

# **Appendix D: Report of the Primary Data Component**

Community Needs Assessment

Draft – October 2, 2014

The New York Academy of Medicine (NYAM)

**QUEENS COMMUNITY NEEDS ASSESSMENT:  
REPORT OF THE PRIMARY DATA COMPONENT  
OCTOBER 2014**

**SUMMARY**

**BACKGROUND**

The goal of the Delivery System Reform Incentive Payment (DSRIP) program is to promote community-level collaborations and focus on system reform in order to reduce avoidable inpatient admissions and emergency room visits for the Medicaid and uninsured populations in New York State. To inform the health system transformation that is required under the DSRIP program, emerging Performing Provider Systems (PPSs) must submit a comprehensive Community Needs Assessment (CNA) with their Project Plan applications. The Queens PPS's CNA included primary and secondary data analysis. This report describes the primary data methodology and analysis and has been developed as an attachment to the full CNA, and to provide more in-depth information to the PPS's, which may be useful for DSRIP project planning, as well as planning and implementation of programs and services outside of the DSRIP program.

**METHODS**

The Center for Evaluation and Applied Research (CEAR) at The New York Academy of Medicine (NYAM) conducted the primary data portion of the CNA, which included 605 surveys of community residents, and 18 focus groups and 22 interviews with Queens residents, providers, and other stakeholders. The protocol was developed in collaboration with selected PPS's in Queens, Brooklyn, the Bronx, and Manhattan and was implemented in partnership with the PPS's as well as a number of Community Based Organizations.

The primary data component was designed to address anticipated gaps in the secondary data, including: 1) community member and stakeholder perspectives on health issues, including their causes and impact; 2) data on populations (e.g., particular immigrant groups) and issues (e.g., links between incarceration and health) that might be obscured in population-based data sets; 3) significant detail on issues identified; and 4) recommended approaches to address identified problems. Overarching questions for the primary data component, which—consistent with DSRIP—focused on Medicaid and other low-income populations, as well as the uninsured, included:

- To what extent are community and environmental conditions conducive to health promotion and disease prevention?
- What are the primary health concerns and health needs of residents, overall and according to neighborhood and socio-demographic characteristics?

- What are the health related programming and services available to community residents, what organizations are providing the services, and what are the service gaps?
- Are there differences in access, use and perceptions of health related programming and services according to neighborhood and according to ethnic, racial, and language groups?
- In what ways can health promotion and health care needs be better addressed, overall and for distinct populations?

## **FINDINGS**

Queens community members and other stakeholders are clearly interested in partnering with hospitals and being part of solutions that promote good health and reduced hospitalizations. Many are wary, fearing that hospitals will not fully engage with the community going forward, as most lack experience doing so and the financial incentives of health system re-engineering are unclear. The predominant theme in Queens is seemingly “diversity,” given the large numbers of foreign born – as well as a sizable African American population in particular neighborhoods. This diversity brings with it strengths, as well as multiple challenges regarding language, culture, and economics. Focus group and interview participants articulated specific barriers to good health and good health care, many of which were related to poverty and its consequences, including long work hours, unstable housing, and the need to prioritize expenditures—even among basic needs. For specific groups, including the disabled, LGBTQ, criminal justice involved, and the homeless, health-related barriers were compounded, due to both attitudinal and practical considerations.

Focus group and interview participants also articulated potential “fixes,” such as increased ease of access for medical visits (e.g., reduced wait time, reduced insurance restrictions, increased integrated care); improved provider sensitivity; and a range of supportive services, including community health workers, care coordinators—particularly for difficult to manage medical conditions and high risk populations—and navigators. Health education, addressing (for example) prevention, screening, disease management, insurance, and the normalizing of mental health issues, was considered essential at the individual and the community level, to ensure that the population has the knowledge and skills necessary for independent action that promotes their own good health.

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**INTRODUCTION**

The goal of the Delivery System Reform Incentive Payment (DSRIP) program is to promote community-level collaborations and focus on system reform in order to reduce avoidable inpatient admissions and emergency room visits by 25% over five years for the Medicaid and uninsured populations in New York State. To inform the health system transformation that is required under the DSRIP program, emerging Performing Provider Systems (PPS's) must submit a comprehensive Community Needs Assessment (CNA) with their Project Plan applications. The Queens PPS's CNA, conducted from July through September, included primary and secondary data analysis and had the following aims:

- To describe health care and community resources;
- To describe the communities served by the PPSs;
- To identify the main health and health service challenges facing the community; and
- To summarize the assets, resources, and needs for proposed DSRIP projects.

This report describes the primary data methodology and analysis and has been developed as an attachment to the full CNA, and to provide more in-depth information to the PPS's, which may be useful for DSRIP project planning, as well as planning and implementation of programs and services outside of the DSRIP program.

**METHODS**

**PROTOCOL DESIGN**

The Center for Evaluation and Applied Research (CEAR) at The New York Academy of Medicine (NYAM) conducted the primary data portion of the CNA, which included surveys of community residents, and focus groups and interviews with Queens residents, providers, and other stakeholders (see appendix for data collection instruments). The protocol was developed in collaboration with selected PPS's in Queens, Brooklyn, the Bronx, and Manhattan and was approved by the NYAM Institutional Review Board (IRB).

The primary data component was designed to address anticipated gaps in the secondary data, including: 1) community member and stakeholder perspectives on health issues, including their causes and impact; 2) data on populations (e.g., particular immigrant groups) and issues (e.g., links between incarceration and health) that might be obscured in population-based data sets; 3) significant detail on issues identified; and 4) recommended approaches to address identified

problems. Overarching questions for the primary data component, which—consistent with DSRIP—focused on Medicaid and other low-income populations, as well as the uninsured, included:

- To what extent are community and environmental conditions conducive to health promotion and disease prevention?
- What are the primary health concerns and health needs of residents, overall and according to neighborhood and socio-demographic characteristics?
- What are the health related programming and services available to community residents, what organizations are providing the services, and what are the service gaps?
- Are there differences in access, use and perceptions of health related programming and services according to neighborhood and according to ethnic, racial, and language groups?
- In what ways can health promotion and health care needs be better addressed, overall and for distinct populations?

### **DATA COLLECTION**

**Community Engagement:** Consistent with DSRIP CNA guidance, NYAM conducted primary data collection in collaboration with numerous community organizations, which were identified in collaboration with PPS representatives, and represented a range of populations (e.g., older adults, immigrant populations) and neighborhoods. As described below, community organizations assisted in recruitment for and administration of focus groups and surveys. All organizations assisting with survey administration or focus group facilitation were provided with written guidelines including information on data collection and the general research protocol, the voluntary nature of research, and confidentiality. Organizations also participated in an in-person or phone training on data collection conducted by NYAM staff. Community organizations partnering in the research received an agency honorarium consistent with their level of responsibility.

As described in a subsequent section, community members and stakeholders were largely responsive to the request to participate in the CNA. Although several expressed concern that their input and recommendations would not ultimately be used in the selection and planning of DSRIP projects, they appreciated the ultimate DSRIP aims and the opportunity to have their opinions heard.

**Data Collection Activities:** As noted above, the primary data component involved three distinct methodologies:

- **Resident Surveys:** 605 surveys were completed by Queens residents, ages 18 and older. Survey questions focused on basic demographics, health concerns (individual and

community-wide), health care utilization, barriers to care, and use of community and other services. Survey respondents were identified and recruited by local organizations, including community based organizations, senior centers, social service and health providers, and through NYAM initiated street outreach in targeted neighborhoods—consistent with PPS service areas—where we wanted to ensure sufficient representation, including Jamaica, Flushing, Woodside and Corona. Surveys were self-administered or administered by NYAM staff or staff or volunteers at community organizations, who were trained and supported in survey administration by NYAM staff and consultants. The surveys were translated into 10 languages: Arabic, Bangla, Chinese (simplified and traditional), Haitian Creole, French, Hindi, Korean, Polish, Russian and Spanish. Participants received a Metrocard valued at \$10 for completing the survey.

- Key Informant Interviews: Twenty-two key informant interviews were conducted, including 27 individuals. Key informants were selected with input from the PPS's. A portion had population specific expertise, including particular immigrant groups, older adults, children and adolescents. Others had expertise in specific issues, including supportive housing, care coordination, corrections, and homelessness. All key informant interviews were conducted by NYAM staff using a pre-written interview guide. All key informants were asked about perceptions of health issues in the community, barriers and facilitators to good health, health care and other service needs, and recommendations for services and activities that may benefit the local population. Follow-up questions, asked on *ad hoc* basis, probed more deeply into the specific areas of expertise of key informants. The interview guide was designed for a discussion lasting 60 minutes; in fact, interviews ranged from 45 to 120+ minutes. All key informant interviews were audiotaped and professionally transcribed to ensure an accurate record and to allow for verbatim quotations. (See Appendix for the list of Key Informants by name, position, and organization.)
- Focus Groups: Eighteen focus groups were conducted for the Queens Community Needs Assessment, involving over 200 participants. Most of the focus groups were with community members, recruited by collaborating CBOs. Populations targeted included, but were not limited to, older adults, Asian and Latino immigrant populations, LGBTQ, and individuals with disabilities. The mean age of survey participants was 53; 56% were female; 12% were Black, 41% Asian, and 25% Latino; 47% were on Medicaid and 14% were uninsured; 43% reported speaking a language other than English at home. In addition to the resident groups, we conducted a small number of focus groups with community leaders, as well as providers, including behavioral health providers, care coordinators, and physicians, so as to ensure that the perspective of key stakeholders was incorporated into the findings. These groups were coordinated by collaborating PPS's.

Focus groups lasted approximately 90 minutes and were conducted using a semi-structured guide, with questions that included, but were not limited to: perceptions of health issues in the community, access to resources that might promote health (e.g., fresh fruit and

vegetables, gyms), use of health services, access to medical and behavioral health care, domestic violence, and recommendations for change. Follow-up questions were asked on *ad hoc* basis, based on responses heard. Focus groups were conducted by CEAR staff members and consultants retained by CEAR, each of whom was trained in the established protocol. Many of the resident focus groups were co-facilitated by representatives of CBOs that were also trained on the focus group protocol. Focus groups in languages other than English and Spanish were conducted solely by trained community partners. Participants received a \$25 honorarium, in appreciation of their time and insights. All focus groups were audio recorded, so that transcriptions and/or detailed reports could be developed for each, and to allow for verbatim quotations.

**DATA MANAGEMENT AND ANALYSIS**

Surveys: Survey data were entered using Qualtrics, a web-based survey platform. They were analyzed according to standard statistical methods, using SAS. Means and proportions were generated, overall and by neighborhood. Although the survey sample cannot be considered representative of the catchment areas in a statistical sense, and gaps are unavoidable, the combination of street and organizational outreach facilitated engagement of a targeted yet diverse population, including both individuals connected and unconnected to services.

Survey respondents came from all Queens neighborhoods; socio-demographic characteristics included: 64% female, 11% Black/African American, 20% Latino, 54% Asian (primarily Chinese, South Asian, and

Korean), 72% foreign born, 39% limited English proficient, 70% living below the poverty line,

<b>Table 1: Demographic characteristics</b>	
<b>Characteristic</b>	<b>(n = 605)</b>
<b>Age (Mean, SD)</b>	50.2 (19.8)
18-20	3.6%
21-44	39.3%
45-64	29.1%
65-74	11.7%
75-84	10.3%
85 and older	4.1%
Unknown	1.8%
<b>Gender</b>	
Female	64.0%
Male	35.7%
Transgender	0.3%
<b>Sexual Orientation</b>	
Heterosexual	94.4%
LGBTQI	5.7%
<b>High school graduate or higher</b>	80.5%
<b>Hispanic</b>	19.5%
<b>Race (N=584)</b>	
White	20.2%
Black or African American	10.8%
Asian	53.9%
American Indian or Alaskan Native	1.0%
Native Hawaiian or other Pacific Islander	0.2%
Other/mixed/unknown	13.9%
<b>Limited English proficient</b>	38.6%
<b>Foreign born</b>	71.7%
<b>Health Insurance</b>	
Medicaid	43.0%
Medicare	25.6%
Private/commercial	16.1%
VA/Other/More than one	17.8%
None	19.3%

43% on Medicaid and 19% uninsured. The mean age of respondents was 50.2, with a standard deviation of 19.8 (see Table 1).

Interviews and Focus Groups: Transcripts and focus group reports were maintained and analyzed in NVivo, a software package for qualitative research. Data were coded according to pre-identified themes relevant to health, community needs, and DSRIP, as well as themes emerging from the data themselves (see Appendix for code list). Analysts utilized standard qualitative techniques, involving repeated reviews of the data and consultation between multiple members of the research team. Analyses focused on 1) common perceptions regarding issues, populations, recommendations, etc., 2) the unique knowledge and expertise of particular individuals or groups and 3) explanatory information that facilitated interpretation of primary and secondary source data.

## **FINDINGS**

### **IMPORTANCE OF COMMUNITY ENGAGEMENT**

As noted above, key informants and focus group participants largely welcomed engagement in the community needs assessment and appreciated the opportunity to provide input that might be used for the re-engineering of health care in NYS. They were enthusiastic about the basic DSRIP aim of shifting health-related efforts from inpatient services to the community, where the focus can be on prevention and health maintenance. As described in some detail within this report, CNA participants had numerous ideas regarding health promotion, disease management, and improved health systems. However, a number of respondents expressed skepticism and concern that suggestions from the community—and recommendations in the interest of community based organizations—would be ignored by the hospitals that are applying for DSRIP funds, in part because the DSRIP goals are seemingly contrary to their financial interests and inconsistent with usual practice.

*The hospitals don't like doing things outside of the hospitals... They always try to do it themselves and do it...acting as if they're going to incorporate the community, the nonprofit organizations, community-based organizations and so on. But they find any way possible to not include them and to do it within their own structure. They're challenged with having to change ... in a way that's going to hurt them [i.e., reducing readmissions and revenue], and then they're also told that they're forced to integrate the community and community providers and they're not used to doing that. So there's a lot of fanfare ... but in reality it it's not in their best interest to do either one of the two things, integrate the community and community providers, community service providers, or to reduce their inpatient hospitalizations by 25%. (key informant, multiservice organization)*

The importance of alignment with community-based recommendations and the need for solutions that address the social determinants of health were emphasized. For example:

*My greatest fear is that hospital will get the money from DSRIP and they will define what to do. As opposed to going outside the door, getting people and saying, "Listen, what do you think that we could do to really minimize this problem" ... You really have to seriously listen to [community] and then they really have to be partners. You know, you just cannot use the community for something and then discard. (key informant, CBO)*

*We may not like every aspect of the waiver, but it is much better than past waivers. But there's still concerns, legitimate concerns that include how things are going to be done in terms of engaging communities. ... you can write it all in the document and say all you want, but we're talking about, historically, hospitals not knowing how to do it. (key informant, health advocacy)*

*The [PPS's] really, I think, often naturally gravitate towards the medical solutions. And what we try to say is, "Yes, but without housing you're never going to achieve that." And when you go talk to the frontline staff, whether they're in your emergency department, your social work department, your nurses, they're going to tell you that this guy needs housing. We were on a panel a while ago, and [a doctor] opened by talking about how she had started a double shift on a Saturday morning, and discharged a guy who was homeless. He came into the emergency department inebriated, had fallen. They kind of fixed him up. She discharged him. That night he came back and had smashed his face and was inebriated. And as she was ordering the expensive tests to see if he had facial fractures, and the plastic surgeon, and everybody had come in, she knew that she would kind of repair this thing. But that he was just going to be back. And until we got housing for him, she was just doing Band-Aids. (key informant, health advocacy)*

There were also concerns regarding the mismatch between, on the one hand, an emphasis on prevention and community engagement, and on the other, clinical and utilization measures that may not reflect the highest priorities of the community. For example, addressing obesity, particularly among children, is unlikely to impact hospitalizations and ER use in the short term.

*I think that's a real challenge, because when we're looking at things like DSRIP, we're looking at preventing hospitalizations, ... Children who are obese don't get hospitalized. They get hospitalized and they use higher cost services when they become adults but then all this money is gonna be gone. So you know, so nobody's looking at doing something that you need 15 years to have an impact on. Everybody's looking at something that you can have an impact on today or tomorrow. (key informant, provider)*

## **POPULATION DESCRIPTION**

**Poverty:** Given the DSRIP and CNA focus on low income populations, the significance of poverty and its implications is unsurprising. As noted above, 70% of survey respondents were living below the federal poverty line; in Jamaica, 78% of respondents were living below the poverty line and 62% report that in the last year they sometimes worried about not having enough to eat. Overall, 53% of survey respondents report that they worried about not having enough to eat (see Appendix for detailed data tables).

Although the health related implications of poverty may vary by population, common themes were evident: poverty was describing as directly affecting health; affecting prioritization (or de-prioritization) of health behaviors; and as affecting access to health related resources, including nutritious food, stable and well-maintained housing, health care coverage, and medical services:

*Most of us parents are constantly working, and many times we don't have the time to commit to cooking a healthy meal every night – and so, we resort to fast food. (focus group participant)*

*We also have identified that there's food insecurity because of lack of available funds to maybe buy the groceries that they need. So people are making those decisions every day about, “Well, what can I buy, what can I afford with my limited amount of income for this month?” And oftentimes nutrition suffers in that mix, because they'll get their medication instead of buying the food. And sometimes we found they won't get their medication either. (key informant, CBO)*

The behavioral implications of living in poverty were clear to focus group participants and to key informants that worked closely with community members. There was frustration that many health care providers appeared to lack a similar level of understanding.

*I'm just gonna reflect on a conversation I had with a father who was there with this 12-year-old son who was already showing signs of pre-diabetes and he just, he looked at me and he says, “You, there is no way you are ever going to understand my life.” I said “You're absolutely right. I can hear what you're telling me but I don't understand how hard it is for you to have food in your house, and how hard it is for you to get your child to eat the right things and exercise which is the only way that's gonna prevent him from getting diabetes as this point.” But I think that what he expressed is his frustration that the general medical community could not understand the problems of people living in poverty when their children have health problems. (key informant, provider)*

Foreign Born: Among the most consistent themes across data collection activities was the concentration of foreign born in Queens, and the seemingly unprecedented diversity of many of the target neighborhoods, particularly Elmhurst, Corona, Jackson Heights, and Flushing. Seventy-two percent of survey respondents were foreign born. Large foreign born populations in Queens include Chinese (from different countries and provinces), Koreans, Latinos (from Puerto Rico, Ecuador, Colombia, Dominican Republic, and elsewhere), and a growing—and increasingly diverse—South Asian population, including groups from India, Pakistan, Bangladesh, and Nepal. Although there are many overlaps, each of these communities has needs related to culture, language, education, and economics, which may impact on health and healthcare use. In addition, the strengths of these and other immigrant communities were emphasized, which may include close family ties, strong work ethics, and healthy eating habits relative to American born populations. Common themes from key informants and focus groups representing diverse population groups included some combination of:

- Significance of language access across the spectrum of services;
- Difficulties meeting basic needs, leading to extended work hours and emotional stresses;
- Prioritization of work, children and education over health;
- Lack of sufficient information on health and health services;
- Minimal knowledge, interest, and engagement in prevention services;
- Low utilization of health care services, relative to other populations;
- Cultural issues, including greater stigmatization of particular health conditions;
- Relatively high rates of non-insurance, due to multiple factors including ineligibility; and
- Fear of medical bills, medical debt, and deportation.

*In the Borough of Queens, one of the biggest barriers to healthcare is the ethnic diversity that exists here. So it's not even just about language. Language, of course, is a barrier, but more easily addressed than cultural barriers. And in some cultures, seeking out healthcare is just not something that they do. They're not comfortable with it, especially if a person has a questionable immigration status. They're extremely hesitant... So a lot of times what happens is that the emergency room becomes a primary care provider, because they don't have preventive care. They're not keeping up with regular routine visits, they're not monitoring their status. (key informant, CBO)*

Concerns about language access obviously suggest concrete requirements with respect to knowledge and skills. Although many CNA participants described significant capacity among Queens providers, there was some concern regarding training, skills, and credentials of dual role interpreters (i.e., bilingual staff who are asked to interpret on an *ad hoc* basis) and gaps in services remain, particularly for smaller language and ethnic groups, and for particular services, including mental health care and specialist services:

*The main issue [in the Nepali community] is language .... Our family member shouldn't have to explain medical conditions to us unless they are also medical practitioners, because even an educated and good English speaker may not understand medical terms, and so they aren't able to interpret what is going on. (focus group participant)*

*When you look at specialty care, say around mental health, for example, if an individual wants to go to someone who's culturally competent, we don't have a lot of Asian-Americans who are going into fields like mental health or behavioral health issues. (key informant, health advocacy)*

CNA participants were consistent in their reports of very long work hours among multiple foreign born groups. Descriptions of 16 hours days, six or seven days a week were not uncommon. Small business owners felt the need to keep shops open for extended hours, taxi drivers report 12 hour shifts without a break, and laborers work multiple jobs because pay is low. Key informants and focus group participants reported that some workers are supporting large families in the US, while also sending funds to relatives in their home country. Such long work hours impact health and access to health care services

*Small business that include the liquor stores to laundromats to deli stores. They're the most common ones [Koreans] have. So, because you are small business owner or worker who work at those small businesses, your working hours are much longer, because they are open at 7:00 up to like 10:00-ish. And you barely get to have a day off. And then a lot of workers also work in restaurant field so that's also long, labor intensive work. (key informant, CBO)*

*We see people [in the Latino community] who have very low paying jobs. But as long as they're able to have their children in school, as long as they're able to maybe send them to a community college – really the vision and the longer term goal is about their children, and their children having better futures... I don't like frame it as it's their concern and that it's their fault, but they're so concerned about jobs that other things kind of fall to the wayside. So health is a key part of that really. (key informant, CBO)*

Independent of work and language access issues, key informants and focus group participants described cultural, attitudinal, perceptual and knowledge-based barriers to care among the foreign born, including greater stigmatization of particular health conditions, difficulties navigating the health insurance and care system, low prioritization of preventive care services, and fear of medical bills and deportation if they engage with any part of “the system.”

*[Arab] women if they have breast cancer, they try to hide it as much as they can, because they don't want the community to know that their girls might get it. They might inherit it*

*from the mother. Nobody will marry their daughters, so all these problems, they feel like they don't let anyone in the community – even though confidentiality is a very big issue for us and very important for us, but they feel very protective of themselves. They don't want anybody to know about health issues and health problems. (key informant, CBO)*

Fear of medical bills and deportation was greatest among the undocumented but affected other immigrant groups, as well.

*You also have insurance literacy and like, “What does a co-pay mean?” And some of the complexity of some of the plans, the way they're designed, you have co-payments and then you have co-insurance which is distinct. And then on top of that you have your premiums. And so, that's – we say this all the time, but that type of stuff is confusing to all of us, so how [immigrants] are able to navigate that moving forward and use their insurance, is huge. (key informant, health advocacy)*

*Oftentimes they would forego getting any care, getting screenings, or even if they were deathly ill, they will totally wait until the end, and even with people who had insurance, because they were afraid of the cost of care. (key informant, CBO)*

*Those are some of the most prevalent cases we get. Where people say, “I have this bill. I don't know how I could ever pay this bill.” Often, even though in many cases we will help resolve the bill through the financial assistance policy, the person never wants to go back to the hospital again because that happened... Any hospital... Often they'll have gone for like one appointment, and they get like a \$7,000 bill. It just doesn't make sense to them. So it's just scary, right? So it does feel like hospitals don't really get the impact that a scary bill can have to their patient's desire to ever come back to the hospital. (key informant, CBO)*

It was reported that immigrants that regularly returned to their home country used medical services there. It was also reported that immigrants received prescription medicines from their home country, as the costs of medicine were generally much lower outside the US.

### **PHYSICAL HEALTH ISSUES**

**Overview:** Survey respondents felt that the most common physical health concerns in their community were diabetes (53%), high blood pressure (46%), cancer (36%), obesity (33%), and heart disease (33%) (see Table 2). Similarly, the most common areas where they reported additional health information was needed were diabetes (53%), exercise and physical activity (47%), and cancer/cancer prevention (40%). Community members clearly recognize that obesity was linked to diabetes and heart disease and talked about the need for healthy eating and physical activity. For some, change was described as challenging:

*I am more familiar with the right ways of nutrition and I am trying to get used to it as much as I can. (focus group participant)*

Others report that they—and other community members—are making efforts to exercise and to eat well, so as to remain healthy.

*I used to think, ‘if I don’t eat rice, I’m not eating’ but now I don’t eat rice, and I am still alive. (Focus group participant)*

*Seniors are aware of exercise. In my neighborhood there are two groups along the parkway for seniors to do exercise: Tai Chi. In my neighborhood, residents walk in their walkers around the houses. Here in Flushing, in the park, a lot of people are doing activities. Seniors are more aware than before. (Focus group participant)*

*People are getting more health conscious, joining a gym... Not where we ought to be, but as [the Haitian] community we’ve definitely made some progress in the direction that we should*

*have in obesity and child obesity—a little better, understanding it and making some kind of life change. (key informant, CBO)*

<b>Table 2: Health Concerns</b>	
	<b>Queens (N=599)</b>
Adolescent health	8.0%
Asthma	19.4%
Arrest and incarceration	6.3%
Cancer	36.0%
Diabetes	52.8%
Disability	11.7%
Drug and alcohol abuse	25.5%
Family planning/birth control	6.0%
Hepatitis	7.4%
Heart disease	32.7%
High blood pressure	45.6%
HIV	10.5%
Maternal and child health	9.5%
Mental health (e.g. depression, suicide)	23.2%
Obesity	33.3%
Pollution (e.g. air quality, garbage)	13.5%
Sexual transmitted infections	7.5%
Stroke	11.2%
Teen pregnancy	9.4%
Tobacco use	24.4%
Violence or injury	12.4%
Other	3.0%

Just over one-quarter of survey respondents reported being in fair or poor health. The most commonly reported health issues were high blood pressure and high cholesterol (both approximately 28%) and chronic pain (19%). Fifteen percent reported having diabetes (see Table 3). There appeared to be some variability in health and health concerns according to

population. According to one key informant working with older adults, reported that African Americans had more illnesses at a younger age, compared to other populations, possibly due to historically poor access to health care services in minority communities. Survey respondents in Jamaica were more likely to report that HIV was a health concern (26.4%, compared to 11% for the full sample) and more likely to report having asthma (19% compared to 11% for the full sample). Overweight and obesity rates were highest in Jamaica and in the Western Queens UHF neighborhood (Corono, Elmhurst, Jackson Heights, etc.) —53% in each, compared to 44% for the full sample (see Appendix). The Asian population appeared to have better dietary behavior (more vegetables, although commonly fried) and greater levels of physical activity (e.g., walking, yoga, tai chi) than other populations. However, smoking rates were reported to be high, particularly among Asian men.

<b>Table 3: Health Status</b>	
	<b>(N=605)</b>
<b>Perceived health status</b>	
Excellent/very good/good	72.6%
Fair/Poor	27.4%
<b>Body mass index (Mean, SD)*</b>	
	25.2 (5.2)
Underweight	4.7%
Normal	51.0%
Overweight	29.5%
Obese	14.8%
<b>Health Issues Faced</b>	
Asthma	10.5%
Cancer	4.5%
Chronic pain	19.4%
Depression or anxiety	16.9%
Diabetes	15.3%
Drug or alcohol abuse	2.6%
Heart disease	12.9%
Hepatitis C	1.9%
High blood pressure	28.3%
High cholesterol	27.7%
HIV	1.9%
Mobility impairment	10.3%
Osteoporosis	13.9%

*I think Asians and Koreans in general, especially men, there are many smokers. Just in our populations, so smoking is another issue. If you actually walk on Main Street [in Flushing], there are a lot of people smoking. (key informant, CBO)*

Access to healthy foods was described as sufficient in most neighborhoods (76% of survey respondents reported that healthy food was available or very available), although limitations were described in Jamaica. (63% reported healthy food was available or very available). According to one Jamaica based provider: *We preach to our patients and they go home and they don't have much in the way of good options (key informant, health care provider)*. Even where healthy food was available, some CNA participants

reported that purchase of unhealthy choices was common.

*I live in Elmhurst. Generally, most of the supermarkets are Asian, we have a Stop and Shop and generally the food is very healthy.... And we have choices, so we are not, even when we go to the Corona Park and Rego Park, that area, when we go to the*

*supermarket we have choices still. The food is generally healthy. The meat and the fish and the vegetables, we have options. (focus group participant)*

*I shop at the Trade Fair on Astoria Boulevard on 99th street. You can see the shopping carts filled with a lot of junk food. (focus group participant)*

The ability to manage health conditions was impacted by a number of factors, including broader environmental conditions (e.g., indoor and/or outdoor pollution in the case of asthma), knowledge, attitudes, disease management skills, conflicting priorities, depression, and poverty. Although the implications of these factors on health and disease management are described throughout this report, additional comments illustrating these factors include:

*[In the South Asian community] they don't consider high blood pressure or diabetes. It doesn't show. They don't feel anything unless it is very very acute, so they don't think it needs to be [addressed].... Like, "Oh, it's okay." They don't feel it, so to them it's okay. And you probably remember, a kind of fatalistic attitude. So it's the good deeds that you have done, you can take a few, it's all there, it's all karma, it's all something. It's like, if you need to go you need to go, that sort of thing. That's there, right? And it's a coping strategy as well. (key informant, CBO)*

*So their medications in the early part of the year, they can keep up with. And then toward the latter part of the year, they have difficulty and sometimes have to make that decision whether to fill the prescription or fill their shopping cart. Or they start taking their medication every other day. You know, they find very creative ways of making it last. (key informant, CBO)*

*There are people who are very fragilely or inappropriately housed. Like a 65-year-old man with extreme diabetes, who is living in the 4th-floor walkup in his daughter's overcrowded apartment, sleeping on the couch. That man is not going to have good health outcomes. He's stressed. He's not getting out. Can't get a good meal. (key informant, health advocacy)*

## **BEHAVIORAL HEALTH ISSUES**

**Mental Health:** Behavioral health issues were seen as common in all populations. Twenty-three percent of survey respondents reported that mental health issues were a main concern in their community; 17% report personally facing depression or anxiety. For immigrant groups, depression and isolation were reported to result from the pressures of migration and assimilation, long work hours, and social isolation. Typical comments include:

*I think there's just a lot of trauma about what [Latino immigrants have] left, and then the process of trying to integrate here. And to some extent, a good amount of isolation.*

*When you're working so much, you don't really have as much time to seek out other things that are not hard work. So we've seen that as kind of crisis moments where people come in and they're like, "I can't take this anymore." (key informant, CBO)*

*From day one in the United States there is mental pressure. There is depression and frustration because my experiences, qualification and education from [Bangladesh] are not compatible with the demands here. There is no job satisfaction. We aspire to do well in this country, but the realization of not being able to is frustrating. (focus group participant)*

*The Chinese population is depressed because they came from their home to a new environment. Maybe they felt they had a good life back then, but here it's a different situation. And the language barrier makes it so they don't have as many friends to talk to. (focus group participant)*

Depression was also cited as relatively common in older adults, with implications for physical health and disease self-management.

*And also one of the issues on the physical side that is connected with isolation is poor nutrition. A person oftentimes when they're alone has no incentive to cook or to eat. And we find that many of the [older adult] clients that [we see] are nutritionally compromised. (key informant, CBO)*

*When people entering old age stop working. Work is very important, because it distracts you, physically and mentally. If you don't have work, you fall little by little into depression. (focus group participant)*

Alcohol and Other Drugs: Substance abuse, particularly alcohol, was described as problematic for individuals and for health care delivery. There were suggestions that alcohol issues were particularly pronounced among foreign born populations.

*I grew up in New York in my 20s and we drank hard and we partied, but I feel like the new immigrants are not acclimated to the amount of alcohol that's available and the way we drink. I don't know the answer to this. But I see on Roosevelt Avenue people crazy drunk like I've never seen before, so those people are not being reached [in AA]. Maybe different languages in this neighborhood are not being reached and represented (focus group participant)*

Emergency department staff reported that caring for patients with alcohol issues was difficult and put a strain on ED resources. Comments from a focus group of emergency department providers include:

*We see a pretty large group of patients with alcohol related issues. And so those patients are very regular here and very difficult, despite trying to get interventions for them, whether it be psychiatric interventions or substance abuse interventions. It's extremely difficult to get them connected and to get them to stay in any kind of program. So we can see them more than once a day, and it wouldn't be surprising....And I'll also say there are some private hospitals in the area that the expectation is the patients are going to come here. We're an HHC hospital. This is an intoxicated patient. You bring them to the city hospital.*

*Once we admit a patient with intoxication, we treat and release, they go back and drink... We can give names of places [for treatment], but many patients do not follow... They go out, drink and come back.*

#### **ACCESS TO RESOURCES AND SERVICES**

**Resources for Good Health:** As noted above, survey respondents in most neighborhoods reported that healthy foods were available or very available (76%). Residents of Jamaica were least likely to report that healthy foods were available (63%). Places to walk, exercise and play were also reported to be available in most neighborhoods (79%). In contrast, just 34% of respondents reported that affordable housing was available or very available (see Table 4). Consistent with this survey result, multiple key informants described crowded and instable living conditions, with implications for health and well-being:

*Because of increase in rent, more families are moving in together, even with strangers. Children are exposed to all kinds of things as a result. Toxic stress. You go to school with all the stress, and the little things just make you explode. (key informant, provider)*

*The other issue is they're staying with friends and relatives and cousins, they move a lot. So they have different homes and different parents or families, and children move so much that that also causes the same destruction in whatever set up that they've got ... The phones change every other day, the phones change, because they don't have the money to pay the bills, and now you're stuck with, "How do you reach this guardian?" You have a child who's sick and you need to get hold of mom or dad, and it's very hard to reach them (key informant, provider)*

*There's a lot of housing issues and things that [the Asian community doesn't] really want people to know about. We room together in like a two, three bedroom, you know, three or four families living together, these kinds of things. (key informant, provider)*

**Medical services:** Approximately one quarter of respondents reported that there was a time in the last year when they needed healthcare but didn't get it. The most commonly noted reasons for that were "not insured" (41% of the subsample), "could not get an appointment soon or at the right time" (17%), and "cost of copays" (13%). They did, however, report relatively good access to most types of medical care. Approximately 80% of survey respondents reported that primary care was available or very available, 77% reported that they had a primary care provider or personal doctor, and 76% reported that had a routine check-up in the last 12 months. However, access obviously varies according to individual characteristics:

	<b>(N=605)</b>
Accessible transportation	86.9%
Affordable housing	34.1%
Dental services	71.2%
Healthy food	76.2%
Home health care	66.4%
Job training	38.4%
Medical specialists	72.4%
Mental health services	54.6%
Pediatric and adolescent services	73.4%
Places to exercise, walk, and play	79.1%
Primary care medicine	79.8%
Social services	67.3%
Substance abuse services	39.1%
Vision services	69.4%

\*Percentage reflects participants who responded very available or available

*I would say the majority of immigrants that we hear about go to HHC. I think that some go to FQHC's. A lot of people though pay out of pocket to go see their own providers. That's actually fairly common. (key informant, health advocacy)*

Seventy-three percent of survey respondents reported that pediatric and adolescent services were available/very available. Seventy-two percent reported that medical specialists are available/very available, although there was significant variability in responses according to neighborhood (e.g., 57% in northwest Queens, compared to 85% in north Queens). Several key informants and focus groups participants reported on relatively poor access to specialist services.

*There's still a ton of people in the community that we've served that have chronic illnesses that are the result of a whole bunch of different factors that primary and preventative care are just not going to be able to address. And so there's a gap in primary care providers' ability to find specialists who are accepting Medicaid or different kinds of insurance. (key informant, health advocacy)*

Behavioral Health Services: Survey respondents reported that behavioral health services are less available than other types of care: 55% reported that mental health services were available/very available (range: 30% in northwest Queens, 79% in central Queens) and 39% reported that substance abuse services were available/very available. Mental health services for children and adolescents were described as particularly limited, as well as culturally and linguistically competent services. As described by a key informant working with the Latino community:

*People going through really crappy situations on a day-to-day basis that wears them down over time. And then, people come to us and they're just like, "Where can I go? Who can I see?" And really what they need is not to be admitted to a long-term thing. They need to have someone to be able to talk to. And, you know, the folks that don't have insurance – there's just nothing for them, right? I guess one thing is the language issue. There aren't a ton of good psychologists or psychiatrists or social workers – maybe some more social workers -- but psychologists or psychiatrists that speak Spanish and can do talk therapy in Spanish. And then the cost thing, you know. Most good providers do not take insurance at all, let alone Medicaid, so that's been huge. It's been a big challenge for us to figure out, as an organization. (key informant, CBO)*

In the words of one primary care provider, “*We often throw our hands up because it is so difficult to find [adolescent mental health] providers.*” According to some providers, services that are available might also be unknown to community organizations and residents—or they might be unaware of processes for accessing them. In addition, behavioral health issues generally carry greater stigma than other health concerns, which tends to limit use of services. Key informants and focus group participants both reported that many affected individuals and families try to address problems internally—or not at all. A key informant emphasized the disparities in perceptions of behavioral health across NYC.

*In New York, if you're white having a therapist is a badge of honor, if you're black it's stigmatized. (key informant, CBO)*

According to key informants that are themselves providers, regulatory issues promote fragmentation of services.

*Depending upon the level of what people talk about, behavioral health can be done within the Article 28. We have psychiatrists who work within the [article] 28 and psychiatry can be in health clinics. They're really there to really confirm and confer. It's called a consultation liaison model and you know, you're really, the rule of thumb and it's hard to get answers out of Medicaid about how many times we can be seen. It's like a maximum of three times. So if someone needs more than just a simple SSRI, you know, you see that the psychiatrist. The psychiatrist may say you know what, "I really think you*

*should go into [article] 31” ... It's not that it's a bad thing, you know but it's just another step ... We do offer short term therapy in our 28 ... We have very limited slots and because of licensure, it has to be secondary to a medical issue because again, the Medicaid rules are very clear. (key informant, CBO)*

A number of providers suggested that there is even poorer integration within behavioral health services themselves than between physical and behavioral health. Behavioral health services are reported to be highly regulated by multiple agencies: Office for People with Developmental Disabilities (OPWDD), Office for Alcoholism and Substance Abuse Services (OASAS), and Office of Mental Health (OMH) with patient care being restricted according to the funding and regulatory agency—despite the frequency of co-occurring disorders. Thus, a mental health provider might be limited in the severity of illness that can be treated, the age of the patient, and other factors.

*Historically, your systems like OMH and OASAS, up until very recently, they really worked in silos. So, if you came into a mental health clinic and in your intake appointment, you said, “You know, I smoke pot a couple times a week,” a red flag would go up. You talk to your supervisor and they say, “They have to go to substance abuse.” So until those doors really become integrated, I mean really become integrated in treatment and acceptance and a model of care, we’re going to continue to run into these types of challenges because it’s very fragmented. (key informant, multiservice organization)*

Dental Care: Seventy-one percent of survey respondents felt that dental services are available or very available in their community; 58% reported having been to the dentist in the prior 12 months. Although focus group participants with good coverage reported using dental services consistently, a number of participants described dissatisfaction with services, commonly due to the high cost.

*I became a citizen but whenever I go to Korea, I’ll do my dental care there, because here it’s so expensive. (key informant, CBO)*

*You go to the doctor for one problem and they tell you 2, 3 more problems. You have a cavity they tell you to get a root canal. (focus group participant)*

Two health care providers described poor oral health (“horrible teeth”) among children.

Insurance: Focus group participants, in response to a question regarding what should change in health care, overwhelming cited insurance, including its expense, complications, and the limitations it places on choice. Limitations on choice were particularly problematic for

individuals with special needs, including individuals with disabilities and limited English proficient individuals. A key informant explained:

*So if you signed up for a plan and that doctor that takes care of your community isn't on that plan then there's not a whole lot you can do. And the other issue is you might be signed up for a provider who says he accepts this plan and then halfway through the year you're locked into the plan, [even] if the provider drops it...They do not have any commitment and so that's been – there's no accountability on the provider side in terms of staying in it. And this is particularly important for immigrants ... when you talk about languages of lesser infusion, where there are not that many providers that speak those languages or have the cultural competence. (key informant, health advocacy)*

Lack of insurance was, not surprisingly, a more common problem in immigrant communities, due to limitations on immigrant eligibility for public insurance programs, as well as more limited access to employer-sponsored care (due to restricted job opportunities). However, community members and key informants also report that income restrictions for Medicaid are unrealistically low, and self-purchased coverage is felt to be too expensive for low-income populations, given the difficulties of paying for basic necessities like food and housing in NYC. Many low income, previously uninsured, community members had been receiving free or very low cost services at FQHC's or HHC facilities; insurance is perceived to be expensive in comparison.

Lack of insurance coverage resulted in neglect of primary care, preventive services, and dentistry; limited access to prescription medications; and use of emergency care for non-urgent issues. Many focus group participants commented that they do not receive care without insurance coverage. For example:

*I was a diabetic. I had to fight [it alone] for 10 years, because I had no insurance and no place to support me. Even I didn't report my disease to my wife and children. I decided to cure it by myself. The problem is that the middle-income and middle age groups in society do not usually benefit from government-controlled health insurance programs like Medicaid and Medicare. (focus group participant)*

### Supportive Services

For populations that have difficulty accessing health care services, whether because of unfamiliarity with the system, age, language, or other factors, supportive services, including transit, health education, navigation, case management, can make a critical difference. For example:

*We have transportation services that allow many seniors access to the centers, because otherwise they'd have no other way of getting here. We provide transportation to medical*

*appointments. And not only do we provide the transportation, but we ... launched an escort program. So in addition to providing the actual transportation, we now will assist by providing a companion to travel with the senior, because what we were finding was that both in physical frailty as well as cognitive frailty, seniors needed more assistance because they often became disoriented or needed that help in navigating through the holes ... and even in medical buildings, you know, it's very difficult. And even though you may have been there before, sometimes it looks different. (key informant, CBO)*

Community Health Workers: Several CNA participants described the significance of community health workers (CHWs), and the multiple roles they played (or could play) in promoting health and appropriate health care use, particularly with respect to complicated components of the health care system, including health insurance and hospitals. From the perspective of CNA participants, training and employment of CHWs not only benefited patients and clients but also provided important training and employment opportunities for community members.

*A great model is the community health worker model. This cooperative idea is training, hiring people from the community to improve people's health. Who's better than someone who's next to you? And maybe not always, because of privacy and other issues. But if he looks like you, and he has family who comes from [the same place], they get trained in a way to do it. It would be great to have more community health workers around everywhere. (key informant, health advocacy)*

*There's some work to be done on the pre, coming into the hospital ... making sure that all the doctors have been pre-certified and pre-cleared, making sure that people did or did not drink or understood exactly all the instructions they needed to follow before coming into the hospital. Making sure that they know where to go when they go to the hospital, so it's not so scary and daunting and maybe so scary and so daunting that perhaps someone doesn't show up, because it just sounds a little too overwhelming. (key informant, health advocacy)*

Particularly for immigrant communities, CHWs—whether they be health educators, navigators, or advocates—helped to ameliorate the pervasive language and cultural barriers. A key informant working with the Latino community commented:

*They are people that come from the community, that speak the language, and that are trained up on how to navigate this hospital, or how to navigate the health insurance system, etc. And so, when you plug in that person as part of the team of people that takes care of someone, and then it just makes a world of difference. So the [patient] isn't confused as to where in the hospital he's supposed to go. They ask their navigator how the primary care department is relating to the specialized care department, and there's communication happening. You know, there's advocacy being done on language*

*resources, on financial aspects... So I don't think it's the magical solution, but having someone that can help guide you through that and make it less of a scary process is huge. (key informant, CBO)*

CHWs were reported to be particularly valuable and effective in ensuring that hospital discharge plans are effectively implemented:

*We see a lot of people that – when they emerge, when they leave the hospital, and they come to us, and we say, “All right, what’s the plan?” And people often say, “I’m not sure.” “All right, when is your next appointment?” And they say, “I don’t know.” So we have to just call [the hospital] and ask, “When is this person’s [appointment]?” So they’ve been discharged, and they’re supposed to understand this stuff, but the people just don’t know... We try to find out what the next steps are. And then, often people get prescriptions, and ... people don’t understand why. If you don’t understand why you’re taking this thing, you’re less likely to keep taking it. So people stop. They get sick again. (key informant, CBO)*

*I think one of the things we do miserably in New York City ... is horrible discharge planning, horrible, horrible. And if there were these advanced primary care workers or at least community health workers, I think one of the main things I would really have them do is think about discharge planning. If [DSRIP] money is going through hospitals, I would really, No. 1, think about discharge planning and how to make that really real and follow-up calls and texts and whatever for all these folks. And making sure that there's really a system, and that the community health worker or advanced primary care worker gets a copy of that discharge plan and follows up with the patient. (key informant, health advocacy)*

**Care Coordination/Case Management:** Across populations and conditions, care coordinator and case management models were described as highly effective approaches for improving health and reducing health care use. Multiple key informants cited research studies that demonstrated positive outcomes during implementation of care coordination programs. Responsibilities of care coordinators included linkage and serving as liaison to multiple providers, health education, assistance with accessing entitlement and supportive services, and monitoring the stability and engagement of clients.

*Children with asthma and other chronic illnesses need care managers, who my suggestion would be that there is some communication from the emergency room to the primary care provider, who then reaches out to the care manager to follow up with that parent on whether or not they were, or using the medication as prescribed, whether they filled the prescription, whether they had the medication. Whether they're using the*

*medication as prescribed during a home visit to make sure that's indeed the case and ensuring that there is a follow up within one week at the pediatrician's office.*

Care coordination was seen as valuable in part because of excessive fragmentation within the healthcare system, though developing care coordination programs did not diminish the need for improved integration of care.

*I think [DISRP is] exciting for a lot of people for different reasons, but we're excited about it because we think that it's an opportunity to potentially change some of [this]. The system doesn't support us.... And when I say "us," I mean me as a representative of the client. The client themselves, it doesn't support them. And that's a problem, and we shouldn't have to be working double time, and we shouldn't have to have another system of people who we pay to coordinate care, because the system is so fragmented. You do need coordinated care and creating that resource is valuable, but this has to get unfragmented, too. (key informant, CBO)*

Unfortunately, funds for care coordination are limited and salaries for the positions are relatively low. Low salaries make hiring difficult and may necessitate selection of candidates that are under-qualified, particularly considering the expectations of the job, which include work with challenging populations, familiarity with multiple psychosocial and health issues—and the services available to address them, as well as the logistic and administrative aspects of the position, including use of multiple electronic health records.

*We have to find people that are from the managed care world, that are from the hospital world. We have to find professionals that understand those worlds and they also have to be database professionals, they have to be able to navigate Navitar, they have to be able to navigate Dashboard, they have to be able to input information into these databases, and into our own database, and to be able to do it many times offsite. You're stuck between a rock and hard place, because people with enough skills and training to work with such a high acuity, in most cases, group of clients. But then also they'll have, like the background is more like data entry... You want them to come in with some of the skills, 50% of the skills, I mean, maybe we have to teach them the other 50%. Maybe they come in with substance abuse skills but they don't know mental health and they don't diabetes and primary healthcare concerns, or maybe it's the other way around. It feels like [it's too much to ask of a person], but you have to make it work. (key informant multiservice agency).*

Lack of trust or engagement (or possibly time) in care coordination on the part of medical providers also was considered to limit the potential effectiveness of care coordination models.

*What's missing is ... saying to individual providers that this is important, and you need to be responsive, and you need to talk to people, and you need to interact with care coordinators. One of the biggest problems and flaws in the system is that in all of our contracts... we're required to go to providers, individual PCP's and psychiatrists, and get information from them both about their care that they're providing to our client or their patient or the lab work that's been done, tests, reports, anything that they're doing with our patient. We need to get access to that information so that we can help to provide better care and to guide that person along in the care that they're getting. So if they get prescribed a specific medication, we can say, "Are you taking that medication? Where are you at with it? Have you filled the prescription?" Those kind of things. The problem is, on the provider's side, they don't get paid. No one's telling them – no one's saying to them from the funder level ... "You must communicate with these people." ... so the providers ignore us. (key informant, multiservice organization)*

Finally, a consistent electronic health record was described as a challenge for agencies offering care coordination services, as they had to utilize multiple systems.

*The State's not equipped to be able to mandate [a consistent electronic health record]. So everybody is left on their own to be able to design their own or to pick and choose an on-the-shelf or off-the-shelf package. And that's been what's causing the mess. So then not only do you have that, but you also don't have the communication between Health Homes to talk about a client, where a client is ... being able to get some kind of a text message or an email saying a client is in an emergency room or a hospital. ...that should be really enhanced where we have much more access to the client's status, where that client is, when the client is in crisis, so that we can intervene and help the client. (key informant, Multiservice agency)*

Health Education: Health education was a common theme in interviews and focus groups, incorporating both education of the broader public and individual level education regarding management of complex health conditions.

*All the hospitals, for example, that saw these kids and saw a lot of admissions hired instructors, asthma care instructors, patient care instructors, who would meet regularly with the asthmatics after the physicians saw them. "Are you taking your meds? What are you taking? What do you do when you do this?" .... So that was patient educators I guess is what they called them, and it worked beautifully for all those diseases. (key informant, provider)*

Topics for education of the broader public included insurance, nutrition, screening, preventive health care, and mental health care. Information related to general awareness and related to

behavior change were both considered important. Health fairs, school based programming, and faith based programming were all seen as important venues for the dissemination of information—and for health screening. For example:

*I would love to see lots of programs in schools to target children. We have millions of people in our schools, in public schools, in private schools. Can we target the children and their parents with workshops? Education materials for them to give it to go home with every child. We'll be targeting millions of people. Public school is a big door for us, open wide for us to reach out to the children and their families, to educate them about preventive services. (key informant, CBO)*

*Teach them how to shop, read labels, especially they need to know what they're eating. Eat small portions. Eat lots of fruits and vegetables. What has sugar; what doesn't have sugar? (key informant, CBO)*

*Some of the communities that we know of—they do a lot of their health education at faith-based organizations. Faith-based organizations have access to space, for example, so many of them I know will open up their space. Groups can rent it out. They'll have exercise classes or dance classes. So I think they play a huge role. And this idea around shared use agreements, I think would be really fantastic to look at. And then civic – I mean civic associations, too, I mean they reach a certain community that might not necessarily be going for social services. So, definitely ways to integrate them. And then they're trusted in their community. They're leaders there, so if you can convince those members or leaders to partner with you on these projects, I think it would be a win-win. (key informant, health advocacy)*

*Mental health services and behavioral health are supposed to be treated as equally important. And so, insurers cannot decline to provide coverage [for mental health services]. And so, but the way that that's – the degree to which that is sort of implemented and I think communicated – education is really important to lots of communities. (key informant, health advocacy)*

*I feel that young [Arab] adults... they are the ones who are going to reach out to their parents and grandparents to educate them about what's going on, about health disparities like breast cancer. It works out for the girls, they want to talk to their mother and grandma, "Did you do your mammogram? Do you know about breast cancer?" Because of the stigma in our community about breast cancer, they don't like to do mammograms. The women are very protective, like, "I'm not going to show my breast to anyone." ... Some of them they never did mammogram in their lifetime. (key informant, CBO)*

## Quality of Care

Several concerns related to quality of care were repeatedly raised in focus groups and key informant interviews. Each of these were reported to contribute to delays in care, neglect of care, poor adherence to medical recommendations, and poor health outcomes.

- Wait times for appointments. For certain specialty services, including dieticians, wait times are reported to be as long as a year.

*People say it's not rational to go to the emergency room for care, but when we talk to people, they would say things like, "Well, I tried to make an appointment with my doctor, and it's like four months in advance." What rational person is going to wait four months rather than go [to the ER]*

- Wait times on the day of a visit and in the ER

*They give you an appointment at 10:00 am and you leave at 5:00 pm (Focus group participant)*

- Short visits that did not allow for health needs to be appropriately addressed. Community members felt that providers do what is expedient rather than what represents the highest quality of care, and ER physicians report that primary care providers refer their difficult cases to the ER, since their allotted time per visit is so brief.

*We try to encourage people to ask questions, and get as much information as possible. And often people feel like the reality is really that they have five minutes with the doctor. (Key informant, CBO)*

- Multiple and complicated referral pathways, that result in significant inconvenience and expense for patients. Limitations on subspecialty services in Queens mean that patients may be referred to hospitals in other boroughs. Furthermore, the possible need for multiple visits (e.g., for tests) discourages timely use of services.

- Poor discharge planning after emergency department visits and inpatient stays. Patients are discharged without a clear understanding of their discharge plan, including medication use and follow-up visits. In addition, follow-up appointments are not necessarily consistent or logical. For example, patients discharged after hospital stays will be referred to other institutions due to financial incentives (or disincentives). Or, in contrast, ED patients that they a primary care provider will be referred to a hospital clinic for follow-up care.

*Kids walk into the emergency room with a Medicaid card that says that they have Health First, and they get prescribed the medicine in the emergency room, and then they get*

*scheduled with a follow-up appointment at that hospital's clinic even though their pediatrician is on the card. Does that make sense? No. (Key informant, provider)*

*If I'm hospitalized at Hospital X, and I have an outpatient service – the expectation ... is that: You've had them on your inpatient service for two weeks. Have this institutional transference and pop them into your outpatient service – whether it be psych or medical. It's not happening [for homeless patients]. They're being sent to walk-in clinics. If it's a voluntary hospital, we're not seeing them take ownership. Sometimes they're sent to an HHC hospital.... The hospitals – and I say this not only about our psychiatrically ill populations but even about our family shelters: They have no clue, for the most part, as to where these homeless people are landing, what services are in the shelters, what connection they have to medical services, what they're able and not able to do. You can't give a single adult or a street homeless person an appointment for a colonoscopy three weeks from now. You can't. If you think that somebody needs a colonoscopy – you have to do it while you have them inpatient. (Key informant, provider)*

- Lack of knowledge, sensitivity, and competency regarding diverse populations, and populations with special health needs.

*Community members have reported back that doctors and health care professionals in general talk about certain illnesses, like diabetes, hypertension, heart [disease] – a lot of these things are inevitable, right? Or kind of like, “Okay, you have hypertension, here’s your medication,” as opposed to actually there are things that you can do, lifestyle changes that you can make. I remember we had a really well-known pastor at an organization we’re working with in the Bronx, and he said that he didn’t know that if you had diabetes, it didn’t mean that you had to have a limb amputated, which is pretty nuts, right? That because you have diabetes it does not mean that you have to lose limbs. I think, for whatever reason, providers may feel like when they’re talking with certain populations that it’s not worth it to talk about what else you can do to address your needs that’s not medication or that’s not amputation. And there may be some cultural biases that are – there are culture biases, I think, that are built into that way of talking to the patient (key informant, health advocacy)*

### **SPECIFIC POPULATIONS**

Low income, uninsured, and immigrant populations, as described above, face a number multiple barriers to optimal health and health care use. However, within these populations, there are a number of groups for which the barriers are exacerbated. These include individuals with disabilities, as well as individuals that are lesbian, gay, transgender, and queer (LGBTQ); criminal justice involved, homeless, or victims or survivors of domestic violence. A number of these groups are also high users of expensive medical services due to a combination of greater medical need and barriers to community based services.

Individuals with Disabilities: Individuals with physical and/or cognitive disabilities are disproportionately low income, unemployed, and have a high number of co-morbidities, including obesity, hypertension, and cardiovascular disease. Despite a high need for services, they reportedly delay care because of poor accommodation (e.g., absence of ramps, sign language interpreters) and providers that are insensitive to both their capabilities and their limitations. These access barriers—and their implications— were described by CNA participants. Unfortunately, barriers are considered more significant in community as compared to hospital settings so may become more pronounced as—consistent with the goals of DSRIP—services move into the community.

*A requirement, for example, that you come to an appointment timely, or if you miss an appointment three times, you can be dis-enrolled from a program or a provider, [is discriminatory]. If you use Access-a-Ride, for example, it is almost impossible to know when you will arrive at a location on a consistent basis. The service is simply of such poor quality that if ... you need door-to-door transportation, you need flexibility in appointment scheduling.*

*In the health setting, practitioners are often listed – clinics are often listed as being wheelchair accessible in managed care program directories. But in fact, according to a survey by the Community Service Society, it was found that these practitioners have steps at their front entrance. The providers don't even know what accessibility means. And so they list themselves as accessible, but when you go to their site or you call them on the phone, they'll say, "Oh yes, we have a few [steps] at our entrance, but that's no big deal."*

*They don't have exam tables that will lower so that you can transfer from a wheelchair. Or they don't provide ASL interpreters, either in person or by video phone or other system. .... They don't give you longer times for your appointment if it's going to take you a long time to dress and undress...*

LGBTQ: The LGBT population have both typical and particular health concerns. Utilization of health care services—even the ER—is reported to be less than needed, due to lack of sensitivity on the part of providers. Although the lack of sensitivity is particularly pronounced with respect to transgender patients, it effects lesbian, gay and bisexual individuals as well.

*So there are health disparities that we know exist among LGBT older people. And part of this has to do with the fact that they're so much less likely to reach out for help and so much less likely to get screening. So there's a higher rate of breast and gynecological cancers among lesbian women. There are higher rates of rectal cancer and prostate cancer among gay and bisexually identified men. (key informant, CBO)*

*They're not willing to be forthcoming with their providers, they withhold information from their providers, they're real reluctant particularly with transgender folks to engage in health care on so many levels and we could talk for hours about trans people like getting disrobed, what room do you go into, what's your name on the form, why doesn't this match your insurance card, why do you have breasts and a penis, can I touch this? (key informant, health care organization)*

*But even when I was in the hospital with my mother. I went there with no makeup. I clearly have boobs, have my long hair. I looked weird, and no one gave me the respect or anything. When I used to open my mouth before, I got attention and I got whatever I needed. Now it's like, "You're a freak, go away." (focus group participant)*

Isolation and perceived stigma lead to mental health concerns in the LGBT population.

*I think for many LGBT people they're separate from other minority groups, the isolation from levels of support starts at a very young age and it's within the family and within the local community and so there is a lot of effective issues that people experience just from an early age onward. I wouldn't say that the prevalence of psychiatric diagnosis is greater but there is a substantial amount of the affective issues of mood anxiety, depression and with those in particular for anxiety and depression, substances play a very key role in modulating mood. (key informant, health care organization)*

Criminal Justice Involved: Working with individuals that have been involved in the criminal justice system requires nonjudgmental staff that are familiar with the practical (e.g., Medicaid deactivations of Medicaid, parole regulations), medical, and psychosocial issues faced, including the limited economic options and high rates of trauma and mental illness. According to a key informant that works in correctional health, this population is comprised of:

*The sickest people in the city, who are the most socioeconomically disadvantaged, the most stigmatized and the least likely to access care in a way that would be, exclusive of using the emergency room and that sort of thing.*

*I think, honestly, with the, state emptying the psychiatric facilities, which nobody liked, but I'm not sure that jail is a better alternative. And right now we're talking about 40% of [the Rikers] population are mentally ill. And about 60 to 80% have some kind of behavioral health issue. And then we're talking about, you know, folks with chronic health conditions and the population in jails is aging, so now we've got diabetes and heart disease at much higher rates.*

A key informant knowledgeable in this field recommends bridging connections directly from jails/prisons to community based organizations and providers upon re-entry, to avoid emergency department use post-release:

*[There are] increased rates of hospitalization and emergency department visits post release. We've shown both those things. So anything that we do to try to systematically reduce hospitalizations would definitely benefit from partnering with local jails to help facilitate what I call warm transitions to primary care for medical and to behavioral health treatment, including drug treatment, substance use treatment so that we can avoid people coming to the emergency room 'cause that's what they're gonna do if they don't have - if they don't have a plan. I think it's kind of a no-brainer.*

Aggressive policing in Queens related to carrying condoms was reported by a key informant and in an unrelated focus group:

*The police around here take the fact that you're carrying a condom, if you're a transgender person, as proof that you're a prostitute and will arrest you. So that's, to say the least, exactly the wrong message. They've actually harassed me, as well, for giving condoms to transgender individuals on the street, accusing me of encouraging prostitution. I have to show them my ID, the letter from the Department of Health that shows my job, and they're like, "It's three in the morning. Why are you out here propositioning them?" And I'm like, "Look, here's my bag. I work for the center. I'm not encouraging them to do anything, I just want them to be safe." (focus group participant, CBO)*

*One good example is this whole access to condoms thing where right now the police can use someone having condoms as evidence of prostitution. So, we've seen that people, particularly in Queens, are stopped, searched, they have condoms, they get arrested... the access to condoms has a direct health component. Because we see people that are like, "I'm not going to carry condoms. I'm not going to use condoms anymore because they're evidence." (key informant, CBO)*

**Homeless Population:** The NYC Department of Homeless Services houses approximately 55,000 people per night through its shelter system; there are an estimated 3,000 people living on the street in NYC. The homeless population includes single adults and families with and without children. Although many are people that have come into the system due to particular interpersonal or economic difficulties, others have behavioral health issues that make it difficult to remain housed, and which may be, in turn, further exacerbated by homelessness. According to a key informant that works with the homeless:

*A lot of clients have very significant mental illness; very significant substance use – largely, alcohol, but ... a lot of opioids. ... Our clients are not different than the highest poverty clients.*

Homeless individuals are reported to be frequent users of emergency services, not only because of health conditions but because of the instability in their lives.

*Our clients use EMS all the time for things that – if one were confident that they had a medical home – they would be calling. A child has a 102 degree fever – this is not a newborn. We would call our pediatrician and ask what to do. But, they are not calling pediatricians.... I think, often feel disconnected. Maybe they've been placed in a borough that is not their home borough, and they're not connected to the doctor who was across the street.*

Recommendations for improved coordination of care, more efficient use of services, and improved health focus on targeted outreach and care coordination involving multiple hospital staff persons, including social workers in the emergency department and on the inpatient service. In addition, key informants in multiple fields emphasized the importance of supportive housing for high need homeless populations.

Domestic Violence: Domestic violence—with wives, older adults and children as potential victims— was a topic that resonated with several interviewees and focus group participants as a significant community concern that has received inadequate attention. Of Queens survey respondents, 28% reported that health education or programs on domestic violence are needed in their community; the proportion was 44% in Jamaica. Domestic violence obviously can result in both physical health (e.g., injury) and mental health issues, including anxiety and depression. Although not necessarily more prevalent, domestic violence issues were particularly relevant in immigrant communities, due to possibly different standards in their home country as compared to the US, stigma, lack of linguistically and culturally appropriate resources, and fear of deportation—particularly in mixed immigration status families.

*They came to U.S. legally with their husband, but because of abuse, and sometimes, oftentimes abusers use their immigration status as a tool to control their partner, so they ended up being undocumented, so it's much harder for them get a job. They ended up working under the table, a lot of labor trafficking issues there too by the employer. (key informant, CBO)*

## DISCUSSION

Queens community members and other stakeholders are clearly interested in partnering with hospitals and being part of solutions that promote good health and reduced hospitalizations. Many are wary, fearing that hospitals will not fully engage with the community going forward, as most lack experience doing so and the financial incentives of health system re-engineering are unclear. The predominant theme in Queens is seemingly “diversity,” given the large numbers of foreign born – as well as a sizable African American population in particular neighborhoods. This diversity brings with it strengths, as well as multiple challenges regarding language, culture, and economics. Focus group and interview participants articulated specific barriers to good health and good health care, many of which were related to poverty and its consequences, including long work hours, unstable housing, and the need to prioritize expenditures—even among basic needs. For specific groups, including the disabled, LGBTQ, criminal justice involved, and the homeless, health-related barriers were compounded, due to both attitudinal and practical considerations.

Focus group and interview participants also articulated potential “fixes,” such as increased ease of access for medical visits (e.g., reduced wait time, reduced insurance restrictions, increased integrated care); improved provider sensitivity; and a range of supportive services, including community health workers, care coordinators—particularly for difficult to manage medical conditions and high risk populations—and navigators. Health education, addressing (for example) prevention, screening, disease management, insurance, and the normalizing of mental health issues, was considered essential at the individual and the community level, to ensure that the population has the knowledge and skills necessary for independent action that promotes their own good health.