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## MEMO

TO: Members, Comprehensive HIV Planning Committee

FROM: Members, Transgender Special Study Advisory Committee

DATE: February 12, 2013

RE: Recommendations in response to the Special Study on access to HIV care and services among transgender consumers in the EMA

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The Transgender Special Study Advisory Committee has reviewed the results of the Special Study on access to HIV services by transgender consumers and recommends the following activities in order to best meet the needs of this population going forward:

1. Using the recommended two-step method of asking both natal sex and current gender expression, the Special Study was able to survey 135 transgender-identified consumers. The Committee recommends that future data collection by the Planning Council continue to utilize this national standard.
2. The Special Study queried topics of concern for the general HIV positive population that were not included in past HIV/AIDS Needs Assessments; specifically, experience with violence, discrimination, and stigma. The Committee recommends that future HIV/AIDS Needs Assessments include questions about these topics to better understand their prevalence in the general HIV positive population.
- 3. Differential treatment by ASO staff specifically due to gender non-conformity was cited as a barrier to seeking HIV services by 29% of the consumers in the Special Study. The Committee recommends that frontline HIV prevention and care staff, including Case Managers, Service Linkage Workers, and front desk/telephone staff, receive training on culturally sensitive interactions with transgender clients. The Committee further recommends that such training include an overview of national and local policies that prohibit discrimination of transgender people in such areas as housing, employment, and public restroom usage, so they may educate their transgender clients about their rights and options.**
- 4. Lack of transportation was cited most often (44%) by the transgender consumers in the Special Study as a barrier to seeking HIV services in the EMA. Often, this was due to fear of how people on public transportation would react to their transgender status. A majority of respondents also had prior experiences with differential treatment in public places due to gender non-conformity, and 6% reported fear of leaving their home at all. The Committee recommends that agencies explore ways to conduct HIV service visits with transgender clients (as clinically indicated) via telephone or internet so as to ensure that services are accessed by this population in light of the barriers revealed by the Special Study. The Committee would also like to see revisions made to the Ryan White Part A/B/State Services Standards of Care to incorporate this recommendation.**
5. Lastly, the Committee recommends sharing the results of this Special Study with funded ASOs for the purpose of engaging in dialogue about additional improvements to HIV care in the EMA for transgender clients. As feasible, these presentations could be followed by technical assistance in how to implement new approaches.

## MEMO

TO: How to Best Meet the Need (HTBMN) Workgroups

FROM: Members, Serving the Incarcerated and Recently Released (SIRR)  
Partnership of Greater Houston

DATE: March 27, 2013

RE: Recommendations in Response to the Special Study on the Referral  
Process for HIV Positive Post-Release Offenders

SIRR has reviewed the preliminary results of the Special Study on HIV positive post-release offenders and recommends the following activities in order to best meet the needs of this population going forward:

1. The recently released consumers who participated in the Special Study reported a need for support groups specifically for HIV positive post-release offenders. SIRR recommends that language be added to the Mental Health service category stating that services provided under this category will have “special attention” to the Special Populations identified in the *2012 Houston Area Comprehensive Plan for HIV Prevention and Care Services*:
  - Adolescents
  - Homeless
  - Incarcerated & Recently Released (IRR)
  - Injection Drug Users (IDU),
  - Men who Have Sex with Men (MSM)
  - Transgender
2. Survey participants were asked to rank a variety of services on a scale of importance upon release from incarceration. Transportation to their HIV medical appointment was ranked 3<sup>rd</sup> most important of all services listed. However, transportation services are not provided upon release from incarceration. To fill this gap in needed services, SIRR recommends that bus passes be distributed through the Early Intervention Services (EIS) program at the Harris County Jail to EIS clients upon discharge.
3. **When HIV medical care was delayed upon re-entry into the community, survey participants cited “I didn’t know where to go [for HIV services]” as the primary reason for delaying care. In addition, only 12.5% of respondents stated that they met with staff from a community-based HIV care services agency prior to release, and only 10.4% received a referral to a community-based HIV services provider. SIRR recommends that the HTBMN workgroups explore ways to increase linkages between HIV service providers and HIV positive offenders prior to their release into the community.**





<p>Services to be Provided:</p>	<p><b>B. Youth targeted Service Linkage, Care and Prevention:</b> Services will be available to eligible HIV-infected and at-risk HIV-negative Youth (ages 13 – 24) residing in the Houston EMA/HSDA with priority given to clients most in need. All Youth who receive services will be served without regard to age (i.e. limited to those who are between 13-24 years of age), gender, race, color, religion, national origin, sexual orientation, or handicap. Services will target low income Youth at risk for, or living with, HIV/AIDS who demonstrate multiple medical, mental health, substance use/abuse and psychosocial needs including, but not limited to: mental health counseling, substance abuse treatment, primary medical care, specialized care, alternative treatment, medications, placement in a medical facility, emotional support, basic needs for food, clothing, and shelter, transportation, legal services and vocational services. Services will also target Youth who cannot function in the community due to barriers which include, but are not limited to, mental illness and psychiatric disorders, drug addiction and substance abuse, extreme lack of knowledge regarding available services, inability to maintain financial independence, inability to complete necessary forms, inability to arrange and complete entitlement and medical appointments, homelessness, deteriorating medical condition, illiteracy, language/cultural barriers and/or the absence of speech, sight, hearing, or mobility.</p> <p><b>Youth Targeted Service Linkage, Care and Prevention</b> is intended to serve eligible youth in the Houston EMA/HSDA, especially those underserved or unserved population groups which include: African American, Hispanic/Latino, Substance Abusers, Homeless and Gay/Lesbian/Transsexual.</p> <p><b>Goal (A): Service Linkage:</b> The expectation is that a single Service Linkage Worker Full Time Equivalent (FTE) targeting Not-In-Care and/or newly-diagnosed PLWHA can serve approximately 80 <u>newly-diagnosed or not-in-care</u> PLWH/A per year.</p> <p>The purpose of <b>Service Linkage</b> is to assist clients with the procurement of needed services so that the problems associated with living with HIV are mitigated. <b>Service Linkage</b> is a working agreement between a client and a Service Linkage Worker (SLW) for an indeterminate period, based on client need, during which information, referrals and service linkage are provided on an as-needed basis. The purpose of <b>Service Linkage</b> is to assist clients who do not require the intensity of <i>Clinical or Medical Case Management</i>, as determined by RWGA Quality Management guidelines. <b>Service Linkage</b> is both <u>office- and field-based</u> and <b>may include the issuance of bus pass vouchers and gas cards per published guidelines</b>. Service Linkage targeted to Not-In-Care and/or Newly-Diagnosed PLWHA extends the capability of existing programs with a documented track record of identifying Not-In-Care and/or newly-diagnosed PLWHA by providing “hands-on” outreach and linkage to care services to those PLWHA who are not currently accessing primary medical care services.</p>
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<p>Service Unit Definition(s): <b>RWGA Only</b></p> <p>Financial Eligibility:</p> <p>Client Eligibility:</p> <p>Agency Requirements: <b>RWGA Only</b></p>	<p>In order to ensure linkage to an ongoing support system, eligible clients identified funded under this contract, including clients who may obtain their medical services through non-Ryan White-funded programs, must be transferred to a Ryan White-funded Primary Medical Care, Clinical Case Management or Service Linkage program within 120 days of initiation of services as documented in both ECLIPS and CPCDMS data systems. Those clients who choose to access primary medical care from a non-Ryan White source, including private physicians, <u>may receive ongoing service linkage services from provider</u> or must be transferred to a Clinical (CCM) or Primary Care/Medical Case Management site per client need and the preference of the client.</p> <p><b>GOAL (B):</b> This effort will continue a program of <i>Service Linkage, Care and Prevention to Engage HIV Seropositive Youth</i> targeting youth (ages 13-24) with a focus on Youth of color. This service will support an innovative service model designed to reach HIV seropositive youth of color not engaged in clinical care and to link them to appropriate clinical, supportive, and preventive services. The specific objectives are to: (1) conduct outreach (service linkage) to assist seropositive Youth learn their HIV status, (2) link HIV-infected Youth with primary care services, and (3) prevent transmission of HIV infection from targeted clients.</p> <p>One unit of service is defined as 15 minutes of direct client services and allowable charges.</p> <p>Refer to the RWPC’s approved <i>FY 2014 Financial Eligibility for Houston EMA Services</i>.</p> <p>A. Not-In-Care and/or newly-diagnosed HIV-infected individuals residing in the Houston EMA.</p> <p>B. High Risk HIV-negative, not-in-care and/or newly-diagnosed HIV-infected Youth residing in the Houston EMA.</p> <p><b>Service Linkage</b> services will comply with the HCPHES/RWGA published <b>Service Linkage</b> Standards of Care and policies and procedures as published and/or revised, including linkage to the CPCDMS data system.</p> <p><u>Agency must comply with all applicable City of Houston DHHS ECLIPS and RWGA/HCPHES CPCDMS business rules and policies &amp; procedures.</u></p> <p><b>Service Linkage</b> targeted to High Risk HIV-negative, Not-In-Care and/or newly diagnosed PLWHA must be planned and delivered in coordination with local HIV prevention/outreach programs to avoid duplication of services and be designed with quantified program reporting that will accommodate local effectiveness evaluation. Contractor must document established linkages with agencies that serve HIV-infected clients or serve individuals who are members of high-risk population groups (e.g., men who have sex with men, injection drug users, sex-industry workers, youth who are sentenced under the juvenile justice system, inmates of state and local jails and prisons). Contractor must have formal collaborative, referral or Point of Entry (POE) agreements</p>
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<p>Staff Requirements:</p>	<p>with Ryan White funded HIV/AIDS primary care providers.</p> <p>Service Linkage Workers must spend at least 42% (867 hours per FTE) of their time providing direct client services. Direct service linkage and case management services include any activities with a client (face-to-face or by telephone), communication with other service providers or significant others to access client services, monitoring client care, and accompanying clients to services. Indirect activities include travel to and from a client's residence or agency, staff meetings, supervision, community education, documentation, and computer input. Direct case management activities must be documented in the CPCDMS according to system business rules.</p> <p><i>Must comply with applicable HCPHES/RWGA published Ryan White Part A/B Standards of Care:</i></p> <p><u>Minimum Qualifications:</u></p> <p><b>Service Linkage Workers</b> must have at a minimum a Bachelor's degree from an accredited college or university with a major in social or behavioral sciences. Documented paid work experience in providing client services to PLWH/A may be substituted for the Bachelor's degree requirement on a 1:1 basis (1 year of documented paid experience may be substituted for 1 year of college). All Service Linkage Workers must have a minimum of one (1) year paid work experience with PLWHA.</p> <p><u>Supervision:</u></p> <p>The Service Linkage Worker must function within the clinical infrastructure of the applicant agency and receive ongoing supervision that meets or exceeds HCPHES/RWGA published Ryan White Part A/B Standards of Care for Service Linkage.</p>
<p>Special Requirements: <b>RWGA only</b></p>	<p>Contractor must be have the capability to provide Public Health Follow-Up by qualified Disease Intervention Specialists (DIS) to locate, identify, inform and refer newly-diagnosed and not-in-care PLWHA to outpatient primary medical care services.</p> <p>Contractor must perform CPCDMS new client registrations and, for those newly-diagnosed or out-of-care clients referred to non-Ryan White primary care providers, semi-annual registration updates for those needing ongoing service linkage services as well as those clients who may only need to establish system of care eligibility. Contractor must issue bus pass vouchers and gas cards in accordance with HCPHES/RWGA policies and procedures.</p>

**FY 2014 RWPC “How to Best Meet the Need” Decision Process**

<b>Step in Process: Council</b>		Date: <b>06/13/13</b>
Recommendations:	Approved: Y_____ No: _____ Approved With Changes:_____	If approved with changes list changes below:
1.		
2.		
3.		
<b>Step in Process: Steering Committee</b>		Date: <b>06/06/13</b>
Recommendations:	Approved: Y_____ No: _____ Approved With Changes:_____	If approved with changes list changes below:
1.		
2.		
3.		
<b>Step in Process: Quality Assurance Committee</b>		Date: <b>05/16/13</b>
Recommendations:	Approved: Y_____ No: _____ Approved With Changes:_____	If approved with changes list changes below:
1.		
2.		
3.		
<b>Step in Process: HTBMTN Workgroup</b>		Date: <b>04/18/13</b>
Recommendations:	Financial Eligibility:	
1.		
2.		
3.		

**2013-2014 HOUSTON ELIGIBLE METROPOLITAN AREA: RYAN WHITE CARE  
ACT PART A/B  
STANDARDS OF CARE FOR HIV SERVICES**

**RYAN WHITE GRANT ADMINISTRATION SECTION  
HARRIS COUNTY PUBLIC HEALTH AND ENVIRONMENTAL SERVICES (HCPHES)**

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## INTRODUCTION

According to the Joint Commission on Accreditation of Healthcare Organization (JCAHO) 2008)<sup>1</sup>, a standard is a “statement that defines performance expectations, structures, or processes that must be in place for an organization to provide safe, high-quality care, treatment, and services”. Standards are developed by subject experts and are usually the minimal acceptable level of quality in service delivery. The Houston EMA Ryan White Grant Administration (RWGA) Standards of Care (SOCs) are based on multiple sources including RWGA on-site program monitoring results, consumer input, the US Public Health Services guidelines, Centers for Medicare and Medicaid Conditions of Participation (COP) for health care facilities, JCAHO accreditation standards, the Texas Administrative Code, Center for Substance Abuse and Treatment (CSAT) guidelines and other federal, state and local regulations.

## Purpose

The purpose of the Ryan White Part A/B SOCs is to determine the minimal acceptable levels of quality in service delivery and to provide a measurement of the effectiveness of services.

## Scope

The Houston EMA SOCs apply to Part A, Part B and State Services, funded HRSA defined core and support services including the following services in FY 2012-2013:

- *Primary Medical Care*
- *Vision Care*
- *Medical Case Management*
- *Clinical Case Management*
- *Local AIDS Pharmaceutical Assistance Program \*LPAP)*
- *Oral Health*
- Health insurance
- Hospice Care
- Mental Health Services
- *Substance Abuse services*
- Home & Community Based Services (Facility-Based)
- Early Intervention Services
- *Legal Services*
- *Medical Nutrition Supplement*
- *Non-Medical Case Management (Service Linkage)*
- Food Bank
- *Transportation*
- Linguistic Services

*Part A funded services*

## Standards Development

The first group of standards was developed in 1999 following HRSA requirements for sub grantees to implement monitoring systems to ensure subcontractors complied with contract requirements.

Subsequently, the RWGA facilitates annual work group meetings to review the standards and to make applicable changes. Workgroup participants include physicians, nurses, case managers and executive staff from subcontractor agencies as well as consumers.

## Organization of the SOCs

The standards cover all aspect of service delivery for all funded service categories. Some standards are consistent across all service categories and therefore are classified under general standards. These include:

- Staff requirements, training and supervision
- Client rights and confidentiality
- Agency and staff licensure
- Emergency Management

The RWGA funds three case management models. Unique requirements for all three case management service categories have been classified under Service Specific SOCs “Case Management (All Service Categories)”. Specific service requirements have been discussed under each service category. All new and/or revised standards are effective at the beginning of the fiscal year.

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<sup>1</sup> The Joint Commission on Accreditation of Healthcare Organization (2008). Comprehensive accreditation manual for ambulatory care; Glossary

## GENERAL STANDARDS

	Standard	Measure
<b>1.0</b>	<b>Staff Requirements</b>	
1.1	<p><u>Staff Screening (Pre-Employment)</u>            Staff providing services to clients shall be screened for appropriateness by provider agency as follows:</p> <ul style="list-style-type: none"> <li>• Personal/Professional references</li> <li>• Personal interview</li> <li>• Written application</li> </ul> <p>Criminal background checks, if required by Agency Policy, must be conducted prior to employment and thereafter for all staff and/or volunteers per Agency policy.</p>	<ul style="list-style-type: none"> <li>• Review of Agency's Policies and Procedures Manual indicates compliance</li> <li>• Review of personnel and/or volunteer files indicates compliance</li> </ul>
1.2	<p><u>Initial Training: Staff/Volunteers</u>            Initial training includes eight (8) hours HIV/AIDS basics, safety issues (fire &amp; emergency preparedness, hazard communication, infection control, universal precautions), confidentiality issues, role of staff/volunteers, agency-specific information (e.g. Drug Free Workplace policy). Initial training must be completed within 60 days of hire.</p>	<ul style="list-style-type: none"> <li>• Documentation of all training in personnel file.</li> <li>• Specific training requirements are specified in Agency Policy and Procedure</li> <li>• Materials for staff training and continuing education are on file</li> <li>• Staff interviews indicate compliance</li> </ul>
1.3	<p><u>Staff Performance Evaluation</u>            Agency will perform annual staff performance evaluation.</p>	<ul style="list-style-type: none"> <li>• Completed annual performance evaluation kept in employee's file</li> <li>• Signed and dated by employee and supervisor (includes electronic signature)</li> </ul>
1.4	<p><u>Cultural and HIV Mental Health Co-morbidity Competence Training/Staff and Volunteers</u>            All staff must receive four (4) hours of cultural competency training and an additional one (1) hour of HIV/Mental Health co-morbidity sensitivity training annually. All new employees must complete these within ninety (90) days of hire.</p>	<ul style="list-style-type: none"> <li>• Documentation of training is maintained by the agency in the personnel file</li> </ul>
1.5	<p><u>Staff education on eligibility determination and fee schedule</u>            Agency must provide training on agency's policies and procedures for eligibility determination and sliding fee</p>	Documentation of training in employee's record

	<p>schedule for, but not limited to, case managers, and eligibility &amp; intake staff annually.</p> <p>All new employees must complete within ninety (90) days of hire.</p>	
<b>2.0</b>	<b>Services utilize effective management practices such as cost effectiveness, human resources and quality improvement.</b>	
2.1	<p><u>Service Evaluation</u></p> <p>Agency has a process in place for the evaluation of client services.</p>	<ul style="list-style-type: none"> <li>• Review of Agency's Policies and Procedures Manual indicates compliance</li> <li>• Staff interviews indicate compliance.</li> </ul>
2.2	<p><u>Subcontractor Monitoring</u></p> <p>Agency that utilizes a subcontractor in delivery of service, must have established policies and procedures on subcontractor monitoring that include:</p> <ul style="list-style-type: none"> <li>• Fiscal monitoring</li> <li>• Program</li> <li>• Quality of care</li> <li>• Compliance with guidelines and standards</li> </ul> <p>Reviewed Annually</p>	<ul style="list-style-type: none"> <li>• Documentation of subcontractor monitoring</li> <li>• Review of Agency's Policies and Procedures Manual indicates compliance</li> </ul>
2.3	<p><u>Staff Guidelines</u></p> <p>Agency develops written guidelines for staff, which include, at a minimum, agency-specific policies and procedures (staff selection, resignation and termination process, job descriptions); client confidentiality; health and safety requirements; complaint and grievance procedures; emergency procedures; and statement of client rights.</p> <p>Reviewed Annually</p>	<ul style="list-style-type: none"> <li>• Personnel file contains a signed statement acknowledging that staff guidelines were reviewed and that the employee understands agency policies and procedures</li> </ul>
2.4	<p><u>Work Conditions</u></p> <p>Staff/volunteers have the necessary tools, supplies, equipment and space to accomplish their work.</p>	<ul style="list-style-type: none"> <li>• Inspection of tools and/or equipment indicates that these are in good working order and in sufficient supply</li> <li>• Staff interviews indicate compliance</li> </ul>
2.5	<p><u>Staff Supervision</u></p> <p>Staff services are supervised by a paid coordinator or manager.</p>	<ul style="list-style-type: none"> <li>• Review of personnel files indicates compliance</li> <li>• Review of Agency's Policies and Procedures Manual indicates</li> </ul>

		compliance
2.6	<u>Professional Behavior</u> Staff must comply with written standards of professional behavior.	<ul style="list-style-type: none"> <li>• Staff guidelines include standards of professional behavior</li> <li>• Review of Agency's Policies and Procedures Manual indicates compliance</li> <li>• Review of personnel files indicates compliance</li> <li>• Review of agency's complaint and grievance files</li> </ul>
2.7	<u>Communication</u> There are procedures in place regarding regular communication with staff about the program and general agency issues.	<ul style="list-style-type: none"> <li>• Review of Agency's Policies and Procedures Manual indicates compliance</li> <li>• Documentation of regular staff meetings</li> <li>• Staff interviews indicate compliance</li> </ul>
2.8	<u>Accountability</u> There is a system in place to document staff work time.	<ul style="list-style-type: none"> <li>• Staff time sheets or other documentation indicate compliance</li> </ul>
2.9	<u>Staff Availability</u> Staff are present to answer incoming calls during agency's normal operating hours.	<ul style="list-style-type: none"> <li>• Published documentation of agency operating hours</li> <li>• Staff time sheets or other documentation indicate compliance</li> </ul>
<b>3.0</b>	<b><u>Clients Rights and Responsibilities</u></b>	
3.1	<u>Clients Rights and Responsibilities</u> Agency has a Client Rights and Responsibilities Statement that is reviewed with each client in a language and format the client can understand. Agency will provide client with written copy of client rights and responsibilities, including: <ul style="list-style-type: none"> <li>• Informed consent</li> <li>• Confidentiality</li> <li>• Grievance procedures</li> <li>• Duty to warn or report certain behaviors</li> <li>• Scope of service</li> <li>• Criteria for end of services</li> </ul>	<ul style="list-style-type: none"> <li>• Documentation in client's record</li> </ul>
3.2	<u>Confidentiality</u> Agency has Policy and Procedure regarding client confidentiality in accordance with RWGA /TRG site visit	<ul style="list-style-type: none"> <li>• Review of Agency's Policies and Procedures Manual indicates compliance</li> <li>• Clients interview indicates compliance</li> </ul>

	<p>guidelines, local, state and federal laws. Providers must implement mechanisms to ensure protection of clients' confidentiality in all processes throughout the agency.</p> <p>There is a written policy statement regarding client confidentiality form signed by each employee and included in the personnel file.</p>	<ul style="list-style-type: none"> <li>• Agency's structural layout and information management indicates compliance</li> <li>• Signed confidentiality statement in each employee's personnel file</li> </ul>
3.3	<p><u>Consents</u></p> <p>All consent forms comply with state and federal laws, are signed by an individual legally able to give consent and must include the Consent for Services form and a consent for release/exchange of information for every individual/agency to whom client identifying information is disclosed, regardless of whether or not HIV status is revealed.</p>	<ul style="list-style-type: none"> <li>• Agency Policy and Procedure and signed and dated consent forms in client record</li> </ul>
3.4	<p><u>Up to date Release of Information</u></p> <p>Agency obtains an informed written consent of the client or legally responsible person prior to the disclosure or exchange of certain information about client's case to another party (including family members) in accordance with the RWGA Site Visit Guidelines, local, state and federal laws. The release/exchange consent form must contain:</p> <ul style="list-style-type: none"> <li>• Name of the person or entity permitted to make the disclosure</li> <li>• Name of the client</li> <li>• The purpose of the disclosure</li> <li>• The types of information to be disclosed</li> <li>• Entities to disclose to</li> <li>• Date on which the consent is signed</li> <li>• The expiration date of client authorization (or expiration event) no longer than two years</li> <li>• Signature of the client/or parent, guardian or person authorized to sign in lieu of the client.</li> <li>• Description of the <i>Release of Information</i>, its components, and ways the client can nullify it</li> </ul> <p>Released/exchange of information forms must be completed</p>	<ul style="list-style-type: none"> <li>• Current Release of Information form with all the required elements signed by client or authorized person in client's record</li> </ul>

	entirely in the presence of the client. Any unused lines must have a line crossed through the space.	
3.5	<p><u>Grievance Procedure</u> Agency has Policy and Procedure regarding client grievances that is reviewed with each client in a language and format the client can understand and a written copy of which is provided to each client.</p> <p>Grievance procedure includes but is not limited to:</p> <ul style="list-style-type: none"> <li>• to whom complaints can be made</li> <li>• steps necessary to complain</li> <li>• form of grievance, if any</li> <li>• time lines and steps taken by the agency to resolve the grievance</li> <li>• documentation by the agency of the process, including a standardized grievance/complaint form available in a language and format understandable to the client</li> <li>• all complaints or grievances initiated by clients are documented on the Agency's standardized form</li> <li>• resolution of each grievance/complaint is documented on the Standardized form and shared with client</li> <li>• confidentiality of grievance</li> <li>• addresses and phone numbers of licensing authorities and funding sources</li> </ul>	<ul style="list-style-type: none"> <li>• Signed receipt of agency Grievance Procedure, filed in client chart</li> <li>• Review of Agency's Policies and Procedures Manual indicates compliance</li> <li>• Review of Agency's Grievance file indicates compliance,</li> <li>• Source Citation: HAB Monitoring Standards; Part I: Universal Standards; Section A: Access to Care #2</li> </ul>
3.6	<p><u>Conditions Under Which Discharge/Closure May Occur</u> A client may be discharged from Ryan White funded services for the following reasons.</p> <ul style="list-style-type: none"> <li>• Death of the client</li> <li>• At the client's or legal guardian request</li> <li>• Changes in client's need which indicates services from another agency</li> <li>• Fraudulent claims or documentation about HIV diagnosis by the client</li> <li>• Client actions put the agency, case manager or other clients at risk. Documented supervisory review is</li> </ul>	<ul style="list-style-type: none"> <li>• Documentation in client record and in the Centralized Patient Care Data Management System</li> <li>• A copy of written notice and a certified mail receipt for involuntary termination</li> </ul>

	<p>required when a client is terminated or suspended from services due to behavioral issues.</p> <ul style="list-style-type: none"> <li>• Client moves out of service area, enters jail or cannot be contacted for sixty (60) days. Agency must document three (3) attempts to contact clients by more than one method (e.g. phone, mail, email, text message, in person via home visit).</li> <li>• Client service plan is completed and no additional needs are identified.</li> </ul> <p>Client must be provided a written notice prior to involuntary termination of services (e.g. due to dangerous behavior, fraudulent claims or documentation, etc.).</p>	
3.7	<p><u>Client Closure</u></p> <p>A summary progress note is completed in accordance with Site Visit Guidelines within three (3) working days of closure, including:</p> <ul style="list-style-type: none"> <li>• Date and reason for discharge/closure</li> <li>• Summary of all services received by the client and the client's response to services</li> <li>• Referrals made and/or</li> <li>• Instructions given to the individual at discharge (when applicable)</li> </ul>	<ul style="list-style-type: none"> <li>• Documentation in client record and in the Centralized Patient Care Data Management System</li> </ul>
3.8	<p><u>Client Feedback</u></p> <p>In addition to the RWGA standardized client satisfaction survey conducted on an ongoing basis (no less than annually), Agency must have structured and ongoing efforts to obtain input from clients (or client caregivers, in cases where clients are unable to give feedback) in the design and delivery of services. Such efforts may include client satisfaction surveys, focus groups and public meetings conducted at least annually. Agency may also maintain a visible suggestion box for clients' inputs. Analysis and use of results must be documented. Agency must maintain a file of materials documenting Consumer Advisory Board (CAB)</p>	<ul style="list-style-type: none"> <li>• Documentation of clients' evaluation of services is maintained</li> <li>• Documentation of CAB and public meeting minutes</li> <li>• Documentation of existence and appropriateness of a suggestion box or other client input mechanism</li> <li>• Documentation of content, use, and confidentiality of a client satisfaction survey or focus groups conducted annually</li> <li>• Source Citation: HAB Monitoring Standards; Part I: Universal Standards; Section A: Access to Care #1</li> </ul>

	<p>membership and meeting materials (applicable only if agency has a CAB).</p> <ul style="list-style-type: none"> <li>Agencies that serve an average of 100 or more unduplicated clients monthly under combined RW/A, MAI, RW/B and SS funding must implement a CAB. The CAB must meet regularly (at least 4 times per year) at a time and location conducive to consumer participation to gather, support and encourage client feedback, address issues which impact client satisfaction with services and provide Agency with recommendations to improve service delivery, including accessibility and retention in care.</li> </ul>	
3.9	<p><u>Patient Safety (Core Services Only)</u></p> <p>Agency shall establish mechanisms to implement National Patient Safety Goals (NPSG) modeled after the current Joint Commission accreditation <i>for Ambulatory Care</i> (<a href="http://www.jointcommission.org">www.jointcommission.org</a>) to ensure patients' safety. The NPSG to be addressed include the following as applicable:</p> <ul style="list-style-type: none"> <li>“Improve the accuracy of patient identification</li> <li>Improve the safety of using medications</li> <li>Reduce the risk of healthcare-associated infections</li> <li>Accurately and completely reconcile medications across the continuum of care</li> <li>Universal Protocol for preventing Wrong Site, Wrong Procedure and Wrong Person Surgery” (<a href="http://www.jointcommission.org">www.jointcommission.org</a>)</li> </ul>	<ul style="list-style-type: none"> <li>Review of Agency's Policies and Procedures Manual indicates compliance</li> </ul>
3.10	<p><u>Client Files</u></p> <p>Provider shall maintain all client files.</p>	<ul style="list-style-type: none"> <li>Review of agency's policy and procedure for records administration indicates compliance</li> </ul>
<b>4.0</b>	<b>Accessibility</b>	
4.1	<p><u>Cultural Competence</u></p> <p>Agency demonstrates a commitment to provision of services that are culturally sensitive and language competent for Limited</p>	<ul style="list-style-type: none"> <li>Agency has procedures for obtaining translation services</li> <li>Client satisfaction survey indicates compliance</li> <li>Policies and procedures demonstrate commitment to the</li> </ul>

	English Proficient (LEP) individuals.	<p>community and culture of the clients</p> <ul style="list-style-type: none"> <li>• Availability of interpretive services, bilingual staff, and staff trained in cultural competence</li> <li>• Agency has vital documents including, but not limited to applications, consents, complaint forms, and notices of rights translated in client record</li> </ul>
4.2	<p><u>Client Education</u></p> <p>Agency demonstrates capacity for client education and provision of information on community resources</p>	<ul style="list-style-type: none"> <li>• Availability of the blue book and other educational materials</li> <li>• Documentation of educational needs assessment and client education in clients' records</li> </ul>
4.3	<p><u>Special Service Needs</u></p> <p>Agency demonstrates a commitment to assisting individuals with special needs</p>	<ul style="list-style-type: none"> <li>• Agency compliance with the Americans with Disabilities Act (ADA).</li> <li>• Review of Policies and Procedures indicates compliance</li> <li>• Environmental Review shows a facility that is handicapped accessible</li> </ul>
4.4	<p><u>Provision of Services for low-Income Individuals</u></p> <p>Agency must ensure that facility is handicap accessible and is also accessible by public transportation (if in area served by METRO). Agency must have policies and procedures in place that ensures access to transportation services if facility is not accessible by public transportation. Agency should not have policies that dictate a dress code or conduct that may act as barrier to care for low income individuals.</p>	<ul style="list-style-type: none"> <li>• Facility is accessible by public transportation</li> <li>• Review of Agency's Policies and Procedures Manual indicates compliance</li> <li>• Source Citation: HAB Monitoring Standards; Part I: Universal Standards; Section A: Access to Care #4</li> </ul>
4.5	<p><u>Proof of HIV Diagnosis</u></p> <p>Documentation of the client's HIV status is obtained at or prior to the initiation of services or registration services.</p> <p>An anonymous test result may be used to document HIV status temporarily (up to sixty [60] days). It must contain enough information to ensure the identity of the subject with a reasonable amount of certainty.</p>	<ul style="list-style-type: none"> <li>• Documentation in client record as per RWGA site visit guidelines or TRG Policy SG-03</li> <li>• Source Citation: HAB Monitoring Standards; Part I: Universal Standards; Section A: Access to Care #3</li> </ul>
4.6	<p><u>Provision of Services Regardless of Current or Past Health Condition</u></p> <p>Agency must have Policies and Procedures in place to ensure that HIV+ clients are not denied services due to current or pre-</p>	<ul style="list-style-type: none"> <li>• Review of Policies and Procedures indicates compliance</li> <li>• A file containing information on clients who have been refused services and the reasons for refusal</li> </ul>

	existing health condition or non-HIV related condition. A file must be maintained on all clients who are refused services and the reason for refusal.	
4.7	<p><u>Client Eligibility</u> In order to be eligible for services, individuals must meet the following:</p> <ul style="list-style-type: none"> <li>• HIV+</li> <li>• Residence in the Houston EMA/ HSDA (With prior approval, clients can be served if they reside outside of the Houston EMA/HSDA.)</li> <li>• Income no greater than 300% of the Federal Poverty level (unless otherwise indicated)</li> <li>• Proof of identification</li> <li>• Ineligibility for third party reimbursement</li> </ul>	<ul style="list-style-type: none"> <li>• Documentation of HIV+ status, residence, identification and income in the client record</li> <li>• Documentation of ineligibility for third party reimbursement</li> <li>• Documentation of screening for Third Party Payers in accordance with TRG Policy SG-06 Documentation of Third Party Payer Eligibility or RWGA site visit guidelines</li> <li>• Source Citation: HAB Monitoring Standards; Part I: Universal Standards; Section B:Eligibility Determination/Screening #1</li> </ul>
4.8	<p><u>Re-evaluation of Client Eligibility</u> Agency conducts six (6) month re-evaluations of eligibility for all clients. At a minimum, agency confirms renewed eligibility with the CPCDMS and re-screens, as appropriate, for third-party payers. Third party payers include State Children's Health Insurance Programs (SCHIP), Medicare (including Part D prescription drug benefit) and private insurance. Agency must ensure that Ryan White is the Payer of last resort and must have policies and procedures addressing strategies to enroll all eligible uninsured clients into Medicare, Medicaid, private health insurance and other programs. Agency policy must also address coordination of benefits, billing and collection. Clients eligible for Department of Veterans Affairs (VA) benefits are duly eligible for Ryan White services and therefore exempted from the payer of last resort requirement</p> <ul style="list-style-type: none"> <li>• Agency must verify 3<sup>rd</sup> party payment coverage for eligible services at every visit or monthly (whichever is less frequent)</li> </ul>	<ul style="list-style-type: none"> <li>• Client file contains documentation of re-evaluation of client residence, income and rescreening for third party payers at least every six (6) months</li> <li>• Review of Policies and Procedures indicates compliance</li> <li>• Information in client's files that includes proof of screening for insurance coverage (i.e. hard/scanned copy of results)</li> <li>• Source Citation: HAB Monitoring Standards; Part I: Universal Standards; Section B:Eligibility Determination/Screening #1 and #2</li> </ul>
4.9	<p><u>Charges for Services</u> Agency must institute Policies and Procedures for cost sharing including enrollment fees, premiums, deductibles, co-</p>	<ul style="list-style-type: none"> <li>• Review of Policies and Procedures indicates compliance</li> <li>• Review of system for tracking patient charges and payments indicate compliance</li> </ul>

	<p>payments, co-insurance, sliding fee discount, etc. and an annual cap on these charges. Agency should not charge any of the above fees regardless of terminology to any Ryan White eligible patient whose gross income level (GIL) is <math>\leq</math> 100% of the Federal Poverty Level (FPL) as documented in the CPCDMS for any services provided. Clients whose gross income is between 101-300% may be charged annual aggregate fees in accordance with the legislative mandate outlined below:</p> <ul style="list-style-type: none"> <li>• 101%-200% of FPL---5% or less of GIL</li> <li>• 201%-300% of FPL---7% or less of GIL</li> <li>• &gt;300% of FPL -----10% or less of GIL</li> </ul> <p>Additionally, agency must implement the following:</p> <ul style="list-style-type: none"> <li>• Six (6) month evaluation of clients to establish individual fees and cap (i.e. the six (6) month CPCDMS registration or registration update.)</li> <li>• Tracking of charges</li> <li>• A process for alerting the billing system when the cap is reached so client will not be charged for the rest of the calendar year.</li> <li>• <u>Documentation of fees</u></li> </ul>	<ul style="list-style-type: none"> <li>• Review of charges and payments in client records indicate compliance with annual cap</li> <li>• Sliding fee application forms on client record is consistent with Federal guidelines</li> </ul>
4.10	<p><u>Information on Program and Eligibility/Sliding Fee Schedule</u></p> <p>Agency must provide broad-based dissemination of information regarding the availability of services. All clients accessing services must be provided with a clear description of their sliding fee charges in a simple understandable format at intake and annually at registration update.</p> <p>Agency should maintain a file documenting promotion activities including copies of HIV program materials and information on eligibility requirements.</p> <p>Agency must proactively inform/educate clients when changes occur in the program design or process, client eligibility rules, fee schedule, facility layout or access to program or agency.</p>	<ul style="list-style-type: none"> <li>• Agency has a written substantiated annual plan to targeted populations</li> <li>• Zip code data show provider is reaching clients throughout service area (as applicable to specific service category).</li> <li>• Agency file containing informational materials about agency services and eligibility requirements including the following: Brochures Newsletters Posters Community bulletins any other types of promotional materials</li> <li>• Signed receipt for client education/ information regarding eligibility and sliding fees on client record</li> <li>• Source Citation: HAB Monitoring Standards; Part I: Universal</li> </ul>

		Standards; Section A: Access to Care #5
4.11	<p><u>Linkage Into Core Services</u> Agency staff will provide out-of-care clients with individualized information and referral to connect them into ambulatory outpatient medical care and other core medical services.</p>	<ul style="list-style-type: none"> <li>• Documentation of client referral is present in client file</li> <li>• Review of agency's policies &amp; procedures' manual indicates compliance</li> </ul>
4.12	<p><u>Wait Lists</u> It is the expectation that clients will not be put on a Wait List nor will services be postponed or denied due to funding. Agency must notify the Administrative agency when funds for service are either low or exhausted for appropriate measures to be taken to ensure adequate funding is available. Should a wait list become required, the agency must, at a minimum, develop a policy that addresses how they will handle situations where service(s) cannot be immediately provided and a process by which client information will be obtained and maintained to ensure that all clients that requested service(s) are contacted after service provision resumes;</p> <p>The Agency will notify The Resource Group (TRG) or RWGA of the following information when a wait list must be created: An explanation for the cessation of service; and A plan for resumption of service. The Agency's plan must address:</p> <ul style="list-style-type: none"> <li>• Action steps to be taken Agency to resolve the service shortfall; and</li> <li>• Projected date that services will resume.</li> </ul> <p>The Agency will report to TRG or RWGA in writing on a monthly basis while a client wait list is required with the following information:</p> <ul style="list-style-type: none"> <li>• Number of clients on the wait list.</li> <li>• Progress toward completing the plan for resumption of</li> </ul>	<ul style="list-style-type: none"> <li>• Review of Agency's Policies and Procedures Manual indicates compliance</li> <li>• Documentation of compliance with TRG's Policy SG-19 Client Wait Lists</li> <li>• Documentation that agency notified their Administrative Agency when funds for services were either low or exhausted</li> </ul>

	<p>service.</p> <ul style="list-style-type: none"> <li>• A revised plan for resumption of service, if necessary.</li> </ul>	
4.13	<p><u>Intake</u> The agency conducts an intake to collect required data including, but not limited to, eligibility, appropriate consents and client identifiers for entry into CPCDMS. Intake process is flexible and responsive, accommodating disabilities and health conditions. In addition to office visits, client is provided alternatives such as conducting business by mail, online registration via the internet, or providing home visits, when necessary. Agency has established procedures for communicating with people with hearing impairments.</p>	<ul style="list-style-type: none"> <li>• Documentation in client record</li> <li>• Review of Agency's Policies and Procedures Manual indicates compliance</li> </ul>
<b>5.0</b>	<b>Quality Management</b>	
5.1	<p><u>Continuous Quality Improvement (CQI)</u> Agency demonstrates capacity for an organized CQI program and has a CQI Committee in place to review procedures and to initiate Performance Improvement activities. The Agency shall maintain an up-to-date Quality Management (QM) Manual. The QM Manual will contain at a minimum:</p> <ul style="list-style-type: none"> <li>• The Agency's QM Plan</li> <li>• Meeting agendas and/or notes (if applicable)</li> <li>• Project specific CQI Plans</li> <li>• Root Cause Analysis &amp; Improvement Plans</li> <li>• Data collection methods and analysis</li> <li>• Work products</li> <li>• QM program evaluation</li> <li>• Materials necessary for QM activities</li> </ul>	<ul style="list-style-type: none"> <li>• Review of Agency's Policies and Procedures Manual indicates compliance</li> <li>• Up to date QM Manual</li> </ul>
5.2	<p><u>Data Collection and Analysis</u> Agency demonstrates capacity to collect and analyze client level data including client satisfaction surveys and findings are incorporated into service delivery. Supervisors shall conduct and document ongoing record reviews as part of quality improvement activity.</p>	<ul style="list-style-type: none"> <li>• Review of Agency's Policies and Procedures Manual indicates compliance</li> <li>• Up to date QM Manual</li> <li>• Supervisors log on record reviews signed and dated</li> <li>• Source Citation: HAB Monitoring Standards; Part I: Universal Standards; Section A: Access to Care #2</li> </ul>

<b>6.0</b>	<b>Point Of Entry Agreements</b>	
6.1	<u>Points of Entry (Core Services Only)</u> Agency accepts referrals from sources considered to be points of entry into the continuum of care, in accordance with HIV Services policy approved by HRSA for the Houston EMA.	<ul style="list-style-type: none"> <li>• Review of Agency’s Policies and Procedures Manual indicates compliance</li> <li>• Documentation of formal agreements with appropriate Points of Entry</li> <li>• Documentation of referrals and their follow-up</li> </ul>
<b>7.0</b>	<b>Emergency Management</b>	
7.1	<u>Emergency Preparedness</u> Agency leadership including medical staff must develop an Emergency Preparedness Plan modeled after the Joint Commission’s regulations and/or Centers for Medicare and Medicaid guidelines for Emergency Management. The plan should, at a minimum utilize “all hazard approach” (hurricanes, floods, earthquakes, tornadoes, wide-spread fires, infectious disease outbreak and other public health threats, terrorist attacks, civil disturbances and collapse of buildings and bridges) to ensure a level of preparedness sufficient to support a range of emergencies. Agencies shall conduct an annual Hazard Vulnerability Analysis (HVA) to identify potential hazards, threats, and adverse events and assess their impact on care, treatment, and services they must sustain during an emergency. The agency shall communicate hazards identified with its community emergency response agencies and together shall identify the capability of its community in meeting their needs. The HVA shall be reviewed annually.	<ul style="list-style-type: none"> <li>• Emergency Preparedness Plan</li> <li>• Review of Agency’s Policies and Procedures Manual indicates compliance</li> </ul>
7.2	<u>Emergency Management Training</u> In accordance with the Department of Human Services recommendations, all applicable agency staff must complete the following National Incident Management System (NIMS) courses developed by the Department of Homeland Security: <ul style="list-style-type: none"> <li>• IS -100.HC – Introduction to the Incident command system for healthcare/hospitals</li> </ul>	<ul style="list-style-type: none"> <li>• Documentation of all training including certificate of completion in personnel file</li> </ul>

	<ul style="list-style-type: none"> <li>• IS-200.HC- Applying ICS to Healthcare organization</li> <li>• IS-700.A-National Incident Management System (NIMS) Introduction</li> <li>• IS-800.B National Response Framework (management)</li> </ul> <p>The above courses may be accessed at:<a href="http://www.training.fema.gov">www.training.fema.gov</a>. Agencies providing support services only may complete alternate courses listed for the above areas All new employees are required to complete the courses within 90 days of hire.</p>	
7.3	<p><u>Emergency Preparedness Plan</u> The emergency preparedness plan shall address the six critical areas for emergency management including</p> <ul style="list-style-type: none"> <li>• Communication pathways</li> <li>• Essential resources and assets</li> <li>• patients' safety and security</li> <li>• staff responsibilities</li> <li>• Supply of key utilities such as portable water and electricity</li> <li>• Patient clinical and support activities during emergency situations. (<a href="http://www.jointcommission.org">www.jointcommission.org</a>)</li> </ul>	<ul style="list-style-type: none"> <li>• Emergency Preparedness Plan</li> </ul>
7.4	<p><u>Emergency Management Drills</u> Agency shall implement emergency management drills twice a year either in response to actual emergency or in a planned exercise. Completed exercise should be evaluated by a multidisciplinary team including administration, clinical and support staff. The emergency plan should be modified based on the evaluation results and retested.</p>	<ul style="list-style-type: none"> <li>• Emergency Management Plan</li> <li>• Review of Agency's Policies and Procedures Manual indicates compliance</li> </ul>
<b>8.0</b>	<b>Building Safety</b>	
8.1	<p><u>Required Permits</u> All agencies will maintain Occupancy and Fire Marshal's permits for the facilities.</p>	<ul style="list-style-type: none"> <li>• Current required permits on file</li> </ul>

## SERVICE SPECIFIC STANDARDS OF CARE

**Case Management (All Case Management Categories)**

Case management services in HIV care facilitate client access to health care services, assist clients to navigate through the wide array of health care programs and ensure coordination of services to meet the unique needs of PLWHA. It also involves client assessment to determine client's needs and the development of individualized service plans in collaboration with the client to mitigate clients' needs. Ryan White Grant Administration funds three case management models i.e. one psychosocial and two clinical/medical models depending on the type of ambulatory service within which the case management service is located. The scope of these three case management models namely, Non-Medical, Clinical and Medical case management services are based on Ryan White HIV/AIDS Treatment Modernization Act of 2006 (HRSA)<sup>2</sup> definition for non-medical and medical case management services. Other resources utilized include the current *National Association of Social Workers (NASW) Standards for Social Work Case Management*<sup>3</sup>. Specific requirements for each of the models are discussed under each case management service category.

<b>1.0</b>	<b>Staff Training</b>	
1.1	<p><u>Required Meetings</u>  <u>Case Managers and Service Linkage Workers</u>  Case managers and Service Linkage Workers will attend on an annual basis a minimum of four (4) of the five (5) bi-monthly networking meetings facilitated by RWGA.  Case Managers and Service Linkage Workers will attend the “Joint Prevention and Care Coordination Meeting” held annually and facilitated by the RWGA and the City of Houston STD/HIV Bureau.</p> <p>Medical Case Management (MCM), Clinical Case Management (CCM) and Service Linkage Worker Supervisors will attend on an annual basis a minimum of five (5) of the six (6) bi-monthly Supervisor meetings facilitated by RWGA (in the event a MCM or CCM supervises SLW staff the MCM or CCM must attend the Supervisor meetings and may, as an option, attend the networking</p>	<ul style="list-style-type: none"> <li>• Agency will maintain verification of attendance (RWGA will also maintain sign-in logs)</li> </ul>

<sup>2</sup> US Department of Health and Human Services, Health Resources and Services Administration HIV/AIDS Bureau (2009). Ryan White HIV/AIDS Treatment Modernization Act of 2006: Definitions for eligible services

<sup>3</sup> National Association of Social Workers (1992). NASW standards for social work case management. Retrieved 02/9/2009 from [www.socialworkers.org/practice/standards/sw\\_case\\_mgmt.asp](http://www.socialworkers.org/practice/standards/sw_case_mgmt.asp)

	meetings)	
1.2	<p><u>Required Training for New Employees</u></p> <p>Within the first ninety (90) days of employment in the case management system, case managers will successfully complete HIV Case Management 101: A Foundation, through the State of Texas TRAIN website (<a href="https://tx.train.org">https://tx.train.org</a>) with a minimum of 70% accuracy. RWGA expects HIV Case Management 101: A Foundation, course completion to take no longer than 16 hours. Within the first six (6) months of employment, case managers will complete at least four (4) hours review of Community resources, and at least four (4) hours cultural competency training offered by RWGA.</p> <p>For cultural competency training only, Agency may request a waiver for agency based training alternative that meets or exceeds the RWGA requirements for the first year training for case management staff.</p>	<ul style="list-style-type: none"> <li>• Certificates of completion for applicable trainings in the case manager's file</li> <li>• Sign-in sheets for agency based trainings maintained by Agency</li> <li>• RWGA Waiver is approved prior to Agency utilizing agency-based training curriculum</li> </ul>
1.3	<p><u>Case Management Supervisor Peer-led Training</u></p> <p>Supervisory Training: On an annual basis, Part A/B-funded clinical supervisors of Medical, Clinical and Community (SLW) Case Managers must fully participate in the four (4) Case Management Supervisor Peer-Led three-hour training curriculum conducted by RWGA.</p>	<ul style="list-style-type: none"> <li>• Review of attendance sign-in sheet indicates compliance</li> </ul>
1.4	<p><u>Child Abuse Screening, Documenting and Reporting Training</u></p> <p>Case Managers are trained in the agency's policy and procedure for determining, documenting and reporting instances of abuse, sexual or nonsexual, in accordance with the DSHS Child Abuse Screening, Documenting and Reporting Policy prior to patient interaction.</p>	<ul style="list-style-type: none"> <li>• Documentation of staff training</li> </ul>
<b>2.0</b>	<b>Timeliness of Services</b>	
2.1	<p><u>Initial Case Management Contact</u></p> <p>Contact with client and/or referring agent is attempted within one working day of receiving a case assignment. If the case manager is</p>	<ul style="list-style-type: none"> <li>• Documentation in client record</li> </ul>

	unable to make contact within one (1) working day, this is documented and explained in the client record. Case manager should also notify their supervisor. All subsequent attempts are documented.	
2.2	<u>Acuity</u> The case manager should use an acuity scale or other standardized system as a measurement tool to determine client needs (applies to TDSHS funded case managers only).	<ul style="list-style-type: none"> <li>Completed acuity scale in client's records</li> </ul>
2.3	<u>Progress Notes</u> All case management activities, including but not limited to all contacts and attempted contacts with or on behalf of clients are documented in the client record within 72 hours of their occurrence.	<ul style="list-style-type: none"> <li>Legible, signed and dated documentation in client record.</li> <li>Documentation of time expended with or on behalf of patient in progress notes</li> </ul>
2.4	<u>Client Referral and Tracking</u> Agency will have policies and procedures in place for referral and follow-up for clients with medical conditions, nutritional, psychological/social and financial problems. The agency will maintain a current list of agencies that provide primary medical care, prescription medications, assistance with insurance payments, dental care, transportation, nutritional counseling and supplements, support for basic needs (rent, food, financial assistance, etc.) and other supportive services (e.g. legal assistance, partner elicitation services and Client Risk Counseling Services (CRCS). The Case Manager will: <ul style="list-style-type: none"> <li>Initiate referrals within two (2) weeks of the plan being completed and agreed upon by the Client and the Case Manager</li> <li>Work with the Client to determine barriers to referrals and facilitate access to referrals</li> <li>Utilize a tracking mechanism to monitor completion of all case management referrals</li> </ul>	<ul style="list-style-type: none"> <li>Review of Agency's Policies and Procedures Manual indicates compliance</li> <li>Documentation of follow-up tracking activities in clients records</li> <li>A current list of agencies that provide services including availability of the Blue Book</li> </ul>
2.5	<u>Client Notification of Service Provider Turnover</u> Client must be provided notice of assigned service provider's cessation of employment within 30 days of the employee's departure.	<ul style="list-style-type: none"> <li>Documentation in client record</li> </ul>
2.6	<u>Client Transfers between Agencies: Open or Closed less than One</u>	<ul style="list-style-type: none"> <li>Documentation in client record</li> </ul>

	<p><u>Year</u></p> <p>The case manager should facilitate the transfer of clients between providers. All clients are transferred in accordance with Case Management Policy and Procedure, which requires that a “consent for transfer and release/exchange of information” form be completed and signed by the client, the client’s record be forwarded to the receiving care manager within five (5) working days and a Request for Transfer form be completed for the client and submitted to RWGA by the receiving agency.</p>	
2.7	<p><u>Caseload</u></p> <p>Case load determination should be based on client characteristics, acuity level and the intensity of case management activities.</p>	<ul style="list-style-type: none"> <li>• Review of the agency’s policies and procedures for Staffing ratios</li> </ul>

### Non-Medical Case Management Services (Service Linkage Worker)

Non-medical case management services (Service Linkage Worker (SLW) is co-located in ambulatory/outpatient medical care centers. HRSA defines Non-Medical case management services as the “provision of advice and assistance in obtaining medical, social, community, legal, financial, and other needed services” and does not include coordination and follow-up of medical treatment. The Ryan White Part A/B SLW provides services to clients who do not require intensive case management services and these include the provision of information, referrals and assistance with linkage to medical, mental health, substance abuse and psychosocial services as needed; advocating on behalf of clients to decrease service gaps and remove barriers to services helping clients to develop and utilize independent living skills and strategies.

<b>1.0</b>	<b>Staff Requirements</b>	
1.1	<p><u>Minimum Qualifications</u>  Service Linkage Worker – unlicensed community case manager  Service linkage workers must have a bachelor’s degree from an accredited college or university with a major in social or behavioral sciences. Documented paid work experience in providing client services to PLWHA may be substituted for the bachelor’s degree requirement on a 1:1 basis (1 year of documented paid experience may be substituted for 1 year of college). Service linkage workers must have a minimum of 1 year paid work experience with PLWHA.  Bilingual (English/Spanish) targeted service linkage workers must have written and verbal fluency in English and Spanish.  Agency will provide Service Linkage Worker a written job description upon hiring.</p>	<ul style="list-style-type: none"> <li>• A file will be maintained on service linkage worker. Supportive documentation of credentials and job description are maintained by the agency and in each service linkage worker’s file. Documentation may include, but is not limited to, transcripts, diplomas, certifications and/or licensure.</li> </ul>
<b>2.0</b>	<b>Timeliness of Services/Documentation</b>	
2.1	<p><u>Client Eligibility – Service Linkage targeted to Not-in-Care and Newly Diagnosed (COH Only)</u>  In addition to general eligibility criteria individuals must meet the following in order to be eligible for non-medical case management services:</p> <ul style="list-style-type: none"> <li>• HIV+ and not receiving outpatient HIV primary medical care services within the previous 180 days as documented by the CPCDMS, or</li> <li>• Newly diagnosed (within the last six (6) months) and not currently receiving outpatient HIV primary medical care</li> </ul>	<ul style="list-style-type: none"> <li>• Documentation of HIV+ status, residence, identification and income in the client record</li> <li>• Documentation of “not in care” status through the CPCDMS</li> </ul>

	<p>services as documented by the CPCDMS, or</p> <ul style="list-style-type: none"> <li>Newly diagnosed (within the last six (6) months) and not currently receiving case management services as documented by the CPCDMS</li> </ul>	
2.2	<p><u>Service Linkage Worker Assessment</u></p> <p>Assessment begins at intake. The service linkage worker will provide client and, if appropriate, his/her personal support system information regarding the range of services offered by the case management program during intake/assessment.</p> <p>The service linkage worker will complete RWGA -approved brief assessment tool within five (5) working days, on all clients to identify those who need comprehensive assessment. Clients with mental health, substance abuse and/or housings issues should receive comprehensive assessment. Clients needing comprehensive assessment should be referred to a licensed case manager. <b><u>Low-need, non-primary care clients who have only an intermittent need for information about services may receive brief SLW services without being placed on open status. Clients issued a value-based bus pass must be maintained on Open Status and be reassessed per SOC.</u></b></p>	<ul style="list-style-type: none"> <li>Documentation in client record on the brief assessment form, signed and dated</li> <li>A completed DSHS checklist for screening of suspected sexual child abuse and reporting is evident in case management records, when appropriate</li> </ul>
2.3	<p><u>Service Linkage Worker Reassessment</u></p> <p>Clients on <b><u>open status</u></b> will be reassessed at six (6) month intervals following the initial assessment. A RWGA/ TRG-approved reassessment form as applicable must be utilized.</p>	<ul style="list-style-type: none"> <li>Documentation in RWGA approved client reassessment form or agency's equivalent form, signed and dated</li> </ul>
2.4	<p><u>Transfer of Not-in-Care and Newly Diagnosed Clients (COH Only)</u></p> <p>Service linkage workers targeting their services to Not-in-Care and newly diagnosed clients will work with clients for a maximum of 90 days. Clients must be transferred to a Ryan White-funded primary medical care, clinical case management or medical case management program within 90 days of the initiation of services.</p>	<ul style="list-style-type: none"> <li>Documentation in client record and in the CPCDMS</li> </ul>
2.5	<p><u>Primary Care Newly Diagnosed and Lost to Care Clients</u></p> <p>Agency must have a written policy and procedures in place that address the role of Service Linkage Workers in the linking and re-</p>	<ul style="list-style-type: none"> <li>Review of Agency's Policies and Procedures Manual indicates compliance.</li> </ul>

	<p>engaging of clients into primary medical care. The policy and procedures must include at minimum:</p> <ul style="list-style-type: none"> <li>• Methods of routine communication with testing sites regarding newly diagnosis and referred individuals</li> <li>• Description of service linkage worker job duties conducted in the field</li> <li>• Process for re-engaging agency patients lost to care (no primary care visit in 6 months)</li> </ul>	
<b>3.0</b>	<b>Supervision and Caseload</b>	
3.1	<p><u>Service Linkage Worker Supervision</u></p> <p>A minimum of four (4) hours of supervision per month must be provided to each service linkage worker by a master’s level health professional. ) At least one (1) hour of supervision must be individual supervision.</p> <p>Supervision includes, but is not limited to, one-to-one consultation regarding issues that arise in the case management relationship, case staffing meetings, group supervision, and discussion of gaps in services or barriers to services, intervention strategies, case assignments, case reviews and caseload assessments.</p>	<ul style="list-style-type: none"> <li>• Documentation in supervision notes, which must include: <ul style="list-style-type: none"> <li>➤ date</li> <li>➤ name(s) of case manager(s) present</li> <li>➤ topic(s) covered and/or client(s) reviewed</li> <li>➤ plan(s) of action</li> <li>➤ supervisor’s signature</li> </ul> </li> <li>• Supervision notes are never maintained in the client record</li> </ul>
3.2	<p><u>Caseload Coverage – Service Linkage Workers</u></p> <p>Supervisor ensures that there is coverage of the caseload in the absence of the service linkage worker or when the position is vacant. Service Linkage Workers may assist clients who are routinely seen by other CM team members in the absence of the client’s “assigned” case manager.</p>	<ul style="list-style-type: none"> <li>• Documentation of all client encounters in client record and in the Centralized Patient Care Data Management System</li> </ul>
3.3	<p><u>Case Reviews – Service Linkage Workers.</u></p> <p>Supervisor reviews each open case with the service linkage worker at least once ninety (90) days, and concurrently ensures that all required record components are present, timely, legible, and that services provided are appropriate.</p>	<ul style="list-style-type: none"> <li>• Documentation of case reviews in client record, signed and dated by supervisor and/or quality assurance personnel and SLW</li> </ul>

Harris County  
**HCPHES**  
Public Health & Environmental Services

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**FY 2012 MID-YEAR YEAR OUTCOMES REPORTS HIGHLIGHTS**

**RYAN WHITE GRANT ADMINISTRATION**

**HARRIS COUNTY**

**PUBLIC HEALTH & ENVIRONMENTAL SERVICES**

**(HCPHES)**

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## **Highlights from the FY 2012 Mid-Year Outcomes Reports**

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### **Community-Based Case Management**

- From 3/1/2012 through 8/31/2012, 4,174 clients utilized Part A community-based case management. According to CPCDMS, 1,736 (42%) of these clients accessed primary care two or more times at least three months apart during this time period after utilizing community-based case management.
- Among these clients, 935 (22%) clients accessed LPAP services, 744 (18%) clients accessed oral health care and 65 (1.6%) clients accessed mental health services at least once during this time period after utilizing community-based case management.

Ryan White Part A  
 OUTCOME MEASURES RESULTS  
 FY 2012 Mid-Year Report

**Community-Based Case Management (Service-Linkage)**  
 All Providers

Outcome Measure	Indicator	Data Collection Method
<b>1.0 Knowledge, Attitudes, and Practices</b>		
1.1. Increased or maintained utilization of primary care services	A minimum of 70% of clients will utilize Part A/B/C/D primary care two or more times at least three months apart after accessing community-based case management (service linkage)	<ul style="list-style-type: none"> <li>• CPCDMS</li> </ul>

**A. Primary Care:**

From 3/1/2012 through 8/31/2012, 4,174 clients utilized Part A community-based case management. According to CPCDMS, 1,736 (42%) of these clients accessed primary care two or more times at least three months apart during this time period after utilizing community-based case management, and 75 (1.8%) clients accessed primary care for the first time after utilizing community-based case management.

Outcome Measure	Indicator	Data Collection Method
<b>1.0 Knowledge, Attitudes, and Practices</b>		
1.2 Increased or maintained utilization of support services	a. A minimum of 30% of clients will utilize Part A/B Local Pharmacy Assistance Program services after accessing community-based case management b. A minimum of 25% of clients will utilize Part A oral health care after accessing community-based case management c. Increase in the percentage of clients who utilize mental health services after accessing community-based case management	<ul style="list-style-type: none"> <li>• CPCDMS</li> </ul>

From 3/1/2012 through 8/31/2012, 4,174 clients utilized Part A community-based case management.

#### **A. Local Pharmacy Assistance Program (LPAP):**

According to CPCDMS, 935 (22%) of these clients accessed LPAP services at least once during this time period after utilizing community-based case management, and 187 (4.5%) clients accessed LPAP services for the first time after utilizing community-based case management.

#### **B. Oral Health Care:**

According to CPCDMS, 744 (18%) of these clients accessed oral health care at least once during this time period after utilizing community-based case management, and 143 (3.4%) clients accessed oral health care for the first time after utilizing community-based case management.

#### **C. Mental Health Services:**

According to CPCDMS, 65 (1.6%) of these clients accessed mental health services at least once during this time period after utilizing community-based case management, and 16 (0.4%) clients accessed mental health services for the first time after utilizing community-based case management.

Ryan White Part A  
 OUTCOME MEASURES RESULTS  
 FY 2012 Mid-Year Report

**Legal Services**

Outcome Measure	Indicator	Data Collection Method
<b>1.0 Knowledge, Attitudes, and Practices</b>		
1.1. Increased awareness about legal issues related to HIV status	Change in the percentage of clients who report increased awareness about legal issues related to HIV status	<ul style="list-style-type: none"> <li>• Self-Administered Client Survey</li> <li>• Unduplicated Clients</li> </ul>

**Survey Question: How confident are you about your knowledge about legal issues related to your HIV status?**

NUMBER AND PERCENT OF RESPONSES:

	Baseline	%	Case Completion	%
1 - Not at all confident	30	43%	0	0%
2 - Somewhat confident	40	57%	4	9%
3 - Confident	0	0%	17	36%
4 - Very confident	0	0%	22	47%
5 - Extremely confident	0	0%	4	9%

AVERAGE RESPONSE:

Baseline =1.57

Case Completion = 3.55

CHANGE OVER TIME: Of those who have completed both assessments. For this question, it is desirable to **increase (or maintain)** the value of the response over time.

<b>Baseline to Case Completion</b>	<b>#</b>	<b>%</b>
Increased	16	100%
Maintained	0	0%
Decreased	0	0%

Outcome Measure	Indicator	Data Collection Method
<b>3.0 Quality of Life</b>		
3.1 Maintenance of family structure	Change in the number of permanency planning cases completed over time	● CPCDMS

Number of permanency planning cases completed for FY 2012 = 71

Outcome Measure	Indicator	Data Collection Method
<b>3.0 Quality of Life</b>		
3.2 Reduced stress due to ability to access legal services	Change in the percentage of clients who report reduced stress due to the ability to access legal services over time	<ul style="list-style-type: none"> <li>Self-Administered Client Survey</li> </ul>

**Survey Question: In the past two weeks, how often have you felt anxious or stressed out about your ability to access legal services?**

NUMBER AND PERCENT OF RESPONSES:

	Baseline	%	Case Completion	%
1 - Never	0	0%	17	36%
2 - Rarely	0	0%	18	38%
3 - Sometimes	8	11%	10	21%
4 - Most of the time	38	54%	2	4%
5 - All of the time	24	34%	0	0%

AVERAGE RESPONSE:

Baseline = 4.23

Case Completion = 1.94

CHANGE OVER TIME: Of those who have completed both assessments. For this question, it is desirable to **decrease (or maintain)** the value of the response over time.

Baseline to Case Completion	#	%
Increased	0	0%
Maintained	1	6%
Decreased	15	94%

Outcome Measure	Indicator	Data Collection Method
<b>4.0 Cost-Effectiveness</b>		
4.1 Reduced reliance on Ryan White Part A funded primary care and support services	65% of completed SSI disability, insurance, public benefits and income-related cases will result in access to or continued access to benefits	● CPCDMS

Type of Case	Number of Benefits-Related Cases Completed FY 2012	Number and Percent of Completed Cases that Resulted in Access (or Continued Access) to Benefits	
SSI Disability	26	11	42%
Insurance	2	1	50%
Public Benefits	3	1	33%
Income-Related	19	17	89%
Other	25	9	36%
<b>Total</b>	<b>75</b>	<b>39</b>	<b>52%</b>

## **FY2013 HOW TO BEST MEET THE NEED FOLLOW-UP DISCUSSION**

Non-Medical Case Management (Service Linkage)

Quality Assurance Committee

May 17, 2012

### **Background**

- The Comprehensive Plan includes the following activity to be completed in 2012:
  - “Re-develop the Ryan White HIV/AIDS Program Service Category definition for Service Linkage (Community-based Non-medical Case Management) during the HTBMTN process to improve linkage to care rates.”
- Since HTBMTN, staff has reviewed and gathered additional feedback.
- We are asking the Quality Assurance Committee to review these ideas and make recommendations for next steps as outlined below.

## Committee Discussion Item #1

- Reduce client transfers or “hand-offs” between SLW and other HIV primary care staff.
  - **Background:** Stakeholders were concerned that the number of times a client transitioned between staff could result in the client falling out of care. The goal would be to increase continuity of staff contact until entry into care is complete. For example, include the SLW in the initial care team, pair the SLW and Medical/Clinical Case Manager during client transition, allow Medical/Clinical Case Managers to initiate client encounter prior to SLW transfer.
  - **Staff Comment:** Concept is supported by and included in the RWGA Case Management training and can be tracked in CPCDMS. Some limitations exist to the Medical/Clinical Case Manager initiating client encounter prior to client registration in CPCDMS.
  - **Possible Action:** Concept can be re-emphasized and discussed in RWGA trainings.

## Committee Discussion Item #2

- Adopt the national standard for linkage to care (90 days vs. the current 120 days)
  - **Background:** Stakeholders were concerned that 120 days is too long for a client’s first HIV medical visit and that it is inconsistent with the national standard. The goal would be to reduce the time between client initiation with a SLW and first entry into primary care.
  - **Staff Comment:** This change would only apply to SLW embedded in testing sites. This change would be appropriate for the Service Definition and/or Standards of Care.
  - **Possible Action:** The Quality Assurance Committee can discuss and provide direction.

## Committee Discussion Item #3

- Increase the level of brief assessment provided by SLW with an emphasis on readiness for care
  - **Background:** Stakeholders were concerned that clients experience fatigue from completing multiple assessments with varying staff during the initial linkage to care stage. They also expressed a need for more ways to assess readiness for care. The goal would be to increase coordination of and completeness of assessments at the earliest stage of client contact.
  - **Staff Comment:** Current Standards of Care require that 100% of clients receiving SLW services have a brief assessment. A Comprehensive Case Management Assessment is then performed by the Medical/Clinical Case Manager. A Comprehensive Case Management Assessment would be currently outside the scope of the SLW job description. An additional validated readiness for care assessment tool could be added to the SLW brief assessment process.
  - **Possible Action:** A specific validated readiness for care assessment tool can be added to the SLW brief assessment process as part of the Standards of Care process (Fall 2012).

## Other Ideas

- Use new media for client communication, e.g., text, Skype, email, etc. – **Allowable per agency policy**
- Establish standards for minimum required communication levels between SLW and client – **Standards already in place**
- Use outreach approaches to locating/linking clients, e.g., use of peers/social networks. – **Concept supported by and included in RWGA Case Management training**
- Increase knowledge and skills of SLWs in techniques that facilitate follow-through on care plans, e.g., motivational interviewing, health literacy instruction, etc. – **Included in RWGA Case Management training. Additional training may be provided by HDHHS specific to SLW embedded in testing sites.**
- Document lessons learned from SLWs for effective linkage methods. – **Refer to RWGA Case Management training for consideration**
- Develop a community-wide standard for linkage to care for funded and non-funded agencies. – **Will require further discussion**

## Other Plan Activities Related to Linkage to Care

- Implement training to Counseling, Testing, and Referral (CTR) providers about their role in linkage to care beginning at post-test counseling/results notification; and establish linkage to care performance measures for CTR providers. **Responsible Party: HDHHS**
- Expand Disease Intervention Specialist (DIS) activities to include a readiness for HIV care assessment at the time of DIS interview as a means of assisting with linkage to care efforts. **Responsible Party: HDHHS**
- Implement plans to conduct a survey of the HIV testing and linkage to care activities of private providers. **Responsible Party: HDHHS**
- Fully implement Phase One of the roll-out of collecting client-level HIV prevention data (ECLIPS) and linking to HIV care data (CPCDMS). **Responsible Parties: RWGA & HDHHS**
- Sustain required annual training for Ryan White HIV/AIDS Program funded case managers on effective client engagement (e.g., motivational interviewing, rapport development, assessment skills, etc.). **Responsible Party: RWGA**
- Identify and disseminate a model protocol for a layperson system navigator program to assist newly-diagnosed HIV+ individuals to enter HIV care. **Responsible Party: RWPC/OS**
- Develop a toolkit for private providers for how to link newly-diagnosed HIV+ individuals into the Ryan White HIV/AIDS Program and system of care. **Responsible Party: RWPC/OS**

# HIV Care on the Front Line

Despite the advent of lifesaving treatment that also controls the spread of HIV/AIDS, 30 years into the AIDS epidemic, almost 1 million Americans living with the virus remain untreated for HIV. For years, the prevailing wisdom has been that the barriers to linking people to care—and keeping them engaged in it—were too great to solve the problem. But a handful of warriors on the front line show that we can indeed keep more people alive while slowing the spread of AIDS.

BY BENJAMIN RYAN

**T**HIRTY YEARS INTO THE AIDS PAN-  
demic, despite the fact that we have much effective treatment for HIV, we haven't tipped the balance in our favor in the fight against AIDS—especially in the United States. The new infection rate for a disease that is preventable has remained flat here for nearly a decade. And yet, around the world, HIV incidence rates are declining: proof positive that we have the tools to turn the tide against HIV. So why can't we do it in America? The short answer is: We can, we're just not applying the best strategies where they're needed most. That may soon change if a few frontline warriors have their way.

In December 2011, a new report issued by the Centers for Disease Control and Prevention (CDC) painted a stark reality. It showed that one in five HIV-positive Americans don't know they're living with the virus. Worse, of the estimated 960,000 Americans who do know they are living with HIV, only about half are in regular medical care. And, stunningly, of the 1.2 million Americans estimated to be living with HIV, a mere 28 percent are on medication that keeps their HIV infection from leading to

AIDS and also helps stop the spread of the virus. One study found that monogamous heterosexuals with HIV who take their medication as prescribed and have an undetectable viral load for at least six months can see a 96 percent reduction in the risk of transmitting HIV to their negative partners.

Today we are armed with powerful, simplified HIV drug regimens, so how is it that we are still failing to treat the HIV community on such a grand scale? For years, people have argued that the barriers to care were simply insurmountable. Indeed, a study conducted in 1999 by the Johns Hopkins HIV Clinic in Baltimore showed how a host of life stressors challenged that city's urban HIV population so severely that the clinic was unable to keep its clients in long-term HIV treatment. At that time, only 37 percent of Hopkins's HIV patients in the study had suppressed viral loads. For people of color, the rate was a dismal 25 percent. Sadly, the data made many HIV doctors across the country reluctant to prescribe HIV meds to at-risk patients.

But the times they are a-changin'. In August 2011, the HIV team at Hopkins released a new study showing a stunning turnaround in the health of the HIV-positive people they treat. Between 2003 and 2009, Hopkins retained an impressive

Achieving  
results  
in DC:  
Sabrina  
Heard

94 percent of its clients—a population that has grown older and included more women and heterosexuals—in care. By 2010, 84 percent of the HIV clients at Hopkins had a fully suppressed viral load. The results proved that new approaches could lead to a new era of access to care for people living with HIV, and that HIV providers can help even the most high-risk populations be effectively treated with HIV therapy. (A third of Hopkins's clients self-reported injection drug use.)

“Antiretroviral Therapy: Now ‘It Just Works’” is the title of an editorial commentary on the Hopkins results written by Paul Sax, MD, clinical director of the HIV program at Brigham and Women's Hospital in Boston, and published in the September 2011 issue of *Clinical Infectious Diseases*. It has become a motto for many who previously abandoned hope for the health of their patients.

In the shadow of the CDC's scary stats from last year, the recent success at Johns Hopkins has led the CDC to issue a rallying call to solve the problem. The federal agency asked public health officials and HIV providers to follow a key element of the Obama administration's National HIV/AIDS Strategy: namely, to improve patient engagement at every step along the continuum of care, starting with a positive HIV test, through immediate linkage to care and commencement of treatment, and including retention in care for the long term.

The Hopkins results suggested that the key to connecting people to—and keeping them in—care is overcoming the constellation of risk factors that affect wide swaths of the HIV population: homelessness, substance abuse, stigma, poverty, lack of transportation, lack of medical coverage, fear or mistrust of the medical system and impatience with red tape and bureaucratic hassles.

Any one of these can cause people to miss their appointments. A missed appointment is the time when HIV providers and social service agencies need to be on high alert for ways to re-engage patients and to work with them to address and resolve those barriers to care. Indeed, doing so involves a lot of hard work and a commitment to getting results.

Richard Moore, MD, director of the Johns Hopkins Hospital HIV Clinic and coauthor of the new study, breaks it down. His team has succeeded against all odds, he says, by providing a kind of home away from home for people living with HIV. Primary care and all kinds of specialty care are provided under one roof. Using an electronic records system in place for two decades to keep tabs on every patient, medical providers work with a team of social workers and other support staff to make sure people don't fall through the cracks.

“If a patient misses a couple of appointments in a row, you wonder if there's something interfering in their life that's making it hard for them to come in, or maybe they're fatiguing in regard to care,” Moore says. “Knowing that patient may be having problems and giving them a call, routing them to see a case worker or something of that sort is one way we use our system to try to troubleshoot before an issue gets out of hand.”

The Hopkins group is also always looking for ways to integrate new HIV treatment guidelines into its practice. And thanks to the electronic re-

Succeeding  
in Harlem:  
L. Jeannine  
Bookhardt-  
Murray, MD

records system, it's easier for providers to monitor the effectiveness of new medical approaches and protocols and to measure their success.

Kaiser Permanente is another group that has been highly effective at engaging and keeping people in its HIV program; 95 percent of the national network's HIV-positive clients have suppressed viral loads. Eager to export Kaiser's model and share the lessons his team learned from years of experience treating people with HIV, Michael Horberg, MD, the program's director, challenges other HIV providers to improve patient retention and care. Kaiser can enter aggregate patient information into a database, allowing Kaiser to compare treatment achievements among HIV providers across the country. Horberg's division offers free mentorship to other health care providers nationwide and presents tools and information on its website, [kp.org/hivchallenge](http://kp.org/hivchallenge).

Meanwhile, the National Quality Center, NQC, an initiative of the New York State Department of Health, has also created a program to export proven care models across the country. Currently, it is working with 400 U.S. HIV providers who serve over 400,000 positive people. Encouraging retention in care is a central goal. [NationalQualityCenter.org](http://NationalQualityCenter.org), the group's website, presents a clearinghouse of information for HIV care providers. The center also offers opportunities for mentorship from academic researchers and other coaches.

Is sharing best practices enough, or do we need structural shifts in health care to get more of these hundreds of thousands of untreated people with HIV into care—and test those who still don't know they have HIV?

“Mentoring is a great idea,” says Moore, adding that his Johns Hopkins clinic has also hosted visiting HIV providers from around the world for mentorship sessions. “Inasmuch as a practice that may not have the resources can get tips about maintaining retention or keeping up to date with guidelines, that's fine. But our rather fragmented health care system doesn't support that very well at the moment. I'm hoping that some of the changes taking place over the next two years will help support that. I don't think that there are easy solutions here.”

While Hopkins produced the evidence that the right techniques work to connect people to and keep them in care, and Kaiser Permanente and the NQC will do their best to help roll out best practices, the best role models remain those organizations (some large and well-funded, some small and struggling) that learn new techniques every day as they fight HIV in some of the most challenging arenas. Often, what distinguishes their work is the ability to provide the critical personal touches that make the difference when it comes to getting people with HIV committed to long-term care. POZ asked representatives of three such groups what works—and why.

### Sabrina Heard: The Women's Collective

Sabrina Heard fights HIV with her personal experience. A recovered addict who's been living with HIV for more than two decades, Heard emerged from years of denial and learned how to care for herself with the help of the Women's Collective, a small social services agency for women with HIV in Washington, DC. Now, as a community health worker at the

group, she spends her days on the front lines, making sure her sisters in the HIV community don't fall into isolation and neglect the way she once did.

Heard's persistence and fierce drive to connect with her clients ensure that the women in her charge are fully integrated into HIV care. As soon as a red flag appears—if a woman hasn't gotten her labs done or visited an HIV specialist within six months, for example—Heard takes action.

"We make *a lot* of phone calls," she says.

Once she reaches a woman who is at risk for dropping out of care, Heard investigates and finds solutions for the full scope of that woman's personal needs, concerns and barriers to care. It's vital to do so, she says.

"If a person is competing for their basic needs, they're going to be concentrating on trying to get some food, making it to the food bank, making it to their housing appointments and things like that, as opposed to making it to their medical appointments," Heard says.

The agency's ongoing relationship with each client allows the providers to make any necessary phone calls on behalf of their clients, preventing, say, the chance that the frustration of being on hold with a doctor's office will lead a woman to throw in the towel. They often send a staff member to accompany a woman to her appointments, helping her communicate better with her doctor.

"If you're not a person who's knowledgeable on the specifics of what the doctor's talking about, honey, all that just sounds like a foreign language," Heard says. "So we try to help explain what the doctor's saying."

Heard also allows the already intimate relationships with her clients to get even more personal.

"I share my story," she says. "I don't mind sharing my experience in different realms with my clients in an effort to encourage them. I let them know how I made it through that particular barrier."

#### **L. Jeannine Bookhardt-Murray, MD: Harlem United**

A community health center for indigent people with HIV, Harlem United is located in the upper reaches of Manhattan. The agency finds the key to its good track record within the notion of community. With a budget of nearly \$40 million and various divisions that provide a panoply of services—including testing, HIV treatment, dental care, counseling, case management and adult day programs—Harlem United has found it takes a village to keep people in care.

Once people are tested, Harlem United ensures that they are seen by one of the nonprofit's HIV doctors the very same day. Someone from the testing division will even walk newly diagnosed people to the clinic, a few blocks away.

"That first visit is crucial," says chief medical officer L. Jeannine Bookhardt-Murray, MD. "If people do not see a provider on the same day [they receive their HIV diagnosis], we know from the get-go that we're going to have trouble getting them into care and keeping them there. The typical patient will just go underground and maybe re-surface in a year or so, or when they're sick."

Harlem United employs an approach based

on teamwork—literally. A newly diagnosed person is assigned a group of staffers to assist him or her with administrative hassles and provide information about living with HIV. Then each client is assigned a long-term case manager who will make sure medical and service appointments are kept, help address problems that may arise, and provide placement in the agency's support groups.

This team-based system, called the Linkage to Care program, has worked. In 2010, only 29 percent of either walk-ins or clients referred to Harlem United through another agency were retained in care, while 68 percent of those entering through the Linkage to Care program were retained. By 2011, that figure had increased to 89 percent.

Ultimately, Harlem United brings clients into the embrace of a large family of people, all looking out for their well-being.

"There is such a personalized touch," Bookhardt-Murray says. "For example, it might be the janitor who knows where this person hangs out in the daytime, and if we've lost the person, the janitor will let us know."

#### **Mark Douglas: My Brothaz HOME**

Too often, while the road to success is clear, it is hardly paved with gold. My Brothaz HOME in Savannah, Georgia, is one of the many struggling HIV services agencies dedicated to reaching people outside major urban areas. Since 2000, the group has provided rapid HIV-antibody testing (testing more than 1,200 people last year) and developed a proven system to link new HIV cases into care. It also offered peer support, advocacy, treatment education and HIV prevention—all with a budget of less than \$140,000. As we go to press, the group has learned it must close its doors, a victim of the economy.

Mark Douglas, the passionate cofounder and executive director of My Brothaz, says the minute they told someone he or she was HIV positive—24 people last year—the group would begin the process of linking that person into care. The first appointment with an HIV specialist was made on the spot. And since My Brothaz knew from experience that people who lack insurance tend to delay treatment, the group helped uncover possible sources of health coverage for new cases—usually a combination of funding from Medicaid and AIDS Drugs Assistance Programs, as well as pharmaceutical co-pay programs, since most clients earned less than \$10,000 per year.

"Everything would be done for them before they walked out the door," Douglas says, describing My Brothaz's efforts to make sure people get connected to health care and services after an HIV diagnosis. "So even after they'd left, we would follow up, calling to make sure that they went to the appointment. And if necessary we would take them to the appointment."

The most important ingredient in the group's 98 percent success rate in linking people into care, Douglas says, was gaining his clients' trust.

"The relationship, the rapport you develop with a client, comes over a period of time. We've been here in the community for 12 years," he says. "We've made them feel at home. Even at the time of learning their HIV status, they still felt supported, loved, valued, important." And that, it seems, is the winning strategy behind every frontline warriors' success. ■

Connecting  
to care in  
Georgia:  
Mark  
Douglas

# Background Brief on the Prevention Benefits of HIV Treatment

January 2013

## Introduction

The advent in 1996 of potent combination antiretroviral therapy (ART), sometimes called HAART (highly active antiretroviral therapy) or cART (effective combination antiretroviral therapy), changed the course of the HIV epidemic [1]. These “cocktails” of three or more antiretroviral drugs used in combination gave patients and scientists new hope for fighting the epidemic [2] and have significantly improved life expectancy—to decades rather than months [1,3].

For many years, scientists believed that treating HIV-infected persons also significantly reduced their risk of transmitting the infection to sexual and drug-using partners who did not have the virus. The circumstantial evidence was substantial, but no one had conducted a randomized clinical trial—the gold standard for proving an intervention works. That changed in 2011 with the publication of findings from the HIV Prevention Trials Network (HPTN) 052 study, a randomized clinical trial designed in part to evaluate whether the early initiation of ART can prevent the sexual transmission of HIV among heterosexual couples in which one partner is HIV-infected and the other is not. This landmark study validated that early HIV treatment has a profound prevention benefit: results showed that the risk of transmitting HIV to an uninfected partner was reduced by 96% [4].

As a concept and a strategy, treating HIV-infected persons to improve their health and to reduce the risk of onward transmission—sometimes called *treatment as prevention*—refers to the personal and public health benefits of using ART to continuously suppress HIV viral load in the blood and genital fluids, which decreases the risk of transmitting the virus to others. The practice has been used since the mid-1990s to prevent mother-to-child, or perinatal, transmission of the virus. Research published in 1994 showed that zidovudine, more commonly known as AZT, when given to HIV-infected pregnant women and to their newborns reduced the risk of perinatal transmission from about 25% to 8% [5]. Since then, routinely testing pregnant women and treating infected mothers with ART during pregnancy, delivery, and while breastfeeding, when practiced according to recommendations, has reduced the mother’s risk of transmitting HIV to her child by 90% [6]. In one study, women who received at least 14 days of ART reduced the risk of transmitting HIV to their babies to less than 1% [7].

## Putting Treatment as Prevention in Perspective

Treatment by itself is not going to solve the global HIV epidemic. On the domestic front, controlling and ultimately ending the epidemic will require a combination of scientifically proven HIV prevention tools as highlighted in

the National HIV/AIDS Strategy (<http://www.aids.gov/federal-resources/national-hiv-aids-strategy/overview/>), including

- Focusing on science-based HIV prevention efforts by supporting and expanding targeted use of high-impact HIV prevention approaches.
- Making better investments by intensifying HIV prevention in the communities where HIV is most heavily concentrated.
- Increasing access to HIV screening and medical care, including through
  - boosting federal investments for AIDS Drug Assistance Programs (ADAPs) to expand access to life-saving medications, and
  - implementing the Affordable Care Act, which will increase health coverage for thousands of Americans living with HIV.
- Sustaining a shared response to the domestic epidemic through the support of HIV prevention efforts across all levels of society, including federal, state, and local governments, faith-based communities, and the private sector.

Providing treatment to people living with HIV infection to improve their health must always be the first priority. Getting an HIV test is the first step to identifying persons with HIV infection and the pivotal entry point into the medical care system for both treatment and prevention. More than 1.1 million persons in the United States are living with HIV, and almost 1 in 5 (18.1%) do not know they are infected [8]. By lowering the level of virus in the body, early ART helps people with HIV live longer, healthier lives and also lowers their chances of transmitting HIV to others. Although observational data had suggested that ART significantly reduces viral load and the risk of sexual transmission of HIV in heterosexual couples where one partner is infected and the other is not [9,10], it was the HPTN 052 study that definitively showed that early treatment of HIV-infected persons dramatically cuts the rate of new infections. Studies of communities with high concentrations of injection drug users (IDUs) and men who have sex with men (MSM) have shown that as ART use increased within the community, the community’s viral load declined, as did rates of new HIV diagnoses [11,12]. However, it is critical to remember that the prevention benefit of treatment is not 100%, and there has been at least one report of HIV transmission from a person with suppressed viral load to an uninfected sexual partner [13].

For persons living with or at risk for HIV infection, emphasizing these fundamental safeguards will continue to be crucial:

- Knowing their HIV status through routine testing.
- Getting into care soon after HIV diagnosis and starting antiretroviral treatment.
- Remaining in care and staying on HIV treatment.
- Modifying behaviors that reduce the probability of getting or spreading HIV—such as using condoms properly and consistently, reducing numbers of partners, and avoiding sharing needles and syringes.

## Test and Treat

The ability of antiretroviral drugs to prevent secondary transmission of HIV from an infected person to an uninfected sexual or drug-using partner has led to several proposed “test-and-treat” strategies. Test-and-treat programs are based on the premise that the rate of new HIV infections will be maximally reduced by using aggressive methods to test and diagnose all people living with HIV infection, treat them with ART regardless of CD4 cell count or viral load at diagnosis, and link them to care. In one study, mathematical modeling suggested that a universal test-and-treat-strategy in which all adults aged 15 years or older are tested annually could control the South African epidemic, reducing both HIV incidence and mortality to less than 1 case per 1,000 people per year within 10 years of full implementation of the strategy—and reducing prevalence of HIV infection to less than 1% within 50 years [14]. Other investigators have not been as optimistic about the ultimate benefits of this strategy. Only 50% of persons in the United States with HIV remain in care [15,16], and about 18% do not know they are infected; these persons may contribute to the onward transmission of HIV. In addition to expanding testing and treating HIV infection earlier, overcoming the challenges of undiagnosed infection and poor engagement in care will result in better care of HIV-infected populations and reduced numbers of new HIV infections [17,18].

## Challenges and the Future of HIV Prevention

The landmark HPTN 052 clinical trial was conducted almost solely among heterosexual couples who, as part of the study, received frequent counseling related to HIV, sexually transmitted diseases (STDs), and family planning. Results of a recent observational study of more than 38,000 serodiscordant heterosexual couples across China showed that treating the HIV-infected partner reduced the risk of transmitting HIV to the uninfected partner by 26%—a much more modest effect than that found in the HPTN 052 study couples. Unlike the couples enrolled in HPTN 052, the couples in China were not part of an intensive study, and data were not available on sexual risk factors, adherence to antiretroviral treatment, or virological treatment outcome measures [19]. Additional data are needed to estimate the prevention benefit of treatment for other populations, such as MSM, IDUs, and persons with acute or primary HIV infection [20], and in other settings such as North America and during routine clinical care.

As HIV treatment has evolved from a complicated regimen of numerous pills taken several times a day with severe side effects to a now once-daily pill with few side effects, some persons living with HIV may have become complacent about maintaining safer sex and safer injection use practices. Since HIV treatment became widely available in developed countries, several studies have shown a resurgence of HIV infections and increases in STDs, in particular syphilis, and especially among MSM [21]. Some studies have cautioned that the prevention benefits of effective ART would be offset by risk compensation, meaning that increases in risky sexual and injection-drug-use behavior might be observed as effective ART is widely disseminated [22-24]. However, results of one meta-analysis demonstrated that HIV-positive persons receiving ART, compared with those not receiving ART, did not show increased sexual risk behavior, even when therapy resulted in an undetectable viral load [25]. Yet, persons with HIV who believe that using ART or having a suppressed viral load protects them against transmitting HIV may be more likely to engage in unprotected sex or other risky behaviors. These behaviors might be amenable to change through prevention messages and other effective approaches [25-28]. Making sure that preventive behaviors are sustained in communities facing higher risk of HIV infection is crucial [29].

The future of HIV prevention will be shaped by operational and implementation research on the efficacy of combination prevention strategies, of which treatment may be one component [30-32]. Providing treatment to all HIV-infected persons will be an important step—a recommendation that is included in the current *Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents* [33]. The Department of Health and Human Services panel based its recommendations primarily on mounting evidence showing the harmful impact of ongoing HIV replication on AIDS and non-AIDS disease progression. In addition, the updated recommendations reflect emerging data showing the benefit of effective ART in preventing secondary transmission of HIV. Although the panel agrees that this public health benefit of ART is significant, its recommendations on when to begin ART are based primarily on the benefit of treatment to the HIV-infected individual [33]. If treatment is to achieve its full prevention potential, current gaps in the HIV prevention, treatment, and care continuum must be narrowed or closed. Considerable changes in the US health care delivery system will be required to accommodate the increased demand for services that expanded testing, treatment, and linkage and retention in care will bring [34].

Now that early ART of HIV-infected persons has been shown to be very effective at preventing secondary transmission of HIV among individuals, the current goal is to determine the extent to which ART can be used broadly and effectively to reduce the spread of HIV within a population. At least two community randomized trials that use ART as their basis are planned [35], and the results could determine the conclusive benefit of this successful intervention [36].

Still, resource constraints, logistical hurdles, emergence of drug-resistant viral strains, adherence to therapy regimens,

and risk compensation remain concerns that scientists, health care providers, policy makers, and communities must confront if the individual and public health benefits of treatment are to be fully realized [37].

## What CDC Is Doing

Much of CDC's funding supports and expands prevention services for persons living with HIV, including

- Linkage to care and treatment, and interventions to improve retention in and re-engagement to care, prevention, and treatment for people living with HIV.
- Referral to other medical and social services, such as substance abuse and mental health services.
- Behavioral interventions and other risk-reduction services for HIV-positive persons and their sexual or needle-sharing partners to reduce the likelihood of HIV transmission.

Three evidence-based interventions have proved effective in treatment settings and can be delivered by providers as brief messages during clinic visits: **Partnership for Health** (<http://www.effectiveinterventions.org/en/HighImpactPrevention/Interventions/PfH.aspx>), **Options** (<http://www.cdc.gov/hiv/topics/research/prs/resources/factsheets/options.htm>), and **Positive Choice** (<http://www.cdc.gov/hiv/topics/research/prs/resources/factsheets/positive-choice.htm>).

CDC's **Prevention IS Care** (<http://www.cdc.gov/actagainstaids/>) campaign also emphasizes ongoing, brief prevention counseling to help health care providers integrate into routine care simple approaches to prevent transmission by persons living with HIV. Medical visits provide a vital opportunity to reinforce HIV prevention messages, discuss sexual and drug-related risk behaviors, diagnose and treat other STDs, review the importance of medication adherence, and foster open communication between provider and patient.

Expanded HIV testing efforts will help more people know their status so that they can get life-saving treatment and will strengthen the impact of efforts to increase adherence to treatment, particularly in areas where large numbers of persons remain undiagnosed.

Additionally, CDC and the Health Resources and Services Administration have supported studies that suggest several promising opportunities to improve retention in care, including collaborating with other service providers to identify persons poorly retained in care, enhancing outreach programs, and addressing unmet psychosocial needs [38,39].

## Summary

To realize the full prevention benefit of treating HIV infection, we should keep in mind four overarching tenets:

- HIV testing is the foundation for both prevention and care efforts.
- Early identification of infection empowers individuals to take action that benefits both their own health and the public health.

- Early treatment of infected persons substantially reduces their risk of transmitting HIV to others.
- The prevention benefit of treatment can only be realized with effective treatment, which requires linkage to and retention in care, and adherence to antiretroviral therapy.

## References

1. Dieffenbach CW, Fauci AS. Thirty years of HIV and AIDS: future challenges and opportunities. *Ann Intern Med* 2011;154:766-771.
2. Gulick RM, Mellors JW, Havlir D, Eron JJ, Gonzalez C, McMahon D, et al. Treatment with indinavir, zidovudine, and lamivudine in adults with human immunodeficiency virus infection and prior antiretroviral therapy. *N Engl J Med* 1997;337:734-739.
3. Palella FJ Jr, Delaney KM, Moorman AC, Loveless MO, Fuhrer J, Satten GA, et al.; for the HIV Outpatient Study investigators. Declining morbidity and mortality among patients with advanced human immunodeficiency virus infection. *N Engl J Med* 1998;338:853-860.
4. Cohen MS, Chen YQ, McCauley M, et al. Prevention of HIV-1 infection with early antiretroviral therapy. *N Engl J Med* 2011;365:493-505.
5. Connor EM, Sperling RS, Gelber R, Kiselev P, Scott G, O'Sullivan MJ, et al. Reduction of maternal-infant transmission of human immunodeficiency virus type 1 with zidovudine treatment. Pediatric AIDS Clinical Trials Group Protocol 076 Study Group. *N Engl J Med* 1994;331:1173-1180.
6. CDC. Achievements in public health: reduction in perinatal transmission of HIV infection—United States, 1985–2005. *MMWR* 2006;55:592-597.
7. Townsend CL, Cortina-Borja M, Peckham CS, de Ruiter A, Lyall H, Tookey, PA. Low rates of mother-to-child transmission of HIV following effective pregnancy interventions in the United Kingdom and Ireland, 2000-2006. *AIDS* 2008;22:973-981.
8. CDC. *HIV Surveillance Supplemental Report* 2012;17(No. 3, part A). [http://www.cdc.gov/hiv/surveillance/resources/reports/2010supp\\_vol17no3/index.htm](http://www.cdc.gov/hiv/surveillance/resources/reports/2010supp_vol17no3/index.htm). Published June 2012.
9. Quinn TC, Wawer MJ, Sewankambo N, Serwadda D, Li C, Wabwire-Mangen F, et al. Viral load and heterosexual transmission of human immunodeficiency virus type 1. Rakai Project Study Group. *N Engl J Med* 2000;342:921-929.
10. Attia S, Egger M, Müller M, Zwahlen M, Low N. Sexual transmission of HIV according to viral load and antiretroviral therapy: systematic review and meta-analysis. *AIDS* 2009;23:1397-1404.
11. Montaner JS, Lima VD, Barrios R, et al. Association of highly active antiretroviral therapy coverage, population viral load, and yearly new HIV diagnoses in British Columbia, Canada: a population-based study. *Lancet* 2010;376:532-539.

12. Das M, Chu PL, Santos GM, et al. Decreases in community viral load are accompanied by reductions in new HIV infections in San Francisco. *PLoS One* 2010;5:e11068.
13. Sturmer M, Doerr HW, Berger A, Gute P. Is transmission of HIV-1 in non-viraemic serodiscordant couples possible? *Antivir Ther* 2008;13:729-732.
14. Granich RM, Gilks CF, Dye C, De Cock KM, Williams BG. Universal voluntary HIV testing with immediate antiretroviral therapy as a strategy for elimination of HIV transmission: a mathematical model. *Lancet* 2009;373:48-57.
15. Marks G, Gardner LI, Craw J, Crepez N. Entry and retention in medical care among HIV-diagnosed persons: a meta-analysis. *AIDS* 2010;24:2665-2678.
16. CDC. Vital signs: HIV prevention through care and treatment—United States. *MMWR* 2011;60:1618-1623.
17. Gardner EM, McLees MP, Steiner JF, Del Rio C, Burman WJ. The spectrum of engagement in HIV care and its relevance to test-and-treat strategies for prevention of HIV infection. *Clin Infect Dis* 2011;52:793-800.
18. Marks G, Gardner LI, Craw J, Giordano TP, Mugavero MJ, Keruly JC, et al. The spectrum of engagement in HIV care: do more than 19% of HIV-infected persons in the US have undetectable viral load? *Clin Infect Dis* 2011;53:1168-1169.
19. Jia Z, Ruan Y, Li Q, et al. Antiretroviral therapy to prevent HIV transmission in serodiscordant couples in China (2003-11): a national observational cohort study. *Lancet* 2012 Dec 1.
20. Conway B, Tossonian H. Comprehensive approaches to the diagnosis and treatment of HIV infection in the community: can 'seek and treat' really deliver? *Curr Infect Dis Rep* 2011;13:68-74.
21. CDC. Trends in primary and secondary syphilis and HIV infections in men who have sex with men—San Francisco and Los Angeles, California, 1998–2002. *MMWR* 2004;53:575-578.
22. Katz MH, Schwarcz SK, Kellogg TA, et al. Impact of highly active antiretroviral treatment on HIV seroincidence among men who have sex with men: San Francisco. *Am J Public Health* 2002;92:388-394.
23. Porco TC, Martin JN, Page-Shafer KA, et al. Decline in HIV infectivity following the introduction of highly active antiretroviral therapy. *AIDS* 2004;18:81-88.
24. Blower SM, Gershengorn HB, Grant RM. A tale of two futures: HIV and antiretroviral therapy in San Francisco. *Science* 2000;287:650-654.
25. Crepez N, Hart TA, Marks G. Highly active antiretroviral therapy and sexual risk behavior: a meta-analytic review. *JAMA* 2004;292:224-236.
26. de Wit JB, Aggleton P, Myers T, Crewe M. The rapidly changing paradigm of HIV prevention: time to strengthen social and behavioural approaches. *Health Educ Res* 2011;26:381-392.
27. Kalichman SC, Cherry C, Amaral CM, et al. Adherence to antiretroviral therapy and HIV transmission risks: implications for test-and-treat approaches to HIV prevention. *AIDS Patient Care STDS* 2010;24:271-277.
28. Luchters S, Sarna A, Geibel S, et al. Safer sexual behaviors after 12 months of antiretroviral treatment in Mombasa, Kenya: a prospective cohort. *AIDS Patient Care STDS* 2008;22:587-594.
29. DeGruttola V, Smith DM, Little SJ, Miller V. Developing and evaluating comprehensive HIV infection control strategies: issues and challenges. *Clin Infect Dis* 2010; 50 (Suppl 3):S102-107.
30. Buchbinder SP, Liu A. Pre-exposure prophylaxis and the promise of combination prevention approaches. *AIDS Behav* 2011;15 (Suppl 1):S72-S79.
31. Dieffenbach CW, Fauci AS. Universal voluntary testing and treatment for prevention of HIV transmission. *JAMA* 2009;301:2380-2382.
32. Padian NS, McCoy SI, Karim SS, et al. HIV prevention transformed: the new prevention research agenda. *Lancet* 2011;378:269-278.
33. Panel on Antiretroviral Guidelines for Adults and Adolescents. Guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents. Department of Health and Human Services. March 27, 2012:1-239. Available at <http://aidsinfo.nih.gov/ContentFiles/AdultandAdolescentGL.pdf>. Accessed April 16, 2012.
34. Forsyth AD, Valdiserri RO. Reaping the prevention benefits of highly active antiretroviral treatment: policy implications of HIV Prevention Trials Network 052. *Curr Opin HIV AIDS* 2012 Mar;7:111-116.
35. Smith K, Powers KA, Kashuba AD, Cohen MS. HIV-1 treatment as prevention: the good, the bad, and the challenges. *Curr Opin HIV AIDS* 2011;6:315-325.
36. Cohen, MS, McCauley M, Gamble TR. HIV treatment as prevention and HPTN 052. *Curr Opin HIV AIDS* 2012 Mar;7:99-105.
37. Hammer SM. Antiretroviral treatment as prevention. *N Engl J Med* 2011;365:561-562.
38. Giordano TP. Retention in HIV care: what the clinician needs to know. *Top Antivir Med* 2011; 9:12-16.
39. Gardner LI, Marks G, Craw JA, et al.; for the Retention in Care Study Group. A low-effort, clinic-wide intervention improves attendance for HIV primary care. *Clin Infect Dis* 2012;55: 1124-1134.

**Additional Resources:****CDC-INFO**

1-800-CDC-INFO (232-4636)  
 cdcinfo@cdc.gov  
 Get answers to questions and locate HIV testing sites.

**CDC HIV Web Site**

[www.cdc.gov/hiv](http://www.cdc.gov/hiv)

**CDC National HIV Testing Resources**

<http://hivtest.cdc.gov>  
 Text your ZIP code to KNOW IT or 566948. Locate an HIV testing site near you.

**CDC National Prevention Information Network (NPIN)**

1-800-458-5231  
[www.cdcpin.org](http://www.cdcpin.org)  
 Technical assistance and resources.

**AIDSInfo**

1-800-448-0440  
[www.aidsinfo.nih.gov](http://www.aidsinfo.nih.gov)  
 Treatment and clinical trials.

**AIDS.gov**

[www.aids.gov](http://www.aids.gov)  
 Comprehensive government HIV resources.

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# Using Surveillance and Other Data to Improve HIV Care Linkage and Retention

*A report from a  
Think Tank convened  
by Project Inform,  
held November 6 & 7, 2012  
San Francisco, California*



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## Introduction

On November 6 and 7, 2012, Project Inform brought together 30 HIV community advocates and public health officials as a “Think Tank” to explore a number of questions regarding the active use of laboratory data (e.g. CD4 count and viral load)—collected by many departments of public health—to identify individuals who either were never linked to HIV care or who fell out of care. Based on this data, efforts would then be made to link those individuals to health care and other services.

The Think Tank was a timely addition to national discussions about the degree to which public health departments may use surveillance and other data more actively than in the past to promote the health of people living with HIV and to prevent ongoing transmission. In fact, a number of jurisdictions in the United States and its territories already have projects that use collected data for HIV care linkage and retention purposes underway or in the planning stages. Essentially, jurisdictions are using surveillance and other data for care linkage and retention purposes in three ways:

1. Direct outreach to health care providers and community-based organizations to advise them that a patient or client may be out of care;
2. Electronic linkages between surveillance databases and the electronic medical records of large health care systems; and
3. Direct outreach to people living with HIV who have been defined as out of care.

Project Inform convened the Think Tank because, outside of public health agencies and the Centers for Disease Control and Prevention (CDC), there has been relatively little discussion and exploration of these activities by community based organizations and their constituents about the potential for both good and harm that could result from these activities. In fact, since programs of this type were first proposed in the mid-2000s there has sometimes been controversy and community opposition.

Project Inform intended the Think Tank to be an opportunity to educate the community about the legal, ethical and practical challenges involved in these activities as well as the processes that were employed by several health departments in planning and carrying out activities using surveillance and other data for care linkage and retention. In addition, Project Inform wanted to provide an opportunity for community advocates and public



## Using Surveillance and Other Data to Improve HIV Care Linkage and Retention

*a think tank convened november 6/7, 2012*

health professionals to engage one another in dialogue about the kind of stakeholder engagement and principles, policies, and procedures that might ensure that the greatest good could be achieved with the least harm.

To that end, the planning committee for the Think Tank formulated a list of critical questions to explore. These included:

1. Could the active use of collected HIV laboratory data contribute in a meaningful way to achieving the goals of the National HIV/AIDS Strategy?
2. Do the benefits of this approach outweigh the risks?
3. If we recommend that additional jurisdictions consider this approach, what policies and procedures should guide their implementation?
4. What things should not be done in furtherance of this approach?
5. Do Think Tank participants support the adoption of legislation in all states mandating the reporting of CD4 and viral load test results to public health departments if only to monitor progress on HIV care linkage and retention?
6. If a department of public health is able to identify those who have never been linked to care or who are out of care, is it ethical not to take action to improve HIV-positive individuals' health and well-being and to attempt to reduce ongoing HIV transmission?
7. Is it the responsibility of the public health department, or individual service providers, to engage in processes to link or re-link HIV-positive individuals into health care and other care supportive services?
8. Do Think Tank participants approve of more active uses of laboratory data (in the abstract) to improve HIV care linkage and retention?
9. If departments of public health were to engage in direct contact with health care providers to call to attention individual patients who are thought to be out of HIV care, what strategies would make such activities least harmful and most acceptable to the community?
10. If departments of public health were to engage in electronic transfer of surveillance data to electronic medical records databases within health care systems to call to attention individual patients who are thought to be out of HIV care, what strategies would make such activities least harmful and most acceptable to the community?
11. If departments of public health were to engage in direct contact with people with HIV to engage or re-engage them in health care, what strategies would make such activities least harmful and most acceptable to the community?
12. Are there community engagement processes and procedures that would be most likely to successfully engage HIV community advocates and health care providers prior to engaging in new uses of laboratory data for care linkage and retention programs?



## Using Surveillance and Other Data to Improve HIV Care Linkage and Retention

*a think tank convened november 6/7, 2012*

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During the course of the meeting, participants discussed the ethical, legal and practical challenges involved in these activities and developed a list of recommendations to help ensure that when health departments initiate new programs there is sufficient and meaningful community engagement. Participants also formulated policies and procedures to maximize benefits and minimize harms from these activities. Lastly, the group including

AIDS service organizations, academics, health departments and other non-federal agency stakeholders voted on and unanimously accepted a consensus statement affirming that the potential benefits of these activities are sufficient that stakeholder engagement should take place. These recommendations and the full consensus statement are contained within the report.

## Background: The Challenges

Before enumerating the recommendations of Think Tank participants it is important to understand the drive to locate and re-engage those out of care and the consequences of not doing so. In July 2010, President Barack Obama made history by introducing the first National HIV/AIDS Strategy (NHAS)<sup>1</sup> ever produced for the United States. This is notable in that since 2003 other countries that received funding for HIV services through the United States President's Emergency Plan for AIDS Relief (PEPFAR) were required to put such a plan in place in order to qualify for funding.

At the White House press conference, where activists and policy makers gathered together to celebrate the introduction of the plan, President Obama laid out the NHAS's key goals:

- to reduce new HIV infections;
- to increase access to care and improved outcomes for people living with HIV;
- to reduce HIV-related disparities and health inequities;
- to reduce HIV-related stigma; and
- to achieve a more coordinated national response to the HIV epidemic.

Though most people understood that it would take hard work to meet these goals, none could have predicted the enormity of the challenge laid out just over a year later by two scientific papers estimating the linkage and retention in health care of HIV-positive individuals in the United States, and the degree of viral suppression of those on treatment.

In the first paper, Edward Gardner, from the Denver Department of Health, and his colleagues,<sup>2</sup> projected that of the 1.1 million individuals estimated to be living with HIV in the United States only 59% were linked to care and just 39% were retained in care. Of the 350,000 individuals estimated to require antiretroviral (ARV) therapy only 75% were actually on treatment, and of those on treatment fully 20% did not have fully suppressed virus, leaving them open to both HIV- and non-HIV-related health problems, and making it more likely that they could pass on HIV to others. Given that Gardner's figures were based on old treatment guidelines suggesting treatment at 350 CD4 cells (new guidelines recommend treatment for anyone regardless of CD4 count), the number of people requiring HIV treatment who are not receiving it, and even worse the number with suppressed virus is far lower than it ought to be.

The CDC released a second comparable set of data in July 2012.<sup>3</sup> In the CDC analysis, of the 1.1 million infected with HIV in the United States, just 37% were estimated to be retained in care, 33% were being prescribed ARV therapy, and only 25% had fully suppressed HIV. Rates of care retention and viral suppression were even lower for younger people, and for African Americans and Latinos. This is particularly concerning given that a recent paper published in *The Lancet*<sup>4</sup> hypothesized that lack of access to affordable quality healthcare among African American men who have sex with men (MSM) is a key driver behind the sky-rocketing incidence and prevalence of HIV in that community.

Much remains to be done to ensure that when a person receives an HIV-positive diagnosis he or she immediately linked to health care—preferably quality health care and necessary supplementary support services, such as housing, nutrition services, mental health care and treatment for substance abuse disorders. Just as challenging, however, is retaining people in care once a successful linkage has been made.

There are multiple reasons that people fall out of care. Nearly one third of people with HIV are estimated to have no health insurance,<sup>5</sup> and

many do not qualify for Ryan White health care, which is a payer of last resort. Moreover, even with supplementary funding from Congress, the AIDS Drug Assistance Programs (ADAPs) have not fully eliminated waiting lists to receive free medication, and in some states waiting lists were only closed out after those states made it more difficult to qualify for the programs.

Additionally, the overlapping syndemics of HIV, poverty, substance use and other mental disorders, aggressive incarceration of black and Latino males for petty offenses, homophobia, racism and domestic violence have made it exceedingly difficult for HIV-positive individuals who suffer under these conditions to remain engaged in health care, or to find health care that is sensitive to their needs.<sup>6</sup> In fact, Laura Bogart, PhD, from Harvard Medical School, and Somnath Saha, MD, MPH, from the Oregon Health and Science University, and their colleagues found in separate studies<sup>7,8</sup> that experiences of perceived racism within the health care system were a primary driver of not receiving and adhering to ARV therapy.

Clearly, more needs to be done to meet the challenges laid out in the NHAS.



## Background: Examples of Existing Programs

Community-based organizations (CBOs) have been retooling to bring their programs into accordance with the NHAS, as have public health departments. Among the most aggressive approaches are those being taken under an HIV Prevention Trials Network (HPTN) grant in Washington, D.C. and the Bronx in New York City, dubbed HPTN 065 or Testing and Linkage to Care-Plus (TLC-Plus).

In those programs, HIV-testing staff is responsible to make a linkage to care within 24 hours of a positive diagnosis. Once that linkage is made, some individuals are offered monetary compensation for remaining successfully in care and maintaining full viral suppression. Other cities are attempting similar approaches.

In Massachusetts, where there exists nearly universal health care, rates of retention are estimated to be at an exceptionally high 95% to 99%, with viral suppression rates exceeding 70%.<sup>9</sup> In San Francisco, which similarly seeks to offer care to all city residents, retention and viral suppression rates are both approximately 50% through 2011.<sup>10</sup> Yet even in these cities, which have extraordinary resources compared with many of the most impacted communities in other parts of the country, care linkage and retention is not perfect.

For this reason, the CDC and many local health departments have been exploring other methods to locate those who were never linked

to care, or who fell out of HIV care along the way. One promising avenue is the use of laboratory data already being collected for surveillance purposes (e.g. CD4 count and viral load), as well as databases from Medicaid, Medicare, Ryan White and private insurers, not only as a proxy for understanding rates of care linkage and retention but as tools to discover those out of care and take action to bring them into it.

Several such programs are explored in depth below but, in essence, there have thus far been three primary models for the utilization of collected laboratory data, as previously mentioned.

In the examples immediately following, public health experts have chosen to take one or more of these types of actions in furtherance of the health and well-being of people living with HIV, and secondarily to attempt to reduce HIV incidence. Three geographic areas are profiled: Washington, D.C., the state of Louisiana, and King County in Washington state.

**WASHINGTON, DC**

Collected laboratory data is used for several purposes in this jurisdiction, both passively (to simply track the epidemic) and actively (to intervene where lapses in care are found). At heart, this data allows public health experts in D.C. to track how well providers in the city are doing with respect to HIV care linkage and retention, and therefore how closely the city is meeting the goals of the NHAS. More recently, however, the city chose to adopt procedures whereby the city directly engages with health care providers and CBOs regarding the care and health status of individuals cared for by those institutions.

*How it works:*

Designated as a “Recapture Blitz” by the D.C. Department of Health, the program operates in two directions. Providers are asked to send lists to the HIV/AIDS, Hepatitis, STD, and TB Administration (HAHSTA) of the public health department of patients who have disappeared from care for at least six months. HAHSTA matches those names with its own database to determine which individuals are actually out of care compared with those who may have died or who have simply engaged in care at another location. Data systems include electronic laboratory data, ADAP enrollment and eHARS (HIV surveillance). Once the match is complete, each provider receives a dataset based on the information provided to HAHSTA to say either, “Yes this person has been engaged in care at another location,” or, “No, this person is not engaged in care.”

For those found to be out of care, each CBO or provider attempts to make direct contact with the clients to re-engage the person within 90 days. The DC program does not limit the number of contacts. In some instances, a provider may have contacted the individual as many as 13 times to re-engage the client.

HAHSTA also uses surveillance data to actively link people to care. One such program is the Strategic Multisite Initiative for the Identification, Linkage and Engagement in Care of Youth with Undiagnosed HIV Infection Linkage-to-Care (SMILE). To ensure that all youth (ages 12-24) diagnosed with HIV are linked to and engaged in HIV clinical care, HAHSTA collaborates with the Children’s National Medical Center as well as five other youth service providers to use surveillance and lab data to verify linkage to care among newly diagnosed youth under the age of 25.

HAHSTA also creates reports documenting the success of providers in retaining individuals in care and ensuring viral suppression of those on ARV therapy.

*History of community engagement:*

Officials at HAHSTA began working with several community-based providers in 2009 to develop active data use strategies. Family Medical Counseling Service (FMCS) began its care linkage and retention program independently in 2009. HAHSTA approached FMCS and

invited other providers to discuss potential best practices. During this stage, topics of discussion included logistics of data matching, security and confidentiality and strategies for engagement, monitoring and evaluation.

A few months later, the D.C. area began to pilot a new district-wide program. Data from the program indicated that more than 300 people were re-engaged in care. As the pilot proved successful, HAHSTA further engaged with key health care providers and CBOs in the city to determine how best to scale up the program. This activity is now part of Ryan White Part B funding. The match is also conducted upon the request to the HAHSTA strategic information program. Given the active ongoing coordination and collaboration with providers, HAHSTA is able to determine the acceptability of this intervention among providers and CBOs, and it reports that the program thus far has achieved high levels of acceptability and that providers are appreciative of the services provided by HAHSTA.

Engagement with CBOs also influenced the selection of the DC model in the SMILE protocol. While 15 other jurisdictions conduct SMILE, DC is the only jurisdiction using a model that focuses on the use of surveillance data to evaluate real-time linkage to care and to direct client engagement and follow-up by providers and CBOs conducting testing, linkage and retention activities.

Surveillance data can also be used in aggregate to answer important questions. When the TLC-Plus study was launched in Washington, D.C. some in the community raised concerns that this program—which offers intensive care linkage and treatment for those found to be HIV-positive—would be “forcing people onto treatment.” In analyzing surveillance data, however, HAHSTA found that 55% of all of individuals receiving a new HIV diagnosis between 2005-2009 had CD4s of 500 or less, making them immediately eligible for treatment according to 2011 U.S. Department of Health and Human Services (DHHS) Treatment Guidelines at that time. Given that current ARV treatment guidelines recommend treatment for all “ready” HIV-positive individuals, regardless of CD4 count, the strategy to offer treatment to all is consistent with those guidelines. The sensitivity with which treatment should be offered, and how individuals who choose not to start ARVs should be supported, was outside the scope of this Think Tank. It should, however, be an active topic of discussion between providers and the community.

### **LOUISIANA (LaPHIE):**

Funded in 2007 by a Special Projects of National Significance (SPNS) grant from the Health Resources and Services Administration (HRSA), collaborators from the Louisiana Department of Health and Hospitals Office of Public Health (OPH) and the Louisiana State University (LSU) hospital system sought to build an information exchange program

between the public health department and the state's largest provider of HIV care, to address the problem of missed opportunities to provide HIV care linkage and improve retention.

### *How it Works:*

The Louisiana Public Health Information Exchange (LaPHIE) is a collaboration between the LSU, the OPH and the Louisiana Public Health Institute. The OPH first uses reportable laboratory data to create a dataset of persons who either were never linked to care following an HIV diagnosis or have fallen out of HIV care. Through a privacy protected data exchange system with the electronic medical record (EMR) system of eight LSU hospitals' emergency rooms, outpatient and inpatient settings, the OPH embeds a message into a patient's EMR about their HIV care status.

- When any patient registers at an LSU hospital, his or her identifying information is added to the LSU computer system.
- LSU electronically notifies the OPH (via LaPHIE) that the patient has arrived at an LSU facility, by securely sending a message with minimal patient identifiers to a secure, designated LaPHIE server housed at the OPH.
- When the OPH receives a message from LSU, the LaPHIE logic checks its "out-of-care" patient dataset to determine if the patient is listed there.
- If the OPH finds a match in the out-of-care dataset, it automatically sends

a standard, disease-specific electronic message to the LSU EMR system. For instance, that a person may never have received their HIV test results or that no viral load or CD4 count is on record within a specified period of time.

- The LSU system receives and stores the message from the OPH. It then displays the message as a pop-up alert for authorized clinicians who open the patient's EMR within the visit timeframe. When a clinician clicks on the alert, he/she sees a list of suggested actions, which can be checked off on screen as actions are taken.
- After the clinician visit, the LSU system automatically returns a message to the OPH with current contact information and a report listing the actions taken in response to the message.

In addition to prompting action for people who have been out of care for 12 months, because they never picked up their HIV test results, never got linked to care, or fell out of care, the system also issues alerts for those who tested positive for syphilis or tuberculosis (regardless of HIV status) who do not appear to have completed treatment.

### *History of Community Engagement:*

Sharing protected health care and public health information is a complex (but solvable) technical problem. Yet implementing a system like LaPHIE raises many non-technical challenges and questions. Under

what circumstances is it legal to share health information between health care providers and public health professionals? Is it ethical? Is building a system like LaPHIE the right thing to do in terms of protecting the health of individuals and the health of the community as a whole?

To address such questions before building the exchange, the LaPHIE partners created a legal compliance and ethics workgroup consisting of public health officials, HIV-positive individuals, doctors and nurses, attorneys familiar with federal and state health laws, HIV advocates, and a medical ethicist. Over the course of a year, the workgroup developed a list of legal questions to be answered, reviewed relevant legislation, and discussed plans for an exchange with national experts in confidentiality and biomedical ethics. The group also enlisted the expertise of an independent market research firm charged with conducting interviews and focus groups to gather information on how potential patients would view the project.

Based on this legal and ethics analysis, the workgroup concluded that the LaPHIE project ought to be implemented because it worked to protect both individual and population health. They also found that, in Louisiana, there were no laws prohibiting information sharing for the purpose of improving individual care. In fact, the group found Louisiana legislation that facilitated

communication between public health authorities and health care providers to improve treatment.

These conclusions were fortified by the focus group and interview results from Louisiana residents, many of whom were HIV-positive, in which surveyed individuals showed support for the sharing of protected information with nurses and doctors if the purpose was to give patients information and provide improved health-care. To date, HIV-positive individuals identified by LaPHIE have not expressed objections to the system, and it has even been described in an evaluation interview as a “good system.”

#### **KING COUNTY, WASHINGTON STATE:**

The department of public health in King County, which includes the city of Seattle, has chosen to employ one of the more controversial methods for ensuring HIV care linkage and retention: direct contact with HIV-positive individuals who have been identified as not linked to care, or not retained in care. The department, however, understanding the sensitivities around such activities did engage actively with both health care providers and people living with HIV before launching their project.

#### *How it works:*

The surveillance branch of the King County Department of Public Health periodically reviews data on individuals reported to be

HIV-positive. Laboratory data are included in this analysis and individuals who have never had their CD4 or viral load tested, or who have no lab data for at least 12 months, or had a CD4 count  $\leq 500$  and viral load  $> 500$  at the time of last report, are designated as possibly out of care.

As a preliminary step to direct contact, a King County Department of Public Health Disease Intervention Specialist (DIS) first reaches out to the healthcare provider of record to offer the provider an opportunity to opt-out of the program on behalf of individual patients. If the provider requests that the DIS worker not contact the individual, no direct contact is attempted.

If the provider approves of a direct contact, a DIS follows up using contact information provided at the time of the last contact or HIV test. The DIS workers assigned to this project focus solely on HIV care re-engagement activities and are selected for demonstrated ability to establish rapport with PLWHA and HIV providers and effectively work with hard-to-reach individuals. The first DIS hired to do this work is a peer who is open about his HIV status with program participants when contextually appropriate. A second DIS with similar skills in reaching the most vulnerable populations was hired in the fall of 2012.

A very specific script is used at the initial phone attempt to protect privacy and con-

fidentiality. In the initial contact, no mention is made of HIV status or any other communicable disease. Instead, individuals are told that the health department is conducting a new program, and that for a \$50 stipend, people are being asked to come in for interviews regarding the program. If the person being sought is available to speak by phone, further information about the reason for the call and the nature of the interview are provided.

If a person consents to be interviewed in person the DIS ascertains the primary reasons that a person may be out of care and helps to guide them toward resources that may help them re-enter and remain in care. After the interview, the DIS sends summaries of the encounter to the participant's medical provider and case manager if the participant consents.

### *History of Community Engagement:*

The King County Department of Public Health went through several periods of direct engagement with both people living with HIV and HIV care providers to determine the acceptability of the program concept and obtain feedback to guide development of the program. During the process both one-on-one interviews and focus groups were conducted.

During these interviews and focus groups the majority of people living with HIV indicated that they found it acceptable

to be contacted for this purpose by the department of public health, that they would view the program as another source of support for their care, and that they thought it would be good for the health department to “make sure no one falls through the cracks.” Many did indicate, however, that they felt “other people with HIV” might object to the service even when they themselves did not.

Interestingly, those most opposed to this service were HIV medical care providers. Although medical providers had a range of opinions, varying from very supportive to neutral to negative, several were concerned about the program concept when interviewed between 2009 and 2010. The most common reasons for objecting were that the program had the potential to negatively impact the patient-physician relationship by delivering messages that could counteract or seem to counteract information the providers had discussed with their patients, that patients would be opposed to an invasion of their privacy, and that the health department was overstepping its bounds and should have higher priorities than conducting this program.

## **PROGRAM OUTCOMES**

Data are still emerging on these three programs, all of which are relatively new. Officials from Washington, D.C. have previously reported at meetings that roughly one quarter of those who were found to be out of care were successfully reached by providers and kept a medical appointment after entering the Recapture Blitz program.

In Louisiana, the LaPHIE system issued 549 alerts between February 2009 and July 2011, identifying 419 HIV-positive individuals. Nearly one-quarter had not had a CD4 count or viral load test since diagnosis. Of the remainder, nearly half had been out of care for at least 18 months. Following the alert and intervention of the provider, of 344 patients who had at least six months of follow-up, 85% had at least one CD4 count and/or a viral load test after being identified.

In King County, data from the pilot phase of the program were recently reported. Of 260 eligible individuals, health care providers allowed the public health department to contact 194 of them. The health department was able to successfully contact 113 of whom 75 completed an initial intervention designed to identify and address issues that led the individuals to be out of care.

## Background: Ethical and Legal Considerations

### *Ethics:*

Public health surveillance began near the end of the 19th century primarily as an effort to track the spread of disease within a given geographic area or demographic community. Early strategies evolved, however, so that the passive collection of data morphed into proactive efforts to contain the spread of disease. In the middle of the 20th century, public health authorities began tracking chronic non-infectious illnesses such as cancer. Though public health activities have evolved to adopt greater ethical standards for the protection and privacy of individuals about whom data are collected, there remains a tension between individuals who predominantly favor only passive collection and reporting of health information versus those who favor more active applications of data for the control of diseases as diverse as syphilis and diabetes.<sup>11</sup>

The Public Health Leadership Society (PHLS)—an association of senior public health professionals devoted to providing leadership and guidance to public health workers and government public health agencies—has published ethical guidelines<sup>11</sup> for public health officials. The tension between passive and active uses of data are directly referenced in the guidelines by the statement that, “People are responsible to act on the basis of what they

know. Knowledge is not morally neutral and often demands action.”

Specifically, when does the knowledge of illness in an individual or community acquire sufficient certainty that it would be unethical not to use collected data for promotion of health in an individual or to protect the health of others?

This question isn’t always easy to answer, but the pendulum has begun to swing in recent decades from those favoring only passive surveillance to those favoring intervention. This is largely due to new technologies that make it possible to quickly and accurately document specific health problems—ranging from unsuppressed HIV levels indicating HIV care status and lack of treatment success to elevated A1C levels, indicating poor blood sugar control in diabetics. The ethical question therefore tilts from whether it is ethical to intervene with providers and patients to whether it is ethical not to intervene if one has such important knowledge about the health of his or her citizens. To ensure that such action is ethically balanced and acceptable to the individuals about whom the actions will be taken, the PHLS has developed a list of requirements for public health activities, a few of which are listed below:

- Public health should achieve community health in a way that respects the rights of individuals in the community.
- Public health policies, programs, and priorities should be developed and evaluated through processes that ensure an opportunity for input from community members.
- Public health should advocate and work for the empowerment of disenfranchised community members, aiming to ensure that the basic resources and conditions necessary for health are accessible to all.
- Public health institutions should provide communities with the information they have that is needed for decisions on policies or programs and should obtain the community's consent for their implementation.
- Public health programs and policies should incorporate a variety of approaches that anticipate and respect diverse values, beliefs, and cultures in the community.
- Public health programs and policies should be implemented in a manner that most enhances the physical and social environment.
- Public health institutions should protect the confidentiality of information that can bring harm to an individual or community if made public. Exceptions must be justified on the basis of the high likelihood of significant harm to the individual or others.
- Public health institutions and their employees should engage in collaborations and affiliations in ways that build the public's trust and the institution's effectiveness.

Programs, such as those implemented in D.C., Louisiana and Seattle/King County do not come without risks for harm to individuals, to relationships between health departments and providers and to entire health care systems.

On an individual level, potential harms are varied and depend a great deal not only on the intervention being used, but also on how interventions are employed. As one advocate said whom Project Inform interviewed in the lead-up to planning the Think Tank, "The devil is in the details."

Perhaps the most intensive harms that could occur if laboratory records are used for care re-engagement are those that arise from efforts by health departments to contact individuals directly.

Some programs using DIS workers are better conceived and run than others and operate with greater sensitivity to the potential for harms. Without sensitivity to the particular circumstances of HIV-positive individuals at risk of domestic violence, for instance, any activity that might result in the disclosure of the individual's HIV status could result not merely in injury, but even death. As the recent murder of Cicely Bolden in Texas made clear, when violent and unstable individuals learn of the HIV-status of their sex partners the results can be deadly.

Likewise, harms to undocumented individuals may potentially be great, particularly for those in situations where widespread knowledge of their HIV status could jeopardize their housing and community support, two things immigrants to the United States, in particular, depend on quite heavily to merely survive.

Finally, if DIS workers act without sensitivity in their efforts to track down and re-engage individuals who are out of care, there is a significant risk of increasing HIV-related stigma, which studies have revealed is a prominent reason that individuals fail to get linked to care or to remain in care.<sup>13</sup> Inadvertent disclosure with potential for stigma harm can also occur in the course of intervention by staff of clinics and CBOs, especially those serving multiple health conditions and/or in cramped conditions that impair privacy.

Programs that are set up to notify clinicians and workers at CBOs also have the potential for harm. If tracking of patient outcomes is used in a fashion to punish providers with larger percentages of patients out of care this can result in a degradation of relations between health officials and providers, a relationship that is vital if public health is to be adequately promoted.

This is particularly true if funding decisions are tied directly to levels of HIV care retention and/or viral suppression. While accountability is important, it also runs the risk of punishing those who choose to work with the most

challenging populations or in the most challenging geographic locations. As the battles over public education reform have made clear, it can be far too easy to disrupt tenuous safety nets in impoverished communities in the zeal for improved accountability.

### *The Law*

The legal considerations specific to active uses of collected laboratory data fall into two categories: requirements to report such data to departments of public health and whether such information may be shared outside the departments.

In the early years of the epidemic, the grave harms that rose out of the revelation of a person's HIV status—not limited to loss of jobs, homes and loved ones, but also physical violence—as well as the high degree of stigma associated with the disease led many individuals to go without being tested for HIV or even electing to seek medical care. In order to better ensure people's well-being, and to encourage HIV testing, many states adopted strict confidentiality and privacy laws, as well as laws explicitly allowing anonymous testing. As well, for roughly two decades an AIDS diagnosis, but not an HIV diagnosis, was a names-based reportable illness in many states.

As stated above, the traditional reasons to report illnesses rose out of attempts to control the spread of highly infectious diseases. In more recent times health departments have dramatically added programs to address chronic non-infectious health conditions in

addition to communicable diseases. HIV, along with other STDs, fall somewhere in between as it is not the public at large, but only the sex and drug-using partners of those infected who risk becoming infected themselves.

As for laboratory data, 36 states, 2 territories and the cities of Washington D.C. and Philadelphia also currently mandate the reporting of all values of CD4 and viral load test results to departments of public health in addition to reporting HIV diagnoses. At the time that such statutes were put in place, however, the primary purpose was to monitor clinical HIV disease outcomes. Active uses of such data were not always considered when these laws were put in place and in some cases were explicitly disavowed as part of the process for gaining buy-in to name-based case and laboratory reporting. It is likely that community advocates for those laws would not consent to or approve of the ways that such data are now being used.

Another important legal consideration is how data on individuals living with HIV may be shared outside the public health department. The Health Insurance Portability and Accountability Act (HIPAA), which mandates that individuals must provide written consent for the sharing of their private medical information as well as various state laws protecting the privacy of health information, provides a legal framework for protecting and sharing health data. HIPAA explicitly states that where state laws are more protective than HIPAA, then state laws control the transfer of such information.

There are provisions within the HIPAA legislation allowing for the sharing of collected personal health information “to a person who is at risk of contracting or spreading a disease or condition where state law authorizes the disclosure as necessary to carry out public health interventions or investigations.” Moreover, most current activities where information about laboratory data is provided to professionals outside the department where it has been collected do not actually involve sharing information that is not already known or accessible to the health care professional being contacted.

For instance, in Washington, D.C., HAHSTA is simply alerting a medical care provider that no new laboratory data has been collected within a six-month time frame. This information is generally already available to the provider unless a person has transferred their healthcare to a different provider. While the specific activities undertaken by the LaPHIE program differ from these examples, legal experts consulted by the program determined that those activities do not run afoul of either HIPAA or any state laws in place regarding the collection and maintenance of HIV-specific information by the department of public health.

In other states, such as Massachusetts and California, the boundaries of state law regarding sharing of data related to HIV and other sensitive data are less clear, despite recent legislative updates.

A remaining issue that deserves special emphasis is the criminalization by 32 U.S. states and territories of the failure to disclose HIV status during sexual encounters, often regardless of whether there was any real risk of transmission. Such laws are a travesty, and have resulted in significant harms to thousands of people living with HIV globally and well over 1,000 within the United States since such laws were first implemented. Beyond the harm to individuals who are charged, these laws and related enforcement policies contribute greatly to the stigmatization of people with HIV, which in

turn makes it significantly more difficult to engage and maintain HIV-positive people in care.

In some cases where individuals have been charged with a crime, law enforcement officers have subpoenaed public health departments for confirmation of HIV status. It is conceivable that authorities might subpoena CD4 or viral load data to support or enhance criminal charges related to sexual activity or non-disclosure. Health departments should consider these kinds of risks as they go about designing new public health interventions.

## THINK TANK RECOMMENDATIONS

The Think Tank participants were asked to engage in six separate discussions to answer the questions laid out at the beginning of this report. Those six discussions included:

- defining policies and procedures for each type of activity that would reduce risks and enhance benefits;
- defining stakeholders who should be consulted during the planning and execution of activities as well as describing what meaningful engagement would look like;
- identifying further how local jurisdictions should contend with the need for innovative care linkage and retention activities;
- identifying actions and priorities for advocates and others to forward these issues on a national level;
- developing and voting on a consensus statement regarding the use of surveillance data and other data for care linkage and retention; and
- defining issues for further follow-up and exploration.

A survey conducted prior to the Think Tank identified many of the concerns that were later addressed during these discussions. At the meeting's outset, a number of community advocates expressed serious reservations about using collected surveillance and other data in the ways described earlier in this report. Those concerns are described below as well as recommendations to help address them.

## *Policies and Procedures*

Workshop participants were challenged to enumerate the potential risks and benefits of each type of approach mentioned above to find those out of care. These included: direct provider contact; electronic information exchanges, and direct patient contact.

In summary, the most frequently cited concern was that “one size does not fit all.” In other words, whatever approach or approaches are employed must be sensitive to the circumstances and needs of a local jurisdiction. For instance, activities with greater risks for harm, particularly in some communities or parts of the country, may actually be considered favorably in cities or counties with long-lasting and positive relationships between public health departments, providers and the community, but not favorably in areas where there has been difficult or minimal relations between all stakeholders or where HIV-related prosecutions are more prevalent.

Another overarching recommendation was that health departments, where it is legal and feasible, should consider using multiple sources of data in assessing who is out of care. Non-surveillance data could include Ryan White data and Medicaid databases.

Another key concern stressed, regardless of the approach being considered, was the need for early, extensive and meaningful stakeholder engagement before launching a program, with a particular emphasis placed on the need for engagement with people living with HIV. Such

engagement must not stop, however, as soon as a program is launched, but instead should be part of program evaluation and quality improvement. Meaningful engagement is defined in the next section and specific recommendations are included as well.

There was a sentiment among community advocates at the Think Tank that the approach most likely to enjoy support from the community and the least likely to risk harms is direct outreach by health departments to HIV care providers. Conversely, the greatest amount of concern was for programs where DIS workers are used by health departments to directly reach out to people living with HIV who appear to be out of care. If direct contact with patients is employed as a strategy, however, Think Tank participants felt that the best model would be the use of a peer care coordination or navigation model and that emphasis should be placed as much on meeting the social service needs of those who are out of care as in getting them into see a health care provider.

Lastly, the sentiment was expressed by some that technological tools being utilized by private insurers and other for-profit health care entities are far superior to those available to many public health departments and that funders, policy makers and advocates should keep this in mind when prioritizing resources for system upgrades.

Specific risks, benefits and considerations for each of the three primary approaches are listed in detail here.

## *Direct outreach to providers*

### POTENTIAL BENEFITS

- If done properly this could significantly improve the health and well-being of people living with HIV who have fallen out of care.
  - This could be among the least expensive of the three types of activities.
  - Of the three types of activities this has the advantage of being the least likely to result in coercion of patients.
  - Of the three types of activities this is most likely to be accepted by the community.
  - Such efforts take advantage of existing relationships between providers and patients and this could strengthen those relationships. Provider effort to reach out to patients could lead at least some patients to feel better cared for by providers.
  - Enhancing relationships between public health and providers not only maximizes the use of data, but also can actually improve the quality of the data through bidirectional transfers of information.
  - Consent from the patient to be contacted if they fall out of care could be easily obtained at the time of care entry.
  - Implementation of this strategy could identify workforce shortages and allow for redirection of funding resources.
- Many providers currently have limited capacity for follow-up: this approach relies on time and resources from providers and their staff.
  - Some providers could feel this is invasive and that the public health department is “grading” them. This could jeopardize relations between public health and providers.
  - Providers and their staff don’t necessarily have training in care linkage and re-engagement. If poorly conducted, these activities can breach privacy and increase the risk for stigma.
  - Some risk factors for being out of care, such as ongoing substance use or insecure housing, are difficult to solve: simply reaching out to the provider won’t address those problems.
  - If public health data is incomplete or out of date it could lead to wasted effort.
  - If there are not strict and well thought out protocols for the transfer of information about patients to providers, there could be breaches of privacy.

### POTENTIAL RISKS AND LIMITATIONS

- This approach does not address people who were never linked to HIV care in the first place.

### PRACTICES TO EMPLOY TO REDUCE HARMS AND MAXIMIZE BENEFITS

- Departments of public health (DPHs) should develop goals and a communication strategy about the risks and benefits of this approach before contacting clinicians for feedback and program design.
- DPHs should be consistent in how people are defined as being out of care.

- DPHs should use all means possible to ensure the highest quality data and utilize Institutes of Medicine or Health and Human Services definitions of out of care.
- DPHs should thoroughly and meaningfully engage providers and medical societies to help design and evaluate programs.
- DPHs should utilize AIDS Education and Training Centers to enhance training on care linkage and retention for providers and staff. Those engaging in care re-engagement activities should be trained to be compassionate, caring, respectful and non-coercive.
- DPHs should, where possible, help providers acquire resources and personnel for care coordination activities, particularly if providers are serving vulnerable populations.
- DPHs should limit access of data by the role of the provider (e.g. limit data sharing to providers and support staff who will be taking lead responsibility for care linkage and retention).
- DPHs should ask providers to be transparent with patients about care recapture efforts that will be undertaken if a person falls out of care.
- DPHs should explore the legality and capacity to share data across multiple providers.
- DPHs should prioritize resources toward the most vulnerable patient populations and methods that have the greatest likelihood of success.

## *Electronic Exchanges*

### POTENTIAL BENEFITS

- If done properly this could significantly improve the health and well-being of people living with HIV who were never linked to care or who have fallen out of care.
- This approach addresses people who were never linked to care, not just those who have fallen out of care.
- This approach takes advantages of missed opportunities for care linkage and retention and finds people where they are.
- This approach may reduce disparities in health care by re-orienting responsibility for care linkage and retention to multiple provider types.
- This approach allows for the least amount of information about a person to be transmitted outside of the public health department and a more secure protocol for information transmission.
- This approach is narrowly constrained for specific purposes and potentially avoids mission creep.
- If combined with care coordination and social services this approach could have a high degree of success at care linkage and re-engagement.

**POTENTIAL RISKS AND LIMITATIONS**

- This approach is more complex and resource intensive technologically than programs that reach out directly to providers or those out of care.
- This approach may ultimately be limited to jurisdictions with large public health care institutions that serve a substantial proportion of people living with HIV and that have high quality electronic medical records.
- If poorly conceived or maintained there could be data leakage to those other than direct care providers, such as support staff.
- This approach relies heavily on providers with little to no expertise in HIV appropriately linking or re-engaging people who are out of care.
- People who are out of care could feel that their confidentiality has been breached if an emergency room provider or other non-HIV specialist engages them about their HIV status. This could lead to increased stigma and discrimination.
- If care linkage and re-engagement activities are not tracked closely it could cause public health officials to remove people from out of care lists prematurely.
- HIV care coordination specialists might not be available at the time of care re-entry to aid in addressing the reasons that people were never linked to care or fell out of care in the first place.
- If data are not of high quality it could lead to false alarms.

- The system, especially the specific activity prompts, could be designed too rigid and inflexible to adequately address the best level of provider and patient interaction.

**PRACTICES TO EMPLOY TO REDUCE HARMS AND MAXIMIZE BENEFITS**

- DPHs should engage multiple stakeholders during the planning process, including information technology and privacy experts, legal and ethics professionals, HIV and non-HIV providers and especially people living with HIV and community advocates. The LaPHIE model is a good model to follow in this regard.
- DPHs should use all means possible to ensure the highest quality data to determine who is out of care and utilize Institutes of Medicine or Health and Human Services definitions of out of care.
- DPHs should consider, if feasible and legal, using multiple sources of data.
- If technologically possible, DPHs should explore an opt-out model at the time of HIV testing or allow people testing to assert what types of information they consent to be shared in an electronic exchange system.
- DPHs should offer or encourage training to the providers who are likely to receive electronic message prompts from the public health department, especially emergency and urgent care providers. This is especially important as individuals who were never linked to care may differ in important ways from those who have

dropped out of care. Moreover, increasing provider knowledge of social service and care coordination services in the community can increase the likelihood that the factors leading to poor care linkage and retention may be addressed.

- DPHs should consider, if technologically feasible, a phased rollout to give time for the program to be tested.

### *Direct outreach to patients*

#### POTENTIAL BENEFITS

- If done properly this could significantly improve the health and well-being of people living with HIV who were never linked to care or who have fallen out of care.
- This approach addresses people who were never linked to care and not just those who've fallen out of care.
- If using a peer or near-peer care coordination model this could allow for barriers to care to be addressed quickly and adequately by the DIS worker.
- This approach is scalable.
- This approach could more easily locate some of the hardest to reach individuals who are out of care.
- In many jurisdictions this type of effort would be covered under existing DIS protocols.
- Depending on how it is deployed, this effort could reduce the number of hand-offs between medical and social service providers.

#### POTENTIAL RISKS/LIMITATIONS

- Some community advocates were fundamentally opposed to this approach under any circumstance, citing concerns about privacy, stigma, discrimination and even, possibly, vulnerability to prosecution of those found to be out of care.
- If DIS workers inadvertently breach privacy during the course of attempting contact this could result in severe harms to the person who is out of care.
- If DIS workers are improperly trained they could increase feelings of stigma and discrimination among those out of care. Further, DIS workers may use coercive techniques to try to link or engage individuals.
- This is a resource- and labor-intensive approach to care linkage and retention. Some health departments may not have the resources to employ this type of effort properly or would have to make unacceptable trade offs regarding other public health programs.
- Even if a method to obtain consent to be contacted is employed that consent may later be withdrawn by the person out of care.

#### PRACTICES TO EMPLOY TO REDUCE HARMS AND MAXIMIZE BENEFITS

- DPHs should engage in extensive consultation with key stakeholders, particularly people living with HIV, community advocates, health care providers and privacy experts during the design process and to evaluate the program after it is launched.

## Using Surveillance and Other Data to Improve HIV Care Linkage and Retention

*a think tank convened november 6/7, 2012*

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- DPHs should perform cost-analyses to ensure proper funding when determining what types of care linkage and re-engagement processes to employ.
- If technologically possible, DPHs should explore an opt-out model at the time of HIV testing. If this is not possible, DPHs should issue a formal recommendation to those performing HIV testing to inform clients that DIS workers may later try to reach them if the person appears to be out of care.
- DPHs should use all means possible to ensure the highest quality data and utilize Institutes of Medicine or Health and Human Services definitions of out of care.
- If DIS workers are deployed, DPHs should use continuous quality improvement methods to ensure not only the success of the effort, but also the acceptability by providers and patients. Further, DPHs should track and evaluate contact efforts that are made and when a contact is made indicate whether it was positive or negative for the person being outreached to.
- DPHs should consider hiring peers or near-peers as DIS workers and utilize a care coordinator model for these workers. Emphasize connections to services that address barriers to care when contacts are made.
- DPHs should consider reaching out to providers for consent to contact patients and to evaluate data accuracy before reaching out to those out of care.
- DPHs should consider allowing providers to approach the public health department for aid in locating those who have been lost to care.
- DPHs should consider deputizing community-based care coordination experts as health department officials to allow for peer or near peer workers to be utilized.
- DPHs should seriously consider the local reality on the ground including the availability of local social services to address care linkage and retention barriers, the current and historical relationship between the health department and the community and likelihood of criminal prosecution for HIV non-disclosure or exposure.

## Meaningful Stakeholder Engagement

Stakeholder engagement is a recommended best practice for many types of public health efforts and this is especially true when it comes to the use of public and private data to enhance HIV care linkage and retention efforts. Stakeholder engagement can be used to define goals and likely barriers, weigh important legal and ethical considerations and identify processes and procedures to minimize potential harms.

Stakeholder engagement procedures can range from private meetings and focus groups to surveys or even open public forums or the provision of time for written public comment on proposed activities.

Simply asking for the input of important stakeholders “late in the game” is insufficient, especially if that input is not likely to be adopted because departments have moved too far along with planning to allow for changes identified during the stakeholder engagement process. For this reason, the participants involved in the Think Tank stressed that not only should stakeholder engagement occur in the development phase, it should be meaningful.

Engagement should occur early in the planning process and health departments should be clear during the engagement process what elements of a proposed project can be changed and which cannot. Participants also recommended strongly that stakeholder engagement be used on a continuous basis even after the launch of programs to ensure quality control,

transparency and proper accountability to stakeholders.

In order to make proper decisions about the use of collected data for care linkage and retention purposes, there are certain activities that participants recommended that certain activities be conducted before engaging stakeholders. These may include:

- assessing the quality of the data to be used and procedures necessary to bring data sources to at least a minimum level of reliability;
- conducting cost analyses of the types of activities being anticipated and identifying potential funding sources and trade-offs if other activities would have to be curtailed in order to implement new programs; and
- developing a list of over-arching goals and communications strategies to ensure that stakeholders can be properly informed about the logistical, practical, legal and ethical issues that may arise from these activities.

### STAKEHOLDERS TO ENGAGE

When considering the use of surveillance data and other data for care linkage and retention there are multiple types of stakeholders who should be consulted before, during and after activities are launched. Each brings a unique contribution to ensure that programs are feasible, effective and have limited potential to cause harm to people living with HIV or to their health care providers. Below is a list of potential stakeholders, the types of contributions they can offer to planners and implementers of programs and optimal methods for gaining feedback.

### PEOPLE LIVING WITH HIV

Given the nature of HIV stigma, discrimination and even criminalization, both in the past and present, active uses of private medical data have substantial potential for harms. For this reason, it is vital that the concerns and input of people living with HIV be actively sought, especially if the health department plans to have direct contact with people identified as out of care.

It is further ideal if health departments envision people living with HIV as partners in the development of care linkage and retention efforts rather than as passive recipients or subjects of such services. Such a philosophical approach is more than semantic: it can have a powerful impact on the magnitude and quality of the feedback from these vital stakeholders and on the design and conduct of programs.

Focus groups are an ideal way to solicit input from people with HIV during the planning process, because they allow for dialogue, education and clarification. One-on-one interviews offer similar benefits, but are more labor intensive. Surveys may also be employed, and they do offer anonymity and the ability to reach larger numbers of people. They may be preferable for program evaluation than for program planning, however. It should also be stressed that efforts should be made to seek feedback from individuals who are most likely to be directly impacted by programs or who share important demographic, social and economic characteristics with individuals who are most likely to be out of care.

### COMMUNITY-BASED ORGANIZATIONS (CBOs)

Though some CBOs offer primary medical care and legal services, many do not. They do, however, often provide vital services that can affect how individuals are linked or retained in care and may engage in public policy and advocacy activities to protect and promote the well-being of people living with HIV. One advantage to seeking input from CBO representatives is that they may be particularly sensitive to the ongoing unmet needs among their constituents and may have greater understanding of the stakes involved in launching care linkage and retention services based on surveillance and other data.

Both focus groups and surveys may be employed with CBO representatives, though

focus groups are likely superior, particularly for planning purposes. Moreover, participants at the Think Tank recommended providing both context and questions to CBO representatives prior to a focus group or survey so that input from constituents and associates may be gathered. When program plans enter the final phase, DPHs may also make time for public commentary to be solicited.

#### HIV CARE PROVIDERS

HIV health care providers have a fundamental charge to preserve the health and well-being of the people they care for. For this reason, they can and should be active partners in efforts designed to improve HIV care linkage and retention, regardless of the method employed, but especially for programs where clinicians will be called upon to engage or re-engage their patients in health care. Additionally, clinicians can often be vital sources of information on the status of their patients. As such, surveillance officials can potentially strengthen the quality of their data by working collaboratively with clinicians.

Health departments may utilize a number of methods for soliciting feedback from clinicians. Focus groups may be particularly useful during the planning phase of programs though direct one-on-one interviews and surveys may also be employed, especially when evaluating the success of programs.

#### LEGAL AND ETHICAL EXPERTS

HIV has been and continues to be an exceptional disease when it comes to concerns over privacy of medical information. Early in the epidemic people with HIV were put at risk of not only their housing and employment should their HIV status become known, but also their physical safety. Also, prejudice and discrimination on the part of friends and family members are other risks that may occur with the breach of privacy. Sadly, there remain significant risks even today for people with HIV from inadvertent disclosure of HIV status to persons other than the person a program is seeking to engage or re-engage in care. Thus, specific privacy laws have been passed over the past 30 years to protect against these types of harms.

Moreover, not all states have the same statutes in place to define how HIV data may be used. This has led to a patchwork of different responses to those laws on a national basis. Legal experts are, therefore, necessary to ensure that proposed activities are consistent with laws currently in place or to propose changes in legislation that would be needed in order to proceed with certain activities.

In recent years there have been arguments about the need for a continued exceptional status for HIV privacy over and above other communicable or chronic diseases. This tension is made especially poignant given the potential for active uses of collected data at the present time to be used directly to promote the health of those who are out of care.

Because of the potential for both benefit and harm, it is crucial that public health departments engage legal experts, privacy advocates and ethicists to ensure that minimal harms are introduced.

#### INTERNAL STAKEHOLDERS WITHIN HEALTH DEPARTMENTS AND INFORMATION TECHNOLOGY EXPERTS

Care linkage and retention efforts can be costly and consume significant staff resources to properly implement them. Moreover, there may be different philosophies among health department staff members about when, how and whether private medical data may be used for anything other than passive surveillance of the HIV epidemic. Internal stakeholders may be particularly helpful in identifying potential practical and logistical obstacles to the implementation of various efforts. For these reasons, internal stakeholders should be consulted at the most formative point in developing new programs as well as in the evaluation of programs post-launch.

Information technology (IT) experts, both those working internally for health departments as well as outside consultants, are also highly recommended during the planning phase to assess the best methods for generating accurate “out-of-care” data and are absolutely vital in developing the architecture for programs that employ electronic sharing of collected data with private health care providers.

Participants recommended direct discussion and consultation, both in groups and individually, to solicit feedback from internal stakeholders and IT experts.

#### FUNDERS AND INSURERS

Certain activities would benefit from contact with key funders, insurers and government agencies. These would include AIDS Drug Assistance Program coordinators, officials from HRSA and the CDC, Ryan White Directors, state Medicaid officials and officials from the Center for Medicare and Medicaid Services (CMS).

#### ADDITIONAL RECOMMENDATIONS FOR HEALTH DEPARTMENTS

The majority of the recommendations made by the Think Tank participants for state and local health departments have already been covered by addressing policies and procedures and meaningful stakeholder engagement. Several further recommendations were made, however.

The first recommendation was to challenge assumptions that an activity that works well in one jurisdiction will necessarily have the same success in another. Both internal (within the DPH) and external factors can profoundly influence program design and execution. As well, the social and demographic factors of people living with HIV who are most likely to be out of care may differ from one location to another and these demand individualized approaches.

Another recommendation, which on its surface may seem obvious, is for health departments to do at least something about care linkage and retention, and not to bury their heads in the sand when confronted with these important challenges. While there may be difficult obstacles to overcome, these should not be excuses for inaction.

One thing that is also obvious from the previous sections is the need not to act unilaterally or to cling rigidly to conceptions that are held before engaging stakeholders. Think Tank

participants urged health departments to keep an open mind throughout the stakeholder engagement process.

There was a strong recommendation for local jurisdictions to explore using a peer navigator model for care linkage and retention—whether or not surveillance data are used. Think Tank participants recognized, however, that while this model has great promise, there are not yet high quality data on its efficacy nor are there significant funding streams available for these types of programs at the present time.



## Recommendations for Advocacy Efforts

A larger discussion also took place that focused as much on what community advocates should do as what health departments should consider. Some of the recommendations are about harmonizing and consolidating efforts on data use and integrity, ensuring that states have the tools they need to at least track care linkage and retention and the need to seriously address HIV criminalization. Following are the recommendations and their rationale:

- Advocates and other stakeholders should harmonize the work of the Institutes of Medicine, Health and Human Services (HHS), CDC and various advocacy groups who are working on issues related to data integrity, core indicators for defining linkage and retention in care, and uses of multiple data sources, both public and private. This was seen to be a high priority issue as data integrity and completeness will be paramount not only for active uses of data described in this report, but also fundamentally to track how well people are being linked and retained in care more generally. Such data could also be used to issue report cards on care linkage and retention down to the local level, though some of the participants cautioned against using care linkage and data too punitively.
- Advocates should work with legal advocacy organizations and local advocates to consider legislation that would mandate reporting of CD4 counts and viral loads in every state. Moreover, community and legal stakeholders should review laws on data privacy to ensure a proper balance between privacy concerns and the ability to use data more actively to promote health among people living with HIV.
- Advocates should also work, however, to ensure that legislation is passed in every state to severely curtail how collected surveillance data may be used to aid in HIV-related prosecutions and be limited perhaps to cases where HIV transmission occurred.
- Advocates and public health departments should partner to introduce legislation to ensure proper penalties outlined in state law in cases where privacy breaches regarding client-level data occur.
- Public health officials and HIV advocates should engage in discussions about the adoptions of electronic medical records, by both private and public institutions, to ensure that the appropriate data are collected and that data sharing is not technologically impeded.

## Using Surveillance and Other Data to Improve HIV Care Linkage and Retention

*a think tank convened november 6/7, 2012*

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- Advocates should work to ensure that Ryan White funding continues and that explicit funding for care linkage and retention programs be considered.
  - Advocates and public health officials should engage in efforts to explore how the types of programs considered in this report could be tailored for cities, counties and states in the South East of the United States and in areas with significant rural epidemics as these have among the highest HIV incidence rates at the present time.
  - Recognizing that care linkage and retention are frequently associated with the offer of antiretroviral therapy, Think Tank participants recommended that medical boards and associations expand their efforts to ensure that HIV care is offered consistent with federal DHHS treatment guidelines.
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## Consensus Statement

Finally, Think Tank participants were asked to consider whether it would be possible for all present to agree on a simple consensus statement regarding the subject under question: Are more active uses of surveillance and other data acceptable for the purposes of linking and retaining HIV-positive individuals in care?

A strenuous discussion followed, which, in short, amounted to community advocates wanting to ensure that a consensus statement would be interpreted through the lens of other recommendations that had already been made to minimize harms and to ensure full stakeholder engagement.

During the discussion, two notable trends emerged. First, that public health officials present reaffirmed their dedication to meaningful stakeholder engagement. Second, that several community advocates arrived at the Think Tank fundamentally opposed to using surveillance data in a more active fashion, but that they had been convinced that the potential for benefits was significant.

With the safeguards enumerated above in place, local and state jurisdictions should begin reaching out to the community and other stakeholders to consider activities of this sort. The advocates stressed that the use of surveillance data was not the sole means for improv-

ing care linkage and retention, and that other types of efforts are either already in place or being planned that would not rely on this type of data. Nevertheless, they felt that the types of programs going on in Washington, D.C., Louisiana and King County, Washington were promising enough that other jurisdictions should explore similar efforts.

In the end, and after multiple rounds of suggested wording changes, AIDS service organizations, community-based organizations, academics, health departments and other non-federal agency stakeholders attending the meeting unanimously agreed to the following consensus statement:

*“The benefits [to more active uses of collected data] potentially outweigh the risks so that we encourage local jurisdictions to actively engage stakeholders in considering the use of surveillance data along with other tools to systematically increase access to care, ensure better linkages to services, and improve retention in care.”*

## Conclusion

As stated many times at the Think Tank, the best of public health policy and practice is a true partnership between health officials and the community whose lives and health those officials are seeking to improve. The consensus statement reached by the participants is a symbol for what can be achieved when everyone works together with a common goal.

The efforts described that are taking place in Washington, D.C., Louisiana and King County, Washington exemplify the types of programs that may be employed to improve HIV care linkage and retention. They are not, however, the only locations that have launched such programs or that are planning to do so. It is Project Inform's sincere wish that public health officials in these additional jurisdictions have employed the types of policies and procedures outlined in this report and that meaningful stakeholder engagement has occurred or will occur if programs have yet to be launched.

In the event that such stakeholder engagement has not occurred, or not to the degree outlined in this report, the community can and should insist that such efforts be undertaken, not merely to shape or reshape programs, but also to provide constant and ongoing evaluation and quality assurance.

No single action is going to solve the care linkage and retention failures that occur among thousands of people in the United States. Implementation of the Affordable Care Act will hopefully extend health care to thousands of uninsured HIV-positive individuals and expand the menu of health care services available.

Implementation is likely to have great challenges, however, and is not of itself a solution to the many factors that lead people to fall out of care.

Likewise, the types of programs described should also not be seen as a sole solution to care linkage and retention programs. Their promise, as previously described, will rely heavily on the ability of health care providers and social service providers to adequately address the factors that caused someone to fall out of care in the first place.

That said, the early signs of success of these programs are encouraging and given the continued magnitude of the epidemic in the United States such success is urgently needed.

The value of a tool depends greatly on the intent and the skill with which it is being used. The tools described in this report will similarly depend on the intent and skill with which they are employed. Project Inform hopes that the recommendations outlined here help to ensure that health departments, in true partnership with the community, are better equipped and able to achieve the end goal, to ensure that people living with HIV have access to and remain engaged with high quality health care.

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## Bibliography

- Office of National AIDS Policy. "National HIV/AIDS Strategy for the United States." 2010 July. ([www.whitehouse.gov/sites/default/files/uploads/NHAS.pdf](http://www.whitehouse.gov/sites/default/files/uploads/NHAS.pdf))
- Gardner E, McLees M, Steiner J, Del Rio C, Burman J. "The Spectrum of Engagement in HIV Care and its Relevance to Test-and-Treat Strategies for Prevention of HIV Infection." *Clin Infect Dis*. 2011 Mar 15;52(6):793-800.
- Centers for Disease Control and Prevention. "HIV in the United States: The Stages of Care." 2012 July. ([www.cdc.gov/nchhstp/newsroom/docs/2012/Stages-of-CareFactSheet-508.pdf](http://www.cdc.gov/nchhstp/newsroom/docs/2012/Stages-of-CareFactSheet-508.pdf))
- Millett G, Peterson J, Flores S, et.al. "Comparisons of disparities and risks of HIV infection in black and other men who have sex with men in Canada, UK, and USA: a meta-analysis." *The Lancet*. 2012 July; HIV in men who have sex with men: 11-18
- Board on Population Health and Public Health Practice. "Monitoring HIV Care in the United States: A Strategy for Generating National Estimates of HIV Care and Coverage." 2012
- Pecoraro A, Royer-Malvestuto C, Rosenwasser B, et al. "Factors contributing to dropping out from and returning to HIV treatment in an inner city primary care HIV clinic in the United States AIDS Care." 2013 Feb 21. [Epub ahead of print]
- Bogart LM, Landrine H, Galvan FH, Wagner GJ, Klein DJ. "Perceived Discrimination and Physical Health Among HIV-Positive Black and Latino Men Who Have Sex with Men." *AIDS Behav*. 2013 Jan 8. [Epub ahead of print]
- Saha S, Korthuis PT, Cohn JA, Sharp VL, Moore RD, Beach MC. "Primary Care Provider Cultural Competence and Racial Disparities in HIV Care and Outcomes." *J Gen Intern Med*. 2013 Jan 10. [Epub ahead of print]
- Munar D. Romney. "Care and HIV/AIDS: A Look at Massachusetts Offers Insight on National Health Care Reform." *Positively Aware*. November/December 2012
- Holman J, Schneider K, Watson K, Mathur J, Flynn A. "HIV/AIDS Consumer Study, Massachusetts and Southern New Hampshire." 2011. ([www.mass.gov/eohhs/docs/dph/aids/consumer-study-june-2011.pdf](http://www.mass.gov/eohhs/docs/dph/aids/consumer-study-june-2011.pdf))
- Fairchild A, Alkon A. "Back to the Future? Diabetes, HIV, and the Boundaries of Public Health." *Journal of Health Politics, Policy and Law*, Vol. 32, No. 4, 2007 August.
- Public Health Leadership Society. "Principles of the Ethical Practice of Public Health." 2002. ([www.apha.org/NR/rdonlyres/1CED3CEA-287E-4185-9CBD-BD405FC60856/0/ethicsbrochure.pdf](http://www.apha.org/NR/rdonlyres/1CED3CEA-287E-4185-9CBD-BD405FC60856/0/ethicsbrochure.pdf))
- Naar-King s, Bradford J, Coleman S, Green-Jones M, Cabral H, Tobias C. *AIDS Patient Care and STDs*. June 2007, 21(s1): S-40-S-48.

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# TRANSGENDER POST-RELEASE CASE MANAGEMENT

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TRANSGENDER POST-RELEASE CASE MANAGEMENT is an individual level intervention which links transgender HIV+ individuals soon to be released or recently released from a correctional facility to health services. The key characteristics of Transgender Post-Release Case Management are: face-to-face meetings with inmates in a local facility or collect call conversations from distant facilities; use of case managers who are from the primary target population; acceptance and non-judgment of the client; development of a risk reduction plan that includes HIV and health service goals; and tracking of the client’s progress.

### CURRENT ACTIVITY SETTING

*Community-Based Organization for Ex-Offenders,  
Case Management Discharge Planning*

- ✓ Directly links the client to medical care
- ✓ Gets the client in a conversation about starting medical care
- ✓ Brings the agency closer to where HIV+ people are so that the conversation can begin

## I. DESCRIPTION

### OBJECTIVES

- ▶▶ To help transgender individuals recently released from a correctional facility reintegrate into society and into health and social services
- ▶▶ To identify pre-release and recently released HIV+ individuals who are currently out of HIV care and to assist them in re-establishing their medical care

### POPULATION SERVED

- ▶▶ The primary target population is transgender (male-to-female and female-to-male) individuals soon to be released or recently released from a correctional facility.
- ▶▶ The secondary target population is gay, lesbian, and bisexual individuals who are soon to be released or recently released from a correctional facility.

### ACTIVITY DESCRIPTION

Transgender Post-Release Case Management offers support to transgender, gay, lesbian, and bisexual individuals living with HIV in establishing independence and health connections after release from incarceration.



QUICK NOTES:

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*“You have to prepare people to take control of their health. Until the client is ready, there’s not much you can do.”*

— DISCHARGE PLANNER

- ▶▶ A new case is initiated in one of two ways: 1) a correctional facility notifies the agency of an inmate who self identifies as, or is believed to be, transgender, gay, lesbian, or bisexual; or 2) a client contacts the agency after being discharged.
- ▶▶ The case manager, who is also a member of the primary target population, schedules an assessment appointment to determine whether the client is eligible for agency services.
- ▶▶ If the client is in a local correctional facility, the case manager can hold the meeting there, with the permission of the facility administration. If the client is in a distant facility, the case manager can talk with the inmate by phone about needed services. In either instance, the case manager informs the client of the agency’s service portfolio.
- ▶▶ In face-to-face meetings, the case manager’s demeanor and attitude communicate acceptance and non-judgment of the client, who may have experienced discrimination or abuse because of their appearance, behavior, or gender identification.
- ▶▶ Clients wishing to receive services sign a consent form granting permission for the release of information to the agency.

#### **Post-Release Meetings**

- ▶▶ Upon release, the client meets with the case manager at the agency, where s/he finds posters, signage, reading material, and other features to encourage cultural identification, safety and acceptance. At this first meeting, the client signs a formal “informed consent to release” allowing other agencies to help with establishing a continuum of care services.
- ▶▶ The case manager gathers intake information that includes emergency contacts, medical care history, known medical conditions, current medications, sources of income, and a breakdown of monthly expenses. The case manager also requests photo IDs, a birth certificate, release papers, the name of the parole officer and the terms of the client’s parole, if applicable.
- ▶▶ In the case of parole, the case manager may choose to inform the parole officer that the client is receiving services from the agency.
- ▶▶ The client and case manager do a behavioral risk assessment.
- ▶▶ After gathering the necessary information, the case manager and client develop a risk reduction plan. This plan includes safer sex goals, HIV risk reduction goals, and a list of needed support services. The client and case manager put together a comprehensive, 60-day life plan.
- ▶▶ Once satisfied with the plan, the client signs the document thereby committing to the plan.
- ▶▶ Depending on the information received from the client, referrals are made for specialized support services, general health care, mental health services, specialized health care, food banks, and social services.
- ▶▶ The case manager helps the client identify a medical provider and promptly schedules an appointment.
- ▶▶ The case manager then begins the task of completing an AIDS Drug Assistance Program application and a city health insurance application so that the client can initiate or re-initiate anti-retrovirals or HIV-related medications (assuming clinical assessments deem them necessary).
- ▶▶ This entire process takes four to five hours. The agency provides lunch to the client.
- ▶▶ On the following day, the client returns and receives copies of the completed paperwork.
- ▶▶ The case manager emphasizes to the client that the “ball is rolling” to get them the care they need.
- ▶▶ The case manager tracks progress by asking the client to call in after each appointment with a provider to report on the experience.
- ▶▶ If the client has no place to stay, the case manager helps to find emergency or transitional housing.
- ▶▶ After the 60-day life and service goals are met, the case manager establishes a meeting schedule consistent with the urgency of the client’s needs. The case manager also remains in touch with the client’s parole officer.
- ▶▶ The agency holds case management meetings to ensure that clients are receiving necessary services and to assess their progress in meeting goals.

## PROMOTION OF ACTIVITY

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- ▶ Outreach by community organizations
- ▶ Brochures distributed to correctional facilities
- ▶ Local media advertisements for the agency and the population served
- ▶ Advisory councils of people living with HIV
- ▶ Court referrals to agency
- ▶ Word of mouth

## II. LOGISTICS

### STAFF REQUIRED

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Two case managers who serve as discharge planners

### TRAINING & SKILLS

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Training in comprehensive cultural competency specific for this population

### PLACE OF ACTIVITY

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- ▶ A private office and drop-in area at the agency
- ▶ Meeting place in correctional facility

### FREQUENCY OF ACTIVITY

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As needed

### OUTSIDE CONSULTANTS

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Graphic design professionals to develop brochures

### SUPPORT SERVICES

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- ▶ Transportation vouchers
- ▶ Meals during long visits to the agency

### CONDITIONS NECESSARY FOR IMPLEMENTATION

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- ▶ Funding streams must be in place.
- ▶ Agency must have a strong working relationship with correctional facilities.

## III. STRENGTHS AND DIFFICULTIES

### STRENGTHS

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- ▶▶ Demonstrates to clients that the agency comes through with promised services
- ▶▶ Establishes and maintains trust with the client
- ▶▶ Creates a climate of support, understanding, and safety for clients
- ▶▶ The agency staff members are also members of the targeted population

### WEAKNESSES

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Clients may leave care and treatment because of substance use relapses or mental health problems.

### DIFFICULTIES FOR CLIENTS

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- ▶▶ Lack of transportation to appointments can be a serious barrier since transportation assistance does not cover non-medical appointments.
- ▶▶ It is difficult for some clients to obtain a government-issued identification card, and legal employment is impossible without it.

### DIFFICULTIES FOR STAFF

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- ▶▶ It is sometimes extremely difficult to maintain the “full attention” of a client when discussing health care needs—especially if that person has other pressing needs or priorities.
- ▶▶ Some clients do not take their care seriously.
- ▶▶ The substance use relapse rate is high.

### OBSTACLES FOR IMPLEMENTATION

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There is a documented gap in funding for services targeted to the transgender population.

### ACTIVITY NOT SUITED FOR

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The identified heterosexual population, severely mentally ill clients, and active substance users.

## IV. OUTCOMES

### EVALUATION

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- ▶▶ Case evaluations are managed through case management reports.
- ▶▶ The case supervisor monitors and tracks referrals through a database to determine the number of times per month a client accesses local services.
- ▶▶ Calls from clients at correctional facilities are logged.
- ▶▶ Client surveys provide feedback at different stages of service provision.
- ▶▶ The data from each annual report is compared to the data in past annual reports.

## EVIDENCE OF SUCCESS

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- ▶▶ Case management reports and referral monitoring show an increase in moving clients from post-release homelessness to independent living.
- ▶▶ Client tracking shows an increase in linking clients to HIV medical care.
- ▶▶ The number of clients served has increased over previous years.

## UNANTICIPATED BENEFITS

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Opens relationships between staff and criminal justice agencies, mental health agencies, and the police department

## “CONNECTING TO CARE” ELEMENTS OF ACTIVITY

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- ▶▶ The agency fills emergency needs first; the client feels cared for when assured they are not going to be homeless and that they will be linked to a full array of services.
- ▶▶ The message sent through the agency literature and promotion is that the agency “makes miracles happen every day.” Clients identify with that idea.
- ▶▶ The case manager is a mixture of compassion, personality, and patience.
- ▶▶ Clients understand that the case manager is serious about the work, and that all interventions will have follow-through.
- ▶▶ The service is explicitly client-centered.
- ▶▶ The case manager commits to clients with a willingness to go “the extra mile” and a spirit of compassion that wins clients’ confidence and trust.

## KEEP IN MIND...

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- ▶▶ It is important to have compassion and a mission to serve the transgender community.
- ▶▶ Moving people from homelessness to independent living is a key factor in getting and keeping transgender individuals in care.
- ▶▶ Focus on clients who demonstrate a serious desire to get and stay in care.