diseases (STD) data system	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Transmission cluster investigation tracking system	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Tuberculosis data system	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Please specify below other data systems that are not listed above:			
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Q7:** The next HIV surveillance system provided by CDC will be document-based. Below is a list of high-level functionalities that the next HIV surveillance system provided by CDC could implement. Please indicate the level of importance of each of the functionalities for your program's operation:

	Check One Only		
	Not at all Important	Moderately Important	Extremely Important
1. Consume <sup>s</sup> electronic health data <sup>†</sup> using HL7 standards and FHIR in real time or close to real time. <sup>s</sup> Receive, triage, check data quality, match, and load <sup>†</sup> E.g., electronic case reports, electronic laboratory reports, electronic health records	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Support surveillance workflow management (e.g., an automated and intelligent notification/tickler system that alerts users of upcoming or incomplete surveillance tasks).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Facilitate, support, and evaluate the following investigation activities:			
Cases of Public Health Importance (COPHI)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Transmission cluster investigation and reporting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Partner services provision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Receipt of HIV medical care (e.g., laboratory tests, medical visits, use of antiretroviral medications)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Health status (e.g., co-infections, viral suppression)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Perinatal exposure investigation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

		Check One Only		
		Not at all Important	Moderately Important	Extremely Important
<b>Fetal and Infant Mortality Review (FIMR)</b>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Please specify below other investigation activities that are not listed above:</b>				
<hr/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<hr/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<hr/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<hr/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<hr/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>4.</b>	<b>Perform the following tasks automatically and on a fixed time table (e.g., in real time):</b>			
	Identify potential duplicate reports of the same person	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Identify molecular transmission clusters	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Detect HIV Type-1 drug resistance mutations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Update meta data (e.g., zip code, county and city FIPS, CLIA code)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Geocode addresses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Perform calculations (e.g., stage of disease at diagnosis)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Perform data quality checks & notify potential data quality issues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Provide a summary view of the data that have been entered for a person	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<b>Please specify below other tasks that are not listed above, but should be performed automatically and on a fix time table:</b>			
	<hr/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<hr/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<hr/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<hr/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>5.</b>	<b>Support the following data management activities:</b>			
	Easy to add a new type of document into the system	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Easy to add a new data field into an existing document	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Provide system test environment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Perform searches (e.g., a case, a document, a facility)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Electronically batch import documents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



	Check One Only		
	Not at all Important	Moderately Important	Extremely Important
Electronically batch updates of existing documents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Electronically batch delete documents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Move document(s) between persons	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Perform deterministic matches at the person-level	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Perform probabilistic matches at the person-level	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Perform linkage with data from the U.S. Census Bureau	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Health care facility maintenance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Health care provider maintenance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Create and maintain jurisdictional-level data fields (i.e., local fields)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Facilitate data sharing between HIV surveillance programs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Produce analytic datasets	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Please specify below other data management activities that are not listed above:			
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>6. Support the following analysis and evaluation activities:</b>			
Identify transmission cluster using time-space method	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Analyze transmission cluster data	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Analyze HIV Type-1 drug resistance mutations data	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Produce reports (e.g., those that are similar to the national products)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Evaluate surveillance system performance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Statistical modeling (e.g., multiple imputation, statistical estimations, predictive analysis)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Provide data visualization capabilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Please specify below other analysis and evaluation activities that are not listed above:			
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

		Check One Only		
		Not at all Important	Moderately Important	Extremely Important
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.	Be able to transmit data to CDC automatically on a fixed timetable as well as allow user intervention (if additional data transmission is necessary)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8.	Give jurisdiction control of user access and user rights	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9.	Encrypt data at rest and data in transit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10.	Provide online documentation of the system	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11.	Please specify below other critical functionalities at a high level that are not listed above:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

End of survey