15767 - Characteristics of HIV Cases in North Carolina's CAREWare who are Not Known to Statewide HIV Surveillance

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BACKGROUND

Case-based surveillance of HIV infection is a public health activity that enables health authorities to better understand the course of HIV disease in jurisdictions within the United States.

In North Carolina, case-based HIV surveillance relies on direct provider reporting of HIV diagnosis among residents and laboratory reporting of diagnostic screening tests, HIV RNA (viral load) tests, and CD4 tests, which have been mandated since 2013. Compilation of these reports enable health departments to register new cases, perform case investigations, and compute health indicators for this population, including, the most notable of which is the HIV care continuum.

North Carolina integrated HIV surveillance and program data beginning in 2016 with a system called the North Carolina Engagement in Care Database for HIV Outreach (NC ECHO). The system incorporates data from HIV surveillance, Ryan White part B services, and Medicaid HIV-related claims to better track care and identify systematic gaps in HIV data collection.

The system has been receiving HIV care data for 52 months.

PURPOSE

We sought to understand people living with HIV (PLWH) who did not match to routinely-linked HIV data. Further, we wanted to understand whether non-linkage to HIV surveillance data could be explained gaps in data quality.

Finally, we sought to understand if truly unreported HIV could be understood within the context of data already captured in CAREWare (jProg Inc.).

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METHODS

We used a query to identify people in NC ECHO linked HIV surveillance and care data to identify Ryan White clients with lab-based a marker of HIV care who were not linked to a North Carolina HIV surveillance state case number. Each non-matching record is represented by a Ryan White Unique Record Number (URN), a string of letters and numbers that serve as a semi-deterministic identifier based upon elements of first and last name, date of birth, and gender.

We investigated each non-matching URN manually. We performed a thorough manual search of the database for a potential match to state case based upon similarity of first name, last name, date of birth and social security number, as available in CAREWare and HIV surveillance case records.

The outcome of unmatched CAREWare URN records reviewed was categorized into 4 outcomes:
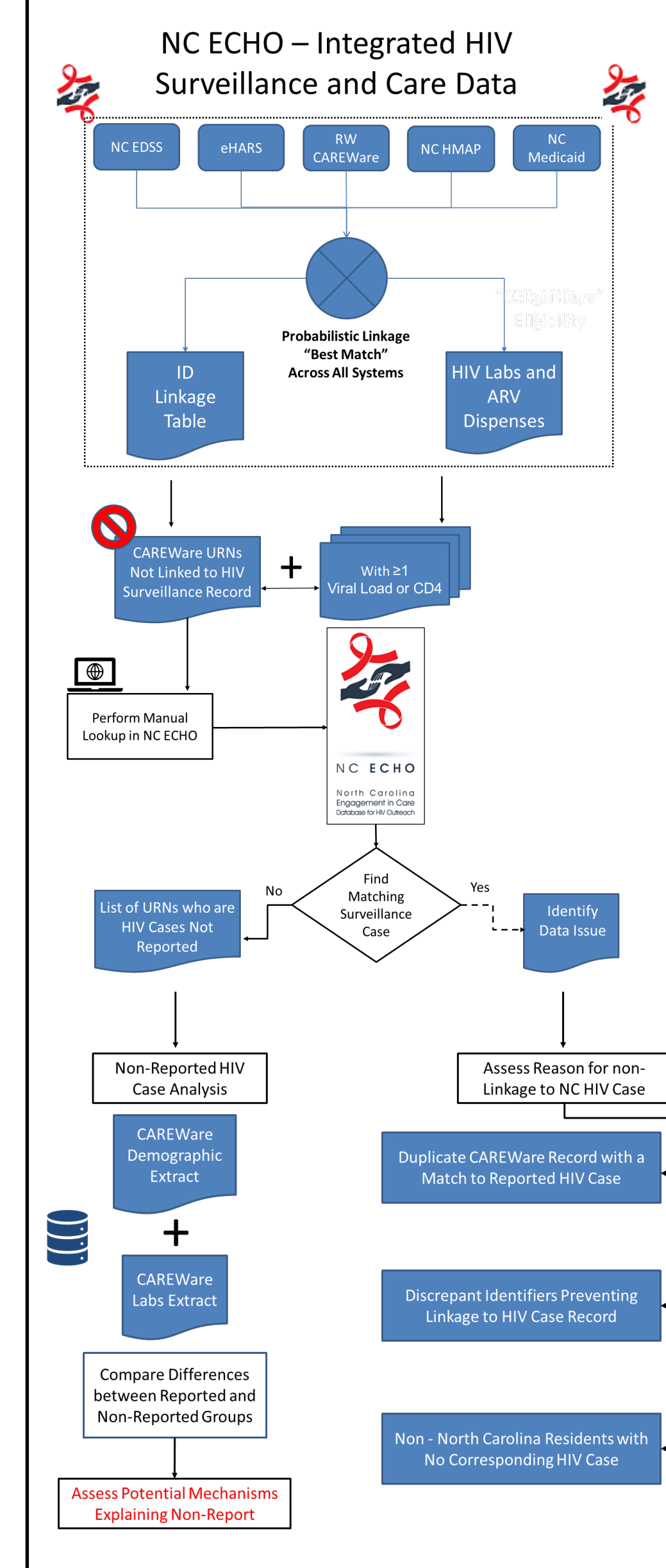• a match between a surveillance case record to a different, **duplicate URN** for the individual,
• identification of matching CAREWare and surveillance case records that did not occur due to **discrepancies in identifiers** preventing their linkage;
• CAREWare URN records of non-North Carolina residents that are **ineligible for case reporting**, and
• all other remaining records that require further review as **likely unreported HIV cases**.

To understand service history between non-reported HIV cases and URNs linked to HIV cases, we identified frequently utilized service categories (Table 1).

To better understand client-specific factors differentiating groups of non-reported HIV cases from URNs linked to HIV cases, we and are presenting results based on recorded telephone area code among those with valid 10 digit phone numbers (Table 2).

To understand patterns of viral suppression among unreported HIV cases, we examined year of last viral load test and suppression status, including the category of "undetectable" at common lower limits of detection for HIV RNA assays (Table 3).

RESULTS

Table 1. Service Distribution of Reported and Unreported HIV Cases

Frequently Utilized Ryan White Services among Reported HIV Cases

Service Category	Clients	Service Days*, Median	IQR
Outpatient/Ambulatory Health Services	26,315	17	32
Medical Case Management	25,138	5	14
Non-Medical Case Management	14,728	6	18
Referral: Health Care/Supportive	14,594	3	7
Health Ed./Risk Reduction/Prevention	13,159	1	3

Frequently Utilized Ryan White Services among Unreported HIV Cases

Service Category	Clients	Service Days*, Median	IQR
Outpatient/Ambulatory Health Services	487	6	12
Non-Medical Case Management	309	10	23
Medical Case Management	272	6	10
Referral: Health Care/Supportive	165	3	4
Medical Transportation Services	135	2	7

* Unique Days with One or More Services

Table 2. North Carolina Area Codes among Ryan White Clients in CAREWare*

	Unreported	Reported	Total	
Out of Area	112	4775	4887	Risk Ratio (95% CI)
NC Area	261	25904	26165	2.3 (1.9 - 2.9)
Total	373	30679	31052	

*Among client URNs with non-missing phone number
North Carolina Area Codes: 252, 336, 704, 743, 828, 910, 919, 980, 984

Table 3. Viral Suppression Status of CAREWare Clients Not Detected by HIV Surveillance, by Year of Last HIV RNA Test

	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	Total
Undetectable	1	7	10	9	22	8	5	8	2	5	2	15	18	28	20	28	15	88	291
Suppressed	0	0	4	3	8	14	13	13	7	3	7	0	0	0	0	1	3	4	80
Not Suppressed	1	14	32	40	55	37	9	6	4	2	0	1	2	0	2	1	1	2	209
Total	2	21	46	52	85	59	27	27	13	10	9	16	20	28	22	30	19	94	580

SCHEMATIC

NC ECHO – Integrated HIV Surveillance and Care Data

CONCLUSIONS

This work shows that people not known to HIV surveillance were likely to be undetectable during their period of Ryan White funded care in North Carolina, particularly in recent years.

Unreported HIV cases utilize services consistent with re-establishment of care. Their higher proportion of phone numbers with area codes outside of North Carolina indicate prior history in another geographic area.

Unreported cases have been referred to the HIV Surveillance program for case investigation.

Sensitivity of Lab Reports in Generating Case Investigations: PLWH new to a jurisdiction with persistently undetectable viral load results may be continually classified as "**not a case**" based upon lack of an affirmative diagnostic signal of HIV in lab report data.

Biases from Underreporting HIV Care Outcomes: PLWH who transfer residence from one state to another while undetectable may "fly under the disease surveillance radar" until receipt of a diagnostic signal. This will leave the previous state of residence with a gap in their HIV surveillance care continuum data. This will impact each state's continuum until inter-jurisdictional notification occurs.

CAREWare Data Quality: Person records in CAREWare are prone to duplication. Some level of duplication can be attributed to historic system policies, EMR integrations settings, identity and data management practices over time.

Work on the scope and estimated impact of URN duplication on service volume was presented in previous work at the 2018 Ryan White Conference.