Exchanging Data between an Established HIV Registry and a New Hepatitis C Registry to Enhance Data Quality and Completeness — Arkansas, 2013

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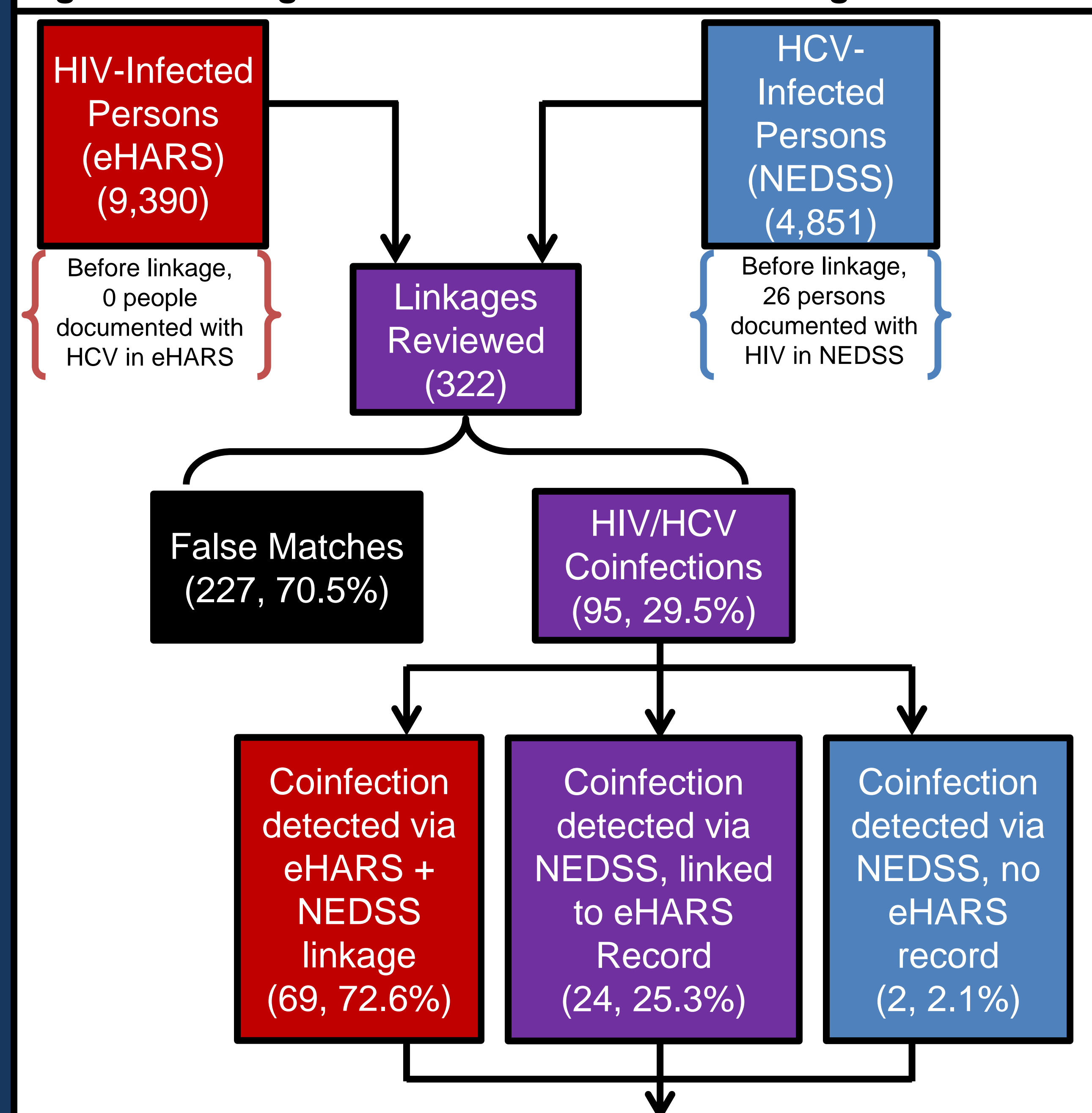## Arkansas Department of Health (ADH)

Background

- Human Immunodeficiency Virus (HIV) is a sexually transmitted or bloodborne virus that causes immune suppression, potentially leading to Acquired Immune Deficiency Syndrome (AIDS)

- Hepatitis C virus (HCV) infection is the most common bloodborne viral infection in the United States and can lead to cirrhosis, hepatocellular carcinoma, and the need for liver transplant

- HIV/HCV coinfection is estimated to occur in approximately 25% of persons with HIV and among 50% - 90% of injection drug users infected with HIV in the United States[1]

- Persons living with HIV infection are recommended to be screened for HCV by the Centers for Disease Control and Prevention (CDC)[1]

- Persons living with HIV and HCV are at risk for a faster progression to life-threatening liver damage than persons with HCV alone[1]

- The Enhanced HIV/AIDS Reporting System (eHARS) is used nationally to capture information on persons infected with HIV

- In January 2013, ADH began using the National Electronic Disease Surveillance System (NEDSS) for acute and chronic HCV surveillance

- Link Plus software is a probabilistic matching tool created by the CDC's National Program of Cancer Registries to match individuals in registries by assigning scores to indicate the probability of a true match

Methods

- Resource limitations for HCV follow-up necessitate a targeted surveillance strategy to the persons below, who were recorded in NEDSS beginning in 2013:
  1. Aged <30 years
  2. Incarcerated in a state or federal correctional facility
  3. In 2014, persons born 1945–1965 received via electronic lab reporting
  4. Reported on a document along with the persons listed above

- All individuals with HIV infection in Arkansas were recorded in eHARS

- Individuals in NEDSS were matched to individuals in eHARS by first name, last name, and date of birth using Link Plus software, which generates a score from 0 to ∞ indicating the strength of the match (higher score indicates a better match). The following strategies were used:
  1. Pairs scoring ≥14 were accepted
  2. Pairs scoring <14 and ≥10 were reviewed manually and accepted if at least one of the following criteria matched: address, race, sex, or middle name, and the match could not be disproven via information obtained by internet search of the person's name
  3. Pairs scoring <10 and ≥2 were reviewed as above if one of the following criteria was met: same first letter of first name, same first two letters of last name, same month, day, or year of birth, or same month or day of birth if month and day were switched in one registry

- Demographic and risk factor information were examined using SAS 9.3 (SAS Institute, Cary, NC)

Results

Figure 1. Linkage of Arkansas' HIV and HCV Registries

HIV-Infected Persons (eHARS) (9,390) — Before linkage, 0 people documented with HCV in eHARS

HCV-Infected Persons (NEDSS) (4,851) — Before linkage, 26 persons documented with HIV in NEDSS

Linkages Reviewed (322)

False Matches (227, 70.5%)

HIV/HCV Coinfections (95, 29.5%)

Coinfection detected via eHARS + NEDSS linkage (69, 72.6%)

Coinfection detected via NEDSS, linked to eHARS Record (24, 25.3%)

Coinfection detected via NEDSS, no eHARS record (2, 2.1%)

- There were 6,025 persons living in Arkansas with HIV-infection as of May 1, 2014
- If HCV prevalence among HIV-infected persons is approximately 25%, an estimated 1,506 individuals are living with HIV/HCV coinfection in Arkansas
- Matching detected 6.3% (95) of the expected 1,506 individuals

- An eHARS file of 9,390 persons with HIV-infection who had ever lived in Arkansas was linked to a file of 4,851 persons who were documented to have HCV-infection

- In total, 322 linkages were identified (Figure 1)
  1. Of 81 linkages with a score >14, 81 (100%) were accepted
  2. Among 34 linkages with a score of 10-14, 12 (35.3%) were accepted
  3. Among 205 linkages with a score <10, 0 (0%) were accepted
  4. Two persons did not link to an eHARS record but were documented with HIV-infection in NEDSS

- In total, 26 (27.4%) persons were identified with HIV/HCV coinfection via case follow up procedures for HCV; 2 did not match to an eHARS record

- The identification of 69 (72.6%) HIV/HCV coinfected individuals was attributable to the linkage of the HIV and HCV registries

- The majority of HIV/HCV coinfected persons were male, diagnosed with HIV-infection in the years 2000 – 2009 at age 30 – 49 years, and currently aged ≥50 years (Table 1)

- Coinfected cases were primarily white race; one-third were black, in contrast to the population of Arkansas, of which blacks comprise approximately 11%

- Approximately half of cases had been diagnosed with AIDS during or before 2013

- The most common risk factor was injection drug use (IDU); while 40 cases (42.1%) had a history of IDU documented in eHARS, only 6 (6.3%) had the same risk factor documented in NEDSS

Table 1. Characteristics of HIV and HCV Coinfected Arkansans

Characteristic	Number	%	Characteristic	Number	%
Total	95	100.0	**Total**	95	100.0
Sex			**Year of HIV Diagnosis**		
Female	27	28.4	1980 – 1989	9	9.5
Male	68	71.6	1990 – 1999	26	27.4
Current Age (as of January 1, 2014)*			2000 – 2009	39	41.1
20 – 24	2	2.1	2010 – 2014	19	20.0
25 – 29	10	10.6	Unknown	2	2.1
30 – 34	6	6.4	**Age at HIV Diagnosis (Years)**		
35 – 39	5	5.3	<30	32	33.7
40 – 44	15	16.0	30 – 49	52	54.7
45 – 49	16	17.0	≥50	9	9.5
50 – 54	20	21.3	Unknown	2	2.1
≥55	20	21.3	**HIV Risk Factor (Documented in eHARS)**		
Race			Male who has Sex with Men (MSM)	28	29.5
White	52	54.7	Injection Drug Use (IDU)	29	30.5
Black	32	33.7	MSM/IDU	11	11.6
Other or Unknown	11	11.6	Heterosexual	15	15.8
HIV or AIDS Status			Unknown	12	12.6
AIDS	51	53.7	**History of Injection Drug Use (Documented in NEDSS)**		
HIV (Non-AIDS)	42	44.2	Yes	6	6.3
Unknown	2	2.1	No or Unknown	89	93.7

*Current age not applicable for 1 person who died during 2013.

Conclusions

- Use of alternate data sources to enhance information available on persons with HCV is important given resource limitations that challenge thorough investigation of each HCV case

- A total of 95 HIV/HCV coinfected cases were identified and registry linkage was mutually beneficial to enhancing data quality and completeness of both registries, in particular with risk factor information

- Registry linkage using an HCV registry established approximately 1 year earlier captured 95 of an estimated 1,506 individuals living in Arkansas with both HIV and HCV

- Results were used to enhance completeness of information on HCV-infected Arkansans by updating risk factor and demographic information in NEDSS and to identify HIV-infected Arkansans who were potentially undocumented in eHARS

- HIV and HCV registry matching will be completed annually to continue the exchange of demographic and risk factor information

Limitations

- All HCV-infected persons in Arkansas are not documented in NEDSS, therefore, registry matching does not adequately characterize the prevalence of HIV-HCV coinfection in Arkansas

- Although eHARS serves as the primary registry and source of data to estimate the number of Arkansans with HIV-infection, it likely underestimates the true burden of HIV due to underreporting by physicians, laboratories, and other sources

References

[1]Centers for Disease Control and Prevention (2013). HIV and Viral Hepatitis. Accessed from http://www.cdc.gov/hepatitis/Populations/PDFs/HIVandHep-FactSheet.pdf.

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