2016 NATIONAL RYAN WHITE CONFERENCE ON HIV CARE & TREATMENT

# Building Effective Linkage and Reengagement Services:

## Lessons Learned From the Merck Foundation HIV Care Collaborative

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HIV CARE COLLABORATIVE
Supported by Merck Foundation

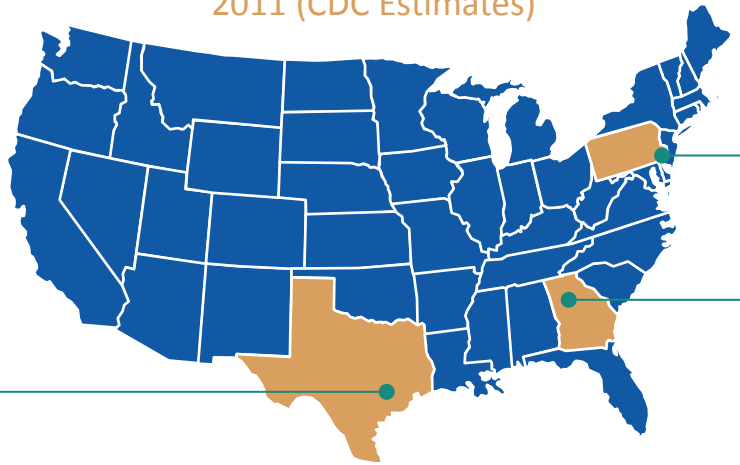
# HCC PARTNERS WAS THE KEY TO OUR SUCCESS

| | |
|---|---|
| **National Program Office (NPO)** | George Washington University<br>Milken Institute School of Public Health |
| **Bridging the Gap Initiative** | Fulton County Department of Health and Wellness (Georgia) |
| **Expanded Linkage to Care Initiative** | Houston Department of Health and Human Services (Texas) |
| **Engaging HIV+ Patients in Care Initiative** | Philadelphia Department of Public Health (Pennsylvania) |

# HCC ORGANIZATIONAL SETTINGS:
# IMPROVING LINKAGE TO CARE IN HIGHLY IMPACTED AREAS

› The HCC serves three Metropolitan Statistical Areas (MSAs) highly impacted by the HIV/AIDS epidemic including Atlanta/Fulton County, Houston, and Philadelphia

**MSA HIV/AIDS Population-Adjusted Rates**
2011 (CDC Estimates)



## HOUSTON MSA

| | |
|---|---|
| AIDS Diagnosis Rate | **19.3** |
| AIDS Rank Among MSAs | **12** |
| HIV Infection Rate | **26.8** |
| HIV Infection Rank Among MSAs | **12** |

## PHILADELPHIA MSA

| | |
|---|---|
| AIDS Diagnosis Rate | **15.1** |
| AIDS Rank Among MSAs | **16** |
| HIV Infection Rate | **20.6** |
| HIV Infection Rank Among MSAs | **24** |

## ATLANTA MSA

| | |
|---|---|
| AIDS Diagnosis Rate | **23.4** |
| AIDS Rank Among MSAs | **6** |
| HIV Infection Rate | **37.4** |
| HIV Infection Rank Among MSAs | **8** |

# HCC demonstrates feasibility and effectiveness of enhanced HIV linkage to care and re-linkage strategies in public health settings

## What we did

- Aligned with the National HIV/AIDS Strategy, the HCC teams with local health departments (LHDs) to connect newly diagnosed HIV+ clients to high quality treatment and reconnect other HIV+ clients lost to care
  - HCC National Program Office (NPO) provides TA, evaluates the HCC, and fosters a "learning community" among sites

## Our mission: helping link HIV+ people to the care they need

- Our partners assess clients' needs, care barriers, and treatment readiness
  - Develop and undertake individualized care plans, including linkage to medical care
  - Coordinate with the care team and monitor client progress
  - Transition clients to medical case management (MSM)

# EVIDENCE-BASED RECOMMENDATIONS FOR LINKAGE AND RETENTION IN CARE

- Systematic monitoring of *entry* into HIV care
- Systematic monitoring of *retention* in HIV care
- Brief strengths-based case management for individuals with a new HIV diagnosis
- Intensive outreach for individuals not engaged within six months of a new HIV diagnosis
- Use of peer or paraprofessional patient navigators

Thompson MA et al. *Ann Intern Med* 2012;156

# HCC INTERVENTION INCLUSION CRITERIA

## For inclusion in HCC programs, clients must be:

- 18 years of age at enrollment
- Not incarcerated
- Written confirmation of HIV seropositivity
- Residing in Philadelphia PA, Harris County TX, or Fulton County GA

- **Newly identified as being HIV+ and never in care**
- **Out of HIV care for at least six months before enrollment**
- Transferring HIV+ individuals
- Loosely engaged HIV+ individuals with frequent broken OAMC appointments

# HCC WORKFORCE

Age: Mean 43 years of age (27-55 years)

Gender: 61% male, 39% female

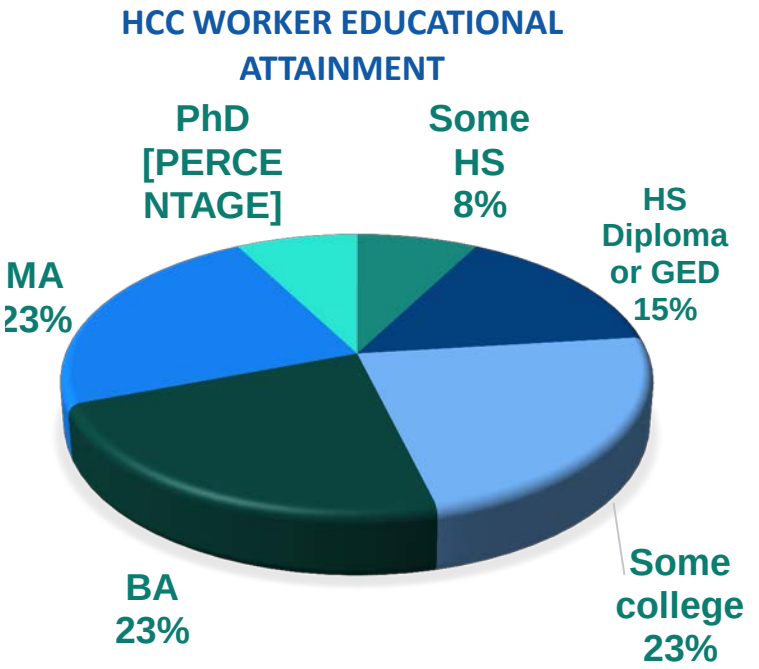
Race/Ethnicity: 77% African-American, 15% Hispanic, 8% non-Hispanic White

Work Experience: Mean 13 years (3-24 years)

HIV Experience: Mean 6 years (<1-19 years)

Time in HCC Employment: Mean 17 months (3-25 months)

**Turnover: 46% of HCC workers voluntarily separated from HCC employment**



## LESSONS LEARNED IN EMPLOYING HIV LINKAGE AND RETENTION WORKERS IN LHDs

- Worker turnover impacts productivity, continuity of care, and quality of services
  - Departing workers had significantly lower mean total years of paid employment than other workers (16 years versus 10 years)
  - Career advancement or relocation drove turnover
  - New policies for ensuring continuity of services were needed to prevent gaps, leading to clients being lost to care
- Administrative simplicity and reduced paperwork is needed
  - Ryan White (RW) Program intake, assessment, and recertification contributes greatly to administrative and client burden
  - Workers with low educational attainment tend to be challenged in chart documentation
- Trained, experienced supervisors with linkage and QM skills are key

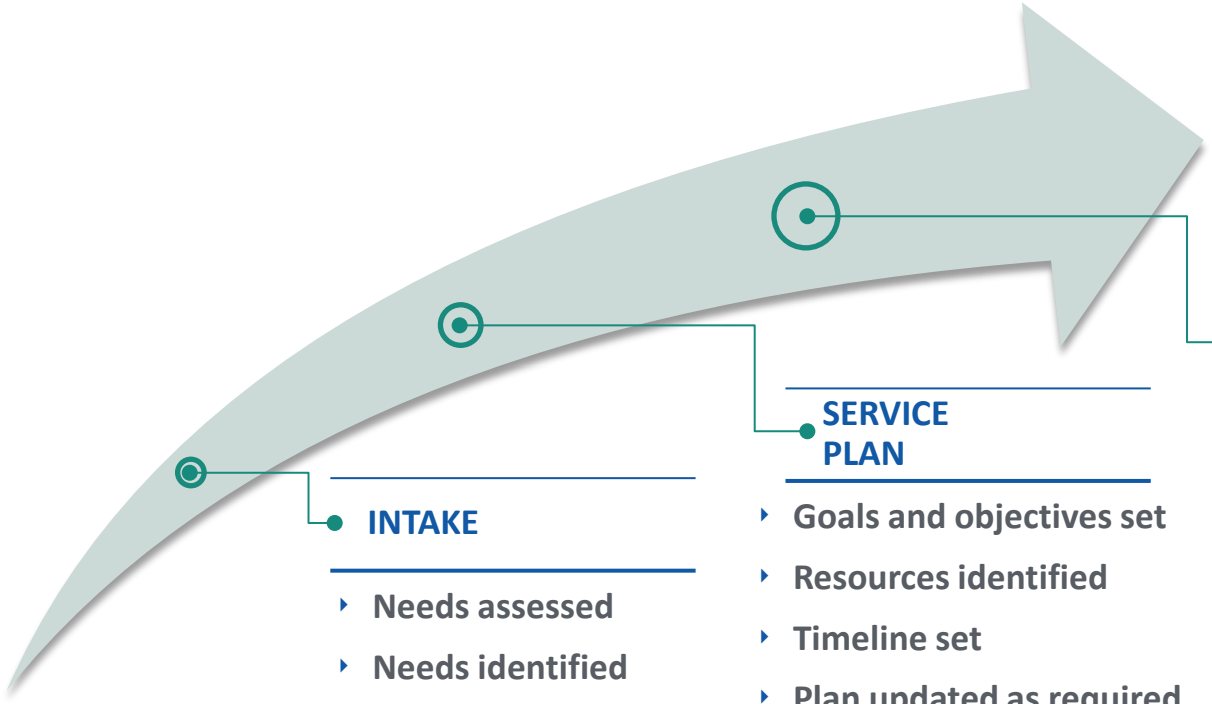
# LINKAGE PROGRAM MANAGEMENT

Oversee overall implementation and management of linkage services including

- Process planning and implementation with defined timelines
- Ensure tasks are defined and sequentially ordered
- Standardize methods such as protocols and procedures
- **Carefully monitor workers' activities, including read progress notes**
- Lead and support regularly scheduled worker case conferences
- Oversee clinic flow and staff work activities
- Monitor and evaluate  data collection and program outcomes
- Oversee quality management activities
- Coordinate with other programs to avoid duplication and gaps

# THE PATH TO CARE: AN HCC LINKAGE WORKER'S INTERVENTION

## *From Initial Assessment and Service Planning to the Documentation Cycle*



### INTAKE

- Needs assessed
- Needs identified

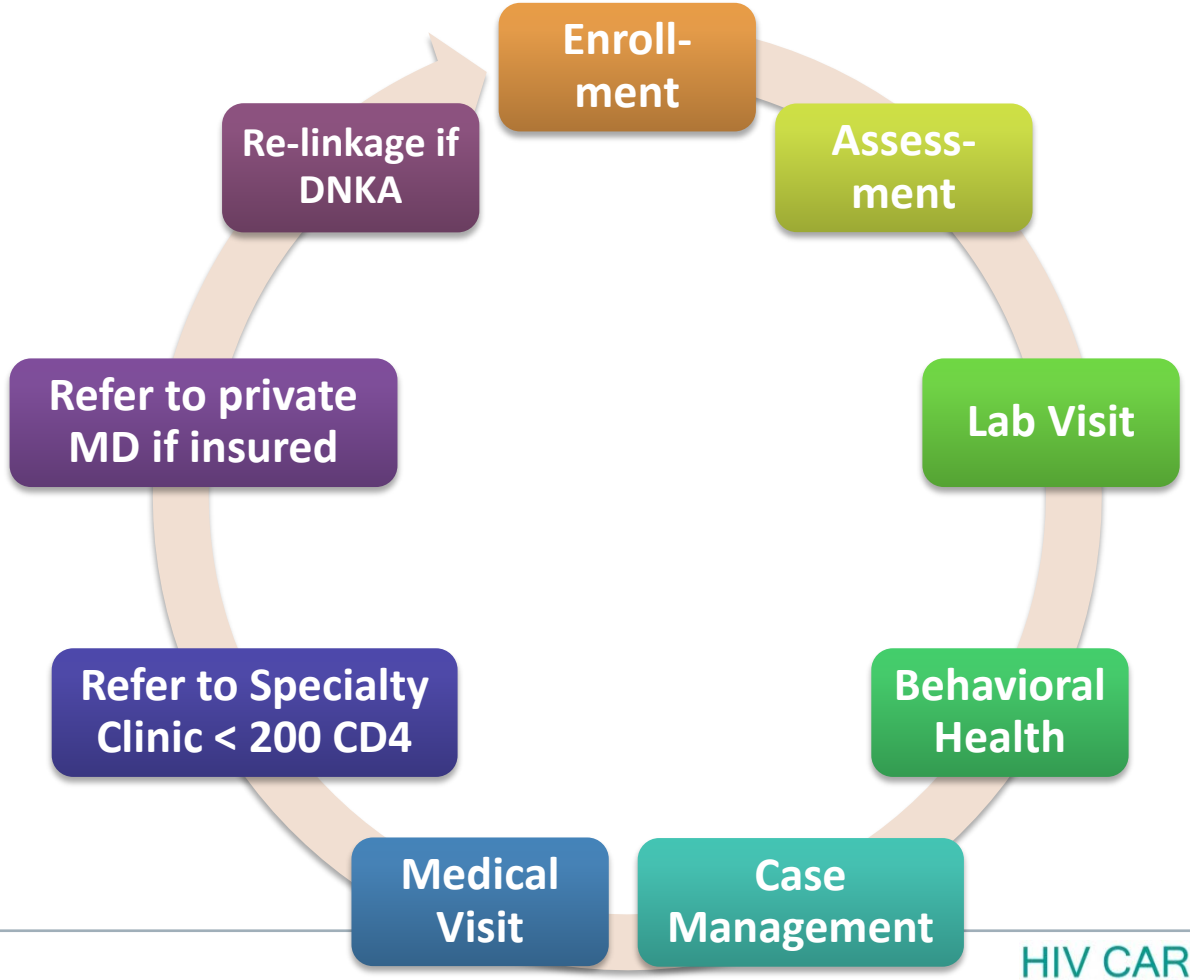
### SERVICE PLAN

- Goals and objectives set
- Resources identified
- Timeline set
- Plan updated as required

### REFERRAL & GOAL OUTCOMES

- Service referrals made
- Verify referral completed and service provided
- Assess if goals/objectives are achieved and identify outcomes

# LINKAGE CONTINUUM



# HCC WORKERS PROVIDE A BRIDGE TO QUALITY HIV TREATMENT AND CARE

**HCC workers help clients to overcome barriers to treatment access by:**

- Identifying barriers to outpatient ambulatory medical care (OAMC), making referrals and following up to ensure barriers are addressed
- Coordinating OAMC follow-up with medical providers
- Reminding and assisting clients to schedule labs and OAMC visits
- Arranging transportation, child care, and other logistics before OAMC visits
- Providing ongoing coaching to help clients keep appointments and ensure medication adherence
- Participating in case conferences or case staffing to coordinate services

HCC grantees employed workers with training and experience in public health and human services

# HCC SERVICE DELIVERY DESIGN FEATURES

| Design Features | Fulton County HWD | Houston DHHS | Philadelphia DPH Ambulatory Health Services (AHS) |
|---|---|---|---|
| **Linkage Services Site** | Co-located With HIV, STI, and TB Clinic | Houston DHHS Bureau of HIV/STI and Viral Hepatitis Prevention | Eight AHS Community-Based Clinics |
| **Target Population** | ▪ Newly Identified HIV+ EMA Residents | | ▪ Newly Identified HIV+ EMA Residents |
| | ▪ Individuals Previously Lost to Care | ▪ Individuals Previously Lost to Care | ▪ Individuals Previously Lost to Care |
| | ▪ Individuals Transferring From Another Community | ▪ Individuals Transferring From Another Community | ▪ Individuals Transferring From Another Community |
| | | | ▪ Patients At High Risk for Dropping Out of Care |
| **Client Recruitment Strategies** | ▪ Patient self-referral<br>▪ Referrals from community-based CTS<br>▪ FCHWD STI and TB clinics and HIV CTS<br>▪ FCHWD HIV and STI DIS | ▪ HIV epidemiology databases<br>▪ DHHS HIV and STI disease investigation specialists<br>▪ HIV clinic lost-to-care lists | ▪ Patient self-referral<br>▪ Referrals from community-based CTS<br>▪ AHS primary care and STI clinics |
| **Intervention** | **Three-Month HCC Linkage Intervention** | | |

# HCC SERVICE DELIVERY DESIGN FEATURES

| Design | Fulton County HWD | Houston DHHS | Philadelphia DPH AHS |
|---|---|---|---|
| **Medical Care Provider** | ▪ FCHWD For Uninsured Patients With CD4 > 199 | ▪ Harris Health (Uninsured, Medicaid, or Medicare) | ▪ DPH Ambulatory Health Services (AHS) |
| | ▪ Grady Infectious Disease Practice For Uninsured Patients Ever With CD4 > 199 | ▪ Houston Area Community Services (HACS) | |
| | ▪ Referral to HIV Clinics or Private ID Practices If Patient Insured | ▪ Legacy Community Health Services | |
| | | ▪ St. Hope Foundation (SHF) | |
| **MCM** | AIDS Atlanta (Co-Located at FCHWD) | Harris Health, HACS, Montrose Counseling Services, SHF | Action AIDS (Co-Located at AHS Clinics) |
| **HCC Worker Integration** | Linkage workers integrated into HIV/STI epi and partner services | Linkage workers integrated into HIV/STI epi and partner services | Linkage workers integrated into AHS clinical care teams |
| **HCC Linkage Services Model** | ▪ Provide HCC intervention, then transition client to MCM and clinical care team<br>▪ Interact with care team to ensure engagement in care<br>▪ No ongoing interaction with client after case closure | ▪ Provide HCC intervention<br>▪ Arrange for medical appointments, then transition client to MCM<br>▪ No to minimal interaction with clinical care team<br>▪ No ongoing interaction with client after case closure | ▪ Provide HCC intervention and participate in AHS clinics and post visit multidisciplinary team meetings<br>▪ Transition client to Action AIDS MCM<br>▪ Interact with care team to ensure engagement in care<br>▪ Interact with client after case closure if the client is lost to care |

# EFFECTIVE LINKAGE STRATEGIES

- Arrange for transportation
  - Taxi, Uber, bus pass, drive the client yourself if appropriate
- Explain to new clients or those new to the area how the RWHAP system works and required documents
  - Remind clients about documentation
- Explain to client how OAMC and MCM visit scheduling works to avoid broken appointments
- ARTAS may be beneficial
  - Many clients cannot meet for several sessions or do not have funds to pay for transportation and lost wages
- Remind client about upcoming OAMC visit
- Accompany client to initial RWHAP, lab visit, and OAMC visits

# EFFECTIVE LINKAGE STRATEGIES

- If not accompanying the client to initial appointments, confirm the OAMC visit was kept
  - Clinics should notified worker ASAP if a client does not keep their initial lab and medical visits
  - Check the clinic's scheduling system
  - If appointments are not kept, ***immediately*** contact the client and find out why
  - Schedule another visit or arrange for a walk-in visit
- Intensive linkage activities are needed to engage clients in care
  - The longer the time between contacts, the more likely the client will not link to care

# EFFECTIVE LINKAGE STRATEGIES FOR LINKAGE WORKERS AND MCMS

- Warm hand-shake between linkage worker and MCM or other care team members can facilitate durable linkage
- Caseloads must be realistic to address demand for services
  - The larger the caseload, the less likely you are able to provide high quality, meaningful services
- The greater the extent to which workers are integrated in the healthcare team, the greater their success in helping clients link to care
- The longer it takes to link a client in care, the more likely you will be able to locate them
- Recognize that some clients are “just not that into you” and develop strategies to motivate them to get into care

# EFFECTIVE RETENTION STRATEGIES

- Collaboration between linkage workers and MCMs to transition clients to ongoing OAMC and MCM services
- Establish an ongoing MCM relationship with the client to the extent feasible based on your caseload
  - Make good on your promises
  - Avoid last-minute crisis management by scheduling periodic check-ins to reinforce problem solving
- Assess reasons why clients previously dropped out of care to gain insights into how to engage the client effectively
- Determine from progress notes when clinician wants the patient to return for their next visit, ensure that the appointment is made and fits the client's schedule, remind the client about upcoming appointment

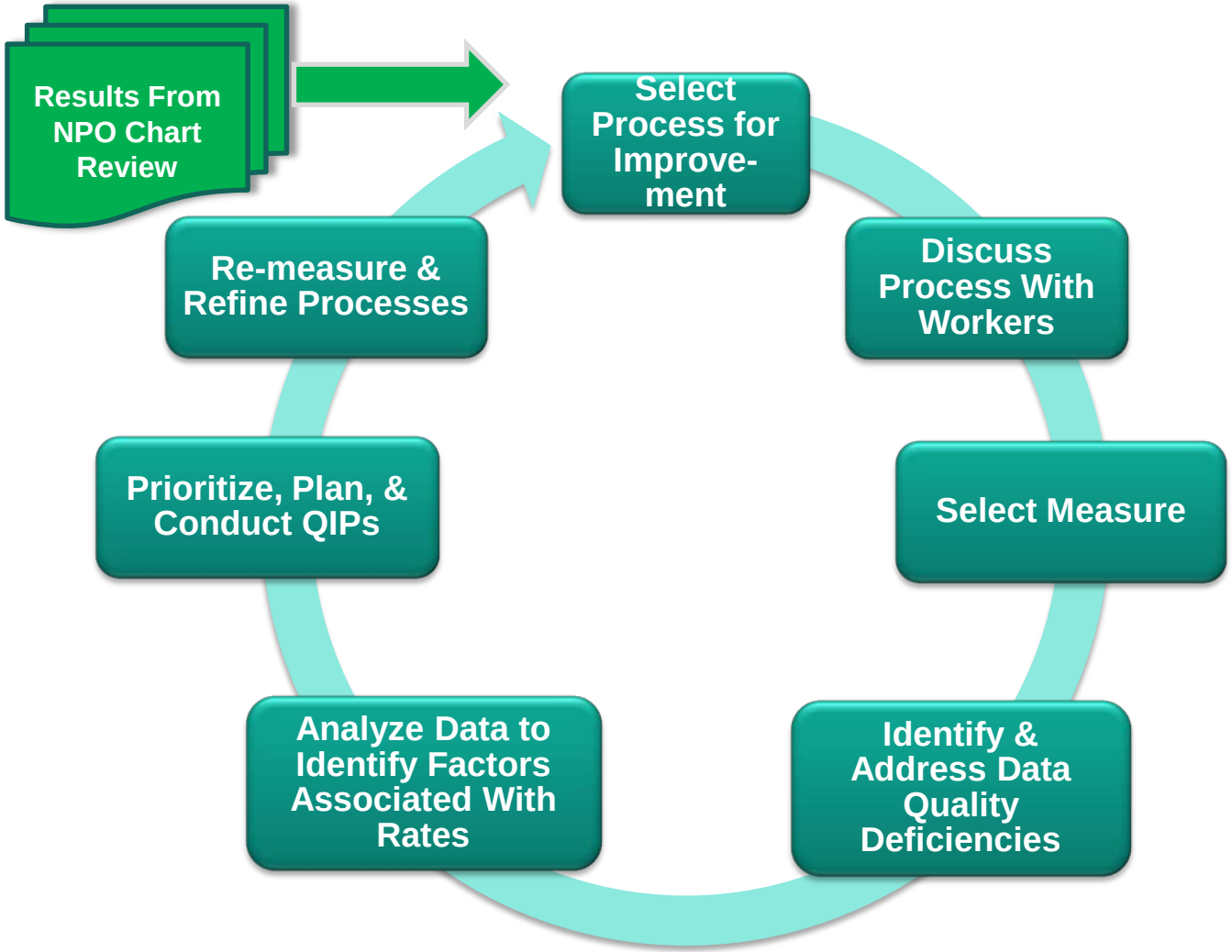
# EFFECTIVE RETENTION STRATEGIES

- Clinics should notified you ASAP if a client does not keep their ongoing lab and medical visits
- Check for a pattern of frequent broken, cancelled, and rescheduled appointments and address contributing factors
- The longer you wait to contact a client after broken appointments, the more likely you will be unable to locate them
  - Attempt to locate clients on lost-to-care lists on a timely basis
  - Do not wait six months to locate them
- Carefully listen to concerns and complaints of clients, including dissatisfaction with clinic or clinician services
  - With the help of your supervisor, address concerns and complaints
- Have realistic expectations, your priorities may not be their priorities

# EFFECTIVE CLIENT CASE FINDING STRATEGIES

- Can't find the client? Check out these sources
  - All phone numbers, emergency contact, person most likely to be in contact with the client, mail a letter, home visits to most recent address
  - ER and inpatient records if EHR is available
  - Field records if HIV epi and vital record databases are available *and* timely
  - Local jails and state prisons, RW client-level data systems, Lexis/Nexis or other general search engines
  - Referral to LHD Disease Investigation Specialist if all available strategies

# HCC CQM Approach



# LESSONS LEARNED IN EMPLOYING HIV LINKAGE WORKERS IN LHDs

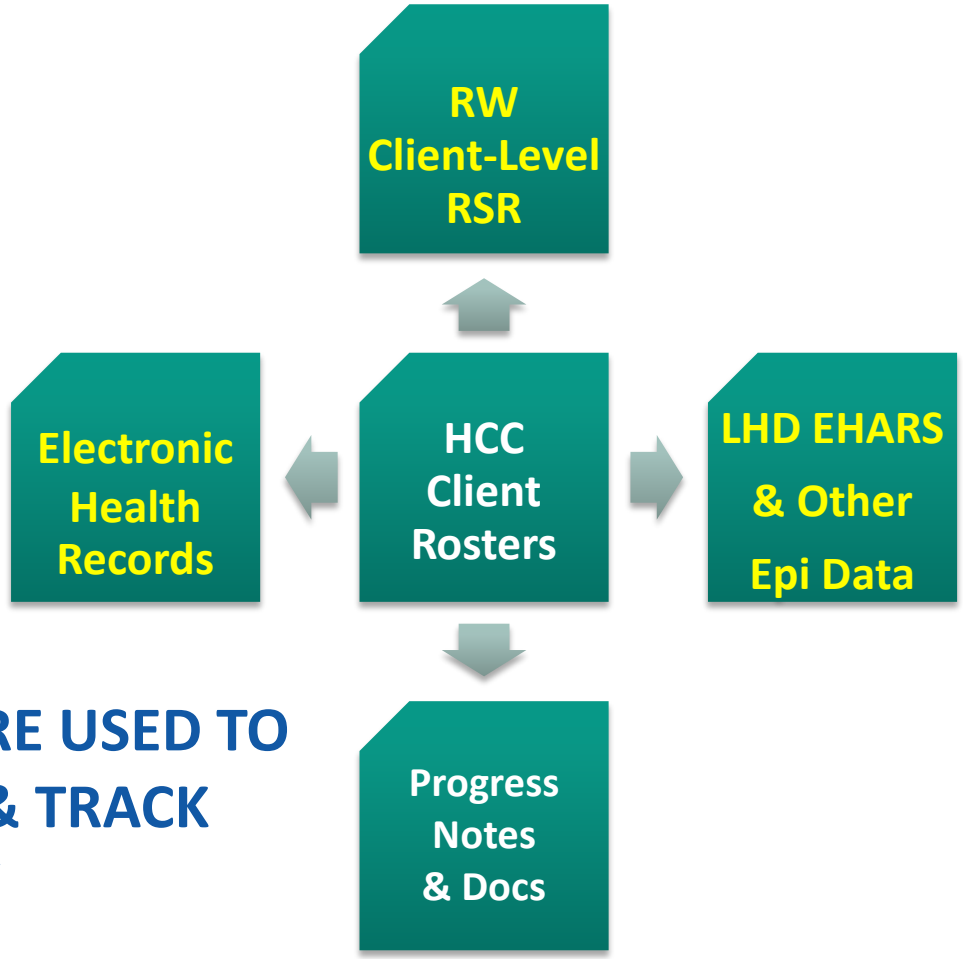
- Launching new linkage and re-linkage programs in LHDs can be SLOW
  - Service linkage functions do not readily fit LHD employment classification systems
  - Workers require initial and periodic training
- Ongoing, informed supervision is critical to ensure high quality services
  - In-service training through case conferencing and problem solving
- Successful HCC workers have ready access to EHRs and clinic scheduler
  - Must be able to address broken appointments through immediate intervention
- Integration of HCC workers in HIV clinical settings is critical in
  - Ensuring and tracking the transition of clients to OAMC and case management
  - Promoting communication among team members
- Clinical team members benefit from training on collaboration with linkage workers

# CROSS-SITE EVALUATION'S GOALS

- Assess the fidelity between the HCC intervention design and its implementation
- Document how the intervention was modified to address clients' needs and challenges experienced by linkage workers
- Identify and implement ways to improve HIV linkage and OAMC services received by HCC clients
- Document the impact of the HCC intervention on process and outcome measures
- Contribute to the peer reviewed literature on HIV linkage models
- Appraise the investment of the Merck Foundation in the HCC

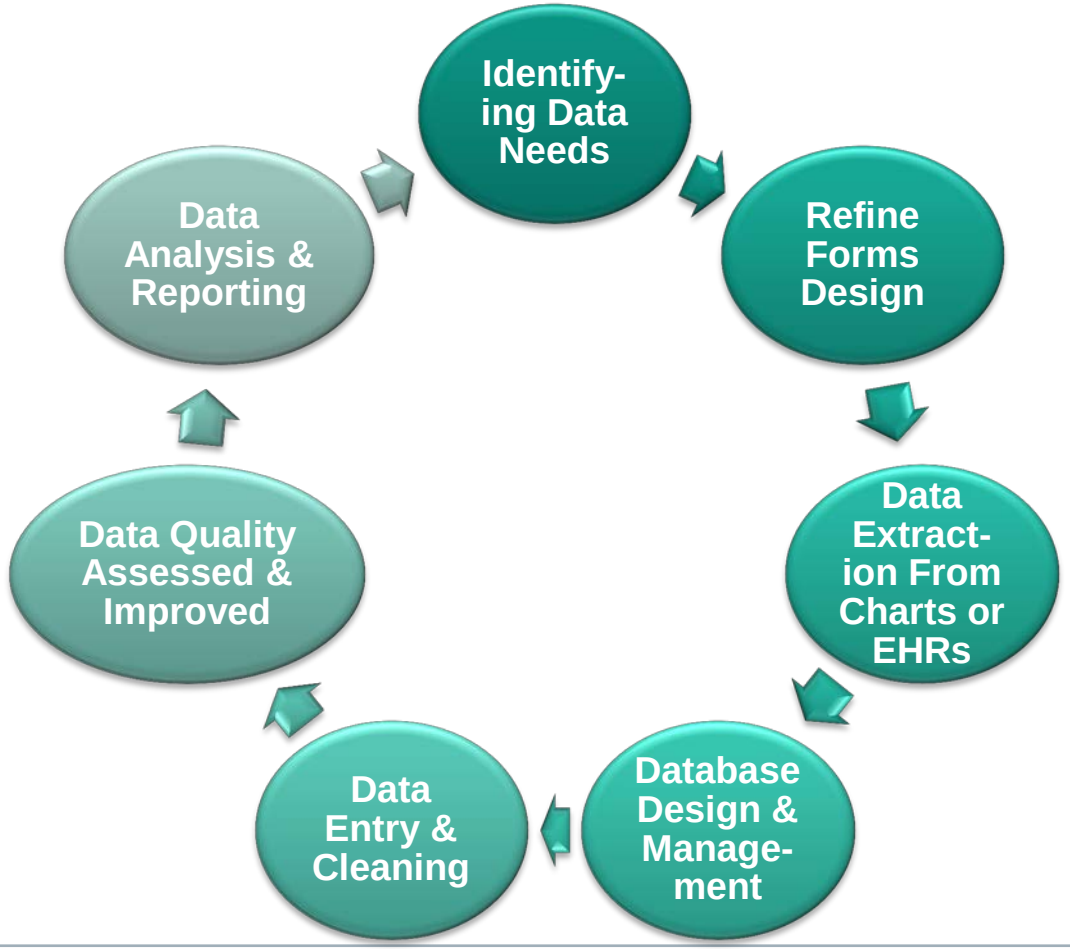
# LINKAGE AND RE-ENGAGEMENT PROCESS MEASURES

- Completed cycle: assessment, ICP, referral, and goal attainment
- Case closure rate
- Time (months) in from intake to closure (productivity measure)
- HCC worker turnover rate
- HCC worker continuity of care
- Time from intake to first OAMC visit




# EXISTING DATABASES WERE USED TO EVALUATE HCC SERVICES & TRACK CLIENTS LONGITUDINALLY

# HCC DATA QUALITY ASSESSMENT AND IMPROVEMENT PROCESSES



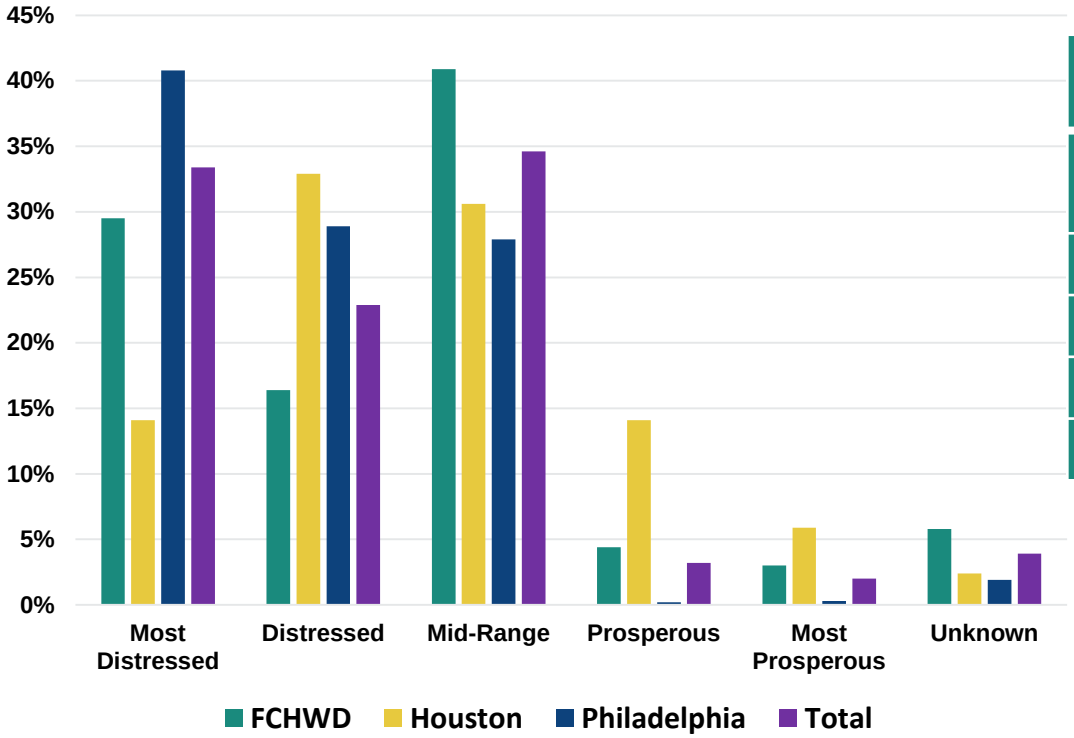
# COMMON HCC CLIENT CHARACTERISTICS

- African American or Latino males in their 30s and 40s
- Low income and uninsured
- HIV-infected via male-to-male or heterosexual transmission
- Among insured clients, Medicaid and Medicare are the most common insurers
- Most lost-to-care clients were out of care for at least several years
- Linkage barriers include homelessness, unstable housing, recent incarceration, no transportation, no telephone, employed in low pay jobs without sick leave

# COMMON HCC CLIENT CHARACTERISTICS

- High rates of chronic conditions including HTN, DM, HCV, chronic mental illness, and drug or alcohol addition
- Unmet needs include photo ID to enroll in RW, affordable housing, behavioral health, disability benefits, and pharmacy assistance
- Relocation to HCC communities was particularly common among FCHWD clients, with high rates of transient movement among Southern states

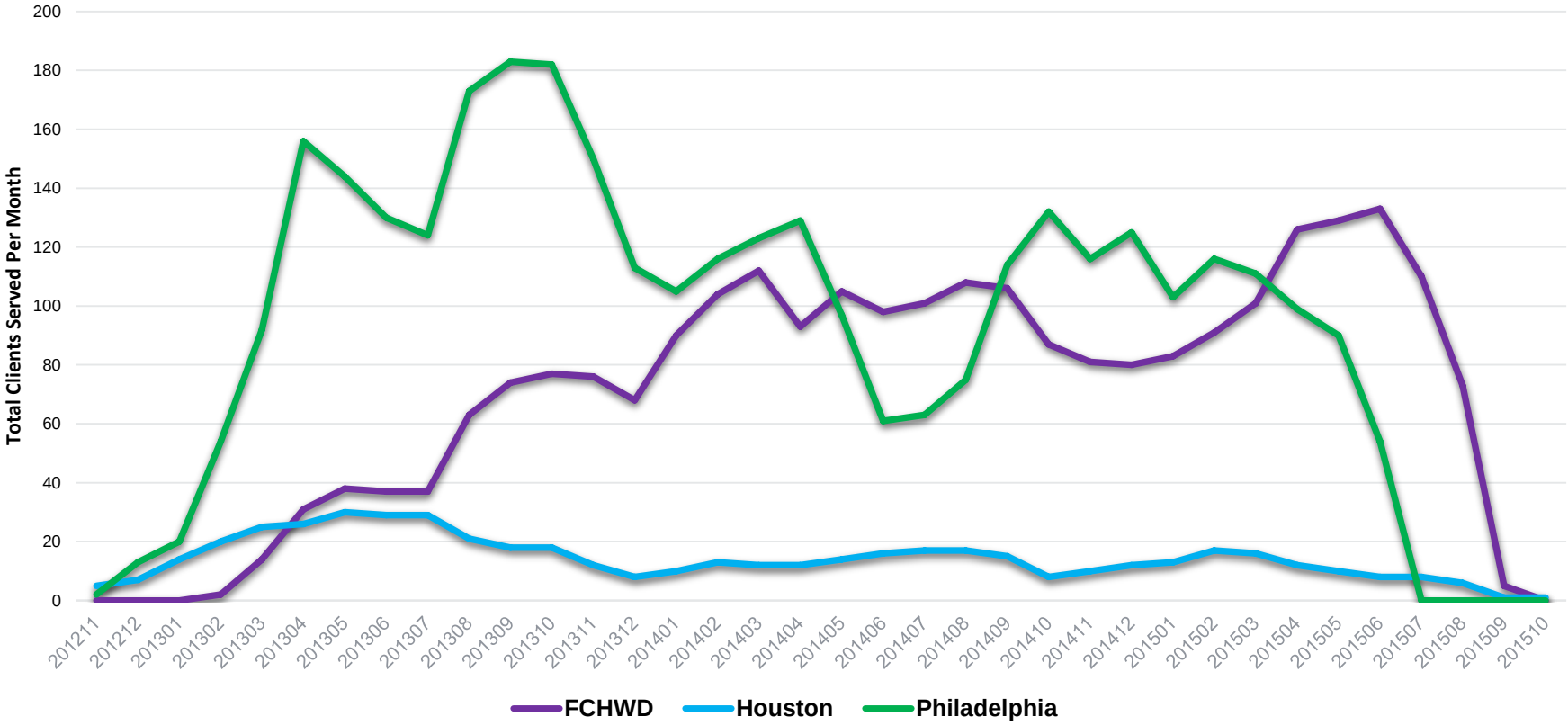
# RESIDENCE OF HCC CLIENTS IN DISTRESSED COMMUNITIES




**Mean Selected Distressed Community Index Scores, ZIP Codes of Residence of HCC Clients**

| Linkage Program | No High School Degree | Housing Vacancy | Adults Not Working | Below FPL |
|---|---|---|---|---|
| FCHWD | 14% | 20% | 46% | 28% |
| Houston | 24% | 13% | 41% | 26% |
| Philadelphia | 21% | 17% | 54% | 33% |
| Total | 18% | 18% | 49% | 30% |

# HCC SERVICE DELIVERY DESIGN FEATURES BY PROGRAM SITE



# WHAT SERVICES WERE PROVIDED BY HCC WORKERS?

| Service Category | Mean # of Units of Service | # of Clients Receiving Service* | % of Clients Receiving Service |
|---|---|---|---|
| Telephone Call With Client | 5.93 | 310 | 53.6% |
| Contact With Other Provider | 5.66 | 386 | 66.8% |
| Attempt to Contact Client | 5.64 | 384 | 66.4% |
| Supervision | 3.28 | 420 | 72.7% |
| Face-to-Face Encounter | 3.21 | 304 | 52.6% |
| Broken Appointment By the Client | 2.70 | 291 | 50.3% |
| Mail Correspondence With Client | 2.64 | 314 | 54.3% |
| Transportation Voucher | 2.53 | 146 | 25.3% |
| Service Referral | 2.14 | 226 | 39.1% |
| Home Visit | 1.35 | 57 | 9.9% |

# HCC ENROLLMENT, PROCESS, AND OUTCOME MEASURES

| HCC PROCESS MEASURES | Site | | | |
|---|---|---|---|---|
| Site | FCHWD | Houston | Philadelphia | Total |
| Total # of HIV+ adults enrolled in HCC | 675 | 85 | 578 | 1,338 |
| Linked within 30 days | 80% | 6% | 67% | 51% |
| Linked in 31 to 90 days | 12% | 22% | 18% | 17% |
| Linked > 90 days | 8% | 72% | 15% | 32% |
| HCC OUTCOMES | | | | |
| Six-month retention rate of HIV+ adults | | | | |
| Undetectable ≤ 50 copies | 12% | 81% | | 46% |
| Suppressed 51 - 200 copies | 21% | 6% | | 13% |
| Detectable 201 - 100,000 copies | 57% | 12% | | 34% |
| Highly Detectable > 100,000 copies | 11% | 1% | | 6% |

# LESSONS LEARNED IN UNDERTAKING THE HCC INTERVENTION

- HCC three-month intervention period was initially challenging for workers
- HCC workers initially reported that it was too short for many clients
  - Workers tended to provide intensive services right after enrollment and then decreased activities as new clients were assigned
  - Clients exceeding the intervention period had not received services for a considerable number of weeks or their workers had quit and their case not transferred or closed
- Supervisors and workers used CQM processes to identify ways to streamline services, resulting in shortened intervention cycles
- Efficiencies were found that resulted in greater productivity
- For clients needing longer intervention, supervisors must review the clients' charts, case conference with the worker, and approve the longer intervention

# AREAS OF IMPROVEMENT

- Duration of the HCC intervention needed to be shortened to free HCC workers to serve more clients
  - In Year 1, the average time of HCC enrollment was about 5.5 months across the three sites, with a substantial number of clients enrolled from 5 to 9 months
  - Case closure rates varied significantly among HCC sites, and was impacted by poor documentation
  - HCC worker attachment and reluctance to discharge HCC clients was in play
- Scope of HCC workers' practice needed to be addressed to avoid "scope creep"
  - While HCC workers are not case managers, they sometimes provided case management to address short-term needs while awaiting case management
- These areas of improvement were addressed in Years 2 and 3

# OTHER AREAS OF IMPROVEMENT

- Improvement was needed in
  - Documentation
  - Ascertainment of pre-HCC HIV testing and treatment histories and HIV risk factors
  - The “hand off process” to transition clients from the HCC worker to the care team
  - Ensuring the team is ready for the hand off and does not contribute to loss to care
  - Established formats for progress notes
- Training was needed for HCC workers
  - Strategies for locating clients
  - Documenting intake, assessment, and intervention activities
  - Eligibility determination for RW and other services

# LESSONS LEARNED IN UNDERTAKING THE HCC INTERVENTION

- **The RW eligibility determination process and lack of open OAMC appointment slots contributes to loss to care**
- Patterns of cancelled, rescheduled, and broken appointments predict loss to care
- Demand for HCC services varies by site
  - For one HCC site, community CTS and internal referrals exceed capacity to provide services and creative approaches were needed to expand capacity
- Using surveillance lists to identify HIV+ individuals not in care had low yield
  - HIV clinics' loss to care lists tended to be out of date, and most clients were in care elsewhere or had died, relocated, or been incarcerated
- **Previously lost to care individuals reengaged in care through the HCC have a higher likelihood of being lost again than newly identified HIV+ individuals**
  - Intensive linkage activities are needed to retain clients in care

# CASE 1

Ms. Jones is a 40 year old multi-ethnic woman who has been HIV+ for 10 years. She has been lost to care from your clinic for six months

**Current Dx:**

- Hyperglycemia
- Bipolar Disorder
- History of substance abuse
- Smoker

**Issues:**

- No viral suppression
- Non-compliant with OAMC visits and HIV medications
- Homeless, with persistent housing issues
- Refused referral to behavioral health program
- Non-working phone number

**What is your linkage plan?**

# CASE 2

Ms. Swift is a 32 year old African American woman infected with HIV since 2011. She had been in HIV care episodically since diagnosis. She was referred to your clinic by DIS for linkage services.

**Current DX:**

- High risk sexual activity (2015)
- Trichomonas vaginitis and syphilis (2015)
- Hep B carrier
- Last HIV/AIDS CD4 250
- Hep C+, no meds
- Alcohol and cocaine abuse
- Bipolar disorder, no meds
- Hx of Pneumocystis pneumonia and oral candidiasis

**Issues:**

- History of IVDU
- Active crack user
- History of prostitution and unprotected sex (2015)
- Reports physical and verbal abuse by boyfriend
- Paranoid bipolar disorder, inpatient admission (2015)
- Couch surfs
- Telephone frequently out of service

**What is your linkage plan?**

# CASE 3

Ms. Diaz is a 35 year old Hispanic transgender client (MTF) who has been HIV+ for 12 years. She reported dissatisfaction with MCM at her clinic. Her health record documents that her MCM instructed her to come to clinic to pick up her HIV and other meds. Ms. Diaz reported that Medicaid transportation is unreliable and has not scheduled an appointment in 5 months.

**Current DX**

- AIDS, CD4 13 (2016)
- VL over 500,000
- Gastroparesis, avascular necrosis, HTN, KS, Hep B carrier, peripheral neuropathy, recent hip fracture and related inpatient stay
- Depression

**Issues**

- Infrequent OAMC visits
- Patient reports being unable to pick up meds due to unreliable Medicaid transportation
- Wheelchair bound
- No psych referral
- Now lost to care

## How will you locate Ms. Diaz and re-engage her in care?

# CASE 4

Mr. Ryan is a 47 year old White male who has been HIV+ for 18 years

**Current DX:**

- Hyperlipidemia, diabetes, lumbar disc disease, incontinence, peripheral neuropathy, gout, HTN, morbid obesity
- Depression

**Issues:**

- Depression, refused psychiatric treatment
- Chronic pain
- Had employment problems, then lost his job and health insurance
- Running out of money
- Loosing home to foreclosure
- Has begun breaking OAMC appointments
- Reports that he sees no reason to take his HIV medication and stay in care

**What is your retention plan?**

# Questions and Discussion

**For Today's Presentations and to Learn More About the HCC, Check Out**

**Hivcarecollaborative.org**

**or contact Dr. Julia Hidalgo at**

**Julia.hidalgo@positiveoutcomes.net**

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