

Appendix A: Retreat Agenda



HPTN 061 Black Caucus Retention Meeting
Leesburg, VirginiaUSA
3 – 5 December 5, 2010

Meeting Agenda

Meeting Objective: To discuss current clinical research retention activities focusing on lessons learned and/or constraints in order to provide recommendations to the HPTN 061 Protocol Team related to the improvement of retention rates in HPTN 061.

Time	Topic and Objectives	Facilitators	Materials
Friday, December 3, 2010			
12:00 pm until 5:30 pm	Arrival and Check In NationalConferenceCenter 18980 Upper Belmont Place, Leesburg, Virginia20176 703.729.8000		
5:30 pm until 7:00 pm	Dinner in the Main Dining Court		
7:00 pm until 7:15 pm (15 minutes)	Welcome <ul style="list-style-type: none"> • Ground rules • Review of Agenda and Meeting Objectives • Review of Materials–Goals of HPTN Retention 	Dr. Sheldon Fields&Dr. D.P. Wheeler (by phone)	1. Agenda
7:15 pm – 8:00 pm (45 minutes)	HPTN 061 Clinical Research Sites Retention Plan Updates <i>Objective: To provide clinical research sites 5 minutes to share successes and challenges as they relate to retention efforts in HPTN 061.</i> <ul style="list-style-type: none"> • Atlanta, GA • Boston, MA • Los Angeles, CA • New York, NY (BloodCenter) • New York, NY (Harlem) • San Francisco, CA • Washington, DC 	Jonathan Lucas/Boris Powell	2. Clinical Research Site PowerPoint Presentations 3. Clinical Research Sites Retention SOPs

8:00 pm until 8:15 pm (15 minutes)	HPTN 061 Participant Data <ul style="list-style-type: none"> • Demographics • Socio-Economic Status • What this means for the sites in terms of “real” numbers needed!!!! 	Christopher Watson	4. SCHARP HPTN 061 Demographics Report/Table
8:15 pm until 9:00 pm (45 minutes)	Retention of Black MSM in Biomedical Research Literature Review Findings <i>Objective: To discuss as a full group retention efforts of BMSM in other bio-clinical and/or behavioral research studies and identify common themes found in the literature.</i>	Christopher Chauncey Watson	5. Retention Articles
9:00 pm until 9:15 pm	Day 1 Wrap-Up <ul style="list-style-type: none"> • Action Items and Next Steps • Dismissal 	Dr. Sheldon Fields	
Saturday, December 4, 2010			
6:30 am until 8:00 am	Breakfast in the Main Dining Court		
8:00 am until 8:10 am	Recap of Day One and Review of Day Two Agenda	Dr. Sheldon Fields	
8:10 am until 9:30 am	Identification of Barriers to Address and Formation of Small Working Groups <i>Objective: To review presentations and documents presented previously and identify 5 key barriers to retention to be focused on for possible solutions.</i> <ul style="list-style-type: none"> • Identification of Common Successes • Identification of Common Challenges • Identification of Areas for Improvement • Identification of Innovative Strategies 	ALL	
9:30 am until 10:30 pm	Retention Working Groups Break Out Sessions <ul style="list-style-type: none"> • Recommendation Formation • Action items 		6. Electronic Recording Template
10:30 am until 11:00 am	Break		

11:00 am until 12:00 pm	Retention Working Groups Break Out Sessions (cont.)		
12:00 pm until 1:15 pm	Lunch in the Main Dining Court		
1:00 pm until 3:00 pm	Retention Working Groups Break Out Sessions (cont.)		
3:00 pm until 3:30 pm	Break		
3:30 pm until 5:00 pm	Retention Working Group Recommendations <ul style="list-style-type: none"> • Small group Report Out and Discussion • Merging of Ideas • Formation of Action Plan 	Group Leaders	
5:00pm until 5:30 pm	Day 2 Wrap-Up <ul style="list-style-type: none"> • Action Items and Next Steps • Dismissal 	Dr. D.PWheeler check-in or available by phone	
5:30 pm until 7:00 pm	Dinner in the Main Dining Court		
Sunday, 5 December 2010			
6:30 am until 8:00 am	Breakfast in the Main Dining Court		
8:00 am until 8:10 am	Recap of Day Two and Review of Day Three Agenda	Dr. Sheldon Fields	
8:10 am until 10:00 am	Retention Recommendations <ul style="list-style-type: none"> • Review of Retention Recommendations and Action Plan • Site specific Implementation • Recommendation Formation 	Group Leaders	
10:00 am until 10:30 am	Break		
10:30 am until 11:30 am	Retention Working Groups Break Out Sessions <ul style="list-style-type: none"> • Final report formation • Action items • Timeline for actionable items 	Groups Leaders	

11:30 am until 11:45 am	Day 3 Wrap-Up <ul style="list-style-type: none">• Action Items and Next Steps• Dismissal	Dr. Sheldon Fields and Dr. D.P Wheeler by phone	
11:45 am	Lunch in the Main Dining Court		

Appendix B: Copies of Clinical Site Presentations



ATLANTA
Emory University
HPTN 061

Retaining a hard to reach population

Topics of Discussion

- Challenges Related to Retention
- Retention Approaches
- Lessons Learned

Challenges Related to Retention

- Environmental Factors
 - Space constraints
 - Study setup/ Implementation (Feasibility???)
 - Retention Reporting (Actual vs. Target Close Dates)
- Staffing
 - Staff working across other HPTN studies
 - Lack of ample Study Staff
- Length of Study Visits
 - Population turned off over the amount of time needed to complete visit
 - Redundancy and length of questions on computer questionnaire
- Difficult to Reach Sub-Populations
 - Homeless population- over 50% enrolled reside in transitional housing
 - Exchange for sex, money or drug participants
- Community Misconceptions
 - What is really in it for me?

Retention Approaches

- What Worked? Approaches that consistently contribute to significant study participant retention
 - Assembling a Street Team/Retention Team
 - Verifying locator information on the spot.
 - Community Partners
 - Compensation
 - Participants appreciate staff professionalism
- Approaches that did not have the expected impact on study participant retention
 - HIV testing(documentation vs. word of mouth)
 - Retention Events (what's good for one sub-population isn't good for all)
 - Community Partners (competition of services)
 - PHN?

Lessons Learned

- We have a presence in the community.
- We have to **out** reach and not except **in** reach.
- Offer more retention events that engage participants efficacy in regards to service access and delivery
- Rely less on community partners for logistic of retention events
- Participants feel that staff really care



HPTN 061 Retention Snapshot: Project SOS, Boston

061 Black Caucus Retention Retreat,
National Conference Center, Leesburg, VA
December 3, 2010
Benjamin Perkins, MA, MDiv, Project Director,
The Fenway Institute, Boston, MA

The Challenges

- Challenges Related to Retention
 - Retaining subpopulations of participants.
 - “Contact instability.”
 - Chronic rescheduling.
 - X-factors: we don’t always know what we don’t know!

Retention Approaches

- STI results calls (regardless of results).
- 2 FTE Retention Specialists & implementation of weekly retention team meetings.
- Retention ads & tear-off flyers.
- Linking participants to other TFI services and activities.
- Real-time verification of phone contact info during study visits.
- Drop-in hours for study visits.
- Evening calls.
- Retention methods tracking (to gauge success of various methods).
- Revision of locator form (thanks GWU!).

Lessons Learning

- Try everything!
- Consult with other researchers who have worked with population
- Analyze retention data to identify potential subpopulation trends, and develop retention strategies based on the data.
- Be willing to course-correct quickly!

Unanswered Questions

- How do various individual, organizational, structural and regional characteristics facilitate and/or hinder retention (e.g., sexual identity, SES, employment status, TFI reputation, and lack of cohesive Black gay community)?
- How does study design facilitate or hinder retention (e.g., length of time between study visits, ACASI length, PHN opt-in, “in-vitro” vs. “in-vivo” design, etc.)?
- Would incentivizing check-ins be a retention facilitator?

The BROTHERS Project



Gregory D. Victorienne, Christopher Hucks-Ortiz, MPH & The UCLA Team
HPTN 061 Black Caucus Retention Mtg – 03 December 2010

Who We Recruited: (n=279)

	# or Mean	% or S.D.
Age (median = 40)		
18-30	97	35%
31-40	46	16%
41-50	99	35%
50+	37	14%
Partner/Spouse		
No partner	260	93%
Male	16	6%
Female	3	1%
Working		
Full-time/Part-time	66	24%
Unemployed	159	57%
Unable to work	59	20%

Who We Recruited (n=279)

	# or Mean	% or S.D.
Annual Income		
<\$5,000	106	38%
\$5,000-\$9,999	45	16%
\$10,000-\$19,999	66	24%
\$20,000-\$29,999	34	12%
>\$30,000	28	10%
Frequent Insufficient Income		
Never	137	49%
Once in awhile	96	34%
Fairly often	29	10%
Very often	17	6%

Incidence of imprisonment: 2.9%

Who We Recruited (n=279)

	# or Mean	% or S.D.
Education		
< H.S.	50	17%
H.S.	116	42%
Some College	90	32%
Bachelors +	23	9%
Household Status		
Alone	97	35%
Partner	22	8%
Roommate	72	26%
Relatives	44	16%
No home/other	44	16%
Current Healthcare?	102	37%

Who We Recruited (n=279)

	# or Mean	% or S.D.
Sexual Identity*		
Homosexual	81	29%
Gay	127	46%
Bisexual	90	32%
Heterosexual	7	3%
Same gender loving	47	17%
Sexual	35	13%
Queer	10	4%
Two spirited	12	4%
Questioning	7	3%
Polyamorous	1	<1%
Pansexual	2	1%
Straight	10	4%

* Multiple responses possible

Retention Challenges

- **Imprisonment**
- **Poverty**
- **Social Instability** – no jobs or stable housing that facilitates retention
- **Site Issues**
 - Insufficient locator information; transitional housing, homelessness, substance use, family issues
 - Subjects do want to participate; may know staff (privacy concerns)
 - Lengthy enrollment visit/data burden; Some subjects do not want to return b/c it "takes too long"
 - No dedicated retention team on staff
 - Clinical site location, means of transportation to site
 - Subjects in correctional system, unable to get release date
 - Institution restrictions
 - Network restrictions

Participants Incarcerated: n=16

- 15 Subjects in the California Correctional System
 - 1 scheduled for release in 12/2010
 - 2 scheduled for release in 01/2011
 - 1 scheduled for release in 05/2011
 - 1 in Substance Abuse Treatment
 - 1 in Correctional Mental Institute
- 1 in Virginia Correctional System



Who & Where They Are: n = 21

- Moved out of the city or state – 8
 - In contact with subject / family member –5
 - No contact with subject – 3
- Valid address / No response – 1
- Refuse to participate in FU – 1
- Deceased – 1
- In contact with family relative - 2
- Whereabouts unknown – 8



Successful Retention Approaches

- Great customer service
- Energetic staff reflective of study population
- Research clinic culturally appropriate
- Providing subjects appointment cards
- No appointment needed – Come on in!
- Appreciation Items / Kwanzaa Cards
- Weekly team meetings discussing "Hot Cases"
- Contacting Index participants
- Community Advisory Board input

Successful Retention Approaches

- Facebook, MySpace
- Posting flyers where recruitment occurred
- Use of electronic search engines
- Home Visits, know if subject is actually at address
- Sponsorship and visibility at community events
- Ongoing check with correctional system websites
- Participate with local organizations [CAB et al.]
- Appreciation packages to CBOs
- Ongoing community engagement with stake holders

Future Retention Efforts

- Evening & weekend hours for follow-up calls via Google www.googletextdrop.com
- Participant appreciation gathering – TBD
- "Research Day" Presentations at ITMT Mens Grp
- Presentations to CBOs, Prevention Planning Committee, and stake holders
- Provide in-service presentations [HIV/ Substance Abuse 101] to CBOs
- Appreciation packages to CBOs

Lessons Learned

- Collect additional locator information from subject
- Photo copy of a valid California ID of subject to locate in the field
- Do not enroll subjects who are homeless, unstable housing, and without a valid California ID card
- Verify address & alternative contact information is correct
- Follow-up with all subjects on a regular basis
- Knowledge of local SROs & Social Services residences where HIV+/Substance Abuse /Mental Illness live

UCLA Team

- Judith Currier, MD, CTU Grant Investigator
- Steven J. Shoptaw PhD, Site Principal Investigator
- Pamina M. Gorbach, DrPH, MPH, Co-Investigator
- Nina T. Harawa, PhD., Co-Investigator
- Cathy J. Reback, PhD, Co-Investigator
- John K. Williams, MD, Co-Investigator
- Christopher Hucks-Ortiz, MPH, Project Manager
- Jackie Benavente, MFT, Clinical Therapist
- Traci Bivens, Qualitative Interviewer
- Christopher Blades, Peer Health Navigator
- Adam Carranza, Peer Health Navigator
- Pedro Chavez, Risk Reduction Counselor
- Christian Fleming, Peer Health Navigator
- Maria Sipin, Community Health Representative
- Aimee-Noelle Swanson, PhD, Clinic Manager
- Gregory D. Victorienne, Community Educator
- Demetria Villanueva, Lab Technologist



HPTN 061 Black Caucus Retention Meeting

Craig Hutchinson, MPH
Project Achieve
New York Blood Center

Presentation Outline

- Retention rates
- Challenges related to retention
- Retention Analysis Report
- Retention approaches
- Lessons learned

6- and 12-month Retention Rates

- 6-month visit
 - 82% with 13 of the 15 men who have missed their appointment are still in the window period.
- 12-month visit
 - 100% retention rate

Challenges Related to Retention

- Locator information
- Arrest and outstanding warrants
- Lack of means of transportation
- Housing issues
- Self-realization of seroconversion
- Already having access to services
- Staff not the face of the study
- ACASI
- Scheduling follow-up appointments
 - Oracle system
 - At-A-Glance
- No incentive for PCN services

Retention Analysis Report – Union Square

- Lower educational level
- Unstable housing
- No PCN visit
- Never tested for HIV
- No previous research study experience
- Symptoms of depression

Retention Approaches

- Reminder phone calls, emails, and letters
- Using PCN appointments as a reminder
- Word of mouth
- Brothers Appreciation Reception
- Incentive
- Wanting to be involved in other research studies

Lessoned Learned

- Report negative STI results with participants
- More counselor engagement between study visit
- More mental health support
- More tools for negative men

Harlem 061

Retention Summary

Presentation Outline

- Retention Challenges addressed with Identical Recruitment Efforts
- Flyers, Word of Mouth, Staff Support/Presentation
- Stick to What Works

Challenges Related to Retention

- The weather has caused a push in our fieldwork efforts. We're making home visits and field visits where applicable. Cold weather may be partially associated with trying to get into prison system for warm food and shelter
- Staffing is Terrific
- Length of Study Visit irrelevant
- Difficult to Reach Sub-Populations aren't easy
- Large portion of our missed visits are incarcerated
- Community Misconceptions haven't surfaced

Retention Approaches

- Keep the care in the work – ALL STAFF
- Stay Positive

Lessons Learned

- Teamwork Makes The Dream Work
- It's About Care

HPTN 061 Retention San Francisco

December 3, 2010

Challenges Related to Retention

- Phone Numbers Rapidly Changed
- Retention Specialist Needed, but Consistent Contact with Same Staff Member Contributes to Retention
- Length of study visits undesirable and/or a challenge to ppts with full time jobs
- Marginally Housed Participants
- Participants in Residential Treatment
- Research Naivety or Mistrust

Retention Approaches

- Bi Monthly Check-ins
- Exhausting all contacts on locator form
- Peer Health Navigation
- Flexible Scheduling
- Retention Tracking Spreadsheet
- Calling at different times of day
- Calling disconnected numbers repeatedly over a period of time

Lessons Learned

- Incentivized periodic check-ins for future studies
- Ask for permission to contact via Facebook and other social networking sites
- Monthly check-ins vs. Bi-monthly
- Information Release for Residential Tx facilities and SROs
- Enter contact info directly into the database while with participant
- More realistic retention goals

GWU Retention Efforts

Black Caucus Meeting
December 2010

Presentation Outline

- Challenges Related to Retention
- Retention Approaches
- Lessons Learned

Challenges Related to Retention

- Transient community
- Length of Study Visit misconceptions
- Difficult to Reach Sub-Populations
- Community Misconceptions

Retention Approaches

- Weekend Case Finding
- Monthly Calls
- Retention Roundtable at staff meetings
- Additional trainings
- Persistent

Lessons Learned

- Weekend case finding works
- Reaching clients after normal business hours
- STD results *potentially* impact retention
- Persistence is key!

Appendix C: Burden/Benefit Analysis Recommendations

HPTN Black Caucus Burden/Benefit Analysis Work Group Strategy:			
Group Leader: Mr. Jamaal Clue			
Group Members: Mr. Rudy Carn, Dr. LaRon Nelson, Mr. Christopher Chauncey Watson, Dr. Leo Wilton			
Retention Strategy	Task	Responsible	Concluding Strategies
1. Increase flexibility around how we engage people in the study so that we can be more accommodating to their dynamic social circumstances.	<p>Goal: Identify site-level barriers to participants' attendance at follow-up visits. For example, availability of lab hours, office hours, location, and length of visit, staffing, transportation</p> <p>Activity 1: Develop a brief tool for sites to report identified site barriers.</p> <p>Activity 2: Disseminate to Black Caucus delegates at each site for completion with input from site staff and return to Black Caucus</p> <p>Activity 3: Develop list of surmountable barriers and strategies to overcome them.</p> <p>Activity 4: These items will be included in the Black Caucus Retention Report</p>	<p>Jamaal Clue; Chauncey Watson</p> <p>Jamaal Clue</p> <p>Work Group</p> <p>Dr. Fields/Dr. Wheeler</p>	<p>1. We need to streamline the follow-up visit process: Assess and Implement the Harlem Model</p> <ul style="list-style-type: none"> • Great degree of variation in terms of visit length (Harlem 30-60 min; Others: 3-4 hrs) <p>Side Note: Harlem has the highest retention rate of any site.</p> <p>2. Implement universal, opt-out PHN services and standardize PHN implementation across sites.</p> <ul style="list-style-type: none"> • Sites mentioned a barrier to retention is the other, more pressing "life issues" that ppts are dealing with • Positive relationship between PHN and retention has already been shown • PHN could address these other "life issues" <p>3. Expand windows of opportunity for follow up visits.</p> <ul style="list-style-type: none"> • Make it possible for visits to occur in the evenings and/or on weekends • Some sites mentioned structural barriers in terms of building hours and lab processing: these must be noted as structural barriers and a

			<p>limitation to study retention</p> <p>4. Implement a mechanism of interim engagement for participants</p> <ul style="list-style-type: none"> • Between study visits, there should be multiple moments of contact with participants • Format could be a simple monthly call from staff, preferably a staff member with whom the ppt has had contact • Boston has implemented monthly social events at the local CBOs in which all ppts are invited to <p>5. Location of Study Site: Transportation Reimbursement or Incentives</p> <ul style="list-style-type: none"> • Some sites expressed the actual locale of the site as a barrier • Implementation of transportation reimbursement measures: gas cards and/or metro/train cards • Some sites are not located conveniently in Black communities (UCLA, Fenway) and make reaching participants a challenge
<p>2. Identify ways to make the follow-up sessions shorter? Can split up the follow-up visits so that folks have two pleasant experiences versus one frustrating experience.</p>	<p>Identify what is essential to be collected for the first half of the visit and what can be triaged to the 2nd half of study visit.</p> <p>Activity 1: Description of GW's process for splitting study-visits to accommodate scheduling needs of participants.</p>	<p>Chauncey Watson</p>	<p>1. A Copy of the GW Site Split Visit Recommendations is included</p> <p>2. We suggest following up with Harlem to see if their model is congruent with the GW model</p>

	<p>Activity 2: Review by Work Group for addition of potential considerations for shortening visits.</p> <p>Activity 3: Review completed and returned to Chauncey for finalization</p> <p>Activity 4: Inclusion in Black Caucus Retention Report</p>	<p>LaRon E. Nelson</p> <p>Chauncey Watson</p> <p>Sheldon Fields Darrell Wheeler</p>	
<p>3. Identify and address the parallels between staff and participant attrition; provide cultural competency training to all study personnel (site, protocol, coordinate center).</p>	<p>Assess the staff regarding their experience of burnout and psychological fatigue; identify a expert trainer in cultural sensitivity</p>		<p>1. A Psychological Fatigue Assessment Tool should be created for site staff</p> <p>2. The data should be aggregated and presented to a third party. The data should be re-presented to staff by Clinical Supervisors at each site.</p> <p>3. Clinical Supervisors should have site specific data and national data that allows for them to “process staff experiences” at the site level and national level.</p> <p>4. There needs to be training on promoting anti-oppression, anti-racism practices in research and human resource management processes.</p> <p>Possible Future endeavors: Black Caucus can identify appropriate trainings based on the outcomes of other work groups’ efforts to define and clarify the term</p>

			<p>“cultural competency”</p> <p>*The Work Group was unsure as to whether this should be an immediate strategy or a strategy for future consideration. There was consensus that this is a larger issue that should be addressed by HPTN and the Black Caucus</p>
<p>4. Provide participants with a cell phone that will allow us to reach them, and that will allow us to re-fill phones with minutes on a regularly scheduled basis, if needed.</p>	<p>Goal: Propose the use of cell phones as a tool to increase retention among participants who have unstable service access.</p> <p>Activity 1a: Retrieve proposal and budget developed by GW for increasing cell phone availability as a retention strategy.</p> <p>Activity 1a: Describe alternate proposal for using cell phone technology to increase access to participants in order to improve retention.</p> <p>Activity 2: Review both proposals and provide feedback</p> <p>Activity 3: Submit alternate proposals to Wakefield for review and comment from the perspective of the Ethics Working Group.</p> <p>Activity 4: Include in the final recommendation for use of cell</p>	<p>Chauncey Watson</p> <p>Borris Powell</p> <p>Work Group</p> <p>Jamaal Clue</p> <p>Sheldon Fields</p>	<p>1. Offering cell phones to participants at this point may be futile, but there are other recommendations in terms of communicating with participants:</p> <p>Implement a texting mechanism of interim engagement for participants</p> <ul style="list-style-type: none"> Implementing a systematic text system across sites may be helpful in maintain contact with participants <p>Retrieve email address of ppts at the study visits</p> <ul style="list-style-type: none"> Some sites are already doing this in order to keep in contact with participants <p>If client is homeless, get the contact information of one professional contact the ppt confides in: social worker, case manager, psychologist, pastor</p> <ul style="list-style-type: none"> Hypothetically speaking, this should be a role the PHN is playing

	phone strategy		Future studies on Black MSM may want to include a cell phone component. A sample agenda from the cell phone usage proposal at GW is attached.
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HPTN Black Caucus Barrier Identification Tool

PLEASE RESPOND TO: JAMAAL CLUE (JAMAALCLUE@GMAIL.COM)
BY MONDAY, DECEMBER 13, 2010 AT 5PM - EST

IDENTIFIED LIMITATIONS	CURRENT STRUCTURE
<i>Ex. Location</i>	<i>Only 1 clinic location to perform clinical procedures in NW that is not near a metro stop and/or bus stop.</i>
Location	
Clinic Times	
Laboratory	
Length of Visit	
Staffing	
Transportation	
Other:	
Other:	
Other:	

Split Visits recommendation for
HPTN 061 Follow up Visits

Day 1

Case Report Forms

Blood Draw/HIV Test

Risk Reduction Counseling

Day 2

ACASI

Social Sexual Network

Split visits should try to occur within 7 days of each visit.

Rationale: *CRF and Blood are critical measures that need to be collected*

When to consider a split visit:

- Participant expresses time constraints (for any reason).
- Participant discusses length of visit is too much/too long
- Staff shortage or inability to perform all duties needed for follow up visit

Appendix D: Intervention Delivery Recommendations

HPTN Black Caucus Retention Work Plan

2010 – 2011

Group Leader: Christopher Hucks-Ortiz

Group Members: S. Wakefield, Craig Hutchinson, Boris Powell, Jermel L. Wallace

Topic Area 1: Intervention Delivery – Cultural Competency		
Goal: To increase cultural competency at a site levels that will maximize retention efforts		
Retention Strategy	Inputs/Resources	Outputs/Impact
What has been learned about cultural competency since the beginning of the project (incl. what it means; definition). Discussion should explain what clinical coordinators and PI and learned or experienced in regards to dealing with the target population. Staff feasibility retention retreat (i.e. Who we enrolled, where we enrolled, etc)	Survey Monkey that will capture ideas from a number of staff without identifying staff roles	Summarize cultural competency issues by site Summary guide for continuing discussion and use as further retention planning and staff development
Principal investigators and Study Coordinators will maximize engagement and presence in the areas of retention and cultural competency.	Together they will review the survey results.	Identify training opportunities and rewards for program success.
Site Teams will consider the barriers associated with recruiting and retaining the target population.	Sites will have a discussion of 061 BC Retreat report findings <ul style="list-style-type: none"> • Include some results from Process Project & BC SWOT 	Identify cultural factors and program activities that address barriers to retention.

Site teams will review roles/responsibilities for disparate burden of retention activities	Create a document listing each staff member's retention responsibilities to ensure that all staff plays a role in 061 retention success. *retention starts at enrollment	Increase productivity and raise morale for retention staff.
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Topic Area 2: Intervention Delivery – Racial and Sexual Identity of Staff/ Staff Gender		
Goal: To increase acceptability and functionality of staff		
Retention Strategy	Inputs/Resources	Outputs/Impact
Identify study staff capacity to address participants needs at each site based on orientation, race, gender, & class.	Review SCHARP data report summaries about who actually is enrolled in study.	To ensure and maintain a compassionate connection to enrolled participants.
Formulate questions to participants that will allow sites to better understand what and or who the participant wants to see or hear from at various parts of the study visit.	ie. Operationalize asking what participants may prefer rather than assuming?	Focuses on the needs of the participant Individualize the retention approach for each participant
Have sites identify levels of continuity by presenting best practices	Brings focus on how staff is utilized to interact with participants. (retention calls, follow up, scheduling) utilize recruitment staff to conduct retention activities	Utilize recruitment staff to conduct retention activities

Topic Area 3: Intervention Delivery – Clinical Site Capacity		
Goal: To ensure and increase capacity for retention through considerations of participant need		
Retention Strategy	Inputs/Resources	Outputs/Impact
Identify on a per participant/ per site basis barriers associated with hours of operations and service access. <ol style="list-style-type: none"> 1. What hours of operations will work for you? 2. Are you available on Saturdays for appointments? 	Offering late evenings, early morning or Saturday appointments	Provides alternatives and flexibility to the needs of the population
Identify innovative approaches to retention. Consider remote study visits	Offer transportation vouchers, bus passes, and cab services.	Promotes flexibility for retaining participants
In what capacity can we utilize mobility to reach out to the target population?	Offer home visits, virtual visits, community satellite sites, split visits, and remote visits	Increases productivity to retention approaches
How do sites improve their representation in the community by investing in community based organizations/ events.	Utilizing Club Promoters to promote retention events through e-blast	Provides community representation
Provide staff time to Community based organization to assist with true partnerships.	Support CBO events with resources and/or staff time (Black HIV awareness day- Feb. 6 th)	Increase project visibility and strengthens existing community relationships. Makes participation a part of community
Educate community based organizations on the research being conducted	Provide literature to CBO's that offer insight to the barriers and factors that impede retention	Increases knowledge on the population being served
Incorporate 061 retention in recruitment plans for co studies	Develop flyers or other print reminders to have available	Reduces co enrollment and

	during tabling and other outreach events	increases community visibility
Improve organization capacity to support AAMSM staff and initiatives	<p>Clinical support for staff and participants</p> <p>Internal support groups (i.e. Black, gay)</p> <p>Workshops</p> <p>Mental Health/ wellness</p> <p>Discussion around micro aggression (& define)</p>	<p>Reduces burnout</p> <p>Increase productivity</p> <p>Gives a sense of accomplishment</p> <p>Boost morale</p>
Educate IRB members/staff about the particular needs of 061 populations.	Articles that focuses on the 061 cohort as a venerable population	Use their expertise to guide anything that may have been overlooked by 061 Caucus

Topic Area 4: Intervention Delivery – Clinical Research Collaboration		
Goal: To decrease competition for services by collaborating with community resources		
Retention Strategy	Inputs/Resources	Outputs/Impact
1. Set local retention goals based on current enrollment, literature, etc	Shift paradigm of conversations. Review current data ie., retention success, challenges, possibilities	Reduction of non productive elements of competition between sites



Clinical Research Site Cultural Competency Report Form

Black Caucus Retention Work plan- Intervention Delivery

Clinical Research Site:

Date Submitted:

The information collected on this reporting form will be used by the HPTN 061 Black Caucus to ensure that any emerging issues related to cultural competency at clinical research sites (CRS) participating in HPTN 061 are addressed appropriately and in a timely manner. Cultural competency issues include concerns about race, ethnicity and culture, as well concerns about gender identity, sexual orientation and sexual preference. Any concerns that you share will be kept confidential, but please refrain from using any identifying information when completing this form. Forms should be submitted to Dr. Sheldon Fields (Sheldon.Fields@URMC.Rochester.edu) by (enter date here).

1. At any point (in your work on HPTN 061) have you witnessed an uncomfortable event/situation/faux pas that you believe may have stemmed from a lack of cultural awareness/humility that have occurred at your site that may have a negative impact on the conduct of HPTN 061. If there is more than one issue please describe each one separately.
2. Did you report it to a supervisor?
3. If not, were you afraid to report it to a supervisor?
4. What was the outcome? [Describe your clinical research site's response to the issue(s) identified in the previous response. If there was more than one issue please describe each response separately.]

5. Were you satisfied with your sites response to the issue(s)? Why or why not?

6. If you were not satisfied with the response(s) what, in your opinion, would have been an appropriate response to resolving each of the issue(s)?

7. What makes the approach(es) that you recommended in the previous response a more appropriate response to the issue(s)?

8. Describe the types of cultural sensitivity/awareness technical assistance that the Black Caucus can provide/recommend to your CRS related to the conduct of HPTN 061.

9. Please provide any other comments about cultural competency issues at your CRS that you would like to share with the Black Caucus or other study leadership?

Appendix E: Community Engagement Recommendations

HPTN Black Caucus Retention Work Plan 2010 – 2011

Group Leader: Gregory D. Victorianne

Group Members: Dr. Lawrence Bryant, Chadwick K. Campbell, Yovannys Kenney, Jonathan Paul Lucas

Topic Area: Community Engagement		
Goal: To promote long term community relations and investment to improve community perception and trust of researchers conducting HIV prevention trials.		
Retention Strategy	Inputs/Resources	Outputs/Impact
<p>1. The HPTN 061 Black Caucus will develop a standard locator form to be used by each clinical research site participating in the BROTHERS study.</p> <p>Rationale: Establishing a standard locator form with standard collection procedures will ensure that each site is collecting as much locator information as possible.</p>	<ul style="list-style-type: none"> • CRS will provide work versions of the locator forms by December 7 • Team will combine form and submit BC by December 9 • Locator forms will be submitted to protocol team by December 13 • Protocol team will review assessment and reevaluation of locator forms and distribute to CRSs for IRB approval 	<ul style="list-style-type: none"> • Improved locator forms
<p>2. Clinical research sites participating in HPTN 061 will ensure that there is staff dedicated solely to retention</p>	<ul style="list-style-type: none"> • BC CE WG will collect data 	<ul style="list-style-type: none"> • Increased staff output and

<p>activities and that those staff member receive adequate support.</p> <p>Rationale: Encouragement from study investigators, high morale and internalized expectations will enable staff to remain focused and energized.</p>	<p>from each CRS related to retention staff and distribution of retention responsibilities by December 13</p> <ul style="list-style-type: none"> • BC CE WG will make recommendations to HPTN 061 PIs for reallocation of existing staff and responsibilities by December 17 • HPTN 061 PIs will meet with CRS to make recommendations on reallocation of staff or hiring adequate retention staff as soon as possible 	<p>morale</p> <ul style="list-style-type: none"> • Efficient use of project resources
<p>3. Clinical research sites participating in HPTN 061 will initiate monthly communications with study participants to build rapport and ensure that locator information is updated on a regular basis.</p> <p>Rationale: Minority communities have a low level of trust in researchers. Building rapport through positive interactions may improve retention.</p>	<ul style="list-style-type: none"> • BC Leadership will meet with PIs to discuss monthly communications on PI weekly call January 7. • PIs will meet with CRS PIs and/or study coordinators to discuss implementation of monthly participant communication by January 14 • CRS will contact each study participant and establish regular 	<ul style="list-style-type: none"> • Regularly updated locator information • Improved rapport with study participants

	<p>communication channels such as emails, text messages, letters, and telephone calls with participants by January 30.</p> <ul style="list-style-type: none"> • CRS will contact participants monthly via method preferred by the participant after initial contact. 	
<p>4. Clinical research sites participating in HPTN 061 will solicit staff input related to participant retention on a weekly basis and ensure that recommendations for novel approaches to retention activities are given serious consideration.</p> <p>Rationale: Empower the front line staff</p>	<ul style="list-style-type: none"> • BC Leadership will meet with PIs to discuss monthly communications on PI weekly call January 7. • PIs will meet with CRS PIs and/or study coordinators to discuss implementation of weekly retention meetings by January 14 • CRS initiate weekly retention meetings and begin solicitation of ideas from staff by January 30. • CRS will contact participants monthly via method preferred by the participant after initial contact 	<ul style="list-style-type: none"> • Increased communication among staff and upper management • Increased staff capacity

Site Logo would go in this space

HPTN 061 Locator Form

The information on this form will help us stay in touch with you with information related to your study visits. This information will be kept confidential. It will not be given to anyone without your written permission.

Date: _____

Please Print: Full legal name: _____

 Nickname First Middle Initial Last
 Date of Birth (mm/dd/yy): _____

Permanent Address: _____

 (Street Address) (Apt # or Post Office Box)

 (City) (State) (Zip code)

Home Phone: (____) _____ Cell Phone: (____) _____ Work Phone: (____) _____

1. How long have you lived here? _____
2. May we visit your residence if we lose contact of you Yes No
3. Do you plan to move any time soon? _____ If so, do you know where to? _____
4. Does anyone else live with you?
 Alone With a friend/roommate With your family
 With a partner / boyfriend / significant other Other:

5. Name: _____ Relationship: _____

 First Middle Initial Last

6. Do you have a Driver's License / State Identification Card **[Required to enroll]** _____ Yes
 _____ No
 Number / State _____

Alternate address:

7. Is there another address where you stay? _____ Yes _____ No

Address: _____

 Office Box (Street Address) (Apt # or Post

 (City) (State) (Zip code)

Phone: (_____)_____ Phone: (_____)_____

Where do you reside most of the time? _____

Days and times you might be there: _____

8. Do you currently live in a shelter Yes No Name of Shelter _____

Can we leave a message for you? Yes No

Address: _____

(Street Address)

(Apt # or Post Office Box)

(City)

(State)

(Zip code)

Person to contact in case of emergency:

9. Name: _____ Relationship: _____

_____ First MI Last

Home Phone: (____)_____

Cell Phone: (____)_____

10. Spouse's name, if applicable: _____ Cell Phone: (____)_____

Permanent Address: _____

(Street Address)

(Apt # or Post Office Box)

(City)

(State)

(Zip code)

11. Your email address: _____ Alternate email address: _____

Can we contact you on Facebook? _____ Can we contact you on Twitter? _____

Can we contact you on MySpace? _____ Other (name site) _____

Do you have a personal web page? If yes, please provide _____

I.M. name: _____

A.I.M. name: _____

May we send you:

Appointment reminders Yes No Project updates Yes

No

General / Future studies Yes No Text messages Yes

No

12. Do you attend college/trade school? Yes _____ No _____

If yes, name: _____ Department _____

13. Please provide **2** friends who usually know how to reach you if you should move or change contact information?

Name: _____

First

MI

Last

Address: _____

 _____ (Street Address) _____ (Apt # or Post Office
 Box)

_____ (City) _____ (State) _____ (Zip code)
 Cell Phone: (____) _____ Email Address: _____

Name: _____
 _____ First MI Last

Address: _____
 _____ (Street Address) _____ (Apt # or Post Office
 Box)

_____ (City) _____ (State) _____ (Zip code)
 Cell Phone: (____) _____ Email Address: _____

14. Is there a case worker, doctor, community clinic, or other contact that you see regularly?
 If necessary, may we contact this person? Yes [] No []

Name: _____
 _____ First MI Last

Agency: _____
 Phone: (____) _____ Email Address: _____

Address: _____
 _____ (Street Address) _____ (Apt # or Post Office
 Box)

_____ (City) _____ (State) _____ (Zip code)

15. Are you currently in a Substance Treatment Program? Yes _____ No _____

Name of Counselor : _____
 _____ First MI Last

Place: _____
 Address: _____

_____ (Street Address)
 _____ (City) _____ (State) _____ (Zip code)

Days & times you might be there: _____

Where do you attend meetings? _____

16. Have you ever been arrested? Yes [] No []

Are you currently on probation / parole? Yes [] No []
 If yes, which? Probation _____ Parole _____ Dept. of Corrections Number _____

When did this start (mm/yy)? _____ When does it end (mm/yy)? _____

Name of supervising official: Name: _____
 _____ First MI Last

Address: _____

 (Street Address) (Suite
 number)

 (City) (State) (Zip code)

17. Can you tell us of a couple of places you hang out or meet with friends? (ex. Club/Bar, Restaurant, Bookstore, Coffee Shop, Park, Library, Shopping Mall, Video Arcade)

1. Place: _____
 Address: _____

 (Street Address)

 (City) (State) (Zip code)

Days & times you might be there: _____

2. Place: _____
 Address: _____

 (Street Address)

 (City) (State) (Zip code)

Days & times you might be there: _____

18. Who do you know that is also participating in the study? Can we contact them if we lose contact with you?

Name _____ Telephone Number _____
 Yes No

Name _____ Telephone Number _____
 Yes No

How should we identify ourselves when we are attempting to reach you _____

Sites can provide their own examples

Health Clinic / Research Site Yes No
 Friend Yes No

Future Participation

We will keep this completed form on file for the duration of the study. We would also like to keep this information on file after this study so we may contact you future studies. Agreeing to be contacted about future studies does not mean that you have agreed to take part in any future studies or that you will be eligible for any future studies. At the time of those studies, you will be free to choose whether or not to participate, if eligible.

If at any time after this study, you do not want us to contact you, you may refuse at any time. May we keep this information on file after this study so we may contact you about future studies?
 Yes No

DO NOT CONTACT AT HOME IF BOX IS CHECKED!!!!

HPTN 061 Contact Log




Participant Name or ID Number _____













(please print) Last First













6 month visit target window: _____ to _____ [allowable window end date: _____]










12 month visit target window: _____ to _____ [allowable window end date: _____]

The purpose of this log is to document attempts at participant contact. This log should be kept confidential and maintained in a locked file as it contains sensitive client information.

Call #	Type of contact <small>(Describe which number/address used)</small>	Date	Time	Staff Initials	Outcome <small>(Circle all that apply)</small>	Comment
	<input type="checkbox"/>  <input type="checkbox"/> TXT <input type="checkbox"/>  <input type="checkbox"/> 				Visit Scheduled Updated Locator 3 rd Party Contact No Contact	

Call #	Type of contact (Describe which number/address used)	Date	Time	Staff Initials	Outcome (Circle all that apply)	Comment
	<input type="checkbox"/>  <input type="checkbox"/> TXT <input type="checkbox"/>  <input type="checkbox"/> 				Visit Scheduled Updated Locator 3 rd Party Contact No Contact	
	<input type="checkbox"/>  <input type="checkbox"/> TXT <input type="checkbox"/>  <input type="checkbox"/> 				Visit Scheduled Updated Locator 3 rd Party Contact No Contact	
	<input type="checkbox"/>  <input type="checkbox"/> TXT <input type="checkbox"/>  <input type="checkbox"/> 				Visit Scheduled Updated Locator 3 rd Party Contact No Contact	
	<input type="checkbox"/>  <input type="checkbox"/> TXT <input type="checkbox"/>  <input type="checkbox"/> 				Visit Scheduled Updated Locator 3 rd Party Contact No Contact	

Call #	Type of contact (Describe which number/address used)	Date	Time	Staff Initials	Outcome (Circle all that apply)	Comment
	<input type="checkbox"/>  <input type="checkbox"/> TXT <input type="checkbox"/>  <input type="checkbox"/> 				Visit Scheduled Updated Locator 3 rd Party Contact No Contact	
	<input type="checkbox"/>  <input type="checkbox"/> TXT <input type="checkbox"/>  <input type="checkbox"/> 				Visit Scheduled Updated Locator 3 rd Party Contact No Contact	
	<input type="checkbox"/>  <input type="checkbox"/> TXT <input type="checkbox"/>  <input type="checkbox"/> 				Visit Scheduled Updated Locator 3 rd Party Contact No Contact	
	<input type="checkbox"/>  <input type="checkbox"/> TXT <input type="checkbox"/>  <input type="checkbox"/> 				Visit Scheduled Updated Locator 3 rd Party Contact No Contact	

Call #	Type of contact (Describe which number/address used)	Date	Time	Staff Initials	Outcome (Circle all that apply)	Comment
	<input type="checkbox"/>  <input type="checkbox"/> TXT <input type="checkbox"/>  <input type="checkbox"/> 				Visit Scheduled Updated Locator 3 rd Party Contact No Contact	
	<input type="checkbox"/>  <input type="checkbox"/> TXT <input type="checkbox"/>  <input type="checkbox"/> 				Visit Scheduled Updated Locator 3 rd Party Contact No Contact	
	<input type="checkbox"/>  <input type="checkbox"/> TXT <input type="checkbox"/>  <input type="checkbox"/> 				Visit Scheduled Updated Locator 3 rd Party Contact No Contact	

Locating Hard-to-Reach Participants

Please document what you have done for participant. PTname or ID - _____.

Activity	Attempt 1 Date/initial	Attempt 4 Date/initial	Attempt 3 Date/initial	Attempt 4 Date/initial	Attempt 5 Date/initial
Contacted all persons on locator form (state disposition)					
Repeated contacts all persons on locator form					
Reverse lookup for participant					
Reverse lookup for friend					
Reverse lookup for family					
Reverse lookup for other (specify)					
Inmate search					
Certified letters (keep returned letters in locator binder)					
Facebook / My Space					
Yahoo/Google search					
Email/texts sent (specify #, time)					
Visited address and queried residents for updated					

information					
Visited area proximal to house/hangout (specify where)					
Returned to place of recruitment (specify where)					

Helpful Links:

Site Specific information

