Clinic-Based Retention in Care: Description, Outcomes, and Lessons Learned

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Disclosures

Jenna Donovan has no financial interest to disclose.

Byrd Quinlivan has no financial interest to disclose.

Aimee Wilkin receives research funding from Gilead, Janssen and Pfizer but that does not affect this presentation.

Amy Heine has no financial interest to disclose.

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Learning Objectives

1. The learner will understand how Out-of-Care lists can be generated and worked in various clinic settings
2. The learner with be able to describe key findings of this intervention, both qualitative and quantitative, and how they can be used to inform future implementation of similar protocols
3. The learner will be able to assess the needs and capacity of their own clinic to develop retention efforts.

Obtaining CME/CE Credit

If you would like to receive continuing education credit for this activity, please visit:

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Setting: HIV in North Carolina

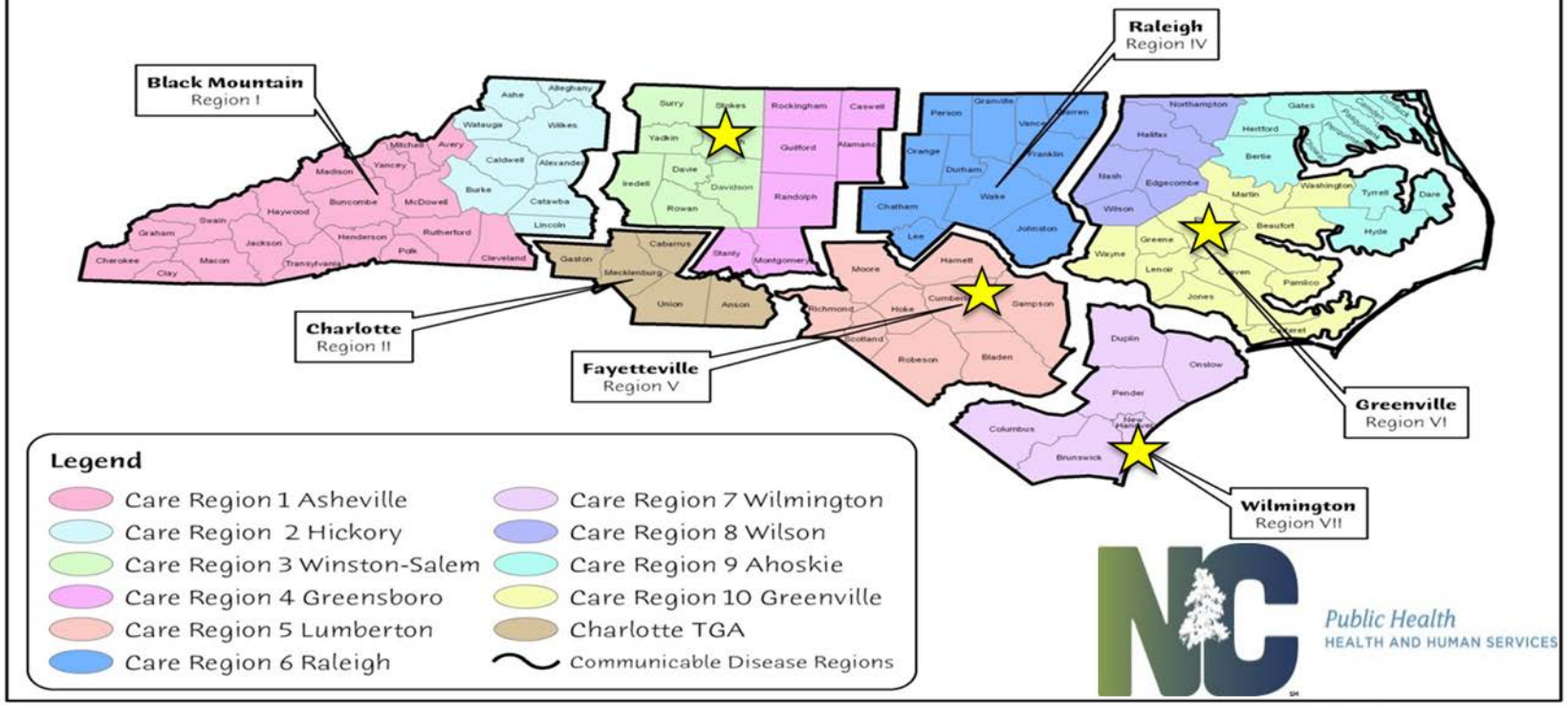
North Carolina HIV/AIDS Epidemiology

- **28,101**: estimated total number of persons living with HIV at the end of 2013
- **1,347**: reported new diagnoses of HIV infection in 2012
- **15.0 per 100,000:** three-year average HIV diagnosis rate (2011-2013)
- **31.0 per 100,000:** three-year average HIV diagnosis rate in Mecklenburg County (Charlotte)- county with the highest rate in the state
- African Americans accounted for **64%** of all new HIV cases in 2013

NC HIV Care Structure

- NC receives HRSA Ryan White Part B funds through the NC Department of Health and Human Services, Division of Public Health
- Part B funds are distributed among 10 HIV Ryan White HIV care regions – covering 95 of NC's 100 counties
- Remaining 5 counties are in the HRSA Part A TGA area, funded through the Mecklenburg County Health Department (in Charlotte)

North Carolina Division of Public Health Communicable Disease Branch Regions and HIV Prevention and Care Regions



Challenges in NC HIV Care: Prior to NC-LINK

- NC HIV Prevention (6) and Care Regions (10) within the state were not aligned
- Large geographic distances with limited fieldwork capacity for linkage and retention staff within regions/clinics
- Efforts to re-engage clients being conducted at state level were challenging when conducted by DIS (punitive role)
  - Need for a more supportive role for working with clients and more training
- Lack of streamlined processes for clinics/regional networks of care to collaborate with others across the state to locate clients or document efforts (i.e. could lead to duplicative work)

NC LINK Overview

What is NC-LINK?

- Four-year HRSA Special Projects of National Significance (SPNS) demonstration project
  - NC one of six states to receive funding
- Follows the goals of the National HIV/AIDS Strategy
  - Purpose: Increase the number of people living with HIV/AIDS engaged in consistent care by creating a system of linkages along the HIV Continuum of Care in NC
- Funded through the Communicable Disease Branch at the North Carolina Division of Public Health
  - Partnership between Duke University, University of North Carolina-Chapel Hill and intervention sites around the state
- Key strategies: alternative HIV testing and retention and reengagement efforts for quality and consistent HIV care

Overview of Final NC-LINK Interventions

- Clinic-based HIV Testing
  - Offers an individual who accompanies an HIV-positive patient to a clinic appointment the opportunity to receive free and confidential rapid HIV testing at the clinic
- Retention Protocol
  - Implemented at the clinic and regional levels to re-engage patients who have not had an HIV care appointment in a designated time period (usually 6-9 months)
- State Bridge Counseling – Linkage and Re-engagement
  - Program at NCDHHS, Communicable Diseases Branch to ensure rapid linkage to care for people who have been newly-diagnosed with HIV and to re-engage PLWH who have been out of care ≥12 months

NC-LINK Pilot Phase (2012-2013)

- Learning Collaborative Model
- Formal Collaborative Structure
    - Conference calls monthly with pilot sites
    - Stakeholder meetings, at six months
    - Presentations by test site staff
    - PDSA cycles
    - Availability of team for technical assistance
- 4 clinic, 2 statewide interventions tested
- 4 interventions selected for expansion: HIV Partner Testing, SBC Linkage, Retention Protocol, SBC Reengagement

NC-LINK Expansion Phase (2013-2014)

- Expanded the interventions deemed successful during the pilot phase to additional sites throughout North Carolina:
- HIV Partner Testing
  - 2 Regional Networks of Care
- Retention Protocol
  - 4 Regional Networks of Care
- State Bridge Counselors
  - Each Prevention Region has at least 1 SBC with an additional 3 Special Population SBCs provided through CAPUS funding

Focus: Clinic-Based Retention Protocol

Retention Protocol Overview

- Focuses on improving the capacity of regional and clinic based retention staff to retain HIV+ individuals in care and to engage those who are lost-to-care back into consistent HIV care
- Piloted at large academic medical center with approximately 2,000 HIV patients
- Determined best processes for looking for clients as well as methods for retention staff to document their efforts
- Decided to utilize CAREWare - required software for Part B providers in NC
  - Allowed for electronic referrals between providers that share the same client in different institutions/agencies.
- Currently have 4 Part B Regional Networks of Care (with a total of 13 agencies) participating in the Retention Protocol

Step by Step Process of NC-LINK Retention Protocol

- On the first day of the month, clinic runs a list of out-of-care clients (those who have not had a medical care visit in 6-9 months or more)
  - Data manager runs the out-of-care list through clinic EMR or CAREWare (CW)
  - List is checked to remove clients who are not truly out-of-care due to special circumstances or who have upcoming appointments
- Clinic/community-based retention staff receive list from clinic via an electronic CW referral
- Retention staff work on locating client for roughly 30 days
  - Work conducted from clinic/agency - not generally done via fieldwork

Examples of Local Efforts to Locate Clients

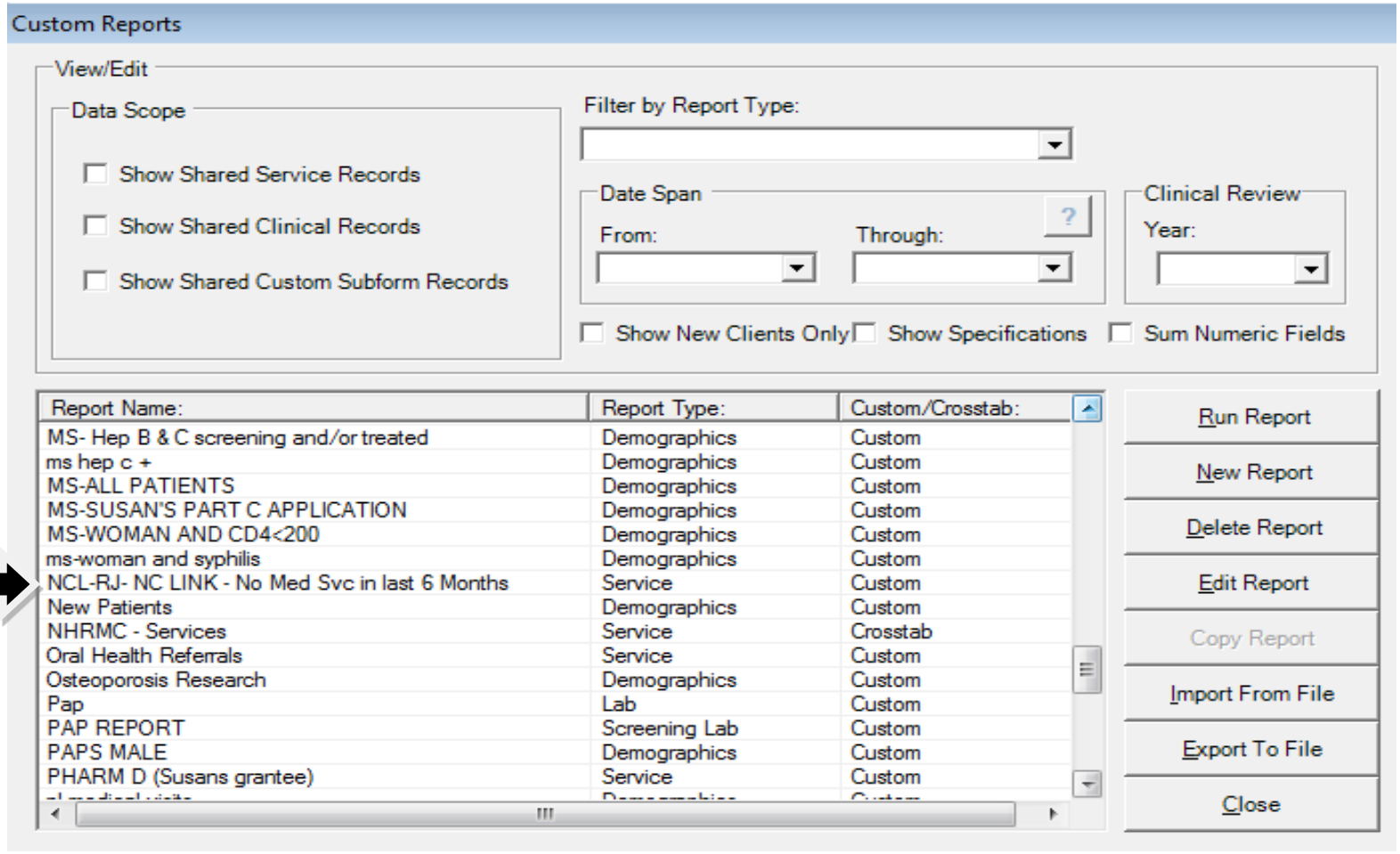
- Check EMR/local CAREWare for any contact since the last medical visit
- Call all of patient's phone numbers in the chart as well and any old numbers (3 phone calls on 3 separate days)
- Conduct internet search of local jails, state prisons, federal prison system
- Check the Social Security Death Index and Google search for potential obituaries and other information about the patient (i.e. pipl.com)
- Check the state Medicaid Provider Portal to see if they have been in care elsewhere, accessed EDs or had an inpatient stay, and if there is different contact info in the record
- Call last pharmacy and see if any other refills have occurred since last medical visit and get any contact info available/info on other prescribing providers
- Call any home health agency/dialysis center/other provider that can be identified to obtain current contact info or get a message through to the patient
- Send out a generic letter to last known address encouraging patient to get in touch if no phone calls have been successful

Step by Step Process of Retention Protocol (cont.)

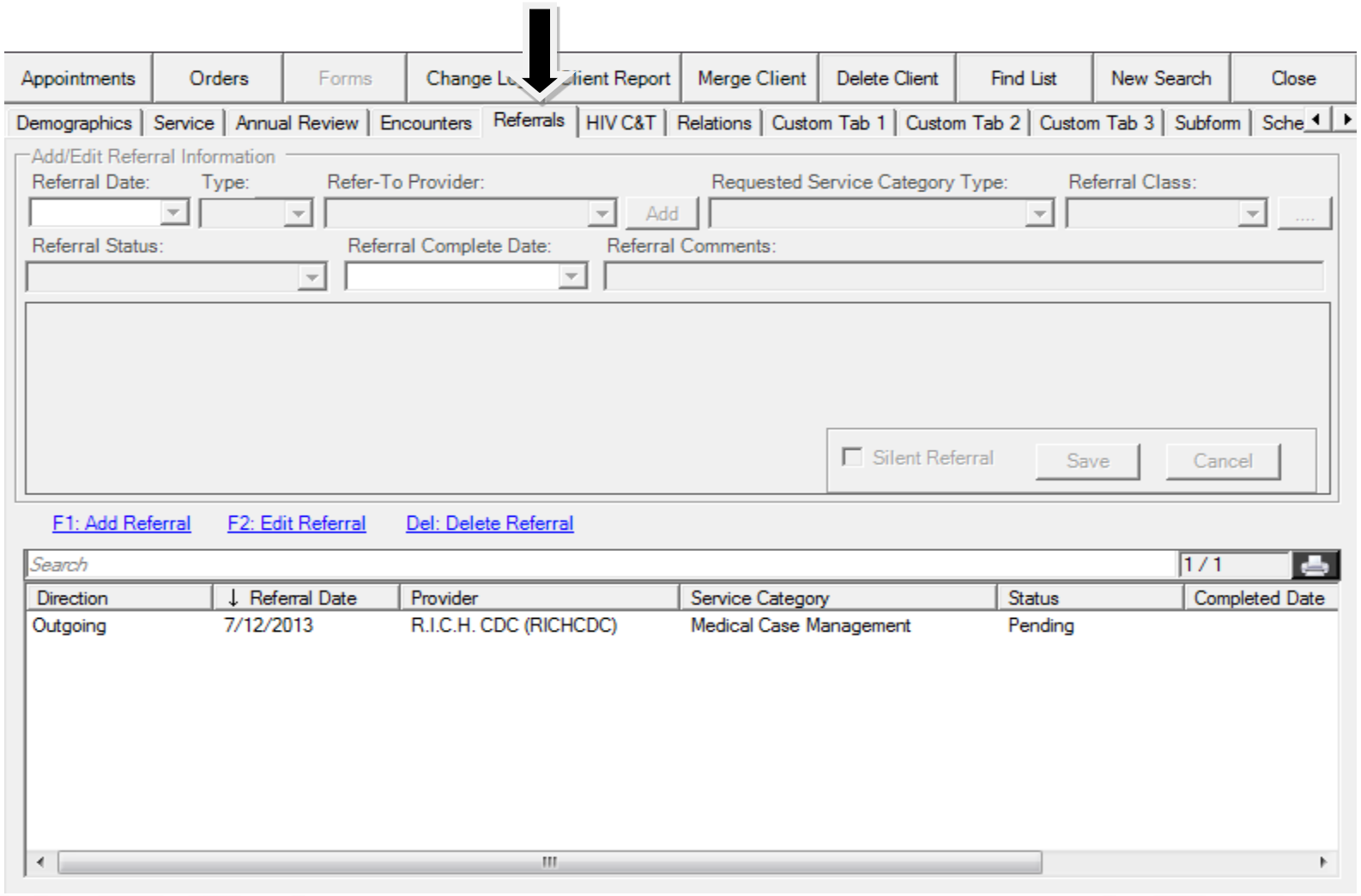
- After 30-day time period of locating, retention staff document efforts and provide outcomes via CAREWare
- Clinic closes out clients who have been located or a definitive outcome has been determined. Outcomes documented include:
  - Re-engaged in care at referring provider
  - Re-engaged in care with new provider
  - Deceased
  - Re-located
  - Incarcerated
  - *Located, not re-engaged in care to-date*
  - *Unknown-not located*
- "Unknown, not located" clients and "Located, not re-engaged in care to-date" clients referred to State Bridge Counselor for state-level follow-up/field work

CAREWare Demonstration

On or near the first day of the month, the clinic ran an Out-of-Care report to list all patients who have not had a medical care visit in 6 months or more.

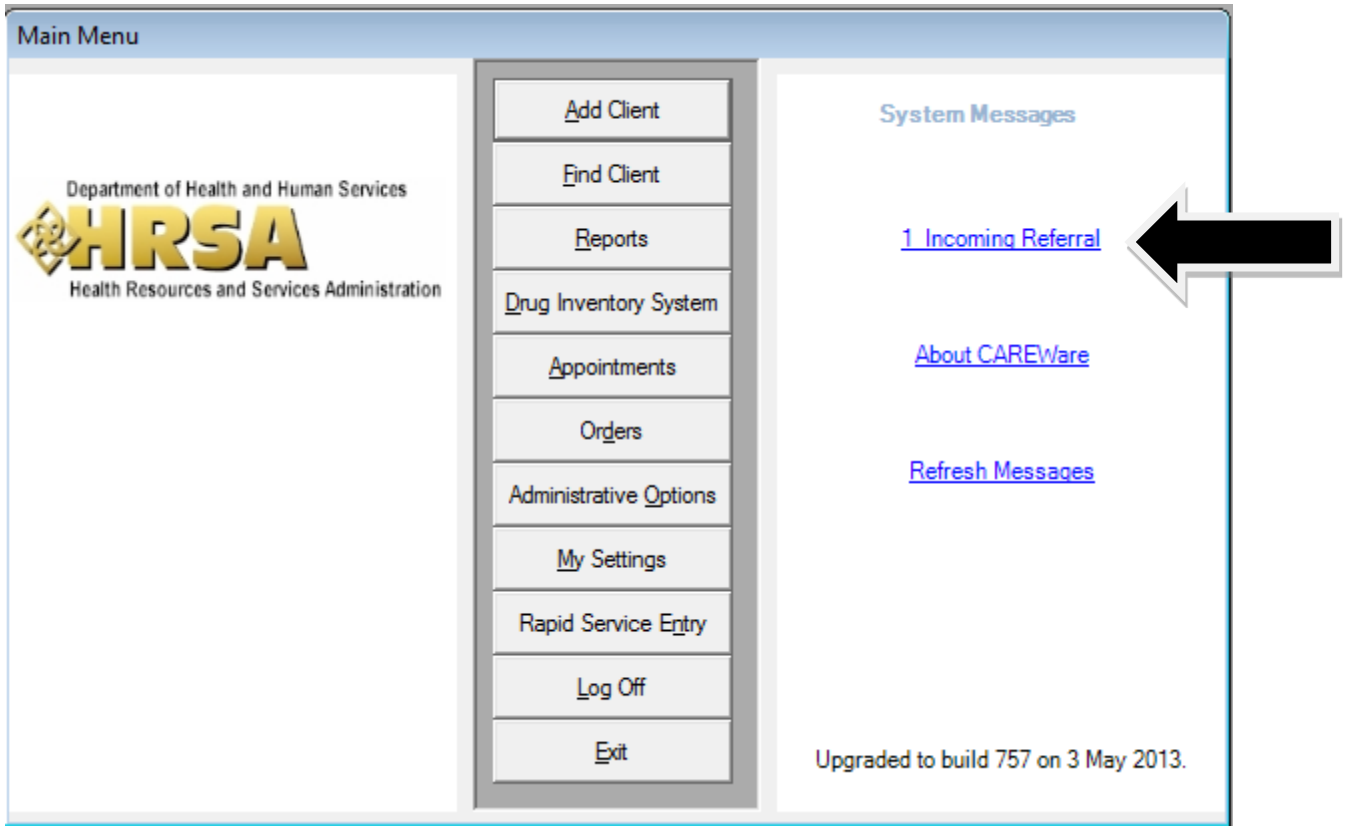


From the list generated by the out-of-care report, an outgoing internal referral to clinic retention staff was entered at the clinic for each client being referred for clinic-based retention services.

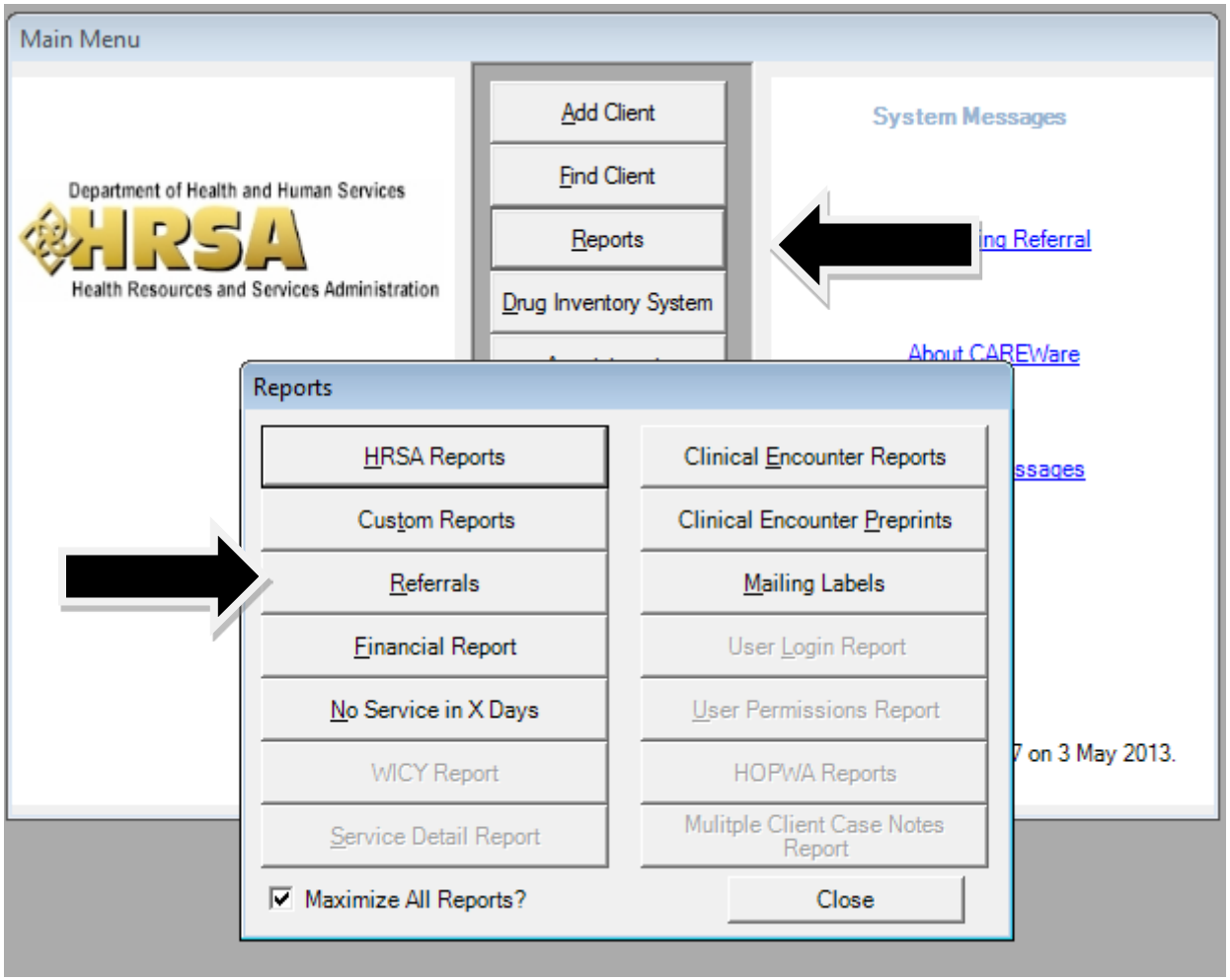


Outgoing referrals were displayed on the main menu screen of the clinic's domain.

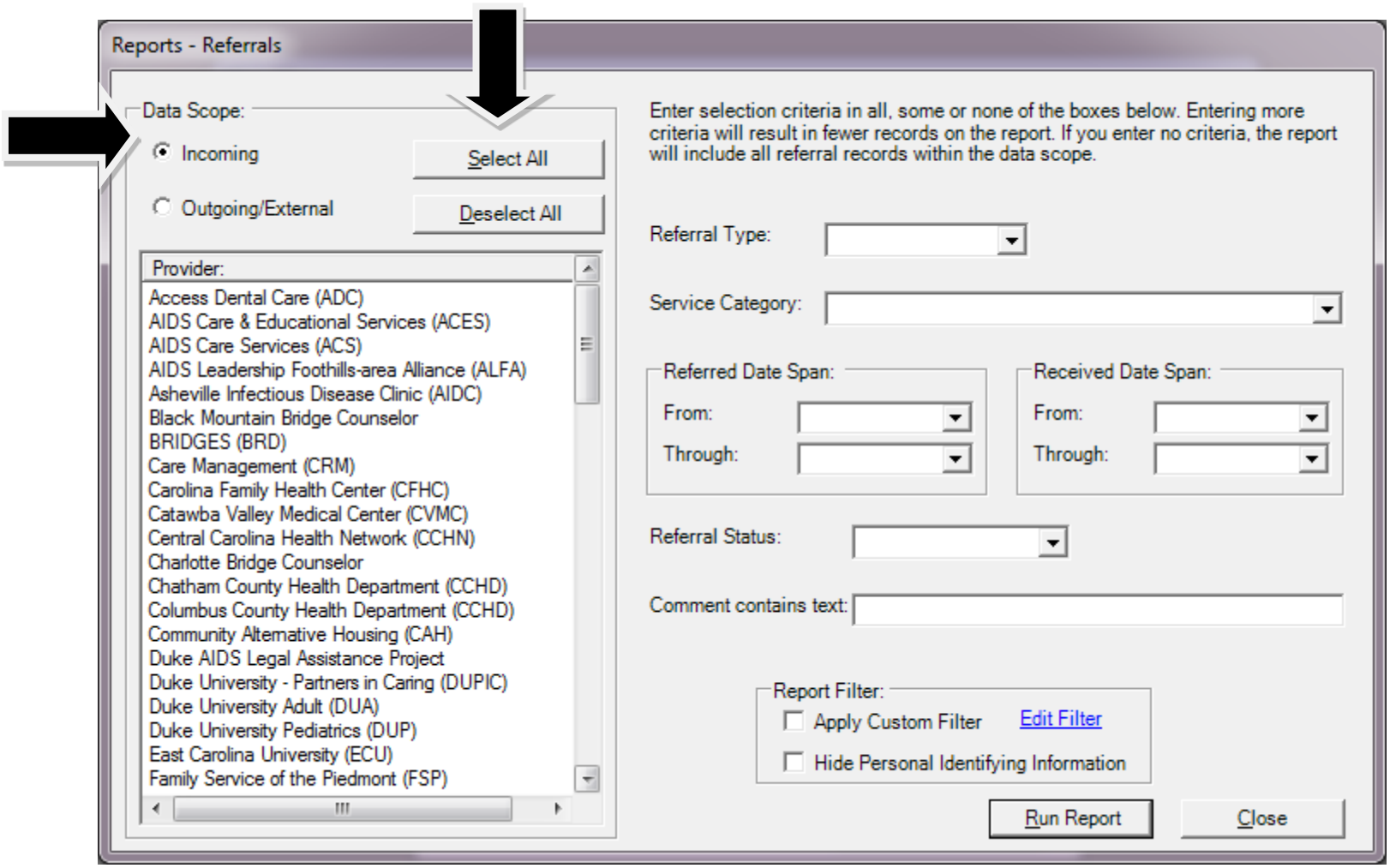
After the referrals were made, the incoming referrals were displayed on the main menu screen when the retention staff logged in to CAREWare.



Both outgoing and incoming referrals in CAREWare were monitored and tracked. Reports to do so were created by going to the main menu in CAREWare, clicking ‘reports’ then selecting ‘Referrals’



Either *Outgoing/External* or *Incoming* and then *Select All* were selected, followed by clicking *Run Report.*



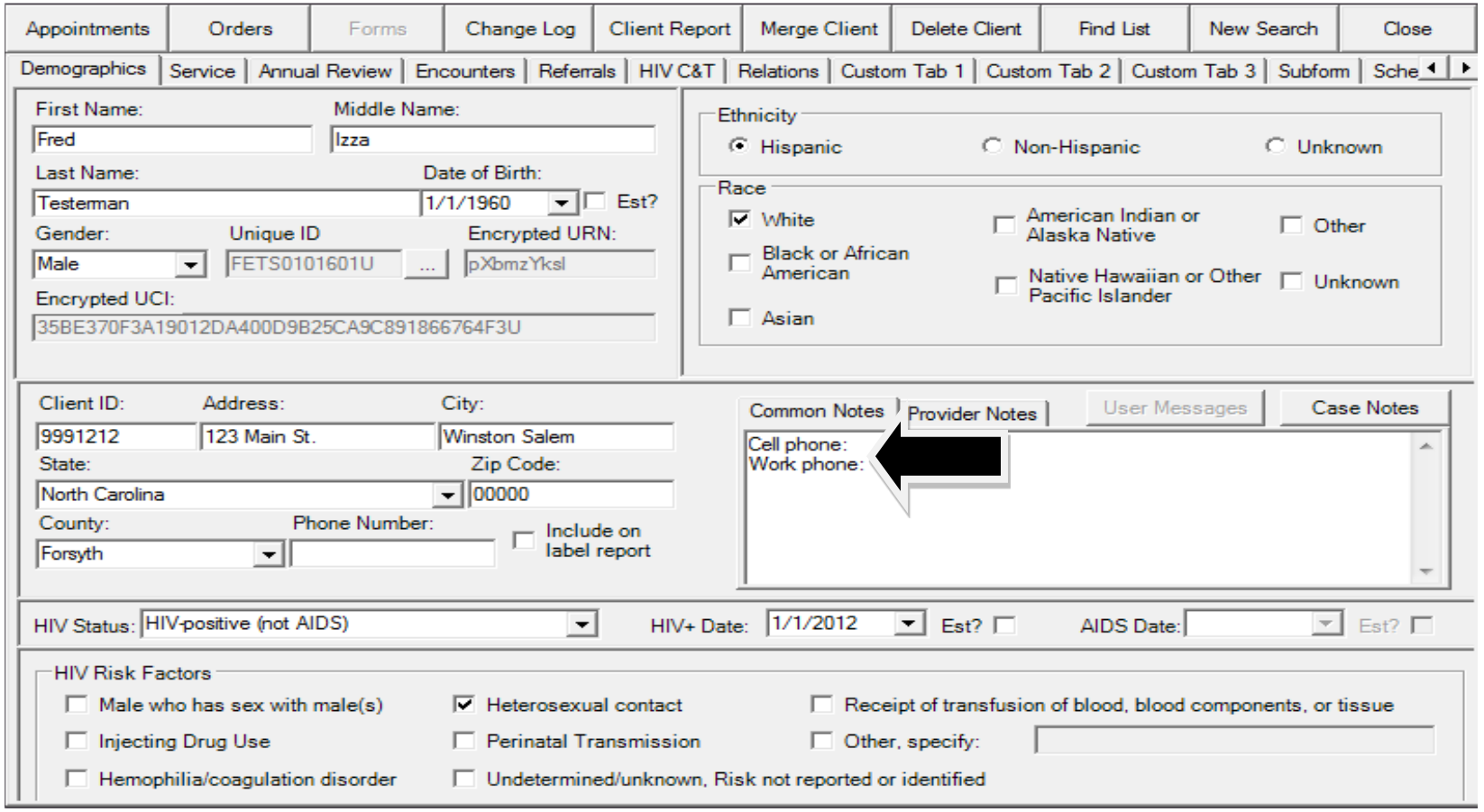
A Referrals report showed all incoming or outgoing referrals and their current status (pending or completed) but could be customized to show specific status' only or results within specific date spans, etc. The **Received Date** on the report is the completion date, or the date the client referral was resolved/closed by clinic retention staff or the State Bridge Counselor (if additional referral was necessary).

UNC/OB/GYN, UNC-Chapel Hill, University of North Carolina School of Dentistry, Unspecified, Urology, Urology Assoc. of Southeastern NC, Urology Clinic of Jacksonville, Village Surgical Associates, Wake County Bridge Counselor, Wake County HIV Case Management, Wake Forest University Health Sciences, Wake Med Medical Center, Walter B. Jones ADATC, Walter O'Berry (DDS), Warren Opthalmology, Wayne Memorial Hospital, Wellcare, William McNulty, MD, William Pringle,DDS, Wilmington Cardiology, Wilmington Endocrinology, Wilmington ENT, Wilmington Gastroenterology, Wilmington Health Access for Teens (W.H.A.T.), Wilmington Health Assoc., Wilmington Orthopedic Group, Wilmington Physical Therapy, Wilmington Plastic Surgery Specialists, Wilmington Surgical Associates, Wilson Ear, Nose, & Throat, Wilson Medical Center, Wilson Medical Imaging, Wilson Neurology, Wilson OB/GYN, Wilson Surgen, Wilson Urology, Wirick and Assoc. (DDS), Women's Healthcare Associates

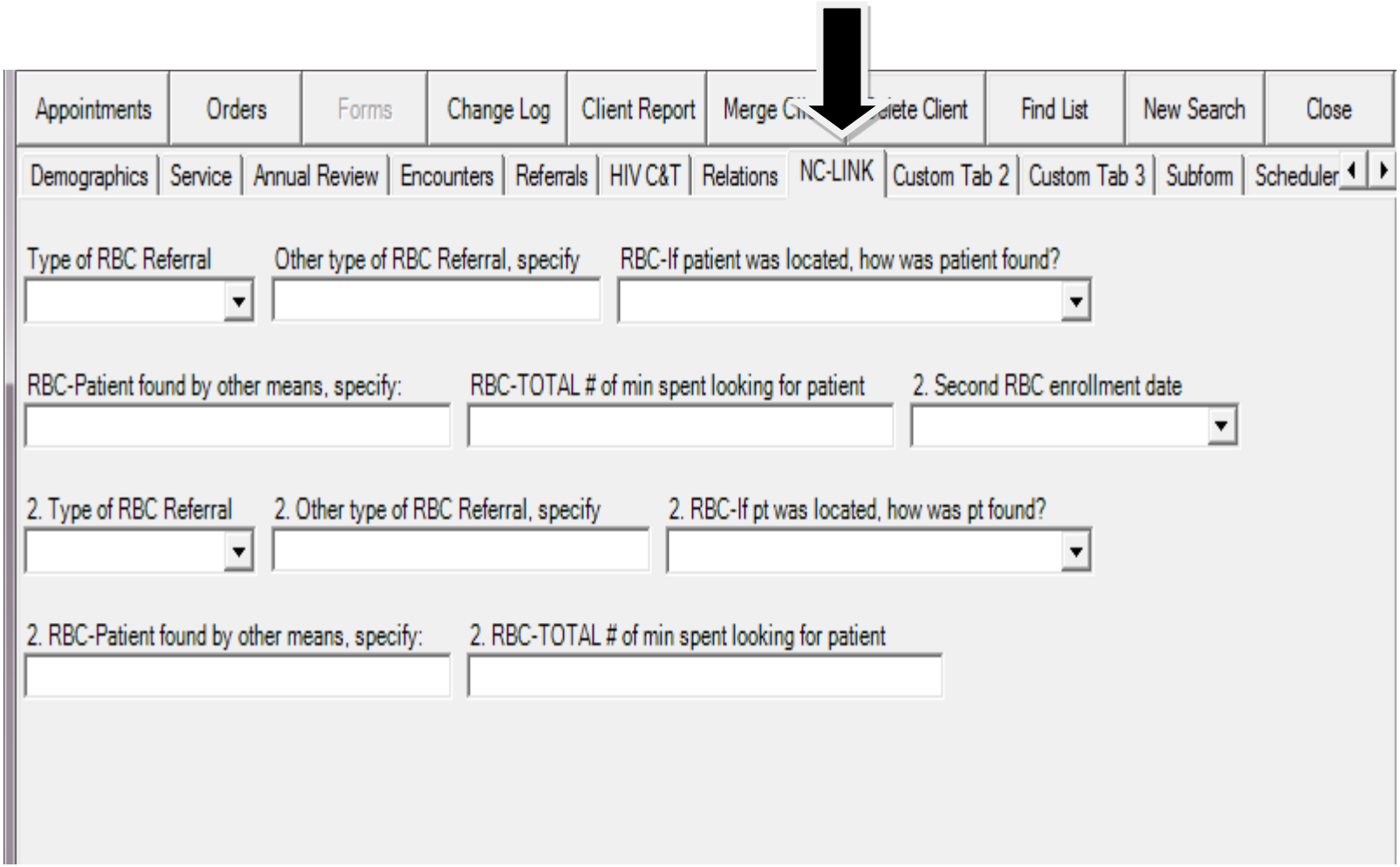
Referred To Charlotte Bridge Counselor

Name:	Srv Category:	Referral Date:	Referral Status:	Received Date:	Referral Comment:
Testerman, Fred Izza	Medical Case Management	7/1/2013	Pending		client is lostto care. Last medical appt was Nov 2012

Demographics tab: As retention staff worked on patient referrals, they updated demographic information on each patient in the appropriate fields. Any additional contact phone numbers were entered in the common notes field.

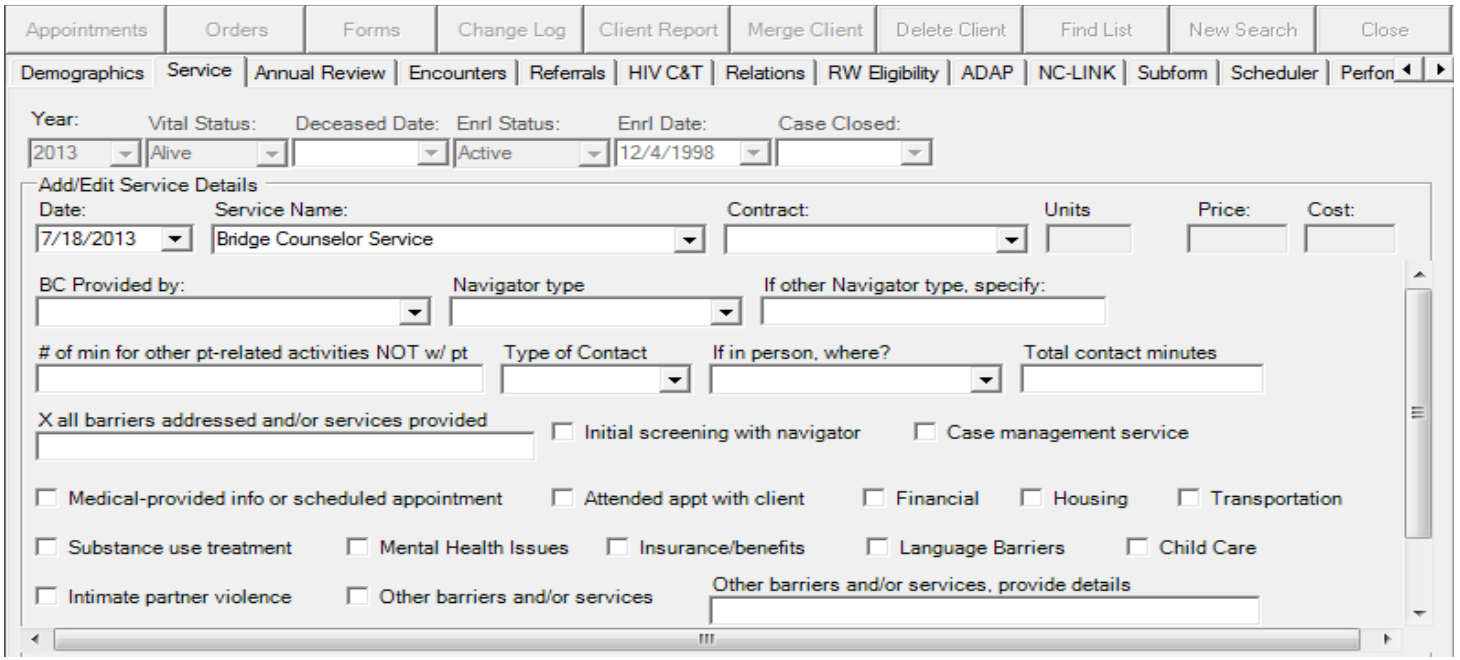


A custom **NC-LINK tab** was created to track the time and activities retention staff used to attempt to locate and re-engage out-of-care patient referrals.



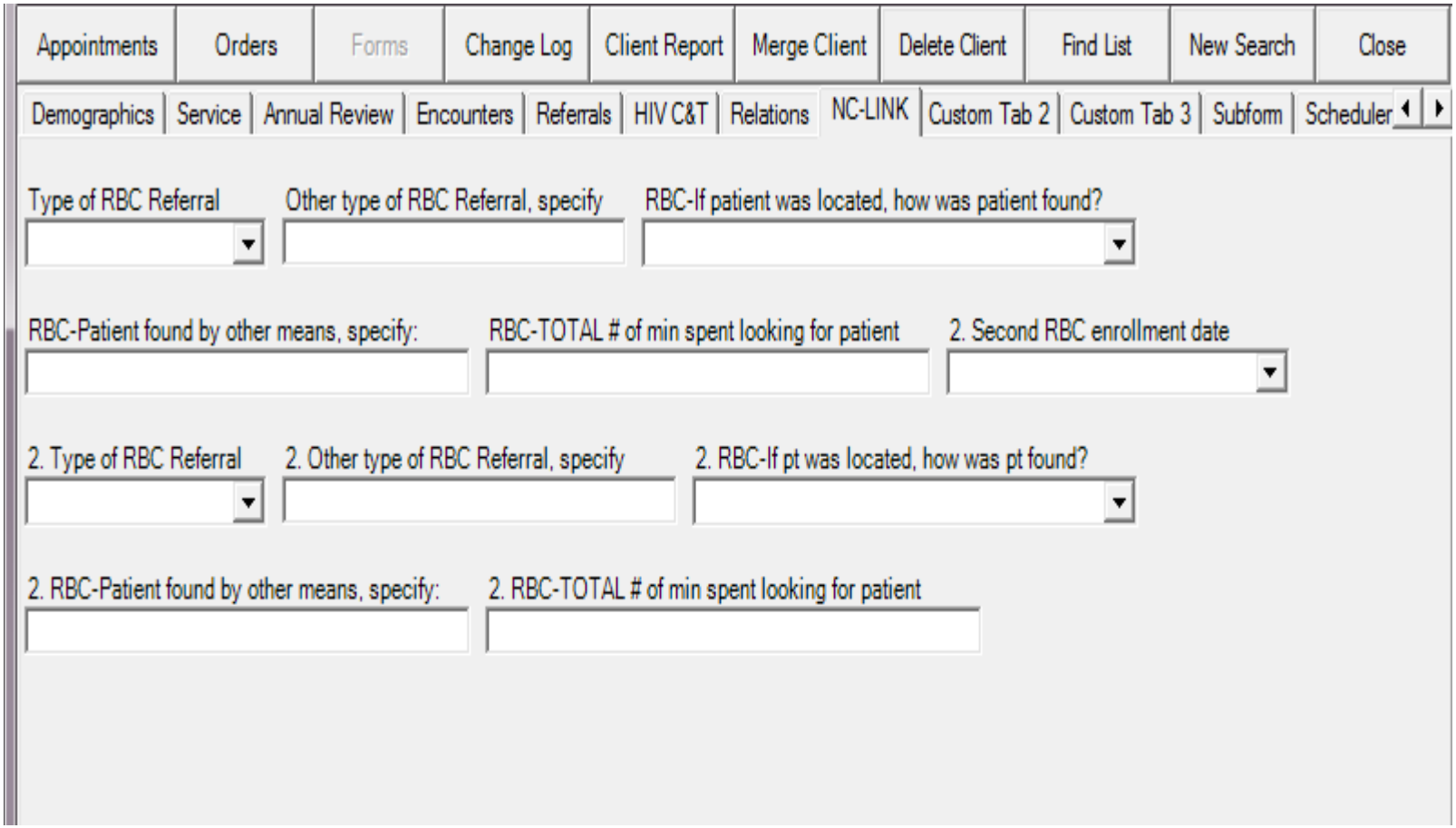
After locating the client, **every** time the retention staff worked on a client record, a Bridge Counselor Service was entered in CAREWare (potentially multiple entries on a single day), entering:

- BC Provided by (name of retention staff member)
- Navigator type (role of retention staff member)
- # of min for other pt-related activities NOT w/ pt (number of minutes spent working on activities on behalf of the client, but not with the client)
- Type of contact (referred to a contact *with* the client, if there was one that day)
- If in person, where? (referred to the location of the in-person contact with the client)
- Total contact minutes (referred to the TOTAL number of minutes spent in direct contact with the client.
- Click on all checkboxes that reflect barriers that were addressed and/or services that were provided during that encounter with the client.

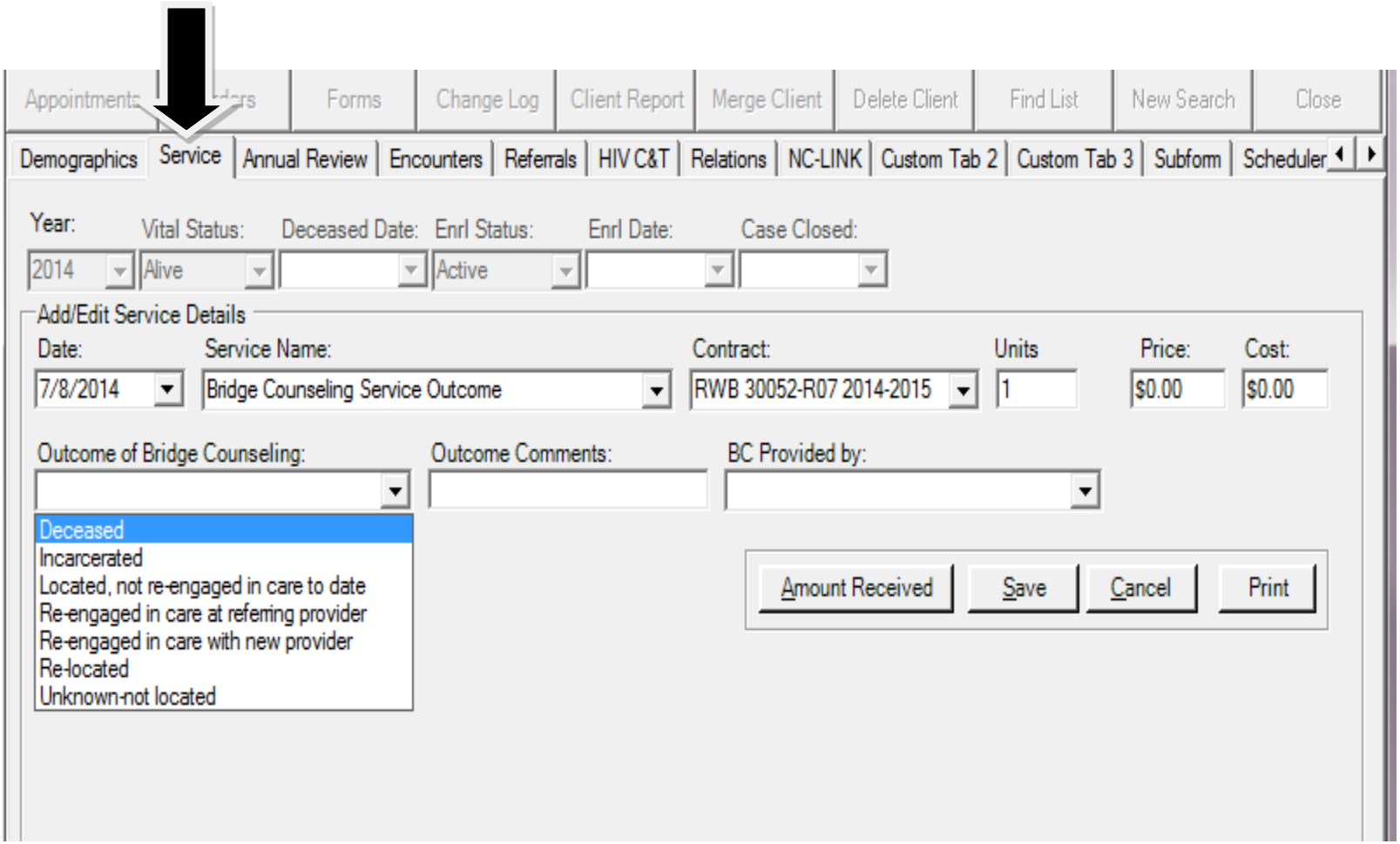


At the end of the month, the retention staff closed the records in their CAREWare domain for which clinic based retention activities were completed by:

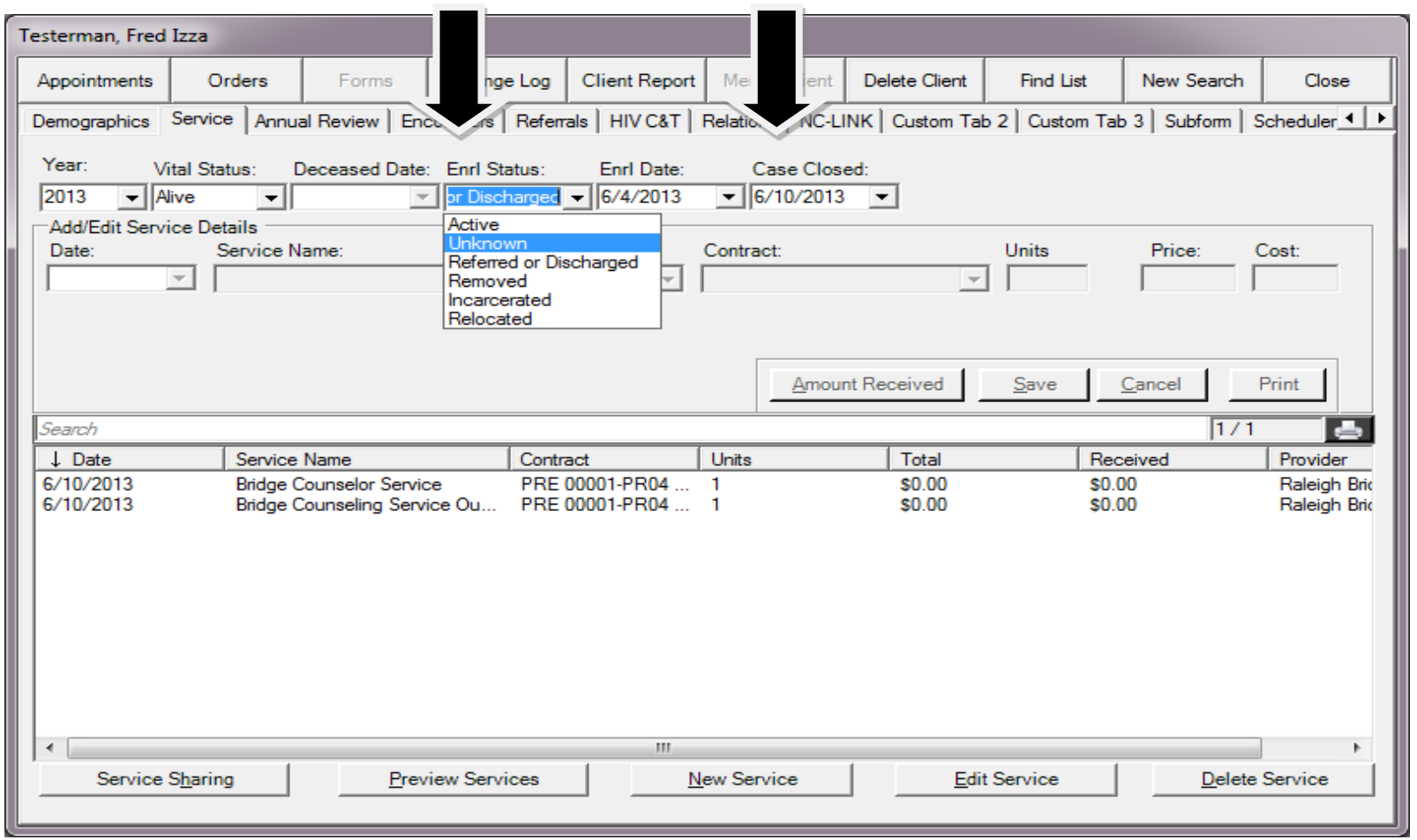
1) Making sure that all data fields were completed on the NC-LINK tab.



2) Entering a Bridge Counseling Service Outcome service on the Service tab in CAREWare for each client that was referred to them for Bridge Counseling that month and completing all custom service fields.



3) Still on the Service tab, changing the Enrl Status to the most appropriate choice: Referred or Discharged, Incarcerated, or Relocated. The date the work was completed for the client record was entered in the Case Closed: field. The Vital Status was changed if the client is found to be deceased and the Deceased Date was entered, if known.



Referral for Additional Follow-up

- Clients with a regional bridge counseling outcome of “Located, not re-engaged in care to-date” or “Unknown-not located” were referred to the appropriate State Bridge Counselor (SBC) by the clinic retention staff or data manager via CAREWare using the electronic referral functionality.

- When the SBC located the client or exhausted all resources looking for the client, the SBC closed the record in CAREWare.

- Those clients with an SBC outcome status of deceased, relocated, incarcerated, re-engaged in care with new provider, unknown-not located, or located, not re-engaged in care to date, were closed in the clinic domain of CAREWare. These closed client records could be re-opened if the client returned to the clinic for care.

Lessons Learned

First Steps Before Implementing Retention Protocol

- A "cleaned" patient database (e.g. EMR, CAREWare, etc.) that will be used to run regular out-of-care lists
  - First out-of-care lists that were run were very long (200-300 patients for larger clinics) that had to be carefully combed through to ensure patients were truly out-of-care and not deceased, relocated, actually in care, etc.
    - Time-consuming process to go through the list, but important to start with an accurate list
    - Need staff members and time for them to clean the database- hard for busy and over-burdened clinic staff, but important for data accuracy
    - Once lists are cleaned up, monthly lists are much smaller and easier to manage
- Clear and agreed-upon definition for an out-of-care patient (e.g. no HIV medical visit in 6 months, 9 months, 12 months?)
- Delineated roles and responsibilities for staff members involved with the protocol (e.g. data managers, bridge counselors, medical providers, etc)

Important Ingredients to a Successful Retention Protocol

- Run out-of-care lists regularly so they do not increase in size and become harder to manage
  - Helpful to run monthly at the same time (e.g. 1st of the month, 5th of the month) so it becomes a routine part of work
- Leadership buy-in and encouragement is important
  - Help prioritize bridge counseling efforts as important for busy staff
  - Buy-in from the IT group to get data from EMR is critical
- Training is key for managing data, referrals and bridge counseling efforts
  - Staff turnover is always an issue
- Need dedicated staff time and space to successfully conduct bridge counseling activities and document these efforts
  - Helpful to have a specific person to do bridge counseling and a data entry/data manager for managing list/handling referrals
- Strong working relationships within HIV care network and collaborations with outside agencies for bridge counseling efforts is critical (e.g. other clinics, local ASOs, health departments, etc.)

Lessons Learned: New Data Entry

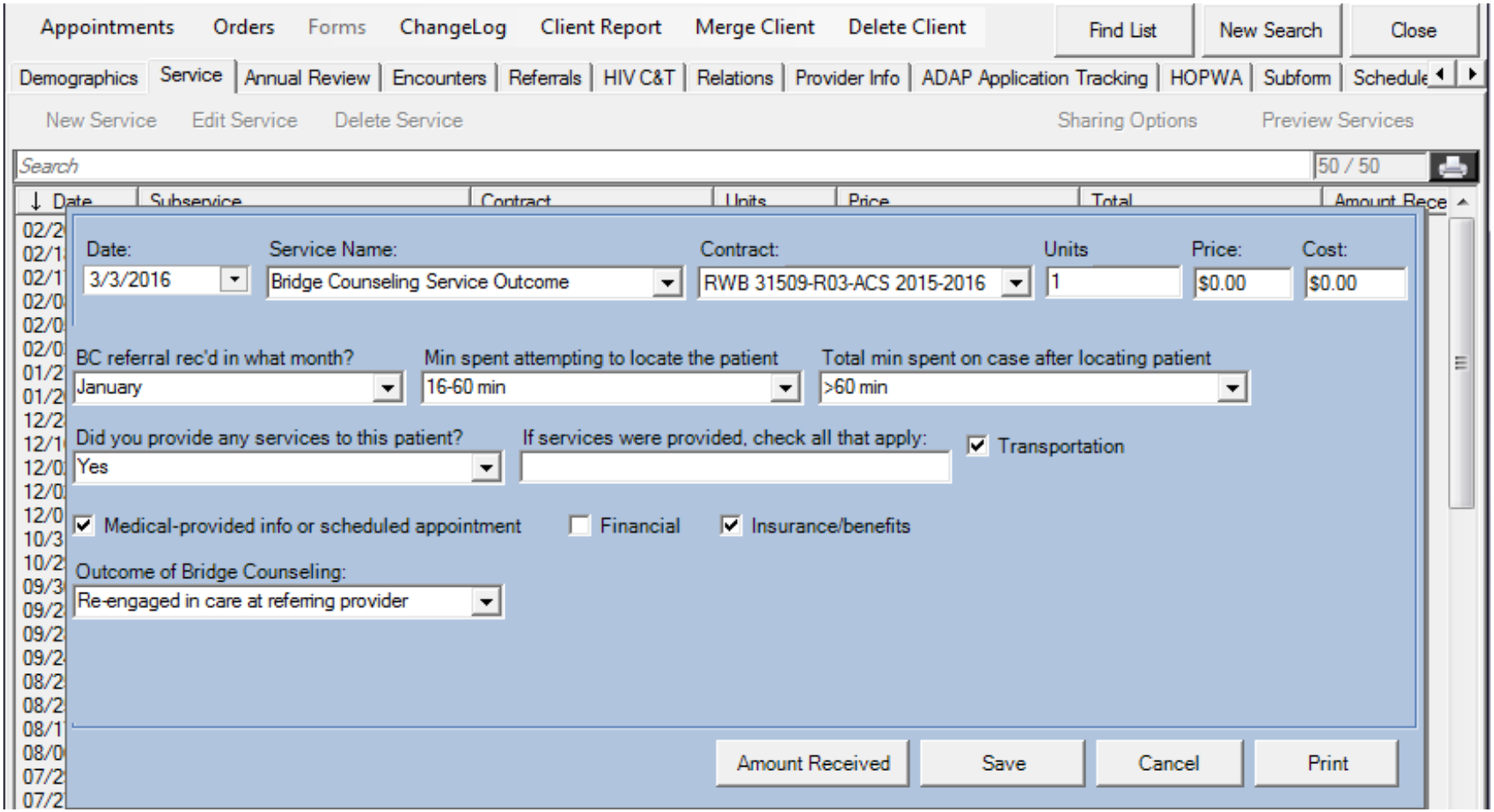
- Process of running out-of-care list and sending electronic referrals for clinic-based retention work did not change
- Streamlined the data entry process for activities and time to locate and re-engage the patient. No longer have a separate NC-LINK tab and the data entry screen captures the information below:
  - What month the referral was received
  - Min spent attempting to locate the patient – now in categories
    - 1-15 min
    - 16-60 min
    - >60 min
  - Total minutes spent on case after locating patient
    - None/Not applicable
    - 1-15 min
    - 16-60 min
    - >60 min
  - Did you provide any services to this patient?
    - Yes or No
  - If services were provided, check all that apply:
    - Transportation
    - Medical- provided info or scheduled apt
    - Financial
    - Insurance/benefits

Lessons Learned: New Data Entry (cont.)

- Also modified the possible outcomes of the retention staff activity
  - Deceased – Found to be deceased
  - Re-located out of state – Found to be living out of state
  - Re-located to new region in NC – Found to now be living in a new region, but still within North Carolina
  - Incarcerated – Found to be incarcerated
  - Re-engaged in care at referring provider – Successfully returned to clinic
  - Re-engaged in care with new provider within region – Known to be attending care at a different provider but within the same region.
  - *Located in region, not re-engaged in care – Patient was found, but did not return to the clinic, or any that you know of, for care. Should be referred to SBC*
  - *Unknown- not located – Could not locate client, should be referred to SBC*

- Patients with outcomes of "Unknown- not located" and "Located in region, not re-engaged in care" are still referred to the SBC for additional follow-up.

The new data entry is captured by recording a Bridge Counseling Service Outcome entry on the Service tab in CAREWare.



Important Ingredients to a Successful Retention Protocol (cont'd)

- Need to decide time-frame for when to stop looking for out-of-care patients
  - Difficult because you don't want to "give up" on looking for patients, but also need to be able to keep the list moving forward and recognize limited staff time and resources
- A patient no-show/cancellation policy also helps identify patients at-risk for becoming out-of-care.
  - Developing a policy of calling and rescheduling patients who missed their appointment helped keep clients from falling out of care and helped decrease the size of the out-of-care list

Interactive Checklist: Implementing the Intervention in your own clinic Small Group Activity

NC-LINK Retention Protocol Checklist

Out of Care: An active patient who has not had a medical visit in _____ months or more

Action	Job Title of Person Responsible	Name, if Available	Necessary Time (% FTE)
Run a report in _____ CAREWare or in the provider's electronic medical record software on the _____ of each month (or closest business day to the 1st) of all patients with "Active" status with no medical visit in ____ months or more.			
Clean the list (e.g. remove individuals with upcoming appts, already on another list, special cases, etc.)			
Place referrals for bridge counseling services (if using CAREWare can put referrals into CAREWare using the electronic referral functionality)			
Conduct bridge counseling activities			
Resolve all current referrals by completing the case closure process.			
Review all client records that have been closed by retention staff. Ensure enrollment status' are updated as appropriate and refer "Located, not re-engaged in care to date" or Unknown-not located" records to re-engagement staff (State Bridge Counselors – SBC)			
Once the re-engagement activities are finalized, review the outcomes of all the client cases and ensure enrollment statuses are updated as appropriate			

Retention Protocol Checklist - Larger Agency ~2,000 patients

Out of Care Definition: An active patient who has not had a medical visit in 9 months or more

Action	Job Title of Person Responsible	Necessary Time to Complete Task
Run a report in CAREWare by the 1st of each month of all patients with "Active" status with no medical visit in 9 months or more.	Data Manager	~5 minutes
Clean the list (for upcoming appts in next 2 months). Document results on Excel spreadsheet.	Data Manager	½ day per month
Place referrals for bridge counseling services into CAREWare using the electronic referral functionality	Data Manager	½ hour per day
Conduct bridge counseling activities	Patient Navigators	40-50% 1 FTE combined
Resolve all current referrals by completing the case closure process.	Data Manager	½ hour per day
Review all client records (if utilizing external retention staff) and finalize outcomes. Refer "Located, not re-engaged in care to date" or Unknown-not located" to SBC	Data Manager	½ hour per day
Once the SBC finalizes counseling activities, review the outcomes of all the client cases completed by the SBC and ensure enrollment statuses are updated as appropriate per the SBCs findings.	Data Manager	½ hour per day

Retention Protocol Checklist - Smaller Agency ~200 patients

Out of Care Definition: An active patient who has not had a medical visit in 6 months or more

Action	Job Title of Person Responsible	Necessary Time to Complete Task
Run a report in CAREWare by the 1st of each month of all patients with "Active" status with no medical visit in 9 months or more.	Data Quality Analyst	5-10 mins per month
Clean the list (for upcoming appts in next 2 months). Document results on Excel spreadsheet.	Data Quality Analyst	30 mins per month
Place referrals for bridge counseling services into CAREWare using the electronic referral functionality	Data Quality Analyst	1 day per week
Conduct bridge counseling activities	Patient Navigators	1 day per week
Resolve all current referrals by completing the case closure process.	Bridge Counselor	½ hour per day
Review all client records (if utilizing external retention staff) and finalize outcomes. Refer "Located, not re-engaged in care to date" or Unknown-not located" to SBC	Bridge Counselor	(included in 1 day per week)
Once the SBC finalizes counseling activities, review the outcomes of all the client cases completed by the SBC and ensure enrollment statuses are updated as appropriate per the SBCs findings.	Bridge Counselor	(included in 1 day per week)

Discuss Activity and Q&A with Local Staff

John Switzer– Data Manager

Emily Andrews – Patient Navigator

Share experiences and answer audience questions

Data Manager Q&A

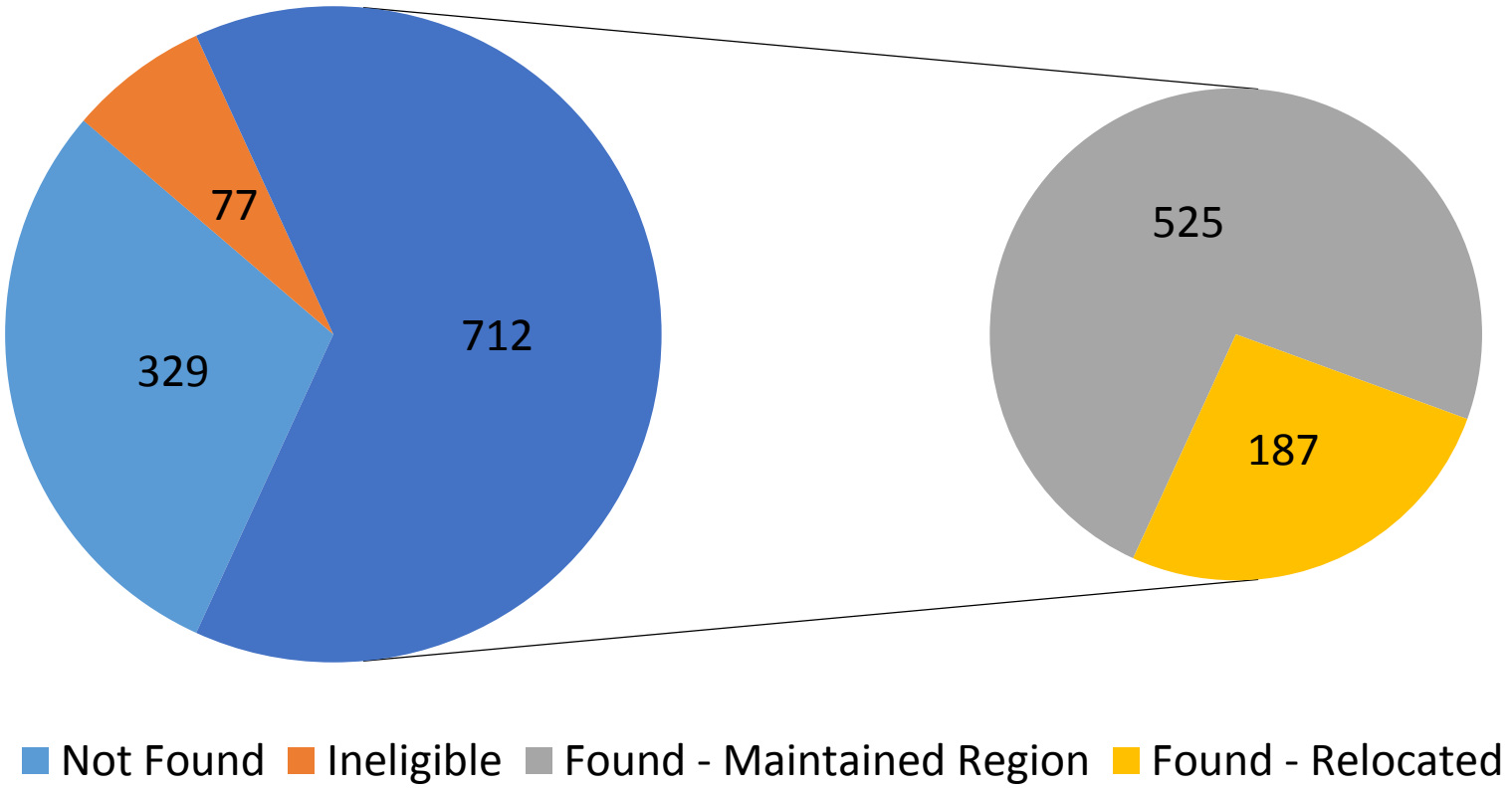
- What are some common issues that come up with running the list?
- What are some of the common technical or programmatic issues with referrals?
- What do you do for folks who have been on the list for more than one month?

Patient Navigator Q&A

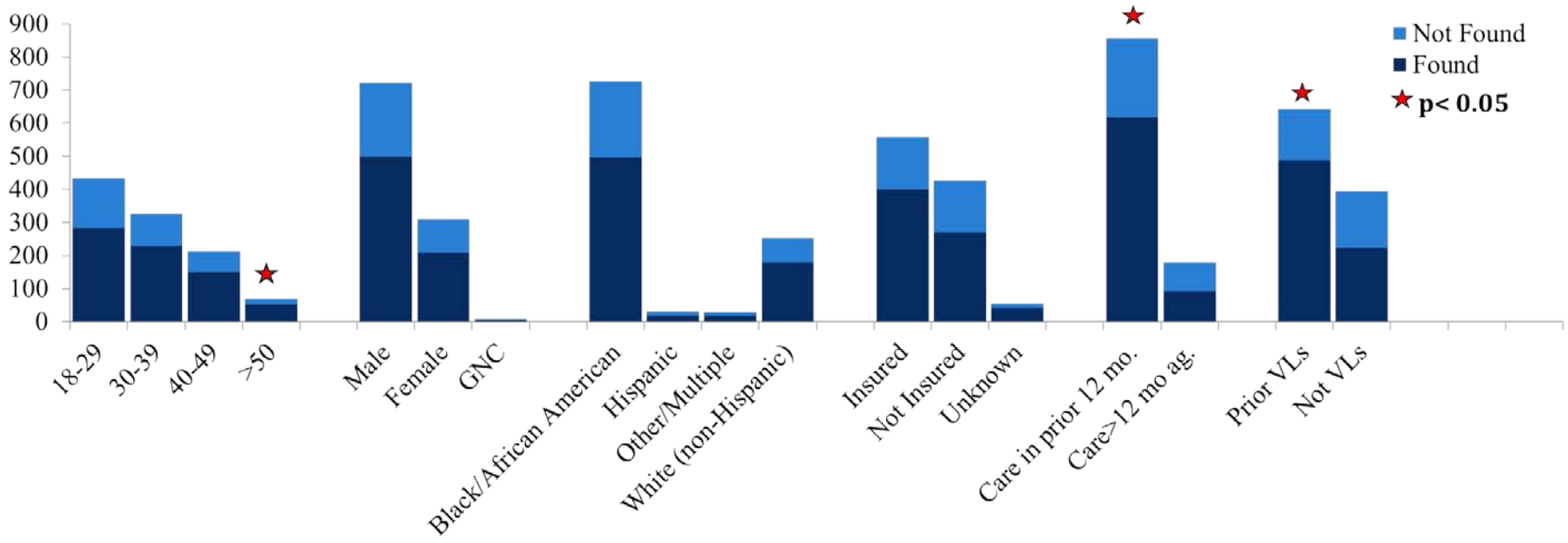
- What is your process after receiving a referral? – is there a strategy for the order in the list?
- What seems to be your most useful retention strategy? What about search strategy?
- Can you share some information about the amount of time/effort spent looking for patients

Outcomes of the NC LINK Retention Intervention

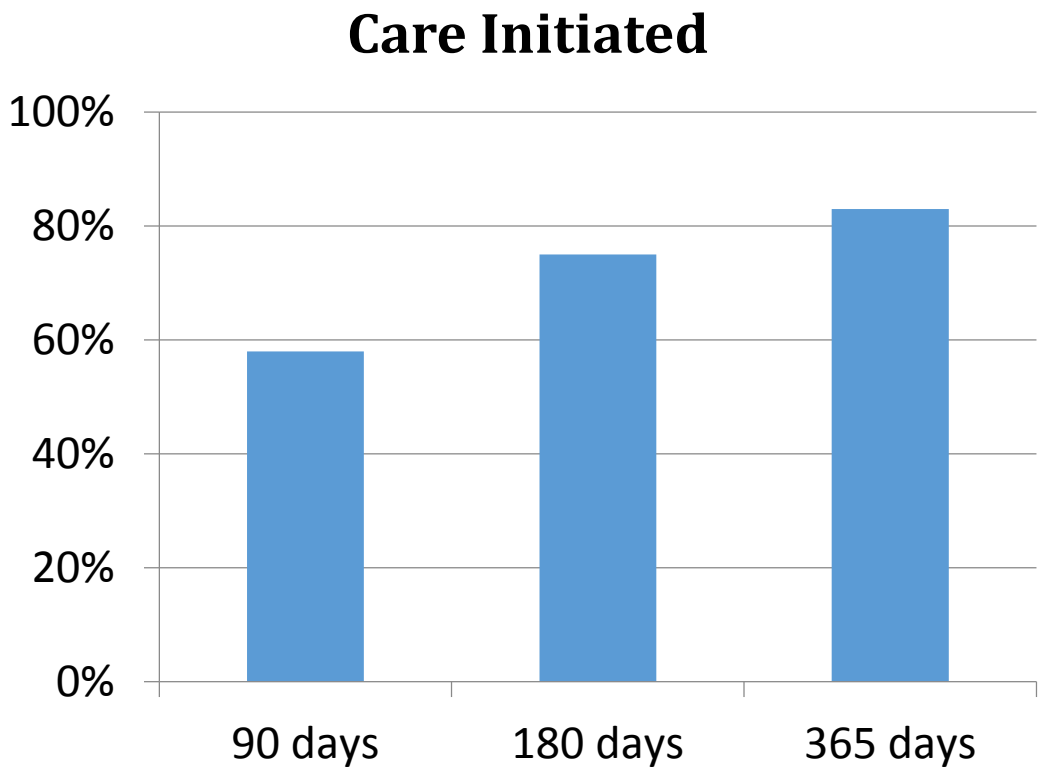
Retention Intervention Outcome among PLWH who were identified as Out-of-Care



Characteristics of Eligible Out-of-Care PLWH
(Not found = 329; Found = 712)

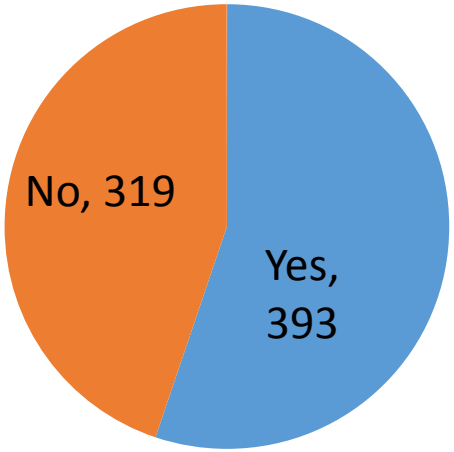


HIV Care Outcomes: Care Initiated

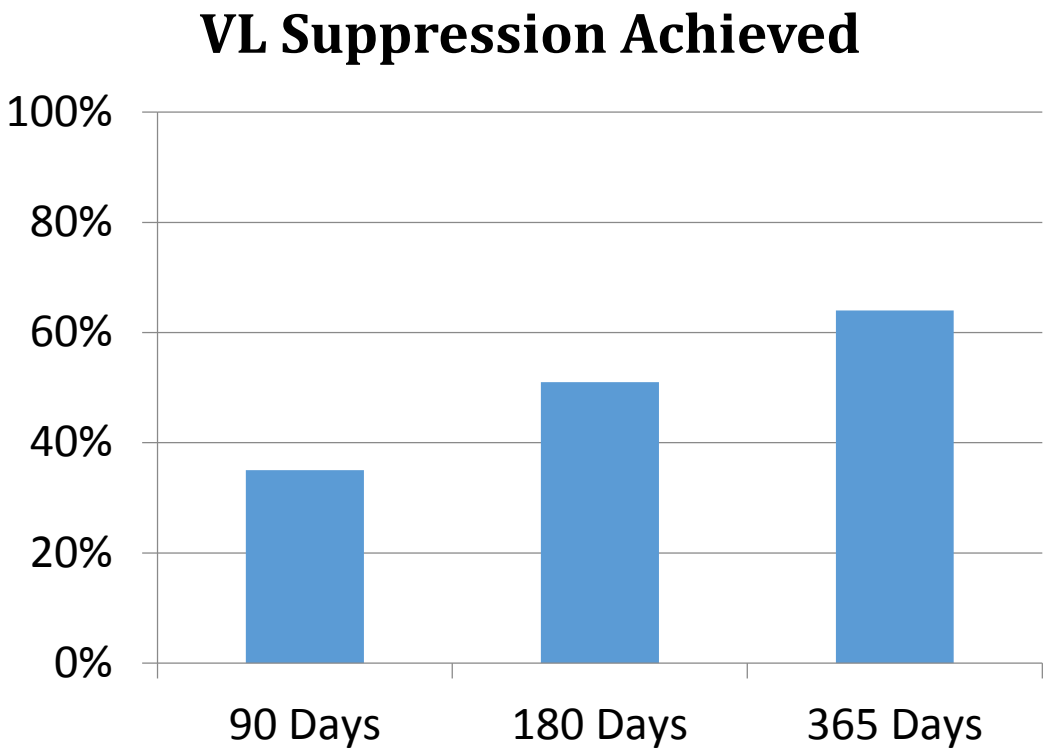


HIV Care Outcomes: HAB Measure

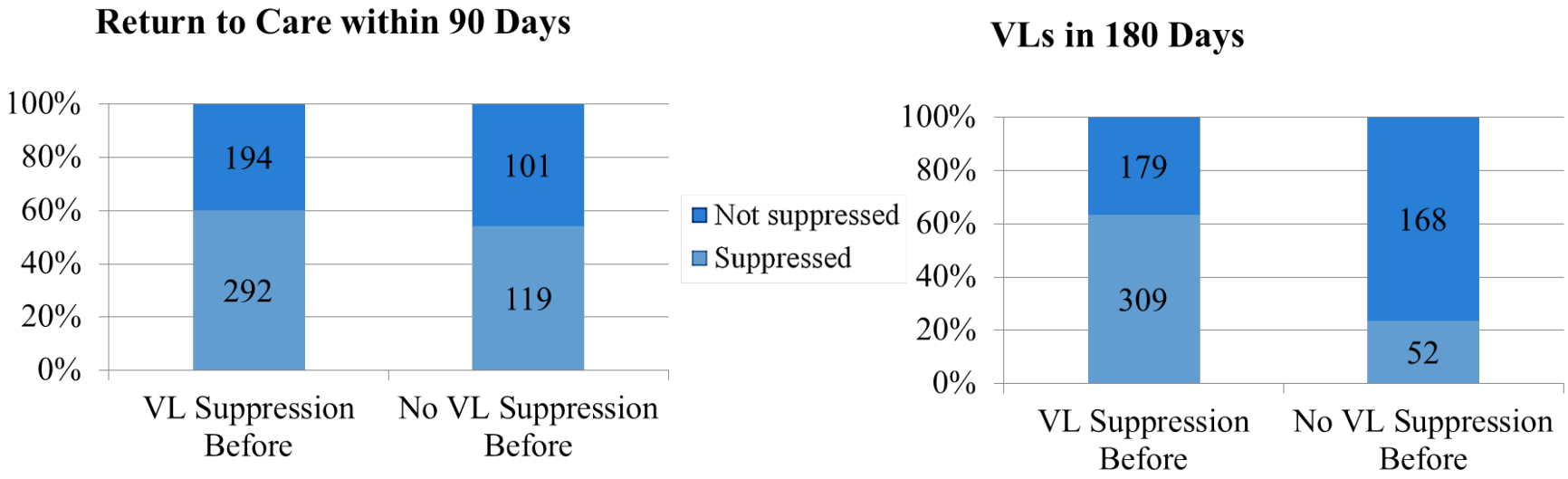
Meets Retention in Care HAB Measure: 2 care markers > 90 days apart



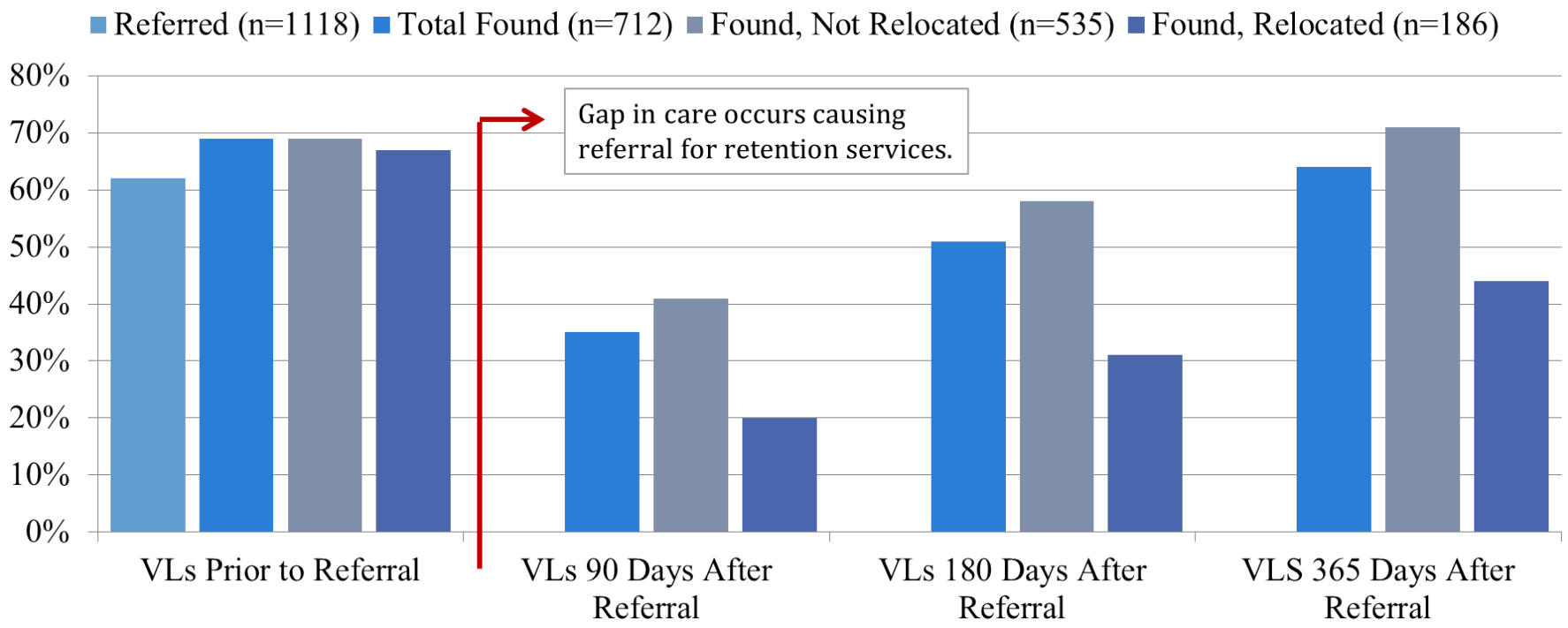
HIV Care Outcomes: VL Suppression



Outcomes Based on Prior Viral Load Suppression



12 Month VL Suppression by Retention Outcome



Questions?