

Treatment Issues

The HIV/AIDS and Cancer Community Research Collaboration

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In mid-2009, a team of researchers from the Memorial Sloan-Kettering Cancer Center (MSKCC) and the City College of New York (CCNY) reached out to staff at Gay Men's Health Crisis (GMHC) to explore the possibility of creating an academic-community partnership to investigate the emerging issues at the intersection of HIV and cancer. The need for such a project was a direct result of advances in the treatment of HIV, which have extended life expectancies of HIV-positive people into their 60s and 70s, and it is now estimated that by 2020 over half of all people with HIV will be over 50 years of age.¹ With the aging of the epidemic, non-AIDS related malignancies now account for more deaths of HIV-positive persons than AIDS-related cancers.² This change in mortality for HIV-positive persons mirrors the impact of cancer in the overall population, but there are some very specific differences that distinguish the way cancer affects people living with HIV or AIDS.

To help community-based organizations that serve HIV-positive persons deal with these emerging issues, MSKCC, CCNY, and GMHC formed the HIV/AIDS and Cancer Community Research Collaboration. Since its inception in September of 2009, the Collaboration has developed three different projects aimed at increasing the capacities of community-based organizations (CBOs) to address issues at the intersection of HIV and cancer. This work has been supported by funding from the National Cancer Institute through the CCNY-MSKCC Partnership for Cancer Research, Training, and Community Outreach.

The Partnership aims to address cancer health disparities and their impact on minority communities and marginalized populations, and working with the HIV-positive

population is a natural extension of this mission. The stigma and discrimination faced by people living with HIV, along with the economic difficulties created by their medical and mental health needs, mean that almost half of this population lives in precarious conditions near poverty or close to it. While HIV incidence (new cases of infection) has leveled off or declined in many segments of the population, new infections are rising at an alarming rate among young gay and bisexual men of color.³

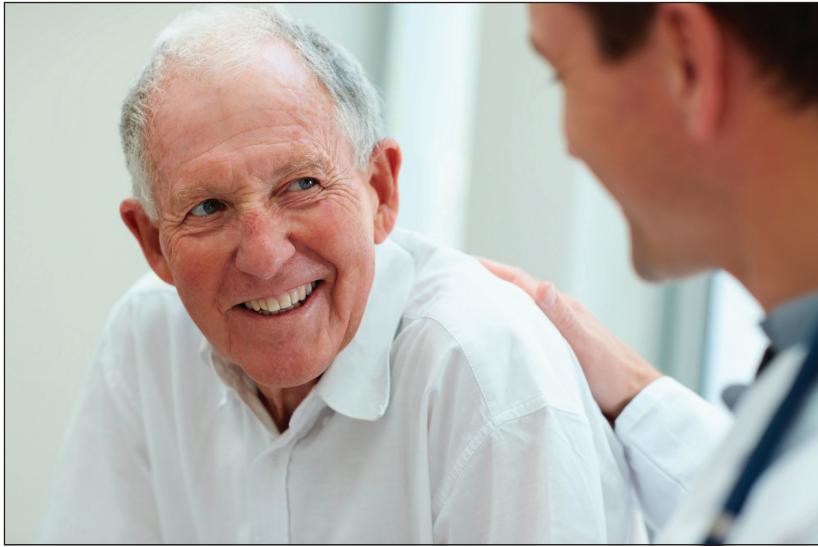
People living with HIV and AIDS face increased risks for a number of cancers. Aging alone brings increased

risk for breast, prostate, and other cancers. The immune system deficiencies that affect people living with HIV increase the risk for both AIDS-defining and non-AIDS-defining malignancies, especially anal, cervical, and tonsil-

lar cancers—related to human papillomavirus (HPV)—and liver cancer—related to hepatitis B and C infections.⁴ The high prevalence of tobacco use among people living with HIV, at 2 to 3 times the rate in the general population, brings with it a marked increase in the risk for lung, head and neck, and bladder cancers.⁵ Along with the medical risks, the incidence of cancer among people living with HIV creates many challenges in service provision to the population, including mental health issues, access to medical care, and other concerns related to poverty and social marginalization.

The intersection of HIV and cancer is a new field, and the HIV/AIDS and Cancer Community Research Collaboration was built on principles of “community-based participatory research” (CBPR) in which academic and community partners together define issues of concern to the community, design research programs to create

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new knowledge and practices related to those issues, and work to analyze and disseminate their findings. CBPR recognizes the synergy to be gained by bringing together the different kinds of expertise that come from academic research and practical experience in community settings

The principal community partner in the research team is GMHC, which was founded in 1982 as the first organization dedicated to the fight against AIDS. With over 11,000 clients, GMHC has been the leader in the community response to AIDS, and it provides the Collaboration with extensive access to locally-based knowledge about the needs of people living with HIV and the challenges involved in providing services to this population. Prior to the development of the Collaboration, GMHC had already begun to explore the issues involved in aging and HIV, and in 2010 it released a landmark policy paper assessing the state of the field, "Growing Older With the Epidemic: HIV and Aging."

To increase the community presence in the Collaboration's work, GMHC convened a Community Advisory Board

(CAB) comprised of organizations in New York City that serve people living with HIV. Over the three years of the project, the CAB has included representatives from AIDS Center of Queens County, AIDS Community Research Initiative of America (ACRIA), Bronx AIDS Services, Bronx Community Pride Center, Brooklyn AIDS Task Force, Fortune Society, Harlem United Community AIDS Center, Harm Reduction Center, Iris House, the National LGBT Cancer Network, the Staten Island Pride Center, and the North Jersey Community Research Initiative.

The Collaboration's first project was to develop and implement a needs assessment of CBOs that serve people living with HIV in the tri-state area of New York, New Jersey, and Connecticut. Across 2010, the Collaboration

worked with the CAB to identify the existing capacities among CBOs that work with people living with HIV, their interests in cancer-related programming for HIV-positive clients, and other topics that could be included in a needs assessment survey. This formative work with the CAB showed that CBOs working with people living with HIV presented capacities including strong relationships and cultural competency with their clients, a holistic view of client health, experience in prevention activities, and a desire for new knowledge about cancer and HIV. They expressed a strong interest in programming related to cancer education and prevention, suggesting that future projects develop accordingly. The results of this work with the CAB were published in an article

entitled "At the Intersection of HIV/AIDS and Cancer: A Qualitative Needs Assessment of Community-based HIV/AIDS Service Organizations" in the journal *Health Education and Behavior* in 2012.⁶

Based on this work, the Collaboration developed a community needs assessment survey that was sent to 104 CBOs across the three states in the fall of 2010. The survey received responses from 60 organizations. The CBOs sampled were those that provided supportive services to people living with HIV, rather than medical clinics and large community health centers. These CBOs have a higher level of contact and personal interaction with people living with HIV, who often look to agencies such as GMHC and the CAB organizations as their main support in living with HIV. Further, the Collaboration members felt that these CBOs probably faced greater needs in the

uptake of cancer programming than the larger medical clinics and community health centers, which have medical staff and greater resources for referrals. The survey's findings are now being analyzed by

the Collaboration's partners and will be submitted for publication by January 2013.

In September 2010, the Collaboration began a second project, "Feasibility of Tobacco Assessment and Intervention with Low-Income Persons Living with HIV-AIDS in Community-Based AIDS Service Organizations." This project tests a motivational biomarker feedback intervention that aims to reduce tobacco use by people living with HIV. Tobacco cessation was indicated by the CAB as an important area of cancer prevention programming that can be taken up by CBOs that work with people living with HIV, who use tobacco at a rate 2 to 3 times that of the general population (47-67% in different studies, compared with about 19% in the general population).

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Participants in the intervention will be solicited from CBOs in New York City. This project is based on the hypothesis that people who smoke tobacco might respond favorably to evidence that tobacco cessation increases lung capacity. Pilot research showed that people living with HIV who smoke cite improved breathing as one of the things they would most like to improve in their lives, and the intervention uses a spirometer to measure "lung age" and then recommends options such as calling the New York State Quit Line as a way to seek help in reducing tobacco use.

This project is in its early phases of development and should be completed by the end of 2013.

In September 2011, the Collaboration began a third project, "Increasing the Capacity of ASOs to Educate and Refer to AMC Trials" (INCASO). This project is being implemented over a two-year period from 2011 through 2013 and will test a program to increase the capacity of CBO staff to educate and refer their HIV-positive female clients of color to clinical trials run by the AIDS Malignancy Consortium (AMC). The AMC is a National Cancer Institute-supported clinical trials group founded in 1995 to support innovative trials for AIDS-related cancers. INCASO addresses important problems in clinical trials implementation with people living with HIV and minority populations, who are under-represented in clinical trials enrollment across most areas of medical research.

Among the biggest challenges is the history of exploitation of minority groups in clinical trials, such as the infamous "Tuskegee Experiment" on syphilis in Black men that was carried out from 1932 to 1972. In that experiment, U.S. Public Health Service officials tested interventions on Black men with syphilis without ever informing the men of their condition or the known treatments for it. Regulatory standards for the ethical treatment of clinical research participants have changed dramatically since the Tuskegee Experiment was exposed, but the effects of this and other such episodes continue to depress enrollment in clinical trials among minority populations. Without adequate enrollment of all persons who might benefit from a treatment innovation, however, it is difficult to understand the general effectiveness of new treatments across different population groups. Underenrollment thus holds back our ability to develop treatments that will enhance quality of life and increase life expectancy. The Collaboration hopes that INCASO can provide a model for using CBOs as sites to increase enrollment in AMC and other clinical trials that will benefit people living with HIV.

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With over three years of work developing new knowledge and training for CBO staff on the issues at the intersection of HIV and cancer, the Collaboration has gained a solid understanding of the high interest that CBOs serving people living with HIV have in cancer programming for their clients, the needs these organizations face in developing this programming, and the benefits it will provide for people living with HIV. In the next year, the Collaboration will use the experience gained across its first three projects to develop a more comprehensive intervention to train CBO staff in HIV-related cancer programming. This project will bring training to the tri-state area over a five-year period, evaluating the intervention in an effort to provide best practices that

can be implemented nationally.

The HIV/AIDS and Cancer Community Research Collaboration is an innovative model of community-based participatory research that demonstrates the positive gains to be made in academic-community partnerships. By bringing GMHC into the research partnership, investigators at MSKCC and CCNY gained both an inside perspective on service programming in a major CBO as well as access to other CBOs that helped to refine the Collaboration's research aims, questionnaires, and analysis. With community-based participation, the Collaboration meets CBOs where they are in contemplating the uptake of cancer programming with people living with HIV, while also providing methods for enhancing their capacities and programming in this area. The needs and interests of CBOs are apparent, based on the Collaboration's work. In 2012, the Collaboration's first article on our needs assessment was published in the journal *Health Education and Behavior* and it shows great interest among the Collaboration's CAB CBOs in increased cancer education and prevention



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programming in organizations that serve people living with HIV, as well as an eagerness to participate in research and integrate new knowledge about HIV and cancer into their work.⁷ Preliminary work on the community needs assessment of ASOs in the tri-state area confirms this interest while also finding that there are important differences in the capacities of small and large CBOs to develop cancer programming. Specifically, smaller organizations expressed greater needs for education and information about cancer and the links between HIV and cancer, as well as partnerships that can build programming and refer clients to culturally competent providers who can address their needs.⁸ With these findings and the other initiatives that the Collaboration is currently developing, we hope to provide a strong basis of knowledge and evidence on how organizations that serve people living with HIV can support their clients as the management of HIV as a long-term chronic condition becomes an increasingly important focus of work in HIV/AIDS care and prevention.

John A. Gidry, PhD is director of the Community Health and Research Department, whose work includes community based participatory research, social marketing, health promotion, capacity building and technical assistance, and programming for youth and women. His books include Globalizations and Social Movements (with Mayer Zald and Michael Kennedy) and Engaging the Community in Decision Making (with Roz Lasker). Prior to joining GMHC, Dr. Gidry designed, implemented, and managed "Pathways to Collaboration," a national community-based participatory research project funded by the Kellogg Foundation through the New York Academy of Medicine (2004–08).

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Gay Men's Health Crisis presents

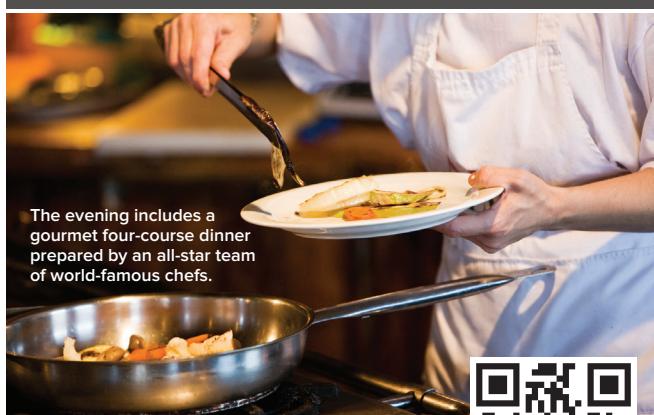
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