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Informing Data to Care: Contacting Persons Sampled for the Medical Monitoring Project

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Abstract

Background: Data to Care (D2C) is a public health strategy that uses HIV surveillance and other data to identify persons in need of HIV medical care. The Medical Monitoring Project (MMP), which employs similar methods to contact and recruit HIV-positive persons, may inform predictors of successful contact for D2C programs.

Setting: MMP is a CDC-funded surveillance system that collects nationally representative data on adults with diagnosed HIV in the United States and Puerto Rico.

Methods: Using MMP's 2016 data collection cycle, we present contact rates (i.e., proportion of HIV-positive persons successfully contacted for MMP), by the age of contact information and age of laboratory test results available from HIV surveillance data.

Results: Nationally, 27.6% of eligible persons did not have a recorded laboratory test done within the past year (project area range: 10.8%–54.6%). The national contact rate among persons with labs older than one year was 37.0% (project area range: 16.5%–67.1%). Higher contact rates were found among persons with more recent laboratory tests. Similar results were found by age of contact information. Nationally, the most common reason for MMP ineligibility was that the person was deceased; the most common reason for not being contacted was lack of correct contact information.

Conclusion: MMP findings suggest that D2C programs would benefit from efforts to improve the quality of HIV surveillance data and local surveillance practices—in particular, death ascertainment, the completeness of laboratory reporting, and the routine updating of contact information. Strengthening collaboration and integration with existing MMP programs may be beneficial.

Keywords

HIV; public health surveillance; Data to Care; Medical Monitoring Project

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Background

Nearly half of the 1.1 million people living with human immunodeficiency virus (HIV) in the United States in 2015 were not virally suppressed, putting their health at risk and increasing the likelihood of HIV transmission.[1,2] The HIV care continuum is a model used by the Centers for Disease Control and Prevention (CDC) to monitor population-level progress from HIV diagnosis to successful treatment of infection, as measured by HIV viral suppression. The model indicates that lack of engagement in HIV medical care is a primary barrier to achieving viral suppression. To address this barrier, CDC initiated Data to Care (D2C) as a public health strategy that uses HIV surveillance and other data to identify persons living with diagnosed HIV who are in need of HIV medical care or other services and facilitate linkage to those services, with the ultimate goal of increasing the proportion of persons living with HIV who achieve and maintain sustained viral suppression.[3] However, using surveillance records to find persons who are not receiving HIV care has been a challenge for D2C programs and related projects.[4–7]

The Medical Monitoring Project (MMP) is a CDC-funded surveillance system that collects nationally representative interview and medical record abstraction data on behaviors, medical care, and clinical outcomes among adults living with diagnosed HIV infection in the United States and Puerto Rico. MMP conducts annual, geographically stratified sampling of adults with diagnosed HIV from the National HIV Surveillance System (NHSS), and trained data collectors located in local health departments attempt to contact sampled persons and recruit them to the project. Because the need to find persons reported to NHSS for MMP is similar to D2C, process outcomes from MMP can provide useful information on best practices for contacting persons and predictors of successful contact, which can be used to improve D2C programs. In this manuscript we will discuss findings from MMP's 2016 data collection cycle, including contact rates, defined as the proportion of persons with diagnosed HIV who were successfully contacted for MMP, nationally and by the age of contact information and age of laboratory test results available from HIV surveillance data, in order to inform efforts to increase the numbers of persons successfully reached by D2C programs.

Methods

Full MMP methods have been described elsewhere,[8] but briefly, MMP has a two stage sample design in which 16 states and 1 territory were first selected for participation (hereafter referred to as project areas). For operational purposes, the six cities within the sampled project areas that are separately funded to conduct HIV surveillance are funded to conduct MMP independently from the rest of the state; thus, there are 23 MMP project areas. In the second stage, MMP selects from NHSS annual random samples of adults (aged ≥18 years) with diagnosed HIV who are presumed to be living in one of the MMP project areas on the sampling date. As a part of NHSS, states in the United States and the District of Columbia have reported cases of acquired immunodeficiency syndrome (AIDS) to the CDC since 1981. Implementation of confidential name-based HIV surveillance varied by jurisdiction, but by April of 2008, all 50 states and District of Columbia had implemented

confidential name-based HIV surveillance. Personally identifiable information on cases is not reported to CDC, but is maintained securely by state and local health departments. The MMP sample is drawn from NHSS on December 31 of the year prior to the data collection cycle (e.g., December 31, 2015 for the 2016 data collection cycle). Every year, a total of 9,700 persons (with minimum state/ territory sample size of 400 persons) are selected (Table 1). Data collection begins in June of the cycle year and ends the following May. Thus, the data collection period for the 2016 data collection cycle was June 2016 through May 2017.

Health department staff in participating project areas use multiple sources of information to contact and recruit sampled persons for MMP. Primary sources of information include: local HIV surveillance system records, other available health department sources (such as surveillance databases for other conditions), social services records, and people search engines (e.g., LexisNexis®, TLOxp®), as permitted by local regulations. Barring any local restrictions on mode of contact, project areas attempt to locate sampled persons via mail, phone, email, text message, and home visits. Project areas may also work with local HIV care providers to contact sampled persons who have received medical care as evidenced by laboratory test results captured by NHSS. Participants are given a token of appreciation of approximately $50 in cash or cash equivalent for participating in the MMP interview and medical record abstraction. Regardless of participation, MMP staff attempt to offer all sampled persons linkage or re-engagement to HIV medical care services, in addition to any needed information and referrals for other medical, prevention, or ancillary services. All MMP recruitment and data collection practices adhere to CDC's Data Security and Confidentiality Guidelines for HIV, Viral Hepatitis, Sexually Transmitted Disease, and Tuberculosis Programs,[9] as well as local security and confidentiality protocols, which ensure the integrity, confidentiality, and security of MMP data.

In this analysis, we present data from MMP's 2016 data collection cycle, the second MMP cycle to use NHSS as a sampling frame for selecting persons with diagnosed HIV for contact and recruitment. Prior to the 2015 data collection cycle, MMP sampled HIV patients from lists obtained from HIV care facilities. We examine 2016 cycle data derived from multiple sources. First, all sampled persons receive a final disposition (Table 2) from the MMP project area by the end of the data collection cycle, which enables the person to be placed in 1 of 3 categories: eligible contacted (persons who were successfully contacted by phone, mail, or in person, regardless of participation in MMP), eligible not contacted (persons who were not able to be contacted but were assumed to be eligible for MMP) and ineligible (persons who were ineligible for MMP participation). First, we calculated the proportion of persons in each of these categories, as well as detailed reasons persons were not contacted or were found to be ineligible, nationally and the range by project area. We also present the national and anonymized project area contact rates, defined as the proportion of eligible persons successfully contacted, and the improvement in contact rates from the 2015 to 2016 data collection cycles. Second, we examined two characteristics available for all sampled persons: age of contact information recorded in the local HIV surveillance system and age of last reported HIV-related laboratory test recorded in NHSS, and explored variation in contact by these characteristics, nationally and by project area. Contact information was defined as the most recent complete address or phone number for a sampled person that was recorded in local HIV surveillance system records; local

surveillance programs do not send street addresses or phone numbers to CDC. If available, contact information is recorded in the surveillance system at HIV diagnosis and may be updated if new contact information is found in additional information sent to the surveillance program or through other routine surveillance activities. Although MMP staff search other sources of contact information during MMP recruitment if local surveillance data do not yield a response, we limited independent variables for this analysis to the laboratory and contact information that was recorded in the local HIV surveillance system in order to determine the likelihood of contact for persons based on attributes of the surveillance system. Lab information is collected by the local surveillance program and is sent to NHSS. Laboratory tests were primarily HIV viral load and CD4 T-lymphocyte tests, but also included all HIV-related tests, such as HIV antibody, genotype, and incidence tests. The age of last contact information and age of laboratory test were calculated from the sample date, December 31, 2015.

Results

Among 9,700 persons sampled, 593 (6.1%) were found to be ineligible (project area range: 3.5–15.0%). The most common reason for ineligibility was death prior to the sampling date (Table 3). Among 9,107 eligible persons, 5,759 (63.2%) were contacted (i.e., contact rate; range: 50.3–75.1%). Over half (51.1%) of persons who were not contacted were unable to be located (i.e., project area staff attempted to find the person but were unable to confirm they had the correct contact information), followed by persons who did not respond to the project area's contact attempts (41.2%). Comparing the 2016 cycle to the 2015 cycle, the contact rate improved 7.5 percentage points, from 55.7% to 63.2%, and many project areas improved substantially. The percentage point change from 2015 to 2016 among project areas ranged from −4.6 to 23.2%; 18 of 23 project areas increased their contact rate (data not shown).

As D2C programs often focus contact attempts on persons who do not have a recorded laboratory test within the past year, we also examined contact rates among this group. Nationally, 27.6% of sampled persons did not have a recorded laboratory test within the past year, and this percentage ranged from 10.8% to 54.6% among project areas (data not shown). The national contact rate among persons with laboratory tests older than one year or missing laboratory tests was 37.0% (project area range: 16.5%–67.1%), compared with 73.2% among persons with laboratory tests <1 year old (project area range: 62.9%–82.5%) (Figure 1).

As both the age of laboratory test results and the age of available contact information can affect the likelihood of contacting sampled persons, we examined the distribution of the sample and contact rates by these factors more closely. Nearly three-quarters of the national sample (72.4%) had a recorded HIV-related laboratory test result less than or equal to 1 year old, 10.9% had a laboratory test that was 2–3 years old, 8.5% had a laboratory test that was 4 to 10 years old, 7.4% had a laboratory test older than 10 years, and 0.8% were missing laboratory test data (Table 4). There was moderate variation in the distribution of the age of laboratory test results among project areas. Contact rates decreased with increasing age of laboratory test results; the national contact rate was 73.2% among persons with a laboratory

test result less than or equal to 1 year old, 55.4% among those with a laboratory test that was 2 to 3 years old, 32.0% among those with a laboratory test that was 4 to 10 years old, 18.7% among those with a laboratory test older than 10 years, and 7.1% among those with missing laboratory test data. There was substantial variation among project areas in their ability to contact persons with laboratory tests older than 1 year; project area contact rates ranged from 62.9% to 82.5% among those with a laboratory test equal to or less than 1 year old, from 33.3% to 73.4% among those with a laboratory test that was 2 to 3 years old, from 9.5% to 62.1% among those with a laboratory test that was 4 to 10 years old, from 3.4% to 77.8% among those with a laboratory test older than 10 years, and from 0.0% to 100.0% among those with missing laboratory test data.

Over two-thirds of the national sample (66.7%) had contact information in the local HIV surveillance system that was less than or equal to 1 year old, 10.6% had contact information that was 2 to 3 years old, 10.4% had contact information that was 4 to 10 years old, 7.0% had contact information older than 10 years, and 5.3% had missing contact information. There was substantial variation in this distribution across project areas; the proportion of the sample that had contact information that was less than or equal to 1 year old ranged from 15.2% to 94.8%, 2 to 3 years old ranged from 0.5% to 23.5%, 4 to 10 years old ranged from 1.0% to 38.6%, older than 10 years ranged from 0.0% to 33.3%, and missing ranged from 0.8% to 23.0%. Within groups, the contact rate was 73.8% among persons whose contact information was less than or equal to 1 year old, 53.5% among persons whose contact information was 2 to 3 years old, 39.8% among those with contact information that was 4 to 10 years old, 33.5% among those with contact information older than 10 years, and 35.3% among those with missing contact information in the local HIV surveillance system. Persons with missing local HIV surveillance system contact information were sometimes able to be contacted using other sources of contact information, such as health department databases or people search engines. Again, there was substantial variation among project areas; contact rates ranged from 61.7% to 84.6% among those with contact information equal to or less than 1 year old, from 0.0% to 76.2% among those with contact information that was 2 to 3 years old, from 0.0% to 77.3% among those with contact information that was 4 to 10 years old, from 0.0% to 77.3% among those with contact information older than 10 years, and from 0.0% to 79.1% among those with missing contact information.

Discussion

In the 2016 data collection cycle, MMP staff were able to contact nearly two-thirds of persons with diagnosed HIV sampled from NHSS, ranging from one-half to three-quarters of the sample contacted across project areas. We also saw improvements in contact rates between the first and second cycles of data collection for the vast majority of project areas. However, because project areas were able to apply to the 2016 data collection cycle lessons learned in the pilot project that informed MMP methods[10] and the first cycle of implementation, we may not see the same rates of improvement across future cycles.

A relatively small proportion of persons sampled for MMP were found to be ineligible (6.1%), although this proportion ranged from 3.5–15.0% across project areas. The most common reason for ineligibility was that the person was deceased, which highlights the

importance of ensuring death ascertainment activities are up-to-date before pursuing D2C work in order to minimize the use of program resources to find persons who do not need outreach. However, identifying persons with incorrect information in the HIV surveillance system can be a way to identify gaps in reporting, reporting errors, or incomplete death ascertainment activities, which can then be addressed to improve the accuracy of the surveillance system.[4]

Approximately one-third of persons sampled (n=3,348) were not contacted and, of these, the majority (n=1,711) were not able to be located using information in the HIV surveillance system and other databases, which indicates the importance of efforts to improve the quality and completeness of contact information in the HIV surveillance system and doing routine linkage with other databases to update contact information. However, a substantial portion of persons who were not located did not respond to MMP staff's outreach attempts, perhaps reflecting a lack of interest in or suspicion about the legitimacy of the project. MMP staff send introductory letters on health department stationary in order to assure the person of the veracity of the project. MMP staff vary the mode and timing of contact attempts in order to increase the likelihood of reaching sampled persons.

Examining contact rates among persons with a laboratory test older than 1 year indicates that a little over a third were successfully contacted, and this ranged substantially among project areas. A relatively small proportion of persons did not have a recent laboratory test, and contact was less likely with increasing age of laboratory test results. However, many MMP project areas were able to successfully contact persons with older laboratory tests, which may reflect the intensity of MMP recruitment efforts. Contact may also have been affected by the completeness of laboratory test reporting in the jurisdiction. The timing of implementation of complete laboratory reporting has varied by jurisdiction, and not all jurisdictions have complete laboratory reporting.[11] Although the likelihood of contact decreases with increasing age of laboratory test results, for some areas limiting D2C outreach among persons with older laboratory tests (e.g., greater than 4 years old or greater than 10 years old) could omit a sizable portion of persons living with HIV in the jurisdiction. However, the resources needed to reach these persons and the generally low response that can be expected may be important factors to consider for D2C planning.

As was the case for age of laboratory test results, the age of contact information available for the person in the HIV surveillance system was associated with likelihood of successful contact, with persons with more recent contact information being more likely to be contacted. Some project areas had a substantial proportion of sampled persons with older contact information and many project areas were able to successfully contact persons with older or missing contact information. Variation in the ability to contact persons with older or missing contact information may reflect differences across project areas in the updating of contact information in their HIV surveillance system; other projects have found that the quality of contact information in the surveillance system affects the likelihood of successful contact.[4,6,10] Additionally, older contact information may reflect stable residence for some persons, as the age of contact information often reflects the earliest date that person was known to be residing at the address.

The use of MMP to inform D2C processes has some limitations. First, missing or older laboratory tests in NHSS could reflect lack of receipt of HIV care or incomplete laboratory reporting; thus success in contacting persons with older or missing laboratory tests may not necessarily equate with success in finding out-of-care persons. Other multi-state studies have found that many persons identified by HIV surveillance as being out of care were not truly out of care due to death, migration, or incomplete laboratory reporting.[6] Second, MMP contact materials sent to sampled persons described the project as a health survey for which a monetary token of appreciation is offered; because outreach for D2C differs from these methods, responses to D2C outreach may differ, although it is difficult to say for certain whether response would be higher or lower. Third, because MMP collects data on an annual basis, the sampling does not allow for reporting delays. For D2C activities, some reporting delay could be incorporated to ensure adequate time for comprehensive death ascertainment activities and laboratory reporting. Finally, MMP samples from NHSS, which de-duplicates cases across jurisdictions; local D2C programs may not have access to all information reported by other jurisdictions when identifying cases for outreach from their local HIV surveillance system.

In conclusion, MMP offers insight into how a D2C program with the same design across multiple jurisdictions might perform. Over one-third of all persons without a laboratory test in the past 12 months were contacted, with higher rates of contact among persons with more recent laboratory tests. The findings confirm that successful contact among persons sampled from NHSS depends on the quality of HIV surveillance data and local surveillance practices—in particular, death ascertainment, the completeness of laboratory reporting, and the routine updating of contact information. Standardized national “one-size-fits-all” design changes to increase contact rates would be difficult to make due to substantial variation among project areas. Examining local MMP outcome data can inform local efforts to improve contact rates, for example, by identifying areas for improvements to HIV surveillance data completeness or intensified staff efforts. D2C programs may benefit from strengthening collaboration and integration with existing MMP programs to further increase the utility of HIV surveillance data for contacting persons in need of support to access HIV medical care.

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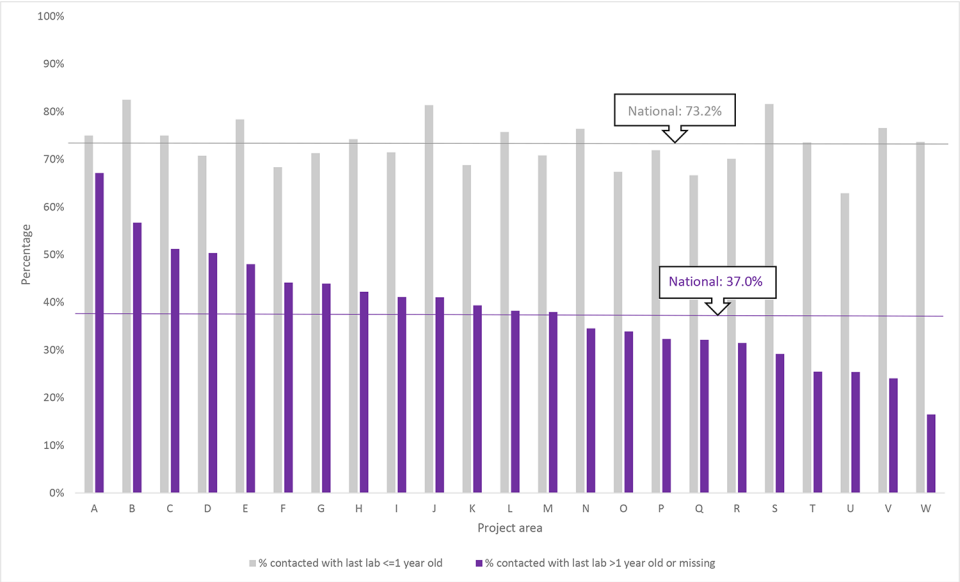

Figure 1:

Proportion of sampled persons contacted by age of last HIV-related laboratory test result, by project area—Medical Monitoring Project, 2016.

Table 1.

Sample Sizes by Project Area—Medical Monitoring Project, 2016.

Project area	Persons sampled
California (excluding Los Angeles County and San Francisco)	500
Chicago, Illinois	400
Delaware	400
Florida	800
Georgia	500
Houston, Texas	400
Illinois	200
Indiana	400
Los Angeles County, California	400
Michigan	400
Mississippi	400
New Jersey	500
New York City, New York	800
New York State (excluding New York City)	200
North Carolina	400
Oregon	400
Pennsylvania (excluding Philadelphia)	200
Philadelphia, Pennsylvania	400
Puerto Rico	400
San Francisco, California	400
Texas (excluding Houston)	400
Virginia	400
Washington	400
Total	**9,700**

Table 2.

Sampled Person Dispositions—Medical Monitoring Project, 2016.

Dispositions		Category
Accepted	Accepted - Agreed to participate	Eligible Contacted
Refused	Refused – Time	
	Refused – Privacy concerns	
	Refused – Too personal	
	Refused – MRA concerns	
	Refused – Mental health	
	Refused – Physical health	
	Refused – No reason given	
	Refused – Other	
	Refused – Facility objects to contact-CDC and site agree not to contact directly	
Other	Other – Deceased on or after sampling date	Eligible Not Contacted
	Other – Jurisdiction of residence does not allow cross-jurisdictional data collection	
	Other – Cannot locate	
	Other – Cannot locate-no local STATENO, unable to obtain name/identifying info from other jurisdiction	
	Other – Unable to give informed consent	
	Other – Incarcerated and project area has no access	
	Other – No interpreter available	
	Other – No response to contact by project area	
	Other – No contact attempt made	
	Other – Other	
Ineligible	Ineligible – Deceased prior to sampling date	Ineligible
	Ineligible – <18 years old on sampling date	
	Ineligible – No HIV diagnosis prior to sampling date	
	Ineligible – Resided outside of United States on sampling date	
	Ineligible – Resided in a non-MMP jurisdiction on sampling date	
	Ineligible – Duplicate	

Table 3.

Reasons for ineligibility and non-contact—Medical Monitoring Project, 2016.

Disposition	Detailed Disposition	N	Percent of disposition group	Project area range	Percent of total sampled
Ineligible	Deceased prior to sampling date	260	43.8%	5.9 – 73.9%	
	Resided in a non-MMP jurisdiction on sampling date	172	29.0%	6.9 – 75.0%	
	Resided outside of United States on sampling date	67	11.3%	0.0 – 52.9%	
	No HIV diagnosis prior to sampling date	65	11.0%	0.0 – 62.5%	
	Frame error *	22	3.7%	0.0 – 28.6%	
	Duplicate	5	0.8%	0.0 – 8.3%	
	<18 years old on sampling date	2	0.3%	0.0 – 4.2%	
	Total N within group	593			6.1%
Eligible not contacted	Cannot locate	1711	51.1%	10.2 – 87.1%	
	No response to contact by project area	1379	41.2%	7.1 – 81.3%	
	Incarcerated and project area has no access	111	3.3%	0.0 – 10.6%	
	Deceased on or after sampling date	109	3.3%	0.0 – 6.4%	
	No contact attempt made **	38	1.1%	0.0 – 7.1%	
	Total N within group	3348			34.5%
Eligible contacted	Total N within group	5759			59.4%
Total		**9700**			**100%**

* Sampled cases later found to be ineligible for MMP due to merged cases, duplication ineligibility, etc.;

** Includes persons for whom jurisdiction of residence does not allow MMP data collection or cases where project area was unable to obtain name/identifying info from another jurisdiction.

Table 4.

Proportion of sample and contact rate by age of last HIV-related laboratory test result and age of most recent contact information—Medical Monitoring Project, 2016.

			Years				
			<=1	**2–3**	**4–10**	**>10**	**Missing**
Age of last HIV-related laboratory test	Proportion of sample	National	72.4%	10.9%	8.5%	7.4%	0.8%
		Project area range	45.4 – 89.2%	5.8 – 21.2%	2.6 – 18.0%	2.4 – 14.6%	0.0 – 4.0%
	Contact rate within group	National	73.2%	55.4%	32.0%	18.7%	7.1%
		Project area range	62.9 – 82.5%	33.3 – 73.4%	9.5 – 62.1%	3.4 – 77.8%	0.0 – 100.0%
Age of contact information	Proportion of sample	National	66.7%	10.6%	10.4%	7.0%	5.3%
		Project area range	15.2 – 94.8%	0.5 – 23.5%	1.0 – 38.6%	0.0 – 33.3%	0.8 – 23.0%
	Contact rate within group	National	73.8%	53.5%	39.8%	33.5%	35.3%
		Project area range	61.7 – 84.6%	0.0 – 76.2%	0.0 – 77.3%	0.0 – 77.3%	0.0 – 79.1%

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