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# Queens Library HealthLink: Fighting Health Disparities through Community Engagement

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## Queens Library HealthLink: Fighting Health Disparities through Community Engagement

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**Keywords:** health disparities, cancer, Queens, partnership, community organizing, immigrants

### **Abstract**

Queens, New York is a diverse urban environment and home to many recent immigrants and low-income populations, which are known to have lower access to healthcare and are thus at higher risk for a wide range of negative health outcomes. Queens residents face serious cancer disparities, with late-stage cancer detection rates for breast, colorectal and prostate cancers far surpassing national averages. Developed to address such disparities, Queens Library HealthLink (HealthLink) is a four-way partnership that seeks to increase access to cancer screening, care and education in medically underserved neighborhoods in Queens. Through 20 of the 62 Queens Public Libraries, HealthLink organizes community members into Cancer Action Councils that develop and tailor interventions suited to community needs, assets and priorities, as well as perform evaluation of their work. This article describes the partnership, its program outcomes and case examples of successful initiatives in order to present HealthLink's relevance to other urban public libraries as a model for reaching broad, underserved audiences with health information and services.

### **Background**

Queens, New York is home to particularly diverse populations. Forty-six percent of Queens' 2.3 million residents are foreign born. Approximately one in eight lives in poverty and more than half speak a language other than English at home (U.S. Census Bureau, 2010). Queens residents represent almost every country in the world and speak an estimated 138 or more languages (McCall, 2000).

Research demonstrates that immigrants (Goel, et al, 2003) and other racially diverse populations (Shariff-Marco, Klassen, & Bowie, 2010) are less likely to be screened for cancer and suffer disproportionately from cancer and other negative health outcomes (Ward, et al, 2004). According to data collected at Queens Cancer Center, which is part of New York City's public hospital system, the rates of late stage detection for breast and prostate cancers are approximately six times the national averages (Goytia, et al, 2009). The cultural and linguistic diversity of urban areas, such as Queens, is associated with unique barriers to accessing healthcare, including a lack of culturally and linguistically appropriate services, fear surrounding immigration status, lack of health insurance and inability to pay for care (Freij, Rejeske, Gurvitch, Ferrandino, & Weiss, 2010; The Henry J. Kaiser

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Family Foundation, 2003). These challenges necessitate nontraditional settings for health outreach and services.

Queens Library HealthLink (HealthLink) is a five-year research program funded by the National Cancer Institute (RO1 CA119991-01, Rapkin PI) in 2006 to reduce disparities in cancer prevention and stage of detection in Queens. HealthLink is a collaborative initiative that connects a medical research institution, Albert Einstein College of Medicine (<http://www.einstein.yu.edu>), a cancer center nested in a public hospital system, Queens Cancer Center of Queens Hospital Center ([http://nyc.gov/html/hhc/qhn/html/center\\_excellence\\_cancer.html](http://nyc.gov/html/hhc/qhn/html/center_excellence_cancer.html)), and a cancer education and outreach organization, the Queens Region American Cancer Society, ([www.cancer.org](http://www.cancer.org)), with an urban public library system, Queens Library ([www.queenslibrary.org](http://www.queenslibrary.org)), to reduce cancer disparities.

In recent years, there has been heightened interest in utilizing public libraries as vehicles to reduce health disparities by providing access to health services and information and as venues for community health outreach programs. Common themes noted in literature include educating librarians to disseminate health information and improve health literacy (Humphreys, Ruffin, Cahn, & Rambo, 1999; Ruffin, Cogdill, Kutty, & Hudson-Ochillo, 2005), as well as using library computer labs as sites for training the public to use online health information resources (Pomerantz, Muhammad, Downey, & Kind, 2010). Because Queens community members view their local public libraries as trusted community centers and report actively utilizing them as sources of health information (Goytia, et al, 2005), HealthLink utilizes public libraries as bases for community organizing, data gathering, planning and implementation of local health promotion programs, as well as sites for dissemination of results.

HealthLink is grounded in a community-based participatory research (CBPR) approach. CBPR equitably includes community and academic partners in all stages of research, allowing both types of partners to share ownership and contribute expertise. CBPR emphasizes shared power, action for the mutual benefit of all partners, co-learning and capacity-building and builds on community assets to integrate knowledge gained through research with action to address health disparities (Israel, et al, 2010).

### **Program Design**

Two HealthLink Specialists (Specialists) with master's degrees in public health were employed by the Queens Library and were responsible for coordinating outreach, community organizing and project activities. Working through the public library gave the Specialists access to local facilities and resources and allowed them

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to benefit from the trust community members had in their libraries. In addition, the Specialists lent public health expertise to library staff in order to support customer service and provide library programming.

The Specialists' main responsibility was to identify and organize community leaders to form Cancer Action Councils (CACs). CACs were groups of community volunteers, representing community-based organizations, religious institutions, local businesses, cancer survivors, civic leaders, health providers and residents. CAC members used their knowledge of their respective communities to tailor programs to meet local needs and extend the reach and effectiveness of standard cancer education, screening and treatment services. CACs were responsible for asset and needs assessment, program planning, data interpretation and generating resources as needed.

The Specialists developed CACs in phases, with each of the two Specialists creating one new CAC every four months, until 20 were formed in library service areas throughout Queens. The 20 CAC neighborhoods were selected based on several criteria: percentage of the population living below the federal poverty level; percentage of the population that was foreign-born; percentage of the population that was African American, Hispanic and Asian (with the goal of including both heterogeneous and homogeneous neighborhoods); as well as cancer burden, defined by cancer incidence data.

One Specialist worked intensely with each CAC for one year, cultivating leadership and increasingly delegating responsibilities to CAC members with the goal of CAC sustainability in mind. During the first year, CACs gained skills, knowledge of resources and the professional connections needed to continue their work independently. Thereafter, CACs took on a more active role in their sustainability, turning only to the Specialists for guidance as needed. Ideally this process took approximately 12 months, but varied substantially by CAC. During the first year, each CAC received and evaluated data detailing cancer-related community needs. In addition, CACs conducted program evaluation with Specialists' support, giving members the opportunity to revise, refine and consider new approaches.

In line with the core principles of CBPR, the HealthLink model recognized that those who lived and/or worked in a neighborhood best understood the needs and cultures of their communities. Community leaders were best suited to reach their neighbors and social networks, especially with sensitive health information. By tailoring programs to local needs and inviting community members to perform outreach, CACs were able to maximize the impact that each intervention had in a given community.

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The activities of the CACs were evaluated through multiple methods. In addition to program evaluation performed by the CACs and Specialists, a research team, composed of staff and interns at Albert Einstein College of Medicine, continuously collected anonymous surveys in the 20 HealthLink neighborhoods. These surveys, which gathered information about sources of health information, library use, barriers to healthcare, adherence to cancer screening recommendations and insurance status, served not only to inform CAC program planning, but also evaluated CAC performance and reach. This paper utilizes data from program evaluation and case examples to highlight the impact of community engagement on library programming.

### **CAC Initiatives**

Since the first two CACs began their work in October 2007, more than 12,000 people have been reached through outreach and educational programs, and approximately 600 have been screened for cancer (and provided with follow-up care when needed). In addition to providing programs and connecting community residents to services, CACs have organized cancer awareness campaigns and created printed materials, such as neighborhood resource guides.

Although many HealthLink events take place within libraries, CACs are able to facilitate programming outside the libraries through their professional and social networks, as well. Holding events at community locations, such as public housing developments, churches, mental health day programs, community centers, and Head Start facilities, enables HealthLink to reach the broader Queens community. Over a four-year period, the CAC network has grown to include nearly 50 local community organizations and businesses. The HealthLink partnership has introduced and familiarized CAC members and their networks with cancer screening guidelines and services, as well as available public healthcare. Three examples of successful CAC initiatives are described below to illustrate the diversity and community-driven nature of CAC projects, as well as their impact on the community.

#### **Example 1: Connecting New Immigrants/Adult Learners and Public Hospitals**

The Flushing Library service area is home to approximately 80,000 people, 70% of whom are foreign-born. The largest subpopulation in Flushing is Chinese, but there are also considerable Spanish, Korean, Hindi and Russian-speaking populations. While the diversity of the Flushing community is one of its greatest assets, it is also associated with serious challenges related to accessing healthcare. Nearly 30% of

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residents speak English ‘not well’ or ‘not at all’ and one in five residents lives below the poverty level (New Americans Program, 2006).

The Flushing CAC identified students participating in Queens Library’s Adult Learner Program (ALP) as their intended audience. The ALP students are largely English for Speakers of Other Languages (ESOL) students, but also students of Adult Basic Education and Pre-GED classes. Given specific barriers to care that students expressed to ALP staff (See Figure 1), QCC was selected as an ideal partner to offer cancer prevention education and screening services (Sabino, Stevenson, et al, 2010).

Fear/confusion surrounding the healthcare system	Language barriers
Lack of knowledge and understanding about specific medical procedures and public health services	Various cultural and social norms surrounding health
Low levels of education	Low socioeconomic status
Lack of legal documentation	Lack of health insurance

Figure 1: Reported Barriers to Care

As a public hospital, QCC is accessible to all, regardless of immigration status, insurance status or ability to pay. More than 80% of the 17,000 patients obtaining care at QCC annually fall below the federal poverty level, and QCC provides service to patients who speak approximately 140 languages (Goytia, et al., 2009). The Flushing CAC determined that an ALP class visit to QCC would be the most effective way to introduce students to public health care options (Sabino, Stevenson, et al., 2010).

The class visit, tailored to their level of English proficiency, provided students with important cancer and smoking cessation information, awareness of QCC and available local resources, and even the opportunity to schedule screening appointments on-site. Individuals who chose to be screened were then registered with the public hospital system, allowing them to access other medical services as needed, on a sliding scale if they were uninsured. Students reported sharing the information they learned with their classmates, friends and family members. Subsequent class discussions revealed that bringing students who were apprehensive about public hospitals into QCC served to dispel common misconceptions (e.g., public hospitals offer a poor quality of care and are unsanitary)



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and reduced fear and confusion surrounding the healthcare system. Many ALP students had never been to a hospital, had little or no knowledge of routine screenings or were fearful to seek care due to their immigration status. After the visits, students felt much more informed. Qualitative data from ALP student progress logs suggested increased cancer-related knowledge. For example, an Arab woman in her mid-thirties reported, “I learned how to make an appointment with the doctor office. When we see the doctor we should bring ID with photo, insurance and appointment card.” A middle-aged Caribbean man explained, “I learned what age for women and men need screening test.” Another Caribbean male student in his forties reported, “I learned genetic causes of disease and the environmental cause of disease. I know some cheap medical centers” (Sabino, Stevenson, et al., 2010). Video recordings (<http://www.youtube.com/user/QueensHealthLink#p/u/6/TL9oBvFxz3I>) also suggest increased cancer knowledge (Queens HealthLink, June 2, 2010).



Figure 2: ALP Class Visit to QCC

### Example 2: Quilting for Cancer Awareness

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Pomonok is the small community where Flushing and Jamaica, Queens meet, predominantly Asian and African-American communities, respectively. The Pomonok community possesses diversity in age, income and ethnic diversity (New Americans Program, 2006). When one CAC member explained during a meeting that she had lost one of her quilting partners to breast cancer, the members of the Pomonok CAC conceptualized and implemented a project that they thought would interest people in their community: a commemorative cancer quilt.

The CAC publicized regular quilting classes for beginners at the local library and community center, which were taught by a Queens Library Customer Service Supervisor and Community Center Youth Administrator. In addition to teaching a new skill, the quilting classes also served as forums for formal lectures delivered by health educators, informal discussion about local cancer resources and social support for those going through traumatic cancer experiences. Word of mouth carried the project well beyond Queens. Cancer survivors, and others affected by the illness, traveled miles to attend classes; individuals from other states also contributed by mailing their quilt blocks.

Participants were grateful for the opportunity to share their cancer stories and hear those of their fellow quilters. One CAC member who participated in the quilting project expressed, “When I learned of this quilting project, I thought that I must do blocks in memory of two of my family members, my mother... and a sister... I’m just glad that their memory will continue to live on as we display this quilt in the borough of Queens” (Bridges, 2011).

The commemorative quilt eventually grew into four commemorative quilts, a book in which quilters could share photos and the stories behind their individual quilt blocks, a film in which they could share their cancer experiences verbally and a new cohort of CAC members to develop future initiatives. When informed of the project, the director of QCC immediately offered exhibit space within the hospital so the quilts could be shared with the larger Queens community.

Upon completion of the four quilts, the Pomonok Community Library Manager reflected:

As a HealthLink Library, our mission is to encourage people in any and every way possible to embrace healthy lifestyles, to educate themselves on both health and disease, and most importantly, to maintain an ongoing relationship with their doctor...[This project led to] a number of neighborhood people coming together in an old-fashioned quilting bee. These women were both young and old, ranging from college students to those in their 80s and older. Some were long time friends, but most were strangers to each other. But they all share one thing in common: They had all been intimately

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impacted by cancer, either personally or through the ordeal of a beloved family member or friend. As the women of Pomonok worked on their individual quilting blocks, they continued the healing process within themselves. They laughed, they cried, and in the end they created several magnificent quilts representing 18 different cancers. (Sharon Banks, 2010)



Figure 3: Quilting for Cancer Class at Pomonok Library



Figure 4: Pomonok Commemorative Cancer Quilt

### Example 3: Entertainment for Your Health

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It is often difficult to motivate participants to attend a program about cancer, due to existing fear and stigma surrounding the illness. However, library staff members who participate in the Pomonok CAC pointed out that entertainment programs attract large audiences. Drawing upon this knowledge, they invited the neighboring Central Library CAC to join forces to design “Entertainment for your Health,” a unique combination of health information, music and dance. The Pomonok and Central Library CACs were HealthLink’s first two CACs formed. One hundred twenty-five individuals attended the program on October 3, 2009 at the Central Library in Jamaica, Queens.

A local surgeon, known for his ability to connect with audiences through his easy-to-understand lectures, was invited to provide participants with basic cancer information. Following his presentation, a local, well-known senior dance troupe of vibrant and energetic performers, the Rockaway Revue, provided the entertainment portion of the program. One audience member shared feedback with one of the Specialists immediately following the program: “Seeing the seniors...perform and joining in with them was such an awesome experience for me” (Michel, 2009). Audience members were receptive of the information provided by the doctor, as well, and requested a follow-up program, which CAC members also coordinated.

As one of HealthLink’s first large-scale events, “Entertainment for your Health” inspired new ways of advertising local programs. For example, one CAC member appeared on a weekly NAACP live television show and another wrote a rap song to advertise the event, which she performed with fellow CAC members. A video of this rap was posted on YouTube (<http://www.youtube.com/user/QueensHealthLink#p/u/11/ZeeYWH3V6Js>) and led to the development of the Queens Library HealthLink YouTube Channel (Queens HealthLink, 2010).



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Figure 5: Entertainment for your Health

### Implications for Libraries

Community involvement in program planning and implementation gives libraries the potential to impact their patrons in new and potentially life-saving ways. Recognizing community leaders' knowledge and expertise enables public libraries to connect with diverse and otherwise difficult to reach audiences. For example, CAC members designed both "Entertainment for your Health" and the commemorative cancer quilting project to present information in a manner they knew their neighbors would find interesting. As a result, these programs attracted considerable participation and media attention. Participants were entertained while receiving crucial health information and social support.

Partnerships like HealthLink also improve community capacity—the characteristics of communities that affect their ability to identify, mobilize and address social and public health problems (Goodman, et al., 1998). Utilizing public libraries to bring CAC members together for networking and other capacity-building events (e.g., Cancer 101 Train-the-Trainer Programs, Grant Writing Workshops and Health Advocacy Trainings) cultivates multiple leadership roles. Through these types of events, emerging leaders successfully engage and mobilize their fellow community members (Sabino, Michel, et al., 2010). This leads to positive feedback from neighbors, the media and the larger community. Queens Library HealthLink has been recognized by the American Library Association, Urban Libraries Council and the New York State Regents Advisory Council on Libraries for its innovative and impactful approach to providing library services.

Developing and maintaining relationships with health organizations and service providers in the community can be built into existing program infrastructure within libraries. For example, programs linking Queens Library's Adult Learner Program and Queens Cancer Center could be permanently incorporated into ESOL curricula, not only aiding in the sustainability of the initiative, but also providing opportunities to systematically meet the needs of the ESOL and Adult Basic Education students.

### Conclusion

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HealthLink's success in reaching and providing programs to diverse, underserved populations suggests that public libraries can serve as ideal places for community organizing and outreach to address cancer disparities. They are natural settings for the development of culturally relevant outreach, programming and service delivery. HealthLink's four-way partnership model has the potential to be adapted appropriately and replicated in other communities that possess similar institutions. If a comparable partnership is not feasible, smaller scale initiatives that reflect the aforementioned case examples could potentially be implemented. Disparities in health are characteristic of all urban environments and represent a critical social justice issue (Leisey, 2008). HealthLink's outcomes suggest that urban libraries have the potential to not only serve their communities, but transform them.

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