NYU Winthrop Hospital
Community Health Needs Assessment
2019

Your Health Means Everything.™

NYU Winthrop Hospital

259 First Street

Mineola, NY 11501

www.nyuwinthrop.org

1-866-WINTHROP

Adopted by the Board of Directors June 18, 2019

INTRODUCTION

Mission Statement: It is the mission of NYU Winthrop Hospital to provide high-quality, safe, culturally competent, and comprehensive healthcare services in a teaching and research environment, which improve the health and well-being of the residents of Nassau County and contiguous county areas…based on a profound commitment to an enduring guiding principle – "Your Health Means Everything."

Community Health Needs Assessment

Section 501r (3) of the Internal Revenue Service requires a hospital organization to "conduct a community health needs assessment (CHNA) every three years and to adopt an implementation strategy to meet the community health needs identified through the CHNA." To complete this requirement and produce the most effective assessment possible, NYU Winthrop Hospital participated in the collaborative assessment that was conducted by the Long Island Population Health Improvement Program (LIPHP), the grant initiative of the Long Island Health Collaborative (LIHC).

The LIHC is an expansive membership of Long Island hospitals, the Nassau and Suffolk County Departments of Health, academic partners, community-based organizations, physicians, health plans, school and libraries, local municipalities and other community partners, who hold a vested interest in improving community health and supporting the New York State Department of Health (NYSDOH) Prevention Agenda (https://www.lihealthcollab.org/member-resources/membership-directory). The Prevention Agenda is New York State's health improvement plan, the blueprint for state and local action to improve the health and well-being of all New Yorkers and to promote health equity in all populations who experience disparities.

This multi-disciplinary entity of the LIHC meets bi-monthly to work collectively toward improving health outcomes for Long Islanders. NYU Winthrop Hospital is one of the founding members of this initiative. Since 2015, the LIHC has received its funding from the NYSDOH Population Health Improvement Program (PHIP) grant. A primary responsibility of the LIHC is data collection and analysis, which is manifested in the supervision of the Community Health Needs Assessment process for the Long Island region.

In 2019, members of the Long Island Health Collaborative reviewed extensive data sets selected from both primary and secondary data sources to identify and confirm NYS Prevention Agenda priorities for the 2019-2021 Community Health Needs Assessment cycle. Designated categories for the Prevention Agenda include: Prevent Chronic Disease; Promote a Healthy and Safe Environment; Promote Healthy Women, Infants and Children; Promote Well-Being and Prevent Mental and Substance Use Disorders; and Prevent Communicable Diseases. Our assessment was guided by these categories and the social determinants of health that affect heath inequities.

I. DEFINITION AND DESCRIPTION OF COMMUNITY SERVED

Nassau County

Nassau County sits east of the borough of Queens and west of Suffolk County. It is comprised of two cities (Long Beach and Glen Cove) and three townships (Hempstead, North Hempstead, and Oyster Bay).

Total population: 1,363,069 (48.5% male; 51.5% female); those aged 65+ comprise 16.8% of the population and those aged 35 to 64 comprise 41.1% if the population. In terms of income, the median is $105,744; 26.5% of the population earn less than $74, 999 with about a third of that group earning less than $34,999 annually.

The region is predominately white at 68.9% with 11.5% Black/African American, and 9.1% Asian. Hispanic or Latino represent 16.4% of the population. The percentage of the population (5 years and over) that speak a language other than English is 28%. Of those who speak a language other than English, 42% report they speak English "less than very well." In terms of education, for those age 25 and over, 23.3% are high school graduates, 24.3% hold a bachelor degree, and 20% hold a graduate professional diploma. The percentage of people with health insurance is 94%.[1]

A "snapshot" of Nassau County from 2019 County Health Rankings & Roadmaps from the University of Wisconsin Population Health Institute – factors that drive health – rank Nassau County as number 2 in New York State for Health outcomes, and number 1 for Health Factors. Based on health factors, including socioeconomic determinants, health behaviors, clinical care and physical environment, Health Behaviors are ranked at 1, an improvement from number 2 reported in our 2016 assessment. Approximately 5% of the population is uninsured, an improvement of 5% reported in 2016.   Primary care physician rates improved; about 700 patients to one doctor, compared to 1,200 to one in NYS[2] .

Nassau County is unique in that it presents complex polarity, representing a wide range of both healthy and sick community members from opposite ends of the health spectrum. There are eight communities in which a variety of socioeconomic factors lead to vast health disparities. These communities, identified by the Nassau County Department of Health, are known as "select communities." The term denotes a group of zip codes within Nassau County that were analyzed against the rest of the county population. This analysis has helped to locate and display many of the health disparities that exist within the county. The selected communities were chosen with the assistance of an index comprised of multiple socioeconomic and health-related factors.

The five socioeconomic factors included are:

- Percent of individuals within the community that have a high school diploma (or GED equivalent)
- Median Household Income (USD)
- Percent of single parent families within the community
- Percent of individuals renting their current home
- Infant Mortality Rate

Selected communities were chosen by the DOH using both the index and the selection of populations historically categorized as "at risk" in previous assessments and include: Elmont (11003), Inwood (11096), Freeport (11520), Glen Cove (11542), Uniondale (11553), Roosevelt (11575), Hempstead (11550), and Westbury (11590).

NYU Winthrop's Service Area

NYU Winthrop's service area is defined geographically and by patient population. The Hospital's primary/core service area has historically been Nassau County, specifically Core Areas A, B and C (see map below). The secondary service area, represented by Areas D and E, is also considered in the Hospital's strategic planning process for purposes of establishing new programs and services. Based on an analysis of our patient populations (See Table 1 below), Care Areas A, B & C account for 77.81% of discharges.
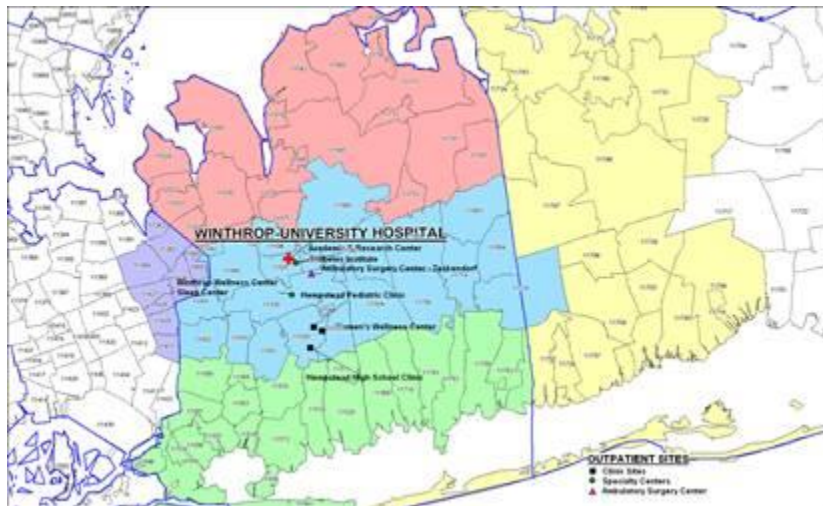
Blue: *Core A;* *Green*: *Core B;* *Pink*: *Core C;* *Purple*: *Core D;* *Yellow*: *Core E*

Table 1

Discharge Data 2018		
(excluding normal newborns)		
Core Areas	**Total**	**% of Total**
A	17,934	51.65%
B	7,833	22.56%
C	1,181	3.40%
Nassau Total	**26,948**	**77.61%**
D	2,268	6.53%
E	574	1.65%
Other	4,931	14.20%
TOTAL	**34,721**	**100%**

Nearly 33% of NYU Winthrop patients come from select communities in Core Areas A, B & C (see Table 2), with a higher percentage of patients from select communities coming from Core Area A – 40.76%. Two of these communities, Hempstead (11550) and Westbury (11590) are geographically close to the hospital and represent 63% of residents from select communities admitted to the hospital (3,250 patients from Hempstead; 2,135 from Westbury). Significant attention is paid to these communities.

Table 2

Discharge Data 2018

Core Areas	Total Select Communities	NYUWUH Patient Total	% of NYUWIN Total Select Communities
A	7,109	17,443	40.76%
B	1,279	7,502	17.05%
C	170	1,125	15.12%
TOTAL	**8,558**	**26,070**	**32.83%**

II. PUBLIC PARTICIPATION

To collect input from community members and measure the community perspective as to the biggest health issues in Nassau County, we utilized an ongoing regional survey called the Long Island Community Health Assessment Survey. This survey is available online via a Survey Monkey link and is available to residents at public events, workshops, educational programs, interventions, etc., which are offered by LIHC partners. It is also distributed through hospital websites, social media outlets, libraries, schools, insurance enrollment sites, community-based organizations and more. A certified translation of the survey is available in the following languages: Spanish, Polish, and Haitian Creole. Large print copies are also available to those living with vision impairment. It is also available on the NYU Winthrop website under "community health."

To assist with delving into the health concerns experienced by the underserved communities relating to the Social Determinants of Health, the LIPHIP contracted with EurekaFacts to conduct a qualitative research study.   The study consisted of focus groups with Long Island residents who indicated difficulty in accessing healthcare in the previous year, and interviews with leaders of community-based organizations who serve these populations.

In addition, NYU Winthrop maintains an ongoing dialogue with the community. The Hospital meets with local community partners from underserved areas quarterly, to keep abreast of health needs within the community, share ideas and discuss solutions. This group, NYU Winthrop's Community Cultural Advisory Council, represents local communities who are low-

income, have minority populations and experience health disparities. Their participation in this initiative helps to keep the hospital abreast of ongoing and emerging issues.

Health concerns of the community are also revealed through post-satisfaction surveys from more than 25 hospital-based lectures held each year and requests from outside organizations for speakers on specific topics. Interaction with the public at the NYU Winthrop Welcome Center, which serves as the site of several health education programs and support groups, provides further insight. Staff here also documents calls to the 1-866-WINTHROP number; queries reflecting health concerns are reviewed when planning programs.

Although the 2016 CHNA is posted on our website and written comments were solicited, none were received.

III. PROCESS & METHODS USED TO CONDUCT THE CHNA

Data analysis efforts were coordinated through the LIHC, which serves as the centralized data return and analysis hub. Two cluster groups were formed, the CHNA workgroup and the Data Advisory Group. Key members included the Commissioners of the both the Nassau and Suffolk Departments of Health, epidemiologists, Nassau-Suffolk Hospital Council representatives, and Long Island hospital representatives. A list of members of these workgroups is in Appendix A.

DATA SOURCES

Primary data sources: Long Island and Eastern Queens Community Health Assessment Survey (CHAS) (Appendix B) and the results from focus groups and key community-based organization leader interviews. The latter results were compiled in the report – Focus Groups and In-Depth Interviews (See Appendix C).

Secondary data sources: Publically-available data sets were reviewed to determine change in health status and emerging issues within Nassau County. Sources of secondary data: Statewide Planning and Research Cooperative System (SPARCS), New York State Prevention Agenda Dashboard, Prevention Quality Indicators (PQI), Behavioral Risk Factor Surveillance System (BRFSS), Extended Behavioral Risk Factor Surveillance System (eBRFSS), New York State Community Health Indicator Reports (CHIRS), and New York State Vital Statistics.
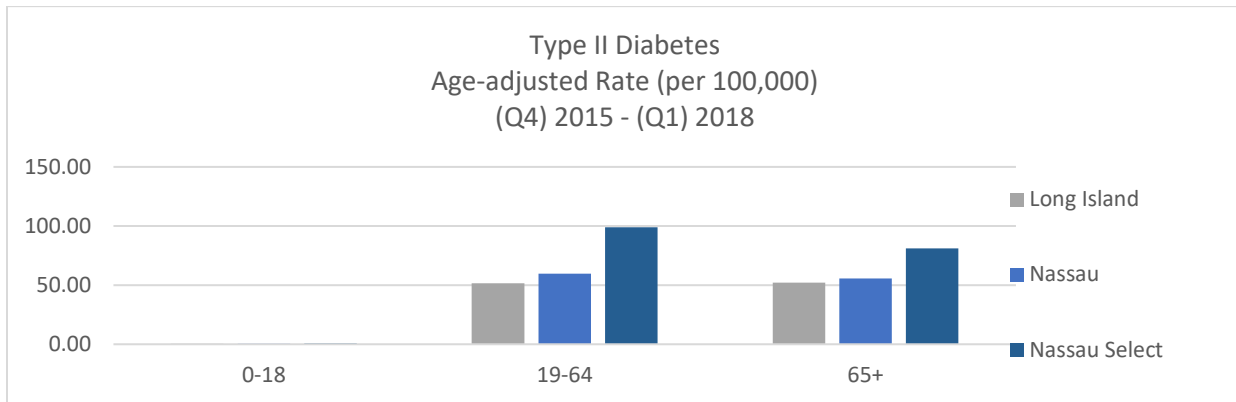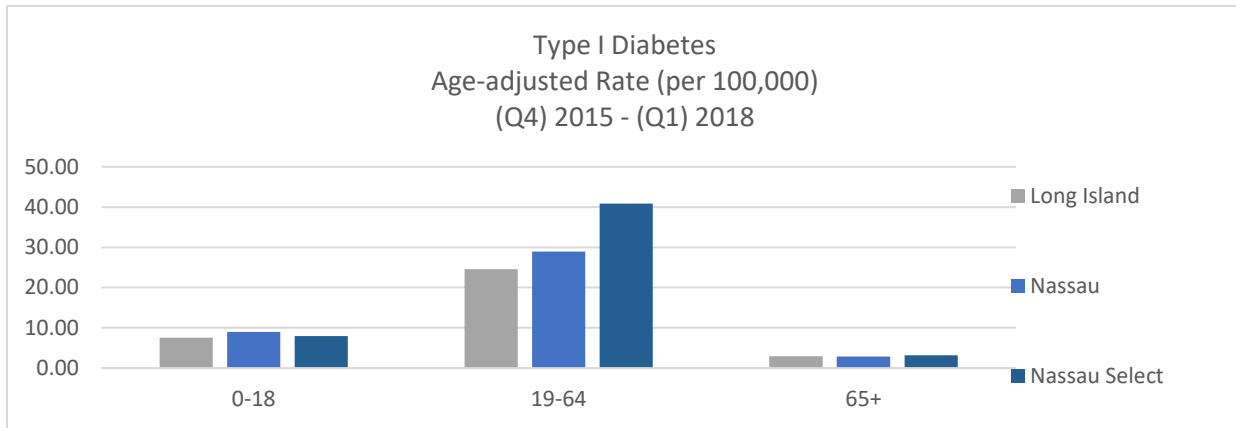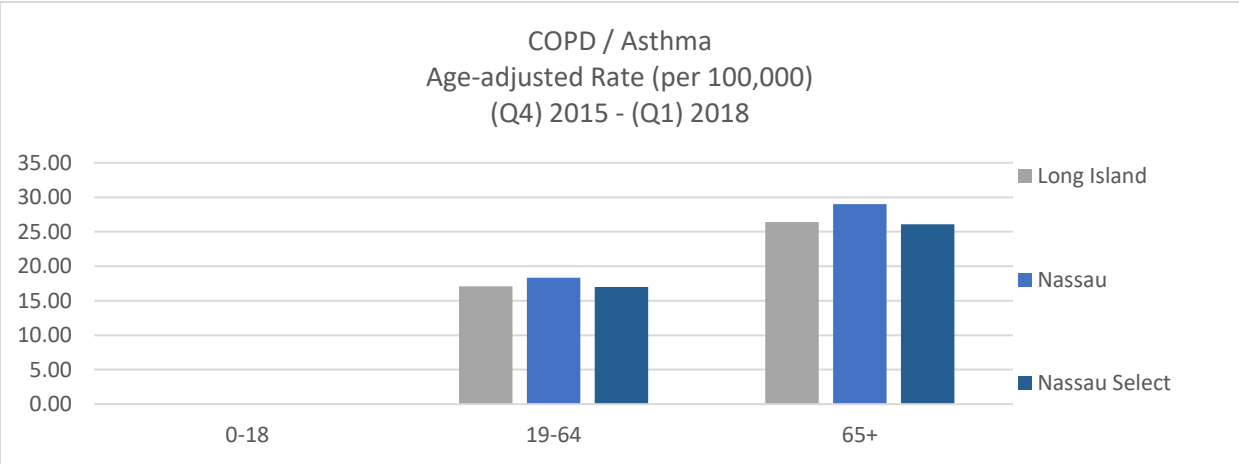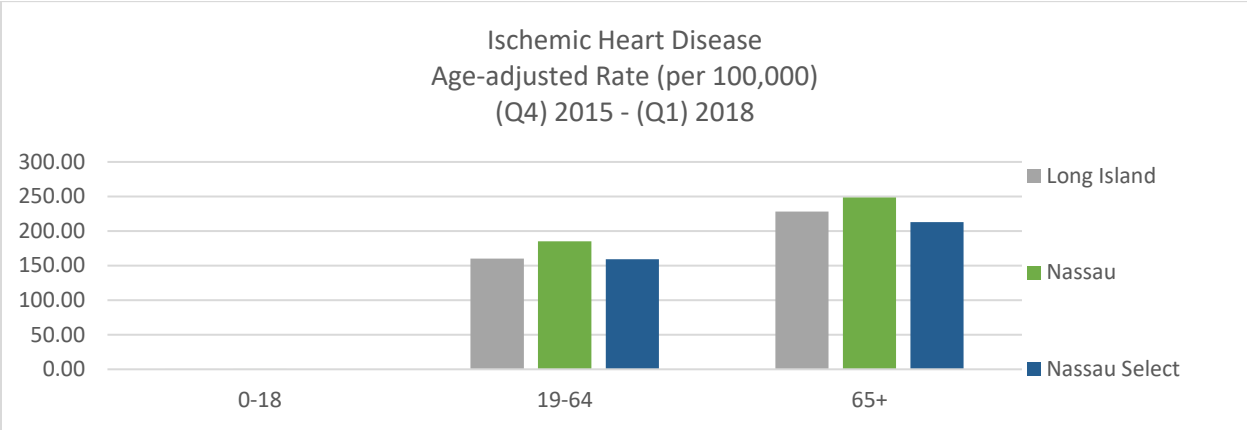
DATA DEPICTION OF HEALTH STATUS OF COMMUNITY

The following bar charts illustrate the prevalence of chronic disease in Nassau County. They include the SPARCS data on all cancers, types 1 & 2 diabetes, heart disease, and chronic obstructive pulmonary disease/asthma.

Please note the similar statistics between the 19-64 and 65+ age groups for cancer.

Cancer Rollup*
Age-adjusted Rate (per 100,000)
(Q4) 2015 - (Q1) 2018
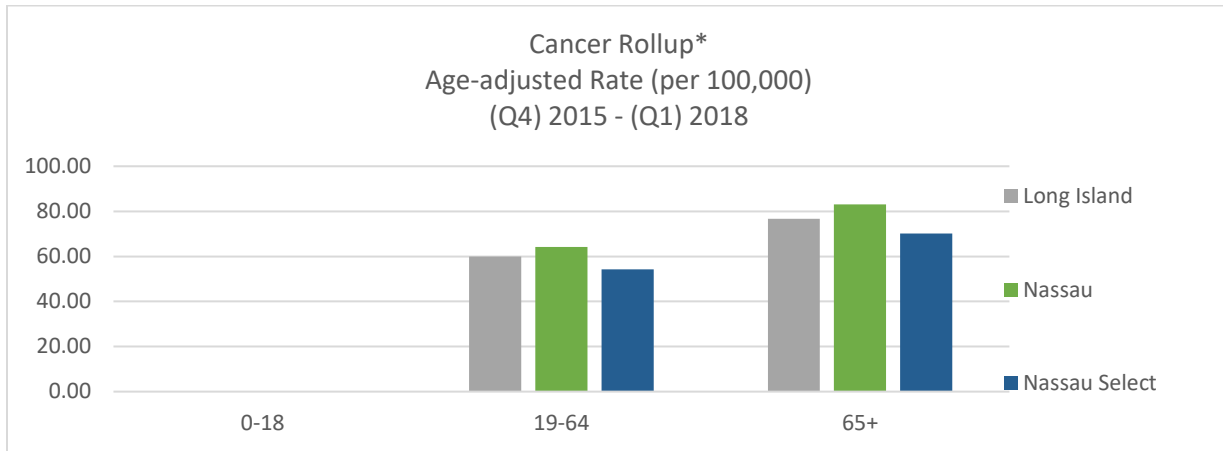
Note the higher rate of diabetes Type I among the 19-64 age group, especially in select communities.

Type I Diabetes
Age-adjusted Rate (per 100,000)
(Q4) 2015 - (Q1) 2018

Type II Diabetes
Age-adjusted Rate (per 100,000)
(Q4) 2015 - (Q1) 2018

Stroke
Age-adjusted Rate (per 100,000)
(Q4) 2015 - (Q1) 2018

Ischemic Heart Disease
Age-adjusted Rate (per 100,000)
(Q4) 2015 - (Q1) 2018

COPD / Asthma
Age-adjusted Rate (per 100,000)
(Q4) 2015 - (Q1) 2018
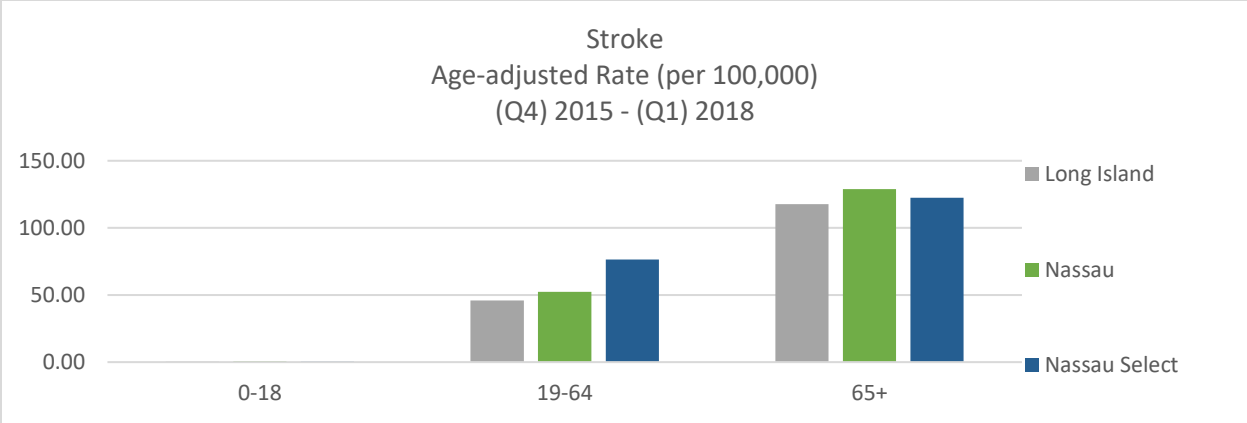
The following bar charts illustrate the issue with mental health and substance misuse. It is especially difficult among the 19-64 years of age group. Abuse of opioids and non-opioids is occurring at about twice the rate among the overall Nassau Population compared to the select communities.

Mental Disorder
Age-adjusted Rate (per 100,000)
(Q4) 2015 - (Q1) 2018

Substance Abuse: Opioid
Age-adjusted Rate (per 100,000)
(Q4) 2015 - (Q1) 2018

Substance Abuse: Non-Opioid
Age-adjusted Rate (per 100,000)
(Q4) 2015 - (Q1) 2018
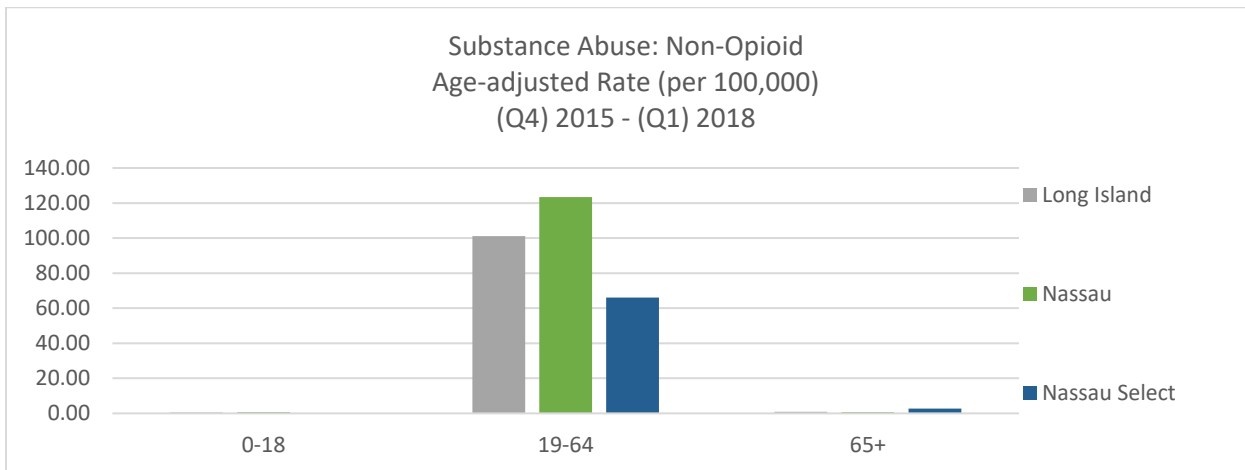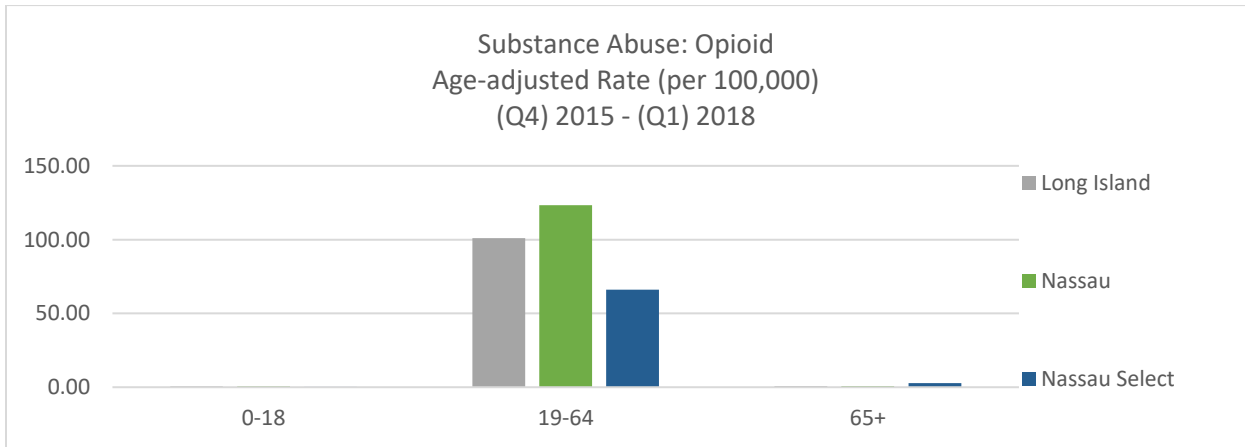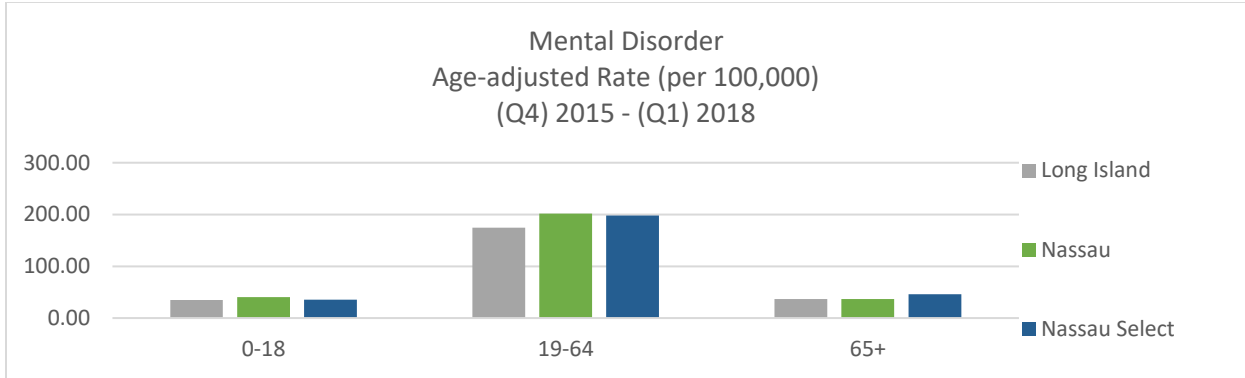
PREVENTION QUALITY INDICATORS

Chronic conditions, if treated early and properly in the community, prevent hospital admissions. PQI 92 is defined as a composite of chronic conditions per 100,000 adult population. Conditions included in PQI 92 are: diabetes with short and long-term complications, uncontrolled diabetes without complications, diabetes with lower-extremity amputation, chronic obstructive Pulmonary Disease, asthma, hypertension, heart failure, or angina without a cardiac procedure. Time period for map below is **January 1 – December 31, 2017.**

The Agency for Healthcare Research and Quality draws the indicators from SPARCS data. The map below shows the areas in Nassau County representing the most significant numbers of preventable cases per 100,000 of the adult population. Quintile 5 represents 1509 – 1778 per 100,000 adult cases. As displayed within the PQI Chronic Composite for Nassau County, there is notable occurrence of chronic disease among a majority of communities, particularly among those connected to low economic status.

The yellow dot indicates NYU Winthrop Hospital. Please note that one of the select communities in quintile 5 is in close proximity to the hospital. This is Hempstead, previously highlighted under NYU Winthrop's Core Area A service area as having a high admissions rate:
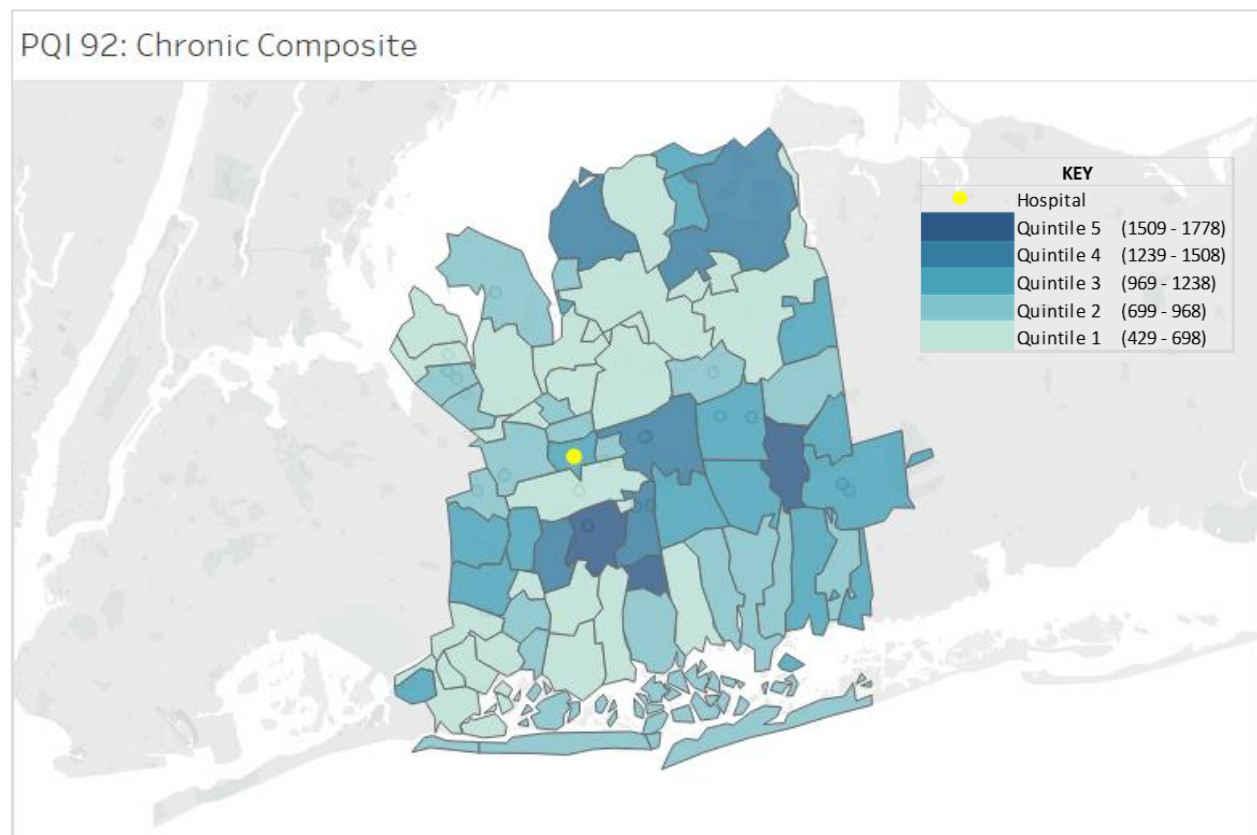
<u>Vital Statistics Data</u>

To gain a better understanding of the long-term effects of disease on communities with health disparities, we reviewed the causes of death according to age groups and separated select communities from the rest of Nassau County. For the purposes of this report, we are only highlighting ages 45 and above. Prior to that age group, 0 to 17 identifies the perinatal period as the highest cause of death; ages 18-24, 25-34 and 35-44 identify unintentional injuries.

Nassau Select Vs Rest: 2014-2016 Average
65+ year at death (per 100,000)
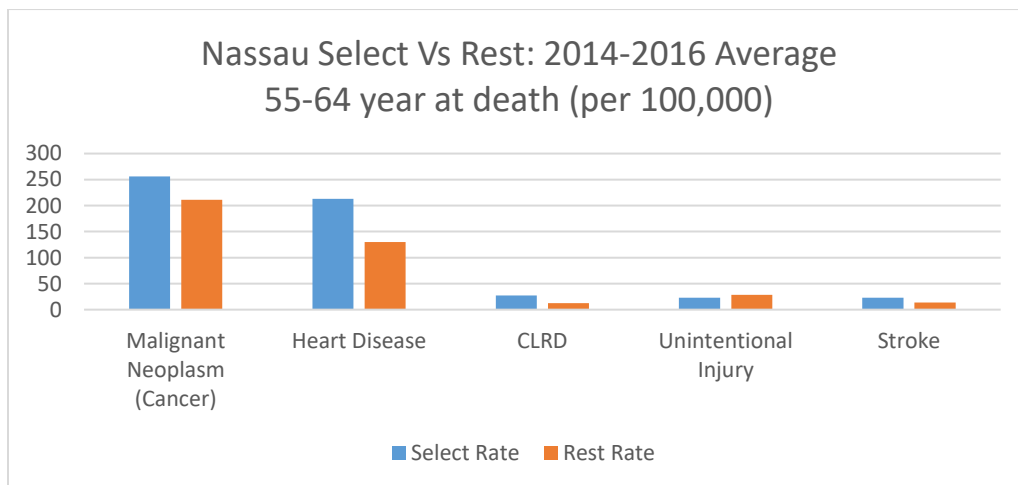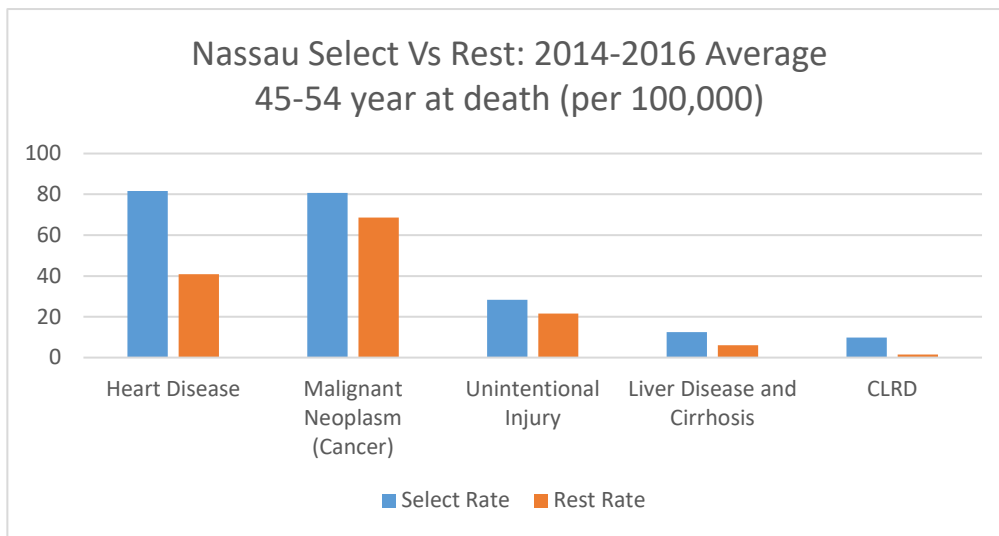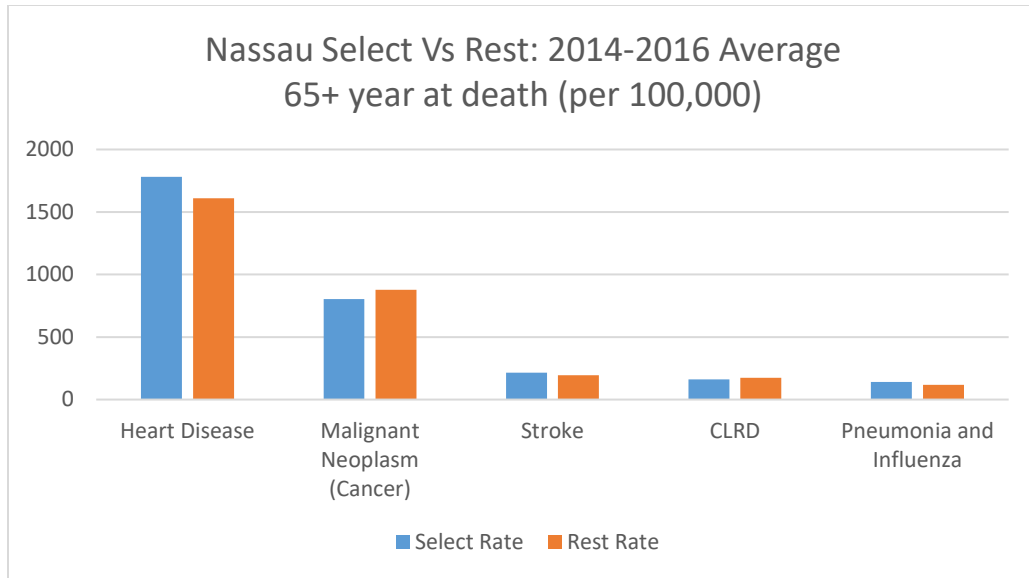
METHODOLOGY

The Community Health Needs Assessment Survey
A barometer of the perception of health needs and barriers experienced by individuals and communities – provides a snapshot in time of the main health challenges facing communities.

Surveys were distributed by paper and electronically, though Survey Monkey, to community members. The electronic version placed rules on certain questions: for questions 1-5, an individual could chose as many responses as they'd like. Although rules were written on the paper survey, people often did not follow them. Surveys were downloaded on December 18 2018. Weights were added to the surveys which did not follow the rules, i.e., for each of the questions that had more than three responses. No weight was applied to the questions with less than three responses because they had the option to select more and chose not to.

1644 surveys were collected between January 1 and December 31, 2018. For a full version of the spreadsheet that includes interactive tables to analyze results based on demographic factors, visit: https://www.lihealthcollab.or/data-resources.aspx

The following tables highlight the most relevant questions on the survey. Questions 1 & 2 helped determine the highest area of concern for community residents. Chronic disease was highly rated in Nassau County and the select communities, so this quickly identified as a significant health need. Questions 3, 4 and 5 addressed factors related to the social determinants of health.

1. What are the biggest ongoing health concerns in the community where you live?

2018 Rank	Concern	Percentage
1	Cancer	17.08%
2	Drugs & Alcohol Abuse	14.72%
3	Diabetes	12.88%
4	Heart disease & stroke	11.23%
5	Obesity, Weight Loss Issues	9.49%

2. What are the biggest ongoing health concerns for yourself?

2018 Rank	Concern	Percentage
1	Heart disease & stroke	17.9%
2	Cancer	14.56%
3	Obesity/Weight Loss issues	13.77%
4	Diabetes	13.26%
5	Women's Health & Wellness	13%

3. Potential barriers People face when getting medical treatment:

2018 Rank		Percentage
1	No insurance	20.8%
2	Unable to pay co-pays/deductibles	16%
3	Fear	14.1%
4	Don't Understand Need to see a Doctor	13.14%
5	There are no barriers	10.99%

4. What is most needed to improve the health of the community?

2018 Rank		Percentage
1	Insurance	20.8%
2	Unable to pay co-pays/deductibles	16%
3	Fear	14.1%
4	Don't Understand Need to see a Doctor	13.14%
5	There are no barriers	10.99%

5 .What health screenings or education services are needed in your community?

2018 Rank		Percentage
1	Blood Pressure	12%
2	Diabetes	9.62%
3	Cancer	9.26%
4	Cholesterol	8.47%
5	Mental Health/Depression	8.33%

Focus Groups and In-Depth Analysis Report

The LIHC contracted with EurekaFacts to conduct a qualitative research study to assist in the CHNA process and selection of NYS Prevention Agenda priorities for the 2019-2021 cycle. The objective was to understand the health concerns through the lens of the Social Determinants of Health. The study concentrated on communities with health disparities and consisted of the following: four two-hour focus groups with LI residents who indicated difficulty in accessing healthcare the previous year, and 15-minute in-depth interviews with 26 leaders of health-related community organizations who serve select populations. Twelve in-depth interviews of Long Island residents lasting half an hour each were also added as an insufficient number of participants attended two of the four focus groups.

Focus groups were held during the week of January 28 through February 1, 2019. Nassau representation was held in Freeport and Elmont; Suffolk groups were held in Wyandanch and Riverhead.

The in-depth interviews of CBOs were conducted from January 7 until February 13, 2019. Sixteen were from Nassau County and 10 from Suffolk; many organizations are active in both counties. Nineteen interviews explicitly discussed Nassau County and locations therein. All five social determinants of health and both counties received full representation. The CBOs are distributed roughly across the five Social Determinants of Health, as can be seen in the table below. A list of the organizations who participated is in Appendix D.

CBO Focus for Interview	Nassau	Suffolk	Total
Neighborhood and Built Environment	2	2	4
Health and Health Care	5	3	8
Social and Community Context	3	1	4
Economic Stability	3	1	4
Education	3	3	6
Total	16	10	26

Twelve in-depth interviews were held from February 12 through February 20, 2019. There were three men and nine women; the sample was split evenly between Nassau and Suffolk. Five of the six participants in Nassau County came from Hempstead and one from Elmont.

BRIEF DESCRIPTION OF REPORTED SOCIAL DETERMINANTS OF HEALTH RISK FACTORS

1) Neighborhood and Built Environment – concerns about pollution leading to cancer, water safety, access to healthy food were expressed. Many participants indicated difficulty in accessing and affording healthy food, which could potentially lead to chronic diseases such as diabetes and obesity. Gang violence was also a significant concern, particularly the

exposure of drug and gang violence on children, which could potentially lead them to model violent behavior. Several participants indicated that afterschool activities could help children from getting involved with gang violence.

2) Health and Health Care – Access to health and health literacy were major themes among participants. Two of the largest concerns were the affordability of health insurance and lack of knowledge about health insurance; the lack of knowledge results in not knowing the benefits of different health insurances relevant to an individual's conditions. Participants also mentioned healthcare disparity, which is associated with the issue of affordability. Health literacy – knowledge of prevention of disease, healthy diet and how to seek help were commonly mentioned concerns. Participants said that some people do not know why they are sick and how they can seek help to make the situation better.

3) Social, Family, and Community Context – Education, lack of parental involvement (sometimes due to their own health issues or other poverty-related challenges), incarceration, and racism were among the leading concerns. Participants also expressed concerns about the adverse effects of social media, including addiction to social media, lack of face-to-face interaction, and cyberbullying of children.

4) Economic Stability - Unemployment, poverty, homelessness, lack of affordable housing and access to healthy food were among the leading concerns. These conditions also have a negative impact on the elderly and disabled. Poverty was also linked to mental health issues.

5) Education – Concerns included poor school systems, education quality and illiteracy, as well as a lack of adequate health education about disease, treatment options, healthy food and providers. Most participants believe illiteracy has a cause and effect relationship with poverty or low income.

Analysis of responses from focus group participants and interviews with community-based organization leaders support the results of the quantitative data analyses. The chart below ranks the top five specific health concerns within the Prevention Agenda Priorities by the number of times it was referenced when asked about the highest priorities to be addressed.

Ranking	Specific Health Concern	Number of References	Prevention Agenda Priority
1	Mental Health	13	Promote well-being and Prevent Substance Use Disorders
2	Violence	12	Promote a Healthy and Safe Environment
3.	Substance use disorders	9	Promote well-being and prevent mental & substance Use disorders
4	Diabetes	7	Prevent Chronic diseases
5	Cancer	6	Prevent Chronic Diseases

Looking more broadly, the number of times that the **Prevention Agenda Priorities** were referenced while discussing the highest priority health concerns yielded the following ranking:

Ranking	Priority	Number of References
1	Promote well-being and prevent mental and substance use disorders	23
2	Promote a Healthy and Safe Environment	20
3	Prevent Chronic Diseases	18
4	Prevent Communicable Diseases	7
5	Promote Healthy Women, Infants & Children	2

To summarize, Long Island residents and CBO leaders interviewed indicated that there were significant health concerns among all five of the NYS Prevention Agenda Priorities. Both groups indicated that there were key challenges within the prevention of chronic diseases, promotion of a healthy and safe environment, and promotion of well-being and prevention of mental and substance use disorders. Residents expressed concerns within these areas, including cancer prevention and screening, diabetes, violence, mental health and access to healthy foods.

IV. SELECTION OF PUBLIC HEALTH PRIORITIES AND DISPARITY

On March 27, 2019, the LIHC distributed results of all its data analyses to LIHC CHNA workgroup participants. Large data files were posted on google drive. Workgroup participants were asked to review all the quantitative and qualitative data in advance of the Priority Selection Meeting.

That meeting took place on Friday, March 29, 2019 at 9:30 a.m. at the offices of the Nassau-Suffolk Hospital Council in Hauppauge, NY. The LIHC's data analyst walked participants through screen shots of the relevant findings. Participants also viewed the Prevention Agenda dashboard, diving deep into the goals, objectives, and recommended interventions for each priority. Present at the meeting either in-person or via phone were representatives from each

of the two local health departments on Long Island and representatives from each of Long Island's hospitals/health systems, as well as staff of the LIHC.

Attendees discussed the results and based the selection of priorities on the following criteria:
- The overwhelming evidence presented by the data, especially the first two questions of the survey.
- The activities/strategies/interventions currently in place throughout the region
- The feasibility of achieving momentum and success with a chosen priority, taking into account the diversity of partners and community members served

After an official vote, the priorities aligned with the NYS Prevention Agenda were selected unanimously:
- o Chronic Disease Preventive Care and Management
- o Promote Well-Being & Prevent Mental & Substance Use Disorders

The **health disparity** in which partners are focusing their efforts rests on the inequities experienced by those in low-income neighborhoods. As such, low-income – one social determinant of health – precludes members from low-income communities from accessing preventive and/or medical care due to their difficulty to afford co-payments/deductibles (if insured) or care at all if they are uninsured. Additionally, financially-stressed individuals have difficulty affording nutritious foods, leaving them more vulnerable to poorer chronic disease management outcomes, since nutrition and diet play a pivotal role in almost every chronic disease.

NYU Winthrop's Community Cultural Advisory Council (CCAC)

At the April 3, 2019 meeting of the CCAC, the results of the collaborative community needs assessment were shared with community partners. Health concerns and possible ways to address needs were discussed.

- Discussions determined that education about chronic disease prevention is still needed
- Concerns were also raised about mental health issues, drugs and alcohol abuse
- Health literacy and patient navigation services were reported to be crucial

Members of the CCAC at that meeting included:

Agency	Representative
EOC of Nassau County	Health Manager
Family & Children's Association	Assistant VP Senior & Adult Services
Girl Scouts of Nassau County	Fund Development Officer
Hempstead Hispanic Civic Association, Inc.	Executive Director
Hispanic Brotherhood of Rockville Centre	Executive Director

	Co-Director
Hispanic Counseling Center	CEO
	Program Coordinator
LI Asthma Coalition	Director
Nassau BOCES	Teen & parenting Program
Nassau County Coordinator Agency for Spanish Americans (CASA)	Director
Nassau County Dept. of Health	Commissioner, NC Department of Health
North Shore Child & Family Guidance	Director of the Leeds Place
Noticia (Spanish Newspaper)	Publisher/Co-Owner
Project independence	Deputy Commissioner, Department of Services for the Aging
SHIP/AHEC	Community Advocate
St. Brigid's Church (Westbury)	Immigration Ministry

In addition to the two significant needs identified by collaborative partners: 1) The prevention and management of chronic disease and 2) To promote well-being and Prevent Mental and Substance Use Disorders, NYU Winthrop is highlighting the following additional areas of need:

- Healthy & Safe Environment – Fall prevention continues to be an issue of concern among the aging population of Long Island
- Improvement of health literacy – many people don't understand the importance of a healthy lifestyle, or how to access resources when needed
- Birth-related disparities – there is a greater disparity among Black women, as opposed to White or Hispanic. A lower percentage of Black women receive adequate prenatal care than white women: 79.7% to 89%; Hispanic rates are 81.6%. The disparity continues with premature births (13.4% Black, 8.5% white and 8.8% Hispanic) and low birthweight births (12.5% Black and 7.0% white, 7.1% Hispanic).[3]
- Healthy Foods - the lack of healthy food affordability, convenient options, transportation, as well as time to prepare healthy food were significant challenges

PRIORITIZATION

The following criteria were utilized in determining the prioritization of needs:

- SPARCS data (2015-Q1 2018); NYSDOH Vital Statistics (2014-2016); Prevention Quality Indicators PQI 92 Chronic Composite, Nassau County 2017
- New York State Prevention Agenda Dashboard & Priorities

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[3] https://www.health.ny.gov/statistics/community/minority/county/nassau.htm

- NYU Winthrop's Admission Data
- Health disparities within our core market area
- The severity of the public health need
- Perceptions of the community identified in community survey, focus-group and in-depth interviews
- Resources – both hospital and community-based

The prioritization process included discussion with community partners, internal discussions with the Hospital's Senior Administration and review with the Board of Directors, an examination of resources, and a determination of the feasibility of possible interventions. Priorities were ranked based on the burden, scope and urgency of the health need across the service area, health disparities in select communities, resources, and the importance the community placed on addressing the needs.

RANKING

1. Prevention & Management of Chronic disease
2. Mental & Substance Use Disorders Prevention
3. Improvement of Health Literacy
4. Improvement of birth-related disparities
5. Healthy foods – improve access and educate about convenient options

INFORMATION GAPS

Although the qualitative report indicated that certain health concerns dominated across Long Island, it should be noted the report was not specifically separated by county to clarify the ranking of priorities according to Nassau County residents. This, however, was mitigated by conversations with our Community Cultural Advisory Council members. Also, although vast attempts were made, it was difficult to obtain a better number of surveys from communities with health disparities.

V. EXISTING FACILITIES AND RESOURCES

In addition to the resources that Winthrop is planning to commit, such as staffing, space and materials, Nassau County has a number of available resources to help meet community needs. Our County boasts 12 hospitals (including Winthrop), an adequate number of primary care physicians, five federally qualified health care centers in areas of high need, and numerous community-based organizations. Community members can access resources at our website, www.nyuwinthrop.org. Resources can also be accessed at www.**hites**ite.org/ and www.**211**.org/; these sites exist in real-time and are routinely updated. They help connect community members and health/social services providers with social determinants of health services.

A summary of assets and resources within Nassau County that can be mobilized and employed to address the health issues identified is maintained by the vast network of Long Island Health

Collaborative. The LIHC actively promotes relevant resource databases listed on the LIHC website that are available for public use. They invite consumers and health/social service providers to provide feedback on resources to ensure the most timely and comprehensive representation as possible. The website is: https://www.lihealthcollab.org/healthy-resources

VI. EVALUATION OF IMPACT – ACTIONS TAKEN SINCE 2016

Our 2016 CHNA identified the significant health needs of the prevention and management of chronic disease and a reduction in obesity. These were addressed collaboratively by Hospital and community partners in the Long Island Health Collaborative. Since the targeted objectives addressed lifestyle changes to improve outcomes, it was hoped that through the collective impact model, public awareness and education would help motivate individuals to make the changes necessary to adopt a healthy lifestyle. Additional public health priorities we addressed were fall prevention and an increase in cancer screenings.

Programs are evaluated by pre- and post- evaluation forms, community demand, and outcomes. The following is a brief summary of actions taken since 2016 to address these concerns.

CHRONIC DISEASE MANAGEMENT & PREVENTION

The **CDC evidenced-based National Diabetes Prevention** program, offered at our Diabetes Education Center, has received positive feedback. Since 2016, more than 300 individuals participated in the one-year program and approximately 80% were motivated to change behavior. An average of 33% were from communities with health disparities.

A summary of a review of post-evaluation surveys revealed the following:

"I know more about lifestyle changes" – 94% strongly agree, 6% agree
"Able to maintain lifestyle changes" 45% strongly agree; 58% agree; 6% disagree;
 "Better understanding of physical activity – 90% strongly agree, 19% agree; 1% disagree

The Stanford Program for Chronic Disease Management, challenging to implement because of changes in staffing and training schedules, began classes out in the community in 2018. As of this date, three programs were held in our core service area, with one of them being a community with health disparities. Feedback has been positive, with 90% of individuals making an action plan to control their health. Participants' comments also indicated the following:

"I eat healthier." "I exercise more." "I learned to keep a medical journal."

Tai Chi – evidenced-based for arthritis and fall prevention, it is also proven to be an excellent strategy to relieve stress and improve mental health. Our Tai-Chi program is offered twice a week, for 8 weeks. Approximately 150 individuals have participated in the program, offered at the hospital and in the community. Demand is high. Post-satisfaction surveys indicate an increased feeling of wellness, improved energy, posture and confidence. Sample comments:

"The program is a morale booster." "It releases tension." "It makes me relax." "I have less anxiety, learned how to walk without losing my balance, and feel better after the class."

OBESITY

NYU Winthrop utilizes the **5-2-1-0 healthy lifestyle program** in obesity prevention, both out in the community at Head Start and in the NYU Winthrop clinic. Challenges are the same for both locations; parents are often reluctant to understand that their child is obese. Consistent, culturally relevant messaging continues to address this.

Head Start Partnership – During 2017 and 2018, we serviced two locations in Hempstead and Westbury. All children are weighed and given a packet of information about the program. Parents receive a follow-up letter about their child's BMII and are offered healthy lifestyle education through a workshop, but no parents have participated. Our relationship with Head Start is positive, despite the fact that the overall obesity rates are not showing a positive change.

Stats were measured for the same children who participated in the program during the school year. Change is difficult to assess, given the varying growth rates of children. However, measures were as follows:

Westbury
Fall 2016 to Summer 2017 – a 12% reduction in obesity
Fall 2017 to Summer 2018 – No change in Obesity rate – 22.4% of children are obese, however, there was a reduction in the High rate of obesity of 5%

Hempstead
Fall 2016 to Summer 2017 – No reduction in obesity – 24% of children are obese
Fall 2017 to Summer 2018 – A 2% reduction in obesity; 24.3% of children are obese

In 2019, Head Start requested that we bring the program to two more sites: Freeport and Roosevelt. Consistent messaging continues at Head Start, to both parents and children.   NYU Winthrop staff also attends parent meetings to cultivate the relationship and promote wellness.

Hempstead Children's Health Clinic – The 5-2-10- program is explained to families. Children who are obese are referred to an endocrinologist, who is now in the practice one or two Saturdays a month to provide easier access for parents.

Currently, approximately 22% of the children within the practice are obese. There has been a 90% counseling rate for all parents; 100% of those who are obese receive 5-2-1-0 counseling. Those with a BMI of 95% or more received special dietary counseling and surveillance.   Compliance rate of families for those requested to return for 3-month follow-up visit for obesity was 44%. Again, parents are resistant and don't want to hear that their child is unhealthy. This challenge continues to be addressed with consistent, culturally relevant messaging to parents.

The obesity rate at the Hempstead Children's Clinic is similar to the rate at Head Start, at approximately 22%.

Breastfeeding is an evidenced-based obesity intervention. NYU Winthrop, A Baby Friendly Hospital, tracks the number of women who choose to breastfeed when their child is born, and the number of women who attend support groups. Our records show that from January 2017 to April, 2019, an average of 41% of women were exclusively breastfeeding upon discharge. Approximately 5 to 15 mothers attend support groups with their babies each week. To date, 166 women have attended support groups.

This past year, the Hospital developed a new program called LATCH hour.   It is for women who are having issues with the LATCH for infants up to 4 weeks old; 15 new mothers participated as of April, 2019.

Cancer Screenings – the Division of Cancer Services worked to increase the following cancer screenings in the community:

- Colon Cancer – NYU Winthrop committed to the "80% by 2018" American Cancer Society pledge to increase colorectal cancer screenings (80% of the eligible population screened by 2018). An important component of the 2016 goal was to overcome challenges and barriers to screening and increase cancer screening awareness. NYU Winthrop worked with community organizations to encourage participation among their clients, and also held hospital-based programs to promote cancer awareness.

  A common barrier was insurance. NYU Winthrop had several meeting with insurance experts, who educated staff about accessing insurance, so staff could in turn, educate the community. The impact of this initiative was revealed in the most recent Oncology Nurse Navigator Program Patient Satisfaction survey:
  - 2015 – 25% of those surveyed required information and/or education regarding insurance plans and coverage
  - 2018 – 15% of those surveyed required information and/or education – a 10% improvement

  As of the end of 2018, 2008 screening colonoscopies were completed

- Breast Cancer – NYU Winthrop participated in the National Accreditation Program for Breast Centers (NAPBC) Patient Navigation Initiative. A patient navigator assisted women with making appointments for a screening mammography. The navigator, who speaks five languages, identifies and addresses any barriers to care on a case-by-case basis. Procedures are in place to get financial assistance for screening.

This program targets the underserved. NYU Winthrop partners with CBOs and churches in select communities to promote the initiative.

NAPBC Program	2017	2018	Jan to April 2019
# of Women Contacted	686	991	522
In Need of Screening	87%	51%	67%
Complete Screenings	47%	75%	42%

Fall Prevention – NYU Winthrop has offered a four-part series on fall prevention for several years. Approximately 200 individuals have participated since our 2016 CHNA. The series addresses fall prevention tips, and exercises that improve balance, flexibility and strength.   Post-satisfaction surveys indicate an increase in an awareness of environment, limitations, possible home modifications and physician visits to check eyesight and review medications.

The program was revamped in early 2019 to implement a cognitive component. The goal is to connect mind and body to gain optimal health status in the individual. This has been well received, with requests from participants for more classes.

As mentioned above, the Tai Chi program that is offered also targets fall prevention. A six-month follow-up survey of the classes offered in 2018 revealed that **no one** has experienced a fall.

VII. DISSEMINATION TO THE PUBLIC

The CHNA is posted on the NYU Winthrop Hospital website, and accessed under the Community Health section on the main page.   It may be viewed and printed in hard copy. The website address is https://www.nyuwinthrop.org/community-health-needs-assessment. An account is not needed to view the document. Hard copies of the Community Health Needs Assessment are available without charge to anyone upon request by calling the NYU Winthrop Welcome Center at 1-866-946-8476.

 In addition, an announcement about the completion of the CHNA is published in a press release to local community newspapers, and the report is shared with community partners.

Appendix A

CHNA Workgroup

- Lawrence Eisenstein, MD, Commissioner, Nassau Country Dept. of Health
- Tavora Buchman, Epidemiologist Nassau County Dept. of Health
- Celina Cabello, Epidemiologist, Nassau County Dept. of Health
- James Tomarken, MD, Commissioner, Suffolk County Dept. of Health
- Linda Mermelstein, Suffolk County Dept. of Health
- Grace McGovern, Suffolk County Dept. of Health
- Althea Williams, Suffolk Care Collaborative
- Brooke Oliveri, Eastern Long Island Hospital
- Carolyn Villegas, Long Island Community Hospital
- Christine Hendriks, Catholic Health Services of Long Island
- Gabrielle Pareja, South Nassau Communities Hospital
- Janine Logan, Nassau-Suffolk Hospital Council
- Kimberly Whitehead, Nassau-Suffolk Hospital Council
- Pascale Fils-Aime, Nassau-Suffolk Hospital Council
- Paul Love, Nassau-Suffolk Hospital Council
- Cathryn Beeman, Nassau-Suffolk Hospital Council
- Jennifer Jamilkowski, Stony Brook Medicine
- Lauren Brookmeyer, Stony Brook Medicine
- Yvonne Spreckles, Stony Brook Medicine
- Joanne Newcombe, South Nassau Communities Hospital
- Kate Zummo, South Nassau Communities Hospital
- Linda Sweeney, Eastern Long Island Hospital
- Nancy Copperman, Northwell Health System
- Nancy Uzo, Mather Hospital
- Stuart Vincent, Mather Hospital
- Karen Tripmacher, NYU Winthrop Hospital

Data Advisory Group

- David Mbaya, Northwell Health System
- Sue-Ann Villano, New York Care Information Gateway
- Stephanie Kubow, Northwell Health System
- Thomas D. MacGinley, Healthix

NYU Winthrop Hospital

LONG ISLAND COMMUNITY HEALTH ASSESSMENT SURVEY

Your opinion is important to us!

The purpose of this survey is to get your opinion about health issues that are important in your community. Together, the County Departments of Health and hospitals throughout Long Island will use the results of this survey and other information to help target health programs in your community. Please complete only one survey per adult 18 years or older. Your survey responses are anonymous. Thank you for your participation.

1. What are the biggest ongoing health concerns in <u>THE COMMUNITY WHERE YOU LIVE</u>? (Please check up to 3)

☐ Asthma/lung disease   ☐ Heart disease & stroke   ☐ Safety

☐ Cancer   ☐ HIV/AIDS & Sexually   ☐ Vaccine preventable diseases

☐ Child health & wellness   Transmitted Diseases (STDs) ☐ Women's health & wellness

☐ Diabetes   ☐ Mental health   ☐ Other (please specify)

☐ Drugs & alcohol abuse   depression/suicide   _____

☐ Environmental hazards   ☐ Obesity/weight loss issues

2. What are the biggest ongoing health concerns for <u>YOURSELF</u>? (Please check up to 3)

☐ Asthma/lung disease   ☐ Heart disease & stroke   ☐ Safety

☐ Cancer   ☐ HIV/AIDS & Sexually   ☐ Vaccine preventable diseases

☐ Child health & wellness   Transmitted Diseases (STDs) ☐ Women's health & wellness

☐ Diabetes   ☐ Mental health   ☐ Other (please specify)

☐ Drugs & alcohol abuse   depression/suicide   _____

☐ Environmental hazards   ☐ Obesity/weight loss issues

3. What prevents people in your community from getting medical treatment? (Please check up to 3)

☐ Cultural/religious beliefs   ☐ Lack of availability of doctors ☐ Unable to pay co-pays/deductibles

☐ Don't know how to find doctors   ☐ Language barriers   ☐ There are no barriers

☐ Don't understand need to see a   ☐ No insurance   ☐ Other (please specify)

   doctor   ☐ Transportation   _____

☐ Fear (e.g. not ready to face/discuss health problem)

4. Which of the following is MOST needed to improve the health of your community? (Please check up to 3)

☐ Clean air & water   ☐ Mental health services   ☐ Smoking cessation programs

☐ Drug & alcohol rehabilitation services   ☐ Recreation facilities   ☐ Transportation

☐ Healthier food choices   ☐ Safe childcare options   ☐ Weight loss programs

☐ Job opportunities   ☐ Safe places to walk/play   ☐ Other (please specify)

☐ Safe worksites   _____

5. What health screenings or education/information services are needed in your community? (Please check up to 3)

☐ Blood pressure   ☐ Eating disorders   ☐ Mental health/depression

☐ Cancer   ☐ Emergency preparedness   ☐ Nutrition

☐ Cholesterol   ☐ Exercise/physical activity   ☐ Prenatal care

☐ Dental screenings   ☐ Heart disease   ☐ Suicide prevention

☐ Diabetes   ☐ HIV/AIDS & Sexually   ☐ Vaccination/immunizations

☐ Disease outbreak information   Transmitted Diseases (STDs) ☐ Other (please specify)

☐ Drug and alcohol   ☐ Importance of routine well visits   _____

6. Where do you and your family get most of your health information? (Check all that apply)

☐ Doctor/health professional	☐ Library	☐ Social Media (Facebook, Twitter, etc.)
☐ Family or friends	☐ Newspaper/magazines	☐ Television
☐ Health Department	☐ Radio	☐ Worksite
☐ Hospital	☐ Religious organization	☐ Other (please specify)
☐ Internet	☐ School/college	_____

For statistical purposes only, please complete the following:

I identify as: ☐ Male   ☐ Female   ☐ Other

What is your age?   _____

ZIP code where you live: _____   **Town where you live**: _____

What race do you consider yourself?

☐ White/Caucasian	☐ Native American	☐ Multi-racial
☐ Black/African American	☐ Asian/Pacific Islander	☐ Other (please specify)
		_____

Are you Hispanic or Latino?   ☐ Yes   ☐ No

What language do you speak when you are at home (select all that apply)

☐ English	☐ Portuguese	☐ Spanish	☐ Italian	☐ Farsi	☐ Polish
☐ Chinese	☐ Korean	☐ Hindi	☐ Haitian Creole	☐ French Creole	☐ Other

What is your annual <u>household</u> income from all sources?

☐ $0-$19,999	☐ $20,000 to $34,999	☐ $35,000 to $49,999
☐ $50,000 to $74,999	☐ $75,000 to $125,000	☐ Over $125,000

What is your highest level of education?

☐ K-8 grade	☐ Technical school	☐ Graduate school
☐ Some high school	☐ Some college	☐ Doctorate
☐ High school graduate	☐ College graduate	☐ Other (please specify)
		_____

What is your current employment status?

☐ Employed for wages	☐ Self-employed	☐ Out of work and looking for work
☐ Student	☐ Retired	☐ Out of work, but not currently looking
☐ Military		

Do you currently have health insurance? ☐ Yes   ☐ No   ☐ No, but I did in the past

Do you have a smart phone?   ☐ Yes   ☐ No

Long Island Health Collaborative, Population Health Improvement Program for the Long Island Region

Focus Groups and In-Depth Interviews

March 26, 2019

Smart Research Solutions

Table of Contents

This report was prepared in compliance with ISO 20262 International
quality standard for market, public opinion, and social research.

1. Executive Summary

The Long Island Health Collaborative, (LIHC), the Population Health Improvement Program (PHIP) for Long Island, contracted with EurekaFacts to conduct a qualitative research study to assist it in the selection of New York State Prevention Agenda Priorities for the 2019-2021 period. They also sought to gather data to inform the Community Health Needs Assessment (CHNA) process and subsequent implementation plans for hospitals and local health departments, understanding the health concerns through the lens of the Social Determinants of Health. The study consisted of several phases of data collection: four two-hour focus groups with Long Island residents who indicated difficulty in accessing healthcare in the previous year, and 15-minute in-depth interviews with 26 leaders of health-related community-based organizations (CBOs) who served these populations. Twelve in-depth interviews of Long Island residents lasting half an hour each were also added as insufficient numbers of participants attended two of the four focus groups.

1.1 Key Findings & Takeaways

Prevention Agenda Priorities

Long Island residents and CBO leaders indicated that there were significant health concerns among all five of the New York State Department of Health Prevention Agenda Priorities. However, both groups indicated that there were key challenges within the prevention of chronic diseases, promotion of a healthy and safe environment, and promotion of well-being and prevention of mental and substance use disorders. Residents expressed numerous concerns within these areas, including cancer, diabetes, violence, access to healthy food, and mental health. CBO leaders discussed the services they provided in these areas and acknowledged numerous structural challenges in play. There may be opportunities to provide health education on key topic areas to interested audiences as well as exploring collaborative efforts to address structural barriers.

Long Island residents and CBO leaders were asked which health concerns were the highest priorities to address. Based on the number of times a topic was referenced during this portion of

the discussion, the top five most commonly referenced specific health concerns are ranked as follows:

Ranking	Specific Health Concern	Number of References	Prevention Agenda Priority
1	Mental health	13	Promote Well-being and Prevent Mental and Substance Use Disorders
2	Violence	12	Promote a Healthy and Safe Environment
3	Substance use disorders	9	Promote Well-being and Prevent Mental and Substance Use Disorders
4	Diabetes	7	Prevent Chronic Diseases
5	Cancer	6	Prevent Chronic Diseases

Table 1: Ranking the top five specific health concerns within the Prevention Agenda Priorities by the number of times it was referenced when asked about the highest priorities to be addressed

Looking more broadly, the number of times that the Prevention Agenda Priorities were referenced while discussing the highest priority health concerns yields the following ranking:

Ranking	Prevention Agenda Priority	Number of References
1	Promote Well-being and Prevent Mental and Substance Use Disorders	23
2	Promote a Healthy and Safe Environment	20
3	Prevent Chronic Diseases	18
4	Prevent Communicable Diseases	7
5	Promote Healthy Women, Infants, and Children	2

Table 2: Ranking the Prevention Agenda Priorities by the number of times it was referenced when asked about the highest priorities to be addressed

Social Determinants of Health

Participants in the focus groups and in-depth interviews, or IDIs, discussed the many ways that each of the Social Determinants of Health impacted community health outcomes. Of the five

determinants explored, residents and CBO leaders agreed that Economic Stability has significant influence in terms of accessible transportation and financial insecurity. Participants agreed that for Health and Healthcare, access to affordable insurance and healthcare were significant challenges. Long Island residents suggested more outreach and health education would help them connect to available resources and address barriers such as fear or stigma. Discussions about Neighborhood and Built Environment emphasized the structural challenges in terms of lack of affordable housing or access to healthy food options. Among residents, key challenges in Social, Family, and Community Context are the many negative impacts of incarceration on the individual and his or her family. Education, in terms of early childhood education or primary or secondary education, received less emphasis than the other four determinants of health.

2. Introduction

Project Goals

The Long Island Health Collaborative (PHIP) contracted EurekaFacts to conduct a series of qualitative focus groups and interviews with underserved residents of Long Island and leaders of community-based organizations (CBOs) who perform work related to this population. Goals of the project were to understand the barriers to healthcare access and community-level priorities of residents who lack healthcare access. The results of this study will be used to guide PHIP's work with the New York State Department of Health Prevention Agenda Priorities 2019-2021. These priorities guide public health efforts for a multi-year period for county health departments, hospitals, and CBOs. The five Prevention Agenda Priorities for 2019-2021 are as follows:

- Prevent chronic diseases
- Promote a healthy and safe environment
- Promote healthy women, infants, and children
- Promote well-being and prevent mental and substance use disorders
- Prevent communicable diseases

Additionally, PHIP wanted to understand barriers to healthcare access and community-level priorities through the lens of Social Determinants of Health. These determinants explore the ways that where people live, work, play, and age directly or indirectly impact their health outcomes. The Social Determinants of Health used in this research were defined as the following:

- *Economic Stability:* Housing security, employment, food security, and transportation
- *Education:* Language and literacy, early childhood education, high school education
- *Health and Healthcare:* Access to health, health literacy, access to a trusted provider, access to primary care
- *Neighborhood and Built Environment:* Access to healthy foods, affordable/quality housing, crime and violence
- Social, Family, and Community Context: Social cohesion, civic participation, incarceration, and institutionalization

The definitions were taken from the New York State Department of Health[1]. The Prevention Agenda Priorities and Social Determinants of Health were used to guide the design of all research instruments and analysis methods.

3. Methodology

3.1 Design

To understand the community-level priorities of residents who experience barriers to healthcare access, this study involved three separate data collection efforts:

1. Focus groups with people facing barriers to healthcare on Long Island;
2. In-depth interviews by phone with the same population as above; and
3. In-depth interviews by phone with leaders of Community-Based Organizations (CBOs) providing services that impact the health of people on Long Island.

All aspects of the study were approved by EurekaFacts' Institutional Review Board (IRB).

Long Island Residents

Focus Groups

To understand the barriers to healthcare and community-level priorities of residents, a series of two-hour focus groups were held on Long Island with people from Nassau and Suffolk Counties: Freeport (Nassau), Elmont (Nassau), Riverhead (Suffolk), and Wyandanch (Suffolk). These groups aimed to include people primarily from the communities of Elmont, Freeport, Roosevelt, Hempstead, Wyandanch, Central Islip, Brentwood, and Riverhead. The Nassau groups had 12 participants each, while the Suffolk groups had four participants. Focus group topics included discussion around the five Prevention Agenda Priorities, barriers to seeking healthcare, Social Determinants of Health, and sources of health information.

As two of the four focus groups had fewer than the minimum of eight participants, twelve 30-minute phone interviews were conducted with people in both counties to supplement the data. Using a mixed approach of focus groups and in-depth interviews has been demonstrated to result in more detailed, relevant, and useful data, as focus group participants excel at group

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[1] Categories and definitions taken from New York State Department of Health CBO Directory: https://www.health.ny.gov/health_care/medicaid/redesign/dsrip/vbp_library/cbo_directory.htm

brainstorming and discussing novel solutions, while in-depth interviews provide richer and more detailed data[2].

In-Depth Interviews

Semi-structured in-depth interviews were held with 12 residents of Long Island who met the same eligibility criteria as focus group participants. The in-depth interviews were designed as a phenomenological qualitative study, in which the research team sought to understand a community or population's experience around a specific phenomenon. In this case, the research focused on the experience of health and healthcare on Long Island among underserved populations viewed through the lens of the five Prevention Priority areas and the Social Determinants of Health. Although the number of in-depth interviews required to reach an adequate depth of understanding of an issue is greatly debated, Guest and colleagues[3] conducted a systematic examination of the number of interviews required to establish overarching themes within a nonprobabilistic sample from a demographically-defined group for qualitative research, although not for a phenomenological study specifically. Their results indicated that twelve interviews were required to establish saturation, although basic themes were evident after six interviews. Starks and Trinidad[4] note that sizes for interview samples in phenomenological studies are often ten or smaller, an approximate range which is echoed elsewhere[5]. While acknowledging that perspectives on qualitative sample differ, the research team felt confident that twelve interviews would provide a rich dataset and clear themes.

Similar to the focus group discussion, the interview topics included the five Prevention Agenda Priorities, barriers to seeking healthcare, Social Determinants of Health, and sources of health information.

Community-Based Organizations

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[2] Sugovic, M., Nooraddini, I., Sherehiy, B. (2016). Evaluation of safety label design: Comparison between cognitive interviewing versus focus group methods. *Proceedings of the Human Factors and Ergonomics Society Annual Meeting, 60*(1), 1632-1636.

[3] Guest, G., Bunce, A. and Johnson, L. (2006). How many interviews are enough?: An Experiment with Data Saturation and Variability. Field Methods, 18(1), pp. 59-82.

[4] Starks, H. and Trinidad, S. B. (2007.) Choose your method: A comparison of phenomenology, discourse analysis, and grounded theory. *Qualitative Health Research, 17*(10), 1372-1380.

[5] Morse, J. 1994. Designing funded qualitative research. In Handbook for qualitative research, ed. N. Denzin and Y. Lincoln, 220–35. Thousand Oaks, CA: Sage.

To identify areas of need from the perspective of CBOs, the third data collection effort included 26 phone interviews lasting 15 minutes each with leaders of CBOs. Interview topics included a brief description of the organization and the interviewee's role, health concerns related to the Social Determinants of Health, specific populations impacted by them, and barriers and facilitators to health from the perspective of the Social Determinants of Health.

3.2 Participants

Long Island Residents

The research team sought to recruit 8-12 participants for each of the four focus groups. Participants were required to meet certain characteristics, including household income, geography, and access to healthcare. Household income eligibility was determined as the median income for the county plus one standard deviation. The maximum eligible household income in Suffolk County was $74,999 and $99,999 for Nassau County. To determine whether a potential participant faced barriers to healthcare, and was thus eligible for this research, recruitment agents asked the following question: "During the past 12 months, was there ever a time when you felt that you needed health care, but you could not receive it because of cost, transportation, or some other reason?"[6] Initially, participants who did not reside in the four locations for the focus groups were screened out, but this practice generated low recruitment numbers. PHIP and EurekaFacts agreed to modify the screener and allow others from Long Island into the groups. As noted above, to achieve data saturation with qualitative interviews, the recommended sample size of 12 interviews needs to occur within a demographically-defined group. This sample was considered eligible due to the geographic location, income (defined as the median income level plus one standard deviation), and self-reported challenges in accessing healthcare. Within this sample, there was a mix of demographics in terms of gender, race, ethnicity, and education level.

Recruitment

Eligible participants were found through the following methods, in decreasing order of importance: lists of phone numbers, social media advertising, referrals, advertising and outreach

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[6] Adapted from Law, M., et al. (2005.) Meeting health need, accessing health care: The role of the neighbourhood. *Health & Place, 11*, 367-377.

by CBOs, and in-person recruitment. Focus group participants received a $75 Visa gift card incentive for participation and were eligible for an additional incentive for referrals, while interview participants received a $40 Visa gift card.

Challenges encountered – Focus Groups and Residents IDIs

EurekaFacts attempted to recruit up to 12 participants in each of the four focus group locations: Hempstead, Elmont, Riverhead, and Wyandanch. Recruitment efforts included the use of a purchased list of 4,000 cell phone records distributed evenly across the four locations, Craigslist and Facebook advertisements, referrals, and assistance from local CBOs who provide services to the target population. Challenges included lower than expected response rates to our social media campaigns and Craigslist advertisements, as well as the reluctance of CBOs to agree to meet with EurekaFacts representatives or permit on-site recruitment. Additionally, the recruiting team faced logistical challenges in reserving spaces at public libraries.

Steps taken to address challenges

In consultation with LIHC staff, recruitment agents shifted through the process to respond to challenges in using the phone list and social media advertisements. New strategies included enlisting the help of community organizations based on Long Island, such as workforce development organizations, to provide access to their members, display our flyer on their website and physical premises, and allow EurekaFacts to conduct on-site recruitment at their premises. Referral incentives were also added to facilitate snowball sampling. In consultation with LIHC staff, the focus group screener was modified to remove zip code restrictions and allow participants from various regions withon Long Island to participate in the study, given that they met other qualifying criteria. All changes in recruitment methods were submitted and approved by the EurekaFacts internal IRB.

Community-Based Organizations

The list of CBOs for interviews was provided in a file by PHIP, which also indicated the Social Determinants of Health addressed by the CBOs. The determinant used for the focus of the in-depth interviews was initially assigned based on the list from PHIP and confirmed with the organization prior to the facilitation of interviews. The research team intended to have equal representation across the five Social Determinants of Health and between both counties.

Recruitment

CBOs were recruited using a 5-minute phone screener which followed an initial email contact from either LIHC or EurekaFacts. CBOs were selected from a list of 111 CBOs provided by LIHC, as well as a supplemented lists of food pantries and libraries once the original list was exhausted.

Challenges encountered – Community-Based Organizations

EurekaFacts attempted to recruit 26 CBOs from a larger list of 111 organizations that PHIP provided. Challenges encountered during this recruitment effort were mainly related to fulfilling quotas for geography and social determinants of health. The main challenge for geography requirement was having fewer organizations primarily serving Suffolk County, although 16 of the 26 CBOs interviewed were active in both counties. Additionally, there were many organizations in the health and healthcare segment and very few in the economic stability or the social and community context segments. Other challenges included unwillingness of some of the organizations to participate, and a large number of unreturned voicemails. After making three call attempts on each of the records on the list, EurekaFacts decided that no more calls should be made according to best practices and company policy, and PHIP was notified.

Steps taken to address challenges

EurekaFacts worked more closely with PHIP to address issues related to low response rates from CBOs, and to encourage more participation from these organizations. PHIP personally reached out to several CBOs, after which they received written approval from some organizations to be interviewed. EurekaFacts then contacted and scheduled interviews with these organizations. During the interviews, EurekaFacts interviewers prompted some organizations who were active in more than one Social Determinant of Health area to be interviewed on a topic with less representation, therefore fixing some of the quota challenges faced. Because interviews with CBOs reflected that 16 of the 26 organizations were active in both counties, it was concluded after discussion with PHIP that both counties were adequately represented. Likewise, since the average organization reported working in 2.5 determinants of health areas, it was also safe to conclude that all areas were sufficiently covered. All changes in recruitment methods were submitted to and approved by the EurekaFacts internal IRB.

3.3 Materials Development

Long Island Residents

Focus Group Discussion Guide Design

The discussion guide was developed in close consultation with the members of the Long Island Health Collaborative's (LIHC) Community Health Needs Assessment (CHNA) Preparation Workgroup. A list of concepts to explore was first generated and shared with the group for approval. After receiving feedback, revising, and gaining approval from the members of the workgroup, this list was expanded into a complete discussion guide using the Delphi Method to gain consensus. This focus group guide was submitted and approved by the workgroup as well as the EurekaFacts Internal IRB. The guides explore perceptions for the highest priority community health concerns, barriers to treatment, health impacts of the Social Determinants of Health, and sources of information. It is important to note that the decision to exclude questions about health and healthcare as a Social Determinant of Health were made at the time of the discussion guide concept list generation, as the focus of much of the interview was on issues related to access to health, health literacy, and access to a trusted provider.

<u>Delphi Method</u>

Focus groups were conducted using the Delphi methodology, wherein participants wrote answers down in private and passed their answers into a box, with the moderator selecting answers, placing them on a flipchart, and then leading a discussion on the answers without identifying the source of the answer. This methodology allowed sensitive topics—including health concerns and barriers to healthcare in the community, the topic of discussion—to be discussed candidly with a veil of anonymity, even around peers or relatives.

The Delphi methodology involves multiple steps. First, participants answer a question anonymously by submitting written comments on post-it notes. Second, these responses are reported back to the group for discussion. Third, participants are provided the opportunity to anonymously submit their answers again, during which they may choose to revise their answers due to the discussion. At this time, there may be additional discussion identifying the common themes. If there is insufficient consensus, the process may be repeated multiple times until the group has reached a conclusion. Due to time constraints, the full Delphi protocol was used for the highest priority items, such as the discussion, "Top Health Concerns in their Community." For other topics, EurekaFacts used a truncated version in which we follow the first two steps – anonymously writing answers and discussing them – but did not repeat the third anonymous

written answer submission. This truncated version can be seen for "Barriers to Getting Treatment." For all other items, participants only discussed the topic, without a written component. This approach, blending the full and modified Delphi methodology with the traditional focus group approach of discussion, mitigates some of the challenges in focus groups while capitalizing on group consensus-building.

Residents In-Depth Interview Discussion Guide Design

The in-depth interview guide for Long Island residents was adapted from the focus group discussion guide. The interview guide and focus group guide addressed the same topics but questions were modified from a group discussion to an individual interview. Topics covered included community health priorities, barriers to treatment, Social Determinants of Health, and sources of health information. This interview guide was submitted and approved by the CHNA workgroup as well as the EurekaFacts Internal IRB.

CBO Discussion Guide Design

The interview discussion guide was developed in close consultation with LIHC CHNA Preparation Workgroup. As with the focus group discussion guide, a list of concepts to explore was first generated and shared with the workgroup members for approval. After receiving feedback, revising, and gaining approval from the workgroup, this list was expanded into a complete interview guide. The 15-minute interviews provide descriptions of the organizations' work and the challenges related to the Social Determinants of Health facing the communities they serve, examples of factors that support communities in becoming healthier, and suggestions for how to address the barriers communities face to receiving healthcare. This interview guide was submitted and approved by the workgroup as well as the EurekaFacts Internal IRB.

3.4 Procedure

Focus Groups

Two-hour focus groups were held in publicly accessible locations: hotel conference rooms and public libraries in Freeport (Nassau), Elmont (Nassau), Riverhead (Suffolk), and Wyandanch (Suffolk). Participants signed an informed consent form to participate and have the conversation recorded prior to their participation. A highly experienced moderator was trained on the project

and discussion guide before facilitating the focus groups. All focus groups were audio recorded and transcribed for analysis.

In-Depth Interviews with Long Island Residents

Interviews were conducted by phone and lasted 30 minutes. Interviewees gave verbal consent to participate and have the conversation recorded. Interviews were conducted by the Project Director or a member of the research team who was trained in conducting interviews for qualitative research and closely monitored for quality assurance. Interviews were audio recorded and extensive notes from the interviews were used as the basis for analysis. In-depth interview participants were assigned unique identifiers to protect their identities.

In-Depth Interviews with Community-Based Organizations

Fifteen-minute phone interviews with leaders of CBOs were conducted to gather their insights. Participants were asked to self-identify which of the five Social Determinants of Health their organization worked on to fulfill recruitment quotas. Participants verbally agreed to participate and allow for the conversation to be audio recorded. Like the interviews with residents, interviews were conducted by the Project Director or a member of the research team who was trained in conducting interviews for qualitative research and closely monitored for quality assurance. Participants were assigned a unique identifier to preserve their confidentiality. Extensive notes were taken during interviews, which were used as the basis for qualitative analysis.

3.5 Analysis

The research team used Directed Content Analysis (DCA) for coding and analysis, which is an ideal approach when there is an existing framework or theory which needs to be validated or expanded[7]. With this approach, codes are pre-defined based on theories, frameworks, or previous research and applied during analysis, although new codes are created on an ad hoc basis as well. For the purposes of this project, codes were based on the Prevention Agenda Priorities, Social Determinants of Health, as well as the LIHC's Community Health Assessment Survey.

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[7] Hsieh, H.F. & Shannon, S. E. (2005.) Three approaches to qualitative content analysis. *Qualitative Health Research, 15,*(9), 2177-1288.

Both the focus groups transcripts and in-depth interview notes were analyzed using the NVivo Software, Version 10. The coding effort for this project was scaled according to available resources. A team of four coders trained in DCA analyzed focus group transcripts independently, such that each transcript was analyzed by two different coders. After coding, coders compared codes and discussed discrepancies in coding before reaching a consensus. Data were reviewed at least twice to ensure saturation of coding. The same analytical codebook was used to analyze the focus group transcripts and in-depth interviews with codes representing the Prevention Agenda Priority areas as well as subtopics, Social Determinants of Health, geography, barriers to treatment, and sources of health information. Word clouds were generated from focus group participant comments and written notes from the Delphi Method. These word clouds contain exact words and phrases from participants to show the range of topics discussed.

The analysis was reviewed by the focus groups moderator to ensure accuracy. Likewise, notes from the in-depth interviews with residents and CBO leaders were analyzed using the same methods. The analytical codebook for CBO leader interviews included the Prevention Agenda Priority areas as well as subtopics, Social Determinants of Health, geography, barriers to treatment, healthcare services provided, and special populations.

4. Results

4.1 Long Island Residents

Focus Groups

Group Description

The four focus groups were held in the Freeport Memorial Library (Freeport), the Riverhead Free Library (Riverhead), the Floral Park Motor Lodge (Elmont), and the Radisson Hotel Hauppauge-Long Island (Wyandanch) during the week of January 28th through February 1st. There were twelve participants in the Elmont focus group, five men and seven women. The Riverhead focus group had two men and two women, a total of four participants. The Freeport focus group had twelve participants, four men and eight women. The Wyandanch focus group had four women and no men. Table 3 shows the demographics for the focus group participants.

Demographic	FG Count		Demographic	FG Count
Total	33		Less than $10,000	6
			$10,000 to $14,999	7
Female	22		$15,000 to $24,999	6
Male	11		$26,000 to $34,999	3
			$35,000 to $44,999	4
Not Hispanic	28		$45,000 to $54,999	1
Hispanic	5		$55,000 to $64,999	1
			$65,000 to $74,999	3
Asian	1		$75,000 to $99,999	2
Black or African American	24			
Other	4		0 through 12th grade (no diploma)	3
White	4		High school graduate (or equivalent)	13
			Post-high-school vocational or technical training	2
18 – 24-year old	2		Some college (no degree) or 2-year college degree	8
26 – 34-year old	4		College graduate (4-year degree)	4
35 – 44-year old	8		Graduate or professional degree	3
45 – 54-year old	6			
55 – 64-year old	10			
65 or over	3			

Table 3: Demographic characteristics of focus group participants

Priority Health Concerns

Chronic Disease

Figure 1: Results from the Delphi Method for discussing Chronic Illnesses

Participants were asked to brainstorm for common chronic diseases. Results from this brainstorm are shown in the word cloud in Figure 1, which represents exact words and phrases used by participants in response to the question. All groups easily identified many different diseases, though with some confusion over type or category. Overall, cancer, hypertension, and arthritis were widely mentioned across all four locations. Cancer was often mentioned along with stress. Additionally, participants frequently voiced their concern about the cause and effect relationship between the difficulty of access to healthy foods and chronic diseases such as cancer, hypertension, and obesity. Smoking and tobacco use were rarely mentioned as chronic diseases for all four focus groups.

Communicable Disease

Figure 2: Results from the Delphi Method for discussing Communicable Diseases

Participants were also asked to brainstorm for communicable diseases. Results from this brainstorm are shown in the word cloud in Figure 2, which represents exact words and phrases used by participants in response to the question. Most participants mentioned sexually transmitted infections, hepatitis, and HIV. Chickenpox, the cold, and the flu were the most frequently mentioned infectious diseases, while the flu and measles were frequently mentioned for access to immunizations.

Healthy Women, Infants, and Children

Figure 3: Results from the Delphi Method for discussing Women, Infants, and Children

Participants were asked to list what they believed to be top health concerns affecting women, infants, and children. Results from this brainstorm are shown in the word cloud in Figure 3, which represents exact words and phrases used by participants in response to the question. Breast and ovarian cancers were the leading concerns voiced by participants regarding women's health. Poor sex education and unsafe sex practices, as well as lack of using protection, were cited as the main causes of teen pregnancy and the spread of sexually-transmitted diseases STDs. Mental health, bullying, mumps, measles, and lead poisoning were among the most cited concerns affecting children. There were no health concerns discussed that affected infants.

Mental Health, Well-Being, and Substance use

Figure 4: Results from the Delphi Method for discussing Mental Health Well-Being, and Substance Use

Participants were also asked to list what they believed to be top health concerns related to mental health, well-being, and substance use. Results from participants' brainstorming of important mental health and substance use issues in their community are shown in the word cloud in Figure 4, which represents exact words and phrases used by participants in response to the question. Mental illnesses were widely cited by participants as being a main issue affecting their respective communities, especially given the far-reaching social and economic consequences that usually accompany mental illness, and the stigma associated with seeking treatment. Participants also discussed the cause and effect relationship that they believed exists between poverty, homelessness, incarceration, or bullying on one hand and mental health on the other hand. Depression, bipolar disorder, schizophrenia, suicidal thoughts, obsessive-compulsive disorder (OCD), and anxiety were among the leading mental health concerns discussed during the focus group sessions. Additionally, alcohol and substance use disorder – including opioids and prescription medication abuse – were said to be significant risks that are becoming commonplace in the focus group communities. Drug abuse and violence were said to be closely-related especially during the Riverhead discussion group.

Healthy and Safe Environment

Figure 5: Results from the Delphi Method for discussing Healthy Environment

When asked to identify factors affecting the general health environment, participants mentioned air and water quality, food safety, violence, and distracted driving as the leading issues affecting their respective communities. Results from this brainstorm are shown in the word cloud in Figure 5, which represents exact words and phrases used by participants in response to the question. Smoking in public areas was cited as a concern, as were rodent and insect infestations, litter, asbestos, and abandoned homes, especially in the Hempstead area. Participants also voiced their concern with the increasing gang violence, which was particularly significant in the Riverhead focus group session. Abusive relationships and bullying were also mentioned. Speeding and failure to stop at a stop sign were a main concerns for traffic safety. Regarding food safety, participants mentioned chemically-treated produce, genetically-modified food, and lack of access to organic food in most low-income communities as the top food safety

concerns. Participants also expressed concerns about the lack of control or knowledge concerning food ingredients, including whether food labels are accurate, clear, and understandable. Chemically contaminated water was the main source of concern when it came to water quality.

Priority Concerns

Figure 6: Results from the Delphi Method for discussing Top Concerns

After participants finished discussing all their health concerns in the community, they were asked to narrow the list and to point out the biggest priorities for health in their community. Results from this conversation are shown in the word cloud in Figure 6, which represents exact words and phrases used by participants in response to the question. Homelessness, cancer, mental illness, and violence were the top concerns that were frequently mentioned by participants across all four locations.

Homelessness

Homelessness was frequently cited by participants when asked to list the biggest health concerns in their community. Participants believe problems such as mental illness, inadequate housing, and poverty are the reasons for homelessness. Participants often mention the circular relationship between homelessness and crime. One participant from the Freeport explained this relationship, "If people who don't have anywhere to live, then you have more crime... It's a vicious cycle, and it keeps getting worse and worse." Another participant from Wyandanch pointed out the benefit of housing homeless individuals by sharing the following personal experience with the group:

> *"I had a client that he was horrible. He couldn't take care of his health, hygiene. He was all the time sick, and he was homeless. Once we got housing for him, you talk to him, and it's another person. He could organize himself. He's taking care of his health. Has a big difference, big difference on him."*

Cancer

Another concern that was frequently cited by participants when asked to list the biggest health concerns in their community is cancer. When discussing cancer, the emerging themes usually involved the uncertainty of the causes of cancer and the phenomena of an increasing amount of cancer patients. Pollution and difficulty of access to healthy food are often talked about as the main suspect of causing cancer. One participant from Riverhead expressed his/her concern on the topic by stating:

> *"Why do we have so many cancer clusters here? Why are so many breast cancer people here? ...where factories left polluted products on the earth and just left it there and forgot about it. And then years later, developed cancer clusters."*

Mental illness

As previously mentioned, mental illnesses were widely cited by participants as being the main issue affecting their respective communities. When discussing anxiety and depression, a participant from Wyandanch pointed out the stigma associated with seeking treatment by stating "I think that a lot of people suffer from it . . . and might not know it because they don't go to therapies, or they don't have access to a therapist to go and assess that." Social and economic consequences such as homelessness, poverty/unemployment, incarceration, and violent episodes between people or with the police are often mentioned along with mental illness.

Violence

Violence is another top concern pointed out by participants across all four locations, with particular significance in the Riverhead focus group session. Drug and gang activity are often talked along with violence. Besides worrying about physical safety, the negative impact of violence on children's development is also a big concern. One participant from Riverhead illustrated this concern by stating:

> *"I'm afraid to let my child go out because they might be influenced when I'm not there, they might be grabbed up by a gang. If they're going through a tough time in their life, which children and teenagers usually do, they might end up in a gang because that might be the easy way out."*

Barriers to Treatment

Figure 7: Results from the Delphi Method for discussing Barriers to Treatment

When asked to list the factors most likely to make it difficult to access healthcare services, participants mentioned affordability, including insurance co-pays and expensive medications as a leading reason. Results from this brainstorm are shown in the word cloud in Figure 7, which represents exact words and phrases used by participants in response to the question. Not having medical insurance and the partial or no coverage for some treatment plans, medical conditions, or medications, in addition to long waiting lists were also among the barriers cited. Other factors included difficulty finding a doctor who speaks their language, especially when the spoken language is neither English nor Spanish. Some participants stressed the importance of teaching immigrants English because this will allow them wider access to healthcare (including to understand advice, information, results, etc.) and to be able to read the instructions and medication labels that are usually written in English. Participants also spoke about health behaviors perceived as related to one's cultural or religious practice, emphasizing the need for cultural sensitivity from healthcare providers.

Difficulty navigating health insurance related complexities and a lack of sufficient health education were also listed as possible treatment barriers. Some participants in Freeport and Elmont mentioned that some men tend to not seek medical attention unless it was an emergency or after their condition has advanced; while some in Riverhead noted the use of emergency departments for non-emergency care. Stereotypes and stigma were cited as social barriers to seeking treatment, especially for mental health. Transportation was also a concern. Participants stated that most people in their communities can't afford a car, so they end up relying on expensive and overcrowded public transportation while traveling to receive treatment, which can often be inconvenient. Participants also mentioned that they are less likely to call an ambulance during emergencies because they can't afford the bill. Some participants also stressed that lack of education about the importance of vaccines in preventing disease, or lack of information and knowledge regarding treatment options for diseases were preventing some people from seeking treatment they really need. Others cited fear of bad health news as a reason to not seek information or care. Still, others spoke about a lack of time as most parents worked long hours to pay rent, which prevented them from seeking medical care for themselves or their children.

Priority Barriers and Solutions

Participants were asked to list the most common barriers from what was discussed during this section of the focus group discussion. Affordability, not seeing the benefit in going or being afraid to go, lack of health insurance, not knowing how to find providers, and lack of convenient transportation were the leading causes for not having sufficient access to healthcare services.

Participants were also asked to propose solutions to help overcome the barriers that were discussed earlier. Participants from Elmont and Freeport believed education in schools would address the barriers of not seeing the benefit in going or being afraid to go, not knowing how to find providers. They also believed that outreach and support from churches or social services agencies could help people obtain and afford insurance and where to get culturally-sensitive care. Participants from Riverhead proposed a solution of having a "navigator," which helps residents understand how their insurance works. Most proposed solutions for affordability are leaning toward the themes of more local job opportunities and universal free healthcare.

Social Determinants of Health

Economic Stability

GettingDiabetes
HealthCareIsTooExpensive
FoodGivesHighBloodPressure
LimitedAccessCreatesInstability
CreatesWellnessPromotesAndBalance
FoodIsCostly
LackOfFunds Money NoKnowledge
Stagnated Housing
LackOfTool
LackOfGoodFoodEqualsPoorHealth
QualityOfLifeAndStandards
HeatingAHomeIsCostly
HardToPayFor AllHaveImpact

Figure 8: Results from the Delphi Method for discussing Economic Stability

Participants were asked to list the main issues that affect their economic and financial stability as it relates to health in their community. Results from this brainstorm are shown in the word cloud in Figure 8, which represents exact words and phrases used by participants in response to the question. Unemployment, poverty, homelessness, lack of affordable housing, and access to healthy food were among the leading concerns that came up during the discussions.

Access to healthy food

The difficulty of affordability and access to healthy foods was a dominant theme when discussing economic stability. When healthy foods are difficult to access, residents choose to go to stores and restaurants that are closer and more easily accessible but do not feature healthy foods, such as fast food restaurants. Even when healthy foods are accessible, the majority of the participants think healthy foods or organic foods are too expensive.

Homelessness and lack of affordable housing

When discussing homelessness, many participants express their concern for their personal safety from people who are homeless. Lack of affordable housing was described as also being related to mental illness.

Unemployment and Poverty

Unemployment and poverty were often mentioned together throughout the discussion across all four locations. Many participants believe unemployment and poverty are tied closely with many health concerns in their community. One participant from the Freeport focus group stated "You have poor employment, now you have poor housing. And you have poor food." Other participants also mentioned the negative impact of poverty on mental health, as demonstrated by one participant from Wyandanch in the following quote:

> *"I think that lack thereof, poverty it causes mental health problems... You're probably not going to be seeking healthcare and trying to go to a doctor if you don't have a house. Going to try to find a home."*

Education

Figure 9: Results from the Delphi Method for discussing Education

When asked to speak about education-related challenges in their communities and the effect of these challenges on participants' perceived wellbeing and access to healthcare, participants mentioned leading concerns including poor school systems and education quality and illiteracy, as well as lack of adequate health education about diseases, treatment options, healthy food, and providers. Results from this brainstorm are shown in the word cloud in Figure 9, which represents exact words and phrases used by participants in response to the question.

Lack of adequate health education

Lack of adequate health education about diseases, treatment options, healthy food, and insurance was commonly mentioned concerns regarding the lack of adequate health education. When discussing the topic, participants from Freeport expressed their concern on the importance of health education for the parents. They believe parents' behaviors have impacts on their children. Regarding education on healthy foods, one participant from Freeport stated, "If the parents keep on going to McDonald's and all this kind of potato chips all the time. The parents need to have education."

Education quality and Illiteracy

Concerns regarding education quality were mainly around large class sizes and the lack of healthy and safe class/school activities. The following discussion on education quality was quoted from the Freeport discussion group:

> "I think sometimes that maybe some of the classrooms [sic] are a bit large for the teachers to handle. Make the classrooms a little bit smaller."

Most participants believe illiteracy has a cause and effect relationship with poverty or low income. Many also believe that parents have a great influence on children's educational path, as one participant from Freeport stated the following:

> "That's with the parents, who may be embarrassed because they have a lack of education, and they have fear. They don't want to be upset or pushed to the side. Or they don't want their children to be embarrassed or have fear. So that empowerment and that lack of knowledge and education, that's when all that comes in."

Neighborhood and Built Environment

Figure10: Results from the Delphi Method for discussing Neighborhood and Built Environment

Participants were asked to speak about factors in their neighborhood and environment that they believed to affect their health and wellbeing. Results from this brainstorm are shown in the word

cloud in Figure 10, which represents exact words and phrases used by participants in response to the question. Contaminated air and water, asbestos, access to quality food, gang violence, drugs and crime, and affordable housing were among the leading concerns mentioned.

Access to Healthy Food

Many participants indicated difficulty in accessing and affording healthy food. Participants stated that affordable pricing and accessibility of fast food restaurants resulted in increased consumption in such foods, which could potentially lead to chronic diseases such as diabetes and obesity in the long run. One participant from Riverhead explained this phenomenon:

> *"A lot of times when... if healthy food is so costly, that a lot of people go to the junk food, which is not. And I have nothing against Taco Bell, but I'm just saying. You know, the Taco-Bell's, the Wendy's, the Burger King, all that stuff is not good for us. Do we eat it? Yeah. But daily, it's got fats; it's got fried everything. Popeyes is, I think, coming into town now. I mean, these are just not good for the health. And they lead to diabetes. Ketchup, soda, sugar all leads to disease if they're consumed too much. And that's what's happening to our communities and has been for a while."*

Crime and Violence

Numerous participants indicated that gang violence was of significant concern, particularly on the exposure of drug and gang violence on children, which could potentially lead children to model violent behavior. Several participants indicated that afterschool activities could help children from getting involved with gang violence. One participant from Riverhead described the concern of gang violence:

> *"Because it's gangs and crime and it's no good for kids growing up. What they see, what they have to see. They have to see these things, going to their friend's house or whatever, they have to-- it's there. There's no avoiding it sometimes."*

Pollution

Several participants expressed concerns about pollution. One participant stated that industrial chemical waste had been connected to cancer. Other participants had concerns about air pollution from cars' emission. As one participant from Riverhead described:

> *"Shoreham used to have a Kodak plant, a photography plant. And some of my friends used to play in the water that had the chemicals within it. They'd bring the dolls home,*

and a number of friends of mine died of cancer later on through the years. So for me, it had a huge impact because then we were like, "Where did that person go? What happened to that person and that person and that person?" They had a common thread. So it's just a huge issue for me because I just know about it…We have a lot of groundwater problems on Long Island."

<u>Social, Family, and Community Context</u>

Figure 11: Results from the Delphi Method for discussing Social, Family, and Community

Participants were also asked to speak about social, family, or community-related challenges and the effects of those challenges on their perceived wellbeing and quality of life. Results from this brainstorm are shown in the word cloud in Figure 11, which represents exact words and phrases used by participants in response to the question. Education, lack of parental involvement (sometimes due to their own health issues or other poverty-related challenges), incarceration, and racism were among the leading concerns. Participants also expressed concerns about the adverse effects of social media, including addiction to social media, lack of face to face interaction, and cyberbullying on children.

Incarceration

Multiple participants commented on the mental impacts of incarceration on other family members. One participant from Elmont stated the following on the mental impact of having a

family member in jail: "Incarceration. I guess if you have a family member go away that leaves you stressed. You can't eat. Mentally, that messes you up."

Incarceration of mental illness patients was another significant concern. Serval participants noted that authorities often mistreat individuals with mental illnesses. Instead of receiving proper treatment for their mental health, these individuals often end up in prison. The following quotes illustrate participants' views of incarceration of mental illness patients: "Yeah. People being incarcerated for mental health issues when they should be getting help for their mental health issues instead of being incarcerated" (participant from Elmont). Another participant stated: "When they're being criminalized, it's not, 'Oh, this person may have had anxiety. This person may suffer from mental health.' No. It's just… they're just going to jail "(participant from Wyandanch).

Social Cohesion

Many participants described their communities as friendly but noted that nevertheless, groups did not mix. One concern revolved around people's unwillingness to help others that were undergoing difficult circumstances. One participant from Wyandanch provided an example:

> *"And I want to share also that I was a victim of domestic violence. And when that happened to me, I went to-- literally knocking on the neighbor's door, and they didn't open the door for me."*

Several participants also referenced the connection between discrimination and stress. One participant from Riverhead explained:

> *"I'm with [Participant 2]. I mean, I think it's stressful if you are-- if a person is a particular color, and they think, 'Gee people are going to assume things about me,' or certain sex, 'They're going to assume things about me.' Or they're heavy, or they're thin, or they're old. They're going to fear discrimination, and that could lead to stress everyday walking around. They're going to go, 'Oh, that person must be filled in the blank.' And they don't even know that person. That person might be the nicest, best person in the world that has their back but because they're a certain look or they wear certain clothes we judge, they're judged."*

Health and Healthcare

As the topic of the focus groups was Health and Healthcare, participants were not explicitly asked about this as a Social Determinant of Health. Therefore, there is no word cloud accompanying this Social Determinant of Health. Based on the focus group discussion, access to health and health literacy are major themes across participants.

Access to Health

Two of the largest concerns regarding access to health were the affordability of health insurance and lack of knowledge about health insurance. Participants usually quickly reached consensus with statements such as:

> *"I think it's [health insurance] still not affordable for everybody. I know a lot of people cannot afford, and when they seek, they go to the doctor, they pay for 150, 200 for the consultation, but they cannot afford to pay $400 every month" (participant from Elmont).*

Lack of knowledge about health insurance results in unknowing the benefits of different health insurances and which would best address them. Participants also mentioned healthcare disparity, which is associated with the concern for affordability. As one participant from Elmont described, "You have poor healthcare in inner-city neighborhoods. Their healthcare is not the same as saying as if you live [in other neighborhoods]. Their medication is not the same."

Health Literacy

Knowledge of prevention of diseases, healthy diet, and how to seek help are commonly mentioned concerns regarding health literacy. Many participants from Elmont said that some people do not know why they were sick and how they can seek help to make the situation better. A participant from Elmont described his/her concern regarding health literacy: "Some of them don't know. They just don't know. They may be sick, and they don't even know to go get it."

General education was often mentioned when discussing health literacy. Many participants see a strong correlation between general education and health literacy. One participant from Elmont expressed his/her opinion on the relationship between a healthy diet and education by stating the following:

"They put out a warning, "Don't eat these certain things." So, if you're not educated, you don't know what 10 grams of sugar is. You don't know what 0 trans-fat is, carbohydrates. You can't even read the words."

Other Health Concerns

Some health concerns which were moderately mentioned related to poor dental care – including gum disease and cavities – and disabilities, mainly childhood associated disabilities such as congenital disabilities, Down Syndrome, pervasive developmental disorders, and other intellectual disabilities.

Sources of Health Information

As the concluding topic for discussion during the focus groups, the moderator asked participants to discuss the various sources they use to obtain health-related information. The following is a summary of that discussion, though a key finding is how some believe it necessary to corroborate information across multiple sources.

Community: Schools, churches, libraries, and hospitals were the most cited sources of information within the community, and in some cases, people wanting to help others avoid the bad experiences that they endured by encouraging them to seek information from hospitals and schools.

Doctors: People across all four locations indicated that they also relied on doctors, nurses, dieticians, and other medical practitioners for health-related information. A majority of participants emphasized that information from doctors is the most trustworthy.

Family: People across all four locations indicated that they used family advice for health-related issues. Grandmothers were the most commonly cited go-to family members for health information.

Google: People across all four locations reported using Google to search their symptoms. However, much skepticism emerged about how online health information exaggerates the severity of issues, conditions, etc.

Health Websites: WebMD was the most cited website for seeking health-related information.

News Sources: Television, magazines, and newspapers were cited as common news sources for seeking health-related information. For instance, a respondent from Riverhead identified a local television personality who speaks with authority about health issues.

Peers: People reported asking or receiving health-related information from trusted peers. Yet there were discussions with respect to keeping information about one's health private in efforts to avoid stigma, embarrassment, isolation, etc.

Social Media: YouTube and the Centers for Disease Control and Prevention's social media pages were the most cited social media sources for seeking health-related information.

In-Depth Interviews

Sample Description

Twelve residents of Long Island were interviewed from February 12th through February 20th. There were three men and nine women, and the sample was split evenly between Nassau and Suffolk Counties. Five of the six participants in Nassau County came from the Hempstead area and one came from Elmont. In Suffolk County, three participants lived in or around Brentwood, two in Riverhead, and one in Mastic. Table 4 shows the demographics for the in-depth interview participants.

Top Health Concerns

Priority Health Concerns Identified by Participants

Similar to the focus group discussions, participants discussed important community health concerns for each of the five Prevention Agenda items. At the conclusion of the discussion, participants indicated what they believed to be the highest community health priorities. Across the 12 participants, chronic illness was highly represented as a high priority, along with cancer, diabetes, and obesity. Mental health and substance use were also indicated to be high priorities, as were HIV/AIDS, crime and violence, and the cross-cutting issue of difficulty accessing care.

Chronic Disease

Cancer

Cancer was identified as a high priority on Long Island. Participants indicated that they perceived cancer to be a common and severe health concern, particularly for breast cancer.

Demographic	IDI Count		Demographic	IDI Count
Total	12		Less than $10,000	1
			$10,000 to $14,999	2
Female	8		$15,000 to $24,999	1
Male	4		$26,000 to $34,999	3
			$35,000 to $44,999	3
Not Hispanic	9		$45,000 to $54,999	1
Hispanic	3		$55,000 to $64,999	1
			$65,000 to $74,999	0
Asian	0		$75,000 to $99,999	0
Black or African American	6			
Other	3		0 through 12th grade (no diploma)	1
White	3		High school graduate (or equivalent)	2
			Post-high-school vocational or technical training	0
18 – 24-year old	1		Some college (no degree) or 2-year college degree	5
26 – 34-year old	2		College graduate (4-year degree)	2
35 – 44-year old	4		Graduate or professional degree	2
45 – 54-year old	1			
55 – 64-year old	3			
65 or over	1			

Table 4: Demographic characteristics of in-depth interview participants living on Long Island

Participants indicated concerns about accessing diagnostic and treatment services for cancer. Specifically, for diagnosis, there were concerns that cancer may be difficult to detect and multiple participants indicated a lack of access to affordable mammograms. Participants also expressed concerns that health insurance did not adequately cover treatment. Several participants had personal experience with cancer, either through a loved one or themselves receiving a diagnosis. As one participant from Riverhead described,

> *"Well, one of the things is breast cancer. The hospitals where you could go to get mammograms in my community, in Riverhead, stopped giving mammograms and you're supposed to go up island to a place that is about 45 minutes to an hour away…That's not good. It makes it difficult to get a very important screening, and you know, most doctors' offices don't have the equipment to give a mammogram."* (Participant ID PHIP-R-DD021219)

Diabetes

Diabetes was another health topic indicated as a high priority in participants' communities. Participants indicated that diabetes was common and resulted in severe consequences. As with cancer, participants discussed concerns over the degree to which diabetes could be diagnosed early and that health insurance does not cover treatment sufficiently. Several participants also expressed personal experience with diabetes.

Obesity

Obesity was the third form of chronic illness identified by participants as a high priority. Participants indicated that obesity was very common in their communities. Participants discussed obesity both in terms of personal decisions and the structural environment. Multiple participants stated that obesity was related to life choices or parenting, due to eating too much unhealthy food, and observing that typically both parents and children experience obesity as parents pass unhealthy behaviors to their children. Other participants drew a connection between obesity and the lack of access to affordable, healthy food, and being forced to eat fast food or other types of unhealthy options. As one participant from Hempstead described, "There's not the best access to affordable healthy food in my hood, it's there, but not everyone can afford it. So a lotta people eat fast food. And therefore we see a lot of childhood obesity." (Participant ID PHIP-R-TTS021519). Participants did not discuss physical activity relating to obesity.

Other Chronic Illnesses

During the discussions, a few other health conditions were identified as important in their communities. One participant from Riverhead spoke at length about the risks involved in Lyme Disease, noting its severe outcomes and susceptibility, "It is easy to get a tick from numerous sources and likewise easy to overlook a tick." Other participants noted high blood pressure as a concern but did not discuss the condition in detail.

Communicable Disease

HIV/STIs

Participants identified HIV and other sexually transmitted infections (STIs) as significant health concerns in their communities. They discussed the lack of available information about HIV/AIDS, HPV, and herpes. Multiple participants noted that many people engaged in risk

behaviors of unprotected sex with multiple partners, not understanding the risk involved. A participant from Elmont described:

> *"People need to know more about them, even docs need to know more about what unprotected sex can cause. A lotta people are sexually active without understanding risk factors. A lot of it can be dangerous, it can destroy lives. If you have numerous partners, you have to check yourself out for STDs on the regular. If you have partners across the years, you have to check yourself out to make sure you don't give it to others."* (Participant ID PHIP-R-CSN021419,)

These individuals also lack a sense of susceptibility to STIs. Participants stated that there is a need for people to be open about their HIV status to their partners. Other concerns noted were a need for healthcare and health insurance to effectively manage HIV, as well as concerns about the HPV vaccine only being available for younger people. Other participants indicated that concerns for HIV and STIs were associated with younger people, and stated that due to their age and life stage, it was no longer a significant concern for them.

Other Communicable Diseases

In addition to HIV, participants identified a few other concerns related to communicable diseases. Several participants noted that few people get the flu vaccine. One participant expressed anxiety about the safety of the vaccine and stated that while she did not get the vaccine, she ensured her children were vaccinated. Participants also noted the risks of passing the flu to others when people were forced to go to work or school while sick with the flu, also observing that people were at a higher risk of catching the flu because they were mentally and physically exhausted. One participant with cancer expressed concern about catching the flu from someone in his immunocompromised state.

Healthy Women, Infants, and Children

Children's Health

Participants identified numerous important health concerns related to children, many of which included an underlying component of economic hardship. Obesity was a key concern, related to parenting choices as well as an unhealthy environment with little exposure to healthy and affordable options. Several participants noted that families could not afford healthy food options and faced challenges, such as not meeting eligibility requirements for food stamps, trying to

support multiple children on a single income, or having incarcerated or addicted parents. Participants also stated that there were significant challenges in accessing affordable healthcare in the form of dentists or pediatricians, as well as the need for more affordable health insurance for children.

Social and community factors were also identified as key health concerns related to children. Multiple participants identified concerns related to gangs and violence, noting that children witness and may mimic violent behavior. Participants identified the need for safe afterschool activities to give children a place to go as well as a prevention method for getting involved in gangs or violence.

Many participants identified children's mental health as a significant concern. They discussed the negative impact of substance use and parental incarceration on children, resulting in children having to raise themselves, manage their school work and other stresses alone. The impacts of these stressors manifest in children having suicidal ideation and engaging in substance use.

Schools were identified as a key component for child health and wellness as several participants stated concerns about the impact of schools on children's well-being. Several participants indicated that children were in overcrowded classrooms, impacting their ability to learn. Some also discussed the presence of fighting on the playground. A few participants stated the potentially negative influence of teachers who were more concerned about living paycheck to paycheck rather than caring for the children, as well as the influence of those who were too quick to discipline children. These participants believed that these teachers' negative behavior could harm the trust between students and teachers.

Women's Health

The areas of greatest concern for women's health were access to cancer screenings. Multiple participants indicated that breast cancer is a specific concern on Long Island, and that lack of affordable mammograms were a challenge to access. Some local hospitals had stopped providing mammography services, resulting in the need to travel significant distances to find affordable mammography. One participant indicated that free or low-cost mammograms were available in Brooklyn and Queens, hoping that this service would be provided to Long Island residents as well. Similarly, several participants noted that while pap smears were important, many women did not get them.

Family Planning/Teen Pregnancy

Family planning or teen pregnancy were rarely discussed among participants. Comments included the need for access to sex education, as children in middle school were getting pregnant. There were mixed perspectives on the availability of reproductive health services, as one participant indicated that these services were available but inconvenient, while another indicated that her local Planned Parenthood fulfilled this need.

Mental Health, Well-Being, and Substance Use

Mental Health

Nearly every participant discussed mental health challenges as being a high priority, often relating them to the result of living in a state of economic instability. One participant from Hempstead described:

> *"I don't know anyone that is depressed but…I'm sure on some level you kind of are – because of the way things are going, it just seems like there is no end… Life on Long Island, you know, every time you turn around, the taxes going up, your healthcare going up, everything going up except for your income. Sooner or later, you get to that tipping point. That's a lot of stress."* (Participant ID PHIP-R-KP021219)

Participants also noted that many people could not focus on their mental health needs until they had taken care of other concerns such as paying for insurance or caring for children and other family members.

Access to treatment was also a significant concern for mental health. Many participants noted the stigma around seeking mental healthcare, preferring to handle their problems "in house" instead. Within the Hispanic community, seeking mental healthcare was particularly stigmatized, with many people holding the view that people like them did not have problems with mental health, and were "tougher" than that. Many participants emphasized the need to talk about mental health to address the stigma as well as receiving more health education so that people could recognize mental health concerns, take them seriously, and obtain care. One participant also noted the challenges with seeking mental healthcare, even with insurance, as she had been receiving mental health services from a community organization but could no longer do so when the organization stopped accepting her insurance. Another participant stated that she had

experienced intimate partner violence but had been unable to locate an affordable treatment provider to help her cope.

As previously stated, children's mental health and the impacts of incarceration were also key themes. Participants noted that children who were growing up without parents present due to substance use disorders or incarceration, were experiencing suicidal ideation, developing substance use disorders, and generally feeling alone and isolated. Participants noted that incarceration had a negative effect on adults as well, as they could not receive adequate care and treatment while in prison. Incarceration could also result in the development of lasting mental health concerns.

One participant had experienced a brief psychiatric hospitalization. She indicated that the experience was extremely negative and potentially harmful to those with mental illness. It took many hours to see the psychiatrist who indicated that she should be released immediately. The participant stated that the hospital conditions included rooms overcrowded with uncomfortable beds, and lack of secure storage, resulting in the need to sleep with eyeglasses on and fully clothed. The participant used the anecdote to illustrate the need for access to better mental health services.

Substance Use

Substance use was commonly cited as a community health concern. Participants specifically named opiates, including heroin, as well as marijuana, and crack cocaine as being the most abused in their communities. There was also a need for increased treatment access, but also the need for treatment access for people who were incarcerated. Several participants noted that while incarcerated, people were unable to access substance use treatment. Interview participants also stated that substance use was a barrier to being able to work.

Alcohol Abuse

Fewer participants discussed alcohol abuse, although several indicated that it was very common. Participants noted that there were many overlapping issues between mental health, substance use, and alcohol abuse.

Healthy and Safe Environment

Violence

Multiple participants indicated that gang violence was a significant concern in their communities, and frequently covered by local news stories. Participants were concerned about modeling of violence to children and the need for safe afterschool activities. There was some anxiety about speaking up about violence out of concern for family or personal safety.

Health Environment

Nearly all participants commented on the lack of access to stores with healthy food options. Stores with healthy foods were further away and located in neighborhoods where the individual would not necessarily feel comfortable shopping. Lack of reliable transportation presented a significant barrier to accessing stores with healthy foods. Due to these barriers, many people in the communities ate fast food. Participants also noted the strong influence of their environment in shaping their health choices and outcomes.

Additional Concerns Related to Environment

Participants also expressed concerns about the influence of other environmental factors. One participant stated that there was a relationship between cancer and the agricultural sector: fertilizers would get into the aquifer and lead to breast cancer. Another participant was concerned about the impact of noise pollution from a nearby racetrack and a train. Other participants worried about possible air pollution from chemical plants or fumes from other sources, such as a local dump or automotive sources.

Other Concerns: Access to Healthcare

Access to primary, specialty, and dental care was another high priority concern expressed by interviewees. Participants noted challenges in finding affordable local healthcare practitioners. Some Participants indicated having to travel up to 20 miles to access care, a trip which requires taking multiple connecting buses. As previously discussed, mammograms were a specific service that multiple participants indicated was a challenge to access from an affordable local provider. Significant difficulty in accessing affordable mental healthcare was another important theme mentioned by numerous participants. The upshot to these barriers to accessing treatment is that many people do not get routine tests as part of their healthcare, leading to delayed diagnosis and treatment. Access to healthcare for children was another key theme, as dentists and pediatricians are expensive. One participant also noted that dental care is easily

neglected in children due to parental stress and feeling overwhelmed with their other responsibilities.

Barriers to Treatment

Priority Barriers

Interviewees were asked to identify important barriers to accessing healthcare. Participants indicated that the most significant barriers were the inability to afford care, lack of sufficient health insurance coverage, lack of access to mental healthcare due to stigma or other barriers, inability to qualify for insurance, and challenges in finding a local healthcare provider.

Inability to Afford Health Insurance and Healthcare

High cost was the most significant barrier discussed by participants. They indicated that many people could not afford healthcare, even with governmental subsidies, due to the high cost of co-pays and deductibles. They also noted that while it was too expensive to get insurance for many, particularly for those who were relatively low income, they also could not afford to go without insurance at the risk of further financial hardship or bankruptcy. One participant noted that while people on public assistance had some support in obtaining health insurance, many who were working were caught between the challenges of not qualifying for assistance in obtaining insurance while not being able to afford plans on their own.

There are several services indicated as being too expensive for many residents, including cancer screenings such as mammograms, children's healthcare in terms of going to a pediatrician or dentist, or receiving mental health treatment for a variety of concerns. Participants also indicated that many people could not afford transportation, whether through the public system or otherwise. Undocumented immigrants were indicated as being particularly at risk since they could not obtain health insurance due to their immigration status.

> *"There's certain things that I need, that I can't get because my HMO won't cover it. And I just got approved for the HMO a couple days ago, and I went to my doctor's appointment and the medicines aren't covered. Things the doctor thinks I need to take and then the Medicaid plan doesn't cover it, that's not fair. You shouldn't be treated differently if you don't have sufficient funds available, we all have the same basic human rights. These medicines are available in [another place] but not here, but it's not our fault." (Participant ID PHIP-R-CSN021419, Elmont)*

Participants indicated that the inability to afford care was the result of multiple economic stressors. Due to the high cost of living on Long Island, many people were forced to work multiple jobs, none of which provided health insurance. Medicare and Medicaid were reported as being too expensive and often provided insufficient coverage for medical care. Many interviewees communicated a sense of significant financial vulnerability, such as one participant who reported being dependent on his spouse's job for health insurance. Without this insurance, they had few alternatives for obtaining insurance, as even the options available on state exchanges were out of their price range. Participants reported not being able to afford treatment for their chronic illnesses or transportation to or from medical appointments, resulting in difficulty obtaining necessary medication. Due to these challenges in affording care, many in the community delayed treatment or diagnosis, and got sicker as a result. Many people end up in the emergency room due to delayed treatment, as emergency services became their de facto medical provider. Mental healthcare was particularly impacted by affordability, as residents frequently prioritize other financial requirements such as rent over their mental health needs.

Insurance does not cover services

Another common barrier to treatment discussed by participants was that HMO plans on Medicaid may not cover everything needed or be accepted by various doctors. Multiple participants discussed challenges with doctors or other services opting out of accepting Medicaid. As previously noted, one participant reported receiving treatment for depression at a local community-based organization, but when they stopped accepting her insurance, she was forced to go elsewhere. Several participants stated that Medicaid does not cover the necessary medications for cancer or HIV. Participants discussed the need for better coverage for children's health and wellness as well.

Transportation

Transportation was named as one of the biggest barriers to accessing healthcare. Many participants discussed not being able to many services related to healthcare, including insurance, treatment, or paying for rides to get to appointments when they did not own a car. Lack of access to reliable transportation was also noted as a significant barrier when participants are unable to find local practitioners and are forced to travel long distances for affordable care.

Transportation is a barrier for multiple reasons. Some participants indicated a lack of awareness of existing services, such as being able to take taxis to access healthcare and have the ride covered by insurance. Many participants discussed a public transportation system that was inadequately meeting their needs:

> *"Transportation, I mean they do have Medicaid taxis but people don't like to take them because they have to wait like 2 hours. They come on time to pick you up but then you have to take a 2-hour wait to take you back home. There is public transit, there's buses, there's the railroad. But where I live, I'd have to walk, which I can't because I'm disabled, a 20-minute walk just to get to the bus stop. There're no buses that go down the road that I live off of. And that's a problem in and of itself. And even then the buses come every hour, it's not like the City [of New York] where buses come every 10 min."* (Participant ID PHIP-R-MSS021819, Riverhead)

Don't know how to get treatment

Lack of understanding of how to access resources or services was cited by numerous participants as a barrier. Several participants commented on people who lack functional literacy being unable to navigate the healthcare system or access resources. Many people also do not have an adequate understanding of available services. Participants indicated that immigrants have specific difficulty understanding how to get treatment and other services. Due to the lack of cohesion in many communities, there is little community-level collaboration to navigate the system. On a related noted, one participant noted the complexity in signing up for Medicaid or Medicare. She indicated that it used to be easier to recertify but the procedures have changed so that people have to do an interview and either work on their application online or in person at the office. More complicated procedures result in fewer people getting through the process.

Stigma/afraid to go

Reluctance to obtain healthcare services came down to stigma or fear of medical bills. Mental healthcare is stigmatized, as participants reported that people are embarrassed to seek treatment and are concerned about being treated differently. Some participants reported that this stigma is particularly strong in the Hispanic community. Participants also discussed the fear of receiving large medical bills as a major barrier to seeking services.

Other Barriers

Other barriers discussed by participants include population-specific concerns. Multiple participants commented that many people are immigrants who do not speak the language and have difficulty obtaining Spanish-language health education. One participant indicated that there is a lack of trust in American doctors among some in the immigrant community. American doctors are perceived to care less about how their patients are feeling. She stated that doctors from other cultures take more time with patients while American doctors run tests, state they found nothing, and sent patients home regardless of their pain or discomfort. Another participant noted the challenges faced by homeless populations who lack sufficient documentation (e.g., social security cards, identification) to seek services.

Participants did not indicate that not seeing the benefit in going to medical care, having a lack of time or clinics offering inconvenient office hours, or a lack of childcare were barriers to healthcare access.

Social Determinants of Health

Economic Stability

Transportation

The lack of reliable transportation was a key theme under economic stability and its relationship to community health. Many could not afford cars, car insurance, or public transportation. One participant noted that her region was a bit rural and lacked sufficient public transportation infrastructure. Due to these challenges in accessing transportation, participants indicated that many people were forced to eat unhealthy options because they were close and accessible. Other participants noted the difficulty in maintaining a job without reliable transportation, indicating that without a job, many people cannot afford healthcare.

Employment

In addition to challenges with employment if one lacks reliable transportation, one participant stated that having a previous history of incarceration is a major barrier to finding a job. Without this stable source of employment, many people are forced to go back to selling drugs or stealing, resulting in a self-perpetuating cycle.

Food

Participants indicated that many people do not have enough money for food and are forced to shop at inexpensive but unhealthy places. Food for a family can be very expensive, and despite working multiple jobs, some cannot afford the hundreds of dollars it can cost to purchase one to two weeks' worth of food. Some families do not qualify for SNAP benefits but still need assistance, leading to a situation where they cannot afford to buy food and children go hungry.

> *"People are not making enough money. The average housing income is $60,000 on Long Island, but what is that number based off of? What can health conscious mothers and fathers truly afford? They go shopping at the Dollar Tree…They are just getting food they can afford, Chinese food, they are not having the right mindset for eating habits."* *(Participant ID PHIP-R-CS021219, Brentwood)*

Finances

Financial insecurity was cited as a major challenge by all participants. Many expressed a sense of significant vulnerability: should someone lose their job, they lose their health insurance and access to healthcare. For example, if someone is reliant on their spouse's income and insurance, they are particularly vulnerable:

> *"You always hear the story – so and so gets sick, dies, there's no health insurance, there's no medical insurance, and now you're a single parent and you've got these bills…plus no insurance."* *(Participant ID PHIP-R-KP021219, Hempstead)*

This sense of insecurity had a major impact on the mental health of people in the community, as they felt stress from the cost of living continuing to increase while their incomes remained the same. Several participants remarked that it is not possible to take care of one's mental health until other needs have been met, such as paying bills and caring for children or family members. Participants also noted the significant economic impact on a family when a parent is incarcerated, as they potentially lose the breadwinner of the household.

Education

Several participants emphasized the need for early education programs in setting up children for success. Another common theme was the need for afterschool programs and youth centers to give children a safe and healthy activity and as prevention for joining gangs. One noted the need for more encouragement for young people to go to school or get connected to financial aid, such as through assistance completing the FAFSA.

Several participants commented on the lack of quality education, resulting in students graduating high school but not knowing how to read or write. Two participants remarked on the role of teachers in supporting students. They indicated that teachers must care about the children, and not just be living paycheck to paycheck. Likewise, there was a comment about schools needing more funding and improvement to better support teachers. They also indicated that teachers need to take discipline seriously and understand its negative impact on kids. Spanish-speaking children are of particular concern, as they are not receiving sufficient support in school and thus not learning.

Spanish-speaking adults were again highlighted as having specific needs. If individuals cannot speak English, they have difficulty accessing services. There is a need to help more immigrants learn English, as well as to translate more materials to Spanish. There is also a need to educate immigrants on how the healthcare system works, and how to get connected to healthcare services, transportation, and education.

<u>Health and Healthcare</u>

Multiple participants highlighted the importance of health education. Several noted that seeking help is a learned behavior, as children learn from their parents. If the parents are educated, the children will learn as well. There is a need for health education on all types of health conditions, but particularly around safe sex practices, mental health stigma, healthy cooking, and eating. Multiple participants emphasized the need for concrete information, preferably in the form of face to face interaction such as through community meetings. Spanish-speaking populations particularly need health education in their own language. There is also a need for more information on services available and how to get connected. This information is particularly of use for immigrants who are unfamiliar with the American healthcare system.

Access to Care

As previously discussed, access to primary, specialty, and dental concern were significant concerns for many participants. They indicated that many people go without necessary testing such as cancer screenings, because they cannot find an affordable and local healthcare provider. Some people have to travel significant distances to access care. Several participants indicated that accessing health providers for children was difficult due to the cost. Mental healthcare is particularly difficult to access and is also not taken seriously in many communities.

Health Disparities

Multiple participants noted that certain populations face unique challenges which have health implications. Participants expressed the greatest amount of concern for Hispanic populations, including undocumented immigrants and individuals who are Spanish-speaking only. Undocumented immigrants are at particular risk due to their inability to get health insurance. One participant stated that during the work season, immigrants who have come for work live in overcrowded, substandard housing. Individuals who are Spanish-speaking only face particular challenges in accessing health education about safe sex practices and other topics in their language, and many children who only speak Spanish struggle in school because they do not receive the attention and support they require. Participants indicated that these populations face significant challenges in understanding the healthcare system and getting connected to resources. There is a stigma in this community for seeking mental health services as well. These challenges parallel those faced by other minority populations on Long Island, who also fear that their health concerns are not taken seriously by the medical community.

Several other groups were identified as having unique challenges with health implications. One participant spoke at length about the challenges facing seniors, such as having difficulty navigating systems to get access to community and health-related resources. For example, seniors are particularly vulnerable to a lack of adequate transportation infrastructure. This participant indicated the need for a caseworker to help seniors navigate systems and get connected to services. People who are homeless also have difficulties utilizing community healthcare services if they do not have access to documentation, such as social security cards, birth certificates, and forms of identification. Lastly, people with disabilities face unique challenges in public transportation if they cannot get to a bus or rail station. Likewise, affordable housing is a significant challenge for people with disabilities. Without affordable housing, health needs can be delayed or ignored.

Neighborhood and Built Environment

Access to Healthy Options

Many participants indicated the difficulty in accessing stores with healthy food options. Participants indicated that these stores tended to be farther away, requiring transportation to access them. Due to transportation barriers on Long Island, many residents choose instead to go to stores and restaurants that are closer but do not feature healthy foods, such as fast food.

> *"The stores, y'know that do sell unhealthy products, cigarettes, all of this is unhealthy, that's another thing. I believe if you want to be better you got to do better, but how can you do better if you're in an environment like that, you know?" (Participant ID PHIP-R-CSN021419, Elmont)*

Crime and Violence

Crime and violence were key themes in discussion with residents. As previously noted, numerous participants indicated that gang violence was of significant concern, particularly for children who may mimic violent behavior. One participant indicated that some residents feel anxious about speaking up about it out of concern for their safety and that of their families. Several participants indicated the need for safe afterschool activities for children as a form of prevention for getting involved with gang violence.

Pollution

A couple of participants expressed concerns over pollution, particularly as it relates to cancer. One participant stated that she believes that fertilizers from farms get into the water aquifer and have been connected to breast cancer. Other participants had concerns about air pollution from various sources including chemical plants or landfills.

> *"We say that people need to take responsibility for their lives and pull themselves up, and they do, but there are certain things you can't control, you can't control the uncontrollable." (Participant ID PHIP-R-CSN021419, Elmont)*

Insufficient Infrastructure

Numerous participants stated that infrastructure on Long Island was insufficient. There is a significant lack of affordable housing, particularly for people who are young or have disabilities, and this results in in people needing to use shelters.

> *"Housing – they have a lot of people in shelters who can't find a good apartment to stay in. There are lots of people in the streets with nowhere to stay, having to go to shelters." (Participant ID PHIP-R-TH021219, Hempstead)*

> *"Housing is very difficult to find– affordable housing, affordable housing for younger people, affordable housing for disabled people – these are very difficult to find. And I feel like a lot of people who looking for affordable housing and things of that nature, they*

tend to put healthcare on the back burner, you know, having a home, having a shelter, is more important to people than their actual health. I've seen a lot of situations where people were very, you know, neglectful of their health and it was detrimental for their health, but you know, they were seeking housing, seeking employment, and you know, a lot of barriers." (Participant ID PHIP-R-MC021319, Brentwood)

<u>Social, Family, and Community Context</u>

Incarceration

Impacts from incarceration were discussed by most participants. For the individual incarcerated, several participants stated that they receive minimal healthcare and insufficient treatment for mental health or substance use concerns. One participant had a relative who was incarcerated for several years and developed mental health issues as a result, increasing the risk that he may be jailed again later. Several participants commented that having a previous history of incarceration can prevent someone from being able to secure a job, resulting in the individual being forced back to old behaviors of selling drugs or stealing and the possibility of creating a self-perpetuating cycle. Incarceration also has significant impacts on family structure. One participant noted that having a parent jailed can remove the family breadwinner and force the other parent to operate as a single parent. Incarceration, as well as substance use, can result in children growing up without parental support and essentially raising themselves. These children must manage going to school and feeding themselves. Some children go hungry because there is not enough money available.

Social Cohesion

Multiple participants described the diversity in their communities in positive terms but noted challenges. People were unwilling to help each other or share information about available healthcare services. A few of the participants also referenced discrimination in the form of police treating African Americans more harshly or receiving suspicious looks while trying to shop. Numerous interviewees indicated concerns with gang violence and safety.

Family Violence

Domestic violence arose as a topic with a few of the participants. One participant had been in a relationship involving intimate partner violence and was continuing to live with the mental health

effects of the experienced violence. Another participant mentioned that physical and sexual abuse of children was a concern in communities.

Sources of Health Information

Internet sources of health information were cited by every single interviewee. Participants also indicated that doctors were a reliable and trustworthy source of information.

Online

Nearly all participants indicated using Google to search for health information. Many searched by symptoms or keywords to understand health conditions, while others used it to locate healthcare providers and check their reviews. Many participants indicated relying on multiple sources of information, whether by looking at multiple sites online about a given topic or by reading information online and verifying it with knowledgeable and trustworthy people. Several participants specifically referred to government sites as credible sources of information, while others discussed using WebMD to learn about health conditions. Few participants relied on social media as significant sources of health information.

Doctors

Numerous participants indicated that their doctors are helpful and trustworthy sources of information. Several participants indicated including doctors' opinions as they searched for multiple sources of information, either by verifying information with a doctor after reading about it or seeking a second opinion by searching for doctor's opinions online.

Other

Participants were mixed on the role of peers or family as sources of information. Some indicated that their friends and family were credible while others stated that they did not receive health information from them or treated it with some skepticism, wanting to hear the information from at least three sources before accepting it. People were seen as credible sources of information if they were educated in health or had experienced a health condition of interest, such as pregnancy. The public library was cited by one participant as a possible source of health information.

4.2 Long Island Community-Based Organizations

Sample Description

In-depth interviews (IDIs) were conducted with 26 CBO leaders in Nassau and Suffolk County from January 7th until February 13th. 16 CBO leaders were interviewed from Nassau County, and 10 leaders from Suffolk County. These CBOs are distributed roughly across the five Social Determinants of Health, as can be seen in Table 5:

CBO Focus for Interview	Nassau	Suffolk	Total
Neighborhood and Built Environment	2	2	4
Health and Health Care	5	3	8
Social and Community Context	3	1	4
Economic Stability	3	1	4
Education	3	3	6
Total	**16**	**10**	**26**

Table 5: Distribution of participating CBOs according to county and Social Determinant of Health

Many organizations are active across multiple Social Determinants of Health (SDH), with the average organization providing services in 2.5 focus areas. These organizations also provide services related to SDHs that were not captured in screening, for example, by including services in the "Other (Please specify)" option. Almost all interviews touched on issues relating to other SDHs. Likewise, 16 of the 26 CBOs are active in both counties, and their interviews often reflected their work in both counties: 19 interviews explicitly discussed Nassau County and locations therein while 14 explicitly mentioned Suffolk County and locations therein. Therefore, all five Social Determinants of Health and both counties received full representation in this research.

The range of healthcare services provided varied widely from organization to organization and SDH to SDH. That said, several services were provided by many organizations across focus areas. Community education was the most commonly provided healthcare service. Food access and housing were other very commonly provided services, especially by Economic Stability organizations. Among pure healthcare services, many organizations provided mental health services in the form of outpatient counseling and psychotherapy, and some residential care and

psychiatry. Transportation services were also commonly provided by non-education organizations to address the transportation issues on Long Island. Primary care services for children and adults were also commonly provided, even by non-healthcare organizations, which worked to help clients find doctors and set-up appointments. On the other end of the spectrum, family planning services were provided by none of the CBOs interviewed, and dental, prenatal, breastfeeding, and immunization services were also rarely discussed.

Social Determinants of Health

Economic Stability

Health Concerns

Mental health and a healthy environment (used to mean a stable housing situation and access to healthy food) were the two most-cited health concerns by Economic Stability organizations. CBO leaders often noted how the stress caused by being financially insecure and working multiple jobs could lead to mental and sometimes physical health problems. As Nassau County organization leader ALN012819 noted, "There's this high demand, high output that people feel they need to keep up with – both kids and adults – and self-care becomes secondary."

In the observation of some CBO leaders, a safe and healthy environment is out of reach for many on Long Island due to lack of money. Several CBOs that addressed homelessness or hunger noted that some on Long Island cannot afford housing and have to sleep on the streets or in their cars.

Populations of Interest

People with disabilities and seniors were the most referenced populations by Economic Stability organizations. Both populations were considered to face significant issues with access with respect to getting around, finding and holding a job, and finding accessible and affordable places to live. As Nassau County organization leader LCN020419 noted, "Disabilities lead to emotional issues which make it difficult to get housing for many people. Even government provided housing requires an ability to function independently." Seniors also faced particular challenges relating to affordability given that many of them no longer have an income and are living from pensions, social security incomes, or retirement savings. As interviewee ZBS012419

noted, "Seniors are the hardest hit. Access to food is still a challenge for them, as is finding affordable places to shop."

Barriers

The biggest Economic Stability barrier to accessing healthcare described by the CBOs was transportation. CBOs note that the Island is laid out for cars and that getting around is difficult for those who cannot afford a car. Even for those who have cars, the infrastructure is poor. As Economic Stability organization leader in Nassau County LFN011819 noted, "The roads are bad, so your car will get messed up, if you even have a car." Frequent reference was also made to the poor state of the Island's public transportation system, especially with regards to Suffolk County. CBOs note that public transit runs infrequently and does not take people where they need to go, such as the grocery store or doctors' appointments, especially given that the public transit system is primarily designed to move people East-West. Neighborhood and Built Environment leader CBN020719 explained that "the service is very poor out here. It mostly runs here east and west, so not very accommodating for people who need to go locally, who need to go to grocery store, doctor, or exercise program. The bus program is NICE (Nassau Inter-County Express)." Health and Healthcare organization leader CCS011119 explained that "The main issue with the economic aspect is transport: Long Island is very spread out, and Suffolk is a large county where the public transit system is not great. Buses generally run 9-6 on the hour in the best-case scenario. In rural areas they don't run as often, not as late, and don't go where people need to go."

Facilitators

Government welfare programs, especially the Supplemental Nutrition Assistance Program (SNAP), were cited as facilitating health for Long Islanders by Economic Stability organization leaders. As Suffolk County Economic Stability organization leader YRS011819 said, "Our clients get benefits, and sure that's helpful. We still have SNAP; cutting that back would be a real issue for us and our clients."

Education

Health Concerns

Nutrition and eating habits were the biggest health concern mentioned by education organizations. This concern dovetailed with the other most-discussed concerns for education organizations: overweight and obesity, physical activity, and a healthy environment. The focus

on nutrition and eating habits stemmed partially from the fact that some education organizations had community nutrition education as their focus. But it also came up in other interviews as well.

Much of the focus on nutrition centered on access to healthy food, especially given how some of the organizations worked with areas in Nassau and Suffolk Counties that are considered "food deserts" due to the dearth of healthy food and fresh produce options available. One CBO leader in Suffolk, KKS021119, described the lack of healthy food choices rather bluntly: "There's an overwhelming number of bodegas, corner stores, where they entice people to just buy [unhealthy food]." The lack of healthy food choices was found by organization leaders to undermine the positive efforts of healthcare organizations, with Nassau CBO leader JRN020519 saying that "Everybody can get health insurance but that doesn't mean they're healthy; they can get a doctor's visit but they can't address the other things that make people healthy, like healthy food and having income." Access to healthy food was often linked to barriers from other social determinants of health, including transportation, affordability, and culture. Lack of transportation to and from grocery stores, and a general lack of transportation preventing disadvantaged people from leaving their communities to get healthy food, were found to limit access to healthy food. An education organization leader in Suffolk County, ZBS012419, argued that lack of transportation shapes people's food choices in ways that discourage eating fruits and vegetables: "Let's go back to transportation. If you are borrowing someone's car or in a taxi, you'll buy more non-perishable items like non-perishables so they'll last a couple weeks. You won't buy things like fresh fruits and veggies that are healthier but don't last." The high cost of healthy food, both real and perceived, and the generally high cost of living on Long Island leaving working families with no time and money to buy and prepare healthy food, also emerged frequently. Finally, providing nutrition education across cultures can be a challenge to do so in a culturally appropriate manner. One solution identified by a CBO leader is to identify alternative preparation methods of traditional foods that allow members of the community to continue eating culturally important foods while maintaining a high level of nutrition.

Populations of Interest

Children received much attention for education efforts, partly due to collaborative efforts with schools. People with Limited English Proficiency was another priority population. Some organizations discussed providing health education in many languages in addition to English and Spanish. One organization indicated that the majority of residents in communities served speak a language other than English.

Barriers

Language and literacy issues featured prominently in interviews with Education organizations. The need for materials to be translated into other languages, especially Spanish, was stressed by several organizational leaders. AEN012219, an education leader from Nassau County, said that "We need to bridge the gap of language barriers. We work with people speaking 50+ languages, the most common being Spanish, Arabic, Bengali, African dialects, and French/Haitian Creole." Given that a quarter of Long Islanders speak a language other than English at home[8], translating materials into other languages is important. Others noted the lack of sign-language interpreters for the deaf and hard-of-hearing community, which can deny them access to healthcare. As CBO leader VLS021319 of Suffolk County noted, "Healthcare facilities may not be accessible to those with a disability – e.g. a traditional exam table, but if in wheelchair they can't get onto it – impacts the type of medical exam they receive. Visually impaired won't have access to printed materials e.g. preventative info, hearing impairment won't have same access in community to those provide healthcare info. Cognitive impairments – can't interpret info given – so we must take a health literacy perspective: how are healthcare providers communicating to people?" CBOs also encountered issues with literacy, with participant ALS020719 noting that "just because we translate materials into Spanish doesn't mean that the Spanish speaking person can read."

Facilitators

School and school district nutrition coordinators were noted as highly effective by some CBO leaders. These staff were cited as being highly knowledgeable and skilled at nutrition, including the provision of healthy food at low cost. However, the lack of resources available to these coordinators were also discussed.

Health and Healthcare

Health Concerns

 The major health concerns brought up by Health and Healthcare organizations were children's health, a healthy environment, and chronic conditions, especially heart disease. Children and their health issues – both physical and mental – were a major focus of organizations across

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[8] United States Census Bureau. (2017.) *Language Spoken at Home: 2013-2017 American Community Survey 5-Year Estimates.* Retrieved February 28, 2019 from https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_17_5YR_S1601&prodType=table

social determinants of health. The importance of breastfeeding and some of the barriers that prevent it from being more widely practiced (e.g., lack of education and knowledge, drug and alcohol use by mothers, the stigma against breastfeeding in public places denying working mothers the ability to breastfeed their kids, etc.) came up in several interviews. The importance of breastfeeding to the mother as well as to the child was also discussed. The lack of healthy environments, used to mean safe, clean, and drug-free living spaces, was also important. As CBO leader LCN02041 noted:

> *"Not having a stable environment for people with mental illness or chemical dependence challenges is one of the biggest challenges, it's hard to help people without a safe space to sleep at night."*

Just as important as what is being discussed in the interviews is what is left out. Through all 26 IDIs, communicable diseases were only discussed a total of five times across three interviews. Communicable diseases were discussed the most in one Health and Healthcare interview with an organization that provided services to HIV-positive people but were only mentioned twice otherwise.

Populations of Interest

Children and low-income people were cited by Health and Healthcare organizations as populations of interest. Children were the most frequently discussed population across focus areas, although they were of greatest concern to Education and Health and Healthcare organizations. Low-income people were a concern of Health and Healthcare organizations because of how income is a frequent barrier to receiving care, at least in their observation. Several Health and Healthcare organizations work largely or primarily with low-income people because they provide free or reduced cost services.

Barriers

Money – both affordability on the patient side and lack of funding on the organizational side – was the biggest barriers encountered by Healthcare organizations. While several organizations noted that health insurance was freely available for most from the state and federal governments, this was not enough to ensure the affordability of healthcare. As Suffolk County healthcare organization leader SVS012619 noted, "It's not just about access to healthcare, it's about affordability. We have a lot of access, we just don't have a lot of affordable access." Cost

was an especially large issue for specialty services such as dental care or cardiology, which are less likely to be covered by insurance.

On the organization side, lack of funding was both the most cited and most severe issue. Most organizations cited government funding as their main source of income, noting that there was little if any private-sector funding. Furthermore, many did not deem the government funding that is available to be sufficient. When asked about steps that could build on positive factors and promote healthy communities, some organizations gave one-word answers such as "Resources," "Money," or "Funding."

Facilitators

A major factor that helps communities get healthier, according to CBO interviews, is the access to health insurance for citizens, including federal programs such as Medicaid and Medicare as well as state-level programs such as the Children's Health Insurance Program (CHIP).

Neighborhood and Built Environment

Health Concerns

Violence – domestic violence and street crime – came up in several interviews with Neighborhood and Built Environment organizations as a health concern, although it was not focused on to the extent that it was in the focus groups and resident in-depth interviews. Violence was seen to influence other aspects of health. In some communities in Suffolk County, individuals feel unsafe going outside and thus are not physically active. As CBO leader KKS021119 noted, "They face safety issues, they may not be able to get out and get the exercise that they need… If neighborhoods are not safe, kids can't go out into playgrounds, parents won't let their kids out. If there's gang activity or more crime, people can't get out as much." The physical and mental health effects of domestic violence was also noted by an organization that focused on domestic violence. The organization leader, CS0111119, cited the Adverse Childhood Experiences framework to explain how trauma can cause physical health problems and substance use later in life: "More trauma makes one more likely to have adverse outcomes physically such as diabetes and heart disease."

Populations of Interest

People with disabilities were cited by several Neighborhood and Built Environment organizations as populations of interest. Organization leaders cited the lack of accessible environments on Long Island, particularly referencing the physical infrastructure, healthcare

facilities, and transit systems. CBN020719, the leader of a Neighborhood and Built Environment leader in Nassau County, noted:

> *"The buses are obligated to take people with disabilities and provide paratransit. But I had a phone call with a lady in a wheelchair not that long ago who was literally crying because the bus wouldn't come to the curb. If you're in a wheelchair, how are you going to get on the bus if it won't come to the curb? Even if it kneels or has a lift or anything like that. And of course there was no curb cut."*

Another population of interest the leaders spoke about were the elderly. CBN020719 talked about the health risks associated with falling due to poor infrastructure, this risk increases dramatically if the person was older:

> *"Of course one of largest causes of injury is falls, especially among older people but also for all age groups. One of leading causes of falls is that the infrastructure here is in such poor shape. We evaluate infrastructure for safety, look at where to go when walking because walking is good for health. We work with injury prevention coordination at local hospitals and engineering organizations to revise infrastructure."*

Barriers

Transportation was the most commonly cited barrier by Neighborhood and Built Environment organization leaders. Other barriers often mentioned were participants' fear of the "system," used to mean the healthcare system and also social services organizations, as well as not knowing how to find services. Fear of the system was often, though not always, linked to immigration status, as CBOs noted that undocumented immigrants were afraid of using social services lest they be deported. Likewise, the perception that a social services organization is unwelcoming and difficult to navigate for both citizens and non-citizens was cited as an important barrier by multiple participants. Lack of affordable housing was also cited as a barrier facing residents of Long Island, especially low-income groups, and it was said to prevent vulnerable groups and victims of abuse from escaping their situations as one leader CSN011119 noted: "Lack of affordable housing makes it harder to escape situations that they're in, very often trapping people in abusive relationships."

Facilitators

The Neighborhood and Built Environment organizations interviewed gave very different answers to what facilitates the community to become healthier with regards to the Neighborhood and

Built Environment. Some mentioned the usefulness of collaboration within the non-profit sector, a theme that was present in many interviews across Social Determinants of Health. As Nassau County leader DNN012319 noted, "No one can be siloed." CSN011119, a Neighborhood and Built Environment leader in Nassau, explained further that "strong collaboration within the nonprofit sector means that we can access services that we don't provide through other nonprofits." CSN011119 also stressed the importance of tackling the issue around lack of affordable housing, noting that:

> *"People struggle to find apartment rentals that meet financial criteria. Need to increase requirements for affordable housing within communities (e.g. certain percentage of developments should be affordable)."*

Others talked about specific policies that would help, with New York City's Vision Zero plan for eliminating pedestrian/vehicle collisions coming up in multiple interviews as something to emulate. Still, others talked about the importance of outreach to help the general public understand what sort of services organizations offered for free or at a reduced cost. The theme of outreach to overcome a lack of awareness emerged in a few interviews across Social Determinants of Health, with CBO leader LBN010719 explaining that "service availability is there, but knowledge in the community about these services – we can do a better job at this, but the services are there."

Social, Family, and Community Context

<u>Health Concerns</u>

Health concerns noted often by Social, Family, and Community Context were access to primary and specialty care, elder care services, and mental health concerns. Mental illnesses and the difficulty of addressing them with a shortage of bilingual therapists (as currently exists according to one interviewee) was noted as an important health concern. Access to care, both primary and specialty, was another major concern. Some organizations also cited lack of access to health-related information, especially noting behavioral health as a major health concern. As MSS012619, a CEO of a health and healthcare organization explained:

> *"Access to quality behavioral health information and services, including treatment, self-help, family support, peer support, and care coordination. Some specific important issues that we address include psychiatric - depression, schizophrenia, different forms of bipolar, personality and disorders - as well as co-occurring substance disorders."*

Substance use was also believed to be a real risk in parts of Long Island. As one leader CCS011119 noted: "Opiate crisis: many of our clients could come from a reasonably well to do household status, the crisis is affecting both poor and rich."

Populations of Interest

Immigrants were the most commonly discussed population of interest for Social, Family, and Community Context organization leaders. Organizational leaders frequently referenced the particular difficulties immigrants face in becoming healthy. Some CBOs noted that immigrants are not eligible for free health insurance services, such as Medicaid, which are a big boon to the health of low-income communities. However, the most commonly cited issue for immigrants was fear.

Barriers

A major Social, Family, and Community Context barrier to accessing healthcare discussed by the CBO leaders is immigration status. Interviews often noted that being undocumented complicates getting health insurance, in part by denying eligibility for Medicaid and Medicare, and discourages individuals from going to the doctor due to fear that any interaction with officials, including hospitals, could lead them to be deported. Fear was a common theme in interviews concerning immigrants. As the leader of a Health and Healthcare organization in Suffolk County noted, "Undocumented people are at elevated risk and have significant fear – they are not coming for help. They have seen a drop in family center usage in areas with Latino populations." Several organization leaders noted that this fear is connected to current policies and rhetoric coming from the Federal government.

Organizations focusing on all Social Determinants of Health cited cultural issues as barriers in multiple ways. Many CBO leaders discussed the reticence of populations to utilize services. For Hispanic immigrants, cultural differences sometimes closely related to immigration status concerns, such as fear of being reported and deported. These fears were associated with lower utilization rates of services, which had implications for their health status.

Other cultural issues discussed by CBO leaders included cultural competency. As GSN011719, the leader of an education organization in Nassau County, noted: "There's a cultural component. People resent someone coming in saying you can't eat all the staples you eat. Instead, say 'you eat this, how can you eat it healthier.'" For organizational cultural competency

issues, reference was made to the need to accommodate immigrant, ethnic and religious minority, and LGBTQ cultures.

Facilitators

Social, Family, and Community Context organizations again emphasized the importance of collaboration within the nonprofit sector and between nonprofit organizations and healthcare organizations. One leader in this topic area, JDS012619, summarized it succinctly:

> *"Collaboration is it. That's it! If we collaborate together, we can deal with a lot of these problems, we just need to come together as a community. With that we can deal with housing, transport, affordability, and bringing medical providers to the people; as long as we stay singular in the community, it's not going to work."*

Others stressed the importance of government intervention to help ease some of the burden currently borne by nonprofits and other community organizations. One leader, DNN012319, suggested providing the following:

> *"…grants to offset cost of care, including federal help. Medicare for All, that could help. Having more people insured, that could help. We have to address the immigration concern. Uninsured are primarily people who are undocumented, though we don't ask about citizenship."*

Prevention Agenda Priorities

Prevent Chronic Diseases

Many CBOs do work related to chronic diseases, as well as nutrition and exercise, such as conditions of overweight, obesity, and heart disease. Cancer emerged only twice in a total of two IDIs. Efforts included decreasing unnecessary hospitalizations and providing services to populations with chronic conditions. Most organizations focused on providing health education on nutrition, cancer and cancer screenings, physical activity, and other preventive health behaviors. Public libraries in Suffolk County represent a significant asset in health education on these subjects as education and resources are shared with staff at the system level, allowing them to share the information with their patrons. The focus of the library system is to facilitate a connection between their patrons and health resources around chronic diseases including obesity, diabetes, or heart disease. Some organizations work to provide health fairs or effect change at the community or structural level through policy or environmental changes, such as

promoting healthy food options at schools or building community gardens to offer access to healthy food and physical activity opportunities. CBO leaders observed that people who need access to health insurance typically have chronic diseases and that these populations are particularly vulnerable to economic challenges.

Prevent Communicable Diseases

Communicable diseases rarely emerged as a topic in the CBO interviews. One organization provides services to people who are HIV-positive, including access to housing, while another organization included providing flu vaccines as one of their services.

Promote a Healthy and Safe Environment

Quality Housing

Several CBO observed that access to quality housing is a significant challenge. There are problems with overcrowding and substandard housing with heating or plumbing issues, with these housing problems frequently occurring in low-income or rural areas. CBO leaders noted that having access to a stable environment is important for those with mental health or substance use disorders.

Access to Healthy Food

Access to healthy food was a major theme among CBOs. Interviewees noted that there are areas throughout Long Island that are considered food deserts, indicating few options for healthy and fresh food. Challenges are compounded by the lack of transportation, resulting in reliance on unhealthy food options from bodegas. An education organization leader in Suffolk County, ZBS012419, argued that lack of transportation shapes people's food choices in ways that discourage eating fruits and vegetables:

> *"Let's go back to transportation: if you are borrowing someone's car or in a taxi, you'll buy more non-perishable items like non-perishables so they'll last a couple weeks. You won't buy things like fresh fruits and veggies that are healthier but don't last."*

Healthier options were also reported to be less affordable. One CBO leader noted that some people on Long Island live in homes without kitchens, forcing them to rely on prepared foods

(typically fast food). The lack of healthy food affordability, convenient options, transportation, as well as time to prepare healthy food were significant challenges to healthy food access. Quite a few CBOs interviewed operated food pantries or soup kitchens for community members.

Violence

Several organizations discussed violence from different perspectives. Some organizations focused on the lasting mental health components and dynamics within abuse. Many public libraries provide resources around emergency preparedness, including active shooter trainings. One organization provides community education around sexual assault and human trafficking. However, there were no gang violence prevention programs discussed. Violence was discussed as a deterrent for children playing outdoors and healthy physical activity.

Other Topics

Some CBOs discussed issues related to traffic safety in terms of traffic calming procedures, adequate lighting, speed control, and facilitating other types of traffic over cars. The lack of sidewalks and general walkability was also noted by several CBOs.

Promote Healthy Women, Infants, and Children

Women's Health

Most CBOs who discussed women's health focused on breastfeeding support. Organizations working to support breastfeeding mothers noted that often, women do not have a location to breastfeed. One organization provides extensive resources around breast cancer, including education and empowerment to get screened and engage in health behaviors to reduce risk. This organization provides community education opportunities around breast cancer, what is involved in screenings, and prevention, working to address the common experience of fear of screenings. The organization also provides psychosocial support groups for women dealing with various stages of breast cancer.

Children's Health

Children's mental health received the majority of CBO focus in this prevention priority area. Several organizations discussed providing mental health services for populations including children. Factors that influence child mental health include housing insecurity and for some children, pressures to succeed academically and a lack of knowledge on healthy coping.

Promote Well-Being and Prevent Mental and Substance Use Disorders

Mental health was the biggest issue raised. Several organizations provide mental health services and noted the relationship between substance use and mental health conditions as symptoms of trauma. CBO leaders noted, however, the need for more bilingual mental health therapists. Interviewees indicated that mental health and substance use disorders can make it difficult for someone to successfully hold down a job, and there is an important relationship between stable housing and management of these issues. Mental health and substance use are related to homelessness. The lack of economic stability can also cause mental health problems from stress. Several organizations indicated a need for health education related to mental health.

4.3 Overview of Results for the Prevention Agenda Priorities

Across both populations of Long Island residents and CBO leaders, certain themes regarding the Prevention Agenda Priorities became apparent. It is clear that promotion of a healthy and safe environment, prevention of chronic diseases, and promotion of well-being and prevention of mental and substance use disorders were considered high priorities by both participant groups. Residents of Long Island stated that they were priority health concerns in their communities and CBO leaders indicated that these health concerns were important and receiving varying levels of support from their organizations. However, it was not clear how these priorities should be ranked. Long Island residents were asked which health topics were the highest priorities to address and CBO leaders were asked to prioritize the topics discussed. Based on the number of times a health concern was referenced during this portion of the discussion, a list of 20 specific health concerns was generated. The top five most commonly referenced specific health concerns are ranked as follows:

Ranking	Specific Health Concern	Number of References	Prevention Agenda Priority
1	Mental health	13	Promote Well-being and Prevent Mental and Substance Use Disorders
2	Violence	12	Promote a Healthy and Safe Environment
3	Substance use disorders	9	Promote Well-being and Prevent Mental and Substance Use Disorders
4	Diabetes	7	Prevent Chronic Diseases
5	Cancer	6	Prevent Chronic Diseases

Table 6: Ranking the top five specific health concerns within the Prevention Agenda Priorities by the number of times it was referenced when asked about the highest priorities to be addressed

The full list of 20 specific health concerns indicated as high priorities translated to a ranking of the Prevention Agenda Priorities according to the number of times any topic within the category was referenced. According to this ranking, promotion of well-being and prevention of mental and substance use disorders, promotion of a healthy and safe environment, and prevention of chronic diseases were the highest priorities, in that order.

Ranking	Prevention Agenda Priority	Number of References
1	Promote Well-being and Prevent Mental and Substance Use Disorders	23
2	Promote a Healthy and Safe Environment	20
3	Prevent Chronic Diseases	18
4	Prevent Communicable Diseases	7
5	Promote Healthy Women, Infants, and Children	2

Table 7: Ranking the Prevention Agenda Priorities by the number of times it was referenced when asked about the highest priorities to be addressed

The finding of the top three Prevention Agenda Priorities aligns with the discussions from the focus groups and in-depth interviews. It also closely parallels the ranking of the specific health concerns within the priority categories.

5. Discussion

5.1 Prevention Agenda Priorities

Prevent Chronic Diseases

Cancer

When discussing cancer, participants indicated that it was highly prevalent and there appeared to be an increase in diagnosis. They expressed concern about possible causes, including pollution and the lack of access to healthy foods. There was also concern about access to screening and healthcare, particularly for mammograms.

Few CBOs discussed their work with cancer. One organization interviewed provides breast cancer education and support individuals. The organization educates individuals about screening and health behaviors in efforts to lower their risk of breast cancer. Long Island residents and this organization agreed that access to screening and care represent significant challenges.

Diabetes and Obesity

Diabetes was also an important concern for participants because it was perceived as being very common and having severe consequences. Similar to participants' discussions on cancer, when discussing diabetes and obesity, participants expressed concern about access to treatment and care. Obesity was also perceived by participants as having a high prevalence rate. Participants diverged in their beliefs about obesity, some believing that it is caused by personal choices, and others believing that is influenced by the impact of their environment and lack of access to healthy foods.

Diabetes and obesity were the focus of several of the CBOs, though many of the organizations do some work related to chronic diseases. Many CBO leaders observed that underserved populations are dealing with these chronic conditions, and that individuals with chronic diseases are particularly vulnerable to economic challenges. Much of the work that the CBOs do related to chronic diseases involve community education, particularly around healthy food and nutrition. Several of the CBOs interviewed described efforts at multiple levels of the social-ecological model for public health, providing education and resources to individuals directly affected, but also at the organizational level. For example, a major public library system was described as sharing resources related to obesity and diabetes, among other topics, to the staff at their

various branches in order to reach a greater audience. Another organization worked to provide healthier options at schools for children and advocated for policy change.

Implications

These results suggest that many in the community are interested and eager to learn about cancer and how to protect themselves, potentially representing an opportunity for cancer health education to a receptive audience. As many forms of preventive health behaviors for cancer overlap with health behaviors to prevent diabetes and obesity, there may be opportunity for coordination in health education. Results suggest a structural barrier in the form of insufficient access to treatment and care, particularly for breast cancer screenings, due to affordability, insurance coverage, and access to transportation. There may be community-level challenges as well, in the form of fear of screenings. CBOs' efforts at addressing the structural factors for obesity and diabetes through change in environment and policy represent a strength in the public health approach.

Promote a Healthy and Safe Environment

Violence

Violence, primarily related to gangs and drug use, was a significant concern expressed by residents in both the in-depth interviews and the focus groups. Much of this concern was related to children who may mimic or get involved in gang violence or parents' concern for their children's lack of safety and inability to play outside. Residents expressed the need for afterschool programs to provide children with a safe place to go as a way to prevent involvement in gangs. There was also some concern about domestic violence.

The CBOs interviewed focused their attention on the resulting trauma from violence and exploration of mental health concerns and substance use disorders as potential symptoms. They also acknowledged the violence as a deterrent to outdoor activity for children, preventing them from having the opportunity for safe physical activity in their neighborhood. There is some community education occurring around violence, in the form of education on rape, sexual assault, and human trafficking.

Community members perceive gang and drug-related violence as an important health concern, but there appear to be few efforts at addressing or preventing violence. There was no mention of gang prevention, although some organizations are working to address the mental health

factors associated with violence. The lack of safe afterschool options for children represents a challenge, particularly as several residents discussed families with one or both parents unavailable to support their children due to substance use disorders or incarceration. While a few CBOs were doing work to increase parenting skills, there may be opportunity for greater education in this area.

Access to Healthy Food

The lack of access to affordable healthy food due to food deserts and insufficient transportation was a significant theme among residents and CBOs. Although there was a large effort described at healthy nutrition education, there appear to be fewer efforts at a structural level to make healthy food options more accessible. Due to healthy nutrition education performed by various CBOs, there may be a demand for healthier options, and many residents indicated interest in healthy, organic options. However, there is an insufficient supply of healthy food options. Some housing units may lack a kitchen, thus even if healthy foods were made available, some community members may be unable to take advantage of them.

Quality Housing

Multiple residents discussed concerns with housing quality in terms of pest control, litter, abandoned homes, and overcrowding. These concerns were echoed by the CBO leaders who observed that these substandard homes tend to be found in low-income and rural areas. Results suggest that a lack of quality housing represents an important structural challenge.

Promote Healthy Women, Infants, and Children

As previously discussed, residents indicated significant concern around the prevalence of breast cancer and access to screenings. For children's health, many residents expressed concern over mental health issues, gang violence, and the difficulty in accessing children's healthcare. Although residents indicated a need for afterschool programs, few organizations discussed providing these sorts of programs. Several organizations discussed providing mental health services to children, but there appears to be a greater need indicated by comments from Long Island residents. Domestic violence and child abuse also emerge in conversation with residents, but few organizations discussed programs aimed at parents to improve parenting skills. This may represent an opportunity to leverage health education efforts to support parents. CBOs also discussed breastfeeding support, although it did not arise as a concern for residents.

Promote Well-Being and Prevent Mental and Substance Use Disorders

Mental health was a major theme among discussion with residents. Many stated that it is significant because it underlies so many other problems, a position supported by CBO leaders. Residents and CBO leaders observed the connection between mental health and poverty, homelessness, incarceration, and violence. Many residents also discussed the difficulty in access to treatment as well as stigma presenting a significant barrier. Access to treatment while incarcerated was an important theme among residents but was not discussed by CBOs. Although several CBOs indicated providing mental health services, there appears to be an important need for both services as well as health education. However, it may be that greater awareness and outreach is needed to help connect residents to available services. Substance use disorder involving opiates, marijuana, and crack cocaine were frequently discussed by residents, and many noted that they may be a form of self-medication from mental health issues. Residents and CBO leaders agreed that implications from substance use disorders include difficulties in finding or holding down a job. Due to the significant interest in mental health concerns by residents, there may be an opportunity to provide health education to an invested audience and reduce some stigma.

Prevent Communicable Diseases

Long Island residents indicated that STIs, particularly hepatitis and HIV, were important health concerns in their communities due to their prevalence and severity. Many residents noted that unsafe sex practices were common and that there was a need for education. However, of the CBOs interviewed, few provided any services related to communicable diseases other than a reference to a housing program for people who are HIV positive and the provision of flu shots. There appears to be significant interest and concern about STIs with little indication from the CBOs interviewed of organizational effort applied to this area. However, it should be noted that there may be efforts in addressing STIs by CBOs who were not included in the interview sample.

5.2 Social Determinants of Health

Economic Stability

Challenges related to economic security were a major theme for residents and CBO leaders, primarily related to structural challenges of lack of transportation and financial insecurity.

Housing security

Many residents discussed homelessness as an important community health concern and identified the relationship between mental illness, inadequate housing, poverty, and crime. CBO leaders also noted the importance of housing security in the maintenance of mental health and substance use treatment. While several CBOs indicated providing services for homeless populations, it is unclear whether residents indicated a greater need for services than currently exist.

Transportation

Lack of access to reliable transportation was a major structural barrier described by both residents and CBOs. Both groups indicated that the public transit system is inadequate and provides insufficient service for local trips, such as going to the grocery store or attending health appointments. While some CBOs provide transportation services, there is a clear and significant need for greater support to transportation services throughout Long Island, including rural areas.

Financial security

Financial security is an issue discussed heavily by Long Island residents. Many participants strongly indicated feeling vulnerable and insecure in their financial standing. Residents and CBO leaders agreed that there is an important relationship between financial security and mental health. There was also agreement that although there are services available for people who are very low-income, there are important challenges facing families of moderate income. As the cost of living on Long Island is very high, expenses related to health insurance, food, housing, and childcare represent a significant portion of a family's budget. As a result, some families will choose to forgo health insurance, although residents indicated a strong desire to have health insurance when available. This income level may represent a need for greater support and services from community-based organizations.

Education

Residents and CBO leaders both commented on the challenges around school quality. Many people cannot read, and there is a need for afterschool programs for children. The impacts of illiteracy were discussed by both residents and CBO leaders as having important health implications, such as the ability to understand written health education. On a related note, this challenge extends to Spanish-speaking populations as well, since not all of them can read in

Spanish. However, few CBOs discussed early childhood, primary, or secondary education. Nearly all CBOs interviewed for education discussed health education, which is explored under "Health and Healthcare."

Health and Healthcare

Access to Healthcare

The challenges around healthcare access represented a major theme for residents and CBO leaders. While several CBO leaders discussed their primary care service provision, residents strongly indicated the need for more affordable and locally accessible services, particularly related to mental health, cancer screenings, and dental care. Access and affordability of health insurance that would provide sufficient coverage was another major theme for residents. While several CBOs indicated that Medicaid and Medicare were a boon to low-income residents, many residents indicated clear frustration with the lack of coverage for necessary services. Lack of access to healthcare was also related to transportation barriers.

As several residents indicated confusion in navigating the system to access resources, there appears to be an opportunity for CBOs, such as libraries, to assist those in need. Many residents noted that various services exist, but that they lacked awareness of them or did not know how to take advantage of them.

One important note is the unique challenge of Hispanic populations in accessing healthcare. Participants discussed significant fear in using healthcare systems and resources out of concern for drawing attention to oneself, risking deportation. These populations are less likely to seek needed healthcare and instead rely on emergency departments. Much of these concerns overlap with issues related to Social, Family, and Community context as current political rhetoric and emphasis on deportation appears to have the impact of making them fearful of using available resources. However, it is not known the extent to which these fears are shared by Hispanic populations residing the country who are not undocumented immigrants, nor is it known what other factors may be impacting access to healthcare for Hispanic citizens. Future research efforts are recommended to explore these questions.

Health Literacy

Most CBOs who provided health education focused on nutrition and eating habits. Some CBOs noted challenges involving providing this education in culturally appropriate ways. While

residents indicated interest in learning more about these topics, they also expressed interest in understanding disease prevention, safe sex, and other topics as ways to improve the health of families, not just individuals. Residents recommended that health education be presented in more concrete formats and preferably through face to face interactions. Residents indicated that Spanish speaking populations particularly need access to health education in their language. Several CBOs indicated that they provide health education in many languages, so there may be an opportunity for greater awareness and marketing of these resources.

Neighborhood and Built Environment

Residents spoke extensively about structural challenges related to violence, access to healthy food, and access to affordable housing, much of which was supported by comments from CBOs. Residents and CBOs agreed that there is a lack of healthy and affordable food access, driven by the combination of food deserts and lack of transportation infrastructure. CBOs indicated attempts to provide access to healthy foods through food pantries, soup kitchens, and community gardens, as well as other environmental and policy changes. Although there are many efforts at providing nutrition education, greater effort appears to be needed to provide access to healthy foods. Crime and violence were also important themes, as many residents stated that there was gang violence impacting their communities. However, few CBOs interviewed indicated efforts at gang violence prevention work or providing safe places for children to go after school. There may be opportunities for CBOs to provide activities and places for children to go as a method of preventing gang violence. Residents and CBO leaders emphasized the serious lack of affordable housing as an important structural barrier to community health, which may need to be addressed at a policy level to encourage more quality affordable housing development. The health impacts from air and water pollution was a concern indicated by several participants, although few CBOs indicated efforts in this area. While it is unclear whether there are health threats from air or water sources, the level of concern among residents suggests that some health education may be helpful.

Social, Family, and Community Context

The lasting impacts from incarceration were key themes among discussions with residents. Residents noted that incarceration is associated with lack of access to mental healthcare, as well as significant impacts on employment, family structure, and family finances. However, very few CBOs mentioned issues related to incarceration or institutionalization. This discrepancy

may represent a gap between the community's concerns and health priorities, and services offered by CBOs.

Social cohesion was addressed by residents and CBOs. Several residents discussed problems with discrimination. CBOs discussed the need to provide for special populations such as Spanish-speaking populations and seniors. Many CBOs discussed immigration status as a significant barrier to seeking healthcare out of fear of deportation. Health clinics in some Hispanic areas have seen a decrease in usage. Barriers facing undocumented immigrants include community-level challenges in the form of discrimination, institutional barriers with culturally competent services, and structural barriers in terms of the current emphasis on deportation.

6. Conclusions

The goal of this study was to inform the process used by the members of LIHC's CHNA Preparation Workgroup to select which of the five New York State Prevention Agenda Priorities to focus on for the 2019-2021 period, as well as to inform the Community Health Needs Assessment process and subsequent implementation plans for hospitals and local health departments through the lens of the Social Determinants of Health. Results from focus groups and in-depth interviews with underserved Long Island residents were compared to results from in-depth interviews with community-based organization leaders who provide services to these populations.

6.1 Prevention Agenda Priorities

Of the five Prevention Agenda Priorities, prevention of chronic diseases, promotion of a healthy and safe environment, and promotion of well-being and prevention of mental and substance use disorders received significant attention from residents on Long Island and from CBOs. These three priority areas were indicated as of significant concerns to residents while receiving varying levels of support and intervention from CBOs. Based on participant comments about the highest priorities, promotion of well-being and prevention of mental and substance use disorders appears to be the top priority, particularly related to mental health and substance use. Promotion of a healthy and safe environment was the second highest priority, mostly in terms of concerns related to violence. Prevention of chronic diseases was the third highest priority, and mostly related to concerns related to diabetes and cancer. It may be beneficial to explore

additional approaches and collaborative efforts to address these areas through health education, as well as environmental and structural changes.

6.2 Social Determinants of Health

Economic Stability is a significant influence upon the health of Long Island residents in their opinions as well as those of CBO leaders. The greatest impacts relate to accessible transportation and financial insecurity. Issues related to Health and Healthcare also dominated discussions with residents and CBO leaders, in terms of challenges to healthcare and insurance access, as well as health literacy and education. Residents recommended greater education to help them connect to available resources and address barriers such as fear or stigma. Many residents and CBO leaders also discussed the many structural challenges related to Neighborhood and Built Environment, such as lack of affordable housing or access to healthy food options.

6.3 Limitations

This research has some important limitations. As all three data collection methods involved qualitative research, it is important to note that while they provide a deep understanding as to experiences related to health and healthcare, they do not measure the prevalence of these experiences among the population of residents on Long Island or CBO leaders, as a survey with a representative sample would be needed for those conclusions. Furthermore, it is important to note that the focus groups in Suffolk County did not fill to capacity, although the resident in-depth interviews provided some additional insight into their perspectives on community health priorities.

7. Appendices

7.1 Focus Group Discussion Guide

Long Island Health Collaborative *Population Health Improvement Program*	EUREKA FACTS

Focus Group Protocol

Focus Group Information:

Moderator	
Location	
Date	
Time	

Materials:

- *Pad of large sticky notes for each participant*
- *Thin black markers for each participant*
- *Easel with note sheets for the moderator*
- *Box or container for participants to place notes into*

Introduction and overview

(10 minutes total)

(3 minutes)

Hello and welcome to this group discussion. My name is _____, and I am tonight's facilitator. First, it is important to know that I work for EurekaFacts, a marketing research firm, and I do not work for any organization involved in health care in your community. EurekaFacts has been contracted by the Long Island Health Collaborative to conduct this focus group session. My role is to help get a conversation going and to make sure we cover a number of important topics that they would like your input on.

Let's go around the room now and introduce ourselves. *[Include quick ice breaker activity here]*

Rules for Focus Groups

(2 minutes)

I would like to thank you all for taking time out of your day to come here and discuss your ideas. The overall goal is to hear your thoughts about health**.** In particular, we are interested in your views about **things that impact the health of people in your community.**

- We value your experience and we are here to learn from you. Your thoughts are very important to all of us in the research team, and so we will be recording the audio from today's meeting so that we won't miss anything you say.

- Participating in today's meeting is completely voluntary. You have the right to withdraw from the group at any time without penalty.

The total length of time of the focus group meeting is expected to be about **two hours.** There will be a 10-minute break in the middle. There are a few "ground rules":

- I might move you along in conversation. Since we have limited time, I'll ask that off-topic questions or comments be answered after the focus group session.

- I'd like to hear everyone speak so I might ask people who have not spoken up to comment.

- Please respect each other's opinions. There's no right or wrong answer to the questions I will ask. We want to hear what each of you think and it's okay to have different opinions.

- We'd like to stress that we want to keep the sessions confidential so we ask that you not use names or anything directly identifying when you talk about your personal experiences. For example, if you talk about a friend, or specific places, don't use their full names or give the kind of information that could be used to fully identify someone. We want to keep their identities anonymous.

- We also ask that you not discuss other participants' responses outside of the discussion. However, because this is in a group setting, the other individuals participating will know your responses to the questions and we cannot guarantee that they will not discuss your responses outside of the focus group.

- Please do not film or record any part of this session. Please silence and put away your phones and other electronic devices.

Overview of "Delphi Method"

(5 minutes)

Let's talk about the sticky notes and markers in front of you. For some of the questions today, I will ask you the question, and then I want you to write your response down on those sticky notes, one idea per note. You will put the notes in that box and then pass the box to me. I will stick the notes onto this easel, and together we will see which notes similar and which ones are different, putting them into groups. We want the notes to be anonymous, so don't write your name on it, and you don't have to say which one you wrote. We will use these notes to start many of our conversations today.

- Let's practice doing this now. I'm going to ask you a question and I want you to write down your answers, one idea per note. Make sure you write legibly and in big letters. What is your favorite season? Write down your answer on the sticky note, put it in the box, and pass it to me.

    [Moderator takes the box full of notes, mixes them up, and places them on the easel, grouping the notes that say the same thing. Then, pointing to one of the seasons:]

- Let's talk about this group. Why do you think someone would say this is their favorite?

    [Discuss the pros/cons to that season, and then move on to the next season – until it seems like the group understands how it will work.]

- We will use this method for many of the discussion questions today. For other questions, we will just talk without writing anything. I will tell you when to write something down and when we will just talk about it. Ok?

DO YOU HAVE ANY QUESTIONS SO FAR?

Ok, let's get started.

Top health concerns in your community

(30 minutes)

Step 1: Group generation

To start our conversation today, let's talk about types of health concerns. We are going to brainstorm for a moment. You don't need to write anything down for this part because we are just going to talk about them.

- (2-3 minutes) Let's first talk about common *chronic diseases* in a general way. These are diseases which you can't catch from another person and that you have for a long time. For example, diabetes and asthma are both common chronic health diseases because you don't catch them from other people and you might have them for many years. What other common examples of chronic diseases or health conditions can you think of?

    [Moderator writes "Chronic Diseases" on easel pad and writes down the other examples from participants.]

    Suggest, if they do not come up: Diabetes, asthma or lung disease, cancer, heart disease or stroke, obesity or overweight

- (2-3 minutes) Let's move to the next topic: important *communicable diseases*. These are diseases which can be spread from one person to another in a variety of ways. For example, HIV and the flu are both important communicable diseases because they can be spread from other people. What other examples of infectious diseases can you think of?

    [Moderator writes "Communicable Diseases" on easel pad and writes down the other examples from participants.]

    Suggest, if they do not come up: HIV/AIDS, other sexually-transmitted infectious (e.g. herpes), and diseases that can be prevented with vaccines, like the flu or measles

- (2-3 minutes) Now let's talk about common health issues *for women, children, and infants* in particular. These are health concerns like reproductive health or childhood obesity. What other common examples of health conditions that impact women, children, and infants can you think of?

    [Moderator writes "Women, infants, and children" on easel pad and writes down the other examples from participants.]

> **Suggest, if they do not come up:** cancer screenings (mammograms, pap smear), breastfeeding, dental health in kids, childhood vaccinations, obesity or overweight, bullying

- (2-3 minutes) Let's shift to focusing on common issues with *well-being, mental health, and substance use.* These are health issues that can include a person's resilience or overall ability to bounce back after a setback, or things like depression and anxiety disorders. What other common examples of well-being, mental health, and substance use issues can you think of?

  > *[Moderator writes "Well-being, mental health, and substance use" on easel pad and writes down the other examples from participants.]*

  > **Suggest, if they do not come up:** *positive relationships with others, depression, anxiety, suicide, alcohol abuse, and opioid abuse*

- (2-3 minutes) Finally, let's talk about common ways that your environment impacts your health. For example, neighborhood violence and having access to stores that carry healthy foods are aspects of your environment that affect your health. What other common examples of environmental conditions can you think of?

  > *[Moderator writes "Healthy and safe environment" on easel pad and writes down the other examples from participants.]*

  > **Suggest, if they do not come up:** environmental hazards (e.g. pollution), safety, and traffic accidents.]

Step 2: Individual generation I

- (*2-3* minutes) Now, with all of these different types of health concerns and issues in mind, what do you think are the **biggest health concerns** in your community? Write down one or more thoughts on the sticky notes provided, using one sticky note for each thought. Be sure to write in very big, legible letters.

  > [*Moderator writes "Health concerns in your community" on easel pad. After 1-2 minutes of participants writing and putting their notes into the box, Moderator takes the box full of notes, mixes them up, and places them on the easel, grouping the notes that say similar things.*]

Step 3: Discussion of individual ideas I

- (*6-7* minutes) Let's talk about your responses for a few minutes and think through what the biggest concerns for your community might be. Remember, you don't need to say what your answer was, and you can change your mind about your answer. What do people think about (*one of the groups of responses*)? How big of a concern is this in your community? Why is this a concern for you, or do you not worry about it as much?

- o [*Briefly discuss each grouping. Ensure discussion focuses on the specific community. While there may be many concerns, remember that we are interested in identifying the biggest concerns.*]

Step 4: Individual generation II

- (*6-7 minutes*) Now that we've had a chance to talk about these issues, I'd like to get your written responses again. So, just like before, please write down what <u>you</u> think the biggest priorities for health in your community are. You can write the same ideas you wrote last time, or you can write something different.

Step 5: Build consensus

- o [*Allow 1-2 minutes then collect notes. Take 5 minutes to help the group identify the top 3-4 concerns*]

Barriers to getting treatment

(15 minutes)

Step 1. Individual generation

- (2-3 minutes) Sometimes people cannot or do not get care for their health problems. What do you think prevents people from getting treatment in your community? Some examples might be lack of insurance, transportation, embarrassment or stigma, and not knowing how to get treatment. Please write your response on a note.

    [*Moderator writes "Barriers to health care" on easel. After 1-2 minutes of participants writing and putting their notes into the box, Moderator takes the box full of notes, mixes them up, and places them on the easel, grouping the notes that say similar things.*]

Step 2. Discussion of individual ideas

- *(5 minutes)* Let's talk about these your responses and think through what the biggest barriers in your community might be.

    [*Discuss groupings of notes. Ensure discussion focuses on the specific community. While there may be many concerns, remember that we are interested in identifying the biggest concerns.*]

Step 3. Build consensus

- *(2-3 minutes)* What would you all say the biggest factors are for your community? Let's discuss them.

    [*Help group reach a consensus. Record top 3 barriers.*]

Step 4. Group generation of solutions

- *(5 minutes total for all questions about education and services)* What kind of education or services do you think would help with (*Barrier 1 from consensus list*)? Let's discuss them.

  [*Repeat previous question for each of the top barriers.*]

Break

(10 minutes)

- OK, let's take a 10-minute break. Let's be ready to go at (*time*).

Social determinants of health

(30 minutes, 7 min. per topic)

- Welcome back! I hope everyone got a chance to stretch their legs, use the restroom, and take care of personal needs. Please return to your seats. Now, we're going to talk in more detail about how your community and environment affect your health. Don't respond out loud yet, just write your response on a sticky note.

Step 1. Individual generation I (*economic stability*)

- *(1-2 minutes)* How does *economic stability* impact health of your community? In other words, how do *housing, employment, food, and transportation* impact health in your specific community? Write your answers down on the notes and place them in the box.

  [*Allow 1-2 minutes to write responses*]

  o OK, now everyone please pass your notes to me.

  [*Collect and shuffle notes, place them on easel grouped by housing, employment, food, transportation, and other categories.*]

Step 2. Discussion of individual generation I (*economic stability*)

  o *(5 minutes) Let's discuss your responses for a few minutes. Remember, you don't need to say what your answer was, and you can change your mind about your answer. What do people think about (one of the responses)?*

Step 3. Individual generation II (*education*)

- *(1-2 minutes)* How does *education* impact health of your community? In other words, how do issues like *literacy and early childhood education* impact health in your specific community? Write your answers down on the notes and place them in the box.

     [*Allow 1-2 minutes to write responses*]

   o   OK, now everyone please pass your notes to me.

     [*Collect and shuffle notes, place them on easel grouped in categories. Discuss responses in each of the categories.*]

Step 4. Discussion of individual generation II (*education*)

   o   *(5 minutes)* Let's discuss your responses for a few minutes. Remember, you don't need to say what your answer was, and you can change your mind about your answer. What do people think about (*one of the responses*)?

Step 5. Individual generation III (*neighborhood and environment*)

- *(1-2 minutes)* How does *your neighborhood and environment* impact health of your community? In other words, how do issues like *having access to types of food stores, the level of safety, amount of pollution, and other similar issues* impact health in your specific community? Write your answers down on the notes and place them in the box.

     [*Allow 1-2 minutes to write responses*]

   o   OK, now everyone please pass your notes to me.

     [*Collect and shuffle notes, place them on easel grouped in categories.*]

Step 6. Discussion of individual generation III (*neighborhood and environment*)

   o   *(5 minutes)* Let's discuss your responses for a few minutes. Remember, you don't need to say what your answer was, and you can change your mind about your answer. What do people think about (*one of the responses*)?

Step 7. Individual generation IV (*social factors*)

- *(1-2 minutes)* How do *social factors* impact health of your community? In other words, how do issues like *how tight knit a community is, the amount of discrimination a person faces, or incarceration* impact health in your specific community? Write your answers down on the notes and place them in the box.

[*Allow 1-2 minutes to write responses*]

- o   OK, now everyone please pass your notes to me.

[*Collect and shuffle notes, place them on easel grouped in categories.*]

Step 8. Discussion of individual generation IV (*social factors*)

- o   *(5 minutes)* Let's discuss your responses for a few minutes. Remember, you don't need to say what your answer was, and you can change your mind about your answer. What do people think about (*one of the responses*)?

Sources for health information:

(5-7 minutes)

- -   We are done with the writing portion of this group and will just discuss questions now. Where do you get information about your health?

  - o   What information is easy to access? For example, are there certain *websites or people* who are easy to get health info from, or are there certain *health topics* that it's easy to get info on?

    Probe: Social media, health websites, news sources, peers, family, community. If they say "google", probe for more detail: what are their search terms, how do they know if they can trust the information from a site

Conclusions:

(5-10 minutes)

- -   *(2-3 minutes)* Is there anything else you want to talk about that we haven't addressed?

- -   *(2-3 minutes)* What was the most important thing that we discussed today?

Thank you all again for sharing your thoughts, feelings, and experiences with us today. We so appreciate it!

7.2   Long Island Resident In-Depth Interview Guide

Interviewer Questions

Complete these questions before the interview.

Ref #	Question/Prompt	Response
	Preliminary Information	
1	Name of interviewer	
2	Date, time	
3	Participant ID	
4	Participant City	

Road Map of Discussion

Issues / Information to be Discussed	Length Allotted to Discussion (minutes)
Overview, consent	*2, does not count toward interview length*
Top Health concerns	10-12
Barriers to getting treatment	3-5
Social Determinants of Health	6-8
Sources of Health Information	3
Conclusion	1-2
Total Time (minutes):	**30**

Overview and Consent

(5 minutes)

INTERVIEWER INSTRUCTIONS: *The interviewer should not read the script word for word, but should be familiar with its contents and conduct the interview in a natural and conversational manner, paraphrasing or giving further explanation as appropriate.*

Script:
Hello, my name is _____ and I am a researcher with a company called EurekaFacts conducting a project on behalf of the Long Island Health Collaborative. Thank you for agreeing to speak with me today and answer my questions.

*I wanted to talk to you today because you live on Long Island and have had some trouble accessing healthcare recently. The overall goal is to hear your thoughts about health. In particular, I am interested in your views about **things that impact the health of people in your community.***
Now, before we continue, it is important that you know that, as part of the research team, I am neutral on this topic. Please keep in mind that there are no 'right' or 'wrong' answers.

I value your experience and am here to learn from you. Your thoughts are very important to all of us in the research team, and so I will be recording the audio from today's meeting so that we won't miss anything you say. Participating in today's conversation is completely voluntary. You may choose to decline to answer any question and stop the interview at any time. You have the right to withdraw from the group at any time without penalty.

You may not directly benefit from this research; however, we hope that your participation in the study may help the Long Island Health Collaborative help more people on Long Island get the healthcare they need.

I anticipate that this interview should last around 30 minutes today. I will be taking notes and also recording our conversation with your permission, but everything that you tell me will be kept confidential and treated in a secure manner. Your answers in this study will remain private. Your name will not be shared with anyone outside of this study, except as otherwise required by law.

Do you agree that you are at least 18 years old, understand this consent language, and agree to participate in this research study?
       ☐ Yes → If Yes, continue
       ☐ No →If No, Terminate and use script at end of document

Do you consent to having this conversation recorded?
       ☐ Yes → If Yes, continue
       ☐ No → If No, Terminate and use script at end of document

Start recording

For the purposes of this recording, this is <u>(interviewer)</u> interviewing participant (-<u>)</u> on <u>(date)</u> for the Long Island Health Collaborative.

Top Health concerns (10-12 min total)

To start our conversation today, we're going to briefly talk about types of health concerns. We're going to be talking about health in pretty broad terms,

Chronic diseases (1-2 min)

Let's first talk about common *chronic diseases* in a general way. These are diseases which you can't catch from another person and that you have for a long time. For example, diabetes and asthma are both common chronic health diseases because you don't catch them from other people and you might have them for many years. Other examples might be lung disease, cancer, or obesity.

In your opinion, what are the important chronic diseases in your community, and why?

Communicable diseases (1-2 min)

Let's move to the next topic: important communicable diseases. These are diseases which can be spread from one person to another in a variety of ways. For example, HIV and the flu are both important communicable diseases because they can be spread from other people. Other examples might be HIV/AIDS, sexually-transmitted infections like herpes, and diseases that can be prevented with vaccines, like the flu or measles.

In your opinion, what are the important communicable diseases in your community, and why?

Women, infants, children (1-2 min)

Now let's talk about health issues for women, children, and infants in particular. These are health concerns like reproductive health or childhood obesity, cancer screenings like mammograms or pap smears, breastfeeding, kids' dental health, obesity in children, bullying.

In your opinion, what are the important health conditions that impact women, children, and infants in your community, and why?

Well-being, mental health, substance use (1-2 min)

Let's shift to focusing on common issues with well-being, mental health, and substance use. These are health issues that can include a person's resilience or overall ability to bounce back after a setback, or things like depression and anxiety disorders. This can also include positive relationships with others, or issues like suicide, alcohol or drug abuse.

In your opinion, what are the important health conditions involving well-being, mental health, and substance use issues in your community, and why?

Healthy and safe environment (1-2 min)

Finally, let's talk about common ways that your environment impacts your health. For example, neighborhood violence, having access to stores that carry healthy foods, traffic accidents, or having clean and safe places to live are aspects of your environment that affect your health.

In your opinion, what are the important environmental conditions that affect health in your community, and why?

Top health concerns in your community (1-2 min)

Now, we have just talked about a lot of different types of health concerns in your community: chronic diseases, communicable diseases, women / infants / children, well-being and mental health, and a healthy and safe environment.

With all of that in mind, what do you think are the biggest health concerns in your community and why?

Barriers to getting treatment (3-5 min total)

Sometimes people cannot or do not get care for their health problems. Some examples might be lack of insurance, transportation, embarrassment or stigma, and not knowing how to get treatment.

What do you think prevents people from getting treatment in your community?

Which are the biggest barriers?

Social Determinants of Health (6-8 min total)

Now, we're going to talk in more detail about how your community and environment affect your health.

Economic stability (1-2 min)

How does economic stability impact health of your community? What I mean by that is, how do housing, employment, food, and transportation impact health in your specific community?

Education (1-2 min)

How does education impact health of your community? In other words, how do issues like literacy and early childhood education impact health in your specific community?

Social factors (1-2 min)

How do social factors impact health of your community? In other words, how do issues like how tight knit a community is, the amount of discrimination a person faces, or incarceration impact health in your specific community?

Sources of health information (3 min)

- Where do you get information about your health?

    Probe: Social media, health websites, news sources, peers, family, community. If they say "google", probe for more detail: what are their search terms, how do they know if they can trust the information from a site

What information is easy to access? For example, are there certain *websites or people* who are easy to get health info from, or are there certain health topics that it's easy to get info on?

Conclusions (2 min)

Is there anything else you want to talk about that we haven't addressed?

What was the most important thing that we discussed today?

Thank you again for sharing your thoughts, feelings, and experiences with me today. I truly appreciate it!

Termination Script

Termination for lack of consent to participate or record

Thank you so much for agreeing to talk with me today. I need your consent to participate or record the interview, and so we will stop this interview, I appreciate your willingness to answer my questions, and those are all the questions I have at the moment. Have a great day.

7.3 Community-Based Organization In-Depth Interview Guide

Long Island Health Collaborative Community-Based Organization Leader

In-Depth Interview Guide

Interviewer Questions

Complete these questions before the interview. Confirm questions 4-6 with the participant during the Overview for quality assurance.

Ref #	Question/Prompt	Response
	Preliminary Information	
1	Name of interviewer	
2	Date	
3	Participant ID	
4	Participant's Role/Title	
5	Participant's Type of Organization	☐ Economic Stability ☐ Education ☐ Health and Healthcare ☐ Neighborhood and Built Environment ☐ Social, Family, and Community Context ☐ None of the above (Thank and terminate)
6	Participant's length of time at current job	☐ Less than one year (Thank and terminate) ☐ One year or longer (Please specify) _____

Road Map of Discussion

Issues / Information to be Discussed	Length Allotted to Discussion (minutes)
Overview, consent, eligibility confirmation	*5, does not count toward interview length*
Introduction and social determinants of health	2-3
The impact of the SDH on health	10
Conclusion	3
Total Time (minutes):	**15**

Overview and Consent

(5 minutes)

INTERVIEWER INSTRUCTIONS: *The interviewer should not read the script word for word, but should be familiar with its contents and conduct the interview in a natural and conversational manner, paraphrasing or giving further explanation as appropriate.*

 Script:

Hello, my name is _____ and I am a researcher with a company called EurekaFacts conducting a project on behalf of the Long Island Health Collaborative. Thank you for agreeing to speak with me today and answer my questions.

I wanted to talk to you today because your organization has been identified as providing services that impact the health of people on Long Island. The purpose of this in-depth interview is to understand your perspectives regarding the intersection of [Social Determinant of Health] and health in the community. Your responses to this interview will help improve the understanding healthcare needs on Long Island.

Now, before we continue, it is important that you know that, as part of the research team, I am neutral on this topic. I am interested in getting your point of view to understand how you have observed [SDH] impact health in the communities you serve. Please keep in mind that there are no 'right' or 'wrong' answers. There are no known risks to participating in this study. You may choose to decline to answer any question and stop the interview at any time. There will not be any penalties if you choose not to participate in this study or decline to answer any questions.

You may not directly benefit from this research; however, we hope that your participation in the study may help the Long Island Health Collaborative improve access to healthcare for Long Island residents.

I anticipate that this interview should last around 15 minutes today. I will be taking notes and also recording our conversation with your permission, but everything that you tell me will be kept confidential and treated in a secure manner. Your answers in this study will remain private. Your name will not be shared with anyone outside of this study, except as otherwise required by law. Any results that come from this study will be presented as an aggregate and your name will not be linked to your answers. By agreeing to participate in this interview survey, you are allowing the Long Island Health Collaborative to use the information from this study.

Do you agree that you are at least 18 years old, have read and understood this consent language, and agree to participate in this research study?

      ☐ Yes → If Yes, continue

☐ No → If No, Terminate and use Script A (at end of document)

Do you consent to having this conversation recorded?

    ☐ Yes → If Yes, continue

    ☐ No → If No, Terminate and use Script A (at end of document)

Confirming eligibility

Social Determinants of Health: Types and Descriptions	
Economic Stability	E.g. housing security, employment food security, transportation
Education	E.g. language and literacy, early childhood education, high school education
Health and Healthcare	E.g. access to health care, health literacy access to trusted provider/primary care
Neighborhood and Built Environment	E.g. access to health foods, affordable/ quality housing, crime and violence
Social, Family, and Community Context	E.g. social cohesion, civic participation, incarceration / institutionalization

Is your organization involved in work related to [Social Determinant of Health]? For the purposes of this interview, [SDH] is defined as work addressing [give SDH example from chart above].

    ☐ Yes → If Yes, continue

    ☐ No → If No, Excuse and use Script B (at end of document)

Does your organization serve communities located in [County]?

    ☐ Yes → If Yes, continue

    ☐ No → If No, Excuse and use Script B (at end of document)

Ok, let's get started.

[Begin recording]

This is _____ [interviewer name] interviewing participant ID _____ on _____ [date] for the Long Island Health Collaborative.

Introduction (2 minutes)

1. To get started, could you very briefly describe your organization and your role in it?

2. We will be focusing on how your organization's work intersects with [SDH] and health in the community. Could you briefly describe for me how your organization addresses [SDH]?

Social Determinant of Health and the Community (10 minutes)

3. For the purposes of this interview, I'm using the term 'health' very broadly, it includes mental health, environmental health, substance use and any other aspect of health. What are the specific health concerns related to [SDH] that are important to the communities that your organization serves in [County]?

4. Are there any specific groups of people (such as women, Hispanics, or other types of groups) that are most impacted by [SDH], or have special challenges?

   If they need clarification on types of groups, they may be based on demographic variables or on other characteristics, e.g. chronic pain patients and employment, people without access to personal transportation and healthcare access, etc.

5. What are the factors related to [SDH] that make it **harder** for your communities become healthier?
   Examples, if needed: specific laws, cultural norms, factors in the environment, etc.

   a. What steps could be taken to address those factors and promote healthy communities?

6. What are the factors related to [SDH] that support your communities in becoming healthier?

   Examples, if needed: Policies related to this issue that positively impact health, or programs/resources that may be beneficial

a. What steps could be taken to build on the positive factors and promote healthy communities?

Conclusions (3 minutes)

7. Is there anything else you want to talk about that we haven't addressed?

8. What is the most important thing for me to take away from our conversation today regarding [SDH] and your communities?

Thank you so much for your time and insight, your input is very important and useful to us. Again, your responses will be kept confidential. You have been very helpful, and I appreciate it.

Have a great day.

Termination Scripts

Script A – *Termination for lack of consent to participate or record*

Thank you so much for agreeing to talk with me today. I need your consent to participate or record the interview, and so we will stop this interview, I appreciate your willingness to answer my questions, and those are all the questions I have at the moment. Have a great day.

Script B – *Termination for not meeting eligibility criteria*

Thank you so much for agreeing to talk with me today. Since all of my questions have to do with [SDH], health, and the communities in [County], I need to speak **with people at organizations which work in those areas.** I appreciate your willingness to answer my questions, and those are all the questions I have at the moment. Have a great day.

Appendix D - Community-Based Organizations

Name of Organization	Primary Focus
Child Care Council of Suffolk, Inc.	Education
Long Island Advocacy Center	Education
Rosa Lee Young Childhood Center	Education
YES	Education
CASA Nassau County Coordinating Agency for Spanish Americans	Economic Stability
EAGER TO SERVE, INC.	Economic Stability
Interfaith Nutrition network, Inc.	Economic Stability
Maureen's Haven	Economic Stability
Maryhaven Center of Hope	Economic Stability
Federation of Organizations	Health & Healthcare
Fidelis Care	Health & Healthcare
LI Asthma Coalition	Health & Healthcare
LGBT Network	Health & Healthcare
Nassau-Suffolk Hospital Council, Inc.	Health & Healthcare
Circulo de la Hispanidad, Inc.	Neighborhood & Build Environment
Concern for Independent Living, Inc.	Neighborhood & Build Environment
LI Against Domestic Violence	Neighborhood & Build Environment
Centro Corazon De Maria	Social & Community Context
Community Program Centers of LI	Social & Community Context
Girl Scouts of Nassau County, Inc.	Social & Community Context
St. John the Evangelist Roman Catholic Church	Social & Community Context
Suffolk Independent Living Organization	Social & Community Context
Uniondale Community Council, Inc.	Social & Community Context
YES Community Counseling Center	Social & Community Context