Linkage to care demonstration project: 
A Practice Based Intervention to facilitate emotional and cognitive responses for rapid linkage to HIV care

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Los Angeles LGBT Center

- Main Location: Hollywood
  - HIV Testing & Counseling
  - STI Clinic
  - HIV Clinic
  - Pharmacy
  - Mental Health Services
  - Substance Use Treatment

- The SPOT (located in a popular club area)
  - HIV Testing & Counseling
  - STI Testing & Treatment
Los Angeles LGBT Center

HIV Testing Visits 2013 = 16,091 (no prior positive)
Unique Testers 2013 = 11,030 (no prior positive)
Incident (acute) HIV 2013 = 257 incident infections
HIV Positivity Rate 2013 = 2.89% (among MSM alone)

LTC Rate Jan-Mar 2014 (all) = 85%
Linkage rates prior to application for Grant

• Our first methodologically rigorous linkage study in 2009 found a rate of only 46% (linkage within 6 months of diagnosis)

• Structural interventions beginning in mid-2010 led to an average linkage rate of 69% by the end of the first quarter of 2011 (we added staff to both the testing and HIV clinics, and set protected HIV clinic appointment slots for newly diagnosed individuals).
  – November 2011: PATH Grant was submitted with an intervention intended to address the 69% LTC rate

• Addition of a Clinical Linkage Specialist (an LCSW who had been a mental health counselor in our Mental Health Clinic) in 2/2012 increased the linkage rate to 85-90% by the time of the Grant award.
Challenges to Protocol Development and Implementation

- Interventions described (post grant submission/pre-award) had already significantly improved our LTC rate, so grant intervention originally planned was no longer relevant. What kind of intervention would be informative?

- Yet we wanted to investigate the possible contribution of some, as yet unexplored, potential barriers during this very critical time.

- Often emotionally fraught nature of HIV diagnosis disclosure session does not lend itself to traditional research methods with extensive data collection instruments and rigid fidelity to procedure.
Challenges to Protocol Development and Implementation

• Investigation team was a collaboration of clinic based and public health based investigators. Not all were clinically experienced, resulting in significant challenges to finding a balance between the need for good data and the need to be completely responsive to the emotional needs of the client.

• We needed to develop a new instrument which, although modified and fashioned after other validated instruments, was not itself validated for use in this particular setting.
So, what did we do?

• We took a nontraditional approach:
  – Identified that we already had a successful process as our SOC
  – Working backwards we used qualitative interviews and data to deconstruct and then formally articulate the elements of our SOC approach
  – This process was one of using Practice Based Evidence (successful LTC rate) to inform our protocol so that it could be replicable
Our LTC intervention

• Characterizes linkage to care as a non-linear constellation of actions and choices, which are influenced by qualitative, behavioral and structural elements
• Describes the detailed steps in our disclosure and linkage process
• Seeks to determine whether the existence of certain specific early affective responses in an individual with a new HIV diagnosis can predict the prompt linkage or failure to link to HIV care
• Uses these findings to develop a Best Practices Protocol for linkage to care that can be replicated in other testing and clinical settings.
Clinical Linkage Specialist Program

- **Goals and Objectives**
  - Primary goal: capture core components of the linkage to care program at the LAGLC Sexual Health Program and evaluate feasibility, acceptability and success rate of using them to achieve LTC within 3 months of Dx.
  - Secondary goals *(and this is the research question)*:
    - Identify factors positively and negatively associated with rapid linkage to care
    - Document proportion of clients retained in care at 12 months
    - Administer cognitive/affective survey within 2 weeks of HIV diagnosis to evaluate possible barriers and facilitators to linkage to and retention in care
## Initial Affective and Cognitive Attributes Survey (IACAS)

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Not Sure</th>
<th>Agree</th>
<th>Strongly Agree</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>FEAR ASSESSMENT</strong></td>
<td></td>
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<tr>
<td>1. Getting into care would make me feel less afraid of dying.</td>
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<td>2</td>
<td>3</td>
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<tr>
<td>2. I am afraid of what may happen to me as a result of the HIV infection.</td>
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<td>2</td>
<td>3</td>
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<td>5</td>
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<tr>
<td>3. I believe that treatment for HIV may be harmful to me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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</tr>
<tr>
<td>4. I am afraid I will infect others.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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<tr>
<td><strong>STIGMA ASSESSMENT</strong></td>
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<tr>
<td>5. Family and/or friends will avoid me.</td>
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<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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</tr>
<tr>
<td>6. Family and/or friends will look down on me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>7. Family and/or friends will treat me differently.</td>
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<td>2</td>
<td>3</td>
<td>4</td>
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</tr>
<tr>
<td>8. Health care workers will treat me differently because of HIV.</td>
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<tr>
<td>9. Health care workers will treat me differently because of alcohol or drug use.</td>
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<td>2</td>
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<td>10. HIV makes me feel like a bad person.</td>
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<td>2</td>
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<td>4</td>
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<tr>
<td>11. I feel ashamed because of HIV.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<td>12. Having HIV is disgusting to me.</td>
<td>1</td>
<td>2</td>
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<tr>
<td><strong>KNOWLEDGE ASSESSMENT</strong></td>
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<td>13. I believe I can rely on my body to tell me if or when the HIV is making me sick.</td>
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<td>2</td>
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<td>14. I believe there is a benefit for a doctor to help me monitor my health with HIV</td>
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<td>2</td>
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<td>15. I believe it’s important to start taking HIV medications as soon as possible</td>
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<td>2</td>
<td>3</td>
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<tr>
<td>16. I am concerned about the details of my HIV infection remaining private</td>
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<td>2</td>
<td>3</td>
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<td>5</td>
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<tr>
<td>17. If I am not living healthy, including drinking and using drugs, HIV treatment will not be effective.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td><strong>ASSESSMENT OF ATTITUDES, BELIEFS, OTHER</strong></td>
<td></td>
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<tr>
<td>18. Now that I’m HIV positive I am worried about the people who depend on me</td>
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<td>2</td>
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<td>5</td>
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</tr>
<tr>
<td>19. There are people in my life who I can count on to help me deal with this</td>
<td>1</td>
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</tbody>
</table>
Clinical Linkage Specialist – Intervention Phase 1

Counseling and support at delivery of HIV test result

- Administers a Verbal Consent to clients who are interested
- Uses a Client-centered approach with motivational interviewing
- Focuses on a client’s immediate reactions to receipt of an HIV positive diagnosis
- Identifies needs targeting linkage to care
- If possible, administers IACAS and use client’s responses to inform this and subsequent discussions
- Frames care as helpful, adaptive response to diagnosis and emphasizes process of adjustment to normalize fears and worries
- Is highly flexible
- Develops action plan for linkage
- Arranges for follow up (phone or in person)
Clinical Linkage Specialist – Intervention Phase 2

Immediate Follow-up and Support

- Follows up (phone &/or face to face) w/in 24 - 72 hours of initial diagnosis
- Administers survey, if not already done, using client’s responses to inform this and subsequent discussions
- If client is ready for linkage, assists with needed referrals
- Encourages face to face check-ins during other clinic appointments
- Continues flexibility and stresses CLS availability to promote a sense of responsive care system
- Continues emphasis on client’s personal strengths and social support, helps client develop concrete skills to navigate care
Tailored, increasing or decreasing outreach based on linkage status

- Administers IACAS at 3 and 6 months post-enrollment
- For those who link, tapers contacts as retention established
- For those who don’t link, intensified and targeted outreach
  - Promotes linkage by introduction of client to care team members to help establish relationships
  - If missed appointments, CLS begins intensified outreach to explore issues/barriers/challenges
- If all attempts are rebuffed, CLS continues to make periodic attempts to re-engage client by remaining supportive and continuing to build trust and support
Screening and Recruitment

- Enrollment started March 2014
- Data through 5/28/2014, Screened: n=74

- Enrolled: n=20 (27%)
  - Linked to care: n=4
  - Average time to link to care: 5 days (range: 1-15 days)

- Not enrolled: n=54 (73%)
  - Ineligible due to enrollment criteria (n=24)
    - Almost all were “unable to contact client”
  - Already positive (n=13)
  - Linked to care previously or at another facility (n=7)
  - Not clinically appropriate (n=2)
    - Too emotionally distraught
  - Declined (n=3)
  - No reason given (n=5)
Lessons Learned

• Flexibility and balance is required when conducting research in a clinical setting, especially when the emotional needs of the client and flow requirements of a high volume clinic are paramount

• Clinical staff must be involved but in collaboration with other trans-disciplinary team members

• In this endeavor informing your protocols from Practice Based Evidence should be seriously considered.