



CHAIR'S CHALLENGE

UNITE TO END THE EPIDEMICS 2017-2018

Electronic Re-engagement: North Carolina's Engagement in Care Database for HIV Outreach (NC ECHO)

TARGET POPULATION: People Living with HIV (PLWH) who are out-of-care

LOCATION: North Carolina

PROGRAM DESIGN: Construction of an integrated HIV care information system to identify out-of-care clients, with probabilistic record linkage, query, and reporting capabilities

ESTIMATED COST: \$580,000 for development including information technology (IT) project manager for two years with on-going annual maintenance of approximately \$86,000

FUNDING SOURCE: HRSA Special Projects of National Significance (SPNS) award, ongoing maintenance with Ryan White HIV/AIDS Program (RWHAP) Part B program funds

SUMMARY

NC ECHO is a database that collects standardized data on people living with HIV (PLWH) from five NC DHHS data sources. The database generates an out-of-care list each month and assigns names to state and regional bridge counselors for follow up. Since its inception, NC ECHO has assigned 1,908 individuals to state and/or regional bridge counselors.

CORE ACTIVITIES

Since 2008, North Carolina has developed and refined a system of re-engagement for PLWH using state and regional bridge counselors. Several sources of HIV data have been periodically integrated for ad hoc analysis, including the patient-based surveillance system, North Carolina Electronic Disease Surveillance System (NCEDSS), which integrated all reportable conditions in 2012. However, with an increasing emphasis on the HIV Continuum of Care model and Data to Care (D2C) initiatives, North Carolina utilized a SPNS award to

integrate data from several programs' databases, developing a consolidated database that links client records, pools client HIV care markers, and identifies clients in need of re-engagement. The goal was to create a tool that could identify, in near real time, PLWH who were out-of-care based on specific markers and laboratory reports, and seek to re-engage them in care as quickly as possible using protocols developed for the clinical, regional, and state level.

NC ECHO was developed as a database that operates by receiving standardized data on PLWH from five NC DHHS data sources: NCEDSS (disease surveillance and electronic laboratory reporting), eHARS (HIV registry), CAREWare (including Ryan White Parts B, C, D), ADAP, and Medicaid.

The database is uniquely equipped to generate and save lists of clients who match out-of-care criteria based upon address, vital status (e.g., living) and time since most recent care engagement. Upon successful re-engagement/investigation, clients are removed from the list. The database performs regularly scheduled data imports, probabilistic record linkage based upon the similarity of key identifiers across disparate data systems, and determines eligibility for client outreach based upon residency and vital status information. The web-based application allows for a comprehensive, unified client lookup, returning client information from each data system, as well as a summary of HIV care services (i.e. lab tests, antiretroviral dispenses) and accompanying dates.

NC ECHO generates an out-of-care list each month, sorts the list to eliminate people who are unlikely to be found (e.g., those that have been lost to care for more than two years), and assigns names to state and regional bridge counselors for follow up. These linkage experts will then call, visit the last known addresses of, and use other investigative techniques often employed by disease intervention specialists (DIS) to locate and re-engage people in care.

In addition, NC ECHO's data integration platform enables the state's HIV programs to perform systematic validation of data quality, including identifying duplicative client records, data entry errors, and gaps in electronic laboratory reporting. Programs can utilize this information to improve data quality or alter business processes.

NC ECHO serves as a robust resource for providing HIV quality measurements that have significantly impacted the ability to locate and re-engage clients in the nine months since its inception, and contributed enormously to related data challenges along the HIV Care Continuum.

DATA

NC ECHO was inaugurated in September 2016 with the following results:

- Approximately 9,300 clients have been identified as out-of-care to date
- Over 3,500 client records have been manually linked after manual review
- The out-of-care list has been sorted to eliminate those who have left the state, are deceased, or are deemed likely to be unable to reach due to the age of the record

Since the inception of NC ECHO, 1,908 individuals were assigned to state and/or regional bridge counselors:

- 1,150 were newly diagnosed; 76% were confirmed to be in care
- 613 were previously diagnosed; 74% were confirmed or re-engaged in care

EVALUATION

No formal evaluation of the development of NC ECHO has been undertaken. However, it is evident that NC ECHO is performing as designed, identifying out-of-care PLWH and completing the feedback loop as those individuals are located and re-engaged. As data matures and a full year of activity is achieved, there are plans to more formally evaluate the efficacy of this intervention model.

OUTCOMES

North Carolina has systematized the formation of out-of-care lists for follow-up by: establishing the roles of state and regional bridge counselors; training these individuals for linking and re-engaging individuals into HIV care; and developing lists of individuals requiring re-engagement based upon residential eligibility and timing of care data.

NC ECHO's unified client lookup and data extract capabilities enable program staff to securely view data across the five source systems. Security controls include multi-factor authentication and inactivity timers. Similarly, analysts can extract data directly from the system, including the identifier linkage table. NC ECHO's pooled lab and antiretroviral dispense history provide a more comprehensive picture of HIV care consistent with the HIV Care Continuum. This is a new resource for inquiry and systematic data validation.

FUNDING & COST

NC ECHO was conceived and funded with a SPNS award specifically targeting linkage and re-engagement efforts, known as NC SPNS-LINK. Protocols for clinics and regional and state bridge counselors were developed. Plan, Do, Study, and Act (PDSA) cycles were completed in collaboration with the University of North Carolina – Chapel Hill and Duke University. NC ECHO was designed and built as an IT project using a project manager to guide all aspects of its development. Since its launch, the NC ECHO interface is maintained with Ryan White HIV/ADS Program (RWHAP) Part B funds by the HIV Care Epidemiologist.

STRENGTHS

- Combined HIV care and surveillance program data serves to streamline development, securing deployment of out-of-care lists for re-engagement efforts
- Removing siloes from HIV care data enables comprehensive assessment of program gaps and best practices

LIMITATIONS

- When matching individual records across disparate data sources, probabilistic linkage methods yield a more comprehensive linkage over time compared to previously employed deterministic matching methods. However, as probabilistic linkage methods are only partially automated, continuous skilled manual review is required.
- Despite being the most comprehensive source of public HIV care program data for PLWH in North Carolina, the database does not contain information on HIV care paid for by private insurance

STAKEHOLDERS

North Carolina Dept. of Health and Human Services (DHHS), including the Communicable Disease Branch, Division of Public Health, AIDS Care Program, AIDS Drug Assistance Program (ADAP), Field Services Unit; HIV/STD Surveillance Unit - Surveillance Systems Unit; North Carolina Division of Medical Assistance (Medicaid); DHHS Information Technology; University of North Carolina – Chapel Hill; and Duke University.

PROGRAM CONTACT

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