**Memorial Sloan-Kettering Cancer Center**
**IRB Protocol**

**IRB#: 07-027A(2)**

# The Queens Library HealthLink Project

MSKCC NON-THERAPEUTIC/DIAGNOSTIC PROTOCOL

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IRB
PB

**Amended: 7/8/08**

**Collaborating Institution (s):**
**(If applicable)**

The Queens Cancer Center (QCC)

The Queens Borough Public Library System (QBPL)

The American Cancer Society of Queens (ACS)

Caritas Health Inc. DBA Mary Immaculate Hospital (MIH)

## 1.0 PROTOCOL SUMMARY AND/OR SCHEMA

The Queens Library HealthLink project is a five-year study to determine whether community involvement in cancer control can improve and sustain rates of screening and behavior change, above and beyond results achieved through more traditional public health measures. In this project, public library branches provide a base of operations for organizing communities, gathering data, planning and implementing local health promotion experiments, and disseminating results. The project will work with 20 of the 63 public library branches in Queens, serving neighborhoods with the lowest socioeconomic status, high rates of late-stage cancer, and a mix of ethnic compositions. In each community, we will follow a common approach to collaborative program development based on our ACCESS model (Rapkin et al., 2006) to determine the health promotion and cancer screening activities that are best suited to local priorities, cultures, preferences and opportunities. With libraries as our base, we will form twenty “Cancer Action Councils” comprising networks of local organizations and stakeholders. Over twelve months these Councils will work with “HealthLink Specialists” on our team to develop programs and services to benefit a wide range of residents within each target community. Although we anticipate that each community will have different needs and require different strategies, we expect that this intensive process of collaborative program development will lead to sustained improvements in key cancer control outcomes. Both proximal and distal indicators of primary program outcome are used to gauge the direct impact of HealthLink activities on information requests, screening and referral, as well as the diffusion of benefits to the wider community. Organizations collaborating on this project include the Queens Borough Public Library System, the American Cancer Society-Queens Division, the Queens Cancer Center, Caritas Health Inc. DBA Mary Immaculate Hospital, and Memorial Sloan Kettering.

The Queens Library HealthLink Project is a population-based intervention, intended to improve cancer control at the community level. In order to evaluate this intervention, we use an interrupted time-series design with multiple baselines. In this design, each community serves both as its own control and as a comparison for other communities. The overall project timeline and design is presented in **Figure 1**. In this Figure, time progresses from top to bottom, over 60 months. Colored sections represent concurrent control, experimental and evaluation activities.

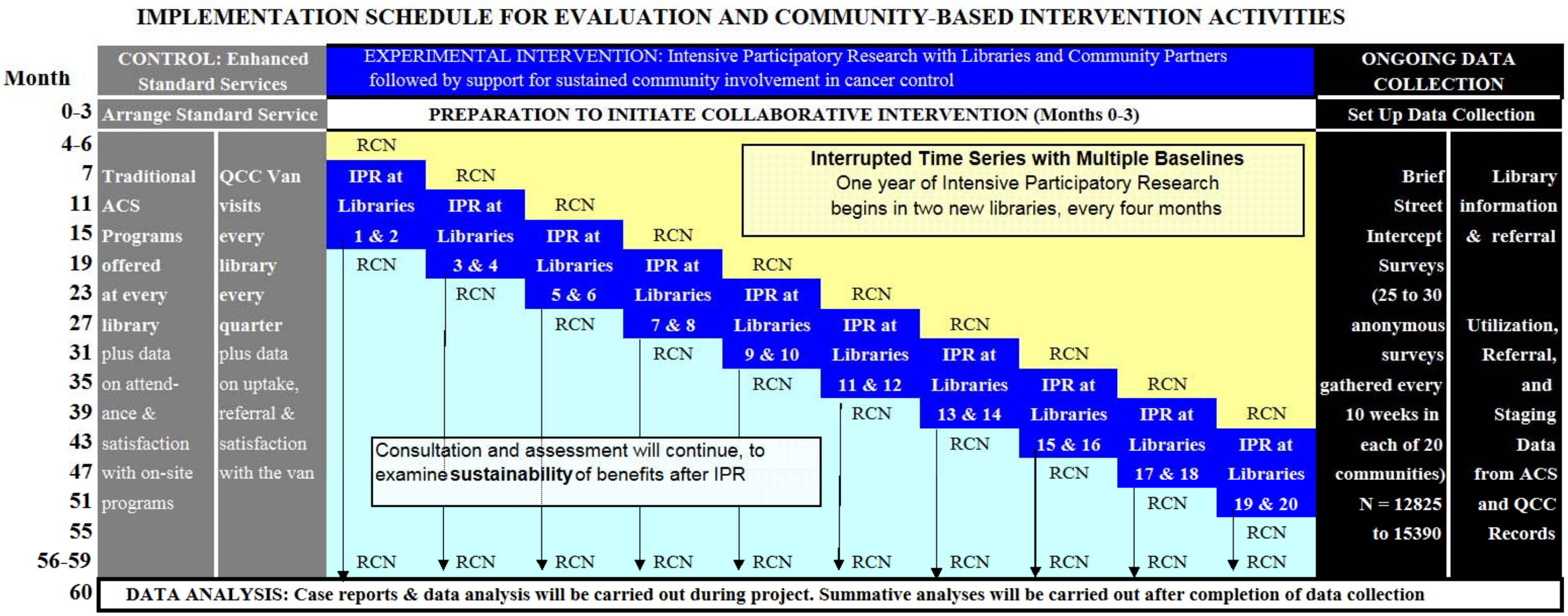
As Figure 1 depicts, the first three months of the project will be a start-up period, during which time we will collect our first wave of data on cancer referral, screening and utilization. Starting in month 4, we will provide training and materials to staff of all 20 branch libraries, so that libraries can begin to offer on-going access to a wide variety of available cancer education, information, referral, and screening programs. This constitutes the **control condition**. Services available in the control condition constitute an enhanced standard of care, in that they are all already available to the Queens Community, but they are rarely organized and packaged to be readily and consistently accessible at a single site. These services include low-reading difficulty educational materials and on-site programs offered by the American Cancer Society, screening through the NYS DOH Healthy Living Partnership, regular visits by the Queens Health Network Mobile Cancer Screening van, and follow-up care available through the Queens Cancer Center. Under the control condition, all programs and services will be delivered following usual procedures: Although the branch libraries will serve as local hosts, programming is largely set in advance, with minimal community input. This model of service delivery is referred to as a "top-down" approach, in the sense that fixed services are offered by the public health experts such as the ACS, MIH and QCC, with community members as relatively passive recipients. Based on our multiple baseline design, neighborhoods will receive only control condition services for between 3 to 36 months.

Under the **experimental condition** all of the services in the control condition remain available, supplemented with an intensive, year-long process of community organizing, participatory research, program planning and implementation. The experimental intervention will be organized by library-based "HealthLink Specialists," trained to implement an expanded version of the ACCESS program development model (Rapkin et al, 2006). The experimental intervention includes: the formation of the local "Cancer Action Council" (CAC); collection and presentation of local surveillance data to inform program planning by CAC; outreach measures to extend the reach and effectiveness of the standard ACS and QCC services; and the initiation of new cancer programs and services to address unmet needs identified by the CAC. Over a twelve month period, each CAC will receive information on community needs related to cancer, as well as feedback about their results of their programs. Thus, each CAC will have opportunities to revise and refine its strategies, and to test new approaches. As Figure 1 shows, the intervention begins in the first two communities in month seven. Branch libraries will continue to cycle on to the experimental intervention every four months, as earlier communities complete their intensive collaboration with the HealthLink Specialists.

After this one year process of intensive planning is finished, we want to examine the **sustainability** of our community planning approach and any on-going impact on rates of cancer screening and health behavior. Although the HealthLink Specialists will discontinue their hands-on involvement with each CAC, we expect the CAC to remain in place as an established body to guide community cancer control efforts. The idea is to see whether CACs can continue their work of community organizing and planning autonomously, with appropriate interaction with and support from public health providers. Ideally, the activities and role of the CAC will be cemented in place after one year, making for a seamless transition after completion of the intensive intervention. CACs may continue their activities in any way they see fit. In order to support sustained gains, all enhanced standard (control condition) services will remain in place. CACs may also initiate consultations with the HealthLink Specialists, and they may request local surveillance data, as they deem necessary. We will examine whether CACs stay in place and for how long, how their membership and activities change, and whether and how they continue to work with HealthLink Specialists, ACS, MIH, QCC and other public health providers.

As Figure 1 depicts, our **evaluation** (Ongoing Data Collection) will continue before, during and after intensive collaborative research and planning, in order to determine whether and how the intervention promotes and sustains changes cancer screening and health behavior. Ultimately, we want to determine whether and how the ACCESS model can be used to get community stakeholders actively and meaningfully involved in monitoring and addressing access to cancer screening and prevention services, to improve public health outcomes.

FIGURE 1: Protocol Schema



### IMPLEMENTATION SCHEDULE FOR EVALUATION AND COMMUNITY-BASED INTERVENTION ACTIVITIES

| Month | CONTROL: Enhanced Standard Services | | EXPERIMENTAL INTERVENTION: Intensive Participatory Research with Libraries and Community Partners followed by support for sustained community involvement in cancer control | | | | | | | | | | ONGOING DATA COLLECTION | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 0-3 | Arrange Standard Service | | PREPARATION TO INITIATE COLLABORATIVE INTERVENTION (Months 0-3) | | | | | | | | | | Set Up Data Collection | |
| 4-6 | | | RCN | | | | | | | | | | | |
| 7 | Traditional ACS Programs offered at every library plus data on attendance & satisfaction with on-site programs | QCC Van visits every library every quarter plus data on uptake, referral & satisfaction with the van | IPR at Libraries 1 & 2 | RCN | | | | | | | | | Brief Street Intercept Surveys (25 to 30 anonymous surveys gathered every 10 weeks in each of 20 communities) N = 12825 to 15390 | Library information & referral |
| 11 | | | | IPR at Libraries 3 & 4 | RCN | | | | | | | | | |
| 15 | | | | | IPR at Libraries 5 & 6 | RCN | | | | | | | | |
| 19 | | | RCN | | | IPR at Libraries 7 & 8 | RCN | | | | | | | |
| 23 | | | | RCN | | | IPR at Libraries 9 & 10 | RCN | | | | | | |
| 27 | | | | | RCN | | | IPR at Libraries 11 & 12 | RCN | | | | | Utilization, Referral, and Staging Data from ACS and QCC Records |
| 31 | | | | | | RCN | | | IPR at Libraries 13 & 14 | RCN | | | | |
| 35 | | | | | | | RCN | | | IPR at Libraries 15 & 16 | RCN | | | |
| 39 | | | | | | | | RCN | | | IPR at Libraries 17 & 18 | RCN | | |
| 43 | | | | | | | | | RCN | | | IPR at Libraries 19 & 20 | | |
| 47 | | | | | | | | | | RCN | | | | |
| 51 | | | | | | | | | | | RCN | | | |
| 55 | | | | | | | | | | | | RCN | | |
| 56-59 | | | RCN | RCN | RCN | RCN | RCN | RCN | RCN | RCN | RCN | RCN | | |
| 60 | DATA ANALYSIS: Case reports & data analysis will be carried out during project. Summative analyses will be carried out after completion of data collection | | | | | | | | | | | | | |

**Interrupted Time Series with Multiple Baselines**
One year of Intensive Participatory Research begins in two new libraries, every four months

Consultation and assessment will continue, to examine **sustainability** of benefits after IPR

RCN = Library **readiness**, **capacity**, and community **needs** assessment, includes interviews with key informants (librarians and community opinion leaders), observational assessment of library environments, focus groups to determine appropriate education and outreach strategies, and library-based collection of additional anonymous intercept surveys to determine how well the groups we are reaching represent the broader community
We will update information at the completion of intensive planning and again at the end of the project to examine the time gradient of sustainability

IPR = Experimental **Intensive Participatory Research** starts with formation of the local Cancer Action Council & involves one year of joint program planning & testing

Note: Throughout the project, we will also gather intervention process data to determine (1) how much consultation and assistance is required from project health-link specialists; (2) how much advanced work and support libraries and their partners are able to provide ACS, and (3) how much libraries and their partners are able to do the front-end work required by the QCC van. These variables would affect possible areas of costs and savings that would be involved in expanding and/or replicating this program.

## 2.0 OBJECTIVES AND SCIENTIFIC AIMS

Our specific aims and research questions are:

1. To determine whether community-based participatory action research leads to more effective cancer prevention and control in underserved communities compared to traditional, "top-down" programs.

2. To examine how communities engage in the participatory research process, in order to develop locally tailored initiatives for cancer education, prevention and control.

3. To examine whether and how long program effects are sustained after completion of the intensive collaborative program planning intervention.

## 3.0 BACKGROUND AND RATIONALE

### 3.1 Background

*Queens County Overview*

Queens County is one of the five boroughs of New York City, and is well known for its kaleidoscopic demographic characteristics. According to 2000 U.S. Census data, Queens is the second-most populated county in New York State, with more than 2.2 million residents, and continues to be the fastest-growing county in New York State. If Queens were an independent municipality, it would rank as the fifth-largest city in the U.S., just behind Chicago in terms of total population. (U.S. Census, 2002, Ranking Tables, S06) The borough is one of the most tightly packed urban areas in the U.S, with a predominance of multi-family structures and a density greater then 20,400 residents per square mile. Queens is also a county of numerous distinct neighborhoods – many of them former Colonial-era townships.

Of central importance to this protocol is the unprecedented ethnic, linguistic and cultural diversity that makes Queens easily the most diverse county in the nation. Overall, minority groups comprise 67.1% of the total population, with significant representation from subgroups within each of the major ethnic subgroups. Queens has seen an influx of new residents from virtually every nation of origin, including Mexico, China, the Philippines, India, Korea and El Salvador, among others (Census, American Community Survey Profile, 2002); more than 47% of all Queens residents are foreign born, a level of immigration surpassed only by Miami-Dade County in Florida, at 51%. Slightly more than 25% of Queens residents are not U.S. citizens and 53% of residents speak a language other than English in the home, with more than 27% of residents speaking little if any English. In fact, New York City public schools serve children in

Queens who speak at least 150 languages and dialects (NYCDOE, 2004). Queens also ranks eleventh among counties nationwide for its total of African American/black residents, with a population of more than 446,000. Nearly one in six Queens residents lives in poverty. The borough also continues to struggle with educational attainment, with about three-quarters of residents having completed high school or equivalency exams but only 15% completing four-year College. Many immigrants are illiterate in their native languages, and a majority of residents have limited English proficiency and poor health literacy.

### *The Queens Cancer Experience*

In 2004, the American Cancer Society estimated a continued trend of increasing cancer incidence for Queens, as well as the nation, which combines decreasing mortality, for all sites for men and women combined (ACS, 2004; Weir, et al., 2003). In terms of new diagnoses, in the late 1980's there was an average of 8,868 cases of cancer diagnosed per year; in 1996-2000 the average was 9,725 new cases per year. This increase in number of cases is not just a reflection of population changes, as age-adjusted rates increased during this time for both men and women. For men, incidence increased from 423 per 100,000 units of population to 514 per 100,000 and for women from 375 per 100,000 to 406 per 100,000. In contrast, long-term improvement in survivorship has reduced death from cancer by 11.6% during the same time-period, from 4,213 deaths per year in the late 1980s to 3,725 deaths per year for 1996-2000 (NYS Cancer Registry). New York State Cancer Registry data for 1996-2000 show the majority of cancer cases and cancer death in Queens results from four primary cancer sites, including breast, prostate, lung/bronchus and colorectal cancers. A closer look shows a more complex picture, suggesting that progress has not come to all residents. Indeed, Queens has a lower rate of early stage detection than the rest of New York State, and segments of the population experience elevated rates of late-stage detection.

Data provided by the Queens Cancer Center reveal a close up view of the cancer disparities between Queens and the U.S. Due to the catchment areas served by its parent organization, the Queens Health Network (QHN), QCC serves an overwhelmingly minority population (above 80%) which includes more than 100 different ethnic groups. This population suffers from cancer disparities common among the medically underserved (Ward, et al., 2004). This population includes many immigrants, who are the least likely to get screened (Goel, et al., 2003). In all major cancer sites, QHN has seen an increased likelihood of late state presentation and increased rates of mortality. For instance, the rate of late-stage detection found at QHN for breast cancer is almost three times the national average, and nearly twice the national average for prostate and rectum cancers.

## 3.2 Rational

*Concepts and Theoretical Models Guiding the Queens Library HealthLink Project*

The complex portrait of health disparities in Queens suggests important lessons. The data from the Queens Cancer Center show very high rates of late stage diagnosis for some cancers. Yet disparities do not break neatly or simply along racial or ethnic group lines. For example, even though gross differences among racial/ethnic groups in mammography rates have closed, the fact that about one in four women are still not adhering to recommended screening guidelines suggests that we need to look at factors that interact with race. Similarly, comparable rates of smoking among racial/ethnic groups do not mean that factors that sustain this behavior are comparable or that these groups would respond to identical interventions. Thus, informed by the work of Freeman (2004), the premise behind our proposed participatory approach is that the best way to address racial, ethnic and class related disparities is to work at the local level, to account for a mix of influences.

This project is guided by Berger and Neuhaus' (1996) theory of community empowerment through the development of mediating structures, as well as work by Wandersman (2003) on community science, and work by Israel and colleagues (1998), Minkler and Wallerstein (2003), and Lasker and Weiss (2003) on community partnerships. Our group has applied these concepts in participatory research on cancer awareness and screening through our ACCESS cancer education and outreach project (Rapkin et al., 2006), and we have also written about the utility of this model as an alternative to paternalistic approaches to the development and dissemination of preventive community interventions for HIV (Rapkin and Trickett, 2006). The ACCESS model is founded on the observation that “one-size-fits-all” programs administered and controlled by centralized service delivery bureaucracies have failed to meet the needs of underserved communities (cf. Green, 2001). As an alternative to this “top-down” approach, we posit that solutions to problems of health access and health behavioral change must be crafted at a local level, in response to local history, ecology, and culture(s) (Syme, 2004).

In this model, the role of central institutions (e.g., the municipal health care system, the federally funded cancer screening program, the NCI-designated cancer center) is to empower community-based organizations to develop, administer and evaluate locally tailored programs that fulfill central policy objectives (e.g., more screening, less smoking, better primary care access). We contend that this approach is the most potent way to ensure cultural sensitivity and appropriateness in efforts to address health disparities (Jumper-Thurman, et al., 2004; Yoshikawa et al., 2003). Further, urban neighborhoods have their own attributes that influence diffusion of information and program participation, and thus the application of our model. These neighborhood attributes are both structural (e.g., employment rates, public assistance receipt, family concentration, ethnic diversity, residential instability) and related to social organization (e.g., social cohesion and trust, dilapidation, deviance and crime) (Cutrona et al., 2005; Browning & Cagney, 2002; Kirby & Kaneda, 2005; Leventhal & Brooks-Gunn, 2000; Ross & Mirowsky, 2001; Sampson et al., 1997).

For this community empowerment model to work, a number of critical elements must be in place (Foster-Fishman et al., 2001; Lantz, 2001). First, there must be provisions to develop and sustain collaborative partnerships between mediating structures and central institutions. This involves provision for joint planning and problem definition over a sustained period. Second, these local organizations must have access to enhanced resources and technical assistance needed to fulfill their role as mediating structures. Third, there must be on-going evaluation of program process and outcomes, to understand whether and how locally crafted strategies are working, and to revise plans as needed. As we and others have noted (Rapkin and Trickett, 2006; Wandersman, 2003; Green, 2001), this model of public health practice is quite consonant with the participatory action research paradigm (Arcury, 2000; Schulz et al., 2002).

In participatory research, researchers and community members collaborate on an on-going basis in an iterative process of problem definition, problem solving, and evaluation (Williams and Lykes, 2003), which may involve building research or programmatic skills, development of necessary tools, mobilization of new resources, and broadening and deepening relationships (Foster-Fishman et al., 2001). This model is particularly applicable to addressing the problem of cancer-related health disparities, which requires sustained adherence to preventive health behavior and screening regimens, integrated pathways to care that may be readily accessed if and when needs arise, and adaptability in the face of emerging technologies and evolving recommendations for optimal self care. Additionally, drawing from the social disorganization framework (Elliott et al., 1995; Sampson & Groves, 1989; Shaw & McKay, 1942), we hypothesize that community organizing may serve to offset neighborhood factors that impede use of health programs and services. The Queens Library HealthLink project is poised to implement this empowerment model in a targeted, community-specific manner through the library system, to identify and address disparities in prevention, screening, and care related to the major cancer diagnoses that affect Queens County.

### *Rationale for Participatory Health Promotion Research in the Public Library System*

Every state and each territory in the U.S. has a public library system. Research suggests that libraries possess characteristics that potentially make them ideal settings from which to conduct health outreach activities (Pasick, Hiatt and Paskett, 2004). Many public libraries are embedded in underserved communities and are an important resource to community residents. They provide information in languages spoken in that community, such as information about employment opportunities and available social services; give access to computers and the Internet; are a venue for public gatherings, such as workshops and study groups; and often provide desirable programs for adults and youth free of charge, including English as a Second Language (ESL), literacy courses, and various after-school programs (American Library Association, 2004; Queens Borough Public Library, 2005).

Given libraries' connection to local community culture and history and their role as trusted repositories of information of all sorts, these settings are uniquely positioned to provide health information to medically underserved populations as well as to facilitate outreach for screening and other kinds of preventive care (e.g., vaccinations). Individuals who are medically underserved often experience multiple health care problems and needs (Schiffman et al., 1991; Hoffman et al., 2004). Thus, any health-related inquiry to a librarian offers an opportunity to connect underserved patients to multiple systems of care.

The Queens Borough Public Library System in particular, offers an ideal setting for this project because of its established leadership role in reaching the diverse, medically underserved communities of this borough. The Queens Library has high penetration into these underserved communities, with 63 branch libraries and 6 Adult Learning Centers. Librarians speak the language(s) of the communities they serve and are a trusted source of information. Customers now have access to books and other library materials in 78 languages. The system is widely used, with the largest circulation of any library system in the country every year since 1994. A population-based survey commissioned by the Library's Board of Trustees conducted in 1994 indicated that 78% of Queens residents had visited a library branch in the past 12 months. 87% of Chinese respondents, 64% of Hispanic respondents and 61% of African American respondents were Queens Library card holders. In 2003, there were 862,000 active borrowers and 478,000 people attended 22,000 free programs offered by the library. Volunteers donated 52,000 hours of service, including an adult literacy program (http://www.queenslibrary.org/About/index.asp).

Review of the literature indicates that very little work has been done to examine the potential role of public libraries in cancer screening, diagnosis, and clinical trials. Public health initiatives carried out with academic, medical and/or public libraries as partners have focused largely on improving information delivery via the Internet (Voge, 1998; Guard et al., 2000), and assessing the perceptions of librarians in their role as health information professionals (Wood et al, 2000; Scherrer, 2004). Additionally, there are a number of articles about various ways to work with libraries to address information needs of the community (Guard et al., 2000; Nicholas & Marden, 1998; Hollander, 2000). Another topic of recent interest is librarian training in health care and information diffusion (Wessel, Wozar & Epstein, 2003).

To realize the potential of libraries as points of entry into multiple systems of health care, a number of challenges have to be addressed. Because public libraries serve many missions, fostering access to care would have to be coordinated with many other tasks. Libraries are dense information environments, so health-related programming and activities may not stand out against the backdrop of many other offerings. Libraries would need to educate their patrons and communities about the possibility of obtaining health information and access. For this reason, our project introduces HealthLink

Specialists into the libraries, with specialized training and support to mobilize the library and its surrounding communities in effective tailored health promotion activities.

### 3.3 Work Accomplished/Preliminary Studies

*The MSK ACCESS Program*

The ACCESS model was developed by Rapkin, Massie and colleagues (Rapkin, et al., 2006) to guide our efforts to partner with community-based organizations to develop and sustain cancer-related awareness and screening programs (R25 CA 66812, Massie, PI). ACCESS provides a general approach for carrying out and evaluating public health promotion partnerships between community organizations and academic institutions. In implementing our initial ACCESS grant, we worked with representatives of 67 eligible community-based organizations, including religious institutions, neighborhood organizations, senior centers, hospital and community-based clinics, arts and cultural organizations, residential mental health treatment facilities, school-based programs, and one drug treatment program.

The ACCESS model involves a cyclical process of information gathering, participatory planning, implementation, evaluation and re-assessment (see Appendixes B.1, B.2, and B.3). When we started the ACCESS project, we were concerned that agencies serving the most under-resourced and disenfranchised communities were likely to have the fewest resources for taking on new program areas, like cancer screening. Thus, our model was designed to be highly scalable, both in terms of the kinds of consultation and support offered to agency participants, and the kinds of programmatic goals agencies set out to achieve. This sort of adaptability to local circumstances will also be critical for work in the library system. Several key features of the ACCESS model will be adapted to support participatory research activities in this project, including:

- Setting Readiness Assessment: ACCESS staff amassed data about each participating site from multiple sources, including all agency contacts, site visits, agency literature such as brochures or annual reports, and formal informational interviews. We used these data to determine an agency's initial readiness and capacity to carry out cancer related programs and activities along dimensions ranging from consistency with agency mission to physical facilities. Reliability was excellent for most dimensions. Out of 64 separate coding decisions, kappa exceeded .90, for 33, exceeded .80 for another 15, and exceeded .70 for another 9 (kappa ranges from –1 to 1, and chance agreement is 0). The codebook, coding materials and detailed reliability results can be found in the Appendix (see Appendix B.4).

- Community Barometer Needs Assessment: Working together, site liaisons and ACCESS outreach staff would gather data from potential participants in cancer-related services at the agency, using a brief survey instrument that we assembled to gain information necessary for program planning. The anonymous Barometer included information about health service use, cancer history, screening adherence, knowledge of breast cancer signs, beliefs and fears about cancer, and perceived risk, as well as preference for various programs and basic demographics. Barometer findings and discussion of its use as a planning tool are described in Lounsbury et al. (2006).

- Program Planning Meetings: Using available data, site liaisons and ACCESS staff would meet to consider possible cancer-related activities for the agency. In order to prevent foreclosure on any given approach, we used a problem-solving paradigm to guide planning discussions, including problem identification, generation of alternative solutions, analysis of consequences for both clients and the agency, and development of means-ends plans. In our work in the libraries, these Program Planning meetings will be held with the Cancer Action Councils representing an even broader range of community perspectives.

- Consultation and Capacity Building: Agencies could receive technical assistance from ACCESS staff as needed to implement programs. Senior ACCESS investigators and post-doctoral fellows provided assistance in the following areas: development of formal program planning procedures (37% of participating agencies), creation of specialized data collection instruments or procedures (beyond the Barometer) (12%), assistance with local grant writing (10%), specialized curriculum development (9%), development of outreach strategies (7.5%), training in data analysis skills (6%) and assistance recruiting and orienting board members and community leaders to serve as project advisors (6%).

- Program Implementation: After completion of planning and capacity building, agencies were ready to implement programs of cancer-related activities. Activities varied widely in scope. Just over half of the agencies (53%) that we worked with implemented educational programs or events covering one or more of the following topics: general information about breast cancer and screening (49%), family risk and genetics (24%), breast self-examination (30%), obtaining mammography (18%), information on wellness and health promotion (13%) and other related topics (e.g., doctor-patient communication, volunteerism, caregiving) (12%). A smaller proportion of CBOs (18%) sponsored events on-site where women were screened in mobile mammography vans (9%) or trained in breast self-exam (9%). The flexibility of the ACCESS model allowed sites to make best use of existing resources and to meld cancer-related activities with each agency's culture and character.

- Program Evaluation: In order to better understand factors that influenced CBOs' level and pattern of cancer-related activity, we examined whether measures of baseline setting readiness and capacity affected cancer-related activities. Further, we also examined whether capacity affected the type and extent of new cancer-related activities directly or indirectly by influencing the degree of contact the agency had with ACCESS staff. In statistical terms, we wanted to determine whether contact with ACCESS mediated the influence of CBOs' initial capacities on the cancer related activities that they undertook. Briefly, we found that agencies with high baseline capacities tended to engage in more on-site screening and further capacity building. Capacities that affected these outcomes included prior staff experience in health education and outreach, assignment of specific staff members to carry out cancer-related programs, and agency accessibility. Detailed results of these analyses may be found in Rapkin et al. (2006).

*The "ASK ME Campaign"*

ACS, QCC and MSK worked alongside the Queens Borough Public Library to leverage the library's extensive reach in the borough to achieve mutual health promotion objectives. Specifically, in 2003, we were brought together by the ACS to work on our first four-way collaboration, to increase utilization of the CDC's Breast and Cervical Cancer Early Detection Program, which is administered in Queens by the ACS. Our goal was to deploy the "ASK ME Campaign," which used a variety of materials and outreach to promote breast cancer screening among uninsured or underinsured women. QBPL librarians were important partners in designing the implementation of this campaign.

The first phase of the campaign consisted of training for librarians on breast health awareness and breast cancer screening. This training was conducted in September 2003 by QCC director Dr. Kemeny, supported by ACS staff. Drs. Elliott Goytia and Rapkin conducted the evaluation. Senior Librarians from 59 of the 63 Queens Public Libraries attended the training. A description of our early experiences in implementing the first phase of this project were presented at the 2004 Meeting of the American Library Association (O'Connor, 2004) and are detailed in a paper published by the journal Cancer, Culture and Literacy (Goytia et al., 2005). Briefly, results indicate that Queens librarians are seen as a significant resource in their communities for information about a variety of health and disease prevention topics. Although health outreach to medically underserved residents had not previously been a primary mission of these libraries, many librarians saw great need in their communities and the vast majority felt that assisting residents in getting access to services for early cancer detection should be a major priority for the Library. Librarians reported that they were willing to actively participate in health outreach campaigns, and that they were comfortable working with patrons in this way. They also felt that participation in this type of health intervention would not take too much time from their current work duties. Despite these positive indications, we also found that many libraries lacked necessary capacity to be effective partners in a health outreach effort. Librarians were misinformed about breast cancer and screening services. They also did not make full use of available referral, including the ACS and Cancer Information Services. Many librarians recognized their need to be better informed, and a number indicated that they wanted additional training about breast cancer or other health topics. Librarians also said that they would like more assistance meeting the needs of the communities they serve (Goytia et al., 2005).

Indeed, when we moved to implement the ASK ME Campaign in the libraries in late 2003-early 2004, we found that 1/3 of the branches carried out the program as intended, 1/3 partially implemented the program, and 1/3 failed to implement the program at all. Even in those sites where the campaign was conducted as intended, uptake of consumers was quite slow (Goytia et al., 2005). As a result, the QBPL, ACS and MSK began a process of joint planning to identify challenges involved with implementing health outreach in the libraries. We determined that it would be necessary to provide the public library system and its employees with the capacity and specific tools they need to begin to address disparities in care. This included up-to-date, accurate health and disease information, information on public health programs specifically designed for at risk or medically underserved populations that the library serves, and information about how to use referral resources effectively. Librarians also requested more seminars and community workshops conducted by health professionals who are trained in cultural and issues of the particular community. We also saw the need for resources, skills, and support to conduct important health outreach efforts. Lessons learned through implementation of the ASK ME program guided several decisions in shaping this project: to hire HealthLink Specialists to work in and with participating branch libraries, to offer substantial technical assistance to the libraries, and to provide direct on-site referrals to screening, primary care and the QCC.

*Collaborative Projects among Core Partners that Support the Present Protocol*

About three years ago, the organizations collaborating on this project began working together on a regular basis to address common objectives and lend support to various activities. We have established a number of joint cancer control projects and services in the Borough of Queens. These on-going projects provide unique opportunities to support the outreach and evaluation activities described in this protocol:

- Mobile screening van: QCC received funds from various sources to purchase a mobile screening van to serve the borough of Queens. The van was customized to QCC's specifications and delivered in summer 2006. The van will be deployed as a mobile "one-stop shopping" unit for cancer awareness, screening and referral. In addition to mammography, an exam room on the van will permit pelvic exams and Pap smears, and resources for patient education. In addition, patients served by the Van will receive a referral into primary care, if needed. The Queens Health Network Van will be an outreach vehicle for Queens Cancer Center, and will have capacity to provide over 4,700 screenings per year. Given the fortuitous concurrence of the arrival of the van with the initiation of the library research project, we were able to arrange a schedule of van visits to QBPL sites that correspond to the needs of the present protocol. Rapkin and colleagues have worked with QCC to develop routine forms and databases for tracking utilization of all van services and referrals. These anonymous measures are incorporated into this protocol. In addition, QCC will develop a separate protocol to track health utilization of community members served by the van.

- NYS Department of Health Tobacco Cessation Program RFA: QCC, ACS and MSK joined together to respond to a grant designed to increase physician awareness of clinical guidelines for treating tobacco dependence and to increase referrals of clients into cessation services within the Queens Health Network. This program is called "Queens Quits!" ACS staff provides clinician education and academic detailing for community-based physicians affiliated with QHN, while QCC staff members perform similar education within the hospitals. MSK has trained these trainers, and provides evaluation support for this program. Queens Quits! will accept and track referrals for smoking cessation assistance from the library-based outreach conducted as part of this project.
- Cancer Information Health Literacy Project: With internal resources plus $30,000 support from the Independence Community Foundation, ACS and its partners have completed the first phase of the NYC Cancer Health Literacy Project. Through this project, we have developed improved health education materials to meet the information and patient navigation needs of low literacy consumers. We now have an archive of five easy-reading, "health decision tools" to support cancer prevention, early detection screening, patient navigation and treatment, with an electronic portal providing "documents on demand" to health systems, libraries and community-based organizations. Educational materials were developed at or below the sixth grade level, to address colon, breast, cervical, and prostate cancer screening and tobacco cessation. Materials are presently available in 16 different languages. MSK and City College of New York investigators are working with ACS to evaluate these documents as decision aids for families. All documents are in electronic format suitable for storage on the Queens Library's computer networks and are designed for low-cost printing. These materials will provide a resource that may be used in a number of different ways by our project staff. We will be able to monitor downloads of these documents (by topic and by language) initiated by different libraries, as an indicator of cancer information seeking.
- The Lance Armstrong Foundation Community-Based Centers of Survivorship Care and Research Project: As a part of our ongoing collaboration, QCC and MSKCC were awarded a grant from the Lance Armstrong Foundation to support development and evaluation of a Primary Care Survivorship Clinic within QCC, a New York City public hospital. The goal of this project is to help establish continuity of care for cancer patients treated at QCC through the integration of primary care services within a cancer treatment setting. It is believed that this primary care clinic will foster better communication between a patient's primary care physician and his or her oncologist, and will offer a novel resource to oncologists who do not have the time to address patients' non-cancer related health concerns and complex service needs. This clinic is available to accept referrals from the library-based outreach, if we encounter cancer survivors who have special screening and follow-up needs.

## 4.0 OVERVIEW OF STUDY DESIGN/INTERVENTION

### 4.1 Design

**Overview:** We will evaluate the Queens Library HealthLink project using an interrupted time-series design with multiple baselines. This approach is particularly well-suited to community intervention research because it is more practical than randomized controlled trials (Biglan et al. 2001; Department of Education, 2005), and because it ensures that communities receive equal benefits of the research. In this design, each community serves both as its own control and as a comparison for other communities.

The first three months of the project will be a start-up period, during which time we will begin collection of street-intercept interview data as well as cancer screening utilization, referral and staging data. Beginning at month four, all 20 branch libraries will enter into our enhanced standard condition that ensures access to a comprehensive array of "traditional" cancer education and early detection program intervention; this will be our **control condition**. Based on the multiple baseline design of this study, the communities will spend from 3 to 36 months receiving this intervention only. At the beginning of month seven, we will initiate the intensive, participatory research intervention at two of the twenty branch libraries; this will be our **experimental condition**. We refer to this as an **intensive participatory research** intervention because communities will join us in examining needs assessment data, generating hypotheses about the kinds of interventions that may address these needs, and testing the impact of community-generated strategies. Distinctions between the enhanced standard (control) and collaborative program development (experimental) interventions are displayed in table 2 followed by detailed descriptions in sections 4.3 and 4.4.

Our experimental intervention is intended to improve upon gains in cancer control that can be achieved by the enhanced standard programs alone by increasing the reach and effectiveness of these established programs, and by initiating new cancer control activities that fill identified gaps. This intensive participatory research program development phase will last for one year in each branch library. After one year, each branch library and its Cancer Action Council will be in a position to continue cancer-related planning and programming with local public health providers, drawing upon Queens HealthLink staff as needed. Every four months, two additional branch libraries will begin the one-year collaborative program development intervention. Branch libraries will continue to cycle on every 4 months, as earlier libraries complete the intensive period of the program. In each community, we will conduct follow-up consultation and monitoring, to determine whether and how gains of the experimental intervention can be sustained after one year. This design permits a minimum of six months of follow-up evaluation in all 20 libraries (see Figure 1).

**Research Questions and Hypotheses**: This design will allow us to address our central question (indeed, the central question of all participatory methods): whether the participatory processes involved in collaborative program development can promote gains in cancer control beyond those achieved through a comprehensive mix of high quality programs and services that were not developed and implemented with community involvement. In order to answer this question, we will focus on the following outcomes: requests for cancer information made at community libraries; attendance at and frequency of cancer educational programing; awareness of accessible cancer screening services and tobacco cessation programs; changes in usage of cancer screening services; and changes in cancer staging data. Indicators of these changes will be gathered from multiple sources (described in detail in sections 7 and 9), and change will be determined against all available baseline data for each community, as well as comparisons across communities.

Our design will allow us determine whether awareness, access and utilization gains associated with the participatory intervention are sustained at the community level and for how long. In order to examine temporal trends, we will continue to monitor the outcomes listed above. We will also examine mechanisms of sustainability including: the frequency of and attendance for cancer outreach events organized by local Cancer Action Councils (CACs); the types of programs organized by local CACs; and local CACs' ability to work together as a group. Our intervention staff will remain available for consultation upon request after completion of the twelve-month intensive participatory research phase. We will track whether and how the CACs continue their work, and the extent that they can do so independently in the absence of an intensive intervention.

Due to the community-based nature of this work, so-called "contamination" among sites could occur. However, in the present study, this does not present a threat to validity to our methods. Indeed, from a public health perspective, such effects are appropriate and advantageous. Rather, we will explicitly monitor mechanisms of influence across sites. First, we will determine how HealthLink Specialists draw upon "lessons learned" from earlier libraries in their work with later libraries. We will also determine whether Cancer Action Councils at libraries entering the program later choose to draw upon ideas gleaned from other communities, including contacts among CACs from different sites. As we discuss below, our community surveillance methods will also address exposure to library-based programs in all communities before, during and after the time that intensive participatory research is introduced.

**Population-Level Indicators:** We hypothesize that study effects at the population level will mediated by changes in the capacities of the library and the network of organizations involved in the CACs to contribute to tailoring cancer control programs to meet local needs. In this study, the "population" is defined as residents and other regular inhabitants (e.g., workers, church members, etc.) of the various neighborhoods surrounding, and therefore served by, each public library branch. Based on the overall population of Queens and the number of branch libraries, an average of about 35,000 residents is served by each branch. Although neighborhood sizes vary widely as a function of residential density and natural or built boundaries between neighborhoods, each branch serves a community including tens of thousands of adults eligible for cancer screening. Note that communities served by libraries are not homogeneous; rather, each branch addresses the particular mix of ethnic and linguistic groups in its area. Thus, libraries and their CACs will need to prioritize what cancer-related problems to address, and how to tailor their approaches to the relevant sub-populations that they serve. Population level effects will be measured using a variety of continuous tracking indicators, that we will derive or capture from multiple sources, including:

Proximal Indicators (from individuals actually in contact with our services)

- Requests for cancer information generated from the libraries.
- Participation in and satisfaction with ACS on-site programs.
- Utilization of and satisfaction with the QHN Van services.
- Referrals for screening, primary care, etc. initiated from these activities.

Distal Indicators (from community sampling or administrative data sources)

- Anonymous street intercept surveys, measuring self reported cancer knowledge, cancer screening behavior and behavioral intentions, access to primary care, and exposure to library-based programs.
- Trends in ACS and MIH referrals and screening, aggregated by zip code/ library service area.
- Uptake in the Queens Quits tobacco cessation program aggregated by zip code/ library service area.
- Trends in QHN primary care utilization and cancer screening, aggregated by zip code/ library service area.
- Referrals to QCC, including diagnosis and staging aggregated by zip code/ branch library service area, including

We will track these indicators before, during and after the intensive collaborative program development intervention in each community. The pre-experimental intervention period (shaded yellow in Figure 1) will range from 3 to 36 months across the 20 communities, during which period continuous assessment will occur. These data provide will be used to examine the stability of each of these population indicators and to establish pre-experimental trends in screening. We will measure whether, when and how changes in these indicators are associated with the presence of the intervention. We expect to proximal indicators to be most sensitive to specific program activities. Distal indicators should show movement as community members gain awareness of library-based programming, and as benefits of successive outreach and education efforts accrue. We will have the ability to examine whether gains associated with this intervention are sustained over time by continuing to track these indicators after completion of the year-long intensive participatory intervention.

This intervention is founded on the premise that there are many different ways to reach a given cancer control objective, and what will work depends on the strengths and limitations found in different communities. We expect that the particular mix of people and organizations that play a role will necessarily vary widely in each setting. However, we expect overall gains in population indicators to be directly related to net increases in community readiness, investment in the problem of cancer, and capacity to affect public health programming. Further, we expect that sustained gains at the population level will be associated with stable community capacity for cancer control, and that disruptions in these capacities will be associated with some decrease in benefit. In the context of this over-arching hypothesis, our design will allow us to explore which capacities are associated with specific cancer control indicators in different communities, and also within the different ethnic and linguistic sub-populations represented across communities.

### 4.2 Intervention Overview

This project is being carried out as collaboration among five organizations; briefly, summarized as follows:

- MSKCC is providing overall project leadership, staff training to carry out phase I and II of the intervention and all data collection and analysis.
- The Queens Borough Public Library (QBPL) is employing the HealthLink Specialists who will carry out the collaborative program development intervention in each of 20 selected branch libraries.
- ACS Queens Region is providing its usual community program offerings, which include 14 different workshops focusing on topics related to cancer prevention, early detection and treatment (see Appendix A for a list of program offerings) as well as easy reading documents on cancer screening in 16 languages. ACS will also provide administrative data from the New York State Healthy Living Partnership for cancer referrals and screening that will be aggregated by zip code to represent the communities that each library branch serves. As of mid-June, 2008, the Queens Healthy Living Partnership was divided equally in half between Eastern and Western Queens. ACS is the lead partner for the Western Queens Healthy Living Partnership.
- MIH is providing its usual community program offerings which include their Mobile screening unit and outreach programs. MIH will also provide administrative data from the New York State Healthy Living Partnership for cancer referrals and screening that will be aggregated by zip code to represent the communities that each library branch serves. As of mid June, 2008, MIH is the lead partner for the Eastern Queens Healthy Living Partnership.
- QCC/QHN is providing cancer screening visits from its mobile van, three times per year per library, as well as data from the van. QCC will also provide administrative data on health utilization aggregated by neighborhood. It will provide all follow-up clinical care as needed.

Table 2. Summary of Intervention Components

Services Available as Part of the ENHANCED STANDARD OF CARE (Control Condition)

1. Cancer treatment and care will be available through QCC regardless of ability to pay or immigration status
2. Healthy Living Partnership telephone referrals through the ACS and MIH to free or low cost cancer screening.
3. Each Library will be provided with:
    - Complete list of ACS program offerings
    - A program request form and ACS outreach staff contact information
    - ACS easy reading documents in 16 languages
4. Training will be offered to librarians at participating libraries including:
    - Overview of 14 available ACS cancer program offerings, and opportunity to schedule these as desired
    - Instructions on how to request ACS programs
    - Overview of appropriate cancer information sources for library patrons
    - On-line access to ACS easy reading pamphlets in 16 languages
    - Instructions on how to refer library patrons to the Healthy Living Partnership Hotline
    - QCC van visit schedule
    - Instructions on how to help library patrons pre-register for an appointment with the QHN mobile screening van
5. QHN mobile screening van will visit each participating library 3 times per year

Components Added through INTENSIVE PARTICIPATORY RESEARCH (Experimental Condition)

1. Two HealthLink Specialists, based out of the libraries, will conduct local community organizing around cancer in the community served by each participating library. The HealthLink Specialists will:
    - Identify local leadership
    - Organize Cancer Action Councils (CACs) at each participating library
    - Facilitate CAC meetings using a problem solving model based on MSK ACCESS
2. Cancer Action Councils will:
    - Review local data on cancer incidence, service use, screening, knowledge and program awareness.
    - Identify local cancer priorities (areas of unmet need)
    - Identify or design appropriate cancer outreach programming and target goals for their community
    - Implement outreach programs
    - Monitor the success of implemented programs against their targeted goals
3. HealthLink Specialists and Cancer Action Councils will be provided with a resource manual including:
    - Program overviews and tool kits from all Cancer Control Planet programs
    - “How to” instructions for different types of community needs and assets assessments
    - Descriptions and tools for current community organizing strategies.
    - Tools to guide partnership development efforts
    - A list of organizations that have organized or participated in cancer and other health outreach programming in their community
4. Cancer Action Councils will be provided with updated data quarterly on community level usage of cancer services, screening behavior, knowledge, and program awareness.

Support for SUSTAINING BENEFITS OF INTENSIVE PARTICIPATORY RESEARCH

1. Plans will be in place for Cancer Action Councils to continue their work, including:
    - Methods to grow and/or replenish Council membership
    - On-going relationships with community providers and agencies
    - Needs for programmatic support from ACS, QCC, MSK and Library staff
    - Funding needs and fund raising opportunities
2. All Enhanced Standard Services will remain in place to promote sustained use
3. Councils will continue to receive tracking data for planning and review

4. Councils may initiate technical and program assistance from HealthLink Specialists

### 4.3 Enhanced Standard Intervention (Control Condition)

As noted above, for the duration of this project, all participating libraries will be set up to offer the full range of cancer control programs offered by the major public health entities in Queens: ACS cancer information, education, outreach and screening programs, MIH outreach and screening programs, visits from the QHN screening van three times per year, and direct referral to services of QCC. These services will complement the assistance that many librarians already provide to patrons seeking health information (see Goytia et al., 2005). Several factors determined our selection of this mix of services for the comparison condition:

- We wanted to provide an equivalent array of services in order to determine how libraries and their communities make use of these services.
- In our preliminary research, we found that libraries varied in their ability to incorporate cancer related services. We want to see whether and how the intensive collaborative program planning intervention improves use of these resources.
- ACS, MIH and QCC programs provide an opportunity to gather indicators of screening and service uptake, as well as measures of program participation at the library prior to the intensive intervention.
- These ACS, MIH and QCC programs facilitate access to screening, smoking cessation and care regardless of ability to pay. We needed to ensure that this level of access was available at all libraries.
- Most fundamentally, it would be trivial to test whether community-planned programs were superior to “usual services” found in these communities, which tend to be piecemeal and inconsistent across communities. Ensuring our that our control intervention constitutes an enhanced standard of care allows us to compare whether our participatory research intervention can promote gains in cancer control beyond benefits that can be achieved through a mix of high quality programs and services that were not developed and implemented with community involvement. In other words, is there an advantage to a collaborative, participatory process above and beyond what can be reasonably achieved with good top-down programming alone?

The following services will be arranged through the ACS and MIH:

- Each library will be provided with a list of available, traditional ACS program offerings as well as contact information enabling them to arrange ACS cancer education events at their community library branch. Initiation of ACS programing will be up to each individual library branch. Libraries will be able to select any programs of interest to them, schedule as many or as few ACS educational events as they choose, and promote these events in any way that they see fit. Program topics cover a wide range of issues, including all major cancer screening regimens, smoking cessation, nutrition, and familial risk, as well as information for cancer patients, survivors and their families. ACS staff will gather information on attendance as well as brief participant satisfaction surveys.

- As noted above, the Queens ACS has developed a series of cancer information brochures designed to be easy to read, and currently available in 16 languages. Brochures promote screening for breast, cervical and colorectal cancer, prostate cancer awareness, and smoking cessation. Brochures are available on-line, for ready delivery on demand. ACS will provide information to Queens librarians to encourage use of these materials. ACS will track downloads that are requested from each branch library, by cancer topic, language, and date. Downloads will be tracked automatically when library patrons or librarians click on the link for the desired document.
- The ACS and MIH administer the New York State Department of Health Healthy Living Partnership in Queens, which ensures affordable access to breast, cervical and colorectal screening (FOBTs) and necessary follow-up care to all Queens residents. Library staff will be provided with the training and information needed to refer patients to these services. Anonymous data on referrals initiated by library staff will be tracked and summarized by date, ethnicity/language, and screening completion status.

The QHN and MIH Mobile Cancer Screening van is a major resource for direct delivery of breast and cervical screening, as well as cancer education and referral. From the point of view of this research, monitoring activity associated with the van is like sending a standard “probe” into each community on different occasions, in order to observe what happens. We have arranged for the van to visit each of the libraries selected for this study three times per year, at four month intervals. It is important to emphasize that we do not expect to see substantial variation in the number of mammograms and pelvic exams performed on the van. Generally, screening vans pre-schedule appointments to justify the costs of deployment to a given location. However many other activities associated with the van can vary considerably from site to site and time to time, and will be monitored at every van visit to all libraries:

- Requests for referrals to colorectal screening and for mammograms and pap tests that cannot be fulfilled by the van; anonymous data on outside referrals initiated by the van staff will be tracked and summarized by date, ethnicity/language, and screening completion status when available (e.g., when screening is provided by QCC, MIH. or through the ACS partnership).
- Referrals requests to primary care providers.
- Referrals requests for tobacco cessation counseling through our Queens Quits program, including whether the referral is completed.
- Brochures and materials handed out.
- Educational sessions offered and attended.

- Proportion of return screens versus first time screens; we want to encourage participants to obtain annual mammograms, colorectal screens and pap tests as part of routine primary care; thus, we would like to reach a higher proportion of new and never-screened patients on the van.

In addition, as a component of the Queens Health Network, QCC will also help us to address any clinical care needs that we encounter during this program, through referral to Queens or Elmhurst Hospital Centers.

The control condition will be implemented beginning in month four, by providing information sessions to orient branch librarians to cancer control services available to their communities. Each library will be set up to routinely connect patrons to ACS and QHN services through existing referral numbers. Library computers will be set up to allow patrons direct access to download and print ACS information materials in multiple languages. A schedule of QCC van visits will be implemented at the library. In addition, branch librarians will have the opportunity to select as many or as few of the 14 ACS cancer information workshops to offer, at whatever frequency and in what ever format they choose, as part of their calendar of community programs.

## 4.4 Intensive Participatory Research (Experimental Condition)

Our experimental intervention will introduce a process of community-based participatory research, based on the ACCESS model. The intervention will organize a local Cancer Action Council, bringing onboard key stakeholders and community agencies to join the branch library in planning and implementing cancer control programs. The intervention will be carried out by HealthLink Specialists who will guide the Councils in cycles of needs assessment, feedback, planning, resource identification, capacity building, program implantation and evaluation, as detailed below. As noted above, our enhanced standard services and resources offered as part of the control condition provide a foundation for the experimental condition. Councils will have the opportunity to determine whether and how they want to modify and deploy these resources, to best meet community needs. Councils may also choose to look beyond these services, to bring in alternative programs, work with other health providers, and attempt unique strategies. Whatever approaches they pursue, Councils will be asked to establish appropriate measurable objectives, to determine whether their ideas are working as intended.

*Activities of the HealthLink Specialists*: HealthLink Specialists will begin working with each library at the beginning of the intensive participatory research phase. HealthLink Specialists will be employees of the Queens Borough Public Library system dedicated to this project. Specialists will be hired to provide special expertise in public health education and programming, including participatory research methods, cancer screening and preventive health. They job is to facilitate the process of program planning, implementation and evaluation in their assigned neighborhoods. Specialists will be responsible for forming and supporting local Cancer Action Council members to plan and implement cancer-related activities, arranging logistics for on-site programs and coordinating technical assistance and programmatic support with senior investigators. Each HealthLink Specialist will work intensively with no more than three library communities simultaneously.

*Formation of Local Cancer Action Councils:* Specialists' first task will be to convene a Cancer Action Council in each community. Working with the local librarians, the Specialists will approach key stake holders, including clergy, educators, civic leaders, health providers and business owners, to serve on the Council and/or to identify volunteers. Specialists will also work to bring cancer survivors and family members of cancer patients onto the Council. Council membership will represent the various ethnic, national and linguistic groups comprising each neighborhood; members will also include branch library volunteers and staff. We expect that Councils will have about 8-10 members to start, including, ideally, two elected (or self-selected) co-conveners who would facilitate and coordinate the work of the group. The purpose of these convener positions is to help move the group forward and sustain it; they would be honorific and could be rotated at intervals chosen by each Council. Councils will be an open forum. We expect Council membership to grow and evolve as the project matures in each community.

*Intervention Model:* At its core, the HealthLink Specialists' work with Councils adheres closely to the widely-used "social problem solving" paradigm (see Appendix B.5). Data presented to the Council provide an opportunity for problem identification, prioritization and goal setting. For each problem, Council members will be encouraged to brainstorm about alternative solutions and strategies. HealthLink Specialists will facilitate identification of solutions by offering Councils access to available public health resources, such as NCI's "Cancer Control Planet" website and similar materials from sources such as ACS, NYS DOH, and CDC. Councils will consider possible desired and undesired consequences to select strategies. Once strategies are selected, Councils will develop implementation plans, identify resources and supports needed to carry out plans, and set objectives in terms of measurable outcomes. Councils will receive feedback on results of their programs, to help them revise strategies and consider subsequent steps. The ACCESS program planning workbook (see Appendix B.6) provides materials that HealthLink Specialists will adapt to facilitate problem solving with the Councils.

*Cancer Action Council Activities:* Local Cancer Action Councils will work with HealthLink Specialists and project investigators to carry out participatory research in their communities. Councils will have real-time access to aggregate tracking indicators data gathered by project evaluation staff. Our staff will also help them to obtain any other information they request (e.g., journal articles, registry data, consults with oncology experts). Councils will be charged with interpreting data, setting priorities, identifying and developing strategies, implementing programs, and monitoring their results. Note that the Councils can draw upon staff from ACS and QHN to offer alternative workshops, modify van procedures, etc. Councils may also bring in “outside” services (for example, cancer screening providers from a local hospital other than QHN), broaden their scope to place cancer control in the context of broader community needs (for example, transportation, insurance, child care), and even bring in other community interventions (e.g., the Witness Project, Black Pearls, SHARE). We expect that all Councils will have more on their plate than can be reasonably addressed in twelve months, including needs of different segments of the community, different diseases and different barriers to care. HealthLink Specialists will encourage Councils to set priorities, to view their work as on-going, and to start out with problems that they can address more readily to achieve early successes. This approach is intended to motivate a sustained role for the Council, beyond the twelve months of intensive work with the HealthLink Specialist. Councils will hold full meetings at least once per month. Councils may adapt a sub-committee or task force structure to carry out specific tasks and roles. Other community volunteers may join to work on programs or carry out necessary tasks.

*Council Orientation:* Cancer Action Council members in each community will participate in a training and orientation session when they enter into the collaborative program development intervention in order to prepare them for their role. Orientation will include an introduction to health disparities and cancer incidence in the population, risk factors for the major cancers, implications of detecting cancer at different stages, screening tests, and barriers to preventive health care that affect substance users. We will also discuss the Queens Library HealthLink program in detail and provide examples of how Councils might work in their neighborhoods. Medical aspects of this presentation will be handled by Drs. Kemeny or Goytia. Data on disparities will be presented by ACS Outreach staff. Drs. Rapkin, Weiss, Lounsbury, or other MSKCC faculty will present the participatory research process. HealthLink Specialists will organize and serve as co-hosts for these meetings.

*Community Cancer Needs Assessment*: As the first step in participatory research, Council members will decide what data they want to have to begin the planning process. Council members will receive packets that provide data on local cancer rates, cancer-related services, and barriers or facilitators to care. They will also receive graphic summaries of data from street intercepts, prior van visits, and other previous library-based outreach efforts under the control condition. Councils will determine what additional data, if any, they want to obtain, and from which sector(s) of the community. Specialists will present options for needs assessment methods, including community forums, surveys, and focus groups. Council members will develop a workable strategy to obtain data in their communities and will carry out this assessment to guide their future decisions. MSK research staff and trainees will assist Councils in collecting, processing and interpreting data, and will be available to train Council members who want to learn more about data coding and presentation. Note that these data are being gathered to guide program planning, and do not factor into our evaluation of tracking indicators. Nonetheless, Councils will work with project investigators to ensure that all data are gathered and handled in a manner that conforms to human subjects guidelines.

*Data on Tracking Indicators:* As noted previously, we will gather and collate data from several sources on trends in screening, health behavior and access to care, in order to measure overall outcomes of this program. We will make these aggregated and de-identified data available to Cancer Action Councils upon their entry to the collaborative program development intervention and at regular intervals, to support program planning and evaluation. As data are obtained, Council members will meet with Specialists and senior staff to review barometer data and to brainstorm about possible cancer-related activities. Specialists will review needs assessment data and facilitate the problem-solving process to think through programmatic solutions and to arrive at step-by-step (means-ends) implementation plans. Planning will be informed by examples of strategies, program models and cancer education materials for Council members to consider.

*Addressing Linguistic Diversity and Translation Support*: Council members (and when possible, Specialists) will reflect the diversity of the communities that they represent and serve in this project. All needs assessment, program planning and evaluation will be offered in the language(s) that are most familiar to target audiences. This will be accomplished by drawing upon library personnel and community members to assist with teaching, needs assessment and outreach as needed. Queens Library has considerable linguistic diversity among its professional staff, and offers programs in multiple languages. ACS and MIH Outreach workers are also available to address linguistic needs. Queens Library and ACS have in-house support for translation of materials, and we have provided funds for additional translation as needed.

*Consultation and Technical Assistance*: In addition to selection of teaching material, Cancer Action Councils' plans for cancer related activity may require training or capacity building prior to implementation. We have made provisions for approximately 25 hours of consultation with investigators and other senior project staff members per neighborhood per year during the intensive participatory research phase. Consultation requests may be prompted at any time during a Council's planning and implementation process. Needs/opportunities for consultation may also be identified by Specialists or other staff during our team meetings. Following the ACCESS model, senior staff members from all partnering organizations will be available to provide consultation to libraries in the following areas:

- On-site training and programs about cancer screening and prevention.

- Further analysis of clients' health needs.
- Assistance identifying and establishing referral networks to get clients into care.
- Helping to create or adapt health education materials and media tailored to clients.
- Direct linkage to the NYS Department of Health Community Partnerships and other ways to offset costs of screening and follow-up care for clients.
- Assistance identifying funding and putting together proposals for health promotion grants.
- Assistance networking with other treatment libraries to conduct joint health activities.

*Funds for Cancer and Preventive-Health Related Activities:* We have set aside $750 per branch library to support libraries' cancer-related and preventive health activities during the intensive participatory research phase. Funds may be used to offset costs related to setting up or advertising events, for meetings or events, and for any other cost related to the program. Funds will not be used for salary, for costs of screening or medical care, or for transportation to sites of care. Note that most educational and information material can be obtained and reproduced at minimal or no cost from ACS, NCI, etc.

*Program Implementation*: Cancer-related and preventive health activities will vary widely, depending upon each Neighborhood's identified needs, available resources, planning processes, culture, and context. Our premise is that offering communities opportunities and resources to evolve preventive health activities from the ground up will foster effectiveness and sustainability. All Councils will be charged with addressing major cancer burdens that affect their communities. Beyond that, we will encourage each agency to identify preventive health needs, barriers to care and risk behaviors that they are willing and able to take on. The Queens Health Link project will not prescribe activities or program approaches. However, in order to convey how this program works, it will be useful to describe examples of activities that libraries may plan and implement. Note that the list below is derived from the types of activities carried out by agency participants in the original ACCESS program:

- Provide cancer screening brochures at community locations, including an on-site person who can answer questions and connect them directly to accessible services.
- Organize volunteers to serve as community navigators, to take clients to screening appointments.
- Advocate for better access to care and better treatment with a local public hospital or clinic.
- Create a "buddy system" to help women make health changes and go for screening together.
- Organize and identify incentives for physical activity, in conjunction with a local YWCA.
- Incorporate health information examples in an English as a Second Language programs.

- Have agency clients or past clients who are cancer survivors meet with community members to discuss their experiences, and show that it is worthwhile to get screened.
- Arrange for co-located primary care and check ups in a community's prevalent languages.
- Train and provide incentives for community volunteers to become peer educators, to promote cancer screening and other desired behaviors in their communities.

*Program Scope and Workforce*: Each Cancer Action Council will be responsible for determining the size, scale and timing of their intervention activities. In part, this will be dictated by the person-power that they can mobilize to carry out an event. The public libraries already attract many volunteers, and we anticipate that these programs will draw upon and increase the libraries' voluntary work force. The HealthLink Specialist will guide the Cancer Action Council in gauging the scale of their activities to fit with available person-power, and to figure out ways to make the activity as attractive and feasible as possible for desired volunteers from the community. Volunteer support and recognition will be considered in planning these programs. Indeed, broadening involvement and creating a positive and supportive atmosphere in all Queens HealthLink activities will help to engage the community and foster awareness and diffusion of our cancer control and prevention objectives.

*Program Monitoring:* Whatever their programmatic focus, Cancer Action Councils will specify measurable program objectives as part of their program planning process. Appropriate measures will depend entirely on the nature of their hypotheses and their programs, but will often include such indicators as attendance, satisfaction, distribution of materials, number of requests for information, number of referrals made, etc. Councils will be able to use these "tailored outcomes" as feedback, to make decisions about further program changes. This information may be supplemented by group or individual interviews with program participants, to obtain feedback about the program. Council members will also be asked to provide their own appraisal of program outcomes, using a suggested set of debriefing questions that we will make available to the Cancer Action Councils.

*Documentation of Tailored-Intervention Programs:* At the completion of an intervention cycle, HealthLink Specialists will be charged with preparing a standard write-up of the intervention rationale, plans, implementation experience and outcomes. Queens HealthLink program documents will be made available to other neighborhoods as they plan their own interventions. Council members will be encouraged to look critically at their program. Are they satisfied? Will they offer it again? What have they learned about how to improve the program? We anticipate that over time, the Councils will want to modify and expand programs. They will also want to extend their efforts to different priority areas and different segments of their communities. We have not stipulated the number of planning cycles and programs that each Council will undertake. Rather, we will encourage them to accomplish as much as they can with available time and resources, and we will monitor these activities as part of our process analysis. We will also encourage and assist Cancer Action Councils in presenting their programs and experiences to various audiences, including local media, particular community groups or professional forums, and even scholarly publications.

*Safeguards to ensure appropriate program content*: In any collaboration involving community members, there is potential for abiding misconceptions and myths about cancer to influence decisions, leading to ineffective and even harmful strategies. The participatory research process that we are using has built in safeguards to prevent this. Cancer Action Councils will plan programs following a problem solving model that explicitly requires consideration of potential adverse consequences. All programs will be implemented with steps to monitor outcomes to maximize positive outcomes and detect negative trends. We will take the following steps to further ensure that Cancer Action Councils target areas of demonstrated cancer need and that cancer outreach programs are consistent with the current evidence on cancer prevention, screening and care:

1. Cancer Action Council membership will be constituted by HealthLink Specialists, and will necessarily include community leaders and stakeholders who recognize the value of early cancer detection and preventive health, and who are understand that the Council will be drawing upon public health data and academic research.

2. Both HealthLink Specialists and Councils will be provided with training on current standards in cancer prevention, screening and care.

3. Council selection of strategies and programs will be supported by information and resources from previously successful cancer outreach programs, including a resource binder with all relevant NCI Cancer Control Planet programs.

4. HealthLink Specialists will engage Councils in a problem solving paradigm in which all identified programs will be geared towards addressing specific kinds of local cancer burden.

5. If a situation arises in which a program selected by Council members could be inappropriate for local community members, HealthLink Specialist will be trained to intervene and redirect efforts towards interventions that better meet demonstrated needs.

6. Project investigators are available to meet with Council members to discuss misconceptions and misinterpretations that may lead to adverse consequences.

*Sustainability*: During the sustainability phase, Councils will need to function more autonomously. HealthLink specialists will no longer be available to organize meetings, seek out new members, initiate programs, or serve as the primary liaison to ACS, QCC and other providers. These functions will need to be assumed by the Councils. However, all resources under the control condition will remain in place. Councils will continue to receive tracking data from the HealthLink project to support their program planning. Councils will also be able to initiate contacts with HealthLink specialists to obtain any assistance they require. The key to sustainability is that Councils will need to become proactive in their cancer control activities and accordingly, will need to maintain their membership and resources.

Cancer Action Council members will be told at the time they are recruited that Councils will receive active support from HealthLink Specialists over the first 12 months only. They will also be aware that we expect them to consider ways to sustain their work beyond this time, to continue to address problems of cancer. We will ask Councils to begin to consider the following issues regarding sustainability, as part of their on-going planning process:

- Long-projects or changes they would like to undertake
- On-going relationships with community providers and agencies
- Methods to grow and/or replenish Council membership
- Workload and roles of Council members (all volunteers)
- Volunteer recognition
- Needs for programmatic support from ACS, MIH, QCC, MSK and Library staff
- Need for data and technical support from HealthLink staff and other sources
- Funding needs and fund raising opportunities

It is possible that Cancer Action Councils may choose to disband, become disorganized or cease to be productive at some point after the completion of the intensive planning period. It is also possible for them to become independent from the library, to split into multiple groups (e.g., perhaps along lines of ethnicity or religion), or to shift their focus to community needs other than cancer. Councils may also arrange for other community bodies to assume some or all of their functions. Whatever transpires, we will continue to monitor Council activities as well as the changes that they undergo. We will also observe the impact of these changes on our various tracking indicators. If warranted, we will seek support for a competing continuation to address the critical question of maximizing and sustaining the public health impact of this structural community intervention beyond the five years of the current study.

*Program Manual for Cancer Action Council Members:* We will develop a program manual clearly outlining all relevant Queens Health Link procedures, responsibilities, risks and benefits for members of Cancer Action Councils. This program manual will outline the expectations involved in Council membership. It will also discuss project goals and who is responsible for certain tasks and program timeline and procedures. Specifically, it will:

- Clearly outline the purpose of the Queens HealthLink Project and associated evaluations, including all the ways in which data will be used.
- Describe the process of needs assessment, planning, implementation and evaluation that Councils will undertake.
- Establish consultation, cancer information, data and other Queens Health Link resources.
- Establish procedures for obtaining Barometers and Tracking data.
- Set up a timeline and dates for Council meetings.
- Explain sub-committee structure and possible assignments (community-specific).
- Ask members for at least a one year commitment for Council membership.
- Establish that we will maintain confidentiality of all participants, including information raised in Cancer Action Council discussions.
- Establish that we will only report neighborhood and library data in aggregate form, or in case reports that Cancer Action Council members may help to prepare as authors. .

Program manual will be signed by the HealthLink Specialists and each Council member.

## 5.0 CRITERIA FOR ELIGIBILITY

In general, participants in this project will be sampled within study neighborhoods. Eligible neigborhoods include low income areas in the Borough of Queens. Boundaries of neighborhoods are determined according to the cachment areas served by branches of the Queens Borough Public Library System (QBPL). Our plans for selecting neighborhoods and associated branch libraries for participation in this project are detailed in Section 6, below.

Inclusion Criteria:

This project is intended to reach participants over the age of 18 within each sampled neighborhood, inclusive of both women and men of all ethnic and language groups. As such, our outcomes assessment strategy is similarly inclusive. Specific sources of data and sampling strategies for different measures are detailed in Section 7, as part of our assessment plan.

Exclusion Criteria:

Individuals younger than 18 years of age will not be included in this study.

## 6.0 RECRUITMENT PLAN

Study investigators met with leadership of the QBPL to select 20 of the 63 branch libraries to participate in this study. The selection process for study libraries and their respective neighborhoods was as follows:

1. All 63 library neighborhoods were ranked in order of the percent of the population living below the poverty line base on 2000 census information. Poverty rates were somewhat uniformly distributed, ranging from 3.5% to 41.8% with no clear break points in the middle range. In order to have a large group of neighborhoods to consider, we decided to include neighborhoods with greater than 11% of the population living below the federal poverty line. 35 neighborhoods met this criterion. Of these, we decided to retain the 10 poorest communities, regardless of other factors.
2. The remaining 25 library neighborhoods were then ranked in order of the percent of the population that is foreign born. Neighborhoods with the largest foreign born populations (greater than 60%) were selected. Four communities were selected based on this criterion.
3. The remaining 21 library neighborhoods were then ranked according to proportion of African Americans. Three neighborhoods with greater than 60% African Americans were selected.
4. The remaining 18 library neighborhoods were then ranked according to racial diversity. Neighborhoods with the greatest racial diversity were selected. Three libraries with the highest racial diversity were initially selected (roughly equal proportions of white, Hispanic, African American, and Asian).
5. A final adjustment to the list of diverse neighborhoods was made in order to ensure that different geographic areas of the borough were represented, by changing one of the highly diverse neighborhoods that was adjacent to two other selected communities.

We also wanted to ensure that selected library neighborhoods represented a high range of cancer burden. We determined this based on New York State cancer registry data and Health Department statistics. “Cancer Incidence Scores” were created for each neighborhood based on New York State’s cancer registry zip code data. Scores were created by tallying the State’s six-level prevalence categories for the four most prevalent cancers by gender (breast, prostate, male and female lung, and male and female colorectal). For each of these six cancer by gender categories, zip codes received a score on a six point scale as follows: 0) more than 50% below expected; 1) 15% to 50% below expected; 2) within 15% below expected; 3) within 15% above expected; 4) 15% to 50% above expected; or 5) more than 50% above expected. Zip codes do not align perfectly with the libraries’ neighborhood service areas, so we estimated the proportion of each zip code represented in each neighborhood to derive a combined score by neighborhood. The theoretical range of this composite score 0 to 30. The observed range for the 35 poorest Queens neighborhoods was 6 to 16, and our selected neighborhoods ranged from 7 to 14.

## 7.0 ASSESSMENT/EVALUATION/DISSEMINATION PLAN

This study draws on a variety of sources of data to provide a thorough evaluation of cancer control indicators, intervention processes and contextual factors hypothesized to influence project implementation and outcomes. For clarity, we discuss the rationale for each source and data collection method. Specific variables are outlined in the following section of the protocol, on measures. Copies of each of these measurement instruments are included in the protocol appendix. Please see Table 3 at the beginning of Section 9 (Outcomes) for a crosswalk of how the measures described below relate to each of the study outcomes.

### 7.1. Neighborhood Environmental Observation (Appendix C.1 and C.2)

A growing body of evidence suggests that neighborhood structural environment has a direct impact on both individual and community health (Israel et al., 2005; Laraia et al., 2006). This work emphasizes the importance of "social capital" in affecting health, crime rates, and other outcomes. Neighborhood observation also provides insights regarding access to care. We expect that our intensive collaborative program planning intervention will achieve outcomes more quickly in communities with more stable, high quality environments.

Unobtrusive environmental observation will be conducted by MSKCC staff along with student interns. We will observe randomly sampled blocks within the twenty selected Queens neighborhoods. Geographic Information System (GIS) software will be used to randomize and select 10% of all street segments within each library neighborhood. Staff will then complete a neighborhood inventory using methods adopted from both Israel and Laraia's work. We will assess each side of the selected street segments (block face) for a total sample of over 2500 block faces. The neighborhood inventory will focus on the condition of residential and commercial structures, available community resources (such as parks, medical offices, hospitals etc), and the types of resident and non-resident activities taking place at the time of observation (ie. gardening, talking to neighbors etc.).

This measure involves unobtrusive observational assessment only. No individuals will be approached or questioned. Further, observation procedures involve coding of conditions that can be openly observed from public thoroughfares by casual passersby. Observers will not enter private property for any reason. If residents approach observers with questions about their presence in the neighborhood, staff will explain that they are working on a study to understand access and barriers to health care in the neighborhood and provide them with a phone number that they can call if they would like further information. Neighborhood observational data will be conducted once during the course of this study, between the months of May 2007 and September 2007. This timing means that we will be able to provide findings to all 20 Cancer Action Councils, to factor into their planning (e.g., about physical barriers, location of facilities, safety concerns, high traffic areas for advertising programs, etc.).

To be included in the Neighborhood Environmental Observation, a block face must be located in one of the 20 participating QBPL community library areas. Street segments will be excluded if they meet any of the following definitions, according to the NYC Department of Planning, DCPLION Single Line Street Base Map (NYC Department of City Planning, 2006):

- Paper Street: This is a legally mapped, but not built street.
- Private Street: This is a physically existing street which is not owned by the City and is not officially mapped as a public street.
- Alley: Narrow streets / passageways between and behind city buildings.
- Physical, non-street boundary: Physically existing un-addressable boundary (such as a rock wall cemetery edge).
- Street segment indicated as Non-Pedestrian: Primarily roadways, inaccessible to pedestrian usage.
- In addition, staff will be instructed to not survey any location where they feel their safety might be a concern.

In order to further ensure the safety of our research staff, data collection will always be conducted in study neighborhoods by two or more staff at a time and observation will only be conducted during daylight hours. Joint coding will also permit determination of inter-rater reliability in coding neighborhoods.

### 7.2. Anonymous Street Intercept Surveys (Appendix D)

We will conduct brief Street Intercept surveys in the 20 target neighborhoods in order to assess the diffusion of cancer information and the impact of the Queens Health Link program on the broader community. The Street Intercept survey includes a subset of standard items from the BRFSS to assess knowledge, adherence and intent to adhere to age, gender and risk-appropriate recommendations for cancer detection and prevention as well as questions relating to cancer survivorship. The intercept also includes items regarding access to routine primary and preventive care, perceived barriers to care, and standard measures of collective efficacy and community cohesion and trust (Sampson et al., 1997). Use of the Queens Public Library System, awareness of the library-based program programs including the QCC van, and personal exposure to or participation in these programs will also be assessed. Intercept data will provide one of our major sources of information concerning population rates of screening and service use. These data will be used to examine whether changes in indicators are associated with programs implemented by the CACs as part of our collaborative program development intervention. Cancer Action Councils will receive summaries of Intercept data, in order to consider local trends in their planning process.

In conducting our Street Intercept interviews, we will draw on the previously validated methodologies of Bleakley et al., 2004 and Ellen et al., 2004. Street Intercept interview participants will be approached on the street, or in locally frequented public venues, such as grocery stores, pharmacies, barbershops, hair salons, laundromats, and malls. High pedestrian traffic venues within each library neighborhood will be identified in advance, and community census tract data will be used to increase the likelihood that individuals approached are as representative of the targeted community as possible. Nonetheless, because the Street Intercept respondents by nature constitute a convenience sample, we will continuously monitor the demographic distribution of individuals interviewed. In all instances where collected samples have begun to significantly differ from community demographic profiles in terms of race, ethnicity, age or gender, we will specifically target under-represented populations. Further, at each time of data collection, we will gather data at different times of day (during daylight hours) and at different locations. Street Intercept Surveys will be repeated every 10 weeks in each neighborhood for the duration of this project, to track changes in these indicators within neighborhoods over time (24 times per neighborhood over 240 weeks or 4 years and 8 months).

We will ask for information anonymously, and will not track these individuals. We expect to gather data on 25 to 30 community residents per occasion (500-600 per measurement wave; 625-750 per community), to permit examination of trends within neighborhoods. Surveys will be conducted by MSKCC staff, with the help of student interns from LaGuardia Community College (LCC), Columbia University's Mailman School of Public Health, New York University's Steinhardt School of Culture, Education, and Human Development and Hunter College's Program in Urban Public Health. These students will conduct interviews in languages spoken by the local community.

Note that we will not obtain written consent from survey participants, as all data collected will be collected anonymously. Information on gender, race or other minority status will be collected as such information about participants is related to our aims and research questions. Participants will be informed of the purpose of the study and that they can skip interview questions or end the interview at any time. All participants will be given a card with phone numbers that they can call for referrals to all ACS and QCC services or to receive additional information about the study. Agreement to complete the survey constitutes sufficient indication of informed consent. The following script will be used when approaching potential participants:

INTERVIEWER READ: "*Hello, my name is ________________, and I am from the Queens Library HealthLink Project. This is a joint project between the Queens Library, the Queens Cancer Center, the American Cancer Society, and Memorial Sloan-Kettering Cancer Center. We are talking to people today to find out information about this neighborhood and health services in the area. I'd like to tell you more about it, if you have a moment...*

*This survey is part of a project to improve community health. My questions will only take about 10 minutes. I will not ask for your name, address or other personal information that can identify you. You do not have to answer any questions you do not want to, and you can end the interview at any time. Of course, it is better to have complete information, because everyone's answers count. Any information that you give me will be kept confidential. If you have any questions, I will provide a phone number for you to call to get more information.*

*First, let me make sure that you are eligible to complete the survey…*

*Over five years, we will be talking to more than 12,000 people in Queens, including about 600 from this area. We need this much information to help plan programs that are needed in different parts of the community.*

*The card that I gave you tells how to contact us to find out more about the Queens Library HealthLink Project. It also shows where to call to get information on cancer and to set up cancer screening appointments."*

In order to ensure the safety of our research staff, data collection will always be conducted in study neighborhoods by two or more staff at a time and surveys will only be conducted during daylight hours. All surveys will be conducted in public locations with high pedestrian traffic volume and staff will be instructed to not conduct surveys in any location where they feel concern for their safety.

The subject population will include men and women of all ethnic and racial backgrounds who currently reside in or spend time in one of the 20 identified Queens neighborhoods. To be eligible for the street intercept survey, an individual must meet the following criteria:

- Able to respond to interview questions
- Age 18 or older
- Regular member of the specific community of focus* during the given observation period. Community membership is defined by meeting **one** of the following criteria:
  1. Current residency in one of the Queens zip codes within or immediately surrounding the neighborhood served by a given branch library.

     OR
  2. A visitor to one of the 20 identified neighborhoods for work or personal reasons approximately five days per week, and self identification as being part of that community

* When we are surveying a given neighborhood, we may encounter residents of other target communities. We will not recruit these individuals unless they meet membership requirements for the community being surveyed on that specific occasion.

We will attempt to exclude subjects who state that they have previously participated in the street intercept survey. We do not expect high number of repeat surveys, because we will conduct interviews at different locations and times within the same neighborhood, and because we are not offering an incentive.

### 7.3. Utilization of Available Screening Services

Utilization of available screening services will be measured through tracking the use of the mobile screening van from QHN that will visit each of the local community library branches selected for this study three times per year, at four month intervals. As we mentioned previously, we do not expect to see substantial variation in the number of mammograms and pelvic exams performed on the van. Generally, screening vans pre-schedule appointments to justify the costs of deployment to a given location. However many other activities associated with the van can vary considerably from site to site and time to time, and will be monitored at every van visit to every library. For tracking purposes, QHN will provide aggregated data for each van visit detailing the number of individuals screened (mammography and pap tests), on-site requests for screening (i.e., individuals who want to be screened but did not make an appointment), requests for referrals to colorectal screening, requests for referrals to primary care doctors, requests for referrals made to Queens Quits! smoking cessation programs, and associated educational program attendance. This overall tally of activities will be included as part of our tracking data.

In addition, QHN staff will be asking each person who requests services or referrals from the van to consent to have their individual information tracked, so that we can determine whether services are actually used as well as results of screening. QHN staff will seek permission to access medical records for research purposes, and also to contact them by telephone or mail to get updated information. Note that the van is a service of the QHN and van personnel will be solely responsible for obtaining this written informed consent. We mention this complementary protocol here because information from the van is an important part of our overall evaluation plan. Although MSKCC staff will not be directly involved in these procedures, we will be listed as having access to respondents' personal health information, in order to permit MSK staff to assist in follow-up calls. We will provide the "QHN Mobile Van Services Follow-Up" protocol to the MSK IRB when it becomes available.

### 7.4. Administrative Data from the , MIH and QCC on Cancer Staging and Screening

In addition to the van, QCC and its parent organization, QHN, provide cancer screening and follow-up care to a large number of patients each year. As administrators of New York State's Healthy Living Partnership both ACS and MIH provide a large number of screening referrals and enable the costs of breast, cervical and colorectal (FOBT) screening and subsequent follow-up care to be covered by the State for the under and uninsured. Administrative data from ACS, MIH and the QCC on screening appointments and cancer staging will be de-identified and aggregated by zip code/neighborhood, ethnic/language group, and time, to supplement data that we gather from surveys and van visits. These data will be used to monitor community wide changes in the utilization of available screening services by zip code and will allow comparisons to be made between library neighborhoods over time. QCC cancer staging data will also be gathered to monitor whether any changes occur in staging of cancer at diagnosis. Although we do not expect to see changes in cancer staging in the initial 5-years of this project, this is important information to collect for monitoring long-term and cumulative benefits, if we are able to sustain programs in the public library as we anticipate.

QCC, MIH and ACS will obtain permission to share aggregated de-identified information with MSKCC for purposes of the present protocol. We will provide the IRB with up to date documentation of this arrangement as needed.

### 7.5. Branch Library Readiness, Capacity and Needs Assessment (Appendix E)

Baseline information pertaining to branch library readiness, capacity and resource needs to carry out cancer related activities will be gathered just prior to the initiation of the experimental intervention in each of the 20 libraries. Information will come from a variety of sources:

- Semi-structured interviews with branch library managers, conducted by the HealthLink Specialists.
- Staff field notes of visits to the branch library.
- Unobtrusive assessment of the physical, social and information environment at the library.
- Examination of existing documents about the branch, such as web sites, brochures, calendars and reports.

Library leadership and staff at each branch will be fully informed that we are assessing the libraries' involvement in and resources for conducting health and cancer-related programs. This information about library-level variables does not refer to individuals, and so traditional notions of confidentiality of individual information are not an issue. Branch libraries and CACs will each receive information on their own library's readiness, capacity and needed resources at the beginning of the intensive collaborative program planning intervention. Publications and external reports will include aggregate results at the setting level.

It is important to note that sources of available information will necessarily differ among branch libraries. As discussed in reference to the ACCESS project, we have developed a reliable coding system to combine all available sources of information. In order to facilitate coding, every dimension of capacity is associated with explicit behavioral reference points. Staff review available materials, independently assign codes, and then go back and arbitrate disagreements. As noted above most dimensions exceed kappa=.7 prior to arbitration (see Appendix B.4. for the Coding Manual by Jansky and Rapkin, 2001). Dimensions of setting readiness include ratings of branch library leaderships' interest in cancer prevention, relevant services at the branch library, branch library history of involvement in cancer and health information, tangible and staff resources, accessibility, safety and aesthetics.

Readiness, capacity and needs assessments will be repeated after the 12 month intensive intervention phase, to determine the extent to which branch libraries increased their capacities to sustain active programs of cancer education and outreach. We expect that these capacities will be associated with continued program benefits during the sustainability phase. We will repeat the readiness, capacity and needs assessment one final time for all programs, after month 56. This will allow us to determine whether new (or existing) capacities developed for mounting public health programs, making screening referrals, hosting the van and other activities are sustained in branch libraries, and for how long.

### 7.6. Entrance Surveys of Community Volunteers Who Join Local Cancer Action Councils (Appendix F)

Initial surveys of each Cancer Action Council Member will be administered via individual questionnaires, which each member will complete individually. CAC Surveys will serve the dual purpose of helping the HealthLink Specialists become familiar with the membership of the CAC, and helping orient members to issues that are important to the CAC. The survey content includes the following:

- Volunteers' goals for joining the CAC.
- Prior experiences planning and participating in community collaboration, outreach, and public health initiatives.
- Organizational affiliations and ties.
- Initial concerns about health in the community.

CAC volunteers will include men and women of all ethnic and racial backgrounds who currently reside in or spend time in one of the 20 identified Queens neighborhoods. To be eligible for CAC membership, an individual must meet the following criteria:

- Age 18 or older
- Identified by the HealthLink specialist or a branch librarian as someone who can appropriately represent a local constituency, community organization, or provider relevant to the success of the CAC
- Willing and able to participate actively in monthly or bi-monthly Council meetings.

Note that we will not consent CAC members because all information collected will be gathered as part of their service as volunteers and no personal health data will be collected. CAC members may refuse to participate in the survey or decline to answer any survey questions.

### 7.7. Community Barometer Assessment to inform CAC Planning (see Street Intercept Survey in Appendix D)

Cancer Action Councils will have the opportunity to work with HealthLink Specialists and other project staff and volunteers to conduct an initial Barometer Assessment with 30-50 individuals in their community to obtain additional needs assessment data. In the present study, Barometers will consist of the same items included on the Brief Street Intercept Survey, supplemented by questions specified by the local CAC. The CAC will determine who to target and where to best obtain data, based on their preliminary ideas and plans for cancer-related activities. This will allow CAC members to compare needs of their potential program targets with the broader neighborhood in terms of health service use, cancer history, screening adherence, knowledge of cancer signs, beliefs and fears about cancer, and perceived risk, as well as preference for various programs and basic demographics.

Barometer data will be collected anonymously using instructions similar to the Street Intercept. The main difference is that these data will be gathered as needed from samples and settings purposively chosen to meet the needs of Cancer Action Councils. Barometers may also be repeated as needed throughout the planning phase to support CAC planning and evaluation. In addition, CACs may choose to add items the Barometers, as needed to further program goals. This sort of community-steering of the assessment is consonant with the participatory research approach that characterizes this study.

### 7.8. Anonymous Satisfaction Measures for Education and Outreach Programs (Appendix G)

We will administer a participant satisfaction measure to determine whether programs developed, adapted or deployed through participatory community planning better meet community needs. These brief, anonymous satisfaction measures will be administered to groups of program attendees by ACS, QCC and QBPL staff, CAC members, or other library volunteers involved in implementing specific education, information, peer support and screening programs. Satisfaction measures will allow us to determine whether collaborative program development leads to greater participant satisfaction with cancer outreach programs. Satisfaction measures also will be used by the CAC to guide program planning.

After educational and outreach events at the community libraries, appropriate program leaders or support staff will approach program participants to ask them to complete the anonymous satisfaction survey. Surveys will be pre-coded to indicate date, location and nature of the program attended. The following script will be used when approaching potential participants:

*"Thank you for participating in [the program]. We want to learn a little about you and find out your reactions to the program, to get a better idea of how to meet community needs. You don't have to put your name on the form. You can just drop it off in this box when you are done. Would you be willing to take a few minutes to complete a short survey about the program you just attended? If you prefer, [project personnel, not program presenter] will be available for a few minutes to talk with you about today's program."*

Program participants who verbally agree will be provided with a paper questionnaire and pencil, and will be asked to return the surveys to the box when they are finished. Alternately, the option to talk about the program is included, in part, to accommodate low literacy participants without singling them out. In such cases, the form will be completed by project personnel during discussion of the program. Eligible respondents include any individual attending any cancer-related activity associated with this project, with the exception of CAC members, project students, and staff. No written consent will be obtained as no personal or identifying information will be collected and questions will be focused on the participants' reaction to the program which they just attended. Participants may decline to complete the survey or skip questions. They may continue to make use of any Queens Library HealthLink programs without completing surveys. Information on age, gender, race or other minority status will be collected to inform evaluation and planning.

### 7.9. Cancer Action Council Process Evaluation (Appendix H)

Cancer Action Council members will be interviewed by HealthLink Specialists to gather information about change in the Council members' goals and their experiences participating in the project. These surveys will serve as important process measures and will provide insight into the successes and failures that take place during each individual community's local organizing process. These data will help to explain why certain neighborhood programs may be more successful than others. Further, these CAC comments will be synthesized and shared with future branch libraries and CACs interested in adapting a similar program or activity in their communities. The following script will be used when interviewing CAC members:

> *"The purpose of this survey is to understand how well the Cancer Action Council has been functioning in a number of different areas since its inception six months ago. By "Cancer Action Council," we mean the group of community members that has been meeting regularly and working together to research and discuss ways to improve access to cancer services in your community area. Because you are a member of this Council, it is very important to learn about your experiences, including what is working for you and what is not.*
>
> *All of the information you provide in this questionnaire will be kept strictly confidential. Please do not put your name anywhere on the questionnaire. We will not be focusing on individual responses; we will be looking at all of the Council members' responses as a whole. Information gained from this survey will help everyone in the Queens Library HealthLink Project learn about what the Cancer Action Council is doing well and how it can improve and have the best chance of achieving all of its goals.*
>
> *There are no right or wrong answers to the questions. Thoughtful and honest responses will give the most useful information. "*

### 7.10. Requests for Cancer and Health Information Made at Community Libraries (Appendix I.1 & I.2)

As we demonstrated in our earlier research (Goytia et al., 2005), librarians at public libraries are frequently approached to provide information on health and health services. However, many librarians are not fully informed about accessible services and tailored information available, and many feel uncomfortable addressing questions that deal with more complicated or personal needs. As part of our traditional intervention, ACS field staff will work with branch librarians to: 1) provide information about how to make referrals to the New York State Healthy Living Partnership and 2) orient them to ACS' downloadable document-on-demand web site that has easy-reading brochures about breast, cervical and colorectal cancer screening, prostate cancer awareness, and smoking cessation for printing, currently available in 16 languages. As part of our collaborative planning intervention, librarians will also have opportunities to work with HealthLink Specialists, participate on their local CAC, and/or receive additional training and resources to better handle community requests.

We will implement three separate assessment procedures to monitor librarians' delivery of health information and referrals, and whether and how this function changes over the course of this project:

- Three times per year throughout the project, we will ask librarians to complete a brief log, indicating the number and nature of health information requests that they receive. We will e-mail this log to every librarian who provides direct service the general public in each of the 20 selected branches, and ask them to fill in the table for requests over the preceding four weeks. It will take librarians 5 to 10 minutes to complete this log and return it by e-mail reply. Requests will also include an open-end question asking for feedback about how the cancer-related programs are working at their branches, and to solicit their suggestions.
- The Queens ACS Healthy Living partnership call-in number will log referrals that they receive from the branch libraries. ACS records will indicate source, date, time and purpose of calls from potential screening clients referred by branch libraries.
- We will also work with ACS and QBPL to set up an automated system to track when and how often librarians print easy-reading brochures on different topics for their patrons. We will ask librarians to print these one page documents only when they are requested and not to make extra copies, to help ensure a more accurate reflection of patrons' document use.

Library staff members will be fully informed that we are interested in how they handle information requests and that we are tracking referrals and downloads. We will restate this every time we send them the information logs. We have arranged with library leadership to keep information regarding the performance of individual branch librarians completely confidential. Data will only be reported in aggregate form, in a way that does not single out any librarian or any branch.

### 7.11. Logs of HealthLink Consultation and Support to CACs and Branch Libraries

Starting at the initiation of the intensive program planning intervention, the HealthLink Specialist will maintain a log of all contacts that project staff have with the CACs and with the branch libraries. This information is needed to understand the kinds of technical assistance required to get cancer-related programs up and running in different communities. It will also be useful to see how usage changes over the course of the intensive intervention year, in conjunction with different programmatic issues. We will also examine how use of project assistance changes after completion of the intensive intervention, to determine the extent of support needed to sustain programs. We will track the following information over time, in each community:

- Planned CAC meetings with HealthLink Specialist
- Planned contacts of HealthLink Specialist with individual CAC/Library staff, initiated by specialist/other
- Librarian or CAC training programs conducted at the libraries
- Troubleshooting contacts of specialist with individual CAC/Library staff, initiated by specialist/other
- Consultation requests for assistance from senior investigators for program issues, staff training, research/evaluation issues, fund raising, or partnership issues
- Programs for the community conducted by partnership senior investigators
- Clinical, mental health and social service back-up requests

We will construct variables to summarize the extent of support that the HealthLink project provides in each of these areas. These variables provide a time-varying covariate that should mediate the influence of the HealthLink intervention on key indicators of health behavior, as well as measures of setting readiness and capacity.

### 7.12. Record of Cancer-Related Education and Outreach Activities and Programs in Each Community

In order to accurately gauge the impact of the HealthLink Program, we will attempt to account for the presence of programs and activities initiated by other agencies and services. HealthLink Specialists and ACS community outreach staff will meet monthly to specify programs and activities conducted at the library, programs carried out at affiliated agencies (i.e., agencies represented by CAC members), and programs conducted at other local venues, unrelated to our project. We will assess the following information for each program:

- Program purpose (i.e., opening of a new mammography provider, an annual health fair with a smoking cessation counseling booth, cervical vaccine roll out, etc.)
- Target audience(s) size and composition (ethnicity, gender, age, etc.)
- Neighborhoods served
- Duration and frequency

Note that we do not view these programs as "competing" with our work in the libraries. Rather, if our program is successful at raising public awareness of cancer-related services and resources, it could increase the uptake and impact of other concurrent community programs. Indeed, other community agencies interested in cancer programming may be invited to take part in the local Cancer Action Council. In any case, we will use our indicators data to track effects of these programs on our data in time series analysis.

### 7.13 Program Evaluation Process (Appendix J)

In order to evaluate the effectiveness of programs that are implemented by CACs, HealthLink Specialists will guide CACs through a standard process of program evaluation. This process will draw on established program planing and evaluation methods (Fetterman and Wandersman, 2005) and will be conducted in two stages. During the first stage, Health Link Specialists will work with CACs <u>prior to program implementation</u> to establish a program goal as well as targets for appropriate outcome and process measures. The second stage of the standard program evaluation process will take place <u>after the program has been implemented</u> and will ask CAC members to assess whether they met their targeted goals and process measures. Based on their results CACs will then be asked to identify the successes and failures of their program as well as ways in which the implemented program could be improved. Finally CAC members will decide whether or not the program is one that should be used again. Program evaluations will be conducted as a group in order to allow for brainstorming, discussion and clarification, and only one evaluation form will be completed per program.

Information gathered from program evaluation forms will provide important insight into factors impacting the processes of change occurring within each community. Further, these evaluations will provide extensive case examples of program tailoring and community level innovation.

### 7.14 Video taping of Cancer Action Council Meetings (Appendix K)

In order to capture the complexity of how the Cancer Action Councils (CACs) operate and change over time, we plan to conduct video recordings of Cancer Action Council planning meetings. These tapes will be used solely for dissemination of the project as a model for other communities; they will not be a part of the formal protocol data collection process and will not be used for program evaluation or any other research purposes.

Each Cancer Action Council meets approximately once every two or three weeks, depending on the schedules of members, and each meeting lasts for 1.5 – 2 hours. Not all meetings will be recorded; the overall goal is to have recordings represent a variety of time periods during the CAC development process. We estimate that for each Cancer Action Council, meetings will be recorded quarterly. Full meetings will be recorded in digital video, and recordings will be done either by the HealthLink Project Coordinator or Research Study Assistant. All video files will be stored in a password-protected server.

These video tapes will be used to illustrate the progression of the Cancer Action Councils. Specifically, this would entail presentation of video clips at educational conferences, as well as presentation of video material to community groups or partnerships that are interested in or are in the process of implementing a program similar to the Cancer Action Council model. Recording will occur only if all CAC members at the meeting to be recorded have signed a film and video release forms that explains how their image will be used. These release forms will be given to CAC members prior to the first recording date.

General permission to videotape the CAC meetings has already been obtained from the Queens Library provided that all individuals appearing in the video recording give their written approval. As the library has jurisdiction and oversight over all activities taking place with its premises, the standard library film and video release form will be used (please see Queens Library Film/Video Release form in appendix K):

## 8.0 TOXICITIES/SIDE EFFECTS

There are no expected side effects of this program. The risks of Queens Library HealthLink activities are minimal. The Queens Library HealthLink project will refer people to fully-certified providers of standard screening programs and health care. Participants may choose to undergo specific screening tests and procedures as a result of this program. Physical and psychological risks associated with these screening procedures (e.g., colonoscopy) will be explained as part of routine care, and are not part of this protocol.

If we encounter cases of serious emotional distress or critical unmet needs, we will take appropriate steps to refer participants to needed services. Clinical, mental health and social services offered by the Queens Health Network (the municipal health care system in Queens and QCC’s parent institution) will be available to all participants, regardless of their ability to pay for care or US citizenship. Participants may decline or withdraw from the study without penalty, and may continue to make use of Queens Library HealthLink resources and programs**.**

## 9.0 PRIMARY OUTCOMES

As described in Section 7, data for primary outcomes will be gathered from multiple sources in order to examine the participatory processes as well as behavioral outcomes at the individual, library and community levels. Table 3 below describes the role for all study measures. In Table 3a, we summarize our primary proximal and distal study outcome measures. We expect that the intervention will have immediate effects on primary outcomes, by increasing screening and referrals coming from the library and from van visits. Over time, we expect to see movement in more distal indicators based on anonymous intercept and administrative data. Table 3b includes measures of mediating mechanisms that we expect to change if our intervention works as intended, including effectiveness of CAC planning, more frequent cancer control services and programs, greater satisfaction with these programs, greater desire of CAC members to sustain these achievements, and greater levels of CAC activity and involvement with HealthLink Specialists and staff. Table 3c summarizes variables that we expect will moderate intervention effects. Some of these factors may themselves be changed by the program. For example, intensive participatory research should lead to desired proximal and distal outcomes more quickly when libraries have greater resources and capacity to conduct programs. As CACs carry out their work, they may be able to attract greater resources to the libraries (e.g., funds, staff interest, information resources, etc.). Similarly, we expect that CAC members' initial investment and skills will affect program effects, and that these too should increase during the program. In addition, consistent with a process of diffusion of innovation, we expect that word about our efforts in the library will take hold more quickly in more cohesive communities. Similarly, it is likely that benefits will materialize more quickly when there is greater community stability and fewer competing concerns. However, we expect that the ultimate magnitude of intervention effects will be greatest in communities with fewest resources.

**Table 3a. Summary of Study Measures: Primary Proximal and Distal Outcomes**

| **Rationale for Assessment** | **Measurement Source or Procedure** | **Specific Variables** | **Timing and Frequency of Data Collection** |
|---|---|---|---|
| Distal Outcomes | Anonymous Street Intercept Surveys (7.2, Appendix D) | • Self Reported Cancer Screening<br>• Cancer Knowledge<br>• Information Seeking<br>• Access to Care | Occurs in each neighborhood every 10 weeks throughout the study |
| Distal Outcomes | Administrative Data from the ACS and QCC on Cancer Screening and Staging (7.4) | • Screening referrals made though the Healthy Living Partnership (ACS, MIH)<br>• Number of annual screenings completed at each hospital participating in the Healthy Living Partnership (ACS, MIH)<br>• Cancer staging (QCC) | Gathered quarterly for the duration of the study |
| Proximal Outcomes | Requests for Cancer and Health Information Made at Community Libraries (7.10, Appendix I.1 & I.2) | • Number of referrals initiated by librarians<br>• Number of cancer related health requests made to librarians<br>• Number of other types of health requests made to librarians<br>• Number of downloads of ACS easy reading documents on cancer | Compiled quarterly |
| Proximal Outcomes | Utilization of Available Screening Services (QHN Van) (7.3) | • Number of individuals screened (mammography and pap tests)<br>• Number of on-site requests for screening<br>• Number of referral requests for colorectal screening<br>• Number of referral requests for primary care doctors<br>• Number of referral requests to smoking cessation programs (referral will be to Queens Quits)<br>• Attendance at associated educational programing | Gathered after each van visit – 3 times per year in each community |

**Table 3b**. **Summary of Study Measures: Mediators of Intervention Effects**

| Rationale for Assessment | Measurement Source or Procedure | Specific Variables | Timing and Frequency of Data Collection |
|---|---|---|---|
| Effective community planning will increase services. | Record of Cancer-Related Education and Outreach Activities and Programs (7.12) | • Number of Cancer Outreach Activities and Programs | Compiled quarterly |
| Successful programs will be lead to primary outcomes. | Program Evaluation Process (7.13) | • Program implementation and target goal achievements | After every CAC-initiated program |
| Community Planning should lead to more useful and satisfying programs. | Anonymous Satisfaction Measures for Education and Outreach Programs (7.8, Appendix G) | • Whether programs meet participants information goals<br>• Number of program participants who have attended other Queens Library HealthLink programs<br>• Whether program participants would attend future programs<br>• How participants heard about the program they attended | After every program conducted as part of this project |
| CAC members should want to sustain programs. | Cancer Action Council Process Evaluation (7.9, Appendix H) | • How CAC members goals have changed from their entrance interview<br>• How well CACs work together as a group<br>• Barriers that CACs face | 6 and 12 months after the creation of the CAC |
| Greater CAC activity will be associated with greater impact and sustained effects. | Logs of HealthLink Consultation and Support to CACs and Branch Libraries (7.11) | • Number of CAC meetings with HealthLink specialist<br>• Number of HealthLink Specialist contacts with individual CAC members<br>• Number of Librarian or CAC training programs<br>• Number of troubleshooting sessions between CACs and HealthLink Specialists<br>• Number of CAC consultation requests for assistance from senior investigators | Compiled quarterly |

**Table 3c. Summary of Study Measures: Setting Outcomes and Contextual Moderators**

| Rationale for Assessment | Measurement Source or Procedure | Specific Variables | Timing and Frequency of Data Collection |
|---|---|---|---|
| Greater library program capacity will increase effects;<br>This capacity should increase. | Branch Library Readiness, Capacity and Needs Assessment (7.5, Appendix E) | • Physical environment including building condition, and space for events<br>• Social environment<br>• Information environment<br>• Current program offerings<br>• Staff training<br>• Staff language skills (i.e. do the languages spoken by staff match those of patrons)<br>• Library Hours | Occurs at the beginning of the study and after the completion of the experimental intervention in each library |
| Intervention effects will emerge more quickly as a function of CAC Volunteer readiness, prior experience and relevant expertise. | Entrance Surveys of Community Volunteers Who Join Local Cancer Action Councils (7.6, Appendix F) | • Volunteers' goals for joining the CAC<br>• Prior experiences planning and participating in outreach and public health initiatives<br>• Familiarity with local clinical and preventive health services<br>• Organizational affiliations and ties<br>• Descriptive personal background information<br>• Initial concerns about health and cancer in the community<br>• Initial ideas for community projects that the CAC could pursue | At the beginning of each library's experimental intervention |
| Intervention effects will diffuse more quickly in cohesive communities. | Anonymous Street Intercept Surveys (7.2, Appendix D) | • Collective Efficacy<br>• Community Cohesion and Trust | Occurs in each neighborhood every 10 weeks throughout the study |
| Intervention impact will be greater in communities with greater need. | Neighborhood Environmental Observation (7.1, Appendix C.1) | • Condition of residential and commercial structures<br>• Available community resources (such as parks, medical offices, hospitals etc)<br>• Types of resident and non-resident activities | May, 2007 – September, 2007 |

## 10.0 CRITERIA FOR REMOVAL FROM STUDY

NOT APPLICABLE: As this study is a community wide trial, no individuals will be removed from the study. Participation in study activities is voluntary and open to all community members who meet the stated eligibility criteria.

## 11.0 BIOSTATISTICS

This project is a population based intervention that uses an interrupted time-series design with multiple baselines (Biglan et al. 2001; Department of Education, 2005). This approach is particularly well-suited to community intervention research because it is more practical than randomized controlled trials, and because it ensures that communities receive equal benefits of the research. A total of 20 branch libraries in the Queens Library system will be recruited to participate in this study. In this design, each community serves both as its own control and as a comparison for other communities. As shown in the study time line (Figure 1), libraries and their respective communities will be enrolled in the study and followed continuously for the entire study period. All libraries enter the program in the control condition. Libraries will spend between three and thirty-six months receiving the control condition (“enhanced standard services”). Beginning in month four, two libraries will transition into the experimental intensive participatory research intervention (IPR). Every four months, two additional libraries will begin the intervention. The IPR lasts for 12 months, after which time libraries enter the “sustainability” phase. The order in which libraries will transition into the experimental condition will be determined during the start-up phase. Libraries will enter at random. However, we will “yoke” pairs of libraries together to ensure that order of entry is relatively balanced with respect to community characteristics (i.e., we do not want all the predominately Hispanic communities to enter first and all the Chinese communities to enter last).

Outcome indicators are summarized in Table 3 (section 9, pp. 44-47). Outcomes indicators will be derived from anonymous street intercept surveys on self-reported cancer screening, administrative data from QHN, MIH and ACS, and library and van referrals records. Each of these measures will be drawn from numerous individual observations.

Analytic plans for specific study aims are as follows. The plans are consistent with the recommended analytic strategies for group-randomized trials (Gruenewald, 1997; Murray, 1998; Murrary, Varnell, Blistein, 2004). We will base this discussion on the analysis of street intercept data, although similar considerations will guide our approach to other measures.

**Aim 1. To determine whether community-based participatory action research leads to more effective cancer prevention and control in underserved communities compared to traditional, “top-down” programs.**

Linear mixed-effects models with smoothing techniques (e.g., kernel estimation) are the primary analytic method to model the time-varying changes in the primary endpoints (e.g., cancer knowledge, access to care, and information seeking). The effect of the IPR intervention as compared to the standard intervention will be evaluated by the parameter estimate of a dummy variable that indicates the intervention condition. A second time-dependent dummy variable will be created to indicate the sustainability phase. The standard (control) intervention phase will be the reference level.

Statistical Power for Mixed-Models Analysis: We estimated the statistical power of a mixed-effects model using Horton et al.'s simulation method (2004). The parameter estimate for the IPR dummy variable will be used to test the effectiveness of the proposed community-based participatory action research against the standard (control) phase. Take accurate knowledge of local library-based cancer control programs as an example of an endpoint, we will be interviewing 30 individuals every 10 weeks in each neighborhood for over 4.5 years. This will yield a sample of 13,500 respondents who provide data anonymously during street intercept interviews in each of the 20 neighborhoods (Iguchi et al., 1994; Ellen et al., 2004; Kalichman et al, 2006) for a total of 675 anonymous interviews nested within each library setting.

We applied Horton's method to a mixed model with random respondent effects (nested within libraries) and a random time effect (in 10-week increment). Based on data from our original ACCESS study (Lounsbury et al, 2006 – appendix B.3), we assumed an intraclass correlation of 0.15 over the 5 repeated assessments per library per year and a coefficient of 0.18 for the dummy variable that indicate the IPR phase, treating the control phase as the reference. With altogether 675 repeated assessments nested within each library setting, there will be a power of 87.5% at a two-sided alpha error rate of 0.01 to detect a fixed-effect of 0.18 for the IPR dummy variable. The IPR fixed-effect coefficient will be tested with a *t*-test as described in Brown and Prescott (2006, pp. 76-79) for the null hypothesis that cancer knowledge assessed in the street intercept surveys during the IPR phase will be equal to the scores assessed during the control phase. An effect size of 0.18 is considered a "small" effect size for such a contrast in psychosocial research (Cohen, 1992). Thus there is sufficient statistical power to detect a "small" and greater effect in the primary endpoints such as knowledge of programs.

### Other considerations for Aim 1

Our interrupted time series design necessarily means that some libraries will receive the control phase (enhanced ACS, MIH and QCC services) for a longer period of time. This design may entail a problem that the experimental condition will tend to look better than the control if there are secular trends of increasing cancer awareness and screening uptake. A potential bias like this may be accentuated by a delayed effect of the control interventions. Adding non-participating libraries as controls may address this issues. However, this design modification may introduce potential problems because the non-participating libraries are mostly within higher SES neighborhoods. We do not believe they are suitable controls for the target libraries, which have been identified based on the year 2000 census data on the percentage of population living below the poverty line (see pp. 29-30 for the selection criteria).

We will endeavor to model the impact of this potential bias. The overall plan is to use mixed models with kernel smoothers to visually inspect this effect, and test them with a few post hoc "before and after" contrasts (see Ch 2, Diggle et al., 2005). We also plan to follow Murray's recommendations (2004 in Am J of Pub Health) to use "before" and "after" contrasts (used sparingly) to gauge the extent to which the conclusions we draw from the mixed models are affected by a delayed effect during the Standard Intervention phase. We continue to see advice from our colleagues.

This analytic plan will permit us to use mixed models with a random time effect to examine several questions related to community context and introduction of participatory interventions. First, it is possible that length of exposure to enhanced standard programs will generate greater interest in cancer-related programs and foster community involvement when our participatory planning process is introduced. Alternatively, it is possible that prolonged availability of traditional “top-down” programs will increase awareness, screening and prevention to some ceiling-level, making further benefits of participatory programs difficult to determine. A third alternative is that the increment in cancer-related awareness and behaviors due to the participatory intervention is additive, creating a similar benefit regardless of the community’s prior exposure to standard programs.

**Aim 2. To examine how communities engage in the participatory research process, in order to develop locally tailored initiatives for cancer education, prevention and control.**

Aim 2 will involve descriptive statistics to summarize the changes in process variables such as community cohesion and trust, program attendance, degree of contact with consultants, and changes in agency capacities. These analyses will be primarily carried out at the library level. As noted above, we will examine whether and how library readiness and community resources moderate the effects associated with collaborative program development through community-based participatory research. Our overall hypothesis is that IPR will be more beneficial in communities with lower social capital, fewer resources and greater barriers. This follows directly from the observation that the processes associated with participatory research (fostering lines of communication, identifying and mobilizing resources, persistent and iterative program planning) may each serve as antidotes to various challenges evident in underserved communities.

**Aim 3. To examine whether and how long program effects are sustained after completion of the intensive collaborative program planning intervention.**

In aim 3, we will use mixed-effects models to examine whether or not cancer knowledge measured by street intercept surveys during the <u>sustainability</u> phase is equal to that measured during the control phase. The parameter estimate for the sustainability dummy variable will be used to test the sustainability of the proposed community-based participatory action research against traditional programs. Similarly, mixed-effects models will be used to test the sustainability of the IPR program with respect to access to care and information seeking.

### General Analytic Approaches for the Proposed Interrupted Time-Series Design

Before specific research questions are addressed, several types of data manipulation and exploratory analyses may be considered. Transformations will be used if needed to produce variables that conform to the distributional assumptions. Exploratory analyses will generally employ both the usual t-test and the Wilcoxon rank-sum test to protect against violations of normality assumptions. Similarly, along with the usual analysis of variance procedures, Wilcoxon signed-rank tests will be used for paired data and Kruskal-Wallis tests will be used for k-group comparisons. Categorical variables, including dichotomous factors, will be summarized by proportions and compared among groups using Fisher's exact test. Adjustments to the alpha level will be considered using the method of Hochberg and Benjamini (1990).

Preparation of Data: Data from all sources will be prepared on an on-going basis. Street intercept data will be gathered by interview, so we expect missing data to be minimal. MSKCC research staff will work with QCC, ACS and QBPL staff to ensure that the measures that they collect are complete. Sporadic missing data will be imputed using regression methods. Given the relatively small N of neighborhoods (20), we will reduce variables at this level by dropping those with highly skewed distributions, combining highly correlated measures into scales, and creating conceptually-based dimensions (e.g., of readiness and capacity). N of cases is sufficient at the individual level to permit empirical exploration of patterns of adherence and risk (e.g., cluster analysis) within and across sampling waves.

Sources of tracking data including van data, as well as ACS, MIH and QCC administrative data will be gathered at the neighborhood level defined by either zip code or library neighborhood. Tracking data lend themselves to more traditional analysis of trends, including event history analysis to model the introduction of specific types of programs or activities (e.g., here is when the neighborhood decided to take on colon cancer), latent growth curve modeling (e.g., to see if there are processes or patterns that account for major patterns in the data) and correlated time series (e.g., to determine if program activities lead to expected changes in screening rates in about two months). Note that data will be broken down by groups within neighborhoods when possible, to permit more sensitive assessment of temporal trends for different groups.

Mediation: Our study includes a number of measures to examine mechanisms associated with program effects. As with outcomes, indicator measures are measured continuously, and we will examine trends in these variables, including number of programs, satisfaction with programs, and level of CAC activity. Mediation measures can be included as time-varying covariates in tests of initial and sustained effects, to determine whether and how they account for changes in proximal and distal outcomes.

Individual Moderator Variables: For street intercept and tracking analyses, individual characteristics (ethnicity, language, age, gender, and library involvement) may be included to examine whether program effects differ for different segments of the community. This will be accomplished by creating aggregate scores for subgroups of interest. In addition to modeling race, language or age differences per se it will also be of interest to explore whether being a member of the predominant ethnic or language group in a given neighborhood influences outcomes of the community-tailored programs (e.g., are we reaching members of less prevalent minority groups as well as the large groups within each community?).

Setting and Ecological Moderator Variables: During the start-up period, HealthLink Specialists will gather data on library readiness and capacity to host health-related programs, and community organizational and structural variables that may effect access to care and program participation. These variables will be included as moderators at the community level in HLM analysis. For example, we will examine whether the changes in tracking measures between standard and IPR conditions are greater in lower-resource communities.

## 12.0 SUBJECT REGISTRATION AND RANDOMIZATION PROCEDURES

### 12.1 Subject Registration

**NOT APPLICABLE: We will not be obtaining informed consent or registering participants for any part of this study.**

### 12.2 Randomization

NOT APPLICABLE: No randomization will take place in this study as the design relies on a pre/post analysis and all participating communities will receive the same interventions.

## 13.0 DATA MANAGEMENT ISSUES

A Research Data Coordinator, Research Study Assistant (RSA), and pre-doctoral fellows will be assigned to the study. Their responsibilities include project compliance, data collection, abstraction and entry, data reporting, regulatory monitoring, problem resolution and prioritization, and coordinate the activities of the protocol study team.

The data collected for this study will be entered into a secure password protected database. Source documentation, kept in a locked filling cabinate, will be available to support the computerized patient record.

### 13.1 Quality Assurance

Reports will be generated every month to monitor participant accruals for street intercept interviews and to ensure that we are meeting our targeted goals described in section 7 above. Routine data quality reports will be generated to assess missing data and inconsistencies across all of our data collection instruments. Accrual rates and extent and accuracy completed measures will be monitored periodically throughout the study period and potential problems will be brought to the attention of the study team for discussion and action

Random-sample data quality and protocol compliance audits will be conducted by the study team, at a minimum of two times per year, more frequently if indicated.

### 13.2 Data and Safety Monitoring

The Data and Safety Monitoring (DSM) Plans at Memorial Sloan-Kettering Cancer Center were approved by the National Cancer Institute in September 2001. The plans address the new policies set forth by the NCI in the document entitled "Policy of the National Cancer Institute for Data and Safety Monitoring of Clinical Trials" which can be found at: http://cancertrials.nci.nih.gov/researchers/dsm/index.html. The DSM Plans at MSKCC were established and are monitored by the Office of Clinical Research. The MSKCC Data and Safety Monitoring Plans can be found on the MSKCC Intranet at:

*http://mskweb2.mskcc.org/irb/index.htm*

There are several different mechanisms by which clinical trials are monitored for data, safety and quality. There are institutional processes in place for quality assurance (e.g., protocol monitoring, compliance and data verification audits, therapeutic response, and staff education on clinical research QA) and departmental procedures for quality control, plus there are two institutional committees that are responsible for monitoring the activities of our clinical trials programs. The committees: *Data and Safety Monitoring Committee (DSMC)* for Phase I and II clinical trials, and the *Data and Safety Monitoring Board (DSMB)* for Phase III clinical trials, report to the Center's Research Council and Institutional Review Board.

During the protocol development and review process, each protocol will be assessed for it's level of risk and degree of monitoring required. Every type of protocol (e.g., NIH sponsored, in-house sponsored, industrial sponsored, NCI cooperative group, etc.) will be addressed and the monitoring procedures will be established at the time of protocol activation.

## 14.0 PROTECTION OF HUMAN SUBJECTS

### 14.1 Privacy

- Survey information in this study will be collected anonymously and all of responses will be kept confidential and stored on a secure database on the departmental drive. The standard privacy text does not apply to this study as no PHI will be collected from participants.

### 14.2 Issues Concerning Research in Community Settings

This project involves an intervention at the level of community sites. As such, it raises unique concerns that do not arise in studies that sample only individuals. It will be useful to anticipate and outline these areas of concerns and to explain our efforts to maximize benefits and minimize potential risks of this research.

Sampling and Recruitment of Communities: We have adopted inclusive procedures for targeting neighborhoods, according to known or suspected cancer health disparities and barriers to care. All neighborhoods in this study will receive enhanced cancer-related services. Community participation will be an open and inclusive process. Our main community participants, the Cancer Action Councils, will be selected to represent key segments of their communities. By working at the neighborhood level, it is easier to ensure that Cancer Action Councils are representative of their communities.

Confidentiality of Site-Level Information: Communities will control access to their specific information. Investigators will discuss differences in cancer trends related to community characteristics, but will not associate findings with specific neighborhoods. Study investigators will work directly with Cancer Action Council members in preparing case study reports, to ensure that we are able to protect community identities. Otherwise, we will not release or report information in ways that would permit identification of specific locales.

Limits to Confidentiality of Specific Sources within Libraries, and Safeguards: Branch libraries will serve as the home base for this project in 20 communities. Data on libraries will be gathered from staff. We will ensure that these individuals are fully aware that we plan to use information from our interviews to describe Library Readiness and

Capacity. Our coding system integrates and triangulates data from several sources, which serves to obscure sources of any particular perspective.

Community Oversight: Communities participating in the study will control access to their specific information. Investigators will discuss differences in cancer trends related to community characteristics, but will not associate findings with specific neighborhoods. Study investigators will work directly with Cancer Action Council members in preparing case study reports, to ensure that we are able to protect community identities. Otherwise, we will not release or report information in ways that would permit identification of specific locales.

Benefits to Settings: We expect that neighborhoods and libraries will benefit from participation in this project in several ways, through capacity building in areas needed to plan and implement cancer-related programs, such as grant writing and staff training. Libraries and Cancer Action Councils will receive media materials, barometer and indicator data and summary data reports at no cost.

Emphasis on Tailoring Over Targeting in Resource Dissemination and Training: We must be mindful of the possibility that capacity-building programs can promote the “rich getting richer” syndrome. Information yielded by setting and community evaluations could demonstrate that greater baseline capacity to get involved in cancer outreach leads to greater success. This might encourage some to steer resources to higher-resource communities and settings. At times this may be appropriate. However, in order to reach the most vulnerable of the underserved, it may be necessary to tailor programs to libraries and communities that are not “ideal” in terms of setting readiness. Although capacity building with resource-poor sites may seem to slow the diffusion of cancer screening and information, ultimately this may be the only way to reach certain groups in greatest need and reduce disparities. As we discuss, we hypothesize that participatory planning may be particularly beneficial in these communities.

## 15.0 INFORMED CONSENT PROCEDURES

For all measures:

Standard informed consent procedures will be waived for this protocol for the following reasons:

1. The research presents no more than minimal risk of harm to subjects and involves no procedures for which written consent is normally required outside of the research context.
2. The only record linking the subject and the research would be the consent document and the principal risk to any participant would be potential harm resulting from a breach of confidentiality.

### 15.1 Research Authorization

Standard research authorization procedures will be waived for this protocol for the following reasons:

1. The research presents no more than minimal risk of harm to subjects and involves no procedures for which written consent is normally required outside of the research context.
2. The only record linking the subject and the research would be the consent document and the principal risk to any participant would be potential harm resulting from a breach of confidentiality.

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## 17.0 APPENDICES

**Appendix A_** *Workshops Provided by the American Cancer Society*

**Appendix B.1_***ACCESS Model Presentation*

**Appendix B.2_***ACCESS Partnership Model Paper*

**Appendix B.3_**The Community Barometer

**Appendix B.4_***ACCESS Setting Readiness Code Book*

**Appendix B.5_***ACCESS Internal Protocol and Procedures Guide*

**Appendix B.6_** *ACCESS Problem Solving Workbook and Materials*

**Appendix C.1_***Neighborhood Environmental Observation*

**Appendix C.2_***Neighborhood Environmental Observation - Training Module*

**Appendix D_** *Anonymous Street Intercept Survey*

**Appendix E_** *Branch Library Readiness, Capacity and Needs Assessment Semi-Structured Interview*

**Appendix F_** *Entrance Surveys of Community Volunteers Who Join Local Cancer Action Councils*

**Appendix G_** *Anonymous Satisfaction Measures for Education and Outreach Programs*

**Appendix H_** *Cancer Action Council Process Evaluation*

**Appendix I.1_** *Requests for Cancer and Health Information Made at Community Libraries - ACS Easy Reading*

**Appendix I.2_** *Requests for Cancer and Health Information Made at Community Libraries - Librarian Survey via E-mail*

**Appendix J_** *Program Evaluation Process*

**Appendix K_**Film/Video Release Form