A strategic framework for improving linkage & retention in HIV care
February 2016 * Sophy S. Wong, MD

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

<table>
<thead>
<tr>
<th>Pick low-hanging fruit.</th>
<th>Level-up!</th>
<th>Master it.</th>
</tr>
</thead>
<tbody>
<tr>
<td>① Track</td>
<td>② Follow-up</td>
<td>③ Connect</td>
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<tr>
<td>★ act on missed visits</td>
<td>★ do personal reminder calls immediately after a missed visit</td>
<td>★ provide a reliable way to reach your team directly and quickly</td>
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<tr>
<td>★ track gaps in care &gt;6 months</td>
<td>★ implement multi-disciplinary team follow-up protocols including how the team reviews tracking data &amp; delegates follow-up</td>
<td>★ one-on-one adherence counseling</td>
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<tr>
<td>★ ask about adherence</td>
<td>★ implement follow-up protocols for missed visits and gaps in care</td>
<td>★ ask about health beliefs</td>
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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

• 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 or https://docs.google.com/document/d/1qooJrV5ch12OH8jZaPMDoEsE6GxCK8lDZroQjAErPMLg/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/wished 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, the case may be referred to Georgia Schreiber, Linkage to Care Coordinator Georgia.Schreiber@acgov.org or 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 at the Department of Public Health at: Georgia.Schreiber@acgov.org or 510-268-7650

+For filing grievance, contact Keith C. Waltrip at the Office of AIDS keith.waltrip@acgov.org or 510.268.7653

This document was last updated May 14, 2015.
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 (no-show)
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.
   For patients in other counties, please contact your HIV public health case investigators.
8. Documentation of patient outreach is completed in the chart.

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.
Adherence Counseling at each visit

1. Assess adherence in a neutral and open way:
   a. Over the last 30 days, how would you rate your adherence? Excellent, very good, good, fair, or poor. (Anything less than excellent has been associated with viral rebound.)
   b. How are you doing with your medications?
   c. How many doses do you think you missed in the last month?
   d. How many doses did you take more than an hour off your scheduled time?
   e. What time are you taking your medications? What reminders do you use? Is it working for you?
   f. Viral loads: show how viral load measures correlate with adherence
   g. Look for lab clues: AZT and \( \uparrow \text{MCV} \); ATV and \( \uparrow \text{bili} \); cobi and DLG \( \uparrow \text{Scr} \)

2. Check pharmacy refills: were the medications completed and refills picked up on time?

3. Listen and try to understand beliefs around medications

4. Assess side effects

5. Review strengths with adherence, ask about needs and expectations

6. Reinforce that the highest level of adherence possible will have best outcomes.

7. Create an action plan for adherence. Evidence-based strategies (2004 APHA) include:
   a. Tailor the regimen to the patient’s needs and schedule
   b. Simplify the regimen and reduce side effects when possible
   c. Address and treat side effects
   d. Pill boxes / medi-sets
   e. Alarms: on phone, on clock
   f. Incorporate pill taking with daily cues: brushing teeth, taking a shower, breakfast, TV show, etc.
   g. Address cultural issues and beliefs: cold/hot, stigma, etc.
   h. Regular, consistent clinic visits to provide medication reconciliation and counseling
   i. Enlist the help of the team (MA, program coordinator, providers)
   j. If available: consider incentives for coming in and demonstrating viral load suppression

8. Document the counseling done in the progress note

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. Consider using financial/travel/food incentives for certain patients

Assessment questions: validated screening tools

**Depression – (PHQ2):**
1. During the past month, have you often been bothered by feeling down, depressed, or hopeless?
2. During the past month, have you often been bothered by little interest or pleasure in doing things?

**Substance use – (CAGE questionnaire):**
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)?

**Intimate partner violence (IPV, HITS screener):** How often does your partner....
1. Physically hurt you?  
2. Insult you or talk down to you?  
3. Threaten you with harm?  
4. Scream or curse at you?