

Assessing Cancer Programming Needs and Resources of ASOs and their Clients:

Using Qualitative Findings to Develop a Quantitative Survey

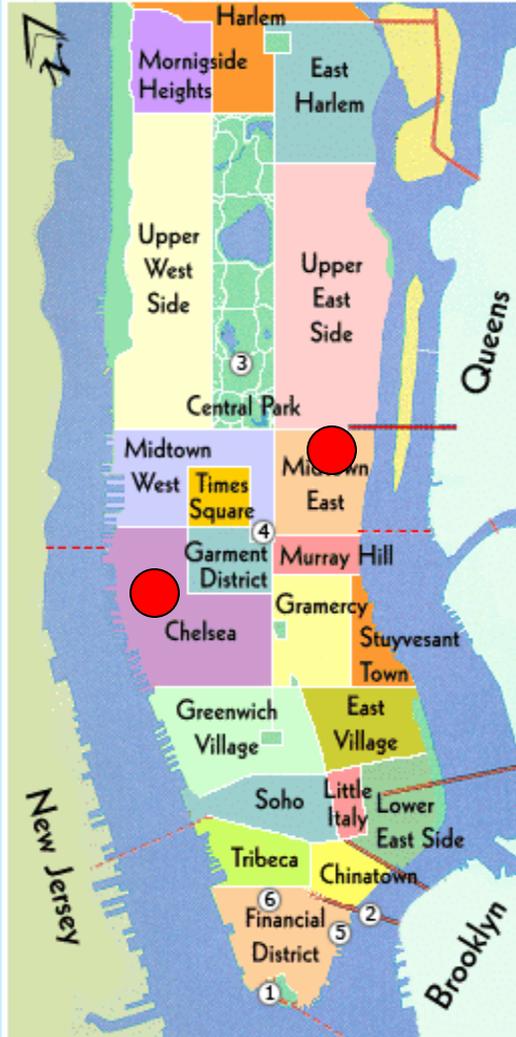
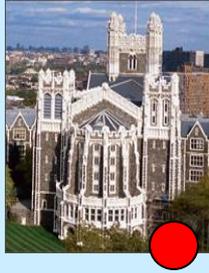
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8th Annual Texas Conference on Health Disparities

May 30, 2013

the
City College
of New York

THE SOPHIE DAVIS
SCHOOL OF BIOMEDICAL
EDUCATION



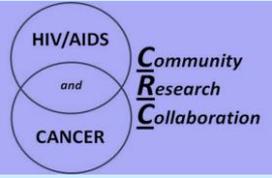
GMHC
GAY MEN'S HEALTH CRISIS



MEMORIAL SLOAN-KETTERING CANCER CENTER
ESTABLISHED 1884

Memorial Sloan-Kettering
Cancer Center

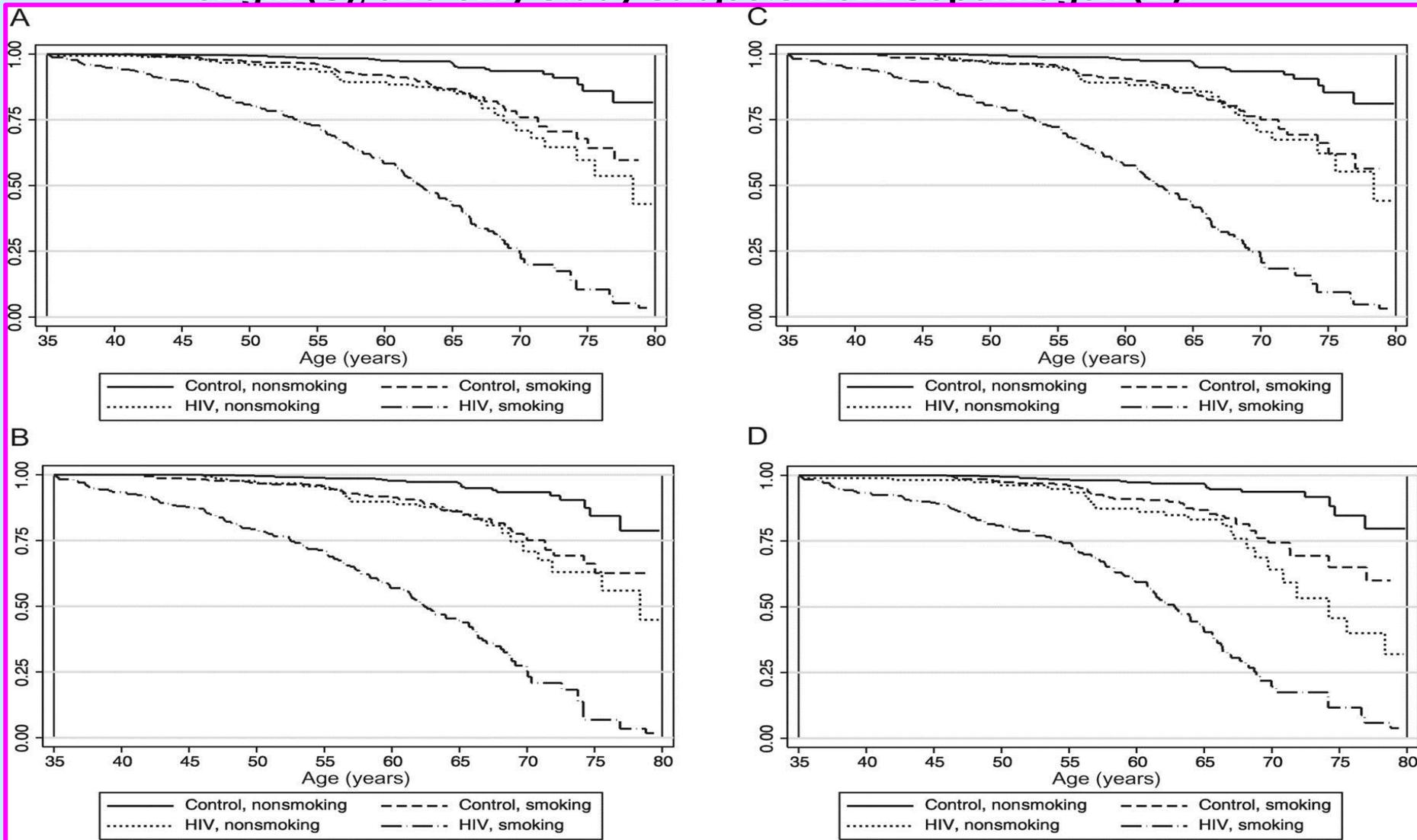




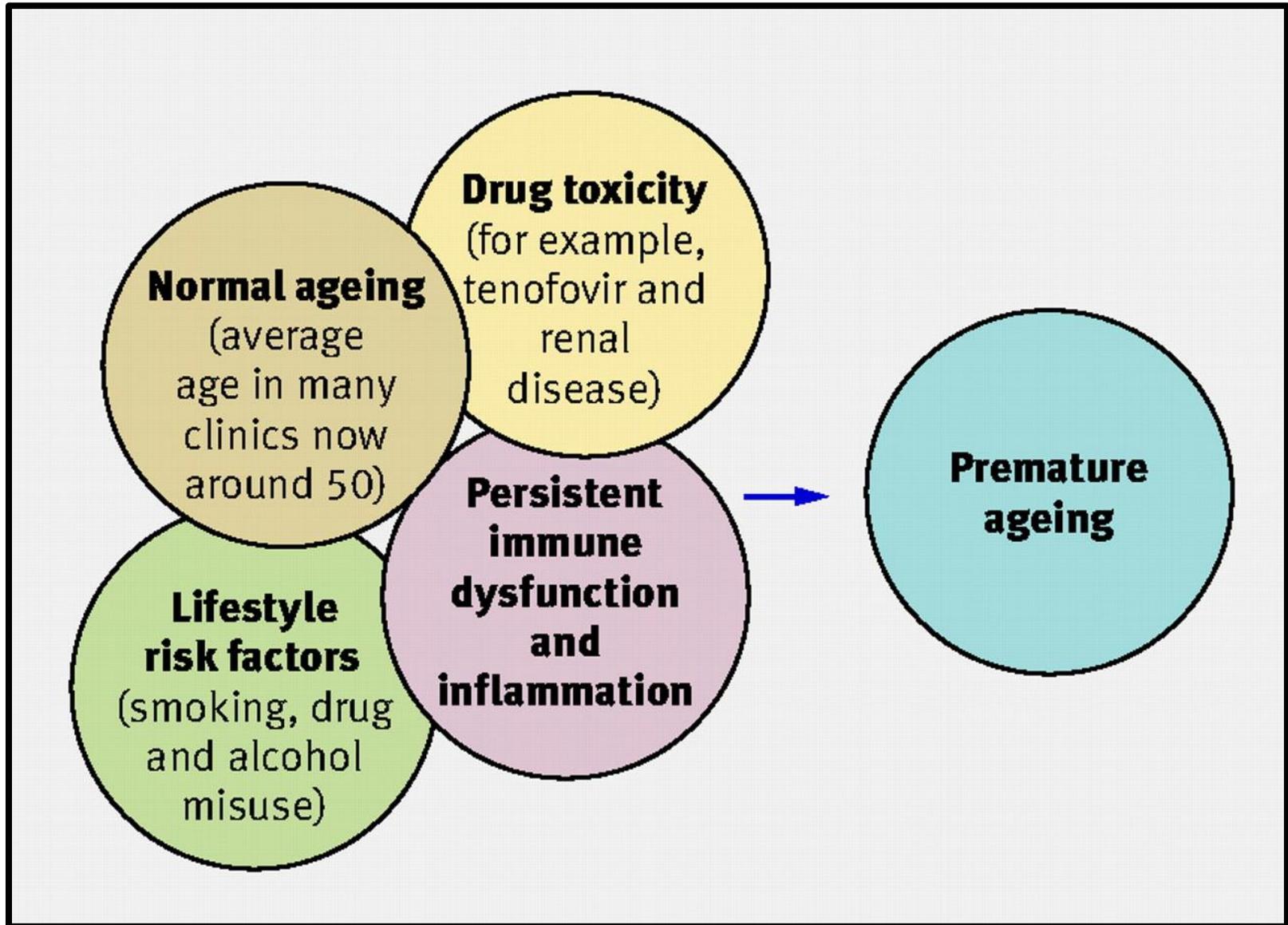
Why HIV/AIDS and Cancer?

- Improved life expectancy for Persons Living with HIV/AIDS (PLWHA)
 - Increasing concern about other health threats
- PLWHA at higher risk for multiple AIDS and non-AIDS defining cancers
 - ~25% of all AIDS deaths are due to non-HIV-related causes
 - Non-HIV-related cancers contribute substantially to this mortality
- Contribution of lifestyle factors and HIV-associated immune impairments
- **PLWHA smoke at 2-3x rate of U.S. population (45-74% vs. 20%)**
- Poverty: 57.1% of PLWHA have annual incomes below \$10,000; 67.4% are unemployed (CDC)
- Rates of HIV infection disproportionately elevated in African Americans and Latinos, who also experience disparities in cancer outcomes
- Intersection of HIV/AIDS and cancer challenges communities serving PLWHA and researchers focused on reducing health disparities

Kaplan-Meier curve showing survival by age, stratified by HIV and smoking status for all study subjects (A), only males (B), only study subjects of Danish origin (C), and only study subjects from Copenhagen (D).



Helleberg M et al. Clin Infect Dis. 2013;56:727-734

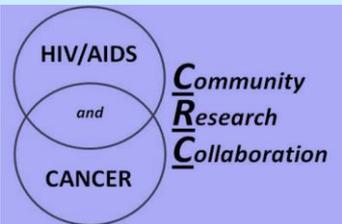


Deeks S G , and Phillips A N BMJ 2009;338:bmj.a3172

Aims

1. Develop collaborative research partnership with CBOs serving underserved and racial/ethnic minority PLWHA
 2. Explore and identify mutual interests at the convergence of HIV/AIDS and cancer, including—
 - Cancer prevention**
 - Ex: tobacco use cessation
 - Early detection**
 - Cancer screening
 - Access to treatment**
 - Identifying barriers to treatment and clinical trials participation
 3. Design and conduct community needs assessment (CNA)
- Also:**
4. Use information to apply for NIH funds to launch project to address identified needs





Steps Toward Project Completion

Focus groups

- 3 groups: Cancer prevention, detection/screening, and treatment

Develop needs assessment survey

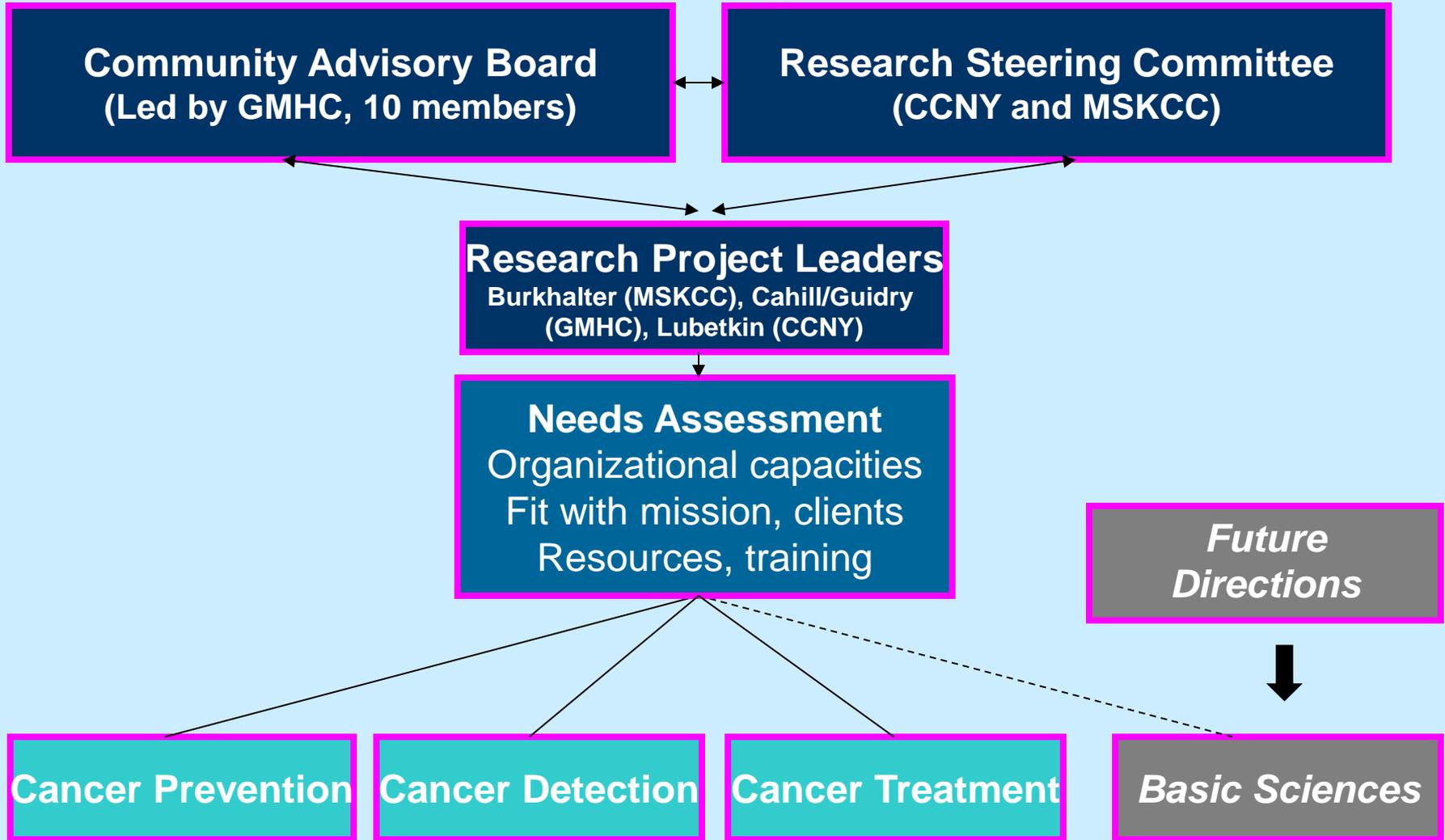
- Use CAB feedback and analysis of focus group themes

Administer NAS to ~50 community HIV/AIDS providers

- Analyze results and summarize report, submit to CAB

Submit a NIH grant application
addressing identified community needs
regarding HIV/AIDS and CANCER

HIV/AIDS and Cancer Community Research Collaboration



Assembling the CAB

Multiple criteria for membership considered:

1. Diversity in mission and services offered to PLWHA
 2. Diversity in subpopulations served
 3. Geographic diversity (considered all NYC boroughs)
 4. Representatives and alternates should have extensive knowledge about services and structure of their agencies
 5. Agree to attend quarterly meetings
- Diverse missions:
 - HIV+ women; incarcerated/formerly incarcerated; lesbian, gay, bisexual, and transgender population; AIDS-related cancer and research
 - Only 3 of 10 provide cancer-focused programming

Focus Group Topics and Questions

Table 2. Focus Group Topics and Questions

Questions about the nature of organizations' past or present cancer-related activities

- Describe current cancer-related activities
- If offered, how are those activities framed or promoted?

Sample Question (Focus Group 1, Cancer Prevention): Is the activity or program thought of and promoted as “cancer prevention”? If not, please explain in what conceptual model such programs are framed.

Fit of cancer-related activities at these organizations

- What would make integration successful or unsuccessful
- Potential barriers and challenges
- Considerations in serving minorities or underserved PLWHA clients
- Community partnerships and resources

Sample Question (Focus Group 2, Cancer Detection): What considerations would have to be given in promoting cancer screening to ethnic and racial minorities/underserved PLWHA clients?

Types of cancer-related activities these organizations would consider expanding or initiating

- Activities they would consider
- Reasons for their consideration
- Resources needed to expand or add services
- Education and training

Sample Question (Focus Group 3, Cancer Treatment/Survivorship): What additional resources (financial, training, etc.) would your organization need to provide or expand cancer treatment or survivorship services?

Interest of these organizations in participating in research concerning cancer

- Experiences in the conduct of research
- Interest in participating in research
- Capacity for research participation

Sample Question (Focus Group 3, Cancer Treatment/Survivorship): What capacity (knowledge, experience, skills, or resources) does your organization have for conducting research or program evaluation in the area of cancer treatment or survivorship-related activities?

Ending/conclusion of the focus group

- Discussion of any topics that were not previously covered
- Identification of important, “take away” messages

Sample Question (Focus Group 1, Cancer Prevention): What issues that we have discussed do you think are most important for us to take away from this focus group?

Note. PLWHA = persons living with HIV/AIDS.

Focus Group 1 Results– Cancer Prevention

Nature of Organizations' Past or Present Cancer Prevention Activities

- CAB members' organizations do not tend to explicitly offer cancer prevention services. Many offered smoking cessation programs (not framed as cancer prevention).

Fit of Cancer Prevention with Organizations' Mission and Services

- Multiple barriers to implementing cancer prevention programs, including stigma, resistance from both the clients and the staff, lack of resources, low priority of prevention, and lack of culturally competent services. There is also a need to educate senior level individuals in their organizations.

Type of Cancer Prevention Services Organizations May Consider

- CAB members expressed interest in many different cancer prevention-related services. For example, they would like to incorporate interventions that work from lessons of HIV/AIDS or ones that deal with fear and stigma.

Common Themes Across Focus Groups

Theme 1: Most agencies had limited experience implementing cancer-focused programs, and when they had, the programs were not framed as cancer specific

Theme 2: Agencies need resources and collaborative partnerships in order to effectively incorporate cancer services

Theme 3: Staff and clients must be educated about the relevance of cancer to HIV/AIDS

More Themes

Theme 4: Agencies are interested in education about linkages between HIV/AIDS and cancer

Theme 5: Cancer care providers should be culturally competent and understand the needs of PLWHA

Theme 6: Agencies see opportunities to improve their services by participating in research but are wary about the loss of autonomy and irrelevant research findings

Based on These Themes: Community Needs Assessment

Development of Questionnaire:

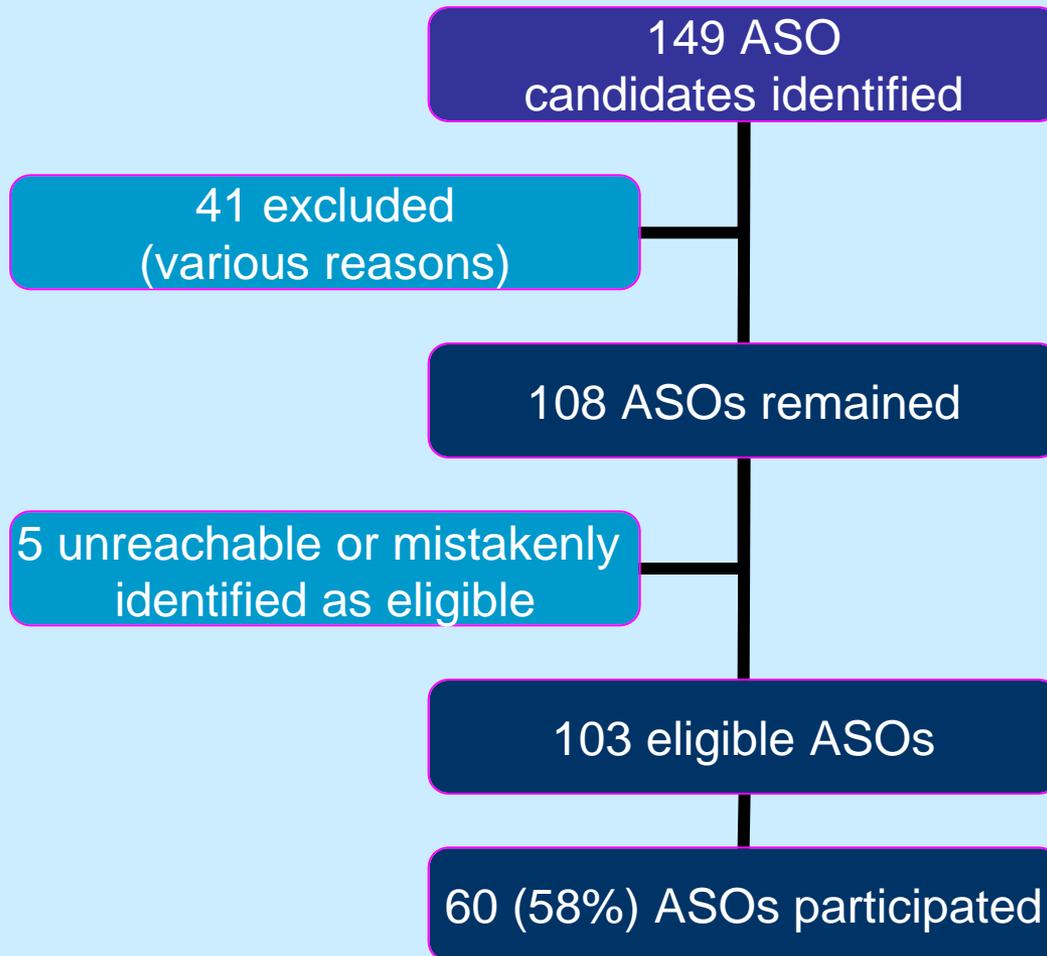
1. Respondent and Organization Characteristics
 - 17 items, informational
2. Cancer-Related Activities Your Organization Does or Might Consider Doing
 - 12 items: Yes/No
 - If No (per item): Organizational interest in this activity? Yes/No
3. Formats of Cancer-Focused Activities Your Organization Uses or Might Consider Using
 - 9 items (different formats, e.g. printed materials, individual sessions, group sessions, peer-to-peer, etc.): Yes/No
4. Organizational Capacities
 - 10 items: 4-point scale

Community Needs Assessment, II

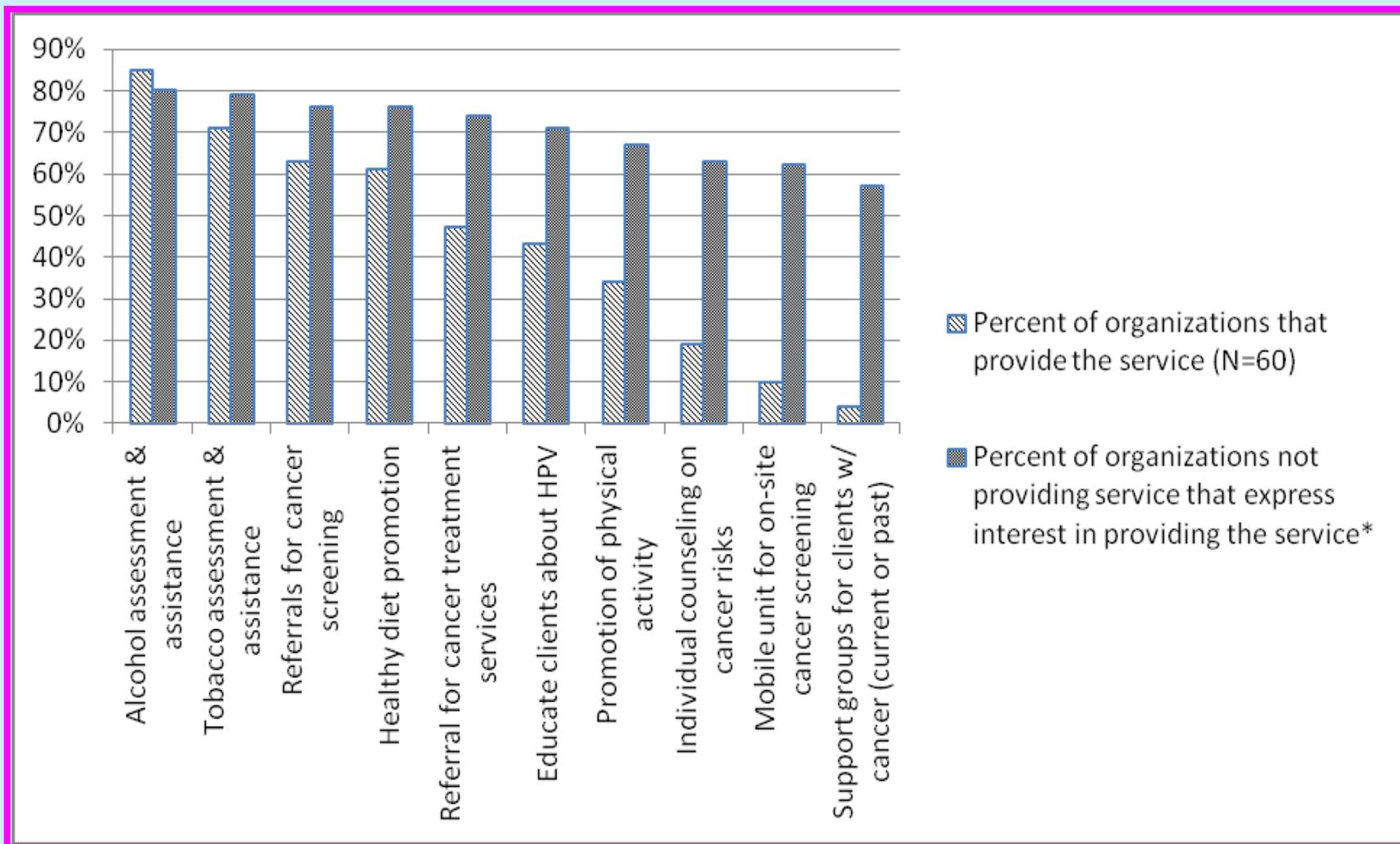
5. Organizational Needs: Education & Information about Cancer
 - 6 items: 3-point scale
6. Organizational Needs: Culturally Competent Cancer Care
 - 3 items: 3-point scale
7. Organizational Needs: Partnerships
 - 5 items: 3 point-scale
8. Interest and Readiness to Integrate Cancer-Related Activities
 - 4 items: 4-point scale
9. Research Participation
 - 2 informal questions
 - 5 items on “perspectives on research”: 5-point scale

Sample

- Definition of ASO?
 - Community-based, nonprofit, primary focus providing HIV/AIDS-related services, typically social services; excluded medical providers, clinics, or hospitals
- Viewed HIV/AIDS service providers from NY, NJ, and CT



Selected Results: Levels of Experience and Interest in Cancer-Related Programming



WHAT ARE YOUR ORGANIZATION'S CAPACITIES?

How much do you agree with each of these items?	Completely/Partly disagree	Neither agree nor disagree	Partly/Completely Agree	N/A
1. Our <u>clients</u> are aware and knowledgeable of the impact of cancer on PLWHA.	32.6%	11.6%	55.8%	
2. Our <u>clients</u> are aware and knowledgeable of their own personal cancer risks.	36.2%	12.8%	51.1%	
3. Our <u>staff</u> is aware and knowledgeable of cancer concerns and risks for PLWHA.	14.9%	14.9%	70.2%	
4. My organization's <u>leadership</u> is aware and knowledgeable of cancer concerns and risks for PLWHA.	15.7%	13.7%	70.6%	
5. My organization is aware and knowledgeable of the aging of the HIV/AIDS population and the opportunity it presents to enhance or re-focus services.	3.9%	7.8%	88.2%	
6. My organization has funding that could support cancer-focused activities or services.	89.6%	2.1%	8.3%	1 NA
7. Our staff is knowledgeable about health insurance coverage (e.g., private payers, Medicaid) for cancer services (e.g., mammograms, cancer treatment).	26.0%	8.0%	66.0%	
8. My organization is knowledgeable about free or low cost cancer screening services for our clients.	28.6%	8.2%	63.3%	
9. My organization is able to help clients address their <u>substance use</u> problems (e.g., providing programs to address these issues or the ability to refer them out).	6.0%	4.0%	90.0%	
10. My organization is able to help clients address their <u>mental health</u> problems (e.g., providing programs to address these issues or the ability to refer them out).	9.8%	2.0%	88.2%	
11. My organization's mission statement supports the Integration of cancer-related services into current programming.	31.4%	23.5%	45.1%	
12. Our initial client assessment or intake captures, or could capture, information related to cancer concerns.	18.0%	10.0%	72.0%	

Organizational Needs	No Need (%)	Some Need (%)	Great Need (%)
<i>Education on cancer concerns among PLWHA for...</i>			
• Clients	5	37	58
• Staff	5	41	54
• Leadership	17	46	37
<i>Information/Data on...</i>			
• Clinical research trials regarding cancer treatment/prevention	7	56	37
• Links between HIV/AIDS and cancer	5	31	64
• Impact of cancer on PLWHA clients served by	5	33	61
<i>Need for ability to refer...</i>			
• To culturally competent cancer providers	17	41	42
• Undocumented/uninsured clients to cancer care providers	10	37	53
<i>Need ways/means to strengthen relationships between clients and medical providers</i>			
	7	47	46
<i>Need for relationships/partnerships with...</i>			
• Community businesses (to spread message about cancer risk for PLWHA)	34	37	29
• Cancer care providers (for information and referrals)	7	49	44
• Other CBOs (for knowledge sharing on HIV/AIDS and cancer)	19	44	37
• Public health agencies (for support of expanding services to include cancer concerns)	5	34	61
• Community volunteers (for implementation of cancer-related activities)	24	32	44

Based on These Results

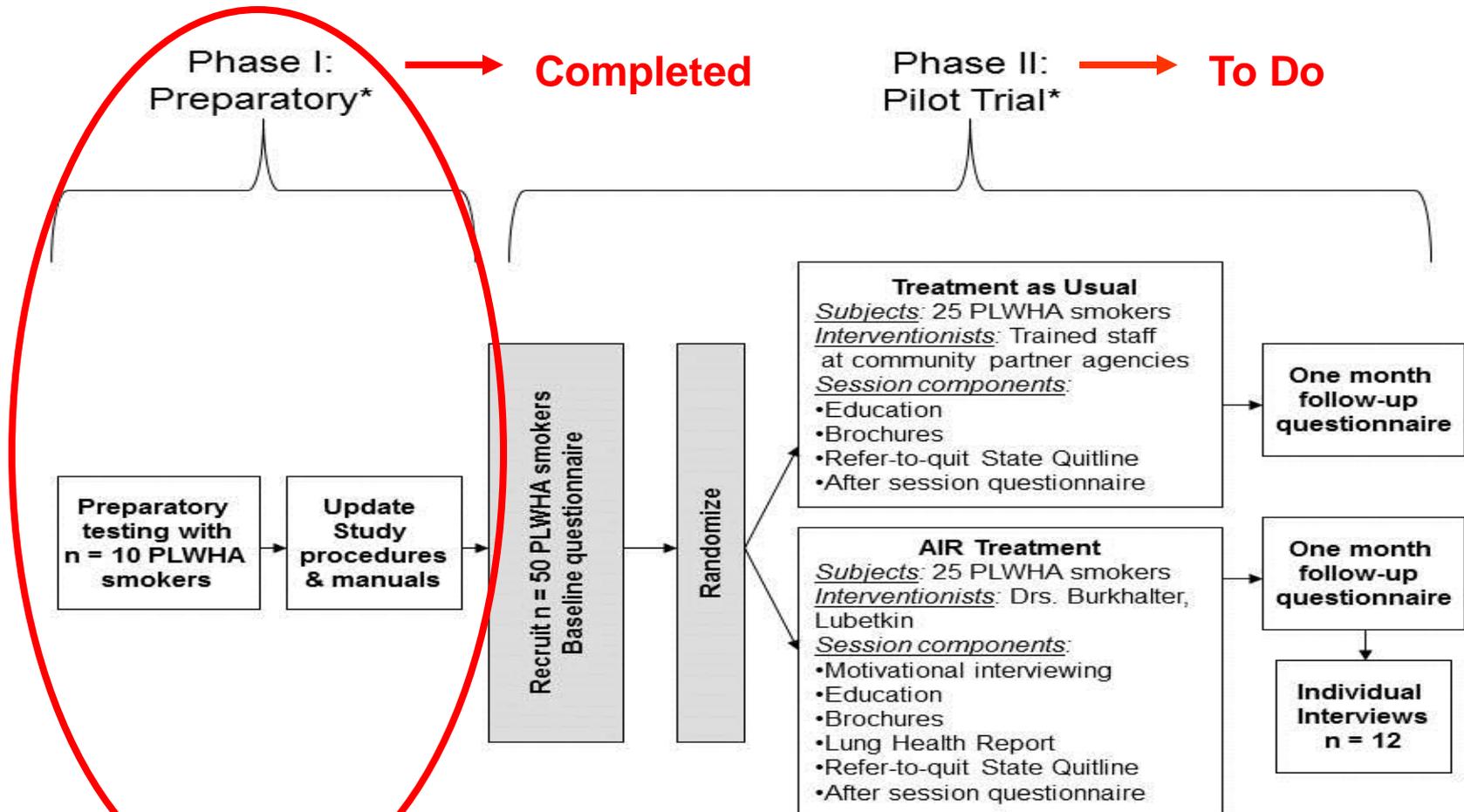
- Community-academic research partnerships hold potential to explore training and technical assistance methods to enhance the abilities of ASOs to bring cancer-programming to their clients
- Using CNA results to create other cancer-focused education programs for ASOs

Example: AIR Trial

- Developed a tobacco use intervention that:
 - Focuses on motivating PLWHA who smoke
- Provides respiratory feedback via a “lung health report”
- Supports uptake of evidence-based public health cessation services, i.e. Quitline, Medicaid coverage of cessation medications, uses motivational interviewing



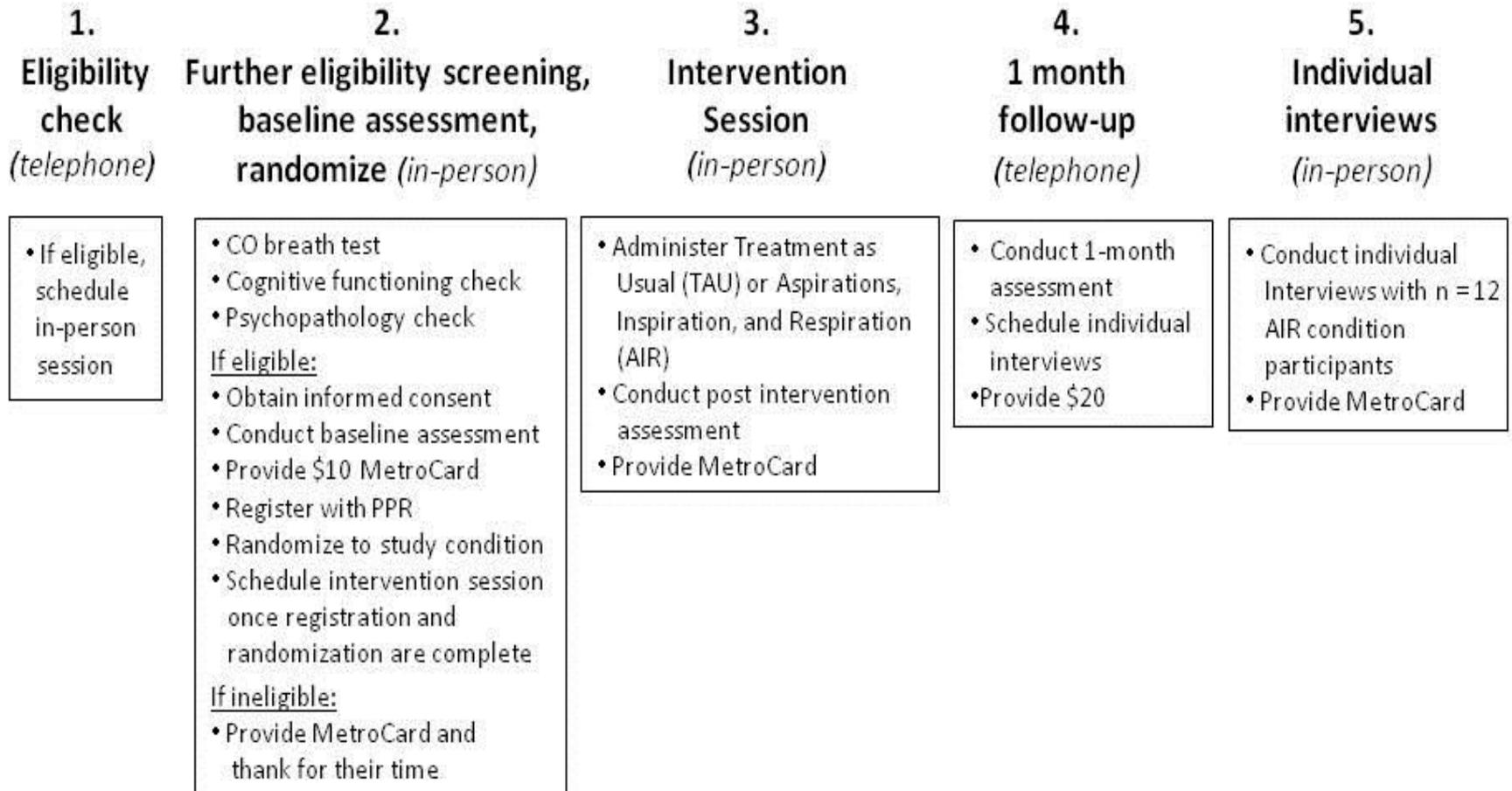
Study Schema



*Recruitment and intervention conducted at participating Community Advisory Board members' (AIDS service) organizations

Phase II: Pilot Trial

Participant flow and procedures



Step 4: NIH Grant Submitted

- Submitted R25 Cancer Education Grant to NCI (Jan '13)
“Disseminating Cancer Prevention and Control Education to Community-Based HIV/AIDS Service Organizations”
- Application to be reviewed June 2013

Aims

- 1. Community Core** promotes relevance of cancer to leadership within ASOs to increase demand (pull) for evidence-based cancer prevention and control education activities within their organizations
- 2. Education Core** disseminates (push) cancer prevention and cancer control education to ASOs and to increase their capacities to implement education with their clients
- 3. Evaluation Core** assesses educational intervention's impact on organizational and staff outcomes and evaluates process of study's activities as they relate to outcomes