A strategic framework for improving linkage & retention in HIV care

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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 2.36[2]
- Having >2 missed visits after diagnosis is associated with all-cause mortality: HR 3.20[2]
- For those retained in care, having >2 missed visits is associated with mortality: HR 3.61[2]
- PLWHA not diagnosed or retained in care are responsible for 92% of HIV transmissions[3]
- PLWHA not retained in care are responsible for 61% of HIV transmissions[3]
- 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

★starred items indicate that they've been studied with at least moderate-to-high quality evidence

	Pick low-hanging fruit. 	**Level-up!** 	**Master it.** 
① **Track**	★ act on missed visits ★ track gaps in care >6 months ★ ask about adherence	★ track those not retained in care ★track missed refills	★ track >2 missed visits ● use public health surveillance data to monitor new diagnoses and those lost to care
② **Follow-up**	★do personal reminder calls immediately after a missed visit ● implement follow-up protocols for missed visits and gaps in care	★ implement multi-disciplinary team follow-up protocols including how the team reviews tracking data & delegates follow-up	● use data systematically to allocate resources ★ multi-disciplinary team meets regularly to analyze data and develop personalized action plans
③ **Connect**	● provide a reliable way to reach your team directly and quickly ★one-on-one adherence counseling ★ ask about health beliefs ★ provide once daily regimens, pill boxes, adherence reminders	★provide strengths-based intensive case management (ARTAS) ● build a coalition with testing and care sites ● involve patient input on programs and services	★train peers to provide strengths-based case management ● develop coordinated warm hand-off and retention protocols with the coalition with testing and care sites

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 presented at CROI]

East Bay HIV Linkage & Retention Advisory Group

Warm Hand-off and Retention Protocols

client identified

- **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.

phone contact

- 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* or *https://docs.google.com/document/d/1qooJV5cH12OH8jZoPMDsE6GxCK8lDZroqlj4EmRPMig/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.

appointment coordination

- 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.

intake appointment

- 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.).

3-month follow-up

- 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 Kelly Stempel at the Alameda County Department of Public Health: Kelly.Stemple@acgov.org or 510-268-7649

+For additional help if clients are lost to follow-up, and/or identifying whether clients are in jail, newly diagnosed or previously diagnosed, for new diagnoses you may contact Kelly Stempel at the Department of Public Health Kelly.Stemple@acgov.org or 510-268-7649 for people who have been in care but are now lost to follow-up, 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.

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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 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, Linkage Coordinator 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.

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