

Description of the North Carolina Data to Care Initiative (use of HIV surveillance data for HIV care engagement and re-engagement activities)

The following program description was written by current and former staff at the North Carolina Division of Public Health. The description is provided as an example of how a jurisdiction is conducting Data to Care work. CDC has not been involved in the development, implementation or evaluation of this program.

This document will describe Data to Care activities in North Carolina. The North Carolina Division of Public Health has utilized HIV surveillance data to trigger disease intervention efforts for more than two decades. With the recognition that prompt entry into HIV care has immediate impact on interrupting transmission as well as improving the health of persons infected with HIV, more emphasis has been placed on identifying individuals who have either fallen out of care or who have never accessed care after their diagnosis with HIV. The document was prepared by a subcontractor to DANYA who previously held a management position in the NC DPH Communicable Disease Branch and represents activities, procedures and protocols in place as of July 1, 2014.

Background

At the end of 2006 North Carolina launched three strategies to reduce the transmission of new HIV infections and to assure that people living with HIV were either linked to care or re-engaged in care. They were: 1) increase testing, with particular emphasis on the most vulnerable and adversely affected populations; 2) when diagnosed with HIV, assure that every person is immediately scheduled for a medical appointment; 3) follow up with the provider to assure that the client attended the appointment and if not reach the client and re-schedule. Additionally, efforts are now underway to identify clients who have fallen out of care after initial appointments, and to reach out and follow up with them. The “Data to Care” initiative requires the coordination of the HIV/STD prevention, AIDS Care, AIDS Drug Assistance Program and surveillance programs and is the top priority of the Branch. The goal is to leave no patient behind.

General Description

North Carolina is considered a high morbidity state by the Centers for Disease Control and Prevention (CDC), ranking 8th in estimated number of HIV infection diagnoses (regardless of stage) in the most recently published national HIV Surveillance Report (citation) but ranked 12th with respect to annual rate for 2011.

For the purposes of this description, the NC Data to Care Initiative is considered to be a mixed model. There are routine health department-client contacts that are in place as well as provider-

client contacts for those clients who have had a previous engagement with a provider agency. The initial linkage attempt is primarily performed by health department staff, usually the Disease Intervention Specialist (DIS) in the Field Services Unit (FSU) when a newly identified patient is interviewed. The immediate notification of DIS upon the report of a newly identified HIV-positive individual has been routine for the HIV Surveillance program for more than 20 years in NC. Relinkage activities may be conducted by either State Bridge Counselors (who are part of the FSU) or provider staff trained as Regional Bridge Counselors, who part of the Ryan White funded regional networks of care across the state. In the health department, all of the current State Bridge Counselors (SBC) are former DIS who have additional training in re-engagement techniques. The Regional Bridge Counselors in the provider offices that are active in relinkage have a variety of backgrounds but have also been provided the training to emphasize re-engagement. These Regional Bridge Counselors are part of every regional network of care, which encompass the entire state. The primary responsibility of Bridge Counselors is to identify and locate clients who have fallen out of care, as determined by a lack of clinical visits, laboratory monitoring of CD4/viral loads or regularly filled prescriptions for antiretrovirals. State Bridge Counselors are also responsible for confirming that clients attended their first appointments, rather than relying on self-report; SBCs will also schedule additional appointments as needed. In order to provide assistance to the Bridge Counselors and other staff who are tasked with bringing clients back into care, the HIV Surveillance program, Ryan White CAREWare and ADAP programs collaborate to produce an “out of care” list based on matching the laboratory reports for CD4 and/or viral load results reported to the HIV surveillance program, the CAREWare database or the ADAP database. A more in-depth description of this process is described in the NC Data to Care Initiative section below.

Overview of HIV Surveillance Activities

The activities related to all communicable disease surveillance, prevention and care are completely integrated and housed in a single administrative component of the NC Division of Public Health, the Communicable Disease Branch (CDB). This administrative as well as procedural integration is the key to the successful implementation of data linkage across program areas in the agency. Complications from issues such as data sharing agreements or MOUs to enable information to be readily shared and utilized are therefore not an issue in this jurisdiction. The administrative oversight for all programs involved in the care linkage/re-engagement activities (Data to Care Initiative) ensures effective collaboration among all of the programs.

In addition to the normal core HIV case-based surveillance activities, North Carolina participates in the HIV Incidence Surveillance program, and was approved for funding for supplemental Geocoding and Data Linkage activities under the current NHSS funding opportunity. NC has also been a participant in the Medical Monitoring Program since the inception of that project. Surveillance for all communicable diseases was formerly supported by a single unit. A new unit, Systems Surveillance, was recently created to provide more direct informatics support for the syndromic surveillance system, the activities related to monitoring receipt of HIV care and the

NC Electronic Disease Surveillance System (NC EDSS). This redirection of effort should improve the efficiency related to HIV (and other STD) surveillance activities that support the use of surveillance data to identify clients who either have never been in care or who have fallen out of HIV medical care. North Carolina has initiated HIV partner services from a surveillance report since HIV infection was made a reportable communicable disease in 1990. A routine part of the partner services interview with a newly diagnosed patient has always been the attempt to refer the patient to available medical services immediately. When a client is encountered who has not been receiving regular care for HIV, the DIS attempts to link the client back to HIV care.

N.C. Data to Care Initiative

Background: There are multiple Data to Care activities supported by several of our federal partners (the Centers for Disease Control and Prevention (CDC), Health Resources and Services Administration (HRSA), the Office of Minority Health, Substance Abuse and Mental Health Services Administration (SAMHSA) and others) that are all centered on the evaluation of care delivery for persons living with HIV/AIDS and efforts to ensure that those who are not in care get in care. These are very broad activities and include (1) identifying how many people we know of living with HIV/AIDS who are receiving care; (2) determining when a person who had been receiving care drops out of care; (3) devising strategies to locate people not in care and to link or re-engage them with the healthcare system and a mechanism to monitor the outcome. The Communicable Disease Branch in the Epidemiology Section is uniquely positioned to monitor and report on all of these activities since the Branch houses the HIV Surveillance program, the Ryan White CARE program and the AIDS Drug Assistance Program (ADAP). The Communicable Disease Branch's Surveillance Units provide routine analysis for the Branch using databases created for each of the three programs.

Data Sources: The Branch has access to four separate data systems that contain both clinical and service delivery data elements for persons living with HIV. The major sources are our disease surveillance systems – the NC Electronic Disease Surveillance System (NC EDSS), and the HIV/AIDS Reporting System (eHARS). NC EDSS, a SQL Server based system, is the primary database housing HIV surveillance data, and data extracted from NC EDSS populate eHARS. NC EDSS is a highly customized commercial system marketed by Consilience Software, housed on the NC Public Health Information Network. The eHARS software is a CDC-supplied product used to manage HIV surveillance data that all HIV surveillance jurisdictions use. We are able to build extracts from both NC EDSS and eHARS as either comma delimited or Excel files, with the additional option in NC EDSS to create XML output.

Data are also extracted from our CAREWare data system that contains both clinical and service delivery data for persons who receive Ryan White services. In general, the persons with records in CAREWare represent a subset of all persons identified with HIV in the eHARS and NC EDSS systems. The final two data systems are our AIDS Drug Assistance Program (ADAP) that provides both medication services information and viral suppression for ADAP users and

anticipation of the NC Medicaid data that should be available after that Division completes its transition to a new billing and coding system.

All of the data sources described above provide full identification information for the patient (name, DOB, address, provider name and address). The data elements identified are available to the state Bridge Counselors, the Field Services DIS serving the geographic region in which the patient resides, and the state surveillance office.

Definition for “out of care”: NC has elected to use a definition for “out of care” (also known as “not in care”) that identifies patients who are known to be HIV positive and who have had no routine HIV monitoring laboratory tests reported (CD4 or viral load) or no evidence of a clinical visit to a provider in the previous **9 months**. Stated another way, if a patient has no routine monitoring lab results reported or an appointment with a provider within 9 months, NC considers that patient to be out of care. We include both newly diagnosed as well as prevalent patients in the group for which we seek information about laboratory and clinical visits.

Prioritization for follow-up for care linkage and re-engagement

There are four groupings of patients for whom care engagement (or re-engagement) is in place at this time. In some instances the patient is newly diagnosed and known to the Branch but the need for immediate referral for treatment is necessary to provide immediate medical intervention to interrupt disease transmission. The fourth category represents those patients who have a greater likelihood of being found and contacted by the Bridge Counselors.

- Pregnant women (especially if the woman has an earlier HIV diagnosis).
- Patients diagnosed with acute HIV infection.
- An ADAP client who has not filled a prescription for antiretrovirals.
- Patients who have been out of care for 2 years or less.

NC EDSS is a primary source of information since it has data elements to indicate if a patient is pregnant as part of a disease event report. The data fields associated with pregnancy information include provider and expected delivery data that enable follow-up after delivery to be scheduled. There are also similar data elements to identify a patient who may have acute HIV infection either based on laboratory test results (e.g. presence of HIV-1 RNA but no HIV-1 antibody response) or clinical suspicion of acute HIV pending laboratory follow-up that can be used to identify priority patients. The majority of the acute cases managed are identified by NC State Laboratory of Public Health testing and the database flags are set automatically via an electronic laboratory report.

ADAP prescription monitoring is performed monthly by staff in the ADAP office. A client who has regularly filled a prescription for antiretrovirals who does not pick up a dispensed prescription is contacted by a Program Consultant to determine why the prescription was not picked up. The NC ADAP uses a pharmacy network to provide medications and the network

reports utilization on a monthly basis back to the program. If the ADAP consultant is not successful contacting the patient, the clinic where the patient was last seen and the appropriate Bridge Counselor are contacted and take over the attempts to locate the patient and identify the reason for missing their medication pickup. Note that the timeframe for ADAP follow-up for missed medication pickup is much shorter than the previously described “out of care” timeframe of 9 months.

Identification of prevalent patients who have had no indication of HIV care within the 9 month “out of care” definition is currently a multistep process that includes matching patients across the eHARS, and CAREWare databases (with Medicaid to be added later). NC EDSS is not used in the crossmatching because the fields utilized are regularly extracted from NC EDSS and uploaded to eHARS. Once in eHARS, data manipulation is simpler using existing data management tools and algorithms that are very familiar to the analysis staff. The use of eHARS also leverages the ongoing interstate deduplication efforts and death certificate matches that are performed on a regular basis. NC EDSS may not be updated when a patient moves to a different jurisdiction since those updates are all manually entered. The initial source for matching and out of care determination starts with patients who have had no evidence of HIV care (clinical visit, laboratory monitoring for CD4/viral load, or antiretroviral prescription) within two years. Experience suggests that if a patient has not had any activity reported for more than two years, the likelihood of being able to locate that patient declines dramatically. By starting with a two year window and then looking for those patients who have no care within 9 months we believe the probability of a successful search to locate the patient is much greater. As the out of care clients in the 2 year cohort is exhausted, patients who have longer intervals of no reported contact will be selected and contact will be attempted. The lists (tables) generated are typically Excel or Word tables and are shared with appropriate staff by copying the files to secure server locations and making staff aware of the file location. The electronic files are not sent via email. In some instances a printout may be created and sent via surface mail/FedEx to a particular worker.

Once the list of out of care patients has been built, state Bridge Counselors in the seven Field Services regions are contacted about patients residing in their catchment areas and they begin the process of trying to locate patients. All state Bridge Counselors recently received Antiretroviral Treatment and Access to Services training (ARTAS, an individual-level, multi-session, time-limited intervention with the goal of linking recently diagnosed persons with HIV to medical care) as a part of their ongoing job development to bring a base skillset to their counseling activities. A recent contract has been engaged with Accurint for use of their Lexis/Nexis database; one state staff member has access to this, for the purpose of a making a final attempt to locate clients lost to care when all other efforts have failed.

All activities described thus far are statewide in scope. The services provided to patients are primarily delivered by CDB staff located in the seven regional offices housing the DIS and Bridge Counselors. DIS are usually the first individuals to contact a newly diagnosed patient

unless the patient was seen by a private provider. As part of the initial interview with a patient, DIS review the disease diagnosis to provide the patient an opportunity to ask questions about the diagnostic procedure, notify the patient about HIV control measures that are required by NC, offer information or referral for care for HIV and introduces the patient to the partner services activities. DIS offer the option to have the patient's partners notified by DIS (without identifying the patient) or to assist the patient in notifying their partners themselves. DIS facilitate HIV testing for partners by either providing transportation or in some instances drawing a "field blood" for testing. DIS may contact a patient more than once after the initial interview, especially if the person has been named as a contact or suspect by other patients interviewed. In some situations, a second interview is done to verify or review information provided by either the original patient interview or information provided by another individual that is pertinent to the specific case under investigation. Of course, these interviews are also an essential tool in linking newly diagnosed HIV positive people to medical care as well.

As part of ongoing data quality management by the Ryan White providers (NC has ten Regional Networks of Care plus the Charlotte/Mecklenburg Transitional Grant Area), clinics are encouraged to regularly evaluate their patient census to determine if a patient has not been seen within a 9 month interval, in which case an attempt is made to reach that patient to encourage their return. If the agency has identified an out of care patient and needs help contacting the patient they have access to the State Bridge Counselors for assistance. Work has already been done to assist local clinics in developing protocols for identification and re-engagement of clients who are out of care. After working through the internal protocol, State Bridge Counselors receive clinic referrals. Ryan White providers do not have access to statewide surveillance databases so their evaluation for out of care is only within their CAREWare domains. If a patient has relocated to another region of the state or to another state, the Ryan White provider may be unaware of that change in address. However, State Bridge Counselors do have access to the statewide data and can readily assist.

Through the Special Projects of National Significance (SPNS-LINK) award a proposed out-of-care database (called NC ECHO) is under development and has gained preliminary approval; it will be developed through contract with Duke University. NC ECHO will contain common elements from CAREWare, ADAP and NC EDSS in order to provide near real time data that indicate who is out of care and in need of re-engagement outreach.

Staffing

There are nine State Bridge Counselors (full FTEs) tasked to contact, counsel link and re-engage patients identified as out of care across the state. One of the nine State Bridge Counselors housed in the Field Service Regional Offices works closely with the NC Department of Public Safety to monitor HIV-positive inmates who have been released to ensure they are linked to follow-up medical services once they have been released. This activity is relatively new to the care linkage programs and is funded by the Care and Prevention in the US (CAPUS) funding

opportunity which NC received in 2013 as part of the Secretary's Minority AIDS Initiative. HIV-positive prison releasees were identified as a group who are at high risk of not receiving on-going HIV care follow-up for more than a few months after their release. The dedicated Bridge Counselor position is able to monitor discharge planning and follow-up with agencies where releases have been referred.

The State and Regional Bridge Counselors are only part of the entire team of staff needed to enable the process to function. The initial database management and cross-matching involves the assistance of the eHARS data manager, the two CAREWare data managers and efforts of two epidemiologists. Each of these additional data support staff devotes approximately 10% effort while the two epidemiologists devote 25% to 50% of their time to performing crossmatches and also working with other staff to improve data quality and reliability. Additional day-to-day support is provided by the Field Services Unit staff, primarily the DIS in the regional offices, to assist with follow-up and patient location

Funding

The Bridge Counselor positions are funded through the HIV Prevention budget and the Ryan White Part B budget. The eHARS data manager is a full FTE in the National HIV Surveillance System (NHSS) budget, the two CAREWare data managers and one epidemiologist are funded through the HRSA Ryan White Part B funding initiative and the remaining epidemiologist is funded by the HRSA Special Projects of National Significance (SPNS) LINK project. Bridge Counseling can also be funded through state appropriations if funding levels allow.

Information Dissemination

The steps taken to improve care linkage and re-engagement are shared with the provider community through the routine meetings with the provider networks as well as the quarterly meetings with the SPNS-LINK participants.

Time Frame for Development

The components necessary to "assemble" the ability to link patients to care using surveillance data have been in place for approximately 15 years. An initial attempt to identify patients who had fallen out of care and to locate them was made in 2006 (approximate date) but failed due to the lack of funding for staffing to locate patients. The results of the HPTN 052 trial in 2012 galvanized the Branch to redirect existing resources and seek additional funding to provide sufficient staffing to effectively do the job, in order to assure viral suppression and thus reduce HIV transmission.

Data Systems

The key data system that enables NC to assess care engagement status is NC EDSS. It is a fully functional disease surveillance system that covers all reportable communicable diseases in North

Carolina, and provides the ability to identify and examine developing syndemics. In addition to the minimal data elements required by the CDC for reporting purposes, some diseases also have additional data elements collected relating to case management and disease investigation. NC EDSS was implemented in its final release in December 2012 with the addition of HIV/AIDS and syphilis reporting to the system that had been in place since 2008 for all other reportable diseases in NC. NC EDSS is used by all local health departments in North Carolina, the seven Field Services Regional Office staff and the central office surveillance staff. The system receives and processes electronic laboratory reports from the NC State Laboratory of Public Health as well as an increasing number of both commercial and hospital-based laboratories. Logic exists to attach laboratory results to existing cases if appropriate (e.g. a viral load result for an existing HIV patient) or to create a new disease event even if a patient exists with the same diagnosis (e.g. a gonorrhea lab test for a patient reported with gonorrhea 4 years ago). NC EDSS is a person-centric multiple event surveillance system and as such offers a view of all disease events (with laboratory and investigation results) for an individual. With the implementation of NC EDSS the ability to monitor referrals for care (both the referral as well as the outcome) was included as part of the disease report process. Security for access to data elements is role based for users so not all users are able to access all reports for a patient.

Other Supporting Activities

HIV Acute Program

North Carolina has had an acute HIV screening program in place since 2003 where all specimens that test negative for HIV antibodies through the NC State Laboratory for Public Health are pooled and then tested for HIV RNA to identify acute HIV infections. The program also encourages private providers who have a patient with clinical manifestations suggestive of acute HIV infection submit specimens for both HIV antibody and HIV RNA testing. Patients identified with acute HIV infection are contacted by a DIS within 36-48 hours of the result being reported to the surveillance unit. For clients who are tested by the local health departments (or other DPH supported testing venues), contact may be within 12 hours or less depending on the timing of the laboratory result. Arrangements are immediately made for the client to see an HIV provider.

HIV Prevention

The HIV Prevention program is a critical part of the integrated statewide prevention activities initiative in the CDB. North Carolina has a robust Field Services Unit tasked to provide partner services that is integrated with respect to contacting both HIV and syphilis patients and contacts. The same Disease Intervention Specialists (DIS) pursue interviews and service referrals for original patients identified with HIV infection and contacts irrespective of the diagnosis. The merged partner services activities have been in place in North Carolina for over 25 years. In

addition to partner services, HIV prevention activities are carried out by supported community-based organizations, local health departments, and historically black colleges and universities. In addition, services are offered in collaboration with the NC Department of Public Instruction and NC Department of Public Safety (formerly the NC Department of Correction). Examples of the services are HIV, syphilis, gonorrhea, syphilis and hepatitis C testing in local health departments, rapid HIV testing, support for HIV testing in emergency departments, HIV testing in federally qualified community health centers, HIV testing in substance abuse centers, health education and risk reduction services and clinical care through local health department STD clinics. The Program is focused on reducing health disparities by assuring that testing reaches those most at risk for HIV/STD infection, and every effort is made to integrate testing with community outreach and services. “Safe Spaces”, an initiative that works to reach young minority MSM in their own communities with the leadership provided by minority MSM, is a new and very important part of our community outreach strategy. Safe Spaces is intended to reach young HIV positive men, link/re-engage them in care and work to overcome the stigma that these men often report as a result of being HIV positive, minority and MSM. Safe Spaces will also provide testing to the partners of participants and teach sexual health and empowerment to participants.

The Branch’s media campaign is called Get Real, Get Tested, Get Treatment and is designed to reach different target audiences through TV commercials and posters. To date, audiences have included African American women, African American MSM, people who have fallen out of care and general population with educational and linkage information.

HIV Care

The AIDS Care Program has been in in the same administrative unit as the HIV/STD Prevention program since 1996. The goals for the AIDS Care Program are to: 1) Ensure the provision of primary medical and ancillary services to low-income HIV-infected persons in North Carolina (Ryan White HIV/AIDS Program); 2) Provide support for the purchase of HIV medications for needy individuals who have no medical insurance (AIDS Drug Assistance Program or ADAP); 3) Ensure the provision of housing and housing-related services to low-income HIV-infected individuals and their families (Housing Opportunities for People with AIDS or HOPWA).

HIV medical care funded through the Ryan White HIV Care Act is directed to eleven patient management Networks for Care with catchment areas that cover all 100 counties in North Carolina. These Networks are a combination of medical centers, local health departments and community organizations.

In addition to the support for primary medical services through Ryan White funding, nine service areas receive Ryan White/HOPWA funding awards and two agencies receive funding for either an innovative emerging communities project or a primary medical project beyond the scope of the Regional Networks of Care.

The AIDS Care Program also places a strong emphasis on linkage to care. A required component for each of the Networks of Care includes Regional Bridge Counseling in order to assure that a systemic effort is in place to re-engage clients who fall out of care and work to build a seamless system of services for those who are newly diagnosed.

Collaborations with Other Agencies

There are two strong collaborations that enable NC to extend the reach of linkage and re-engagement activities. One is the SPNS-LINK project that provides funding for several Ryan White provider agencies to develop strategies and methodologies to improve linkage to care. One of the objectives of the project is to develop a mechanism and data support to identify patients who had dropped out of care and to reintroduce those patients back into HIV care; evaluation of outcomes is a strong component of this project. The CDB's HIV/STD Director and a noted clinician in the UNC School of Medicine are co-Principal Investigators for the SPNS-LINK project and through that relationship, NC has been able to leverage the activities developed by the project to include re-engagement activities in the process. Wake County Human Services provides a strong collaborative link with its retention and reengagement work, as well as offering STD services through a PCSI model (Program Collaboration and Service Integration). Wake performs outstanding data analysis and has created an 'acuity scale' of need for clients living with HIV that the state is beginning to use as a model.

Another strong collaboration is between the Communicable Disease Branch and the UNC School of Medicine's Division of Infectious Diseases. A partnership has existed between the agencies for approximately 15 years where HIV prevention and community engagement has been supported by multiple funding sources. Currently one of the UNC clinicians is working within the day-to-day operations of the CDB to enhance clinical availability for the Branch DIS and other counselors. Following the results of the HPTN 052 trial led by Dr. Myron Cohen, NC adopted a series of efforts to better ensure that HIV positive patients were receiving adequate antiretroviral medications to embrace treatment as prevention. In partnership with the Communicable Disease Branch, the UNC Division of Infectious Diseases also operates a call center (ONECall) to provide linkage for medical services directly to HIV positive individuals.

Links to Program-related Resources

<http://epi.publichealth.nc.gov/cd/stds/program.html>

<http://epi.publichealth.nc.gov/cd/stds/figures.html>

<http://www.med.unc.edu/infdis/news/new-hiv-call-center-will-link-patients-to-life-saving-care>

<http://www.med.unc.edu/infdis>