Why does linkage & retention in care matter?

- 40% of PLWHA in the US are linked and retained in care; California: 38%¹
- Not being retained in care for 24 months after diagnosis (DHHS definition of 2 visits for each 6-month period at least 60 days apart) is associated with all-cause mortality: HR 2.36²
- Having >2 missed visits after diagnosis is associated with all-cause mortality: HR 3.20³
- For those retained in care, having >2 missed visits is associated with mortality: HR 3.61²
- PLWHA not diagnosed or retained in care are responsible for 92% of HIV transmissions³
- PLWHA not retained in care are responsible for 61% of HIV transmissions³
- If we get 90% of PLWHA diagnosed and 90% on ART, we could reduce HIV incidence by 50%⁴

### 3 steps & 3 levels for improving retention in care

<table>
<thead>
<tr>
<th>① Track</th>
<th>② Follow-up</th>
<th>③ Connect</th>
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</thead>
<tbody>
<tr>
<td>✭ act on missed visits&lt;br&gt; ✭ track gaps in care &gt;6 months&lt;br&gt; ✭ ask about adherence</td>
<td>✭ do personal reminder calls immediately after a missed visit&lt;br&gt; ✭ implement follow-up protocols for missed visits and gaps in care</td>
<td>✭ provide a reliable way to reach your team directly and quickly&lt;br&gt; ✭ one-on-one adherence counseling&lt;br&gt; ✭ ask about health beliefs&lt;br&gt; ✭ provide once daily regimens, pill boxes, adherence reminders</td>
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<td>✭ track those not retained in care&lt;br&gt; ✭ track missed refills</td>
<td>✭ implement multi-disciplinary team follow-up protocols including how the team reviews tracking data &amp; delegates follow-up</td>
<td>✭ provide strengths-based intensive case management (ARTAS)&lt;br&gt; ✭ build a coalition with testing and care sites&lt;br&gt; ✭ involve patient input on programs and services</td>
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<tr>
<td>✭ track &gt;2 missed visits&lt;br&gt; ✭ use public health surveillance data to monitor new diagnoses and those lost to care</td>
<td>✭ use data systematically to allocate resources&lt;br&gt; ✭ multi-disciplinary team meets regularly to analyze data and develop personalized action plans</td>
<td>✭ train peers to provide strengths-based case management&lt;br&gt; ✭ rapid ART&lt;br&gt; ✭ develop coordinated warm hand-off and retention protocols with the coalition with testing and care sites</td>
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References: ¹ eHARS data, 2011-2013, ² Mugavero, CID 2014, ³ Skarbinski, JAMA 2015, ⁴ Kelly, JAIDS 2015
A summary of evidence-based strategies for retention in care

The following is summarized from a 2015 literature review conducted by a working group with the East Bay Linkage & Retention network as well as the 2012 Thompson et. al. Annals of Internal Medicine article, *Guidelines for Improving Entry Into and Retention in Care and Antiretroviral Adherence for Persons With HIV: Evidence-Based Recommendations From an International Association of Physicians in AIDS Care Panel*.

**Most highly recommended practices**
[Level IA & IIA: strong recommendations with excellent or high quality evidence]
- Monitor entry into care and have a follow-up plan for no-shows
- Monitor retention in care, including no-show rates and gaps in care
- Obtain self-reported adherence: anything less than “excellent” is suspect
- Educate on specific adherence tools: pillboxes, medi-sets, phone alarms, daily triggers
- One-on-one ART education
- One-on-one adherence counseling
- Provide pillbox organizers for homeless patients

**Moderately recommended practices**
[Level I-IIIB: moderate recommendations with excellent, high or medium quality evidence]
- Strength-based case management, especially during the first 3 months in care
- Multidisciplinary education and counseling: engage other members of the care team; the patient may connect with particular team members
- Monitor pharmacy refill data and contact patients if refills are not picked up on time
- Use reminder devices for adherence
- Use once-daily ART regimens
- Case management for homeless patients
- Youth-focused support interventions

**Unrated practices that have been studied and have shown efficacy in some settings**
- **Assess client** for depression, substance use, housing, transportation, childcare, food insecurity, IPV and/or health beliefs that may interfere with engaging in care
- **Financial/travel/food incentives** for certain patients: the impact for financial incentives is greatest when used for smaller, non-hospital-based clinics and in patients with histories of not being virally suppressed (2015 HPTN 065 TLC+ study, CROI)
- **Rapid ART** (offering ART the same day as diagnosis) has been shown in RCTs to reduce mortality 12-months after diagnosis in Haiti (Koenig, AIDS 2016), increase uptake of ART by 36% in South Africa (Rosen 2016, CROI abstract 28) and from 85% to 100% in San Francisco (Pilcher, JAIDS 2016), increase viral load suppression rates in South Africa by 26%, and increase retention in care 6-months after diagnosis from 85% to 90% in San Francisco.
East Bay HIV Linkage & Retention Advisory Group
Warm Hand-off and Retention Protocols

• When a client is identified to be
  • newly diagnosed and not yet engaged in HIV primary care
  • transferring from one provider to another or recently moved to area
  • transferring from the jail, and/or
  • out of care
  • For clients with a preliminary positive rapid test, proceed with linkage process on the same day and if possible, obtain and process a confirmatory test specimen.
  • Obtain a release of information for the agencies you will be coordinating care with.

• Referring worker discusses and decides on HIV care site with client, based on client preferences.
• Referring worker may consult the East Bay HIV Clinic List via Google document: [http://tinyurl.com/alcohiv](http://tinyurl.com/alcohiv) or [https://docs.google.com/document/d/1qoojV5ch12Oh8jZoaPMDsE6GxCK8idZrogkJ4EmRPMig/edit?usp=sharing](https://docs.google.com/document/d/1qoojV5ch12Oh8jZoaPMDsE6GxCK8idZrogkJ4EmRPMig/edit?usp=sharing)
• Referring worker calls the receiving worker and/or clinic to obtain intake appointment time. Ideally the phone number is one that can be answered immediately or responded to within an hour.
• If a message is left, the receiving worker is expected to respond to the message within 3 business days.
• Referring worker gets a current and reliable phone number and address for client (when possible) and shares the contact with receiving worker.

• Referring worker, client, and receiving worker agree on an intake appointment date and time.
• Ideally this will be at a time where the client, referring worker, receiving worker, and provider can be present.
• Ideally the intake appointment will be within 2 weeks and at the latest within 1 month.
• Referring and receiving workers provide direct contact phone numbers (ideally cell numbers) to the client.

• If permitted/desired by client, referring worker accompanies or meets the client at the receiving care site.
• Referring worker ensures that the client and receiving agency has the information, records and release of information needed for continuity of care, and introduces her/him to the receiving worker.
• Optional: referring worker stays with client for the intake visit.
• If the client does not show up, the referring worker immediately tries to contact the client for follow-up.
• In a case when the referring worker is not able to attend the appointment or be involved in the linkage, the receiving worker notifies the referring worker, via phone or secure or encrypted email message, that the client successfully attended the intake appointment and saw the provider.
• Receiving worker asks about, identifies and addresses the client's immediate needs (health beliefs, insurance, resources for mental health, IPV and substance abuse, housing, transportation, food, benefits, etc.).

• Referring worker contacts the receiving worker to confirm if the client continues to actively receive HIV medical care with labs, medication refills and/or provider visits.
• If active HIV medical care can be confirmed in 3 months, the referring worker closes the client's linkage case.
• If a client has not followed up in 3 months and neither the receiving nor referring worker is able to contact or locate the client, please work with Georgia Schreiber at the Alameda County Department of Public Health: Georgia.Schreiber@acgov.org, 510-268-7650.

+For additional help if clients are lost to follow-up, and/or identifying whether clients are in jail, newly diagnosed or previously diagnosed, you may contact Georgia Schreiber: Georgia.Schreiber@acgov.org or 510-268-7650. For problems related to organizations involved in this warm hand-off process, please contact Dr. Nicholas Moss, Director of the HIV STD Section at Nicholas.Moss@acgov.org or 510-268-7635.

This document was last updated August 18, 2016.
Retention Protocol

Assessment questions to include at client interviews (initial and annual):
Research shows that discussing the following topics with clients helps retain them in care.

**Health beliefs:** to discuss with care team
What do you think about having HIV? Taking HIV medications? Coming to clinic appointments?

**Depression – (PHQ2):** for provider counseling and behavioral health referrals. During the last month...
1. Have you often been bothered by feeling down, depressed, or hopeless?
2. Have you often been bothered by little interest or pleasure in doing things?

**Substance use screening – (CAGE questionnaire):** for substance abuse counseling
1. Have you ever felt you ought to cut down on your drinking or drug use?
2. Have people annoyed you by criticizing your drinking or drug use?
3. Have you felt bad or guilty about your drinking or drug use?
4. Have you ever had a drink or used drugs first thing in the morning to steady your nerves or to get rid of a hangover (eye-opener)?

**Food insecurity:** for food resource referrals. During the last month...
1. How often did you eat less than you felt you needed to because there wasn’t enough money for food?
2. How often were you worried that you might run out of food before you got more money?
3. How often couldn’t you afford to eat balanced meals?

**Intimate partner violence (IPV):** for counseling and referrals
1. Have you ever been emotionally or physically abused by your partner or someone important to you?
2. Are you afraid of a past or current partner?
3. Has anyone forced you to have sexual activities?

**Intensive support in the first 3-6 months of care:**
1. Develop a system for making ~3 contacts (phone, text, in-person) with a new client in the first 3 months to ensure they are getting the services they need and have your direct contact number.
2. Provide personal outreach reminders for at least the first 3 medical visits and/or in-person counseling follow-up during those visits.
3. For harder-to-reach clients, consider accompanying the client to the first 3 medical visits.

**When a patient misses a visit: follow-up at the time of the missed visit**
1. The MA or case manager attempts to contact the patient on the same day via phone and/or emergency contacts (family, partner, etc.). If patient is reached, our staff checks to see how the patient is doing and reschedules the appointment time accordingly.
2. If there are urgent issues, the patient is rescheduled on the same day and at least within a week.
3. If there are no urgent issues, the patient is rescheduled within the next month.
4. If unable to reach the patient the same day, the HIV case manager or linkage coordinator is alerted and will attempt to reach the patient over the next month via phone, text message, and email.
5. An update about patient contact is given to the provider each week.
6. If the patient cannot be reached by phone, text message or email within a month, send a certified letter to the patient’s address.
7. If the patient still has not responded and/or her/his status has not been verified (e.g. successfully transferred care to another provider) within 3 months, for Alameda County clinics, the MA or case manager will contact Georgia Schreiber at the Alameda County Department of Public Health, to investigate the patient’s care status: Georgia.Schreiber@acgov.org, 510-268-7650. For patients in other counties, please contact your HIV public health case investigators.
8. Documentation of patient outreach is completed in the chart.
When patients have not been seen in the last 3-6 months (out of care)

1. At least once per month a member of the HIV team prints a list of the patients who have not been seen at the clinic in the last 3 months and/or 6 months.
2. The patient’s travel and incarceration status is reviewed by the clinician. For example, the patient is known to be traveling or abroad, and has a follow-up plan upon return.
3. The HIV case manager is alerted and will attempt to reach the patient over the next month via phone, text message, and email.
4. Attempts to contact the patient will be recorded in the NextGen telephone template.
5. An update about patient contact is given to the provider each week.
6. If the patient cannot be reached by phone, text message or email within a month, we will send a certified letter to the patient’s address.
7. If the patient still has not responded and/or her/his status has not been verified (e.g. successfully transferred care to another provider) within 1 month, the HIV Coordinator will contact Georgia Schreiber, Linkage Coordinator at the Alameda County Department of Public Health, to investigate the patient’s care status: Georgia.Schreiber@acgov.org, 510-268-7650.

Patients who miss more than 2 visits in a 24-month period

Rationale: Patients who miss more than 2 visits in a 24-month period are at higher risk for mortality (2014 Mugarvero, et. al.). These are patients who may benefit from proactive intensive case management and hence increase their chances for long-term retention in care and adherence to medications.

• Missed visit definition = patient does not contact us to cancel, reschedule, or come to the appointment
1. Patients with >2 missed visits in a 24-month period will be flagged on the tracking/registry sheet
   • The HIV team case manager will monitor # of missed visits/24 months, and flag
   • The tracking sheet will be updated and shared with the team weekly or at least monthly
2. Personalized intensive case management and retention plans will be developed for each patient

When to mark patients “inactive”

1. Patient is confirmed to have transferred care to another HIV provider (including while incarcerated).
   a. Patient verbally confirms and is able to name the new HIV provider and date of the next visit.
   b. Provider (including jail or prison) confirms transfer of care, verbally or in written form.
   c. Nursing home residence with HIV consultation confirmed with patient, nursing home staff, or HIV consultant
   d. The Public Health Department confirms that the patient has moved out of the region and/or has transferred care to another HIV provider.
2. Patient is confirmed to be deceased by public health or a death registry report.

Strategies for clients with difficulty engaging in care

1. Assess client for depression, substance use, housing, transportation, childcare, food insecurity, IPV and/or health beliefs that may interfere with engaging in care
2. Engage other members of the care team; the patient may connect with particular team members
3. Personalized case management services: youth-focused support, personality matches, etc.
4. Use motivational and strengths-based counseling techniques
5. Provide one-on-one ART and adherence education and counseling
6. Provide pillbox organizers or ask pharmacies to dispense medications in medi-sets
7. Share other adherence tools: cell phone reminders, triggers during their usual daily routine
8. Monitor pharmacy refill data and contact client has not picked them up
9. Consider using financial/travel/food incentives for certain patients
Building a linkage & retention collaborative learning network: our experience in the East Bay, CA

Sophy S. Wong, MD

Purpose:
We worked with the Alameda County Office of AIDS in Oakland, CA to build a linkage and retention collaborative learning network in the East Bay region of the California Bay Area to address our drop-off in care between diagnosis and treatment for HIV. At the time of our launch in 2012, only 40% of people living with HIV/AIDS (PLWHA) in the US were estimated to be linked and retained in care, and only an estimated 37% of PLWHA in Alameda County were linked and retained in care.\(^1\) There is evidence that not being retained in care is a significant marker for mortality (HR 2.36-3.61),\(^2\) and those not yet linked or retained in care account for 92% of new HIV transmissions.\(^3\)

Our goal was to build a stronger system and network for HIV diagnosis, linkage to and retention in care in order to reduce mortality rates from HIV infection and to reduce new infections.

The larger group meets in person four times a year to discuss and implement practices in linkage and retention, including once during the East Bay HIV Update conference. Participants include case managers, social workers, clinic managers and administrators, and program staff from the East Bay agencies who provide HIV testing, linkage and care services, as well as staff from Alameda, Contra Costa and Solano County Departments of Public Health. As of November 2017, we have 128 active members in our email network, and 40-60 people who participate at each in-person meeting.

At a glance: 2013-2017 East Bay linkage/retention network

<table>
<thead>
<tr>
<th>2013</th>
<th>2014</th>
<th>2015</th>
<th>2016</th>
<th>2017</th>
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<tbody>
<tr>
<td>70%</td>
<td>73%</td>
<td>83%</td>
<td>94%</td>
<td>90%</td>
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Data notes: Linkage rates for 2012-2013 include all Alameda County (by labs within 90 days of diagnosis in eHARS) and 2014-2016 linkage rates include HIV ACCESS RW-C clinics (by attended HIV medical visit within 90 days of diagnosis in the clinic EHR).
More details about our processes:

- **2012:**
  - development of a local HIV care cascade
  - analysis of local linkage and retention rates
  - sub-analysis of demographics least likely to be retained in care or virally suppressed

- **2013:**
  - February 28, 2013: inaugural linkage & retention network meeting at the Alameda County Office of AIDS

  During this inaugural meeting, we presented the local HIV care cascade, linkage and retention rates and sub-analyses. We presented some potential strategies to improve our linkage and retention rates, and the participants voted on their top choices. This inspired an open discussion and helped surface a glaring need for community communication standards between staff at difference organizations (for example, knowing whom to call at a clinic and timely call-backs and responses). Collectively, we decided that we needed more opportunities to get to know each other face-to-face, an updated direct contact list, and a one-page warm hand-off protocol that outlines expectations of how and when a staff member should respond to calls for linkage to care. To develop the warm hand-off protocol, we presented a draft of a linkage protocol that was in use at one of our network clinics, and in the large group had facilitated discussions to determine standard response times, times to initial HIV care visits, and resources. All network members are welcome to provide input, share, and participate by email when unable to attend in person.

  Documents and resources developed in 2013:
  - **Shared definitions:** development of shared definitions of linkage to care (HIV medical visit kept with an HIV care plan in place after diagnosis)
  - **Network contact list:** single points of contact and important information needed about agencies, whom they can serve, which insurance plans they receive, etc.
  - **Warm hand-off protocol:** development and implementation of a shared warm hand-off protocol through which agencies agree to try to provide more responsive and intensive support to clients who are newly diagnosed and facilitate their linkage to care, with in-person options when available; the original goals are to have an intake within 3 days and the initial HIV care visit within 2 weeks.

- **2014:**
  - In 2014 the Affordable Care Act (ACA) was implemented, which significantly increased Medicaid coverage for our clients, and also resulted in complex and sometimes confusing transitions in care and medication coverage that our network members had to help clients navigate. To respond to this need, we held trainings on the ACA transitions. Other high priority areas of need included support services for people with mental health and substance abuse disorders, so trainings were also held on these topics. We further strengthened the development of our linkage and retention protocols by adding Pay-for-Performance funding for HIV ACCESS (Ryan White Part C) clinics to have comprehensive protocols written and in place.

  Network activities accomplished in 2014:
  - Affordable Care Act implementation and benefits transitions trainings and [cheat-sheet](#)
  - Mental Health resources and training
Substance Abuse resources and training
- HIV ACCESS pay-for-performance program including the development and implementation of linkage and retention protocols
- Continuous updates in contact list and warm hand-off protocols
- Linkage & retention protocols

- **2015:**
  Network members continue to request more training and support around strategies for helping clients with substance abuse and mental health disorders link and stay in care, so we formed a working group to conduct a literature review on evidence-based interventions for these populations. With the publication of HPTN 065 (TLC-Plus), there was interest in piloting ways to effectively use financial incentives to engage difficult-to-reach clients in care. We also explored the possibility of getting our updated linkage contact list online through the OneDegree platform.

Network activities accomplished in 2015:
- Best practices literature review and trainings
- Incentives: development of pilot programs
- Skills-based trainings in strategies to facilitate connection with clients
- Framework for linkage & retention document
- Exploration of online contact/collaborative platforms: One Degree
- Continuous updates in contact list and warm hand-off and linkage & retention protocols

- **2016**
  Network members request strengthening systems with the county jail, Santa Rita Jail, so we have a meeting with the Santa Rita Jail HIV provider and discharge planner to help us understand the system and how we may improve it. Members also request skills-based trainings for mindfulness and client-centered approaches, which we incorporate to each of our half-day meetings. With the implementation of rapid ART more widely in San Francisco, there is now interest in the East Bay to also implement, which we will be exploring as an integrated part of the warm handoff and linkage protocols.

Network activities accomplished in 2016:
- Santa Rita Jail: understanding transitions in and out of the county jail
- Skills-based trainings in self-care and supporting resilience among clients
- Rapid ART: sharing experiences from San Francisco and developing our plan
- Comprehensive Integrated HIV plan input
- Continuous updates in contact list and warm hand-off and linkage & retention protocols
- Youth services workshop: improving engagement of young people into HIV services

- **2017**
  We have integrated our activities into the larger, community-wide East Bay Getting to Zero collaborative efforts. Network members identified priority areas for interventions to improve linkage and retention: updates in access to health care (eligibility, insurance), addressing LGBTQ cultural competency and disparities in the African American community with improvements in counseling and communication skills, access to resources.

Network activities accomplished in 2017:
- Updates in health care access workshop
- Sex Positivity training
- Getting to Zero strategic action planning workshop
Rapid ART protocols have been implemented in the RW Part C community health clinics
Integration into East Bay Getting to Zero as one of the key strategies and working groups

Example network meeting and training agenda:

November 16, 2017 Getting to Zero workshop: HIV epi updates and strategic action planning

Learning objectives:
1. Review the most current Getting to Zero efforts, local HIV epidemiology and testing/care data.
2. Identify the top 2 goals/metrics for linkage/retention.
3. Determine at least 2 new or modified collaborative action steps for improving HIV linkage and retention outcomes and address disparities that we will work on in the next 6 months.

Outcome metrics: increased retention rate among clients served by participants in the next 12 months.

Agenda:
9:00 am: arrival, sign-in, networking and snacks
9:15 am: introductions and networking activity
9:40 am: warm hand-off linkage success stories
9:45 am: ACPHD updates, Retention Group report-back, Covered CA guide and other announcements
9:50 am: Background & update in Alameda County HIV linkage/retention epidemiology
10:00 am: Contra Costa HIV epidemiology update (Martin Lynch, CCHSD)
10:15 am: Overview of Getting to Zero and Fast Track City efforts
10:20 am: Q&A, discussion
10:30 am: break
10:40 am: Lessons Learned from the SF GTZ retention working group (Miguel Ibarra, SFDPH)
11:00 am: Action planning!
  • Examples of action projects: evidence-based interventions & innovative projects
  • Invitation for other action planning ideas, poll and vote on top-choice topics
11:15 am: Action planning small groups: choose your project group!
11:35 am: large group report-back on action project goal(s), steps and timelines
11:50 am: wrap-up summary and plan for next session

Outcomes:

Resources & documents:
  o Warm hand-off and linkage and retention protocols
  o Affordable Care Act transitions cheat sheet
  o Best practice literature review summary
  o Framework for linkage & retention

Linkage rates for Alameda County:
• 2012 county-wide baseline 90-day linkage rate = 70% (HIV labs done at least once after diagnosis)
• 2013 county-wide linkage rate (program launch year) = 73%
• 2014 HIV ACCESS (Ryan White Part C community health clinics) linkage rate = 83%
• 2015 HIV ACCESS linkage rate = 94%
• 2016 HIV ACCESS linkage rate = 90%

For more information, check out our website: www.BayAreaAETC.org