

National HIV Surveillance System (NHSS)

Attachment 4(d)

Data to Care Reporting Guidance for PS18-1802 and PS20-2010 Recipients

Data-to-Care Reporting Guidance

Centers for Disease Control and Prevention

Division of HIV/AIDS Prevention

Data to Care Evaluation Workgroup

January, 2019 (revised June 2021)

Data-to-Care Reporting Guidance

Table of Contents

Summary.....	2
Preparation of this Document	2
Main Steps in Data-to-Care Not-in-Care Programs	3
Data-to-Care Not-in-Care Logic Model.....	4
Evaluation Questions.....	5
Indicators.....	5
Table 1. Key data-to-care not-in-care outcome indicators	5
Variables Needed to Assess Key Outcome Indicators	6
Table 2. Data-to-care not-in-care data elements and definitions.....	6
Methods for Calculating Key Outcome Indicators	10
Table 3. Data-to-care not-in-care indicators, numerators, denominators, and methods of calculation.....	10
Collecting Data for Data-to-Care Not-in-Care Variables.....	11
Example of a data collection tool	12
Reporting Data for Data-to-Care Not-in-Care Variables to CDC via eHARS	13
Table 4. Example data-to-care not-in-care data: availability and reporting timeline	13
Data Management and Quality Assurance of Data-to-Care Not-in-Care Data	14
Data Security and Confidentiality.....	14
Appendix.....	15
Figure 1. Data-to-Care Health Department Model: Key Steps	16
Figure 2. Data-to-Care Collaborative Model: Key Steps.....	17

Data-to-Care Reporting Guidance

Summary

The Centers for Disease Control and Prevention (CDC) needs accurate reporting of three key Data-to-Care (D2C) outcome indicators to monitor and evaluate outcomes for CDC funded programs, ensure accountability for funds appropriated by the U.S. Congress for HIV prevention, and inform the Division of HIV/AIDS Prevention's (DHAP) planning. The three D2C indicators described in this document are included in the PS18-1802 Evaluation and Performance Measurement Plan (EPMP) under Strategy 4 and also in the PS20-2010 EPMP under the Treat Strategy. To monitor and evaluate D2C outcomes among those Not-In-Care (NIC), CDC has developed a logic model that includes the six main operational steps of D2C NIC investigations and added 10 variables to eHARS to evaluate D2C NIC programs. These variables are located in the eHARS Adult Case Report Form (ACRF) document under the "Follow-up Investigation" tab in eHARS version 4.10.5 and later. Further details about each variable may be found in the eHARS Technical Reference Guide (TRG).

- This guidance updates previous Data-to-Care Guidance for PS18-1802 Recipients January 2019 and may be used to guide reporting and evaluation of other D2C funded programs (e.g., PS20-2010).
- Since January 2019, all health departments receiving CDC funds (e.g., PS18-1802, PS20-2010) must collect data for the 10 D2C NIC variables.
- Health departments must enter or import D2C NIC data into eHARS at least twice yearly, by the June and December eHARS data transfers.
- Data transfers should include all records for which an investigation was opened. They should not be limited to just those records for which an investigation has been completed.

Preparation of this Document

The Division of HIV/AIDS Prevention (DHAP), Centers for Disease Control and Prevention, led the development of Data-to-Care indicators previously described in the PS18-1802 Evaluation and Performance Measurement Plan. DHAP then requested the input of PS18-1802 recipients on how to accurately measure and report these variables and held a series of webinars in the summer and fall of 2018. The resulting document is the culmination of this collaboration between DHAP and PS18-1802 health departments including: Alaska, Colorado, District of Columbia, Louisiana, Maryland, Michigan, Nebraska, New Jersey, New York State, Philadelphia, San Francisco, South Carolina, Tennessee, Washington, and Wisconsin. DHAP would like to acknowledge the essential role staff from these health departments provided in order to finalize the first guidance document. The document was revised in June 2021 by DHAP to expand the scope to accommodate additional NOFOs funding D2C programs and provide additional guidance.

Main Steps in Data-to-Care Not-in-Care Programs

The graphic below depicts the six main operational steps involved in a D2C NIC program.



Data-to-Care Not-in-Care Logic Model

The logic model for the D2C NIC strategy is shown below. CDC has identified two short-term and one intermediate intended outcomes—indicated with bold font in the logic model—that will be followed for monitoring D2C NIC program outcomes at the national and jurisdictional level.

Data-to-Care Logic Model: Identifying persons diagnosed with HIV who are not in HIV medical care and linking them to care			
Activities	Outputs	Short-term Intended Outcomes	Intermediate & Long-term Intended Outcomes
Step 1 – Identification <ul style="list-style-type: none"> Generate a list of persons with HIV (PWH) presumed not to be in HIV medical care 	<ul style="list-style-type: none"> # of persons presumed not to be in HIV medical care 	<ul style="list-style-type: none"> Increased identification of PWH who are not in HIV medical care 	<ul style="list-style-type: none"> Increased HIV viral load suppression among PWH Improved health outcomes for PWH Reduced HIV transmission
Step 2 – Investigation <ul style="list-style-type: none"> Use other data sources to investigate care status Prioritize list for outreach Conduct outreach to locate, contact, and interview persons on prioritized list to verify care status 	<ul style="list-style-type: none"> # of persons prioritized for outreach # of persons located, contacted, and interviewed # of persons confirmed not to be in HIV medical care 		
Step 3 – Linkage to Care <ul style="list-style-type: none"> Link persons confirmed not to be in care to HIV medical care 	<ul style="list-style-type: none"> # of persons linked to HIV medical care 	<ul style="list-style-type: none"> Increased linkage to and retention in HIV medical care among PWH 	
Step 4 – Support Services <ul style="list-style-type: none"> Link to support services that facilitate retention in HIV medical care and adherence to treatment 	<ul style="list-style-type: none"> # of persons linked to support services that facilitate retention in HIV medical care and adherence to treatment 	<ul style="list-style-type: none"> Increased linkage of PWH to support services that facilitate retention in HIV medical care and adherence to treatment 	
Step 5 – HIV Prevention Services <ul style="list-style-type: none"> Provide or link to HIV prevention services, including partner services 	<ul style="list-style-type: none"> # of persons provided or linked to HIV prevention services, including partner services 	<ul style="list-style-type: none"> Increased provision of or linkage to HIV prevention services, including partner services 	
Step 6 – Feedback Loop <ul style="list-style-type: none"> Update surveillance data with information obtained through data-to-care process 	<ul style="list-style-type: none"> # of surveillance records updated 	<ul style="list-style-type: none"> Increased completeness, timeliness, and quality of HIV surveillance data 	

Evaluation Questions

CDC has identified three evaluation questions to address at the national level:

- To what extent are D2C programs accurately identifying PWH who are not in HIV medical care?
- To what extent are D2C programs linking not-in-care PWH to HIV medical care?
- To what extent do PWH who are linked to HIV medical care through D2C programs achieve viral suppression?

Indicators

CDC will be tracking three key indicators to measure the three outcomes selected for monitoring D2C NIC program outcomes at the national and jurisdictional level. These indicators, and the numerators and denominators needed to calculate them, are shown in the table below. A SAS program will be made available for health departments to generate these indicators from eHARS locally for local use. Health departments may identify additional measures or indicators to follow at the local level, based on specific jurisdictional needs or special populations their programs are aiming to reach. See Evaluation and Performance Measurement plans for description of specific NOFO requirements.

Table 1. Key data-to-care not-in-care outcome indicators

Intended Outcome	Evaluation Question	Indicator	Numerator & Denominator
Increased identification of PWH who are not in HIV medical care.	To what extent are health departments able to use HIV surveillance and other data to identify PWH who are not in HIV medical care?	<u>D2C NIC Identification:</u> Percentage of presumptively not-in-care PWH with an investigation opened (initiated) during a specified 6-month evaluation time period, who were confirmed within 90 days after the investigation was opened not to be in care	<u>Denominator:</u> Number of presumptively not-in-care PWH with an investigation opened (initiated) during a specified 6-month evaluation time period
			<u>Numerator:</u> Of those in the denominator, the number confirmed within 90 days after the investigation was opened not to be in care
Increased linkage to HIV medical care among PWH identified through D2C activities.	To what extent are health departments able to link to HIV medical care PWH who are confirmed through D2C activities not to be in care?	<u>D2C NIC Linkage:</u> Percentage of PWH confirmed during a specified 6-month evaluation time period not to be in care, who were linked to HIV medical care within 30 days after being confirmed not to be in care	<u>Denominator:</u> Number of PWH confirmed during a specified 6-month evaluation time period not to be in care
			<u>Numerator:</u> Of those in the denominator, the number linked to HIV medical care within 30 days after being confirmed not to be in care
Increased HIV viral load suppression among PWH identified through D2C activities.	To what extent is HIV viral load suppression achieved among PWH who are linked to HIV medical care after	<u>D2C NIC Viral Suppression:</u> Percentage of PWH linked to HIV medical care during a specified 6-month evaluation time period,	<u>Denominator:</u> Number of PWH linked to HIV medical care during a specified 6-month evaluation time period

Intended Outcome	Evaluation Question	Indicator	Numerator & Denominator
	being confirmed through D2C activities not to be in care?	who achieved HIV viral suppression within six months (180 days) after being linked to care	Numerator: Of those in the denominator, the number who achieved HIV viral suppression within six months (180 days) after being linked to care

Variables Needed to Assess Key Outcome Indicators

To calculate outcome indicators, it is necessary to collect and enter in eHARS the data needed to perform the calculations. For example, the “identification” indicator, which can be used to monitor progress in using HIV surveillance and other data to accurately identify PWH who are not in HIV medical care, measures the percentage of presumptively not-in-care PWH with a D2C NIC investigation opened (initiated) during a specified 6-month evaluation time period that were confirmed not to be in care. To calculate this indicator, the following information must be collected:

- The date the person was placed on the presumptive NIC list
- Whether a not-in-care investigation was opened (initiated)
- If a not-in-care investigation was opened, the date it was opened
- For those with an investigation opened, whether the person was confirmed not to be in care
- If they were confirmed not to be in care, the date this determination was made

CDC has added 10 variables to eHARS for which health departments receiving CDC funds must collect and report data so their D2C NIC indicators can be calculated. The table below presents the new variables, along with their labels, value options and definitions. Health departments planning to monitor additional indicators as part of their local D2C evaluations will need to identify the variables needed for calculating their local-use indicators and collect those data for those variables, as well.

Table 2. Data-to-care not-in-care data elements and definitions

Data element	Variable	Definition
Data element 1 (<i>invest_type_cd</i>)	Type of investigation	
	0 – Transmission cluster (TC)	
	1 – Not in care (NIC)	
Data element 2 (<i>invest_ident_method</i>)	How person was first identified as NIC (presumptively or confirmed)?	The source from which you have identified the person as NIC.
	01 - Health department HIV surveillance system (e.g., eHARS)	By using data in a “self-contained” HIV surveillance system only.
	02 – Health department integrated data system	By using data in an integrated data system, which contains HIV surveillance data as well as other types of data (e.g., care data), or by running an application that automatically integrates data from multiple sources, such as eHARS, CAREWare, and Medicaid databases.
	03 – Provider report	By a health care provider.
	04 – Transmission cluster investigation	Through the investigation of a transmission cluster.

Data element	Variable	Definition
	05 – Elevated viral load investigation	Through the investigation of persons with elevated HIV viral load.
	06 – Partner services investigation	Through partner services investigations.
	07 – Medical Monitoring Project (MMP)	Through MMP activities (e.g., MMP participant interview).
	88 – Other	Other sources that do not fit in any of the above.
Data element 3 <i>(invest_ident_dt)</i>	Date first identified as not in care (presumptively or confirmed)	
Data element 4 <i>(invest_incl)</i>	Included for investigation?	Was the person included in or excluded from investigation to confirm their care status?
	Y – Included in investigation	Health department made further efforts to investigate after person was placed on presumptive NIC list. This may include (but is not limited to) matching the presumptive NIC list to other data systems or programs to determine residence, vital status, and care status; or conducting a field investigation.
	N – Excluded from investigation	Did not meet programmatic criteria for follow-up.
Data element 5 <i>(invest_start_dt)</i>	Date investigation opened*	If feasible to collect, this is the earliest date that any investigation was conducted following generation of the presumptive NIC list (regardless of whether the presumptive NIC list was generated from a “self-contained” HIV surveillance system or an integrated system). If field investigation, this would be the date the field investigation began . If matching with other data, it would be the date the database or record search began. If both a field investigation and database or record search are conducted, you would use the earlier of the two dates.
Data element 6 <i>(invest_dispo)</i>	Disposition, care status investigation	Result of the investigation.
	1 – Deceased	There is evidence that the person is dead (you will be prompted to update the person’s vital status and date of death in eHARS).
	2 – Resides out of jurisdiction	There is evidence that the person resides outside of the D2C catchment area defined by the health department (you will be prompted to add the out-of-jurisdiction address into eHARS).
	3 – In care	There is either laboratory (in eHARS), self-report, or other evidence that the person is receiving regular HIV medical care.
	4 – Not in care (confirmed)	Confirmed with the person that he or she is indeed NIC.
	5 – Unable to determine	Unable to obtain adequate information to determine care status.
Data element 7 <i>(invest_dispo_dt)</i>	Investigation disposition date	Date a person’s care status disposition was determined.
Data element 8	Basis of care status investigation disposition	How was the care status disposition determined?

Data element	Variable	Definition
<i>(invest_dispo_method)</i>	1 – Database/record search, only	Health department only searched databases for residential location, vital status, and care status and did not conduct field investigation or contact the individual.
	2 – Patient contact/field investigation, only	Health department learned the person’s residential location, vital status, and care status only through field investigation or contacting the health care provider or the individual.
	3 – Database/record search and patient contact/ field investigation	A combination of the above two methods.
Data element 9 <i>(int_dispo)</i>	Disposition, linkage or re-engagement intervention	<u>Linkage or re-engagement intervention</u> – Defined as an action taken by the program to facilitate a client’s entry or re-entry into HIV medical care (e.g., ARTAS, scheduling the appointment, reminding the client of the appointment, accompanying the client to their appointment, follow-up to ensure that the appointment took place). <u>Linked to or re-engaged in care</u> – Defined as the client attending an appointment for HIV medical care after having been identified as being NIC.
	1 – No intervention initiated	Program did not offer any linkage or re-engagement intervention to the client.
	2 – Linkage/re-engagement intervention declined by client	Program offered intervention, but it was declined by the client.
	3 – Returned to care before intervention was initiated	The client entered or resumed care without any additional linkage intervention.
	4 – Linkage/re-engagement intervention initiated; client was not successfully linked to/re-engaged in care	The client did not enter or resume care, despite the program’s intervention efforts.
	5 – Linked to/re-engaged in care, documented	The client was linked to/re-engaged in care by the program’s intervention, and this was confirmed through documentation [e.g., laboratory data, report from medical care provider (verbal or written), medical record review, other record review, other database, ARV prescription filled or refilled].
	6 – Linked to/re-engaged in care, client self-report, only	The client was apparently linked to/re-engaged in care by the program’s intervention, but this was determined only through client’s self-report, without any additional confirmation
	7 – Linkage/re-engagement status unknown	It is unknown whether the client entered or returned to care.

Data element	Variable	Definition
Data element 10 <i>(int_dispo_dt)</i>	Date returned to, linked to, or re-engaged in care	<p>If return, linkage, or re-engagement was confirmed: Date of documented evidence that client attended an HIV medical care appointment after being identified as NIC (e.g., laboratory report, verbal or written report from medical care provider, medical record review, other record review, other database, ARV prescription filled or refilled).</p> <p>If return, linkage, or re-engagement was determined by client self-report, only: Date client reports having attended an HIV medical care appointment after being identified as NIC.</p>

* In eHARS, only the term “opened” is used in reference to the investigation; however, the terms “opened” and “initiated” are synonymous.

Methods for Calculating Key Outcome Indicators

The table below shows the methods for calculating each of the three key outcome indicators. An example of the evaluation time period [E₁, E₂] could be [07/01/2019, 12/31/2019].

Table 3. Data-to-care not-in-care indicators, numerators, denominators, and methods of calculation

Indicators	Numerators & Denominators	Methods of Calculation
<p>Identification: Percentage of presumptively not-in-care PWH with an investigation opened (initiated) during a specified 6-month evaluation time period, who were confirmed within 90 days after the investigation was opened not to be in HIV medical care</p>	<p>Denominator: Number of presumptively not-in-care PWH with an investigation opened (initiated) during the evaluation time period [E₁, E₂]</p>	<p>Total number of unique cases satisfying the following criteria:</p> <ul style="list-style-type: none"> • <i>invest_ident_method</i> = "01" or "02" or "03," and • <i>invest_incl</i> = "Y" and E₁ ≤ <i>invest_start_dt</i> ≤ E₂
	<p>Numerator: Of those in the denominator, the number confirmed within 90 days after the investigation was opened not to be in HIV medical care</p>	<p>Of the cases satisfying the above criteria, the number of cases with:</p> <ul style="list-style-type: none"> • <i>invest_dispo</i> = "4" and • <i>invest_dispo_dt</i> – <i>invest_start_dt</i> ≤ 90 days
<p>Linkage: Percentage of PWH confirmed through D2C activities during a specified 6-month evaluation time period not to be in care, who were linked to HIV medical care within 30 days after being confirmed not to be in HIV medical care</p>	<p>Denominator: Number of PWH confirmed during the evaluation time period [E₁, E₂] not to be in HIV medical care</p>	<p>Total number of unique cases satisfying the following criteria:</p> <ul style="list-style-type: none"> • <i>invest_ident_method</i> = "01" or "02" or "03," and • <i>invest_dispo</i>= "4" and E₁ ≤ <i>invest_dispo_dt</i> ≤ E₂
	<p>Numerator: Of those in the denominator, the number linked to HIV medical care within 30 days after being confirmed not to be in HIV medical care</p>	<p>Of the cases satisfying the above criteria, the number of cases with:</p> <ul style="list-style-type: none"> • <i>int_dispo</i> = "3", "5" or "6", and • <i>int_dispo_dt</i> – <i>invest_dispo_dt</i> ≤ 30 days
<p>Viral suppression: Percentage of PWH linked through D2C activities to HIV medical care during a specified 6-month evaluation time period, who achieved HIV viral suppression within six months (180 days) after being linked to HIV medical care</p>	<p>Denominator: Number of PWH linked to HIV medical care during the evaluation time period [E₁, E₂]</p>	<p>Total number of unique cases satisfying the following criteria:</p> <ul style="list-style-type: none"> • <i>invest_ident_method</i>= "01" or "02" or "03," and • <i>int_dispo</i> = "3", "5" or "6", and • <i>invest_dispo</i>= "4" • E₁ ≤ <i>int_dispo_dt</i> ≤ E₂
	<p>Numerator: Of those in the denominator, the number who achieved HIV viral suppression within six months (180 days) after being linked to HIV medical care</p>	<p>Of the cases satisfying the above criteria, the number of cases with:</p> <ul style="list-style-type: none"> • <i>sample_dt</i> – <i>int_dispo_dt</i> ≤ 180 days <p>[where <i>sample_dt</i> is the earliest specimen collection date that is on or after <i>int_dispo_dt</i> and is associated with an HIV-1 viral load test result that is below (<) 200 copies/mL or the result interpretation is below detection limit]</p>

Collecting Data for Data-to-Care Not-in-Care Variables

Health departments implementing D2C NIC programs can use a variety of approaches for tracking activities and outcomes. Some programs have developed unique electronic case management systems, some have created databases using commercial software programs (e.g., Excel, REDCap, Access), some may opt to use eHARS. Health departments should identify best practices to facilitate tracking activities and outcomes. Health departments with existing D2C databases should crosswalk the 10 eHARS D2C NIC variables with their current D2C databases and modify or add variables in their current databases, as necessary. Data may be extracted from these databases and electronically imported into eHARS. Health departments newly implementing D2C NIC programs and developing local D2C data systems should ensure that the 10 eHARS D2C NIC variables are included in these systems.

The eHARS D2C NIC variables are not included on the hard copy of the CDC Adult Case Report Form (ACRF) and health departments are not required to document this information in hard copy. However, for some D2C workers documenting the information for the variables in hard copy can facilitate this process. On the following page is an example of a template that includes all the eHARS D2C NIC variables, labels and skip patterns. This example template can be tailored to suit jurisdictional data collection needs and can also be used by health departments with existing systems for cross-walking purposes. Spending time up front to ensure variables in local systems are comparable and data are extracted correctly will help ensure that high quality data are reported and used for evaluation.

Understanding the definitions of the D2C NIC variables will ensure that the data entered into D2C data systems are reliable, standardized, consistent, and valid. If there are different interpretations of the definition of variables in the systems used or by staff, the indicators calculated in eHARS from the D2C NIC data may not accurately reflect program performance. Training and guidance may include:

- a. Definitions of variables and response options
- b. Rationale for why each variable is collected and how variables may be used to answer specific questions
- c. Explanation of skip patterns and conditional relationships between variables
- d. Description of the data collection process and tips for avoiding common errors during data collection

Finally, it is important to solicit and incorporate feedback from staff and system users about the data collection and import/entry processes in the beginning and throughout the project period.

Example of a data collection tool that could be used for collecting data during data-to-care not-in-care investigations

1. How person was first identified as not in care <i>invest_ident_method</i>															
<input type="checkbox"/> 01- Health department HIV surveillance system (e.g., eHARS) (<i>go to #2</i>)	<input type="checkbox"/> 03- Provider report (<i>go to #2</i>)	<input type="checkbox"/> 06- Partner services investigation (<i>go to #2 and then #7</i>)													
<input type="checkbox"/> 02- Health department integrated data system (<i>go to #2</i>)	<input type="checkbox"/> 04- Transmission cluster investigation (<i>go to #2 and then #7</i>)	<input type="checkbox"/> 07- Medical Monitoring Project (MMP) (<i>go to #2 and then #7</i>)													
	<input type="checkbox"/> 05- Elevated viral load investigation (<i>go to #2 and then #7</i>)	<input type="checkbox"/> 88- Other (<i>go to #2</i>)													
2. Date first identified as not in care <i>invest_ident_dt</i>								M	M	D	D	Y	Y	Y	Y
3. Included for investigation? <i>invest_incl</i> (Date investigation opened <i>invest_start_dt</i>)															
<input type="checkbox"/> Yes → <i>Date investigation opened</i>				M	M	D	D	Y	Y	Y	<input type="checkbox"/> No (<i>Excluded → Stop Here</i>)				
4. Disposition, care status investigation <i>invest_dispo</i>															
<input type="checkbox"/> 1- Deceased (<i>go to #5 - 6 and then STOP</i>)					<input type="checkbox"/> 4- Not in care (confirmed) (<i>go to #5 - 7 and linkage date if linked</i>)										
<input type="checkbox"/> 2- Resides out of jurisdiction (<i>go to #5 - 6 and then STOP</i>)					<input type="checkbox"/> 5- Unable to determine (<i>go to #5 - 6 and then STOP</i>)										
<input type="checkbox"/> 3- In care (<i>go to #5 - 6 and then STOP</i>)															
5. Investigation disposition date <i>invest_dispo_dt</i>								M	M	D	D	Y	Y	Y	Y
6. Basis of care status disposition? (Optional) <i>invest_dispo_method</i>															
<input type="checkbox"/> 1- Database/record search, <u>only</u>					<input type="checkbox"/> 3- Database/record search <u>and</u> patient contact/field investigation										
<input type="checkbox"/> 2- Patient contact/field investigation, <u>only</u>															
7. Disposition, linkage or re-engagement intervention (answer only if confirmed not in care) <i>int_dispo</i>															
<input type="checkbox"/> 3- Returned to care before intervention was initiated					<input type="checkbox"/> 1- No intervention initiated										
<input type="checkbox"/> 5- Linked to/re-engaged in care, documented*					<input type="checkbox"/> 2- Linkage/re-engagement intervention declined by client										
<div style="display: flex; align-items: center;"> <div style="border-left: 1px solid black; border-right: 1px solid black; border-bottom: 1px solid black; width: 100px; height: 100px; margin-right: 10px;"></div> <div style="text-align: center;"> <p>Date returned to, linked to, or re-engaged in care <i>int_dispo_dt</i></p> </div> </div>					<input type="checkbox"/> 4- Linkage/re-engagement intervention initiated, not successfully linked to/re-engaged in care										
					<input type="checkbox"/> 7- Linkage/re-engagement status unknown										
<input type="checkbox"/> 6- Linked to/re-engaged in care, client self-report, only					M	M	D	D	Y	Y	Y	Y			

*Examples of types of documentation: laboratory data, report from medical care provider (verbal or written), medical record review, other record review, other database, ARV prescription filled or refilled.

Reporting Data for Data-to-Care Not-in-Care Variables to CDC via eHARS

The 10 variables CDC has added to eHARS, for which recipients are required to collect and report data for evaluation of their D2C programs, are located in the eHARS Adult Case Report Form (ACRF) document under the “Follow-up Investigation” tab in eHARS version 4.10.5 and later. Further details about each variable may be found in the eHARS Technical Reference Guide (TRG). Note, programs may include children (i.e., under 13 years of age) in their D2C NIC investigations. Outcomes for these investigations should be reported by creating an ACRF and documenting the 10 variables under the “Follow-up Investigation” tab as done for adults.

CDC needs accurate reporting of the three key D2C NIC outcome indicators to monitor and evaluate outcomes for D2C programs, ensure accountability for funds appropriated by the U.S. Congress for HIV prevention, and inform DHAP’s planning. Data transfers should include all records for which an investigation was opened. They should not be limited to just those records for which an investigation has been completed. Health departments will enter or import D2C NIC data into eHARS at least twice yearly, by the June and December eHARS data transfers (see table below).

Table 4. Example data-to-care not-in-care data: availability and reporting timeline

	Indicator 1: Confirmation of NIC status within 90 days after investigation opened	Indicator 2: Linkage to HIV medical care within 30 days after person confirmed NIC	Indicator 3: Achievement of viral suppression within 6 months (180 days) after person linked to care
Evaluation Time Period 1: January 1 – June 30			
Data available locally in jurisdictional databases ¹	October 31, Year X	August 31, Year X	January 31, Year X+1
Data entered or uploaded into eHARS	December data transfer, Year X	December data transfer, Year X	June data transfer, Year X+1
Evaluation Time Period 2: July 1 – December 31			
Data available locally in jurisdictional databases ¹	April 30, Year X+1	February 28/29, Year X+1	July 31, Year X+1
Data entered or uploaded into eHARS	June data transfer, Year X+1	June data transfer, Year X+1	December data transfer, Year X+1

¹Allowing 30 days for reporting and data entry

Data Management and Quality Assurance of Data-to-Care Not-in-Care Data

Routine quality assurance checks should be implemented on processes throughout the data life cycle to ensure completeness and timeliness of data—including data collection/documentation, data entry/import, and reporting data to CDC. Guidance for D2C NIC data management and quality assurance are forthcoming. Guidance and tools will be added to this document as they are developed.

Data Security and Confidentiality

All data used in D2C NIC activities should be handled in a secure and confidential manner in accordance with the National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP) Data Security and Confidentiality Guidelines:

<http://www.cdc.gov/nchhstp/programintegration/docs/PCSIDataSecurityGuidelines.pdf>.

This includes all instances in which data are shared with partners internal and external to the health department. All partners should be made aware and comply with security and confidentiality guidelines and protocols, including how data should be transferred, stored, and used.

Appendix

Below are flow diagrams depicting the steps involved in identifying persons with HIV who are not in HIV medical care and linking them to care in two models: the Health Department Model (Figure 1) and the Collaborative Model (Figure 2). These diagrams were used as a basis for CDC's data-to-care (D2C) not-in-care (NIC) evaluation and may be helpful to some health departments as they flesh out their D2C NIC program descriptions.

Figure 1. Data-to-Care Health Department Model: Key Steps

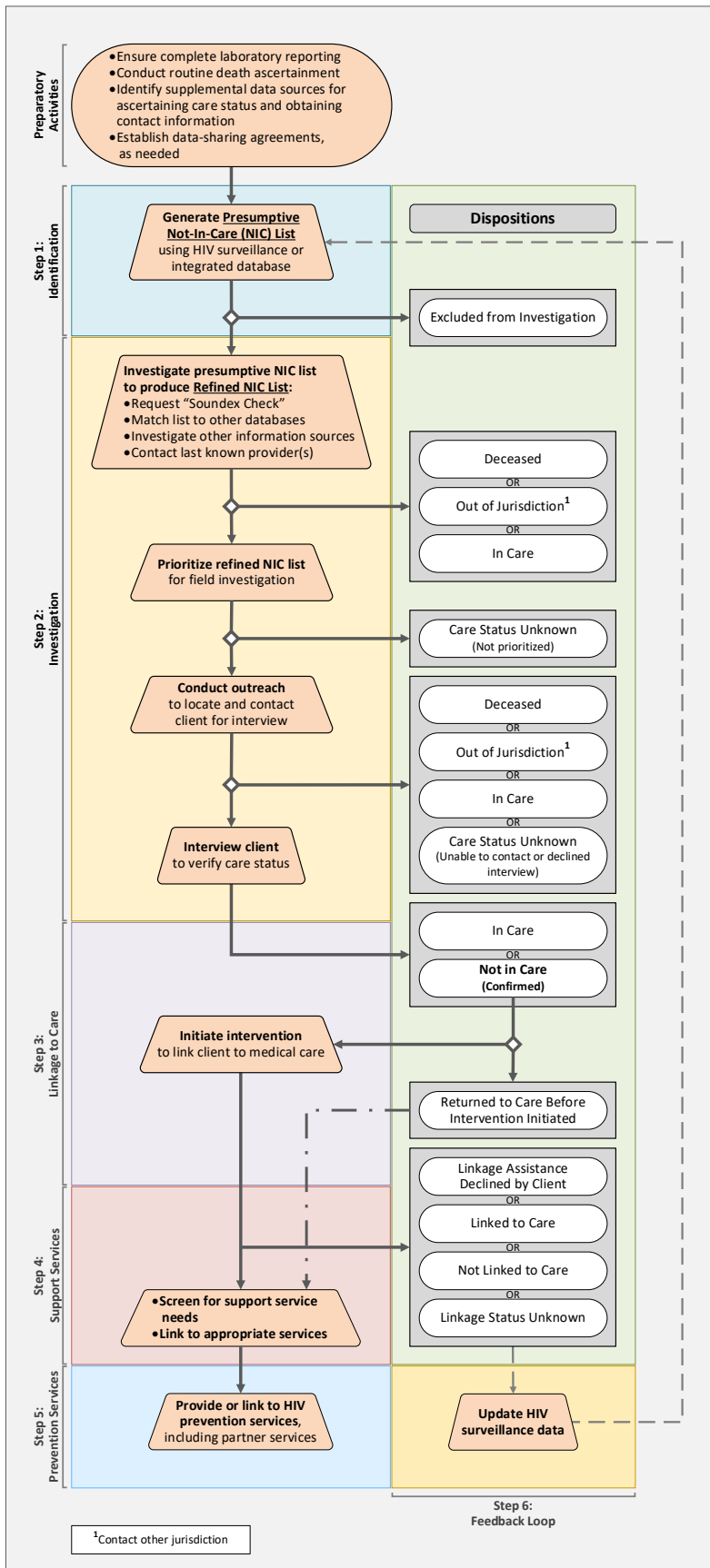


Figure 2. Data-to-Care Collaborative Model: Key Steps

