Most Accurate Data Sources for Obtaining Contact Information on Adults Diagnosed with HIV for Public Health Purposes

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Division of HIV/AIDS Prevention

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BACKGROUND

Out-of-Care Persons Are a Key Population

- Elevated risk for morbidity/mortality
- Elevated risk for transmission

Important for research, surveillance, and targeted intervention

Existing HIV Surveillance Systems Provide Limited Data on Out-of-Care

- National HIV case surveillance system
 - Mandated HIV reports on new cases and lab testing
- Medical Monitoring Project (MMP)
 - Actively collected interview and medical record data
 - Historically selected participants through HIV facilities
- Both based on contact with health system

Setting

- Case Surveillance-Based Sampling (CSBS) demonstration project
 - Pilot of a new sampling method for MMP based on all diagnosed adult HIV cases
 - Includes people receiving and not receiving HIV care
 - Intended to fill knowledge gaps on out-of-care population
- Poster: Inclusion of HIV-Diagnosed Persons Not Receiving HIV Care in the Medical Monitoring Project

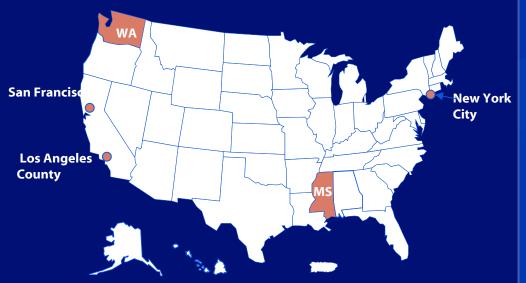
Importance of Current Analysis

- Use of surveillance data to identify and contact out-of-care persons increasingly common
- New methods needed to generate leads for location
- Systematic comparison of data sources not yet performed



CSBS Basics

- All living HIV-diagnosed
 adults eligible
- 5 project areas
- Attempted to use multiple data sources



Interview and medical record abstraction

Process Data

- Collected by interviewers
- Included:
 - Data sources used
 - Accurate data sources, i.e. information that led to the correct contact information

Data Analysis

- Data used from first 2 project years (11/2012-6/2014)
- Data from one project area excluded due to data anomalies currently under investigation
- Organization of results
 - Accuracy of case surveillance
 - Accuracy of additional data sources



Dataset Overview

- Complete recruitment data for 1793 persons
- Accurate contact information was obtained for 1172 (65%) of sampled persons

Accuracy of Specific Types of Case Surveillance Information Among Located Persons 2012-2013*

		Project Area				
		PA1 (N=198)	PA2 (N=369)	PA3 (N=248)	PA4 (N=357)	Total (N=1172)
Any Personal Info		98 (50%)	223 (60%)	54 (22%)	147 (41%)	522 (45%)
	Address	42 (21%)	223 (60%)	50 (20%)	143 (40%)	458 (39%)
	Phone	99 (50%)	9 (2%)	7 (3%)	135 (38%)	250 (21%)
Facility		141 (71%)	304 (82%)	155 (63%)	286 (80%)	886 (76%)

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23 Additional Data Source Types

- Public health: STD, partner services
- Clinical: HIV care facility, Ryan White
- Internet: People search engines, Google
- Non-internet: Department of Motor Vehicles

Data Sources Most Commonly Consulted for Contact Information—2012-2013 (N=1793)

Data Source Used	% of Sampled Persons for Whom Source Used
HIV Care Facility	62
STD or Partner Services	58
People search engine, e.g. Lexis-Nexis ¹	46
Ryan White Administrative Database	31
Prison or Jail	28
Internet Search, e.g. Google ²	28
Supplementary HIV laboratory surveillance database	26
Social Services Databases	20
Integrated disease surveillance system	18
ADAP List ³	4

1. Includes: Lexis-Nexis, Spokeo, and MetroSearch

- 2. Includes: Google, WhitePages, and 411
- 3. AIDS Drug Assistance Program (ADAP)

Most Commonly Consulted Data Sources Vary by Site—2012-2013*

	PA1	PA2	PA3	PA4
	Auxiliary HIV Database, 90%	Prison/Jail, 97%	HIV care facility, 81%	HIV care facility, 55%
	Ryan White Database, 83%	People search, 92%	People search, 43%	Auxiliary HIV Database, 26%
	STD/Partner Services, 71%	Public Services Data, 90%	STD/Partner Services, 43%	STD/Partner Services, 25%
	HIV care facility, 50%	STD/Partner Services, 91%	Ryan White Database, 29%	People search, 24%
	People search, 18%	Internet, 87%		Ryan White Database, 22%
		Social Services Databases,72%		ADAP, 11%
		HIV care facility, 64%		Internet, 10%
*0~	databases consulted for $\geq 10\%$	Integrated disease surveillance system, 63%		

Data Sources Providing Accurate Contact Information Among Located Persons—2012-2013 (N=1172)

Database Used	Provided Accurate Information, %
HIV Care Facility	54
Integrated disease surveillance system	19
People search engine, e.g. Lexis-Nexis ¹	15
Ryan White Administrative Database	11
Social Services Databases	8
STD or Partner Services	8
Supplementary HIV laboratory surveillance database	7
Internet Search, e.g. Google ²	4
ADAP List	2
Prison or jails	1

1. Includes: Lexis-Nexis, Spokeo, and MetroSearch

3. AIDS Drug Assistance Program (ADAP)

2. Includes: Google, WhitePages, and 411

Data Sources Most Commonly Providing Accurate Contact Information Among Located Persons by Site—2012-2013*

PA1	PA2	PA3	PA4
HIV care facility, 66%	Integrated disease surveillance system, 59%	HIV care facility, 71%	HIV care facility, 50%
Ryan White Database, 51%	HIV care facility, 39%	People search, 12%	People search, 13%
Auxiliary HIV Database, 41%	Social Services Databases, 27%		
STD/Partner Services, 22%	People search, 23%		
	Internet, 10%		

*Only databases providing accurate information for \geq 10% of persons investigated are included.

Adjusted Response Rate by Project Area—2013

	Interviews Completed (%)
PA1	93 (48.0)
PA2	131 (44.5)
PA3	84 (42.7)
PA4	146 (49.4)
Total	454 (46.1)

DISCUSSION

Limitations

- Data sources only queried until sampled person found
- High performing health departments with complete or near complete lab reporting

Conclusions

- Multiple data sources helpful
 - Most helpful data sources varied from project area to project area
- HIV care facilities and HIV surveillance most accurate
- Routine collection and importation of contact information into case surveillance databases helpful
- Developing new or expanded access to data sources such as electronic medical records or social services databases likely to improve success



For more information please contact Centers for Disease Control and Prevention

1600 Clifton Road NE, Atlanta, GA 30333 Telephone: 1-800-CDC-INFO (232-4636)/TTY: 1-888-232-6348 Visit: www.cdc.gov | Contact CDC at: 1-800-CDC-INFO or www.cdc.gov/info

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.



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